

Ticced off!



An investigation into the societal perceptions and stigma that surround Tourette Syndrome and the effect this has on those who live with the disorder.

By Estelle Winders

Table of Contents

Introduction	3
Log	5
Chapter one – Societal perceptions of Tourette Syndrome.....	8
Chapter two – Tourette’s on the screen and in print.....	13
Impact of social perceptions on people who live with TS	19
Conclusion.....	26
Resource list	28
Appendix	47
Appendix 1 - Survey for individuals with Tourette Syndrome (TS).....	47
Appendix 2 - Survey for parents of children with TS.....	52
Appendix 3 - Survey for the general public.....	56
Appendix 4 -Interview with Brad Cohen (US).....	60
Appendix 5 - Interview Amanda, spokesperson for the GreaTS (US).....	62
Appendix 6 - Interview with Seonaid Anderson, research manager at Tourettes Action (UK)...	63
Appendix 7 - Interview with Adam Ladell (Australia).....	64
Appendix 8 - Interview with Rose (Australia).....	65
Appendix 9 - Interview with Robyn Latimer, president of the Tourette Syndrome Association of Australia	66
Appendix 10 - Interview with an anonymous adult with Tourette Syndrome	67
Appendix 11 - Interview with Tommy, a thirteen year old boy with Tourette Syndrome	69
Appendix 12 - Fictional portrayals of TS content analysis grids.....	71
Appendix 13 - Non-fictional portrayals of TS content analysis grid	72

Introduction

Tourette Syndrome is one of the most misunderstood conditions on the planet, yet it effects as many as ten per thousand children.¹

I decided to focus on Tourette Syndrome for my PIP after discovering the social stigma that comes alongside the neurobiological disorder following my diagnosis in 2015. Through reminiscing on past events within my micro world I was able to draw upon many of society's misguided perceptions of my disorder. One such occasion was a visit to a neurologist when I was fifteen. This doctor informed me that I showed all the symptoms of Tourette's, however diagnosing me would be unwise, as I would be "putting a label on myself". This made me wonder how society's negative view of Tourette's could have such an impact on my diagnoses and the ways in which I deal with my disorder.

Through my PIP I plan to investigate whether or not there is a stigma surrounding Tourette Syndrome, as well as the agents that have contributed to society's misleading perceptions of the disorder. Based on these factors, my focus question is:

"How have societal perceptions of Tourette Syndrome and the stigma that surrounds it developed in the western world and what impact do these have on those who live with the disorder?"

Both qualitative and quantitative research methodologies have been implemented to obtain useful information to create the foundation of my PIP. I constructed surveys for specific groups of people, such as one for people with Tourette Syndrome, one for parents of children with Tourette Syndrome and one for the general public, to establish a better understanding of society's attitude towards Tourette Syndrome and the impact such conceptions have on those

¹ US National Library of Genetics. (28th JUNE 2016). Tourette Syndrome. <https://ghr.nlm.nih.gov/condition/tourette-syndrome#synonyms>, accessed 4/7/2016

who live with Tourette Syndrome. Interviewing people with the disorder allowed me to gather qualitative data and differing perspectives on how Tourette Syndrome has affected individuals throughout their lives. By conducting content analysis on a variety of mediums I was able to see how Tourette Syndrome is portrayed within different industries. I have also been able to look back at my own experiences of living with Tourette Syndrome to gain a better understanding of the stigma. Secondary research has been conducted to find out more about the social perceptions of Tourette Syndrome and its impacts.

For a cross cultural perspective I have compared how perceptions differ across the globe, including across rural and urban environments, by surveying and interviewing people connected to Tourette Syndrome organisations from Australia, America and the United Kingdom.

Whilst conducting my research I needed to be aware of ethical considerations to ensure that I do not offend anyone who lives with Tourette Syndrome, however as I myself have Tourette's I feel that I have been able to create questions that are sensitive towards others with the disorder.

Upon completion of this research project, I hope to have enhanced my social and cultural literacy by developing an understanding of how Tourette Syndrome is perceived within both the micro and macro worlds and the impacts these perceptions have on others who live with Tourette Syndrome.

Log

In term four 2015 I began to think of topic ideas for my PIP. I then realised that I wanted to include Tourette Syndrome in some way, as the topic meant a lot to me. My focus then turned to what area of Tourette Syndrome I specifically wanted to look at. After reading the negative comments on a Youtube video titled *Tourette's: the Highlights* (2009) I decided that I would investigate societal perceptions of Tourette Syndrome and determine whether or not there was a stigma surrounding it. I then looked at the different research methodologies I could use in order to carry out my research, eventually selecting surveys, interviews, content analysis and personal reflection on my own experiences, as well as undertaking a large amount of secondary research. On the 6th November our Society and Culture class participated in the Society and Culture Teacher's Association PIP day via video conference. This gave me a good idea of what I needed to do in order to carry out the task.

In January I began the process of content analysis by researching portrayals of Tourette Syndrome in film and popular culture. I then developed a table in which I could break the information into different sectors. I viewed a number of films and documentaries and read the book *Welcome to Biscuitland: a year in the life of Touretteshero* (2012) by Jessica Thom, a prominent advocate for Tourette Syndrome in the United Kingdom. Over the following month I continued to watch a number of documentaries that showed what it was like to live with Tourette Syndrome. One of these was *Tourettes on the Job*², which allowed me to investigate the impact of Tourette Syndrome in later life. I also began conducting secondary research that would be helpful when writing my report.

As the new school year started my PIP was not given as much attention whilst I dealt with the many assignments I needed to complete for my other subjects, however I continued to do content analysis on fictional films featuring characters with Tourette Syndrome. Term two

² BBC, aired on ABC 2 on Friday 29th January 2016

was the most productive due to the addition of some class time to discuss and provide group feedback. I created three different surveys and used social media as a way to encourage people to fill them out. I posted the survey for people without Tourette Syndrome on my personal Facebook page and asked various family members to share my post in order to attain responses from a wide variety of people from all environments. I issued paper copies to the year eleven society and culture class and various year seven students at my school to fill out in order to get the perspective of younger people. I then posted the survey for people with Tourette Syndrome and the one for parents of children with Tourette's in a closed support group run by the Tourette Syndrome Association of Australia. This gave me a large number of responses from people of all ages and allowed me to investigate the impact of societal perceptions and stigma upon people with Tourette's.

I then began to conduct interviews with individuals from Australia, America and the United Kingdom who have experience with Tourette Syndrome in order to gain a better understanding of the stigma surrounding the disorder. To do this I researched organisations dedicated to raising awareness and providing support for people with Tourette Syndrome. With the emails found on their websites, I then contacted the various organisations to ask if they would be willing to be interviewed. Every single one replied and agreed to be interviewed. Due to my remote location and the fact that most of these organisations were overseas, I had to send my interview questions via email however I found that this led to lengthy responses that were highly useful. I was able to secure a phone interview with the president of the Tourette Syndrome Association of Australia, who then sent me her notes from a recent talk about social stigmas of Tourette Syndrome that she had presented at a conference.

In June I began the process of writing my report. This took more time than I anticipated and I found that I needed more primary and secondary research to assist me in my writing. I

searched for more individuals with Tourette's to interview and for statistics to ensure that the evidence I was giving was completely accurate. I made sure I referenced my primary and secondary sources as soon as I used them in order to make sure I had not left any out.

In July I was still writing my report and had broken each chapter down into subcategories in order to make sure I was covering all aspects of my topic. As I am very passionate about my topic, I found the writing process immensely enjoyable. However, when it came to edit the report I discovered that I had gone extremely over the word limit and had to scale back my writing, leaving only the most important and relevant information. I then continued to edit my report in the lead up to the due date in order to ensure that there were no spelling mistakes or grammatical errors.

Chapter one – Societal perceptions of Tourette Syndrome

Tourette Syndrome is prevalent in one per cent of children and in five per thousand adults³, yet it is still a highly misunderstood disorder. Within my research I aimed to find out whether perceptions of Tourette Syndrome have evolved over time and if they had become more positive. I learnt that these perceptions are perpetuated by a number of factors that have changed with the advancement of society's morals and values.

Throughout history, many religious groups associated the symptoms of Tourette Syndrome with demonic possession. The first written account of Tourette Syndrome is believed to have been in 1486 in the *Malleus Maleficarum*, a guide to witchcraft penned by Jakob Sprenger and Heinrich Kraemer, two Dominican Monks. The subject in question was unable to stop these behaviours, so his symptoms were attributed to an act of the Demon and he was supposedly cured by exorcism. In medieval times, the church was the single most dominant institution in England⁴, thus this treatment of individuals exhibiting tic-like behaviour can be associated with the morals and values enforced by the church system upon the general public. These early perceptions of Tourette Syndrome created the foundations for the stigma that remains in modern day society

Since medieval times, perceptions of the disorder have evolved and people with tics are less frequently perceived as performing "sinful" acts. However, a minority of people today still believe that Tourette Syndrome is a form of demonic possession. In a blog post, British Tourette Syndrome activist Jessica Thom shared an email she had received that told her she "was in urgent need of exorcism". The sender of the email believed that "every person with Tourettes Sin-drome is possessed by a spirit of Satan" and that Thom's Tourette's could be

³ Tourette Syndrome Association of Australia Inc., April 2011

⁴ Alixe Bovey. (Date of publication unknown). *Church in the Middle Ages: from dedication to dissent*. <http://www.bl.uk/the-middle-ages/articles/church-in-the-middle-ages-from-dedication-to-dissent> (British Library online), accessed 6/7/2016

cured through spiritual intervention. Thom shared the email as it “*perfectly captures a specific attitude towards disability – one that attributes blame and casts judgement on the person with the condition*”⁵. The email reflected the negative views displayed in the article “*Tourette Syndrome: Synaptic or Demonic?*” In the article from a website dedicated to scripture, the author states that the children who live with Tourette Syndrome are not suffering from a neurological disorder, but suffering at the hands of their “father” and need “*salvation from Satan’s clutches*”.⁶ These misconceptions can have an extremely negative impact on the people who live with Tourette Syndrome as they are an unfavourable portrayal of the disorder and give misleading information about their condition.

