

## The State Level Infrastructure for Addressing Health Disparities

Linking State Infrastructure to Person-Level Needs



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Infrastructure View of Health Intelligence – <u>Network-of-Networks</u> or <u>System-of-Systems</u>





Source: MMWR 2012, CDC Vision for Public Health Surveillance in the 21<sup>st</sup> Century



## The Problem Statement

• The current *health systems* intelligence relies on <u>outdated</u>, <u>poorly</u> <u>organized</u>, and <u>unfiltered intelligence</u> network that diminishes multilevel stakeholder (e.g., patients, providers, health care organizations, communitybased groups, policy, and researchers) situational awareness capabilities and results in unacceptable levels of vulnerability and risk.





Source: http://www.dhs.gov/sites/default/files/publications/niac-intelinfo-sharing-final-report-01-10-12-508.pdf



### The Challenge: Data Integrity, Care Safety and EHR



6

National Institute of Standards and Technology (NIST). **Technical Evaluation, Testing, and Validation of the Usability of Electronic Health Records: Empirically Based Use Cases for Validating Safety-Enhanced Usability and Guidelines for Standardization**. NISTIR 7804-1 . September 2015. URL: http://dx.doi.org/10.6028/NIST.IR.7804-1



## HIT Impact Study from AHRQ

- Evidence suggests electronically exchanging health information may
  - reduce duplicative laboratory and radiology testing
  - lower emergency department costs
  - reduce hospital admissions
  - improve public health reporting
  - increase ambulatory quality of care
  - improve disability claims processing
- Barriers still remain
  - lack of participation
  - inefficient workflows
  - poorly designed features
- Future research is needed to
  - address comprehensive questions
  - use of more complex, adaptive, and rigorous designs
  - deploy a more coordinated and systematic approach to studying the electronic exchange of health information





# Laying the groundwork for research and development for Smart HIT and Systems Change





AMERICAN HEALTH INFORMATION MANAGEMENT ASSOCIATION HPM 625 (section 001) Applied Public Health Informatics: Diagnosis and Design of Public Health System Intelligence Department of Health Policy and Management School of Public Health University of North Carolina at Chapel Hill

#### Standards for Learning Health System

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#### Commentary

Learning health system

Leveraging health informatics to foster a smart systems response to ( CrossMark health disparities and health equity challenges

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ARTICLE INFO	ABSTRACT
Article history:	Informaticians are challenged to design health Information technology (IT) solutions for complex prob-
Received 9 September 2016	lems, such as health dispatities, but are achieving mixed results in demonstrating a direct impact on
Revised 13 December 2016	health outcomes. This presentation of collective intelligence and the corresponding terms of smart
Accepted 13 February 2017	health, knowledge ecosystem, enhanced health dispatities informatics capacities, knowledge ecohange,
Available online 16 February 2017	big-data, and situational awareness are a means of demonstrating the complex challenges informatics
Keywords:	professionals face in trying to model, measure, and manage an intelligent and smart systems response
Health disparities	to health disparities, A critical piece in our understanding of collective intelligence for public and popu-
Health inequities	lation health rests in our understanding of public and population health as a living and evolving network
Population health	of individuals, organizations, and resources. This discussion represents a step in advancing the conversa-
Technology assessment	tion of what a smart response to health disparities should represent and how informatics can drive the
Smart health	design of intelligent systems to axisis the diminiating health disparities and achieving health equipt,
Knowledge exchange	© 2017 Published by Elsevier Inc.

#### 1. Defining collective intelligence in public and population health manageme

In 2007 Carley et al, published a discussion on social computing entitled, "[Moving] from Social Information to Social Intelligence" [1] In a complementary discussion, the same author examines what "smart agents and organizations of the future" would look like [2]. Each of these discussions explore a common theme: understanding the fields of computer science and informatics as drivers of individual and collective intelligence in fields such as public and population health [1,2]. IBM also addresses the topic of health system-derived intelligence in a report entitled, "Clinical Decision Intelligence: Medical Informatics and Bioinformatics Infrastructure for a Clinical-Decision-Intelligence System" [3]. While individual intelligence is an established construct in the literature, collective intelligence remains an evolving concept. As a result, the notion of a "smart public or population health organization" remains equally ambiguous in nature [4]. If informatics professionals should lead the charge in (1) fostering collective intelligence. (2) designing smart public and population health organizations, and (3) managing highly adaptive health systems, what measures of progress should we rely upon, and how might

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health informatics professional's toolkit.

