# Summary of UK TRE working group session on Citizen Agency

09/01/2024 Zoom call:

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## Summary:

Eight attendees (13 registered), from commissioning to members of the public via practicing IG panel and SDE/TRE platform people, discussed the scope and remit of the statement, following an explanation of its naissance by Pete Barnsley (Lead of Working Group) – see slides. There were a wide range of viewpoints expressed on the role of citizens, all very supportive of the need to ensure citizen agency in the emerging TRE/SDE infrastructure.

“My data is in the system but I cannot see it - this is very weird for me… researchers get it before we do… we (citizen) can make it better by correcting it… and wearable providers will know things before I do and we want agency on that as well.”

“We need to consider how and if low citizen engagement (or access to any facilities helping with agency) would bias any research using the data.”

“As a citizen I mainly don’t want my data to be used against me. If data is leaked and trust betrayed, we need to be able to go in and see what happened and have a say.”

“It seems important to make sure researchers have access to all data and not only for those people who have opted in and proactively choosing to engage their data for research. Ie Opt Out access is a key model.”

“This is about a culture shift of views, a discussion such that the TRE community enables citizen agency in its resulting creations.”

“What would be the consents model for such a mediated interaction between datasets and researcher projects via the citizen.”

“It is not just about the data quantity but about the quality, and engaging citizens to help enhance quality (completeness) of data, even if it is early adopters first that go on to encourage other, then this is a good thing.”

“We want to share this working groups mission more widely to get others voices into this discussion”

**Citizen Agency models: Associated Info from participants**

IG Patient Panels

Patient and Public Involvement and Engagement (PPIE)

Be part of research: <https://bepartofresearch.nihr.ac.uk/>

Solid: <https://www.inrupt.com/>

Use My Data: <https://www.usemydata.org/>

Northern Ireland Public Involvement Enhancing Research (PIER): <https://research.hscni.net/pier-ni-public-involvement-enhancing-research>

**Slides shared on session:**

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Page 6: Agenda for the session.

Page 1-2: Data Domain visualisation of Today SDE/TRE and Proposed separation to Research Edge.

Page 3-4: Outline why citizen consent will be essential in future as problems drive linked data need.

Page 5: The Citizen Data Domain offering some agency between their SDE and TRE use.

## 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 citizen Engagement is used / needed?**

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

**Where would citizens engage within an SDE/TRE infrastructure ecosystem?**

A discussion and presentation of the many places in SDE/TRE ecosystem where engagement will / does / should occur. For example, engagement within patient panels and within PPIE groups is valid and remains. But equally a new “consent” based gate on data flows between SDE and TRE locations is another. An application showing the citizen the research projects using their data is another.

**What services would the Citizen and Researchers have as a result**

A presentation of the types of facility and capability that both the citizen and the research would have / be expected to do and also how these two enhance and engage the connection between researchers and citizens.

**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?**

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.

## Suggested Scope statement for Working Group

The Citizen Agency Working group is focussed on documenting and outlining possible roles for the citizen within the data research arena.

Specific focus centres on the Secure date Environment / Trusted Research Environment facilities.

It is not about defining how SDE/TREs, nor research projects, should engage with citizens. It is all about keeping the citizen enabled and the SDE/TRE UK community keeping the facilities it builds and architects open to citizen agency.

As a minimum it is about being transparent to citizens as to why SDE/TRE are structured and work in the way they do – however involved / excluded the specific citizen is from that world.