Harmonizing Primary Care
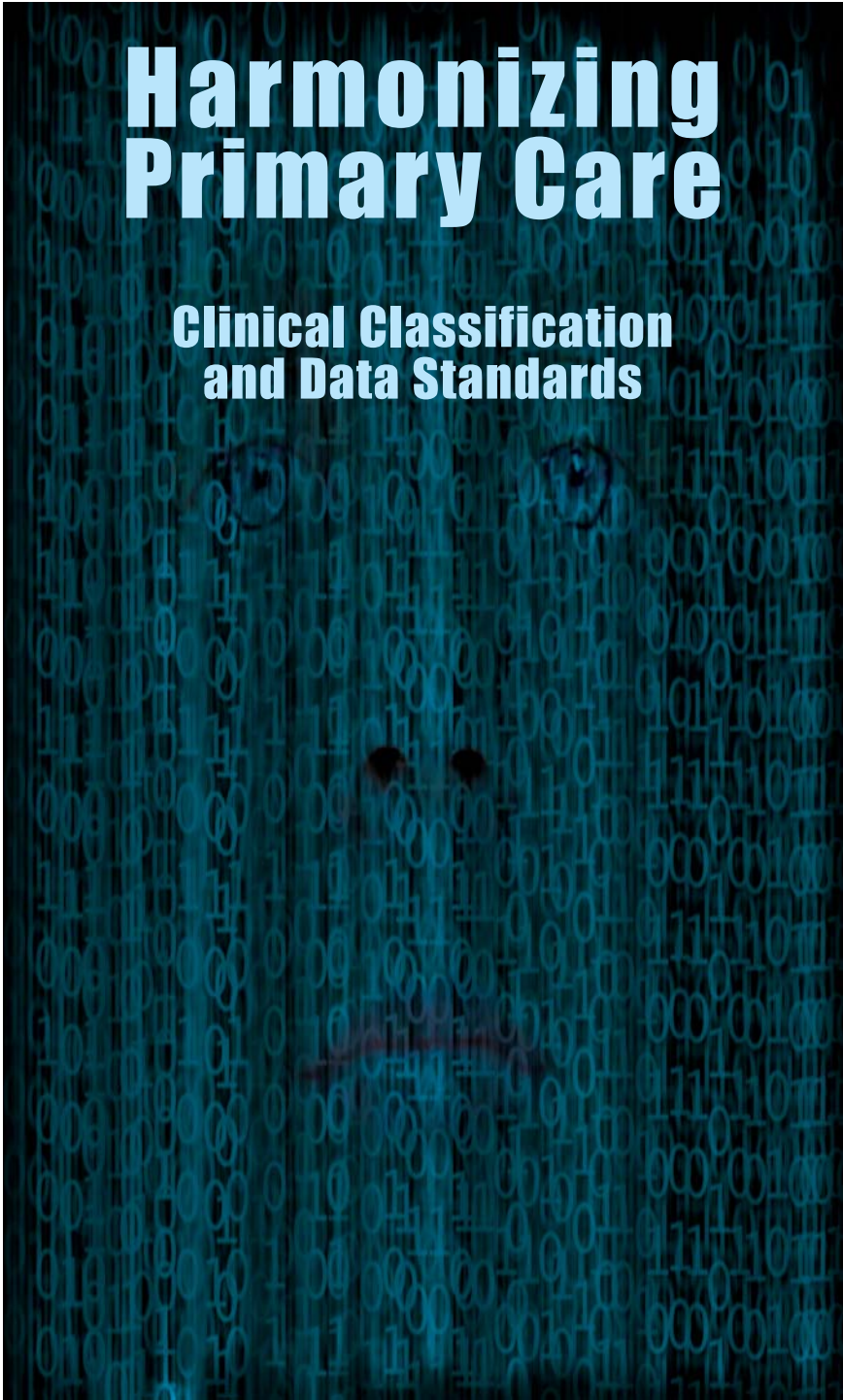
Clinical Classification and Data Standards

Conference Report: Harmonizing Primary Care Clinical Classification and Data Standards

Conference Report:
Harmonizing Primary Care
Clinical Classification and Data Standards
October 10th and 11th, 2007
Washington, DC

Robert L. Phillips, Jr., MD MSPH
Michael Klinkman, MD MS
Larry A. Green, MD

Table of Contents

_____

Part Two: Invited Papers

Conference Report: Harmonizing Primary Care Clinical Classification and Data Standards

Abstract

Purpose
To engage the primary care and health IT standards communities in the task of identifying and advocating for health IT standards that better support primary care practice and be harmonized with other health settings and standards. The objectives were fourfold:

- Understand the importance of a dedicated primary care classification in the era of SNOMED
- Present the case for a "primary care information model" that captures the core data elements that describe the clinical domain of primary care
- Identify which of the currently available clinical classifications and terminologies have the most value for primary care clinicians and their patients
- Explore the paths to create or advocate for standards to implement the "primary care information model"

Scope
Conference attendees included experts from AHRQ, WHO, NLM, CDC, NCVHS, SNOMED, the US HIT National Coordinator, health IT vendors, and primary care organizations.

Methods
Expert presentation and panels, facilitated discussion, and concept mapping

Results
Out of this milieu came agreement about urgent needs for data standards needed to support the integration of patient- and clinician-derived data in primary care. Harmony, not conformity, should be the goal. At least 13 strategies were produced.

Key Words
Data standards, primary care, classification, harmonization

Executive Summary: Harmonizing Primary Care Clinical Classification and Data Standards

Standards for health information technology (Health IT) are evolving rapidly in the U.S. and around the world, but primary care is largely being ignored. Primary care physicians struggle to adapt their workflow to conform to the requirements of poorly-designed health IT systems, and progressively more granular data is entered into systems from which it can not yet be meaningfully extracted.   With support from AHRQ, the Robert Graham Center convened a small conference on primary care classification to engage the international primary care community in the task of identifying and advocating for health IT standards that can better support primary care practice and be harmonized with other health settings and standards.

Conference attendees, including experts from the AHRQ, WHO, NLM, CDC, NCVHS, SNOMED, the US HIT National Coordinator, health IT vendors, and national and international primary care organizations, participated in a series of open discussions on the following topics:
- The importance of a dedicated primary care classification in the era of SNOMED
- The case for a "primary care information model" that captures the core data elements that describe the clinical domain of primary care
- Which of the currently available clinical classifications and terminologies have the most value for primary care clinicians and their patients?
- What paths can be taken to create or advocate for standards to implement the "primary care information model?"

Discussion on each topic was guided by an expert "position paper," circulated prior to the conference and introduced by brief oral commentaries by the authors and selected expert respondents. The discussion revealed a high level of consensus on the following points:
- Primary care remains at the center of the US health enterprise
- Most of its "standards" are retrofitted from other settings and are inadequate

- Most of the use cases now being used to develop standards do not consider core primary care concepts such as patient perspective ("the patient's own voice") or the episode of care
- A small set of simple but robust components, used flexibly, can support the primary care information model
- Absent development of dedicated standards, primary care will not be able to produce *meaningful* quality measures, provide *useful* feedback to clinicians, demonstrate its value to payers, or provide point-of-care, personalized evidence to support patient-centered care
- The International Classification of Primary Care (ICPC) is not perfect but is currently the best clinical classification for primary care—and due to existing mappings, may actually make the change from ICD-9CM to ICD-10CM in the US a less painful process for primary care physicians.

The **key decision** made by attendees was that it was very important to act now to develop and promote the data model for *personal doctoring in the medical home* to support the transformations of health IT and personalized health care that are already underway.

The **second aim** of the conference was to create a **strategy map** to carry this work forward. There was general agreement to move as soon as possible into real-world trials of the information model to test the medical home's capacity to implement the model and measure the delivery of patient-centered care. A separate list of possible actions, ranging from modifications to ICD-10-CM to advocacy with Federal agencies responsible for health IT, was generated. The following actions were thought to be achievable in the short term (6-12 months):

- Assemble a "steering committee" to explore demonstration options for the primary care data model and data standards as soon as possible
- Consider forming a Health IT Commission or specifically assign this role to an existing commission
- Consider engaging Google, Microsoft or other large database management group to create tools to turn data into information at point of care and for patients (may link up with AAFP consideration of a national patient database)

- Look for alliances with payers/purchasers (National Business Group on Health?), AHRQ, National Library of Medicine to incorporate demonstration information models within Medical Home demonstrations
- Work with one or two specific vendors who may be willing to test ICPC and a point-of-care information model
- A rigorous and longitudinal advocacy agenda nationally and internationally
- Request review of the conference report and specific response from AHRQ, NCVHS, and other primary care organizations
- Explore the development of a Primary Care data standards working group to coordinate advocacy and to develop a plan for data standards direction (work within usual processes or do we go directly to vendors)

In summary, participants in this intense and stimulating conference distilled complex issues of classification, epistemology, terminology, and coding into a focus on the ***medical home*** concept. Participants saw a genuine opportunity to improve the quality of health care for virtually everyone by improving the health IT framework to support the integration of patient and clinician-derived data in the primary care medical home.

> "***The single most transformational step toward achieving the goal of a learning healthcare system would be the development and implementation of IT industry standards***"[1]

Introduction and Purpose of the Conference

On October 10th and 11th, 2007, the Robert Graham Center hosted the conference, ***Harmonizing Primary Care Clinical Classification and Data Standards***. The conference was supported by the US Agency for Healthcare Research and Quality and in-kind contributions by the American Academy of Family Physicians. The conference grew out of concern that health information technology standards were evolving rapidly without sufficient attention to primary care, the largest platform for health care in the US, with half a billion visits each year. Many people receive care in primary care and no where else. Yet primary care lacks an information model to make sense of the cost or quality of care that occurs there—or how it affects care delivered elsewhere. Efforts underway to 'harmonize' data standards are actually less about harmony and more about conformity. Harmony would permit flexibility within settings, take advantage of the richness wrought by that flexibility, but focus on how to facilitate extraction or sharing of critical information between settings. A similar discussion was supported by AHRQ in 1995, focusing on the opportunity to advance both the technology and terminology of clinical care. In the intervening decade, the technology effort took precedence over data standards. Primary care organizations have participated in many standards organizations but have been largely outnumbered and have not put many resources into making their case more strongly. The next real effort to raise an alarm about the lack of focus on data standards came in 2003, when a multinational group of primary care researchers produced the ***Banff Declaration*** which called for primary-care specific standards stating:

> "*Primary care physicians in the United States have an immediate need for a simple and honest way to routinely record and retrieve data reflecting their perspective. The primary care perspective must be*

incorporated into the nation's data standards and electronic health records. Clinical research and a fully integrated health information system can not be sustained without practical, easily used primary care data standards."

One year later, the US Future of Family Medicine Task Force report envisioned that the electronic health record would be the core enabling technology to implement a new model of practice that has become the Patient-Centered Medical Home. The task force emphasized that this new model of practice would need, "an informatics infrastructure that supports practice-based research, quality improvement, and the generation of new knowledge."

Since the first AHRQ conference in 1995, pressure has been building to revive a primary care-specific data model, and there are several other reasons why the timing is right:

1. The primary care community and legislators are rallying around the "Medical Home" concept and actively demonstrating new models of practice. They mention that the Medical Home will need robust IT systems but offer little detail of what it should be able to do. The Medical Home will only succeed if it can turn the data it collects into information.
2. There is a shift from ICD-9CM to ICD-10CM, a threshold event that both forces terminology change and might create opportunity of the introduction of a linkable primary care classification.
3. There is growing need to demonstrate practice quality and this begs for primary care classification, ways of looking at episodes of care, and harmonization with other classifications and vocabularies used for billing and communicating with other settings.

Scope

The Agency for Healthcare Research and Quality has a mandated role in developing these standards, and this conference was a logical extension of AHRQ's investments made in health IT for ambulatory care. There are also many other national and international stakeholders and

standards-developers whose input is essential to arriving at a primary care data model that works in concert with other data standards. More than 50 people participated, representing AHRQ, WHO, NLM, CDC, NCVHS, SNOMED, the US HIT National Coordinator, health IT vendors, and national and international primary care organizations

Methods

The first part of the conference focused on using four commissioned papers solicited from national and international experts that addressed:

1. **Why is it so important to have ordering principles for primary care data and information?**

2. **What are the most important ordering principles for primary care that MUST be captured by a primary care classification and which are currently lacking?**

3. **Of current clinical classifications and terminologies, which ones have something to offer primary care and patients?**

4. **What are the data standard paths that could be taken to create standards or otherwise put in place the ordering principles for primary care?**

Each was presented and used in facilitated discussion guided to meet the aims of the conference. There was at least one reactor to each paper.

Between the two main parts of the first conference day, Drs. Henk Lamberts and Inge Okkes of the Netherlands demonstrated how data collected in a more ideal primary care information model can produce prior probabilities of possible diseases for a patient presenting with abdominal pain. These data were collected in the Transhis project which collected more than 200,000 patient years worth of visit data aggregated by episode of care. Based on a patient's particular demographic data, they were able to produce a prioritized list of disease probabilities and link directly to clinical guidelines.

In the second part of the conference, organizations involved in setting standards for health data, and for using these standards to develop electronic health records participated in a panel discussion convened by Marjorie Greenberg of the National Center for Health Statistics. They provided personal and organizational perspectives on the current state of health data standards and what the essential steps are needed to connect US sanctioned primary care standards to these efforts. They were asked to specifically address the political and practical hurdles in achieving a standard primary care classification and other data standards.

The last part of the conference focused on formulating a **strategy** **map** to cover the subsequent 12 to 18 months, to arrive at a primary care information model that is supported in the US by public policy and readily used in the interoperable electronic health record.

Conference Summary

The conference was well-attended with passionate participation of nearly fifty people from diverse backgrounds and perspectives including four different countries, six Federal agencies or centers, and the *World Health Organization*. It seemed to "hit a receptor site" that was ready for response. The commissioned papers stimulated thoughtful reactions that clarified and expanded their messages, but did not refute them (see summaries in appendices). Participants brought considerable expertise from their experience in government, practice, administration, technology, and business to the conference, and frank and candid sharing of views transpired. Out of this milieu came agreement, and to a surprising extent consensus, about urgent needs in the United States that rest on foundational thinking about data standards. There was not general agreement about how to arrive at functioning standards, but several strategies resulted from this disagreement. The conference organizers summarized the results as follows.

There was considerable agreement that in an information age, an information-intense business like healthcare cannot afford to be hamstrung by its information technology. This point was made several times at the Institute of Medicine Annual Meeting just 2 days prior to the

conference and in the Institute of Medicine Roundtable on Evidence-Based Medicine report released in July of 2007 (see text box at end of this report). The US cannot achieve the safe, high quality care it aspires to have absent reliable and patient-centered information management. Healthcare is one of the largest and most reliable economic engines in the US economy and yet its only consistent data streams are owned by payers. Primary care is the largest platform for care in the US. Primary care, is the point where most people bring their undifferentiated symptoms, where most people resolve their symptoms, where most people have their chronic health conditions managed, where most medications are prescribed, and yet it is even farther behind most other healthcare sectors in establishing the models and standards for effective data management. Most of its standards are retrofitted from other settings and are inadequate to capture the evolution of problems over time and to measure results. Most of the use cases now being used to develop standards do not consider primary care or the patient-physician visit. Primary care should be made a priority for data standards and data model development. Until it is made a priority, primary care providers will not be able to produce *meaningful* quality measures, produce useful feedback to clinicians, demonstrate value to payers, or provide point-of-care, personalized evidence for patient care. Attendees acknowledge that measures, feedback and decision-support are being developed but they are anemic compared to what could be done. This was most fully realized in a demonstration of what can be produced by a primary care information model in the Netherlands.

The key decision made by attendees was that it was very important to act now to establish the data model for personal doctoring in the medical home to enable progress on important transformations of health care that are already underway, and to a stunning extent dependent on communication and use of data. These emerging transformations most strongly connect to the quality movement in the United States and may hold great promise for providing all residents of the United States with high quality care in a manner that the country can sustain for many years to come. Data standards for primary care will be needed to enable these new models of practice. A time of unusual transformative change seems to have arrived, presenting opportunities ripe for action.

The framework into which this conference's proceedings fits best starts with the Institute of Medicine's six aims of health care, emphasizing the most transformative aim of all, "patient-centered care." Then, recognizing the solid evidence base for the necessity of robust primary care in high performance, sustainable health care systems, the conferees united around the concept of the "medical home," for every person. The attributes and expectations of the medical home are established and push primary care into the information age. The means of executing the medical home functions depend a great deal on information management and, indeed, represent medicine's largest information problem. Harnessing the medical home for the care envisioned by the IOM while connecting it to population health objectives requires explicit development of data models, classifications, vocabularies, and mapping to insure appropriate care for individuals, ongoing quality improvement, and interoperability with the rest of the health care system. Medicine is an information business and primary care cannot 'own' its business model in primary care if it doesn't 'own' its data model—if it cannot make the information work for the people cared for there.

The Chair of the Board of the American Academy of Family Physicians acknowledged that achieving a primary care information model was important—that this had been demonstrated in the conference--but that he didn't understand most of the specifics discussed. It was pointed out that this is not unique to primary care or to medicine. As Carl Sagan noted in his book, *The Demon Haunted World*, most of us don't understand the technology we use—our cell phones, our computers, our iPods—but we expect them to work and for standards to be operating in the background to make them interoperable. Primary care physician organizations are an important audience to convince about the importance of investing resources in standards advocacy.

Results: Needed Standards

From this rich buffet of possible and important developments, a small number emerged during the conference as particularly crucial to immediate progress. The medical home requires information systems

that yield at least five outputs necessary for measuring and improving quality:

> Patient Registries (defining who is a patient at the medical home)
> Physician Designated as Personal Physician (defining who this patient chooses as their personal doctor)
> Why Patients Come When They Do (in the patient's own words)
> Goals for Each Patient (what this particular individual is seeking to achieve in terms of, for example, prevention, chronic disease management, function, organ donation, resuscitation)
> Clinically Meaningful Episodes of Care (the key unit of analysis for estimating value of care)

As the location where referrals are initiated and care is integrated, the medical home's information system also must be able to interface with all other locations of care for those patients registered with it and import/export information critical for integrated, evidence-based care, safely and without wasteful duplication. In many instances, this information will come from patients themselves.

When this vision of the medical home is realized, the nation will have an organizing focus where what medicine has to offer can be matched to what people need and want. The health care occurs and its consequences can be measured at the level of the individual, the practice, systems, and the public. It will not be able to achieve these important objectives absent appropriate data standards.

Participants acknowledged an extended historical period when various ideas about primary care and its data requirements have matured, but not taken root in the United States, for example the International Classification of Primary Care. Nonetheless, there is a substantial primary care enterprise in the US ready for renewal, and there is experience and guidance within and outside the United States that can be tapped to make a leap forward. Participants from their own experiences could identify impediments to establishing the medical home, most of them eventually tracking to insufficient capitalization of the primary care setting, making it a relatively minor market of interest

for health information technology developers. However, primary care itself must bear responsibility for not fully *understanding the information model* of the medical home and what data elements and standards are necessary to achieve the essential outputs. Participants probed and debated various strategies for moving forward under these circumstances, identifying possible actions that might enable progress. Given the current state of coding systems (ICD9CM in the US), embedded knowledge, granularity and availability it appears the current best primary care solution towards solving these three simultaneous equations is the marriage or mapping of ICPC to more granular systems. This may be a particularly helpful strategy to NCVHS and WHO in their efforts to get the US move to ICD10, ie, if primary care physicians can migrate to a more intuitive and easier coding scheme than they are currently using (ICPC) that automatically maps to ICD10, it may reduce resistance to the change.

There was agreement that a forceful step forward could be taken now by, not only thinking carefully about the classification and coding of primary care, but to move into testing of a "primary care information model" sufficient to support the medical home. Such a demonstration would test the medical home's capacity to measure the delivery of patient-centered care that is satisfying to people, payers, and clinicians. The experiences from the demonstration would be expected to provide direction for the production of robust, widely-disseminated information systems for use in the nation's "medical homes." Participants recognized that many practical experiments are already underway and more anticipated, e.g. the CMS medical home demonstrations. Practical trials of the underlying data model and standards are likely to be KEY FOUNDATIONAL WORK for medical home demonstrations, complementing efforts, not competing with them.

The essential features of such a demonstration were beyond the scope of the conference, but likely include a public-private partnership (possibly NLM, AHRQ, IT developers/providers), various types of primary care practices in different regions and communities of different sizes. The key focus would be on the service to patients, not on protectionism, e.g. of historical roles and instrumentation. An oversight committee comprised of individuals selected for their expertise and commitment (vs their

representation of an industry or constituency) could guide the demonstration.

There was sufficient agreement by the end of the conference among participants to suggest that the following actions are sensible and achievable in the short term:

1. A small subgroup of participants should be assembled as a temporary steering committee to explore how testing of the data model and data standards necessary for the medical home can proceed as soon as possible. Initially, this steering committee can be organized and convened by the grantee for this conference.

2. A subgroup of participants identified by the grantee for this conference should review the lengthy list of possible actions to select particularly timely and relevant items from the list and define step-wise actions that could be taken in the next 6 months by interested parties.

3. The Agency for Healthcare Research and Quality, primary care organizations, especially the American Academy of Family Physicians, and the National Committee on Vital and Health Statistics, should consider these strategies purposefully and may want to respond to this report.

4. Present the conclusions of the conference to the NCVHS at its November, 2007 meeting (completed).

In summary, participants in this intense and stimulating conference consolidated decades of thinking and distilled complex issues of classification, epistemology, terminology, and coding into a focus on the medical home concept, where participants saw a genuine opportunity to improve the quality of health care for virtually everyone by improving primary care, while helping control costs. It appears to be a propitious moment to establish the primary care information model sufficient to support the medical home and thereby guide the establishment of EHRs capable of executing the crucial function of personal doctoring in the

medical home. It would be prudent to seize the opportunity now available as primary care practices enter a period of transformative re-design.

