

Three young boys are standing in a laboratory setting. The boy on the left is wearing a white lab coat over a yellow t-shirt and has his arms crossed. The boy in the middle is wearing glasses, a yellow t-shirt, a blue and red striped neckerchief, and a stethoscope around his neck. The boy on the right is wearing a black blazer over a yellow t-shirt and has a name tag that reads "DR PHAMA RESEARCHER".

Socialising the Genome

Dr Anna Middleton
Head of Society and Ethics Research
Wellcome Genome Campus
Cambridge, UK

Finding ways to connect.....









DNA and big data

Millions of
genomes being
researched...

**When might
people donate
their genomic
data?...**



ExAC Browser (Beta)



The
100,000
Genomes
Project



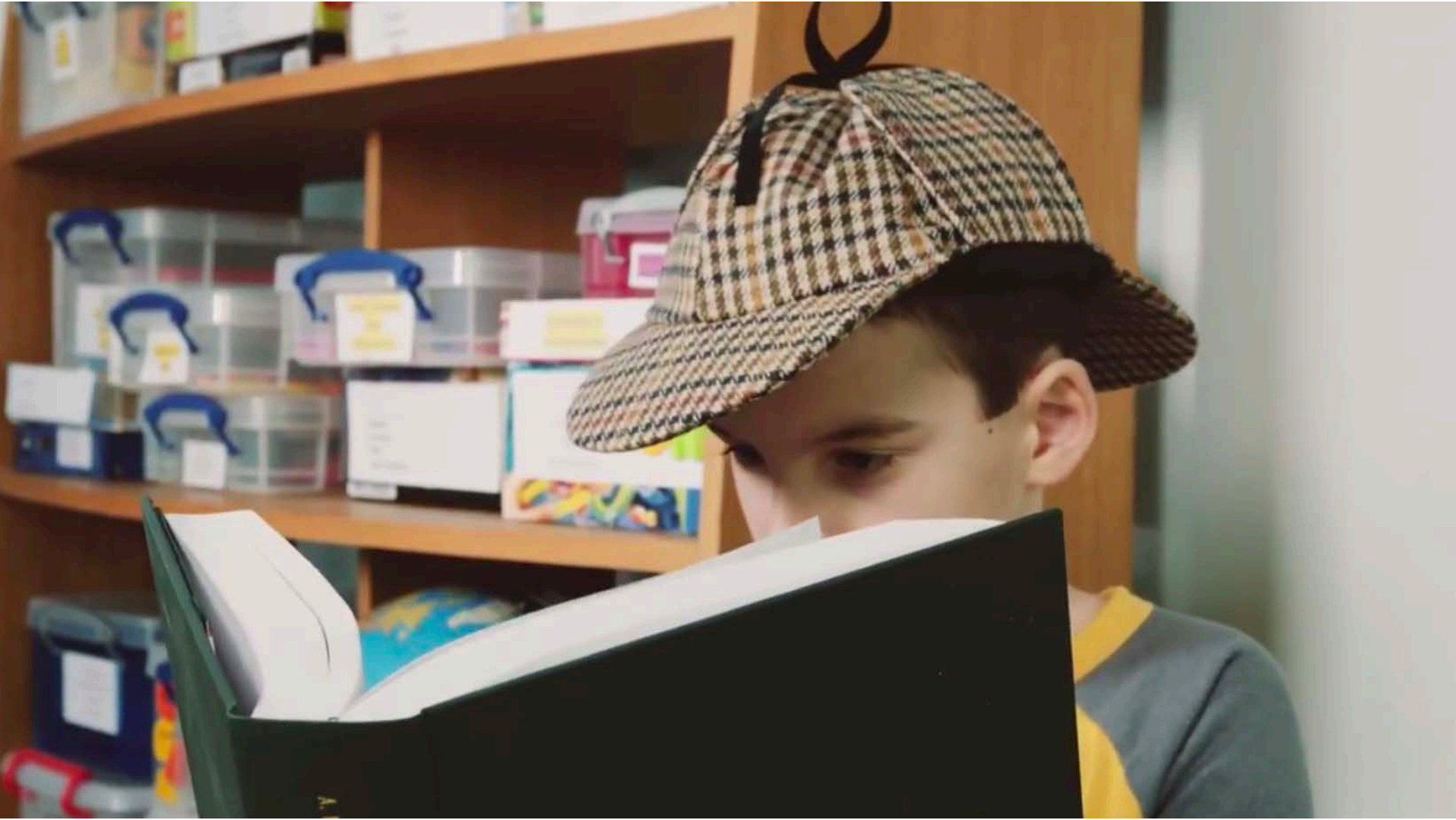
What are the
benefits of
donating data?