Public health informatics is an evolving domain in which

practices constantly change to meet the demands of a highly

complex public health and healthcare delivery system. The

typical definition for a variety of domains of informatics (e.g.,

public health, population health, nursing, clinical, medical,

health, consumer, and biomedical) centers on the "application

of information science and information technology to [a

specific domain of] practice, research, and training" [1, 2].

This definition of informatics relies on a technical view of

the health system. A technical view of informatics largely

identifies more tangible products such as databases, decision-

support tools, information systems, web portals, and mobile

devices as the primary means of addressing complex health

Public health informatics systems expressed as a func-

tion of intelligence can be understood in terms of two

codependent pathways of (1) generating health information

issues, improving care, and reducing health disparities.

Informatics Metrics and Measures for a Smart Public Health

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Public health informatics is an evolving domain in which practices constantly change to meet the demands of a highly complex

public health and healthcare delivery system. Given the emergence of various concepts, such as learning health systems, smart health

systems, and adaptive complex health systems, health informatics professionals would benefit from a common set of measures and

capabilities to inform our modeling, measuring, and managing of health system "smartness." Here, we introduce the concepts of

organizational complexity, problem/issue complexity, and situational awareness as three codependent drivers of smart public health

systems characteristics. We also propose seven smart public health systems measures and capabilities that are important in a public

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Systems Approach: Information Science Perspective

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**Review Article** 

cited.

1. Introduction





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#### A Computational Perspective of Knowledge Empowerment for Healthcare Decision Making: **Computational Perspective of** Knowledge Empowerment

Timothy Jay Carney, University of North Carolina, School of Public Health, Chapel Hill, NC, USA

#### ABSTRACT

People in a variety of settings can be heard uttering the phrase that "knowledge is power" or the relatively equivalent concept that "information is power." However, the research literature in particular lacks a simple and standardized way to examine the relationship between knowledge and power. There is a lack operational quantitative definitions of this relationship to adequately support the building of complex computational models used in addressing some longstanding public health and healthcare delivery issues like differential access to care, inequitable care and treatment, institutional bias, disparities in health outcomes, and eliminating barriers to patient-centered care. The objective of this discussion is to present a relational algorithm that can be used in both conceptual discussions on knowledge empowerment modeling, as well as in the building of computational models that want to explore the variable of knowledge empowerment within computer simulation experiments.

#### **KEYWORDS**

Computational, Decision Making, Empowerment, Health Disparities, Health Equity, Intelligence, Knowledge, Modeling, Uncertainty, Wisdom

#### INTRODUCTION

To begin we start by asking a series of simple questions: How does knowledge lead to empowerment? How and under what conditions does empowerment reduce health disparities and promote health equity? The common expression "knowledge is power" and the less common equivalent "information is power" express the value of knowledge as key resource in social and organizational arrangements. Knowledge dependent social and organizational arrangements-as seen from the perspective of the primary of user of knowledge-focuses largely on knowledge as a key driver of decisions/choices and tasks/actions in the pursuit of some set of personal or collective goals. We will assume in this discussion that knowledge is also used to foster learning that is typically leveraged to maximize gain and minimize harm in meeting public health and healthcare delivery objectives.

The overarching research goal that generated this targeted discussion focuses on the role of knowledge in helping public health and healthcare delivery system stakeholders at all levels support informed choices and actions, manage uncertainty, and engage in meaningful communication and knowledge exchange. We want to view this topic through the lens of a complex multilevel health



