

Connecting for Health Data Standards Working Group

Standards for transferring data to and from
the personal health record

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MARKLE FOUNDATION
CONNECTING FOR HEALTH
A Public-Private Collaborative

Connecting for Health Vision

Providers, those responsible for population health, and most importantly, consumers will have ready access to timely, relevant, reliable, and secure health care information through an interconnected, electronic health information infrastructure, to drive better health and health care.



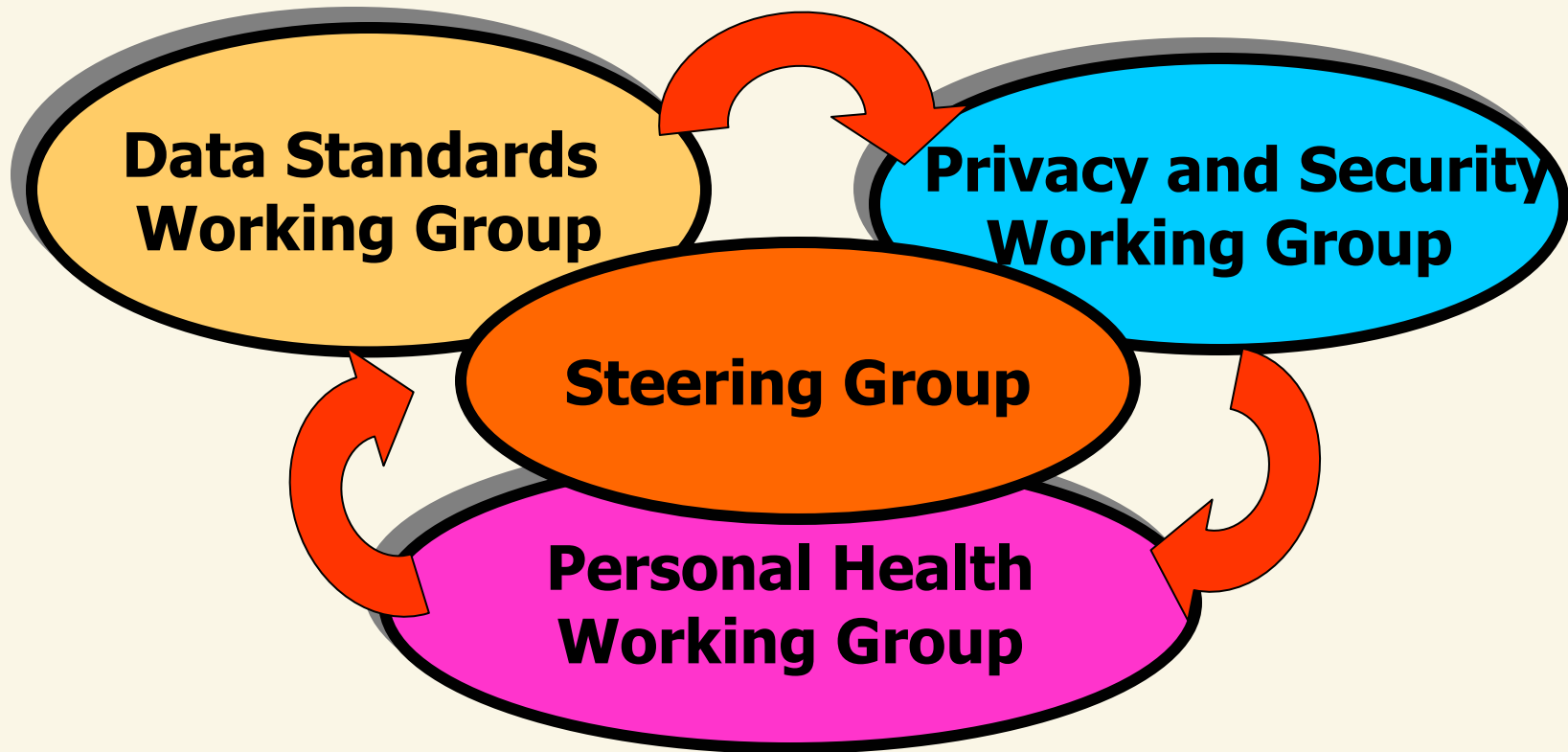
Connecting for Health Purpose

- Three Goals

- Accelerating the rate of adoption of clinical data standards
- Sharing best practices for secure and private transmission of medical information
- Understand what consumers will need and expect from a interconnected, electronic health information infrastructure and identifying key steps for meeting their needs.



