Joint Initiative Council

JIC Executive Meeting

Sunday 1st May 2016

Face-to-Face: 13:00-18:00 (local time)

Record of Discussion

Location: Face-to-face at VUmc Hoofdgebouw – Amsterdam, the Netherlands

Meeting documentation:

https://confluence.ihtsdotools.org/display/JIC/2016-05-01+May+face-to-face+-+JIC+Meeting

1. Welcome, Apologies.

The Chair welcomed the Council members to the meeting. Apologies are noted above.

2. Minutes of last meeting (20160413 – teleconference)

Approved. An abbreviated 'Record of Discussion' will therefore be posted on the JIC website.

3. Agenda approval, requests for AOB

Agenda approved. An executive asked to add an ISO/TC215 update on the 80003 Series to the agenda. This was agreed.

4. Review of actions from previous meeting

Action list: https://confluence.ihtsdotools.org/display/JIC/JIC+Action++List

Outstanding actions were listed as agenda items below…

5. JIC Standards Set Work – Patient Summary

5.1. Overview

Documents:

- Briefing note which focuses on key issues and points for discussion – 'JIC Patient Summary SS update 20160501 v0.01'
- Summary slide set - 'Agenda item 5 – JIC SS update 201605 v0.01'

An executive gave the presentation linked above. It was noted that there is a need to separate Regulatory Governance from Information Governance. Issues were raised around normative and informative, so these need to be clear. Also need to consider governance around procurement and this could be potentially done by providing a checklist.

5.2. Communications

The JIC Chair stated that the JIC needs to look for more clinicians, so perhaps we could issue communications beyond the JIC website and our community (e.g. via Doug Fridsma at AMIA & INTERPAS, through the people who contribute to our working groups, and via Kaiser Permanente's people). He suggested that an informative press release be sent in June. An executive agreed, saying that there was definitely a need for more clinicians to review the different aspects of work. Another executive reported there are various European clinical groups and they would be happy to be contacted for information. The Chair said that the WHO has a fairly successful model of clinical engagement, so he could contact them about this.

An executive said that ISO/TC215 is looking at how to better engage with clinicians so they may also be able to assist in future. It was acknowledged that there are two perspectives with this – the first is participation, and the second is review and being informed. The questions were asked – do we need a clinical advisory group, and how do we avoid duplication across SDOs?

Action 1	The Chair to contact the WHO re clinical engagement for Standard Set work.
Action 2	The SS working groups to prepare updated materials so that a focussed call for clinicians can be issues.

5.3. Update from each task group

5.3.1. Use case development (DNE)

Documents:

- 'JIC – Patient Summary Standards Set – Identification Analysis Task group – May 2016 update'
- Slide set - Use Case Working Group – Summary Update May 2016

An executive gave the presentation linked above. They stated that the work had evolved over the last few days and that Chronic Disease had become the focus. Advice from clinicians is that the proposed changes make the set more meaningful, and more feedback will come though subsequent meetings. An executive stated that there had been a lobbying by Vince to understand the proposed changes to use case. It could be emergency or another facility – COPD and Asthma narrow things but are a good place to start. We must try to ensure that we have the use case applicable in more than one jurisdiction. An executive said he was looking at JIC to do work across countries, and not just on COPD/Asthma. Wider clinical advice in Europe says that a broader group is needed; otherwise the work becomes less valuable. An executive replied that problem presentation should not drive data sets too specifically – yes, COPD is important but there should be a wider framework. The Chair said ultimately we need to focus on information to support safe care to cover most requirements. An executive agreed, saying it has to be generalizable. By stating Chronic Disease, we are defining a specific dataset. We need to cover Drugs and Immunization etc. to support across jurisdictions. We must not ignore cross-borders, and should not exclude topics like diabetes. The Chair agreed, saying a fundamental base set needs to cover basic information that is available, and then have examples that it can be modified to support. An executive said that Transition of care across jurisdictions should be the starting point. By refining things, data side gets simpler and simpler. We must not lose why we are doing this – the transition and dealing with gaps and overlaps (where more than one standard is doing the same thing). Must be more general than unconscious use case. An executive said that we should support a range of chronic conditions (such as heart disease and diabetes) and the commonalities across them. They asked what does Europe want to cover? An executive said that as soon as we become condition specific we are in trouble. Examples can be used to show what can be done, but not asking for disease

specific data. Non-condition specific standards should come out of this, though we will need anchor points/ use case to get clinicians engaged. An executive said it should be a range of pre-existing conditions – not specifying "chronic." Another executive said that with "jurisdiction specific versus cross border" it was unanimously agreed for cross jurisdiction. They asked – is it just a 'family doctor to Emergency' link? An executive replied that it is anywhere in the patient journey. The Chair said that "relevance" should be stressed – what is the basic information needed by a physician to treat the patient? What is relevant to the safe care of the patient in an unplanned event? An executive asked – if we are accessing the primary care summary, how do we get a common view? Another executive replied that how the summary comes into existence is out of scope; we must assume there is a patient summary at point of care. The Chair replied that EHR may be an example but trends are changing to digital systems, which share – for example – the regular diabetes readings uploaded by a patient. An executive asked if this was about creating? Another executive replied that the original description was about accessing information. The Chair said that here is a basic set of elements that get pulled out of a record, with examples of this. He said it is about the need to capture (access & transfer), not about creating. He said that his hope would be to define a basic set to check against, but it does not have to match everything. It should be a basic set, regardless of the system – it is guidance, a core that makes up summary.

