Exploring the implications of genetic testing in mental health care

Submitted by

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(Signature)…………………………………………………...
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Abstract

Now is a time of dramatic change in mental health care as the world is witnessing a proliferation of research into the genetics of mental disorders. Despite several genetic test developments there is a paucity of qualitative research exploring the issues concerning its potential future introduction. This inspired my primary research question: What are the main implications regarding the developments being made in genetic testing for mental disorders in terms of their proposed introduction in a clinical setting? This was investigated through 33 semi-structured interviews with a range of psychiatric professionals from a single NHS trust location in the South West of England. As research has demonstrated that different medical professionals consider issues in mental health care in different ways (Colombo, et al. 2003; Fulford and Colombo, 2004) participants’ personal constructs of mental disorder were examined to see if their accounts of the tests differed on the basis of their unique conceptualisations of mental distress. An additional component feature in this research relates to what these developments may ultimately represent or provide psychiatry and mental health care as a result of being able to consider mental disorders in terms of underlying biology. Historically there has been a persistent attempt to determine the underlying genetic components of mental distress, however, this always seems to fail or the next big development is always ‘just around the corner’ - this observation is considered when the major developments in psychiatric genetics are examined in light of the sociological field of the ‘promissory nature of science’ (Borup, et al. 2006) - I suggest that the developments in genetic testing for mental distress represent an iconic continuation of this process. Interview transcripts were subjected to thematic analysis and five themes were developed that cover aspects such as how the tests’ introduction will alter perceptions in mental health care, issues concerning the tests’ practical impact, their possible shortcomings, and how they may alter clinical practice. My findings indicate that, in the majority of themes, personal approaches to mental disorder do appear to influence participants’ accounts of the tests. The overall trend is that if an interviewee personally endorsed a biological approach to understanding mental disorder they would be willing to see the tests used in clinical practice. There were two areas of thematic agreement between all psychiatric professionals regardless of their conceptualisations of mental disorder. These concerned the impacts genetic testing could have on different aspects of the legitimacy of mental disorders and the significance of using the tests to aid in treatment rather than diagnosis. Implications of my thematic findings for patient groups, mental health services, and policy makers are discussed.
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1.0 - Introduction
This thesis investigates the developments occurring in the field of psychiatric genetics. In 2007, a Californian-based genomics research-company called Psynomics (www.psynomics.com) released the world’s first direct-to-consumer genetic tests advertised for use in mental-health care, their first test purports to determine an individual’s chance of developing bipolar disorder and their second test claims to determine patient response to anti-depressant medication. Since 2007, a series of additional advances have taken place, such as development of the world’s first blood-based test for the diagnosis of schizophrenia (www.veripsych.com), further research into pharmacogenetics (www.suregene.net), and personal genome companies, such as ‘23andme’ (www.23andme.com), have made similar tests available as part of their service packages. There is a considerable amount of interest in these advances from commentators and health care services alike. Commentators are quick to suggest the potential pitfalls of the tests (Mitchell, et al. 2010) while health care service providers (such as the Department of Health and the Medical Research Council) appear to be interested in exploring the use of such developments in a clinical setting. However, although there are examples of these direct-to-consumer genetic tests penetrating the online market place, there is a great deal of active research being conducted that focuses on the biological underpinnings of a variety of mental disorders. Several research intensive groups have been established that specialise in such endeavours. One example of this is the MRC Centre for Neuropsychiatric Genetics and Genomics, which is based in Cardiff Wales. The MRC web page (http://www.mrc.ac.uk/Ourresearch/Unitscentresinstitutes/UnitCentreDetails/MRC006217) presents the following aims of the institute:

The centre will tackle mental illnesses like schizophrenia and bipolar disorder, degenerative brain diseases like Alzheimer’s, Huntington’s and Parkinson’s, and developmental disorders like dyslexia and childhood depression. Its main aims are:

- Using genetics to improve understanding of the major disorders of the brain, building on the existing world-leading research expertise at the university;
- Training a new generation of scientists who can put this knowledge into practice with patients;
- A series of public events to break down misunderstandings about mental disease and genetic science;
- Creating a new professorship in translating our genetic knowledge into practical treatments.

On their website (http://medicine.cf.ac.uk/cngg/) there is a short video summary of the research this group is engaged with, Professor Michael Owen, the director of the institution, makes the following comment close to the start of the video:

*The research mission of the centre really has two components. The first is to try and understand the genetics of psychiatric disorders, particularly to identify the specific genes which predispose people to becoming mentally ill. And the second is to try and use this*
information better to understand the disorders, to try and help us develop better treatments and better approaches to diagnosis.

So although there may be a gulf between some of the research currently being conducted by institutes like the MRC group, which appear to still be exploring the kinds of issues groups like Psynomics claim to have already navigated, the overall trajectory is the same. Regardless of whether it is a self-regulated research group that has developed and released a genetic test independently, or whether it is a government-funded institution, it would seem that real efforts are being made to investigate the biological components of mental disorders and how this new knowledge base could translate into patient care.

This project aims to explore and uncover the issues surrounding the introduction of psychiatric genetic testing now that it is an emergent reality. I intend on investigating this by interviewing people who are likely to be implicated with the tests’ use - psychiatric professionals. ‘Psychiatric professional’ is the term used in this research to refer to anyone who works as a professional and is involved in the care of individuals who experience mental disorders - such as - nurses, psychiatrists, family therapists, occupational therapists and psychologists. I am suggesting that speaking to psychiatric professionals about these tests is one way to develop insights relevant to their potential future introduction in a clinical setting.

This work expands on several previous studies that explored the implications of genetic testing for mental disorders in a variety of different ways. The main contrast between this and other investigations is that here, emphasis is placed on the observation that the care of individuals who experience mental disorders is a multi-agency process (Colombo, et al. 2003 ; Rodgers and Pilgrim, 2005 ; Winston and Robinson, 2005). In accordance with this, there will be a focus on the proposition that different disciplines, and different psychiatric professionals within these disciplines, have unique personal conceptualisations of mental disorder (Colombo, et al. 2003 ; Fulford and Colombo, 2004). In the absence of a universally recognised explanation for the cause of mental disorder (APA, 2000 ; Coppock and Dunn, 2009), and given there is also significant controversy concerning their effective treatment (Puri and Treasaden, 2010), there are many different ways of making sense of mental disorder - and these are observable in a clinical setting (Colombo, et al. 2003). This phenomenon will be recognised in this research through inclusion of a methodological technique that assesses and determines participants’ different personal constructs of mental disorder – through assessment of their personal models of mental disorder (Harland, et al. 2009 ; Siegler and Osmond, 1966). This issue will be explored and discussed in detail later on during the thesis itself. However, for the time being, the feature to be aware of is that given the contested and elusive nature of the cause and most appropriate treatment for mental disorders, people can personally make sense of these issues in a variety of different ways. For example, one common contrast is between the role of medical and psychological intervention in conceptualising, diagnosing, and treating mental disorders. We will later see that although there is a set of around six common models adhered to in Western psychiatry, there are potentially infinite ways of making sense of mental disorder (Colombo, et al. 2003 ; Fulford and Colombo, 2004 ; Harland, et al. 2009 ; Siegler and Osmond, 1966). The intention of including this methodology is to see if participants who communicate different models of mental disorder consider the implications of genetic testing in different ways. To my knowledge this is the first research project recognising this concept and using
it as a method to navigate some of the possible issues concerning the introduction of genetic testing in mental health care.

When consulting the literature it becomes clear that qualitative investigations into the tests, and therefore a detailed understanding of the issues relevant to the early stages of their possible introduction, is lacking. This could be due to the observation that genetic testing for mental disorders is a relatively new development, and because of this, previous research into the issue has been conducted in a largely hypothetical context (for a summary, see Lawrence and Appelbaum, 2011). Although the indication is that genetic testing for mental disorders is, in some instances, considered favourably (Finn, et al. 2005; DeLisi and Bertisch, 2006), these projects do not investigate and explore the possible implications of these developments in a detailed way. My research intends to tackle this deficit through the use of qualitative methodologies with a view to gaining comprehensive insights into the potential implications of genetic testing for mental disorders.

This project will also contribute to our understanding of the criteria used in the assessment of genetic tests. A series of standardised criteria has been established, and these are considered in light of each new genetic test when they are developed and set up for use in the public domain (CDC, 2010). These criteria will be used as a platform for discussion and inspiration in this research project. Specifically, there will be a focus on the tests’ clinical utility as this component is considered crucial when examining developments in genetic test technologies, especially in the field of mental disorders (Mitchell, et al. 2010). However, there is not much previous research to draw upon when considering a genetic test intended for use in this way. The only other instance (Machtar, et al. 2007) where a remotely similar genetic test’s clinical validity and clinical utility was assessed ended poorly. A contributing factor to this is the original research team’s choice of methodology, as they investigated the test’s criteria through a meta-analysis of previously conducted research articles. However, at the time, appropriate papers were not available and it was impossible to answer their original research questions. This indicates previous issues concerning the understanding of these developments are related to methodological choices as well as an assumption that previous research papers can aid in assessment of the tests. These issues will be considered and navigated to ensure that relevant data is generated to facilitate appropriate analysis in light of my research questions. Primarily, I will be developing my own data through interviewing psychiatric professionals about the implications of the tests.

Although each of the previous studies that precede this research is significant, an additional factor that warrants attention is the sheer scale of mental disorders in terms of their overall economic impact and what they do for those who experience them. This illustrates the importance of conducting research on a genetic test technology that may help in easing the burden placed on society by the immediate effects of mental disorders.

1.2 - Scale of mental disorders

One way to illustrate the scale of mental disorders is to look at the government’s annual spending on the issue. A recent Department of Health investigation reports that the total investment in adult mental health services in the financial year 2011/2012 was £6.629 billion (Department of Health, 2012). However, this figure is dwarfed when compared to the estimated total economic burden that is thought to result from the impacts of mental disorders in a wider sense. In 2003, estimates
indicated that the combined cost of mental disorders in the United Kingdom, when factoring in features such as economic output, loss of productivity, and impacts on well-being were close to £77 billion (Department of Health, 2003). However, more recent suggestions predict that the cost may now be closer to £105 billion (Department of Health, 2011). Mental disorders are thought to contribute to work-place sickness of absence, costing the UK economy £8.4 billion a year, resulting in over £15 billion lost in reduced productivity (The Sainsbury Centre for Mental Health, 2007). Considering these statistics, mental disorders represent around 23% of the United Kingdom’s total burden of ill-health, and this accounts for the largest single cause of all disability. Close to 11% of the United Kingdom’s annual secondary health care budget is spent on mental disorders and some estimates predict that these costs could double over the next two decades (Department of Health, 2011).

However, although the economic impacts of mental disorders are clearly significant, an additional component to be aware of is the human scale and the impact these experiences have on people in the United Kingdom. The following statistics are taken from the Mental Health Foundation web site (Mental Health Foundation, 2012):

- 1 in 4 people will experience some kind of mental health problem in the course of a year
- Mixed anxiety and depression is the most common mental disorder in Britain
- Women are more likely to have been treated for a mental health problem than men
- About 10% of children have a mental health problem at any one time
- Depression affects 1 in 5 older people
- Suicides rates show that British men are three times as likely to die by suicide than British women
- Self-harm statistics for the UK show one of the highest rates in Europe: 400 per 100,000 population
- Only 1 in 10 prisoners has no mental disorder

Summarising all of these statistics in one sentence, it would perhaps be appropriate to say mental disorders are quite common among the general population. Therefore, any research that could potentially aid in easing the impact or sheer scale of these issues needs to be conducted as this is sociologically a weighty issue. However, both the economic impacts and the potential human burden are made significantly bigger when their predicted global consequences are considered, like they were in a recent Lancet commentary (Hock, et al. 2012, p.1367). Here is the opening paragraph from the paper:

Mental disorders account for 13% of the global disease burden, and major depression alone is expected to be the largest contributor by 2030. The economic effect is great, with mental disorders expected to cost nearly a third of the projected US$47 trillion incurred by all noncommunicable diseases by 2030. Meanwhile, the burden on people living with mental disorders is incalculable. Many of these disorders are lifelong and cross generations; they also affect neighbours, friends, and beyond in a ripple of concentric circles. A striking
example of the effect on family members is the association between maternal depressive symptoms and underweight and stunting in children reported in many countries.

Although these are only predictions, they make for extremely sobering reading. Not only does the current situation with regard to human suffering as a result of experiencing mental disorder appear quite serious, it is also predicted to get worse in the future. In addition to this the amount of spending on mental disorders will increase alongside these changes. Perhaps as a consequence of these bleak predictions, as well as an understanding of the current situation, the UK government appears to be making some significant efforts to raise public awareness to the realities of mental disorder and the impact it can have on peoples’ lives and their overall well-being. The most up to date account of this is published in the government paper ‘No Health without Mental Health: Implementation Framework’ (Department of Health, 2011, p.3). The first paragraph of this paper focuses on several issues covered here already, in terms of their scale, but this report also focuses on a slightly different aspect, that mental health is central to an overall healthy lifestyle:

*Mental health is everyone’s business. As ‘No Health without Mental Health’ states, ‘good mental health and resilience are fundamental to our physical health, our relationships, our education, our training, our work and to achieving our potential.’*

The rest of this document examines various aspects the government identified that need to be pursued when considering the idea ‘there is no health without mental health’. These range from combating the stigma associated with mental disorders, people who use the services having an increased role in how they engage with care provisions, early intervention, access to evidence based treatments, and considering the role of mental disorders in the work-place. However, in this document there is no mention of the advances that have been made in the field of psychiatric genetics. Other papers need to be consulted that allude to the plans to investigate the use of genetic testing in mental health care. These will be examined in detail in Section 5 of the Literature Review chapter, but broadly there are two papers that cover this aspect.

**1.3 - Official requests to conduct research into the underlying genetics of mental disorders**

The first indication is contained within a report published by the Medical Research Council that reviews the state of mental health research in the United Kingdom. This report suggests that the UK is well placed to be at the cutting edge of research into extending our understanding of mental disorders. This inquiry could contribute to these research proposals. The second report that focuses on similar issues was published in January 2012 by the Human Genomics Strategy Group. This document focuses on the potential ways a genomic research development could be used in a clinical capacity. Both of these papers in combination act as a prelude to where this project stands – they both indicate that there is a need to investigate these sorts of developments, in their early stages.

**1.4 - Influence of advances and developments in personalised medicine**

The developments being made in the field of genetic testing are occurring at a particularly timely and appropriate period in the history of medicine. Although the facts and figures regarding the global burden of mental disorder are distressing and sobering to read, it is essential to realise that the genetic research and development being conducted offer future hope to combat the ever growing impacts of mental disorders. Another way of illustrating why this is an appropriate time to conduct research along these lines is to consider the current state of play regarding the advances
being made in personalised medicine. In the preface to the working paper ‘Personalized Medicine: Trends and prospects for the new science of genetic testing and molecular diagnostics’ (United Health Group, 2012, p.4), a quote from Dr. Francis Collins, Director of the U.S. National Institutes of Health, is provided:

*Without question, man’s knowledge of man is undergoing the greatest revolution since Leonardo. In many ways, personalized medicine is already here.*

Not only does this suggest that personalised medicine should be regarded as a significant development, but it is one that is already here to benefit from. If the final paragraph of Dr. Collins’ 2003 editorial ‘The Genome Era and Mental Illness’ is to be believed, the aftermath of the human genome project and the translation of this research into clinical tools certainly has the potential to positively change the treatment landscape for mental disorders:

*In the same way that antibiotics revolutionized the treatment of infectious diseases in the 20th century, genome research stands ready to revolutionize the treatment of mental illness in the 21st century. But we in the biomedical research community cannot do this alone. We need the support of all those who have fought so hard over the years to raise awareness of mental illness and help the millions struggling with these conditions. Working together, we can build the bridge between today’s dreams and tomorrow’s reality. (Collins, 2003, p.30)*

Although this quote is clearly looking towards a positive future in the field of biomedical research into mental disorders, it is difficult to ignore the fact that the quote is almost a decade old. If we fast forward to more recent times there is still just as much promise in what this technology has to offer health care. For example, in a recent edition of Nature (Nature, 2011, p.161) there is an article focusing on major drug companies, such as Novartis, redirecting their research efforts away from strict neuroscience and launching new programs to investigate the genetics of psychiatric and cognitive disorders. The Nature article suggests this move is likely to have implications on future developments that will aid in both the identification and the treatment of individuals who experience mental disorders:

*Recent population-based, genome-wide association studies have identified many different genetic variants that individually confer tiny increased risk of disease, but which may act together to substantially increase a person’s susceptibility...Scientists hope that understanding the biological function of these risk genes may yield new clues about how to prevent or treat diseases....Companies also hope that they will be able to find genetic biomarkers — a particular DNA sequence or variation, for example — that will allow them to identify individuals who are likely to respond to a particular drug...*

Considering everything presented so far, there are a number of issues to deal with and when they are examined together, conducting a research project into the early stages of the developments being made in the field of psychiatric genetics is noteworthy for several reasons. Increased research into the genetics of mental disorders is occurring at a time where there is a considerable burden being faced by their impacts. However, although this research is currently ongoing, and we have started to see it translate into marketed tests, the implications of these developments are unknown. To my knowledge there is no *qualitative* investigation into the implications of genetic testing for
mental disorders, with a view to determining some of the main issues surrounding their use. The aforementioned United Health Group working paper concludes:

*Continued advances in genetics, genomics and proteomics have the potential to change medicine dramatically over the next several decades. In short, we can do more to realize the full potential of these new scientific discoveries, and improve the health of the population. It is time to do so.* (United Health Group, 2012, p.9)

Therefore, especially when considering the disease burden imposed by mental disorders, this is socially an important issue that is under-explored and ripe for investigation. As we have all of the main constituent elements here at our disposal, not devoting time to this enquiry now would be a mistake - we need to do anything that can help in this endeavour. If we are currently witnessing the very earliest stages of this sort of research and development, conducting this project now is valuable so we can be well prepared for future tests, or any related progression, via the insights gained here.

**1.5 - Aims**

This thesis intends on exploring these features by considering three main research questions:

1) **What, according to psychiatric professionals, are the main considerations and primary implications regarding the developments being made in genetic testing for mental disorders in terms of their proposed introduction in a clinical setting?**

2) **Do participants’ communicated models of mental disorder have any influence on how they view these proposals and can their responses be differentiated on the basis of the models they communicate?**

3) **From this, what are the main issues concerning the tests’ potential introduction that different demographics (patients, staff and policy makers) need to take into consideration and be aware of?**

In order to investigate these questions, semi-structured interviews with a spread of 33 psychiatric professionals, from a selection of different disciplines, who work in a position where they have clinical-contact in the care for people who experience mental disorders, will be conducted. As a springboard for discussion and to provoke relevant thoughts on the issues of interest, a two-page ‘participant information’ pack was created from the information that Psynomics made available regarding their tests. This will be given to participants in the interview setting, to provide an overview of the sort of testing that has been made available and is hopefully indicative of the future test developments. Although there will be discussion and commentary specific to the Psynomics tests, the idea is to gain insights applicable to genetic testing for mental disorders in a wider sense.

**1.6 - Thesis structure**

Following this Introduction chapter, this thesis will present: a literature review, a methodological chapter, presentation of the findings and a conclusion/discussion chapter.

**Literature Review**

The literature review is split up into six main sections:
1) Clarification of terms used in the research: In this section I focus on resolving several issues important to the direction of this research. I spend time examining the multi-agency nature of the care for individuals who experience mental disorders and I begin to allude to the different theoretical frameworks different psychiatric professionals typically adhere to.

2) The contested nature of mental disorder: In this section I focus on some of the difficulties and issues encountered when referring to mental disorders. We will see that there are a multitude of ways different individuals make sense of mental disorders as a phenomena. Ultimately we will see that determining the ontological basis of mental disorders is impossible, but we can consider them in terms of their epistemological standing.

3) Models of mental disorder: This section is devoted to the previous work that informs our ability to categorise the different ways of making sense of mental disorders. Use of this methodology will mean the need to clarify the nature of mental disorders is avoided; additionally the intention is that assessment of participants’ communicated models of mental disorder can be used to navigate their accounts of the Psynomics tests.

4) Previous research into genetic testing for mental disorders: A handful of studies has been conducted that examine some of the very early developments being made in genetic testing for mental disorders, as well as their potential implications. However, the majority of this previous research was completed through consideration of a hypothetical test, adopting a quantitative methodology, and by speaking to a restricted demographic of participants. All of these issues will be considered with a view to informing the best way to ensure this research produces appropriate and meaningful results.

5) Mental health genetic research initiatives and proposals in the United Kingdom: There are several official government endorsed papers that focus on the merits, opportunities and issues to consider when investigating the use of genetic test developments in a clinical setting. These will be examined in this section with a view to informing the direction of this study. Other than illustrating the timeliness of this research there will be a focus on the assessment criteria that are routinely applied to new genetic test developments.

6) Currently available and future developments in the field of genetic tests for mental disorders: Although the Psynomics developments will be used as a spring-board to elicit participants’ responses on the tests, there is a heritage of research, such as linkage, twin, and family studies, which focus on the underlying genetics of mental disorders previous to the advent of the Psynomics tests. These will be presented to provide adequate context for the research findings that are specific to the developments in genetic testing.

**Methodology**

In this chapter I describe the methods used to generate the data in this research project, how this was analysed and how the thematic findings were developed. The methodological technique used in this research is an example of thematic analysis (Braun and Clarke, 2006). I will also focus on examining the underlying philosophical paradigms and frameworks that underpin aspects of this research project – including the philosophical assumptions relating to the assessment of participants’ communicated models of mental disorder (Colombo, et al.
2003; Fulford and Colombo, 2004) as well as my personal world views and how these influence design of the research.

Findings

In the Findings chapter, I present the collection of five themes that resulted from my thematic analysis of the 33 semi-structured interviews conducted with a range of psychiatric professionals. These are: 1) Prioritisation of genetic explanations for the diagnosis and treatment of mental disorders; 2) Receipt of a test result, practical considerations, and the potential consequences; 3) Representations of mental disorder in light of the tests’ introduction; 4) What the tests can’t do; and 5) Using genetic testing for the treatment of mental disorders rather than the diagnosis of mental disorders. These themes will be presented after an initial introduction that examines the role of participants’ communicated models of mental disorder and how these influence their commentary on genetic testing. However, throughout each of the five main themes contained within this chapter there will also be specific references to instances where participants’ communicated models of mental disorder also appear to play a role in their accounts of the tests.

Discussion/Conclusion

Here I will argue that the developments in genetic testing for mental disorders have the potential to significantly alter the landscape of mental health care. Essentially if a governmental body was to give the go ahead to these sorts of technologies being used in a clinical setting, there are a number of aspects they would need to be aware of from the points raised by the participants in this research. In terms of thematic findings I will focus on areas where there was apparent agreement between participants about the tests’ implications regardless of their communicated models of mental disorder – these findings relate to the tests’ influence on the legitimacy of different aspects concerning mental disorders and using the tests to aid in the treatment of mental disorders rather than their diagnosis.
2.0 – Literature Review

Exploring the potential implications of genetic testing in mental health care will require analysis and a review of a number of different fields. This will range from consideration of the breakdown of psychiatric professionals typically found in a ward based environment, what is it they are all interacting with and treating – essentially what is mental disorder, the frameworks that a genetic test is routinely assessed in the United Kingdom, as well as a historical view of the field of psychiatric genetics. The final section regarding the history of the field of psychiatric genetics is an important one because there are going to be a wide selection of additional issues to consider - such as the historical developments leading up to the tests, some of the controversies concerning these developments and the sociological framing of these debates.

2.1 - The nature of psychiatry and mental disorders

This section of the chapter will clarify two aspects central to this research project, the first part will examine ‘psychiatry’ and the second will investigate ‘mental disorder’. Although these terms may be familiar they are more complex than they initially appear and require further explanation. For example, there is no universally accepted approach to the phenomena of mental disorder and because of this people have been shown to make sense of the issue in different ways (Colombo, et al. 2003; Fulford and Colombo, 2004). This means in a clinical encounter it is possible for different psychiatric professionals to have different views on what the individuals they care for are experiencing (Rodgers and Pilgrim, 2005). This suggests complete acceptance of the term ‘mental disorder’ would be a mistake because there is so much to consider and be aware of when using the concept. We will later learn that mental disorder can be considered a ‘higher level’ concept. A feature of higher level concepts is that although they are used frequently, their true complexity is hidden from us and we run into problems with their use when we focus on them in detail and think about their application across contexts.

When considering the nature of psychiatry we will see that it is a medical speciality concerned with the treatment of individuals who experience mental disorders, however, there are several additional features to consider. For instance, we will learn that psychiatry is not a single discipline operating from a single framework, but it consists of many different professional perspectives operating together at the same time (Colombo, et al. 2003; Fulford and Colombo, 2004). Psychiatry is a multidisciplinary medical speciality that consists of different professional groups who have been shown to conceptualise mental disorders in different ways. Initially this will be illustrated through examining the roles of the psychiatrist and the psychologist as they approach mental disorders from two distinct frameworks. However, we will also see that there are other disciplines that also play a pivotal role in the care for individuals who experience mental disorders. Therefore, it would be inaccurate to make claims relating to psychiatry overtly because there are several different disciplines practising within the speciality at the same time. When considering all of these aspects in light of this research as a whole, I want to assert that I am approaching psychiatry as an area of medical practice where the treatment of people who experience mental disorders typically occurs.

When considering the nature of mental disorder it will become clear that there are difficulties concerning exactly what is being discussed. This centres on there being no ontological reference point for the ‘object’ of mental disorder (Ahn, et al. 2009; Phillips, et al. 2012). However, the
phenomena can be considered in terms of how different people personally make sense of this ‘object’. In this case the question changes from ‘what is a mental disorder’ to ‘what is a mental disorder and how do we know them’. Approaching the issue in this way means that rather than considering the ontological basis of mental disorders, the situation changes to considering their epistemological standing. The contrasting ideas between psychiatrists and psychologists will again be revisited to illustrate these points.

After this, we will see a methodological technique exists that can be used to determine how any individual personally makes sense of mental disorders. This is achieved through assessing respondents’ models of mental disorder. Given the suggested absence of an ontological ‘object’ for mental disorders, different people can make sense of this ‘object’ in different ways, and how they go about doing this can be modelled and categorised (Colombo, et al. 2003; Fulford and Colombo, 2004). This methodology will be used to view and differentiate between different participants’ accounts of genetic testing on the basis of the models they communicate.

Before these aspects are investigated, I want to explore two terms often used when referencing the phenomena that the medical speciality of psychiatry is devoted to treating – mental disorders. It is common for the terms ‘mental disorder’ and ‘psychiatric disorder’ (and sometimes other related terms) to be used interchangeably in similar scenarios (Coppock and Dunn, 2009). This could cause confusion and therefore requires attention.

2.1.1 - Mental disorders and psychiatric disorders

Both of the terms ‘mental disorder’ and ‘psychiatric disorder’ are referencing the same thing. This is illustrated in the following report that focuses on infertility problems in women being linked to mental disorders. The term mental disorder is used several times in this article (Nauert, 2012), but so are the terms psychological anguish, mental health, and psychiatric disorder. Although the name changes it does not detract from the reports overall message - it is always clear what these different terms are referencing. Clarification of this is provided when the author conflates two terms when focusing on a single diagnosis. Schizophrenia is mentioned in both the following extracts, but in the first instance it is called a psychiatric disorder and in the second it is called a mental disorder:

*These higher risks were evident in alcohol and substance abuse, schizophrenia and eating disorders, although appeared lower in affective disorders including depression. The results suggest that failure to succeed after presenting for fertility investigation may be an important risk modifier for psychiatric disorders.*

*Women who remained childless after their initial fertility investigation had a statistically significant higher risk of hospitalisations for all mental disorders than the women who went on to have a baby. But infertility was also linked to a significantly greater risk for alcohol/substance abuse, schizophrenia and other mental disorders.*

Focusing on this distinction is important because it will aid in how different aspects are referenced later on in the thesis – specifically it will help when clarifying and separating the terms psychiatry and mental disorder. But why have I chosen to use the term mental disorder in this thesis? Choice of terminology is crucial because it suggests an allegiance to a particular set of perspectives (Warner, 2009). In her review of the sociology of mental health, Joanne Warner points out the distinction between ‘mental illness’ and ‘mental and emotional distress’. The former term is typically used in
situations where it is thought ‘mental disorders’ can be identified, diagnosed, and treated via medical means, she notes that when using this terminology the contested nature of diagnostic categories is downplayed. The latter term is used to imply a more problematic stance in relation to the issues under discussion. Although I acknowledge that the expression mental disorder is not free of any association (for critical review of essentially every common term used in psychiatry please refer to www.antipsychiatry.org) and is therefore likely to be unpopular with some people, I am choosing to use it in this project for several reasons. Firstly, there needs to be some word used to reference the something the medical speciality of psychiatry is devoted to dealing with. I am proceeding under the assumption that any phrase is as good as any other providing I am honest about its connotations and potential conflicts with other perspectives. Secondly, the developments in the field of psychiatric genetics are implying a situation whereby they can be identified, diagnosed, and treated via medical means — therefore the term is in direct accordance with the aforementioned example.

2.1.2 — A helpful take on Psychiatry

In this section my intention is to point out that psychiatry is a special and rather unique area of medical practice. However, simply leaving it at this would be a mistake, because there are several additional aspects to consider as the practice itself is built up of a selection of detailed and complex components. For example, the practice of psychiatry — which is ultimately concerned with the diagnosis and treatment of an individual who experiences mental disorders — is a multidisciplinary activity. The multidisciplinary team is made up of psychiatrists, psychologists, nurses, social workers, general practitioners and a number of other groups. However, the situation becomes complicated when we realise that these different disciplinary groups, as well as individuals from within these groups, can have dramatically different conceptualisations of mental disorder. Perhaps one of the most distinctive splits observed in psychiatric practice is seen when the typically recognised conceptual approaches of two disciplines are compared and contrasted — those of psychiatrists and psychologists - as members of these groups differ dramatically in their academic training. Psychiatrists are medically trained, while psychologists are not, they conceptualise mental disorders via the science of psychology. However, later on we will see that this contrast should only be used as a ‘rule of thumb’ because even within these groups there are recognised accounts of differential models operating with respect to the same individual at the same time.

In the medical text book ‘Review of General Psychiatry - 5th Edition’ (Goldman, 2000, p.2) psychiatry is characterised as follows:

*Psychiatry is a discipline of observation and probing inquiry, a basic science of behaviour, and a clinical science of mental disorder and emotional responses to physiological change, somatic illness, and life events. Critics in neuroscience characterize psychiatry as brainless; critics within psychological medicine fear that psychiatry will become mindless. Students everywhere are concerned that the medical curriculum not be witless. Our aim is to present psychiatry with the proper mix of brain, mind, and wit.*

Although this characterisation contains a great deal of information about what psychiatry is and even alludes to some of its popular criticisms offered from other disciplines, it is outdated and does not focus on anything other than the role of the psychiatrist. This is understandable because the book it came from is aimed at people who are training or work in a medical context. Considering
this, it is difficult not to recognise that psychiatry is the dominant discourse, in terms of the perspectives outside of sociology, used to conceptualise mental disorders in developed countries (Warner, 2009). Psychiatry is a speciality within medicine and its practitioner, the psychiatrist, is trained to aid in the diagnosis, prognosis, aetiology, and treatment of mental disorders (Rodgers and Pilgrim, 2005). However, psychiatrists are not the only disciplinary group who care for people with mental disorders. I want to explore some of these aspects in the next part of this chapter. Specifically, I want to examine some of the differences between psychiatric and psychological approaches to mental disorders.

2.1.3 – A focus on psychiatric and psychological approaches

The first section of the information pack aimed at recruiting medical school graduates or people interested in the treatment of mental disorders into a career in psychiatry, ‘Make a Difference. Improve Lives – a Career in Psychiatry’ (Royal Colleague of Psychiatrists, 2012), discusses ‘What is Psychiatry’, and the following is offered:

*Psychiatrists are medically qualified doctors who specialise in the care of patients with mental disorders.*

When considering the ways specific aspects are referenced, this extract provides a distinction that needs to be recognised from this point on, and this will help clarify terms when they are used throughout this research. This is the separation of psychiatrists away from the phenomena of mental disorders. Although it will soon become clear that psychiatrists are rather distinct in their professional role, the same caveat - separation of the discipline away from mental disorders - would still apply if the focus was on psychologists, family therapists, nurses, or pharmacists. *The distinction is that each of these disciplines is concerned with the care of people who experience mental disorders.* The crucial issue being that mental disorders are the phenomena different disciplines within the medical speciality of psychiatry are devoted to treating. The next part of the ‘What is Psychiatry’ information booklet focuses on the range of mental disorders patients who receive care from psychiatrists are likely to experience:

*Our patients experience a range of mental health problems, including psychotic disorders, depressive disorders, anxiety and stress related disorders, dementia, personality disorders and addiction problems.*

The same varieties of mental disorder are also attended to by clinical psychologists. This is explained in similar recruitment pamphlet (British Psychological Association, 2010):

*Every day clinical psychologists help a wide range of people of all ages with all sorts of problems. Some have particular emotional or mental health problems, such as depression or schizophrenia. Others have difficulties with their thinking (also known as ‘cognitive’ problems). These can take many forms, such as problems with memory or perception after a head injury, a learning disability or dementia.*

Therefore psychiatrists and psychologists appear to share similarities if we think about the focal point of both disciplines – they are both concerned with the care of people who experience mental disorders. However, although both specialities may concern themselves with the same phenomena they are very distinct in how they each interact with it. Both the Royal Colleague of Psychiatrists
(RCP) and the British Psychological Association (BPA) acknowledge this; here is what the RCP say about the distinction:

*Some people are confused about the difference between a psychologist and a psychiatrist. A psychiatrist is a medical doctor who specialises in psychiatry. Clinical psychologists are usually individuals who, after a first degree in psychology, spend a further 3 years studying clinical psychology and then have a particular expertise in the delivery of psychological treatments.*

Here, the distinction between psychologists and psychiatrists is that a psychiatrist is a medical doctor specialising in psychiatry, this was mentioned in the very first extract, ‘Psychiatrists are medically qualified doctors who specialise in the care of patients with mental disorders’, but here we are starting to see some of the emergent differences between both of these disciplines. In this case, although psychologists are doctors, they are not medical doctors. This difference is elaborated on a stage further in the information provided by the BPA:

*Clinical psychologists and psychiatrists often work in the same clinics and see people with similar problems, but there is a clear difference between them. Clinical psychologists’ key role is to consider what the science of psychology tells them about how to help with the problem. And psychiatrists’ key role is to consider what the science of medicine tells them about how to help with the problem. They are each able to do this because the first stage in training as a clinical psychologist is a degree in psychology, whereas the first stage in training as a psychiatrist is a degree in medicine.*

Therefore the main difference between psychiatrists and psychologists is that psychiatrists rely on their training in the science of medicine to help them interact with mental disorders, while psychologists rely on their training in the science of psychology. The BPA provide an example illustrating how each discipline would likely approach a patient who is depressed:

*So if you are depressed...a psychiatrist is best placed to help you think about whether a biological treatment like antidepressant drugs may help. And a clinical psychologist is best placed to help you think about whether a psychological therapy like cognitive behavioural therapy may help.*

Although the two groups share common ground with respect to acknowledging the role they play when interacting with individuals who experience mental disorders, the RCP information illustrates that psychiatrists have some unique rights and privileges that do not appear to be possessed by psychologists:

*The psychiatrist in the team is uniquely qualified to make diagnoses, evaluate and manage risk, and draw up treatment plans for those patients with the most complex disorders. We then use our expertise to engage with our patients, who may be in considerable distress, to ensure the implementation of treatment plans involving physical, psychological and social interventions...A particular responsibility of the psychiatrist is the treatment of those patients who lack insight and capacity. We may treat patients using the Mental Health Act and the Mental Capacity Act. A thorough knowledge of the law and the need to safeguard the best*
interests of the patient is therefore a key aspect of the work of a psychiatrist, particularly when treating those patients who are the most ill.

2.1.4 – Relationship to the characterisation of psychiatry

Both psychiatrists and psychologists play an important role in interacting with individuals who experience mental disorders, but each discipline has a different set of fundamental approaches, limits and restrictions concerning what its members are able to do. In terms of the characterisation of psychiatry, this section of the discussion has separated the phenomena of mental disorder away from the speciality of two disciplinary groups within the practice. The important aspect to keep in mind is that mental disorders are the phenomena both psychiatrists and psychologists interact with – but they go about doing this in remarkably different ways. The fundamental distinction being that psychiatrists are medical professionals and psychologists are not because they have not received medical training. This observation provides a valuable clarification when considering the character of psychiatry in mental health care because it removes both disciplines away from the group of people to whom it is typically applied – the individuals who experience mental health problems. The biggest issue here is the resolution of terminology and a realisation of scale.

Psychiatry is a specialised area of practice, which involves professionals who operate from different theoretical frameworks – such as psychiatrists and psychologists who differ in their professional training. However, I think it could be easy to get confused with respect to all of these different points of reference as well as the different terms being used. For example, although psychiatry is the area of medical practice concerned with the diagnosis and treatment of individuals who experience mental disorders, there are different disciplines operating from within this practice. So far I have focused on some of the differences between psychiatric and psychological approaches to mental health care, however, in a following section we will learn that there are other professional groups to consider. What makes this even more complex is that psychiatry as an area of practice is itself multifaceted.

Examining the ‘Make a Difference : Improve Lives – a Career in Psychiatry’ recruitment pack there are case studies that focus on the different areas within psychiatry that someone interested in the profession can aspire to begin training in. Observing this reveals how multifaceted psychiatry really is, for example, there is child and adolescent psychiatry, forensic psychiatry, general psychiatry, old age psychiatry, and medical psychotherapy. Each of these areas focus of different demographics of people – such as their age or the variety of mental disorder they present with. Considering this puts into perspective how broad psychiatry as a medical speciality really is, and thinking about this illustrates why I need to be precise when I refer to different aspects of it.

So although a relatively ‘stock’ definition of psychiatry is available from various places - the one below is from ‘NHS Choices’ web page (http://www.nhs.uk/conditions/Psychiatry/Pages/Definition.aspx) - it is significantly more complex than this because there are other issues to consider:

*Psychiatry is a medical field concerned with the diagnosis, treatment and prevention of mental health conditions. A doctor who works in psychiatry is called a psychiatrist.*

Even if this definition is intended for general information it is still important to realise that it neglects some subtle aspects alluded to when considering the previous information from the RCP and BPA.
For example, there is no mention of the different points of view, or the different theoretical frameworks that psychiatrists and psychologists would traditionally be thought to operate from. It also neglects to mention that psychologists are also doctors, who do also work in the field of psychiatry, but rather than using the science of medicine to intervene with mental disorders they use the science of psychology.

So far, this discussion separates ‘mental disorder’ away from ‘psychiatry’, this is important because mental disorder is a very complex term within psychiatry itself. We will see that although psychiatry may be concerned with the phenomena of mental disorder, there is a great deal of controversy regarding what ‘it’ (mental disorder) actually is - and this issue also requires detailed consideration. Additionally, it might be easy to make generalisations, such as referring to ‘psychiatry’ as an entity in isolation but doing this would not be accurate because psychiatry is extremely multifaceted. What has become clear is that psychiatry is a medical speciality where different disciplines, which can have different conceptualisations of mental disorder, all practice together. This has been illustrated through observing the differences between the role of psychiatrists and psychologists and how these different groups approach the phenomena of mental disorder. However, psychiatrists and psychologists are not the only disciplinary groups who come into clinical contact with individuals who experience mental disorders. Psychiatry is much broader than this as it is made up of nurses, occupational therapists, and family therapists who are also involved in providing care. Ignoring the role played by these groups would be a mistake because they have a significant amount of contact with patients in clinical settings.

2.1.5 - The multidisciplinary team in psychiatry and mental health care

Mental disorders are treated by a team of trained professionals who all have varying skill sets and experience, this is examined in the paper ‘The multidisciplinary team and the non-pharmacological treatment of schizophrenia’ (Winston and Robinson, 2005):

(Figure 1 – Taken from Winston and Robinson, 2005, p.44 a comparative diagram of the roles and skill sets in multidisciplinary teams.)

Other than psychiatrists and psychologists Winston and Robinson note that nurses, social workers, GPs, support workers, occupational therapists, physiotherapists, and the patient themselves are additional members of the multidisciplinary team involved with treating mental disorders. There are many shared skills between these groups; but each also has its own specialised set of core skills they provide in their professional role.
It is important to be aware of these issues when conducting this research as it will have important consequences on the methodological design and implication of this work. For example, as psychiatry is such a diverse field being able to interview a range of professional groups within the speciality would be beneficial because they each receive different training and, as we know from examining psychiatric and psychological perspectives earlier, they are likely to understand and interact with mental disorders in different ways. Therefore, it is imperative to contact a range of different disciplines within the practice of psychiatry because this will provide a holistic view of the field of psychiatric genetics. But it is also important to be aware of the contrasting viewpoints each psychiatric professional operates from, as these may have an influence on the way they consider the implications of genetic testing.

To clarify, this research is interested in exploring the clinical implications of the developments being made in the field of psychiatric genetics and mental health care. Psychiatry is one, and perhaps the most likely, location where this activity occurs – therefore it would seem reasonable to seek the opinions of those involved in the practice about the tests. However, simply referring to psychiatry in isolation and not devoting any time to considering how the speciality is constructed would be a mistake. Although psychiatrists may be the most readily associated medical practitioners of this speciality, the reality is other disciplines also contribute to the care of individuals with mental disorders, and these different disciplines have different ways of making sense of mental disorder (Colombo, et al. 2003 ; Winston and Robinson, 2005). What makes this even more complicated is there is not even overall agreement between the psychiatrist community about how they themselves go about interacting or conceptualising mental disorders (Rodgers and Pilgrim, 2005). This observation will be tackled in a future section of this thesis when different conceptual models of mental disorder are explored. Before this I want to explore the concept of mental disorder.

2.2 – Exploring the concept of mental disorder

The concept of mental disorder is at the foundation of psychiatry (Varga, 2011), however, despite its important place in the field there is no popular agreement on how it should be referenced or defined. The American Psychiatric Association (APA) acknowledges this in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (APA, 2000, p.xxx):

The concept of mental disorder, like many other concepts in medicine and science, lacks a consistent operational definition that covers all situations.

As this research is concerned with investigating genetic tests intended to aid in the diagnosis and treatment of mental disorders, time needs to be spent focusing on this issue because without clarification regarding what the tests actually focus on there could be future complications. For example, there may be differences between different people concerning exactly what it is being investigated - because there is not a universal definition of the term ‘mental disorder’, the term may mean different things to different people. To illustrate this, some of the differences between medical and psychological approaches to the issue will be investigated. After this some different additional approaches to understanding mental disorder will be examined, and finally an approach that will feature heavily throughout this research project, which is intended to represent all the possible ways of making sense of mental disorder, will be presented.
2.2.1 - Psychiatry and psychology

As noted previously, psychiatrists and psychologists differ in the content of their academic training. This contrast is discussed in a number of different contexts. For example, consider the following quote taken from a paper that examines the relationships between different disciplines within psychiatry (Stein, et al. 1981, p.89):

*Psychiatrists have emphasized that psychologists need to be firmly rooted in biology, medicine, and in clinical experience. Psychologists retort that psychiatrists need to absorb the advances in theory and method made by academic psychology. Psychologists caricature modern psychiatrists as pill pushers, guardians of social conformity; while psychiatrists counter-stereotype psychologists as knowledgeable only of psychodynamics, and amateurs at best. Psychologists argue that psychiatrists trade on their patients' transference and dependency; while psychiatrists argue that psychologists try to cure quickly what they don't first understand.*

Although this alludes to the idea that there is a degree of inter-professional conflict between the two schools, the important aspect is that each discipline is aware, and keen to point out, the perceived shortcomings of the other. I think a significant source of this conflict is based in the contrasting theoretical frameworks that they both operate from – as they are mentioned in this quote. This suggests that examination of these ideas will help in this investigation of these approaches. To do this, a lesson in the way mental disorders can be considered in Western societies is required.

2.2.2 – Medical/biological and psychological models of mental disorder

If the DSM definition of mental disorder is considered, mental disorders are understood as being a ‘clinically significant behavioural or psychological syndrome or pattern that occurs in an individual and that is associated with present distress’ (APA, 2000, p.xxx). However, the causes of these disturbances are bitterly contested, as there is not an agreed-upon understanding of what elicits them (Coppock and Dunn, 2009). For example, in the case of bipolar disorder it is acknowledged to have both a biological component, because individuals have been shown to respond to medication, and a psychosocial element, because individuals also respond to talking therapies (Craighead and Mikilowitz, 2000). So where does the root of these contested ideas regarding the causes of mental disorder lie? Clearly there are instances where contrasting approaches can work together, such as the aforementioned example of bipolar disorder, but is this the exception rather than the rule? I think these issues rest on and can be explained in terms of distinct models of illness. This can be seen when contrasting the medical/biological model with the psychological model.

Mental disorders are often thought to be illnesses, and in Western culture, illnesses are thought to have biological bases (Ahn, et al. 2009). Considering illness in terms of the medical model the belief is that the diagnosis of a mental disorder would involve the naming of an objective disease process (Coppock and Dunn, 2009). Additionally, the biological model considers manifestations of a suspected mental illness in terms of tissue and cell pathology (Dilts, 2000). The biomedical model has dominated the popular approach to medical care in the West for the last 200 years and this model is based on five assumptions: the mind and body can be treated separately, the body can be repaired like a machine, there is a reliance on technological advances and procedures, explanations of disease focus on biological causes and that every disease is caused by a disease agent - such as a
virus (Tyrer and Steinberg, 2000). This model would assume that mental disorders operate in this way too.

However, if the psychological model is considered, a significantly different situation arises. The overriding theoretical framework is different, and as a result so is the way an individual presenting with a mental disorder would typically be assessed and treated. The psychological model of mental disorder considers a current mental disorder presentation as being the result of former mental states (Dilts, 2000). This model makes no reference to impaired nervous function or any other physiological complications, but considers mental disorders in terms of patterns of previous mental states, (thoughts, feelings, perceptions, cognitions and behaviours) culminating in the current observed presentation. A practitioner who adopts the psychological model of mental disorder would treat a mental disorder through a series of one-to-one therapy sessions. The ultimate goal of these sessions is to change fluctuations in mental state, which caused the individual to seek (or require) help in the first instance, so that the person can rectify the issue and lead a ‘normal’ life (Tyrer and Steinberg, 2000).

If the aforementioned Stein and colleagues quote is revisited (Stein, et al. 1981) there appears to be differences in how the contrasting disciplines within psychiatry adopt and refer to each model. If both models are considered it appears that psychiatrists sometimes endorse biological models and psychologists sometimes endorse psychological models in their practice, this difference refers back to the earlier example when both disciplines initial training were contrasted when considering the character of psychiatry. There are additional documented examples where this is also considered the case. For example in the book ‘Common Mental disorders: A Bio Social Model’ David Goldberg and Peter Huxley write:

_Mental disorders can be studied at two levels...about how the brain works, or...how man behaves as social animals. The former approach uses powerful new methods of enquiry...from molecular biology, neuropharmacology and immunochemistry...the latter uses methods...from epidemiology and social sciences. Recent...advances in...biology have lead to...emphasis on the former, so that some psychiatrists approach the subject as though they need to know little more than the way in which the cerebral functions can become disorganised during episodes of mental illness. At the other end of the spectrum are those psychotherapists and social workers who believe that abnormal behaviour can be wholly explained in social and psychological terms... (Goldberg and Huxley, 1992, p.1)_

An important aspect to be aware of is that there have been different claims made about the predominant model of mental disorder and how it functions as an exemplar for popular understanding at a given time or location. For example, in American psychiatry many assert that the biomedical model is predominant and psychological terms are treated as metaphors for biological processes (Ahn, et al. 2009). Anne Rodgers and David Pilgrim in their book ‘The Sociology of Mental Health and Illness’ write, ‘Western psychiatry is an eclectic enterprise. It does, however, have dominant features. In particular, diagnosis is considered to be a worthy ritual for the bulk of the profession and biological causes are favoured along with biological treatments.’ However, if we look back into the history of psychiatry we see that before the advent of a taxonomic classification system for different diagnoses, and the use of pharmaceutical intervention, a specific variant of the psychological model was very popular; this is represented by Sigmund Freud’s brand of
Psychodynamic therapy. Psychodynamic therapy focused on understanding mental disorders via unconscious forces, subtle language patterns, lapses of memory, slips of the tongue, and the analysis of dreams (Puri and Treasaden, 2010). Therefore the popular approach to conceptualising mental disorders is prone to change on the basis of competing theories and ideas that resonate at the time. These are representative of a particular model in operation being dominant over any other at a specific time. One suggestion concerning the decline of talking therapies in the shadow of biological explanations is provided in the following quote from the medical text book ‘Psychiatry: an Evidence Based Text’ (Puri and Treasaden, 2010, p.14):

By the 1990s, the ‘talking therapies’, although intellectually established in terms of art, criticism, and literature, had run into a series of debates as to effectiveness, cost–benefit, and the nature of ‘distress’. Why talk à la Woody Allen to a shrink three times a week for 15 years, when Prozac could make you feel alright within a month?

This quote subtly hints at an additional point that needs to be mentioned, which will be explored later on in this review. Although there certainly appears to be an observed split between those who endorse the biological model of mental disorders and those who adhere to psychological models, the implications of this disparity are likely to run a great deal deeper than it would first seem. A possible reason for this is that people with mental disorders often fall into a system that means they can sometimes get treated in a way that is perhaps too reliant on the biological model of mental disorder. Framing mental disorders in terms of biology means that they can be intervened with in this way, essentially via pharmaceutical use, and this ultimately equates to financial profit. In the book ‘Models of Madness’ John Read, Loren R. Mosher and Richard P. Bentall note that although different people may personally make sense of mental disorders in terms of difficulties originating in their life circumstances, one very powerful branch of the profession, biological psychiatry, insists on prioritising the role of biology over alternative explanations. This is thought to be encouraged by the support of the pharmaceutical industry in order to promote the use of medication that costs money and maximises profits (Read, et al. 2004, p.116). This indicates that sometimes there can be a conflict of interests when considering mental disorders and what they are. This transcends discussion so far and acts as a convenient bridge into the next section, which will focus on some of the other recognised ways of understanding mental disorders.

2.2.3 - Additional accounts of mental disorder
This look into biomedical and psychological models is only part of the story, as there are many diverse approaches to understanding mental disorders recognised over the world. For example, mental disorders are conceptualised in different way in different cultures. In predominantly Muslim countries, if medical and religious intervention has failed to benefit an individual’s mental state, their family may turn to traditional healing practices such as the Zar Cult. This is the belief in evil spirits that possess people and cause them suffering – including mental disorders. Once the spirits enter a person they are never removed but they are appeased through the use of Zar. Zar provides relief from possession and it consists of a person entering a trance through dancing, singing, snake handling, and the beating of drums. This happens until the individual gets exhausted and collapses and this is said to mark the removal of the evil spirit from the affected subject (Endraws, et al. 2007). Similar approaches to the cause and treatment of mental disorders, reflective of cultural understanding and heritage, have also been documented in Harare Zimbabwe (Patel, 1995).
Rather than thinking about the strict biological or psychological reasons why or how mental disorders manifest, some academic institutions attempt to understand their evolutionary origins. In the paper ‘Anxiety: An Evolutionary Approach’ (Bateson, et al. 2011) the authors suggest that to gain a better understanding of anxiety disorders there needs to be a better appreciation of the anxiety response. This means considering its symptoms in terms of their proposed evolutionary function as well as the mechanisms underlying them. Ultimately they argue that anxiety functions to prepare the individual so they can detect and deal with threats. They reach this conclusion through examining individual symptoms and reasoning how they may endower a person with specific survival benefits. For example, the authors suggest the symptom of insomnia confers alertness, and the symptoms of restlessness and increased heart rate are due to the body preparing itself for immediate action if a threat is perceived.

Finally, there are some scholars on the topic of ‘mental disorder’ who adamantly refute the legitimacy of the phenomena. An iconic exemplar of this is seen in the paper ‘The Myth of Mental Illness’ (Szasz, 1960). Szasz’s main thesis is that the myth of mental illness functions as a smoke screen that legitimises a form of social control and enables one party to dominate moral conflicts over another. He reasons that mental disorders are defined in terms of determining behavioural defiance on the basis of certain psychosocial, ethical, or legal norms – yet they are invariably treated in terms of intervening with an individual’s biology or removing them from society and withdrawing certain rights. He makes the point, ‘Since medical action is designed to correct only medical deviations, it seems logically absurd to expect that it will help solve problems whose very existence had been defined and established on non medical grounds’ (Szasz, 1960, p.115).

These examples demonstrate that there are a multitude of different approaches to conceptualising the phenomena of mental disorder. Although there may be dominant approaches to their diagnosis, prognosis, aetiology, and treatment – which for the most part fall within the remit of biological frameworks in psychiatry (Rodgers and Pilgrim, 2005) – this does not mean that this is the only frame work in which mental disorders are considered. Rodgers and Pilgrim point out psychiatrists can be influenced by other discourses such as psychology, philosophy and sociology, but we also know that the psychiatrist does not have to be privileged when considering this dynamic, there are other disciplines that also aid in the treatment of mental disorders and these should be recognised.

Given what was established in the previous section, that the care of individuals who experience disorders is a multi agency activity, and what has been established in this section, that there are multiple perspectives relating to how this could be achieved – it is important to be aware of this when conducting this research. Primarily, the implication will be that different psychiatric professionals are likely to adopt different stances with respect to their conceptualisation of mental disorder, and because of this they are possibly going to consider the implications of genetic testing for mental disorders in different ways. However, so far this account has only been concerned with the perspectives of those closely involved with mental disorders - perspectives within psychiatry, what about the typically recognised discourses from within social science? As this research is interested in gaining insights into the developments being made in the field of psychiatric genetics, it is important to recognise the landscape where this is intended to occur is far from simple. However, it is also important to be aware of the dominant sociological perspectives regarding mental disorders because I need to be transparent in what it is I intend to achieve, and how I am going to do it in this project.
2.2.4 - Sociological perspectives regarding mental disorders

A detailed insight into several sociological perspectives concerning mental disorders is available in the previously referenced book ‘The Sociology of Mental Health and Illness’ (Rodgers and Pilgrim, 2005). However, here I want to focus on three approaches and the distinctions that are discussed by one of the authors in isolation, David Pilgrim, professor of mental health policy at the University of Central Lancashire. These are presented in his 2007 paper ‘The Survival of Psychiatric Diagnoses’.

Pilgrim notes that psychiatric diagnoses have been bitterly critiqued in a multitude of different ways, and he asks how and why it has survived as a form of popular reference. The point of the paper is not necessarily to provide a detailed answer to this directly, but his intention is to pave the way for future research into the question, and part of this will occur through sociological investigation. This means being able to reflect on previous work in terms of its epistemological and ontological discourses about the nature of mental disorder, as well as being transparent about our own approaches to the issue. He provides three contrasting approaches that are also mentioned in other accounts with a similar level of detail (Baltrušaitė, 2003 ; Rodgers and Pilgrim, 2005 ; Warner, 2009):

- **Medical naturalism**
  The ontological assumption is that mental abnormality simply exists ‘out there’, awaiting verification by expert observers. The epistemological assumption is that these naturally occurring categories are inherently pathological.

- **Radical constructivism**
  The ontological assumption is that reality is socially constructed - mental disorder does not simply exist awaiting verification. The epistemological assumption is we can only know the world via the ways we represent it.

- **Critical realism**
  The ontological premise is that the world exists and is real but our investigations of it are saturated with interests and values. The epistemological consequence is that we must approach all knowledge claims sceptically or “critically”. This task is even more important in the human sciences because we are part of our own context. (Pilgrim, 2007, p.539).

Previous research into mental disorders can be considered in light of these discourses. For example, efforts on behalf of the American Psychiatric Association to categorise and classify mental disorders in the DSM would reflect medical naturalism; because the assumption is mental disorders are real phenomena suitable for classification in this way. Although the standalone methodology chapter in this thesis will elaborate on all of the necessary details in light of the complete research design, focusing on this point for a moment is important when all of the background that has been provided so far is considered. For example, how do these discourses integrate with what has been discussed so far with respect to research into mental disorders being a complex issue, in terms of dealing with the multitude of different conceptual approaches that have been observed?
2.2.4 – Navigating the ambiguities of mental disorder

Although the APA may offer a definition for the term mental disorder in the DSM, there is still no overall agreement on the concept. It is impossible to be adequately defined in a way that satisfies everyone who is interested in it. Although there may be recognised approaches that dominate certain situations, such as the reliance of the biomedical model in America (Ahn, et al. 2009), or even attempts to combine multiple models, such as the biopsychosocial model (Engel, 1980), these have all been criticized in different ways. For example, some argue that the biopsychosocial model should be discarded as it has outworn its use as a relevant approach to conceptualizing mental disorders, and that the notion itself rejects the important ‘art’ oriented humanistic aspects of psychiatric practice (Ghaemi, 2009).

Is there any way to navigate these issues? One possible way to proceed would be to recognise what is common between all of these examples, as every example recognises there is something being referenced when we discuss mental disorder, but what is that something? It is not as if people say they do not understand what we mean when we use the term mental disorder in conversation. I think this idea could be considered in terms of mental disorders’ ontological and epistemological standing. As the previous discussion has attested, the ontological status of mental disorders is difficult to determine, indeed this claim is supported in other accounts that also look into this issue (Ahn, et al. 2009 ; Phillips, et al. 2012). This is likened to the idea that there are a multitude of different perspectives to the phenomena of mental disorders. Given the elusive nature of the ‘object’ of mental disorder, different people have the opportunity to speculate on what this is for themselves - therefore the question can now change. Rather than asking ‘what is a mental disorder?’ we now ask, ‘what is a mental disorder and how do we know them?’

This observation was inspired from the research article ‘The six most essential questions in psychiatric diagnosis: a pluralogue part 1: conceptual and definitional issues in psychiatric diagnosis’ (Phillips, et al. 2012) that examines a series of philosophical questions concerning the DSM-5 revision and its possible updates. Part of this paper spends time examining the issues of ontology and epistemology in the study of mental disorders. A thought experiment was devised and several scholars of psychiatry were asked to provide their commentary concerning how these aspects relate to different philosophical approaches. American psychiatrist and philosopher Claire Pouncey offers the following insight into the ‘ontic’ status of mental disorders:

Mental disorders generate ontological scepticism on several levels. First, they are abstract entities that cannot be directly appreciated with the human senses, even indirectly, as we might with macro- or microscopic objects. Second, they are not clearly natural processes whose detection is untarnished by human interpretation, or the imposition of values. Third, it is unclear whether mental disorders should be conceived as abstractions that exist in the world apart from the individual persons who experience them, and thus instantiate them. Together, these reasons to doubt the ontic status of mental disorders become quite persuasive. (Phillips, et al. 2012, p.6)

When thinking about all of these issues, research into anything relating to mental disorders or psychiatry has the potential to be extremely complicated and care needs to be exercised when designing a project on the topic, because there is so much to be aware of and to consider. For example, if the ‘ontic’ status of mental disorder is this difficult to discern, how should we approach
this issue in this project? Is it a mistake that other research in the field does not devote time to these ideas? For example, much of the research that will be reviewed later in regard to the early stages of genetic testing for mental disorders seems to simply accept what mental disorder ‘is’ without these sorts of discussions, is this an oversight? As we know from the previous discussion, there appear to be a multitude of different approaches that are implying some form of ‘status’ or ‘object’ for mental disorders, how can anyone go about keeping a grasp on all the possible explanations, ideas and theories that exist without prioritising one over the other, or maybe even ignoring several completely? What are the implications regarding discipline association? We know that although there may be rough splits between disciplines and their adherence, or rejection, of particular models – such as psychologists typically viewing mental disorders in terms of psychology rather than underlying biology – is this applicable to every member of the discipline? I do not think this is likely to be the case, especially when psychiatrists are considered because their training is very broad and encompasses a variety of different perspectives (Rodgers and Pilgrim, 2005).

Is there any way all of these different questions can be dealt with, possibly in a way that satisfies everyone, is respectful of their disciplinary background, and encompasses all the possible accounts of mental disorder? I think there is, and I also think it can be utilised to good effect in this research project. This is achieved by determining each individual’s personal account of mental disorder, and rather than concerning ourselves with dominant paradigms that are prone to change, criticism or incompatibility with other approaches, we focus on unique personal insights into mental disorder and use these as a basis for this enquiry. This is achieved through assessing participants’ models of mental disorder. Before this idea is introduced and explained in detail I want to revisit the issues of ontology and epistemology in social science research into mental disorders as this is important in understanding the methodology of this research.

2.2.5 - Ontology and epistemology of social science research into mental disorders

The ontological basis of mental disorders can be refuted, and as a consequence of this I am suggesting that the best we can currently do is consider them in terms of their epistemological foundations. This is ideally suited and integrates well with the application of the models of mental disorder approach, but before this is introduced and all of these components are linked together and explained, I want to briefly refer to these two claims about the nature of social reality as they are important to the ways that mental disorders are going to be conceptualised in this research project. These perspectives are provided by Joanne Warner in her paper ‘The Sociology of Mental Health’ (Warner, 2009, p.632):

- Ontology refers to the claims of assumptions that a particular approach to social enquiry makes about the nature of reality – claims about what exists, what it looks like, what units make it up and how these units interact with one another.

- An epistemology is a theory of knowledge; it presents a view and a justification of what can be regarded as knowledge – what can be known, and what criteria such knowledge must satisfy in order to be called knowledge rather than beliefs.

As mentioned previously, the ‘ontic’ status of mental disorder is difficult to define; however, there is more promise in approaching the issue in terms of its epistemological basis. This will be explored
through assessment of psychiatric professionals’ models of mental disorder. Rather than attempting to discern the ‘object’ of mental disorders in terms of something we can see or touch, we change direction and try to assess how people go about the process of knowing this ‘object’.

2.3 - Models of mental disorder

I was aware that I would have to deal with the concept of characterising mental disorder at some point in my thesis, but my knowledge of this particular methodology came about through sheer luck. I gave a departmental talk in my first year that focused on the issue of characterising mental disorder and after the presentation one of my colleagues sent me the links to two papers (Colombo, et al. 2003 ; Fulford and Colombo, 2004) that were hugely influential to my research. Initially my interest in the technique was to satisfy the need to characterise mental disorder. However, it soon became apparent that the approach could also be used to deal with the fact that the treatment of mental disorders is a multidisciplinary effort. In this section I want to focus on several areas. First of all I want to explain how the underlying philosophy of the methodology can be used to deal with the question of ‘what is a mental disorder’. After this I want to provide some relevant background to the idea and its use in other contexts.

