Maudsley Centre for Child and Adolescent Eating Disorders

NHS South London and Maudsley NHS Foundation Trust

Workshop on Formulation in ARFID

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Victorian Centre of Excellence in Eating Disorders Training - 26 March 2024

Webinar outline

- Introductions and context
- Brief recap on current assessment and treatment guidance for ARFID
- Moving from assessment to intervention –formulation and multi-disciplinary treatment planning
- Case example
- Questions and discussion as we go

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Assessment and treatment guidance

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Diagnosis and presentation

- ARFID occurs in children, adolescents and adults - onset can be acute or difficulties can be longstanding
- Weight can vary across the weight spectrum – from very low through to very high weight
- Risk and impact can occur across multiple domains
  - Physical
  - Nutritional
  - Psychosocial functioning
  - Family
- Diagnosis requires evidence of impairment

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Rationale for formulation-based approach

- ARFID is phenotypically heterogeneous – clinical presentations show considerable variability in features and domains of risk

- High reported rates of co-occurring conditions
  - can assist with understanding development and maintenance
  - adaptations may be required

- **Three examples** of reasons behind the observed avoidance/restriction embedded in the diagnostic criteria:

An **apparent lack of interest** in eating or food, e.g.:
-easily distracted
-high arousal
-poor interoceptive awareness
-low hunger drive

Avoidance based on **sensory** aspects of food, e.g.:
-temperature
-taste
-appearance/colour
-smell
-texture
-brand specificity

Concern re aversive consequences of eating, e.g.:
-specific fear of vomiting/choking/ discomfort, etc.
-traumatic association
-food 'neophobia'

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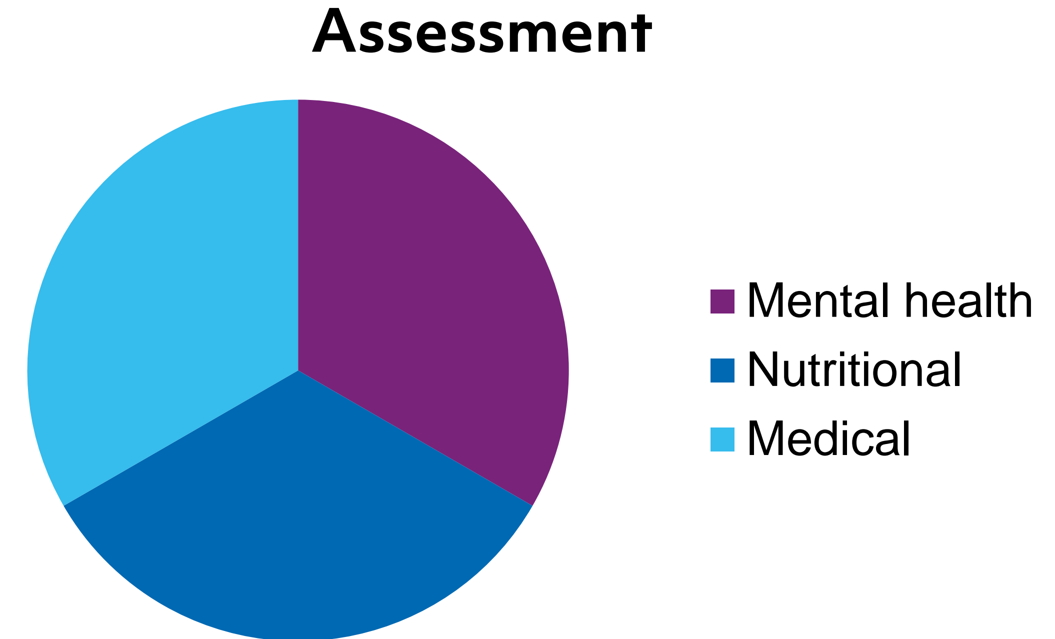
Consensus guidance on clinical assessment

- A mental health clinician should complete the diagnostic interviews and assessment of psychosocial impairment and functioning
- Nutritional/dietary assessment should determine the adequacy of dietary diversity, and caloric needs to maintain weight/growth and development



