









# Welcome to the FREED Network Shared Learning Conference will commence at 9.30am

This event will be recorded. Please let the organisers know if you do not wish to be included



The Future of Early
Intervention for
Eating Disorders:
FREED and beyond

# Housekeeping

- Fire alarm test at 11am. If the fire alarm sounds outside of this time go to the ground floor via the stairs, exit via the courtyard gates and cross the road. Please wear your badge.
- Toilets to the left of the stage as the audience faces it, and past the Snow room.
- This event is being recorded. If you do not wish to be included, please let organisers know.
- Organisers will be wearing an orange sticker on their name badge if you need any assistance.
- Please can all complete the evaluation of the event before the end of the day. Evaluation survey link has been circulated or you can use the QR code provided on the tables.
- Posters are available to view during lunch, both digitally and in the Snow Room.
- Slides and recording will be distributed asap following the event.
- Q&A will be via the Slido app or website with code #FREED (please specify which speaker you are asking, if any, when submitting your question).
- Please tag #FREED if tweeting during the event







# Welcome!

# Professor Ulrike Schmidt and Dannie Glennon





# Early Intervention in Eating Disorders: An International Perspective

Professor Eric van Furth

# Session 1: The FREED Journey

Chair: Karina Allen



#### **TheAHSN**Network







# FREED: From Inspiration to Implementation

Ulrike Schmidt, Danielle Glennon, Karina Allen, Regan Mills, Lucy Hyam, Helena Gilchrist, Giulia Di Clemente & Jess Griffiths



A research-led evidence-based model & care pathway

For young people aged 16-25 with a first episode of any eating disorder

Person-centred, developmentally-informed, tailored to the illness stage

Builds on models of early intervention for other mental disorders, e.g. psychosis

Reduces duration of untreated illness, improves clinical outcomes & leads to cost savings

Can be integrated into any service model (adult, allage, 0-25)



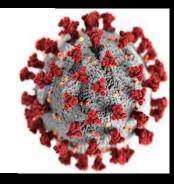








2020-2023 National Roll Out



2014-2019
Develop model, refine & test
Develop resources, website & training
Initial scaling

Schmidt et al., 2016; Brown et al., 2018; McClelland et al., 2018; Fukutomi et al., 2020; Austin et al., 2021a,b, '22; Flynn et al., 2021; Potterton et al., 2020,'21, '22; Richards et al., 2021

Allen et al., 2020, '22; Richards et al., 2022; Hyam et al., 2022; Hyam et al., in preparation

National Roll Out of FREED in Numbers

54

Mental Health
Trusts have FREED
in their geography

5,526

Patients had FREED screening call

3,861

Patients have had a FREED assessment

2,225

Patients have started evidence-based treatment under FREED

Estimated

£9,950200

Saving to the NHS based on 2225 patients at £4,472 savings per patient

Austin et al., 2022; Richards et al., 2022; Hyam et al. in preparation

#### **National Roll Out of FREED in Numbers:**

**Replication of Clinical Outcomes** 

71%

of FREED patients are below the clinical cut off on the EDE-Q global score after treatment (vs 65% in our earlier FREED-Up study)

59%

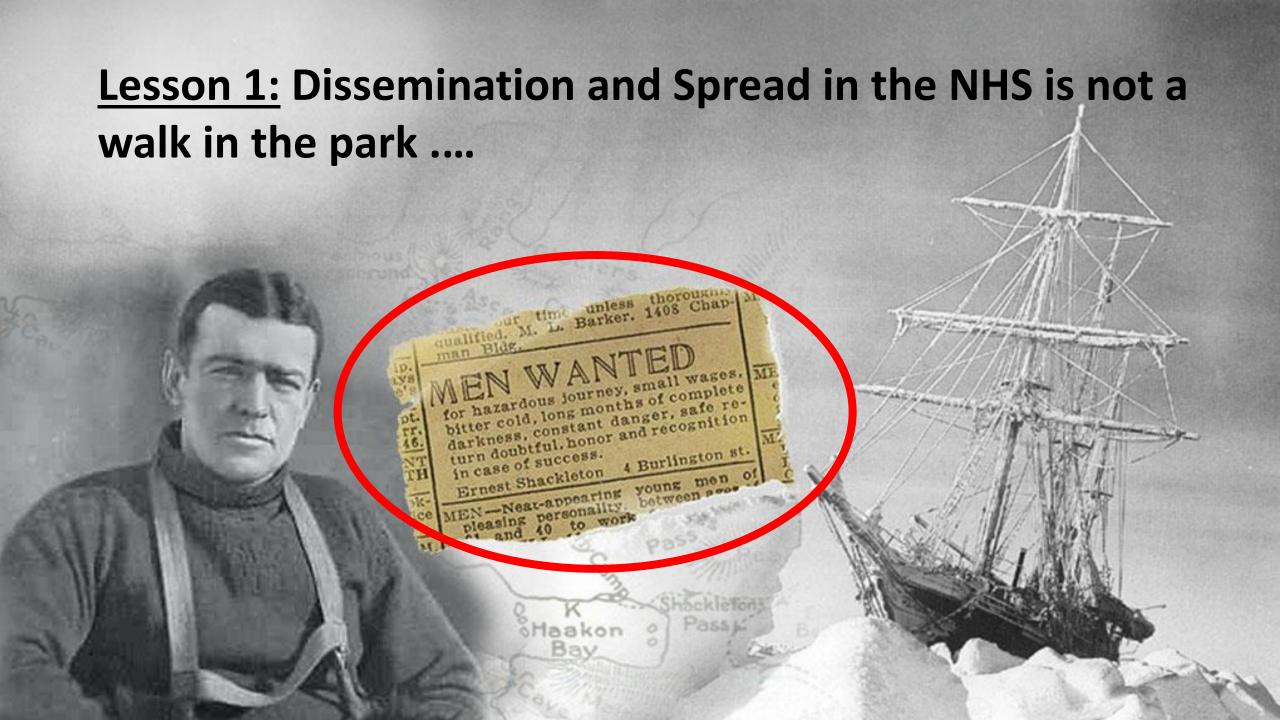
of FREED AN patients are weight recovered at ~ 1 year vs 52% of FREED AN and 18% of AN patients receiving usual treatment in our earlier study

"I nearly dropped out of university last year, when my anorexia was at its most aggressive.

I can only thank FREED for quite literally saving my life."

# What lessons have we learnt along the way?

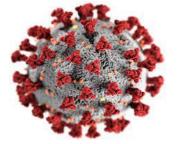






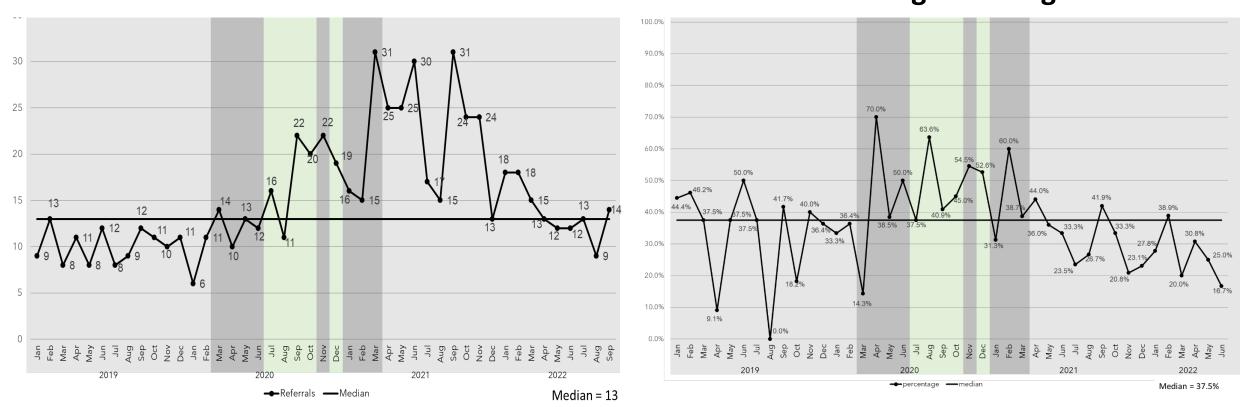
#### The Impact of COVID on FREED Services





#### **Referrals Received**

#### **Percentage AN Diagnosis**



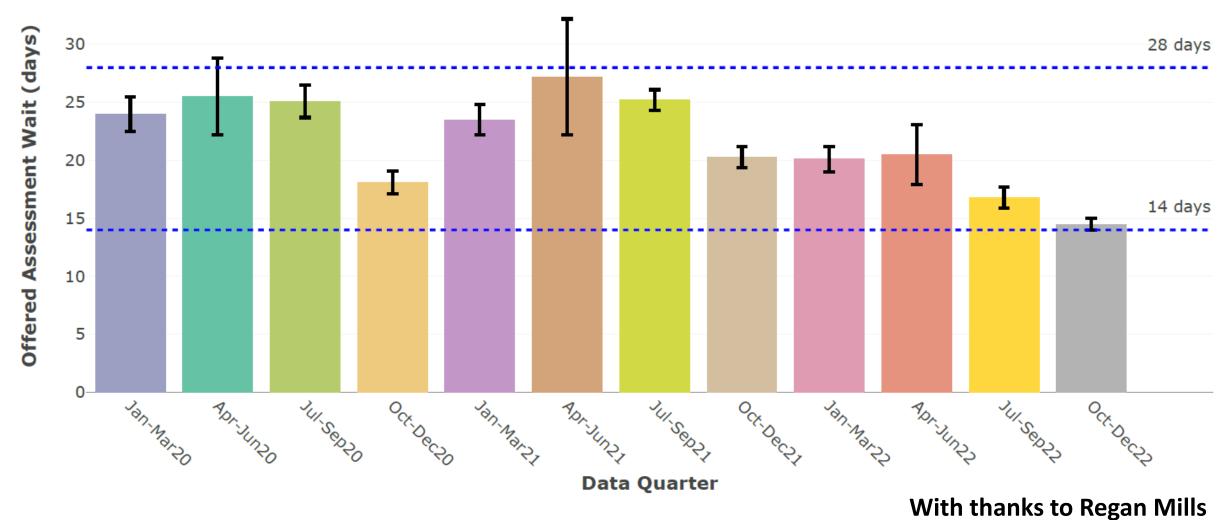
- Increase in referrals of 40% at peak period (March to Oct 2021); mainly in AN
- Severity similar to pre-pandemic

Lesson 2: Keep the main thing the main thing, i.e. focus on shortening duration of untreated ED (DUED), by getting people assessed & treated quickly)





#### **Time from Referral to Assessment**



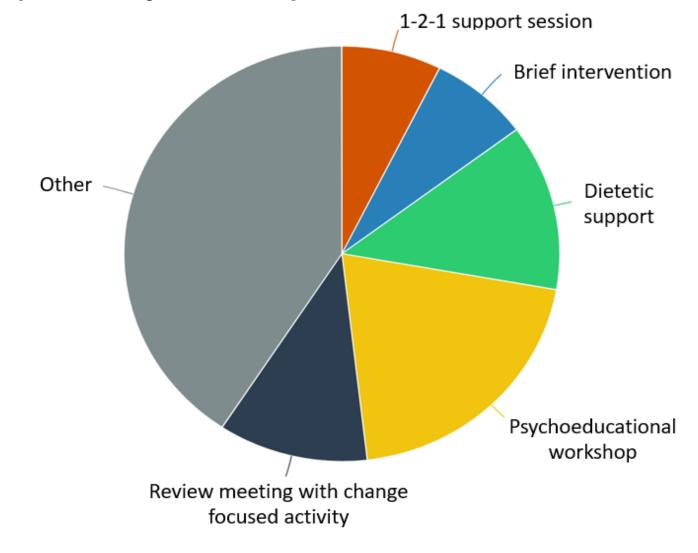
#### **Lesson 3: Every Challenge is An Opportunity for Creativity**

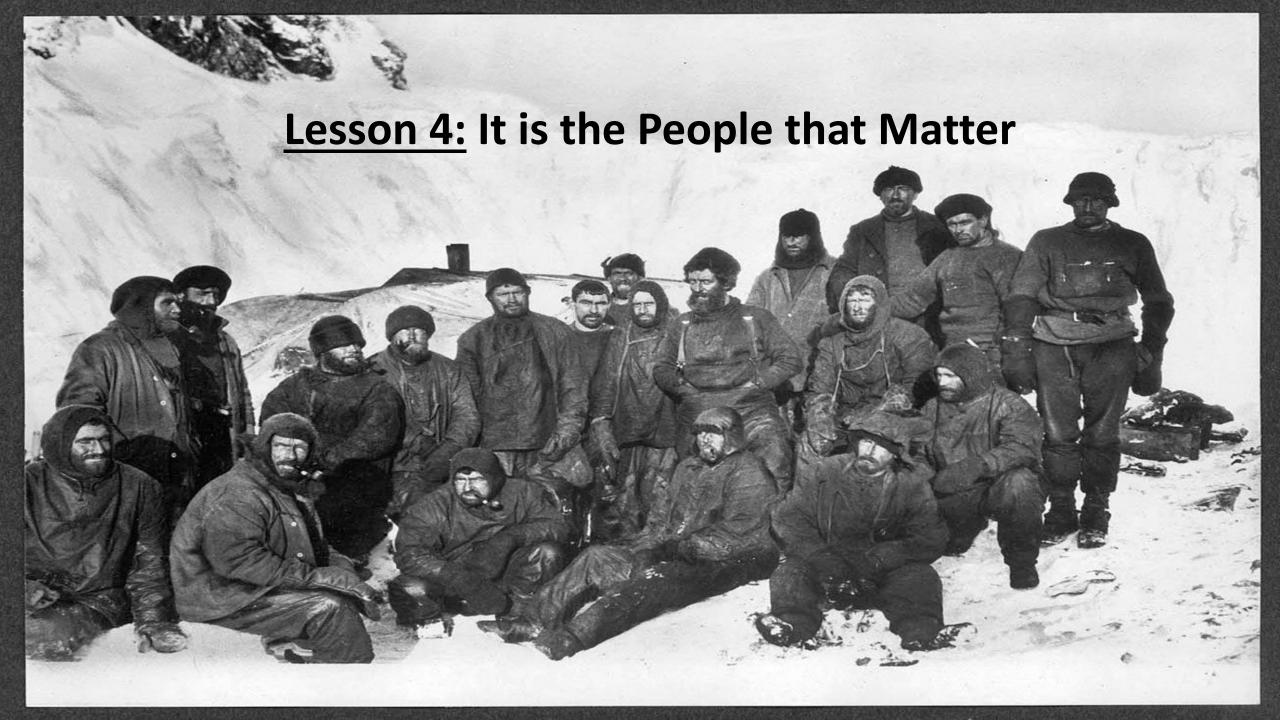




# Example: Introduction of Change-Focused Active Support Prior to Start of NICE-Concordant Treatment (n=967 patients)

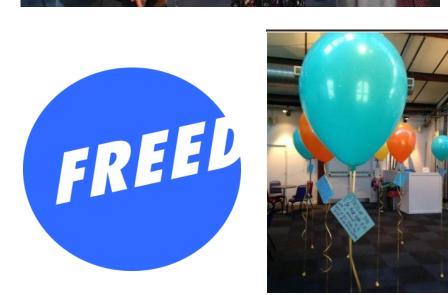








## **The FREED Community**





#### **TheAHSN**Network

# Early Intervention Eating Disorders: AHSN National Programme 2020 - 2023

Laura Semple, Director National Programmes, The AHSN Network

Jillian Owens, National Programme Manager Early Intervention Eating Disorders, The AHSN Network and Health Innovation Network South London

March 2023

#### Science Network Yorkshire & Humber **INNOVATION AGENCY** East Midlands **Academic Health** Science Network Eastern Innovation AHSN west midlands **UCLPartners** West of England Academic Health IMPERIAL COLLEGE HEALTH PARTNERS **Kent Surrey Sussex** Academic Health Science Academic Health **South West**

#### **TheAHSN**Network

A connected 'network of networks'

15 Academic
Health Science
Networks
(AHSNs) –
established
2013

## Our purpose & core objectives

### Our ambition is to transform lives through health & care innovation by:

- Generating a rich pipeline of demonstrably useful evidence-based innovations
- Supporting adoption and spread of proven evidence-based innovations across England
- Tackling health inequalities is a golden thread in all AHSN activities



# Improving the health of patients



**Driving economic** growth



Saving money in health and care



#### ...and national

- A connected network of 15 local organisations, creating a national 'network of networks'
- Small 'virtual' central team supports effective national AHSN collaboration
- Agreed national priorities enable rapid scaling
- Ability to 'import' and 'export' innovations between local areas
- Collective expertise on key challenges, such as adoption and spread of innovation
- Mental Health is a priority for all 15 AHSNs

# **Early Intervention Eating Disorders: AHSN National Programme**

The AHSN Network, working in close collaboration with our commissioners the NHSE Innovation Research and Life Sciences Team, select a number of innovations for national spread and adoption.

These innovations have evidence of their efficacy, they align to NHSE policy and priorities, they are scalable and applicable outside of their area of origin.

FREED was selected for the AHSN Early Intervention Eating Disorders national programme to commence in April 2020





# Spread and adoption



**Sustain:** AHSNs work with local and national teams with the aim that FREED is integrated way as **Sustain** business as usual in services

**Adopt:** AHSNs and SLaM provided adopters with continuing access to expertise, support, networking, collaboration opportunities, and online resources.

**Adopt** 





**Implement:** AHSNs and the FREED team provide Eating Disorder Services with business case templates, implementation **Implement** tools, pathway development and recruitment advice

**Raise awareness:** With national leadership from the HIN, all 15 AHSNs began to create the conditions for spread and adoption, raising awareness of the innovation and evidence of the benefits

Spread



**Understand context and evidence:** Existing evidence for the FREED model and system need were reviewed for acceptability as a national programme, and the most effective methods for wide spread and adoption were considered

Analyse

## **National Programme Impact**



2100+

2107 patients benefited from FREED from April 2020 to December 2022 with more expected by end March 2023.



15

All 15 AHSNs provided resource and local support for the Early Intervention Eating Disorders programme



55 +

55 new FREED
Champions posts have been filled, with more being recruited



£8.8million

Expected return on investment (ROI) is £4,166 per patient.

2,100 patients = an estimated total return of 8.8 million in 3 years

# **Key learning**

"Seeing how passionate our FREED champions are about making a difference feels like we're leaving it in very capable hands" – AHSN Lead

- **Workforce**: attracting a pipeline of appropriately skilled staff is a significant challenge for eating disorder services including FREED. However FREED is reported to be a motivating and morale boosting model within teams.
- **Referrals:** Unprecedented increase in referral volume and complexity, caused by the COVID-19 pandemic. Despite this FREED has been adopted within the footprint of all eligible Mental Health Trusts.
- **Funding:** Ring fencing and recurrent funding for FREED services is vital to support sustainability, research and continuous improvement to embed long term benefits of early intervention.

# **Key Learning**

"Of all the projects I've worked on at the AHSN, FREED has the most supportive and inclusive community, both internally and externally" – AHSN Lead

- Multidisciplinary engagement: a joined up approach is needed to ensure early intervention is as early as possible. Existing good practice in FREED includes engagement with universities and primary care networks.
- **FREED network:** the network approach, including communities of practice, buddy groups, shared learning, webinars and more, has been well received and reported as instrumental to success for many services.
- **Innovation:** continuous development of the FREED model and accessibility of the earliest possible intervention can be supported through a variety of innovative, digital and other methods.

# Views from the frontline

What do AHSN leads and clinical teams think about FREED?

Lucy Hyam (PhD student) FREED Network King's College London Katie Richards



# Background

- AHSN programme drawing to a close.
- What can we learn, how can we plan for the future?





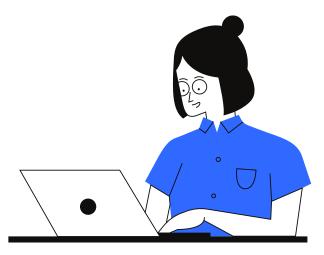
- What are the **challenges** and **facilitators** to implementing FREED, and what **adaptations** have been made to the model?
- How **sustainable** is FREED?



March - June 2022



7 focus groups with 26 clinical FREED staff.



13 semi-structured interviews with AHSN programme leads.

What were the common themes across clinicians and AHSN leads?

### High value

#### **AHSN Leads**



- Lots of 'will' and enthusiasm among AHSN leads, clinicians, and FREED Champions.
- FREED seen as desirable, common-sense approach with ability for high patient benefit.
- Compelling, sufficient evidence base.

Everyone I speak to understands the drive and the need for this which is not always the case in some national programmes. So, it really is refreshing. We never have naysayers as it were. We only have operational challenges.

#### To increase value...

- What about patients outside of FREED criteria?
- Desire to see more research on accessibility and transitions.



### High value

#### **Clinicians**



- Fitting with values as a clinician, being excited.
- Seeing quick changes for patients encouraging, assessments are inspiring.
- FREED engagement call commonly praised.
- Using early intervention principles for everyone.

What it pushed us to do was to think about how we were going to be able to offer treatment earlier... we set up some online groups to offer people something whilst they're waiting for the one-one treatment. So I do think that came from FREED starting... it sort of pushed that to happen.





"Because of the quick turnaround, when these people were severely unwell presenting for the first time, because there wasn't a long waiting list we were able to act upon it. So that's really reassuring that FREED has a place which is vital to keep our patients safe. With the clients I've seen on my caseload, seeing them really bloom into who they wanted to be. Really looking at, achieving those goals such as going to university or ... whatever it might be, those big life events that fall within that sort of age category."

FREED Champion

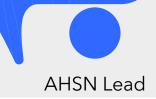
### Community and network

#### **AHSN Leads**



- Good relationships between AHSN, services, and SLaM/KCL national team.
- AHSNs bringing everyone together.
- Need to sustain networking opportunities, difficult for clinicians to manage.

...we already had a site that was preadopted. So we were able to use our preadopted site as a model for our other site to say "look, this is what they're doing. It's going really well" and you've got this contact here if you wanna ask them questions.



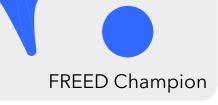
### Community and network

### **Clinicians**



- AHSNs hugely helpful.
- Accessibility and speed of help from SLaM/KCL national team.
- Resource sharing, facilitated by implementation supervision.
- Supervision and networking was reassuring 'we're all in this together' attitude.
- Meeting clinicians from all over the country.

The FREED community, all the Champions, all the lovely people I've met, throughout this whole thing, sharing resources which then informs better practice for all of our service users. I think that's one of the most amazing things that I've got from this.



### Implementation/operational challenges



### Highly complex condition

- Increased acuity.
- Increased referrals.
- High ambivalence.



they're on their knees in terms of acuity, complexity, the numbers of referrals that were coming in.

**AHSN Lead** 

# NHS staff recruitment challenges

- Difficulty recruiting FREED champions.
- AHSNs helping to "think creatively together".



So they've launched, but they have had to pause it because of workforce issues, using that opportunity to look at staffing and recruitment.

**AHSN** Lead

### Implementation fragility

- 'Pausing' or 'partial adoption' of FREED.
- Limits the reach of early intervention.



there's still more to be done to make sure that they're secure, they're delivering the full model as intended and people understand what the core bits are of FREED...

**AHSN Leac** 



# How can we make FREED sustainable?



AHSN leads and clinicians were positive about sustainability despite the challenges.



Implementation is still fragile in some areas, work on fidelity is needed.



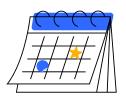
Stable funding needed to ensure sustainability in the long term.



Networking opportunities need embedding. More training also desired.











## Is it sustainable?

I don't think we have a choice for it to be sustainable or not. We can't. Early intervention isn't an option, it's a necessity... the will is there.

**AHSN** Lead

### Thank you!

AHSN leads & FREED clinical staff
Katie Richards
Claire Torkelson & Olivia Yeadon-Ray
FREED national team













### Academic Health Science Network, North East And North Cumbria

**Setting Up A Service** 

David Tate, Senior Eating Disorders Practitioner,
FREED Champion at Tees Esk and Wear Valleys, and
FREED Programme Lead at North East and North Cumbria AHSN







### **OUR ICS**



#### **North Cumbria ICP**

Population: 324,000

1 CCG: North Cumbria

Primary Care Networks: 8

1 FT: North Cumbria Integrated Care NHS Foundation Trust (NCIC)

1 Council Area: Cumbria County Council (with 4 District Councils)

North West Ambulance Service

#### **NENC ICS-wide**

North East Ambulance Service FT covers: North of Tyne and Gateshead ICP; Durham, South Tyneside and Sunderland ICP; Tees Valley South ICP

CNTW Mental Health FT covers: North Cumbria ICP; North of Tyne and Gateshead ICP; plus part of South Tyneside and Sunderland ICP

TEWV Mental Health FT covers: Tees Valley ICP; plus part of South Tyneside and Sunderland ICP

Newcastle upon Tyne Hospital FT: provider of highly specialised and specialised national and regional services (including transplant, paediatric specialisms and major trauma)

#### North of Tyne and Gateshead ICP

Population: 1.079M

3 CCGs: Northumberland, North Tyneside, Newcastle Gateshead

Primary Care Networks: 24

3 FTs: Northumbria, Newcastle, Gateshead

4 Council Areas: Northumberland, North Tyneside, Newcastle, Gateshead

#### Durham, South Tyneside and **Sunderland ICP**

Population: 997,000

4 CCGs: South Tyneside, Sunderland, North Durham\*,

Primary Care Networks: 24

2 FTs: South Tyneside & Sunderland, County Durham

and Darlington 3 Council Areas: South Tyneside, Sunderland, County Durham

\*County Durham CCG from 1st April 2020

#### **Tees Valley ICP**

Population: 852,000

4 CCGs: HAST\*, Darlington\*, South Tees\*, HRW

Primary Care Networks: 17

3 FTs: County Durham and Darlington, North Tees & Hartlepool, South Tees

6 Council Areas: Hartlepool, Stockton on Tees, Darlington, Middlesbrough, Redcar & Cleveland, North Yorkshire

\* Tees Valley CCG from 1st April 2020 Yorkshire Ambulance Service







Cumbria, Northumberland, Tyne and Wear

NHS

Tees, Esk and Wear Valleys
NHS Foundation Trust

### **North East And North Cumbria ICS**

Primary care networks

of the Largest MH
Trusts in the
country (CNTW
and TEWV)





Vast number of independent and voluntary sector organizations

Area's of High-Density population with some of the highest levels of deprivation in the country to large expanses of low populated rural areas

Aspirational
Model for
Eating
Disorder
Services
Across the
Lifespan in
North
Cumbria,
Northumberl
and, Tyne and
Wear

Community
Assets and
Infrastructure
including CVS

### Delivery at Place:

- Step up and step down support from VCSE; use and signpost available community assets to promote ED awareness, further support people and support their support network
- Resources to support a person's support network
- · Support embedded in trailblazer, primary mental health and CYPS teams to prevent escalation
- Preventative strategies in place, eg for CYP (anxiety, stress, sexuality, relationships, gender, influence of social media
- Early Intervention in place (FREED) and schools, primary care and others have tools in place to allow early identification
- Collaborative working with voluntary sector and secondary care integral to offer
- Parenting tools in place, including early recognition
  - Robust processes in place for safe medical monitoring and pathways into more specialist care as appropriate
- Robust approach to all transitions across the lifecourse, especially CYP to adult services
- Seamless GP service sometimes covering two GP practices involvement, but never none where the patient lives

Specialist
Outreach, Home
Treatment &
Community
Services

**Specialist MDT** 

Consultation and

Advice

7 day support, with in built capacity to navigate individuals through all transitions Specialist ED psychological, medical and nurtritional interventions available at all steps

#### • Delivery at ICP/Multi Locality Level:

- Joint working with primary care primary care remains accessible to provide physical monitoring close to home, supported by specialist services as required for consultation and interpretation of results/management of risk
- Close joint working between specialist &community services so risk is managed proactively (eg at times of transition)
- · Clear support of carers and involvement of carers/lived experience in planning of care
- Community mental health teams provide care to people engaged with them who also have an eating disorder
- Pathways to support joint working across wider system (eg higher education, business/employers) to support users and the workforce/employer
- Equitable, timely access to NICE-compliant psychological, medical and nutritional support, including for those with SEED
- Services support the wide range of Eating Disorders and are needs (rather than BMI) led and outcome-based
- Care Co-ordination and planning within and across services/pathways

### Delivery at Trust (sub regional) level:

- All new referrals (16 25yrs) screened by FREED champion, contacted within 48 hours of referral, assessed within 2 weeks and start treatment within 4 weeks of referral
- Excellent peer support, time and resources for consultant, nurses and MDT
- Specialist capacity to minimise inpatient bed usage and eliminate out of area admissions
- Equitable and excellent mental health services for all to prevent mental ill health of adults impacting on children
- Structured support/supervision for CTT workforce
- Capacity to support people with long-term eating disorders and to offer intensive community and home treatment

Intensive Day Services (adults)

#### **Delivery at Regional Level:**

- · Intensive day services to delivery step up and step down care at a more specialist and intensive level
- Flexible approach to mitigate against any inequalities (eg geography)

### Inpatient

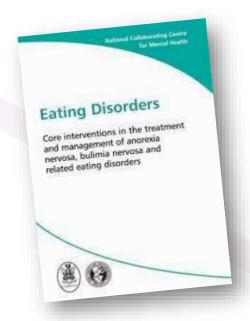
### Delivery at Regional Level

- Specialist inpatient services (psychiatric or acute medical depending on need) for those most acutely unwell
- Clear pathways and processes in place across the system to ensure all individuals moving areas (eg for university) can be robustly supported by local teams, eg for medical monitoring
- Minimal use of beds as capacity for appropriate intervention and support is available within a community based model



# Quick access too NICE approved therapy treatments

# Mantra, CBT, SSCM, Specialist psychology







Three teams make up the FREED Mini team starting with 6 staff and is now up to 15 active FREED mini team members



Team consist of the full Doctors, Nurses, Phycologists, and admin staff from adult and CAMHS ED teams



All FREED Mini team members have completed the SLaM FREED training



Over 30 Adult and CAMHS team members have completed the SLaM FREED online training.



Close working with CAMHS and having FREED Mini team members from Adult and CAMHS teams has supported the important part of Transitions.



FREED phased implementation using a soft launch model then a full launch.



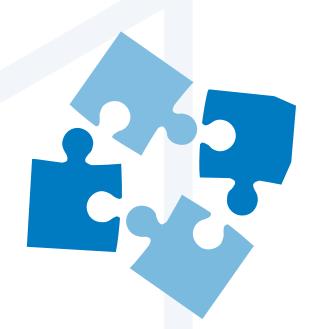
Since TEWV have started the "Freed Programme", over 26 patients have benefited from this.



