

The GAMY Project: young people's attitudes to genetics in the South Wales valleys

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Abstract This paper explores young people's attitudes to genetics. It describes a qualitative study involving a group of teenagers in a deprived South Wales valley town over a period of 18 months. The GAMY (Genetics and Merthyr Youth) Project involved a series of interactions with participants, including 2 interviews, 4 group days and 4 genetics tasks through which these young people learned about, and then reflected upon, issues relating to genetics and health. We have gathered data about the informed attitudes of teenagers to genetics based on deliberative learning and reflection over a long period of time, and as such this paper provides useful insights into the underlying values that are guiding young people's views and the factors that are shaping their responses to new genetic technologies. Attitudes to genetics are complex and not easily generalisable. There were low levels of familiarity with, and knowledge of, genetics from the outset. Most young people did not have pre-existing attitudes towards genetics and had given little or no thought to the topic before the project began. However, levels of awareness and general genetic literacy increased as the project progressed. This study suggests that over time young people can develop an awareness of genetics that makes sense to them; they demonstrate that they can think creatively about genetics, and they are able to engage in considering genetic and other risk factors when thinking about health and disease.

Keywords Genetics · Health · Young people · Qualitative · Deliberation

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Introduction

Will we ever really know what the public think about genetics and genomics? A growing amount of research in the UK and elsewhere is investigating public understanding of, and attitudes towards, genetics and genomics. Much of the research in this area has been undertaken on a short-term basis using a range of inquiry methods such as opinion polls, surveys, focus groups, consensus conferences and citizens' juries (Bates 2005; Doolin and Motion 2010; MORI 2005; People Science & Policy Ltd/TNS 2008; Sturgis et al. 2010; Gavelin et al. 2007; Iredale et al. 2006; Powell and Kleinman 2008). Similarly, much of this research has been conducted with adults.

We believe more research with young people is necessary, not only because they account for one quarter of the UK population (National Statistics Online 2010), but because they are the generation most likely to be affected by advances in genetic and reproductive technologies.

Teenagers are heterogeneous; they have multiple views which can vary widely. Yet the category is still meaningful to differentiate from adults. In this paper, we describe a project which investigated the views of young people aged between 15 and 19 years to genetics over an extended period of time and explored how their understanding of genetics changed after being exposed to genetic information delivered in such a way as to facilitate participants acquiring a genetic literacy that would make sense to them in the context of their own lives in the South Wales valleys.

We did not start from the assumption that these teenagers would have any pre-existing attitudes to a topic that many may have not given any serious thought to before. Instead we focused on exploring some of the underlying factors that shaped their responses to genetics over time as

they had the time and opportunity to engage in deliberative learning and reflection over an 18 month period.

Whilst this paper cannot do justice to the lengthy and rich deliberations that took place throughout the whole of the study, in describing the GAMY Project we feel able to suggest some tentative conclusions about young people's attitudes to genetics.

Method

The aim of this study was to explore young people's views of genetics, particularly in relation to health, and whether their attitudes would change after being engaged in a series of group days and tasks that were intended to promote genetic literacy. Our approach to data collection fell within the field of Rapport's new qualitative methodology which supports a variety of techniques to capture the multi-dimensional perspective from which participants view the world (Rapport 2004).

Recruitment

The eligibility criteria for participation in the project were for the young people to be aged between 15 and 19 years and to live in Merthyr Tydfil, a deprived town in the South Wales valleys, UK (Welsh Assembly Government 2008). Recruitment was conducted in collaboration with a number of local community groups in Merthyr Tydfil and took place between February and March 2008. Project information was sent to over 50 community professionals and agencies in contact with young people living in the area and distributed in youth centres and a local college, as well as through press releases and postings on our university website. A number of talks were held at local schools and the college, providing an opportunity to spread information about the project amongst young people and to respond to any queries directly.

All young people (9 males and 12 females) who expressed an interest in the project were invited to an introductory day in Merthyr in April 2008. Of the 21 participants who signed up initially, 19 took part in the first group day and 9 remained fully engaged with the project at the end of the designated schedule of activities in 2009. Table 1 details the socio-demographic characteristics of participants.

