

General Practice Data for Planning and Research

NHS Digital

Presented by:
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GP data saves lives

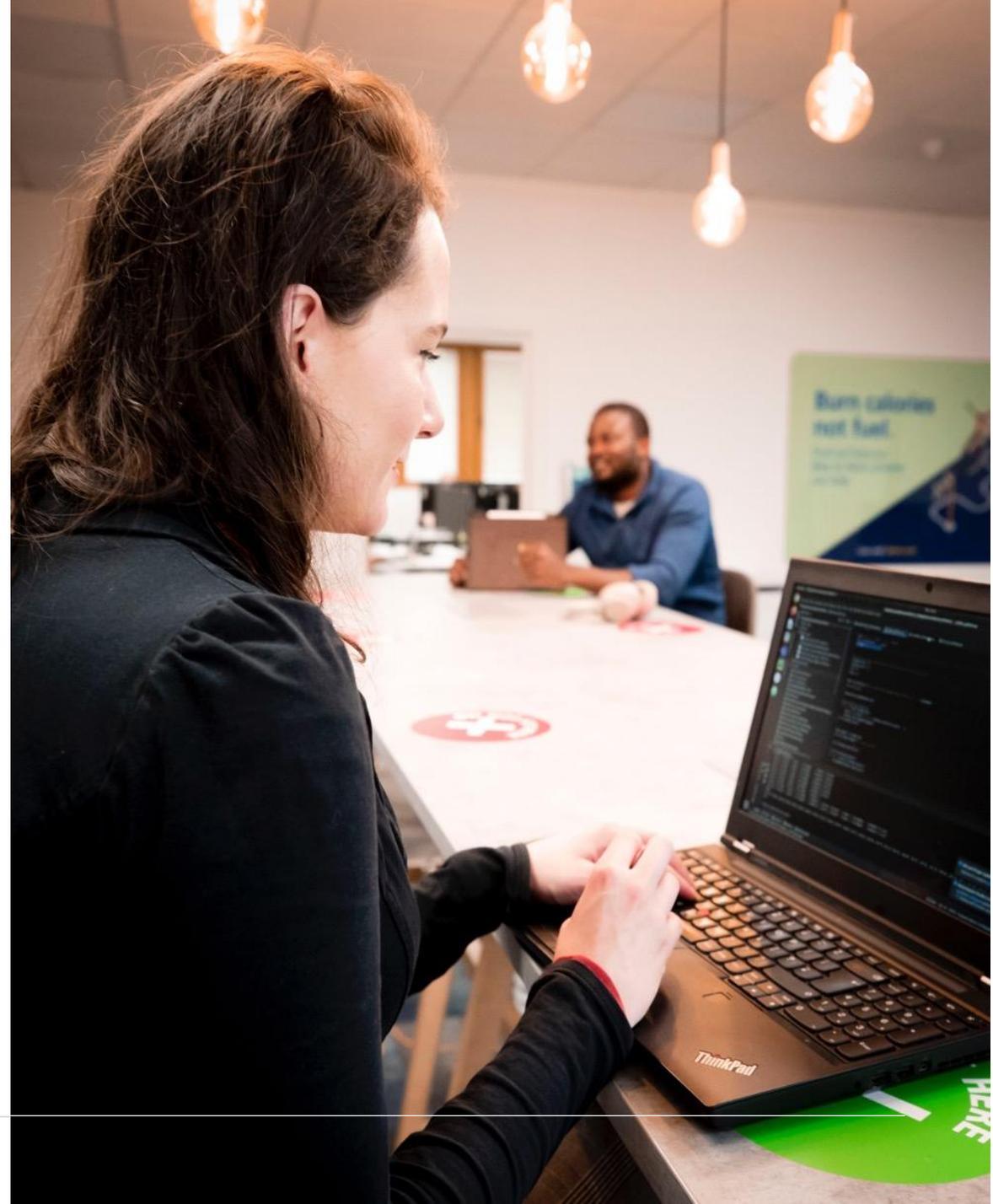
- **Oxford University RECOVERY Trial**
Cut deaths from COVID by a third – **saved** 22,000 lives in the UK and **one million worldwide**
- **Shielded Patient List**
Rapidly **identified and protected** those most vulnerable to COVID, gave them access to the services they needed and **prioritised them for vaccination**
- **Long COVID**
Provided evidence to support the urgent commissioning of long COVID support services
- **National Diabetic Retinopathy Screening**
Identifies individuals who need an urgent sight test, **preventing blindness**
- **Learning Disabilities Observatory**
Identifies disparities in care and outcomes, **improving learning disability services**

What is GP data for planning and research and why introduce it now?

- This is an **improved replacement** for the decade-old General Practice Extraction Service.
- It needs to be replaced with a **more efficient, consistent, cost-effective and privacy-preserving system.**
- The GP Data for Planning and Research data collection will **improve healthcare services** and enable research that results in **better treatments.**
- This new improved system has been **developed in collaboration** with doctors, patients and experts in data, privacy and ethics to ensure relevant safeguards are in place for patients.

How will data be accessed?

