

General Population and Patient Survey

SURVEY

Thank you for participating in this survey. The purpose of this survey is to understand your opinions about healthcare issues.

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

SCREENER

A. Into which of these age groups do you fall? [CHECK QUOTAS]

- Under 21 >> TERMINATE
- 21-26
- 27-44
- 45-64
- 65 or older
- Prefer not to answer >>>TERMINATE

B. Are you male or female? [CHECK QUOTAS]

- Male
- Female
- Prefer not to answer >> TERMINATE

C. Are you of Hispanic or Latino origin? [CHECK QUOTAS]

- Yes
- No
- Prefer not to answer >> TERMINATE

D. What race do you consider yourself to be? [CHECK QUOTAS]

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or other Pacific Islander
- White / Caucasian
- Other
- Prefer not to answer >> TERMINATE

E. In which US state do you live? [CHECK QUOTAS]

DROP DOWN BOX

F. **Have you ever had a serious illness or injury (for example, cancer, heart disease, joint replacement) that required you to seek care from a specialized physician (for example, oncologist, cardiologist, orthopedic surgeon)?**

Yes

No >> CHECK QUOTA ON OQ SAMPLE

G. **Have any of your close family members (such as a child, spouse, or parent) ever had a serious illness or injury (for example, cancer, heart disease, joint replacement) that required them to seek care from a specialized physician (for example, oncologist, cardiologist, orthopedic surgeon)?**

Yes

No >> CHECK QUOTA ON OQ SAMPLE

I don't know >> CHECK QUOTA ON OQ SAMPLE

ON OQ SAMPLE EITHER F OR G MUST HAVE A 'YES' RESPONSE TO CONTINUE

This survey asks your opinions on how doctors and health systems gather information to improve **standard medical practices**. (By health system, we mean the network of doctors and hospitals where a patient receives care.)

For example, even though many drugs are approved by the Food and Drug Administration (FDA) and are commonly used to treat the same disease, doctors often don't know which ones are the best overall choices. Health systems might want to compare these commonly used treatments directly to see which ones work best for their patients.

This national research survey is being distributed on behalf of the University of Washington and Stanford University. Researchers there are interested in the ethics of research of medical practices.

The survey includes 3 short videos for you to watch and will take about 30 minutes to complete.

If you have questions about the survey, please contact the research team at romp@uw.edu. If you have questions about your rights as a research participant, you can call the University of Washington Human Subjects Division at (206) 543-0098.

MEDICAL OUTCOMES / TRUST

To start, we would like to ask you about your views on trust in healthcare.

1. **How much do you trust the doctor you see most often to put your well-being above all other considerations when treating your medical problems?**

I trust my doctor a lot

I trust my doctor somewhat

I distrust my doctor somewhat

I distrust my doctor a lot

2. **How much do you trust your health system to put your well-being above all other considerations when treating your medical problems? (By health system, we mean the network of doctors and hospitals where you receive care.)**

I trust my health system a lot

I trust my health system somewhat

I distrust my health system somewhat

I distrust my health system a lot

Q1-2 ON SAME SCREEN

VIDEO ONE

Now please watch this 3-minute video. Click on the arrow in the center of the video to start playing it. When the video is over, please click on the red arrow at the bottom of your screen to continue.

INSERT VIDEO 1 HERE

3. To help us improve the video as an informational tool, please tell us what you understood about the following, based on the video.

	True	False
Doctors agree about which treatment for high blood pressure is best.	1	2
A doctor's decision about what medication to prescribe is based on multiple influences.	1	2
Sometimes there is not enough information for doctors to know which standard medical practices are best.	1	2

After new medical treatments are approved by the FDA and become part of standard medical practices, more research may still be needed to compare these treatments to learn which is best. For each of the following statements, please indicate your level of agreement.

4. To find out which standard medical treatments are best, health systems should conduct research.

Strongly agree
Somewhat agree
Somewhat disagree
Strongly disagree

5. Although research on standard medical practices might determine the "best" medical treatment to start with for the average patient, that treatment might not be the best one to start with for me.

Strongly agree
Somewhat agree
Somewhat disagree
Strongly disagree

Q4 - Q5 ON ONE SCREEN

6. Now we would like you to think about patient trust. To maintain your trust as a patient, how important is it that your doctor tells you when he / she is uncertain about which treatment is best for you?

