

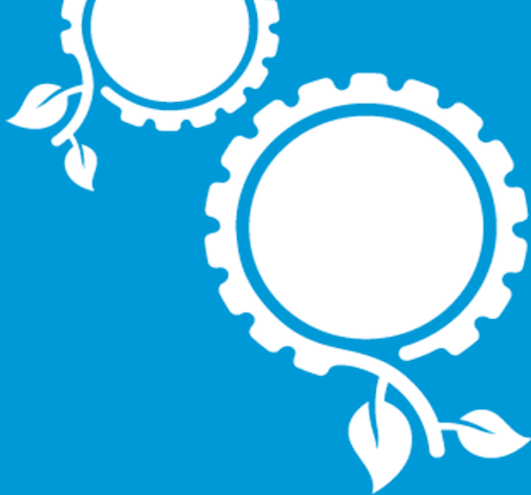


Working Knowledge

Engaging Others

Engaging Voice-Hearers

by
Hearing the Voice



'Engaging Voice-Hearers'
A Project Short by Angela Woods

First published by
Working Knowledge/Hearing the Voice
February 2015

Hearing the Voice
Durham University, UK

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www.workingknowledgeeps.com
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Engaging Voice-Hearers

Whatever the focus of your interdisciplinary research project, it is likely that you will be engaging with groups of people whose interests and needs differ, sometimes quite radically, from that of the traditional academic researcher (whoever that might be). In this Project Short, we look at the opportunities and pitfalls presented by engaging with these specific groups of stakeholders. We draw on the example of Hearing the Voice's experiences of working with a diverse group of people who share one thing in common: hearing a voice that no-one else can hear.

1. Voice-hearers: who are they?

The term 'voice-hearer' is not a medical, scientific or diagnostic label but a term which arose in the context of individuals describing their experience. As we understand and use it, the term 'voice-hearer' can mean one, some or all of the following:

- ◇ Voice-hearers are individuals just like everybody else. They are people who hear or have heard voices in all communities, from all backgrounds, at all stages and from all walks of life. Some voice-hearers are distressed by their experiences, others are not; some voice-hearers have never discussed their experiences, others have spoken or written about them extensively; some voice-hearers seek the support of mental health services, religious counsellors or spiritual healers, others do not.
- ◇ Voice-hearers can be individuals who are vulnerable. Many voice-hearers have experienced trauma (especially during childhood), have other unusual or distressing experiences, are users of mental health services, can be isolated from friends, family and community networks, and may suffer from profound stigma and self-stigma on account of the prejudice and misconceptions that still surround voice-hearing in most Western contexts.
- ◇ Voice-hearers can be people who self-identify as 'voice-hearers'. Some voice-hearers choose to embrace this term not as a diagnosis but as a positive identity that describes a key aspect of their experience and signals affiliation with a wider network of voice-hearers.

- ◇ Voice-hearers can be participants in and facilitators of hearing voices groups locally, nationally and internationally. The UK Hearing Voices Network, chaired by Jacqui Dillon, links over 190 hearing voices groups across the UK. Intervoice, the World Hearing Voices Movement, represents voice-hearers in 28 different countries and holds congresses annually across the world. The leaders of these groups seek to empower other voice-hearers, challenge stigma and discrimination, and improve access to care and support across a range of contexts.

What's been most important for us as a group of researchers is, very simply, listening to people. This requires bracketing our assumptions not just about what it is like to hear voices 'in general', but about what it is or has been like for this individual to hear voices within their particular life circumstances. A respect for people's experience further necessitates respect for the language they use to describe it – 'auditory verbal hallucination' may be the key term in clinical disciplines, but is regarded as offensive by some voice-hearers who believe it discredits the reality of their experience. By the same token, there are some who are uncomfortable with the term 'voice-hearer' because it doesn't adequately capture the full depth and complexity of what they are going or have been through. 'What terms are most meaningful to you?' is a simple (and for many researchers utterly disarming) way to start the conversation.

While Hearing the Voice engages with a wide range of individuals, we also respect that in certain contexts people are empowered by their communities to speak on behalf of other voice-hear-

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ers. Leaders in the Hearing Voices Movement have engaged in countless conversations with voice-hearers; their insights are often profoundly valuable as a consequence, and they can speak with an authority that reaches beyond the individual to the collective level. At the same time, we recognise that this authority can itself be contested by others within the movement, and may not

be definitive or absolute. Particularly through our project reference group and inclusive multi-platform communications policy, we make an active effort to reach a wide range of groups and individuals to ensure that the diversity of voice-hearing experiences, identities and activism is represented. For instance, in our 'What is it like to hear voices?' study, we went to considerable lengths to elicit participation in the questionnaire by individuals affiliated with a range of UK and international mental health advocacy organisations, as well as the general public.

