

Redefining Our Picture of Health:

**Towards a Person-Centered Integrated Care,
Research, Wellness, and Community Ecosystem**

A White Paper of the 2017 AMIA Policy Invitational

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Acknowledgements

AMIA wishes to acknowledge and extend our sincere gratitude to a broad community of contributors across the AMIA membership and other stakeholders for their participation in the 2017 AMIA Policy Invitational. We especially would like to thank Liz Salmi, Hugo Campos, and Kim Goodsell for bringing their patient and consumer views to this effort.

We also wish to thank Susan Hull (Chair), Jeremy Warner (Vice Chair) and the entire [API17 Planning Committee](#) for their many hours of work leading into and during the Policy Invitational.

Finally, we wish to thank the Commonwealth Fund for their generous support that made possible the participation of our patient and consumer advocates.

Introduction

Information Technology (IT) and data have become central components in managing the health of individuals, groups, and populations.

However, the primary model for healthcare information technology (health IT) today is institution-focused, deployed around narrow use cases, and most often focused on the resolution or management of acute or chronic illness, rather than the promotion and maintenance of health and wellbeing. This model has resulted in innumerable data silos,

which are divorced from the way patients, their families, and their caregivers wish to maintain health and wellness, experience care delivery, participate in research, and contribute to and benefit from their communities.

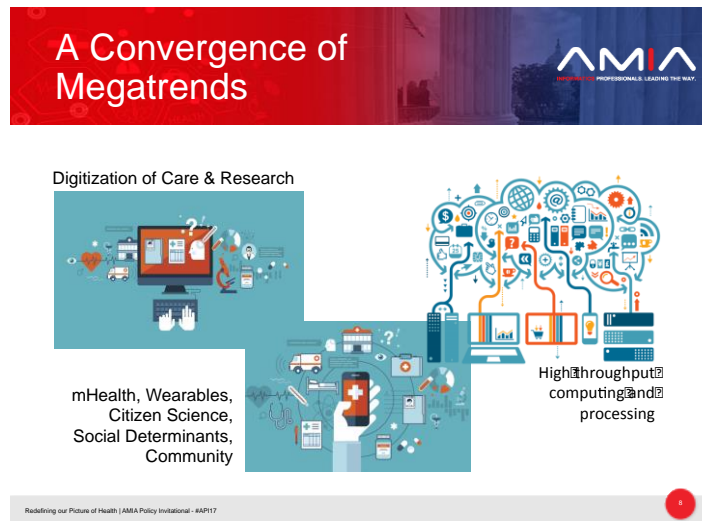
Despite recent advances, the current picture provided by health IT remains analogous to early instant photographs: grainy, blurry, rarely taken, easily smudged, susceptible to misrepresentation, and representative of but a single moment in time. While the digitization of care, through the deployment of electronic health records (EHRs) and personal health records (PHRs) across the country has improved the resolution of our picture, we are still far from the high-definition, focused, three-dimensional pictures of health to which we aspire.

“Supporting individuals to own their health information is the most important thing we can do to level the playing field.”

- Liz Salmi, OpenNotes

Every year, the American Medical Informatics Association (AMIA) convenes a two-day Policy Invitational meeting to address specific policy topics of broad relevance to the membership.

Past Policy Invitationals have addressed the opportunities and challenges around personalized medicine,¹ unlocking the potential of EHRs,² and re-examining the relationship between clinical practice and clinical research.³ The 2017 AMIA Policy Invitational (API17) set out to *Redefine Our Picture of Health*, through the lens of patients and families, rather than those of provider institutions, payers, and health IT vendors.



What we learned was that such an undertaking would require development of an integrated, sociotechnical ecosystem that enables an individual (the “n-of-1”) to improve the health of populations (the “n-of-many”), and *vice versa*. This sub-theme of how the n-of-1 relates to the n-of-many reflects the general shift in perception from the person-as-patient to the individual and their community as meaningful data co-producers and consumers, within or outside the health/illness context.

