

# Consent

Why we need a consent model for eHealth



# SPIRE Consents

- Aggregated
  - No Consent
- Pseudonymised
  - National Data Set ? LES / NES etc
  - Implicit Consent into
  - Can opt out
  - All or Nothing?
- Bespoke / Patient ID
  - Explicit in or out
  - Per Project?



# MSDI Patient Consent Manager

- Separate from GP systems (and others)
- Reads / Writes to the GP System
- “Synchronisation” to / from
- Dependency on GP system record structure?
- Compatible with?



# So what's the issue?

- Complex consent models
- Overlaps other systems / boundaries / organisations
- Multiple data extract services UK wide
  - Multiple Consent Models
  - Multiplying terminology codes
- Multiple interfaces in different systems
- Not patient facing
- Not interoperable
  - Semantic loss (My Project is not Your Project)

# Terminology

- Consent report
- Obtaining consent
  - Verbal consent for examination
  - No consent for electronic record sharing
  - Gillick competent for consent
  - Patient consent given for repeat dispensing info transfer
  - Consent for Primary Care Trust to review patients records
  - Patient consent given for retinal screening
  - Patient consent given for supply of home oxygen
  - Consent given for electronic record sharing
  - Patient consented to randomised clinical trial
  - Declined consent for PCT to review patient record
  - Consent to share demogra.info for retinal screening provided
  - Consent to share demograp info for retinal screening implied
  - Consent to share demogra.info for retinal screening withheld
  - Consent to shar clinical info for retinal screening provided
  - Consent to share clinical info for retinal screening inferre
  - Consent to share clinical info for retinal screenin withheld
  - Consent given to share patient data with specified 3rd party
  - Declined consent to share pt data with specified 3rd party
  - Consent withdrawn to share pt data with specified 3rd party
  - Parental consent for contraceptive treatment
  - Lacks capacity to give consent (Mental Capacity Act 2005)
  - Consent given for meteorological health forecasting
  - Declined consent for notification of drug misuse
  - Consent given for communication by SMS text messaging
  - Declined consent for short message service text messaging
  - Unable to consent to information sharing
  - Consent given for communication by email
  - Consent given for cardiovascular health risk assessment
  - Consent given follow-up after smoking cessation intervention
  - Consent given for smoking cessation data sharing
  - Patient consent given for medical photography
  - Declin cons follow-up evaluation after smoking cess interven
  - Declined consent for smoking cessation data sharing
  - Consent given by person with parental responsibility
  - Consent declined by person with parental responsibility
  - Declined consent for student to access clinical record
  - Declined consent for researcher to access clinical record
  - Consent for communication by mail withdrawn
  - Consent given for follow-up by smoking cessation team
  - Declined consent for follow-up by smoking cessation team
  - Consent given to share clinical information with GP

