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# **How UK Psychiatric Geneticists Understand and Talk About Engaging the Public**

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## **Abstract**

The paper examines how leading UK psychiatric geneticists talk about public engagement. Scientific fields have distinctive publics, with specific goals for, concerns with, and obstacles to engagement. In psychiatric genetics these publics include people with psychiatric disorders, policymakers, and even medics. We found that psychiatric geneticists justify public engagement by using the language of ‘stigma’ in multiple ways. There is a belief in a deficit model of stigma – that stigmatizing attitudes among the general public and government are the result of insufficient knowledge of the biological causes of psychiatric disorders. ‘Stigma’ is, however, also co-opted to do rhetorical work within biomedicine, marking differences in therapeutic optimism as pathological. We suggest that the wider field of UK psychiatry is seen as mostly consisting of therapeutic pessimists, while the psychiatric geneticists are in a minority of therapeutic optimists. These attitudes are the product of the historical and social context of the field.

**Key Words:** Psychiatric Genetics, Public Engagement, Public Understanding of Science

## **Introduction**

More than twenty years ago, Levy-Leblond (1992) argued for a more nuanced study of the relationship between science and scientists, and the ‘public’. He pointed out that ‘the public’, accept and use complex science and technology – driving vehicles, interacting with computers and using sophisticated domestic appliances – regardless of any Public Understanding of Science (PUS) programmes. That, since 1992, ‘the public’ has become overwhelmingly IT literate further strengthens the point; people are generally capable of adapting to the changes of a technoscientific society with ease. Further still, citizens today think about themselves through scientific lenses. Nelkin and Lindee (1995) show how people reflect on their appearance and manner as genetic. This is not to say that, when it comes to science and technology, efforts to inform and engage ‘the public’ are not important, but to stress the necessity of more critical approaches. Levy-Leblond ends his discussion by asking whether we should supplement studies of the public understanding of science, with studies of scientists’ understanding of the public (see Wynne, 1993).

Studies of scientists’ understanding of the public have been conducted since Levy-Leblond’s editorial. Few now treat ‘scientist’ as a single category, as it is widely recognised that with scientific communities being culturally, as well as practically, different, such lumping together of a wide range of people working from various disciplines would confuse and dilute the insights that might be gained. Indeed, ‘splitting’ scientists is easier than dividing ‘the public’; scientists wear their

membership of the culturally, economically and politically distinct ‘tribes’ (Abbott 1998, 2001; Gieryn, 1999; Knorr-Cetina, 1999) on their lab coats.

The risks, rewards, and practicalities of public engagement also vary tremendously between specialisms. When we talk about the PUS, what do we mean (Michael, 1992) when science is no single thing (Gieryn, 1999)? We can easily see that, for example, publics’ attitudes towards theoretical physics are not the same as publics’ attitudes towards fields of research that employ animal experimentation. Different sciences have different relationships with certain invested ‘publics’ – patients, workers, consumers, protestors, etc. Given this, it is no surprise that we should expect scientists from different fields of work to have very different – and often contradictory – attitudes and understandings of publics, public understanding and public engagement.

This paper though argues that the level of resolution required to understand the attitudes of ‘scientists’ towards public engagement and communication needs to be particularly fine; our example of the distinct views of psychiatric geneticists would likely be obscured in general surveys of ‘geneticists’ or ‘psychiatrists’, and certainly would be invisible to studies using categories such as ‘biology’ or ‘biomedicine’. This paper therefore considers the single field of psychiatric genetics. Psychiatric genetics has a history of political controversy and, when viewed by outsiders, scientific failure. This leads to particular attitudes towards engagement with distinct publics: patients, politicians, medical and psychiatric practitioners, scientific funders, and the ‘general public’. Using interviews with leading scientists working in the field, the paper explores the way in which this sub-group of scientists understand publics and public engagement.

## **Why Do Scientists Engage?**

Efforts to boost public understanding of / engagement with science have been part of United Kingdom science policy for the last three decades (Haran 2011; Miller, 2001). The ‘Bodmer Report’ (The Royal Society, 1985) argued that, in a democratic society, public opinion is a major influence in science policy decision-making, and that an uninformed public would be vulnerable to misleading (and unscientific) ideas. Individuals would not only make ‘personal’ choices on the basis of these beliefs, but these ideas would affect their attitudes as *citizens* towards policy. The report recommended that the Royal Society should make improving the public understanding of science one of its major priorities.

Despite this ‘watershed moment’ (Ziman, 1991), between 1985 and the ‘Science and Society’ report (House of Lords, 2000) there appeared to be little change in ‘scientific literacy’ (Miller, 2001). Furthermore, the implicit argument justifying much public understanding of science policy: that increased understanding of science leads to increased public acceptance of science and the products and policies based on science, has not been supported by surveys of public opinion (Weldon, 2004). The so-called ‘deficit model’ of public understanding of science appeared to be failing to deliver (Gross, 1994; Miller, 2001) and thus became a target for social-scientific critique (Stilgoe, 2007).

The deficit model assumes that negative public attitudes towards science are the result of a knowledge deficit that can be corrected by providing the public with more

scientific information. Critics of this approach proposed models of public understanding and engagement - based on dialogue that take account of the ways in which people use, define, and make sense of science (Irwin and Wynne, 1996; Miller, 2001). It follows that such approaches to PUS must consider 'publics' rather than 'the public' since different groups engage with and understand science in different ways (Renn, 2006; Turney, 1996). Despite these arguments and criticisms (Irwin and Michael, 2003), large-scale surveys designed to capture the attitudes of 'the public' dominate official reports on the public understanding of science (see, for example, Besley and Nisbet, 2013; Ipsos MORI, 2011).

