Open@Epic CONFERENCE 2025

It Takes a Village

The Role of Community Engagement in Effective Standards Creation

Presenter

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Co-Founder and Director of

Terminology, HL7 Gravity Project®

About Us

Open@Epic CONFERENCE 2025

Gravity Project

A collaborative initiative, an HL7 Accelerator, with the goal to develop consensus-driven data standards to support the collection, use, and exchange of data to address the social determinants of health (SDOH).

About Me

Former farmer, current rural family nurse practitioner, long time community organizer, accidental terminologist, standards developer, standards policy advisor.

Learning Objectives

1. Understand the benefit of standards within the goals of healthcare
2. Articulate how representative design is critical for effective standards development
3. Identify paths to engaging in the standards development process
4. Implement what you have learned to come join us…

Agenda

01 How the farmer and rural primary care provider became a standards champion

02 On standards, a primer

03 The role of purposeful design toward representative and effective standards

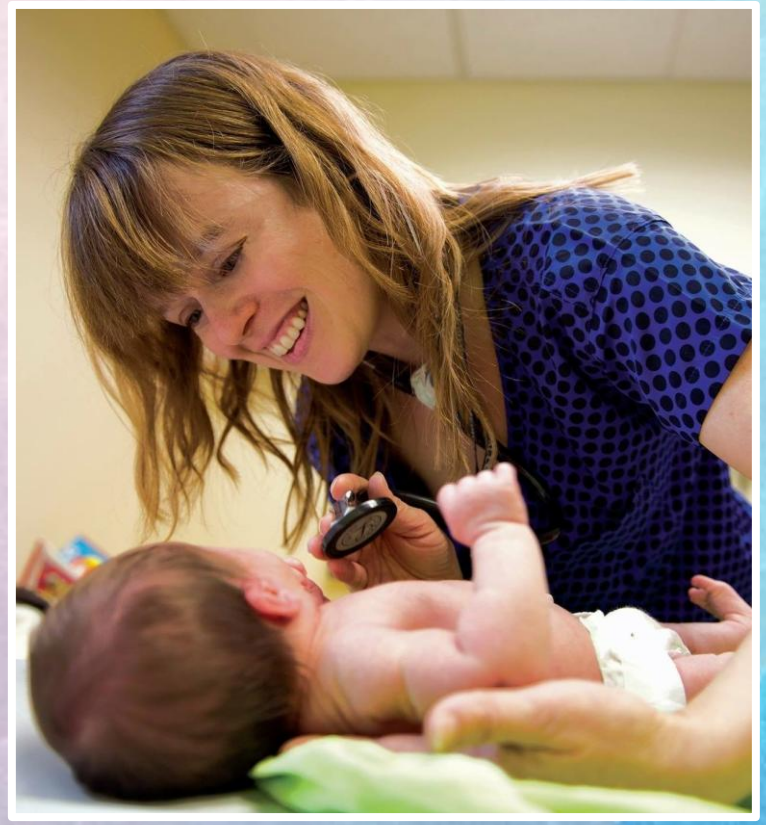
04 How to join the consensus collective

How the Farmer and Rural Primary Care Provider Became a Standards Champion

Our Rural Health and Standards as Access

Professional arc – the path to the **accidental terminologist**

Roles in **standards development**



My Guiding Questions

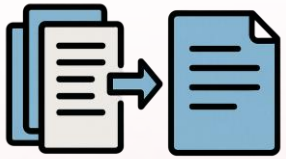
How can we measure **care** as opposed to **clicks**?

How can we build **systems** that feel helpful?

How can we name the **social conditions and interventions** that matter?

How do we **make it easier to do the right thing**?

