Hearing the Voice

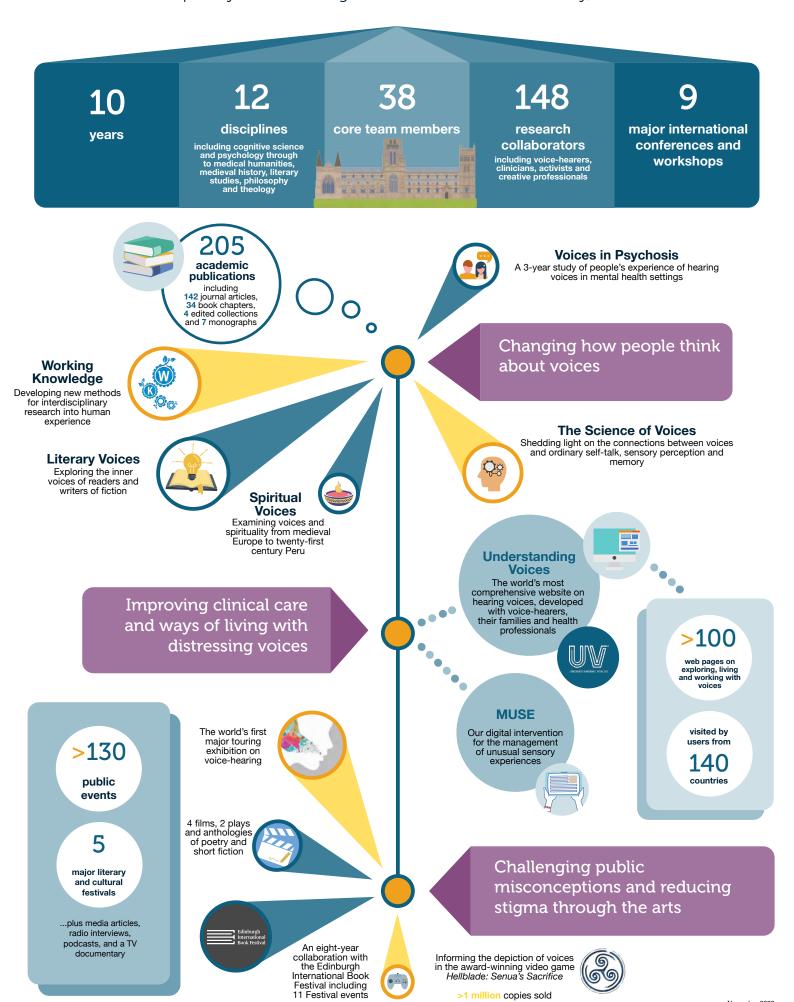
Interdisciplinary voice-hearing research

2012-2022



Hearing the Voice

Interdisciplinary voice-hearing research at Durham University, 2012-2022



"We have been enormously privileged to listen to, learn from and collaborate with people who hear voices throughout Hearing the Voice.

Early conversations with Jacqui Dillon, Marius
Romme and Sandra Escher at Durham's
Institute of Advanced Study led to ten years
of engagement at World Hearing Voices
Congresses in Cardiff, Thessaloniki, Madrid,
Boston, The Hague and Montreal. Throughout
this time, we partnered on pioneering initiatives
with Intervoice, the English Hearing Voices
Network, Voice Collective and voice-hearing
communities within Durham and across the UK.
We hope Hearing the Voice has made a positive
contribution to people's lives as well as to our
wider understanding of hearing voices, and that
it can inspire future projects and collaborations."

Professor Charles Fernyhough (Principal Investigator) and Professor Angela Woods (Co-director)

Up to 1 in 10 people hear voices that others don't. These experiences can be highly stigmatised, rarely talked about, and often hidden from public view.

Yet it is now increasingly recognised that voice-hearing is not a mere symptom of pathology but an important aspect of many people's lives. It can be distressing and upsetting, but also positive and meaningful.

Based at Durham University, <u>Hearing the Voice</u> was an interdisciplinary research project that set out to shed light on this phenomenon. It brought academics from anthropology, cognitive neuroscience, history, linguistics, philosophy, English studies, medical humanities, theology and psychology together with clinicians, artists, activists and experts by experience in order to improve the way people understand, clinically treat, and live with experiences of hearing voices.