Data collection

The timeline for the project is included as Table 2 but basically participants were interviewed twice; preliminary interviews were conducted with 19 young people between April and June 2008. A semi-structured schedule was used

Table 1 Self reported socio-demographic information for participants ($n = 21$)

Age	
15	2
16	9
17	6
18	1
19	3
Gender	
Male	9
Female	12
Ethnicity	
White British	4
White Welsh	7
White (not specified)	10
Religion	
Christian	6
Pentecostal	1
No religion	11
Data not provided	3
Education/employment status	
School	10
College	9
Training	1
Not in employment, education or training	1
Disability	
Yes	3
No	18

to guide the interviews, which lasted on average 30 min, exploring participants' initial thoughts about genetics in relation to health. Final interviews were carried out with 9 participants at the end of the project between April and June 2009. The topics previously discussed were revisited to explore changes in attitudes. Between April 2008 and April 2009 there were 4 group days where all participants met together. At each group day, we developed bespoke games and activities as a way of sharing genetic information with the group in order to support their exploration of particular genetics topics. Table 3 describes these group days.

Day 1 was the introductory day. Participants were invited to name the project and chose for themselves The GAMY Project (Genetics and Merthyr Youth). An introduction to genetics was provided, which focused on factors that might influence health; genetics in the media, and ethical issues surrounding genetic technologies and reproduction.

The second group day focused on inheritance and health. To help participants understand how traits are passed down to offspring, they took part in an activity

Table 2 GAMY project activity timeline

January 2008	Project starts
February–March 2008	Recruitment
April 2008	Group day 1: Introductory day (task 1 set)
April–June 2008	Preliminary interviews
June 2008	Genetics task 1: Digital photographs
July 2008	Group day 2: Inheritance and health (task 2 set)
August 2008	Genetics task 2: Family tree
October 2008	Group day 3: Genetics and reproductive decision making (task 3 set)
	Techniquetrip
November 2008–January 2009	Genetics task 3: Digital stories
February 2009	Group day 4: Genetics and common health conditions (task 4 set)
March 2009	Genetics task 4: Digital photographs
April–June 2009	Exit interviews
July–December 2009	Data analysis
January 2010	GAMY participant celebration

where the “genes” encoding the traits of two marshmallow monster parents were randomly inherited by an offspring and participants decoded the resulting genotype to produce a baby. A family tree was drawn for the resulting marshmallow monster family, introducing the symbols used by health professionals to illustrate family history information and showing how participants could draw their own family tree. Games were played on the day to help participants explore the concept of gene and environmental interactions in health and to look at the role of chance in developing traits.

Day 3 focused on genetics in pregnancy. A short presentation was given to explain the relevance of genetics during pregnancy and outline antenatal screening and testing options available in the UK. Description of some genetic conditions, such as Down syndrome, facilitated discussions about whether participants would consider termination of pregnancy for such disorders, and the potential uses of pre-implantation genetic diagnosis (PGD) were debated.

The final group day focused on the role of genetics in common health conditions. An activity using building blocks was used to help participants explore how genetic and environmental factors affect risk for heart disease. Participants then discussed issues surrounding genetic testing, using a case study of a family with the BRCA gene. These issues were explored further by an external speaker who talked about her experience of familial hypercholesterolemia. One final-day component was a questionnaire on attitudes towards the interactions between genetics,

environment and lifestyle, and common health conditions. It was administered at the start and end of the day.

Following each group day, participants were asked to use creative media to complete a task related to the genetic topics covered that day. These included taking digital photographs, creating a family tree and producing a digital story. Each participant was given a digital camera which they were allowed to keep, enabling them to complete their tasks. Table 4 describes the objective of each task and the number of participants completing the task.

Data analysis

Interviews were digitally recorded, transcribed verbatim and subject to a thematic analysis (Strauss and Corbin 2008). Data were organised by categories and subcategories, which were developed according to the interview questions and emergent themes. Categories were compared and refined to identify underlying themes. Data were analysed by two team members independently and cross-checked by a third member.

The analysis of visual data, such as digital photographs and video stories, was guided by the work of Van Manen (1990). Members of the project advisory group, colleagues, participants and other young people also contributed to this analysis. These procedures allowed the team to check upon validity, minimise misunderstandings, and obtain solid interpretations and explanations of the data in order to represent participants’ views (Miles and Huberman 1994).

Ethical considerations

The study was approved by the ethics committee of the Faculty of Health, Sport and Science at the University of Glamorgan. General ethical principles in health and social research were applied. Young people were excluded if they did not have the mental capacity to consent. An information sheet with details about the study and participation was provided to potential participants, who were also given an opportunity to raise questions so that they could make an informed decision about participation. Consenting took place at the introductory day and was checked on a regular basis to make sure they were happy to continue with project activities. Although participation was voluntary, money was given after participants were interviewed, attended a group day or completed a task, to thank them for their time and effort. A free lunch was provided on each group day.

