

<b>Institution:</b> 10007140 Birmingham City University		
<b>Unit of Assessment:</b> UoA4 – Psychology, Psychiatry and Neuroscience		
<b>Title of case study:</b> Developing tools to support the dietary practices, health, and wellbeing of people with cystic fibrosis		
<b>Period when the underpinning research was undertaken:</b> 2014 to 2020		
<b>Details of staff conducting the underpinning research from the submitting unit:</b>		
<b>Name(s):</b>	<b>Role(s) (e.g. job title):</b>	<b>Period(s) employed by submitting HEI:</b>
Dr Helen Egan	Reader in Health Psychology	2011 to present
Dr Michael Mantzios	Reader in Health Psychology	2014 to present
Dr Rebecca Keyte	Lecturer in Psychology	2017 to present
<b>Period when the claimed impact occurred:</b> 2014 to 2020		
<b>Is this case study continued from a case study submitted in 2014?</b> N		
<b>1. Summary of the impact</b> (indicative maximum 100 words) <p>We developed the first evidenced based tools and interventions underpinned by psychological theory for people living with Cystic Fibrosis (PwCF). These address the problems of non-adherence to demanding treatment regimens and engagement in health risk behaviours (HRB), and significant problems with eating. These tools increased knowledge and confidence in healthcare professionals and thus influenced healthcare practices. One tool was aimed at patients to address the challenges of adherence and health risk behaviours and another addressed problematic eating behaviours. Both resulted in a greater understanding of how to manage their condition. Combined with the influence on healthcare practices, PwCF had an improvement in the level of care they received.</p>		
<b>2. Underpinning research</b> (indicative maximum 500 words) <p>Treatment regimens for PwCF are burdensome, taking between 3-4 hours daily. PwCF frequently experience health deteriorations, require hospitalisation, and this happens regardless of their adherence efforts. Such extensive regimens thus reduce motivation. Non-adherence to regimens and engagement in HRBs are significant issues impacting morbidity and mortality. Our research was vital because little work had been published in double-blind peer review outputs, which addressed such problems in PwCF.</p> <p>Our comparison (<b>R01</b>) of weekday and weekend adherence to treatment regimens in adults showed adherence was higher during the weekend and was predicted by sex, anxiety, depression and lung function. This research identified psychosocial factors associated with non-adherence in addition to time and high treatment burden. Findings provided a strong rationale for investigating adherence qualitatively.</p> <p>Life expectancy for PwCF has rapidly increased over the last 20 years in the UK from 18 to 47 years, presenting new challenges for healthcare professionals (HCPs) and adult patients. HCPs now need to account for new risk factors because of PwCF's increased life expectancy, including PwCF's self-management of treatment regimens and HRB such as drinking, smoking and illicit drug use. Our qualitative studies with patients identified (<b>R02</b>) that psychological factors influenced engagement, including a desire for normalcy where HRB minimised illness identity and a life-oriented perspective where engagement was for fun. A dilemma was highlighted between adhering to treatment regimens and missing treatments to improve psychological wellbeing.</p>		

**There was a lack of patient knowledge on the CF specific impact of HRB, with little relevant information provided by HCPs.**

Interviews with HCP (**R03**) identified risky behaviours in PWCF were a major concern and that education regarding the adverse health effects of HRB was not currently embedded within clinical practice. Lack of HCP knowledge in HRB was reported. **Our research demonstrated the need for improved knowledge and integration of health risk behaviour information and interventions within CF care.**

#### **Eating behaviour and nutritional status**

Weight and BMI are independent predictors of mortality, but CF frequently results in a compromised nutritional status due to significantly increased energy needs, malabsorption of fat, distressing digestive symptoms and lack of appetite.

We (**R04**) evaluated the evidence on eating behaviours and interventions, highlighting a lack of evidence based knowledge and practice in adult eating behaviours and the need for evidence based research to inform interventions to support optimal nutritional intake.

This qualitative study (**R05**) **highlighted the amount of time and cognitive effort in self-regulating eating**; strategies to reduce effort included avoiding food preparation, easy to swallow foods, reliance on crisps and chocolate and distraction techniques to eat sufficient calories. Eating lacked pleasure, was viewed as another treatment to endure, and created high anxiety due to concerns that fluctuating health would result in weight loss and exacerbate symptoms of CF.

We investigated the link between emotional eating and BMI in PwCF (**R06**). Higher levels of emotional eating significantly predicted higher BMI, which is often desirable, but an increase in levels of emotional eating is not due to its negative effects on mental health. Mindfulness and mindful eating moderated this relationship, suggesting their utility for creating an eating intervention that supports both improved physical and psychological outcomes.

