# Summary of UK TRE working group session on Citizen Agency

17/01/2024 Zoom call:

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## Summary:

Ten attendees (15 registered), from commissioning to members of the public via practicing IG panel, and ethics leads 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 but with balance on the risks (such activity could have) through public transparency and engagement in the process at all stages.

“Citizens have agency now – through involvement in panels as part of information governance within SDE/TREs”, ”There is a difference between consented and unconsented research…and unconsented should not be thrown away”, “we could think of this as similar to policing-by-consent”

“gov/nhs bodies are increasingly asking for more patient engagement”, “getting lay people involved is hard, although there are expert panels who understand”, “within the rules (to confidential advisory group for section 251), it is incumbent to make reasonable efforts to contact unconsented cohorts, to let people know how you are intending to use their data… but what does reasonable mean, and what is effort, … a national conversation on reasonable effort is a good idea”.

“A *social licence* is needed for any “database”, to be able to operate”.” Have we asked the citizens if that social licence is valid”, “ … if you have social licence then consent is easier to get or not need”, “ a social licence means more trust…and we need not rely on citizen’s autonomy to consent as much”, “I don’t think we can use banking as a comparator to SDE/TREs”, “the control citizens have should not undermine the value of the dataset”, “full control over their data could do a lot of damage to the provision of healthcare and research”, ”get any agency upfront on social contract, concerns and the alleviation of them”.

“Bias due to under representation is a problem to think through”, “getting a self-selecting cohort is a danger – literate, health literate and tech literate citizens”, ”expert groups may create this bias indirectly”, ”On the wide ranging datasets slide(4) this looks similar to Facebook – what is it that Facebook offers that convince people to allow this?”, “who can see this data about me and why”, “A national opt out is a blanket for all data, it does not have any granularity to allow certain data to be used and others not”, “the majority of people don’t care that their data is used, but a vocal minority do…we need to be careful presenting these detailed ideas to the public,… and the point of linking the data (done by research project and ethics discussions)”,”..these groups can use a story / surprise to champion their cause and trigger mass public unrest and unfounded concerns”.

“An opt-in could work if there was a lot of work – build trust, data standards, re-join and re-deidentify – and would the government want to do this”, “need to start the conversation around trustworthiness...as Trusted by whom – authority or citizen”, “an agency model - Citizens seeing their data and how it is used - will help build trust and social licence”, “without a model like this we risk going in circles like with GDPR”, “key we minimise (Manage) no of ‘surprises’ the citizen sees – ie in a cancer study where they think they have not been told they have the disease”.

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

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

IG Patient Panels: participant panels, access review committee

Smart Data UK – consent research: <https://www.gov.uk/government/publications/smart-data-research-on-consent-liability-and-authentication>

PEDRI: <https://www.pedri.org.uk/>; <https://dareuk.org.uk/pedri-publishes-resource-survey-report/>

Nuffield Research: <https://www.nuffieldtrust.org.uk/news-item/questions-of-trust-exploring-the-national-data-opt-out-rate>

Caldicott principles: <https://www.gov.uk/government/publications/the-caldicott-principles>

**Slides shared on session:**

**** 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 Data 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.