Results

The focus of these results is not on performance outputs, such a science learned, but rather it tries to convey

Table 3 GAMY project group days

Theme of day	Activities
Day 1: Introduction to genetics (<i>n</i> = 18 participants)	<p>First thoughts—what does genetics mean to you?</p> <p>What are we going to do? The aim of the project, the commitment involved, our ideas for activities and naming the project</p> <p>Web of health issues—what factors influence health, and how are they related?</p> <p>Genetics and the media—how is genetics represented in the media?</p> <p>Genetics and health—the influence of lifestyle and genetics on health</p> <p>Genetics and ethics—what do you think about ‘designer babies’?</p>
Day 2: Inheritance and health (<i>n</i> = 13 participants)	<p>GAMY monsters—the influence of genes and environmental factors on the traits exhibited by an individual, and how these genes are passed down through generations</p> <p>The GAMY family tree—how to draw a family tree and what information this can provide</p> <p>Risk in the GAMY family—the chance or risk of displaying a trait may be influenced by genes and by environmental factors</p> <p>Telling your family story—including the fundamental components of what it is about, how it develops and where it ends</p>
Day 3: Genetics and reproductive decision making (<i>n</i> = 9 participants)	<p>Genetic options during pregnancy—screening and diagnostic tests available, options if a problem is found and pre-implantation genetic diagnosis (PGD) and the concept of “designer baby” technology to avoid having a baby with a genetic condition</p> <p>Designer babies—what would your designer baby look like?</p> <p>What would you do? Attitudes towards termination (abortion) for various genetic conditions</p> <p>Ethics and ‘designer babies’—debating some of the ethical issues surrounding ‘designer baby’ technology</p> <p>How to make a digital story—to express ideas about these issues</p>
Day 4: Genetics and common health conditions (<i>n</i> = 9 participants)	<p>Electronic voting—to look at knowledge and opinions about risk for common health conditions, and whether these change over the course of the day activities</p> <p>Risk and heart disease—Risk activity showing combined effect of genetic and environmental factors</p> <p>On risk for heart disease, with most genes having a small impact but one gene alteration leading to a greatly increased risk</p> <p>The role of genetics in common health conditions—presentation about heart disease and breast cancer, and the role of genetics</p> <p>Genetic testing: breast cancer (BRCA) gene case study—exploring genetic testing and the implications for individuals and families</p> <p>Genetic testing: Familial Hypercholesterolemia—talk from an individual who has had genetic testing and has modified her behaviour due to her increased risk</p>

something of the quality of the experience that participants had and the awareness of genetics that was acquired. Participants expressed a range of views throughout the duration of the project. Three major themes were identified: attitudes about genetics in general; the perceived impact of genetics and other factors on health, and perceptions of genetics and reproductive decision making.

General attitudes towards genetics

At the preliminary interviews, participants were asked about what they felt when they found out the project was about genetics. Most felt it was something really hard to explain. To 16-year-old Connor, it was like “*a swear word*”, saying: “*You think, well genetics, well what sort of swear word are you saying to me?*” Most participants

Table 4 Genetics tasks for the GAMY Project

Task	Objectives of tasks	Participants completing task
Task 1: Digital photography	To capture ideas about genetics in relation to: genetics and me; genetics and my family; genetics and my community; genetics and health	14
Task 2: Family trees	To research family background and draw a family tree to explore how traits, including health, are shared between relatives	10
Task 3: Digital stories	To produce a digital story on the topic of genetics and reproduction	10
Task 4: Digital photography	Similar to Task 1. Capture any change in ideas about genetics	6

thought that their knowledge of genetics was “*sketchy*”, and felt unable to talk about their views. For example, Jessica replied: “*I haven’t got a clue. There’s nothing I knew about that... it’s just something I have never spoken about like, it’s not a topic of conversation.*” Some misunderstandings occurred, as Jordan was unsure whether flu and viruses were related to genetics. When asked about whether people could inherit diseases from their parents, he replied:

I suppose so. It’s like you see all these things in Africa, this woman has AIDS, her kids has AIDS, that’s not exactly genetics, I don’t know, probably is but depends on the circumstances really. If someone has cancer and gives birth to a child, the child ain’t going to have cancer when they are born.... But something such as AIDS and HIV and that will be passed on because of something else (Jordan, 1st interview).

