Avoidant Restrictive Food Intake Disorder (ARFID) and the Service Provision Wish-list:

A contribution to the evidence base to inform the improvement of ARFID Service Provision in the NHS

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Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature 

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Date: 16th of June 2022

Overview

This thesis investigates Avoidant Restrictive Food Intake Disorder (ARFID), with a specific focus on characterising and enhancing the evidence base to inform clinical services. Part one presents a systematic scoping review illustrating ARFID research through the lens of Sackett's (1996) evidence-based practice model. Evidence-based practice, as conceptualised by Sacket (1996) stipulates that (1) research evidence, (2) clinical expertise and (3) patient preference are equally essential components when determining best practice. Results of the literature review suggest, that while there has been a recent increase in ARFID research there is a misbalance in how this research maps to Sackett's evidence-based practice model, as there is currently only one study of patient preference in relation to ARFID. The results are discussed with specific emphasis placed on clinical recommendations.

Part two reports on an empirical study that used a mixed method approach with the aim of contributing to an evidence base that can inform the improvement of ARID service provisions in the NHS. The quantitative component of part one investigated the heterogeneous presentation of ARFID by analysing pre-existing clinical data. Based on those findings it then made inferences regarding heterogeneity amongst children with ARFID and how it can be parsed, resulting in tentative recommendations as to how this information may be used to improve service delivery for this population. The qualitative study consulted carers whose children have accessed ARFID services and sought recommendations on improving AFRID service provisions.

Part three is a critical appraisal, offering personal reflections and thoughts regarding the research process in its entirety. The challenges of recruiting are discussed, and the complexity of studying ARFID as a new condition is considered. Finally, the appraisal comments on the bi-directional relationship between research and clinical practice.

Impact Statement

ARFID is a new diagnostic entity that was added to the DSM-5 in 2013 (APA, 2013), and as such remains an underdiagnosed and under-recognized condition that is widespread and causes distress to many of those affected.

Findings of this study are intended to be disseminated in the relevant psychological journals. The current theoretical gaps regarding ARFID are explored across both papers. The methodological difficulties of studying a newly defined condition is also considered, whilst proposing directions for future research in line with these findings. These reflections may aid in informing the design of future research in this field.

The results provide additional knowledge and insight into ARFID, whilst building on the existing literature. Firstly, by scoping and reviewing the diverse literature on ARFID and mapping these on to the three-legged stool of evidence-based practice. The results highlight that ARFID is a fast-evolving field, in which there is a move away from individual case reports and a move toward papers based on systematically and rigorously collected data. Nevertheless, they have emphasised that the voice of stakeholders remains underrepresented in the current literature. This is an important finding for the field, as research has recognised that the inclusion of patient preferences has resulted in better motivation, degree of integration and ability to recognise and verbalise focalised problems (Berg, 2019).

The second part of this thesis, thereby builds upon the findings of the first, by filling the gap in research and including the voice of stakeholders in shaping psychological practice and service provisions. Currently, there is no care pathways for ARFID that has gained national consensus. Eating Disorder services, which are currently expected to treat the condition, are not equipped to manage the often complex mental and physical comorbidities these clients present with (Coglan & Otasowie, 2019). This thesis aimed to firstly understand

the heterogeneous presentations of ARFID further and how this can be parsed, to make tentative recommendations as to how services may be optimised. Secondly, it consulted stakeholders to gain insight into their ideas on how to improve ARFID service provisions. This study is the first to give stakeholders a voice in shaping ARFID services. These findings are particularly impactful, as they suggest that tangible and economic recommendations can be made, including the education of gate keepers such as GPs, the tailoring of interventions and environment to fit the needs of this population and joined up working amongst NHS services.

As such, this thesis achieves impact by enhancing understanding of ARFID and its clinical care. The first part of the thesis gives an understanding of current developments and makes suggestions for future relevant research to advance the field. The second part of the thesis, allows unique insight into the heterogeneity of the condition and makes recommendation on how service delivery for this diverse population may be optimised.

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Part one: Literature Review

Avoidant Restrictive Food Intake Disorder: A systematic scoping review of the current literature according to evidence-based practice

Abstract

Aims: Avoidant/restrictive food intake disorder (ARFID) was added to the DSM in 2013 (APA, 2013) and describes a group of patients who engage in avoidant or restrictive eating behaviours, without shape and weight concerns or a desire to get thinner (Bourne et al., 2020). Evidence-based practice, stipulates that effective patient care can only be determined by consulting (1) research evidence, (2) clinical expertise and (3) patient preference equally. This paper was based on an existing literature review by Bourne et al. conducted in 2020 and is heavily influenced by this paper. This scoping review aimed to provide an overview of the ARFID literature and to systematically map these findings on to the three legs of evidence-based practice. Through this, it aimed to identify the gaps within the literature and subsequently make recommendations regarding further research within the field.

Method: After an initial database search, 1005 references were identified. When matched against pre-existing eligibility criteria, 171 publications were identified as being relevant for the review. Subsequently, these papers were mapped onto the three legs of the evidence base (1) research evidence, (2) clinical expertise and (3) patient preference. these legs, the papers were then categorised according to five subject areas: (i) Diagnosis and assessment, (ii) prevalence, (iii) Clinical characteristics (iv) treatment interventions, (v) clinical outcomes, as per Bourne's review.

Results: The current evidence suggests a significant development regarding the first leg of evidence-based practice, with a paucity within the third leg. While ARFID is recognised as a distinct clinical entity, understanding remains limited in all five subject areas.

Conclusions: Avenues for future research are discussed, with specific focus placed upon the development of including patient preference. Gaining more insight into the processes that are currently thought to maintain the condition would have a favourable impact on informing the

expansion of targeted treatment interventions, whilst refining screening tools and impacting clinical outcomes.

1. Introduction

1.1. Avoidant Restrictive Food Intake Disorder (ARFID)

Avoidant Restrictive Food Intake Disorder (ARFID) was formally introduced as a diagnostic category in 2013 to the Diagnostic and Statistical Manual, Fifth Edition (DSM-5; American Psychiatric Association, 2013) and the International Classification of Diseases, 11th Edition (ICD-11) in 2018 (World Health Organisation, 2018). ARFID is characterised as a persistent disturbance in feeding or eating, which may result in significant weight loss, difficulties gaining weight, growth compromise, severe malnutrition, supplement dependency and/or a marked interference with psychosocial functioning (Bourne et al. 2020). Together with anorexia nervosa (AN), bulimia nervosa (BN), binge eating disorder, rumination disorder and pica these disorders form the 'feeding and eating disorders' section of the DMS-5. Whilst ARFID falls under the umbrella of an eating disorder, individuals presenting with ARFID are a heterogeneous group who engage in restrictive and avoidant eating without weight or shape concerns, or a desire to get thinner (Claudino et al., 2019).

The current diagnostic criteria for ARFID stipulate three main processes that maintain many cases of the condition: (1) avoidance based on the sensory characteristics of food (hereafter: sensory sensitivity), (2) apparent lack of interest in food or eating (hereafter: lack of interest) and (3) concern about the aversive consequences of food (e.g. vomiting and choking) (hereafter: fear of aversive consequences). These are not proposed as being mutually exclusive and may co-occur (American Psychiatric Association (APA), 2013). These three suggested drivers of ARFID are not considered to be an exhaustive list, but rather are intended as guides to the initial stages of understanding ARFID's underlying causes, as it is acknowledged that other causal processes may reinforce avoidant or restrictive eating in ARFID (Bourne et al., 2020).

While ARFID research is burgeoning, there are few reviews synthesising published information about ARFID. Bourne et al. 2020 identified, only three systematic reviews prior to 2020, one of which focused on the evaluation of the diagnostic validity of the DSM-5 ARFID criteria (Strand et al., 2019), the second reviewed the use of cyproheptadine (which is a potent antihistamine) in encouraging appetite and weight gain for people with ARFID (Harrison et al., 2019), whilst the third assessed the level of care offered to patients with chronic food refusal, including those with ARFID (Sharp, Volkert, et al., 2017). Since 2020 there has been considerable development in the field, reflected in the publication of further ARFID-relevant reviews. Dalle Grave (2020) focused on treatments available for ARFID, whilst Yule et al. (2021) discussed nutritional deficiency diseases secondary to ARFID and comorbid Autism Spectrum Condition (autism). An additional review focused on scurvy as a sequela of ARFID in autism (Sharp et al., 2020). Another focused on the comparison between ARFID and AN, highlighting the intersection of gastrointestinal symptoms and malnutrition for both conditions (Gibson et al., 2021).

A systematic scoping review was offered by Bourne et al., (2020), which provides the most comprehensive overview of the literature to date. This review synthesised current research on ARFID and tried to identify key gaps in the evidence base. Bourne grouped the burgeoning ARFID literature into five main categories: (i) Diagnosis and assessment (subcategories: diagnostic instruments, screening instruments), (ii) prevalence, (iii) clinical characteristics, (iv) treatment Interventions (subcategories: pharmacological, psychological, multi-modal approach) and (v) clinical outcomes. This review was heavily reliant on Bourne's review, and as such similarities might be found in this paper.

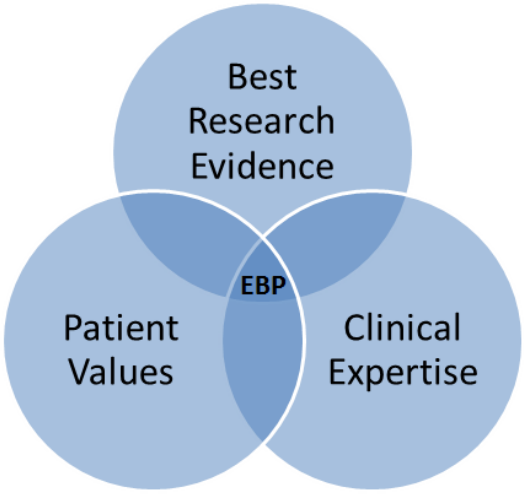
1.2. Evidence-based practice

Historically, evidence-based practice is founded on scientific evidence (Sur & Dahm, 2011), with the aim of reducing clinician bias in decision making and eliminating outdated practices in favour of evidence grounded in scientific research (Leach, 2006). Both physical and mental health domains have tended to have a hierarchy of evidence (Evans, 2003), with science (in particular, randomised control trials (RCTs) and systematic reviews and meta analyses) being considered the best and main source of information (Evans, 2003). Within this pyramid empirical research resides at the top, whereas expert opinion or experience are at the bottom level of evidence quality (Chalmers et al., 1983) and are therefore given less weight.

However, mental health is a fast-evolving field, new diagnoses are often under-researched and RCTs or systematic reviews have not yet been conducted. In these cases, scientific research alone cannot inform the holistic care clinicians aim and strive for. To accommodate this, Sackett et al. (1996) designed an approach that would determine best practice not only to be a product of research evidence, but also clinical expertise and patient values, preferences and characteristics. Sackett named these the ‘three legged stool’ of evidence-based practice, and each of the components are deemed essential to provide optimal care for the treatment of those with mental health conditions and is designed to aid clinical decision making (Spring, 2007). Additionally, it enhances effective psychological practice by encouraging the application of psychological assessment, therapeutic relationships and case formulation that are empirically supported (APA, 2002).

Figure 1

Evidence-based Practice: "The three legged stool" (Sackett et al., 1996)



1.2.1. Research leg

The first 'leg' of the evidence –based stool, research, relies on the most current empirical evidence (RCTs, systematic reviews etc.) to support and outline the most effective treatment options (Sackett et al., 1996). Its aim is to reduce clinical bias, and human judgement errors (Dawes et al., 1989). Despite this, clinicians may shy away from using research evidence effectively (Peterson et al., 2016), as some believe that there are meaningful differences between those in routine settings and the sample in clinical trials (Lilienfeld et al., 2013). Others are sceptical of the relevance of scientific data to evaluate the often subjective criteria of psychotherapy outcomes and processes (Lilienfeld et al., 2013).

1.2.2. Clinical expertise leg

Clinicians may employ the second 'leg' of evidence-based practice, clinical expertise, to compensate for these shortcomings in research or if the relevant research has not yet been

conducted. Clinical expertise is often decomposed into clinical judgement and clinical experience. Clinicians make use of their own clinical skills and past experiences to understand and formulate in line with a patients unique health state and diagnosis (Straus et al., 2018). This may be particularly relevant, when there are concerns or questions regarding treatment or patient care is not adequately addressed in the existing literature (Kahneman & Klein, 2009). Moreover, research in its nature is often based on understanding a treatment for a singular mental health condition, whilst patients often present with co-morbid difficulties (Peterson et al., 2016), making clinical expertise more relevant. However, clinical expertise has shown to be subject to biases, as solely relying on this might result in 'therapist drift', making it difficult to maintain treatment integrity (Dawes et al., 1989).

1.2.3. Patient preference leg

Finally, Patient preferences and values are the third 'leg' of evidence-based practice. This may shape the clinician's selection of interventions. Understanding patient's preferences and expectations may have a role in how well clients engage in their therapy or how effective treatment is and should therefore be incorporated in any clinical decision-making process (Peterson et al., 2016). Comparatively little research has been conducted in understanding how patient's characteristics, values and circumstances may inform clinical decision making, signalling the need for further research.

1.2.4. Evidence-based practice and ARFID

The three above mentioned 'legs' (research evidence, clinical expertise and patient preference) together form Sackett's model of Evidence-based practice. Evidence-based practice is a transdisciplinary approach designed to promote life-long learning (Sackett et al., 1996). Whilst evidence-based practice is the gold standard of clinical interventions in theory,

it is more likely that not all of its three legs are employed equally when clinicians make decisions regarding treatment options. ARFID, only added to the diagnostic manuals as recently as 2013, has received increased research interest, but is far from being an established condition with multiple RCTs to rely upon when informing clinical decision making. Therefore, this field in particular relies on the other two legs of evidence-based practice - clinical expertise and patient preference - to inform their decision making. Adopting Sackett's three legged stool, in which the fundamentals of evidence-based practice are based on a combination of each of the three aforementioned elements, is the necessary first step in improving patient treatment (Peterson et al., 2016). Presently, the majority of research undertaken still focuses on empirical evidence and views RCTs and systematic reviews as the gold standard and little research has been conducted to establish how well the different stools of evidence are represented in the literature.

1.3. Current paper

While Bourne's recent scoping review paper gives an overview of ARFID research up to 2020, it does not characterise the literature according to how it can support evidence-based practice, as conceptualised by Sackett. The present scoping review aims to extend Bourne's findings by conducting a new search including search terms up to July 2021 and mapping the papers found onto the three legs of the evidence base: (i) Research evidence, (ii) Clinical Experience and (iii) Patient Preference. Additionally, in contrast to Bourne's review, which focused on empirical literature, the present review will also include 'clinical wisdom' literature (e.g. literature relevant to the second 'leg' of the evidence-based practice stool). Thus, the review sought to investigate whether the ARFID literature incorporates all legs of evidence-based practice equally and establish how well these three respective legs are

represented. This paper aims to give an overview of the current literature of ARFID, rather than giving a detailed account of the contents of the papers. This will allow researchers to see gaps within the literature, as well as give an indication of how well the field is currently implementing these findings.

It aims to (1) map the literature onto the three-legged stool of evidence-based practice according to Sackett and (2) identify key gaps in the evidence base.

2. Methods

2.1. Literature search

Similarly, to Bourne's review and following a consultation with the subject liaison librarian of psychology and biosciences, a systematic search was carried out in July 2021. Electronic databases were searched including Embase, PsychInfo, Scopus, Web of Science, Medline and Cochrane Library to identify relevant studies. The search terms "ARFID" or "Avoidant Restrictive Food Intake Disorder", were used without filters, restrictions or limits. As the aim of the study was to provide a brief overview of the existing literature and capture how this related to evidence-based practice, it was decided that the search terminology would be adequate in capturing all necessary studies relevant for this review. Therefore, no further search terms, search variations or keyword combinations were used.

2.2. Eligibility criteria

Based on Bourne's (2020) review, following eligibility criteria were determined. Papers adhering to these were included in the review:

1. Full-text publications with primary, empirical data explicitly relating to ARFID as a diagnostic entity (as described in the DSM-5 or ICD-11).
2. Opinion pieces or commentaries relating to ARFID as a diagnostic entity (as described in the DSM-5 or ICD-11).
3. Papers including one or more individuals of any age, who held a diagnosis of ARFID. This included single case studies or case series presenting quantitative and qualitative data regarding the presentation, course, treatment or outcome of ARFID
4. Articles in English

2.3. Exclusion criteria

Studies were excluded from the review under following conditions:

1. Literature reviews or articles synthesising information about ARFID.
2. Articles or studies that mentioned ARFID briefly, but did not focus on it specifically.
3. Conference abstracts

2.4. Screening and selection process

The initial search of the databases generated a total of 1970 publications. 965 papers were duplicate publications and removed from the analysis. Following this, titles and abstracts were manually screened, with articles unavailable in English, book chapters, conferences abstracts and publications not relating to ARFID as a feeding or eating disorder were also excluded (Bourne et al. 2020). For publications passing the initial screening against eligibility criteria, the full text was retrieved. The subsequent 171 papers were broadly read and then coded into the three evidence-based practice groups: (1) research evidence, (2) clinical experience and (3) patient preference. The abstracts of the papers were also screened for their

study design, if they were part of the research evidence leg of evidence based practice. This was included in the tables created below.

3. Results

3.1. Overall results

Following a search across the aforementioned databases, 171 studies were identified for inclusion in the review. To adhere to the aims of the study, which was to categorise the publications according to the three legged stool of evidence-based practice (Sackett et al., 1996), the articles were first categorised into three main areas: (1) research evidence (2) clinical expertise and (3) patient preference. Based on the systematic scoping review by Bourne et al. (2020), within these three categories, the articles were further classified into five subject areas according to their central focus: (i) diagnosis and assessment, (subcategories: diagnostic instruments, screening instruments) (ii) prevalence, (iii) clinical characteristics, (iv) treatment interventions (subcategories: pharmacological, psychological, multi-modal approach) and (v) clinical outcomes.

Details of the publications included in the review are outlined in tables. These will be divided in reference to the evidence-based practice legs. The tables are based on the format and structure used by Bourne et al. (2020). As this study builds upon the findings of the aforementioned review, some study findings are reported similarly.

3.2. Subcategorisation according to evidence-based practice

The articles identified for inclusion in the review, were first categorised in accordance with their evidence-based practice stool leg. Once identified in which leg of the stool the

paper belonged, they were then subsequently grouped using Bourne's taxonomy of ARFID research as mentioned above.

The graphs below indicate the division of the subcategories in accordance with their evidence-based practice legs.

Figure 2

Visualisation of subcategorisation of the 'three-legged stool'

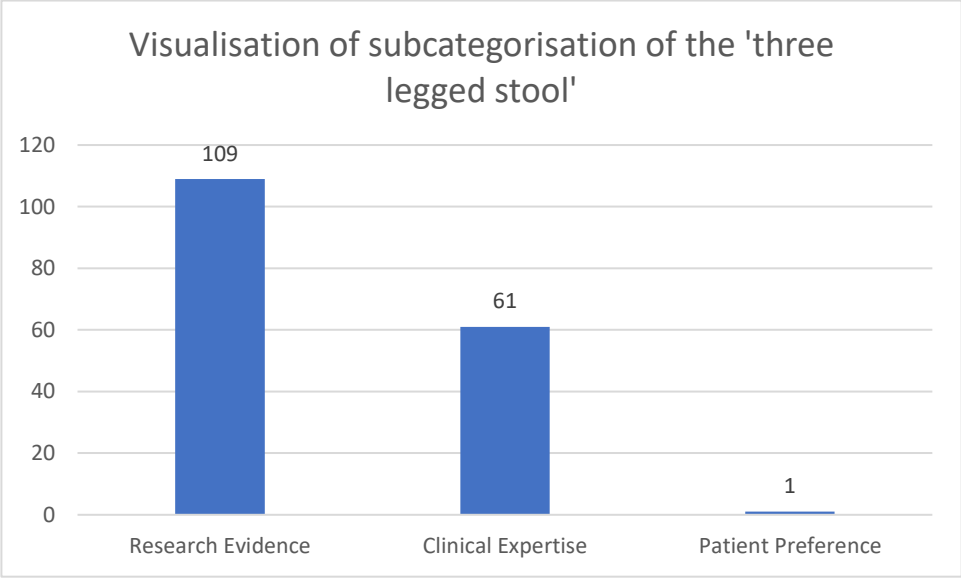


Figure 3

Visualisation of division between subcategories

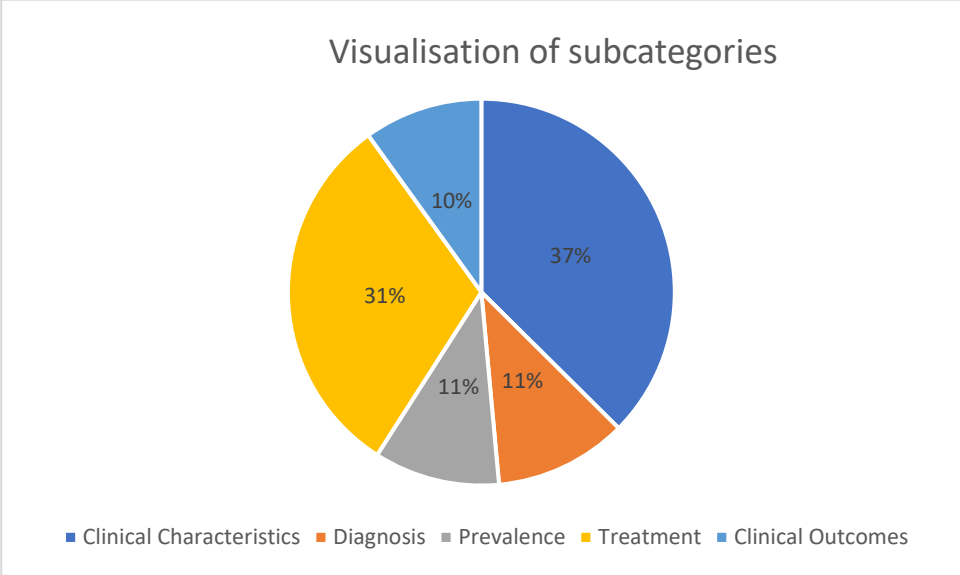


Figure 4

Visualisation of division between subcategories according to evidence-based practice

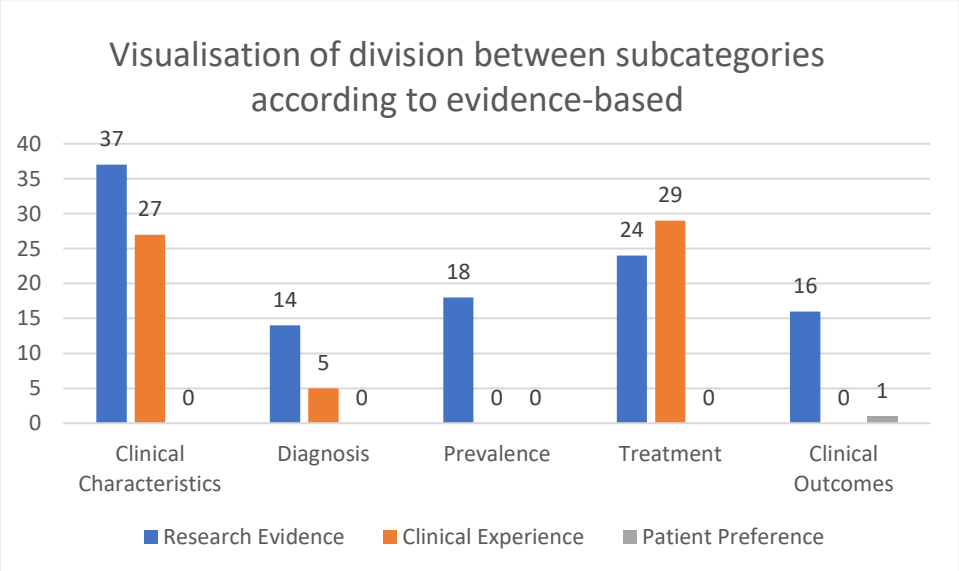
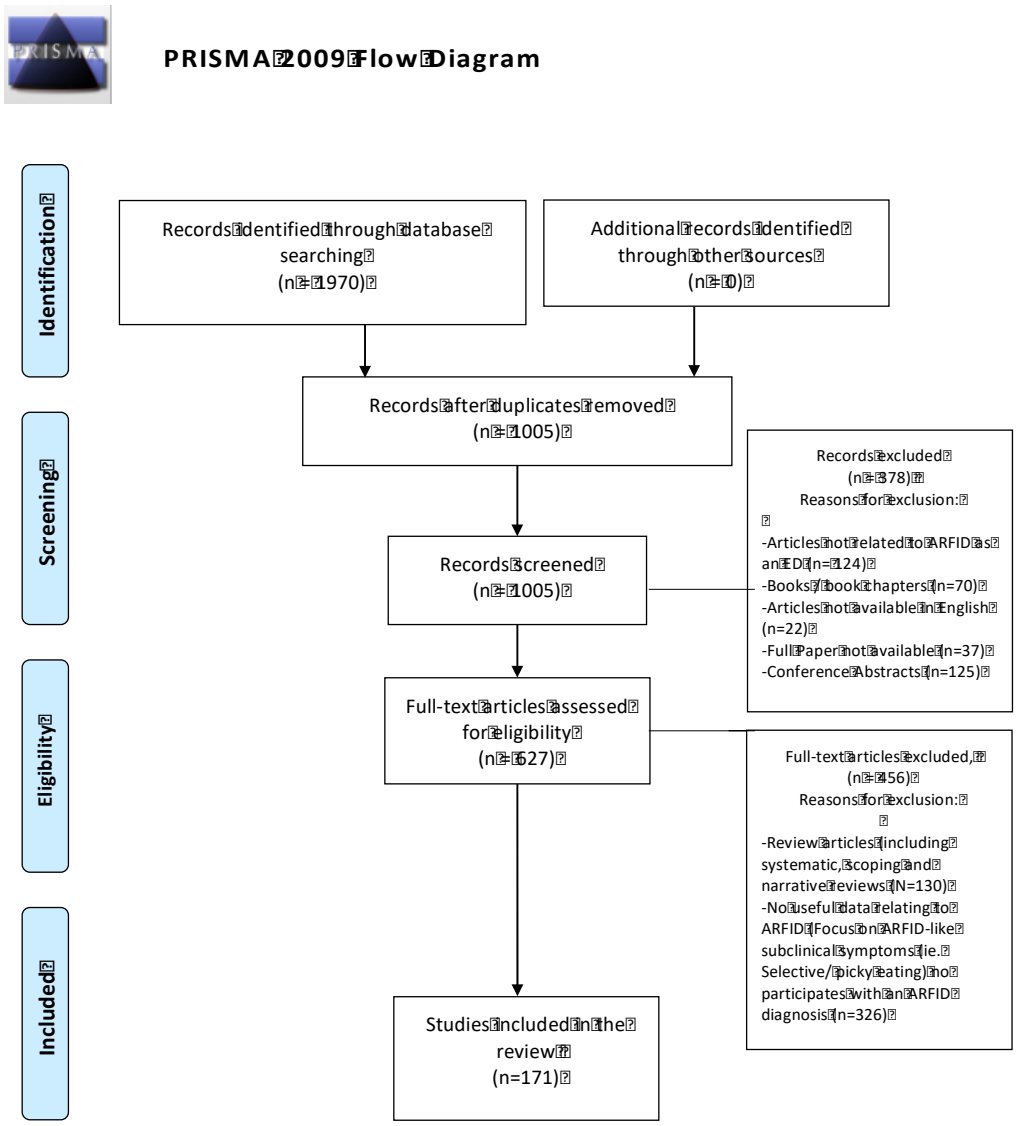


Figure 5

Flow diagram of reviewed studies



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

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3.2.1. Stool leg 1 – Research evidence

Identified articles were placed in this category if they presented data that had been systematically collected and analysed or if there were dependent and independent variables that were manipulated in the study.

The first leg of evidence-based practice included 109 articles. These included: 14 articles focusing on diagnosis and assessment, 18 articles concentrating on prevalence, 37 articles focusing on clinical characteristics, 24 on treatment and 16 on clinical outcomes.

3.2.1.1. Diagnosis & assessment

The articles identified within this section (n=14), were further subcategorised into papers focusing on diagnostic instruments (n=7) and screening instruments (n=7). Please see Table 1.

a) Diagnostic instrument

As ARFID has a heterogeneous presentation a well validated and standardised clinical instrument is needed to confer diagnosis. Seven articles focused on tools used to evaluate ARFID symptoms and generate a diagnosis. As found in Bourne's review the Pica, ARFID and Rumination Disorder Interview (PARDI) (Bryant-Waugh et al., 2019), is a semi-structured interview, relying on multiple informants. The PARDI assesses the presence of ARFID and offers dimensional ratings across its three main profiles. As such, it is particularly sensitive to the three ARFID profiles and therefore promises to be an effective diagnostic instrument. Findings regarding the reliability and validity of the data, indicate good acceptability and feasibility, as well as good internal consistency relating to the three

ARFID profiles (sensory sensitivity – 0.77, lack of interest in food or eating – 0.89 and fear of aversive consequences – 0.89).

The Eating Disorder Examination-ARFID module (EDE-ARFID) (Schmidt et al., 2019), is designed as a diagnostic instrument, as well as a tool which gathers clinically relevant information relating to ARFID psychopathology (Bourne et al. 2020). Further, the Hierarchical Taxonomy of Psychopathology (HiTOP) aimed to develop a quantitative system of nosology and defined 15 specific feeding and eating disorder constructs in their study, with a specific subgroup for ARFID (Sellbom et al., 2021). The Eating Pathology Symptoms Inventory-Clinician Rated Version (EPSI-CRV), based on the Eating Pathology Symptoms Inventory (EPSI) (Coniglio et al., 2018), measures dimensional constructs assessed in the self-report version of the EPSI and generates DSM-5 diagnoses (Forbush et al., 2020).

Other articles described measures that are not designed for ARFID diagnosis specifically. These included: the visceral sensitivity index, which gave insight into gastrointestinal complaints in individuals with eating disorders (Brown et al., 2021) and the Stanford Feeding Questionnaire (SFQ), which aimed to distinguish children with ARFID from control children and assess their picky eating habits (Iron-Segev et al., 2020). Finally, the Adult Picky Eating Questionnaire (APEQ) (validated in China) (He et al., 2019) is a validated 16-item self-report scale to assess picky eating behaviours and attitudes.

Current research efforts to design and validate diagnostic instruments that are able to identify ARFID behaviours and capture significant clinical change have thus far shown promising psychometric validity (Bryant-Waugh et al., 2019).

b) Screening instruments

A further seven publications presented empirically collected data on screening instruments, which were intended to recognise ARFID behaviours, produce initial symptomatic data and assist with clinical decision making.

The Nine Item ARFID Screen (NIAS), exclusively focuses on selective and restrictive behaviours in adults (Zickgraf & Ellis, 2018). The NIAS was further validated in China (He et al., 2021). Following this, its subscales, which were designed to distinguish ARFID presentations and screening ARFID were also validated (Burton Murray et al., 2021).

Based on the DSM-5 Criteria for ARFID (APA, 2013), the Eating Disorder Disturbance in Youth Questionnaire (EDY-Q, (Dyck & Hilbert, 2016)), is a 12-item, self-report measure, aimed to identify the early-onset of eating disturbances in eight to 13 year olds. Kurz et al., (2016) examined this questionnaire for convergent and discriminant validity and found initial evidence for the presence of distinct variants of avoidant and restrictive eating behaviours (Bourne et al. 2020).

Other screening tools include an online screening for eating disorders across the US (Fitzsimmons-Craft et al., 2019), the SCOFF (Sick, Control, One, Fat, Food) questionnaire and the Eating Disorders Assessment for DSM5 (EDA-5) both of which were assessed for their validity and ability to pick up eating disorders in general medical and psychiatric settings (Owens et al., 2021).

Table 1

Summary of ARFID articles relating to research evidence & diagnosis and assessment

Author (Year) and Country	Country	Subcategory	Study Design	Name of Measurement Instrument	Purpose of Study	Age Group
Kurz et al., (2016)	Switzerland	Screening Instruments	Validation Study	Eating Disturbances in You Questionnaire (EDY-Q)	Self-report scale screening for ARFID symptoms based on DSM-5 criteria	Child and Adolescent
Coniglio et al., (2018)	USA	Diagnostic Instrument	Validation Study	Eating Pathology Symptoms Inventory (EPSI)	45-item self-report measure for eating pathology, assessing symptoms of disordered eating	
Zickgraf & Ellis, (2018)	USA	Screening Instrument	Validation Study	Nice Item Avoidant Restrictive Food Intake Disorder screen (NIAS)	Brief multidimensional instrument measuring eating behaviours associated with ARFID.	Adult
Bryant-Waugh et al., (2019)	UK, Switzerland & USA	Diagnostic Instrument	Validation Study	Pica, ARFID and Rumination Disorder Interview (PARDI)	Multi-informant, semi-structured Interview assessing the presence and severity of ARFID (in addition to PICA and rumination Disorder)	Child & Adolescent & Adult
Fitzsimmons-Craft et al., (2019)	USA	Screening Instrument	Survey	Online Screen	Determine the scope of an online eating disorder screener, as well as examine probably eating disorder diagnostic and risk breakdown in an adult population.	Adult
Schmidt et al., (2019)	Germany	Diagnostic Instrument	Validation Study	Eating Disorder Examination: ARFID Module	ARFID module for the child and parent version of the Eating Disorder Examination (CheEDE)	Child & Adolescent
Forbush et al., (2020)	USA	Diagnostic Instrument	Validation Study	Eating Pathology Symptoms Inventory Clinical Rated Version (EPSI-CRV)	To build upon the EPSI and generate DSM-5 Diagnoses	Adults
Iron-Segev et al., (2020)	Israel	Diagnostic Instrument	Validation Study	Stanford Feeding Questionnaire (SFD)	Aimed to assess whether an instrument assessing for picky eating would be able to	Child & Adolescent

					distinguish children with ARFID from control children	
Brown et al., (2021)	USA	Diagnostic Instrument	Validation Study	Visceral Sensitivity Index (VSI)	Validating the VSI in an ED sample	Child & Adolescent
Burton Murray et al., (2021)	USA	Screening Instrument	Validation Study	Nice Item Avoidant Restrictive Food Intake Disorder screen (NIAS)	Validating and determining clinical cut offs for the three subscales within the NIAS	Adult
He et al., (2021)	China	Screening Instrument	Validation Study	Nice Item Avoidant Restrictive Food Intake Disorder screen (NIAS)	Assessing validation of the NIAS in China	Adult
He et al., (2021)	China	Diagnostic Instrument	Validation Study	Adult Picky Eating Questionnaire (APEQ)	Validation of the APEQ in China, assessing symptoms of ARFID	Adults
Owens et al., (2021), USA	USA	Screening Instruments	Validation Study	SCOFF (Sick, Control, One, Fat, Food) and Eating Disorders Assessment for DSM-5 (EDA-5)	Application of questionnaires within a medical setting and exploration of whether they determine diagnosis sooner	Adult
Sellbom et al., (2021)		Diagnostic Instrument	Validation Study	Hierarchical Taxonomy of Psychopathology (HiTOP)	Developmental of provisional scales for somatoform spectrum and eating disorders	Adults

3.2.1.2. Prevalence

All 18 articles focusing on prevalence were found in the research based leg of evidence-based practice, for more detail on the articles please see Table 2.

