



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

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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.

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