

Public knowledge and information sources for clinical trials among adults in the USA: evidence from a Health Information National Trends Survey in 2020

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ABSTRACT

Background

Lack of clinical trial awareness has been identified as a barrier to clinical trial recruitment. Identifying factors associated with clinical trial knowledge could inform ongoing efforts to improve diversity in clinical trials.

Methods

Using data from the Health Information National Trends Survey, 2020, we examined the knowledge of clinical trials, associated characteristics, sources of clinical trial information and motives to participate in clinical trials among the general population in the USA.

Results

Of 3,772 US adults, 41.3% reported not knowing about clinical trials. Prevalence of having no knowledge of clinical trials was higher among Hispanic adults (51.8%) and non-Hispanic Black adults (41.8%) compared with non-Hispanic White adults (37.4%; $p=0.013$). Other significant predictors of knowledge about clinical trials included higher education, online health information-seeking behaviour and patient portal access. Most respondents (73.2%) reported that healthcare providers were the most trusted source of information. Helping other people (71.6%) was the primary motivation for clinical trial participation, followed by financial compensation (12.5%) and receiving better treatment (5.1%).

Conclusion

There is a gap in knowledge about clinical trials among the US population. Development of multimodal approaches, including online and offline information broadcasting, is needed to improve knowledge and clinical trial recruitment in diverse populations.

KEYWORDS: clinical trial, public knowledge, recruitment

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Introduction

Over the past 3 decades, researchers have consistently documented disparities in clinical trial participation.^{1,2} For instance, clinical trials that have been used to support the US Food and Drug Administration approval of drugs have shown an underrepresentation of Black / African American and Hispanic/Latinx participants.^{3,4} Representative participation in clinical trials is necessary to inform the development of medical treatments and interventions that can translate into effective use in diverse populations and address health inequalities.^{5,6} Prior research suggests that clinical trial knowledge may play a key role in clinical trial participation and help to address longstanding disparities in clinical trial participation.^{7,8}

Recent studies show that clinical trial knowledge is low globally. A survey of 12,427 individuals across 68 countries in 2017 found that more than half of participants were unsure about where clinical trials were conducted.⁹ The COVID-19 pandemic provided a key opportunity to educate the public about clinical trials, given the numerous ongoing trials to support vaccine and treatment development.¹⁰ A few studies have started to explore clinical trial knowledge during the COVID-19 pandemic.^{1,11,12} However, there has been limited study nationally to assess clinical trial knowledge or trusted sources of information for clinical trials.

Therefore, it is timely to assess clinical trial knowledge among a representative sample of US adults. To our knowledge, there has been no known study to assess public knowledge of clinical trials and trusted information sources in recent years. Currently available estimates of general knowledge about clinical trials are outdated and limited to inform ongoing efforts. To address these gaps, we conducted this study to assess the knowledge of clinical trials and identify factors associated across individual demographic and health-related characteristics; and to learn about sources of clinical trial information and people's motives to participate in clinical trials by the level of knowledge among US adults in 2020. Information about knowledge gaps and

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trusted information sources may help inform future interventions to increase clinical trial participation.

Methods

Data source

We analysed data from the National Cancer Institute's Health Information National Trends Survey (HINTS) 5 Cycle 4, which was conducted between February 2020 and June 2020 to provide information on the US public's health-related behaviours, perceptions and knowledge. HINTS is a cross-sectional survey that is nationally representative of civilian, non-institutionalised US adults. HINTS data are publicly available, deidentified data and were, therefore, deemed exempt from review by the University of Florida. Further information on survey methodology is available elsewhere.¹³ This study follows the STROBE guidelines.

Study population

A total of 3,865 respondents completed the HINTS 5 Cycle 4 survey. Respondents who did not answer the question about knowledge of clinical trials (n=93) were excluded from the analyses. The final study sample was made of 3,772 respondents, who represented a weighted sample of 249,896,898 US adults aged 18 years or older.

Study variables

The outcome variables for this study were derived from questions in Section G: Clinical Trials of the HINTS 5 Cycle 4 survey.

Knowledge of clinical trials

The primary outcome of our study was determining the level of knowledge about clinical trials among the survey respondents, which was derived from the survey question:

Clinical trials are research studies that involve people. They are designed to compare new kinds of health care with the standard health care people currently get. For example, a new drug or a new way for patients to track their diets. How would you describe your level of knowledge about clinical trials?