The search yielded 18 articles focusing on the prevalence of ARFID. As found in Bourne's (2020) review, there are significant differences in prevalence estimates, with initial estimations amongst clinical ED populations ranging from 1.5% to 64% (Ornstein et al., 2013, Fisher et al., 2014, Forman et al., 2014, Nicely et al., 2014, Norris et al., 2014, Eddy et al., 2015, Williams et al., 2015, Cooney et al., 2018, Krom et al., 2019, Goldberg et al., 2020) and <1% - 15.5% in non-clinical cohorts (Hay et al., 2017; Gonçalves et al., 2019). Studies conducted in other countries show a range of 3-4% with an estimate in France of 3% (Bertrand et al., 2021) and 4.1% in Singapore (Chua et al., 2021). However, ARFIDs true prevalence remains unknown, as insufficient epidemiological studies have focused on the prevalence rates of ARFID (Bourne et al. 2020). Most of the studies in this section are retrospective chart reviews within specific populations. Effective gathering of this data is associated with a number of challenges, and research has found that they lack sound methodological standards (Gilbert et al., 1996) and these estimates should therefore be viewed with caution. A structured assessment tool which can detect the entire range of ARFID presentations and is overseen by a trained individual may give better indication of true prevalence figures.

While most articles focus on the prevalence of ARFID in a child and adolescent population, two studies focus on the prevalence of ARFID in adults (Hay et al., 2017), with varying results (Bourne et al. 2020). One study showed lower values for ARFID prevalence than their counterparts that explored the prevalence of the disorder in children, namely 0.3% in 2014 and 0.3% in 2015 (Bourne et al. 2020). Another study compared ARFID to AN

prevalence in adults (Nakai et al., 2016), showing a relatively high distribution of ARFID at 9.2%.

Table 2

Summary of ARFID articles relating to research evidence & prevalence

Author	Country	Study Design	Sample Size (n=)	Gender, age range (mean, SD)	Sample	Type of Assessment	Population	ARFID prevalence estimate
Ornstein et al., (2013)	USA	Within Subject	215	88.6% female 8- 21 years (15.4 ± 3.3	Patients who presented for an ED evaluation to adolescent medicine physicians (2010 to 2011)	Clinical interview (retrospective or concurrent presumptive diagnosis assigned)	Child & Adolescent	14%
Fisher et al., (2014)	USA & Canada	Retrospective Chart review	712	8-18 years	Patients who presented to 7 adolescent medicine ED programmes (2010)	Retrospective Chart review	Child & Adolescent	13.8%
Forman et al., (2014)	USA	Retrospective Chart review	700	86.3% female 9–21 years (15.3 ± 2.4)	Patients who presented to 14 adolescent medicine ED programmes (2010)	Retrospective Chart review	Child & Adolescent & Adult	12.4%
Nicely et al., (2014)	USA	Retrospective Chart review	173	92% female 7–17 years (13.5 ± 2.03	Patients admitted to an ED day programme between 2008-2021	Retrospective Chart review	Child & Adolescent	22.5%
Norris et al., (2014)	Canada	Retrospective Chart review	205	13.7 ± 2.5	Patients received an initial ED intake assessment (2000 and 2011)	Retrospective Chart review	Child & Adolescent	5%
Eddy et al., (2015)	USA	Retrospective Chart review	2231	4% female 8–18 years (13.0 ± 3.0)	Consecutive new referrals to 10 paediatric gastroenterology clinics in 2008	Retrospective Chart review	Child & Adolescent	1.5%
Williams et al., (2015)	USA	Within Subject	422	2% female 4–219 months (54.5 months ±41.0)	Children referred to a MDT paediatric feeding programme	Clinical assessment (assessment of dietary intake, BMI measurement and physical examination)	Child & Adolescent	32%
Nakai et al., (2016)	Japan	Retrospective Chart review	1029	Predominantly female (n=1017)	Patients seeking treatment for an ED (Kyoto University Hospital; 1990 and 2005)	Retrospective Chart review	Adult	9.2%

Hay et al., (2017)	Australia	Survey	2732 (2014 3005 (2015)	>15 years	Population based study. 10 dwellings within metropolitan or rural districts in South Australia systemically selected participants were selected from each household.	Eating behaviour interview	Child & Adolescent	2014: 0.3% (0.1-0.5) 2015: 0.3% (0.2-0.6)
Cooney et al., (2018)	Canada	Retrospective Chart review	369	< 18 years	Patients assessed for an ED in a tertiary care paediatric hospital (2013 and 2016)	Retrospective Chart review	Adult	8.4%
Goncalves et al., (2019)	Portugal	Within Subject	330	50.9% female 5–10 years (7.6 ± 1.2	Primary school children and their parents, fluent in Portuguese	Child and parent self-report questionnaires (including ARFID questionnaire based on DSM-5 criteria)	Child & Adolescent & Adult	15.5%
Krom et al., (2019)	The Netherlands	Cross sectional	100	64.1% female Mean age 1.85	Patients referred due to feeding difficulties (Diagnostic Centre for Feeding Problems in the Emma Children's Hospital / Amsterdam UMC)	Participants assessed in line with DSM-5 criteria for ARFID	Child & Adolescent	64%
Goldberg et al., (2020)	Canada	Cross sectional		Females only 8-18 years	Females presenting to a tertiary care paediatric and adolescent gynaecology clinic in Toronto, between October 2017 and April 2019	Patients assessed by medical professionals and the Eating Disorders in Youth Questionnaires (EDY-Q)	Child & Adolescent	3.7%
Murray et al., (2020)	USA	Retrospective Chart review	410	73% females 18-90 years	Consecutive referrals to a tertiary care centre for neurogastroenterology. Examinations from January through December 2016.	Retrospective Chart Review	Adult	6.3%
Bertrand et al., (2021)	France	Cross sectional	401	0-18 years	Patients who were part of the general paediatric population	Participants assessed against DSM-5 criteria for ARFID	Child & Adolescent	3%
Chua et al., (2021)	Singapore	Cross sectional	797	21-77 years	Adult population in Singapore	Participants assessed using the Standford Washington Eating Disorder Screen	Adult	4.1%
Koomar et al., (2021)	USA	Cross sectional	5157	0-18 years	Patients who already have a diagnosis of Autism Spectrum Condition (ASC)	Participants assessed using NIAS, Inflexible Eating Behaviours (INFLEX)	Child & Adolescent	21%

3.2.1.3. Clinical characteristics

Within the subcategory clinical characteristics, 37 articles were found. Please see Table 3 for more detail. These can be subcategorised into understanding ARFID medically and psychologically. As well as comparing it to other restrictive EDs and understanding their nutritional set up.

Despite the heterogeneous presentation of ARFID, clinical populations show demographic similarities (Bourne et al. 2020). Current findings suggests that patients are often younger than their ED counterpart, that they are more likely to be male and that they describe a longer duration of illness in contrast to AN and BN (Norris et al., 2014, Forman et al., 2014, Nicely et al., 2014). Most of this knowledge is currently based on studies that have a relatively small sample size, as well as focusing on individuals having presented to ED programmes or sought support from individuals who specialise in EDs (Ornstein et al., 2013, Fisher et al., 2014, Forman et al., 2014) and thereby require further validation within ARFID specific services (Bourne et al. 2020).

The search identified multiple studies which compare the psychological and medical profile of patients with ARFID to those with other restrictive EDs, particularly AN (Alberts et al., 2020, Aulinas et al., 2020, Becker et al., 2021) as well as the general population (Cañas et al., 2021). Whilst there were similarities in their dietary restriction, patients with ARFID displayed distinct clinical presentations compared to those with other EDs (Bourne et al. 2020). These included a history of abdominal pain and a longer illness duration (Maertens et al., 2017, Izquierdo et al., 2019). Despite the phenotypical similarity between AN and ARFID, a core difference is that those with ARFID do not have weight and shape concerns. Research understanding the medical and psychological profile of ARFID further to gain accurate understanding of how the disorder presents, as well as furthering insight into the three main drivers of ARFID remain necessary.

A number of studies also reported on the gastroenterological difficulties that individuals with ARFID may present with (Nicholas et al., 2021), such as gastroparesis (Burton Murray et al., 2020) or disorders of gut-brain interactions (Murray et al., 2021). Similarly, a number of studies focused on the nutritional set up of those with ARFID, exploring macro- and micronutrient intake (Schmidt et al., 2021), malnutrition in ARFID (Lin, Jhe, et al., 2021) and general dietary intake (Harshman et al., 2019). Many of these studies display small sample sizes and do not account for differences in degree of malnutrition or varying nutritional needs depending on age. Studies in this subsection give indication on the heterogeneous nature of ARFID, which make findings difficult to generalise.

Research outlined how the different ARFID presentations may vary drastically from one another, resulting in difficulties in understanding the disorder amongst health care professionals (Jackson et al., 2021). Indeed, presentations of ARFID have shown to vary in accordance with the main driver of food avoidance (Bourne et al. 2020). This has yielded studies that focus on the validity of the three main drivers of ARFID: sensory sensitivity, lack of interest and fear of aversive consequences of food (Norris et al., 2018, Zickgraf et al., 2019, Reilly et al., 2019). While there have been reports about the distinct features of the three drivers, (Thomas et al., 2017, Lucarelli et al., 2017) individuals often present with characteristics that co-occur or overlap (Murphy & Zlomke, 2016, Aloi et al., 2018). Research focusing on capturing the heterogeneity of the disorder and understanding its underlying causes better is needed to make recommendations and conclusions regarding the prevalence or possible treatment options for those with ARFID (Bourne et al. 2020).

Table 3

Summary of ARFID articles relating to research evidence & clinical characteristics

Authors, (year)	Country	Study Design	Study Aim	Age Group
Norris et al., (2018)	Canada	Retrospective Chart review	To describe and assess characteristics of ARFID and its subtypes	Adult
Thapliyal et al., (2018)	Australia	Survey	To compare male & female and their likelihood of being prescribed antidepressants whilst having and ED	Child & Adolescents
Becker et al., (2019)	USA	Between Subject	To compare ARFID and AN and to explore how a more holistic definition of ARFID can be developed	All
Coelho et al., (2019)	Canada	Between Subject	To assess the overlap between OCD, ED and body checking	Child & Adolescents
Duncombe Lowe et al., (2019)	USA	Effectiveness Study	To examine differences of ARFID by age, weight status and symptom duration	Child& Adolescents
Feillet et al., (2019)	France	Survey	To assess nutritional risk for those with ARFID and its clinical implications	Adult
Harshman et al., (2019)	USA	Between Subject	To compare children and adolescents with full/subthreshold ARFID and healthy controls regarding diet variety and macro- /micro- nutrient intake	All
Izquierdo et al., (2019)	USA	Between Subject	To measure implicit attitudes regarding thinness / dieting in adolescents with fat-phobic / non-fat-phobic AN, low weight ARFID and those with no ED	All
Keery et al., (2019)	USA	Between Subject	To map out physical and psychological characteristics of ARFID population and compares to subthreshold and full AN	Child & Adolescents
Lieberman et al., (2019)	Canada	Retrospective Chart review	To compare psychological and medical characteristics of children AN and ARFID	Child & Adolescents
Prasetyo, Kurnia, et al., (2019)	Indonesia	Cross sectional descriptive study	To predict promotive behaviour in the mothers of Indonesian Children with ARFID	Child & Adolescents
Reilly et al., (2019)	USA	Retrospective Chart review	To explore potential co-occurrence of behavioural phenotypes in ARFID	Adult
Schorr et al., (2019)	USA	Cross sectional	To investigate bone mineral density & hip strength in men with AN, ATYP and ARFID	Adult

Trompeter et al., (2019)	Australia	Between Subject	To investigate whether fear of negative evaluation is associated with a greater likelihood of developing an ED	All
Zickgraf et al., (2019)	USA	Retrospective Chart review	To describe clinical characteristics of patients diagnosed with selective/neophobic presentation of ARFID	Child & Adolescents
Alberts et al., (2020)	UK	Retrospective Chart review	To measure mineral bone density in ARFID & AN; found BMD not as important as ARFID in AN	All
Aulinas et al., (2020)	USA	Exploratory cross-sectional	To understand medical complications and endocrine iterations in ARFID vs. AN vs. HC	Child & Adolescents
Cerniglia et al., (2020)	Italy	Between Subject	To assess the differences between the three groups regarding and comparing it to a control group, regarding: emotional behavioural functioning, quality of mother-child feeding interactions, and maternal psychopathological risk.	Child & Adolescents
Kambanis et al., 2020)	USA	Survey	To assess prevalence of psychiatric conditions and suicidality in those with ARFID	All
Tsang et al., (2020)	USA	Retrospective Chart review	To examine levels of orexigenic ghrelin and anorexigenic peptide YY in ARFID, AN & HC	Child & Adolescents
Zickgraf et al., (2020)	USA	Between Subject	To identify selective eating patterns in different populations including ARFID	Child & Adolescents
Becker et al., (2021)	USA	Between Subject	To characterise patients who need hospital admissions for ARFID	Child & Adolescents
Burton Murray et al., (2021)	USA	Survey	To highlight gastroenterological difficulties in ARFID patients	Child & Adolescents
Cañas et al., (2021)	Spain	observational comparative	To examine sociodemographic and clinical difference between ARFID, AN & HC	Child & Adolescents
Chew et al., (2021)	China	Retrospective Chart review	Description of the diversity of children with restrictive early onset eating disorders and comparison to older adolescents with eating disorders	All
Cimino et al., (2021)	Italy	Between Subject	To explore the interplay between Children's dopamine transporter (DAT1) genotype and methylation, dysregulation and maternal	Adult
Cooper et al., (2021)	USA	Retrospective Chart review	To examine gastrointestinal history of weight-related discharge outcomes in underweight inpatients with AN and ARFID	All

Hilbert et al., (2021)	Germany	Validation Study	To examine the symptoms in adults and evaluating the Eating Disorders Youth Questionnaires (EDY-Q)	All
Inoue et al., (2021)	Japan	Between Subject	To assess comorbidity of ASC in AN and ARFID	All
Kerem et al., (2021)	USA	Within Subject	To establish co-existence of ARFID and being overweight/obese; to characterised neurobiological features of ARFID	Child & Adolescents
Lin et al., (2021)	USA	Between Subject	To assess the association of malnutrition, pre-morbid weight status and ED illness duration with symptoms of anxiety & depression	Child & Adolescents
Murray et al., (2021)	USA	Between Subject	Assess interactions between gut problems and ARFID	Child & Adolescents
Nadeau et al., (2021)	USA	Between Subject	Assesses selective eating in children with ASC and ARFID	Child & Adolescents
Nicholas et al., (2021)	USA	Between Subject	Attempts to address gap by characterising presentation of ARFID in adults with and without	Child & Adolescents
Schmidt et al., (2021)	Germany	Between Subject	To examine and consider the presence of ARFID in paediatric clinical samples	Child & Adolescents
Schöffel et al., (2021)	Germany	Between Subject	To systematically assess and analyse the food intake in ARFID individuals who have sought treatment	Child & Adolescents
Zanna et al., (2021)	Italy	Retrospective Chart review	To compare clinical characteristics of restrictive EDs including AN, Atypical AN and ARFID	Child & Adolescents

3.2.1.4. Treatment

The articles found in this section focused on the treatment of ARFID (n=24). To mirror Bourne's (2020) review, these were further subcategorised into a) Psychological treatment (n=16), b) Pharmacological Treatment (n=4), and c) a Multi-Modal approach (n=4). Please see Table 4 for more details.

a) Psychological treatment

Sixteen studies focused on psychological treatment, of which some explored cognitive behavioural therapy (CBT) as an effective treatment for ARFID. CBT approaches were largely used to formulate and challenge fears associated with eating and anxieties about consuming food, in the absence of weight and shape concerns (Thomas et al., 2020). Some of these studies aimed to compare its efficacy when contrasting treatments for those with AN (Wagner et al., 2020, Maginot et al., 2017). While ARFID presents heterogeneously, there is no current evidence that the different presentations necessitate different interventions. As demonstrated by Durmont et al. (2019), a flexible CBT approach may be useful in treating ARFID with differing presentations (Bourne et al. 2020). To further validate this hypothesis, more studies should focus on exploring the heterogeneity of the disorder and test patient responses to the administered treatment.

Family Based Treatment (FBT) was also discussed as a means to treat ARFID (Lock et al., 2019,Lock, 2021,). FBT is commonly used within EDs as it empowers caregivers, reduces familial guilt and supports recovery at home. FBT-ARFID is similar in that respect but also addresses the different ARFID presentations including sensory sensitivity, lack of interest and fear of aversive consequences (Lock et al., 2019). While this is a promising

treatment avenue that has signalled great success for other restrictive EDs, it would be beneficial to have RCTs or larger scale studies to confirm these findings.

In addition to FBT, a number of papers focused on the role of parents and how they may provide and implement interventions at home. Including behavioural approaches generally (Brown & Hildebrandt, 2020), or behavioural activation that might promote routines of exploration and play during meal times (Caldwell et al., 2018), as well as cognitive-behavioural family based interventions (Lane-Loney et al., 2020). Research has shown that caregivers can also support children who engage in selective eating through teleconsultation and attendance at group educational sessions (Dahlsgaard & Bodie, 2019).

b) Pharmacological treatment

Four studies described the benefits of pharmacological treatment of ARFID, specifically using medication and therapeutic interventions in conjunction with one another (Gorrell et al., 2020). Due to its success when treating AN (Brewerton, 2012), Olanzapine specifically has been highlighted as a another treatment strategy to relieve anxiety and heighten appetite (Brewerton & D'Agostino, 2017).

Sharp et al. (2017), conducted a double-blind, placebo controlled study to explore the use of medication when treating chronic food refusal. Participants (n=15) who had a diagnosis of ARFID were randomly assigned to one of two conditions. While all participants were given daily intensive behavioural interventions, only eight of these were also given D-cycloserine (DC), as an adjunct to their psychological therapy. DC is a drug that supports the receptors within the amygdala, which enhance learning and memory. It is thereby a different way of supporting behavioural therapy. DC was found to enhance the response to the

behavioural intervention, although larger clinical trials are necessary to confirm this finding (Bourne et al. 2020).

c) Multi-modal approach

Four papers focused on a multi-modal approach to treat ARFID, of which many focused on the role of multidisciplinary interventions for treating children with feeding disorders (Serban et al., 2020), including expertise from dieticians, psychologists, speech and language therapists, psychiatrists and other medical health professionals. A randomised pilot trial investigated the treatment of chronic food refusal in a day treatment programme, which showed promising results in effectively addressing the challenging nature of food refusal and confirms the efficacy of multi-modal treatment options (Sharp et al., 2016).

Table 4

Summary of ARFID articles relating to research evidence & treatment

Authors, (Year)	Country	Type of Treatment	Study Design	Study Aim	Treatment / study	Age Group
Sharp et al., (2016)	USA	Multi Modal	Pilot Study	To investigate the preliminary efficacy and feasibility of a manual based behavioural feeding intervention, for those with chronic food refusal or enteral feeding depedency	Manual based behavioural feeding intervention, including integrated eating aversion treatment. Follow up - 1 month post treatment	Child & Adolescent
Maginot et al., (2017)	USA	Multi-modal	Retrospective Chart review	To evaluate whether a higher calories rehabilitation protocol for treating inpatients with restrictive EDs is safe	Inpatient nutritional rehabilitation protocol. 15.3 days average stay	Child & Adolescent
Brewerton & D'Agostino, (2017)	USA	Pharmacological	Retrospective Chart review	To record the clinical development of ARFID patients treated with low doses of adjunctive olanzapine	low—dose olanzapine (alongside meal /behavioural therapy and other treatment modalities offered to ED patients). Olanzapine treatment average 53.4 ± 22.4 days	Child & Adolescent
Sharp et al., (2017)	USA	Pharmacological	Double blind, placebo	To examine the preliminary efficacy and feasibility of combing D-cycloserine with a behavioural intervention for children with chronic food refusal	Randomisation to intensive behavioural intervention + D-cycloserine + placebo over 5 days (15 meals in total). Follow up - 1 month post treatment	Child & Adolescent
Caldwell et al., (2018)	USA	Psychological	Pre-post Study	To examine the use of behavioural activation to train parents in managing mealtimes for children with sensory aversions in their home environment	Promoting Routines of Exploration and Play During Mealtime intervention (for 18-36mths old children)	Child & Adolescent
Dahlsgaard & Bodie, (2019)	USA	Psychological	Pre-post Study	To report the feasibility, acceptability and initial outcomes of the Picky Eaters Clinic	7 sessions (90 mins each) of parent led behavioural intervention. follow up - 3 months post treatment	Child & Adolescent

Gray et al., (2018)	USA	Pharmacological	Pre-post Study	To evaluate the use of mirtazapine as treatment for ARFID	6 patients treated with mirtazapine as monotherapy and 8 on additional medications Average dose of Mirtazapine was 25.5mg Follow up - 6-months post treatment and monthly follow-ups after that	Child & Adolescent & Adult
Guss et al., (2018)	USA	Multi Modal	Survey	To assess the inpatient medical management of adolescents with ARFID		NA
Clark et al., (2019)	USA	Multi-Modal	Pre-post Study	To examine the role of telehealth and how this enhances interdisciplinary feeding treatment	Treatment from different disciplines including dietetics, psychologists, SLT	Child & Adolescent
Lock et al., (2019)	USA	Psychological	Feasibility Study	To measure the feasibility of conducting an RCT comparing FBT-ARFID to usual care	Participants were randomised to receive a) immediate treatment with FBT for ARFID or b) usual care for a period of 3 months (and then offered FBT-ARFID)	Child & Adolescent
Prasetyo, Pramaisela, et al., (2019)	Indonesia	Psychological	Cross sectional	Analysing effect of parental engagement in ARFID treatment	Promoting parental involvement	Child & Adolescent
Brown & Hildebrandt, (2020)	USA	Psychological	Pre-post Study	To explore feasibility of parent facilitated behavioural treatment (based on learning theory and Family based treatment)	Treatment involves components of empirically support FBT for EDs augmented with anxiety interventions such as food hierarchies	Child & Adolescent
Crowley et al., (2020)	USA	Psychological	Pre-post Study	To treat change-resistant feeding behaviour of 7 young children with ASD	Matching-law based interventions	Child & Adolescent
Gorrell et al., (2020)	USA	Pharmacological	Retrospective chart review	To explore whether psychotropic medication might be useful to treat EDs	Explore patterns of medication use	Child & Adolescent
Lane-Loney et al., (2020)	USA	Psychological	Retrospective chart review	To describe a flexible, cognitive behavioural, family orientated programme on ARFID presenting within a larger PHP for eating disorders	Family centred CBT programme	Child & Adolescent

Serban et al., (2020)	USA	Multi Modal	Pre-post Study	Assessing the economic feasibility of the intensive treatment programmes for paediatric treatment programmes (ARFID included)		
Shimshoni et al., (2020)	USA	Psychological	Pilot Study	To assess the acceptability, feasibility and treatment satisfaction of Supportive Parenting for Anxious Childhood Emotions in ARFID	Supportive Parents for Anxious Childhood Emotions	Child & Adolescent
Thomas et al., (2020)	USA	Psychological	Pre-post Study	to evaluate acceptability, feasibility and proof-of-concept for cognitive-behavioural therapy for ARFID (CBT-AR) in children and adolescents	20-30 sessions of CBT-AR	Child & Adolescent
Wagner et al., (2020)	USA	Psychological	Pre-post Study	To measure caregiver accommodation and how this might affect treatment of ARFID and AN	individuals in a PHP were asked to participate with similar levels of accommodation	Child & Adolescent
Couturier et al., (2021)	Canada	Psychological	Retrospective Chart review	To develop adapted clinical practice guidelines for the provision of virtual care for children and adolescents living with an eating disorders, during the COVID-19 pandemic and beyond	Psychological interventions including, CBT, FBT and MANTRA	Child & Adolescent
Kirkwood et al., (2021)	USA	Multi Modal	Replication Study	To examine the extinction procedures to treat food or liquid refusal	Extinct procedures	Child & Adolescent
Lock, (2021)	USA	Psychological	Pre-post Study	Confirming the Efficacy and Mechanisms of FBT for Children with low weight ARFID	FBT	Child & Adolescent
Mensi et al., (2021)	Italy	Psychological	Pre-post Study	To Assess family functioning in families before and after treatment for ARFID	Family Feeding Programme	Child & Adolescent
Prasetyo et al., (2021)	Indonesia	Psychological	Cross Sectional	To understand and analyse the effect of environmental factors, child factors and caregiving behavioural systems and the family's ability to care for the child	Promoting behavioural interventions in the family	Child & Adolescent

3.2.1.5. Clinical outcomes

Due to the recent addition of ARFID to the psychiatric nosology, there is a paucity of research that has monitored outcomes comparatively to other EDs (Bourne et al. 2020). Within this leg of evidence-based practice, 16 papers focused on clinical outcomes. Of these papers, 14 papers concentrated on short term clinical outcomes for ARFID amongst a larger and heterogeneous sample of other restrictive EDs, please see Table 5 for more detail.

A number of articles in this category specifically focused on the comparison between clinical outcomes of ARFID in contrast to other EDs (Espel-Huynh et al., 2020, Reilly et al., 2020) or AN specifically (Kurotori et al., 2019, Norris et al., 2020, Trompeter et al., 2021, Nakai et al., 2017). Studies comparing weight gain in ARFID comparatively to AN have had varying results, with some showing that ARFID patients required longer periods of inpatient admissions than those with AN (Strandjord et al., 2015), whilst others indicated that there was no significant difference in weight gain across the two conditions (Fjeldstad et al., 2021).

Additionally, one study focused on inpatient nutritional rehabilitation (Peebles et al., 2017). Although this study was limited through a small sample, it indicated that ARFID patients are more likely to rely on nasogastric feeds and their weight restoration may take longer than for patients with other EDs (Bourne et al. 2020).

It is important to distinguish between the treatments employed in these studies, as some might address weight restoration with specific emphasis on weight and shape concerns. As those with ARFID do not experience a desire to get thinner, treatment may not have been adequately tailored to this population. Thus, recovery rates may vary, as the idiosyncratic nature of ARFID has not been taken into consideration. This results in a limitation of the current literature, which does not allow for an arcuate judgment of recovery rates.

Clinical outcome papers focused on ARFID exclusively included studies concentrating on inpatient nutritional rehabilitation (Strandjord et al., 2015), outcomes after hospitalisation (Kapphahn et al., 2017, Ornstein et al., 2017, Makhzoumi et al., 2019) and the use of telehealth to provide outpatient follow up (Peterson et al., 2021). These studies seem to exclusively focus on physical rehabilitation and rely largely on medically monitoring low-weight patients. Outcomes relating to weight restoration alone do not provide a comprehensive picture of ARFID recovery, further studies should explore psychological or psychosocial recovery rates, to provide a holistic understanding of how we can treat ARFID effectively.

Two papers contributed to longer-term outcome data for ARFID, as found by Bourne et al. (2020). Lange et al., (2019) followed 56 children, who were originally treated for low-weight EDs after a mean of 15.9 years. Results indicated that ARFID, in contrast to other EDs, maintained its presentation giving insight into the symptomatic stability of the condition. Another study focused on weight restoration at 11 years of age after being diagnosed with infantile anorexia and ARFID. Results indicate that 61% still exhibited moderate to severe malnutrition (Lucarelli et al., 2018) after treatment. No further studies were conducted with long-term outcome data for ARFID.

Table 5

Summary of ARFID articles relating to research evidence & clinical outcomes

Author (year)	Country	Study Design	Aim	Treatment	Age Group
Strandjord et al. (2015)	USA	Retrospective Chart Review	To compare patients with AN and ARFID (regarding differences in treatment response, presentation and 1-year outcomes)	Patients hospitalised for medical stabilisation Follow-up - 1 year after discharge	Child & Adolescent
Kapphahn et al. (2017)	USA	Retrospective Chart Review	To assess outcomes at for patients who were hospitalised and those who were not at a 1-year follow up	Different treatments: medical hospitalisation, psychiatric hospitalisation, residential ED treatment, intermediate level care and outpatient treatment	Child & Adolescent & Adult
Nakai et al. (2017)	Japan	Retrospective Chart Review	To compare the clinical presentation of AN and ARFID	Inpatient treatment programme, including individual somatic therapy and psychotherapy; and nutritional management and enteral feeding Patients stayed less than 3 mths; Follow-up 85.2 mths	
Peebles et al. (2017)	USA	Pre-post Study	To evaluate outcomes at admission, discharge and 4-week follow up for patients with ED	Medical stabilisation for inpatients nutritional rehabilitation. Follow up at 4 weeks after discharge	Child & Adolescent & Adult
Ornstein et al (2017)	USA	Retrospective Chart Review	To compare outcomes of being treated in a family centred PHP for EDs and ARFID	PHP focusing on significant weight loss and failure to gain weight as a result of severe food restriction (5 days per week of 8.5hrs a day)	Child & Adolescent
Lucarelli et al. (2018)	Italy	Longitudinal	Analysing relationship between severity of malnutrition and subsequent emotional / behavioural development and mothers long term psychopathological symptoms	Patients and mothers receiving psychoeducation at time of diagnosis, but disengaged for various reasons Patients mean age of 2 and thereafter at 5, 7 and 11 years	Child & Adolescent & Adult
Kurotori, I. (2019)	Japan	Retrospective Chart Review	Comparison of characteristics and outcomes of ARFID and restrictive AN in Japan	Hospitalisation for medical stabilisation	Child & Adolescent

Lange et al. (2019)	Sweden	Longitudinal	Comparing long term outcomes between low weight ARFID and childhood onset AN; regarding: psychiatric diagnosis, social and occupational functioning	Follow up after a mean 15.9 years	Adults
Makhzoumi et al. (2019)	USA	Retrospective Chart Review	To assess weight restoration and outcomes of patients with AN and ARFID	The John Hopkins IP-PHP including meal-based behavioural rapid refeeding protocol and dialectical-behavioural, cognitive-behavioural and family based therapies	Child & Adolescent & Adult
Espel-Huynh et al. (2020)	USA	Pre-post Study	Assess treatment trajectories of different EDs of patients treated in residential care	Residential care packages	Child & Adolescent & Adult
Reilly, et al. (2020)	USA	Longitudinal	Exploring longitudinal naturalistic outcomes for Eating Disorder's in a day patient hospital	Hospital treatment	Child & Adolescent
Norris et al. (2020)	Canada	Retrospective Chart Review	Examining treatment trajectories of those initially diagnosed with ARFID, later reconceptualised as AN	Family and individual treatment and psychotropic medication	Child & Adolescents
Trompeter et al. (2020)	Australia	Between subject	Comparison of clinical outcomes for those being treated for EDs and those living in the community	Treatment provided within ED specific settings	Child & Adolescent
Fjedlstad et al. (2021)	Denmark	Longitudinal	Longitudinal study re: Understanding weight gain trajectories between ARFID & AN	Weigh restorative treatment	Adults
Peterson et al. (2021)	USA	Pilot Study	Analysis of whether telehealth follow ups influence clinical outcomes	Using telehealth as a follow up	Child & Adolescents

3.2.2. Stool leg 2 – Clinical expertise

Articles were placed in this section if they were opinion pieces by clinicians, or case reports which drew on idiosyncratic findings of (a) specific individual(s).

Within this section, 61 articles were identified to be part of the second leg of evidence-based practice, including 5 articles on diagnosis and assessment, 27 articles focusing on clinical characteristics and 29 on treatment.

3.2.2.1. Diagnosis & assessment

Five papers were identified to focus on Diagnosis and Assessment (Table 6). Papers in this subsection focused on the new addition of ARFID as a diagnostic entity in the DSM-5 and whether this allowed for a more accurate characterisation of the heterogeneous client group, which authors largely agree it does (Claudino et al., 2019, Thomas et al., 2015, Amoretti, 2021). Case reports in this section primarily focus on the impact of delay in diagnosis (Rajendram et al., 2021), or other health conditions masquerading as ARFID (McDonald et al., 2021). Thus, highlighting common difficulties those with ARFID experience in their journey to obtaining a valid diagnosis.

Table 6

Summary of ARFID articles relating to clinical expertise & diagnosis and assessment

Author (Year)	**Country**	**Type of Paper**	**Purpose of Study**	**Age Group**
Thomas et al., (2015), USA	USA	*Commentary*	Analysis of the reliability of diagnoses of the new DSM-5 criterion	
Claudino et al. (2019)	Italy	Research Paper	Assess recommended changes in the ICD, examining clinician's ability to consistently used the new guidelines and establish their overall clinical utility.	
Amoretti, (2021)	Italy	Commentary	Discussion of whether Feeding Disorders should be classified as a mental disorder and whether they show dysfunction and distress	
McDonald et al., (2021)	Canada	Case Report	ARFID as secondary to health diagnosis	Child & Adolescent
Rajendram et al., (2021)	Canada	Case Report	Example of delayed diagnosis of ARFID	Child & Adolescent

3.2.2.2. Clinical characteristics

Clinical characteristics were discussed within 27 papers, whilst being part of the second leg of evidence-based practice, clinical expertise. Please see Table 7 for more details.

While a section of these studies focus on the treatment and description of clinical characteristics within the heterogeneous group (Pitt & Middleman, 2018), the literature also illustrates how ARFID may present with various medical and psychiatric comorbidities, such as attention deficit hyperactivity disorder, autism, internet gaming disorder and traditional eating disorder pathology (Bryant-Waugh, 2013, Chandran et al., 2015, Pennell et al., 2016, Lucarelli et al., 2018, Hadwiger et al., 2019, Becker et al., 2020, Benezech et al., 2020, Lim et al., 2020, Lin et al., 2021, Oliveira, 2021, Sato et al., 2020, Soffritti et al., 2020, Strand, 2021). Further, ARFID patients show a high degree of co-morbidity with anxiety disorders (Norris et al., 2018a), but patients are less likely to develop a mood disorders than those with other EDs (Fisher et al., 2014). Although these studies show important information about the heterogeneous client group, it would be beneficial to have large studies or case series to give more weight to the existing findings.

Case studies also illustrated how ARFID may develop in light of various secondary medical (Chiarello et al., 2018, Burton Murray et al., 2020) or psychiatric illness (Kambanis et al., 2020) including food avoidance in light of drug abuse (Lazare, 2017) and OCD (Coelho et al., 2019). Other studies show food restriction as a consequences of gastrointestinal discomfort post-surgery (Tsai et al., 2017), while there are two studies of ARFID occurring in conjunction with psychosis (Wassenaar et al., 2018, Westfall et al., 2018)

According to its diagnostic criteria, ARFID often presents as being driven by either (i) sensory sensitivity, (2) lack of interest in food or (3) fear of the aversive consequences of

food. Nevertheless, there is currently no conceptual or empirical evidence that indicates that these discrete groups exist (Bourne et al. 2020). Rather, that ARFID may present alongside a myriad of psychological and physical disorders which may account for the consistently broad range of ARFID presentations (Bourne et al. 2020).