- Very important to maintain my trust
- Moderately important to maintain my trust
- Somewhat important to maintain my trust
- Not at all important to maintain my trust

VIDEO TWO

Now please watch this 3-minute video. Click on the arrow in the center of the video to start playing it. When the video is over, please click on the red arrow at the bottom of your screen to continue.

INSERT VIDEO 2 HERE

7. To help us improve the video as an informational tool, please tell us what you understood about the following, based on the video.

	True	False
Trying to figure out the best treatment using medical record review can sometimes give researchers the wrong answer.	1	2
With randomization, you can never change the medication you are taking.	1	2
Randomization is the “gold standard” for comparing medications.	1	2

Now we would like to ask you to think about issues related to your trust as a patient in your health system. In order to maintain your trust as a patient, how important are each of the following?

8. When my health system shares information from my medical record with other health systems to improve care for all patients, it notifies me that it is doing so.

- Very important to maintain my trust
- Moderately important to maintain my trust
- Somewhat important to maintain my trust
- Not at all important to maintain my trust

9. My health system uses an ethics committee to oversee research activities.

- Very important to maintain my trust
- Moderately important to maintain my trust
- Somewhat important to maintain my trust
- Not at all important to maintain my trust

10. My health system includes a patient advisory board to help oversee research activities.

- Very important to maintain my trust
- Moderately important to maintain my trust
- Somewhat important to maintain my trust
- Not at all important to maintain my trust

Q8 – Q10 ON ONE SCREEN

VIDEO THREE - MEDICAL RECORD REVIEW PERMISSION

Now please watch this 2-minute video. Click on the arrow in the center of the video to start it playing. When the video is over, please click on the red arrow at the bottom of your screen to continue.

INSERT VIDEO 3 HERE

Now we would like you to think about the videos and imagine your health system using medical record review to compare 3 high blood pressure medications in newly diagnosed patients.

Doctors don't know which of these medications is better at preventing heart disease. Each doctor decides which medication to use based on his or her judgment and on patient preferences.

Please assume the following when you are answering the following questions:

- These are commonly used, FDA-approved medications.
- Each medication causes occasional mild side effects.
- The out-of-pocket costs to the patient are the same.

11. If you were newly diagnosed with high blood pressure and this research using medical record review were happening in your health system, how would you prefer to be notified about this research?

I would not need to be notified about this research using medical record review >>> SKIP TO Q15

My health system would give me a document containing general information about this research >>> SKIP TO Q15

Doctors or other medical personnel would discuss this research with me and then ask for verbal permission to participate >>>CONTINUE TO Q12, THEN SKIP TO Q14

Doctors or other medical personnel would discuss this research using medical record review with me and then ask for written permission or consent to participate >>>CONTINUE TO Q12

FOR QS 12 – 19, USE THE FOLLOWING TEXT ON EACH SCREEN

Continue to imagine your health system using medical record review to compare 3 high blood pressure medications in newly diagnosed patients.

12. Who would you prefer to ask you for your permission or consent to participate in this research using medical record review?

My doctor

A researcher or research nurse who is not involved in my care

No preference

13. If getting written permission or consent would make this research using medical record review too difficult to carry out, how would you prefer to be notified about this research?

I would not need to be notified about this research using medical record review >>>SKIP TO Q15

My health system would give me a document containing general information about this research >>>SKIP TO Q15

Doctors or other medical personnel would discuss this research with me and then ask for verbal permission to participate >>>CONTINUE TO Q14

I would prefer this research using medical record review not be conducted >>>SKIP TO Q15

14. If getting verbal permission would make this research using medical record review too difficult to carry out, how would you prefer to be notified about this research?

I would not need to be notified about this research using medical record review

My health system would give me a document containing general information about this research

I would prefer this research using medical record review not be conducted

15. How would knowing that this research using medical record review was going on in your health system affect your trust in your health system?

Greatly increase trust in my health system

Somewhat increase trust

Would not change trust

Somewhat decrease trust

Greatly decrease trust in my health system

16. How would knowing that this research using medical record review was going on in your health system affect your trust in your doctor?

Greatly increase trust in my doctor

Somewhat increase trust

Would not change trust

Somewhat decrease trust

Greatly decrease trust in my doctor

Q15 – Q16 ON ONE SCREEN

17. Would you be willing to consider having your medical records reviewed for this research on high blood pressure medications?

Yes

No

18. Compared to just having your doctor prescribe the medications, how much additional risk do you think there is to you from this research using medical record review?