The responses were recorded as 'I don't know anything about clinical trials', 'I know a little bit about clinical trials' and 'I know a lot about clinical trials' and classified into three groups: 'Don't know', 'Know a little' and 'Know a lot', respectively.

Most trusted source of information about clinical trial

Study respondents were asked to select their most trusted source of information about clinical trials:

Imagine you had a need to get information about clinical trials. Which of the following would you most trust as a source of information about clinical trials?

The sources listed were 'My health care provider', 'My family and friends', 'Government health agencies', 'Health organizations or groups (for example, the American Cancer Society, American Lung Association)', 'Disease-specific patient support groups' and 'Drug companies'. The sources with a limited number of responses were categorised as 'others'.

Motives to participate in clinical trial

The survey questionnaire listed eight motives to participate in a clinical trial, including 'I would be helping other people by participating', 'I would get paid to participate', 'I would get support to participate such as transportation, childcare, or paid time off from work', 'If my doctor encouraged me to participate', 'If my family and friends encouraged me to participate', 'I would want to get better', 'I would get the chance to try a new kind of care' and 'If the standard care was not covered by my insurance'. Respondents' responses were recorded as 'Not at all', 'A little', 'Somewhat' and 'A lot' to express the strength of their motives.

Demographics and other covariates

Respondents' age in years (18–49, 50–64 or 65+), sex (men or women), race/ethnicity (non-Hispanic White, non-Hispanic Black, Hispanic or other), education (less than high school, high school graduate, some college, college or higher), marital status (married, divorced/widowed/separated or single), annual family income (less than \$20,000, \$20,000 to <\$35,000, \$35,000 to <\$50,000, \$50,000 to <\$75,000 or \$75,000+), employment (employed or not employed), census region (northeast, midwest, south, west), health insurance (yes or no), general health (excellent, very good, good, fair or poor), chronic conditions (hypertension, diabetes, heart disease, lung disease or cancer) and number of visits to provider (0, 1–2, 3–4 or 5+) were included as covariates. We also included factors that might affect access to digital recruitment for clinical trials, such as patient portal access and online information-seeking behavior.¹⁴ We accounted for these demographics and other health-related variables in the adjusted analysis to control for their direct or indirect effect on outcomes.

Statistical analysis

We used bivariate analyses to assess the association between respondents' demographic characteristics, their knowledge of clinical trials, information sources and motives to participate in clinical trials. We conducted multivariable analyses using logistic regression to examine predictors of having any knowledge about clinical trials (including those who responded 'Know a little' and 'Know a lot') after controlling for covariates listed earlier. Due to the small sample size and missing responses, multivariable models to examine information sources and motives of clinical trial participation were not included. Thus, we only report the bivariate associations between the level of clinical trial knowledge, information source and clinical trial participation motives. All analyses accounted for the complex survey design and sampling weights were used to generate nationally representative estimates. The full model included the complete set of variables and the reduced model included only those variables that had $p < 0.10$ in the univariate analysis. All analyses were conducted using SAS v9.4 (SAS Institute, Marlow, UK). We determined statistical significance at a two-sided $p < 0.05$.

Results

Sample characteristics

Of the 3,772 respondents, 51.2% were women, 52.1% were 18–49 years old, 27.7% were 50–64 years old, 20.1% were 65 years old or above, 63.2% were non-Hispanic White, 11.7% were non-Hispanic Black, 16.2% were Hispanic and 8.7% were from other racial/ethnic groups (Table 1). Out of the total sample, 41% reported that

Table 1. Demographic characteristics of survey respondents: Health Information National Trends Survey, 2020