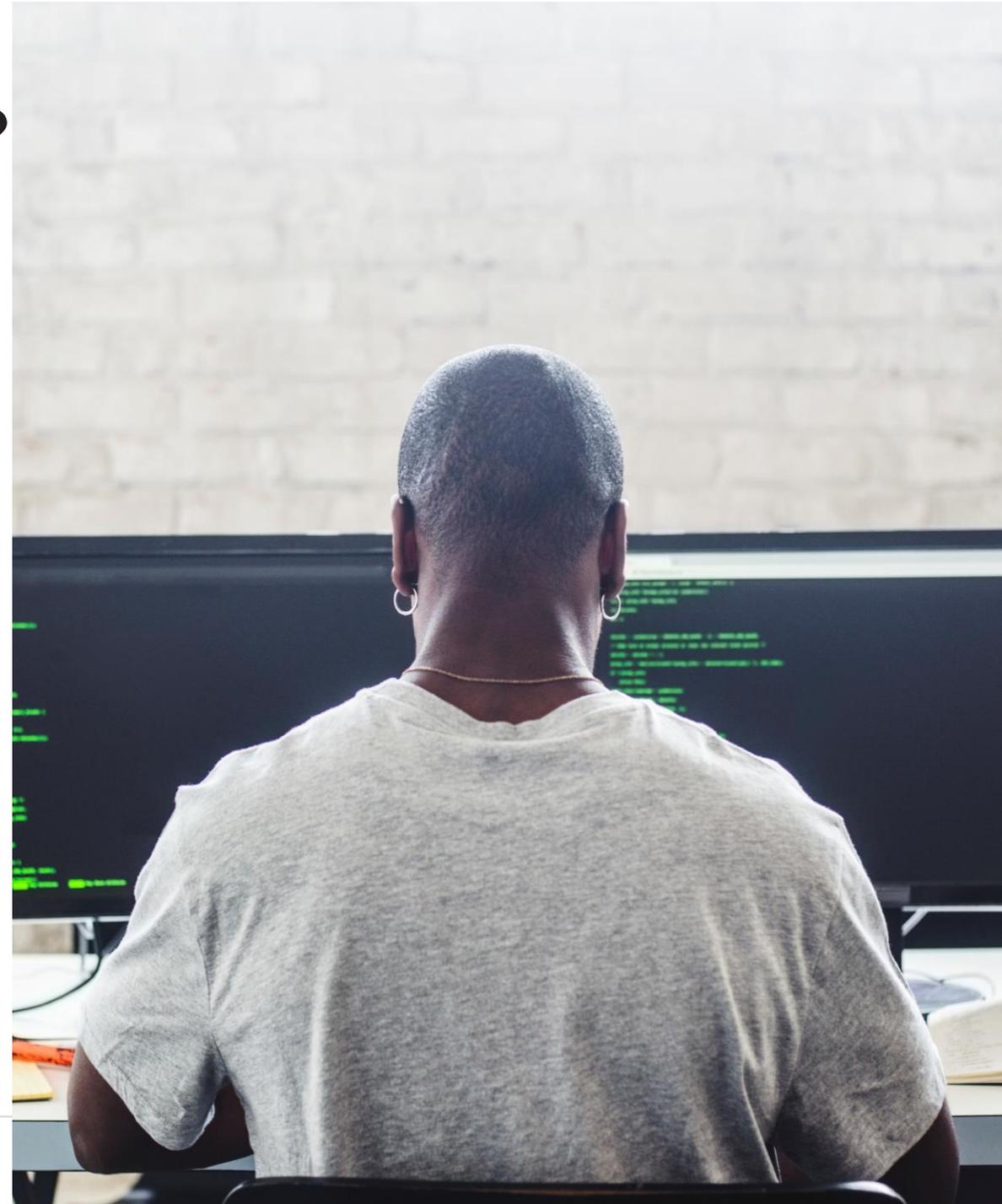
- **We are working to ensure that all data will be accessed in a Trusted Research Environment (TRE)**
- A TRE is a secure data access environment that data recipients will log into, rather than receiving physical copies of data.
- We aim for all GP data to be accessed in a TRE, though it will take time to develop this in some cases.
- Commercial organisations will not be able to declare that they have a TRE and receive the data.



How will my data be kept secure?

We take our responsibility to safeguard the data we hold incredibly seriously.

- Your data will be pseudonymised and encrypted when collected and held within NHS Digital
- Organisations can only use the data to plan services or carry out clinical research
- There is oversight of these requests from IGARD, an independent group of data sharing experts and the Professional Advisory Group, a board of GPs
- All successful applications are covered by detailed Data Sharing Agreements which cover security of data and specified uses, and published in our release register
- We regularly audit organisations to ensure they use the data for what they say they will and that they keep it securely
- **We never share or sell data for marketing or insurance purposes.**



Opting out

You have two ways to opt out of sharing your data

1. Type 1 Opt-out

Prevents data sharing by your GP practice, other than for individual care.

Collect a form from your GP or from our website and return to your GP a week before 1 September if you don't want NHS Digital to collect your GDPR data.

2. National Data Opt-out

Prevents sharing of identifiable patient data by us, other than for individual care.

Subject to exceptions such as legal obligation to share and public health

Links on NHS Digital website and NHS.uk as well as a phone option.

3. You always have the option to retract your opt outs if you wish at any time



What happens if I opt out?

Data needs to reflect the population to draw sound conclusions.

If a large number of people opt out then the data becomes less useful for planning services and conducting research.

This is a particular problem if people from certain areas or groups are more likely to opt out.

Our plans for public communications

Data saves lives.

It is crucial that the public understands how their data is used and what their choices are.

The first data collection has been deferred from 1 July to 1 September 2021 to provide more time to work with patients, doctors, health charities and others to increase public awareness of the collection, understanding of its vital benefits and the rights of patients to make informed choices.

Although GPs are the people most trusted by patients to inform them about their health and care, we recognise GPs are under pressure. We will do more to increase public awareness ourselves, as well as working with the GP profession to produce material that makes it easy for GPs answer their patients questions.

We will soon launch a substantial campaign to publicise this activity and tell people about their choices which will run throughout the summer.

