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RESEARCH ARTICLE

Public Trust in Health Information Sharing: A Measure of System Trust

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Objective. To measure public trust in a health information sharing in a broadly defined health system (system trust), inclusive of health care, public health, and research; to identify individual characteristics that predict system trust; and to consider these findings in the context of national health initiatives (e.g., learning health systems and precision medicine) that will expand the scope of data sharing.

Data Sources. Survey data ($n = 1,011$) were collected in February 2014.

Study Design. We constructed a composite index of four dimensions of system trust—competency, fidelity, integrity, and trustworthiness. The index was used in linear regression evaluating demographic and psychosocial predictors of system trust.

Data Collection. Data were collected by GfK Custom using a nationally representative sample and analyzed in *Stata* 13.0.

Principal Findings. Our findings suggest the public's trust may not meet the needs of health systems as they enter an era of expanded data sharing. We found that a majority of the U.S. public does not trust the organizations that have health information and share it (i.e., the health system) in one or more dimensions. Together, demographic and psychosocial factors accounted for ~18 percent of the observed variability in system trust. Future research should consider additional predictors of system trust such as knowledge, attitudes, and beliefs to inform policies and practices for health data sharing.

Key Words. Public trust, health information, technology

Data sharing on a large scale is integral to emerging national initiatives (e.g., learning health systems and precision medicine) and promises to address the well-known and chronic maladies of the health system—soaring costs, poor quality, and excess and preventable morbidity and mortality—by getting the right information to the right person at the right time through integrating research and clinical care. To realize this vision, the de facto and de jure boundaries between health care, public health, and research are becoming increasingly permeable to permit the rapid exchange of information (Williams et al. 2012). Accommodating expanded access to data and information relies

on a strong “fabric of trust” (Grossman and McGinnis 2011) that information is used responsibly and ethically, maximizing the benefits while minimizing the harms from data breaches, misuse of information, or faulty algorithms reaching incorrect conclusions. As increased data sharing stretches the current disjointed regulatory and policy environment, the texture and resilience of this “fabric of trust” will be challenged in its capacity to protect the public and its vulnerable populations and to assure data will be used in ways that reflect societal values (Frisse 2015).

Trust is a multidimensional dynamic between two parties characterized by an *expectation or willingness to impart authority and accept vulnerability to another in fulfilling a given set of tasks*. It is established and maintained by a trustor who draws on past experience with, and beliefs or attitudes about, the trustee’s competency, reliability, reputation, honesty, or interestedness to set the boundaries of a trusted relationship (Hardin 2002; Cook, Hardin, and Levi 2005; Nannestad 2008; Cook, Levi, and Hardin 2009; Farrell 2009). The trustor or trustee can be an individual, organization, institution, or system. In this article, we present findings from a nationally representative survey of the U.S. public’s level of trust in the organizations that have health information and share it, that is, the “health system,” broadly defined to include health care practice, research, and public health. Combining these key components into an index of trust in an integrated health information system (“system trust”), we then identify characteristics of the trustor (i.e., individuals) that influence system trust.

Trust in Health Information Sharing

Integrated health information systems aim to promote collaboration by connecting health care practice, to research, to public health through social and technical systems. Such systems enable the sharing of data across sectors and support learning (Faden et al. 2013). The organizations and individuals that represent the health system in part or in whole are those that have health information and share it and include, for example, health care providers, public health departments, payors, and health researchers.

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Trusting the organizations that have health information and share it as a unified integrated health information system is important for three reasons. First, because the web of relationships that must function to deliver coordinated care is sufficiently complex, any opportunity for trust rather than direct oversight facilitates operations and enhances efficiency. Second, trust is important because there is considerable information asymmetry between the public and the health professionals that control and manage access to health information; if the public trusts the health system to act in their best interests, however, this information gap is an acceptable one. And finally, despite hugely robust technology and policy to manage information throughout its life cycle—from collection to analysis to transfer and storage—that can largely maintain privacy and confidentiality, these protections are not infallible. In fact, large-scale data breaches are increasingly common. For example, health plans (Anthem, Premera Blue Cross) and health providers (UCLA Health) were affected by breaches in which 78,800,000, 11,000,000, and 4,500,000 individuals were affected in 2015 alone (HHS 2015). These cases underscore the importance of the public, on balance, trusting the health system to deal with such issues expeditiously and in ways that prevent harm.