Table 7

Summary of ARFID articles relating to clinical expertise & clinical characteristics

Authors, (Year)	Country	Type of Paper	Study Aim	Treatment / study	Age Group
Bryant-Waugh, (2013)	UK	Case Report	To present an example of a patient with ARFID	CBT intervention with parental involvement; strategies included cognitive restructuring, goal setting and anxiety management.	Child & Adolescents
Chandran et al., (2015)	Australia	Case Report	To discuss an ARFID patient with multiple complex medical co-morbidities	Inpatient setting with MDT approach. Nasogastric tube feeing, anxiety medication, psychotherapy and family therapy	Child & Adolescents
Pennell et al., (2016)	Canada	Case Series	To report two cases of patients with comorbid ADHD and ARFID	(1) Inpatient case with 0.5mg risperidone, hoping restore appetite and tackle anxiety followed by biweekly outpatient care. (2) Inpatient care, 30mg of risperidone and similar parameters to the first patient	Child & Adolescents
Lazare, (2017)	Canada	Case Report	To describe a patient with a diagnosis of ARFID, complicated by cannabis used and a subsequent diagnosis of Addison's disease	Admittance to inpatient medicine service to treat Addison's disease	Adult
Lucarelli et al., (2018)	USA	Case Report	To present a case of a girl with ARFID and autism	Feeding therapy (systematic desensitisation approach with subsequent rewards)	Child & Adolescents
Maertens et al., (2017)	Canada	Case Series	To discuss present two cases with significant weight loss, fear of vomiting and food restriction	(1) 20mg Escitalopram and 5mg Olanzapine (1xdaily). CBT offered for exposure to germs and contamination and for body image acceptance (2) admitted to ED unit at 13-years old. 5mg Olanzapine, later switched to 25 mg Clomipramine. CBT with graded exposure to address illness fears	Child & Adolescents
Schermbrucker et al., (2017)	Canada	Case Report	To report a case of ARFID and the role of culture in diagnosis	Admittance to ED unit for nasogastric feeding and weight restoration. Fluoxetine to target anxiety symptoms; unsuccessful treatment with food exposure Follow-up 2 months post discharge	Child & Adolescents

Thomas et al., (2017)	USA	Case Report	To describe a case of ARFID following to an acute choking incident	Hospitalisation; subsequent CBT to target choking phobia and to diversify dietary intake. Follow up 1 year after initial assessment	Child & Adolescents
Tsai et al., 2017)	USA	Case Report	To present a case of ARFID resulting from testicular cancer surgery	22-day inpatient stay, liquid nutritional supplements, IV fluid administration 7.5mg mirtazapine.	Adult
Chiarello et al., (2018)	Italy	Case Report	To present someone ARFID	Inpatient admittance with MDT approach, by outpatient CBT and parental psychoeducation	Adult
Pitt & Middleman, (2018)	USA	Case Series	To present two cases of ARFID	Hospitalisation for malnutrition including nasogastric tube, family therapy and behavioural treatment plans to reinforce oral food consumption	Child & Adolescents
Wassenaar et al., (2018)	USA	Case Series	To present the case of ARFID with comorbid psychosis, Gitelman Syndrome	inpatient care including specialised ED treatment, Medication & nutritional rehabilitation	Adult
Westfall et al., (2018)	USA	Case Series	To present a case of ARFID with comorbid religious delusions and psychosis	Olanzapine 5mg daily for psychosis and weight gain. Patient subsequently disengaged. Readmitted after 15 months and placed on nasogastric feeding. Trial of olanzapine, haloperidol, crypoheptadine, megestrol and risperidone acetate failed. Clozapine resolved acute psychosis and refusal to eat.	Child & Adolescents
Hadwiger et al., (2019)	USA	Case Report	To present two cases with ARFID and internet gaming disorder	Inpatient treatment for refeeding, malnutrition protocol, psychoeducation and family therapy.	Child & Adolescents
Lai et al., (2019)	Singapore	Case Series	To describe the clinical profile of ARFID patients	Inpatient / outpatient treatment with MDT team. patients took part in nutritional rehabilitation with a dietician and two were referred to psychologists	All
Becker et al., (2020)	USA	Case Series	To discusses the overlap between ARFID and traditional shape and weight concerns	Treatment focused on weight gain	Child & Adolescent
Benezech et al., (2020)	USA	Case Report	To examine Scurvy as a consequence of restrictive diet	Treatment for scurvy	Child & Adolescent
Lim et al., (2020)	Singapore	Case Report	To explore different care options for a 20months old boy with ARFID	Weight restoration and hospitalisation	Child & Adolescent
Sato et al., (2020)	Japan	Case Report	To explore gluten intolerance and dairy intolerance in an individual with ARFID	Medically focused treatment	Child & Adolescent

Soffritti et al., (2020)	Spain	Case Report	To present a Case of ARFID with atypical development including Downs Syndrome	Initially medical treatment	Adult
Yanagimoto et al., (2020)	Japan	Case Report	To explore physical repercussions of ARFID including: Iron deficiency anaemia, stunted growth and developmental delay	Focus on nutritional treatment	Child & Adolescent
Jackson et al., (2021)	New Zealand	Research Paper	To explore changes in perspective from 2013 to 2018 regarding understanding of pick eating amongst health professionals (medical practitioners, dietitians and SLT)	Quantitative and Qualitative study exploring understanding re: ARFID amongst professionals	Adults
Lin et al., (2021)	USA	Overview	To review most common oral and gastrointestinal manifestations of ED's and the emergency complications (acute gastric dilation and superior mesenteric artery syndrome)	Medical treatment for comorbid difficulties in EDs	Adults
Mensi et al., (2021)	USA	Commentary	To comment on why gastroenterologist should consider ARFID	Understanding ARFID in context of gastroenterological difficulties	Child & Adolescent & Adult
Strand, (2021)	Sweden	Commentary	To explore colour based food preferences in autism and ARFID		

3.2.2.3. Treatment

The articles found in this section focused on the treatment of ARFID (n=29), please see Table 8. These were further subcategorised into a) Psychological treatment (n=17), b) Pharmacological Treatment (n=2), and c) Multi-Modal (n=10).

a) Psychological treatment

There were 17 papers on the psychological treatment within the clinical expertise leg of evidence-based practice.

Largely, these papers were case reports with unique or specifically complex cases discussing similar approaches as the research papers, including CBT (King et al., 2015, Aloi et al., 2018, Görmez et al., 2018), FBT (Matheson et al., 2020) and parental home support (Fischer et al., 2015). In contrast to the majority of research papers, case reports often detailed how to adapt treatment for adults (Marino et al., 2020), or discussed cases with complex co-morbidities. This section gives insight into the difference between larger scale research papers that often have strict inclusion criteria and are looking for homogeneity, and the reality of treating a disorder in clinically based settings. Case reports in this section thereby provide information on how these may be treated effectively should ARFID be one of many difficulties encountered by the client, rather than the only one.

b) Pharmacological treatment

Within case reports, Buspirone (Okereke, 2018) and Mirtazapine (Tanıdır & Hergüner, 2015) have also been presented as treatment strategies, although Mirtazapine has

shown varying results, with a potential increase in anxiety with increased dosage (Gray et al., 2018). To validate these findings larger scale studies may be useful.

c) Multi-modal approach

Eight of the studies in this section focused on a multi-modal approach. These were case reports focusing on the development and implementation of telehealth in treatment (Clark et al., 2019), specifically its involvement in facilitating interdisciplinary treatment, whilst also discussing the implications of the COVID-19 pandemic (Cooper et al., 2020). However, many of these papers are brief opinion pieces that present an overview of the pertinent risk factors in eating disorders during COVID-19. While the papers offer ideas for modifying the intervention to accommodate for the unique challenges presented by the pandemic, they do not offer evidence as to whether these interventions have been successful thus far.

Some of the reports in this section also offered insight into the efficacy of combining already existing treatments such as family based and trans-diagnostic treatments (Eckhardt et al., 2019) , which have been successful for individuals discussed within case reports. The idea of combining different treatment modalities or treatments has not yet been established within the first leg of evidence-based practice, and future papers may want to focus on making the above findings more generalisable.

Table 8

Summary of ARFID articles relating to clinical expertise & treatment

Authors, (Year)	Country	Type of Paper	Type of Treatment	Study Aim	Treatment / study	Age Group
Fischer et al., (2015)	USA	Case Report	Psychological	To evaluate an intervention for chronic food selectivity in an adolescent with ARFID	Intervention combining clinical (Behavioural treatment and CBT) and simultaneous in-home component (enforced by parents). Follow up 1- and 3- months post treatment.	Child & Adolescent
King et al., (2015)	USA	Case Report	Psychological	To present a case of ARFID successfully treated with CBT	Inpatient treatment – 8 session of CBT including psychoeducation, cognitive restructuring, systemic desensitisation (in vivo exposure) Follow up 8-months post treatment.	Child & Adolescent
Tanıdır & Hergüner, (2015)	Turkey	Case Report	Pharmacological	To present a case of ARFID treated with mirtazapine	Initial behavioural approach. Initial 10 mg/day fluoxetine which was increased to 30 mg/day for 2 months without success 15 mg/day mirtazapine for 6 months successful	Child & Adolescent
Murphy & Zlomke, (2016)	USA	Case Report	Psychological	To present a case of ARFID treated with behavioural feeding intervention	Behavioural feeding intervention with parent involvement Follow up - 6 weeks post treatment	Child & Adolescent
Aloi et al., (2018)	Italy	Case Report	Psychological	To use CBT with family involvement in treating ARFID	CBT with family involvement	Adult
Brigham et al., (2018)	USA	Commentary	Multi Modal	To evaluate the current treatment plans available for ARFID		All
Görmez et al., (2018)	Turkey	Case Report	Psychological	To present a case of ARFID treated with CBT	CBT with in vivo exposure, systematic desensitisation and cognitive restructuring	Adult

Lenz et al., (2018)	USA	Case Report	Multi-modal	To present ARFID case successfully treated with intensive inpatient behavioural intervention	Initial outpatient treatment within CBT framework (family & individual therapy) Subsequent inpatient admission. follow up - 4 months post discharge.	Child & Adolescent
Okereke, (2018)	USA	Case Report	Pharmacological	To present ARID case successfully treated with buspirone	Individual and family therapy 50mg/day Sertraline Buspirone 5mg (2x daily) increased to 7.5mg (2x daily) at 1 month follow up and 10 mg (2x daily) at 6 month follow up Follow-up - 1,2,4,6 and 8 months post treatment	Child & Adolescent
Spettigue et al., (2018)	Canada	Case Series	Psychological	To examine treating ARFID with modified FBT / psychopharmacological treatment	FBT & CBT Medication: Olanzapine, fluoxetine and cypoheptadine	Child & Adolescent
Bloomfield et al., (2019)	USA	Case Report	Psychological	To examine treating ARFID with teleconsultation	Parent teleconsultation (behavioural intervention to increase variation in diet) Follow up - 1 & 4 months post treatment	Child & Adolescent
Dumont et al., (2019)	The Netherlands	Case Series	Psychological	To examined a 4-week exposure based CBT day treatment for adolescent with ARFID	CBT treatment based on exposure, designed to address a variety of ARFID presentations follow up - 3 months post treatment	Child & Adolescent
Eckhardt et al., (2019)	USA	Case Report	Multi Modal	To explore a treatment plan for a 9-year-old, combing FBT with trans-diagnositic treatment for emotional disorders	FBT Trans-diagnostic treatment for emotional disorders	Child & Adolescent
Lock, Robinson, et al., (2019)	USA	Case Series	Psychological	To illustrate the use of FBT in three case reports	FBT	Child & Adolescent
Milano et al., (2019)	USA	Overview	Multi Modal	To examine different approaches of dealing with feeding disorders in a variety of settings		Child & Adolescent

Naviaux, (2019)	Ireland	Case Report	Multi Modal	To shed light on how ARFID is treated on paediatric wards	Use of mirtazapine, partial hospitalisation model and FBT	
Taylor et al., (2019)	Australia	Case Report	Psychological	To assess treatment for ARFID with older individuals	Use of behavioural intervention	Child & Adolescent
Yaşar et al., (2019)	Turkey	Case Report	Psychological	To conceptualise how trauma may lead to EDs	EDMR and CBT	Adult
Zucker et al., (2019)	USA	Case Report	Multi Modal	To present an ARFID case treated with acceptance based interceptive exposure	8 weekly sessions and subsequent 4 bi-monthly sessions of acceptance based interceptive exposure treatment, Feeling and Body investigators (FBI)–ARFID division	
Bryant-Waugh, (2020)	UK	Commentary	Psychological	To discuss the role of kindness when recognising, treating and understanding ARFID		
Cooper et al., (2020)	USA	Commentary	Multi Modal	To present literature related to the risk of EDs in the context of the COVID-19 pandemic and how interventions may be modified		
Matheson et al., (2020)	USA	Overview	Psychological	To give recommendations to administered FBT via Telehealth	FBT	Child & Adolescent
Marino et al., (2020)	USA	Case Report	Psychological	To present possibility of treating ARFID with DBT	DBT	Child & Adolescent
Rienecke et al., (2020)	USA	Case Report	Psychological	To present treatment for the three subtypes of ARFID	Adapted eating disorder treatment	Child & Adolescent
Rosania & Lock, (2020)	USA	Case Report	Psychological	To explore use of FBT in a 9-year-old with sensory sensitivity and ARFID	FBT	Child & Adolescent
Chen et al., (2021)	China	Commentary	Multi-Modal	To describe and evaluate the different treatment modalities for EDs in China	NA	NA
Dolman et al., (2021)	USA	Case Report	Multi Modal	To examine successful multi-modal treatment for a boy with ARFID	CBT, FBT, pharmacological	Child & Adolescent

Magel et al., (2021)	Canada	Commentary	Psychological	To provide an overview of ARFID and how community clinicians can be trained to treat it appropriately	N	NA
Taylor, (2021)	Australia	Case Report	Psychological	To provide further insight into exit criterion treatment	Treatment was solely behaviour-analytic and consistent of demand fading, choice, differential attention, contingent access and exit criterion Conducted repeated edible preference assessments and used a changing criterion single case experimental design across three food variety groups of decreasing preference	Child & Adolescent

3.2.3. Stool leg 3 – Patient preference

Articles were placed within this leg of evidence-base practice, if the views, experiences, or the voice of services users or stakeholders were included.

Only one article was identified to be part of the third leg of evidence-based practice. This article focused on clinical outcomes.

3.2.3.1. Clinical outcomes

The only study that was found as part of the third leg of evidence-based practice – Patient preference – was found within this section (Table 9). Richmond et al. (2020) conducted a qualitative study focusing on the definition of recovery from EDs. The study outlined how recovery might be defined differently by different stakeholders, and involved the perspective of patients, their parents and clinicians. Results indicated that there was focus on (a) psychological wellbeing, (b) eating-related behaviours and attitudes, (c) physical markers and (d) self-acceptance of body image. The study indicated that clinicians focused primarily on theme a and c in terms of understanding recovery in contrast to patients and parents, who found theme b equally important. This study also highlights the difficulties of comparing EDs that are influenced by weight and shape concerns, ie, AN and BN, with a condition such as ARFID. For example, self-acceptance of body image will not be as relevant for individuals recovering from ARFID as it may be for other EDs. Conducting research papers that include the opinion of stakeholders specifically for ARFID may be beneficial to understanding the field better. Moreover, this study highlights the importance of involving stakeholders in discussions around clinical parameters to promote effective treatment management.

Table 9

Summary of ARFID articles relating to patient preference & clinical outcomes

Author (year)	Country	Type of Paper	Aim	Treatment	Age Group
Richmond et al. (2020)	USA	Research Paper	Understanding the different definition of recovery by different stakeholders	Qualitative examination of 'recovery' as a concept in ED	Child & Adolescent & Adult

4. Discussion

This systematic scoping review aimed to (1) map the literature onto the three-legged stool of evidence-based practice according to Sackett and (2) identify key gaps in the evidence base.

4.1. Research evidence

In summary, since its introduction to the DSM-5 in 2013, research and clinical interest in ARFID has grown (Bryant-Waugh et al., 2021). Bourne's scoping review, conducted in 2020 yielded a total of 77 papers to analyse, this review analysed 171 papers. Specifically, the number of journal articles has increased, with a further 32 papers having been published since 2020, signifying an increase in the first leg of evidence-based practice: research evidence. When considering the hierarchy of evidence, this suggests a move away from lower-tier individual case reports and a move toward papers based on systematically and rigorously collected data. While this increases the quality of research, this paper evidences that many studies conducted are still negatively impacted by small sample sizes or questionable methodological approaches.

As discussed by Bourne et al. (2020) this becomes evident, when considering studies published with the subcategory 'prevalence', which is particularly relevant when gauging potential need for clinical service provision. The great variability in their estimation of ARFID within clinical ED populations 1.4% to 64% (Ornstein et al., 2013, Fisher et al., 2014, Forman et al., 2014, Nicely et al., 2014, Norris et al., 2014, Cooney et al., 2018, Krom et al., 2019) and < 1% - 15.5% in non-clinical cohorts (Hay et al., 2017, Gonçalves et al., 2019) suggests that ARFIDs real prevalence remains unknown. This may partially be due to how data is collected, as many of the studies were conducted within North America and are based on individuals presenting to ED clinics. Yet, these treatment seeking patients are likely to only represent a sub-set of the wider population who might meet ARFID diagnostic criteria (Bourne et al., 2020). More accurate general population estimates, as well as clinical population estimates in a range of settings need to be conducted to draw firmer conclusions. It is likely that prevalence of ARFID may change when it's diagnosis becomes more established and recognised (Coglan & Otasowie, 2019). Scrutinising this subcategory in more detail evidences that ARFID research is not yet fully established and that further development in each of the subcategories is necessary to influence the development in another. For example, the difficulties associated with the effective gathering of prevalence data may be combatted with the development of a structure assessment tool, which is sensitive to the different ARFID presentations.

Regarding the study design of the papers detailed in this leg of evidence base practice, a number of different methodologies have been used, including longitudinal studies, between subject designs and retrospective chart reviews (RCR). RCR in particular are a popular technique used to review medical information within a certain time frame, and enable a research team to answer multiple questions within one study (Matt & Matthew, 2013). This technique may be specifically useful for ARFID research, as it enables an efficient way of

analysing existing data. However, research by Gilbert et al. (1996), has indicated that RCRs may lack sound mythological standards. RCRs, when poorly conducted, may be criticised for their lack in creating well-defined, clearly articulate research questions and may also not consider sampling issues amongst others (Matt & Matthew, 2013). These in turn may have significant influence both on the quality of the research, as well as the reliability and validity of the findings provided in the studies. Whilst this is not the case within all RCRs conducted, future research may want to focus on using well-established methodology to support on their conclusions or mitigate the known issues by enhancing the methodological rigor of the RCRs.

In the context of the hierarchy of evidence, RCTs and systematic reviews are considered the best and main source of information (Evans, 2003). Currently, no RCTs have been conducted within the field or ARFID and systematic reviews, whilst present remain limited. Thus, with reference to the model of hierarchy of evidence, ARFID research has not yet reached its pinnacle. The lack of RCTs at this stage of the research seems unsurprising, as consistent statements regarding epidemiology, aetiology or effective treatment interventions by their definition rely on substantial bodies of evidence, which in turn take time to accumulate.

Moreover, as the research regarding ARFID remains in its infancy, RCTs may not be the most suitable research design to utilise. Cross-sectional designs, pre-post designs and longitudinal study designs, all employed within current ARFID research, may be more informative in answering epidemiological questions regarding the condition. It is worth noting, that qualitative studies may be particularly helpful when answering questions regarding ARFIDs presentation and the effectiveness of certain interventions. As seen within the tables, most studies within this section employ quantitative research methodology.

Employing a more diverse forum of research methodology, including qualitative research may enable firmer conclusions to be made.

Current research focuses on broad understandings of ARFID, trying to establish knowledge in a myriad of different fields on a surface level, which is to be expected within a field as new as ARFID. Nevertheless, the state of the current literature poses difficulties for policy makers, stakeholders and clinicians when aiming to deliver effective care for individuals with ARFID.

Furthermore, the lack of specific treatment guidance or reliable RCT's may be a product of the clinically heterogeneous presentations of ARFID, as these may limit the ability to make uniform recommendations. While studies indicate that ARFID is a discrete clinical entity with a specific symptomatic profile and distinctive demographic characteristics, such as occurring more in men and generally occurring in a younger population (Bryant-Waugh et al., 2021), the heterogeneity of the condition has not been fully captured. Research has shown that there are three main drivers of ARFID, however, it is also understood that this list is not exhaustive and that these drivers may overlap and co-occur (Murphy & Zlomke, 2016). Moreover, other factors such as cognitive inflexibility, or a need for control and a preference for routine may also account for the onset and perpetuation of ARFID. These alternative causal processes are commonly seen in autism and anxiety disorders and may encourage restrictive or avoidant eating behaviours. Exploring these areas in more detail may give a more thorough understanding of the main drivers of ARFID. Through this, we may be able to refine screening tools, impact clinical outcomes or inform prevalence figures. Developing understanding in one area of ARFID may thus have positive implications for another domain.

4.2. Clinical expertise

Clinical expertise, which in this study was largely made up of opinion pieces, commentaries and case reports was particularly relevant when trying to understand ARFID in its earlier stages of research. While papers continue to be published in this subsection, these now largely focus on more complex descriptions of the condition, in which creative and alternative treatment recommendations are necessary. Particular focus is placed on both clinical characteristics and treatment of ARFID and clinicians often comment on the difficulty of treating ARFID effectively. Generally, the treatment for ARFID stipulates an increase in amount and variety of food eaten, by tackling the underlying driver of food avoidance or restriction. A number of promising treatment options which warrant further exploration have been established at reducing or resolving ARFID behaviours, including family-based therapy (Lock, Robinson, et al., 2019), CBT (Dumont et al., 2019) or adjunctive pharmacological intervention (Sharp, Volkert, et al., 2017). Nevertheless, in addition to these findings, this leg of evidence-based practice highlights that clinicians are often able to effectively treat ARFID by drawing on their expertise from treating other mental health conditions, such as anxiety or autism. This has been evidenced by case reports in which clinicians have combined different treatment modalities to effectively treat complex cases of ARFID (Eckhardt et al., 2019) and may be relevant when considering future development of treatment modalities and adapting clinical guidelines.

As several questions regarding ARFID remain inadequately addressed by the current literature, clinical expertise continues to be a critical part of treating ARFID effectively. Due to the heterogeneity of ARFID, its diverse psychological comorbidities and the continued questions regarding the main drivers of ARFID, clinical expertise and assessment skills remain essential (Bourne et al. 2020). Moreover, formulations should aim to include physical state, age and psychosocial context (Treasure et al., 2015), which are not always given

enough weight in empirical research. Within ARFID, clinical expertise may transcend scientific knowledge, as the experience of the expert results in a greater understanding and ability to be flexible when presented with hitherto unmet clinical needs (C. B. Peterson et al., 2016). Clinical expertise often includes situational and contextual awareness (Schön, 2017) that remain vital when treating and recognising ARFID. Moreover, another function of clinical expertise literature is to inform and shape studies that will contribute to the first leg of the evidence-based practice stool (research evidence), by identifying treatments that may then be further tested in RCTs, or generating measure that can be formally evaluated.

4.3. Patient preference

To our knowledge, no prior paper has summarised the ARFID literature in accordance with the model of evidence-based practice (Sackett, 1996). While our findings indicate both an overall increase in research within the field and specifically within the research-leg of evidence-based practice, it also highlights the paucity of research based on patient preference and characteristics. Only one paper was found to be part of this category.

Research within the field of eating disorders indicates that inclusion of patient preferences has an overall positive impact on treatment (Peterson et al., 2016), reduces rates of attrition and improves outcomes (Swift et al., 2013). The growth within one leg of evidence-based practice (research) and the lack of development in another (patient preference), emphasises the void between scientific discoveries and the intricacies of clinical practice. By focusing research on the inclusion of patient preference, this gap may be narrowed and it can be insured that clinical observations become meaningful and relevant for stakeholders. Moreover, a patient should have the right to self-determination, and be able to influence their own life (Berg, 2019). Through inclusion of patient choice, both the efficacy

and efficiency of an intervention may be influenced and may provide clinicians with lower attrition rates, or higher treatment success rates.

Studies providing insight into lived experience may also provide further awareness into the mechanisms behind ARFID. Through excluding this source of information valuable insight into the condition may be lost. At this point, many questions remain open. The drivers of ARFID are not fully understood, nor are its comorbidities and clinicians have not fully grasped how to recognise ARFID effectively. It seems that this is a pivotal point in ARFID research, where it is possible to shape understanding and treatment interventions by including patient views. Thus, at this point, conducting RCTs, which may be at the higher end of the hierarchy of evidence, may not be the only way to advance the field. Further focus should be placed on the inclusion of stakeholders to provide patient focused, holistic and idiosyncratic formulations, and ensuring a bottom-up approach to clinical interventions.

4.4. Evidence-based practice

Sackett stipulated that the model at hand is a tripartite model and defines this as the amalgamation of empirical research with clinical expertise in the context of patient characteristics, culture and preference (Berg, 2019). This study evidences that currently the ARFID literature does not fit a tripartite model but is mainly defined by research evidence followed by clinical expertise.

This may be in part due to the hierarchy of evidence, which places scientifically based research at the top of the pyramid, while placing clinical expertise and patient preference toward the bottom (Hoffmann et al., 2013). While this may be particularly relevant to the medical field, in which the principles of the hierarchy of evidence originate, it may be less useful when applied to psychology. Many medical treatments remain effective irrespective of

the involvement of a clinical expert or without taking patient preference into consideration (Berg, 2019). However, within psychology many factors empirically associated with effective treatment and positive outcomes are linked to clinical expertise and patient preference and characteristics (Zilcha-Mano, 2017). Factors such as therapeutic alliance, goal consensus, as well as positive regard and affirmation outweigh the specifics of different treatment modalities (Wampold, 2015). While involving patients in the clinical decision making process has shown result in better motivation, degree of integration and ability to recognise and verbalise focalised problems (Berg, 2019).

Within ARFID, great emphasis has been placed on advancing research evidence. However, the lack of information from clinical research studies, coupled with concerns from clinicians regarding the applicability of research findings to clinical populations, suggest that final decision-making regarding treatment selection remains guided by the other two legs of the evidence-based practice stool (Peterson et al., 2016). Understanding that it is the combination of each of these three elements, seems a necessary initial step in improving patient care.

5. Clinical Implications & Further Research

Despite the considerable increase in research within this field, knowledge gaps remain and a need to develop a more refined understanding of all aspects of ARFID is necessary. This review has indicated considerable development within both the research leg and clinical expertise leg of evidence-based practice, whilst clearly displaying a paucity in the involvement of stakeholders. Due to the heterogeneous phenotype of those with ARFID, it remains important to include the voice of stakeholders to ensure development of effective understanding and later treatment. So far, ARFID has been commissioned to be treated within

ED services, increasing the chances of bias in ARFID research particularly when focusing on prevalence or treatment efficacy. However, gaining more insight into ARFID has shown that the condition is complex and necessitates multi-disciplinary treatment, including dietetic and physical monitoring. These resources are often not available in ED services. By gaining more insight into the condition and involving stakeholders it will be possible to influence substantial aspects of care including: diagnosis and assessment, treatment, clinical outcomes and service delivery.

Moreover, although the field has developed holistically, there are noticeable differences in the quality of research conducted within the five subcategories this review has divided the papers into (Bourne et al. 2020). For example, whilst we have a more thorough understanding of clinical characteristics, the main drivers of ARFID are not fully understood in their entirety. Similarly, the exact prevalence of ARFID remains unknown due to great variability within the studies conducted. A way to mitigate these difficulties, may be the implementation and development of reliable and valid assessment instruments which can detect a range of presenting features. These are essential for the accurate diagnosis of ARFID, to gain more dependable prevalence data and to measure outcomes of treatment trials more precisely (Bourne et al. 2020).

While we currently have insight into a subsection of the clinical population who access ED treatment facilities, it is important to assess and understand ARFID from a broader perspective. Exploring differences in sex/ gender, comorbidities, age and whether these would vary in accordance with the different drivers of ARFID are important to understand the condition further. Research in this area would provide information about possible risk factors, allow insight into prevention strategies and provide early intervention for those affected by ARFID.

6. Limitations

Similarly to Bourne's 2020 paper, the search terms for this paper were 'ARFID' or 'Avoidant Restrictive Food Intake Disorder' without limitations or restrictions. This was done to capture papers relating to ARFID as a diagnostic entity. While clinical opinions pieces were included in the review, it may be beneficial to widen the scope and include papers on subclinical presentations of ARFID, to gain better insight into different treatment options, early intervention and symptoms and potential risk factors.

Furthermore, this review focused on ARFID as a diagnostic entity. Widening the scope of research to include papers adjacent but not limited to ARFID, such as 'picky eating' or studies pre-dating the introduction of ARFID may give valuable insight to the field (Bourne et al. 2020).

The reliability of the categorisation process is also limited. It would have been helpful to get an independent rater to validate the categorisation used and consult the levels of agreement following this. Due to the time and resource limitations of this research this was not possible at this stage, but would be considered for possible publication.

An inclusion criterion for this paper was to only incorporate papers in the English Language. The original search identified another 22 papers in different languages. However, these papers were not deemed essential for the review, as they often focused on validating and providing evidence of well-known phenomena of ARFID in their local culture. Future research may want to include papers in other languages to capture a holistic representation of the current literature.

Additionally, book chapters were excluded from the review, as the aim was to capture easily accessible information on ARFID. There are only a finite number of books published on ARFID in particular, however, further research might want to include books also. By

including other sources such as blogs, tweets or more informal sources of information it may also be possible to increase the findings reported within the third leg of the stool. Future research may want to consider including these sources, given the current scarcity of lived-experience evidence.

7. Conclusion

This review was able to map the existing literature onto the legs of evidence-based practice effectively. The review clearly indicated that research in this area is burgeoning, with specific emphasis placed upon increasing 'research evidence'. While this signals great advances in the field overall, the field has not yet reached the pinnacle of the hierarchy of evidence. Furthermore, by categorising the existing papers into their evidence-based practice leg, the review contributes to understanding the gaps in the literature and paucity of stakeholder representation. The review comments on the disparity of the three legs of evidence-based practice, whilst giving indication of what areas need to be further explored.

8. References

Alberts, Z., Fewtrell, M., Nicholls, D. E., Biassoni, L., Easty, M., & Hudson, L. D. (2020). Bone mineral density in Anorexia Nervosa versus Avoidant Restrictive Food Intake Disorder. *Bone*, *134*, 115307. https://doi.org/10.1016/j.bone.2020.115307

Aloi, M., Sinopoli, F., & Segura-Garcia, C. (2018). A case report of an adult male patient with Avoidant/Restrictive Food Intake Disorder treated with CBT. *Psychiatria Danubina*, *30*(3), 370–373. https://doi.org/10.24869/psyd.2018.370

Amoretti, M. C. (2021). Do Feeding and Eating Disorders Fit the General Definition of Mental Disorder? *Topoi*, *40*(3), 555–564. https://doi.org/10.1007/s11245-020-09712-3

Aulinas, A., Marengi, D. A., Galbiati, F., Asanza, E., Slattery, M., Mancuso, C. J., Wons, O., Micali, N., Bern, E., Eddy, K. T., Thomas, J. J., Misra, M., & Lawson, E. A. (2020). Medical comorbidities and endocrine dysfunction in low-weight females with avoidant/restrictive food intake disorder compared to anorexia nervosa and healthy controls. *The International Journal of Eating Disorders*, *53*(4), 631–636. https://doi.org/10.1002/eat.23261

Becker, K. R., Breithaupt, L., Lawson, E. A., Eddy, K. T., & Thomas, J. J. (2020). Co-occurrence of Avoidant/Restrictive Food Intake Disorder and Traditional Eating Psychopathology. *Journal of the American Academy of Child and Adolescent Psychiatry*, *59*(2), 209–212. https://doi.org/10.1016/j.jaac.2019.09.037

Becker, K. R., Keshishian, A. C., Liebman, R. E., Coniglio, K. A., Wang, S. B., Franko, D. L., Eddy, K. T., & Thomas, J. J. (2019). Impact of expanded diagnostic criteria for avoidant/restrictive food intake disorder on clinical comparisons with anorexia nervosa. *The International Journal of Eating Disorders*, *52*(3), 230–238. https://doi.org/10.1002/eat.22988

Becker, K. R., Mancuso, C., Dreier, M. J., Asanza, E., Breithaupt, L., Slattery, M., Plessow, F., Micali, N., Thomas, J. J., Eddy, K. T., Misra, M., & Lawson, E. A. (2021). Ghrelin and PYY in low-weight females with avoidant/restrictive food intake disorder compared to anorexia nervosa and healthy controls. *Psychoneuroendocrinology*, *129*, 105243. https://doi.org/10.1016/j.psyneuen.2021.105243

Benezech, S., Hartmann, C., Morfin, D., Bertrand, Y., & Domenech, C. (2020). Is it leukemia, doctor? No, it's scurvy induced by an ARFID! *European Journal of Clinical Nutrition*, *74*(8), 1247–1249. https://doi.org/10.1038/s41430-020-0640-5

Berg, H. (2019). Evidence-Based Practice in Psychology Fails to Be Tripartite: A Conceptual Critique of the Scientocentrism in Evidence-Based Practice in Psychology. *Frontiers in Psychology*, *10*. https://www.frontiersin.org/article/10.3389/fpsyg.2019.02253

Bertrand, V., Tiburce, L., Sabatier, T., Dufour, D., Déchelotte, P., & Tavolacci, M.-P. (2021). Estimated Prevalence and Care Pathway of Feeding and Eating Disorders in a French Pediatric Population. *Nutrients*, *13*(6), 2048. https://doi.org/10.3390/nu13062048

Bloomfield, B. S., Fischer, A. J., Clark, R. R., & Dove, M. B. (2018). Treatment of Food Selectivity in a Child with Avoidant/Restrictive Food Intake Disorder Through Parent Teleconsultation. *Behavior Analysis in Practice*, *12*(1), 33–43. https://doi.org/10.1007/s40617-018-0251-y

Bourne, L., Bryant-Waugh, R., Cook, J., & Mandy, W. (2020). Avoidant/restrictive food intake disorder: A systematic scoping review of the current literature. *Psychiatry Research*, *288*, 112961. https://doi.org/10.1016/j.psychres.2020.112961

Brewerton, T. D. (2012). Antipsychotic agents in the treatment of anorexia nervosa: Neuropsychopharmacologic rationale and evidence from controlled trials. *Current Psychiatry Reports*, *14*(4), 398–405. https://doi.org/10.1007/s11920-012-0287-6

Brewerton, T. D., & D'Agostino, M. (2017). Adjunctive Use of Olanzapine in the Treatment of Avoidant Restrictive Food Intake Disorder in Children and Adolescents in an Eating Disorders Program. *Journal of Child and Adolescent Psychopharmacology*, *27*(10), 920–922. https://doi.org/10.1089/cap.2017.0133

Brigham, K. S., Manzo, L. D., Eddy, K. T., & Thomas, J. J. (2018). Evaluation and Treatment of Avoidant/Restrictive Food Intake Disorder (ARFID) in Adolescents. *Current Pediatrics Reports*, *6*(2), 107–113. https://doi.org/10.1007/s40124-018-0162-y

Brown, M., & Hildebrandt, T. (2020). Parent-Facilitated Behavioral Treatment for Avoidant/Restrictive Food Intake Disorder: A Case Report. *Cognitive and Behavioral Practice*, *27*(2), 231–251. https://doi.org/10.1016/j.cbpra.2019.05.002

Brown, T. A., Reilly, E. E., Murray, H. B., Perry, T. R., Kaye, W. H., & Wierenga, C. E. (2021). Validating the visceral sensitivity index in an eating disorder sample. *International Journal of Eating Disorders*, *54*(6), 986–994. https://doi.org/10.1002/eat.23471

Bryant-Waugh, R. (2013). Avoidant restrictive food intake disorder: An illustrative case example. *The International Journal of Eating Disorders*, *46*(5), 420–423. https://doi.org/10.1002/eat.22093

Bryant-Waugh, R. (2020). Avoidant restrictive food intake disorder: In need of a dose of kindness? *Clinical Child Psychology and Psychiatry*, *25*(3), 712–715. https://doi.org/10.1177/1359104520929054

Bryant-Waugh, R., Loomes, R., Munuve, A., & Rhind, C. (2021). Towards an evidence-based out-patient care pathway for children and young people with avoidant restrictive food intake disorder. *Journal of Behavioral and Cognitive Therapy*, *31*(1), 15–26. https://doi.org/10.1016/j.jbct.2020.11.001

Bryant-Waugh, R., Micali, N., Cooke, L., Lawson, E. A., Eddy, K. T., & Thomas, J. J. (2019). Development of the Pica, ARFID, and Rumination Disorder Interview, a multi-informant, semi-structured interview of feeding disorders across the lifespan: A pilot study for ages 10-22. *The International Journal of Eating Disorders*, *52*(4), 378–387. https://doi.org/10.1002/eat.22958

Burton Murray, H., Dreier, M. J., Zickgraf, H. F., Becker, K. R., Breithaupt, L., Eddy, K. T., & Thomas, J. J. (2021). Validation of the nine item ARFID screen (NIAS) subscales for distinguishing ARFID presentations and screening for ARFID. *The International Journal of Eating Disorders*, *54*(10), 1782–1792. https://doi.org/10.1002/eat.23520