Connecting for Health

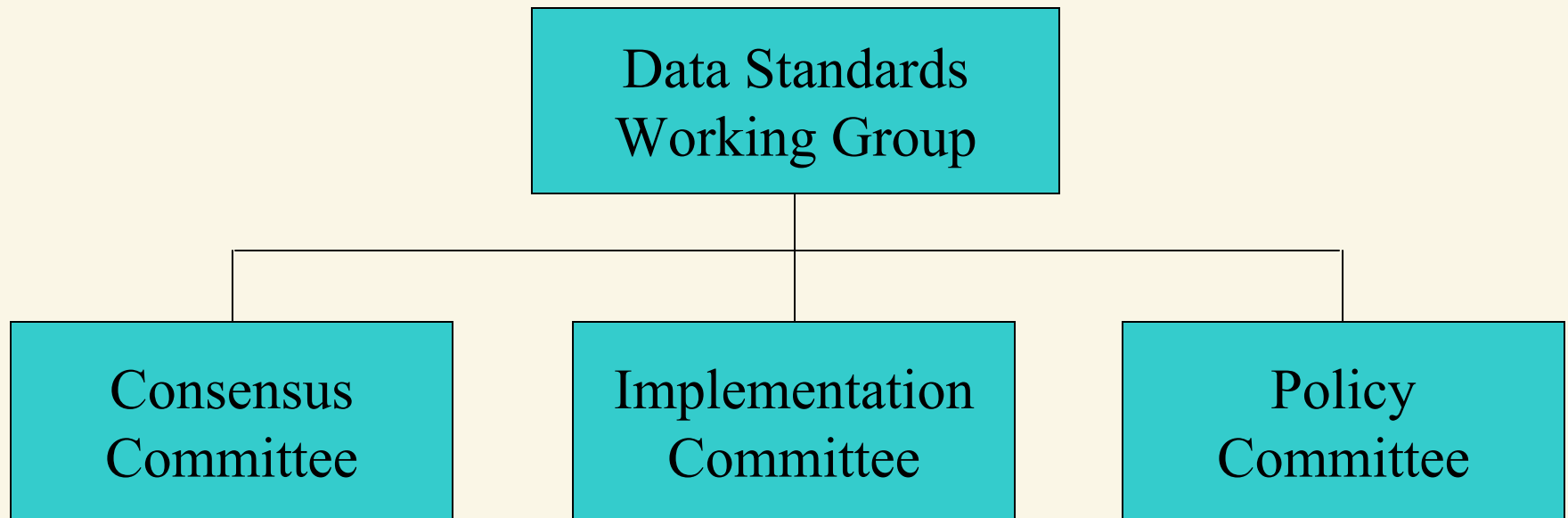


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Data Standards Working Group - Goals

- Identify and cause to be created the necessary standards and definitions to enable the movement of data and knowledge for improving health care
- Accelerate the adoption of data standards

Data Standards Working Group Overview



Issues ...

- DSWG has not specifically focused on standards for the Personal Health Record.
- What is the model for the Personal Health Record and what does its interaction with the EHR look like?
- What additional work must be done to meet the needs of the Personal Health Record?

Standards Assessment Matrix

Standard Type	Balloted	Vendor +	User +
RIM	yes	yes	yes
Data Types	yes	yes	yes
Terminology	in progress	in progress	in progress
Clinical Documents	yes	yes	yes
Clinical Templates	no	no	no
Data Interchange	yes	yes	yes

Standards Assessment Matrix

Standard Type	Balloted	Vendor +	User +
Implementation Manual	yes	yes	yes
Business rules	no	no	no
Decision support rules	yes	some	some
Identifiers	yes/no	yes/no	yes/no
Tool Sets	n/a	yes	yes
Guidelines	some	some	some

