

# Attitudes towards genomic data sharing



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for Genomics & Health

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# People are Powerful



- If you want people to donate their DNA and medical information for future use
- They need to be on board
- You only know if they are on board if you ask them
- Once we understand attitudes and beliefs from multiple different perspectives, then we can devise good quality policy

88% public don't know what a genome is

Surveys need to be engaging  
(Wyse, 2013)



# 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**

[www.YourDNAYourSay.org](http://www.YourDNAYourSay.org)

# The Social-Survey

- Based on a format we know works (e.g. DDD project)
- Three of us worked full time on design, checked in with Task Team
  - (piloting, face-validity testing, readability, 16 iterations)
- 'Inspire, Engage, Build' (Hess, 2015)



# Your Challenge...

- How to orientate the public with the subject matter
- Explain what genomic and phenotypic information is
- What is genomic data donation/sharing?
- What are databases
- What are open and authorised access?
- In 1 minute







Charlie



# Topics covered

- Is genomic data different to other data?
- What are the perceived harms from identification?
- What would people donate for?
- What would help them decide to donate their data?
- What does trust look like?



# The plan

- Translated into multiple languages (Russian, French, Polish started, Japanese, Arabic, Swedish planned)
- Data collection through 2017-2018
- Recruitment via any online source
- E.g. social media, blogging, media



**The first 200  
completed surveys....**



Majority are patients or 'public'

- 91% 'familiar with DNA/genomics'
- Spread of ages, geography and demographics

**Is DNA information  
different to other  
medical information?**

# Yes

63% (n = 128) thought DNA information is different to other medical information

**Why?**





“DNA is different because not all of it is medically relevant”

“DNA can uniquely identify me”

“I could change my blood pressure with better behaviour. I cannot change my DNA”

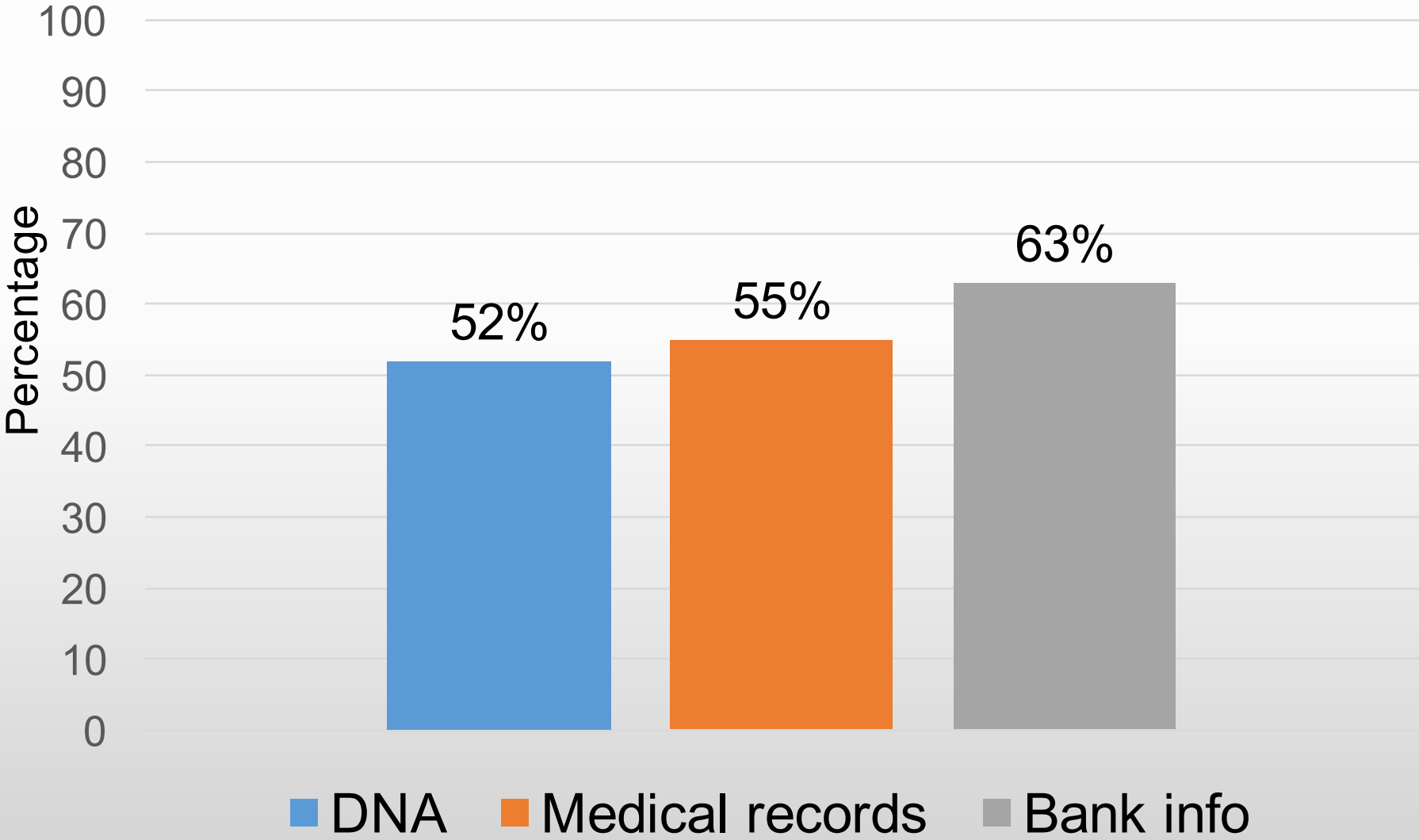
“My DNA can tell others more about me than I know about myself”



