



PRIORITISING
PARTICIPATION:
YOUR GENOME,
YOUR RESEARCH
AGENDA

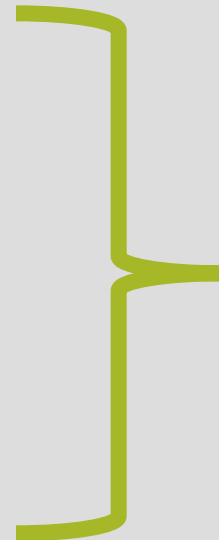


WHO'S HERE?

- Patients interacting with the 100,000 Genomes Project
- Patient advocates and representatives (cancer and rare diseases)

- Collection of social scientists:

- Anna Middleton
- Saskia Sanderson
- Celine Lewis
- Pauline McCormack
- Simon Woods
- Christopher McKeivitt
- Steve Scott
- Becky Gilmore
- Sandra Howgate



Think? Behave? To
improve the patient
experience

WHY ARE WE HERE?

- To hear experiences, from a patient perspective
- To decide together, what the most important research questions should be in the future
- To end with a list of research questions to take forward

IN RELATION TO EXPERIENCES OF...

- Engaging with genetics (or not)
- Communication about genetics
- Ethical issues raised by genetics
- Providing consent for testing/sequencing
- Waiting for results
- Even if you have not had access to sequencing, you can still contribute your experience

WHY?

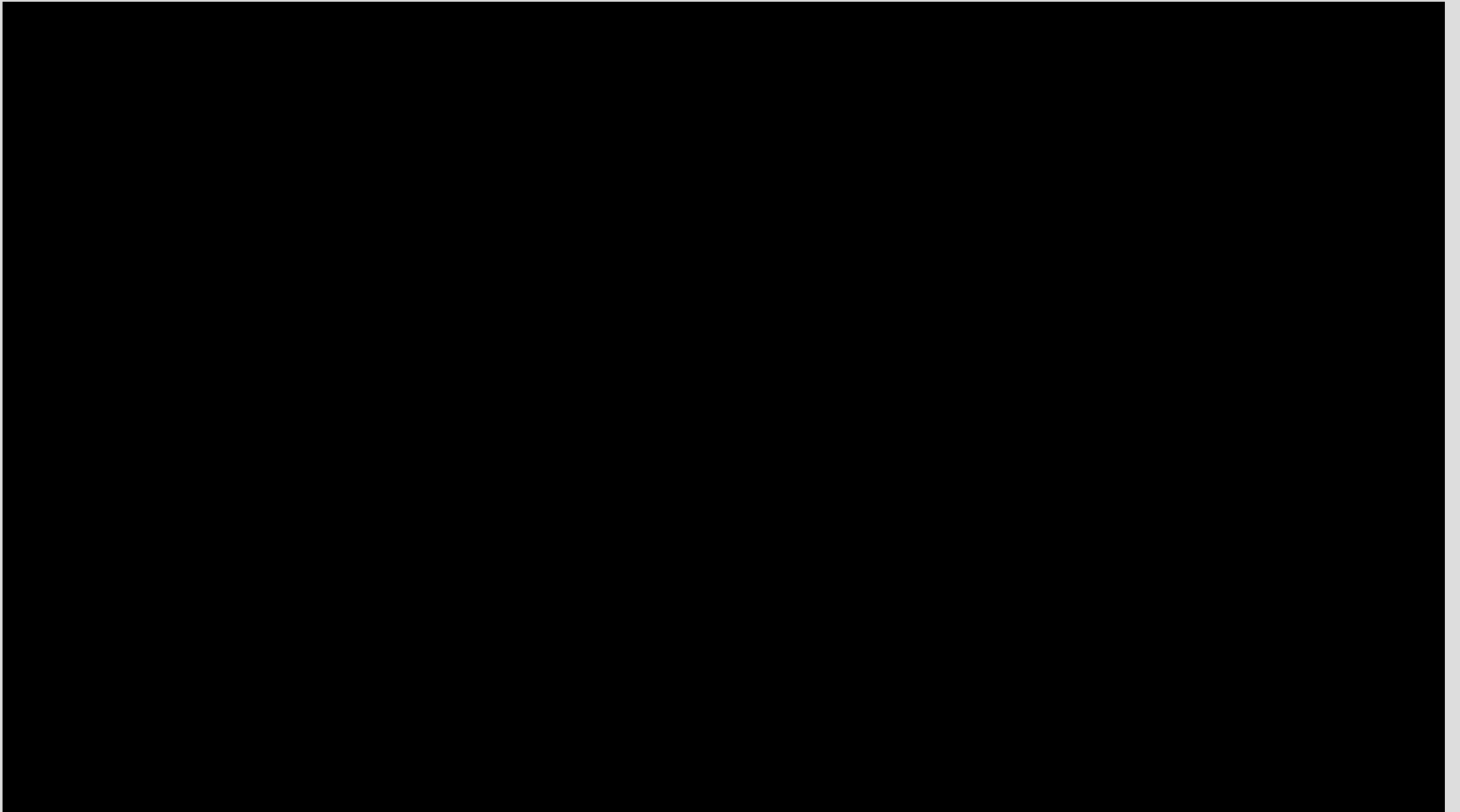
So future social science research
answers questions that are important to
patients (and not just important to
researchers or doctors)

