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RESEARCH PAPER

Towards an evidence-based out-patient care pathway for children and young people with avoidant restrictive food intake disorder



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Received 9 October 2020; received in revised form 3 November 2020; accepted 4 November 2020

KEYWORDS

Avoidant restrictive food intake disorder; ARFID; Multi-modal; Multi-disciplinary; Care pathway; Evidence-based

Abstract Despite growing research and clinical interest in avoidant restrictive food intake disorder (ARFID), robust, evidence-based guidance on optimal treatment interventions, appropriate clinic structures, and modes of service delivery remain absent. Current consensus recommendations include a multi-disciplinary, multi-modal approach to assessment and treatment, with out-patient care being appropriate for the majority of patients, yet to date there is no clear guidance on how this might best be organised or implemented. This lack of guidance is due to a number of factors, that include the time required to conduct the necessary controlled trials and other well-designed investigations and for the subsequent body of research evidence to build. Lack of specific treatment guidance may also be related to the heterogeneous nature of ARFID clinical presentations potentially limiting the likelihood of uniform recommendations. This situation presents a challenge for clinicians required to engage in evidence-based practice, and for health care planners, providers, and policy makers. We describe here a proposed evidence-informed framework for care, subjected to preliminary testing and currently in use in an out-patient eating disorders service for children and young people aged 2–17 years. The use of the simplified care pathway diagram is illustrated with three case examples, and intended to serve as a possible model for further testing in a range of settings. In the face of ongoing

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uncertainty and inconsistency in the clinical management of ARFID, our intention is to share our experience in the form of an evidence-informed, trialled approach to structuring and providing intervention for this patient population.

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Introduction

Avoidant restrictive food intake disorder (ARFID) was introduced as a diagnostic category in the fifth revision of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) ([American Psychiatric Association \(APA\), 2013](#)) and subsequently added to the 11th revision of the International Classification of Diseases (ICD-11) ([World Health Organization \(WHO\), 2018](#)). In both systems it is classified as one of the 'Feeding and Eating Disorders'. The clinical presentations now meeting diagnostic criteria for ARFID are not new ([Waller, 2019](#)), yet prior to its introduction one of a number of diagnostic categories or terms might have been used. This variability in clinicians' practice may be related to professional background or clinical setting, as well as the recognised heterogeneity of ARFID manifestations. For example, individuals now receiving an ARFID diagnosis may have previously received a diagnosis of an 'unspecified' or 'not otherwise specified' eating disorder or anxiety disorder, a feeding disorder, or one of a range of descriptive terms not previously included in the main classification systems (DSM-IV-TR, [American Psychiatric Association, 2000](#); ICD-10, [World Health Organization, 1992](#)). This lack of consistent use of terminology has contributed to a limited body of evidence and absence of clear management guidance.

As individuals with avoidant or restrictive eating behaviours present to a range of clinical settings, it is concerning that awareness of ARFID remains limited among health-care professionals. Anecdotal accounts from treatment-seeking families support published findings that initial help-seeking for childhood eating difficulties does not always result in appropriate onward referral ([Cardona Cano et al., 2015](#)). Where the need for further assessment or input is recognised, referrals are inconsistently made to a range of health-care settings. For children and young people, referrals may be directed to paediatric clinics, dietetic or speech and language therapy services, mental health or neurodevelopmental services, or eating disorder teams. As ARFID requires multi-disciplinary assessment and intervention due to the co-occurrence of physical and mental health aspects of its presentation, many such services are not adequately structured to fully meet the needs of this patient population.

Since its introduction, research and clinical interest in ARFID has grown. The increasing number of published journal articles is welcome, as there remains much to be learned about every aspect of ARFID. This situation is unsurprising, as reliable statements about epidemiology, aetiology, effective treatment interventions, and service delivery relating to any clinical presentation rely on significant bodies of evidence, which take time to accumulate. Nevertheless, the current situation poses challenges for clinicians, health-care providers, and policy makers wishing to ensure delivery of evidence-

based, appropriate, effective care for individuals with ARFID.

Overview of current evidence to guide service development for ARFID

The following sections briefly summarise current knowledge across key areas essential for planning and delivering optimal clinical services.