Eddy et al., IJED 2019, 52:361-366

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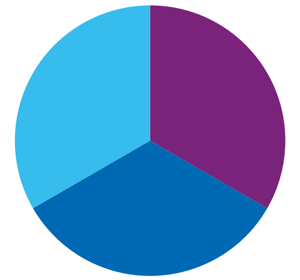
Consensus guidance on clinical assessment



- A medical professional is recommended to complete the medical assessment of avoidant/restrictive eating
- This should include a physical assessment to ascertain weight/growth status, eating history, and assessment of acute and potential long-term medical and nutritional complications of avoidant/restrictive eating such as sequelae of low weight or obesity, as well as malnutrition, which can occur in individuals with ARFID across the weight spectrum
- Medical assessment should also explore presence of underlying systemic or gastrointestinal disorders which may contribute to the onset or persistence of ARFID or may explain the presentation
- Additional opinion and input from specialists may be needed for some – e.g. swallow evaluation, gastroenterology opinion, assessment of sensory processing

Eddy et al., IJED 2019, 52:361-366

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Diagnostic items to cover

- Current eating behaviour, current intake, and onset/trajectory of difficulties
- Factors driving the avoidance/restriction - to include interest in food and eating, sensory based avoidance, and concerns related to eating
- Impact of avoidance/restriction and related risk – to include on weight and height (BMI/BMI centile), nutritional adequacy of intake and any deficiencies, oral supplement or tube feed dependency, and impact on social/emotional functioning
- Ruling out other explanatory causes – to include specific personal circumstances and context; presence of another eating disorder related to weight/shape concerns; presence of other medical or mental disorder(s) than could account for clinical picture

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Current consensus on treatment

- "For all eating disorders (including ARFID), the main treatment as delineated in the current national and international guidelines is a form of **psycho-behavioural therapy** which can most usually be provided on an **outpatient basis**"

- "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**"

- "Research is urgently needed for ……ARFID" (Current approach to eating disorders: a clinical update. Hay P. Intern Med J. 2020 Jan; 50(1):24-29)

- "Each patient with ARFID presents with a unique set of medical, nutritional and psychological factors that requires an **individualized and multi-disciplinary approach** in the management of this difficult to treat disorder" (Fisher et al., Curr Gastroenterol Rep 2023;25:421-429)

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Psycho-behavioural treatment developments

Case Reports > Int J Eat Disord. 2019 Apr;52(4):466-472. doi: 10.1002/eat.22996. Epub 2018 Dec 31.

Feeling and body investigators (FBI): ARFID division-An acceptance-based interoceptive exposure treatment for children with ARFID

Nancy L Zucker[1,2], Maria C LaVia[3,4], Michelle G Craske[5,6], Martha Foukal[2], Adrianne A Harris[1,2], Nandini Datta[1], Erik Savereide[2], Gary R Maslow[2]

> Int J Eat Disord. 2020 Oct;53(10):1623-1635. doi: 10.1002/eat.23341. Epub 2020 Jul 27.

SPACE-ARFID: A pilot trial of a novel parent-based treatment for avoidant/restrictive food intake disorder

Yaara Shimshoni[1], Wendy K Silverman[1], Eli R Lebowitz[1]

Review > Curr Opin Psychiatry. 2018 Nov;31(6):425-430. doi: 10.1097/YCO.0000000000000454.

Cognitive-behavioral treatment of avoidant/restrictive food intake disorder

Jennifer J Thomas[1,2], Olivia B Wons[1,3], Kamryn T Eddy[1,2]

> Behav Anal Pract. 2023 Jul 6;17(1):176-188. doi: 10.1007/s40617-023-00821-0. eCollection 2024 Mar.

Evaluating a Treatment Package for Avoidant/Restrictive Food Intake Disorder to Increase Food Variety

Ashley S Andersen[1], Meeta R Patel[1,2]

Case Reports > Int J Eat Disord. 2019 Apr;52(4):447-458. doi: 10.1002/eat.23053. Epub 2019 Feb 25.

