



*Time to win  
the race against  
eating disorders!*

# Learning About FREED

## First Episode Rapid Early Intervention for Eating Disorders

**Ulrike Schmidt, MD PhD FRCPsych**  
**Professor of Eating Disorders, KCL**  
Email: [ulrike.schmidt@kcl.ac.uk](mailto:ulrike.schmidt@kcl.ac.uk)



**@FREEDfromED**  
**@EDIFYresearch**

# Talk Map

## Introduction to Eating Disorders (EDs)

### The Story of FREED

- Rationale, Model & Data
- National Roll-Out (during COVID)

### Next Steps:

- **FREED-Mobile:** Intervening earlier
- **EDIFY:** Delineating Illness & Recovery Trajectories



EDIFY

# The Spectrum of Eating Disorders

An Extension to the Global Burden of Diseases Study

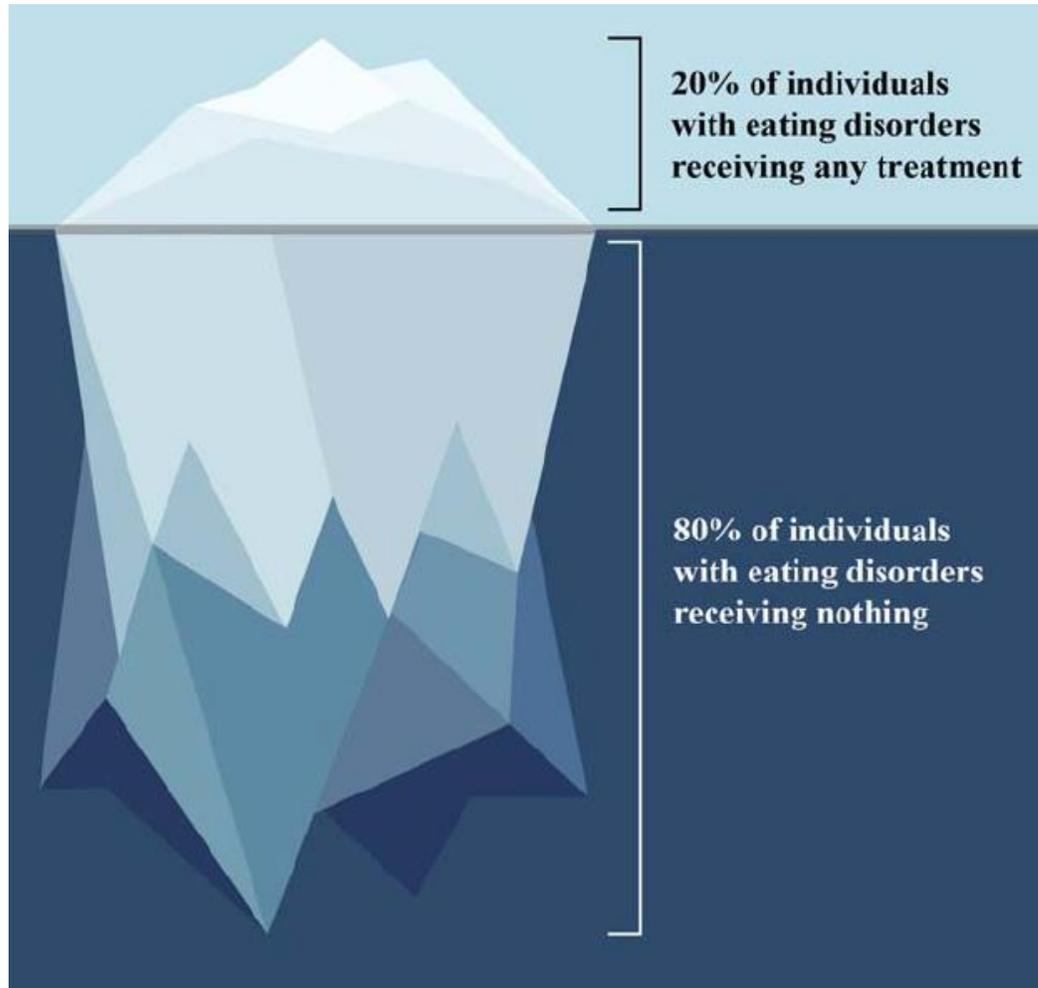
Santomauro et al., Lancet Psychiatry 2021



For review see: Treasure, Duarte & Schmidt (2020) Lancet; Giel, ...Schmidt et al. (2022) Nature Rev Dis Primers

# Eating Disorders (EDs) Treatment Gaps and Delays

## Treatment Gaps



## Treatment Delays

**Average duration of untreated eating disorder (DUED) (i.e. time from onset to first evidence-based treatment):**

- Anorexia Nervosa (AN) = 29.9 months
- Bulimia Nervosa (BN) = 53.0 months
- Binge Eating Disorder (BED) = 67.4 months

**We are a long way away from delivering early intervention!**

# Eating Disorder Services for Young People are Disjointed

Median Age of Onset for Different Psychiatric Disorders



Solmi et al., 2021



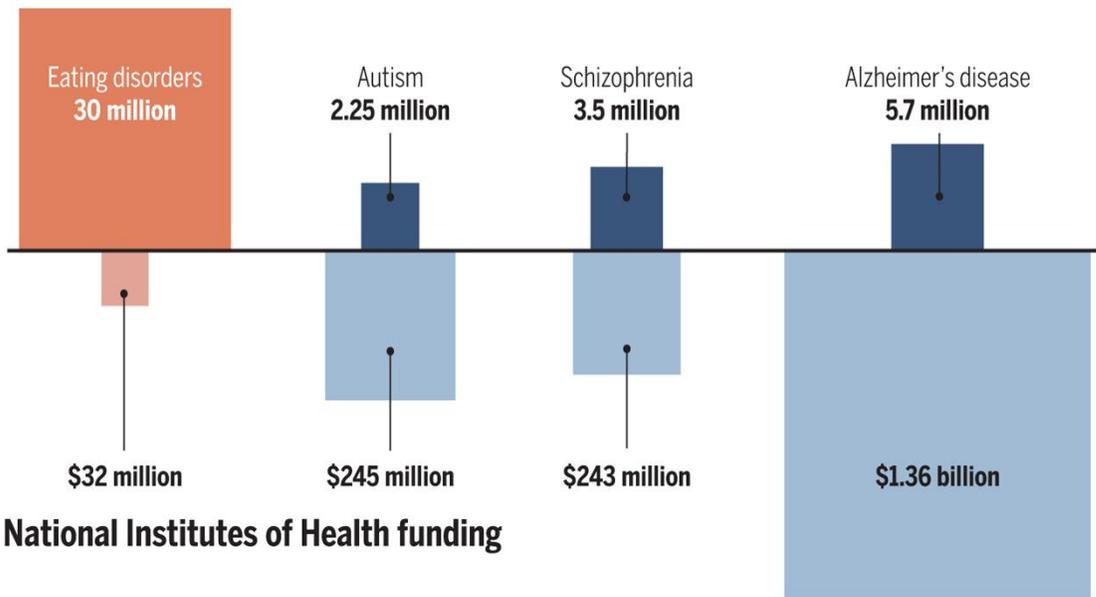
You have reached your 18<sup>th</sup> birthday & your care will be transferred!



# Eating Disorders Research Has Been Severely Underfunded

## Research Funding for Mental Disorders

Individuals affected



National Institutes of Health funding



Cousin-Frankel (2020) Science; Guy et al. (2022) BJPsych;

[www.beateatingdisorders.org.uk/about-beat/policy-work/all-party-parliamentary-group-appg-on-eating-disorders/](http://www.beateatingdisorders.org.uk/about-beat/policy-work/all-party-parliamentary-group-appg-on-eating-disorders/)

# The Story of FREED

## First Episode Rapid Early Intervention for EDs

Nineteen-year-old who died from anorexia 'failed by every NHS organisation that cared for her'

Teenagers 'deterioration and death were avoidable', says ombudsman

Jennifer Cockrell | Friday 8 December 2017 01:00 GMT | 19 comments



Like Click to follow



Ignoring the alarms:  
How NHS eating disorder  
services are failing patients



I AM WAITING

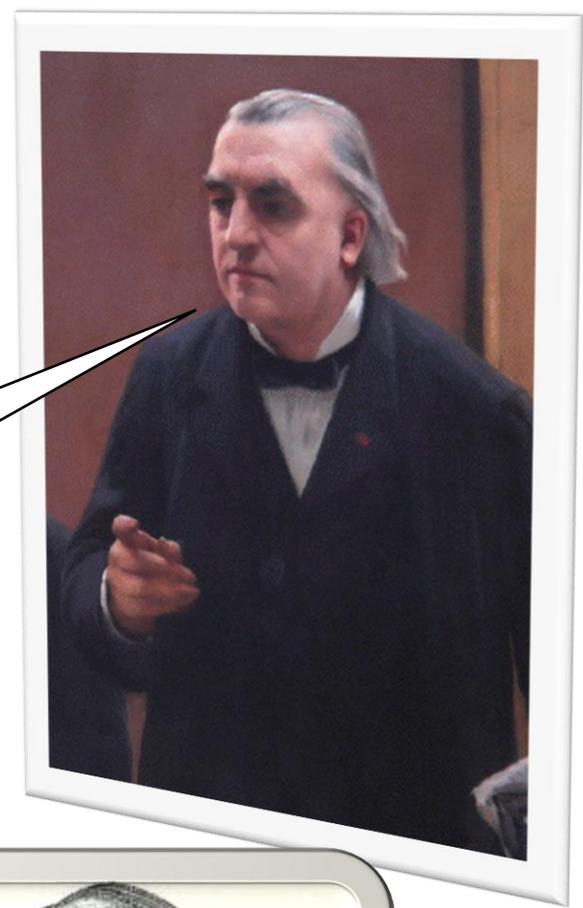
How good a fit is the psychosis model of high risk, early stage, late stage illness for eating disorders?