Below is a brief overview of the topics, conversations, findings, and recommendations that emerged during the day-and-a-half in-person meeting. Key recommendations emerged in the areas of “Consumer- & User-Centered Regulatory Environment,” “Person-Centered Inputs and Person-Driven Outputs,” and “Integrative and Inclusive Policy Development & Planning.”

Background

For the last several years, new data types and technologies have begun to sharpen and, in some cases, redefine how we understand the health of individuals, groups, and populations. For example, the adoption of EHRs and other health IT in care delivery and research has dramatically increased the amount of available health data for any episode of care, and to the comprehensive longitudinal health record over time. The addition of rich contextual data about patients – and supplied by patients – including environmental, geographic, socio-behavioral, and genomic data, are adding digital definition to patients’ stories. Recent advancements in mobile health applications add various kinds of person-generated data to already complex clinical data, and offer new ways to engage in care and research. Advances in basic and clinical research, coupled with increasingly ubiquitous digital technology, enable a single patient’s picture of health to inform the pictures of many patients’ health.

3000 years ago, medicine was healthcare provider-oriented and concerned itself primarily with catastrophic disease. 150 years ago, medicine has become patient-oriented but is still dominated by the medical establishment and built around the chronic disease model. In the past 5-10 years, technology has enabled the patient to become an active participant and driver in certain aspects of their healthcare. In the near future, technology will increasingly allow the person to drive not only their care, but also their participation in research and wellness in the context of their community.

- Jeremy Warner, MD, MS,
API17 Vice Chair

These trends are converging to deliver a more refined and complete picture of health, where personalized care can deliver treatments tailored to the individual, where a single patient can inform and improve the health of populations, and where the “n-of-Many” can be leveraged to better understand the “n-of-1 and *vice versa*.”

Process

Eighty informatics professionals, policy experts, patient advocates, health IT industry advisors, and other invited guests participated in a day-and-a-half meeting to develop policy recommendations that promote patient-centeredness and the integration of often-siloed domains of care, research, wellness, and community. This diverse group had representation from clinicians, technologists, researchers, citizen scientists, patients, and laypersons. To set the stage for success, the AMIA Policy Invitational Planning Committee (PIPC) initiated an intentional design meeting structure that included detailed breakout instructions,⁴ facilitation, and interactive group participation. Outputs were generated in real-time and were used to develop a set of policy recommendations to support this emergent process.

The PIPC developed a series of illustrative personas and scenarios representing experiences related to care, research, wellness, and community, set approximately 5 to 10 years in the future. The Care and Research scenarios utilized “Coping Clare” and “Struggling Sam” personas, originally developed by the Commonwealth Fund, to address high-cost, high-need patients.⁵ These scenarios respectively depicted a future where voice-activated artificial intelligence, called HealthLana, and genomic sequencing, through REMCO-Labs, are ubiquitous. Meanwhile, PIPC members developed the Wellness and Community personas for “Rueful Raphael” and “Expecting Eugenie.” These scenarios represent potential futures, some utopian (in Expecting Eugenie) and some distinctly less so (Rueful Raphael) where mHealth applications and employee wellness programs dominate the lives of their respective personas. The full description of the personas and scenarios are available in [Appendix A](#).



Prior to the meeting, participants reviewed the personas and scenarios and engaged in virtual discussions via AMIAConnect, AMIA's online member engagement platform.⁶ The meeting thus launched with a clear articulation of the gap between the current and idealized future state of patient- and family-centered care, research, wellness, and community. Planners and participants addressed each scenario separately in their initial work, recognizing the goal to achieve a person-centered, integrated, self-reinforcing, and technology-enabled future. Keynotes and panels were staged at intervals to provide inspiration, context, and provocation to support the iterative group work. [Appendix B](#) links to API17 meeting overview and panelists.

Small scenario-specific groups worked during the first day with their respective persona through a series of facilitated activities: (1) Identifying major and critical challenges to achieving each ideal scenario (or avoiding the blighted ones); (2) Identifying emergent themes across challenges; (3) Prioritizing the themes; (4) Conducting detailed analysis of the themes; and (5) Drafting initial policy recommendations. To develop policy recommendations that would integrate rather than isolate our domains of focus, the scenario-specific cross cutting issues were examined and categorized by a subgroup of the PIPC, and then framed as six problem statements.

