

# Stimulus Materials

Stage C

Final version for groups 5.3.24

## **One line description:**

Secure Data Environments and Trusted Research Environments are a controlled way of accessing health data that is not identifiable for use in research that can save and improve lives.

# Animated video script: 'Scene' 1 – introduction

### Voice over:

Whenever we go to a GP, a hospital or a pharmacy, information will be collected about us and our medical history. Only healthcare professionals who are directly involved in your care will be able to access your full patient record. But some of the information from your record may also be useful for specific purposes beyond your individual care, for research to improve health, care and services across the NHS.

If small amounts of data that cannot identify people from many patients are linked up and pooled, researchers and doctors can look for patterns in the data, helping them develop new ways of predicting or diagnosing illness, and identify ways to improve clinical care.\*

Animation visual: *A patient visiting a GP. Information being entered on a computer. Visual of data flowing together from across the UK into one group and a visual representation of patterns being identified (e.g. a line linking data with a light at the end).*

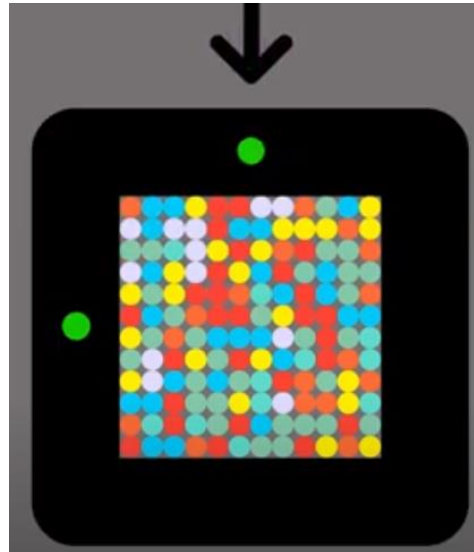
# Animated video script: 'Scene' 2 - intro to SDE/TRE

## Voice over:

Secure Data Environments and Trusted Research Environments are highly secure environments where these large amounts of health data can be stored and accessed.

## Animation visual:

*Animation of a secure storage facility for data. Examples for illustration below:*



## Animated video script: 'Scene' 3 – how accessed

### Voice over:

To access this data, researchers go through an approval process and there are several criteria that they must meet before they receive approval. Researchers within NHS organisations, universities, charities and private companies such as pharmaceutical companies are examples of who could apply for approval to access this information.

Once researchers receive approval from an access review committee, they can access the information.

### Animation visual:

*Show animation of several researchers including those listed above (some in lab coats) making an application. Show researchers receiving a tick of approval.*



## Animated video script: 'Scene' 4 – what data

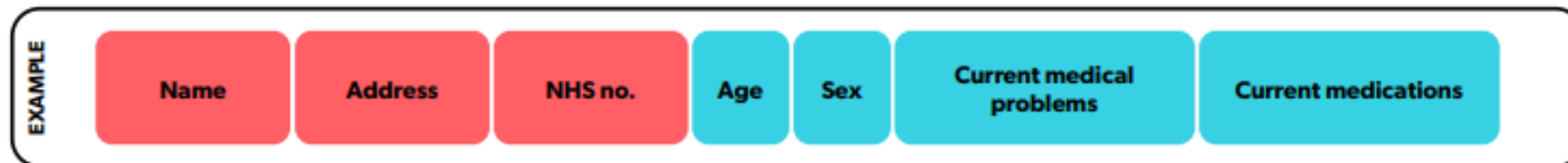
### Voice over:

Before they can directly access the data in the highly secure environment, any identifiable information such as names and NHS numbers, are removed. This data is called de-identified data.

Data is not taken out, only the results from the analysis are taken out except in exceptional circumstances. This means that multiple copies of the data do not need to be sent out or downloaded.

### Animation visual:

*Show a line of data with identifiable information at one end and health data at the other (e.g. as below). Show the identifiable information being removed and replaced with a number before it can be viewed by a researcher. Show data staying inside the secure storage and graphs coming out (i.e. not the data itself).*



## Animated video script: 'Scene' 5 – benefits

### Voice over:

Secure Data Environments and Trusted Research Environments help make research cost-effective and collaborative. They also provide access to information that can identify better ways to predict and diagnose illness, help develop new treatments and monitor the safety of existing treatments, support planning of health services, and help address health inequalities.

### Visual:

*Show visual of researchers grouped together looking at a shared whiteboard to highlight collaboration. Show information flowing to a clinician in a hospital setting who speaks to a patient who then smiles alongside their family.*



# One line description alternatives:

Secure Data Environments and Trusted Research Environments are a controlled and safe way of accessing health data that is not identifiable for use in research that can save and improve lives.

**OR**

Secure Data Environments and Trusted Research Environments are a place where only approved users, including researchers, NHS providers, NHS or local authority planners, and charities, can access non-identifiable health data for use in research that can save and improve lives.

**OR**

Secure Data Environments and Trusted Research Environments are a place where approved researchers within and outside of the NHS can access NHS data that is not identifiable for analysis without them having to download the data.



# Alternative descriptions of how accessed:

To access this data, researchers go through an approval process and there are several criteria that they must meet before they receive approval. Researchers within NHS organisations, universities, charities and private companies such as pharmaceutical companies are examples of who could apply for approval to access this information.

**OR**

To access this data, researchers go through an approval process and there are several criteria that they must meet before they receive approval; these are called the five safes. Researchers within NHS organisations, universities, charities and private companies such as pharmaceutical companies are examples of who could apply for approval to access this information.