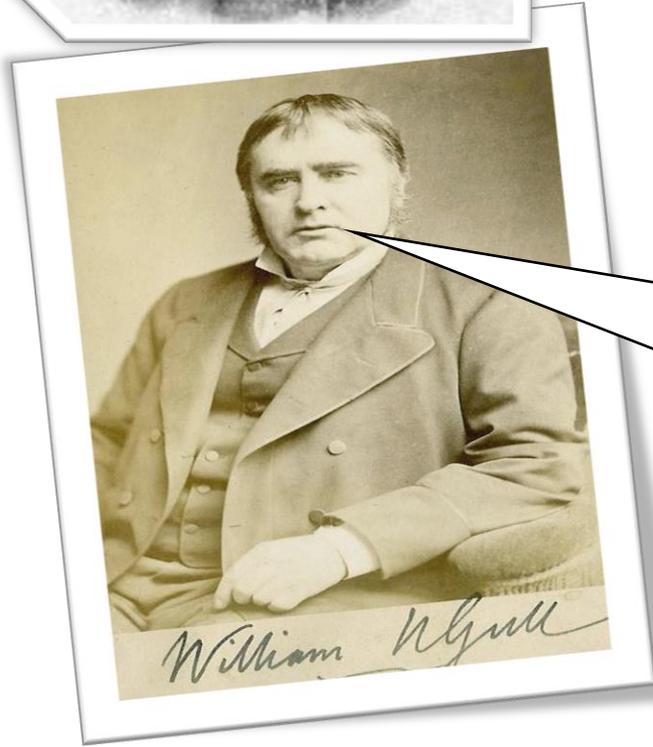
# Historical Evidence



*Woe to the physician who, misunderstanding the peril, treats (it) as a fancy without object or duration....*



*Persuade the parents to undertake energetic measures at the beginning and not wait until the disease has taken deep root.*

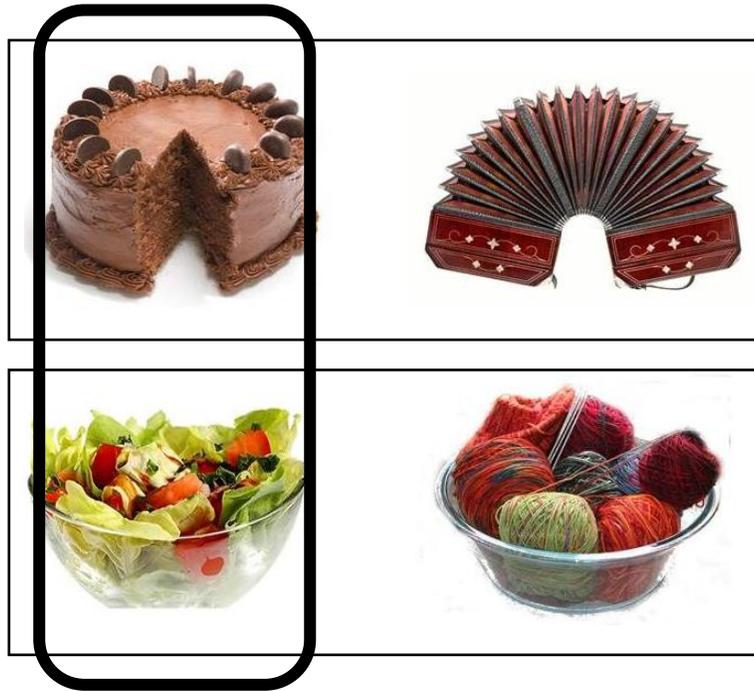


*Early active intervention with regular nourishing foods, application of warmth, & control of restless activity, plus a dessert spoon of brandy every 2-3 hours.*