The second day included large group exploration and refinement of the six problem statements. Then, participants self-selected into small groups around their interest and expertise. These small groups analyzed, edited, and refined the statements considering emergent issues related to the socio-political environment and the kinds of technology, infrastructure, and business incentives needed to address the problem. Groups developed and presented a series of policy recommendations including:

- Designating each as a new policy, a modification of existing policy, or the removal of existing policy;
- Consideration of legislation, regulation, or other action; and
- Identification of stakeholders and potential stewards.

What emerged from group discussion was a set of issues related to each scenario, and a corresponding set of policy recommendations for each.

Key Cross-Cutting Issues

Some of the scenario-specific issues emerging from the breakout sessions shared concepts across the scenarios. These cross-cutting issues were categorized into a series of six problem statements. An additional seventh issue, Supporting Diverse People, was identified during the large group discussion.

Cross-Cutting Issues as Problem Statements

1. **Data Standards:** There is uncertainty over how to coordinate the development, identification, use, and financial support of data standards in clinical care, research, wellness and community.
2. **Data Governance & Ethics:** In the future, information systems and devices intended for personal health will perform tasks and have functions that are traditionally the purview of health care practitioners and their technology. There is no governance, oversight, or ethical framework in place to manage the risks and benefits in managing personal data across care, research, wellness and community.
3. **Data Sources Across Home & Community:** Data sources for care, research, wellness, and community will continue to proliferate. There is a lack of coordinated capacity for data collection (from all types of sources) across home and community.
4. **Participatory Methods & Citizen Science:** Few methods exist today for analyzing and interpreting diverse, novel, and non-standard data streams relevant to health, across clinical care, research, wellness, and community.
5. **Outcome Measures:** We lack widely used and accepted person-defined outcomes, clinically meaningful outcomes, and health-related quality of life outcome measures.
6. **Trust & Transparency:** The number of commercial and non-proprietary information resources will proliferate, and we lack a coordinated framework that ensures trust, safety, efficacy, and transparency.
7. **Supporting Diverse People:** The users of consumer and professional IT devices vary with respect to ability (technical, physical, cognitive, etc.), motivation, culture, health literacy, context of use, and other dimensions. There must be ways to account for differences of their needs for participating in care, research, wellness and community through functionality, information presentation, privacy, etc.

"Algorithms in AI and Deep Learning are only as good at their data."

- Andrea Hartzler, PhD, University of Washington

Guiding Principles and Policy Framework

API17 concluded with a series of policy recommendations developed for each problem statement (these can be found in [Appendix C](#)). These recommendations are reorganized and categorized into a policy framework intended to promote a person-centered informatics infrastructure and data ecosystem. Underlying this framework is a set of guiding principles that are meant to inform deliberations over development of the person-centered informatics infrastructure and data ecosystem which API2017 sought to envision. Below, in Table 1, we translate these guiding principles into policy principles, which are – in turn – meant to inform development or refinement of regulations, legislation, guidance documents, and other policies to help enable this informatics infrastructure and data ecosystem. The guiding principles are: (1) Partnership; (2) Individual Control; (3) Transparency; (4) Data as a Social Good; and (5) Diversity.

TABLE 1

	Guiding Principle	Policy Principle
Partnership	Patients, care givers, and research participants are integral partners in the development of digitally supported health.	Public policies and programs that are meant to support and encourage (trusted and safe) digitally supported health should include patients, care givers, and research participants as integral partners.
Individual Control	Individuals have rights to access and use data collected by technologies that support their health.	Public policy should make data open, available, and controllable by those from whom the data derive.
Transparency	Individuals deserve transparency in how their data are used and re-used by technologies that support their health.	Public policy should incentivize transparency, openness, and consistency among data source terms and conditions – for use and reuse – within and outside the current purview of HIPAA (e.g., wearables, medical devices, remote monitoring sensors, mobile apps, websites including social media, patient portals, health information exchanges, and EHRs).
Data as a Social Good	Decisions related to data access and data sharing are fundamental expressions of social and ethical norms in a modern, connected society.	Public policy should encourage socially responsible and ethically consistent data access and data sharing that enable the n-of-1 to improve the health

