

Institution: University of Hertfordshire		
Unit of Assessment: 04 – Psychology, Psychiatry and Neuroscience		
Title of case study: New clinical approaches for the effective diagnosis and treatment of		
obsessive-compulsive and related disorders		
Period when the underpinning research was undertaken: 2006-2019		
Details of staff conducting the underpinning research from the submitting unit:		
Role(s) (e.g. job title):	Period(s) employed by	
	submitting HEI:	
Professor of Psychiatry	2007 – present	
Professor of Cognitive Psychology	2005 – present	
Reader in Health Research Methods	2005 – present	
Senior Research Fellow	2013 – present	
	sity of Hertfordshire nt: 04 – Psychology, Psychiatry and Neuroscien r: New clinical approaches for the effective diagr ive and related disorders nderpinning research was undertaken: 2006- nducting the underpinning research from the Role(s) (e.g. job title): Professor of Psychiatry Professor of Cognitive Psychology Reader in Health Research Methods Senior Research Fellow	

Tim GaleVisiting Professor of Psychology2015 – presentPeriod when the claimed impact occurred: 1 August 2013 – 31 December 2020Is this case study continued from a case study submitted in 2014? N

1. Summary of the impact (indicative maximum 100 words)

Research undertaken at the University of Hertfordshire (UH), in collaboration with Hertfordshire Partnership University NHS Foundation Trust (HPFT), has advanced the psychobiological understanding, effective diagnosis, treatment and management of obsessive-compulsive and related disorders. This work led to the reclassification of obsessive-compulsive and related disorders within the World Health Organisation's international standard for reporting diseases and health conditions, resulting in more effective diagnosis and treatment. It has led to revisions of clinical guidelines and contributed to changes in clinical practice, which have benefitted patients with debilitating conditions that can be extremely challenging to treat.

2. Underpinning research (indicative maximum 500 words)

Obsessive-Compulsive Disorder (OCD) affects 1-2% of the population. It is characterised by the presence of either obsessions or compulsions, or commonly both, and can cause significant functional impairment and distress. Led by Fineberg, research by the Centre for Health Services and Clinical Research and the Cognitive Neuropsychology Research Group has investigated psychopharmacological and neurocognitive factors in OCD, and novel treatments for a condition widely recognised as very challenging to treat. Studies were carried out in collaboration with HPFT, where Fineberg is also Consultant Psychiatrist, research lead, and clinical lead of one of England's four specialist NHS centres of excellence for the treatment of OCD.

Identifying mechanistic commonalities in different OCDs

Laws and Fineberg have conducted neurocognitive and brain imaging analyses to better understand the mechanisms of OCD. They identified a common cognitive endophenotype profile in people with a range of OCD-related disorders and demonstrated that a common set-shifting problem exists in people diagnosed with OCD and a group of parallel psychiatric disorders. Cases of Obsessive-Compulsive Personality Disorder (OCPD), a condition characterised by perfectionism, were found to show significant cognitive inflexibility coupled with executive planning deficits, whereas decision-making remained intact. Laws and Fineberg concluded that this profile of impairment overlaps with that of OCD and implies that common neuropsychological changes affect individuals with these disorders [**3.1**]. Laws and Fineberg drew similar conclusions from studies into Body Dysmorphic Disorder (BDD), a condition relating to perceived appearance [**3.2**]. This combined work suggested a need to rethink the diagnostic classification of these conditions. The rationale for creating a new grouping of Obsessive-Compulsive and Related Disorders, also including hoarding disorder, in the WHO's International Classification of Diseases (ICD) was co-published by Fineberg in 2016 [**3.3**].

Exploring long-term health and cost burden of OCDs and wider neurological disorders

Working with Gale (UH/HPFT) and the Psychiatric University Hospital, Zurich, Fineberg led investigations into the impact of OC symptoms on psychosocial function and the effect of early-

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onset symptoms. They concluded that clinically relevant OC syndromes start early and are associated with substantial distress, treatment-seeking activity and, in the case of OCD, functional disability [**3.4**]. Following on from this work, Fineberg led an international consensus group on early intervention, looking at how treatment in childhood can potentially avoid the most serious, hard-to-treat cases in later life [**3.5**]. Fineberg and Wellsted used European health economic data to analyse the prevalence and the financial and long-term health burden of psychiatric and neurological disorders, including OCDs, in the UK. The study concluded there were 45m cases of brain disorders in the UK costing £112bn a year [**3.6**].