technology (HIT) policies that ensure our ability to Gov-

ern Intelligence as a byproduct and (2) allowing innova-

tions in HIT to shape and inform public health systems

policy and practice to ensure that we Govern Intelligently,

In the former case, public health informatics professionals

endeavor to generate HIT policy to guide national, state, and

local information architecture, information infrastructure,

and information integration efforts that ultimately guide

how public health meets the needs of stakeholder/agents

such as patients/families/health consumers, communities,

providers/healthcare organizations, researchers, policymak-

ers, and disease-centric communities of practice through

the meaningful supply of intelligence. Such intelligence

can inform stakeholder understanding about the burden

of disease, spread of an outbreak, health alerts and food

recalls, disease clusters, community needs assessments, and

health risk assessments. In the latter case, public health

informatics professionals seek to find innovative ways to

leverage HIT to improve the way we govern by seeking ways

health issues like health disparities and achieving health equity? First, we must define the term collective intelligence. Carley et al. provide a set of core competencies for informatics profession als who are attempting to model, measure, or manage collective intelligence in any public or population health setting [1]. According to Carley, some measure of collective intelligence is achieved by (1) modeling and analyzing social behavior, (2) capturing human social dynamics (e.g., within a given workflow or clinical pathway), (3) creating artificial social agents to represent both classes of individuals (e.g., providers, administrators, families, public health practitioners, policy makers, researchers) and their roles in the care process (e.g., patient navigators, care coordinators,

specialty care, support service providers, public health program managers), and (4) generating and managing actionable social knowledge (i.e. how individual-tacit knowledge [an individual's know-how or expertise] is converted into shared explicit knowledge [organizational knowledge products and artifacts]). While these descriptions still do not fully explain what collective intelligence is, they move us closer toward developing a toolkit to assess social or organizational aspects of a public or population health system. Essentially, we want to better understand how to move from a massive array of individual (person-level) patient encounters and experiences-that are

typically captured in tacit forms-to collective (population-level)

this change our trajectory in our approach to dealing with complex

## We Didn't Have all the Answers but we Generate More Questions



- 1. How do we even begin to standardize our understanding of such esoteric constructs like organizational wisdom, org know-how, org IQ?
- 2. How to introduce standards to shape how smart surveillance can make us as multilevel decision makers (public health, health care practice, health consumers/patients)?
- 3. What does it mean to have mandated intelligence requirements in our surveillance and HIT that we are still not meeting? <u>http://www.gao.gov/products/GAO-11-99</u>
- 4. What standards, policies, and organizational arrangements shaping a national LHS (as a thing)?
- 5. Are there maturity standards that can help us to chart our course over the next decade?
- 6. Problems, issues, challenges moving forward?



In trying to understand <u>State Level Infrastructure for Addressing Health</u> <u>Disparities</u> what view do we rely upon?







Machine View

Network View







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Voted One of the 100 Most Influential Journals in Biology & Medicine over the last 100 Years	Ali S. Khan, Aaron Fleischauer, and Samuel L. Groseclose are with the Centers for Disease Control and Prevention, US Department of Health and Human Services, Atlanta, GA. Aaron Fleischauer and Julie Casani are with the North Carolina Division of Public Health, North Carolina Department of Health and Human Services, Raleigh.	
by the Special Libraries Association	Correspondence should be sent to Ali S. Khan, Centers for Disease Control and Prevention, 1600 Clifton Road, Mailstop C-12, Atlanta, GA 30333 (e-mail: <u>askhan@cdc.gov</u> ). Reprints can be ordered	
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Think of State Health Ecosystem as a System-of-Systems (or Network-of-Networks)



Researchers





Patients/Health Consumers



# State Level Infrastructure for Addressing Health Disparities

Manuscript Overview and Highlights



## Overview of the Manuscript



- Abstract
  - Assumptions
- Introduction
- Informatics Capacity for Addressing Health Disparities
- The Health Disparities National Surveillance Challenge
- Mandating Smarter Public Health and Healthcare Delivery
- State Level Organizational Structure, Policy, and Culture to Address Health Equity and Health Disparities
- Innovative Practices and Perspectives that can Inform State-Level Strategies
- Guidelines and Recommendations (call-to-action)



## **Over-Arching Questions**



- How can we position states to address health disparities (HD), Health Equity (HE) and the Social Determinants of Health (SDOH) in a whole-person/human-centered manner?
- How can we resolve the temporal gap and lack of state-level infrastructure for integrated surveillance of HDs, HE, and the SDOH?
- How can we address the uneven information technology capacity between states where we have super-high performers receiving continued support and other states lagging behind?
- What role can —and should— state-level leadership play in the management of individual health delivery, decision making, and resource distribution that lends itself to uneven, differential care and treatment?
- How can we resolve the paradox of state-level leadership and population diversity the can help generate increased forms of "social empathy" for the policy and practice that addresses the most vulnerable sectors of society?
- What does full citizen participation for cross-sector engagement, empowerment, and transparency look like in states where the culture is typically rigid, closed, and regulatory in nature?
- How do we ensure that the new models for precision medicine (and the evolving precision public health movement) have adequate state protections to ensure the implementation does not exacerbate health disparities?
- What should a state-level HD, HE, and SDOH performance dashboard look like (e.g., measures, end-users, interface)?



