

Institution: Bournemouth University		
Unit of Assessment: 4		
Title of case study: Pinpointing prosopagnosia: the professional and social impact of achieving NHS recognition		
Period when the underpinning research was undertaken: 2014 – 2020		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Professor Sarah Bate Dr Peter Hills	Professor of Psychology Associate Professor of Psychology	2010-current 2014-current
Dr Nicola Gregory Dr Rachel Bennetts Dr Anna Bobak	Senior Lecturer in Psychology Lecturer in Psychology Postdoctoral Research Assistant	2011-current 2013-2016 2012-2016
Period when the claimed impact occurred: 2014 – 31 December 2020		
Is this case study continued from a case study submitted in 2014? No		
1. Summary of the impact <p>Prosopagnosia, a cognitive condition affecting adults and children, is a chronic failure to recognise facial identity. Bournemouth University (BU) research established that the condition is more widespread than Autism Spectrum Disorder (ASD) and can detrimentally impact occupational and educational progression and psychosocial health. These findings, presented in the House of Commons in 2014, resulted in the first NHS recognition of prosopagnosia. The consequent increase in awareness and diagnoses have dramatically improved the wellbeing of affected individuals and their families. BU's resources for managing prosopagnosia are featured by the NHS, and offer the only large-scale, comprehensive intervention programme for children worldwide.</p>		
2. Underpinning research <p>Prior to the turn of the century, reported cases of 'prosopagnosia' ('face blindness') were extremely rare [E9]. People experiencing this cognitive disorder cannot recognise the facial identity of others and, consequently, often experience extreme distress. In 2012, BU launched a dedicated research centre led by Professor Bate (the Centre for Face Processing Disorders) to investigate the condition.</p> <p>Since 2014, external investments (e.g. a GBP102,737 British Academy Mid-Career Fellowship awarded to Bate) and charitable donations (e.g. from the Murphy-Neumann Trust and Wates Foundation), totalling nearly GBP155,000, have allowed Bate's team to make major strides in uncovering the clinical presentation of prosopagnosia, and to develop techniques for ameliorating it.</p> <p>Bate began by conducting a large-scale investigation of face recognition difficulties in primary school children [R1]. This offered the first prevalence estimate of prosopagnosia in childhood (1.2-4%). It showed that, despite low awareness of the condition in the community, prosopagnosia is more common than other, better-known developmental disorders such as ASD.</p>		

To better understand why prosopagnosia had remained 'socially hidden', we interviewed adults with the condition, their significant others, and parents of children showing face recognition difficulties. Transcripts revealed strong evidence that prosopagnosia frequently causes embarrassment in social, educational and occupational settings, and often triggers active attempts to escape from, or avoid, them. We developed a detailed analysis of the strategies people use to cope with these situations to create the first evidence-based list of recommendations for coping with the condition [R2].

These early studies also suggested that self-referral for prosopagnosia was an unreliable means of diagnosis. Subsequent research confirmed that self-referral did not reliably index the severity of symptoms and suffered from gender bias effects [R3]. Accordingly, we identified an alternative means of rapid screening in a second interview study, developing a list of behavioural symptoms for use by educationalists, clinical psychologists, caregivers or family members in identifying candidates for a prosopagnosia diagnosis [R4].

Objective testing of face recognition skills is, however, still required to confirm a prosopagnosia diagnosis. To ramp up our objective testing capability, we recruited a sample three times larger than any previous prosopagnosia investigation to re-evaluate existing computerised diagnostic tests. This improved the efficacy of our methods and allowed us to identify a new and previously unrecognised subtype of the condition that affects long-term memory for faces [R5].

The BU team's systematic and detailed understanding of prosopagnosia has led to the development of training programmes designed to improve face recognition skills in adults and children with the condition. Last year, we created a modified version of the family game *Guess Who?* to improve children's ability to recognise faces. After playing the game, our sample of typical children showed an 8% improvement in face memory, compared to those in a control condition [R6]. Very recent clinical trials using this regime have produced similar improvements in both adults and children with prosopagnosia, and anecdotal feedback suggests these improvements also transfer to everyday real-world face recognition experiences.

3. References to the research

R1-6 were all subject to rigorous peer review.

R1: Bennetts, R.J., Murray, E., Boyce, T., and Bate, S. (2017). "Prevalence of face recognition deficits in middle childhood," *Quarterly Journal of Experimental Psychology*, 70, 234-258.
<https://doi.org/10.1080%2F17470218.2016.1167924>

R2: Adams, A., Hills, P., Bennetts, R., and Bate, S. (2020). "Coping strategies for developmental prosopagnosia," *Neuropsychological Rehabilitation*, 30, 1996-2015.
<https://doi.org/10.1080/09602011.2019.1623824>

R3: Murray, E., and Bate, S. (2020). "Self-ratings of face recognition ability are influenced by gender but not prosopagnosia severity," *Psychological Assessment*, 7, 200884.
<https://doi.org/10.1037/pas0000707>

R4: Murray, E., Hills, P.J., Bennetts, R.J., and Bate, S. (2018). "Identifying hallmark symptoms of developmental prosopagnosia for non-experts," *Scientific Reports*, 8, 1690.
<https://www.researchgate.net/deref/https%3A%2F%2Fwww.nature.com%2Farticles%2Fs41598-018-20089-7>

R5: Bate, S., Bennetts, R., Gregory, N.J., Tree, J., Murray, E., Adams, A., Bobak, A.K., Penton, T., Yang, T., and Banissy, M. (2019). "Objective patterns of face recognition deficits in 165 adults with self-reported developmental prosopagnosia," *Brain Sciences*, 9, 133.
<https://doi.org/10.3390/brainsci9060133>