# Timeline Of Events As You Implemented FREED – TEWV Foundation Trust



- December 2020 Freed Champion in post (fixed term)
- Jan 2021 Planning freed, liaising with stake holders Support AHSN
- Feb 2021 Freed planning adult/children's services
- March 2021 Training freed mini team.
- April 2021 Soft Launch of Freed pathway.
- May 2021 First Slam data submission
- June 2021 IG data agreement signed.
- July 2021 Freed trust signed agreement finally signed and live.
- August 2021 Full freed live.
- September 2021 Media launch with Slam, TEWV, Freed
- October 2021 Substantive freed Champion in post.
- November 2021 Working with Provider collaborative CNTW, and Cumbria
- Feb 2022 Eating disorder awareness, CNTW –TEWV engagement promotion.
- March 2022 4th Slam data submission.
- April 2022 group Mantra training through Slam
- May 2022 CNTW appoint Freed Champion Victoria Frater,
- Dave Tate started "secondment one day a week to the ASHSN", supporting CNTW implementing freed
- June 2022 5<sup>th</sup> Slam data submission
- Ongoing, supervision with Slam, AHSN, CNTW, to develop and grow freed.





# Setting Up Our Freed Service

TEWV NHS, Freed developing, planning, Soft launching and implementation, 14 months freed live

FREED to meet regional priorities and demographic needs. Access and waiting time standards

"Service within a service". Complementing current service provision.

Online SLaM training and initial SLAM FREED training completed

Setting up "Freed", between 3 eating disorder teams, Adult ED Teams and children's services (CAMHS X 2Teams) Tees Valley and Durham and Darlington.

Reached out to engage stakeholders including service users, GPS and Universities and work in partnership with AHSN EIED LEADs

Presentations to Gps, locally out service provision and referral pathways.

Liaised with other FREED Teams Nationally to learn from progress to date. – ongoing supervision with Slam.

Weekly freed mini huddle – monthly transition meetings

Referral targets – assessment, freed calls, access too nice approved interventions.







Work Closely with Universities Mental Health and Student support teams, Raising awareness of FREED and the benefits of early intervention and cross working. Close working links have been established with weekly meetings and Clinics. Running out patient physical health clinic at two locations. All

Engaged with Primary care and GPs specifically, going out and meeting them raising awareness of FREED and referrals are made directly to our access team (single point access). Linking to access and waiting times targets

26 new patients to eating service have benefitted from freed pathway since April 2022 too present, with an average wait time from referral to assessment 17 days. Compared to 78 non freed patients new in service since April 2022, with average wait time from referral to assessment 22 days.

Age freed patient 20yrs compared too none freed 22 years old.

With support of the mini team, especially Chris Meigan our assistant psychologist, to use google forms, to mean all questionnaire online EDE-Q 6, CIA, PHQ 9, GAD 7. Results 90% responses at start point

Working closely with our access, team, as we have one key point of access for all referrals

Linking with other freed champions, as lot of freed patients move around different areas, especially with University.

# Timeline Of Events As You Implemented FREED – TEWV Foundation Trust

- Promoting staff and patients about the benefit of Freed.
- Utilizing network, Slam, training.
- Monthly implementation supervision groups.
- Freed compliments and enhances current service delivery.
- Sharing group practice with other eating disorder teams.
- Working across Adult and Children's services (transition points)
- Psycho education –
- Reduction in DNA for assessment –
- Screening of assessment
- Data collection helps with service development (provider collaborative)















# BEDS FREED Pathway

Heidi Jackson

Berkshire Eating Disorders Service

Monday 27<sup>th</sup> March 2023



# Overview and Remit of Adult BEDS

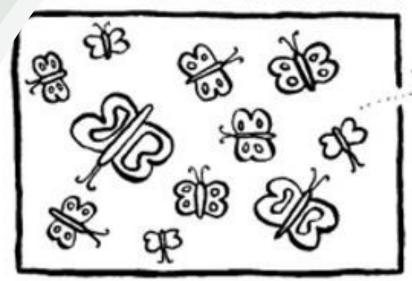
- BEDS is an all-age, community-based specialist assessment and treatment service for people:
  - presenting with a diagnosis of an eating disorder:
    - Anorexia Nervosa
    - Bulimia Nervosa
    - Binge Eating Disorder
    - Otherwise Specified Feeding or Eating Disorder
  - aged 18+
  - Registered with a GP in Berkshire
  - Offers NICE concordant treatments

# BEDS prior to FREED, why we chose to adopt FREED

The FREED values aligned with the service in terms of responsiveness, inclusivity, creativity and improving standards of care.



### - BUTTERFLY of FREEDOM



"Why do you fly outside the box?"

"Ifly outside the box because I can."

"But we know the box. We are SAFE inside the box."

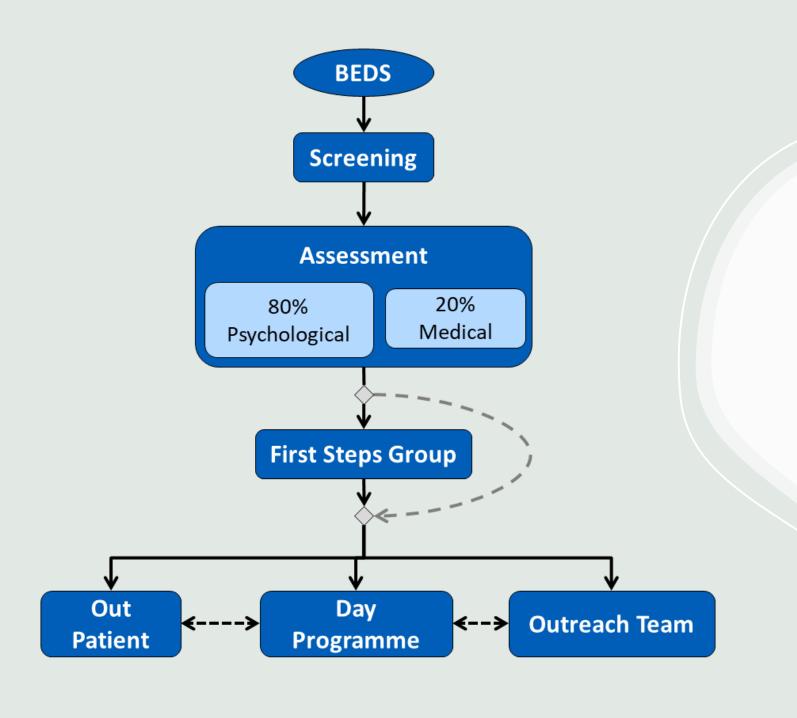
That, my friend, is why I leave it.
You may be SAFE...

IAM FREE!"

- Service Manager
- Clinical Team Lead/Clinical Psychologist
- Clinical/Counselling Psychologists
- Consultant Psychiatrist/Psychiatrist
- Psychological Therapist
- Counsellor
- Specialist dietitians
- Specialist Nurses
- Social Worker
- Assistant Psychologists
- Art Therapist
- Occupational Therapist
- Administrators
- Systemic Family Therapist

### Multidisciplinary Team





# BEDS Pathway

# **Outpatient Treatments**

Screen & Assess referrals

First Steps Group/Individual First Steps Group

Group Treatments

**Individual Psychological Therapy** 

Family Therapy

Specialist Dietetic Support

**Psychiatric Consultation** 

Family and Carers' support Group

### **Day Programme**

Intensive group treatment for individuals with severely restrictive eating and low and/or rapidly declining weight

Structured and focused on meal support as well as behaviour change

Involves group therapy, occupational therapy, dietetic support and individual psychological therapy

8 places

4 days/week from 9am to 2pm

12-week blocks

# **Outreach Team**







THERAPEUTIC INPUT THAT
SUPPORTS BEHAVIOURAL
CHANGE

**KEY WORK** 

INPATIENT LIAISON AND PRE AND POST INPATIENT STAYS

# **SHaRON**

BEDS offers a Support, Hope and Recovery Online
Network (SHaRON) to service users as well as
their parents, carers or partners. It is a
safe, confidential space where users can seek advice
and support both from members of BEDS staff
(during the hours of Mon-Fri 9-5) and from each
other (24/7). All content on the network is
moderated by staff, and also by recovered patients
who contribute to this network as peer moderators.

As well as live chats, blogs and discussion forums, a library of resources and podcasts are accessible on SHaRON

### Family and Carers Peer Support Group

To provide an opportunity to talk to others in a similar position as well as talk to professionals

For carers to share experiences and gain access to information and support

To provide a safe place to talk about concerns and successes

To provide education around eating disorders

To provide a break from being a carer.

### Our FREED pathway

Pathway has been adapted to meet the needs of BEDS and is ongoing.

- 1. Referral received by FREED team and placed on FREED tracker. Start the clock!
- **2. 48-hour call completed to assess suitability & book assessment.** Key aims; i) engage the client, ii) 'screen' of onset of eating disorder and suitability for FREED, and iii) Provided key information and iv) book in the assessment there and then.
- 3. FREED 90-minute assessment which includes psycho education within 2 weeks of referral received. Flexible working to meet the needs of clients and best effort to meet deadline.
- 4. 2-3 weeks following assessment an additional 1:1 session looking at any nutritional change and maintain therapeutic relationship. We provided this to avoid breaking momentum whilst waiting for FSG.
- 5. First steps group as soon as available Group has been adapted to meet treatment status and now inline with CBT evidence-based intervention.

### **Snap shots**

- 161 assessments completed under FREED pathway, 135 of those FREED eligible
- 16 clients have completed treatment to recovery phase and been discharged
- Really struggling to get clients into treatment quickly. So needed to reevaluate our first steps group -an intervention that is offered for all clients. Initially designed for a getting ready group with no expectations of change. We introduced all the key principles of CBT-e in the programme which made it an approved evidence based treatment. Those time frame targets have become much more achievable for many.
- Successful transitions/preparation for university group 10 clients mix of FREED and Non FREED excellent feedback developing further for summer camp next year. Longer and to include finances, self esteem work, cooking and carers involvement.
- FREED always on agenda in our MDT meetings and attend all age for clients under 18 that may benefit from FREED approach
- Attending and contributing to implementation supervision and other eating disorder best practice forums
- Close working with GP at RHU some clients seen for treatment to avoid secondary care and also preventative work for sub clinical presentations.

# Session 2: Strengthening FREED and Developing Early Intervention Further Chairs: Dr Giulia Di Clemente and Dannie Glennon





# FREED Inequalities Toolkit

**Becca Randell - CYP Mental Health Implementation Lead** 

Kent Surrey and Sussex Academic Health Science Network

Kent Surrey and Sussex Applied Research Collaboration



### Why do we measure health inequalities?

Health inequalities are said to exist when individuals with a social disadvantage have less access to effective treatment and relevant support, leading them to experience poor treatment outcomes or reduced quality of care.

Monitoring how various aspects of health differ between various population groups is vital to identifying people from vulnerable groups.

### Inequalities and eating disorders

"Research also shows eating disorder behaviour prevalence rising at a faster rate for individuals of lower socioeconomic status compared to individuals of higher socioeconomic status" (Moreno) EDs have historically been thought to afflict "skinny, white, affluent girls". As such, higher-weight individuals, racial/ethnic minorities, those from socioeconomically disadvantaged backgrounds, and males may not recognise their need for treatment, may not be properly screened for EDs, and/or may not be referred to treatment."

(Sonneville)

### Purpose of the toolkit

- Better understand the local population needs or demographics of young people presenting with an eating disorder across Kent, Surrey and Sussex.
- Understand who is using and being offered the FREED programme and if this offer is equitable across the local population of young people who have an ED.
- Aligns with the adaptation of the Core20PLUS5
- Service quality improvement/transformation





# NEW FREED INEQUALITIES TOOLKIT

Helping healthcare professionals to better understand the demographic needs of young people with eating disorders.

Kent Surrey Sussex Academic Health Science Network



# How inequalities are measured across FREED Programmes in Kent, Surrey and Sussex



### **Engaging Partners**

Gain commitment from key partners and stakeholders, including FREED Champions and Service Leads



#### **Establishing Inequalities Measures**

Agree metrics, outcomes, data sharing, Information Governance and start collecting data to establish baseline. Connect with Trust Information Governance (IG) Leads



### **Demonstrating Impact**

Continuous data collection and review of impact, maintaining a health inequalities focus. Utilising data to support service innovation and improvement, to positively impact the care of young people with eating disorders



#### **Providing Tailored Support**

Regular meetings and peer support for the service. Feedback progress, share learning and celebrate success



Sustain and embed health inequalities focus to support better care

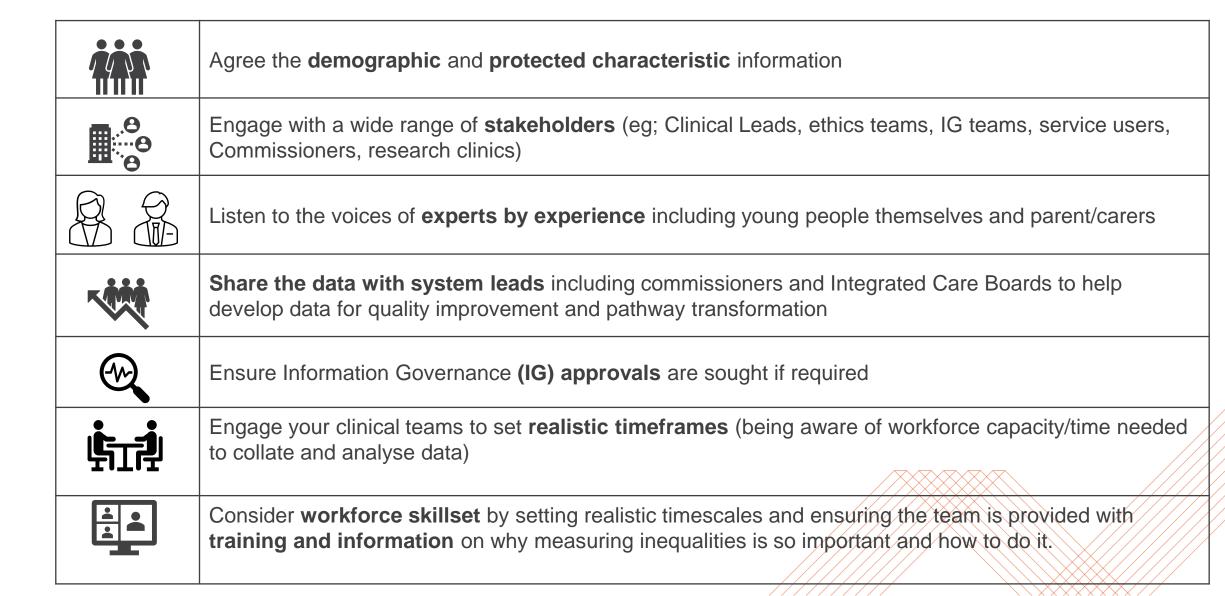


## Voice of lived experience

"I already had baggage of being bullied, as I was being called freak, weirdo, not normal... I did not fit in and really started suffering at the age of 14/15. It all started with the bullying... ED is never just that alone, it ties it with other issues, depression, anxiety, seeking the control of eating as help"

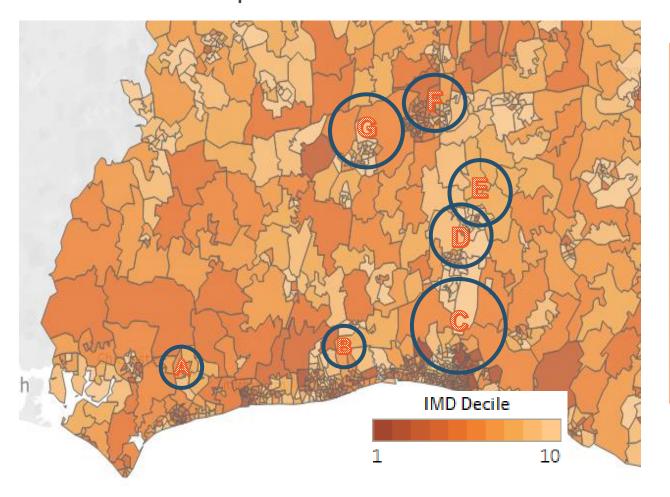
Young 17 yr old gay male

## **Top Tips for Measuring Inequalities**



# **Example Map of Deprivation**

### IMD Map from KSS Dashboard

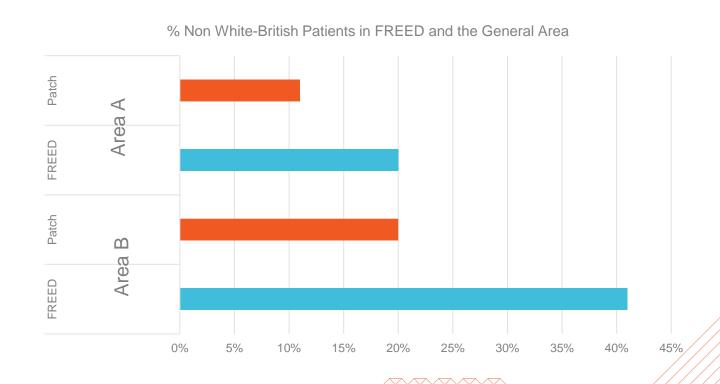


Patch	Number Patients	IMD
Area A	20	7-10
Area B	20	8-10
Area C	50	1-10
Area D	30	3-7
Area E	30	9-10
Area F	25	6-10
Area G	40	7-10

### Example of Ethnicity Breakdown

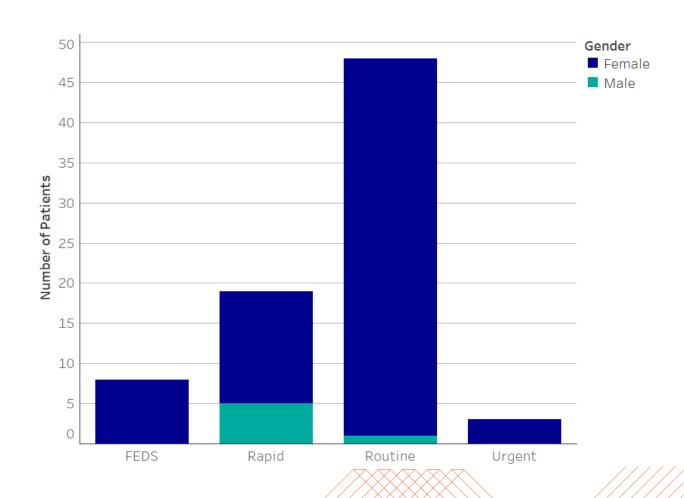
 There was a larger proportion of non-white British patients within the service compared to the areas the patients are from.

In Area A, 40% of FREED patients were non-white British compared to 20% of the population within the area



## Example of gender data

- The gender split of patients was over 10 females for each male (10:1). Research indicates that this is typical of an eating disorder service but highlights systemic health inequalities within eating disorders.
- x patients were transgender males. There were x transgender females recorded.
- The small number of male patients compared to female patients makes identifying trends difficult and a larger sample size would be needed to draw conclusions.
- Higher number of males in rapid category



And so? .....

"Anyone can be affected by an eating disorder, but eating disorders do not affect everyone equally. Some young people are less likely to be recognised and more likely to face barriers to receiving treatment."

#### **Celebrating FREED across South East of England**

- Voices of FREED patients through video (Kent, Surrey and Sussex)
- Working in partnership across south east
  - SE FREED Community of Practice
  - Peer support in ED survey and webinar
  - Eating Disorder Innovation Webinar
  - Pilot ED digital CBT









exploring the art of the possibility

Early intervention, Remote monitoring, Digital support and much more.

NHS

### **Peer Support** in Eating Disorder services webinar

Wed 1 March 9:30 - 12:00

- · How to implement Peer Support
- Models and examples of Peer Support with an Eating Disorder service
- · Training, organisational readiness & supervision
- Input from FREED National programme expert-by-experience
- Voluntary care sector and Peer Support
- · BEAT Peer Support Training Experiences from pilot across the South
- · Case studies from those impacted by Peer Support.











#### For information

<u>Eating disorders | Improvement -</u> <u>Academic Health Science Network</u> <u>(kssahsn.net)</u>

or email:
Becca.randell@nhs.net

# NEW FREED INEQUALITIES TOOLKIT

Helping healthcare professionals to better understand the demographic needs of young people with eating disorders.

rrey Sussex nic Health Science



# FREED: Valuing Lived Experience in Early Intervention for Eating Disorders

Kirsty Stapledon, Peer Support Worker

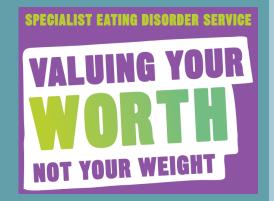
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Dr Sheryllin McNeil, Consultant Clinical Psychologist

Specialist Eating Disorder Service, Forward Thinking Birmingham

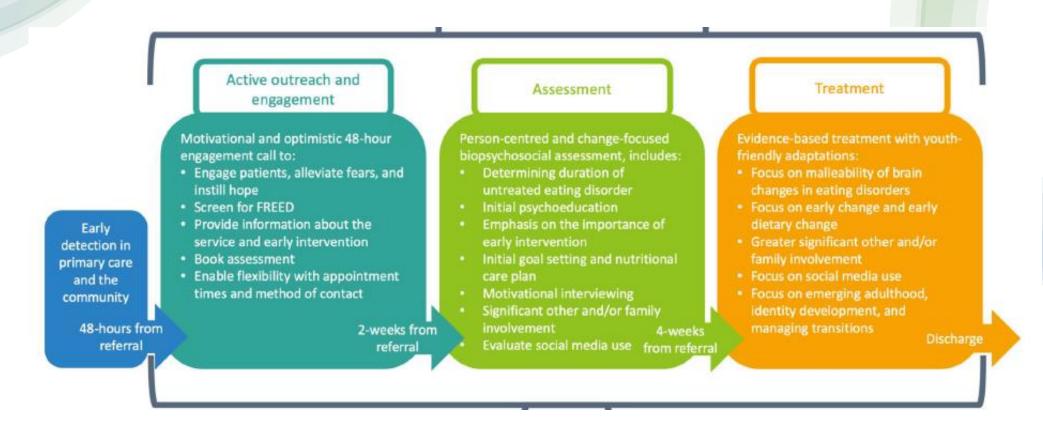
Monday, 27th February 2023







# Lived Experience – For the Journey



Lived Experience





The Model: Addressing delays

Components	Aims: To shorten duration of untreated illness and increase likelihood of recovery in young people 16-25, with recent onset Eds (<3 years)							
Structure	<ul><li>Service-within-a-service</li><li>FREED champion (dedicated time)</li><li>Mini-teams</li></ul>							
Processes & Procedures	<ul> <li>Screening call within 48 hours of referral</li> <li>Assessment and treatment targets</li> <li>FREED-patient tracker for prioritisation</li> </ul>							



# It ain't watch you do it's the way that you do it...

Components	Aims: To shorten duration of untreated illness and increase likelihood of recovery in young people 16-25, with recent onset EDs (<3 years)
Content	<ul> <li>Evidence-based treatments with youth-friendly adaptations, e.g.:</li> <li>Focus on malleability of brain changes         <ul> <li>highlighting need for early nutritional action</li> </ul> </li> <li>Involvement of parents where possible</li> <li>Exploring social media use</li> <li>Focus on managing 'adulting', incl. identity development &amp; transitions</li> </ul>
Style	<ul><li>Person-centred &amp; youth friendly</li><li>Motivational</li></ul>



#### ... that's what gets results

- In a systematic review of 126 studies looking at predictors of ED outcomes, symptom remission was the key focus and used as a key outcome in over 80% of studies (Vall & Wade 2015).
- In our clinical settings the focus is often the same we look at what we can measure/compare. (We've even got a FREED tracker for it!)
- Important not to lose sight of the all important moderators in recovery in our attempts to address those all important service and patient related delays.
- How we define ED recovery is a major influence on how we understand and moves towards it.
- A recovery framework, championed by Peer Support, running throughout your FREED model can help to promote collaboration and ensure we are focused on what recovery truly means and does for the person seeking it.



# The CHIME conceptual framework of personal recovery

Recovery	is	an	active	process

Individual and unique process

Non-linear process

Recovery as a journey

Recovery as stages or phases

Recovery as a struggle

Multidimensional process

Recovery is a gradual process

Recovery as a life-changing experience

Recovery without cure

Recovery is aided by supportive and healing environment

Recovery can occur without professional intervention

Trial and error process

- Peer Support in SEDS is heavily informed by the CHIME conceptual framework (Mary Leamy,\* Victoria Bird,\* Clair Le Boutillier, Julie Williams and Mike Slade, 2011)
- Conducted a systematic review of 97 papers on personal recovery in order to develop a conceptual framework.
- The framework consists of 13 characteristics of the recovery journey

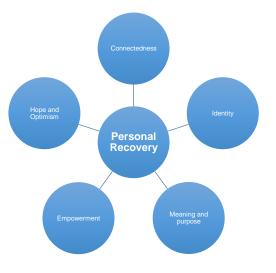




# Principles/Processes of CHIME informed, FREED focused Recovery:

- Connectedness: This describes the sense of being positively connected to other people and ourselves
- Hope & Optimism: There can be no change without the belief that a better life is both possible and achievable.
- Identity: This refers to the maintenance or construction of a positive sense of self.
- Meaning: We all find meaning and purpose in different ways so this can be deeply personal. For some it may overlap with their sense of connectedness, for others it may relate to their faith.
- Empowerment: This refers to one's belief in one's own capacity to take the wheel in recovery. Supporters can also empower us by emphasizing choice.









#### Why Lived Experience CHIMEs

As someone with Lived Experience CHIME 'struck a note'

Lived experience within the FREED model involves supporting patients and parents to CHIME, connect with themselves and reclaim their lives once more.







### Putting the Optimism back into Outreach

Belief in Recovery

Hope and Optimism

Positive
Thinking

Early
detection in
primary care
and the
community

Motivational and optimistic 48-hour engagement call to:
 Engage patients, alleviate fears, and instill hope

Screen for FREED

- Provide information about the service and early intervention
- · Book assessment
- Enable flexibility with appointment times and method of contact

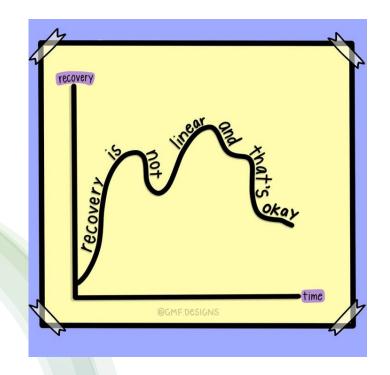
Active outreach and engagement Motivation

Dreams and Aspirations





#### Key Outreach Messages:



#### 1. Full recovery is possible

- It may seem difficult to see how it can be possible, but it is possible
- It may feel hard to imagine what life without an eating disorder (with all of the thoughts, rules and beliefs that go with it) will be like, but that life can become a reality.
- Using the fact we also felt this way. If it is possible for us it is possible for them too.

#### 2: You are not broken

• You are not broken. You never have been and never will be. This means that fundamentally, you as a person do not need 'fixing'.

Underneath the thoughts, beliefs, rules and behaviours of the eating disorder is you - the whole, undamaged, spectacular you who is always there.

#### 3: You are not the eating disorder

- The eating disorder is something you are going through right now, but it's not who you are.
- Even though it may feel like it some (or a lot of the time), it will never be who you truly are.
- This means we don't need to be so afraid of letting the eating disorder go. We are always whole human beings, no matter what we may be going through.



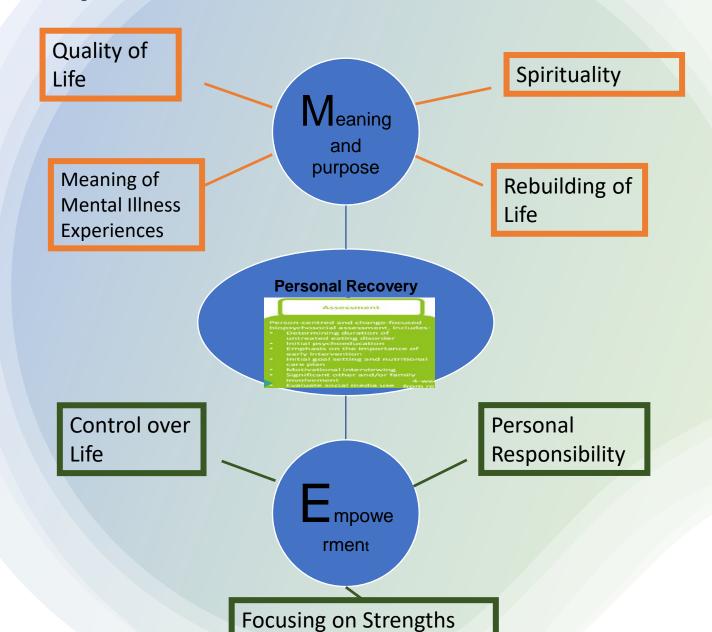
Remaining hopeful and optimistic means never giving up, even in the times where it was critical, for me, it was always telling myself that this won't be the end. I always had a goal, no matter how unrealistic in the moment that it seemed, the main one being my career. I was going to be well enough to be a nurse. I was going to get better. I was going to get better even in the times when I was getting worse. I always told myself that it wouldn't be forever and when those around me said I never would. I would always say 'watch me'.

I had to remain hopeful and I had to remain present, it stopped me from giving up and now, a few years later than expected. I'm a student nurse, thriving.

I'm helping those who feel scared like I once did, need support, like I did and I'm giving back. I did make it, and forcing myself to keep the faith in myself, even when it felt impossible, was so worth it



### **Empowerment at Assessment**







# Engaging with Change

- Eating disorders are a way of coping with the world so letting them go is scary stuff!
- From our own experiences of eating disorders and eating disorder treatment, we felt it was important to explore what is meaningful to the person in order for them to find what truly motivates them in recovery.
- This is backed up by qualitative research, which shows the importance of finding both hope and meaning in increasing motivation to recover (Venturo-Conerly et al., 2020).
- Finding this meaning and motivation can be difficult to do alone, and sometimes we lose hope that we will recover. Hearing from someone from lived experience has been shown to increase hope and inspire motivation in eating disorder recovery (Lewis & Foye, 2022).



# Empowerment: Being the Author of your own recovery

- From the outset we work to ensure people know that we see their worth beyond the numbers on the scale and support them to become the authors of their own recovery.
- Having someone with lived experience to guide them through contemplating recovery, its pros and cons and using other motivational techniques helps the struggling individual to feel more hopeful about recovery and eventually find ways of making recovery meaningful to them.