The word genetics made some participants think about “*scary things*”, such as science, “*big scary strands of DNA*”, genes, chromosomes, cloning and stem cells, something that “*you’d expect scientists to know about and not like just normal people*” (Angharad, 1st interview). Most participants had only very basic knowledge about genetics which they learned at school. For example, following group day 1, photographs that participants submitted to represent the subject “Genetics and Me” mainly focused on standard scientific pictures and images of classrooms, science posters, chromosomes and the double helix. This indicated that participants associated science with the environment where they were taught and often did not connect such knowledge to genetics, as the following quotes indicate:

...so like in school science, perhaps I have just known it as science rather than genetics. (Connor, 1st interview)

Like I knew loads about genetics and DNA but I didn’t realise I knew it, ‘cos like I had done it in school and college and things, but it was just in the

back of my mind. I wasn’t bothered about it (Angharad, 1st interview).

Similarly, on group day 1, after looking at some stories about genetics in magazines and newspapers, most participants said that they had seen these kinds of stories fairly frequently, but had not necessarily associated them with the topic of genetics. For example,

I was a bit in like those magazines that my Nan reads, you’ve always got a bit, oh, I’ve had this child to save this child and now they are both alive, like that survival stories, but I didn’t really, you know, like... (Rebecca, 1st interview).

I liked the thing we done when you had to look through magazines and find articles just because you read a magazine and you skip over things or yeah you read an article you know about when you get a baby... like before I didn’t realise that that had something to do with genetics and I think before I just passed it off, but now you realise there is so much scientific work going on behind that (Angharad, 2nd interview).

Nine participants who were interviewed at the end of the project felt their understanding of genetics had increased, recognising greater personal awareness of the issues: “... ‘*cos when I came here I knew nothing about genetics and then it’s kind of I know more, I’m more aware of it*” (Angharad, 2nd interview). Learning about genetics was perceived to be different, interesting and easier to understand, compared to how they felt genetics had been taught at school, as Bethan said:

It was a different way of learning, ... it was an easier way to understand like what we have been taught like really in school ... like we had done genetics in school, but like ‘cos I prefer to do things with my hands like with the project like the games with the ears, it was silly stuff like that helped with me understand what I knew already (Bethan, 2nd interview).

There was a shift from genetics being viewed as a scientific subject to learn at school to something that had relevance to every life. Participants reported that all of the four group days and activities had contributed to their understanding, although different individuals found different aspects helpful. All participants at the end of the project were more aware of the impact of genetics in society and noticed more genetics-related information in the media.

Once you pick up on one thing you go, oh it's all genetics. It's amazing if you look at a newspaper how much is in there (Darryl, 2nd interview).

I think I am more aware now of when something comes up in the media of how you know, how genetics can affect. The things that we have looked at as well like pregnancy and the designer babies kind of thing, how they have sort of come into the media now. I am more aware of things now when before you just thought oh that's that and you didn't know anything about it (Rebecca, 2nd interview).

With this increased awareness, came the confidence to discuss genetics issues and formulate ideas. For example,

I think differently about genetics now, I think more than what I did because I digged deeper into it. Before I was just scratching the surface, like knowing what I know from school but now it's gone really deep and it's knowing how anything affects genetics, everything, lifestyle, health, family. It's really opened up like a big book kind of thing for me to read (Leah, 2nd interview).

... before I would come up with a few ideas and they were sketchy, like you could ask me about genetics and I'd give you a few words and um I wouldn't have said anything to do with, but I just know now, whereas I have that knowledge behind me sort of thing (Angharad, 2nd interview).

Similarly, Darryl and Rebecca indicated that they had talked about genetics, such as “designer babies” with their friends and family. Conversations between family and friends also centred on similarities and differences in personal characteristics between generations, as Aron indicated. His parents and grandparents often talked about how he was intelligent like his grandmother's side of the family and how his bad posture was the same as his grandfather. He stressed in the first interview: *“It is genetics, but when we talk about it it's not labelled as genetics. It's just labelled as general chit chat like.”*

Perceived impact of genetics on health

Certain diseases were reported to run through participants' families, such as asthma, diabetes, hay fever, dyslexia and cancer. However, at the start of the project, most participants appeared to be unaware of the role of genetics in such diseases. When asked about what they thought initially about the role of genetics in health, participants replied:

I don't know. I never thought about that. I don't think they are particularly very important for what you've got. It's more of your own health intake really (Eirlys, 1st interview).

No, not really because I had never really associated it with health, it's just you and the way you develop and your genes but now it seems it does have an effect on your health, you know the way you live your life (Rebecca, 1st interview).

Following the introductory day, when asked to submit digital photos on the topic “Genetics and my family”, some participants included images representing health issues, such as a picture of an eye with cataracts. This might suggest that they did have some ideas about the effect of genetics on health. Following the second group day, participants were asked to explore their family health history and 10 presented a family tree. However, only a few contained comprehensive information about family health, and only one participant used the common genetic symbols introduced on group day 2.