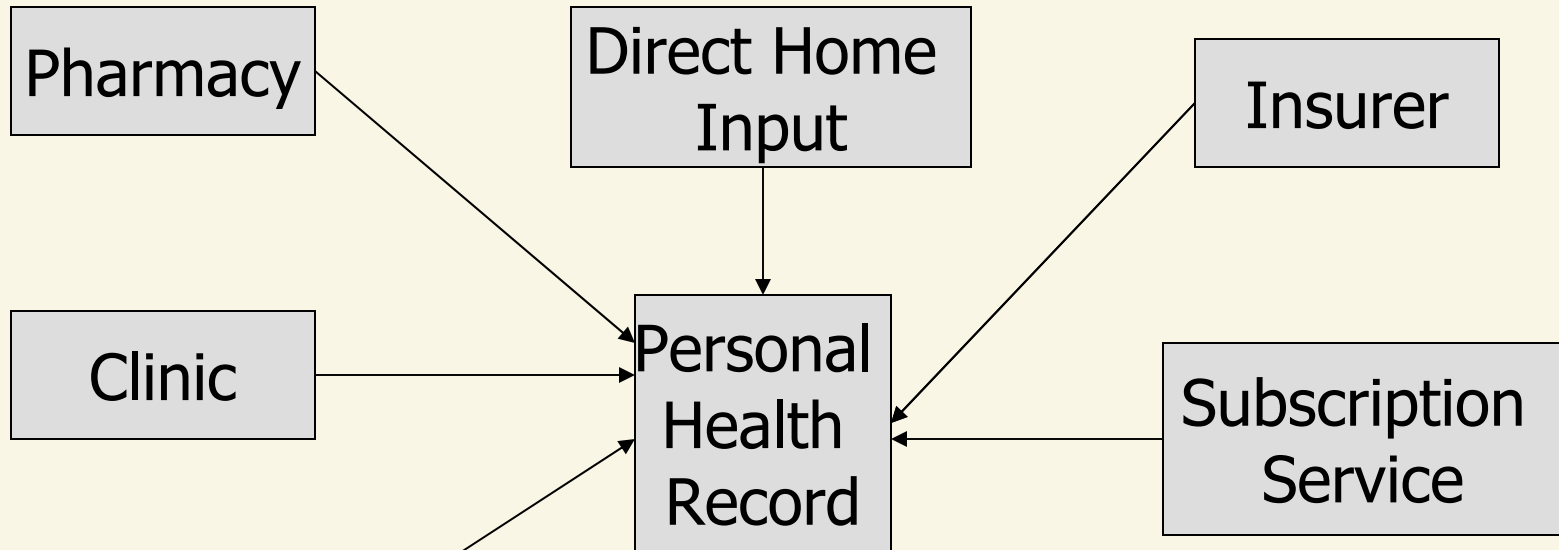
Standards Assessment Matrix

Standard Type	Balloted	Vendor +	User +
Reusable Components	yes	yes	yes
Data Elements	some	yes	yes
Disease registries	some	yes	yes
Educational Components	no	no	no
Images	yes	yes	yes
Security	no	no	no