Notwithstanding its criticisms, the Bodmer Report led to increasing encouragement for scientific fields to open up to the public (Haran, 2012). Although the language might have since shifted (Miller, 2001), 30 years on the call for scientists to *engage* with publics has never been louder (Barnett *et al.* 2012; Bauer, Allum and Miller, 2007; Davies, 2008; Poliakoff and Webb, 2007; Wilsdon and Willis, 2004 ;). In the UK, funding bodies such as the Medical Research Council (MRC) encourage their scientists to communicate and discuss their work with public groups, with such activities commonly described as *public engagement* (Research Council United Kingdom, 2013).

In UK academic science, public engagement or (PEST) – the Public Engagement with Science and Technology (Irwin, Jensen and Jones, 2013) is no longer merely an abstract civic responsibility; it is also a metric considered when allocating research funding (Pearson, 2001). Today, universities have a 'duty' to communicate with the public and to engage with public groups and non-expert communities (Times Higher

Education, 2009). Indeed, the Research Excellence Framework (REF) places greater emphasis on the ‘impact’ of research than its predecessor, the Research Assessment Exercise (RAE)<sup>i</sup>. This has led to academic departments investing in public engagement, which is understood by some institutions as a pathway to (or synonymous with) impact (Ponting, 2011; Watermeyer, 2012). Prestigious prizes are awarded to those who promote the public understanding of science and funding applications have sections to complete on public engagement. Accordingly, with the terms and conditions under which science is produced, circulated, and accredited changing (Porter, *et al.*, 2012), explorations of the ways in which ‘scientists’ conceptualise ideas of ‘the public’ and ‘publics’, and their motivations to ‘engage’ is particularly timely (Davies, 2008; Poliakoff and Webb, 2007; Stilgoe, 2007).

### **The Challenge for Psychiatry and Psychiatric Genetics**

Psychiatric genetics - and its public profile – has particular characteristics that distinguish it from other fields of biomedicine. These differences are not only scientific – psychiatric illnesses are difficult to diagnose, and such diagnoses are unlikely to map directly onto biological categories (Burmeister, McInnes and Zöllner, 2008; Morgan, McKenzie and Fearon, 2008; Green, 2014) – but also political – governments have a history of misusing and abusing both psychiatry and notions of biological heritability (Propping, 2005; Kerr and Shakespeare, 2002). Psychiatric genetics has inherited a controversial history from its parent disciplines (Arribas-Ayllon, Bartlett and Featherstone, 2010; Sedgwick, 1982; Turney and Turner, 2000). As Propping (2005) writes ‘The false doctrine of eugenics and its practical application by the Nazi regime paved the way for the development of a prevailing anxiety in

society that psychiatric genetics might lead to stigmatisation or even a revitalisation of eugenics' (p2).

Yet there is optimism in psychiatric genetics, arising from the belief that mental illnesses are understandable in biological terms and, therefore, medically tractable (Craddock and Owen, 2010; Kauffman, Johnson and Pardes, 1996; Stoltenberg and Burmeister, 2000). Writing about the new genetics in general, Kerr, Cunningham-Burley and Amos (1997) have illustrated that, with these visions of the past and the future co-existing in the present, geneticists tend to clearly demarcate the 'eugenic past', in which information about heredity was put to use by the state, from a future in which individuals and families use genomic information for their own benefit.

The way in which psychiatric geneticists present a narrative of their discipline is therefore important, with current perceptions of psychiatry and psychiatric genetics ambivalent at best. Smith (2008) argues that few people, apart from psychiatrists, care about the practice of psychiatry. Yet they should, he argues, as the burden of mental illness is enormous. Treating mental illness accounts for 10.8% (£10.4 billion per year) of the National Health Service budget (Department of Health, 2010), While the cost of work-related mental ill health is estimated to be another £30 billion per year (Centre for Mental Health, 2010). Some doubt that psychiatry will ride to the rescue, arguing that advances in treating psychiatric disorders have been rare (Hamer, 2002). However, the argument that these sorts of statistics demand that psychiatry should be of public interest, is not only (or even at all) a high-minded argument that 'the public' should be able to play their part as citizens (Irwin, 2001), but that psychiatry *needs* a public. Disciplines need public and political support else they become marginalised.



Public engagement in psychiatry should therefore be constituted in a way that would both serve a common good and maintain the standing of the profession (Smith, 2008).

In psychiatric genetics, scientists face the added challenge of genetic stigmatisation (Propping, 2005). Stigma is widely recognised as one of the biggest obstacles to mental healthcare (Sartorius, 2007), and efforts to understand and reduce stigmatising attitudes are central to many public programmes that deal with mental health (Time to Change, 2010, 2011). However, there is the fear that the geneticisation of mental illness could reinforce stigma (Goldacre, 2010; Rose, 1998). In the accounts on public engagement provided by psychiatric geneticists in this paper, references to stigma feature prominently, with a ‘deficit model’ understanding of the role of public engagement common – informing the public of the genetics of mental illness will reduce stigma, bringing public attitudes in line with the attitudes of the scientists.

However, while researchers speak of public engagement as a means to tackle the ‘stigma’ of mental illness, we find that they also refer to the ‘stigma’ that they face as psychiatrists and as psychiatric geneticists. Researchers express concerns regarding the standing of psychiatry and psychiatric genetics within medicine and the effect this has on spoiling (Goffman, 1963) their professional identity. As we have described, the history of the politicisation of both psychiatry (see Crossley, 2006 for psychiatry and social movements), and genetics has left its mark on the field. Propping described the way in which this ‘sinister history’ hangs over the field as if it were ‘Damocles’ sword’ (Joseph, 2006, p151; Propping, 2005, p3). More, unlike some other branches of research into the genetics of illnesses, psychiatric genetics has a history of failing to meet optimistic predictions for the identification of ‘genes for...’ And further still,

regardless of advances in genetics, from Genome Wide Association Studies (GWAS) to Next-Generation Sequencing (NGS), psychiatric genetics struggles to a far greater degree with classification and, relatedly, the identification of biomarkers, than ‘somatic’ illnesses. Against this background, psychiatric genetics must engage with the public.

