INTERNATIONAL PATIENT SUMMARY

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VC CEN/ TC 251
Introduction to the International Patient Summary (PS) Standard
  - Surprise and confusion

Organisational Perspective
  - Pain and Gain (possible costs)

Healthcare Perspective
  - Pain and Gain (possible benefits)

Standardisation Perspective
  - International?
  - Interest
  - Initiatives

Personal Summary (PS, sic) “A View from a Mountain”

OVERVIEW
There are none... so, a very short presentation!

A little surprising?

- There are so many variants and different types of 'summary' (e.g. discharge summaries, handovers)
- Patient Summaries are part of the healthcare fabric, commonplace and even mundane
- There are many local implementations, some national, and even regional in operation
- Some of these have been well established for years
- Standardisation is arguably more efficient if the thing to be elevated to a standard already exists and is proven to work in practice, so an ideal target?

A little confusing, and the confusion explains why!
THE LEGACY CHALLENGE…

- Return of investment is important and there is no desire to change, particularly if something is currently working.
- Worse still, the ubiquitous and pervasive nature of the ‘summary’ means widespread disruption and upheaval from any change.
- What is the incentive to change?
- …

THE ‘GREEN FIELD’ OPPORTUNITY…

- Adopting and fast tracking something that others have got to work.
- Avoiding vendor lock-in, avoiding past mistakes, gaining economies of scale.
- Minimise risk, costs and opening up new markets.
- …

ORGANISATIONAL & VENDOR COSTS
PATIENT PERSPECTIVE

- Improving Patient Safety - supporting more informed prescribing by providing timely access to accurate information
- Improving the Efficiency of Patient Care - reducing the time, effort and resources required to obtain this information
- Improving the Effectiveness of Patient Care - supporting the delivery of appropriate care to patients
- Improving Patient Experience - reducing repetition whilst supporting patient recall and those with difficulties

CLINICIAN PERSPECTIVE

- Improving Decision Support - removing uncertainty by giving the clinician instant access to additional and reliable information to better inform their decision
- Improving prescribing/medicating practice - identifying medication discrepancies and reducing errors
- Improving clinician productivity - reducing the time taken to treat the patient without duplication of effort/tests
- Improving overall management - Patients are less likely to need to be referred to another service

HEALTHCARE BENEFITS*

*adapted from Summary Care Record, HSCIC website, 2016
The cross-border value/International debate
The interest of the SDO community
The Initiatives (particularly JIC) will be discussed
International:

- Making the PS Structure & Content available for global use (independent of whether the demand is for cross-border or within a national state, or locally across organisations)

Interest:

- There are powerful stakeholder requirements for SDOs to get this done NOW, e.g. eHN, EU, EU-US, US Meaningful Use...
- It is not rocket science, and implementations exist, albeit not in an ‘idealised form’, therefore it should not too difficult...
- It is not ‘Big Data’; it has all the advantages of being ‘Little Data’!
  
Even so,

- “The value of data lies in their use.”
- “Data have no value or meaning in isolation”
- “They can be assets or liabilities or both.”
- “The information necessary to interpret data is specific to the problem”

AN INTERNATIONAL STANDARD FOR PATIENT SUMMARY?
“Data exist within a knowledge infrastructure- an ecosystem comprising stakeholders, technologies, organisations, objects and relationships between them.”

“Data and their uses are proliferating far faster than privacy law or information policy can catch up…”

“Moving data over networks involves a delicate balance of security, rights, protections, interoperability, and policy.”

“Documenting data in ways to make them useful for others to discover, retrieve, interpret and reuse is … difficult”

Extracts from “Big Data, Little Data, No Data” by Christine L. Borgman

PS: ‘LITTLE DATA’ BUT NOT EASY!
Assume the audience has more knowledge about the European initiatives, so

- eHN Patient Summary Guidelines v2
- EU projects (e.g. epSOS, Trillium Bridge, eStandards)

More explanation here on the following:

- Meaningful Use... Clinical Summaries
  - HL7 INTERPAS project
- ISO TC 215 Reference Standards Portfolios (Bundles)
  - Clinical Imaging
- JIC Standards Sets
  - Patient Summary for unplanned/emergency Care
- eHN Patient Summary Guidelines v2
- EU projects (e.g. epSOS, Trillium Bridge, eStandards)
- Meaningful Use... Clinical Summaries
  - (a little more detail follows on the nuances and differences between the EU and US initiatives)
Definition of Terms: Clinical Summary – An after-visit summary that provides a patient with relevant and actionable information and instructions (containing the patient name, provider’s office contact information, date and location of visit, an updated medication list, updated vitals, reason(s) for visit, procedures and other instructions based on clinical discussions that took place during the office visit, any updates to a problem list, immunizations or medications administered during visit, summary of topics covered/considered during visit, time and location of next appointment/testing if scheduled, or a recommended appointment time if not scheduled, list of other appointments and tests that the patient needs to schedule with contact information, recommended patient decision aids, laboratory and other diagnostic test orders, test/laboratory results and symptoms.)
The ellipses on the previous slide, flag the differences

The ellipses on the next slide show that the idea of packaging/bundling tools and rules are fairly commonplace...
(i) Create. Enable a user to create a clinical summary for a patient in human readable format and formatted according to the standards adopted at ...
(ii) Customization. Enable a user to customize the data included in the clinical summary.
(iii) Minimum data from which to select. EHR technology must permit a user to select, at a minimum, the following data when creating a clinical summary:
   (A) Common MU Data Set** (which, for the human readable version, should be in their English representation if they associate with a vocabulary/code set)
   (B) The provider’s name and office contact information; date and location of visit; reason for visit; immunizations and/or medications administered during the visit; diagnostic tests pending; clinical instructions; future appointments; referrals to other providers; future scheduled tests; and recommended patient decision aids.
*Additional certification criteria may apply. ... HL7 Implementation Guide for CDA Release 2: IHE Health Story Consolidation. The use of the “unstructured document” document-level template is prohibited. *Additional standards criteria may apply. ...