As health information sharing extends health systems to be inclusive of an increasingly diverse set of organizations, the health system is likely to take on characteristics not captured in the interpersonal trust established between a provider and a patient. When the system is viewed as a whole, trust in that system becomes analogous to political trust, in which an individual may trust his senator or local representative, but has very little confidence in Congress generally. In the political context, lack of trust in the system is associated with lack of participation (i.e., low voter turnout) and it can undermine political will. In the health care context, we see this type of trust has effects on, for example, support of the Affordable Care Act (Hetherington and Rudolph 2015). While it is true that many consumers have confidence in their own providers, having trust in the system will be important in ensuring its viability as a part of the social fabric.

Assessing Trust in Health Information Sharing

Surveys of trust in health care systems typically encompass several dimensions, including communication, honesty, confidence, competence, fidelity, system trust, confidentiality, and fairness (Ozawa and Sripad 2013). To develop a single measure of trust in integrated health information sharing systems (i.e., system trust), we examined four dimensions: fidelity,

competency, integrity, and trustworthiness. Our work expands most on the work of Mark Hall and colleagues in developing the Wake Forest Scale that has been applied to a number of relevant aspects of health system organization at large, including trust in physicians (Hall et al. 2002a,b; Balkrishnan et al. 2003), the medical profession (Hall et al. 2002a,b), and insurance companies (Zheng et al. 2002; Goold, Fessler, and Moyer 2006).

In examining fidelity, integrity, competency, and trustworthiness dimensions, *fidelity* captures benevolence, that is, the act of a trustee prioritizing the needs and interests of the trustor (Mayer, Davis, and Schoorman 1995). At the system level, this means that the organizations that share health information value and prioritize the needs of the public whose health information they have. *Integrity* is defined as honesty or following the principles of nondeception by not hiding mistakes or being fair in their treatment of people. *Competency* refers to having the ability and expertise to minimize errors and achieve goals. Notably, the public may not have the knowledge to judge competency as experts; however, they are likely to have an instinctual knowledge or perception of system capacity. Fidelity, integrity, and competency are all forms of rational or calculative trust because the trust between parties can be justified. *Trustworthiness*, however, captures an individual's intuition, rather than his or her rational or calculative basis for trust (Hall et al. 2001). To represent these four key components in a single, overall metric of system trust, we created a composite index that would allow us to investigate predictors of this complex trust fabric.

Identifying Predictors of Trust

For national initiatives around precision medicine or learning health systems, the ability to deliver timely, accurate, and person-centered care will rely on upon how well health information systems can capture the population of patients like them to enable better insight into complex care decisions. Thus, to develop systems that meet the increased demands of these new initiatives, we need to better understand the characteristics of the public that does and does not trust the current system and thus may or may not participate. Trust may ultimately drive a single action or opinion, but it is motivated by multiple emotive, cognitive, and behavioral aspects of an individual's belief structure (Lewis and Weigert 1985, 2012). An individual's socialization, for example, will shape his or her deference to the scientific community and willingness to accept the vulnerability of trusting its authority and actions. These considerations, as well as other demographic factors such as education, race and

ethnicity, employment status, etc. inform an individual's habitus, or social position, and ultimately his/her cultural capital (Bourdieu 1984) and trust repertoire (Mizrachi, Drori, and Anspach 2007) that shape agency, power, and capacity to act.

Regardless of the context for trust, some individuals are more likely to exhibit trusting attitudes than others. Individual-level factors create world views, embody social structures, and reflect the experience of everyday life. These factors are particularly relevant antecedents to trust in cases involving complex systems—like large, integrated and interoperable health information systems—comprised of unfamiliar actors or unfamiliar actions because the trustor has little more on which to base his trust beyond these intrinsic characteristics. In this article, we examine the role of demographic factors (e.g., age, sex, education) and psychosocial factors that capture an individual's propensity to trust such as self-esteem, altruism, self-efficacy, one's general outlook on life, and a generalized trust (i.e., expectancy that people are reliable) (Das and Teng 2004) on people's trust in health information sharing systems. These psychosocial factors capture an individual's general propensity to trust. For example, those with high self-esteem are better equipped to trust because they are more likely to feel worthy of being included in relation to another (Leary and Baumeister 2000).

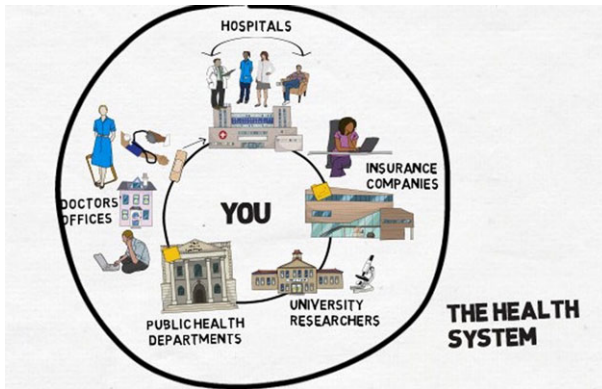
METHODS

Questionnaire Development

Given the complex nature of the health system as a network of organizations that have health information and share it, the first component of the survey was a short (90 seconds) animated video to describe the health system as the network of relationships among health care providers, departments of health, insurance systems, and researchers to provide a common understanding of the health system and the extensiveness of data sharing. The video highlighted examples of data sharing that are currently common practice in health and health care—for example, incidence reporting to public health departments and research use of biospecimens. The neutral tone of the video was reviewed by an expert committee and then by a convenience sample of 15 individuals. The final image for the video is shown in Figure 1, and the complete segment is available online (<https://youtu.be/L-BCwBYPoYc>).