2. Why engage?

There is a large and growing literature on the importance of ensuring that health research is not divorced from the people it most directly impacts. Mainstream medical research is now required to consider 'Public and Patient Involvement' across all phases of a research programme; organisations such as the Institute of Psychiatry, Psychology and Neuroscience's Service User Research Enterprise and the US-based Lived Experience Research Network champion survivor and service-user *led* research; and studies are conducted independently by a wide range of advocacy groups. Tokenism, marginalisation, inequality and exploitation are just some of the well-documented dangers that have been encountered in collaborations between 'experts by experience' and 'experts by profession'.

In Hearing the Voice, we have sought to engage with voice-hearers (including as members of our core and extended research teams) for four key reasons:

1. We seek out new conversations in order to listen to and learn from people's lived experience, and to have our ideas and disciplinary perspectives challenged and enriched.
2. We seek to collaborate with voice-hearers in the design and conduct of research, not only to recruit participants for a range of empirical and other studies.
3. We want to become allies in advocacy, working together to reduce stigma, encourage greater dialogue about the experience of voice-hearing, and address issues of social justice.

4. We want to ensure that our project is not simply interesting to, but directly benefits, voice-hearers.

As our work unfolds, we've come to appreciate that our goals as researchers are not always in alignment with the interests of voice-hearers, and that some of the things we value, such as specialist academic publications, are not considered as important as, say, practical interventions in the provision of mental health services. Identifying and reflecting upon these differences has been central to our learning on the project, not least in demonstrating to us that despite working in radically different disciplines, researchers will often have more in common with other researchers than with non-academics. (This applies to everything from the privileging of originality, to questions of salary and job security.) It is not always possible or desirable to pursue the same goals, it is important to recognise and respect where and why we might diverge, as we explain in more detail below.

3. An ethics of engagement

As in any research project, empirical studies conducted by Hearing the Voice must seek approval from relevant university ethics committees. But there are also occasions – for example, in some of our public engagement activities – for which no formal structures are in place. Our work across Hearing the Voice is underpinned by the following values and convictions:

- ◇ Our starting point is to approach voice-hearing as an experience, not a symptom or sign of underlying pathology
- ◇ We try not to make assumptions but rather listen to and respect people's individual experiences
- ◇ We try to recognise when people are speaking on behalf of others and the fact that they are empowered to do so
- ◇ We are looking for partners, not simply participants, in research and in encouraging wider dialogues about the experience of hearing voices
- ◇ As researchers, we reflect upon our own personal and political entanglements with, and commitments to, particular voice-hearers, groups, or issues

One thing that has become clearer to us the more we work with voice-hearers is that people are all too frequently subject to stigma – from employers and service-providers, as well as friends and family. There is no single or easy answer as to whether an individual should embrace a public identity as a voice-hearer, and as researchers we are certainly not in a position to make that decision on anyone's behalf. However, we are

conscious that, in an internet age of ubiquitous Google-ability, 'coming out' as a voice-hearer might have far-reaching consequences, negative as well as positive. These concerns inform the practical end of our ethics of engagement, where we are careful to ensure that explicit permission is sought from the person regarding how and in what contexts they are represented in relation to the project.

4. Engagement in action: Four case studies

2011: An activist fellowship

Professor Marius Romme and Dr Sandra Escher are pioneers and founders of the global Hearing Voices Movement and the Maastricht Approach to working with people who hear voices. Although they are not themselves experts by experience, they have transformed the lives of many voice-hearers as well as the way many clinicians now approach psychosis. Durham's Institute of Advanced Study (IAS) offered Marius and Sandra a three-month fellowship to join us in Durham in the lead-up to our application for Wellcome Trust funding for Hearing the Voice. This was in many ways a revelatory, as well as challenging, experience for us as researchers.

Following a public lecture which attracted over 350 people, Marius and Sandra ran a number of training programmes for clinicians working in the North-East as well as for people who hear voices. As participants in these sessions we gained new insight into what for us were wholly new ways of working with voices, and were able to develop relationships with clinicians and service-users that would lead to partnerships in the arts, in empirical studies and in the establishment of a regular Joint Special Interest in Psychosis group. With IAS and Wellcome Trust support, we also hosted the first major international interdisciplinary workshop on voice-hearing during their visit, which helped us further our connections and collaborations within the field.