Schwenk N, Gilliam M, Karkanias J
Institute of Medicine Roundtable on Evidence-Based Medicine
Information Technology Sector Statement
July, 2007

Medicine is: Procedure & *Information Management*

"*The single most transformational step toward achieving the goal of a learning healthcare system would be the development and implementation of IT industry standards*"

"In conjunction with standards, there is a *necessity of a common vocabulary*"

"Currently many of the *clinical information technology systems* available for clinicians simply *duplicate* work flow processes that have been developed and honed in the *"paper world."*

"In the continuum of data collection, aggregation, synthesis, and delivery, is clinical decision support for the provider. This is the ability to guide clinical decisions based on individual clinical and biologic data in the context of relevant clinical evidence as well as *experiential information gathered from mining data on previous patients with similar conditions*."

"*Novel ways* to view clinical data and its relationship with other data will need to be developed to help *digest the meaning of relationships*."

Strategy Map for Developing and Demonstrating a Primary Care Information Model

Strategy Map for Developing and Demonstrating a Primary Care Information Model

Strategy	Tactics	Lead Organization(s) and People	Collaborators or Partners	Target
Link New Data Standards to Success of Medical Home and Personal Health Record	Engage Google and Microsoft about a mutually beneficial project that improves capacity of electronic clinical and personal health records. Microsoft/Google would get a huge, regularly updated, de-identified database of episodes of care off of which they can help people develop much more accurate query tools and tailored decision support specific to theirconditions, outcome probabilities, and treatments. Primary care physicians would get capital to build and test a primarycare based information model in practice and data management tools that turns their data into meaningful information Could also include a public-private component	AAFP David Kibbe Steven Waldren AHRQ	Institute of Medicine (relevant to Roundtable on Evidence-Based Medicine); American College of Physicians (ACP); American Academy of Pediatrics (AAP); National Quality Forum (NQF)	Google Microsoft
Change Standards	Create a Commission on Health Informatics to organize the AAFP's role. Should include people from ACP and AAP. Push ICPC as an industry standard in the US for primary care. ICPC as the best available classification for a starting point to get to clinically meaningful episodes of care and patient centered care. ICPC is mapped to ICD9CM, ICD10CM and soon SNOMED; and primary care physicians would find it much easier than using any other classification (and it would put their EHR to work putting out the other codes as needed). It requires a different EHR database than currently exists in the US but there are EHRs operating in other countries that could be brought to the US and modified.	AAFP Steven Waldren AAFP Mike Klinkman AHRQ	ACP AAP NQF AQA WONCA WHO AHRQ HIT group	HITSP CCHIT HL7 ANSI EHR developers/vendors

Strategy	Tactics	Lead Organization(s) and People	Collaborators or Partners	Target
Demonstrations of data model and importance to the Medical Home	Suggest that the CMS and health plan Medical Home demos could incorporate some of the key elements of the ICPC as test beds. Demonstrate use of routinely collected data in the medical home to improve quality.	AAFP Bruce Bagley John Swanson AHRQ	Helen Burstin ACP AAP	CMS contractor Mathematica—Lead Mai Pham at the Center for Studying Health System Change United HealthCare's advanced medical home project
Change Standards	Create a Commission on Health Informatics to organize the AAFP's role Propose to HITSP/HL7/CCHIT that EHRs that include Reason for Visit in the patient's voice and physician-directed episodes as criteria related to quality for future ambulatory certification criteria. This would help make the record more patient-centered while adopting an EHR strategy for establishing episodes.	AAFP Steven Waldren AHRQ	Helen Burstin NCQA—NCQA has ongoing relationships with CCHIT related to standards and quality ACP AAP	HITSP HL7 CCHIT IHE

continues

Appendix B: Strategy Map for Developing and Demonstrating a Primary Care Information Model

Strategy	Tactics	Lead Organization(s) and People	Collaborators or Partners	Target
Link New Data Standards to Success of Medical Home and Personal Health Record	Engage Google and Microsoft about a mutually beneficial project that improves capacity of electronic clinical and personal health records. Microsoft/Google would get a huge, regularly updated, de-identified database of episodes of care off of which they can help people develop much more accurate query tools and tailored decision support specific to theirconditions, outcome probabilities, and treatments. Primary care physicians would get capital to build and test a primarycare based information model in practice and data management tools that turns their data into meaningful information	AAFP David Kibbe Steven Waldren	Institute of Medicine (relevant to Roundtable on Evidence-Based Medicine);	Google Microsoft
		AHRQ	American College of Physicians (ACP); American Academy of Pediatrics (AAP); National Quality Forum (NQF)	
	Could also include a public-private component			
Change Standards	Create a Commission on Health Informatics to organize the AAFP's role. Should include people from ACP and AAP.	AAFP Steven Waldren	ACP AAP NQF AQA WONCA WHO AHRQ HIT group	HITSP CCHIT HL7 ANSI EHR developers/vendors
	Push ICPC as an industry standard in the US for primary care. ICPC as the best available classification for a starting point to get to clinically meaningful episodes of care and patient centered care. ICPC is mapped to ICD9CM, ICD10CM and soon SNOMED; and primary care physicians would find it much easier than using any other classification (and it would put their EHR to work putting out the other codes as needed). It requires a different EHR database than currently exists in the US but there are EHRs operating in other countries that could be brought to the US and modified.	AAFP Mike Klinkman AHRQ		

Strategy	Tactics	Lead Organization(s) and People	Collaborators or Partners	Target
	Pursue some strategic alliances with payers, health plans, and purchasers—demonstrate the value of physician-directed episodes as an alternative to commercial episode groupers based on claims data. They have a strong interest in episodes to understand where their opportunities are to better manage costs and care.	AAFP Bob Phillips Mike Klinkman Wilson Pace Bruce Bagley	Helen Burstin Henk Lamberts & Inge Okkes (Transhis team) AAP ACP AHRQ	e-Health Initiative National Business Group on Health Blue Cross/Blue Shield United Healthcare Aetna
	Work through National Business Group on Health Primary Care Working Group to find Fortune 100 partners for building/testing primary care data model. These companies are hungry for information to make better benefits decisions for their employees. They also want meaningful information on employee health outcomes and cost effectiveness of care. All of these could be enhanced by better, simpler data models in primary care.			
	Choose an existing EHR system that has a robust primary care data model (registry function, episode structure, captures patients' reason for visit, names personal physician/medical home, has a unique patient identifier) and elaborate to the American operational requirements.	AAFP Steven Waldren Commission on Informatics Mike Klinkman	Colleagues using such systems: Michigan, Canada (Toronto), Netherlands, Malta, Spain, England AHRQ	EHR vendors AHRQ HITSP/CCHIT ONC
	Partner with one or two US electronic health vendors to radically improve their products for primary care. Produce EHRs that can improve and measure quality, boost practice management efficiencies, cut staff requirements.	Wilson Pace		

Strategy	Tactics	Lead Organization(s) and People	Collaborators or Partners	Target
Education Demonstrate Value	Develop a simple presentation (perhaps online) that explains how the key aspects of a primary care information model and classification system (ICPC, for example) change the practice of primary care to improve quality, to understand costs, to improve patient-centeredness, to enable decision-support tools, to promote guideline use, to improve diagnosis/test selection/treatment	AAFP Mike Klinkman Kurt Elward Wilson Pace Bob Phillips	ACP AHRQ Helen Burstin Henk Lamberts & Inge Okkes (Transhis team)	Purchasers, payers, health plans EHR Vendors Standards groups Physicians
Education Demonstrate Value	Establish a very large data base from whence episodes can be constructed and measured. Use this to demonstrate to physicians the value of episodes (decision support, quality, feedback demonstrate value) and to payers (value, value, value)—The Transhis Project (Netherlands) has such a resource but it is not widely distributed or demonstrated	AAFP Bob Phillips Transhis Team AHRQ	NCVHS ACP AAP	eHealth Initiative National Business Group on Health Payers Vendors Physicians
Coordinate Strategies and Tactics	Establish a strategy oversight group to coordinate and keep track of effort. Find partners who are committed to high performance primary care and work together	AHRQ AAFP Patient Centered Care Collaborative	ACP, AAP, NCVHS, NQF (Helen Burstin), Patient organization, Vendor	Standards groups Vendors Physicians Purchasers & Payers
Demonstration of data model and importance to Medical Home	AHRQ—NLM primary care data model demonstration that incorporated and tested several classification systems to study how data and concept mapping can be linked to guidelines, quality metrics, outcomes, and payment—and which perform best. Should be built around a robust primary care data model that captures episodes, and reason for visit—not just classification	AHRQ Mike Fitzmaurice Jon White NLM NQF	AAFP Mike Klinkman Wilson Pace Henk Lamberts & Inge Okkes (Transhis team)	Practice-based research networks

Strategy	Tactics	Lead Organization(s) and People	Collaborators or Partners	Target
	Create a UMLS primary care domain	AAFP AHRQ	NCVHS AAP, ACP	National Library of Medicine
	Take the primary care practice vision and begin to develop an articulated information/workflow model. Identify what exists and what needs to be re-engineered. **Call for AHIC, ONC, HL7 and HITSP to develop more and better primary care use-cases**	AAFP AHRQ	NCVHS AAP, ACP	HL7 HITSP ONC AHIC

Paper Summaries and Invited Responses

Primary Care, the Medical Home, Personal Doctoring, and Classification and Data Needs
Larry A. Green, MD

The largest platform of formal health care delivery needs and deserves classifications, vocabularies, and coding systems aligned with its work. The availability of modern information technology now coincides with the formulation of the concept of the medical home with a personal physician. This idea is attractive to and supported by many clinicians, patients, and policy-makers and presents another opportunity for progress. The redesign of primary care practice to further enable personal doctoring within a medical home and the creation of the nation's health information infrastructure are underway. This gives impetus to getting on with whatever it takes to establish classification, terminology and coding to enable high performance frontline health care. There is an urgent need to at least: (1) secure patient registries, (2) capture patients' concerns as they present them for care, (3) establish and record patients' goals, (4) accurately label the troubles and problems that fill the work-day of those in the medical home, (5), organize clinically meaningful episodes of care, and (6) exchange health-related information among the medical home and other health care settings needed to resolve patients' problems correctly.

Immediate progress in establishing excellent primary care through personal physicians in medical homes is "trying to happen" now. Evidence to date supports moving in this direction and predicts a salutary impact on individuals and the nation. Optimizing performance at this level of care and integrating patient-centered primary care with

the entire health system depends in part on establishing explicitly the classification, vocabulary, and coding systems suitable for routine daily use. It is time for action.

Reactor, James Campbell (SNOMED)

- No whining!
- Have to share a model of meaning and a model of work.
- Multidisciplinary care plan is a central feature.
- We lack the features of the "sharable guideline knowledge base."
- Dialogue is essential, e.g. between the meaning model folks and the vocabulary folks.
- A finite list of concepts is not ever going to exist—classifications and vocabularies will always change.
- "Better to be roughly right than precisely wrong."
- "Let's be sure we put in the record exactly what the clinician needs to say."
- "Now is the time to not be talking about new coding systems, but how to push the NCVHS agenda forward to harmonize systems."

Reactor, Bob Hungate (Physician Patient Partnerships for Health)

- Quality improvement is what we want.
- We've been talking about episodes of care at least since 1981.
- "I hear a lot of ready, ready, ready here . . just do it."
- "I don't see overt leadership for what primary care needs here."
- "Because of the sheer complexity and tendency to do things for ourselves, progress together is slow."

Reactor, Asif Syed (College of American Pathologists, SNOMED)

- Sufficient granularity of terms is essential.
- There are many, many use cases associated with any particular patient concern.
- Press for one terminology.

Primary Care Coding
Wilson Pace, MD

While there are holes in the coding universe when it comes to primary care, the bigger overall issue has to do with creating a data model that supports the needs of a medical home in dealing with individuals as well as a population of individuals. To improve this process primary care needs to take an active role in defining the appropriate groupings, granularity and content of the coding systems in use in EMRs. Primary care clinicians have learned to consider the location of research in deciding if the results are valid for their setting. Likewise, primary care clinicians, as well as those organizations developing knowledge bases for primary care, need to recognize that adding together the views of a variety of other specialties does not lead to an effective primary care data model.

Primary care has developed such a taxonomy, the International Classification of Primary Care (ICPC). The concept of ICPC was never to be an all inclusive nomenclature, but instead to create a unifying approach to understanding a patient's requests for help/service and a clinician's responses to the requests over time. Inherent within ICPC are two different approaches to "ordering" medical data. One ordering approach is embedded within the coding structure itself, all codes are related to an "organ system"[9] - as opposed to some being organ system related, some causation related, some service related and some agent related (as is the case in ICD and most granular nomenclatures). The second is in the use of "episodes of care" which create order across various requests for service and across time. These ordering principles are captured at a level of detail that is guided by the frequency of use within primary care. By only coding the more frequently occurring processes and problems the system helps assure that the signal (those activities correctly coded) is greater than the coding noise- those activities incorrectly coded due to infrequent use and code ambiguity. Furthermore, the system assures that the data obtained from ICPC coded, episode oriented record is grouped such that secondary analysis provides meaningful confidence intervals.

Given the current state of codification system use, embedded knowledge, granularity and availability it appears the current best primary care solution towards solving these three simultaneous equations is the marriage or mapping of ICPC to more granular systems. The two most widely available systems and ones for which the mapping is complete or underway are the ICD systems and SNOMED CT. ICD allows clinicians around the world to share morbidity and mortality data in an established format. Mapping ICPC to ICD allows users to more logically and quickly find the appropriate ICD rubrics, and, more importantly, facilitates the logical grouping and analysis of data across episodes of care. The mapping of ICPC to SNOMED CT will allow other components of a medical record to achieve a level of granularity and modification required for clinical decision support. Simply mapping the two systems to each other will not accomplish this. The very difficult step of determining the correct levels of granularity and the correct data elements to codify are currently either left to the EMR manufacturers or to individual clinicians or organizations.

The Transhis project of Lamberts and Okkes has demonstrated that remarkable insights into care processes, patient requests for and decisions regarding care and clinician decision making can be gained by appropriately linking approximately 1300 codes.

As long as we have a wide variety of vendor specific approaches to primary care data collection, presentation, linking and analysis we will continue to make slow and arduous progress in our attempts to use digital processes to improve care. Currently, the major successes are either home grown applications often built on home grown EMRs or are those vendors that take on the work of remapping and re-interpreting the electronic data within an EMR as well as developing clinical decision support algorithms at levels that are useful for specific disciplines. Rapid improvement in this process as well as the care delivered to individuals is likely to be slow until more widespread adoption of a primary care data model occurs.

Notable Quotes:
- "Some of us put ICPC at the center of the world, others SNOMED"

- Said to him: "Don't worry, Wilson, doctors will get the definition of episode right, most of the time."
- We physicians get good at ordering and presenting complex things, then we put it in a record system, and then we can't make sense out of it . . . we generally lose them.
- "We're only planning for the electronic record, codes themselves are not important. It's how constructs are presented and linked over time."
- "Our fundamental problem is we start with billing!"
- What exists, exists for a reason and typically addresses that reason, sometimes in public domain, sometimes commercial, e.g. LOINC. RxNorm, CPT, Medcin, SNOMED CT, ICPC, ICD-10.
- "The way ICPC works for me is to start with it, and it leads me to other places I need to go to—it incorporates time, the critical thing we need."
- "We should use SNOMED as a nomenclature, not a data organization structure. . . all fields, not just primary care, must get their data structure straight."
- Pleaded to stop the hubris and work together, accepting "fluidity" of concepts is a certainty.
- "There still are holes, e.g. allergies, patient preferences, guideline exception, adverse events, medical decision-making, patient generated data inputs."
- "Crushing rocks is not sculpting things."

Reactor, Helen Burstin (National Quality Forum)

- "I'm learning concepts here today that need to be incorporated into broader conversations, especially quality . . . There are things here I still don't get."
- "The timing is really right because the quality movement is focusing on episodes of primary care—alternatives to black box episodes derived from claims data."
- "What is the additional burden—how do we incorporate anything else in primary care?"
- "I still don't get what is missing in SNOMED."
- "We're not going away from ICD-9 anytime soon."
- Maybe demonstrate the value of primary care by managing symptoms and/or risk factors, instead of diseases.

Classifications, terminologies, and their use in primary care health information technology: towards a primary care data model

Michael Klinkman, MD, MS

In 2007, four years into the National Health Information Infrastructure effort, we still lack a coherent approach to health information technology (HIT) to support primary heath care delivery. Our collective failure to develop and promote standards for primary care data exchange has led to HIT chaos: private-sector electronic medical record vendors create and sell expensive products that do not meet the needs of primary care physicians, physicians struggle to adapt their workflow to conform to the structure of EHRs, and progressively more granular data is entered into systems from which it can not be meaningfully extracted. *We cannot demonstrate the value of primary care to the health system until we can accurately enter and retrieve data about the core processes of primary health care.*
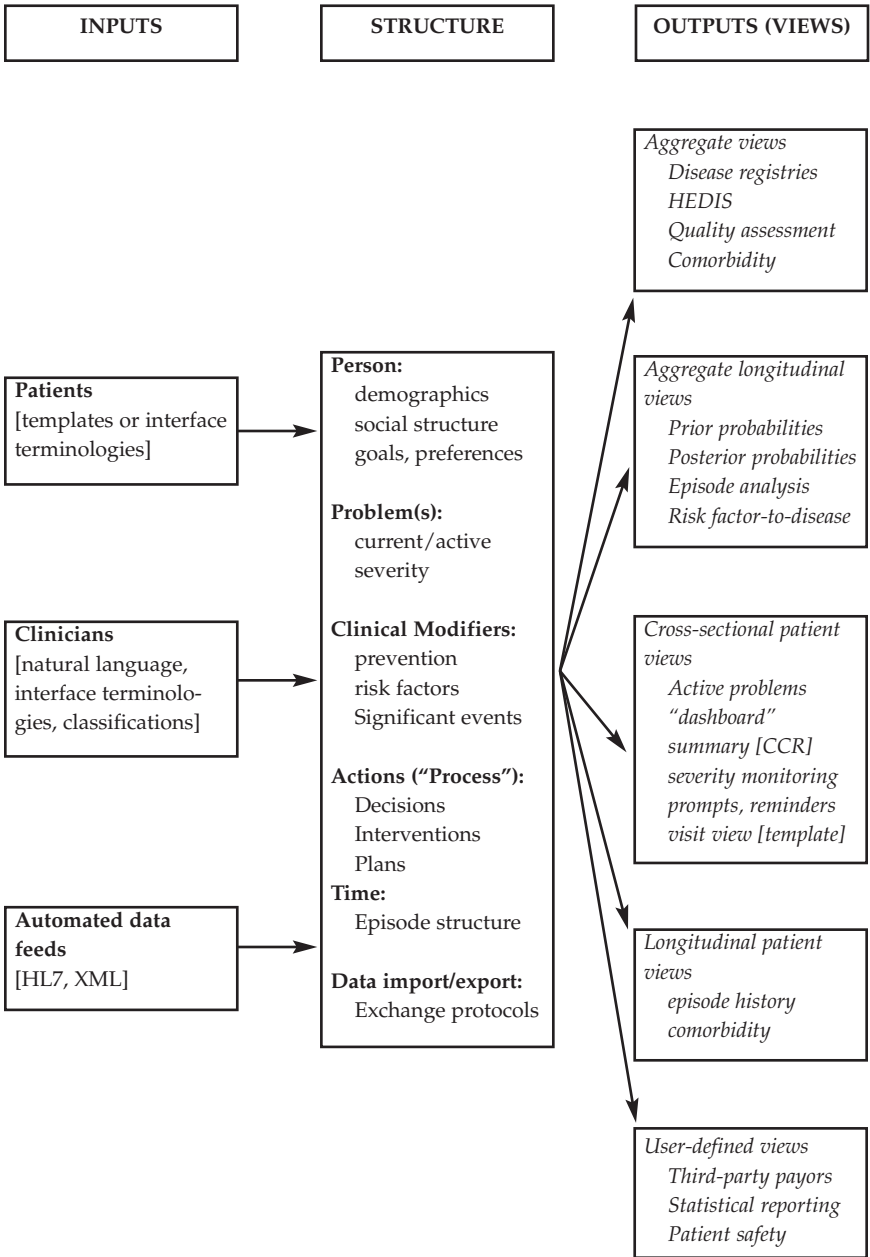
A model must reflect, as accurately as possible, the clinical domain of primary care. If that domain is "taking care of people who have problems over time in the context of their personal lives," we need to collect meaningful data about *people*, the *problems* that affect their health now, the problems that they are *at risk* to develop, how *time* affects the care we deliver, and the *context* in which care takes place. We also need to be able to collect and report out data about the quality of care we provide for a growing list of medical conditions. These data elements must be collected during routine clinical workflow, which includes brief contacts over telephone or Web, indirect contacts through ancillary providers and practice staff, as well as direct clinical encounters. Simplicity and transparency are essential to this process.

An episode of care, defined as "a series of temporally contiguous health care services related to a specific health problem or provided in response to a request by the patient," follows a clinical problem from its presentation to its resolution. It provides the most accurate representation of the process and cost of health care delivery for a particular problem.   In ICPC, the starting point for an episode of care is the reason for encounter (RFE) as expressed by the patient, which

codifies a patient-centered approach to care. Several studies have confirmed that the RFE has a powerful influence on the process and outcome of an episode of care.

ICPC-2, released in 1998 in paper and 2000 in electronic format, was designed from the start to be incorporated into electronic health record (EHR) software with a conversion map to ICD-10. In this use, the underlying data structure of ICPC provides the "backbone" to enable the proper organization and retrieval of clinical data. This approach has been extensively tested in the Netherlands and Malta, where an ICPC-ICD-10 thesaurus has been embedded in the Transhis EHR software used by dozens of Dutch and Maltese GPs to code diagnoses in both ICPC and ICD terms. More recently, teams in Australia, Belgium, Canada, and the United States have created EHRs using the combination of ICPC plus clinical terminology or ICD mapping.