Psychoanalyst Sandor Ferenczi, a disciple of Freud, was intrigued by tics, believing that they were related to the act of masturbation and that tics were ways of expressing erotic feelings through vocalisation⁷. In the article “*Psycho-analytical observations on tics*” (1921), Ferenczi suggested that people afflicted with tics were both infantilised and narcissists who lived under the rule of desire and could withstand neither restrictions, nor being opposed. Ferenczi’s theory could have possibly further misguided people’s perceptions of Tourette Syndrome by giving a negative description of those who live with the disorder and therefore building upon the stigma.

The way in which Tourette Syndrome is viewed by society has changed overtime, however the people who live with the syndrome are still prone to prejudice due the many misconceptions of the disorder held by the general public. Surprisingly, in a survey for people

⁵ Jessica Thom. (2012). Repossessed. www.touretteshero.com/2012/10/04/repossessed, accessed 13/6/2016

⁶ Unknown author. (Date of publication unknown). Tourette Syndrome: Synaptic or Demonic? www.a-voice.org/main/Tourette, accessed 10/6/2016

⁷ Francisco M.B. Germaniani, Anna Paula P. Miranda, Peter Ferenczy, Renato P. Munhoz and Helio A.G. Teive. (2012). Tourette’s syndrome: from demonic possession and psychoanalysis to the discovery of genes

without Tourette's a large number of respondents were able to identify three non-stereotypical correct facts about Tourette Syndrome, however this may be due to rising levels of awareness. Approximately eighty per cent of people with Tourette Syndrome are also effected by comorbid conditions throughout their lives, such as Attention Deficit Disorder (ADD), Attention Deficit Hyperactivity Disorder (ADHD), Obsessive Compulsive Disorder (OCD), Oppositional Defiance Disorder (ODD), dysgraphia, echolalia, anxiety and sensory processing disorders⁸, however only forty three per cent of those surveyed knew these conditions often coincided with Tourette Syndrome. Surveyed parents of a child with Tourette Syndrome agreed that most people are unaware of these conditions and the general consensus was that their children found their comorbid conditions just as difficult, if not harder to live with than their tics. Multiple parents stated that many medical professionals were also unaware of these coinciding conditions.

The word stigma can be defined as a mark of shame or disgrace⁹ and has been applied to all areas of society. The stigma of Tourette Syndrome

“Depicts that because of the disorder and the social complications behind it, people with Tourette are outcasts and do not fit in because of their differences. It has come to be because people stray away from things that are not “normal”. Therefore, because of the movements and sounds that uncontrollably occur in people with Tourette Syndrome that do not occur in most others, they are stigmatised for their disorder¹⁰.”

Ninety per cent of survey respondents with Tourette Syndrome and ninety four per cent of surveyed parents of a child with Tourette Syndrome agreed that there is a stigma surrounding the disorder. Many said that their tics have been perceived as being performed on purpose

⁸ Valsamma Eapen, Rudi Crncec, Sarah McPherson and Corina Snedden. (2013). Tic Disorders and Learning Disability: Clinical Characteristics, Cognitive Performance and Comorbidity

⁹ Australian Pocket Oxford Dictionary, sixth edition (2009)

¹⁰ Interview with Amanda from the GreaTS, conducted 28th May 2016

and can be voluntarily stopped, or that it is seen as humorous and only consists of involuntary swearing. These stigmas had an immense impact on those who live with the disorder and their macro world interactions, with responses such as finding going out in public difficult, uncomfortableness when telling others they have the disorder, discrimination and difficulty finding employment.



Currently, there is no cure for Tourette Syndrome, however acceptance and awareness of the disorder can be an immense benefit to those who live with it. Sixty nine per cent of surveyed people with Tourette Syndrome said that they had been accused of ticcing either on purpose or to gain attention. The respondents said that incidents such as these made them feel angry, sad, misunderstood and as though their condition was not being treated seriously. One respondent commented,

“People (even relatives) don’t understand the complexities of tics so they play them down.

They don’t understand the exhaustion or the pain and discomfort some tics can give.”

¹¹ Figure 2: Mr Fish Lee. Tourette’s Life. [Comic strip]. Available at: <https://www.facebook.com/touretteslife/> [Accessed Friday 29th July 2016]

Fifty-six per cent of survey respondents said that a relative had either not accepted or made jokes about their Tourette's, showing that the prejudice and stigma of Tourette Syndrome can intrude upon the micro world, a place where people are supposed to feel accepted.

Seventy nine per cent of parents of a child with Tourette Syndrome said that someone had told their child to stop ticcing. According to the parents, this made their children feel frustrated, upset, alone, helpless and self-conscious. Forty one per cent of parents said that in the past their child had been accused of putting on tics in order to seek attention. One parent elaborated on this by saying,

“On many occasions there has been an assumption that she could somehow manage to control tics, which was extremely frustrating for her.”

These statistics are representative of society's general view of Tourette Syndrome, as the lack of understanding described by survey respondents stems from the many misconceptions surrounding the disorder. The large amount of incorrect information about Tourette Syndrome and misleading portrayals of the disorder could possibly be a leading factor in why so many people with Tourette Syndrome are subject to such large amounts of scepticism.

Chapter two – Tourette’s on the screen and in print



A character with Tourette Syndrome yells obscenities directed at other people from a car in the 1999 film “Deuce Bigalow: Male Gigolo”.¹²

Fifty-seven per cent of survey respondents indicated that their first introduction to Tourette Syndrome was through film and television. In order to investigate the factors that influence societal perceptions I conducted content analysis, from which I was able to determine that American comedy films provided the most misleading accounts of Tourette’s.

The concept of Hollywood Tourette’s and how it is used as a comedic device

From my research I was able to conclude that the most common portrayals of Tourette Syndrome were exaggerated and many of the characters with Tourette’s were shown in the worst of circumstances. The majority of these characters also had coprolalia, tics that involve the uttering of curse words, even though coprolalia only affects around ten per cent of people with Tourette’s.¹³ In the American comedy films *Deuce Bigalow: Male Gigolo* (1999) and *Not Another Teen Movie* (2001), the characters with Tourette’s seemed to only have coprolalia tics, which were often directed at other characters and their roles within the two films were purely for comedic purposes. Interestingly, these two characters were female,

¹² Fig. 1 Mitchell, 1999. *Deuce Bigalow: Male Gigolo*

¹³ New Jersey Centre for Tourette Syndrome. (2016). 20 facts about Tourette Syndrome you may or may not know. <http://www.njcts.org/tsparents/20-facts-about-tourette-syndrome-you-may-or-may-not-know>, accessed 14/7/2016

when in reality males are three to five times more likely to have Tourette Syndrome than females¹⁴. The second most prominent thing I noticed was that within many comedy films is that Tourette's is described as purely "saying what you think". An example of this is the film *Our Idiot Brother* (2011), in which two characters, neither of whom has Tourette Syndrome, are arguing and one is constantly blurting out uncomfortable truths. The other character replies with "*Dude, do you have Tourette's?*" This transforms Tourette Syndrome into the punch line of a joke and can prevent audiences from developing a proper understanding of the disorder.

Eighty six per cent of surveyed people with Tourette's agreed that it is often portrayed as being comedic or greatly exaggerated in the film industry. Such misrepresentations can have an immense impact upon the people who live with the disorder. Whilst many people who completed my surveys said that they ignore the incorrect portrayals, others said that the distortion of Tourette Syndrome in film made them feel sad, angry, frustrated, misunderstood, belittled, embarrassed and ashamed. Multiple people said that the people making these films seem to think ticcing makes good comedy, yet have no idea what it is like to actually live with the disorder and how such misconstrued examples can have a negative impact on those who have Tourette Syndrome. Many of the parents I surveyed who have a child with Tourette Syndrome said that whilst their children were too young to comprehend these misrepresentations, such portrayals upset them as parents. Those whose children had witnessed the caricature way in which Tourette's is portrayed in film said that it made the child distressed and embarrassed. Both parents of children with Tourette Syndrome and people who live with the disorder indicated that the exploitation of Tourette's within the media and film industries sets a precedent for the development of incorrect societal

¹⁴ Centres for Disease Control and Prevention. (2012). A National Profile of Tourette Syndrome, 2011-2012. <http://www.cdc.gov/ncbddd/tourette/data.html>, accessed 14/7/2016

perceptions in order to make an erroneous judgement on those who actually live with Tourette Syndrome.

The role of the media in the perpetuation of social perceptions and stigma of Tourette Syndrome

Stories that appear in the media are often dramatised in order for them to appear more appealing to the public and this is the case for many stories about Tourette Syndrome. In an interview with the president of the Tourette Syndrome Association of Australia¹⁵, I discovered that quite often when someone within the media wishes to run a story on Tourette Syndrome the journalist only wants to show the most severe or stereotypical cases of Tourette's and will sometimes turn away when offered a milder case to report on. In an interview I conducted, the research manager at Tourette's Action in the UK stated

“The most interesting thing for media companies is that they want to find people with the most extreme forms of TS (Tourette Syndrome) as it makes a more interesting story for TV or film. I think sometimes that people with milder TS may get a little frustrated that this receives such focus.”¹⁶

Eighty seven per cent of people from the general public whom I surveyed stated that they had learnt about Tourette Syndrome through television and film, therefore these over exaggerated or inaccurate media portrayals could be a major factor in the perpetuation of damaging societal misconceptions.

