

U.S. Public Opinion about Personalized Medicine

Survey Shows Public Optimism about Personalized Medicine

Major scientific advances, such as those driving the emergence of personalized medicine, often generate significant public excitement, but also can prompt wariness as well. Personalized medicine is a growing practice area that holds great promise to improve patient care and at the same time make the health care system more efficient.

Although most experts recognize the value of this innovative approach the public’s view may lag. As more patients are likely to encounter personalized tests and treatment options, the Personalized Medicine Coalition (PMC) commissioned a survey to gauge consumer awareness, knowledge, and attitudes about personalized medicine. KRC Research conducted a nationally representative survey of U.S. adults,¹ building on consumer focus groups conducted by KRC for PMC in 2013.

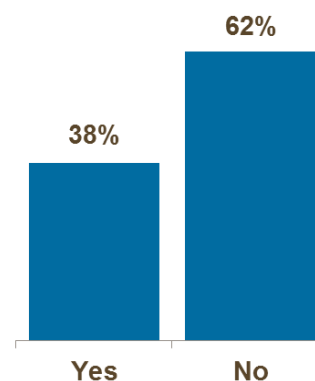
The survey found that:

- The large majority of people have not heard of personalized medicine but react positively when it is described to them.
- Most feel 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.

Detailed Survey Findings

- **Most consumers do not know what personalized medicine is.** Only 4 in 10 have heard the term, “personalized medicine”—six in 10 have not heard of it. Among those who have heard the term, only 2 in 10 (16%) feel very informed.
- 11% say their doctor has discussed or recommended personalized medicine to them.

Heard of Personalized Medicine



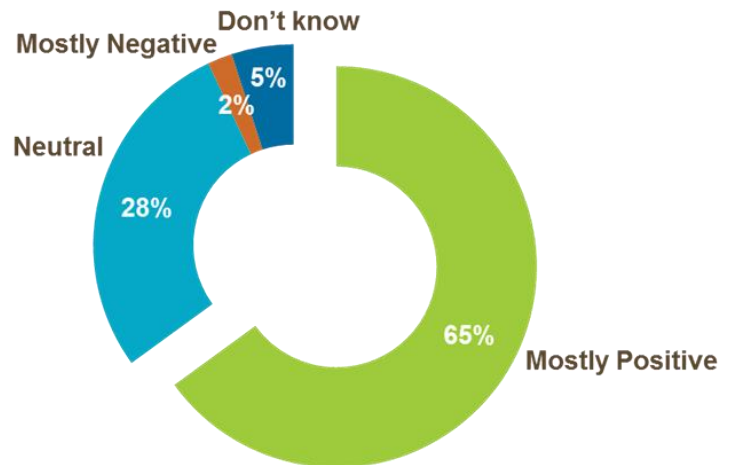
“I’m going to read you a list of words and terms. For each one, tell me if you heard or read anything about that term before today: Personalized medicine.”

Description of Personalized Medicine

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.

Attitude Toward Personalized Medicine

- **Consumers' reaction to personalized medicine is mostly positive.** After hearing a description (shown above), two-thirds said their reaction was mostly positive (65%), a third (28%) said neutral, and 2% said mostly negative. In focus groups, consumers told us that the reason they feel positive about personalized medicine is because it is proactive, patient-centered, and helps streamline doctor/patient decision-making.



"What is your reaction to the description of personalized medicine—mostly positive, mostly negative, or neutral?"

- **Real world examples of personalized medicine are important to raising awareness.** In our 2012 consumer focus groups, participants were shown examples of current uses for personalized medicine and asked for their thoughts and reactions. The examples proved to be a key way to educate people by making abstract concepts "real" to the participants.
- **Consumers have many questions and want to learn more.** Most (69%) are interested in learning more about how personalized medicine works; 18% are not too interested and 9% are not at all interested in learning more. Consumers in both the survey and focus groups had a wide-range of questions:
 - How effective is personalized medicine? What is the success rate, track record, history?
 - How accurate are predictions?
 - What are the negatives—are there risks or side effects?
 - How much does it cost? Will insurers cover it?
 - How will the test or procedure be performed? What does it involve?
 - What are the advantages or benefits? Could I benefit?
 - How will data be used?
- **Most consumers would be willing to have a diagnostic test for purposes of personalizing prevention or treatment.** Should their doctor recommend personalized medicine, a large majority (77%) say they would be very (37%) or somewhat (40%) likely to have a diagnostic test to use for developing a personalized prevention or treatment plan.

WHAT THE RESPONDENTS SAID:

Is there anything about personalized medicine that is particularly exciting?