**Do bank details, DNA  
information, medical  
information, holiday photos need  
the same level of protection  
online?**

No

# What data needs the highest level of protection?

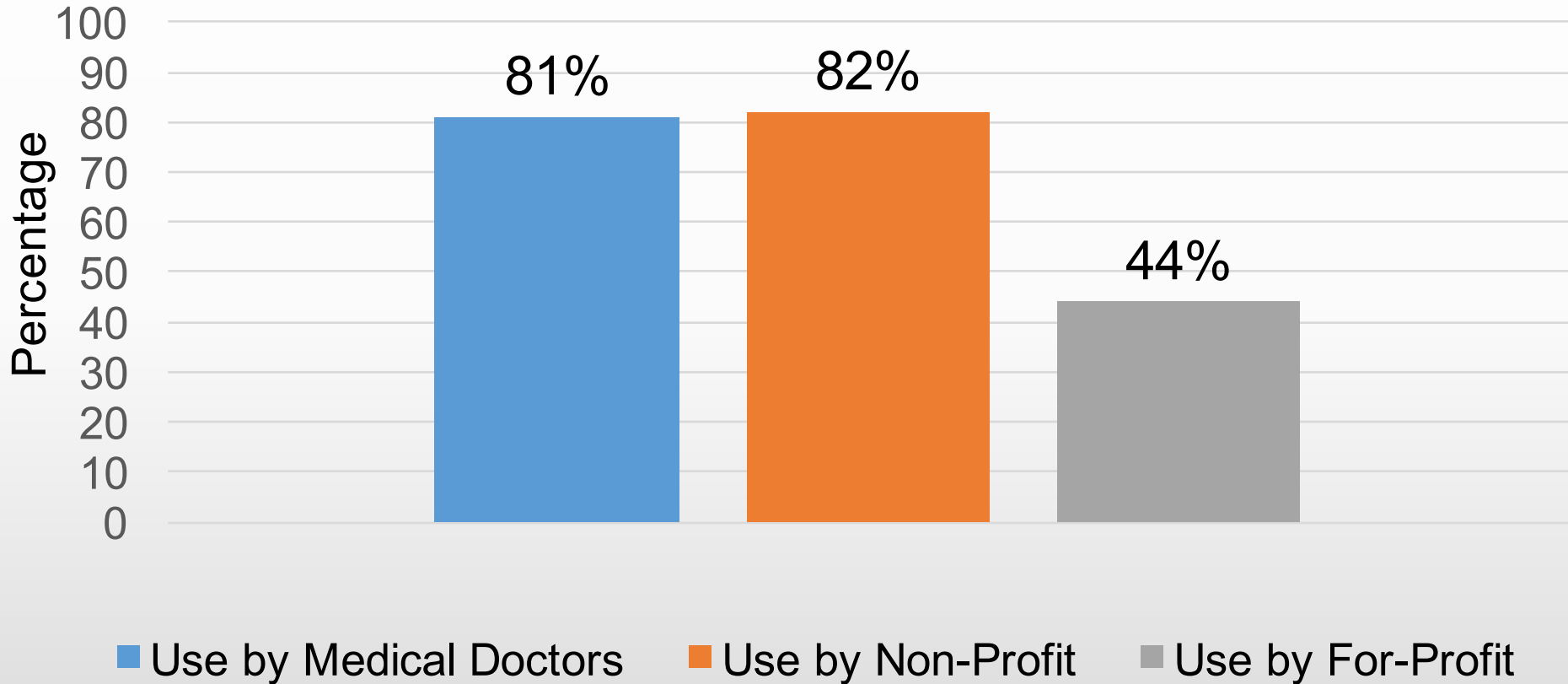


**Genomic Data is different  
but not necessarily more  
'risky' in terms of needing  
higher levels of protection**

**Would you donate your DNA and  
medical information?**



# "I would donate my DNA and medical information for..."





“I don’t mind for profit researchers accessing the information providing they [*do not*] restrict access to benefits generated from that research”