¹⁵ Interview with Robyn Latimer, president of the Tourette Syndrome Association of Australia, conducted on the 18th March 2016

¹⁶ Interview with Seonaid Anderson, resource manager at Tourettes Action (United Kingdom), conducted 4th July 2016

Sharing the stigma – social media and its impact upon social perceptions of Tourette

Syndrome

The frequent evolvement of technology has seen radical developments in the creation of social media and the way in which society views, processes and shares information. This has been both a positive and a negative for people who live with Tourette Syndrome as it has created a platform for raising awareness and provided a way to connect with others who live with the disorder, however it has also allowed for the stigma to be spread in an immense manner. YouTube videos such as *Tourette's Guy* (2007), in which a man pretends to have Tourette Syndrome by yelling out random phrases and curse words, have accumulated over thirty million views yet provide a negative connotation to the disorder and often alludes to misconceptions of how people with Tourette Syndrome really act as well as the severity of their symptoms. Other viral videos include “*3 Men With Tourette's On a Holiday*” (2012) that do include people who actually have Tourette Syndrome and aims to reduce the stigma surrounding Tourette's, however many of the five million viewers misinterpreted the video as being comedic, leaving comments such as “*this has to be the funniest disease ever invented*” and “*I love this. Every time I need a laugh I put in tourettes holiday on you tube it's brilliant*”, proving how many members of society do not see Tourette Syndrome as a serious neurobiological condition, instead as something to poke fun at. YouTube attracts more eighteen to thirty four year olds than any cable network in the US¹⁷, creating a global platform that allows the stigma surrounding Tourette Syndrome to spread even further at a phenomenally faster pace. For many people, these videos are their first introduction to Tourette Syndrome, therefore instilling false perceptions and immediately creating a sense of ignorance towards the disorder. These videos can impact on the people who live with Tourette Syndrome, with one person I surveyed answering

17 YouTube. (2016). Statistics. <https://www.youtube.com/yt/press/statistics.html>, accessed 15/7/2016

“People I’ve been around in the past have seen these kind of things and judged me based on them”.

The implementation of social media has also assisted in the expansion of the stigma surrounding Tourette Syndrome, through users “liking” and sharing content that alludes to incorrect perceptions of the syndrome, as well as leaving comments that are belittling to those who actually have the disorder. These forms of modern day communication are available to society any where and any time and not only assist in the spread of misleading YouTube videos, but also introduces other ways in which to create false perceptions of the disorder. One such example is the cultural phenomena of Internet memes – a virally transmitted cultural symbol or social idea that normally takes form in an image, video or piece of text that are typically humorous in nature. Upon analysis of many of the memes created about Tourette Syndrome, I determined that the most common themes represented were cursing, loud vocal outbursts and people with the disorder just saying whatever is on their mind. Most of the memes were designed to be humorous, but were actually derogatory towards people who have the condition. This material can be especially damaging towards younger people with Tourette’s and create a false image for the disorder, with one surveyed girl aged under twelve saying

“People think I am like those people on Facebook that are pretending to have Tourette’s but I am not like that. It is not funny, it hurts and is not nice”.

Adam Ladell, a sixteen year old known for attaining second place on *The Voice Australia 2016* (Nine Network), started his YouTube channel *TicTwitchTeen* in 2014 to speak to and help others who, like him, have Tourette Syndrome. Ladell agreed that the viral videos about Tourette’s impact society’s view on the disorder and that many see them as comedic

entertainment. A video Ladell posted of himself singing went viral, gaining over fifteen million views. In an interview conducted with Ladell¹⁸ he said,

“On one side there were a lot of positive comments but on the other there were a lot of comments related to bullying.”

18 Interview with Adam Ladell, conducted 14th July 2016

Impact of social perceptions on people who live with TS

Whilst most people with Tourette Syndrome can lead happy and successful lives, the impact of society's perceptions of the disorder and the stigma that extends from such misconstrued perceptions can be influential on their ability to have the same life experiences as others. The effect of the consequences of these ill-conceived societal perceptions on crucial moments in the life of people with Tourette Syndrome, such as coming of age rituals, the socialisation process, forming relationships and seeking employment, was evident in primary findings.

Socialisation is a lifelong process of learning in which the individual learns to deal with the social world by gaining knowledge and understanding of the rules and expectations for the social situations they may find themselves in. For youth with Tourette Syndrome, the influences of secondary socialisation typically consist of the people who carry the most misconceptions about their disorder.

Stage five of Erik Erikson's theory of personal and social development states that between the ages of twelve and eighteen peers emerge as a critical influence, with the need to conform at its highest point. The social group sets out norms to help the youth master uncertainty, including what clothes to wear, what music to listen to and what language to use. Youth who are perceived as "different" from their peers may become victim to social exclusion, which could include children and adolescents with Tourette Syndrome.

In a study by the University of Washington¹⁹ ninety-six youth with Tourette Syndrome completed a quality of life measure that assessed their sense of self, their social relationships, their environment and a global assessment of their satisfaction of how their life was going at that point in time. Their answers were then compared to youth who had Attention Deficit

¹⁹ Tari Topolski PhD, 2015, Quality of life among youth with Tourette Syndrome, <https://www.tourette.org/blogs/teen-talk/quality-life-among-youth-tourette-syndrome/>, 27/5/2016

Hyperactivity Disorder, youth who had mobility limitations and used either wheelchairs or crutches and youth who did not have any type of chronic condition. In all areas, those with Tourette Syndrome reported the lowest quality of life scores. Results showed that youth who had more severe tics or had Obsessive Compulsive Disorder or Attention Hyperactivity Disorder as comorbid conditions reported feeling more unwelcome, spent less time with friends and had more family arguments than youth who had milder tics and no comorbid conditions. The most common themes mentioned were about the difficulties youth faced in school due to the ridicule they received because of their tics or their tics interfering with their ability to complete exams. A number of the participants felt a need to protect themselves and they believed the only solution was to socially isolate themselves from their peers. The main message taken from this study was that the stigmatisation of Tourette Syndrome is hurtful and has an impact on both the quality of life and the socialisation process of those who live with the condition.

A 2007 study by the University of Wisconsin-Milwaukee²⁰ stated that those with Tourette Syndrome are viewed as more withdrawn and less popular than their peers. The paper made reference to a 1998 survey of individuals with Tourette Syndrome about their educational experiences which revealed that sixty eight per cent had difficulties getting along with classmates and seventy per cent of children with Tourette Syndrome were teased by their peers because of their tics. Children and adolescents with Tourette's may also experience difficulties with teachers and tend to be more withdrawn and aggressive than students without the disorder. This led the professors conducting the 2007 study to conclude that children with Tourette Syndrome appear to have an increased risk of social rejection and isolation. This is further extended upon by suggesting that an alternative explanation for the social difficulties

²⁰ Brook A Marecks, Kristoffer S Berlin, Douglas W Woods and W Hobart Davies, 2007, Impact of Tourette Syndrome: A Preliminary Investigation of the Effects of Disclosure on Peer Perceptions and Social Functioning

of individuals with Tourette Syndrome is the negative perceptions and stigmatisation of the disorder from the general public, which can be amended by changing people's attitudes towards the syndrome.

In my own experience, I was not diagnosed with Tourette Syndrome until the age of sixteen and was part of a small, supportive year group at a rural school, so my disorder never caused me to become a subject of bullying or discrimination, however I found it difficult to come to terms with my diagnoses. Telling people I had Tourette Syndrome was difficult as I did not want to be perceived as different from everybody else. I did not fit the stereotype outlined by society of someone with Tourette Syndrome and, as I did not know anyone else with Tourette's due to the isolated location of my home town, I felt no one understood what I was going through. Socialising with other adolescent females became challenging, as whilst they were expressing their desires for straighter hair or flatter stomachs all I wished for was to stop making strange noises and the ability to control my body. The main factors that influenced these feelings were the extreme ways in which Tourette's is portrayed within film and the media. I also discovered that I had to educate many people within my micro world about Tourette Syndrome, as many of them had only previously witnessed Tourette's through the exaggerated mediums commonly seen in film and television.

Thirty per cent of survey respondents to a survey for people with Tourette's were aged between thirteen and eighteen and all struggled at some point during the coming of age process due to societal perceptions of their disorder and the impact this had on their sense of self. Confidence was a major predicament for these adolescents, who came from both rural and urban environments, with responses such as finding their disorder embarrassing, problems assimilating with their peer group and unwillingness to socialise due to tics. Three teenagers said that schooling had become an issue for them, stating their teacher's inability to understand their condition, not being eligible for extra educational assistance and being

excluded by peers and teachers as reasons for their lack in confidence. A large amount of these students were victims of bullying, which effected their confidence and sense of identity. In some cases, this unfair treatment led to mental health issues such as depression and anxiety, which further complicated their efforts to create a sense of belonging within their peer group. One boy from a rural environment said that he had been bullied because of his tics and is now home schooled due to his teacher's lack of understanding. An adult respondent said that during high school she developed social anxiety as a result of trying to supress her tics so they would be less noticeable to others. In an interview with Tommy²¹, a thirteen-year-old boy with Tourette Syndrome, he said that the stress of not being able to fit in and finding it hard to focus had impacted upon his schooling.

Impact of social perceptions and stigma on adult life

In a large number of cases, tics tend to cease around the age of twenty five as the brain becomes fully developed so many people who suffered Tourette Syndrome as a child are able to live a tic-free adult life²². However, this is not always the case and there are many adults who still live with the disorder and its comorbid conditions. For some of these adults the many damaging societal perceptions and stigma of their disorder stays with them throughout their lives, impacting on important life features such as employment, relationships and personal wellbeing.

The difficulties of obtaining employment whilst living with Tourette Syndrome are explored in the British documentary *Tourette's on the Job* (2016). The documentary showed a broad range of cases, most of whom found it hard to make friends and interact within the macro world, as well as trouble seeking employment. One of the people in the documentary is Brad

²¹ Interview with Tommy (name used with permission), conducted 14th July 2016

²² Interview with Robyn Latimer, president of the Tourette Syndrome Association of Australia, conducted on the 18th March 2016

Cohen, an American teacher, who was rejected by twenty four schools because of his loud vocal tics before one gave him a chance. In an interview²³, Brad said his Tourette's had caused him to be excluded from restaurants, movies and libraries, as well as causing issues on airplanes. Five Australian survey respondents over the age of eighteen said that their condition had impacted on their career prospects. Four said that they had either not been selected for or made redundant from a job due to their Tourette Syndrome. In an interview, Amanda from the GreaTS²⁴ stated,

“Finding employment is a difficult topic; some people put Tourette Syndrome on their application while others choose to explain to their employer in person, and some even think it will hinder their chances of employment and decide not to say anything.”