The Revelation and Purpose



Although healthcare and health data is complex, they **can be simpler**

Nothing comes to **rural healthcare** unless regulations say it must

Patients and communities know the data that matters

Standards are the path forward

On Standards, a Primer

Standard Types: A Focused Primer

Terminology Standards

- Conceptual building blocks
- Address the ability to represent concepts in an unambiguous manner between a sender and receiver of information (a key facet of United States Core Data for Interoperability)
- SNOMED CT, ICD-10-CM, LOINC, RxNorm, etc…

Transport Standards

- Context
- Address the **format** of messages exchanged between computer systems, document architecture, clinical templates, user interface and patient data linkage
- **HL7® FHIR® Standard**

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Standards Purpose

Understanding, efficiency, safety

Ability to represent concepts in an **unambiguous** manner between senders and receivers of information, in **structured** and **consistent** methods, and within **intelligent interoperable** formats that convey concept meaning, purpose, and context…

Sharing critical stories: Intelligible information consistently shared (with consent) between patient care teams, care settings, and care platforms toward health for people, families, and the communities they live within

Purposeful Consensus Design Toward Effective Standards

Our Consensus & Due Process Within Accredited Standards

American National Standards Institute

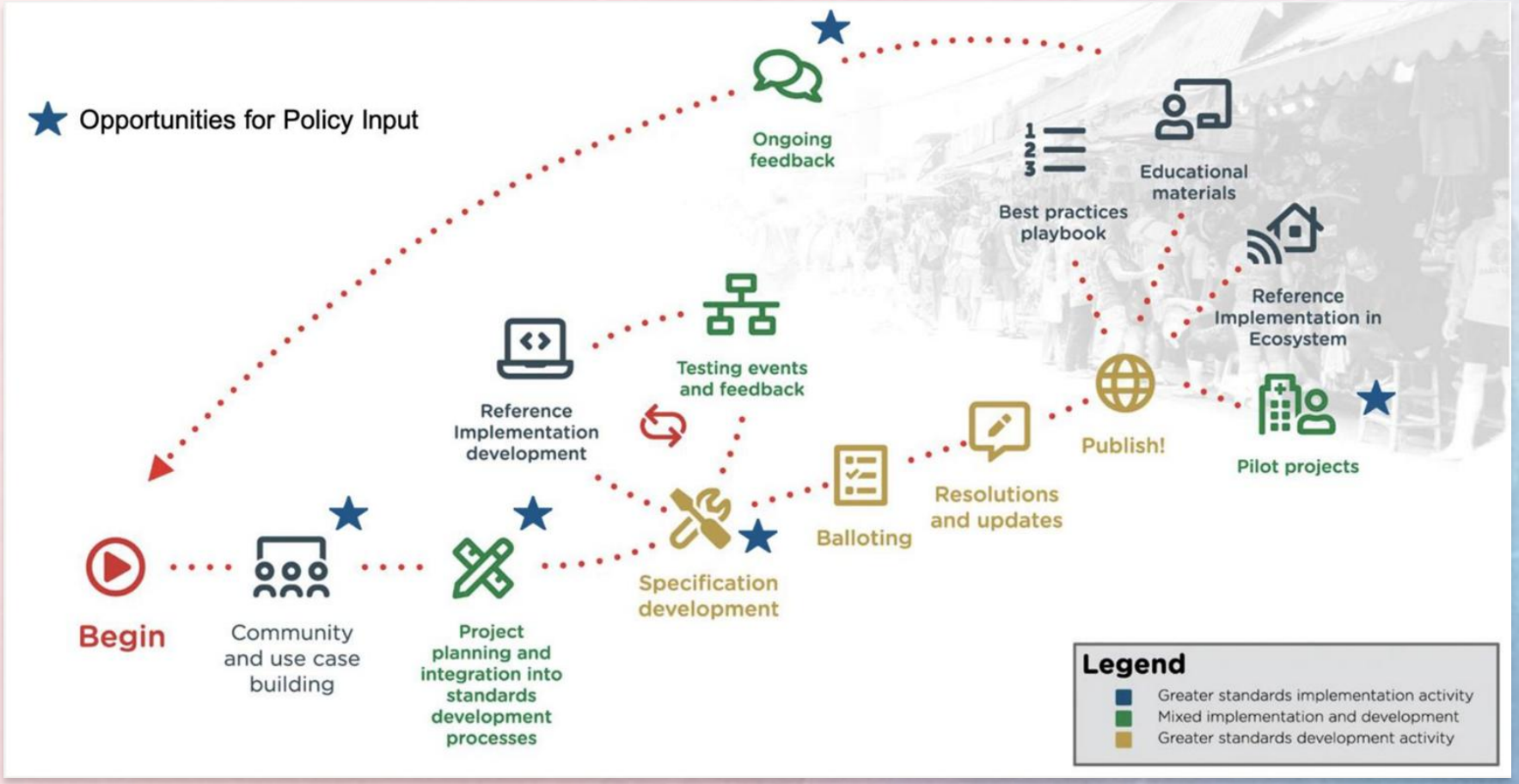
Oversees standards activities within the U.S. and offers the guiding principles woven throughout accredited standards bodies