A lot of additional risk

A little additional risk

No additional risk

RANDOMIZATION PERMISSION

Still thinking about the videos, now imagine that your health system is using randomization to compare the 3 blood pressure medications in newly diagnosed patients.

Each patient and their doctor will know which medication the patient is getting.

Their doctor will provide usual medical follow-up and will not change the medication unless the patient or doctor has concerns.

19. In your opinion, how acceptable is it for health systems to use randomization to compare how well different standard treatments work?

Always acceptable

Usually acceptable

Sometimes acceptable

Rarely acceptable

Never acceptable

20. If you were newly diagnosed with high blood pressure and this research using randomization were happening in your health system, how would you prefer to be notified about this research? (Please choose only one.)

I would not need to be notified about this research using randomization >>>SKIP TO Q24

My health system would give me a document containing general information about this research >>> SKIP TO Q24

Doctors or other medical personnel would discuss this research with me and then ask for verbal permission to participate >>>CONTINUE TO Q21, THEN SKIP TO Q23

Doctors or other medical personnel would discuss this research using randomization with me and then ask for written permission or consent to participate >>>CONTINUE TO Q21

FOR Qs 21 – 26, 29 - 30, USE THE FOLLOWING TEXT ON EACH SCREEN

Continue to imagine your health system using randomization to compare 3 high blood pressure medications in newly diagnosed patients.

21. Who would you prefer to ask you for your permission or consent to participate in this research using randomization?

My doctor

A researcher or research nurse who is not involved in my care

No preference

22. If getting written permission or consent would make this research using randomization too difficult to carry out, how would you prefer to be notified about this research?

I would not need to be notified about this research using randomization >>>SKIP TO Q24

My health system would give me a document containing general information about this research >>>SKIP TO Q24

Doctors or other medical personnel would discuss this research with me and then ask for verbal permission to participate >>>CONTINUE TO Q23

I would prefer this research using randomization not be conducted >>>SKIP TO Q24

23. If getting verbal permission would make this research using randomization too difficult to carry out, how would you prefer to be notified about this research?

I would not need to be notified about this research using randomization

My health system would give me a document containing general information about this research

I would prefer this research using randomization not be conducted

24. How would knowing that this research using randomization was going on in your health system affect your trust in your health system?

Greatly increase trust in my health system

Somewhat increase trust

Would not change trust

Somewhat decreases trust

Greatly decreases trust in my health system

25. How would knowing that this research using randomization was going on in your health system affect your trust in your doctor?

Greatly increase trust in my doctor

Somewhat increase trust

Would not change trust

Somewhat decrease trust

Greatly decrease trust in my doctor

Q24 – Q25 ON ONE SCREEN

26. Would you be willing to consider participating in this research using randomization?

Yes >>>CONTINUE

No >>>SKIP TO Q28

27. IF YES: Please tell us more about why you would be willing to consider participating in this research using randomization.

OPEN-ENDED QUESTION >>>SKIP TO Q29

28. IF NO: Please tell us more about why you would not be willing to consider participating in this research using randomization.

OPEN-ENDED QUESTION

29. How much additional risk do you think there is to you from this research using randomization compared to just having your doctor prescribe the medications?

A lot of additional risk

A little additional risk

No additional risk

30. To what extent would knowing each of the following affect your willingness to participate in research using randomization, if at all?

	Greatly decrease willingness	Somewhat decrease willingness	No impact	Somewhat increase willingness	Greatly increase willingness
Knowing I could change high blood pressure medications if I needed to	1	2	3	4	5
Knowing which high blood pressure medication I was taking	1	2	3	4	5
Knowing my doctor recommended participation	1	2	3	4	5
Knowing the only way to really know which medication is better would be to use randomization	1	2	3	4	5

Imagine that you are the medical decision-maker for one of your close family members (such as a child, spouse, or parent) and they are eligible to participate in this research using randomization.

31. Would you consider giving permission for them to participate?

Yes >>>CONTINUE

No >>>SKIP TO Q33

32. IF YES: Please tell us more about the reasons why you would consider giving permission for them to participate.

OPEN-ENDED SKIP TO INSTRUCTIONS BEFORE Q34

33. IF NO: Please tell us more about the reasons why you would not consider giving permission for them to participate.

OPEN-ENDED

RANDOMIZATION WITH SERIOUS CONDITION

Finally, consider a more serious health condition that increases your risk for stroke. There are 3 commonly used medications that can reduce your risk, but they all have serious side effects. Imagine your health system using randomization to compare these 3 medications in newly diagnosed patients. These are FDA-approved medications, but doctors don't know which of these medications is better.