### **3. References to the research** (indicative maximum of six references)

**R01.** Keyte, R., Egan, H.H, Jackson, C., Nash, E., Regan, A., & Mantzios, M. (2017). A weekend / weekday comparison in adherence to daily treatment regimens for adults with cystic fibrosis. *Health Psychology Reports*. DOI: <https://doi.org/10.5114/hpr.2018.72331>

**R02.** Keyte, R., Egan, H., Nash, E. F., Regan, A., Jackson, C., & Mantzios, M. (2019). An exploration into experiences and attitudes regarding risky health behaviours in an adult cystic fibrosis population. *Psychology, Health & Medicine*, 1-7. DOI: <https://doi.org/10.1080/13548506.2019.1706750>

**R03.** Keyte, R., Egan, H. H., & Mantzios, M. (2019). Healthcare professionals' perceptions of risky health behaviours: a qualitative evaluation of preventative measures for populations with cystic fibrosis. *Chronic illness*, 1742395319856395. DOI: <https://doi.org/10.1177/1742395319856395>

**R04.** Mantzios, M., Egan, H.H, & Patchell, C. R. (2016). Can existing knowledge on eating behaviours and obesity support people with Cystic Fibrosis who are nutritionally compromised?. *Frontiers in Psychology*, 7, 1477. DOI: <http://dx.doi.org/10.3389/fpsyg.2016.01477>

**R05.** Egan, H. H., Mantzios, M., Nash, E. F., Barrett, J., & Regan, A. M. (2017). A qualitative study: mindful eating attitudes and behaviours in a cystic fibrosis population. *Journal of Cystic Fibrosis*, 16, S147. DOI: [https://doi.org/10.1016/S1569-1993\(17\)30667-7](https://doi.org/10.1016/S1569-1993(17)30667-7)

**R06.** Egan, H., Keyte, R., Nash, E. F., Barrett, J., Regan, A., & Mantzios, M. (2020). Mindfulness moderates the relationship between emotional eating and body mass index in a sample of people with cystic fibrosis. *Eating and Weight Disorders-Studies on Anorexia, Bulimia and Obesity*, 1-7. DOI: <https://doi.org/10.1007/s40519-020-00969-6>

#### 4. Details of the impact (indicative maximum 750 words)

CF care presents a difficult challenge for clinicians, and patients, and resources are typically focused on managing physical symptoms. Clinicians report having little psychology experience and knowledge, and clinical psychologists have limited resources which are focused on serious mental health issues. The research team collaborated with HCPs to develop interventions based on our research for use by the wider clinical team, with a view to improving psychological support in HRB and eating behaviours.

We created three tools:

- Encouraging discussions regarding HRB: A toolkit to identify patients at higher risk of non-adherence and HRB
- A Guide to Mindful Eating for PwCF
- Mindful Eating Practices for PwCF (CFMEP)

##### **A toolkit to identify patients at higher risk of non-adherence and HRB**

We identified that, in the UK, there are no current national standardised practices for embedding HRB information into CF care; this is undertaken retrospectively when individuals flag that they are already engaging in HRB. We developed a psychological screening tool to be completed by patients with an accompanying guide for HCP, which aimed to identify PwCF who were at risk of engaging with HRB, including non-adherence, as a means of coping with their CF.

The screening tool was introduced to CF Specialist Nurses at a UK national CPD training day, promoting discussion and debate and raising awareness around the increasing prevalence of HRB. The screening tool was evaluated as being user friendly and useful addition to clinical practice for detecting patients at risk of engaging in HRB.

The screening tool was piloted with a small number of patients and gained a positive response (**S01**); of the 8 participants who responded to the questionnaire, 6 strongly agreed that the tool would be relevant to them. Everyone agreed that the format was fit for purpose, user friendly and would encourage discussion with clinicians improving patient experience and clinical practice, for example:

*I think it looks really straightforward to understand and would be really useful. Our clinic doesn't use anything like this, and it would be great if they did.  
Easy to understand and covers a range of topics that could be covered to help us with Cystic Fibrosis discuss ways in which we could get help from. I like that the form is filled out before a clinic appointment so that you can get your thoughts down on paper first without the pressure or anxiety of opening up to someone first.*

Clinicians from The West Midlands Adult CF Team now use the HRB screening tool as part of their annual review with patients, as our research suggested that new modular therapies to treat CF increased the risk of engagement in HRB as improvements in symptoms reduced the salience of risk associated with HRB. During the COVID pandemic, clinical care was moved online but clinicians continue to help PwCF identify their HRBs and this helps clinicians know what HRBs their patients are engaging in (**S02**).