The project was generously funded by the Wellcome Trust from 2012 to 2022.

Here we present a selection of some of the project's most significant findings. More information about our research including a full list of publications can be found at:

hearingthevoice.org



Hearing voices isn't just about hearing things

Public perception is that hearing voices is always a symptom of severe mental illness such as schizophrenia and psychosis, and that the voices people hear are loud, commanding and dangerous. But this is a myth.

"I did not hear the voices aurally. They were much more intimate than that, and inescapable..."

Anonymous

In collaboration with the Lived Experience Research Network, we conducted the largest ever study to strip away these assumptions and ask people to describe what it is like to hear voices in their own words.

We confirmed that people hear many different kinds of voices (some with their own distinct personalities) and that despite associations with negative emotions like fear and anxiety, some people also hear positive and supportive voices.

While many people told us that their voices were similar to hearing somebody talking in the same room, we found that hearing voices is not just a matter of hearing sounds. Lots of people experience 'thought-like' or 'silent' voices that don't sound like people talking out loud. Some people see, smell and feel their voices in particular parts of the body. Voices can also be accompanied by other bodily sensations, like feeling hot or tingling in the hands and feet.

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(4): 323-331.

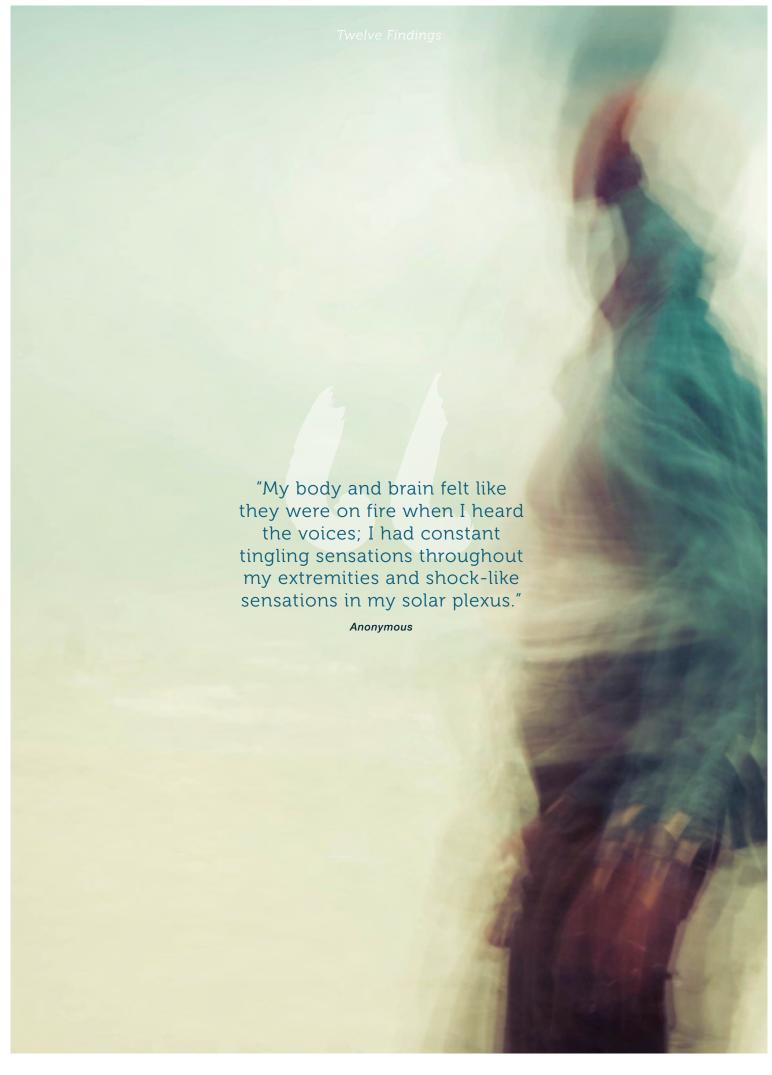
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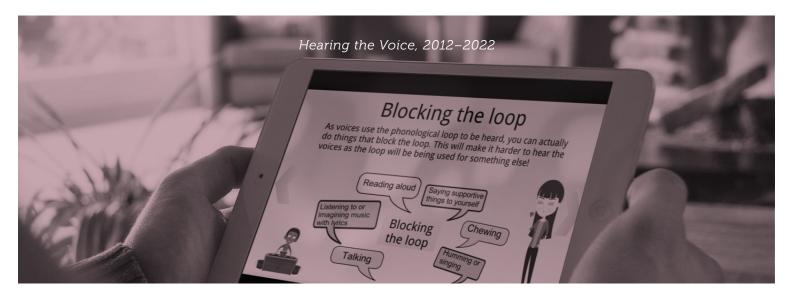
40% of voices have complex personalities