Inputs, Structure, And Outputs In The Primary Care Data Model

INPUTS	STRUCTURE	OUTPUTS (VIEWS)

Aggregate views
  Disease registries
  HEDIS
  Quality assessment
  Comorbidity

Patients
[templates or interface terminologies]

Person:
  demographics
  social structure
  goals, preferences

Problem(s):
  current/active
  severity

Aggregate longitudinal views
  Prior probabilities
  Posterior probabilities
  Episode analysis
  Risk factor-to-disease

Clinicians
[natural language, interface terminologies, classifications]

Clinical Modifiers:
  prevention
  risk factors
  Significant events

Actions ("Process"):
  Decisions
  Interventions
  Plans

Cross-sectional patient views
  Active problems
  "dashboard"
  summary [CCR]
  severity monitoring
  prompts, reminders
  visit view [template]

Time:
  Episode structure

Automated data feeds
[HL7, XML]

Data import/export:
  Exchange protocols

Longitudinal patient views
  episode history
  comorbidity

User-defined views
  Third-party payors
  Statistical reporting
  Patient safety

The next figure illustrates one way in which classifications and terminologies might fit together to support primary care HIT. At the center of the Figure is ICPC, which can provide the episode structure and high-level aggregation (of diagnoses, symptoms or actions) required to facilitate data retrieval and make it feasible for individual practices to mine their own data. The next ring includes the core classifications in the WHO Family of International Classifications, mapped to ICPC and offering the increased granularity necessary for individual patient records. However, in some areas – social problems, symptoms and complaints- ICPC has more content coverage and granularity. In addition, actions (process) are represented in WHO-FIC by ICHI, which has not been fully developed. The outer ring is SNOMED-CT, which promises highly granular coverage of all clinical concepts, but which has limited content in the areas of symptoms and social problems at present. Note that risk factors represents an area in which ICPC and ICD coverage is limited and SNOMED-CT coverage is evolving.

With the proper mappings in place, primary care practices will be able to work at any of the three levels. However, given the combination of time constraints, breadth of information demand, and need for simple data retrieval inherent to primary care, the flexible use of the relatively simple components contained in ICPC can enable effective self-directed HIT in primary care practices.
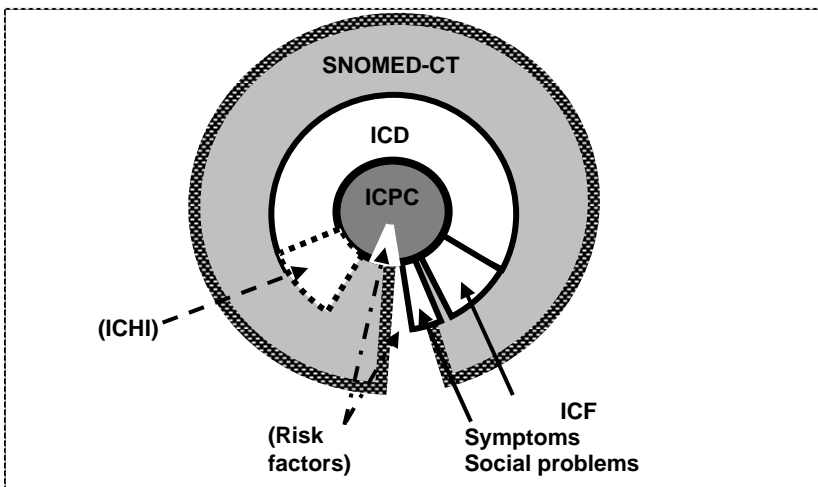
Notable Quotes:

- "I'm a practicing family physician, not a geek."
- We have people, problems, context, EHR's, comorbidity, a desire to get things right.
- We need to be able to use our practice's data locally, feed a bigger system, code context, report clinical modifiers, follow things over time, who has "x," who "gets" things, who "needs" things, and know what happened "out there."
- ROBUST SIMPLICITY!
- Primary care's <u>data model</u> needs to be made explicit—its structure, inputs (like PHR), outputs.
- "Physicians are dying in practice now because they are feeding EHRs that don't give them anything back."

Reactor, Stanley Chin (Director of Practice Development, Altarum Institute)

- We are where we are—(1) data flow to billing systems and (2) we burden primary care docs who don't have the capital to pay for what we want from them.
- The data model must reflect the care model.
- "Health doesn't emerge in the 15 minute visit."
- "The physician is one, but only one, of several hubs around which data will flow—a transformative idea."

Pathways (and Detours) to HIT Standard Development, Acceptance, and Implementation: From Idea to Production
David Kibbe, MD, MBA and Steven Waldren, MD

Dozens of standards are in use today that have to do with health information, communications, and technology.   The purpose of this brief essay is not to comment on the value or usefulness of any particular standard, but instead, to describe some of the ways in which new standards come into being. What we will discuss are the ingredients that are necessary to take an idea for a standard to its use in the real world, that is, to production. We'll also touch upon the ways in which a standard development process can be forced to take a detour or even be stopped dead in its tracks.

One way to make YourStandard a production standard would be to get people to use it. If enough people make use of YourStandard, it will become a standard.   Using this pathway to standardization is often referred to as de facto standard development, and there are literally hundreds of examples of de facto standards, from Microsoft's Windows operating system to the XML tagging and schema of e-prescribing information used in SureScript's network exchange hub. Another way for a group of individuals or organizations to develop a standard involves going through a formal consensus drive standard development process, another option is to require the use of the standard through regulation. Prime examples in health care IT are the transaction code sets required in the HIPAA regulation and the e-prescribing standards required in the Medicare Modernization Act. Regulation can be a strong instrument to drive the adoption of a standard, yet unfortunately it usually means that there is a market failure relative to the standard.

It is the nature of technology markets that product makers want things "to fit together." For this reason, there have evolved many paths to the development of standards. Each path grew out of need to support a combination of timeliness, acceptance, distribution, and maintenance. All paths are valid; the choice depends on the needs of the entities coming together to produce the standard.

Notable Quotes:

- "If necessity is the mother of invention, the market is its god."
- "Henry walked up and had some of his own medical record on his USB drive." (a better idea!)
- Google and Microsoft have entered the field with consumer organized health information.
- "You've really screwed up. The CCR is great but you haven't chosen a vocabulary. You can't be interoperable until you do." (Adam Bosworth)
- Wild cards: regulation, espionage and dirty tricks, coexistence, proprietary interests/fees.
- "The closer the use of a standard is tied to consumer-oriented business cases, and to use cases in support of those, the more likely it is to be developed, maintained, and used.
- "Business case trumps theoretical use-case."
- "Standards can be as much about protection of an industry or the companies in that industry, as it can be about progress or innovation."
- Compete to solve problems not yet addressed, rather than for a place amongst the existing players.

Reactor, Paul Biondich (Regenstrief Institute, Inc)

- "I practice and build systems around the practice. . . I write code AND use it."
- "The work that needs to be done is not about transport and communication between systems, but in terminology and vocabulary."
- Alternative approach is to take existing standards and use them to achieve tasks.
- Primary care lacks involvement—the primary care organizations need to make an investment in standards development, harmonizing with reference terminologies.
- "Where does primary care end and specialty care begin?" "What is the desired granularity of the vocabulary?" "Build in refreshment processes."
- "You can never plow a field by turning it over in your mind; I'm nervous about people who dream."

Collaborator Panel

Convened by Marjorie Greenberg, Executive Secretary for NCVHS and Liaison to the World Health Organization

Marjorie Greenberg for Simon Cohn (Chair of the NCVHS)
- NCVHS is holding forth, is engaged, cares—especially about communication among providers that improves quality.
- NCVHS has recommended as core terminology SNOMED, LOINC, RxNorm.
- Lots of others in use that need to be harmonized.
- Committed to following up with this group at the NCVHS meeting.

Kin Wah Fung (National Library of Medicine)
- "An info-mortician."
- "Whatever this conference decides, you will find the NLM to be an ally in getting it done."
- "UMLS organizes medical terms according to their meanings, sweeping them into a concept unit identifier, that never changes, never are lost for future reference. It is a common data platform for the distribution of terminologies, specifically for the HIPPA-covered data sets."
- "Three mapping projects are underway at NLM."
- UMLS distributes terminologies, free of charge, and provides a mechanism for harmonizing data standards through mapping and publishing validated mappings.

T. Bedirhan Ustun (World Health Organization)
- "We're not re-inventing the wheel, we are designing the wheel for the future, and actually are interested in transportation."
- "All countries are re-inventing primary care."
- "How do we convert our analogue practices into digital world?"
- "Computers are stupid; they don't ask questions."
- Transforming primary care AND digitalizing health care at once—can lead to insufficient success, blaming the wrong party.
- Remember mental health and personal functioning.
- "A rose is a rose in either primary care or specialty care."
- "Must have an information system that can zoom in and out."

- Ontology=an explicit operationalization of a domain. "Ontology can bring us out of (this mess.)"
- "The biggest flaw in ICD is defining diseases without defining what a disease is." (We need some type of rubric indicating if a term is useful in primary care, specialty care, research, and national statistics.)

Robert Barker (NextGen)
- "My job is to help my company make money."
- "80% certainty of the right information is not good enough." Zero error in mapping and interoperability to other clinical IT applications is expected.
- "Competing vendors of clinical IT services work together to get to standards to avoid redundancies and expense."
- "You have to go through HITSP and on to CCHIT, if endorsed."

Group responses after Collaborator panel:
- "What we heard about at lunch is not about a coding system, but a model of care that requires a substantial remake of existing information systems."
- "Maybe we need a primary care focus in IHE where the conceptual model of information can be established."
- Get over the assertion that the existing systems can provide the services and outputs primary care requires.
- "I listen to this with great interest as a patient, encouraged by shifting emphasis from coding to information management.
- Primary care does not have the capital to get this going—a billion dollars or so for a start
- "The computer companies can't and won't solve this problem. The House of Medicine needs to. . .capture the essence of medical practice."
- "Computer companies are getting doctors used to using computers."
- "This conversation today is getting more at the problem than any group I've been in yet, and that's encouraging."
- "The typical clinician will not be present in the venues where key decisions about standards are made."
- "Show up."

- Functional requirements, ordering principles, data standards, and vocabularies can move along together, but those who care must focus to get results.
- "I don't understand 80% of what went on here today—and I don't want to."

Primary Care, the Medical Home, Personal Doctoring, and Classification and Data Needs

Larry A. Green, MD
University of Colorado Health Sciences Center
Department of Family Medicine

Primary care has been characterized by it attributes of comprehensiveness, continuity and longitudinality, accessibility and point of first contact, affordability, and accountability. These attributes service a critical, foundational function in health care systems that the US Institute of Medicine (IOM) defined as, "The provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community."[1,2] The nature of primary care is complex. It is grounded in both the biomedical and the social sciences; clinical decision making in primary care differs from that in specialty care; primary care has at its core a sustained personal relationship between patient and clinician; primary care does not consider mental health separately from physical health; it has important intrinsic opportunities to promote health and prevent disease; and primary care is information intensive.[2]

The IOM emphasized that primary care is *primary* not in the sense of simple or easy, but rather as care that is first, foremost, and fundamental. It is this function that is known to make health care more effective, efficient and equitable. Nations with better primary care have better results with lower expenditures.[3-7] Given the high cost, mediocre performance (in terms of population health statistics), growing numbers of people without means of payment for health care[8,9], and unsustainability of current expenditure patterns of the current US health care system[10], there is an urgent need in the United States to revisit

primary care and how it is organized and enabled. The nation's health depends on it.

The sheer size of the primary care enterprise is captured in the ecology of care model that quantifies for the population where people actually get health care. The numbers of individuals per thousand receiving care in various settings each month has been amazingly persistent for more than 40 years, despite major changes in health care delivery and financing.[11;12] The most recent estimates indicate that of 1000 people of all ages and backgrounds in the US, in a typical month some 800 identify a health concern of some sort, with 327 contemplating getting medical care. Of these 1000 individuals, about 217 actually see a physician in a doctor's office each month, with a slight majority of these visits occurring in primary care physician offices, i.e. the offices of family physicians, general internists, and general pediatricians.   These numbers dwarf the numbers of individuals getting care in complementary medicine settings (65 per 1000), hospital outpatient clinics (21 per 1000), by home health care agencies (14 per 1000), in emergency departments (13 per 1000), in community hospitals (8 per 1000), and in academic health center hospitals (less than 1 per 1000). Thus, the largest platform of formal health care delivery in the United States is the primary care physician's office. This platform has been based on clinical structures that date back to the early 1800's in France, and has labored under a mismatch between its aspirations and opportunities and its capacities and technologies— until now.

Primary care represents medicine's biggest information management problem. By definition, all health problems exist in primary care; and by virtue of its integrating function, it interfaces with all other elements of health care. The requirements for information exchange are huge, made even more complex by the contemporary expectation of personal access to medical information by millions of individuals who may or may not be patients, at the moment. It is remarkable that primary care has achieved so much in the pre-information age world. Now that information technologies are maturing sufficiently to help primary care, there are compelling opportunities to deliver unprecedented health care that spans prevention, acute care, and chronic care.

The Medical Home

The "medical home" has emerged in the past two years as the next rendition of robust primary care. The medical home concept was first articulated by pediatricians to draw attention to the need for such a place in the care of children with chronic disabilities and diseases.[13] Decades later, this concept has been augmented beyond a place to receive care to a fundamental shift in the system of providing care. In an extraordinary congruence not often seen, the American Academy of Family Physicians, American Academy of Pediatrics, American College of Physicians, and American Osteopathic Association have all endorsed the medical home concept and agreed on its key characteristics in a statement of joint principles. (http://www.aafp.org/online/etc/medialib/aafp_org/documents/policy/fe d/jointprinciplespcmh0207.Par.0001.File.tmp/022107medicalhome.pdf, accessed 19Oct2007) These principles include:

1. The medical home represents a relationship between an individual and the health care system, that provides a point of first contact, is continuous over time, and provides or secures comprehensive services.
2. The medical home relies on teamwork to get the right things done at the right time.
3. Comprehensive service means that people of every age and background are welcomed into the medical home and that the services rendered or secured for patients are sufficient to resolve their problems to the extent possible.
4. The key function of the medical home is integration of care for a particular individual. Integration means the pulling together of what often are apparently disparate parts into a coherent whole that has meaning for the patient and the health care system.
5. Quality and safety are hallmarks of the medical home, relying on recurring measurements that depend on electronic health records and information technologies sufficient for interoperability across care settings, decision support at the point of care, and assessment of results that matter to people.
6. Access is reliable in the medical home, achieved through face to face visits, but also through other channels including

        asynchronous communications by email, telephone, and via the internet.

7. A crucial characteristic of the medical home is derivative from the above capacities, --value. When the medical home functions correctly, care and results improve and expenditures are more controllable.

These principles and their interactions to provide people with high performance health care are illustrated in Figure 1.[14]

Figure 1
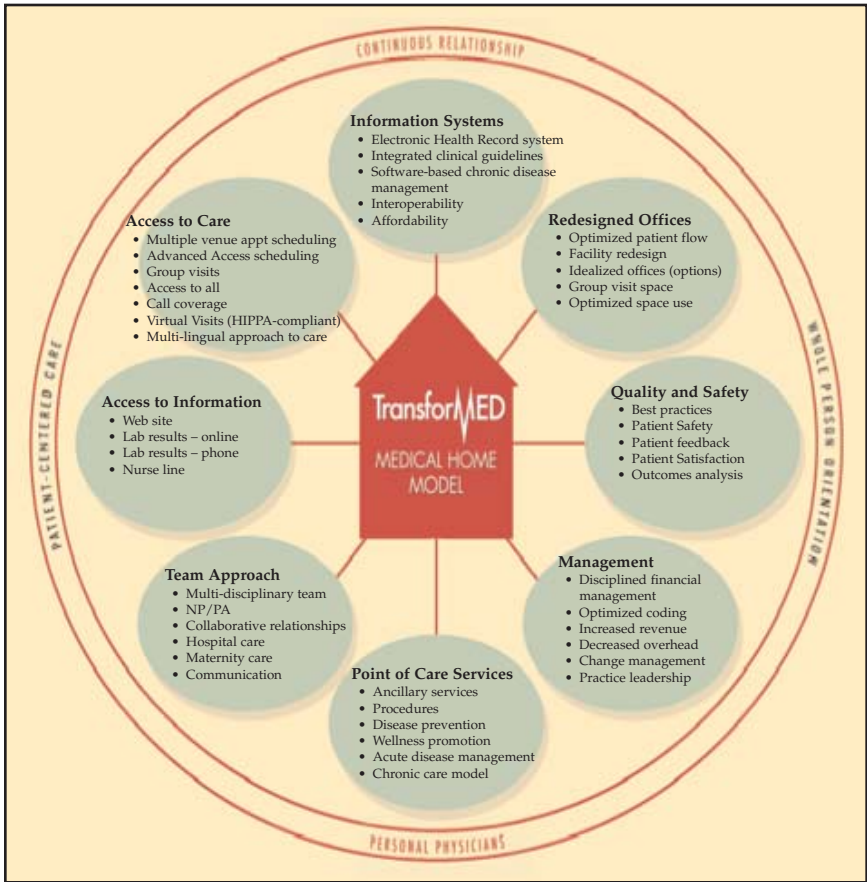
The Personal Physician

The invention during the past half century of a spectrum of "new" health care providers, e.g. advanced practice nurses, physician assistants, and medical assistants, continues unabated with additions from pharmacy and mental health as well as emerging new roles[15], practice change experts[14], and on site medical information technologists. People welcome care from these health care providers, and busy physicians welcome their help. Nonetheless, when random samples of people were surveyed and interviewed in 2003, they did not indicate that what they were seeking from the health care system was a medical assistant or personal nurse. They wanted a personal physician, but often indicated that unfortunately, they no longer existed, revealing a lack of discrimination among the general public concerning the various types of health care providers.[16;17] This comports with history and the belief that all societies create a special role for a respected healer. While some might envision a brave new world of more than 300 million individuals being their "own doctors," diagnosing themselves and shopping on line for the best price for what they conclude they want, most people, especially those with one or more chronic illness, hope to have a personal physician on whom they can rely for expert advice and help, when they need it.

Such a "personal physician" is destined to populate "medical homes." The nature of this physician and his/her role was captured with remarkable clarity by Sir T. F. Fox, nearly half a century ago.[18] His words ring relevant and true today:

"The doctor we have in mind, then, is no longer a general practitioner, and by no means always a family practitioner. His essential characteristic, surely, is that he is looking after people as people and not as problems. He is what our grandfathers called "my medical attendant" or "my personal physician"; and his function is to meet what is really the primary medical need. A person in difficulties wants in the first place the help of another person on whom he can rely as a friend—someone with knowledge of what is feasible but also with good judgment on what is desirable in the particular circumstances, and an understanding of what the circumstances are."

"The more complex medicine becomes, the stronger are the reasons why everyone should have a personal doctor who will take continuous responsibility for him, and, knowing how he lives, will keep things in proportion—protecting him, if need be, from the zealous specialist . . .The personal doctor is of no use unless he(she) is good enough to justify his(her) independent status."

"An irreplaceable attribute of personal physicians is "the feeling of warm personal regard and concern of doctor for patient, the feeling that the doctor treats people, not illnesses, and wants to help his patients not because of the interesting medical problems they may present but because they are human beings in need of help."

"Personal medicine must be more closely related to specialist medicine than it often is at present . . . the personal doctor should preserve a measure of geographical and psychological independence from the specialists and their elaborate institutions."

These eloquent statements were based on personal observations of the United States, from West Virginia coal mining towns to Kaiser clinics to Harvard. They ring true today and were echoed in the findings of the recent Future of Family Medicine project that people are hungry for " . . . a doctor who will stick with me, even if I have the wrong problem, and need to go somewhere else."[19]

So What Does This Have to Do with Classification and Data Needs
A classification is a set of ordering principles. The ordering principles of the US health care delivery system emphasize data capture and distribution necessary for billing, and diagnostic coding systems in use are built on a system begun to describe autopsy findings. It is illogical and counter-intuitive to assume that the ordering principles and coding needs of the medical home and personal physicians are and will be met by classifications and coding schemes suitable for insurance adjudication and subspecialty medicine. The very nature of the medical home enterprise is specific, with particular needs for data acquisition and use.

This is a propitious moment. The design of the nation's health information infrastructure coincides with the re-design of the nation's largest platform of formal health care delivery. The ordering principles, terminology, and coding can and should be harmonized and implemented in a way that enables, rather than tortures, frontline health care in the new models of practice now emerging. This is an opportunity not to be missed.

Data and Classification Needs of the Medical Home
The medical home, like the rest of health care, must attend to confidentiality and privacy issues, point of care evidence-based decision support, reporting requirements and accountability, and data and processing standards sufficient to support data exchange across the spectrum of locations and types of health care ("interoperability"). As in other health care settings, the routine use of information systems should enable, not distract from, care centered on the patient. The nature of the medical home and the work of personal doctoring, however, would be expected to require some particular capacities, just as the surgical suite, the imaging department, the clinical laboratory, and the emergency department. To some extent, the classification and data needs of the medical home and primary care have not yet been perceived in the United States to merit explicit design and careful implementation. These needs of the medical home include a host of opportunities worthy of immediate attention, including the following:

1. The medical home, by design, is population-focused, on patients who claim a particular practice location as their medical home, where they

can receive the care they need from their personal physician and expert team.   Accurate and current listings of the patients for whom the medical home is accountable (registries) are essential for associating patients and personal physicians, denominating rates and measures, analyses of performance, outreach and follow-up, and in short, the integration of comprehensive services needed for acute care, chronic care, and prevention. It is not possible to provide outstanding, patient-centered care without knowing who the patients are and who is responsible for them. Such a capacity requires unduplicated identification of patients, registries, and designation of the medical home and who is the personal physician.   Personal medical records, and specifically summary documents, should include a modifiable field that indicates each person's medical home and personal physician.

