

HIT Policy Committee
Meaningful Use Workgroup
Improving Public Health
Washington, DC, July 29, 2010

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Thank you for the invitation to offer comments at this important workshop. My oral comments will relate, too briefly, to three sets of key issues: the architecture underlying Meaningful Use data exchange, relevant education and training, the necessity for evaluation and research, and generating public investment and support for a learning healthcare system to improve health status. My written comments expand on these points in greater depth since they are directly relevant to the topic of this workshop. They relate to work undertaken for well over a decade including my tenure as the Chair of the National Committee on Vital and Health Statistics in the late 1990s and, more recently, while I served as the president and chief executive officer of the American Medical Informatics Association. As a result, many of the papers reflect the work of groups with whom I was directly involved. The references are arranged as follows: architecture and related issues (references 1-6), education and training (7), research and development (6, 7) and public investment and support (8 – attached in full to this submission as an appendix).

I refer to this workshop as being important. Why is it so important in my own thinking? The EHR Meaningful Use expedition is the opportunity of a lifetime for Population Health and Public Health. With the right structures and stewardship of data we have the potential before us of making a major impact on the social determinants of health. The social determinants of health are defined by WHO as access to health care; poverty; education; and work, leisure, and living conditions. (10) For nearly fifty years, public investment aimed at optimizing health status in America has disproportionately invested in the delivery of direct health care services. The investment in basic biological and biomedical research has been about right but education and also poverty especially as it relates to children have been ignored in relative terms. (11) Public policy has echoed the Russian adage that the shortage will be divided among the poor.

With the passage of the HITECH Act of 2009 plus the Patient Protection and Affordable Care Act of 2010, the nation has a rare chance of a lifetime to heal the schizophrenic rift between public health and clinical medicine that has been the norm for this nation for well over a century. (12) If Electronic Health Records (EHRs) with a focus on meaningful use are set within a congenial system architecture that allows for functional interoperability of patient, personal, and population health records, great progress may result.

The Policy Committee is advised respectfully to keep this in mind as HITECH 'rolls out' toward this new reality. Somewhat like the US intelligence community post-9/11 there are many agencies involved and both HITECH and PACA. Not only are they often competitive with one another, the two laws are basically massive prescriptions for action that resemble toy kits for the grandchildren, e.g., assembly is required, batteries are not included and the instructions for assembly are not understandable. To paraphrase Jeff Goldsmith's recent comments at a Blue Ridge Academic Health Group meeting, the recommended initiatives for cost and quality control in the health reform act resemble "a stampede of hobby horses". Only with tremendous attention to detail and follow-up will there be sufficient commitment to integration and a focus on connectivity plus standards that are evidence-based, locally relevant, and compared with appropriate cohorts across the nation capable of supporting evaluation and continuous improvement in health outcomes. The ONC Strategic Vision is a solid one but delivering on it will become a major challenge. Starting the population health workshop with heavy input from the periphery, e.g. state health agencies, is right on target since the heavy lifting must be done there but with the aid and support of the center.

Architecture and Related Issues. The SHARP programs related to Healthcare Application and Network Platform Architectures and Secondary Uses of EHR Data may wish to stay in touch with the recommendations that will emerge from the new NAS study just getting underway at the behest of CMS to enhance its data system capabilities relating to quality, safety, etc. Specific efforts should focus solely on the learning care system from a *population health* management perspective. Another federal program that would be wise to link into this dialogue is the Clinical Translational Science Awards and their regional community engagement activities. For example, Michiner at Duke University identified the need for a new primary care clinic for based upon an analysis of population 'geo-coding' clinical visits to all providers in the region. This analysis reveals a region outside Durham that wasn't accessing needed primary care services. A new clinic is now there and is helping to mitigated health disparities as a result. It was the equivalent of Conan Doyle's Silver Blaze, the dog who didn't bark. Yet another exciting development relating to this domain is the recent federal Community Health Status Indicators initiative (see <http://communityhealth.hhs.gov/homepage.aspx?j=1> , accessed July 20, 2010. The Population Health Sciences Program at the University of Wisconsin-Madison, including the RWJF Health and Society Scholars program are yet another source for research and collaboration as well as education (see <http://www.pophealth.wisc.edu/Home>, accessed July 20, 2010. Rarely have we seen such a confluence of important initiatives getting underway. Integrating efforts may prove impossible but periodic meetings and workshops among these players as well as the community health centers would make great sense. Key elements of this vision have been recommended by authors and groups for over fifteen years including Duncan (13) and, most recently, Friedman and Parrish (14).