System trust and its predictors were measured by a 117-item survey. Questions from the General Social Survey (Smith et al. 2016), National

Figure 1: Final Image Shown to Survey Participants in Video Describing Health Information Sharing [Color figure can be viewed at wileyonlinelibrary.com]



Note. Full video available online: <https://youtu.be/L-BCwBYPoYc>

Election Survey (Feldman and Steenberg 2001), the General Self-efficacy Scale (Schwarzer and Jerusalem 1995), and the Rosenberg Self-Esteem scale (Rosenberg et al. 1995) were used to survey psychosocial factors. We used the single-item measure of health status that is commonly used in population health surveys asking respondents to rate their health as “poor,” “fair,” “very good,” or “excellent” (Bowling 2005). The survey included additional questions—not included in the scope of the present analysis—about respondents’ knowledge, attitudes, and beliefs, as well as trust in specific institutions (health care providers, researchers, and public health), quality of experience, perceived control, and adequacy of policy oversight.

Measures of the dependent variable—system trust—were adapted from prior studies identified in a literature review of trust in the health system (Ozawa and Sripad 2013) and contextualized for the survey as needed. Most questions were derived from the Wake Forest Study (Hall et al. 2001), one of the most widely used and cited studies of trust in health care, but other surveys were also included (Rose et al. 2004; Thompson et al. 2004; Egede and Ellis 2008; LaVeist, Isaac, and Williams 2009; Platt and Kardia 2015).

Respondents answered questions about “how true” they believed a series of statements to be along a four-point, unipolar Likert scale: “Not at all true” (1), “Somewhat true” (2), “Fairly true” (3), and “Very true” (4). We piloted this scale, and our survey questions used a sample of MTurk workers ($n = 447$). Comparing the “how true” scale to the frequently used “Agree/Disagree” Likert scale in our pilot study, we detected a statistically significant

acquiescence bias associated with the Agree/Disagree scale leading us to choose the “how true” scale (Platt and Kardina 2015).

Sample

Respondents were surveyed in February 2014 using GfK’s probability-based, nationally representative sample consisting of noninstitutionalized general population adults (KnowledgePanel). Eligible participants were randomly selected and contacted via e-mail to invite participation. Of 2,082 individuals contacted to participate, 52.9 percent agreed. Of the 1,103 responses collected, 41 were excluded due to constant refusal and an additional 51 respondents were excluded from data analysis due to item missingness. The median completion time of the final survey was 22 minutes. GfK calculated poststratification weights corresponding to the U.S. Census demographic benchmarks for age, sex, household income, education, and race and ethnic background to reduce bias from random sampling error.

Statistical Analysis

Indices for system trust and three psychosocial characteristics (self-efficacy index, self-esteem index, and altruism index) were created as the sum of the participant’s responses to those survey questions divided by the number of questions answered. Chronbach’s alpha was calculated to evaluate the internal consistency of the system trust index and is reported in Table 1. Paired *t*-tests were used to test whether there were significant differences in participants’ ratings of the health system’s fidelity, integrity, competence, or trustworthiness. Weighted ordinary least-squares (OLS) regression analysis was used to estimate the linear relationship between overall trust in the health system and each trustor factor separately before estimating a multivariable model using all independent variables. Standardized regression coefficients were used to assess the relative magnitude of the effect of each of the independent variables on system trust. Statistical significance is reported for associations with *p*-value of less than .05.