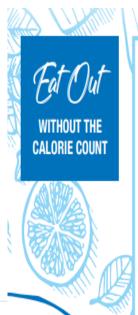
Knowing what meaning I want life to have, outside of my ED, has helped me to continue with recovery and fighting against the ED voice in my head every single time I sense it wanting to overpower me again SEDs patient



The Empowering/ Energising Effect of Lived Experience

Supporting service users to stepping into your Power: Social Change





The Eating Out Without the **Calorie Count Campaign** (#EWOCC)

NITS FOURIGION TRUST

#### For Starters:

Calorie information on menus can cause difficulties for many young people recovering from eating disorders and/or eating difficulties.

> EWOCC is encouraging local Birmingham Restaurants to be RECOVERY FRIENDLY.

#### What being a recovery friendly restaurant means:

Ensuring alternative menus (without calorie information) are available to all. This way those on their recovery journey can feel safe and enjoy all that your restaurant has to offer alongside other patrons.

#### What you can do:

Show your support and be a part of this exciting campaign:

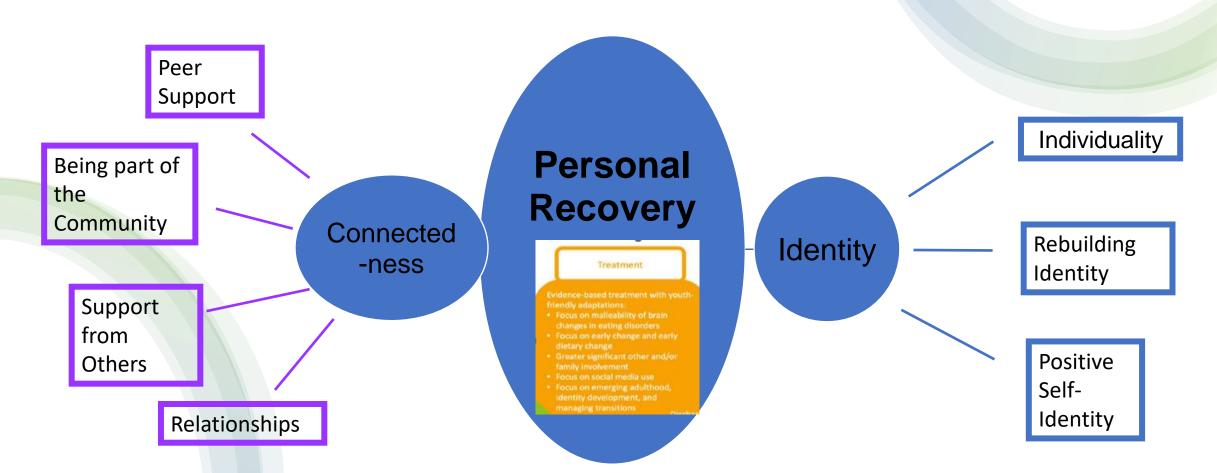
Display the EWOCC logo in your restaurant window. Visit: forwardthinkingbirmingham.nhs.uk/EWOCC to

For more information please visit our website.





#### CHIMING THROUGH TREATMENT







#### How Lived Experience CHIMEs

An often over-looked part of eating disorder recovery involves finding 'self' again.

This is especially true when many patients strongly identify with their condition and might not fully know who they are outside of this just yet.

Even more true for this age group, emerging into adulthood – these are <u>the</u> identity crisis years even without an ED. Who am I? Who will I be?



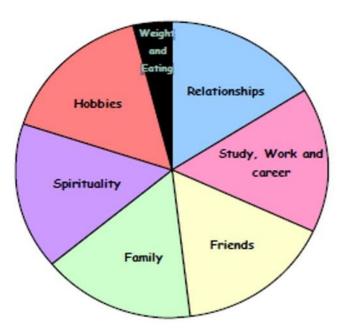




#### Addressing the 'I' in CHIME











#### The Bridges and the Benefits

- Lived Experience practitioners support co-production within pathways and inform improvement of service delivery, supporting the reduction of Service Related delays.
- Experts by experience can provide a powerful voice that is able to challenge assumptions & motivate organisations to do things differently; pinpointing areas for change/development e.g. Recovery Focused Language Training for Staff.
- Self-reports to date have shown that sharing lived experience could also be significant in reducing patient related delays - increasing levels of motivation for those seeking treatment and reducing stigma.
- Those with lived experience can also help advocate for the needs of those seeking treatment, bringing a much needed "been there" perspective to both patients and clinicians.
- Evidence suggests that support from peers who have experienced mental illness can significantly reduce readmission for acute psychiatric hospitalisation.



Birmingham Women's and Children's

#### Let FREEDom from ED CHIME

"I find it really helpful when my peer support worker shares their own struggles and what has helped them, it makes me feel understood and it allows me to try new ways of coping/dealing with my own struggles. It also makes me feel hopeful about recovery"

"I found it helpful to speak with someone who understands what I've been going through. I felt comfortable speaking about my experiences." "It was really inspiring, the peer support worker was really understanding and it was helpful in showing me different ways to cope and how to live a life away from the ED"

"The CHIME programme has been brilliant for me. It has been an integral step between being fully in services and being discharged. Going to CHIME sessions weekly has improved my mental health, including my work-life balance. My peer support worker has been a great mentor, I feel I can be open and honest with them and they have been brilliant in helping me work through the later stages of recovery. After our CHIME sessions I leave feeling boosted and motivated to continue to persevere with recover"



# the Change you want to SEE



# Allowing others to SEE

# the Change they want to

BE



#### Summary

- Lived Experience within Early Intervention is effective at **every** phase of the FREED.
- Involving Lived Experience practitioners in service delivery can support early engagement in change and treatment overall. Bringing creativity and innovation to the reduction of treatment delays and <u>Live</u>ning up NICE guidelines!
- Lived Experience adds powerful <u>authenticity to the work</u> useful when raising awareness and championing certain causes and voices.
- Involving Lived Experience practitioners in service delivery can support the widening diversity, inclusion and representation within services.
- The experience of involvement <u>for</u> the Expert by Experience is a positive one for them also, bringing great deal job/role satisfaction, boosting confidence, creating a sense of pride and self-worth and maintaining meaning and motivation.





FREED Conference: 27<sup>th</sup> March, 2023

# How best to involve families in treatment for transition age youth:

Data from a randomised controlled trial of multi-family groups vs family therapy

#### **Dr Julian Baudinet**

Consultant Clinical Psychologist
Maudsley Centre for Child and Adolescent Eating Disorders





# **Emerging** adulthood

4. Service & treatment changes

Potterton, et al., 2020; Hudson et al., 2007; Kessler et al., 2013; Micali et al., 2013; Steinhausen and Jensen, 2016



Q:

How do we involve family members and loved ones in the most helpful, developmentally appropriate ways?

ICCAFD — not to be used without permission



#### Findings from a Randomised Controlled Trial (RCT)

(Eisler, et al., 2016)

- Multi-centre RCT in England
- Family therapy (FT-AN) vs Multi-Family Therapy (MFT)
- N = 169 with AN or EDNOS-AN

Age: 12-20 years

>16 years: 38.3%

>18 years: 8.4%

Eisler et al. BMC Psychiatry (2016) 16:422 DOI 10.1186/s12888-016-1129-6

**BMC** Psychiatry

#### RESEARCH ARTICLE

Open Access

# A pragmatic randomised multi-centre trial of multifamily and single family therapy for adolescent anorexia nervosa



Ivan Eisler<sup>1,2\*</sup>, Mima Simic<sup>2</sup>, John Hodsoll<sup>1</sup>, Eia Asen<sup>3,4</sup>, Mark Berelowitz<sup>5</sup>, Frances Connan<sup>6</sup>, Gladys Ellis<sup>2</sup>, Pippa Hugo<sup>7</sup>, Ulrike Schmidt<sup>1,8</sup>, Janet Treasure<sup>1,8</sup>, Irene Yi<sup>9</sup> and Sabine Landau<sup>1</sup>

#### Abstract

Background: Considerable progress has been made in recent years in developing effective treatments for child and adolescent anorexia nervosa, with a general consensus in the field that eating disorders focussed family therapy (often referred to as Maudsley Family Therapy or Family Based Treatment) currently offers the most promising outcomes. Nevertheless, a significant number do not respond well and additional treatment developments are needed to improve outcomes. Multifamily therapy is a promising treatment that has attracted considerable interest and we report the results of the first randomised controlled trial of multifamily therapy for adolescent anorexia nervosa.

Methods: The study was a pragmatic multicentre randomised controlled superiority trial comparing two outpatient eating disorder focussed family interventions - multifamily therapy (MFT-AN) and single family therapy (FT-AN). A total of 169 adolescents with a DSM-IV diagnosis of anorexia nervosa or eating disorder not otherwise specified (restricting type) were randomised to the two treatments using computer generated blocks of random sizes to ensure balanced numbers in the trial arms. Independent assessors, blind to the allocation, completed evaluations at baseline 3 months.

12 months (end of treatment) and 18 months.

Results: Both treatment groups showed clinically significant improvements with just under 60% achieving intermediate outcome (on the Morgan-Russell scales) at the end of treatment in the FT-AN group and mo in the MFT-AN group - a statistically significant benefit in favour of the multifamily intervention (OR = 2.55 \* 552; p = 0.019). At follow-up (18 months post baseline) there was relatively little change compared to end although the difference in primary outcome between the treatments was no longer statistically significant significant gains in weight were accompanied by improvements in mood and eating disorder psychopath Approximately half the patients in FT-AN and nearly 60% of those in MFT-AN had started menstruating.

Conclusions: This study confirms previous research findings demonstrating the effectiveness of eating disorder focused family therapy and highlights the additional benefits of bringing together groups of families that maximises



# Family Therapy for Anorexia Nervosa (FT-AN) Brief Description

#### Phase 1: Engagement

- Outpatient treatment
- Typically a 6-12 months, 10-20 sessions
- Manualised and evidence based
- First-line recommended for adolescent AN & BN (NICE, 2017)

Phase 4: Ending







# Multi-Family Therapy for Anorexia Nervosa (MFT-AN) Brief Description

#### **Outpatient Group**

- 6-8 families
- 8-10 days (10am-4pm)
- ~6-9 months

#### **3 Components**

- 1. Introductory afternoon
- Intensive workshop
   (4 consecutive day)
- 3. Follow-up days (4-6 single days)

+ Single FT-AN as needed in parallel





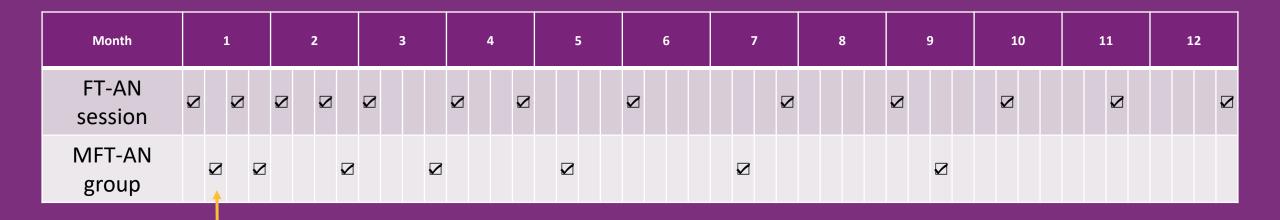
# FT-AN & MFT-AN Example Treatment Timeline

Month	1	2	3	4	5	6	7	8	9	10	11	12
FT-AN session					Ø	Ø			Ø	Ø	Ø	





# FT-AN & MFT-AN Example Treatment Timeline



4 full days, 10am-4pm



Time / Day	Activity
10:00-11:00	Activity 1
11:00-11:30	Snack + Break
11:30-1:00	Activity 2
1:00-1:30	Lunch
1:30-2:00	BREAK
2:00-3:00	Activity 3
3:00-3:30	Snack + Break
3:30-4:00	Reflection / Feedback



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2:00-3:00	Activity 3
3:00-3:30	Snack + Break
3:30-4:00	Reflection / Feedback







When I'm feeling\_\_\_\_\_ (emotion),

You'll see me\_\_\_\_\_ (doing),

And I need\_\_\_\_\_,

Not to be confused with\_\_\_\_ (other emotion).

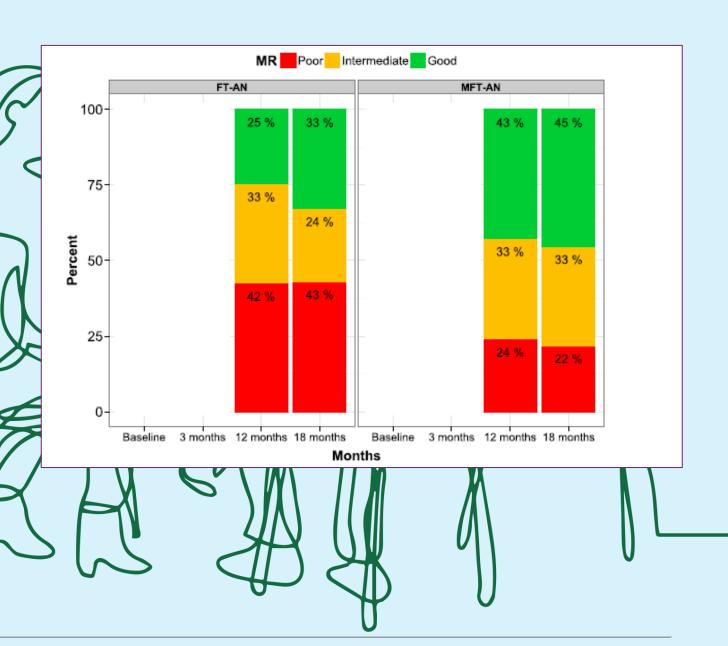
# **Example** activities





# Main findings

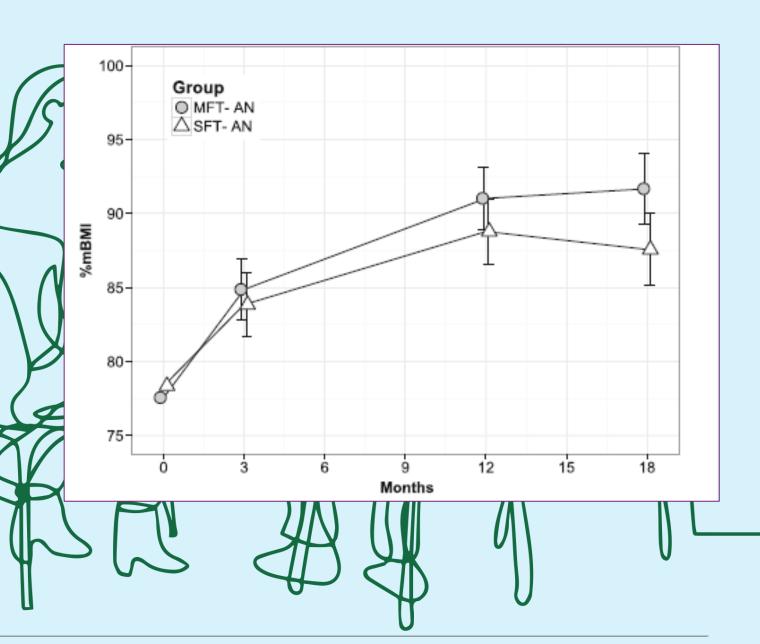
- MFT-AN has advantage over FT-AN at EOT
- No difference between groups at 6-month followup





# Main findings

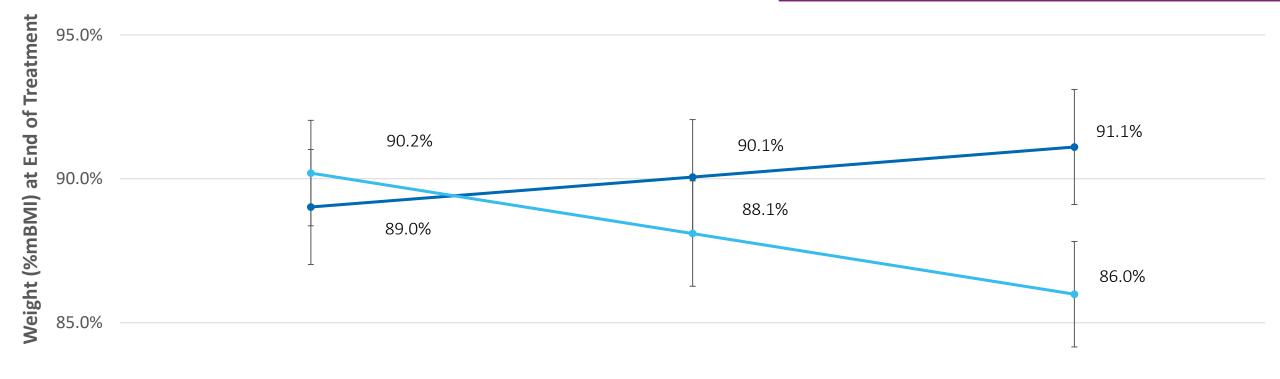
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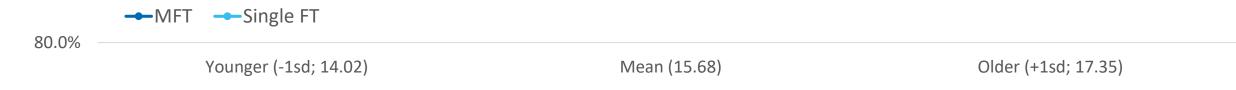






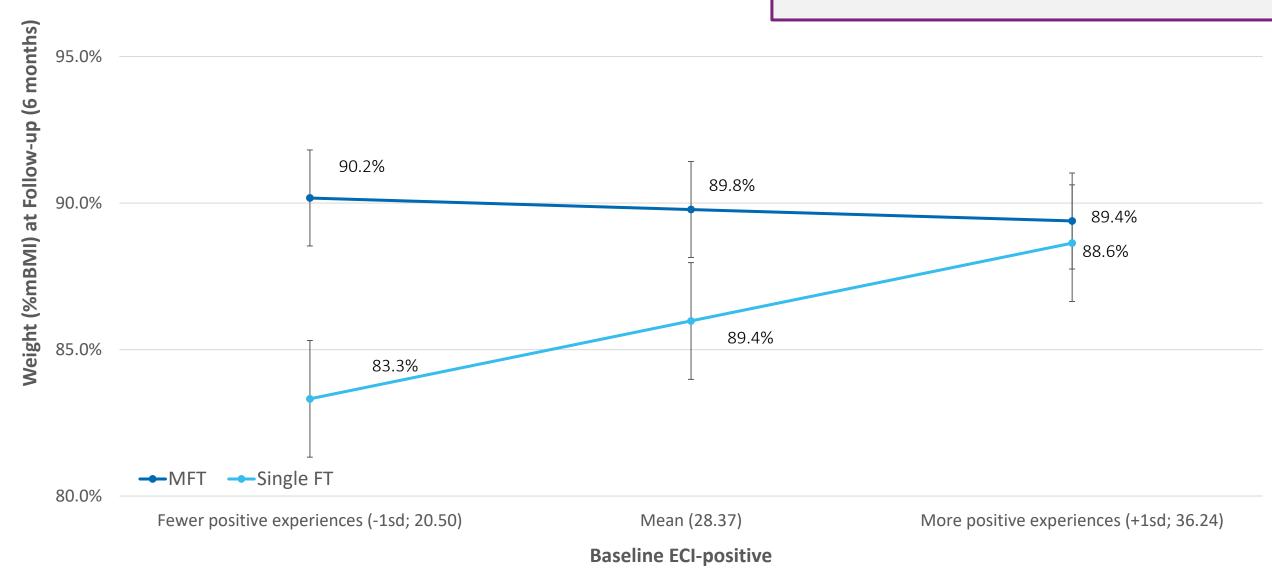
# Age





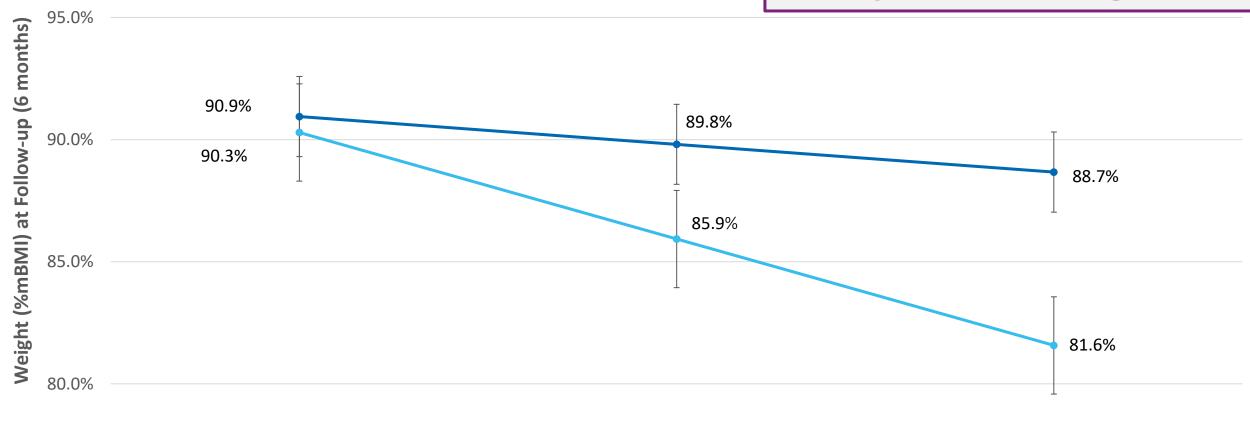


# **ECI-Positive**



100.0%

# **Early ED change**





Mean (-0.71)

Minimal reduction or slight increase in ED symptoms (+1sd; +0.58)



1.

MFT may be particularly help older adolescents and emerging adults

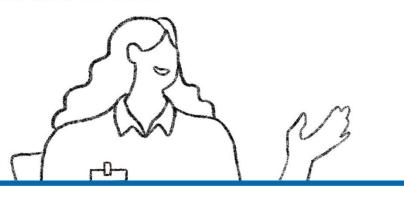
Main Findings 2.

MFT may buffer against some individual and family factors that may be associated with poorer outcome in FT-AN

# But, why?

### **MFT Content**

- Broader
- More flexible
- Very responsive to group need



### **MFT Process**

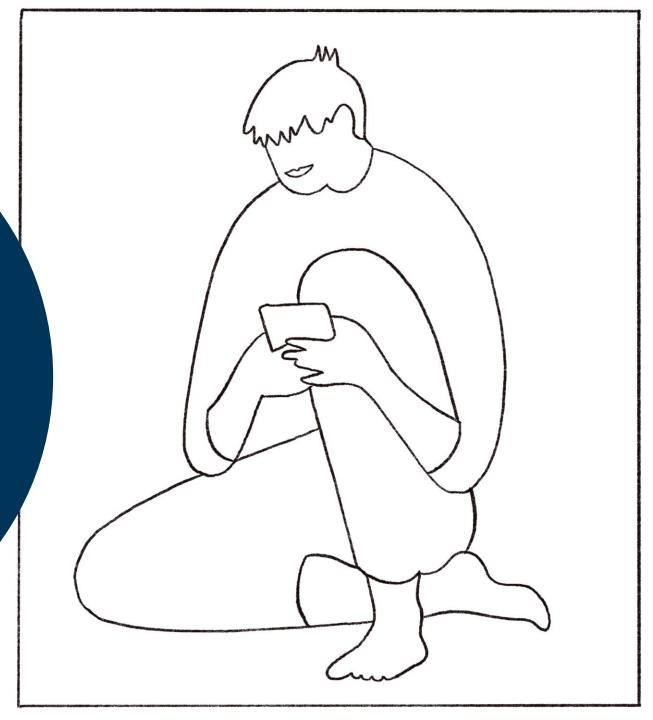
- More time to engage people early and as individuals & as families
- More separated time with young people
- Connection, observing and sharing with others at same transitional period in life
- Feeling less isolated
- May be more developmentally appropriate to share some things with peers than parents
- Mix of family, peer and staff support
- Group process may buffer against individual/family factors that may block engagement

### **Trial factors**

- DUED <12m
- 33.8% MFT with 3m
  - MFT just more?



The unique combination of therapist, family and peer support with broader focus (life and eating) and intensity early in treatment might meet the developmental needs of this group most effectively





**Future directions ...** 

YP and parent experience?

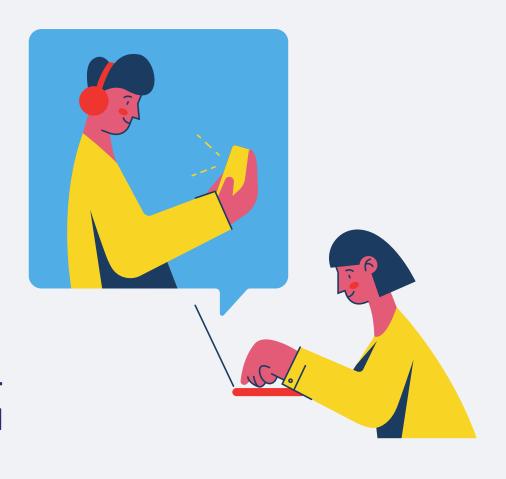








A Randomised Controlled Feasibility Trial of a Smart-Phone Friendly Multi-Modal Decision Making Tool (FREED-M) to Improve Help-Seeking















# Contents

What is this presentation going to cover?

1 Background

**2** FREED-M Intervention

**3** FREED-M Study

4
Current progress

# The problem: Patient-related barriers to help-seeking

- 1. Attitudes/
  Beliefs
- Shame
- Selfstigmatisation as undeserving
- Negative attitudes towards seeking help

- 2. Knowledge-Based
- Inability to recognise severity of illness
- Lack of knowledge about available help

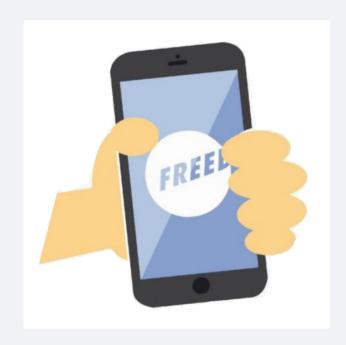
3. Motivation

 Ambivalence about change

# FREED-M

### First Episode Rapid Early Intervention for Eating Disorders - Mobile

- Online intervention tool to increase motivation and help-seeking in young people
- Developed in co-production with young people with EDs



FREEDM.UK

# Intervention Components

Module 1: Help-Seeking

Week 1

**Personalised Feedback** 

**Animation** 

Resources

Module 2: Social Media

Week 2

**Personalised Feedback** 

**Animation** 

Resources

Module 3: Gut Health

Week 3

**Personalised Feedback** 

**Animation** 

Resources

Module 4: The Brain, Recovery etc

Week 4

**Personalised Feedback** 

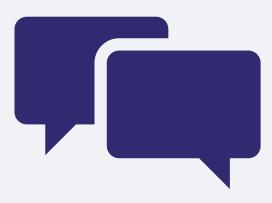
**Animation** 

Resources

### Personalised Feedback

- Increases depth and likelihood of processing information (Musiat et al., 2012)
- Positive effect on psychotherapy outcome (Knaup et al., 2009; Sapyta et al., 2005)
- Studies using personalised feedback in ED interventions have had promising results (i.e., Schmidt et

al., 2006; Lopez et al., 2008)



# Animations

- Facilitates in-depth information processing,
   development of new perspectives, and self-discovery
   (Ogston-Tuck et al., 2016)
- Increases satisfaction and emotional connection (i.e., Meppelink et al., 2017)
- Engaging visual materials (i.e., Davies et al., 2017)





# Animation 1: Getting support for your eating difficulties



Dr Rachel Potterton



# Resources



### Help and support for an eating disorder

This is our guide to seeking help for an eating disorder. It includes stepby-step information on how to seek eating disorder treatment, tips for talking to friends and family, and details of self-help resources.

We know it can be really hard to reach out for help. However, the sooner you seek help, the sooner things can start to get better.

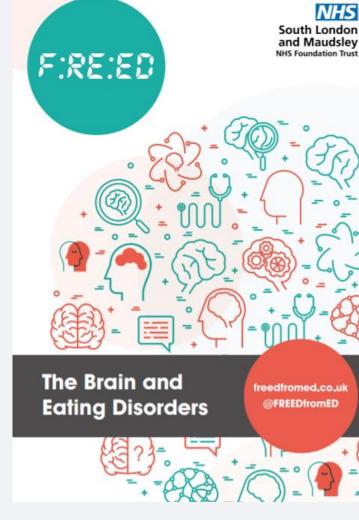
You don't have to take our word for it. This guide was developed jointly by clinicians and young adults with experience of eating disorder treatment. They know what it is like to be struggling with an eating disorder alone and share their advice throughout the guide.

> "I genuinely never thought I could feel this OK around food and the like. It just shows that you never know how capable you are of getting better until you try and can get the help you need."

> > FREED service user

"An eating disorder is the most lonely thing in the world. It doesn't have to be. Ask for help!" FREED service user

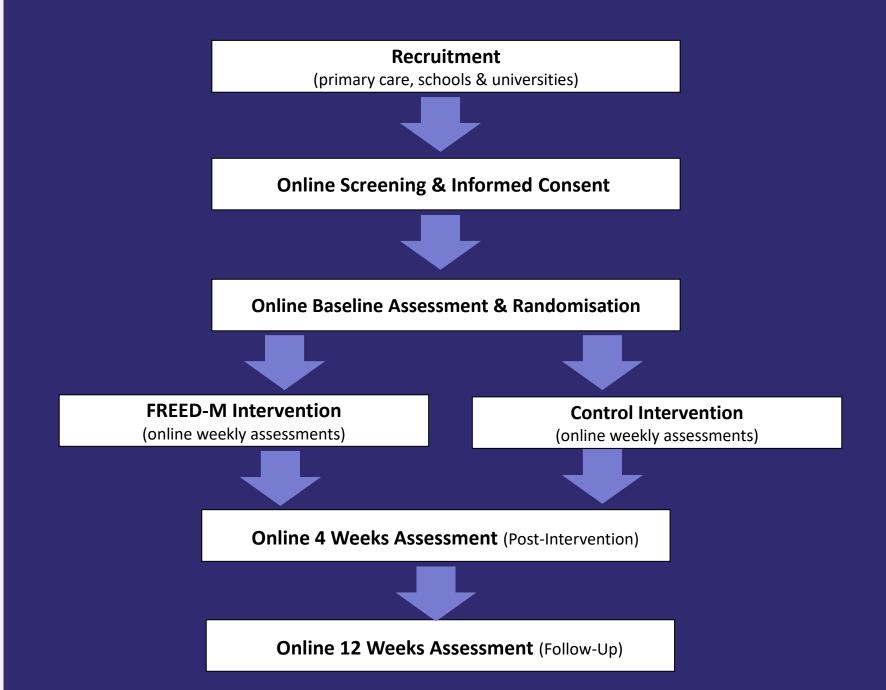
**■** @freedfromed



NHS



# The Trial



# Participants



### Target Sample

116 participants

### Inclusion criteria

- Participants aged 16-25 years
- Probable eating disorder (SCOFF)
- Living in England or Wales

### **Exclusion criteria**

• Current or previous specialist ED treatment

# Current Progress

- Study end date: 31 May 2023
- 83 participants signed up and randomly allocated as of 22 March 2023
- 111 participants screened out
  - In regular treatment
  - Doesn't meet cut-off score on SCOFF
  - Out of the country



# Interested in getting involved?

We would love your help!