2. The medical home sits at the interface between people with any and all of their health related concerns—and---the full capacities of the entire health care delivery system. Many, but not all, of these concerns that are brought by people constitute a clinical problem for which a response by the health care system could be expected to do more good than harm. Obviously, why people come is of crucial importance to those working in the medical home, and vocabularies and classifications used to capture and order these reasons from the patients' perspectives are necessary. These initial contacts now come in face to face visits, phone calls, emails, and webpage entries. This is the granular substrate that ignites the entire health care enterprise and around which the medical home must organize its work, staffing, policies, and procedures. Information from the patient's perspective about why they want some help is distinctly different from professionally processed diagnoses that emerge after care is rendered. Unfortunately today in the United States, there is no sufficient repository of this critical, patient-centered information; and it will not exist to guide patient-centered care until appropriate classification, vocabulary, and coding is established.

3. Patient-centered care is enabled when the health care system and the patient agree about the problem to be addressed and how to approach it. Clarity as to the goal(s) achievable that the patient wants is very important, but not often declared explicitly. A reliable way of recording and updating goals for particular patients that is incorporated into their

medical record would be an important enabler of the integrated, patient-centered care the medical home aspires to provide.

4. There is an adage that it is usually better to be roughly right than precisely wrong. This adage is pertinent to the medical home and its classification and coding needs. At this level of health care it is important to sort problems in terms of importance, urgency, and treatability, as well as in terms of risks, findings, diseases, and diagnoses. Extremely precise labels and codes are often inappropriate. Indeed, premature closure to obtain "false precision" is contraindicated. Real medicine, like real life, is always provisional at some level. In the medical home it is very important to sort the patients' concerns into the right territory to assure timely, correct treatment.

At this level of health care, for example, determining the fatigue that bothers a patient might be depression, cancer, or an autoimmune disease needs to be established, and while evaluation proceeds it needs to be labeled "roughly right," as fatigue that is important and needs the attention of the health care system, but not yet as bipolar disease, lymphoma, or rheumatoid arthritis. The medical home needs a convenient way of using a manageable and relatively small number of codes to label appropriately and track all the patients' particular concerns, troubles and diseases to help guide their on-going, longitudinal care.

Many "problems" patients have *never* become diagnoses, and remain "undiagnosable" despite any amount of consultation and testing. These problems are best left as what they are, problems that concern a patient but for which a specific treatment is not indicated. Many opportunities to promote health should not even be considered a problem or diagnosis, e.g. to exercise more often than at present or to eat more fruit and vegetables.

A classification, vocabulary and coding system that expects a mix of concerns of uncertain significance, signs and symptoms, opportunities and needs, diseases and diagnoses is important in the medical home. Its basic structure would begin with what concerns the patient, and it

would assume that this concern might evolve over time and be labeled differently according to the most recent understanding of the situation.

5. In the medical home, continuing relationships between patients and personal physicians anticipates and expects ongoing interactions, during which problems evolve or resolve and service continues when problems require subspecialty clinical and community-based services. One of the most important units of analysis to learn more about medicine and enhance the performance of the entire health care delivery system is an episode of care. Episodes of care add the effects of time to other currently reported data, such as visits or diagnoses. A hospital discharge summary characterizes an episode of hospital care for a defined period of time, represents and example of an episode of care in a hospital setting, and is more useful than a mere notation that the patient was hospitalized. In the medical home, all sorts of episodes of care occur that are not usefully captured by the mere noting that a visit occurred or that a diagnosis was made. Some episodes are short, some are longer, and some never end until death.

The classification and coding approach for the medical home should be able to organize care into episodes concerning particular problems that patients have and what is done for them. Such analyses are essential to assess efficiency of care, so crucial to sustainable health care for the nation. Such episodes must have meaning to patients, clinicians, and payers.   A classification system appropriate for the medical home and longitudinal doctoring by personal physicians would order problems and treatments into episodes so that outcomes and value is knowable, and so that both diagnostic and prognostic capacities of the medical home are improved and care is rendered safely.

6. The integrating function of the medical home requires information sharing with potentially every other component of the health care system as well as with patients and their families. Thus, the classification, coding, and data processing standards used must connect readily (harmonize) with classifications, coding, and data processing standards used elsewhere in the health care system (images, laboratory results, consultation reports), and in the homes of patients.   Particularly important, if elusive, opportunities await having connectivity amongst

the medical home, public health, mental health, and community-based services needed for prevention and chronic disease care. The idea of "interoperability" is not elective in the medical home. The internet is essential infrastructure, and a data standard that summarizes key patient-centered data that can travel with the patient and across the internet would be a great enabler of sharing critical, summary information across settings.

Two Examples of Why There is Urgency in Getting On With Explicit Classification and Data Standards for Primary Care and the Medical Home

Until the health care system is organized to integrate care for patients instead of fragmenting it, the effectiveness of health care will be less than what is achievable and expenditures for health care are likely to be uncontrollable and escalate beyond sustainability.[10;20] The "medical home" is to a large extent the rediscovery of primary care in the information age.   Its value has been captured by HealthPartners in the following figure (Figure 2).   This figure acknowledges the 80/20 rule about 80% of expenditures for care involving 20% of patients and illustrates the evolution of health problems over time. It accurately presents the huge opportunity for the medical home to operationalize "moving people from right to left and keeping them there." In the grand scheme of medicine, this is a huge opportunity to create value for individuals and the nation and help address the compelling policy issues of timely care and economic sustainability.

Figure 2
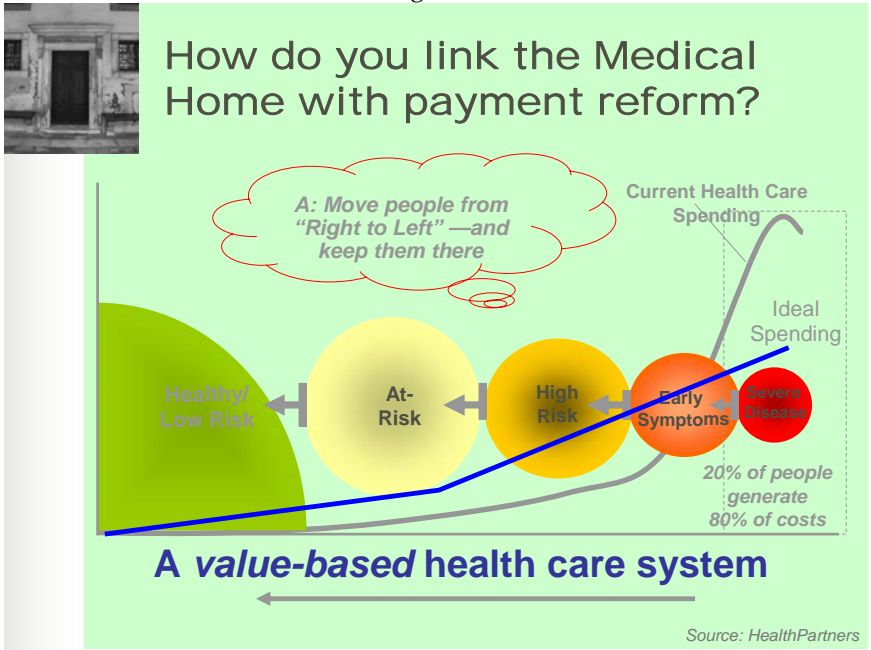
Source: HealthPartners
Used with permission

Another example of why getting classification, vocabularies, and coding right in the medical home are substantial gaps in medical knowledge that depend for their resolution on active discovery processes within the medical home. Two pressing examples of work needed now are (1) linking genetic discoveries to real people with real problems and (2) determining the prognosis of early complaints, signs, and symptoms and how they do and do not connect to current conventions for naming diseases. Medicine's book of knowledge will never be sufficient until this type of work is undertaken; leaving the work of frontline clinicians distorted and impaired by unresolved selection and observer biases inherent in knowledge derived from other populations of people in other health care settings.

Conclusion
The largest platform of formal health care delivery needs and deserves classifications, vocabularies, and coding systems aligned with its work. The availability of modern information technology now coincides with

the formulation of the concept of the medical home with a personal physician. This idea is attractive to and supported by many clinicians, patients, and policy-makers and presents another opportunity for progress. The redesign of primary care practice to further enable personal doctoring within a medical home and the creation of the nation's health information infrastructure are underway. This gives impetus to getting on with whatever it takes to establish classification, terminology and coding to enable high performance frontline health care. There is an urgent need to at least: (1) secure patient registries, (2) capture patients' concerns as they present them for care, (3) establish and record patients' goals, (4) accurately label the troubles and problems that fill the work-day of those in the medical home, (5), organize clinically meaningful episodes of care, and (6) exchange health-related information among the medical home and other health care settings needed to resolve patients' problems correctly.

Immediate progress in establishing excellent primary care through personal physicians in medical homes is "trying to happen" now. Evidence to date supports moving in this direction and predicts a salutary impact on individuals and the nation. Optimizing performance at this level of care and integrating patient-centered primary care with the entire health system depends in part on establishing explicitly the classification, vocabulary, and coding systems suitable for routine daily use. It is time for action.

References

1   Institute of Medicine. Defining primary care: An interim report. Washington, D.C.: National Academy Press, 1994.

2   Donaldson M, Yordy K, Lohr KN, Vanselow NA. Primary care: America's health in a new era. Washington,DC: National academy press, 1996.

3   STARFIELD BARB, SHI LEIY, MACINKO JAME. Contribution of Primary Care to Health Systems and Health. The Milbank Quarterly 2005; 83(3):457-502.

4   Baicker K, Chandra A. Medicare Spending, The Physician Workforce, And Beneficiaries' Quality Of Care. Health Affairs 2004;hlthaff.

5   Franks P, Fiscella K. Primary care physicians and specialists as personal physicians: Health care expenditures and mortality experience. J Fam Pract 1998; 47:103-104.

6   Macinko J, Starfield B, Shi L. The contribution of primary care systems to health outcomes within organization for economic cooperation and development(OCED) countries,(1970-1998). HSR: Health Service Research 2003; 38(3):831-865.

7   Starfield b and Horder J. Interpersonal continuity: old and new perspectives. Br J Gen Pract, July 2007:527-529.

8   Collins S, Davis K, Doty M, Kriss J, Holmgren A. Gaps in Health Insurance: An All-American Problem. Commonwealth Fund . 2006. Commonwealth Fund.

9   Collins S. Congressional Testimony-- Universal Health Insurance: Why It Is Essential to a High Performing Health System and Why Design Matters. 6-26-2007. Committee on the Budget, US Senate.

10 DeVoe J, Dodoo M, Phillips RL, Jr., Green L. Who will have health insurance in 2025? American Family Physician 2005; 72(10):1989.

11 White K, Williams T, Greenberg B. The ecology of medical care. N Engl J Med 1961; 265(18):885-892.

12 Green LA, Fryer GE, Yawn BP, Lanier D, Dovey SM. The ecology of medical care revisited. N Engl J Med 2001; 344(26):2021-2025.

13 Sia C, Tonniges TF, Osterhus E, Taba S. History of the Medical Home Concept. Pediatrics 2004; 113(5):1473-1478.

14 Sullivan D. TransforMED tries to Rebuild Family Medicine. Family Practice Management 2007; 14(5):21-28.

15 Woolf SH, Glasgow RE, Krist A, Bartz C, Flocke SA, Holtrop JS et al. Putting It Together: Finding Success in Behavior Change Through Integration of Services. Annals of Family Medicine 2005; 3(suppl_2):S20-S27.

16 Family Practice Working Party, Organization of Academic Family Medicine. Future of Family Medicine. Future of Family Medicine Task Force . 2003. 8-11-0003.

17 AAFP, AAFP Foundation, American Board of Family Practice, Association of Departments of Family Medicine, Association of Family Practice Residency Directors, NAPCRG et al. The Future of Family Medicine. Ann Fam Med 2[Supplement 1], s3-s32. 2004.

18 Fox TF. The personal doctor and his relation to the hospital. Lancet 1960; 1:743-760.

19 Green LA, Graham R, Bagley B, Kilo CM, Spann SJ, Bogdewic SP et al. Task Force 1. Report of the Task Force on Patient Expectations, Core Values, Reintegration, and the New Model of Family Medicine. Annals of Family Medicine 2004; 2(suppl_1):S33-S50.

20 Institute of Medicine. Crossing the quality chasm: A new health system for the 21st Century. Washington, DC: National Academy Press, 2001

Classifications, Terminologies, and Their Use in Primary Care Health Information Technology: Towards a Primary Care Data Model

Michael S. Klinkman, MD, MS
University of Michigan
Department of Family Medicine

What are the most important ordering principles for primary care that MUST be captured by a primary care classification, and how? What elements that comprise the domain of primary care are NOT documented sufficiently to understand and improve health care?

I. INTRODUCTION.
In 2007, four years into the National Health Information Infrastructure effort, we still lack a coherent approach to health information technology (HIT) to support primary heath care delivery. The Future of Family Medicine Task Force report envisioned that the electronic health record would be the core enabling technology to implement the New Model of Family Medicine.

> *"A standardized electronic health record, adapted to the specific needs of family physicians and the patients they serve, will constitute the central nervous system of the New Model Practice."*
>
> *"…electronic health record systems must permit the collection, analysis, and reporting of the clinical decisions and their outcomes that primary clinicians make every day."*
>
> *"The system should provide an informatics infrastructure that supports practice-based research, quality improvement, and the generation of new knowledge."*

We are nowhere near to realizing this vision. Our collective failure to develop and promote standards for primary care data exchange has led to HIT chaos: private-sector electronic medical record vendors create and sell expensive products that do not meet the needs of primary care physicians, physicians struggle to adapt their workflow to conform to the structure of EHRs, and progressively more granular data is entered into systems from which it can not be meaningfully extracted. *We cannot demonstrate the value of primary care to the health system until we can accurately enter and retrieve data about the core processes of primary health care.*

In order to regain control over our HIT future, we must develop and collectively agree upon a primary care data model that contains the core data elements that describe the clinical domain of primary care. We must then work to gain acceptance for that model in the NHII and to embed that model in all primary care EHR products. This paper describes a primary care data model, how it might be operationally constructed using available components, and our collective experience to date with those components.

II. THE NEW MODEL "MEDICAL HOME" IN ACTION: MRS. WHITE

Mrs. White, a 55 year old woman you have known for years, books an appointment to see you this afternoon, and electronically submits from home her reasons for encounter - new symptoms of fatigue and nausea and discussion about screening tests. When she arrives, your EHR face sheet displays her active health problems (overweight, dyslipidemia) and medications (lovastatin), and prompts you that she is in need of a mammogram. As you clarify her symptoms and enter them into her record, you run a decision support routine that uses your PBRN's longitudinal epidemiologic database to calculate a list of likely diagnoses and their relative odds ratios for primary

care patients in her demographic group. You discuss these possibilities with Mrs. White, decide to assess the most likely diagnoses with laboratory tests, and confirm that she has new-onset Type 2 diabetes.

Entering her diagnosis into her record automatically enrolls her in your practice diabetes registry, sends an email notification to her with the website for on-line patient education and asks her to schedule a visit with your practice nurse, who does diabetic training sessions. She self-monitors glucoses and posts results to the practice through the secure patient portal, where they are forwarded to your nurse who reviews the pattern of results. After a brief honeymoon period, her glucoses rise and you send her an email message to begin metformin, and send to her local pharmacy an electronic prescription for metformin.

At her follow-up face-to-face encounter with you 3 months later, your EHR prompts you to carry out initial diabetic care measures and reminds you that her last recorded LDL-C is above target range. You spend much of this encounter discussing how she is adapting to her diagnosis and helping her set treatment goals, which are entered into the record. After the visit, she continues to monitor and forward her home glucose readings for review and adjustment of medications, and forwards all questions to the practice through her patient portal.

As a new member of the diabetes disease registry, her data are included in the practice summary report on diabetes disease management compiled every 6 months for review within the practice and forwarded yearly to her insurance company to calculate pay-for-performance bonus payments.

All of these functions can be carried out using existing HIT, but they have not yet been integrated into a platform that can function within the severe workflow constraints of primary care. Successful integration will require a simple and robust primary care data model.

III. ESSENTIAL COMPONENTS OF A PRIMARY CARE DATA MODEL.

A model must reflect, as accurately as possible, the clinical domain of primary care. If that domain is "taking care of people who have problems over time in the context of their personal lives," we need to collect meaningful data about *people*, the *problems* that affect their health now, the problems that they are *at risk* to develop, how *time* affects the care we deliver, and the *context* in which care takes place. We also need to be able to collect and report out data about the quality of care we provide for a growing list of medical conditions. These data elements must be collected during routine clinical workflow, which includes brief contacts over telephone or Web, indirect contacts through ancillary providers and practice staff, as well as direct clinical encounters. Simplicity and transparency are essential to this process.

> *"It's the core clinical office of transactions, of note taking, of record keeping, of data access that still is languishing, and no surprise – they're the most complicated in terms of technology, culture, and workflow, and I think they're obviously the next big area."*
> *- David Brailer, MD, PhD, National Coordinator for Health Information Technology: Interview published in BMJ, 16 October 2004*

The key **structural components** for a data model capturing the process of personalized health care include, at a minimum:

- **Episode structure**. This enables clinical data to be placed in the context of time. Without this structure, clinical data loses much of its meaning and its validity (see below).
- **Patient background**. This includes demographic, social, geographic information, much of which is currently captured by paper and electronic records.
- **Active problems**. This is in concept similar to the "problem list" in current practice; these are the health problems currently known to and addressed by the clinician or practice. It does not contain previously-experienced clinical events (example: hysterectomy) or risk factors that do not represent active conditions. In a model that adheres to the episode structure,

each active problem has a "history" tracing its path from initial reason for encounter (first point of contact with the health system) to its current status. This feature enables the calculation of specific disease probabilities for presenting symptoms as well as the proportion of symptoms that resolve without diagnosis.

- **Clinical modifiers**. This component includes previously experienced clinical events or risk factors that are important to the care process but are not active clinical problems. These might include significant medical events (the hysterectomy excluded above, MI, old CVA) and risk factors (genetic, biochemical or historical).

- **Patient goals, preferences, and requests**. This component provides a place to capture patients' expressed goals, priorities and preferences for care, limits to care (advance directives fit here), and the reasons why patients choose to seek care (the *reason for encounter*, the starting point of most episodes of care).

- **Process data**. This component includes data describing the decisions made in the course of care: laboratory or ancillary service use, referral decisions, procedures performed, pharmacy orders, exception or error reporting, and disposition (follow-up plans).

- **Information exchange protocols.** This component will enable interoperability of clinical data: for example, the incorporation of important data obtained outside of the practice (cardiac catheterization conducted by a cardiologist to investigate chest pain) or structured export of data to assist consultants when referral is made.

When stored in an EHR database, data from these components can be assembled, retrieved, and displayed to support clinical workflow, clinical decision support, quality assessment, and standard and ad hoc data analysis and reporting. Examples of useful individual patient data views would include: an episode view (disease-specific care over time), data view, chronological view, visit view (the standard view of current EHRs), and specific summary views ("dashboard" views, Summary Record view), and "outstanding issues" view (open prompts or clinical reminders) (see Figure 1).

Inputs, Structure, And Outputs In The Primary Care Data Model

INPUTS	STRUCTURE	OUTPUTS (VIEWS)

Aggregate views
  Disease registries
  HEDIS
  Quality assessment
  Comorbidity

Patients
[templates or interface terminologies]

Person:
  demographics
  social structure
  goals, preferences

Aggregate longitudinal views
  Prior probabilities
  Posterior probabilities
  Episode analysis
  Risk factor-to-disease

Problem(s):
  current/active
  severity

Clinicians
[natural language, interface terminologies, classifications]

Clinical Modifiers:
  prevention
  risk factors
  Significant events

Cross-sectional patient views
  Active problems
  "dashboard"
  summary [CCR]
  severity monitoring
  prompts, reminders
  visit view [template]

Actions ("Process"):
  Decisions
  Interventions
  Plans
Time:
  Episode structure

Automated data feeds
[HL7, XML]

Longitudinal patient views
  episode history
  comorbidity

Data import/export:
  Exchange protocols

User-defined views
  Third-party payors
  Statistical reporting
  Patient safety

How can all this be accomplished within the time and simplicity constraints imposed by primary care workflow? We must build with a small set of very simple components, and offload data entry from the clinician at the point of care wherever possible.
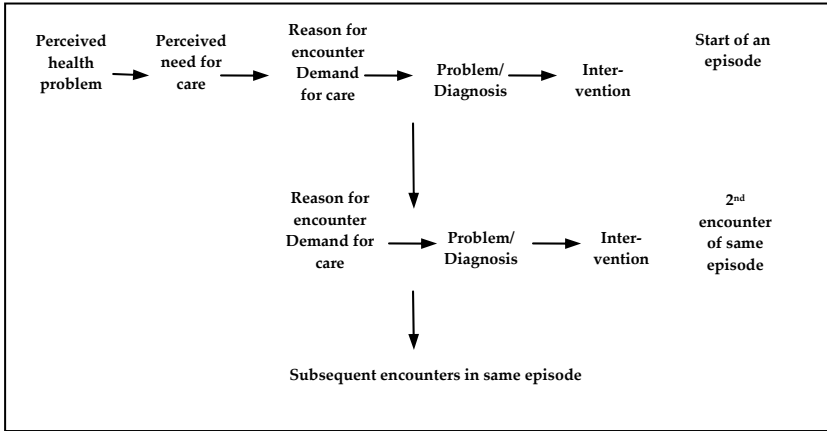
IV. OPERATIONALIZING THE DATA MODEL: AVAILABLE TOOLS.

1. ICPC: providing the episode structure of the data model

The International Classification of Primary Care (ICPC), first published in 1987 under the auspices of Wonca (the World Organization of Family Doctors), provides the best available framework for the data model. In its current version, ICPC includes three of the structural components listed above, **episode structure**, **active problems**, and (limited) **process data**, and its next version will address clinical modifiers and patient goals and preferences as well as providing improved process data.

