Advance Directive Information (ADI) Interoperability w/FHIR

PACIO Community Facilitator
Patient Empowerment Sponsor
Advance Directive Interoperability (ADI)

Project Need

• Systems used to create and update patient-generated advance care plans through a patient-directed process need a way for individuals to communicate information about their advance medical care goals, preferences, and priorities.

• Individuals need a way to generate and update information related to their advance directives so that their current wishes can inform provider-generated care plans.

• Interoperable exchange of the advance directive information supports more effective sharing of advance directive information across transitions in care and enables practitioners to create person-centered care plans that align with a patient’s values, goals of care, treatment preferences, and quality of life priorities when a patient cannot communicate for themselves.
ADL External Drivers

• The aging population receiving healthcare in skilled nursing facilities and assisted living communities have been under forced isolation to reduce the risk of contracting COVID-19.

• During COVID as well, those requiring medical care have found themselves during a transition of care without anyone to accompany them to influence medical care or be at their side.

• The impact is a sense of disempowerment, isolation, and a disconnection with the world they can no longer safely interact freely with.

• Never before has the availability of verifiable digital advance directive information been so essential to delivering care.

• The role of technology and expanded adoption by the aging population, providers, and care teams has brought to the forefront the expectation of seamless accessibility of advance directive information.

• An additional factor is an increased understanding that a person’s goals, preferences, and priorities for care are a critical element in a person-centered healthcare system.
ADl Project Scope

• This project will create FHIR implementation guidance for Advance Directives Interoperability (ADI).

• The Post-Acute Care Interoperability (PACIO) Community has a strong interest in the topic of advance directives and will support the community engagement and technical FHIR IG development needed for ADI. ADI is a complex area that involves many stakeholders. MITRE, CMS, ONC and many other stakeholders (both clinical and technical) comprise the PACIO Community.

• This project will develop FHIR profiles for several existing FHIR resources to represent advance directive content such as: living will, durable medical power of attorney, personal health goals at end of life, care experience preferences, patient instructions (obligation, prohibitions, and consent), and portable medical orders for life-sustaining treatments.

• The FHIR IG will cover the use of RESTful API interactions for query, retrieve and verification of advance directive information between systems.

• The guidance will be consistent with FHIR US Core IG and will build upon existing standards such as: HL7 CDA® R2 Implementation Guide: Personal Advance Care Plan (PACP) Document, Release 1 - US Realm STU Release 2 August 2020 and HL7 CDA® R2 Implementation Guide: C-CDA R2.1: Advance Directives Templates, Release 1 - US Realm

  • PACP http://www.hl7.org/implement/standards/product_brief.cfm?product_id=434
Project Proposal: PSS-1664

• Project Proposal
  • Accepted on October 8th

https://jira.hl7.org/browse/PSS-1664
Project Scope Statement

• Project Sponsor: Accepted
  • Patient Empowerment (10/1)

• Project Co Sponsors:
  • Community-Based Care and Privacy: (10/6) - monthly updates (1/27/21 Q2 Time Block)
  • Patient Care (10/7) – Updates at the Care Plan WG meetings and upon request (1/27/21 Q2 Time Block)
  • Orders and Observations (10/8) - Updates based on progress and focus and particularly during design and as part of O&O calls (Q1 WGM; 1/27/21 Q2 Time Block)

• PMO – Received October 9, 2020

• US Realm (10/27) and FHIR Management Group (10/28) voted to approve the PSS
  • US Realm would like the ADI FHIR IG to work with Structured Doc to ensure that the previous work related to CCDA is incorporated into the FHIR IG work.