### Some ideas for recruitment:

- Display posters/leaflets
- Mention the study during assessments
- Email patients currently on the waiting list for treatment or assessment
- Open to any other creative ideas!



**Email:** 

FREEDMobile@kcl.ac.uk

For more information

### Ulrike Schmidt (CI)

- Karina L. Allen
- Helen Sharpe
- Molly Davies
- Kimberley Goldsmith
- Sarah Byford
- Vanessa Lawrence
- Danielle Glennon
- Victoria A. Mountford
- Nina Grant
- Vibhore Prasad
- Rachel Potterton
- Luiza Grycuk
- Priya Popat

# Thank you for listening!

Any questions?



FREEDMobile@kcl.ac.uk



'Getting started' on the road to recovery; Developing a virtual psychoeducation and motivation group for FREED DEVON PARTNERSHIP NHS TRUST

#### Aim

The aim of the group is to give rapid access to psychoeducation and support to young people referred to our FREED pathway. The goals are to increase understanding about eating disorders (EDs) and its effects, to set goals for change, to increase motivation, confidence and ability to change, and to reduce isolation.

The group adheres to the following core FREED principles:

- (1)early change by utilising a group setting, we are able to deliver psychoeducation quickly as part a rolling 6-week programme delivered by both FREED staff and the wider CEDS team;
- (2)person-centred and flexible care although there are specific modules, the group is also flexible and client-led as we ask for written feedback via email after each session so we can be responsive to group needs and preferences

#### Results

We have collected pre- and post-group data (EDE-Q, CORE-OM and

decreases in EDE-Q and CORE-OM scores and statistically significant for the EDE-Q scores and confidence to change scores. Data also shows that we have had very good retention of numbers in the group which we believe are FREED principles that we have adhered to.

**Evaluation tools** 

emails after each session

#### Methods

After initial FREED assessment, clients are offered the group as their initial intervention. The group is delivered by 2 facilitators (Assistant psychologist & other qualified staff) virtually using MS Teams.

#### Overview of group format

Week 1: introduction, overview plus goal

Week 2: Peer support led recovery story & Physical/psychological effects of EDs Week 3: Nutrition and EDs (Dietetics)

Week 4: CBT 1: Intro to CBT - ED

Week 5: CBT 2: Cognitive re-structuring and behavioural experiments

Week 6: flexible to group and review

After each group session participants are sent emails asking them for feedback about how they found the session and to respond to any questions/issues. Post group 1:1 review offered

#### Conclusion

A group as initial intervention n FREED pathway appears to be effective in engaging motivated and start making early changes. By evaluating it in multiple ways, we have developed some practice-based evidence for this approach which combines psychoeducation, CBT principles of change and peer led recovery stories. This which adheres to all the FREED principles and may be more cost effective than 1:1 support.

This group was a south west collaboration: shared initially by Somerset ED service and we have also subsequently shared our group West including Cornwall and Plymouth.





#### **Health Innovation Manchester**





#### **Project aims**

- · Earlier intervention and treatment of eating disorders in young people.
- Reduction in the length of time young people have untreated eating disorders.
- Work with local Eating Disorder service providers to support adoption of the FREED model in areas where is no equivalent service in place.

#### **Methods**

- Brought together service leads to share learning.
- Data visualisation tool created by Insight and Intelligence team which allows Eating Disorder leads a way of tracking the data on a more regular basis than the FREED centralised reports.
- · Project manager support and guidance available whenever needed.
- Strong working relationships with key stakeholders and colleagues.
- Press releases for launch events.

#### Results

- FREED services embedded into localities across Greater Manchester (Heywood Middleton Rochdale, Stockport, Manchester, Salford, Bury)
- Successful data visualisation tool created and used by services.

#### **Conclusion**

In summary, The FREED project has been a success, with services embedded over a number of localities Greater Manchester.









# Somerset Eating Disorder Service FREED evaluation project

Ellen Webster & Dr Sarah Biddell, Somerset NHS Eating Disorders Service for Adults Victoria Salmon, Cathy McCabe & Louise Hall, South West AHSN, Exeter, UK

#### **Project aims**

- To evaluate the implementation of the FREED pathway within Somerset from 2019-2022.
- To create a set of baseline data for future comparison projects.
- To inform learning for our team and the wider service.

#### Results

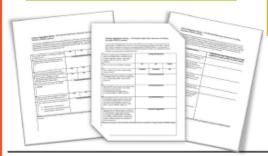
- High compliance rates for time based FREED targets (engagement call, Assessment) and principles of proactive engagement and psychoeducation.
- Lower compliance rates for principles such as ROMs and emerging adulthood.
- General sense of a gap in knowledge from referrers of Eating disorder criteria, FREED criteria, and awareness of the FREED pathway.

#### Methods

- Audit: Audited clients (n=44)
   referred to FREED pathway
   between April 2021 March 2022
   against the FREED standards.
- Surveys: Sent surveys to clients, clinicians and referrers exploring their experience of being on the pathway/referring on the pathway/delivering FREED pathway

#### Conclusions

- FREED model has been implemented well across Somerset, with some particular areas of high levels of adherence, though also some areas of low adherence.
- A need to continue to attend to the knowledge and promotion of the FREED model internally, as well as awareness and understanding of the FREED pathway and eating disorders more generally externally.
- Would also be helpful to get the views of services users as there was no uptake of survey invite.









### **Diversifying the FREED Workforce**

Ulrike Schmidt (SLaM/KCL), Dannie Glennon (SLaM)
Aileen Jackson, Jill Owens, Andy Scott-Lee (Health Innovation Network South London)
Funded by NHSE Community Mental Health

#### **Project aim**

Produce a feasibility report detailing the benefits and limitations of diversifying the eating disorders workforce through recruitment of six band 5 Experts By Experience employed at 0.2 wte to three national FREED sites.

#### Methods

- A pilot study is being used to define and explore best practices in involvement of Experts by Experience
- To support the study, a Waterfall Project Management methodology has been used

#### Results (so far)

- Three sites have been selected from the ten that applied
- Involvement models have been defined utilising latest research and best practice guidance
- Key measurement tools and criteria have been defined.
- Recruitment at the three sites is in process. Pilot commencement April 2023

#### **Forecast Conclusions**

- Development of a workable, adaptable model of Expert by Experience inclusion
- Three case studies for FREED Services to use as examples
- Learning on the benefits and challenges of Expert by Experience inclusion being shared widely













## *The***AHSN***Network*

# Collaborative working across the South East AHSNs: Early intervention in eating disorders

Sally Forbes (Wessex AHSN), Ellie Mason (KSS AHSN), Becca Randell (KSS AHSN), Matt Williams (Oxford AHSN)

#### Peer support

South East Academic Health Science
Networks (AHSNs) conducted a Peer
Support audit, to explore the potential role
of peer support in eating disorders.
Surveys aimed at NHS workforce, service
users and carers gathered the views and
experiences of peer support.

With over 100 respondents, the audit findings will be used to co-create a South East AHSN Peer Support Webinar which was held on 01 March 2023. For more information visit Pear Support in Eating disorders (wessexahsmang.ulc) or click on the LINK.

Download the full survey objectives, methodology and analysis here.

#### Community of practice

South East AHSNs established a Community of Practice to support colleagues interested in and engaged with the adoption of the FREED model across the region.

Well attended meetings were conducted every two months with input from FREED Network colleagues (South London and Maudsley) and the Health Innovation Network (HIN), as well as guest speakers from across the country to share innovations and best practice.

This has encouraged connections and support between eating disorders teams within AHSN geographies and beyond.

# Measuring inequalities in eating disorders

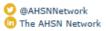
KSS AHSN has developed a FREED inequalities toolkit to provide practical guidance to help eating disorder services to better understand demographics and protected characteristics of young people with eating disorders.

For more information visit <u>Eating</u> <u>disorders</u> | <u>Improvement</u> - <u>Academic Health Science Network</u> (<u>kssahsn.net</u>)or <u>click here</u>.

#### **Innovation in eating disorders**

The Art of the Possibility: Innovation in Eating Disorder event was held on 10 November and showcased five innovators - Digital CBTe, FREED-Mobile (FREED-M), Tunstall, Florence, and MaST - to 90 clinicians and commissioners across the south east. These were innovations suggested by members of the SE Eating Disorders Early Intervention Collaborative as potentially interesting or beneficial ideas, rather than having been selected by a formal approach or due diligence process.

As a result of this event, two eating disorder services across the south east will be potentially piloting the CREDO digital CBTe self help tool.



## *The***AHSN***Network*

## **FREED Transitions E-Learning**

Ulrike Schmidt (SLaM/KCL), Dannie Glennon (SLaM)
Aileen Jackson, Jill Owens, Andy Scott-Lee (Health Innovation Network South London)
Funded by NHSE Community Mental Health

### **Project aims**

Develop an e-learning module informed by research, lived experience and best practice guidance for FREED eating disorder services to utilise as guidance when managing service user transitions between children's to adults services within and between regions, including moves to university.

#### Results so far

- Module content defined through a workshop which included lived experience service users and carers
- E-learning approach in development alongside clinical experts and lived experience representation.
- Content alignment with local and national guidance/protocol.
- User knowledge survey developed

#### Methods

The views of service users and service teams will be utilised to:

- Test needs prior to module development
- Develop module content with clinical leads and experts by experience
- Develop the best elearning style
- Test user experience during prototype stages

#### Forecast Conclusions

An interactive e-learning module will be developed that will support with managing transitions that foster the highest patient outcomes.









# Welcome back!



How Early Intervention in Psychosis developed from an idea to a sustainable programme and what we can learn from this

FREED conference, 27<sup>th</sup> March 2023

Max Birchwood



## **Dedicated Teams for FEP** 'early intervention teams'

JAMA Psychiatry | Original Investigation

#### Comparison of Early Intervention Services vs Treatment as Usual for Early-Phase Psychosis A Systematic Review, Meta-analysis, and Meta-regression

Christoph U. Correll, MD; Britta Galling, MD; Aditya Pawar, MD; Anastasia Krivko, MD; Chiara Bonetto, MD; Mirella Ruggeri, MD; Thomas J. Craig, PhD; Meretta Nordentoft, MD; Vinod H. Srihari, MD; Sinan Gulolesuz, MD; Christy L. M. Hui, PhD; Eric Y. H. Chen, MD; Marcelo Valencia, PhD; Francisco Juanez, PhD; xert G. Robinson, MD; Nina R. Schooler, PhD; Mary F. Brunette, MD; Kim T. Mueser, PhD; Bohort A. Rosonbock, MD: Patricia Marcy, RSN: Joan Addington, PhD: Sup F. Estroff, PhD: James Robinson, MEd: David Ponn, PhD: Joanne B. Severe, MS: John M. Kane, MD

PORTANCE The value of early intervention in psychosis and allocation of public resources has long been debated because outcomes in people with schizophrenia spectrum disorders

OBJECTIVE To compare early intervention services (EIS) with treatment as usual (TAU) for early-phase psychosis

DATA SOURCES Systematic literature search of PubMed, PsyciNEO, EMRASE, and Clinical Trials gov without language restrictions through June 6, 2017.

STUDY SELECTION Randomized trials comparing EIS vs TAU in first-episode psychosis or early-phase schizophrenia spectrum disorders.

DATA EXTRACTION AND SYNTHESIS This systematic review was conducted according to PRISMA guidelines. Three Independent Investigators extracted data for a random-effects meta-analysis and prespecified subgroup and meta-regression analyses

MAIN OUTCOMES AND MEASURES. The coprimary outcomes were all-cause treatment discontinuation and at least 1 psychiatric hospitalization during the treatment period.

RESULTS Across 10 randomized clinical trials (mean [SD] trial duration, 16.2 [7.4] months range, 9-24 months) among 2176 patients (mean [SD] age, 27.5 [4.6] years: 1355 [62.3%] male), EIS was associated with better outcomes than TAU at the end of treatment for all 13 meta-analyzable outcomes. These outcomes included the following: all-cause treatment. discontinuation (risk ratio [RR], 0.70; 95% CL 0.61-0.80; P < .001), at least 1 psychiatric hospitalization (RR, 0.74; 95% CI, 0.61-0.90; P = .003), involvement in school or work (RR, 1.13; 95% CI, 1.03-1.24; P = .01), total symptom severity (standardized mean difference [SMD], -0.32; 95% CI, -0.47 to -0.17; P < .001), positive symptom severity (SMD, -0.22; 95% CI, -0.32 to -0.11: P < .001), and negative symptom severity (SMD, -0.28: 95% CL -0.42 to -0.14; P < .001). Superiority of EIS regarding all outcomes was evident at 6, 9 to 12, and 18 to 24 months of treatment (except for general symptom severity and depressive symptom severity at 18-24 months).

CONCLUSIONS AND RELEVANCE In early-phase psychosis, EIS are superior to TAU across all meta-analyzable outcomes. These results support the need for funding and use of EIS in patients with early-phase psychosis.

JAMA Psychiatry. 2018;75/6):555-565. doi:10.1001/jamapsychiatry.2018.0623 Published online May 2, 2018.

Author Affiliations: Author Corresponding Author: Christoph U. Correll, MD. Department of Psychiatry, The Zucker Hillside Hospital, 75-59 263rd St., Glon Oaks,

NY 11004 (ccorrell@northwell.edu).

Editorial page 545

## Treatment delay at the first episode linked to poorer outcome

💃 📵 Effect of delaying treatment of first-episode psychosis on symptoms and social outcomes: a longitudinal analysis and modelling study

Richard J Drake, Nusrat Husain, Max Marshall, ShonW Lewis, Barbara Tomenson, Imran B Chaudhry, Linda Everard, Swaran Singh, Nick Freemantle, David Fowler, Peter B Jones, Tim Amos, Vimal Sharma, Chioe D Green, Helen Fisher, Robin M Murray, Til Wykes, Iain Buchan,

Mental Health (R | Drake Ph Prof SW Lewis FMedSci), of Manchester, Manchester, UK; Manchester Academ

Foundation Trust, Prestwich

Department of Psychiatry, Zlauddin University, Karachi, Pakistan (Prof I B Chaudhry); Birmingham and Solihuli NHS, Mental Health Foundation, Trust, Birmingham, U Mental Health & Wellbeing. University of Warwick Warwick, UK (Prof S Singh Mi

Lencer Psychiatry 2020; Background Delayed treatment for first episodes of psychosis predicts worse outcomes. We hypothesised that delaying 7:602-10 treatment makes all symptoms more refractory, with harm worsening first quickly, then more slowly. We also See Comment page 563 hypothesised that although delay impairs treatment response, worse symptoms hasten treatment, which at Division of Psychology & presentation mitigates the detrimental effect of treatment delay on symptoms.

Methods In this longitudinal analysis and modelling study, we included two longitudinal cohorts of patients with first-PRODUCTION CONTINUESCENCE PRODUCTION THE PRODUCTION OF THE PRODUCT 399 patients aged 16-35 years from 11 services between April 1, 2006, and Feb 28, 2009). Patients were assessed at baseline, 6 months, and 12 months with the Positive and Negative Symptom Scale (PANSS), Calgary Depression representation of the control of the Scale. Regression was used to compare different models of the relationship between duration of untreated psychosis (DUP) and total symptoms at 6 months. Growth curve models of symptom subscales tested predictions arising from

Findings We included 948 patients from the NEDEN study and 332 patients from the Outlook study who completed Manchester UK(R) Drake, baseline assessments and were prescribed dopamine antagonist antipsychotics. For both cohorts, the best-fitting PROTN Husain, Prof SWLewis, BTomemon, Prof IB Chaushy, models were logarithmic, describing a curvilinear relationship of DUP to symptom severity: longer DUP predicted CDGreen BSc reduced treatment response, but response worsened more slowly as DUP lengthened. Increasing DUP by ten times predicted reduced improvement in total symptoms (ie, PANSS total) by 7-339 (95% CI 5-762 to 8-916; p<0-0001) in NEDEN data and 3.846 (1.689 to 6.003; p=0.0005) in Outlook data. This was true of treatment response for all symptom types. Nevertheless, longer DUP was not associated with worse presentation for any symptoms except Manchester UK (R) Drake, symptom types. Nevertheless, longer DUP was not associated with worse presentation for any symptoms except depression in NEDEN (coefficients 0-099 [95% CI 0-033 to 0-164]; p=0-0028 in NEDEN and 0-007 [-0-081 to 0-095]; Lancashire Care & South p=0.88 in Outlook).

Continuous Interpretation Long DUP was associated with reduced treatment response across subscales, consistent with a harmful PROTEMMATABILIMO): process upstream of individual symptoms' mechanisms; response appeared to worsen quickly at first, then more slowly. These associations underscore the importance of rapid access to a comprehensive range of treatments, especially in the first weeks after psychosis onset.

Funding UK Department of Health, National Institute of Health Research, and Medical Research Council

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Tot D Fowler's Department of Psychiatry. School of Clinical which delayed treatment might cause harm remains lithium might mitigate a range of later problems.

worsening presentation. In the TIPS trial, for patients in Institute for Clinical Trials, Prolonged duration of untreated psychosis (DUP) predicts the control areas that had longer DUP, psychosis and London, UK worse symptoms of all types and poorer social functioning excitement were increased only at presentation, while Prof N Freemantie Prof); School and quality of life for 2 years<sup>1-1</sup> after presentation or depression and disorganisation were worse only at followof Psychology, University of longer, 4: Earlier detection improved outcomes in the quasi-up, in proportion to their greater severity at presentation. Sussex, Brighton, UK

Partnership MRS 2 Sussex
Partnership MRS Footsdation

early intervention services 2 spring introduction of searly

and didtionally, if exacerbation of one symptom worsens others, depending on which symptoms are primary, early Trust Worthing UK treatment services worldwide. Yet the mechanism by monotherapy with antipsychotics, antidepressants, or

Medicine, University of unclear. Evidence of direct neurotoxicity is inconsistent. DUP and outcome might be associated only via Cambridge, Cambridge, UK Symptoms could simply accumulate over time, some unmeasured patient characteristic or residual

### 'Ultra-high risk' identified predicts transition to psychosis

REVIEW

#### The Psychosis High-Risk State

#### A Comprehensive State-of-the-Art Review

Paolo Fusar-Polt, MD, PhD; Stefan Borgwardt, MD, PhD; Andreas Bechdolf, MD; Jean Addington, PhD; Anita Riecher-Rössler, MD, PhD: Frauke Schultze-Lutter, PhD: Matcheri Keshavan, MD: Stephen Wood, MD, PhD: Stephan Ruhrmann, MD, PhD; Larry J. Seidman, MD, PhD; Lucia Valmaggia, MSc, PhD; Tyrone Cannon, PhD; Eva Velthorst, MSc, PhD; Lieuwe De Haan, MD, PhD; Barbara Cornblatt, MBA, PhD; Ilaria Bonoldi, MD; Max Birchwood, DSc; Thomas McGlashan, MD; William Carpenter, MD; Patrick McGorry, MD; Joachim Klosterkötter, MD, PhD; Philip McGuire, MD, PhD; Alison Yung, MD

Context: During the past 2 decades, a major transition in the clinical characterization of psychotic disorders has occurred. The construct of a clinical high-risk (HR) state for psychosis has evolved to capture the prepsychotic phase, describing people presenting with potentially prodromal symptoms. The importance of this HR state has been increasingly recognized to such an extent that a new syndrome is being considered as a diagnostic category in the DSM-5.

Objective: To reframe the HR state in a comprehensive state-of-the-art review on the progress that has been made while also recognizing the challenges that remain.

Data Sources: Available HR research of the past 20 years from PubMed, books, meetings, abstracts, and international conferences.

Study Selection and Data Extraction: Critical review of HR studies addressing historical development, inclusion criteria, epidemiologic research, transition criteria, outcomes, clinical and functional characteristics,

neurocognition, neuroimaging, predictors of psychosis development, treatment trials, socioeconomic aspects, nosography, and future challenges in the field.

Data Synthesis: Relevant articles retrieved in the literature search were discussed by a large group of leading worldwide experts in the field. The core results are presented after consensus and are summarized in illustrative tables and figures.

Conclusions: The relatively new field of HR research in psychosis is exciting. It has the potential to shed light on the development of major psychotic disorders and to alter their course. It also provides a rationale for service provision to those in need of help who could not previously access it and the possibility of changing trajectories for those with vulnerability to psychotic illnesses.

Arch Gen Psychiatry. Published online November 19, 2012. doi:10.1001/jamapsychiatry.2013.269

In our opinion, prevention of psychosis in the prepsychotic precursor stages is possible. GERD HURER, 1987

URING THE PAST 2 DEcades, a transition in the clinical characterization of psychotic disorders has occurred. The construct of a clinical high-risk state for psychosis (hereinafter: HR) (also known as the "at-risk mental state" [ARMS],2 "prodromal," and "ultra-high-risk" [UHR] state) has evolved to capture the prepsychotic phase, describing people presenting with potentially prodromal symptoms.3 The importance of this HR stage of psychosis has been increasingly recognized to such an extent that an attenuated

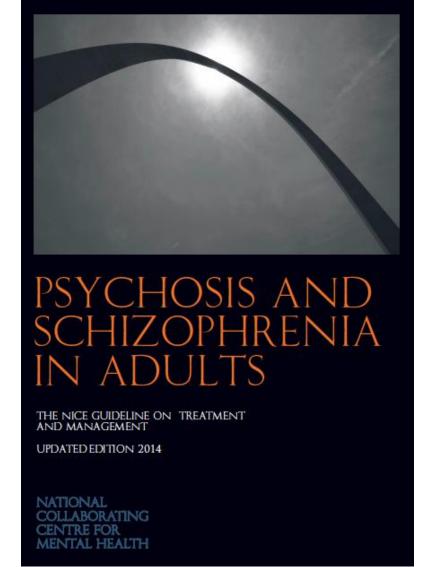
psychosis syndrome is being considered as a new diagnostic category in the DSM-5.4 This category was introduced with the goal of developing treatments for prevention of psychotic disorders.54 However. its role as a diagnosis is being debated. 10-15 This new conceptualization of the HR state would see indicated prevention16 of psychotic disorder as just one of many treatment outcomes. Prodromal symptoms and signs of psychosis are, thus, considered pleiotropic and are related to several potential outcomes, including the development of nonpsychotic disorders. rather than being unique to psychotic disorders. Thus, the proposed syndrome in the forthcoming DSM-5 can be considered analogous to chest pain (a condition requiring diagnosis and treatment and

Author Affiliations are listed at

the end of this article.

ARCH GEN PSYCHIATRY PUBLISHED ONLINE NOVEMBER 19, 2012 WWW.ARCHGENPSYCHIATRY.COM

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#### 14.3FIRST EPISODE PSYCHOSIS

### 14.3.1 Early intervention in psychosis services

- 14.3.1.1 Early intervention in psychosis services should be accessible to all people with a first episode or first presentation of psychosis, irrespective of the person's age or the duration of untreated psychosis. [new 2014]
- 14.3.1.2 People presenting to early intervention in psychosis services should be assessed without delay. If the service cannot provide urgent intervention for people in a crisis, refer the person to a crisis resolution and home treatment team (with support from early intervention in psychosis services). Referral may be from primary or secondary care (including other community services) or a self- or carer-referral. [new 2014]
- 14.3.1.3 Early intervention in psychosis services should aim to provide a full range of pharmacological, psychological, social, occupational and educational interventions for people with psychosis, consistent with this guideline. [2014]
- 14.3.1.4 Consider extending the availability of early intervention in psychosis services beyond 3 years if the person has not made a stable recovery from psychosis or schizophrenia. [new 2014]









Phase 1: Campaigning for service reform and the emerging science of the early intervention in psychosis

Phase 2: The trials

Phase 3: Implementation studies and challenges

Phase 4: National standards and performance monitoring.

Phase 5: El non-responders: improving outcomes.

Phase 6: Phase-specific interventions.

Phase 1: Campaigning for service reform and the emerging science of the development of psychosis



# Lost Generation

Why young people with psychosis are being left behind, and what needs to change.

British Journal of Psychiatry (1992), 161, 783-790

Sec Psychiatry Psychiatr Epidemiol (1991) 26: 95-99

© Springer-Verlag 1991

Psychiatric Epidemi

Social Psychia

#### The Influence of Ethnicity and Family Structure on Relapse in First-Episode Schizophrenia

A Comparison of Asian, Afro-Caribbean, and White Patients

MAX BIRCHWOOD, RAY COCHRANE, FIONA MACMILLAN, SONJA COPESTAKE, JO KUCHARSKA and MARGARET CARISS

There is overwhelming evidence that the outcome for people with achizophrenia in Western industrialised countries is inferior to that of those living in the Third World. Extended family structures, greater opportunities for social reintegration, and more positive constructions of mental illness have been offered as possible explanations for this effect. The Asian community in the UK retains many of these features as well as strong links with native cultures of origin. The issue arises as to whether similar differences in outcome may be observed in the UK. An exploratory study was undertaken, examining the early progress of schizophrenia in a first-episode sample in = 137), and based on systematic examination of case-note data. A lower rate of relapse/readmission in the first 12 months after discharge was found in the Asian (16%) as compared with white (30%) and Afto-Caribbean (49%) patients. Available evidence suggested that speed of access to care, living with a family, and employment may account for this effect. Medication compliance may have contributed to differences in relapse between white and Afto-Caribbeans but was not a factor influencing the low rate among Asians. The limitations and strengths of case-note studies are discussed at length, and it is concluded that a prospective study is warranted and would be highly instructive.

There is now overwhelming evidence that the outcome for people with schizophrenia in Western industrialised countries is markedly inferior to that of those in the Third World (Lin & Kleinman, 1988).

Murphy & Rahman (1971) were among the first to make this observation in their study of African and Indian schizophrenic patients living in Mauritius. They found that after a 12-year follow-up involving 98% of their original sample, 64% reported no further episodes, as compared with 49% in a comparable UK sample followed up after 5 years (Brown et al, 1966). This apparent resistance to relapse has been documented in less industrialised countries by Verghese et al (1989) in India and Waxler (1979) and Mendis (1986) in Sri Lanka. A recent investigation using similar methods (Leff et al, 1987) compared first-episode samples in London and Chandigarh (a predominantly urban area of north India). They found a 9-month relapse rate of between 14% and 18% in Chandigarh, compared with 29% in London, a difference which did not appear to rest on the use of maintenance neuroleptic drugs (Leff et al, 1990).

The problem of achieving true comparability of sampling, measurement, outcome, and other criteria across cultures has been dealt with in the transcultural schizophrenia research programme of the World Health Organization (WHO, 1979; Sartorius et al., 1986). In the first of these studies, a cross-sectional

sample covering eight countries was followed up over 2 years. On all measures, a greater proportion of patients in Agra (India), Cali (Colombia), and Ibadan (Nigeria) had more favourable, less disabling outcomes than did patients in Aarhus (Denmark), London, Prague, and Washington, DC. A further epidemiological study covering ten countries of first-episode patients (Sartorius et al., 1986) found a uniform annual incidence rate (1 per 10 000) but a variable 2-year outcome between countries, once again favouring less industrialised nations. In industrialised countries 40% of patients showed a 'severe' pattern (more than one episode and incomplete remission), as compared with 24% in developing ones.

Several hypotheses have been offered to account for this finding. The opportunity to engage in socially valued and productive roles may be enhanced in less industrial societies where there is a more flexible use of labour. The WHO fleldworkers in India, for example, had difficulty in interviewing ex-patients as the latter were so busy – the men in the fields and the women in domestic work. It is interesting to note that the pattern of recovery in Moscow paralleled that of less industrialised countries, perhaps a reflection of the emphasis on full employment and vocational rehabilitation in the former USSR (Warner, 1983).

According to another hypothesis, the extended family structure may help to diffuse burden and

# Second generation Afro-Caribbeans and young whites with a first admission diagnosis of schizophrenia

D, McGovern<sup>1</sup> and R, Cope<sup>2</sup>

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Accepted: October 16, 1990

Summary. A study of young Afro-Caribbeans and whites diagnosed as suffering from schizophrenia on a first admission suggests that the over-representation of Afro-Caribbeans with this diagnosis is not explained by mis-diagnosis. The Afro-Caribbeans were more likely to live alone and to be in contact with the police or prison services before admission. They were also more likely to be admitted compulsorily, especially on forensic orders, They were less likely to make and maintain voluntary contact with the services. There was little difference in the physical treatment given to both groups but the Afro-Caribbeans were more likely to be re-admitted in subsequent years and one third of the Afro-Caribbean males were treated at some time in forensic units. Results are discussed with reference to previous literature and some recommendations made.

In a previous study of first psychiatric admissions we reported that second generation Afro-Caribbeans had greatly increased rates of first hospital admissions with a diagnosis of schizophrenia, compared to similarly aged whites (McGovern and Cope 1987 a). There had been no previous studies of second generation Afro-Caribbeans and the increased rates of schizophrenia were greater than any reported in other studies comparing first generation Afro-Caribbean migrants and whites (Cochrane 1977; Carpenter and Brockington 1980; Dean et al. 1981). Subsequently a small, carefully designed, prospective study in Nottingham, using clear diagnostic criteria revealed an even greater excess of schizophrenia in young Afro-Caribbeans (Harrison et al. 1988).

There is surprisingly little systematic research on the susequent differential experiences of Afro-Caribbeans and white patients in terms of types of treatment given and co-operation with treatment. One study (Littlewood and Cross 1980) of a mixed diagnostic group of out-patients suggested that Afro-Caribbeans received more physical treatments than white patients. In the United States, black patients are more likely to receive physical than dynamic treatments regardless of the diagnosis

(Cole and Pilisuk 1976; Thomas and Sillen 197, bimpe 1981).