ICPC was designed to capture and code three essential elements of each clinical encounter: the patient's *reason for encounter*, the clinician's *diagnosis*, and the (diagnostic and therapeutic) *interventions*, all organized in an *episode of care* data structure that links initial to all subsequent encounters for the same clinical problem (see Figure 2). With fewer than 1000 rubrics organized into 17 body system chapters, its alphanumeric codes are easy to master, and the specific diagnostic terms include all diagnoses with a prevalence of more than 1.5 per 1000 patients. This approach permits coding of 95 percent or more of primary care encounters, and enables the calculation of prior and posterior probabilities for important diseases [1, 2]. Published experience with ICPC has confirmed the validity of its key elements [3-6], and worldwide experience with ICPC has confirmed its utility in identifying and analyzing the clinical content of episodes of care for several common primary care problems [1, 2, 4, 6].

FIGURE 2: SCHEMATIC VIEW OF EPISODE OF CARE.

Perceived health problem	Perceived need for care	Reason for encounter Demand for care	Problem/ Diagnosis	Inter- vention	Start of an episode

Reason for encounter Demand for care → Problem/ Diagnosis → Inter- vention

2nd encounter of same episode

Subsequent encounters in same episode

The importance of the episode structure in primary health care.
Family physicians manage problems over time, and a second, third, or fourth encounter with a particular patient for a specific problem does not begin at the same point as a first encounter. Knowledge gained at a first encounter affects decisions made at subsequent encounters. Tests are ordered one time and not repeated. Diagnoses can and do change. Patient preferences are elicited or learned and later used to guide decisions. The element of time itself can serve as a substitute for investigation of a problem.   None of these core aspects of primary health care can be assessed if actions are taken out of the time or episode context in which they occur.

An episode of care, defined as "a series of temporally contiguous health care services related to a specific health problem or provided in response to a request by the patient" [7, 8], follows a clinical problem from its presentation to its resolution. It provides the most accurate representation of the process and cost of health care delivery for a particular problem [7, 9-12].   In ICPC, the starting point for an episode of care is the reason for encounter (RFE) as expressed by the patient, which codifies a patient-centered approach to care.   Several studies have confirmed that the RFE has a powerful influence on the process and outcome of an episode of care [13, 14].

In ICPC the episode of care can be operationally constructed. It begins with a new RFE and ends at the last encounter in which the problem is addressed. Acute and chronic health problems can be distinguished by rule (example: asthma is by rule a chronic problem with no end to the episode of care) or by clinician decision that the specific problem has resolved. More importantly, ICPC accommodates the recording and tracking of multiple episodes at each encounter, enabling an accurate capture of the breadth of clinical work performed at the encounter. This is critically important. Primary care clinicians often manage several health problems at once: the average number of problems addressed during a primary care encounter ranges from 1.3 to 5.1 [15, 16] (also, unpublished data, University of Michigan Department of Family Medicine). To accurately measure the quality and effectiveness of primary care, this breadth of effort must be accounted for.

The episode construct is also important in understanding care for chronic health conditions. Chronic conditions often begin as acute complaints, and failing to record the transition between these states will distort our understanding of the natural history of chronic health problems [2, 4, 6, 17]. Patients with chronic conditions progress through stages of care as well as stages of severity, and the process of care varies depending on the stage. For example, at the time of initial diagnosis of hypertension clinicians may perform studies (laboratory studies, echocardiography, etc), arrange consultation with nutritionists, and prescribe medications in a flurry of activity, then see patients only occasionally for prescription refills – unless blood pressure is not controlled, which may initiate another flurry of visits and medication prescriptions. The chronic episode of hypertension could be divided into "in-control" and "out of control" stages, and the portion of time in each could be used as one measure of quality of care. Alternatively, the episode could be divided into simple and complex hypertension based on the presence of target organ damage, or divided into one-year time blocks. If clinicians simply record what they do using simple codes, the episode can be sorted or staged retrospectively to meet specific analytic needs.

There are several important questions about the content and quality of primary health care that can only be answered with episode-oriented data [18]. For example, estimating the quality of care for major depressive disorder requires knowledge of whether the patient is in the acute or

maintenance phase of treatment, and the arbitrary partitioning of claims data to establish treatment phase is both cumbersome and inaccurate [19-22]. It is not possible to accurately assess the impact of medical and mental health comorbidity on quality and outcomes of care without understanding the temporal relationships between problems, or whether they are actively being addressed during an observation period.

Barriers to ICPC adoption in the U.S.

The primary barrier to the use of ICPC in the US has been its lack of specificity. With only 686 available codes for diagnosis, in its native form it clearly can not provide the level of granularity necessary for individual patient records. Its value in the era of EHRs is that it structures the core data elements of the primary care domain in order to better understand its content. ICPC-2, released in 1998 in paper and 2000 in electronic format, was designed from the start to be incorporated into electronic health record (EHR) software with a conversion map to ICD-10 [5, 23-25].   In this use, the underlying data structure of ICPC provides the "backbone" to enable the proper organization and retrieval of clinical data. This approach has been extensively tested in the Netherlands and Malta, where an ICPC-ICD-10 thesaurus has been embedded in the Transhis EHR software used by dozens of Dutch and Maltese GPs to code diagnoses in both ICPC and ICD terms [6, 26]. More recently, teams in Australia, Belgium, Canada, and the United States have created EHRs using the combination of ICPC plus clinical terminology or ICD mapping [27-30] [plus unpublished Wonca International Classification Committee reports].

The main obstacle to the successful translation of any of this work into the US has been the required link between clinical documentation and payment, which drives commercial medical software development in the US.   Because the US still uses ICD-9-CM as its official classification, it has been impossible to adapt international software that employs an ICPC-to-ICD-10 map. This problem has now been solved. In 2005, the most recent update of ICPC (ICPC-2-R) was published in book and electronic form and provided to all US and Canadian Departments of Family Medicine. This publication included an electronic thesaurus cross-mapping a clinical terminology database to ICPC, ICD-9-CM, and ICD-10 codes [31].

Experience with the full conversion structure between ICPC and ICD has identified areas in which ICPC offers more granularity (symptom and complaint codes, social and emotional problems) as well as areas in which ICD is far more granular (most diagnostic codes).

2. Clinical terminologies/ classifications: providing granular data for individual records

Collective international experience with ICPC and the "native" ICD confirms that classifications are not sufficiently granular to support the diagnostic content of the individual patient record. General diagnostic categories (rash, generalized) do not provide the level of detail required for a patient problem list. To increase granularity of ICD, several countries created extended versions derived from the native classification, generally labelled as ICD- N- XM. In the US, the version currently in use is ICD-9-CM. In other settings, clinical terminologies have emerged, ranging from grassroots efforts to capture clinical content in wording familiar to practicing clinicians (Read codes, ENCODE-FM, ICPC-Plus) to comprehensive hierarchical modelling of clinical concepts (SNOMED) to practical and sometimes *ad hoc* efforts to facilitate assignments of diagnostic codes (pick lists in EHRs).

The content of clinical terminologies includes not only diagnoses, but interventions, procedures, and functional status. SNOMED represents perhaps the best-known effort to create a comprehensive, hierarchical terminology encompassing all concepts in the domain of clinical medicine. Its sheer size, as well as its complexity, has led to the creation of subsets of terms for use in specific clinical settings and efforts to create mappings (to link one or more terms to a specific rubric in a less granular classification).

The combination of a classification and a terminology has been promoted as a way to combine the utility of a classification with the specificity of a terminology when used in EHRs, but their creation and maintenance requires significant and ongoing effort. As described above, developers who have implemented ICPC in EHRs have extended its diagnostic specificity through linkages to one or more clinical

terminology sets, and the ICPC-2-R electronic thesaurus provides a first-effort map between ICPC and ICD-9-CM.

What elements that comprise the domain of primary care are NOT documented sufficiently to understand and improve health care?

V. WHICH COMPONENTS NEED FURTHER DEVELOPMENT?

1. Clinical modifiers.

The paper medical record (or chart) used in primary care often contained a *face sheet*, visible at first glance when opened. In many practices, the face sheet included a loosely-organized list of "significant events," not current diagnoses, that the clinician believed were important to always keep in mind when making medical decisions for that patient. This functionality has been built in to some EHR products, but as a free-text repository that does not enable systematic retrieval or analysis. These significant events, where present, can provide important context when seeking to assess outcomes or improve quality of care. For example, a prior history of hysterectomy can exclude a patient from the denominator in assessing Pap smear rates, and a positive family history of colorectal cancer should lead to prompts for earlier and more frequent screening.

Work to build a typology of clinical modifiers, and to create classification(s) where necessary, has only now begun. It is a high priority for the Wonca International Classification Committee (WICC), which has commissioned a Working Group to develop a typology as a first step toward classification. It will probably be necessary for this group to consult with content area experts in genetic diseases and genomics as this work progresses.

2. Severity and staging of problems.

Some work has been done to link severity assessment to specific health problems. The Wonca/COOP charts and the DUSOI were linked to ICPC diagnoses in pilot work conducted by Wonca and WICC, but neither

approach proved feasible and useful for routine use [32-34].   With the continued development of EHRs, linking outcome / severity assessment tools to specific diagnoses (for example, programming a severity measurement instrument to "pop-up" at each encounter for a patient with a specific health problem) has become possible, but the extent to which these linkages are in everyday use is not known.

Staging of health problems will require considerable conceptual work before a practical solution can be designed. For example, we do not know how to accommodate problems that represent complications of another primary health condition – diabetic neuropathy or retinopathy. Each is dependent on the presence of the "parent" condition diabetes. Do they represent separate problems, or a "complication phase" in staging of a single condition?

3. Patient goals, preferences, and requests.

Some of the pieces that make up this component are already in existence. The *reason for encounter* field has been present in ICPC since its creation, but is not universally used. In current US primary care practice, a distilled version of the reason for encounter is often recorded by office medical assistants prior to the encounter as the *chief complaint(s)*. The utility of the chief complaint is limited in 2 ways: first, it does not capture the patient's own expression (it reflects the assistant's interpretation and filtering); second, as free-text it is not easily retrievable, even if preserved in an electronic record.   While it would be relatively simple from a technical standpoint to introduce the ICPC RFE field in an EHR, it would require considerable effort to retrain primary care clinicians to modify their workflow to elicit and record the RFE.

However, it would be very easy to enable patients to record their own RFE(s) in the EHR at the point of care as one of several related data elements best and most accurately entered by patients. Other elements would include advance directive summaries, specific goals or preferences for care, and patient self-report functional status, HRQOL, or disease-specific severity or outcome measures.   At the University of Michigan, we have explored the feasibility of electronic point-of-care severity monitoring and comorbidity screening for all patients with

depressive disorder; patients complete the required instruments on-line at the beginning of their visit, or from home prior to their visit. This is an area in which progress can be made very quickly, and is another area of focus for WICC.

4. Process data.

Much process data (for example, laboratory test results) can now be entered into patient records through automated data feeds, while other data must be manually entered. ICPC provides a rudimentary classification for process events linked to specific health problems, but revision and expansion of the conceptual framework, as well as linkages to commonly used terminologies (CPT-4), is clearly needed and will be incorporated into ICPC-3. Work on patient safety and error is in its very early stages, and it is unlikely that a consensus regarding classification or measurement will soon emerge.

VI. SELECTED INPUTS AND OUTPUTS IN THE DATA MODEL (see Figure 1).

1. INPUTS

Patient inputs.
Many physician-patient interactions currently take place via routine email. Despite less than optimal security, this *ad hoc* and unstructured communication channel has proven highly valuable for clinical care, but email exchanges are frequently not entered into the medical record. The advent of EHRs has made it feasible for patients to routinely enter information into the health record via direct entry at the point of care or through secure Web interfaces (patient portals). Patient portals can be an integral part of an EHR, or they can be supplied and supported by independent vendors and tightly or loosely linked to a practice EHR.

Regardless of the specific technology, patient input provides a method to operationalize a patient-focused approach to treatment. Patients will be able to:
- Initiate an episode of care through specific requests

- Carry out follow-up indirect encounters for existing episodes of care (for example, posting blood glucose results so that the clinician can adjust diabetes treatment or reporting side-effects from medications recently prescribed)
- Ask general questions that might not of themselves warrant a direct encounter
- Schedule an appointment time for a problem that requires a direct encounter
- At the point of care, enter RFE(s) directly into the patient record for review and response by the clinician
- Complete disease-specific outcome assessment(s) and post results to the record and clinician
- Directly enter background health information, demographic information, and preferences for care into the record
- Access, review, and correct their own health information (subject to potential limitations regarding clinician free text / narrative, for example, psychiatrist clinical notes)

The above list of interaction and service types mentioned above have the potential to enhance or complicate the clinician-patient relationship, and will be difficult to implement if reimbursement for indirect encounters continues to lag behind that of direct visits. Some patients will embrace these new service types to orchestrate a virtual medical home to replace their former physical medical home, while others (including many older or less affluent patients) may not be able to access and manage the technology required. Practices will need to find a reasonable balance point in managing workflow that will expand from the traditional model of individual office encounters to a new model encompassing a range of e-services and direct services. It is not yet clear whether the full "consumer" model of *ad hoc* patient-directed service delivery will work for health care services, as diagnostic evaluation and treatment is not a classic consumer good. For the foreseeable future, a blended model in which primary care practices provide a medical home to guide patients through choices and options will likely be necessary.

Provider inputs.
This is perhaps the single most difficult issue to solve in the transition to electronic health records. Provider time and capacity for direct data

entry is limited while the pressure to code or enter more data at the encounter is increasing. Neither free text entry nor template-driven data entry solve this problem for primary care physicians. Free text limits data retrieval, while templates restrict and constrain entry, particularly for undifferentiated symptoms. It has also proven difficult for clinicians to manage multiple templates during encounters with patients with more than one presenting problem. It is not yet clear what clinical data must be systematically entered at encounters and what form that entry will need to take. The promise of SNOMED-CT is that every clinical data bit (every concept) relevant to care can be coded, entered, and retrieved, but the benefit of carrying this out is not clear and the cost will be very high.

These issues aside, provider inputs can take several forms:

- Provider-initiated episodes of care, when a new clinical finding is discovered
- Direct clinical observations (clinical exam findings, key observations): as discussed above, this is the area in which most work needs to be done
- Problem lists (diagnoses)
- Provider decisions or actions; tests ordered, studies ordered, medications or devices prescribed, consultations or referrals ordered: e-prescribing fits under this general heading
- Planned follow-up
- Entry of clinical modifiers can take place at any time (see above).

Automated inputs.
Our ability to do this is limited by the absence of formal standards for clinical information exchange, but once protocols are established, electronic data can be moved from multiple sources to the EHR.

- Results of laboratory tests can be transmitted to the record and posted to a practice in-box; "handshake" procedures can be written so that results not received in a specified time period are flagged for attention, addressing one common patient safety issue
- Results of clinical procedures, once recorded, can be transmitted in the same way

- Immunization records held in repositories can be posted to the EHR with patient authorization
- Documents such as consult requests can be posted, and responses from consultants can be tagged and posted to practice in-box as for laboratory results: handshake procedures can be written to track referrals that have not been completed, another way to address potential patient safety issue
- In less complex systems, simple .PDF files can be taken in to a documents repository in the EHR
- Pharmacy prescription fills can be routed back to the originating practice, with handshakes used to track adherence to prescribed medications

Third-party inputs.

At present, third-party payors maintain preferred drug formularies, physicians and services covered, and other benefit structure information on the Web, but this information is not actively linked to individual patient records. Providers and practices spend a great deal of time manually reviewing formularies to ensure insurance coverage for prescribed drugs, obtaining authorizations for equipment, or determining which specialty providers are in-network. It should be possible to link specific patients to their third-party rules and restrictions by downloading relevant third-party information at the time prescriptions or referrals are created. Third parties could automatically update their downloadable rules and formularies so that current rules apply each time prescriptions are written. This would greatly reduce practice workload and could enhance patient adherence.

2. OUTPUTS/VIEWS

The list of potential outputs, or views, is virtually unlimited. This section will mention a few views of general interest to demonstrate the flexibility of this simple data model.

Aggregate cross-sectional views.

These views look much like currently-available practice summaries provided by some insurance companies. One common example is the disease-specific "quality" report that lists patients carrying a specific

diagnosis, and their status with regard to several quality parameters. These are of limited utility as currently constructed, as they contain patients who do not have the condition in question or who do not receive care in the practice and often contain missing, outdated, or inaccurate clinical information.

With properly structured and valid diagnostic data, practices can easily create and maintain their own practice *"quality dashboards."* Our experience with the University of Michigan ClinfoTracker database confirms that self-maintenance of disease registries and linkage to laboratory data can enable a practice to efficiently and effectively produce this type of aggregate view of data, and can enhance practice-based efforts to improve quality of care. We have produced disease-specific HEDIS reports in-house for the past 10 quarters at a cost far below that experienced by other UMHS practices (see Use Case report).

Aggregate longitudinal views.
The Dutch Transition Project has amply demonstrated the power of large-scale, episode-oriented primary care databases [1, 3, 14, 17, 35]. With sufficient numbers of patients, aggregate longitudinal views of the data can provide valid estimates of prior and posterior probabilities in primary care; for example, the posterior probabilities of specific diagnoses for individual presenting symptoms (see Table 1) . These views can be of tremendous value in developing our understanding of primary care clinical epidemiology.

TABLE 1: Prevalence and posterior probabilities of certain diagnoses in 797 episodes of care starting with the reason for encounter *Shortness of Breath/Dyspnea* in patients 65-74 (N=17,103). From the Dutch Transition Project.

ICPC Diagnosis	Prevalence (%, 95% SE)	Posterior Probabilities (OR, 95% CI)
R78 Acute Bronchitis	30.2 +3.2	6.9 (5.9 - 0.1)
R02 Shortness Of Breath	14.9 +2.5	47.3 (39.2 - 65.2)
K77 Heart Failure	10.4 +2.1	14.6 (11.0 - 19.4)
R95 Emphysema/COPD	5.0 +1.5	21.5 (13.8 - 33.5)
R98 Hyperventilation	4.6 +1.5	12.6 (0.3 - 19.0)
R81 Pneumonia	4.3 +1.4	4.9 (3.3 - 7.1)
R96 Asthma	3.6 +1.3	13.4 (0.3 - 21.4)
R74 URI (Head Cold)	2.9 +1.2	0.4 (0.2 – 0.6)
K76 Ischemic Heart Disorder	2.3 +1.0	1.4 (0.8 – 2.2)
K78 Atrial Fibrillation	1.9 +0.9	3.1 (1.8 – 5.3)
R91 Chronic Bronchitis	1.5 +0.8	9.2 (4.7 – 0.3)
A85 Adverse Effect Medication	1.1 +0.7	0.2 (0.1 – 0.4)

SOURCE: Transition Project, Lamberts and Okkes, et al

Cross-sectional patient views.
Several useful cross-sectional patient views can be described.

- Active problem list - produced by the University of Michigan Department of Family Medicine ClinfoTracker software at the time of each encounter, this includes all chronic problems, all active acute problems, and all relevant (active) prompts for disease-specific care
- Similar views corresponding to views available in summary sheets in the paper record, or to front-page templates in electronic records
- Patient "dashboard" – summarizing current status (complete or missing) and/or values for disease-specific care elements, such as lipid profile, HBA1c, urine microalbumin, and diabetic foot exam for diabetic patients
- Patient summary record, similar in form to the Continuity of Care Record and transferable to other health care settings;

analogous to the "face sheet" in paper records. This record would contain the core necessary information to guide clinical decisions – personal demographics, chronic health problems, significant past medical history and medical risk factors, current medications, medication allergies

- Severity monitoring instruments for each of the patient's chronic health conditions

Longitudinal patient views.
These views would offer a window into comorbidity as it develops in real-world practice by enabling retrieval of all episodes and core process occurring over a specified time window. Specific views could include an *episode history*, displaying all episodes occurring over a one to two-year interval. This view will also enable calculation of the complexity of care provided by clinicians (the number of chronic problems managed over time, the number of active episodes per encounter or per year) and may reveal patterns of comorbidity not previously seen or described, providing new insight into the area of multi-morbidity.

User-defined views (third-party views).
User-defined views would provide summaries of patient data tailored to the specifications of the third party; for example, a summary report of HEDIS quality of care measures for all patients with a particular insurance plan to determine whether a practice was qualifies for a pay-for-performance bonus payment, or a report of the proportion of recommended preventive screening procedures completed by Medicare patients.

VII. SUMMARY: HOW CAN EXISTING PARTS FIT TOGETHER TO SUPPORT PRIMARY CARE HIT?

Figure 3 illustrates one way in which classifications and terminologies might fit together to support primary care HIT. At the center of the Figure is ICPC, which can provide the episode structure and high-level aggregation (of diagnoses, symptoms or actions) required to facilitate data retrieval and make it feasible for individual practices to mine their own data. The next ring includes the core classifications in the WHO Family of International Classifications, mapped to ICPC and offering the

increased granularity necessary for individual patient records. However, in some areas – social problems, symptoms and complaints- ICPC has more content coverage and granularity. In addition, actions (process) are represented in WHO-FIC by ICHI, which has not been fully developed. The outer ring is SNOMED-CT, which promises highly granular coverage of all clinical concepts, but which has limited content in the areas of symptoms and social problems at present.   Note that risk factors represents an area in which ICPC and ICD coverage is limited and even SNOMED-CT coverage is evolving.

With the proper mappings in place, primary care practices will be able to work at any of the three levels. However, given the combination of time constraints, breadth of information demand, and need for simple data retrieval inherent to primary care, the flexible use of the relatively simple components contained in ICPC can enable effective self-directed HIT in primary care practices.