2.3.1 - Brief background and how the methodology can be used when considering mental disorder

Development and application of the models of mental disorder methodology initially stemmed from a series of problems in community mental health care (Fulford, 2001). Several research reports and official enquiries investigated a series of failings in community care (Report of the Clinical Standards Advisory Group, 1993; Rogers, et al. 1993) and came to the conclusion there needs to be better communication between disciplines within psychiatry to facilitate better care of patients. However, as Fulford points out, these studies were not able to determine why communication breaks-down. The hypothesis, and subsequent research conducted in the field of models of mental disorder is focused on the idea that there is a breakdown in care due to communication problems that are a result of the different ways people understand mental disorders (Fulford, 2001). With the suggestion being different people, with different backgrounds and experiences, may bring different models of mental disorders into practice.

The research team concluded that the differences that emerge between different practitioners approaches to mental disorders are conceptual. They reason that philosophy is concerned with conceptual problems and that the use of ordinary language philosophy brings to these conceptual problems three main features – an understanding of its origins, a methodology for dealing with it, and the production of practically relevant results (Fulford, 2001). A significant aspect of ordinary language philosophy is that when it comes to concepts we are better at using them than we are defining them. This is particular to what are described as higher level concepts – ones that we use to structure and make sense of the world, the example of ‘time’ is provided - we can measure time, but we cannot define time.

The same reasoning can be applied to mental disorder, although we may superficially appreciate what we are talking about when we use the term ‘mental disorder’ it is actually something that is very hard for us to define, however, if we pick a related ‘lower level’ concept we have more success. Fulford gives the example of a chair, which is easier to define than furniture, which is in turn easier to define than functional object. When this applies to mental disorders, we have problems defining
the higher level concept – mental disorder, but it is easier to define its related lower level concept aspects, such as delusion of guilt.

The final philosophical issue concerning the background of the models of mental disorder approach and using it to define mental disorder, relates to our every day use of higher level concepts. This suggestion is based on the work of Oxford philosopher John Austin (Austin, 1956). Austin suggests that we are so familiar with using higher level concepts that their real complexity is hidden from us. It is only when something goes wrong with the use of a concept that we run into problems and difficulties. Fulford suggests that this problem can actually be exploited to come up with a solution to the issue. He makes the connection that just like diabetes led to the discovery of insulin, the difficulties faced concerning the concept of mental disorder can be used to provide an answer to the problem.

Fulford and Colombo (2004, p.133) give an analogy when trying to define ‘what is mental disorder’, to a mural on the walls of a darkened room with a group of people each using a pocket torch to illuminate a small section that is unique to them. The link to be made here is that upon combining each ‘piece’ of the mural you will have the whole picture – and the same should, theoretically, hold true when characterising mental disorder. The philosophical feature relating to this idea is inspired via the work of Cambridge philosopher Ludwig Wittgenstein and his work on the use of language. His work on higher level concepts relates to the suggestion that when we try to define them, we typically grip onto one particular aspect of the meaning that is available to exclusion of all the others. Therefore we only ever gain a partial view of the problem at hand, and ‘the illusion’ is that we take a part for the whole. Fulford and Colombo suggest this feature should be applied to the study of mental disorder, examining all suggestions offered by everyone and collectively examining the statements in order to gain the best possible hold on the situation, rather than excluding ideas, combining them all in order to illuminate the higher level concept.

This is illustrative of the issues regarding the ontology and epistemology of mental disorders. It is impossible for any person in the darkened room to ever be completely aware of what the painting is actually representing. Although they may be able to make a guess, and they may even be right on the basis of what they can see – they are never going to be completely sure of what it is, this applies to the situation regarding the epistemological nature of mental disorder. The people in the room are never going to be completely sure of what their pocket torch is highlighting, so if they were asked to suggest what it was the chances are they would make an informed guess on the basis of what they could see. They would be guessing what the ‘object’ is on the basis of the way they perceive their section. If the painting on the wall was replaced with ‘mental disorder’ the situation could be likened to a psychiatrist being able to ‘see’ biological aspects, while a psychologist may ‘see’ psychological aspects. It is impossible to currently determine exactly what ‘it’ is, its ontology, so the best we can do is determine what people think ‘it’ is (or how they know it), its epistemology.

2.3.2 – A closer look at models

Although this background may provide an answer to the problem regarding a working definition of mental disorder as a concept, there is not a great deal of background concerning what models of mental disorder are, how they are defined and how they are determined. The Fulford and Colombo paper ‘Six Models of Mental Disorder: A Study Combining Linguistic-Analytic and Empirical Methods’
(Fulford and Colombo, 2004) provides a detailed account of this. The authors provide the following definition of models:

*Models...are the conceptual frameworks, or sets of ideas, by which, in any given area, people structure and make sense of the world around them.* (Fulford and Colombo, 2004, p.136)

The next question to ask is what are the conceptual frameworks used in the definition of ‘models’? Conceptual frameworks have actually been referenced several times throughout this discussion. For example, the biological and psychological models discussed earlier are conceptual frameworks that different people use to structure and make sense of the world around them, so are the anti-psychiatry, the evolutionary and the cultural suggestions offered earlier. Through reviews of the literature (Colombo, 1997; Fulford, 1998; Siegler & Osmond, 1966) Fulford and Colombo (2004) identify six formal models of mental disorder that people typically subscribe to: the medical (organic), social, cognitive/behavioural, psychotherapeutic, family, and conspiratorial model. They use this framework as a basis for design and construction of a table that defines a series of 12 parameters (such as diagnosis/definition, interpretation of behaviour, labels, aetiology, treatments, functions of the psychiatric hospital) each parameter is placed alongside the series of models they discovered from their literature search. Below (Figure 2) is an example of this table:

<table>
<thead>
<tr>
<th>Questions addressed</th>
<th>Models/elements</th>
<th>Medical (organic)</th>
<th>Social (cues)</th>
<th>Cognitive-behavioural</th>
<th>Psycho-therapeutic</th>
<th>Family interactions</th>
<th>Conspiratorial</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is the nature of mental disorder?</td>
<td>Physical health—illness continuum</td>
<td>Health/illness continua</td>
<td>Physical health/illness continuum</td>
<td>Normal-abnormal continuum</td>
<td>Continuum of emotional distress difficulties</td>
<td>Whole family is sick not just patient</td>
<td>Mental illness is a myth. A continuum of deviance</td>
</tr>
<tr>
<td>Interpretation of behaviour</td>
<td>Symptoms of illness are a rough guide to severity</td>
<td>Symptoms indicate degrees of stress</td>
<td>Taken at face value, seen as acceptable/not acceptable</td>
<td>Disclose/interpret symbolically to give it meaning</td>
<td>Look at behaviour of all family members</td>
<td>Mental illness is a myth. A continuum of deviance</td>
<td></td>
</tr>
<tr>
<td>Labels</td>
<td>Based on a patient’s collection of symptoms</td>
<td>Person is seen as a victim of social forces and not as ill</td>
<td>Should focus on actual problem behaviour</td>
<td>Discussion about labels hide the individual</td>
<td>Externalize an illness which is inherent in the family itself</td>
<td>Mental illness is a myth. A continuum of deviance</td>
<td></td>
</tr>
<tr>
<td>Aetiology</td>
<td>Physiological changes in the brain, Genetic factors</td>
<td>Social and economic stress, cultural conflict, marginal status, etc.</td>
<td>Inappropriate learning, poor coping skills, etc.</td>
<td>Unusual traumatic early experiences</td>
<td>Patient acts in response to family pressures</td>
<td>Mental illness is not something that is socially defined</td>
<td></td>
</tr>
</tbody>
</table>

Figure 2 – Models of mental disorder table. Taken from Colombo, et al. 2003, p.1559

Examining each of the ‘models’ that run across the top row and the ‘elements’ that run down the left most column it becomes clear that this table is certainly reflective of a number of different conceptual approaches to psychiatry, some of these have been included in this review chapter. For example, looking at the ‘Medical (organic)’ column there is clearly an emphasis on the role of an individual’s biology being causative for their mental disorder, the ‘Psycho-therapeutic’ column is reflective of psychodynamic therapy, while the ‘Conspiratorial’ column is perhaps representative of some of the anti-psychiatry debates. These models were assessed by taking the participant through a case vignette, which described a man called Tom who is presenting with schizophrenia-like symptoms. From a semi-structured interview, with questions relating to each component of the model, their responses were coded in accordance with the model of mental disorder they communicated. An example concerning the aetiology question is provided. Interviewees were asked “What do you think caused Tom to behave like this?” A psychiatrist replied, “…well to this type of problem there is strong evidence of a genetic contribution and Tom’s family history seems to
support this. So in this case, Tom probably has schizophrenia, which has a genetic basis”. This response would have been coded as agreeing with the medical model dimension for aetiology.

A small selection of instances where conceptual models of mental disorder have been previously used will be reviewed next. All methodologies in each of these papers are remarkably similar, essentially they involve identifying a collection of popular conceptual models from within the literature and seeing which variants people adopt as their personal approaches to mental disorder. However, I am not aware of any research that explains the process as well as the twin papers from Colombo, Fulford and colleagues, especially in terms of the underlying philosophy of the technique. Therefore, once the other examples have been presented I will reintroduce their work as it provides additional information that is important to consider in this project.

2.3.3 - Models of Madness - Siegler and Osmond 1966

Fulford and Colombo suggest this is the first example where different models of mental disorder were identified and classified. Siegler and Osmond’s paper is concerned with the multitude of different explanations that exist for patients who present with what was recognised as being schizophrenia. Their account begins with the following:

"Schizophrenia is disputed territory. Thus, the numerous theories put forth to explain it are of all sorts: biochemical, genetic, religious, psychoanalytic, sociological, cross-cultural, international, legal, moral, and so forth. (Siegler and Osmond, 1966, p.1193)"

The authors argue that schizophrenia is not only a medical problem, but it is also a social problem, and because of this there are various ways of dealing and interacting with it, such as its legal or moral implications. Recognised ways of dealing with schizophrenia use popular theories, while others are based on theories that are poorly understood. Some of these approaches are thought to be incompatible with one another, and sometimes people may not be aware that they are using several different models to conceptualise schizophrenia at any one time. The authors suggest that being aware of the different models used when referring to schizophrenia will mean that people will better understand the frame works by which they operate, and this will enable greater transparency when developing strategies relevant to the care of affected individuals.

The authors identified several different theories about schizophrenia and organised them into six groups: medical, moral, psychoanalytic, family interaction, conspiratorial, and social. The different theories were made into models by arranging each of them alongside a set of dimensions that were originally derived from the medical model. The authors did this because they must be derived from somewhere and the medical model was reasoned to be the most strongly held at the time. The set of dimensions are as follows:

- Course of the illness - diagnosis, or definition, aetiology, interpretation of behaviour, treatment, prognosis, and suicide.
- Incarceration of the patient - function of the hospital, termination of hospitalization, and personnel.
- Defining responsible conduct for the participants - rights and duties of patients, rights and duties of families, and rights and duties of society.
The six models that the authors defined are then pulled apart and considered in terms of each of these dimensions. I am going to present the aetiology dimension of first two models (the medical and the moral models) as a comparison, the exact same format is utilised for every dimension of every model:

*The aetiology of schizophrenia is not yet known, but, with present medical progress, there is every reason to hope for answers in the near future.*

*Aetiology is a great mystery in the moral models, unless the patient-inmate comes from a family with similar behaviour, in which case it is probable that he learned it directly from them. However, this is not important; the main thing is to change the behaviour. (Siegler and Osmond, 1966, p.1197)*

This research essentially provided the ground work for the models of mental disorder approach. Although the authors do not go any further than identifying six popular models of schizophrenia and offering some suggestions concerning how the treatment programs for affected individuals are likely to benefit from being aware of the different models they operate from, the foundations for this approach were originally provided in this paper. Similar methodologies have been used in other research papers, for example, the previous table (Figure 2) in the Fulford and Colombo work on mental disorders uses this framework exactly.

### 2.3.4 - A study of psychiatrists’ concepts of mental illness – Harland, et al. 2009

The intention of this paper was to investigate trainee psychiatrists understanding of mental disorders in terms of the different models available. A total of thirty two questions (four questions relating to a total of eight models) were devised and participants were asked to provide their answers in a five point Likert scale - ranging from 1, signifying strong disagreement, to 5, signifying strong agreement. The four questions were designed to capture the foundations of each model with respect to the aetiology, classification, research, and treatment of four specific disorders - antisocial personality disorder, depression, generalized anxiety disorder, and schizophrenia. Here is an example of the questions from the 'biological' set of questions:

1. The disorder results from brain dysfunction
2. The ideal classification of the disorder would be a pathophysiological one
3. The appropriate study of the disorder involves discovery of biological markers and the effects of biological interventions
4. Treatment of the disorder should be directed at underlying biological abnormalities

The authors conclude that *trainee* psychiatrists are predominantly committed to the biological model of schizophrenia, but generally are not committed to one model overtly. They also suggest that improved understanding of how professional groups make sense of mental disorder may aid in multidisciplinary team working.
2.3.5 - Psychiatrists' models of mental illness and their personal backgrounds (Toone, et al. 1979; Kreitman, 1962)

This paper was referenced in the previous Harland and colleagues work as it used a very similar methodology and was completed in the same location some thirty years prior to their 2009 contribution. However, the intentions of the two papers are quite distinct. This paper (Toone, et al. 1979) was more interested in determining communicated models of mental disorder on the basis of respondents’ background, and the authors found that participant adherence to different models is dependent on a variety of factors such as their educational history and thoughts concerning mental disorders when growing up. However, the pertinent issue here is how they achieved this. The Toone and colleagues research was heavily inspired by the research study ‘Psychiatric Orientation: A Study of Attitudes among Psychiatrists’ (Kreitman, 1962). The broad aim of this research was to investigate the ‘orientation’ of psychiatrists in terms of their endorsement of two dominant approaches – the ‘medical’ approach typically used in general medicine and what would be recognised at the ‘psychological’ approach.

Just like the Harland and colleagues research, a questionnaire was designed that factored in these two contrasting psychiatric orientations and psychiatrists were asked to mark their allegiances to their preferred orientation, the difference being that the Kreitman paper only adopted these two approaches as opposed to the eight from the Harland research. Essentially this research determined that different professional experiences correlated with different psychiatric orientations in practice. A similar summary can also be offered of the Toone and colleagues’ paper, the research team point out that individuals need to be aware of the contrasting differences that different practitioners in psychiatry hold. This research paper elaborated on the Kreitman work by adding the models of behavioural therapy and social psychiatry while determining participant support for each model by asking them to fill out a questionnaire, answering questions using a Likert scale.

2.3.6 - Return to Fulford and Colombo research

With some of the background, and an understanding of the context where similar approaches have been previously used, I want to finish this section of the chapter by focusing on the research that originally inspired my interest in using this approach. This account will mention some of the important issues that need to be considered when designing the methodology in this research project.

2.3.7 - Quantitative and qualitative issues

There are two main features to contend with when considering this methodology, and these stem from the observation that in each example participants’ models of mental disorder were determined qualitatively, on the basis of models that were previously identified from the literature. Although in every example the authors were able to demonstrate that either different models existed, or that different people adhere to different models, I think these findings were somewhat constrained by the choice of methodology. This centres on the fact that although open ended responses were given to each question concerning ‘Tom’ the framework these responses were coded against is constrained by the literature they adopted when designing the research. What if a response was given that was not represented by one of their identified models?
The authors themselves point out that all of the models they defined could be wrong (Fulford and Colombo, 2004, p.133). Although the technique originally developed by Siegler and Osmond, which identified models and constructs them in terms of 12 dimensions, was used in Fulford and Colombo’s research – and on initial inspection these do appear to account for some of the most popularly recognised approaches to mental disorder in the literature – I do, to an extent, agree with their suggestion that the models they identified could be wrong. Perhaps not wrong in as much as they do not correspond with peoples personal ideas about mental disorders, but because they perhaps could be a little too restrictive to account for all of the possible thoughts on this issue. I intend to navigate this possibility in this research by adhering to strictly qualitative methodologies. This will be explained in detail in the methodology chapter, but for the time being, asking participants about their thoughts and opinions on mental disorders during the interviews is the way I propose to do this. This means that rather than being constrained by any set of models before I start the research I can code participants’ responses in accordance to the models they communicate, with a fundamental grasp of the models available, rather than trying to fit their responses into any predefined category. However, the next question that requires thought is what will I really be eliciting when I ask different people about their thoughts and opinions on mental disorders?

2.3.8 - Addressing the implicit/explicit division

Fulford and Colombo (2004, p.136) recognise this issue and they write:

> Asking people, whether professionals or users, directly about mental disorders will elicit, mainly, their explicit views. The most familiar explicit model, nowadays, is perhaps the so-called “biopsychosocial” model. Most people in health care will say that it is to this that they ‘sign up.’ If the linguistic-analytic insight is right, on the other hand, if with such concepts use is a surer guide to meaning than explicit definition, then their practice, how they actually respond to and deal with mental disorders, will be driven by their implicit models of disorder.

Therefore, I need develop a series of questions that are detailed enough so they elicit implicit models of mental disorder. I intend to do this by asking them detailed questions about how they personally respond and deal with mental disorders; this will be explained in the methodology chapter.

2.3.9 - Summary

Clearly no technique used in the study of mental disorders is perfect and completely free from any complexities or issues. I am not under the illusion that the methodology introduced here, which will be described fully in my methodology chapter, is necessarily perfect, but I do think it will serve two main benefits when used in this project. First of all it will negate the complex issue of contending with the nature of mental disorders. I am assuming that when I use the phrase everyone will know what I mean and they will subsequently attach their own meaning to the term – which will be explored through my open ended questioning. Secondly, determining the participants’ models of mental disorder in the way described will hopefully enable some form of differentiation of responses about the developments in genetic testing for mental disorder on the basis of the models they communicate. We know that different disciplines within psychiatry orientate around different theoretical frameworks for understanding mental disorder, this could mean that different psychiatric professionals who communicate different models of mental disorder may have different views on the developments being made in genetic testing for mental disorders.
2.4 - Previous research into genetic testing for mental disorders

There is not a great deal of research available concerning the developments being made in genetic testing for mental disorders, this could be reason enough to design and conduct further investigation in the field. Although repeating previously conducted research in a different location, or with a different demographic of respondents may prove insightful, having a grasp on previous contributions means there is a higher chance of being novel and insightful. However, above all of this the intention is to produce work that extends the knowledge base, even if just a small amount and perhaps in a new direction. Before these contributions are considered it is important to realise exactly what each paper in this literature review section is actually doing, and after this to be aware of the gap this research intends to fill.

Much of the previously conducted research in this field has essentially focused on determining people’s attitudes and beliefs towards genetic testing in a selection of different scenarios – such as patients’ views on the introduction of hypothetical genetic testing for bipolar disorder (Trippitelli, et al. 1998) or similar studies focusing on psychiatrists’ thoughts about similar developments (Hoop, et al. 2008). This study follows in this tradition; however, there are going to be several differences between this research as well as the intention and methodologies adopted by previous efforts. As far as I am aware there is no published research that examines psychiatric professionals’ thoughts and beliefs regarding a previously released genetic test. Although they have been withdrawn from the market, the previously available tests from Psynomics will be used as a spring board for discussion to elicit responses about these developments. In addition to this we will see that this project will also differ from the papers in this literature review in other ways. First of all this project is going to be contacting a wide range of disciplines involved with the treatment and care of individuals with mental disorders. Other accounts are predominantly oriented around eliciting mainly psychiatrists, or other smaller groups’ accounts of the tests. I do not feel that these research contributions are reflective of the multidisciplinary team of professionals involved in mental health care. The other major distinction will be awareness of differential communicated models of mental disorder and the possible implications these may have on respondents’ consideration of the tests.

Although the criteria typically used to assess genetic testing developments will not have a primary role in this research, this is another area where my project differs slightly from previously conducted research. The next part of this literature review will focus on the ways that genetic tests are traditionally assessed and that previous attempts to do this in the field of mental disorders have been largely fruitless. Therefore, this research has the potential to contribute to this body of work through inclusion and consideration of this methodology; these criteria are not mentioned in any real detail in the papers about to be presented.

2.4.1 - Summaries of relevant research

Robust reviews of the literature regarding attitudes and beliefs in relation to the potential impact of genetic testing for mental disorders have already been conducted. The most detailed and comprehensive review I can find is the paper ‘Genetic Testing in Psychiatry: A Review of Attitudes and Beliefs’ (Lawrence and Appelbaum, 2011). As this paper summaries the most up to date and relevant research on the topic there is no point repeating what has already been achieved elsewhere. However, I want to offer a distinction between the contrasting methodologies adopted
by all of the papers included in their review, with a view to demonstrating how this research fills a clear gap in the literature.

At the end of their paper Lawrence and Appelbaum provide a breakdown of all the papers they included in their review. They make a distinction of the basis of quantitative surveys and qualitative studies. There are a total of 18 quantitative surveys and just 6 qualitative studies. Rather than simply suggesting that meta-analysis of the relevant papers has been completed I want to point out some of the restrictions in each paper with a view to the standing of this research as well as informing its methodological design.

2.4.2 - Quantitative surveys of beliefs about genetic testing in psychiatry

Although each of the studies Lawrence and Appelbaum included in this section contribute something to investigating the developments being made in genetic testing for mental disorders, they all suffer from the same set of fundamental issues. Firstly, their choice in methodology means that exploring detailed meanings and insights into the potential implications of genetic testing for mental disorders is impossible. For example, although several papers (Finn, et al. 2005; DeLisi and Bertisch, 2006) may demonstrate that the majority of psychiatrists would be willing to use genetic testing in their clinical practice, there is little exploration of the issues surrounding why they would, or the possible implications of their choices. This is an artefact of the methodological design of the research contributions themselves. There is nothing intrinsically 'wrong' with this quantitative approach, because it serves an important purpose in isolation and all of the results provide important grounding when considering the role of this work, because they suggest that genetic testing for mental disorders is something worth researching. However, rather than ascertaining that a large percentage of psychiatrists would be willing to use genetic testing in their clinical practice, I feel that a more useful insight, given the opportunities available to me, would be to gain a better understanding of the broader and significantly more detailed implications now they are a tangible reality.

The second concern I have with the majority of research papers included in Lawrence and Appelbaum’s meta-analysis is the breakdown of participants included in the projects. My primary concern is that the breakdown is not reflective of the multidisciplinary nature of the teams that typically provide care for people with mental disorders - the majority of papers focus on psychiatrists in isolation, individuals with mental disorders and their family, or members of the public. There is only one paper (Mrazek, et al. 2007) that provides any real spread of participants, in terms of their disciplinary roles in mental health care, however, there is a significant disproportion of psychiatrists (n = 31) compared to nurses (n = 3), a social worker (n = 1), a psychologist (n = 1), and researchers (n = 2). Criticising these contributions is only relevant when my research goals and methodological perspectives are considered, but one clear implication of this disparity is that the participants recruited in the research papers included in Lawrence and Appelbaum’s analysis are not representative of the participants I am interested in speaking to now that genetic testing for mental disorders is an emergent reality. This reflects my suggestion that the care of people with mental disorders is a multidisciplinary effort and this typically involves several different disciplines who each bring a unique set of skills to the table. More specific than this, the primary intention is to get the most holistic view of the developments as possible, and I intend to do this by speaking to a spread of professionals from within psychiatry.
Finally, all of these research papers have been conducted in a largely hypothetical context. The majority have been executed with a view to ascertaining different peoples’ thoughts and opinions on the developments in genetic testing for mental disorders with little to no appreciation of the biological nuances of the technologies’ actual operation, limits, restrictions, or overall applicability. This is something that Lawrence and Appelbaum recognise in the summary of their analysis:

"However, the data...are based largely on projections regarding future genetic tests, rather than on tests currently available." (Lawrence and Appelbaum, 2011, p.11)

I consider this to be another reason why this research project is timely. There could be differences between some of the previous findings and any that I generate because I will be using a previously released test to elicit responses. Actually using a previously released genetic test to elicit responses would be the simplest way of avoiding a research study that is based on the thoughts, opinions and attitudes of the developments in a strictly hypothetical fashion. This could mean that contrasting my findings with previously published ones will require some lateral thinking because of the differences in methodological design. However, the previous discussion still applies in relation to this point, specifically that the Psynomics tests are unlikely to be a reflection of the future of psychiatric genetic testing. Also, given the current state of the science, these technologies are a long way off from being used in the clinical setting.

2.4.3 - Qualitative studies of beliefs about genetic testing in psychiatry

All of the previously provided caveats and critiques, apart from the issue concerning quantitative methodologies, apply to these qualitative research studies. Adopting a qualitative framework for this research contribution does seem like a sensible way to pursue my research goals given the historical track record of research in the field. For example, although all of the papers included in this qualitative section are not focusing on the developments like I propose to, they are all successful in eliciting detailed responses from participants about the issues the authors are interested in exploring. The issue here is that the responses and insights developed do not really have anything to do with my research intentions now we have seen genetic testing for mental disorders penetrate the market and there are new proposals to investigate their clinical impacts.

This is partly due to these studies operating in a largely hypothetical context. A previous research paper, which is perhaps the closest to this study in terms of its design and research goals, is concerned with the publics’ interest in predictive genetic testing, including direct-to-consumer genetic testing, for susceptibility to major depression (Wilde, et al. 2010). This study found that the majority of participants would be interested in genetic testing for depression if it were available, however, after discussing some of the implications and considering the potential positive and negative implications 24 of the 36 participants changed their minds. Participants were concerned about possible discrimination and they had privacy concerns over the tests’ clinical use. Wilde and colleagues claim that participants were largely against the idea of direct-to-consumer genetic testing for mental disorders. The authors suggest that their study highlights the importance of education about psychiatric genetics, the suite of treatments, and support that is available prior to the tests’ future use. However, although there may be similarities, in terms of the methodology used in the Wilde and colleagues’ research and what I intend on doing, this is still far removed from what it is I want to achieve in this project. For example, I’m focusing more on the potential clinical ramifications of these tests and although commentary may be provided about issues such as education, my
intention is to get a broad and detailed view into the developments from psychiatric professionals – rather than that of the general public.

It is at this point where introducing another summary of the research into genetic testing in psychiatry is warranted, the paper in question is ‘Predictive and Diagnostic Genetic Testing in Psychiatry’ (Mitchell, et al. 2010). This paper reviews many of the research articles included in the Lawrence and Appelbaum paper, and the authors arrive at essentially the same conclusion and offer the same criticisms of the previous work. However, the authors also include a section specific to the criteria typically used to assess genetic test developments for their use in an official capacity. These aspects will be considered in detail in the following section of the literature review.

2.4.4 – Summary

All of the previous research into the implications of genetic testing for mental disorders can essentially be gained from two separate review papers (Lawrence and Appelbaum, 2011; Mitchell, et al. 2010). However, it is the former paper that summarises all of the research in a far more succinct way. Keeping in mind that all research was conducted in a hypothetical context, for the most part attitudes towards genetic testing among clinicians, patients, and the general public are favourable. However, the majority of concerns were voiced over issues relating to possible discrimination and not being able to cope after receiving a test result.

Although these findings serve a purpose in isolation, they do not necessarily enlighten my research goals any further than knowing genetic testing for psychiatric disorders is something that most people questioned in a small number of studies, by the same pool of authors, are willing to entertain. In this research I need to be able to investigate these issues in a new way. In an extremely simplistic form, one way of looking at this situation would be that we are beginning to see the translation of research into genetic test developments for the diagnosis and treatment of mental disorders into usable genetic tests. However, there is a distinct lack of qualitative empirical work investigating this issue in the literature. In order to bridge this gap it seems reasonable to seek the thoughts and opinions of people who are likely to come into contact with individuals who may choose to use the tests personally, or alternatively, speak to people where the tests may become part of the clinical framework in the future. Admittedly the developments of these tests are still in their early stages, but it seems reasonable to use a test that has already been made available to provoke discussion about their possible implications. This is going to be one of the major contrasts of this research compared to previous efforts. However, one aspect from the Mitchell and colleagues’ review paper that can certainly be used as further inspiration as to how this should be achieved is seen in the criteria that are traditionally used in the assessment of genetic test technologies. These will be examined in the next section along with some additional resources that suggest research of this kind should be conducted.

2.5 - Mental health genetic research initiatives and proposals in the United Kingdom

There are several features to examine when considering the current situation regarding the assessment of genetic test technologies in the United Kingdom. These issues are positioned in a significantly more complex scenario with respect to the implications of genetic testing for mental disorders. Although research into the biological aspects of mental disorder, as well as the use of genetic technologies in the clinical setting, is something currently receiving a lot of promotion and attention, we will learn that translating these research goals into useful and informative outcomes is
not a straightforward task. Part of this problem is due to ways that genetic technologies are typically assessed. We shall see that the criteria customarily used to appraise genetic test technologies, which principally orientate around physical health, do not adequately translate over to the assessment of mental disorders because of methodological flaws and a lack of previous research. However, a specific aspect of these criteria can be adapted and used for inspiration in this investigation.

The first step in the process is to acknowledge the need to actively conduct research along these lines. Currently there are several initiatives regarding increased research into the ramifications and use of genomic technologies in health care generally as well as the biological underpinnings of mental disorders. To begin with these will be presented and examined separately as, initially, they appear quite distinct – but my ultimate goal is to combine these two strands of research, with the intention of providing further justification for this project. As it stands, the suggestions made concerning research into the inclusion of genetic technologies in health care do not make very many references to mental disorders and psychiatry, while the suggestions that have been made in the review for future mental health research does not focus on the use of genetic test technologies. However, I want to argue that the two approaches do correlate well with one another. Once these aspects have been reviewed links can be made between the two documents that pave the way for this research project and how it intends to move beyond the suggestions previously made in the articles examined. Finally we will see how this project will develop and build upon the research papers examined in the previous sections.

In addition to this I will revisit and discuss several areas where I am forced to make some tentative links with respect to the current status of the field and my research goals. For example, the tests I will be using as a springboard for discussion with the group of psychiatric professionals have been independently developed in the United States and have been released as direct-to-consumer genetic tests that have recently been withdrawn from the market. This means they have been subject to different procedures and scrutiny than they would do in the UK, and as a consequence I need to consider them accordingly. In addition to this we will also learn that although specific tests are being used to provoke discussion the aim of this research is to document and examine psychiatric professional’s overall thoughts about introducing these developments into the clinical setting. However, as specific tests are going to be used to do this, there is inevitably going to be a degree of consideration and insight gained that is particular to these developments in isolation, but the intention of this project is to develop a better understanding of the broader implications of the tests’ potential use.

2.5.1 - Medical Research Council – Review of Mental Health Research Report 2010

The Office for Strategic Co-ordination of Health Research (OSCHR) commissioned the Medical Research Council (MRC) to produce a report on the future of research into mental health in the UK. There are several areas where the MRC reports suggestions and this research projects intentions align. The report concludes:

...that the UK is currently well-placed to be at the forefront of advances in our basic understanding of mental ill health; in developing new options for prevention, early detection and treatments; in assessing the effectiveness of treatment and preventive strategies and developing systematic guidelines for treatment and patient management; and in modelling the best ways to introduce new care options into health systems. (MRC, 2010, p.2)
Genetic tests that aid in the diagnosis of mental disorders (like the Psynome1 diagnostic test) as well as those centred on treatment (such as the Psynome2 pharmacogenomic test) fit in well with this conclusion. Especially the part concerned with ‘assessing the effectiveness of treatment and preventive strategies and developing systematic guidelines for treatment and patient management’ – as the Psynomics developments could operate as treatment or preventative tools, indeed this is something Psynomics themselves claim (http://psynomics.com/about_what.php). However, this case becomes strengthened when the report’s major strategic aims are considered:

**Promotion of preventive strategies**

A. *Understanding the biological and social life-course determinants of mental illness and wellbeing, primarily by exploiting the UK’s research strengths in genetics, neuropsychology, brain imaging and population sciences;*

B. *Developing primary preventive strategies based on early detection of high risk states;*

C. *Identifying the cognitive and neurobiological basis of well being and healthy development;*

D. *Promoting good mental health at key life stages particularly in childhood and adolescence.*

**Developing therapy**

A. *Exploiting established UK strengths to increase innovation in mental health research, for example by:*

   i) *Taking a cross-symptom approach: that is, understanding the psychological basis of aberrant processes such as inattention, impulsivity and aggression that may underpin maladaptive behaviour in different clinically-diagnosed psychiatric disorders;*

   ii) *Exploiting new molecular genetic methods and UK expertise in developmental neuroscience;*

B. *Identifying individuals at risk in order to target intervention by, for example, using stratified medicine to identify subgroups with common pathogenesis that may be specifically responsive to existing and new drug or psychological treatments;*

The longer-term vision is to develop and evaluate ways of preventing the onset of mental illness through a better understanding of its biological and social causes. In the short-term we need to develop and improve existing treatments and target interventions based on an individual’s vulnerability and resilience. *(MRC, 2010, p.3)*

All of these points, as well as the report’s conclusion, serve as justification for this research project. Not only is this work timely given the current situation with respect to the developments being made, but there are also published documents that suggest this type of work needs to be conducted. The MRC are encouraging research into the biological underpinnings of mental health, this could be achieved by examining a genetic test development and its possible clinical impact. However, some further clarification is also needed with respect to this as I am making some links and assumptions concerning the MRC suggestions and how they align with examining genetic testing specific to the context of this research. The above points clearly advocate and encourage research
into the biological aspects of psychiatric disorders, although the authors do not explicitly mention genetic tests like the ones Psynomics offer, this is one way the MRC’s desires to explore these developments could be fulfilled. The MRC are suggesting that genetic and biological research into the cause and the treatment of mental health needs to be conducted; this is one way where investigating a previously released genetic test could play a role.

2.5.2 - Direct-to-consumer genetic tests and the MRC suggestions

As the field of genetic testing for mental disorders is still very much in its infancy, I am implying that the biological aspects, which the MRC suggest should be researched, are represented by the tests Psynomics offer. Although the MRC make no explicit mention of genetic test technologies, especially DTC genetic test technologies, I am choosing to use the Psynomics developments as the foundation for pursuing research in this way, there are two main reasons for this. First of all the Psynomics tests have previously been made available to the public, therefore there is a great deal of information obtainable about how they work to examine and analyse. Secondly, the two Psynomics tests align perfectly with the two main orientations presented in the MRC report – prediction/diagnosis and pharmacogenomic testing. Several of the additional points made by the MRC are also echoed by Psynomics themselves. The company writes (http://psynomics.com/about.php):

Psynomics’ mission is to improve the lives of people living with mental illness by identifying the genetic basis of such disorders and applying that knowledge to provide faster, more effective and less costly diagnostic tools and therapies.

For example, the last paragraph of the MRC document, points out that there needs to be evaluation of the ways to prevent the onset of mental illness and treatments need to be developed based on an individual’s vulnerability when using such technologies, this is very similar to the claims Psynomics are making themselves. However, in addition to this the MRC document also points out that the United Kingdom is ideal for pursuing this type of research as it already has a proven track record in several of these areas. It is here where another discussion of a major difference between the current state of psychiatric genetic testing and the potential role of this research project needs to take place. Psynomics state (http://www.psynomics.com/pdf/model_report.pdf):

These tests have not been cleared or approved by the Food and Drug Administration (FDA). The FDA has determined that such clearance or approval is not necessary. These tests are used for clinical purposes. They should not be regarded as investigational or for research. The laboratory is regulated by the Clinical Laboratory Improvement Act of 1988.

This is a significant issue that requires clarification for the purposes of what I am trying to achieve in this research project. Psynomics have essentially been able to use existing legislation in order to side step the need to externally validate their tests. This is due to Psynomics being an American company; therefore the rules that regulate DTC genetic tests are different than they would be in the United Kingdom (Hogarth, et al. 2008). This issue needs to be considered when thinking in terms of this research project because it is an additional area where I am using a previous example, the Psynomics developments and how they are yet to receive any official appraisal, and applying them in a new direction.

As the Psynomics developments have been released independently of any external validation one issue that needs clarification is – what if a similar test was to be offered in the UK? What sort of
consideration would this require? Consulting the second document that suggests genetic research into medical conditions needs to be encouraged and the results should be translated into clinical tools, reveals this. Being able to consider this question is important because this research may be able to provide some insights into this issue as well.

2.5.3 - Human Genomics Strategy Group Report January 2012 - ‘Building Our Inheritance’

The second publication that has implications in relation to the overall situation of this research project is called ‘Building our inheritance: Genomic technology in healthcare’. This report was published by the Department of Health’s Human Genomics Strategy Group (Department of Health, 2012) and is concerned with using developments in genome sequencing within clinical care. Summarising the overall stance of the paper the authors are very much looking to endorse the developments that are being made in genomic medicine and want to include these advances in routine health care, delivered by the NHS. This report sets out the future trajectory of research into the development and use of genetic testing technologies in the UK. However, it also contains chapters that suggest how lab based research developments should realistically translate over to usable tests, and how those who currently work in the field need to be prepared when these technologies are made available.

The report makes two specific references to mental health and both of these suggestions are related to the two tests available from Psynomics. In the section of the report focused on ‘Transforming Diagnosis and therapeutic decision making: stratified medicine’ the authors write:

*Genomic research is also beginning to indicate differences between variants in many conditions. An interesting example here is schizophrenia, where a recent study has highlighted small but important genetic differences in patients, suggesting there may in fact be multiple genetic variants in the disorder.* (Department of Health, 2012, p.24)

Although somewhat far removed from the two candidate genes Psynomics have linked to bipolar disorder, the authors are indicating and perhaps alluding towards a time where these small genetic differences could be examined and the variants could be accordingly typed. There are also suggestions as to the role of pharmacogenomic testing in the field of psychiatry – this operates in much the same way as the Psynome2 test purports to:

*...carbamazepine is an anticonvulsant and mood-stabilising drug used widely in the treatment of epilepsy and bipolar disorder, but around 1 in 10 patients experience significant adverse reactions to it. Recent studies have identified that possession of a specific gene variant (HLA-A*3101) is a predisposing factor for hypersensitivity reactions to carbamazepine which could potentially lead to testing patients for this variant before prescribing the drug.* (Department of Health, 2012, p.25)

Both of these instances point out the desire to pursue research into the advances being made in the field of psychiatric genetic testing. However, so far, there has been very little discussion of exactly what needs to be achieved in order to do this, or the most suitable way that this should happen. Chapter 4 of the Human Genomics Strategy Group report is involved with clarification of this issue.
2.5.4 - Translating genomic innovation to establish clinical validity and clinical utility

The Human Genomics Strategy Group indicates these developments will require rigorous and stringent assessment before they are adopted in a clinical setting. One possible way to achieve this would be to assess and establish each test’s clinical validity and clinical utility. This is a methodology that has been developed and is used to assess genetic test developments globally. These features will be examined in greater detail later on, but for the time being the definition of each term is as follows (CDC, 2010):

The clinical validity of a genetic test is a measure of how well the test predicts the presence or absence of the phenotype, clinical disease or predisposition.

The clinical utility of a genetic test will inform patient management and result in an improved outcome.

Therefore, in accordance with the Human Genomics Strategy Groups suggestions, when considering new genetic test developments being able to comment on their clinical validity and their clinical utility is imperative. But how is this actually executed? Contained within the document is a selection of official channels by which genetic test developments are currently assessed – this is represented and governed by the United Kingdom Genetic Test Network – UKGTN.

The UKGTN is the collection of groups in charge of the evaluation of all the new tests for genetic disorders, the groups consist of genetic testing laboratories, clinicians, commissioners and patient support networks. They aim to ensure that high quality genetic testing services are introduced throughout the UK through analysis of the tests’ analytical validity, clinical utility and clinical validity via the use of a standard ‘gene dossier’ process. It would seem reasonable to suggest that consideration of this ‘gene dossier’ process, in light of the tests offered by Psynomics, is likely to progress our current understanding of their implications. This appears to be especially relevant with respect to the issues of the tests’ clinical validity and clinical utility.

2.5.5 - Implications in this research

So far we know that the Psynomics developments are yet to receive any sort of official appraisal. Psynomics themselves point out that their tests have only received internal validation, from the laboratory that developed the technologies, they also point out that their tests have not received any form of evaluation from the FDA. So in several respects this research project is going to focus on a number of issues that currently need considering. As the Psynomics technologies are readily available to consider, these will be used as the inspiration material in this research. This means that information about the tests, which the company have made available, can be incorporated into the research methodology and used to provoke discussion about some of the issues the UKGTN are likely to be interested in when examining a new genetic test development. However, being too focused on the Psynomics developments is a mistake.

Although these are the most readily available developments we have to consider in the overall field of genetic testing in psychiatry, it could be easy to lose sight of the bigger picture. Not only are there government endorsed proposals to conduct research into using genetic test developments in the clinical setting, there are also drives towards the future of research into mental health being represented by these developments as well. I want to point out that although the Psynomics
technologies are going to be used as a spring board for discussion the overall aim is to get a better understanding of the general implications of introducing genetic testing for psychiatric disorders in the clinical setting. This includes consideration of the ACCE criteria and how they apply to the developments the field of psychiatric genetics more generally.

2.5.6 - Test criteria

The next feature that needs exploration is the ‘gene dossier’ process, which is used to assess the genetic test developments in accordance with the UKGTN’s suggestions. The UKGTN’s web page (http://www.ukgtn.nhs.uk/gtn/Home) contains several links to a selection of report papers that reveal how this issue should be approached. The main document is a paper called ‘Paper for UK GTN Steering Group Meeting Testing Criteria for Molecular Genetic Tests’ (Kroese, 2005, p.1). This document contains all of the criteria used in the assessment of genetic test technologies in the UK and makes specific references to what needs to be included in the ‘gene dossier process’. Here are all the elements of the gene dossier process as outlined in the aforementioned report paper:

*The Gene Dossier provides a standardised format for the presentation of key information about a genetic test. This is needed to inform the final decision on clinical utility and provision. The areas covered in the gene dossier include:

- **details of the condition**
- **prevalence of the condition**
- **target population for the test**
- **complexity of the test**
- **clinical context in which the test is to be used**
- **analytical validity**
- **clinical validity**
- **clinical utility of the test**
- **cost of the test**

Clearly there is a lot more to the assessment of a newly developed genetic test technology than analysis and consideration of its clinical validity and clinical utility. We will later find out that this research project will not be an investigation into each of these features one after another, but an investigation into what psychiatric professionals think is important to consider when thinking about introducing the test – this research will predominantly represent an investigation, and discussion, into the utility of genetic testing for mental disorders. However, from what the authors of the previous Human Genomics Strategy Group Report say, consideration of these issues is paramount to the successful introduction of genetic test developments. But how are the features of clinical validity and clinical utility routinely assessed in accordance with the UKGTN’s wishes? In reality clinical validity and clinical utility are actually two parts of a bigger framework initiative, which is referred to as the ACCE criteria. The report notes that, *The major framework for such evaluations is the ACCE framework developed by the Office of Genomics and Disease Prevention, CDC, USA. ACCE stands for*
Analytical validity, Clinical validity, Clinical utility and the Ethical, legal and social implications of genetic testing.’ Examining the information provided by the CDC about the ACCE criteria significantly enlightens the potential trajectory of this research project.

2.5.7 - The CDC and the ACCE criteria

The CDC has a web page devoted to all of the necessary information about the ACCE genetic test criteria (CDC, 2011). The first issue that needs clarification is what do the ‘A’ and the ‘E’ parts of the acronym stand for? ‘A’ corresponds to analytic validity which is concerned with how accurately and reliably the test measures the genotype of interest. ‘E’ is involved with the ethical, legal, and social implications that may arise in the context of using the test. Analysis of both these elements is required, alongside Clinical utility and Clinical validity, for a comprehensive review of any genetics test complete ACCE criteria. A total of forty-four questions that aid in this are provided (CDC, 2012), however, in isolation I think these questions are difficult to comprehend and would be very difficult to answer in a research project such as this. For example, some of these questions, such as the ones in the analytic validity section, are very specific to different types of research enquiry and to answer them would rely on conducting lab-based biological research. However, other clues as to how genetic test developments should be appraised are provided in the link called Evaluation of Genomic Applications in Practice and Prevention – which is abbreviated to EGAPP.

In 2004 the CDC launched the EGAPP initiative to evaluate emergent genetic test developments. Their main objective was to provide reasoned insights into the technologies on the basis of available scientific information – with a view to informing anyone interested in the application of the tests with the most accurate information possible (CDC, 2010). What makes the EGAPP initiative so useful is that they actively adopt the ACCE criteria when making assessments of genetic test developments (EGAPP Team, 2012). Another reason the EGAPP initiative is so useful is that they have a selection of previously conducted research analyses on a wide range of previously developed genetic tests available to read.

I want to reiterate that I am making several leaps when finally getting around to assessment and consideration of the EGAPP protocol. Originally I began this section by introducing the UKGTN and pointed out they specifically mention that part of their gene dossier process is inspired by and includes analysis of a genetic test’s clinical validity and clinical utility. The UKGTN indicate in their reports that these aspects were provided by the CDC who are credited with developing the ACCE criteria. This brings us full circle to consideration of the EGAPP protocol. It may be reasonable to ask why I have gone to such great lengths to point out all of these different systems and I want to assert that previous allusions to the assessment of a mental health-related genetic test technology on behalf of the UKGTN are actually somewhat vague. I have suggested that research into the genetic underpinnings of mental disorder, and the translation of this into test technologies, is implied given the current research climate along with the official suggestions that are being made to investigate this. However, there are currently no completed UKGTN gene dossier accounts of a mental health related genetic test available to examine. This is partly due to the progression of the field, as no genetic tests have been developed for analysis in this way, and this reality lends to my ambition to consider the EGAPP initiative here in this research because this group has completed review documents that examined a genetic test technology that is certainly related to mental health. This is the only appraisal of this sort that I can find – so although the UKGTN cannot provide a complete gene dossier for a genetic test linked to this project, the EGAPP initiative can. Therefore, given what I
propose to do, considering this document is vital as it represents the closest example of what I am trying to achieve in this part of the research. However, we shall see that in this instance their methodology still suffers from significant flaws as it relies on previously conducted research to inform their work. The point of this particular example is to present the currently recognised ways that genetic tests are appraised and illustrate that the system normally used to do this is far from ideal.

2.5.8 - EGAPP initiative and Testing for Cytochrome P450 Polymorphisms

Before the EGAPP P450 research project is examined with a view to inspiring how this research takes shape I need to point out that exploration is intended to get a better appreciation of how this would routinely be achieved for the purposes of a UKGTN gene dossier investigation. As this is the only investigation that I can find from any source related to the assessment of a mental disorder genetic test, and the UKGTN themselves adopt aspects of the ACCE criteria, which essentially resolve down into the EGAPP initiative procedures, I’m devoting some time to considering these implications. An additional feature that I need to point out is that the research paper about to be presented is focused on a pharmacogenomic test. Therefore when it comes to the empirical assessment of risk-assessment technologies in this research study, I’m attempting to do something that has not been approached in the same way previous to this.

The report into the P450 testing is called Testing for Cytochrome P450 Polymorphisms (CYP450) in Adults with Non-Psychotic Depression Prior to Treatment with Selective Serotonin Reuptake Inhibitors (SSRIs) (Matchar, et al. 2007) had one major research objective, which broadly draws upon all the features of the ACCE criteria previously discussed. Their aim was to determine if testing for cytochrome P450 (CYP450) polymorphisms in adults entering selective serotonin reuptake inhibitor (SSRI) treatment for non-psychotic depression leads to improvement in outcomes, or if testing results are useful in medical, personal, or public health decision making (http://www.ahrq.gov/clinic/tp/cyp450tp.htm). The research team conducted a meta-analysis of around 1200 research papers and from reading their abstracts included 37 research articles in their final analysis. Here is a summary of their results:

Results:

There is mixed evidence regarding the association between CYP450 genotypes and SSRI metabolism, efficacy, and tolerability in the treatment of depression, mainly from a series of heterogeneous studies in small samples.

There are no data regarding:

a. If testing for CYP450 polymorphisms in adults entering SSRI treatment for non-psychotic depression leads to improvement in outcomes versus not testing, or if testing results are useful in medical, personal, or public health decision making.

b. If CYP450 testing influences depression management decisions by patients and providers in ways that could improve or worsen outcomes.

c. If there are direct or indirect harms associated with testing for CYP450 polymorphisms or with subsequent management options
And here is their final conclusion:

There is a paucity of good-quality data addressing the questions of whether testing for CYP450 polymorphisms in adults entering SSRI treatment for non-psychotic depression leads to improvement in outcomes, or whether testing results are useful in medical, personal, or public health decision making. (Matchar, et al. 2007, p.5)

Therefore the research team were unable to provide any form of appraisal what-so-ever about this development - they were not able to come to any form of conclusion about the implications of P450 genotyping due to the lack of previous relevant research. Some interesting issues emerge when the questions the research team set themselves about the implications of this technology are considered. These essentially fall back to what we now know of in terms of examining the technologies clinical validity and clinical utility. For example, question five from the Matchar and colleagues research paper is ‘What are the harms associated with testing for CYP450 polymorphisms and subsequent management options?’ from the definitions provided so far, this is likely to be a clinical utility oriented question. Here is their conclusion regarding this question:

To address this question, we sought to identify studies in which patients treated with SSRIs were tested for CYP450 genetic polymorphisms, and in which investigators reported on harms or negative outcomes associated with testing or with subsequent management options. It may be hypothesized that, like other genetic tests, CYP genotyping could raise issues of labelling (“treatment-resistant” in the case of UMs) in the minds of providers, patients, or third-party payers that may negatively impact outcomes. This question of harm therefore is very relevant as we consider feasibility of CYP genotyping in practice. Even after relaxing our inclusion criteria to include all methods used for genotyping and all indications for SSRI treatment, we were unable to identify any studies that directly addressed any aspect of this question. (Matchar, et al. 2007, p.25)

The same can also be concluded regarding the report’s questions that are predominantly oriented around clinical validity concerns. The authors are not able to provide any concrete analysis of the relevant implications due to lack of previously conducted research. Therefore one way to avoid such a problem in this project would be to develop my own data to ensure I can gain some insights into the issues I am interested in. However, the final aspect that requires consideration relates to the ways that these criteria are traditionally assessed. Specifically, what is clinical utility?

2.5.9 - Reintroducing the ACCE criteria

I have suggested that the previous attempt to apply the ACCE criteria to a related development in psychiatric genetic testing has been fruitless. I asserted that this is partly due to the methodological approach used by the research teams, which have largely been meta-analysis of previously conducted research. However, part of the problem could also be due to applicability of the criteria themselves, it may turn out they are not suitable for consideration of a genetic test used in mental health care. The currently most up to date examination of the implications of psychiatric genetic testing that mentions aspects of the ACCE criteria is the paper ‘Predictive and Diagnostic Genetic testing in Psychiatry’ (Mitchell, et al. 2010). Their paper makes the following predictions and conclusions about the clinical validity and clinical utility of genetic testing for mental disorders:
The ability of a genetic test to achieve its intended purpose is limited due to a low measure of clinical validity, thus leading to low efficacy and low effectiveness. Because of these low measures, the appropriateness of its clinical utility is also argued to be low, because the expected benefit will be small and the expected negative consequences will be significant. (Mitchell, et al. 2010, p.237)

However, Mitchell and colleagues are only making predictions about the clinical utility of genetic testing for mental disorders. This is very different from actually conducting any research on the topic – something this research aims to contribute towards. However, although there may be prescribed definitions of what constitutes the ACCE criteria in research settings – such as the definitions provided by the CDC - the reality is that the definitions themselves are also subject to scrutiny and critique. I have already suggested that this research project can in no way contribute to assessment of the clinical validity of the developments being made in genetic testing for mental disorders; rather this research is more concerned with the utility of these tests. But are there any issues to be aware of when considering this aspect? Is clinical utility a term that is difficult to define? A recent Nature editorial (Lesko, et al. 2010) on the topic makes some suggestions about the concept and even makes reference to some points that are likely to be integral to this project:

Despite general agreement that clinical utility assessments are multidimensional and may include economic, clinical, and/or humanistic domains, there is no consensus on its definition or how to robustly demonstrate it to the satisfaction of multiple stakeholders. (Lesko, et al. 2010, p.729)

So although a relatively official definition of the term may be ‘The clinical utility of a genetic test will inform patient management and result in an improved outcome’ (CDC, 2012) it would appear that what goes into the working of the definition is more complex than this. For example, consider the issue of multiple stakeholders. Exactly who is the term clinical utility really intended to be used by? Will patients have any say in it? Will medics? What about nurses? These issues are briefly considered in the Nature editorial and the authors conclude that there is no answer to the question of ‘What is Clinical Utility?’ because it’s very much dependent on the eye-of-the-beholder. Therefore, clinical utility implications will differ on the values and interests of those who are consulted about the issue. However, the authors also conclude that when determining this, clinical utility must be flexible enough to raise questions about the benefit and harms of the interventions from a diverse group of stakeholders. Finally, Lesko and colleagues also note that as the definition of clinical utility is difficult to grasp and is dependent on so many different perspectives, another issue to consider is that of personal utility:

Clinical utility refers to...the value of information to the person being tested. If a test has utility, it means that the results...provide information that is of value to the person...because he or she can use that information to seek an effective treatment or preventive strategy. Even if no interventions are available to treat or prevent disease, there may be benefits associated with knowledge of a result. (Lesko, et al. 2010, p.730)

Considering this exploration of the term clinical utility is vital in this research project for several reasons, however, most of all this is important given the design of this research project. For example, we now know that clinical utility is not a term that is easy to define, and part of this relates to exactly who is consulted in the appraisal and exploration of this issue. Executing research that
places emphasis on the observation that mental health care is multidisciplinary, seems like a sensible way of navigating the issue regarding different stakeholder views. An additional component that could prove beneficial or important in this research relates to assessment of the participants’ communicated models of mental disorder. From this examination of clinical utility there does not appear to be any consideration for differences in opinion concerning the nature of what the tests are being applied to. For example, how would a genetic test for mental disorders be heralded by an individual who used the ‘Zar Cult’ to appease evil spirits? Although this is an extreme example, this research may contribute to our understanding of the ACCE criteria through being sympathetic to the multitude of views regarding what mental disorder ‘is’, as there may be differences of opinion in relation to clinical utility issues dependent on the models of mental disorder the participants communicate.

2.5.10 - Summary
From this section there is a better appreciation of what would typically go into the official appraisal of a genetic test technology if it were to be released in Europe. This was shown through tracing the roots of the developments known as the ACCE criteria and examining where they have previously been used to do this. However, we know that these criteria have never successfully been applied to any development relating to the underlying genetics of mental disorders. This coupled with what was discussed in the previous section concerning efforts to investigate people’s attitudes and beliefs about the tests means that the time is right for detailed investigation into these issues – specifically (given the design limitations of this research) ones relating to the utility of the developments. The primary advantages to adopting a qualitative methodology being, that I will be able to gain an in depth understanding of the implications of the tests, but I will also be able to avoid the pitfalls of the previously examined P-450 research paper because rather than relying on previously conducted data I will be developing my own.

The other aspect to note is the criteria themselves. The ACCE criteria, and specifically the clinical utility component in isolation, are going to be part of the inspiration for this project. However, as demonstrated in the previous section an additional feature of this research that lends itself to the novelty of this project will be combining these features with participants’ personal accounts of mental disorder. Inclusion and awareness of the ACCE criteria is vital in this research project because the tests are not simply released independent of any external validation, there needs to be some consideration of the processes these tests are going to face before release in the United Kingdom. Although this project is not totally devoted to this aspect in isolation, is inclusion is warranted so that in the future policy makers can be aware of any issues this project discovers.

2.6 - The history of the field of psychiatric genetics.
There is a long heritage of research into the genetic components of mental disorders that paves the way to where we are currently placed today. However, before I start to examine this I want to clarify several points. Although there are a selection of popular technologies and techniques used in the field of psychiatric genetics, such as, twin, linkage, and genome-wide association studies, that have all been used to make the claim that there is an identifiable underlying genetic component to mental distress, there are other examples from within the history of psychiatry that could be considered as serving a similar purpose. However, these examples do not necessarily involve the search for an underlying genetic link. I think there are examples from the recent history of mental healthcare that
make psychiatry appear as if it is like other areas of medicine, ones who use pharmacological intervention and have access to an objective system for diagnosis that enables categorisation of the disorders they are concerned with. This is quite different from the search for a genetic marker for major mental illness, but both examples share major similarities – they make psychiatry and mental health care appear as if it is a legitimate medical activity, one that emphasises the role of biology in diagnosis and treatment. Therefore, although this discussion is principally concerned with the history of the field of psychiatric genetics, there will also be a focus on some of these accessory components too. I feel that neglecting these aspects would be a mistake because when it comes to consideration of these issues both strands can be used to make, or imply, the same suggestion – that mental health care is a legitimate activity that has parallels with other areas of medicine because psychiatry is increasingly moving towards biological explanations for mental distress. The important point in this case will be to consider what the introduction of genetic tests for mental disorders could do for this dynamic.

In addition to this, another issue these different features have in common relates to their associated controversy - and we will see that this is a significant point with respect to the way related aspects should be navigated in this research. Firstly the field of psychiatric genetics is controversial because of its historical burden; its early roots can be traced back to some of the Nazi eugenic programs around the time of the first World Wars, not mentioning this would be a mistake as some modern day concerns of the field relate back to this time period. The second issue, and the one that will be focused on more in this project, will centre on the suggestion that despite the continual pursuit of a genetic link for mental disorders, there is evidence to suggest that this activity has for the most part been fruitless. Essentially one of the reasons the field of psychiatric genetics is so controversial is because many of the findings (that imply an underlying genetic link for mental distress) can be refuted.

2.6.1 - The field of psychiatric genetics around 1900 – early family and twin studies.

In terms of investigations into the underlying genetics of psychiatric disorders at and around this period of time, perhaps the most famous example concerns the application of Mendel’s laws to the familial inheritance of psychiatric disorders. This approach is illustrated by the schizophrenia research conducted by eventual Nazi collaborator Ernst Rudin (Rudin, 1916). Rudin was originally interested in seeing if schizophrenia fit the traditional Mendelian mode of inheritance. Although his study demonstrated that this was not the case, his research did show that there are higher rates of the disorder among affected relatives than within samples in the general population (Gottesman and Shields, 1976; Propping, 2005). The next historical example that is common in the literature around this time occurred in 1928, this is represented by a systematic twin study (Luxenburger, 1928) that was conducted to try and find the ‘manifestation rate’ of the genetic factor of schizophrenia. Gottesman and Shields (1976, p.360) note:

...the principal object of the classical comparison of genetically identical and genetically dissimilar twins brought up in the same home was to test the hypothesis that the genes really did make a difference and that familial aggregation of schizophrenia was not simply due to the shared family environment.

These two studies represent something of a landmark series of events in the field of psychiatric genetics, the effects of which are still being felt today. This relates to the observation that (although
different research examples than the ones quoted are typically used) family and twin studies are routinely used as evidence for the genetic basis of mental disorders - this evidence can be seen in almost any text book, review article, or original research that looks into the issue. Some of these examples will be examined here but I want to emphasise that this is quite a controversial feature in the field of psychiatric genetics. Although we will see there is a great deal of interest in using modern bio-molecular techniques to elucidate the genetic components of mental disorders, these investigations have not conclusively determined that any genetic components are really involved in eliciting mental distress. Regardless of the perceived importance of this more modern research, and despite, for the most part, its continual failure, twin and family studies are still used to emphasise the role of genetics in the field of mental disorders. This observation will be important later on in this review when some rhetorical aspects are considered in mental disorder research, as well as the precedent that has been established through the sociology of expectation when examining these issues.

To begin with, I am going to simply provide a selection of examples where either the results of family and twin studies, or the actual presence of these studies, are used as evidence for the genetic basis of mental disorders. These first examples focus on bipolar disorder in isolation:

- **Family and twin studies attest to the importance of genetic factors influencing susceptibility to bipolar disorder and to its genetic and phenotypic complexity** (Craddock and Sklar, 2009, p.99).

- **Although the etiology and pathology of bipolar disorder remain largely unknown, evidence for a substantial genetic contribution is well established. Twin and adoption studies dating back decades have demonstrated that genetic factors were primarily responsible for bipolar disorder** (DePaulo, et al. 2001, p.153).

- **Family, twin, and adoption studies have been essential in defining the genetic epidemiology of bipolar disorder over the past several decades. Family studies have documented that first-degree relatives of affected individuals have an excess risk of the disorder, while twin studies (and to a lesser extent, adoption studies) suggest that genes are largely responsible for this familial aggregation** (Smoller and Finn, 2003, p.48).

- **There is a broad consensus that the etiology of bipolar disorder (BPD) has a genetic basis. This consensus rests substantially on genetic epidemiology studies that have demonstrated the high familiality and heritability of BPD** (Wendland and McMahon, 2010, p.19).

However, there are other more general examples that are broader because they either focus on other mental disorders, or they are used as representative instances for a variety of mental disorders:

- **Family, twin and adoption studies have provided major evidence for the role of genetics in numerous psychiatric disorders including obsessive-compulsive disorder, panic disorder, major depressive disorder, bipolar disorder, schizophrenia and Alzheimer’s disease** (Shih, et al. 2004, p.260).
A number of approaches have been used to evaluate the role of heredity in OCD (Obsessive Compulsive Disorder). Twin studies have examined rates of concordant monozygotic twins versus discordant monozygotic twins with OCD. A review of this literature reveals a concordance rate of 63% in monozygotic twins and supports the notion that genetic factors are implicated in the expression of OCD (Kay and Tasman, 2006, p.615).

Although these are interesting observations in isolation, I want to take a deeper look into some of these issues and consider some of the controversy surrounding the role of family, twin, and adoption studies in the field of psychiatric genetics – as they have come under serious attack from numerous commentators.

2.6.2 - Controversy in family and twin studies.

In terms of framing where this research project is situated I predominantly choose to consider these ‘issues of controversy’ in the field of psychiatric genetics as follows:

- A claim is made about the underlying genetic components of mental disorders
- This claim is somehow refuted

Although this is a common pattern between all of the successive methodological or technological breakthroughs in the field, we will also see that despite any criticism, the field still continues forward all the time – acknowledging past successes, playing down or not mentioning failures, and maintaining an overall positive future outlook for research. Doing this means that both sides of the story are considered and it is then possible to see where the genetic tests are likely to be situated in this overall dynamic. For the purposes of this discussion I am not really too concerned with any of the detailed specifics of the studies themselves, instead I am more interested in what these different research contributions represent in, or provide, the field of psychiatric genetics. This always falls back to the claim that mental disorders have an underlying genetic component, and what being able to have this provides the field of psychiatric genetics.

As mentioned previously, twin and family studies are commonly used as evidence to champion the genetic basis of psychiatric disorders. However, problems are encountered when the research that is critical of twin studies is considered, and there is a great deal of literature concerned with this – most of which focuses on the methodological issues and assumptions associated with the technique.