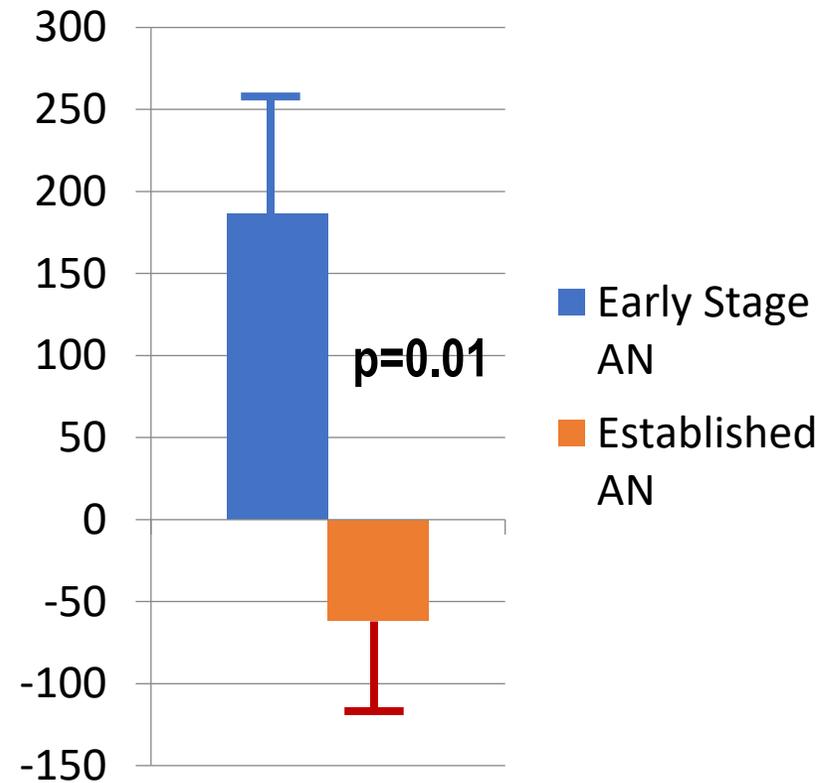




# Attention to Food Stimuli in Early Stage vs Established AN: An Eye-Tracking Study



Gaze Duration Bias: Food/Non-Food



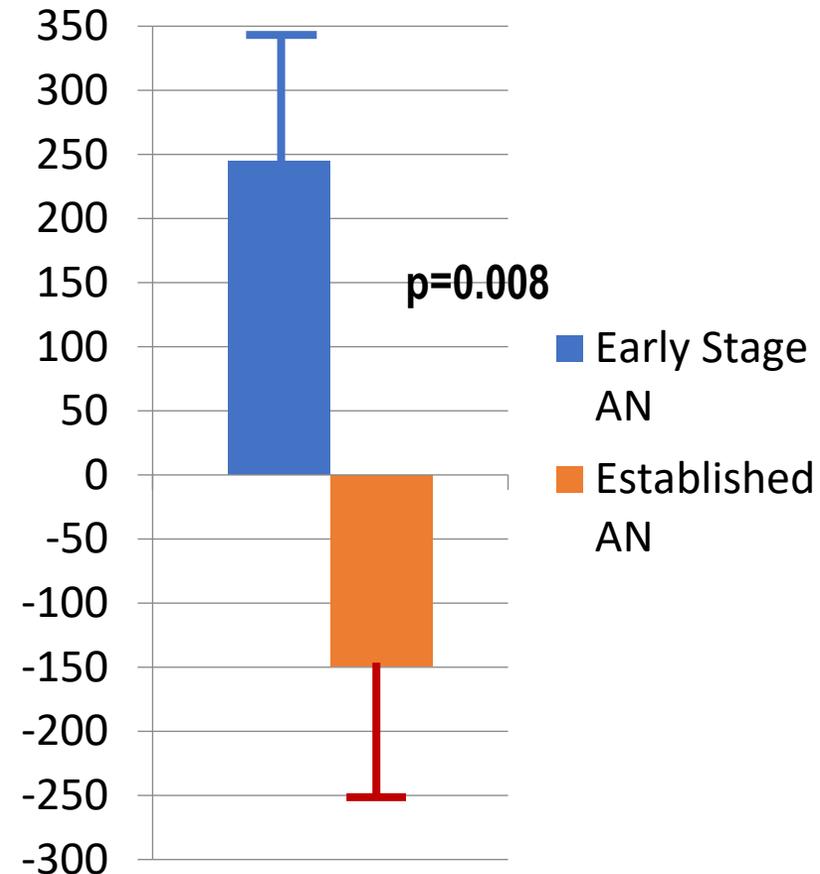


# Attention to Food Stimuli in Early Stage vs Established AN

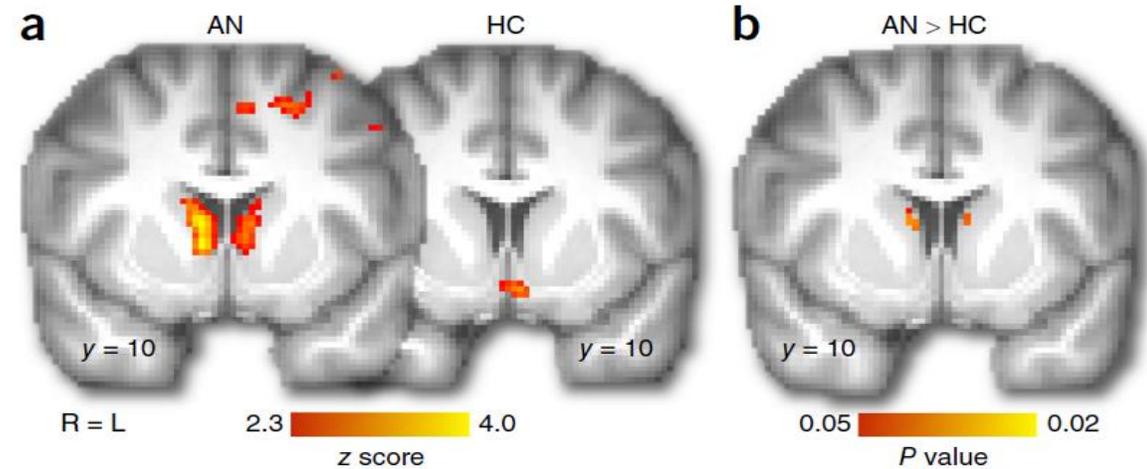
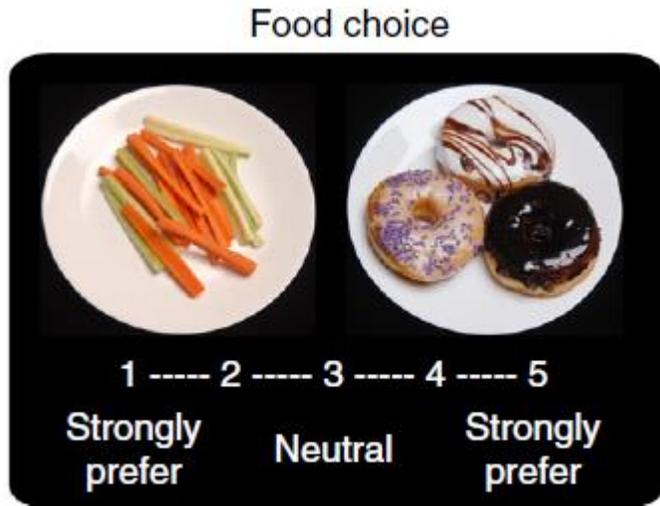


**Conclusion: In AN attentional bias away from food develops over time, making it easier not to eat**

## Gaze Duration Bias: High Calorie Food



# Neural Systems Involved in Maladaptive Food Choices in AN



- AN participants engage the dorsal striatum more than HC when making choices about what to eat.
- In AN, activation in fronto-striatal circuits was correlated with food consumption the following day.
- Dorsal striatum has a critical role in learned automatic behaviours.

## Conclusion:

- **Food choices in AN become a ‘bad habit’ which makes them hard to shift**
- **NB – Additional evidence in AN suggests that the strength of ED related habits strongly correlates with illness duration**

# FREED

## Early Intervention for EDs



ADULTING  
PLEASE WAIT...

### Aims:

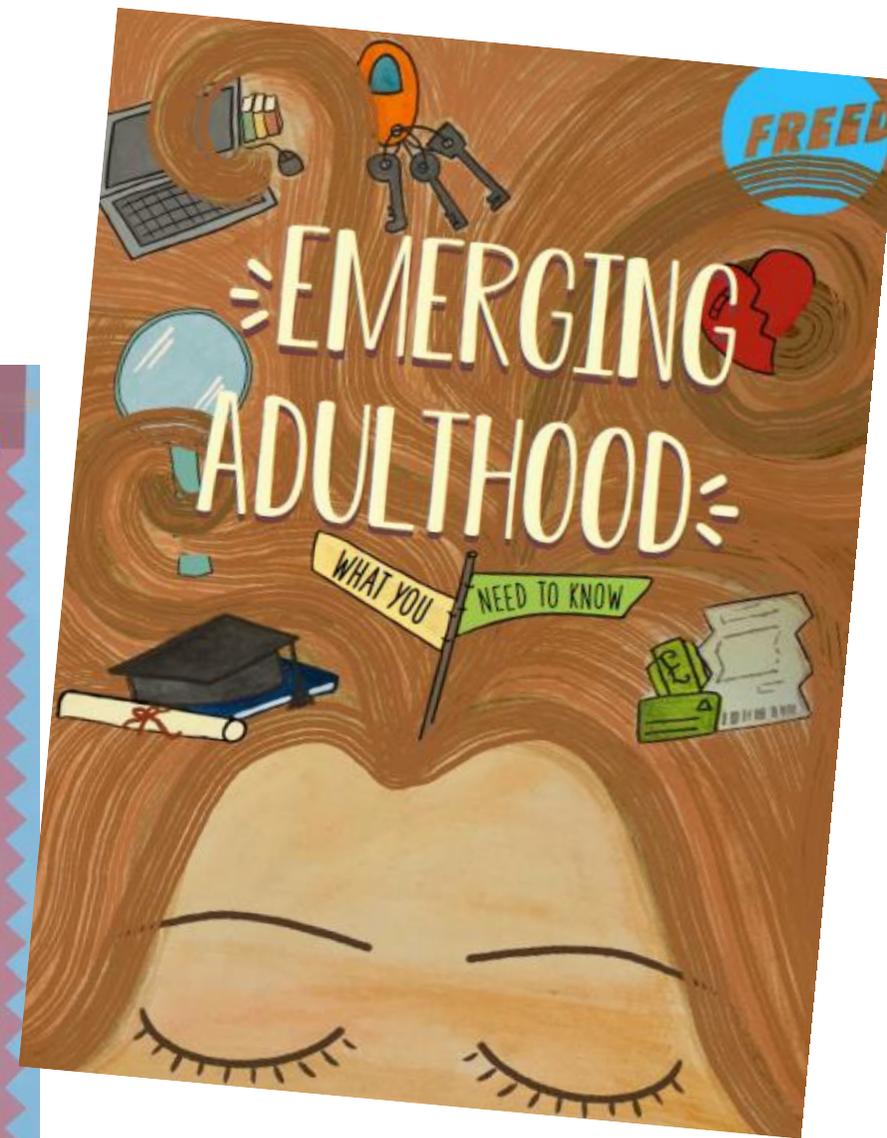
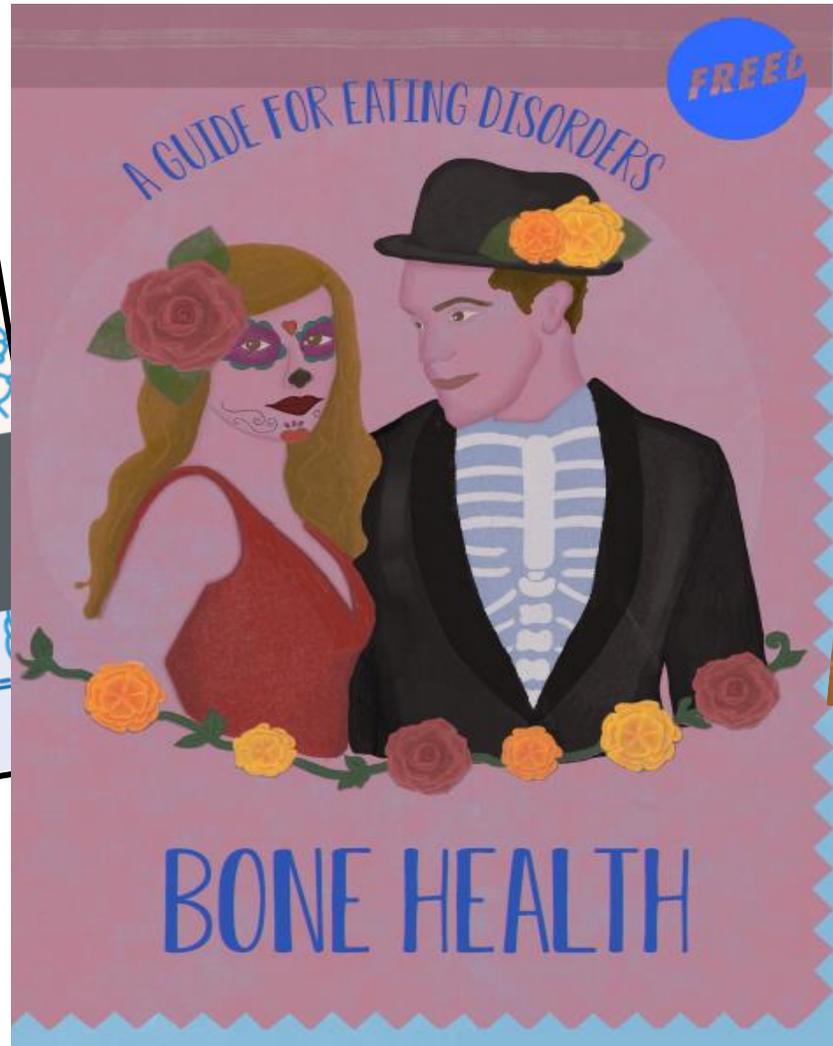
- Provide developmentally & stage appropriate services for young people (aged 16-25) with recent onset ED (<3 years duration)
- Reduce Duration of Untreated ED (DUED) & improve outcomes





# The Model

Components	
<b>Structure</b>	Service-within-a-service <ul style="list-style-type: none"><li>• FREED champion with protected time</li><li>• Mini-team</li></ul>
<b>Processes &amp; Procedures</b>	<ul style="list-style-type: none"><li>• Waiting time targets</li><li>• Screening call within 48 hours of referral</li><li>• FREED-patient tracker for prioritisation</li><li>• Weekly huddles and supervision</li></ul>
<b>Content</b>	Evidence-based treatments with youth-friendly adaptations, e.g.: <ul style="list-style-type: none"><li>• Focus on malleability of brain changes → highlighting need for early nutritional action</li><li>• Involvement of parents where possible</li><li>• Explore social media use</li><li>• Focus on managing ‘adulthood’, incl. identity development &amp; transitions</li></ul>
<b>Style</b>	<ul style="list-style-type: none"><li>• Person-centred &amp; youth friendly</li><li>• Motivational</li></ul>



