On the top floor of a waterside pub that was historically frequented by 18th Century sailors and smugglers, members of the public were invited to sit back, sip their pints of beer and learn about the science behind dementia. *International Innovation* caught up with the Maladies of the Mind speakers

In only its second year, the Pint of Science Festival successfully delivered playful, engaging and accessible scientific talks in pubs across the UK, Ireland, France, Italy, US, Spain, Germany, Brazil and Australia. On 18-20 May, science enthusiasts around the world attended sold-out events on topics including cigarettes and alcohol, climate change, parallel universes, robotics, and dreams and reality.

One such event, Maladies of the Mind, focused on the myriad, complex effects of dementia. Three speakers from varying science and art backgrounds offered their views on the science, psychology, R&D landscape and artistic interpretation of this chronic mental disorder. Between talks, the audience explored an interactive art installation, ‘I am still here’ – a maze of games demonstrating the challenges of dealing with the symptoms of dementia.

**DEMENTIA: WHAT IS OUT OF WHACK IN THE BRAIN?**

**Professor Andy Randall**

Andy Randall is Professor in Applied Neurophysiology at the Universities of Exeter and Bristol, UK. His current research focuses on neurophysiological changes that take place in the development of neurological diseases such as Alzheimer’s disease.

How has your academic career led to your focus on central nervous system neurophysiology in health and disease? What initially sparked your interest in this field?

I am a neurophysiologist, which means I spend my life measuring electricity in the brain. I graduated from the University of Bristol in the 1980s and then specialised in fundamental neurophysiology research. I currently lead two laboratories and focus on dementia research.

My interest in neurophysiology began while studying my undergraduate degree in biochemistry. This isn’t an obvious route into the field, but it created an interest in cell-signalling, which led me to complete my final year project in a neurophysiology lab. Here, I started doing patch-clamp recording (a type of neurophysiology), which had been developed in the 1980s and was quite new and exciting back then. I attached electrodes onto cells to record their electrical activity and, seeing this appear live before my eyes, became rapidly hooked. I’ve continued to be fascinated by watching how cells behave in real-time – to me it’s magical!

Are there any particular challenges faced with communicating dementia science to the public?

I find there are no particular challenges with talking specifically about dementia. The challenge with science communication, more generally speaking, is pitching it at the right level for the target audience. What’s great about Pint of Science is that the audience has some basic knowledge or interest in science.

**Age-related dementia is increasingly discussed in the media. Do you think it is accurately portrayed?**

It’s great that dementia is increasingly out there in the media, but there is some misreporting – and that’s from both academia and journalism. People love to use dementia as a ‘time bomb’ analogy, for example. But a dementia epidemic won’t simply blow up in our faces; we can see it coming, which gives us time to try to do something about it. I think it depends where in the media you are looking. What the *Independent* or *Guardian* would write is different to what the *Daily Express* would write, for example. Some newspapers tend to pick on information that is easy to understand, for example ‘drink five cups of coffee a day’ or ‘eat walnuts and you will avoid dementia’. These studies are blown out of proportion and tend to be badged as a cure. While such findings are promising, they need a phenomenal amount of further research.

Do you believe science will succeed in tackling the root cause of dementia, producing methods of prevention or even, one day, a cure?

I have no doubt that it is within the capability of science and mankind to eliminate Alzheimer’s disease. We will be able to do it, but the timelines of when you may see this happening are really just speculation at this point.

People talk about finding a cure by 2050. By then I will be one of those people who will have a one in four chance of getting Alzheimer’s disease. However, at that time it might actually be a one in six or seven chance. Some of the basic methodologies that have recently appeared could have a massive impact in the future, such as genome editing, which in theory could be used to eradicate the genetic risk of dementia, although the ethics around future employment of these approaches will need serious consideration.

A cure is achievable but will be phenomenally expensive and will need an extraordinary amount of work, but I would say it is unquestionably doable!
Richard Cheston worked for 20 years as a consultant clinical psychologist before taking up a position at the University of the West of England, UK, as Professor of Dementia Research.

**Could you briefly introduce yourself and your research aims?**

My background is in clinical psychology and my particular research area focuses on the experiences of people with dementia and how ideas or concepts from mainstream psychology, especially around terror management theory, could help us make sense of their experiences. More importantly, my team wants to find new and better ways of understanding the experiences people face with dementia and supporting them.