Addressing the problem of treatment-resistant OCD

Fineberg and Wellsted ran a randomised controlled feasibility study, funded by NIHR [**G1**], of the clinical and cost effectiveness of cognitive behavioural therapy (CBT), selective serotonin reuptake inhibitors (SSRIs) and their combination in the management of OCD. They found that combined treatment appeared the most clinically effective option, especially over CBT, but the advantages of sertraline monotherapy were not clearly sustained beyond 16 weeks. However, sertraline monotherapy was found to be the most cost effective [**3.7**]. Fineberg was a local principle investigator on the UK's first Deep Brain Stimulation (DBS) study for OCD (lead: UCL). It found, through the treatment of six patients with treatment-refractory OCD, that DBS could significantly reduce OCD symptoms. Following on from this, Fineberg and Wellsted were awarded an NIHR grant [**G2**] to investigate transcranial stimulation as a scalable, non-invasive alternative to DBS.

Problematic Use of the Internet: an emerging mental health challenge

Since 2017, Fineberg has chaired a European network **[G3]** on problematic use of the internet (PUI) and its impact on health and wellbeing. The Action is a multidisciplinary network of researchers with broad global expertise (including clinicians, policy makers, patients, bio- and information-technology industries, etc.). The goal is to advance understanding of the psychobiological basis of different forms of PUI and the societal cost and burden, and to spearhead development of treatment and prevention programmes. A manifesto published by the group in 2018 establishing the key research questions has become a key point of reference in this emerging field **[3.8]**.

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

3.1 Fineberg NA, Day GA, de Koenigswarter N, Reghunandanan S, Kolli S, Jefferies-Sewell K, Hranov G, Laws KR. The neuropsychology of obsessive-compulsive personality disorder: a new analysis. CNS Spectr. 2015 Oct;20(5):490-9. https://doi.org/10.1017/S1092852914000662. 3.2 Jefferies-Sewell K, Chamberlain SR, Fineberg NA, Laws KR. Cognitive dysfunction in body dysmorphic disorder: new implications for nosological systems and neurobiological models. CNS Spectr. 2017 Feb;22(1):51-60. https://doi.org/10.1017/S1092852916000468. 3.3 Stein DJ, Kogan CS, Atmaca M, Fineberg NA, Fontenelle LF, Grant JE, Matsunaga H, Reddy YCJ, Simpson HB, Thomsen PH, van den Heuvel OA, Veale D, Woods DW, Reed GM. The classification of Obsessive-Compulsive and Related Disorders in the ICD-11. J Affect Disord. 2016 Jan 15;190:663-674. https://doi.org/10.1016/j.jad.2015.10.061. 3.4 Fineberg NA, Hengartner MP, Bergbaum CE, Gale TM, Gamma A, Ajdacic-Gross V, Rössler W, Angst J. A prospective population-based cohort study of the prevalence, incidence and impact of obsessive-compulsive symptomatology. Int J Psychiatry Clin Pract. 2013 Aug;17(3):170-8. http://doi.org/10.3109/13651501.2012.755206. 3.5 Fineberg NA, Dell'Osso B, Albert U, Maina G, Geller D, Carmi L, Sireau N, et al. Early intervention for obsessive compulsive disorder: An expert consensus statement. Eur Neuropsychopharmacol. 2019 Apr;29(4):549-565. https://doi.org/ggw9gm **3.6 Fineberg NA**, Haddad PM, Carpenter L, Gannon B, Sharpe R, Young AH, Joyce E, Rowe J, Wellsted, D, Nutt DJ, Sahakian BJ. The size, burden and cost of disorders of the brain in the UK. J Psychopharmacol. 2013 Sep;27(9):761-70. http://doi.org/10.1177/0269881113495118 3.7 Fineberg NA, Baldwin DS, Drummond LM, Wyatt S, Hanson J, Gopi S, Kaur S, Reid J,

Marwah V, Sachdev RA, Pampaloni I, Shahper S, Varlakova Y, Mpavaenda D, Manson C, O'Leary C, **Irvine K**, Monji-Patel D, Shodunke A, Dyer T, Dymond A, Barton G, **Wellsted D**.