Consensus: "Substantial agreement has been reached by directly and materially interested parties. This signifies the concurrence of more than a simple majority, but not necessarily unanimity. Consensus requires that all views and objections be considered, and that an effort be made toward their resolution"

Due Process Essential Requirements: (select list) Openness, Lack of Dominance, Balance, Coordination and Harmonization

https://www.ansi.org/american-national-standards/ans-introduction/essential-requirements

Consensus and Due Process Essential Requirements: HL7® FHIR® Standards Development and Implementation



From "FHIR 101 for the Policy Community" @ HL7

Consensus and Due Process Essential Requirements: Terminology Standards Development

Gravity Terminology Curation Process

Well-Established, Rigorous and Efficient

EVIDENCE-BASED → Leveraging literature, and national domain subject matter experts

CONSENSUS-DRIVEN → Centering community perspectives to ensure pragmatism in open HL7-aligned public process

SEMANTICALLY CONSISTENT → Aligned with federal and community social care taxonomies

PRINCIPLED → Grounded in the ethics of Data Justice and Social Justice

Formal 6-Month Cycle

February & August Start

Pre-Work → Identify → End-to-End Review → Consensus Vote → Analyze → Terminology Build → Maintain

Convening Community: Open Consensus-Based Recommendation Development

Submissions to Standard Code Systems

HCPCS · LOINC · ICD-10 · cpt · NIH U.S. National Library of Medicine · SNOMED CT

On Lack of Dominance, and Balance

"It takes a village"

- Fundamentally, to have lack of dominance and balance in outcomes, lack of dominance and balance must be crafted by design
- Within research we call this "purposeful sampling"
- Within community organizing we work through the principles of "not about us without us"
- But regardless, this means consensus not just by who is in the room (convenience)… but crafted to ensure a comprehensive set of perspectives including entities most affected (who are often not at the table)

On Paths to Ensuring Lack of Dominance and Balance

Mini-Gravity Example

- Designated membership in governance
- Supported patient and lived experience expertise (National Health Council standards)
- Intentional focus groups to foster balance and lack of dominance- Social Care Voice Codesign
- Continual outreach and welcoming as a ANSI requirement

On Labor

- Data standards are, fundamentally, communication ~ language
- Any path toward learning a language requires labor, diligence, process, evaluation
- Implementing and continually aligning with standards to facilitate understanding is labor as well- labor of creation, transition, and maintenance
  - With understanding, efficiency, and safety on the flip side

How to Join the Consensus Collective

Start With Your Questions

How can I help make standards reflect my knowledge and perspective?

