

Consumer Confidence in Public and Private Organizations to Use Their Digital Health Data Responsibly



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Interactions with wearable devices, smartphones, and social media generate user data, which can reveal sensitive health information. Those data can be used to improve individual and community health, but also raise security and privacy concerns.^{1, 2} Given potential benefits alongside substantial privacy risks, it is important to evaluate how consumers view organizations and entities that collect and re-use their personal digital health data. We surveyed US consumers to assess their confidence in sixteen public and private organizations to use their digital health data responsibly.

METHODS

The survey was administered in English and Spanish between July 10 and July 13, 2020. Survey respondents were sampled and recruited from the Ipsos KnowledgePanel®, a panel representative of the US population.³ Hispanic and African American respondents were oversampled. This study was considered exempt by the Institutional Review Board at the University of Pennsylvania.

Respondents rated their confidence in each of sixteen public and private organizations to use their digital health data responsibly. Ipsos provided respondents' sociodemographic data. Additional survey items measured political ideology, health status, and whether respondents were victims of stolen digital information.

We used post-stratification weights to account for oversampling to make the findings representative of the US adult population. We used multivariable logistic regression

models to estimate associations among respondent characteristics and confidence in the responsible use of digital health information. We used multiple imputation to account for incomplete responses ($n = 139$ [4.0%]). Analyses were conducted in Stata version 16 (StataCorp LP).

RESULTS

Of 6284 individuals contacted, 3497 (56%) responded. Most respondents (66–78%) responded they were at least somewhat confident in doctors' offices, the Centers for Disease Control and Prevention, and university hospitals (Fig. 1). Fewer respondents expressed confidence in Facebook, Google, and cell phone companies (14–27%).

In multivariable models, the factor most associated with expressed confidence was political ideology (Table 1). Self-identified liberals expressed greater confidence than conservatives in university hospitals (77% vs 58%, $p < 0.001$), federal government (45% vs 36%, $p < 0.001$), and Apple (33% vs 28%, $p = 0.046$). Prior theft victims expressed lower confidence in university hospitals (61% vs 69%, $p < 0.001$), federal government (35% vs 43%, $p < 0.001$), and health insurance companies (44% vs 53%, $p < 0.001$), but not Apple. Black respondents expressed greater confidence than White respondents in insurance companies (57% vs 49%, $p = 0.004$) and Apple (38% vs 29%, $p < 0.001$), but not in university hospitals or federal government. Similarly, Hispanic respondents reported greater confidence in insurance companies (54% vs 49%, $p = 0.046$) and Apple (38% vs 30%, $p < 0.001$). Respondents aged greater than 45 generally reported lower confidence in all four organizations. Differences by income, geography, and health status were small and generally not statistically significant.

DISCUSSION

In this study, respondents reported greatest confidence in clinical and research-based organizations and public institutions including government agencies and health departments

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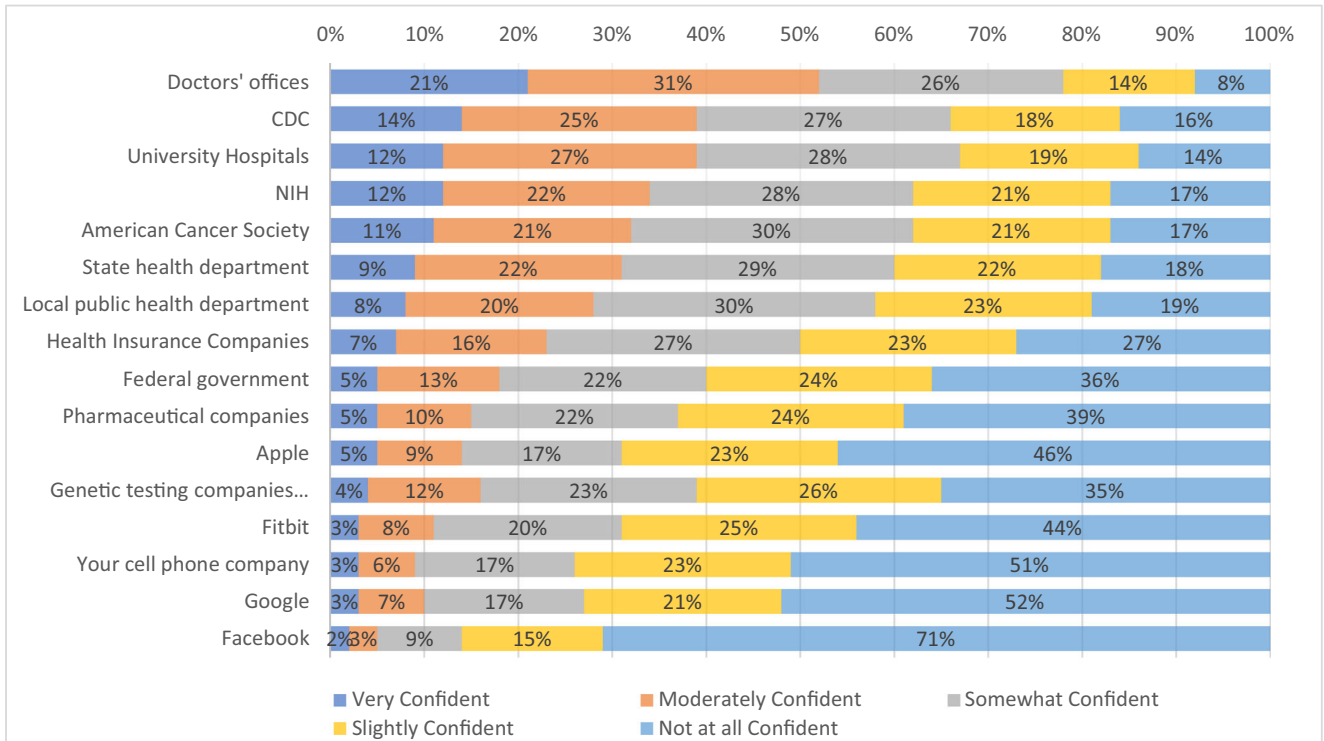