Below is the final paragraph from the paper ‘Twin Studies in Psychiatry and Psychology : Science or Pseudoscience?’ (Joseph, 2001). Other than providing a summary of one of the main methodological criticisms of family and twin studies, it also places emphasis on the observation that this technique is commonly used to prioritise the genetic components of mental disorders:

*Today, most psychiatric conditions are believed to carry a genetic predisposition, and twin studies are frequently cited in support of this belief. However, we have seen that apart from methodological problems, the conclusions drawn from the twin method are based on an unsupported theoretical assumption. The equal environment assumption of the twin method is untenable however it has been defined, and studies of reared-apart twins fail to control for the common environmental influences shared by twins reared-together and twins reared*
apart. To the extent that, like family studies, twin studies are confounded by environmental factors, twin researchers’ claim that their studies demonstrate the influence of genetic factors should be treated with extreme caution. There is little reason to accept that studies of twins, whether reared together or reared-apart, measure anything more than environmental influences, error, and bias. (Joseph, 2001, p.80)

Before we move along with this look at the history of psychiatric genetics I want to examine how and if this dynamic can be seen in a situation where its possible implications could play an increased role in this research. For example, so far, it feels as if many of the examples used to illustrate this are quite antiquated in terms of where we are today. Although the intention is to provide a historical overview of the field, starting with the earliest relevant example I could find from 1916, it is also important to examine the relevance of this today, perhaps in a teaching or educational context. So here I want to briefly examine this dynamic as it appears in the educational textbook ‘Psychiatry: An evidence-based text’. I am choosing to do this because it seems reasonable to assume that as the intention of this resource is to educate and inform people interested in psychiatry about various issues concerning the practice, this is one area where it is possible to practically observe some of the themes being discussed.

Similar instances to the examples above, where twin and family studies are used as evidence for the underlying genetic aspects of mental health, are provided in the ‘Genetics’ chapter of this book. The following example will relate to bipolar disorder because one of the Psynomics tests is related to this psychiatric presentation:

Family, twin and adoption studies consistently indicate a strong genetic component to BPAD. Heritability of BPAD is high, in the region of 85 per cent (McGuffin, et al. 2003). Twin studies show a markedly elevated concordance rate of BPAD in monozygotic compared with dizygotic twins – 40 per cent versus 5 per cent (McGuffin, et al. 2003). (Puri and Treasaden, 2010, p.475)

If the McGuffin and colleagues paper is obtained it appears to be a fairly standard twin study into the heritability of bipolar disorder. However, upon examination, it certainly appears as if it could be critiqued in similar ways to the aforementioned points (Joseph, 2001). For example, there is very little consideration or discussion relating to the phenomena of actually being a monozygotic or dizygotic twin in this research, and there is no real discussion of any of the detailed history behind determining their actual psychiatric diagnosis. Although the paper states that a DSM diagnosis was made on the basis of clinical presentation or available information, one potential additional dimension that I feel would add dramatic colour to the research would be an investigation into some of the events that perhaps triggered the diagnosis. Although these sorts of criticisms seem to be commonplace in the field of family, twin, and adoption studies, I do feel they are worth mentioning – in many cases it is the complete emphasis on the biology of the disorder, and the assumptions that this research is thought to adhere to, which is often the most problematic and the source of most controversy.

However, other than an awareness of this, how does any of what has been discussed help in situating this research? Or has any of this enlightened anything that requires future thought or consideration? In terms of the proliferation of ideas about the genetic nature of mental disorders, I feel this does achieve several things. For example, despite any concerns of the research or its
criticisms possibly being outdated, the evidence of twin studies demonstrating that mental disorders have a strong genetic component is being used in relatively up to date educational textbooks. This means the claim that mental disorders have a genetic component is being seen in the literature. However, currently this is only being backed up with this one branch of evidence. To reiterate, at this stage the important issue to be aware of is that evidence from twin and family studies is being used as evidence for the genetic basis of mental distress. We will later see that this can be considered as a rhetorical device used in research articles to establish a specific research agenda. In this case the evidence from twin and family studies is still used alongside more modern bio-molecular research in the field of psychiatric genetics to imply, or claim, that mental disorders have a genetic factor.

One way to consider the evidence, and approach it for the purposes of this research, would be to simply acknowledge that this situation exists and it is important to be aware of this for appropriate contextualisation. For example, although there may be an emphasis placed on observation that twin studies act as evidence for the role of genetic factors in mental illness, in ‘Psychiatry: An evidence-based text’ there are also instances where psychological models play a role in mental disorders too – instances of these are peppered throughout the book. So simply focusing on the biological aspects could be considered as only half of the story. However, thinking about this makes me consider why there is such an emphasis placed on the biological aspects of mental disorders, even if the research results that have been produced so far are not particularly compelling. This issue will be considered in greater detail later on after this historical overview has been completed, but for the time being it is prudent to establish a narrative basis at this early stage.

It would seem that escaping the controversy surrounding the field of psychiatric genetics is impossible, yet despite all of the concerns that are voiced, it still continues as a form of scientific research. However, it is also important to be aware that research into the field of psychiatric genetics or the biological aspects of mental health may not be ‘value-free’ as there are examples from within the history of psychiatry that clearly show the influence of interested third parties – such as the pharmaceutical industry – having an influence on the trajectory of research and the dissemination of findings (Read, et al. 2004).

As an example of the previous point relating to the establishment of a strong genetic narrative surrounding mental disorders, one way to approach this would be to consider who is producing the work that supports this specific line of thinking. For example, consider the aforementioned paper by McGuffin and colleagues (McGuffin, et al. 2003) that emphasises the genetic aspects of bipolar disorder – what are some of the possible theoretical affiliations with respect to the authors of this paper? Looking at his online staff profile (http://rg.kcl.ac.uk/staffprofiles/staffprofile.php?pid=917) it would seem he has a strong interest in researching the bio-molecular aspects of mental disorders, and according to his biography (http://www.iop.kcl.ac.uk/staff/profile/default.aspx?go=10199), he carried out one of the first genetic marker association studies into schizophrenia. It may be reasonable to suggest that given the elusive nature of an objective genetic marker for the sorts of mental disorders he is interested in; it could be prudent to maintain a narrative that ensures such research continues in the future. In a later section we will look into aspects relating to this observation in greater detail when these issues are considered in light of the sociology of expectations.
2.6.3 - Additional movement in a biological direction – 1930 to 1970.

Family and twin research into mental disorders is controversial for reasons other than the critique of its scientific credibility. Although this is a methodology still referenced today to establish or emphasise the genetic basis of mental disorders, there is an example from the annals of history that illustrates another reason why research into the field of psychiatric genetics may be tainted with controversial events from the past. This concerns the affiliation of scientists in the sterilisation legislation and the mass murdering of psychiatric patients in Nazi Germany. Although there will be no analysis of these events, focusing on this period of time is important for two reasons. First of all, in some parts of the world – such as Germany – research into the field of psychiatric genetics disappeared completely as a scientific discipline (Propping, 2005). While in other areas there were some monumental changes in research foci that would eventually see translation and application into the field of psychiatric genetics - these would evolve into the ‘modern’ molecular technologies that are more similar to the developments that inspired the Psynomics tests. However, I think that there are some additional and very important issues to consider around this period of time in addition to changes being seen in the field of psychiatric genetics. Although the examples that are going to be considered next do not focus on the field of psychiatric genetics, they do have a very similar purpose – they all achieve different things for how different issues in psychiatry and mental health care are emphasised. In this case I think that the developments about to be examined all serve the purpose of making mental health care seem more real or legitimate – through emphasis on the biological underpinnings of mental disorders or through establishing a classification system to aid in the diagnosis or the communication of different diagnoses and the use of medication in mental health care.

2.6.4 - Psychiatric medication and different hypotheses.

Being able to use medication in psychiatry gives the impression that mental disorders are biological issues, because they are suggested to be amenable to biological manipulation. The consequence of this is psychiatry can either make the claim that mental disorders are biological in origin, or the same idea can be implied in various different ways, such as through popular understanding (Higgins and George, 2007) or perhaps teaching, like the previous example from the psychiatry textbook. For example, in the following extract, taken from an introductory textbook aimed at psychiatry students and practitioners (David and Preven, 2000, p.10), the use of medication is directly equated to the elucidation of the biological components of mental illness:

If...a medication originally introduced to treat nausea but also effective in treating delusional thinking is discovered to decrease central nervous system dopamine neurotransmission, a hypothesis implicating excessive dopamine neurotransmission as the cause of delusional thoughts is generated. This example is somewhat oversimplified but illustrates the concurrent evolution of somatic treatments and the science of neurobiology. The medications have helped elucidate biological mechanisms of mental illness, as has research with chemical probes structurally similar to the medications. Modern psychopharmacology is the science of influencing central nervous system neurotransmission.

In this part of the discussion the key section is ‘The medications have helped elucidate biological mechanisms of mental illness’ - the author is making the claim that mental disorders have a component that is governed by a ‘biological mechanism’, which implies that mental health is, in part,
a biologically oriented phenomena – and the author is linking this observation to the use of medication. A major part of this implied move concerns the impact of the dopamine hypothesis on psychiatry and popular understanding of the subject matter of the profession.

Other scholars (Leo and Lacasse 2007) have also suggested that this idea has significant implications for the character of what it is psychiatrists do in their everyday practise. Although they are critical in their account, they note that in this case the treatment of mental disorders through this paradigm certainly places emphasis on the biological components of mental disorders:

For the psychiatry profession, the theory was a major driving force behind the rise of biological psychiatrists within the profession, and moved the profession from one involved in talking to patients about everyday problems, to a profession that was treating their patients’ organic diseases—just as the internists were treating diabetics suffering from insulin shortages, the psychiatrists were now treating depressed patients suffering from serotonin shortages. Depression was no longer seen as just a natural response to stress, there was now an underlying biological factor which was the cause of the depression. (Leo and Lacasse 2007, p.2)

However, I think that problems are encountered when the antecedent that inspired this initial suggestion is considered; this concerns over-reliance on the dopamine hypothesis as an explanation for the biological components of mental disorder. In this case the authors (David and Preven, 2000) are equating the discovery of a drug that is suggested to modify brain chemistry with the actual mechanism by which the mental disorder is thought to operate. If this suggestion is taken in isolation there may not be anything necessarily ‘wrong’ with this, for instance, it could be taken on the premise that it is just a hypothesis that should be used to consider the aetiology of mental distress. However, in recent years there has been a great deal of interest in examining the basis for this approach to mental health terminology, and refuting the legitimacy of these claims. One famous example of this is Irving Kirsch’s research into the difference between medication response and the use of placebos in the treatment of depression - which culminated in his 2010 book ‘The Emperor’s New Drugs’. Kirsch found out that in drug trials, placebos duplicated the effects of anti-depressants in around 80 to 90 percent of cases, thus casting the dopamine hypothesis into doubt.

Other than demonstrating the implied move towards increasingly biological explanations for mental disorders, this brief examination of the use of psychiatric medication illustrates another important point – that, even before we get to consider the impetus of genetics in psychiatry, the issues surrounding this biological ‘move’ are highly controversial. This issue needs to be considered when this research is situated. For example, it appears the suggestion (despite any possible criticism) that mental disorders ‘are due to a chemical imbalance’ is quite a popular way of considering mental distress (David and Preven, 2000 ; Leo and Lacasse 2007) - what influence would having a suggested genetic link for mental disorders have on this dynamic? In terms of dissecting these issues for the purposes of this research project, and looking to the future where this research is situated, a great deal will be revealed later on when some of the rhetorical features relating to this phenomena are considered. However, for the time being I want to suggest that given the interest in genetic testing for mental health care, from a research and policy perspective, these developments could be seen as a continuation of the idea established in this section – that mental disorders have a strong biological component.
2.6.5 - The role and the influence of the DSM in psychiatry and mental health care.

The DSM plays a very similar role to the introduction of medication used in mental health care. Although on initial consideration these two events may appear relatively distinct, they ultimately serve a similar purpose – to enable psychiatry to orientate towards, and place emphasis on, biological explanations for mental distress. However, one area where there is a significant difference between these examples concerns the observation that the DSM, ironically, does not necessarily place that much emphasis on the role of biology in isolation. Before the examples relating to this are given, I want to spend some time clarifying what this means. In the previous instance, emphasis was placed on the suggestion that the use of medication, suggested to ‘fix’ an underlying biochemical imbalance, implied that mental disorders were inherently biological phenomena. The situation is slightly different with the DSM example as there is no real emphasis on the underlying biology of mental disorders in this way. Rather, in this example the ‘movement of psychiatry in a biological direction’ is implied through the claims psychiatry can make, and what it is able to do, as a result of having this tool available to use. Essentially this will mean that the gulf between the treatment of mental and physical disorders is shortened because psychiatric practitioners have a methodology for the identification of pathology that is similar to ones routinely used in other areas of medicine.

The DSM originally began life as a document intended to help gather information about the statistical aspects of what we would now consider to be mental disorders. Although the intention of this document may have been to define, categorise and document all known mental disorders (APA, 2013) it has seen some major, and very controversial, ‘disorder’ revisions over its history – such as the inclusion and eventual removal of homosexuality and the possible inclusion of a presymptomatic ‘at risk’ diagnosis. However, although it would be possible to conduct case studies on each of these examples individually, I think it is possible to gain quite a detailed insight into psychiatry’s orientation towards biological approaches simply through consideration of what the DSM represents in isolation. Visiting some of the work published by Dr. Thomas Szasz helps us do this, not only do his contributions question the role of the DSM in psychiatry, but they also focus on the promotion of the idea that biological issues cause individuals to experience mental ill-health.

His essay ‘The Illegitimacy of the Psychiatric Bible’ (Szasz, 2010) is concerned with the tendency for everyday behaviours to fall under the scrutiny of mental health professionals. His account begins by considering the suggestion that with future publications of the DSM nobody is going to be ‘normal’ - more and more people will be considered as having a mental disorder as the boundaries for normalcy are continually reduced. However, from within this, not only does he provide evidence that mental disorders are becoming similar to physical disorders, in the ways that people consider and refer to them, he also provides a critique of this approach in the context of DSM nomenclature. Quotes from former President of the United States, William Clinton, and Surgeon General David Satcher are provided:

“Mental illness can be accurately diagnosed, successfully treated, just as physical illness” (President William Clinton). “Just as things go wrong with the heart and kidneys and liver, so things go wrong with the brain” (Surgeon General David Satcher). (Available at http://www.fee.org/the_freeman/detail/the-illegitimacy-of-the-psychiatric_bible#axzz2VSKeDbcs)
Although these quotes do not focus on the DSM directly, they certainly fit in with the theme of psychiatry increasingly orienting towards a biological approach, for example, in both of these instances comparisons are being made between mental and physical illnesses and I think that the result of doing this will mean that people think or believe that both situations are the same as each other. This is something that Szasz bitterly contests in much of his work, with perhaps the first instance being his essay, and later his book, called ‘The Myth of Mental Illness’ (Szasz, 1960, Szasz, 1961). However, in this essay (Szasz, 2010) there is more of a focus on the suggestion that the translation of these ideas into universal diagnostic criteria essentially act as a tool that legitimises this suggestion:

*When psychiatry was in its infancy the belief that all human “dysfunctions” are manifestations of brain diseases was a naive error. In its maturity the mistake was treated as a valid scientific theory and the justification for a powerful ideology and the powerful institutions based on it. Today, in its senescence, psychiatry is deceit and selfdeceit—coercion concealed as objective science (“medical diagnosis”) and benevolent help (“medical treatment”). As a result, paraphrasing Orwell, telling the truth becomes “a revolutionary act.” (Available at http://www.fee.org/the_freeman/detail/the-illegitimacy-of-the-psychiatric-bible#axzz2VSKeDbs)*

If other offerings by Szasz are considered (Szasz, 2000) additional critical insights into the DSM and what it represents in society are gained. For example, in the following extract Szasz suggests that the DSM acts as a tool that makes mental disorders appear like they are ‘real diseases’:

*In short, psychiatrists and their allies have succeeded in persuading the scientific community, courts, media, and general public that the conditions they call mental disorders are diseases—that is, phenomena independent of human motivation or will. Because there is no empirical evidence to back this claim (indeed, there can be none), the psychiatric profession relies on supporting it with periodically revised versions of its pseudo-scientific bible, the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders. (Available at http://www.szasz.com/usatoday.html)*

If all of these suggestions are considered together Szasz certainly had some concerns with the DSM and what it represents in mental health care. Szasz considers the portrayal of what psychiatry calls ‘mental disorders’ being tantamount to ‘diseases of the brain’ as an error, and in this case a scientific theory is being used to exercise social control. However, as there is no evidence for this, the psychiatric profession is dependent on the DSM (and its theories) as it legitimises what they do. Regardless of any lack of evidence for what mental disorders ‘are’ the DSM acts as a buffer with respect to any attack because it is used by the psychiatric community for the very purpose of making the disorders they are concerned with treating seem ‘real’.

Focusing on an example that was provided by Thomas Szasz is bound to resonate in the way it did in this instance. I consider Szasz the archetype of the anti-psychiatry movement and he is clearly very famous for this approach – so practically anything I chose to quote from his body of work is bound to be linked with some form of controversy about popular psychiatric approach. However, I feel that although his ideas may be extreme they do aptly summarise one school of thought about the DSM and what it represents for mental health care. However, just like earlier when I suggested that it is
important to consider the source of certain suggestions (McGuffin, et al. 2003), it is also important to consider the context that some of these anti-psychiatry suggestions were offered.

The 1960s was a time of change in psychiatry. Not only did the world begin to see the effects of developments like the introduction of psychiatric medication and the DSM, but other significant changes occurred. When looking through the literature there are two main focal points at this period in time. First of all there is a distinct shift away from psychodynamic psychiatry towards placing an emphasis on biological causality. Gerald Grob, Professor of the History of Medicine, in his paper 'The Attack on Psychiatric Legitimacy in the 1960s : Rhetoric and Reality' notes that after World War II the prestige and status of psychiatry reached a previously unsurpassed peak, as the environment was more conducive to community and outpatient treatments via the use of psychological models that emphasised life experiences. However, just as this became an established approach to psychiatry the field saw a number of distinct changes. Within the speciality, biologically inclined psychiatrists began to undermine the foundations of psychological theory and there was a dramatic rise in the number of non-medical mental health specialities that weakened the control of psychiatry over the practice of psychotherapy.

In terms of situating these developments in light of the multitude of different ‘models of mental disorder’ examined in a previous section, one way to approach this would be a decline of the psychological model and a rise of the biomedical model - this idea fits in with the generally observed ‘shift’ towards biological explanations for mental distress during this period of time. However, this is not the only change in models seen around this period of time. If the Szaszarian example is considered in context, around the time of 1960 saw the genesis of what would possibly be referred to as the ‘anti-psychiatry’ model. In the aforementioned paper, Gerald Grob suggests that the roots for these changes lay partly in the political landscape of the time – such as an influx of Jewish medical school graduates choosing psychiatry as a specialisation who brought with them a more liberal approach to overall psychiatric thinking.

Although some of the aspects that are present behind the research efforts themselves will be examined in greater detail later on, for the time being I want to finish off this section acknowledging that there was an emphasis placed on the overall biological aspects of mental health up to around 1960. These are somewhat different from the research in the field of psychiatric genetics, but they serve a similar purpose – they make psychiatry and mental health care appear in a different light. In this case, it makes mental health care appear as if is involved with ‘real’ medical issues that can be rectified with the use of medication, and that the profession is similar to other areas of medicine that deal with ‘definitive’ illnesses. When considering what the developments in the field of psychiatric genetic testing potentially offer in this dynamic this is an important point to keep in mind as the possible consequences of these developments are huge. For me the most pressing issue to consider here is what could happen if any of the advances being made in the field pf psychiatric genetics did ever combine somehow with a tool such as the DSM. Although completely speculative at this point it does not seem too progressive or outlandish to suggest that one possible avenue for such research streams would be to combine in the future. For example, as the research in the previous section, which seemed to implicate calcium ion signalling in a selection of mental disorders, indicated, there maybe a time when genetic differences may aid in determining a diagnosis – in this case – it may be possible to link differences in calcium ion signalling with different psychiatric presentations. Regardless of the form in which this knowledge base is actually used in practice, I
think this body of work is making inroads to a situation whereby it could be possible to help classify psychiatric disorders. So perhaps one day we will see similar research in a context that helps us classify mental disorders? Perhaps a future version of the DSM will contain evidence from the field of psychiatric genetics in addition to the pre-existing diagnostic criteria? Therefore the DSM, in its current form, seems to go some way to emphasise psychiatry moving in a biological direction (as it provides psychiatry with similar tools to that of other areas of medicine), however, one issue to consider is how the developments in the field of genetic testing may integrate with this observation in the future.

2.6.6 - Linkage studies – 1970s, 1980s and 1990s.

Linkage and association analyses are commonly employed methods used to locate and define susceptibility genes for diseases (Berrettini, 2007) by looking for differences in allele frequencies between populations of patients and healthy controls. If the patient population has a specific allele more frequently than the control population, then that allele is said to be associated with the disorder (Gill and McGrath, 2010). The development of the technologies used to execute this sort of research, as well as some major successes that pinpointed chromosomal locations for Cystic Fibrosis and Huntington’s disease, caused researchers to apply the same methods of analysis to investigate mental disorders. Just like the previous example focusing on twin and adoption studies, this methodology has seen some significant controversy when applied in this field, as initial hope (or according to some academics and commentators, hype) was met with bitter disappointment.

The two papers most commonly quoted as early examples of this in the literature are a study into bipolar disorder linked to DNA markers on chromosome 11 (Egeland, et al. 1987) and an investigation into a susceptibility locus for schizophrenia on chromosome 5 (Sherrington, et al. 1988). However, very soon after these papers were released into the public domain their findings were questioned as other research teams were unable to replicate both groups’ initial findings (Propping, 2005). In terms of reviewing this particular focus into the field of psychiatric genetics, there is nothing too problematic here. One way to approach these discrepancies would perhaps be to consider the previous research (Egeland, et al. 1987; Sherrington, et al. 1988) being an out-and-out mistake, and the subsequent papers that point out that their original findings are impossible to replicate are simply correcting the information that was made available in the public domain. The Egeland group did publish a paper two years later (Kelsoe, et al. 1989) that did re-evaluate their findings in light of new evidence. However, it is possible that these retractions were somewhat embarrassing for the research teams involved, and perhaps the field of psychiatric genetics at the time too.

Regardless of these early problems, linkage studies have subsequently been carried out into a selection of different mental disorders. Before some of the issues relating to bipolar disorder in isolation are considered, I want to point out that there is still a certain degree of more modern controversy with regard to this methodology and its use in ascertaining the genetic basis of mental disorders. A notorious linkage study representative of this being the DISC1 research conducted in schizophrenia.

DISC1 stands for ‘Disrupted In Schizophrenia 1’ and it is a gene whose mutant truncation has been associated with several psychiatric disorders - linkage studies have identified the DISC1 gene on chromosome 1 confirming susceptibility to schizophrenia (Gill and McGrath, 2010). However, this
research still remains extremely controversial. For example, in an editorial edition of the British Journal of Psychiatry there is an article called ‘Is DISC1 really a gene predisposing to psychosis?’ (Crow, 2007). This article revolves around the idea that the evidence for DISC1 was previously overestimated in a 2006 article (Muir, et al. 2006); their primary argument being that there is a lack of research evidence available to make such claims. There is a similarity here to the previous examples that focus on the early linkage studies in mental health – there are sometimes problems among concerned scholars in relation to the claims that are being made about certain research efforts. Although this example seems to trail off in the literature and does not seem to resolve as well as the Egeland and colleagues’ research, there are similar problems when different people consider the findings in different ways.

However, there is a slightly different picture when some of the linkage studies into bipolar disorder are considered, as there appears to be less evidence of any direct controversy about the results and they seem to be presented in a relatively ‘open’ way. For example, I do not detect any overt examples where there are serious questions or concerns about the findings, in a fashion similar to the earlier Egeland research. If anything, when all of the evidence is considered there appears to be a popular shift among the linkage study research community into bipolar disorder that seems to indicate that although there may be a small degree of promise with some of the results, the general consensus is that no linkage study into the condition has yielded decent results. However, it is important to keep in mind that this situation is being observed after it happened; we have the benefit of hindsight in order to consider these issues. At the time the chances are these studies were conducted with a degree of hope and expectation about what they could offer the research community, but looking back at them we realise that they did not turn out to provide anything significant to our understanding of mental health. This observation forms an important component of an issue that will be explored in a later section, when these issues are considered in light of the sociology of expectation.

Considering this, there is a temporal shift in the accounts offered through meta-analysis of review studies over the last 10 years. More recent accounts of the literature appear to arrive at the conclusion that there are no common and constantly reputable loci for the disorder (Craddock and Sklar, 2009; Barnett and Smoller, 2009):

*Although several regions have been implicated, it is clear that, as for most other common familial diseases, the linkage paradigm has been unable to accurately and reproducibly identify the loci involved in bipolar disorder. This observation enables us to conclude that there are no common loci of large effect involved in the genetic etiology of bipolar disorder. (Craddock and Sklar, 2009, p.100)*

*Linkage analysis works best where genetic risk is conferred by a relatively small number of genes, each of which has a relatively large effect on disease risk. The limited success of linkage studies in psychiatric genetics is therefore taken as evidence that such genes do not underlie risk for BPD. (Barnett and Smoller, 2009, p.333)*

In contrast to this, older accounts that focus on the state of the science are more willing to consider evidence provided by the inroads being made using this methodology (DePaulo, et al. 2001; Shastry, 2004). However, contained within these accounts is a degree of appropriate caution about the
future prospect of these methodologies to determine the genetic components of the disorder (DePaulo, et al. 2001, p.155):

*It is likely that this summary of a story in progress includes some leads that will not prove accurate and omits others that will. The value of most negative linkage studies is minimal because linkage can rarely be excluded under the assumption of substantial heterogeneity.*

However, although the linkage study research into bipolar disorder appears to be a dead end, there are still instances where the findings from these research endeavours are still used in educational contexts. For example, in the aforementioned medical text book ‘Psychiatry an Evidence Based Text’ (Puri and Treasaden, 2010, p.275) the chapter section on the genetics of bipolar disorder contains the following extract:

*A number of areas of the genome have repeatedly shown linkage with bipolar disorder. Some of these regions (4p16.1, 11p15.5, 12q24.31, 18p11.21, 21q22.2–3, 22q12.3) are particularly interesting because they contain genes that have been identified in association studies of BPAD. (Puri and Treasaden, 2010, p.275)*

This section of the chapter heavily relies on one review paper ‘The genetics of bipolar disorder: genome ‘hot regions,’ genes, new potential candidates and future directions’ (Serretti and Mandelli, 2008) to inform readers about the linkage studies in the disorder. Upon reading this paper it appears to review studies that are in the middle of the previously discussed transition period between 2001 and 2007, when there was initial optimism and increased interest in linkage studies into bipolar disorder, but this later culminated in the suggestion that such endeavours are fruitless. The issue here is not necessarily related to any problems with the research itself, as suggested previously – if the most recent studies are considered it would seem that scholars are quite open about the insight limitations provided by these studies – however, I do see problems when potentially conflicting evidence is included in a way that it could influence popular understanding about the disorder. For example, regardless of the fact that there is only a very small section of bipolar disorder linkage studies included (and we know these are not particularly reliable), the textbook still indicates that there are areas of the genome that show linkage with bipolar disorder. There are no sections that really question this observation and the problem is that the contested nature of these studies is being ignored. So my concern in this case is that some people may think, certainly if they did not look any further than the medical textbook, that linkage studies for bipolar disorder do show appropriate linkage to regions of the genome.

In terms of an exemplar for research into the field of psychiatric genetics these linkage studies do not provide any real benefit or useable worth because the overall view is that they do not contribute anything solid to the claim that mental disorders have an underlying genetic component. However, this research does show that making these links are sometimes more difficult as there is a significant degree of controversy surrounding their use – such as the early exemplars from Egeland and colleagues. One way of considering these linkage studies could be as a chronological stepping-stone between the former family, twin, and adoption studies and some of the more modern research that will be discussed shortly. However, looking at some of the narratives contained within these papers there are additional similarities other than these linkage studies representing the next chronological stage in research. Like the previously documented instances where evidence from family studies is used as continual ‘proof’ for the genetic underpinnings of mental disorders, there is a similar
phenomena being observed in some of these linkage studies. However, in these cases the evidence of a linkage study that fails to really prove anything relating to the genetic underpinnings of a mental disorder cannot be used as evidence for the contrary, instead there is a constant look towards the future in relation to what the associated field can offer. Here are two examples from papers already examined in this review:

In the future, advances in basic neuroscience research may provide a better understanding of the underlying neurobiological states of mood disorders that will enable physicians treat the condition most effectively (Shastry, 2004, p.276)

It is likely that this summary of a story in progress includes some leads that will not prove accurate and omits others that will. The value of most negative linkage studies is minimal because linkage can rarely be excluded under the assumption of substantial heterogeneity. Nonetheless, at the most attractive loci on the bipolar disorder horizon, the difficulty in isolating the best candidate polymorphisms and proving the pathogenicity of any one of them promises to be a difficult task (DePaulo, et al. 2001, p.155)

Later on in this review we will see that this constant ‘look towards the future’ narrative is also used in other research articles that adopt more modern methodologies and techniques. These issues will form an important part of the review when some of the literature and relevant ideas concerning the sociology of expectation are considered later.

2.6.7 - Candidate gene association studies – post the 1990s.

Candidate gene association studies operate in a similar way to the previously reviewed linkage studies. However, they differ slightly, as specific candidate genes that are thought to have a central role in the aetiology of the disorder, will be chosen and searched for the elucidation of Single Nucleotide Polymorphisms (SNP’s) that are unique and more frequent to case groups. Candidate gene association studies are important to consider as there are a selection of previously released genetic tests that adopt this methodology as their modus-operandi, this includes the Psynomics developments and a test for schizophrenia that is available from the online personal biotech company ‘23 and Me’. When considering these sorts of studies they represent something of an anomaly with regard to the historical track record of the underlying genetics of mental disorders. On the one hand there appear to be institutions willing to endorse such findings as they are using this research in marketed genetic test technologies (such as Psynomics and ‘23andme’), while on the other hand most review papers essentially arrive at the conclusion that this methodology is not going to provide any reputable foundation for further investigation, or that much larger sample sizes will be needed to have any confidence when using the methodology in this way. However, in the history of the genetics of mental disorders, the Psynomics tests and the research that contributed to their development, represent perhaps the biggest example of an actual marketed technology being made available into the public sphere.

As the Psynomics tests are going to be used as a springboard for discussion about the overall implications of genetic testing for mental disorders, these will be focused on in this section of the review. When compared and contrasted against several other candidate gene association studies I feel that the Psynomics example is fairly representative of this type of research, the only major
difference being that the research has been translated into a previously made available online genetic test.

**2.6.8 - The Psynomics research.**

Psynomics have three papers available in the ‘Key Scientific Information’ section of their web page (http://www.psynomics.com/about_papers.php) and they essentially paint the picture for all of the research conducted into the development of their tests. Their first paper (Kelsoe, et al. 2000) is an exploratory linkage study that identified a potential susceptibility loci on chromosome 22, while their second and third papers (Barrett, et al. 2003; Barrett, et al. 2007) focus in on this region and suggest that mutations in a specific G protein is linked to a bipolar presentation. Up to this point there is not a great deal to say about these findings. However, when they are considered in terms of what the marketed genetic test claims to do, there are some issues that need to be pointed out. For this section the ‘model report’ document (http://www.psynomics.com/pdf/model_report.pdf) that summarises all of the Psynomics findings will be heavily referenced, this document is intended to provide anyone interested in the technology with a brief overview of the research that went into the development of the tests and how the results should be considered.

In their 2007 paper (Barrett, et al. 2007) the research team discovered two SNP variants in the GRK3 gene that are associated with the disorder – the ‘P-5 mutation’ and the ‘E/H haplotype’ – possession of either one of these mutations, place an individual at an increased likelihood of having bipolar disorder. According to Psynomics having the ‘P-5 mutation’ means an individual is at a ‘3x Increase in likelihood of having Bipolar Disorder’, while having the ‘E/H haplotype’ means an individual is at a ‘2x Increase in likelihood of having Bipolar Disorder’. However, I have some concerns about these statistics because they appear to be basing these findings on the basal rate of bipolar disorder found in the general population, which is commonly quoted at around one percent of the population (Hock, et al. 2012). There is nothing necessarily wrong with doing this, because for the statistics to make sense they have to be compared from a base line reading, however, I think that when these findings are taken and expressed in different terms they might lose some of their initial impact.

For example, say we have a group of 100 people all sat in a room together and they are all willing to participate in an experiment using the Psynome1 test. If the standard rate likelihood of having bipolar disorder is considered, then one of these people will be likely to develop the disorder at some point in their lives. If this test was applied to an individual and it happened to register as being positive for the genes that Psynomics have linked to the disorder, then that particular individual is going from a ‘one in one-hundred’ chance to a ‘between a two or three in one-hundred’ percent likelihood chance of having bipolar disorder. When these gains are considered in isolation, and alongside some of the additional caveats that are needed for a validated test result, I do not feel that they are particularly impressive – there are some serious limitations of the science that need to be considered here.

For example I do not know if the increase in percentage likelihood reading offered by the Psynomics test would really be enough to have any confidence in what it actually purports to do – this is especially salient with regards to the fact that Psynomics stipulate that for their tests to be valid for the individual actually taking the test, a family member needs to have a diagnosis of bipolar disorder. If this is the case would it not be easier to take an in-depth look into the affected individuals’ family tree and use this as a basis for considering their psychiatric presentation?
Although there are other groups offering genetic tests that use a similar methodology, such as the schizophrenia test that is currently available to order online from the personal genome research company ‘23 and Me’, it appears that candidate gene association studies into mental disorders have on the whole *failed* to produce robust and reliable results (Barnett and Smoller, 2009). However, this issue is not necessarily the important one in this case - regardless of any of the ultimate failures when investigating the use of this methodology, this approach represents the closest we have ever got to seeing an actual genetic test used for these mental health presentations even remotely linked to a clinical context. Therefore in the history of the field of psychiatric genetics these developments represent a number of significant points. Although it is possible to critique the science behind the tests, as well as the additional criteria that need to be adhered to in order for a test to be valid, or maybe even discount them as useless – one thing that is hard to deny is what these tests ultimately *represent* in the quest to determine the genetic underpinnings of mental disorders.

The science behind them may be outdated, and the Psynomics efforts have been withdrawn from the online marketplace, but out of all the biological research that has gone into mental distress these efforts are the closest we have ever got to a real genetic test in this field. The issue of what the tests *represent* is the important factor here in this discussion, it has been established that the tests’ scientific credibility is actually very poor, but in this case I do not think this is the important point. If these developments are considered in terms of the successive ‘waves of development’ seen in the field of psychiatric genetics they are significant simply for the amount of controversy they have evoked and what they represented at the time of their release. In several ways, it could be possible to argue that having these tests as a development that has been released and is available to consider is a good thing, as clearly this is an area of extreme academic and clinical interest, so perhaps the issues salient to these technologies will also be important to consider for future developments? However, in addition to this it is also important to keep in mind that it is not necessarily the scientific credibility of the test that is important here, it is also vital that we are aware of the area in which similar developments may eventually be used – such as a ward based clinical environment. Ultimately I think it is important that we think about how mental health professionals make sense of the implications of these potential future developments in the context of their clinical practice as soon as we can.

However, another aspect that warrants discussion here concerns some of the background of Psynomics as a research institution themselves. For example, just like the previous look into some of the work published by McGuffin and colleagues, which appears to establish a narrative surrounding the related research into the underlying genetics of mental disorders, are there any parallels to draw here? It is important to remember that the pinnacle period of time where there was a great deal of discussion about the Psynomics tests was around 2008, so although the discussion concerning these particular examples has died down somewhat, and is perhaps even a little old, a great deal can be learnt from looking back at articles from the period. However, it is also important to consider these issues as historical ‘snapshots’ of the research and its associated factors from some five years ago. The research team associated with Psynomics have moved onto different projects since 2008 and some of them appear to be translating their research efforts into some of the more current and up-to-date approaches.

The following insights were gained from a Depression and Bipolar Support Alliance newsletter that was originally made available in California in 2008, but was simultaneously released online
The article ‘Experts troubled by at-home tests for bipolar’ contains some insights into one of the main contributors to the development of the Psynomics tests, Dr. John Kelsoe, and even provides some interview quotes from him about his research. The article begins by claiming that Kelsoe has spent his entire career trying to determine the biological roots of bipolar disorder, and looking at his University of California web page (http://psychiatry.ucsd.edu/faculty/jkelsoe.html) this certainly seems to be the case. The article raises the point that Kelsoe may have started offering the tests a little too soon, as Psynomics themselves were investigating additional genetic avenues for further research, suggesting that other genetic components may be responsible for the disorder as well. In correspondence to this a quote from Kelsoe himself is provided:

Why are we starting before it’s finished? You’ve got to start somewhere...Even if we knew everything about the genes, which we certainly don’t; it’s never going to be 100 percent predictive. (California News, 2008, p.6)

Regardless of any initial optimism from the company, who estimated they would have sold 30,000 tests in the first five years of their release, Psynomics soon withdrew their tests from the online marketplace. Personal contact with the company indicates that the main reason for this is due to the controversy over the ‘Myriad’ case, and despite assurances that they were going to produce more tests in recent years, nothing has been seen from them yet.

Consideration of the Psynomics tests is important in this review as I feel they are perhaps representative of several issues covered so far, but I also think these aspects can be seen in some of the future topics that will be explored. The Psynomics technologies represent quite an iconic snapshot of the historical developments seen in the field of psychiatric genetics, and although we have perhaps seen the last of these particular efforts, they do serve as food for thought with regard to any future potential developments. One of the main points I take away from examining the Psynomics developments is that the science behind the tests is rather limited in terms of what it can offer in a practical capacity. This limitation needs to be considered alongside what the tests represent in a theoretical capacity, specifically, what developments such as this offer the overall field of psychiatric genetics. Although it still seems as if the developments are being refined, and even perhaps a long way off before they are even used in a clinical setting, it is important that these changes are investigated from this perspective.

2.6.9 - Genome Wide Association Studies and beyond -- Post 2000.

In this final section of this historical overview of the field of psychiatric genetics I want to focus on the more modern methodologies that are used as evidence for the underlying genetic components of mental disorders. To begin with I will briefly focus on GWAS research and after this I will examine some recent and novel suggestions that have been made concerning the genetic aetiology of mental disorders. Unlike any of the previous examples that look for specific genes or locations in the genome, GWAS work as follows (http://www.nature.com/scitable/topicpage/genetic-variation-and-disease-gwas-682):

Genome-wide association studies (GWAS) represent a recently developed research technique with many implications on both a global and an individual scale. GWAS seek to identify the single nucleotide polymorphisms (SNPs, pronounced "snips") that are common to the human
genome and to determine how these polymorphisms are distributed across different populations. On a broad scale, these studies help scientists uncover associations between individual SNPs and disorders that are passed from one generation to the next in Mendelian fashion. On a small scale, GWAS can be used to determine an individual’s risk of developing a particular disorder.

For the purposes of this review, everything that needs to be summarised with respect to GWAS research can be found in a very recent paper – ‘Identification of risk loci with shared effects on five major psychiatric disorders: a genome-wide analysis’ (Psychiatric genetics consortium, 2013). From a large scale study the research team found four different SNP loci in the genome that exceeded the cut-off point for genome wide significance. The really interesting finding from this research is that for all of the disorders analysed (autism spectrum disorder, attention deficit-hyperactivity disorder, bipolar disorder, major depressive disorder, and schizophrenia) the research team found that variation in calcium-channel activity genes seem to have correlated effects on psychopathology.

However, although this is an interesting finding – and one that is focused on in the discussion of the article - one additional aspect where I feel this paper is really quite progressive in its ‘disorder recruitment and consideration’ methodology. The authors aggregated the risk factors for the five disorders on the basis of their underlying biological components rather than on the basis of descriptive and subjective diagnoses. This meant that it was possible to make biological inferences between disorders rather than having to consider them in terms of their traditional presentation. The authors note:

*The finding that genetic variants have cross-disorder effects is an empirical step towards helping clinicians understand the common co-occurrence of clinical phenotypes in individual patients. (Psychiatric genetics consortium, 2013, p.7)*

However, although the authors finish their paper by suggesting that calcium signalling could be an important future avenue in mental health research, they do also point out that the effect sizes of genome-wide significant loci are individually quite small and the variance they account for is insufficient for predictive or diagnostic usefulness by themselves – therefore this is unlikely to translate into a test development anytime soon. In terms of the various narrative aspects that have been pointed out in the previous research articles, this paper seems to lack these devices. For example, there is no mention of twin and family studies as proof that mental disorders are genetic in origin and there is no real mention of being able to translate this research into a genetic test technology either – the only ‘looking towards the future’ aspect concerns further investigation into the role of calcium channel signalling in mental distress.

However, there are other important aspects in relation to this paper that need to be pointed out. First of all I think that even if the authors are appropriately cautious about their findings and suggestions, it is difficult to ignore the fact that these findings are still going to equate mental disorders with genetics. A news article from the National Institute of Mental Health confirms this suggestion. Soon after the research paper was published several news outlets began to report on the findings, and from consideration of this article, titled ‘Five Major Mental Disorders Share Genetic Roots’ (http://www.nimh.nih.gov/news/science-news/2013/five-major-mental-disorders-share-genetic-roots.shtml) I think it would be difficult to read it and not come away thinking that some progression linking mental disorders with genetics has been made – regardless of how small this may
actually turn out to be. In addition to this, when looking through the long list of contributors to this research at the end of the paper, there are a number of names that are now familiar to us from this section of the literature review – such as Patrick Sullivan, John Kelsoe and Michael O’Donovan. As mentioned, these scholars have a deep interest in examining the genetic underpinnings of mental disorders and they are affiliated with research groups whose primary interest is investigating these issues. Although issues similar to this have been highlighted throughout this review, aspects like this will play a bigger part in the following section of the literature review that will look at features of the sociology of expectations with respect to the ongoing genetic research into mental disorders.

Before the final example - that moves slightly beyond GWAS research - is considered, it is interesting to note that there is an additional commentary article (Serretti and Fabbri, 2013) attached to the same PDF file the above paper originally came from, and this paper does make some promissory claims about the overall movement of the field. Here is how the authors end their commentary:

> Although some methodological limitations remain, much progress has been made. New generation exome and full genome sequencing and genome-wide pathway analysis are among the most appealing methodologies. We therefore believe that genetics, possibly thanks to more comprehensive phenotype and endophenotype assessments, can contribute to prediction and prevention of psychiatric diseases, along with the identification of molecular targets for new generations of psychotropic drugs. (Serretti and Fabbri, 2013, p.2)

In the following section of the review we will learn that placing emphasis on suggestions such as this actually provide researchers in the field of psychiatric genetics with a useful tool that enables their research activities to continue. Constructing a narrative around their research that continually points towards the future hopes of the science serves an important purpose for attracting funding, promotion of the field, and ultimately enabling it to continue. Before these aspects are discussed in detail I want to focus on an example that will act as a bridge to the consideration of this body of work.

‘Genetic architectures of psychiatric disorders: the emerging picture and its implications’ is a review paper (Sullivan, et al. 2012) that examines the previous five years’ worth of genetic research into a suite of different mental disorders. Summarising this paper it would appear that the review team are extremely positive about the relationship between psychiatric disorders and their underlying genetic contributions. This is how the article ends:

> Elucidation of the genetic architectures of psychiatric disorders is an attainable goal with existing technologies...Few predictions are perfectly safe, but we would argue that genetics is a particularly good bet for psychiatry. (Sullivan, et al. 2012, p.549)

In the article itself the authors review the most up to date evidence that links a selection of psychiatric disorders (Alzheimer’s disease, attention-deficit hyperactivity disorder, alcohol dependence, anorexia nervosa, autism spectrum disorder, bipolar disorder, major depressive disorder, nicotine dependence and schizophrenia) to, what they consider robust and replicable genetic findings. The quantitative claims from the large number of biologically driven studies into all of the listed disorders are presented. However, this is not necessarily the most salient aspect of this paper – the discussion that follows the summary of the genetic research into these mental disorders covers some of the most important ground where this research is concerned. For example, the
authors emphasise the idea that psychiatric disorders are polygenetic; with respect to this they make the following suggestion:

> The polygenicity of psychiatric disorders poses intriguing difficulties: how can these many genes be coherently tied together? A parsimonious hypothesis is that the polygenic basis of a psychiatric disorder is manifested in the regulation or function of one or more known or novel pathways. Genetic variation at many different loci could introduce numerous slight alterations that result in a pathway that is insufficiently robust in response to an environmental insult or that leads to an inappropriate developmental programme. Risk for a complex psychiatric disorder could be conferred by the emergent properties of the pathway itself rather than any single component... Indeed, if one or more psychiatric disorders eventually prove to be pathway diseases, there could be clinical benefit. We conjecture that it might be considerably easier to coax an existing but dysfunctional biological pathway into the normal range than to replace components that have been broken by Mendelian mutations. (Sullivan, et al. 2012, p.547)

This statement makes for a significant contrast when considering its implications in light of any of the previous research. Not only is this alluding to a time were it could be possible to diagnose a disorder using this methodology, but it is also hinting that it may be possible to manipulate the biological pathway to treat the disorder. This, and a selection of additional points, are examined in the paper ‘Between Bedside and Bench : Puzzling over schizophrenia’ (Sullivan, 2012, pp.210-211). Further clarification concerning the ways that pathway diseases actually manifest, and are researched, is explained:

> At present, we can only be vague about the meaning of the term ‘pathway’; current knowledge is limited, and the fundamental pathways could be biochemical, regulatory, developmental or anatomical and might correspond to a known pathway or a hitherto cryptic process. The idea arising from the observation of high polygenicity in schizophrenia is that the functional unit conferring risk may not be any single node but rather the pathway itself. Thus, schizophrenia may be a cardinal example of a pathway disease...

There are other references to the way this type of research may ultimately benefit those who experience mental disorders:

> Knowledge derived from this work could lead to the fulfilment of the ultimate promise of genomics—primary prevention of the development of schizophrenia in those at risk and the development of more effective therapeutics in an era where big pharma has turned sharply away from psychiatric drug development. Critically, it is possible that any such pathway is intrinsically modifiable and that people with schizophrenia are not ‘doomed from the womb’ but rather could anticipate return to relatively normal long-term function.

There is a selection of sociological work that focuses on a very specific aspect of the ever increasing and ever complex genetically oriented research into psychiatric disorders. Consideration of this body of work is important because the research being embarked upon in this project could conceivably be considered as a possible extension in this particular field of enquiry. The papers about to be examined are concerned with a selection of the sociological implications of genetic research into mental disorders. Considering the implications of these suggestions is important because other than
this research being in a related field, there is also a chance for this project to extend upon these foundations. However, the work about to be considered emphasises some of the issues concerning how and why genetic research into mental disorders continues in the way it does - there is little to no consideration of any potential clinical or perhaps societal impacts of any tests themselves, something this thesis aims to investigate.

In the article ‘Schizophrenia and the Narrative of Enlightened Geneticization’ (Hedgecoe, 2001) Adam Hedgecoe investigated the ways that clinical geneticists construct a narrative around their research into schizophrenia that appeases critics by pointing out some of the limitations of genetic research, and allowing for the role of non genetic contributions, while at the same time subtly privileging genetic explanations and approaches. This exact notion is observed in the previous examination of the most up to date ‘pathway disease’ research into mental disorders. For example, Sullivan (Sullivan, 2012, p.210), offers the following account that mentions both the complex polygenetic nature of schizophrenia and the potential role of the environment:

For schizophrenia, the hypothesis is that polygenetic variation alters a biological pathway...There are many ways in which such a pathway could mediate liability to schizophrenia—by being insufficiently robust or overly rigid in response to environmental insult, for example, or by coding an inappropriate developmental program.

A related research article that uses a very similar methodology to the Hedgecoe work is ‘Complexity and accountability: The witches’ brew of psychiatric genetics’ (Arribas-Ayllon, et al. 2010). Here the authors focus on the observation that research into the genetics of psychiatric disorders is an increasingly complex activity, however, this evolution of complexity is not just an account of the technical expertise needed to detect the biological underpinnings of mental distress; the authors suggest that increasing complexity also plays a rhetorical role. The authors suggest that this approach to scientific accounting accomplishes a number of objectives, such as, exonerating previous failures in psychiatric genetics, allowing for the inclusion of non genetic factors that “insulates the field from criticisms of determinism by according these factors an indeterminate role” and allows for related research to continue as result of the precedent established via adoption of this complicated technical approach. However, the authors also make the following suggestion concerning the increasingly complex nature of research into psychiatric disorders:

...it confers a kind of respectability to biological psychiatry by adopting the same rhetoric of complexity as that of the much larger and less controversial programmes such as those investigating diabetes and heart disease. (Arribas-Ayllon, et al. 2010, p.20)

Considering the impacts of these studies in terms of this project’s intended trajectory there are several issues to consider and keep in mind. First of all elucidating the underlying genetics of mental disorders is considered an increasingly complex pursuit – this has clear implications when using a ‘simple’ genetic test to determine insights into the future of this development in a clinical setting. Specifically, the Psynomics tests probably are not an accurate reflection of the research that is implicated as being sympathetic to realities of complex mental disorders. However, an additional facet that may also have a bearing on this project is the suggested sociological impact of this type of research. From both the papers in this section (Arribas-Ayllon, et al. 2010 ; Hedgecoe, 2001) it appears that the stance adopted by research scientists in regard to these features serves an important function in regard to the rhetoric of such activities. In these examples trying to determine
the biological aspects of mental disorder has an impact on issues such as neutralising attacks on such controversial research – because an allowance for non genetic factors is incorporated into the narrative alongside an explanation for previous failures. However, in addition to this, constructing such a complex narrative ensures that research into these issues can continue while also providing the activity with the same justification that research into other equally complex disorders has – such as diabetes or heart disease.

The issue is that these contributions are largely concerned with the research environment. Although the Arribas-Ayllon and colleagues paper suggests the Psynomics developments are an example of how different degrees of ‘complexity’ in mental health research are susceptible to commercial interests, there are no allusions to how their suggestions may impact upon the ultimate goal of this sort of research, the use of clinical tools that can aid in the treatment of mental disorders. Therefore, there is the possibility that as this research is focusing on the clinical aspects of these developments, regardless of what form they may eventually take, there may be findings generated that also focus on the status of different aspects within the field. However, in this instance this is likely to be concerned with aspects of psychiatric practice rather than the research that goes into production of the tests.

2.6.10 - Summary.

My intention in this section was examine some of the historical developments and changes in the field of psychiatric genetics. This is important so that any future genetic test development can be placed into its appropriate context in relation to the current research climate. When considering all of the issues I generally choose to think about a genetic test development as an iconic extension of what has already been established here, one that is really yet to happen, but is being actively investigated by the research community. However, contained within all of the presented examples is an additional aspect, which requires further attention, and is salient to the situation of this research project. In every example presented it is always as if mental health care and psychiatry more broadly are constantly moving towards biological explanations for mental distress, and as time progresses this idea is constantly evolving.

However, this notion is a controversial one - as in essentially every instance the evidence for this claim can be refuted. Despite this difficulty, this examination of the field of psychiatric genetics has shown that all of these developments have been used to imply or make the claim that there is an underlying biological cause for mental distress – and the important aspect to consider is what do the possible future developments in the field of psychiatric genetic testing provide in this situation? What would being able to use such a test do for certain aspects of psychiatry or mental health care?

Additionally, this review introduced the idea that when considering research in the field of psychiatric genetics it is important to keep in mind issues that may not immediately be apparent when examining research for the first time. For example, one aspect I believe to be very important is that despite any of the past failures or the extreme controversy surrounding the field – research into psychiatric genetics is something that is still continually being perused. A major part of this is the narrative established by the authors in these research articles, they appear to constantly emphasise the idea that mental disorders do have a strong genetic component, even if it means referring back to older twin and adoption studies to make this point, or continually suggesting that breakthroughs are just around the corner. Several of these issues will be focused on in this next section that
examines how the developments in the field of genetic testing for mental disorders can be considered in light of what they essentially promise to do in the long term, as well as some of the accessory features associated with this observation.

2.7 - The sociology of expectation and the field of psychiatric genetics.

With this analysis and consideration of the field of psychiatric genetics, it is possible to extend this account in a slightly new direction, albeit one that was hinted at constantly throughout the last part of the review. This pertains to the consideration of the developments being made in the field of psychiatric genetics in light of what is referred to as the sociology of expectation. From my reading on the topic this is a sensible area to focus the inquiry as there appear to be a number of parallels to draw between what is observed and discussed in this literature and what is currently occurring in the field of psychiatric genetics.

However, I feel there is perhaps a subtle disconnect between some of the issues contained within the literature on this topic and mapping these over to the field of psychiatric genetics. For example, one of the major differences here concerns what the developments in genetic testing for mental disorders actually represent in the progression of mental health care as an institution. From the previous review on the topic, one of the ways to view the developments in field of psychiatric genetic testing could be as one important ‘arm’ of psychiatry as a medical institution. Although, from considering some of the work of scholars like Thomas Szasz, aspects and elements of psychiatry can be criticised for numerous reasons, I think the reality is that regardless of these warranted attacks, psychiatry - in one form or another - is here to stay and is an extremely important part of medicine. Regardless of its difficult and often controversial track record, any questions about the efficacy of medication, criticisms about it not being a medical or a scientific discipline – it is hard to deny just how important psychiatry is in modern society.

Therefore I choose to consider the developments in the field of psychiatric genetics as a single part of the story here, and this is partly due to difference between the research being undertaken in the field and the actual practice of psychiatry itself. The difficulty is located in appreciating how these two areas converge, support, and interact with one another. For example, although we will see that there is an embedded narrative in the research in the field of psychiatric genetics, and it is possible to pinpoint instances in its history that fit in with the central themes of ‘the sociology of expectation’, it is important to consider how these changes may interface more broadly with the practice of psychiatry itself. This could be considered in terms of what the developments in the field of psychiatric genetics ultimately represent and provide for the overall field of psychiatry and psychiatric practice. So in several ways there are actually two aspects at work here. On the one hand there are the developments in the field of psychiatric genetics to consider, and on the other hand there are how these developments serve psychiatry as an overall institution.

2.7.1 - The sociology of expectation

From my reading on the topic, the sociology of expectation is fundamentally concerned with the analysis and understanding of the role of future expectations and promises in different scientific and technological fields (Borup, et al. 2006; Van Lente, 2012). However, often linked within this overall analytical approach is a discussion concerning some of the constant failures of such endeavours, for example, a common theme running throughout these investigations relates to the suggestion that research streams – such those seen in the biotechnology industry – often make some big claims
(that penetrate popular discourse and understanding) about what they are working towards, but these claims never seem to materialise (Brown, 2003). Even from this very brief consideration of the field some clear parallels can be drawn to the field of psychiatric genetics. For example, we have seen a multitude of different attempts trying to determine the genetic basis for mental disorders, yet they always seem to fail, but the search still continues – like it has for over the last 100 years. I also made some suggestions with regard to how this happens, such as several of the authors continually implying that mental disorders have a genetic component through a number of different strategies. However, in the context of this project the issue that needs to be considered is what role does the developments in the field of genetic testing for mental disorders play in this dynamic? For example, one way to approach this is to consider if all of the issues and features previously discussed in the historical overview of psychiatric genetics are simply another example of hype and expectation. And, if so, how should all of this be approached or considered when dealing with this research question in this project? Essentially, what do the developments in the field of genetic testing represent in this dynamic?

So what I want to do in this section of the literature review is put much of what has been considered so far in this review in the context of literature on the sociology of expectation. In their editorial on the topic Mads Borup and colleagues (2006) provide a section-by-section breakdown of the process - this framework will be synthesised and used as a comparative baseline in this research. For the most part I think it is possible to consider examples from the field of psychiatric genetics in terms of the prescribed frame work that will be adhered to in the following section; however, I think that there are some instances where there are some significant differences that will require thought and explanation. For example, in the sociology of expectation literature a common aspect that is often discussed relates to the fact that in maintaining the expectation around a certain enterprise there is often a continual ‘look towards the future’ with an ‘abandonment of the past’ – in terms of the technological or methodological developments in the current climate. Borup and colleagues note:

In this way, expectations of technology are also seen to foster a kind of historical amnesia—hype is about the future and the new—rarely about the past—so the disjunctive aspects of technological change are often emphasized and continuities with the past are erased from promissory memory. (Borup, et al. 2006, p.289)

I do not think this is necessarily the case in the field of psychiatric genetics. First of all there appears to be a continual reliance on some of the much older research to emphasise the claim that mental disorders have a strong genetic element. In addition to this, there are still instances where research that could be considered questionable is used to imply the same idea. For example, from the previous account I pointed out that educational text books included evidence regarding linkage studies in their sections on the genetics of mental disorders, despite the overall trend in more modern research indicating that linkage studies are not reputable or appropriate for suggesting such ideas. Another issue that needs to be pointed out in this case concerns the previous observation in relation to what these developments actually provide or enable psychiatry as an institution to claim or to do. For example, although the historical examination of the developments in the field of psychiatric genetics was important to discuss, in order to place the tests in their appropriate context, I think that an alternative way to frame these changes is through aspects of psychiatry increasingly orienting towards biological explanations for mental distress. In this discussion, this may be a point that is unique to an investigation that is concerned with psychiatry, as it already has a long and
controversial track record with some of the claims, or the promises, it has made – the dopamine hypothesis being an example of this. However, in this case I feel as if it is not necessarily the dopamine hypothesis itself that is the cause for concern, but rather what this represents in the history of psychiatry as a controversial and hotly debated area of medicine.

So with this way of approaching the situation I want to reiterate that this section has two main priorities. First of all this section of the review is concerned with placing the developments in the field of psychiatric genetic testing into the context of the sociological literature regarding ‘the sociology of expectations’. However, in addition to this it is also of paramount importance to be aware of what this does for psychiatry as an institution more broadly – this relates to my observation regarding psychiatry increasingly prioritising or placing emphasis on the biological components of mental disorders. Therefore in the following discussion there will be points that relate to both of these issues. However, there is one final point to make when considering the set-up that has been established here. When considering these issues it is important to make a distinction between the genetic research and what this represents – in terms of what has already been established and how this is likely to play out in the future. In order to do this the following discussion needs to be presented in the form of analysing a claim. Here the claim is that there is an underlying genetic factor for major mental illness and this can be identified. However, it is also vital that the accessory consequences of this claim are considered, specifically how they fit in with what has been observed in this review – that psychiatry is orientating towards emphasising the biological aspects of mental distress. The problem here is that there are already examples of this that also could fit in with the sociology of expectations literature – so when this discussion proceeds there will often be references to both of these aspects as they both mutually reinforce each other. Therefore the following account will focus on issues that have previously been mentioned in this review, albeit in a different context, with a view to situating this in terms of the latest developments in the field of psychiatric genetics.

2.7.2 - The Sociology of Expectations in Science and Technology – central themes and findings.

In their paper ‘The Sociology of Expectations in Science and Technology’ Mads Borup and colleagues (2006) provide a breakdown analysis of the all major components that contribute to the central themes and findings relevant to an introduction to the sociology of expectation. Each of these will be discussed and considered here in terms of a component aspect of the field of psychiatric genetics.

2.7.3 - Expectation as Constitutive Force

Borup and colleagues note:

*First and foremost expectations are ‘constitutive’ or ‘performative’ in attracting the interest of necessary allies (various actors in innovation networks, investors, regulatory actors, users, etc.) and in defining roles and in building mutually binding obligations and agendas. At the most general level we can understand expectations to be central in brokering relationships between different actors and groups. Indeed, it would be hard to picture the formation of technology developments and innovation without some kind of shared, though flexibly interpreted, cluster of guiding visions. (Borup, et al. 2006, p.289)*

The key word in this section is ‘constitutive’ – that is to do with how the ‘expectation’ or the ‘promissory’ process begins to establish and attracts the interest of different allied groups. There are
several instances where this process can be observed in the field of psychiatric genetics, and a number of these have been mentioned in this thesis so far. For example, in the introduction chapter I focused on some of the research intensive institutions that have been established whose primary focus is to investigate the underlying genetics of mental disorders, the example provided related to the MRC Centre for Neuropsychiatric Genetics and Genomics. It could be argued that a major task for an institution such as this is to promote itself and continue its research agenda any way it can. One aspect relating to this, which will be the primary focus on the very final section of this review, relates to how aspects of the sociology of expectation can be seen in research articles released in the field of psychiatric genetics. This was an issue alluded to in the previous historical account of the field, where the role of genetics being implicated to a mental health presentation is constantly implied throughout work published on the topic.

Another area where a similar situation is observed relates to some of the articles considered in section 2.5 of this chapter (Mental health genetic research initiatives and proposals in the United Kingdom). Although the main emphasis of this section is to cultivate an awareness of the processes by which a genetic test is assessed in the United Kingdom, the first part of this chapter reveals that recently there has been some real interest in exploring the early implications of the developments being made in the field of psychiatric genetics in the clinical sphere. This is an example the fostering of a relationship between multiple groups about the promissory nature of the field of psychiatric genetics – in this case the MRC and the Human Genomics Strategy Group are both focusing on the possibility that genomic research can be used to aid in the diagnosis and the treatment of mental disorders.

However, in terms of the prolonged emphasis on the biological components of mental disorders, it is vital to consider there are other examples that are very similar to this that already exist. The link between emphasising the biological aspects of mental disorders via the use of psychiatric medication was discussed in the previous section, however, one aspect that was not discussed in any depth relates to the relationship between pharmaceutical companies and the propagation of this idea – that is suggested to be largely motivated through financial interests (Read, et al. 2004, p.21). In their paper ‘Biological Psychiatry: Practice in Search of a Science’ Joseph Wyatt and Donna Midkiff (2006, p.136) make the following observations:

The financial interests of the pharmaceutical industry have dovetailed with the guild interests of organized psychiatry. Both have much to gain by promoting the biological causation model of mental and behavioural disorders. By 2003 the drug industry was underwriting 70% of all clinical drug trials in the United States and there were accusations that negative studies were being terminated prior to publication. All of this was paying off for the pharmaceutical industry. By 2001-2002 three psychotropic medications (Zyprexa, Zoloft and Paxil) were among the top ten revenue producing prescription drugs in the United States. They accounted for over $7.5 billion in sales. Each showed greater than 10% sales growth from 2001-2002.

Therefore, in terms of the continual emphasis being placed on the biological components of mental disorders, this is an aspect that warrants attention in this discussion as well. This is not to say that a similar dynamic is necessarily present in the research in the field of psychiatric genetics, but both of these streams go quite some way to reinforce one another, always moving towards increasingly
biological explanations for mental distress. In terms of this research this section will concern how the developments in the field of psychiatric genetics integrate with this dynamic. We know that initial aspects of this ‘brokering of relationships’ has been seen, but another important component to be aware of is how this will play out in the future developments in the field.

2.7.4 - Expectations and Temporal Variability

In their second theme concerning the sociology of expectation Borup and colleagues note:

> Expectations usually have a temporal patterning over time. This is often manifested in alternating cycles of hype and disappointment. This phenomenon of early promise/later disappointment suggests that while expectations are essential to mobilizing effective interest, an early surge in hype is necessary in order to get a hearing. (Borup, et al. 2006, p.290)

If the history of the developments in the field of psychiatric genetics are referred back to, this ‘temporal patterning...of hype and disappointment’ can be seen in the successive ‘methodological and technological waves’ previously discussed – this is represented by the advent of twin, family, and adoption studies, the introduction of linkage and candidate gene studies, the introduction of GWAS research and even some of the proposed future work suggested by Sullivan and colleagues. However, if we remember that the claim being considered here is that there is an underlying genetic factor for major mental distress, then there are instances where this ‘temporal patterning of hype and disappointment’ does not adhere to the ‘alternative cycles’ suggested in the theme.

