The Data Domains: The Present Picture:
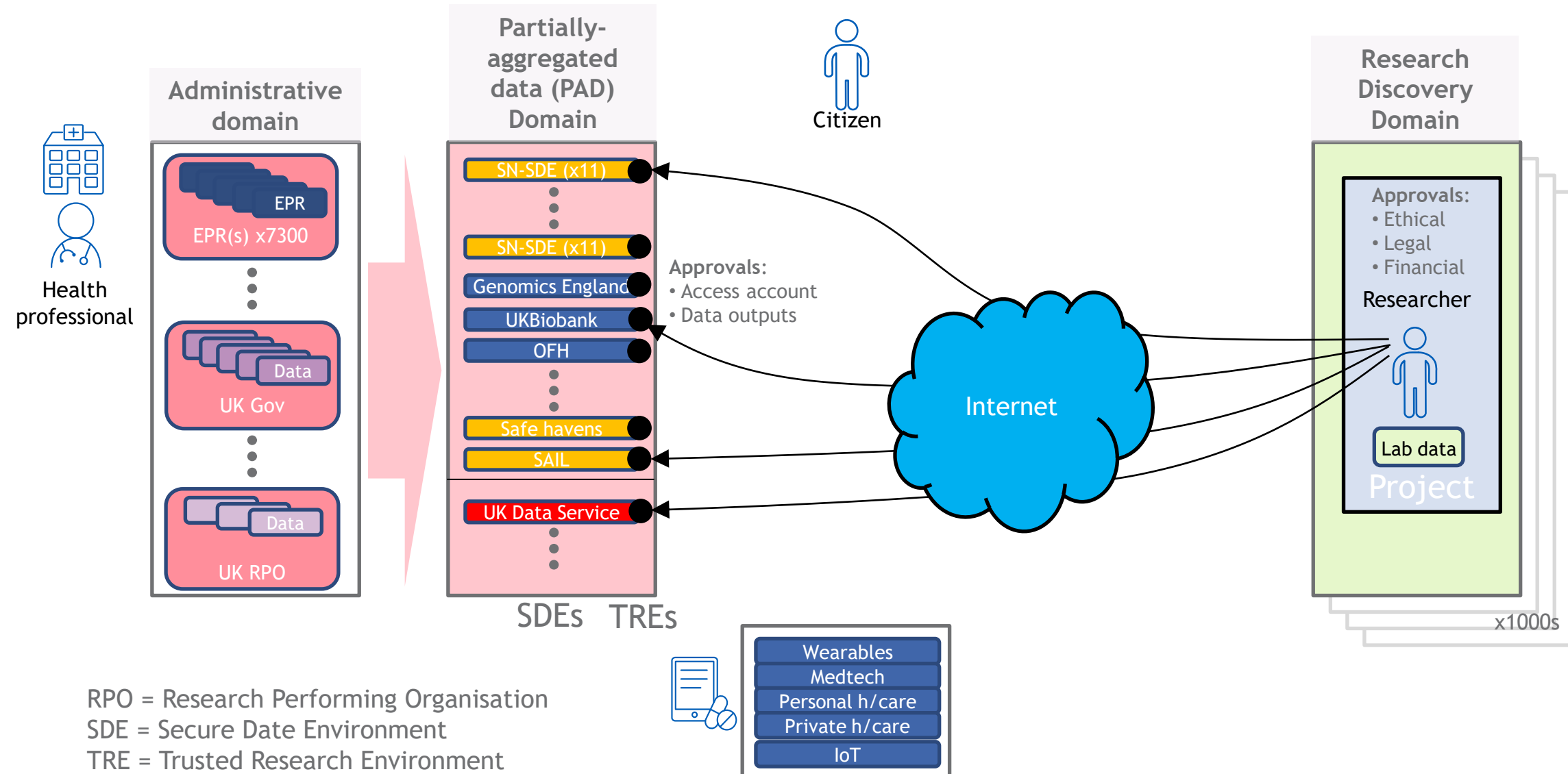
* Datasets have add-on TREs.
* Approved projects negotiate (again) for approved access. Data chain of custody fragmented.
* Duplication of admin, extending time to research output.