Personal Health Record

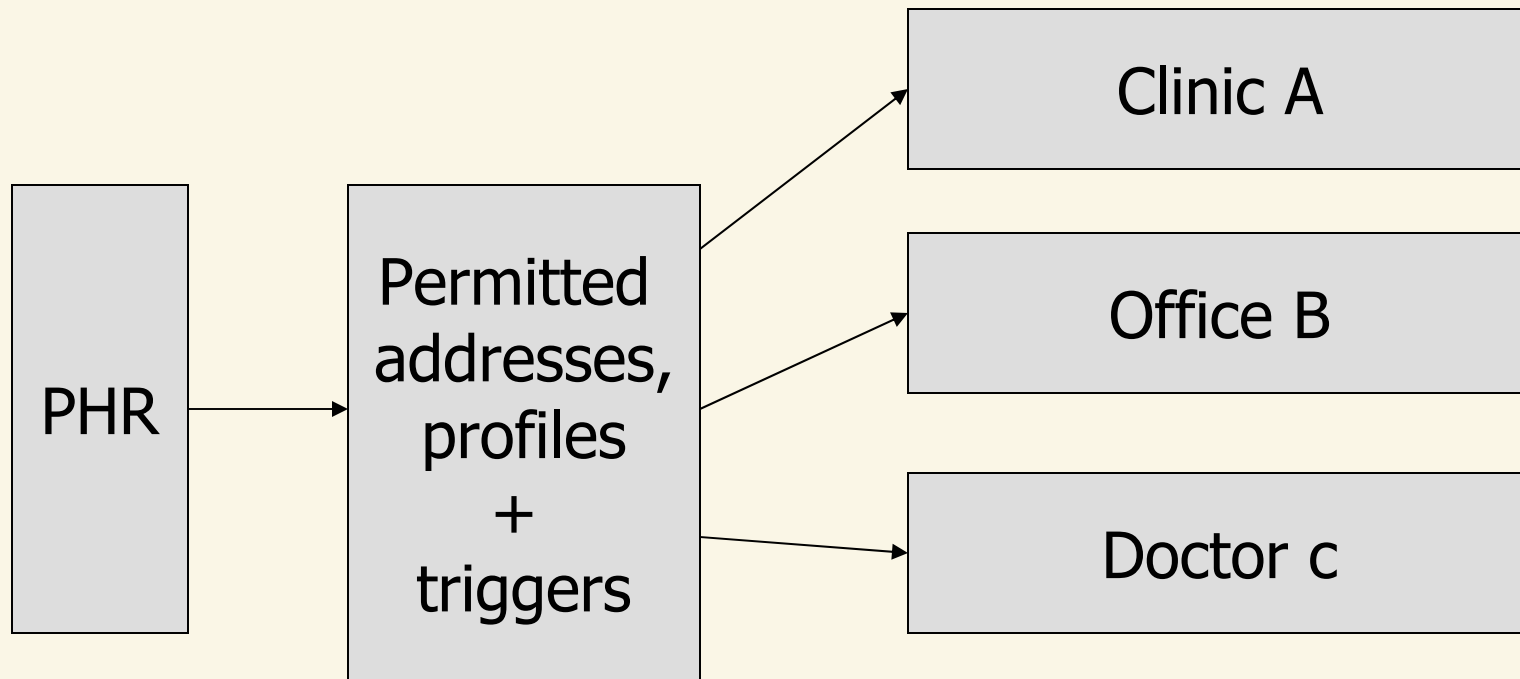
- Model to meet consumer needs and understanding and permit individual responsibility for planning and execution of their own care.
- May ultimately become first line of care with PCP providing backup and linkage.
- Focus on individual responsibilities, functioning, behavior and work management not just data repository.
- Contains personalized linkage to knowledge, particularly in disease and treatment options.
- Information displays driven by query, personal preferences, and behavioral needs.
- Some home entry of data coupled with controlled downloads from provider encounters.
- Person-controlled release.

Data Flow to PHR



1. Personal Computer
2. Clinic
3. Commercial Service

Data Flow From PHR



Person Control and Monitoring of Data Access

- Access through summary, aggregated person-centered health record (population record)
- Person controls list of permitted access by name of person, group, or facility
- Access log maintained for any-time view by patient

Other Standards

- Person guidelines
 - Taking a new drug
 - How to make a choice
 - How often to be tested
 - What it means to me
- Education Snippets
 - Diseases
 - Testing
 - Treatments

Status of standards for PHR

- RIM – ok
- Data types - ok
- Terminology – need work, expanded definitions
- Data element definitions and data set specifications – need work
- Clinical documents – need expanded content
- Clinical templates – need work
- Data Interchange – need uses cases, trigger events, and new messages
- Reusable components – person specific needed

Status of standards for PHR

- Business rules – need definition and work
- Decision support – need content
- Clinical guidelines – need content, consumer orientation
- Knowledge and educational documents and enhanced descriptions – little existing activity

Other

- Specifications for PHR including content, architectural definition, linkage rules
- Tool sets for data input, other
- Improved search engines, content quality indicators, standardized queries and disease-specific FAQ
- Disease Registries for consumers
- Health Goals for consumers