This quote is allegorical of the consequences of society's misconstrued perceptions of Tourette Syndrome, their effect upon those who live with the disorder and how some people with Tourette's feel that they have to hide their condition in order to assimilate within the work place.

The stigma that has been created from the varying misconceptions can also be a burden when beginning a relationship. Trust and acceptance are important factors in a relationship, so if someone were unable to accept their partner's disability, it would be hard for the relationship to continue. For some people with Tourette's it can be difficult to be entirely open when trying to have a relationship with someone that doesn't know or understand their disorder. Starting a family can be even more daunting for someone with Tourette's as there is a possibility the child will also have Tourette Syndrome, causing a difficult decision for that couple to make, as they have already experienced the stigma surrounding the disorder and may not want their child to go through the same thing.

²³ Interview with Brad Cohen, conducted 26th May 2016

²⁴ Interview with Amanda from the GreaTS, conducted 28th May 2016



The impact of Tourette Syndrome on forming romantic relationships is further explored in Britain's *The Undateables* (2012-2016), a reality television programme featuring people with a disability searching for a partner. Throughout the series, three people with Tourette Syndrome are shown and they discuss the impact their disorder has on their romantic conquests. The first episode features Luke²⁶, a comedian who is petrified of approaching a girl for fear of offending her with involuntary obscenities. In the past, his Tourette's had intervened with his dating life, including an incident when a motor tic caused him to throw a drink over a girl he was on a date with. Whilst on a blind date, he suppresses his tics for over two hours, which caused him a lot of pain. Twenty eight year old Ruth²⁷ said her motor and vocal tics had caused her to feel alienated by society and that her previous boyfriend had not been supportive of her disorder. The concept of dating was challenging for Ruth as she has no

²⁵ Figure 4: Mr Fish Lee. Tourette's Life. [Comic strip]. Available at: <https://www.facebook.com/touretteslife/> [Accessed Friday 29th July 2016]

²⁶ *The Undateables*. (2012). Richard/Luke/Penny, series 1, episode 1, Channel Four, 3rd April 2012

²⁷ *The Undateables*. (2012). John/Ruth/Zoe, series 3, episode 2, Channel Four, 9th January 2014

The Undateables. (2012). Daniel/Ruth/Michael, series 4, episode 4, Channel Four, 26th January 2015

control of what vocal tics may come out whilst on a date and in the past her motor tics have caused her to involuntarily kick and hit her dates.

Conclusion

My personal interest project greatly increased my social and cultural literacy and created a channel for me to connect with a large number of people in similar situations to mine. I was greatly surprised by the support and assistance I received from a wide variety of sources, from which I was able to attain an understanding of the societal perceptions and stigma of Tourette Syndrome and how they impact upon those who live with the disorder. I found that people with Tourette Syndrome and parents of children with the disorder were very open with me when completing my surveys as I understood their feelings and was able to tailor questions that would not be offensive or insensitive towards them.

If I were to ever repeat this research process I would change a few elements in order to gain a more effective response. I would include more open answer questions within my survey as I believe the large amount of multiple choice questions I included limited the amount of qualitative information I could draw conclusions from. I would also hold focus groups in order to achieve a better understanding of both societal perceptions of the disorder and how the stigma affects those who live with it. However, due to my remote location I was limited in the ways in which I was able to conduct my research. As I do not know anyone else with Tourette Syndrome in my area I was unable to hold face to face interviews or focus groups.

I relied heavily on technology when gathering my research. I had to conduct most of my interviews with organisations dedicated to assisting people with Tourette Syndrome by email due to time differences and their overseas locations, yet I believed this to still be successful as I found I was given more detailed responses. I used social media to distribute most of my surveys, which was actually a highly effective method as I was able to reach a large amount of respondents from both rural and urban environments that otherwise would not have responded.

I believe that whilst undertaking this PIP I was able to increase my social and cultural literacy by developing a deeper understanding of how western world perceptions of Tourette Syndrome have perpetuated a stigma and the impact this has on both the micro and macro world of the people who live with the disorder. From the feedback I received on my surveys, I found that through my research I was raising awareness for Tourette Syndrome and changing the perceptions of others, therefore increasing their social and cultural literacy. One organisation in England asked if they could post our interview and an article I wrote on their website, which received over two thousand views in the first few days after posting, thus raising further awareness for the syndrome. Through doing this project I was able to personally understand the stigma of my disorder and became more comfortable talking to others about it.

Resource list

Books:

Lee, Caspar and Riordan Lee, Emily, 2016, Caspar Lee, Michael Joseph (an imprint of Penguin Books), England

This biography of YouTube creator Caspar Lee, written by Lee and his mother, features a chapter about Lee's childhood experiences with Tourette Syndrome. The chapter accurately describes Tourette Syndrome and the societal perceptions surrounding the disorder. It shows the perspectives of both a child with the disorder and their parent and addresses the pain caused by tics.

Patterson, James and Friedman, Hal, 2008, Against Medical Advice, Grand Central Publishing, USA

Against Medical Advice is a fictionalised account of Cory Friedman's experience of growing up with Tourette Syndrome, written by his father Hal Friedman and family friend, author James Patterson. The novel was a fairly accurate description of life with severe Tourette Syndrome and the impacts it has both physically and mentally on the sufferer and their family, however it is not fully a primary source as it was not written by Cory himself and some events may have been exaggerated in order for the book to be more appealing to audiences.

Thom, Jessica. 2012, Welcome to Biscuitland: A year in the life of Touretteshero, Souveneir Press Ltd, England

The book *Welcome to Biscuitland: A year in the life of Touretteshero* consists of a year's worth of diary entries penned by Tourette's activist Jessica Thom and allows readers to gain an understanding of what it is like to live with Tourette's. As the author has Tourette

Syndrome, it is an accurate portrayal that not only educates people about the difficulties of living with Tourette's and shows how her condition is viewed by society, but also encourages audiences to see the humorous side of her tics.

Whitley, Marea Hannah. 2004, Black Bird, Books and Writer's Network, Australia

Black Bird, the autobiography of a girl with Tourette Syndrome who grew up in the Catholic education system in the 1960s, was helpful in determining past perceptions of the disorder.

Wilson, Dr Jeni Not Just Ticked Off – stories and strategies for managing Tourette

Syndrome, date of publication unknown, Tourette Syndrome Association of Victoria

This guide published by the Tourette Syndrome Association of Victoria gives a helpful background of the disorder and includes stories from children with Tourette Syndrome and their parents. The title also inspired the name of my PIP.

Newspaper and magazine articles:

Baker, E. (8th May 2016). Tourette's group key. The Examiner, 9/6/2016

This article recognises that one in one hundred people live with the lifelong neurological disorder Tourette Syndrome and gives a definition of the term tic. It states that there is no cure and that empathy and understanding are crucial to the wellbeing of people with the disorder. It features an interview with Rebecca Harrington, a mother of a child with Tourette's, who said that the misconceptions that surrounded the disorder could lead to feelings of isolation, with swearing being the biggest misconception. The article is valid as it promotes correct facts about Tourette Syndrome and recognises comorbid disorders.

Brown, Tara (reporter), Taylor, Steven and Naillan, Hugh (producers), 12/9/2008, Out of Control, www.sixtyminutes.ninensn.com.au, 6/11/2016

This Sixty Minutes Australia report consists of an interview with a teenage girl who lives with Tourette Syndrome and portrays the seriousness of her debilitating condition. However, it has the tendency to be exaggerated, biased and over dramatised in order to sell the story. Whilst it aims to raise awareness for Tourette Syndrome, the report includes a disclaimer at the start for offensive language and behaviour by the girl with Tourette's.

Conway, D. (11th May 2016). Bravery to face life in "cruel" world. Wentworth Courier, p. 13, 9/6/2016

The article, written during Tourette Awareness Week 2016, features an interview with seventeen year old HSC student Jonty Willett, who lives with TS. Willett stated that his condition was very misunderstood and often very frightening for people who did not understand. According to Willett, who aims to promote that Tourette sufferers are not "freaks" and "weirdos", the worst thing people have done is imitate his tics. The article also says that having Tourette Syndrome can be expensive, with tic-relieving medication not receiving any form of government compensation, despite costing approximately \$245 every six weeks. The article is relevant as it correctly educates people about TS and addresses the social stigma surrounding it, as well as discussing the different societal perceptions. However, there is a slight dramatisation of the headline and opening statement in an attempt to draw readers in.

Elliot, Chris. (Monday 29th February 2016). "Challenging stereotypes about Tourette Syndrome". The Guardian, accessed 13/6/2016

The article discusses how Tourette Syndrome is often used as a "cheap joke" within the media and that the way the disorder is viewed and reported on in the media needs to change. It also states that people who live with TS should not be labelled as "sufferers" as it

reinforces a lot of the stereotypes about Tourette's. It was useful in determining the different stereotypes of Tourette Syndrome.

French, Chris. (Wednesday 9th July 2014). "Pope Francis and the psychology of exorcism and possession". The Guardian, accessed 10/6/2016

The article discusses Pope Francis formally recognising the International Association of Exorcists, a group of priests from around the world who supposedly cast out demons. The article mentions many medical conditions, including Tourette Syndrome, that had previously been misinterpreted as demonic possession and how exorcism was used as a means of a cure. The article accurately describes Tourette Syndrome and points out that only ten per cent of sufferers have coprolalia.