CERTIFICATION CRITERIA*
§ 170.314(E)(2) CLINICAL SUMMARY
The goal of this project is to identify minimally required clinical data with associated vocabulary subsets for patient clinical summary, and to build international templates based on HL7 CDA R2 standard with vocabulary subsets to support data elements within those templates.

Now relaunched as INTER PA S (2015)
INTERPAS wishes to be done with the target of it becoming an HL7/ISO standard.

Either INTERPAS will be an input to the JIC work, or more probably due to its expected completion date of 2017, JIC might provide a way to provide a guidance framework for when it is implemented.
ISO TC 215 REFERENCE STANDARDS PORTFOLIO (RSP) FOR CLINICAL IMAGING USE CASES
It is on Clinical Imaging, and therefore content-wise it is not relevant;

However, the value for considering it, is because the structure of the ISO bundle and the development process is expected to be complementary to the JIC work.

Both initiatives are prototypical.

The ISO RSP will be published and normative, whereas the JIC Standards Sets will be an informative, authoritative recommendation.
JIC STANDARDS SET: PATIENT SUMMARY

April 2016
The JIC will contribute to better global patient health outcomes by providing strategic leadership in the specification of sets of implementable standards for health information sharing.

JIC SAN FRAN DECLARATION, 2015
The first Use Case was agreed to be the Patient Summary since many nations are undertaking this work and SDOs are involved at different levels but not always coordinated.

Use Case (initial high level description)

A physician (i.e. Healthcare actor) wants relevant patient data to address the healthcare matter of the patient (subject of care) with legitimate access and use of relevant summary patient data at the point and time of care, irrespective of where and how it is held.
JIC EARLY PROTOTYPE PROCESS

High-level Topic

Use Case Descriptions

Standards content, tools & rules

= Standards Set
A coherent collection of referenced standards and standards artefacts that support a specific use case

ADAPTED DEFINITION OF A JIC STANDARDS SET (SS)
ORGANISATION OF THE JIC
DEVELOPMENT OF PS STANDARDS SET
## Work Steps and Task Groups

<table>
<thead>
<tr>
<th>Activities/Steps</th>
<th>Leads</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Group 1</strong></td>
<td></td>
</tr>
<tr>
<td>Detailed use case development</td>
<td>Elizabeth Keller</td>
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<tr>
<td>- Clinically focused group</td>
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<td>- Use case format</td>
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<td><strong>Group 2</strong></td>
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<tr>
<td>Standards identification and analysis</td>
<td>Don Newsham</td>
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<td>- Standards categorization approach (draft)</td>
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<tr>
<td>- Template for a JIC Standards Set (draft)</td>
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<td><strong>Group 3</strong></td>
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<tr>
<td>Implementation and guidance document development</td>
<td>Stephen Kay</td>
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<td><strong>Group 4</strong></td>
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<tr>
<td>Conformity Assessment</td>
<td>Mike Nusbaum</td>
</tr>
<tr>
<td>- Initial framework pending work of groups 1 &amp; 2</td>
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</tr>
<tr>
<td>Gaps and overlaps identification</td>
<td>Coordination Group</td>
</tr>
<tr>
<td>Standards set recommendations / gap action</td>
<td>Coordination group and JIC members</td>
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Implementation and Guidance Sub-group, not yet started, as it is dependent upon the other groups to deliver.

Would really welcome volunteers?
JIC is well placed for this work since JIC can draw directly on resources from SDOs and ensure coordination and collaboration.

JIC is developing 2 key products:
- recommendations for the Patient Summary Standard Set
- a methodology for developing further JIC Standards Sets

JIC are not developing products but leveraging existing work which is already either developed or in development – e.g. Trillium Bridge, epSoS and INTERPAS (HL7)

JIC is targeting one year for completion of the Patient Summary Standards Set – end of 2016
A JIC Foundation and Scope report for Patient Summary Standards Set – 1 October 2015, sets out initial approach being taken and is identified as work in progress - JIC website. Updated version after JIC meeting, May 2016

FAQs on JIC website which will be regularly updated

Set of slides summarising the work which will be updated – JIC website

Draft plan and resource requirements will be maintained and updated as the work progresses

Contact the Standards Set coordination group through the JIC website or Jane Millar jmi@ihtsdo.org

http://www.jointinitiativecouncil.org

PARTICIPATION FROM THE COMMUNITY
A view from the mountain...

AND FINALLY...
A small party from the eStandards’ consortium decided to reach the top to witness a sunrise.

The party included the author who had assumed that the land rovers provided at the beginning would continue by road to the summit or near by...Wrong!

I went so far, but did not reach the summit; I had time to reflect on the differences between the all-singing, all-dancing EHR in all of its glory, as opposed to a much more discrete, but nevertheless a mundane and commonplace object, made beautiful.
Are we there yet?  Not there just yet... rocks all the way up...

BROAD VIEW EN ROUTE TO THE EHR
Light making the mundane, special and visible... That looks interesting!

COMING INTO FOCUS...
More clarity as more is hi-lighted...

PS: SMALL BUT RADIAN'T!
“Having the right data is usually better than having more data”

THANK YOU; ANY QUESTIONS?
Slides 20, 24, 26, 27 were provided by Jane Millar and the JIC Coordinating group.