

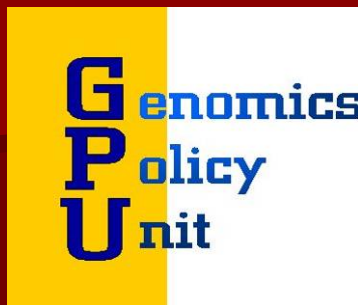


Engaging Young People in Genetics: The GAMY Project

Rachel Iredale and Kim Madden

Genomics Policy Unit

University of Glamorgan



Project Background

- Much research has been short-term using traditional methods of inquiry
- Need to develop more sophisticated ways of 'hearing' what is said about genetics
- Public understanding is not a fixed entity
- Mostly conducted with adults
- Voices of young people not often heard in the genetics debate
- First generation to have these techniques at their disposal
- Methodologically challenging

Research Question

What are the influences on young people's attitudes to genetics, particularly in relation to cancer genetics and cardiac genetics; how are these attitudes formed; how are they located in particular communities, such as Merthyr Tydfil in South Wales; how do they relate to other attitudes; and do they change over time when young people engage with a series of tasks that are intended to promote genetic literacy?

Project Aims

- To engage young people with genetics
- To understand the influences on their attitudes to genetics, particularly in relation to disease, reproduction and lifestyle
- To promote genetic literacy
- To inform debates about engaging hard-to-reach communities with science and technology

Participants

- Young people aged 16-19
- Living in Merthyr Tydfil
- 12 in school/training/further education
- 8 NEETs
- Data collection in a 12 month period
- Co-producers of rich qualitative data that reflects their thoughts about genetics

Data Collection

- 21 young people signed up
- Introductory day - April 2008
- One-on-one interviews
- 3 group days: learnt about an aspect of genetics and received a 'genetics task'
- Tasks completed using mixed media, e.g. digital photos, short films
- Exit interviews
- A project celebration – September 2009



Genetics Topics

- Genetics in the media
- Inheritance
- Risk and chance
- Families and health
- How to draw a family tree
- Genetics during pregnancy
- Designer Babies
- Ethical issues

Genetic Tasks



- Digital photography
- Digital story telling
- Short film making
- Video 'sound bites'
- DNA extraction, Techniquest
- Radio broadcast, BBC Wales



Introductory Day



- 18/21 turned up
- GAMY (Genetics and Merthyr Youth) chosen as the project name

- Initial thoughts about genetics explored
- Discussed genetics in the media, genetic risk and Designer Babies



Group Day: Inheritance

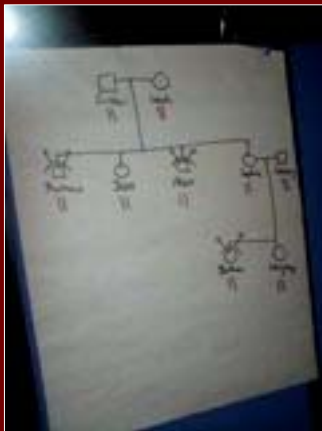
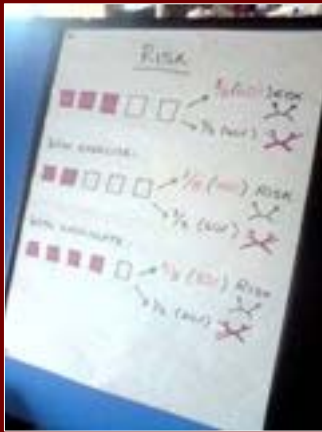
- To understand that traits are partially controlled by genes, and how these genes are passed through families
- To learn how to draw a family tree
- To explore risk in relation to genes, environmental factors and health
- To think about their families and what traits are being passed through the generations
- To explore their own family story in relation to health