If this were the case, it might be possible to consider the situation in terms of the continual technological or methodological evolution implied through each of the successive breakthroughs, and although this might be the overall trend for some scientific establishments, there are exceptions in the case of psychiatric genetics. For example, and as mentioned previously, to this day there continues to be a reliance on quoting findings from older twin, family, and adoption as evidence for the genetic basis of mental disorders. Previously I discussed how this body of research could be considered controversial – as these research studies can be critiqued – however, in this case this issue is not important. In this case it is more to do with how this evidence is used to back up a specific claim. As this argument is still used in modern day situations, it is as if the ‘cycle of twin study hype’ never really died down, but for the most part it continues to be maintained and is still used to back up the claim that mental disorders have a genetic basis.

Considering this, it prompts me to think about exactly who these ideas and suggestions apply to. For example, although this may be a generalised frame work for considering the ways that the promissory nature of a certain technological process occurs I am not entirely sure of how this would apply to those who are closely invested in the phenomena. An example of this would relate to scholars who still use the evidence of twin and adoption studies in their modern day research in order to make the point that mental disorders have a genetic basis. To these people this still remains an important piece of evidence to use in their case, and (from this perspective) this could be considered as ‘promise that was never broken’. However, in a later section we will see that another important point to consider in these cases is precisely who is making the claim in each respective situation, and perhaps why they are making this claim.
There are additional aspects to think about in this theme as well. Borup and colleagues point out that that the promises made by an institution have implications for monetary aspects, essentially to secure funding, as well as to steer a research initiative in a particular direction:

*Initial promises are set high in order to attract attention from (financial) sponsors, to stimulate agenda-setting processes (both technical and political) and to build ‘protected spaces’.* (Borup, et al. 2006, p.290)

Examples of this process can clearly be seen in the history of psychiatric genetics. Although this first example does not specifically focus on the early twin, family, and adoption studies that emerged around the same period of time, it does illustrate how related early research gained financial backing from wealthy institutions. The first example is taken from the chapter ‘The Invention of Schizophrenia’ from the book ‘Models of Madness’ (Read, et al. 2004, p.21-22) and it concerns a sum of funding given to Emil Kraepelin to continue research into the heritability of mental disorders from the Rockefeller Foundation:

*Kraepelin succeeded in obtaining from the Rockefeller Foundation the sum of $250,000 for his project, the first gift to be made by this organisation in Europe. A further gift from the Rockefeller Foundation increased the sum to $350,000 under the stipulation that there should be strict adherence in the institution to Kraepelin’s fundamental idea.*

In addition to this John Read makes an important additional point that is worth considering:

*We will probably never know whether there was any connection between the Rockefellers’ owning the petroleum industry, the discovery that petroleum by-products could be used to produce medicines, and the stipulation in Kraepelin’s contract.*

This statement is important as it has similarities to the previously discussed points that focused on psychiatry and its relationship with the pharmaceutical industry – there is evidence to suggest that the two institutions are closely linked to one another – and the same suggestion is being made here. Regardless of the validity of this statement, as it should really only be considered as conjecture, the fact that it shares similarities with more common situation is the important point.

Although these more modern examples do not contain the collusion aspect contained in the previous instance, there are plenty of modern day cases where research initiatives in the field of psychiatric genetics receive significant financial backing on the basis of using advances in genetic technology to develop our understanding of mental illness. For example the European Commission awarded 7.5 million euros to a research group established by Peter McGuffin to investigate patient response to antidepressant medication on the basis of their genetic profile (http://gendep.iop.kcl.ac.uk/PRESS/GENDEPBriefing261104.pdf).

### 2.7.5 - Expectations and Socio-spatial Variability

The third theme presented by Borup and colleagues focuses on an issue raised in a previous section of the review, the implications of these expectations for different people involved with the technological promise:

*Just as importantly, expectations and future uncertainty are seen to vary between different groups involved in technological development. So, in addition to the temporal variabilities*
just discussed, fields also exhibit social variabilities where people will attach different levels of trust to expectations. The obduracy of the emerging technology is different for different groups. (Borup, et al. 2006, p.292)

This thematic section takes on a slightly different form than the previously discussed components, as here there is an explicit focus on the technological development as well as the underlying claim that mental disorders have a genetic basis. So in this case there needs to be some consideration of the issues, aspects, and processes that directly relate to an actual genetic test development. However, in this case this is quite a good example of the implied move towards increasingly biological explanations for mental distress, because we do not really have that many tests available to consider as exemplars of technological innovation. Indeed, if the promissory nature of the discipline is taken to its ultimate end, it is possible that there may never be a test that is appropriate for us to analyse and consider. For example, although there is a clear focus on the Psynomics technologies in this thesis – because they are one example of the former developmental trajectory of the field – they should not be considered representative of the ultimate shape of the field as they rely on older linkage inspired methodologies that are not reflective of the most modern approaches.

However, it is possible to discuss some of the historical and present day narratives surrounding these developments by looking at a selection of review papers, and exploratory research articles on the topic, which contain some form of commentary about these issues. Before these are examined, there are several points that require clarification in relation to the above theme and how it will be explored here in this research.

In the context it is presented, I am not fully aware of what is meant when Borup and colleagues use the word ‘trust’ when focusing on ‘expectations’ – because this is not adequately explained in the paper - yet I still feel this is maybe important in this section because several related aspects have been alluded to previously. Here I am choosing to consider the term ‘trust’ as the belief in the claim that is being made about the central phenomena in question. So in this case it is possible to focus on the overall claim, that mental disorders have a strong biological component, rather than the technological product that could support this idea. For example, if the suggestion that twin studies represent evidence that mental disorders have a genetic basis is considered, then there is certainly a contrast in the apparent ‘levels of trust’ in this claim. On the one hand there are the research groups producing work along these lines, like the ones mentioned in the previous ‘field of psychiatric genetics around 1900’ section, who would appear to trust this claim as they use it frequently in their research articles (Craddock and Sklar, 2009; DePaulo, et al. 2001). While on the other hand there are scholars who would appear to refute the claim on the basis of their critical analysis (Joseph, 2001).

There are other instances where similar patterns emerge between different groups and their alternating ‘levels of trust’ in the field. Consider the following quote from the paper ‘The Genetic Basis of Depression’ (Hodgson and McGuffin, 2013, p.81):

\[A \text{ number of genes of interest have been highlighted, although a genetic variant, that is unequivocally associated with increased risk for the disease, is yet to be identified. However, technologies and methodologies are evolving rapidly, and genetic approaches have helped shape how we conceptualise depression as an illness.}\]
This quote encapsulates many aspects of this investigation into the sociology of expectation in the field of psychiatric genetics, and I want to briefly mention these before this ‘social variability’ theme is dealt with. This quote clearly emphasises the aforementioned ‘temporal’ observation – for me this is the major point of this extract. It is almost as if the authors say ‘some genetic links have been made, but they are not that specific to the disorder, but technology is evolving quickly so there should be some developments soon’ – this fits in with the central promissory theme discussed earlier – there is a constant ‘look to the future’ regarding the developments being made in the field of psychiatric genetics. However, in this case the issue to consider relates to the individuals who are making the statement about the field of psychiatric genetics. Peter McGuffin has already been mentioned here, but to clarify, he is a psychiatrist who appears to have a strong and clear interest in the genetic components of mental distress. It is not possible to find as much information about Karen Hodgson, but she appears to be a researcher who has similar interests, which essentially focus on exploring the genetic basis of mental disorders. The broader issue here is that, as long as these two individuals are representative, or part of, this particular research community, they appear to have a high degree of trust in this research and what it does for the claim that mental disorders have a genetic component.

In contrast to this there are researchers in the field who have very different views on the role of genetic technologies and research in mental health care. This following example is slightly different because rather than being a review article of genomic research it comments on the overall state of the scientific developments around the time the Psynomics tests were initially released. In their paper ‘Clinically Responsible Genetic Testing in Neuropsychiatric Patients: A Bridge Too Far and Too Soon’ David Braff and Robert Freedman (2008) take a far more cautious stance on the issues surrounding the Psynomics developments. They point out that future developments are likely to occur, but they need to be considered appropriately and part of this will mean being honest about what the tests purport to do in the long run – what sort of insights they really offer about an individual's chances of developing a mental disorder or their response to treatment. This stance is cautious when it is contrasted to the stance that Psynomics took close to this time. Psynomics appeared to have a great deal of trust in the expectation that mental disorders have a genetic component as they released genetic tests that essentially made this claim.

Developing an awareness of this thematic component of the sociology of expectation is important as I feel that an element of this has been inbuilt into this research project – this is in reference to consideration of the participants communicated models of mental disorder. This means that it may be possible to use this as a tool to differentiate between different participants’ thoughts, insights, and opinions about the developments in genetic testing for mental disorders on the basis of the models of mental disorder they communicate. With everything that has been focused on in this section of this review this seems to be the most opportune instance where some of the sociological theory in relation to the promissory nature of science can be put into practice. From the previous sections we know that the general public are more-or-less willing to entertain the use of the tests, and that the majority of psychiatrists would also be willing to explore use of the tests in a clinical situation – both examples of different groups having differing levels of trust in the technological development, however, I suggested there is very little understanding of why this could be the case. With a better understanding of the internalised frameworks that people use to make sense of mental disorders, we can use these features to examine their thoughts on the test developments.
In this final part of the breakdown of the sociology of expectation we will look at an aspect that was subtly presented throughout the previous historical examination of the field – how aspects relating to this are presented in what is written about psychiatric genetics.

2.7.6 - Imagination, Materiality and Embodiment

In their final component of this process Borup and colleagues make the following observation in relation to the sociology of expectations:

*Expectations circulate in various forms and shapes. This raises searching problems for us in thinking about expectations as essentially rhetorical or material in character. That is, to what extent are expectations the enunciated views and ideas of people (utterances), and in what way do they become ‘inscribed’ in texts, actions, bodies, materials, objects and machines (embedded)? What is the relationship between imagination and materiality? That is, what are the routes of transmission between expectations, embodiment and materiality, and specifically the way and by what means promissory abstractions about the future take on substance, becoming materially embedded in structures, routines, systems, matters, etc? Materiality in the form of artifacts or actions related to science and technology development serve as a materialized indicators of expectations and thereby contribute to expectation dynamics. (Borup, et al. 2006, p.292)*

For this section I feel that the main issue to consider concerns some of the ways that ideas, thoughts, and suggestions about the field of psychiatric genetics penetrate different areas of life. For example, how different ideas regarding the underlying genetic components of mental disorders are established, maintained, and communicated between individuals in a certain area – such as an academic community or perhaps the general public. Adopting this approach I feel that the most appropriate way to consider this would be to examine some of the described devices that are commonly found in research and review papers in the field of psychiatric genetics. Doing this is the most appropriate way to evaluate the majority of the aspects contained within the above quote as I think that scientific papers are an authoritative and common way that ideas are communicated in academic contexts - so these will be examined in this section.

The first aspect to consider here relates to the rhetorical features seen in these papers. In the context of their (Borup and colleagues) suggestion I feel that the main issue here relates to what can potentially happen as a result of peoples thoughts, approaches, and ideas about a situation and how these ultimately translate into what is found or emphasised in research or review articles. This specifically concerns the first part of the above quote:

*Expectations circulate in various forms and shapes. This raises searching problems for us in thinking about expectations as essentially rhetorical or material in character. That is, to what extent are expectations the enunciated views and ideas of people (utterances), and in what way do they become ‘inscribed’ in texts, actions, bodies, materials, objects and machines (embedded)? What is the relationship between imagination and materiality? (Borup, et al. 2006, p.292)*

The major point of interest here relates to how what ends up in these papers is a result of the authors’ views and ideas about the situation and how these subtly reinforce or solidify a specific idea – in this case that mental disorders have a strong genetic component that is detectable and useful to
understand. Essentially this concerns how the views of specific people are ultimately considered representative of a certain stream of work. Examples of this have been seen several times in the previous historical summary of the field of psychiatric genetics, but in several respects I feel that this final component of the ‘sociology of expectations’ adds another dimension to everything that has been considered so far.

For the purposes of this section I have chosen to use the definition of ‘rhetoric’ that is provided in the paper ‘Complexity and accountability: The witches’ brew of psychiatric genetics’ (Arribas-Ayllon, et al. 2010). This is a good paper to use because I feel its main aim is very close to what is being achieved in this section of the review. Here the authors focus on the observation that research into the genetics of psychiatric disorders is an increasingly complex activity, however, this evolution of complexity is not just an account of the technical expertise needed to detect the biological underpinnings of mental distress; the authors suggest that increasing complexity also plays a rhetorical role that enables genetic research into mental disorders to continue. They define rhetoric as:

...the everyday organization of descriptions and explanations, and their relation to different and competing versions of the truth. (Arribas-Ayllon, et al. 2010, p.5)

To illustrate this lets consider quite a modern example from the field of psychiatric genetics and see how this actually plays out in the literature. In the paper ‘Genetic architectures of psychiatric disorders: the emerging picture and its implications’ Patrick Sullivan and colleagues (2012) the authors end with the following claim:

In psychiatric genetics, we are at the end of the beginning, not the beginning of the end. Remarkably, in a field that is characterized by a checkered history and few confident aetiological clues, the genetics knowledge base has advanced considerably during the past 5 years, and results to date contain clear indications that further study will yield greater insight. Elucidation of the genetic architectures of psychiatric disorders is an attainable goal with existing technologies (albeit that are both costly and cost-effective). Few predictions are perfectly safe, but we would argue that genetics is a particularly good bet for psychiatry. (Sullivan, et al. 2012, p.549)

This exemplifies everything that has been discussed in this section of the review, as well as illustrating the final point concerning the influence of different peoples’ views ‘shaping’ the status of the field. The main focal point of this quote relates to the emphasis being placed on the ‘future promissory implications’ of psychiatric genetics – Sullivan and colleagues make five separate references to this feature in this very small extract. However, in this case, perhaps the most pressing issue relates to the very fact that this idea is itself being constantly perpetuated throughout the relevant literature and what can possibly happen as a result of this. In this example the issue to be aware of is why such ideas maybe popular in the literature and what it is they ultimately achieve. To develop this awareness one approach, which has been used several times throughout this review already, is to consider the various authors of the source that makes the specific claim. So who are Sullivan and colleagues, and where could some of their interests be situated when making the claim that mental disorders have a strong genetic component?
From looking at the authors departmental research project pages, each of them appear to be heavily invested in exploring the underlying genetic aspects of mental disorders. Patrick Sullivan (http://genetics.unc.edu/faculty/sullivan) is a professor of genetics and the director of a research group that specialises in exploring the genetic basis of complex disorders in public health. The first listed interest is in researching schizophrenia, here is what his research page has to say about this endeavour:

*This is a chronic and debilitating mental disorder that affects approximately 1% of the human population. Although it is clear that genetics plays a role in schizophrenia, specific genes that have a causal role in the disease have yet to be identified. The Sullivan lab is conducting a series of studies to elucidate its etiology. In addition, pharmacogenetic studies are underway to determine the mechanism of action of antipsychotic drugs that are currently used to treat some of the symptoms of schizophrenia.*

In the overall context of this discussion the second sentence is the most important because it mirrors what has already been said with regard to the field constantly looking towards the future with respect to the research trajectory, as well as the continual emphasis on the role of genetics in this situation. However, in this section of the discussion, the most important feature relates to the observation that Patrick Sullivan in a researcher who has a clear interest trying to understand mental disorders through genetic components. The same conclusion can be reached when visiting the research pages of Mark Daly (http://chgr.org/index-faculty_daly.html) and Michael O'Donovan (http://medicine.cf.ac.uk/person/prof-michael-conlon-odonovan/research). Both of these scholars appear to be heavily invested in the use of molecular techniques for exploring the underlying components of mental disorders.

In terms of framing this observation in relation to different rhetorical aspects used in scientific articles, the main issue here concerns the observation that there is a constant emphasis on the underlying genetics of mental disorders that seems to be reflected in the authors’ area of speciality and interest. If the previous history of the field of psychiatric genetics is revisited then there are several instances where these different rhetorical aspects can be seen to reinforce the exact same idea. Perhaps with the exception of linkage studies (although the results of these are still used in educational text books) almost any example can be picked and considered in this way. For example, it is quite clear, despite any of the criticisms that can be made of the methodology, twin studies are still routinely quoted as evidence for the genetic basis of mental disorders. This is an example of a very specific ‘everyday organization of a description and an explanation that relates to a different version of the truth’ – the authors responsible for writing the articles that make this claim are implying that mental disorders have a strong biological determinate. The same reasoning could be applied to the GWAS research, as well as the possible future ‘pathway disorder’ research alluded to by Sullivan and colleagues. In the case of GWA research the evidence is used to imply that mental disorders are potentially a result of many genes interacting together, and that related research should continue in the future, and in several respects the future suggestion regarding ‘pathway disorders’ is used to imply the same claim.

**2.8 - Summary.**

At this point it is important to maintain continuity in appropriateness when considering these aspects of the sociology of expectations. For example, I think it is very important to consider that
many of the issues navigated in this section could be considered in terms of opposing points of view – this makes sense as this is essentially an example of conflicting rhetorical devices in action. In this instance we have scholars who are placing heavy emphasis on the role of underlying genetics in mental disorders. While from the previous historical look into the field of psychiatric genetics we know that there are different people who would bitterly contest this idea, and in many ways my review of the literature would perhaps align more with this side of the debate than the former. I think given the actual current state of the science it is actually quite difficult to currently place any faith in the inroads that have been made with respect to the genetic components of major mental disorders at this point in time. However, in this instance it is also important to consider that any allegiance to either perspective is not the important issue here. In this case the most important issue to consider relates to the actual framework of the sociology of expectations itself and how all of this relates to what has been discussed in this section. Regardless of any potential criticism of the field of psychiatric genetics this review shows that many of the aspects examined align with several of the fundamental observations of the sociology of expectations – a narrative has been established that enables research into the underlying genetics of mental disorders to continue.

Therefore it is vitally important to consider what all of this is heading towards for the purposes of this review and this research project, specifically what the advent of genetic testing for mental disorders could potentially represent in this process. Up to this point in the discussion, and in the previous historical examination of the field, I have emphasised the suggestion that aspects of mental health care and psychiatry appear to be moving towards increasingly biological explanations for mental distress – this can also be seen in the discovery and use of medication as well as the introduction of the DSM. It is important to point out that these examples can also be considered in terms of contrasting rhetorical aspects, for example, I consider the criticisms of the DSM offered by Thomas Szasz to be rhetorical in nature as these are essentially his personal descriptions and explanations in relation to his take on different and competing version of the truth. However, with the advent of genetic testing for mental disorders we are in quite a novel situation that I do not think we have necessarily encountered before now. Several rhetorical aspects in relation to the research that proceed the tests have been considered, and in line with this it is also clear that the tests development also represent the aforementioned implied move towards biological explanations for mental distress. However, one aspect that has yet to be discussed relates to what do the tests represent, or provide in this situation?

This is where I feel as if there is a certain strength when considering the sociology of expectations and applying the features considered to the developments in genetic testing for mental health care. All four of the themes that have been discussed in this section can be considered in light of what was previously alluded to when thinking about the future of genetic testing for mental disorders. For example, from an earlier section of this literature review it is clear that there are governmental and policy based initiatives that are looking into the use of genomic technologies in the diagnosis and the treatment of mental disorders. This is an example of relevant research efforts successfully developing relationships with other interested allies to investigate the use of such technologies outside of a laboratory setting.

In addition to this the developments in genetic test for mental disorders could also be considered in terms of the ‘temporal patterning’ and ‘alternating cycles of hype and disappointment’ aspects discussed earlier. The Psynomics tests would certainly fit in with this suggestion, as they were an
example of ‘hype’ when they were initially released, but now they would perhaps be more appropriately considered as a ‘disappointment’. However, it is also important to consider the idea that the most up-to-date research into the genetics of mental disorders (that will presumably have a future view of being used as a clinical tool) could also be considered as another example of this ‘hype’ – just one that we are currently seeing being played out in the research literature and, if this follows the historical pattern, is set to disappoint in the future when problems are encountered.

In terms of the differing thoughts and opinions about the developments between different groups involved in the future expectations of psychiatric genetics, this is another example that has been seen before and applies directly to this situation. For example, there are groups who previously had dramatically different levels of ‘trust’ in the early stages of genetic testing for mental disorders – such as Psynomics who appeared to be heavily invested and trusting in their research efforts, and some of the scholars who were critical of these moves (Braff and Freedman, 2008). However, in terms of this research project this is an aspect of the sociological theory that can be used in conjunction with the models of mental disorder research as an advantage. If different levels of trust are attached to these developments one way to approach this would be to consider the possible discussed implications from different psychiatric professionals on the basis of the models of mental disorder they communicate.

The final point in regard to the rhetorical aspects in the sociology of expectations is something that has to be determined from considering what is written in research and review articles on the topic. From the previous discussion point there are certainly examples of this from within the literature. However, it could be easy to downplay the importance of this theme and what it ultimately provides the field of psychiatric genetics. For example, I feel as if the mentioned rhetorical aspects are closely linked with some of the issues regarding the field constantly looking towards the future of research. An example of this can be seen in the aforementioned research on mental disorders being indicative of ‘pathway disorders’ (Sullivan, et al. 2012, p.211):

Knowledge derived from this work could lead to the fulfilment of the ultimate promise of genomics—primary prevention of the development of schizophrenia in those at risk and the development of more effective therapeutics in an era where big pharma has turned sharply away from psychiatric drug development. Critically, it is possible that any such pathway is intrinsically modifiable and that people with schizophrenia are not ‘doomed from the womb’ but rather could anticipate return to relatively normal long-term function.

The rhetorical aspects observed by Borup and colleagues are largely concerned with how the views of different people become inscribed in texts – such as the review article this quote is taken from. However, it is in instances such as this where links can be suggested that move between peoples enunciated views on an issue and how these aid in the continuity and maintenance of a stream of research. In this example Sullivan and colleagues are scholars who have an interest in exploring the genetic aspects of mental disorders, this is likely to influence their research interests and what they write about the topic, however, as the above extract demonstrates, pursuing this line of research also means that a emphasis is constantly being placed on the future promises of the science as well.

Therefore I think it is important to move forward with a view to considering what the developments in the field of genetic testing for mental disorders could do in terms of this dynamic. Although concerns have been voiced over the appropriateness of any genetic test based research into various
mental disorders, the reality is this is not necessarily the important point in this argument. The bigger picture is going to be dependent on what these sorts of developments will do or provide psychiatry and mental health care in the long term. If the thread of what has been discussed here in the sociology of expectation is followed, then the tests could represent a continuation of the process that has already been established in the field of psychiatric genetics. For example, it is possible to draw parallels between what the use of a genetic test represents for psychiatry and what quoting evidence from twin, family, and adoption studies also represents for psychiatry. It seems clear that the evidence from family studies is commonly used in articles as evidence for the fact that mental disorders have a genetic component, but the reality is this suggestion can be refuted – this is an example of conflicting rhetoric in action. However, the important issue here relates to the observation that despite any critique, or how controversial this maybe, this idea is routinely seen in relevant articles. The same could be said for the future of psychiatric genetic testing. In this case the issue relates to the idea that having a test available to use, regardless of its actual ability to do what it claims to do, will still imply that mental disorders have a strong biological component.

The really significant issue in this research project is likely to relate to what the developments in the field of psychiatric genetic testing, when translated to genetic test technologies, are going to potentially represent in mental health care or provide psychiatric practice. Although it could realistically be argued that the previous attempts to release tests from Psynomics failed to make any real impact in the field, other similar tests - in some form - are likely to become available in the future, so it is important to place everything into context when considering what it is I intend to do in this research project. This is why a historical examination of the relevant history is important to include in this review alongside issues relating to the participants communicated models of mental disorder, the makeup of a mental health care team, the previous research examining peoples thoughts and opinions on genetic testing, and the criteria by which such developments are assessed – as these are all issues that proceed this research.

2.8.1 - Development of research questions and implications in this project.

This is a timely and important study given the current research climate, the interests in genetic testing for mental disorders, and the opportunities available to me as a researcher to explore all of these different aspects. Although the Psynomics tests used as a springboard for discussion about the implications of genetic testing in mental health care have been withdrawn from the market, I am proceeding under the assumption that similar tests will be made available in the future – so early investigation into their potential implications is vital at this stage. Therefore when considering everything presented in this literature review I am going to make the following suggestions about all of the relevant fields and how these have contributed to the development of my research questions.

The first aspect to be aware of is that a great deal of emphasis has been placed on the strictly research aspects relating to the field of psychiatric genetics. Although this genetic knowledge is constantly being developed, and whilst this is not entering the clinic at this point in time, it is important that we start to think about how mental health professionals make sense of the implications of these developments in the context of their clinical practice. In order to do this it is vital that some of the realities of mental health care are observed, considered, and factored into this project – in order to obtain a multifaceted view of the tests potential introduction. For example, as the first half of the literature review demonstrated, mental health care is a multi-agency activity made up of many different professional groups who have been shown to have dramatically different
conceptualisations of what mental health actually is and as a result of this they consider and interact with people who experience mental health difficulties in dramatically different ways. Therefore being able to navigate participants responses on the basis of the models of mental disorder they communicate, and seeing if there are any differences in relation to their thoughts on the tests on the basis of these differing models seems like an important feature to factor into this research. This aspect contributes to my second main research question in this project:

*Do participants’ communicated models of mental disorder have any influence on how they view these proposals and can their responses be differentiated on the basis of the models they communicate?*

In terms of the remaining two questions I feel this turns into a case of considering all of the additional aspects included in the literature review. First of all it is important to cultivate an awareness of the criteria by which a genetic test is traditionally assessed when it is released in the United Kingdom. Other than there being a clear desire to investigate the possible use of such proposed developments in a clinical setting; I feel that it is just as important to consider the process by which this would normally happen. This is why discussion of the ACCE criteria in the middle of the literature review was so important – as it provided the semblance of a frame work by which a genetic test should be appraised. I am not under the impression that this research is going to provide a complete and detailed account of this process, but I do envisage that speaking to psychiatric professionals about their thoughts and opinions on a previously released genetic test will go someway to progressing our understanding on the topic.

However, in terms of the second half of the literature review the most important issue to consider is that the developments being made in the field of psychiatric genetic testing are part of a long heritage of research attempting to determine the underlying biological components of mental distress. Although it is important to place this thesis in the overall context of mental health care, it is equally important to consider this research in terms of the developments being made in the field of *psychiatric genetics* – as this is as vital to our overall understanding as well. The main focal point of this aspect of the literature review was to point out that the historical developments in the field of psychiatric genetics have been dogged by a number of controversies, changes, and a great deal of critique. However, despite these problems, this is a stream of research that still receives a great deal of attention and it appears as if advances are being made all of the time, this is partly due to some of the rhetorical devices that appear to be used by those involved in this variety of research. For example, from consideration of the sociology of expectations in scientific research, it would appear that several different components from within the history of psychiatric genetics could be viewed in this way. Instances of this are the constantly reoccurring periods of initial hope with respect to genetic breakthroughs in psychiatric research (such as the first linkage studies in the 1980s) and how these tend to always lead to disappointment.

Awareness of these issues means that not only can aspects regarding the practical application of the tests be investigated and considered – such as when a genetic test could be used, or what it could do for the ways that different groups consider mental health problems – but in addition to this it maybe possible to determine how the test developments in the field of psychiatric genetics extend on what has been established in the promissory science literature too. For example, I suggested that in many ways one of the main issues to be aware of when considering a future genetic test for a psychiatric
disorder is what it ultimately represents or provides for mental health care and psychiatry. However, given what I propose to do in this research there is quite a change in direction here – this relates to consideration of a possible technology away from a strictly research based setting to one located in a practical ward oriented clinical environment. This is part of the inspiration for my primary and third research questions:

*What, according to psychiatric professionals, are the main considerations and primary implications regarding the developments being made in genetic testing for mental disorders in terms of their proposed introduction in a clinical setting?*

*From this, what are the main issues concerning the tests’ potential introduction that different demographics (patients, staff and policy makers) need to take into consideration and be aware of?*

An issue that requires navigation in this project, in relation to the promissory nature of the field of psychiatric genetics, is that the historical aspects previously examined – regardless of any criticism that can be made of them – strongly imply that mental disorders have a significant genetic contribution. However, aside from the Psynomics tests, there has been very little evidence of any of this work extending beyond the research realms and being used in a clinical capacity. Although this is still something we are yet to see in a capacity that satisfies any critics, the interesting issue – that this research will contribute to – relates to how when such tests do becomes available in the future how they extend upon this dynamic.
3.0 – Methodology

The qualitative analytic method used in this research project is an example of thematic analysis, a method for identifying, analysing, and reporting themes within data (Braun and Clarke, 2006). To develop the themes presented in the findings chapter I conducted thirty-three semi-structured interviews with a range of psychiatric professionals to obtain their thoughts, ideas, opinions, and insights into the potential implications of genetic testing in mental health care - once the interviews were transcribed thematic analysis was then applied. The complete practical execution of this process will be discussed in greater detail later on in the chapter, but broadly this involved coding and annotating each of the interview transcripts in order to build up a large number of codes. Once these codes were developed they were then considered with a view to building complete themes from the data.

For purposes of total transparency I want to point out that a significant proportion of my methodological ‘thinking’ actually came from my investigation into using grounded theory in this research project. For quite a long period of time I was proceeding under the assumption that this project was an example of grounded theory research – therefore a great deal of my thinking and reasoning about the underlying aspects of this work were generally in keeping with this methodological approach – however, despite all of this, it would not be accurate to say this work is an example of grounded theory, a significant reason for this is that this research is not concerned with the generation of any theory and is therefore not an example of ‘true’ grounded theory. However, we will later see that there are several instances where components of both methodological processes converge with one-another and they both share similar characteristics with respect to their execution – especially with regard to the development of themes. Before this is explained, an appraisal of the underlying philosophical assumptions that form the theoretical framework of this research project need to be presented because the methodology chosen for any research study needs to follow and reflect the philosophy of the project in terms of its underlying ontology and epistemology.

I want to point out that a significant breakthrough in my methodological techniques education came as a result of discovering the excellent book ‘Qualitative Inquiry and Research Design – Choosing Among Five Approaches’ by John W. Cresswell (Cresswell, 2007). This book will be heavily referenced in the next section as it really helped me understand many aspects related to the methodology and related execution of this research.

3.1 - Philosophical, Paradigmatic and Interpretive frameworks

Creswell (2007; 17) states there are five philosophical assumptions that lead to an individual’s position and stance on qualitative research. These are ontology (theories about the nature of reality), epistemology (ideas about the nature of knowledge), axiology (acknowledges the role of values), rhetorical (concerning the language of research) and methodological (views about the ways in which we can obtain knowledge). The qualitative researcher chooses a stance on each of these, with the choice having practical implications on the design of a research study and how to conduct it. However, when examining each of these five assumptions, there are only three that are commonly discussed in research methodology text books (Crotty, 1998) – ontology, epistemology and methodology.
Cresswell goes on to discuss that after researchers have made their choice regarding these issues, they further shape their research by bringing the study into the lens of paradigms or world views. Here a paradigm or a world view is defined as “a basic set of beliefs that guide action” (Cresswell, 2007). Each of the available paradigms will adhere to or reflect a different set of philosophical assumptions and beliefs. The research in this thesis is conducted from the viewpoint of a social constructionist researcher, which, as Cresswell points out, is often combined with interpretivism. Researchers who adopt a social constructivist/interpretivist paradigm tend to share the following beliefs about the nature of knowledge and reality. For the most part, a relativist ontology is adhered to; this assumes that reality is constructed on an intersubjective basis through the meanings and understandings developed socially and experimentally. A subjectivist epistemology assumes that the researcher and the subject being investigated are linked in a way so that who we are and how we understand the world is central to how we understand ourselves, others, and the world more broadly (Cohen and Crabtree, 2006).

There are a number of interconnecting factors that are going to contribute to my choice regarding these aspects. For example, I need to not only consider my own stance and opinions in relation to this study, the arena that I intend to actually gather the data, the research question itself, and the ways that I plan on analysing the data, but I also need to appreciate the fact that I’m going to be talking to individuals from different disciplines who work with people who experience mental disorders - who also have their own set of internalised ideas about the matter that is the primary focus of the study. There are two main issues that take precedence over any other possible feature that need to be examined when making these sorts of considerations in relation to the design and execution of this research. This is the fact that I am actively including the participants’ own personal models of mental disorder when they are discussing the implications of the Psynomics developments, and in keeping with the ways that the data is actually going to be analysed and presented, the particular version of thematic analysis that is going to be used. In this project I am going to adopt a constructivist thematic analysis methodology. As previously mentioned, there needs to be synergy between the underlying theoretical frame work and the methodological techniques utilised. Therefore clarification about these issues is required before this particular variety of thematic analysis is explained any further.

3.1.1 - Interpretivist ontology, epistemology, methodology and method

Paradigms in social science research can be considered in terms of their three main philosophical assumptions concerning ontology, epistemology and methodology (Cresswell, 2007). The methodology that I choose needs to mirror the project’s ontology and epistemology. Thinking about the context of the study as well as some of the work that has inspired me helps provide further context concerning all of these issues. Considering the work discussed in the literature review as well as detailed appreciation of this study’s primary research questions, I consider a major component in the background of this research being the controversy surrounding mental disorders. For example, no definitive definition of the subject matter at the very heart of this project has actually been reached and although there are a variety of different approaches to mental disorder, it is still something that is shrouded in much mystique. For example there are scholars, such as Thomas Szasz (Szasz, 1961, Szasz, 2011) and his academic collaborator Jeffery Schaller, who, although they still do use the term ‘mental illness’ or ‘mental disorder’, claim that it actually does not exist. However, I think that the implications of this may go a little bit deeper because these different approaches to
mental disorder have previously been linked to different aspects of practice (Colombo, et al. 2003; Fulford and Colombo, 2004).

Therefore in this research project a major aspect that requires thought concerns the controversy surrounding how mental disorders are going to be referenced. As a result of this, I am conducting research that is underpinned by a social constructivist world-view, which places an emphasis on the observation that the ‘object’, which in this case is mental disorder, can be made sense of by the research participants in a multitude of different ways. In doing this, one possibly valid approach is to totally reject the suggestion that the phenomenon exists at all. Extending this feature to its fullest, there is actually no ‘real’ or ‘correct’ way to make sense of the object of mental disorder. Subsequently, psychiatry as a medical speciality is in a difficult situation because of this, as different personal suggestions concerning the construction of the object of mental disorders have been shown to cause problems when it comes to decision making in multidisciplinary teams (Fulford and Colombo, 2003). The literature that informs the design, development, and implications of methodological research further illuminates this suggestion. Michael Crotty, when discussing the philosophical assumptions underlying a constructivist world view, states that the way we make sense of things is tantamount to the way things actually are (Crotty, 1998). In a similar vein, David Silverman confirms what has already been suggested in respect to the unison between choice of methodology and underlying philosophical assumptions, suggesting that the methods used take on a very specific meaning according to the methodology that is used (Silverman, 2001).

3.1.2 - Revisiting the work of David Pilgrim

In the second section of the literature review I introduced a number of sociological perspectives that are often adopted in social science when conducting research into mental disorders (Pilgrim, 2007, p.539). I want to briefly revisit these perspectives and demonstrate how they align with the methodological insights that have been provided in this chapter so far. The three perspectives presented were:

- Medical naturalism
  
The ontological assumption is that mental abnormality simply exists “out there”, awaiting verification by expert observers. The epistemological assumption is that these naturally occurring categories are inherently pathological.

- Radical constructivism
  
The ontological assumption is that reality is socially constructed - mental disorder does not simply exist awaiting verification. The epistemological assumption is we can only know the world via the ways we represent it.

- Critical realism
  
The ontological premise is that the world exists and is real but our investigations of it are saturated with interests and values. The epistemological consequence is that we must approach all knowledge claims sceptically or “critically”. This task is even more important in the human sciences because we are part of our own context.
The question that needs to be asked is do any of these viewpoints align the perspectives and standpoints already discussed? Creswell’s book is aimed at providing a solid introduction to qualitative research in social science and as a consequence, there is no focus on the sociology of mental disorders directly. However, Pilgrim’s work is specifically focused around mental disorders; therefore this should also be considered in this methodology chapter.

Regardless of what resource is consulted (Cohen and Crabtree, 2006; Creswell, 2007; Pilgrim, 2007) there is a great deal of similarity when the variety of perspectives used by researchers in social science to investigate mental disorders are considered. For example, tracing the roots of social constructionist research and learning that this is typically combined with interpretivism (Creswell, 2007), we learn that this approach normally advocates a relativist ontology and a subjectivist epistemology (Cohen and Crabtree, 2006). When considering these two standpoints regarding the nature of reality and how we know it, several similarities with the previously mentioned radical constructivism and critical realism approaches emerge. Both of these perspectives will be contrasted later, but before doing this I want to focus on the ontological and epistemological features mentioned by David Pilgrim with respect to radical constructivism (that is a different name for social constructivism) in isolation.

3.1.3 – Pilgrim’s ontology

In this research project I am advocating the ontological premise exhibited by radical/social constructivism. Here the ontological assumption is that reality is socially constructed, that mental disorder does not simply exist awaiting verification. Mental disorder cannot be conceptualised in terms of being an object with definitive characteristics, but rather how different people represent it. This idea is closely linked to the relativist ontology suggested by Cohen and Crabtree (2006). This assumes that reality as we know it is constructed inter-subjectively through the meanings and understandings developed socially and experientially. My likening of these two features relates to the suggestions previously made concerning how best we can go about knowing the ‘object’ of mental disorders. Rather than being able to conceptualise mental disorders in the same way a microbiologist may be able to identify a microbe, the approach being used in this research is via the different ways people intersubjectively understand and make sense of these disorders. Using this microbe example for a little bit longer there are several levels to this issue. First of all, I am proceeding under the assumption that microbes are ontologically definite – they can be objectively seen, provided the right tools are available to do so; and secondly, they will exist independently of anyone’s personal standpoint. The same cannot be said for mental disorders, as they cannot be ‘seen’ in the same way a microbe can. In this case I am suggesting that one suitable way of approaching mental disorders is through the participants’ intersubjective understandings of the issue.

3.1.4 – Pilgrim’s epistemology

Regarding the theory of knowledge when considering the interpretivist paradigm, Cohen and Crabtree (2006) note that we cannot separate ourselves from what we know. The investigator and the object of investigation are linked in such a way that how we are and how we see things is a central part of how we understand ourselves, others, and the world. I think this suggestion does align with what Pilgrim mentions with respect to the epistemological aspects of radical/social constructivism. For example, the first aspect where I would argue there is a degree of similarity is
when considering the assessment of individual participants’ models of mental disorder. We know that models are the ‘conceptual frameworks, or sets of ideas, by which, in any given area, people structure and make sense of the world around them’ (Fulford and Colombo, 2004; 136) and adherence to different models has been shown to be dependent on a variety of factors, such as personal experiences, thoughts and opinions, academic training, and, to an extent, disciplinary allegiance. This suggests that different people are likely to make sense of mental disorders in different ways on the basis of a selection of different factors. Given that in this research mental disorder is being conceptualised in terms of its epistemological status or how people understand or know mental disorder, it would seem appropriate to adopt a world view sympathetic of this suggestion.

However, there are some additional points that I want to make with respect to these issues. In this research I am taking the stance that reality cannot be separated from our knowledge of it with respect to how mental disorders are conceptualised, primarily for the reason that there are many schools of thought relating to what mental disorders actually ‘are’ and these are dependent on a multitude of different factors. However, in this research, I need to not only be aware of my own thoughts and opinions, I need to also be aware of the different possible view points adopted by my research participants with respect to the phenomena of mental disorders. This is where assessment of the participants’ models of mental disorders will hopefully prove its worth in this research - because not only is it sympathetic to the multitude of different explanations for mental disorder, including the suggestion it does not exist, but using this approach can also enlighten us as to why participants hold these views.

However, I also want to briefly mention some of the differences between social constructivism and social realism approaches to mental disorders in social science research because I think it would be a mistake not to. My main focus here is going to be related to the ‘status’ of mental disorder. From my reading of these issues, an important contrast between these two philosophical positions depends on ideas relating to the nature of the object actually existing. In the case of social constructivism, the position is that the object of interest, mental disorder, is going to be constructed through an individual’s intersubjective understanding – as mentioned previously the ‘ontic’ status of mental disorders can be refuted, but we can consider them in terms of their ‘epistemic’ standing. While in the case of critical realism, the assumption is that there is something there to conceptualise, that mental disorder does exist but our investigations of it are saturated with interests and values. For example, in the literature review chapters I spent some time focusing on the distinction between the psychiatric and psychological approaches to mental disorder – this example could realistically be viewed from the philosophical position of social realism because both approaches are essentially making two separate claims for what mental disorder ‘is’ on the basis of their independent frameworks. However, I think this idea falls short when the suggestion that mental disorders do not exist is considered. Although Thomas Szasz is likely to know what is being referred to when the term ‘mental disorder’ is used, in the same way I am likely to know what someone means when they use the term ‘ghost’, he still refutes the suggestion that it is a phenomenon that can be ontologically constructed. This refers back to his argument that mental illness is a myth (Szasz, 1960), in this case mental illness isn’t a ‘thing’, or a ‘physical object’ but a metaphor used to dominate, understand, and intervene in certain social problems. In this case, mental disorder is not real in the same sense that a microbe is real, but it is a social construction and should be navigated appropriately.
It is at this point where quite a difficult situation is reached. Szasz would refute the notion of mental disorder, however, other institutions or groups may suggest that even if it does not exist in the same way cancer or diabetes might – in as much as it cannot be physically discerned – it does still exist. They may argue that there are distinct behaviour sets or patterns that are so abnormal that they cause problems to the individual and to those around them – even if there is no detectable cause or reason for this. To an extent, I agree with this suggestion because there is something being observed in the individual, such as an odd or dangerous behaviour. However, I cannot categorically say that this is a mental illness – perhaps it is some sort of behavioural issue? Perhaps it is the tertiary stage of African trypanosomiasis causing the individual to behave in this way? For example, when writing this it makes me think that in order to have a mental disorder you actually need to have two people – a person who is being observed and another to suggest they have a mental illness. If we were to consider Szasz’s thesis for a little longer this observation may align with his idea perfectly, but it is important to point out this is something of a paradox. On the one hand, I am working with the suggestion that mental disorders are ontologically questionable, while on the other, I am working with the idea that there is something people can account for when considering this issue. A clue that enlightens this endeavour, and almost acts as a bridge between these approaches, is provided in the previously referenced paper ‘The Sociology of Mental Health’ (Warner, 2009, p.639). Joanne Warner writes:

*In order to clarify the epistemological position in relation to ‘mental disorder’, Busfield has advocated the use of alternative terms to social construction, such as ‘social framing’ or ‘social structuring’. These retain the emphasis on social processes in shaping how mental and emotional distress is understood, whilst not denying the ‘material reality’ of the phenomena associated with it.*

This is a good approach to this issue as it recognises all of the aspects discussed so far and it navigates the issue in a way that puts a clear emphasis on the social components, specifically the intersubjective nature, of how the object of mental disorder is constructed and understood. I am not going to attempt to distil the different categories down any further than this. I am moving forward, acknowledging that a major part of the methodological frame work of this research is through the different ways people intersubjectively make sense of mental disorders.

To summarise, in this research I am going to be navigating participants’ intersubjective thoughts about mental disorders in order to ascertain their insights and opinions on the developments in the field of psychiatric genetics. However, research in mental health presents a unique set of problems due to the controversial nature of the topic and the issues concerning how it is defined. I am advocating the idea that our understanding of the world – for things that are not ontologically dependent on our understanding, like stones, the sky, and the moon - can be navigated socially and in the specific subjective context that we find them. In this case intersubjective does not mean idiosyncratic, but rather it is a way of framing the execution of sociological research. Mental disorder is not observable in the same way a stone is and in this case I am choosing to approach this task by making sense of mental disorder through intersubjective meaning-making. I am using a constructivist understanding of what mental disorders are, rather than focusing on them as ontological objects.
3.1.5 – Additional sociological approaches

This investigation of the sociological theory for mental disorders is only part of the story with respect to the multitude of different ways sociological studies theorise the issue. However, this part of the discussion has essentially introduced the final aspect of the triad in terms of the approaches that are typically used in this endeavour. Along with the previously examined medical and psychological approaches to mental disorder, sociological approaches are additional ways of conceptualising the phenomena. In his contributing chapter to the book ‘A Handbook for the Study of Mental Health’, Allan V. Horwitz writes:

Unlike psychological and biological perspectives that look at personal qualities and brain characteristics, sociologists focus on the impact of social circumstances...The distinctive emphasis of sociological approaches is on how processes such as life events, social conditions, social roles, social structures, and cultural systems of meaning affect states of mind. Social perspectives assume that different individuals who are in the same circumstances will have similar levels of mental health and illness. That is, what determines how good or bad people feel does not just depend on their own personalities or brains but also on the sorts of social conditions they face. These conditions vary tremendously across different social groups, societies, and historical eras. (Horwitz, 1999, p.7)

He later notes:

Sociological approaches share the idea that mental health and illness are not just qualities of individuals but also stem from various aspects of social circumstances. What social groups people belong to, what historical periods and societies they live in, and what cultural values they hold profoundly shape how people feel about themselves, how likely they are to become mentally ill, the kinds of problems they are likely to develop, what they do if they develop mental difficulties, and the kinds of help that are available to them. (Horwitz, 1999, p.8)

From doing some further reading on the topic on sociological theory in mental health (Baltrušaitë, 2003; Horwitz, 1999) there are almost a bewildering array of possible approaches available to the interested social science researcher to investigate these issues. For example, in the paper ‘Theorising mental disorder : A sociological approach’ (Baltrušaitë, 2003), a selection of approaches to the study of mental disorder from within social science are examined. There is an emphasis on the work of sociologists such as Parsons and the functionalist model of mental disorder, a discussion of labelling theory, and an examination of the works of Michael Foucault and his theories about mental disorder. However, when researching each of these I cannot help but think they are not, in isolation, suitable for what it is I am trying to do in this research. I think that certain variants of sociological theory are highly dependent on what is being investigated and the limitations being imposed on the enquiry through its design. For example, I need to be honest about the restrictions of what I am doing in this research – which is speaking to a relatively small number of psychiatric professionals about the implications of genetic testing for mental disorders. Reflecting on the nature of what it is I intend to do and how I intend to do it, this situation allows for a contrast between some of these theoretical approaches.

For instance, reflecting on the perspectives now covered, a clear distinction between biological and psychological approaches, in contrast to sociological perspectives, is the location of ‘mental
disorder’. In the two former approaches mental disorder is somehow contained within the individual, while in the latter the cause is due to the individual’s external situation. However, given what I want to do in this research, I do not feel that choosing between these approaches is necessarily that important to me as an investigator given the research question and how I intend to investigate it. What I need is to be aware of, and sympathetic to, is the selection of models that are traditionally adhered to by practicing psychiatric professionals. As suggested previously, a significant component of this research is the awareness of the participants’ communicated models of mental disorder. Inherent to this suggestion is an understanding of the location of this research – a clinical environment that is inhabited by psychiatric professionals who have been shown to adhere to a fairly broad selection of models as a consequence of a number of factors, such as their academic training and their personal thoughts on mental disorder. Links can be made if the definition of models is revisited:

Models...are the conceptual frameworks, or sets of ideas, by which, in any given area, people structure and make sense of the world around them. (Fulford and Colombo, 2004, p.130)

I think this way of approaching mental disorders has a strong similarity to adherence of social constructivism in this research project – in both cases there is an opportunity for essentially any personal account of mental disorder. So, although in the theoretical literature there is often a distinction between biological, psychological and social models of mental disorder, I am advocating an approach that is aware and open to any potential explanation of mental disorder, and I am certainly not suggesting there is going to be any incompatibility between any of these approaches. For example, consider the following examination of constructionist views of mental illness from Allan Horwitz:

The greatest strength of social constructionist views of mental illness is their sociological conceptualisation of the nature of mental symptoms, a conceptualisation that does not rely on psychology or biology...Biological psychiatry, for example, which defines mental illness as a disease of the brain, legitimises a particular construction of social reality that has great credence in contemporary Western societies...The legitimacy provided symptoms viewed as products of brain disorders results not from the actual locus of symptoms in the brain, but from the credence that a particular culture gives to disorders thought to result from brain malfunctions. Attributing symptoms to elevated levels of serotonin has no more inherent validity as a cultural explanation than attributing them to unconscious forces or to demonic possession. The explanation and functioning of social systems of classification are questions independent of the explanation of the types of symptoms individuals develop. (Horwitz, 1999, p.70)

Here, although Horwitz initially begins this account through separation of sociological conceptions away from psychology or biology, he ultimately provides an account that encompasses every possible explanation for the phenomena of mental disorders. In this case Horwitz is equating different accounts of mental disorder as being dependent on the cultural climate in which they are being observed - this is the approach being advocated in this research project.
3.2 - Choosing methods

With the background concerning the nature of this enquiry completed, the next question to ask is what methods should be used in this research study? As hinted previously, this is going to depend on what it is I want to achieve throughout this process and how I want to do it. However, it extends further than this because the process is not only restrained in relation to what I want to achieve, I also need to be frank and honest about my own personal approaches to social science enquiry, and this is partly going to depend on my reading and analysis of the studies contained in the literature review of this project. For example, when consulting relevant studies that have been conducted in the field, individuals’ models of mental disorder have been determined using quantitative research methods.

Within the social sciences there are two main schools of research methods used, quantitative and qualitative. Quantitative research refers to the approaches in empirical inquiry that collect, analyse, and display data in a numerical, rather than a narrative, form (Donmoyer, 2008). This is in direct contrast to qualitative research methods that are best for addressing why questions. These methods are typically used to explore a new phenomenon and to capture an individual’s thoughts, feelings, or interpretations of a process (Given, 2008). Consideration of this dichotomy is already starting to provide hints as to the most appropriate way to go about conducting this research - using qualitative methods.

John Cresswell (Cresswell, 2007, p.40) provides a discussion concerning ‘When to Use Qualitative Research’ that focuses on each of these issues in isolation. Each of the points raised in his discussion can be considered in light of this research study:

- We conduct qualitative research because we need a complex detailed understanding of the issue of interest.

This could certainly be the case when considering what has, or has not, already been achieved in the field of psychiatric genetic testing and what it is I have proposed to do in this research project. Previous research and government requests have paved the way for a detailed appraisal of psychiatric genetic technologies now that they are in development. Additionally, because several have been released, they can be used as exemplars to gain a better understanding about the broader implications of the developments.

- We conduct qualitative research when we want to empower individuals to share stories, hear their voices, and minimise the power relationships between a researcher and participants in the study, we also want to understand the contexts or settings in which participants in a study address a problem or an issue.

As the genetic test developments are yet to receive any sort of in-depth appraisal, adopting a qualitative approach by contacting those directly linked to using the technologies in a clinical setting seems appropriate as this is a probable way to assess the developments. The intention is to generate data reflective of the individuals’ personal experiences and unique understanding of mental disorder in relation to the research questions. Minimising the power relationship between the participant and I will have to come down to my experience and abilities in conducting interviews as a qualitative researcher. An aspect of this process will also be due to having an appreciation that mental disorders
are understood in different ways and I need to keep this in mind when conducting the interviews and analysing the data.

- Finally, we use qualitative research to develop theories when partial ones exist for current problems and issues.

This could be considered as directly relating to one of this studies research questions regarding the previously unanswered question concerning psychiatric professionals seeing any use of genetic testing in their clinical practice, and attempting to investigate this question qualitatively. Additionally, the government proposals examined in my literature review suggest that research in genetic testing in psychiatry needs to occur. Therefore this dynamic lends itself very well to this sort of investigation because there is a lack of previously conducted research.

The next question is which of the numerous methodological approaches that are available to me as a researcher do I choose to use? As suggested previously, this is dependent on what exactly I want to do in combination with all of the underlying assumptions that I have discussed. I want to propose the use of a thematic analysis inspired methodological approach in this research study.

3.2.1 - Constructivist Thematic Analysis.

As mentioned, the methodological approach used needs to be one that reflects the overall world view orientations of the research study. I have discussed the fact that I am approaching this study from the viewpoint of a constructivist researcher; therefore using a methodology that supports this framework is paramount to maintaining continuity, validity and focus. All of these issues will be discussed and explained here. For this section I will rely heavily on the excellent paper ‘Using thematic analysis in psychology’ (Braun and Clarke, 2006) as it helped clarify several points concerning how I need to go about executing this important aspect of the research project.

When considering ‘What is Thematic Analysis’ Braun and Clarke note:

_Thematic analysis is a method for identifying, analysing, and reporting patterns (themes) within data. It minimally organises and describes your data set in (rich) detail. However, it also often goes further than this, and interprets various aspects of the research topic._ (Braun and Clarke, 2006, p.6)

In terms of what has already been established and suggested in this project so far, even from this brief quote, the merits of this methodology become apparent. Given the relative lack of research into the potential developments in the field of psychiatric genetic testing, using a methodology that can systematically report on all of the emergent themes from within the data and simultaneously _interpret_ components of the topic would be extremely beneficial. In the context of this project I liken this to me essentially being able to ‘report’ (and put into context) the thematic issues discussed by participants with an awareness of some of the components that may inform these issues. In this case, this relates to the potential role of the participants communicated models of mental disorders influencing their accounts of the developments in the field of psychiatric genetics.

In their paper, Braun and Clarke spend a lot of time focusing on some of the methodological complexities and issues when using this approach in qualitative research projects. For example, they mention that several other recognised methodological approaches actually resemble thematic
analysis as they share several similarities — such as ‘true’ grounded theory — but they also focus on
the importance in relation to researchers being transparent about what went into their research,
specifically how the research was conducted. The aspects relating to the actual development of the
themes will be discussed later on, however, before this I want to briefly examine some of the
integral aspects that need to be addressed when conducting a thematic analysis in this project.

3.2.2 - ‘Inspired by’ Grounded Theory Thematic Analysis.
As mentioned several times up to this point, the methodological approach used in this research
project has been inspired by what would typically be discussed in a grounded theory project.
Consulting the Braun and Clarke paper helps illustrate why I may have been under the impression
this research resembled grounded theory, but this paper also helps clarify several associated issues
relating to this. It appears that both grounded theory and thematic analysis actually share very
similar characteristics, the main focal point that both methodologies use the same process with
regards to the ways the data is coded and themes are developed. Braun and Clarke offer the
following insight:

Regardless, the goal of a grounded theory analysis is to generate a plausible – and useful -
theory of the phenomena that is grounded in the data. However, in our experience, grounded
theory seems increasingly to be used in a way that is essentially grounded theory “lite” - as a
set of procedures for coding data very much akin to thematic analysis. Such analyses do not
appear to fully subscribe to the theoretical commitments of a “full-fat” grounded theory,
which requires analysis to be directed towards theory development. We argue, therefore,
that a “named and claimed” thematic analysis means researchers need not subscribe to the
implicit theoretical commitments of grounded theory if they do not wish to produce a fully
worked-up grounded-theory analysis. (Braun and Clarke, 2006, p.8)

On reflection, my previously idealised ‘version’ of grounded theory would perhaps be better
considered as an example of this ‘lite’ grounded theory, and not the ‘full-fat’ version described
above. However, I still want to make it clear that although this is not an example of grounded theory
research, investigating the methodology did influence the ways I considered the process of data
analysis and thematic development. On reflection, it would seem that the way this was most
influential was in terms of the development of my themes — how the data was coded and how the
themes were ‘built’ in this project. As this has now been clarified I am going to stop referencing
grounded theory and move forward focusing on the thematic analysis methodology. Before the
analytic process relating to this research project is described, I am going to briefly focus on some of
the worldview assumptions being made in this project.

In the previous section I stated and discussed all of the worldview and framework associated
assumptions that I am making in this research project, however, I have yet to align these completely
with my choice of thematic analysis as the methodology used in this research. Braun and Clarke
point out that thematic analysis is a suitable methodology that can be used in a constructionist
fashion. I mentioned that a significant factor influencing the design of this research was the
observation that different psychiatric professionals adhere to, and communicate, different models of
mental disorder. This observation fits in with the following extract:
from a constructionist perspective, meaning and experience are socially produced and reproduced, rather than inhering within individuals. Therefore, thematic analysis conducted within a constructionist framework cannot and does not seek to focus on motivation or individual psychologies, but instead seeks to theorise the socio-cultural contexts, and structural conditions, that enable the individual accounts that are provided. (Braun and Clarke, 2006, p.14)

The important aspect to be aware of is that participants’ accounts of the tests are possibly going to be influenced by the ways they make sense of mental disorders; therefore this is a process that needs to be factored into the methodology of this project. Essentially I am not assuming, as Braun and Clarke point out, ‘a unidirectional relationship between meaning and experience and language’ – in this case I am trying to factor in to the research some of the processes that people are going to use to make sense of the developments in genetic testing for mental disorders. This is similar to what Braun and Clarke mention when discussing ‘latent’ themes:

In contrast, a thematic analysis at the latent level goes beyond the semantic content of the data, and starts to identify or examine the underlying ideas, assumptions, and conceptualisations – and ideologies - that are theorised as shaping or informing the semantic content of the data. If we imagine our data three-dimensionally as an uneven blob of jelly, the semantic approach would seek to describe the surface of the jelly, its form and meaning, while the latent approach would seek identify the features that gave it that particular form and meaning. Thus for latent thematic analysis, the development of the themes themselves involves interpretative work, and the analysis that is produced is not just description, but is already theorised. (Braun and Clarke, 2006, p.13)

In this case I consider being able to utilise the participants’ models of mental disorders as a way of being able to understand and appreciate what went into their accounts of the developments in genetic testing for mental disorders, rather than simply considering their accounts in isolation from this initial observation. When examining some of the finer details concerning the implications of a social constructionist world view, Creswell (2007) presents a series of points that, when considered in terms of what this study is setting out to achieve, as well as the proposals made in relation to how this is going to be achieved, validate the benefit of this approach. For example, he points out that when relying on participants’ viewpoints about a situation, their subjective meanings are negotiated socially and historically. This is applicable and linked to me wanting to contact a wide range of psychiatric professionals in this study because psychiatry is a multi-disciplinary area of medicine that is partly governed by power relations between different professions (Colombo, et al. 2003). Therefore getting a wider spread of participants will mean that the data collected is as applicable as possible. This is also closely linked to my incorporation of the participants’ communicated models of mental disorder into the methodology. Although adoption of this approach is secondary to the main research focus of this study, inclusion of this aspect is novel and warrants some extra detailed analysis, as it is, theoretically, functioning in two main capacities. First of all it is being used to avoid having to constantly deal with the question of ‘what is mental illness’, and secondly this approach acknowledges that different individuals have different approaches to the topic and this may influence the way they consider the field of psychiatric genetics.
3.2.3 - Overall analytical method

Although the systematic process - by which the data was analysed - on paper, mimics the relatively prescribed framework found in the Braun and Clarke article, I want to stress that it is a great deal different to actually go through the process of developing the themes than it is to read about how to do it. So what I want to do here is describe how I actually did this in this research project.

First of all I have to admit that research in Social Science is a great deal different than in Natural Science, here I am referring to my training as a biologist and some of the experiences I had moving over to this discipline. In my previous ‘life’ I never gave any thought or consideration to any of the issues that are seemingly so important in Social Science research. For example, although this may be a consequence of how different disciplines are actually taught, when we would conduct experiments or research in biology it, looking back, felt rather prescriptive. Systems could be measured in (what I considered) constant, reliable and dependable ways and I never really thought about my influence on the situation, and I routinely ‘accepted’ research and my findings with very little consideration of what went into it. Although this may say a great deal about my abilities or credentials as a biologist, one of the aspects I had many problems with in sociology was the fact that there is such a diverse number of approaches available to us a researchers.

This is not a criticism of the sociological field but rather an honest account of my, initial, naivety and confusion as a novice researcher. So when it comes to discussion of the methodology and how it was executed and applied in this research my aim is to ensure that adequate ground work is provided so that if someone else wanted to conduct such a study then they would have everything they needed in order to do so. If this parallel is drawn to research in biological science this would be similar to providing all of the necessary steps for someone else to carry out an experiment for themselves. Formerly I may have been under the impression that as long as the instructions were followed exactly then essentially the same results would be gained by a different research team, however, from consideration of the research that looks into elucidation of the underlying genetic aspects of mental disorder, I now understand this impression may have been false. If anything my move over to social science has diminished this idea even further. For me personally, something that I am still coming to terms with is finding my voice as a social scientist, what I can say, what I cannot say and how I go about doing this. For example, I was quite bewildered by the sheer complexity of the methodological tools and techniques available to social science researchers – if the grounded theory example is used, there appears to be a great deal of controversy over exactly how to conduct a grounded theory study, and one of the questions I keep asking myself is “What is it I am really doing in this research?”

For the sake of transparency I want to attempt to clarify the point where this research stopped being totally inspired by grounded theory and became an example of thematic analysis. My initial fondness and ultimate choice of using grounded theory pertained to my thoughts in relation to what it provided me as a researcher in this project – a framework for situating the research and a relatively robust process for its execution. So I would not be telling the truth if I did not maintain that this methodology was extremely influential on my overall thinking about how to conduct this research study. However, regardless of any of the thinking that went into the foundations of this research what we really have in the final investigation is a thematic analysis and an associated presentation. Despite this change in analytic approach I do not feel that this detracts from my contribution – if anything I am being completely frank about what influenced me in this research and hopefully this
will enable in others being sympathetic with the methodology, my thinking, and what went into development of the themes.

A great deal of work went into the development of the five themes presented in this research project, and in their construction there was a great deal of initial ‘clutter’ and ‘mess’ that evolved into what is presented here in this research. Although the instances presented here are the ‘tidiest’ evolution of the themes, perhaps one aspect that is not really translated very well in this thesis concerns just how difficult, and messy, this process really was to achieve. To try and illustrate this I want to describe the process as close as I can in regard as to how it happened in this project.

The first point that I want to clarify is in regard to establishing the participants communicated models of mental disorder as, initially, I tried to keep this separate from the development of the themes themselves. However, it soon became apparent that upon reviewing the codes and building up themes it was actually impossible to do this because the two issues were so closely linked and they could not be separated. For example, consider the sub-theme of ‘Psychiatric legitimacy’, in this context I am not particularly concerned with what the theme turned out to be in the discussion of this thesis, but rather how it started and developed up to the way it was presented in the findings chapter.

There were many codes peppered throughout the series of the 33 interviews that ultimately contributed to this theme. However, the actual arrival at this theme in the way it is presented is far from simple or straightforward. For example, here is an extract, from an interview with a clinical psychologist, which contributed to the development of this theme:

*Int:* Do you think the introduction of these technologies could alter the way the public think about psychiatry or mental health problems?