A new cognitive behavior therapy for adolescents with avoidant/restrictive food intake disorder in a day treatment setting: A clinical case series

Eric Dumont[1,2], Anita Jansen[1], Diana Kroes[2], Eline de Haan[2], Sandra Mulkens[1,3]

Randomized Controlled Trial > Int J Eat Disord. 2019 Jun;52(6):746-751. doi: 10.1002/eat.23077. Epub 2019 Mar 29.

Feasibility of conducting a randomized clinical trial using family-based treatment for avoidant/restrictive food intake disorder

James Lock[1], Shiri Sadeh-Sharvit[2], Alexa L'Insalata[1]

Most promising psychological interventions:
CBT – individual or parent-led; Behavioural approaches; Family interventions

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Treatment

- Variability in ARFID presentations seems suggests that a range of treatment approaches may be required, with appropriate adaptations as indicated
- A range of types and intensities of psychological intervention are showing promise – but there remains no large scale RCT evidence, with evidence underpinning any guidance classified as 'weak'
- Caution needed in generalisability of emerging findings across ARFID populations and presentations

Consensus around need for multi-disciplinary assessment and treatment with multi-modal management

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Moving from assessment to treatment planning

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Formulation

The 5-P model

Predisposing
Precipitating
Presenting
Perpetuating
Protective

Explore → Understand → Accept → Challenge → Change

Exotic
Underwear
Always
Causes
Chaos

Bryant-Waugh, R. (2006)
Pathways to recovery: Promoting change within a developmental systemic framework.
Clinical Child Psychology and Psychiatry 11: 213-224

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Evidence Based Practice

The integration of clinical expertise, patient values, and best research evidence into the decision-making process for patient care

Best research evidence - usually found in clinically relevant research, conducted using sound methodology

Clinical expertise – clinicians' cumulated experience, education and clinical skills

The patient brings to the encounter **his or her own personal preferences** unique concerns, expectations, and values

Sackett D, 2002; Peterson et al 2016

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Journal of Behavioral and Cognitive Therapy (2021) 31, 15—26

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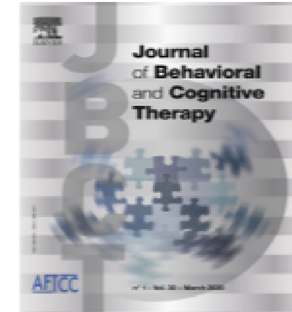
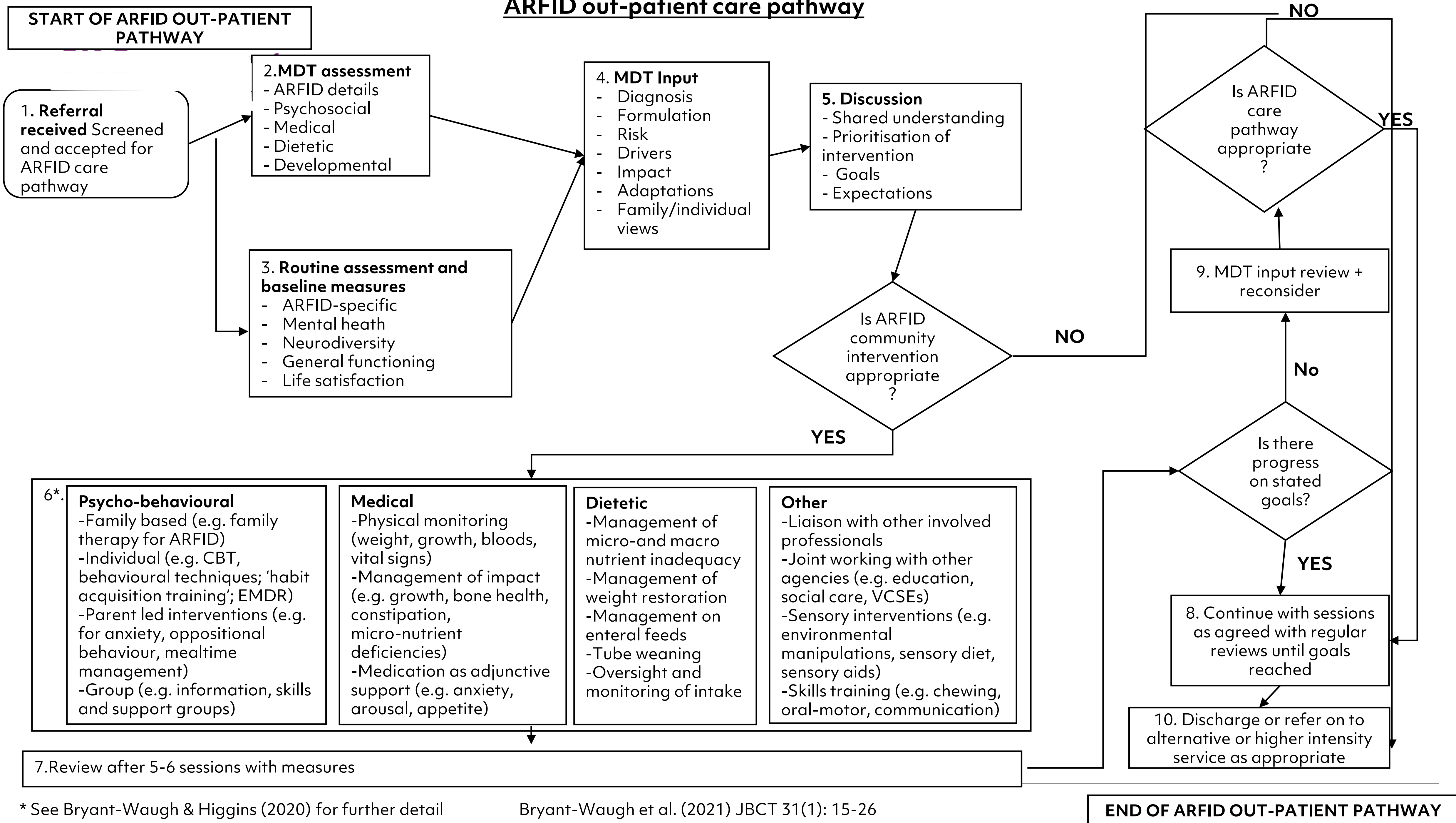


