



## Use my data, use my DNA

*How patients, who want to make sure that their samples and data are used for medical research, can ensure that this happens*

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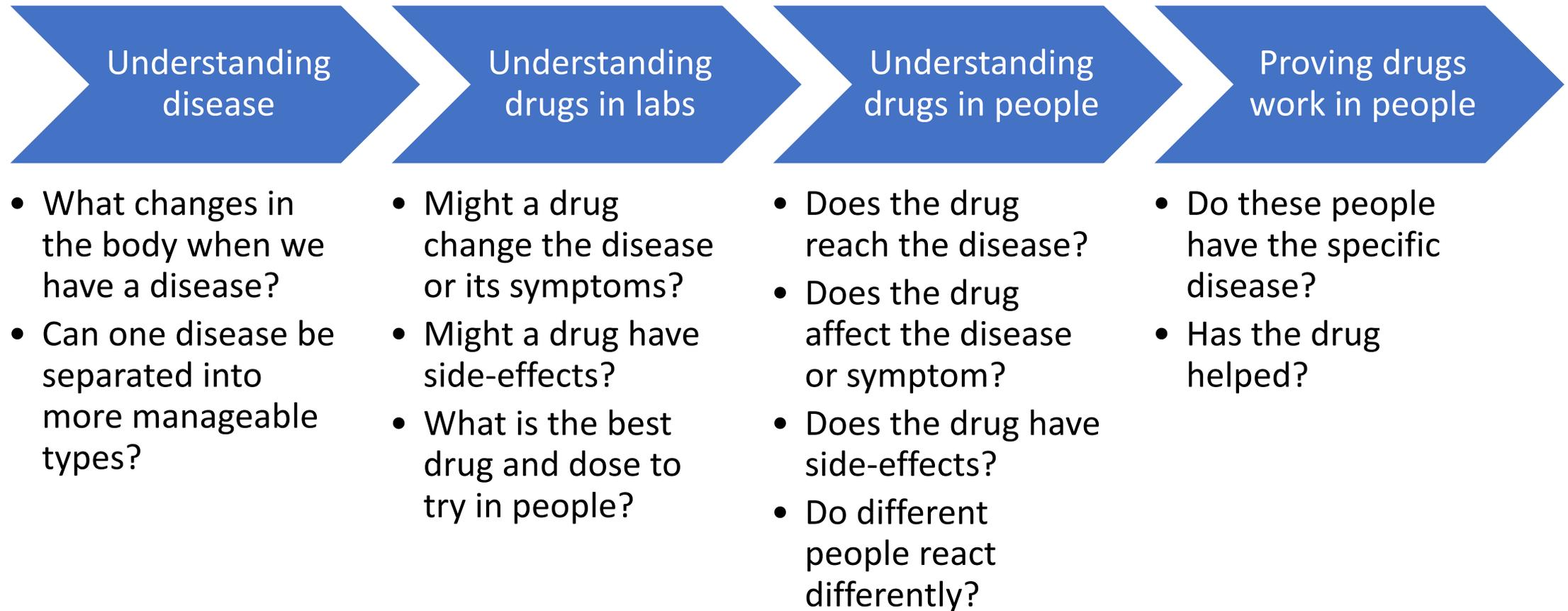


# What are samples



- What are samples?
  - Human biological samples
    - Blood, Cancer, Urine
    - others
- Why are they taken?
  - For diagnosing disease
  - For understanding disease
  - For future research
- How many are there?
  - NHS tests 80 million samples a year
  - Cancer diagnosis: 10 million stored
  - Research studies: less than 1 million
  - Future research banks: 3-5 million