But not everything was smooth sailing. Marius and Sandra have strong views about the nature, origin and meaning of voice-hearing experiences, and an equally strong scepticism towards many of the psychological and neuroscientific models we were proposing to investigate. These frank and occasionally heated discussions helped us to clarify our thinking around specific research questions as well as the overarching goals of the project, and gave us an insight into some of the politics and tensions that are specific to the Hearing Voices Movement in its critique of mainstream and biomedical approaches to hallucination. Many voice-hearers outright reject psychiatric and scientific frameworks for understanding voices and are highly critical of the provision of mental health services. So how could we take on board their experiences, evidence and view-points without alienating other academics, clinicians and voice-hearers with whom we were or wanted to be working?

Marius and Sandra's fellowship led directly to them co-editing with us a special issue of the journal Psychosis entitled 'Voices in a Positive Light' and to increased voice-hearer participation in the International Consortium on Hallucinations Research. They remain warm but critical friends of the project and in their capacity as members of our Advisory Board number among our most important interlocutors.

2012-13: 'Adam Plus One'

As part of our commitment to improving public understanding of voice-hearing and reducing mental health stigma and discrimination, Hearing the Voice produced 'Adam Plus One', a three-minute film about one individual's experience of psychosis and hearing voices.

We first met Adam after he had participated in a series of workshops run by Sandra Escher to support people who hear voices in telling their stories of recovery. Adam gave an incredibly brave and powerful presentation of his experience at a public event in 2011, and when the project was invited to participate in the Wellcome Trust funded Cinema and Psychosis film festival at the Barbican we immediately thought of him.

Adam worked with Mary Robson, our creative facilitator and an independent production team to make a three-minute film about his experience which premiered at The Barbican in March 2013 to an audience of over 200 people. It was subsequently shown in Lionel: The Spaceship of Our Imagination as part of the Wellcome Trust Wonder Season (April 2013); at the North-East Mental Health Day in Newcastle upon Tyne in October 2013, which was sponsored by the national Time to Change campaign; and in research presentations and clinical training sessions organised by Hearing the Voice. Adam's permission is sought every time the film is screened.

As a result of the film, Adam appeared on BBC Radio 4's Saturday Live in March 2013 to talk about his experiences with the interviewer Sian Williams. The broadcast was widely praised by listeners for its sensitive and sympathetic portrayal of voice-hearing and mental health issues.

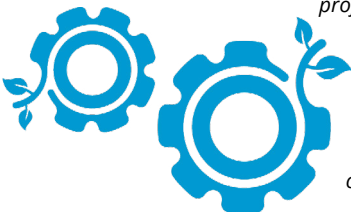
Hearing the Voice is now supporting the making of a further series of films featuring voice-hearers from diverse social groups and backgrounds, bearing in mind these key lessons from 'Adam Plus One':

Consider ethical issues. Especially when films deal with sensitive or controversial issues, consider whether the participants' anonymity needs to be protected and how this should be ensured. It is important that all parties understand when and in what contexts the film will be screened or made available. 'Adam Plus One' is not available online. We took inspiration and advice from Australian company Dadaa's Lost Generation project in drawing up agreements with the subjects of the films we make. We take the view that the rights of the film are the property of the subject and that they grant us permission to show the films in certain contexts.

Develop a dissemination strategy. Be selective about where the film is screened and formulate a dissemination strategy that maximizes impact and helps to get 'the message' across to the target audience.

Work with professional partners. Our film benefited from the expertise and understanding of a production crew who had previous experience of working with vulnerable individuals and could guarantee Adam's creative autonomy. They ensured that the final product was of a professional standard and that the subject matter was handled with sensitivity.

Build trust and co-create. Invest time and energy into building relationships, providing sources of support and involving the subject(s) of the film in each stage of the production process so that they feel a sense of 'ownership' over the final product.



2012-14: Building networks in the North-East

We invited Jacqui Dillon, the Chair of the Hearing Voices Network in England, to join the Hearing the Voice Advisory Board in 2011, and have worked closely with her to engage members of the voice-hearing community in the North-East through a series of events. These included a three-day Hearing Voices Group Facilitation and Network Development Training workshop delivered by Jacqui (February 2013); two HVN North-East Networking events (February & May 2013); and a series of interactive research showcases attended by 40–50 mental health professionals, group facilitators, mental health service-users and voice-hearers and their families and carers from Durham and surrounding areas (May 2013 & January 2014).

