Board Report: IHE Patient Care Coordination Domain

**Sponsors:**

* Health Information Management Systems Society (HIMSS)
* American College of Physicians (ACP)

**Leadership:**

* Secretariat: Sarah Bell, HIMSS ([sarah.bell@himss.org](mailto:sarah.bell@himss.org))
* Board Representative: Tone Southerland, OneRecord
* Committee Co-chair: Andrea Fourquet, eHealthSign
* Committee Co-chair: Emma Jones, Allscripts

**Membership Rosters:**

* [Combined Planning and Technical Committee Roster](https://docs.google.com/spreadsheets/d/1C070uur89V3WtohS2NvXcR1aiIYPKzfayutuhmNCYrg/edit#gid=0)

**Vision and Mission Statements:**

* The **Vision** of PCC is to continually improve patient outcomes through the use of technology connecting patients and their care providers across healthcare disciplines and care paths.
* The **Mission** of PCC is to develop and maintain interoperability profiles to support coordination of care for patients where care crosses providers, patient conditions, and health concerns.

**Activity:**

**2020 Activity**

* PCC published 3 new profiles in 2020
* International Patient Summary (IPS) Published – includes CDA and FHIR templates
* A total of 19 Change Proposals were processed in 2020
* Efforts were made (and some are still underway) to update FHIR-based PCC profiles to R4
  + 4 profiles using HL7 FHIR R4: ACDC, DCP, IPS, QEDm
  + 4 profiles using HL7 FHIR STU3: DCTM, PMDT, PCS\*, RIPT\*
  + 3 profiles HL7 FHIR DSTU2: RECON, GAO, CMAP\*\*
  + \* R4 in progress; \*\*deprecated
* Ongoing work to align EMS profiles to International Patient Summary (IPS) profile
* Collapsed technical and planning committees into a single committee. Restructuring of working schedules and relationships with other IHE domains has been completed (ITI, QRPH) in response to decreased industry/volunteer engagement (due at least in part to the global Covid pandemic)
* Github is replacing use of the FTP server in alignment with what’s happening in other IHE domains
* Github FHIR Profile publication automation is in progress

**2019 Activity**

* PCC published 1 new profile in 2019
* Moved to a continuous cycle publication
* Process change moving away from FTP and onto Google sheets – for rosters, change proposals
* A total of 5 Change Proposals were processed in 2019

**2018 Activity**

* PCC published 3 Profiles in 2018 and has received 1 Profile proposal for the 2019-2020 cycle.
* Current Cycle Timeline/Milestones are published on the [IHE wiki](https://wiki.ihe.net/index.php/Domain_Milestone_Dates)
* Dynamic Care Team Management (DCTM) has been selected for the [ONC 2018 Interoperability Standards Advisory (ISA)](https://www.healthit.gov/isa/sharing-patient-care-teams-care-planning-multiple-clinical-contexts)
* [Electronic Medical Documentation Interoperability (EMDI)](https://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/Electronic-Medical-Documentation-Interoperability/Overview.html) Program accepted the 360 Exchange Closed Loop Referral (360X) Profile and National Extension for adoption.
* Six (6) Change Proposals submitted in 2018
* Established a more detailed profile deprecation process
* Decision made to combine planning and technical committees to streamline our processes and work efforts as per IHE Governance.
* Reviewing role of Nursing Subcommittee – collaborating with HL7 nursing groups to better understand engagement opportunities
* Developing a continuous cycle publication approach
* Of the 9 FHIR-based PCC Profiles, 3 are using DSTU 2, 5 are using STU 3, and one is using R4. PCC is working to update all of these profiles to use R4.

**2017 Activity**

* The IHE Dynamic Care Planning (DCP) Profile has been included in the [ONC 2017 Interoperability Standards Advisory (ISA)](https://www.healthit.gov/isa/Sharing_Patient_Care_Plans_for_Multiple_Clinical_Contexts) under the Care Plan section. Additional profiles have been considered such as the PCC Obstetric Care Profiles.