Burton Murray, H., Jehangir, A., Silvernale, C. J., Kuo, B., & Parkman, H. P. (2020). Avoidant/restrictive food intake disorder symptoms are frequent in patients presenting for symptoms of gastroparesis. *Neurogastroenterology & Motility*, *32*(12), e13931. https://doi.org/10.1111/nmo.13931

Caldwell, A. R., Skidmore, E. R., Raina, K. D., Rogers, J. C., Terhorst, L., Danford, C. A., & Bendixen, R. M. (2018). Behavioral Activation Approach to Parent Training: Feasibility of Promoting Routines of Exploration and Play During Mealtime (Mealtime PREP). *The American Journal of Occupational Therapy: Official Publication of the American Occupational Therapy Association*, *72*(6), 7206205030p1-7206205030p8. https://doi.org/10.5014/ajot.2018.028365

Cañas, L., Palma, C., Molano, A. M., Domene, L., Carulla-Roig, M., Cecilia-Costa, R., Dolz, M., & Serrano-Troncoso, E. (2021). Avoidant/restrictive food intake disorder: Psychopathological similarities and differences in comparison to anorexia nervosa and the general population. *European Eating Disorders Review: The Journal of the Eating Disorders Association*, *29*(2), 245–256. https://doi.org/10.1002/erv.2815

Cerniglia, L., Marzilli, E., & Cimino, S. (2020). Emotional-Behavioral Functioning, Maternal Psychopathologic Risk and Quality of Mother-Child Feeding Interactions in Children with Avoidant/Restrictive Food Intake Disorder. *International Journal of Environmental Research and Public Health*, *17*(11), E3811. https://doi.org/10.3390/ijerph17113811

Chalmers, T. C., Celano, P., Sacks, H. S., & Smith, H. (1983). Bias in treatment assignment in controlled clinical trials. *The New England Journal of Medicine*, *309*(22), 1358–1361. https://doi.org/10.1056/NEJM198312013092204

Chandran, J. J., Anderson, G., Kennedy, A., Kohn, M., & Clarke, S. (2015). Subacute combined degeneration of the spinal cord in an adolescent male with avoidant/restrictive food intake disorder: A clinical case report. *International Journal of Eating Disorders*, *48*(8), 1176–1179. https://doi.org/10.1002/eat.22450

Chen, J., Guo, L., Gu, L., & Han, H. (2021). The introduction of treatment and the cultural adaptability of western psychotherapies for eating disorders in China. *The International Journal of Eating Disorders*, *54*(1), 102–106. https://doi.org/10.1002/eat.23437

Chew, C. S. E., Kelly, S., Baeg, A., Oh, J. Y., Rajasegaran, K., & Davis, C. (2021). First presentation of restrictive early onset eating disorders in Asian children. *International Journal of Eating Disorders*, *54*(1), 81–87. https://doi.org/10.1002/eat.23274

Chiarello, F., Marini, E., Ballerini, A., & Ricca, V. (2018). Optic neuropathy due to nutritional deficiency in a male adolescent with Avoidant/Restrictive Food Intake Disorder: A case report. *Eating and Weight Disorders - Studies on Anorexia, Bulimia and Obesity*, *23*(4), 533–535. https://doi.org/10.1007/s40519-017-0409-6

Chua, S. N., Fitzsimmons-Craft, E. E., Austin, S. B., Wilfley, D. E., & Taylor, C. B. (2021). Estimated prevalence of eating disorders in Singapore. *The International Journal of Eating Disorders, 54*(1), 7–18. https://doi.org/10.1002/eat.23440

Cimino, S., Marzilli, E., Babore, A., Trumello, C., & Cerniglia, L. (2021). DAT1 and Its Psychological Correlates in Children with Avoidant/Restrictive Food Intake Disorder: A Cross-Sectional Pilot Study. *Behavioral Sciences*, *11*(1), 9. https://doi.org/10.3390/bs11010009

Clark, R. R., Fischer, A. J., Lehman, E. L., & Bloomfield, B. S. (2019). Developing and Implementing a Telehealth Enhanced Interdisciplinary Pediatric Feeding Disorders Clinic: A Program Description and Evaluation. *Journal of Developmental and Physical Disabilities*, *31*(2), 171–188. https://doi.org/10.1007/s10882-018-9652-7

Claudino, A. M., Pike, K. M., Hay, P., Keeley, J. W., Evans, S. C., Rebello, T. J., Bryant-Waugh, R., Dai, Y., Zhao, M., Matsumoto, C., Herscovici, C. R., Mellor-Marsá, B., Stona, A.-C., Kogan, C. S., Andrews, H. F., Monteleone, P., Pilon, D. J., Thiels, C., Sharan, P., … Reed, G. M. (2019). The classification of feeding and eating disorders in the ICD-11: Results of a field study comparing proposed ICD-11 guidelines with existing ICD-10 guidelines. *BMC Medicine, 17*(1), 93. https://doi.org/10.1186/s12916-019-1327-4

Coelho, J. S., Zaitsoff, S. L., Pullmer, R., Yamin, D. F., Anderson, S., Fernandes, A., & Stewart, S. E. (2019). Body checking in pediatric eating and obsessive-compulsive disorders. *Journal of Obsessive-Compulsive and Related Disorders*, *23*, 100475. https://doi.org/10.1016/j.jocrd.2019.100475

Coglan, L., & Otasowie, J. (2019). Avoidant/restrictive food intake disorder: What do we know so far? *BJPsych Advances*, *25*(2), 90–98. https://doi.org/10.1192/bja.2018.48

Coniglio, K. A., Becker, K. R., Tabri, N., Keshishian, A. C., Miller, J. D., Eddy, K. T., & Thomas, J. J. (2018). Factorial integrity and validation of the Eating Pathology Symptoms Inventory (EPSI). *Eating Behaviors*, *31*, 1–7. https://doi.org/10.1016/j.eatbeh.2018.07.004

Cooney, M., Lieberman, M., Guimond, T., & Katzman, D. K. (2018). Clinical and psychological features of children and adolescents diagnosed with avoidant/restrictive food intake disorder in a pediatric tertiary care eating disorder program: A descriptive study. *Journal of Eating Disorders*, *6*(1), 7. https://doi.org/10.1186/s40337-018-0193-3

Cooper, M., Collison, A. O., Collica, S. C., Pan, I., Tamashiro, K. L., Redgrave, G. W., Schreyer, C. C., & Guarda, A. S. (2021). Gastrointestinal symptomatology, diagnosis, and treatment history in patients with underweight avoidant/restrictive food intake disorder and anorexia nervosa: Impact on weight restoration in a meal-based behavioral treatment program. *Journal of Eating Disorders*, No Pagination Specified. https://doi.org/10.1002/eat.23535

Cooper, M., Reilly, E. E., Siegel, J. A., Coniglio, K., Sadeh-Sharvit, S., Pisetsky, E. M., & Anderson, L. M. (2020). Eating disorders during the COVID-19 pandemic and quarantine: An overview of risks and recommendations for treatment and early intervention. *Eating Disorders*, *0*(0), 1–23. https://doi.org/10.1080/10640266.2020.1790271

Couturier, J., Pellegrini, D., Miller, C., Bhatnagar, N., Boachie, A., Bourret, K., Brouwers, M., Coelho, J. S., Dimitropoulos, G., Findlay, S., Ford, C., Geller, J., Grewal, S., Gusella, J., Isserlin, L., Jericho, M., Johnson, N., Katzman, D. K., Kimber, M., … Webb, C. (2021). The COVID-19 pandemic and eating disorders in children, adolescents, and emerging adults: Virtual care recommendations from the Canadian

consensus panel during COVID-19 and beyond. *Journal of Eating Disorders*, *9*(1), 46. https://doi.org/10.1186/s40337-021-00394-9

Crowley, J. G., Peterson, K. M., Fisher, W. W., & Piazza, C. C. (2020). Treating food selectivity as resistance to change in children with autism spectrum disorder. *Journal of Applied Behavior Analysis*, *53*(4), 2002–2023. https://doi.org/10.1002/jaba.711

Dahlsgaard, K. K., & Bodie, J. (2019). The (Extremely) Picky Eaters Clinic: A Pilot Trial of a Seven-Session Group Behavioral Intervention for Parents of Children With Avoidant/Restrictive Food Intake Disorder. *Cognitive and Behavioral Practice*, *26*(3), 492–505. https://doi.org/10.1016/j.cbpra.2018.11.001

Dalle Grave, A. (2020). Treatment of avoidant/restrictive food intake disorder: A systematic review. *IJEDO*, 13–23. https://doi.org/10.32044/ijedo.2020.04

Dawes, R. M., Faust, D., & Meehl, P. E. (1989). Clinical Versus Actuarial Judgment. *Science, New Series*, *243*(4899), 1668–1674.

Dolman, L., Thornley, S., Doxtdator, K., Leclerc, A., Findlay, S., Grant, C., Breakey, V. R., & Couturier, J. (2021). Multimodal therapy for rigid, persistent avoidant/restrictive food intake disorder (ARFID) since infancy: A case report. *Clinical Child Psychology and Psychiatry*, *26*(2), 451–463. https://doi.org/10.1177/1359104520981401

Dumont, E., Jansen, A., Kroes, D., de Haan, E., & Mulkens, S. (2019). A new cognitive behavior therapy for adolescents with avoidant/restrictive food intake disorder in a day treatment setting: A clinical case series. *The International Journal of Eating Disorders*, *52*(4), 447–458. https://doi.org/10.1002/eat.23053

Duncombe Lowe, K., Barnes, T. L., Martell, C., Keery, H., Eckhardt, S., Peterson, C. B., Lesser, J., & Le Grange, D. (2019). Youth with Avoidant/Restrictive Food Intake Disorder: Examining Differences by Age, Weight Status, and Symptom Duration. *Nutrients*, *11*(8), E1955. https://doi.org/10.3390/nu11081955

Dyck, Z. van, & Hilbert, A. (2016). *Eating Disorders in Youth-Questionnaire*.

Eckhardt, S., Martell, C., Duncombe Lowe, K., Le Grange, D., & Ehrenreich-May, J. (2019). An ARFID case report combining family-based treatment with the unified protocol for Transdiagnostic treatment of emotional disorders in children. *Journal of Eating Disorders*, *7*, 34. https://doi.org/10.1186/s40337-019-0267-x

Eddy, K. T., Thomas, J. J., Hastings, E., Edkins, K., Lamont, E., Nevins, C. M., Patterson, R. M., Murray, H. B., Bryant-Waugh, R., & Becker, A. E. (2015). Prevalence of DSM-5 avoidant/restrictive food intake disorder in a pediatric gastroenterology healthcare network. *The International Journal of Eating Disorders*, *48*(5), 464–470. https://doi.org/10.1002/eat.22350

Espel-Huynh, H. M., Zhang, F., Boswell, J. F., Thomas, J. G., Thompson-Brenner, H., Juarascio, A. S., & Lowe, M. R. (2020). Latent trajectories of eating disorder treatment response among female patients in residential care. *International Journal of Eating Disorders*, *53*(10), 1647–1656. https://doi.org/10.1002/eat.23369

Evans, D. (2003). Hierarchy of evidence: A framework for ranking evidence evaluating healthcare interventions. *Journal of Clinical Nursing*, *12*(1), 77–84. https://doi.org/10.1046/j.1365-2702.2003.00662.x

Feillet, F., Bocquet, A., Briend, A., Chouraqui, J.-P., Darmaun, D., Frelut, M.-L., Girardet, J.-P., Guimber, D., Hankard, R., Lapillonne, A., Peretti, N., Rozé, J.-C., Simeoni, U., Turck, D., Dupont, C., & Comité de nutrition de la Société française de pédiatrie (CNSFP). (2019). Nutritional risks of ARFID (avoidant restrictive food intake disorders) and related behavior. *Archives De Pediatrie: Organe Officiel De La Societe Francaise De Pediatrie*, *26*(7), 437–441. https://doi.org/10.1016/j.arcped.2019.08.005

Fischer, A. J., Luiselli, J. K., & Dove, M. B. (2015). Effects of clinic and in-home treatment on consumption and feeding-associated anxiety in an adolescent with

avoidant/restrictive food intake disorder. *Clinical Practice in Pediatric Psychology*, *3*(2), 154–166. https://doi.org/10.1037/cpp0000090

Fisher, M. M., Rosen, D. S., Ornstein, R. M., Mammel, K. A., Katzman, D. K., Rome, E. S., Callahan, S. T., Malizio, J., Kearney, S., & Walsh, B. T. (2014). Characteristics of avoidant/restrictive food intake disorder in children and adolescents: A 'new disorder' in DSM-5. *The Journal of Adolescent Health: Official Publication of the Society for Adolescent Medicine*, *55*(1), 49–52. https://doi.org/10.1016/j.jadohealth.2013.11.013

Fitzsimmons-Craft, E. E., Balantekin, K. N., Graham, A. K., Smolar, L., Park, D., Mysko, C., Funk, B., Taylor, C. B., & Wilfley, D. E. (2019). Results of disseminating an online screen for eating disorders across the U.S.: Reach, respondent characteristics, and unmet treatment need. *The International Journal of Eating Disorders*, *52*(6), 721–729. https://doi.org/10.1002/eat.23043

Fjeldstad, M., Kvist, T., & Sjögren, M. (2021). Weight Gain in Adults with Avoidant/Restrictive Food Intake Disorder Compared to Restrictive Anorexia Nervosa-Pilot Findings from a Longitudinal Study. *Nutrients*, *13*(3), 871. https://doi.org/10.3390/nu13030871

Forbush, K. T., Bohrer, B. K., Hagan, K. E., Chapa, D. A. N., Perko, V., Richson, B., Christian, K., Christensen, K. A., & Wildes, J. E. (2020). Development and initial validation of the Eating Pathology Symptoms Inventory-Clinician-Rated Version (EPSI-CRV). *Psychological Assessment*, *32*(10), 943–955. https://doi.org/10.1037/pas0000820

Forman, S. F., McKenzie, N., Hehn, R., Monge, M. C., Kapphahn, C. J., Mammel, K. A., Callahan, S. T., Sigel, E. J., Bravender, T., Romano, M., Rome, E. S., Robinson, K. A., Fisher, M., Malizio, J. B., Rosen, D. S., Hergenroeder, A. C., Buckelew, S. M., Jay, M. S., Lindenbaum, J., … Woods, E. R. (2014). Predictors of outcome at 1 year

in adolescents with DSM-5 restrictive eating disorders: Report of the national eating disorders quality improvement collaborative. *The Journal of Adolescent Health: Official Publication of the Society for Adolescent Medicine*, *55*(6), 750–756. https://doi.org/10.1016/j.jadohealth.2014.06.014

Gibson, D., Watters, A., & Mehler, P. S. (2021). The intersect of gastrointestinal symptoms and malnutrition associated with anorexia nervosa and avoidant/restrictive food intake disorder: Functional or pathophysiologic?—A systematic review. *International Journal of Eating Disorders*, *54*(6), 1019–1054. https://doi.org/10.1002/eat.23553

Gilbert, E. H., Lowenstein, S. R., Koziol-McLain, J., Barta, D. C., & Steiner, J. (1996). Chart reviews in emergency medicine research: Where are the methods? *Annals of Emergency Medicine*, *27*(3), 305–308. https://doi.org/10.1016/s0196-0644(96)70264-0

Goldberg, H. R., Katzman, D. K., Allen, L., Martin, S., Sheehan, C., Kaiserman, J., Macdonald, G., & Kives, S. (2020). The Prevalence of Children and Adolescents at Risk for Avoidant Restrictive Food Intake Disorder in a Pediatric and Adolescent Gynecology Clinic. *Journal of Pediatric and Adolescent Gynecology*, *33*(5), 466–469. https://doi.org/10.1016/j.jpag.2020.06.004

Goncalves, S., Vieira, A. I., Machado, B. C., Costa, R., Pinheiro, J., & Conceicao, E. (2019). Avoidant/restrictive food intake disorder symptoms in children: Associations with child and family variables. *Children's Health Care*, *48*(3), 301–313. https://doi.org/10.1080/02739615.2018.1532796

Gonçalves, S., Vieira, A. I., Machado, B. C., Costa, R., Pinheiro, J., & Conceiçao, E. (2019). Avoidant/restrictive food intake disorder symptoms in children: Associations with child and family variables. *Children's Health Care*, *48*(3), 301–313. https://doi.org/10.1080/02739615.2018.1532796

Görmez, A., Kılıç, A., & Kırpınar, İ. (2018). Avoidant/Restrictive Food Intake Disorder: An Adult Case Responding to Cognitive Behavioral Therapy. *Clinical Case Studies*, *17*(6), 443–452. https://doi.org/10.1177/1534650118795286

Gorrell, S., Lebow, J., Kinasz, K., Mitchell, J. E., Goldschmidt, A. B., Le Grange, D., & Accurso, E. C. (2020). Psychotropic medication use in treatment-seeking youth with eating disorders. *European Eating Disorders Review: The Journal of the Eating Disorders Association*, *28*(6), 739–749. https://doi.org/10.1002/erv.2788

Gray, E., Chen, T., Menzel, J., Schwartz, T., & Kaye, W. H. (2018). Mirtazapine and Weight Gain in Avoidant and Restrictive Food Intake Disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, *57*(4), 288–289. https://doi.org/10.1016/j.jaac.2018.01.011

Guss, C. E., Richmond, T. K., & Forman, S. (2018). A survey of physician practices on the inpatient medical stabilization of patients with avoidant/restrictive food intake disorder. *Journal of Eating Disorders*, *6*, 22. https://doi.org/10.1186/s40337-018-0212-4

Hadwiger, A. N., Middleman, A. B., & Pitt, P. D. (2019). Case series: Gaming vs. eating-comorbidity of ARFID and IGD. *Eating and Weight Disorders: EWD*, *24*(5), 959–962. https://doi.org/10.1007/s40519-019-00639-2

Harer, K., Baker, J., Reister, N., Collins, K., Watts, L., Phillips, C., & Chey, W. D. (2018). Avoidant/Restrictive Food Intake Disorder in the Adult Gastroenterology Population: An Under-Recognized Diagnosis?: 417. *Official Journal of the American College of Gastroenterology | ACG*, *113*, S247.

Harrison, M. E., Norris, M. L., Robinson, A., Spettigue, W., Morrissey, M., & Isserlin, L. (2019). Use of cyproheptadine to stimulate appetite and body weight gain: A systematic review. *Appetite*, *137*, 62–72. https://doi.org/10.1016/j.appet.2019.02.012

Harshman, S. G., Wons, O., Rogers, M. S., Izquierdo, A. M., Holmes, T. M., Pulumo, R. L., Asanza, E., Eddy, K. T., Misra, M., Micali, N., Lawson, E. A., & Thomas, J. J. (2019). A Diet High in Processed Foods, Total Carbohydrates and Added Sugars, and Low in Vegetables and Protein Is Characteristic of Youth with Avoidant/Restrictive Food Intake Disorder. *Nutrients*, *11*(9), E2013. https://doi.org/10.3390/nu11092013

Hay, P., Mitchison, D., Collado, A. E. L., González-Chica, D. A., Stocks, N., & Touyz, S. (2017). Burden and health-related quality of life of eating disorders, including Avoidant/Restrictive Food Intake Disorder (ARFID), in the Australian population. *Journal of Eating Disorders*, *5*, 21. https://doi.org/10.1186/s40337-017-0149-z

He, J., Ellis, J. M., Zickgraf, H. F., & Fan, X. (2019). Translating, modifying, and validating the Adult Picky Eating Questionnaire for use in China. *Eating Behaviors*, *33*, 78–84. https://doi.org/10.1016/j.eatbeh.2019.04.002

He, J., Zickgraf, H. F., Ellis, J. M., Lin, Z., & Fan, X. (2021). Chinese version of the Nine Item ARFID Screen: Psychometric properties and cross-cultural measurement invariance. *Assessment*, *28*(2), 537–550. https://doi.org/10.1177/1073191120936359

Hilbert, A., Zenger, M., Eichler, J., & Brähler, E. (2021). Psychometric evaluation of the Eating Disorders in Youth-Questionnaire when used in adults: Prevalence estimates for symptoms of avoidant/restrictive food intake disorder and population norms. *The International Journal of Eating Disorders*, *54*(3), 399–408. https://doi.org/10.1002/eat.23424

Hoffmann, T., Bennett, S., & Del Mar, C. (2013). *Evidence-based practice across the health professions*. https://www.clinicalkey.com.au/dura/browse/bookChapter/3-s2.0-C20110042990

Inoue, T., Otani, R., Iguchi, T., Ishii, R., Uchida, S., Okada, A., Kitayama, S., Koyanagi, K., Suzuki, Y., Suzuki, Y., Sumi, Y., Takamiya, S., Tsurumaru, Y., Nagamitsu, S., Fukai,

Y., Fujii, C., Matsuoka, M., Iwanami, J., Wakabayashi, A., & Sakuta, R. (2021). Prevalence of autism spectrum disorder and autistic traits in children with anorexia nervosa and avoidant/restrictive food intake disorder. *BioPsychoSocial Medicine*. https://doi.org/10.1186/s13030-021-00212-3

Iron-Segev, S., Best, D., Arad-Rubinstein, S., Efron, M., Serur, Y., Dickstein, H., & Stein, D. (2020). Feeding, Eating, and Emotional Disturbances in Children with Avoidant/Restrictive Food Intake Disorder (ARFID). *Nutrients*, *12*(11), 3385. https://doi.org/10.3390/nu12113385

Izquierdo, A., Plessow, F., Becker, K. R., Mancuso, C. J., Slattery, M., Murray, H. B., Hartmann, A. S., Misra, M., Lawson, E. A., Eddy, K. T., & Thomas, J. J. (2019). Implicit attitudes toward dieting and thinness distinguish fat-phobic and non-fat-phobic anorexia nervosa from avoidant/restrictive food intake disorder in adolescents. *The International Journal of Eating Disorders*, *52*(4), 419–427. https://doi.org/10.1002/eat.22981

Jackson, B. N., Turner, L. A. T., Kevany, G. L., & Purdy, S. C. (2021). Five years of avoidant/restrictive food intake disorder: No consensus of understanding among health professionals in new zealand. *Speech, Language and Hearing*, No Pagination Specified. https://doi.org/10.1080/2050571X.2021.1926620

Kambanis, P. E., Kuhnle, M. C., Wons, O. B., Jo, J. H., Keshishian, A. C., Hauser, K., Becker, K. R., Franko, D. L., Misra, M., Micali, N., Lawson, E. A., Eddy, K. T., & Thomas, J. J. (2020). Prevalence and correlates of psychiatric comorbidities in children and adolescents with full and subthreshold avoidant/restrictive food intake disorder. *The International Journal of Eating Disorders*, *53*(2), 256–265. https://doi.org/10.1002/eat.23191

Kapphahn, C. J., Graham, D. A., Woods, E. R., Hehn, R., Mammel, K. A., Forman, S. F., Fisher, M., Robinson, K. A., Rome, E. S., Hergenroeder, A., & Golden, N. H. (2017). Effect of Hospitalization on Percent Median Body Mass Index at One Year, in Underweight Youth With Restrictive Eating Disorders. *The Journal of Adolescent Health: Official Publication of the Society for Adolescent Medicine*, *61*(3), 310–316. https://doi.org/10.1016/j.jadohealth.2017.03.020

Keery, H., LeMay-Russell, S., Barnes, T. L., Eckhardt, S., Peterson, C. B., Lesser, J., Gorrell, S., & Le Grange, D. (2019). Attributes of children and adolescents with avoidant/restrictive food intake disorder. *Journal of Eating Disorders*, *7*, 31. https://doi.org/10.1186/s40337-019-0261-3

Kerem, L., Van De Water, A. L., Kuhnle, M. C., Harshman, S., Hauser, K., Eddy, K. T., Becker, K. R., Misra, M., Micali, N., Thomas, J. J., Holsen, L., & Lawson, E. A. (2021). Neurobiology of Avoidant/Restrictive Food Intake Disorder in Youth with Overweight/Obesity Versus Healthy Weight. *Journal of Clinical Child and Adolescent Psychology: The Official Journal for the Society of Clinical Child and Adolescent Psychology, American Psychological Association, Division 53*, 1–14. https://doi.org/10.1080/15374416.2021.1894944

King, L. A., Urbach, J. R., & Stewart, K. E. (2015). Illness anxiety and avoidant/restrictive food intake disorder: Cognitive-behavioral conceptualization and treatment. *Eating Behaviors*, *19*, 106–109. https://doi.org/10.1016/j.eatbeh.2015.05.010

Kirkwood, C. A., Bachmeyer-Lee, M. H., Sheehan, C. M., Mauzy, C. R., & Gibson, L. A. (2021). Further examination of the treatment of multiply controlled inappropriate mealtime behavior. *Journal of Applied Behavior Analysis*, *54*(1), 429–450. https://doi.org/10.1002/jaba.738

Koomar, T., Thomas, T. R., Pottschmidt, N. R., Lutter, M., & Michaelson, J. J. (2021). Estimating the Prevalence and Genetic Risk Mechanisms of ARFID in a Large Autism Cohort. *Frontiers in Psychiatry*, *12*, 849. https://doi.org/10.3389/fpsyt.2021.668297

Krom, H., van der Sluijs Veer, L., van Zundert, S., Otten, M.-A., Benninga, M., Haverman, L., & Kindermann, A. (2019). Health related quality of life of infants and children with avoidant restrictive food intake disorder. *International Journal of Eating Disorders*, *52*(4), 410–418. https://doi.org/10.1002/eat.23037

Kurotori, I., Shioda, K., Abe, T., Kato, R., Ishikawa, S., & Suda, S. (2019). An Inpatient Observational Study: Characteristics And Outcomes Of Avoidant/Restrictive Food Intake Disorder (ARFID) In Children And Adolescents In Japan. *Neuropsychiatric Disease and Treatment*, *15*, 3313–3321. https://doi.org/10.2147/NDT.S218354

Kurz, S., van Dyck, Z., Dremmel, D., Munsch, S., & Hilbert, A. (2016). Variants of early-onset restrictive eating disturbances in middle childhood. *The International Journal of Eating Disorders*, *49*(1), 102–106. https://doi.org/10.1002/eat.22461

Lai, D., Chee, A., & Kwok, V. (2019). A case series on the clinical profile of avoidant–restrictive food intake disorder in Singapore. *Proceedings of Singapore Healthcare*, *28*(4), 280–283. https://doi.org/10.1177/2010105819838290

Lane-Loney, S. E., Zickgraf, H. F., Ornstein, R. M., Mahr, F., & Essayli, J. H. (2020). A Cognitive-Behavioral Family-Based Protocol for the Primary Presentations of Avoidant/Restrictive Food Intake Disorder (ARFID): Case Examples and Clinical Research Findings. *Cognitive and Behavioral Practice*. https://doi.org/10.1016/j.cbpra.2020.06.010

Lange, C. R. A., Ekedahl Fjertorp, H., Holmer, R., Wijk, E., & Wallin, U. (2019). Long-term follow-up study of low-weight avoidant restrictive food intake disorder compared

with childhood-onset anorexia nervosa: Psychiatric and occupational outcome in 56 patients. *The International Journal of Eating Disorders*, *52*(4), 435–438. https://doi.org/10.1002/eat.23038

Lazare, K. (2017). Addison's Disease and Possible Cannabis Withdrawal Syndrome Presenting as an Eating Disorder in a Thirty-Year-Old Female. *Case Reports in Endocrinology*, *2017*, 4096021. https://doi.org/10.1155/2017/4096021

Leach, M. J. (2006). Evidence-based practice: A framework for clinical practice and research design. *International Journal of Nursing Practice*, *12*(5), 248–251. https://doi.org/10.1111/j.1440-172X.2006.00587.x

Lenz, K. R., Mitan, L. A., Kleinhenz, S. R., & Matthews, A. (2018). When Outpatient Care Is Not Enough: Successful Use of an Inpatient Behavioral Intervention for a Child With ARFID. *Clinical Case Studies*, *17*(6), 469–481. https://doi.org/10.1177/1534650118796562

Lieberman, M., Houser, M. E., Voyer, A.-P., Grady, S., & Katzman, D. K. (2019). Children with avoidant/restrictive food intake disorder and anorexia nervosa in a tertiary care pediatric eating disorder program: A comparative study. *The International Journal of Eating Disorders*, *52*(3), 239–245. https://doi.org/10.1002/eat.23027

Lilienfeld, S. O., Ritschel, L. A., Lynn, S. J., Cautin, R. L., & Latzman, R. D. (2013). Why many clinical psychologists are resistant to evidence-based practice: Root causes and constructive remedies. *Clinical Psychology Review*, *33*(7), 883–900. https://doi.org/10.1016/j.cpr.2012.09.008

Lim, T. S. H., Aw, M., Slosky, L., & Nyp, S. S. (2020). Beyond Picky Eating. *Journal of Developmental and Behavioral Pediatrics: JDBP*, *41*(8), 656–658. https://doi.org/10.1097/DBP.0000000000000846

Lin, J. A., Jhe, G., Vitagliano, J. A., Milliren, C. E., Spigel, R., Woods, E. R., Forman, S. F., & Richmond, T. K. (2021). The Association of Malnutrition, illness duration, and pre-morbid weight status with anxiety and depression symptoms in adolescents and young adults with restrictive eating disorders: A cross-sectional study. *Journal of Eating Disorders*, *9*(1), 60. https://doi.org/10.1186/s40337-021-00415-7

Lin, J. A., Woods, E. R., & Bern, E. M. (2021). Common and Emergent Oral and Gastrointestinal Manifestations of Eating Disorders. *Gastroenterology & Hepatology*, *17*(4), 157–167.

Lock, J. D. (2021). *Confirming the Efficacy/Mechanism of Family Therapy for Children With Low Weight Avoidant/Restrictive Food Intake Disorder (ARFID)* (Clinical Trial Registration No. NCT04450771). clinicaltrials.gov. https://clinicaltrials.gov/ct2/show/NCT04450771

Lock, J., Robinson, A., Sadeh-Sharvit, S., Rosania, K., Osipov, L., Kirz, N., Derenne, J., & Utzinger, L. (2019). Applying family-based treatment (FBT) to three clinical presentations of avoidant/restrictive food intake disorder: Similarities and differences from FBT for anorexia nervosa. *International Journal of Eating Disorders*, *52*(4), 439–446. https://doi.org/10.1002/eat.22994

Lock, J., Sadeh-Sharvit, S., & L'Insalata, A. (2019). Feasibility of conducting a randomized clinical trial using family-based treatment for avoidant/restrictive food intake disorder. *The International Journal of Eating Disorders*, *52*(6), 746–751. https://doi.org/10.1002/eat.23077

Lucarelli, J., Pappas, D., Welchons, L., & Augustyn, M. (2017). Autism Spectrum Disorder and Avoidant/Restrictive Food Intake Disorder. *Journal of Developmental and Behavioral Pediatrics: JDBP*, *38*(1), 79–80. https://doi.org/10.1097/DBP.0000000000000362

Lucarelli, L., Sechi, C., Cimino, S., & Chatoor, I. (2018). Avoidant/Restrictive Food Intake Disorder: A Longitudinal Study of Malnutrition and Psychopathological Risk Factors From 2 to 11 Years of Age. *Frontiers in Psychology, 9*, 1608. https://doi.org/10.3389/fpsyg.2018.01608

Maertens, C., Couturier, J., Grant, C., & Johnson, N. (2017). Fear of Vomiting and Low Body Weight in Two Pediatric Patients: Diagnostic Challenges. *Journal of the Canadian Academy of Child and Adolescent Psychiatry, 26*(1), 59–61.

Magel, C. A., Hewitt, K., Dimitropoulos, G., von Ranson, K. M., & McMorris, C. A. (2021). Who is treating ARFID, and how? The need for training for community clinicians. *Eating and Weight Disorders: EWD, 26*(4), 1279–1280. https://doi.org/10.1007/s40519-020-01007-1

Maginot, T. R., Kumar, M. M., Shiels, J., Kaye, W., & Rhee, K. E. (2017). Outcomes of an inpatient refeeding protocol in youth with anorexia nervosa: Rady Children's Hospital San Diego/University of California, San Diego. *Journal of Eating Disorders, 5*, 1. https://doi.org/10.1186/s40337-016-0132-0

Makhzoumi, S. H., Schreyer, C. C., Hansen, J. L., Laddaran, L. A., Redgrave, G. W., & Guarda, A. S. (2019). Hospital course of underweight youth with ARFID treated with a meal-based behavioral protocol in an inpatient-partial hospitalization program for eating disorders. *The International Journal of Eating Disorders, 52*(4), 428–434. https://doi.org/10.1002/eat.23049

Marino, J., Hardin, R., Gasbarro, A., Dansereau, V. A., & Fischer, S. (2020). Outpatient treatment for adults with complex eating disorders and co-morbid conditions: A decision making model and case example. *Eating Disorders, 28*(2), 171–183. https://doi.org/10.1080/10640266.2020.1723372

Matheson, B. E., Bohon, C., & Lock, J. (2020). Family-based treatment via videoconference: Clinical recommendations for treatment providers during COVID-19 and beyond. *The International Journal of Eating Disorders*, *53*(7), 1142–1154. https://doi.org/10.1002/eat.23326

Matt, V., & Matthew, H. (2013). The retrospective chart review: Important methodological considerations. *Journal of Educational Evaluation for Health Professions*, *10*, 12. https://doi.org/10.3352/jeehp.2013.10.12

McDonald, H. M., Lin, T., & Bursztyn, L. L. C. D. (2021). Multifocal germinoma masquerading as avoidant restrictive food intake disorder: A case of severely decreased food intake and malnutrition. *European Journal of Clinical Nutrition*, 1–4. https://doi.org/10.1038/s41430-021-00896-4

Mensi, M. M., Orlandi, M., Rogantini, C., Provenzi, L., Chiappedi, M., Criscuolo, M., Castiglioni, M. C., Zanna, V., & Borgatti, R. (2021). Assessing Family Functioning Before and After an Integrated Multidisciplinary Family Treatment for Adolescents With Restrictive Eating Disorders. *Frontiers in Psychiatry*, *12*, 653047. https://doi.org/10.3389/fpsyt.2021.653047

Milano, K., Chatoor, I., & Kerzner, B. (2019). A Functional Approach to Feeding Difficulties in Children. *Current Gastroenterology Reports*, *21*(10), 51. https://doi.org/10.1007/s11894-019-0719-0

Murphy, J., & Zlomke, K. R. (2016). A behavioral parent-training intervention for a child with avoidant/restrictive food intake disorder. *Clinical Practice in Pediatric Psychology*, *4*(1), 23–34. https://doi.org/10.1037/cpp0000128

Murray, H. B., Bailey, A. P., Keshishian, A. C., Silvernale, C. J., Staller, K., Eddy, K. T., Thomas, J. J., & Kuo, B. (2020). Prevalence and Characteristics of Avoidant/Restrictive Food Intake Disorder in Adult Neurogastroenterology Patients.

Clinical Gastroenterology and Hepatology: The Official Clinical Practice Journal of the American Gastroenterological Association, *18*(9), 1995-2002.e1. https://doi.org/10.1016/j.cgh.2019.10.030

Murray, H. B., Kuo, B., Eddy, K. T., Breithaupt, L., Becker, K. R., Dreier, M. J., Thomas, J. J., & Staller, K. (2021). Disorders of gut-brain interaction common among outpatients with eating disorders including avoidant/restrictive food intake disorder. *The International Journal of Eating Disorders*, *54*(6), 952–958. https://doi.org/10.1002/eat.23414

Nadeau, M. V., Richard, E., & Wallace, G. L. (2021). The Combination of Food Approach and Food Avoidant Behaviors in Children with Autism Spectrum Disorder: "Selective Overeating". *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-021-04945-6

Nakai, Y., Nin, K., Noma, S., Hamagaki, S., Takagi, R., Teramukai, S., & Wonderlich, S. A. (2017). Clinical presentation and outcome of avoidant/restrictive food intake disorder in a Japanese sample. *Eating Behaviors*, *24*, 49–53. https://doi.org/10.1016/j.eatbeh.2016.12.004

Nakai, Y., Nin, K., Noma, S., Teramukai, S., & Wonderlich, S. A. (2016). Characteristics of Avoidant/Restrictive Food Intake Disorder in a Cohort of Adult Patients. *European Eating Disorders Review: The Journal of the Eating Disorders Association*, *24*(6), 528–530. https://doi.org/10.1002/erv.2476

Naviaux, A.-F. (2019). Management of ARFID (Avoidant Restrictive Food Intake Disorder) in a 12-year-old on a Paediatric Ward in a General Hospital: Use of Mirtazapine, Partial Hospitalisation Model and Family Based Therapy. *Psychiatria Danubina*, *31*(Suppl 3), 421–426.

