Section A		
Institution: Durham University		
Unit of Assessment: 4 - Psychology, Psychiatry and Neuroscience		
Title of case study: Normalising voice-hearing: from phenomenology to clinical practice		
Period when the underpinning research was undertaken: Between 2014 and 2019		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s)	Role(s) (e.g. job title)	Period employed by submitting HEI
Charles Fernyhough	Professor of Psychology	October 2003 – present
Ben Alderson-Day	Asst Professor of Psychology	November 2012 – present.
Period when the claimed impact occurred: Between August 2013 and July 2020		
Is this case study continued from a case study submitted in 2014? No		
Section B		

Section B

1. Summary of the impact

Durham-based research is serving to normalise – and thus reduce distress caused by – hearing voices (or auditory verbal hallucinations; AVH), a highly varied experience with deep significance for people's lives. We achieved impact by improving (1) the treatment of voice-hearing for over 300 people in NHS services in Northern England, via a novel digital therapy manual; (2) psychoeducation and therapeutic information available to voice-hearers, families and carers, through a major new online resource, *Understanding Voices* (viewed by more than 16,500 people in 2020); and (3) public understanding of AVH and unusual experiences via the award-winning video game, *Hellblade: Senua's Sacrifice* (over 1 million players worldwide).

2. Underpinning research

Hearing voices that others cannot hear can be highly distressing. Research conducted by Durham University's Hearing the Voice (HtV) project is helping to minimise this distress by widening and deepening knowledge about the experience: for people who hear voices, their families and carers, clinicians and the general public. A key part of this approach is *normalisation*: the idea that distressing experiences fall within the range of typical experience and have their origin in everyday psychological processes. Normalisation helps individuals to put their experiences into context and understand where they come from, and forms a key part of many psychotherapeutic approaches to voice-hearing, hallucinations and psychotic experiences more broadly.

Durham's research supports normalisation in multiple ways. First, it examines the nature and prevalence of hallucination-like experiences in the general population (between 5% and 15% of adults), and the fact that some people hear voices without being distressed by them. Our empirical work frequently explores the incidence and characteristics of voicehearing in the general population [R1], and has included research with a rarely-studied population of frequent voice-hearers who do not seek clinical help [R2]. Second, it attempts to understand connections between typical and unusual experience by looking at how they share roots in universal psychological processes, such as inner speech, memory and sensory perception. For example, we conducted the first neuroimaging study of the dialogic (or conversational) qualities of ordinary inner speech and their implications for AVH [R3], and we have shown how certain kinds of memory skills – namely, those that allow us to track real versus imagined events – relate to brain morphology and hallucination-proneness in patients with schizophrenia [R4]. Third, our research has highlighted the diversity of hallucinated voices (which may vary in their vividness, personification, emotional content and personal meaning), and how they exist on a continuum or 'spectrum' with everyday experiences that are not commonly thought of as pathological (such as having an imaginary friend, attributing personalities to animals or objects, or experiencing embarrassing thoughts). This was demonstrated in the largest ever mixed-methods study of AVH [R5] - involving more than 150 voice-hearers – in which we showed that the experience of hearing voices has important connections to bodily sensations, feelings of presence and ordinary thought processes. The therapeutic implications of this heterogeneity, and our research into the cognitive processes linked to AVH, have underpinned the development of a cognitive behavioural therapy (CBT)

package for help with distressing voices. In line with our research, the approach contains normalising information that is sensitively tailored to the varied and specific needs of voice-hearers [R6].