*Par:* Yes and yes. The introduction of these technologies implies some success in these technologies, okay, so if there is some success marketed for these technologies then it proves that this is all medical and biological – so therefore its power to the psychiatrists elbow. (Participant rejects the biological model of mental disorder)

From this short response there were several initial codes developed, for example, on initial reading I highlighted the words ‘technology’, ‘introduction’, ‘medical model’, ‘power’, ‘proof’ and made little notes in the margin such as ‘new technological success’, ‘psychiatric legitimacy’, ‘proof that it is biological’ and ‘power to psychiatrists’. When considered together I had a selection of different codes to examine, however, these also needed to be compared and contrasted with every single other similar thematic instance in the interview series. Let’s consider these ideas in light of an additional section from another interview:

*Int:* What do you think using genetic information as an aid to the diagnosis of psychiatric disorders could do for practicing psychiatry?

*Par:* I think first of all it will bring a huge attitude change to psychiatry from other medical disciplines. They think we are not doctors and we just do what we want. So I think it will gather more respect for the psychiatric field itself. Patients will have more faith in us, as clinicians we will be more confident and the anti-psychiatry movement will lose some of
their ammo – saying it’s a pseudoscience and stuff like that. (Participant endorses the biological model of mental disorder)

Some of the initial codes from this section were aspects such as ‘attitudes’, ‘respect’, ‘faith’, ‘anti-psychiatry’, and although these feature in other themes developed in this research – such as the issue of ‘faith’ being tantamount to the empowerment possibilities these tests provide – I felt that this quote was actually encapsulated far better by the overall theme of ‘psychiatric legitimacy’. However, I was only really able to do this from an understanding of the codes from the aforementioned interview. Although some insight can be gained from this in isolation, an additional ‘level’ to this process is consideration of the participants communicated models of mental disorder with respect to these codes and these notes – this is especially important with respect to the development of the theme of ‘psychiatric legitimacy’ because models of mental disorder were so important to its genesis.

Not only did I need to consider the content of what was being said by each of the participants, I also needed to consider the source the statements too. For me the major link between these two quotes (in context of the overall legitimacy theme) was when the psychologist mentions the tests’ providing ‘power to the psychiatrists elbow’ and when the psychiatrist mentions ‘gather more respect for the psychiatric field’. Both of these suggestions are very similar to one another and I would suggest they both reinforce the same idea about the possible consequence of the tests introduction, but the theme was significantly illuminated when their contrasting models of mental disorder were taken into account. In this case I considered this process as an additional ‘level’ of analysis, not only was I concerned with coding the interviews and the development of the themes, I was also interested in examining some of the accessory issues with regard to the participants contrasting models of mental disorder. For me I chose to consider this almost like an additional inbuilt validation process, one that I did not necessarily predict or plan in the design of this research.

Although the same questions were asked to each participant, so it would be reasonable to expect similar responses about the issues probed, an additional way of approaching the replies was to examine them in terms of the participants communicated models of mental disorder; the aforementioned example is representative of this. Seeing the similarities and the differences within each of these themes really brought the study to life and began to illustrate the depth of my thematic findings in with regard to the participants views of mental health.

3.2.4 - Stages of Coding

Interviews were first subjected to what would typically be referred to as open coding - each interview was read very closely and broad codes emerged – as illustrated in the above ‘psychiatric legitimacy’ example. In this case I printed out each interview and annotated it by hand, coding all of the interview data as I went along and read it. From my first reading of the interview transcripts I felt I had a good grasp of the data, however, I wanted to translate my initial findings into the computer program NVivo so I could start to formulate and modify my ideas more effectively than I could on paper. So I repeated the close readings on the computer program and afterwards I had a collection of 211 individual codes. From here I organised all of the codes into groups that I considered to have some sort of thematic similarity with one another, an example of this is contained within the following figure (Figure 3). For example, each of the interview statements included in the figure would have been highlighted by me as being ‘Not Diagnostic’ and
‘Deterministic’, so I collated all of the instances where this occurred and combined all of the examples together. This continued until all of the 211 initial codes had been accounted for and combined together.

![Diagram of 'Criticisms of the Tests' theme]

**Figure 3 – Development of ‘Criticisms of the Tests’ theme**

In terms of the chronological process by which this occurred I have to admit that I opted for (what I believed to be) pragmatism in my approach to doing this. For example, the process of developing codes was iterative as the research process continued. In this case I coded my first interview as soon as I could after having transcribed it, this meant that the interview was fresh in my mind from spending around 7 hours of listening to small sections of audio and typing them out, but in addition to this it meant that when I had the second interview to code I could do so with the insights gained from coding the first. The process continued throughout the project – once I had all of the codes from the first two interviews I could see if they were present in interview three, and so on. Once I had completed the initial coding the paper versions of the interviews the whole process was completed again on NVivo – only this time I was able to look over all of the interviews for any codes that I may have missed the first time around. For example, a code may have presented itself in interview ‘15’, which I may have missed moving forward the first time, however, translating everything into the program meant I could revisit everything again.

From the initial 211 codes, I combined all of the statements generated down into 45 categories – illustrated in the second tier of the diagram labelled, like the ones labelled, ‘Prediction’, ‘Denial’ and ‘Reductionist’. Each of these 45 categories was inspected and combined further, on the basis of what I thought each category was really saying to articulate the participants’ stories concerning their views and opinions about the introduction of genetic technologies into the clinical setting. From further condensing down the 45 categories, I arrived at the 5 major themes that constitute the primary findings of this research project.
The difficulty here is that although there maybe frameworks provided in the literature concerning how to design and conduct a thematic analysis in a research project, I feel that any reading on the topic is not really an accurate reflection of the reality of what it is like to actually conduct one. For me, part of this is due to the emphasis placed on how different people think about or approach situations – and this is the difficult aspect to communicate, and one that I feel is downplayed in the Braun and Clarke paper. For example, I do not believe that coding an interview transcript would necessarily raise that many problems when thinking about conducting this research again, by a different researcher, in a different context – in terms of reliability – as I think that the process can be broken down into an almost ‘line-by-line’ or ‘word-by-word’ format. I would suggest that anyone involved in social science research or interested in this work would more than likely generate the same variety, and perhaps number, of codes as I did. However, one area where I feel there may be some differences could relate to the ways that the themes are built up, as I have to admit this is a process I found very difficult indeed.

Essentially this process involved me sitting down with a list of the 211 initial codes and trying to find links between what was being presented in that particular instance – this would often involve linking aspects of the different codes with an example of the interview transcript associated with the code and thinking about what these extracts were telling me. An example of this is contained within the aforementioned ‘psychiatric legitimacy’ example. Although in one of the initial codes I designated the first section ‘technology’, this was not really anything to do with the ultimate character of the theme that was generated – although the participants were discussing the tests as a technological development, the bigger issue, from my consideration in this analytic process, relates to the impacts concerning ‘psychiatric legitimacy’.

However, I did not stop at this point in the analysis. As discussed, there was a process of continually refining all of the themes when arriving at the 5 that are presented in this research project. The theme of ‘Psychiatric Legitimacy’ was an example of the move between the 211 initial codes and the 45 categories; however, I did not think that reporting all of the 45 different ‘category’ issues would be possible in this project, having such a large number also made me think that I probably had some more work to do. I remember speaking to one of my supervisors about all of this and I was given a very important piece of advice – one that I did not gained from reading the Braun and Clarke paper. I was told to examine the themes at a higher level of abstraction. I chose to view this suggestion in terms of stepping back from all of the data for a while and trying to see any new links between what was there on the computer screen, the pages and pages of ‘code lists’ I was working with, and the notes I had been making.

I continually asked myself the questions “What is this code, or theme, really doing, or saying?” and “Are any of these aspects linked together at all, how are these issues related to each other?” – slowly the picture began to emerge in front of me and this culminated in the themes presented in this research. To illustrate this I will focus on the first theme presented in the results chapter of this project – ‘Prioritisation of genetic explanations for the diagnosis and treatment of mental disorders’. When I was trying to build up my themes I was attempting to find a way of appropriately linking up all of the codes I developed - so when I was actually looking at my code ‘Psychiatric Legitimacy’ I spent a great deal of time thinking about what this theme was telling me. I remember thinking to myself “What needs to happen for any of this to work?” and I came to the conclusion that an important step in the process will depend on a patient actually taking the test in the first place. As it
turns out this ‘mental exercise’ was very important in shaping the way I began to interact with all of the codes and how they became themes. So I began to think about the patient choosing to take the test, or the test somehow being used in a clinical setting, and what this process means in the context of this research – upon considering this I reasoned that essentially what is happening here relates to what can happen as a consequence of using genetic information in mental health care. From this point on the rest of the themes began to fall into place as they are all essentially variations of this overall idea. For example, the themes of ‘Psychiatric Legitimacy’ and ‘Streamlining different areas of practice’ were originally considered separately – but the feature that links the both of them relates to the aforementioned observation concerning what is actually happening in both of these instances. Both of these thematic aspects concern what can happen as a consequence of prioritising genetic explanations for mental disorders as a result of actually using the tests.

3.3 - Determining participants models of mental disorder

As discussed in the literature review, participants’ models of mental disorders are typically assessed through asking a series of questions and the participants’ answers being coded in assessment with a series of predetermined models – either in the form of questionnaires or interview questions. A similar approach will be used in this research project. However, there will be some subtle differences from the papers examined in the literature review chapter. For example, my questions are going to be as open-ended as possible and there will be no case vignette describing a mental disorder, or an individual in a specific mental health related scenario. I coded participants’ responses on the basis of the answers they offered to the following questions:

- What are your thoughts on the causes for mental disorders?
- What are your thoughts on the effective treatments for mental disorders?
- What are your thoughts on the causes for eating disorders?
- What are your thoughts on the effective treatments for eating disorders?
- What are your thoughts on the causes for bipolar disorder?
- What are your thoughts on the effective treatment of bipolar disorder?

This will be somewhat similar to the grounded-theory-inspired methodology that has been described in relation to the analysis conducted on the data pertaining to this study’s primary research question. If the participant says something like “I think that mental disorders are caused by an individual’s genetic constitution” then I will annotate this section of their interview as being “biological”. If the participant was to suggest that mental disorders do not exist and they are social constructs, I would code their response as being “anti-psychiatry”. This is my proposal regarding the best way to elicit participants’ implicit models of mental disorder. As discussed in the literature review, if people who work in psychiatry are asked about their thoughts regarding mental disorders outright, they are likely to talk about their explicit model, which is thought to be the “biopsychosocial” model (Fulford and Colombo, 2004, p.136). I want to avoid this for a number of reasons. First of all, if this is a likely outcome, then making inferences about the implications of genetic testing for mental disorders on the basis of the models they communicate would be impossible because every participant’s model would be the same. This would be disappointing
because it would mean that a significant proportion of the methodological design of this research would be wasted. However, considering that ‘how they actually respond to and deal with mental disorders, will be driven by their implicit models of disorder’ (Fulford and Colombo, 2004) it seems reasonable to ask each participant the above questions in order to satisfy this issue.

However, there is one additional component to clarify here. Why would I choose to ask participants about their thoughts on mental disorders generally, and then focus on bipolar and eating disorders specifically? This was in an attempt to get a holistic view on the participants’ models of mental disorder, essentially addressing the aforementioned issue concerning the implicit/explicit divide, by including some specific mental disorders, which means that comparisons can be drawn between participants’ ideas and what is typically discussed in the literature. For example, it has been suggested that eating disorders could represent a way of coping with identity problems and help with aspects of personal control thought to manifest due to a combination of factors such as sociocultural issues, family aspects, cognitive, and biological components (Polivy and Herman, 2002). While bipolar disorder, other than being heavily linked to the Psycheme1 test, is thought to have a basis that is rooted in terms of biology and interpersonal relations (Craighead and Mikilowitz, 2000). Although these are essentially both examples of different models of mental disorder operating in relation to two disorders, these conceptualisations can be used as a comparative baseline for participants’ responses.

3.4 - Participant recruitment

A total of 33 semi-structured interviews were conducted with a range of psychiatric professionals employed by the NHS and who work in a number of different trust locations within the South West of England. Interviews were conducted between July and November 2010. The sampling frame consisted of psychiatric professionals who have clinical contact with psychiatric patients who responded to an invitation to participate in the research study. The recruitment process used two main routes: (1) participants were contacted though their ward-based staff pigeon holes via a paper information pack that explained the research study and contained a reply slip that, once returned to me, registered their interest; (2) some participants were recruited in somewhat of a ‘snowball’ fashion – after completing a number of interviews, the participant asked me if I had spoken to their colleague who they thought would be interested in participating in this research, and in this case the interview participant forwarded an electronic version of the information pack, on my behalf, to the person they suggested.

A total of 75 information packs were sent to different psychiatric professionals from within the trust locations where NHS ethical approval was granted. From this, 27 individual reply slips were returned, and the remaining 6 participants were recruited over email in the ‘snowball’ fashion described. Contact was made either by telephone or e-mail to organise the interview at a time and place that was convenient for the participant. Care was taken to verbally walk the respondent through all of the points in the consent process and emphasis was placed on the fact that participation was completely voluntary, that they were able to withdraw from the study at any time, for any reason, and that they would remain anonymous throughout the whole process. All respondents signed written consent forms to participate in the study before being interviewed. No one withdrew from the study during its execution or once it was completed.
3.4.1 - Breakdown of interview participants (n = 33)

Staff nurses – x11

Nursing Assistants – x3

Psychologists – x3

Psychiatrists – x8

Occupational therapists – x2

Dieticians – x1

Drama therapists – x1

Nurse Consultants – x2

Ward Manager – x1

Family therapists – x1

The breakdown of interview participants roughly reflects the ratio of psychiatric professionals that would be typically found on a ward that caters for people with psychiatric disorders. In my experience there are more nurses on a ward than there are psychiatrists, which in turn outnumber the psychologists. However, what this breakdown does not reveal is the different clinical areas that each of the participants specialise in. Participants were recruited from four main clinical areas – a rehabilitation and recovery unit, an eating disorders unit, a forensic psychiatry setting, and an acute psychiatric unit – and when speaking to many of them in the interviews, there were instances where they mentioned that they have experience in other settings. For example, I did not anticipate speaking to a dietician, even when I managed to organise a meeting with the consultant psychiatrist who was in charge of the eating disorder unit to discuss speaking to their staff group - this never occurred to me as being a possible recruitment subject. During the interview with the dietician I was told that other than being based in the eating disorder unit, extra responsibilities were recently added that mean other mental health units were also visited. The interview also contained commentary that went beyond the remit of using the tests in an eating disorders unit in isolation. This was common to almost all of the participants included in the study, and although responses often directly reflected their particular speciality, commentary was also given on a broader basis.

3.4.2 - Execution of the interview

Each interview was audio-recorded on a portable digital hard disk Dictaphone machine where the files were later transported over to a home computer and were all transcribed verbatim. The average length of the interviews was 55 minutes with the shortest interview lasting 35 minutes and the longest interview lasting 1 hour 20 minutes. The first part of the interview was intended to serve two main purposes. First, to ease the participant into the interview process while ascertaining their models of mental disorder, by asking the participant about their thoughts on the causes and treatments of mental disorders generally, then focusing on two specific disorders in isolation – bipolar disorder and eating disorders. After this the information pack that contained the information relating to the Psynomics genetic tests was presented to the participant. At this point the recording
was stopped while the participant and I read through the information packs together. When the participant was ready the recording was restarted and they were asked if they had any questions about what they had just read. When their questions were answered, we proceeded with the second section of the interview.

The second section of the interview focussed on the participant’s individual thoughts and opinions on the genetic technology and how it might be used, as well as its broader implications, in clinical practice. As a means of ending the interview the participant was given the opportunity to ask me if they had any questions about anything that we had discussed or if they had any questions about anything relating to this research. Although some participants chose not to ask me anything, around half asked me about my thoughts on the topic, five participants asked me about other related developments in the field and one participant suggested that it would be interesting to speak to service users about the topic.

All of the interview material is available in the appendix of this project. Included is the information pack that was given to each participant and the semi-structured interview schedule.

3.4.5 - Interview questions.

1) What are your thoughts on the causes behind mental disorders/eating disorders/bipolar disorder?

2) What are you thoughts on the effective treatment for mental disorders/eating disorders/bipolar disorder?

Introduction of Psynomics research component

3) What are your initial thoughts and opinions on these developments?

4) How might you envision using such a test in your clinical practice?

This question will differ from person to person as I will be speaking to different professionals within the profession. However, as prompt for discussion the following questions can be asked as a basis for data generation.

- What do you think using genetic information as an aid for diagnosing a mental disorder will do in terms of practicing psychiatry?

- What do you think using genetic information as an aid for the treatment of a mental disorder will do in terms of practicing psychiatry?

5) Do you see these tests/this test raising any particular difficulties for you in your clinical practice? For example, in informed consent, or in whether choosing to use the technology?

6) How likely do you think is it that this technology will significantly improve patient outcomes?

7) What about the broader impact on psychiatry? Is it likely to be taken up by your colleagues, or do you think there is scope for it to be incorporated into overall practice?
3.4.6 - Ethical considerations

NHS ethics approach was granted for this research project, in accordance with health care guidelines (http://www.nres.npsa.nhs.uk/applications/is-your-project-research/).

3.4.7 - Credibility, transferability, dependability and conformability in this research.

This section will be a short discussion concerning how to judge the quality of my findings with respect to the credibility, transferability, dependability, and conformability of this research project. Each of these components will be considered individually and the breakdown of definitions are provided by a single article on the topic ‘Strategies for Ensuring Trustworthiness in Qualitative Research Projects’ (Shenton, 2004), however, it is important to note that this paper essentially appears to be a positive synthesis and review of ‘Guba’s constructs’. These are the four criteria proposed by Guba (1981) that help qualitative researchers in pursuit of a trustworthy study, focusing on these issues is important for this reason alone. However, in addition to this, the Shenton paper appears to be especially concerned with appeasing the criticisms of qualitative work offered by positivist researchers, he reasons that consideration of ‘Guba’s constructs’ is an appropriate and valid way to do this, as these correspond with the criteria traditionally employed by the positivist investigator in their research.

3.4.8 - Credibility.

According to the Shenton synthesis of the field, credibility is concerned with the ways researchers have confidence in their research and that they have accurately recorded the phenomena under scrutiny. In terms of judging the quality of my findings in this way a major component concerning the credibility of this research relates to what Shenton refers to as ‘peer scrutiny’. Every single theme presented in the findings chapter was developed with the close supervision of my supervisory team. I was lucky enough to be able to meet with my first project supervisor on almost a weekly basis, and although this served as a good opportunity to ensure I continually produced work in a timely fashion, for me the main benefit I was afforded through doing this was a continual and detailed discussion of my themes. For example, I was able to talk through and discuss all of the themes as they were being developed, and as it was sometimes hard to separate myself from the data, because I was working with it everyday for months on end, this meant that sometimes the discussions we had would significantly shape the themes and illustrate things I may have been oblivious to. An example of this that I remember very clearly concerns the third theme in the findings chapter that is to do with different representations of mental disorders in light of the tests’ introductions. To begin with my initial ‘version’ of this theme was largely concerned with the role of the media, however, it was not until I was speaking to my supervisor about this idea when links were made between this issue and the other main component of the theme, which related to public perceptions of the tests potential introduction.

I also had the opportunity to present some of my initial findings, to a larger number of peers, at the post-graduate PhD student research conference held at the university. In the year I presented a paper, the theme of the conference was ‘Tension and Cohesion in Social Science Research’, when thinking about how I could satisfy this topical issue I thought it would be a good idea to focus on some of the thematic aspects relating to the inclusion of participants models of mental disorder in this research. Therefore I attempted to use a major aspect of the methodology used throughout this research and translate it into a way of navigating some of the thematic findings developed and
ultimately presented at this conference. The reception of the presentation was positive and one of the main issues I took away from the experience was that the design of the research methodology was robust, sound, and workable. This experience also caused me to reflect on the density of my findings in relation to the design of the research study itself, as I feel I was essentially trying to achieve two main goals in this research. First of all I tried to determine some of the issues psychiatric professionals considered important to the introduction of genetic testing, such as their thoughts on how the tests could alter services. However, the second ‘layer’ to this was to consider some of these issues with respect to participants contrasting models of mental disorders. Throughout the findings chapters there are many examples of both of these aspects working together, therefore there is a degree of congruence with respect to my findings in this regard. Essentially this falls back to different accounts of the tests on the basis of the models of mental disorder communicated by each participant and the finding that if the participant endorses the biological model, in almost every case, they consider different thematic aspects favourably. The fact that, in almost every instance, participants who rejected the biological model of mental disorder essentially held contrasting views about these issues is testament to adequate methodological design, research execution and ultimately the reliability of my findings.

Another aspect of this projects’ credibility relates to the as-close-as-possible illumination of the methodological techniques used as well as the narrative concerning this approach used throughout the research – this again refers back to the use of participants models of mental disorder to explore the issues relevant to the introduction of the tests. The fact that the initial observation concerning ‘what is mental disorder’, which prompted me to consider some of the fundamental ways that different psychiatric professionals consider issues in mental health care, was such a prominent feature throughout all aspects of this research, is evidence of the fact that this was a credible approach to use.

3.4.9 - Transferability.

With respect to transferability Shenton makes the following observation:

To allow transferability, they provide sufficient detail of the context of the fieldwork for a reader to be able to decide whether the prevailing environment is similar to another situation with which he or she is familiar and whether the findings can justifiably be applied to the other setting. (Shenton, 2004, p.63)

In this research project the main way this issue was satisfied is through the provision of enough background information with respect to exactly how the results were generated, in this case a significant part of this concerns an awareness of the contrasting models of mental disorder typically endorsed by different psychiatric professionals. The primary finding of this research is that, for the most part, participants models of mental disorder do influence their accounts of the tests – the trend being that if a participant endorses the biological model of mental disorder they would be more willing to see the test used, or they considered its implications more favourably than a participant who rejected the biological model. In this case I feel there is a degree of possible conflict as I do not feel there is any way to totally prove the following suggestion, but assuming that the make up of participants is reflective of the make of psychiatric professionals found on other locations in the United Kingdom, if the research was to be conducted again I think similar findings
would likely to be developed – or at the very least it would be possible to contrast my findings with observations in other settings.

Given that models of mental disorder are essentially universal in this regard, in as much as everyone will, in one way or another, have some form of internalised framework to make sense of mental disorder, then, providing the environment was similar, and similar participants were involved in the research, then my findings would be applicable in other settings. One reason I think that this would be the case is because it is possible to gain quite a detailed insight into these issues from my thematic findings in isolation. In all but one of the themes presented in the findings chapter there are examples where participants models of mental disorder clearly influence their thoughts and ideas about a particular theme. Therefore there are several ‘levels’ to each of the themes that can be considered. For example, the content of the themes itself – such as an aspect like the legitimacy of mental disorders – but there is an additional contextual level with regard to the contrasting views about this aspect in terms of the participants communicated model of mental disorder. The reason why my research goes some way to satisfying the issue of transferability is that the previously discussed pattern concerning participants views of the tests, which is dependent on their models of mental disorder, was observed in almost every theme. Therefore I think a significant aspect of the transferability of this projects findings will come from the actual detail of the findings themselves. I went to great lengths to ensure that the results chapters are an accurate portrayal the thematic aspects I developed – and the ‘art’ to this is to ensure that every theme is illustrated to the best of my abilities, as contextually ‘rich’ as possible but also considerate and sympathetic to the design of the research project itself.

3.4.10 - Dependability.

With regard to this criterion Shenton notes:

> In addressing the issue of reliability, the positivist employs techniques to show that, if the work were repeated, in the same context, with the same methods and with the same participants, similar results would be obtained. (Shenton, 2004, p.71)

In terms of the context of this research project I feel that being frank, honest and transparent about the process the data was generated is the best way to ensure dependability. Essentially the dependability of this research will rest on an adequate methodological description for this project to be completed again at a different time and a different place. I feel that this has been provided in the methodology section of this thesis, but there is an area where I feel it is difficult to totally replicate this research. Although, it is possible to give a breakdown of what I did right up until execution and transcription of the interviews, it would be very difficult to walk another person through the exact process after this point. For example, I point out exactly how I applied the thematic analysis to the data sets, but I can not categorically say that if another person was to conduct this research they would interact and ‘see’ the data in exactly the same way as me, therefore the chances are there may be some differences in the final themes. However, given the detail provided in the earlier chapters of this thesis another researcher should be able to follow what I did in order to mechanically repeat this project again.

3.4.11 - Conformability.

In the abstract of his paper Shenton mentions that:
Finally, to achieve confirmability, researchers must take steps to demonstrate that findings emerge from the data and not their own predispositions. (Shenton, 2004, p.63)

There are several instances where I addressed this issue in this research project. Perhaps the main aspect relates to my constant collaboration with my supervisory team at essentially all stages of the research process. Both of my supervisors have a great deal of experience in social science research, many more times than me, and they helped me design and conduct the research over the period of the PhD program. Part of this would often involve sitting down with both of them, sometimes one at a time and sometimes all three of us together, with my annotated interview transcripts or some of the notes I had made about an interview, and discussing my ideas pertaining to the development of the themes. Another way this issue has been illustrated in this research project relates to the way that the suggestions concerning ‘psychiatric legitimacy’ were integrated back into the sociological literature on the topic. I mentioned that ‘psychiatric legitimacy’ was, to begin with, simply a code I used to annotate sections of the interviews that featured this aspect. It was not until later on when I started to see the connections between different issues that I investigated the topic a little bit more and looked into some of the relevant literature. I feel that the aspects of this thematic observation align very well with what is written in the relevant sociological literature on the topic of legitimacy, therefore being able to make links like this suggests that although this main finding initially stemmed from my ‘reading’ of the interviews, it also has similarities and connections with the relevant sociological literature. As the theme of psychiatric legitimacy was one of the main findings of this research project this confirms it is a topic that is relevant to the wider sociological literature rather than my own preconceptions.

In addition to this I have to admit that when I embarked on this research project I may have been slightly blinkered with respect to the different conceptualisations of mental disorder that are possible for a psychiatric professional to adhere to. Ironically, this problem actually stems from my employment in a number of mental health care settings as a nursing assistant. Although it sounds rather naive looking back on it now, I never really gave any real thought as to why or how people develop or experience mental health problems, it is almost like I took it for granted or just accepted that people experienced these sorts of problems in their lives. So when my PhD mentor asked me “What is your definition of mental illness?” it was a question that really took me by surprise. Ultimately this point returns back to my methodological choices in this research – namely the inclusion of participants contrasting models of mental disorder as a method for navigating the issues relating to the introduction of psychiatric genetic testing. Having a methodology that allows for any possible approach to the topic of mental disorder greatly improves the chances of being sympatric to any approach people may consider – even ones that I may not be totally familiar with. Although there was quite a steep and detailed learning curve with respect to the theory and application of this approach I think that ultimately it befitted the research as it enabled me to provide thematic findings that placed a great deal of emphasis on the data, and the process it was developed, rather than my own preconceptions.
4.0 - Findings

My findings indicate that participants who communicate different models of mental disorder consider the implications of genetic testing in different ways. This is illustrated when examining contrasting accounts of the tests and considering them in light of the respondents’ communicated models of mental disorder. The overall indication is that interviewees who endorse a biologically oriented approach to mental disorder would be more willing to use the tests in their clinical practice, while those who reject a biologically oriented approach to mental disorder would be less willing to use the tests in their clinical practice. From analysis of contrasting accounts, one possible explanation for this is that the tests’ emphasis on the biological components of mental disorder either correlates or conflicts with the ways participants personally make sense of mental disorder and this influences their accounts of the developments. Although specific themes will focus more on contrasting models of mental disorder and how these influence respondents’ thoughts on the implications of genetic testing, I want to summarise this issue in isolation first. This will be achieved through examination of three participants who each communicate slightly different models of mental disorder and provide commentary on choosing to use the tests in their personal practice.

4.0.1 - Participant willing to use both tests in clinical practice

Participant 28, a consultant psychiatrist who works in an eating disorders setting, endorses a biological model of mental disorder alongside a selection of other models:

\[\text{Int : Can you tell me some of your thoughts on the causes for mental disorders?}\]

\[\text{Par: The causes for mental health disorders are multi factorial...like trauma, environmental factors, and there are also genetic causes of mental health disorders, such as we know there is a link in bipolar disorder and I’m aware of research that points towards a genetic predisposition if you have schizophrenia.}\]

Participant 28 claimed they would have no reservations about using either the diagnostic or treatment oriented tests in their personal clinical practice:

\[\text{Par : I would have absolutely no problems doing this. It makes my life easier; it makes the patient’s life easier. It reduces morbidity, it is time effective, cost effective.}\]

4.0.2 - Participant rejecting diagnostic test but endorsing pharmacogenomic test

Participant 20, a psychiatrist working on a rehabilitation and recovery unit has a very similar approach to participant 28 about the causes for mental disorders:

\[\text{Int: First of all can you tell me some of your thoughts on the causes for mental disorders?}\]

\[\text{Par: First of all I think it’s a really fascinating area and I don’t think there are hard answers either way at the moment. To me it makes sense that there is a combination of genetic susceptibility and then environmental influences as well.}\]

However, the participant would not be willing to use both of the tests in their clinical practice; the following quote shows they would be willing to use the pharmacogenomic test, but not the diagnostic technology:
Int: Then if I was to ask the question could you see using this in your clinical practice – the first test...

Par: No.

Int: What about the second test?

Par: Yes, absolutely and I would want more data. Yeah any drug has side effects, if it’s biologically active enough to have a beneficial effect, it’s got side effects as well. So you are weighing up that risk balance – so if you have something that tells you its unlikely to be positively effective, you have to question whether you are going to expose the patient to the risk of side effects.

4.0.3 – Participant rejecting both tests

The following quotes are from participant 12, a psychologist who works in a forensic mental health setting. Unlike the previous two examples this participant does not mention the role of genetics or biology, instead they focus on the role of an individual’s environment and their lived experiences:

Int: Can you tell me some of your thoughts on the causes for mental disorders?

Par: I think the main causes are kind of psychosocial, environmental factors – having crappy child hoods, growing up with racism and poverty, stress and trauma.

When asked if they would use either of the tests in their personal practice, the participant rejected both. Although the participant is intrigued by the prospect of pharmacogemonic testing, they suggest that the current progression of the science is not adequate for them to have confidence in this test:

Par: As they stand at the moment – the first one I wouldn’t. Just based on this information sheet I wouldn’t. There is something about this particular one (Psynome 2) ; I’m not sure about it because I can’t make it out one hundred percent...Yeah maybe five years down the line when a lot more work on how people metabolise, that’s what I would be interested in. And I’m not the one who doles out the pills, I’m the one who sits down and talks to people.

4.0.4 - Summary of participants’ communicated models of mental disorder

The difference between the first two accounts and the third is that participant 12 rejects the medical model as part of their personal approach to making sense of mental disorders, while both participant 28 and 20 endorse the medical model. This could be evidence why there is a difference in each participant’s claim about their willingness to use the tests in their own clinical practice. As suggested previously, the emphasis on genetics through virtue of using the tests corresponds or conflicts with the participants’ personal approach to making sense of mental disorder. As there is such a difference in all participants’ personal models of mental disorder, being able to summarise every individual account is impractical. However, there is a pattern in all the responses that can be summarised diagrammatically.

Only three outcomes were ever indicated throughout the 33 interviews. The participant would be happy to use both the tests in their clinical practice, the participant would not be willing to use the diagnostic test but would be willing to use the pharmacogenomic test, or the participant would not
be willing to use either test. These statements can be linked to their internalised ways of conceptualising mental disorders:

(Figure 4 – Diagrammatic representation of the participants’ communicated models of mental disorders and their respective thoughts on the technologies)

Participant 28 is represented by the ‘Would use both tests’ bubble, participant 20 is represented by the ‘Reject diagnostic test. Endorse pharmacogenomic test’ bubble, and participant 12 is represented by the ‘Reject both tests’ bubble. The issue is that the first two outcomes derive from the same antecedent – participants endorsing the medical model in their personal approach to conceptualising mental disorders. The final difference in choosing to use the tests is due to more than their communicated models of mental disorder. Their decision to use both the developments, or just one of them, comes down to features such as their thoughts on how the introduction of the tests may alter the treatment landscape, aspects of practice, or psychiatric services. For example, participant 20 and participant 28’s final accounts differ dramatically in overall content. Participant 28 discusses the practical benefits these developments could offer – these amount to improved economics and service efficiency. However, participant 20 does not mention these things anywhere throughout their interview.

This suggests that although participants may communicate the same models of mental disorder there are other aspects that contribute to them choosing to use the tests in their personal practice. However, given the methodological approach used to assess these features, the issue that appears to have a significant impact on this decision is their adherence or rejection of the medical/biological model. My suggestion being the tests’ biological modus operandi either conflicts or correlates with the way they personally conceptualise mental disorders.

Assessment of the participants’ communicated models of mental disorder is secondary to my primary research aim in this project - to explore the implications of genetic testing for mental disorders. What will follow is the collection of themes developed from my grounded-theory-inspired analysis of the interview data. In many cases there will be sections in each theme where examples from participants who communicate contrasting models of mental disorder will be presented to illustrate contrasting points. Although five themes were developed, there is not synergy between all of the participants concerning the issues that are going to be presented. Different accounts are due
to different views on the tests and the reasons for this are partly due to participants’ contrasting models of mental disorder.

4.1 - Theme 1 - Prioritisation of genetic explanations for the diagnosis and treatment of mental disorders

Participants made several suggestions concerning what could happen as a consequence of the tests’ presence implying a distinct genetic ‘object’ for the construction of mental disorders. Although some insights are concerned with the clinical setting, there are also suggestions that extend beyond this that have an impact on the overall status implications of different aspects in mental health care. These issues will be illustrated in the first part of the theme that looks at how genetic test developments may influence different aspects of the legitimacy of mental disorders.

4.1.1 - Legitimacy of mental disorders

Participants suggested genetic testing could make the diagnosis and treatment of mental disorders appear to be an increasingly scientific endeavour. Participants who communicated contrasting models of mental disorders arrived at the same conclusion regarding this idea and how it could influence the status of different disciplines and their traditionally recognised approaches in mental health care - the indication being that orienting around genetic explanations for mental disorders will mean that medical and biological approaches to their diagnosis and treatment are increasingly legitimised. A consequence of this will mean that the role of the medically-inclined psychiatric professional is legitimised in mental health care. These ideas are examined in the following interview extracts. The first statement comes from a psychiatrist who endorses the biological model of mental disorder, and the second comes from a psychologist who rejects the biological model of mental disorder. Both respondents are discussing what could happen as a consequence of introducing the tests in a clinical setting:

I think first of all it will bring a huge attitude change to psychiatry from other medical disciplines. They think we are not doctors and we just do what we want. So I think it will gather more respect for the psychiatric field itself. Patients will have more faith in us, as clinicians we will be more confident and the anti psychiatry movement will lose some of their ammo – saying it’s a pseudoscience and stuff like that. (Interview 16 – A Psychiatrist who endorses the biological model of mental disorders and works in an acute ward environment)

I’m sure it could do wonderful things for psychiatry. As I have been accused of being anti-psychiatry a lot in my time – I’m not sure that would be a good thing from my point of view. A lot of this for me is about strengthening the psychiatric position. By that I mean the stuff around rigid diagnostic criteria, that equalling a particular drug treatment and that firming up the belief it’s a genetically inherited biological disorder. And to me that thing is far too powerful and damages people’s lives anyway – and I think this could bolster that, and I think that would be a bad thing. (Interview 10 – A Psychologist who rejects the biological model of mental disorder and works in a rehabilitation environment)

Both participants are saying essentially the same thing about the consequences of the tests’ introduction, but they are both approaching the issue from two decidedly different theoretical standpoints. There is also a contrast in what each participant thinks will result from this – participant 16 appears to welcome the changes, while participant 10 is suspicious of them. However, the bigger
issue is that each participant mentions that the developments are going to benefit biologically-inclined psychiatrists and their role in mental health care. In the first quote, the psychiatrist is suggesting the tests could mean rather than diagnosing and treating mental disorders in the traditional way, which the participant acknowledges is criticised by various groups, being able to utilise these developments will mean that psychiatric approaches to mental health care will no longer suffer from these issues. There will be an empirical evidence basis for psychiatric approaches in mental health care. In addition to this the participant mentions that both patients and clinical staff will have more confidence in receiving or providing treatment because of these developments. Although the quote from the psychologist is quite a lot different in terms of its overall feel – as the participant is critical of these developments – essentially the same conclusion is still reached. The participant suggests these developments are going to benefit predominantly psychiatric approaches to mental health care, despite their personal problems with the tests.

4.1.2 - Models and their influence on the legitimacy of mental disorders

These contrasting accounts are examples of different models of mental disorder influencing participants’ thoughts on the introduction of genetic testing. These were established at the start of the interview by asking the respondent to comment on their ideas about the causes and treatments of mental disorders. The psychiatrist began their interview by saying:

*Basically, there are, the idea of causes at different levels – multi-factorial basically. So, genetics will be the first thing that I think about, then the psychosocial factors which will, then environmental factors which might include drugs, or the living conditions.* (Interview 16)

The first aspect the psychiatrist mentions in isolation is an individual’s genetics - this signifies adherence to the biological/medical model of mental disorders. However, it is important to note that this is only one of the models this participant adheres to, along with a selection of others. As mentioned at the start of the Findings chapter, the issue is adherence to this model – rather than focusing on it in isolation. The clinical psychologist began their interview by saying:

*I mostly see mental disorder as being caused by experiences of powerlessness. That can kind of be on the individual level, so that’s kind of abuse – physical, sexual, emotional abuse - and on a more general social level – things around poverty, disenfranchisement, being in the minority, being powerless within society.* (Interview 10)

The psychologist elaborated on their thoughts on how to effectively treat mental disorders:

*How you see the problem is a very individual thing, as a psychologist I tend to see people’s problems as repressed feelings – often to do with trauma and powerlessness. I think of getting to the root of the problem is getting in touch with anger and thinking about how to express anger electively, or getting in touch with grieving and loss and expressing that and feeling like its okay to be sad.* (Interview 10)

In terms of adherence to or rejection of the biological model of mental disorder, the issue here is that the psychologist never mentioned that they personally make sense of mental disorders in this way at any point during their interview. In contrast to this, the psychiatrist commented on their thoughts about the causes for bipolar disorder, saying:
Yeah I think bipolar has a very good genetic association. Many twin studies have confirmed that, if I’m not wrong. (Interview 19 – A Psychiatrist who endorses the biological model of mental disorder, participant works in a forensic mental health setting.)

The psychiatrist’s statements endorse the biological model of mental disorders. While the psychologist’s internal model of mental disorders appear to be a combination of available models. There are references to the ‘social realist model’ of mental disorders, but there are also aspects of the ‘psychological model’ creeping into their account too.

The contrast between these accounts is the psychiatrist endorses the biological model, while the psychologist does not. In terms of being able to differentiate participants’ thoughts on genetic testing in light of their communicated models of mental disorder, this is the only discernable difference that accounts for this disparity given the design of this research. Although both participants are almost suggesting the same thing about the introduction of the technology, the psychologist is considering the developments in terms of the potential damage that can result from biological intervention in mental health care, while still acknowledging that biologically-inclined psychiatrists are likely to benefit from this because of the implications for their disciplinary status. The psychiatrist does not appear to hold these sorts of views and does not consider the tests in this way – it is almost as if the psychiatrist is using the tests as a way to counter some of the criticisms their profession receive. Ultimately, both participants acknowledge the tests could be used to provide psychiatry with the tools to make it a ‘scientific’ area of medicine now a biological determinant is being introduced. This was a common theme throughout the whole series of interviews. In each of the following examples the participants suggest introduction of the technology will imply the care for individuals who experience mental disorders is going to be increasingly considered as a biological phenomenon. The ‘object’ of mental disorder is going to be portrayed in terms of genetics and people are likely to interact with the phenomena in these ways. This first quote is from a psychologist:

_Int: Do you think the introduction of these technologies could alter the way the public think about psychiatry?

_Par: The introduction of these technologies implies some success in these technologies okay, so if there is some success marketed for these technologies then it proves that this is all medical and biological – so therefore it’s power to the psychiatrist’s elbow. (Interview 12 – a Psychologist who rejects the biological model of mental disorder, works in a forensic mental health setting.)

In this next quote the participant states right at the start of the interview that they are working within a predetermined framework provided by the ward where they are employed. However, they still conclude that the tests’ default genetic stance will offer substantial benefit to overall practice as it will provide an additional evidence basis to make diagnoses and to provide treatments:

...over the last two years I have been working with a theoretical orientation that makes it clear to everyone that the best indication we have is that anorexia has a genetic element to it, a vulnerability. So I’m not practised as a clinician expressing the view that anorexia seems likely to have a genetic basis as well as a sociographic basis. If I had ten psychiatrists and they were telling me that we are having problems with diagnosis – we are being too general
or we don’t know the wood from the trees and it’s a real issue and actually having a test to confirm these down here would be helpful – I’d be interested by that, and in that situation it could help confirm it would give a different evidence base to confirm a clinical picture that would increase. (Interview 33 – a psychologist who, through the prescribed approach of their place of work, endorses the view that mental disorders have, in part, biological components.)

The following quote is from a psychiatrist who works in a forensic mental health setting. Here the participant acknowledges the tests could act in a capacity that increases other medical disciplines’ faith in the ways mental disorders are typically dealt with in psychiatry, as well as the role of the psychiatrist themselves. However, there is also commentary relating to the respondent’s thoughts on the additional factors that cause and maintain a mental disorder – in this example the affected individual’s lived experiences:

Par: Its interesting psychiatry for a long time has been shunned by the rest of medicine – so they have always considered us not to be very scientific perhaps. And perhaps genetic testing will bring us closer back into the bosom of the physicians and the surgeons because we will have ‘proper’ things to tell, but I think the art in psychiatry is about being able to explore with a person what their experiences are because its not just about what they experience there and then, its about how they have come to that point in their life and where they would like to go from there on. (Interview 18 – Psychiatrist who endorses an eclectic range of models of mental disorder, including biological, social and psychological approaches.)

Like all of the previous examples, here the participant acknowledges that the developments being made in the field have the potential to make the diagnosis and treatment of mental disorders appear more scientific, but for them personally this does not make any difference due to they way they make sense of mental disorder. Although the participant mentions the developments offer the potential to make psychiatry align with other areas of medicine that also use empirical evidence to diagnose and treat, they note that one of the unique and empowering things about psychiatry is the distinct lack of such an approach – there is a certain benefit from being able to share in patients’ experiences in this manner.

Although the two accounts are very different in their overall feel, this quote has a major similarity with the first from the psychologist (Interview 10) featured at the start of this section. This similarity being that the participants are aware the developments will benefit a certain demographic of psychiatric professionals, but not necessarily themselves. In both of these examples the participants make sense of mental disorder in ways that do not necessarily depend on biological understandings.

This finding concerning the legitimacy of different aspects of mental disorder will be examined in the final chapter of this thesis. Although elements of this will creep through the rest of the thematic findings, there are two main issues to keep in mind. First of all, respondents regardless of their communicated models of mental disorder arrived at essentially the same conclusion regarding the tests’ introduction – that the ‘object’ of mental disorder is going to be constructed in terms of genetics. This observation has importance due to the emphasis that was placed in the Literature Review chapter on mental disorder being an ontologically difficult concept. Following on from this, the theme of legitimacy in mental health care will also have implications in relation to several broader issues, such as the role of the psychiatrist, public understanding of mental disorder, and patient confidence in care. However, although I will focus on these issues specifically, the interview
participants made a selection of other suggestions concerning the tests’ introduction having an impact on legitimacy in mental health care.

4.1.3 - Legal issues regarding the legitimacy of mental disorders

In keeping with the theme of prioritising genetic explanations for the diagnosis and treatment of mental disorders, participants made a series of suggestions relating to how the Psynomics tests could be used in legal and insurance settings. Interviewees suggested the tests results could be used as extra evidence that a patient remains in hospital and is treated, essentially ‘proving’ that a patient has a mental disorder. This was discussed by a psychiatrist who works on an acute admissions ward:

\begin{quote}
Int: Often you have quite a lot to do with lawyers?

Par: Yes quite often you are admitting someone against their wishes – on a Section 2 or 3. They have the right to appeal against their section so they have this mental health review tribunal. And a judge will be there, a lay person not related to the hospital. A doctor will be there. So we have to prove to them that we think he has a psychiatric diagnosis, he can be a risk to himself or others – so that will be the reason why we want him in hospital. And some lawyers can really fight tooth and nail against it even if they know the patient is a risk to themselves and others, they can really fight you hard.

Int: So this could be an ace in the hole?

Par: In a situation like this if we know pretty sure this chap has a problem and he can be a risk to himself or others and then the test is coming as positive – probably he does have it, that can be useful tool I guess yeah. (Interview 16 – A Psychiatrist who endorses the biological model of mental disorders and works in an acute ward environment)
\end{quote}

Rather than focusing on a Mental Health Act Section, the following example focuses on using the tests in a legal situation where an individual is in court because they committed a crime. This quote is from a psychiatric nurse who works in a rehabilitation and recovery setting:

\begin{quote}
Par: I suppose maybe if I was a solicitor and I had some sort of person I was representing who was experiencing some sort of mental health problem...you could buy this test and say that my client has a raised GRK3 variant and it might impress the jury. (Interview 13 – Qualified Nurse who work in a rehabilitation setting, participant claims that mental disorders are mult-factorial, however, no explicit mention of biological components in their account.)
\end{quote}

Participants spent time discussing a number of additional situations whereby the introduction of a biological determinate for the diagnosis and treatment of mental disorders will impact on the field. Although there may be associated consequences for the legitimacy of different features within psychiatry, the following part of this theme moves away from this issue in the ways examined so far and reflects participants’ ideas on what these developments could do for practical aspects in mental health care.

4.1.4 - Streamlining different areas of practice

The term ‘streamlining’ comes from my original notation of the interview transcripts. Originally this started out as my way of saying that the tests have the potential to economise, speed up, or
somehow make more efficient an area of mental health care. In the following themes there are instances where all of these apply, but for the purposes of this project I have chosen to consider and name them all as ‘streamlining’ different aspects of practice. Participants discussed a triad of ideas when considering how genetic testing for mental disorders has the potential to streamline different areas of practice. These were the reduction of the amount of trial and error typical of prescribing psychiatric medication, the introduction of additional therapies once a patient is stable on medication, and the resource-saving that could result from this. As discussed below, the participant mentions that a pharmacogenomic test could be a useful tool to reduce the amount of trial and error involved when finding the correct combination or dosage of psychiatric medication for an individual presenting with a mental disorder:

Par: My interest in genetic testing is how people respond to medications. So if you have to look about gene expression and how that influences neurotransmitters and those kinds of things I think that will be very valuable...it’s not always an easy task to marry up whether people will benefit from it (medication) because you probably wouldn’t know until four to six weeks later. And whether they would find it intolerable and therefore would have to discontinue it, so if my means of saying well you have these particular genes, which probably will relate in some way to the underlying disorder, you’re likely to respond to this particular medication group. That would probably be quite interesting to have as an extra tool. Because I guess at the moment if you have depression I will offer you all these anti-depressants as part of your treatment – I have very little view on which one will be better or worse, because I don’t know how they will respond to you, so will give you the choice. And if you’re fortunate they will work in four to six weeks and you will get a good response and you will feel better. But after four weeks if it doesn’t work we will have to go through the whole process again and another month later it might still not be the right one for you, then we might have to consider a third choice or a combination. Things delay and you’re struggling and you’re having a lot of difficulties so I guess if there is, through understanding genes, and if that could ever be translated in how people might respond to medication groups, then that might shorten that period of time, and hence people’s period of being unwell will be shortened and ultimately that will be a good thing. (Interview 18 – Psychiatrist who endorses an eclectic range of models of mental disorder, including biological, social and psychological approaches.)

This participant discussed the length of time it can take to get patients stable on the correct medication – this quote discussed the possibility of having three ‘trial medication’ cycles each lasting between four and six weeks. In this case the developments in genetic testing could help reduce this time period, potentially eliminating it completely, because there will be an indication of how patients will respond to the medication prior to taking any. Other participants hinted at instances where a patient had been in hospital for considerably longer than this six-week timeframe and were still not receiving any therapeutic benefit from their medication. This following quote extends upon the previous example and reflects the participant’s thoughts on using the test on a patient who is already involved in psychiatric care. This participant works in a specialist unit where people who have enduring chronic mental health problems are admitted for rehabilitation, and they reason that a pharmacogenomic test could be used as a tool to get patients on the correct medication regime, who, over a long period of time have yet to find the dosage or combination that is optimal for them:
Par: Thinking now about testing and people we work with, there are people who have tried all sorts of medications with very little response, and I’m guessing that would be really valuable. The more I think about it the more beneficial I think it could be, I can think of individuals who go through a whole host of medication changes for six, nine, twelve months and there is no therapeutic benefit. And unless you can get their medication right, and the balance right, nothing else can fall into place. (Interview 1 – qualified Nurse who works on a rehabilitation and recovery unit, participant predominantly endorses the idea that a person's environment contributes to their mental health, however, also to a lesser extent also endorses the biological model.)

This quote introduces the second aspect of the triad. When treating psychiatric disorders, for the most part the first component dealt with is getting the patient stable on medication and after this, alternative treatment can be introduced, such as providing the patient with psychological therapies or counselling. Participants pointed out that there is a significantly improved chance of patients engaging with additional treatments if they are first stable on medication. A psychiatrist, when discussing the possible benefits of associating genotypes with medication response, said:

Par: I think well, I will divide it into two groups - one is from a patient perspective and one is from a service perspective. Often I find in fact that a person’s motivation and willingness to engage with other parts of treatment follows with the pharmacological intervention – the faster you can get into that phase as well, again, that will support the facilitation of discharge…From a patient’s perspective, where would you rather be? Working with a structure to your day and earning a decent amount of money – or being on benefits? Again it’s all about recovery - don’t get me wrong, I know there are several people who want to take on the patient role and want to be in hospital, but in majority, people want to recover and live a fulfilled life. Looking at those broad aspects it’s a win-win situation. (Interview 17 – A Psychiatrist who is based in a forensic mental health setting, participant strongly endorses the biological model of mental disorders.)

From this suggestion, there is an additional component to consider – that patients will ultimately benefit from this development because they will recover sooner. This is another area where participants who communicated contrasting models of mental disorder arrived at similar conclusions about the tests. For example, participants who specialise in specific therapy with patients, such as the psychologists, the occupational therapists, and the drama therapist all mentioned there are times when they need a patient to be stabilised on medication before they can engage with them. These participants predominantly rejected the biological model of mental disorder in their personal practice, yet they still rely on the benefits this approach provides. This is illustrated in the following quote from a drama therapist:

Par: As far as physiological, as far as pharmaceutical treatment is concerned, I have a lot of ambivalence about that. On one level, I have to own, one of the reasons I can work with people in the recovery and independent living services is that they are on medication. If they weren’t, people would often be in a very florid psychotic state, and I wouldn’t be able to work with them – so I have to own that. On the other hand it’s very clear to me that medication represses feeling, so in a sense, there is a dilemma there. I want to work with people in relation to the feeling material that has been repressed since childhood and when I’m
meeting them they have been given medication to help keep them from that feeling material. (Interview 27 – drama-therapist who is based in a rehabilitation setting, personally rejects the biological model of mental disorder, but understands the importance of this approach in general.)

The final part of the triad is related to the potential resource-saving that could result from using the technologies. According to the psychiatrist in interview 17 this is referred to as ‘patient flow’ and this may increase as a result of stabilising a patient on medication through using the tests - the patient is more susceptible to additional therapies and their time spent in hospital is potentially reduced so they can be discharged quicker. Their response discusses the two main parameters involved with patient flow (frequency and length of admission) and suggests these technologies could save the NHS money in the long term:

From a service perspective, especially in today’s economic climate, what’s really important is something called patient flow – how long they are admitted for. Two parameters to look at here is the frequency of admissions and the more important thing, the duration of admissions. The quicker you can identify the right medication for the right person and treat it accordingly, the quicker they are discharged. Remember this is only one part of treatment, from my point of view at least, in terms of medication. Either way it will support the process of facilitating a faster discharge, I’m not saying discharge someone unsafely into the community, but I’m saying you might get a faster response. From a service and NHS perspective – wow – you could save millions. I mean it’s a huge impact in health services in general. (Interview 17 – A Psychiatrist who is based in a forensic mental health setting, participant strongly endorses the biological model of mental disorders.)

Although this streamlining triad was a common theme acknowledged in some way by the majority of participants included in this research, not everyone interviewed considered the developments to be as beneficial as the previous examples suggest. This is reflected in the following quote from a nurse consultant:

Int: If these technologies ever were to be introduced into the NHS in any way, how do you think it might alter current practices?

Par: I should imagine it would alter hugely! I think people would only get a service if people had a definitive diagnosis, it would be like a little production line really. You would come in and have your saliva taken and it’s almost as if well, you know. If I came along to get that done, I’ve got some presenting issues, whether or not it’s bipolar, there is something that’s not right – that’s taken me to my GP whose done a referral and I get a letter and its says come along to the clinic and we want to do this test, so I go along and have that done, and it would seem to me that if I had a negative result you’re out of the door. But hey, I still feel how I feel. So what are you going to do for me? How are you going to help? Well we’re not going to do that because you don’t fulfil these criteria. (Interview 2 – Nurse Consultant based in an acute setting, holds a range of models of mental disorder including biological, psychological and social approaches.)

Here the respondent is concerned about what could happen as a consequence of prioritising the role of genetic explanations for mental disorders in favour of any other, a significant part of this account
being their reference to a ‘production line’. Although this is not something mentioned explicitly in the previous examples regarding patient discharge as soon as possible, I feel there are similarities between both statements, but the example above is a more extreme account of the previous. Both sets of quotes focus on the same issue, but there is a clear difference in the extent that the participants think the introduction of genetic testing could change services.

It is here where responses can be compared and contrasted in relation to contrasting models of mental disorder. This following example will focus on two participants (a nurse consultant and a consultant psychiatrist) in isolation, and although the suggestions are representative of the study cohort in terms of model allegiance and opinions on the tests, they are interesting anomalies because they both made references to colours in their interviews.

At the start of the interview each participant is asked about their thoughts on the causes as well as the most effective treatments for mental disorders, in order to establish their communicated models of mental disorder. The nurse consultant starts off by giving quite a common account – that mental disorders are a combination of a genetic predisposition and some sort of environmental trauma, such as sexual abuse or the death of a loved one. Participants were asked if they could comment on the ways that these two components interact and if there was any way they could be separated. This is what the nurse consultant had to say:

*Int: Do you separate those ideas from genetic arguments? Or are they separated at all...*

*Par: I don’t think I do separate them particularly. If I’m honest, when I meet somebody it’s more based on my relationship with them, instead of thinking if it’s going to be this or it’s going to be that – it is what it is, really. And when working with someone, it’s looking at them to identify what they think the issues are, in a way it’s irrelevant what I think in terms of what the origin is...* (Interview 2)

In this account, the participant suggests that when they meet a patient a significant issue concerning how they engage with them will be their personal relationship with them, rather than identifying the specific origin of what caused them to experience a mental disorder. This is contrasted in the following account from a consultant psychiatrist:

*Par: Well there is a whole gambit of treating options we have in mental health. It all depends on how one is trained and how I was trained was to see mental health as a biopsychosocial event and one has to see the person in the context of either the family or the society or the community – and see what environmental factors impinge on the way they present. The first port of call is not medication, is it usually supportive or psychological interventions depending on the presenting symptoms. Besides the psychosocial support, there is of course then the medication aspect of it and that could be, some people believe in homeopathic, others believe in other organic compounds that they wish to take, and then obviously there is the hard core pharmaceutical interventions. There is ECT as well, which we use and is very effective. And these can be done on an outpatient or an inpatient and can be formal or informal admissions. (Interview 28 – Consultant Psychiatrist working in an eating disorder clinic, participant adheres to the ‘bio-psycho-social’ models of mental disorder.)*
At this point there is really nothing that significant when these contrasting accounts are observed in isolation. However, later on in the interviews both participants elaborated on these aspects in quite a unique way and this represents perhaps the most distinct insight into the respondents’ models of mental disorder and their thoughts on the introduction of genetic testing from the whole interview series. This relates to each participant referring to psychiatry as being ‘grey’. The nurse consultant is suggesting that it is hard to make concrete ‘yes or no’ decisions in psychiatry because the care for people with mental disorders is not ‘black and white’, as there are too many variables to consider. However, quite the opposite account is being offered by the consultant psychiatrist, who is suggesting that the tests could be used to separate out the black and white in order to remove the greyness often encountered in psychiatry. This is what the nurse consultant had to say:

Par: So you have an individual and they present with a range of symptoms and there is some lack of clarity regarding their diagnosis - which there often is, you only need to look in a set of health records, you know people can have five or six different diagnoses. And by the sixth if they haven’t responded to this medication then they have a personality disorder. I’ve seen it hundreds of times. If an individual needs some clarity on what their diagnosis is, and you know, they’ve had five or six and they’re not sure and they’ve been given support and they understand the implications – that’s one thing. It’s about them having an informed choice – the capacity to make the decision. What I wouldn’t want is that everybody has this test, that would be the difficulty for me. That makes it very complicated, it makes it very grey. But I think psychiatry is grey, I don’t think it’s black and white and it never has been. Probably in my lifetime it won’t be, perhaps in years to come it will be much more black and white than that. Even if it’s something about someone who has been in the system for years, they’ve now managed to get themselves a diagnosis of borderline personality disorders and they believe they’ve got bipolar, they take the test and they haven’t got it. There is the kind of repercussions for them as individuals as well, really. It’s about seeing people as just their genes rather than them as a whole, that what I worry. Like the medical model now tends to kind of be, like, reductionist – rather than them as social beings who have to relate to families. (Interview 2)

The above quote focuses on the options that are available to both patients and staff with regard to the treatment and diagnosis of mental disorders. However, the participant is suggesting that it is not as easy as making decisions on the basis of a genetic complement, because there are many additional components to take into account when dealing with patients. Essentially the opposite account is offered by the consultant psychiatrist. Here the participant is suggesting that the tests could offer an answer to the greyness that is found in psychiatry with respect to the options available to patients and staff:

Par: It could revolutionise the practice of psychiatry. The reason I say that is because since I’ve been practicing as a consultant and I’ve had the opportunity to see my colleagues work with similar clients but in a different way, and the kind of fluffiness or greyness that purveys psychiatry, it would be helpful to have definitive outcomes not only for the treating physicians and the medical teams, but for the patients themselves...So I think in order to crystallise a diagnosis it would be really helpful to address the greyness one gets in psychiatry, which is very prevalent – especially in the way psychiatry is practised some times. (Interview 28)
What really puts these contrasts into perspective are the participants’ answers to one of the last interview questions that asks if they would be willing to use these tests in their own clinical practice. The consultant psychiatrist replied:

Par: I would have absolutely no problems doing this. It makes my life easier; it makes the patient’s life easier. It reduces morbidity, it is time effective, cost effective. If this is what it says on the label, it can only be good. (Interview 28)

While at the end of the nurse consultant’s interview the following statement is provided:

Par:...If you then could have the perfect treatment – but we haven’t got the perfect treatment. So if you could guarantee and you had your genes tested and it was guaranteed then – so it wasn’t dependent on other genes - but it was an absolute guarantee. And then you could equally guarantee this treatment would stabilise you, that’s one thing. I can never see us reaching that, in that case I can’t see the benefit of it. It doesn’t take into account any variables, does it? It doesn’t take into account the relationship you have with your mother, if you don’t have a job. A bit like what you said about testing for suicide, that’s not looking at any of the psychosocial stressors, that’s just thinking, purely in terms of there is some deficit or excess of something, we will find out what it is, we will do something, and it’s fine. (Interview 2)

This investigation into these accounts provides quite a detailed insight into the ways that individuals who communicate two contrasting ideas about mental disorders consider the implications of genetic testing. However, the interesting aspect is that it was not the assessment of the participants’ models at the start of the interview that necessarily determined this; it was their reference to different colours later on – as both participants mentioned that psychiatry is ‘grey’. I interpret this to mean that making decisions in psychiatry is sometimes difficult; it is tough to provide ‘yes’ or ‘no’ answers to practical questions – that are tantamount to ‘black’ and ‘white’ decisions. The real contrast comes about when the participants’ accounts of the tests are considered. The nurse consultant suggests the tests are currently inadequate to resolve the greyness, because there is much more to mental disorder than genetics – such as personal relationships. The psychiatrist appears to endorse the converse idea, that the tests could resolve the greyness, making several aspect of their personal practice easier.

This observation relates back to Figure 4 in the last section of this discussion. Although rejection/endorsement of the biological model of mental disorder is an important aspect in the participants’ accounts of the Psynomics tests, there are additional features that play a part in this as well. However, it is difficult to resolve this issue much further than this. For example, although contrasting models of mental disorder have a clear implication on the respondents’ accounts of genetic testing in mental health care; it is also important to consider the observation that these models will also be related to other ideas concerning the tests’ introduction. In this case, difference aspects of mental health care being ‘grey’.

When considering the theme of what can happen as a consequence of prioritising the role of genetic explanations for mental disorder, several participants discussed an issue that was completely unanticipated when designing the project and in examining previously conducted research. This is
what the possible influence of the developments being made in genetic testing for mental disorders may have for the DSM.

4.1.5 – Participants’ commentary relating to the DSM

A small number of interviews discussed the DSM and alluded to the potential influence the Psynomics developments could have alongside it. Participants were quite cautious when considering the role of genetic testing in tandem with the established criteria used to make a psychiatric diagnosis and, for the most part, participants suggested testing could be used alongside current methodologies. Participants who did not endorse the biological model of mental disorder were more critical of the DSM and its potential relationship with genetic testing than participants who endorsed the biological model. This is seen in the following quote from a clinical psychologist:

Par: I try not to think about the DSM in any form because I find it makes me angry, but again, what’s the point? We are all at risk now (Participant picks up the Psynomics information pack and shakes it a little bit closer to my face). So actually is this a really good exercise in normalising it? Its just rubbish, it’s a way of expanding the categories and giving people more pills and more diagnosis to keep the system working the way it is now. It’s like the psychopath thing. How do you know someone is a psychopath? Because they fulfil the criteria that diagnoses them as a psychopath! Then it is socially constructed...But just because it’s a social construction doesn’t mean for each individual and their individual experience of what it is, what comes in this umbrella term, doesn't require or invite intervention. (Interview 12 – Psychologist who rejects the biological model of mental disorder.)

Carrying on from this, ideas very similar to those discussed above featured in another interview with a clinical psychologist. When considering the existing DSM workings, this quote suggests that the whole approach is fundamentally flawed as it is not sensitive enough to cater for an individual’s highly specific needs – the participant giving an example of a friend who gets on very well with a medication that would not normally be prescribed in light of their particular psychiatric diagnosis. In the second part of the quote the participant begins to discuss their thoughts on what the possible introduction of an ‘at risk’ category could do for mental health care:

Int: All it’s doing is adding more weight to a DSM diagnosis...

Par: And why do we need that? As far as I understand it from my many conversations with doctors about this, there is something about linking specific medications to specific diagnosis – and saying if you have this then you need that. But I also know from my clinical experience, individual drugs affect individuals so massively different – I have a friend who takes olanzapine because he has a bipolar diagnosis and for him it’s a wonder drug. It’s not what you would be automatically prescribed, but it works for him. So to me it’s about working out individual drug strategies, I don’t think you can have these big diagnostic X = Y approaches.

