Inside an unquiet mind

Music and science join forces to explore mental ill health

Hanna M. Critchlow, Paul Herrington & Simon Gunton

Science is dramatic and scientific discoveries are almost always emotional journeys. The effect of scientific progress on societies and individuals can similarly be profound, especially where it improves lives by providing new treatments or by offering greater understanding of illness. The challenge is to communicate those improvements to the public in a way in which they are understandable, relevant and have a positive impact on the relationship between science and society. It is therefore important for scientists to engage with the public, both to explain the scientific point of view and to connect their research—often conducted in isolation—with the people it might help or affect. In doing so, both scientists and the public can address their preconceptions about one another.

In the context of mental health, science comes up relatively short in terms of ‘cures’, but our understanding of the function and malfunction of the brain is improving, as are treatments and therapies to improve the quality of life of those affected and those who care for them. Communicating the complex scientific ideas involved is challenging, and innovative ways of doing so are at the forefront of the public discourse.

In this vein, the UK charity Squeaky Gate (<http://www.squeakygate.org.uk/>) has been working with the University of Cambridge Research Strategic Initiative, Cambridge Neuroscience (<http://www.neuroscience.cam.ac.uk/>), since 2009 to provide an artistic platform through which to facilitate discussion between scientific researchers, healthcare workers and patient groups. Their productions have attracted diverse audiences, including those interested in the arts or science in general and, in the case of their 2011 production, *Inside an Unquiet Mind II* (IUQM II), mental health

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issues specifically. IUQM II was hosted at Pembroke College (Cambridge, UK) in 2011 as part of the public Brain Awareness Week (www.dana.org/brainweek/) and the Cambridge Science Festival (www.cambridgesciencefestival.org). It combined art and science to bring together a cast including those directly affected by mental ill health, those working in the mental healthcare setting and those undertaking neuroscientific research (Fig 1). Over 30 weeks, the group worked collectively to develop and produce a 45 min show—aiming to raise awareness and acceptance of mental ill health—that was performed on four occasions to public audiences.

The involvement of scientists with the production was integral to its success and their interaction with the end-users of mental health care seemed to have a positive impact on their approach to their research. “This project gave me an opportunity to see behind the scientific terms and realise that there are human beings suffering. It also gave me some extra motivation for my personal research—maybe one day what I’m discovering now will be helpful for patients,” commented one of the scientific cast members. More importantly, perhaps, it also brought into focus for some researchers their own preconceptions. “The experience taught me a lot about my own prejudices—which I am ashamed to admit—and sensitivities to public opinion, and helped me to understand some of the

difficulties involved in living with these debilitating conditions,” explained one scientist. This experience was shared by non-scientific members of the cast: “It was amazing to be able to witness somebody understanding something from a different point of view—for example, neuroscientists coming in with a fear of being around people with mental health issues—and watching them get rid of their fear while they were working with us and getting to know us as individuals,” commented one cast member. “The fact that neuroscientists and mental health professionals were prepared to come and hang out with us and work with us changed my perception of myself as a ‘service user’,” said another.

The science also added weight to the message that mental ill health, similarly to any other illness, has a biological basis

Theatre pieces were incorporated sequentially between the scientific presentations to keep the audience engaged and to increase interaction among the cast. By structuring the production to include the scientific presentations as part of the musical elements (Sidebar A), the science was interwoven with personal accounts of living with mental ill health to help explain the issues and to provide hope for future improvements in treatment. Audience feedback indicated that 85% of people had learnt something new about current scientific research into the brain and mind, and that 78% of people said that IUQM II changed their perception of people with mental health issues.

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Fig 1 | Participants involved in the *Inside an Unquiet Mind II* project. Fourteen service users and students, seven Cambridge neuroscientists (including senior lecturers, PhD students and postdoctoral researchers), five mental health service professionals (including consultant psychiatrists, psychiatric nurses, occupational therapists and support workers).

This was particularly important for one cast member with bipolar disorder, who said that the inclusion of science in the performance changed the perspective of one family member who came to see *IUQM II*. “[She] had seen me perform musically before, but not alongside scientists. This production had a different impact on her. She had never done any research on bipolar and didn’t really understand it. It’s really shifted our relationship and we get on a lot better. She now seems to understand that my illness is biological, that there is a reason and that it’s not my fault—I can’t just cure myself by doing something or acting in a different way.” A similar sentiment was expressed by another cast member, who felt that the science allowed the audience to ‘see’ that mental ill health is real. “[S]omething I feel very strongly about, was the impact of the scientific talks about brain scanning images, which illustrated

conclusively that disorders such as bipolar are physical disorders of the brain. I believe sufferers and the public alike struggle to understand, or even know, that mental disorders are caused by physical problems of the brain and are not just ‘in your head’.”