Nicely, T. A., Lane-Loney, S., Masciulli, E., Hollenbeak, C. S., & Ornstein, R. M. (2014). Prevalence and characteristics of avoidant/restrictive food intake disorder in a cohort of young patients in day treatment for eating disorders. *Journal of Eating Disorders*, *2*(1), 21. https://doi.org/10.1186/s40337-014-0021-3

Nicholas, J. K., Tilburg, M. A. L., Pilato, I., Erwin, S., Rivera-Cancel, A. M., Ives, L., Marcus, M. D., & Zucker, N. L. (2021). The diagnosis of avoidant restrictive food intake disorder in the presence of gastrointestinal disorders: Opportunities to define shared mechanisms of symptom expression. *Journal of Eating Disorders*, No Pagination Specified. https://doi.org/10.1002/eat.23536

Norris, M. L., Robinson, A., Obeid, N., Harrison, M., Spettigue, W., & Henderson, K. (2014). Exploring avoidant/restrictive food intake disorder in eating disordered patients: A descriptive study. *International Journal of Eating Disorders*, *47*(5), 495–499. https://doi.org/10.1002/eat.22217

Norris, M. L., Santos, A., Obeid, N., Hammond, N. G., Valois, D. D., Isserlin, L., & Spettigue, W. (2020). Characteristics and clinical trajectories of patients meeting criteria for avoidant/restrictive food intake disorder that are subsequently reclassified as anorexia nervosa. *European Eating Disorders Review: The Journal of the Eating Disorders Association*, *28*(1), 26–33. https://doi.org/10.1002/erv.2710

Norris, M. L., Spettigue, W., Hammond, N. G., Katzman, D. K., Zucker, N., Yelle, K., Santos, A., Gray, M., & Obeid, N. (2018a). Building evidence for the use of descriptive subtypes in youth with avoidant restrictive food intake disorder. *The International Journal of Eating Disorders*, *51*(2), 170–173. https://doi.org/10.1002/eat.22814

Norris, M. L., Spettigue, W., Hammond, N. G., Katzman, D. K., Zucker, N., Yelle, K., Santos, A., Gray, M., & Obeid, N. (2018b). Building evidence for the use of

descriptive subtypes in youth with avoidant restrictive food intake disorder. *The International Journal of Eating Disorders*, *51*(2), 170–173. https://doi.org/10.1002/eat.22814

Okereke, N. K. (2018). Buspirone Treatment of Anxiety in an Adolescent Female with Avoidant/Restrictive Food Intake Disorder. *Journal of Child and Adolescent Psychopharmacology*, *28*(6), 425–426. https://doi.org/10.1089/cap.2018.0005

Oliveira, S. B. (2021). Why Is Avoidant-Restrictive Food Intake Disorder Relevant to the Pediatric Gastroenterologist? *JAMA Pediatrics*, *175*(5), 455. https://doi.org/10.1001/jamapediatrics.2020.5784

Ornstein, R. M., Essayli, J. H., Nicely, T. A., Masciulli, E., & Lane-Loney, S. (2017). Treatment of avoidant/restrictive food intake disorder in a cohort of young patients in a partial hospitalization program for eating disorders. *The International Journal of Eating Disorders*, *50*(9), 1067–1074. https://doi.org/10.1002/eat.22737

Ornstein, R. M., Rosen, D. S., Mammel, K. A., Callahan, S. T., Forman, S., Jay, M. S., Fisher, M., Rome, E., & Walsh, B. T. (2013). Distribution of eating disorders in children and adolescents using the proposed DSM-5 criteria for feeding and eating disorders. *The Journal of Adolescent Health: Official Publication of the Society for Adolescent Medicine*, *53*(2), 303–305. https://doi.org/10.1016/j.jadohealth.2013.03.025

Owens, R. A., Attia, E., Fitzpatrick, J. J., Phillips, K., & Nolan, S. (2021). Eating Disorders: Identification and Management in General Medical and Psychiatric Settings. *Journal of the American Psychiatric Nurses Association*, 1078390321999713. https://doi.org/10.1177/1078390321999713

Peebles, R., Lesser, A., Park, C. C., Heckert, K., Timko, C. A., Lantzouni, E., Liebman, R., & Weaver, L. (2017). Outcomes of an inpatient medical nutritional rehabilitation

protocol in children and adolescents with eating disorders. *Journal of Eating Disorders*, *5*(1), 7. https://doi.org/10.1186/s40337-017-0134-6

Pennell, A., Couturier, J., Grant, C., & Johnson, N. (2016). Severe avoidant/restrictive food intake disorder and coexisting stimulant treated attention deficit hyperactivity disorder. *The International Journal of Eating Disorders*, *49*(11), 1036–1039. https://doi.org/10.1002/eat.22602

Peterson, C. B., Becker, C. B., Treasure, J., Shafran, R., & Bryant-Waugh, R. (2016). The three-legged stool of evidence-based practice in eating disorder treatment: Research, clinical, and patient perspectives. *BMC Medicine*, *14*, 69. https://doi.org/10.1186/s12916-016-0615-5

Peterson, K. M., Ibañez, V. F., Volkert, V. M., Zeleny, J. R., Engler, C. W., & Piazza, C. C. (2021). Using telehealth to provide outpatient follow-up to children with avoidant/restrictive food intake disorder. *Journal of Applied Behavior Analysis*, *54*(1), 6–24. https://doi.org/10.1002/jaba.794

Pitt, P. D., & Middleman, A. B. (2018). A Focus on Behavior Management of Avoidant/Restrictive Food Intake Disorder (ARFID): A Case Series. *Clinical Pediatrics*, *57*(4), 478–480. https://doi.org/10.1177/0009922817721158

Prasetyo, Y. B., Kurnia, A. D., Masruroh, N. L., Nursalam, N., Hargono, R., Ahsan, A., & Kumboyono, K. (2019). Factors influencing promotive behaviours in mothers of Indonesian children with avoidant restrictive food intake disorder. *Journal of Taibah University Medical Sciences*, *14*(5), 454–459. https://doi.org/10.1016/j.jtumed.2019.07.003

Prasetyo, Y. B., Pramaisela, F., Masruroh, N. L., Nursalam, Hargono, R., & Ahsan. (2019). Indicators of Parental Engagement and Health Promotion Behaviour in Caring for Children with Avoidant Restrictive Food Intake Disorder. *Indian Journal of Public*

Health Research & Development, *10*(10), 2082. https://doi.org/10.5958/0976-5506.2019.03157.7

Rajendram, R., Psihogios, M., & Toulany, A. (2021). Delayed diagnosis of avoidant/restrictive food intake disorder and autism spectrum disorder in a 14-year-old boy. *Clinical Case Reports*, *9*(6), e04302. https://doi.org/10.1002/ccr3.4302

Reilly, E. E., Brown, T. A., Gray, E. K., Kaye, W. H., & Menzel, J. E. (2019). Exploring the cooccurrence of behavioural phenotypes for avoidant/restrictive food intake disorder in a partial hospitalization sample. *European Eating Disorders Review: The Journal of the Eating Disorders Association*, *27*(4), 429–435. https://doi.org/10.1002/erv.2670

Reilly, E. E., Rockwell, R. E., Ramirez, A. L., Anderson, L. K., Brown, T. A., Wierenga, C. E., & Kaye, W. H. (2020). Naturalistic outcomes for a day-hospital programme in a mixed diagnostic sample of adolescents with eating disorders. *European Eating Disorders Review*, *28*(2), 199–210. https://doi.org/10.1002/erv.2716

Richmond, T. K., Woolverton, G. A., Mammel, K., Ornstein, R. M., Spalding, A., Woods, E. R., & Forman, S. F. (2020). How do you define recovery? A qualitative study of patients with eating disorders, their parents, and clinicians. *International Journal of Eating Disorders*, *53*(8), 1209–1218. https://doi.org/10.1002/eat.23294

Rienecke, R. D., Drayton, A., Richmond, R. L., & Mammel, K. A. (2020). Adapting treatment in an eating disorder program to meet the needs of patients with ARFID: Three case reports. *Clinical Child Psychology and Psychiatry*, *25*(2), 293–303. https://doi.org/10.1177/1359104519864129

Rosania, K., & Lock, J. (2020). Family-Based Treatment for a Preadolescent With Avoidant/Restrictive Food Intake Disorder With Sensory Sensitivity: A Case Report. *Frontiers in Psychiatry*, *11*, 350. https://doi.org/10.3389/fpsyt.2020.00350

Sackett, D. L., Rosenberg, W. M., Gray, J. A., Haynes, R. B., & Richardson, W. S. (1996). Evidence based medicine: What it is and what it isn't. *BMJ : British Medical Journal*, *312*(7023), 71–72.

Sato, Y., Shinozaki, M., Sasaki, H., Shiinoki, M., Shimizu, T., Yasui-Furukori, N., & Shimoda, K. (2020). Gluten-Related Disorder and Lactose Intolerance Concomitant With Avoidant/Restrictive Food Intake Disorder. *The Primary Care Companion for CNS Disorders*, *22*(4), 0–0. https://doi.org/10.4088/PCC.19l02517

Schermbrucker, J., Kimber, M., Johnson, N., Kearney, S., & Couturier, J. (2017). Avoidant/Restrictive Food Intake Disorder in an 11-Year Old South American Boy: Medical and Cultural Challenges. *Journal of the Canadian Academy of Child and Adolescent Psychiatry*, *26*(2), 110–113.

Schmidt, R., Hiemisch, A., Kiess, W., von Klitzing, K., Schlensog-Schuster, F., & Hilbert, A. (2021). Macro- and Micronutrient Intake in Children with Avoidant/Restrictive Food Intake Disorder. *Nutrients*, *13*(2), 400. https://doi.org/10.3390/nu13020400

Schmidt, R., Kirsten, T., Hiemisch, A., Kiess, W., & Hilbert, A. (2019). Interview-based assessment of avoidant/restrictive food intake disorder (ARFID): A pilot study evaluating an ARFID module for the Eating Disorder Examination. *The International Journal of Eating Disorders*, *52*(4), 388–397. https://doi.org/10.1002/eat.23063

Schöffel, H., Hiemisch, A., Kiess, W., Hilbert, A., & Schmidt, R. (2021). Characteristics of avoidant/restrictive food intake disorder in a general paediatric inpatient sample. *European Eating Disorders Review*, *29*(1), 60–73. https://doi.org/10.1002/erv.2799

Schön, D. A. (2017). *The Reflective Practitioner: How Professionals Think in Action*. Routledge. https://doi.org/10.4324/9781315237473

Schorr, M., Drabkin, A., Rothman, M. S., Meenaghan, E., Lashen, G. T., Mascolo, M., Watters, A., Holmes, T. M., Santoso, K., Yu, E. W., Misra, M., Eddy, K. T.,

Klibanski, A., Mehler, P., & Miller, K. K. (2019). Bone mineral density and estimated hip strength in men with anorexia nervosa, atypical anorexia nervosa and avoidant/restrictive food intake disorder. *Clinical Endocrinology*, *90*(6), 789–797. https://doi.org/10.1111/cen.13960

Sellbom, M., Forbush, K. T., Gould, S. R., Markon, K. E., Watson, D., & Witthöft, M. (2021). HiTOP Assessment of the Somatoform Spectrum and Eating Disorders. *Assessment*, 10731911211020824. https://doi.org/10.1177/10731911211020825

Serban, N., Harati, P. M., Munoz Elizondo, J. M., & Sharp, W. G. (2020). An Economic Analysis of Intensive Multidisciplinary Interventions for Treating Medicaid-Insured Children with Pediatric Feeding Disorders. *Medical Decision Making: An International Journal of the Society for Medical Decision Making*, *40*(5), 596–605. https://doi.org/10.1177/0272989X20932158

Sharp, W. G., Allen, A. G., Stubbs, K. H., Criado, K. K., Sanders, R., McCracken, C. E., Parsons, R. G., Scahill, L., & Gourley, S. L. (2017). Successful pharmacotherapy for the treatment of severe feeding aversion with mechanistic insights from cross-species neuronal remodeling. *Translational Psychiatry*, *7*(6), e1157. https://doi.org/10.1038/tp.2017.126

Sharp, W. G., Berry, R. C., Burrell, L., Scahill, L., & McElhanon, B. O. (2020). Scurvy as a Sequela of Avoidant-Restrictive Food Intake Disorder in Autism: A Systematic Review. *Journal of Developmental and Behavioral Pediatrics: JDBP*, *41*(5), 397–405. https://doi.org/10.1097/DBP.0000000000000782

Sharp, W. G., Stubbs, K. H., Adams, H., Wells, B. M., Lesack, R. S., Criado, K. K., Simon, E. L., McCracken, C. E., West, L. L., & Scahill, L. D. (2016). Intensive, Manual-based Intervention for Pediatric Feeding Disorders: Results From a Randomized Pilot

Trial. *Journal of Pediatric Gastroenterology and Nutrition*, *62*(4), 658–663. https://doi.org/10.1097/MPG.0000000000001043

Sharp, W. G., Volkert, V. M., Scahill, L., McCracken, C. E., & McElhanon, B. (2017). A Systematic Review and Meta-Analysis of Intensive Multidisciplinary Intervention for Pediatric Feeding Disorders: How Standard Is the Standard of Care? *The Journal of Pediatrics*, *181*, 116-124.e4. https://doi.org/10.1016/j.jpeds.2016.10.002

Shimshoni, Y., Silverman, W. K., & Lebowitz, E. R. (2020). SPACE-ARFID: A pilot trial of a novel parent-based treatment for avoidant/restrictive food intake disorder. *International Journal of Eating Disorders*, *53*(10), 1623–1635. https://doi.org/10.1002/eat.23341

Soffritti, E. M., Passos, B. C. L., Rodrigues, D. G., Freitas, S. R. de, & Nazar, B. P. (2020). Adult avoidant/restrictive food intake disorder: A case report. *Jornal Brasileiro de Psiquiatria*, *68*, 252–257. https://doi.org/10.1590/0047-2085000000253

Spettigue, W., Norris, M. L., Santos, A., & Obeid, N. (2018). Treatment of children and adolescents with avoidant/restrictive food intake disorder: A case series examining the feasibility of family therapy and adjunctive treatments. *Journal of Eating Disorders*, *6*, 20. https://doi.org/10.1186/s40337-018-0205-3

Spring, B. (2007). Evidence-based practice in clinical psychology: What it is, why it matters; what you need to know. *Journal of Clinical Psychology*, *63*(7), 611–631. https://doi.org/10.1002/jclp.20373

Strand, M. (2021). Eggs, sugar, grated bones: Colour-based food preferences in autism, eating disorders, and beyond. *Medical Humanities*, *47*(1), 87–94. https://doi.org/10.1136/medhum-2019-011811

Strand, M., von Hausswolff-Juhlin, Y., & Welch, E. (2019). A systematic scoping review of diagnostic validity in avoidant/restrictive food intake disorder. *The International Journal of Eating Disorders*, *52*(4), 331–360. https://doi.org/10.1002/eat.22962

Strandjord, S. E., Sieke, E. H., Richmond, M., & Rome, E. S. (2015). Avoidant/Restrictive Food Intake Disorder: Illness and Hospital Course in Patients Hospitalized for Nutritional Insufficiency. *The Journal of Adolescent Health: Official Publication of the Society for Adolescent Medicine*, *57*(6), 673–678. https://doi.org/10.1016/j.jadohealth.2015.08.003

Straus, S. E., Glasziou, P., Richardson, W. S., & Haynes, R. B. (2018). *Evidence-Based Medicine E-Book: How to Practice and Teach EBM*. Elsevier Health Sciences.

Sur, R. L., & Dahm, P. (2011). History of evidence-based medicine. *Indian Journal of Urology : IJU : Journal of the Urological Society of India*, *27*(4), 487–489. https://doi.org/10.4103/0970-1591.91438

Swift, J. K., Callahan, J. L., Ivanovic, M., & Kominiak, N. (2013). Further examination of the psychotherapy preference effect: A meta-regression analysis. *Journal of Psychotherapy Integration*, *23*(2), 134–145. https://doi.org/10.1037/a0031423

Tanıdır, C., & Hergüner, S. (2015). Mirtazapine for Choking Phobia: Report of a Pediatric Case. *Journal of Child and Adolescent Psychopharmacology*, *25*(8), 659–660. https://doi.org/10.1089/cap.2015.0145

Taylor, T. (2021). Use of an Exit Criterion for a Clinical Paediatric Feeding Case in-Home. *Journal of Developmental and Physical Disabilities*, *33*(3), 475–488. https://doi.org/10.1007/s10882-020-09759-5

Taylor, T., Haberlin, A., & Haberlin, J. (2019). Treatment of avoidant/restrictive food intake disorder for a teenager with typical development within the home setting. *Journal of Adolescence*, *77*, 11–20. https://doi.org/10.1016/j.adolescence.2019.09.007

Thapliyal, P., Mitchison, D., Miller, C., Bowden, J., Alejandro González-Chica, D., Stocks, N., Touyz, S., & Hay, P. (2018). Comparison of mental health treatment status and use of antidepressants in men and women with eating disorders. *Eating Disorders*, *26*(3), 248–262. https://doi.org/10.1080/10640266.2017.1383788

Thomas, J. J., Becker, K. R., Kuhnle, M. C., Jo, J. H., Harshman, S. G., Wons, O. B., Keshishian, A. C., Hauser, K., Breithaupt, L., Liebman, R. E., Misra, M., Wilhelm, S., Lawson, E. A., & Eddy, K. T. (2020). Cognitive-behavioral therapy for avoidant/restrictive food intake disorder: Feasibility, acceptability, and proof-of-concept for children and adolescents. *The International Journal of Eating Disorders*, *53*(10), 1636–1646. https://doi.org/10.1002/eat.23355

Thomas, J. J., Brigham, K. S., Sally, S. T., Hazen, E. P., & Eddy, K. T. (2017). Case 18-2017—An 11-Year-Old Girl with Difficulty Eating after a Choking Incident. *The New England Journal of Medicine*, *376*(24), 2377–2386. https://doi.org/10.1056/NEJMcpc1616394

Thomas, J. J., Eddy, K. T., Murray, H. B., Tromp, M. D. P., Hartmann, A. S., Stone, M. T., Levendusky, P. G., & Becker, A. E. (2015). The impact of revised DSM-5 criteria on the relative distribution and inter-rater reliability of eating disorder diagnoses in a residential treatment setting. *Psychiatry Research*, *229*(1–2), 517–523. https://doi.org/10.1016/j.psychres.2015.06.017

Treasure, J., Stein, D., & Maguire, S. (2015). Has the time come for a staging model to map the course of eating disorders from high risk to severe enduring illness? An examination of the evidence. *Early Intervention in Psychiatry*, *9*(3), 173–184. https://doi.org/10.1111/eip.12170

Trompeter, N., Bussey, K., Forbes, M. K., Mond, J., Hay, P., Basten, C., Goldstein, M., Thornton, C., Heruc, G., Byrne, S., Griffiths, S., Lonergan, A., Touyz, S., &

Mitchison, D. (2021). Differences between Australian adolescents with eating disorder symptoms who are in treatment or not in treatment for an eating disorder. *Early Intervention in Psychiatry*, *15*(4), 882–888. https://doi.org/10.1111/eip.13027

Trompeter, N., Bussey, K., Hay, P., Griffiths, S., Murray, S. B., Mond, J., Lonergan, A., Pike, K. M., & Mitchison, D. (2019). Fear of negative evaluation among eating disorders: Examining the association with weight/shape concerns in adolescence. *The International Journal of Eating Disorders*, *52*(3), 261–269. https://doi.org/10.1002/eat.23018

Tsai, K., Singh, D., & Pinkhasov, A. (2017). Pudendal nerve entrapment leading to avoidant/restrictive food intake disorder (ARFID): A case report. *The International Journal of Eating Disorders*, *50*(1), 84–87. https://doi.org/10.1002/eat.22601

Tsang, K. K., Hayes, L. C., Bujoreanu, S., Samsel, C. B., & Ibeziako, P. I. (2020). Characterization Study of Patients Presenting to an Acute Care Pediatric Hospital Identified With Avoidant/Restrictive Food Intake Disorder. *Hospital Pediatrics*, *10*(7), 600–607. https://doi.org/10.1542/hpeds.2020-0010

Wagner, A. F., Zickgraf, H. F., & Lane-Loney, S. (2020). Caregiver accommodation in adolescents with avoidant/restrictive food intake disorder and anorexia nervosa: Relationships with distress, eating disorder psychopathology, and symptom change. *European Eating Disorders Review: The Journal of the Eating Disorders Association*, *28*(6), 657–670. https://doi.org/10.1002/erv.2786

Wampold, B. E. (2015). How important are the common factors in psychotherapy? An update. *World Psychiatry*, *14*(3), 270–277. https://doi.org/10.1002/wps.20238

Wassenaar, E., O'Melia, A. M., & Mehler, P. S. (2018). A causality dilemma: ARFID, malnutrition, psychosis, and hypomagnesemia. *The International Journal of Eating Disorders*, *51*(9), 1113–1116. https://doi.org/10.1002/eat.22939

Westfall, N. C., Mavrides, N. A., & Coffey, B. J. (2018). Multidisciplinary Management of Adolescent Early-Onset, Treatment-Resistant Schizophrenia Complicated by Avoidant/Restrictive Food Intake Disorder and Catatonia in Acute Exacerbations. *Journal of Child and Adolescent Psychopharmacology*, *28*(9), 663–666. https://doi.org/10.1089/cap.2018.29157.bjc

Williams, K. E., Hendy, H. M., Field, D. G., Belousov, Y., Riegel, K., & Harclerode, W. (2015). Implications of Avoidant/Restrictive Food Intake Disorder (ARFID) on Children with Feeding Problems. *Children's Health Care*, *44*(4), 307–321. https://doi.org/10.1080/02739615.2014.921789

Yanagimoto, Y., Ishizaki, Y., & Kaneko, K. (2020). Iron deficiency anemia, stunted growth, and developmental delay due to avoidant/restrictive food intake disorder by restricted eating in autism spectrum disorder. *Biopsychosocial Medicine*, *14*, 8. https://doi.org/10.1186/s13030-020-00182-y

Yaşar, A. B., Abamor, A. E., Usta, F. D., Erdoğan Taycan, S., & Kaya, B. (2019). Two cases with avoidant/restrictive food intake disorder: Effectiveness of EMDR and CBT combination on eating disorders (eng). *Journal of Clinical Psychiatry*, *22*(4), 493–500. https://doi.org/10.5505/kpd.2019.04127

Yule, S., Wanik, J., Holm, E. M., Bruder, M. B., Shanley, E., Sherman, C. Q., Fitterman, M., Lerner, J., Marcello, M., Parenchuck, N., Roman-White, C., & Ziff, M. (2021). Nutritional Deficiency Disease Secondary to ARFID Symptoms Associated with Autism and the Broad Autism Phenotype: A Qualitative Systematic Review of Case Reports and Case Series. *Journal of the Academy of Nutrition and Dietetics*, *121*(3), 467–492. https://doi.org/10.1016/j.jand.2020.10.017

Zanna, V., Criscuolo, M., Mereu, A., Cinelli, G., Marchetto, C., Pasqualetti, P., Tozzi, A. E., Castiglioni, M. C., Chianello, I., & Vicari, S. (2021). Restrictive eating disorders in

children and adolescents: A comparison between clinical and psychopathological profiles. *Eating and Weight Disorders: EWD*, *26*(5), 1491–1501. https://doi.org/10.1007/s40519-020-00962-z

Zickgraf, H. F., & Ellis, J. M. (2018). Initial validation of the Nine Item Avoidant/Restrictive Food Intake disorder screen (NIAS): A measure of three restrictive eating patterns. *Appetite*, *123*, 32–42. https://doi.org/10.1016/j.appet.2017.11.111

Zickgraf, H. F., Murray, H. B., Kratz, H. E., & Franklin, M. E. (2019). Characteristics of outpatients diagnosed with the selective/neophobic presentation of avoidant/restrictive food intake disorder. *The International Journal of Eating Disorders*, *52*(4), 367–377. https://doi.org/10.1002/eat.23013

Zickgraf, H. F., Richard, E., Zucker, N. L., & Wallace, G. L. (2020). Rigidity and Sensory Sensitivity: Independent Contributions to Selective Eating in Children, Adolescents, and Young Adults. *Journal of Clinical Child and Adolescent Psychology: The Official Journal for the Society of Clinical Child and Adolescent Psychology, American Psychological Association, Division 53*, 1–13. https://doi.org/10.1080/15374416.2020.1738236

Zilcha-Mano, S. (2017). Is the alliance really therapeutic? Revisiting this question in light of recent methodological advances. *American Psychologist*, *72*(4), 311–325. https://doi.org/10.1037/a0040435

Zucker, N. L., LaVia, M. C., Craske, M. G., Foukal, M., Harris, A. A., Datta, N., Savereide, E., & Maslow, G. R. (2019). Feeling and body investigators (FBI): ARFID division-An acceptance-based interoceptive exposure treatment for children with ARFID. *The International Journal of Eating Disorders*, *52*(4), 466–472. https://doi.org/10.1002/eat.22996

Part Two: Empirical Study

Avoidant / Restrictive Food Intake Disorder (ARFID) and the Service Provision Wish List: A contribution to the evidence base to inform the improvement of ARFID service provision in the NHS.

Abstract

Aims: Avoidant Restrictive Food Intake Disorder (ARFID) is a new diagnostic category added to the DSM-5 in 2013 (APA, 2013). At present, there is limited evidence regarding best clinical practice for people with ARFID. The aim of this study was to contribute to an evidence base that can inform the improvement of ARFID service provisions in the NHS.

Method: A mixed method approach was used to explore the optimisation of service delivery for those with ARFID. The heterogeneous presentation of ARFID was investigated using pre-existing quantitative clinical data to examine whether three predetermined subgroups (reflecting autism diagnostic status, age and weight) had an influence on the commonly observed drivers of ARFID: (i) avoidance based on the sensory characteristics of food, (ii) apparent lack of interest in eating or food and (iii) fear of aversive consequences of eating (e.g. Choking, vomiting). Based on these findings, the study made inferences regarding the heterogeneity amongst children with ARFID and how it can be parsed, to make recommendations to improve service delivery. The qualitative part of the study consulted carers whose children had accessed ARFID services and sought recommendations on improving ARFID service provisions though semi-structured interviews.

Results: Quantitative analysis indicated that autism diagnosis and age had a statistically significant association with the sensory sensitivity driver of ARFID. There were no statistically significant associations between, the independent variables (autism diagnosis, age or weight) and the other ARFID drivers (lack of interest and fear of aversive consequences). The qualitative data analysis yielded two themes on current service limitations and how these could be addressed: lack of knowledge (subthemes: service limitations, implications for client journeys and underestimation of impact of reported difficulties) and the service provision wish list (subthemes: better knowledge among professionals, adaptations to improve fit with individual need, reducing burden on families and joined up working).

Conclusions: Understanding the ARFID population better and taking stakeholder views into consideration may give insight into actionable suggestions of improving ARFID service provisions.

1. Introduction

1.1. Avoidant Restrictive Food Intake Disorder (ARFID)

Avoidant Restrictive Food Intake Disorder (ARFID) is a new diagnostic category which was introduced to the Diagnostic and Statistical Manual, Fifth Edition in 2013 (DSM-5, American Psychiatric Association, 2013) and the International Classification of Diseases 11th Edition (ICD-11) in 2018 (World Health Organisation, 2018). Together with anorexia nervosa (AN), bulimia nervosa (BN), binge eating disorder, rumination disorder and pica, ARFID forms the 'feeding and eating disorders' section of the DSM-5. ARFID is characterised by a persistent disturbance in feeding or eating, which may result in significant weight loss, failure to gain weight, severe malnutrition, growth compromise, supplement dependency and/ or marked interference with psychosocial functioning. While ARFID falls under the umbrella of an Eating Disorder (ED), in contrast to other EDs such as AN and BN, those with ARFID are a heterogeneous group who engage in restrictive and avoidant eating without weight and body image concerns and no desire to get thinner (Claudino et al., 2019).

The current diagnostic criteria for ARFID indicate three commonly observed drivers that maintain the condition: (1) avoidance based on the sensory characteristics of food (hereafter: sensory sensitivity), (2) apparent lack of interest in food or eating (hereafter: lack of interest) and (3) concern about the aversive consequences of food (e.g. vomiting and choking) (hereafter: fear of aversive consequences). These drivers may vary in severity, can co-occur and are not mutually exclusive (American Psychiatric Association (APA), 2013). The diagnostic manuals further suggest that there are likely to be additional causal processes that underpin restrictive or avoidant eating in ARFID and that the drivers listed above are merely a guide to the initial stages of understanding ARFIDs underlying causes, rather than an exhaustive list (Bourne et al., 2020).

This heterogeneity of ARFID presentations pose problems in providing effective and efficient treatment within mental health services (Magel et al., 2021). ARFID compromises multiple aetiologies and clients often present with complex medical or neurodevelopmental co-morbidities such as Autism Spectrum Disorder (hereafter 'autism'), Attention Deficit Disorder (ADHD) or other learning disabilities and a range of co-occurring medical conditions (Norris et al., 2014). Due to this complexity of presentations, clinicians may experience a lack of confidence when making diagnosis of ARFID (Coglan & Otasowie, 2019). Currently, it is also not known whether ARFIDs heterogeneity may require different pathways or different service provisions. As such the condition is currently under-recognised and underdiagnosed, which results in limited awareness of ARFID and subsequently inadequate commissioning and management on a service level (Coglan & Otasowie, 2019).

1.2. Current understanding of ARFID

Chapter one of this thesis has shown that since its introduction to the DSM-5 in 2013, clinical and research interest in ARFID has grown (Bryant-Waugh et al., 2021). Nevertheless, many existing studies of ARFID are based on small clinical samples, with overlapping clinical presentations and focus on individuals who have presented to an ED service or were being treated by a physician specialising in EDs (Bourne et al., 2020). Questions regarding the main drivers of ARFID also remain under-researched (Norris et al., 2018a). This is unsurprising, as dependable statements concerning aetiology, treatment interventions and effective service delivery rely on significant bodies of evidence that accumulate over time (Bryant-Waugh et al., 2021).

Currently, individuals affected by avoidant or restrictive eating present to a diverse forum of clinical settings. Thus, the limited awareness regarding ARFID among health-care

professionals remains concerning (Bryant-Waugh et al., 2021) and has created significant gaps in providing adequate service provision (Coglan & Otasowie, 2019). As of 2018, NHS England's access and waiting-time standards have stipulated that ARFID should be treated in local ED services (NHS England, 2015), yet most of these services are not equipped to treat ARFID effectively or to manage the often complex mental and physical co-morbidities these clients present with (Coglan & Otasowie, 2019). ARFID is also currently not included in the National Institute for Health and Care Excellence (NICE) guidance for EDs and is not seen as a priority in established ED services compared to AN or BN (Coglan & Otasowie, 2019). Thus, the present situation poses difficulties for clinicians, stakeholders and policy makers when wishing to deliver evidence-based care for individuals with ARFID (Bryant-Waugh et al., 2021).

1.3. National pilot

In recognition of ARFID being treated within local ED services and the potential gap in adequate service provision, a National Avoidant and Restrictive Food Intake Disorder Pilot (hereafter: national pilot/ pilot) was commissioned to gauge the level of awareness of ARFID and services' current ability to treat the condition (Bryant-Waugh et al., 2020). The pilot examined clients' journey throughout ED services, mapping their referral and subsequent treatment within community ED services. Funding was provided for seven sites across different regions of England to take part in the pilot and was coordinated by a London site. The pilot confirmed that the majority of services seeing young people with avoidant or restrictive eating difficulties are currently not providing effective integrated medical, dietetic and psychological input required for the management of ARFID (Bryant-Waugh et al. 2020).

The pilot has provided valuable insight into the co-morbidities individuals with ARFID present to services with, has highlighted inconsistencies across care and drawn attention to the difficulties that may arise when treating individuals with ARFID effectively. The pilot similarly provides data, collected in routine clinical care, that may hold potentially valuable information about the heterogeneous presentation of ARFID, by giving insight into client characteristics such as autism diagnosis, age, sex and weight amongst others; and through the completion of questionnaires that can provide information regarding the drivers commonly observed to cause and/or maintain ARFID. Through understanding the population that presents to these services in more detail, ARFIDs heterogeneity may be further classified, which may enable tentative recommendations for improvement of current ARFID service provisions.

Moreover, while the pilot has identified shortcomings on current service provisions, it has not yet yielded recommendations regarding optimal service delivery for those with ARFID, or make suggestions for future improvements. Little is known about the type of services that stakeholders would find useful, or what adaptations can be made to effectively and efficiently care for those with ARFID. While clinicians may be able to identify aspects of service delivery that can be improved, to our knowledge no study has sought to incorporated the voice of stakeholders in shaping ARFID services. By taking client preference into consideration, services may make adaptations that feel meaningful for the population they are aiming to treat.

1.4. Current study

1.4.1. Quantitative study

The study will be divided into two distinct parts. The first of which, hereafter referred to as the quantitative study, will use pre-existing, routine clinical data to investigate the heterogeneity of those presenting to ARFID services in the national pilot. It will examine whether three pre-determined subgroups (defined according to autism diagnostic status, age and weight) have an association with the commonly observed divers of ARFID (sensory sensitivity, lack of interest in food or fear of aversive consequences). Based on these findings, the study will then make inferences regarding the heterogeneity amongst children with ARFID and how it can be parsed to make recommendations as to how service delivery can be improved.

1.4.1.1. Subgroups and their determination

a) Autism

Autism is a life-long neurodevelopmental condition characterised by impairments in two domains of functioning: (i) social reciprocity and communication and (ii) restricted, repetitive or stereotyped patterns of behaviours, including atypical sensory processing (Cermak et al., 2010). Up to 89% of children with autism exhibit food selectivity (Ledford & Gast, 2006), a far higher percentage than the 25% to 35% of typically developing children who are considered to be picky eaters (Leung et al., 2012). The DSM-5 recognises that ARFID is a 'fairly frequent presenting feature of autism spectrum disorder and extreme and narrow food preferences may persist.' (APA, 2013).

There is a clear association and relationship between children with autism and ARFID, which requires further exploration. This association may partly be mediated by the

sensory processing difficulties that are a core diagnostic characteristic of autism. Children with autism may show greater susceptibility in developing ARFID with a sensory sensitivity driver, but to our knowledge no study has formally evaluated this. Understanding the relationship between autism and ARFID may allow us to make cautious inferences to improve service delivery. These may include highlighting the value of developing distinct clinical pathways dependent on autism status, or a particular focus within a clinical intervention when delivered to autistic young people.

b) Age and weight

The age of onset for EDs such as AN or BN has classically been situated in adolescent and young adults (Halmi, 2005). Compared to those with AN and BN, some studies have found that ARFID clients are younger (Norris et al., 2014). Children with ARFID typically develop difficulties with eating that persevere beyond the neophobia (unwillingness to try new foods) stage, typically between 2 and 6 years old (Norris et al., 2016). While most clients with ARFID report consistent difficulties with eating, ARFID can also have an acute onset particularly following an adverse experience whilst eating (ie. Choking, vomiting) (Zimmerman & Fisher, 2017). Therefore confirming, that ARFID clients may present to services at any age (Zimmerman & Fisher, 2017).