Int: What are your views on the DSM possibly having an ‘at risk’ category in it?

Par: (Laughter) Oh my God! I think it’s so dangerous, one of my real issues with diagnostic labelling, other than how unreliable it is, is around the power to define people. I’m very interested in social constructivism, very interested in narrative therapy that goes along with
that – which is all about how powerful others define us. Once we have been given that story, we live that particular story out. So if you give someone the story as a child that they are at risk of bipolar disorder, all of their behaviours will be seen through that lens. What we are going to do is create a generation of people who have these disorders they are at risk from, by telling them they are at risk of it. And by starting to see them in that way - by constructing them in that way. (Interview 10 – Psychologist who rejects the biological model of mental disorder.)

For these participants the DSM is clearly a contentious issue. Both respondents are concerned over the power it has to define an individual and frame their lives in terms of the individual being ‘ill’ or ‘at risk’. The participants also allude to the process that various DSM diagnostic categories are socially constructed and they both appear critical of this move, with the indication being, regardless of how a mental disorder is typically defined, an individual’s experience of it is very real, but these two scenarios do not necessarily correspond with one another. In both accounts, there are allusions towards the DSM operating as a device that enables biologically-inclined practitioners to use medical intervention rather than any other. Taken to an extreme, this ignores any other alternative approach and prioritises the role of biological intervention in mental health care.

Later on in each of the interviews I asked these participants to comment on the scenario of whether genetic evidence would ever be included in a future DSM revision. Both participants had remarkably similar thoughts and opinions on these issues. Essentially they were both extremely critical of this move and there are echoes of their previous statements in these accounts. For example, the participants point out there is going to be too much emphasis placed on the biological components of mental disorders and these will strengthen the psychiatric position. However, additional criticisms were also offered, the following is from one of these psychologists in isolation:

Par: I would have so many issues with this sort of stuff being included in the DSM, where to begin? I mean to start with, it’s further evidence that mental illness is biological, and I guess that including this in the DSM would be the most extreme form of ‘go ahead’ possible. But another problem I would have is that a strong element in the way we talk about mental disorders is simply down to the way they are defined – so essentially we are trying to find biological markers for mental health issues that never really ‘existed’ in the first place, not in the way I think all of this stuff is trying to go. It’s almost as if doing this will prove that mental disorder are real…

Int: Can you explain how this relates to your thoughts on the causes of mental disorders?

Par: Well I see mental health to be problems in living more than anything else. I’m not denying that this isn’t real – it is very real indeed, because the experiences people have are hard to refute, but what we are talking about here is so much emphasis on a biological cause. And to me that just makes me feel very uneasy because I think sorting out the lived experience issues is the thing to do here. Not say that you have this gene and we are going to give you this medication. That is way too powerful to my mind and not even an accurate account of the problem. Sure, it might be part of it, but placing this much emphasis on it? No thanks. But it will also fall back to the things we were talking about earlier regarding psychiatric approaches being promoted. This, again, makes me a little nervous because this will essentially be ignoring a complete evidence basis, the one that I operate from. So I would
be very concerned if this sort of approach became completely prioritised in mental health care. (Interview 12 – Psychologist who rejects the biological model of mental disorder.)

Another contrast can be made at this point about the participants’ suggestions and their communicated models of mental disorder. In the aforementioned account the participant clearly rejects the biological model of mental disorder and is also critical of the DSM and its standing in mental health care. In the following account, from a psychiatrist who endorses the biological model of mental disorder, the respondent almost starts off on a similar idea – by noting that the DSM or the ICD should not be considered a ‘gold standard’ when making a diagnosis. However, when the participant starts to talk about the role of genetic testing, they claim that providing the test is reliable, it should replace everything currently used in this endeavour:

Int: What do you think using genetic information as an aid to the diagnosis of a mental disorder could do for practicing psychiatry – because up to this point there is nothing...

Par: No there’s not, you’re right, I think. Remember that the DSM and ICD are essentially classificatory systems. That’s all they are, they do not, under any circumstances say that they are the be all and end all in terms of the person must fit into this particular category. There is rarely the ideal diagnostic patient in terms of filtering in virtually every criteria – and I think that’s where the clinician’s experience comes into effect. In terms of incorporating that information, it could prove to be difficult. The reason being that what this classification system does is provide a guide as to what one needs to consider when establishing a diagnosis. Now I appreciate that this is essentially a diagnostic test - be mindful of that - what it should do is obviously provide the clinician some degree of flexibility. Because as you said yourself no test is 100%. And I think if it’s a 100% then yes that should replace everything, the ICD 10 and the DSM 4! (Interview 17 – Psychiatrist who strongly endorses the biological model of mental disorder.)

This has similarities to the previous ‘colours’ discussion as the respondent is discussing the test in a capacity whereby its presence eclipses currently established procedures and methodology in psychiatry. However, both of these examples concerning genetic testing and its potential influence on the DSM are quite extreme – in each example the participant suggests that it should not be adopted into practice or the developments should be at the forefront of diagnosis. However, there were also suggestions offered by participants that represented somewhat of a middle road between the two previous extremes, such as the following quote from a ward manager of a rehabilitation and recovery unit. Here the participant is extremely weary of using a test result in isolation from any other available clinical evidence, unlike the suggestion offered from the psychiatrist. Instead the respondent points out that the tests could be used alongside what is traditionally used to make a psychiatric diagnosis to get a better understanding of what the patient is really experiencing:

Int: Can you tell me some of your initial thoughts on being introduced to these developments please?

Par: I guess slightly horrified. And that’s my initial reaction. We are going to be testing, we are using a standardised test for people, and that for me, carries concerns about misdiagnosis labelling – it’s all of those areas. And whether it would be sensitive enough to an individual’s story, and to the wealth of information that the individual invariably carries
with them for a long time. I felt I was more comfortable about using it to confirm a DSM diagnosis, as opposed to the earlier stages. I would have grave concerns if it was used in isolation or there are some psychiatric symptoms, but not enough to lead people to seriously consider whether bipolar was a consideration. But to support a DSM diagnosis, I think that could be quite useful. (Interview 7 – Ward manager of a rehabilitation and recovery unit, participant does endorse the medical model in their personal approach to mental disorders, but not to the exclusion of a selection of other approaches, such as trauma and environmental stress.)

Here the participant is pointing out that the developments in genetic testing could be used to support a DSM diagnosis. Although they express clear concerns over what could happen if the role of genetics was completely prioritised, like the above quotes from the psychologists, they reason the tests could prove useful if used alongside other available techniques. One difference between these accounts, which would appear to be related to their communicated models of mental disorder, is the degree that the participant considered the implications of these developments in terms of how they could alter the current clinical landscape. For example, from the small number of participants who discussed the DSM, the participants who rejected the biological model of mental disorder were highly suspicious of the idea and did not consider the implications alongside any other available technique, alluding to a system of mental health care not too dissimilar to the ‘production line’ suggestions made earlier in this theme. However, in contrast to this observation, participants who endorsed a biological approach to mental disorders would be more willing to see the tests used in this capacity.

The final component section of this theme will pick up from this part of the discussion. Although it will not focus on the role of the DSM as much, there is still an emphasis on using the result of a test to aid in the ways mental disorders are conceptualised. In this case how the tests could be used in a situation where there is debate regarding exactly what mental disorder a patient is presenting with.

4.1.6 - Resolution of diagnostic uncertainties and the prescription of appropriate medication

Some participants suggested the tests could be used as a tool that can resolve certain diagnostic uncertainties. In this case the participants mentioned that when patients present with certain mental disorders it is sometimes difficult to accurately determine their exact diagnosis because some psychiatric presentations share similar characteristics. This issue will relate to the observation that introduction of the tests is bringing in a new evidence base for making a diagnosis that can be used in conjunction with traditional approaches in order to differentiate between complicated presentations. For the time being this can only be considered in terms of the available technologies, so there are a range of mental disorders this currently will not apply to. However, the Psynome1 test was considered sufficient in being able to help clinicians because the test aids in the diagnosis of bipolar disorder, and respondents explained that this can often share characteristics with a number of other mental disorder presentations.

The following quote from a psychiatric nurse explains some of the problems that are faced when trying to diagnose someone who is presenting with symptoms that are indicative of bipolar disorder and a selection of other possible psychiatric disorders. In this example the participant draws upon experiences where they have seen elements of bipolar disorder spill over into other recognised psychiatric diagnostic categories and the difficulties that result from this:
Par: ...It’s very difficult to say that person is purely bipolar. Yes a lot of people do have that diagnosis, but there are also a lot of people around with a diagnosis schizoaffective disorder - when you get very high or very low you get thoughts that are more of a psychotic nature. Who is to say? It’s all probably part of the same continuum...I’ve seen people being re-diagnosed and I’ve talked to various consultants and actually, when diagnosing, you’ve got this big manual of (DSM), it can still be really difficult to actually pinpoint and say this person has bipolar disorder because they may present to you as high, but also be seeing pink elephants. With psychotic symptoms, you wouldn’t say that was bipolar disorder, you might say it was schizoaffective. But on the other hand you could say that because they were bipolar, when they get to the extremes of that, it causes that through whatever else was going on in your head. (Interview 21 – Qualified nurse who endorses the biological model of mental disorder.)

Other participants had similar views to this and they suggested that the predictive test could be used as a tool that effectively resolved some of these diagnostic uncertainties. A number of participants suggested that if there was concern over a patient’s diagnosis, for example, if a patient presented in a similar way to the instance described above, tests could be used to either rule out or confirm a diagnosis of bipolar disorder and from this the patient could be dealt with in the most efficient manner possible. In the following exchange, with a psychiatrist who works in an acute admission unit, these issues were discussed early on in the interview:

Int: In several of the interviews I have done and from my own background reading, making a psychiatric diagnosis isn’t as easy as...

Par: No, they say if there are five psychiatrists in a room there can be ten diagnoses!

Int: Then what would the introduction of the genetic component do for that established confusion?

Par: It would suddenly reduce, especially from the first test. There are a lot of people, I don’t know if these tests are specific for bipolar disorder or they can be used for schizoaffective disorders – you are not sure if they are schizophrenics or they are bipolar or they are schizoaffective. So, if there is a specific thing for bipolar disorder – I know it’s very difficult to say that, but it would be quite helpful actually.

Int: If there was a query if someone had schizoaffective disorders or was experiencing bipolar disorder, administering the test in that situation would be good to confirm...

Par: Yeah, more than schizoaffective disorder or bipolar disorder – let’s say between schizophrenia and bipolar disorder if I can get a clear cut thing, this is more like a bipolar disorder than schizophrenia. Schizoaffective disorder lies in the middle so it won’t be much use to me, schizoaffective disorder from bipolar disorder, but if it’s bipolar disorder, then it can be clear cut and there is a clear distinction between bipolar disorder and schizophrenia, that’s very helpful yeah. (Interview 14 – Psychiatrist who endorses the biological model of mental disorder.)

From being able to get a better hold on the nature of the mental disorder that a patient is presenting with, the logical consequence is being able to have more choice in the selection of treatments that
are available. In the following quote, the discussion revolves around the observation that not only does this mean specific medication prescriptions have a further evidence base for their justification – because in some cases certain pharmacological interventions can have certain risks attached to them - but there will also be an increased confidence in the care received:

If I had ten psychiatrists and they were telling me that we are having problems with diagnosis – we are being too general or we don’t know the wood from the trees and it’s a real issue and actually having a test to confirm these down here would be helpful – I’d be interested by that, and in that situation it could help confirm it would give a different evidence base to confirm a clinical picture that would increase. If the treatment had associated risks, if the drug meant treatment was intrusive and difficult, and we would rather not do it than do it, it would mean we can be more selective so when we do intervene with our medication that is somewhat toxic it helps us reassure our patients and ourselves and their families that we think this really is the treatment of choice. So you could get better compliance from the use of it – both clinicians and the sufferers may then have the motivation to keep taking it and to manage the side effects – even if they are not particularly pleasant. (Interview 33 – a psychologist who, through the prescribed approach of their place of work, endorses the view that mental disorders have, in part, biological components.)

In keeping with the above suggestions, respondents mentioned that sometimes a patient’s diagnosis can change over time, and these tests could play an important role in that process. The following quote from a nurse who works on a ward that is involved with equipping patients who have long term enduring illness with the life skills needed to function outside of hospital, spent some time considering the information made available in the Psynomics ‘participant information pack’. Here the participant quotes some of the text from the information pack and considers how this should be approached when dealing with a patient, more specifically when there is some confusion about their diagnosis. The participant then goes on to discuss an instance where a patient has been misdiagnosed and how this could change if the tests were to be used:

Par: (Reading from the participant information pack) “Patients with the SS genotype that’s a negative test are at a higher risk of hypo-mania or mania in response to anti-depressants” so if I’ve got that right, if you’re giving a patient, a previously undiagnosed bipolar patient, anti-depressants, they’re going to develop hyper-mania. I think that’s what it says, so my immediate thought is without this sort of testing, somebody could go on, misdiagnosed and wrongly treated for years – perhaps all their life.

Int: Have you ever encountered such an instance?

Par: Yeah, I mean, diagnosis is really as far as I’m concerned… people have a diagnosis. But I’ve seen people on our ward who have their diagnosis changed because being called schizophrenic is very damning and damaging, but for this particular individual, to be re-diagnosed as bipolar was easier to accept. So I’m guessing in this instance he had been treated as a schizophrenic, medicated as one, but wasn’t – I think this happens all the time. (Interview 1 – Qualified nurse who is based in a recovery environment, endorses a range of models, including the biological model.)
This participant is suggesting two main issues. First of all, there needs to be efficient and accurate diagnosis if there is to be effective treatment – because of the potential where a patient possesses an SS genotype and is given anti-depressants and they become manic as a result – this is obviously counterproductive and possibly very dangerous for the patient. Their second point is that when it comes to receiving a psychiatric diagnosis there are some that are easier to accept than others. The related follow-up quote supports this idea, and begins to discuss some of the reasons why this could be the case:

*Int:* What are some of your thoughts on this perhaps being introduced?

*Par:* I can think about people who would absolutely much prefer to have a diagnosis, I’ll say depression, it might be bipolar disorder – than schizophrenia. I can think many times over the years particularly families, parents, find that much more acceptable, and I think probably not as stigmatising as having a psychotic illness. So I can understand as a parent not wanting my child to have a diagnosis of schizophrenia and pushing to have some sort of test. I might think they have bipolar disorder – I don’t know how I would feel if they didn’t, I can see some benefits. (Interview 2 – Nurse Consultant who endorses the biological model of mental disorder – but not to the exclusion of other models.)

4.2 - Theme 2 – Receipt of a test result, practical considerations and their potential consequences

Participants discussed the implications regarding what could happen as a consequence of receiving a test result. The first part of this theme will examine the positive impacts discussed by participants - there will be a focus on how patients could become empowered as a consequence of receiving a test result. After this, some of the additional issues concerning the practical aspects of using the tests will be discussed, such as when and where they should be used.

4.2.1 - Patient empowerment from receiving a test result

Empowerment was a common theme throughout many of the interviews. For most participants this involved being able to provide patients with as much information about their experiences of mental disorder as possible. Psychiatric professionals discussed patient empowerment benefits with respect to both of the Psynomics tests. In this first example the participant, a nurse who works in an acute admission setting, is discussing the percentage likelihood statistics from the Psynome1 test:

*Par:* It’s three times as much...but it’s about empowering people with information all the time isn’t it? And this is empowering them with something, and you have to empower them with information on how a possible mood disorder may develop. So in conjunction with everything else, it might be really useful. (Interview 4 – Qualified Nurse who working in an acute in-patient ward, makes sense of mental disorders through the stress vulnerability model – which places emphasis on a biology and external factors causing mental disorders.)

In the following example the participant discussed the notion of empowerment and its role in medication prescription and recovery. Again, like the previous example the interviewee is discussing anything that can be achieved to provide the patient with information about their situation that is likely to contribute to empowerment in the long term. In this example, the participant is discussing the role of the Psynome2 test and how it can have a role in patient recovery:
Giving patients some degree of empowerment is a whole part of the recovery model. In mental health, the principals of recovery – which are essentially about empowerment -are key, in terms of promoting the individual to participate in their own health care as much as possible. In that sense anything that empowers patients is good. (Interview 17 – A Psychiatrist who endorses the medical model of mental disorders.)

In these examples, participants actually use the term empowerment when considering the potential implications of the Psynomics tests. Empowerment is likely to mean different things to different people, and in isolation it is quite a vague term that perhaps is not that different from some of the higher level concepts discussed in the literature review. With this in mind several interviewees discussed a selection of issues that elaborated on some of these ideas, and these are all representative of the patient empowerment theme, but they each focus on specific aspects.

This is reflected in the following example; initially the participant began by discussing issues relating to use of the Psynomics tests at a very early stage in order to make the correct diagnosis and aid in suitable medication prescription. After considering these issues the participant suggested the tests could also work in a capacity that improves patients’ confidence in the care they are receiving. Respondent 4, a nurse who works on an acute psychiatric ward suggested, when considering Psynome II, that a patient’s confidence in care is likely to improve if they are given a scientific test that suggests that a certain medication will work better for them:

I think the other thing is confidence, if you have a test and you’re feeling quite low. If someone says we’ve done a test and there is a good chance that the medication will work on you, we’ve done a scientific test on you and its proven to work, then I think that makes you feel more confident about the medication you’re going to take. You can sort of involve that in the discussions with people, people worry about taking whatever – will it work, will it not work, how it will make me feel... (Interview 4)

Participants suggested that the technologies would act as a tool that not only improved the patient’s outcomes on a treatment basis, but their introduction would also change patients’ attitudes towards service provisions. These features were discussed by participant 28, a consultant psychiatrist who specialises in eating disorders:

It would be helpful to have definitive outcomes not only for the treating physicians and the medical teams, but for the patients themselves. There are a lot of patients out there that think they have manic depression, but they don’t have manic depression. They have symptoms that are being treated but they don’t have a diagnosis...As a patient I would love to know what was really wrong with me, and I would do my best to stay stable, and if I knew what I was being treated for, I’d play my role to stay well. Compliance is most probably one of the biggest frustrations one has as a treating physician. I believe if a patient knows what the illness is definitively, the evidence is there in black and white and they feel the symptoms and they see the quality of their life deteriorate... It would make a massive difference in how they view their illness and how they will take responsibility in staying well. It will be definitive. (Interview 28 – Consultant Psychiatrist based in an eating disorder setting, endorses a range of models including biological approaches.)
This example focuses on both the service providers and the patient groups individually. The participant is suggesting that both groups could benefit from being able to orientate around a test result, in this example, essentially both groups will become empowered. This suggestion has similarities to the previous theme concerning what can happen as a consequence of prioritisation of biological approaches in mental health care. Only this moves one stage further than that and focuses on a specific beneficial consequence of this development. There is an allusion to the participant’s models of mental disorder creeping into this account as well. The participant mentions ‘the evidence is there in black and white’ and this refers back to the ‘colours’ discussion in the previous theme. Later on in this account there will be a focus on the instances where participants did not consider a test result in these ways - some participants did not think that receiving a test result was as empowering as these accounts suggest, they considered it potentially damaging to a patient. The contrast in these accounts can again be viewed through participants’ differing models of mental disorder.

4.2.2 – Additional benefits of receiving a diagnosis

Although these quotes are similar to the ones presented previously they provide further evidence relating to psychiatric professionals’ thoughts on the merits of being able to use this new evidence base in routine practice. However, although there are still elements of patients being empowered through these developments, these quotes are suggesting that a result of this will mean providing care for these individuals will also be made easier. There are two main reasons for this. First of all this is a new evidence base that practitioners can engage with, and secondly, orienting around genetic explanations will cause patients to connect with treatment services:

*I think anything that can help us learn about the person will be helpful. And to the person themselves, if I was the patient I would like to know about that and I would like to know how likely it is for me to have an illness… If that was a huge possibility then I will think about it and do things about it in my life maybe differently. In that sense I think it will be helpful – even if it’s not possible at the moment to do anything about it in a way, but you can do something about something else* (Interview 31 – Psychiatrist who endorses the biological model of mental disorder).

*There are a lot of patients out there that think they have manic depression, but they don’t. They have symptoms that are being treated but they don’t have a diagnosis. Patients need a diagnosis, in order to manage themselves and be managed better. As a patient I would love to know what was really wrong with me, and I would do my best to stay stable, and if I knew what I was being treated for, I’d play my role to stay well.* (Interview 28)

Aside from acknowledging that a test result may empower patients with as much information about their disorder as possible, and this could also benefit staff groups because patients will potentially engage with treatment more effectively, participants discussed some of the practical aspects of using the tests in this capacity. This is different than the previous examples because the focus is being moved onto the *practical* aspects of the tests’ use.

4.2.3 - Using the tests for early intervention

From the majority of participants, a common suggestion was the tests could be used as a tool for *early intervention*. Almost every participant discussed the fact that a patient’s prognosis is often
made worse if their mental disorder is left undiagnosed and untreated for an extended period of time. They considered the Psynomics technologies to be a sensible way to reduce the chances of this happening, providing they were used at a clinically appropriate time. Some of these issues were discussed in the following quote from a participant who is a nursing assistant on a rehabilitation unit:

Par: Well, potentially those who are diagnosed early have a better chance of recovery, perhaps they are treated early and perhaps their symptoms are not so great. Maybe they will be able to cope with whatever symptoms with other therapies other than medication – with C.B.T for instance, being able to cope with certain situations without medication. I’m not against the use of medication, in some cases it’s a marvellous thing, but it can be more damaging to their physical health, for instance, in the long term. So, a person that’s not been diagnosed – left stewing away for 5 years, is probably less resistant to alternative therapies, than they are to... maybe medication is the only answer. They might have to go on medication for the rest of their lives, and also it is damaging. I see people, they are lethargic, they have a lack of motivation, it does have an effect on their physical health – the organs in their body deteriorate, their social skills disappear. Whereas if you catch it early enough you hope that the skills they had when growing up, they still retain, and can move on and grow. I think that, from the little pamphlet I’ve just read, that these tests could help with all of these things – on both accounts. People will be diagnosed earlier and they will be given the correct medication sooner – providing they were given at the correct time. (Interview 5 – Nursing Assistant who endorses the biological model of mental disorders.)

Both of the tests Psynomics offer were considered by respondents as being able to help with early intervention. However, participants had far more to say about the pharmacogenomic test in comparison to the diagnostic technology. Interviewees' concerns over the implications of the predictive test predominantly centred on the issues relating to a psychiatric diagnosis and what this really means. This feature will be examined in detail elsewhere, but briefly, this is centred around how the ‘diagnosis’ given to a patient only really provides clinicians with so much information in the long term, and essentially all this boils down to is the name of the disorder. Although as the previous examples attest, this can in some cases be important for patient compliance, the more important aspect to consider is where you go beyond this, specifically, how the disorder is treated. The following quote discusses some of these features – specifically being able to have a flexible approach to the selection of medication that will work best for that person that is not restricted by their diagnosis:

Int: What do you think using genetic information as an aid to diagnosing a mental disorder could do for practising psychiatry?

Par: It could be a very useful tool in the arsenal for people that are diagnosing. I’m not always sure that diagnosing is the be all and end all, simply because you get this continuum of how people present and what drugs work for them. Because someone has bipolar disorder it doesn’t mean that an anti-psychotic won’t work for them in some way. Yeah but I suppose if you had the test and it said this person has bipolar disorder you might then say yes that particular SSRI that has been developed may target that particular problem. That could be
helpful... complicated, but helpful. (Interview 15 – Qualified nurse based on a rehabilitation and recovery unit who endorses the biological model of mental disorder.)

Out of all of the issues examined in this research project this was another feature that unified all research participants when taking into account their communicated models of mental disorder. Almost every participant considered the pharmacogenomic test as a tool that could somehow help in improving patient outcomes. As discussed, many of the other issues examined in this thesis have quite a contrasting set of viewpoints from those who hold different models of mental disorder, but there seems to be a large degree of agreement about positive patient advances and early intervention from practically all participants who were interviewed when considering this test. In the following quote from a psychiatrist, some of the benefits from being able to get people on their optimum medication as soon as possible are discussed:

*Int:* With regards to the second test, what do you think using genetic information as an aid to the treatment of mental health disorders will do for practicing psychiatry?

*Par:* Once again I think it would be incredible to have that information, because one wastes a lot of time and money trying to get the right medication for the patient. When you start treating them with an anti-depressant and SSRI for instance. It will also inform the NICE guidelines because they have very rigid pathways you need to follow when you have certain mental health conditions. There are certain first line treatments you have to go through and they are usually SSRIs. It would be really useful to have more information about which SSRI would be most suitable for the condition and that person. So they don’t have to go through these. (Interview 17 – Psychiatrist who endorses the biological model of mental disorders.)

4.2.4 - When and where

Interview respondents discussed several additional aspects relating to when and where the tests should be used. Participants considered offering the tests to patients during their first contact with medical services when there is a suspicion that there may be some sort of psychiatric issue being experienced. For many included in the study this did not necessarily mean using the technologies in specialised psychiatric services, participants actually suggested that it might be prudent to offer the tests via General Practitioner (GP) routes. The following quote, from a newly qualified doctor, who at the time of interview was doing a six-month rotation on an eating disorders unit, offers several insightful points regarding this issue:

*Well this I think has quite a lot of uses, I can see it now in the GP surgeries when people come in and they kind of meet the criteria for being prescribed your bog standard SSRI, the information they get given is wait 4 weeks and see if it works, it might not work, if it does that’s great - we will review it – sometimes it doesn’t work and they have to go on a higher dosage and it can be a drawn out process. So if you had any evidence before to suggest how they might get on with it, that would be very useful. (Refers to participant information pack) I think the most useful bit of it is the actual bit that rules out whether it would be useful – the people that have two short sections - because that might influence clinical management of the patient. If they were mildly depressed and you were considering to start them on treatment – if you ask the patient, they might say, ‘well I might wait for the counselling’ – they often get given SSRIs in the mean time to tie them over because there are long waiting*
lists. If you’re able to say well there is a chance because of your genotype that you might have a poor response – what do you want to do? The patient might say, ‘I want to wait for the counselling’, so it can help you decide on the management. But also it has to be interpreted with caution because there is that poor chance, that there might equally be a chance that the person does respond to them – you just can’t protect it. (Interview 32 – Newly qualified medic doing a rotation on an eating disorder unit, participant endorses a variety of different models, including psychological and biological approaches.)

This quote represents many of the other participants’ overall thoughts and opinions about the potential use of pharmacogenomic testing in mental health care. It is important to point out that contained within this suggestion are additional themes that have been discussed previously – such as the merits of being able to get patients stable on medication as soon as possible and being able to manage patients more effectively as a consequence of this. Similar to the ideas presented here, the majority of other interviews mentioned that there is nothing wrong, when considering the issues of treatment, with using the pharmacogenomic test as a default tool as soon as patients present with psychiatric symptoms. This quote goes to quite some length to inform the patient about the developments and discusses some of the precautions a practitioner needs to consider, such as clinical management of the patient and taking time to examine all of the possible treatment avenues available when it comes to prescribing medication. However, participants who endorsed the use of genetic testing for mental disorders, for the most part suggested that if it was deemed appropriate, this test should be used as soon as possible so that treatment can be introduced and its potential impacts maximised.

Regarding the diagnostic test, the majority of psychiatric professionals were also specific about when and where it should be used. It should be realised that their commentary was specific to the Psynome1 test for bipolar disorder; therefore these implications are going to be focused on this test in isolation. Participants were only concerned with using this test providing there was a specific need to do so. For example, to help distinguish between different diagnoses or the patient had a family history of bipolar disorder and they wanted to see if they possessed the gene that puts them at an increased risk of developing the disorder.

4.2.5 - Prophylaxis

It is important to point out that no participants ever discussed using psychiatric medication as a prophylactic measure to treat mental disorders before they were experienced. However, participants did have a selection of ideas about what an individual may choose to do if they did receive a positive test result in a series of specific situations. In the case of using the test if there is a family history of bipolar disorder the individual is essentially going to be seeing what their likelihood of developing the disorder is presymptomatically, and participants suggested that lifestyle modification is perhaps the best way to minimise the chances of experiencing a mental disorder in the future. The following example from a psychiatrist elaborates on some of these thoughts and ideas. The participant acknowledges that it is very hard to totally reduce all of the possible precipitating factors in someone’s life that may have an effect on their future mental disorder, but efforts can be made to try and reduce this as much as possible and the result of this is a reduced chance of developing a mental health problem:
What you have in the genetics is you have a predisposing factor; then you have to have a precipitating factor. Sometimes I think people are going to develop an illness no matter what. If they have the genetics they might create and develop the illness...But there are issues... I have seen people who might have the genetics but you can also point at some stress factors in their lives that precipitated the illness. I don’t know how you can minimise all the stress factors in everyone’s lives, but at least you can maybe work on that - stress and anxiety management - so you prepare the person. Say if I knew that my father had bipolar disorder and I had one of these things and my predisposition to develop the illness is higher than the rest of the population – I wouldn’t use drugs. I wouldn’t put anything biological on that, drugs, anything. I will try and have a job that isn’t too stressful, I will try and protect myself in that way. Maybe you don’t get into financial adventures in the same way – you modify your life and live it a little but more carefully maybe. (Interview 31 – Psychiatrist who endorses the biological model of mental disorders.)

A small number of participants made further suggestions relating to what an individual could do in light of receiving a positive test result. The following quote from a psychiatric nurse gave a personal insight into these prophylactic measures and suggested how these could also be incorporated into the sort of treatments that are on offer from the unit where they work:

I guess you can make sure people have check ups every so often so they don’t get into a pattern of doing something destructive... You can make a WRAP plan – like we do. That might be one of the things that you can do to say to someone, okay you do have this predisposition...Actually I do know one guy who had got bipolar disorder and still has it, I met him at a party. And he was saying that he makes sure he keeps enough money in the bank, he takes jobs that are low stress and has a check list that he takes every three months. Am I washing, am I sleeping, am I doing this, am I doing that – things that he knows about himself. So, in many ways that’s like a WRAP plan, a bit of a relapse indicators thing that we tend to have here. (Interview 6 – Qualified nurse, although participant acknowledges the biological model of mental disorders, they appear to think that mental disorders are fundamentally the result of family dynamics.)

WRAP stands for Wellness Recovery and Action Plan, this is a document that is discussed and signed by a patient and their named nurse when they are in hospital. Part of this agreement reflects upon the patient’s relapse indicators and the sort of things that they need to be aware of to avoid their mental state deteriorating once they have become stable.

Although participants’ suggestions regarding taking the test and receipt of a test result have all been largely positive up to this point, especially in terms of the empowerment benefits that could occur, some participants did not consider the developments in this capacity at all. The next part of the theme will focus on some of these aspects.

4.2.6 - Negative consequences of receiving a test result

Several participants who, for the most part, were less endorsing of the biological model of mental disorder in their own personal practice had a significantly different interpretation of what receiving a test result could do for a patient. Rather than suggesting that a patient would be empowered, some participants suggested that the outcome could perhaps provoke anxiety or even in some cases will
make the patient feel like there is something dramatically wrong with them - the test result maybe even acting as a catalyst for experiencing mental disorder. The following response provides some commentary on the increase in percentage likelihood figures linked to the Psynome1 test. For the most part, participants were not impressed with these readings and figures – these aspects are covered in another theme (What the tests cannot do). However, here the focus is on the process of receiving the test result in the very first instance and what this may do for a patient. The issue here is that regardless of the test’s actual predictive value or its clinical validity, the experience and the process of receiving a test result could prove to be the major factor that needs to be considered:

*Int*: It’s around one percent. So if you go from a one percent to a three percent chance of developing bipolar disorder, would you still feel as concerned?

*Par*: I think I would feel more concerned because I’ve had a genetic test telling me that. Rather than I’ve got a one percent chance of getting schizophrenia. One in four people will probably get that, well, I’ll take my chances. If you did a genetic test on me and said I have a three in, you know, a three percent chance of getting it I think it would cause me no end of stress...and I just think that could just kind of tip me over. (Interview 2 – Nurse consultant, although they acknowledge the role of biology in mental disorders, participant is more orientated around personal interactions and their social situation contributing to an individuals situation.)

In this example the participant points out that simply receiving a test result could elicit responses that are undesirable, even if the test has poor predictive value in terms of what it can say about the chances of developing bipolar in the future or confirming a diagnosis. The participant is alluding to a scenario whereby the patient’s situation is actually made worse from receiving any test result. This could be considered as the opposite of empowerment, something that is suggested in the following quote from a psychologist:

Yeah, but then it would depend on why they were then coming to me. It would make a difference in the kind of work we did – if they came to me and said I think about this as being a genetic disorder and I’m perfectly happy with that but what I want is a bit of help to manage it, I will say okay that’s fine we can look at strategies to manage it. But I would also be wanting to think with them about evaluating that belief. Because I think that the belief it’s a genetic disorder can help people to let go of guilt, but I think it can also disempower people, it can make them a victim of their own experience. And also because I think psychosis is about disowning your experience and blocking out bad things that have happened to you, there is a risk if you go around thinking you have just got a genetic disorder, you don’t actually look at those bad things and think about the impact of them. (Interview 12 – Psychologist who rejects the biological model of mental disorder.)

Other than illustrating that some participants, who do not personally adopt the biological model of mental disorder in their personal practice, are wary of the possible harm these developments could bring to patients’ lives in terms of potential disempowerment, this quote also alludes to another important issue. It focuses on how different parties are educated about the developments being made in genetic testing for psychiatric disorders. Although in the above quote the participant is almost referring to the test as if it is already a routine part of practice and they would be willing to talk to the patient about the potential implications of its use, the indication is that introducing the
tests is far from simple as there are a raft of additional issues that require thought. The following part of this theme will look at some of these issues.

4.2.7 - Education - management, applied use and consent

Aside from the participants’ narratives surrounding issues relating to the applied uses of the technologies and the possible implications their introduction could have on the ways that patients choose to consider their personal situation when receiving the test result, much discussion centred on some of the practical considerations involved with using the tests. These issues included the provision of genetic counselling, education about the tests for patients as well as staff, and ensuring that the tests were delivered in a sensitive and timely way.

One common issue that emerged from the interviews was management. This issue has several facets that each relate to different considerations and aspects of the tests’ use, an important point being how patients are going to manage their disorder. However, this also extends to issues such as how patients will manage themselves after receiving a test result and how patients are going to be managed in the process of choosing to use the test and after receiving the result. When considering some of the possible management benefits of the Psynome1 test a participant suggested the following:

Par: It could help you to learn better coping strategies, or better ways of coping with things. Education...

Int: Can you elaborate on some of those thoughts?

Par: I think self awareness, people aren’t aware of the problems coming up till its too late and they have to be convinced. I think a lot of people develop illness at a certain stage in their life but if they have that education beforehand they are better aware beforehand of how to manage it and actually say hang on, I’m doing this and it isn’t helpful. I think that might be helpful, to be aware of that, and then things you could do even if it’s to delay difficulties that might become worse if you didn’t become aware of it. Like, not spending all your money – so, perhaps learning how to manage your money better, and having clearer warning signs... (Interview 21 – Qualified nurse who considers mental disorders to be partly genetic in origin, with the lifestyle choices being the other main contributing factor.)

This consideration is aimed at people prior to being hospitalised or when they are outside of a hospital setting, essentially how they are able to manage their disorder independently when away from the services provided by the NHS. Much of the additional commentary provided on education and management echoed these sentiments almost exactly - if individuals are better educated about the tests, their use and what the results mean, then the likelihood is that they, and their disorder, will be managed more effectively. The majority of participants agreed that one of the fundamental ways to achieve this was to educate, and as a result, empower, the patient about their situation. The theme of empowerment was discussed previously but it needs to be introduced again here as it serves in a slightly different context. Elsewhere the theme of empowerment is discussed alongside a selection of features that all contribute to positive patient advances, along with issues such as confidence in care and developing healthy therapeutic relationships between staff and patients. In this case participants consider the patient being afforded insights into their condition working in a way that allows them to lead the sort of life that they want to live. The following quote comes from
a participant discussing the merits of being able to give the patient any sort of information that actively empowers them to exert more control over their living situation and lead a “normal” life:

Int: Thinking on my feet for a second, one of the elements of assessing this test is how it will actually empower the patient and if it can actually provide any benefit for them. So with regards to your statement, in that this solidifies an objective marker for the patient, is that of some importance to you?

Par: Yes it does, giving patients some form of hope about their situation, empowerment basically, is a big part of recovering from their experiences and living a normal life. Another factor in this example would be the patient being offered the opportunity to engage, manage and take control of their own treatment – but one which is heavily dependent on this scientific basis – rather than their own ideas on the topic of recovery, which can be pretty woolly sometimes and essentially, just means that the patient wants to gamble and play video games all night. Personally I don’t think this is recovery, but perhaps this isn’t the point in this case, it’s about what could happen through the introduction of these tests, so really anything that empowers patients and could help their recovery is good to me. I guess the bigger issue could be what is recovery, what does this mean? That’s probably a conversation for another day, but broadly I consider it being able to live outside of hospital with the capability of doing normal things – like go to work and look after yourself. (Interview 9 – Consultant Psychiatrist who considers mental disorders to be the result of many factors interacting together in unknown ways – including genetics.)

The participant is suggesting that a consequence of an increased understanding about their genetic profile is increased awareness about their personal situation and the results that can come from this. Interestingly there is quite a contrast between the patient learning about their disorder and what it is that the participant is suggesting they may do with that information – which is essentially using it to try and modify their lifestyle so they are able to do ‘normal’ things. However, although this was a common idea generated from the interview series, participants also stressed that this issue needed to be approached with sensitivity and consideration. One of their major concerns was that patients should not simply be ‘given’ the test and their test result, but that they should also be adequately informed about as many aspects of the related implications as possible. A number of these points are included in the following quote from a participant, who at the time of interview was doing their training as an occupational therapist. The participant explains that the patient really needs to be fully aware of all the implications involved with using the technology before choosing to take the test. The quote suggests that without a clear understanding of all the necessary implications, there is a chance patients could be vulnerable because they are not properly prepared, or they do not fully appreciate what a test result means:

Par : I think that’s a tricky one because obviously the patient has the right to know things, but I think they would need to be educated on what it means and the implications of it rather than just being told you’re positive. A clear understanding before the result... Because even if it came out negative they would still know what the test was about. And if it came out positive I think you’re probably more likely to remember what you heard before you get the test result – the shock factor of ‘oh my god, I’m positive, now what does that mean’, you’re not going to be listening or taking in information. (Interview 26 – trainee Occupational
Going one stage further than this, a smaller sample of respondents made suggestions concerning the features patient groups need to be aware of before taking the test, as well as some of the additional services that need to be provided after receiving the test result. Several participants actually suggested that it was not necessarily taking the test that was the important event, but it was what happened afterwards that mattered. The one unifying theme common to all of the respondents’ ideas and concerns over using the technology was that the patient is receiving a result from what appears to be a very serious scientific test, and the consequences of receiving this sort of information are currently unknown. Some of these concerns are voiced in the following quote. Here the participant is explaining that the important skill to perfect is how you get this sort of information over to the patient so they take what is happening on board and are actively able translate this into benefiting their life:

Par: I’m the type of clinician that tries to work with trying to iron out problems. So I’m seeing this as a diagnostic tool. Off the top of my head, if a person agrees to the spit test, and it could be used to help a person understand there is something inside you that is not your fault – you need to work with us.

Int: Having a standard in that capacity - helping the client recognise that they have a problem that isn’t their fault - can you elaborate on how important the notion of empowerment for the client is?

Par: I’m a sane person and relatively stable so the empowerment bit would be very important. However, these people can be really sensitive to the professionals telling them ‘you are wrong, there is something wrong with you’. So the skill, for me, would be how do you get the information across for them to take it in and believe it...I would hope that they don’t go off and kill themselves after hearing the information. I’d like to think we could help them confirm ‘yes’ or ‘no’ and ‘don’t worry you can still lead your life. We can still help you thrive’. (Interview 26)

Examining the ideas participants offered relating to this situation, there are several features to consider that move beyond being able to effectively deliver test result information. This is subtly hinted at in something the participant said in the previous example - patients being sensitive to psychiatric professionals telling them “there is something wrong with you”. Other participants’ consideration of how the results are communicated went some way to examining this idea several stages further. The following exchange is from an interview with a nurse consultant who goes into detail about the sort of preparation, groundwork, and care that needs to be taken when taking a patient through all of the necessary steps to take a test, as well as the possible consequences that could stem from the patient coming to terms with receiving a positive test result:

Par: To check with people, ‘Have you had this test? Is it something you would want to have?’ Then talking about ‘Okay, what are you going to do as a response if it’s positive?’ Doing that psychological preparation, that’s the informed consent, isn’t it? There is that bit about we should never ask a question and get an answer if we have no clarity about what we are going to do with the answer. You don’t ask questions just because you can, you ask questions
because you want to do something with what you find out. And there would need to be that individual conversation and I’ve never worked in HIV services, but when it was first heralded I had conversations with people who worked in the service. A lot of the work that was done before the test ever took place was what do you do with yourself if the result is positive. Not only are we finding out – but we are thinking before you do that, psychologically if the person wasn’t in a place to cope with it...

Int: You shouldn’t have done the test in the first place.

Par: Right. For me that would be a similar element here. Yes I guess we would routinely be offering it for the person to say yes or no. And if they said yes, then that exploration of ‘okay lets work through ‘what if’’. And I guess for some people because there isn’t that clarity, it might leave them feeling a little despondent as well if they thought that there wasn’t something else they might do to stop the swing from going too high. People run the risk of losing so much, not just finance but social standing. Often, they have behaved in ways that friends have found difficult to deal with – so they lose those connections. It kind of has huge consequences for people. (Interview 33 – A Psychologist who adheres to the prescriptive model framework from their place of work, that mental disorders have both a genetic and environmental component.)

This quote touches upon a previously unexplored idea - there needs to be adequate preparation in order for the patient to be completely prepared for whatever the eventuality of the test result is. The participant points out that, “you ask questions because you want to do something with what you find out”. This means that once the tests have been introduced as a clinical option there needs to be detailed discussion surrounding their use with the patient and perhaps their families. From this idea the discussion moves towards examining issues such as the patient’s capacity to make informed decisions about the sort of treatment options that are available to them and the accessory issues such as possibly providing genetic counsellors as part of the psychiatric services.

The following quote from a psychologist who works on a unit that specialises in the treatment of people who have eating disorders begins to examine some of these issues. In this quote the participant starts off by pointing out some of their concerns surrounding partial information in their practice. From what is suggested in this quote the participant does not seem to have too many reservations about using the Psynomics developments in the clinic. In fact, they even subtly predict that in the next fifty years genetic testing for psychiatric disorders is likely to be something as common place as prenatal testing in current times. However, their major point centres around reaching a time where everyone involved with the tests’ use is completely aware of all the issues and caveats surrounding their use:

I’m weary about partial information – it seems like we have quite a long way to go about shared information, about these are the side effects. I have seen some good practice on my own ward – about helping people make decisions and to be thoughtful, but we have a long way to go before people are taking meds they feel informed about and they feel listened to, so they can be part of a partnership. So we have quite a long way to go about open relationships and shared expertise and information. In that medical consultation culture you are then going to add something else which also needs a lot of transparency and talking about – and what if it’s poorly prepared? The psychological fallout from something like that
could really not even be worth going there. Genetic testing is emotive for a lot of people, it’s hard for people to think around – we are used to it in antenatal or Huntington’s. So you have got widespread antenatal genetic testing at the age of five months – so lots of the population having dealt with it there. And along comes this test for psychiatric disorders and I think if mental health genetic testing took the initiative at present I would be concerned that they modelled good practice because it’s a new area that in the next 50 years we are going to have to think about. And it’s not an easy area for us to think about socially. I don’t see it generally being well prepared; I see a medical consultation style which reflects a power imbalance which has been played out again and again. It’s something that we are trying to work on - transparent collaboration with patients - and along comes this. So it’s like how much partnership, and how much open information, and how transparent is the whole thing – so I have concerns about this. (Interview 33)

Taking into account all of the suggestions made in this quote there are two specific areas that really present themselves as points of interest. Firstly, adequately educating both patients and staff about the technologies so both groups are sufficiently prepared for understanding all of the implications surrounding the tests if they are to be introduced. Secondly, this discussion has centred around a very specific aspect of catering for patient groups alone, for instance the possible issues centred around patients managing themselves and actually delivering the information to them in an appropriate way. However, there has been no discussion relating to the issues of exactly how patients will become aware of these features, and this is perhaps especially pertinent considering that the original context that the tests were thought to be distributed was online.

4.2.8 – Counselling services

For many participants their suggestions concerning this observation centred on the provision of some sort of in-house counselling service that provided the patient with adequate information about all aspects relating to use of the tests. Many participants were keen to point out and discuss some of the details related to use of the technology, like some of the issues presented in the following quote from a psychiatrist who works on a rehabilitation and recovery ward:

*Int*: What about the second test?

*Par*: Yes absolutely and I would want more data. And when it says SSRI response poor, what does that actually equate to? So, good, what they have given you is these two are twice as good as that, but you don’t know what poor means. If it turned out that poor meant only a quarter of people, I think in counselling patients you might well say to them that would be really helpful information to have, actually there is a chance you might still respond to this – but the chance may be only whatever it is. Given that, do you still want to try this, or do you want to think about something else? So yeah any drug has side effects. If it’s biologically active enough to have a beneficial effect, it’s got side effects as well. So you are weighing up that risk balance – so if you have something that tells you its unlikely to be positively effective, you have to question whether you are going to expose the patient to the risk of side effects. (Interview 20 – Psychiatrist who endorses the biological model of mental disorder.)

Here the participant is addressing their immediate thoughts about the pharmacogenomic technology after reading the Psynomics information pack. A significant proportion of this quote
reflects the participant’s suggestions relating to being as honest as possible with the patient about all of the treatment options that are currently available to them. However, there is also a very real sense of active communication between the practitioner and the patient in the ‘counselling’ oriented approach they suggest. In this instance the participant hints towards providing the opportunity for open two-way discussions between the patient and the psychiatric professional about all of the options that are currently available to them.

The following quote comes from an interview with a clinical psychologist who is based on a ward that specialises in the treatment of people with eating disorders. This quote contains the aforementioned idea relating to transparency of using the tests, but it also contains references related to a number of the clinical considerations that need to be thoroughly thought out before a patient chooses to use the test themselves:

*Par: So we are offering people this range of ways. Those would be my initial concerns. Lots of choice, letting them know about themselves and what might be helpful – what are your fears and concerns and what might be helpful. That is a lot of psychological preparation. I would be very keen – you can’t un-know what you know and you can’t undo what you have done. So that thoughtful care pathway for people thinking a ‘no’ or maybe to get to a point of ‘I said no, but I know if I change my mind I can’ – all of that would be important - I can see that, but for me you would have to make the whole thing much more transparent, you would have to come out and say our state of knowledge is poor, good, not so good around treatment options – so you don’t over egg the pudding, so people don’t think its going to be more helpful than it is. This might be helpful – so tell me how I am going to benefit from knowing this rather than not knowing it. (Interview 33)*

The section of this quote, “you can’t un-know what you know and you can’t undo what you have done” is perhaps the most profoundly applicable to all of the issues being examined and discussed here because it has universal connections to all of the features brought up by the participants. For example, if this idea was taken as being a central theme of consideration for test use, in as much as it was a prominent theme of the counselling sessions that a patient embarked upon when wanting to use the technologies, the practitioners are going to be as transparent and honest as they can be about all aspects of the tests as well as its application – providing that they make this clear to patients from the offset.

**4.2.9 - Practitioner education**

In order for these tests to have some sort of benefit in the long term, a degree of knowledge about their use will be required by all of those who are involved with patient care. From the Psynomics web page there only appears to be acknowledgement of physicians when it comes to those who may be interested in using the test from a clinical stand point. However, the reality is that it probably will not just be medics that are interacting with patients about use of the technology – the rest of the multidisciplinary team will be too. On this topic, a number of respondents mentioned that when the tests are introduced it would be wise to provide some sort of educational update about the developments so all psychiatric professionals would be aware about what they claim to do and how they operate.
This is reflected in the following quote from a ward manager of a rehabilitation and recovery unit who has been working in psychiatry for twenty-five years. The participant explains that if these technologies were to be introduced then the likelihood is that some of the staff who currently work in the field would perhaps need some additional training about the developments as they are quite progressive:

*Int:* Can you see using these tests raising any difficulties in clinical practice?

*Par:* I can see the general kind of discomfort being an issue for staff. Maybe not those who are training now, but those of us who are kind of a bit long in the tooth, so, I think there are those issues – I think they would be across the board, not just in nursing but in other professions as well.

*Int:* Such as the psychologists and the medics?

*Par:* Even OTs - if we are talking about how we work with people, and people’s stories and how their life experience impacts on them then we start talking about ‘tickey box’ kind of tests, I think there would be a lot of concern generally about that.

*Int:* You kind of alluded to the ‘modern’ approach...

*Par:* I think it’s through experience. It’s partly through experience, and I guess advances. These advances weren’t around 20 years ago when I trained. Generally, never mind in this area, so it might be a societal shift to the younger people that are coming through, not the mature students, who have more of an acceptance. This is the way we are going - kind of more formalised more standardised tests for a whole range of areas, so why shouldn’t we think about that being in mental health the same as you do with physical health? They might have that view. So I think there is that issue for those who are older and we haven’t grown up with it, but I think there is the issue that we will struggle to move away or think differently from what our experiences have taught us over the years. (Interview 7 – Nurse ward manager who endorses a range of different models for mental disorder including biological explanations.)

The participant is discussing some of the possible future considerations surrounding the introduction of the tests and the consequences this could have on certain staff who have been working in psychiatry for some time. In this case the participant is wary of the possibility that some of these developments may be too new and that certain members of staff are perhaps unaware of the progression that has been made in genetic research that is now being translated into clinical treatment options. Therefore a significant component regarding the tests’ future introduction will also be practitioner education so they are aware of these changes.

Some of these issues relating to awareness of the tests’ development and potential introduction will play a significant role in the next major theme. This focuses on the ways that other groups of people, such as the public, are likely to consider mental disorders as a consequence of these developments being introduced.
4.3 – Theme three – Representations of mental disorder in light of the tests’ introduction

A major theme developed from the data relates to participants’ suggestions concerning the different ways mental disorders are represented. In this theme ‘representation’ refers to the ways that different groups consider or understand mental disorders and those who experience them. Specifically, this theme will focus on the respondents’ suggestions concerning the public’s ideas on these issues once the tests are commonplace in clinical practice. This section will focus on mental disorders’ current representational standing and any possible future changes once the tests are introduced. Although these ideas do not focus on the tests’ use in a clinical setting directly, the amount of time respondents devoted to discussing these issues would suggest this is important and requires attention. Therefore the majority of issues presented in this theme are additional aspects that will require consideration when thinking about the tests’ future introduction. In several respects these aspects link back to some of the points raised in the introduction of this thesis – especially the issues concerning governmental proposals focusing on ‘good’ mental health being part of a healthy overall life style and the burden of living with a mental disorder.

4.3.1 - Public perceptions of mental disorders and the genetic testing

Participants made many comments relating to the public’s current perceptions of mental disorders, but ideas were also provided that examined the public’s possible changes in attitude towards mental disorders once the tests are introduced. Close to the end of the interview each participant was asked ‘What do you think the introduction of these technologies could do for the public’s perceptions of mental disorders?’ From the participants’ responses, there was a lot of speculation about the role of the media and its influence on popular perceptions about psychiatry and mental disorders.

4.3.2 – The media

When considering the role of the media there needs to be some examination of what it is participants are actually referring to. The two main ‘faces’ of the media mentioned in this study were journalistic – such as newspaper reports and news bulletins on television, or the radio. The second being popular ‘celebrity culture’ such as people like Stephen Fry or Kerry Katona discussing their mental health issues in the public domain. However, when it came to participants discussing ‘celebrity culture,’ a distinct split existed between the instances where it was mentioned. The split existed with regard to the specific context that the mental disorder was being discussed. For example, when discussing bipolar disorder a number of participants mentioned Stephen Fry and his public experiences with the disorder, while when discussing eating disorders participants made reference to glossy magazines with seemingly impossible images of female ‘beauty’ – which are often linked to size zero models, airbrushed photographs and cosmetic surgery. These instances were often examined when discussing the participants’ thoughts on the causes for mental disorders. When examining representations of mental disorder, although the media was still discussed in the same context as before, the additional interpretation offered by participants was its influence in the journalistic sense. Many participants made references to newspaper reports or television news bulletins that featured mental health topics and stories.

There are two main issues to consider when examining the media’s influence with respect to this part of the research project and participants’ suggestions about how it may influence public perceptions of mental disorder. The first element is concerned with considering pre-existing
thoughts about psychiatry and mental disorders. Participants suggested that the public’s thoughts and opinions are often informed by popular news reports that often go some way to reinforcing the stigma associated with psychiatric conditions by focusing on instances where mental health is linked to a severe event, such as a murder. Following on from this, some of the participants also suggested that the ways genetic test technologies are promoted by any relevant body, such as the companies who have developed the tests, are paramount to the public’s eventual understanding of the developments. A consequence of this is that the influence of the tests on the public’s perceptions of psychiatry is partially dependent on how the public find out about the technologies themselves and in what context this is explored.

The following quote, from an occupational therapist, is representative of the sort of suggestions that were often made about the public and their understanding of mental illness. In this case the participant is reflecting on their recent trip to a general hospital for a minor medical complaint. The interviewee comments on the way that a staff member was observed talking about their general medical complaint - in a way the participant considered inappropriate. The respondent suggests this would have never happened with a psychiatric condition, as there is a difference between what can be said about physical health problems and what can be said about mental health problems; this is mainly due to the fact that mental health problems are still largely misunderstood and the consequence of this is that mental disorders suffer from being stigmatised:

Par: I think it has a long way to go, it’s just chipping away at the surface at the moment. I recently had an incident where I thought I had something at the general hospital and somebody talked about it. And I thought I would get the sack if I talked about anyone’s problems here. It’s almost like it’s okay to talk about physical illness. Nobody minds, well, they think you don’t mind other people knowing you have a physical illness – I’m not sure about that. Mental illness you can’t talk to anyone about anything, the confidentiality is much more precious and kept here than it is over there. And that’s to do with stigma I think.

Int: People don’t understand mental illness…

Par: They are fearful of it, and it’s been seen as ‘other’ and different – I don’t want contact with these people because they might pollute me and they might kill me. All the newspaper media stuff that gives people the wrong impression. (Interview 13 – Occupational Therapist who claims they are sceptical of genetic causes for mental disorders and places much more emphasis on emotional control and healthy family interactions.)

Many other participants often discussed how it was the media’s portrayal of mental disorders that informed the public’s perceptions, and how ultimately this influences their thoughts about the issue. Their suggestions as to the public’s tendency towards stigmatising mental disorders were influenced by a number of major factors. Firstly, the media reports that the public had easy access to - the sort of media reports that actually informed their understanding of mental disorders were often made in the context of some sort of extremely disturbing event. Secondly, participants suggested that often the media reports focus on a specific set of disorders that the public are not actually fully aware of, that is, the account of mental disorder that is offered is erroneous or uses a series of words that the consumers are not familiar enough with in order to make a reasoned and informed decision about what they are being presented with. A selection of these components is presented in the following quote from a nurse who works on an acute admission ward:
Part of the problem is that often the most horrific and dangerous issues are the ones that get reported and these are the ones that the public learn about. There may be some examples where someone is a little eccentric, a little bit loose and a little bit mad – I seem to remember a really old member of parliament who was in the public eye for awhile. However, the real issue is the stabbings, the killings, the woman drowning her kids, the sex offences, all the really bad stuff that gets linked to a mental disorder. This will generally be schizophrenia. And I think that making links like this is always going to be wrong because, yeah I admit the people who do these really fucked up things are likely to have a mental disorder, and they probably went through some bad things as children, and some of them may have schizophrenia. But I think the way it’s presented in the news and stuff is wrong. These things only happen in a very, very small number of cases but the result is that everyone will think that all schizophrenics are like this, but they aren’t! The reality is only a fraction of one percent are, but these are the cases which are reported and the public learn about these! (Interview 23 – Qualified Psychiatric nurse who endorses the biological model of mental disorder.)

The following quote, from a nurse consultant who works in an acute admission forensic mental health setting, represents some additional ideas and elaborates on some new ones. Here the participant starts off by suggesting that these tests could be used as a tool that allows for a safer society because the improved treatment options mean that some of the possible, presumably negative, societal impacts of a selection of serious mental health disorders are significantly reduced. However, the contrast the participant offered to this is that the public are often reminded about issues such as the risk posed by psychiatric patients in light of very high profile incidents that they are linked to. The participant uses the phrase ‘scapegoated’ when describing the issue and this is certainly a feature that lends itself heavily towards the idea that the media portrayals are not always necessarily as reasoned or as fair as one might hope:

**Int:** What do you think using this test as an application could do for public perceptions of psychiatry?

**Par:** I think you would get a mixed view. I’m sure there would be a school of thought that would think that it would be helpful in a sense, and I’m really broadening this now, if we could test for psychopathy, schizophrenia, suicide, you know we could then treat all of those things and we would have a really safe society... if you think back to the care program approach and all of the concerns that they had about people like Christopher Clunis...those very high media things where someone that’s had a mental illness murders somebody – it seems like an individual is scapegoated, and then all the stuff about risk, that’s come in over the years, we hear about risk assessment – you have to this, you have to do that – the language you use, the things that’s been expected have changed over the years. (Interview 2)

Although none of these extracts focus on any issues relating to the actual introduction of the tests, it is important to realise participants suggested that various media outlets are important to the public’s representations of mental disorders. This observation carries over to the interviewees’ suggestions relating to impacts of the tests and how the public will understand and learn about these developments.
4.3.3 - Public perceptions in light of the tests’ introduction

When asked ‘What do you think these tests could do for the public’s perceptions of psychiatry’ close to the end of the interview, participants offered a relatively standard answer that suggested these tests are likely to either ‘improve’ or ‘worsen’ the public’s perception of psychiatry, mental health, and those who have a psychiatric diagnosis. As the following quote from a psychiatric nurse demonstrates – having a genetic link for psychiatric disorders is either going to act in a deterministic way that propagates the idea that those with a mental disorder are different, or it will make people realise that this is a problem within affected individuals that cannot be helped and that a mental disorder can happen to anyone. However, as we will see, when other accounts are examined, although participants typically suggested this relatively standard ‘improve or worsen’ idea about the test and its use, they often coupled this with an additional concern or idea about the technology. In the following example the participant suggests that the media, specifically tabloid newspapers, will have some influence on the way the public eventually hear about the technologies and how this can subsequently inform their opinions on the tests and how they consider them alongside mental disorders:

Int: My last question is what do you think these technologies could do for the public’s perception of psychiatry?

Par: I can see both sides of this. I can see the public thinking ‘well that confirms it, people are doomed to be different and should be excluded’ and all those things. Or it could go the other way – they could think ‘it could be any of us’, which it can. And actually help them to see ‘yes, it could be any of us, but people are taking enough care to make sure we getting the right treatments – medication’ which would be nice. Yes, that might not be within the control of psychiatry or government or anything else because people seem to believe what they read in the tabloid newspapers, so it depends what the journalists say. Because the journalists like the sensational stories and they will fiddle around with the statistics until it suits them, which might have a tiny little grain of truth in, but will generally be incredibly misleading. (Interview 15 – Qualified Nurse who endorses the biological model of mental disorders.)

This participant is obviously concerned about the media’s role in informing public understanding about the technologies. As previously mentioned, participants, for the most part, gave very similar accounts when discussing the public’s perceptions of psychiatry, but it was their subtle follow up ideas and suggestions that provided the interesting contextual differences that illuminated the theme. For example, the following quote from a consultant psychiatrist demonstrates this feature. The participant offers the typical ‘it could go either way’ response, but there are also a host of additional ideas and suggestions that are interesting as they all feature in other themes generated in this study:

Int: What do you think these tests could do for the public perceptions of psychiatry?

Par: By definition the tests are offering a story, which is, you have this problem because you have this faulty gene. So the test and the marketing around it would promote a biological model of causation and probably treatment, so it could create a kind of public perception that this is a genetic disorder expressed in behavioural and psychological terms – and that could go either way. One stream of anti-stigma work has been making the analogy between
mental illness and physical illness. So if you’re ill, you’re ill. It’s not your fault, it’s not a moral issue, you haven’t brought it on yourself. And so, seeing the physical dimensions of mental illness can be a way of thinking it’s an illness like any other – as opposed to a different category of human experience. And I’m in two minds: I don’t think I have a very clear view on that, really – whether it is destigmatising to see it as a physical illness, or if the implied determinism – you’re a ticking time bomb, you can’t help it, and you can’t do anything to modify your fate - actually adds to stigma, it adds to fatalism. When you know the reality is in life these things are still rather mysterious. So I’d be hard pushed really to have any confident prediction of what the public perception would be, but I think there would be one and maybe the public isn’t one thing. The public is all kinds of tribes who may be inclined to pick up this information and use it in different ways. (Interview 8 – Consultant Psychiatrist who endorses the biological model of mental disorder.)

This response offers several other suggestions in addition to the previous one from the psychiatric nurse – for instance, the participant elaborates one stage further in relation to the topic of stigma. However, when it comes to the issue of how information about the tests is presented to the public, there are some obvious similarities. The account from the nurse suggests that the media’s portrayal of the tests is an important feature that needs careful consideration when examining how the public think about and consider mental health issues. The account from the psychiatrist almost elaborates one stage further by actively suggesting that the way the technologies are marketed is likely to go some way in informing the public’s perceptions about psychiatry in light of these new developments. In this account the participant directly references stigma in the context of the tests operating as a ‘destigmatising’ force that presents mental disorders in the same light as physical disorders.

Therefore ensuring that these tests are portrayed in a sensitive way in the media is likely to be crucial to their ‘public perception’ success – in as much as the chances of increasing the stigma of mental disorder either remains the same or is somehow reduced. Although there is no real concrete allusion that start to fill in some of these gaps and provide some early suggestions. This change depends largely on finding a way to alter the public’s perception about mental disorders, and ensuring that the Psynomics technologies are released into an environment where they do no perceivable harm. One potential way of doing this is to educate the public about mental disorders and the developments in genetic testing. There were a small number of instances where the participants suggested this as a means of improving the public’s perception of psychiatric disorders and in the long term reduce associated stigma. The following quote, from an interview with a psychiatrist who works in a forensic mental health setting, illustrates this idea:

*Int:* What are some of your initial thoughts on how this technology will influence stigma?

*Par:* With patient education, as we were talking about earlier, and I think often people think, ‘oh my God, it’s my fault’ – or something like that. But I think identifying the fact that it’s somewhat contributed... and like I said earlier that genetics contributes, it is again not the only reason why someone suffers from a mental disorder. The finding there, of severe depression in terms of the phenotype, I think is a fair point, but I think at the same time there will be people who suffer from severe depression and the question will be why did it arise, this may not explain the aetiology of the disorder but it may aid the treatment of the
disorder. So I think helping the person identify all these different things would be useful again in terms of educating them, and actually educating members of the public. Let’s put it this way, the typical patient with a mental disorder in a forensic setting is considered someone who is horrible, does drugs, is dangerous, uses alcohol, has tattoos all over their body, has hepatitis and all these horrible infections – and I don’t want him living in my neighbourhood, because of a violent past. The more you can educate the public about mental disorders, the likelihood of the stigma being taken away is far greater. And I think in my view the idea of genetic component contributions to what we are seeing highlights the fact that this isn’t something that someone is doing out of choice. (Interview 17 – Psychiatrist who endorses the biological model of mental disorder.)