5.3.2. Standards Identification and Analysis (DNE)

Documents:

- Draft Standards Set template produced by DNE's group for discussion – 'Standards Set – Patient summary v0.2'

An executive gave the presentation linked above. They stated that standards for patient summary do exist. The Trillium Bridge work is good, as is the provisional INTERPAS work. Work is focusing on SDO standards and not necessarily what countries have. INTERPAS potentially have what is in a patient summary. The question for the Use Case Group is whether it is appropriate, and can feed into INTERPAS as adjustment. But it means we can only refer to an emerging standard in the SS or we can say something needs to be developed. An executive asked if the plan was to specify the requirements? The executive replied that yes, we could do this, and point to ones which have portions of the data required. An executive said that INTERPAS is in a formative stage so can inform. An executive said that also the European guidelines are being revised for November 2016. So we can point to current relevant artifacts but also identify where they diverge. It becomes even more difficult for implementation guidance. An executive agreed, stating that we may also be identifying a gap and that we should tackle from the requirements and data element point of view. An executive said that the ISO TC/215 WG3 framework should be looked at (also presented at CAG1). Another executive asked should the JIC view gap analysis/requirements, and as a group of SDOs make recommendations on how work in each SDO can fill the gaps? An executive asked are we doing a standard for each element? Another executive said it was capturing the higher ground. An executive asked – is it a core set that is extensible, or a larger set? The view had been mixed in the use case group. An executive replied that European guidelines are suggesting some terms are mandatory and some are optional. An executive asked how could we really contribute, given the resources and link in more efficiently and effectively to the work? The Chair replied – let's get back to purpose. You want everyone on the globe to have a basic set of info that can be presented to any clinician wherever you present. We on the JIC are all organizations that are meant to know what is required. We should start with a core set, pass to a clinical group for validation at the lowest common denominator focusing on best practice at this time. If we as a Council do not put a stake in the ground it is a key issue – people are looking at the JIC to do this, and no one else is willing to. An executive stated that European guidance takes the approach of a basic core set) which can be extended. An executive said he agreed with this framework. The Chair said that we have to

more clearly identify clinicians to do the first validation, and then look to bigger organizations such as the AMA. An executive said that Europe can input to development level, make resources available and they will turn it into a specification for Europe. An executive introduced the draft Standard Set template and the slide refers to the document which has been sent out for comment. An executive said that some of the artefacts are specifications if governments are funding, as per WTO descriptions. An executive said the template fits identification and analysis, but that we have not talked yet about the artefacts around the standard set, what does it include? This goes to the issue of rules and tools as well to make up the package. An executive stated that how the Standard Set relates to the Use Case still needs to be identified. An executive referenced the diagram of ISO where the bundle is loosely held together by pillars but needs the other pieces. The list needs to include all we might consider, and then define down (constrain) for the use case. An executive said the documentation needs to pull together the work of all groups. An executive reflected therefore that the document should also collate links to other documents covering implementation guidance. This will also identify the gaps. An executive said that it should include localization, and it is also up to those on the JIC to inform our affiliates of their role.

On the next step slides, the Chair said we need to make a decision on what is in or out and we need to seek guidance from clinicians. If things are out we need to clarify why we need an independent view from clinicians that can advise the JIC, so we have an open and transparent decision. An executive said that he broadly agreed, but all has to be effective after the Standard Set is created and also must try to be as un-technical as possible, but each lead has to take responsibility for their area. An executive said we must recognize the bridge across, so we can put it out there to get feedback. A Structure/Framework for feedback need to be decided on, with maybe 5 or 6 categories.

5.3.3. Implementation and guidance document development (SKA)

Documents:

- Discussion paper from Steve Kay with regard to implementation guidance for discussion – 'SK JIC Standards Set Impl Guide Discussion April 2016'

An executive gave the presentation linked above. They said that it accompanied the document for feedback. The Use Case and Standards Identification were always going to be first. Conformity Assessment follows, the Implementation and Guidance follows that, to make the whole picture clear. They said there are three ways of looking at this:

1) The SS is essentially ALL guidance based, as it informs people about what is out there, brings to their attention any shortcomings, and makes recommendations on how to proceed. That said, the current 'communications' are still confusing people and there is still the belief that we are creating a 'new standard' or 'profile' and the difference between IHE profiles and the JIC Standards Sets is unclear to many. So there is a need for the JIC to get the marketing in place (i.e. indicating the difference between Profiles, RSPs and Standard Set perhaps as a new set of FAQs). We perhaps should make it clearer about our intent to align more closely with the ISO RSP by inserting "reference " before 'standard' in our current definition.