[www.FREEDfromED](http://www.FREEDfromED)



# Two Quasi-Experimental Studies: FREED-Pilot and FREED-Up

## AIMS:

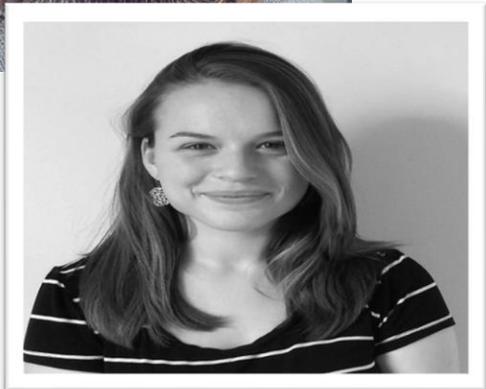
## Effectiveness:

Compared to treatment as usual (TAU) is FREED able to improve:

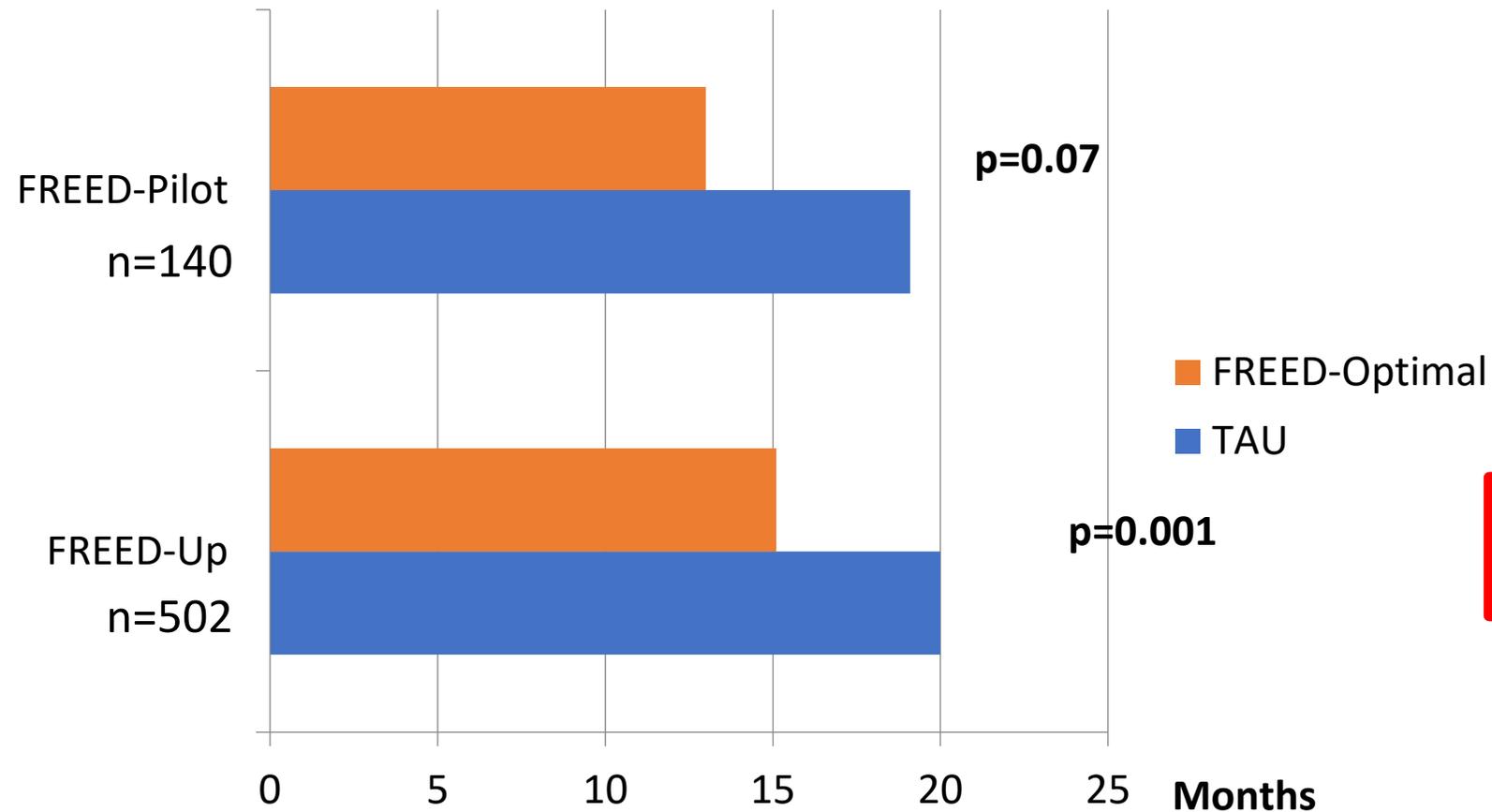
- Duration of untreated ED (DUED) & waiting times?
- Treatment uptake?
- Clinical outcomes?

Is FREED cost-effective?

What are the views of patients on FREED?

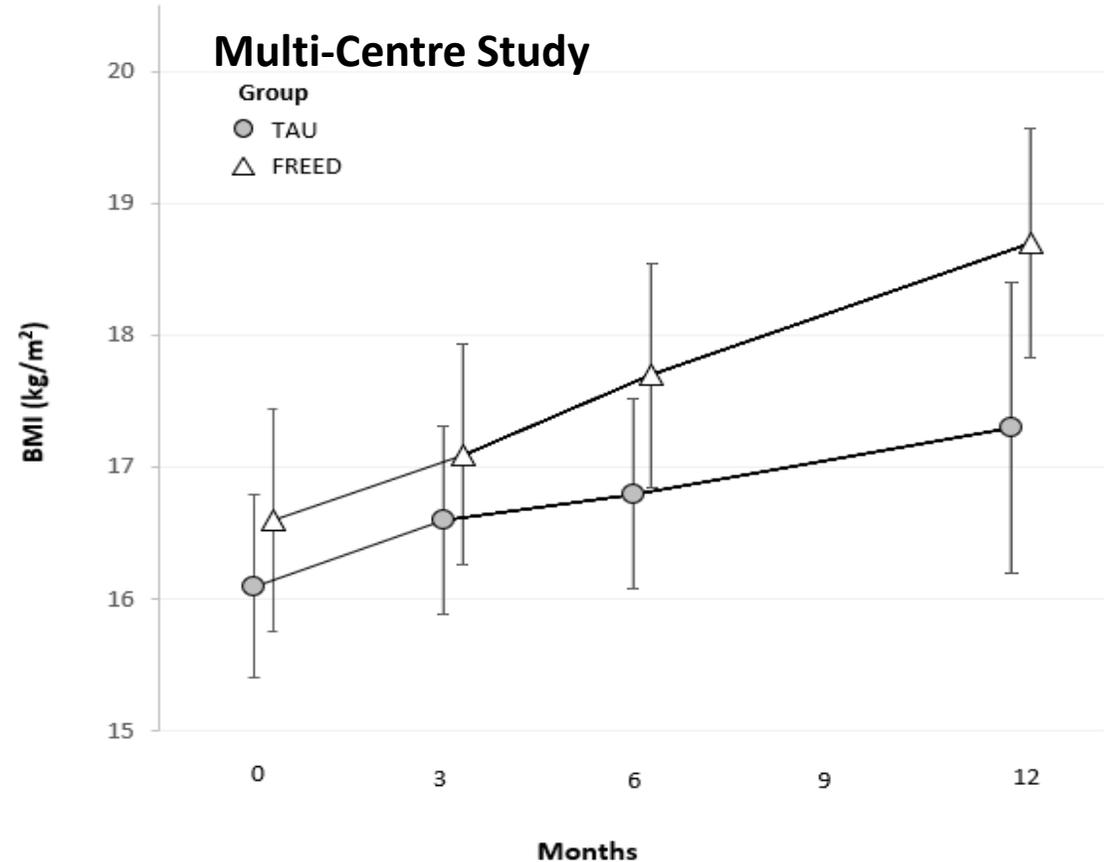
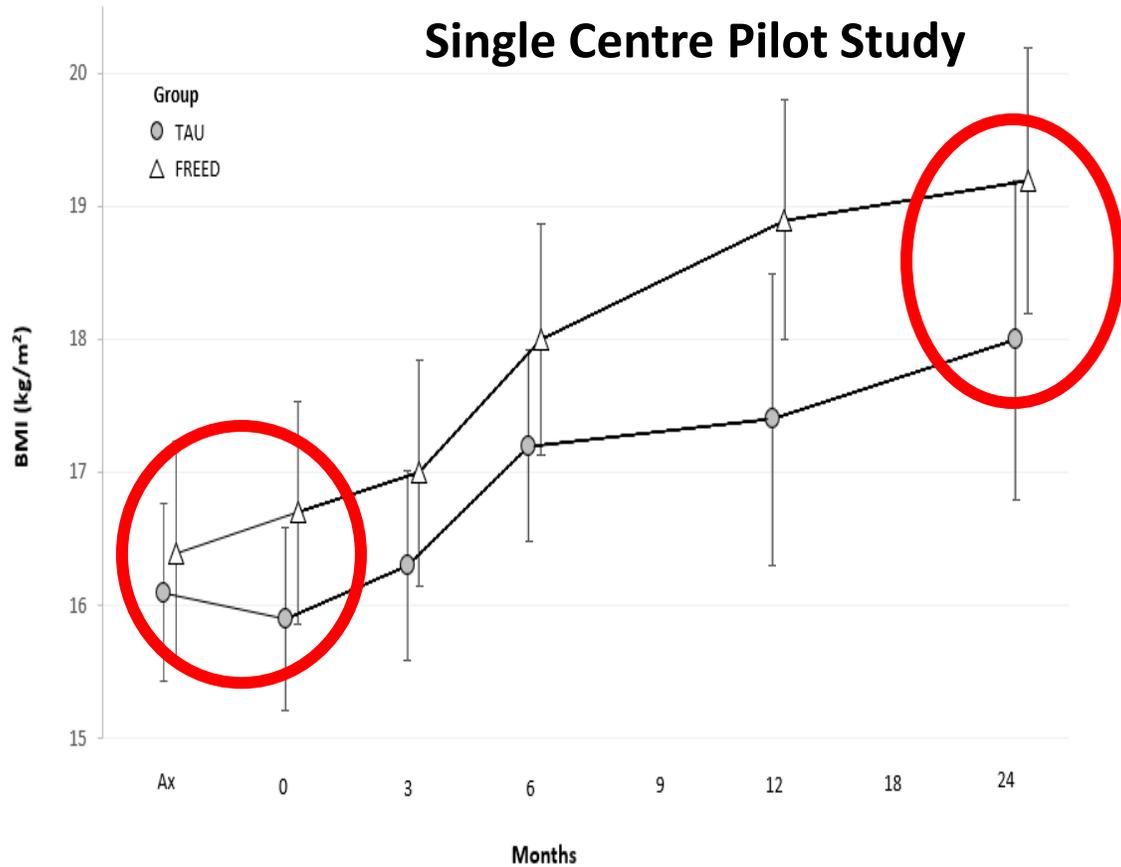