RESULTS

Descriptive statistics for demographic variables describing the sample are listed in Table 2. The sample is split nearly evenly with respect to men and

Table 1: Descriptive Statistics: System Trust and System Trust Dimension Indices

<i>The organizations that have my health information and share it . . .</i>	<i>Frequency (% “Somewhat True” or “Very True”)</i>	<i>Mean (SD)</i>
Fidelity	Index	2.8 (0.48)
Do not care about helping people like me*	14.4	3.41 (0.81)
Value my needs	52.4	2.57 (0.85)
Would not knowingly do anything to harm me	66.2	2.89 (0.95)
Care most about research*	36.9	2.72 (0.86)
Care most about what is convenient for its practitioners*	42.6	2.60 (0.89)
Care most about holding costs down*	37.4	2.55 (0.81)
Competency	Index	2.8 (0.50)
Are very good at conducting research	48.1	2.53 (0.80)
Have a good track record of using health information responsibly	50.2	2.55 (0.84)
Have specialized capabilities that can promote innovation and discovery	52.0	2.61 (0.79)
Should be more careful than they are in sharing health information*	46.2	2.46 (0.98)
Are not good at their jobs*	9.35	3.53 (0.73)
Make more mistakes*	13.4	3.24 (0.77)
Trustworthiness	Index	2.6 (0.77)
Can be trusted to keep my health information secure	44.7	2.50 (0.87)
Can be trusted to use my health information responsibly	52.3	2.59 (0.86)
Think about what is best for me	47.0	2.49 (0.88)
Act in an ethical manner	61.4	2.75 (0.83)
Integrity	Index	2.5 (0.67)
Try hard to be fair in dealing with others	48.5	2.78 (1.01)
Would try to hide a serious mistake*	35.5	2.24 (0.93)
Tell me how my health information is used	37.0	2.37 (0.90)
Would never mislead me about how my health information is used	42.5	2.49 (0.67)
System Trust Index Chronbach’s $\alpha = 0.8389$ (indices); 0.8838 (all items)		10.7 (2.0)

*Reverse coded.

women; 76 percent are white, non-Hispanic; 9 percent are black, non-Hispanic; 10 percent are Hispanic; and 5 percent are other. Forty percent have less than a bachelor’s degree education, and 60 percent have annual household incomes <\$50,000. Half of respondents are working as an employee, and an additional 7 percent are self-employed. Approximately one in five are retired (22 percent), and a comparable proportion are laid off or on disability (14 and

Table 2: Descriptive Demographic Statistics and Predictors of System Trust

	Frequency (n = 1,011)	Univariable OLS		Multivariable OLS	
		b*	p-Value	Model R ² b*	0.1898 p-Value
Demographic factors					
Sex					
Male	49.3%	0.011	0.768	0.029	0.397
Age					
18–29	15.4%	Ref	Ref	Ref	Ref
30–44	21.7%	0.019	0.716	–0.010	0.822
45–59	30.2%	0.044	0.388	–0.035	0.487
60+	32.7%	0.143	0.006	0.015	0.825
Race/ethnicity					
White	75.8%	Ref	Ref	Ref	Ref
Black, NH	9.2%	0.019	0.664	–0.005	0.895
Hispanic	9.7%	–0.115	0.010	–0.098	0.028
Other, NH	5.3%	–0.040	0.232	–0.024	0.433
Education					
Less than high school	8.9%	Ref	Ref	Ref	Ref
High school	31.1%	0.071	0.325	0.024	0.719
Some college	28.7%	0.023	0.741	–0.032	0.611
BA or above	31.3%	0.048	0.494	–0.037	0.589
Income					
Less than \$50,000	60.4%	0.043	0.262	0.010	0.784
Employment status					
Has employer	50.0%	Ref	Ref	Ref	Ref
Self-employed	7.3%	–0.110	0.003	–0.107	0.001
Laid off	13.6%	–0.043	0.288	–0.006	0.867
Retired	22.3%	0.080	0.036	0.003	0.954
Disability	6.8%	–0.040	0.440	0.005	0.910
Health status (in general, would you say your physical health is . . . ?)					
Excellent	12.1%	–0.063	0.163	–0.006	0.895
Very good	39.0%				
Good	35.5%				
Fair	11.1%				
Poor	2.27%				
Political affiliation					
Liberal	23.8%	Ref	Ref	Ref	Ref
Moderate	35.9%	0.015	0.736	0.061	0.145
Conservative	40.3%	0.005	0.913	0.073	0.146
Support for Affordable Care Act:					
Approval (1)/disapproval (4)	Mean: 2.9 (SD = 1.1)	–0.109	0.007	–0.081	0.050
Psychosocial factors					
Self-esteem index		0.173	<0.001	0.052	0.243

continued

Table 2: *Continued*

	Frequency (<i>n</i> = 1,011)	Univariable OLS		Multivariable OLS	
		<i>b</i> *	<i>p</i> -Value	Model R ²	0.1898
				<i>b</i> *	<i>p</i> -Value
Altruism index		0.139	0.001	0.103	0.012
Self-efficacy index		0.137	<0.001	0.053	0.243
Negative outlook		-0.272	<0.001	-0.228	<0.001
Generalized trust		0.284	<0.001	0.206	<0.001

Bold values indicate statistical significance at the 0.05 level.