2) The 'Implementation and Guidance' sub-group is mainly dependent upon the other sub-groups delivering, as its document will serve as a 'wrapper' to the other deliverables. It will have to include the 'use case descriptions', the classification/selection of particular standards/profiles that are relevant, the gaps and the conformity assessment piece too. It will have to complement the templates by providing the other defining parts of the Standards Sets. These will be oriented towards the readers of the Standards Sets, expressing some of the ideas in the various interoperability frameworks that are available. There will need to be a balance between the global and the national dimensions to help build bridges. However, there will need to be a balance and that is very much tilted towards the international dimension, but we

will need to mention potential jurisdiction/legal matters that we become aware of. The other balance to be undertaken, is that the 'Implementation and guidance document' is not going to be at the level of a traditional 'Implementation guide' (e.g. XML schema and the like). Rather it will be an informed commentary that cannot be at the apple pie and motherhood levels but neither can it be too detailed given the multiples of specifications involved... The prototype process and its response will critique the appropriate levels.

3) The 'total package' will define the JIC Standards Set, but there are real Issues around time-lines. Some work can be done now, but the dependencies mean that the I&GD will be the last piece of the jigsaw and delays in the other groups will necessarily impact. There is currently no subgroup of people yet, and volunteers will be sought at this meeting. The good news is the wrapper aspect means that some of the content is already there or will be coming from the other groups (thanks!). The final feedback on the standards set and the method, however, will occur at the end of the process, and this probably means after the Norway meeting, so perhaps we should begin to manage expectations.

An executive referenced deliverables on the slide. They agreed to add in information in the work plan under 'guide.' When people read our package they will come with difference views and therefore do need the framework. Perhaps there should be a questionnaire mechanism that captures feedback on how a country is doing work (recognizing there are regional solutions). An executive replied that this is not about localization, which is out of scope. Another executive agreed, but said it would be useful to be able to point to exemplars in different ways of viewing patient summaries so that people can learn. There should be a balance between localization and global examples. He said he does think that the JIC will need to have an agreed view of what interoperability is across SDOs. The Task Force will help with this work – though it has to come at the end and be the last thing done, which may make timelines difficult. The Chair said he agreed with this approach. Some of the guidance will be simple reference to local policy but others will be complex as in moving data from country to another. An executive said that equally there will be gaps – he has already discussed issues around consent internationally. The Chair said he agreed and that advise to users needs to be considered. An executive said that this may be a pillar for all standard sets, so it will need to be tailored to a use case. Another executive said that a mapping exercise is needed and ISO will be willing to do this, driven by use case. An executive said some of the documents he had sent out address these issues

6. Unique Device Identifier (UDI) update

Documents:

- Presentation by CHA – UDI Guidance
- Good practice for UDI implementation in Health IT processes and Systems
- DICOM document

An executive gave the presentation linked above.

They stated that the work item was agreed in San Francisco in April 2015, and the guidance is normative and global. They stated that he had worked with a group for the first draft, which required some re-engineering. The new draft is more focused on supply chain and carrying the info using HL7). They said that DICOM had sent in work but it was not supply-chain related so would not be part of this guidance. An executive said they disagreed somewhat with this. They said we should see the image as a persistent object, so important to try to link the works. The Chair said that hypothetically, there are many uses for UDI. In this example, if swapped machine and a recall is required, there is a benefit to then be able to

quantify how many results you need to review. So maybe it should break down into categories and various types of things you would expect for UDI. An executive agreed, saying that FHIR will likely be doing work in this area too. The Chair said we should be inclusive about how UDI applies to the health system. An executive then agreed to add in a chapter and annex. Another executive said that the Functional Model is likely to address this in the future. An executive said we really need to push this once completed, as it is a game-changer in safety

Action 3	UDI document to be updated with a chapter and annex.
Action 4	Final review by small group should include the HL7 representations.
Action 5	JIC member review

7. FHIR Discussion

Documents:

- FHIR Executive Tutorial (excerpted), Lloyd McKenzie (Gevity), 27 April 2016 (for FHIR North Connectathon)
- Intro to FHIR, Richard Ettema (AEGIS), 29 February 2016 (for HIMSS Annual Conference)
- Fundamental Principles of FHIR, HL7 Wiki, 16 February 2016