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Optimal treatment for obsessive compulsive disorder: a randomized controlled feasibility study of the clinical-effectiveness and cost-effectiveness of cognitive-behavioural therapy, selective serotonin reuptake inhibitors and their combination in the management of obsessive compulsive disorder. Int Clin Psychopharmacol. 2018 Nov; 33(6): 334-348. <u>https://doi.org/ggw75n</u> **3.8 Fineberg NA**, Demetrovics Z, Stein DJ, Ioannidis K, Potenza MN, Grünblatt E, Brand M, Billieux J, Carmi L, King DL, Grant JE, Yücel M, Dell'Osso B, Rumpf HJ, Hall N, Hollander E, Goudriaan A, Menchon J, Zohar J, Burkauskas J, Martinotti G, Van Ameringen M, **Corazza O**, Pallanti S; COST Action Network, Chamberlain SR. Manifesto for a European research network into Problematic Usage of the Internet. Eur Neuropsychopharmacol. 2018 Nov;28(11):1232-1246. doi: 10.1016/j.euroneuro.2018.08.004.

Key grants

G1 NIHR (PB-PG-0712-28044) A randomised controlled feasibility trial comparing the clinical and cost effectiveness of cognitive behavioural therapy (CBT) and selective serotonin reuptake inhibitors (SSRI) and their combination in the management of obsessive compulsive disorder. £260,751. PI Fineberg, Co-I: Wellsted.

G2 NIHR (PB-PG-1216-20005) FEasibility and Acceptability Of Transcranial Stimulation in Obsessive Compulsive Symptoms (FEATSOCS). £262,281. PI: Fineberg, Co-I: Wellsted. **G3** European Cooperation in Science and Technology (COST) (CA16207). European Network for Problematic Usage of the Internet. £527,577. Action Chair: Fineberg.

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

Research led by Fineberg at UH has advanced clinical understanding of the neuroscience underpinning OCD and the broader concept of 'compulsivity'. The key impacts reported here stem from improved understanding of a wider group of obsessive-compulsive and related disorders (OCRDs), leading to better diagnosis for patients and improved treatments. This has been achieved through a range of clinical guidelines, direct impact on clinical practice, professional education and raising public awareness.

The ICD-11: reclassification of obsessive-compulsive disorders improves diagnosis

The UH research that led to publications 3.1 and 3.2 fed directly into significant changes made to the World Health Organisation's global standard for diagnostic health information, the new International Classification of Diseases (ICD-11), which had not been updated since 1994 [5.1]. Fineberg sat on the Workgroup on Obsessive-Compulsive and Related Disorders, where she successfully argued for the classification of OCD and related compulsive disorders as a new diagnostic group of disorders based on a shared compulsive neurobiology. For the first time it was shown that hypochondriasis is not a somatic condition (as per the ICD-10 classification) but part of a family or spectrum of OCDs. A new section for 'Obsessive-compulsive or related disorders' was included [5.2] when ICD-11 was released in June 2018 and formally adopted by Member States in May 2019. As paper 3.3 states, this new grouping was designed to contribute to more accurate identification and appropriate treatment of affected patients. Two examples of new classifications are Hoarding Disorder and Gaming Disorder, both included for the first time. The decision to include Hoarding Disorder was described by psychiatrists as 'extremely significant' according to reports in the Guardian and The Telegraph [5.3]. A peer-reviewed, multiauthor study, published online in May 2020, demonstrated the clinical efficacy of the updated ICD-11 guidelines [5.4]. By studying the responses of 1,717 mental health clinicians to case vignettes, use of the ICD-11 guidelines resulted in more accurate diagnosis of OCD and related disorders compared to the ICD-10 guidelines, particularly in differentiating presentations from one another [5.4].