### **The Centre: the Research Setting**

This paper focusses on a single, internationally significant, laboratory – the Centre. The Centre includes laboratory-based and clinical researchers, conducting genetics and genomics research to understand the biological causes of mental illness. The paper draws on empirical evidence from two inter-related research projects at the Centre conducted between 2009 and 2012. As such, the research can be considered a case study (Thomas, 2011).

The first project (2009-2010) was a small-scale qualitative study consisting of nine interviews with senior academics, both clinicians and laboratory scientists, heavily involved in public engagement. The project explored scientists’ understandings of publics and their reasons for ‘engaging’. The authors did not define ‘publics’ for the interview participants; interview participants chose which groups to discuss as publics and with which psychiatric genetics needed to engage.

The second project (2009–2012) consisted of 20 interviews with scientists at the Centre. Respondents were a mix of early-career and senior researchers. The focus of the project was to explore the work practices of the field of psychiatric genetics as it

became a ‘big science’ (Authors; Arribas-Ayllon, Bartlett and Featherstone, 2010; Sullivan, 2011).

In addition to interview data, ethnographic research informs the analyses of this paper. Author 2 spent time in the Centre’s laboratories, and attended seminars and conferences with members of the Centre. Author 1 was employed by the Centre as a sociologist, with additional public engagement duties. Not being a psychiatric geneticist, his position granted him a level of critical distance. To a degree, Author 1 can be said to have been performing inadvertent participatory action research (Whyte, 1991), organising public engagement activities for psychiatric genetics/geneticists while thinking critically and sociologically about publics and engagement.

The Centre itself has played important roles in GWAS of mental illness. This type of research is ‘big science’ (Hevly, 1992). Large-scale science requires significant resources; technical, economic, cultural and social, the maintenance of which often requires support from specific ‘publics’. In particular, this kind of research into human health requires access to research participants – people with psychiatric disorders. Successful research therefore demands the support of people with psychiatric disorders, along with their families, carers, and medical professionals. From the research participants material of scientific value is extracted – which in psychiatric genetics includes not only DNA but also detailed mental health histories derived from case notes and in-depth face-to-face interviews. Unlike most ‘somatic’ illnesses, detailed phenotypic data can only be collected by engaging with the research participant’s subjectivity. There are no convenient biological markers for disorders such as schizophrenia. Further, given that psychiatric geneticists are wary of

treating disorders such as schizophrenia as if they are mapped one-to-one onto a single underlying biology, it is considered important to collect detailed phenotypic data as a way of tackling the phenotypic and (presumed) biological heterogeneity of the disorder<sup>ii</sup>. Public engagement is seen as one way to promote and help recruit participants to these projects.

The imperatives and demands involved in public engagement with psychiatric genetics (and other big biomedical projects) are therefore distinct from those that figure in some other scientific fields. The Centre has to invest in its publics in order to do research. As part of this investment, in 2009, the Centre launched a public engagement programme, designed to engage with a variety of publics. This paper explores how scientists at the Centre conceptualise the public, their reasons for engaging with publics, and the messages they want to communicate. Interview extracts have been anonymised, with details of particular programmes of research omitted.

### **The Publics of Psychiatric Genetics**

Studies in the public understanding of science show us that we should not think of the public as a homogenous group, but rather that we should think of publics as they relate to science (Renn, 2006; Wynne, 1995). Unsurprisingly, scientists at the Centre have publics that they prioritise. We can separate these publics into four types. The first group is ‘the general public’.

“Who do I think my public is? I suppose I would like to think there [are] several. Obviously there’s the kind of general public, the people reading newspapers and magazines, and watching television [...] I would like to get across to them” (Professor Norris).

To this ‘general public’, scientists at the Centre want to convey general messages about the science and the (potential) impact of research.

“[...] The more general message is about the importance of research in mental health and the stigma and understanding illness and complexity and that is really, I think, aimed at the very widest possible spectrum of the public” (Professor Davidson).

These general messages cover ground which includes developments in understandings of the brain, the stigma of mental illness, and the complexity of psychiatric research. Professor Stevenson’s description of the messages that she wants to communicate is typical.

“I don’t think the public thing [has] moved on [from] complex disease, genes being deterministic. I think the other thing [...] for] people to realise [is] that...for these sorts of studies we’re only capturing a very limited type of genetic variation. There’s still loads of genetic research to go on before we’re capturing all the variation. And of course there’s non-inherited factors [...] These complexities have got environmental contributions, [especially] for some of the disorders we’re studying”. (Professor Stevenson).

Getting across to the public the complexity in psychiatric genetics is seen as a priority. As well as the message that there will be no ‘gene for’ discoveries, Professor Stevenson stresses that it is also important to communicate the incomplete nature of the science and that there is still more research to be done.

While the messages will be different between disciplines, *every* scientific discipline has a ‘general public’. Although we see how issues specific to psychiatric genetics are raised when discussing engagement with the general public (for instance, stigma and complexity), the differences between scientific specialisms become pronounced when specific publics are considered. We will discuss three of psychiatric genetics most prominent publics; people with mental illnesses, medical professionals, and policy makers.

Psychiatric genetics requires the participation of people with psychiatric conditions in order for research to be done. In psychiatric genetics, this participation is much more involved than in other large-scale genetics research, for example detailed interviews covering distressing periods in the participants’ lives are required. Engaging with this group of people is seen as a priority at the Centre.

“For me – a key group that I think to do some work and to interact with is - is people with psychiatric disorders” (Professor Johnson).

And:

“The people I think would have most interest are those that have experience of [the disorder] either within their families or are concerned about developing it themselves in later life for various reasons” (Professor Wilson).

Despite all senior staff recognising that people with psychiatric disorders are a key group to engage with there were differences in priority. Professor Johnson points out that the interests of clinicians and those of laboratory scientists can be quite different, and that these differences influence the publics that they wish to engage.