Figure 1 Confidence in organizations to treat digital health information responsibly. Weighted distribution of responses to the 16 survey questions evaluating confidence in public and private organizations to use their digital health information responsibly. Respondents were asked, “We are going to name some institutions, companies, and organizations that might collect and use digital health information from you. How confident are you that they will use your digital health information responsibly?”.

to responsibly use their digital health data. However, a majority reported low confidence in digital technology and health care companies. Such companies form the digital economy’s backbone and are large sources and users of personal digital data. Moreover, some health care organizations use tools from digital technology companies that leak patient data.⁴

Certain populations have greater privacy concerns — notably conservative and older respondents. Despite high confidence in university hospitals, conservatives expressed substantially lower confidence in university hospitals compared to liberals. Academic hospitals and researchers developing, testing, and deploying digital technology health programs should know about these privacy concerns. These results also highlight the importance of seeking the public’s input in designing policies to protect sensitive digital health data, par-

ticularly given evolving trust in institutions during the COVID-19 pandemic.⁵

Our study has limitations. We did not examine differences by other factors (e.g., education level, occupation) that may be important predictors for confidence in institutions. Additionally, dichotomizing our outcome eased interpretation but may have led to some data loss.

Since the Supreme Court overturning *Roe vs. Wade*, reports have raised awareness of how digital tracking by technology companies could reveal health-related behaviors (e.g., accessing reproductive health services). However, policy and conventions about privacy remain largely restricted to engagements with clinicians, hospitals, and health insurance companies. Low confidence in certain entities reflects this absence of attention and may stem from fear of unwarranted tracking,²

Table 1 Confidence in Public and Private Organizations by Respondent Characteristics^{a,b}