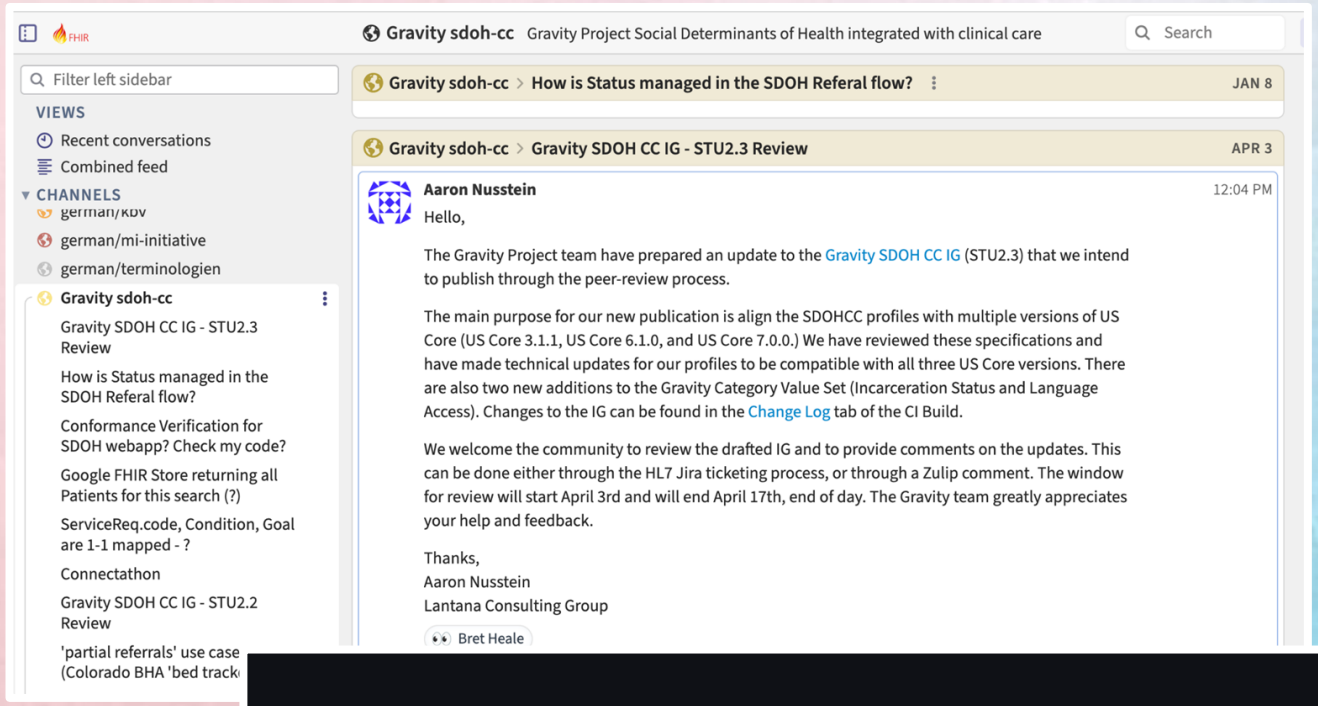
How do I align my platform with standards regulatory requirements?

How do I design solutions for a multitude of use cases (even if I am driven by one)?

How do I get to hang out with all of the fun people within the standards community?