RESEARCH PAPER

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

Rachel Bryant-Waugh[a,b,*], Rachel Loomes[a], Alfonce Munuve[a], Charlotte Rhind[a]


ARFID out-patient care pathway
START OF ARFID OUT-PATIENT PATHWAY
1. Referral received Screened and accepted for ARFID care pathway
2.MDT assessment
- ARFID details
- Psychosocial
- Medical
- Dietetic
- Developmental
3. Routine assessment and baseline measures
- ARFID-specific
- Mental heath
- Neurodiversity
- General functioning
- Life satisfaction
4. MDT Input
- Diagnosis
- Formulation
- Risk
- Drivers
- Impact
- Adaptations
- Family/individual views
5. Discussion
- Shared understanding
- Prioritisation of intervention
- Goals
- Expectations
Is ARFID community intervention appropriate ?
NO
YES
Is ARFID care pathway appropriate ?
NO
YES
9. MDT input review + reconsider
No
Is there progress on stated goals?
YES
6*.
Psycho-behavioural
-Family based (e.g. family therapy for ARFID)
-Individual (e.g. CBT, behavioural techniques; 'habit acquisition training'; EMDR)
-Parent led interventions (e.g. for anxiety, oppositional behaviour, mealtime management)
-Group (e.g. information, skills and support groups)
Medical
-Physical monitoring (weight, growth, bloods, vital signs)
-Management of impact (e.g. growth, bone health, constipation, micro-nutrient deficiencies)
-Medication as adjunctive support (e.g. anxiety, arousal, appetite)
Dietetic
-Management of micro-and macro nutrient inadequacy
-Management of weight restoration
-Management on enteral feeds
-Tube weaning
-Oversight and monitoring of intake
Other
-Liaison with other involved professionals
-Joint working with other agencies (e.g. education, social care, VCSEs)
-Sensory interventions (e.g. environmental manipulations, sensory diet, sensory aids)
-Skills training (e.g. chewing, oral-motor, communication)
8. Continue with sessions as agreed with regular reviews until goals reached
7.Review after 5-6 sessions with measures
10. Discharge or refer on to alternative or higher intensity service as appropriate
END OF ARFID OUT-PATIENT PATHWAY
* See Bryant-Waugh & Higgins (2020) for further detail
Bryant-Waugh et al. (2021) JBCT 31(1): 15-26