This paper presents a detailed analysis of first sions of second generation Afro-Caribbeans and with a diagnosis of schizophrenia, based on an ancase notes. We describe the clinical picture in morand whether the symptomatology corresponder search diagnostic criteria. Also we compare how A ribbeans and whites enter the psychiatric systiphysical treatment received, co-operation with treatment received, co-opera

#### Method

In previous papers (McGovern and Cope 1987 a, b scribed the method for recording first psychiatric sions to a Birmingham Hospital over the 4 year 1980 to 1983. Afro-Caribbean patients aged bets and 29 years on admission, were classified as generation. They were compared with a similarl white, British group. Our use of the term second ation is somewhat idiosyncratic, and includes both born Afro-Caribbeans and young Afro-Caribbeans and young Afro-Caribbeans and young Afro-Caribbeans and the following info was recorded:

Demographic data

Age; whether or not employed; marital status married, cohabiting, separated, divorced); living stances (whether living alone or with family); age gration (if applicable); family history of mental (Family history was noted as positive if it was re that a first or second degree relative received tre from a psychiatrist). British Journal of Psychiatry (1986), 148, 115-120

# The Northwick Park Study of First Episodes of Schizophrenia I. Presentation of the Illness and Problems Relating to Admission

E. C. JOHNSTONE, T. J. CROW, A. L. JOHNSON and J. F. MacMILLAN

Collaborators: Drs B. Alapin, V. Baraniecka, U. Baruch, C. Benedek, M. Bowman, J. Bradley, J. Bruce, M. Carney, J. Candy, B. Chester, P. d'Orban, G. Edwards, K. Granville-Grossman, J. Hailstone, J. Hajioff, R. Henryk-Gutt, H. Hershon, Z. Huq, P. Jeffreys, M. Joyston-Bechal, W. Knapman, C. McEwedy, S. Mann, S. Montgomery, G. Nanayakkara, D. Owens, D. Pariente, R. Pinto, D. Pitcher, P. Pilkington, J. Price, R. Priest, M. Salasa, A. Shah, F. Sebastian-Pillai, H. Sergeant, G. Silverman, S. Spencer, J. Stead, C. Tonks.

Patients referred over 28 months from nine medical centres for a trial of prophylactic neuroleptic medication following first episodes of schizophrenic illness (462) were assessed with the Present State Examination, WHO scales for disability, past history, and socio-demographic factors, and a rating of disturbed behaviour; 253 fulfilled the study criteria; of the 209 who did not.54 did not meet the diagnostic criteria, 65 had a history of a previous episode, and in 15 the psychotic illness was found to have an organic basis. The interval between onset of illness and admission varied widely, but was often more than one year and associated with severe behavioural disturbance and family difficulty e.g. in arranging appropriate care. Current arrangements for initiating management of first schizophrenic illnesses are frequently unsatisfactory.

Little systematic information has been collected on the mode of onset, presentation, and early course of schizophrenia. While data on age of onset (Noriek & Odegard, 1966), rates of first admission (eg Dean et al. 1981), psychopathological aspects (Gillies, 1958: Chapman, 1966), and outcome (Cooper, 1961; Nyman & Jonsson, 1983) are available, there is no formal study of the duration and nature of the disturbance preceding first admission. Nor have the circumstances of admission been systematically examined. Similarly, while it is established that neuroleptic medication is effective in preventing relapse after discharge (Leff & Wing, 1971; Hirsch et al, 1973; Hogarty et al, 1973; Rifkin et al, 1977), a small proportion of patients remain well without active medication. If there is a group who experience only one or infrequent episodes of illness, such patients would be under-represented in studies of the generality of schizophrenic episodes, and thus the prophylactic value of neuroleptic medication may be exaggerated.

We examined the prophylactic effect of neuroleptic medication following first schizophrenic episodes in a large sample of patients, intending to assess the early course of the illness and the determinants of satisfactory outcome with and without active medication. We also studied the nature of the behavioural disturbance and social difficulties at presentation and the early outcome in clinical, social, and judicial terms, as well as the relationship of expressed emotion (EE) in the family to

relapse following a first episode. This paper describes the nature and selection of the total referred sample of 462 cases and the difficulties occurring in the interval between onset and admission.

#### Method

To obtain an adequate sample, collaboration was sought from consultant psychiatrists in several medical centres within 35 miles of Harrow; collaborators were asked to make a referral to Northwick Park whenever a suitable patient was admitted, i.e. aged between 15 and 70 years, with a first psychotic illness, not unequivocally affective. For the purposes of referral, a "psychotic illness" was defined as one characterised by the presence of delusions or hallucinations occurring in clear consciousness. The clinicians were asked to refer any case that they thought might be suitable and to err on the side of over- rather than under-referral; referred patients remained under their care. and in the hospital to which they had been admitted. They were assessed there by the project psychiatrists (JFM; ECJ; TJC) using Present State Examination (PSE) (Wing et al. 1974), Past History and Sociodemographic Schedule (PHSD) (Jablensky et al, 1980), Disability Assessment Schedule (DAS) (Jablensky et al. 1980), Camberwell Family Interview (CFI) (Vaughn & Leff, 1976) and Disturbed Behaviour Rating (DBR).

The PHSD concerns personal data, the presentation of the illness, and tiems of personal and family history; it is completed by the interviewer on the basis of an account from an informant as well as the patient. The DAS consists of two sections; one completed by interview of relatives or others who had been living with the patient before admission, and the other by interview with the nursing

# The need for service reform: if it's broke, fix it..

- Low engagement of YP in services & treatment (and poor early outcome)
- Long treatment delay (DUP 1-2 years)
- High use of coercion at entry to services
- "CAMHS don't do psychosis, AMHS don't do young people"
- Low acceptability of CMHT/hospital service model.

# NICE Guidelines for schizophrenia (2014)

"Despite the fact that CMHTs remain the mainstay of community mental health care, there is surprisingly little evidence to show that they are an effective way of organizing services. As such, evidence for the effectiveness of CMHTs in the management of schizophrenia is insufficient to make any evidence-based recommendations" (P261)





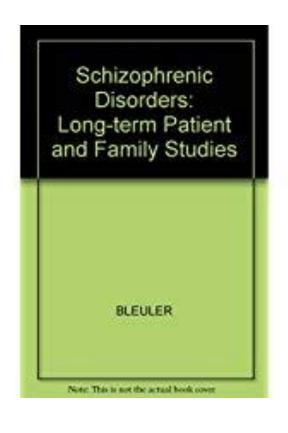
First UK International Conference

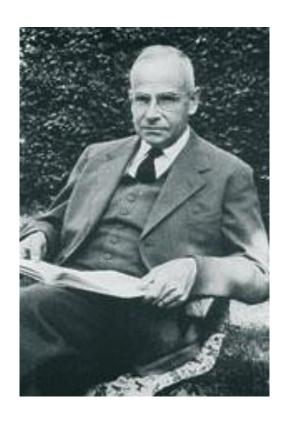
### EARLY INTERVENTION IN PSYCHOSIS



Stratford-upon-Avon, England

2nd and 3rd June 1997 (CPD Validation applied for)







Burghölzli, Zurich

- 'Plateau effect': ceiling of disability early in manifest course
- > Open culture of community integration and meaningful activity
- ➤ Functional and symptomatic outcomes best in pre-neuroleptic era; comparable today??

#### Early intervention in psychosis

The critical period hypothesis

MAX BIRCHWOOD, PAULINE TODD and CHRIS JACKSON

Background We consider the evidence for the proposition that the early phase of psychosis (including the period of untreated psychosis) is a 'critical period' in which (a) long-term outcome is predictable, and (b) biological, psychological and psychosocial influences are developing and show maximum

Method First-episode prospective studies, predictors of outcome and the genesis of patients' key appraisals of their psychosis are reviewed.

Results The data support the notion of the 'plateau effect', first coined by Tom McGlashan, which suggested that where deterioration occurs, it does so aggressively in the first 2-3 years; and that critical psychosocial influences, including family and psychological reactions to psychosis and psychiatric services, develop during this period.

Conclusions The early phase of psychosis presents important opportunities for secondary prevention. We outline a prototype of intervention appropriate to the critical period. The data challenge the widely held assumption that first-episode psychosis is a benign illness posing little risk.

Interventions in psychosis, whether biological or psychosocial, have been generally blind to the phase and age of illness. Such neglect reflects the dominance of the two main paradigms of care, in which treatment is provided in acute crisis care to achieve prophylaxis, and also in 'rehabilitation' involving amelioration of disabilities occasionally within a framework of relative asylum (Birchwood & Macmillan, 1993). Community outreach models frequently involve a blend of these two approaches. These paradigms are founded upon Kraepelinian nosology and while long-term follow-up studies demonstrate the heterogeneity of outcomes in psychosis, they do nevertheless appear to support the two paradigms: between a quarter and one-third of those affected have either single or multiple episodes with little or no residual symptoms; whereas the remainder have multiple episodes with varying and often increasing impairment (Shepherd et al., 1989). The early phase of psychosis may thus be viewed as a period during which it is possible to determine which path an individual is ultimately likely to follow. A radically different view argues that the early phase of psychosis is a major influence and that the early phase of psychosis is a 'critical period' with major implications for secondary prevention of the impairments and disabilities that accompany psychosis. In this paper, we will summarise evidence in support of this proposition and outline a prototype

#### CRITICAL PERIODS

#### Prospective follow-up studies of people with first-episode psychosis

of intervention appropriate to the 'critical

The bulk of follow-up studies of psychosis have taken samples of convenience which are inevitably drawn from those main-

distorted picture, in particular biased in favour of chronicity, will be presented, although first-episode studies are not without their own problems. For example, determining their epidemiological representativeness is one issue that has been demonstrated only in the Determinants of Outcome of Severe Mental Disorder study (DOSMD: Jablensky et al., 1992). However, the follow-back and the prospective studies do permit certain conclusions and key hypotheses may be tested. Since we are concerned with a supposed critical period of early psychosis, in this section we will focus only on first-episode prospective studies.

#### Clinical and social outcomes

Strauss and Carpenter (1977) demonstrated that clinical recovery was not a pre-requisite for social recovery; in fact they reported substantial desynchrony between, for example, residual symptoms and social functioning, the correlations being no greater than 0.5. Normal processes as well as abnormal ones contribute to social readiusement (Birchwood et al. 1988) and the first-episode studies follow the same general rule. The correlation between symptoms and functioning are of the same order (Shepherd et al, 1989) and social outcome in the early phase is better than might be expected in the light of clinical outcome alone. Shepherd et al (1989) showed that 30% of people suffered moderate to severe social impair ment whereas 70% have multiple episodes and/or residual symptoms over the first five years, Mason et al (1995) echo this point, "the status of symptoms may have little relevance to every-day social functioning". Schubart et al (1986) and the linked study of Biehl et al (1986) examine the course of social disability over the first five years using the World Health Organization Disability Assessment Schedule (WHODAS; WHO, 1992). Neither baseline clinical symptoms nor age or gender predicted social outcome at five years; only WHODAS scores at six months predicted outcome at one, two, three and five years, Like Strauss & Carpenter (1977) they find that the best predictor of social outcome is an earlier measure of social functioning. The corollary of this is that improving clinical functioning by itself will not guarantee improved social functioning, taining contact with services. Thus, a other interventions, both 'technical' and

# Translating to EIP: the 'CRITICAL PERIOD'

"Early phase of psychosis is a stormy one, plateauing thereafter"

- Early trajectories predict long term trajectories
- The *plateau effect*: ceiling of disability/symptoms early in manifest course (Bleuler)
- Adolescent social functioning best predictor of early phase social functioning

From :Birchwood, M and Macmillan, JF (1993) Early intervention in schizophrenia Australia & New Zealand Journal of Psychiatry 27 374-8

BRITISH JOURNAL OF PSYCHIATRY (2001), 178, 506-517

# Recovery from psychotic illness: a 15- and 25-year international follow-up study

G. HARRISON, K. HOPPER, T. CRAIG, E. LASKA, C. SIEGEL, J. WANDERLING,

K. C. DUBE, K. GANEY, R. GIEL, W. AN DER HEIDEN, S. K. HOLMBERG,

A. JANCA, P. W. H. LEE, C. A. LEÓN, S. MALHOTRA, A. J. MARSELLA,

Y. NAKANE, N. SARTORIUS, Y. SHEN, C. SKODA, R. THARA, S. J. TSIRKIN,

V. K. VARMA, D. WALSH and D. WIERSMA

'The predictive strength of early pattern of course and sociocultural setting support the case for early intervention strategies with social and drug interventions' (p516)



The British Journal of Psychiatry (2009) 194, 18-24. doi: 10.1192/bjp.bp.107.048942

### Beyond the critical period: longitudinal study of 8-year outcome in first-episode non-affective psychosis

Niall Crumlish, Peter Whitty, Mary Clarke, Stephen Browne, Moayyad Kamali, Maurice Gervin, Orfhlaith McTigue, Anthony Kinsella, John L. Waddington, Conall Larkin and Eadbhard O'Callaghan

The critical period hypothesis proposes that deterioration occurs aggressively during the early years of psychosis, with relative stability subsequently. Thus, interventions that shorten the duration of untreated psychosis (DUP) and arrest early deterioration may have long-term henefits

To test the critical period hypothesis by determining whether outcome in non-affective psychosis stabilises beyond the critical period and whether DUP correlates with 8-year outcome; to determine whether duration of untreated illness (DUI) has any independent effect on outcome

#### Method

We recruited 118 people consecutively referred with

first-episode psychosis to a prospective, naturalistic cohort

Negative and disorganised symptoms improved between 4 and 8 years. Duration of untreated psychosis predicted remission, positive symptoms and social functioning at 8 years. Continuing functional recovery between 4 and 8 years was predicted by DUI.

#### Conclusions

These results provide qualified support for the critical period hypothesis. The critical period could be extended to include the prodrome as well as early psychosis.

#### **Declaration of interest**

None. Funded by the Stanley Medical Research Institute.



The British Journal of Psychiatry (2017) BJPsych | 11ne british Journal of 15,58227, 211, 350–358. doi: 10.1192/bjp.bp.117.201475

#### **Review article**

### Remission and recovery from first-episode psychosis in adults: systematic review and meta-analysis of long-term outcome studies<sup>†</sup>

John Lally, \* Olesya Ajnakina, \* Brendon Stubbs, Michael Cullinane, Kieran C. Murphy, Fiona Gaughran and Robin M. Murray

Remission and recovery rates for people with first-episode psychosis (FEP) remain uncertain.

To assess pooled prevalence rates of remission and recovery in FEP and to investigate potential moderators.

We conducted a systematic review and meta-analysis to assess pooled prevalence rates of remission and recovery in progressive deteriorating course of illness is not typical. FEP in longitudinal studies with more than 1 year of followup data, and conducted meta-regression analyses to investigate potential moderators.

Seventy-nine studies were included representing 19072 patients with FEP. The pooled rate of remission among 12301 individuals with FEP was 58% (60 studies, mean follow-up 5.5 years). Higher remission rates were moderated © The Royal College of Psychiatrists 2017.

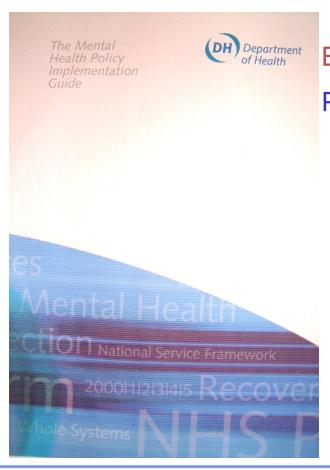
by studies from more recent years. The pooled prevalence of recovery among 9642 individuals with FEP was 38% (35 studies, mean follow-up 7.2 years). Recovery rates were higher in North America than in other regions.

Remission and recovery rates in FEP may be more favourable than previously thought. We observed stability of recovery rates after the first 2 years, suggesting that a Although remission rates have improved over time recovery rates have not, raising questions about the effectiveness of services in achieving improved recovery.

#### **Declaration of interest**

#### Copyright and usage

# Sustaining engagement and intervention through the 'Critical Period' with specialised teams

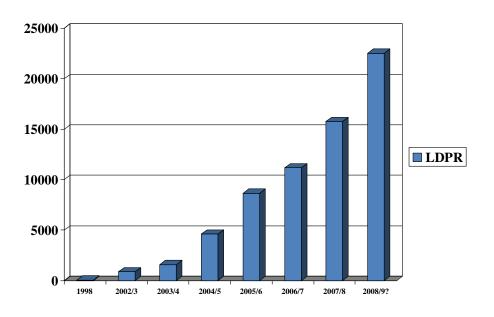


EIS model was a 'best guess' in 2001.

Progenitor service, 1994-: Birmingham.

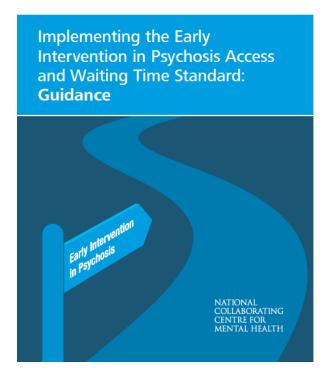
- Adapted ACT model
- 1:15 case ratio
- 3 years
- Emphasis on psychosocial
  - + vocation interventions
- Engagement in low stigma channels
- Youth sensitive and youth co-designed

# EI provision across England







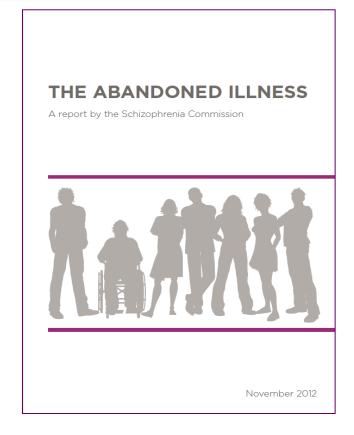


Early intervention is crucial to improving outcomes. The Commission's view is that Early Intervention in Psychosis (EIP) has been the most positive development in mental health services since the beginning of community care.

We recommend that all Clinical
Commissioning Groups commission Early
Intervention in Psychosis services with
sufficient resources to provide fidelity to
the service model. It is crucial that the
NHS Commissioning Board holds local
commissioners to account for this and we
recommend that early intervention services
are included in the NHS Commissioning
Outcomes Framework.

"We can be really proud of our early intervention services which are popular and have been shown to work. Now we need to build on that success by extending the approach to cover the whole service."

Liz Meek, Member of the Commission



The Abandoned Illness
The Schizophrenia Commission, Nov 2012

www.schizophreniacommission.org.uk
Chair: Prof Sir Robin Murray

# Phase 2: Trials

#### JAMA Psychiatry | Original Investigation

### Comparison of Early Intervention Services vs Treatment as Usual for Early-Phase Psychosis A Systematic Review, Meta-analysis, and Meta-regression

Christoph U. Correll, MD; Britta Galling, MD; Aditya Pawar, MD; Anastasia Krivko, MD; Chiara Bonetto, MD; Mirella Ruggeri, MD; Thomas J. Craig, PhD; Mereta Nordentoft, MD; Vinod H. Srihari, MD; Sinan Guloksuz, MD; Christy L. M. Hui, PhD; Eric Y. H. Chen, MD; Marcelo Valencia, PhD; Francisco Juarez, PhD; Delbert G. Robinson, MD: Nina R. Schooler, PhD: Mary F. Brunette, MD: Kim T. Mueser, PhD: Robert A. Rosenhack, MD; Patricia Marcy, BSN; Jean Addington, PhD; Sue E. Estroff, PhD; James Robinson, MEd: David Penn, PhD: Joanne B. Severe, MS: John M. Kane, MD

IMPORTANCE The value of early intervention in psychosis and allocation of public resources has long been debated because outcomes in people with schizophrenia spectrum disorders have remained suboptimal.

OBJECTIVE To compare early intervention services (EIS) with treatment as usual (TAU) for early-phase psychosis.

DATA SOURCES Systematic literature search of PubMed, PsyciNFO, EMBASE, and Clinical Trials.gov without language restrictions through June 6, 2017.

STUDY SELECTION Randomized trials comparing EIS vs TAU in first-episode psychosis or early-phase schizophrenia spectrum disorders.

DATA EXTRACTION AND SYNTHESIS This systematic review was conducted according to PRISMA guidelines. Three independent investigators extracted data for a random-effects meta-analysis and prespecified subgroup and meta-regression analyses.

MAIN OUTCOMES AND MEASURES. The coprimary outcomes were all-cause treatment. discontinuation and at least 1 psychiatric hospitalization during the treatment period.

RESULTS Across 10 randomized clinical trials (mean [SD] trial duration, 16.2 [7.4] months: range, 9-24 months) among 2176 patients (mean [SD] age, 27.5 [4.6] years; 1355 [62.3%] male), EIS was associated with better outcomes than TAU at the end of treatment for all 13 meta-analyzable outcomes. These outcomes included the following: all-cause treatment. discontinuation (risk ratio [RR], 0.70; 95% CI, 0.61-0.80; P < .001), at least 1 psychiatric hospitalization (RR, 0.74; 95% CI, 0.61-0.90; P = .003), involvement in school or work (RR, 1.13; 95% CI, 1.03-1.24; P = .01), total symptom severity (standardized mean difference [SMD], -0.32; 95% CI, -0.47 to -0.17; P < .001), positive symptom severity (SMD, -0.22; 95% CI, -0.32 to -0.11; P < .001), and negative symptom severity (SMD, -0.28; 95% Ct. -0.42 to -0.14; P < .001). Superiority of EIS regarding all outcomes was evident at 6, 9 to 12, and 18 to 24 months of treatment (except for general symptom severity and depressive symptom severity at 18-24 months).

CONCLUSIONS AND RELEVANCE In early-phase psychosis, EIS are superior to TAU across all meta-analyzable outcomes. These results support the need for funding and use of EIS in patients with early-phase psychosis.

JAMA Psychiatry. 2018;75(6):555-565. doi:10.1001/jamapsychiatry.2018.0623 Published online May 2, 2018.

#### The Lambeth Early Onset (LEO) Team: randomised controlled trial of the effectiveness of specialised care for early psychosis

Tom K J Craig, Philippa Garety, Paddy Power, Nikola Rahaman, Susannah Colbert, Miriam Fornells-Ambrojo, Graham Dunn

#### Abstract

Objective To evaluate the effectiveness of a service for early

Design Randomised controlled clinical trial.

Setting Community mental health teams in one London borough.

Participants 144 people aged 16-40 years presenting to mental health services for the first or second time with non-organic, non-affective psychosis

Interventions Assertive outreach with evidence based biopsychosocial interventions (specialised care group) and standard care (control group) delivered by community mental

Primary outcome measures Rates of relapse and readmission to hospital.

Results Compared with patients in the standard care group, those in the specialised care group were less likely to relapse (odds ratio 0.46, 95% confidence interval 0.22 to 0.97), were readmitted fewer times (\$0.39, 0.10 to 0.68), and were less likely to drop out of the study (odds ratio 0.35, 0.15 to 0.81). When rates were adjusted for sex, previous psychotic episode, and ethnicity, the difference in relapse was no longer significant (odds ratio 0.55, 0.24 to 1.26); only total number of readmissions (β 0.36, 0.04 to 0.66) and dropout rates (β 0.28, 0.12 to 0.73) remained significant.

Conclusions Limited evidence shows that a team delivering specialised care for patients with early psychosis is superior to standard care for maintaining contact with professionals and for reducing readmissions to hospital. No firm conclusions can. however, be drawn owing to the modest sample size.

ter outcomes for people with early non-affective psychotic disorders than existing services. We hypothesised that, over an 18 month period, people receiving specialised care would have more frequent contact with mental health services, fewer relapses, and fewer readmissions to hospital than patients receiving standard care.

#### Methods

borough of Lambeth and presenting to mental health services for the first time with non-affective psychosis (schizophrenia, schizotypal, and delusional disorders, F20-29; international claswho had presented once but had subsequently disengaged without treatment from routine community services. We excluded exclude asylum seekers who were liable to enforced dispersal.

population from ethnic minority groups and unemployment is around twice the national average (2001 census). Community mental health services are provided through five multiprofes-

Assertive outreach for early psychosis

The Lambeth Early Onset (LEO) Team is a community team comprising 10 members of staff (team leader, part time consultant psychiatrist, trainee psychiatrist, half time clinical psycholo-

Schizophrenia Bulletin vol. 41 no. 5 pp. 1192-1203, 2015 doi:10.1093/schbul/sbv058 Advance Access publication May 20, 2015

We investigated whether a specialist team could achieve bet-

We considered all people aged 16-40 years living in the London sification of diseases, 10th revision). We also considered people those with organic psychosis or a primary alcohol or drug addiction. Non-English speakers were not excluded, but we did

Lambeth is the seventh most deprived of the 976 local authority boroughs in England and Wales.22 It has a sizeable

Cite this article as: BMJ. doi:10.1136/bmi.38565.415000.E01 (published 2 September 2005)

### **Papers**

#### A randomised multicentre trial of integrated versus standard treatment for patients with a first episode of psychotic illness

Lone Petersen, Pia Jeppesen, Anne Thorup, Maj-Britt Abel, Johan Øhlenschlæger, Torben Østergaard Christensen, Gertrud Krarup, Per Jørgensen, Merete Nordentoft

#### Abstract

Objectives To evaluate the effects of integrated treatment for patients with a first episode of psychotic illness. Design Randomised clinical trial.

Setting Copenhagen Hospital Corporation and Psychiatric

Participants 547 patients with first episode of schizophrenia spectrum disorder.

Interventions Integrated treatment and standard treatment. The integrated treatment lasted for two years and consisted of assertive community treatment with programmes for family involvement and social skills training. Standard treatment offered contact with a community mental health centre.

Main outcome measures Psychotic and negative symptoms (each scored from 0 to a maximum of 5) at one and two years'

Results At one year's follow-up, psychotic symptoms changed favourably to a mean of 1.09 (standard deviation 1.27) with an estimated mean difference between groups of -0.31 (95% confidence interval -0.55 to -0.07, P=0.02) in favour of integrated treatment. Negative symptoms changed favourably with an estimated difference between groups of -0.36 (-0.54 to -0.17, P<0.001) in favour of integrated treatment. At two years' follow-up the estimated mean difference between groups in psychotic symptoms was -0.32 (-0.58 to -0.06, P=0.02) and in negative symptoms was -0.45 (-0.67 to -0.22, P< 0.001), both in favour of integrated treatment. Patients who received integrated treatment had significantly less comorbid substance misuse, better adherence to treatment, and more satisfaction with treatment.

Conclusion Integrated treatment improved clinical outcome and adherence to treatment. The improvement in clinical outcome was consistent at one year and two year follow-ups.

patients who had experienced a first episode of psychosis.5 The null hypothesis investigated was that there would be no differences between integrated treatment and standard treatment with regard to psychotic and negative symptoms, treatment adherence, admissions, use of bed days, substance abuse, accommodation status, labour market affiliation, and user satisfaction

#### Participants and methods

Patients were included from all inpatient and outpatient mental health services in Copenhagen (Copenhagen Hospital Corporation) and Aarhus County. From January 1998 until December 2000, 547 patients aged 18-45 years with a diagnosis in the schizophrenia spectrum ((ICD-10 codes in the F2 category) and who had not been given antipsychotic drugs for more than 12 weeks of continuous treatment were included in the trial.

The included patients were centrally randomised to integrated treatment or standard treatment. In Copenhagen, randomisation was carried out through centralised telephone randomisation at the Copenhagen Trial Unit. The allocation sequence was computer generated, 1:1, in blocks of six, and stratified for each of five centres. In Aarhus, the researchers contacted a secretary by telephone when they had finished the entry assessment of each nationt. The secretary then drew one lot from among five red and five white lots out of a black box. When the block of 10 was used, the lots were redrawn. Block sizes were unknown to the

The trial was pragmatic, comparing integrated treatment defined by a set of protocols with treatment as usual.6

Feasibility and Effectiveness of a Multi-Element Psychosocial Intervention for First-Episode Psychosis: Results From the Cluster-Randomized Controlled GET UP PIANO Trial in a Catchment Area of 10 Million Inhabitants

Mirella Ruggeri\*, 1,2, Chiara Bonetto<sup>1</sup>, Antonio Lasalvia<sup>1,2</sup>, Angelo Fioritti<sup>3</sup>, Giovanni de Girolamo<sup>4</sup>, Paolo Santonastaso<sup>5</sup>, Francesca Pileggi<sup>3</sup>, Giovanni Neri<sup>6,7</sup>, Daniela Ghigi<sup>8</sup>, Franco Giubilini<sup>9</sup>, Maurizio Miceli<sup>10</sup>, Silvio Scarone<sup>11</sup>, Angelo Cocchi<sup>12</sup>, Stefano Torresani<sup>13</sup>, Carlo Faravelli<sup>14</sup>, Carla Cremonese<sup>15</sup>, Paolo Scocco<sup>16</sup>, Emanuela Leuci<sup>9</sup>, Fausto Mazzi<sup>17</sup>, Michela Pratelli<sup>8</sup>, Francesca Bellini<sup>8</sup>, Sarah Tosato<sup>1,2</sup>, Katia De Santi<sup>1,2</sup>, Sarah Bissoli<sup>1</sup>, Sara Poli<sup>1</sup>, Elisa Ira<sup>1</sup>, Silvia Zoppei<sup>1</sup>, Paola Rucci<sup>3,7</sup>, Laura Bislenghi<sup>12</sup>, Giovanni Patelli<sup>12</sup>, Doriana Cristofalo<sup>1</sup>, Anna Meneghelli<sup>12</sup>, and The GET UP Group<sup>18</sup>

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Supplemental content

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### Cost-effectiveness of an early intervention service for people with psychosis<sup>†</sup>

Paul McCrone, Tom K. J. Craig, Paddy Power and Philippa A. Garety

To compare the costs and cost-effectiveness of an early intervention service in London with standard care.

individuals in their first episode of psychosis (or those who had previously discontinued treatment) were recruited to the be cost-effective when compared with standard care. study. Clinical variables and costs were measured at baseline and then at 6- and 18-month follow-up. Information on quality of life and vocational outcomes were combined with 
Declaration of Interest costs to assess cost-effectiveness.

increase costs and Background

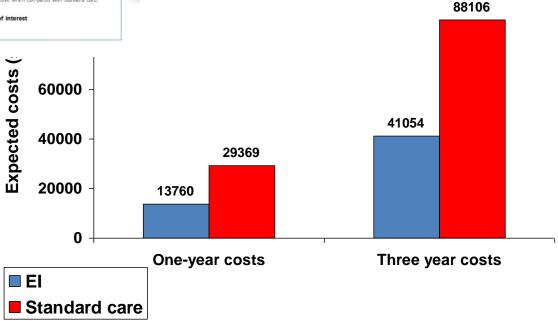
Results

A total of 144 people were random
There is concern that delaying treatment for psychosis may
were £11 d85 in the early intervent
were £11 d85 in the early intervent
the standard care group, with the
with standard come.

With standard come. Background

There is concern that delaying treatment for psychoisis may have a negative impact on its long-term course. A number of were £11.685 in the early intervent course, to number of were £11.685 in the early intervent course, to number of were £11.685 in the early intervent with standard care group, with the significant (95% CI -£112.8 to 23 combined with improved vocative care.) very high likelihood of being cost-effects.