Activities: GAMY Monsters



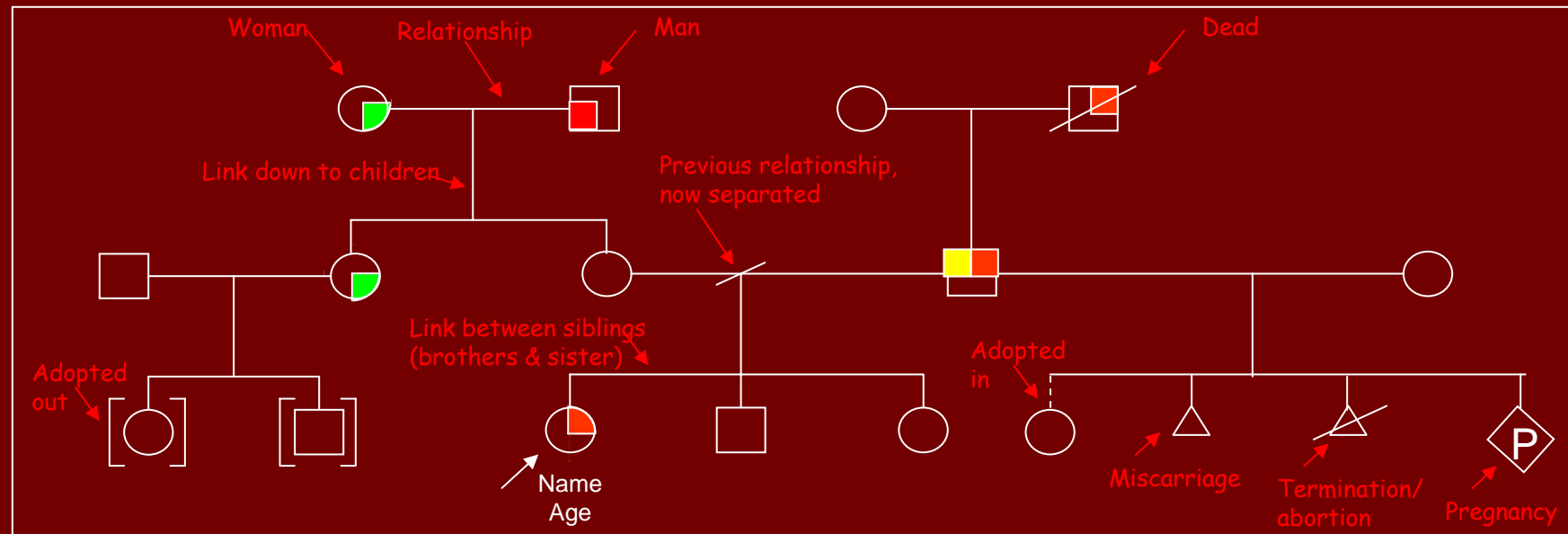
- Each pair had 2 parent monsters, along with their genotype (6 genes, 2 copies of each)
- Each parent randomly passed on one copy of each gene
- Participants ‘decoded’ the baby’s genotype to make their own baby monster

Activities: Risk and Genetics







- Parents have 2 cards, representing 2 copies of 1 gene.
- Altered copy represented by red card, leading to a risk of growing extra ears.
- The risk of growing ears is known, and affected by lifestyle choices.
- Participants holding the altered copy of the gene draw blocks out of a bag to discover whether they will grow ears.
- Parents then randomly pass one copy of the gene to the next generation.

Activities: Drawing A Family Tree



Key:

-  Sporty
-  High blood pressure
-  Breast cancer
-  Heart disease



Extracting DNA



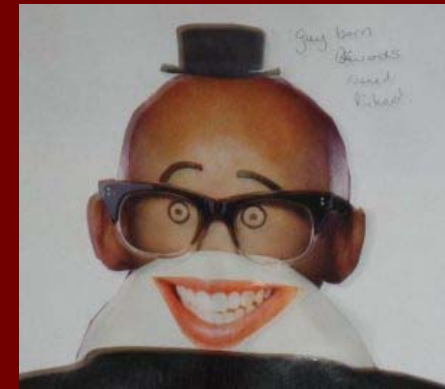
- 4 participants (and us!)
- 1½ hour workshop
- Produced necklace containing our DNA
- Time to look around Techniquest



Group Day: Genetics and Pregnancy

- To understand why parents need to think about genetics during pregnancy
- To learn more about genetic technologies, such as preimplantation genetic diagnosis
- To explore attitudes towards genetic testing in pregnancy and termination
- To debate ethical issues surrounding genetic technology and reproduction, such as sex selection & saviour siblings
- To learn how to express ideas through digital storytelling

Activities: Designer Babies



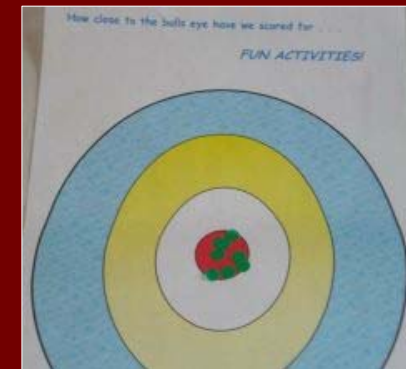
Feedback

Feedback from group days generally very positive

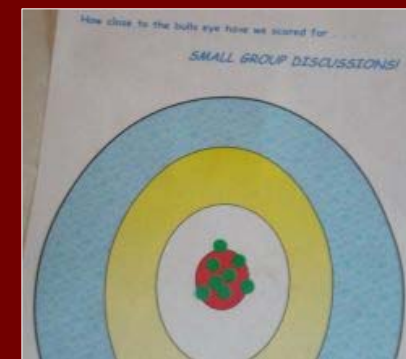
How close to the bull's-eye have we scored for...



