

The Contribution of Information Standards to Healthcare Service Improvement

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- GP and Hospital Software - Integration and data sharing
- GP2GP and Electronic Prescribing
- HL7UK: National Standards
- HL7.org: XML, Implementation, Technical Steering Committee, Board
- Laitek: Medical Image Migration
- Everis: Health and Social Care integration
- BSI: UK Lead for Healthcare Information Models for CEN/ISO
- BSI: Health and wellness apps. Quality criteria across the life cycle

Information Standards – a health check

- The Problems
- An Inventory of Standards
- A History (personal)
- Loosely connected reflections
- Recommendations

The Problems with Standards

- There are too many standards to choose from...
- There is no suitable standard for what we are doing
- Standards just add complexity
- Our customers are not asking for standards
 - Or stop asking when they see the cost
- The standards keep changing
- Standards stop innovation

Information Standards – there are so many

- Generic
- Interaction-specific
- Domain-level
- Process

Generic

- Architectures (Enterprise, Information, Document, Service, ...)
- Components (Templates, Clinical Statements, FHIR Resources, Archetypes,...)
- Terminologies and classifications (SNOMED-CT, ICD, etc)
- Clinical Headings and classifiers

Interaction-Specific

- Patient Summary
- Lab Orders and reports
- Electronic Prescribing
- Adverse Event Reporting
- Admission, Discharge and Transfer
- Discharge Letter

Domain-level

- Immunisations
- Diabetes
- Heart Failure
- Health and Social Care Collaboration
- Laboratory Test Definition Catalogue

Process

- Care Pathways (Patient Focused)
- Workflow (Health Professional Focused)

There are fewer process standards – because this tends to be determined locally depending upon organisational boundaries, funding, and capabilities.

The Problems with Standards

- There are too many standards to choose from...
 - there are lots of problems to solve
- There is no suitable standard for what we are doing
 - But there is probably a starting point or a framework
- Standards just add complexity
 - Visible complexity – blank sheets of paper make it easy to deny complexity
- Our customers are not asking for standards
 - Or stop asking when they see the cost
- The standards keep changing
 - So select with care
- Standards stop innovation
 - They provide a framework that enables innovation and opens markets

Projects

- GP2GP
- Electronic Prescribing
- Discharge Summaries
- Retinal Screening
- End of Life Care
- Discharge to Social Care
- Medical Image Migration
- Lab Test Catalogue

GP2GP -- 13606 + HL7v3

- 3-4 suppliers
- Clear scope, well understood professional context
- Fairly complex content
- Strong user demand and policy support (5.8 million transfers)

Pro	Con
<ul style="list-style-type: none">• Independent basis for negotiation• Existing specification material• Community Review• Extensible solution	<ul style="list-style-type: none">• Slower decision making• More changes• Unfamiliar concepts and language• Brittle tools• Reuse harder than hoped

Electronic Prescribing -- XML

- 6 suppliers
- Clear scope, well understood business process
- Simple content
- Effective existing paper process

Pro	Con
<ul style="list-style-type: none">• Familiar data item names• Schema for testing• Familiar technology	<ul style="list-style-type: none">• England-only solution• In-house maintenance process• Maintenance ended with project

Electronic Prescribing – HL7v3

- 3-20 suppliers
- Clear scope, well understood business process
- Effective existing paper process

Pro	Con
<ul style="list-style-type: none">• Contractual compliance	<ul style="list-style-type: none">• More changes• Unfamiliar concepts and language• Many new concepts• Brittle tools• Reuse harder than hoped• No international benefit realised

Discharge Summaries – Kettering XML

- 30-50 suppliers
- Clear scope, well understood business process
- Simple content -- document metadata + CDATA blob
- Effective existing paper process

Pro	Con
<ul style="list-style-type: none">• Familiar data item names• Schema for testing• Familiar technology	<ul style="list-style-type: none">• England-only solution• No maintenance process• Limited availability of Specification

Discharge Summaries – HL7 CDA

- 20-50 suppliers
- Clear scope, well understood business process
- Extensible content -- document metadata + content model
- Effective existing paper process

Pro	Con
<ul style="list-style-type: none">• Extensible• Schema for testing• Global standard – widely used	<ul style="list-style-type: none">• England-only templates• Profiles for specific use cases• Profiles hard to adapt and reuse

Retinal Screening – HL7v3 then XML

- 3 suppliers on framework agreement
- Well understood process and data items
- Nationally aligned HL7v3
 - Gave Extra concepts and technical challenges
 - National Project that was not part of National Program
- Reverted to domain-based XML messages
 - Mapping to National HL7v3 was valued
 - Implementing National HL7v3 was not

End of Life Care – Gold Standards Framework

- Communication vital
 - 80% of deaths can be anticipated
 - Planning avoids crisis
 - preferences change fast
 - 50% of NHS complaints involve end of life
- Consequences of information crucial
 - What happens when a patient is on a pathway matters more than the definition of the pathway elements
- Process and care needed
 - Knowing whether information is complete and up-to-date vital

Discharge to Social Care

- No well understood, stable responsibilities
- Isolated culture and financial arrangements
 - Local Authorities provide social care
 - NHS provides healthcare
- Lack of Realism
 - Insufficient funds for mandated services
 - Delivered by heroic individual effort
- Information standards need effective collaboration on the ground

Medical Image Migration - DICOM

DICOM designed for transactional use not bulk transfers

- Intensive use of application resources to generate and serve DICOM objects
- Slow
 - One million seconds is 11 days
 - One million minutes is 2 years
- No immediate human review – retries have to be automated

Ways that Standards are used

- Content
 - Use as-is
 - Profile – constrained use
 - Standard as a starting point -- Extend/constrain as needed
- Contractual
 - Internal teams
 - Partnerships
 - Tenders and Customer-supplier agreements
- Community
 - Education
 - Networking
- Marketing

Intended Use

A clear purpose when using a standard makes it easier to establish:

- What is good enough conformance
- Risks and Opportunities for improvement
- Benefits (or their absence)
- Scope limits

Information and communication

- Thinking together with Words
 - What matters is the decisions – not the precise meanings
 - We do not talk with dictionaries in our hands
- Context is often vital in healthcare
 - “Risk of falling” for a cyclist is not the same as for a walking-stick user
 - Text in notes can contradict coded records (“not” or “family history” makes a big difference)
- Communicating communities have their own dialects
 - “Preferred place of care: Home” only useful if you know how this should affect the care you provide.

Learn from Linguistics - be pragmatic

- Healthcare IT is used to enable collaboration
- Collaboration requires effective communication

- Information and definitions are one aspect of language (Semantics)
- Context and effective use is also needed (Pragmatics)

- Cooperative Principle
 - Concise, Reliable, Relevant, Clear

Delightful Standards

- Datatypes
- Domain-specific content
- Concise datamodels
 - HL7 CDA Templates
 - HL7 FHIR Resources
- Constrained Terminology
 - SNOMED referencesets
 - Valuesets
- Enterprise Architecture
 - Linking information to policy and purpose

A Pragmatic Plea

- Clarity of purpose in health information
- Use Standards to enable collaboration at scale
- Use Pragmatic Standards to deliver Pragmatic IT
 - Concise
 - Reliable
 - Relevant
 - Clear