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# PUBLIC PERSPECTIVES ON PERSONALIZED MEDICINE

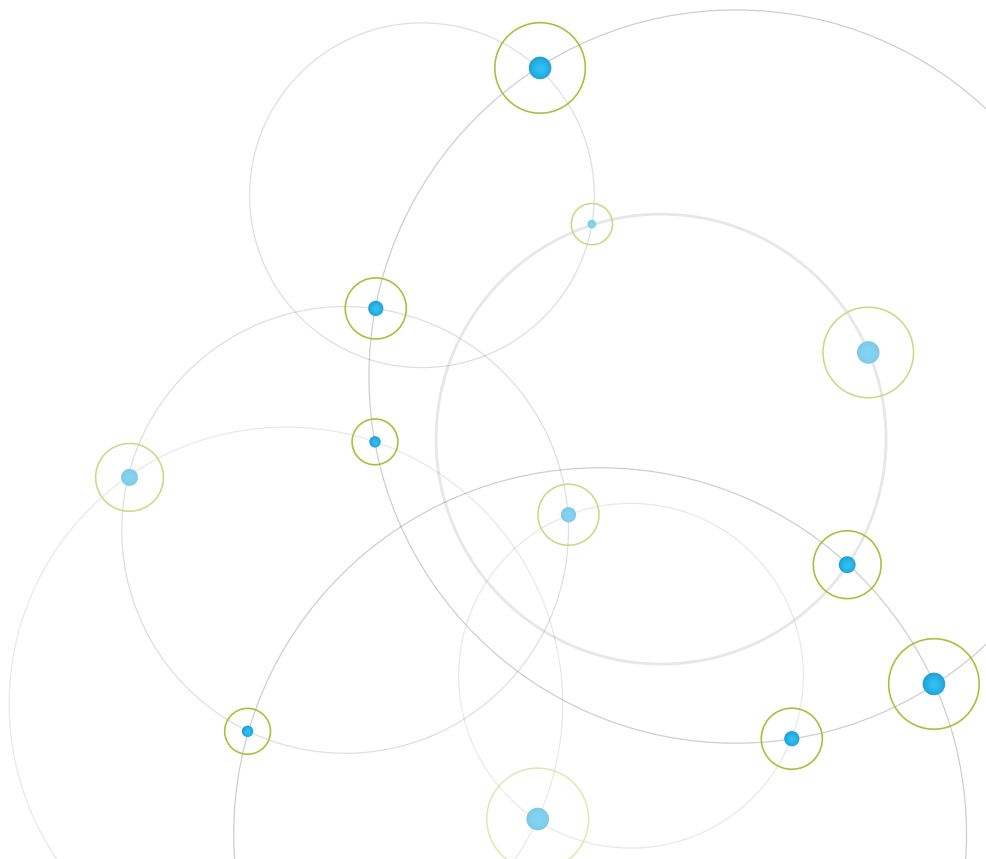
A Survey of U.S. Public Opinion

MAY 2018

Conducted for



Conducted by



# KEY FINDINGS

1. Most Americans are not familiar with personalized medicine. The vast majority want to learn more about it.
2. When personalized medicine is described to Americans, most are excited about the field's potential.
3. Most Americans believe insurance companies should pay for personalized tests and treatments.
4. Some Americans have concerns about personalized medicine. Most of these concerns are related to insurance coverage, costs and the potential for discrimination based on personal health data. Most are not aware of the privacy protections in place to protect patients from discrimination.

# A NEW PARADIGM

Personalized medicines now account for one of every four new drugs approved by the U.S. Food and Drug Administration (FDA). Each of these products is designed for a small population of patients that is highly likely to benefit from the treatment based on the presence of measurable biological characteristics. As such, the therapies are designed to increase the percentage of patients who are actually helped by the treatments they are prescribed, making health care more efficient and effective.

But because personalized medicines and the tests needed to inform their use break the mold of a health system that was optimized to deliver medicine based on population averages, the incoming wave of personalized medicines presents challenges related to regulation, reimbursement and clinical adoption. These challenges are often compounded by the fact that personalized medicine presents a different value proposition than the traditional one-size-fits-all model.

Understanding the extent to which the American public is informed about and supportive of the personalized medicine paradigm can thereby help decision-makers in the public and private sectors consider and communicate about policies and practices that may influence the pace at which personalized medicines are integrated into the health system.

To better understand the American public's perspectives on personalized medicine, the Personalized Medicine Coalition and *GenomeWeb* commissioned KRC Research to conduct a representative survey of 1,001 Americans in the Spring of 2018 to measure awareness of and opinions about the field and its stated benefits.

The results of the survey demonstrate that most Americans are not familiar with the concept of personalized medicine. After reviewing information about its benefits, however, the majority of Americans are excited about the field and want to learn more about it. Most believe insurance companies should cover personalized tests and treatments. Some have concerns about the field, which are often related to insurance coverage, costs and the potential for discrimination based on health data. Most are not aware of the Genetic Information Nondiscrimination Act, which prohibits the use of genetic data for certain discriminatory purposes.