An executive stated that their suggestion to the JIC would be to think about extent to which FHIR should be bought into a standards state (HL7 is working towards it consuming things) like CDA). Working on tying the functional model to FHIR. ISO 21089 is also including reference to FHIR with regards to the functional model. The Chair asked - from the JIC perspective, as FHIR is in the market place would it be useful to look at the impact on other JIC standards? An executive replied that it would need a time-stamp since it is continued development. Another executive asked if there would be a FHIR resource for all HL7 products? The executive said that there is a mapping exercise, also FHIR is in formative stages so now is the time to get heads around it and influence development and the balloting process (e.g. consistency across FHIR resources), so FHIR has introduced levels of maturity against W5 conformance. An executive stated that there is work in Australia to look across FHIR, CDA etc. Whilst keeping it at DSTH, in reality it is being implemented. We need to recognize what is happening. Governance on how to keep things together is a big issue. Another executive said they agreed, and as HL7 is part of the JIC, we should work out together how we should be involved. Another executive said that ISO WG1 and WG2 have presentations for EHA at HL7 as they thought ISO needed to do more.

In conclusion, the Chair stated there should be an item on this in the November face-to-face meeting with discussion from EHA and Wayne Kubick focusing on what HL7 want form JIC and the SDOs

Action 6	A FHIR discussion to be added to the agenda in November, including what HL7 want from the JIC and SDOs

8. Discussion on JIC involvement in external projects such as EU/US MoU, INTERPAS etc

The Chair stated that this was an item raised on the last JIC call, as an open question about what role the JIC should play in external projects. An executive said the JIC should reach out to groups and work to have them come to us. The Chair said that this point should be discussed further when more executives are present, so that it can be decided what the JIC as a body is prepared to do. It is good that groups are seeking endorsement from the JIC but what do we want to do beyond that? An executive agreed, saying

there is also the question of how we manage official representation – what does that mean and how do we do it? Another executive stated that saying we cannot be involved with a project is a bit negative, but our standards (of JIC members) are the ones these projects are supporting and/or using. The key benefits to attending Cambridge, for example, to pump message re using JIC standards. It is the role of the chair, or someone delegated, to manage conflicts of interest and regional views. An executive said that a simple approach has to be mutually beneficial. A light touch is required unless something is actively opposing JIC members work. The Chair agreed, saying there should not be any 'over-kill' with a formal process. Take messages and report back, including bringing any requests for action.

9. openMedicine Discussion

Documents:

- Updated presentation by CCH

The presentation linked above was given on behalf of another executive. They clarified that defining an e-prescription is not in scope, and the presenting executive replied that it was not included. They stated that the next meeting would be 20th-21st June in Washington DC, Standards group

10. e-Standards Development Lifecycle Discussion

(For official JIC endorsement of the eStandards Case on Formal Standardization).
Documents:

- Draft Endorsement Statement
- Presentation: The case for formal standardization in large-scale eHealth deployment

An executive gave the presentation linked above, stating that it had already been presented previously. He said they were preparing a report on SDOs supporting e-Health deployment and the case for formal standardization at different levels and perspectives. Their conclusion was that SDOs and users need to work together across the health informatics standards lifecycle. They said he was asking for endorsement of deliverables 3.1. An executive said that further clarification was needed on point 4. Another executive said we should work together on supporting standards sets through the lifecycle. An executive said that the endorsement document might need some re-wording, though they acknowledged that it was late in the day to produce specific wording. Another executive asked what the process would be? The Chair said he agreed with points 1 to 3 but agreed that he wasn't sure about the wording of point 4 and the provided suggestions.

Action 7	Comment and or approval to be sought from each SDO *(Post script: RST circulated a revised endorsement statement to JIC executives on 3rd May 2016, asking for each SDO to follow its internal process to endorse the deliverable in the context of the JIC and accept (or reject) the revised wording in attached document. Alternatively, if organizations were also willing to provide an individual letter of endorsement for this deliverable, this was also welcomed).*

An executive asked - should we be embracing getting rid of the "D" in SDO and focusing on the lifecycle? All agreed to this. Another executive said he had read the previous version and it was very good but he also saw it as a communications tool for JIC work.

Draft recommendations to be posted on Confluence and over the next few month work on getting input to roadmap. Starting with Patient Summary as the first collaborative activity. An executive said it would be useful to use the definition of the standards lifecycle which incorporates the Use Case. Another executive agreed, and said that also a realistic scenario for the local implementation (vendors, providers etc.) would be useful. Current realistic scenarios do not take in to account the Standard Sets. New business

10.1. ISO/TC215 update on 80003 series

An executive from ISO reported that ISO TC/215 is putting together a Task Force to decide on how to move forward with this.

11. Adjournment

The meeting was adjourned after the Chair thanked the attendees for their time.

12. Next meeting

Confirmed as a teleconference on Wednesday 8th June 2016 (20:00-21:00 UTC)