##### **A Guide to Mindful Eating for PwCF and Mindful Eating Practices for PwCF**

The need for Eating Behaviour Interventions specific to the needs of PwCF was highlighted by the clinical team at West Midlands Adult CF centre (**S02**). We developed the 'Guide to Mindful Eating for PwCF' and 3 CF specific Mindful Eating Practices based on evidence from our research studies. Initial versions were shared with Specialist CF Dietitians at a national CPD event and promoted discussion around the need for changes in practice to include psychological interventions such as mindful eating. Lack of knowledge in mindful eating and CF specific needs were identified as barriers to implementation.

The guide and tools were trialled with dietitians (N=12) (**S01**) and PwCF (N=9) (**S01**). 8 dietitians completed the questionnaire and consented to have their response included in the REF submission. Prior knowledge of mindful eating was reported as 'no knowledge' (2), 'slight knowledge' (4) and 'moderate knowledge' (2). Everyone reported increased knowledge after reading the guide with 5 reporting 'moderately knowledgeable' and 3 'very knowledgeable'. The tools were evaluated as useful, easy to use, and implementable in clinical practice:

*"This is exactly what is needed, theory and knowledge on mindful eating alone would not make me fully embrace this with patients but with this tool I would feel more confident."*

*"Easy to understand, quite intuitive to use [...] Definitely useful to help understand food choices etc"*

Our 'guide to the psychology of eating behaviours for people living with Cystic Fibrosis' provided information to clinicians with limited existing knowledge on this topic, and along with our tools, was used to identify the most effective ways of using elements of mindful eating behaviours to support individuals with their specific needs.

Overall, 8 PwCF consented to have their data included in the REF submission. On initial evaluation, all agreed that the guide was easy to understand and that the tools would be helpful in practice.

*"It was really good to understand mindful eating and to know about this"*

*"It was honestly extremely interesting and I will definitely be implementing it a lot more."*

Four PwCF were asked to engage with using the tools over a period of two weeks (**S03**), all reported that their knowledge of mindful eating had increased and 3 people reported that they had incorporated elements of the tools into their eating practices and found them helpful in identifying unhealthy eating patterns and eating a more varied diet:

*"The timetable diary of the food I'm eating clearly shows the pattern on how I consume food that isn't healthy as a habit"*

*"I had started to think about eating better due to diabetes and weight gain this just gave me another tool in the box"*

### Overall changes in clinical practice

Clinicians have noted that their practice of care has been improved as a result of proposals put forward by the research team. For example, the clinical psychologist the team worked with noted:

*"Using the **evidence based, collaborative research** produced over a number of years, the team made several proposals for **improving care which have been adopted by clinicians**. These have included improving knowledge of HRBs*

*amongst clinicians and incorporating the HRB questionnaire into annual reviews with patients” (S04)*

Additionally, the same clinical psychologist noted that:

*“The research collaboration and the tools which have been created on the basis of the research conducted by Egan, Keyte and Mantzios influenced the way **we offered care for adults** with Cystic Fibrosis, particularly with how **we approached discussing engagement in health risk behaviours** and eating behaviours. The research demonstrated that some patients felt that there was a lack of clear information provided on the specific impact of HRB’s on CF and **this is now made more explicit by HCPs on our team**. Raising awareness of the gap in knowledge with our team was an important step in **improving practice to identify patients at risk** of engaging in HRBs and providing them with specific information on risks to enable patients to make more informed decisions regarding their health behaviours”*

The lead respiratory consultant noted:

*“the **research conducted by the team at Birmingham City University helped us provide a greater level of care** at the West Midlands Adult CF Centre. The research and the outcomes that our collaboration was able to achieve has clear implications for other health practitioners in their on-going treatment of adults with CF”. (S02)*

The work of Egan, Mantzios, and Keyte has therefore influenced clinical practice in terms of how HCPs deliver their care for PwCF. Additionally, the research has helped PwCF identify their own HRBs, which in turn helps HCPs to provide more guided and tailored healthcare advice.

#### **5. Sources to corroborate the impact** (indicative maximum of 10 references)

**S01** Questionnaires asking HCPs and PwCF to evaluate the tools

**S02** Testimonial letter from the Consultant Physician in Department of Respiratory Medicine for the Heartlands NHS Trust **[Named corroborator 001]**

**S03** Questionnaire and follow-up questionnaire asking PwCF to use and evaluate the mindful eating tools

**S04** Testimonial letter from the Lead Clinical Psychologist at Heartlands NHS Trust **[Named corroborator 002]**