Our study of voice-hearing in mental health service-users in the North-East of England showed that many people experience voices that are personified – experienced as if they were characters or people with their own distinctive personality traits, life histories, beliefs and intentions.

These kinds of voices can happen quite early on, even before someone first begins to seek clinical help.

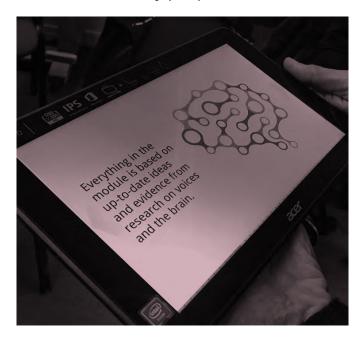
Voices with complex personalities and characteristics aren't always commanding or related to past trauma, but mainly provide company and a source of conversation.





Cognitive behavioural therapy can be tailored to different types of voices

Psychologists have lots of different theories about why people hear voices.



Cumbria, Northumberland, Tyne and Wear Some voices seem to be linked to inner speech – the inner voice that accompanies thinking, as when you say to yourself 'Remember to buy coffee' while heading out for work in the morning. One dominant theory says that voice-hearing experiences arise when someone mistakenly attributes an episode of inner speech – i.e. one of their own thoughts – to an external source. Other voices seem to require different explanations. For example, it is plausible that some voices are best understood as having their roots in memory, often memories of early trauma. Voices can also be related to 'hypervigilance' – being in an elevated state of arousal or threat detection that may lead you to perceive whispers or abusive remarks in environmental noise.

In collaboration with clinicians from the Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust, we developed a novel form of cognitive behavioural therapy that specifically targets these different types of voices.

The therapy – known as Managing Unusual Sensory Experiences (MUSE) – is delivered by a clinician using a tablet device and has now been used in the treatment of over 300 patients in mental health services in the North of England.

Early trials have had positive outcomes, resulting in reduced distress, severity and frequency of voices, as well as improvements in how people cope. On common scales for measuring hallucinations, patients reported a 29% general reduction in voice-hearing experiences, rating them as 21% less severe, 22% less frequent and 37% less distressing after treatment with MUSE.

Dodgson, G., Alderson-Day, B., Smailes, D., Ryles, F., Mayer, C., Glen-Davison, J., Mitrenga, K. and Fernyhough, C. (2020). <u>Tailoring cognitive behavioural therapy to subtypes of voice-hearing using a novel tabletised manual: a feasibility study.</u> <u>Behavioural and Cognitive Psychotherapy</u> 49(3): 287-301.

Dodgson, G., Aynsworth, C., Mitrenga, K.J., Gibbs, C., Patton, V., Fernyhough, C., Dudley, R., Ewels, C., Leach, L., Alderson-Day, B. and Common, S. (2021), Managing unusual sensory experiences: A feasibility trial in an At Risk Mental States for psychosis group. Psychology and Psychotherapy: Theory, Research and Practice, 94: 481-503.

Voice-hearers are better at detecting hidden speech in unusual sounds

We asked people who regularly hear voices and do not have a mental health problem to listen to a set of disguised speech sounds known as sine-wave speech while they were having an MRI brain scan.

Sine-wave speech is often described as sounding a bit like birdsong or alien-like noises. However, after training people can understand the simple sentences hidden underneath (such as 'The boy ran down the path' or 'The clown had a funny face').

Usually these sentences can only be understood once people have been told to listen out for speech or have been trained to decode the disguised sounds.

In our experiment, many of the voice-hearers recognised the hidden speech before being told it was there, and on average they tended to notice it earlier than other participants who had no history of hearing voices.