Metro web reporter, 8/1/2012, David Cameron apologises for Ed Balls Tourette Syndrome gaffe, www.metro.co.uk, 6/1/2016

British MP David Cameron made an insensitive Tourette Syndrome joke concerning a fellow politician who did not have the condition. The article does not educate about Tourette's and shows that Tourette Syndrome is often used to joke about someone who swears a lot. I can use the article to show how the stigma of Tourette Syndrome even extends to politics.

Miller, Anne. (13th November 2010). "American Idol" segment helps push Tourette's syndrome into cultural mainstream. Washington Post, 6/1/2016

The author's husband has Tourette Syndrome, therefore the article is an accurate account of the disorder. Correct medical facts are given and it talks about the social stigma of Tourette Syndrome, as well as the misrepresentations in popular culture. The article contains interviews with many different people, therefore a broad range of perspectives and cases are shown.

Tay, Daniel. (28th July 2014). How one woman's battle with Tourette's and discrimination turned her into an advocate for fairness in the workplace, Tech in Asia, 18/5/2016

The lengthy article tells the story of Malaysian woman Ann Khoo, who faced a lot of work place discrimination because of her Tourette Syndrome. Khoo said that as a teenager she struggled with self-acceptance and self-confidence and believes that society can be accepting if they were educated enough to understand. The article is highly useful as it is not only medically accurate; it shows how discrimination can affect someone with Tourette Syndrome throughout different phases of their lives, especially when it comes to employment.

Myall, Steve. (24th January 2015). The Undateable's stars are wed: Tourette's sufferer and model become inseparable after meeting on show. The Mirror, 18/5/2016

The article reports on the wedding of Tourette's sufferer Brent Zillwood and model Challis Orme after they met on British dating programme *The Undateables*. The article does little to dispel the misconceptions of Tourette Syndrome and Zillwood's coprolalia tics have been censored. The article also puts forth the view that people with Tourette's are "undateable". On a positive note, it shows that people with Tourette Syndrome can find happiness in later life despite the stigma surrounding their disorder.

Swinton, S. (12th May 2016). Tourettes week highlights stigma. Maitland Mercury, 31/5/2016

The article consists of an interview with Bill Hackney, the father of a twelve year old boy with Tourette Syndrome. Mr Hackney believes there is a stigma surrounding the condition and said that people often related Tourette's to swearing, however this was not always the case. The article was helpful as it showed the impact the stigma of Tourette Syndrome has on children who live with the disorder.

Author unknown, (15th November 2012). Tourette's keeper Owen Thompson, 14, given two-match swearing ban, Metro, 5/4/2016

Short article about a fourteen year old UK boy with Tourette Syndrome who was banned from playing football for two weeks and fined twenty five pounds for foul and abusive language, even though his Tourette Syndrome makes him prone to obscene outbursts. As the football association stated that the boy's "lack of respect" was not related to his condition it is unknown if this article can be counted as valid due to the lack of information within.

Unknown author. (17th May 2016). Adam finds his voice. Knox Leader, 9/6/2016

This article contained an interview with year eleven St Joseph's College student Adam Ladell, who lives with Tourette Syndrome and successfully auditioned for the Nine network's *The Voice*. Ladell states that he wants to show others that anything is possible, despite conditions or disabilities they may have, as well as educate people about Tourette Syndrome. The article displays a positive message about Tourette Syndrome and does not mention coprolalia. It also addresses the fact that tics can be painful and difficult to live with.

Images:

Figure 1: LEE, Mr Fish. Tourette's Life. [Comic strip]. Available at:

<https://www.facebook.com/touretteslife/> [Accessed Friday 29th July 2016]

This image was used on the cover page of my PIP to show the impact of societal perceptions on those who live with Tourette Syndrome, as well as recognising comorbid disorders.

Figure 2: LEE, Mr Fish. Tourette's Life. [Comic strip]. Available at:

<https://www.facebook.com/touretteslife/> [Accessed Friday 29th July 2016]

This image was useful in supporting statistics from my survey about people with Tourette Syndrome being told to stop ticcing.

Figure 3: MITCHELL, Mike. Deuce Bigalow: Male Gigolo. [film still]. Available at: <http://quotesgram.com/deuce-bigalow-tourettes-quotes/> [Accessed Monday 11th July 2016]

This image was used to show how Tourette Syndrome is often portrayed incorrectly within the film industry.

Figure 4: LEE, Mr Fish. Tourette's Life. [Comic strip]. Available at: <https://www.facebook.com/touretteslife/> [Accessed Friday 29th July 2016]

This image portrayed how some people with Tourette Syndrome perceive their disorder and how it can impact upon the formation of romantic relationships.

Films and fictional television programmes:

Deuce Bigalow: Male Gigolo. (1999). [DVD] USA: Mike Mitchell

The female character with Tourette Syndrome in the film displays coprolalia and some violent neck jerking tics and reinforces the stereotype that Tourette's is purely cursing.

Front of the Class. (2008). [DVD] USA: Peter Werner

This film is based on the life of Brad Cohen, a teacher with Tourette Syndrome who was rejected by twenty five schools because of his vocal tics. This film is unique as Brad does not have coprolalia and shows the impact societal perceptions have on people with the syndrome.

Harvie Krumpet. (2003). [DVD] Australia: Adam Elliot

The Academy Award winning animated film follows the life of Harvie Krumpet, who was diagnosed with Tourette Syndrome as a child. Harvie breaks some stereotypes of Tourette

Syndrome in film as he does not have coprolalia and he appears to also have Obsessive Compulsive Disorder, a common comorbid condition of Tourette Syndrome. This is a fairly accurate representation of the symptoms of Tourette Syndrome, however Harvie is at some points portrayed as simple and referred to a “retarded” by other characters, despite Tourette’s not having any impact of the intelligence of the sufferer. It also shows the impact societal perceptions of Tourette Syndrome have on those who live with the disorder and the way in which they affect things such as schooling, assimilation and forming relationships.

Jumpin’ Jack Flash. (1986). [DVD] USA: Penny Marshall

In one scene within this film, a woman is violently swearing at a cop and another man pretends she has Tourette Syndrome in order to excuse her cursing. This gives audiences the assumption that Tourette’s is just cursing and is an example of the “Hollywood Tourette’s” concept.

Not Another Teen Movie. (2001). [DVD] USA: Joel Gallen

Sandy-Sue, the character in this film with Tourette Syndrome, is portrayed as a perky cheerleader who randomly blurts out obscenities and vulgar phrases. This film is another example of the “Hollywood Tourette’s” concept.

Our Idiot Brother. (2011). [Netflix] USA: Jesse Peretz

This film was not specifically about Tourette Syndrome, however a joke about the syndrome was made between two of the characters during an argument and is an example of Tourette Syndrome being viewed as merely saying whatever is on your mind.

South Park: Le Petit Tourette. (2007). [Television programme]. USA: Trey Parker

In this episode, a character fakes having Tourette Syndrome in order to say whatever he wants without getting in trouble and is forced to go to a Tourette support group. Many of the characters were stereotypical cases of Tourette Syndrome and displayed coprolalia, however there was one girl who demonstrated her simple motor tics. The episode also addressed comorbid disorders and showed how some tics go unnoticed, as well as social isolation, bullying and harassment due to loud vocal tics.

The Road Within. (2015). [DVD] USA: Gren Wells

The Road Within is about a young man called Vincent who's Tourette Syndrome includes both coprolalia and copraxia (tics that involve performing obscene gestures). Following the death of his mother he is sent to a mental rehabilitation centre. Whilst this film does show the physical pain of living with Tourette Syndrome, it alludes to Tourette's being a mental health or psychiatric disorder when it is in fact neurobiological.

Documentaries and television programmes:

I Have Tourette's but Tourette's Doesn't Have Me. (2005). [DVD] USA: Ellen Goosenberg Kent

This American documentary consisted of interviews with a group of children who have Tourette Syndrome and was useful in seeing how the stigma and societal perceptions of the disorder affect younger people.

Tourettes: Let Me Entertain You. (2012). [BBC online] United Kingdom: Reggie Yates (British Broadcasting Cooperation)

After hearing that music can have an immense impact on people living with Tourette Syndrome, BBC Radio One presenter Reggie Yates decided to bring together a group of young people with Tourette Syndrome to put on a performance and increase their confidence.

The documentary showed a range of individual cases of Tourette Syndrome that differed in severity. Whilst some participants had both coprolalia and copraxia (such as raising their middle fingers), people without coprolalia also took part. Both the physical and emotional repercussions of living with Tourette Syndrome were shown. Ruth, a twenty five year old woman who had to drop out of university after her tics were too disruptive at lectures and struggled to regain confidence, explains the implications of Tourette's in later life. Other participants talked about being bullied at school and being alienated in adult life to a lack of societal understanding. Many talk about their desire to be normal. Overall, the documentary was an accurate representation of the neurobiological disorder as it showed a wide range of tics, showed both male and female sufferers, discussed the challenges of living with Tourette Syndrome, acknowledged tic suppression and was not designed to be comedic. Whilst the documentary did have a clear aim of changing the social perceptions surrounding Tourette Syndrome, it did not mention any comorbid disorders and how they impact upon the people who live with Tourette Syndrome.

The Undateables.. (2012 - 2016). [Television programme]. Channel 4.

The Undateables is a British television programme the documents people with a disability in their search for love. Over five seasons, four different people with Tourette Syndrome discuss how having Tourette's has affected their dating life. This was helpful in both examining societal perceptions of Tourette's and looking at the impacts those perceptions have on people in later life. I watched the following episodes featuring people with Tourette Syndrome:

- *The Undateables. (2012). Richard/Luke/Penny, series 1, episode 1, Channel Four, 3rd April 2012*

- *The Undateables. (2012). Michael/Brent/Sarah, series 2, episode 1, Channel Four, 8th January 2013*
- *The Undateables. (2012). John/Ruth/Zoe, series 3, episode 2, Channel Four, 9th January 2014*
- *The Undateables. (2012). Michael/Brent/Ray/Steve/Kate, series 3, episode 3, Channel Four, 23rd January 2014*
- *The Undateables. (2012). Daniel/Ruth/Michael, series 4, episode 4, Channel Four, 26th January 2015*
- *The Undateables. (2012)/ Brent/Steve/Ray/Carolyne/Matthew, Channel Four, 2nd February 2015*

Twitch and Shout. (2013). [sbs.com.au]. Australia and USA: Aaron Lewis

A reporter spends a week at Camp Twitch and Shout, an American camp for children with Tourette Syndrome that allows them to escape social isolation and bond with other children in similar situation to them. This documentary allowed me to gain an understanding of social perceptions from a child's point of view.

