

Understanding Patient Data:

“What words to use when talking about health data”

SDE and TRE resource aimed at the public. This will be tested in workshops with the public and in depths with stakeholders.

Draft 3 6.3.24



Stimulus 1 – summary of interim top line findings

Knowledge of the uses of health data remains limited

including concepts such as the use of large health data sets for research, and de-identification.

For SDEs/TREs participants cared most about:

1. Whether data is identifiable.
2. That the data is safe.
3. Who has access.
4. What the data is used for; what is the benefit.

Providing full transparency on the technical detail of SDEs/TREs was challenging;

participants lacked interest and found much of it too complex. A simpler description following the flow of data was preferred.

More detailed reassurance was sought in three areas:

- a) Who is accessing the data (Safe people).
- b) What data they are accessing (Safe data).
- c) How the data is kept safe (Safe settings).

The level of information sought differed across the sample;

some were comfortable with 1-line, others wanted reassurance in the three areas highlighted and a small minority sought further depth.

Several phrases held widespread appeal

and were more easily understood. These have been incorporated into Stage C materials. The **format preferred for the resource was an animated video.**



Stimulus 2:

- Example 1-line description of an SDE/ TRE
- Example video script and description of animations for an SDE/ TRE



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).*

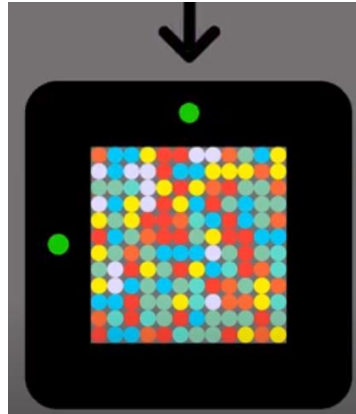
Animated video script: 'Scene' 2 - intro to SDE/TRE

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

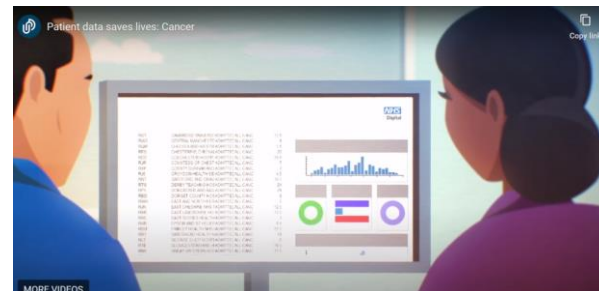
Voice over:

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

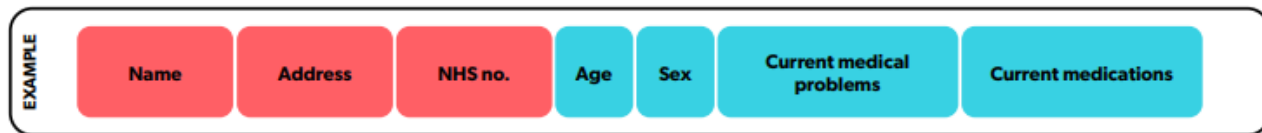
Voice over:

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.



Stimulus 4: Further information

- Text on topics that could sit as links to further information or as text beneath an animation.
- Some participants sought further detail on how approval is granted, and how data is kept secure.
- We have included a description of the difference between TREs and SDEs for you to review so we can test this with the public in the next workshops.



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.

How the 'secure' environment is kept secure

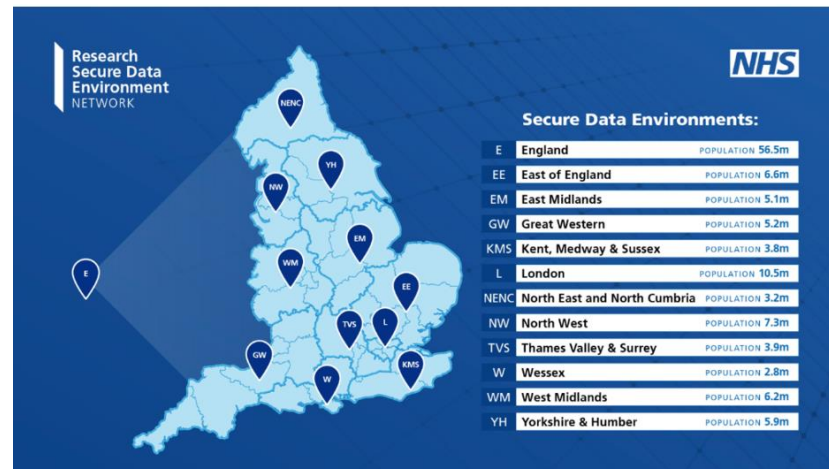
Participants who were more concerned about their health data were keen to understand:

- How the data is kept 'secure' in the secure environment and safe from hacking.*
- How does a Secure Data Environment guard against someone copying the data for example using a screen shot*

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.



Think there's something we should add?

Write to us at hello@understandingpatientdata.org.uk



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