Welcome to bit.ly/hl7patients - HL7’s Patient Empowerment Workgroup

A 2021 HL7 Gold Star workgroup

New to HL7 or our workgroup? See our Welcome Newcomers page with orientation video

Mission

Approved Jan 30, 2020

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.

Charter

Approved Feb 20, 2020

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.

Work Products and Contributions to HL7 Processes

This group participates in standards work with specific focus on the patient perspective. We do this by:

1. Providing and promoting an entry point and focal point for patients, caregivers and advocates interested in participating in the HL7 standards work. Examples include:
   • Conducting outreach activities with patients and patient advocacy groups to promote understanding, adoption, and ensure participation in the development of standards.
   • Producing education materials and providing community support and mentoring for patient and caregiver voices who participate in HL7 activities.

2. Ensuring that appropriate impacts on patients, both positive and negative, are a consideration of the standards work and are appropriately documented as part of all relevant HL7 standards. Examples include:
   • Curating a broad range of patient-centric stories, scenarios, personas, use cases, and data element definitions.
   • Domain modeling that takes the patient perspective into consideration.
   • Assisting in the standards development process by providing patient subject matter expertise regarding both needs and impacts.
   • Patient centric guidelines for standards developers and implementers

3. Defining, assisting and/or coordinating standards and implementation guides. Examples include:
   • Drive the development of standards to enable patient-facing applications to provide feedback concerning errors in the patient’s record
   • Defining best practices regarding patient-generated health data (PGHD) and patient-reported outcomes (PROs) (including, but not limited to, health concerns, device data, notes, questionnaire responses)
   • Creating use cases that depict the point of view and information exchange requirements of patients and caregivers.
   • Providing feedback on interoperability requirements between and among consumer health apps, devices, EHRs, PHRs, aggregator platforms, etc.

Decision Making Practices:


Current priorities

See our Priorities page.

Formal Relationships With Other HL7 Groups
PE has no formal relationships with other HL7 groups, though numerous are anticipated.

Formal Relationships With Groups Outside of HL7

PE has no formal relationships with groups outside of HL7.