Prevalence

Prevalence estimates are important in gauging potential need for clinical service provision, yet estimated rates of ARFID in general populations remain unknown. Much of the published evidence on prevalence in clinical populations has come from North America, with the highest number of papers relating to prevalence estimates in eating disorder (ED) programmes for children and adolescents. Findings that up to 22.5% of patients in such programmes receive a diagnosis of ARFID ([Nicely, Lane-Loney, Masciulli, Hollenbeak, & Ornstein, 2014](#)) contrast with lower estimated rates in other clinical settings seeing this age group, e.g. paediatric gastroenterology (1.5%; [Eddy et al., 2015](#)) and adolescent gynaecology (3.7%; [Goldberg et al., 2020](#)). The reported clinical features of patients with ARFID described in ED settings suggest that these individuals may have previously received a DSM-IV diagnosis of EDNOS (eating disorder not otherwise specified; [American Psychiatric Association, 2000](#)), mostly presenting with low weight ([Ornstein, Essayli, Nicely, Masciulli, & Lane-Loney, 2017](#); [Spettigue, Norris, Santos, & Obeid, 2018](#)). However, such patients are likely to represent only a sub-set of the wider population of treatment-seeking individuals who might meet ARFID diagnostic criteria. For example, paediatric feeding clinics report seeing a significant number of individuals meeting ARFID criteria, with one study reporting up to 32% of patients doing so ([Williams et al., 2015](#)). Data from autism clinics also suggest a notable co-occurrence of autism and severe food selectivity, which in many instances would warrant an ARFID diagnosis ([Sharp et al., 2018](#)). Although further research in a wider range of populations and types of service provision is needed to draw firm conclusions, existing evidence confirms that individuals with ARFID represent a recognised clinical population with guidance on clinical management needed to ensure optimal care.

Aetiology

An understanding of causation is helpful in determining appropriately targeted treatment for any disorder or

condition. Recent conceptualisations of aetiology include proposals that neurobiological and neuro-behavioural mechanisms may underpin the onset and perpetuation of ARFID presentations. One proposed dimensional model posits that biological abnormalities in sensory perception, homeostatic appetite, and fear responsiveness, underlie the three commonly observed drivers of avoidance or restriction of food intake, i.e. sensory based avoidance, lack of interest in food or eating, and concern about aversive consequences of eating (American Psychiatric Association, 2013), respectively (Thomas et al., 2017). Through proposing a dimensional model these authors highlight that although the strength of these driving influences may vary in severity, they are not mutually exclusive, which has also been observed by others (Bryant-Waugh, 2019; Reilly, Brown, Gray, Kaye, & Menzel, 2019; Zickgraf, Lane-Loney, Essayli, & Ornstein, 2019). An alternative conceptualisation of aetiology in ARFID proposes that cognitive and behavioural inflexibility and/or neurobiological abnormalities in sensory processing, commonly seen in autism and anxiety disorders, could encourage restrictive eating behaviours, a limited food repertoire and/or rigidity relating to eating behaviour (Zickgraf, Richard, Zucker, & Wallace, 2020). Disgust has also been proposed as having a central role in aetiology, through mediating the association between anxiety and ARFID (Harris et al., 2019). The heterogeneity in clinical ARFID presentations, to include duration of eating difficulties with some being acute onset and others more longstanding, suggests that there may be interactions between different underlying mechanisms contributing to the onset and perpetuation of ARFID that warrant further research (Bourne, Bryant-Waugh, Cook, & Mandy, 2020); Thomas et al., 2017).

Existing treatment guidance

Currently there are no empirically supported treatments for ARFID, consequently, specific recommendations remain absent from the most recent publications on comprehensive practice guidance for EDs, e.g. from Australia and New Zealand (Hay et al., 2014), from the UK (National Institute for Health and Care Excellence (NICE) guidelines, 2017), and from Canada (Couturier et al., 2020). Hay concludes that 'for all eating disorders (including ARFID), the main treatment ... is a form of psycho-behavioural therapy which can most usually be provided on an out-patient basis', further stating that 'in addition to specific psychological therapy, treatment needs to address important nutritional, physical and mental health co-morbidities and thus is ideally from a multi-disciplinary team' (Hay, 2020). Limited evidence is available regarding psychological interventions, medication, and service configuration, which is summarised below. Despite sensory-based avoidance and nutritional deficiencies forming part of the ARFID diagnostic criteria (American Psychiatric Association, 2013; World Health Organization, 2018), evidence on specific sensory and dietetic interventions applicable to out-patient settings remains elusive. All current practice guidance documents conclude that further research is needed before any firm recommendations can be made across any domain and that the strength of any evidence to date is weak (Couturier et al., 2020). Even if one or more treatment interventions or modes of service

delivery prove to be effective, it is questionable whether a one-size-fits-all approach will be indicated.