*b** = standardized beta coefficient.

7 percent). On the political spectrum of liberal, moderate, or conservative, nearly one-quarter identified as liberal (23.8 percent), 36 percent identified as moderate, and 40 percent as conservative. At the time the survey was given, about 40 percent of respondents had a favorable view of the Affordable Care Act/Obamacare—comparable to a Kaiser Family Foundation poll that asked a similar question at the same time and found 35 percent of Americans had a favorable view of the ACA, 47 percent unfavorable, and 18 percent were unsure (Henry J. Kaiser Foundation 2014).

Descriptive statistics of the 20 survey questions underlying the system trust measure that captured fidelity, competency, integrity, and trustworthiness are listed in Table 1. With respect to the public's responses about the fidelity of the system, only 14.4 percent felt that the health system does not "care about helping people like me," and two-thirds felt the system would not knowingly do harm (66.2 percent). However, substantial fraction of the sample stated that the system cares most about research (36.9 percent), what is convenient for its practitioners (42.6 percent), and about controlling costs (37.4 percent). A large number of individuals indicated confidence in the competency of the health system in stating that they are good at their jobs (90.7 percent), and only 13.4 percent believe the health system makes more mistakes. The sample is nearly split with respect to the system's track record of using health information responsibly (50.2 percent) and in feeling that the system should be more careful in sharing health information (46.2 percent). In its beliefs about the health system's overall trustworthiness, 61.4 percent believe the organizations that have health information are ethical, but only 44.7 percent think they can be trusted to keep health information secure and only about half believe they can be trusted to use health information responsibly (52.3 percent). On measures evaluating integrity, 48.5

percent feel the health system tries hard to be fair in dealing with others. However, 35.5 percent stated that they believe the health system would try to hide a serious mistake, 37.0 percent felt they would be told how their health information is used; and only 42.5 percent believed they would not be mislead about health information use.

Fidelity, competency, integrity, and trustworthiness indices were approximately normally distributed along a continuous scale of how true a set of statements were for an individual (range: 1–4). Fidelity and competency had the highest mean indices and were both 2.8. The mean of trustworthiness was 2.6 and for integrity was 2.5. Paired t-tests indicated that people believed the health system had significantly lower trustworthiness and integrity than fidelity and competence ($p < .001$) (see Table 3).

Psychosocial factors included variables measuring self-esteem, self-efficacy, altruism, having a negative outlook, and generalized trust (see Table 4). Indices measuring self-esteem, altruism, and self-efficacy were based on four questions each: Chronbach's alpha for self-esteem questions was 0.75; $\alpha = 0.69$ for altruism; and $\alpha = 0.79$ for self-esteem. Having a negative outlook and generalized trust were evaluated based on a single question using the General Social Survey, "I think the quality of life for the average person is getting worse, not better" and "Generally speaking, most people can be trusted". All psychosocial factors were measured along a four-point scale; the mean of self-esteem was found to be 3.4 (SD = 0.59); 2.7 for altruism (SD = 0.65); 2.9 for self-efficacy (SD = 0.64); 2.13 for negative outlook (SD = 1.0); and 2.3 for generalized trust (SD = 0.82).

Demographic and Psychosocial Predictors of System Trust

System trust, derived from the sum of dimension-specific indices, has a scale of 4–16, and the range of observed values was 5–16 with a mean of 10.7 and

Table 3: System Trust Dimensions: Paired Absolute Differences among System Trust Indices (Two-Tailed *t*-Test)

	<i>Fidelity Index</i>	<i>Competency Index</i>	<i>Trustworthiness Index</i>	<i>Integrity Index</i>
Fidelity index	—			
Competency index	0.0004	—		
Trustworthiness index	0.24**	0.24**	—	
Integrity index	0.33**	0.33**	0.097**	—