# How are samples used in drug research and development



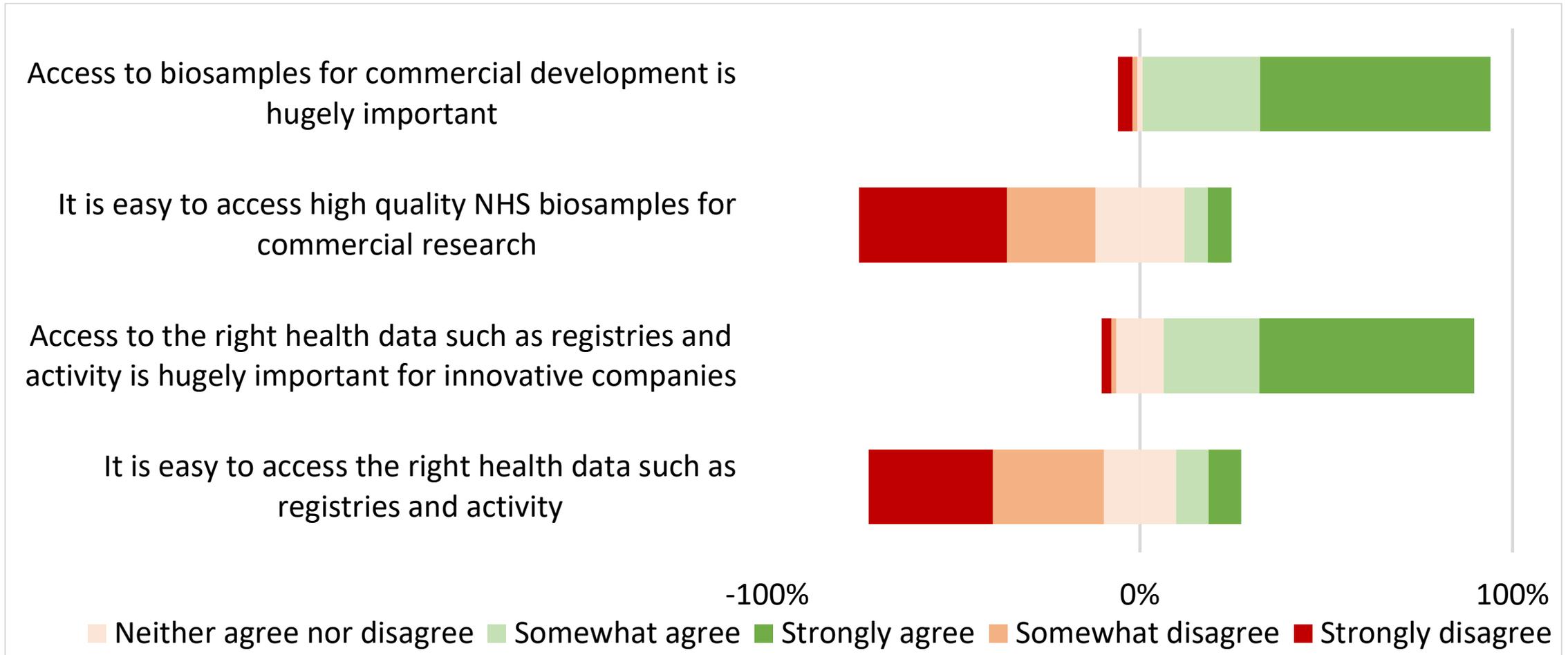
# The context for sample and data use in the UK