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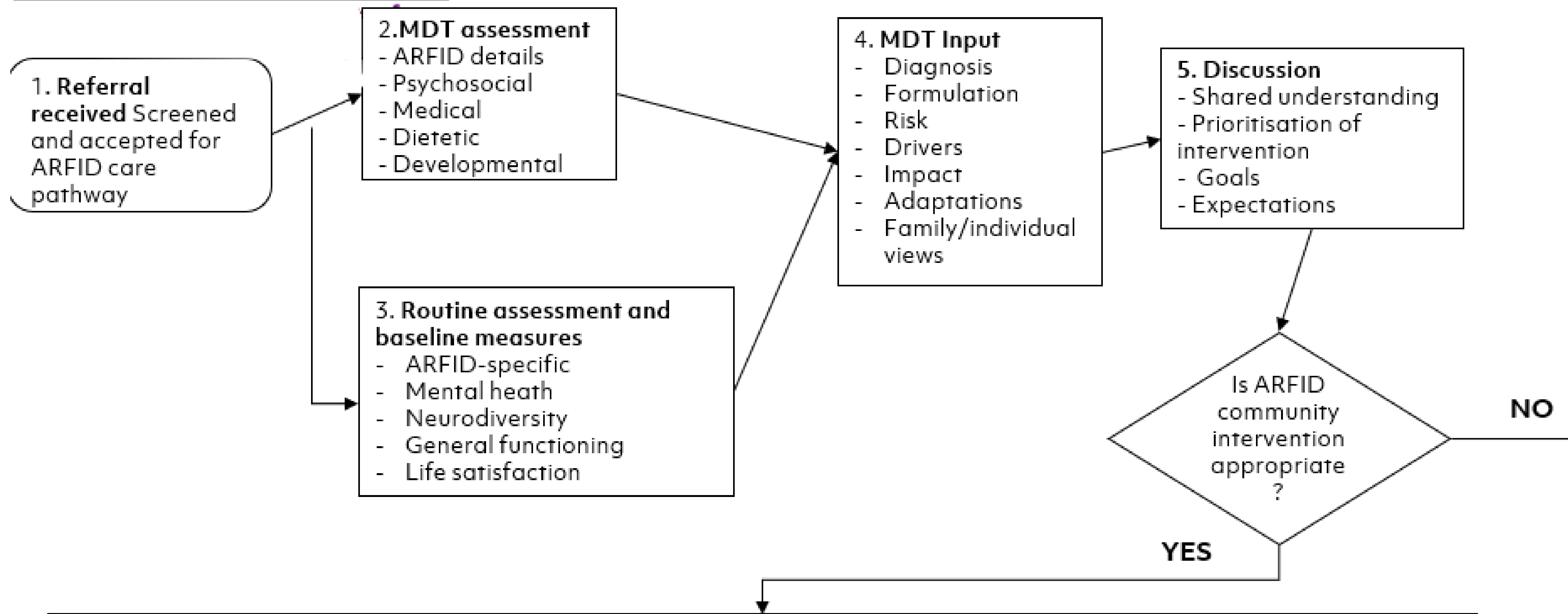