Increasing your
knowledge of
genetics

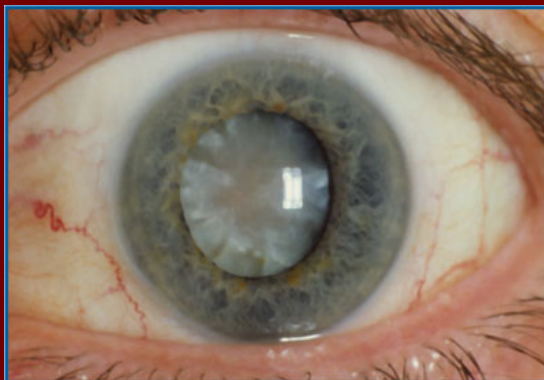


Fun activities



Small group discussions

Digital Photos



THE GAMY PROJECT



Official Website
<http://www.gamyproject.org.uk>

URL
<http://www.bebo.com/GAMYProject>

Profile Created
April 2008

Profile Views
183 times

Share the Luv
♥ 1

No Applications Pending

- [Invite](#)
- [Upload Profile Photo](#)
- [Edit Profile](#)
- [Change Skins](#) | [Change Modules](#)
- [Send-It](#)
- [Stop Being a Moderator](#)

«««««The GAMY Project»»»»»
(GENETICS AND MERTHYR YOUTH)













This is for those involved in the GAMY project - it was great to meet you all at the introductory day. We've spoken to most of you since the project was started. We will be meeting up with each of you to have a chat about your ideas or suggestions about the project.

We are also going to be setting up a blog so watch this space!!

The GAMY Project says:
"WELCOME TO THE FIRST GAMY BABY - NICKI HAD A BABY BOY THIS MORNING. CONGRATULATIONS!!!!!!!!!!" (1 week ago)
[Update](#) | [Delete](#)


Members **GENETICS**

[View All 19 Members](#)

 Nicki Taverner	 Rachel Iredale	 Jo Harris	 Maria Hancock
 Kim Madden	 Thomas Mahoney	 Shane Williams	 Aron
 Doris	 Darryl	 Rhys Williams	 Sophie Victoria

The Wall **GENETICS**

[View All](#) [Add a Brick](#)

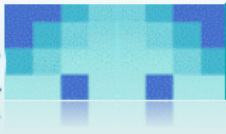


Find out about Genetics

White Board **GENETICS**

[View All](#) [Draw Write on the Board](#)

Interview with a journalist
Anyone interested in being interviewed



THE GAMY PROJECT

GENETICS AND MERTHYR YOUTH

Welcome

The GAMY Project has been studying genetic literacy and the family history of young people in the South Wales valleys for the past two years.

Twenty participants aged 16-20, have taken part in various activities, exploring attitudes to genetics, how these attitudes are formed, how they are located in particular communities and how they change over time.

Participants have engaged in genetic activities including constructing family trees, taking photos, and producing digital stories.



Find us on...



Website Design by EngageWith



hey kim

im ok thnx u?

im sori i cudnt meet up wiv u i waz reli
buzy wiv college wrk and thingz so im
sori abwt tht

i wud like 2 catch az i av been reli buzy
and wud like 2 catch up wiv evry1
can i ask - wat wil the 2 minute digital
story b about?

can it b about anything or a specific
topic tht the gamy project has picked
for us?