Psychological interventions

A variety of psychological intervention approaches have been described, often in the form of case reports or small case series, with a few proof-of-concept or pilot study papers. These have predominantly been treatment interventions shown to be effective in other eating or anxiety disorders, adapted to an ARFID (or ARFID-like) presentation. They include cognitive behavioural therapy (CBT), presented in case reports (Aloi, Sinopoli, & Segura-Garcia, 2018; Fischer, Luiselli, & Dove, 2015; King, Urbach, & Stewart, 2015), a case series with adolescents in a day treatment setting (Dumont, Jansen, Kroes, de Haan, & Mulkens, 2019), and a proof of concept study with children and adolescents (Thomas et al., 2020). Similarly, family-based treatment for anorexia nervosa in adolescents has been adapted for ARFID (Eckhardt, Martell, Lowe, Le Grange, & Ehrenreich-May, 2019; Fitzpatrick, Forsberg, & Colborn, 2015); Lock et al., 2019a), with case reports describing its use in the context of different drivers of food avoidance or restriction (Rosania & Lock, 2020), and a recent feasibility trial (Lock, Sadeh-Sharvit, & L'Insalata, 2019b). Behavioural interventions in ARFID-like presentations are well-established in the feeding disorders, autism, and learning disability literature and increasingly discussed with specific reference to ARFID (Pitt & Middleman, 2018; Sharp et al., 2016). Other treatment approaches documented in the literature include predominantly CBT or behaviourally-based parent-led approaches (Bloomfield, Fischer, Clark, & Dove, 2019; Brown & Hildebrandt, 2020; Murphy & Zlomke, 2016; Shimshoni, Silverman, & Lebowitz, 2020), an acceptance-based exposure treatment for children (Zucker et al., 2019), and eye movement desensitisation and reprocessing (EMDR) where the ARFID presentation is characterised by choking phobia (De Roos & de Jongh, 2008). Of the psychological interventions trialled with young people with ARFID, family based treatment for children and CBT have been identified as promising therapies (Couturier et al., 2020).

Medication

The use of a range of medications has been reported as associated with positive effects in patients with ARFID (or ARFID-like presentations), to include olanzapine (Brewerton & D'Agostino, 2017; Spettigue et al., 2018); cyproheptadine (Spettigue et al., 2018); D-cycloserine (Sharp et al., 2017); risperidone (Pennell, Couturier, Grant, & Johnson, 2016); aripiprazole (Sivri, Gülsen, & Yilmaz, 2018); fluoxetine (Spettigue et al., 2018); fluvoxamine (Spettigue et al., 2018); escitalopram (Hoşoglu & Akça, 2018); and mirtazipine (Gray, Chen, Menzel, Schwartz, & Kaye, 2018; Tanidir & Hergüner, 2015). Of the medications trialled with young people with ARFID to date, atypical antipsychotics have been identified as potentially promising (Couturier et al., 2020).

Modes of service delivery

As with the other EDs, the expectation is that care for ARFID can mostly be provided on an out-patient basis (Hay, 2020). This may take the form of in-person appointments, but increasingly might include the use of virtual appointments

or telemedicine (Bloomfield et al., 2019). A smaller number of patients may require more intensive treatment provision, with examples of multi-disciplinary, multi-modal in-patient care (e.g. Spettigue et al., 2018) and day-patient care in the ARFID literature (Ornstein et al., 2017; Dumont et al., 2019). More intensive treatment provision is most likely to be indicated in the presence of high physical or high psychiatric risk, determined using appropriate local or national guidelines.

Evidence-informed care for children and young people with ARFID

Against this background we developed an evidence-informed decision-making framework in the form of a 10-step out-patient care pathway for the assessment and treatment of children and adolescents with ARFID. In developing the pathway, we have been guided by the three-component model of evidence-based practice (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996), which emphasises the importance of integrating research evidence, clinical expertise, and patient values, and has been described as essential for providing optimal care in the treatment of EDs (Peterson, Becker, Treasure, Shafran, & Bryant-Waugh, 2016). Also included is the recommendation that assessment and treatment should be approached from a multi-disciplinary and multi-modal perspective (Eddy et al., 2019; Hay, 2020). We have additionally taken individual differences in presentation into account, to include: variable profiles in terms of factors contributing to and maintaining avoidant or restricted intake; variability in duration of difficulties, their impact and related risk; and factors such as age, intellectual abilities, co-occurring mental health problems,