RPO = Research Performing Organisation
SDE = Secure Date Environment
TRE = Trusted Research Environment

The Data Domains: The Goal:

* Peer Connected SDEs to project TRE platforms. Orchestrated project configuration
* Open logs and analytics for infringement of data policies and risks.
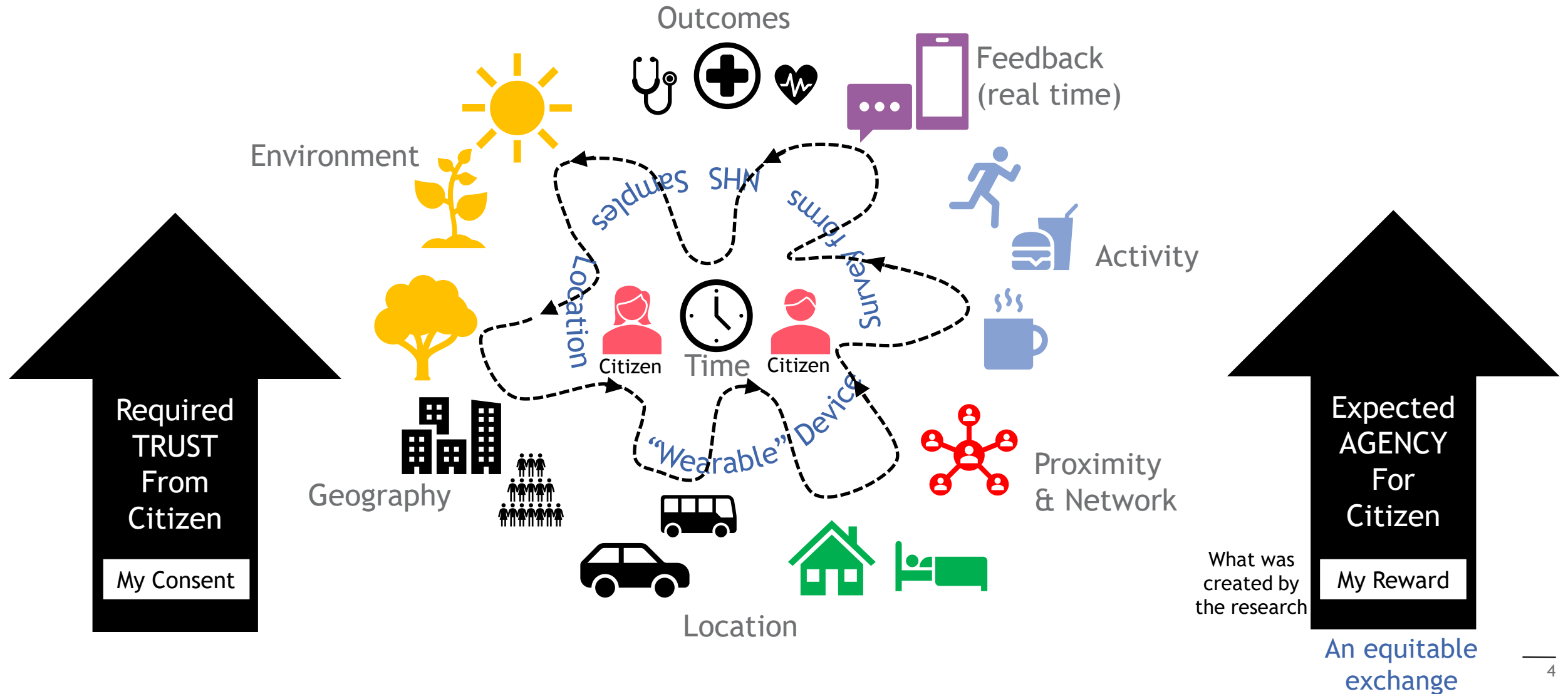* SHARE architecture – extending the control of SDEs into the collaboration projects.
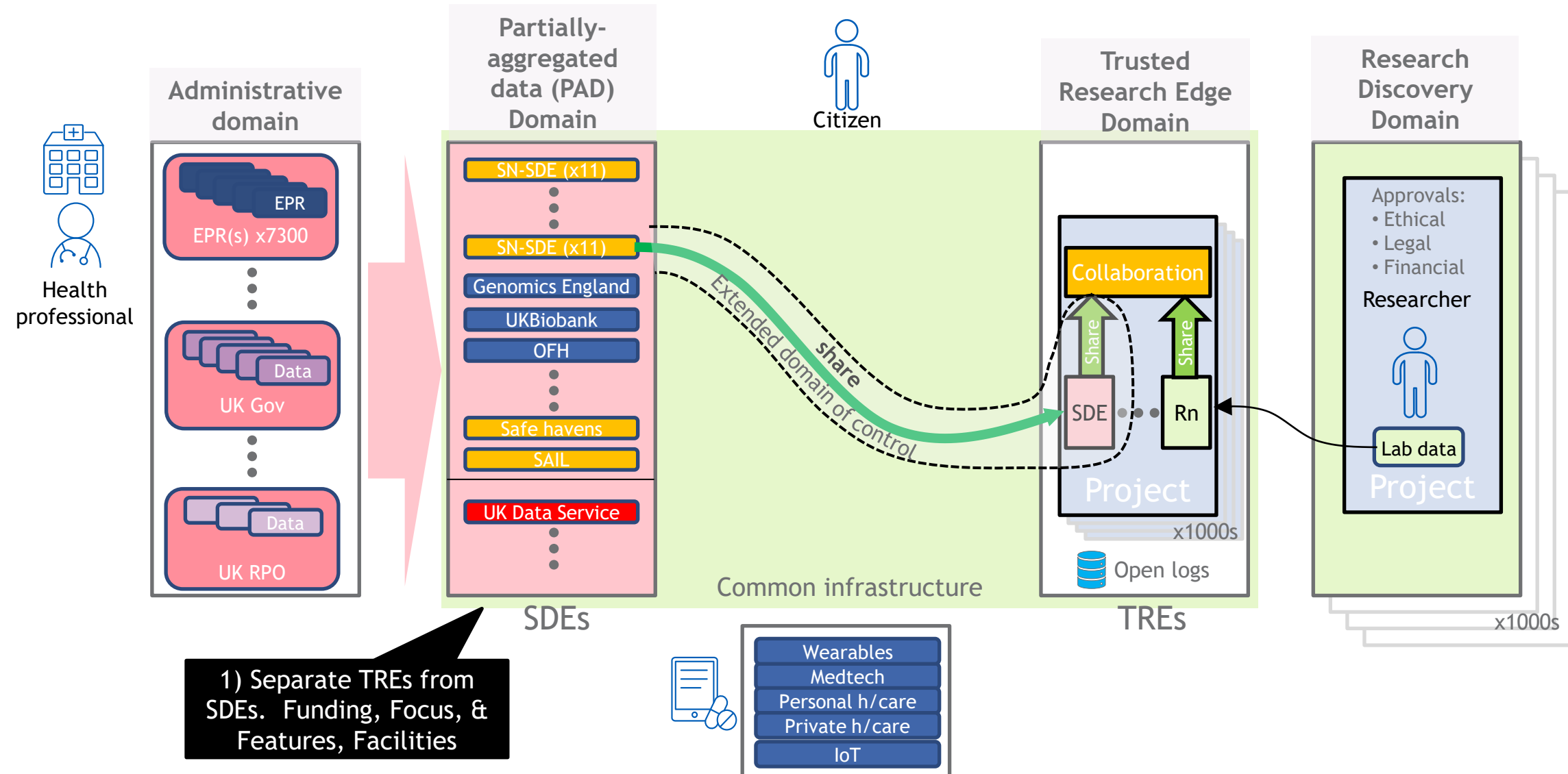
The citizen and their increased / retained agency.