Problematic Use of the Internet (PUI)

The COST Action group on PUI had clear aims on achieving impact on both professionals and patients. The consensus statement **[3.8]** was widely covered in both general and professional media. The group produced a book aimed at the general public, *Learning to deal with Problematic Usage of the Internet* which was published on their own website and on the COST website. The group has provided research evidence and support for the new ICD-11 diagnosis

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of Gaming Disorder, and has engaged with clinical colleagues and health service commissioners, successfully lobbying for development of new clinical services to treat Gaming Disorder in 2019. In October 2020, the group held a training event for clinical professionals on 'Problematic Use of the Internet.' This took place online and was attended by 104 people from 23 different countries globally. It was followed by an event for the general public which was attended by 77 people from 24 different countries.

Changing clinical treatment and consensus guidelines for OCD and related disorders

Fineberg was co-author of the British Association for Psychopharmacology's new guidelines on pharmacological treatment of anxiety disorders, post-traumatic stress disorder and obsessivecompulsive disorder, published in 2014. The guidelines provided updates for diagnosis and clinical management, and further approaches for patients not responding to first-line interventions [5.5]. Fineberg authored Section 21: 'Management of obsessive-compulsive disorder'; research paper **3.4** was among those cited. Whereas the original 2005 guidelines had recommended treatment of patients with a standard SSRI dosage for 12 months to prevent relapse, the revised 2014 guidelines recommended a more nuanced approach: patients should be treated with a personalised dosage (often higher than the standard) for 12 months-plus, in line with findings from the Fineberg-led studies [5.5]. The guidelines were in place from May 2014 to the end of the REF impact assessment period and were downloaded 9,876 times during this time [5.6].

In 2018, Fineberg successfully advocated for the 2006 NICE guidelines for OCD to be updated; to fill the immediate need for up-to-date, research-based guidance, she worked with colleagues under the banner of the International College of Obsessive Compulsive Spectrum Disorders (ICOCS) to publish a consensus statement on treatment options [5.7]. With the same group, she led a second consensus statement on Body Dysmorphic Disorder [5.8]; this cites paper 3.2 and other papers from the same team.

Fineberg, drawing on **3.1-3.4**, was also instrumental in developing new, peer-reviewed international consensus standards of care for specialist assessment and care units for OCD [**5.9**]. Published in 2016, these standards were a response to the lack of consensus over the key functions that these units should perform. The new standards included recommendations relating to the quality of clinical facilities, specialist staffing, diagnostic procedures and assessment, and patient management and follow-up. In 2018-19 Fineberg then sat on the OCD committee for the revision of the Royal College of Psychiatrist's standards for community mental health services (ACOMHS), which were published in January 2020.

Impact on clinical services: the Hertfordshire Obsessive Compulsive Disorders Service The care standards described above form the basis of the clinical practice of Fineberg and colleagues at the Hertfordshire Obsessive Compulsive Disorders Service, based in Welwyn Garden City. It is one of four NHS England Commissioned OCD services providing care and treatment to people who have failed to respond to all available pharmacological and psychological treatments whilst under the care of their local NHS Mental Health Trust. According to the Service's website: 'The research expertise in applied neuroscience, provided by our services, in collaboration with the Universities of Hertfordshire and Cambridge, is used ... to drive forward novel and more effective treatment interventions [5.10].' Over the impact period, the service has treated 120 of the most treatment-resistant patients from around the UK.

Training and CPD for clinicians

UH research also runs through a pocketbook for clinicians and patients called 'Obsessive-Compulsive and Related Disorders', co-authored by Fineberg (with two others) and published in 2015. It was Highly Commended in the Psychiatry category of the British Medical Association Book Awards 2016 [**5.11**]. Fineberg also reviewed and updated the Royal College of Psychiatrists' online CPD modules on OCD in 2020 based on her ongoing research [**5.12**]. Fineberg leads a biannual BAP-accredited CPD session for psychiatrists that draws on her UH research and her own practice. Around 1,500 psychiatrists have taken this session over the impact period.