# Duration of Untreated ED (DUED) in FREED vs Treatment as Usual (TAU) in Both Studies



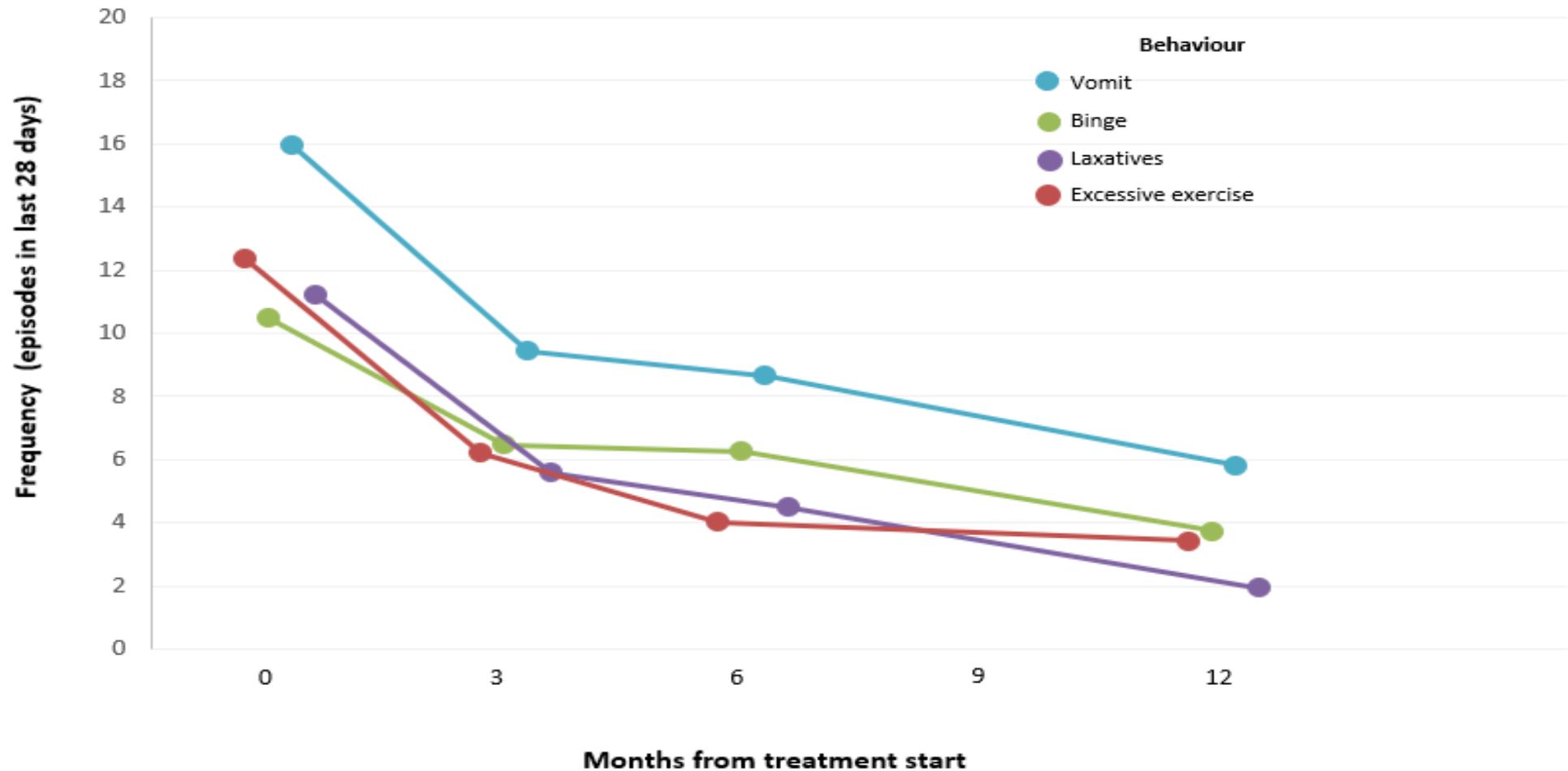
**FREED reduces DUED by 4-6 months**

# Clinical Outcomes in AN Across Two Studies: FREED vs Treatment as Usual



**Weight recovery rates at 12 months: TAU: 18% vs FREED: ~ 53-60%**

# FREED-Up Study: Estimated means of binge-purge behaviours for FREED patients with BN, BED or OSFED



# FREED-Up Study: Service Utilisation & Cost Savings in FREED vs TAU

- **Treatment uptake:** FREED 97% vs Tau 72%
- **No. of outpatient-sessions:** FREED = TAU, i.e. ~ 16-20 sessions
- **Need for intensive treatment:** FREED < TAU [6.6% vs 12.4%]
- **Cost-savings of £ 4,400 per patient** after introduction of FREED (includes the cost of the FREED champion)



# FREED-Up Study: Patient Experience of FREED

- > 100 FREED patients reported their experience:
- 95% were very positive about their Rx.
- Patients valued both being seen quickly & the developmentally informed adaptations.
- They thought that both contributed to their recovery

“Understanding that you need help is a massive step. Asking for it is also so monumental. Having a service like this that makes asking so easy and natural is so, so vital. It feels amazing to have been part of a service that acts so quickly and makes you feel safe.”

*“I nearly dropped out of university last year, when my anorexia was at its most aggressive. FREED's rapid intervention prevented this. I am slowly regaining the energy levels that anorexia drained from me. I can only thank FREED for quite literally saving my life.”*

**FREED**

# Adopted in 2020 for Rapid National Scaling in England: “FREED-4-ALL”

## Implementation Strategy

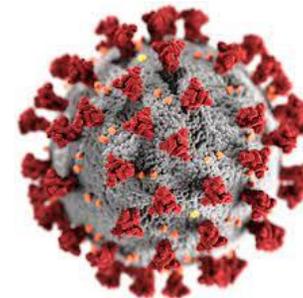
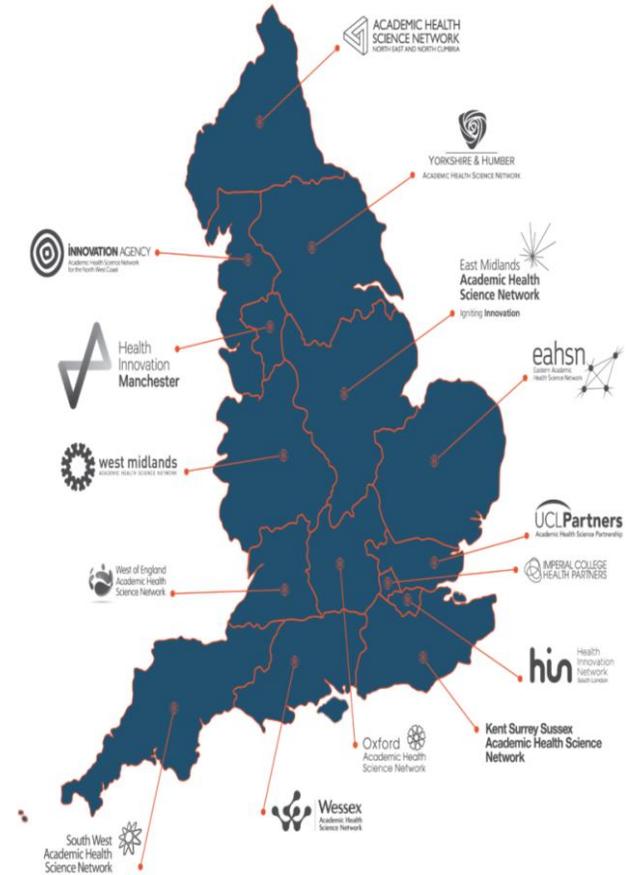
### Preparatory Phase:

- Building a business case & Service Mapping Exercise in England
- AHSN contact & awareness raising with all ED teams in England

### Training, Implementation & Embedding

- FREED website with treatment & implementation resources
- Online & face-2-face implementation training & team supervision
- Strong patient & carer involvement
- FREED network:
  - Emphasis on partnership & cross-site learning
- Quantitative & qualitative evaluation of implementation

## The AHSN Network



[www.FREEDfromED.co.uk](http://www.FREEDfromED.co.uk)

# COVID-19: The Shadow Pandemic of Mental Health (MH) Problems

## Impact on ED services

- Internationally, a marked rise in new cases and in deterioration & relapse in established cases
- Internationally, a marked rise in ED admission rates
- FREED referrals have dramatically increased, i.e. there are ~ 2.5 times as many cases as before the pandemic.