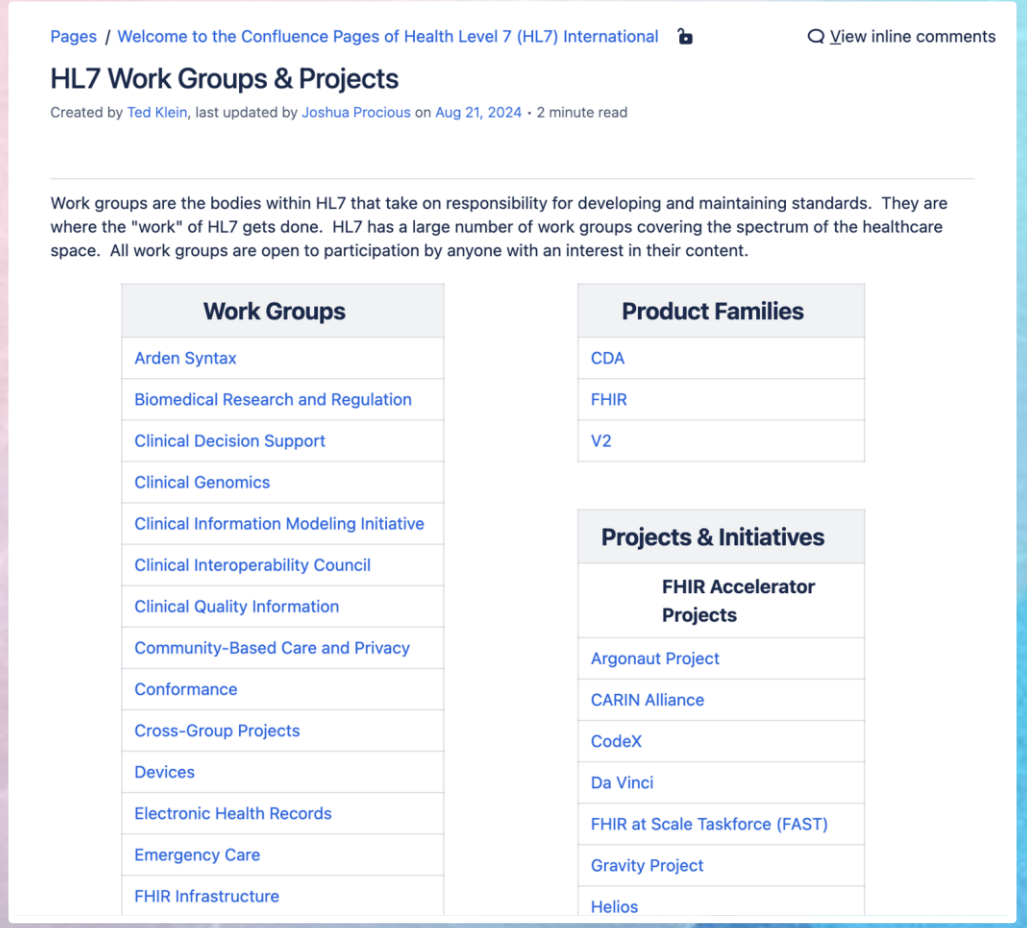
HL7® User Guide: Stage One

- HL7 is a collective of Work Groups, Projects and Initiatives, and Governance Groups
- **New!** AI navigation via navigator.hl7.org
- Accessible participation via chat.fhir.org zulip
  - Ask any question!
  - Review conversations about key topics
- Test **and learn** at a Connectathon!



HL7® User Guide: Stage Two

- Participate in HL7® workgroups and projects
  - WGs and projects can be accessed through the HL7 confluence
  - Most WGs and Projects and Initiatives have open access with calendars and meeting links available on each entity's Confluence page.
  - Browse! Find your people and topics. And please, join us! https://confluence.hl7.org/spaces/HL7/pages/4489802/HL7+Work+Groups+Projects
  - You can also access any scheduled open call on the HL7 conference call calendar https://www.hl7.org/concalls/
- Gravity!



Pages / Welcome to the Confluence Pages of Health Level 7 (HL7) International

View inline comments

HL7 Work Groups & Projects

Created by Ted Klein, last updated by Joshua Procious on Aug 21, 2024 • 2 minute read

Work groups are the bodies within HL7 that take on responsibility for developing and maintaining standards. They are where the "work" of HL7 gets done. HL7 has a large number of work groups covering the spectrum of the healthcare space. All work groups are open to participation by anyone with an interest in their content.