“If I had to choose one group where I thought ‘yeah it would be worth concentrating’ [those with psychiatric conditions] would be for me...Obviously that’s going to be different for other people in the Centre. I think probably the perspective [...] comes from being a clinician scientist [...] It strikes me as a clinical academic what you have is contact (in your clinical work as well as your research) with people [and] with the disorders that you’re studying and so taking advantage of that, building on that seems very sensible to me; which if you’re a basic scientist then there maybe [...] other groups that you are targeting.” (Professor Johnson).

Such differences - even between psychiatric geneticists - only highlight the necessity for science and scientists to be considered in their variety. Clinical researchers work *with* different materials and *do* different things to the geneticists in the laboratory. This shapes their view of public engagement even when working on the same projects.

Medical professionals are another priority public for psychiatric geneticists. Scientists at the Centre hope that their work will inform medical practice. Some might argue that these medical professionals are not publics, but rather are a group of people with [competing] expertise in mental illness. Nevertheless, by and large medical professionals are not the disciplinary peers of psychiatric geneticists. The scientists at the Centre are not [only] engaging medical professionals in a general discussion of mental illness, but are attempting to get this group to engage with the specific findings of psychiatric genetics, of which they are, as a group, non-experts. The psychiatric geneticists at the Centre are not imagining that medical professionals will be engaging with the findings of their research by way of seminars and papers, but by methods and material designed for communicating with people outside the discipline. Medical professionals, in common with other stakeholders in issues of mental illness, such as patients, families and policymakers, do have expertise in *mental illness*. However, in general, the practicing psychiatrist does not have the disciplinary competence – neither contributory nor interactional expertise (Collins and Evans, 2002) – in *psychiatric genetics*. Even if this is not the case, among the psychiatric geneticists at the Centre there was a presumption that medical professionals dealing with mental illness were largely ignorant of - and in some cases resistant to – genetic understandings of psychiatric disorders. The scientists imagine and understand engaging with these groups as if they were publics<sup>iii</sup>.

“There’s clearly the technical aspects of what we do, I would say that it’s psychiatrists and neuroscience researchers are the main people that that is aimed at.” (Professor Davidson).



And:

“I would like to get across things to other healthcare, mental health professionals [...] I think some of them/us are responsible for all these incorrect ideas about stigma” (Professor Norris).

According to Barker (2004), the language of engagement ‘suggests an element of reciprocal and collaborative knowledge production... [that requires] collaboration with communities in the production of knowledge’ (p 126). Psychiatric geneticists work within the wider worlds of psychiatry and healthcare. Even if one were to suggest that these groups should not properly be thought of as publics and more as critical audiences, the fact is that scientists at the Centre understood healthcare professionals as a public to engage with in their public engagement programme. Therefore an exploration of scientists’ understanding of publics and public engagement must consider this. Note also the assumption that informing publics of the findings of psychiatric genetics will reduce stigma – this is a recurrent theme in the interviews.

The final priority group are policy makers. While ‘the public’ might, in theory, support research through taxation, it is politicians and policy makers who decide on the details and distributions. This is true of any science, no matter how distant its content is from the concerns of state and civil society. Psychiatric genetics, however, as with all biomedical science, promises findings of significance to policy makers.

“Then I suppose there are the sorts of people who influence policy and so on.”

(Professor Norris)

And:

“The more general message is about the importance of research in mental health and the stigma and understanding illness and complexity that’s really [...] aimed at the very widest possible spectrum of the public which would include politicians and policy makers.” (Professor Davidson).

Politicians and policy makers (and the ‘general public’) are targets for engagement as they are the funders of science. All sciences need to maintain political support (Yearley, 2005). As a biomedical science though, psychiatric genetics also needs to engage more specific publics who might use the content of their research. Most specifically, psychiatric genetics needs to engage with a public consisting of people with psychiatric disorders. Public engagement at the Centre is understood as a way to attract participants by communicating the value, purpose, and promise of the science. Public engagement is, therefore, in no small part understood as an activity that maintains the resources required to do science.

### **The Promise of Psychiatric Genetics**

The promise of psychiatric genetics is that mental illnesses will be rendered diseases like any other. Not only will mental illness be understandable biologically, and

medically tractable, but the stigma specifically associated with *mental* illness will be undone.

“I am very keen to persuade people that psychiatric disorders are tractable to scientific approaches which I don’t think that everybody believes. I think [...] there is a prevailing view now in society and amongst politicians that they’re untreatable, chronic conditions that require social care and the main thing that I want to get across to people is that these [...] severe psychiatric disorders are disorders of the brain that can be approached by genetics and neurosciences and that that is the way to develop new treatments.” (Professor Norris).

A short history of classifications in psychiatry is important here. The current psychiatric classificatory system, based on grouping disorders together by common patterns of symptoms, owes much to the 19th century psychiatrist, Emil Kraepelin. However, the usefulness of the Kraepelinian classificatory system has recently been called into question (Jablensky, 1999; Craddock and Owen, 2007; Craddock and Owen, 2010).

These questions may precede a paradigm shift (Kuhn, 1970) in psychiatry. Psychiatric geneticists anticipate that a better understanding of the biology of mental illness – derived from techniques such as GWAS, NGS, and brain imaging - will produce diagnoses that better match the underlying biology and, as Professor Norris describes, improved treatments. The system used to classify psychiatric disorders will be aligned with that of other medical fields (Singh and Rose, 2009). To quote prominent psychiatric geneticists, “The history of medicine suggests that therapeutic and

prognostic decision-making are usually facilitated, often greatly, as classifications move closer to the underlying biological mechanisms. For this reason, it is desirable to move towards a classification that maps the expression of illness onto the underlying biological systems” (Craddock and Owen, 2010, p94).

Scientists working in psychiatric genetics are keen to present the specialism as essentially the same as other branches of biomedicine. For Professor Norris, one function of public engagement is to inform people of the biological basis of mental illness. This, he argues, will challenge the stigma that arises from beliefs that mental illness is outside the scope of biomedical understanding and treatment. ‘Society needs to know what work the centre is conducting’ in order to ensure that ‘society and politicians’ are ready for therapies derived from psychiatric genetics. Understandings of psychiatry as fundamentally biomedical are therefore coupled with an attitude of *therapeutic optimism*.

