

## Primary planning

When I began the course Genetics: Science and Society, I didn't believe that what I was going to learn about would affect me. I thought the almost futuristic technologies being used to manipulate our genes wouldn't have an immediate impact on me, nor would it require me to engage in the many perceptions surrounding genetics any further than the course. But I was wrong, and genetic screening was one of the aspects that really got me thinking about the genetic decisions I would personally have to make in the future. Therefore I decided to produce my SDA about genetic screening, specifically pre-natal screening, as a way to better inform myself and others, of the multiple viewpoints explored in lectures. I chose to focus on Down's syndrome, as I felt it was one of the most contested conditions currently being screened for, and one which sparks strong opinions.

To present my findings I chose to produce a short-form reflexive and participatory documentary<sup>1</sup>, aimed at predominantly young female adults, like myself, but also anyone who believes they will become parents at some stage in life, male or female. A short-form documentary (15-30 minutes), was the appropriate length to make sure that all viewpoints were considered to a great enough extent that the piece could act as an educational tool for anyone wishing to explore the process of screening. This length is popular amongst documentaries aired on BBC3 such as 'The Cost of Cute: The Dark Side of the Puppy Trade', 'Diabulimia: The world's most dangerous eating disorder' and 'Drugs Map of Britain'<sup>2</sup>, which all take a lesser-known and/or contentious subject and produce an informative look into it in about 30 minutes, much like what I wanted to achieve. Also, by documenting my personal journey and understanding of screening for Down's syndrome, through meeting people who had different life experiences, this could hopefully allow any watchers to embark on a similar journey or inspire them to do so, hence why I pursued a reflexive (personal) and participatory (other's input) form.

As well as allowing me to express my understanding in a creative way, which I hope to further in the future through a career in science communication, a documentary felt a more accessible format than an essay for example, on this specific area. Being able to see people's facial expressions and body language was another way in which the audience could access the differing arguments and the personal nature of people's decisions, which couldn't be conveyed in a written piece.

By the end of the documentary, I wanted the audience watching to realise that the decision to screen was not an easy one, and that it could have massive implications to the population of people with Down's syndrome. Additionally, I wanted the audience to think and pursue future discussions about the decision to screen and the multiple areas that affect it, such as the way in which Down's syndrome is seen in society, to ensure they make a well-informed choice about it. The societal implications of genetic technologies needs more discussion amongst the general public, which I hope is a message that this documentary puts across.

## Documentary content

When planning the documentary, I wanted to apply the content and methodologies that were covered throughout the course to the situation of screening for Down's syndrome. I also spent extensive time researching existing documentaries and written pieces about screening,

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<sup>1</sup> Wikipedia. Documentary mode [internet]. [Cited 2018 Mar 25]. Available from: [https://en.wikipedia.org/wiki/Documentary\\_mode](https://en.wikipedia.org/wiki/Documentary_mode).

<sup>2</sup> BBC. Documentaries on BBC3 [internet]. [Cited 2018 Mar 25]. Available from: <https://www.bbc.co.uk/bbcthree/category/docs>.

specifically for Down's syndrome, such as Sally Phillips' 'A World without Down's Syndrome'<sup>3</sup>, and a comment piece from *The Guardian*, entitled 'Whether to have a baby with Down's syndrome – it's not a simple choice'<sup>4</sup> (other influences are included in my bibliography).

The first section focuses on the science and facts behind genetics, Down's syndrome and screening (weeks 2 and 3), that I researched on government and scientific websites, included in my bibliography. I felt it was important that the audience were given the facts before being exposed to differing opinions, in case they had never come across the concept of screening before.

The following section explores the attitudes of an expectant mother Emily, my mum Lilian, and parents from the Ups of Downs, whose children have Down's syndrome. After setting up interviews with the various groups, ensuring that balanced arguments would be made, I focused on producing questions that reflected the various facets that surround screening for Down's syndrome (see accompanying documents). I explored people's own attitudes and decisions towards screening (week 5), influenced by their own life experiences, as well as finding out first-hand from Emily what the process is currently like for mothers in the UK (week 9). Stemming from this I discovered what people thought could be changed about the current process, and in the political legislation surrounding Down's syndrome (week 7) and whether this would impact on a person's decision-making process. Additionally I found out people's perceptions of Down's syndrome in the media and society (week 8), and how much this affects people's decisions during screening. To finish each interview, I posed several ethical statements regarding screening and termination of disabled fetuses (week 4). They were; 'Nearly all pregnant women are now encouraged to consider the prospect of disability in their unborn child' (F. Boardman, p.35)<sup>5</sup>, 'Suffering claim - 'A life with a disability inevitably involves suffering' (J. Harris, p.380)<sup>6</sup>, and 'It is a parent's genetic responsibility to terminate a disabled fetus' - which I constructed myself to pose as a discussion point.