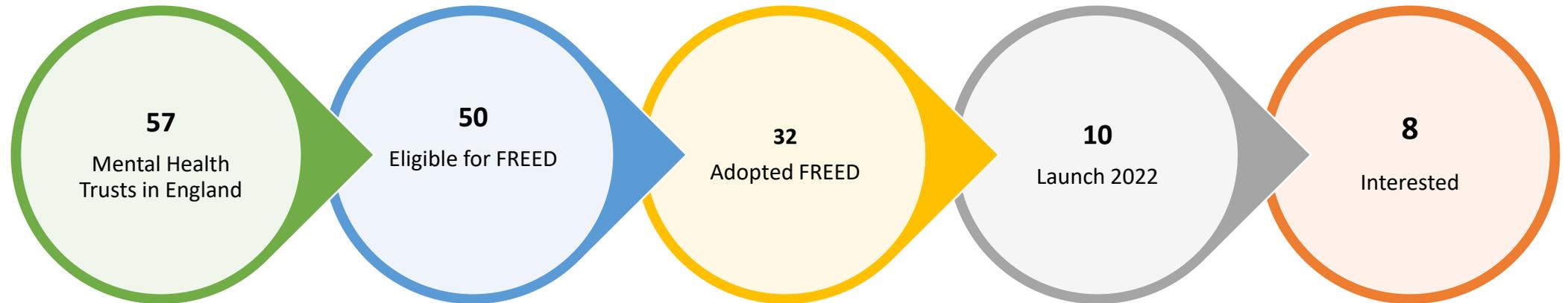
**How can we do rapid national scaling of  
FREED in this context?**

**Arrrggghhhhh!**





# Keep calm and carry on scaling.....





# FREED-UP vs FREED-4-All

	FREED-Up ( <i>n</i> = 278)	FREED-4-All ( <i>n</i> = 2473)
Age in years (Mean)	20.2	19.9***
Diagnosis %		
Anorexia Nervosa	35%	46%***
Bulimia Nervosa	27%	25%
Binge Eating Disorder	1%	4%*
OSFED/Atypical EDs/ARFID	37%	25%***
DUED in months (Mean)	17.9	14.9***

\*\*\**p* < .001 \*\**p* < .01 \**p* < .05

**FREED-4-All patients are a little younger, more have AN & DUED is shorter**

# Clinical Outcomes in FREED-Up Vs FREED-4-All

		Pre-treatment	Post-treatment	
		Mean	Mean	Mean difference
EDE-Q Global [range: 0-6]	FREED-Up	4.03	2.85	1.18***
	FREED-4-All	4.06	2.04	2.02***
BMI (AN only)	FREED-Up	16.42	17.67	1.25***
	FREED-4-All	17.41	19.08	1.67***
Binge episodes	FREED-Up	6.41	3.70	2.71***
	FREED-4-All	4.83	2.19	2.64***
Vomit episodes	FREED-Up	6.97	3.27	3.70***
	FREED-4-All	5.84	1.43	4.41***

Similar significant improvements across all measures in both groups

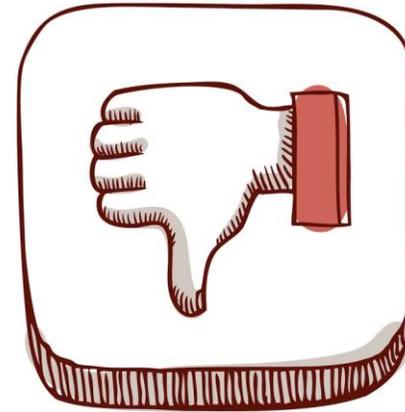
# Views on Facilitators & Barriers to FREED Implementation

## Clinicians & Implementation Specialists (AHSN leads)

*"It's an obvious thing to do, that makes complete sense"*

*"I think it's incredibly important because I believe it works."*

*"We've got FREED patients who are fully recovered and smashing life out of the park - it's awesome to see"*



*"...trying to embed it in a service that has many, many demands ...and ...within a system that just feels quite overstretched."*

Is it sustainable?

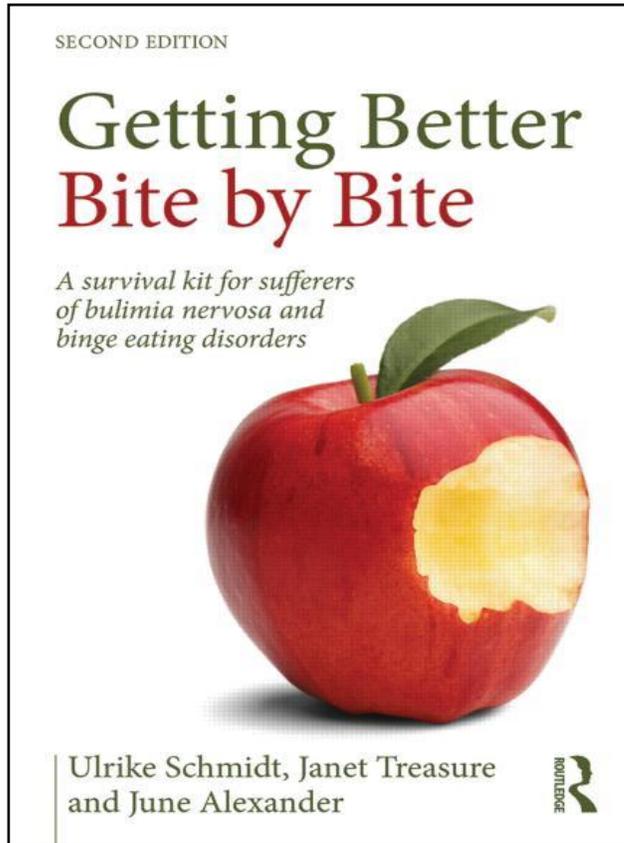
*"Without shadow of a doubt. ...it just takes a small mind shift .... [FREED]...develops and extracts the best of those services and utilises some new resources and some new methods of thinking and working".*

# How can overstretched ED services sustain delivery of FREED?

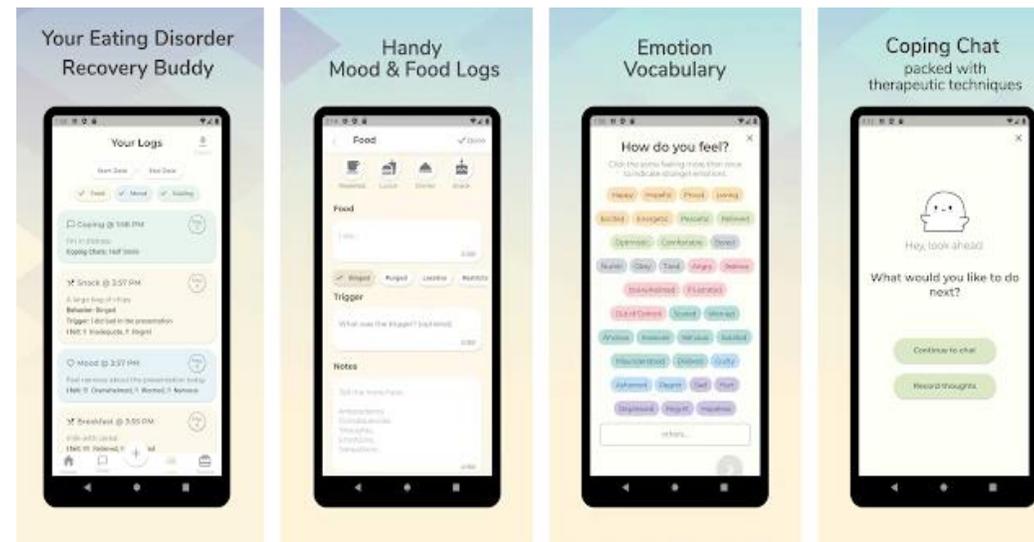
## Some potential solutions

- Abbreviated treatments (e.g. CBT-10 for non-underweight patients; Waller et al., 2019)
- Shifting from individual to group treatment (e.g. group-MANTRA for anorexia nervosa, Startup et al., 2021)
- Supplemented with online psychoeducation workshops & support groups
- Task shifting, e.g.
  - Carers - online skills training & carers' support groups
  - Peer-support workers (either lived experience or emerging adults i.e. at similar developmental stage)
- Disruptive innovations
  - Telemedicine
  - Internet
  - Mobile Apps

# Our Current Model of Delivering Guided Self-Help for Patients with BN or BED



- Programme delivered by psychology assistants & PhD students
- Guidance Via Teleconferencing
- GBBB – 8 sessions over 12 weeks + Brighter Bite App
- Excellent Uptake, Retention & Outcomes