As a therapeutic optimist, the psychiatric geneticist must believe in the efficacy of pharmaceuticals and other medical treatments. However, Professor Norris suggests that society is dominated by *therapeutic pessimists*. Public engagement is justified as a means to change public attitudes by making them aware of the biological basis of psychiatric disorders. This ‘deficit model’ approach to public engagement often draws on the example of other fields of medical research. Amongst centre members, it is common for psychiatric genetics to be compared to the position of cancer research in the middle of the twentieth century.

“Forty, fifty years ago, cancer was regarded as an incurable condition that was very stigmatised, people didn’t talk about it. When I was a medical student on the ward, you never told someone they had cancer. [...] You said ‘Well, you’ve got a bit of a growth or you’ve got a neo-plastic disorder.’ And people often wouldn’t be told that they were going to die, that they were terminable. And people would never use the word and were ashamed of it. What happened is, in spite of that, [researchers] had this sort of war on cancer, money was put into research big-time and it became the norm for every single patient, pretty much, with cancer, to be in a drug trial of some sort, or part of research. That improved the care because it attracted smart people into wanting to do it. Smart people want to do things that are exciting, in a way that they can make a difference [...] It raised the profile and people started to talk about [it], and now you’ve got to the situation where cancer’s much less stigmatised and also that there are [...] plenty [of] new treatments around. And this is where we are now in mental illness.

It would make a great difference though, if we were doing research in clinics [...] Look at Alzheimer’s. Alzheimer’s is much less stigmatised than dementia used to be and that’s because it has a name, but it’s also because it has pathology, it has some potential treatment, it has some genetics. That hasn’t made it more stigmatised, it’s much less stigmatised [...] If we could do the same for schizophrenia or bipolar disorder and depression, that’s what we want.” (Professor Norris).

The argument goes that, if public groups would treat psychiatry and psychiatric genetics as just another branch of biomedicine and mental illnesses as diseases like any other then the stigma of mental illness would be reduced. For Professor Norris, this argument should be the impetus driving psychiatric geneticists to engage. Stigma is produced by ignorance of underlying biology.

A wide variety of medical conditions have been stigmatised at one time or another (Scambler, 1998, 2009), but the stigma of mental illnesses appears particularly damaging and resilient (Goffman, 1968; MacRae, 1999). Professor Norris describes a past in which people were too ashamed to even say the word ‘cancer’. Many cancers were untreatable, fatal conditions. The medical profession waged ‘war’<sup>i</sup> on the disease, and the improved understanding and treatment of cancer, led, so Professor Norris argues, to a reduction in stigmatising attitudes. Within psychiatry, Professor Norris points to Alzheimer’s disease as a case in which increased knowledge has led to optimism for future treatments and, in doing so, reduced the associated stigma.

Professor Norris’s account is that of a *therapeutic optimist*. Mental illness is a disease like any other. They are biologically tractable, which will lead to treatments. In turn, this will reduce stigmatising attitudes. This makes the basis for an appeal for public support and the maintenance of the resources required for research. These arguments privilege the power of scientific knowledge to change society. Therapeutic pessimists, by contrast, are likely to prioritise discussions of the role of the history, culture, and politics of mental illness and stigma.

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<sup>i</sup> The metaphor of waging war on a disease is commonplace in biomedicine (Gwyn, 2002; Vincent, 2007).

Professor Edwards provided a similar, if slightly more conservative, perspective. He was asked what he would like public engagement to have achieved over the next five to ten years.

“That people with certain [...] types of illness, and their relatives and so on, would be aware that this stuff [research] was going on and that we were a group...[that] if you wanted information or you wanted to participate in research, would be [your] first point of call. The way people with sick kids know of Ormond Street, the way many people with cancer know of the cancer research foundation – you know, all these type of things. I mean, psychiatry, psychiatry research, psychiatric illness, is really not known about by people who need to know about it. Now how much benefit they'll get out of it in that short time frame is a different matter. But it would be good for people to have a feeling of optimism that the cure is not round the corner, there may never be the cure, but that there was at least some kind of momentum” (Professor Edwards).

Professor Edwards tempers the linear optimism of ‘research→knowledge→treatment’ by saying; ‘there may never be the cure’. Nonetheless, this account is still that of a therapeutic optimist who sees in public engagement an opportunity to spread this optimism. All science (Haran, 2011) involves telling stories about a potential future; not all have to deal with a past containing abuses and unfulfilled promises. Psychiatric geneticists often rely on drawing a comparison with other branches of biomedicine that are free from such troubled histories.

### **An Illness Like Any Other...**

At the Centre, comparisons between psychiatric genetics and cancer research are not limited to the standing of the fields and the stigma associated with the conditions. Centre members also draw parallels between the role of genetics in cancer and mental illness. The Centre's expertise lies in conducting genetic research to discover susceptibility genes for psychiatric disorders. Susceptibility genes increase the risk, sometimes by a very small degree, of developing a disease. The model of genetic contribution to common mental illness is understood to one of many genes, each of small effect. This is unlike the classical Mendelian genetics with which the public are familiar, in which a mutation in a single gene plays a major role in determining whether or not a person develops a disease. When Centre members face public audiences, they make comparisons to the genetics of diabetes, heart disease, cancer, etc. to explain what they mean when they say that 'mental illnesses are genetic'.

“It's particularly a challenge when you use the media...You cannot readily explain these things in ten seconds, or two sentences. So it is a huge challenge [...] When I try and do it, I kind of resort to analogies that people maybe understand a bit clearer in their own life, which people [might grasp] slightly better - concepts like risk of heart disease where not everyone who doesn't exercise dies of a heart attack next week. And then not everyone who does exercise stays immune from heart attacks. People [...] they don't necessarily understand it very well, but, I mean, there are a lot of analogies and that's how I tend to do it. But it's pretty difficult to get people to understand it, or for me to be able to persuade people [to support the research] or for me to be able to communicate it, I do acknowledge that.” (Professor Edwards).