State-Level Assumption Statement (SL-AS) Number	Assumption Statements
SL-AS1	No two State infrastructures are alike and therefore, the population dynamics, health priorities, and equity/disparities challenges will vary by state
SL-AS2	Given SL-AS1, No one intervention design or program strategy will have the exact same impact on any two state infrastructures
SL-AS3	Few , if any, State leadership (e.g., governors, state senators, state health officials) racial make-up accurately mirrors those typically most impacted by racial disparities.
SL-AS4	No State infrastructure surveillance system has the ability to monitor and track person-level risk and exposure level to health disparities and health inequity trigger events and policy and intervention strategies that are informed by the current surveillance systems must rely on population-level aggregates to inform prediction, ratios, and strategies
SL-AS5	State infrastructures nor health systems routinely monitor or track that person-level risk (SL-AS4), it is thus not woven into technology framework and decision support (e.g., the EHR does not prompt me that my pregnant patient is at higher risk of any specific harms because she is African American), and consumers are not empowered with a choice of the best and safest healthcare setting and information infrastructure relevant to their personal risk.
SL-AS6	The term "State" is broader in scope than just the State Health Department and encompasses all associated components inherent in a State jurisdictional boundary and how they are connected, interact, and organize for change.





## Overview and Key Discussion Points Aspects

 No national electronic surveillance or registry system for health disparities.

#### Towards Shared Situational Awareness and Actionable Knowledge



\* Systematic and continuous collection, analysis, and interpretation of data, closely integrated with the timely and coherent dissemination of the results and assessment to those who have the right to know so that action can be taken (Porta MA, Dictionary of Epidemiology, 5th Ed., Oxford University Press, 2008). † Vital registration, cancer registries, and exposure registries § Medical and laboratory records, pharmacy records.

¶ Weather, climate change, and pollution.

\*\* Criminal justice information, Lexis-Nexis, and census.

Reproduced and Modified Graphic from Source: MMWR 2012, CDC Vision for Public Health Surveillance in the 21<sup>st</sup> Century



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Need for Comprehensive Assessment of Impact





## Rationale



 States, and their corresponding network of localized public jurisdictions, private corporations, academic centers, community advocacy, and integrated health centers/clinics/hospitals, have a unique ability to convene those stakeholders on behalf of their populations.



The fundamental informatics question for States

• To determine if they have adequate informatics capability to identify and organize a response to variations in environmental stressors expressed as systems-, organizational-, and individual-level trigger events, as they occur (or near real-time) before such events become realized as population-level measures of health disparities.



## State Need for Whole-Person/Human-Centered Design Strategies



 health information technology stands at the precipice of state citizenry engagement, empowerment, and informing of individuals. Health IT also serves to provide infrastructure on the proper monitoring and collective action required to properly address health disparities.



## Top-Down Engagement from States is Typical



• Typically, citizens, most often classified as patients, are only thought of from the standpoint of privacy and confidentiality. In this context they are viewed more so as sources of data and less so as co-owners of the technology infrastructure. This design strategy is often mirrored in healthcare delivery information technology development (e.g., EHR, PHR, CDS, CDWs, etc.) as well.



## Limitations



- This is not a data-driven study or systematic review of State practices
- There are varying vantage points one can assume (e.g., state health official, state health department or other state agencies, governors office, surveillance, social services, etc.) and the writing groups' biases may be inherently infused into the arguments.
- The topic is massive and in pairing down the outline some critical information may have been left out
- The typical approach is to outline a litany of State success stories or samples of technology at work...while there is a limited amount of space dedicated to such in this manuscript, the emphasis was placed on critically evaluating the structural barriers we hypothesize stand in the way of total elimination of health disparities across all States.

