Building a Consent Architecture

Draft aims of the 'Building a Consent Architecture' Project

- Build an interoperable, working Consent Management Architecture Model across the North West Coast, building on existing work from:

  - ❖ Health Information Sharing Preferences (HISP) app design
  - ❖ Assessing/applying authentication approaches/standards already in development
  - ❖ Assessing/applying consent management models/approaches already in development

- Utilising existing distinct LHCR/PHR use cases to identify clinical/technical/governance/interoperability/culture challenges:

  - ❖ Tele-Dermatology Project in Merseyside (TBC)
  - ❖ Breast Cancer Project in Lancashire and South Cumbria (Parsek)

- Capable of supporting our local LHCRs, S2C and Population Health Management goals
- Capable of initiating NHS wide discussions on architecture and approaches
- Developed with Patient Engagement

N.B. These slides present a very simplistic, early view of the potential direction of travel for this project. Much more detailed work will be required if the project proceeds.

Building a Consent Architecture

The original HISP App project scope covered only the design and presentation of the opportunity to capture patient consent.
It did not address three additional elements necessary for full Consent Management:

- User Authentication
- Consent Record Storage and Maintenance
- Consent Permissions transmission and application
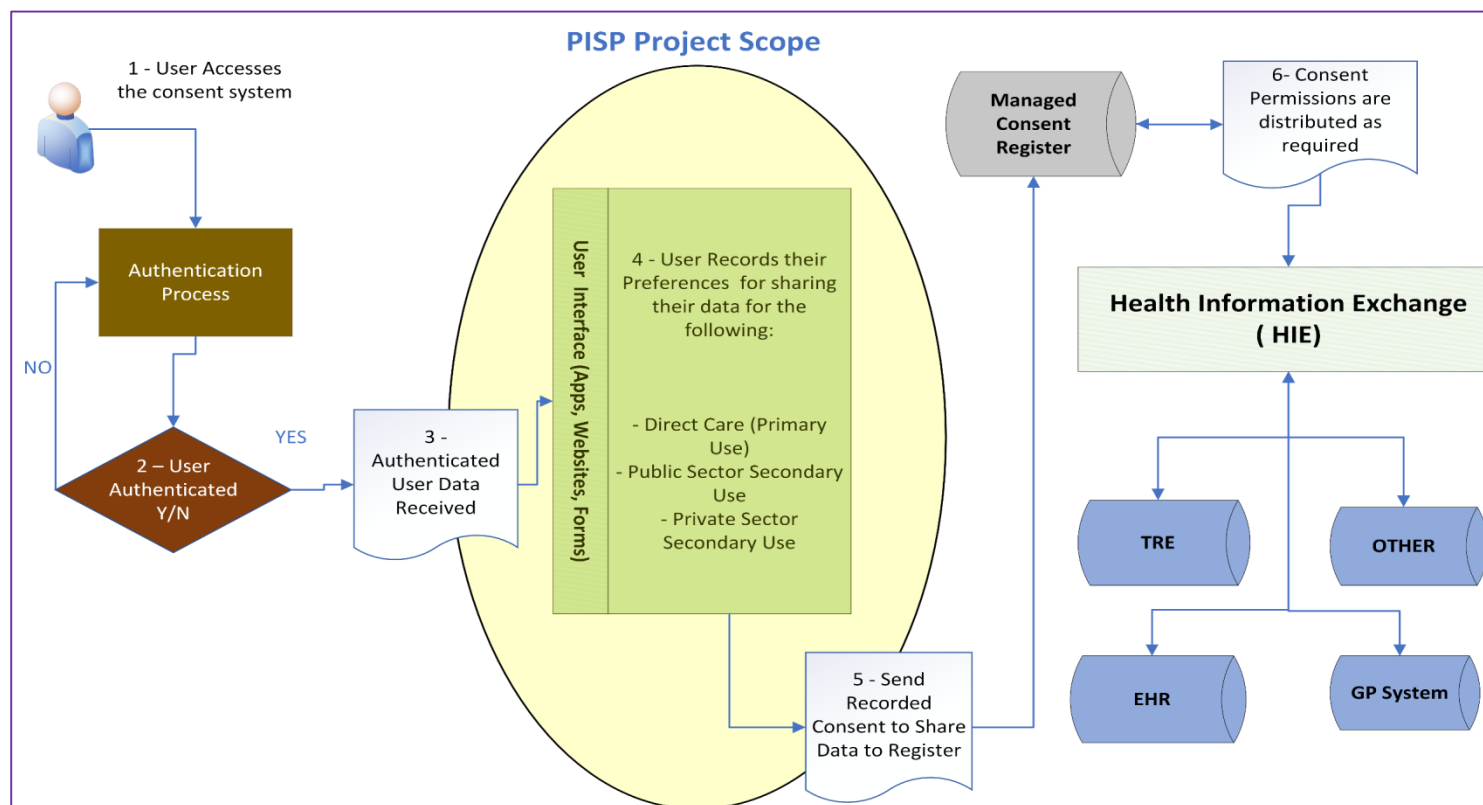
The 'Building a Consent Architecture' Project proposes developing the original work to address these three critical areas.