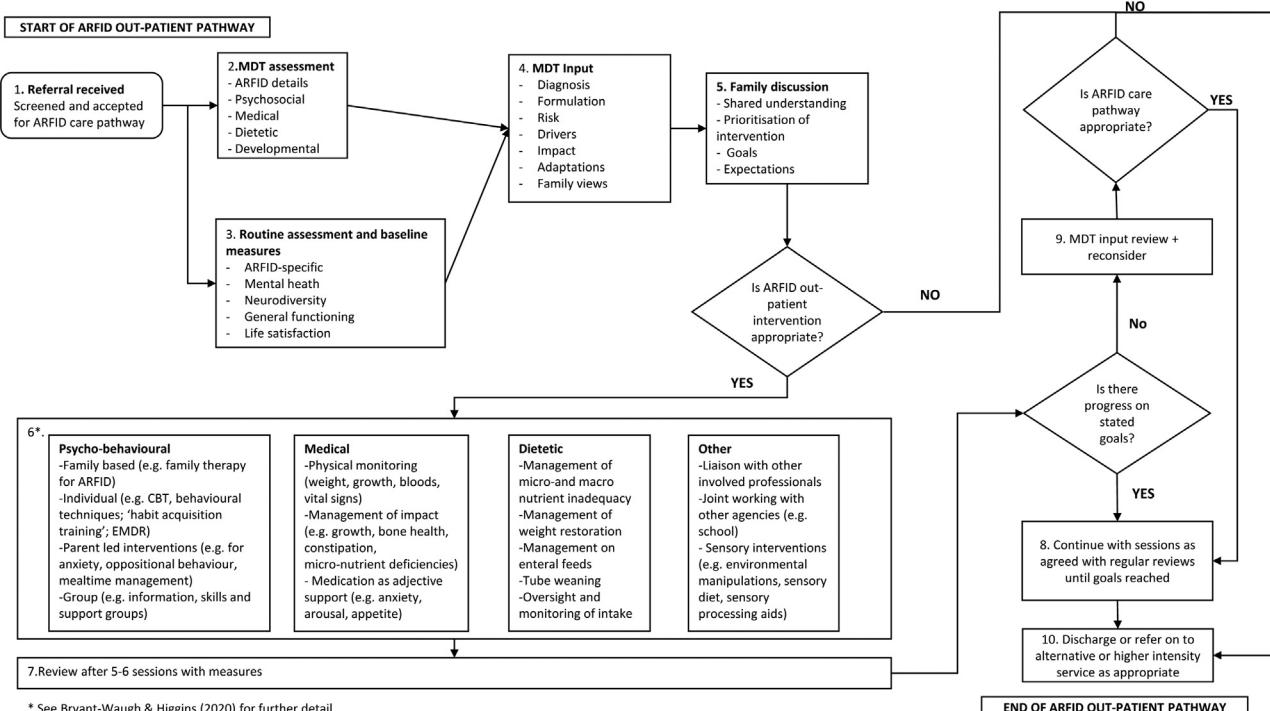
neurodiversity, and medical conditions. Throughout, we have considered available evidence and information from research, clinical experience, and the families following the pathway. We outline this below as a means of capturing our experience and as a possible model for further testing and improvement across a range of settings. Given the current wait for specific evidence-based recommendations to be generated, we argue that it is nevertheless possible to structure clinical care whilst adhering to evidence-informed principles. The evidence supporting the inclusion of each component of the pathway is described briefly below, followed by three case examples to illustrate its application in practice in an out-patient ED setting for individuals aged 2 to 17 years (see Table 5).

Proposed care pathway model

Fig. 1

Step 1

In line with evidence suggesting delays in appropriate treatment can hamper recovery and increase morbidity in a range of disorders to include EDs (Currin & Schmidt, 2005), and consistent with policy documents advocating early intervention (National Collaborating Centre for Mental Health [NCCMH], 2015; NHS, 2019), an emphasis is placed on removing referral barriers where possible and ensuring ease of access. Services providing assessment and treatment for young people with ARFID might expect to receive referrals from mental health and paediatric clinicians, family physicians, school nurses and other educational staff, social workers, youth workers, as well as self- and parent-initiated referrals. Screening of referrals requires determination



* See Bryant-Waugh & Higgins (2020) for further detail.

Figure 1 ARFID out-patient care pathway.

of the appropriateness and urgency of assessment. This includes checking that any avoidance or restriction of food intake does not appear to be primarily related to a disturbance in experience of body weight or shape as this is an exclusion criterion for ARFID.

Step 2

Assessment includes a semi-structured clinical interview including: details of presenting difficulties and their development over time; co-occurring mental health difficulties and neurodevelopmental conditions; personal, developmental, social, educational, and family history and context; medical history; and discussion about the food diary completed in advance by the family. A standard physical evaluation is also required. In this way, past and current psycho-social, physical, nutritional and developmental aspects of the clinical presentation can be covered. Consistent with consensus recommendations this requires multi-disciplinary participation, at a minimum to include medical and mental health professionals, and ideally also dietitian input (Eddy et al., 2019; Hay, 2020). Additional assessment of other aspects of presentation including

sensory processing, oral-motor development, or swallow function may be indicated, involving input from occupational therapists, speech and language therapists, or other specialist clinicians. Direct observation of eating behaviour, mealtime management, and response to specific foods may also be helpful. Further guidance regarding multi-disciplinary assessment can be found in (Bryant-Waugh & Higgins, 2020).

Step 3

The use of standardised assessment and baseline measures is included as part of routine practice in line with policy guidance (Law & Wolpert, 2014; NCCMH, 2015). Resulting data can be used to assist in refining understanding and characterisation of ARFID presentations, to inform service planning, and to provide information about individuals, including highlighting risk. Family members are invited to complete age-appropriate self- and parent-completed ARFID specific measures, as well as measures of commonly co-occurring mental health difficulties, general functioning, life satisfaction, and other domains such as neurodiversity. Table 1 represents an example of a possible assessment bat-

Table 1 Example of routinely administered measures as part of ARFID care pathway.

