



The European Institute For
Innovation Through Health Data

GOVERNANCE DESIRE 😊:
**DESIGN, SPECIFY,
IMPLEMENT, ASSURE**

DESIRE - D^Esign, S^{PEC}ify, I^Mplement, assu^{RE}

- What we can do now...

DESIGN

founded on First Principles: distil requirements, develop solution

IMPLEMENT

use the right tools for the specifications

SPECIFY

the rules, guidance and expectations

ASSURE

Quality Seal for Research Platforms QS4RP

First Principles - 😍 DESIRE not ire 😞

- Don't Wannacry 😞
- Demonstrate trustworthiness 😊
- Develop relationships with ☐



the “Natural Person”
honouring how people
want their data used



the Data Source
their legal and ethical
responsibilities will not be
compromised



the Data Processor
security expectations
have to be tractable

Core Principles: Transparent Trustworthiness

- Development of solutions are open to all interested parties
- Design of solution is open to comment
- Implementation is negotiable



First Principles - Realistic Design and Specification

- If specifications are unrealistic or cannot be implemented with existing solutions or latest advances, they cannot be specifications
- No reinvention - if someone has developed one earlier...
- No solutions looking for problems - understand the need and match against latest advances
 - Blockchain, Differential Privacy, Homomorphic Encryption...



DEsign

- Regulatory and good practice requirements (enshrined in QS4RP Process)
- Codes of practice
- Standard operating rules and procedures
- Baseline security guidelines:
 - minimum security tools that need to be in place
 - firewalls
 - physical protection
 - intrusion detection
 - frequent core infrastructure and tooling software updates
 - openly audited - in terms of management and activity

Specify

- Access control rules, roles and privileges, purposes etc.
- Audit rules and audit log access
- Security policies covering networks of patient data sources
- Determine what can be implemented immediately and what lends itself to newer tools and approaches

Implement

- JFDI!
 - where this is practicable
- Capitalise on existing efforts for deploying newer tools
- Manage expectations - don't get an ant to push an unnecessary juggernaut
- Iterative
- Blockchain - being used for Audit and transparency (DeepMind)
 - can it be used for managing consent and contractual elements that the consent asserts?

assuRE: Quality Seal for Research Platforms

- Assures all stakeholders of the reliability and trustworthiness of the platform and services
- Assesses and then recognises the competence of the service provider
 - in upholding privacy protection legislation and information security standards
 - in complying with the i~HD Principles and Standard Operating Rules
- Accelerates adoption of harmonised approach throughout Europe
 - gives confidence to all parties that products, processes and services fulfil specified requirements/criteria

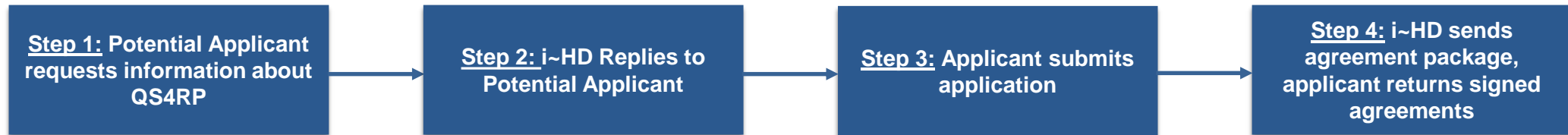
QS4RP

through contract with

EUROREC

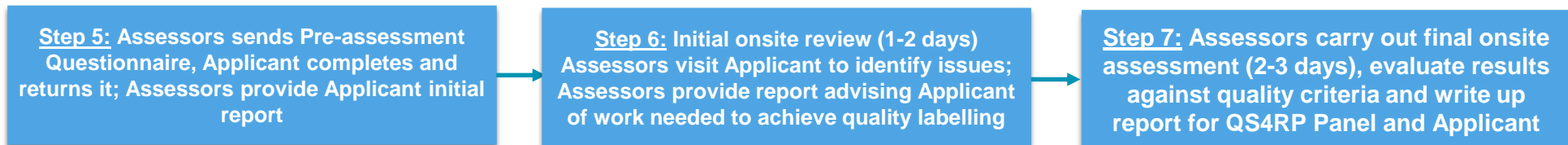
QS4RP Process

Stage 1: Statement of Interest and Application



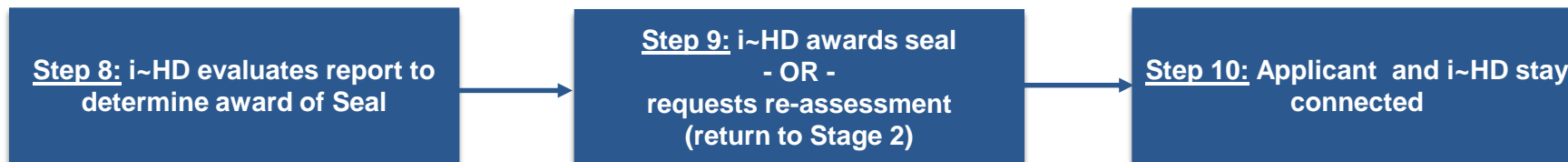
Stage 1 Procedures Owner: 

Stage 2: Assessment



Stage 2 Procedures Owner: 

Stage 3: Award Determination



Stage 3 Procedures Owner: 

So what do we DESIRE?

- We need the patient community to help us answer that...