	University hospitals		Federal government		Health insurance companies		Apple	
	%	% difference (CI)	%	% difference (CI)	%	% difference (CI)	%	% difference (CI)
Political ideology								
Liberal	77.0	[Ref]	44.7	[Ref]	48.2	[Ref]	32.6	[Ref]
Moderate	66.8	-10.3 (-14.3, -6.2)	41.2	-3.5 (-8.1, 1.1)	52.8	4.6 (-0.1, 9.2)	32.3	-0.2 (-4.5, 4.1)
Conservative	58.4	-18.6 (-22.9, -14.3)	36.1	-8.6 (-13.3, -3.9)	49.0	0.8 (-4.0, 5.6)	28.1	-4.5 (-8.9, -0.1)
Race								
White	66.8	[Ref]	39.4	[Ref]	49.3	[Ref]	29.1	[Ref]
Black/African American	64.6	-2.3 (-7.0, 2.5)	41.3	2.0 (-3.0, 6.9)	56.7	7.4 (2.4, 12.4)	37.8	8.6 (3.8, 13.5)
Other	68.6	1.7 (-6.2, 9.7)	47.9	8.6 (-0.5, 17.6)	47.1	-2.2 (-11.1, 6.8)	36.1	7.0 (-1.6, 15.5)
2+ races	75.9	9.0 (0.9, 17.2)	48.8	9.4 (-0.8, 19.6)	53.7	4.4 (-5.7, 14.6)	38.9	9.8 (-0.0, 19.6)
Ethnicity								
Non-Hispanic	67.5	[Ref]	39.8	[Ref]	49.3	[Ref]	29.6	[Ref]
Hispanic	63.9	-3.6 (-8.0, 0.8)	44.1	4.3 (-0.3, 8.9)	54.1	4.7 (0.1, 9.4)	37.9	8.3 (3.8, 12.8)
Household income								
< \$24,999	64.4	[Ref]	43.4	[Ref]	53.2	[Ref]	33.6	[Ref]
\$25,000-\$49,999	65.4	0.9 (-5.5, 7.4)	39.2	-4.2 (-10.9, 2.4)	50.1	-3.0 (-9.8, 3.7)	31.6	-2.0 (-8.4, 4.4)
\$50,000-\$99,999	66.6	2.2 (-3.7, 8.0)	38.7	-4.8 (-10.8, 1.3)	49.0	-4.2 (-10.4, 2.0)	28.8	-4.8 (-10.5, 1.0)
> \$100,000	68.9	4.5 (-1.5, 10.4)	41.7	-1.8 (-8.0, 4.4)	50.0	-3.2 (-9.5, 3.1)	31.6	-2.0 (-7.9, 4.0)
Region								
Northeast	67.4	[Ref]	35.6	[Ref]	52.5	[Ref]	31.6	[Ref]
Midwest	65.7	-1.8 (-7.4, 3.9)	39.1	3.5 (-2.5, 9.4)	47.3	-5.2 (-11.3, 1.0)	27.1	-4.6 (-10.2, 1.1)
South	66.1	-1.3 (-6.3, 3.7)	43.3	7.7 (2.4, 13.0)	49.9	-2.5 (-8.0, 2.9)	31.0	-0.6 (-5.6, 4.4)
West	68.9	1.5 (-4.0, 6.9)	40.9	5.2 (-0.6, 11.0)	51.2	-1.3 (-7.2, 4.7)	34.0	2.4 (-3.2, 8.0)
Age								
18-29	71.6	[Ref]	44.1	[Ref]	53.8	[Ref]	37.1	[Ref]
30-44	70.2	-1.4 (-7.0, 4.2)	44.7	0.5 (-5.7, 6.8)	52.7	-1.1 (-7.5, 5.2)	36.6	-0.5 (-6.5, 5.5)
45-59	64.8	-6.8 (-12.5, -1.2)	40.4	-3.8 (-10.0, 2.5)	50.7	-3.1 (-9.4, 3.2)	31.3	-5.8 (-11.7, 0.1)
60+	62.7	-8.9 (-14.4, -3.3)	34.4	-9.7 (-15.7, -3.7)	44.7	-9.1 (-15.2, -3.0)	21.1	-16.0 (-21.6, -10.4)
MSA status								
Non-metropolitan	62.8	[Ref]	39.2	[Ref]	48.8	[Ref]	31.0	[Ref]
Metropolitan	67.6	4.7 (-0.8, 10.2)	40.7	1.5 (-4.4, 7.4)	50.3	1.6 (-4.4, 7.5)	31.0	0.0 (-5.6, 5.7)
Health status								
Excellent	63.1	[Ref]	39.2	[Ref]	48.9	[Ref]	33.8	[Ref]
Very Good	70.7	7.6 (1.6, 13.6)	41.6	2.4 (-3.9, 8.7)	52.8	3.9 (-2.6, 10.5)	32.8	-1.0 (-7.0, 5.0)
Good	65.0	1.9 (-4.3, 8.1)	40.7	1.5 (-4.9, 7.8)	49.3	0.4 (-6.2, 7.0)	29.9	-3.9 (-9.9, 2.1)
Fair/Poor	65.7	2.6 (-4.9, 10.1)	38.2	-1.0 (-8.5, 6.6)	46.4	-2.4 (-10.2, 5.3)	26.9	-6.9 (-13.9, 0.1)
Victim of theft ^c								
Yes/Maybe	60.9	[Ref]	35.3	[Ref]	44.1	[Ref]	29.2	[Ref]
No	69.4	8.5 (4.7, 12.3)	42.7	7.4 (3.5, 11.3)	52.7	8.6 (4.5, 12.6)	31.8	2.7 (-1.0, 6.4)

MSA, metropolitan statistical areas

^aWe accounted for missing data by using multiple imputation by chained equations (MICE) with the following model for 20 imputations:

age + education level + household head + housing type + household income + household ownership status + number of children in household + number of adults (>18) in household + marital status + metropolitan status + Hispanic/not-Hispanic + US state

^bAdjusted predicted probabilities from multivariable logistic regression models. The percent column reflects adjusted percentages of individuals who report being "somewhat confident," "moderately confident," or "very confident," in each respective institution to use their digital health information responsibly, stratified by respondent characteristics. The % difference column reflects adjusted percentage differences in respondent confidence in each respective institution between each respondent characteristic relative to the reference group

^cIncluded whether the respondent had ever been a victim of stolen information on the internet or identity or credit card theft

exploitation, and unregulated collection and use of health data. Stronger data protections and greater individual and community control⁶ may improve trust in health-related uses.

Data Access and Responsibility: Drs. Grande and Gupta had full access to all of the data in this study and take responsibility for the integrity of the data and the accuracy of the data analysis.

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