OVERVIEW OF THE AFTERNOON

- What's happening in the NHS?
- Social science research
- Discuss and learn together

WHAT'S HAPPENING IN THE NHS

- Testing of genes to see how these link to disease
- Testing multiple genes in one go (“genome sequencing”)
- What results can people expect (primary and additional looked for findings)
- What is the 100k Genomes Project?



Three young boys are standing in a row against a light blue wall. The boy on the left is wearing a white lab coat over a yellow shirt and is looking to his right. The boy in the middle is wearing glasses, a yellow shirt, a red and blue striped necktie, and a stethoscope around his neck. The boy on the right is wearing a black blazer over a yellow shirt and has a name tag that reads "DR. PHILIP RESEARCHER".

**EXAMPLES OF WHAT SOCIAL
SCIENTISTS ARE EXPLORING...**

- What are patients' and families' attitudes towards returning 'additional looked-for findings'?
- To what extent should children be involved in the informed consent process, and should children always be re-consented when they turn 18?
- How does genetic medicine affect notions of responsibility for one's own health?

Q: IN YOUR OPINION, WHAT ARE
THE **MOST PRESSING AND**
IMPORTANT PSYCHOLOGICAL,
SOCIAL AND/OR ETHICAL
QUESTIONS WE SHOULD BE
ANSWERING WITH OUR
RESEARCH?

TODAY'S PLAN

AGENDA

12:00	Welcome and introduction
12:20	Format of discussions
12:30	Session 1: Getting involved in the study
13:00	Lunch
13:45	Session 2: Receiving genome sequencing results
14:30	Refreshment break
15:00	Session 3: Open space session
16:15	Thanks and closing remarks
16:30	Close

DISCUSSION FORMATS

- Facilitator on each table
- Discuss a specific topic on use of DNA sequencing
- Share discussions with the rest of the room
- Discussions captured by illustrator

DISCUSSION GUIDELINES

- Share your experiences and knowledge
- Ask questions and make statements
- Explain what you think and how you feel
- Speak for yourself not others
- Allow others to finish before you speak
- Respect differences

OPEN SPACE SESSION

- What do you want to discuss?
- Anything you want to explore further?
- Share any questions at anytime on graffiti wall

GRAFFITI WALL



What are you enjoying?



What could be improved?



Open space questions

SESSION I: GETTING INVOLVED!

- What would help you decide to take part in the study and/or genetics services?
- What information would you like before you decide to take part?
- What do you expect from this process?



20 minutes

REMEMBER TO TELL US...



What are you enjoying?



What could be improved?



Open space questions

SESSION 2: RECEIVING RESULTS

- What is it important to discuss?
- Who should be involved in these discussions?
- What do you think the long term impact will be after your involvement?



30 minutes

HOW'RE WE DOING?



What are you enjoying?



What could be improved?



Open space questions

SESSION 3: OPEN SPACE

- Anything you haven't had chance to discuss?
- Anything you want to discuss in more detail?
- Write your question on a piece of paper
- Stick it on the graffiti wall



10 minutes

RULES OF OPEN SPACE

- You can join any discussion you like
- You can leave a discussion at any time
- You can move to join another discussion



30 minutes

BEFORE YOU GO...

You have 3 stickers:

- Place the stickers next to the questions most important to you
- You can put all your dots on one question or share them between questions



THANK YOU FOR BEING HERE AND
CONTRIBUTING