# Early intervention teams most effective when DUP is low

# Comprehensive Versus Usual Community Care for First-Episode Psychosis: 2-Year Outcomes From the NIMH RAISE Early Treatment Program

John M. Kane, M.D., Delbert G. Robinson, M.D., Nina R. Schooler, Ph.D., Kim T. Mueser, Ph.D., David L. Penn, Ph.D., Robert A. Rosenheck, M.D., Jean Addington, Ph.D., Mary F. Brunette, M.D., Christoph U. Correll, M.D., Sue E. Estroff, Ph.D., Patricia Marcy, B.S.N., James Robinson, M.Ed., Piper S. Meyer-Kalos, Ph.D., L.P., Jennifer D. Gottlieb, Ph.D., Shirley M. Glynn, Ph.D., David W. Lynde, M.S.W., Ronny Pipes, M.A., L.P.C.-S., Benji T. Kurian, M.D., M.P.H., Alexander L. Miller, M.D., Susan T. Azrin, Ph.D., Amy B. Goldstein, Ph.D., Joanne B. Severe, M.S., Haiqun Lin, M.D., Ph.D., Kyaw J. Sint, M.P.H., Majnu John, Ph.D., Robert K. Heinssen, Ph.D., A.B.P.P.

**Objective:** The primary aim of this study was to compare the impact of NAVIGATE, a comprehensive, multidisciplinary, team-based treatment approach for first-episode psychosis designed for implementation in the U.S. health care system, with community care on quality of life.

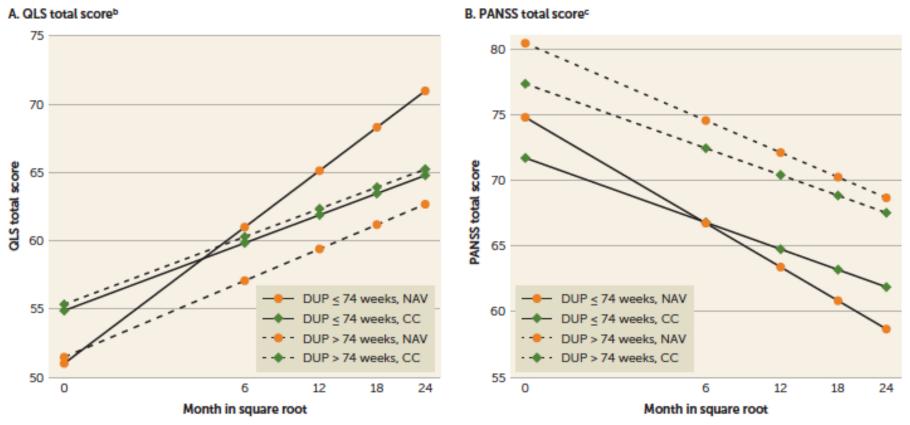
Method: Thirty-four clinics in 21 states were randomly assigned to NAVIGATE or community care. Diagnosis, duration of untreated psychosis, and clinical outcomes were assessed via live, two-way video by remote, centralized raters masked to study design and treatment. Participants (mean age, 23) with schizophrenia and related disorders and ≤6 months of antipsychotic treatment (N=404) were enrolled and followed for ≥2 years. The primary outcome was the total score of the Heinrichs-Carpenter Quality of Life Scale, a measure that includes sense of purpose, motivation, emotional and social interactions, role functioning, and engagement in regular activities.

Results: The 223 recipients of NAVIGATE remained in treatment longer, experienced greater improvement in quality of life and psychopathology, and experienced greater involvement in work and school compared with 181 participants in community care. The median duration of untreated psychosis was 74 weeks. NAVIGATE participants with duration of untreated psychosis of <74 weeks had greater improvement in quality of life and psychopathology compared with those with longer duration of untreated psychosis and those in community care. Rates of hospitalization were relatively low compared with other first-episode psychosis clinical trials and did not differ between groups.

**Conclusions:** Comprehensive care for first-episode psychosis can be implemented in U.S. community clinics and improves functional and clinical outcomes. Effects are more pronounced for those with shorter duration of untreated psychosis.

Am J Psychiatry 2016; 173:362–372; doi: 10.1176/appi.ajp.2015.15050632

FIGURE 3. Heinrichs-Carpenter Quality of Life (QLS) Total Score and PANSS Total Score: Effects of Shorter or Longer Duration of Untreated Psychosis (DUP) Based on a Model With Square Root Transformation of Months<sup>a</sup>



<sup>&</sup>lt;sup>a</sup> In the model, DUP and DUP by square root of time by treatment terms were included as covariates in addition to the covariates listed in Table 2. The DUP by square root of time term was found not to be significant for either outcome. PANSS=Positive and Negative Syndrome Scale; CC=Community Care; NAV=NAVIGATE.

<sup>&</sup>lt;sup>b</sup>DUP by treatment by square root of time interaction, p=0.003.

<sup>&</sup>lt;sup>c</sup>DUP by treatment by square root of time interaction, p=0.043.

Are gains from intensive early intervention maintained?

### Five-Year Follow-up of a Randomized Multicenter Trial of Intensive Early Intervention vs Standard Treatment for Patients With a First Episode of Psychotic Illness

The OPUS Trial

Mette Bertelsen, MSc; Pia Jeppesen, MD, PhD; Lone Petersen, PhD; Anne Thorup, MD, PhD; Johan Øhlenschlæger, MD, PhD; Phuong le Quach, MD; Torben Østergaard Christensen, PhD; Gertrud Krarup, MD; Per Jørgensen, MD; Merete Nordentoft, MD, PhD, MPH

Table 5. Remission and Relapse During Last 2 Years Before 5-Year Follow-up<sup>a</sup>

	5-Year Follow-up, No. (%)				
	Intensive Early-Intervention Program (n=151)	Standard Treatment (n=150)	Differences in Percentages (95% CI)		
Episodic course of illness <sup>b</sup>	21 (14)	19 (13)	-2 (-0.06 to 0.1)		
Continuous course of illness <sup>c</sup>	67 (45)	65 (44)	-2 (-0.12 to 0.1)		
Not psychotic <sup>d</sup>	62 (41)	64 (43)	2 (-0.13 to 0.09)		

Abbraviation, CL confidence interval

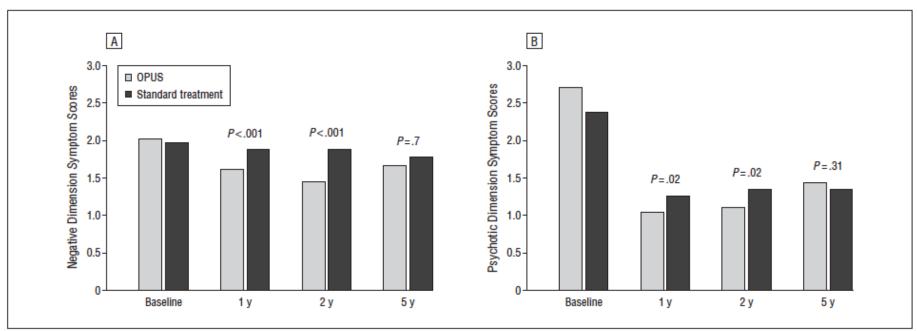


Figure 2. Mean symptom values for patients in the intensive early-intervention program (OPUS) vs standard treatment, according to the Scale for Assessment of Psychotic Symptoms and Scale for Assessment of Negative Symptoms<sup>25</sup> at baseline, 2-year follow-up, and 5-year follow-up for the negative (A) and psychotic (B) dimensions. Values range from 0 to 5.

# How do we maintain gains from early intervention?

RESEARCH REPORT

# Comparing three-year extension of early intervention service to regular care following two years of early intervention service in first-episode psychosis: a randomized single blind clinical trial

Ashok Malla <sup>1,2</sup>, Ridha Joober <sup>1,2</sup>, Srividya Iyer <sup>1,2</sup>, Ross Norman <sup>3</sup>, Norbert Schmitz <sup>1,4</sup>, Thomas Brown <sup>1,4</sup>, Danyael Lutgens <sup>1,2</sup>, Eric Jarvis <sup>1,5</sup>, Howard C. Margolese <sup>1,6</sup>, Nicola Casacalenda <sup>1,5</sup>, Amal Abdel-Baki <sup>7</sup>, Eric Latimer <sup>1,4</sup>, Sally Mustafa <sup>2</sup>, Sherezad Abadi <sup>2</sup>

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This study aimed to determine if, following two years of early intervention service for first-episode psychosis, three-year extension of that service was superior to three years of regular care. We conducted a randomized single blind clinical trial using an urn randomization balanced for gender and substance abuse. Participants were recruited from early intervention service clinics in Montreal. Patients (N=220), 18-35 years old, were randomized to an extension of early intervention service (EEIS; N=110) or to regular care (N=110). EEIS included case management, family intervention, cognitive behaviour therapy and crisis intervention, while regular care involved transfer to primary (community health and social services and family physicians) or secondary care (psychiatric outpatient clinics). Cumulative length of positive and negative symptom remission was the primary outcome measure. EEIS patients had a significantly longer mean length of remission of positive symptoms (92.5 vs. 63.6 weeks, t=4.47, p<0.001), negative symptoms (73.4 vs. 59.6 weeks, t=2.84, p=0.005) and both positive and negative symptoms (66.5 vs. 56.7 weeks, t=2.25, p=0.03) compared to regular care patients. EEIS patients stayed in treatment longer than regular care patients (mean 131.7 vs. 105.3 weeks, t=3.98, p<0.001 through contact with physicians;  $134.8 \pm 37.7$  vs.  $89.8 \pm 55.2$ , t=6.45, p<0.0001 through contact with other health care providers) and received more units of treatment (mean 74.9 vs. 39.9, t=4.21, p<0.001 from physicians, and 57.3 vs. 28.2, t=4.08, p<0.001 from other health care professionals). Length of treatment had an independent effect on the length of remission of positive symptoms (t=2.62, p=0.009), while number of units of treatment by any health care provider had an effect on length of remission of negative symptoms (t=-2.70, p=0.008) as well as total symptoms (t=-2.40, p=0.02). Post-hoc analysis showed that patients randomized to primary care, based on their better clinical profile at randomization, maintained their better outcome, especially as to remission of negative symptoms, at the end of the study. These data suggest that extending early intervention service for three additional years has a positive impact on length of remission of positive and negative symptoms compared to regular care. This may have policy implications for extending early intervention services beyond the current two years.

Key words: First-episode psychosis, extension of early intervention service, regular care, positive symptoms, negative symptoms, outcome, remission

# Impact of extended EIP?

➤ Patients in the E-EIP: remission of positive symptoms for ~50% longer period than CMHT care (mean 92.5 vs. 63.6 weeks, standardized beta 50.34, t=54.47, p<0.001).

Extending EIP for three additional years has a positive impact on length of remission of positive and negative symptoms compared to regular care.

➤ NB. Not differentiated by need. 'Maintenance dose'?

# How does it work?: More interventions delivered

Table 2 Clinical care received during follow-up

	Number of interventions (mean ± SD)		Length of treatment (weeks, mean ± SD)	
	EEIS	Regular care	EEIS	Regular care
Physicians	74.9 ± 43.6*	$39.9 \pm 69.1$	131.7 ± 37.4*	$105.3 \pm 51.5$
Other health care providers	57.3 ± 37.3*	$28.2 \pm 59.6$	134.8 ± 37.7**	$89.8 \pm 55.2$

EEIS – extended early intervention service

<sup>\*</sup>p<0.001, \*\*p<0.0001

# How does it work?: Better satisfaction, more engagement

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DOI: 10.1111/eip.13004 | Checupted: 24 May 2020 | Checupted: 24 May 20

#### BRIEF REPORT

WILEY

Patient satisfaction with random assignment to extended early intervention for psychosis vs regular care: Relationship with service engagement

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#### Funding information

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#### Abstract

Aim: We investigated whether individuals varied in their satisfaction with being randomized to an extension of early intervention (EI) for psychosis or regular care after 2 years of EI, and whether satisfaction was associated with service engagement 3 years later.

Methods: Following randomization, patients (N = 220) indicated if they were happy with, unhappy or indifferent to their group assignment. Follow-up with service providers was recorded monthly.

Results: Patients randomized to extended EI were more likely to express satisfaction with their group assignment than those in the regular care group (88.2% vs 31.5%,  $\chi^2$  = 49.96, P < .001). In the extended EI group, those happy with their assigned group were likelier to continue seeing their case manager for the entire five-year period than those who were unhappy/indifferent ( $\chi^2$  = 5.61, P = .030).

Conclusions: Perceptions about EI, indicated by satisfaction with being assigned to extended EI, may have lasting effects on service engagement.

#### KEYWORDS

early intervention services, engagement, first-episode psychosis, randomization, satisfaction

# Acta Psychiatrica Scandinavica

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ACTA PSYCHIATRICA SCANDINAVICA

# Short duration of untreated psychosis enhances negative symptom remission in extended early intervention service for psychosis

Dama M, Shah J, Norman R, Iyer S, Joober R, Schmitz N, Abdel-Baki A, Malla A. Short duration of untreated psychosis enhances negative symptom remission in extended early intervention service for psychosis

Objective: To test whether duration of untreated psychosis (DUP) < 3 months, recommended by the World Health Organization/ International Early Psychosis Association, enhances the effects of an extended early intervention service (EEIS) on symptom remission. Method: We examined data from a randomized controlled trial in which patients who received 2 years of treatment in EIS for psychosis were subsequently randomized to either 3 years of EEIS or 3 years of regular care (RC). Using a DUP cut-off ≤ 12 weeks (approximately < 3 months), patients were split into two groups. Length of positive, negative and total symptom remission were the outcomes. **Results:** Patients (N = 217) were mostly male (68%) with schizophrenia spectrum disorder (65%); 108 (50%) received EEIS (58 had DUP <12 weeks: 50 had DUP>12 weeks). Interaction between treatment condition (EEIS vs. RC) and DUP cut-off ≤ 12 weeks was only significant in multiple linear regression model examining length of negative symptom remission as the outcome (adjusted  $\beta = 36.88$ [SE = 15.88], t = 2.32, P = 0.02). EEIS patients with DUP  $\leq 12$  weeks achieved 25 more weeks of negative symptom remission than EEIS patients with DUP > 12 weeks.

Conclusion: Having a short DUP may be critical in deriving long-term benefits from EIS for psychosis, including EEIS settings. This work empirically supports policy recommendations of reducing DUP <3 months.

M. Dama <sup>1</sup>, J. Shah<sup>2</sup>, R. Norman<sup>3</sup>, S. Iyer<sup>2</sup>, R. Joober<sup>2</sup>, N. Schmitz<sup>2</sup>, A. Abdel-Baki<sup>4</sup>, A. Malla<sup>2</sup>

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Key words: psychotic disorders; schizophrenia; young adult; early intervention; health services accessibility

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Trial registration: ISRCTN Registry, ISRCTN11889976.

Accepted for publication April 3, 2019

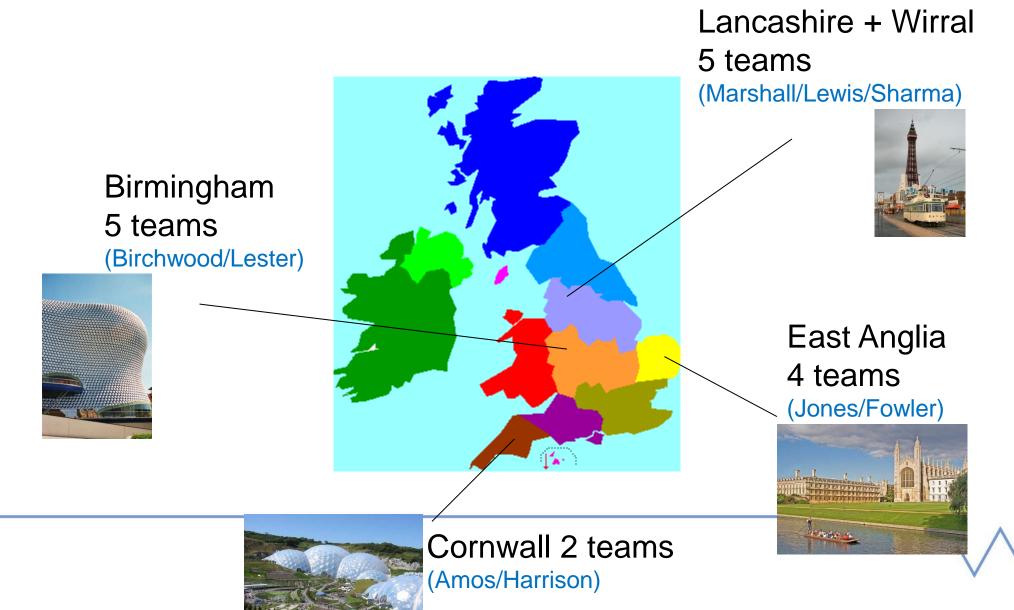
#### Significant outcomes

- Having a short DUP of 12 weeks or less may increase the length of negative symptom remission by 25
  more weeks among patients receiving treatment in an extended early intervention service for psychosis
- These results are independent of known confounds including the age at onset of psychosis, premorbid functioning, having a diagnosis of schizophrenia spectrum disorder and the severity of negative symptoms at the time of randomization
- This work provides important empirical support for the World Health Organization and International Early Psychosis Association's recommendation of having a DUP of less than 3 months in early intervention services for psychosis

# BUT, it won't work well if DUP is long

Phase 3: Implementation studies: DUP; EIP 'non-responders'; fidelity and cost-effectiveness.

# The National/SUPER EDEN sites





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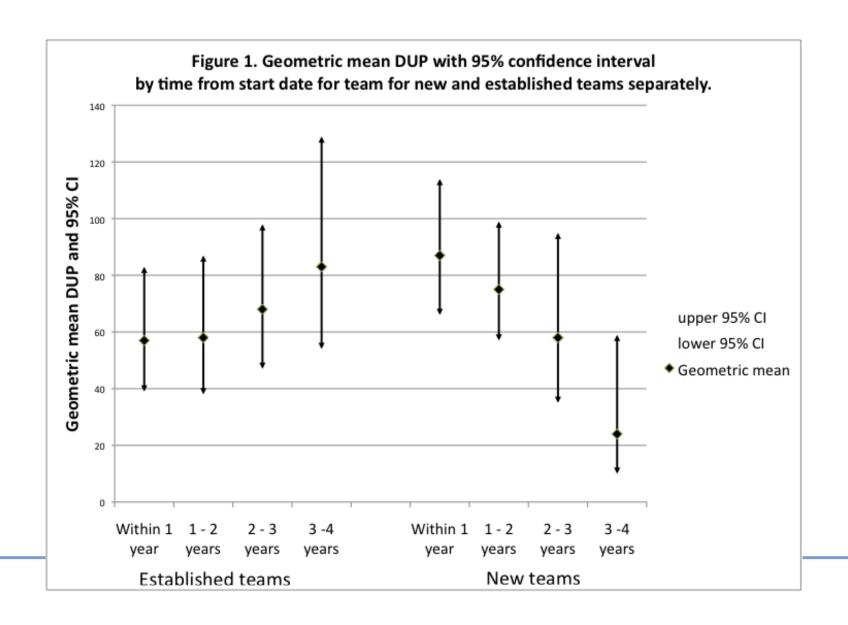


# Impact of early intervention services on duration of untreated psychosis: Data from the National EDEN prospective cohort study



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#### 🦒 🕕 Effect of delaying treatment of first-episode psychosis on symptoms and social outcomes: a longitudinal analysis and modelling study



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Background Delayed treatment for first episodes of psychosis predicts worse outcomes. We hypothesised that delaying treatment makes all symptoms more refractory, with harm worsening first quickly, then more slowly. We also See Comment page 563 hypothesised that although delay impairs treatment response, worse symptoms hasten treatment, which at Division of Psychology 2 presentation mitigates the detrimental effect of treatment delay on symptoms.

> Methods In this longitudinal analysis and modelling study, we included two longitudinal cohorts of patients with firstepisode psychosis presenting to English early intervention services from defined catchments: NEDEN (recruiting 1003 patients aged 14-35 years from 14 services between Aug 1, 2005, and April 1, 2009) and Outlook (recruiting 399 patients aged 16-35 years from 11 services between April 1, 2006, and Feb 28, 2009). Patients were assessed at baseline. 6 months, and 12 months with the Positive and Negative Symptom Scale (PANSS), Calgary Depression Scale for Schizophrenia, Mania Rating Scale, Insight Scale, and Social and Occupational Functioning Assessment Scale. Regression was used to compare different models of the relationship between duration of untreated psychosis (DUP) and total symptoms at 6 months. Growth curve models of symptom subscales tested predictions arising from

> Findings We included 948 patients from the NEDEN study and 332 patients from the Outlook study who completed baseline assessments and were prescribed dopamine antagonist antipsychotics. For both cohorts, the best-fitting models were logarithmic, describing a curvilinear relationship of DUP to symptom severity: longer DUP predicted reduced treatment response, but response worsened more slowly as DUP lengthened. Increasing DUP by ten times predicted reduced improvement in total symptoms (ie, PANSS total) by 7.339 (95% CI 5.762 to 8.916; p<0.0001) in NEDEN data and 3.846 (1.689 to 6.003; p=0.0005) in Outlook data. This was true of treatment response for all symptom types. Nevertheless, longer DUP was not associated with worse presentation for any symptoms except depression in NEDEN (coefficients 0.099 [95% CI 0.033 to 0.164]; p=0.0028 in NEDEN and 0.007 [-0.081 to 0.095]; p=0.88 in Outlook).

> Interpretation Long DUP was associated with reduced treatment response across subscales, consistent with a harmful process upstream of individual symptoms' mechanisms; response appeared to worsen quickly at first, then more slowly. These associations underscore the importance of rapid access to a comprehensive range of treatments, especially in the first weeks after psychosis onset.

Funding UK Department of Health, National Institute of Health Research, and Medical Research Council,

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Prolonged duration of untreated psychosis (DUP) predicts worse symptoms of all types and poorer social functioning (Prof N Freemantle PhD); School and quality of life for 2 years11 after presentation or longer.45 Earlier detection improved outcomes in the quasiexperimental TIPS study,6 as did introduction of specialist Partnership NHS Foundation early intervention services, 7-8 spurring introduction of early others, depending on which symptoms are primary, early Trust, Worthing, UK treatment services worldwide. Yet the mechanism by (Prof D Fowler); Department of which delayed treatment might cause harm remains Medicine, University of unclear. Evidence of direct neurotoxicity is inconsistent. 1,00,11

worsening presentation. In the TIPS trial, for patients in the control areas that had longer DUP, psychosis and excitement were increased only at presentation, while depression and disorganisation were worse only at followup, in proportion to their greater severity at presentation. Additionally, if exacerbation of one symptom worsens monotherapy with antipsychotics, antidepressants, or lithium might mitigate a range of later problems.

DUP and outcome might be associated only via Cambridge Cambridge UK Symptoms could simply accumulate over time, some unmeasured patient characteristic or residual

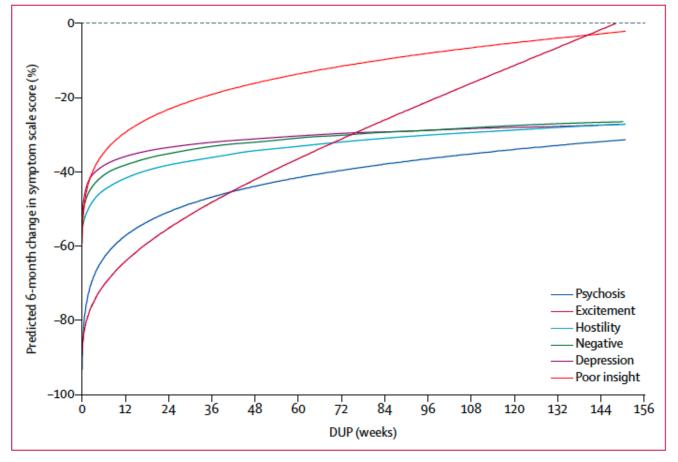


Figure 2: Predicted change in untransformed symptom scale scores over 6 months as a proportion of baseline, against DUP

Symptom change was calculated from natural log-transformed scores adjusted for centre, drug use, and demographics. Only the first 3 years of DUP are shown. DUP=duration of untreated psychosis.

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## DUP in UK (the National EDEN study)

**Table 4**Duration of untreated psychosis in days for each EIS.

	n	Min	Max	Median	Mean	95% CI for mean	Geometric mean	95% CI for geometric mean	Number and percentage of patients with DUP under 6 months
Established EIS									
Birmingham Central	66	0	2905	45	237	127 to 346	40	22 to 72	47 (71.2%)
Birmingham East	67	0	2022	141	296	195 to 398	85	51 to 142	37 (55.2%)
East Anglia Norfolk	146	0	5652	102	385	252 to 518	90	66 to 124	90 (61.6%)
CAMEO South	98	0	4748	47	257	130 to 384	43	28 to 66	72 (73.5%)
Wirral	27	0	3598	113	322	47 to 596	69	28 to 165	17 (63.0%)
West Cheshire	18	0	298	73	93	52 to 133	52	25 to 109	16 (88.9%)
East Cheshire	11	5	783	133	261	67 to 455	73	15 to 347	6 (54.5%)
All established teams	435	0	5652	77	300	240 to 361	64	53 to 78	285 (65.8%)
New EIS									
Lancashire	189	0	5435	146	438	333 to 544	133	103 to 173	100 (52.9%)
Birmingham BEN	98	0	4821	34	208	94 to 321	24	15 to 40	76 (77.6%)
Birmingham South	79	0	1900	141	307	217 to 397	100	66 to 154	43 (54.4%)
Norfolk Kings Lynn	11	0	1471	12	300	- 18 to 617	15	1 to 157	7 (63.6%)
Solihull	31	3	2807	87	357	144 to 569	92	45 to 187	19 (61.3%)
CAMEO North	23	0	857	110	200	100 to 299	68	29 to 159	13 (56.5%)
Cornwall	122	0	6185	67	272	141 to 402	57	40 to 82	82 (67.2%)
All new teams	556	0	6185	89	325	271 to 378	72	60 to 86	340 (61.5%)
All teams	986	0	6185	82	314	274 to 354	68	60 to 78	625 (63.4%)

Still late intervention (DUP>6 months) for ~ 1/3

## Why is DUP still so long?

# Reducing duration of untreated psychosis: care pathways to early intervention in psychosis services

Max Birchwood, Charlotte Connor, Helen Lester, Paul Patterson, Nick Freemantle, Max Marshall, David Fowler, Shon Lewis, Peter Jones, Tim Amos, Linda Everard and Swaran Singh

#### **Background**

Interventions to reduce treatment delay in first-episode psychosis have met with mixed results. Systematic reviews highlight the need for greater understanding of delays within the care pathway if successful strategies are to be developed.

#### **Aims**

To document the care-pathway components of duration of untreated psychosis (DUP) and their link with delays in accessing specialised early intervention services (EIS). To model the likely impact on efforts to reduce DUP of targeted changes in the care pathway.

#### Method

Data for 343 individuals from the Birmingham, UK lead site of the National EDEN cohort study were analysed.

#### **Results**

One-third of the cohort had a DUP exceeding 6 months. The greatest contribution to DUP for the whole cohort came from delays within mental health services, followed by help-seeking delays. It was found that delay in reaching EIS was strongly correlated with longer DUP.

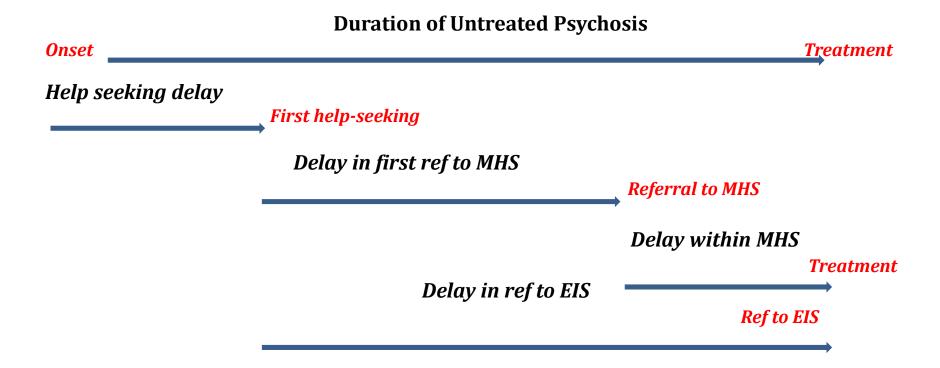
#### **Conclusions**

Community education and awareness campaigns to reduce DUP may be constrained by later delays within mental health services, especially access to EIS. Our methodology, based on analysis of care pathways, will have international application when devising strategies to reduce DUP.

#### **Declarations of interest**

None.