Similarly, weight can vary greatly in the ARFID population (APA, 2013). Children with ARFID may be severely underweight or of relatively normal weight on first glance (APA, 2013) depending on the selection of their preferred foods. Current studies indicate that those with ARFID present to services with higher weight than those with AN but lower than those with BN (Fisher et al., 2014).

Both age and weight are variables that have been recognised as noteworthy correlates for other EDs, although their association within ARFID remains inadequately understood (Lieberman et al., 2019). Getting better insight into how these factors associate with different types of ARFID presentations, may allow for service/referral pathways to be tailored appropriately, for example by designing different protocols depending on age or weight.

1.4.2. Qualitative study

The second part of the study, hereafter referred to as the qualitative study, aims to consult carers whose children have accessed ARFID services and seek recommendations on improving service delivery for this population. This part of the project aimed to give stakeholders a voice in the design of the services they use. The research focuses on the opinion of parents or carers who children who have accessed ARFID services. This decision was based on multiple factors, and was made on the basis that it would be the most holistic approach to answering the research question. As a number of children who have been treated in the service also have co-morbid autism, conducting semi-structured interviews with this population may have led to pragmatic difficulties, specifically if they are non-verbal. Moreover, individuals suffering from ARFID may be affected at any age. Therefore, including carers allowed us to explore the needs of individuals with a wider age range. Future research may want to focus on including the voice of children as well, to enable more holistic recommendations to be made.

Analysis will be facilitated through conducting semi-structured interviews. A qualitative approach was chosen for this part of the study, as it can generate descriptions of the challenges that carers have experienced and will therefore allow a deeper understanding

of opinions and recommendations regarding ARFID service provision (Fredheim et al., 2011).

1.5. Research aims & objectives

The aim of this study is to contribute to an evidence base that can inform the improvement of ARFID service provisions in the NHS.

The study will do this by fulfilling following objectives:

1. To gain further understanding of the heterogeneous presentation of ARFID by analysing the quantitative clinical data obtained in the national ARFID pilot. The study will examine whether three pre-determined subgroups (defined by autism diagnosis status, age, and weight) have an association with the commonly observed drivers of ARFID ((i) sensory sensitivity, (ii) lack of interest in food or (iii) fear of aversive consequences of food).

2. To make inferences based on findings from the national pilot regarding heterogeneity amongst children with ARFID and how it can be parsed, to make tentative recommendations as to how service delivery can meet the needs of this diverse population more effectively.

3. To consult carers whose children have accessed ARFID services and seek recommendations on improving service delivery for this population.

2. Methods

As aforementioned this study was divided into two distinct parts: a quantitative and a qualitative study. These will be discussed below.

2.1. Design

2.1.1. Quantitative study

The design of this study was an exploratory correlation design and analysed whether there was an association between the independent and dependent variables.

The independent variables were:

(i) autism diagnosis: Yes/ No

(ii) Age of participants: The age of the participants has been divided into three subgroups: 2-7 year olds, 8-13 year olds, and 14+ year olds. These were chosen to parallel the division of age groups used in the national ARFID pilot.

(iii) Weight: Weight was measured in Median Body Mass Index (Median BMI) and will be referred to as weight for height (WFH). Low WFH (< 85%) will be compared to normal (85-115%) and high WFH (>115 %). These mirrored the categorisations used in the pilot.

The dependent variable was the parent version of the Pica, ARFID and Rumination Disorder Interview Questionnaire (PARDI-AR-Q, hereafter PARDI). The PARDI has three subscales, which map onto the commonly observed drivers of ARFID: sensory sensitivity, lack of interest and fear of aversive consequences (for more information see: measures).

2.1.2. Qualitative study

Seven semi-structured interviews were conducted with carers who have a current or historic caring responsibility for individuals with ARFID. Written informed consent was obtained from all participants.

2.2. Research governance

2.2.1. Quantitative study

The data obtained as part of the national pilot, is made up of routinely collected outcome measures and its collection was approved by NHS England. As part of the pilot, each of the participating sites gave their informed consent for the data to be anonymised and pooled following the completion of the pilot. This data, collected in routine clinical practice, was analysed for the current study as a service audit, registered with the Research and Development (R&D) Department of the London NHS trust that is home to the service that led the national pilot. All data obtained as part of this process was fully anonymised by the sites before being analysed by the researcher and it excluded any identifiable information. The data was then further reduced to only include information specifically relevant to the analysis of this project. No identifying information was seen by the researcher or will be depicted in this study.

2.2.2. Qualitative study

The London site which coordinated the national pilot was also used as a base for the qualitative study. Research governance was considered thoroughly. As this study primarily aims to aid with and advance ideas for service development, it was deemed that the appropriate research governing body was the R&D Department of the NHS trust. The study was presented to the R&D department as a Patient and Public Involvement (PPI) project

which would evaluate the optimisation of service delivery for those with ARFID. The study was given favourable approval in February 2022. Prior to taking part, participants were informed about the study's procedure (see Appendix A) and informed consent was obtained. The semi-structured interviews in which the participants were taking part, were designed to be a pleasant experience that was non-intrusive and non-threatening. Nevertheless, participants were informed that they could discontinue at any time.

2.3. Procedure

2.3.1. Quantitative study

The national ARFID pilot (Bryant-Waugh et al. 2020) was commissioned to include seven Child and Young People Community Eating Disorder (CYP-CED) services across different regions of England. Data was collected between November 2019 and March 2020 from each client presenting to the service with possible symptoms of ARFID, as part of routine clinical procedures. Each participant completed the same set of routine outcome measures one of which was the Pica, ARFID and Rumination Disorder Interview – ARFID Questionnaire (PARDI-AR-Q), which was analysed in this study.

All sites were given the same set of instructions as to how to collect, monitor and store the data they collected during the pilot. This data was anonymised, obtained from the sites, collated, cleaned and analysed by the researcher.

2.3.2. Qualitative study

Carers were interviewed via Microsoft Teams by the researcher. Interviews lasted approximately 60 minutes. Interviews followed a semi-structured format, with questions that were pre-agreed. These were designed by the study team, approved by the clinical ARFID

team at the testing site, as well as the governing body who approved this study as an PPI project (for a list of questions please see Appendix B).

Topics for the interview were based on three key areas:

(i) Experiences of receiving help for ARFID and participants' journeys into services generally

(ii) Participants' experience of attending the service at the London site and areas for development / improvement

(iii) Development / improvement ideas for ARFID services generally, with emphasis on the possible adaptations for the three subgroups identified as part of the quantitative study (autism diagnosis status, age and weight)

Examples of the questions asked were: 'What was your experience of accessing ARFID specific services?' and 'What do you think would be helpful to add or develop as part of your care?' and 'Do you have any ideas for how the service can be improved / any useful adaptations that could be made for neurodiverse young people?'. The interviewer would sometimes ask follow-up questions, if the answer of the participant needed further clarification.

2.4. Participants

2.4.1. Quantitative study

Participants were included in the analysis if they presented with symptoms of ARFID to one of the seven sites across England between November 2019 – March 2020. There were no exclusion criteria.

Across the seven sites, 120 children and young people presented to the services in the allocated timeframe. Of these 120 children and young people, 51 (42.5%) were male and 69 (67.5%) were female. The children were grouped into three different age groups, 21 (17.5%) were between 2-7 years old, 62 (51.7%) were aged between 8-13 years old and 37 (30.8%) were 14+ years old. Due to a substantial number of different ethnicities with small sample sizes, ethnicity was categorised into 'white' and 'ethnic minorities'. Ethnic minorities included: Black British, Black African, Black Caribbean, Asian British, and other mixed or mixed unspecified. The sample was predominantly white (86.7%) followed by ethnic minorities (13.7%).

2.4.2. Qualitative study

a) Recruitment

Participants were recruited through the PPI register of the London service leading the national pilot, on which they had voiced their interest in being consulted regarding service improvement in the future. Participants were approached by the clinical lead of the ARFID team at the London site. Participants were considered eligible if they have a current or historical caring responsibility for someone with a diagnosis of ARFID who had been/ was currently being treated by the London site. This yielded a total of six participants. Following this, the study was opened up to carers of clients treated by the London site who had not registered their interest in PPI projects. One additional participant was recruited.

Recruitment was stopped at the beginning of April 2022. Preliminary data analysis at this stage indicated that the data was sufficiently saturated in the context of the homogeneous sample of this study. Upon preliminary analysis, it became evident that carers largely shared similar views and that the ideas generated within the interviews were related. More varied

opinions may have been obtained if recruitment had been extended to include a more diverse sample. Therefore, although a larger sample had been targeted, the research team felt that seven participants were enough to conclude recruitment, given the time restraints of the thesis.

b) Sample

In total, seven carers completed the interviews. Six of the participants were mothers to a child with ARFID, and one participant was a father. The service in which this research took place, was a national service and offers support for those within catchment areas, but also to individuals from other regions of the country if no local support is accessible. Three of the participants were within the catchment area of the London site, four were national clients, outside of catchment area.

All participants children had a diagnosis of ARFID, the age of the children ranged from 3 to 17. Two of the children had a diagnosis of autism, five did not hold a diagnosis. Three children were male, four children were female.

2.5. Measures

2.5.1. Quantitative study

The Pica, ARFID Rumination Disorder interview – ARFID Questionnaire (PARDI-AR-Q)

The PARDI-AR-Q is a self-report measure of the symptoms of ARFID, based on the Pica, ARFID, and Rumination Disorder Interview (PARDI), (Bryant-Waugh et al., 2019).

The PARDI-AR-Q in conjunction with a subsequent clinical interview, may be used to predict the likelihood of an ARFID diagnosis and can measure the severity of impact of self-reported symptoms, and offers a rating of the common ARFID drivers (sensory-based avoidance, lack of interest in eating or food, and concern about aversive consequences of eating). The PARDI-AR-Q does not evaluate possible exclusion criteria for an ARFID diagnosis, such as the presence of other possible conditions that may form the basis for feeding and eating difficulties (ie. AN, BN or other medical / mental conditions that could account for the eating disturbances).

The PARDI-AR-Q offers final scores for Diagnostic prediction (Yes/No), severity of impact (0-6), Sensory based avoidance (0-6), Lack of interest (0-6) and concern about aversive consequences (0-6).

Some example questions of the parent PARDI-AR-Q include:

1. Sensory sensitivity: 'Over the past month, has your child been particularly sensitive to variation in taste (for example, noticing slight differences in taste of foods), which has put them off eating any foods or trying any new foods?'
2. Lack of interest: 'Over the past month, how often has your child forgotten to eat or found it difficult to make time to eat?'
3. Fear of aversive consequences: 'Over the past month has your child been avoiding or restricting the amount or type of food they eat, because they have said or indicated they were afraid that something bad might happen, like being sick, choking, having and allergic reaction or being in pain?'

For a complete version of the PARDI-AR-Q, please see Appendix C.

2.6. Statistical analysis

2.6.1. Quantitative study

Descriptive statistics were performed using SPSS 28 (IBM, 2022), both on the independent variable (autism diagnosis, age and weight) and the dependent variable (parent PARDI subscales).

A total of three one-way Multivariate Analysis of Variance (MANOVAs), were conducted to the see whether the independent variables (autism diagnosis, age and weight) had an association with the dependent variables (Parent PARDI subscale: sensory sensitivity, lack of interest and fear of aversive consequences). Significant MANOVAs were followed up with a Tukey Honest Significant Difference (HSD) post-hoc test to identify where the significant interaction lay (Bray & Maxwell, 1982). In this study, $p<0.05$ was considered statistically significant.

The MANOVA output gives values to four different test statistics: Pillai's Trace, Wilks' Lambda, Hotelling's Trace and Roy's largest Root. For this paper, Pillai's Trace was reported as this was deemed most robust to violations of assumptions (Bray & Maxwell, 1985).

Effect sizes were measured using Partial eta squared (Partial η2) (Cohen, 1988). Partial η2 'measures the proportion of variance explained by a given variable of the total variance remaining after accounting for variance explained by other variables in the model' (Haase, 1983). The value for Partial η2 ranges from 0 to 1, with values closer to 1 representing a higher proportion of variance. The subsequent rules are used to interpret values for partial η2 (Cohen, 1988):

- .01 → small effect size
- .06 → medium effect size

- .14 or higher → large effect size

The number of participants in each of the MANOVAs (one each for autism diagnostic status, age, weight) differed due to missing data. Data was considered missing if clients did not have a value for the independent variables (autism diagnosis status, age and weight). To established whether the amount of missing values may have an effect on the analysis and its significance, independent sampled t-tests were run. Completed data was compared to missing values, to determine whether the amount of missing data had an impact on the parent PARDI subscales (sensory sensitivity, lack of interest and fear of aversive consequences).

A chi-square test will be run to explore whether there is a relation between the independent variables if statistically significant results are obtained within the MANOVA.

2.6.2. Qualitative study

a) Analysis

All interviews were recorded live with the software embedded in Microsoft Teams. All interviews were subsequently transcribed by the researcher, using N-vivo software. The interviews were then coded individually line by line. Data was analysed using thematic analysis methodology (Braun & Clarke, 2006). This was an inductive analysis. The researcher identified preliminary themes after coding the data line for line. This was done with the Braun & Clarkes (2006) steps in mind. Following the coding process, the research team then met to discuss the themes generated multiple times to guarantee that the themes were actually representing the data analysed. This was done with the aim of generating meaningful themes that echoed the depth of the experiences the participants had.

b) Positionality statement

Research is an ongoing process and a shared space, shaped by both research and participants (England, 1994) and therefore both play a role in the research process (Bourke, 2014). My positionality, which 'reflects the position that the researcher has chosen to adopt within a given research study' (Savin-Baden & Major, 2013, p. 71) influences how I conducted the research, as well as its outcomes and results (Holmes, 2020). I aim to clarify my own positionality, in order to acknowledge the effects that this might have had on the outcome of this paper.

I am a white, heterosexual, cisgender female and I have lived in the United Kingdom for 9 years but was not born here. I have experience of working with a specialist feeding disorder team prior to commencing training, which is likely to have shaped my desire to undertake this research project, and the way in which it was conducted.

All participants in this study were white, middle class, Europeans. I expected that my position as a white female would enable me to connect specifically well with this population. This was based on the assumption that people experiencing some level of commonality tend to gravitate toward each other (Fries-Britt & Turner, 2001). I found this to be the case during my research, in which I felt participants were open and willing to share relevant and highly personal information with me.

My own experience of having worked in a field adjacent to the one I am researching has shaped the focus I have placed within this research study, evident by my desire to want to give stakeholders a voice. My values of wanting to aid those in distress will have also influenced my perception of the data and may have drawn my attention to the deficits of the current healthcare systems, whilst aligning myself with the participants' perception of

services not catering for their needs adequately. I acknowledge that I may have further blind spots that I have not considered in this statement, as I did not seek to explore the invisible facets of identity that may have influenced the participants' positionality.

During this work I have tried to maintain a reflexive approach, by acknowledging and disclosing myself in my work and aiming to understand its influence upon and within the research process (Holmes, 2020).

3. Results

3.1. Quantitative results

3.1.1. Descriptive statistics

Due to the data being collected in busy clinical settings, the data sets were not always complete and data was missing. Missing values were excluded from the analysis. The total number of participants (N=120), were available for some of the factors explored below, but not for all. The number of participants will therefore vary between analyses, but will be clearly indicated.

3.1.2. Descriptive statistics of independent variables

Descriptive statistics were derived for each independent variable (autism diagnosis status, age and weight). Participants were included in the respective analyses if they had a value for one of the independent variables. This influenced the number of participants for each analysis. For example, there were 66 individuals who had a value for autism diagnosis (yes/no). Of these 66, 39 had a diagnosis of autism, whereas 27 did not. These descriptive characteristics can be found in Table 1.

Table 1

Descriptive Statistics broken down to autism diagnosis status, age and weight

Item	Autism & PARDI (%)	Age & PARDI (%)	Weight & PARDI (%)
Autism Diagnosis	**66**	**66**	**53**
Autism diagnosis	39 (*59.1*)	39 (*59.1*)	30 (*56.6*)
No Autism Diagnosis	27 (*40.9*)	27 (*40.9*)	23 (*43.4*)
Age Group	**66**	**120**	**74**
2 – 7 Years	9 (*13.6*)	21 (*17.5*)	13 (*17.6*)
8 – 13 Years	36 (*54.5*)	62 (*51.7*)	39 (*52.7*)
14+ Years	21 (*31.9*)	37 (*30.8*)	22 (*29.7*)
Weight Group	**53**	**74**	**74**
Low (<85%)	17 (*32.1*)	22 (*29.7*)	22 (*29.7*)
Medium (85-115%)	31 (*58.5*)	43 (*58.1*)	43 (*58.1*)
High (>115%)	5 (*9.4*)	9 (*12.2*)	9 (*12.2*)

3.1.3. Descriptive statistics of dependent variable

A total of 120 parents completed the parent PARDI. Table 2 shows the mean values and standard deviations for the parent PARDI. The data indicates that the highest ratings were given in the subscale sensory sensitivity, with the lowest score in the fear of aversive consequences subscale.

Table 2

Mean values and standard deviations (SD) for the parent PARDI subscales

Item	Mean (SD)	Range
Parent PARDI (N=120)		
Sensory Sensitivity	3.94 (1.95)	0 – 6
Lack of Interest	3.75 (1.71)	0 – 6
Fear of Aversive Consequences	2.88 (2.86)	0 – 6

3.2. Biases

3.2.1. Independent sample T-Test

Independent sample t-tests were run to explore whether the missing values had an effect on the PARDI subscale scores. Table 1 gives indication of the differences in sample sizes due to missing data. Autism diagnosis and weight were explored. Age was not analysed, as it did not contain any missing values.

An independent sample t-test was run to establish whether there was a difference between completed values for autism diagnosis (N=66) and missing values (N=54) on the parent PARDI subscales. There was no statistically significant difference between completed

measures and the missing values on any of the PARDI subscales: sensory sensitivity (t(64)=3.32, p=.099), lack of interest in food (t(64)=1.58, p=.111) and fear of aversive consequences (t(64)=1.11, p=.943).

An independent sample t-test was run to establish whether there was a difference between completed values for weight (N=74) and missing values (N=46) on the parent PARDI subscales: sensory sensitivity (t(117)=-.17, p=.357), lack of interest in food (t(117)=-.53, p=.195), and fear of aversive consequences (t(117)=-2.18, p=.188).

3.2.2. Chi-Square

To establish whether the statistically significant results obtained in the MANOVAs below were due to a bias in the data, a chi-square test of independence was performed to examine the relation between age and autism diagnosis. The relation between these variables was not significant, X^2 (2, N=66) = .47, p=.791.

3.3. Multivariate analysis of variance (MANOVA)

3.3.1. Autism diagnosis and parent PARDI subscale results

A one-way MANOVA was conducted to determine whether there was an association between autism diagnosis (yes/no) and the PARDI subscales: (i) sensory sensitivity (ii) Lack of interest and (iii) fear of aversive consequences. Table 3 shows the mean values and standard deviations for the each of the PARDI subscales dependent on an autism diagnosis being present or not.

Table 3

Mean values and standard deviations (SD) for the MANOVA (autism & parent PARDI)

Autism Diagnosis	**Sensory Based Avoidance** Mean (SD)	**Lack of Interest** Mean (SD)	**Concern of Aversive Consequences** Mean (SD)	**N**
No Autism	3.05 *(2.01)*	3.13 *(1.86)*	2.05 *(2.37)*	**27**
Autism	4.60 *(1.62)*	3.81 *(1.53)*	2.71 *(2.32)*	**39**
Total	3.69 *(2.00)*	3.41 *(1.75)*	2.32 *(2.35)*	**66**

Using Pillai's Trace statistic there was an overall significant association between autism diagnosis and the parent PARDI subscales with a large effect size: Pillai's Trace = .154; F (3, 62) =3.78; p=.015; Partial η2=.154.

There is a significant association between autism diagnosis on the parent PARDI subscale with a large effect size for (i) Sensory based avoidance (F(1,64) = 11.04; p<.001; partial η2=.147. There were no significant association between autism diagnosis and the parent PARDI subscale (ii) lack of interest (F(1, 64) = 2.50; p=0.119; partial η2=.038) or on (iii) fear of aversive consequences (F(1,64) =1.23 ; p=0.272; partial η2=.019).

3.3.2. Age and parent PARDI subscale results

A one-way MANOVA was conducted to determine whether there was an association between age groups (2-7 years; 8-13 years and 14+) and the PARDI subscales: (i) sensory sensitivity (ii) Lack of interest and (iii) fear of aversive consequences. Table 4 shows the mean values and standard deviations for the each of the PARDI subscales dependent on age group.

Table 4

Mean values and standard deviations (SD) for the MANOVA (age & parent PARDI)

Age Group	**Sensory Based Avoidance** Mean (SD)	**Lack of Interest** Mean (SD)	**Concern of Aversive Consequences** Mean (SD)	**N**
2- 7 Years	4.91 *(1.87)*	4.23 *(1.81)*	2.70 *(2.27)*	**21**
8-13 Years	3.96 *(1.83)*	3.59 *(1.60)*	3.18 *(2.34)*	**62**
14+ Years	3.34 *(2.02)*	3.73 *(1.84)*	2.47 *(3.80)*	**37**
Total	3.94 *(1.95)*	3.75 *(1.71)*	2.88 *(2.86)*	**120**

Using Pillai's Trace statistic, there was an overall significant association between age and the PARDI subscales with a small effect size: Pillai's Trace = .097; F (6, 232) =1.97; p=.032; partial η2=.049.

There is a significant association between age group and the parent PARDI subscale with a medium effect size for (i) Sensory based avoidance (F (2,117) = 4.58; p=.012; partial η2=.073). There were no significant association between age group and the parent PARDI subscale (ii) lack of interest (F(2,117) =1.10; p=.338; partial η2=.018) or on (iii) fear of aversive consequences (F(2,117) = .43; p=.473; partial η2=.013).

The significant association was followed up with Tukey's HSD post-hoc test. The mean scores for the self-PARDI (i) sensory based avoidance subscale were statistically significant between 2-7 year olds and 14+ year olds (p=.009), but not between 2-7 year olds and 8-13 year olds (p=.125) or 8-13 year olds and 14+ year olds (p=.257).

3.3.3. Weight and parent PRADI subscale results

A one-way MANOVA was conducted to determine whether there was an association between weight groups (85%; 85-115%; >85%) and the PARDI subscales: (i) sensory sensitivity (ii) Lack of interest and (iii) fear of aversive consequences. Table 5 shows the mean values and standard deviations for the each of the PARDI subscales dependent on weight group.

Table 5

Mean values and standard deviations (SD) for the MANOVA (weight & Parent PARDI)

Weight for Height Group	**Sensory Based Avoidance** Mean (SD)	**Lack of Interest** Mean (SD)	**Concern of Aversive Consequences** Mean (SD)	**N**
Low (<85%)	3.40 *(1.83)*	3.98 *(1.41)*	2.70 *(2.18)*	**22**
Medium (85-115%)	4.00 *(1.95)*	3.95 *(1.44)*	2.47 *(2.93)*	**43**
High (>155%)	4.80 *(1.88)*	2.66 *(2.26)*	1.48 *(1.55)*	**9**
Total	3.92 *(1.31)*	3.80 *(1.64)*	2.42 *(2.19)*	**74**

Using Pillai's Trace statistics, there was an overall significant association between weight and the PARDI subscales with a medium effect size: Pillai's Trace = .201; $F(6, 140) = 2.61$; $p = .020$; partial $\eta 2 = .101$.

However, subsequent univariate results showed no significant association of WFH and the Parent PARDI subscale (i) Sensory based avoidance ($F(2,71) = 1.90$; $p = .156$; partial

η^2=.051) and no significant association between the Parent PARDI subscale (ii) lack of interest (F(2,71) =2.58; p=.037; partial η^2=.068) or (iii) fear of aversive consequences (F(2,71) =1.02; p=.356; partial η^2=.028). Following this, a post-hoc test was performed to see whether there were any significant associations to be detected. The post-hoc test also indicated no statistically significant results.

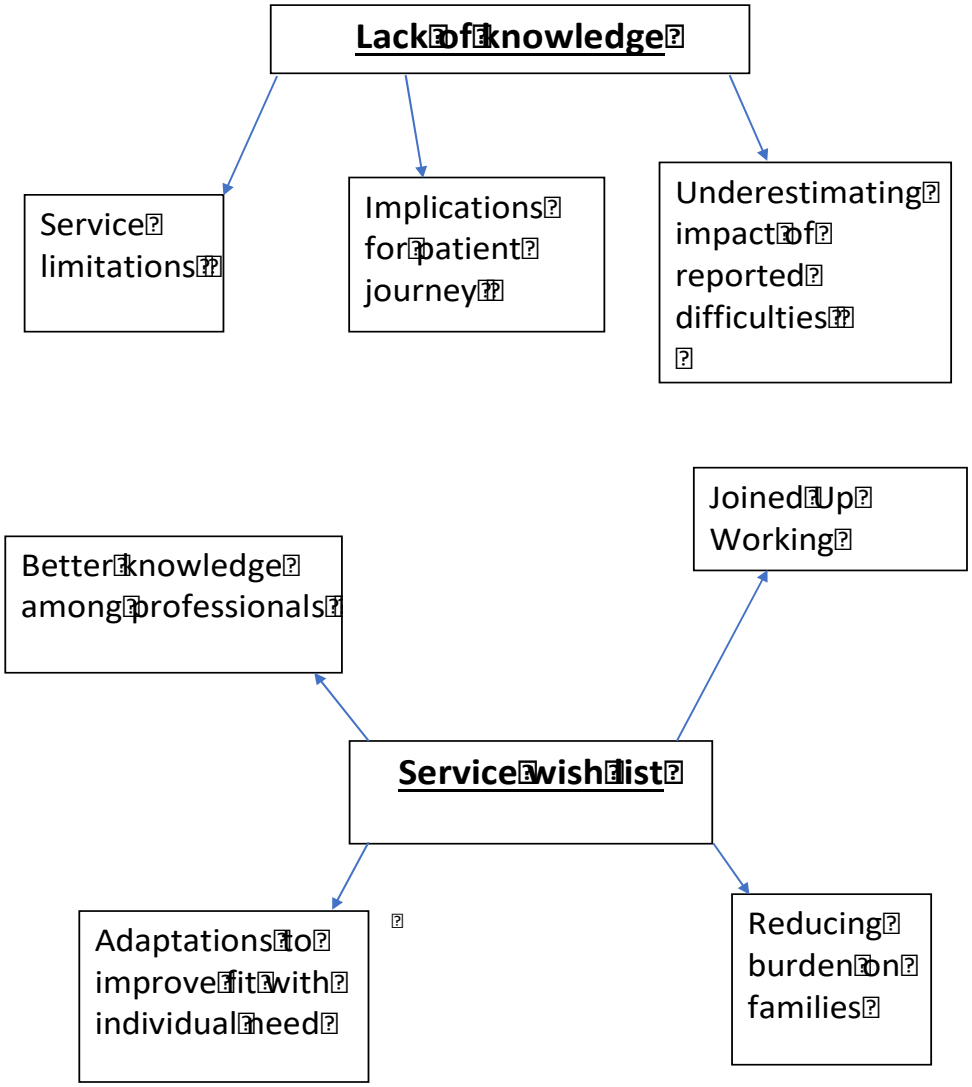
The multivariate test focuses on the correlation between the dependent variables, and therefore has more power to identify group differences. The subsequent post-hoc test functions similarly to a univariate test (Field, 2013). These give insight into where significant interactions lie, however, they are not necessarily useful for interpretation as the groups may vary along a mixture of the dependent variables (Field, 2013). Therefore, it is possible that multivariate tests may be significant and the following univariate tests are not. To understand this interaction in more detail, a post-hoc test is recommended, which as detailed above also shows no significant interaction (Field, 2013) in this analysis. Therefore, we can conclude that while there is a statistically significant interaction between WFT and the Parent PARDI subscales overall, these are not very strong and therefore will not be further discussed.

3.4. Qualitative results

Two themes arose from the interviews, with three and four subthemes respectively. The main themes and their subthemes are summarised in the thematic map (Figure 1). Themes and subthemes are summarised under their theme heading. Two themes were identified: ‘lack of understanding’ and ‘service provision wish list’.

Figure 1

Main themes and subthemes results from thematic analysis



3.4.1. Lack of understanding of ARFID

A lack of understanding of ARFID by others impacted all carers, both in terms of receiving support and within their personal lives. The theme was further divided into three subthemes, discussed below.

3.4.1.1. Service limitations

Carers indicated that a lack of understanding directly resulted in service limitations. Specifically, gate keepers (e.g. GPs, schools, paediatricians) were incremental in their journey to receiving treatment for ARFID. Lack of knowledge at this pivotal point resulted in a delay in receiving a diagnosis, appropriate referrals or being seen for treatment.

'You know, like they just don't understand the extent of this ARFID. The GPs still do not understand it, he didn't have a clue what to do with my child.' (Carer 2)

Lack of knowledge amongst professionals resulted in carers being 'pinged around', as ARFID was either not recognised within teams, or teams voiced concerns in being able to treat the condition.

'CAMHS didn't want to deal with it, the GP didn't want to deal with it and the eating disorders team didn't want to deal with it. They were just going "it's not for us, it's for them". They kept pinging me around because they had no idea what to do or what ARFID even was' (Carer 5)

Four of the carers commented on how the lack of knowledge resulted in uncertainty regarding treatment pathways and ongoing care.

'We're not very well versed in how the NHS works and how to get the best out of it (…), I found out about ARFID from a TV programme and after knowing what it was, I didn't know where to go from that point'. (Carer 4)

3.4.1.2. Implications for Client Journey

Lack of knowledge also resulted in implications for client journeys. Carers described a lack of continuity of care and families 'falling through the net'. One parent explained that it took seven years to receive help, as professionals did not know what was impacting their child.

'So, I've been trying to get help for my little girl since she was, since I weaned her (…) and I was constantly backwards and forwards with the health visitor, the doctor. And (…), they kept saying, she's she seems fine. They weren't any help, because they didn't know what was wrong with her. It just all took so long' (Carer 6)

Carers also indicated that a lack of knowledge led to a lack of local support, as services were not equipped to treat ARFID. Four of the carers were not local to the specialist ARFID service, which led to complications in accessing the right help or getting funding for specialist services. Carers explained that the concern of not having support locally often made them feel isolated, misunderstood, as well as fearful of the future.

'For us, it feels so positive to get any help at all, because it's been such a battle (...). I know there will be point when we have no time left (in child services) and I might be left with a very ill child, he will have turned 18 and there will be nothing and nobody will know what to do. So, I am worried about the future and the lack of services there will be when we need them.' (Carer 1)

3.4.1.3. Underestimating impact of reported difficulties

Carers discussed the impact of ARFID on the wider systems surrounding their child, e.g. immediate families, school and friendships. Four carers spoke about the 'invisible' impact on their families, and how this was often underestimated by healthcare professionals who minimised this. This resulted in carers having to self-advocate for their families and repeatedly discussing difficulties with healthcare professionals before they were acknowledged.

'it was a good six months, really a bit more of us going back and forth and voicing our concerns before we were being listened to' (Carer 5)

One Carer explained that she had to go back to the GP three times before being taken seriously, while six others described having to do research themselves and presenting their findings to the GP before getting a diagnosis of ARFID. Parents experienced that their concerns were often attributed to fussy or picky eating instead of a diagnosable condition and

explained how they had to overcome multiple barriers for their child to be given an appropriate ARFID assessment.

'I felt like I had to be a warrior mum (…), no one understood what it was or what this meant on a daily basis. I even printed out the ARFID website, all the information, all the signs and symptoms and what to do and where to go. (…) took it to my GP surgery and said to him, I have all this information for you, it's quite a new thing and you might not be familiar with it. But can you read through it and he said "yeah, I'll take it to my GP weekly meeting, because 13 heads around the table are more useful than 1 head, and we'll get back to you.' I've never heard anything back. Even when I took that information in and he took it to the meeting, there's 13 GPs sitting around, but none of them did anything." (Carer 2)

3.4.2. The service provision wish list

The first theme lack of understanding of ARFID, impacted the suggestions carers made for improvement of ARFID service provisions. The subthemes will be discussed below.

3.4.2.1. <u>Better knowledge amongst professionals</u>

All carers indicated that through better knowledge amongst professionals, the quality of their care could have been significantly improved. Carers suggested training gate keepers to ensure better knowledge amongst professionals. All participants emphasised the importance of being treated by an expert in the field who understood the idiosyncrasies of ARFID. Knowledge regarding the comorbidities ARFID presents with, such as autism or ADHD was highlighted as equally important. Two carers further commented on the necessity

of professionals having knowledge regarding the existence of specialist services and the appropriate referral pathways to facilitate optimum care.

'Some people think of ARFID as just a bit of fussy eating and I think actually you can become quite unwell and you know you can be very underweight. So, I think a better understanding all the way around would be good' (Carer 2)

3.4.2.2. Adaptations to improve fit with individual need

Carers stressed the importance of maintaining a flexible approach to clients and adapting treatment interventions specific to individual need. This included idiosyncratically adapted adjacent treatment to talking therapies, including art therapy or playtime. Two carers also highlighted the importance of adjusting the focus of the intervention to the developmental age rather than biological age. Adapting the intervention to fit family culture was also emphasised.

'for me an important adaption is making things fit the family culture that you're working with, because there's so many wonderful ways to parent brilliantly' (Carer 2)

Adapting the environment to fit individual need was also discussed. Amongst suggestions were autism friendly play areas, including sensory equipment and soft play. Carers also suggested the adaptation of the environment for different ages, encouraging play areas for younger children and more sophisticated entertainment for older children. The

importance of the waiting area and its potential impact on the child's willingness to commence or adhere to treatment were also highlighted.

But if it looks like a hospital, then I know he will be anxious and stressed (…), so making rooms look more friendly would be helpful.' (Carer 5)

Five carers commented on the importance of information sharing, both prior and during appointments, regarding content and clarity. Carers suggested making information packs regarding the clinical environment, the treating clinicians and an appointment timetable and to best prepare the child, specifically for children with autism.

'I did all my usual preparation, showed him (child with autism) pictures of where we're going, showed him a map (…). He liked to know the exact times of when things happen. It would have been really helpful to get that information from the team, it would've been really good to see who we were going to see' (Carer 1)

3.4.2.3. <u>Reducing burden on families</u>

Carers outlined several practical solutions to reducing the burden of help seeking. These included: quick referral times, quick appointment times after being referred to a specialist service, choice of treatment delivery (ie. Online v. face to face), extra time for appointments and more flexibility with funding. Carers also commented on the need for representation in ARFID teams, including different ethnicities amongst others.

'So, initially I was quite concerned about the online therapy, because up to that point he (son) had refused online appointments. He doesn't leave the house very often, so going into London would probably have been quite concerning. It was helpful when the service told me I could do what I would feel best with.' (Carer 1)

3.4.2.4. Joined-up working

The importance of joined up and continuous care between services were emphasised in providing more effective and efficient service provisions.

'I think that's part of the problem, isn't it? Because you can't just go to one person, like a GP or a paediatrician and ask them what can I do, because they don't know on their own. So, having a service where everyone can work together and having that coordination is important' (Carer 3)

The need for local services were highlighted to attain help quicker. One parent spoke about the positive implications of having a crisis plan in place with their local hospital and how this minimised distress. Four carers suggested treatment for ARFID should be incorporated into local ED teams to facilitate better care management, due the multidisciplinary set up of ED teams.

'(…) Eating disorders would have a nutritionist, wouldn't they? And all those sort of people, and, like, you know, paediatricians as well. So, I think it would, I think it would be easier to tag onto an eating disorders clinic than anywhere else' (Carer 3)

Finally, carers suggested to have peer and parent support within their local team, as they have found the experience of having and being diagnosed with ARFID isolating.