		of the n-of-many, and the n-of-many to inform the treatment of the n-of-1.
Diversity	Special emphasis should be applied so that all populations can participate in, access, and benefit from advances in technologies that support health.	Public policy must ensure that diverse and underserved people and populations are able to participate in, access, and benefit from advances made in digital health across ability, culture, health literacy, and socioeconomic status.

With these principles in mind, we propose a policy framework (Figure 1) meant to address the cross-cutting issues identified by API17 participants and encourage a more person-centered, integrated care, research, wellness, and community ecosystem.



FIGURE 1

This policy framework reflects recommendations developed by API17 participants to the cross-cutting issues and includes the principles derived from that conversation. We anticipate that this framework could be applied to both pragmatic issues, such as data standards, quality measurement, care delivery reimbursement, research incentives, citizen science, and workforce needs, as well as conceptual issues related to the ethics of data sharing, governance, and data ownership.

Draft Summary Recommendations

As applied to our cross-cutting issues, the policy framework informs current policies and programs, and makes clear the need to develop new ones. While not comprehensive, the recommendations below, developed by API17 participants, highlight ways in which the federal government can facilitate a more person-centered, integrated care, research, wellness and community ecosystem.

CONSUMER- & USER-CENTERED REGULATORY ENVIRONMENT

1. A public-private collaborative should develop an infrastructure and governance framework that (1) recognizes the diverse and proliferating data from home to community sources and that (2) provides mechanisms for data source identification, registration, and production of relevant metadata for the appropriate re-use of such data. Experience with implementation of a national Unique Device Identifier⁷ ecosystem could inform this effort, and its application to mHealth and other software data should be explored.
2. Federal agencies involved with digital health, such as the Office of the National Coordinator for Health Information Technology (ONC), the Federal Trade Commission (FTC), the Food and Drug Administration (FDA), Centers for Medicare and Medicaid Services (CMS), and others, should develop a framework to support trust, safety, efficacy, and transparency across the proliferation of commercial and non-proprietary information resources.

"We are called to the promise of health ecosystems and communities where we are empowered to co-produce knowledge, health, and value for the n-of-1 and n-of-many. Our wellbeing and shared humanity require policy frameworks that connect us rather than break us apart."

**- Susan Hull, MSN,
RN-BC, API17 Chair**

PERSON-CENTERED INPUTS & PERSON-DRIVEN OUTPUTS

3. The Patient-Centered Outcomes Research Institute (PCORI) or other major funder should develop new participatory research methods that engage and empower community members as citizen scientists and active members of community health governing bodies and patient advisory councils.
4. The Centers for Medicare and Medicaid Services (CMS) and the National Institutes of Health (NIH) should fund development of person-driven goal and outcome measures beyond those developed by

PROMIS⁸ and support demonstrations and pilot studies, considering high profile use cases such as the All of Us Research Program⁹ and requirements for the Medicare annual wellness exam.¹⁰

- 5. CMS and NIH should fund development of methods for passively collecting data that standardize measures for populations to integrate outcomes defined by individuals that are relevant to their own health and clinical/health outcomes measures.**

INTEGRATIVE AND INCLUSIVE POLICY DEVELOPMENT & PLANNING

- 6. Federal Agencies should identify ways to balance the allocation of resources to health, recognizing the influence social, economic, and environmental risk factors have as predictors of health disparities at both the individual and community level. They should enable and fund a distributed, open infrastructure that supports shared access to community-and regional-based social and behavioral determinants of health data to impact care, research, wellness, and community outcomes.**
- 7. A U.S. Federal Government Interagency Ethics Working Group should be established to consider the social and ethical dimensions of emerging technologies – such as “-omic” sequencing, augmented intelligence, and increasingly distributed care and research models – and their applications to both individual and population health. This working group should be a blue-ribbon panel with an explicit focus on data as a social good and data sharing, especially regarding data from traditional and non-traditional sources of consumer and medical information system.**

