

<b>Institution: University of Wolverhampton</b>		
<b>Unit of Assessment: 3 Allied Health, Dentistry, Nursing and Pharmacy</b>		
<b>Title of case study: Improving the wellbeing of populations at risk of digestive and eating disorders</b>		
<b>Period when the underpinning research was undertaken: 2014 - 2019</b>		
<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 Darren Chadwick	Reader in Applied Psychology	2010 - Present
Dr Wendy Nicholls	Senior Lecturer in Applied Health Psychology	2005 - Present
Dr Satvinder Purewal	Senior Lecturer in Health Psychology	2014 - Present
Professor Matthew Brookes	Professor of Gastroenterology	2019 - Present
Professor Helen Steed	Professor of Gastroenterology	2019 - Present
<b>Period when the claimed impact occurred: 2015 - 2020</b>		
<b>Is this case study continued from a case study submitted in 2014? N</b>		
<b>1. Summary of the impact</b>  <p>Innovative research at the University of Wolverhampton has been used to improve the quality of life of those from particular groups 'at risk' of digestive and eating disorders. Achievements include promoting the understanding of Inflammatory Bowel Disease (IBD) management in South Asian women, particularly during pre-conception and pregnancy, through a pioneering art project 'Living in Silence'. In addition, the research has resulted in improvements to how speech and language therapists' (SaLTs) understand dysphagia in people with learning disabilities. This was achieved through substantial contributions to sector-leading Public Health England (PHE) guidance documents. Further impacts relate to impacts relate to research on obesity, which has led to patient-centred interventions for obesity and binge-eating at Birmingham Community Healthcare NHS Trust and City Hospitals Sunderland NHS Trust, as well as a succesul online intervention delivered to 1200 participants.</p>		
<b>2. Underpinning research</b>  <p>Digestive and eating disorders are often considered a 'taboo' subject, which leads to widespread underdiagnosis and lack of treatment, causing poor quality of life and significant long-term implications to health. For more than a decade, research at the University of Wolverhampton has focussed on a broad range of digestive/eating disorders and associated complications for particular 'at risk' groups, including dysphagia management in people with learning disabilities; the causes of food craving and obesity; and the psycho-social impacts of IBD. This research has been enhanced in recent years through a new partnership with clinical gastroenterologists based at Royal Wolverhampton NHS Trust. The 5 findings [F] that have led to significant impacts are detailed below:</p> <p><u>F1. Psychosocial effects of IBD on women's reproductive health</u></p> <p>IBD can cause substantial negative psychological issues, particularly during pregnancy. In the first comprehensive systematic review on the psychosocial effects of IBD on women's reproductive health [R1], a range of important findings were discovered including:</p> <ul style="list-style-type: none"> <li>One-fifth to one-third of IBD patients choose voluntary childlessness, compared to a general population childlessness frequency of &lt;10%, due to pregnancy-related fears and concerns.</li> </ul>		

- Around one-fifth of patients stop taking their medication during pregnancy in the belief that it may be associated with complications in pregnancy.
- There is a lack of understanding of IBD-related issues amongst people from Black Asian Minority Ethnic (BAME) backgrounds.

The study highlighted the need to improve pre-conception counselling with women as an effective tool for improving understanding of the risks of pregnancy for IBD patients. It indicated the potential to reduce the incidences of voluntary childlessness through improved information on the topic.

#### F2. UK IBD healthcare standards

In collaboration with IBD UK and other clinicians across the country, Brookes provided a substantial contribution to the development of the UK standards for healthcare of adults and children with IBD [R2]. The resulting 59 Standards covered domains such as “pre-diagnostic referral pathways, protocols and timeframes” and “holistic care of the newly diagnosed patient”. The results of the project highlight the need for patient empowerment and personalised care to be central to IBD management [R2]. This study also led to the development of an IBD Service Benchmarking Tool that facilitates enhancement and quality improvement for healthcare services for all people with IBD and reduces inequalities in access and care for particular ‘at risk’ groups.