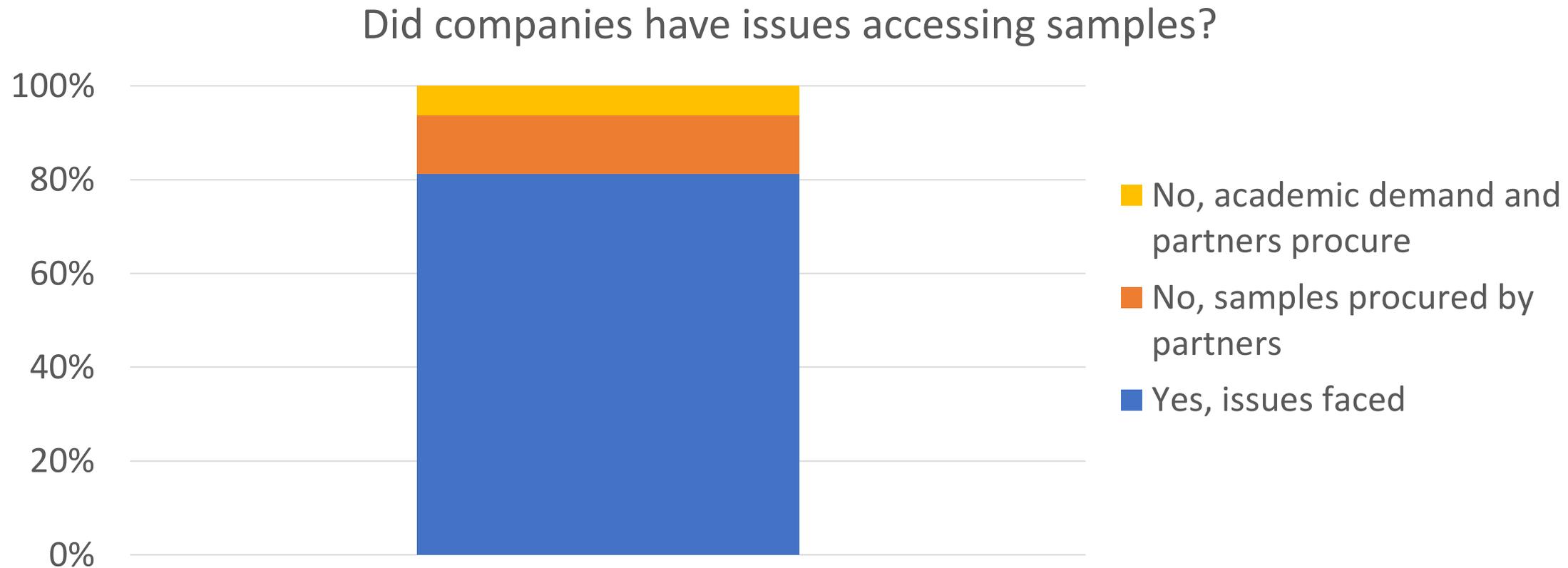
# The UK produces many good quality samples and data

- UK's pathology capabilities and informatics infrastructure is excellent
- Many millions of samples and data are taken for care
- Some of these also have patient consent for R&D
- E.g. Genomics England

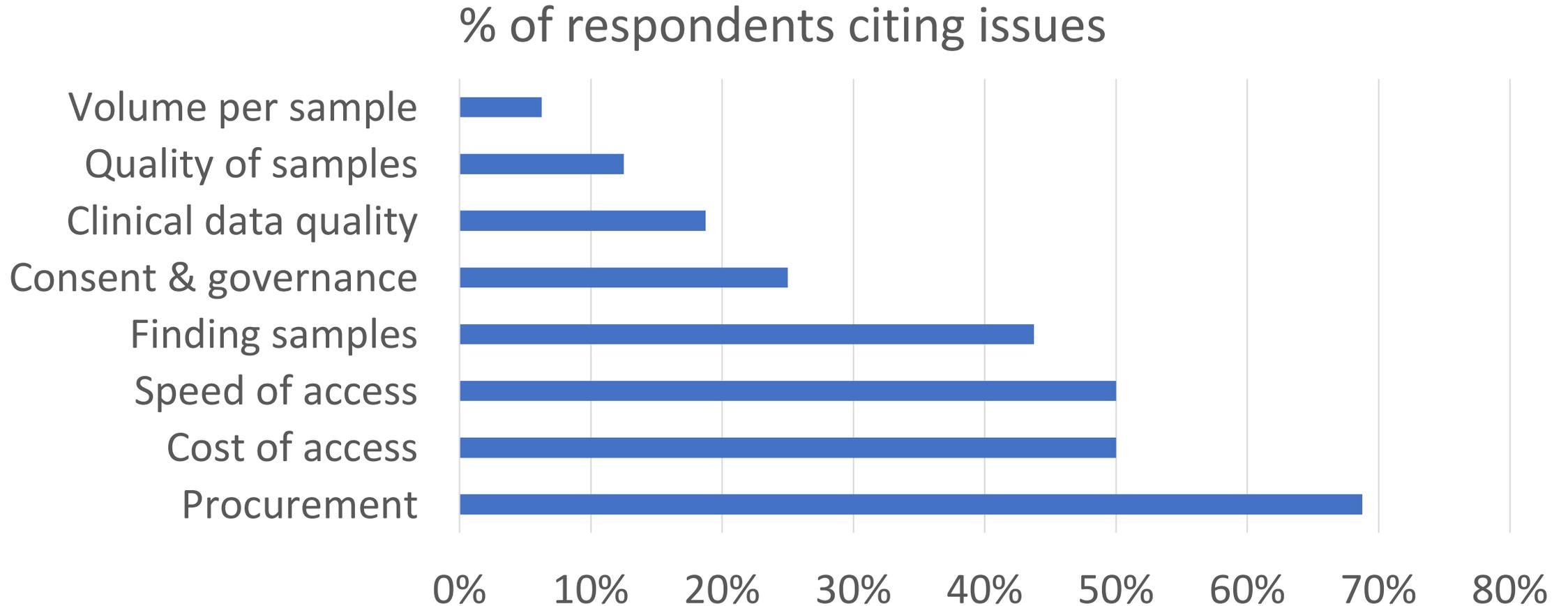
# UK research companies see samples and data as important but difficult to use