Despite the importance of the science to the production, however, an important aspect for developing the drama lay in the anonymity of group identity for each individual during the production process. That is to say, scientists, people experiencing mental ill health, clinicians and care workers were not defined as such. This was intended from the outset to enable the group to work together as equals. This method of interaction allowed barriers to be broken down and attempted to dissolve any misconceptions existing between the different groups. The same anonymity was also used during the event—the audience were not aware to which group each performer

belonged, allowing the preconceptions of the audience to be challenged. So although the science and the scientists contributed significantly to the piece, their role was not specifically as ‘scientists’, but as members of the cast along with everyone else. “*Inside an Unquiet Mind* provided a space whereby questions could be asked of each other and honestly answered. We were able to look far beyond the role of medication and science and began to explore ideas around wellbeing, society, new research and shared working that we all hope will lead to new performances and material,” commented one of the scientific cast members.

The performance itself was set in the day room of a psychiatric hospital. The production explored some of the experiences of living with mental ill health and outlined the scientific research being undertaken to try to develop more

efficacious treatments. All advertising and promotional material accompanying the event had been deliberately minimalistic to ensure that the audience would not know what to expect (Fig 2). On arrival, the audience were offered 'psychotic' cocktails (Sidebar B) served against a backdrop of genuine and bewildering scientific posters. Each poster was typically littered with the language of neuroscience, complete with detailed experimental protocols and scientific graphs. "I walked into the foyer and couldn't make any sense of the posters. After the gig I looked at the posters again, and understood them a bit better," commented one audience member. Although posters are important communication tools among researchers, for a general audience they present a baffling array of largely nonsensical words and images. This is a particularly important message for scientists trying to communicate their research, as one of the scientific cast members acknowledged: "Walking into this public engagement forum where our posters were on display emphasised this point. [...] This production made me realise that because neuroscience is increasingly interdisciplinary [...] it would make sense to apply the lessons learnt communicating research to the public to the design of posters that would be more accessible to scientists from other fields. By communicating more clearly we may then be able to form new collaborations across fields to the benefit of future research."

The audience were ushered into the theatre and the performance began with a television programme, *Neuroscience Today*, in which a news anchor reported on drastic cuts for funding for the neurosciences in the UK. The 'programme' was presented by Hannah Critchlow, Strategic Manager for Cambridge Neuroscience with a background in cell and molecular neuropsychiatry: "The main message that I tried to convey was how prevalent mental ill health is and that there is a continued requirement for funding into brain sciences [...] emphasising the disparity between funding for brain illnesses and other, less prevalent and less debilitating disorders [...] I then introduced leading psychiatrists and scientists who

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Sidebar A | Science and mental health in music

Inside an Unquiet Mind II featured four musical performances to communicate the experience of living with mental ill health, the science behind mental ill health, and the effects of the medications with which it is treated. The music also explored the prejudice and misunderstanding of mental ill health. Lyrics and musical scores were original and were written collaboratively in the workshops on the basis of personal experiences. Full lyrics can be accessed here:

http://www.squeakygate.org.uk/index.php?option=com_k2&view=item&id=166:inside-an-unquiet-mind-ii&Itemid=70

Largactil Shuffle

Largactil, also known as chlorpromazine, was the first notable antipsychotic drug to be introduced to psychiatry in the late 1950s. It is important to bear in mind that until chlorpromazine came along, hospitalized patients had to contend with locked doors, electroconvulsive therapy, insulin shock therapy and even surgery such as lobotomies to 'treat' their condition. Despite its obvious advantages, however, it was not without side effects or the risk of long-term damage. The *Largactil Shuffle* depicts two of the main side effects of the drug—a typical shuffling gait with an inability to lift one's feet, and the frustrating dampening of libido that robbed patients of their sexual identity.

Risperidone Rap

Risperidone is a newer breed of antipsychotic medication that the lyricist was taking as the latest in a very long line of prescription drugs to try and manage the 'highs' of her bipolar disorder. The lyrics depict the chaotic energy of being high, the lyricist's frustration with the mental health services over the past four decades, and, most poignantly, the lost life opportunities that result from a major long-term mental illness.

Send in the Gowns

This stylized representation of a psychiatric ward day room and the bonding and antagonistic interactions of patients was profoundly moving. The sparse musical representation focused powerful attention on the relationship between the two vocalists in wheelchairs. The lead performer commented: "I suffered from depression and was able to identify with the lyrics of *Send in the Gowns* very strongly. I drew on my previous experience to lend the performance the emotional depth the song deserved. The lyrics reflect the feelings and struggles of being mentally ill."

Neuroleprosy Blues

Neuroleprosy is a pun on neuroleptic (antipsychotic medication) and leprosy indicating social exclusion. The *Neuroleprosy Blues* looks at the wide range of side effects to early antipsychotic medication and how the general public often took these visible signs as representing the schizophrenic or psychotic illness itself.

highlighted their current research that aims to help improve treatment for those affected by mental ill health," she said.