Even by group day 4 many participants remained unaware of the role that genes could play in common conditions. When asked about whether he would change his behaviour if there was a chance of having a heart attack, Rhys said *“Well, that's different. That's not really inherited is it? That's just a dodgy heart like... don't stress out like other than that anything happening.”* In contrast, the role of behavioural factors in health was repeatedly highlighted. Darryl argued in the first interview: *“A gene is a gene. You can be more likely to get one thing or less likely to get it. Like your lifestyle could bring on cancer, stuff like that and heart disease”*. Most were aware of healthy living campaigns focussing on the role of diet, drinking, smoking, exercise and drugs. The key influences on health were identified as diet and exercise:

It all depends on you as a person, depends on how much fast food you eat and exercise and stuff like that, not so much about genetics, but the health part of it would be depending on the person (Bethan, 1st interview).

I think diet, definitely diet. And just mainly exercising, overall physical health rather than anything else

because you know I don't smoke or anything that puts me at risk of having bad health (Eirlys, 1st interview).

A 16-year-old male gave an example to illustrate his point on the importance of healthy lifestyle:

... say for example, you have a person and they have the best genes, right, they have perfect genes that would make them very, very healthy but they smoke, they drink, they do drugs, they eat unhealthily, they don't exercise... I can't see that being right (Connor, 1st interview).

Some photographs that participants submitted following the introductory day reflected these perceptions. Food-related images, such as fruit and vegetables, fast-food, sweets and cakes, were presented by all to illustrate the subject "Genetics and Health". Images of cigarettes, smoking and cancer were also incorporated, indicating a good understanding of the impact of behaviour on health.

By the end of the project, most participants felt that they were more aware of the role of genetics in health. For example, Jordan thought that only his mother, his brother and he had webbed toes, but was surprised to find that this trait could be traced back generations. Angharad stated:

I think I am more aware of genetics in the family. Like things that I would have passed off before, I realise now that it's because it's been passed down through my family... I think when I was looking at my family, I realised how much of them was in me, whereas before I wouldn't have noticed that, but it was because I was having to take photos of everyone and I could study them really closer, I then realised wow you know (Angharad, 2nd interview).

Some participants also became more aware of the interactive influence of genetics and environmental factors on health, as Darryl said:

What your parents got or what your grandparents got influence you quite a bit, do you know what I mean, especially with environmental factors, it's not all genetic, any environmental factors can make a massive impact (Darryl, 2nd interview).

This perception was shared by Jordan who reported that he was overweight and had believed this was just due to genetics. However, his view had changed with a significant loss of weight in the months prior to his second interview:

With everything taught as genetics I thought it's in my blood. I'm just going to get fatter until I am just a bowling ball that just rolls around the room to get food from the kitchen. But no I've lost 3 stone like and I realise that it's not in my genetics as such, it is but it isn't.... But um I know now that your body is

not 100% genetics, it's 50% genetics, 50% lifestyle so I believe that even if you do, if everyone in your family has cancer like that there must be a way that you can stop it through your lifestyle, I think that's possible (Jordan, 2nd interview).

Most participants thought it important to modify their lifestyles immediately if they knew they were at high risk of having a genetic predisposition to a disease, such as heart disease or cancer, but others felt that people should enjoy their teenage years with little restriction on their lifestyle. Participants with the latter view thought that they were too young to think about health promotion:

... if you live your life in panic and frustration you're gonna die quicker.... But if you start panicking now, your life is going to be full of panic, I'm too laid back to panic. If the doctor said now you have angina, better chill off on the cup cakes like, it's not going to bother me one bit (Jessica, 1st interview).

On the last group day participants completed a questionnaire about ranking the importance of environment, genetics and lifestyle as main causes of cancer (Table 5). Before the activities, only one participant considered that the order was lifestyle, environment, genetics; after the activities, five participants ranked the variables in that order. Genetics was ranked as the least influential variable. When asked the same question regarding heart disease (Table 5), all but one of the participants changed their mind on the rank order. Counting the positioning of each variable, environment was considered the most influential and lifestyle the least influential variable for heart disease.

