

# Depersonalised data for research



## The value of data and the costs

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# Data can generate value

## Data used in research can generate value

- **Social value** – new knowledge that can help improve health services and outcomes.
- **Economic value** – new products and technologies that create jobs and growth.
- **Financial value** – payments and profits from the products and technologies.



## But, this is not without ethical issues

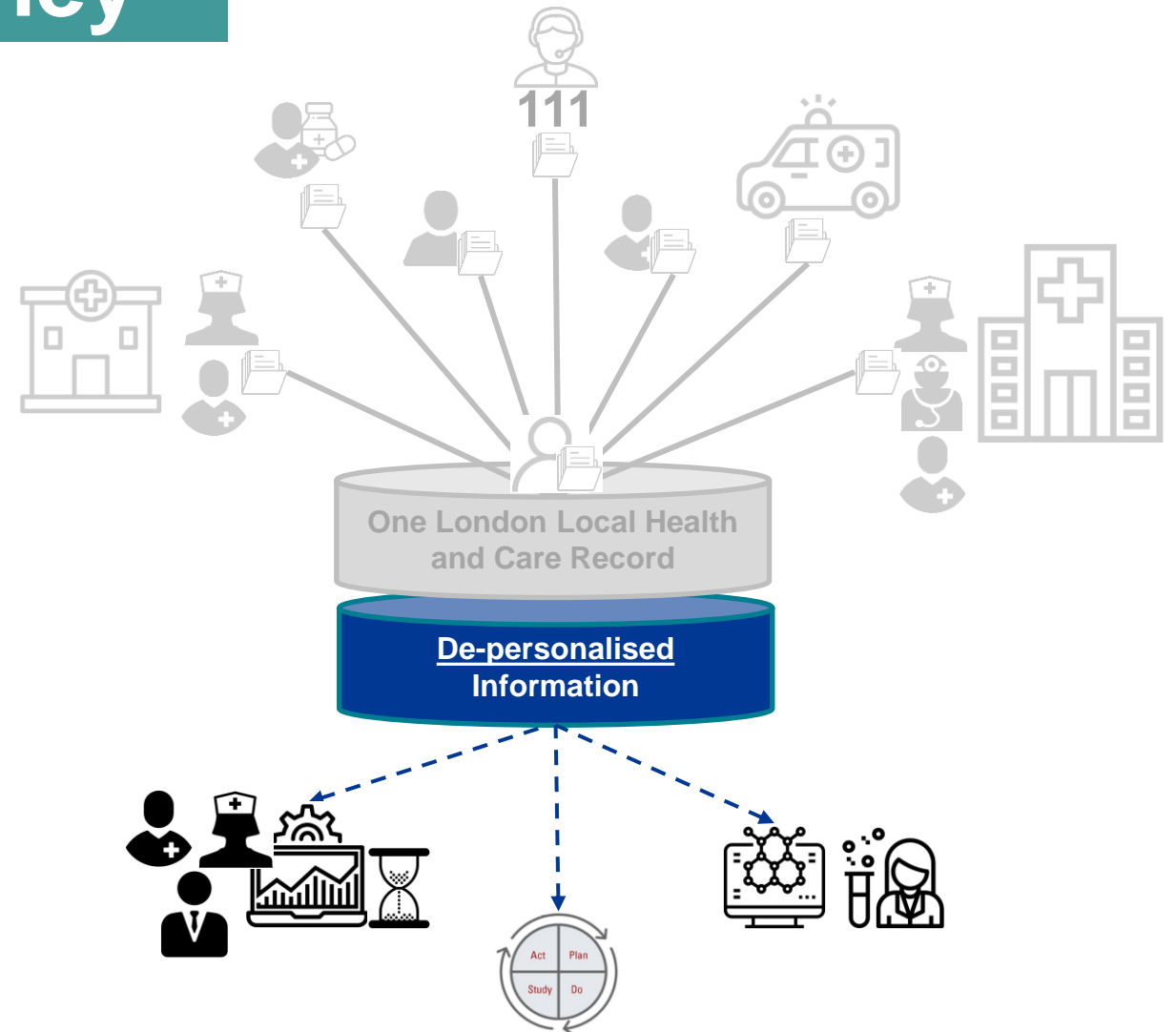
- **Social value** – some research could be unacceptable (approvals process create ‘safe projects’).
- **Economic value** – people might care about the distribution of economic opportunity.
- **Financial value** – people might care about the level and distribution of profit resulting from research.



# Doing all of this costs money

## What is it that costs money?

- Acquiring
- Curating
- Storing
- Securing
- Analysing



# Those costs can be recouped

1. Charges and funding can be generated from research to **cover the costs of the data infrastructure for research.**
2. Charges and funding could also be used to **cross-subsidise the data infrastructure for individual care.**

Research hubs are trying to determine the right operating model to:

- ensure **partnerships are productive**, so that they generate the right type of value from research.
- ensure **partnerships are fair**, so we maintain the infrastructure and share the benefit appropriately.