OCD and related disorders during COVID-19

The onset of the COVID-19 pandemic in 2020 had a significant negative effect on mental health, particularly for people with pre-existing anxiety-related disorders. The general spike in anxiety about the virus fuelled existing obsessive fears of contamination in some people with OCD and further triggered harmful compulsive actions. Fineberg led a working group of clinical experts from ICOCS together with the Obsessive-Compulsive and Related Disorders Research Network of the European College of Neuropsychopharmacology to produce a consensus statement in April 2020 with the aim of delivering pragmatic guidance to clinicians for managing this complex challenge [**5.13**]. In July 2020, under the PUI COST Action [**G3**] she was part of an expert group which formulated consensus guidance on preventing problematic internet use during the COVID-19 pandemic – which was an increased risk as activities such as work, socialising and education moved online [**5.14**].

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

5.1 WHO releases new International Classification of Diseases (ICD-11)

https://www.who.int/news-room/detail/18-06-2018-who-releases-new-international-classificationof-diseases-(icd-11)

5.2 Obsessive-compulsive or related disorders section, ICD-11: <u>https://icd.who.int/browse11/l-</u>m/en#/http%3a%2f%2fid.who.int%2ficd%2fentity%2f1321276661

5.3 News reports on the new classification of obsessive-compulsive or related disorders. <u>https://www.telegraph.co.uk/news/2018/08/14/hoarding-classified-mental-disorder-first-time-world-health/; https://www.theguardian.com/society/2018/aug/18/it-looks-like-youre-a-lazy-idiot-hoarders-welcome-medical-classification</u>

5.4 Accuracy of diagnostic judgments using ICD-11 vs. ICD-10 diagnostic guidelines for obsessive-compulsive and related disorders. <u>https://doi.org/10.1016/j.jad.2020.03.103</u>

5.5 Evidence-based pharmacological treatment of anxiety disorders, post-traumatic stress disorder and obsessive-compulsive disorder. British Association for Psychopharmacology, 2014. <u>https://www.bap.org.uk/pdfs/BAP_Guidelines-Anxiety.pdf</u>

5.6 Email from British Association for Psychopharmacology confirming number of downloads.

5.7 Clinical advances in obsessive-compulsive disorder: a position statement by the International College of Obsessive-Compulsive Spectrum Disorders.

http://doi.org/10.1097/YIC.000000000000314.

5.8 Body dysmorphic disorder: a treatment synthesis and consensus on behalf of the International College of Obsessive-Compulsive Spectrum Disorders and the Obsessive Compulsive and Related Disorders Network of the European College of

Neuropsychopharmacology. <u>http://doi.org/10.1097/YIC.00000000000342</u>

5.9 Standards of care for obsessive-compulsive disorder centres. Int J Psychiatry Clin Pract. 2016 Sep; 20(3): 204-8 <u>https://doi.org/10.1080/13651501.2016.1197275</u> (Fineberg co-author)

5.10 Hertfordshire Obsessive Compulsive Disorders Service, The New QEII Hospital. <u>https://www.hpft.nhs.uk/services/community-services/highly-specialised-services-for-obsessive-compulsive-disorders-ocds-and-applied-neuroscience/hertfordshire-obsessive-compulsive-disorders-service/</u>

5.11 Obsessive-Compulsive and Related Disorders, Oxford Psychiatry Library (<u>Fineberg co-author</u>): <u>https://www.amazon.co.uk/Obsessive-Compulsive-Related-Disorders-Psychiatry-Library/dp/0198706871</u>

5.12 Royal College of Psychiatrists, CPD Online.

https://elearning.rcpsych.ac.uk/learningmodules/assessmentandmanagementofo.aspx. https://elearning.rcpsych.ac.uk/learningmodules/assessmentandmanagementof-1.aspx.

5.13 How to manage obsessive-compulsive disorder (OCD) under COVID-19: A clinician's guide from the International College of Obsessive Compulsive Spectrum Disorders (ICOCS) and the Obsessive-Compulsive and Related Disorders Research Network (OCRN) of the European College of Neuropsychopharmacology. <u>http://doi.org/10.1016/j.comppsych.2020.152174</u>
5.14 Preventing problematic internet use during the COVID-19 pandemic: Consensus guidance. http://doi.org/10.1016/j.comppsych.2020.152180