hpe 2 c u sn kim

magz

yea thtz nt a problem kim

thnx 4 tht

yea thursday wud b gr8 kim thnx

wil c u thn

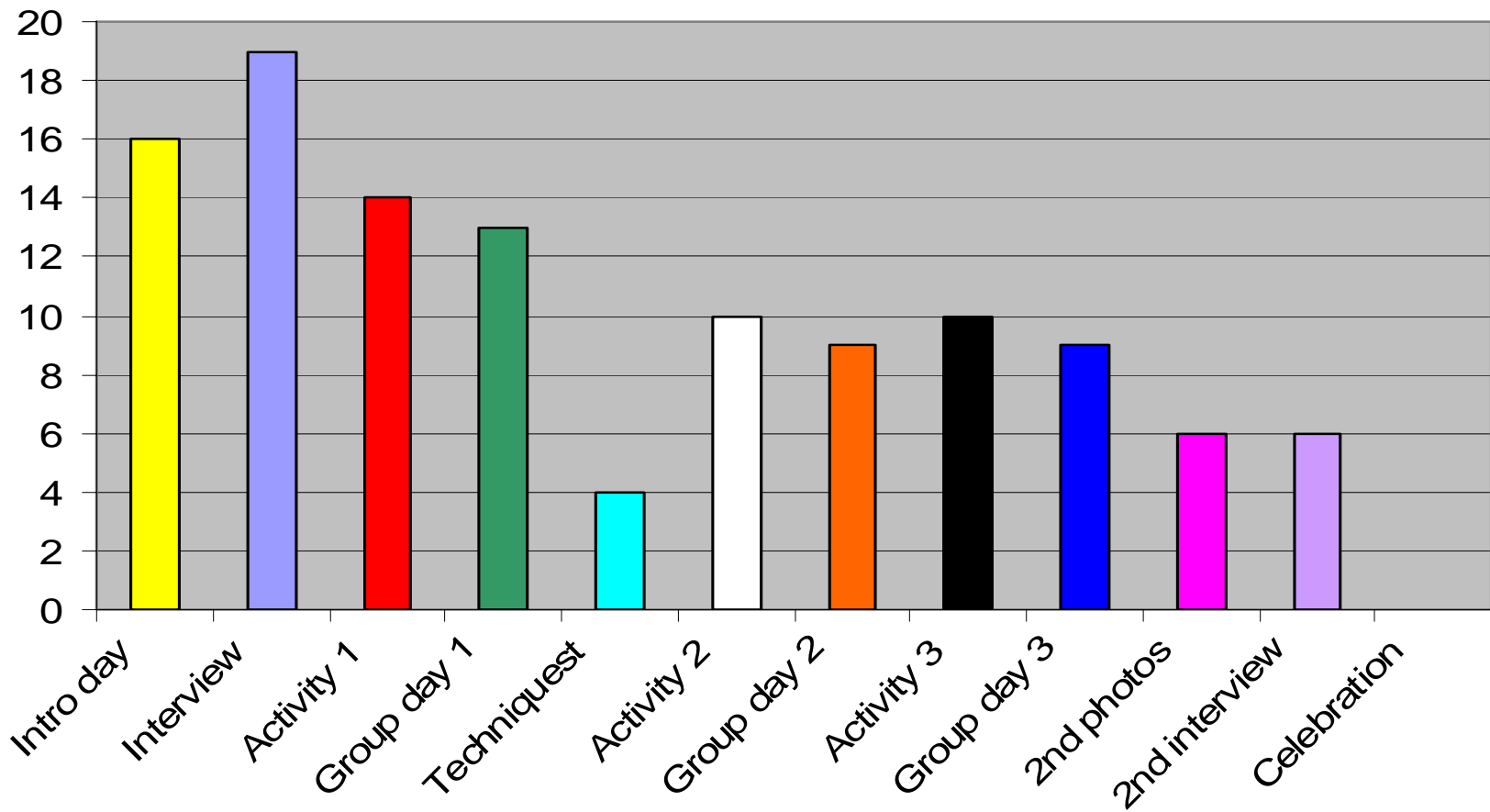
magz



THE GAMY PROJECT

GENETICS AND MERTHYR YOUTH

Participation Patterns



Benefits of participation

- A chance to have their opinions heard
- An opportunity to learn more about how genetics affects health and illness
- The option to learn skills in digital photography, movie-making etc
- Involvement in a project which looks good on their CV
- Some financial remuneration
- 'Products' of data collection shared with the community.

Tentative Conclusions



Young people

- Have multi-layered understandings of the concepts and issues surrounding genetics
- Did not start off genetically literate
- Had low levels of awareness about the role family history has in health and disease
- Did not discuss genetics within their own families, but began to do so with their peers
- Could engage with genetics over an extended period of time, given enough time, opportunity and support
- Think creatively about genetics
- Acquire a genetic literacy that makes personal sense to them and is located within their own particular environment and community



Working with Young People



What can help?

- Make links with trusted members of the community and established groups – encourage nominations
- Promote your activities directly to your target group
- Be open and transparent when recruiting
- Provide information which is brief, clear and to the point
- Highlight the benefits of participation and try to ensure that involvement has currency for participants
- Be honest about what you can offer in return and make clear your availability to support participants for the duration of the project

Working with Young People



- Use methods of communication young people are familiar with, e.g. text and social networking sites
- Maintain up-to-date contact details
- Be adaptable and responsive
- Dedicated time needed to nurture relationships and involvement of individuals
- Collaborate and consult to promote engagement and ownership
- Make time to facilitate group bonding activities
- Be creative when devising learning and data collection activities
- Paperwork makes young people groan – interactive scaling activities get a response!

Thank You

Rachel Iredale and Kim Madden

Email: riredale@glam.ac.uk or
kmadden@glam.ac.uk

Tel: 01443-483075

www.gamypproject.org.uk