FIGURE 3: RELATIONSHIP BETWEEN ICPC, ICD, and SNOMED-CT
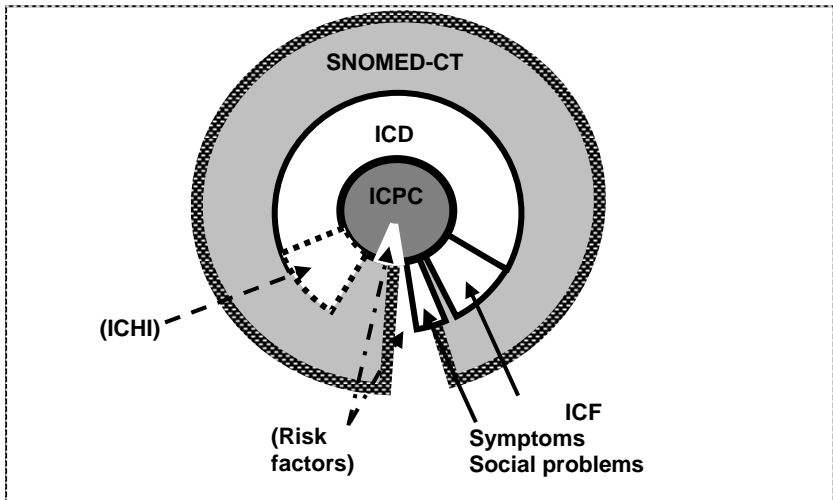
References

1. Okkes IM OS, Lamberts H. The probability of specific diagnoses for patients presenting with common symptoms to Dutch family physicians. Journal of Family Practice 2002;51(1):31-6.
2. Kenter EGH, Okkes IM, Oskam SK, Lamberts H. Tiredness in Dutch family practice. Data on patients complaining of and/or diagnosed with 'tiredness'. Fam Pract 2003;20(4):434-40.
3. Lamberts H, Schade. Surveillance systems from primary-care data: from a prevalence-oriented to an episode-orented epidemiology. In: N.D. EwJeN, ed. Surveillance in Health and Disease. Oxford: Oxford University Press; 1988:75-89.
4. Lamberts H, Wood M, Hofmans-Okkes I, editors. The International Classification of Primary Care in the European Community with a Multi-Language Layer. New York: Oxford University Press; 1993.
5. Okkes IM, Becker HW, Bernstein RM, Lamberts H. The March 2002 update of the electronic version of ICPC-2. A step forward to the use of ICD-10 as a nomenclature and a terminology for ICPC-2. Fam Pract 2002;19(5):543-6.
6. Okkes IM GA, Oskam SK, Lamberts H. Advantages of long observation in episode-oriented electronic patient records in family practice. Methods Inf Med 2001;40(3):229-35.
7. Hornbrook MC, Hurtado AV, Johnson RE. Health care episodes: definition, measurement and use. Med Care Rev 1985;42(2):163-218.
8. Solon JA, Feeney JJ, Jones SH, Rigg RD, Sheps CG. Delineating episodes of medical care. Am J Public Health Nations Health 1967;57(3):401-8.
9. Lamberts H, Hofmans-Okkes I. Episode of care: a core concept in family practice. Journal of Family Practice 1996;42:161-9.
10. Lamberts H. Episode-oriented epidemiology in family practice: the practical use of the International Classification of Primary Care (ICPC) as illustrated in patients with headache. In: Norton P, Stewart M, Tudiver F, Bass M, Dunn E, eds. Primary Care Research: Traditional and Innovative Approaches. Newbury Park, CA: Sage Publications; 1991:40-72.
11. Steinwachs D. Episode of care framework: utility for medical effectiveness research. In: Grady M, Schwartz H, eds. Medical Effectiveness Research Data Methods: DHHS, PHS, Agency for Health Care Policy and Research.; 1992:161-71.
12. Keeler E. Using episodes of care in effectiveness research. In: ML Grady HS, ed. Medical Effectiveness Research Data Methods: DHHS, PHS, Agency for Health Care Policy and Research; 1992:161-71.
13. Hofmans-Okkes I. An international study into the concept and validity of the 'reason for emcounter'. In: Lamberts H, Wood M, Hofmans-Okkes I, eds. The International Classification of Primary Care in the European Community, with a Multi-Language Layer. Oxford: Oxford University Press; 1993:34-42.
14. Hofmans-Okkes I, Lamberts H. Longitudinal research in general practice: the importance of including both patients' and physicians' perspective on medical events. Scandinaian Journal of Primary Health Care; 1993-2 (Supplement-1993):42-8.
15. Flocke S, Frank S, Wenger D. Addressing multiple problems in the family practice office visit. Journal of Family Practice 2001;50:211-6.
16. Beasley JW, Hankey TH, Erickson R, et al. How Many Problems Do Family Physicians Manage at Each Encounter? A WReN Study. Ann Fam Med 2004;2(5):405-10.

17. Lamberts H, Oskam SK, Okkes IM. The clinical relation between symptoms and final diagnosis in general practice, determined by means of posterior probabilities calculated on the basis of the Transition Project. Ned Tijdschr Geneeskd 2005;149(46):2566-72.

18. Klinkman MS. Longitudinal Data Collection in Primary Care Research. In: Selected Proceedings, Practice-Based Research Networks Research Methods Conference. San Antonio, TX: American Academy of Family Physicians Press; 2002.

19. Kern EFO, Maney M, Miller DR, et al. Failure of ICD-9-CM Codes to Identify Patients with Comorbid Chronic Kidney Disease in Diabetes. Health Services Research 2006;41(2):564-80.

20. Hebert PL, Geiss LS, Tierney EF, Engelgau MM, Yawn BP, McBean AM. Identifying Persons with Diabetes Using Medicare Claims Data. American Journal of Medical Quality 1999;14(6):270-7.

21. Aronsky D, Haug PJ, Lagor C, Dean NC. Accuracy of Administrative Data for Identifying Patients With Pneumonia. American Journal of Medical Quality 2005;20(6):319-28.

22. Pakhomov S, Weston SA, Jacobsen SJ, Chute CG, Meverden R, Roger VL. Electronic medical records for clinical research: application to the identification of heart failure. . American Journal of Managed Care 2007;13(1):281-8.

23. Committee WIC. International Classification of Primary Care: 2nd Edition. Oxford: Oxford University Press; 1998.

24. Lamberts H, Hofmans-Okkes IM. The classification of psychological and social problems in general practice: 1. ICPC in relation to ICD-10. Huisarts En Wetenschap 1993;36 ((Suppl)):5-20.

25. Okkes I, Jamoulle M, Lamberts H, Bentzen N. ICPC-2-E: The electronic version of ICPC-2. Differences from the printed version and the consequences. Family Practice 2000;17:101-7.

26. Soler JK. TRANSHIS- the Maltese experience with ICPC-2. it-tabib tal-familja 2000:19-22.

27. Nease DE, Jr., Green LA. ClinfoTracker: A Generalizable Prompting Tool for Primary Care. J Am Board Fam Pract 2003;16(2):115-23.

28. Bernstein RM, Hollingsworth GR, Viner G, Shearman J, Labelle C, Thomas R. Reliability issues in coding encounters in primary care using an ICPC/ICD-10-based controlled clinical terminology. Journal of the American Medical Informatics Association 1997;21 (Symposium Supplement):843.

29. Britt H. A new coding tool for computerised clinical systems in primary care--ICPC plus. Aust Family Physician 1997;26(Supp 2):S57-S9.

30. Verbeke M, Schrans D, Deroose S, De Maeseneer J. The International Classification of Primary Care (ICPC-2): an essential tool in the EPR of the GP. Stud Health Technol Inform 2006;124:809-14.

31. Committee WIC. ICPC-2-R: The International Classification of Primary Care, Revised Second Edition. Oxford: Oxford Medical Publications; 2005.

32. Okkes IM, Veldhuis M, Lamberts H. Severity of episodes of care assessed by family physicians and patients: the DUSOI/WONCA as an extension of the International Classification of Primary Care (ICPC). Fam Pract 2002;19(4):350-6.

33. Parkerson GR, Jr., Bridges-Webb C, Gervas J, et al. Classification of severity of health problems in family/general practice: an international field trial. Fam Pract 1996;13(3):303-9.

34.   Westbury RC, Rogers TB, Briggs TE, et al. A multinational study of the factorial structure and other characteristics of the Dartmouth COOP Functional Health Assessment Charts/WONCA. Fam Pract 1997;14(6):478-85.

35.   Okkes IM PG, Fryer GE, Yamada T, Bujak M, Oskam SK, Green LA, Lamberts H. The role of family practice in different health care systems: a comparison of reasons for encounter, diagnoses, and interventions in primary care populations in the Netherlands, Japan, Poland, and the United States. Journal of Family Practice 2002;51(1):72-3.

Primary Care Coding

Wilson D. Pace, MD
Director, AAFP National Research Network
University of Colorado Health Science Center

I.   Attempts to organize medical concepts

Clinicians and epidemiologists have been working on understanding the scope of their work and the public's health through categorization for over 150 years. The International Classification of Diseases (ICD) has it origins in the mid 1800's when it was called the International List of Causes of Death.[1] The list was designed to bring greater consensus to the causes of world wide mortality. Only much later was morbidity information added. The formal addition of diseases occurred in the 6th revision in 1946. The current name ICD was adopted with the 7th revision in 1955. The 9th revision saw the addition of clinical modifications by insurance companies and others to use the system to better understand the provision of care instead of just morbidity and mortality. Sections dealing with historical information, prevention activities, procedures and physical agents were also added or expanded. The full ICD-9CM version of the system was large and cumbersome. Its greatest utility is its wide spread use. In 1994 ICD-10 was adopted by the WHO and has since had the clinically modified version released. ICD-10 was formally "adopted" by the USA in 1999.[2]

Over 2 decades ago, it became obvious that greater specificity was needed in medical terminology beyond mortality and morbidity

information. In 1965 the American College of Pathologists released its first system to codify pathology findings, the Systematized Nomenclature of Pathology or SNOP. The original system was expanded to include other medical terms with the release of the first version of the Systematized Nomenclature of MEDicine (SNOMED) in 1974. Over the ensuing 25 years the system has grown in size and complexity.[3,4]

In the mid-1980s a company called Abies began offering an early electronic medical record (EMR) to United Kingdom general practitioners that allowed each clinic to create a system of codes for storing clinical data for easier recall. James Read was a relatively early user of the system and saw the advantages of including a coding system in the Abies EMR that was uniform across all users and set out to develop such a coding system for general practitioners. This was perhaps the first attempt to develop a nomenclature specifically for electronic data capture. The original system allowed users to add local codes and these local codes were used to drive further development. The Read Clinical Classification (RCC) system was designed from the outset to be used only in electronic systems, thus an upper case and lower case letter we considered different and codes were to be selected by their descriptions not the code itself. The coding system was hierarchical in nature but kept running out of room in selected hierarchies, despite the greatly expanded number of coding options at each level. After the system was purchased by the Crown the code length was expanded to and terms and medical concepts for other specialties were begun to be added.[5,6] With the additional needs placed on selected levels of the hierarchy, problems again surfaced. The system has now moved towards a relational format much like other large nomenclature systems which try to be all inclusive in their codes and the logical relationships between codes.

While the RCC system was one of the early codification approaches designed to be integral with EMRs, others were moving in this direction as well. SNOMED moved to be recognized as a granular coding system for electronic records. Likewise, a number of proprietary approaches to dealing with granular data coding have had various levels of success. Perhaps the most widely used current proprietary system is called

Medcin®. This system has grown to include extensive "knowledge engines" and now freely distributes the underlying coding system but sells licenses for use of the various knowledge engines.[7]

Codification of the detail in a medical record has been considered the ultimate goal for an EMR for some time. The expected return and gains for this level of data standardization have been difficult to predict. As EMRs become more widespread it has become apparent that, even with carefully developed data collection templates, a highly coded record is a very difficult end to achieve. Furthermore, and perhaps more importantly, it is becoming apparent that this may not be the correct focus of our efforts, at least in primary care. While selected data elements are very useful in an easily machine readable format, the full history, review of systems and physical exam details are rarely used in clinical decision support or for clinical improvement processes. Clarifying the best ways to capture electronic data elements for improving and understanding primary care will require a better understanding of the correct level and extent of data codification. This appears to require a more robust understanding of the unique data needs of primary care and the development of systems to meet those needs.

II. Primary care has need for overall order and appropriate depth

The debate and utility of highly specific or granular concepts, versus less granular representations continues to repeat itself through out medical history. The failure to recognize the inherent differences between nomenclatures and taxonomies has been repeatedly played out as an argument between reliability and validity versus data loss. Instead of being recognized as inherently different principles. For this paper we will consider a nomenclature to be a codification system that attempts to code the universe of meaningful elements in the medical domain. While this sounds straight forward, as will be pointed out later, there are many interpretations of how to best do this. Taxonomy is a system that attempts to create order around a particular construct or view of the medical domain. For instance, oncology has a very specific approach to grouping and describing neoplasms that is useful to them and less so for primary care providers. In this view, medicine would have a number of

taxonomies that serve the needs of specific sub-components of the system. Frequently, this distinction has not been recognized and developers of nomenclatures have attempted to embed taxonomic concepts into the coding structure of a nomenclature.

A number of groups worked on developing "comprehensive" systems to represent medical concepts in the 1980's and 1990's. Many of these systems included both a nomenclature and a "knowledge base" that related, sorted or otherwise processed the nomenclature to facilitate clinical use. All of these systems (i.e. SNOMED, Read Clinical Classification, Medcin) were and are based on the concept of "discrete medical concepts." If one stepped back, it became clear relatively early on that the very concept of a "discrete medical concept" was less than clear. At one point in the late 1980's to early 1990's the RCC system (which considered itself to be comprehensive) had identified 65,000 medical concepts and 150,000 codes to describe these concepts. Meanwhile, SNOMED at that time contained approximately 250,000 codes with over 100,000 medical concepts and Elmer Gabrelli (an early natural language processing expert) claimed to have identified over 1 million concepts needed to code hospital records alone. As one moved up the hierarchy which existed within these competing approaches to reach "higher levels of order" the concept of a single "unifying theory" of medical classification became even more tenuous. The US National Library of Medicine long ago abandoned the concept of finding the "one" correct system and focused on relating various systems to each other and creating a comprehensive set of relationships between various coding systems. During this time, concepts from physical science and biology – such as the Linnaen system to organize living organisms – were frequently touted as the optimal approach and it was merely a matter of attention to detail, and perhaps parochialism that kept medicine from producing an "all inclusive" nomenclature.

The basic difference between a nomenclature for physical items (such as living things) and one that includes both physical items and theoretical constructs (such as medical concepts) was not clearly realized. Trying to code theoretical constructs immediately leads one to the inevitable occurrence of many different instances of similar, but not identical,

constructs and thus, a virtually impossible task to code them all. Medical coding systems continue to struggle with the concept of a "discrete medical concept" trying to decide when modifiers, such as location, laterality and extent of disease, create new "concepts" or represent modifiers of a single concept. Different users of the data tend to see issues of this nature differently. This leads one back to the concept of taxonomies that help to order the underlying nomenclature for improved use across different medical constructs.

Primary care has developed such a taxonomy, the International Classification of Primary Care (ICPC).[8] The concept of ICPC was never to be an all inclusive nomenclature, but instead to create a unifying approach to understanding a patient's requests for help/service and a clinician's responses to the requests over time. Inherent within ICPC are two different approaches to "ordering" medical data. One ordering approach is embedded within the coding structure itself, all codes are related to an "organ system"[9] - as opposed to some being organ system related, some causation related, some service related and some agent related (as is the case in ICD and most granular nomenclatures). The second is in the use of "episodes of care" which create order across various requests for service and across time. These ordering principles are captured at a level of detail that is guided by the frequency of use within primary care. By only coding the more frequently occurring processes and problems the system helps assure that the signal (those activities correctly coded) is greater than the coding noise- those activities incorrectly coded due to infrequent use and code ambiguity. Furthermore, the system assures that the data obtained from ICPC coded, episode oriented record is grouped such that secondary analysis provides meaningful confidence intervals. (Henk Lamberts personal communication) As a taxonomy, ICPC can be linked to more granular systems, such as ICD or SNOMED, to allow more granular detail to be captured when and where it is appropriate. Correctly utilizing ICPC as a guide to this process may facilitate the location of the correct granular code. Though it would seem that moving from the 1200+ codes of ICPC to the 14,000+ codes of ICD-9CM is a straight forward one to many problem, given the different underlying constructs of the two systems a complete match from ICPC to ICD or vice versa requires human

intervention. Thus, the more granular coding systems cannot be automatically mapped back to the corresponding ICPC code, i.e. the ICPC view of the primary care world is not a simple condensation of the more granular ICD, SNOMED or Medcin view of the world.

III. Single hierarchical models have generally failed as semantic nomenclatures

Another realization that has crystallized over the past 10 to 15 years is that the complexity of medical concepts is not well encapsulated using a simple hierarchical approach. Furthermore, the combining of different primary approaches to creating hierarchies into a single coding system – such as the ICD system which in one section uses organs, in other causative agents and in another service activities – does not solve the complex relationship issues. Furthermore, the end product of such a system is cumbersome to use and prone to coding errors. Newer approaches to comprehensive coding systems recognize that the code itself is just a machine readable identifier and as such does not need to contain any inherent information. All inherent information that we wish to attach to the code can be more readily handled as an associated database. This approach does not limit a code to being within one hierarchy or grouping, but allows it to correctly sit in as many ordering systems as is desired. Therefore, a code such as pneumococcal pneumonia can be found in the groupings of infectious conditions, bacterial conditions, pneumococcal infections, inflammatory conditions and pulmonary conditions and be appropriately placed within each of these groups.

Large coding systems for which there is no underlying meaning to the code itself do not lend themselves to manual use. Thus, nomenclatures with this structure are only useful within electronic systems and are therefore a relatively recent proposition. Systems of this nature, which are likely to become the standard approach for handling medical nomenclature, require ordering databases to be used. Currently, these relational databases are often built with the concept that there is an "ultimate truth" to the way data elements should be linked to be clinically useful. The reality is that this level of detail is highly discipline

specific. Thus, it may be necessary to create a primary care relevant relational database that can draw from the total body of work that has gone into creating a nomenclature, but refines and constrains the nomenclature as appropriate for primary care.

IV. Consideration of primary care activities reveals many layers of activity that could be coded

Currently available coding systems address many but not all the needs of primary care. One approach to describing the domains within primary care for which coded data would be useful is as follows:

1. Patient derived information
    a. Reasons for visit
    b. Patient description of symptoms with appropriate modifiers
    c. Family and social history
    d. Background information
        i. Clinical modifiers
        ii. Significant Medical events
    e. Allergies and reactions
2. Clinician derived information
    a. Physical exam
    b. Other clinical observations
3. Process data
    a. Problems
    b. Medications
    c. Labs, imaging
    d. Decisions – including rationale
    e. Referrals
4. Synthesized data
    a. Clinical decision support
    b. Guideline tracking
    c. Exception tracking
    d. Adverse event tracking
    e. Patient goals and preferences

No current nomenclature covers all these areas in a unified manner. Furthermore, even if the relevant codes were available in one of the

current nomenclatures, primary care is based on a sustained relationship between a patient and a clinician, a medical home. Thus, this large volume of data must be appropriately linked over time to create a meaningful description of the individual as well as to efficiently manage and learn from the care process. The ability to understand care processes and advance knowledge may be just as great or greater from less granular but appropriately linked data than from highly granular sets of information.[10,11]

The Transhis project of Lamberts and Okkes[12] has demonstrated that remarkable insights into care processes, patient requests for and decisions regarding care and clinician decision making can be gained by appropriately linking approximately 1300 codes. But, as a clinician trying to provide state of the art care to an individual, one is also aware that 1300 codes do not provide sufficient detail to apply reasonable clinical decision support, either by the clinician or electronically. The Transhis project has given primary care a window into the possibilities of advancing knowledge and improving care if we link the appropriately granular code within an appropriately developed taxonomy and coding structure.

V.   Combining systems to provide both inherent organization and required depth allows taxonomists to co-exist with nomenclaturists

It is time for primary care and hopefully the rest of medicine to abandon the useless activity of arguing over the relative merits of a taxonomy versus a nomenclature. Spending time demonstrating the power of one nomenclature to "appropriately code" some predefined set of clinical data (i.e. 1,000 hospital discharge summaries or 1,000 text based ambulatory records) has not utility in creating a useful dataset from which learning and advances in patient care will flow. It is this author's belief that with the exception of a few notable areas where no coding concepts exist, both SNOMED CT and Medcin contain adequate descriptive codes to handle the critical granular primary care data points. It is also important that we recognize the difference between blindly "coding" every potential piece of data in a record and carefully focusing coded data collection on those data elements that will drive our

clinical decision processes. Thus, we end up with at least three different axes on which to build a record set to improve the delivery of primary care. We must have codes grouped appropriately both over time and as subsets of data required to make informed decisions and analyses. The time element appears to be best satisfied by episodes of care which appear to be created and manipulated most easily by using ICPC. We must have the correct granularity of detail at the next level of coding below ICPC to be able to efficiently and correctly codify information that will drive the clinical decisions at the point of care. The level of granularity and even the data elements to codify should be driven by our current state of clinical decision support or knowledge. Medcin appears to have attempted to meet these needs by creating "universal" medical knowledge engines to help drive the data collection and analysis process. ICPC has worked at this by creating a discipline specific approach to supporting these data needs. In essence, the data needs of any particular medical discipline require solving three simultaneous equations – order, granularity and data elements.

Given the extensive differences required in the clinical decision processes between different medical disciplines it is this author's belief that it is impossible to solve for these three different equations in a "universal" manner. It is incumbent upon each major area of medicine to create unique solutions that best suit that discipline's needs. Furthermore, it is important to recognize that the data elements that require codification and the level granularity as well as how to group clinical will change over time and thus any solution must be dynamically supported and hopefully be self regenerating.