#### F3. Supporting the management of dysphagia in people with learning disabilities

Dysphagia is disproportionately common in people with learning disabilities and has a number of significant negative consequences for health and quality of life, including reduced self-determination and choice around eating and drinking; reduced nutritional status; aspiration of food and drinks into the airway and lungs; and the potential for respiratory infections, asphyxia and death [R3]. In a study surveying 38 SaLTs, a number of barriers to safe dysphagia management were identified including beliefs, knowledge, and emotional responses held by carers towards management strategies which impeded their implementation [R3]. A further randomised control trial found that a training intervention to support the modification of fluids to a safe thickened consistency to facilitate oral transit of the bolus and enable safer swallowing was effective [R4].

#### F4. Binge eating disorder in obese adults

Binge eating disorder is a relatively common eating disorder amongst obese individuals but is poorly understood. It can be a significant challenge for individuals, leading to higher rates of mental illness and poorer quality of life. A comprehensive literature review highlighted that depression was consistently associated with binge eating, with particular negative impacts including sadness, tension and instability of emotion [R5]. Resulting recommendations from the study facilitate more effective identification of binge eating disorder [R5].

#### F5. UK version of the Food Craving Inventory

Food cravings are a common occurrence particularly amongst dieters and those with eating disorders. In the UK just under 70% of non-dieters report food cravings, rising to over 90% in those dieting. Such cravings are cited as a key reason for failure to lose weight when dieting and can often have a significant contribution to obesity problems. In 2013, Nicholls developed a UK version of the American ‘Food Craving Inventory’, a tool developed to self-diagnose specific food cravings in individuals [R6]. The translation used 234 participants, to modify and validate the tool for use in UK settings [R6]. The resulting UK Food Craving Inventory is an effective tool for aiding clinical practice and accurately highlighting risk foods for those struggling with food cravings.

### **3. References to the research**

All papers have gone through a stringent double-blind peer-review process.

R1. Purewal, S., Chapman, S., Czuber-Dochan, W., Selinger, C., Steed, H., & Brookes, M. J. (2018). Systematic review: the consequences of psychosocial effects of inflammatory bowel disease on patients’ reproductive health. *Alimentary Pharmacology & Therapeutics*, 48(11-12), 1202-1212. <https://www.doi.org/10.1111/apt.15019>. (REF 2 Output)

R2. Kapasi, R et al. (2019). Consensus standards of healthcare for adults and children with inflammatory bowel disease in the UK. *BMJ*, 24;11(3), 178-187. <https://www.doi.org/10.1136/flgastro-2019-101260>.

R3. Chadwick, D. D. (2018). Dysphagia Management for People with Intellectual Disabilities: Practitioner Identified Processes, Barriers and Solutions. *Journal of Policy & Practice in Intellectual Disabilities*, 14(4), 319-331. <https://www.doi.org/10.1111/jppi.12216>.

R4. Chadwick, D.D., Stubbs, J., Forvague, S., Anderson, D., Stacey, G. & Tye, S. (2014). Training support staff to modify fluids to appropriate safe consistencies for adults with intellectual disabilities and dysphagia: An efficacy study. *Journal of Intellectual Disability Research*, 58(1), 84-98. <https://www.doi.org/10.1111/jir.12013>.

R5. Nicholls, W., Devonport, T.J., & Blake, M. (2016). The association between emotions and eating behaviour in an obese population with binge eating disorder. *Obesity Reviews*, 17(1), 30-42. <https://www.doi.org/10.1111/obr.12329>.

R6. Nicholls, W., & Hulbert-Williams, L. (2013). British-English translation of the Food Craving inventory (FCI-UK). *Appetite*, 67, 37-43. <https://www.doi.org/10.1016/j.appet.2013.03.010>.

#### Underpinning grants

Brookes, M. The lived experience of family planning of female patients diagnosed with inflammatory bowel disease (IBD) and their partners during key reproductive stages – a qualitative study. Crohn's & Colitis UK. GBP72,653.17. 2017 - 2021. Underpinned R1.