Building a Consent Architecture

To develop the work started by the HISP project, we are proposing to build a Consent Management element onto two existing projects across the Merseyside and Lancs & South Cumbria LHCR footprints.

The use cases suggested are:

- Tele – Dermatology Pathway (Merseyside) – Aiming to enable the capture of Dermatology Images within Primary Care to allow for those to be transferred for assessment into Dermatology Specialists, reducing the number of unnecessary Outpatient Attendances. Some patient data is also captured alongside the images

- Breast Cancer Pathway (Lancs & South Cumbria/Parsek) – Patient Assessment Questionnaire delivered at regular intervals to monitor the ongoing well-being and outcomes of Breast Cancer patients over time. Expected to capture this data for approx. 9,000 patients

Both projects will need to add the Consent architecture element to their current project scope.

Building a Consent Architecture

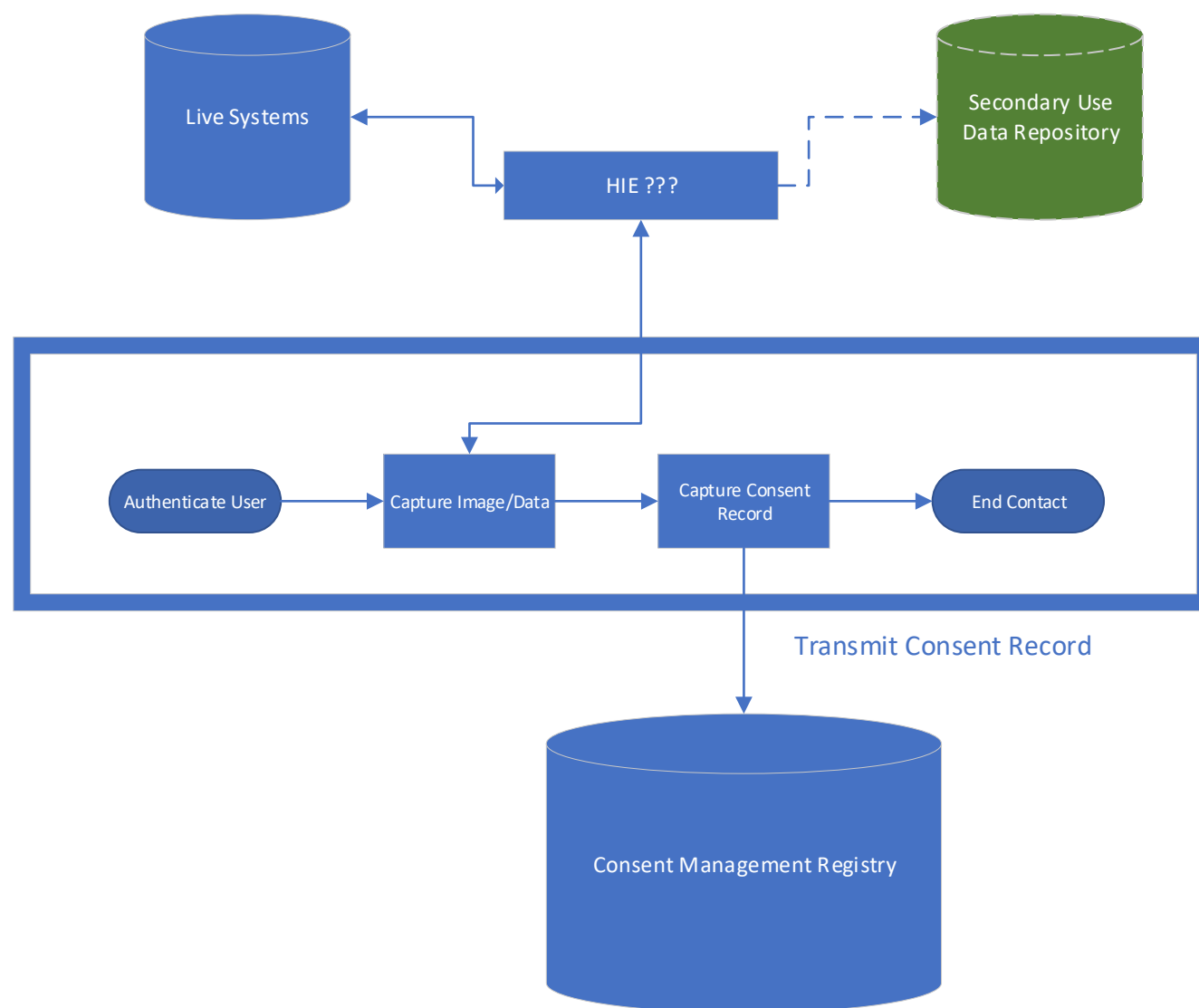**Simple Model – Consent Capture**

Key Questions:

- What Consent questions are we asking?
- Who hosts/manages the Registry?
- What design/form does the Registry take?
- How is the Consent Record formatted for transmission?
- Common Identifier required for Consent Record Owner?

Tele-Dermatology (Merseyside)

Authenticate User → Capture Image/Data → Capture Consent Record → End Contact

Transmit Consent Record

Consent Management Registry

Transmit Consent Record

Breast Cancer (Lancs & South Cumbria)

Authenticate User → Capture Data → Capture Consent Record → End Contact

INNOVATION AGENCY

CONNECTED HEALTH CITIES

Building a Consent Architecture

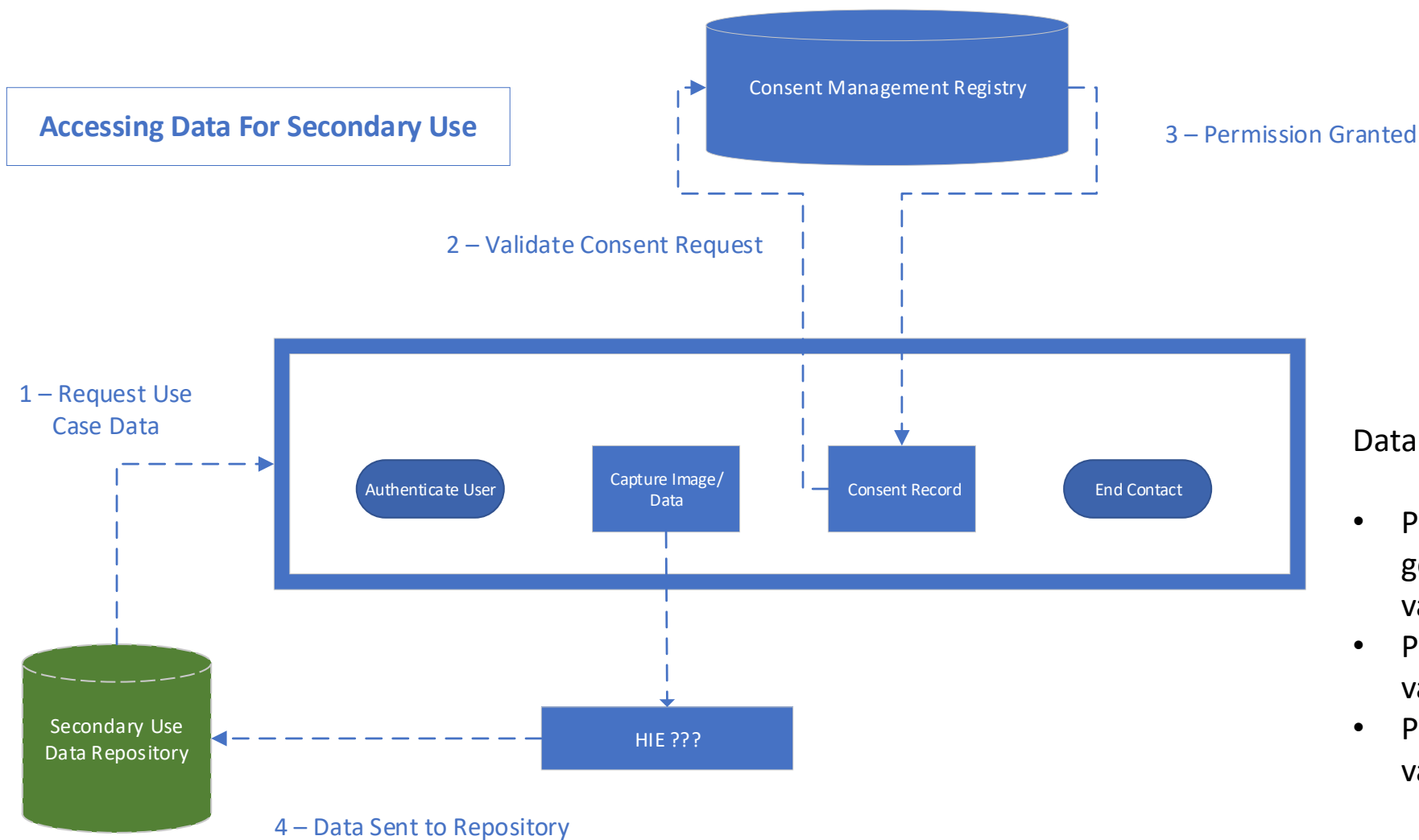**Simple Model – Data Transfer Capabilities**