# Making Early Intervention Earlier

## FREED-Mobile

### Smartphone-friendly online decision-making tool

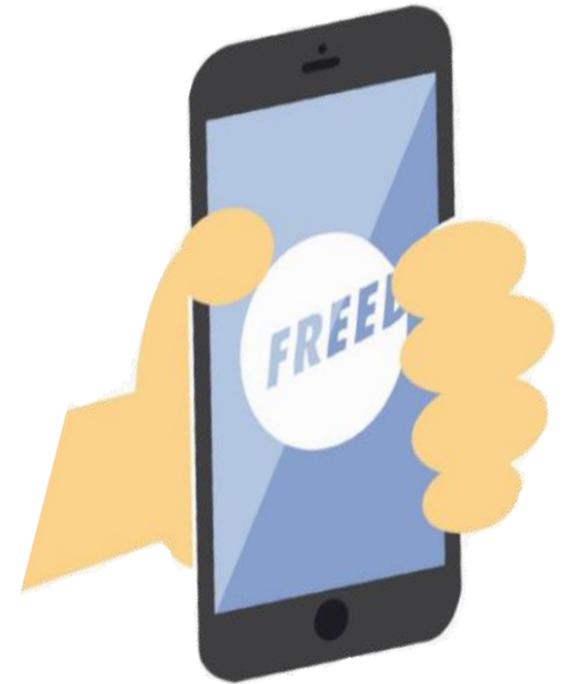
#### Aims:

- To improve knowledge about EDs & motivation to seek treatment and facilitate early steps towards change.
- Reach young people earlier & shorten duration of untreated illness (DUEI) further

#### 4 once-weekly modules on different topics

##### Each module has:

- Personalised feedback on questionnaires
- Animated films
- Associated downloadable written resources
- Opportunity for written reflection on materials



# Animation 1: Help Seeking

GETTING SUPPORT FOR YOUR EATING DIFFICULTIES

## Next Steps

- Nearly finished making the intervention
- Now planning a feasibility trial on FREED-M recruiting from schools, Universities and from primary care
- Conducting stake holder interviews

What I liked about it is it wasn't pushy.

Really good that you've got a guy in there because I think men are very often overlooked.

I like the story and the diversity of stories. I think that's an important thing.



UK Research  
and Innovation

# EDIFY



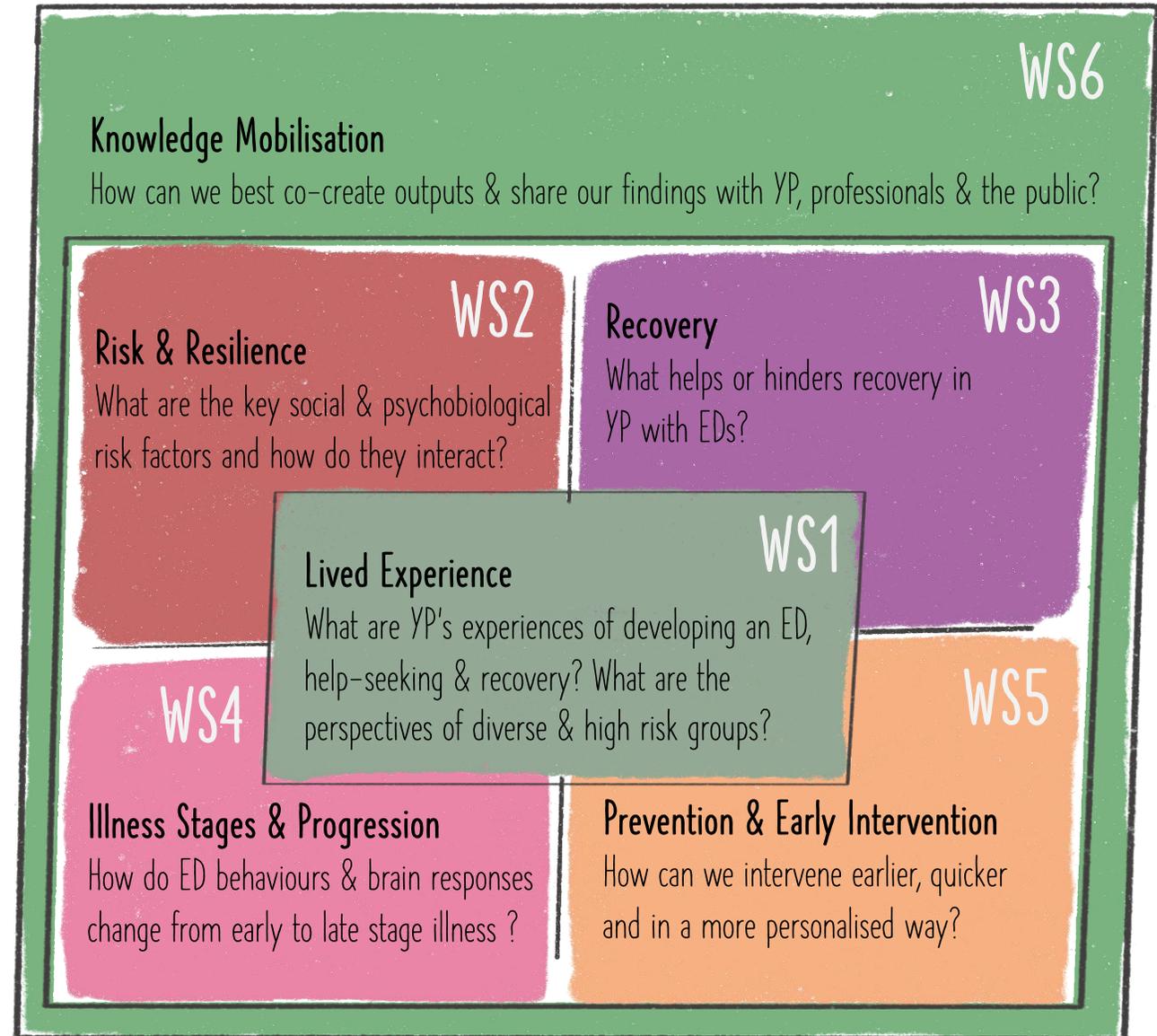
**Eating Disorders: Delineating illness and recovery trajectories to inform personalised prevention and early intervention in young people.**

## A 4-Year Programme

- Six integrated workstreams (WSs)
- Engaging 800+ Young People (YP) with EDs
- Combining cutting-edge neuro- & social science and bioinformatics with arts & humanities
- Shared participants & measures

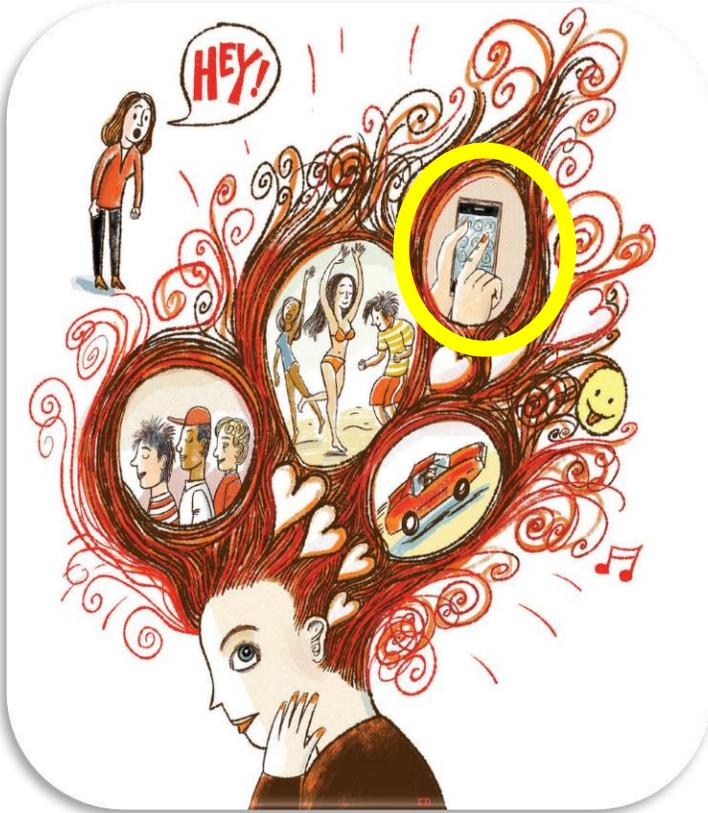


**LEADERS UNLOCKED**

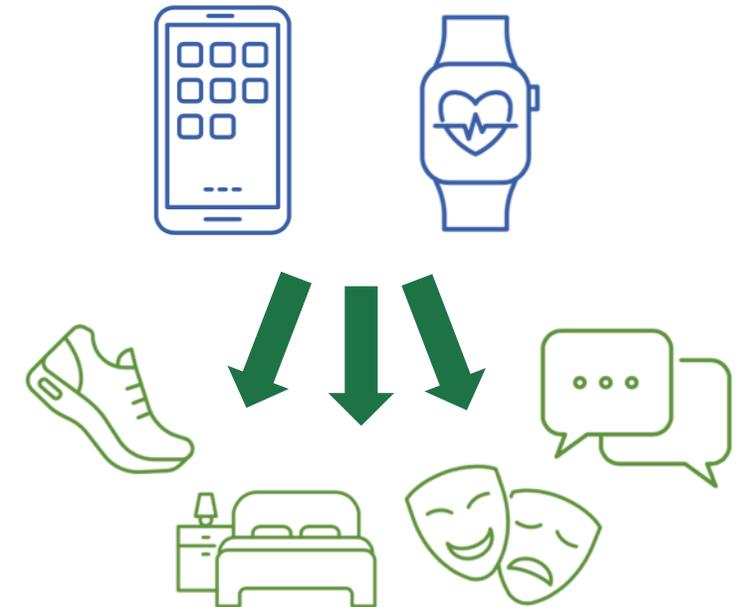


# Workstream 3: Recovery

# EDIFY



- A new cohort of YP with first episode ED (from FREED services)
  - 240 YP with AN, 240 YP with bulimic-type (BN, BED), 120 healthy YP.
- Followed for 1 year (and perhaps longer)
- ‘Deep phenotyping’ using remote measurement technology (active & passive sensing), ecological momentary assessments, and repeated standard ED assessments