Knowledge of clinical trials	Total	Don't know	Know a little bit	Know a lot	p-value
Population					
Unweighted, n	3,772	1,406	1,930	436	
Weighted, n (%)	249,896,898	103,224,262 (41.3)	123,208,910 (49.3)	23,463,727 (9.4)	
Race/ethnicity					
					0.013
Non-Hispanic White, n (%)	2,209 (63.2)	696 (37.4)	1,237 (52.3)	276 (10.1)	
Non-Hispanic Black, n (%)	548 (11.7)	229 (41.8)	268 (51.5)	51 (6.68)	
Hispanic, n (%)	585 (16.2)	301 (51.8)	229 (40.4)	55 (7.66)	
Other, n (%)	297 (8.7)	114 (45.9)	141 (43.3)	42 (10.7)	
Education					
					<0.0001
Less than high school, n (%)	266 (8.00)	177 (68.1)	75 (29.6)	14 (2.15)	
High school graduate, n (%)	686 (22.3)	396 (53.5)	262 (44.1)	28 (2.28)	
Some college, n (%)	1,061 (39.2)	407 (41.8)	577 (51.6)	77 (6.46)	
College or higher, n (%)	1,640 (30.3)	366 (23.8)	971 (55.9)	303 (20.1)	
Family income					
					0.0001
>\$20,000, n (%)	725 (16.4)	369 (50.1)	290 (41.2)	66 (8.52)	
\$20,000–\$34,999, n (%)	472 (11.2)	203 (43.3)	231 (50.6)	38 (5.97)	
\$35,000–\$49,999, n (%)	507 (12.5)	209 (49.4)	250 (42.5)	48 (7.98)	
\$50,000–\$74,999, n (%)	640 (17.9)	232 (39.0)	352 (54.1)	56 (6.86)	
\$75,000, n (%)	1,411 (41.7)	384 (35.8)	799 (51.8)	228 (12.3)	
Employment					
					0.050
Employed, n (%)	1,684 (52.9)	546 (38.7)	918 (50.2)	220 (11.0)	
Not employed, n (%)	2,022 (47.0)	827 (43.8)	988 (48.8)	207 (7.29)	
Health insurance					
					0.001
Yes, n (%)	3,531 (90.9)	1,290 (39.2)	1,826 (50.7)	415 (10.0)	
No, n (%)	195 (9.01)	96 (60.1)	86 (36.0)	13 (3.80)	
General health					
					0.0002
Excellent, n (%)	434 (12.3)	115 (32.4)	230 (49.5)	89 (17.9)	
Very good, n (%)	1,337 (37.4)	437 (39.4)	731 (50.5)	169 (10.0)	
Good, n (%)	1,368 (36.1)	548 (43.0)	695 (50.6)	125 (6.34)	
Fair, n (%)	509 (12.0)	239 (48.5)	228 (43.4)	42 (8.03)	
Poor, n (%)	105 (2.01)	56 (55.7)	38 (35.7)	11 (8.44)	
Patient portal use					
					<0.0001
No, n (%)	2,165 (59.7)	997 (48.9)	993 (45.2)	175 (5.77)	
Yes, n (%)	1,529 (40.2)	369 (28.7)	908 (56.1)	252 (15.0)	
Online health information-seeking behaviour					
					<0.0001
No, n (%)	1,135 (27.5)	641 (57.1)	430 (38.9)	64 (3.86)	
Yes, n (%)	2,637 (72.4)	765 (35.2)	1,500 (53.2)	372 (11.4)	
Number of visits to provider					
					0.002
0, n (%)	494 (16.8)	246 (52.0)	200 (41.7)	48 (6.18)	
1–2, n (%)	1,248 (37.3)	459 (42.5)	650 (48.2)	139 (9.18)	
3–4, n (%)	1,083 (24.3)	391 (35.1)	567 (55.2)	125 (9.59)	
≥5, n (%)	915 (21.5)	295 (37.6)	499 (50.1)	121 (12.1)	

they did not know anything about clinical trials, 49% reported that they only knew a little bit about clinical trials and 9.4% reported that they knew a lot about clinical trials.

Prevalence of having no knowledge of clinical trials was higher among Hispanic adults (51.8%) and non-Hispanic Black adults (41.8%) compared with non-Hispanic White adults (37.4%; $p=0.013$). Respondents with the less than high school education were more likely to report no knowledge about clinical trials compared with those with high school or higher education (less than high school (68.1%), high school (53.5%), some college (41.8%) and college or higher (23.8%); $p<0.001$). Respondents with lowest annual family income were also more likely to report no knowledge about clinical trials compared with higher family income groups (less than \$20,000 (50.1%), \$20,000 to <\$35,000 (43.3%), \$35,000 to <\$50,000 (49.4%), \$50,000 to <\$75,000 (39.0%) and \$75,000+ (35.8%); $p<0.001$). Other factors associated with having no knowledge of clinical trials included unemployment, lack of health insurance, poor general health and no visits to their healthcare provider. Age, marital status, census region or having chronic condition was not associated with clinical trial knowledge (see supplementary material S1, Table S1, for full bivariate analysis results). Respondents who reported patient portal use and online health information-seeking behaviour were more likely to report knowing about clinical trials.