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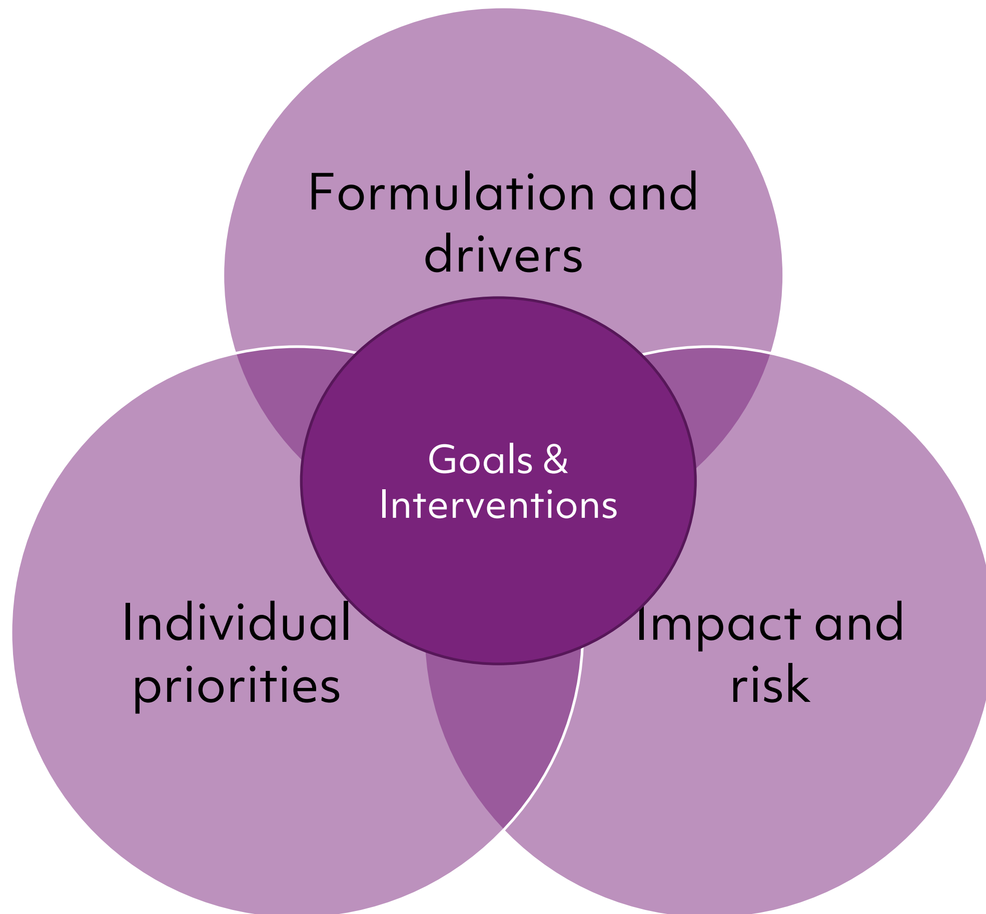
Agreeing goals for behavioural change



Assessment information and individual/family hopes are integrated with MDT perspectives and concerns to arrive on a set of shared goals that aim to change eating behaviour in a focussed way

This then contributes to improvements in

- physical state
- nutritional adequacy
- mental health and well-being/ psycho-social functioning

in an appropriate way for that individual

ARFID Risk Domains – Clinican rated

Please rate all domains on a scale from 0 to 4

0 = no risk identified
1 = some risk but not of immediate concern
2 = moderate risk requiring consideration when prioritising intervention
3 = high risk requiring planned action
4 = very high risk requiring immediate action

1. Weight, growth and physical development ☐
2. Nutritional adequacy of diet ☐
3. Impact on YP's social and emotional development ☐
4. Impact on family functioning ☐

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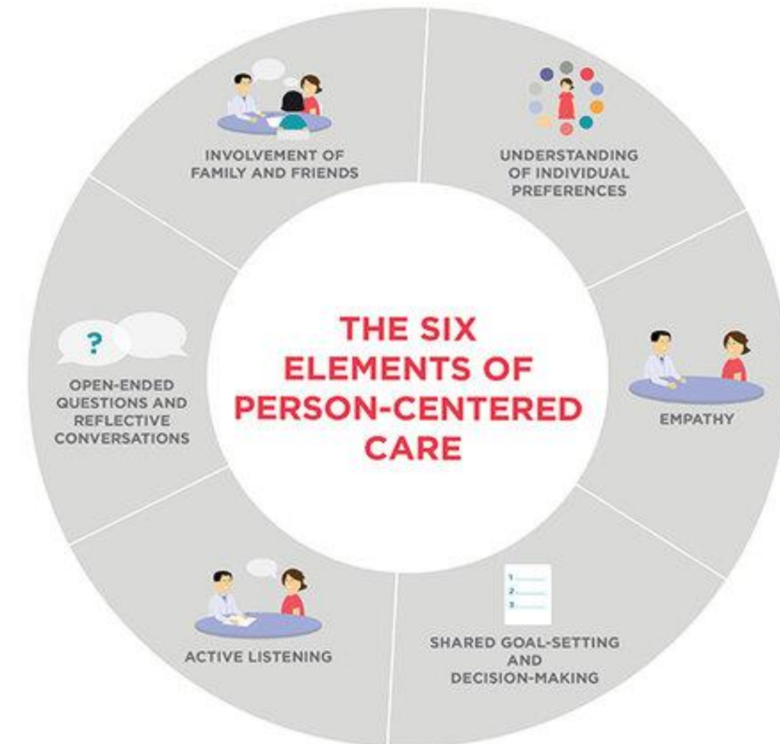
Impact and individual and family priorities

