

Patient Summary Working Group Meeting

Meeting Summary

Meeting Chair: Allana Cameron			
<u>Date and Time</u>	<u>Location</u>	<u>Note Taker</u>	<u>Next Meeting Date</u>
February 27, 2024, 1:00pm – 2:00pm ET	Virtual	Sadrina Petit, Project Analyst, Digital Health Interoperability	March 5, 2024, 1:00pm – 2:00pm ET
Meeting Agenda: <ol style="list-style-type: none"> 1. Welcome & Update 2. Ballot Submission Stats 3. Ballot Submission Reconciliation Discussion 4. Next Steps 			
Presenters			
<ul style="list-style-type: none"> • Allana Cameron, Product Manager, Patient Summary • Raman Dhanoa, FHIR Specialist, Dogwood Health Consulting • Lloyd McKenzie, Chief Standards Officer, Dogwood Health Consulting • Sheridan Cook, Standards Lead 			
Invited Guests			
Public			

1. Welcome and Introductions

A. Cameron welcomed all participants to the working group meeting and introduced Raman Dhanoa, Lloyd McKenzie and Sheridan Cook. Meeting materials and recording of the session will be made available on the InfoCentral working group.

The Infoway team presented each of the agenda items as outlined above.

The presentation deck is available [Patient Summary Working Group Meeting](#)

The video recording is available [Patient Summary Working Group Meeting](#)

2. Ballot Submission Reconciliation Discussion:

Row 9 FHIR Artifact Patient

- The working group discussed how to manage mandatory data elements that might not always be available, like the date of birth. The proposed solution involved allowing estimations where exact data is not known and using the 'data absent reason extension' for cases where the data cannot be provided at all.

- The group emphasized the need for clear guidance on managing missing data elements marked as mandatory, and discussed a plan to add a section to the specification that would provide such guidance. The new section would also cover managing optional and required elements and their cardinality.
- The working group acknowledged the confusion around the 'Must Support' tag, especially regarding what data should be sent and how non-supported data should be handled. The need for further clarification for the implementation community was noted. Examples include the handling of immunization data and the nuances of complex data types like identifiers.
- The discussion highlighted the challenges of standardizing data exchange and ensuring interoperability due to variability in system capabilities, particularly around capturing and handling optional versus mandatory data.

Decisions Reached:

- The working group agreed on adding additional guidance around the use of 'data absent reason' and handling estimated data for mandatory fields like date of birth.
- The working group agreed that 'Must Support' concept needs further clarification, with a suggestion to refine instructions for better interpretation by implementers. The discussion on this topic is acknowledged as ongoing and potentially requiring a dedicated session.

Row 18 FHIR Artifact Patient

- The group discussed how to manage patient names in sensitive healthcare contexts, such as HIV clinics, where patient anonymity might be necessary. The use of 'anonymous' names and the support for such names by receiving systems was debated.
- The working group explored the use of the 'data absent reason' extension for cases where actual names cannot be disclosed, ensuring patient privacy while clarifying why certain data is absent.
- The difference between using an anonymous name (a pseudonym) and omitting the name altogether was discussed, noting that an anonymous name is still a form of identification, albeit not the patient's real name.
- Concerns were raised about the feasibility of exchanging patient summaries without identifiable patient names, especially given the reliance on names for patient identification across jurisdictions in the absence of a common patient identifier.
- The working group leaned towards requiring a valid name in patient summaries to support clinical use and interoperability, with the understanding that 'data absent reason' might not be sufficient in all cases.
- Scenarios such as newborns without assigned names were discussed, with current practices involving placeholders like 'Baby Boy/Girl' along with the mother's surname to ensure some form of identification.
- It was emphasized that patient summaries are intended for clinical information sharing across organizations and should contain identifiable information to fulfill their purpose. The use of summaries for anonymized data exchange, such as for research purposes, was considered secondary.

Decisions Reached:

- The working group agreed on the need to clarify the handling of names in patient summaries, particularly in sensitive contexts or special cases like newborns, ensuring that patient privacy is respected while maintaining the utility of the summaries for clinical purposes.
- The consensus leaned towards making the patient name a mandatory field in patient summaries, with the possibility of adopting the R5 concept of mandatory fields that also require a value, ensuring that some identifiable information is always present.

Actions:

- The specific use case of HIV clinics and the potential for exchanging summaries without patient names will be followed up with TELUS for a clearer understanding, and the findings will be brought back to the working group for further discussion.

Row 13 FHIR Artifact Family member History

- The group discussed the 'FamilyMemberHistory' relationship field, which is mandatory in the base FHIR specification. Concerns were raised about cases where this information isn't discretely present in-patient records and how to handle such situations.
- The working group discussed the use of the 'DataAbsentReason' extension for instances where specific relationship data is missing. This approach aligns with handling other mandatory fields when data is not available.
- The possibility of using an 'unknown' code to represent an undefined relationship was considered. It was noted that this could introduce complexity, as it might require mappings in EMRs to accommodate new codes, potentially complicating the implementation process.
- Discussed scenarios such as cases where a patient might only recall that a family member had a certain condition without knowing the exact relationship. The working group considered whether it's possible to always have precise relationship data in such contexts.
- The flexibility in coding for the relationship field was highlighted, with options including using a generic 'family member' code, an 'unknown' code, or the 'DataAbsentReason' extension. The group acknowledged the need for clarity in guidance to accommodate different implementation scenarios.
- It was suggested that additional guidance might be necessary for handling coded elements, especially where the standard allows for flexibility. This guidance could include the use of generic codes, 'unknown' codes, and the "Data Absent Reason" extension.

Decisions Reached:

- The working group agreed to provide additional clarification in the patient summary guidance document, particularly for handling the 'FamilyMemberHistory.relationship' field when the specific relationship is not known. This would include outlining the use of the 'Data Absent Reason' extension and the options for coding 'unknown' relationships.