• Administrative Steering Division Approval (12/15)

• TSC e-vote and approval 12/21

“The objective of the Project Scope Statement (PSS) is to communicate the type of activities a group is undertaking to achieve specific objectives or to produce specific work products.”

https://confluence.hl7.org/display/PC/PACIO+Project+Advance+Directive+Information+Interoperability+in+FHIR
Advance Directive Interoperability (ADI) FHIR IG Use Case Overview

Use Cases

- Use Case 1: Create and Share/Make Available [Content]
- Use Case 2: Update and Share/Make Available [Content]
- Use Case 3: Request and Access [Content]
- Use Case 4: Verify Current Version of [Content]

Initial Focus Area for STU1 IG

Content

- Advance Directive Information (person-sourced information)
- Episodic Patient Instruction (person-sourced, practitioner-documented information)
- Portable Medical Order for Life-Sustaining Treatments (practitioner-sourced information)
<table>
<thead>
<tr>
<th>Use Case 1: Create and Share/Make Available [Content]</th>
</tr>
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<tbody>
<tr>
<td>Use Case 1a: Create and Share/Make Available Advance Directive Information</td>
</tr>
<tr>
<td>Use Case 1b: Create and Share/Make Available Episodic Patient Instruction</td>
</tr>
<tr>
<td>Use Case 1c: Create and Share/Make Available Advance Portable Medical Order for Life-Sustaining Treatments</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Use Case 2: Update and Share/Make Available [Content]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use Case 2a: Update and Share/Make Available Advance Directive Information</td>
</tr>
<tr>
<td>Use Case 2b: Update and Share/Make Available Episodic Patient Instruction</td>
</tr>
<tr>
<td>Use Case 2c: Update and Share/Make Available Advance Portable Medical Order for Life-Sustaining Treatments</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Use Case 3: Request and Access [Content]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use Case 3a: Request and Access Advance Directive Information</td>
</tr>
<tr>
<td>Use Case 3b: Request and Access Episodic Patient Instruction</td>
</tr>
<tr>
<td>Use Case 3c: Request and Access Advance Portable Medical Order for Life-Sustaining Treatments</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Use Case 4: Verify Current Version of [Content]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use Case 4a: Verify Current Version of Advance Directive Information</td>
</tr>
<tr>
<td>Use Case 4b: Verify Current Version of Episodic Patient Instruction</td>
</tr>
<tr>
<td>Use Case 4c: Verify Current Version of Advance Portable Medical Order for Life-Sustaining Treatments</td>
</tr>
</tbody>
</table>

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Break the Glass (Emergency)
Environmental Scan of Content Types to Represent in the ADI on FHIR IG

• Environmental Scan to Include:
  • Existing Paper-Based Advance Directive Information, Episodic Patient Instructions, Portable Medical Orders for Life-Sustaining Treatment
    • Advance Directive Questions/Answers
    • Personal Advance Care Plan Questions/Answers
    • EPI Questions/Answers
    • PMOLST Questions/Answers
  • Existing VSAC Value Sets (to Identify Harmonization Opportunities)
  • Existing Document Types
  • Existing CDA/C-CDA Header Data Elements
• FHIR Audit Event to Track Document Views
• Use Cases to Apply Environmental Scan Results to:
  • Use Case #1/Content Type #1 fit to Existing Standards, Identify Gaps
  • Use Case #2/Content Type #1 fit to Existing Standards, Identify Gaps
  • Use Case #3/Content Type #1 fit to Existing Standards, Identify Gaps
  • Use Case #4/Content Type #1 fit to Existing Standards, Identify Gaps
Create and Share/Make Available (rev 1)

1a: Create and Share/Make Available Advance Directive Information

Angie has Sickle Cell Disease
She worries that if she contracts COVID-19 and becomes unable to communicate with medical personnel, they won’t be familiar with her history and specific treatment needs.

Create
She uses a consumer-facing tool to create a digital advance directive or upload a scanned copy of her paper advance directive document

Her interoperable digital advance directive information is stored in a registry/repository/HIE/QHIN/EHR

Share/Make Available
Angie makes her advance directive information available to her durable medical power of attorney and primary care physician so if either are contacted by a treating provider in an emergency they can make her ACI available, to inform treatment

Reluctance to allow paper advance directive documents due to infection risk – ineligible as a source of information

Restrictions on Non-Patient Visitors Prohibits Healthcare Agent Presence to Communicate on Her Behalf
Advance Directive Information Parking Lot

• How to account for cognitive status of the person to change during the episode of care?
  • The cognitive status of the person filling out the form needs to be taken into account. Would we document it or pull data in to inform that status?