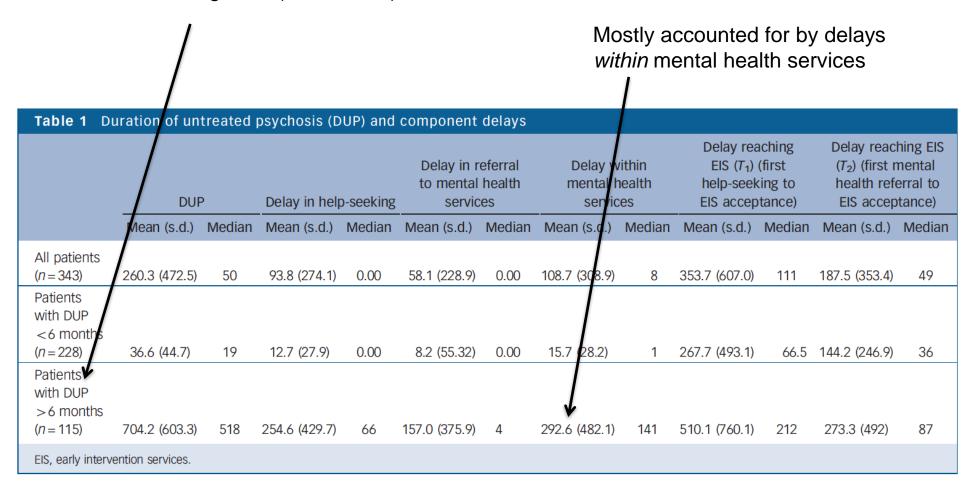
# Duration of Untreated Psychosis – component delays



## 1/3 still have long DUP (> 6 months)

	DUF	<b>,</b>	Delay in help	o-seeking	Delay in r to mental service	health	Delay w mental h servic	nealth	Delay rea EIS (T <sub>1</sub> ) help-seek EIS accep	(first ting to	Delay reac $(T_2)$ (first r health ref EIS accep	mental erral to
	Mean (s.d.)	Median	Mean (s.d.)	Median	Mean (s.d.)	Median	Mean (s.d.)	Median	Mean (s.d.)	Median	Mean (s.d.)	Median
All patients (n = 343)	260.3 (472.5)	50	93.8 (274.1)	0.00	58.1 (228.9)	0.00	108.7 (308.9)	8	353.7 (607.0)	111	187.5 (353.4)	49
Patients with DUP <6 months (n = 228)	36.6 (44.7)	19	12.7 (27.9)	0.00	8.2 (55.32)	0.00	15.7 (28.2)	1	267.7 (493.1)	66.5	144.2 (246.9)	36
Patients with DUP > 6 months (n = 115)	704.2 (603.3)	518	254.6 (429.7)	66	157.0 (375.9)	4	292.6 (482.1)	141	510.1 (760.1)	212	273.3 (492)	87

#### 1/3 still have long DUP (> 6 months)



## Impact of the first mental health contact

CAMHS/CMHTs linked to longer DUP

Table 2         Delays associated with first mental health service contact							
Mean (s.d.)							
First mental health service contact	Delay within mental health services	Delay reaching early intervention services	Duration of untreated psychosis				
Community mental health team $(n = 164)$	174.37 (411.04)	469.23 (727.76)	367.70 (579.41)				
Child and adolescent mental health services (n = 22)	205.95 (326.58)	360.36 (376.23)	283.82 (334.63)				
Home treatment team $(n = 84)$	21.52 (62.22)	173.30 (299.30)	129.05 (238.45)				
Psychiatric hospital (n = 43)	36.25 (97.03)	313.79 (639.75)	166.82 (423.64)				

### Why does first contact with CMHT/CAMHS prolong DUP?

Premature discharge from CMHT common \_\_lengthens DUP

Table 4         Community mental health team response, mental health service delay and duration of untreated psychosis							
	Mental health	service delay	Duration of untre	ated psychosis			
Outcome	Mean (s.d.)	Median	Mean (s.d.)	Median			
Referred to home treatment team	92 (233.5)	13	306 (501.3)	68			
Discharged	482.9 (784.8)	172	631 (848.7)	299			
Referred to early intervention services	91 (139.7)	52	420 (508.1)	203			

Why?
Delays access to EIS, which prolongs DUP

	DUF	o.	Delay in help	o-seeking	Delay in ro to mental service	health	Delay w mental h servic	nealth	Delay rea EIS (T <sub>1</sub> ) help-seek EIS accep	(first king to	Delay reac $(T_2)$ (first r health refo EIS accep	mental erral to
	Mean (s.d.)	Median	Mean (s.d.)	Median	Mean (s.d.)	Median	Mean (s.d.)	Median	Mean (s.d.)	Median	Mean (s.d.)	Median
All patients (n = 343)	260.3 (472.5)	50	93.8 (274.1)	0.00	58.1 (228.9)	0.00	108.7 (308.9)	8	353.7 (607.0)	111	187.5 (353.4)	49
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2 months or more after EIS acceptance. The delay in reaching criteria treatment within mental health services was strongly correlated (r = 0.68, P < 0.001) with delay in accessing EIS ( $T_2$ ), following referral to mental health services when psychotic.







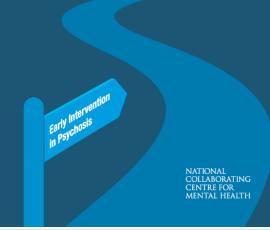


Table 5 Modelling the impact of reducing component delays on duration of untreated psychosis (DUP)								
Delay	365 days	180 days	90 days	60 days	30 days			
Delay in mental health services								
DUP								
Mean (s.d.)	220.9 (377.9)	198.6 (366.1)	183.8 (361.5)	175.3 (359.6)	167 (358.5)			
Median	49	49	49	49	32			
n (%) with DUP >6 months	115 (33.5)	115 (33.5)	115 (33.5)	78 (22.7)	74 (21.5)			
Delay in help-seeking								
DUP								
Mean (s.d.)	223.5 (403.9)	204.6 (392.6)	191.1 (388.7)	184.2 (387.6)	177.0 (386.8)			
Median	49	49	49	49	37			
n (%) with DUP >6 months	115 (33.5)	115 (33.5)	93 (27)	89 (26)	83 (24)			

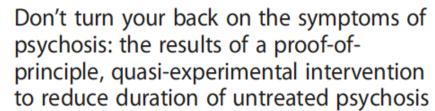
### Reducing treatment delay within mental health services and impact on DUP

Connor et al. BMC Psychiatry (2016) 16:127 DOI 10.1186/s12888-016-0816-7

**BMC** Psychiatry

#### **RESEARCH ARTICLE**

**Open Access** 





Charlotte Connor<sup>1\*</sup>, Max Birchwood<sup>1</sup>, Nick Freemantle<sup>2</sup>, Colin Palmer<sup>1</sup>, Sunita Channa<sup>1</sup>, Clare Barker<sup>3</sup>, Paul Patterson<sup>4</sup> and Swaran Singh<sup>1</sup>

#### Abstract

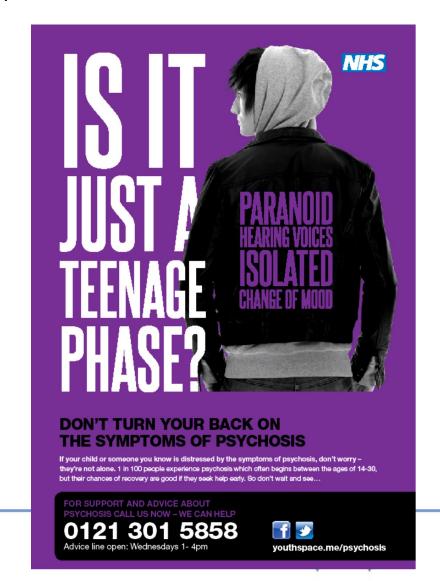
**Background:** No evidence based approach to reduce duration of untreated psychosis (DUP) has been effective in the UK Existing interventions have many components and have been difficult to replicate. The majority of DUP in Birming ham, UK is accounted for by delays within mental health services (MHS) followed by help-seeking delay and, we hypothesise, these require explicit targeting. This study examined the feasibility and impact of an intervention to reduce DUP, targeting help-seeking and MHSs delays.

**Methods:** A dual-component intervention, comprising a direct care pathway, for 16-25 year olds, and a community psychosis awareness campaign, using our youth-friendly website as the central hub, was implemented, targeting the primary sources of care pathway delays experienced by those with long DUP. Evaluation, using a quasi-experimental, design compared DUP of cases in two areas of the city receiving early detection vs detection as usual, controlling for baseline DUP in each area.

**Results:** DUP in the intervention area was reduced from a median 71 days (mean 285) to 39 days (mean 104) following the intervention, with no change in the control area. Relative risk for the reduction in DUP was 0.74 (95 %  $\,$  Cl 0.35 to 0.89; p = .004). Delays in MHSs and help-seeking were also reduced.

**Conclusions:** Our targeted approach appears to be successful in reducing DUP and could provide a generalizable methodology applicable in a variety of healthcare contexts with differing sources of delay. More research is needed, however, to establish whether our approach is truly effective.

Trial registration: ISRCTN45058713 - 30 December 2012.



**Table 5** DUP for EIS clients in intervention and control areas during trial (July 2011 – Dec 2013)

	Help-seeking delay	Delay within MHSs	Delay in reaching EIS	DUP	N = 151
Mean	116.97	124.19	162.30	216.43	74
Median	11.50	21.00	44.00	79.50	
St Dev	229.02	216.45	242.84	335.86	
Mean	41.49	42.32	130.57	103.82	77
Median	1.50	6.50	40.50	39.00	
St Dev	105.93	86.74	225.89	155.00	
	Median St Dev Mean Median	Mean       116.97         Median       11.50         St Dev       229.02         Mean       41.49         Median       1.50	Mean       116.97       124.19         Median       11.50       21.00         St Dev       229.02       216.45         Mean       41.49       42.32         Median       1.50       6.50	Mean       116.97       124.19       162.30         Median       11.50       21.00       44.00         St Dev       229.02       216.45       242.84         Mean       41.49       42.32       130.57         Median       1.50       6.50       40.50	Mean       116.97       124.19       162.30       216.43         Median       11.50       21.00       44.00       79.50         St Dev       229.02       216.45       242.84       335.86         Mean       41.49       42.32       130.57       103.82         Median       1.50       6.50       40.50       39.00

The bold text is to highlight the mean scores

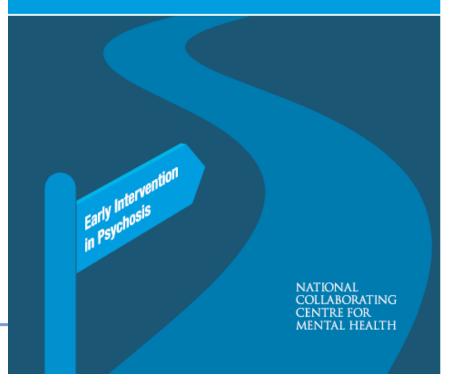
Relative risk for the reduction in DUP = 0.736 (95% CI 0.350 to 0.893; p=.0039)

Phase 4: National standards and monitoring.





# Implementing the Early Intervention in Psychosis Access and Waiting Time Standard: Guidance

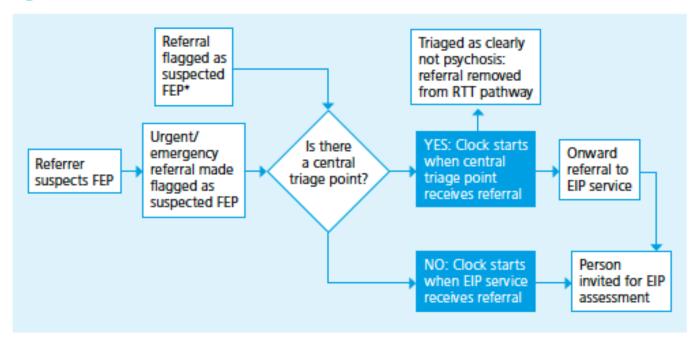


- The standard requires that, from 1 April 2016, more than 50% of people experiencing first episode psychosis commence a National Institute for Health and Care Excellence (NICE)recommended package of care within two weeks of referral. Treatment will be deemed to have commenced when the person:
  - a. has had an initial assessment; AND
  - has been accepted on to the caseload of an EIP service capable of providing a full package of NICE-recommended care; AND
  - has been allocated to and engaged with by an EIP care coordinator.

- 4.2 Measuring and reporting performance against the referral to treatment (RTT) waiting time requirement
- 4.2.1 Measuring the clock start: referral, recognition and initial assessment

#### Referral and recognition

Fig 1: Referral to clock start



<sup>\*</sup> If assessed by the central triage point as suspected FEP this referral should be flagged and moved on to the first episode pathway, and the clock will start on the day the central triage received the referral.

Key: FEP = first episode psychosis; RTT = referral to treatment



**Title: Early Intervention in Psychosis Waiting Times Summary:** Waiting times for patients started treatment for Early Intervention in Psychosis.



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Basis Publ N/A

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Contact: England.eip-data@nhs.net

nou.	December 2015 - March 2015
urce:	SDCS Data Collection - First Episode Psychosis
sis:	Commissioner
blished:	9th May 2019



evel Data	The number of p	atients started treat	ment by week since re	eferral	Total number of	
Period	>0-2 weeks	>2-6 weeks	>6-12 weeks	12 plus	completed pathways (all)	% within 2 weeks
December 2015	523	232	70	61	886	59.0
January 2016	530	251	86	41	908	58.4
February 2016	687	261	78	26	1,052	65.3
March 2016	720	281	96	21	1,118	64.4
April 2016	782	288	102	32	1,204	65.0
May 2016	788	278	62	34	1,162	67.8
June 2016	863	236	51	27	1,177	73.3
July 2016	938	245	54	20	1,257	74.6
August 2016	875	198	51	18	1,142	76.6
September 2016	921	206	43	19	1,189	77.5
October 2016	963	221	48	25	1,257	76.6
November 2016	935	216	34	20	1,205	77.6
December 2016	816	234	37	10	1,097	74.4
January 2017	853	190	66	10	1,119	76.2
February 2017	887	168	36	15	1,106	80.2
March 2017	920	272	40	16	1,248	73.7
April 2017	674	201	39	16	930	72.5
May 2017	886	205	34	11	1,136	78.0
June 2017	873	193	39	22	1,127	77.5
July 2017	824	226	36	14	1,100	74.9
August 2017	816	207	45	16	1,084	75.3
September 2017	818	187	47	15	1,067	76.7
October 2017	836	178	50	18	1,082	77.3
November 2017	787	230	50	22	1,089	72.3
December 2017	699	198	39	19	955	73.2
January 2018	722	238	65	17	1,042	69.3
February 2018	807	185	36	24	1,052	76.7
March 2018	795	178	49	26	1,048	75.9
April 2018	783	204	44	21	1,052	74.4
May 2018	840	210	47	12	1,109	75.7
June 2018	829	190	47	17	1,083	76.5
July 2018	819	210	37	13	1,079	75.9
August 2018	809	234	30	15	1,088	74.4
September 2018	766	171	60	10	1,007	76.1
October 2018	952	197	45	18	1,212	78.5
November 2018	872	213	45	14	1,144	76.2
December 2018	763	169	42	21	995	76.7
January 2019	811	206	49	13	1,079	75.2
February 2019	745	171	53	31	1,000	74.5
March 2019	759	171	46	20	996	76.2

Phase 5: Improving outcomes from Early Intervention

## EIP 'non-responders'

- Clients of early intervention services for 12–30 months
- Low levels of structured activity following 1 year in EIS (defined as ≤30 hrs/week on the Time Use Survey.

## Investigating trajectories of social recovery in individuals with first episode psychosis: a latent class growth analysis

Jo Hodgekins, Max Birchwood, Rose Christopher, Max Marshall, Sian Coker, Linda Everard, Helen Lester,\* Peter Jones, Tim Amos, Swaran Singh, Vimal Sharma, Nick Freemantle and David Fowler

#### Background

Social disability is a hallmark of severe mental illness yet individual differences and factors predicting outcome are largely unknown.

#### Ain

To explore trajectories and predictors of social recovery following a first episode of psychosis (FEP).

#### Metho

A sample of 764 individuals with FEP were assessed upon entry into Early Intervention for Psychosis (EIP) services and followed up over 12 months. Social recovery profiles were examined using Latent Class Growth Analysis.

#### Results

Three types of social recovery profile were identified: Low Stable (66%), Moderate-Increasing (27%), and High-Decreasing (7%). Poor social recovery was predicted by male gender, ethnic minority status, younger age at onset of psychosis, increased negative symptoms, and poor premorbid adjustment.

#### Conclusion

Social disability is prevalent in FEP, although distinct recovery profiles are evident. Where social disability is present upon entry into EIP services it can remain stable, highlighting a need for targeted intervention.

#### Declaration of interest

None.

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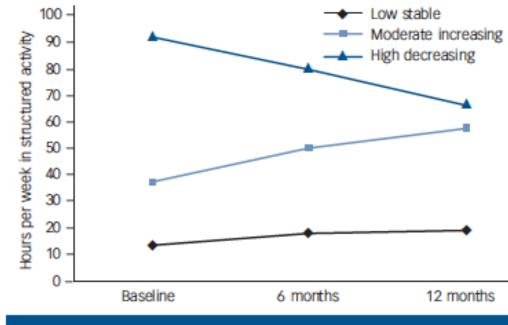


Fig. 1 LCGA model with three social recovery trajectories.

#### Social recovery therapy in combination with early intervention services for enhancement of social recovery in patients with first-episode psychosis (SUPEREDEN3): a single-blind, randomised controlled trial



David Fowler, Jo Hodgekins, Paul French, Max Marshall, Nick Freemantle, Paul McGrone, Linda Everard, Anna Lavis, Peter BJ ones, Tim Amos, Swaran Singh, Virnal Sharma, Max Birchwood

Background Provision of early intervention services has increased the rate of social recovery in patients with first Lancet Psychiatry 2018; episode psychosis; however, many individuals have continuing severe and persistent problems with social 5:41-50 functioning. We aimed to assess the efficacy of early intervention services augmented with social recovery therapy in Published Online patients with first-episode psychosis. The primary hypothesis was that social recovery therapy plus early intervention services would lead to improvements in social recovery.

Methods We did this single-blind, phase 2, randomised controlled trial (SUPEREDEN3) at four specialist early intervention services in the UK. We included participants who were aged 16-35 years, had non-affective psychosis. had been clients of early intervention services for 12-30 months, and had persistent and severe social disability, defined as engagement in less than 30 h per week of structured activity. Participants were randomly assigned (1:1), via computer-generated randomisation with permuted blocks (sizes of four to six), to receive social recovery therapy plus early intervention services or early intervention services alone. Randomisation was stratified by sex and recruitment centre (Norfolk, Birmingham, Lancashire, and Sussex). By necessity, participants were not masked to group allocation, but allocation was concealed from outcome assessors. The primary outcome was time spent in structured activity at 9 months, as measured by the Time Use Survey. Analysis was by intention to treat. This trial is registered with ISRCTN, number ISRCTN61621571.

Findings Between Oct 1, 2012, and June 20, 2014, we randomly assigned 155 participants to receive social recovery therapy plus early intervention services (n=76) or early intervention services alone (n=79); the intention-to-treat population comprised 154 patients. At 9 months, 143 (93%) participants had data for the primary outcome. Social recovery therapy plus early intervention services was associated with an increase in structured activity of 8.1 h (95% CI 2-5-13-6; p=0.0050) compared with early intervention services alone. No adverse events were deemed attributable to study therapy.

Interpretation Our findings show a clinically important benefit of enhanced social recovery on structured activity in patients with first-episode psychosis who received social recovery therapy plus early intervention services. Social recovery therapy might be useful in improving functional outcomes in people with first-episode psychosis, particularly in individuals not motivated to engage in existing psychosocial interventions targeting functioning, or who have Trust, Birmingham, UK comorbid difficulties preventing them from doing so.

Funding National Institute for Health Research

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http://dx.doi.org/10.1016/ 52215-0366(17)30476-5

Norwich, UK () Hodgekins PhD); (Prof P French); Lancashire Care Institute of Psychiatry, Psychology & Neuroscience King's College London, London UK (Prof P McCrone PhD); Birmingham and Sollhuli NHS Mental Health Foundation (L Byerard BSc): University of Birmingham, Birmingham, UK (A Lavis PhD); University of Cambridge, Cambridge, UK (Prof P B Jones PhD); University

## **Social Recovery orientated Cognitive Behavioural Therapy (SR-CBT)**

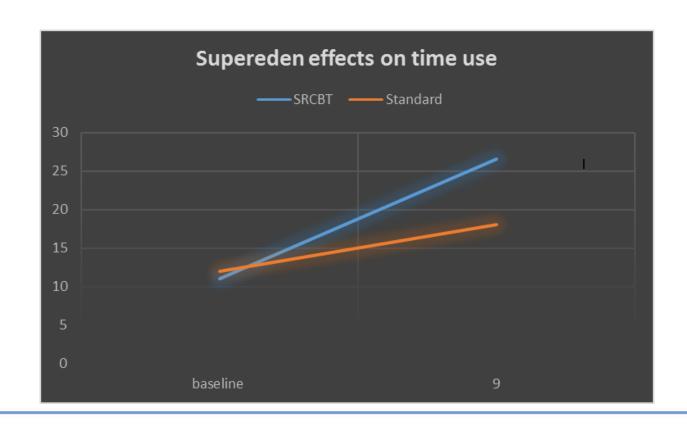
- Identify hopes and expectations as a young person
- Identify and overcome barriers to activity (eg. Hopelessness, social anxiety, family acceptance, stigma)
- Motivational interviewing: short and long term goals.
- Behavioural activation and coaching.
- Intensive outreach approach



## Results

Impact on primary outcome: time spent in 'structured activities'.

Social recovery therapy + EIS was associated with an increase in structured activity of 8.1 hrs/week (95% CI 2.5-13.6; p=0.0050) compared with EIS alone.



	Effect size (95% CI)	p value (intervention vs control)*	Missing data		pvalue‡
			Early intervention services alone (n=79)	Social recovery therapy plus early intervention services (n=75)†	
Primary outcomes					
Structured activity at 9 months	8-080 (2-502 to 13-657)	0.0050	9 (11%)	2 (3%)	0.011
Constructive economic activity at 9 months	5-859 (0-790 to 10-928)	0.024	9 (11%)	2 (3%)	0.034
Secondary outcomes					
Structured activity at 15 months	0-054 (-5-154 to 5-262)	0.98	19 (24%)	7 (9%)	0-037
Constructive economic activity at 15 months	-0.506 (-5.048 to 4.036)	0.83	19 (24%)	7 (9%)	0.046
Positive PANSS 9 months	0-306 (-1-228 to 1-840)	0.69	22 (28%)	9 (12%)	0.068
Negative PANSS 9 months	-1-020 (-2-662 to 0-622)	0.22	22 (28%)	9 (12%)	0.032
General PANSS 9 months	-1-014 (-3-514 to 1-486)	0-42	22 (28%)	9 (12%)	0.043
Positive PANSS 15 months	1-219 (-0-632 to 3-071)	0.19	32 (41%)	18 (24%)	0-071
Negative PANSS 15 months	-0-629 (-2-411 to 1-152)	0-49	32 (41%)	18 (24%)	0.073
General PANSS 15 months	-0-084 (-3-031 to 2-862)	0.96	33 (42%)	18 (24%)	0.081
SANS total at 9 months	9-713 (-14-568 to 33-994)	0-43	20 (25%)	11 (15%)	0.17
SANS total at 15 months	16-798 (-10-553 to 44-147)	0.23	32 (41%)	18 (24%)	0-035
BDI at 9 months	-1-567 (-4-840 to 1706)	0.35	24 (30%)	13 (17%)	0.10
BDI at 15 months	0-748 (-3-261 to 4-757)	0.71	36 (46%)	20 (27%)	0.067
SIAS at 9 months	-2-559 (-6-964 to 1-846)	0.25	26 (33%)	11 (15%)	0.016
SIAS at 15 months	1-490 (-4-132 to 7-111)	0-60	36 (46%)	19 (25%)	0.10
BHS at 9 months	-1-464 (-3-282 to 0-354)	0-11	33 (42%)	16 (21%)	0.020
BHS at 15 months	-1-451 (-3-257 to 0-355)	0-11	37 (47%)	19 (25%)	0.022
ATHS total score 9 months	2-214 (-1-504 to 5-931)	0-24	33 (42%)	21 (28%)	0.15
ATHS total score 15 months	3-860 (-0-266 to 7-987)	0.066	39 (49%)	22 (29%)	0.0060
MLQ total score 9 months	2-193 (-1-496 to 5-883)	0-24	33 (42%)	19 (25%)	0.12
MLQ total score 15 months	0782 (-3.196 to 4.759)	0-70	39 (49%)	23 (31%)	0.043

Data are n (%), unless otherwise specified. This approach assumes that loss to follow-up is associated with poor performance on the scale of interest. PANSS-Positive and Negative 9y mptom Scales. SANSS-Scale for Assessment of Negative Symptoms. BDI-Beck Depression Inventiony. SIASS-Social Interaction Anxiety Scale. BHS-Beck Hopelessness Scale. ATHS-Adult Trait Hope Scale. MLQ-Meaning in Life Questionnaire. "pvalue from complete case analysis. Minus one participant who withdrew and requested that their data be removed. 4p value from joint modeling (multivariate) analyses done to account for missing data.

Table 3: Prespecified outcome analysis and joint models for primary and secondary outcomes

### Secondary outcomes:

- ➤ Negative symptoms ✓
- ➤ Social anxiety, ✓
- ➤ Hopelessness
- ➤ Hope
- ➤ Meaning in life
- ➤ Depression X
- ➤ Positive symptoms X

#### ORIGINAL PAPER



## Five-year illness trajectories across racial groups in the UK following a first episode psychosis

Siân Lowri Griffiths 10 · Tumelo Bogatsu 1 · Mia Longhi 1 · Emily Butler 1 · Beel Alexander 1 · Mrunal Bandawar 1 · Linda Everard 2 · Peter B. Jones 3 · David Fowler 4 · Joanne Hodgekins 5 · Tim Amos 6 · Nick Freemantle 7 · Paul McCrone 8 · Swaran P. Singh 9 · Max Birchwood 9 · Rachel Upthegrove 1

Received: 2 May 2022 / Accepted: 12 January 2023 © The Author(s) 2023

#### Abstract

Purpose Psychosis disproportionally affects ethnic minority groups in high-income countries, yet evidence of disparities in outcomes following intensive early intervention service (EIS) for First Episode Psychosis (FEP) is less conclusive. We investigated 5-year clinical and social outcomes of young people with FEP from different racial groups following EIS care.

Method Data were analysed from the UK-wide NIHR SUPEREDEN study. The sample at baseline (n=978) included White (n=750), Black (n=71), and Asian (n=157) individuals, assessed during the 3 years of EIS, and up to 2 years post-discharge (n=296); Black (n=23); Asian (n=52) and White (n=221)). Outcome trajectories were modelled for psychosis symptoms (positive, negative, and general), functioning, and depression, using linear mixed effect models (with random intercept and slopes), whilst controlling for social deprivation. Discharge service was also explored across racial groups, 2 years following EIS.

Results Variation in linear growth over time was accounted for by racial group status for psychosis symptoms—positive (95% CI [0.679, 1.235]), negative (95% CI [0.315, 0.783]), and general (95% CI [1.961, 3.428])—as well as for functioning (95% CI [11.212, 17.677]) and depressive symptoms (95% CI [0.261, 0.648]). Social deprivation contributed to this variance. Black individuals experienced greater levels of deprivation (p < 0.001, 95% CI [0.187, 0.624]). Finally, there was a greater likelihood for Asian (OR = 3.04; 95% CI [2.050, 4.498]) and Black individuals (OR = 2.47; 95% CI [1.354, 4.520]) to remain in secondary care by follow-up.

Conclusion Findings suggest variations in long-term clinical and social outcomes following EIS across racial groups; social deprivation contributed to this variance. Black and Asian individuals appear to make less improvement in long-term recovery and are less likely to be discharged from mental health services. Replication is needed in large, complete data, to fully understand disparities and blind spots to care.

Keywords Outcomes · Early psychosis · Ethnicity · Deprivation · Inequities

Max Birchwood and Rachel Upthegrove shared joint senior authorship.

- Black and Asian heritage groups do less well under El
- Linked to ongoing deprivation

Received: 9 March 2017 Revised: 26 May 2017 Accepted: 11 July 2017

DOI: 10.1111/eip.12481

WILEY

#### EARLY INTERVENTION IN THE REAL WORLD

#### Cost-effectiveness of early intervention services for psychosis and fidelity to national policy implementation guidance

Muralikrishnan Radhakrishnan<sup>1</sup> | Paul McCrone<sup>1</sup> | Louise Lafortune<sup>2</sup> | Linda Everard<sup>3</sup> | David Fowler<sup>4</sup> | Tim Amos<sup>5</sup> | Nick Freemantle<sup>6</sup> | Swaran P. Singh<sup>7</sup> | Max Marshall<sup>8</sup> | Vimal Sharma<sup>9</sup> | Anna Lavis<sup>10</sup> | Peter B. Jones<sup>11</sup> | Max Birchwood<sup>8</sup>

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Funding information UK Department of Health, Grant/Award number: PO261680

Alm: Early intervention services (EIS) for psychosis are being implemented, internationally. It is important to learn from established examples and define the components and intensity of services that provide good value for money. This study aims to assess the cost-effectiveness of EIS according to how closely they adhered to the recommendations of the English Department of Health 2001 Policy Implementation Guide (PIG).

Methods: EIS from the National Eden Study were assessed using a measure of fidelity to the PIG that rated the presence or absence of 64 recommended items relating to team structure and practice. EIS were then classified into three groups: those with fidelity of 75-80%, 81-90% and 91-95%. Patient-level resource use and outcomes were measured 1 year following inception into the service; costs were calculated and combined with quality-adjusted life

Results: At a threshold of £20 000 per QALY, the 81-90% fidelity group had a 56.3% likelihood of being the most cost-effective option followed by 75-80% fidelity at 35.8% and 91-95% fidelity group (7.9%).

Condusions: The results from England suggest that striving to maximize fidelity may not be warranted, but that dropping below a certain level of fidelity may result in inefficient use of resources.

#### KEYWORDS

costs and cost analysis, early medical intervention, economic evaluation, psychotic disorders, quality-adjusted life years

#### Early Intervention Service (EIS) Fidelity Scale

Respondent #: Date of completion:

	CRITERION		RATINGS/A	MCHORS.	
		(1)	(2)	(3)	(4)
1	The team only accepts clients who have had no more than one episode of psychosis	Greater than 50% of clients had more than one episode at entry	31-50% of clients had more than one episode at entry	11-30% of clients had more than one episode at entry	10% or less of clients had more than one episode at entry
2	The EIS controls access to separate age- appropriate inpatient and crisis facilities <sup>2</sup>	There is no access to separate facilities for young people	There is access to separate crisis and inpatient facilities, but the EIS does not control this access	The EIS has control of separate crisis OR inpatient facilities for young people	The EIS has control of separate crisis AND inpatient facilities for young people
3	The EIS is a stand alone service composed of staff whose sole or main responsibility is to the EIS	The EIS has no separate team identity (made up of individuals who are members of other teams)	The EIS is a distinct team, but greater than 50% of staff have clinical commitments to other teams	The EIS is a distinct team, but 11-50% of staff have commitments to other teams	The EIS is a distinct team, 10% or less of staff have commitments to other teams
4	The EIS team contains two formally trained and accredited cognitive therapists <sup>3</sup>	No members have undergone formal training in CBT for psychosis	One or more members have had non-accredited formal training in CBT for psychosis.	One member has completed an accredited training course in CBT for psychosis	Two or more members have completed an accredited training course in CBT for psychosis

EIS FIDELITY SCALE Page 1 of 18 Version 3

<sup>1</sup> Please check one anchor per criterion using a physical tick for printed forms, or a mouse click on the electronic form. The direction of increasing fidelity is moving from 1 to 4.

<sup>&</sup>lt;sup>2</sup> Facilities meaning crisis care and inpatient facilities.

<sup>3 &#</sup>x27;Formal training' means experience of supervised training as part of a recognised training program. 'Accredited' means awarded a certificate of competence in CBT by a recognised training body.

Phase 6: Phase-specific interventions.

# Vocational intervention in first-episode psychosis: individual placement and support *v.* treatment as usual

Eóin Killackey, Henry J. Jackson and Patrick D. McGorry

#### **Background**

Unemployment is a major problem for people with firstepisode psychosis and schizophrenia. This has repercussions for the economy, social functioning and illness prognosis.

#### Aims

To examine whether a vocational intervention – individual placement and support (IPS) – which has been found to be beneficial in populations with chronic schizophrenia, was a useful intervention for those with first-episode psychosis.

#### Method

A total of 41 people with first-episode psychosis were randomised to receive either 6 months of IPS + treatment as usual (TAU) (n=20) or TAU alone (n=21).