Data Transfer:

- Data will need to be capable of supporting Primary Use Case and Secondary Use Case

Building a Consent Architecture

Simple Model – Data Access

Accessing Data For Secondary Use

Consent Management Registry

3 – Permission Granted

2 – Validate Consent Request

1 – Request Use Case Data

Authenticate User

Capture Image/Data

Consent Record

End Contact

Secondary Use Data Repository

HIE ???

4 – Data Sent to Repository

Data Transfer:

- Process needs to be capable of generating access requests and validating the Consent
- Process needs to communicate with a variety of distinct systems
- Process needs to be capable of validating different consent types

Building a Consent Architecture



**Exchanges for Interoperable Consent Directives**

Minimum actors for streamlining patient-controlled information sharing across web-of-care information systems

Dr. Ed Conley (miconsent.org)

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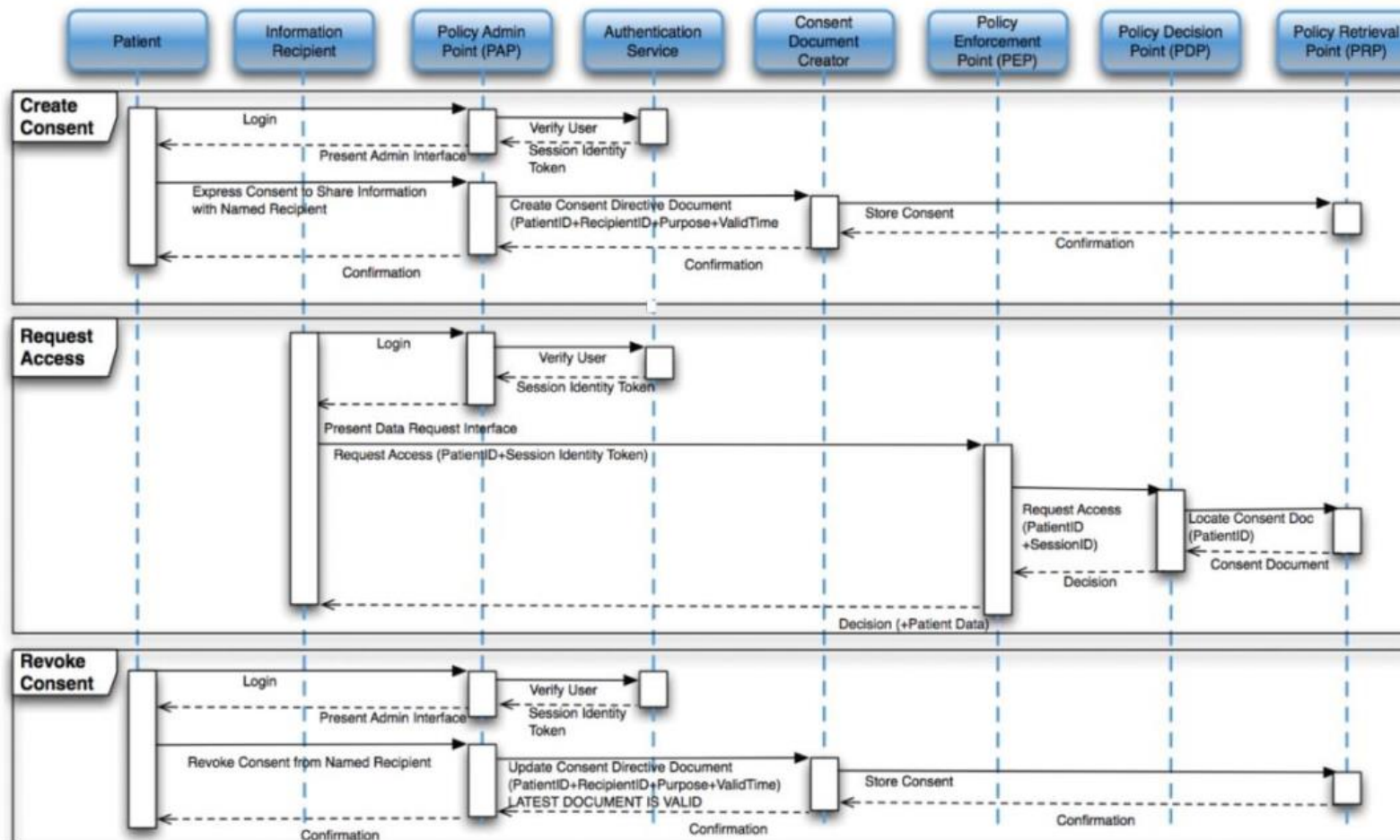
Ed's Model shows the potential complexity in more detail and other approaches will need to be considered.