Predictors of knowledge about clinical trials

The results of covariate-adjusted logistic regression (reduced model) are shown in Table 2. After controlling for demographic and health-related characteristics in the logistic regression model, the racial/ethnic differences in knowledge were no longer significant ($p=0.433$). Independent predictors of knowledge about clinical trials included higher education (college or higher (odds ratio (OR) 4.17; 95% confidence interval (CI) 2.08–8.32; $p<0.001$) or some college (OR 2.14; 95% CI 1.13–4.02; $p=0.019$)), patient portal use (OR 1.55; 95% CI 1.10–2.16; $p=0.013$) and online health information-seeking behaviour (OR 1.62; 95% CI 1.20–2.17; $p=0.002$). The respondents' characteristic that was associated with lower odds of knowing about clinical trials was a lack of insurance coverage (OR 0.55; 95% CI 0.30–0.98; $p=0.045$). Full logistic model results are available in the supplementary material S1, Table S2.

Trusted sources of clinical trial knowledge and motivation for trial participation

Information sources and motives of clinical trial participation by different levels of knowledge about clinical trials are presented in Fig 1. Healthcare providers were identified as the most trusted source of information by the majority of respondents (73.2%) independent of their knowledge status (Don't know (75.3%) vs Know a little (73.7%) vs Know a lot (60.3%); $p = 0.007$). Those with higher clinical trial knowledge are more likely to report that information from government health agencies or other health organisations were the most trusted sources than other knowledge level groups (Fig 1a). Overall, 71.6% of respondents indicated that their primary motivation for clinical trial participation was to help other people, followed by getting paid (12.5%) and receiving better treatment (5.1%; Fig 1b). When comparing motive by knowledge level, 63.9% of respondents who reported no knowledge about clinical trials reported that their motive was helping other people vs 86.8% of respondents who knew a lot about clinical trials; $p<0.001$.

Table 2. Predictors of knowledge of clinical trial using logistic regression, reduced model

	OR	95% CI	p-value
Race/ethnicity			
Non-Hispanic White	Ref	Ref	Ref
Non-Hispanic Black	0.98	(0.62–1.51)	0.916
Hispanic	0.82	(0.48–1.37)	0.433
Other	0.68	(0.42–1.10)	0.116
Education			
Less than high school	Ref	Ref	Ref
High school graduate	1.48	(0.79–2.76)	0.212
Some college	2.14	(1.13–4.02)	0.019
College or higher	4.17	(2.08–8.32)	0.0001
Family income			
>\$20,000	Ref	Ref	Ref
\$20,000–\$34,999	1.11	(0.71–1.73)	0.637
\$35,000–\$49,999	0.78	(0.42–1.42)	0.413
\$50,000–\$74,999	1.01	(0.61–1.63)	0.985
≥\$75,000	0.76	(0.49–1.17)	0.214
Employment			
Employed	Ref	Ref	Ref
Not employed	0.93	(0.65–1.32)	0.691
Health insurance			
Yes	Ref	Ref	Ref
No	0.55	(0.30–0.98)	0.045
General health			
Excellent	Ref	Ref	Ref
Very good	0.98	(0.59–1.59)	0.928
Good	0.90	(0.54–1.47)	0.662
Fair	0.80	(0.45–1.43)	0.453
Poor	0.64	(0.24–1.69)	0.364
Patient portal use			
No	Ref	Ref	Ref
Yes	1.55	(1.10–2.16)	0.013
Online health information-seeking behaviour			
No	Ref	Ref	Ref
Yes	1.62	(1.20–2.17)	0.002

Analysis included variables that had $p<0.10$ in the univariate analysis. CI = confidence interval; OR = odds ratio; Ref = reference parameter.

