# Summary of UK TRE working group session on SDE / TRE Definitions

17/01/2024 Zoom call:

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## Summary:

Five attendees (13 registered), covering commissioning through to technical architecture and delivery of SDE/TREs, discussed the scope and remit of the statement, following an explanation of its naissance by Pete Barnsley / Madalyn Hardaker (Leads of Working Group) – see slides. There were a wide range of viewpoints expressed, all very supportive of the need for an internal community semantic definition set. More of this activity was supported and a lot used slide page 2.

“harmonisation and FAIR will be so much easier with clearer definition ,…, being clearer means funding purpose will be more transparent”, “ the starting definitions (slide 4) are clear and possibly uncontroversial” , “is a great start for people to comment upon”. “Getting our story straight on naming is first must, … NHS area needs it…a bit of a mess at moment”, “the slide 2 is a great visualises this”. “…can we just say that an SDE is where data is curated and managed and a TRE is where the analysis is done, and depending on what dominates your specific platform you get labelled accordingly?”, “what agency, for an IG area, would be needed if we adopted these separations of concern (slide page 2)?”

“CPRD and NHS systems may not allow data to leave their own area…and how does this help”, “data gravity may be important to talk about… health data is often seen as the most important and the approach is if you have other data then pull it in to the environment…everyone is trying to protect their own data…but if data needed is from multiple sources (which is what normally happens) then we need to be more nuanced”, “federating data may be possible using clever tech…not sure that is robust yet …”, “Most data controllers have a principle that they wish to see FAIR data and commitments to share data…but controls are needed for the IG governance duties”, ”but some areas want their own publications and avoid sharing the data with others…”, “every ‘SDE’ has some gravity and a meeting of minds would strengthen all”.

“The use of SDE in NHS and not TRE was driven by the fact that research was not the prime use of the data.”, “research has a different legal basis than health care and planning, which aggravates concerns about usage”, “we don’t need to worry about what terms we end up calling things, as long as we recognise there are two different things – one is about preparing stuff (data) and the other is doing the research in a segregated area”, “over simplification is a big problem that drives policy – like ‘go to the data’ misses the nuance of research”, ”the research community needs to enlighten policy makers to this essential problem”, “it is more than a dataset but an HPC facility and lots of other things … many specialities are involved”, “research does not work like the present picture (slide page 1)”, “NHS coming to this in an old fashioned way…much more complicated”, “cloud native means more than on a cloud”

“having the ability to share and not copy seems very key”, ”…maintaining a ‘ground truth’ and this remaining in the data controllers area, where version control and such is already in hand, is key – so link to extending control working group”, “part of the definition of the SDE is where the data controllers sit”

**SDE/TRE Definition model: Associated Info from participants**

CPRD: <https://cprd.com/cprd-single-study-licence-users-will-be-first-access-cprd-trusted-research-environment-tre>

**Slides shared on session:**

 (same slides used as 09/01/2024 session)

Page 1: Illustration of today with SDE/TREs combined in the partially aggregated data domain.

Page 2: Proposal separating the TRE form the SDE and positioning it within the Trusted Research Edge Domain adjacent to the RPO Research Discovery Domain.

Page 4: A suggested outline draft for the definitions – to be worked on later

Page 3: Agenda for event

## Possible form of a Discussion Paper from this Working group:

Below is an indicative structure for a document to share with the UK TRE community and publish. It would be positioned as a discussion document and not policy. Please comment and critique.

**Why clear definitions are needed:**

An explanation of key reasons why this working group is important to the space overall and the UK TRE community.

**What are the similarities and differences between SDEs and TREs?**

An explanation for why SDEs and TREs are different.

**What are the proposed Definitions**?

Pictures and words that explain the set of “top-level” things (e.g. SDE / TRE, Project) and why they are different from the other things but link with them in a working ecosystem.

**How could this affect Information Governance (IG) processes?**

An outline discussion of the impact on a generalised IG process: the things that will remain the same; the things that will need to change; the things that may need to change; and possible options and advantages that result.

**How does this affect federation models and other working groups such as that looking at Citizen Agency?**

An outline / explanation of the implications of the agency options on how SDE/TREs are federated and the equivalent for any other working groups that have relevance.

**The level of Agreement within the UK TRE Community.**

How much agreement is there within the wide UK TRE community on these definitions? And what is the basis of any disagreement.

## Suggested Scope statement for Working Group

The SDE/TRE Working group is focussed on clarifying the terms used WITHIN the UK TRE community.

As a first phase, it will not aim to influence how existing facilities present themselves, nor how the public understands them.

Specific focus centres on the Secure Date Environment / Trusted Research Environment terms and things directly associated with these areas, the research objects and process.

It is not about a Glossary of terms, it is more about the semantic meaning of the terms, aimed at clarifying what makes things different.

Its first general aim is to be able to quantify how divergent the UK TRE community is on the key parts – possibly using agree / disagree surveys to capture the level of consensus.