U.S. Public Opinion About Personalized Medicine
Nationally representative survey of 1,024 U.S. adults conducted for the Personalized Medicine Coalition

July 2014
Objective

- To measure awareness of and opinions about personalized medicine:
  - Awareness & knowledge
  - Impressions & opinions
  - Experience & likelihood to get a diagnostic test
  - Interest & questions
  - Concerns
  - Benefits

Method

- Nationally representative telephone survey (landline and mobile) of 1,024 American adults age 18 and older.
  - 25 minutes
  - March 5-16, 2014
  - Margin of error is +3 percentage points
Key Findings
Few have heard of personalized medicine and most do not know what it is.

- Just over 1 in 10 say their doctor talked to them about or recommended personalized medicine.

- Knowledge among those who have heard the term is shallow.

- Few associate it with genetic testing or genetic medicine.

Base: Total (N=1024)  
Q5: I’m going to read you a list of words and terms. For each one, tell me if you have heard or read anything about that term before today. Here’s the first one: [ASK ALL ABOUT PERSONALIZED MEDICINE; FOR OTHER TERMS, SPLIT THE SAMPLE IN HALF AND ASK EACH RESPONDENT HALF OF THE TERMS. RANDOMIZE AND READ LIST; RECORD ALL HEARD RESPONSES.]
When informed, most are receptive—and many excited about the prospects.

- Two-thirds feel positive, about a third neutral, a few negative.
- Three-fourths likely to have a diagnostic test.

**DESCRIPTION**

Personalized medicine is an emerging field that uses diagnostic tools to identify specific biological markers, often genetic, to help determine which medical treatments and procedures will be best for each patient. By combining this information with an individual’s medical records and circumstances, personalized medicine allows doctors and patients to develop targeted prevention and treatment plans. The goal is to provide the right treatment in the right dose to the right patient at the right time.

*Base: Total (N=1024)*

Q10: What is your reaction to the description of personalized medicine—mostly positive, mostly negative, or neutral?
Consumers quickly see major benefits.

Knowledge to prevent illness and to pick the right treatments seen as major benefits.

<table>
<thead>
<tr>
<th>Benefit</th>
<th>Major</th>
<th>Minor</th>
<th>Not</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>The information could help me and my doctor choose the treatment that</td>
<td>76%</td>
<td>15%</td>
<td>5%</td>
<td>5%</td>
</tr>
<tr>
<td>is most likely to be effective</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The information could give me more control to prevent or treat illness</td>
<td>72%</td>
<td>18%</td>
<td>4%</td>
<td>6%</td>
</tr>
<tr>
<td>The information could help reduce or avoid treatment side effects</td>
<td>71%</td>
<td>20%</td>
<td>4%</td>
<td>6%</td>
</tr>
<tr>
<td>The information could result in less invasive procedures</td>
<td>69%</td>
<td>19%</td>
<td>5%</td>
<td>7%</td>
</tr>
<tr>
<td>The information could help avoid trial and error medicine</td>
<td>68%</td>
<td>19%</td>
<td>6%</td>
<td>6%</td>
</tr>
</tbody>
</table>

Base: Total (N=1024)

Q18-22: I’m going to read you a list of some of the benefits of personalized testing. For each one, tell me if that would be a major benefit, a minor benefit, or not a benefit for you personally. First, [READ ITEM] – is that a major benefit, a minor benefit, or not a benefit? [RANDOMIZE]
69% are interested—and many have questions. Efficacy, cost, and risks are the top three question topic areas.

Most Frequent Questions

<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>How effective is it? What is the success rate, track record, history?</td>
<td>11%</td>
</tr>
<tr>
<td>Are there any side effects or risks associated with testing?</td>
<td>11%</td>
</tr>
<tr>
<td>How much does it cost?</td>
<td>10%</td>
</tr>
<tr>
<td>How will test or procedure be performed? What does it involve?</td>
<td>8%</td>
</tr>
<tr>
<td>What are the advantages or benefits? Will I benefit, and how so?</td>
<td>8%</td>
</tr>
<tr>
<td>How will the data be used? What is the purpose of the data?</td>
<td>5%</td>
</tr>
<tr>
<td>How accurate is it/the predictions?</td>
<td>5%</td>
</tr>
</tbody>
</table>

Responses with 5% and above have been included. Full list is appended.

Base: Total (N=1024)
Q12: How interested are you learning more about how personalized medicine can be used—very, somewhat, not too, or not at all?
Q16: If your doctor recommended it, what questions would you have about personalized medicine? PROBE: What would you like to have explained to you about personalized medicine? [OPEN END. RECORD VERBATIM RESPONSE.]
74% have no worries, unaided.  
Aided, access and affordability are major concerns.

<table>
<thead>
<tr>
<th>Reason</th>
<th>Major (%)</th>
<th>Minor (%)</th>
<th>Not (%)</th>
<th>Not sure (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The test might not be covered by my insurer</td>
<td>69%</td>
<td>18%</td>
<td>8%</td>
<td>5%</td>
</tr>
<tr>
<td>I might not be able to afford it</td>
<td>67%</td>
<td>19%</td>
<td>9%</td>
<td>5%</td>
</tr>
<tr>
<td>The test could be used to deny coverage for a treatment I want</td>
<td>55%</td>
<td>24%</td>
<td>15%</td>
<td>6%</td>
</tr>
<tr>
<td>My personal information could be used against me</td>
<td>47%</td>
<td>27%</td>
<td>20%</td>
<td>5%</td>
</tr>
</tbody>
</table>

Base: Total (N=1024)
Q23: Is there anything about personalized medicine that is worrisome?
Q24-27: I'm going to read you some reasons some people give for why they worry about personalized medicine. For each one, tell me if that is a major concern, a minor concern, or not a concern for you personally.  First, [READ ITEM] – is that a major concern, a minor concern, or not a concern for you personally? [RANDOMIZE]
Most think insurance should cover personalized medicine, if their doctor recommends it.

Two arguments—which is closest to your opinion?

Personalized medicine is promising, but health care costs are already high and some of these new tests and treatments are too expensive. In order to keep health care affordable, health insurance companies should not cover these tests and treatments.

Because personalized tests and treatments are targeted to a small number of patients, they are more expensive than conventional tests and treatments. But they deliver more value to patients and may help control overall health care spending. Therefore, health insurance companies should cover these tests and treatments.

Base: Total (N=1024)
Q28: I'm going to read you two statements—tell me which one is closest to your own personal opinion, even if neither is exactly right.
Conclusions

- As most do not know what personalized medicine is, there is an opportunity to raise awareness and increase knowledge.

- Most are receptive to—and many are excited about—the potential benefits of personalized medicine, including choosing a treatment that is most likely to work for them and the potential to prevent illness.

- A large majority also recognize the value of these technologies and believe that they should be covered by insurance.
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