The voice-hearers' brains automatically responded to sounds that contained hidden speech compared to sounds that were meaningless, in the regions of the brain linked to attention and motoring skills.

These findings demonstrate what we can learn from people who hear voices that are not distressing or problematic. They suggest that the brains of people who hear voices are particularly tuned to meaning in sounds and show how unusual experiences might be influenced by people's individual perceptual and cognitive processes.



Headphones Flckr user: David Wood



The Baptism of Christ (c. 1622–1623) Guido Reni, Public domain, via Wikimedia Commons

Spiritual voices require careful discernment

Hearing the Voice researchers studied spiritual or religious voices in a variety of contexts, ranging from medieval mysticism through to 21st century mediumship and ayahuasca rituals.

In one of our research strands, we looked at voice-hearing in the Christian tradition and contemporary religious experience. We found that it can be both positive and life-enriching but that it is regularly misunderstood by both mental health professionals and members of faith communities.

On the one hand, meaningful spiritual experiences are often dismissed, wrongly pathologized, and viewed as a symptom of mental illness. On the other, some kinds of voices – e.g. demonic voices – which have historically been regarded as evidence of holiness can be attributed to malevolent spirits by congregations when mental health support is more appropriate.

Spiritual or religious voices and voices that occur within the context of psychosis are not mutually exclusive. Discerning whether a voice comes from God, an angel or something else can take time and spiritual counsel. It requires collaboration between faith leaders and mental health professionals, an affirming approach to spirituality, and an openness within clinical services to the idea that voices can be meaningful, life-enriching experiences.

Cook, Christopher C.H. (2020). Christians Hearing Voices. Jessica Kingsley.

Cook, Christopher C.H. (2018). Hearing Voices, Demonic and Divine: Scientific and Theological Perspectives. London: Routledge.

Powell, Hilary, & Saunders, Corinne (2021). <u>Visions and Voice-Hearing in Medieval and Early Modern Contexts</u>. Palgrave Studies in Literature, Science and Medicine. Palgrave Macmillan.



Spiritual voices often start early in life and involve more than one of the senses

Spiritualism is a religious movement based on the idea that human souls continue to exist after death and communicate with the living through a medium or psychic.



Mediums who "hear" spirits are said to be experiencing clairaudient communications, rather than clairvoyant ("seeing") or clairsentient ("feeling" or "sensing") communications.

We asked members of spiritualist communities across the UK about their experiences of clairaudient communication and compared them with the voice-hearing experiences of people with a diagnosis of psychosis. We found that spiritualists tended to report more 'thought-like' or soundless voices and more voices that were accompanied by other sensory experiences – for example, visual imagery or 'seeing in the mind's eye', as well as tactile sensations and unusual tastes.

Spiritualists were also more likely than mental health service users to hear voices that were positive rather than abusive, violent or commanding, and which they could control.

Many reported having unusual auditory experiences that started spontaneously early in life (often before their exposure to spiritualist beliefs and practices), which they then developed the ability to elicit or influence. They cultivated spirit communication and viewed voice-hearing and clairaudience as a special gift or skill that can be improved with practice.

These findings are important because they can help us understand distressing or non-controllable experiences of hearing voices, and how to support those whose voices occur alongside psychosis or other mental health problems.

The Fox sisters played a key role in the creation of Spiritualism.

From left to right: Margaretta, Kate and Leah
Lithograph after a daguerreotype by Appleby. Published by N.
Currier, New York. Public domain, via Wikimedia Commons

Some fictional characters really do speak for themselves

The idea that writers 'hear' the voices of their characters is a common one. Some even go as far as to claim that the characters in their narratives seem somehow to write themselves: that they, the writer, are a mere conduit for voices that appear to have lives all of their own.

But what does this actually mean? What is it like to hear the voice of a character when writing – a voice that's not intrusive or unpleasant, but which also somehow 'belongs' to someone else?

Dickens' Dream Robert William Buss, Public domain, via Wikimedia Commons

We collaborated with the Edinburgh International Book Festival on the first empirical study of this phenomenon. Nearly 200 Festival authors were asked about the way they experience their characters' voices, how some end up 'acting for themselves' and what role this plays in the creative process.