Research, Development, and Evaluation. It would be advisable to create rolling three year evaluation, research and development reviews and assessments of the population

health dimension. In addition, it may be essential to create within ONC a unit explicitly focused on innovation both administrative as well as relating to program. The tendency of bureaucracies to 'gel' into a version of concrete is well known and specific efforts should be considered to actively manage to such a tendency. The reporting structure for such a unit which might be done on a matrix basis cutting across the units within ONC as well as others mentioned above should report to the Secretary through the ONC Director and the results made public. With all the other activity going on flexibility and innovation could get lost in the shuffle. A periodic review by the Policy and Standards Committee from the perspective of population health would be advisable since our proclivity in the country is so likely to focus solely toward the clinical domain.

Education and Training. Based upon being a referee on the workforce proposals for University-based Training grants (admittedly an incomplete sample), there was a very disproportionate attention given to clinical versus public health leadership. We need far more investment in public health informatics at all levels of expertise, e.g., basic knowledge and skill sets, as well as master's and certificate programs specifically tailored to help state level and local implementation and improvements. For this reason, it is very good news that all nine university-based training sites funded by ONC plan to prepare individuals to practice in public health and that the program goal aims for one-fourth of trainees to be in public health. However, it will be important to monitor these numbers closely since some marketing to potential trainees may be needed to meet this target. Some focus on population health/health services research is also needed.

The interest expressed by leaders within state and local health departments for supporting greater staff development is impressive but having sufficient flexibility to give people time to be away is a major challenge, particularly as the HITECH workload comes in on top of already short staffing situations. Explicit attention needs to be given by the ONC to assure that sufficient resources are giving to support recruitment efforts for both population and public health informatics. Today, the needed workforce in these field is just not there and with the role targeted for leadership being Clinician/Public Health there is a risk that the clinician side will get too much of the focus. Shorter distant education programs are also likely to be particularly helpful. One example is the AMIA 10x10 program (see <http://www.amia.org/10x10>, accessed July 21, 2010). Even short modules as continuing education on essential knowledge and skills can help.

Direct Engagement of the Public for a Learning Healthcare System. With HITECH and PACA now the law of the land, we are in a different space with respect to privacy and confidentiality. No one can lose insurance or insurability based upon health or prior conditions. With a Secretary of DHHS dedicated to evidence-based policy, science and research, we simply must work harder to remove expensive administrative and monetary burdens facing the legitimate research enterprise of the nation, including the entire range of activity from genomic/epigenetic research, population and public health, clinical delivery, health services and health law research, plus policy innovation. While many would say this is neither practical nor achievable, one should consider what has just happened with HITECH and PACA. Who thought those would be achievable? And, what about the shift in tobacco use toward prevention over the past decade? At issue is

primarily the strength of our commitment as health advocates and our belief in the value of biomedical and health research done well. To make progress on this effort will require substantial public education and social marketing. We need to take this on primarily to assure that the public understands what is at stake if research simply becomes too expensive and too much of a hassle for clinicians and public health workers to devote their time to such valuable work. The details for a new piece of health legislation, a “Health Research and Safe Care Act of 2011” are found in the appendix below. (9)

Thank you for this opportunity to offer some views on these important matters. I wish everyone involved a satisfying journey and success measured in better health and greater human happiness. Remember Emerson’s comment, “The first wealth is health.”

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Appendix.