• Should the End Date on an Adv Dir be blank until replaced/altered?

• Should the End Date of existing ADI be enforced or at least be reviewed to prevent mis-matches?

• How to delete/inactivate ADI when updates are made?
  • Idea: A document id that allows the “current” document to be retrieved if more than one of that type exists for a single individual

• How to incorporate artificial nutrition and hydration preferences into ADI?
  • A Dietician note standard exists under 80791-7; is there a provision for a patient-authored statement of dietary preferences (providing, withholding, withdrawing) as relates to ADI?

• How to incorporate existing legal standards pertaining to ADI instead of building a new set of rules?
  • Current State Gap:
    • Legal and clinical perspectives/needs may differ
    • Even with clear legal designations for how to prioritize the documents, the existence and prioritization of ADI documents isn’t communicated to the providers that render care
  • Goal: To create a framework that is accessible to all who interact with the patient

• Could aspects of blockchain be modeled and incorporate into ADI exchange?
Advance Directive Information Parking Lot Cont’d:

- Is there a place we can collaborate on this work?
- Identify a shared space and documents we can capture collaboration and input
- State forms and PACPs in use to analyze and investigate
- In terms of the process and approach, will we start by comparing form to form or by content area within each form?
  - Lisa Nelson: When the CDA/C-CDA standards for this information were built, they gathered all the forms they wanted to evaluate, reviewed them and selected one as a good starting place to build from
  - Each subsequent form analysis was in relation to the starting place, so equal/less/more was able to be rated against the baseline form
  - Each attendee was asked to find a good baseline form to bring to next week’s meeting to present as the baseline we’ll work from
Steven is a 34 year old man who has had Cystic Fibrosis all his life. He created his advance directive a few years ago when his condition sharply worsened. He is eligible for a lung transplant due to his age and disease state.

His advance directive states that he wants no life-sustaining treatment if he has a health crisis that warrants those measures, and is unable to communicate for himself.

Steven doesn’t want to be resuscitated only to wait for a lung transplant that may never happen.

His episodic patient instructions and associated order is made available to other care settings (outside the clinical record) by being stored in a registry/repository/HIE/QHIN/EHR as a result of integration that exists.

Steven’s episodic patient instructions are recorded in the clinical record as an order/clinical note to enable the entire medical team to have visibility to Steven’s instructions during his surgical procedure.

Steven’s surgeon creates an episodic patient instruction order, based on Steven’s instruction that he wants to receive life-sustaining treatment during the current episode of care. Steven feels he has a chance at a longer life with a new lung that he hasn’t been able to consider until now.

Steven gets the call one night that he has been matched to a donor and goes immediately to the hospital for his lung transplant.

The surgeon meets with Steven prior to the procedure and asks him if he has any specific instructions related to the transplant, should a situation arise during surgery that requires life-sustaining treatment decisions be made.
Episodic Patient Instruction (EPI) Parking Lot

• Does it make sense to digitally trap the patient’s instructions, from which the EPI by the surgeon is created, or is verbal current/standard process?

• Should the EPI be time-boxed?
  • Logically the patient instruction related to an episode of care would have a start/end date.
  • Requiring an End Date isn’t always possible because you don’t know when the current episode will end.
  • Does the end of the Episode = the End Date of the EPI?

• What happens when it conflicts with a previously issued advance directive?
  • EPI creation is just intended to just cover a surgery or episode of care.
  • Should the existing ADI be reviewed when an EPI is issued?
  • Would the EPI potentially temporarily replace the Adv Dir, and what does that chain of events look like if enforcement were to be designed?
  • The patient may not understand the relationship between an EPI and ADI, so how can we ensure consistency of decisions across forms/documents?
  • Inconsistency between EPI and ADI forms will lead to confusion about how to care for patient OR between care setting standards that favor 1 form over another.
Frank is a 78 year old man who has end stage kidney disease and receives dialysis 3x per week. He receives long-term supportive services in his home. Frank is cognitively intact.