4.3.4 - Influence of participants’ models of mental disorder on thoughts concerning public perception

Although participants’ suggestions concerning the tests and the public’s perceptions of them could be summarised in the statements provided previously, this theme could also be approached with a consideration of the participants’ communicated models of mental disorder in mind. Like several of the themes presented so far there appears to be a link between participants’ communicated models of mental disorder and their accounts specific to this issue. This is illustrated in the following quotes from two participants. One participant, a psychiatrist interviewed who endorses a biological model of mental disorder alludes to the tests being able to positively alter the public’s perceptions of mental disorders:

Par: I think, its very often to find in the public, that people with mental health disorders in the past were just being naughty, or socially unacceptable - that’s what it used to be in the past, they didn’t actually have brain disorders – they weren’t recognised as being organic dysfunctions within the brain that affected your mind and in turn affected your actions, and your behaviours, and your beliefs, and that sort of thing, which is what we express on the outside and this is what people judge us on. So in a realistic way if you had this it would provide less of a weight for those people. ‘Well actually it’s not my fault, I’m not acting like this because I want to annoy you or because I don’t know what I’m doing. I’m acting like this because I have a mental health disorder.’ So I suppose people would have a different understanding of people with mental health disorders. (Interview 32 – Psychiatrist who endorses the biological model of mental disorder.)

In this case the participant is suggesting that the public historically are not really aware of what mental disorders actually are, sometimes they are considered as individuals simply behaving in ways that are thought to be inappropriate or out of the ordinary – and this has no link to any sort of underlying physiological process. However, being able to explain that there is a valid reason as to why people experience mental disorders could potentially provide an answer to these thoughts and may even go some way to educating people about the broader implications of mental disorders. The overriding aspect of this extract is that people develop a better understanding of mental disorders and the overall feeling is that this is a positive consequence of the tests’ introduction. This is in stark contrast to the following quote from a psychologist who rejects the biological model of mental disorder in their own practice:
Int: Do you think the introduction of these technologies could alter the way the public think about psychiatry and mental health problems?

Par: Yes... In terms of the people themselves who experience mental health problems, I am aware that there is a whole range of people who get labelled with personality disorders who may or may not fit into this quite so neatly. But in terms of the people themselves, for those who seek it for whatever reason, it makes it easier for them to find reason to blame. And for those unfortunates who find themselves caught up in the system I think it gives even more categorical proof why this person does not fit and needs to be treated. (Interview 12 – Psychologist who rejects the biological model of mental disorder.)

Similar ideas are included in the following quote from another psychologist:

Int: How do you think all of this could alter the public’s perceptions of psychiatry?

Par: That’s part of my worry in my dystopian vision of the future. It will reinforce this process of ‘othering’ people with mental distress or people who are different – that this is a physical manifestation of the exact way these people are different – they have a genetic code that is different to ours. And it would just reinforce that and reinforce the stigma and then the need for social control around it as well. There is evidence that shows that stigma is increased by people adopting a biomedical model. So if you see someone as having a disease you are more likely to want to keep your distance from them than if you see them as suffering stress. (Interview 10 – Psychologist who rejects the biological model of mental disorder.)

In both of these examples the participants are discussing how the introduction of the tests is likely to result in predominantly negative results in terms of the publics perceptions of mental disorders. For the most part it will mean that those who experience mental disorder will somehow become distanced from that those that do not. People who, for whatever reason, choose to use the tests and are recognised as having a mental disorder that is linked to a specific section of their DNA, will appear different. Those who rejected a biological model of mental disorder in their personal practice were, for the most part, quicker to make suggestions like the ones above regarding the public’s perceptions of mental disorder in light of the tests. However, there may be some cases (such as the one provided by participant 8, page 130) whereby participants who endorse the biological model of mental disorder acknowledge this is a possibility, but this is as far as it ever goes. They only acknowledge this is a possibility but they don’t seem to align with this viewpoint personally themselves.

4.4 - Theme 4 - What the tests cannot do

So far every theme presented has focused on what can happen as a consequence of actually introducing the tests and using them in a clinical setting. However, a significant amount of commentary was provided that focused on what the tests are not capable of doing. Participants’ commentary ranged from critiquing specific aspects of the tests, to considering how they may integrate with current health care service provisions and the problems with this idea. Essentially participants reasoned that rather than using the developments and spending money on structuring mental health care around them, a better idea would be to use current resources and services more efficiently. Unlike all of the other themes, this one is distinct when the participants’ models of mental disorder are considered. In the previous themes, participants who reject the biological model
of mental disorder in their own practice invariably had something negative or contrary to say about the tests and their use in the discussed themes. This pattern is not observed here, as a wide spread of participants, even ones who endorsed the biological model of mental disorder and still claimed they would personally want to use the tests in their own personal practice, still somehow commented on what the tests cannot do.

4.4.1 – Participants’ criticisms of the Psynomics tests

The first component to examine when considering what the tests are not capable of doing is to look at the participants’ comments, critiques and suggestions concerning the intrinsic nature of the tests.

4.4.2 - Psynome 1

Many of the participants’ criticisms and concerns about the first Psynome test revolved around the first figure contained in the participant information pack that presents the GRK3 genetic comparison between those with a psychiatric diagnosis and those that do not. This figure (included in Appendix 6.0.5) indicates that those who are ‘positive’ for the genes that Psynomics links to bipolar disorder are at a ‘2x or 3x increase in likelihood of having Bipolar Disorder’, or this result can be used to indicate that the patient should be considered as having bipolar disorder given their clinical presentation. The standard incidence of bipolar occurring in the general population is around 1% and Psynomics claim that possessing the gene(s) they link to the disorder increases your chances of developing the disorder two or threefold. However, Psynomics omit the basal incidence of bipolar disorder from their participant information pack.

The following quote, from a psychiatrist who at the time of interview was working on a rehabilitation and recovery unit for people with long term enduring mental health problems, examines these features; however, this quote also discusses some additional concerns about the extra criteria that need to be met in order to produce a valid test result:

*Int: Can you tell me some of your first thoughts on what we just read?*

*Par: I wasn’t terribly impressed with the first test, I think because the levels, I think if I’m reading it right (refers to the participant information pack) – the unaffected gene frequency, the gene frequency in people who don’t have bipolar disorder is one percent or three percent and seven and fifteen. So it’s not a big difference between whether you are affected or unaffected. So then I think to start using that is fairly dodgy, they then go on to say that the GRK3 has not been well studied in other psychiatric disorders – it may also be associated with other illnesses. And actually it’s only significant if there is a family history of bipolar disorder as well, so I don’t know that it actually, well I don’t think it does take you any further forward particularly...And if you don’t know the base line frequency, which they don’t tell you, actually, what does it mean if you’ve got a times two or times three increased risk? I don’t think it’s particularly useful. (Interview 20 – Psychologist based on a rehabilitation and recovery unit who endorses the biological model of mental disorder.)*

The participant points out that there is very little statistical difference between receiving a positive test result and not taking the test in the first instance – or just accepting that everyone has a one percent chance of developing bipolar disorder in their lifetime, and as a consequence of this they question how useful this really is to anyone. However, in addition to this the participant also
questions the additional specific criteria provided by Psynomics that need to be adhered to in order to produce a valid test result, such as, the individual being tested requiring a history of bipolar disorder in their family and the GRK3 gene not being studied yet in other psychiatric disorders. Other participants also picked up on the percentage increase in likelihood statistics offered by Psynomics, however, not every participant knew what the basal rate of bipolar disorder is in the population. For the most part, when the participant discovered the standard population rate likelihood of developing the disorder, just as those who were already aware of the statistic, they were not very impressed with the company’s claims. The following exchange, taken from an interview with a ward manager of a rehabilitation and recovery unit, is representative of this sort of discussion:

Par: What I’d want is how many out of one hundred have it.

Int: Would you like me to tell you?

Par: Yeah.

Int: The standard rate that is often quoted is one in one hundred will develop bipolar disorder as an average. You’re going from a one in one hundred to a three in one hundred chance.

Par: When you present it like that, that is less troublesome to me. Because I think actually there are ninety-seven others that don’t. So presented that way round, unless I was that eighteen year old that had what I thought was a strong family linkage and lots of concerns, that would delay my fears greatly, that kind of, one in one hundred and you have a three times increased risk. (Interview 7 – Nurse ward manager who endorses the biological model of mental disorder.)

A number of other participants discussed the same issues after reading through the Psynomics participant information pack, however others also picked up on the point that the test is only valid for Caucasians of North European ancestry and some openly criticised these criteria as being too restrictive, as many people are essentially excluded from using the test on the basis of their heritage. The following quote, from a dietician who works on a unit that specialises in working with people who have severe eating disorders, examines all of these issues. Their main point is all of these additional criteria provided by Psynomics significantly reduce the pool of people that are actually able to use the test in the first instance:

Int: Can you tell me some of your initial opinions on what you just read?

Par: The first thing that I thought about is that it’s only applicable to a very small demographic of people in terms of who they have done the study on. Caucasians and North European, so that narrows it down quite a lot already and obviously again with the first part – about having a family member who already has a diagnosis of bipolar disorder. So it actually will only apply to quite a small percentage of the population - already you’re wiping out quite a large thing anyway. Just reading it first through it sounds very interesting and it sounds like ‘oh this actually sounds like it might have a use’, but again just a very small use. (Interview 29 – Dietician who doesn’t appear to endorse the biological model of mental disorder in their personal practice.)
However, not every participant was quite as understanding when considering the technology’s additional criteria of use. The following quote is from a nurse who works on a ward that specialises in equipping people who have long term enduring mental health problems with the necessary skills to independently live outside of hospital. Here the participant essentially agrees with all of the points from the aforementioned quote, however, this goes a stage further by indicating some of the practical issues involved with choosing to use this technology. For example, the participant’s main concern about the technologies is centred on the need for a family member to have a diagnosis of bipolar disorder in order to make the result valid. The participant subtly hints towards this being ironic as they mention that when making a psychiatric evaluation you will look through a patient’s family history to inform the final diagnosis any way:

*Int: Can you tell me some of your initial thoughts and opinions on what you just read? Because I noticed you were almost laughing at one point when reading that...*

*Par: Yeah, at the thing about when you have it in the family. It all seems a little bit pointless; it works when someone has a psychiatric disorder. Someone is sat with you and they are struggling and you say ‘have you got any family history’ and they say yes, and you kind of think ‘well, what?’ Laughter.*

*Par: Pointless, I don’t understand what the point is of that. It starts saying it’s only good in this case and this case and you can exclude this and you have Caucasian and North European ancestry and I understand that’s where they have done testing. But at each step it kind of undermines it a little and you can kind of tell if someone is poorly and they have family members that have been similarly poorly, its kind of okay, what do we do about it? The common sense thing, you look really sad one minute and you’re off the wall the next and I noticed your dad used to do strange things as well, what can we do about this? Let’s use solution-focused therapy, we don’t need to take a blood sample and see what your genes are telling us. (Interview 21 – Qualified nurse who endorses the biological model of mental disorder.)*

4.4.3 - Psynome 2

Participants had a lot less to say about the pharmacogenomic test offered by Psynomics and there were no criticisms offered in the same fashion as above. This could be due to the nature that the data was presented in the participant information pack or it could be due to the idea of being able to use the tests in order to *treat* patients rather than giving them a *diagnosis*. As mentioned elsewhere, participants were far more accepting of using genetic testing for mental disorders in this capacity. Critiques of the second Psynomics test were much more oriented around the tests not really being any use to the participants’ personal practice and in the following example this relates to their communicated models of mental disorders. Participants did not critique or point out any ‘fault’ in the pharmacogenomic test from reading the participant information pack, but they suggested the tests are not of any use to them *directly*.

The participant quoted below considers mental disorders to be a manifestation of problematic family interactions and that these are very closely linked to difficulties in expressing or coping with their *feelings*. When discussing the second Psynome technology the participant offers an interesting
account, where on the one hand they need a patient to be stabilised on medication in order to be able to therapeutically engage with them, however, for their specialised form of therapy to really have any benefit to the patient they need to be able to access the sort of thoughts and feelings that the medication in masking in the first instance:

... as far as pharmaceutical treatment is concerned, I have a lot of ambivalence about that. On one level, I have to own, one of the reasons I can work with people in the recovery and independent living services is that they are on medication. If they weren’t, people would often be in a very florid psychotic state, and I wouldn’t be able to work with them – so I have to own that. On the other hand it’s very clear to me that medication represses feeling, so in a sense, there is a dilemma there. I want to work with people in relation to the feeling material that has been repressed since childhood and when I’m meeting them they have been given medication to help keep them from that feeling material. (Interview 27 – Drama therapist based on a rehabilitation and recovery ward who doesn’t personally make sense of mental disorders in terms of genetics but does rely on this approach to an extent.)

Some participants are clearly conflicted about some of the issues related to use of the Psynomics technologies and this quote reflects that. However, despite any distaste for the approaches that are typically linked to current psychiatric practice, the participant also recognises that there are some elements of this approach that do prove beneficial for their practice. Here the participant is recognising there are some instances where they need to rely on traditional psychiatric approaches, in this case the use of medication, in order to provide their specialist services.

4.4.4 - Additional accounts - Existing techniques

Other than offering specific insights into the tests, participants also provided further accounts regarding what the tests are not capable of doing in a typical NHS setting. For example, some participants mentioned that if current resources were used more effectively, or if people did their job more efficiently, then there would be no need to use the tests because of what can happen as a result of developing a healthy professional working relationship with patients and improving their hospital experience.

When considering these new technological developments a number of participants contrasted their ideas and opinions in light of the existing tools and techniques that are available to NHS psychiatric services. In addition to this many participants provided a suite of insights on the current realities of working in the NHS and various issues about mental disorders in general. When considering the technological developments and the possible impacts they may have on care provisions a wide number of participants discussed their role as a carers and what it is they actually do for those who have a psychiatric diagnosis. A large number of participants stressed the importance of developing a real, albeit professional, relationship with the patient in order to maximise the chances of them engaging with appropriate treatments and being set on the path to making a proper recovery. The following quote, from a psychiatric nurse who works on a ward rehabilitating people who have long term enduring mental health problems, discusses some of these ideas. The response presents the participant’s thoughts on the multi-factorial nature of the aetiology of mental disorder and the fact they should be treated accordingly. The participant discusses the importance of forming a healthy therapeutic relationship with a patient and the merits of being able to offer them more than medication in order for their mental disorder to be effectively managed. This quote is also a good
example of the participant explicitly stating their allegiance to a specific model of mental disorder through their professional obligation. However, despite this explicit loyalty the participant is also discussing other personal views that contribute to their implicit models of mental disorder:

Par: I mean, I work as a nurse, therefore I’m not a complete supporter of the medical model because I really don’t believe that medicine is the only answer but I do believe it’s a factor. However as much like mental illness is multi-factorial I believe recovery is as well. Myself, I put a great deal of kudos to the therapeutic alliance, if you can get alongside someone and truly believe in them then you are probably thirty percent of the way there. Then there are other tools, enabling people to look at their thoughts in a different way, tackling their poverty, education, their esteem, where they live. If you are living in a shitty supported accommodation then you’re not going to get better, but if you can actually create an environment that is worthwhile, is supportive, and it is of the best quality, then you’re probably another thirty percent further along the way. (Interview 13 – Qualified nurse who considers mental disorders in terms of their multi-factorial basis.)

When considering the technologies, many of the participants discussed their thoughts on several related issues when it comes to the appropriate use of the tests in the current climate of tools and techniques that are available to psychiatric professionals. From the participants who mentioned this, the overall consensus was if current resources were utilised a little more effectively, the need to use the test when an individual encounters psychiatric services would be negated. In the following quote, the participant explains that in examining Psynome2, what the test claims to do can actually be achieved with diligent use of current resources and existing techniques:

Int: Imagine, for argument’s sake then, and I’m talking about medication treatment rather than diagnosis - if in a perfect world there would be a situation where you could take a test and it would print out a sheet that would say ‘you’re going to respond well to these medications’, would I be right on saying that at least on paper that would be a desirable step?

Par: I think it does, but I think that can happen already without a genetic test. If people have done a thorough assessment and they understand the level of difficulty someone is presenting with and they have an idea of the pharmacology, and what the options are and they can draw on their experiences, I think to a degree that can happen. I’m not saying that it’s perfect, a lot of that, and I think I’ve become more and more aware of it now that it’s not just medics who prescribe. You have non-medical prescribers, and the ones that I’ve spoken to probably do a better job than most of my medical colleagues. Since they’ve done the training what they recognise is that often the doctors don’t do it properly. So they’re not taking the time to think about side effect profiles, so I’m not saying if you did a test, wouldn’t it be wonderful, we will give you this and it will work, it’s almost guaranteed - I can’t argue with that, but there are a lot of things that could be done now that aren’t done. That would rule out the need for that I think. If people did things properly in the first place we probably wouldn’t be in the muddle we are now. (Interview 2 – Nurse consultant who does to an extent endorse the biological model, but for this participant personal relationships are important to good mental health.)
An interesting feature of this quote is the participant mentioning they think non-medical prescribers sometimes do a better job than the trained medics they have seen when it comes to deciding on what medication a patient should take. The participant comments that from their discussions with non-medical prescribers it is not uncommon for doctors not to spend as much time as they perhaps should when deciding on the right choice of medication for patients and as a consequence of this, side effect profiles are not adequately considered. The participant did not elaborate on any of the reasons why doctors sometimes lack this skill, but the point is the conclusion was reached that ‘if people did things properly in the first place we probably wouldn’t be in the muddle we are now’.

Other instances where participants suggested that current resources could be used more efficiently to improve services came up in several of the interviews. In the following quote, from a medic doing their psychiatry training after working in haematology since qualifying after graduating medical school, the participant is discussing some of the resource constraints that are an unfortunate reality of psychiatry in the environment where they work. The participant is explaining that there are not enough opportunities for patients to engage in psychological intervention alongside the suite of existing, and predominantly used, techniques – that are pharmacologically and occupationally-based:

Par: But I think I would still lean on the side that I think. I think interactions between people are incredibly important – right from babyhood upwards. And I think probably a lot more could be done in that area than is done currently.

Int: Are you talking about intervening at infancy?

Par: No I’m not. I think on a societal level I think it’s insane we don’t spend a lot more attention and time teaching people about parenting and how to parent. That’s a broader issue. I think there are a lot of things we could teach in schools that would be a lot more useful than the things that are being taught. But in a setting like this, there is a psychologist based on the ward but she doesn’t have time to see the 16 patients. So not every patient will be seen by the psychologist every week and if they are being seen, it’s one hour every week. I think people should have the opportunity to be in intensive therapy when they are in an inpatient rehab ward. So it feels like we give them drugs, we are doing that side of it, and we are doing the occupation side of things but the kind of really giving people an opportunity to think about things and work stuff through, that doesn’t seem to happen, or not nearly so much. And, this is more than likely a resource issue. (Interview 20 – Psychiatrist who endorses the biological model of mental disorder.)

Although this quote does not explicitly mention the technologies directly, taken in the context of the interview, this participant was discussing the reality of patient care in the NHS. In this case it is difficult to adequately provide patients with talking therapies due to resource constraints. When considering the first Psynome test participants were far more critical of the implications of its use, especially when considering what can already be achieved with existing techniques and resources when making a psychiatric diagnosis. A very common response when a participant was asked about their thoughts on the technology was “What’s the point?” Some participants did not elaborate much further than saying this, simply saying they did not see very much point of using such a technology, while others provided some very detailed and in-depth insights into implications of the tests’ use – contrasting it to the tools and techniques that are already available to them in their clinical practice.
For example, the following quote from a psychiatrist examines a number of features related to what can be determined when making a diagnosis of bipolar disorder from simply examining a patient’s family history and talking to a patient about their experiences:

*Par:* Well I’m not sure what it would mean for me. And perhaps I should qualify that. Because surely in my practice if I see someone with bipolar disorder and part of my diagnosis is I ask them their family history and if they have a positive family history of things, I know they are more likely to have bipolar disorder so therefore the experiences they have could more easily be contributed to bipolar disorder, and this will help me to differentiate between the whole list of differential diagnoses that could in some way present with very similar difficulties. If it’s clear it’s clear. And I’m not sure whether having the extra bit of saying I’ve got a gene, because later they say you can’t interpret the gene if you don’t have a positive family history. So I’m not sure what it adds. Because if I just had a family history, why do I need to have someone take a blood test that will itself provoke a lot of anxiety for that person – do they have it, do they not have it, what does it mean – its great that if we know these people with this particular gene have a three times higher chance of developing bipolar disorder that’s a good thing to know, but I could probably know that from asking if they have a relative with bipolar disorder – its probably more cost effective. (Interview 18 – Psychiatrist who endorses an eclectic range of models of mental disorder, including biological, social, and psychological approaches.)

So far this section has been centred on the participant’s views of the tests’ inability to really contribute any significant information in light of the existing techniques that are available to them. The following quote is representative of the opinions held by psychologists who discussed this topic. This is essentially exactly the same as some of the opinions held by other professionals who participated in the study, however, psychologists seemed to have their own slightly more unified way of describing the phenomena. This revolved around trying to move away from working within the framework where a patient is given a specific diagnosis and a rigid medication regime and moving towards a service where the staff work alongside the patient to collaboratively determine the very best *treatment* that is personal to them and their requirements. In this example the psychologist is criticising the Psynome1 test, the notion of a diagnosis of ‘bipolar disorder’, and what this actually means. Instead of considering bipolar and discussing it with the patient in traditional terms, this alternative approach, called a *formulation*, would consider and discuss bipolar disorder with the patient in terms of experiencing fluctuations in mood, and how this can be effectively dealt with in a way that is appropriate for that individual:

*Par:* For me I can’t see what use it would be – and I guess that’s about the little table here (refers to participant information pack) where it feels like the test is about confirming something – a very specific diagnosis, and because I don’t really go for specific diagnosis, I’m really thinking what’s the point then? I suppose my way of working with people and my argument for how we should be understanding them – it should all be very individual. Rather than working with a diagnosis, we should be working with what we call a formulation. Which is saying this person experiences high and low moods and how can we help them with that. Why do we have to call it a particular disorder and talk about a genetic test – I’m not sure what that adds. I don’t know if it would add anything… Again I’m not sure it could do anything good. My feeling on how we should be working is about individual formulation.
Later on in the interview this psychologist also gives an example of a working formulation developed with a patient who would typically be considered as having bipolar disorder. Here the psychologist explains how a mental disorder can be understood in terms of the individual’s life experiences and living situation; these are two aspects of the formulation. The same goes for the treatment aspect of the formulation, in this case the participant describes the patient actively participating in exercise and practicing mindfulness. The only hint towards actively using anything remotely related to the genetic tests as part of the formulation is if the patient thinks that this could be useful to them:

Very often when I meet with people I say there are other ways of understanding this – you can link it to your life events, link it to when this happened when you were a child, link to the way your father treated you. And through making sense of that maybe try and welcome back some of those feelings that you’ve cut off. And that will mean you don’t need to have these episodes where things come out because you have become a full person with all these things integrated. But I would also offer a more coping strategy oriented approach, where people with bipolar can monitor their mood - if they notice their moods going up or down they can use particular coping strategies to bring their mood back to a midpoint. One of the people I know who has that diagnosis uses mindfulness – if he feels himself starting to climb he meditates and practises mindfulness exercises and that evens things out for him. And when he goes into a dip he uses exercises, so he pushes himself to go for a jog in the morning and that brings his mood up. So I can work with people in that way to look for coping strategies rather than the underlying stuff and sometimes we can talk about medication in that context as well. (Interview 10)

The idea of a ‘formulation’ was also discussed by other study participants. In the following quote, from a psychiatric nurse who works in a rehabilitation and recovery setting, the concept is alluded to. However, there is a subtle difference here as the participant is introducing a novel idea that links into the suggestion of being able to do quite a lot with the tools and techniques that currently exist for psychiatric practitioners. Originally the participant was asked about their thoughts on the likelihood of psychiatric genetic testing being introduced where they work. To begin with, the participant talks about this being something that would need to be considered on a personal basis, however, when asked about some of these specific issues, the participant begins to describe a number of features that possibly represent some of the most progressive thoughts on what can realistically be achieved alongside the introduction of genetic testing. This is for the focus of the tests’ use to be more around treatment issues than diagnostic ones, this idea is central to the final theme in this chapter.

There are three main points the participant discusses. Firstly, the participant mentions that prior to the introduction of the tests, services could benefit from some form of overhaul. Secondly, the participant discusses the drive for the NHS to move away from thinking about people in terms of their diagnosis and ‘labels’. Finally the participant discusses the way that the information is handled and communicated after the patient has received a test result, and how important this is likely to be when deciding what to do and how they should be managed from then on:
Par: That would be down to individuals. Are consultants not doing the right diagnosis? Is enough thought put into medication? What’s right for that person? Should reviews be happening more regularly?

Int: So what do you think about those issues?

Par: Well I’m thinking yes, the whole thing could be revamped and thought of in a different way.

Int: Even before the introduction of genetic testing?

Par: Yes.

Int: How do you think it could be revamped?

Par: I suppose it’s difficult because we are trying to get away from labels and diagnosis, but then if you think about it again – for proper outcomes, you need to have an efficient diagnosis to be effectively treated, so it’s a catch twenty two.

Int: Is this drive a personal one or for the NHS overtly?

Par: I think generally. We are getting away from labels because they are very stigmatising. Thinking about what you’re saying and thinking about people I have nursed in the past that haven’t been adequately medicated, and that’s been proved by beneficial outcomes for them, yeah. It needs tweaking somehow and I don’t know how it would work, or you would get people on board. It’s a very individual view.

Int: Okay then, if you’re trying to move away from labels, what do you think introducing this does for that drive?

Par: I think it’s, like, everything. It’s not always what you say, it’s how you say it. And I think it’s how, once if anyone agrees to this, it’s how it’s managed for that individual, that’s the important thing. If somebody comes for that test result and they have a diagnosis or the likelihood or whatever, I think it’s how it’s managed then and the support that’s offered. I don’t know, I’m guessing at some time you have to be honest enough with people to say they have, or there is a possibility they have, bipolar disorder. I think its all about how it’s handled. One way could be to stop focusing on the diagnosis that a patient has and begin looking at the treatment options - I guess the tests could help with this too, especially the second one.

(Interview 1 – Qualified nurse who endorses the biological model of mental disorders.)

Participants clearly had concerns over the limitations of the two tests offered by Psynomics, but their concerns were very different for each test. For the most part participants had a lot more to say about the limitations of Psynome1 because the general feeling is that it is not sensitive enough to patient’s individual experiences. For many participants an individual’s genetics is secondary to their personal relationship with the patient and a detailed understanding of their life history. Participants were also concerned with the additional caveats that needed to be met when thinking about this test, such as their heritage and the lineage of people the tests were originally developed on. With regards to what pharmacogenomic testing cannot do, participants discussed the tests not being of any use to their personal approaches to dealing with patients who experience mental disorders.
In addition to this, participants also discussed a number of areas relating to the current setup of typical NHS services and that in many ways, adding the genetic tests into this equation will likely prove ineffective, primarily because if current resources were used a little more effectively there is the potential for some significant changes and these may in some cases negate what the tests are intended to do. For example, patients may be able to engage in more effectively delivered talking therapies or some people could execute their job role more efficiently. The introduction of genetic testing for psychiatric disorders would have no positive influence on these issues, and in some cases it could be argued that they should only be introduced once these issues have been investigated and explored – this is something policy makers may have to consider in the future.

Some participants explained how that although the tests may not serve their own clinical practice, there could be instances whereby these developments do provide some form of benefit personal to the patient. If a patient wants to explore their genetics, and if the opportunity is there, participants who personally rejected the biological model of mental disorder were not adverse to this idea – providing it was used in the best interest for the patient. The issue here would be making sure this was indeed the case, and this would perhaps rely on the educational provision as part of the tests’ applied use. However, what this suggestion does reveal is that when it comes to the developments being made in genetic testing for mental disorders, there is certainly the potential to augment the ways that different people go about considering the issues of diagnosis and treatment, as a patient may want to explore these issues personally and participants generally seemed more accepting of using the tests in a treatment capacity. Some of these aspects will be explored in the following theme.

4.5 – Theme 5 - Using genetic testing for the treatment of mental disorders rather than the diagnosis of mental disorders

This theme stems from my finding that the majority of participants would be more willing to use pharmacogenomic or treatment-oriented testing, than predictive or diagnostic testing in their personal clinical practice. This was an additional unifying factor between participants who communicated contrasting models of mental disorder. Regardless of their personal approach to mental health, no matter if they objected to psychiatric classification as an ideal, regardless of the models of mental disorder they communicated, a wide variety of participants thought that a pharmacogenomic test, despite its biological operative stance, could still prove useful to both patients and psychiatric teams. For example this quote comes from a psychologist who works in a forensic mental health setting. This is part of their reply when asked to comment on the Psynome2 test:

...I think there is something about how people metabolise, or how their bodies make use of what’s being put into them. And actually I think that’s as valuable, if not more valuable, for the people who can’t metabolise and get poisoned by it. So in that sense I think there is some worth and value about knowing that about people – whether that is gene, or transporter-linked, you will lose me in the biology of it all, but I do think that is something that has some clinical significance. (Interview 12 – Psychologist who rejects the biological model of mental disorder in their personal approach to mental disorder, however, can see some instances where this approach may be viable.)
So although this participant, as previous quotes from their interview attest, predominantly rejects using a biological test to diagnose mental disorders, they do appear more positive about using genetic information to aid in the treatment of mental disorders – in this case determining that patients metabolise medication at different rates. In the next quote from a psychiatrist who adopts a more biopsychosocial approach to mental health, the participant also claims that the Psynome2 test is likely to prove useful:

*I think that any information that gives you a bit of guidance for something that’s going to be more effective than less effective is quite useful. But, I’ve been in psychiatry for 30 years now and you see huge personal variation in response to treatments. To some degree that’s to do with how people seem to react to different molecules and to a large degree I think it depends on the covariant principals favouring wellness and supporting recovery. So you see people on the same drug seeming to respond to it if their social conditions are more favourable, or if they enter psychological therapy and it helps. Being able to gain any clues as to how this may work in advance is going to be hugely beneficial.* (Interview 8 – Consultant psychiatrist who endorses a wide range of models in their approach to mental disorders.)

This finding in isolation is quite interesting, not only do participants think that genetic testing could be successfully used in this capacity, but participants who communicate contrasting models of mental disorder also arrive at a similar conclusion. Participants clearly acknowledge the importance of being aware of an individual’s personal history and how this may influence future treatment, but they are also aware of the potential role pharmacogenomics could play when therapeutically engaging with patients. This presents a unique situation when considering the potential role of the tests and their place in mental health care, as it focuses on what is actually being observed, quantified, and referenced when interacting with the phenomena of mental disorders.

Although this still focuses on the treatment of mental disorders it raises questions regarding the nature of exactly what it is when we think about individuals presenting with mental disorders in a clinical setting. The core of this issue centres on being able to differentiate an individual’s symptoms apart from their diagnosis and how these two components should be conceptualised and ultimately treated. This is examined in the following quote from a psychiatrist who was doing a clinical rotation on an eating disorder unit during the time the interviews where being conducted. This participant is suggesting that when it comes to the effective treatment of mental disorders, in the absence of actually being able to somehow genetically intervene with the root cause of the issue, the important thing to consider is treatment of the individual with respect to how they are presenting. As there is nothing ‘additional’ that can really happen once you are dealing with patients’ symptoms in isolation:

*Par: If my patient is not responding, then maybe... can you play with the genetics to resolve the depression?*

*Int : That’s in its really early stages, but there is research that has apparently shown positive results using targeted gene therapy in mice – so on an animal model, its been illustrated – however I think we are a few decades away from that.*

*Par: I think that will be a very cutting point for me you know. Sometimes you have someone and you know what the cause of the problem is, but you cannot resolve it. So what you do is*
treat the symptoms because you can’t treat the root, or the person doesn’t allow you to treat the root. And this is a bit the same – you might say okay there is a strong genetic component, so what? How are we going to tackle that, you are going to have to live with the rest of it. If your mood is low, it’s not going to have an impact so you have to put that into consideration. I don’t know how much you can affect that as opposed to affecting the outcome...There is life, relationships, jobs, genetics – whatever. And I think there are things we don’t know, we can’t see and can’t treat, and genetics is one of them – it’s a fixed thing that you carry around with you and unless you change it, that’s it, it’s forever. But if you could modify that to some extent and you knew what to modify then you have a different picture. (Interview 31 – A Psychiatrist who endorses the biological model of mental disorder.)

This extract initially started off by the participant suggesting if there was ever any way that a patient’s genetics could somehow be modified to ‘correct’ their mental disorder presentation. However, it is the accessory issues that concern ‘the root’ of a disorder that are important in this theme. This quote exemplifies quite a subtle issue that is relevant to the different ways mental disorders are considered and the ways we typically refer to them. For example, the participant suggests that in some cases we can determine what causes people to develop mental disorders, but we are only successful in the treatment of their symptoms because the root of the issue, for whatever reason, is impenetrable. However, the feeling is that the symptoms a person experiences, or ones they are observed with, are very different and perhaps separate, or difficult to differentiate, from the root cause of their disorder.

Other participants made suggestions along these lines and in the majority of cases these ideas focused on being able to use the Psynome2 pharmacogenomic test to determine which medication a person would be likely to respond to better, rather than treating their mental disorder in terms of its root cause. The first quote is from a psychiatrist who works in a forensic mental health setting:

Thinking about it...when we think about recovery, in some cases, it’s never really possible to ever resolve what causes the patient to have a breakdown in the first instance. Sometimes it just happens. While in some cases it is possible to put a finger on it, but these are really only educated guesses. So what are we left with here? What can we really do for this person? We can treat their symptoms as best we can. Some of this may involve talking therapy, and sometimes as a psychiatrist I’m on the edge of those services, but it can also involve medication as well. For me this is certainly one way in which this test (Psynome2) could play an important role. I don’t really know how good it will be, but we certainly have a rough idea of what some of these medications do for people – calm them down, perk them up, Clozaril has done some magnificent things for patients as well, so I mean being able to get even the slightest head start on how people will respond previous to engaging in this way will be hugely valuable to medical teams in psychiatry. (Interview 17 – A Psychiatrist who endorses the biological model of mental disorder.)

The second related quote is from a psychiatric nurse who works in an acute ward environment:

An important thing that we need to be aware of is actually what we are able to do for patients when they come here. I mean with all of the service changes we are seeing, you have to be very poorly to actually come into hospital in the first place. I guess my point is that given the pressures that are placed on staff, sometimes its difficult, and whatever we can do
for a patient’s suffering, we should damn well do it. I know there are arguments about medication being a ‘quick fix’ and all that, but sometimes people are experiencing horrible things. I nursed someone just yesterday who was having a terrible problem with hearing voices. Now I don’t know what the cause of this really is, although I do have my suspicions, but all we can really do is manage their symptoms – the obvious one here being their voices. Again, back to the medication being a ‘quick fix’ I know there are criticisms of that approach, but generally medication works so if you could use this test to work out which (medication) the patient would respond to faster then I would say this is a fantastic development to have to use. (Interview 22 – Qualified nurse who endorses the biological model of mental disorder.)

Considering the context these suggestions were offered there are potentially going to be discrepancies between participants’ appraisals of these issues and their communicated models of mental disorder. For example, here both participants endorse the biological model of mental disorder and they both point out that often it is important to treat a patient’s symptoms as soon as possible and this will invariably mean using pharmaceutical intervention. However, from looking at alternative accounts regarding some of these issues, other participants who strongly reject a biological model of mental disorder bitterly oppose these suggestions. This is summarised in the following interview quote from a psychologist. Although the participant does not mention anything to do with using the second Psynome test to aid in overt symptom management, the implication is that the participant would likely refute using the test in such a way because of their conceptualisation of mental disorders. In this case the participant advocates getting to the route of the issue, rather than managing symptoms. This participant notes that for some people this may be a suitable compromise, but doing this still is not a long term solution:

I think getting to the root of the problem is getting in touch with anger and thinking about how to express anger, or getting in touch with grieving and loss and expressing that and feeling like it’s okay to be sad. So to me then medication isn’t tackling the cause of the problem – it’s a way of dealing with the symptoms. For some people that would be the best way because tackling the cause would be too difficult, but for other people, and I think most people – getting to the route of the problem is more acceptable and people feel that it would be more effective. The trouble is that medication is a very quick fix, and psychotherapy is years of pain to get to an uncertain gain. And we do live in a very quick fix culture. (Interview 10 – Psychologist who rejects the biological model of mental disorder.)

It is important to point out that when participants were considering the implications of Psynome2 they did not really provide any detailed critique, like the one received from Psynome1. Although some participants seemed to understand that this test was concerned with the speed people metabolise medication, some participants seemed to think that the second Psynome test was involved with determining which medications people would respond to prior to taking them. This development has yet to be made, but the speed at which people metabolise medications is perhaps a good start at gaining some insight into these issues.
5.0 – Discussion

From discussion of my thematic findings, I will argue that there are going to be a selection of issues to consider when thinking about the introduction of genetic testing in mental health care. Ultimately, the findings of this project could be considered with a view to informing policy makers or government bodies about the potential clinical and societal implications of genetic testing for psychiatric disorders. However, it is also essential to realise that the themes developed here could also have an impact on staff groups, the provision of mental health services, as well as patient groups and their experiences of mental health care. One common theme in this discussion is the fact that participants’ communicated models of mental disorder were incorporated into this project’s methodology, and therefore feature heavily in my thematic findings. In several respects, this makes the discussion slightly more complicated because this is an additional area where the impact of my findings will need to be carefully negotiated. The main issue is that the tests are set for release in an environment that is not homogenised with respect to its conceptualisation of mental disorders; there are multiple models of mental disorder all operating together at the same time in clinical practice. Therefore, it is no surprise that different participants consider the implications of the tests in different ways, and these different conceptual approaches all contribute to the development of my findings.

However, there is also going to be a focus on areas where there is a degree of apparent agreement between participants who communicated contrasting models of mental disorder about the implications of the tests. These issues will be examined in greater detail as they were something of an anomaly among the overall findings. Typically, participants who communicated different models of mental disorder considered the tests in different ways, but there were two thematic instances where this was not observed – using the tests in the treatment of mental disorders, and their influence on different aspects of the legitimacy of mental disorders.

Although it is impossible to discuss the implications of every thematic finding developed and presented in the previous chapter, there are several aspects that I feel are of paramount importance to informing our understanding of the implications of the developments. The first component feature that requires consideration in this process is not necessarily a thematic finding in the same way any of the main five themes generated in my Findings chapter are, but rather a discussion concerning an aspect of this project’s design – the influence of participants’ models of mental disorder.

5.1 – Participants’ models of mental disorder

As discussed in the Literature Review chapter of this thesis, assessment of the participants’ models of mental disorder was included in the research for two main reasons. The key observation is that mental health care is a multi-agency activity, made up of several different professional groups all practising together (Winston and Robinson, 2005), and people from within these groups have been shown to consider issues in mental health care in different ways (Colombo, et al. 2003; Fulford and Colombo, 2004). Seeking a wide range of psychiatric professionals was initially a strategy intended to disaggregate the issues representative of such a diverse professional group on the basis of their professional role. Although I feel this was achieved, this issue was eclipsed by the diversity of opinions generated through awareness and observation of the different models of mental disorder observed in practice.
We know that mental health care is not homogenised with regard to its conceptualisation of mental disorder, and if the tests are going to be released in such an environment, it makes sense that when determining the main issues concerning their introduction, this observation is appropriately negotiated. The intention being that awareness of this issue will mean that findings that are reflective of all psychiatric professionals, regardless of their theoretical orientation, are reported and hopefully considered. However, this raises an additional point with respect to consideration of the findings. When weighing up or balancing the issues raised in this project, it is clear that doing this will not be a straightforward task, as in many cases there are essentially opposing views on each of the points - this can be accounted for in terms of the participants’ conflicting models of mental disorder.

As mentioned in almost every theme in the Findings chapter, participants’ models of mental disorder do appear to influence their accounts of the tests. The overall indication being that participants who endorsed the biological model of mental disorder would be more willing to see the tests used in practice, or considered the implications of the developments more favourably than participants who did not endorse the biological model. A good example of this is the ‘colours’ discussion, where both participants mentioned decision making in psychiatry being ‘grey’, and the tests’ potential role in this process. In this example, the biologically inclined psychiatrist thinks the tests could be used in order to resolve psychiatry being ‘grey’, while the non-biologically inclined nurse consultant thinks using the tests in this capacity is not appropriate – because, for this participant, psychiatry is more about their personal relationship with the patient rather than interacting with them in terms of their genetics. Both participants acknowledge the tests could potentially be used to do exactly the same thing, but their contrasting views on the phenomena of mental disorders mean that the consequences of doing this differ dramatically.

This is illustrative of the careful balancing act that will need to occur when policy makers consider the tests’ future introduction - in the example above, introducing the tests would be welcomed by one participant, but rejected by another. If the developments were to be released tomorrow, policy makers would need to know they are going to receive different levels of acceptance from psychiatric professionals who adhere to different models of mental disorder. Consequently, the only thing I can suggest from my findings in this respect is that genetic testing offers the potential to conflict or correlate with the ways the majority of psychiatric professionals conceptualise mental disorder and, for the most part, implications of the tests are considered accordingly.

However, the reality is psychiatric professionals are only one of the groups concerned with the tests’ possible introduction. Although all of the findings were inspired through speaking to this one demographic, it is equally valuable to consider the findings for other groups as well. For example, what are the implications for patients and their experiences of mental disorder? What about policy decision makers, what are the issues they need to be most aware of?

In several respects, essentially every theme could be considered in this way. For example, the findings relating to ‘what the tests cannot do’ would perhaps be of particular interest to policy makers because of the financial implications of introducing the tests versus using current resources differently. Considering this, it seems reasonable to discuss thematic issues that are pertinent to the largest number of different stakeholders. One way to approach this would be to consider themes that were applicable to the largest number of psychiatric professionals on the basis of their
communicated models of mental disorder. Although the majority of themes contained a significant degree of conflict about the implications of the tests, there were two thematic aspects where similar suggestions were made regardless of the participants’ communicated models of mental disorder. This is observed when considering the suggestions from the participants concerning the influence of the tests on the legitimacy of mental disorders and using the tests to pursue the treatment of mental disorders rather than their diagnosis. I want to elaborate and start to unpack some of the salient and relevant issues concerning these two themes with a view to illustrating the potential ramifications of each observation in more detail. However, before these aspects are discussed, I want to focus on an additional area that featured in the literature review of this project where I feel able to make some suggestions on the basis of my findings.

5.2 - Clinical Utility in the ACCE criteria

From consideration of my thematic findings, this research project could progress our understanding concerning the application of the clinical utility aspect of the ACCE criteria, as well as our appreciation of the whole ACCE criteria in relation to genetic testing in mental disorders. What makes this observation potentially so valuable is that assessment of clinical utility (and the whole of the ACCE criteria) is needed before a test is introduced in a clinical environment. Therefore, the points about to be raised are likely to have implications for policy makers when balancing the issues presented in this research regarding the introduction of the tests.

The first issue I would want policy makers to be aware of is that placing too much emphasis on the traditional definition of the term ‘clinical utility’, and how it integrates with other parts of the ACCE criteria, could be a mistake – especially when considering the implications of a test intended for use in mental health care. It appears that the assessment of clinical utility is highly dependent on who is being consulted when trying to determine it; it is very much dependent on the ‘eye of the beholder’. This idea becomes really important when the observation that mental health care is not really standardised, concerning the ways that mental disorder can be conceptualised, is considered. This suggestion represents an extension of some of the points raised in the literature review, specifically that the term is likely to mean different things to different people (Lesko, et al. 2010). For example, one popular definition of the term clinical utility is ‘how likely the test is to significantly improve patient outcomes’ (CDC, 2010), however, I think that placing too much emphasis on this definition in isolation is a little bit naive as clinical utility may mean a lot more than this. For example, some scholars have suggested that when assessing clinical utility, it is important to examine the benefits and issues concerning other groups involved with the potential use of the test:

Because of its association with clinical endpoints, the term “clinical utility” may be too restrictive; we suggest that utility is a more encompassing concept of net benefit. In particular, we suggest that psychosocial, ethical, legal, and social issues be considered as sources of social utility because they contribute to the net balance between benefits and harms of genetic testing for tested individuals, their families, and the population at large (Grosse and Khoury, 2006, p.450).

This point also illustrates the merits of conducting a social science inquiry into these issues, as, according to Grosse and Khoury, consideration of the broader social issues requires thought when determining the net benefit of the tests. This will be especially important when the thematic finding concerning the legitimacy of mental disorders is discussed because this could have some potentially
significant, and broad, societal consequences. However, determining a test’s clinical utility takes on a significantly different guise when we realise that a test can still provide utility through virtue of simply its presence as a clinical tool in isolation. Ideas relating to this are discussed in the following example:

EGAPP defines the clinical utility of a genetic test as the evidence of improved measurable clinical outcomes, and its usefulness and added value to patient management decision making compared with current management without genetic testing. If a test has utility, it means that the results (positive or negative) provide information that is of value to the person, or sometimes to the individual’s family or community, in making decisions about effective treatment or preventive strategies. (Teutsch, et al. 2009, p.11)

There are two points valuable in regard to this issue. Clinical utility is concerned with what is possible as a result of having the tests available to use, and this is partly dependent on the value provided to different stakeholders through virtue of receiving any test result. A number of the findings presented in the previous chapter align with these suggestions. For example, considering the issue of the tests implying an increased legitimacy for different aspects of mental health care, one group likely to benefit from this are biologically inclined practitioners. Through virtue of having the tests available to use in clinical practice, they will be able to make (and back up) a specific set of claims about the nature of mental disorders – that they are real issues susceptible to medical intervention, which are biologically based. This suggestion is likely to benefit the demographic of psychiatric professionals who adhere to biological/medical models of mental disorder as it will provide an increased legitimacy for this approach. Additionally, I have also developed findings from some participants’ insights into cases where patients may feel empowered through receiving a test result. Both of these observations are likely to be benefits of using the tests, but they relate to two completely different stakeholder groups and do not necessarily depend on anything other than having the test available to use. What makes this discussion even more salient is the suggestion that there are instances where a test could still be included in a clinical setting even if it did not necessarily improve health outcomes:

We understand that from the clinical perspective there can be value in diagnostic testing even without evidence of improved health outcomes, and that testing may be incorporated in clinical practice on that basis. (Grosse and Khoury, 2006, p.450).

These issues will require careful consideration and diligent analysis from policy makers when thinking about the tests’ potential future introduction. To begin with, policy makers will have to deal with the fact that clinical utility is an issue that requires assessment from a number of different stakeholder perspectives. In addition to this, broader sociological issues will need to be balanced when reflecting on the potential impacts of the tests’ introduction. A key aspect of this research is the observation that different psychiatric professionals operate from different models of mental disorder. This appears to be a major reason as to why there are differences of opinion about the potential implications of the tests – and this is something that will need to be navigated when the tests are introduced.

Considering these issues makes me think about the relationship between clinical utility and other aspects of the ACCE criteria – specifically a test’s clinical validity. This observation is crucial when considering this discussion of the findings because the majority of themes developed in this research
ignore, or do not depend on, the actual clinical validity criteria of the tests – these are assessed through specific determination of the tests’ sensitivity, specificity, predicative values, and likelihood ratios (Sun, et al. 2010). Other scholars have questioned the clinical utility of genetic testing in mental health care on the basis of poor clinical validity, such as Philip Mitchell and colleagues in their 2010 paper ‘Predictive and Diagnostic Genetic testing in Psychiatry’:

\[\text{The ability of a genetic test to achieve its intended purpose is limited due to a low measure of clinical validity, thus leading to low efficacy and low effectiveness. Because of these low measures, the appropriateness of its clinical utility is also argued to be low, because the expected benefit will be small and the expected negative consequences will be significant} \text{ (Mitchell, et al. 2010, p.237).} \]

Some of my findings refute this suggestion, and this is an important issue policy makers need to be aware of. My findings indicate, through the exploration of the concept of clinical utility, that the tests offer potentially huge clinical utility benefits – such as making psychiatry seem like a real medical discipline and the impacts on patient empowerment - regardless of their clinical validity. Therefore this is a significant point that will need to be balanced up against all other issues raised in this research.

When considering the ACCE criteria and realising that they perhaps are not ideally suited for applied use on tests oriented around mental disorders (or the criteria may need modification in the future when applied in this context), it makes me think about some of the major differences between physical and mental disorders. Specifically, it makes me think about the nature of these disorders, their differences, and how they potentially integrate with the notion of genetic testing. Although this will begin to move away from considering the ACCE criteria in detail, briefly discussing some of the differences between physical and mental disorders is worthwhile because these suggestions may inform policy makers about these issues. The intention is to illustrate that mental disorders present a series of unique issues and these will require attention - if and when genetic testing in the clinical setting becomes a reality.

The biggest issue is observed when the nature of some of these conditions are considered and contrasted. For example, looking at some of the conditions that the company ‘23 and me’ offer as part of their service package, there are some dramatic differences between the ways these and mental disorders manifest. Although comparing and contrasting a disorder that is traditionally considered as not being mental health based, such as Type 2 Diabetes or different varieties of Cancer, with Bipolar Disorder may initially appear to be a peculiar idea, because the two conditions are so dramatically distinct, the intention is not necessarily to focus on the disorders in isolation, but rather how they align and integrate with the notion of genetic testing and what the consequences of this could be.

One observation relates to exactly what these genetic tests are characterising. For example, when considering genetic testing for BRCA1 and BRCA2, mutations in these genes are linked to a very specific phenotype that is observable, provided the tools are available to view it. When thinking about the GRK3 gene that Psynomics implicates alongside a presentation of bipolar disorder, the same reasoning does not necessarily apply. Although the specific gene mutation is being observed, there are potentially going to be problems when phenotypic endpoints are considered. For example, equating the BRCA mutations to their recognised consequence, tumour growth, seems remarkably
different from equating a genetic mutation linked to a psychiatric disorder to its clinical manifestation. This is where I think some of the participants’ suggestions concerning the developments in genetic testing equating to some sort of empirical validity for mental disorders could fall a little short. Although there may be an element of detectable or empirical gravitas in approaching a mental disorder in these terms, I think it is difficult to extend on this any further than discerning a genetic element that is linked to the mental disorder in question.

Having a genetic link that translates over to the development of a tumour seems entirely different than having a genetic link that translates over to what can really only be described as a patient’s observable behaviour, or assessment of their thoughts and their feelings. The primary reason for this is these two outcomes are measured and conceptualised in dramatically different ways. Tumour growth can be observed and quantified in terms of percentage growth in relation to non-affected tissue, or perhaps we can consider it in terms of out-of-control cellular mechanics. I do not think that depression, bipolar disorder, schizophrenia, or suicidal ideation can be considered in a similar way because of the problems encountered when defining these conditions. Although there may be suggestions concerning the relationship between a genetic variant and the physiological consequence of this, such as Psynomics claiming that ‘GRK3 gene is involved with modulating neurotransmitter levels in the brain’, I do not think this necessarily translates over quite as easily in the field of mental disorders due to the ways that different sorts of illnesses are typically observed. This point again stems from some of the contrasts between the ways that different disorders are traditionally diagnosed, such as the objective identification of disrupted cellular mechanics and the subjective identification of abnormal behaviour – but the next step on from this is considering the ways these established procedures align with the idea of genetic testing.

For example, cancer is routinely diagnosed through the use of tissue biopsy or scans while a mental disorder such as bipolar disorder is diagnosed through the observation of behaviour. It would appear that this is currently the best we can do with the tools and techniques that are available to us when achieving this task. Although this point may be obvious, it provides quite a subtle distinction that needs to be considered when contrasting these conditions. This goes back to the previous point in relation to exactly what these different genetic associations are being linked to. For example, in case of cancer, the genetic association can be linked to an additional phenomenon that can also be empirically observed, in this case a tumour. The same train of thought does not necessarily apply to mental disorders. For example, although there may be genetic associations being developed, the question to ask is what exactly are these contributing to? Even though the following example is extremely specific to the Psynomics tests in isolation (Barrett, et al. 2003), it would appear that the team behind this research are implicating their findings with neurotransmitter levels:

*In summary, we have identified variants in GRK3 which may affect the regulation of gene expression, and have shown that they are associated with increased susceptibility for disease. These data suggest the hypothesis that a dysregulation in the time or place of GRK3 expression results in aberrant neurotransmitter signalling and an increased susceptibility to develop BPD.* (Barrett, et al. 2003, p.556)

However, this discussion takes on a dramatically different guise when some of the suggestions that refute the biochemical imbalance of various mental disorders are considered. This stems from the suggestion that explaining certain mental disorders in terms of chemical imbalances is nothing more
than a hypothesis that has absolutely no scientific evidence to back it up. Although the paper ‘Serotonin and Depression: A Disconnect between the Advertisements and the Scientific Literature’ (Lacasse and Leo, 2005) is particularly concerned with the impetus and the relationship between the pharmaceutical industry and mental illness, the authors present a selection of quotes from scholars within the psychiatric profession that refute the claim that mental disorders, specifically depression, are linked to serotonin deficiency. Such as the following example from Professor Emeritus of Neuroscience, Elliot Valenstein, in a book called Blaming the Brain that reviews the evidence for the serotonin hypothesis:

Although it is often stated with great confidence that depressed people have a serotonin or norepinephrine deficiency, the evidence actually contradicts these claims. (Lacasse and Leo, 2005, p.1212)

And the following quote from a psychiatrist, Stephen M. Stahl, from a textbook used to teach medical students about psychiatric medications:

So far, there is no clear and convincing evidence that monoamine deficiency accounts for depression; that is, there is no “real” monoamine deficit. (Lacasse and Leo, 2005, p.1212)

Although the next section will focus specifically on the legitimacy of mental disorders in isolation, companies such as Psynomics, making claims about the aetiology of mental disorders and orienting around specific explanations that imply causality through a biochemical imbalance medicated through a genetic predisposition, are strongly implying that mental disorders are observable in these ways. However, if the counter evidence is to be taken into account, it is impossible to ever quantify the chemical imbalance directly - this is discussed by Stanford psychiatrist David Burns when asked about the scientific status of the serotonin theory in 2003:

I spent the first several years of my career doing full-time research on brain serotonin metabolism, but I never saw any convincing evidence that any psychiatric disorder, including depression, results from a deficiency of brain serotonin. In fact, we cannot measure brain serotonin levels in living human beings so there is no way to test this theory. Some neuroscientists would question whether the theory is even viable, since the brain does not function in this way, as a hydraulic system. (Lacasse and Leo, 2005, p.1212)

This observation is extremely significant in this discussion as it would indicate that what Psynomics are suggesting is impossible to substantiate, because neurotransmitter levels cannot be measured. I feel that there are also difficulties when attempting to link an objective finding to a mental disorder, which is traditionally defined on the basis of objective behaviours. The situation is remarkably different in the case of physical disorder, because specific aspects of the condition can be objectively quantified with, to my knowledge, far less controversy. Therefore, there are a number of differences when contrasting physical and mental disorders that would perhaps benefit from further thought when thinking about application and assessment of the ACCE criteria. One aspect that will be examined in greater detail in the following section will focus on how these developments could impact on the legitimacy of mental disorders as well as their potential influence on the status of certain disciplinary groups involved in mental health care. However, this point regarding some of the differences between the ways that physical and mental disorders are characterised is something
policy makers may need to consider when thinking about the tests’ future introduction, especially when considering related developments in terms of the ACCE criteria.

What follows is a slightly more in-depth discussion of the two areas of thematic agreement between participants who communicated contrasting models of mental disorder. As suggested, these issues are perhaps more widely applicable – because they were discussed by a wider range of participants. However, both of these themes are also going to have related implications to different stakeholder groups and potentially the clinical utility implications of the tests.

5.3 - Legitimacy of mental disorder

The primary issue is that psychiatric professionals felt that the ability to reference genetics when considering the diagnosis and treatment of mental disorders provided an increased scientific basis for their practice. This is important because several of the participants acknowledged that mental health care and psychiatry actually suffer from wider legitimacy issues – such as other areas of medicine not considering it a scientific discipline or patients not being complicit in treatment due to lack of appropriate explanation for their experiences. However, implicit in this discussion are some of the legitimacy claims inherent to medical professions more generally. We will see that as a result of constructing the object of mental disorders in terms of genetics, psychiatry as an institution will be able to make other wider legitimacy claims – such as, it is a real medical speciality and hence privileged to things such as state licensing, self policing, and will be able to make further claims regarding its overall expertise. However, it should be realised that this discussion also has elements relating to the breakdown of psychiatry as an area of medical practice that featured earlier on in this thesis. It is important to keep in mind that psychiatry is an area of medical practice where there are a number of different disciplines working together in the treatment of mental disorders. As discussed, these disciplines can vary significantly in their conceptualisations of mental disorder because they have been shown to approach the phenomena from vastly different theoretical frameworks. In this case, the issue is that participants, regardless of their professional role or their personal models of mental disorder, still thought the tests’ introduction could serve the same overall purpose – making aspects of mental health care appear more legitimate. Before the possible implications of this are discussed, I want to unpack the term legitimacy because developing a detailed understanding is necessary to put the idea in appropriate context when the implications for different stakeholders are considered.

5.3.1 - Legitimacy defined

The scholar perhaps most associated with the term ‘legitimacy’ is German sociologist Max Weber. There is a great deal of work available from him and other academics who are interested in the topic; however, navigating all of this work is quite a difficult task. There are two reasons for this, firstly there is simply so much to consider, and secondly, it would appear that there is no one universal ‘type’ of legitimacy that can be used in every situation – there are several different ‘versions’ of legitimacy available. However, this is not to say that examining some of the work from Weber does not help in this enquiry, it makes sense to do so as a substantial number of different sources refer back to him.

‘...willingness to comply with a system of rule or to obey commands, that compliance or obedience typically requires a belief in the legitimacy of the system of rule or command and that every system of authority attempts to establish and to cultivate the belief in its own legitimacy’ (Weber, 1947, p.324).

Weber provides us with all of the necessary features of what contributes to legitimacy in this single quote – the primary aspect being that legitimacy is concerned with collective belief in a particular system of rule among members of that system. In this discussion this is tantamount to the object of mental disorders being constructed in terms of genetics, through use of genetic testing in practice, and what is possible as a consequence of doing this. Specifically, what psychiatry as an institution, or specific aspects of it, is able to do through constructing mental disorders in this particular way. However, legitimacy is also concerned with a collective belief that maintains and justifies a particular system of authority; this requires compliance with the requirements of that authority. This means that part of the legitimacy process is involved with individual’s perceptions and ultimately their belief about the claims of a particular system of rule. Therefore, legitimacy as a process is very much a two-way street - it is dependent on both the claims of an institution and the belief in these claims by members of the institution.

One example of how this might work in practice would be that of an election process. If a political party made a series of claims or promises during an election campaign to entice voters, the voters would be likely to believe that the party they voted for is legitimate as long as it provides what it said it would once in power. However, the opposite also holds true when considering the erosion of legitimacy. If a political party made the same promises but did not back up any of its claims once in power, chances are that the people who voted for this party would lose faith in its legitimacy.

In the context of what is implied through introduction of genetic testing for mental disorders, a similar situation is created. Biological research into the treatment and diagnosis of mental disorders is implying an ‘object’ that implicates aspects of mental health care as being an increasingly medical enterprise – rather than one that is psychologically oriented, or even non-existent. The issue that can really only be expanded upon from consideration of my findings is given the two-sided nature of legitimacy, people believe in what can happen as a consequence of orienting around these explanations for mental disorder.

The first issue that requires attention is what is actually happening through virtue of making the tests available as a clinical tool? One important question to consider is, what do the tests actually represent, or provide, in the context of this legitimacy discussion? As the previous discussion attests, legitimacy is concerned with the claims of an institution and the belief (or disbelief) in these claims on behalf of members of the institution. In terms of this research, this relates to what can happen, or the claims that can be made, as a result of prioritising the role of empirical science, specifically genetic evidence, in the diagnosis and the treatment of mental disorders as a consequence of having the tests available to use.

The first issue I want to suggest is the tests potentially offer an answer to the ongoing identity problem being faced in mental health care. Previously I discussed that different professional groups are aware there is something to comprehend when dealing with people who experience mental disorders. However, determining this something (or what causes it) is elusive and this is the cause of much controversy. Another way to approach this issue is that the ‘ontic’ status of mental disorders is
controversial. However, the tests are implying an epistemological legitimacy for mental disorders that constructs its object in terms of genetics. A consequence of this development is the possible implications for professionals who practise and adhere to psychiatric approaches to mental health care; all of these ideas are referenced in sections 1.11 and 1.12 of the Findings chapter. For example, essentially every participant who discussed this noted that the developments are likely to make other medical disciplines believe or think that psychiatry is also a valid medical speciality now it is able to use the same sort of empirical science to diagnose and treat mental disorders. There will be a new form of justification for psychiatric approaches to mental health care.

When making this suggestion on the basis of my findings, I am required to make a distinction with respect to some of the points that were raised in the Literature Review chapter. All of these relate to the ways that mental disorders are typically considered, approached, and treated. For example, I pointed out that psychiatry is a practice; however, from within this practice there are different theoretical frameworks all operating together – iconic exemplars of this being represented by psychiatric and psychological approaches to the issues. However, from the sections of the interviews that inspired this theme there appears to be quite a degree of conflict between these disciplines, specifically with respect to the role of genetic testing in mental health care. For example, when participants who rejected the biological model of mental disorder in their own personal practice mentioned that these developments are going to benefit practitioners who adhere to psychiatric approaches to mental disorder, they never appeared to discuss this in a positive way. This observation has gone some way to clarifying something for me and the way I view mental disorders and the various different ways of conceptualising them. In terms of the small sample who contributed to the data collection in this research project, it always seemed like it is the role of biological components in mental health care that is controversial and questionable. However, having genetic test developments to consider represented something of a rebuttal to these criticisms. Interestingly there was no such critique of psychological approaches to mental disorders from any of the participants. Although practitioners who adhere to the biomedical model of mental disorder have been shown to communicate other models of mental disorder simultaneously, this whole discussion then revolves back to the role of empirical science and its use in strictly psychiatric approaches to mental disorder, but not necessarily psychological ones. This means that this part of the discussion is concerned with the developments in genetic testing for mental disorders making the phenomena appear to be ‘real’, as they are constructing the object of mental disorders in terms of biology, but they are also legitimising predominantly medical approaches to their diagnosis and treatment.

Therefore, it could conceivably be argued that genetic testing in mental health care offers the potential to augment psychiatric legitimacy; the main reason for this being that the majority of participants suggested that inclusion of the tests is likely to benefit practitioners who operate from this theoretical framework. Although the implied consequence of this is that mental disorders appear more ‘real’ (this will be discussed shortly), the issue is that this particular approach to their diagnosis and treatment is legitimised. When considering the idea that the introduction of genetic tests in mental health care has the potential to augment the legitimacy of specific approaches in mental health care, it is prudent to ask the question, why is this so important?