#### **4. Details of the impact**

The novel and significant research in digestive/eating disorders and complications discussed above has led to a diverse and substantial range of impacts [I]. Our research led to enhanced public understanding of the disorders and their related treatment options. It also led to changes in professional practice.

##### I1. Improving public understanding of IBD through new artworks

The University of Wolverhampton is located amongst a sizeable South Asian community, with over 15% of the population of Wolverhampton identifying as Asian ethnicity. The research focussing on IBD and pregnancy [F1] and the potential for inequalities in IBD healthcare [F2] led to the initiation of the 'Living in Silence' project in collaboration with colleagues at the University of Wolverhampton's School of Art and Royal Wolverhampton NHS Trust. Supported by funding from Arts Council England, the aim of "Living in Silence" was to destigmatise and improve understanding of chronic IBD in the South Asian female population in Wolverhampton and the surrounding area through unique and innovative works created by 5 artists. These included a sari with a pattern designed from a microscopic image of a diseased gut and a representation of a make-up table of someone who suffers from IBD.

The exhibition of 'Living in Silence' ran from 16<sup>th</sup> September 2019 to 7<sup>th</sup> October 2019 at New Cross Hospital, Wolverhampton, as well as a one-day exhibition at the House of Lords on 18<sup>th</sup> July 2019. Counts at the hospital exhibition indicated over 1200 visitors, with many thousands further engaging on social media. The Director of Services, Policy & Evidence for Crohn's and Colitis UK identified 'Living in Silence' as an important project informing their #ItTakesGuts campaign and highlighted the importance of the project for changing perceptions, "particularly in the underserved South Asian community" [C1]. Subsequently, Stuart Anderson MP, who attended the exhibition, commended the project and highlighted the importance of improving early diagnosis of digestive conditions [C2]. He also indicated the project helped him shape his key priorities in his role as an MP, specifically relating to the goal of "running campaigns that champion the health and wellbeing of my constituents" [C2].

## 12. Informing health policy and professional practice around dysphagia in people with learning disabilities

The findings on managing dysphagia in people with intellectual disabilities [F3] were incorporated into a variety of PHE policy and guideline documents all published online in 2016 [C3]. Since their initial publication, these documents and Chadwick's primary research have been widely used by practitioners and care workers in Trusts across the country to inform their interventions, training and direct support for people with dysphagia. In November 2020, a highly experienced SaLT, currently working at Bradford District Care NHS Foundation Trust, indicated her use of Chadwick's work to inform her practice in the "care and support of over 200 individuals with intellectual disabilities" and was "aware of his work being used to train and inform the practice of many SaLTs in the UK and internationally" [C4]. The Clinical Lead for NHS Derbyshire Speech and Language Therapy indicated Chadwick's research had directly benefited over 500 of her own patients, whilst also highlighting 35 to 40 SaLTs to whom she recommended his work [C5].

As a testament to the importance of, and demand for, Chadwick's work on this subject, in the first full month the resources were downloaded 97 times by various professionals [C6]. Of these 97, 70 identified as SaLTs, with comments such as "they have encouraged me to look at my practice and be more aware of the difficulties for persons with intellectual difficulties" and "research evidence helps me to understand where compromise might be made and which factors are most important" [C6]. The evidence presented highlights Chadwick's work on dysphagia as a key resource for those working with dysphagia patients with intellectual disabilities, particularly SaLTs.

## 13. Improving the lives of people with obesity

Through directly working with practitioners, a number of key impacts have been achieved, improving the quality of lives of those with obesity and binge eating disorder [F4, F5]. In 2015, a Tier 3 NHS weight management service was established at Birmingham Community Healthcare NHS Trust. This service used the findings on binge eating disorder [F4] to develop interventions for 45 obese patients, particularly focusing on targeting the association between emotions and overeating. The trial lasted over 3 years, offering an improvement on standard treatment, through helping clients gain acceptance and control over their over-eating [C7].