JAMIA 2010;17:367-369 doi:10.1136/jamia.2010.006098

- Viewpoint paper

Activating a full architectural model: improving health through robust population health records

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- **Received** 13 May 2010
- **Accepted** 14 May 2010

In the current issue of *JAMIA*, Friedman and Parrish have crafted an insightful and provocative call for the Population Health Record writ large.¹ This paper contributes in an important way to the literature and appears at a propitious time in our nation's health policy history. Furthermore, it is appropriate for *JAMIA* in that the AMIA Board first called for such a development in 1997.²

The authors present a compelling case, with sufficient details to make clear exactly what is needed. I will therefore not seek to elaborate upon the paper's content except to say that I support it wholeheartedly. Rather, I offer some added thoughts related to overcoming critical policy barriers. My comments will deal with understanding our civilization culturally, and touch on the role and importance that health can yet play in our nation's priorities. Before engaging in these weighty matters, I note that the reason that it took 13 years for this proposal to be so 'timely' now has both technical and governmental components.

The long delay in addressing the population health record—the final one-third of the data architecture that encompasses patient, personal, and population records—relates to the state of information and communications technology at the time that AMIA initially called for PopER. Bill Wolf, until recently President of the National Academy of Engineering, reminds us that even the Apollo moon missions in 1969 only had as much computer 'memory' to work with as one can now buy in an ordinary greeting card to sing 'Happy Birthday' to you. While our minds might have been willing to dream of crunching gigabytes of data on populations in 1997, most of us were at the time forced to live and work in megabytes, still using 3 1/2 inch 'floppy' disks. Electronic health records (EHRs) were largely hospital-based clinical records. Personal health records were just a gleam in a few people's eyes.

On the policy side, it was at that time that the Department of Health and Human Services under Secretary Donna Shalala decided that the government needed advice not only on vital statistics but on all aspects of health information policy. This led to a reformulation of the mission and goals of the National Committee on Vital and Health Statistics, the creation of a National Health Information Infrastructure Working Group, and the ultimate release of two relevant policy documents on National Health Information Infrastructure.^{3 4} While both documents mention population health records, the vision for the population health record as proposed by Friedman and Parrish mostly resembled the old saw about unicorns... 'Yeah, I've heard of them but I haven't seen one'.

Now over a decade later, the US is into our third or fourth National Coordinator for Health IT, depending on how one chooses to count; the country is about to spend billions of dollars on electronic health records and information exchanges to achieve meaningful use; and, regulators and care providers now prepare for a second iteration of the Health Insurance Portability and Accountability Act (HIPAA) that was included in the Health Information Technology for Economic and Clinical Health (HITECH) provisions of the American Recovery and Reinvestment Act of 2009.⁵ For both better and worse, the bulk of policy attention has circulated far more heavily around protection of personal health data as opposed to responsible ways to share it for improving health and healthcare through EHRs—whether or not the data contains a patient, personal, or population focus.

Two additional momentous policy developments now part of the picture potentially bode well for Friedman and Parrish's vision. The Patient Protection and Affordable Care Act of 2010 guarantees citizens lifetime access to health insurance; this development removes the risk and the fear associated with it that inappropriate access to personal health data will render a citizen forever uninsurable.⁶ With this historic law plus the added safeguards for person specific health data included in the American Recovery and Reinvestment Act (ARRA) law, including stiffer penalties for those who willfully ignore these mandates, the nation can now call for better evidence of what works in healthcare and how well it works compared to other treatments based upon data derived from electronic health records. And, it has done just this with 'comparative effectiveness' in ARRA.⁷ The Secretary of Health and Human Services, Kathleen Sebelius, stated that she hopes to make evidence-based decisions based upon data and research.⁸ All these recent policy developments offer potential hope and support for the population health record. With the US now having the policy infrastructure for security and privacy that it needs, including a privacy officer within the Office of the National Coordinator, data management and exchange mechanisms can consider greater and more trustworthy data sharing for those citizens who are open to sharing their data. The question is whether or not we will press to balance all the current protections of data by facilitating access to data as proposed in the UK with its 2007 Research Capability Program in the Department of Health.⁹ Twenty-one NHS data-sets will become available to approved researchers with 'safe havens' for population-based research—read population health record. On the home front, the recent development that touches on a part of the PopER vision is the Community Health Data initiative that seeks to help Americans understand health and healthcare performance in their communities, as well as spark and facilitate action to improve performance—population health records are indeed on the Government's agenda.¹⁰