Measures		Completed by (Parent, young person or clinician)	Time points used (Assessment, ongoing, discharge)
ARFID specific			
PARDI-AR-Q	PARDI (Pica ARFID Rumination Disorder Interview) ARFID Questionnaire ^a	Parent & young person	Assessment & discharge
WMTM	What Matters To Me (Bryant-Waugh & Higgins, 2020) ^a	Parent	Assessment & discharge
Risk domains	ARFID risk domains ^a	Clinician	Assessment & discharge
AIMS	ARFID Intervention Monitoring Scale ^a	Parent & young person	Ongoing
General			
SDQ	Strength and Difficulties Questionnaire (Goodman, 2001)	Parent & young person	Assessment & discharge
RCADS	Revised Children's Anxiety and Depression Scale (Chorpita et al., 2000)	Parent & young person	Assessment & discharge
HoNOSCA	Health of the Nation Outcome Scale for Children and Adolescents (Gowers et al., 1999)	Parent & young person	Assessment
BMSLSS	Brief Multi-dimensional Students Life Satisfaction Scale (Seligson et al., 2003)	Young person	Assessment & discharge
GBO	Goal Based Outcomes (Law & Jacob, 2015)	Young person	Assessment, ongoing & discharge
CGAS	Children's Global Assessment Scale (Shaffer et al., 1983)	Clinician	Assessment, ongoing & discharge
Current view	Current view (Jones et al., 2013)	Clinician	Assessment, discharge
SFQ	Session Feedback Questionnaire (Law & Wolpert, 2014)	Parent & young person	Ongoing
SxS	SDQ Session by Session questionnaire (Hall et al., 2015)	Parent & young person	Ongoing
ESQ	Experience of Service Questionnaire (Brown et al., 2014)	Parent & young person	Discharge
Other			
Food diary	3–5 day food diary ^a	Parent & young person	Assessment, ongoing

NB: PARDI-AR-Q, WMTM; ARFID risk domains and AIMS are currently undergoing reliability and validity testing.

^a All available via: <https://mcaed.slam.nhs.uk/professionals/resources/books-and-manuals/>.

tery, with specific measures used at different time points indicated. Alternative or additional measures or domains can be used.

Step 4

Information from Steps 2 and 3 is jointly considered by the assessing team to determine whether an ARFID diagnosis is appropriate, to arrive at a provisional understanding of the main contributing and maintaining factors to the current clinical presentation (often referred to as a formulation) (Persons, Roberts, Zalecki, & Brechwald, 2006; Rainforth & Laurenson, 2014), and to identify areas and extent of risk. The formulation will include considering possible maintaining factors external to the young person, such as parental accommodations and management style (Wagner, Zickgraf, & Lane-Loney, 2020). The main perceived drivers of the avoidance or restriction of food intake are considered, as well as the impact of the eating difficulties on the health and well-being of the young person and family members. Additional factors such as the age and developmental stage of the individual, the presence of neurodevelopmental conditions, intellectual disability, and other psychiatric co-morbidities or medical conditions require consideration in relation to adaptations required for treatment. Parental health and abilities may also need to be taken into account (Acri & Hoagwood, 2015). This step additionally includes consideration of any barriers to care and of family members' priorities and wishes, with identification of any mismatch with clinical priorities. The use of clinician completed standardised measures is helpful in

capturing clinical information in data form (see example in Table 1).

Step 5

This transition step between assessment and treatment may occur on the same day as Steps 2-4, or shortly after, preferably consisting of discussion between family members and one or more members of the assessing team. In line with evidence-based principles of collaborative, co-constructed care (Langer & Jensen-Doss, 2018; Ng & Weisz, 2016), the objectives are to arrive at a shared understanding of the presentation, to reach agreement on suitability for out-patient care, and if treatment is to be offered, to prioritise targets for intervention and clearly formulate treatment goals. Main behavioural change objectives for ARFID treatment are outlined in Table 2. One or more of these can be identified as appropriate in terms of focus, with prioritisation of input informed by clinical risk, as well as family members' identification of major areas of impact that they wish to work on. Expectations regarding extent and pace of change are helpfully discussed, as these may need addressing if judged to be unrealistic.

Step 6

A main objective of treatment for ARFID is to achieve lasting changes in eating behaviour, in particular through reducing the frequency, extent and impact of avoidance or restriction of food intake. Intervention will usually also include clinical management of the effects of the eating disturbance, which may variably impact health, well-being,

Table 2 Main behavioural change outcomes in ARFID care pathway.