**What particularly interests you about dementia?**

I am intrigued by how people make sense out of their life and find meaning in it. For instance, how do people manage to preserve a sense of self-worth and self-esteem when they are in the middle of this dreadful illness? Rather than see the behaviour of people with dementia, such as searching for parents who died many years before, as the symptoms of dementia, I belong to a tradition in social and clinical psychology that understands their behaviour as a response to the illness.

**Did your talk convey particular key points?**

Although it’s easy to demonstrate the deterioration of the brain via scans and so forth, sometimes researchers have focused on the neurological side at the expense of considering the social aspect of having dementia. People are cared for within complex social systems – homes, institutions and families – and have relationships with others that are extremely important. It’s our connections with others that sustain us, and which help us to find meaning in life, even in the midst of an existential threat like dementia. Dementia is also very much a personal tragedy – and as individuals we respond to it in completely different ways.

**How can gaining a fuller understanding of the impact of dementia on the brain lead to improvements in care?**

While we need to consider the effect of dementia on the brain, we must also think about the impact on people’s minds and souls. The brain is only one level of understanding that we need to have. This is why patients with dementia are so complicated to work with.

**Looking ahead to 20 years’ time, what do you imagine the nature of dementia care will be like?**

We have demographic changes occurring across the world in both developed and developing countries and, as people live longer, their risk of developing dementia is heightened. I hope that improvements in the way we understand person-centred dementia care filter through to the social and personal care that people affected by dementia and their families receive, but the reality is that caring is an expensive, and often devalued, business. There are many carers in nursing homes, for instance, who don’t get the training and support they need. Similarly, most families receive little support and training, even though this has been shown to be enormously effective in preventing the breakdown of care. Caring is often assumed to be straightforward, yet it is actually anything but simple. I hope that in 20 years’ time dementia care will be all-singing and all-dancing, and people will be passionate about caring. I suspect that it probably won’t be, but we all have a vested interest in trying to make it as good as we possibly can.
Can you begin by introducing the interactive art installation ‘I am still here’? Why was this project established and how did you become involved with it?

I come from a performance background and have always been fascinated by immersive environments. ‘I am still here’ aims to create an immersive environment where participants follow a succession of tasks that subject them to different sensations associated with the symptoms experienced in dementia. The installation is set up as a maze that looks like a home, with rooms that remind you of a lounge or a kitchen, for example. At first everything appears normal, but as you navigate through the maze it becomes increasingly bizarre. Through this project, we’re hoping to recreate the journey experienced by people with dementia, who find the world around them becoming increasingly obscure without knowing why or how.

The project is a collaborative effort with Loukia Katsouri, a neuroscientist who specialises in Alzheimer’s disease. When we decided to work together, I started researching dementia and became engrossed in the subject matter. Since then, my mum’s husband has been diagnosed with dementia and the granddad of another collaborator has been diagnosed with Alzheimer’s, so the project has gone from an interest to something more personal.

How can art and science complement one another?

Both art and science are phenomenally interesting in their own right, but some people can feel apprehensive about entering either realm depending on how they’ve engaged with it before. So it’s intriguing to see these sides merge more and help one another. Art and science explain the world in different ways: science focuses on gaining knowledge of the world, while art offers a more subjective, emotive view. It’s interesting when these two disciplines come together.

In what ways have artists, scientists and those affected by dementia collaborated in the development of this art installation?

I’m passionate about working on the triangle of scientist, artist and person directly affected by dementia, and have started to develop an outreach programme where we will run workshops and work with a focus group made up of people with dementia and carers.

With regards to science, Katsouri has taken me through her research and helped me understand the theories behind how dementia forms. One challenge is creating the experience of dementia while also offering a platform to inform people of the science. People may want to have better access to the scientific knowledge, and in this interactive art environment we are aiming to offer information in a more accessible way.

So far, how have people responded to this installation?

People who already knew a little bit about dementia immediately understood the interactive activities. It wasn’t necessarily scientists, but rather people who work with or have personal experience with dementia who had a better grasp of the tasks. As the project is in its early stages, I’m still observing how people react and whether they would like to be provided with more scientific information about dementia. For me, these activities are simply the beginning; a basic set up of where I want to take the project in the near future.