Frank suffers from a chronic health condition that has resulted in a limited life-expectancy of 6-12 months. He creates an advance directive with his caregiver. Frank does not want to have life-sustaining treatment rendered if his condition warrants those measures, if he is unable to communicate for himself.

Frank’s condition worsens sharply one day and he is taken by ambulance to the nearest hospital for treatment. Frank tells the ER physician about his advance directive and the physician writes a DNR order, valid for that hospitalization only, to Frank’s medical record.

Frank is transferred to a skilled nursing facility for post-acute care. The practitioner overseeing his care in the SNF meets with Frank to discuss his goals of care, his hospital DNR, and review his advance directive with him. He recommends creation of a portable medical order for life-sustaining treatment to align with Frank’s desire to prevent an unwanted hospital transfer.

One evening Frank sustains a significant change in condition that renders him unconscious. The SNF care team reviews his portable medical order for life-sustaining treatment document to find he doesn’t want to receive life-sustaining treatment. They call 911 in accordance with facility policy. Emergency access to Frank’s ADI is granted, and the EMS personnel render comfort measures in concordance with his wishes.

The facility’s medical record is integrated to the broader healthcare eco-system which accessed Frank’s advance directive, and now enables his portable medical order for life-sustaining treatment document to be available in a registry/repository/HIE/QHIN so as to inform treatment during a transition of care.

The practitioner ensures the portable medical order for life-sustaining treatment document is added to Frank’s SNF medical record so it is accessible by facility staff in case of emergency. Frank also receives a copy of this new document, which he places in his bedside table.
Portable Medical Order for Life-Sustaining Treatment Parking Lot

- Current State: Portable today = Paper
- In a hospital setting, the neurologist or ICU Attending might complete the P-OLST (in our story)
  - A DNR is customary, with variations such as DNR Full, DNR Partial, No DNR
  - It is typically valid for that stay ONLY
- In a SNF setting:
  - SNFs require an on-staff practitioner care for their residents
  - SNFs will sometimes allow an outside MD (PCP) in to care for their patient, but only as a courtesy
  - The on-staff practitioner must sign a P-OLST for a resident, likely in response to liability concerns
- Goal: To standardize how the order is shared OUTSIDE the EMR, not how it is stored/shared INSIDE the EMR
  - Legal and accessibility barriers also must be considered
  - Care setting preferences can impact which form is completed and how it informs care
- POLST documents vary by state, but the proposed National form could serve as a base to identify the core data elements and additional state-specific variations could be added as optional data elements.
- Some states (e.g., California), request renewal and confirmation of the POLST every 90 days
  - The Council for Compassionate Care in CA has had POLST in the law since 2009
  - How would this requirement be satisfied in a home setting?
Creating a FHIR IG

• **Narrative Parts** Influence the Human
  • Guidance Section
  • Data Elements to FHIR Profiles to FHIR Resources that Contains Them

• **Machine Processable Parts** Influence How the Data is Processed

• [Check the US Core IG 3.2.0 Ballot for a sample template](#)
Basics of CDA/C-CDA and FHIR
CDA Basics

CDA – Clinical Document Architecture is an HL7 v3 document standard. This standard specifies the structure and semantics of “clinical documents” for the purpose of exchange with other providers. One of the documents within this architecture is the CCD.

```xml
<component>
  <section>
    <code code='10157-6' codeSystem='2.16.840.1.113883.6.1'/>
    <!-- This code references « history of family member diseases » -->
    <title>Family History</title>
    <text>
      <table border='1'>
        <thead>
          <tr>
            <th>Family Member</th>
            <th>Problem</th>
            <th>Cause of Death?</th>
          </tr>
        </thead>
        <tbody>
          <tr>
            <td>Father</td>
            <td>Myocardial Infarction</td>
            <td>Yes</td>
          </tr>
        </tbody>
      </table>
    </text>
  </section>
</component>
```
CDA Basics Continued

CCD – Continuity of Care Documents and Continuity of Care Records (CCR) are standard formats for exchanging key clinical information.