Primary targets for intervention	Desired outcomes	Measurement
1. Increase in overall amount eaten (energy)	Weight gain/restoration	Weight
2. Increase in range of food accepted	Improved nutritional status	Blood test, food diary ^a , AIMS ^a
3. Improved pattern of eating (regular meals and snacks)	Improved physical well-being	Food diary ^a , AIMS ^a , ARFID risk domains ^a
4. Acceptance of nutritional supplement	Weight gain/treatment or improvement of nutritional deficiencies/insufficiencies	Weight, blood test, food diary ^a
5. Replacement of dependence on nutritional supplement with oral food intake	Reduction in psycho-social impairment	Food diary ^a , PARDI-AR-Q ^a , AIMS ^a
6. Ability to eat with others	Reduction in psycho-social impairment	Food diary ^a , PARDI -AR-Q ^a , AIMS ^a , Goal based outcomes ^b
7. Ability to eat some of the same foods as others (e.g. with family, friends)	Reduction in psychosocial impairment	Food diary ^a , PARDI-AR-Q ^a , AIMS ^a , Goal based outcomes ^b
8. Ability to eat outside the home/when out/at school, college	Reduction in psycho-social impairment; improved physical well-being	Food diary ^a , PARDI-AR-Q ^a , AIMS ^a , Goal based outcomes ^b
9. Reduction in rigidity around appearance, brands, routines, etc.	Reduction in psychosocial impairment	Food diary ^a , AIMS ^a , PARDI-AR-Q ^a , Goal based outcomes ^b
10. Other related specific behavioural change (e.g. increase in fluid intake where this is minimal)	Variable	Food diary ^a , ARFID risk domains ^a , Goal based outcomes ^b

^a The Food diary, ARFID Intervention Monitoring Scale (AIMS), ARFID risk domains, and Pica ARFID, Rumination Disorder-ARFID-Questionnaire (PARDI-AR-Q) are all available via: <https://mccaed.slam.nhs.uk/professionals/resources/books-and-manuals/>.

^b Goal based outcomes (Law & Jacob, 2015).

Table 3 Treatment options with clinical experience-informed main driver of avoidance/restriction^a of focus (see also Bryant-Waugh & Higgins, 2020).

Psycho-behavioural

Cognitive Behavioural Therapy (ARFID adapted evidence-based, manualised CBT interventions addressing specific fear/phobia, anxiety, emotion regulation; trauma)—most useful in CBA and SBA with anxiety
 Behavioural Therapy (e.g. exposure/reward/habituation/diminishing disgust response)—most useful in SBA and LI
 'Habit Acquisition Training' (e.g. establishing regular eating)—most useful in LI and CBA
 Other individual intervention (e.g. EMDR for CBA)
 Parenting intervention—anxiety focused (CBA)/oppositional behaviour focused (CBA/SBA)/mealtimes management (for CBA/SBA/IA/other)
 Family-based therapy (ARFID adapted evidence-based, manualised interventions for eating disorders) – most useful for CBA and SBA
 Group intervention (e.g. parent/carer; CYP) — can be useful across all drivers of avoidance/restriction
 Enhanced psychoeducation (e.g. additional session from member of MDT re specific aspect of presentation, can be relevant across all drivers of avoidance/restriction)

Medical

Medication (for ARFID related problems, e.g. anxiety (CBA), arousal (LI), appetite (LI); for a co-occurring problem)
 Management of physical impact of avoidance/restriction of food intake (e.g. growth, bone health, constipation, micro-nutrient deficiencies)—relevant across all drivers of avoidance/restriction
 Physical monitoring (weight, growth, bloods, vital signs)—relevant across all drivers of avoidance/restriction

Dietetic

Management of micro- and macro nutrient inadequacies (e.g. micronutrient supplementation, use of fortified foods) – relevant across all drivers of avoidance/restriction
 Management of weight restoration (e.g. food fortification, oral supplements) – relevant across all drivers of avoidance/restriction
 Management on enteral feeds – relevant across all drivers of avoidance/restriction
 Tube weaning – relevant across all drivers of avoidance/restriction
 Oversight and monitoring of food and fluid intake – relevant across all drivers of avoidance/restriction

Other

Liaison with other involved professionals – relevant across all drivers of avoidance/restriction
 Joint working with other agencies (e.g. school based intervention) – relevant across all drivers of avoidance/restriction
 Sensory intervention/sensory diet/environmental manipulation – most useful in SBA and LI

^a LI: low interest in food or eating; SBA: sensory based avoidance; CBA: concern based avoidance.

and day-to-day functioning. This step involves consideration of indications for psycho-behavioural, medical and dietetic interventions as well as other possible interventions that might be indicated on an individual basis and delivered simultaneously as part of a multi-modal approach. **Table 3** outlines evidence-informed interventions for consideration, taking account of variability in presenting features, impact, and drivers of avoidance and restriction. Developmental aspects of presentation may be relevant to the selection of most appropriate interventions, for example behavioural interventions are likely to be more suitable than cognitive behavioural interventions for those of young age or limited cognitive capacity. All aspects of intervention involve the provision of accessible information and some level of parental or family involvement, unless there is an explicit reason for working with the young person alone. Parental involvement can vary, but as a minimum usually involves actively supporting a young person between sessions to engage in therapy tasks designed to move closer towards agreed goals.

Step 7

The practice of reviewing progress at session 5/6 is informed by studies consistently identifying early symptom change as an important predictor of treatment outcome

Table 4 Possible adaptations to the method of delivery of interventions for young people with autism.