Websites:

Australian Bureau of Statistics. (2013). Australian Social Trends, November 2013.

<http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4102.0Main+Features30Nov+2013>, accessed 18/7/2016

I used this website to find statistics on the declining rates of religion in order to write about the impact belief systems have on the societal perceptions of Tourette Syndrome.

Boundless. (15th June 2016). Social Change. <https://www.boundless.com/u-s-history/textbooks/boundless-u-s-history-textbook/the-roaring-twenties-1920-1929-24/the-roaring-twenties-186/social-change-1024-1977/>, accessed 11/7/2016

This article gave me a background on the morals and values during the Freud era that could have had an impact on people's perceptions of Tourette syndrome.

Bovey, Alixe. (Date of publication unknown). Church in the Middle Ages: from dedication to dissent. <http://www.bl.uk/the-middle-ages/articles/church-in-the-middle-ages-from-dedication-to-dissent> (British Library online), accessed 6/7/2016

This was a useful article written by a medievalist about the church system in the middle ages. Whilst it did not mention Tourette Syndrome, it explained the role of the church system in relation to society and allowed me to make a judgement on why the church was such a large factor in the perpetuation of the stigma of Tourette Syndrome in those times.

Centres for Disease Control and Prevention. (2012). A National Profile of Tourette Syndrome, 2011-2012. <http://www.cdc.gov/ncbddd/tourette/data.html>, accessed 14/7/2016

Provided helpful statistics on Tourette Syndrome.

New Jersey Centre for Tourette Syndrome. (2016). 20 facts about Tourette Syndrome you may or may not know. <http://www.njcts.org/tsparents/20-facts-about-tourette-syndrome-you-may-or-may-not-know>, accessed 14/7/2016

This highly useful website listed twenty facts about Tourette Syndrome and mentioned some of the misconceptions, which I was able to implement into my report.

Sphor, Mike. (4th June 2016). 16 young people with Tourette Syndrome share what they want you to know. https://www.buzzfeed.com/mikespohr/16-things-young-people-living-with-tourette-syndrome-want-yo?utm_term=.dvOwroJLO#.nvn9MAWp, 1/6/2016

This article was published on popular culture website *Buzzfeed* and features quotes from sixteen young people about their Tourette Syndrome. A diverse range of cases are shown and correct facts are given. This article can be used to show how perceptions of Tourette Syndrome are changing.

Thom, Jessica. (2012). Repossessed. www.touretteshero.com/2012/10/04/repossessed, accessed 13/6/2016

This blog post provided an insightful look into how Tourette Syndrome is viewed by some belief systems.

Unknown author. (Date of publication unknown). Tourette Syndrome: Synaptic or Demonic?, www.a-voice.org/main/Tourette, accessed 10/6/2016

This article came from a scripture website and contains extreme religious bias. The author does not believe that Tourette Syndrome is a neurological disorder, but that people with Tourette's are possessed by a demon. They also indicate that all children with Tourette Syndrome have coprolalia and that they can be cured by God. They even say that "victims" of Tourette Syndrome "need salvation from satan's clutches". Whilst this article is highly unreliable as the author and date of publication is unknown and it contains great bias, but it does show how some people's perceptions of Tourette Syndrome are influenced by their religion.

US National Library of Genetics. (28th JUNE 2016). Tourette Syndrome. <https://ghr.nlm.nih.gov/condition/tourette-syndrome#synonyms>, accessed 4/7/2016

This website supported by the government of the USA gave highly helpful statistics on Tourette Syndrome.

YouTube. (2016). Statistics. <https://www.youtube.com/yt/press/statistics.html>, accessed 15/7/2016

Provided statistics on the way in which YouTube videos are viewed, which allowed me to gain further knowledge on why videos showing misrepresentations of Tourette Syndrome receive such high numbers of views.

YouTube videos:

Garypoet. (2009). Tourettes – The Highlights. Available at:

<https://www.youtube.com/watch?v=KiCG0wG-5E0>. Accessed 4th November 2016.

Ladell, Adam (TicTwitchTeen). (2015). Boy Singing with Tourette's – Original Song.

Available at: <https://www.youtube.com/watch?v=uYNVcx2TRBA>. Accessed 14th July 2016.

I watched this video after it was referred to in an interview by its creator, sixteen year old Adam Ladell, who uses his YouTube channel TicTwitchTeen to connect with other people who, like him, have Tourette Syndrome. This video went viral and received a large number of comments that showed both positive and negative perceptions of the disorder.

Lee, Caspar. (2013). My Secret. Available at:

https://www.youtube.com/watch?v=vap_eknHZ0E. Accessed 6th July 2016.

Popular YouTube creator Caspar Lee created this video during Tourette's Awareness month in 2013 in order to both tell his subscribers, of which he has over six million, about his own experiences of living with Tourette Syndrome and to raise awareness about the disorder. Lee

talks about being excluded from the classroom as a young child due to loud vocal tics and his peers' lack of understanding.

*MadFrankie008. (2012). 3 Men With Tourette's On a Holiday. Available at:
<https://www.youtube.com/watch?v=dtCUYUBOnzk>. Accessed 14th July 2016.*

Video excerpt from a documentary about three British men with Tourette Syndrome who go on a camping holiday together. Whilst the video aims to raise awareness and reduce the stigma surrounding Tourette Syndrome, many audiences misinterpreted the video as being purely for comedic purposes.

*McDonald, Elizabeth. (2009). Danny Bhoy – Flower of Scotland. Available at:
<https://www.youtube.com/watch?v=cvC4J-WyqvM>. Accessed 15th July 2016.*

A clip from a 2009 show by Scottish stand-up comedian Danny Bhoy, in which Bhoy is discussing the Scottish national anthem. He jokes that it is the “*only national anthem in the world that makes provisions for people with Tourette's*”, as it is apparently considered okay to yell out curse words during the chorus. This reinforces the stereotype that Tourette Syndrome is purely vocal outbursts and coprolalia.

*Sanders, Jamie. (2016). TOURETTES JOKES – Guy with Tourette's Responds. Available at
<https://www.youtube.com/watch?v=zEva5K7-0Q0>. Accessed 12/7/2016.*

A young man with Tourette Syndrome defines the disorder and gives an example of his motor tics and comorbid conditions. He addresses how many comedians use Tourette's as a joke and that it is time for the disorder to stop being used as a punch line. He also stated that while most cases of Tourette's shown on television were inaccurate, most of those programmes were designed to be offensive towards most social groups.

The Tonight Show Starring Jimmy Fallon. (2016). Charades with Kit Harrington, Rose Byrne and Blake Shelton. Available at: <https://www.youtube.com/watch?v=Gkt0IluX4hk>. Accessed 15th July 2016.

A clip from the American talk show in which host Jimmy Fallon makes a joke about guest Blake Shelton having Tourette Syndrome, because Shelton, who does not have Tourette Syndrome, had a random outburst of words. The reaction of the live audience, who laughed, showed how misconceptions about Tourette Syndrome are made.

Tourette's Guy. (2007). The Best of the Tourette's Guy (1 of 4). Available at: <https://www.youtube.com/watch?v=5wcKpoAQKj4>. Accessed 14th July 2016.

Video of a man who claims to have Tourette Syndrome who constantly yells out curse words and random sayings, which portrays a negative view of Tourette Syndrome.

Scholarly Articles:

*Brook A Marcks, Kristoffer S Berlin, Douglas W Woods and W Hobart Davies, 2007, Impact of Tourette Syndrome: A Preliminary Investigation of the Effects of Disclosure on Peer Perceptions and Social Functioning, file:///C:/Users/
/Downloads/Marcks,%20Berlin,%20Woods,%20&%20Davies%20(2007).pdf, 20/5/2016*

This paper discusses the social difficulties of people who live with Tourette Syndrome and lists reasons for which sufferers may be discriminated. It was written by graduate students and associate professors at the University of Wisconsin-Milwaukee and has been very useful in my research into why there is a social stigma surrounding Tourette Syndrome.

Eapen Valsamma, Crncec Rudi, McPherson, Sarah and Snedden, Corina. (2013). Tic Disorders and Learning Disability: Clinical Characteristics, Cognitive Performance and Comorbidity

This article was useful in finding statistics for the comorbid conditions that coincide with Tourette Syndrome and the impact they have on those who live with the disorder.

Francisco M.B. Germaniani, Anna Paula P. Miranda, Peter Ferenczy, Renato P. Munhoz and Helio A.G. Teive. (2012). Tourette's syndrome: from demonic possession and psychoanalysis to the discovery of genes

This article was highly useful when writing chapter one, as it included lots of information on how Tourette Syndrome was perceived in the past, mentioning both the association of Tourette Syndrome with witchcraft and Ferenczi's psychoanalytical theory.

Topolski, Tari PhD, 2015, Quality of life among youth with Tourette Syndrome, <https://www.tourette.org/blogs/teen-talk/quality-life-among-youth-tourette-syndrome/>, 27/5/2016

This paper written by a Research Scientist/Affiliate Assistant Professor at University of Washington discusses the quality of life of young people with Tourette Syndrome. It is relatively accurate, as the perspectives of many adolescents who live with the disorder are included. The report recognises that there is a stigma surrounding Tourette Syndrome and recommends that awareness of the disorder will lead to more frequent social acceptance.