Given the current state of codification system use, embedded knowledge, granularity and availability it appears the current best primary care solution towards solving these three simultaneous equations is the marriage or mapping of ICPC to more granular systems. The two most widely available systems and ones for which the mapping is complete or underway are the ICD systems and SNOMED CT. ICD allows clinicians around the world to share morbidity and mortality data in an established format. Mapping ICPC to ICD allows users to more logically and quickly find the appropriate ICD rubrics, and, more

importantly, facilitates the logical grouping and analysis of data across episodes of care. The mapping of ICPC to SNOMED CT will allow other components of a medical record to achieve a level of granularity and modification required for clinical decision support with several notable exceptions. Simply mapping the two systems to each other will not accomplish this. The very difficult step of determining the correct levels of granularity and the correct data elements to codify are currently either left to the EMR manufacturers (with their template starter sets – which disappoint most users) or to individual clinicians or organizations (with template building – which frustrates most users).

Note that the Medcin solution has not been considered further in this discussion as the business model and licensing fees appear to preclude its widespread use at this time. Furthermore, those primary care clinicians who have used Medcin generated "templates" in EMRs have indicated that there is a great deal of discipline specific work to be done within the knowledge engine. Whether this is true or not is difficult to ascertain without the ability to carefully examine the outputs of the Medcin knowledge bases.

As long as we have a wide variety of vendor specific approaches to primary care data collection, presentation, linking and analysis we will continue to make slow and arduous progress in our attempts to use digital processes to improve care. Currently, the major successes are either home grown applications often built on home grown EMRs or are those vendors that take on the work of remapping and re-interpreting the electronic data within an EMR as well as developing clinical decision support algorithms at levels that are useful for specific disciplines. Rapid improvement in this process as well as the care delivered to individuals is likely to be slow until more widespread adoption of a primary care data model occurs.

VI. Current systems

A.   ICPC

International Classification of Primary Care is a taxonomy designed to order the primary care visit and the interactions of an individual with

the health care system over time. The system is not designed nor intended to be a granular nomenclature. The system is "location," i.e. organ system, oriented. The biaxial system uses chapters (letters) to define organ systems or major groupings of codes and has arbitrarily set a limit of 99 codes per chapter. Unique codes are created by adding a two digit numeric identifier to each letter for a total of 99 possible codes per chapter. Each chapter is further divided into three sections with an arbitrary number of real or potential codes per sub-division. Numeric codes 1 to 29 are reserved for symptoms, codes 30 to 69 are reserved for procedures and administrative activities and codes 70 to 99 are reserved for diagnoses. This results in some chapter sub-divisions leaving out potentially important codes that meet reasonable frequency requirements in some primary care settings (falls is an example of a presenting complaint important in geriatric practices) and having unused rubrics in some chapters. ICPC was designed to be useful in electronic and hand coded systems which is useful for a world-wide coding system but may limit its usefulness in the electronic world. ICPC is conceptualized as an ordering system for primary care. It is not intended to replace granular coding systems, it is intended to allow clinicians to order their thought processes quickly during visits and over time.

B. ICD

International Classification of Disease is the oldest continuously existing medical coding system still in widespread use. The system was originally designed to describe mortality and later morbidity trends world-wide. The system is currently in its tenth rendition and has added codes for procedures, family history and routine health care activities. The 9th version with clinical modifications is in use in the USA while the majority of the world uses the 10th version without clinical modifications. Clinical modifications are available for the 10th edition. Planning for the 11th edition is well underway. The 9th version, as with previous versions, utilizes multiple approaches to locating a code within the overall structure of the system. Options include causation (i.e. infectious agent), location (respiratory), general type of code (V codes for family and personal history or for preventive activities), agent (e-codes for therapeutic and harmful agents) and procedural codes. This variety of

approaches has lead to an entire industry that has developed around the correct coding of medical encounters. ICD-10 has improved on some of the issues identified above with ICD-9. It contains 22 chapters with alphanumeric codes to the 4th digit in the standard version (one alpha character, 2 integers and one decimal place).

The ICD system is widely used to codify morbidity and mortality world wide. Its difficult nuances could perhaps be improved by utilizing ICD as a secondary system behind a true ordering taxonomy. Used in this manner, except for regulatory needs, it is difficult to understand how the semantic limitations of the ICD system, when used as the granular system, improve upon SNOMED CT at the data storage level. Clearly, for international reporting and tracking ICD will continue to be used for the foreseeable future.

C. SNOMED CT

Systematized Nomenclature Of MEDicine Clinical Terms developed from a pathology background with a focus on standardizing terminology in pathology. Over forty years the system grew to include many clinical concepts outside of the pathology realm but with a strong specialty focus. In 1995 SNOMED Terminology Solutions (a division of the American College of Pathologists) began working with Kaiser Permanente to refine SNOMED International into a version called SNOMED Reference Terminology (RT). This version was better designed for modern informatics needs with more advanced description logics, advanced code inter-relationships and a relational database structure for the entire system. In 2002 the United Kingdom Minister of Health agreed to combine the UK Clinical Terms Version 3 (formally the RCC codes) with SNOMED RT to create SNOMED Clinical Terms or SNOMED CT. This combination was designed to capture the original primary care origin of the RCC codes and combine it with the specialty strength of SNOMED. Since its release in 2002 other coding systems have been incorporated into SNOMED CT- e.g. LOINC and mappings to ICD-9 and ICD-10 have been completed. The current version contains approximately 370,000 terms. SNOMED CT®is a clinical terminology with a stated objective "of precisely representing clinical information

across the scope of health care."[3] Content coverage is divided into hierarchies, which are included in the Appendix.

D. LOINC

Logical Observation Identifiers Names and Codes is a vocabulary database of universal identifiers for laboratory and clinical test results. Its purpose is to facilitate the exchange and pooling of results for clinical care, outcomes management, and research. It is produced by the Regenstrief Institute and includes the coding system and a mapping tool (LOINC and RELMA).[13] The coding system is publicly available for use. A small number of other clinical observations have been added, such as vital signs. Because the system is designed to allow laboratories to transmit results to each other, each test is listed with all the operational variants in which it is performed. Therefore, many standard tests have multiple different codes to deal with all the different performance options at the lab level. This makes the full dataset difficult to utilize at a primary care level. Furthermore, even with extensive automated and hand mapping the ability to capture all laboratory data within the 40,000 codes appears limited. A recent article by Khan et. al.(7190} indicated that only between 63% and 76% of the lab tests used at five Indian Health Centers could be mapped to LOINC. The role of this system in primary care would appear to be secondary at this time since it is not captured within SNOMED CT.

E. CPT

Current Procedural Terminology is primarily United States based coding system utilized to transmit billing information. The system was developed by, is supported by and is the proprietary property of the American Medical Association. The system is entirely focused on transmitting information that an insurance company or other financial sponsor can use to determine correct reimbursement. As such, codes may be re-used over time. The decision to add granularity or remove granularity of codes is based upon financial indications, not clinical indications. Thus, this coding system has little to no use in describing clinical care.

F.   Medcin®

Medcin® is a commercially developed system designed to codify clinical propositions or unique clinical concepts. These propositions are then logically linked by a knowledge engine that is designed to support data entry and retrieval. The current version has approximately 270,000 terms with millions of clinical hierarchies that relate terms to each other. For instance, fever would be linked to the term bacterial endocarditis but not to the term ischemic heart disease. Each term also has links to it relevant properties- such as value ranges, units, laterality and cross checks for other coding systems. The coding domains include symptoms, history, physical findings, tests, diagnoses and therapy. The list is long to allow for many "clinically relevant" variations of similar ideas- for instance the Medicomp web site highlights the difference in "wheezing which is worse during cold weather" and "wheezing which is worse with a cold." The frequency with which clinical decision support rests on historical data at this level is unclear at this time. The coding system, without carefully thought out filters for various users, can become burdensome for rapid data capture. For instance typing in "breast cancer" into a Medcin® based problem search list returns over 200 options for coding breast cancer . The list of codes is available at a nominal charge, the full knowledge engine for use in an EMR is much higher in cost. Medicomp claims to be able to create problem oriented views of fully coded medical records on the fly by using the knowledge engine to filter information that is relevant to a given diagnosis. How it would handle an episode of care with changing episode labels (i.e diagnosis) is not clear. Many end users of Medcin® coded templates have described them as long, laborious and with many irrelevant data points to wade through to capture the critical details of a visit.

G.   RxNorm

RxNorm is a standardized nomenclature for clinical drugs produced since 2001 by the National Library of Medicine.[14] RxNorm considers a *clinical drug* to be a pharmaceutical product taken by a patient with a therapeutic or diagnostic intent. The RxNorm project approached clinical drug representation in a series of steps. The initial effort was to

define a Semantic Normal Form (SNF) to represent clinical drugs. SNFs for clinical drugs are canonical representations, as defined by their active ingredients, strengths, and orderable dose forms. SNFs make explicit and/or normalize every active ingredient, strength, unit of measurement, and dosage form for a given clinical drug preparation. The next step has been to populate the SNFs and map them to other coding systems.

RxNorm's standard names for clinical drugs are connected to the varying names of drugs present in many different controlled vocabularies within the Unified Medical Language System (UMLS) Metathesaurus, including those in commercially available drug information sources. These connections are intended to facilitate interoperability among the computerized systems that record or process data dealing with clinical drugs. Current commercially available drug information systems follow different naming conventions, thus a standardized nomenclature can improve the exchange of information between and within organizations. The goal of RxNorm is to allow various systems, using different drug nomenclatures, to share data efficiently at the appropriate level of abstraction.

RxNorm is intended to cover all prescription medications approved for human use in the United States. Over-the-counter (OTC) medications will be added and covered, as well, when reliable information about the medications can be found. Medications - whether prescription or OTC, with more than three ingredients - are not fully represented at the present time.

Future directions

While there are holes in the coding universe when it comes to primary care, the bigger overall issue has to do with creating a data model that supports the needs of a medical home in dealing with individuals as well as a population of individuals. To improve this process primary care needs to take an active role in defining the appropriate groupings, granularity and content of the coding systems in use in EMRs. Primary care clinicians have learned to consider the location of research in deciding if the results are valid for their setting. Likewise, primary care

clinicians, as well as those organizations developing knowledge bases for primary care, need to recognize that adding together the views of a variety of other specialties does not lead to an effective primary care data model.

Appendices

ICD-10 list of chapters

Chapter	Blocks	Title
<u>I</u>	<u>A00-B99</u>	Certain infectious and parasitic diseases
<u>II</u>	<u>C00-D48</u>	Neoplasms
<u>III</u>	<u>D50-D89</u>	Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism
<u>IV</u>	<u>E00-E90</u>	Endocrine, nutritional and metabolic diseases
<u>V</u>	<u>F00-F99</u>	Mental and behavioural disorders
<u>VI</u>	<u>G00-G99</u>	Diseases of the nervous system
<u>VII</u>	<u>H00-H59</u>	Diseases of the eye and adnexa
<u>VIII</u>	<u>H60-H95</u>	Diseases of the ear and mastoid process
<u>IX</u>	<u>I00-I99</u>	Diseases of the circulatory system
<u>X</u>	<u>J00-J99</u>	Diseases of the respiratory system
<u>XI</u>	<u>K00-K93</u>	Diseases of the digestive system
<u>XII</u>	<u>L00-L99</u>	Diseases of the skin and subcutaneous tissue
<u>XIII</u>	<u>M00-M99</u>	Diseases of the musculoskeletal system and connective tissue
<u>XIV</u>	<u>N00-N99</u>	Diseases of the genitourinary system
<u>XV</u>	<u>O00-O99</u>	Pregnancy, childbirth and the puerperium

XVI	P00-P96	Certain conditions originating in the perinatal period
XVII	Q00-Q99	Congenital malformations, deformations and chromosomal abnormalities
XVIII	R00-R99	Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified
XIX	S00-T98	Injury, poisoning and certain other consequences of external causes
XX	V01-Y98	External causes of morbidity and mortality
XXI	Z00-Z99	Factors influencing health status and contact with health services
XXII	U00-U99	Codes for special purposes

SNOMED Hierarchies

- *Clinical finding*
- *Procedure*
- *Observable entity*
- *Body structure*
- *Organism*
- *Substance*
- *Pharmaceutical/biologic product*
- *Specimen*
- *Special concept*
- *Physical object*

- *Physical force*
- *Event*
- *Environments/geographical locations*
- *Social context*
- *Situation with explicit context*
- *Staging and scales*
- *Linkage concept*
- *Qualifier value*
- *Record artifact*

References

1. World Health Organization. History of the development of the ICD. Available at http://www.who.int/classifications/icd/en/HistoryOfICD.pdf. (Accessed 2007 Oct 25).
2. World Health Organization. International Classification of Diseases (ICD). Available at http://www.who.int/classifications/icd/en/. (Accessed 2007 Oct 25).
3. College of American Pathologists. SNOMED Terminology Solutions. Available at http://www.cap.org/apps/cap.portal?_nfpb=true&_pageLabel=snomed_page. (Accessed 2007 Oct 25).
4. College of American Pathologists. SNOMED Clinical Terms User Guide. 2007 Jan; Available at http://www.snomed.org/snomedct/documents/snomed_ct_user_guide.pdf. (Accessed 2007 Oct 25).
5. Chute CG. Clinical classification and terminology: Some history and current observations. J Am Med Inform Assoc 2000 May-2000 Jun;7(3):298-303.
6. Connecting for Health. Read Codes. Available at http://www.connectingforhealth.nhs.uk/systemsandservices/data/readcodes. (Accessed 2007 Oct 25).
7. Medicomp Systems. Medcin: Bringing Point of Care Speed to the EMR. Available at http://www.medicomp.com/index_html.htm. (Accessed 2007 Oct 25).
8. Lamberts H, Wood M. The birth of the International Classification of Primary Care (ICPC). Serendipity at the border of Lac Leman. Fam Pract 2002 Oct;19(5):433-5.
9. World Organization of Family Doctors. ICPC-2: International Classification of Primary Care. 2nd ed. New York: Oxford University Press, 1998.
10. Okkes IM, Groen A, Oskam SK, Lamberts H. Advantages of long observation in episode-oriented electronic patient records in family practice. Methods Inf Med 2001;40(3):229-35.
11. Lamberts H, Hofmans-Okkes I. The core of computer based patient records in family practice: episodes of care classified with ICPC. Int J Biomed Comput 1996 Jul;42(1-2):35-41.
12. Hofmans-Okkes IM, Lamberts H. The International Classification of Primary Care (ICPC): New applications in research and computer-based patient records in family practice. Fam Pract 1996 Jun;13(3):294-302.
13. Regenstrief Institute, Inc. Logical Observation Identifiers Names and

Codes (LOINC®). Available at http://www.regenstrief.org/medinformatics/loinc. (Accessed 2007 Oct 25).

14. National Library of Medicine. Unified Medical Language System: RxNorm. Available at http://www.nlm.nih.gov/research/umls/rxnorm/index.html. (Accessed 2007 Oct 25).

Pathways (and Detours) to HIT Standard Development, Acceptance, and Implementation: From Idea to Production

David C. Kibbe, MD, MBA and Steven Waldren, MD
AAFP Center for Health Information Technology

What are the data standard paths that could be taken to create standards or otherwise put in place the ordering principles for primary care?

Dozens of standards are in use today that have to do with health information, communications, and technology.   The purpose of this brief essay is not to comment on the value or usefulness of any particular standard, but instead, to describe some of the ways in which new standards come into being. What we will discuss are the ingredients that are necessary to take an idea for a standard to its use in the real world, that is, to production. We'll also touch upon the ways in which a standard development process can be forced to take a detour or even be stopped dead in its tracks.

Ideas are the starting place for standards in any industry or field of endeavor. Ideas that become standards usually start as someone's need to accomplish something nationally that is now difficult or impossible except on a small scale or locally. Here, for purposes of illustration and discussion, are two ideas of this kind that someday may become standards.

Suppose that you and your colleagues wished to know the answer to this question for the US population as a whole: Why do people go to the doctor or seek health care from a provider when they do?   Suppose further, that you and your colleagues are not satisfied with the "answers" to this question derivable from claims or billing processes in health plans and Medicare that produce data on health care encounters, e.g. diagnoses such as congestive heart failure, diabetes, pneumonia, etc. After all, these terms are end-points and after-the-fact, and don't capture the reasons from the patient's point of view under many circumstances.

No, if we really want to know why people go to the doctor, we'd have to embrace among the answers to our question items such as "I must change medication due to a change in my health plan," and "a family member died suddenly and I'm afraid my own care hasn't been optimized to prevent this occurring to me," or "I'm going to Hong Kong next week and don't want to be sick when I get there."

But you can't get at these types of answers, because no one collects them now on anything like a large scale. So, you might wish to develop a standard that would capture this kind of information at each primary care visit, through the use of electronic medical records, and thus permit the aggregation of these data for analysis and research.

Let's take another example. Suppose you and your colleagues desire a way to transfer a data set of summary health information about a patient over the Internet, securely and from point-to-point, in much the same way that email messages are handled. You might consider creating a standard protocol that would allow computers to identify the file format, to read and interpret its contents, and to display, store, manage, and respond to the file in particular ways that are convenient, user-friendly, and available for the public to use.

In both of these cases -- and we could think of many others -- the primary purpose of the standard is to allow disparate, possibly competing entities to participate in some new benefit without interfering with competition or incurring unreasonable use of resources. Most modern technology standards can be viewed as a means to optimize resources in an industry or market sector while achieving similarity of a

result or effect. Obvious examples include the standardization of voltage and frequency for AC power grids, and the Internet protocols for handling packets of information across a TCP/IP network.

Now, let's suppose that you and your colleagues were committed enough to take collective action to create your standard, which we'll call "YourStandard" from here on, just to give it a name. What are the pathways that could be taken to move YourStandard from an idea or concept into the realm of use in the real world?

De Facto Standard

One way to make YourStandard a production standard would be, for want of a better description, to get people to use it. If enough people make use of YourStandard, it will become a standard.   Using this pathway to standardization is often referred to as de facto standard development, and there are literally hundreds of examples of de facto standards, from Microsoft's Windows operating system -- which everyone knows about -- to the XML tagging and schema of e-prescribing information used in SureScript's network exchange hub -- which most people, even in health care, have never heard about.

Products and services in an open capitalistic market often have at least an opportunity of establishing themselves, or components of their products and services, as standards, by virtue of the value that they offer to others who use them in association with their own products and services. Once a pattern of consumption develops in which YourStandard has a significant market share, it can be considered a production standard.

Single Entity Driven

How did Microsoft Windows operating system and SureScripts' XML schema become standards?   In the case of Microsoft, it was due to great timing and placement: the first personal computers (PCs) manufactured by IBM in the 1970's chose to utilize DOS, the operating system that they licensed from Bill Gate's company Microsoft. There were a few competitors to DOS, but there were very few competitors to IBM. Once IBM became the dominant maker and seller of PCs with DOS included, and software vendors had started to write software predominantly to

run on DOS, it was virtually impossible for other manufacturers of personal computers to choose another operating system.   Certainly, Apple and its competing proprietary operating system, now OS X, survived and the company has recently prospered, which brings to light the fact that even de facto standards don't necessarily have to own 100% of the marketplace to become considered standards; they just have to have a dominant market share.

In SureScripts' case, a group of organizations representing the great majority of retail pharmacies in the US formed SureScripts as a company for the express purpose of allowing physicians and pharmacists to electronically exchange prescription information for new and refill prescriptions. They needed a mechanism whereby electronic records software used in doctors' offices could send and receive messages directly with pharmacy information systems located in retail pharmacies, and they chose structured XML (eXtensible Markup Language, itself one of the most important Internet standards) to automate the exchange in a consistent, reliable manner between the computers.

Part of SureScripts' program for automating this exchange of messages requires the manufacturers of both the doctors' information technology and the pharmacists' information technology to "certify" with SureScripts that their products are capable of using the specific XML specified by SureScripts for this purpose.   In other words, the manufacturers of these products and services agreed to use the SureScripts XML schema as a standard, and to permit SureScripts to enforce the standardization across a broad spectrum of competing products in the pharmacy and medical practice IT sector.

At the beginning, there was no guarantee that SureScripts XML schema would be successful in attracting users to it, just as when Microsoft started its journey there was no guarantee that it would beat out other, competing operating systems.

In both cases just cited, market forces were the determining factor in the pathway for the development of the standard.   There was risk taken by both companies in competing with others, great reward in having their

products/services become de facto standards, and no way that anyone could predict a priori the outcome.

Community Driven

This same de facto standard approach is seen in open and open source projects. Two prime examples are the Portable Document Format (PDF) and the Apache Web Server. PDF is an open specification by Adobe that can be implemented by any vendor. This open specification and a free PDF viewer from Adobe have allowed PDF to become a de facto standard for representing electronic documents (interestingly PDF 1.7 will be follow a different path, which we will discuss next). The majority of Web servers today run the open source Apache Web Server software. Its free code and reliability have allowed it to be a de facto standard for web server applications.

Formal Consensus Standard

Another way for a group of individuals or organizations to develop a standard involves going through a formal consensus drive standard development process. The developers of technical standards are often, although not always, concerned with interface standards, or standards that detail how products will connect or interoperate with one another, or with one another's components. Safety standards set requirements for products to be safe for humans, animals, and the environment. The scope of work of SDOs may overlap and there are numerous examples of competing standards bodies, both nationally and internationally.

Standards Development Organization

Traditionally standards development through consensus is done under the auspices of a standards development organization, often referred to using the acronym SDO. There are hundreds of these organizations, some of them specialized for specific industries, and some of them in the business of developing standards for multiple industries. Some standards bodies were established for the express purpose of developing, maintaining, and promulgating standards.

Some SDOs are international, and others are primarily national or regional. Some have been around for a long time, and others are of quite recent origin. ASTM International (originally known as the American

Society for Testing and Materials), the International Organization for Standardization (ISO), and the International Telecommunication Union (ITU) have existed for more than 50 years, having been founded in 1898, 1947, and 1865 respectively. In addition to these multi-industry standard organizations, there are many smaller organizations that set standards within more specialized contexts, such as the National Council of Prescription Drug Programs (NCPDP), Health Level Seven (HL7), Institute of Electrical and Electronics Engineers (IEEE), and AIIM - The Enterprise Content Management Association.

