Research on Medical Practices General Population Survey

Thank you for participating in this survey by the University of Washington and Stanford University. The purpose of the survey is to understand your opinions about healthcare issues. If you have questions about the survey, please contact the research team at rompethics@stanford.edu. If you have questions about your rights as a research participant, you can call the Stanford University Human Subjects Panel at 1-866-680-2906.

Your responses are confidential and you will not be identified by name in any results from the survey.

This survey asks your opinions on how doctors and their hospitals and clinics gather information to improve standard medical practices. What do we mean by this?

Research on medical practices compares FDA-approved medicines that some patients are already getting as part of their care. This is different from clinical trials of new medicines that have never been used by patients before.

Often there are several FDA-approved medicines used for the same medical problem. In many cases, these medicines have not been compared to each other. Hospitals and clinics want to do research to see which of the medicines usually work best.

We want to learn what you think about **research on medical practices**.

The survey will take about 30 minutes to complete.

	practices to find ou	ut which commor	nly used medic	cines are usually	most effective	e?
	1	2	3	4	5	6
	Strongly Disagr	ree			;	Strongly Agree
2.	To the best of your	knowledge, have	e you ever take	en part in <u>resea</u>	rch on medica	al practices?
	Yes					
	No					
	Not Sure					

1. How much do you disagree or agree that hospitals and clinics should do research on medical

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Animated video 1
Non-animated video 1
Comic 1
Text 1
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Please indicate whether you think the following statement is true or false:

		True	False	Don't Know
3.	Different doctors might prescribe different medicines for the same patient with high blood pressure.	1	2	3
4.	Sometimes there is not enough information for doctors to know which commonly prescribed medicine is usually most effective for patients.	1	2	3
5.	When a medicine is FDA-approved, that means it is usually more effective than other medicines for the same condition.	1	2	3

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Animated video 2
Non-animated video 2
Comic 2
Text 2
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Please indicate whether you think the following statement is true or false:

	True	False	Don't Know
Everyone who takes part in <u>research on</u> <u>medical practices</u> will get a commonly prescribed medicine.	1	2	3
7. In <u>research</u> on medical practices using <u>medical</u> <u>records</u> , patients get the medicine that their doctor normally prescribes for them.	1	2	3
In research using <u>randomization</u> , the treatment that an individual patient gets is based on chance.	1	2	3
 People who take part in research on medical practices using <u>randomization</u> can't have their medicines changed. 	1	2	3
When a patient first takes part in research on medical practices using <u>randomization</u> , the patient's regular doctor usually chooses the medicine that the patient gets.	1	2	3
11. Research using <u>medical records</u> and research using <u>randomization</u> are basically the same thing.	1	2	3
12. Research using <u>medical records</u> is generally better than research using <u>randomization</u> to find out which medicines are usually most effective.	1	2	3

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Animated video 3
Non-animated video 3
Comic 3
Text 3
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Please indicate whether you think the following statement is true or false:

	True	False	Don't Know
13. When a hospital or clinic is doing <u>research on</u> <u>medical practices</u> , they always ask each patient for permission before including her/him.	1	2	3
14. To take part in <u>research on medical practices</u> , a patient's permission must be given in writing.	1	2	3

EXAMPLE 1: RESEARCH USING RANDOMIZATION

Imagine your hospital or clinic is doing <u>research on medical practices</u> to compare different medicines that some patients already receive. Remember that this research is not testing new medicines.

Researchers are using <u>randomization</u> to compare 3 blood pressure medicines in <u>newly diagnosed</u> <u>patients</u>. These medicines are commonly used to treat blood pressure, but doctors don't know which of these medicines is usually better at preventing heart disease for most patients.

Imagine that you are one of these newly diagnosed patients.

One of these three commonly-prescribed medicines is given to you <u>based on randomization</u>. You and your doctor will know which medicine you are getting. Then, researchers look to see who had better outcomes.

Your doctor will provide usual medical follow-up and your medicine will only be changed if you or your doctor has concerns.

Please assume that:

- These are commonly used, FDA-approved medicines.
- · Each medicine causes occasional mild side effects.
- The out-of-pocket costs to patients are the same.
 - 15. This example is about:

Research using medical records Research using randomization They are the same thing

16. How much do you disagree or agree that hospitals or clinics should conduct <u>research on medical</u> <u>practices</u> using <u>randomization</u> to find out which medicines are usually most effective?

1 2 3 4 5 6
Strongly Disagree Strongly Agree

Remember that you are newly diagnosed with high blood pressure and your hospital or clinic is doing research comparing medicines used to treat high blood pressure. Your hospital or clinic might want to include you in this research.