R6: Bate, S., Adams, A., and Bennetts, R.J. (2020). "Guess Who? Facial identity discrimination training improves face memory in typically developing children," *Journal of Experimental Psychology: General*, 149, 901-913. <https://doi.org/10.1037/xge0000689>

4. Details of the impact

NHS policy change and resources

In June 2014, Bate hosted a House of Commons round table discussion funded by a British Psychological Society (BPS) Public Engagement Grant [E1]. The BU team presented its underpinning research, emphasising the condition's psychosocial impact on adults and children, and highlighting its prevalence. Their aim, in collaboration with Tobias Ellwood MP, the BPS, and influential national charities (the Encephalitis Society, Face Blind UK) [E2], was to gain NHS recognition of prosopagnosia. Shortly afterwards, the House of Commons was able to confirm this had been granted [E3]. Contemporaneously, an Early Day Motion tabled in Parliament acknowledged BU's work and sought further systematic support for the condition [E4].

Later in 2014, after Bate was invited to review its content [E5], the first ever prosopagnosia page was launched on the NHS Choices website (A-Z of conditions) [E6]. This site is used by all UK GP networks and many other healthcare professionals. The page links directly (and uniquely) to BU's Centre for Face Processing Disorders [E6], allowing users' access to BU's symptom checklist [R4] and evidence-based analyses of management strategies [R2]. These resources have been used by more than 20,000 users, spanning every continent of the world.

Professional users (typically clinical, educational and occupational psychologists, psychiatrists, and educational staff) have provided feedback highlighting the role NHS recognition and BU resources have played in enhancing their ability to support people with prosopagnosia [E7]. Prior to NHS listing, prosopagnosia could not be listed in UK medical records; there was simply no box to check. Now it has a unique 'read code' [E8]. Children with prosopagnosic symptoms alone are now unlikely to be diagnosed with ASD. Likewise, should prosopagnosic adults find themselves in hospital, their condition is now less prone to misinterpretation as 'general confusion' or dementia [E9].

Impact on public awareness and diagnosis

Critically, NHS recognition of prosopagnosia also led to increased public awareness. Following the NHS webpage launch (August 2014), general traffic on Bate's website increased threefold, reaching users in more than 70 countries on five continents. Likewise, greater worldwide demand for diagnosis was triggered, increasing clicks onto the diagnosis request page on Bate's website virtually tenfold, from 710 visits in July to 7,069 visits in August alone.

In addition, the already vast international media interest in Bate's work substantially increased in the months following NHS recognition of prosopagnosia (www.prosopagnosiaresearch.org/media). Coverage of prosopagnosia in these high-profile outlets (e.g. *Scientific American*, *The One Show*, *BBC Radio*, *ITV News*, *Telegraph*, *Times*) also served to raise public awareness of the condition, and to prompt hundreds more people to seek diagnosis. Many of BU's research participants' comments explain why a formal prosopagnosia diagnosis improved their mental health, and parents of children with prosopagnosia have expressed their relief at having a formal NHS source of information to share with schools [E10].

Access to intervention programmes

The NHS webpage [E6] also promotes Bate's behavioural intervention techniques for improving face recognition skills in adults and children with prosopagnosia. This resource is unique, extending the successful *Guess Who?* training programme that improved face recognition skills in typical children [R6]. This trial offers the only known opportunity (globally) for prosopagnosic children to access an amelioration programme, and has reached participants from the UK, USA and Australia. Analyses show improvement in face recognition following 10 sessions of training compared with controls, with stronger improvements in children than adults. These findings have enabled Bate's team to increase programme access and to support longer-term training.

Strongly positive parental feedback suggests improvements in recognition transfer to everyday life, and acknowledges the unique opportunity to improve their children's face recognition skills [E10].

5. Sources to corroborate the impact

E1: The British Psychological Society. (2014). *The Psychologist*, Available at: <https://thepsychologist.bps.org.uk/volume-27/edition-8/society> (Accessed 15/03/2020)

E2: Ellwood, T. (2014). *Raising awareness of the condition 'faceblindness' with Bournemouth University*, Available at: <https://www.tobiasellwood.com/news/raising-awareness-condition-faceblindness-bournemouth-university> (Accessed 14/12/2020)

E3: House of Commons. (2014). Letter to Bate, 15 July 2014

E4: UK Parliament. (2014). *Early Day Motions: Prosopagnosia*, Available at: <https://edm.parliament.uk/early-day-motion/47060/prosopagnosia> (Accessed 05/03/2020)

E5: NHS Choices Editor. (2014). Letter to Bate, 12 June

E6:

E6a. NHS. (2014). *Prosopagnosia (face blindness)*, Available at: <https://www.nhs.uk/conditions/face-blindness/> (Accessed 05/03/2020) with the link to the BU page:

E6b. Bate, S. (2011). *Prosopagnosia research at Bournemouth University*, Available at: <http://www.prosopagnosiaresearch.org/> (Accessed 09/03/2020)

E7: Spreadsheet listing professional users of Bate's website and its resources.

E8: Face Blind UK. (2019). *Diagnosis & the NHS*, Available at: <https://www.faceblind.org.uk/diagnosis/nhs/> (Accessed 06/01/2021)

E9: Bournemouth University. (2014). *Face Blindness Awareness Campaign*, Available at: https://www.youtube.com/watch?v=p2A_r40QMvU (Accessed 06/01/2021)

E10: Quotes from people with prosopagnosia and/or their families.