“By aggregating and analyzing large amounts of data, it may be possible to discover patterns that would otherwise remain obscure....this wealth of integrated genomic data and clinical information could reveal the genetic bases of cancer, inherited disease, infectious diseases, and drug responses.”



Global Alliance
for Genomics & Health

What are the
risks of
donating data?



What are genomic databases being used for?



**Exploring
attitudes...**

How we
described this
to the public

Data Access by Others



Global Alliance
for Genomics & Health

welcometrust



**WELCOME
GENOME
CAMPUS**
LIFE-CHANGING SCIENCE

www.YourDNAYourSay.org

Your DNA, Your SAY

[reset answers and start again](#)

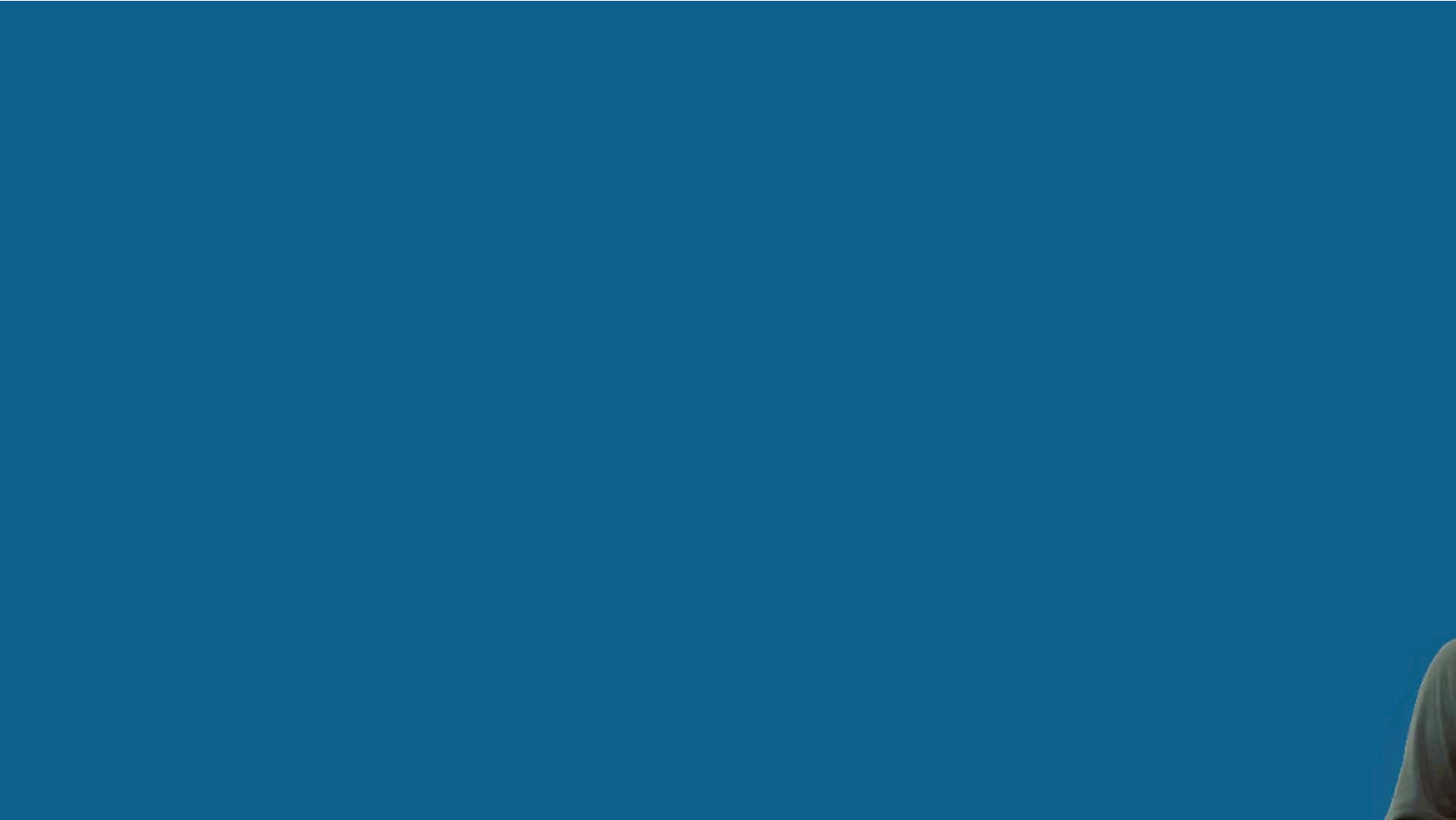


- Welcome
 - Online footprint
 - Data access by others
 - Access by medical doctors
 - Access by non-profit researchers
 - Access by for-profit researchers
 - Perceived harms
 - Expectations of information
 - Trust
 - Socio-demographic questions
 - Submit your response

Welcome



**Preliminary
results!!!**



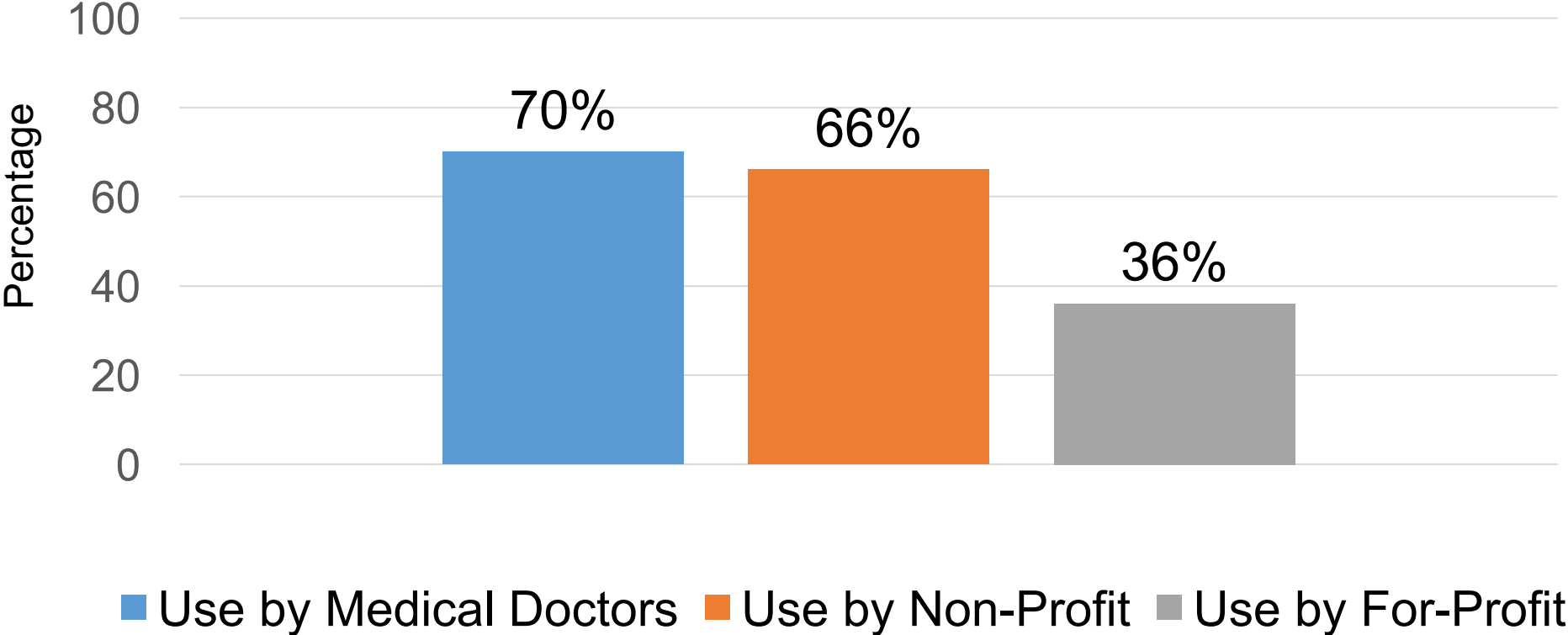




Q: Would
you donate
your data?