Human Resources

Interview with Robyn Latimer, president of the Tourette Syndrome Association of Australia, conducted on the 18th March 2016

This interview was highly useful as I was able to develop an understanding of the perceptions surrounding Tourette Syndrome in modern day Australia and how the stigma surrounding the disorder can be reduced. In that interview I was also granted permission to survey other members of the Tourette Syndrome Association of Australia.

Interview with Rose (name used with permission), an adult with Tourette Syndrome, conducted on the 23rd May 2016

From this interview I was able to determine if the stigma of Tourette Syndrome had evolved over time and how discrimination can impact upon the person with Tourette Syndrome.

Interview with Brad Cohen from the Brad Cohen Tourette Foundation, a teacher who lives with Tourette Syndrome, conducted on the 26th May 2016

This interview allowed me to see how the stigma of Tourette Syndrome can interfere with employment opportunities and also allowed me to incorporate a cross-cultural component.

Interview with Amanda from the GreatTS, conducted on the 28th May 2016

This interview with an American Tourette Syndrome awareness organisation allowed me to gain a better understanding of the factors influencing the misconceptions surrounding Tourette Syndrome and also incorporate a cross-cultural component.

Interview with Seonaid Anderson, resource manager at Tourettes Action (United Kingdom), conducted 4th July 2016

This interview not only allowed me to incorporate a cross-cultural component, but also provided a large amount of useful information and extra resources.

Interview with an anonymous adult with Tourette Syndrome, conducted 13th July 2016

This interview allowed me to see if people's perceptions of Tourette Syndrome had evolved over time.

Interview with Adam Ladell, runner up on The Voice Australia 2016, conducted 14th July 2016

This interview with Adam Ladell was extremely useful in determining how perceptions of Tourette Syndrome can be changed, as during his time on *The Voice* Adam changed how many Australians viewed Tourette Syndrome and created a channel for acceptance. He also explained the implications social media has for people with the disorder.

Interview with Tommy (name used with permission), a thirteen year old boy with Tourette Syndrome, conducted 14th July 2016

This interview was very helpful in gaining the perspective of a younger male with Tourette Syndrome and the impact societal perceptions have on him.

Appendix

Appendix 1 - Survey for individuals with Tourette Syndrome (TS)

1. What is your age? *

Twelve or under

13 -18

19 - 25

26 - 39

40 +

2. What is your gender? *

Male

Female

3. Do you live in a rural or city environment? *

Rural

City

4. At what age were you diagnosed with TS? *

0 - 5

6- 11

12 - 18

19 - 30

31 +

5. Before being diagnosed, did you know much about TS? *

Yes

A little bit

Nothing at all

6. a) Do you have any other comorbid conditions (OCD, ADD/ADHD, dysgraphia, echolalia, etc.)? *

Yes

No

b) If you answered yes to the above question, have you found that most people are unaware that these conditions often coincide with TS?

Your answer

7. a) Do you believe there is a stigma surrounding TS?

Yes

No

b) If you answered yes to the above question, what impact does this stigma have on you?

Your answer

c) Did this stigma prevent you from obtaining a diagnoses? If so, how?

Your answer

8. Do you often get looks from or are judged by strangers who do not understand your condition? *

Always

Sometimes

Never

9. What is the most commonly asked question about your TS? *

Your answer

10. What do you think are the most common misconceptions about TS?

Your answer

11. a) Have you ever faced discrimination because of your TS? *

Yes

No

b) If you answered yes to the above question, in what ways have you faced discrimination?

Your answer

12. a) Have you ever been bullied, teased or ridiculed because of your TS? *

Yes

No

b) If you answered yes to the above question, what impact has this had on you?

Your answer

13. a) Does having TS effect your confidence? *

Yes

No

b) If you answered yes to the above question, in what ways has TS effected your confidence?

What impact has this had on you?

Your answer

14. Has anyone ever told you that your condition is not real? *

Yes

No

15. Have you ever had a relative not accept or make jokes about your TS? *

Yes

No

16. a) Have you ever been accused of ticcing on purpose or for attention?

Yes

No

b) If you answered yes to the above question, how did this make you feel?

Your answer

17. Do others believe that you can stop your tics at will?

Often

Occasionally

Never

18. How often are you told to stop ticcing?

Often

Occasionally

Never

19. a) Do you believe that TS is often portrayed as being comedic or is greatly exaggerated in the media and film industries? *

Yes

No

b) If you answered yes to the above question, how does seeing this misrepresentations of TS make you feel?

Your answer

20. a) Do you think content, such as viral videos on the internet and social media memes, that mock TS prevents society from developing a proper understanding of TS? *

Yes

No

b) If you answered yes to the above question, what impact does this content have on you?

Your answer

Appendix 2 - Survey for parents of children with TS

1. What is your gender? *

Male

Female

2. Do you live in an city or rural environment? *

City

Rural

3. How many children do you have? *

1

2

3

4+

4. How many of those children have TS? *

1

2

3

4+

5. At what age did your child begin to tic or show signs of having TS? *

Your answer

6. Before your child was diagnosed, did you know much about TS? *

Yes a lot

A little bit

Nothing at all

7. a) Do you believe there is a stigma surrounding TS? *

Yes

No

b) If you answered yes to the above question, what do you think this stigma is?

Your answer

c) If there is a stigma, how has this affected your child?

Your answer

8. What do you think are the most common misconceptions about TS?

Your answer

9. What is the most commonly asked questions about your child's TS? *

Your answer

10. a) Have others ever told your child to stop ticcing? *

Yes

No

b) If you answered yes to the above question, how did this make your child feel?

Your answer

11. a) Has anyone ever accused your child of putting on tics for attention? *

Yes

No

b) If you answered yes to the above question, how did this make your child feel?

Your answer

12. a) Has your child ever faced bullying or social exclusion because of their TS? *

Yes

No

b) If you answered yes to the above question, how often has this occurred and how has it impacted upon your child?

Your answer

13. a) Has having TS had an impact on your child's self esteem and/or confidence? *

Yes

No

b) If you answered yes to the above question, in what ways has TS impacted upon their self esteem and/or confidence?

Your answer

14. When out in public with your child, does your child get looks from or are judged by strangers who do not understand your their condition? *

Always

Sometimes

Never

15. a) Does your child have any comorbid conditions (OCD, ADD/ADHD, dysgraphia, echolalia, etc)? *

Yes

No

b) If you answered yes to the above question, have you found that most people are unaware that these conditions often coincide with TS? What impact does this have on your child?

Your answer

16. a) Do you believe that TS is often portrayed as being comedic or greatly exaggerated in the media and film industries? *

Yes

No

b) If you answered yes to the above question, how does seeing these misrepresentations of TS make your child feel?

Your answer

17. a) Do you think social media has assisted in perpetuating the stigma of TS with content such as viral videos and memes? *

Yes

No

b) If you answered yes to the above question, do you think this prevents society from developing a proper understanding of TS?

Your answer

c) What impact does this content have on your child and you as a parent?

Appendix 3 - Survey for the general public

1. What is your age? *

Twelve or under

13 - 18

19 - 25

26 - 39

40 +

2. What is your gender? *

Male

Female

3. Do you live in a rural (country) or city environment? *

Rural

City

4. a) Have you heard of Tourette Syndrome (TS) before? *

Yes

No

b) If you answered yes to the above question, how did you learn about TS?

Through personal experience

The internet

Medical research

Television/film

Other :

5. a) Do you know or have you come into contact with someone with TS? *

Yes

No

b) If you answered yes to the above question, did this encounter change the way you thought about TS? If so, why?

Your answer

6. Please list three things you know about TS *

Your answer

7. Please select all of the statements that you believe describes TS *

Loud and violent physical outbursts

A psychiatric disorder

A combination of involuntary vocal and motor outbursts, often accompanied by other comorbid conditions

Uncontrollable swearing and anger management issues

A disease

A neurobiological disorder

8. Have you heard of the term "tic" before? *

Yes

No

9. Which of the following do you think is the definition of a tic? *

Saying whatever is on your mind

Involuntary vocal and/or motor outbursts

Uncontrollable swearing

10. Were you aware that people with TS also often have other conditions, such as Attention Deficiency Disorder (ADD), Attention Deficiency Hyperactivity Disorder (ADHD), Obsessive Compulsive Disorder (OCD), Echolalia and Dysgraphia? *

Yes

No

11. Do you believe that TS is often portrayed as being comedic or exaggerated in the media and film industries? *

Yes

No

12. a) Do you think TS is often exaggerated in popular culture? *

Yes

No

b) If you answered yes to the above question, why do you think it is exaggerated?

Your answer

13. a) Do you believe it is okay to make fun of someone with TS? *

Yes

No

b) If you answered yes to the above question, why do you think it is okay to make fun of someone with TS?

Your answer

14. Have you ever shared, liked or laughed at a video or meme on social media that makes fun of someone with TS? *

Yes

No

b) If you answered yes to the above question, why did you do this?

Your answer

15. a) Is it okay to make a Tourette's joke? *

Yes

No

b) If you answered yes to the above question, why is it okay? Would you make a similar joke about any other medical condition?

Your answer

Appendix 4 -Interview with Brad Cohen (US)

1. At what age did you begin to tic or show signs of having TS?
2. Do you remember this time? If so, how did you feel about the tics?
3. At what age were you diagnosed with TS?
4. Did you have trouble attaining a diagnosis?
5. As a child, did your TS have an impact on your life? If so, how?
6. Did having TS make your schooling difficult? If so, in what way?
7. Whilst at school, did you face any form of discrimination because of your TS? If so, what impact did this have on you?
8. As a teenager, did having TS impact on your social life?
9. As a teenager, did having TS effect your confidence?
10. Did having TS have an impact on your decision to go on to further education?
11. Were people at university more accommodating of your TS than they were at school?
12. As an adult, have you been discriminated against because of your TS? If so, in what ways has this occurred?
13. Did your TS make it hard for you to find employment? If so, what impact did this have on you?
14. As an adult, has having TS impacted on your social life in any way?
15. As an adult, does having TS have an impact on your confidence?
16. Within your lifetime, do you feel that people's perceptions of TS have changed? If so, has this been for the better or for the worse?
17. Do you believe there is a stigma surrounding TS? If so, how has this affected you throughout your life?