A CCD was NOT intended to be a complete medical history or chart for a given patient/resident. It is a snapshot of information that is broken across 17 sections intended to ONLY be the information critical to effectively continue care in the current setting or during transitions of care, specifically in the context of a patient being transferred from one care setting to another.
CDA Templates as Building Blocks of Data

The consolidated library of reusable Clinical Document Architecture (CDA) templates and common document types for C-CDA R1.0/R1.1 include:

- Consultation Note
- Continuity of Care Document (CCD)
- Diagnostic Imaging Report
- Discharge Summary
- History and Physical
- Operative Note
- Procedure Note
- Progress Note
- Unstructured Document

New as of C-CDA R2.0/R2.1:
- Care Plan
- Referral Note
- Transfer Summary

These same building blocks can then be reused in other CDA document types, facilitating interoperability across a wide range of clinical uses and settings.
The 70 Document Sections in C-CDA R2.1

Example Templates

Transfer Summary

**REQUIRED:**
- Allergies & Intolerances
- Assessment
- Medications
- Problem
- Reason for Referral
- Results
- Vital Signs

**OPTIONAL:**
- Admission Diagnosis
- Admission Meds
- Advance Directive
- Assessment & Plan
- Course of Care
- Discharge Diagnosis
- Encounters
- Family History
- Functional Status
- General Status
- History Past Illness
- History Present Illness
- Immunizations
- Mental Status
- Medical Equipment
- Mental Status
- Nutrition
- Payers
- Physical Exam
- Procedures
- Review of Systems
- Social History
- Vital Signs

**REQUIRED:**
- Allergies & Intolerances
- Medications
- Problem
- Procedures
- Results
- Social History
- Vital Signs

**OPTIONAL:**
- Advance Directive
- Encounters
- Immunizations
- Family History
- Functional Status
- Medical Equipment
- Mental Status
- Nutrition
- Plan of Treatment

CDA and Data Exchange

C-CDA Provides Semantic Building Blocks!
CDA and FHIR – They Can Be Used Together

• CDA is limited to “clinical” use cases and documents that deal with patients.
• Template IDs are required to support interoperability and are required to understand the meaning of instances.
• Requires coded data for Problems, Results, Medications, etc.
• Traditionally a read-only medium.
• Can be challenging to implement.

• FHIR documents have no limitation on their content and can have subjects other than patients.
• FHIR content references existing resources.
• FHIR represents common structures only one way, allowing for less deviation.
• Uses a “required if known” approach, so work-arounds for null are not needed.
• Allows developers to interact with the resources by creating, reading, updating, and deleting them.
• Fast and easy to implement.
### FHIR Resources Anticipated for Use to Represent Advance Directives

<table>
<thead>
<tr>
<th>Health Concerns</th>
<th>Condition (Health Concern)</th>
<th>Goals</th>
<th>Interventions</th>
<th>Observation</th>
<th>Care Plans</th>
<th>Contracts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Status &amp; Outcomes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- **Advise Directives**
  - Goals at End of Life, Care Experience Preferences
  - Intervention Preferences, Instructions
  - Health Statuses that are a Precondition for certain choices
  - Obligations, Prohibitions

- **Care Plan at a point in time**

- **Care Team**
  - DNR Orders
  - Medical/Physician Orders for Life Sustaining Treatment

- **Contracts**
  - Portable Medical/Physician Orders for Life Sustaining Treatment

- **Medical Orders**

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**No New FHIR Resources are needed**
ADI in FHIR Project
Volunteer Request Sent Out Dec. 11, 2020

- AAEM American Academy of Emergency Medicine
- AAHPM American Academy of Hospice and Palliative Care
- ACEP American College of Emergency Physicians
- AHA American Hospital Association
- AHCA American Health Care Association
- AHIMA Long-Term Care Practice Panel
- Altarum Institute
- AMA American Medical Association
- AMDA The Society for Post-Acute and Long-Term Care Medicine
- Apple Health
- ASLME American Society of Law, Medicine, and Ethics
- CAPC Center to Advance Palliative Care
- Carin Alliance
- Carequality
- CommonWell
- CPB Center for Practical Bioethics
- DaVinci Project
- Direct Trust
- eHealth Exchange
- EMS Leadership Academy
- FEHRM Defense Health Agency Federal Electronic Health Record Modernization
- Google Health
- HIMSS LTPAC Committee
- Leading Age
- Mayo Clinic
- MIDEO Institute on Healthcare Directives
- NASL National Association for the Support of Long-Term Care
- National POLST
- NHPCO National Hospice and Palliative Care Organization
- NPCRC National Palliative Care Research Center
- NHDD National Health Decisions Day
- NQF National Quality Forum
- SHIEC Strategic Health Information Exchange Collaborative
- VA Connected Care
- American Academy of Neurology
- American Society of Clinical Oncology
Advance Directive/Personal Advance Care Plan (PACP)
Environmental Scan to Explore/Align w/FHIR