**2016 Activity**

* The Newborn Discharge Summary Profile was included in the ONC 2016 Interoperability Standards Advisory under the [*Questions from December 2016*](https://www.healthit.gov/isa/section-vi-questions-and-requests-stakeholder-feedback)section where ONC is seeking specific feedback on the use of the Newborn Discharge Summary Profile as a subsection to represent Birth and Newborn Data Sets.

**2015 Activity**

* [OpenHIE](https://wiki.ohie.org/display/documents/OpenHIE+Standards+and+Profiles) adds reference to PCC Antepartum Summary Profile

**Most Significant Profiles:**

Overall cumulative Profile testing instances as of 2020 are up to 518 from 451 in 2018. The most significant recent profile is Query for Existing Data for Mobile (QEDm) with 14 test instances which far surpasses other recent profiles. Otherwise, the most significant PCC profiles continue to be those of years past with substantial testing numbers at previous IHE Connectathons. New testing numbers for PCC profiles continue to grow at only a modest rate.

Product registry entries are also on the decline. We are unsure of the reason behind this, perhaps vendors are removing their entries for reasons that we do not know. There may be an opportunity to explore which vendors are removing their entries and engage with those vendors to understand why. This information can inform new product registry improvements that result in broader community usage.

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| --- | --- | --- | --- | --- |
| **Title** | **# vendor (Connectathon)** | **# product (Registry)** | **Description** | **Significance** |
| Cross Enterprise Sharing of Medical Summaries (XDS-MS) | 96 (prev 93) | 6 (prev 13) | Content Profile; describes the content and format and discharge summaries and referral notes. | High testing numbers, includes many base-level templates |
| Exchange of Personal Health Record (XPHR) | 53 (prev 52) | 4 (prev 11) | Content Profile; Describes the content and format of summary information extracted from a PHR system for import into an EHR system, and vice versa. | US ONC MU1, US ONC MU2; High testing numbers, includes many base-level templates |
| Emergency Department Referral (EDR) | 34 (prev 34) | 4 (prev 9) | Content Profile; Communicates medical summary data from an ambulatory EHR System to an EDIS System. | High testing numbers, includes many base-level templates |
| Antepartum Profiles (APS, APHP, APL, APE) | APS: 19 (prev 19)  APHP: 13 (prev 13)  APE: 11 (prev 11)  APL: 9 (prev 9) | APS: 1 (prev 3)  APHP: 1 (prev 4)  APE: 1 (prev 4)  APL: 1 (prev 1) | Content Profiles; Records the aggregation of significant events, diagnoses, and plans of care (APS), H&P, results from standard laboratory tests (APL), and educational material provided (APE) during an antepartum episode. | Only known Obstetric-based content profile in industry. The US ONC Interoperability Standards Advisory (ISA) has shown interest in referencing these profiles. |
| Emergency Department Encounter Summary Profiles (EDES) | TN: 18 (prev 18)  NN: 20 (prev 18)  EDPN: 20 (prev 20)  CTNN: 16 (prev 16) | TN: 2 (prev 6)  NN: 2 (prev 6)  EDPN: 2 (prev 5)  CTNN: 2 (prev 5) | Content Profiles; A set of profiles to record the care actions conducted in an emergency department encounter including: triaging a patient upon presentation (TN), nursing care delivered (NN), and the notes from a ED physician (EDPN). A composite triage and nursing care document (CTNN) is also possible. |  |
| Immunization Content (IC) | 33 (prev 32) | 2 (prev 4) | Content Profile; Describes the content for exchange of immunization data with Immunization Information Systems (IISs), as well as EMR/EHR systems, HIEs, PHRs, and other public health systems. | * Pilot in San Diego Immunization Registry * Although the US ONC 2014 and 2015 Certification program has established the HL7 v2 message as the minimum requirement, a number of US States have started to include this document profile also. |
| Labor and Delivery Summary Profiles (LDHP, LDS, MDS, PPVS) | LDHP: 14 (prev 14)  LDS: 21 (prev 20)  MDS: 4 (prev 4)  PPVS: 11 (prev 11) | LDHP: 2 (prev 2)  LDS: 2 (prev 3)  MDS: 0 (prev 1)  PPVS: 1 (prev 2) | Content Profiles; A collection of Profiles that describe the content that is collected during the intrapartum process. | * Follow on care from Antepartum Profiles * Shares some components with Antepartum Profiles for reuse opportunities * The US ONC Interoperability Standards Advisory (ISA) has shown interest in referencing these profiles. |
| Reconciliation of Clinical Content and Providers (RECON) | 2 (prev 2) | 0 (prev 1) | Integration Profile; Provides ability to exchange lists of clinical data that have been reconciled, the sources used and the provider that conducted the reconciliation action. | Requirements of this profile align with those found in US ONC 2015 Certification. |
| Guideline Appropriate Ordering (GAO) | 4 (prev 4) | 1 (prev 1) | Integration Profile: Supplies a mechanism by which EHR systems can evaluate orders to determine whether these orders conform to guidelines. | Aligns with 2017 US law regarding how providers that are ordering imaging procedures must use physician approved appropriateness guidelines. |
| Newborn Discharge Summary (NDS) | 9 (prev 9) | 1 (prev 2) | Content Profile; Represents a summary of the most critical information to a newborn care provider after discharge from the birthing facility. | Medium to low testing numbers, but signifies interest in the pediatric space |
| Cross-enterprise eReferral Workflow Definition (XBeR-WD) | 6 (prev 6) | 2 (prev 2) | Workflow Profile; Establishes a common set of rules to share between participants involved in an eReferral Workflow | Arsenal IT (Italian National Program) is utilizing PCC workflow profiles to address care coordination issues. |
| Routine Interfacility Patient Transport (RIPT | 2 (prev 0) | 0 (prev 0) |  |  |
| 360 Exchange Closed Loop Referral (360X) | 5 (prev 0) | 3 (prev 0) |  |  |
| Query for Existing Data (QED) | 5 (prev 5) | 1 (prev 1) |  |  |
| Query for Existing Data Mobile (QEDm) | 14 (prev 0) | 3 (prev 0) |  |  |
|  |  |  |  |  |