34. If you were newly diagnosed with this serious condition and this research using randomization were happening in your health system, how would you prefer to be notified about this research? (Please choose only one.)

I would not need to be notified about this research using randomization >>>SKIP TO Q38

My health system would give me a document containing general information about this research >>>SKIP TO Q38

Doctors or other medical personnel would discuss this research with me and then ask for verbal permission to participate >>>CONTINUE TO Q35, THEN SKIP TO Q37

Doctors or other medical personnel would discuss this research using randomization with me and then ask for written permission or consent to participate >>>CONTINUE TO Q35

FOR QS 35 – 38, 41, USE THE FOLLOWING TEXT ON EACH SCREEN

Continue to imagine your health system using randomization to compare 3 commonly used medications for this more serious health condition in newly diagnosed patients.

35. Who would you prefer to ask you for your permission or consent to participate in this research using randomization?

My doctor

A researcher or research nurse who is not involved in my care

No preference

36. If getting written permission or consent would make this research using randomization too difficult to carry out, how would you prefer to be notified about this research?

I would not need to be notified about this research using randomization >>>SKIP TO Q38

My health system would give me a document containing general information about this research >>>SKIP TO Q38

Doctors or other medical personnel would discuss this research with me and then ask for verbal permission to participate >>>CONTINUE TO Q37

I would prefer this research using randomization not be conducted >>>SKIP TO Q38

37. If getting verbal permission would make this research using randomization too difficult to carry out, how would you prefer to be notified about this research?

I would not need to be notified about this research using randomization

My health system would give me a document containing general information about this research

I would prefer this research using randomization not be conducted

38. Would you be willing to consider participating in this research using randomization?

Yes >>>CONTINUE

No >>>SKIP TO Q40

39. IF YES: Please tell us more about why you would be willing to consider participating in this research using randomization.

OPEN-ENDED QUESTION>>> SKIP TO Q41

40. IF NO: Please tell us more about why you would not be willing to consider participating in this research using randomization.

OPEN-ENDED QUESTION

41. How much additional risk do you think there is to you from this research using randomization compared to just having your doctor prescribe the medications?

A lot of additional risk

A little additional risk

No additional risk

Imagine that you are the medical decision-maker for one of your close family members (such as a child, spouse, or parent) and they are eligible to participate in this research using randomization for this more serious condition.

42. Would you consider giving permission for them to participate?

Yes

No

VIDEO EXPERIENCE

Now please take a moment to reflect on your experience of watching the videos

43. As a result of watching the videos about research comparing medical treatments, how has your willingness to participate in this type of research changed?

Much more willing to participate

A little more willing to participate

My willingness to participate has not changed>>>SKIP TO Q46

A little less willing to participate>>>SKIP TO Q45

Much less willing to participate>>>SKIP TO Q45

44. What about the videos made you more willing to participate?

OPEN-ENDED>>>SKIP TO Q46

45. What about the videos made you less willing to participate?

OPEN-ENDED

DEMOGRAPHICS

Finally, please tell us a little about yourself

46. Have you ever had any children (biological or adopted)?

Yes

No

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

Excellent

Very Good

Good

Fair

Poor

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

Yes

No

I don't know

49. Have any of your close family members (such as a child, spouse, or parent) ever participated in a randomized clinical study?

Yes

No

I don't know

50. 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
- College graduate
- Some graduate school
- Graduate or professional degree
- Prefer not to answer

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

- \$30,000 or less
- \$30,001 to \$55,000
- \$55,001 - \$95,000
- More than \$95,000
- Prefer not to answer

We appreciate your participation in this voluntary survey.

If you have questions about the survey, please contact the research team at romp@uw.edu. If you have questions about your rights as a research participant, you can call the University of Washington Human Subjects Division at (206) 543-0098.

The results of this survey may lead to additional questions about how people think about this sort of research. The research team would like to interview some of the survey participants to address these questions. Interviews will be approximately 45 minutes and will take place 2 to 6 months after the survey.

If you are willing to participate, are chosen to do so, and complete the follow-up phone interview, you will receive \$25 in compensation.

Would you be willing to be re-contacted to participate in this follow-up phone interview?

- Yes
- No