The knowledge exchange made possible by these events has been beneficial both to members of the voice-hearing community and to Hearing the Voice researchers. The facilitation training delivered by Jacqui resulted in the development of six much-needed Hearing Voices peer-support groups in the North-East of England at considerable benefit to local communities. The knowledge and contacts gleaned from the HVN Networking Events enabled the formulation of an interactive map of peer-support groups in the region, which is hosted on the Hearing the Voice website and helps to increase the availability of information about local sources of support for people who find their voices distressing. HVN networking meetings similarly enabled people to meet other voice-hearers and HVN members, share ideas and experiences, and discuss the ways in which support can be made more widely available for people who hear voices in the region. And the interactive research showcases provided an opportunity for academics to share the findings of their research with voice-hearers and their families and carers, and talk to them in informal groups about their needs, questions and concerns. The results of these conversations have, in turn, led to the establishment of the Hearing the Voice reference group, fed into the design of future collaborations and engagement activities, and also led to the identification of new issues and questions for research into voice-hearing and other unusual experiences.

These events have taught us the importance of:

Getting to know communities of interest early. Consultation with members of the voice-hearing community during the development phase of Hearing the Voice shaped the questions we ask as researchers, as well as the nature of the engagement activities and the formats that we use.

Using social media effectively. Peer support and advocacy groups are often active on social media. Online communication tools such as Twitter and blogs provide an effective means of advertising events, strengthening relationships and reaching these audiences.

Respecting alternative viewpoints. Voices often have important meanings for an individual and researchers learned to respect and acknowledge this even when the voice-hearer's interpretation of their experiences was in conflict with their own.

2014: Voice Walks at the Shuffle Festival

In summer 2014, Hearing the Voice was asked to take part in Mile End's Shuffle Festival, a community event held in the grounds of the former St Clement's hospital and asylum. Mary Robson, Creative Facilitator, describes what took place:

Voice Walks – a community festival event pioneered by activist, trainer and expert by experience Molly Carroll – are guided walks in which participants encounter voice-hearers and listen to their stories. When we were invited to curate Voice Walks for the 2014 Shuffle Festival, Hearing the Voice decided to give the event an 'anti-stigma' theme to emphasise the fact that voice-hearers are in charge of their tales and their experiences.

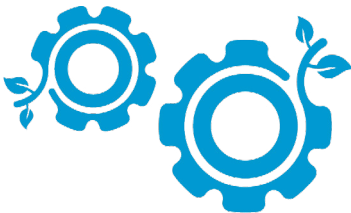
I made a reconnaissance trip to our venue – Tower Hamlets Cemetery Park – to plan our hour-long walks, guided by the Festival's Science Director, Grace Boyle. I was struck by how powerful it would be to hear voice-hearers freely declaim their stories in the shadow of St Clement's, the psychiatric institution where many voice-hearers would have been incarcerated in the past. We decided that the first encounter would be situated near the gate, with another four following close by, giving the walkers time for a reflective stroll back through the woodland.



The day before the event was spent writing placards that were placed at each encounter.

Some of the slogans came from the lived experience of the participants; all invited the audience to listen and potentially rethink their attitudes to voice hearers. During the second and final walk, the placards were picked up and carried along, so that by its last stage there was an impromptu march, with voice-hearers, festival-goers and researchers walking and talking together. People who came on the walk commented that 'It was overwhelming, fascinating and moving...'; 'Inspiring stuff – I will remember these stories...'

I spent the afternoon running an information table near the main entrance to the park, telling anyone who showed an interest about the project and the walks. One man told me about his nephew's experience of schizophrenia, and his friend revealed that he had been given a diagnosis in 2010 and was coping very well 'on the meds'. My early misgivings about voice-hearers being 'put on show' in some way were unfounded. This kind of event can help make the invisible visible, and encourage attitudinal change along the way. It also made apparent the serious attention Hearing the Voice pays to forging meaningful, two-way relationships with voice-hearers. Nothing made this more clear than when one of the voice-hearers, Rai Waddingham, posted the following on Twitter: 'Thanks to everyone taking part in the @ShuffleFestival Voice Walk. Finding our power in solidarity @hearingvoice'.



Working Knowledge is a collection of accessible and user-friendly resources dedicated to the practical ins and outs of interdisciplinary research.

Covering everything from managing a research project's social media presence to conducting experimental design 'hackathons', the series is a must-read for anyone considering funding or embarking on interdisciplinary research.

Series editors: *Charles Fernyhough, Angela Woods and Victoria Patton.*