< # vendor (Connectathon) is a count of successful vendors from Connectathon-results.ihe.net >  
< # product (Registry) is a count of registered Statements from Product-registry.ihe.net >

**Significant Deployment Activity:**

PCC is not regularly made aware of deployment activities and could benefit from a broader effort to collect IHE deployment information such as being driven through the IHE Regional Deployment Domains (e.g., IHE USA, IHE Europe).

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| **Region** | **Organization Name** | **Profiles** | **Status** | **Contact** | **Year** |
| France | ASIP Santé | APS, LDHP, LDS, MDS, IC, RCK | In production | ASIP Santé  <http://esante.gouv.fr/en> |  |
| France | ASIP Santé – National Information System for Emergency Ambulance (for [SAMU Program](http://esante.gouv.fr/services/programme-si-samu)) | RIPT | Under Consideration | ASIP Santé  <http://esante.gouv.fr/en> |  |
| France | ASIP Santé | DCTM | In pilot | ASIP Santé  <http://esante.gouv.fr/en> | 2020-2021 |
| Italy | Arsenal IT | XDS-MS, XBeR-WD, XTB-WS | In production 2016 (XBeR-WD)  Pilot installation Jan 2015 (XDS-MS, XTB-WS) | Arsenal IT  <http://www.consorzioarsenal.it/web/guest> | 2016 |
| United States | North Carolina Health Information Exchange (NCHICA) | XDS-MS | Pilot installation 2008 | <http://nchica.org/> | 2008 |
| United States | Keystone Health Information Exchange (KeyHIE) | XPHR, XDS-MS | In production | Geisenger Health System  <http://www.keyhie.org/> |  |
| United States | Health Information Exchange of New York (HIXNY) | XPHR, XDS-MS | In production | NYeC RHIO  <http://hixny.org/> |  |
| United States | Greater Rochester RHIO (GRRHIO) | XPHR |  | NYeC RHIO  <http://www.grrhio.org/> |  |
| United States | San Diego County Immunization Registry | IC | In production | <https://www.sandiegoimmunizationregistry.org/sdir_home.htm> |  |
| Thailand | Bumrungrad Hospital | PPOC | In production | https://www.bumrungrad.com/en |  |

