20160628\_NBS\_Notes

Attendees: Careema, Joshua, Rebecca, Riki, Willie, Susan, Dari, Brendan, Carrie

**Agenda**

* NBS\_COMPONENT document is here on google docs: <https://docs.google.com/document/d/162wue5qV9a6fORJ1CUT9guCIVnLyq5RZa_CA-hUfjtY/edit?usp=sharing>
  + Did not see many changes except from myself
  + Do we have someone who is willing to take material from HRSA guide and write section 2?
    - Use cases we want to cover:
      * Sending partial results to the ordering provider
        + This may require review of some of the required OBX segments in the summary section
      * Sending final results to the ordering provider
      * Sending partial and final results for follow up / other parties (pediatrician)
        + This may require review of some of the required OBX segments in the summary section
      * Sending final results for surveillance / research / registries
        + These institutions may want more of the data elements form the testing side (including numeric results – for example for tandem Mass Spec) – need to review the vocab requirements and add some business rules
        + May need to mask the data to de-identify appropriately
      * Accommodate follow up monitoring for specific diseases (PKU)
        + As long as still dried bloodspot samples
        + May use underlying LRI, since no longer newborn, may not need ALL the additional data anymore
        + Will most likely create a separate LOINC panel for this
  + Vocab reference placement:
    - Suggest section 3.1 then point to the URL that has the LOINC we are using PLUS add in how to read / translate some of those into the
  + Acknowledgement piece – are we ready to work on this?
    - Transport level (I got a package) is not described in guide
    - Accept ACK (I know it is an HL7 message and I have stored it, so stop sending (and may already know that it is structurally valid, i.e. I will be able to read it) is expected to be synchronous (though it does not have to be per b base standard) – that is what IA is doing, too
    - Question on when the Application level ACK needs to be sent?
      * There is no specific timing requirement – the assumption is that it is asynchronous, so send AFTER you have parsed the message and the system “understands the content”
        + So on the order side, could I wait till I have the specimen in the lab?

Assume yes – would need to be sure partner knows that is the case

Application lev el ACK is more useful on order side that way (can communicate got sample as well as the filler order number)

* + - * + How many LIMS can send Application level ACK when they get an order rather than when they get the sample?

Most LIMS should be able to, but often not implemented

* Review spreadsheet - dive into the message structure section
  + Spreadsheet is here on google docs: <https://docs.google.com/spreadsheets/d/1ZIhrKrWnVN-0FHKoOLU47YW900qOBlA-hbw4CiXh5gc/edit?usp=sharing>
    - The nested OBRs will be a problem….as LRI requires OBR to be followed by Observation groups (OBX + optional NTE) EXCEPT when there are status codes used in OBR-25 that indicate there are NO results YET (like got order, but no specimen, got order and specimen and procedure is scheduled, started procedure, but no result yet), but in NBS guide we have a few levels of nesting:
      * AHIC Panel = OBR
        + AHIC panel summary = OBR

Result 1 = OBX

Result 2 = OBX

* + - * + Newborn screening panel = OBR

Amino acid panel = OBR

Result 1 = OBX

Result 2 = OBX

Result 3 = OBX

Organic acid panel = OBR

Result 1 = OBX

Result 2 = OBX

* + - * + Endocrine panel = OBR

ACH = OBX

CAH = OBX

* + - * + Tandem Mass = OBR

Analyte 1 = OBX

Analyte 2 = OBX

Analyte 3 = OBX

* + - * There are a few options to consider:
        + Use OBX-4 to group

have ST element that can be used for text

If more than 2 levels needed, would have to use ST and create a specific syntax (clin genomics will have that issue)

Have Group (group results overall) and sequence (order results within the group) components, which are numbers

* + - * + Use Order Parent to create linkage between the original order and the OBRs that are sent to group the results into proper categories

Will EHR-S be able to handle getting more OBR than what they ask for, or getting OBRs that don’t match their OBR-4 code at all?

* + - * + Submit a change proposal to add a code to OBR-25 result status code table HL70085 that indicates there are NO results expected ever (the OBR is used as grouper ONLY) – this will require a harmonization proposal as well as a change in LRI, but might be what is needed to support clinical genomics as well
* Riki to create examples of these options and share with the group
  + - * Preference seems to be to drop the higher level grouping OBRs and only send the immediate OBRs
    - The summary result grouping creates issues on the lab end – how useful are these for the hospitals – to get the line list of all the tests that are detected and all the ones that are equivocal etc…? they are getting each of the individual results in addition to these summary reports

Post call email from Dari Shirazi:

Brendan sent me a copy of their paper report and it looks very much like ours. From what you can see, tests results are all reported very simply with no heading like “Newborn screening panel…”. I think our issues are very much related to the way we send the results:

1. For all use cases, eliminate the nested OBRs
   1. Some hospitals might be able to do this but I don’t know if most can – if this was routine, LRI would already have this
2. Create OBRs for just these sections
   1. Newborn Screening Report summary panel
   2. Newborn screen card data panel
   3. Newborn screening test results panel
      1. All the results would go under this including hearing as OBX
3. For hospital reporting, just send the result panel OBR to make the message simple.
   1. Echoing things that the hospital sent us to begin is somewhat useless (card data).
   2. Some systems like SunQuest (from my understanding) cannot manage variable OBXs without charging the hospitals to retool. So sending one message with 10 OBX and the next message with 11 OBX might be difficult for some. We can just use the “XXXXX newborn screen interpretation” for each result to keep the number of OBXs the same. Again, this is for hospitals.
4. For Follow-up, Research, … the message can have multiple OBRs (1 level only). It does make sense to send card data to follow-up because they were not the original submitter so that information is not in their system.

 and 