“In the US, the prices of drugs are astronomical. They cannot use my DNA for free and [*then*] charge prices I cannot afford”

# Being Identified



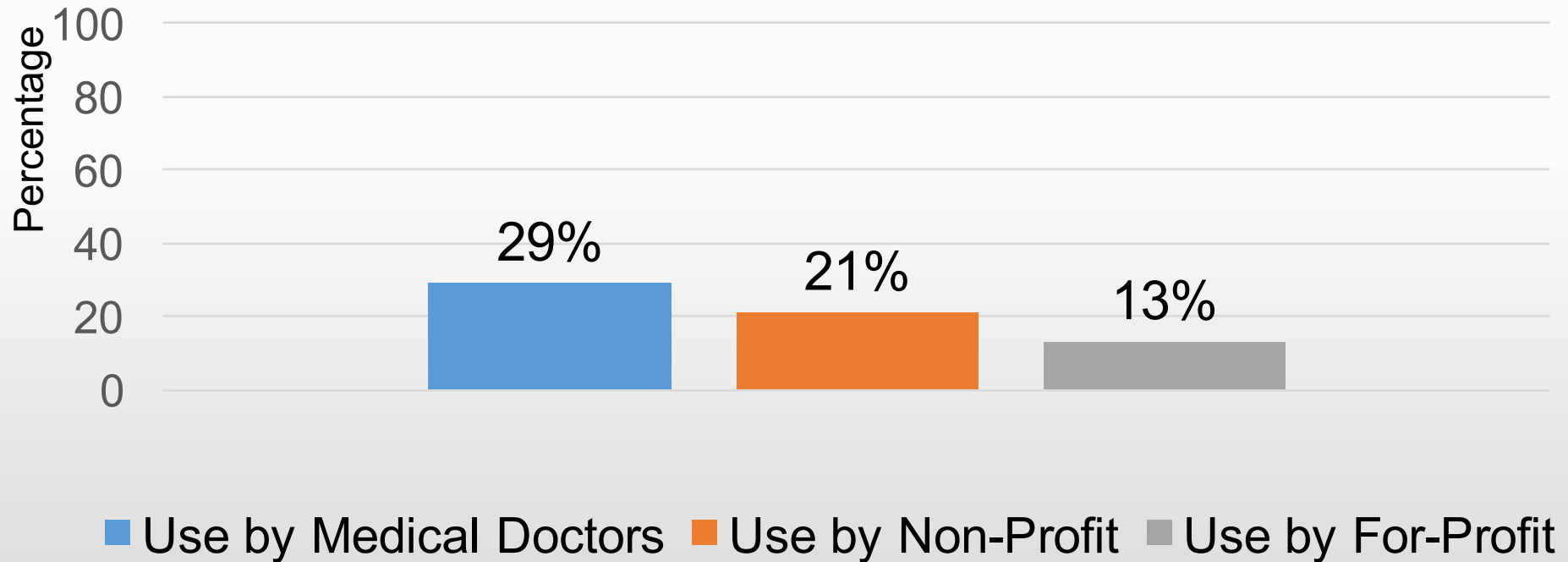
- We assume that people are worried about identification
- But are there some who don't mind?
- Would people still donate their data even if they knew there was a high risk of being identified?



# We asked...

- Let's assume you could donate your DNA and medical information for future use by
  - Medical doctors
  - Non-profit researchers
  - For-profit researchers
- Let's also assume that there was a 90% chance of you being personally identified from you data. Would you still donate?

“I’d accept a 90% risk of being identified if I was asked to donate my data for...”



# Biggest concern?



- Most 'concern' related to 'upsetting relatives (because my DNA info is similar to theirs)'  
68%
- Other concerns - insurance, discrimination etc

# Interested in participating?

- Would you share the project in your networks?
- You can use the films for your own purposes
- If you'd work on a translation you can have that data and be first author on papers





The Making Of...

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

## Participant Values Task Team:

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**wellcome**trust



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