*What predicts recovery? What are early indicators?*

*Are there (subtle) warning signs things aren't going so well?*



# Lived Experience is at the Centre



# The Call for Better & More Personalised Treatments



# Summary

FREED services on course to full national roll out in England

- COVID has added extra demand and complexity.
- It has also has given us a big impetus for testing more flexible ways of treatment and service delivery

ED early intervention research needs to get bolder and brainer

FREED-M and EDIFY may go some way towards achieving this



**With Thanks to:**

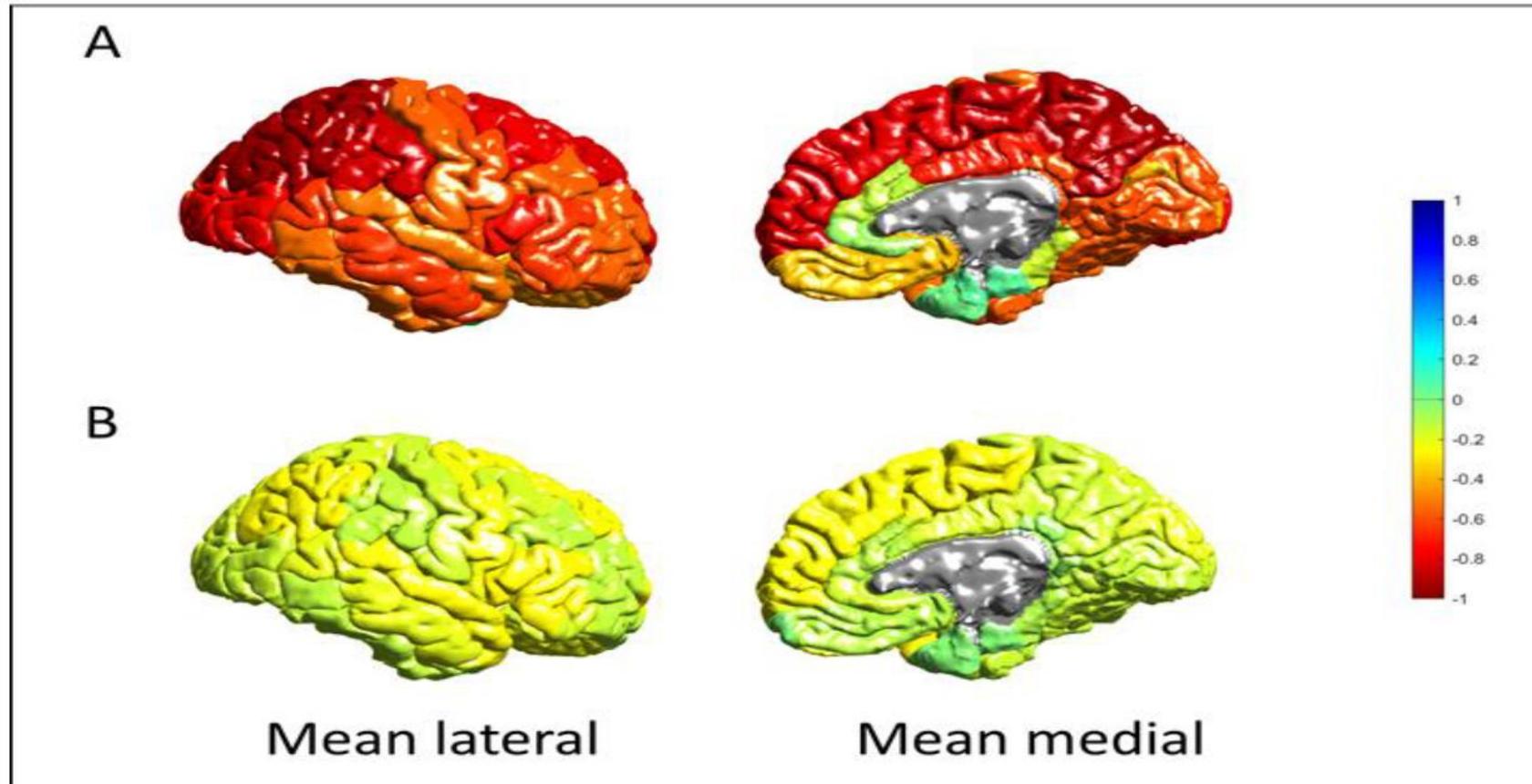


**Funded by: Health Foundation, MRC, NIHR RfPB, UKRI**

# Brain Structure in Anorexia Nervosa

Meta-Analysis data from 685 female AN patients and 963 healthy controls

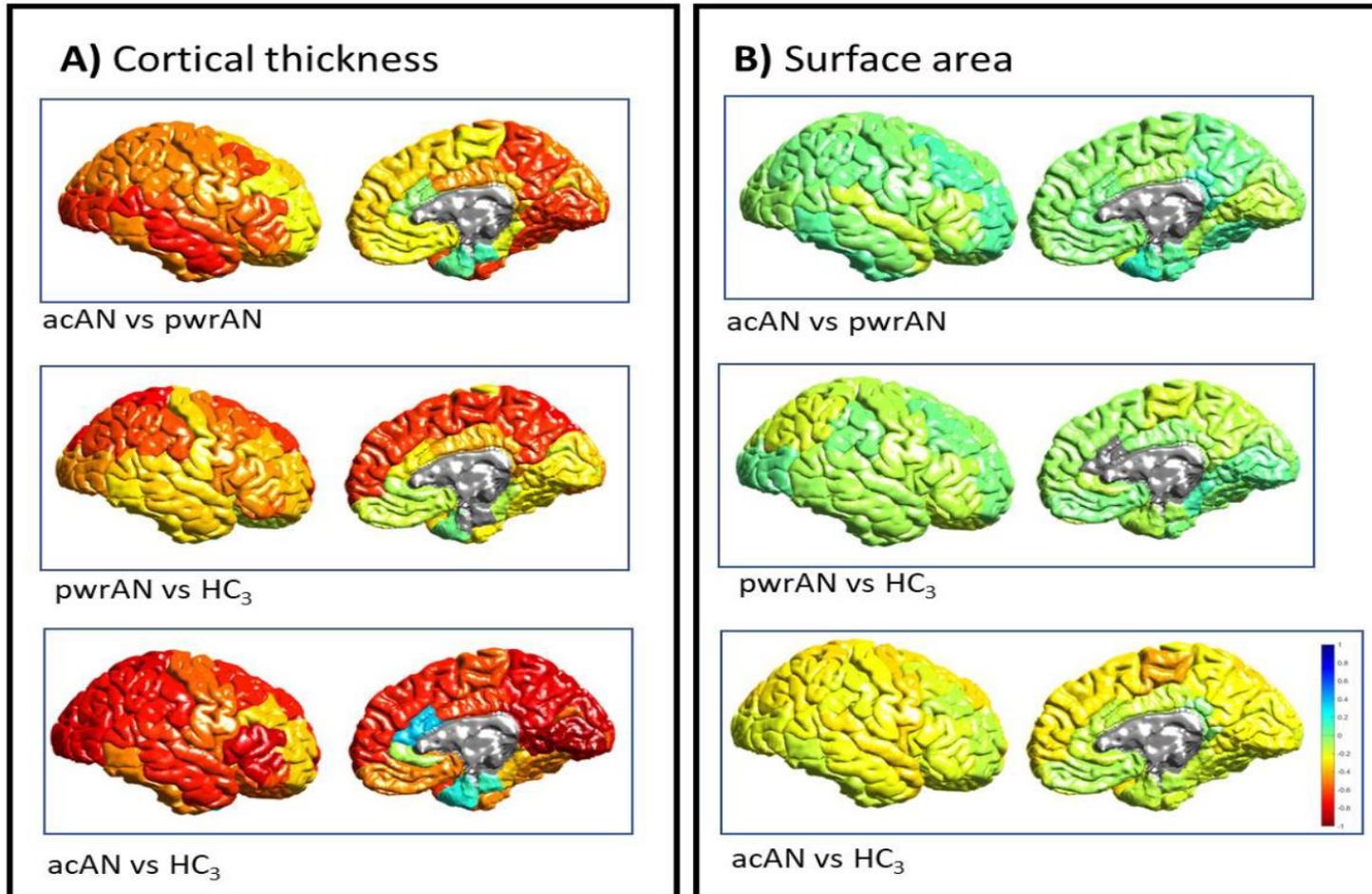
Reductions in (A) Cortical thickness and B) surface area between AN patients and HC.



Warmer colours indicate reductions (Cohen's d effect size; patients vs controls)

Effect sizes observed for cortical thickness deficits in acute AN are larger than for schizophrenia, depression & OCD

# Pairwise Reductions in A) Cortical Thickness and B) Surface Area between acute AN (can), partially weight-restored AN (pwrAN) and healthy controls (HC)



**Reductions in volume thickness and surface area are less severe in partially weight restored patients.**

Clearly there is a 'pseudo-atrophic' state effect in AN, but emerging evidence suggests there may also be scars.

E.g. Recent studies have shown elevated neuronal and glial damage markers in AN (Nilsson et al., 2019; Hellerhoff et al., 2021).