Participants were asked to consider two scenarios in which they carried a genetic alteration which meant that they personally were at high risk of developing first, cancer and second, heart disease. They were then offered the following options to choose from:

- change my lifestyle immediately,
- change my lifestyle when I'm older,
- not change my lifestyle,

Table 5 Ranked main causes of cancer and heart disease

Participant	Cancer before	Cancer after	Heart before	Heart after
1	L	LEG	GLE	GEL
2	LG	LEG	EGL	GEL
3	ELG	LEG	G	EGL
4	GEL	EL	L	GEL
5	ELG	LEG	EL	EGL
6	LEG	LEG	L	LEG
7	LG	ELG	ELG	ELG

E environment, *G* genetics, *L* lifestyle

- there is no point in changing my lifestyle,
- don't know.

All participants chose to change their lifestyles immediately, for both conditions, before and after the activities.

In the after questionnaire, participants had selected lifestyle as the most important risk factor for cancer, so an immediate change of lifestyle was consistent. At the same time, they had considered lifestyle to be the least important factor in preventing heart disease, yet had all said they would change their lifestyles immediately, which is inconsistent with their previous answers, except for one participant who considered lifestyle to be the most important risk factor in all cases and at all time points. Their decision to change lifestyles can be explained by the powerful presentation given by the external speaker on familial hypercholesterolemia, who stressed the importance of lifestyle for the management of her condition.

Hearing a real life story about an inherited condition helped participants to better understand the impact of genetics and environmental factors on illness and made genetics more 'real'. Darryl commented:

First hand speaking is obviously much better than just reading something... 'cos it's all right reading about it but if somebody who's been through it themselves is talking about it it's much more in your face really 'cos you're talking to a real person, they've had it, they've experienced it, they are living through it now, other family members could get it. Much better than reading about it (Darryl, 2nd interview).

Participants were asked to choose from a five point scale of "strongly agree" to "strongly disagree" if they would personally have genetic tests to see if they were at high risk of developing cancer and heart disease, if such tests were available. One participant chose "don't know" for all four answers. One participant agreed to both tests initially, but disagreed with having them by the end of the day. The other five all agreed or strongly agreed with having the tests for both conditions at the start and the end of the day. One participant strongly agreed to have both tests at both time points, but also rated genetics as the least influential factor for both conditions. This could indicate that they did not place great importance on genetic factors for heart disease and cancer, but were willing to take whatever action might become available in the future.

Perceptions of genetics and reproductive decision making

Participants' perceptions about genetic technologies in relation to antenatal testing for genetic disorders and PGD varied, but individual opinions showed little change

throughout the project. Participants generally valued the use of antenatal testing to discover whether a pregnancy was affected by a genetic disorder, but their views on whether to terminate an affected pregnancy varied. At group day 3, issues around termination were discussed. Most participants considered it acceptable if there was a life-limiting condition impacting upon the quality of life of the child, such as Edwards syndrome, "... 'cos if it dies in the first year of life, would you wanna put yourself through giving birth and then die young? I think that's quite traumatic" (Darryl, group day 3).

There was considerable discussion about PGD technology and a general acceptance that it was appropriate to be used for medical purposes. The main perceived benefit was to avoid having a baby with a known genetic condition:

It a good thing really because you know, so many people are getting different illnesses and stuff like that from different genes from the parents. So it would be better if they were made stronger (Margarita, 1st interview).

Another perceived benefit of PGD was to create a baby to save a sibling with a life-threatening disease. For example, Angharad said:

I think it's a good idea to save another child but I don't think somebody should be brought up just to be there as like a medical purpose. I am a bit torn but I think I am swaying towards more like two healthy children and if one is sick and then you had another to help the other one it would be better then. Instead of having one dying child, it's not good (Angharad, 1st interview).

Although acknowledging the potential benefits, Angharad raised some of the ethical issues surrounding using this technology to produce a saviour sibling. This view was shared by a number of others, concerned the sibling would be treated like a commodity rather than being loved. Jessica said:

Yeah you know to give something a bit of a life just to keep something alive. If you're meant to go you are meant to go, like not to be horrible and dissect another kid, it's like plucking a kid off the street and cutting it open and giving its heart to another kid or something (Jessica, 1st interview).

Participants raised concerns on the misuse of PGD technology for gender selection. Using this technology to design a "fake" baby was thought to be "wrong", "unnatural", "inhuman" and "creepy", resulting in a loss of individuality within society. The following participants argued:

... because we should let life take its course in one way but we can also help people who need it, who are

unfortunate enough to undergo the tragedy of being born with um dwarfism or stuff like that, anything like that really so it should be there to help people who are born like that but at the same time we can't use it to design a child to have brown hair, blues eyes, a child to grow so high... which is kind of worrying (Leah, 1st interview).

I don't know. [My boyfriend] thinks it's going to be Hitler all over again like, blonde hair and blue eyes. I don't think it will go that far though (Jessica, 1st interview).