More than two thirds said that they could hear their characters' voices or had characters who acted independently. Many also reported they could see, feel, sense or have conversations with their creations.

Here are some of the things the writers said:

It is like I'm sort of writing in her head... just behind her eyes or something, or I'm up in her head so I can hear her voice...

Sometimes what I thought was a minor character appears and starts to speak and I realise they've become important and inserted themselves into the plot

They do have a separate existence from me [...] It's akin to the feeling of your baby kicking; they are a part of you and yet quite literally not a part of you and something 'other' at the same time.

Sometimes people think there is a link between creativity and madness. However, these findings do not tell us anything about the mental health of writers and are more important for shedding light on the writing process than anything else. Even when the characters had a life of their own and were entirely independent, it was very clear that the writers did not believe that their characters were actually real. And when they were rated on scales of hallucination-proneness – how likely they were to experience hearing voices or seeing visions – the writers did not score differently from other groups of people.

Find out more about what we discovered, explanations for what might be going on, and creative writing exercises based on the research at the project website:

writersinnervoices.org



Around 1 in 7 people hear voices while reading fiction

Systematic studies of experiences of reading are few and far between. As part of our collaboration with the Edinburgh International Book Festival and *The Guardian*, we set out to investigate how readers hear (or don't hear) the voices of characters when they read.

Over 1500 people participated in the study online.

1 in 7 said they had vivid auditory experiences of hearing voices while reading, just like hearing someone speaking in the same room.

A significant number also reported what we call 'experiential crossings' – experiences of characters being present outside the context of reading, often involving more than one of the senses (e.g. vision and touch, as well as hearing).

Sometimes this was described almost as an echo of prior reading experiences, with auditory imagery re-emerging in a particular context or scenario. In other accounts it appeared to shape the readers' style and manner of thinking – as if they themselves had been changed by a character.

For instance, readers reported that the way in which characters talked in a novel started to influence their way of thinking or talking; or that characters have become voices narrating or commenting on their lives:

If I read a book written in first person, my everyday thoughts are often influenced by the style, tone and vocabulary of the written work. It's as if the character has started to narrate my world.

What's your experience of characters' voices when reading? Do you ever hear, see or have other sensory experiences of characters in fiction?



Alderson-Day, B., Bernini, M. & Fernyhough, C. (2017). <u>Uncharted features and dynamics of reading: Voices, characters, and crossing of experiences</u>. *Consciousness and Cognition* 49: 98-109.

Interdisciplinary approaches yield new understandings of voices in literary texts

Our interdisciplinary approach has shed light on the representation of voices and voice-hearing in the work of many great writers in different historical periods, including Margery Kempe, Virginia Woolf, Charles Dickens, Samuel Beckett and Muriel Spark.

For example, literary scholars have long been divided on how to interpret the mysterious voices buzzing, murmuring or whispering within the heads of Samuel Beckett's characters. Some have proposed that they are 'unnatural' and cannot be traced back to any human experience. Others have argued that they are a fictional representation of the auditory verbal hallucinations many people associate with schizophrenia and

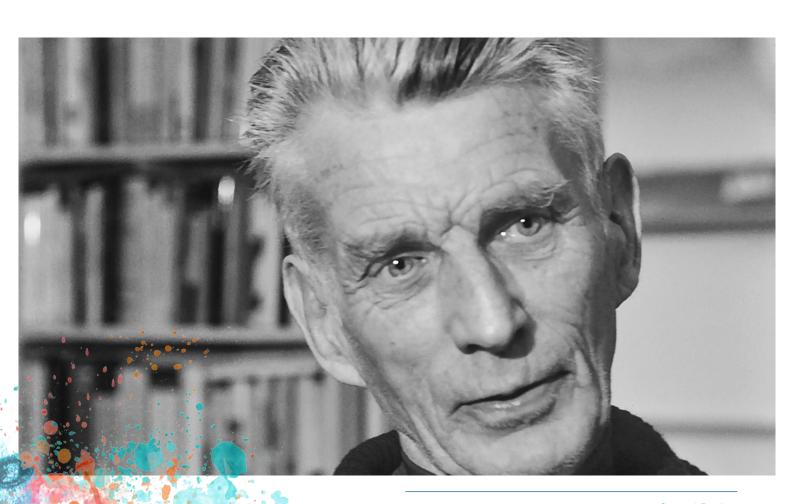
psychosis. Drawing on insights from cognitive psychology, we argued that these voices are best understood as inner speech – the activity of silently talking to, with and within oneself – only 'detuned' and 'de-familiarised' in a way that invites us to explore its functioning within human cognition.