**Demonstrations and Other Events:**

**2020**

* HIMSS Annual Conference was canceled in 2020
* [NACCHO Virtual Conference](http://www.nacchoannual.org/home)
  + Query for Existing Data for Mobile (QEDm)
  + Labor and Delivery Summary (LDS)
  + CDA Occupational Data Options

**2019**

* [2019 HIMSS Annual Conference](https://www.interoperabilityshowcase.org/orlando/2019/himss19-use-case-demosntrations) (United States)
  + [360 Exchange Closed Loop Referral (360X)](https://www.interoperabilityshowcase.org/sites/interoperabilityshowcase/files/himss19_cardiac_patient_and_referral_management.pdf)
  + [Dynamic Care Planning (DCP)](https://www.interoperabilityshowcase.org/sites/interoperabilityshowcase/files/himss19_consumer_centered_care_planning.pdf)
  + XDS-MS/C-CDA

**2018**

* 2018 IHE International Educational Webinar Series
* 2018 ONC Interoperability Forum demonstration of the *360 Exchange Closed Loop Referral (360X)* Profile and National Extension
* 2018 HIMSS Annual Conference (United States)
  + Theme-focused demonstrations including ambulatory, emergency, and acute care settings, public health agencies, clinical research organizations, laboratory services, imaging services, and home care.
  + [Birth Reporting and NICU](https://www.interoperabilityshowcase.org/sites/interoperabilityshowcase/files/birth_reporting_nicu.pdf) – Labor and Delivery Summary Profile
* 2018 RSNA Annual Meeting Education Course: [IHE on FHIR](http://bit.ly/2yyJstq)
  + Included 10 PCC Profiles and National Extensions currently using FHIR

**2017**

* [HIMSS Nursing Informatics](http://www.himss.org/informatics-practice) Education Webinar - Perspectives from the Nursing Informatics Community and IHE:
  + [Part 1: The Foundations of Interoperability](http://www.himss.org/library/foundations-interoperability-perspectives-nursing-informatics-community-and-ihe)
  + [Part 2: Solutions and How to Engage Within Interoperability](http://www.himss.org/library/solutions-and-how-engage-within-interoperability-perspectives-nursing-informatics-community-and-ihe)
  + Presented by PCC domain chairs in office at time of event
* American Academy of Nursing presentation: *Electronic Method for Measuring Nursing Services*
  + Presented the Patient Plan of Care (PPOC) as a framework for EMR data layer integration