Discussion

Using a nationally representative sample, we found more than a third (41.3%) of US adults reported that they did not know about clinical trials in 2020. We also found that there was a higher prevalence of having no knowledge of clinical trials among Hispanic and non-Hispanic Black adults than non-Hispanic

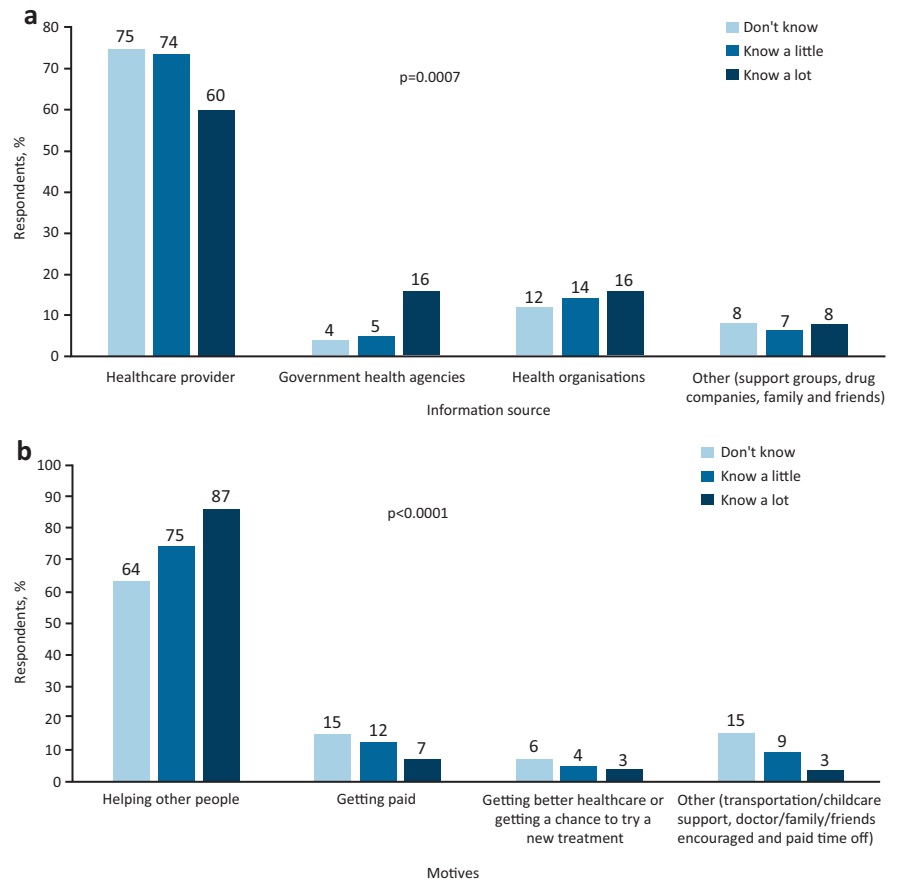


Fig 1. Respondents' knowledge of clinical trials. a) Most trusted information source about clinical trials. b) Motives to participate in clinical trials.

White adults. However, after controlling for demographic and health-related characteristics, these racial and ethnic differences in knowledge were no longer statistically significant. Higher education, patient portal use and online health information-seeking behaviour were significant predictors of knowing clinical trials. In addition, healthcare providers were the most trusted source to get clinical trial information and respondents indicated that their main motivation for participating in a clinical trial was to help other people, followed by reimbursement and receiving better treatment. The findings emphasise the need for promoting clinical trial knowledge by means of healthcare providers and the internet, since these were found to be critical sources of clinical trial information.

A high prevalence of respondents reporting a lack of knowledge of clinical trials suggests that a sizeable proportion of the US population was unaware of this type of research. A previous analysis of HINTS data reported an increase in clinical trial awareness (defined whether they had ever heard of a clinical trial) from 68% to 74% from 2008 to 2012, however, our analysis of the most contemporary HINTS data set revealed that only 59.7% of respondents had knowledge about clinical trials.¹⁵ A possible explanation of this discrepancy could be the difference in the language of questions used for measurement of clinical trial awareness in both studies (eg one asked about whether participants had heard about a clinical trial versus one asked participants to rate their level of knowledge about

clinical trials). Although it is challenging to assess the level of knowledge about clinical trials at a population level, additional efforts focused on increasing public acceptance of trials and facilitating enrolment is necessary for improving clinical trial recruitment.^{16,17}