Due to the challenges of communicating psychiatric genetics to publics', scientists at the Centre use the 'mental illness is like any other illness' argument (*cf.* Read et al., 2006) not only to challenge stigma, but also in order to provide a short-cut to explain the role genetics plays in mental illness. Diseases such as cancer or diabetes provide a reference point with which the public are familiar, allowing scientists to avoid the task of explaining complex genetics from first principles. In addition, improvements in our understandings of, and treatments for, these conditions, ties psychiatric genetics to stories of success.

Professor Davidson also discussed the difficulties of explaining the genetic nature of mental illness.

"A lot of it relates to the fact that people already have ingrained and stereotyped attitudes [and] so they are not very receptive to a different way of looking at it. For example if someone's made up their mind that mental illness, [...] depression say, is a character weakness and it's not an illness and all the rest of it, it's almost impossible to even start a discussion or a conversation because the person [is] just closed to that. [...]"

That's the biggest problem. I think [...] an interesting example came out with all the [news] publicity [...] around the [recent] finding. I think the bit that seemed to touch with everyone were the words [that were reported as] [...] 'so this shows that [this] is a genetic disorder' – now I have to say I'm not sure I would have necessarily used those words myself but when we discussed it

people agreed that if someone had said ‘oh so this research shows that heart disease is a genetic disorder or diabetes is a genetic disorder or cancer is a genetic disorder’, actually people would have understood what that meant in the sense that they would have been much more comfortable with that, but because it was a psychiatric or behavioural problem it was completely different... So if someone had said so that shows that Alzheimer’s is a genetic disease there wouldn’t have been a public outcry. [...] Unless there’s a level of public engagement you can’t possibly transfer the findings into ways of actually changing behaviour and treatment and services, that’s one thing” (Professor Davidson).

Professor Davidson’s account paints a clear picture of the particular challenges that psychiatric genetics faces when trying to engage with the public. Not only is there resistance to the very idea that psychiatric disorders are ‘illnesses’, but there are very different reactions to the genetic explanations for psychiatric disorders than for ‘somatic’ illnesses<sup>iv</sup>. Again, this points to a need to consider scientists’ attitudes towards public engagement at the very ‘local’ scale – the particular challenges facing psychiatric geneticists are not generalisable to other biomedical geneticists, much less the life sciences as a whole.

That something is ‘genetic’ means something different in these ‘public’ places than it does in the laboratory. There is no ‘gene for’ the disorders that the Centre research – as with most things in psychiatric genetics it is a lot more complicated than that (Arribas-Ayllon, Bartlett and Featherstone, 2010; Sullivan, Daly, and O’Donovan, 2012). In the laboratory, that everyone understands the caveats that spring from the

complexity of the genetics under discussion can be taken for granted. A non-specialist audience, Professor Davidson fears, hears ‘genetic’ as ‘gene for’. Despite recognising that the findings could have been better communicated, Professor Davidson maintains that if the story had been about a physical illness there would be no controversy. And, possibly, no ‘story’, in the journalistic sense, a fact that reminds us that in order to engage with a public an audience is needed. Therefore, when scientists engage with the public they must deal with the existing understandings of their science (Turney, 1996). For each science the existing understandings are different, presenting diverse challenges to public engagement.

At the beginning of the quoted extract, Professor Davidson inadvertently acknowledges the criticism of the deficit model. Many people already have ‘knowledge’ about mental illness; as he puts it, ‘stereotypical attitudes’ are ‘ingrained’. There are no empty vessels that can be straightforwardly filled with scientific knowledge. According to Professor Davidson, an understanding of mental illness as a weakness of character prevents public engagement with genetic knowledge of mental illness. This point that people have existing ideas about mental illness that interact with public engagement is a subject Professor Norris discusses, with reference to stigmatising attitudes.

“Everyone knows mental illness runs in families [...] that’s been known for centuries. [...] I think in some societies that’s very stigmatising; in some eastern societies that is very stigmatised. I think [...] we’re much less worried about tainted blood in the west. [...] What people find stigmatising is for it to be suggested to them that their child has a psychiatric disorder because of the

way they might have brought them up, or because of the social circumstances that they have created for them. I think we've got to turn this whole thing round actually. It's something I feel rather passionate about." (Professor Norris).

Professor Norris suggests that the concept of 'tainted blood' no longer holds much traction in Western society. Instead, 'blame' is the most important aspect of stigma to be challenged. A genetic explanation would undermine explanations of mental illness that blame parents, or families, or weaknesses of character. However, if, 'in some eastern societies [tainted blood] is very stigmatised', the cultural basis of stigma is clear. It is not just about an absence of biological knowledge. Psychiatric genetics in 'eastern societies' would need different approaches to public engagement.

While some scientists at the Centre accept that stigmatising attitudes are not simply the product of a belief that psychiatric disorders are not biological in origin, the belief that stigma will be diminished by the discovery of the biological basis of mental illness is widespread. Professor Edwards is an exception:

"There's that type of stigma, they are rotten to the core, or their parents were rotten to the core, and stuff like that. And I suppose it is imagined that a greater understanding, you know, that these are not necessarily disorders of personal [circumstances] could in principle reduce stigma. However there's also stigma and prejudice against people who have biological illnesses that are fully understood. [...] Actually I don't believe that a reduction in stigma necessarily follows from a greater understanding of cause. [...] We know the causes of

Aids, we know the causes of venereal diseases. [...] At the core of all this, it's true that a greater understanding does not necessarily abolish stigma, and I'm not convinced it will increase it, but it just does not follow it will reduce it" (Professor Edwards).