What Matters To Me - A Person Centred Outcome Measure (PCOM) developed with parents of children with ARFID
https://mccaed.slam.nhs.uk/professionals/resources/featured-resources/

- 41 items derived from parent/carer views and experiences - used to determine parental concerns their experience of impact, and what they would like to address



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Drivers of avoidance/restriction

- **PARDI-AR-Q –** Pica ARFID Rumination Disorder – ARFID Section Questionnaire https://mccaed.slam.nhs.uk/professionals/resources/featured-resources/

- Two versions: self 14+ and parent/carer 4+ - both 32 items (cf. EDE-Q)
- Simple rating instructions capturing aspects of presentation

- Diagnostic prediction: YES /NO
- Severity of impact: 0-6

- Sensory based avoidance: 0-6
- Lack of interest: 0-6
- Concern about aversive consequences: 0-6

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Clinically informed decision making

Main driver(s) of avoidance/restriction		
Low interest in food or eating	**Sensory-based avoidance**	**Concern about aversive consequences**
Engagement/ psycho-ed and motivation		
Learning /habit acquisition training - structure/routine	Exposure/behavioural approaches	Systematic desensitization
Arousal regulation	Food scientist/food chaining/tiny tastes	Anxiety management/ trauma-based approaches
Improving attention and focus	Disgust management /confidence building /coping with the unexpected	Cognitive Behavioural or family-based approaches
Support from family/significant other		

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Adapted from: ARFID: a guide for parents and carers. Bryant-Waugh (2019)

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Consideration of co-occurring conditions and context

- Autism
- Attention deficit hyperactivity disorder
- Intellectual disability

- Anxiety disorders
- Obsessive compulsive disorder
- Other mental health conditions

- Contextual family factors, including:
  - Poverty
  - Parental mental and physical health conditions
  - Parental ID
  - Sociocultural factors

- Medical conditions, including:
  - Gastro-related
  - Allergies
  - Other (e.g. epilepsy)

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Common goals for behavioural change

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

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Multi-disciplinary, multi-modal management

Psycho-behavioural	Medical	Dietetic	Other
-Family based (e.g. family therapy for ARFID) -Individual (e.g. CBT, behavioural techniques; 'habit acquisition training'; EMDR) -Parent led interventions (e.g. for anxiety, oppositional behaviour, mealtime management) -Group (e.g. information, skills and support groups)	-Physical monitoring (weight, growth, bloods, vital signs) -Management of impact (e.g. growth, bone health, constipation, micro-nutrient deficiencies) - Medication as adjunctive support (e.g. anxiety, arousal, appetite)	-Management of micro-and macro nutrient inadequacy -Management of weight restoration -Management on enteral feeds -Tube weaning -Oversight and monitoring of intake	-Liaison with other involved professionals -Joint working with other agencies (e.g. education, social care, VCSEs) -Sensory interventions (e.g. environmental manipulations, sensory diet, sensory processing aids) -Skills training (e.g. chewing, oral-motor, communication)

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Bryant-Waugh et al. (2021) JBCT 31(1): 15-26

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Key questions to improve intervention decisions

WHAT - What is main priority to work on? - related to risk and impact

HOW – What is the main mechanism/driver maintaining the difficulty? - to inform intervention approach

WHO – Who are most appropriate people to with? - e.g. individual, parents/carers, couple, whole family, groups, school staff?