In previous literature, individuals who were identified as racial/ethnic minorities were significantly less likely to be aware of clinical trials; for example, a study by Leiter *et al* reported that, although there was a significant increase in clinical trial awareness in Black respondents (from 56.5% in 2008 to 67.1% in 2012), significant racial/ethnic disparities in clinical trial awareness existed (77.5% among White respondents vs 67.1% Black respondents vs 59.8% Hispanic respondents in 2012).^{15,18,19} Interestingly, our analysis did not find a significant difference in clinical trial knowledge across races/ethnicities. Recent large-scale educational efforts and strategies to promote awareness of clinical trials and participation among minority populations may have been effective in increasing knowledge of clinical trials among racial/ethnic minorities.^{20,21} Although our findings indicating an absence of racial/ethnic disparity in knowledge about clinical trials is somewhat encouraging, racial/ethnic disparities in access to clinical trial information, their sites and trial participation are persistent.^{1,22} Thus, more efforts are still needed to understand further barriers to accessing clinical trial information and how available resources could be optimised and used to address racial/ethnic disparities in clinical research.

In this study, respondents reporting patient portal use and online health information-seeking behaviour were more likely to have knowledge about clinical trials. Internet access has provided a new channel for patients to access health information.^{23,24} Previous studies have reported that those who demonstrate online health information-seeking behaviour were more likely to have better health information than those who did not.^{24,25} Web-based patient education could be used as a potential channel for increasing the dissemination of trial information.²⁶ Web-based strategies to disseminate information about clinical trials (such as using social media) are being piloted. Additional research is needed to examine how such approaches affect disparities in trial participation.

Higher education level was independently associated with increased clinical trial awareness, which is consistent with other literature on public awareness and health literacy that suggests that a lack of understanding of scientific evidence is a barrier to clinical trial awareness.¹⁸ Future clinical trial awareness efforts should tailor trial-related information to the individuals' health literacy levels so that they can utilise it.

We also found that healthcare providers continue to be the most trusted source for getting clinical trial information. This finding has been consistent across previous analyses reported for years 2008 and 2012, echoing that patient–provider communication is vital for increasing knowledge and awareness of patients about clinical trials.¹⁵ However, time constraints, insufficient resources and provider perception of patient mistrust (or cultural barriers) have been cited as barriers to providers informing and enrolling their patients into clinical trials.²⁷ The role of healthcare providers in referring patients for trials can be further strengthened to increase clinical trial recruitment; therefore, enhanced incentive and competency training programmes should be provided for providers to help them effectively discuss clinical trials with their patients and address concerns related to access, finances and utility (clinical benefits and harms) using culturally appropriate language.^{27–29} A potential explanation for reducing the US population's knowledge of clinical trials may be the reduced access of patients to their healthcare providers due to the COVID-19 pandemic. Helping other patients appears to be a strong motive behind clinical trial participation among the survey respondents. Feelings of altruism have been cited in the literature as a facilitator to clinical trial participation.³⁰ Future research should focus on altruistic and financial factors as a potentially effective promotion strategy for participation in clinical trials.

Our analysis has some limitations. First, we utilised self-reported survey data, subject to recall biases. Second, the cross-sectional nature of the data limited us from making any causal inferences. Third, the data were subject to selection biases, although HINTS data weights were used for all analyses to address these biases.¹³ Lastly, data were collected amid the COVID-19 pandemic, which may have influenced respondents' knowledge of clinical trials (eg vaccine trials).

Conclusion

In this nationally representative sample, 41.3% of the respondents reported not knowing about clinical trials. Predictors of having knowledge about clinical trials included higher education, online health information-seeking behaviour and patient portal access. Respondents reported healthcare providers as their first and most trusted source of information

about clinical trials, and indicated altruism, financial incentives and better treatment as their main motives of clinical trial participation. Our study addresses an important gap in clinical trial information needs among the US adult population. Multimodal approaches (including online information broadcasting and improved patient–provider communication on sharing trial information) could be effective strategies to improve knowledge and clinical trial recruitment, and ensure equitable benefits from scientific research and discovery. ■

Supplementary material

Additional supplementary material may be found in the online version of this article at www.rcpjournals.org/clinmedicine: S1 – Full bivariate analysis results and full logistic model results.

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