18. Do you think that content on the internet, such as YouTube videos and memes, that mock TS prevent society from developing a proper understanding of the disorder? If so, how does this affect you?
19. Do you think TS has been made into comedic material or greatly exaggerated in television, films and the media? If so, what impact does this have on you?
20. What do you think are the most common misconceptions about TS?
21. Do you have any co morbid conditions? If so, have you found that many people are not aware that these conditions coincide with TS?
22. From your experience as a teacher, have you found that children are more accepting of your TS than adults? If so, why do you think that is? .
23. How can people's perceptions of TS be changed?
24. As part of my research project, I have been looking at how TS awareness is promoted in different countries. Is there much in the way of TS awareness in the US?

Appendix 5 - Interview Amanda, spokesperson for the GreaTS (US)

1. What do you think are the most common misconceptions about TS?
2. Do you think there is a stigma surrounding TS? If so, what is this stigma and how has it come to be?
3. Do people with TS face discrimination because of their disorder? If so, what impact does this have on them?
4. Does having TS have a large impact on adult life? (For example finding employment, relationships, starting a family)
5. Does having TS have an impact on confidence?
6. Do many people with TS worry about how others see them? If so, why?
7. Do you think TS has been incorrectly portrayed in film and television? If so, what impact do these portrayals have on people who live with the disorder?
8. Do you think content on the Internet and social media that mock TS, such as YouTube videos and memes, have helped to perpetuate the stigma surrounding TS? What impact does this content have those who live with the disorder?
9. Is there much in the way of TS awareness in America? (Part of my assignment is looking at how awareness differs in different countries) How does Stand with the GreaTS break down the social stigma surrounding TS?

Appendix 6 - Interview with Seonaid Anderson, research manager at Tourettes Action

(UK)

1. What do you think are the most common misconceptions about TS?
2. Do you think there is a stigma surrounding TS? If so, what is this stigma and how has it come to be?
3. Do people with TS face discrimination because of their disorder? If so, what impact does this have on them?
4. Do many people with TS worry about how others see them? If so, why? How does this impact on confidence?
5. Do you think TS has been incorrectly portrayed in film and television? If so, what impact do these portrayals have on people who live with the disorder?
6. Do you think content on the internet and social media that mock TS, such as YouTube videos and memes, have helped to perpetuate the stigma surrounding TS? What impact does this content have for those who live with the disorder?

Appendix 7 - Interview with Adam Ladell (Australia)

1. At what age were you diagnosed with Tourette Syndrome?
2. Do you have any co morbid conditions? If so, have you found that most people are unaware that these conditions often coincide with TS?
3. What is the most commonly asked question about your TS?
4. What do you think are the most common misconceptions about TS?
5. Do you believe there is a stigma surrounding TS? If so, what impact has it had on you?
6. Have you ever been bullied or discriminated against because of your TS? If so, what impact has this had on you?
7. Has having TS affected your confidence? If so, in what ways?
8. Do you believe that TS is often portrayed as being comedic or is greatly exaggerated in the media and film industries? If so, what impact has this had on you?
9. Do you think content, such as viral videos on the Internet and memes frequently shared on social media, that mock TS prevent society from developing a proper understanding of TS? If so, what impact does this content have on you?
10. How did it feel to change so many people's perceptions of TS whilst on The Voice? Was the amount of support you received from the Australian public surprising?

Appendix 8 - Interview with Rose (Australia)

1. At what age did you begin to tic or show signs of having TS?
2. Do you remember this time? If so, how did you feel about the tics?
3. At what age were you diagnosed with TS?
4. Did you have trouble attaining a diagnoses?
5. As a child, did your TS have an impact on your life? If so, how?
6. Did having TS make your schooling difficult? If so, in what way?
7. Whilst at school, did you face any form of discrimination because of your TS? If so, what impact did this have on you?
8. As a teenager, did having TS impact at all on your social life?
9. As a teenager, did having TS effect your confidence?
10. As an adult, have you been discriminated against because of your TS? If so, in what ways has this occurred?
11. Do you face more discrimination now as an adult than when you were a child? If so, how does this make you feel?
12. Did your TS make it hard for you to find employment? If so, why?
13. As an adult, does having TS effect your social life in any way?
14. As an adult, does having TS have an impact on your confidence?
15. Within your lifetime, do you feel that people's perceptions of TS have changed? If so, has this been for the better or for the worse?
16. Do you believe there is a stigma surrounding TS? If so, how has this affected you throughout your life?

Appendix 9 - Interview with Robyn Latimer, president of the Tourette Syndrome

Association of Australia

1. What experience have you had with Tourette Syndrome?
2. What do you think is the most common misconception of Tourette Syndrome? Why do you think this is?
3. Is there a stigma surrounding Tourette Syndrome? Why is this and how did it come to be?
4. Can this stigma be eliminated? If so, how?
5. Do the social perceptions of the disorder have an impact on the people who live with Tourette's?
6. Does this have an impact on their confidence?
7. Does it affect their social life?
8. Does this carry on to adult life?
9. Does this stigma effect things such as employment?
10. Have you heard of any cases where the social stigma has prevented someone from being diagnosed with Tourette Syndrome?

Appendix 10 - Interview with an anonymous adult with Tourette Syndrome

1. What is your first name (you can leave this question and remain anonymous if you like)?
2. What is your age?
3. At what age were you diagnosed with TS?
4. Did you have trouble attaining a diagnoses? If so, why? Did the stigma or negative societal perceptions of TS prevent you from being diagnosed?
5. As a child, did your TS have an impact on your life? If so, in what way and how did this effect you?
6. Did TS make your schooling difficult? If so, in what way?
7. Whilst at school, did you face any form of discrimination or were bullied because of your TS? If so, what impact did this have on you?
8. Did having TS make it harder for you to interact with your peers? If so, why did having TS make it harder and how did it make you feel at the time?
9. As a teenager, did TS impact at all on your social life?
10. As a teenager, did having TS effect your confidence? If so, why and what impact did this have on you?
11. As an adult, have you been discriminated against because of your TS? If so, in what ways has this occurred and what impact has it had on you?
12. Do you face more discrimination now as an adult than when you were a child? If so, how does this make you feel?

13. Did having TS make it harder for you to find and/or maintain employment? If so, why and what impact did it have on you?

14. Has having TS limited your career opportunities? Are there any jobs you feel you wouldn't be able to do? Why is this and what impact has it had on you?

15. As an adult, does having TS impact your social life in any way? If so, in what ways and what impact does this have on you?

16. Does having TS have an impact on your ability to form relationships? If so, in what way? What impact has this had on you?

17. During your lifetime, do you believe that societal perceptions of TS have evolved? If so, has this been for the better or for the worse?

Appendix 11 - Interview with Tommy, a thirteen year old boy with Tourette Syndrome

1. What is your first name?
2. What is your age?
3. Are you currently attending school? If so, what grade are you currently undertaking?
4. At what age were you diagnosed with Tourette Syndrome?
5. Did being diagnosed have a large impact on your life? If so, in what ways?
6. Has your Tourette Syndrome impacted upon your schooling in any way? If so, please explain.
7. Has your Tourette's made it harder for you to interact with your peers and join friendship groups? If so, what impact did this have on you?
8. Has your Tourette Syndrome made it harder for you to interact with your peers and join friendship groups? If so, what impact did this have on you?
9. Are your peers and teachers understanding about your Tourette's? If so, what things have they done to support you?
10. Does having Tourette's prevented you from participating in any form of extracurricular activity (for example music groups and sporting teams)? If so, why?
11. Have you ever been excluded by others from any extra-curricular activities because of your Tourette Syndrome? If so, how did this make you feel?
12. Have you ever been discriminated against or bullied because of your Tourette Syndrome whilst at school? If so, what impact has this had on you?
13. Has having Tourette Syndrome impacted upon your confidence? If so, has it been a positive or negative influence?
14. Do you find it hard to tell others, including your peers, that you have Tourette Syndrome? If so, why?

15. Has having Tourette Syndrome had an impact on what you want to do in the future? Has having Tourette's limited your career choices? Is there any job that you feel you would not be able to do because of your Tourette's?

Appendix 12 - Fictional portrayals of TS content analysis grids

Synopsis	Was the character's TS exaggerated?	Was a stereotypical case of TS portrayed?	Were the repercussions of living with TS portrayed?	Does the book/film educate its audience about TS?
Where was the film/book set?	How old was the character with TS?	Did the character have coprolalia?	Did the case of TS in the film correspond with correct medical facts about the disorder?	Is the book/film based upon a true story?
Was the character with TS male or female?	Did the character exhibit both motor and vocal tics?	Is the character with TS primarily cast to provide comedy?	Does the character have any other comorbid disorders?	Does the character with TS face bullying or harassment:
Does the novel/film show changing perspectives of TS?		Does TS cause the sufferer to be socially excluded?	Is this an accurate representation of Tourette Syndrome?	

Appendix 13 - Non-fictional portrayals of TS content analysis grid

Synopsis	Was the subject's TS exaggerated?	Was a stereotypical case of TS portrayed?	Were the repercussions of living with TS portrayed?	Does it educate its audience about TS?
Country of origin	How old was the person with TS?	Did the subject have coprolalia?		Did the subject have any other comorbid disorders?
What gender were the people with TS?	Did the character exhibit both motor and vocal tics?	Is the documentary/biography supposed to be comedic?	Issues that arise for the subject:	Does the person with TS face bullying or harassment:
Are changing perspectives of TS shown?		Does TS cause the sufferer to be socially excluded?	Is this an accurate representation of Tourette Syndrome?	