

# Depersonalised data for planning



**Exploring what we mean by  
'depersonalised'**

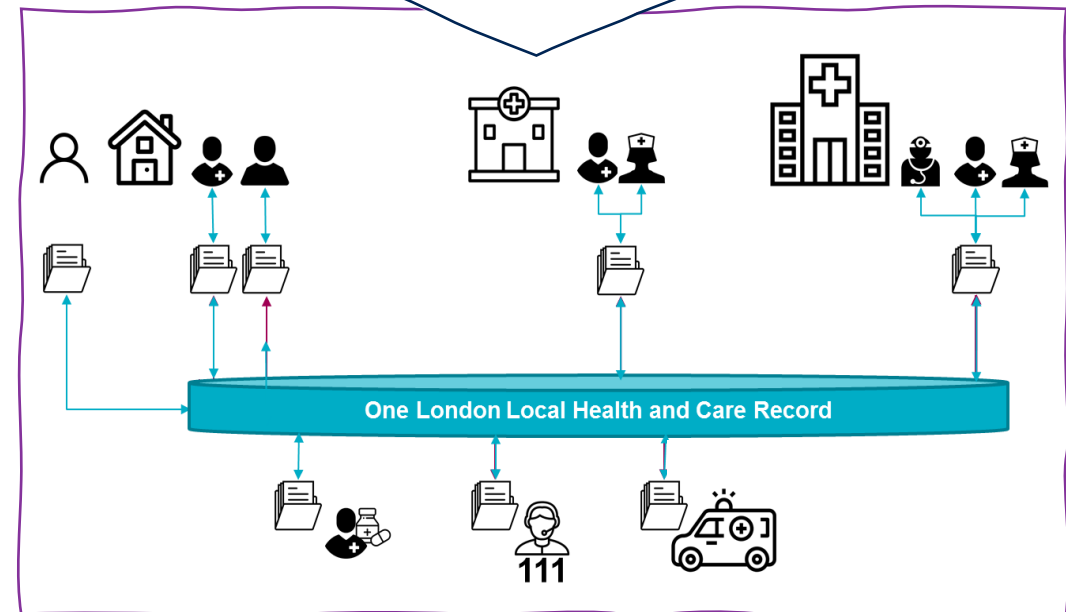
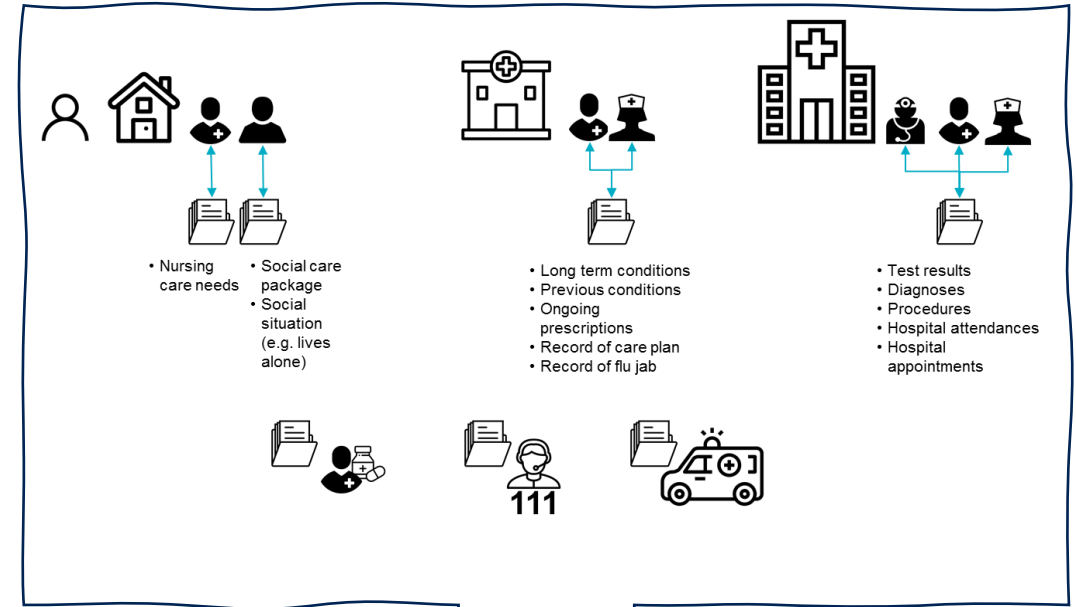
Mark Kewley