Furthermore, using the research findings on binge eating [F5], in 2015 a novel patient information booklet was produced to benefit NHS patients with binge eating disorder, helping to investigate patients' experiences of binge eating and the accompanying emotional aspects. The booklet was used at 2 NHS Trusts (Birmingham Community Healthcare NHS Trust & City Hospitals Sunderland NHS Trust), where practitioners including psychologists and dieticians working in Tier 3 NHS weight management used the research to directly benefit 20 patients with binge eating disorder [C8]. The patients involved evaluated activities as helpful; one patient highlighted the experience of a "lightbulb moment" in understanding their overeating [C9].

More recently in 2020, in partnership with the University of Jyväskylä (Finland), a COVID-19 emotional eating online intervention was delivered internationally to 1200 participants from countries including UK, Spain, Italy, Finland, USA, China, South Korea and the Philippines. The findings on binge eating [F4] and food cravings [F5] were used to produce online self-help materials, including a mindfulness-based script to help with food craving, and a food and mood diary, aimed to help participants develop awareness of their emotional eating behaviours. Participants reported substantial benefits from the intervention, in terms of improved awareness of issues and improved self-control of their binge eating [C10]. Comments from the participants were very positive, including "the connection between my mood and eating made me realise the control I had over my eating habits" [C10].

Finally, effective usage of the Food Craving Inventory [F5] in clinical practice was highlighted by its inclusion in the clinical assessment handbook 'Processed Food Addiction: Foundations, Assessment, and Recovery (2018)'. A Counselling Psychologist for North Bristol NHS Trust identified the handbook as a helpful tool for helping "better understand our participants as well as measure efficacy of our intervention" [C11].

**5. Sources to corroborate the impact**

C1. Testimonial from the Director of Services, Policy & Evidence, Crohn's and Colitis UK

C2. Testimonial from Stuart Anderson MP, MP for Wolverhampton South-West

C3. Public Health England 2016 Dysphagia Guidance documents:

- a) What do we know about dysphagia (difficulty in eating, drinking or swallowing) in people with learning disabilities? - [https://webarchive.nationalarchives.gov.uk/20160704150110/http://www.improvinghealthandlives.org.uk/publications/313917/Dysphagia\\_Factsheets](https://webarchive.nationalarchives.gov.uk/20160704150110/http://www.improvinghealthandlives.org.uk/publications/313917/Dysphagia_Factsheets)
- b) What do we know about supporting people with learning disabilities who have dysphagia (difficulty in eating, drinking or swallowing)? - [https://webarchive.nationalarchives.gov.uk/20160704150110/http://www.improvinghealthandlives.org.uk/publications/313917/Dysphagia\\_Factsheets](https://webarchive.nationalarchives.gov.uk/20160704150110/http://www.improvinghealthandlives.org.uk/publications/313917/Dysphagia_Factsheets)
- c) Making reasonable adjustments to dysphagia services for people with learning disabilities - [https://www.ndti.org.uk/assets/files/Dysphagia\\_RA\\_report\\_FINAL.pdf](https://www.ndti.org.uk/assets/files/Dysphagia_RA_report_FINAL.pdf)
- d) Health Inequalities: Dysphagia - [https://fingertips.phe.org.uk/documents/health\\_inequalities\\_dysphagia.pdf](https://fingertips.phe.org.uk/documents/health_inequalities_dysphagia.pdf)

C4. Testimonial from SaLT from Bradford District Care NHS Foundation Trust

C5. Testimonial from the Clinical Lead for NHS Derbyshire Speech and Language Therapy

C6. Feedback from individuals downloading Chadwick dysphagia publication portfolio from <http://psychology-resources.wlvpsych.co.uk/?projects=intellectual-disability-dysphagia-research/>

C7. Testimonial from Birmingham Community Healthcare NHS Trust

C8. Patient information booklet

C9. Contact details of Worcestershire Acute NHS Hospitals Trust (formerly of Birmingham Community Healthcare NHS Trust) representative

C10. Contact details of University of Jyväskylä representative

C11. Testimonial from Counselling Psychologist from North Bristol NHS Trust