# How approval is granted for researchers

- Access is approved by an access review committee. Some access review committees include members of the public.
- For access to data to be granted, researchers need to demonstrate that their proposal is an appropriate, lawful, and ethical use of the data, that it will deliver clear public benefits and that they will publish their results to enable use, scrutiny and further research. Researchers may have to sign an agreement promising to protect the confidentiality of your data at all times.
- Organisations follow set processes and criteria for the decisions they make about how patient data can be used, some of which are set out in law.

# Who is accessing information

UPD video:

[Who can and cannot access health data \(youtube.com\)](#)

# Further information on data that is not identifiable

UPD video:

[A health data journey \(youtube.com\)](https://www.youtube.com/watch?v=...)

# Why is information being accessed – examples

- The information is used to identify better ways to predict and diagnose illness, to develop new treatments and monitor the safety of existing treatments, for planning services and for addressing health inequalities.
- Examples include:
  - NHS England Secure Data environment: provides academics with access to cardiovascular and cancer data for Covid-19 research.
  - The 1000 genomes project: analyse genomic and long-term clinical data (from health records) to gain insight into the nature of genetic changes that drive cancer evolution. (An opt-in study)

## How data is kept safe

- a. Safe people: only approved researchers are granted access to the data.
- b. Safe projects: data is only made accessible for projects in the public interest.
- c. Safe settings: Data is accessed by researchers in a secure room, or via an approved, remote connection to one.
- d. Safe data: Data is de-identified and only data that is really needed for the project is made accessible.
- e. Safe output: All research findings are checked by staff and no data can be taken out, only analysis and results.

# Security of the secure environment

Most cyber security breaches can be prevented by simple steps, like making sure staff do not use weak or compromised passwords and checking software systems are updated automatically.

Organisations should have plans in place to detect and eliminate malware within their systems. These plans should include measures to minimise the impact of a security breach and to expedite the organisation's response. Organisations should adopt a 'defence-in-depth' approach, using multiple layers of defence with various mitigation techniques at each layer to detect malware and prevent it from causing significant harm.\*

# Examples of SDEs and TREs that exist

NHS England Secure Data Environment

Sub national NHS England Secure Data Environments

Public Health Scotland's National Safe Haven

HSC Northern Ireland's Honest Broker Service TRE

SAIL databank (Wales)

Discover-NOW – a London Secure Data Environment



# Description of data federation

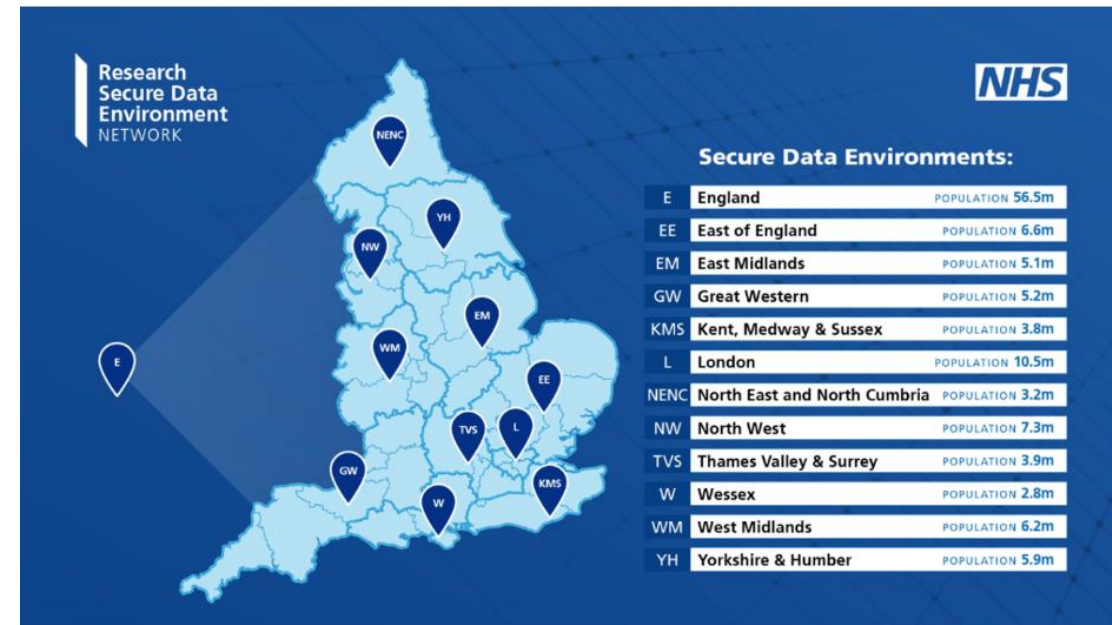
Some SDEs and TREs are storage solutions (i.e. places where all the data is stored), others used something called data federation.

Data federation is software that pulls information from different organisations like NHS trusts and Integrated Care Systems allowing them to connect data they already hold in a secure and safe environment. Unlike other technologies, data federation leaves all data at the source.

# The difference between SDEs and TREs

Trusted Research Environments can be run by any organisation.

Secure Data Environments are run by the NHS and are a type of Trusted Research Environment. There is a national NHS England Secure Data Environment that uses nationally collected data and there are a network of sub-national NHS Secure Data Environments called the NHS Research Secure Data Environment network which use data collected locally.



# Open Safely video example

[OpenSAFELY - YouTube](#)