**Ipsos MORI**



# Why are we doing this?

- **The technology exists** to join-up health and care information.
- In London we have established the **OneLondon programme** to help join-up health and care information.
- But just because we could, doesn't mean we should... and **how to do it is a point of valid debate.**
- We need you to think in a **civic-minded** way to help us shape policy that affects **all of us.**



# This is topical and complex

## The Telegraph

### Can big tech be trusted with your health?

As the global healthcare market nears \$10tn, tech giants like Google and Facebook are battling for your most intimate secrets



It's not just the NHS that holds our health data, but also the apps and fitness trackers we use | CREDIT: Captain Z

Last week, at a conference in London, Dr Pearse Keane beamed an image onto the wall of an orange globe with a dark centre, encircled by red storms and a bright moon. It looked like a dying planet in a distant galaxy. In fact, it was a beautifully detailed scan of the back of a human eye, as awesome in its way as the night sky.

February 2<sup>nd</sup>



### Revealed: how drugs giants can access your health records

Experts say information sold on by Department of Health and Social Care can be traced back to individual medical records



February 8<sup>th</sup>

## MailOnline

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### UK Government sells millions of NHS patients' medical data to US drugs giants after wrongly stating it would be 'anonymous', experts claim

- NHS figures claim patient data can be linked back to individual patient records
- If a patient doesn't want their data used, they must actively 'opt out' of system
- Washington is already after unrestricted access to UK's 55million health records

By ISABELLA NIKOLIC FOR MAILONLINE  
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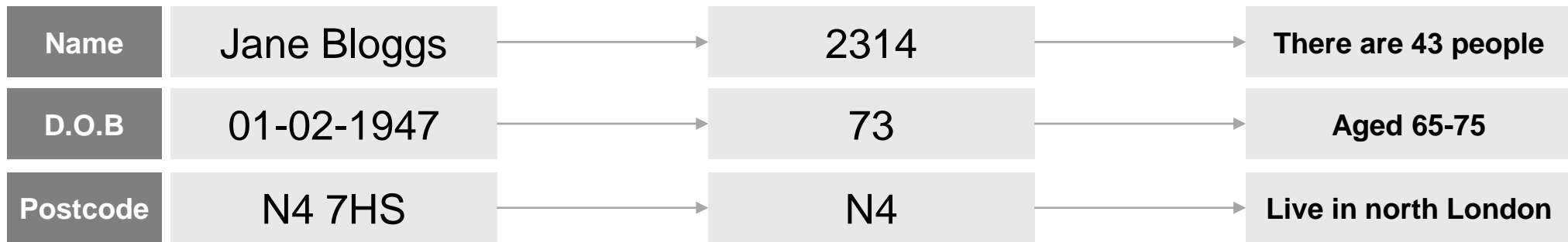
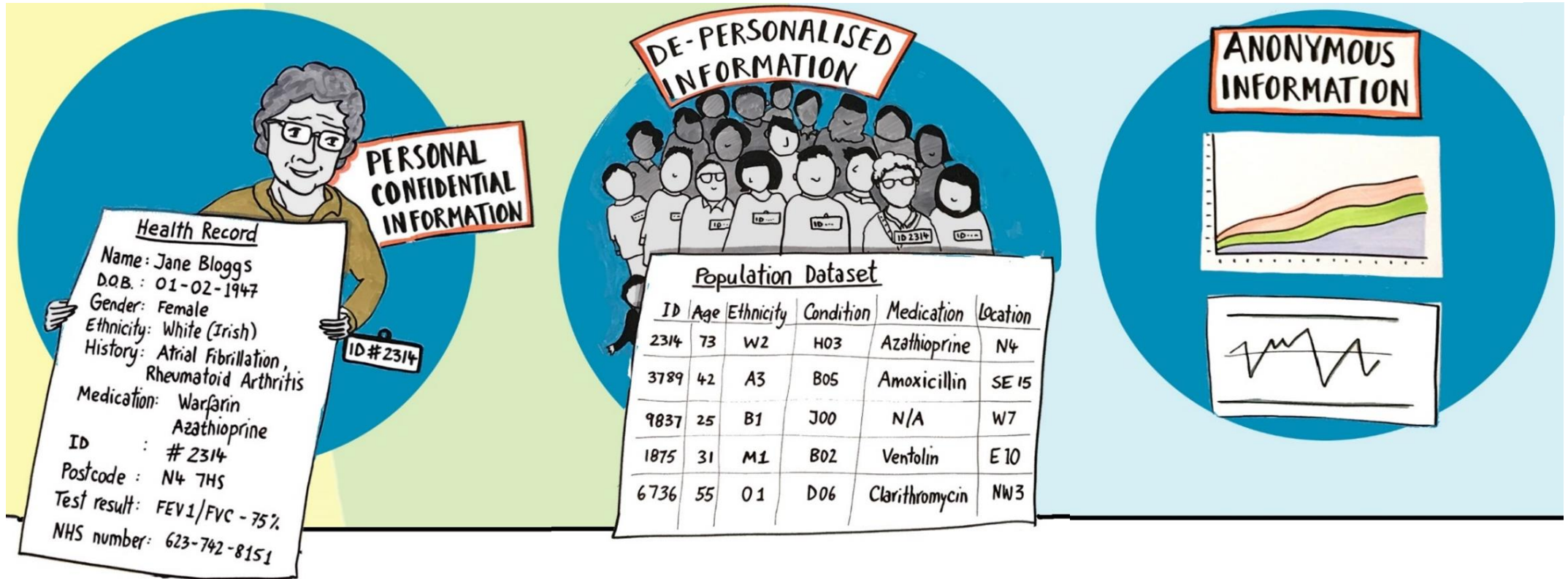
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The Department of Health and Social Care has sold medical data of millions of NHS patients to American drugs companies after falsely saying the information would be anonymous, experts have claimed.