The *Neuroscience Today* broadcast transitioned to filmed interviews with clinicians and research scientists, who explored historic accounts of understanding mental health and the current state of scientific research. To enhance the drama, the people from the videos then emerged from among the audience to continue their research presentations live on stage. These were introduced by Jesus Perez, lead consultant psychiatrist at the Cambridgeshire and Peterborough NHS Foundation Trust's CAMEO Early Intervention in Psychosis Service, UK (www.cameo.nhs.uk) and a research fellow at the Department of Psychiatry at the University of Cambridge, who commented: "My main message to the audience was to provide a sense of the progress in psychiatry over the last five centuries and therefore a message of hope for the service users. [...] I tried to reach everybody—mainly thinking of those who could have the least amount of knowledge in the audience and directing the presentation to these people. [I tried to be] empathetic,

playing with words and images, intending to embrace the audience with the unexpected and curious, while putting the unfamiliar in familiar terms."

Preparing presentations for non-scientific audiences proved to be a challenging exercise for the scientists involved. All realized through their interactions with other cast members that the amount and type of information that could be conveyed was limited. Even so, they wanted to explain the science behind the current understanding of the brain and its disorders. Belinda Lennox, a lecturer at the University of Cambridge's Department of Psychiatry and Honorary Consultant Psychiatrist at CAMEO gave a presentation on 'The many faces of bipolar'. Lennox's research focuses on using functional magnetic resonance imaging (fMRI) to demonstrate the state- and trait-related changes in neural activation associated with the different abnormal mood states of bipolar disorder. "I wanted to get across the very basic message that science is vital to advancing our understanding of mental illness and

Inside an Unquiet Mind II

Music and science join forces to explore issues surrounding mental health

18 & 19 March 2011 / 6.30pm / 8.00pm
New Cellars, Pembroke College, Cambridge
Tickets: £8 / £4 concessions

BOOK ONLINE AT: www.squeakygate.org.uk

Set in a day room of a psychiatric hospital, audience members are invited to join 'patients' for a powerful piece of musical theatre. Includes episodes of 'Neuroscientists Today' with special guests Drs. Jesus Perez, Graham Murray and Belinda Lennox and the world premiere of *A Kettle of Fish*, *The Peoples Project* and the Sarah Jane story.

Psychotic Cocktails will be served.

www.squeakygate.org.uk
Tel: 01223 361164

[...] I wanted to explain what psychosis is—finding it difficult to distinguish what is real and what isn't—and to convey to the audience a sense of the frequency of psychotic experiences in the population (about 10% of people have them), and the frequency of psychotic disorder (about 3%). I also wanted to explain how we can take a scientific approach to try to understand what might, at first, seem an inexplicable phenomenon," Murray explained.

The scientific presentations were interspersed with haunting videos depicting life for individuals diagnosed with psychiatric disorders. The video sequences included the world premiere of *A Kettle of Fish*—a film about bipolar disorder, shown directly before Lennox's presentation. "In making this film, I wanted the public to see the impact of bipolar on a person and to have a better understanding of it," explained the film's creator. "I met somebody a year or so ago and I mentioned my bipolar. He turned around and said: 'bipolar, wow, that's the rock and roll of mental illness'. I was shocked by his comment. I thought about how public perception has gone from one extreme to another. From a totally un-talked about, totally stigmatized illness to 'how cool are you'. I wanted to explain bipolar, how detrimental it can be, but also to explain that with a lot of support and effort the patterns can be managed, that you can find suitable medication and support."

Drown the Clown, a film about psychosis, was shown directly after Murray's presentation on his research investigating the biological basis of delusions and hallucinations.

These video sequences featured people with mental ill health to provide a personal counterpoint to the scientific presentations. "The videos made me better understand what and how some patients feel and why they often struggle to put their own thoughts and feelings into words," Perez explained, "These may have future implications in the way we develop research tools to evaluate psychiatric symptoms."

After the interval, the entire cast—scientists included—took to the stage for an energetic second half. The lively yet moving musical performances were showcased, taking the audience on an emotional journey through the highs and lows of life with a psychiatric disorder. The side effects associated with anti-psychotic drugs were portrayed in the *Largactil Shuffle*, the *Risperidone Rap* and the haunting *Send in*

Fig 2 | Poster advertising the *Inside an Unquiet Mind II* public event. The audience were placed in a state of anticipation on arrival, with advertising and promotional material kept deliberately minimalistic.

improving treatments. I wanted to demonstrate that stigma is based on ignorance and that neuroscience can directly challenge this," Lennox explained. "Having spent so much time giving research presentations to experts, I found the experience of presenting to the general public quite exposing, but also refreshing, to explain the work to a largely lay audience, and to share my enthusiasm for the neurosciences."