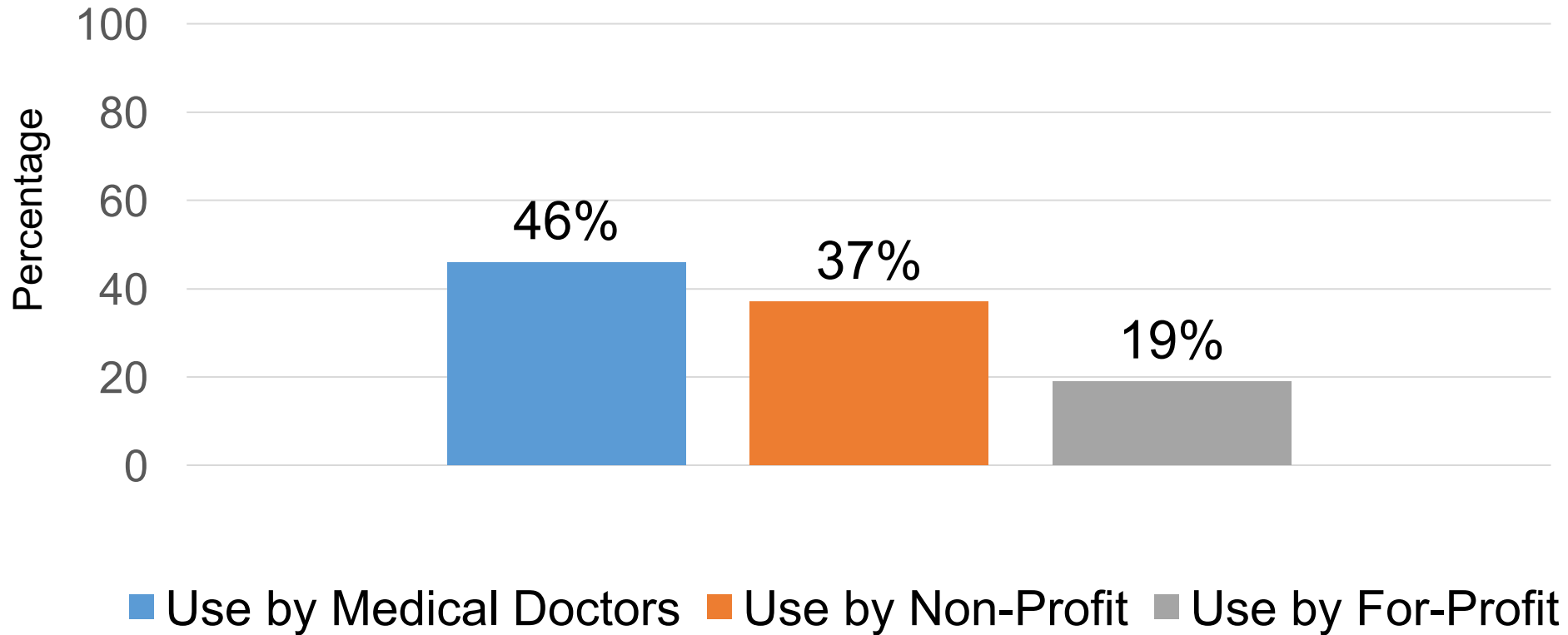
Connected to genomics world (through work or being a patient or research participant)

“Yes, I’d donate my DNA and medical data for...”



Public

“Yes, I’d donate my DNA and medical data for...”



**Concern about
pharma making
profits from free
donation**

**Those who know
about genomics
are more likely to
donate**

Being Identified





**Ihre DNA, Ihre
Entscheidung**

Deutsch

**Your DNA, Your
Say**

English

**Twoje DNA,
Twoje zdanie**

Polski

**O seu ADN, a
sua voz**

Português

**Ваши гены -
Вам решать**

Русский

Arabic, Icelandic, Swedish, Italian, Mandarin, Urdu, Hindi, French... all on their way.....

There is an urgent need to raise consciousness

- What can genomics do for me?
- What can genomics do for medicine?
- How should it be used?
- What sort of society do I want to live in?

Wellcome Genome Campus

Genomics England

Wellcome

Socialising the

GENOME

WHERE SCIENCE AND CREATIVE STORYTELLING COLLIDE



It couldn't have happened
without.....



Global Alliance for Genomics and Health

Natasha Bonhomme

Bartha Knoppers

Adrian Thorogood

Erika Kleiderman

Peter Goodhand

Heidi Howard

Emilia Niemiec

Nadia Kovalevskaya

Participant Values Task Team



Wellcome Genome Campus

Julian Rayner

Julia Wilson

Sam Wynn

Steve Palmer

Don Powell

Lauren Farley

Jon Roberts

Wellcome Trust

Audrey Duncanson