** $p < .001$.

Table 4: Descriptive Statistics: Psychosocial Factors

	Frequency (% "Somewhat True" or "Very True")	Mean (SD)
Self-esteem		
I take a positive attitude toward myself	79.0%	3.16 (0.86)
I wish I could have more respect for myself (reverse coded)	84.5%	3.39 (0.86)
I feel that I have a number of good qualities	85.1%	3.33 (0.78)
All in all, I am inclined to feel that I am a failure (reverse coded)	93.5%	3.72 (0.64)
Self-esteem index (Chronbach's $\alpha = 0.75$)	Median: 3.5	3.40 (0.59)
Altruism		
All people who are unable to provide for their own needs should be helped by others	43.9%	2.49 (0.93)
I always find ways to help others less fortunate than me	49.2%	2.57 (0.83)
The dignity and well-being of all should be the most important concern in any society	66.5%	2.92 (0.92)
One of the problems of today's society is that people are often not kind enough to others	67.2%	2.98 (0.91)
Altruism Index (Chronbach's $\alpha = 0.69$)	Median: 2.8	2.74 (0.65)
Self-efficacy		
If someone opposes me, I can find the means and ways to get what I want	36.2%	2.25 (0.82)
I am confident that I could deal efficiently with unexpected events	71.3%	2.94 (0.83)
I can solve most problems if I invest the necessary effort	78.4%	3.15 (0.81)
I can manage to solve difficult problems if I try hard enough	79.8%	3.18 (0.79)
Self-efficacy Index (Chronbach's $\alpha = 0.79$)	Median: 3.0	2.88 (0.64)
Negative outlook		
I think the quality of life for the average person is getting worse, not better	32.5%	2.13 (1.01)
Generalized trust		
Generally speaking, most people can be trusted	38.9%	2.26 (0.82)

standard deviation of 2.0. In simple (univariable) regression analyses, all of the psychosocial factors were statistically associated with system trust. Those ages 60 and above were found to be more trusting than 18- to 29-year-olds; similarly, those supporting the Affordable Care Act were more trusting of the health system than those who did not ($b^* = -0.109$, $p = .007$). Hispanics, relative to non-Hispanic whites, were less trusting of the health system ($b^* = -0.115$, $p = .010$); those who were self-employed were less trusting of the health system ($b^* = -0.110$, $p = .003$), while retirees were more trusting than those who had an employer ($b^* = 0.080$, $p = .036$). Self-reported health

status was not a statistically significant predictor of system trust in either the univariable or multivariable regression models ($b^* = -0.063$, $p = .163$, and $b^* = -0.005$, $p = .89$, respectively).

In the multivariable OLS model, demographic and psychosocial characteristics explained ~19 percent the variability in system trust (see Table 1). The top two predictors were negative outlook ($b^* = -0.228$; $p < .001$) and generalized trust ($b^* = 0.206$; $p < .001$). The three remaining significant predictors were self-employment ($b^* = -0.107$), altruism ($b^* = 0.103$), and Hispanic ethnicity ($b^* = -0.098$).

DISCUSSION

We found that a majority of the U.S. public does not trust an integrated health information sharing system in at least one or more dimensions. Only 12.5 percent of the public consistently rated the competency, fidelity, integrity, and trustworthiness of “the organizations that have health information and share it” in the top two tiers of the four-point Likert scale. We also found that the public is more inclined to feel the system is competent and has their best interests in mind (i.e., fidelity), but it is less confident in the system’s integrity and overall trustworthiness. For example, only 13.4 percent of respondents said that they felt the health system makes more mistakes (i.e., competency) and 14.4 percent indicated that the health system “does not care about helping people like me” (i.e., fidelity). By the same token, less than half (47.0 percent) indicated that the health system “thinks about what is best for me” or would not “mislead me about how my health information is used” (42.5 percent).

This is consistent with other studies of trust and mistrust that have found a faltering confidence in the health system generally (Blendon, Benson, and Hero 2014) and with those citing greater public confidence in the competence of the health system as compared to its values (i.e., integrity, motives, equity) (Shea et al. 2008). While our study did not compare system trust to interpersonal trust, the low valuation of trust in the health system is consistent with studies that show that health systems are less trusted than physicians (Hall et al. 2001) and with social theories that suggest interpersonal trust is more accessible than trust in abstract systems or trust in institutions (Meyer et al. 2008; Giddens 2013).

Our findings suggest that while trust is a rhetorically powerful stated value underlying many national health initiatives to expand data sharing (see, e.g., Mirnezami, Nicholson, and Darzi 2012; Williams et al. 2012), the public

is far from trusting in these systems. Taking a lesson from the history of Medicare and Medicaid, building systems that engender public trust may be vital to their long-term success. Hetherington (2005) has shown that in the absence of direct benefits, beliefs in a system's incompetency coupled with its mistrust creates a self-fulfilling prophecy in which programs fail to maintain public support not because they are ineffective but because the population believes them to be so. When trust in a system weakens for whatever reason—polarizing political rhetoric or evidence-based outcomes—public support and public funding are reduced, creating programs that are underresourced to the point that they in fact become untrustworthy and ineffective at achieving their goals. The United States has, in the past years, invested billions of dollars in electronic health information infrastructure; sustaining these efforts will continue to be a costly endeavor and is contingent on the political will to support slower, more incremental processes of integrating them into daily practice (Orszag and Emanuel 2010). Sustainable economic and resource investment into these emerging data sharing systems has important implications for the future success of national initiatives such as precision medicine and the learning health system.