3. References to the research

Outputs:

- R1. **Alderson-Day, B.**, McCarthy-Jones, S., Bedford, S., Collins, H., Dunne, H., Rooke, C., and **Fernyhough, C.** (2014). <u>Shot through with voices: Dissociation mediates the relationship between varieties of inner speech and auditory hallucination proneness</u>. *Consciousness and Cognition*, 27, 288-296, DOI: <u>10.1016/j.concog.2014.05.010</u> (JCR impact factor: 2.004; 43/87 Experimental Psychology; 49 citations on Google Scholar).
- R2. **Alderson-Day, B.**, Lima, C., Evans, S., Krishnan, S., Shanmugalingam, P., **Fernyhough**, **C.**, and Scott, S. (2017). <u>Distinct processing of ambiguous speech in people with non-clinical auditory verbal hallucinations</u>. *Brain*, 140, 2475-2489, DOI: 10.1093/brain/awx206 (JCR impact factor: 11.337; 13/271 Neurosciences; 39 citations on Google Scholar; Altmetric score: 298).
- R3. **Alderson-Day, B.**, Weis, S., McCarthy-Jones, S., Moseley, P., Smailes, D., and **Fernyhough, C.** (2016). <u>The brain's conversation with itself: Neural substrates of dialogic inner speech</u>. *Social Cognitive & Affective Neuroscience*, 11, 110-120, DOI: <u>10.1093/scan/nsv094</u> (JCR impact factor: 3.571; 13/77 Psychology; 57 citations on Google Scholar).
- R4. Garrison, J., **Fernyhough, C**., McCarthy-Jones, S., Haggard, M., the Australian Schizophrenia Research Bank and Simons, J. S. (2015). <u>Paracingulate sulcus morphology is associated with hallucinations in the human brain</u>. *Nature Communications*, 6, 8956, DOI: <u>10.1038/ncomms9956</u> (JCR impact factor: 12.121; 6/71 Multidisciplinary sciences; 30 citations on Google Scholar; Altmetric score: 289).
- R5. Woods, A., Jones, N., **Alderson-Day, B.**, Callard, F., and **Fernyhough, C.** (2015). Experiences of hearing voices: analysis of a novel phenomenological survey. *Lancet Psychiatry*, 2, 323-331, DOI: 10.1016/S2215-0366(15)00006-1 (JCR impact factor: 16.209; 3/155 Psychiatry; 141 citations on Google Scholar).
- R6. Smailes, D., **Alderson-Day, B., Fernyhough, C.**, McCarthy-Jones, S., and Dodgson, G. (2015). <u>Tailoring cognitive behavioural therapy to subtypes of voice-hearing</u>. *Frontiers in Psychology*, 6, 1933, DOI: <u>10.3389/fpsyg.2015.01933</u> (JCR impact factor: 2.067; 45/138 Psychology, Multidisciplinary; 31 citations on Google Scholar).
- **Fernyhough, C.**, Woods, A., Aleman, A., Bentall, R. P., Cook, C. H., Macnaughton, J., McCarthy-Jones, S., Ratcliffe, M. J., Saunders, C., Scott, S., Waugh, P., and Weis, S. 'Hearing the Voice.' GBP1,000,000, Wellcome Trust Strategic Award (grant number WT098455; 2012–2015). First award made to a Medical Humanities project in the competitive Strategic Award scheme.

Fernyhough, C., Woods, A., **Alderson-Day, B.**, Cook, C., Saunders, C., and Waugh, P. 'Hearing the Voice 2.' GBP2,900,000, Wellcome Trust Collaborative Award (grant number WT108720; 2015–2020). First award made to a Humanities and Social Sciences project under the new Collaborative Award scheme.

4. Details of the impact

The underpinning research has shaped a variety of activities aimed at normalising voice-hearing. It has informed the development of professional training packages, new resources for voice-hearers and clinical tools for mental health practitioners, as well as an ambitious programme of public engagement that includes arts-based initiatives and video game development (recognised by the AHRC Medical Humanities award for Best Research 2020). It has been widely disseminated through local, national and international media, including radio, television documentaries (e.g., BBC2's *Horizon*), online articles and print journalism [E1]. Beneficiaries of the research include (1) clinicians and mental health practitioners; (2) voice-hearers, their families and carers; and (3) members of the general public.