Religious faith was frequently mentioned as a key reason by those opposing this technology, such as Leah who said:

Designer babies, which we shouldn't really 'cos at the end of the day you are bringing a new life into the world so you should be happy with that kind of thing. But it's just wrong that we try and play God for the fact that messing with DNA (Leah, 1st interview).

By the end of the project participants' perceptions about PGD technology had not changed substantively, but some participants felt that they became more confident in expressing their views. For example, Leah still held on to her religious views:

I think it is totally wrong, we shouldn't be doing it, end of story um whatever happens, happens. Perhaps it could be used to get rid of a disease but I also think that life has its own way of making new diseases, new diseases and more disease we can never get enough of curing diseases. It's God's, like, way of controlling the population (Leah, 2nd interview).

Ethical issues were also raised in many of the digital stories participants produced for task 3 (www.gamyproject.org.uk). Most stories focused on the ethics of "designer baby" technology and its potential use in sex selection and "saviour siblings." Both positive and negative views about reproductive technologies were expressed, indicating the group were able to recognise a range of the ethical concerns pertaining to the application of genetic technologies. Similar concerns were raised again at the second interviews when participants talked about the future of genetics. For example, Darryl replied: "*What are we going to be able to do in the future? It's ethical reasons, what is right to do, just 'cos we got the technology doesn't mean we should use it regardless.*" Public consultation was crucial, as Leah said:

I think people shouldn't ignore your views. They don't have to take them in but they should know them at least.... Genetic people should consult with the public first of all. They should really 'cos it involves

everyone to a certain point, everything and everyone should be informed if they are doing certain stuff to certain things. Everyone has the right to know really (Leah, 2nd interview).

Some participants, especially those who knew someone with a genetic condition, stressed that future development should focus on the potential to modify or "*cure bad genes*". For example, Bethan, whose nephew is deaf possibly due to an inherited predisposition, said at the second interview: "*You could change genes to, say like if I thought my nephew, like when he was deaf you could change his genes then so that he wasn't deaf or stuff like.*" Others argued that greater effort should be made to find out how to cure cancer and other common conditions. For example, Aron, who did not agree with "designer babies", replied:

I think we should look more into how to cure it, that's what I meant, how to cure it and how to like look into it rather than try to change it, do you know what I mean, I just don't think you should eradicate it 'cos at the end of the day something will pop up somewhere else. There's bound to be problems out there with designer babies they haven't found out yet (Aron, 1st interview).

Discussion

The GAMY project has gathered information about young people's attitudes to genetics in South Wales. Bringing together groups of teenagers over a period of time produced a shared sense amongst participants that genetics is important and that the attitudes they hold about genetics are based on deliberative learning.

The GAMY project helped teenagers learn about, become familiar with, and form opinions of, issues they previously knew little or nothing about. Yet the results presented in this paper are only part of the story; they do not account for the other kinds of learning that took place doing the different activities, nor do they really capture how the experiences affected those who took part. At the start of the GAMY Project, participants showed little awareness of the role of genetics in health and illness. A few had some basic understanding of genetics, which they had gained from school, but many misunderstandings persisted. Such findings are consistent with those reported in UK national surveys, indicating insufficient scientific knowledge amongst the general public (MORI 2005; People Science & Policy Ltd/TNS 2008). The key role of school in providing young people with relevant scientific information was highlighted a decade ago in UK government reports on science and technology (House of Common 2002; House of Lords 2000), but this project

suggests that schools—certainly in Wales—are not yet achieving this in a manner that will be useful to young people outside the school environment. It is challenging to understand how school can effectively engage young people in what is perceived to be “scary” science like genetics. Findings from the current study may offer some insights in this area.

Of the 9 participants who remained engaged with the GAMY Project for the full 18 months, all felt their knowledge and understanding of genetics had improved and they were considerably more aware of the role that family history can play in relation to health. They described a greater appreciation of the role of genetics in health, although few felt that they understood this in detail. They also became more aware of information about genetics in the media and there is some evidence to support the influence of media representations, images and metaphors on people’s understanding of complex, controversial scientific issues (Petersen 2001; Valiveronen 2004).

The opportunity to hear from a young person with a genetic condition was valued highly, and helped participants to relate genetics to their everyday lives. Patient stories are increasingly being used in healthcare (Crogan et al. 2008; Holm et al. 2005; Schwartz and Abbott 2007; <http://www.tellingstories.nhs.uk/>). Considering some young people’s reluctance to engage with science, such stories could be used as a very useful means to facilitate learning about complex topics, such as genetics. We suggest that real life stories could be used with young people anywhere to enhance understanding of the impact of genetics on people’s everyday lives.

