

# Life-long Personal Digital Permissions System Use Cases

**NWC Consent Workgroup  
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COLLABORATE | DISCOVER | IMPROVE

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### A data uses permissions system "designed with people for people"

- Involvement:** For 21<sup>st</sup> Century services, managing life-long digital permissions
- Data donorship:** For ethical research, privacy by design, data protection by default
- Learns from:** Connected Health Cities, existing permissions successes and failures

### Examples benefiting from a "Personal Control Point"

- **Local Health Care Record Exemplar *Share2Care*** [PHR, NHS App] explicit consents
- **Personalised disease prevention and population health:** opt-in
- **Research Data Access and Processing** – local and national

### Bounded cases should explain purposes of permitted data use

- **Where there is no clear legal basis to process**
- **ID Assurance mechanisms: fundamental**

### Plain language use case capture

- **Understandable to all:** patients/families, IG, clinicians, data science, implementers
- **Rules of processing:** based on authoritative IG review of use case
- **Explicit permissions:** for sensitive and tertiary uses (e.g. innovation sectors)

### Consistent IG (data processing) rules should accelerate research data provisioning

- **Users with a validated purpose:** access permitted data faster
- **Actionable via semi-automated access control:** data access in requester TRE
- **Legitimate e-signature (attestation):** for comprehensible terms & conditions of use

### Avoiding cognitive overload

- **Avoid endless Terms & Conditions:** co-create core purposes with patients
- **Develop IG rules matching core purposes:** legal, ethical and social constraints
- **Use IG Rule-set:** to build consistent "cross-supplier" data processing services

## Storage of "reference permissions" by nationally-validated ID or pseudo-ID

- **Requesting mechanism:** Query API (in TRE) uses standards to check legitimacy
- **Shared logic:** based on "bottom-up" IG rules of limited complexity
- **Vendor-neutral capability:** front-ends use same submission and query logic

## Cloud-native permits:

- **Re-use of APIs:** standardise value sets for data access control
- **Admission of personal device data:** "d2C" global standards emerging from PCHA
- **Rule-base operations:** e.g. IG-permitted and non-permitted linkage

## Characteristics

- **A real clinical population:** example suggested in Dec 2019
- **Several plug-ins:** Vendor-neutrality requirement
- **Doesn't discard existing apps:** But scalability comes with convergence to the core

## General requirements:

- **NHS Login:** consistent gateway, strive for interoperability
- **Patient acceptability:** T&Cs printable, clinician and data processing checklists
- **Sets tone for national standards:** e.g. re-use of transactions, policy engines

### "Test against regional architecture under proposal"

- **PHR** : work with C&M Elective Care Group → Develop pathway against architecture
- **Exemplars discussed:** Breast cancer care, improved pathway for Teledermatology, incl. patient owned data; Add-in consent model for *Diabetes My Way*

### Demonstration points:

- **Components:** App(s), a revised pathway, proposed digi architecture incl. permissions
- **Adds:** Patient-held data (c.April 2020) moving towards PHR design in Liverpool (Jim)
- **Web-of-care multi-point test:** e.g. at home/mobile, in GP, in acute care

### "Understand rules based on purpose of use"

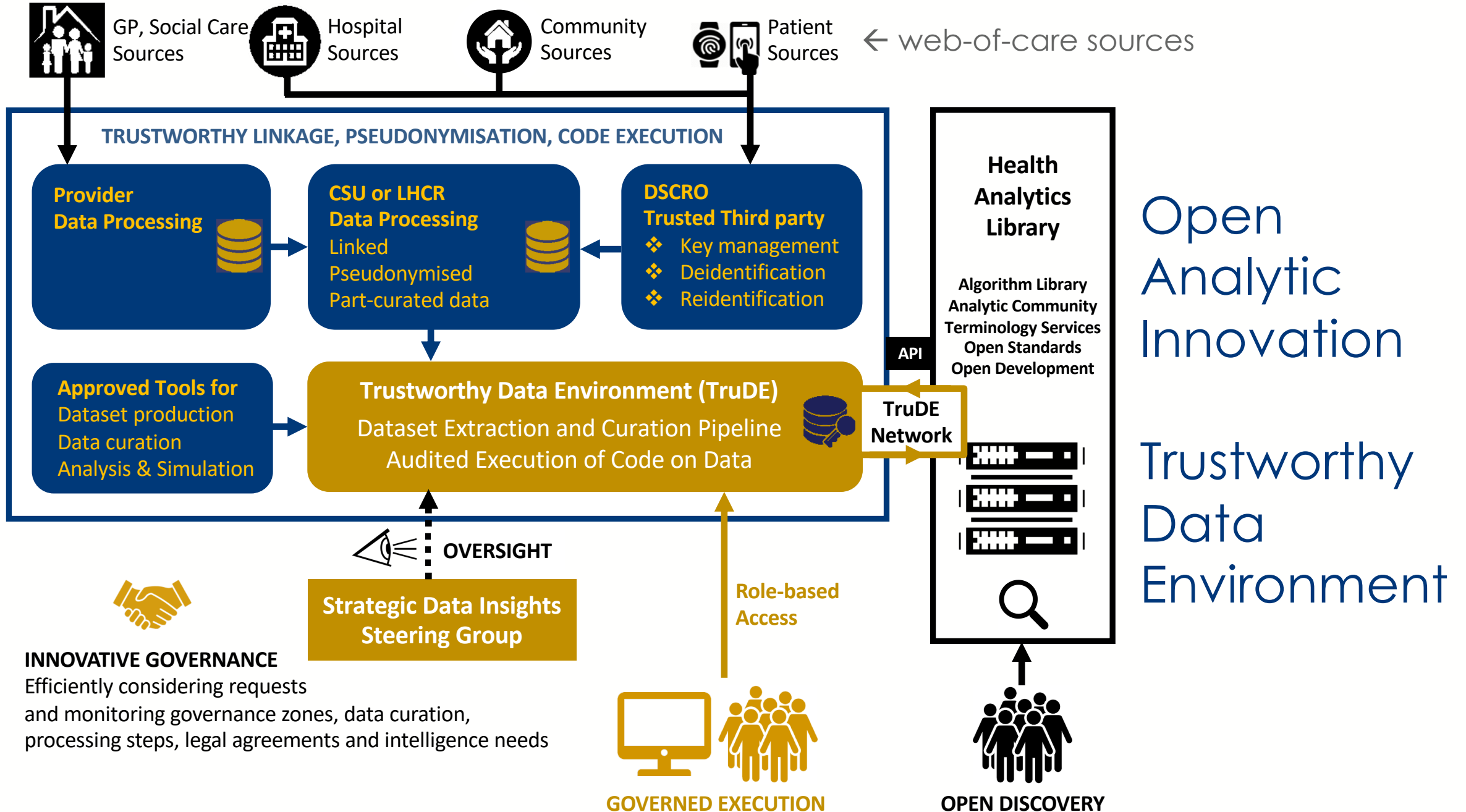
- **Binding:** the intended use to ID, the attestation → actioning of rules → access control
- **Subsequently:** non-confounding rule addition
- **Patient involvement:** Keep patients informed, integral to terms & conditions of use

### Testing at Scale:

- **Tests a wireframe architecture:** Opportunity for deployment in an existing cohort
- **Suppliers:** Implement interoperability specifications, i.e. APIs put in place in App(s)
- **Resourcing:** Team agreements, stakeholder engagements, use case stories into plan



# Background context on Civic Data Trust Analytics



# Background Context on National Data Processing Proposals

## DPS solution