To find out more, download *Literary Voices* – a booklet exploring the inner voices of writers and readers from the medieval period to the present day.

Literary Voices



Bernini, M (2021). Beckett and the Cognitive Method: Mind, Models and Exploratory Narratives. Oxford University Press.





Documentary film 'In the Real' (dir Conor McMormack, 2015; produced by Hearing the Voice) provides powerful examples of alternatives to the Recovery Narrative.

We need alternatives to 'The Recovery Narrative'

Mainstream mental health services, charities and public awareness campaigns are dominated by recovery narratives – stories that depict an individual's positive journey from mental ill health and trauma through to acceptance and recovery as a means of inspiring hope in others.

We examined the Recovery Narrative as a genre and argued that this style of story doesn't speak to all kinds of human experience. The genre limits what is an acceptable narrative of recovery to those that are positive and devalues stories of ambiguity and complexity. The benefits for the storyteller don't always outweigh the potential harms, as the organisations that commission Recovery Narrative downplay the emotional labour involved in telling stories of recovery and the negative consequences of sharing them in the public domain.

The Recovery Narrative often gets used by politicians and policy makers to support their own aims. It makes recovery about returning to work, wages and productivity, rather than making us think about the social, cultural and political factors affecting people's health and causing distress.

We called for more alternatives to the Recovery Narrative and more attention to the spaces and formats through which different aspects of madness, uncertainty and ambivalence can be expressed and embraced.

This work also informs our co-authored online e-learning module for the Royal College of Psychiatrists "Recovery Narrative in Clinical Practice" (available in 2023).

Collaboration requires a creative approach

The use of arts-based and other creative and experimental techniques has helped our researchers understand each other's disciplinary perspectives and ways of thinking. It has created safe and inclusive spaces in which academics, clinicians, activists, people with lived experience and anyone with an interest in voice-hearing can come together to share ideas and experiences and explore new directions for research and real-world change. Creative approaches have also helped with collaborative decision making and project planning across a full decade of research.



(Above and below) Our '<u>Listen Up!</u>' arts roadshow empowered young people from the North of England to express their experiences of hearing voices and produce stigma-busting artworks.

Photography by Andrew Cattermole, 2016.



Twelve Findings





(Above) Our <u>creative facilitator</u>, Mary Robson, welcomes voice-hearers, their families and mental health professionals to the Understanding Voices website prototype testing workshop (March 2019)

(Above and below – top) In a series of interactive and playful workshops at the 2018 Edinburgh International Book Festival, participants were invited to produce maps of their experience of reading a particular book or depicting the story-world of a possible creative writing project. Some of the maps were highly detailed, reflecting deep engagement with the workshop's themes.













(Above – bottom) Creative and experimental approaches were used across Hearing the Voice to support project planning, engage public audiences, and facilitate 'Voice Club' – fortnightly meetings of the research team.

We've made a difference to people's lives

Through working in partnership with voice-hearers, their families and mental health professionals, we've changed public attitudes to voice-hearing, enhanced clinical practice and improved the health and well-being of those who find their voices distressing.

Highlights from our extensive programme of activity include...



Understanding Voices (UV)

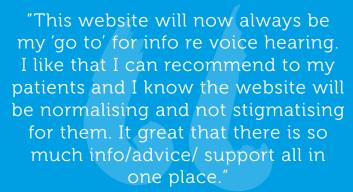
The world's most comprehensive website on hearing voices (understandingvoices.com). Developed in collaboration with over 200 members of the voice-hearing and clinical community, the website contains accessible information and personal stories, including coping strategies and how to find support.

The Understanding Voices website

understandingvoices.com











"I believed something must be 'wrong' with me for hearing voices. UV gave me more confidence and understanding not only of my own experiences, but also others..."

Voice-hearer





This exhibition has given me hope for my future.