**New Profiles/Supplements:**

* **International Patient Summary (IPS)**
  + Leverages the HL7’s IPS Implementation Guides that realize the CEN EN 17269 IPS dataset. Additional options pertaining to occupational Data for health and section constrains for a complete IPS sections support are specified within this profile.
  + <https://www.ihe.net/uploadedFiles/Documents/PCC/IHE_PCC_Suppl_IPS.pdf>
  + TI Published June 2020
* **360 Exchange Closed Loop Acute Care to SNF Transfer (360XL)**
  + Builds upon the 360X profile for closed loop referrals. This supplement uses some of the existing transactions of the 360X profile and adds some new ones in order to address use-case specific requirements for the transition of care form an acute care facility to a long-term skilled nursing facility (Acute to SNF use case) or from an ambulatory care provider to a long-term skilled nursing facility (Ambulatory to SNF use case).
  + TBD
  + TI published December 2020
* **CDA Occupational Data Options**
  + Current IHE Summary profiles do not specify capture occupational data for health in a structured manner in support of patient care. This supplement specifies an option for the IHE summary profile documents to enable conformance testing and option support claims for occupational data interoperability. This document will specify an option for summary documents to communicate detailed occupational data for health.
  + <https://www.ihe.net/uploadedFiles/Documents/PCC/IHE_PCC_Suppl_ODH_Options.pdf>
  + TI Published August 2020
* **CDA Document Summary Sections (CDA-DSS)**
  + The CDA document summary sections can be created by summarizing pertinent information. The data that goes in the summary sections can be user defined or can be based on specified use cases provided by the profile. The CDA document summary sections can be rendered for viewing. Content in some CDA document summary sections can be imported when possible (i.e., contains discrete entries) by the consuming system if desired.
  + <https://www.ihe.net/uploadedFiles/Documents/PCC/IHE_PCC_Suppl_CDA_DSS.pdf>
  + TI Published September 2019

**Revised Profiles/Supplements:**

* **CDA Content Modules Supplement - Revised**
  + Revised regularly as expected
  + <https://www.ihe.net/uploadedFiles/Documents/PCC/IHE_PCC_Suppl_CDA_Content_Modules.pdf>
  + Published
* **Assessment Curation and Data Collection (ACDC) – Revised**
  + Enables assessment developers and curators a means by which they can distribute assessment instruments to healthcare providers, supporting exchange of assessment data in a standardized form using the HL7 FHIR Questionnaire resource. It provides the opportunity for provider organizations to choose from an variety of instruments yet integrate them using a common interface.
  + <https://www.ihe.net/uploadedFiles/Documents/PCC/IHE_PCC_Suppl_ACDC.pdf>
  + TI Published March 2020
* **Query for Existing Data Mobile (QEDm) – Revised**
  + Supports dynamic queries for clinical data elements, including observations, allergy and intolerances, problems, diagnostic results, medications, immunizations, procedures, encounters and provenance by making the information widely available to other systems within and across enterprises to support provision of better clinical care. It defines a transaction used to query a list of specific data elements, persisted as FHIR resources.
  + <https://www.ihe.net/uploadedFiles/Documents/PCC/IHE_PCC_Suppl_QEDm.pdf>
  + TI Published July 2020
* **Dynamic Care Planning (DCP) – Revised**
  + Provides the structures and transactions for care planning, creating, updating and sharing Care Plans that meet the needs of many, such as providers, patients and payers. Care Plans can be dynamically updated as the patient interacts with the healthcare system. FHIR® resources and transactions are used by this profile. This profile does not define, nor assume, a single Care Plan for a patient.
  + <https://www.ihe.net/uploadedFiles/Documents/PCC/IHE_PCC_Suppl_DCP.pdf>
  + TI Published September 2019
* **Dynamic Care Team Management (DCTM) – Revised**
  + Provides the structures and transactions for care team management and sharing information about Care Teams that meet the needs of many, such as providers, patients and payers. Care Teams can be dynamically updated as the patient interacts with the healthcare system. A patient and providers may be associated with multiple types of care teams at any given time. This profile depicts how information about multiple care teams can be shared and used to coordinate care. The care team concepts described in this profile are patient centered with the overarching goal to support collaborative care. Care teams have many different meanings to many different people.
  + <https://www.ihe.net/uploadedFiles/Documents/PCC/IHE_PCC_Suppl_DCTM.pdf>
  + TI Published December 2019