Reviewing the literature, on mental illness and stigma, Goldacre (2010) writes that 'people who want to combat prejudice may need to challenge their own prejudices too', not least their own moral and cultural interpretations. Citing Phelan (2002), Goldacre recognises that there are different types of stigma and that establishing a genetic or biological basis of mental illness could (i) create *associative stigma* for family members labelled as carriers, (ii) increase *the length of stigma* so it exists after symptoms have subsided stating: 'perhaps a partner will wonder: Do I really want to risk having a child with this person, given their genetic predisposition?', and (iii) increase *anticipatory stigma* with young people experiencing stigma before showing any signs of hyperactivity or inattentiveness – 'do they have this condition, just like their father?' Such genetic explanations may increase stigma and discrimination (Rose 1998), reflecting the negative discourses of degeneration and heredity familiar to Victorian psychiatrists.

Publics have particular imaginaries of biomedical disorders in the same way that scientists have particular imaginaries of publics. Comparisons with cancer and other 'physical illnesses' might be useful, but given that research has shown that in developed societies stigma is typically attached to conditions of the mind rather than the body (Albrecht, Walker and Levy 1982), it is not a like-for-like model in so far as using public engagement to de-stigmatise mental illness goes.

## **Stigmatised Psychiatric Genetics (Therapeutic Optimists and Social Optimists)**

Scientists at the Centre, as scientists elsewhere, understand public engagement is at least partly a means of maintaining access to the resources required to do science. Public engagement, by presenting optimistic futures, is seen as a way to secure public and political support. It is also seen as a means of recruiting research participants. However, as we have seen, there is also a more high-minded purpose; to reduce the stigma of mental illness.

However, while scientists at the Centre begin by speaking of the stigma of mental illness and their hope that public engagement, founded on their *therapeutic optimism*, might begin to reduce stigma, we also see the concept of stigma used to describe attitudes towards psychiatry and psychiatric genetics. According to centre members it is not just those with psychiatric conditions who are the victim of negative attitudes, but also those who work in psychiatry. Through a process of marking (Hess, 1992; Simon, 1999), psychiatry is presented as being seen as not quite a ‘real’ medicine by the wider medical community spoiling the identity of psychiatrists as medics (see Goffman, 1963).

“It [psychiatry] really is a joke when you are a medical student. You know, I mean, people really put you off it. I think there is stigma. At medical school you get it and then afterwards, you know, people say but you weren’t one of the weird ones” (Professor Stevenson).

Yet, while psychiatry is positioned at the margins of medicine, it appears that psychiatric genetics is regarded with suspicion by the psychiatrists precisely for its 'scientism' (though the history of the disciplines concerned no doubt plays into these attitudes).

"It's a big problem for psychiatry and more particularly for patients. So there's a general issue which is that in UK psychiatry for quite a long time there's been a terrible nihilism about anything scientific. You know, and partly that's understandable because lots of times people have come up with some finding and it's either not been replicated or it's not fed through to any impact on changing what you do with patients. [...] And so because of the way the UK psychiatric service is run - they're not set up in a scientific sort of way, they're fairly de-medicalised and it's just kind of easier for people to kind of think: 'Oh well, you know, there is no science in this and nothing that gets published is actually worth knowing about' [...] so that's a general thing. And then there's a specific thing which is I think quite a lot of people who went into psychiatry or are in psychiatry have a scepticism about, biological in general and genetic in particular, explanations of illness and they just have a sort of idealistic or theoretical, philosophical abhorrence of it. Not all of them but a proportion of people. [...]"

I mean don't get me wrong, there'll be plenty of psychiatrists out there who will have a perfectly balanced eclectic view of you know, social and psychological factors are important and biological factors too and you know that's all fine. But in terms of what your average jobbing psychiatrist would

think, they wouldn't be keeping up to date with the fact that there's stuff going on.[...] Whereas in the States it'll be completely different [...] there's always been more excitement about science anyway and there's always been more sort of expectation that psychiatrists would kind of know what was going on in neuroscience because it's probably going to have an influence on the way they practise psychiatry at some point. But that's not been what's been ingrained in British psychiatry.” (Professor Davidson).

For Professor Davidson, two factors are responsible for the attitudes towards psychiatric genetics within UK psychiatry. Historically, psychiatric genetics has failed to deliver. Findings have been inconsistent, have not been replicated, and – most importantly – treatments have not arrived. Again, we see the coupling of biological psychiatry with therapeutic optimism. For a psychiatrist, without this optimism there would be little value in taking a biological approach. The evidence that psychiatric illnesses are heritable has been available for some time (Kirov and Owen, 2009), but this general knowledge is of little use in mental healthcare, whilst it carries the risk that such knowledge might deepen stigmatisation. Professor Davidson is frustrated that the resulting mental health infrastructure is little equipped to incorporate new developments in psychiatric genetics into mental health. This also concerns Professor Johnson, who suggests that engagement with the people who will implement the findings of psychiatric genetics is vital.

“It's important because if we do make advances that may change the way that we think about psychiatric genetics, or the way we think about treatments [... ]



it's important that the people out there will need to implement those advances.” (Professor Johnson).

Professor Davidson also posits that psychiatric genetics is given short shrift within psychiatry because many psychiatrists are ideologically opposed to the application of genetics to questions of mental illness. A ‘theoretical abhorrence’, as he puts it, though does not explore what it is about the histories of psychiatry and genetics that would produce such an attitude.

In fact, scientists at the Centre make it clear that biological approaches to psychiatry are anathema in UK psychiatry.

“I think it's more than genetics. I think it's the biological in psychiatry that's the issue, yeah. And I think people are very wedded still to kind of purely psychological and environmental ways of considering psychiatric illness” (Professor Johnson,).

Thinking about Professor Johnson's division between those who take a biological approach and those who take a psychosocial approach, we can suggest that the split is not so much between therapeutic optimists and therapeutic pessimists, but between brands of optimism. Those in psychiatry who put the social and environmental at the heart of explanations of mental illness might well be social optimists. Some at the Centre view these people less than favourably. When given the summary of a literature review suggesting that a biological understanding of mental illness may increase stigma, Professor Norris responded.