#### Results

The IPS group had significantly better outcomes on level of employment (13 v. 2, P<0.001), hours worked per week

(median 38 v. 22.5, P=0.006), jobs acquired (23 v. 3) and longevity of employment (median 5 weeks v. 0, P=0.021). The IPS group also significantly reduced their reliance on welfare benefits.

#### Conclusions

Individual placement and support has good potential to address the problem of vocational outcome in people with first-episode psychosis. This has economic, social and health implications.

#### Declaration of interest

This research was supported by a National Health and Medical Research Council Program Grant (ID: 350241) and an unrestricted study grant from Bristol Myers Squibb. ORYGEN Research Centre is supported by the Colonial Foundation.

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### **ADEPP**

The ADEPP study is a randomised controlled trial with an internal pilot looking at the use of antidepressant for the prevention of depression following first episode psychosis.



The aim of the ADEPP trial is to establish the effectiveness and cost effectiveness of an antidepressant medication (sertraline) for the prevention of a depressive episode following first episode psychosis.

This page explains the ADEPP study for researchers who are taking part in the study, or who are considering doing so. A summary for participants is here.

#### In 'ADEPP'

- > Information for patients
- > Privacy
- > ADEPP
- > Trial documentation
- > Recruitment and participating centres
- > Contact us

# The Early Youth Engagement in first episode psychosis (EYE-2) study

 Cluster randomized controlled trial of effectiveness, cost effectiveness and implementation of the team-based motivational engagement intervention

 evaluated with respect to disengagement & routinely collected outcome data (HoNOS, QPR and DIALOG) in 1059 new FEP service users aged 14-35 in 5 sites across the UK.



## Relapse prevention through ambulatory monitoring of early signs



Psychological Medicine, 1989, 19, 649-656 Printed in Great Britain

Predicting relapse in schizophrenia: the development and implementation of an early signs monitoring system using patients and families as observers, a preliminary investigation\*

MAX BIRCHWOOD, JO SMITHI, FIONA MACMILLAN, BRIDGET HOGG, REKHA PRASAD, CATHY HARVEY AND SANDY BERING

From the Department of Clinical Psychology and Academic Unit, All Saints Hospital, Birmingham

#### The EMPOWER blended digital intervention for relapse prevention in schizophrenia: a feasibility cluster randomised controlled trial in Scotland and Australia



oa

Andrewl Gumley, Simon Bradstreet, John Ainsworth, Stephanie Allan, Mario Alvarez-Jimenez, Loma Aucatt, Maximillian Birchwood, Andrew Briggs, Sandra Bucci, Sue M Cotton, Lidia Engel, Paul French, Reeval Lederman, Shön Lewis, Matthew Machin, Graeme MacLennan, Hamish M.d. eod, Nicola McMeekin, Cathy Mihd opoulos, Emma Morton, John Norrie, Matthias Schwannauer, Swaran P Singh, Suresh Sundram, Andrew Thompson, Chris Williams, Alison R Yung, John Farhall, John Gleeson

Background Early warning signs monitoring by service users with schizophrenia has shown promise in preventing relapse but the quality of evidence is low. We aimed to establish the feasibility of undertaking a definitive randomised 9:477-86 controlled trial to determine the effectiveness of a blended digital intervention for relapse prevention in schizophrenia. See Communit page 474

Methods This multicentre, feasibility, duster randomised controlled trial aimed to compare Early signs Monitoring to Prevent relapse in psychosis and prOmote Well-being, Engagement, and Recovery (EMPOWER) with treatment as usual in community mental health services (CMHS) in Glasgow and Melbourne. CMHS were the unit of randomisation. selected on the basis of those that probably had five or more care coordinators willing to participate. Participants were SAlan MA, HMcLand PhD, eligible if they were older than 16 years, had a schtzophrenta or related diagnosts confirmed via case records, were able to NM:Mentin Ph.D. provide informed consent, had contact with CMHS, and had had a relapse within the previous 2 years. Participants were randomised within stratified clusters to EMPOWER or to continue their usual approach to care. EMPOWER blended a 68 occiding with MD. smartphone for active monitoring of early warning signs with peer support to promote self-management and clinical ARYongMD and Division of triage to promote access to relapse prevention. Main outcomes were feasibility, acceptability, usability, and safety, which was assessed through face-to-face Interviews. App usage was assessed via the smartphone and self-report. Primary end point was 12 months. Participants, research assistants and other team members involved in delivering the intervention of Health Sciences, Faculty of were not masked to treatment conditions. Assessment of relapse was done by an independent adjudication panel masked Biology. M edicino and Health to randomisation group. The study is registered at ISRCTN (99559262).

Findings We identified and randomised eight CMHS (six in Glasgow and two in Melbourne) comprising 47 care Organia-Melbourne Melbourne coordinators. We recruited 86 service users between Jan 19 and Aug 8, 2018; 73 were randomised (42 [58%] to VK Australia EMPOWER and 31 [42%] to treatment as usual). There were 37 (51%) men and 36 (49%) women. At 12 months, main (M About Jirmone Ph.D. outcomes were collected for 32 (76%) of service users in the EMPOWER group and 30 (97%) of service users in the Control for Youth Montal Health treatment as usual group. Of those randomised to EMPOWER, 30 (71%) met our a priori criterion of more than MANAGED interior. 33% adherence to daily monitoring that assumed feasibility. Median time to discontinuation of these participants was and School of Computing and 31.5 weeks (SD 14.5). There were 29 adverse events in the EMPOWER group and 25 adverse events in the treatment as usual group. There were 13 app-related adverse events, affecting 11 people, one of which was serious. Fear of relapse was lower in the EMPOWER group than in the treatment as usual group at 12 months (mean difference -7.53 (Redeman PhD), University (95% CI -14.45 to 0.60; Cohen's d-0.53).

interpretation A trial of digital technology to monitor early warning signs blended with peer support and clinical triage to detect and prevent relapse appears to be feasible, safe, and acceptable. A further main trial is merited.

Funding UK National Institute for Health Research Health Technology Assessment programme and the Australian National Health and Medical Research Council.

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#### Introduction

Schtzophrenta contributes substantially to global burden ment guidelines. of disease, and follows a recurring course; the relapse

attention to relapse prevention in schizophrenia treat-

Birchwood and colleagues pioneered the involvement Foundation Trust, Manchester rate is 80% within 5-years of follow-up.2 Relapses of individuals and carers in monitoring early warning UKG Buci Slawit School of threaten long-term recovery and contribute considerably signs of relapse to enable timely biopsychosocial Public Health and Preventive to treatment costs. "The distress of relapse and risk of interventions." However, there are outstanding questions Medicine (Lingui PhQ traumatisation associated with rehospitalisations warrant regarding the effectiveness of this approach. The quality

Science Centre, University of Manchester Manchester UK:

Melbourne, Melbourne, VIC Australia; Centre for Healthca Randomined Trials (CHaRT) Aberdeen, UK (LAucott PhD GMacLenranMSc); Centre fo Mental Health and Wellbein Research, Warwick Medical Warwick, UK (M Birchwood DS: Research and Policy, London School of Hygiene & Tropical (A Briggs DPhil); Greater

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## The traumatic experience of first-episode psychosis: A systematic review and meta-analysis



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#### ARTICLE INFO

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Keywords: First-episode psychosis Trauma Post-traumatic stress disorder

#### ABSTRACT

Introduction: A psychotic episode may be sufficiently traumatic to induce symptoms of post-traumatic stress disorder (PTSD), which could impact outcomes in first-episode psychosis (FEP). The objectives of this systematic review and meta-analysis were to estimate the prevalence of PTSD symptoms in relation to psychosis in FEP and to identify risk factors for the development of PTSD symptoms.

Methods: We searched electronic databases and conducted manual searching of reference lists and tables of contents to identify relevant studies. Quantitative studies were included if the population was experiencing FEP and if PTSD was measured in relation to psychosis. Prevalence of PTSD symptoms and diagnoses were meta-analyzed using a random effects model. Potential risk factors for PTSD symptoms were summarized qualitatively.

Results: Thirteen studies were included. Eight studies assessed PTSD symptoms, three studies assessed full PTSD, and two studies assessed both. The pooled prevalence of PTSD symptoms was 42% (95% CI 30%–55%), and the pooled prevalence of a PTSD diagnosis was 30% (95% CI 21%–40%). Exploratory subgroup analyses suggest that prevalence may be higher in affective psychosis and inpatient samples. Evidence from included studies implicate depression and anxiety as potential risk factors for PTSD symptoms.

Conclusions: Approximately one in two people experience PTSD symptoms and one in three experience full PTSD following a first psychotic episode. Evidence-based interventions to treat PTSD symptoms in the context of FEP are needed to address this burden and improve outcomes after the first psychotic episode. Further studies are needed to clarify the associated risk factors.

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#### **Original Investigation**

### Prolonged Exposure vs Eye Movement Desensitization and Reprocessing vs Waiting List for Posttraumatic Stress Disorder in Patients With a Psychotic Disorder A Randomized Clinical Trial

David P. G. van den Berg, MSc; Paul A. J. M. de Bont, MSc; Berber M. van der Vleugel, MSc; Carlijn de Roos, MSc; Ad de Jongh, PhD; Agnes Van Minnen, PhD; Mark van der Gaag, PhD

IMPORTANCE The efficacy of posttraumatic stress disorder (PTSD) treatments in psychosis has not been examined in a randomized clinical trial to our knowledge. Psychosis is an exclusion criterion in most PTSD trials.

**OBJECTIVE** To examine the efficacy and safety of prolonged exposure (PE) therapy and eye movement desensitization and reprocessing (EMDR) therapy in patients with psychotic disorders and comorbid PTSD.

**DESIGN, SETTING, AND PARTICIPANTS** A single-blind randomized clinical trial with 3 arms (N = 155), including PE therapy, EMDR therapy, and waiting list (WL) of 13 outpatient mental health services among patients with a lifetime psychotic disorder and current chronic PTSD. Baseline, posttreatment, and 6-month follow-up assessments were made.

**INTERVENTIONS** Participants were randomized to receive 8 weekly 90-minute sessions of PE (n = 53), EMDR (n = 55), or WL (n = 47). Standard protocols were used, and treatment was not preceded by stabilizing psychotherapeutic interventions.

MAIN OUTCOMES AND MEASURES Clinician-rated severity of PTSD symptoms, PTSD diagnosis, and full remission (on the Clinician-Administered PTSD Scale) were primary outcomes. Self-reported PTSD symptoms and posttraumatic cognitions were secondary outcomes.

RESULTS Data were analyzed as intent to treat with linear mixed models and generalized estimating equations. Participants in the PE and EMDR conditions showed a greater reduction of PTSD symptoms than those in the WL condition. Between-group effect sizes were 0.78 (P < .001) in PE and 0.65 (P = .001) in EMDR. Participants in the PE condition (56.6%; odds ratio [OR], 3.41; P = .006) or the EMDR condition (60.0%; OR, 3.92; P < .001) were significantly more likely to achieve loss of diagnosis during treatment than those in the WL condition (27.7%). Participants in the PE condition (28.3%; OR, 5.79; P = .01), but not those in the EMDR condition (16.4%; OR, 2.87; P = .10), were more likely to gain full remission than those in the WL condition (6.4%). Treatment effects were maintained at the 6-month follow-up in PE and EMDR. Similar results were obtained regarding secondary outcomes. There were no differences in severe adverse events between conditions (2 in PE, 1 in EMDR, and 4 in WL). The PE therapy and EMDR therapy showed no difference in any of the outcomes and no difference in participant dropout (24.5% in PE and 20.0% in EMDR, P = .57).

**CONCLUSIONS AND RELEVANCE** Standard PE and EMDR protocols are effective, safe, and feasible in patients with PTSD and severe psychotic disorders, including current symptoms. A priori exclusion of individuals with psychosis from evidence-based PTSD treatments may not be justifiable.

Author Affiliations: Author affiliations are listed at the end of this

TRIAL REGISTRATION isrctn.com Identifier: ISRCTN79584912

Corresponding Author: David P. G. van den Berg, MSc, Parnassia Cognitive Remediation Works But How Should We Provide It? An Adaptive Randomized Controlled Trial of Delivery Methods Using a Patient Nominated Recovery Outcome in First-Episode Participants

Til Wykes\*<sup>1,2,0</sup>, Dominic Stringer¹, Janette Boadu¹, Rose Tinch-Taylor¹, Emese Csipke¹, Matteo Cella¹.<sup>2,0</sup>,
Andrew Pickles¹, Paul McCrone³, Clare Reeder¹, Max Birchwood⁴, David Fowler⁵, Kathryn Greenwood⁵,
Sonia Johnson⁵, Jesus Perez⁻, Rosa Ritunnano⁴, Andrew Thompson⁴, Rachel Upthegrove³, Jon Wilson⁵, Alex Kenny¹o,
Iris Isok¹o, and Eileen M Joyce¹¹

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Background and Hypothesis: Cognitive remediation (CR) benefits cognition and functioning in psychosis but we do not know the optimal level of therapist contact, so we evaluated the potential benefits of different CR modes. Study Design: A multi-arm, multi-center, single-blinded, adaptive trial of therapist-supported CR. Participants from 11 NHS early intervention psychosis services were independently randomized to Independent, Group, One-to-One, or Treatment-as-usual (TAU). The primary outcome was functional recovery (Goal Attainment Scale [GAS]) at 15-weeks post randomization. Independent and TAU arms were closed after an interim analysis, and three informative contrasts tested (Group vs One-to-One, Independent vs TAU, Group + One-to-One vs TAU). Health economic analyses considered the cost per Quality Adjusted Life Year (QALY). All analyses used intention-to-treat principles. Study Results: We analyzed 377 participants (65 Independent, 134 Group, 112 One-to-One, 66 TAU). GAS did not differ for Group vs One-to-One: Cohen's d: 0.07, -0.25 to 0.40 95% CI, P = .655; Independent vs TAU: Cohen's d: 0.07, -0.41 to 0.55 95% CI, P = .777. GAS and the cognitive score improved for Group + One-to-One vs TAU favoring CR (GAS: Cohen's d: 0.57, 0.19-0.96 95% CI, P = .003; Cognitive score: Cohens d: 0.28, 0.07-0.48 95% CI, P = .008). The OALY costs were £4306 for Group vs TAU and £3170 for One-to-One vs TAU. Adverse events did not differ between treatment methods and no serious adverse events were related to treatment. Conclusions: Both active therapist methods provided cost-effective treatment benefiting functional recovery in early psychosis and should be adopted within services. Some individuals benefited more than others so needs further investigation. Trial registration: ISRCTN14678860 https://doi.org/10.1186/ISRCTN14678860 Now closed.

Key words: therapist support/early intervention/goal achi evement/functioning/cognitive training

#### Introduction

Cognitive function is the strongest predictor of social and occupational functioning 4 years later1-3 and limits opportunities offered by evidence-based rehabilitation.4 Cognitive remediation (CR) was developed using the simple model that boosting cognition benefits functioning. Although studies show only partial mediation, meta-analyses have shown durable benefits of CR5-9 and some national guidelines now recommend it. 10-13 The CR White Paper14 highlighted four effective elements: cognitive exercise, developing problem-solving strategies, an active therapist, and facilitating transfer to real-world functioning. A recent meta-analysis demonstrated that CRs with all these elements improved cognitive and functioning benefits.9 One programme has all elements, Cognitive Interactive Remediation of Cognition and Thinking Skills or "CIRCuiTS", and uniquely facilitates

# Social anxiety disorder in first-episode psychosis: incidence, phenomenology and relationship with paranoia

Maria Michail and Max Birchwood

#### **Background**

Social anxiety disorder constitutes a significant problem for people with psychosis. It is unclear whether this is a by-product of persecutory thinking.

#### **Aims**

To compare the phenomenology of social anxiety disorder in first-episode psychosis with that in a group without psychosis. The relationship between social anxiety and psychosis symptoms was investigated.

#### Method

A sample of people with first-episode psychosis (FEP group) was compared with a sample with social anxiety disorder without psychosis (SaD group).

#### Results

Of the individuals in the FEP group (n=80) 25% were diagnosed with an ICD-10 social anxiety disorder (FEP/SaD group); a further 11.6% reported severe difficulties in social encounters. The FEP/SaD and SaD groups reported comparable levels of social anxiety, autonomic symptoms,

avoidance and depression. Social anxiety in psychosis was not related to the positive symptoms of the Positive and Negative Syndrome Scale (PANSS) including suspiciousness/persecution. However, a significantly greater percentage of socially anxious *v.* non-socially anxious individuals with psychosis expressed perceived threat from persecutors, although this did not affect the severity of social anxiety within the FEP/SaD group. The majority of those in the FEP/SaD group did not have concurrent persecutory delusions.

#### **Conclusions**

Social anxiety is a significant comorbidity in first-episode psychosis. It is not simply an epiphenomenon of psychotic symptoms and clinical paranoia, and it has more than one causal pathway. For a subgroup of socially anxious people with psychosis, anticipated harm is present and the processes that underlie its relationship with social anxiety warrant further investigation.

#### **Declaration of interest**

None.



## 25 years of EIP: what have we learned?

- Clear evidence that the status quo is not working/is toxic.
- Sound scientific rationale (Early phase of psychosis a 'critical period' etc)
- Partnership with articulate and energized users, carers, campaigning non-profit. El association international dimension. Get political. A bit evangelical, but not too much.
- Trials. Health economics. NICE.
- Implementation research in real-life settings.
- Candid about non-responders etc; can learn ++ from this.
- Phase-specific interventions

## Thank you

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# Session 3: Where next?

Chair: Jill Owens

# Moving early intervention for eating disorders to the next level

Professor Ulrike Schmidt



The Future of FREED and of Early Intervention (EI) for Eating Disorders: A Researcher's Perspective

Ulrike Schmidt



#### The Different Futures of FREED/EI for Eating Disorders







The Different Futures of FREED/EI for Eating Disorders





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

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Bringing together arts, humanities and sciences to develop personalised care.

Eating disorders are common and affect people of all genders, backgrounds and identities, with devastating impacts on young people's lives.

#### More from the gallery



13/01/23

**EDIFY** 

PaperMate: Lucy Hyam on her new paper: 'The impact of the COVID-19 pandemic on referral numbers, diagnostic mix, and symptom severity in Eating **Disorder Early Intervention** Services in England'.





12/12/22

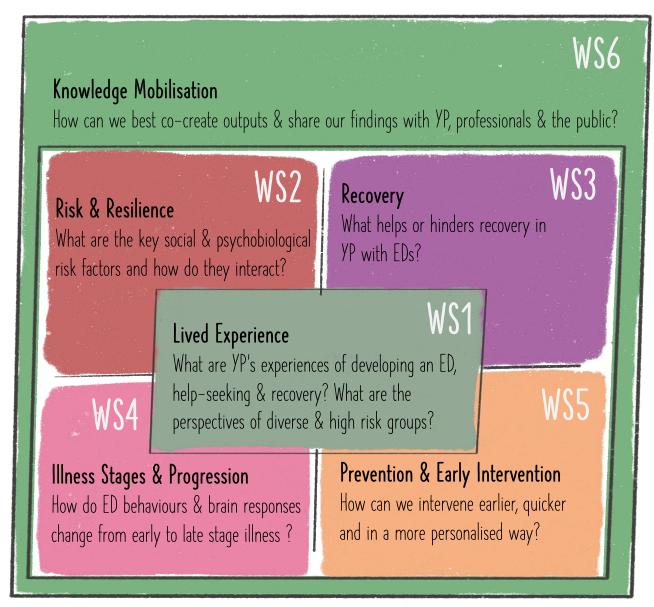
PaperMate: Prof Tracey Wade on her new paper: 'A systematic review: Solutions to problems caused by age transition between eating disorder services'.

#### A 4-Year Programme

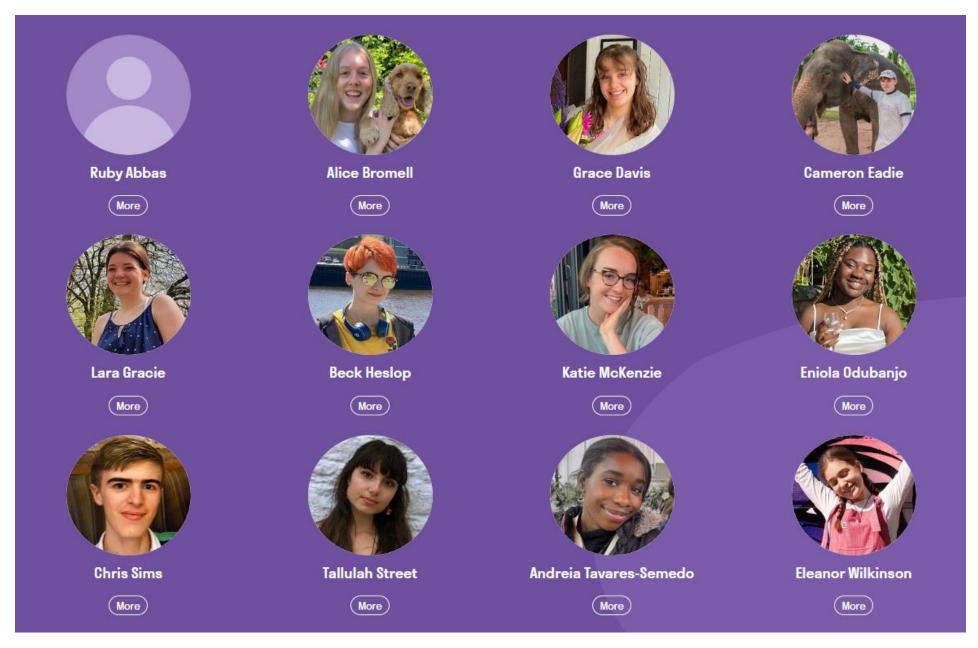
- 6 integrated Workstreams (WSs)
- > 800+ young people with EDs

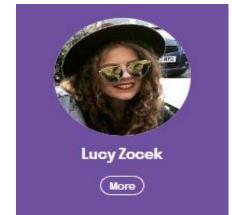






#### **Our Youth Advisors**





15 youth advisors chosen from 70+ who applied

#### Work Streams 3 and 4: 'Recovery' and 'Illness Stages'

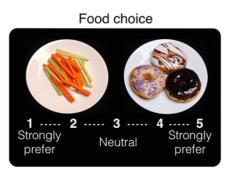


#### **Key Questions:**

How do ED behavioural and brain responses change across the recovery journey and also from early to later stage illness?

What helps or hinders recovery in young people with EDs?

- A new large cohort of young people age 16 to 25 with first episode EDs (AN, BN/BED) and those with more persistent EDs and healthy controls
- Followed for 1 year
- Wide range of behavioural, neurocognitive and neuroimaging assessments
- 'Deep phenotyping' using remote measurement technology







WS 4: Illness stages and progression

## Characterising Illness Stages, Progression and Recovery Trajectories of Eating Disorders in Young People

**Aims:** Investigate illness progression and recovery processes to:

- Tailor treatment to the illness stage and to individuals' recovery journey
- Step in earlier and prevent EDs from progressing further





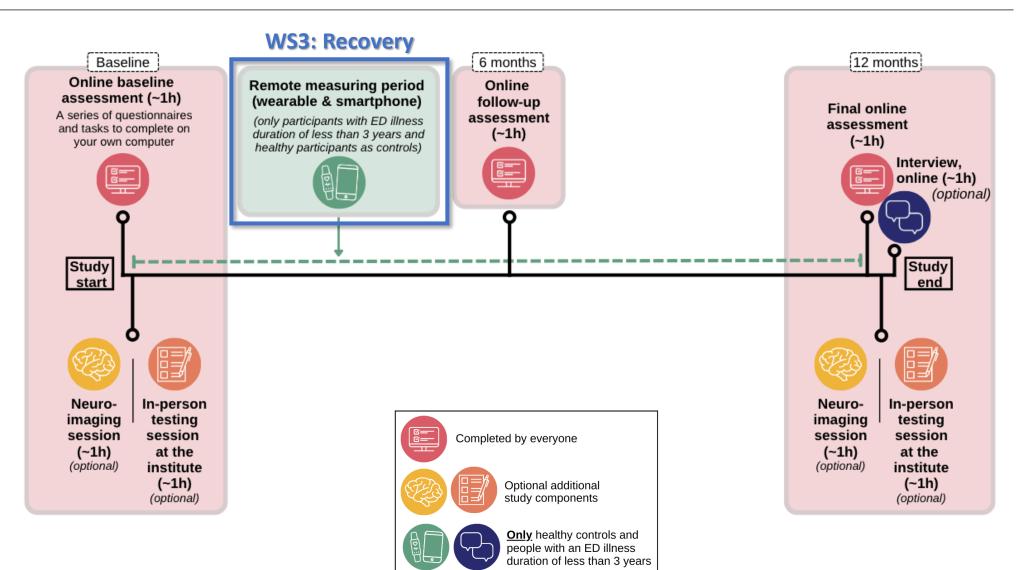




Participants with an ED illness duration of **3+ years** 



Healthy controls





### Remote Measurement Technology



#### 1. Smartphone

#### **RADAR Active App**

Notifications to complete short questionnaires and tasks at regular intervals (for example every two weeks)

#### **RADAR Passive App**

Continuously collects information in the background using built-in sensors on all modern smartphones (e.g. noise levels, battery, Bluetooth connections, relative location, screen time)







#### Remote Measurement Technology



#### 2. Wrist-worn device

Physical indicators of wellbeing, mood and stress-levels:

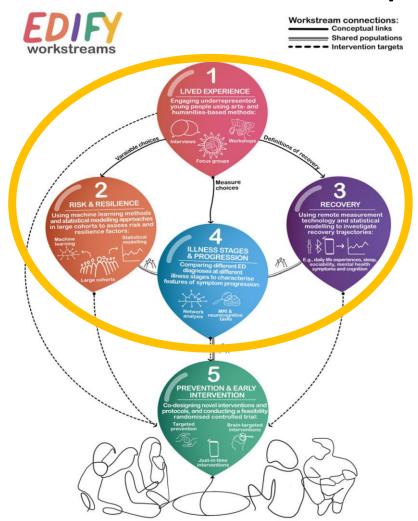
- Pulse
- Temperature
- Sleep
- Respiration rate (breathing pattern)
- Oxygen saturation
- Electrodermal activity (activity of sweat glands)
- Physical activity

Importantly we will not give young people access to these data

#### Workstream 5 'Prevention and Early Intervention'



#### How can we intervene quicker, earlier and in a more personalised way?



Time to apply everything we have learned!

- 1. Based on Story-study findings we will develop a protocol for a 'just-in-time adaptive' intervention
- 2. Trial of non-invasive brain stimulation for young people with persistent AN (e.g. FREED-non-responders)
  - Tailoring intervention to illness stage







#### **RAISE Trial Film**



#### **Summary and Next Steps**



We want to change the story around EDs and around early intervention – FREED & EDIFY together can do this

 We are nearly ready to start recruitment for the Story and Raise studies

Interested in becoming a research site?



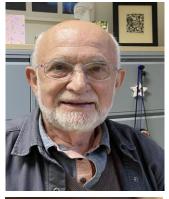


Contact us on: EDIFYresearch@kcl.ac.uk

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#### **TheAHSN**Network

How AHSNs can support services following the national programme

Laura Semple

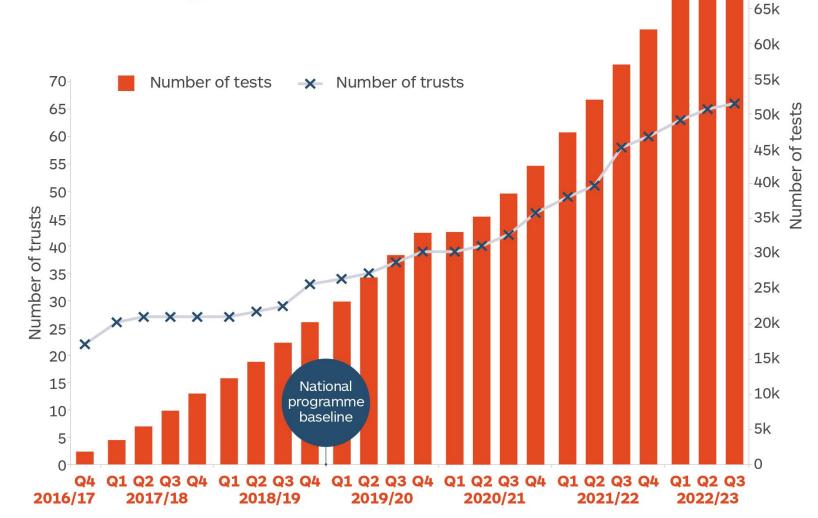
27 March 2023

### Mental health remains priority for the AHSN Network

- Across all 15 Academic Health Science Networks (AHSNs) in England, we've
  identified a variety of innovations in mental health. We work with suppliers,
  NHS & academic partners and people with lived experience.
- Currently we have over 300 innovations on our mental health 'Pipeline', for adults and children & young people across a range of conditions
- Innovations sit within our 'Pipeline', with novel/in development innovations at one end, and well-established, real-world evidence based ones at the other (within one or more AHSNs)
- Innovations with a strong evidence base can be supported into implementation across multiple AHSNs, drawing on the experience gathered from individual AHSNs that have supported smaller scale testing and evidence generation

# FOCUS Transforming ADHD Diagnosis Spread of a across Engli





#### 66 trusts

85k

80k

75k

70k

across 132 sites are now providing an objective assessment reduction in nurse school observations in CAMHS\*

19%

release of clinical time in Paediatric and 9.2% in CAMHS\* 50,000
patients
benefiting since

April 2020

92%

of clinicians said the results helped understand patients' symptoms\* Winner of 3 national awards including

> 2 HSJ awards

<sup>\*</sup> Findings from the National Focus ADHD Evaluation Oct 2022

#### How do AHSNs assess innovations?

- Undertaking extensive work with all stakeholders to ensure innovations are fit for purpose prior to large-scale implementation
- This includes:
  - People with lived experience, through our patient & public involvement (PPI) work
  - NHSE Transformation Directorate, Digital Mental Health and Accelerated Access Collaborative (AAC)
  - NICE
  - National Institute for Health & Care Research (NIHR) and MindTech
  - Office for Life Sciences
  - Medicines & Healthcare products Regulatory Agency (MHRA)
- We support NICE to review innovations within their Early Value Assessment (EVA) programme, which includes mental health innovations. In March 2023 <u>NICE</u> <u>published its first early value assessment guidance</u> on 4 guided self-help digital cognitive behavioural therapy technologies for children and young people.

#### Keen to know more?

- We would love to hear from you please speak with your local AHSN team or feel free to contact me directly
- Please visit our website at <u>www.ahsnnetwork.com</u>
- Find us on Twitter @AHSNnetwork or LinkedIn







# Thank you!

# Professor Ulrike Schmidt and Dannie Glennon