Impact case study (REF3b)

Institution: Bournemouth University

Unit of Assessment: UOA 4

Title of case study: Assessment and treatment of children and adults with face processing impairments.

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

Prosopagnosia, or the inability to recognise faces, affects one person in 50, but public and professional awareness of the condition is low. Bournemouth University (BU) established The Centre for Face Processing Disorders (CFPD) to provide cognitive screening and training programmes to improve recognition skills for affected adults and children. The centre has grown significantly and, having tested over 100 people for prosopagnosia, now treats 30 adults and 10 children through cognitive training and clinical treatment. While patient numbers are moderate to date, the service is unique in the UK and has provided proof of concept for a scalable prosopagnosia diagnosis and a treatment approach. This includes protocols for different conditions including Autism and Moebius syndrome. In addition, the CFPD has orchestrated policy changes within significant health organisations and charities.

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2. Underpinning research (indicative maximum 500 words)

Less than six years ago, the incidence of face processing deficits was thought to be very low. Parris (BU 2008–date) initially in collaboration with colleagues at the University of Exeter, including Bate (BU 2010–date) showed face recognition skills vary substantially within the normal adult population (P1), and variation in childhood is also common. Genuine "face blindness" (prosopagnosia) was, however, believed to be extremely rare. Recent developments in research—combined with the easy availability of information on the internet—have led to dramatic increases in estimated incidence. It is now believed that the developmental form of prosopagnosia affects up to one person in 50 worldwide. Some children with the condition can encounter severe social and educational difficulties, demonstrating an urgent need for a specific developmental screening assessment and appropriate special needs provision. Likewise, adult sufferers who avoid embarrassment through self-imposed social isolation may need specialised psychological intervention.

BU acted swiftly to ensure the research programme could develop rapidly. The Centre for Face Processing Disorders (CFPD) was established, with an initial investment of £100k. Subsequently, Bate has led a prosopagnosia research programme that underpins the clinical impact of the CFPD. For example:

1. Bate demonstrated that intranasal inhalation of oxytocin produces a temporary improvement in face recognition skills in adults with developmental prosopagnosia. This implies that the neural structures that the hormone acts upon are open to modulation, even in prosopagnosia (P4).

2. The CFPD has developed a series of diagnostic tests using eye-tracking software, which assess the visuo-cognitive processing strategies that individuals with prosopagnosia typically employ. This work shows that alternative physiological and behavioural measures can provide bio-behavioural markers of face processing impairments, and highlights the utility of more ecologically valid measures of face processing skills (P2).

3. In collaboration with Poole Hospital neurophysiologist Cole, CFPD has obtained the first evidence that Moebius syndrome – a hereditary form of facial paralysis accompanied by eye movement paralysis – can also result in face recognition impairments. This corroborates previous findings from unimpaired participants that eye movements are essential for face recognition (P3).

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

P1. Bate, S., Parris, B., Haslam, C. and Kay, J. (2010). Socio-emotional functioning and face processing in the normal population. *Personality and Individual Differences*, 48, 239–242. DOI 10.1016/j.paid.2009.10.005.
P2. Bate, S. and Cook, S. (2012). Covert recognition relies on affective valence in developmental prosopagnosia: Evidence from the skin conductance response. *Neuropsychology*, 26, 670–674. DOI: 10.1037/a0029443.
P3. Bate, S., Cook, S.J. and Cole, J. (2013). First report of generalized face processing difficulties in Möbius sequence. *PLos One*, 8(4), e62656. DOI: 10.1371/journal.pone.0062656.
P4. Bate, S., Cook, S.J., Duchaine, B., Tree, J.J., Burns, E.J. and Hodgson, T.L. (2013). Intranasal inhalation of oxytocin improves face processing in developmental prosopagnosia. *Cortex*, pii: S0010-9452(13)00208-6 (e-pub ahead of print). doi: 10.1016/j.cortex.2013.08.006.

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

Researchers at the CFPD have addressed the lack of awareness of prosopagnosia through extensive dissemination of their research findings. Significant impacts include developing diagnosis methods, cognitive training and clinical treatment programmes to help prosopagnosia sufferers. More recently the research has led to policy changes within health organisations and charities. These interventions improve the lives of sufferers, while demonstrating a proof of concept for a scalable prosopagnosia diagnosis and a treatment approach.

Raising awareness

From the outset CFPD's research success depended on recruiting and testing as many adults and children with prosopagnosia as possible. The team set about raising awareness of the condition and the research, whilst directing people to the website for recruitment and preliminary testing (R1). They achieved this through media coverage, which significantly increased public awareness of the condition. This is evidenced by the sharp increase in visitor numbers to the website following key media activity. This is shown in Figure 1, which also illustrates the international reach of CFPD's work. Specifically in the last three years the CFPD's work has featured on BBC South, CBBC, *The Guardian*, *Independent*, *Telegraph*, *Daily Mail*, *Mirror*, *Sun* and *Metro* among others.
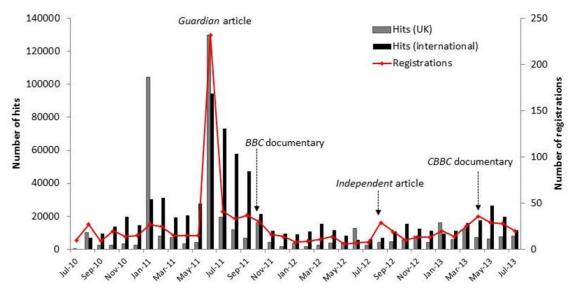

