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.

1. How much do you disagree or agree that hospitals and clinics should do **research on medical practices** to find out which commonly used medicines are usually most effective?

   1. Strongly Disagree
   2. 3. 4. 5. 6. Strongly Agree

2. To the best of your knowledge, have you ever taken part in **research on medical practices**?

   Yes
   No
   Not Sure
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Please indicate whether you think the following statement is true or false:

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<th>True</th>
<th>False</th>
<th>Don’t Know</th>
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<tr>
<td>3. Different doctors might prescribe different medicines for the same patient with high blood pressure.</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<td>4. Sometimes there is not enough information for doctors to know which commonly prescribed medicine is usually most effective for patients.</td>
<td>1</td>
<td>2</td>
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<td>5. When a medicine is FDA-approved, that means it is usually more effective than other medicines for the same condition.</td>
<td>1</td>
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<tr>
<td>6.</td>
<td>Everyone who takes part in <strong>research on medical practices</strong> will get a commonly prescribed medicine.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>7.</td>
<td>In <strong>research</strong> on medical practices using <strong>medical records</strong>, patients get the medicine that their doctor normally prescribes for them.</td>
<td>1</td>
<td>2</td>
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<td>8.</td>
<td>In research using <strong>randomization</strong>, the treatment that an individual patient gets is based on chance.</td>
<td>1</td>
<td>2</td>
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<td>9.</td>
<td>People who take part in research on medical practices using <strong>randomization</strong> can't have their medicines changed.</td>
<td>1</td>
<td>2</td>
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<td>10.</td>
<td>When a patient first takes part in research on medical practices using <strong>randomization</strong>, the patient's regular doctor usually chooses the medicine that the patient gets.</td>
<td>1</td>
<td>2</td>
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<tr>
<td>11.</td>
<td>Research using <strong>medical records</strong> and research using <strong>randomization</strong> are basically the same thing.</td>
<td>1</td>
<td>2</td>
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<tr>
<td>12.</td>
<td>Research using <strong>medical records</strong> is generally better than research using <strong>randomization</strong> to find out which medicines are usually most effective.</td>
<td>1</td>
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<th>True</th>
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<tr>
<td>13. When a hospital or clinic is doing <strong>research on medical practices</strong>, they always ask each patient for permission before including her/him.</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>14. To take part in <strong>research on medical practices</strong>, a patient’s permission must be given in writing.</td>
<td>1</td>
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EXAMPLE 1: RESEARCH USING RANDOMIZATION

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

Researchers are using randomization to compare 3 blood pressure medicines in newly diagnosed patients. 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 based on randomization. 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 research on medical practices using randomization to find out which medicines are usually most effective?

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<th>2</th>
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<th>4</th>
<th>5</th>
<th>6</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Strongly Disagree</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Strongly Agree</td>
</tr>
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</table>

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 be 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

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Now, instead of thinking about what you would prefer for yourself, please think in general about this research on medical practices using randomization 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 either written or verbal permission. 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 that the research is happening.

The research doesn’t happen at all.

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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

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Now, we would like to know what you think about taking part in research on medical practices using randomization to study high blood pressure medicines.
23. Compared to taking high blood pressure medicines as part of medical care, do you think the risks of taking the medicines as part of this research using randomization are less, the same, or greater?

1 2 3 4 5 6 7
Much Less than Medical Care
The Same as Medical Care
Much Greater than Medical Care

24. Imagine your hospital or clinic is doing this research on medical practices using randomization comparing high blood pressure medicines. Would you consider taking part in this research?

Yes
No

EXAMPLE 2: RESEARCH USING MEDICAL RECORDS

Again, imagine your hospital or clinic is doing research on medical practices to compare different medicines that some patients already receive. Remember that this research is not testing new medicines.

But now, imagine that researchers are using medical records to compare 3 blood pressure medicines in newly diagnosed patients. 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. This means that your medical records could be included in this research.

Your doctor decides which medicine to prescribe as usual. Then, researchers review the medical records of patients to see who had better outcomes.

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.

25. This example is about:

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

26. How much do you disagree or agree that hospitals or clinics should conduct research on medical practices using medical records to find out which medicines are usually most effective?

1 2 3 4 5 6
Strongly Disagree

Strongly Agree
Now, please think in general about this research on medical practices using medical records for patients with high blood pressure.

27. 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.

28. Suppose it was not possible to get either written or verbal permission. 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 that the research is happening.

   The research doesn't happen at all.

29. Imagine your hospital or clinic is conducting this research on medical practices using medical records comparing high blood pressure medicines. Would you consider taking part in this research?

   Yes
   No

Now please take a moment to reflect on your experience of taking this survey.

30. How helpful did you find the information provided about research on medical practices?

   1 2 3 4 5 6
   Not at all Helpful Very Helpful

31. As a result of taking this survey, how, if at all, has your willingness to participate in research on medical practices changed?

   1 2 3 4 5 6 7
   Much Less Willing to Participate No Change in My Willingness to Participate Much More Willing to Participate
Finally, please tell us a little about yourself.

32. In general, how would you rate your health today?
   - Excellent
   - Very Good
   - Good
   - Fair
   - Poor

33. What 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. What 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
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

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.

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.