Psychiatric legitimacy is important because of the remarkable and unique things this branch of medicine can do to people. For example, there is still much controversy and debate regarding
several aspects of this practice, such as the use of medication, the use of Electro Convulsive Therapy, its legal status, and the way it classifies and organises the disorders it is concerned with treating. All of these issues are set within the bigger debate alluded to in the literature review concerning some of the alternative opinions regarding the treatment of individuals who experience mental health care – such as the writings of Thomas Szasz on the myth of mental illness.

However, what is equally as important in this discussion is the variety of legitimacy psychiatry is able to promote and align with – for example what is psychiatry able to claim about the nature of mental disorder, how is this established, and what will happen as a consequence of this? This is related to the previous discussion regarding legitimacy – specifically what different groups are able to claim as a consequence of this new technology, in this case what specific groups within the profession of psychiatry are able to claim. Although this is heavily oriented around one group in isolation, the interesting feature is that even participants who did not endorse the biological model of mental disorder or who were not psychiatrists acknowledged this possibility. As mentioned previously, the care of individuals who experience mental disorders has seen some dramatic modifications through time and the important feature is that these different changes have been shown to adopt different ways of approaching mental disorders. In this part of the discussion we are witnessing a strongly genetic oriented approach and change to the ways mental disorders are conceptualised. Many of these different components are all tied together when the work of sociologist Elliot Friedson regarding professional dominance is considered.

5.3.3 – Elliot Friedson and Professional dominance

Elliot Friedson developed the theory of professional dominance in his 1970 book of the same title. His thesis is that an occupation like medicine strives to get institutional privileges from society and the state to become a profession. An important component of professional dominance is that the medical profession is allowed to do things that other members of society are not, this is especially relevant to psychiatry because of the highly controversial things this discipline is able to do. There are two features to clarify here – first of all, who grants the medical establishment these powers and privileges? And secondly, who has a say in the actual technical authority of the profession? When it comes to psychiatry this final point is especially important because of the contested nature of the discipline. This point concerns the epistemological legitimation provided from constructing mental disorders in terms of genetics and interacting with them in this capacity.

Friedson notes that the profession of medicine is able to regulate itself and create its own academic credentials. An important feature to consider is how they are allowed to become so autocratic, and who enables them to do this? Although it is likely to be slightly different in each geographic location it is actually the state where the medical authority establishes itself that enables the profession to operate in the way it does:

*The foundation of medicine's control over work is thus clearly political in character, involving the aid of the state in establishing and maintaining the profession's pre-eminence.... The most strategic and treasured characteristic of the profession - its autonomy – is therefore owed to its relationship to the sovereign state from which it is not ultimately autonomous. (Friedson, 1970, p.83)*
The other aspect to consider in this dynamic is how the developments in genetic testing could contribute to the specific technological authority of the profession. In Friedson’s book there is only one small passage that is in any way related to how the ‘knowledge currency’ of a profession is established and used:

*Clearly, the economic and political autonomy of the medical profession varies from country to country. What seems invariant, however, is its technological or scientific autonomy, for everywhere the profession appears to be left fairly free to develop its special area of knowledge and to determine what are “scientifically acceptable” practices (Friedson, 1970, p.83).*

In the case regarding ‘scientifically acceptable practices’ the important feature is that the profession is essentially free to do whatever it wants in relation to this issue. It has been given the ability to develop its own specialised area of knowledge and apply it however it wants. This small idea takes on a very significant role when considering the introduction of genetic testing in psychiatry and the overall status of the profession, because this means the profession is itself able to determine whatever it wants as being a ‘scientifically acceptable practice’. The issue here is the possible implications of adopting, or increasingly prioritising, the role of genetics as a scientifically acceptable approach to mental health care. As we know from discussions earlier on and from the Literature Review chapter, psychiatry is a popular location where the treatment of mental disorders takes place, the treatment of mental disorders relies on the multidisciplinary team, and an important member of this team is the psychiatrist. Although psychiatrists may sometimes work alongside professionals who do not operate from this view point, the issue still remains, and from what my findings suggest, that this development is going to mean psychiatrists, or predominantly medically inclined practitioners, are likely to benefit due to the legitimacy claims they will be able to make.

It is at this point where a brief reminder concerning the architecture of mental health care is required, because I want to place emphasis on the finding that the introduction of genetic testing is likely to benefit one group from within the multidisciplinary team – those who endorse biological/medical models of illness. As discussed in the second section of the literature review, when comparing and contrasting the training received by psychiatrists and psychologists, different members from within the multidisciplinary team are trained in different ways. In this example, psychiatrists are trained in the science of medicine and psychologists are trained in the science of psychology – both in order to help in the treatment of mental disorders. Although psychiatrists have been shown to operate from an eclectic range of models (Rodgers and Pilgrim, 2005), I want to suggest, certainly on the basis of the interviews, that one model, which is perhaps unique to this group, is the biomedical model.

This is only half of the story when discussing professional dominance and the legitimacy of a specific area in mental health care. Although how the technical authority of a profession is established is critical, the other issue to consider is what can happen because of this. In his account of professional dominance, medical sociologist Donald Light (Light, 1997) notes several additional areas of interest that were mentioned in my interviews:

*Other exclusive rights and powers include prescribing controlled substances, admitting patients to hospitals, ordering tests and procedures, putting patients into a death like state, cutting into their bodies, excusing people from work, enabling people to receive service and*
financial benefits, and exempting people from criminal prosecution in the case of insanity (Light, 1997, p.3657).

The themes developed and presented in my Findings chapter align with some of these points exactly. For example, section 4.1.3 of my Findings chapter presented suggestions relating to participants’ ideas about how the tests could be used in a legal context. However, perhaps the most applicable component part of this list is related to the prescription of controlled substances, which is tantamount to the provision of psychiatric medication. Historically this has been a controversial issue, but the majority of the participants included in this research suggested that a test like Psynome2 could be used to determine which medication patients would be less likely to respond negatively to, potentially being more effective in the long run. The implication of this observation is that the role of the biologically-inclined practitioner and their approach to mental disorder is still legitimised.

5.3.4 - Further aspects of legitimacy as a sociological process

Although some of the background relating to the sociological nature of legitimacy has been explored, and some of the potential professional implications concerning this have been navigated, this topic could be examined in greater detail. Specifically I want to focus on some of the issues relating to legitimacy as a two-way process that is dependent on claims of an institution and the belief in these claims. Having an appreciation that legitimacy is not a static process, but one that can change and is dependent on the two-way relationship between people’s beliefs and the claims of an institution, we get a better idea of what legitimacy is, as a process, and how it operates. In their paper ‘Legitimacy as a Social Process’ (Johnson, et al. 2006, p.57), the Emory-based research team set about exploring a variety of different situations where the term ‘legitimacy’ is used, they then distilled each example down into a form that represents the fundamental essence of every definition. Here are the first three of their four distilled points:

(a) Legitimacy is a problem in the construction of social reality. It consists of the construal of a social object as consistent with cultural beliefs, norms, and values that are presumed to be shared by others in the local situation and perhaps more broadly by actors in a broader community (e.g., the organization or society). Through this construal process, what becomes what is right,

(b) Although legitimacy is mediated by the perceptions and behaviours of individuals, it is fundamentally a collective process. It comes about through and depends on the implied presence of a social audience, those assumed to accept the encompassing framework of beliefs, norms, and values, and, therefore, the construal of the object as legitimate,

(c) Legitimacy depends on apparent, though not necessarily actual, consensus among actors in the local situation that most people accept the object as legitimate,

Each of these separate points reference two particular aspects that are important to this discussion. Firstly, that legitimacy is a problem in the construction of social reality, and secondly (although strongly linked to the first aspect), that legitimacy is based around the construction of an ‘object’. Both of these points confirm and clarify everything that has been presented in this discussion so far. In this case, the ‘object’ in question is ‘mental disorder’ and the second issue is how the shared belief system of everyone in psychiatry is collectively constructing this object, and whether
individuals believe that what can happen as a consequence of this is justified. I want to focus on each of these points separately as I think some of the suggestions being offered here will benefit from appropriate examination, as there are examples from the interview series that almost exactly align alongside the breakdown of legitimacy as a social process. In the following sections the titles each refer to the difference parts of above breakdown of legitimacy as a social process.

5.3.5 - Legitimacy is a problem in the construction of social reality

In the Literature Review chapter there is a discussion relating to the problems concerning the ‘ontic’ status of mental disorders. When attempting to navigate this issue I suggested that a possible approach would be to consider mental disorders in terms of their epistemological standing. For example, all of the different approaches to mental health mentioned in the literature review are each offering a unique epistemological account for mental disorder – such as evolutionary approaches, medical approaches, psychological approaches, approaches advocated in different cultures, and even approaches that refute the legitimacy of the term altogether. Each of the suggestions offered about the nature of mental disorder is essentially one of the possible explanations available to us concerning the construction of this ‘object’. This is tantamount to the painted mural on the walls of a darkened room with different people each having a pocket torch illuminating their individual section and suggesting what the whole image is on the basis of their small visible section.

In isolation there is not anything wrong or problematic with any of this. Essentially all we are faced with is a number of different competing theories about what mental disorder is. Different groups are offering their own take on this issue through the development of an argument that aligns with their particular approach, on the basis of whatever evidence they deem worthy of supporting their ideas. This is where assessment of the participants’ communicated models of mental disorder presents itself again. In this case we have a better understanding of what all of these different approaches to mental health represent. Fulford and Colombo (2004, p.130) suggested that:

Models...are the conceptual frameworks, or sets of ideas, by which, in any given area, people structure and make sense of the world around them.

However, difficulties are encountered when we reflect on some of the historical and present day controversies relating to mental health care and psychiatry more broadly. For example, the pursuit of biological and genetic research into the diagnosis and the treatment of mental disorder represent something of a paradox. On the one hand, explanations of a ‘biological imbalance’ or any other similar explanation that has penetrated popular thought and in many cases this is what people are told, accounts for an individual’s alteration in mental state. However, this approach to conceptualising mental disorder is adamantly refuted in some circles as there is a large body of research that focuses on the suggestion that this claim has never been reliably demonstrated (Lacasse and Leo, 2005). As Colombo and Fulford (2004) suggested when designing their research into determining the multi-agency teams’ models of mental disorders – that problems can emerge due to the different models professionals bring with them into practice – the same idea may apply here. Problems are also encountered when alternative models of mental disorder all vie as being the object of mental disorder at any one time.
Although this sort of split is observed in the literature, and perhaps as part of popular discourse, it is important to remember the location of this research and the applicability of my findings, and as a consequence, the suggestions being made here. This research was conducted in an NHS trust location with a spread of different psychiatric professionals who were shown to operate from a fairly small selection of conceptual models. For the most part, I have made a distinction on the basis of participants’ accounts of the tests with respect to their rejection or endorsement of the biological model of mental disorder. However, in this case the distinction is a little more detailed than this. In terms of the model-based contrast observed in this research, the most significant aspect relates to differences from participants who communicate the biological/medical model of mental disorder and those who adhere to predominantly adhere to psychological models.

In the location where this research took place, these were the two most popular models communicated by psychiatric professionals. There were very few mentions of anti-psychiatry, only one mention of mental disorders manifesting differently in different cultures, no references to evolutionary approaches and the conceptualisation of individual symptoms, and no references to religious intervention. Therefore, in the localised situation where this research took place, it boils down to predominantly two models acting alongside one another, and in this case having a test that places so much emphasis on the genetic aspects of mental disorders is going to strongly align (and strongly conflict) with one of these models in particular. Different models of mental disorder already exist in practice and the advent of genetic testing is likely to add significant weight to biological approaches in particular.

An allusion to this idea was seen in a selection of different interviews, from a range of different participants who communicate different models of mental disorder. The following extracts are abridged examples from the first section of the ‘prioritisation of genetic explanations’ theme:

*I think first of all it will bring a huge attitude change to psychiatry from other medical disciplines. I think it will gather more respect for the psychiatric field itself...we will be more confident and the anti-psychiatry movement will loose some of their ammo – saying it’s a pseudo science and stuff like that. (Interview 19)*

*I’m sure it could do wonderful things for psychiatry...A lot of this for me is about strengthening the psychiatric position. By that I mean the stuff around rigid diagnostic criteria, that equalling a particular drug treatment and that firming up the belief it’s a genetically inherited biological disorder. (Interview 10)*

An additional point to consider is that both of these quotes reference psychiatry specifically. This works in a double context here: Firstly, it has an impact on the construction of mental disorders as an object - one that is consistent with cultural beliefs, norms, and values that works through emphasising biological aspects. However, it also influences and impacts on the previously discussed suggestion concerning the legitimacy of psychiatric approaches to mental health care specifically.

### 5.3.6 - Legitimacy is fundamentally a collective process

This part of Johnson and colleagues’ account of legitimacy relates to what happens outside of the immediate vicinity of where this research was conducted. One area where this is likely to have some influence will be on the public’s perceptions of mental disorder and what can happen as a result of emphasising the biological aspects of it, as there were several examples relating to this throughout
the interview series. The following account hints towards introduction of a predominantly genetic explanation for mental disorder clarifying the public’s previously fragmented appreciation of the concept:

*I think, it's very often to find in the public thought that people with mental health disorders in the past they were just being naughty...they didn't actually have brain disorders – they weren't recognised as being organic dysfunction within the brain that affected your mind and in turn affected your actions and your behaviours and your beliefs and that sort of thing...if you had this it would provide less weight for those people.* (Interview 32).

Other instances very similar to this also presented themselves throughout the interview series:

*The public don't really have a very good appreciation of mental illness as it currently stands...these tests could help in this problem. As I see it if people can understand specifically what (the participant emphasised the word 'what' and picked up the participant information pack) causes mental disorder then the chances are people will think differently about them, they will understand about mental health rather than being in the dark about it.* (Interview 24)

Although this quote focuses on the previously discussed aspect of how the tests may influence the public’s popular representations of mental disorder, it is still applicable in this context. Here, this acts as an extension of the previous component of legitimacy as a social process, but in this instance the construction of mental disorders as a biological object is moving away from those who are directly linked with the issue to those who perhaps are not. The focus is changing from the issues regarding psychiatric professionals’ views to that of the public.

I think this component of legitimacy as a social process has an important bearing on the make up of the object that is being promoted. As I mentioned previously there still remains a great deal of controversy in relation to what actually causes a mental disorder and how they should be treated. Specifically, the notion of underlying genetics causing an individual to experience mental distress, and ‘fixing’ this through biological manipulation being tantamount to treatment. The issue here is that the developments in genetic testing for mental disorders are further perpetuating this suggestion, through virtue of how they purport to operate. However, given the understanding of legitimacy that has been developed here, the fact this approach is open to critique is not the important issue, as legitimacy is concerned with claims about a specific phenomena and the belief in these claims by various people and groups. In this focus of legitimacy as a social process, the emphasis is now placed on how other groups, such as the public go about understanding the phenomena in this way.

5.3.7 - Legitimacy depends on apparent consensus in the local situation that most people accept the object as legitimate

This aspect has been discussed previously, but not in this breakdown of legitimacy in this way. This ties in with the previous suggestion that interview participants who did not personally endorse the biological model of mental disorder still acknowledged that these developments will imply that mental health care is increasingly a biological endeavour. The previous quote from participant 10 that refers to ‘strengthening the psychiatric position’ is an example of this, and so is the following quote from another psychologist who participated in this project:
The introduction of these technologies implies some success in these technologies okay, so if there is some success marketed for these technologies then it proves that this is all medical and biological – so therefore its power to the psychiatrists elbow. (Interview 12)

5.3.8 - Potential implications for different stakeholders

The first thing I want to point out is that several of the issues about to be suggested could also be considered as clinical utility considerations. From the aforementioned discussion we know that clinical utility is a difficult working concept, but we do know it is broadly concerned with the potential benefits of the tests’ availability. In this case the issue focuses on potential stakeholder benefits simply through having the tests available to use as clinical tools. In this example many of the potential stakeholder benefits that could result from introducing the tests are going to focus on these legitimacy aspects. Implicit in these suggestions is the relationship between medicine, the State, and some of the broader social consequences of introducing the tests. This harks back to the earlier suggestion concerning what a government body would need to be aware of when balancing up the issues regarding the tests’ introduction on the basis of my findings. Therefore, considering the original inspiration for this research, a significant focus here will be on pointing out the issues policy makers or government bodies would need to be aware of when introducing the tests.

Perhaps the most common theme running through this part of the discussion is that the genetic test developments provide an explanation for mental disorders in terms of underlying biology. Although this is quite a simple idea, the potential consequences of this are massive. For example, in terms of patient groups, participants discussed that being able to provide services users with an explanation for their experiences could be massively empowering for them. Informants mentioned that patients often want to know what is ‘wrong’ with them, or what can be done for them, and genetic testing is a possible way to achieve this. Respondents also mentioned that having this technology could mean that aspects of practice are easier. For example, there were suggestions that patients would be more likely to engage with treatment as a consequence of the increased understanding about their experiences of mental disorder, afforded through insights into their genetic profile. This could also translate into some of the resource savings that participants suggested may happen through virtue of the tests’ introduction – such as the streamlining of different areas of practice.

However, it is also important to refer back to the discussion on legitimacy and some of its accessory issues. For example, we know that legitimacy is a process that is involved with the claims of an institution and the belief in these claims by members of an institution. In this example the implied claim is that mental disorders are biomedical phenomena through virtue of being able to diagnose and treat them as a consequence of having the tests there to use. The pivotal point in this case is the emphasis on perception and belief. I am proceeding under the assumption that all of these points are not concerned with the tests’ actual ability to do what they claim to do. Although there is a theme that focuses on the claims Psynomics make about the tests they offer – and some of the participants are extremely critical of these – I think the bigger issue here is what could happen as a consequence of these developments more generally. I consider this similar to the previous discussion relating to clinical utility, specifically the suggestion (Grosse and Khoury, 2006) that there can be value in diagnostic testing even without evidence of improved health outcomes. I believe this is the case for the majority of this discussion – there is currently no real evidence that genetic testing can improve health outcomes in mental health care, it has not been demonstrated at all, and perhaps is not confirmed through the Psynomics tests used as inspiration in this research. Instead
this discussion is about the broader issues of the developments, such as what can happen as a result of the tests possibly being used in practice.

This idea also applies to the aforementioned patient empowerment example because the participants only focused on what the introduction of these tests will do for the ways patients think about their situation. Here, there is no mention of anything other than the patient being educated about their situation through anything more than receiving a test result – in this case the validity of the test is secondary to the utility. This is a suggestion I would want government bodies or policy makers to be aware of when considering the tests’ introduction. Regardless of the technology’s actual scientific credentials, my findings suggest simply having the tests available to use can do some remarkable things in terms of the ways mental disorders are considered – through emphasis on the underlying biological components. This is one of the most sensitive issues I think will need to be balanced up when considering the tests’ introduction. Perhaps one of the most salient aspects with regard to this finding is concerned with the status and privileges of different groups within mental health care as well as psychiatry itself. For example, participants who did not personally endorse the biological model of mental disorder suggested that genetic testing in mental health care is likely to benefit medically-inclined practitioners, while medically-inclined practitioners suggested that the developments would make psychiatry appear to be a real medical speciality.

If these tests were to be introduced, the issue here is not necessarily anything to do with their practical application, it is more to do with what they represent. If these tests were introduced, my findings suggest they may open the floodgates heralding a standardised way of conceptualising mental disorders, and this is unlikely to bode well with everyone involved in mental health care. This is another issue I would want policy makers to be aware of and I would suggest this will require a significant degree of assessment. For example, we know from the Findings chapters that in essentially every theme there are contrasting opinions relating to the tests’ potential use – and I have attributed this to differences in the participants’ models of mental disorder. Therefore the tests offer the potential to conflict with some psychiatric professionals’ approaches to mental health care in just the same way they can correlate with others.

5.4 - Treatment rather than diagnosis

The second area of thematic agreement between participants who communicated contrasting models of mental disorder concerned their thoughts on using the tests to aid in the treatment of mental disorders rather than their diagnosis. This is an additional point I would want policy makers to be aware of when considering the tests’ introduction. The primary reason being that participants who did not endorse the biological model of mental disorder in their personal practice acknowledged that using the tests to aid in patient treatment is still a desirable option. This is in stark contrast to their suggestions concerning the implications of diagnostic testing. As mentioned close to the start of this discussion, the overall indication is that participants who do not personally endorse the biological model of mental disorder are less inclined to consider the tests favourably, and are unlikely to consider them for use in their own practice. Therefore, when focusing on treatment issues, policy makers would not necessarily have to concern themselves with the tests conflicting with the psychiatric professionals’ conceptual approaches to mental health care in the same way they would do for diagnostic testing.
However, there are additional issues I would want policy makers to be aware of when considering the introduction of genetic testing for the treatment of mental disorders. Firstly, there were several novel and quite progressive suggestions from participants that will require discussion because their implications in overall mental health care could be highly significant. Examples of this would be the majority of quotes from section 5.0 of the Findings chapter; here, participants discussed that when dealing with patients who are distressed, it is vital to be able to do *something* for them to help ease their symptoms. This means in the absence of an understanding of what caused them to develop a mental disorder in the first place, being able to effectively *treat* their *symptoms* is of paramount importance, and often this will require prescribing a patient medication. In this case, participants suggested that being able to have a better understanding of patient response to certain medications, which will be considered on the basis of the symptoms they present with, is a sensible way of using the tests.

This suggestion is not totally unique as a similar issue is covered by Verhoeven and colleagues in their paper ‘Top-down or bottom-up: Contrasting perspectives on psychiatric diagnoses’ (Verhoeven, et al. 2008). Willem Verhoeven is the Residency Training Director and Head of the Department of Clinical Research at the Vincent van Gogh Institute for Psychiatry in Venray and Professor at the Department of Psychiatry of the Erasmus University. In the excerpt below, Verhoeven and colleagues provide an account of how this approach operates in the context of mental health care:

> This heterogeneity of results is most probably due to the assumption that the nosological categories...are disease entities with clear boundaries. If the reverse way of looking, the so-called bottom-up approach, is applied, it becomes clear that genetic abnormalities are in most cases not associated with a single psychiatric disorder but with a certain probability to develop a variety of aspecific psychiatric symptoms. The adequacy of the categorical taxonomy, the so-called top-down approach, seems to be inversely related to the amount of empirical etiological data. (Verhoeven, et al. 2008, p.409)

This suggests a split in the way we can conceptualise mental disorders. Considering this in terms of the ‘top down’ approach, we are stuck with the traditional ways of thinking about mental health – in terms of assigning individuals who experience mental disorders a working diagnosis, such as depression, schizophrenia, or bipolar disorder. This article is inferring that when a ‘bottom up’ approach is taken to traditional mental health nomenclature we run into difficulty as genetic ‘abnormalities’ do not segregate easily into the traditional ‘top down’ way of thinking. For me, this point acts as clarification on the ‘position’ of genetic information when thinking about mental disorders in this way. I want to assert that using genetic information to diagnose and treat mental disorders aligns with Verhoeven and colleagues’ ‘bottom up’ approach to psychiatric disorders. Their paper concludes:

> The...adherence of psychiatry to etiologically neutral prototypical behavioural syndromes, categorical diagnoses, severely hampers the cross talk with biological research. It should be realized that a gene defect does not code for a categorical psychiatric disorder but for a biological dysfunction that has a certain probability to be associated with a range of psychiatric symptoms. (Verhoeven, et al. 2008, p.414)
The idea is that rather than finding genetic links to whole disorders, emphasis is being placed on discerning the individual biological components that can contribute to symptoms of a disorder. The distinction here is that the Verhoeven paper is focused on the issue of diagnosis and not treatment. Therefore, it is necessary to keep in mind the participants’ actual suggestions pertaining to this issue in this section of the discussion, but I think the suggestions offered in the aforementioned paper can be adapted and translated into treatment-oriented approaches as the emphasis is being placed on understanding the underlying genetics. From the theme developed in section 5.0 of the previous chapter, participants concluded that when dealing with patients, it is sometimes impossible to treat anything other than their symptoms. Here, the link is if symptoms can be alleviated by specific medications, and the efficacy at which a patient will respond to a medication can be predicted through test use, then a unique approach to mental health care is established. Rather than considering mental disorders in terms of ‘top-down’ diagnoses, which are suggested to be incompatible with the genomic evidence, there could be more hope in approaching them in terms of their ‘bottom-up’ genetic underpinning. If this does ever happen I would suggest it is likely to dramatically change the way mental disorders are approached from practically every standpoint. For example, there would be less emphasis on traditional diagnosis and increased focus on combating individual symptoms.

This approach aligns with the notion of personalised medicine discussed in the introductory chapter of this thesis. If the aim of the revolution in genetics and its applied use in mental health care is to provide personalised care for patients I think there could be more mileage in the ‘bottom up’ approach than there would be in the ‘top down’ approach. For example, rather than having 5 patients diagnosed with bipolar disorder, this approach suggests a situation where these 5 people will each have a slightly different formulation that is determined on the basis of how their unique symptoms can be treated.

One potential consequence of these suggestions is the influence on some of the recent debates regarding the DSM-5 revisions. The APA was considering inclusion of a new diagnosis, ‘Attenuated Psychosis Syndrome’, in the 2013 DSM revision that broadly operates as a diagnosable clinical precursor to a full-blown psychotic episode (http://www.dsm5.org/proposedRevisions/Pages/proposedrevision.aspx?rid=412#). However, in early May 2012 the decision was made to remove this diagnosis from the update (http://www.psychologytoday.com/blog/dsm5-in-distress/201205/wonderful-news-dsm-5-finally-begins-its-belated-and-necessary-retreat). One resource that held extremely contrasting viewpoints was an ‘open letter’ to the APA that offered several opinions concerning their ‘at risk’ suggestions (http://www.ipetitions.com/petition/dsm5/). The authors conclude with the following points:

- There is a need for “a revision of the way mental distress is thought about, starting with recognition of the overwhelming evidence that it is on a spectrum with ‘normal’ experience” and the fact that strongly evidenced causal factors include “psychosocial factors such as poverty, unemployment and trauma.”

- An ideal empirical system for classification would not be based on past theory but rather would “begin from the bottom up – starting with specific experiences, problems or ‘symptoms’ or ‘complaints’.”
Although these points do not focus on the biological aspects of mental disorders there is a degree of similarity between this and the idea of using genetic testing to reassess the ways mental disorders are configured, as well as placing the emphasis on their treatment. For example, focusing on the participants’ suggestions that response to medication is something desirable, that can be readily quantified on the basis of an individual’s biology, aligns with the first point regarding a change in the way mental distress is thought about. However, the emphasis here is being placed on biology rather than environmental factors. In terms of the second point, there are similarities between this suggestion and the idea of using genetic testing to focus on and treat ‘bottom up’ individual symptoms rather than ‘top down’ diagnoses.

As a consequence of this, I would want policy makers to be aware that placing emphasis on using the tests to aid in the treatment of mental disorder will likely result in increased acceptance from the majority of psychiatric professionals and concerned commentators. However, I also want to point out that orienting around these aspects also feeds into the previous legitimacy of mental disorders’ argument. Although the focus has moved from diagnosis towards treatment, the biological aspects are still being emphasised, hence I think the main ideas of the argument will work in much the same way as all of the constituent elements are still present. For example, the fact that biological intervention is being used in mental health care may feed into the suggestion that mental disorders are biological in origin. This is tantamount to making a claim about the object of mental disorders and what can happen as a consequence of promotion or alignment with this approach.

An additional point that I want to make with respect to this suggestion is the possible way it could align with the most up-to-date research on the underlying genetics of mental disorders. In the literature review there was a focus on mental disorders as ‘pathway diseases’, and although the research is still in its early stages, and this should perhaps be considered as a working hypothesis right now, I think there could be room for integration of this ‘top down/bottom up’ idea into this approach. Sullivan and colleagues (Sullivan, et al. 2012, p.547) noted:

\[
\text{Indeed, if one or more psychiatric disorders eventually prove to be pathway diseases, there could be clinical benefit. We conjecture that it might be considerably easier to coax an existing but dysfunctional biological pathway into the normal range than to replace components that have been broken by Mendelian mutations.}
\]

If mental disorders did transpire to be reflective of pathway diseases, and they were amenable to the manipulation of biological pathways, this could potentially be one way to both diagnose and treat the individual. Integrating my findings into this possible avenue for genetic research, participants certainly appeared to favour focusing on the treatment-oriented aspects of the biology on mental health rather than the diagnostic. Therefore, if pathway diseases did turn out to be reflective of the biological components of mental disorder, there is a chance this approach will integrate with the majority of participants’ suggestions concerning the use of genetic tests, because the emphasis is being placed on treatment rather than diagnosis.

### 5.5 - Tests in practice

Now the two areas of thematic agreement between participants have been discussed I want to consider some of the implications regarding the tests in practice and the possible consequences of this for different stakeholder groups.
5.5.1 - Practice/professionals
With respect to this group, my findings suggest that the main focal point of the tests’ future introduction will be adequate preparation. There are two main issues to consider here – practitioner education and the possible changes to service that will result due to the tests’ inclusion. Both of these instances are presented in section 2.0 of the findings. As a spread of participants were interviewed, the issue to be aware of is that the tests represent quite a progressive development that offers the potential to alter practice due to the increased emphasis on the underlying genetic components of mental disorder. Participants suggested that there needs to be adequate education about the developments when they are introduced. For example, the quote included in section 2.42 mentions that there may be clinical staff who have been working in the field for quite some time and they may not be aware of the progression of the science and therefore would not be adequately prepared/qualified when the tests are introduced. In this case provision of educational programs about the developments is a worthwhile consideration.

Regarding the changes to service, one of the most pertinent findings concerned the participants’ suggestions relating to where and when to use the tests. In this research participants advocated using the tests as early as possible. A common suggestion being the tests should be given in early contact stages with mental health services, such as in GP surgeries. Although both predictive and pharmacogenomic testing were considered in this way, there was a noticeable difference in the implications of delivering both tests at this time/location. Participants did not have concerns about delivery of the pharmacogenomic test, but they did raise issues regarding the diagnostic technology. In this case participants questioned the implications of receiving a diagnosis at this stage, specifically on the impact this could have on a patient who was not adequately prepared. Therefore policy makers would need to devote time to considering the most appropriate time/place to use diagnostic testing as well as providing adequate educational support to all implicated stakeholders.

5.5.2 – Patients/experience of mental health care
In keeping with this, participants mentioned that a significant component of the tests’ successful introduction will be patient education - before and after the tests are applied. For respondents, this amounted to the provision of appropriate counselling services so that patients were fully aware of the implications of diagnostic/predictive testing at every stage of the process. However, as tools in practice, the developments in genetic testing for mental disorders potentially represent something much bigger than this. From the suggestions offered, being able to understand a disorder in terms of its underlying genetic origin could actually mean a great deal for patients - especially in terms of the potential empowerment benefits often discussed by participants in this study. In many instances, these suggestions focused on what could happen as a result of having an identifiable biological component that accounted for their mental health experiences, and the possibility of intervention because of this.

Although participants noted that patients needed to have a psychiatric diagnosis, and this could be aided through the inclusion of genetic data in mental health care, they also suggested that patients would perhaps take an increased interest or responsibility in managing their care or maintaining their overall health because of the increased understanding afforded through the tests’ use. For example, other than the discussed empowerment benefits, participants suggested that a patient
knowing they were predisposed to a mental disorder would mean they are likely to modify their lifestyle to reduce the chances eliciting a psychiatric episode.

5.5.3 - Policy/delivery implications
In terms of the possible policy implications of delivering these tests, one issue to consider would be economics. Although the issue of financing the developments did not feature in the interviews nearly as much as I anticipated, when considering the accessory features participants discussed—such as the training that will need to occur alongside the tests use—it would be reasonable to suggest that the developments are going to be significantly more expensive than their cost in isolation, due the additional expenses of providing the additional services. However, one of the major suggestions made in this research is the possible resource-saving that could result through the tests’ use. If this did translate into a reality of the tests’ applied use, then when thinking about the funding of these developments the increased economic cost of introducing the tests would need to be offset against the possible savings that could be made due to their introduction.

5.6 - Limitations of the study
Reflecting on what went into this research, there are several areas of limitation that I feel are important to highlight for future research purposes.

One limitation is the demographic makeup and size of the participant interview sample. Although the number of participants recommended for a grounded theory-inspired research project is between 20 and 30 (Cresswell, 2007, p.67) I would like to see if my findings are applicable to other psychiatric professionals from other parts of the country rather than from one trust in the South West of England. Restricting the sample to one overall geographic location could mean that all of the participants being interviewed will encounter a certain demographic of patient, or their suggestions could be isolated to a particular NHS trust and its policies, and this may influence their responses and ideas about genetic tests. Interviewing other participants from other areas of the country or speaking to them about the findings I generated here would be ways of navigating this issue. If this research was to be conducted again I would also like to include participants from other disciplines within psychiatry. I think I would have been able to develop findings that were more generally applicable if I had interviewed a pharmacist, professionals from within adolescent or old age services, and perhaps staff who work in a predominantly ‘general health’ capacity, but also have contact with patients who experience mental disorders.

In addition to this, there were other issues regarding the overall diversity of psychiatric professionals I interviewed in this research. For me this concern comes down to being able to contact a large enough spread of participants with regard to their communicated models of mental disorder. I would have liked to have included more participants who rejected the biological model of mental disorder in their personal practice because these participants were less common than ones that endorsed the biological model.

However, looking back over the project, screening participants with this in mind prior to the research would have been too artificial and perhaps not representative in the way I originally intended to obtain participants. It would also perhaps not be reflective of the reality of NHS mental health care. This falls back to me wanting to design a research study that is respectful of the different theoretical frameworks adopted by different psychiatric professionals— but also being aware of the fact that the
care for individuals who experience mental disorders is a multi-agency activity. Originally this was inspired by the observation that the environment where the tests are likely to be used is highly fragmented – there are a multitude of psychiatric professionals in a ward-based setting, and each of them will have a degree of clinical contact with the patients who will possibly use the tests. So I wanted to contact a good range of participants who are representative of the breakdown of staff observed from my experiences of working in a psychiatric hospital in order to get a full appraisal of the tests. I feel I achieved this, however, I was not necessarily able to contact a wide range of participants with respect to their communicated models of mental disorders, as the large majority of participants somewhat endorsed the biological model as part of their personal approach to mental health care. This could be a consequence of the medical model being so dominant in Western psychiatry – it is what the majority of people engaging with psychiatry in a professional capacity are taught in a class setting (Fulford and Colombo, 2004).

An additional point that I want to reiterate relates to my use of the Psynomics tests to develop my thematic findings throughout this research project. The intention all along has been to develop findings that are concerned with the advent of genetic testing for psychiatric disorders more generally; however, to do this I used the Psynomics tests to provoke discussion relevant to these issues and develop my thematic findings. Therefore, I cannot avoid providing a degree of commentary that is quite specific to the Psynomics tests, however the intention is to evoke a discussion that is sympathetic to the broader issues of genetic testing for mental disorders, and this is how I would want my points in this discussion to be considered and navigated. For example, in the introduction of this thesis I made the claim that genetic testing for mental disorders actually exist. I stand by this suggestion as there are companies currently making claims concerning these sorts of developments and they are certainly offering the tests to potential users. However, I can also understand that some people are likely to find ideas such as these perhaps a little bit difficult to believe. For example, throughout all of this I think it should be realised that these sorts of test developments are far from the clinic; this research is still very much in its embryonic stages. As suggested previously, there is a dramatic difference between an independently developed test being made available online and direct-to-consumer, and from it being used in a clinical environment.

This presents quite a unique situation as in my literature review I suggested that one of the main reasons previous related research has failed is due to the largely hypothetical nature by which it was conducted. I think the reality is we have seen some massive developments in our understanding of the biological underpinnings of mental disorder in recent times, but they are still a very long way off from being used in the clinical setting. However, that is not to say that I have not teased out some important issues for future consideration when, and if, this sort of research ever does become translated into usable clinical tools. Therefore when reflecting on this observation and thinking about the overall generality of my findings I think that a better framing of my findings, and perhaps this whole project, would be to suggest that this research has gone some way to shorten the distance between the hypothetical and the real. Although I still believe that genetic testing for mental disorders is somewhat of a reality, in as much as there are tests that that been developed and they are on offer, there is still quite a lot more research and development ahead before they can be used as clinical tools in the ways government or health care groups would perhaps want.
5.7 – Conclusion

Everything discussed in this final part of the thesis should be viewed as informing different stakeholder groups about the potential implications of genetic testing in mental health care. However, here I want to focus on policy and decision makers as they will need to balance the issues raised in this project when preparing the clinical care environment for the tests’ introduction. My findings suggest that using these tests in a clinical setting is not likely to be a straightforward ‘yes or no’ decision, as there are so many variables to consider. Therefore, rather than framing/considering this as a potential ‘yes or no’ decision, it would perhaps be better to suggest that the points raised are the main issues policy makers will need to contend with when considering the tests’ introduction.

My main original contribution to knowledge, other than the generated findings, is that models of mental disorder appear to be a significant factor in shaping participants’ accounts of genetic testing in mental health care. Although the observation that different people have different opinions about issues in psychiatry on account of their communicated models is not a novel insight, using it to navigate the issues relevant to genetic testing is a unique use of theory. Essentially every theme and suggestion developed in this project stems from this initial observation, and this is the first issue I would want policy makers to be aware of when considering the tests’ impacts. Mental health care is not homogenous with regard to the way it conceptualises mental disorders, and although acknowledging the different frameworks representative of this means my findings are holistic and multifaceted, I think that serious consideration should be devoted to the idea of what can happen as a consequence of introducing a development that is predominantly oriented around biological explanations for the cause and treatment of mental disorders.

Therefore, I would want policy makers to weigh up and balance all of the issues discussed in my thematic findings that are dependent on participants’ contrasting models of mental disorder. For example, in many themes there are conflicting views about the implications of the tests that are attributed to the participants’ contrasting models of mental disorder. An example of this being the ‘colours’ discussion contained in the first theme within the Findings chapter, as both participants suggested that decision-making in psychiatry and mental health care is ‘grey’. The biologically inclined psychiatrist thought the tests could be used to make this problem easier while the non-biologically inclined nurse consultant did not. A similar situation is presented when the issue of using the tests to streamline different areas of mental health care services is considered. Participants who endorsed the biological model of mental disorder never considered these implications in a negative way and suggested the practical benefits that could result from this. However, participants who rejected the biological model of mental disorder focused on the idea that the tests’ prioritisation of biological components would mean that other important aspects when interacting with patients are neglected and ignored.

Consequently I would want policy makers to understand that the tests’ introduction is going to be warmly received by some psychiatric professionals, but not by others. As a result, several of the themes developed and presented in the Findings chapter will need appropriate thought when considering the tests’ introduction. However, there were two areas with significant amount of agreement about the implications of the tests regardless of the participants’ communicated models of mental disorder. These are the tests’ impacts on different areas of the legitimacy of mental disorders and using the tests to aid in the treatment of mental disorders rather than their diagnosis.
In both of these examples, the issue revolves back to what can happen as a result of prioritising the role of genetic explanations for mental disorders.

In the first legitimacy example, participants acknowledged that simply through virtue of having the tests to use, the developments essentially made mental disorders appear more ‘real’ – they provided an epistemological legitimacy for the object of mental disorders in terms of underlying biology. Several participants, even ones who did not personally endorse the biological model of mental disorder, acknowledged this. Additionally, when it comes to using the tests to aid in the treatment of mental disorders, the emphasis is still being placed on the biological or genetic components of mental health rather than any other. Therefore, a core finding of this project is the tests’ possible influence on the legitimacy of mental disorders. Specifically psychiatric legitimacy as this appears to be the approach to mental health that is being prioritised above any other. This is an issue that policy makers would need to consider when introducing the tests.

One question to ask could be why this is so important? Charles E. Rosenberg offers a suggestion in his 1975 paper ‘The crisis in psychiatric legitimacy: Reflections on psychiatry, medicine, and public policy’:

A major justification in medical psychiatry’s legitimacy lies not in its ability to predict, diagnose and cure – nor even in its possible ethical superiority to rival schools of emotional healing – but in the very gravity and the scale of the responsibility is must take. (Rosenberg, 1975, p.255)

Here, Rosenberg is focusing on the scale of the problem psychiatry is faced with, rather than its ability to diagnose, to treat, and even its relationship with other disciplines. The issue is that the introduction of genetic testing in mental health care is likely to have an influence on these additional components as well. Although psychiatry’s actual ability to predict and treat mental disorders through virtue of the tests’ presence is questionable, the issue here is what can happen as a consequence of the claims that can be made through virtue of the tests’ presence. Therefore the discussion could ultimately resolve the relationship, as well as the contrasts, between psychiatry and other schools of emotional healing. In this case, participants’ suggested the tests are likely to have an influence on psychiatric legitimacy and the consequence of this is that the role of biological intervention in mental health care is going to be promoted, prioritised, and subsequently believed. It is here where policy makers will have to devote some serious thought to the possible consequences of the tests’ introduction. The issue to keep in mind is that mental health care and psychiatry do not exist in a vacuum; they are controversial topics that are often in the public eye and are still hotly debated. Therefore, if the suggestions from this research are accurate, introducing the tests and using them in a clinical setting could have a major impact on the way these issues are socially navigated.

In the discussion concerning legitimacy, the primary issue is what can happen as a consequence of a claim, and the belief in this claim. From examination of the participants’ responses, the claim being implied though virtue of the tests’ presence is that mental disorders are increasingly biological issues. Although there has been a focus on what the introduction of genetic testing could do for the dynamic observed in a clinical setting with respect to psychiatric professionals – such as an increased legitimacy for certain practices - policy makers also need to consider what these developments could do for service users. Perhaps the most significant finding relates to the empowerment benefits that
patients could receive as a consequence of being able to orientate around predominantly genetic explanations for mental disorders. Participants suggested that an increased emphasis on biological explanations for mental disorders will mean that patients will have an increased awareness about their experiences and this will cause them to engage with treatment.

I also want to point out that although the cost of the test did not feature heavily in these interviews, the economics behind their introduction is an additional aspect policy makers will have to consider. Introducing the tests will not be as simple as the upfront cost of the technology itself, there will need to be a significant degree of preparation, such as practitioner education and perhaps changes to service timing or structure, which will inevitably cost money. However, the biggest related issue that will require consideration is the eventual cost/benefit ratio through introducing the tests in the long term. For example, participants suggested that there could be resource-saving as a result of being able to get patients stabilised on the correct medication without a trial-and-error period, a result of which will mean that patients can spend less time in hospital. Potentially this could mean there are two opportunities to save money – medication will not need to be wasted and patients may spend less time in a hospital setting.

There are three main points I would want policy makers to be aware of if they were to use the findings of this project to inform their consideration of the tests. In terms of test acceptance from psychiatric professionals, a significant aspect relates to their communicated models of mental disorder. Participants who communicated the biological model of mental disorder were more willing to endorse the developments than participants who rejected the biological model. Recognition of this is important because of the way that the tests were explored in this research project. Typically, genetic tests are not assessed in the way they were here - the criteria traditionally used to do this do not recognise there can be multiple (and conflicting) conceptualisations of the phenomena the tests are intended to operate on.

There are two main thematic areas where there is overall acceptance from participants regardless of their communicated models of mental disorder. These are the tests’ influence on different aspects of the legitimacy of mental disorders and using the tests to pursue treatment rather than diagnosis. Understanding the implications of these two findings could be extremely important from a policy perspective. Emphasising genetics when focusing on the treatment of mental disorders is likely to result in widespread acceptance from the majority of clinical staff. The primary reason for this being that the majority of participants suggested how people respond to medication can, in some way, be attributed to their genetic profile.

However, perhaps one of the most significant findings of my research is the potential influence of the tests on the legitimacy of different areas in mental health care and psychiatry. Several of the developed themes emphasise the suggestion that a consequence of the tests’ introduction is that mental disorders are going to appear to be an increasingly biological phenomenon. Although there are possible benefits due to this, such as patient empowerment and changes to service, the biggest implication concerns the legitimacy of psychiatric approaches to mental health care. This observation aligns with the suggestion that mental health care is not a unified concept, and there are actually several theoretical frameworks operating together at the same time in clinical practice. However, the issue here is that psychiatric approaches to mental health care are increasingly legitimised through virtue of constructing mental disorders in this way.
Although Rosenberg mentions that an issue that needs consideration is the sheer scale of the problem psychiatry faces, it is important to realise that biological, or predominantly psychiatric, approaches should not be considered alone in this endeavour. Although the introduction of genetic test technologies may align with this approach, the most important issue is how all of this will occur in the future and ultimately benefit patients. Therefore, when policy makers balance the issues raised in this project it is perhaps important to emphasise that genetic testing should be considered as a tool that can be used alongside other approaches in mental health care at this very early stage. However, one interesting thematic similarity from the issues raised in this research is that genetic testing for mental disorders has just as many implications for the status of issues in mental health care, such as the legitimacy of different approaches, as it does practical considerations, such as when and where the tests should be used.

What happens from this point onwards remains to be seen, and given the nature of where we currently stand this can really only be speculated. However, I want to finish off this conclusion by making two suggestions on the basis of some of the work that featured in the literature review of this thesis, and both of these issues are broadly concerned with the sociological status of mental health and psychiatry. The first point concerns the Social Studies of Science research (Arribas-Ayllon, et al. 2010; Hedgecoe, 2001) examined at the end of the literature review. These papers focused on researchers in the underlying genetics of mental disorders establishing a narrative that ensured, regardless of any previous failures and the possible influence of any additional components, that their research can essentially always continue. When considering the Arribas-Ayllon and colleagues’ paper (2010, p.19), I included the following quote:

…it confers a kind of respectability to biological psychiatry by adopting the same rhetoric of complexity as that of the much larger and less controversial programmes such as those investigating diabetes and heart disease.

The significant aspect is that almost this exact same situation was observed in one of the major themes of this research. Although there is a shift being seen from strictly research investigations, and therefore the associated narrative surrounding complexity, towards being able to use the results of this sort of research in clinical practice, almost the exact same scenario was observed in this research. However, when focusing on the issue in the context of this research, emphasis was placed on participants’ narratives surrounding the tests that endowed aspects of mental health and psychiatric practice with a new form of legitimacy, one that is suggested to be given to mental health care through the translation of this genomic research into usable clinical tools. One way to approach this could be to consider the accessory functions this development may have on issues such as patient care or the potential ramifications relating to the tests’ influence concerning different representations of mental disorder. Participants suggested that both these components could change dramatically in light of these developments - this is in reference to the tests’ potential empowerment benefits as well as their introduction - meaning mental disorders become better understood as people recognise they can happen to anyone.

However, there is an additional way this point may also need to be considered in the longer term. Although the work of Thomas Szasz has only been mentioned a few times in this research, I want to finish this by considering a passage from his 1969 book ‘Ideology and Insanity’, Szasz writes:
Contemporary psychiatry is a mixture of two very different sorts of things: on the one hand, it is a science, both pure and applied (i.e., the study of man and the practice of psychological healing); on the other, it is a vested interest that controls vast sums of money (allocated to it by the federal and state governments) and wields vast powers (by means of its quasi-legal authority to hospitalise persons without their consent). These two aspects of what we call "psychiatry" have never been adequately separated; moreover, so long as they are not, it will be difficult, if not impossible, for psychiatry to be a "free" science – that it, to search for truth and to teach it without reference to the effect of such enquiry and instruction on the vested interests of psychiatric institutions. The obvious danger of non separation is that of fostering pseudoscience – a system of assertions authoritatively defined as truth and promoted as mental health education to advance the power and the prestige of the psychiatric establishment. (Szasz, 1969, p.169)

It is of paramount importance to understand that any research into psychiatry or mental disorders is situated in a very complex social environment because psychiatry is an extremely controversial area of medicine, and the writings of Szasz certainly confirm this observation. Although research into the underlying genetics of mental disorders certainly relates to the scientific aspects of contemporary psychiatry, it is also crucial to understand that these developments may have an impact on its monetary and authoritative status as well. For example, these developments could perhaps be subject to economic incentives in the future, through treatment being delivered through manipulation of biological pathways, and a large part of this discussion is concerned with the tests providing specific aspects of the practice with increased legitimacy. However, although Szasz appears to consider these components as being largely inseparable from one another, it is important to realise that the developments being made into the genetic underpinnings of mental disorders may begin to start separating the two. This would invariably be a desirable development because a consequence of this could be legitimation of contemporary psychiatry in terms of its scientific abilities, but alongside these changes these developments also offer the chance for psychiatry to break free from its pseudoscientific associations.

In many ways interest in these developments could not arrive at a better time. Regardless of any conjecture concerning what mental disorder is, what causes it, or the best way it should be treated, it is hard to deny the impact this issue has on the world today. It is also important to remember that as time progresses the immediate and long term global impacts of mental disorders are suggested to worsen (Hock, et al. 2012, p.1367). If, as Sullivan and colleagues (2012, p.549) predict, “genetics is a particularly good bet for psychiatry”, then genetics may also be a good bet for easing the global burden of mental disorders through the development of improved diagnostic capabilities and the discovery of effective new treatments methodologies. Therefore, genetic research in psychiatry should be encouraged and investigated to its fullest. However, the reality of the situation is that the biological research this project has been concerned with exploring is still a long way off from being used in a clinical situation. However, that is not to say that we should not start preparing the ground work for its future introduction right now.
6.0 - Appendix
Here are all of the documents used to recruit and inform participants about this research project. Also included is the Psynomics participant information pack as well as the set of questions each participant was asked during their interview. In accordance with the NHS ethical application process, all of the location where the research was conducted identification information has been removed.

6.0.1 – Contact Letter

Dear psychiatric professional,

My name is Christopher Elphick a PhD student from the University Of Exeter and I am conducting research into the development of genetic tests for psychiatric disorders and their potential use in a clinical setting. I would like to invite you to participate in this research study. Please see the attached participant information sheet that contains all of the information about this research, including what I propose to do as well as your possible role in the process.

Thank you for your consideration. If you would like to be included in this study after reading the attached participant information document, please contact the research team using the given contact details or the included reply slip with the stamped addressed envelope and we will arrange the next stage of the research process.

If you have questions or want more information on the study, please contact me by phone (01392 269142) or by email (c.elphick@exeter.ac.uk ). For further information you can contact my supervisors Prof. Stephen Hughes 01392 269133 s.g.hughes@exeter.ac.uk or Dr. Susan Kelly 01392 269139 S.E.Kelly@exeter.ac.uk .

Christopher Elphick.
Participant information sheet for interview study

Title of Project - Genetic testing for psychiatric disorders: Exploring their clinical validity, utility and potential impacts. Investigating practitioner’s responses to the emergence of psychiatric genetic testing.

You are invited to take part in a face to face interview for the above research study. Please read this information sheet thoroughly before deciding whether or not you wish to participate. If there is anything that you do not fully understand, or have any further questions about please contact the research team. If you decide to take part, I thank you. If you decide not to take part there will be no disadvantage to you of any kind and I would like to thank you for considering this request.

What is the purpose of the project?

This doctoral research project aims to study the perceptions and understanding of psychiatric professionals regarding the impacts that recent developments in psychiatric genetics are likely to have in a clinical environment.

What is the purpose of the face-to-face interviews?

The purpose of the interviews is to obtain your views, opinions and concerns regarding the use of genetic technologies in psychiatric practice.

Why have I been chosen?

You are being invited to participate in the above study because you work directly in the field where impacts of the research that has gone into psychiatric genetic are likely to be felt. In addition to this the implications of psychiatric genetics have yet to be considered in this way, and as you work with psychiatric patients on a daily basis your views on the advances are especially important.

What will happen if I take part in the interviews and what else do I need to know?

1. Contact the research team via the included reply slip and stamped addressed envelope, email or telephone – these details can be found at the end of this document – registering your interest in the study.

2. You will be contacted by the research team who will arrange the interview with you at a time and place that is convenient for you.
3. The research team will meet with you. The interview will last approximately 60 minutes, during the interview you will be presented with some printed information about the currently available psychiatric genetic tests in order to provoke discussion.

4. Your permission will be sought to audio-record the interview. All data and results arising from the project will be anonymised and you can be in no way identified. Your identity will not be revealed in any reports or publications through which findings from the study are disseminated.

5. You may withdraw from the study at any time, without giving a reason. Your withdrawal will not affect you in any way.

What are the possible benefits of taking part?

You will be contributing and providing your professional insight to an emergent technological development discipline within psychiatry. In addition to this, because the use of genetic data in psychiatric practice is yet to become routine your input is valued because you will be actively involved in its use.

What are the possible risks or disadvantages of taking part?

The primary disadvantage of taking part in this study is the time that it will take to organise and complete the interview. In addition to this, although you currently work in psychiatry you may still find discussing the topic sensitive therefore if for any reason you wish to withdraw from the study – even during the interview process – you are free to do so. If you have any concerns or you would like to discuss anything about the study feel free to contact the research team, contact details for all of the research team are at the end of this document.

What about confidentiality?

All data, including transcripts from the interviews will be anonymised and you can be in no way identified by name. The dissertation will contain the information ‘Thirty participants representing five different multi agency groups within current psychiatric practice (Pharmacists, Psychologists, Occupational therapists, Nurses and Doctors) operating within the South West of England’ regarding the spread of people interviewed and their geographical location. However, in the data generation process and in the dissertation itself, participants will be referred to via a job title. Such as, ‘G, a psychiatric nurse considers...’ All the information we collect will be treated as confidential and will only be seen by the research team. We will also ensure that the information is stored securely; this will be achieved through electronic storage on a desktop computer. This computer is not connected to the internet, is located at the chief investigators home and is password protected. An identification key will be created that links all of the interview data files with suitable identifiers in order to maintain an appropriate hold on the data in order to efficiently link the audio files and interview transcripts. The key containing the identifying
names, addresses and contact numbers will be held on the password−protected, non
internet connected desktop computer system as a separate Word file by the researcher at
his home. All of the necessary data analysis will be conducted here. The digital audio files
used will be deleted five years after the study. All personal data, such as the identity key
that links your personal data to the interview transcript will be destroyed three months
after the study has been completed.

What will happen to the results of this study?

The primary source of output for these results will be a PhD dissertation Short quotes from
your interview may be quoted in this research papers in a way that will not disclose your
identity. There is also the chance that some of the data generated from this study will be
included in conference presentations and articles.

What will happen to the transcripts of the interviews after the study is over?

My ESRC studentship requires me to offer the interview transcripts into their research data
pool. However, although I’m obliged to make this offer they may not choose to include it
and if they do all of the discussed anonymity measures will still apply, so your identity will
be fully protected. For further information about this please visit http://www.data-
archive.ac.uk/. All transcripts will be handled under the ESRC guidelines that are specifically
tailored to be completely free of all personal identifiable details, thus ensuring your
anonymity and protection.

Who is organizing the study and has is been reviewed by an NHS Research Ethics Committee?

The study is organised by ESRC Centre for Genomics in Society (Egenis), University of Exeter.
A full NHS ethics application was made and submitted to the ‘South West 3 REC’ for review,
before any contact with potential participants was made, and gave a favourable ethical
opinion on this proposed research.

Contacting us

If you have questions or want more information on the study, please contact the Research
Student Christopher Elphick by phone 01392 269142 or by email c.elphick@exeter.ac.uk.
Thank you for your help with this project. For further information you can contact my
supervisors Prof. Stephen Hughes 01392 269133 s.g.hughes@exeter.ac.uk or Dr. Susan Kelly
01392 269139 S.E.Kelly@exeter.ac.uk.
Participant reply slip for interview study

Title of Project - Genetic testing for psychiatric disorders: Exploring their clinical validity, utility and potential impacts. Investigating practitioner’s responses to the emergence of psychiatric genetic testing. This reply slip relates to the study invitation letter and participant information sheet you have received for the above study.

If you prefer you can make contact with the research team to register your interest via the contact information provided on the participant information sheet and the invitation letter. Once this sheet has been completed please put it into the provided stamped addressed envelope and place the letter into a post box.

I have read all of the provided information and would like to participate in the interview process (please tick).

Please provide the following information:

Name: _____________________________________________________
E-Mail: _____________________________________________________
Telephone: __________________________________________________
Position (Nurse/Doctor/etc): _________________________________
Place of work and ward: ____________________________________

Thank you for taking the time to read all of the information and agreeing to take part in this study. A member of the research team will be contacting you shortly.
6.0.4 – Participant consent form

Participant consent form for interview study

Title of Project - Genetic testing for psychiatric disorders: Exploring their clinical validity, utility and potential impacts. Investigating practitioner’s responses to the emergence of psychiatric genetic testing. This consent form relates to the participant information sheet you recently received for the above study ref: (Version 2 – 12th May 2010).

Please tick the boxes and sign. Thank you for your help.

1. I confirm that I have read and understood the information for the above study and have had the opportunity to ask questions about participating in the interviews.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

3. I agree to take part in the above interviews with researcher(s)

4. I agree to the interviews being audio taped and understand that the tapes will be kept securely and although quotes may be used, I will not be identified in any subsequent transcription and publication.

5. I agree to the possibility of the interview transcripts might be entered into the ESRC data pool in accordance with their guidelines, understanding that all discussed anonymity measures will be in place at all times.

______________________________  ________________________________  ____________
Name of participant                  Date                                     Signature

______________________________  ________________________________
Name of Researcher                  Date                                     Signature

1 for the researcher; 1 for your files
6.0.5 – Psynomics Information presented to the interview participant

Diagnostic / predictive testing – Psynome 1 test

GRK3 gene is involved with modulating neurotransmitter levels in the brain. Stress or other factors can increase the release of neurotransmitters. This increase can in turn lead to the development of psychiatric disorders. GRK3 acts as a “brake” in the brain that decreases the brain’s sensitivity to some neurotransmitters. GRK3 therefore, plays a key role in maintaining balance in the brain.

Two different variations in the GRK3 gene have been found that affect its ability to maintain balance: The P-5 mutation and the E/H haplotype. The frequency and effect of these variants are shown below:

<table>
<thead>
<tr>
<th>GRK3 variants</th>
<th>Frequency</th>
<th>Increase in likelihood of having Bipolar Disorder</th>
</tr>
</thead>
<tbody>
<tr>
<td>P-5</td>
<td>3%</td>
<td>1%</td>
</tr>
<tr>
<td>E/H haplotype</td>
<td>15%</td>
<td>7%</td>
</tr>
</tbody>
</table>

The GRK3 test is most useful clinically when there are some psychiatric symptoms present, but the diagnosis is unclear. In this situation, as described above, a positive GRK3 test may indicate a higher probability of Bipolar Disorder.

The table below indicates how the GRK3 test should be interpreted in different scenarios of behavioural symptoms and gene test results.

<table>
<thead>
<tr>
<th>Symptoms by History</th>
<th>GRK3 Test (P-5 or E/H)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No psychiatric symptoms</td>
<td>Positive</td>
</tr>
<tr>
<td>No psychiatric disorder. There is no data to enable interpretation of a positive</td>
<td></td>
</tr>
<tr>
<td>GRK3 test in someone without symptoms.</td>
<td>Negative</td>
</tr>
<tr>
<td>Indeterminate. A negative GRK3 test cannot rule out Bipolar Disorder as other</td>
<td></td>
</tr>
<tr>
<td>genes for Bipolar Disorder may be present.</td>
<td></td>
</tr>
<tr>
<td>Some psychiatric symptoms, but not enough for diagnosis or diagnosis unclear.</td>
<td>Positive</td>
</tr>
<tr>
<td>Bipolar Disorder should be strongly considered. A positive GRK3 test in the</td>
<td></td>
</tr>
<tr>
<td>context of a family history of Bipolar Disorder makes a diagnosis of Bipolar</td>
<td></td>
</tr>
<tr>
<td>Disorder 2-3 times more likely.</td>
<td>Negative</td>
</tr>
<tr>
<td>DSM-IV diagnosis of Bipolar Disorder based on symptoms</td>
<td>Positive</td>
</tr>
<tr>
<td>Bipolar Disorder. A positive GRK3 test helps confirm the diagnosis based on</td>
<td></td>
</tr>
<tr>
<td>symptoms.</td>
<td>Negative</td>
</tr>
<tr>
<td>Bipolar Disorder. Even though the GRK3 test is negative, the patient meets</td>
<td></td>
</tr>
<tr>
<td>criteria for Bipolar Disorder. Genes other than GRK3 may be involved.</td>
<td></td>
</tr>
</tbody>
</table>
The association of the GRK3 gene and Bipolar Disorder have only been shown in Caucasians of Northern European ancestry. If your patient does not have a family member with bipolar disorder or is not a Caucasian of Northern European ancestry, then there is no data at this time to enable interpretation of this result.

The GRK3 gene has not been well studied in other psychiatric disorders. It may also be associated with other illnesses. Therefore, other disorders cannot be clearly ruled out. It is most likely to indicate a higher likelihood of Bipolar Disorder if there are other family members with Bipolar Disorder. For this reason, it cannot be interpreted if your patient does not have other family members with Bipolar Disorder.

**Medication response testing – Psynome 2 test**

The Serotonin Transporter regulates the levels of serotonin in the brain. It is the site of action of SSRI types of antidepressant medication. These drugs block the Serotonin Transporter and increase the level of serotonin. This in turn treats depression in most people.

The Serotonin Transporter has a variation called HTTLPR which has a short (S) and a long (L) form. The L form makes more Serotonin Transporter and has been associated with better response to SSRI antidepressant medications.

One simple interpretation is that people with the L form have more sites in the brain for SSRI antidepressants to work. Everyone has two copies of each gene. Therefore, there are three possible combinations or genotypes: SS, SL and LL. Both SL and LL are associated with good SSRI response and therefore reported as positive by Psynomics, while SS is reported as negative.

<table>
<thead>
<tr>
<th>Serotonin Transporter (HTTLPR) Genotype</th>
<th>Frequency</th>
<th>SSRI response</th>
</tr>
</thead>
<tbody>
<tr>
<td>SS (Negative)</td>
<td>19%</td>
<td>Poor</td>
</tr>
<tr>
<td>SL (Positive)</td>
<td>48%</td>
<td>Good – about twice as likely to respond as SS</td>
</tr>
<tr>
<td>LL (Positive)</td>
<td>33%</td>
<td>Good – about twice as likely to respond as SS</td>
</tr>
</tbody>
</table>

The Serotonin Transporter has also been associated with several other clinical features and responses. These have not been as widely validated as response to SSRI’s but still are worth consideration. They include:

1. Patients with Bipolar Disorder and the SS genotype (Negative test) are at higher risk for hypomania or mania in response to antidepressant medication

2. People with the SS genotypes (Negative test) are at higher risk for developing depression in response to major stresses in life

These results have been validated only in Caucasians. Several studies have suggested that this marker may not be associated with SSRI response in Asians. Hence, if your patient is of Asian descent, these results should not be interpreted to mean they are either more or less likely to respond to SSRI antidepressants. The association with SSRI response has been validated only in
patients with Major Depression. It is not clear that it has the same implications for patients with Bipolar Disorder
7.0 - Reference list


Web page references

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