17. How would you prefer to learn about being involved in this research?

Hospital or clinic staff talks with you about it
Hospital or clinic staff gives you written information about it

18. How important would it be for you to be asked for your permission to involved in this research?
1 2 3 4 5 6 Not at all Important Very Important
19. How would you prefer to give your permission to be involved in this research?
Verbally stating your preference Signing a form
Now, instead of thinking about what you would prefer for yourself, please think <u>in general</u> about this <u>research on medical practices</u> using <u>randomization</u> for patients with high blood pressure.
20. Suppose it was not possible to get written permission . In your opinion, which alternative would be better:
Do the research by getting verbal permission instead of written permission.
The research doesn't happen at all.
21. Suppose it was not possible to get <u>either written or verbal permission</u> . In your opinion, which alternative would be better:
Do the research after posting signs in the hospital or clinic waiting rooms to let patients know tha the research is happening.
The research doesn't happen at all.
We would like to know what you think about taking high blood pressure medicines as part of regular medical care .
22. Do you think there are any risks from taking high blood pressure medicines as part of regular medical care?
Yes No
Now, we would like to know what you think about taking part in <u>research on medical practices</u> using <u>randomization</u> to study high blood pressure medicines.

1	2	3	4	5	6	7
Much Les	s		The Same as			Much Greater
than Medical	Care		Medical Care		t	han Medical Care
24. Imagine your						
	gh blood pressu	re medicine	s. Would you con	sider taking p	art in this res	earch?
Yes						
No						
EVANDI E O. DEOI	EADOU HOINO	MEDICAL	DECORDO			
EXAMPLE 2: RES	EARCH USING	MEDICAL	KECOKD5			
Again imagina yau	r hospital or olin	io ie doina r	rocoarch on mod	ical practice	e to compare	different
Again, imagine you medicines that som						
		,				
But now, imagine th	nat researchers	are using m	nedical records to	o compare 3	blood pressu	re medicines in
newly diagnosed	patients. These	e medicines	are commonly us	sed to treat bl	lood pressure	e, but doctors don't
know which of thes	e medicines is ι	isually bette	er at preventing he	eart disease f	or most patie	nts.
	5.11					
Imagine that you ar included in this rese		newly diagn	osed patients. Th	is means that	t your medica	I records could be
included in this rest	carcii.					
Your doctor decides	s which medicin	e to prescri	he as usual The	n researcher	s review the	medical records of
patients to see who		=	<u>uo uouur</u> . 1110	11, 10000101101		noulcai rocordo oi
Please assume tha	t:					
These are comi	monly used, FD	A-approved	medicines.			
• Each medicine						
The out-of-pock	et costs to patie	ents are the	same.			
OF This everynle	ia abauti					
25. This example	is about.					
Pasaaro	ch using medica	l records				
	ch using medica					
	e the same thing					
They are		9				
26. How much do	vou disagree o	r agree that	hospitals or clinic	es should con	duct researc	h on medical
			out which medici			
		-				
1	1 2		3 4		5	6
Strongly D	Disagree				Stror	ngly Agree

23. Compared to taking high blood pressure medicines as part of <u>medical care</u>, do you think the risks of taking the medicines as part of this research using <u>randomization</u> are less, the same, or greater?

Now, please think <u>in general</u> about this <u>research on medical practices</u> using <u>medical records</u> for patients with high blood pressure.							
	Suppose it was no petter:	ot possible	e to get <u>written p</u>	ermission . In	n your opinio	on, which alterna	ative would be
	Do the resea	irch by ge	etting verbal perm	ission instead	of written po	ermission.	
	The research	n doesn't	happen at all.				
28. Suppose it was not possible to get <u>either written or verbal permission</u> . In your opinion, which alternative would be better:						on, which	
	Do the research		posting signs in t ning.	he hospital or	clinic waitin	g rooms to let pa	atients know tha
	The research	n doesn't	happen at all.				
	magine your hosp records comparin						
	Yes						
	No						
low p	olease take a mon	nent to ref	lect on your expe	erience of takir	ng this surve	ey.	
30. I	How helpful did yo	ou find the	information prov	rided about <u>res</u>	search on n	nedical practic	<u>es</u> ?
No	1 ot at all Helpful	2	3	4	5	6 Very Helpful	
	As a result of takir	•	•	, has your willi	ingness to p	articipate in <u>res</u>	earch on
	1 Much Less	2		4 o Change in M	•	6	7 Much More
'	Willing to Participa	ate	Willing	gness to Partic	cipate	Willir	ng to Participate

Finally, please tell us a little about yourself.

Excellent

32. In general, how would you rate your health today?

	Very Good
	Good
	Fair
	Poor
33. Wh	at is your age?
	18-24
	25-29
	30-34
	35-39
	40-44
	45-49
	50-54
	55-59
	60-64
	65-69
	70-74
	75 or over
34. Are	you male or female?
	Male
	Female
35. Are	you of Hispanic or Latino origin?
	Yes
	No
36. Wh	at race do you consider yourself to be? Check all that apply.
	American Indian or Alaska Native
	Asian
	Black or African American
	Native Hawaiian or Other Pacific Islander
	White / Caucasian

Other

37. Have you ever participated in a randomized clinical study?

Yes

No

I Don't Know

38. What is the highest degree or level of school you have **completed**?

Some High School
High School Graduate (Diploma or GED)
Some College or Associate Degree
Vocational, Business or Trade School
College Graduate
Some Graduate School
Graduate or Professional Degree

Graduate of Professional Degree

39. What was your household's total income last year before taxes?

Less than \$20,000

\$20,000 - \$39,999

\$40,000 - \$59,999

\$60,000 - \$79,999

\$80,000 - \$99,999

\$100,000 - \$149,999

\$150,000 or More

We appreciate your participation in this voluntary survey.

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