Health Information Sharing – Consent Project Proposal

Whichever model is developed must remain aligned with
the broader LHCR/S2C system architectures.
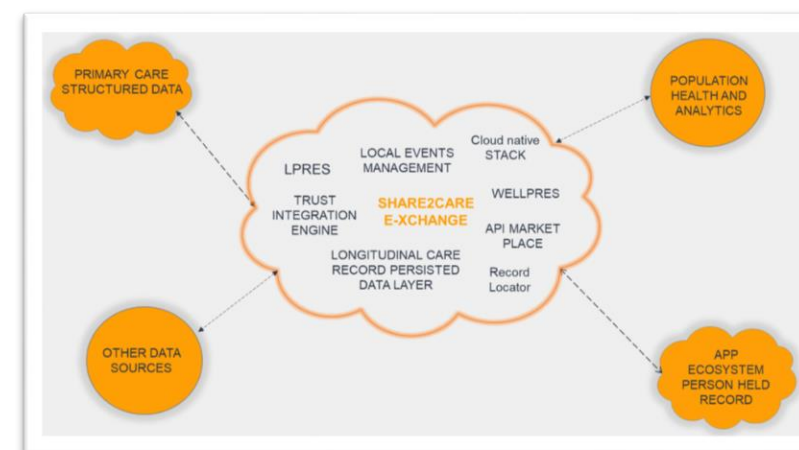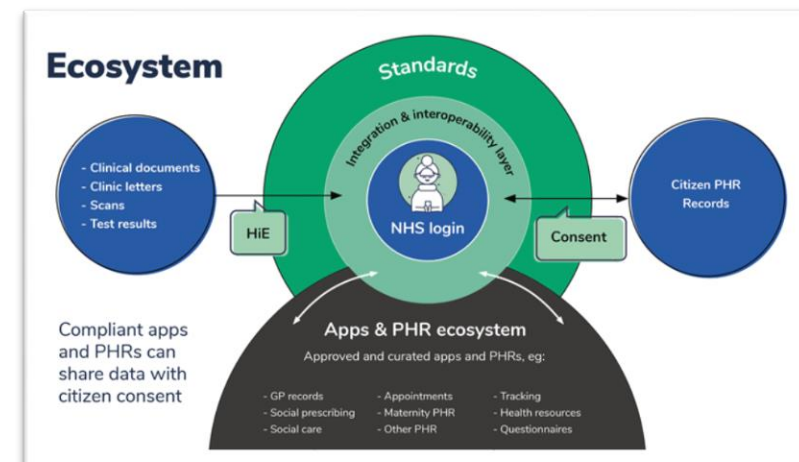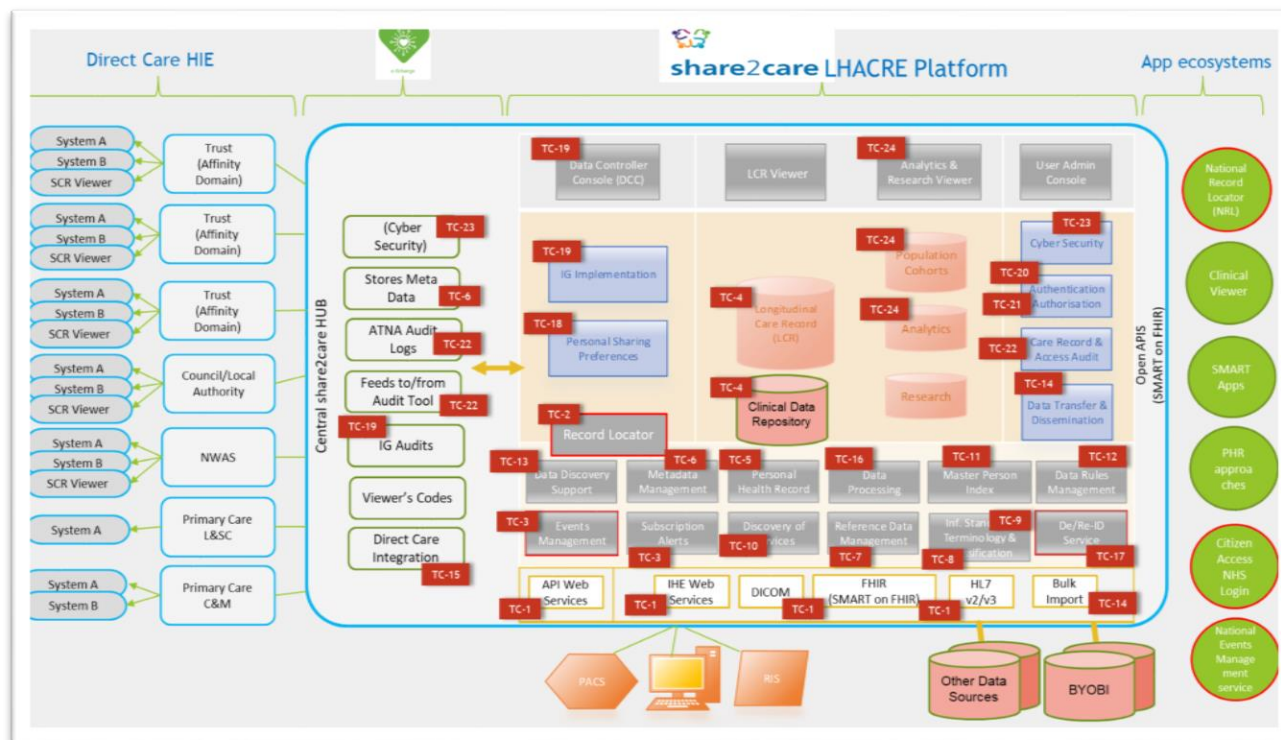
Possibly only two basic Consent Questions:

1. Can we use the data collected in this project to:

    A. Join with internal project data from other patients for a broader understanding of the specific pathway
    B. Join with other data the system holds about you for a broader understanding of population health

2. Can we keep in contact with you to communicate:

    A. Outputs from the analysis work
    B. Changes to the project scope

Health Information Sharing – Consent Project Proposal

Potential resource requirements:

- Agreement from the existing project teams to expand their project scope to include this consent work
  - Parsek
  - Mindwave
  - LHCR Leads
- Consent Registry - development and design group
  - Assess and select most appropriate architectures
  - Finalise registry capability specifications
  - Agree relevant standards
- Consent Registry - construction and maintenance resource
- Message design and construction group
  - Assess and agree messaging standards (e.g. FHiR, HL7 other)
  - Construct message types for the selected projects
  - Align with international standards
- Project facilitation and co-ordination
  - Align work across the regions
  - Monitor national developments in authentication and consent management
  - Drive patient engagement parallel work
  - Monitor project delivery