Axiom: Consent will be a huge part of future research
And so how does (will) it fit with SDE / TRE infrastructures?

Pete Barnsley, PhD
Head of Special Projects, ITO, The Francis Crick Institute

- **Digitisation** and online control of finance data is well established. The NHS app is maturing.
- **Multi £100m investment is proposed** to extend Secure Data Environments (SDEs) / Trusted Research Environments (TREs). Many "TREs" exist today, virtually all tied to "SDEs".
- **Trust** is a key assumed characteristic underpinning data *collection* (let alone *storage* and *sharing* and *research*). But it is an emergent property.

- The **agency of the citizen is moot**, non existent.
- The "state" has embodied **control elsewhere** in Data Controllers and IG.
- As citizens it is 'our' data, but the data is not in 'our' hands.
- **We, as Citizens, have no control**.

- **But: Consent will be critical** for such a research world as reidentification will be highly likely.
- But **no consent infrastructure** exists alongside the SDE and TRE infrastructures

High outcome research will require rich data about citizens. A time "Digital Twin" (Re)Identification risks will always be very high as more data is joined. Common law consent, and informed consent will therefore become a major enabler

Outcomes

Feedback (real time)

Environment

SHN Samples

Survey forms

Activity

Location

Citizen   Time   Citizen

"Wearable" Device

Geography

Proximity & Network

Location

Required TRUST From Citizen

My Consent

Expected AGENCY For Citizen

What was created by the research

My Reward

An equitable exchange

The Citizen Domain offers Agency – The bridge between Aggregated data and Project
* Bring the data to the project.
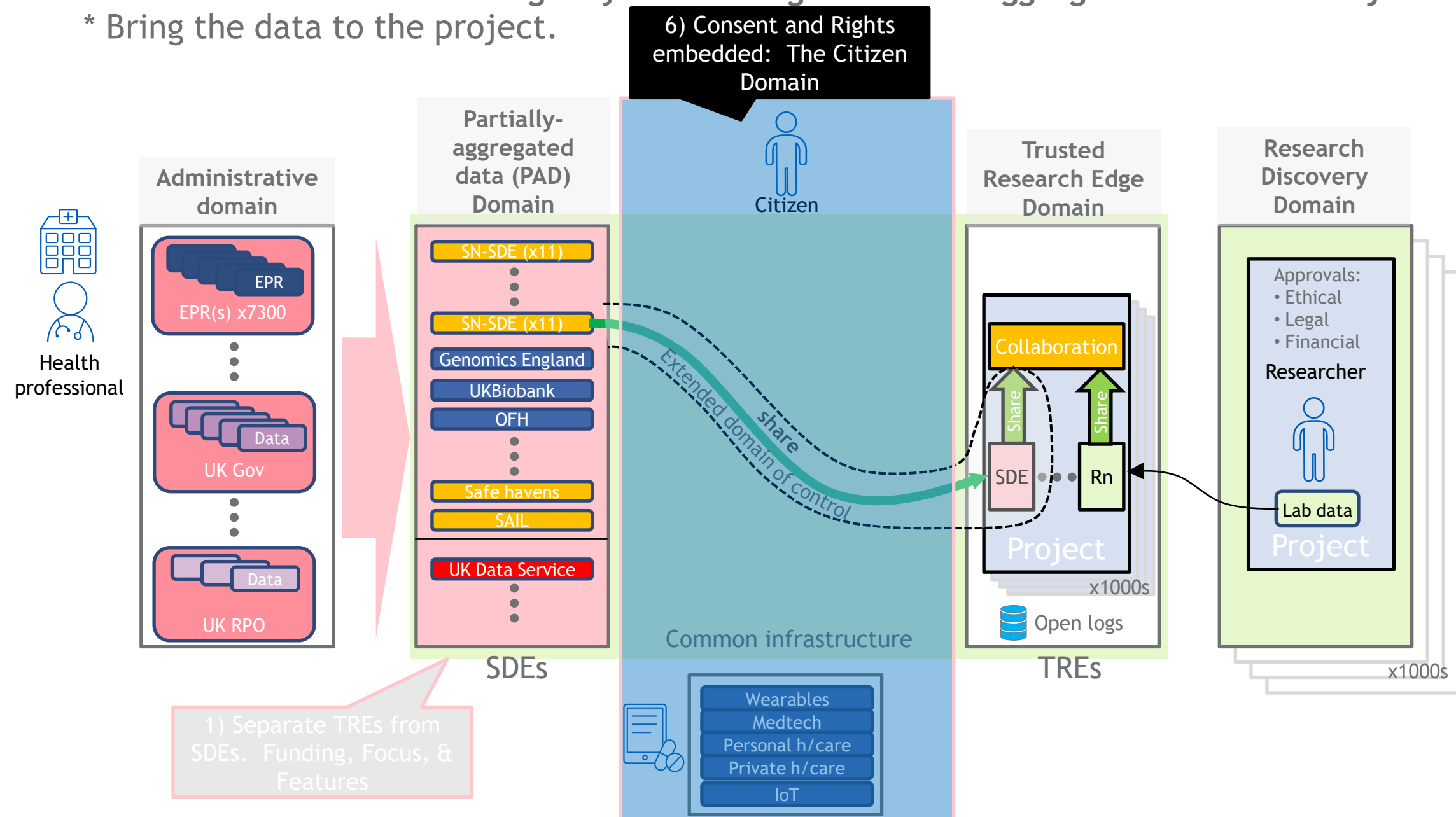
The citizen and their increased / retained agency

Lead:
Pete Barnsley   (Head of Special Projects, Francis Crick Institute, London)

1. **Set up a first open session in January**
   (to allow diaries, **proposal is 11-12 am Tuesday 9th and 10-11am Wednesday 17th**)
   - Expectations of people within the workstream
   - Ideas and scope.
   - Plan for completing output.
   - Liaising with other related workstreams – e.g. Federation

2. **Objective 1: Plan to present at the March TRE Community meeting**
   - Interim progress report.

3. **Objective 2: White paper**
   - Strategy for maintaining the citizens
   - Implications for national initiatives and on other TRE Community workstreams. e.g. information governance