APPENDICES

APPENDIX A: Scenarios and Breakout Activities

[Care Scenario with Coping Clare](#) (Care Breakout Instructions available [here](#))

[Research Scenario with Struggling Sam](#) (Research Breakout Instructions available [here](#))

[Wellness Scenario with Rueful Raphael and Asthmatic Artur](#) (Wellness Breakout Instructions available [here](#))

[Community Scenario with Expecting Eugenie](#) (Community Breakout Instructions available [here](#))

APPENDIX B: API17 Program Agenda and Materials

[API17 Overview, Panelists, and acknowledgements](#)

APPENDIX C: Draft Recommendations Developed by API17 Participants

- 1 There is uncertainty over how to coordinate the development, discovery, use, and payment of data standards necessary for patient-centered care, research, wellness, and community.

DATA STANDARDS

- The Federal government should act to remove financial barriers in development, maintenance and adoption of standards.
 - Standards named in regulation and used by federal government should be developed by SDOs and be transparent and open
 - The Federal government should identify applicable standards for priority use cases and as needed, engage in coordination among SDOs and to facilitate elimination of non-functional variation
 - The Federal government should recognize standards developed by SDOs that are accredited by ANSI or some other internationally-recognized accreditor of SDOs, such as ISO
- 2 There will be increased blurring between consumer and medical information systems and devices. There is no governance, oversight, or ethical framework in place to understand the risks and benefits in handling personal data across care, research, wellness and community.

DATA GOVERNANCE & ETHICAL FRAMEWORK

- **An Interagency Ethic Working Group is needed to enhance the flow of data from traditional and non-traditional sources of consumer and medical information systems and devices, in a socially responsible way to improve health the workgroup should include, among others ELSI, NVHS, CFPB.**
- **Investment to develop infrastructure akin to the one to adopt EHRs, to incorporate SDOH**
- **Support and incorporate personal data into healthcare**
 - **Consumer data incorporated in healthcare maintains its original state / not considered PHI**
 - **Remove disincentives for use of PGHD**
 - **Personal data protections for use – data research involved with TPO provisions for data use – becomes TPO DR (for data research).**
 - **Better balance of allocation of resources to health, rather than medical care. Enable an infrastructure for social determinants of health (e.g., outside of the medical model) akin to our investment in the electronic health record.**

- 3 Data sources for care, research, wellness, and community will continue to proliferate. There is a lack of coordinated capacity for data collection (from all types of sources) across home and community.**

DATA SOURCES ACROSS HOME & COMMUNITY – PROBLEM OF COORDINATING NEW, NOVEL DATA SOURCES

- **The most critical enabler and most powerful disabler of coordinated data sources is transparency and openness**
- **There should be a platform to help registration and use of data**
- **Level the playing field for anyone who wants to contribute to the ecosystem that allows us to leverage health data for health. Platform economy needs to be leveraged in care, but we need to be conscientious about it's development in a way that is not confined to corporate profit.**
- **Metadata and the science around metadata needs to advance so that the data about the data can allow for its proper use and reuse.**
- **Unique device identifier work at FDA could be part of that ecosystem (or expanded upon)**
- **API transparency is needed (standards-based and open so that innovators can link-into and take advantage of institutional APIs)**
- **Registering devices and registering (or identifying) persons**

- 4 There is a lack of methods for understanding and analyzing diverse, novel, and non-standard data streams relevant to health, across care, research, wellness, and community.**

PARTICIPATORY METHODS & CITIZEN SCIENCE

- **Improve the methods for development of new participatory methods**
 - **Make participatory among members of communities being affected (e.g. citizen scientists or patient informaticians)**
 - **Patient researchers and patient informaticians**
 - **Meaningfully engage community participants in data science such as a community research board**
 - **Promote strategies for promotion and tenure to give credit for open collaborative research in addition to traditional metrics.**
- 5 We lack person-defined outcomes, clinical outcomes, and health outcomes measures.**