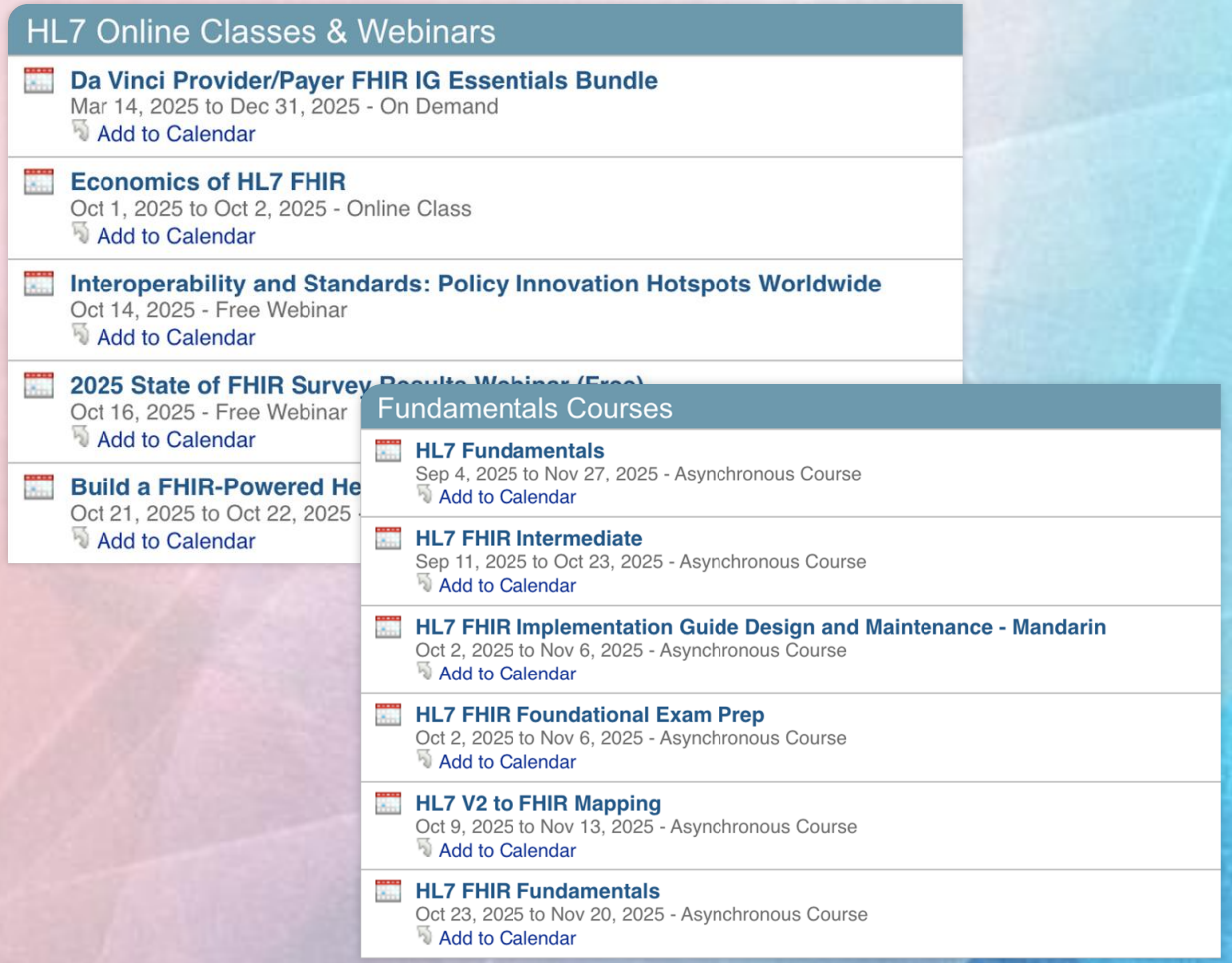
Work Groups
Arden Syntax
Biomedical Research and Regulation
Clinical Decision Support
Clinical Genomics
Clinical Information Modeling Initiative
Clinical Interoperability Council
Clinical Quality Information
Community-Based Care and Privacy
Conformance
Cross-Group Projects
Devices
Electronic Health Records
Emergency Care
FHIR Infrastructure

Product Families
CDA
FHIR
V2

Projects & Initiatives
FHIR Accelerator Projects
Argonaut Project
CARIN Alliance
CodeX
Da Vinci
FHIR at Scale Taskforce (FAST)
Gravity Project
Helios

HL7® User Guide: Education and Training

- HL7®FHIR®Standard Education and Training:
  - Live classes and webinars
  - Asynchronous courses
  - On Demand
  - Working Group Meetings
  - Student Academy



HL7 Education Calendar

Wrapping It All Up

Hopeful Pearls

That standards are our best path to data understanding, efficiency, and safety

That inclusive, representative, purposeful design is a standards development requirement

That this means you are not only welcome, you are *necessary*

And please come join us

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