An innovative new digital **cognitive behavioural therapy (CBT) manual** for distressing auditory hallucinations, Managing Unusual Sensory Experiences (MUSE), has been developed in collaboration with clinicians from the Cumbria, Northumberland, Tyne and Wear

NHS Foundation Trust (CNTW). Accessed on a smart tablet, MUSE draws directly on HtV research into the links between voices, inner speech, memory and ordinary perceptual processing [R1–3, R5–6] in order to provide tailored therapy for different sub-types of AVH. Feedback from NHS staff indicates that the manual has improved the clinical treatment of psychosis in Early Intervention in Psychosis services across the North-East and Cumbria in multiple ways [E2, E3]. Current reports from the Tyne, Esk and Wear Valleys (TEWV) and CNTW NHS Foundation Trusts estimate that approximately 50 NHS mental health staff, working in an area that stretches from York to Berwick-upon-Tweed and westwards to Whitehaven, have used MUSE in the clinical treatment of over 300 patients per year with symptoms of psychosis [E2, E3]. All clinicians who trialled the use of MUSE in the treatment of 22 patients in At Risk Mental State (ARMS) for psychosis said they would recommend the use of MUSE to another therapist working with people with distressing voice-hearing experiences [E3]. Many have reported that it allows for more structure in sessions, that it helps to engage clients, and that the innovative use of technology provided by the tablet (for example, the embedded videos, weblinks and interactive exercises) enables them to explain complex theories about how the mind works in easily understandable, accessible ways. One clinician described MUSE as 'a really good clinical tool' which 'helped my development as a therapist'. Another remarked: 'It's affected all of my practice ... it's improved my knowledge, it's improved my confidence and ... I think patients get a lot of out of the way [voice-hearing is] represented' [E3]. Feedback from patients has been equally positive, with many reporting that psychoeducational materials were easier to grasp when presented through the digital manual than in a normal course of CBT ('... it was better than just talking') [E3]. A feasibility study involving 24 voice-hearers completed in 2018 also demonstrated significant reductions in distress linked to voice-hearing. In recognition of its impact on the clinical treatment of psychosis across the region. MUSE was awarded second place in the Digital Innovation in Health and Social Care category of the North-East and Cumbria's 2019 Bright Ideas in Health Awards.

Along with forming the basis for new clinical tools, Durham's research has been used to directly train mental health professionals in the normalisation of voice-hearing. Working with Voices (April to June 2016) was a four-day training course developed as part of a longstanding collaboration with the TEWV tertiary psychosis team designed to shape clinical practice, influence attitudes of clinicians and contribute to the professional development of NHS psychosis intervention staff. The course was co-produced and co-presented by people with lived experience, with numerous sessions informed by Fernyhough and Alderson-Day's research into the heterogeneity of voices and their cognitive and neural bases. Over 70 psychiatrists, clinical psychologists, mental health nurses, social workers and trainees from the North-East of England attended the training. For a session led by Alderson-Day (which explored the challenges for assessment posed by the heterogeneity of voice-hearing), 81% indicated that it had improved their understanding of how to assess voices, with many reporting that the session was 'very' or 'extremely useful' because of its focus on finding 'measures to use in therapy [that] accurately reflect the service user's experience' [E4]. 96% of participants said that the series of sessions outlining therapeutic strategies for dealing with different sub-types of voices (which drew heavily on R1, R2, R5 and R6 above) improved their knowledge of how to work with people experiencing distressing voices [E4]. Two additional half-day training courses produced in collaboration with Rachel Waddingham (voice-hearer, Chair of the English Hearing Voices Network), which were informed by Fernyhough and Alderson-Day's research on the links between hearing voices and ordinary cognitive processes and the nature and prevalence of hallucination-like experiences in the general population, took place in Glasgow and London (28 February and 3 March 2020). Over 130 voice-hearers and mental health professionals attended these courses, with many practitioners reporting that the training would influence their clinical practice, providing them with new resources to use with clients in order to normalise voice-hearing and reduce selfstigma [E5].