Graham Murray, an honorary consultant psychiatrist at CAMEO and Senior Clinical

Research Associate at the University of Cambridge's Department of Psychiatry and Behavioural and Clinical Neurosciences Institute, presented on 'Perception, delusions and paranoia'. His work uses fMRI, computational modelling, neuropsychology and pharmacological experiments to investigate the basis of psychiatric symptoms in the brain. "As opposed to a presentation to a scientific audience, where I would rely on the slides to guide my delivery, in this case I thought about and carefully chose in advance the phrasing

the Gowns (Sidebar A). The event concluded with an extensive question and answer session. All members of the cast—neuroscientists, mental health service users and mental health professionals—were available to answer the audience's questions.

This session forced the scientists to explore further the impact of their research and to question the role of neuroscience research in society. "An audience member asked if one day we could eradicate mental illness, as we have done with smallpox," commented one scientific cast member. "It wasn't a question I had ever thought of before. My first response was to say that while this was unlikely, given that mental disorders are so complex, we should try to be as ambitious as possible and this could be a long-term aim. A member of the Squeaky Gate cast asked whether, even if we could eradicate mental disorder, would we want to? This made me rethink the issue and realise that fluctuations in our mental states are key aspects of our humanity; the real goal should be to reduce the distress and suffering associated with mental illness."

The *IUQM II* project provided an artistic platform for cast members to creatively discuss mental health issues, work together as equals and learn from each other. The act of a shared performance took everyone out of his or her comfort zone and bonded the group in a collaborative, non-hierarchical working process. Cast members with mental health problems were empowered by the opportunity to present their own experiences to the audience and the scientists in the cast. "It helped to break down the 'them and us' distinction that can exist—for 'us' as service users and 'them' as scientists/clinicians—helping to convey the message that we are all, after all, just people," commented one cast member. "The scientists seemed quite normal, which was a bit unexpected and a bit of an eye-opener," echoed another.

The collaboration also provided research scientists with the opportunity to meet people with mental ill health, learn about their personal experiences and hear the perspectives of patients on an equal footing—that is, out of the clinic. It gave the scientists an opportunity to understand

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Sidebar B | Psychotic cocktails

Cocktails were available for the audience in the foyer of the theatre. Each cocktail represented an antipsychotic drug used in the treatment of psychosis.

Blue Respidone

An atypical antipsychotic used to treat schizophrenia (including adolescent schizophrenia), schizoaffective disorder, the mixed and manic states associated with bipolar disorder, and irritability in children with autism.

Ingredients: vodka, blue curacao, lemonade.

Orange Largactyl (chlorpromazine)

A typical antipsychotic now largely superseded by the newer atypical antipsychotics, which are usually better tolerated.

Ingredients: vodka, peach schnapps, orange juice, cranberry juice.

White Citalopram

An antidepressant drug used to treat major depression and prescribed off-label for some anxiety conditions.

Ingredients: cointreau, tequila, lime juice.

the implications of psychiatric medication, diagnosis and the stigma attached to mental ill health. Their research areas were made real by their involvement in the project, and they described it as a 'humbling' and 'inspiring' experience. They also found the challenge to explain their work to lay audiences rewarding and felt that the lessons learnt could be applied to future interdisciplinary communications.

"...even if we could eradicate mental disorder, would we want to?"

For the audience, the event directly addressed the stigma surrounding mental health issues by emphasizing the biological basis of psychiatric disorders; it explored the caveats and frustrations that exist with the current methods of diagnosis and the limitations of available treatments. "It was an incredibly powerful and moving production [...] It was impossible to separate the neuroscientists and the service users from the cast line-up; the way it should be. The heart-breaking story of stigma and social exclusion [...] made me realize what a desperate need there is for new knowledge about mental illness, and that advancing scientific knowledge is fundamental to improving clinical care," commented one audience member. Importantly, the event also highlighted to the public the requirement for continued funding

for the neurosciences in order to learn more about the brain and develop more efficacious therapies for the future.

The cast believe that the inclusive, collaborative approach taken on this project is a successful method for communicating science and exploring the impact of science on society and vice versa. They also hope that their efforts inspire others—perhaps the readers of this article—to engage in their own, similar projects. The scientists involved gained hugely in terms of putting their research in context, addressing their own preconceptions or prejudices and learning to communicate their science for non-scientific audiences. The Squeaky Gate/Cambridge Neuroscience partnership intends to take *IUQM II* forward by showing the performance to different audiences, including schools; by including the viewpoints of friends and family in the performance itself; and by conducting a robust, scientific study to investigate both the subjective and objective well-being effects offered by adjuvant therapies such as the Squeaky Gate Initiative.

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CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.

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