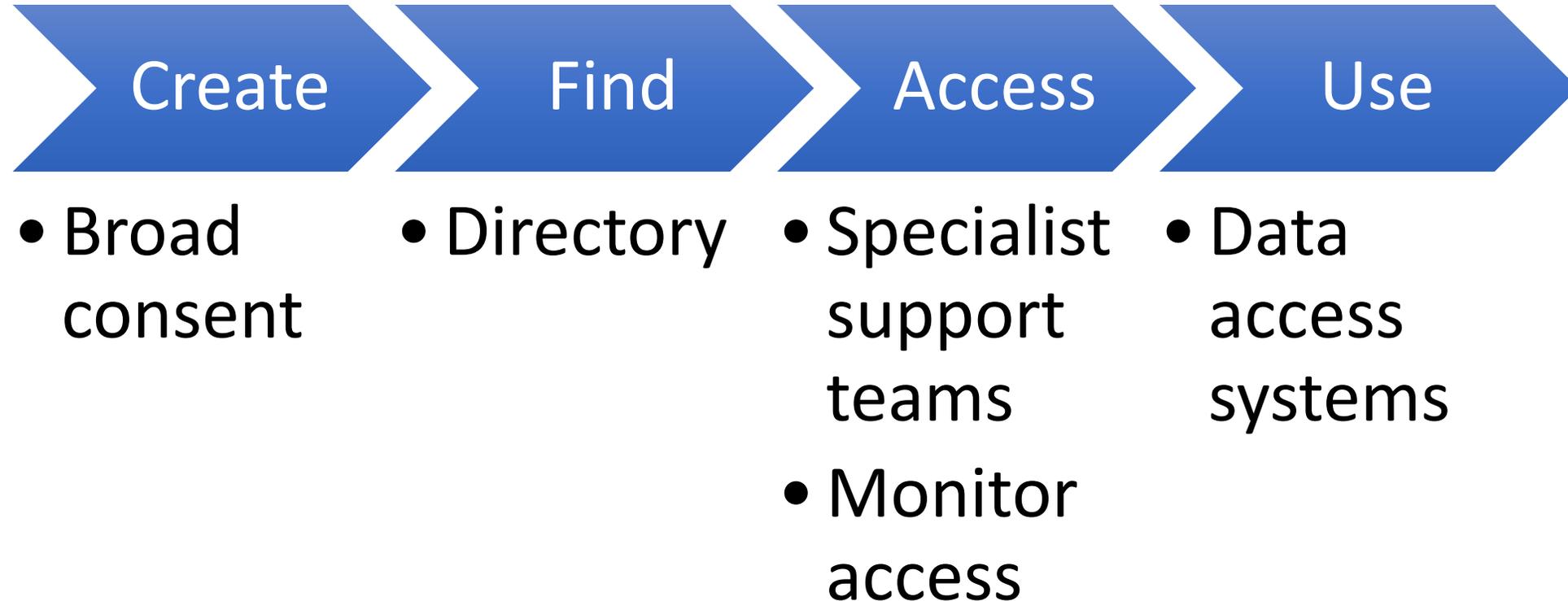
# Most UK companies had an issue accessing samples



# The process of procurement was the most common issue



# There are steps that can help



How patients in the UK can ensure that their consented samples and data are used in medical research



# My ideas

1. Encourage broad consent within NHS
2. Ensure your consented samples & data are visible
3. Ensure your consented samples & data are shared

Questions to your hospital or researcher

- Are my samples & data findable on a web directory?
- How many of the samples & data have ever been used?
- How do you make it more likely my samples & data will be used?

# Your ideas





Thank you

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