• FHIR IG Profiles to Review for Advance Directive Information (Content Type 1):
  • ADI DocumentReference
  • ADI Header Composition
  • Personal Advance Care Plan Composition
  • ADI Guardian
  • Healthcare Agent (FHIR Consent Resource)
  • Healthcare Agent Authority (FHIR Consent Resource)
  • POLST Observation (FHIR Observation Resource only, not the Content Type 3 focus)
  • Personal Intervention Preference (FHIR Observation->Procedure Resource)
  • Organ Donation Observation (FHIR Observation Resource)
  • Autopsy Observation (FHIR Observation Resource)
  • Personal Priorities Organizer (FHIR List Resource)
  • Care Experience Preference (FHIR Observation Resource)

• FHIR Profiles to be used in the ADI FHIR IG but are defined elsewhere:
  • US Core Patient
  • US Core Practitioner
  • US Core PractitionerRole
  • US Core Organization
  • US Core Goal
  • US Core Encounter
Supporting Information About the Project and PACIO Community
Project Proposal and Project Scope Statement

• Project Proposal:
  https://jira.hl7.org/browse/PSS-1664

• Project Scope Statement:
  https://confluence.hl7.org/display/PE/PACIO+Project%3A+PSS+for+Advance+Directives
Patient Empowerment as a Sponsoring WG

Patient Empowerment Mission:

The Patient Empowerment Work Group promotes and amplifies the viewpoint of patients and their caregivers in HL7’s standards work, in support of the HL7 mission.

Patient Empowerment Vision:

In the past decade, the culture of medicine has begun to recognize that healthcare value is measured by the person getting care: the consumer, the patient, and the family. The recipients of care inevitably have a different perspective than those creating and working in the healthcare system, and that perspective needs to be included by direct participation of patients and caregivers in the standards process.
The Post Acute Care Interoperability (PACIO) Project is a collaborative effort between industry, government and other stakeholders, with the goal of establishing a framework for the development of a Fast Healthcare Interoperability Resource (FHIR) technical implementation guide(s) and Reference Implementations to facilitate health information exchange.
PACIO Use Cases

Existing PACIO use cases exchange patient data as a patient transitions through multiple care settings:

- Home and community-based services
- Acute care
- Post-acute care
- Patient/family access to healthcare.

• PACIO Leadership
  • CMS: Lorraine Wickiser
  • ONC: Elizabeth (Liz) Palena-Hall
  • MITRE: Dave Hill, Jessica Skopac, Tina Wilkins, Siama Rizvi, Sean Mahoney

• More details at [https://confluence.hl7.org/display/PC/PACIO+Project+Use+Cases](https://confluence.hl7.org/display/PC/PACIO+Project+Use+Cases)
PACIO Community

- Broad community outreach (Clinical, Industry, Technical)
- Deep FHIR Development capabilities
- FHIR Connectathon testing commitments
- Ballot Reconciliation commitments
- Ongoing terminology maintenance commitments
- Drive community adoption
How to Join the PACIO Community

Membership in the project is open to any participant willing to commit to the roles and responsibilities identified by the working group to support the overall success of the initiative. Contributions may include, but are not limited to:

• Knowledge of the subject matter
• Scalability of implementing the eventual solution
• Willingness to assist in the delivery of key outputs and working group artifacts
• Developing a testing framework for reference implementations
• Testing

Join the PACIO Project by reaching out to info@PACIOproject.org