

Institution: King's Colle	<u> </u>	
Unit of Assessment: U	oA4	
Title of case study: Sav	ving lives and money with national tre	eatments for eating disorders
Period when the under	pinning research was undertaken:	2006 – 2018
Details of staff conduc	ting the underpinning research fro	m the submitting unit:
Name(s):	Role(s) (e.g. job title):	Period(s) employed by
Ulrike Schmidt	Prof of Eating Disorders	submitting HEI:
Janet Treasure	Prof of Psychiatry	From: 01/04/2001
	, ,	From: 08/05/2012
Sabine Landau	Prof of Biostatistics	From: 02/01/2019
Davis dad an the alalm	ed impact occurred: August 2013 -	December 2020

## 1. Summary of the impact

Eating disorders are pervasive, costly and can worsen over time, harming the individual and affecting their wider support systems. Anorexia nervosa has the highest mortality rate of any psychiatric disorder, and is the most expensive for health services to address. King's researchers identified the need for interventions at different stages of disease progression and developed an early intervention approach to all eating disorders (FREED), treatment for long-standing anorexia nervosa (MANTRA), and family and carer support (ECHO). King's research showing that these were effective led to them being included in National Institute for Health and Care Excellence (NICE) guidelines, allowing national and international uptake. The UK Government has committed substantial investment to these services, enabling them to be rolled out across the UK; other countries are also using these approaches.

#### 2. Underpinning research

Eating Disorders (EDs) include anorexia nervosa (AN), bulimia nervosa (BN), binge eating disorder (BED) and related partial or mixed syndromes. They affect up to 15% of young women and 5.5% of young men in Western countries, with prevalence on the rise and disorders starting at a younger age. Mortality rates for those with eating disorders are almost twice as high as the general population, and approximately six times higher for people with AN. One fifth of people can have severe and enduring disease, lasting for many years and having a hugely debilitating effect on the sufferers and their families, as well as incurring an enormous cost to the NHS. In 2013 - 2015, eating disorders cost the NHS between £3.9 to £4.6 billion each year in treatment costs, and £9.4 to £11.1 billion each year in indirect costs. This is particularly worrying considering that in the UK it is estimated that less than a quarter of sufferers of eating disorders receive any intervention and only 15% receive psychological therapy.

King's research identified the need to target different interventions at different stages of disease. The longer an eating disorder persists, the more difficult it is to treat, and the worse the outcomes, with associated neurobiological changes only serving to entrench the disease further. King's conducted a systematic review and meta-analysis of research into the duration of untreated eating disorders (1). This showed long delays before people accessed evidence-based treatment at all stages of disease, an average of 30 months for AN and up to 67 months for other eating disorders. Young adults age 18-25 have particularly long delays when compared to adolescents, and treatments and interventions appropriate in first stages do not work once the disease is more long term (1,2).

King's developed and evaluated FREED, the first evidence-based specialist care model/pathway for young people with a first episode of eating disorders. Based on these findings King's researchers developed FREED (First episode Rapid Early intervention for Eating Disorders) to facilitate rapid person-centred care for young people aged 16-25 with eating disorders. Pilot studies followed by a multi-centre study (n=500 participants) showed that FREED reduces the duration of untreated EDs by 5-6 months, and leads to markedly improved weight



outcomes in those with AN. FREED was also more acceptable and accessible: 97.8% of FREED patients took up treatment, versus 75.4% of treatment as usual (TAU), and recovery rates were around 60% at one year compared to 16% with TAU, with differences maintained at two years (3).

King's developed and evaluated MANTRA, treatment for severe and enduring anorexia nervosa persisting throughout adulthood. Based on their findings of psychological and neurobiological distinctions between persistent AN and early stage eating disorders (2), King's developed a novel maintenance model and treatment approach for AN, MANTRA (Maudsley model of Anorexia Nervosa Treatment for Adults), and demonstrated comparable effectiveness and, crucially, greater acceptability compared to other treatments including gold standard (4), with results maintained at two years (5). This is important because those with persistent AN are often ambivalent about treatment. The model is person-centred, easy to disseminate and relatively brief, addressing the cognitive and emotional aspects of AN, in addition to weight and eating. King's researchers have also collaborated on a multi-centre trial of MANTRA in Australia that replicated its effectiveness when compared to other psychological treatments (6).

King's research with patients and carers produced a programme of support for carers and families. Drawing on research insight from collaborating with carers for over 25 years, King's has included research on carers within FREED and MANTRA, and has also developed a specific intervention for carers for people with severe AN called ECHO (7). This runs in parallel to out- and in-patient treatment, providing carers with information about the illness and how to provide support, without breaching confidentiality. King's developed and tested a module based on this model for carers and demonstrated its clinical effectiveness. Service users showed small but sustained improvements in symptoms, and caregivers were less burdened and spent less time providing care (8).