Implications for Precision Medicine and Learning Health Systems

Both precision medicine and learning health systems share the vision of a system that seamlessly delivers information to provide care that incorporates salient features of an individual's variability to improve outcomes (Friedman, Wong, and Blumenthal 2010; Collins and Varmus 2015). However, such systems will have a host of challenges. There are, and will continue to be, large-scale data breaches, and mistakes will continue to be made with serious consequences to morbidity and mortality (HHS 2015). In addition to technological hurdles, the organizations that have health information and share it must negotiate proprietary issues as well as local policies and politics that often impede or prohibit rapid data exchange. Furthermore, if the infrastructure to support efficient data sharing is seen as a largely public good, these agencies will struggle to find the self-motivation to invest and will thus call on public support for the development and maintenance of the underlying data sharing systems. Insofar as these efforts are being led by industry, competition among vendors is antithetical to interoperability, a key requirement of both precision medicine and learning health systems. As noted above, the trust that is required to invest in systems is not an infinite resource and the initial trust and political will to support data sharing is likely to decay over time. Describing

benefits, being transparent about risks, and compensating harms will be critical aspects to modernizing regulations in data sharing. Using informed consent as a gateway or “access point” (Giddens 2013) into the health information sharing system will be an increasingly critical process for obtaining and sustaining trust.

Meaningful Transparency in Practice: Implications for Informed Consent and the Proposed Revisions to the Common Rule

The proposed changes to the Common Rule that would make allowances (but not requirements) for notification of secondary research use of information and broad consent are examples of recent efforts to modernize the regulatory environment, promote transparency, and increase trust (Hudson and Collins 2015). It is unclear, however, whether such policies will achieve these goals. Well-placed trust (O’Neill 2002) requires two-way negotiation of trust. Transparency, when conceived as merely providing information, falls short of engendering trust, unless it is accompanied by engagement characterized by “active inquiry between two parties.” Such engagement would permit, encourage, and be responsive to questions from the public, thus promoting accessibility of the system and a demonstration of the authenticity of efforts to improve health and mitigate harm from wherever it may arise (O’Neill 2002; Head 2007). This form of transparency is particularly critical when mistrust, rather than trust, is the default state (Baier 1986), as we found in our study. As noted by Mark Hall et al. (2002a,b), trust in systems is a finite resource and particularly hard to build once lost.

Building Trust: Understanding Predictors of Trust

While there are some theories of trust that identify individual attributes such as demographic factors as potentially shaping an individual’s predisposition to trust (Lewis and Weigert 1985, 2012; Meyer et al. 2008), most empirical studies do not find a correlation between sex, age, and education and trust (Altice, Mostashari, and Friedland 2001; Hall et al. 2001; LaVeist, Isaac, and Williams 2009). Some have found differences in trust by race/ethnicity, but these findings are inconsistent across studies (Rose et al. 2004; Armstrong et al. 2008; Egede and Ellis 2008; Shea et al. 2008). Our study included other demographic factors not typically included in previous studies, including employment and political views. Specifically, we found that Hispanics were slightly less likely to trust an integrated health information sharing system than non-

Hispanic whites ($b^* = -0.098$, $p = .021$) and those who are self-employed are less trusting of the health system than those who have a job ($b^* = -0.107$, $p = .001$). In sum, our results are consistent with previous findings that most demographic factors were not associated with system trust and support Luhmann's theoretical claim that system trust is not necessarily associated with demographic characteristics (2000).

Psychosocial factors have been less consistently included in previous studies of system-level trust than demographic factors but, to the extent they have been accounted for, their relationship to trust is inconclusive (Hall et al. 2001). In our study, we examined the relationship between system trust and having a negative outlook or pessimism (i.e., believing that "the quality of life for the average person is getting worse, not better"), generalized trust, self-esteem, self-efficacy, and altruism. We found believing that the "quality of life for the average person is getting worse, not better" is associated with lower levels of trust in health system ($b^* = -0.229$, $p < .001$). Greater trust in the health system was found to be associated with being generally trusting (i.e., believing that "most people can be trusted") ($b^* = 0.206$, $p < .001$) and altruism ($b^* = 0.102$, $p = .012$), measured by an index capturing beliefs such as whether "people who are unable to provide for their own needs should be helped by others" and that "one of the problems of today's society is that people are often not kind enough to others" (see Table 3). Self-esteem and self-efficacy were not associated with system trust after controlling for all other demographic and psychosocial factors. These findings suggest that attitudes and beliefs about how social systems work and treat people generally reflect attitudes and beliefs about how social systems work specifically—in this case, how an individual views the general quality of life and other people is an indicator of how he or she trusts, or mistrusts, the health system. Insofar as systems are a composite of their constituent parts whose social reputation will affect beliefs in system trust, future studies should examine the trust relationship between the public and health care providers, public health, and research, and how these, in turn, relate to system trust.