'It is nice just to see what other people are going through and how they deal with it on a day to day basis.' (Carer 5)

4. Discussion

At present, there is limited evidence regarding the best clinical care for people with ARFID. The aim of this study was to contribute to an evidence base that can inform the improvement of ARFID service provisions in the NHS.

The quantitative study aimed to understand the heterogeneous presentation of ARFID by analysing the data obtained in the national pilot. It examined whether three predetermined subgroups (reflecting autism diagnosis status, age and weight) had an association with the commonly observed drivers of ARFID (sensory sensitivity, lack of interest in food or fear of aversive consequences of food). Results indicated that autistic people and younger children had higher sensory sensitivity than non-autistic people and older children. No other statistically significant interactions were found.

Finally, the paper sought to consult carers whose children have accessed ARFID services and seek recommendations on improving service delivery for this population. Carers identified lack of knowledge amongst gate keepers (GPs, schools, paediatricians) and healthcare professionals to be a main difficulty when seeking treatment for ARFID. This

impacted service limitations, had implications for client journeys and led to an underestimation of difficulties reported by carers. In context of these concerns, carers made several recommendations for future improvements and adaptations: the service provision wish list. This included better knowledge amongst professionals, adaptations to improve fit with individual need (including treatment intervention and environment), practical solutions to reducing burden on families and joined up working amongst professionals.

4.1. Knowledge of ARFID

This study highlighted the need for further knowledge amongst professionals, specifically amongst gate keepers such as GPs, and the general population regarding ARFID and its presentation.

GPs are often the first contact and are essential for managing the clients' needs: they diagnose, instigate continued medical treatment and are the gate-keepers to specialist care (Younes et al., 2005). Collaboration between GPs and mental health services is necessary when providing adequate healthcare to clients with mental health problems (Fredheim et al., 2011). Findings of this study fit with previous literature that has found that collaboration is often deficient, with the results of clients' needs for coordinate services not satisfactorily met and resources ineffectually used (Kisely et al., 2006). A Norwegian study highlighted that by increasing knowledge and competence among GPs, there was an improvement in the treatment of mental health conditions in primary health care (Mykletun et al., 2010).

Carers also specified that further knowledge amongst the general population would decrease feelings of isolation. Research indicates that mental health literacy amongst the general population, which includes knowledge of mental health information, risk factors and

professional help available, promotes early identification of mental health conditions and reduces stigma and embarrassment (Cermak et al., 2010).

Lack of knowledge about ARFID may be deterring services ability to modify and adapt existing treatment programmes to efficiently cater for the idiosyncratic needs of these clients (Adamson et al., 2020). Thus, specifically the education of gate keepers may have an economically positive impact on ARFID service provisions, as ARFID may be recognised earlier and treated more effectively.

4.2. Findings by subgroups

The three predetermined subgroups: autism diagnosis status, age and weight, were analysed in the quantitative and qualitative study. Relevant findings relating to these subgroups will be discussed below.

4.2.1. Autism diagnosis

Nicely et al. (2014) established a high rate of autism comorbidity in ARFID clients. This was supported in this study, where the majority of those with an ARFID diagnosis also had a comorbid diagnosis of autism (57.9%). While the relationship between autism and ARFID is established, it was thus far unclear how an autism diagnosis might influence the phenotype of ARFID.

The quantitative study indicated that those with autism had statistically significant higher sensory sensitivity on the parent PARDI subscale than those without an autism diagnosis. Yet, there were no statistically significant interactions between autism diagnosis and lack of interest or fear of aversive consequences of food. This may have been due to the

relatively small sample size (n=66) for the autism analyses, and different results may be obtained with larger data sets that afford more statistical power.

Children with autism often show difficulties in sensory processing (Cermak et al., 2010), which may have a negative impact on managing daily tasks such as eating (Kern et al., 2007). Sensory sensitivity may subsequently lead to the restriction of food to preferred, manageable and tolerable textures (Twachtman-Reilly et al., 2008). Interventions for ARFID, may therefore specifically want to focus on the sensory properties of food and explore how this might affect food avoidance or restriction. Despite these findings it is important to consider that ARFID drivers are not mutually exclusive and can co-occur, while our findings highlight the importance of considering sensory sensitivity in those with comorbid autism, attention should be paid to the other drivers when offering holistic client care.

Carers further highlighted how current treatment settings may be overstimulating and require adaptation for those with autism (Tint et al., 2017). To reduce the burden of clinical interventions, carers suggested to adapt the environment by offering sensory sensitive play areas within a waiting room, or making rooms appear less clinical. This emphasises the importance of a flexible and individualised approach in care.

4.2.2. Age

The diagnostic criteria for ARFID (APA, 2013) show no age limitations and can therefore be applied to children, adolescents and adults (Zimmerman & Fisher, 2017). Within the quantitative study the majority of children (50%) were within the 8-13 years age bracket.

Results indicated that younger children had statistically significant higher sensory sensitivity on the parent PARDI subscale than older children. This is in line with former research, which has shown the importance of age in the development of varied food texture

preferences (Lukasewycz & Mennella, 2012). For younger children, the sensory properties of food were emphasised as a particularly influential factor when determining eating behaviours, and within these specifically texture was seen as a major reason for rejecting or accepting food (Cappellotto & Olsen, 2021). Sensory based food education at earlier ages has shown to promote the variability in the child's diet (Kähkönen et al., 2018) and may be a relevant finding for ARFID service provisions, in which pathways or interventions may be adjusted accordingly.

There was no statistically significant interaction between age and the other two subscales: lack of interest and fear of aversive consequences of food. This may be due to the varied group sizes within the sample, as not much data was available for the age group 14+. As adolescents are more likely to develop mood and anxiety disorders than younger children (Merikangas et al., 2010), fear of aversive consequences may have been more developed in older age groups and this relationship should be explored in future research.

Carers were able to make meaningful suggestions to adapting interventions or services for the developmental age of a child, rather than the child's biological age. Currently, mental health services operate with age-related eligibility criteria (Belling et al., 2014). Young people are expected to access adult mental health services when turning 18, a disruption that can adversely affect vulnerable young people's health and well-being (Vloet et al., 2011). Due to the heterogeneity of ARFID and its comorbidity with autism and other developmental delays, this arbitrary use of age thresholds demarcates services, creates inflexibility and fails to consider developmental needs (McGorry, 2007). Findings of this study suggest that people of all age/stages of development need to be able to access services that can provide appropriately adapted interventions for their presentation. While irrespective of age and other conditions, the transitions to other services need to be thoroughly planned with care.

4.2.3. Weight

The quantitative study indicated no statistically significant results when exploring the relationship between weight and the ARFID drivers. The lack of a significant finding is important for service-delivery, as many ED and feeding disorder services across the country still orientate themselves on weight, identifying it as a possible admittance criterion (Duncombe Lowe et al., 2019). This might be an inappropriate procedure and admittance should rather focus the distress experienced by the individual, chronicity of symptoms or burden on systems.

Carers found it difficult to make recommendations regarding possible adaptations for weight. This illustrates how ARFID may be under the umbrella of an ED but is not dictated or influenced by shape and weight concerns. Carers indicated that the weight of their child, whilst relevant for their journey through services and possible diagnosis, were not relevant when thinking about the way services provided care for them. This in itself is a relevant finding, as it gives services permission to move away from a weight focused intervention and focus on other parameters that carers found more meaningful.

4.2.4. Reflections regarding diversity, power and privilege

Throughout this paper, the positionality of the researcher and the implications on the process of data analysis was acknowledged. It is also important to consider that this study was designed and executed by a research team who also identify as white, middle class practitioners. This may have had an impact on the design of the study, as well as the recruitment process. One of the limitations of the study is its homogeneous sample, which will be further discussed within the limitations sections of this paper. This may be due to the influence of the research team, who were not able to advertise to a more diverse population or take into consideration the needs of those who are ethnically minorities within this country.

As such, the discussion, the conclusions and following recommendations for clinical services, must be viewed in the context of how this research was conducted and the generalisability of the findings may be limited to a white middle class population.

This phenomenon is a concrete example of how clinical psychology as an institution should continue to strive for inclusivity. The power and privilege that the team experiences as due to being white, will have had a direct influence on the homogeneity of the sample and the lack of diversity that is being represented. While clinical psychology as a profession may be striving for inclusivity, this paper is an example of how this is often not incorporated in the conduction of empirical research. As this research was aiming to give underrepresented stakeholders a voice in the shaping of services, future research or replication studies should actively focus on including researchers and stakeholders who hold a less powerful and privileged position within the system.

5. Clinical Implications and Future Research

The current study indicates that people with ARFID may benefit from service adaptations. Potential avenues for clinical adaptations are listed below.

5.1. Increasing knowledge for gate keepers

Increasing knowledge for gate keepers, such as GPs, schools or paediatricians may be a practical and manageable solution in reducing the burden on help seeking families. Carers spoke about often being ‘pinged around’ services due to clinicians not recognising or knowing how to treat ARFID effectively. Offering training for these institutions may result in

quicker and more confident diagnosis, more effective referrals to specialist services and joined up, local service provision. Future research should focus on establishing how to improve clinician awareness and knowledge regarding ARFID, to facilitate a more flexible approach to current treatment provision.

5.2. Thoughtful transitions between care

ARFID is often comorbid with autism, ADHD and other developmental delays. As such, this population may be particularly vulnerable to the negative consequences of age related eligibility criteria. Transition between child and adult services, often lead to young people falling through the net and dropping out of care during a crucial time (Harpaz-Rotem et al., 2004). Our findings suggest that people of all age and stages of development need to be able to access services that can provide appropriate adapted interventions for their presentation. As such, irrespective of age and other conditions, transition between services need thoughtful planning and care.

5.3. Joined-up service provision

The lack of local service provision was highlighted by carers as being particularly burdensome. Many carers spoke about how this prolonged their journey to services and increased feelings of isolation. As those with restrictive or avoidant eating may present to a myriad of services, it is vital that professionals work with each other to facilitate optimum care. Reducing the fragmentation of the healthcare system, would positive impact clients, as well as having a positive economic impact on the NHS as a whole. It is also in line with the NHS proposed plan for improving mental health services through the integration of systems and services (NHS England, 2019).

5.4. Treatment adaptations for ARFID

5.4.1. Flexible and individualised treatment adaptations

A key theme identified in this study, was the importance of clinicians providing an individualised and flexible approach when working with this population. This included suggestions such as: adaptations in environment, intervention, communication styles, longer appointment times and accommodating sensory difficulties. Adapting treatments to improve fit with individual need may subsequently improve treatment adherence, engagement and outcomes (Duncombe Lowe et al., 2019). Future research may want to explore this in more detail and create a comprehensive list of manageable adaptations. A pertinent idea may be to conduct qualitative investigations regarding the above findings, to deepen our understanding on how these changes may be facilitated.

5.4.2. Increasing treatment options dependent on comorbid conditions

The high level of comorbidity between mental health conditions and ARFID may suggest the advantage of offering a trans-diagnostic treatment approach to ARFID, which is able to address the core symptoms of ARFID and commonly observed comorbidities. Specifically, comorbidities such as autism, ADHD or other developmental delays are important to consider, as about 80% of children with developmental delays have shown to experience feeding difficulties, compared to the 25-45% of typically developing children (Bryant-Waugh et al., 2010). Increasing treatment options dependent on comorbidities may shape service pathways dependent on these or determine the focus of an intervention. This would represent a significant advance within child and adolescent psychology, as providing a treatment proficient in tackling both ARFID and its comorbidities would enhance evidence-based care and would be beneficial for its dissemination (Duncombe Lowe et al., 2019).

5.4.3. Moving away from pathology-orientated research

Finally, as research in the field of ARFID remains pathology-orientated, further research should aim to explore the personal and environmental factors that may counteract the impact of ARFID and contribute to interpersonal success. This could inform mental health and social care interventions by helping professionals to foster such factors in their own clinical interventions.

5.5. Creating clear clinical care pathways for ARFID

Anecdotal accounts from families seeking support for ARFID treatment highlight that initial help-seeking often results in inappropriate onward referral (Cardona Cano et al., 2015). Rather, referrals are inconsistently made to a range of healthcare settings (Bryant-Waugh et al., 2021), including speech and language services or paediatric clinics. This was also evident in this study in which carers spoke about being 'pinged' around different services. Due to the complex nature of ARFID, it often requires multi-disciplinary assessment and intervention, and many services are not sufficiently equipped to effectively cater to this population. This is partly due to the fact that there is currently no national consensus on ARFID's clinical care pathways. Instead, ARFID is currently being managed across a specialist eating disorder services, core child and adolescent mental health services or paediatric services (Coglan & Otasowie, 2019). Further research should focus on establishing clear clinical pathways for those with ARFID, to ensure that families are adequately cared for and to reduce their anxiety whilst seeking support.

5.6. Further Research into ARFID

Our findings also highlight that there is a further need to understand the drivers of ARFID, and how these may influence and aid the recommended treatment options. The phenotype of the condition is not fully understood yet, and so gathering more information and insight into the condition is vital when trying to influence possible treatment options, the development of screening and diagnostic instruments and gathering information about its prevalence.

6. Strengths & Limitations

6.1. Strengths

The strengths of the study lie in its use of a mixed method approach whilst answering the same research question: how to improve ARFID service provisions. The quantitative and qualitative part of the data draw on each other and allow firmer conclusions to be made about possible adaptations.

6.1.1. Quantitative study

Collating the data obtained within different research sites that took part in the national pilot increased sample size and generalisability of findings. Moreover, data collection took place within a real clinical context, allowing us to make practical inferences of this population as they occur in different regions of England.

6.1.2. Qualitative study

Another strength of the study is its use of well-established qualitative research techniques, to evaluate a subject that has clear clinical relevance. This paper interviewed

participants from a plethora of different backgrounds regarding their journey into services, including different waiting times and different geographical areas across England and thus gives a variety of informative perspectives. The use of a semi-structured interview technique allowed a more in-depth exploration of the subject, whilst enabling participants to authentically express their views.

6.2. Limitations

Despite the strengths of the study, its results must be interpreted in the context of several limitations.

6.2.1. Quantitative study

Firstly, the quantitative part of the study highlighted the difficulty of conducting research using data collected in routine practice within busy services. Missing data caused great variations in the size of the sample for different analyses, which may be a reflection of the difficulties regarding the prioritisation of consistently recording data to inform service improvement in a stretched NHS. The national pilot was further commissioned at the start of the COVID-19 pandemic. During this period, there was an increase in staff sickness and focus on crisis management, which may have limited the services ability to gather data effectively.

Secondly, while this study explores autism as a comorbidity of ARFID, it does not explore other psychiatric conditions. A study by Duncombe Lowe we al. (2019) found that 74% of their ARFID sample met criteria for at least one comorbid DSM-5 condition. For example, mood and anxiety disorders are more likely to develop in adolescence (Merikangas et al., 2010) and suicidality and self-harm have been associated with disordered eating

(Sardahaee et al., 2019). Further research should focus on other co-morbidities that present with ARFID and how this might impact service delivery.

Another limitation of the study was the conduction of multiple comparisons, which may have led to possible Type 1 errors (Cohen, 1988). Given the descriptive and exploratory nature of our study, however, family-wise error was not controlled for. In line with this is the lack of control for possible confounding variables: sex, chronicity, ethnicity, socio-economic status or other comorbidities, may have had a significant impact on our findings. However, these were neither measured, nor controlled for in the current study. Similarly, whilst data pertaining to demographic factors was collected, these characteristics were not controlled for within the analyses. Replication of this study controlling for demographic factors (e.g. gender, ethnicity/ culture) and family background variables (e.g. socioeconomic status) could allow for a more in-depth exploration and for more certain conclusions about how these factors might influence the drivers of ARFID.

The study does not distinguish between those who have ARFID chronically or acutely. Research has shown that those with chronic ARFID present to services with significant lower weight than those with an acute ARFID onset (Duncombe Lowe et al., 2019). This is consistent with previous discoveries in which chronicity has been related to more negative outcomes in EDs (Fichter et al., 2017). Weight was a factor in our analysis that yielded insignificant results. A distinction between chronicity and acuity may have generated more relevant results when understanding the ARFID phenotype.

6.2.2. Qualitative study

Within the qualitative study, the sample was largely racially and ethnically homogenous, impeding our ability to generalise our findings to more ethnically and racially

diverse populations. All participants were white, middle-class Europeans. The ARFID service at the London site conducted a population analysis of the clients accessing their services and concluded that 66.1% of the population in the ARFID service were white. The remaining percentage were made up of Black (19.3%), Asian (6.5%), Mixed (13.7%), Other (5.6%) and Prefer not to say (2.4%). Orientating ourselves along this sample, we would have expected at least 2-3 participants from our sample to be from a non-white ethnicity. A larger and more diverse sample may have resulted in more additional themes being derived from the data.

Moreover, when conducting initial data analysis for this part of the study the research team deemed the data to be 'saturated', despite planning for a larger sample. This was based on the understanding that the homogeneity of the sample had an impact on the diversity of opinions that could have been achieved within analysis. The research team concluded that the data was saturated in the context of the population explored within the study. Braun & Clark's reflexive thematic analysis speaks about achieving diversity of perspectives, this was not possible with the current sample. Future research may benefit from targeting ethnically minoritised individuals in particular to enable a more holistic understanding of opinions and perspectives.

Six of the participants taking part in this study were mothers, whilst one was a father. This may be reflective of the idea that females are more likely than males to care for loved ones with mental health difficulties (Sharma et al., 2016). To provide a more holistic appreciate of carers view, future research may want to explore the thoughts and opinions of fathers or other males in caring roles.

The qualitative study was conceptualised as individual interviews. Gathering this information within focus groups may have been beneficial, as it would have allowed for the exchange of ideas between the participants. Participants found it difficult to answer questions

about hypothetical scenarios that did not impact their own child. Within a group, participants may have influenced each other, allowing for a richer exchange of ideas.

7. Conclusion

This study has made tentative recommendations as to how to optimise ARFID service provisions in the NHS. It has found that pre-determined parameters such as autism diagnosis and age may have an impact on the factors that are currently thought to drive ARFID. It has also taken service-users' perceptions and recommendations into consideration when detailing ideas as to how improve service delivery for those affected. The results confirm the heterogeneous nature of the condition and the corresponding heterogeneous needs of a client group, whilst trying to make tangible and actionable recommendations on how services may better meet the needs of stakeholders.

8. Reference

Adamson, J., Kinnaird, E., Glennon, D., Oakley, M., & Tchanturia, K. (2020). Carers' views on autism and eating disorders comorbidity: Qualitative study. *BJPsych Open*, *6*(3), e51. https://doi.org/10.1192/bjo.2020.36

Belling, R., McLaren, S., Paul, M., Ford, T., Kramer, T., Weaver, T., Hovish, K., Islam, Z., White, S., & Singh, S. P. (2014). The effect of organisational resources and eligibility issues on transition from child and adolescent to adult mental health services. *Journal of Health Services Research & Policy*, *19*(3), 169–176. https://doi.org/10.1177/1355819614527439

Bourke, B. (2014). Positionality: Reflecting on the Research Process. *The Qualitative Report*. https://doi.org/10.46743/2160-3715/2014.1026

Bourne, L., Bryant-Waugh, R., Cook, J., & Mandy, W. (2020). Avoidant/restrictive food intake disorder: A systematic scoping review of the current literature. *Psychiatry Research*, *288*, 112961. https://doi.org/10.1016/j.psychres.2020.112961

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Bray, J. H., & Maxwell, S. E. (1982). Analyzing and Interpreting Significant MANOVAs. *Review of Educational Research*, *52*(3), 340–367. https://doi.org/10.3102/00346543052003340

Bray, J., & Maxwell, S. (1985). *Multivariate Analysis of Variance*. SAGE Publications, Inc. https://doi.org/10.4135/9781412985222

Bryant-Waugh, R., Loomes, R., Munuve, A., & Rhind, C. (2021). Towards an evidence-based out-patient care pathway for children and young people with avoidant

restrictive food intake disorder. *Journal of Behavioral and Cognitive Therapy*, *31*(1), 15–26. https://doi.org/10.1016/j.jbct.2020.11.001

Bryant-Waugh, R., Markham, L., Kreipe, R. E., & Walsh, B. T. (2010). Feeding and eating disorders in childhood. *The International Journal of Eating Disorders*, *43*(2), 98–111. https://doi.org/10.1002/eat.20795

Bryant-Waugh, R., Micali, N., Cooke, L., Lawson, E. A., Eddy, K. T., & Thomas, J. J. (2019). Development of the Pica, ARFID, and Rumination Disorder Interview, a multi-informant, semi-structured interview of feeding disorders across the lifespan: A pilot study for ages 10-22. *The International Journal of Eating Disorders*, *52*(4), 378–387. https://doi.org/10.1002/eat.22958

Cardona Cano, S., Tiemeier, H., Van Hoeken, D., Tharner, A., Jaddoe, V. W. V., Hofman, A., Verhulst, F. C., & Hoek, H. W. (2015). Trajectories of picky eating during childhood: A general population study. *International Journal of Eating Disorders*, *48*(6), 570–579. https://doi.org/10.1002/eat.22384

Cermak, S. A., Curtin, C., & Bandini, L. G. (2010). Food Selectivity and Sensory Sensitivity in Children with Autism Spectrum Disorders. *Journal of the American Dietetic Association*, *110*(2), 238–246. https://doi.org/10.1016/j.jada.2009.10.032

Claudino, A. M., Pike, K. M., Hay, P., Keeley, J. W., Evans, S. C., Rebello, T. J., Bryant-Waugh, R., Dai, Y., Zhao, M., Matsumoto, C., Herscovici, C. R., Mellor-Marsá, B., Stona, A.-C., Kogan, C. S., Andrews, H. F., Monteleone, P., Pilon, D. J., Thiels, C., Sharan, P., … Reed, G. M. (2019). The classification of feeding and eating disorders in the ICD-11: Results of a field study comparing proposed ICD-11 guidelines with existing ICD-10 guidelines. *BMC Medicine*, *17*(1), 93. https://doi.org/10.1186/s12916-019-1327-4

Coglan, L., & Otasowie, J. (2019). Avoidant/restrictive food intake disorder: What do we know so far? *BJPsych Advances*, *25*(2), 90–98. https://doi.org/10.1192/bja.2018.48

Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed). L. Erlbaum Associates.

Duncombe Lowe, K., Barnes, T. L., Martell, C., Keery, H., Eckhardt, S., Peterson, C. B., Lesser, J., & Le Grange, D. (2019). Youth with Avoidant/Restrictive Food Intake Disorder: Examining Differences by Age, Weight Status, and Symptom Duration. *Nutrients*, *11*(8), E1955. https://doi.org/10.3390/nu11081955

England, K. V. L. (1994). Getting Personal: Reflexivity, Positionality, and Feminist Research*. *The Professional Geographer*, *46*(1), 80–89. https://doi.org/10.1111/j.0033-0124.1994.00080.x

Fichter, M. M., Quadflieg, N., Crosby, R. D., & Koch, S. (2017). Long-term outcome of anorexia nervosa: Results from a large clinical longitudinal study. *The International Journal of Eating Disorders*, *50*(9), 1018–1030. https://doi.org/10.1002/eat.22736

Fisher, M. M., Rosen, D. S., Ornstein, R. M., Mammel, K. A., Katzman, D. K., Rome, E. S., Callahan, S. T., Malizio, J., Kearney, S., & Walsh, B. T. (2014). Characteristics of avoidant/restrictive food intake disorder in children and adolescents: A 'new disorder' in DSM-5. *The Journal of Adolescent Health: Official Publication of the Society for Adolescent Medicine*, *55*(1), 49–52. https://doi.org/10.1016/j.jadohealth.2013.11.013

Fredheim, T., Danbolt, L. J., Haavet, O. R., Kjønsberg, K., & Lien, L. (2011). Collaboration between general practitioners and mental health care professionals: A qualitative study. *International Journal of Mental Health Systems*, *5*(1), 13. https://doi.org/10.1186/1752-4458-5-13

Fries-Britt, S. L., & Turner, B. (2001). Facing Stereotypes: A Case Study of Black Students on a White Campus. *Journal of College Student Development*, *42*(5), 420–429.

Haase, R. F. (1983). Classical and Partial Eta Square in Multifactor ANOVA Designs. *Educational and Psychological Measurement*, *43*(1), 35–39. https://doi.org/10.1177/001316448304300105

Halmi, K. A. (2005). The multimodal treatment of eating disorders. *World Psychiatry: Official Journal of the World Psychiatric Association (WPA)*, *4*(2), 69–73.

Harpaz-Rotem, I., Leslie, D., & Rosenheck, R. A. (2004). Treatment retention among children entering a new episode of mental health care. *Psychiatric Services (Washington, D.C.)*, *55*(9), 1022–1028. https://doi.org/10.1176/appi.ps.55.9.1022

Holmes, A. G. D. (2020). Researcher Positionality—A Consideration of Its Influence and Place in Qualitative Research—A New Researcher Guide. *Shanlax International Journal of Education*, *8*(4), 1–10.

Kähkönen, K., Rönkä, A., Hujo, M., Lyytikäinen, A., & Nuutinen, O. (2018). Sensory-based food education in early childhood education and care, willingness to choose and eat fruit and vegetables, and the moderating role of maternal education and food neophobia. *Public Health Nutrition*, *21*(13), 2443–2453. https://doi.org/10.1017/S1368980018001106

Kern, J. K., Trivedi, M. H., Grannemann, B. D., Garver, C. R., Johnson, D. G., Andrews, A. A., Savla, J. S., Mehta, J. A., & Schroeder, J. L. (2007). Sensory correlations in autism. *Autism: The International Journal of Research and Practice*, *11*(2), 123–134. https://doi.org/10.1177/1362361307075702

Kisely, S., Duerden, D., Shaddick, S., & Jayabarathan, A. (2006). Collaboration between primary care and psychiatric services: Does it help family physicians? *Canadian Family Physician Medecin De Famille Canadien*, *52*, 876–877.

Ledford, J. R., & Gast, D. L. (2006). Feeding Problems in Children With Autism Spectrum Disorders: A Review. *Focus on Autism and Other Developmental Disabilities*, *21*(3), 153–166. https://doi.org/10.1177/10883576060210030401

Leung, A. K., Marchand, V., & Sauve, R. S. (2012). The 'picky eater': The toddler or preschooler who does not eat. *Paediatrics & Child Health*, *17*(8), 455–457.

Lieberman, M., Houser, M. E., Voyer, A.-P., Grady, S., & Katzman, D. K. (2019). Children with avoidant/restrictive food intake disorder and anorexia nervosa in a tertiary care pediatric eating disorder program: A comparative study. *The International Journal of Eating Disorders*, *52*(3), 239–245. https://doi.org/10.1002/eat.23027

Lukasewycz, L. D., & Mennella, J. A. (2012). Lingual tactile acuity and food texture preferences among children and their mothers. *Food Quality and Preference*, *26*(1), 58–66. https://doi.org/10.1016/j.foodqual.2012.03.007

Magel, C. A., Hewitt, K., Dimitropoulos, G., von Ranson, K. M., & McMorris, C. A. (2021). Who is treating ARFID, and how? The need for training for community clinicians. *Eating and Weight Disorders: EWD*, *26*(4), 1279–1280. https://doi.org/10.1007/s40519-020-01007-1

McGorry, P. D. (2007). The specialist youth mental health model: Strengthening the weakest link in the public mental health system. *The Medical Journal of Australia*, *187*(S7), S53-56. https://doi.org/10.5694/j.1326-5377.2007.tb01338.x

Merikangas, K. R., He, J.-P., Burstein, M., Swanson, S. A., Avenevoli, S., Cui, L., Benjet, C., Georgiades, K., & Swendsen, J. (2010). Lifetime prevalence of mental disorders in U.S. adolescents: Results from the National Comorbidity Survey Replication--Adolescent Supplement (NCS-A). *Journal of the American Academy of Child and Adolescent Psychiatry*, *49*(10), 980–989. https://doi.org/10.1016/j.jaac.2010.05.017

Mykletun, A., Knudsen, A. K., Tangen, T., & Øverland, S. (2010). General practitioners' opinions on how to improve treatment of mental disorders in primary health care. Interviews with one hundred Norwegian general practitioners. *BMC Health Services Research*, *10*(1), 35. https://doi.org/10.1186/1472-6963-10-35

Norris, M. L., Spettigue, W., Hammond, N. G., Katzman, D. K., Zucker, N., Yelle, K., Santos, A., Gray, M., & Obeid, N. (2018). Building evidence for the use of descriptive subtypes in youth with avoidant restrictive food intake disorder. *The International Journal of Eating Disorders*, *51*(2), 170–173. https://doi.org/10.1002/eat.22814

Norris, M. L., Spettigue, W. J., & Katzman, D. K. (2016). Update on eating disorders: Current perspectives on avoidant/restrictive food intake disorder in children and youth. *Neuropsychiatric Disease and Treatment*, *12*, 213–218. https://doi.org/10.2147/NDT.S82538

Sardahaee, F. S., Holmen, T. L., Micali, N., Sund, E. R., Bjerkeset, O., & Kvaløy, K. (2019). Suicidal ideation in relation to disordered eating, body size and weight perception: A cross-sectional study of a Norwegian adolescent population: the HUNT Study. *BMJ Open*, *9*(7), e029809. https://doi.org/10.1136/bmjopen-2019-029809

Savin-Baden, M., & Major, C. H. (2013). *Qualitative Research: The Essential Guide to Theory and Practice*. Routledge.

Sharma, N., Chakrabarti, S., & Grover, S. (2016). Gender differences in caregiving among family—Caregivers of people with mental illnesses. *World Journal of Psychiatry*, *6*(1), 7–17. https://doi.org/10.5498/wjp.v6.i1.7

Tint, A., Weiss, J. A., & Lunsky, Y. (2017). Identifying the clinical needs and patterns of health service use of adolescent girls and women with autism spectrum disorder.

Autism Research: Official Journal of the International Society for Autism Research, *10*(9), 1558–1566. https://doi.org/10.1002/aur.1806

Twachtman-Reilly, J., Amaral, S. C., & Zebrowski, P. P. (2008). Addressing feeding disorders in children on the autism spectrum in school-based settings: Physiological and behavioral issues. *Language, Speech, and Hearing Services in Schools*, *39*(2), 261–272. https://doi.org/10.1044/0161-1461(2008/025)

Vloet, M. A., Davidson, S., & Cappelli, M. (2011). 'We suffer from being lost': Formulating policies to reclaim youth in mental health transitions. *Healthcare Quarterly (Toronto, Ont.)*, *14 Spec No 2*, 32–38. https://doi.org/10.12927/hcq.2011.22361

Wei, Y., McGrath, P. J., Hayden, J., & Kutcher, S. (2015). Mental health literacy measures evaluating knowledge, attitudes and help-seeking: A scoping review. *BMC Psychiatry*, *15*(1), 291. https://doi.org/10.1186/s12888-015-0681-9

Younes, N., Gasquet, I., Gaudebout, P., Chaillet, M.-P., Kovess, V., Falissard, B., & Hardy Bayle, M.-C. (2005). General Practitioners' opinions on their practice in mental health and their collaboration with mental health professionals. *BMC Family Practice*, *6*(1), 18. https://doi.org/10.1186/1471-2296-6-18

Zimmerman, J., & Fisher, M. (2017). Avoidant/Restrictive Food Intake Disorder (ARFID). *Current Problems in Pediatric and Adolescent Health Care*, *47*(4), 95–103. https://doi.org/10.1016/j.cppeds.2017.02.005

Part Three: Critical Appraisal

1. Introduction

This critical appraisal will offer personal reflections and thoughts regarding the completion of this research. It will begin by examining the choice of the project and how the study of Avoidant Restrictive Food Intake Disorder (ARFID) has impacted the design of the study. It will then discuss the process of recruitment and finally reflect upon the bi-directional relationship between clinical practice and research.

2. Choice of project

Commencing my project, I was struck by how my clinical experience shaped my desire to undertake and conduct this research study. My clinical experience of working within eating and feeding disorder services prior to training highlighted the need to develop these services effectively. While feeding and eating disorder services operated under very different remits, they do more or less treat the same: disordered eating and its impact on the individual they are trying to treat. Nevertheless, there is a lack of knowledge and understanding within these teams concerning their counter parts.

Due to the recent addition of ARFID to the diagnostic manuals (APA, 2013), the condition remains under-recognised and underdiagnosed. This may in part be due to clinicians experiencing a lack of confidence when diagnosing ARFID (Coglan & Otasowie, 2019). While it has been stipulated that community eating disorder (ED) services treat ARFID (NHS England, 2015), the current service provision is not able to meet the needs of this client group effectively, which may be due to the complex psychological and physiological comorbidities these individuals present with (Coglan & Otasowie, 2019). This in itself creates a noteworthy gap in access to services and treatment for those with ARFID (Coglan & Otasowie, 2019). I recognised that many cases of ARFID would ‘fall through the

net' due to lack of knowledge by healthcare professionals, so it seemed pivotal to actively include the voice of stakeholders in order to enable service delivery to be beneficial to the individuals who were being treated.

The varied presentations across clients make diagnosis and referral difficult (Norris et al., 2014), and often result in a lack of coordinated responses by professionals (Norris et al., 2016). The feeding disorder team I worked in was a specialist and national service and therefore had the remit and capacity to treat many cases of ARFID. Clients journeys to national services were often brutal and hallmarked by feelings of being misunderstood, mistreated and misdiagnosed (Zucker et al., 2015). Many families I worked with spoke about being 'pinged' around services, partly due to the lack of knowledge about the condition, but also due to the perceived need for complex and multifaceted treatment approaches (Norris et al., 2016).

I am confident that research in general and specifically within newer fields like ARFID will hugely benefit from consulting, involving and listening to stakeholders. As such I hope this project contributes to the evidence base, which could support individuals with ARFID in a more effective way.

3. The study of ARFID

Since its introduction to the DSM-5, research regarding ARFID is advancing steadily, but is still in its infancy. The difficulties of researching a relatively new field and subsequent learning points will be outlined below.

3.1. Literature review

Specifically, when choosing a relevant topic for the literature review, it became apparent that focusing on a single area of research in this field would not provide enough empirical papers to review. This may in part stem from the lack of understanding regarding ARFIDs causal processes (Bourne et al., 2020). It became evident that many areas of ARFID research are linked with one another, and to truly advance the field, a scoping review on the ARFID literature as a whole would be most beneficial. In conjunction with my research supervisors, it was decided to conduct a scoping review and map the papers that were found onto the three-legged stool of evidence-based practice. Evidence-based practice is a three-legged model devised by Sackett et al. (1996), which stipulates that best clinical practice combines (1) research evidence, (2) clinical practice, and (3) patient preference in equal measure.

Since the last scoping review, which was conducted in 2020 (Bourne et al., 2020), the field has grown exponentially, and the papers included in the review have increased from 77 to 171. The wealth of literature is not only due to notable scientific research interest, but also due to the rising awareness regarding the impact that ARFID may have (Bryant-Waugh et al., 2021). As such, research into the phenomenon in a systematic way is fundamental to developing theoretical underpinnings (Suri & Clarke, 2009). Scoping the ARFID literature and investigating how well the field was making use of evidence-based practice seemed a reasonable and profitable undertaking.

Nevertheless, the magnitude of the project was not accounted for in the initial planning stages. At times, I felt overwhelmed and frustrated by the amount of literature that I had to consult before commencing analysis. A main challenge of conducting research on this scale seemed to be the effective organisation of papers and articles read, to make sure that the information I was sharing was reliable and valid. As I had never conducted a literature review

before, I was unsure how to best present my findings, a common difficulty when conducting systematic reviews of this scale (Chen et al., 2016). The results section in particular was difficult, due to the amount of information I aimed to include in the analysis. At times, I thought this project was not feasible for one individual. While it was discussed at this point whether the inclusion and exclusion criteria for the project should be changed, we felt that this would not be possible given the aim of the review.

