



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

James Peach, Medicines Discovery Catapult

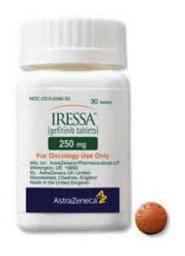






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What I'll try to cover



- How are samples are used in medical research
- The context for sample and data use in the UK
- How patients in the UK can ensure that their samples and data are used in medical research



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



Understanding disease

Understanding drugs in labs Understanding drugs in people

Proving drugs work in people

- What changes in the body when we have a disease?
- Can one disease be separated into more manageable types?
- Might a drug change the disease or its symptoms?
- Might a drug have side-effects?
- What is the best drug and dose to try in people?

- Does the drug reach the disease?
- Does the drug affect the disease or symptom?
- Does the drug have side-effects?
- Do different people react differently?

- Do these people have the specific disease?
- Has the drug helped?

The context for sample and data use in the UK



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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

Access to biosamples for commercial development is hugely important

It is easy to access high quality NHS biosamples for commercial research

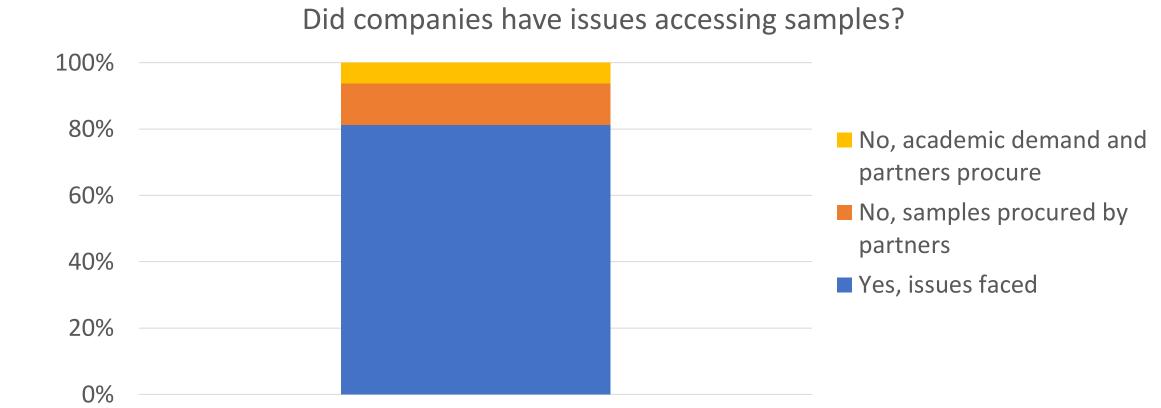
Access to the right health data such as registries and activity is hugely important for innovative companies

It is easy to access the right health data such as registries and activity

-100% 0% 100% Neither agree nor disagree Somewhat agree Strongly agree Somewhat disagree Strongly disagree

Most UK companies had an issue accessing samples





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The process of procurement was the most common issue

% of respondents citing issues

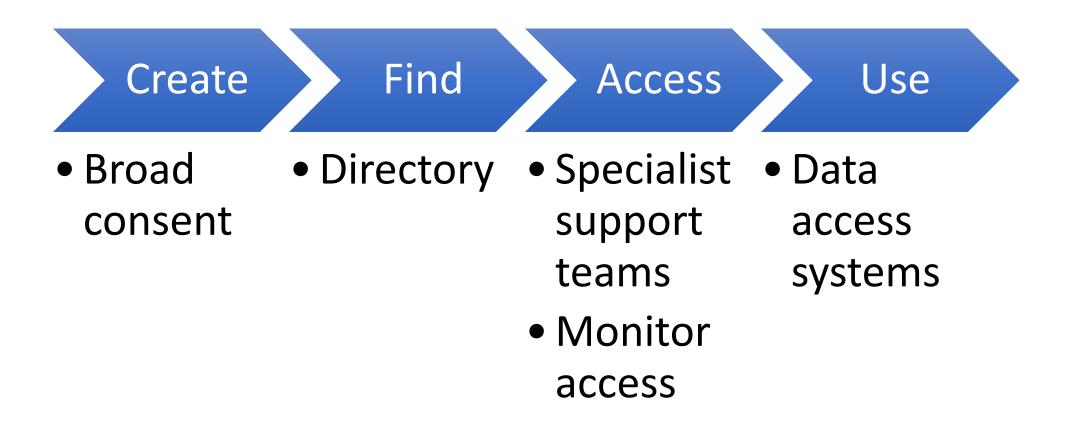
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Volume per sample Quality of samples Clinical data quality Consent & governance Finding samples Speed of access Cost of access Procurement 0% 10% 20% 30% 40% 60% 70% 50% 80%



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

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Thank you

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We work with