By the end of the project, participants felt that they had developed some knowledge of genetics that made sense to them, although few developed multi-layered understandings of the scientific concepts surrounding genetics. Most participants were able to relate what they had learnt about genetics to their personal situation and place it within the context of their local community and their own families. These findings are in line with the contextual model of public understanding of science. Sturgis and Allum (2004) suggest that the public often integrate science with their existing knowledge, life experiences and attitudes, while using scientific knowledge only when needed.

Perceived understanding of genetics made some participants feel confident to discuss genetics in relation to their health and to express their opinions on the application of genetic technologies, such as PGD. This supports the idea that lay people with some background knowledge of genetics can discuss and evaluate biotechnological applications coherently (Bates 2005; Sturgis et al. 2005). There was disagreement on the use of PGD to select gender, but views on its use for medical purposes were generally positive. A key perceived benefit was its use to avoid having a baby with a serious genetic disorder.

However, ethical and moral dilemmas were raised. There was some debate about the right to be born naturally and some participants used religious beliefs to support their views. Considerable research conducted with adults has also revealed ethical issues and challenges associated with prenatal genetic testing and diagnosis, including PGD (e.g. Benn and Chapman 2010; Quinn et al. 2009). In a study on Christian lay understanding of PGD, Doolin and Motion (2010) found that PGD created moral dilemmas that were not easily resolved through religious beliefs and teaching. Findings from the current study contribute to the ongoing debate on ethical issues from a young person’s perspective.

This study suggests that it is possible to increase lay public’s understanding of genetics through engagement and participation, but this does not necessarily lead to more supportive attitudes to applications of new technologies and challenges the core belief of the deficit model that “to know science is to love it”. These findings correspond with studies conducted with adults. Sturgis et al. (2010) found little evidence of changes in attitudes to genomic science as a result of providing factual information, but less educated respondents were more likely to drop out from the study due to this approach to provision. Knight and Barnett (2010) even reported a negative influence of increased knowledge on public approval of future applications of genetic science. Although information alone does not lead to a more supportive public for science, perceived increase in knowledge did provide young people in the current study with necessary information which enabled them to debate on the applications of genetic technologies in relation to reproduction. These findings are consistent with the contextual model, suggesting that an understanding of people’s attitudes to genetics should be considered within a wider social and cultural context in line with other factors, such as age, gender, education and social class (Sturgis et al. 2010). Yet, sometimes the similarity between public views on different areas of science and technology suggest there are underlying values that guide people’s views (Gavelin et al. 2007). For many people the experience of taking part in a project can transform their attitudes to science and the governance of a technology (Gavelin et al. 2007:54). There is a value attached to interactions with other participants both formally and informally. Participants emphasise the importance of face-to-face contact and of having time to listen to, and to discuss with each other, new perspectives. This was a key feature of the GAMY Project and praised highly by all participants who remained with the project to the end.

Limitations

Although this study provides further insight into young people’s perspectives on genetics, some limitations need to

be acknowledged. First of all, only 9 out of 21 participants remained engaged until the end of the project. Some dropped out due to a change in their circumstances, including going to university and changing relationships. It is unclear whether participants found it too difficult to comprehend genetic information or just lost interest and withdrew. Secondly, the study was conducted with a group of young people from one town and their views may not be representative of young people in other communities across the UK. However, we can say that we encountered typical teenage concerns such as making up and breaking up with partners; being hung-over and just simply forgetting to do something—all of which might impact on young people participating in other sorts of research projects. It is always difficult to involve adolescents in research, especially in long term studies. These issues are discussed in Madden et al. (2011).

In conclusion, this study illustrates the complex nature of young people's perceptions about genetics and sheds some light onto their attitudes about genetics and health. The GAMY Project challenges the notion of a traditional didactic classroom approach to teaching young people science topics and calls for innovative and interactive approaches to actively engage young people in learning about science within a wider social and cultural context. The UK government argues for new opportunities for people affected by science and technology issues to have their voices heard (House of Lords 2000). Establishing open, two-way public dialogue with science initiatives is the first step to restore public engagement. Gaining public trust and confidence in scientific development is much more challenging than information provision. Open and transparent debates about the nature and direction of the development of genetic technologies, as well as associated social and ethical issues, can engage the lay public. Young people should be included within this and made to feel like true citizens of a modern scientific society. This study suggests that informed and engaged young people are capable of debating social and ethical issues surrounding genetic technologies, although some of their views are firmly entrenched by the late teens.

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