I felt passionately about contributing to research in this field, yet upon reflection, this may have been a good opportunity to work in conjunction with another trainee to share the burden of analysis. It would also have been beneficial to understand common difficulties when conducting systematic scoping reviews to battle these difficulties from the commencement of my search (Carver et al., 2013).

3.2. Empirical paper

This research project was designed, planned and executed by myself and my supervisors. This was partially due to the COVID-19 pandemic, which necessitated creative new research approaches.

Due to my experience prior to training, I felt like I had a reasonable grasp of the needs of services within this field. Making use of this knowledge, I aimed to conduct a study that would advance the field by giving stakeholders a voice – a voice that was currently under-represented within the literature (Peterson et al., 2016). This decision was fuelled by my findings within the literature review, in which it became evident that there was a need to expand research to including client preferences, values and characteristics. I was struck by how research builds upon existing evidence to shape future research endeavours (Smith, 2008).

I aimed to conduct the study in a psychologically informed, sensitive and ethical manner. I endeavoured to hold the participant experience in mind, from the outset, to ensure research was conducted in a safe and supportive space. Involving client preference in research has resulted in better comprehension of the condition and its impact as well as identifying outcomes that are relevant for clients (Russo et al., 2021), and increasing treatment adherence and engagement (Houle et al., 2013). I believe if there was more understanding on how to optimise service delivery for those with ARFID, clinicians would be able to offer more holistic care. The knowledge gained from the literature review combined with my own experience and empirical research regarding the advantages of the inclusion of stakeholders, confirmed the significance and necessity of conducting research that was relevant to those affected.

4. Recruitment

The initial phases of this thesis including recruitment, the difficulties associated with this and the subsequent learning points will be discussed.

4.1. Research governance

The quantitative part of the study was reliant on pre-existing data, which was collected as part of an ARFID national pilot commissioned by NHS England. This was devised to analyse the efficacy of offering ARFID treatment within community ED services. As such, the trusts collecting the data had given their informed consent for the data to be further disseminated following the completion of the study. Nevertheless, NHS England was contacted to confirm whether this was a reasonable study to undertake. NHS England gave favourable agreement, which allowed us to commence the data collation and analysis swiftly.

The qualitative part of the study, which consulted carers whose children have accessed ARFID services and sought recommendations to improve service delivery, was a service improvement project. As such, the study was presented to the appropriate regulatory body to gain permission for its conduction. The study was presented to the trust as a Patient and Public Involvement (PPI) project. We completed the trusts internal form, registering the project as an PPI project and were granted permission for its conduction in February 2022.

In order for me to conduct the research, an honorary contract needed to be completed. This procedure started at the height of the COVID-19 pandemic, which significantly complicated and prolonged the process and I was only able to get my contract in November 2021, eleven months after the initial application. This was later than originally planned or anticipated and therefore delayed my ability to analyse the data obtained for the quantitative part of the project and necessitated a shorter recruitment frame for the qualitative part. This process highlighted the real-life implications of a stretched NHS environment. In a pressurised and busy context research may not, understandably, always be a priority.

4.2. Recruitment for quantitative study

Conducting meaningful research in clinical settings can often be challenging. I became increasingly aware of this phenomenon when amalgamating data from seven different sites across the UK. While each site participating in the ARFID national pilot had been given the same set of instructions and the same spreadsheet to collect data, the data obtained varied considerably between sites. For most, apart from the organiser of the study, data was missing or inadequately collected. Upon reflection, I wondered about the team's ability to make time and space for data collection.

The modern-day NHS has been subject to meeting increased demands, with little resource to fall back on (Maguire et al. 2017) and thus clinical settings are becoming progressively stretched. Conducting research within clinical settings is not commonplace (Mitchell & Gill, 2014), a circumstance that has not improved in the last twenty years (Holttum & Goble, 2006). This may be due to prioritisation of clinical roles, lack of protected time and work pressures (Mitchell & Gill, 2014), each of which have negative implications on obtaining reliable results. I reflected that these difficulties will have intensified when conducting research in the midst of the COVID-19 pandemic, in which crisis management was the main focus of the NHS. This epitomised to me the complex relationship between wanting to advance the field through conducting research that adds meaningfully to evidence-based practice on the one hand and clinician's ability to conduct this research if they are not given the time or resource to focus on it, on the other hand.

4.3. Recruitment for qualitative study

Recruitment of the sample needed for the qualitative part of the study was done through the ARFID teams PPI register, which included parents who had consented and expressed interest in being contacted when an opportunity like this arose. An initial email was sent out to the individuals identified from the register promoting the study and requesting participants to get in touch with me, should they be interested in taking part. This only yielded response from six participants and was not enough for the study. To promote the study further, I joined team meetings to discuss the questions team members had and provide further information. Despite these efforts, only one more participant was recruited. Team members, including the PPI lead, showed eagerness in regard to the research, with several highlighting how the idea of improving the service would appeal to many of the parents

within the team. This suggested that the difficulties in recruitment were not due to disinterest or dissatisfaction with the study and its purpose.

The struggle instead was seemingly attributable to the dichotomy of fulfilling demands of everyday living and committing to the time to take part in the study. As my aim was to involve the voice of stakeholders, I was bewildered by this difficulty: up until now I assumed research in the area continued to stagnate due to clinicians not paying this group enough attention. Yet, competing priorities (Makan et al., 2015), lack of adequate compensation (Davies & Lund, 2017), or unfamiliarity with the concept of being involved in service improvement as well as stigma are commonly identified as barriers to including stakeholders in clinical research (Murphy et al., 2021).

Moreover, due to the delay in obtaining my honorary contract the recruitment window for this study was very short which may have impacted the number of participants. Ideally, it would have been helpful at this time to extend the recruitment period and immerse myself fully with a busy team and potentially speak to parents in a different forum myself. However, the time pressure, in addition to the strains of my own clinical work in the NHS and other study commitments, rendered this notion unachievable. This experience emphasised the trials of undertaking research part-time and emphasised the advantages of allocating extra time and resources to the conduction of research within teams.

Initially, this research set out to conduct focus groups, as we were optimistic about the number of participants we were able to recruit and due to our desire to make this a meaningful discussion between stakeholders. However, due to the difficulties of recruitment I agreed, after discussion with my supervisors, to amend the study design and reconceptualise the focus groups as individual interviews. The decision to switch to individual interviews was considered thoroughly and was principally a pragmatic decision. However, it is likely that my

anxiety of not being able to complete the project on time was equally incremental in determining my decision not to persist with the recruitment for the focus groups. This period of ineffective recruitment highlighted the energy-intensive nature of research. Additionally, I wondered whether our difficulties in recruitment were an explanation for the lack of research based on the involvement of client preference and characteristics found within the literature review, as it seemed that recruitment was particularly difficult with stakeholders. I also reflected on the issue of representativeness raised by our low response rates and how this might have impacted the generalisability of our findings.

5. Working with stakeholders

After the completion of my review and my subsequent reflections in my own clinical work, I was motivated and empowered by including stakeholders in my analysis. I became aware that closing the gap between the conduction of research and its application is a vital challenge for creating efficient and effective research. While stakeholder engagement is increasingly promoted and seen as an important pathway to achieve impact, the voice of stakeholders often remains underrepresented (Boaz et al., 2018). As such, my primary hypothesis was that stakeholders were often not involved due to clinician choice, or the very real constraints that researchers in clinical fields face. My assumption was that client preferences was neglected at the expense of research evidence, as the hierarchy of evidence clearly stipulates that empirically conducted research is of higher value than opinion pieces that are based on experience (Evans, 2003).

However, after conducting the research and having difficulties recruiting this specific population, I wondered whether the underrepresentation of service users may in part be due

to the lack of interest by the population itself. Even after repeatedly offering the study and linking it clearly to the potential for changing and improving services, only a small number of service users came forward to take part in the study. This significantly impacts the potential for changing and improving services in a way that is catered to stakeholders. Research indicates that the nature of engagement is vital in stakeholder involvement (Murphy et al., 2021). It is possible that had I been able to spend more time on recruitment, I would have been able to recruit a more diverse and larger sample. In hindsight, the study would have benefitted from conceptualising stakeholder engagement more through a combination of existing literature and new empirical findings.

6. The Bi-Directional Relationships

Whilst completing this thesis, I have been struck by the bi-directional relationship between conducting research and working clinically. I noticed how these inform and shape each other and ultimately create a holistic understanding of clinical psychology.

6.1. The impact of clinical work on research

As part of my placements and throughout clinical training, I have been working therapeutically with diverse client groups. Working clinically has informed my hypothesis and the writing of this thesis. Simultaneously, it has laid emphasis on the challenges of researching in this field.

Within all my placements, which included an inpatient acute ward, an early intervention in psychosis service, a disabled children's outreach service, a cardiology unit

and a Post-Traumatic Stress Disorder (PTSD) service for refugees and asylum seekers, eating difficulties were present and often misinterpreted. While the more common eating disorders, specifically Anorexia Nervosa, are largely understood and recognisable by other clinicians, less popular and less well-known conditions, ARFID amongst them, are often misdiagnosed (Magel et al., 2021). Working within the disabled children's outreach service, in which the majority of clients had a diagnosis of Autism Spectrum Disorder (autism), highlighted this gap in knowledge for me. Clinicians were still conceptualising eating difficulties as phases of "picky eating" or side effects of autism in which children have sensory difficulties with food (Yule et al., 2021). Only in the most severe cases was ARFID considered a plausible diagnosis and even then, clinicians often did not know how to capture, categorise or understand the condition, a difficulty often present for clinicians (Coglan & Otasowie, 2019). This resulted in a number of clients not getting adequate help and support, as the child's eating difficulties were not conceptualised as ARFID (Cardona Cano et al., 2015) . Indeed, in all of my placements I have held presentations in order to educate clinicians on how ARFID presents and what its diagnostic categories are. Whilst working within a health placement, I also became aware of the struggles new diagnostic categories face when trying to be established in other fields of mental health and the importance of disseminating information effectively.

This thesis has increased my awareness of the challenges of trying to accurately identify and record ARFID within my research, and the near impossible task of generating categories that are exact in their definition and accurately capture the complexity of this heterogeneous client group. At times this highlighted the value of my study to me, as I was beginning to understand how infrequently ARFID is appropriately diagnosed and how stakeholders often do not receive the right levels of care, which has been observed in prior research (Coglan & Otasowie, 2019). On the other hand, due to the heterogeneous

presentations of ARFID, I was questioning the validity of this thesis and queried its utility in trying to understand the needs of a client group with such individual differences.

This dichotomy in feelings reminded me that psychological research and clinical practice are not disciplines of distinct categories and thus this complexity should not lead to the abandonment of the study of ARFID. Research should, instead, aim to explore these complicated constructs by utilising the best design, tools and skills available, whilst reflecting upon potentially confounding biases and methodological problems within the obtained results.

6.2. The impact of research on clinical work

As clinical psychologists, we are scientist-practitioners. A vital part of this is adhering to evidence-based practice, which is in part informed by research and gives direction toward best clinical practice (Mitchell & Gill, 2014). With this in mind, I have become aware how my own research continues to inform and contribute to my clinical work, specifically within the wider context of working within the NHS. I have found myself more familiar to the issues concerning service delivery, and have deliberated the needs of individuals who make use of these services more sincerely.

My final placement has been within a PTSD service for refugees and asylum seekers. While this groups shares commonalities, such as severe trauma including persecution and torture, they remain a diverse service user group (Carswell et al., 2011). Often these clients have difficulties in receiving the right type of support or are re-traumatised when navigating the asylum process (Griggs et al., 2022). Working within this field has increased my awareness of how difficult it is to provide consistent, thoughtful and tailored support for a

client group that presents with such diverse struggles. My research has informed my understanding of this, by accentuating the need to take stakeholders views into consideration.

My literature review focused on evidence-based practice and how this provides clinical excellence. By including research evidence, clinical expertise and patient preference, Sackett (Sackett et al., 1996) argues, we will be able to provide idiosyncratic, holistic and client centred care - elements that are deemed essential when considering NHS guidelines (NHS England, 2022). My research has opened my eyes as to how this is often not facilitated. Whilst we do our best to capture patterns in the clients that we treat and use clinical expertise to inform our understanding of clinical guidelines, we often do not take patient preference into consideration enough. My placement illustrated just this: we knew that PTSD was to be treated either with trauma focused Cognitive Behavioural Therapy, or with Narrative Exposure Therapy. Clinical experience also taught us that emotions such as shame or guilt might need to be addressed in addition to the traditional PTSD treatment. What we do not know is how to take patient preference into consideration. The service experiences frequent cancellations of their sessions, clients are difficult to engage and often drop out of therapy prematurely. By understanding the needs of the clients better, we may be able to mitigate these difficulties and enable the NHS to make use of its economic resources better, whilst ensuring that we are offering valuable treatment for the client group that we are attempting to help (Russo et al., 2021).

This relationship between research and clinical practice highlights a sense of utility and practicality, which empowers me to continue to contribute to clinically relevant research.

7. Conclusion

Due to my previous work as a research assistant on the validation study of the Pica, ARFID and Rumination Disorder Interview (PARDI), I had been somewhat protected from the process of research governance, study design and recruitment as this was usually undertaken by members of the team more experienced than me. I thus commenced this research with a somewhat naïve sense of confidence. Undertaking research whilst working clinically myself was, at its best, time consuming and, at its worst, anxiety provoking and exasperating. Specifically, the literature review often made me feel out of my depth in terms of knowledge and ability to effectively synthesise the amount of information I had been presented with. However, the necessity to stay flexible, keep moving and find resolutions to difficulties as they arose, were a crucial contributor to influencing me and my growth as a researcher. As we were able to overcome a myriad of difficulties encountered in this process, I am now more attuned to organisational barriers which may obstruct recruitment and feel better able to tackle these in future research endeavours. I am now more aware of the problems of studying a relatively new field and believe I am more confident in mastering these now.

Despite the surface level discussion of the papers presented in the literature review, I believe that I have managed to effectively capture the current ARFID literature. By de-constructing it into the three legs of evidence-based practice, I believe I was able to give indication of what fields to research next whilst also emphasising the importance of including client preference into clinical decision making. I aim to incorporate this knowledge into my own practice, and am hoping that it will influence others working as clinical practitioners or researchers.

The empirical paper allowed me to put into practice what I had found in the literature review, which confirmed to me that research builds upon itself (Smith, 2008). I believe that

in order to shape our services, we need to cater them to the people that we are trying to treat. Therefore, facilitating great client and clinician satisfaction as well as sheltering the NHS from continued economic constraints is vital. Exploring this further has the potential to contribute meaningfully to understanding the needs of the clients we treat and will no doubt be the focus of many research papers in the future.

To conclude, the art of balancing clinical and research demands, amidst a global pandemic and moments of uncertainty, have unequivocally contributed and shaped my learning over the course of this degree. Assembling this thesis has significantly advanced and moulded my adherence and desire to work as a scientist-practitioner. I aim to further develop and maintain these skills when working as a clinical psychologist.

8. References

Boaz, A., Hanney, S., Borst, R., O'Shea, A., & Kok, M. (2018). How to engage stakeholders in research: Design principles to support improvement. *Health Research Policy and Systems*, *16*(1), 60. https://doi.org/10.1186/s12961-018-0337-6

Bourne, L., Bryant-Waugh, R., Cook, J., & Mandy, W. (2020). Avoidant/restrictive food intake disorder: A systematic scoping review of the current literature. *Psychiatry Research*, *288*, 112961. https://doi.org/10.1016/j.psychres.2020.112961

Bryant-Waugh, R., Loomes, R., Munuve, A., & Rhind, C. (2021). Towards an evidence-based out-patient care pathway for children and young people with avoidant restrictive food intake disorder. *Journal of Behavioral and Cognitive Therapy*, *31*(1), 15–26. https://doi.org/10.1016/j.jbct.2020.11.001

Cardona Cano, S., Tiemeier, H., Van Hoeken, D., Tharner, A., Jaddoe, V. W. V., Hofman, A., Verhulst, F. C., & Hoek, H. W. (2015). Trajectories of picky eating during childhood: A general population study. *International Journal of Eating Disorders*, *48*(6), 570–579. https://doi.org/10.1002/eat.22384

Carswell, K., Blackburn, P., & Barker, C. (2011). The relationship between trauma, post-migration problems and the psychological well-being of refugees and asylum seekers. *The International Journal of Social Psychiatry*, *57*(2), 107–119. https://doi.org/10.1177/0020764009105699

Carver, J. C., Hassler, E., Hernandes, E., & Kraft, N. A. (2013). Identifying Barriers to the Systematic Literature Review Process. *2013 ACM / IEEE International Symposium on Empirical Software Engineering and Measurement*, 203–212. https://doi.org/10.1109/ESEM.2013.28

Chen, D.-T. "Victor", Wang, Y.-M., & Lee, W. C. (2016). Challenges confronting beginning researchers in conducting literature reviews. *Studies in Continuing Education*, *38*(1),

47–60. https://doi.org/10.1080/0158037X.2015.1030335

Coglan, L., & Otasowie, J. (2019). Avoidant/restrictive food intake disorder: What do we know so far? *BJPsych Advances*, *25*(2), 90–98. https://doi.org/10.1192/bja.2018.48

Davies, T., & Lund, C. (2017). Integrating mental health care into primary care systems in low- and middle-income countries: Lessons from PRIME and AFFIRM. *Global Mental Health*, *4*, e7. https://doi.org/10.1017/gmh.2017.3

Evans, D. (2003). Hierarchy of evidence: A framework for ranking evidence evaluating healthcare interventions. *Journal of Clinical Nursing*, *12*(1), 77–84. https://doi.org/10.1046/j.1365-2702.2003.00662.x

Griggs, M., Liu, C., & Cooper, K. (2022). Pilot evaluation of a group stabilisation intervention for refugees and asylum seekers with PTSD. *Behavioural and Cognitive Psychotherapy*, *50*(1), 111–116. https://doi.org/10.1017/S135246582100028X

Holttum, S., & Goble, L. (2006). Factors influencing levels of research activity in clinical psychologists: A new model. *Clinical Psychology & Psychotherapy*, *13*(5), 339–351. https://doi.org/10.1002/cpp.501

Houle, J., Villaggi, B., Beaulieu, M.-D., Lespérance, F., Rondeau, G., & Lambert, J. (2013). Treatment preferences in patients with first episode depression. *Journal of Affective Disorders*, *147*(1–3), 94–100. https://doi.org/10.1016/j.jad.2012.10.016

Magel, C. A., Hewitt, K., Dimitropoulos, G., von Ranson, K. M., & McMorris, C. A. (2021). Who is treating ARFID, and how? The need for training for community clinicians. *Eating and Weight Disorders: EWD*, *26*(4), 1279–1280. https://doi.org/10.1007/s40519-020-01007

Maguire, D., Dunn, P. and McKenna, H. (2017), "*How hospital activity in the NHS in England has changed over time*", King's Fund report, 20 December 2016, London, available at:

Makan, A., Fekadu, A., Murhar, V., Luitel, N., Kathree, T., Ssebunya, J., & Lund, C. (2015). Stakeholder analysis of the Programme for Improving Mental health carE (PRIME): Baseline findings. *International Journal of Mental Health Systems, 9*(1), 27. https://doi.org/10.1186/s13033-015-0020-z

Mitchell, A. J., & Gill, J. (2014). Research productivity of staff in NHS mental health trusts: Comparison using the Leiden method. *The Psychiatric Bulletin, 38*(1), 19–23. https://doi.org/10.1192/pb.bp.113.042630

Murphy, J., Qureshi, O., Endale, T., Esponda, G. M., Pathare, S., Eaton, J., De Silva, M., & Ryan, G. (2021). Barriers and drivers to stakeholder engagement in global mental health projects. *International Journal of Mental Health Systems*, *15*(1), 30. https://doi.org/10.1186/s13033-021-00458-y

NHS England (2015) Access and Waiting Time Standard for Children and Young People with an Eating Disorder: Commissioning Guide. National Collaborating Centre for Mental Health

Norris, M. L., Robinson, A., Obeid, N., Harrison, M., Spettigue, W., & Henderson, K. (2014). Exploring avoidant/restrictive food intake disorder in eating disordered patients: A descriptive study. *International Journal of Eating Disorders*, *47*(5), 495–499. https://doi.org/10.1002/eat.22217

Norris, M. L., Spettigue, W. J., & Katzman, D. K. (2016). Update on eating disorders: Current perspectives on avoidant/restrictive food intake disorder in children and youth. *Neuropsychiatric Disease and Treatment*, *12*, 213–218. https://doi.org/10.2147/NDT.S82538

Peterson, C. B., Becker, C. B., Treasure, J., Shafran, R., & Bryant-Waugh, R. (2016). The three-legged stool of evidence-based practice in eating disorder treatment: Research, clinical, and patient perspectives. *BMC Medicine, 14*, 69.

https://doi.org/10.1186/s12916-016-0615-5

Russo, S., Monzani, D., Pinto, C. A., Vergani, L., Marton, G., Falahee, M., Simons, G., Whichello, C., Kihlbom, U., & Pravettoni, G. (2021). Taking into Account Patient Preferences: A Consensus Study on the Assessment of Psychological Dimensions Within Patient Preference Studies. *Patient Preference and Adherence*, *15*, 1331–1345. https://doi.org/10.2147/PPA.S261615

Sackett, D. L., Rosenberg, W. M., Gray, J. A., Haynes, R. B., & Richardson, W. S. (1996). Evidence based medicine: What it is and what it isn't. *BMJ : British Medical Journal*, *312*(7023), 71–72.

Smith, K. M. (2008). Building upon existing evidence to shape future research endeavors. *American Journal of Health-System Pharmacy*, *65*(18), 1767–1774. https://doi.org/10.2146/ajhp070176

Spring, B. (2007). Evidence-based practice in clinical psychology: What it is, why it matters; what you need to know. *Journal of Clinical Psychology*, *63*(7), 611–631. https://doi.org/10.1002/jclp.20373

Suri, H., & Clarke, D. (2009). Advancements in Research Synthesis Methods: From a Methodologically Inclusive Perspective. *Review of Educational Research*, *79*(1), 395–430. https://doi.org/10.3102/0034654308326349

Yule, S., Wanik, J., Holm, E. M., Bruder, M. B., Shanley, E., Sherman, C. Q., Fitterman, M., Lerner, J., Marcello, M., Parenchuck, N., Roman-White, C., & Ziff, M. (2021). Nutritional Deficiency Disease Secondary to ARFID Symptoms Associated with Autism and the Broad Autism Phenotype: A Qualitative Systematic Review of Case Reports and Case Series. *Journal of the Academy of Nutrition and Dietetics*, *121*(3), 467–492. https://doi.org/10.1016/j.jand.2020.10.017

Zucker, N., Copeland, W., Franz, L., Carpenter, K., Keeling, L., Angold, A., & Egger, H. (2015). Psychological and Psychosocial Impairment in Preschoolers With Selective Eating. *Pediatrics*, *136*(3), e582-590. https://doi.org/10.1542/peds.2014-2386

Appendices

Appendix A – Participant Information Sheet

National and Specialist Child & Adolescent Mental Health Services
Maudsley Centre for Child and Adolescent Eating Disorders
The Michael Rutter Centre for Children & Young People
The Maudsley Hospital
De Crespigny Park off Denmark Hill
London SE5 8AZ
Telephone: 020 3228 2545

Patient and Public Involvement Project
Participant Information Sheet for Parents / Caregivers

Title: Improving clinical service delivery for children and young people with ARFID

We would like to invite you to take part in a Patient and Public Involvement (PPI) Project, to help us develop the ARFID service at the Maudsley and to be able to share learning points that could benefit families in other services.

Who is conducting the project and has it been approved?
This PPI project is being carried out by the Maudsley ARFID Team in conjunction with two members of the Clinical, Education and Health Psychology Department at University College London. The project was approved by the South London and Maudsley NHS Foundation Trust CAMHS Clinical Governance Group on 25 January 2022.

The Project Team consists of:

- Dr. Rachel Bryant-Waugh, Consultant Clinical Psychologist, ARFID Team Lead and Project Lead
- Cara Eilender, Honorary ARFID Team Member and Trainee Clinical Psychologist, UCL
- Dr Will Mandy, Professor of Neurodevelopmental Conditions and Joint Course Director, UCL Clinical Psychology Course
- Dr Charlotte Rhind, Clinical Psychologist and ARFID Team PPI Lead

What does the project involve?
This will involve you spending 60 – 90 minutes participating in one of two available online focus group discussion opportunities with other parents/carers, via Microsoft Teams.

Before you decide to take part, it is important that you understand why this project is being done and what participation will involve. Please take time to read the following information carefully and discuss with others if you wish. Do ask us if there is anything that is not clear or if you would like more information. Please take time to decide whether you wish to take part.

Why are we doing this project?
In 2019/2020 the Maudsley ARFID service took part in the NHS England National ARFID pilot which was conducted in seven services across England over a 6-month period. This project aims to extend findings from this pilot, by consulting with parents/caregivers. The aim is to inform clinical service delivery and development in ways that best fit with the needs of young people and their families.

We plan to use the findings of this project to draw up an implementation plan for the Maudsley ARFID service as well as to inform the content of an article for publication in an appropriate clinical academic journal. This will allow your views and experiences to reach a wider audience and benefit other families. The project will additionally be written up as part of Cara Eilender's clinical psychology qualification requirements. No personal identifiers will be used, and your participation will remain anonymous in any written material published.

Who can take part?
You are being contacted as you have previously indicated that you would be interested in hearing about opportunities to help us improve what we do through being included in our Patient and Public Involvement (PPI) register.

Do I have to take part?
No, it is up to you to decide. If you do not wish to take part, it will not affect the care your child receives, or your ongoing relationship with the ARFID Team. If you decide that you are happy to take part, you will be asked to sign and return a consent form (see below). You will be asked to keep a copy of this for your own records.

Should you decide to stop taking part in the project, you can withdraw from it at any point within a month of the focus group you originally joined. You do not have to give a reason for no longer wanting to take part and just need to let us know by emailing cara.eilender2@slam.nhs.uk. If you decide you no longer want to take part, then any information that you have provided up to that point will be deleted unless you agree otherwise.

What will I be asked to do?
We will ask you to complete a consent form to make sure that you understand the project, what participation involves, and that you agree to the group discussion being recorded. You will then be invited to take part in an online focus group with approximately 5-10 other parents using Microsoft Teams. The focus group will be facilitated by Cara Eilender and another member of the ARFID Team. When the project is written up, we will send you a summary of the findings.

The focus group should take around an hour, although we ask for some flexibility with timing depending on how many people attend the focus groups.

Will I be recorded and how will the recorded media be used?
Yes -we need to audio record the focus group to be able to document the discussion. As soon as the focus group is completed the Microsoft Teams recording will be saved in the ARFID Team's secure server. A final transcript will be produced after which the recording will be deleted. All information relating to your identity will be removed in the final transcript.

What are the benefits of participating in this project?
We hope to use the information gathered in the focus groups to inform and adapt our ARFID service. By involving people with lived experience of ARFID, we hope to make the service more relevant and improve on what we already offer. We hope the findings will also be helpful to those running services elsewhere

Will my confidentiality be protected?
We respect your privacy and are committed to protecting your personal data. All the information that we collect during the project will be kept strictly confidential and the recordings from the focus groups will be securely destroyed when the discussion transcript is complete.

Thank you for reading this information sheet and for considering taking part in this project.

If you have any questions, please contact:

Cara Eilender at cara.eilender2@slam.nhs.uk

Rachel Bryant-Waugh rachel.bryant-waugh@slam.nhs.uk

Appendix B – Complete list of questions asked in qualitative interview

Accessing Services

- How was your journey into services?
- What was your first contact with healthcare staff like, after you raised/identified concerns?
- Who did you consult first?
- How did you feel your concerns were received?
- What happened after this initial consultation?
- What was helpful in the journey from first concerns/steps to accessing the service?
- Is there anything that you can think of that might make this journey smoother / that can be improved?

General impressions / improvement ideas for the service

- What has your experience of the service been so far?
- What do you think would be helpful to add or develop as part of your care?
- What would have improved your experience at the services?
- Do you have any wishes? Wishes for ARFID services in general
- What should be prioritised when improving the service?

Specific Service adaptations for subgroups

- Do you have any ideas for how the service can be improved/ any useful adaptations that could be made for different ages? For 2-7? For 8-14? For 14+?
- Do you have any ideas for how the service can be improved/ any useful adaptations that could be made for neurodiverse young people?
- Do you have any ideas for how the service can be improved / any useful adaptations that could be made depending on weight or physical concerns?
- Do you have any ideas how to make the service more inclusive in general? (ie. Race, culture, gender identity)

Appendix C – PARDI-AR-Q

P-AR-Q Parent 4+ V1.1

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PARDI-AR-Q: Parent 4+

The following questions are about your child's eating – some ask about how things currently are, others ask about things over the past month or the past 3 months. Please tick the boxes that apply, or enter the information requested. **Please read each question carefully. Please answer all the questions. Thank you.**

1. Please fill in today's date: ____/_____/_____ (day/month/year)

2. Please fill in your child's date of birth: ____/_____/_____ (day/month/year)

3. Is your child? Male ☐ Female ☐ Other ☐ _____

4. What is your child's height? (please enter numbers): feet ☐ in ☐ **/OR** metres ☐ cm ☐

5. What is your child's weight? (please enter numbers): lbs ☐ **/OR** stones ☐ lbs ☐ **/OR** kg ☐

6. Do you think your child has a problem with eating, involving avoidance or restriction of foods or their eating overall? Yes ☐ No ☐

7. Have other people (for example, doctors, family members, significant others) said that your child has a problem with eating, involving avoidance or restriction of foods or their eating overall? Yes ☐ No ☐

8. Have your child's eating habits led to difficulty maintaining a sufficient weight or, if they are still growing, difficulty gaining enough weight to keep pace with their growth? Yes ☐ No ☐

9. Have your child's eating habits led to them losing weight (in other words, if they have lost weight, this is because of avoidance or restriction and not because of a medical illness, or other reason)? Yes ☐ No ☐

10. If yes to #9 above, how much weight have they lost in the past 3 months? (please enter numbers): lbs ☐ **/OR** stones ☐ lbs ☐ **/OR** kg ☐ **OR** No weight loss over past 3 months ☐

11. Have others (for example, doctors, family members) been concerned about your child's weight loss, or been concerned that they are having difficulty gaining enough weight to grow, or having difficulty maintaining their weight due to their eating habits? Yes ☐ No ☐

12. Have others (for example, doctors, family members) been concerned that your child is not growing taller as they should due to their eating habits? Yes ☐ No ☐ My child has finished growing ☐

13. Have you ever been told by **any health professional** that due to their eating habits your child is not growing as expected, or that their height was less than it should be? Yes ☐ No ☐

14. Over the past month, has **any health professional** said that your child has a nutritional deficiency due to their eating habits (for example, low iron, low vitamin B12, low vitamin C)? Yes ☐ No ☐

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15. Over the past month, has **a healthcare professional prescribed** special supplements (for example, pills, capsules, powders, or drinks containing vitamins and/or minerals and other micronutrients) **specifically to help with your child's nutrition?** Yes ☐ No ☐

16. If yes to #15 above, what has been prescribed and how much does your child take each day?

_____

17. Over the past month, has **a healthcare professional prescribed** special supplements (for example, high-calorie drinks or 'shots', or dessert-style high-calorie supplements) **specifically to help your child maintain or gain weight?** Yes ☐ No ☐

18. If yes to #17 above, what has been prescribed and how much does your child take each day?

_____

19. Is your child currently receiving any tube feeding (receiving food or fluid via a tube in their nose or into their stomach)? Yes ☐ No ☐

20. If yes to #19 above, what is the name of the **food or fluid product taken via the tube** and how much does your child take each day?

_____

21. Does your child's eating cause them difficulties in daily functioning - that is, in how they are able to go about things each day? This might be at school/college/work or when at home. Yes ☐ No ☐

22. Does your child's eating cause them difficulties in interactions with other people (for example, disagreements or arguments with parents, siblings, significant others), or difficulty making or sustaining friendships or other close relationships?
Please circle a number on the line below how difficult **interactions with other people** are for your child because of their eating, ranging from 0 (= no difficulty) to 6 (= extremely difficult)

0 1 2 3 4 5 6

23. Does your child's eating cause them difficulties in social situations, for example does it make it difficult for them to go out with friends, eat at school/college, or stay away from home?

Please circle a number on the line below how difficult **social situations** are for your child because of their eating, ranging from 0 (= no difficulty) to 6 (= extreme /tries to avoid all social situations)

0 1 2 3 4 5 6

24. Over the past month, has your child been particularly sensitive to variation in taste (for example, noticing slight differences in the taste of foods), which has put them off eating any foods or trying any new foods?

Please circle a number on the line below how much **sensitivity to taste** has affected your child's eating, ranging from 0 (= no negative effect/no particular sensitivity to taste) to 6 (= extremely negative effect, for example, leading to refusal to eat many foods, sticking only to a limited number of preferred foods, or extreme caution when eating)

0 1 2 3 4 5 6

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25. Over the past month has your child been particularly sensitive to the texture or consistency of food, which has put them off eating any foods or trying any new foods (for example, does your child stick to foods of a certain texture only or have they had difficulty eating foods that have different textures mixed together such as pasta with sauce or sandwiches)?

Please circle a number on the line below how much **sensitivity to texture or consistency** has affected your child's eating, ranging from 0 (= no negative effect/no particular sensitivity) to 6 (=extremely negative effect, for example, leading to refusal to eat many foods, sticking only to a limited number of preferred foods, or extreme caution when eating)

0 1 2 3 4 5 6

26. Over the past month, has your child been particularly sensitive to the appearance of food, which has put them off eating any foods or trying any new foods (for example, if food does not look "right", such as burnt ends of chips/fries, broken biscuits/cookies, or being the "wrong" colour)?

Please circle a number on the line below how much **sensitivity to the appearance of food** has affected your child's eating, ranging from 0 (= no negative effect/no particular sensitivity) to 6 (=extremely negative effect, for example, leading to refusal to eat many foods, sticking only to a limited number of preferred foods, or extreme caution when eating)

0 1 2 3 4 5 6

27. Over the past month, how often has your child forgotten to eat or found it difficult to make time to eat?

Please circle a number on the line below how often your child has **forgotten to eat or found it difficult to make time to eat**, ranging from 0 (= never) to 6 (=always)

0 1 2 3 4 5 6

28. Over the past month, how often has your child appeared to lack enjoyment in food or eating (even if only certain foods)?

Please circle a number on the line below how often your child has **lacked enjoyment in food or eating**, ranging from 0 (= never) to 6 (=always)

0 1 2 3 4 5 6

29. Over the past month, how often has your child said or indicated they are full before their meal is finished, or stopped eating sooner than others because they had had enough?

Please circle a number on the line below how often your child has **indicated they are full or stopped eating early**, ranging from 0 (= never) to 6 (=always)

0 1 2 3 4 5 6

30. Over the past month has your child been avoiding or restricting the amount or type of food they eat, because they have said or indicated they were afraid that something bad might happen, like being sick, choking, having an allergic reaction, or being in pain?

Please circle a number on the line below how often being **afraid something bad might happen** has affected your child's eating, ranging from 0 (= never) to 6 (=always)

0 1 2 3 4 5 6

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31. Over the past month has your child avoided eating situations because they said or indicated they were worried something bad might happen, like being sick, choking, having an allergic reaction, or being in pain while eating (for example, because they might be served something they usually avoid for these reasons, or because they have had a bad experience in the past)?

Please circle a number on the line below how often your child has **avoided eating situations** due to such worries, ranging from 0 (= never) to 6 (=always)

0 1 2 3 4 5 6

32. Over the past month has your child expressed any physical feelings of panic or anxiety (examples might include a racing heart, sweaty palms, feeling sick) when they have seen something that has made them think something bad might happen, like being sick, choking, having an allergic reaction, or being in pain while eating

Please circle a number on the line below how often your child had **had physical feelings of panic or anxiety** due to such thoughts, ranging from 0 (= never) to 6 (=always)

0 1 2 3 4 5 6

THANK YOU!