Editing this content was challenging, as I felt every discussion brought so many valuable viewpoints, that choosing the ones to include was incredibly difficult. I tried to cover as many aspects as possible in the documentary so as to be able to best inform the audience. The only area that I felt was not explored in as much depth as it was in the interviews I carried out, was the introduction of NIPT on the NHS this year and the impact this would have on people's decisions regarding screening for Down's syndrome. Although a prevalent area at the moment, to consider it fully would warrant its own piece, so I chose to focus on the other aspects of screening, to fit the time constraints of my documentary. At multiple points in the process I asked friends from a range of disciplines such as law and the humanities, to assess the accessibility of the information I was portraying, and amended the documentary accordingly.

The final section of the documentary looks to the future. With the parents from the Ups of Downs I discussed the future of the UK in terms of screening, and the population of people with

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<sup>3</sup> A World without Down's Syndrome [television broadcast]. BBC; 2016 Oct 5. Available from: <https://www.youtube.com/watch?v=x16wGajCHlw>.

<sup>4</sup> Ryan, F. Whether to have a baby with Down's syndrome – it's not a simple choice [internet]. The Guardian. 2016 Oct 5 [cited 2018 Mar 25]. Available from: <https://www.theguardian.com/commentisfree/2016/oct/05/downs-syndrome-baby-disabled-child-aborting-foetus-abnormalities>.

<sup>5</sup> Boardman, F. Negotiating Discourses of Maternal Responsibility, Disability, and Reprogenetics. In: Lewiecki-Wilson C and Cellio J, editors. Disability and Mothering: Liminal Spaces of Embodied Knowledge. New York: Syracuse University Press; 2011. p.34-38.

<sup>6</sup> Edwards, SD. Prevention of disability on grounds of suffering. *Journal of Medical Ethics* 2001; **27**: 380-382.

Down's syndrome. I then concluded the documentary with my own summary and reflection on how I am going to approach this situation in the future, after experiencing this journey. The music I performed in the closing minutes was a solo piano version of 'Departure' from GATTACA, composed by Michael Nyman, drawing attention back to the fact that these decisions all come from the differences in 4 letters, A-T-C-G. Through having the power to manipulate and screen for these differences, everyone is now encompassed by genetics, and has to make life-changing decisions regarding this.

### **Reflection**

Producing this documentary has cemented for me the idea that genetics is a multi-disciplinary field, not contrived to just medical advances, and within these disciplines lies opposing arguments on the use of genetic technologies. Through exploring these differing views, I now feel I have the tools available to make a well-informed decision when the time comes on screening for Down's syndrome, and I hope that is how this documentary could be utilised for others as well. Although it was the wish of the participants to not publish this documentary on social media (see consent form in accompanying documents), which means I cannot judge this statement, just sharing my experience of the process with my friends and family has sparked further discussions.

It has been an emotional yet educational journey delving into 'reprogenethics', highlighted in the concluding minutes of the documentary. Although I believe there is no right or wrong decision on screening for Down's syndrome and that every mother's choice should be respected, I have ended this process not knowing what I would do. I feel I have understood where every viewpoint in the conversations I have had has come from, and at the moment none of them immediately appear to be the right decision for me. I was initially frustrated with the lack of answers and consensus on many areas in genetics, believing that to prevent any misuse of the emerging technologies we needed to act now. However, I now understand why there appears to be none, having reached my own contradiction at the end of the documentary.

Screening for Down's syndrome is just one of many areas of genetics that needs to be more widely considered through a number of perspectives - not just by the general public, but also by larger bodies worldwide, like BEINGS 2015 aimed to do<sup>7</sup>. I hope that through documenting my personal journey, 'Screening for Down's Syndrome' has shown the necessity for doing so.

**Word count:** 1,529.

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<sup>7</sup> Wolpe P, Rommelfanger KS, *et al.* Ethical principles for the use of human cellular biotechnologies. *Nature Biotechnology* 2017; **35**(11):1050-1058.