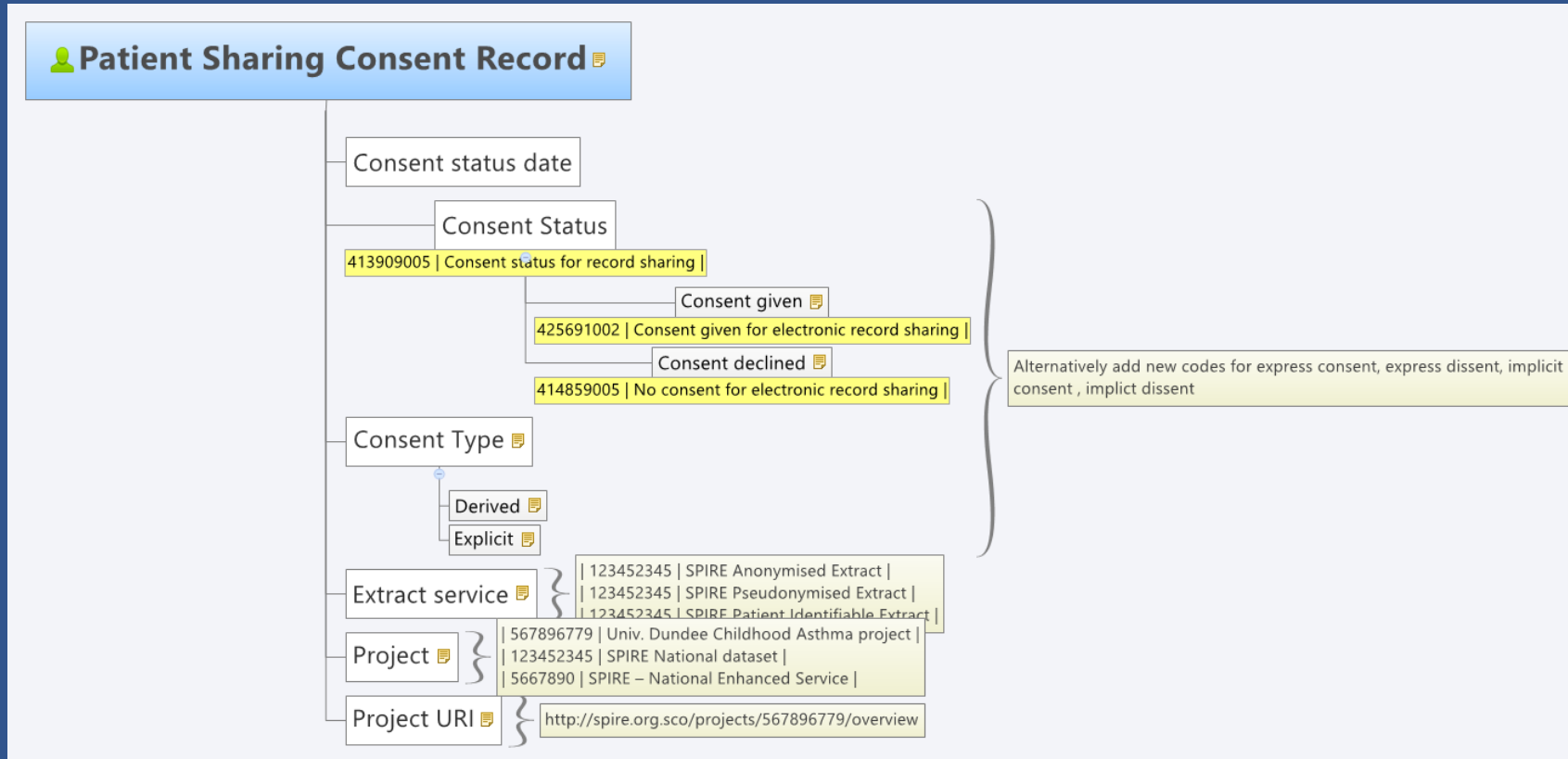
Date	Read Code	Read Description	Comment
14-Jun-2014	xyza1	Awaiting Decision for SPIRE Patient Identifiable Extract University Dundee Childhood Asthma	
12-May-2104	dcba0	Consent Given for SPIRE Patient Identifiable Extract University Glasgow Diabetes	Declines
13-Dec-2013	efgh3	Consent Implied for SPIRE Pseudonymised Extract SPIRE National Dataset	
12-Dec-2013	hijk1	Consent Declined for SPIRE Pseudonymised Extract SPIRE National Enhanced Service	
13-Nov-2013	efgr1	Consent Implied for SPIRE Anonymised Extract QOF Extract	
16-Jul-2011	efgt3	Consent Implied for National Project Emergency Care Summary	
13-Feb-2011	hijv2	Consent Declined for National Project SCI-DC Diabetes Care	
18-Sep-2009	q3C0.	Consent given for upload to local shared electronic record	HB CHD LES
12-Oct-2008	9M0.	Informed consent for national audit	Cytology audit - JM Managing this



# Requirements?

	<b>1</b>	<b>Create and Update Records</b>
<b>2</b>	<b>1.1</b>	Users will be able to add a new consent record for SPIRE projects to the patient's clinical record
<b>2.1</b>	<b>1.2</b>	Users must be able to save a SPIRE Consent change request as a task which may be allocated to any other member of the practice staff
<b>2.1.1</b>	<b>1.3</b>	At the time of adding or changing a consent record, the user must be able to access (via a single action) information on the SPIRE project to which the consent will apply.
	<b>1.4</b>	At the time of adding or changing a consent record, the system will check for the last consent record for that project (if any) and notify the user that previous consent records exist.
<b>2.1.2</b>	<b>1.5</b>	At the time of adding or changing a consent record, the system will advise the user of the patient's current consent status for that project and will advise them what the patient's new effective consent will be if the new record is stored.
<b>2.1.3</b>		
<b>2.1.4</b>	<b>1.6</b>	A history of changes to the consent records for each project will be stored by systems in the patient's record.
	<b>1.7</b>	When the new consent record is changed the system should provide a function to send confirmation of this change and the patient's new effective consent to the patient via SMS or e-mail.
<b>2.1.5</b>	<b>1.8</b>	Users should be able to invoke the functions to add a new consent record from previous consent records for the same project. This will populate the consent record add form with the same project name.

# Archetype Approach





# To support

### SPIRE Consent Management

Show current    Show all

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#### SPIRE Overall Service Consent

Date:

Project:

Status: Consent Given  

Type:

[Click here for more information](#)

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#### SPIRE National Data Sets Consent

Date:

Project:

Status: Consent Given  

Type:    [What does this mean?](#)

The patient has no specific record for this project.  
Consent is given because they have a record for  
SPIRE Overall Service Consent

[Click here for more information](#)

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#### SPIRE Patient Identifiable Research Projects

Date:

Project:

Status: No Consent  

Type:    [What does this mean?](#)

[Click here for more information](#)

### Data Sets Patient Sharing Record - Add

Date:

Service: *SPIRE Data Extracts*

Project:

Status:  Consent Given    Consent Declined

[Click here for more information on SPIRE National Data Sets](#)

# Questions

- Is there a problem at present?
- Would this help?
- Can it be implemented?
- Does it need cross nation agreement?
- When do we need it for?
- Dependency on SNOMED-CT?
- What is the scope?

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