WHEN – When will it be enough? – to ensure realistic expectations about change

Keep the care plan simple, clear and meaningful to all concerned

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Case example

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Case example X: Background

Nearly-18 autistic YP with longstanding avoidant/restrictive eating, mixed anxiety disorder, gender dysphoria

Reason for referral: concerns with ongoing weight loss since d/c from adolescent unit. Highest wt equivalent to 85%/BMI 17.3 aged 16. At referral wt equivalent to 65%/BMI 13.7. Wt loss continuing despite comprehensive local care package (physical monitoring, dietetic input/supplement drinks, 2x/week psychology and occupational therapy input, parental support, outreach visits, multi-agency meetings). Local team seeking advice on least restrictive approaches as alternative to another admission.

History: longstanding history of restricted/limited eating (low interest & sensory sensitivities texture/taste/smell since infant). Always low on weight and growth centiles but weight gradually declined in recent years.

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Case example X: Assessment

Current food intake: irregular (between 2-5 times p/day), eats until feels full - stops early/incomplete meals. Selective and brand-specific but eats broadly from main food groups.

Drivers: longstanding low appetite/interest/feeling sick easily (associated with poor interoceptive awareness), fear-based avoidance (fear of fullness/being sick if too full – more so in recent months), sensory-based avoidance (texture, taste, smell - relatively well managed).

Other factors detected in Ax: smell sensitivity affecting where able to eat. Difficulties perpetuated by perceived pressure from others and 'problem-saturated narrative' around eating

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Case example X: Assessment

Family – multiple family pressures in history as well as family member mental health difficulties

Medication: SSRI, melatonin

No significant medical Hx

YP's goals: to gain weight and to learn limits of hunger

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Intervention plan

ASC/interoception/

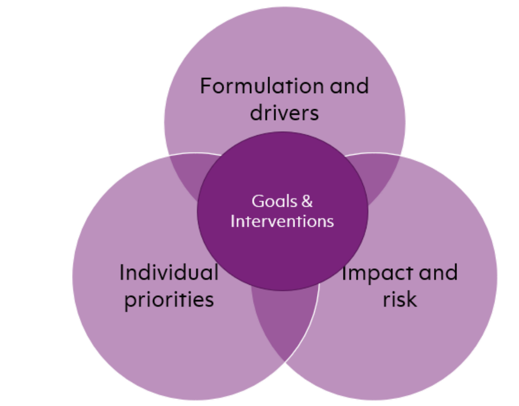
low interest/fear-based

Increase wt & fluid PE/HAT/ CBT ico ASC

Gain wt/limits of hunger

Low weight/fluid/

withdrawal



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Case example X: Treatment recommendations

Time limited (until 18) including:

1) psych-ed (incl. impact of chronic under-eating on hunger/appetite and vicious cycle) and motivational work
2) HAT (phone reminders - YP taking more age-appropriate ownership, need to have a go and eat in spite of hunger. NB: YP feeling in control/charge seemed really important here)
3) CBT-principles and noticing when YP panicking at feeling full with strategies to get calm and carry on. NB: starting with positive formulation seemed key for YP given the problem-saturated narrative and perceived pressure from clinical professionals. Also rating hunger/fullness, being more curious about body sensations.

Other aspects of intervention: Adjustments re smell sensitivity; Swap of SSRI (reduce nausea side effect); Continued physical monitoring by local team

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Case example X: Outcomes/key learning

9 sessions offered, attended (including 1 network meeting)

Progress to weight gain goal: stabilised weight loss and slow but sustained weight gain up to 71%/BMI of 15.7 (up 4.5kg from 65%/BMI 13.7)

YP reported positive shift in attitude towards food/eating and feeling motivated to continue, no longer needing reminders from others. Progress to goal of understanding more about limits (around feeling full). YP reported learning: knowing the difference between 'fake full' (i.e. low appetite) and 'real full' (at limits/genuinely had enough). Knowing that when it's 'fake full' – "I need to push through"

YP also said they updated their relationship to eating – they said if they were to personify their relationship with food: "me and eating might not get along but we can be civil".

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Q&A

Thank You

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