Our study found no statistically significant relationship between system trust and self-reported health. This may be an artifact of a limited assessment of health status and experience with the health system; indeed, one might expect that those with greater need for health care would have a proximate set of experiences from which to form a basis for trust. By the same token, the health system touches nearly all people at some point in their lives and in the lives of their family and acquaintances. Patients often report high trust in the care they receive (Hillen, de Haes, and Smets 2011), suggesting that when in

the system, they are generally confident in the care they receive. Our study suggests that this trust may decline with distance from the health system; that is, if you are not actively engaged in your health care, trust in the health system is low regardless of whether you consider yourself generally in good or poor health. This is supported by surveys that point to declining trust in the medical profession and the health system generally (Blendon, Benson, and Hero 2014), pointing to an area that warrants future systematic investigation. To the extent trust is a dynamic phenomenon, subsequent studies should examine the modifiable features of health care delivery (e.g., having a personal physician, having personal experience with an health system in which physicians and hospitals are under the same umbrella) that may impact trust and may require more sophisticated analyses using, for example, longitudinal panel data and modeling interactions.

Together, demographic and psychosocial factors accounted for about 18 percent of the observed variability in system trust. Future research should consider additional predictors of system trust such as knowledge, attitudes, and beliefs about the health system, as well as the lived experiences of the public. Such factors are likely to inform opinions and beliefs about the trustworthiness of the health system and the policies that govern health information sharing. Possible moderators and mediators of trust, such as risks and benefits, would also be included in a more complete model of trust in the health system. Longitudinal studies, particularly those that allow the evaluation of interventional impacts on system trust, should be undertaken to better evaluate causal relationships.

Limitations

While the Knowledge Panel provides a probability-based, representative sample of the U.S. population and uses robust recruitment methods, our results may be affected by participation and nonresponse bias. In this study, we used sampling weights and a fairly large sample size to mitigate some of these limitations, but they should nonetheless be noted. Additionally, we acknowledge that our study extrapolates from a hypothetical situation. We chose this design given that some individuals may have more experience with a wider set of actors/components of the health system than others. We assume that by and large the average person who is taking the survey does not know the details of what is being shared or not shared between physicians, insurance companies, laboratories, and so on. However, as new national initiatives such as PCORI's PCORNet and Amazon Cloud Services make it possible to link and share

millions of health care records across major medical institutions for translational research (PCORNet aims to link ~80 million health records), it becomes important to understand the extent to which the public supports and trusts the system to effectively use these resources, even as the details are still pending. We recognize that this extrapolation is complex. By the same token, we would face similar limitations to asking about a highly specific use case that could not be generalized.

A Final Case for Trust

Trust is multidimensional and abstract. The analysis presented here suggests that what matters in predicting trust is highly contingent on how trust is defined, by whom, and to what end. Trust building, if it is to be a priority in integrated health information systems, needs to be more specific in its rhetoric and may be served by the development of an ontology of trust in information.

Furthermore, the lack of trust raises the question of what role trust plays in health and health care and whether the “trust fabric” is in need of repair. On the one hand, there is a place for mistrust, or, as described by Mark Hall et al. (2002a,b), “trust but verify,” in individual relationships between physicians and patients. There is also clearly a role for skepticism, “antitrust,” or mistrust in the health system to prevent abuses of power to which the health system is not immune. In the relationship between the public, who does not have the same specialized expertise of health care professionals, researchers, or public health practitioners, the differential in the power relationship between the truster and the trustee can make it difficult for the trustee to judge how much discretionary authority to grant and how to judge the abuse of such discretion (Baier 1986). At the system level, blind trust that automates discretionary power, perpetuates paternalism, and diminishes autonomy is clearly different from well-placed trust that is accountable to active inquiry and to meeting expectations (O’Neill 2002; Kelley et al. 2015).

And yet trust, and well-placed trust in particular, can help to simplify complex systems. Rather than demanding time and expertise in navigating the health information infrastructure, a trusted and trustworthy system can manage decisions on behalf of the public. As the boundaries between health care, research, and public health become less rigid in practice, it is likely to be physicians who become the ambassadors of this larger system (Kelley et al. 2015), although future studies should consider the benefits and liabilities of this added role to the patient–provider relationship, as well as its effects on trust across the system. By the same token, endemic mistrust of integrated

health information systems threatens the effective implementation and long-term sustainability of the networks and effective relationships required to realize the national initiatives of precision medicine and a learning health system.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of this article:

Appendix SA1: Author Matrix.