1. Offering additional emotion recognition training
2. Greater use of written and visual information and structured worksheets
3. Adopting a more cognitively concrete and structured approach
4. Using simplified cognitive activities, such as multiple-choice worksheets
5. Involving a parent or carer in individual therapy sessions
6. Maintaining attention by offering regular breaks
7. Incorporating the young person's special interests into therapy where possible
8. Making environmental adjustments where required (e.g. lower lighting, quieter space)
9. Maintaining consistency in appointment times and location
10. Preparing the young person in advance to manage expectations

Adapted from, Autism spectrum disorder in under 19s: support and management ([National Institute for Health and Care Excellence \(NICE\) guidelines, 2013](#)).

Table 5 Three case examples using the ARFID out-patient care pathway.

Step No.	Case example 1: 17-y/o White British female	Case example 2: 4-y/o Pakistani British male	Case example 3: 9-y/o Black Caribbean female
1	Family physician referral; one-year history of weight loss; no weight/shape concerns; no known medical cause	Parent initiated referral; longstanding selective eating accepting less than 10 foods; no weight/shape concerns; no known medical cause	Paediatric allergist referral; 2-month history of food refusal leading to weight loss; no weight/shape concerns; context of anaphylactic food allergies well managed by allergy clinic; no known medical cause
2	Longstanding selective eating with recent deterioration in range and amount eaten. Intact supportive family. No significant medical or mental health history	Always eaten limited range of foods with unwillingness to try new foods. Parents querying impact on growth and nutrition. Young person unable to sit at table when non-preferred foods present. Screams when parents put new food on table even if someone else eating it. Suspected autism, awaiting assessment. Healthy weight	Recent onset of avoidance of swallowing solid/textured foods, no previous eating difficulties outside of allergy management. Precipitated by series of mild choking incidents. Supportive school and parents, child motivated to eat preferred foods again
3	Main drivers identified as low interest and sensory based avoidance; likelihood of panic and depression identified	Main driver identified as sensory based avoidance	Main driver identified as swallowing phobia in the context of anaphylactic allergies
4	Primary risk: weight (77% median BMI) and physical health; supplement dependent. ARFID diagnosis confirmed	Primary risk: Some risk related to nutrition (protein, iron and certain vitamins); family functioning and impact (high levels of accommodation). ARFID diagnosis confirmed	Primary risk: Weight/growth/physical development (5% median BMI loss), social functioning (unable to eat with peers), family functioning (high levels of accommodation and reassurance-giving). ARFID diagnosis confirmed
5	Diagnosis accepted by family. Young person and parent priority to restore weight and be able to eat bigger portions. Young person additional goal of "not letting my emotions get in the way of eating". Young person and parent motivated to engage in treatment	Diagnosis accepted by family. Shared goals with parent to support young person to move to a more complete multivitamin/mineral supplement; for young person to be able to tolerate sitting at table with non-preferred foods present; to increase range of accepted foods	Diagnosis accepted by family. Collaboratively agreed goals to restore weight, gradually return to usual eating (textured/solid foods) and support parents in developing more confidence with managing their child's anxiety
6	Individual Habit Acquisition Training, including psychoeducation on early satiety (to establish regular eating and increase intake) & CBT intervention (to address thought & emotions leading to avoidance of eating). Focus on individual intervention with parents to joining reviews	Parent-led behavioural intervention. Graded exposure with rewards to encourage sitting at the table with non-preferred foods present. Similar graded exposure approach with rewards then used to build confidence in being able to try more complete multivitamin/mineral supplement and one or two new foods	Parent-led CBT intervention including anxiety psychoeducation, formulation of maintenance of eating difficulties, graded exposure to textured/solid foods with rewards, addressing parental responses to anxiety (reducing reassurance, accommodation), and broader parent-led anxiety management strategies. Regular weight/height monitoring. Young person joined at reviews to enhance engagement.
7	Regular eating established with some weight gain (median BMI 81%). Shared CBT formulation developed for maintenance of eating problems. Some emotion regulation strategies in place and thought challenging commenced. Progress on all parent and young person review measures. Continuation of psychological intervention and ongoing physical and dietary monitoring. After 12 sessions young person at 88% median BMI; physical symptoms all improved. Physical risk reduced. Agreed to continue to approximately 20 sessions with a focus on: further progress on original goals, consolidating changes made, relapse prevention, and parental input at regular reviews	Able to sit at the table with other foods present and had recently managed for first time to sit at a restaurant table. Had introduced several new foods, with some of these being good sources of protein and iron. Progress on all review measures.	Tolerating slightly more textured foods (2-step improvement on exposure hierarchy). Some weight restoration and growth in height. Parents more confident in knowing how to respond to anxiety. Progress on goal-based outcomes and all parent review measures
8		Agreed with parents that no further input needed at present. Parents reported as feeling confident about being able to gradually increase range without further sessions	Continuation of next block of 6 parent-led CBT intervention sessions and weight/height monitoring. After 12 sessions, child continues to tolerate more textured foods (4-step improvement on exposure hierarchy), weight restored and weight/growth-related risk reduced. Agreed to continue to 18 sessions with focus on continuing progress to usual eating goals and consolidating changes made. Additional goal of eating with peers in school added. Plan to review again at session 18
9	N/A	N/A	N/A
10	Discharged after 23 sessions over ten month period Maintaining a healthy weight, no longer using supplement drinks and no longer reporting eating as causing significant distress or as interfering with daily life	Discharged after five sessions over five month period Improved range of accepted foods and parent reporting reduced impact on family due to less family accommodation required. Young person no longer distressed when new foods presented	Ongoing