Voice-hearer

I was pleasantly surprised to learn that there are famous writers that were voice-hearers and that their creativity and work was partly due to the voices that they heard. When I shared this information to our hearing voices group they were just as amazed as I was. Virginia Woolf and Charles Dickens: both literary artists, both voice-hearers!

Exhibition visitor



An exhibition visitor examining a soft restraint shirt from the West Riding Pauper Lunatic Asylum (November 2016) Photography by Andrew Cattermole, 2016

Hearing Voices: Suffering, inspiration and the everyday

The world's first and largest exhibition to explore voice-hearing from personal, scientific, literary, historical, political and spiritual perspectives.

Hearing Voices challenged myths and misconceptions about this hidden and highly stigmatised experience for national and international audiences through online and gallery exhibits in Durham, Edinburgh, Boston, The Hague and Montreal.

The exhibition had a powerful message: Hearing voices is not always a symptom of mental illness and poor prognosis but a rich and complex aspect of human experience.

hearingvoicesdu.org





The 'Everyday Voices' section of the exhibition installed at Palace Green Library, Durham (November 2016–February 2017) Photography by Andrew Cattermole, 2016



"A woven tapestry of stories...
It will educate many viewers'
ideas on what it means to hear
voices, dispelling notions of
shame, opening dialogue,
and empowering progress."

The Quinntessential Review

Dialogues from Babel

A research-inspired stage play bringing the experiences of voice-hearers from the North-East of England, described in their own words, into conversation with the experiences of writers from all over the world.

The play drew on our research with authors at the Edinburgh International Book Festival and forty interviews with mental health service users from Newcastle upon Tyne and surrounding areas. The service users were participants in a three-year study exploring how experiences of hearing voices change over time.

Theatre programme



Team (2012-2022)

Ben Alderson-Day (Associate Director)

Amanda Ellison

Marco Bernini John Foxwell
Felicity Callard Guido Furci
Christopher Cook Peter Garratt
Felicity Deamer Jane Garrison
Guy Dodgson Pauline Harrison
Rebecca Doggwiler Åsa Jansson
David Dupuis Joel Kreuger

(Principal Investigator)

Becci Lee

Jane Macnaughton
Rachel Middleton
Kaja Mitrenga
Jamie Moffatt
Peter Moseley
David Naothine

Victoria Patton

Adam Powell

Matthew Ratcliffe
Mary Robson
Corinne Saunders
Sophie Scott
Patricia Waugh
Rai Waddingham
Sam Wilkinson
Angela Woods
(Co-Director)

Flavie Waters

Collaborators (2012-2022)

Gillian Allnutt Alison Brabban
Andre Aleman Matthew Broome
Paul Allen Luke Collins
Joanna Atkison Zsófia Demién

Joanna Atkison Zsófia Demjén Vaughan Bell Jacqui Dillon Richard Bentall Judith Ford

Lisa Blackman Russell Hurlburt

Renaud Jardri Elena Semino
Nev Jones Jon Simons
Kristinna Kompus Neil Thomas
Simone Kuhn Rachel Upthegrove

Frank Laroi
Eleanor Longden

Simon McCarthy-Jones

Looking for information and support?

Voice-hearing experiences are fairly common and not necessarily a cause for concern. If you find that these experiences continue to cause significant distress or interfere with your relationships or daily activities, you should seek the advice of your GP. Useful sources of information and support include:

Understanding Voices understanding voices.com

A 100+ page website providing evidence-based information and personal perspectives on different ways of understanding voices and supporting people who are struggling to cope.

Topics range from what voices are like and why they happen through to the pros and cons of medication, talking therapies and peer support. The website also contains techniques for managing distressing voices, information for families and friends, and sections on voices and trauma, creativity and spirituality.

Hearing Voices Network (HVN) hearing-voices.org

Offers information, support and understanding to people who hear voices and those who support them. HVN can help you find a peer support group in your area if you live in England. Groups may meet in person or online.

Voice Collective voicecollective.co.uk

A London-based organisation providing information and support for children and young people who hear, see or sense things that others don't. They also offer support for parents, carers and other family members.

Intervoice intervoiceonline.org

Website for the international Hearing Voices Movement, the largest international advocacy movement for people who hear voices and their allies.