#### 3. References to the research

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- 4. Zainal, K.A., Renwick ,B,. Keyes, A., Lose, A., Kenyon, M., DeJong, H., Broadbent, H., Serpell, L., Richards, L., Johnson-Sabine, E., Boughton, N., Whitehead, L., Treasure, J., Schmidt, U. (2016) MOSAIC trial group. Process evaluation of the MOSAIC trial: treatment experience of two psychological therapies for out-patient treatment of Anorexia Nervosa. *J Eat Disord*. 9;4:2. DOI: 10.1186/s40337-016-0091-5
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- **6.** Byrne, S., Wade, T., Hay, P., Touyz, S., Fairburn, C.G., **Treasure, J., Schmidt, U.,** McIntosh, V., Allen K, Fursland A, Crosby R.D. (2017) A randomised controlled trial of



three psychological treatments for anorexia nervosa. *Psychol Med*, 47, 2823-2833. DOI: 10.1017/S0033291717001349

- **7. Treasure**, **J**. & **Schmidt**, **U**. (2020) The cognitive-interpersonal maintenance model of anorexia nervosa revisited: a summary of the evidence for cognitive, socio-emotional and interpersonal predisposing and perpetuating factors. *Journal of Eating Disorders*, 1, 13. DOI: 10.1186/2050-2974-1-13
- **8. Hibbs, R., Magill, N., Goddard, E.,** et al. (2015) Clinical effectiveness of a skills training intervention for caregivers in improving patient and caregiver health following in-patient treatment for severe anorexia nervosa: pragmatic randomised controlled trial. *BJPsych Open,* 1, 56-66. DOI: 10.1192/bjpo.bp.115.000273

### 4. Details of the impact

King's evaluations of FREED, MANTRA and ECHO led to national recommendations and guidelines, accompanied by increased large scale funding from the UK Government to scale up eating disorders services. FREED is a cornerstone of NHS England's (NHSE) commitment to increase community mental health services to reach 370,000 people as part of the NHSE Long Term Plan (2019), supported by UK Government investment of £1 billion [A1,A2]. FREED also features as a Positive Practice Example by NHSE with NICE and the National Collaborating Centre for Mental Health in their Guidance for Commissioners and Providers [A3]. A Royal College of Psychiatrists position paper on eating disorders recommends FREED [A4], and links to the FREED website.

MANTRA is recommended as a first line treatment for adults with AN in the 2017 NICE Guideline 69 Eating disorders: recognition and treatment [A5]. Also on the basis of King's research, the National Collaborating Centre for Mental Health's commissioning guidance for adult eating disorders recommended whole team training in FREED, MANTRA and ECHO approaches [A3]. This led to a UK Government contract of almost £2.2 million for a training programme to be delivered by King's researchers via Maudsley Learning [A6, A7].

Evidence-based implementation established by King's has enabled the uptake of these approaches. FREED was initially available to young people in South London and Maudsley NHS Foundation Trust, extended to 3 other large eating disorders services, then adopted by the Academic Health Sciences Networks which covers 15 regions in England. FREED is described by the NHS as "gold standard" [A1], and was central to the increased NHS funding for new services for children and young people up to the age of 25 [B1]. King's work was so compelling that commissioning guidelines and funding were agreed in some cases before findings were published in peer-reviewed journals, with an early independently produced business case from the Health Economics team at the University of York helping accelerate the roll out [B2]. As part of its 2020 investment of £150 million in eating disorder services, NHS England initially named 18 services where FREED would be implemented [A1]. Our records indicate that at the end of December 2020, 10 trusts were actively using FREED, a further 24 were in the process of implementing it, and 6 more were at the early stages of exploring it [B3]. A FREED-like service based on King's research has also been established in Australia [B4].

There has been a large demand for MANTRA and at King's alone, 400 therapists in the UK have been trained in the UK since 2016 **[B5 - B10]**. Two specialist trainers estimate they have reached 500 UK and international therapists **[B11, B12]**, and as one of these trainers provided some of the King's training, we estimate more than 700 therapists have been trained in the UK in total.

## King's research has benefitted patients and carers, changing and saving lives.

King's research has been the basis for the development of a suite of innovative approaches for eating disorders that place the person and their carers at the centre and allow flexibility and adaptability to reach as many people as possible. Eating disorders, particularly AN, can be fatal and this approach has enabled patients to be seen, recognised and treated.

FREED allows young people with eating disorders access to evidence-based treatment, tailored to their needs, as early as possible. One FREED service user says "I feel like such a different person. My confidence has risen, my control has risen, every element of my life, I feel



more comfortable and happier in", where another says "The best thing to ever happen to me was this, I don't know where I would have been, genuinely don't know where I would have been, if I hadn't got the support when I did" [C1]. Parallel separate resources for individuals and healthcare professionals provide a holistic approach which can be used flexibly, depending on need. This has enabled FREED to be used across a diversity of patients and in a number of settings. It aims to reach all young people who need support, including those not typically captured by eating disorders services, and since 2018 our own records show that FREED has been used to treat over 1,100 patients. Impact and equality assessments are being made available nationally as part of the FREED rollout to ensure all groups are reached [C2].