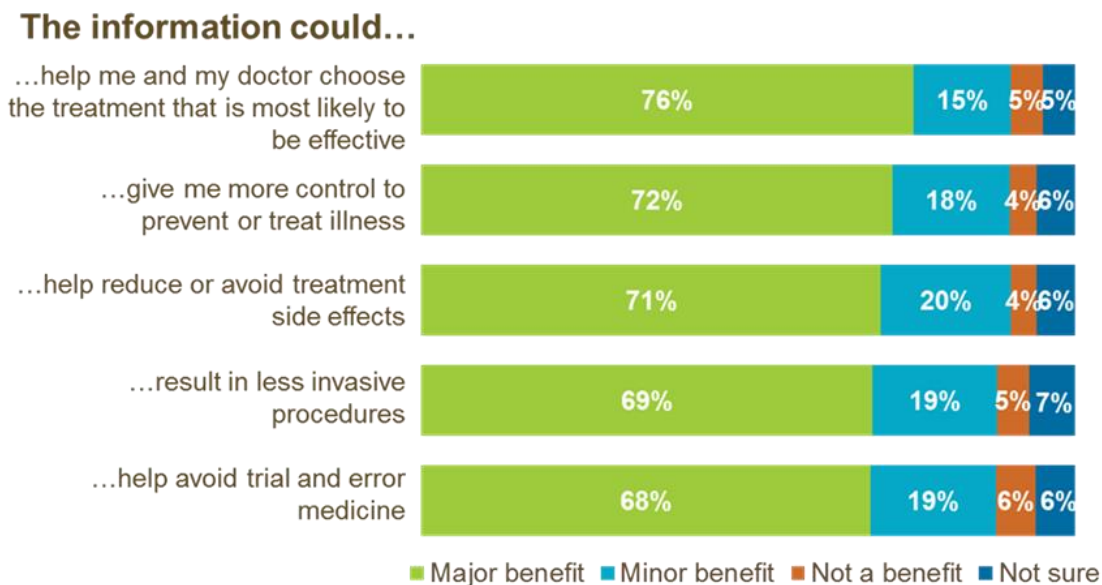
"The idea of potentially curing or fixing medical conditions that might not otherwise be easily cured or may have significant side-effects using more traditional medical means." – Survey respondent

"Mostly that meds and treatments will be customized to my personal needs. Meds and treatments will be more targeted, thus reducing taking excess and unnecessary meds and treatments." – Survey respondent

"I like to know all the information I can possibly know if I'm going into something big so it gives you one more tool to decide which way, then that's helpful to me." –Focus group respondent

- **The idea that personalized medicine can provide useful prevention and treatment information, help avoid or reduce side effects, avoid trial-and-error medicine, and give more control to prevent or treat illness are very compelling benefits.** Unaided, consumers said they felt excited about the potential for individualized testing and treatments, prevention and early detection, and the ability to predict and have better information for decision-making.
- **When given a list of five benefits, large majorities felt all were major benefits for them personally.** Consumers were particularly optimistic about the possibility of having information to help choose a treatment that is most likely to be effective and gaining more personal control to prevent or treat illness. In our focus groups, consumers discussed the importance of having a doctor who is well informed about a patient’s individual health, as well as that of their family. Consumers said they would appreciate having an added tool to help in difficult decision-making in partnership with and under the guidance of their personal physician.

Benefits of Personalized Medicine



"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."

- **Access and affordability are the biggest concerns.** Three-quarters (74%) say they have no concerns when asked if there is anything worrisome about personalized medicine. The main unaided concerns are about risks of potential side effects and costs. Only 3% mentioned privacy concerns.

When read a list of concerns, access and affordability – fear that insurers won’t cover it (69%) or patients can’t afford it (67%)—are major concerns. Other major concerns are that the information could be used to deny coverage for a treatment a patient wants (55%) and personal information could be used against a patient (47%).

WHAT THE RESPONDENTS SAID:
Is there anything about personalized medicine that is particularly worrisome?

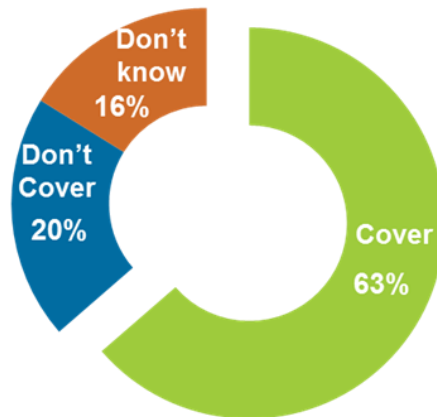
"Cost—if it's too high; and, could the information garnered be used against you at some point?"
 –Survey respondent

"The big fear is, is insurance going to cover this genetic test?" –Focus group participant

- **A majority of consumers believe health insurance should cover personalized medicine tests and treatments, even if they are more expensive than conventional ones.** When given arguments for why personalized medicine should or should not be covered by insurance (shown below), two-thirds support covering personalized medicine tests and treatments over not covering them. In focus group discussions, consumers discussed the trade-offs related to up-front costs and potential long-term savings. Consensus in the focus groups was even stronger that if a doctor prescribes personalized medicine, insurance should cover it.

Coverage of Personalized Medicine

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.

"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."

WHAT THE RESPONDENTS SAID:

Comments About Benefits, Cost, and Coverage

"I think the medical professional should be the driver." –Focus group participant

"Based on the long run that they might be of more value to the patients, I think it might be a good thing and I still want to have the choice. [T]he insurance company should be able to pay for it so that I can have that test and have that choice of making the decision with more information." –Focus group participant

"They should look at a cost benefit. If I'm going to take a \$1,000 test and it's going to save us \$20,000 over the next five years, take the test." –Focus group participant

To learn more, visit www.PersonalizedMedicineCoalition.org. Full survey questionnaire available upon request.

ⁱ KRC Research conducted a nationally representative telephone survey (landline and mobile phone) of 1,024 **American adults age 18 and older**. The survey was conducted **March 5-16, 2014**. Interviews were conducted in English. The margin of error for the total sample is **plus or minus 3 percentage points**.