**Trends:**

* The US ONC Interoperability Standards Advisory continues to reference various IHE PCC profiles
* The IPS work taken on this year resulted in cross collaboration with both HL7 and CEN reflecting broad interest in continued harmonization of CCDA and FHIR templates across SDOs.
* The US government published the USCDI which has impact on the IHE PCC domain work. The USCDI is moving to an annual update cycle, PCC has an opportunity to evaluate use cases against USCDI and identify opportunities of support. Keeping PCC profiles aligned (where possible) may result in additional reference to PCC profiles from US regulation.
* IHE has published a total of 33 (previously 25) Profiles using **FHIR** across 5 (previously 4) domains**. PCC owns 11 (previously 9) or 33% (previously 36%) of these Profiles**. One of these profiles is deprecated (revised numbers are 10 profiles/30%). This represents significant involvement and leadership in the usage of FHIR within IHE. In addition, PCC domain members regularly participate in the [IHE FHIR Work Group](https://wiki.ihe.net/index.php/IHE_FHIR_Work_Group), and [IHE committees collectively maintain a list of IHE Profiles that leverage FHIR](https://wiki.ihe.net/index.php/Category:FHIR). [HL7 maintains a list as well](https://wiki.hl7.org/index.php?title=FHIR_Profiles_from_other_Organizations), but their list is no longer maintained and is currently out of date.
* PCC has published **three** **National Extensions**: The DAF Document Metadata Based Access Implementation Guidance, 360 Exchange Closed Loop Referral (360X), and 360 Exchange Closed Loop Acute Care to SNF (360XL). All of these National Extensions have been published under IHE USA with assistance from the US ONC. Further profiling and constraining of PCC Profiles for use in National Extension work is something that has become a trend in PCC and we should continue to align with opportunities to create additional National Extension work.
* PCC continues its focus on issues that cross patients, providers, or time; building content, integration, and workflow profiles. Many of the smaller interoperability building blocks have been created in the form of Profiles across various IHE domains over the years, and PCC continues to focus on assembling those building blocks into clinical workflows, and harmonizing across content boundaries to provide guidance in healthcare IT interoperability.
* PCC has **worked jointly with many IHE domains** over the past several years to develop Profiles. These domains include Cardiology (CARD), Radiology (RAD), Devices, Quality, Research, and Public Health (QRPH), and IT Infrastructure (ITI).
* Several profiles have been developed in **PCC that focus on Nursing use cases**. This work has been completed under the Nursing Subcommittee that was formalized in 2008. Due to lack of activity the Nursing Subcommittee has been subsumed back into the main PCC planning and technical committee groups.
* PCC work has consistently slowed over the past several years, leading to a committee decision to collapse the planning and technical committees into a single committee to conserve resource usage. The plan is to revisit participation numbers regularly and ramp back up operations as needed. A formally documented plan was written up.

**Summary of Future Plans:**

* The following strategic goals are reviewed periodically by PCC and adjusted as needed based on stakeholder and committee member input to ensure the focus of PCC remains relevant to industry needs. The current strategic goals continue to focus on Workflow and Content.
  + **Workflow**
    - Develop new profiles by reaching out toward other IHE domains to coordinate workflows across care paths.
    - Develop white papers by researching new areas that could benefit from standards-based interoperability guidance.
  + **Content**
    - Coordinate with external standards development organizations (SDOs) to develop and promote the use of content templates that leverage standards such as CDA and FHIR.
    - Develop strategies to support multi-level content template guidance to benefit the global community.
* PCC will continue to coordinate with the QRPH domain regarding joint use of several PCC Section and Entry templates in support of their use in QRPH Profiles, in interest of maximizing the opportunity to re-use templates common to both domains.
* PCC will continue to engage with the ONC ISA to submit Profiles for consideration where appropriate.
* PCC will pursue opportunities to align with the USCDI work where it makes sense to do so, ensuring that any work undertaken provides adequate benefit to the international community.
* PCC is interested in contributing to ideas around joint opportunities with IHE deployment domains, and possibly the board to gather more information about deployed IHE profiles across the globe.