Rooted in King's research, MANTRA has been developed to be an accessible and user-friendly form of treatment that allows patients to understand their role in eating disorders. Therapists can be trained at different levels depending on how closely they work with patients, allowing training to be relevant for both specialist and more general services. A process evaluation revealed that MANTRA is positive for patients, e.g. "Absolutely, definitely feel a bit more comfortable within myself, you know I was feeling very hopeless going back to sort of this time last year... but sort of since working through those issues I've managed, I'm actually in a different job now... and I'm a lot happier there and I'm going out and doing more things..." [C3].

ECHO has been used by several services to support carers of those with eating disorders for example through the New Maudsley Carers group, with over 1,000 carers reached [C4]. One carer of a family member with AN says "I cannot emphasize strongly enough, my belief in the importance and inclusion of carer guidance resources and psychoeducational skills in the treatment of eating disorders... [to] equip carers with skills that empower them and give them the confidence to provide the best possible support to their loved one on their quest towards recovery" [C5]. The ECHO approach has been taken up in a peer-coaching format by the UK's largest eating disorder charity BEAT [C6]. Two books have also been published using the ECHO methods: Skills-based Caring for a Loved One with an Eating Disorder (Treasure et al [C7], and Caring for a Loved One with an Eating Disorder (Langley et al) [C8]. The former has sold 42,000 copies over two editions, and the latter 700 copies [C9].

King's evidence-based approaches have alleviated pressure on services and carers and enabled cost savings. An economic analysis of FREED showed that although FREED requires initial investment, there is a shorter duration of High Intensity Treatment (HIT) for FREED patients, compared to standard care, resulting in savings of between £2,998 and £261,097 per year in one local area, depending on the amount of HIT that is inpatients and how much is day care [B2]. King's researchers carried out health economics assessments of ECHO and showed training for carers reduces admission length on average by 20 days with a saving of £10,000 to £14,500 per case (8). In another analysis a combination of ECHO and MANTRA, the length of inpatient stay for the intervention group was 4.5 weeks less than the comparison group, representing a considerable cost saving [D1].

#### 5. Sources to corroborate the impact

A Sources to corroborate how King's research has informed UK guidelines and investment A1 NHS webpage announcing increased government funding for eating disorder treatments as part of a wider investment in mental health services, and naming FREED as a gold standard 2020

A2 NHS Long Term Plan 2019

A3 National Collaborating Centre for Mental Health Guidance for Commissioners and Providers Appendices

A4 Royal College of Psychiatrists position paper 2019

A5 NICE Guideline 69 Eating disorders: recognition and treatment

A6 Bid document for whole team training

A7 Email from Sean Cross of Maudsley Learning confirming the award of the training contract and funding for A6



# B Sources to corroborate how King's research has led to increased implementation of FREED, MANTRA and ECHO

B1 NHS "Children and young people" confirmation of increased £150 million funding for eating disorder services for children and young people 2020

B2 York Health Economics Consortium, NHS Innovation Accelerator Economic Evaluation Case Study; FREED, 2020

B3 FREED site tracker 2020

B4 Testimonial from Tracey Wade at Flinders University

B5 Mantra training numbers at King's 2016 – 2020

B6 MANTRA training advertisement 2016

B7 MANTRA training advertisement 2017

B8 MANTRA training advertisement 2018

B9 MANTRA training advertisement 2018 and 2019

B10 MANTRA training advertisement 2020

B11 MANTRA trainer testimonial 1

B12 MANTRA trainer testimonial 2

## C Sources to corroborate the impact of King's research on patients and carers

C1 Film about FREED hosted on YouTube and the FREED website

C2 Impact and equality assessment example

C3 Process Evaluation of the Maudsley Model for Treatment of Adults with Anorexia Nervosa Trial. Part II: Patient Experiences of Two Psychological Therapies for Treatment of Anorexia Nervosa. A Lose et al, published in European Eating Disorders Review, 24 January 2014

C4 Testimonial from Jenny Langley of New Maudsley Carers

C5 Testimonial from Pam MacDonald of New Maudsley Carers

C6 ECHO resources hosted on the BEATwebsite

C7 Skills-based Caring for a Loved One with an Eating Disorder book, Treasure et al.

C8 Caring for a Loved One with an Eating Disorder book, Langley et al

C9 Sales figures for books C7 and C8 from publisher Routledge

#### D Sources to corroborate the economic impact of King's research

D1 Evaluation of a novel transition support intervention in an adult eating disorders service: ECHOMANTRA. Adamson et al. Published in Int Rev Psychiatry, March 27 2019