Often, each country or sector of the economy may also have a national standards body whose membership is made up of SDOs, and which may include public, private sector organizations, or both. In the United States, the American National Standards Institute (ANSI) coordinates the development and use of voluntary, consensus standards, setting policies and procedures used by dozens of SDOs. Accreditation of an SDO's policies and procedures signifies that the standards are themselves the product of a standardized process, and is highly valued in the US across a wide and diverse set of industries, including health care IT.

Standards bodies occasionally merge or split off from another. For example, HL7 was established in 1987 when it broke off from the parent E31 Technical Committee of ASTM International. And while it is sometimes assumed that SDOs always create work products that are in the public domain, this is actually not the case in most instances. SDOs routinely retain the copyrights to the standards developed under their auspices, and derive revenue from their publication and use. In general, standards produced by central governments are not amenable to licensing and must be in the public domain.

In areas that are rapidly changing due to economic or technical innovation, such as health care IT, the boundaries that define the scope of work and areas of collaboration between SDOs may become unclear or even contested.

Industry Consortium

The rapid pace of technological evolution may outstrip the ability of generally slow-moving SDOs to keep up. Traditional and highly-

institutionalized SDOs tend to operate slowly, and this fact has seen the emergence of a new class of standards bodies that are industry consortium. Some of these have been very successful in determining international standards, such as the World Wide Web Consortium (W3C) whose HTML, XML, and CSS are used very widely around the world. The Physician Consortium for Quality Improvement, convened by the American Medical Association and including over thirty medical specialty societies, is another example of an industry consortium, in this case concerned with standardized measurements for medical performance and quality of care.

Industry consortia usually come together to develop standards for a very focused domain where that standardization can improve the value of the products and services they produce. Take the Bluetooth SIG, which develops and promotes the standardization of the Bluetooth protocol and devices. Each company that is part of the consortium is producing Bluetooth products and services that depend on those devices to interoperate with other Bluetooth products. Although the standardization puts limits on their products it adds a greater value to their products.

Standard Through Regulation

Let's say YourStandard was produced either through the de facto process or formal consensus process, but Your Standard is not being adopted. One option is to require the use of the standard through regulation. Prime examples in health care IT are the transaction code sets required in the HIPAA regulation and the e-prescribing standards required in the Medicare Modernization Act. Regulation can be a strong instrument to drive the adoption of a standard, yet unfortunately it usually means that there is a market failure relative to the standard. The best outcomes regarding regulation of standard are when standards are being adopted and used but the adoption needs to be aggressively accelerated.

Off the Beaten Path

Certain industries or industry segments can have their own set of operating rules. Coding sets and vocabularies for health care are a special category of standards that have their own somewhat peculiar

development and maintenance history.   Many coding systems, vocabularies, and classification systems co-exist in today's health care environment, and some would say that co-existence is quite uncomfortable because there are so many different owners and managers of them, some public but some very proprietary. The Secretary of the Department of Health and Human Services adopted the following code sets as the "standard medical code sets" of HIPAA:

- International Classification of Diseases, 9th Edition, Clinical Modification, (ICD-9-CM) Volumes 1, 2 and 3, as updated and distributed by HHS.
- National Drug Codes (NDC), as updated and distributed by HHS in collaboration with drug manufacturers.
- Current Procedural Terminology, Fourth Edition (CPT-4), as updated and distributed by the American Medical Association.
- Centers for Medicare & Medicaid Services Common Procedure Coding System (HCPCS), as updated and distributed by HHS.

Additional clinical vocabularies in common usage include:
- SNOMED Clinical Terms (CT)
- Logical Observation Identifiers, Names and Codes (LOINC)
- Multum MediSource Lexicon
- RxNorm
- NCI Thesaurus
- Gene Ontology
- International Classification of Primary Care (ICPC)
- Medical Subject Headings (MeSH)

Picking the Right Path

We have discussed the major paths, and alluded to the paths less traveled, towards developing a production standard. One may ask though, what is the best path for YourStandard. The best path depends on the timeliness and acceptance needed. The formal consensus path allows, in general, for a wider acceptance earlier than the de facto path. Yet typically the formal consensus path talks longer to initial publication of the standard. After evaluating timeliness and acceptance, one should consider the requirements for maintenance and distribution. The de facto path and the industry consortium path typically allow for free

distribution of the standard. As stated previously, the SDO path typically has a license fee – which can vary greatly among different SDOs. These fees support standard development and allow for the SDO to provide a greater support for maintenance of the standard over time.

It is the nature of technology markets that product makers want things "to fit together." For this reason, there have evolved many paths to the development of standards. Each path grew out of need to support a combination of timeliness, acceptance, distribution, and maintenance. All paths are valid; the choice depends on the needs of the entities coming together to produce the standard.

Why Use ICPC on a Routine Basis? The Usefulness of Routine Data Collected with ICPC for Daily Practice and Clinical Decision Making

Henk Lamberts, MD, PhD
Professor Family Practice (Retired)
University of Amsterdam, The Netherlands

Inge Okkes, PhD
Senior Researcher (Retired)
University of Amsterdam, The Netherlands

Introduction

This paper provides some background for the presentation 'Mrs. Aden wants to see you today' given at the October 2007 Primary Care Data Standards Conference organized by the Robert Graham Center and AHRQ. At this conference, the utility of ICPC was high-lighted in several of the position papers. Lacking, however, was a contribution bridging the gap between the available information and conceptual positions on the one hand, and the empirical insights from day to day practice over the past decade. A presentation of data collected in the Transition Project (EFP and EFP-Extended[1]) served as a demonstration project showing the great potential of routine data, based on the comprehensive use of the International Classification of Primary Care (ICPC) and double coded with ICD-10, and collected in the form of episodes of care using an electronic patient record (EPR), 'Transhis'.[1-2]

First we discuss the historical background of the current interest in the USA for ICPC. Next we summarize the advantages of the use of ICPC in an episode of care structure.

How the West was won: ICPC in the USA

Although ICPC was, to a large extent, prepared with US support, it was, inside the USA because of the regulations and requirements of the health care system, not readily accepted for use.[3] Early 2003, as a follow up of the HIPAA Legislation, the National Committee on Vital and Health Statistics NCVHS invited US terminology developers to complete a questionnaire on which system should become a national standard. The Robert Graham Center (RGC) of the American Academy of Family Physicians (AAFP), together with others, proposed ICPC with its mapping to ICD-10(-CM) as the best tool for structuring/retrieving family practice data. Subsequently, a special conclave held at the Annual Meeting of NAPCRG (the North American Primary Care Research group) in Banff, Alberta October 25, 2003, attended by representatives from DHHS, the Institute of Medicine (IOM), SNOMED, and many others, issued a declaration urging widespread adoption of ICPC. Next, NCVHS did in fact recommend to the DHHS Secretary the inclusion of ICPC as an approved classification for use in primary care practices and in the Electronic Health Record (EHR). Also, the National Library of Medicine (NLM) included ICPC in the map-ping/linking of SNOMED-CT to the ICD as a part of the Unified Medical Language System (UMLS). And in August 2004, the Board of the American Academy of Family Physicians (AAFP) decided on the following policy statement: '...that the AAFP should actively support the approval of the ICPC in the US as a designated patient medical record information terminology standard and as a complementary alternative to the potential adoption of ICD-10 CM in family physician's offices'.

In the meantime, however, it appeared to be a problem for the US advocates of ICPC that ICPC was practically unavailable in the USA. Therefore, in an initiative by Maurice Wood, Kerr White and others, supported by NAPCRG and facilitated by Oxford University Press (OUP), the WONCA International Classification Committee prepared ICPC-2-R, specifically meant for the USA market.[4] For that reason, this publication also offered extensive additional material on a CD-Rom

prepared by the University of Amsterdam: an epidemiological database, the ICPC-ICD-10 Thesaurus, a prototype of the EPR, and various tutorials.[1] Published in 2005, the package was sent for free to all Department Chairs and Division Heads in Family Medicine and General Internal Medicine in the USA and Canada. It came with an accompanying letter by Moira Stewart, Larry Green, Kerr White, and Maurice Wood, in which they very carefully explained why family practice needs ICPC; from this letter we cite the following:

 `Currently there are about half a billion visits annually by 190 million patients to primary care physicians in the United States but only 50-60% of problems presented to this level of care can be assigned realistically, or even honestly, International Classification of Diseases(ICD) "disease" labels and codes. New and different classifications, coding arrangements and terminologies are required if the content, distribution, and quality of primary medical care is to be realistically assessed.' (…) 'Only recently has the United States started to embrace the information requirements for primary care and the potential contributions of ICPC. To the ICD the Department of Health and Human Services (DHHS) has added the Systematized Nomenclature of Medicine – Clinical Terminology (SNOMED-CT), an extensive nomenclature that also employs medical terminology for use in the Electronic Health Record (EHR) and elsewhere. SNOMED-CT has many useful features but also severe limitations at the primary care level. Because ICD and SNOMED use medical terminology rather than the language used by patients they are of strictly limited use by the primary care practitioners. Of much greater importance, however, they are virtually useless with-out an organizing framework, for analyzing "episodes of care" or for investigating symptoms and complaints, the earliest manifestations of illness and their natural history and the responses to them as they evolve into full-blown diseases. Fundamental research into this submerged part of the "iceberg" of illness is only possible at the primary care level. There is, in the view of NAPCRG, an urgent need for more research of these phenomena to improve our understanding of the characteristics, quality and appropriateness of primary care and its interfaces with other levels of care. To accomplish this we need a dedicated classification such as ICPC for use in a National Health Information Infrastructure (NHII).'(…)

'The ICPC is the only classification with a relatively simple alpha-numeric structure, that facilitates realistic retrieval of the content of primary care by capturing descriptions of patients' common symptoms, complaints, problems and questions in their own language, their reasons for the encounter with physicians and other healthcare personnel, the physicians' initial and subsequent diagnoses, and the procedures and interventions provided. All these elements are documented sequentially in "episodes of care" – much as Hospital Discharge Abstracts, to a lesser extent, provide data about admissions. As such ICPC, with its 736 classes selected because of their frequent occurrence in primary care settings, has the potential for examining at the provider, practice and population levels the content, distribution, referrals, interventions, mishaps and quality of primary care as well its interactions with other modalities of health care.' (..)

As the first three goals of sending around this package, the letter mentioned:

1. Active discussion of ICPC in departmental meetings and in local, state, and regional primary care professional meetings

2. Increased interest in including ICPC in the EHR by institutional faculty and staff, professional organizations and state and local government personnel concerned with the NHII.

3. Official adoption of ICPC for the EHR, especially by the American Academy of Family Practice.

It is obvious that the October 2007 conference 'Harmonizing Primary Care Clinical Classification and Data Standards' organized by AAFP and AHRQ is to be seen as the result of all these events, and (among other things) aimed at achieving the above goals. The fact that during this conference data from the Transition project were presented as an example of use and utility of ICPC also logically follows from the inclusion of the epidemiological data from this project on the CD-Rom that accompanied ICPC-2-R.

Summing it up: what is so special about ICPC?

The presentation 'Mrs. Aden wants to see you today: a house call for a 73-year old lady with increasing stomach pain since a week, and vomiting since this morning was meant to fill the gap between theory and daily practice at the conference. Dutch data from 10 practices with approximately 25,000 listed patients during 10 years (January 1995-December 2005), with 500,000 episodes, coded with ICPC and, since 2002 also double coded withICD-10, were used as a reference for a detailed case history of a 73 year old lady with gall- stones. This case history was meant as a demonstration of what can be achieved by longtime, routine coding using ICPC in its comprehensive mode, and in an episode of care model (i.e.: coding for each encounter the patients' reason(s) for encounter (RFE), the family physician's (FP's) diagnosi/es, and the intervention(s), and to structure these data in episodes of care that can be followed over time).[2]

Three major areas of usefulness were demonstrated:

1. The database allows physicians to precisely document and easily retrieve the medical history of their patients. The clinical interpretation of these data by a physician under-pins decision-making for an individual patient.

2. A probability engine uses the data to produce sex- and age-specific prior probabilities (occurrence per 1000 patient years) for reasons for encounter, diagnoses, interventions (medication, test results) and their relations over time, reflecting the epidemiology of primary care. This strongly supports clinical decision-making, guideline use, quality assessment, and continuing medical education.

3. The data can generate posterior probabilities (positive and negative likelihood ratios) and relate symptoms/complaints to likely diagnoses and comorbid episodes to one another. Used this way, the data reflect the epidemiology of the practice and the broad clinical competence of primary care physicians when dealing with all health problems, regardless of stage.

It would be an important step to routinely include data on ICPC/ICD-10 coded episodes of care as collected with an EPR such as 'Transhis' in the cumulative data base of a group of US family practices.[1] These data would reflect the collective clinical experience of FPs, and serve as a repository that over time will get adapted to more recent knowledge.

References

1. The website www.transitieproject.nl provides an extended version of the CD-Rom and the following can be downloaded: Three Windows executable programs created with Borland®Delphi, which can be opened only after installation on a hard disk:
   - EFP (Episodes of care in Family Practice): a retrieval program for the Amsterdam Transition Project's data collected with ICPC (1985-2003), allowing standardized epidemiological retrievals: Top 20 (or 40, 60, etc) ranking lists of reasons for encounter (RFEs), diagnoses, and interventions, in their mutual relationships, by sex and age, etc.;
   - EFP-Extended (Episodes of care in Family Practice, Extended Version): a retrieval program for the Amsterdam Transition Project's data with Transhis as an Electronic Patient Record 1995-2004. It offers (in addition to what was already available in EFP) detailed data on prescribed medication, and episode of care data in longer observation periods (4 and 10 years);
   - ICPC2-ICD10 Thesaurus: a diagnostic terminology in English and Dutch for semi-automatic double coding in Electronic Patient Records.
   And further nine files (ppt, Adobe, and Word files) with additional information (an ICPC Tutorial, Manuals for the programs, a Glossary, a Bibliography, an electronic file of ICPC-2-R, and a demo version of 'Transhis', the EPR in use in the Transition project).
2. Okkes IM, Lamberts H. Classification and the domain of family practice. In: Jones R,(ed). The Oxford Textbook of Primary Medical Care. Oxford: Oxford University Press,2003. Vol.1: 139-52.
3. Lamberts H, Wood M. The birth of The International Classification of Primary Care(ICPC). Serendipity at the border of Lac Léman. Fam Pract 2002;19:433-5.
4. Wonca International Classification Committee. ICPC-2-R. International Classification of Primary Care. Revised Second Edition. With a CD-Rom: ICPC in the Amsterdam Transition Project. Oxford: Oxford University Press, 2005.
5. Okkes IM, Oskam SK, Lamberts H. ICPC in the Amsterdam Transition Project. CD-Rom. Amsterdam: Academic Medical Center/University of Amsterdam, Department of Family Medicine, 2005.

_____

Commonly Used Acronyms and Terms

AAFP	American Academy of Family Physicians
AAP	American Academy of Pediatrics
ACP	American College of Physicians
AHRQ	US Agency for Healthcare Research and Quality
ANSI	American National Standards Institute
AQA	Originally known as the Ambulatory Care Quality Alliance, the coalition is now known as the AQA alliance
CCHIT	Certification Commission for Healthcare Information Technology
EHR	Electronic Health Record
HL7	Health Level 7 (develops healthcare standards for ANSI)
HITSP	Health Information Technology Standards Panel
ICD10CM	International Classification of Disease v.10 Clinical Modification
ICPC	International Classification of Primary Care
NQF	National Quality Forum
NCQA	National Committee for Quality Assurance
ONC	Office of the National Coordinator for Health Information Technology
WHO	World Health Organization
WONCA	World Organization of Family Doctors

Conference Participants

Conference Chair
Robert L. Phillips, Jr., MD, MSPH
Director
Robert Graham Center, Policy Studies in
Family Medicine and Primary Care
bphillips@aafp.org

Conference Co-Chair
Michael Klinkman, MD, MS
Co-chair, Wonca International
Classification Committee
University of Michigan
mklinkma@med.umich.edu

Conference Facilitator
Josef Reum, PhD
Associate Dean of Finance and
Administration
George Washington University,
School of Public Health and Health
Services
josefr@gwu.edu

Planning Committee
Robert L. Phillips, Jr., MD, MSPH
Michael Klinkman, MD, MS

Maurice Wood MD, FRCGP, FAAFP
Professor Emeritus, Medical Coll. of
Virginia,
Virginia Commonwealth University
nbl4wd@verizon.net

Bridget Teevan, MIS
Office and Research Coordinator
Robert Graham Center, Policy Studies in
Family Medicine and Primary Care
bteevan@aafp.org

Conference Consultants
Larry Green, MD
Director, Prescription for Health
University of Colorado Health Sciences
Center
Larry.Green@UCHSC.edu

Henk Lamberts, MD, PhD
Professor of Family Practice (retired)
University of Amsterdam, The
Netherlands Henk.Lamberts@planet.nl

Inge Okkes, PhD
Senior Researcher (retired)
University of Amsterdam,
The Netherlands
inge.okkes@yahoo.com

Expert Panel
Larry Green, MD
Michael Klinkman, MD, MS

David Kibbe, MD, MBA
Senior Advisor, Center for Health
Information Technology
American Academy of Family
Physicians
dkibbe@aafp.org

Wilson Pace, MD
Director, AAFP National Research
Network
Green-Edelman Endowed Chair for
Practice-based
Research in Family Medicine
University of Colorado
Health Science Center
Wilson.Pace@UCHSC.edu

Expert Panel cont'd.
Steven Waldren, MD
Director, Center for Health Information
Technology
American Academy of Family Physicians
swaldren@aafp.org

Collaborator Panel
Marjorie S. Greenberg, convener
Executive Secretary, National Committee
on Vital and Health Statistics
National Center for Health Statistics
Msg1@cdc.gov

Robert Barker
Integration Director
NextGen Healthcare Information
Systems, Inc
rbarker@nextgen.com

Simon P. Cohn, MD
Executive Subcommittee Chair, NCVHS
Associate Executive Director, Kaiser
Permanente
Simon.Cohn@kp.org

Kin Wah Fung, MD, MS, MA
Biomedical Terminologies Specialist
National Library of Medicine
kfung@mail.nih.gov

T. Bedirhan Üstün, MD
Coordinator, Classifications and
Terminology
World Health Organization
ustunb@who.int

Paper Reactors
James R. Campbell, MD
Professor Academic Internal Medicine
University of Nebraska Medical Center;
SNOMED
campbell@unmc.edu

Robert Hungate
Physician Patient Partnership for Health
hungater@comcast.net

Asif Syed, MD
College of American Pathologists;
SNOMED
ASyed@cap.org

Michael S. Johnson, PhD
Director, Utility for Care Data Analysis
Kaiser Permanente
Michael.S.Johnson@kp.org

Stanley Chin
Practice Area Lead, Healthcare
Informatics
Altarum Institute
Stanley.Chin@altarum.org

Helen Burstin, MD, MPH
Senior Vice President for Performance
Measures
National Quality Forum
hburstin@qualityforum.org

Paul Biondich, MD, MS
Research Scientist
Regenstrief Institute, Inc
pbiondich@regenstrief.org

Participants
Teresa Baker
Federal Government Relations
Representative
American Academy of Family Physicians
tbaker@aafp.org

Andrew Bazemore, MD, MPH
Assistant Director
Robert Graham Center, Policy Studies in
Family Medicine and Primary Care
abazemore@aafp.org

Carol A. Bean, PhD
Chief Terminology Officer
National Heart, Lung and Blood Institute
National Institutes of Health
cabean@mail.nih.gov

François de Brantes
COO, eHealth Initiative,
National Coordinator, Bridges To
Excellence
eHealth Initiative
francois.debrantes@bridgestoexcellence.org

Farifteh F. Duffy, PhD
Director, National Depression
Management
Leadership Initiative
American Psychiatric Institute for
Research & Education
FDuffy@psych.org

Kurtis S. Elward, MD, MPH
Assistant Professor of Family Medicine
University of Virginia
KSElward@aol.com

J. Michael Fitzmaurice, PhD, FACMI
Senior Science Advisor for Information
Technology
Agency for Healthcare Research and
Quality
J.Michael.Fitzmaurice@ahrq.hhs.gov

David R. Hunt, MD, FACS
Chief Medical Officer
Office of the National Coordinator for
Health
Information Technology
DavidR.Hunt@hhs.gov

Rick Kellerman, MD
Board Chair
American Academy of Family Physicians
rkellerm@kumc.edu

Robert Mayes, MS, RN
Senior advisor on health information
technology
Agency for Healthcare Research and
Quality
Robert.Mayes@AHRQ.hhs.gov

Terry McGeeny, MD, MBA
President and CEO
TransformMed
tmcgeeney@transformed.com

Jason Mitchell, MD
Assistant Director
AAFP Center for Health Information
Technology (CHiT)
jmitchel@aafp.org

Kent Moore
Manager, Health Care Financing and
Delivery
Systems
American Academy of Family Physicians
kmoore@aafp.org

William B Munier, MD
Acting Director, Center for Quality
Improvement and Patient Safety
Agency for Healthcare Research and
Quality
William.Munier@ahrq.hhs.gov

Michele J. Orza, ScD
Acting Director, Board on Health Care
Services
Institute of Medicine
MOrza@nas.edu

Kevin Peterson, MD, MPH
Health Information Technology (HIT)
Work Group Chair, NAPCRG
University of Minnesota
peter223@umn.edu

Walter Rosser, MD
Chair of the Department of Family
Medicine
Queens University (Canada)
rosserw@post.queensu.ca

Steven J. Steindel, PhD
Workgroup on National Health
Information Infrastructure
Centers for Disease Control and
Prevention
sns6@CDC.GOV

Chris van Weel, MD, PhD
President of Wonca
University Medical Centre Nijmegen
The Netherlands
C.vanWeel@hag.umcn.nl