“So, biogenetic causal beliefs in diagnostic labelling by the public are positively related to prejudice fear and desire for distance. [...] The people who think like this are educated, slightly left-wing people without scientific backgrounds in the soft end of sciences or the humanities”. (Professor Norris).

Essentially, therapeutic optimists believe that pharmaceuticals and other ‘medical’ treatments can deal with mental illness. It is hard to be a therapeutic optimist unless mental illness is understood biologically. Social optimists believe that mental illness can be tackled by focussing on the social or environmental, at the level of the individual or as a public health issue. It is easiest to think this way if mental illness is understood as the product of social factors. These two ‘optimisms’ are not necessarily mutually exclusive; being a therapeutic optimist does not demand that one is a social pessimist, and being a therapeutic pessimist does not demand one is a social optimist.

Given Professor Davidson compares the attitudes of UK psychiatrists to the ‘therapeutic optimism’ of psychiatrists in the United States it is important to briefly consider of the cultural and political differences between the countries. That the UK has a universal health care system, a welfare state, and a strong ‘social democratic’ strain to its politics, which are absent or much less pronounced in the US, provides the bedrock on which social optimism might be founded. Again, when considering the ways in which scientists think about publics and public engagement, this asks us to consider the particular context of the science in question.

## **Discussion**

This paper is, first a demonstration that the social, political, and economic context of a particular scientific field influences the way in which scientists understand publics and public engagement. Specific scientific fields have distinctive publics. They engage with these different publics for different purposes: enrolling them for research, soliciting support from interest groups, promoting the specialism and its research to policy makers and stakeholders etc. Studies of ‘science’ and ‘scientists’ obscure this variation, just as studies of ‘the public’ hide the way in which important publics engage with science.

Second, this paper is about psychiatric genetics, and shows the way in which scientists involved in psychiatric genetics use the language of ‘stigma’ in a range of ways to justify public engagement. Most obviously, there is a belief in a ‘deficit model’ of stigma – that stigmatizing attitudes are the result of insufficient knowledge of the genetic (and therefore biological) causes of psychiatric disorders. ‘Stigma’ is also co-opted to do rhetorical work within medicine and science, marking differences in therapeutic optimism and outlook as pathological. Psychiatric geneticists are therapeutic optimists, who see themselves opposing a society dominated by therapeutic pessimism. This pessimism extends to the wider medical profession, which we see when scientists working in psychiatric genetics talk of their field as being stigmatized as well. Not only is psychiatry a poor relation to other branches of medicine, but psychiatric genetics is marginalised when compared to other large scale genetic studies of complex disease. And, quite aside from any ‘disciplinary sneer’, with regard to wider publics, both psychiatry and genetics have identities that have been ‘spoiled’ by their troubled, controversial histories. As psychiatric geneticists,

they often feel overshadowed by their discipline's controversial past – the stigmata that marks their membership of a 'shamed caste' (Goffman, 1963).

It is not surprising, therefore, that psychiatric geneticists justified public engagement as a means to tackle negative attitudes towards psychiatric genetics as well as a tool to reduce the stigma of mental illness. Familiar with the language of stigma, psychiatric geneticists use the term in a variety of ways; people with mental illness are stigmatized, psychiatry is stigmatized, psychiatric genetics is stigmatized, therapeutic optimism is stigmatized. Public engagement in which a programme of informing different groups of the biological basis of mental illness is posited as a means to reduce these 'stigmas' invokes the 'deficit model', relying on the argument that if people outside the specialism knew more their attitudes would come to be more like those of the specialists.

That the particular attitudes towards publics and public engagement held by psychiatric geneticists are not to be understood as directly transferrable to other areas of science is part of the point of this paper. These attitudes are the product of the historical, social and cultural context of the field, pointing to the necessity that studies of scientists' attitudes towards publics and public engagement need to be studies of particular groups of scientists. Even if these studies do not explore the historical, social and cultural context of the field, its economics and its institutional specifics, the relative homogeneity of the group under study will produce informative results (even if these are not explained). The specificity of this paper is then its strength - the generalisable aspect of this paper is that fine grained specificity is a necessity in understanding scientists' conceptions of publics and public engagement, taking

seriously Levy-Leblond's (1992) call for more sophisticated approaches to studying the relationship between scientists and the public. The degree of focus does not prevent some of the insights from this paper being applied more broadly, with the caveat that differences in scientific culture *do* matter (Gieryn 1999).

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<sup>i</sup> The Research Excellence Framework (REF) is, and the Research Assessment Exercise (RAE) was, the system used to assess the quality of research conducted in Higher Education Institutes (HEIs) in the UK.

<sup>ii</sup> At a seminar observed by the author(s), a geneticist presented some work that demonstrated an association between a biological marker and schizophrenia. An audience member asked, 'could this be used in diagnosis?', to which the presenter replied with words to the effect 'well, maybe. But it would still be far more accurate to ask them if they experience delusions'.

<sup>iii</sup> If non-specialists are not to be considered a 'public' because they have experience and/or expertise in the related domains, then an argument can be made that almost any groups with any investment in



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issues addressed by the science in question should not be considered publics. This would include patients, carers, politicians with responsibility for health care, etc., and would mean that ‘public engagement’ would most often be limited to engagement with groups with no discernible stake in the issues at hand. Of course, it may be the case that in some disciplines medical professionals might be considered disciplinary peers of those conducting basic research – for example, in the case of cancer genetics it might very well be the case that oncologists are assumed to possess expertise in genetics that psychiatrists are presumed to lack. This adds weight to our argument that the resolution required to understand scientists’ attitudes towards public engagement and communication needs to be particularly fine.

<sup>iv</sup> Psychiatric disorders have been, and continue to be, discussed in terms of ‘character’ and ‘morality’ in ways that ‘somatic’ illnesses are not.