Figure 1: Page impressions and registrations on www.prosopagnosiaresearch.org by month. Media coverage of the CFPD is highlighted at relevant time points.
Source: Google keywords

Assessment and diagnosis

This strong, positive media interest, particularly following the formal launch of CFPD in 2012, produced a step change in self-referral rate of potential participants. This is evidenced by the fact that more than 900 people with face processing difficulties have now registered on the website, compared with only 50 (40 adults and 10 children) in the 2 years prior to the launch. All registrants are offered a cognitive screening session that establishes whether they meet diagnostic criteria for prosopagnosia. Face processing impairments are evident in other disorders such as Moebius syndrome and Autism so the CFPD team has developed protocols for differential diagnosis and tested over 100 individuals to date.

CFPD maintains research links with laboratories in the USA (Dartmouth College) and Australia (Centre of Cognitive Disorders: Macquarie University and University of Western Australia), and regularly puts international registrants in touch with these facilities, which also provide diagnostic services.

The provision of prosopagnosia assessment is currently unique to the UK and the availability of this service—even on a limited scale—has been highly beneficial to individuals and their families. Frequently, they report a sense of relief when long-standing difficulties in normal social interaction are finally understood (R2).

Treatment

The significance of CFPD's work is in the development and evaluation of research-based programmes for identifying and treating prosopagnosia. These innovations can produce profound improvements in the quality of life of people affected by the disorder.

The CFPD now has more than 30 adults and 10 children enrolled in cognitive training programmes. Participants are typically required to make fine-grained discriminations between pairs of similar faces. The task becomes increasingly difficult as participants progress through levels in a computer-game format, over a 12-week period.

Researchers are now investigating the effectiveness of combining these programmes with oxytocin inhalation (P4) after demonstrating a temporary improvement in face recognition skills following treatment with the hormone. This is the first example of clinical intervention in the treatment of prosopagnosia.

This proof of concept for a scalable assessment and intervention programme has considerable reach, capable of serving the needs of the estimated 300,000 children with prosopagnosia in the UK alone.

Organisational policy change

The CFPD's research, extensive dissemination and lobbying activities have led to significant policy changes within health organisations and charities.

NHS: Following dialogue with Bate, NHS Choices have committed to have prosopagnosia added to the A–Z of conditions (R3). This was confirmed in the House of Commons by Minister of State for Care and Support, Norman Lamb MP on 02/07/2013**,** who said: "NHS Choices will be including information about prosopagnosia in the A to Z of medical conditions on its website later this year. This will help to promote better understanding among the wider general public and ensure that people with prosopagnosia receive the recognition and support they need" (R4).

In addition, Annette Brookes MP assisted in the formulation of an Early Day Motion in Parliament to increase understanding of prosopagnosia as a significant cognitive disorder (R5).

The Encephalitis Society The society provides support, awareness and research for the inflammation of the brain. CFPD worked with the organisation to produce a fact sheet about prosopagnosia. BU's contribution can be confirmed through their Development Manager (R6).

Headway: CFPD researchers have worked with the brain injury association Headway, to produce a fact sheet about how to cope with prosopagnosia. This can be downloaded from Headway's site and BU's input verified through their Information Officer (R7). In addition Headway have added Bate's book *Face Recognition and its Disorders* to its Amazon shop (R8).

Future applications

CFPD is continuing to expand the range of applications of its work. For example, the techniques Bate has developed for improving face recognition in prosopagnosia may also have value in extending the recognition skills in unimpaired individuals. CFPD are currently working with the Scientific Investigation Unit of the Dorset Police Force (R9) and Dorset Search and Rescue (R10) to investigate the potential of this approach to create 'super-recognisers.' The Home Office has also asked CFPD to keep them informed of their findings.

In summary, research by the CFPD has made significant strides in raising awareness, assessing and treating individuals with face processing disorders. The cognitive training programmes, combined with clinical treatment with oxytocin, improve the lives of sufferers. The research has led to important recognition of the disorder by the NHS and other organisations. It is hoped BU's proof of concept for a scalable prosopagnosia diagnosis and a treatment approach will help many more sufferers in the future.

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

R1. Media coverage: www.prosopagnosiaresearch.org/media

R2. Participant testimonials: www.prosopagnosiaresearch.org/about/participant-testimonials

R3. NHS Choices: http://www.nhs.uk/Pages/HomePage.aspx

R4. Committment by Norman Lamb MP
http://www.publications.parliament.uk//pa/cm201314/cmhansrd/cm130701/text/130701w0004.htm#1307021000450

R5. Early Day Motion: http://www.parliament.uk/edm/2013-14/207

R6. CEO of the Encephalitis Society. Contact details available.

R7. Information Officer at Headway. Contact details available.

R8. https://astore.amazon.co.uk/headwathebrai-21

R9. Head of the Police Force's Technical and Forensic Investigations Unit. Contact details available.

R10. Secretary of Dorset Search and Rescue. Contact details available.

R11. Discussion board: www.prosopagnosiaresearch.org/discussion-board.