OUTCOME MEASURES

- **Modify requirements for the Medicare annual wellness exam to collect person-driven goals -> measures outcomes. Need EHR requirements for collection of such data, pilots & demonstrations.**
 - **CMS – send State Medicaid Dir. letters to stimulate interest at the state-level**
 - **CMS should fund development of person-driven outcome measures beyond PROMIS**
 - **Pilot test / implementation through APMs – PTAC should look at PROMs**
 - **Develop methods for passively collecting outcomes data:**
 - **Satisfies standardized measures for populations**
 - **Patient stated goal measures**
 - **All of Us collect patient goals (modification of existing)**
- 6 The number of commercial and non-proprietary databases and knowledgebases will proliferate and we lack a coordinated framework that ensures trust, safety, efficacy, and transparency.**

TRUST & TRANSPARENCY FRAMEWORK

- **Non-Covered Entities must obtain meaningful consent from consumers contributing data.**
 - **Need to make sure that data sharing is not inhibited**
 - **Need to make sure that consent is understandable**
- **Companies are unwilling to share data of consumers – data ownership is at issue – terms of conditions say that companies own the data (not consumers)**
- **We need to craft policies that make data open, available, and controllable by consumers.¹¹**

- if you're forced into using an app for a financial or health purpose, it is really different and should fall under regs & rules

7 The types of people using consumer and medical IT devices are diverse across ability, culture, health literacy, context of use, and other dimensions. There must be ways to account for differences of their needs through functionality, information presentation, privacy, etc.

SUPPORTING DIVERSE PEOPLE

- **Develop best practices:**
 - Ability guidelines
 - Transparent risks and benefits
 - Choice of engagement
 - Bring diverse patients / people stakeholders
 - Report who and what is saved
 - Evidence to support claims
- **Define Research Agenda**
 - Support diversity efficiently and effectively
 - Support for sporadic and continued use
 - Incompatible learning system
 - New methods

APPENDIX D: API Planning Committee members

Susan Hull, *WellSpring Consulting (Chair)*

Jeremy Warner, *Vanderbilt University (Vice Chair)*

Robin Austin, *University of Minnesota*

Elmer Bernstam, *University of Texas*

Sarah Collins, *Partners Healthcare Systems*

Paul Fu, Jr., *Harbor-UCLA Medical Center*

Joseph Kannry, *Mt. Sinai Health System*

Kathy Kim, *University of California, Davis*

Thom Kuhn, *American College of Physicians*

Chris Lehmann, *Vanderbilt University*

Judy Murphy, *IBM*

Carolyn Petersen, *Mayo Clinic*

Wanda Pratt, *University of Washington*

Trent Rosenbloom, *Vanderbilt University*

Mark Segal, *GE*

Tony Solomonides, *NorthShore University HealthSystem*

Victoria Tiase, *NY Presbyterian Hospital*

¹ <https://www.amia.org/2014-annual-health-policy-invitational-meeting>

² <https://www.amia.org/2015-annual-health-policy-invitational-meeting>

³ <https://www.amia.org/2016-health-policy-invitational-meeting>

⁴ **Struggling Sam Breakout Instructions (by way of example)** https://uploads.strikinglycdn.com/files/8e94e3ce-abfd-41ae-bf8d-b4ba57de6d59/Breakout%20Session%20Instructions_Struggling%20Sam_Final.pdf

⁵ **L** <http://www.commonwealthfund.org/publications/blog/2016/dec/making-health-care-better>

⁶ <https://connect.amia.org/API2017>

⁷ <https://www.fda.gov/MedicalDevices/DeviceRegulationandGuidance/UniqueDeviceIdentification/default.htm>

⁸ <http://www.healthmeasures.net/explore-measurement-systems/promis>

⁹ <https://allofus.nih.gov/>

¹⁰ https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/downloads/AWV_chart_ICN905706.pdf

¹¹ <http://hdexplore.calit2.net/wp-content/uploads/2016/05/Evans-Consumer-driven-data-commons-5-12-2016-w-Abstract-HDE-website-text.pdf>