A second key strand of our work on normalisation has involved making our research and knowledge about voice-hearing freely available, nationally and internationally, to voice-hearers, their families and carers. Psychoeducation materials based on the underpinning research [R1–5] have been collated and presented in *Understanding Voices* (UV), a new

web resource developed in partnership with voice-hearers, representatives from leading NHS trusts and mental health charities. The website, which extends to over 100 pages and was launched to an audience of 200 voice-hearers, family members and health professionals in Newcastle-upon-Tyne in September 2019, draws together information about the therapeutic management of distressing voices and resources exploring the cognitive and neural mechanisms underlying AVH, alongside historical, literary and spiritual approaches to the topic. UV makes accessible to a lay audience Fernyhough and Alderson-Day's research into the varied natures of AVH and everyday inner experience, the links between hearing voices and ordinary cognitive processes, and the nature and prevalence of hallucination-like experiences in the general population. It thus helps to challenge the commonly held misconception that AVH is in itself a symptom of severe mental illness and poor prognosis, thereby contributing to a reduction in stigma (and in many cases, self-stigma) associated with the experience. In the first full year of its use, UV has been visited by more than 13,300 unique visitors from the UK, US, Australia and Canada, and more than 1,535 unique visitors from European countries. Overall, the website has had over 16,500 unique users from 140 different countries in all of the continents excluding Antarctica, for a total of 23,763 sessions. The 'Quick Read' PDFs summarising core parts of the site have been downloaded over 2,500 times [E6]. UV is also recommended as a resource for further information on hearing voices by the Rethink and Mind charity websites.

UV is having significant impacts on clinical and voice-hearing communities. In February to March 2020, 50 mental health professionals were recruited to take part in a longitudinal evaluation aimed at assessing its effect on therapeutic practice over a 3-month period. Despite disruption from the Covid-19 pandemic, 26 practitioners completed an online survey probing their initial reactions to the site, in addition to a follow-up questionnaire 12 weeks later. Of these, 92% reported that UV enhanced their clinical practice by improving their knowledge and confidence in working with people who hear voices, helping with psychoeducation and normalisation, increasing empathy with voice-hearers, and providing practical resources to share with clients [E6]. One clinician remarked, 'I always leave the website feeling a little more competent, a little more confident that I've learned something new'. Another said that UV 'will now always be my "go to" for info re voice-hearing. I like that I can recommend [it] to my patients and I know the website will be normalising and not stigmatising for them.' Voice-hearers and their families also reported that UV improved both their understanding of hearing voices and their quality of life by improving the way they live with these experiences [E6]. In a survey of 84 website visitors, 92% of respondents said that, after using UV, they had more positive ways of understanding and interpreting voices, with many voice-hearers remarking that the normalising information on the site improved selfunderstanding and self-esteem, and reduced self-stigma: 'I believed something must be 'wrong' with me for hearing voices... The UV workshop and website gave me more confidence and understanding not only of my own experiences, but also others' [E6]. 90% of visitors reported that the website yielded better knowledge about sources of support, with 83% saying that UV provided them with more coping strategies and practical tips for dealing with different kinds of distressing AVH on a day-to-day basis.

Our underpinning research is additionally serving to improve public understanding of hearing voices locally, nationally and internationally, in two key ways. First, *Hearing Voices: Suffering, inspiration and the everyday*, the first major exhibition on voice-hearing, was installed in Durham's Palace Green Library from November 2016 to February 2017. Fernyhough and Alderson-Day made curatorial contributions to the exhibition and delivered public lectures, interactive workshops and podcast interviews. The underpinning research thus fed directly into gallery and virtual exhibits, which engaged approximately 6,000 visitors, and into the accompanying events programme in which 730 people participated. 27% of 105 surveyed visitors self-identified as having personal experience of voice-hearing and 46% had a professional interest in the topic. 92% rated the exhibition as either 'excellent' or 'good', and 86% reported that it had transformed their understanding of hearing voices, giving them more empathy with voice-hearers and challenging the idea that the experience is always symptomatic of pathology. The 'Everyday Voices' section of the exhibition, which profiled Fernyhough and Alderson-Day's research, was often cited by visitors as being particularly significant in changing attitudes because of its emphasis on the idea that voice-hearing exists