NHS figures claim that patient data which is sold for huge amounts of money for research can be linked back to individual medical records via GP surgeries.

February 9<sup>th</sup>

# What is depersonalised?



# Does it mean anonymous?

| Demographics |    |     |
|--------------|----|-----|
| ID: 1875     | 31 | E10 |

| Known conditions |     |  |
|------------------|-----|--|
| B02              | M42 |  |

| Medications |            |  |
|-------------|------------|--|
| Ventolin    | Sertraline |  |

| Hospital Episodes |       |            |
|-------------------|-------|------------|
| A&E               | Res04 | 04-05-2013 |
| IP-Mat            | Bir06 | 30-03-2014 |
| IP-Mat            | Bir06 | 14-07-2016 |
| IP-Mat            | Bir03 | 19-01-2019 |
| MHOP              | OP07  | 23-07-2019 |

- This is de-personalised: identifiable data have been replaced with less specific fields.
- It is useful because it is 'rich', so it is possible to spot patterns.
- But the more information, the more unique the record.
- In theory, it is possible to infer your identity from the record.
- This requires access to the data, effort and skill...and doing **it is illegal!**
- **De-personalisation therefore does not mean completely anonymous!**

# Can you opt out: Yes...

You can choose to stop your confidential patient information being used for **research and planning**.

Confidential patient information is when two types of information from your health records are joined together:

- Something that can identify you
- Something about your healthcare or treatment



**For example**, your name joined with what medicine you take.

The national data opt-out policy does not apply where information is being used or shared for an individual patient's care.

# Can you opt out: ...but...

The national data opt-out does not apply to your patient data if:

- It is being used to **protect public health** (e.g. to diagnose communicable diseases or control / prevent their spread).
- There is a **legal requirement to disclose information** (e.g. safeguarding purposes, or if information is requested by the police or coroner).
- Clinicians, Caldicott Guardians and managers decide to share information based on **public interest** (e.g. reporting of gun and knife wounds or a patient's fitness to drive).
- A **patient has agreed** to a specific use of data (if a patient has registered a national data opt-out, they can agree to take part in a specific research project or clinical trial, by giving their explicit consent).

# What are we looking at?

- **Benefits and concerns** around wider uses of **de-personalised** health and care information for planning and research.
- What you think about this: what is **acceptable**, and what makes a system feel more **trustworthy**...
- ...and how we deal with the **range of partners who collaborate with the NHS** (including benefits and risks of access).