([Gunlicks-Stoessel & Mufson, 2011](#); [Lutz et al., 2014](#); [Raykos, Watson, Fursland, Byrne, & Nathan, 2013](#)). The use of measures (see [Table 1](#) for example) and feedback from the young person and parents allow for ongoing collaborative decision-making about treatment.

Step 8

If the review evidences progress, interventions agreed in Step 6 are continued as indicated. Regular reviews are helpful in ensuring treatment remains focused on the shared goals established at Step 5. Ongoing reviews also reduce the risk of therapist drift where a decrease in treatment adherence to theoretical model can lead to less effective care ([Waller & Turner, 2016](#)), often occurring in response to complexity and crises ([Schulte & Eifert, 2002](#)). Total number of treatment sessions required can vary significantly according to specific aspects of presentation.

Step 9

If there is a lack of progress or deterioration, the pathway moves from Step 7 to Step 9. Further consideration with the multi-disciplinary team may be required to review the formulation, identify barriers to change, consider whether alternative evidence-informed ARFID interventions might be indicated, or whether additional investigations or onward referral might be required. Other factors in the individual's systems or environment may have hindered progress, e.g. an unexpected loss or change in a parent's circumstances such as financial or health difficulties. Clinician and family expectations of rate of progress might need to be reconsidered and revised in relation to other aspects of the presentation, for example the presence of intellectual disability or autism. Autistic young people may require one or more of the recommended adaptations set out in [Table 4](#) in order to be able to fully access interventions offered. In individuals with longstanding eating difficulties, change may be limited or slow, but nevertheless significantly reduce risk.

Step 10

Once treatment goals have been reached and risk related to the eating behaviour reduced to a safe level, discharge (or onward referral as appropriate) can occur. Consideration is given to what is 'good enough' in terms of behavioural change. Conversations with families at Step 5 about realistic expectations and clear goal setting with time-limited interventions can greatly assist with this and serve to reduce risk of creating unhelpful dependency on the treating clinician or team ([Goode, Park, Parkin, Tompkins, & Swift, 2017](#)). There is variability in the likelihood and extent of anticipated change depending on specific aspects of presentation, to include whether eating difficulties are longstanding or have an acute onset, or the presence of features such as severe autism or intellectual disability. 'Good enough' can be conceptualised as having reached an appropriate level of improvement for the individual concerned that results in meaningful reduction in risk, impairment and distress ([Table 5](#)).

Next steps

We have shared our experience of developing and using a multi-disciplinary, multi-modal out-patient care pathway for children and young people with ARFID. We conceptualise this as an evidence-informed pathway, recognising that a truly evidence-based pathway is not yet possible, and use it to structure and guide our current practice. It sets out to assist clinicians in selecting interventions that represent a best fit in terms of varying factors in presentation of ARFID and in priorities for change, both in terms of risk and what is most important to those directly affected. The pathway requires testing, for example, through implementation trials in a range of health-care settings to assess its feasibility and clinical utility. This could be measured in many ways, including through feedback from clinicians in relation to ease of application, feedback from families in terms of acceptability and impact of clinical service received, positive shifts in measurable outcomes for patients, symptom reduction across different aspects of the ARFID presentation, etc. Components of the pathway might require adaptation to different circumstances and settings and the detail presented here is not intended to be prescriptive

We have not set out to answer the question of where a service for young people with ARFID should best 'sit', and would encourage priority to be given to the development of service structures and organisation that ensure relevant knowledge and clinical expertise can be integrated with families' needs to provide adequately comprehensive care. Delivery of health-care is changing; multi-disciplinary input does not necessarily involve all members of a team being located in the same place and virtual meeting platforms afford an opportunity for efficient and effective use of time. We anticipate that such frameworks will evolve over time in line with continued learnings from research, clinical experience, and the experiences and views of the family members involved.

Funding sources

This work was partially supported by the Children and Young People's Mental Health Programme, National Health Service (NHS) England and NHS Improvement [Avoidant Restrictive Food Intake Disorder (ARFID) in Children and Young People's Eating Disorders Community Pathway Project].

Disclosure of interest

The authors declare that they have no competing interest.

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