on the end of a continuum or 'spectrum' that includes everyday happenings such as vivid inner speech, day-dreaming and intrusive thoughts. (See E7 for more detail, esp. pp. 14–19.) Typical statements from visitors include: 'I am within the NHS and I think the idea of hearing voices not being pathological is very interesting. I will be looking into it further and in my interactions with patients in the future, maybe finding all sorts of explanations'; and 'I feel calmer about being the parent of a son who periodically hears voices. It seems more normal now.' [E7]

Second, Hellblade: Senua's Sacrifice is a video game developed by Cambridgebased game design company Ninja Theory (in collaboration with psychiatrist Prof Paul Fletcher), whose protagonist is a young woman with psychotic experiences. While initially developed as a game about psychosis generally, it quickly became apparent that the simulation of voice-hearing would be key to offering a sensitive and realistic portrayal of the topic. Through collaboration with Fernyhough, the game developers redesigned their approach to voices in the game, drawing heavily on the findings around the diversity of voicehearing experiences reported in reference R5, and other HtV research [E8]. Described by reviewers as a 'highly competent action game and a nuanced, powerful exploration of mental health', Hellblade has sold more than 1 million copies worldwide, has been awarded the Impact Award in the 2017 Game Awards, and won 5 Baftas in the 2018 Bafta Games Awards, including Best British Game and Game Beyond Entertainment [E9]. Reviewers in particular singled out the game's successful approach to voices: 'The game is unsettling in a unique way, a way defined by its incredible voice design... This is clearly one of the key components to the representation of psychosis in the game and it is executed with perfection' [E8]. A survey of Hellblade players conducted by HtV compared attitudes to voice-hearing in gamers before and after Hellblade was released. There was a significant increase in the number of respondents endorsing the item 'I consider myself to be knowledgeable about voice-hearing' after playing the game, compared to before the game's release. 62% of 161 players surveyed said that their attitude towards hearing voices changed as a result of playing the game, with many reporting that the depiction of voice-hearing facilitated a better understanding of (and empathy with) what it is like to hear voices, thereby contributing to improved public attitudes to psychosis more generally [E10]. Comments such as the following were typical: 'I have a family member who suffers from psychosis, and through the depiction of voice-hearing hallucinations in the game, I think I understand their daily struggle a little better.' Voice-hearers have also reported that the experience of playing Hellblade yielded new (and more positive) ways of understanding their own and others' voices, and made individuals feel less isolated, less stigmatised and better understood [E8]. Sample responses include: 'The game allowed me to understand myself, to understand my personal voices... [it] taught me to be stronger' [E8] and 'I've never known how to describe what happens in my mind... I showed [the game] to those I've been unable to be honest with and connected with the people I love. I've never been able to before' [E9]. In June 2018 it was announced that Ninja Theory was being acquired by Microsoft Studios, suggesting a major positive economic impact on the company.

5. Sources to corroborate the impact

- E1. Media coverage dossier
- E2. Testimonial from Guy Dodgson, Clinical Lead for EIP services, North-East and Cumbria (CNTW)
- E3. Raw data from ARMS-MUSE trial interviews
- E4. Raw feedback data from clinicians and mental health professionals who attended 'Working with Voices' training.
- E5. Raw feedback from attendees at 'Knowledge is Power' training (Glasgow & London, February & March 2020)
- E6. Evaluation report: *Understanding Voices* by V. Patton.
- E7. Evaluation Report: *Hearing Voices: suffering, inspiration and the everyday* by V. Patton and A. Woods with contributions from E. Hamlett.
- E8. Hellblade: Senua's Sacrifice evidence dossier.
- E9. Hellblade PR Report, produced by Ninja Theory.
- E10. Hellblade: Draft qualitative results and data table, produced by R. Lee.