America needs broader legislation for two reasons. The first reason is philosophical, while the second is practical. Social science research recently has shown "that modern prosociality is not solely the product of an innate psychology, but also reflects norms and institutions that have emerged over the course of history".¹¹ Hoff points out that a society is not just a random group of people with a shared territory—it is a group that shares cognitive frames and social norms.¹² Recent fear of invasion of personal privacy in the absence of lifelong insurability led to attendant legislation that erected more and more barriers to data access. While well-intended, left to themselves without opportunity for altruistic expressions favoring

'managed' community data sharing (as per the UK initiative), the privacy advocates will continue to erode our capacity to have a learning society and a *learning healthcare system* in particular. As the Institute of Medicine has stated, a learning healthcare system is essential to going forward.¹³

More importantly, without counter-veiling attention at the federal level to balance the continuing restrictions in the name of privacy, we will inexorably transform ourselves from a nation with great historic investment in the common good into a fearful, self-interested set of individuals without positive 'cognitive frames and social norms'. Much public good has come from responsible access to health-related data, and greater good can yet be achieved.

To accomplish the PopER, a new kind of health policy reform must enable access to personal health data for worthy public uses, including population health records and legitimate biomedical and health related research. The US has spent over a decade focused heavily on privacy and security at the expense of equally important social ends such as the uses of data for supporting better public policy, public health and legitimate research. What I propose is neither trivial nor politically palatable to many of the more strident privacy advocates. Unfortunately, too many practicing health professionals undervalue their own stake in preserving a robust learning environment. And, many in the science community know how difficult it is to rouse busy researchers to see that their research depends on more than simply the National Institutes of Health, the National Science Foundation, and Agency for Healthcare Research and Quality budgets.

The 2008 AMIA policy conference got it right when it concluded that the US must refocus public policy with respect to data access if the country is to improve data integrity, continue to secure privacy and security, and facilitate research.¹⁴

The US should pass a 'Health Research and Safe Care Act of 2011'. Through the Department of Health and Human Services, the law would create an opportunity for individual citizens to do the following:

1. 'Opt-out' of having a unique personal health identifier assigned for use in research databases, for example PopER, with an additional option to opt-out for using the same identifier for their own routine healthcare purposes as well.
2. Opt-out of an otherwise automatic consent to share their personal health data for IRB approved research which complies fully with HIPAA security regulations, with the additional opportunity to opt-out of any IRB or national requirements for data anonymization of their individual records.
3. Opt-out of an otherwise automatic consent to share their personal genetic data, if it is available, for IRB-approved research that complies fully with HIPAA security regulations,

with the additional opportunity to opt-out of any IRB or national requirements for data anonymization of their personal genetic data.

In addition, through the law:

4. Use of anonymized data would be available without explicit personal consent.
5. A public-private partnership would be encouraged that would allow citizens to 'opt-in' by submitting their preferred email address onto a well maintained website to take part in IRB-approved clinical trials for which further consent would be required by the researchers. This last feature as well as the personal identifier for healthcare purposes could be managed as part of the regional data exchanges being developed through the HITECH provisions.

Applying human behavior research findings to energy policy, Allcott and Mullainathan argue for policy structures that acknowledge that human behavior is more complex and less idealized than traditional economic models of rational choice.¹⁵ Similarly, since the Secretary as the top official seeks greater evidence and research for better decision making and since default 'no-action' options strongly influence choices and are far less expensive to implement and maintain, 'opt-out' is totally defensible. I agree with Thaler and Sunstein that such 'nudges' are valuable ways to improve public decision-making for better health, wealth, and happiness.¹⁶

Whether or not others will take up the proposed legislation, the US must clearly refocus on the future of population health records. Health is a complex admixture of cultural behaviors, habits, workplace factors, nutrition, and the influence of healthcare delivery services. Friedman and Parrish have done a great service by moving our thinking forward. With 'friendly' public policy and continued efforts, PopER can gain its rightful place alongside the Patient and Personal health record. And, none too soon.

Footnotes

- Aspects of this Viewpoint were presented at the Institute of Medicine Workshop, The Learning Healthcare System in 2010 and Beyond: Understanding, Engaging and Communicating the Possibilities on April 1, 2010 in Washington, DC.
- Competing interests None.
- Provenance and peer review Commissioned; not externally peer reviewed.

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J Am Med Inform Assoc 2010;17:367e369. doi:10.1136/jamia.2010.006098 367