# LIMITED AWARENESS

## Most Americans are Not Familiar with Personalized Medicine

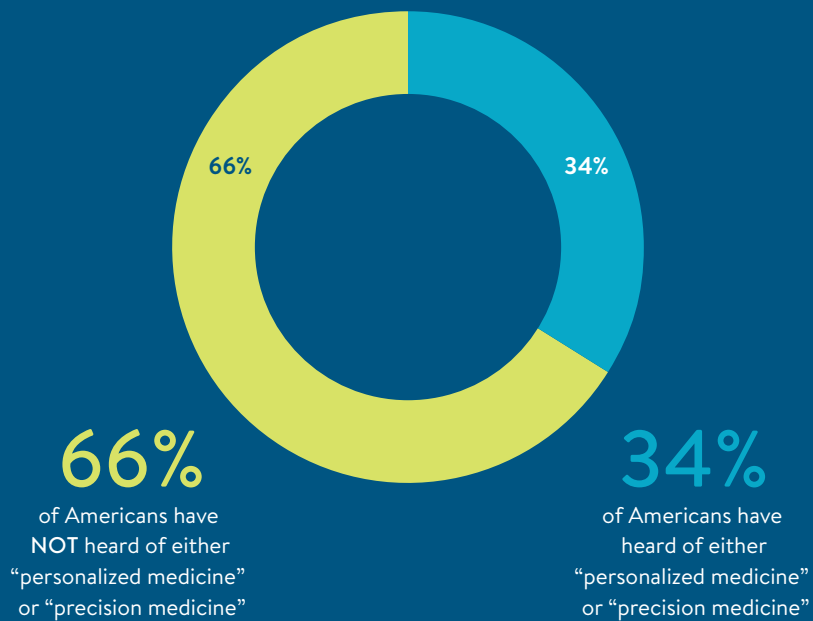
Most Americans are not familiar with personalized medicine. Sixty-six percent of adults living in the United States say they have never heard or read anything about “personalized medicine” or “precision medicine.” Among those who have heard of it, only 13 percent feel “very informed” about the topic. Only 9 percent of respondents said they had heard of the federal government’s flagship program in personalized medicine, called the *All of Us*™ Research Program, and only 10 percent said a medical provider has recommended a genetic test to them. Seventeen percent have heard of genetic counseling, but only 4 percent have spoken to a genetic counselor.

The vast majority of respondents want to learn more about personalized medicine. In fact, 82 percent of U.S. adults reported an interest in more information about the field, and 32 percent said they are “very interested.”

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## Most Americans Have Not Heard of Either “Personalized Medicine” or “Precision Medicine”



These results were derived from the following question:

Which of the following terms have you heard or read something about prior to today?

Please select all that apply.

- Personalized medicine
- Precision medicine

# POSITIVE REACTIONS

## When Personalized Medicine is Described to Americans, Most are Excited About Its Potential

Once they learn about personalized medicine, most Americans are enthusiastic about its potential. In fact, 67 percent of respondents reacted positively to a description of the field. Thirty-two percent were neutral. Only one percent reacted negatively.

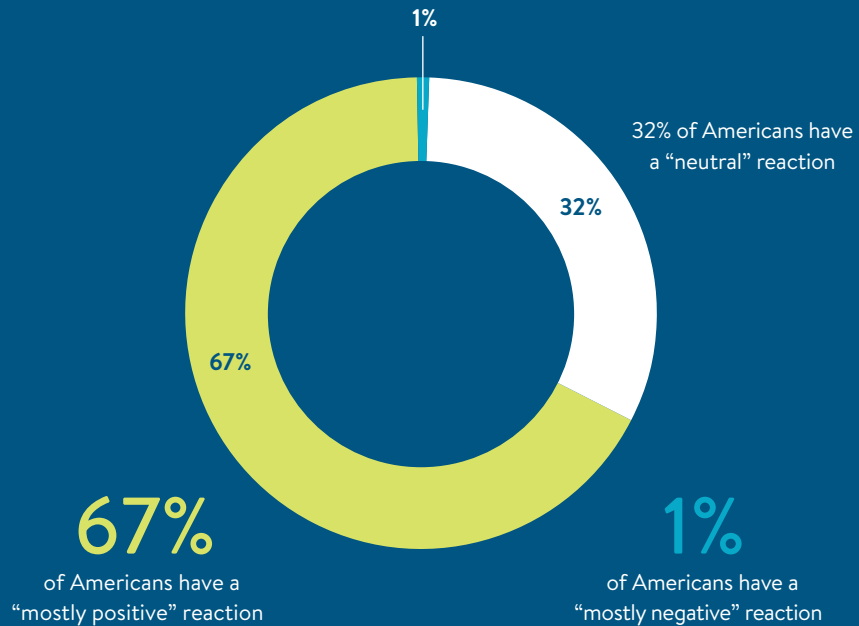
### Description of Personalized Medicine

Personalized medicine, sometimes referred to as precision 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 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.**

## Most Americans React Positively to a Description of Personalized Medicine



These results were derived from the following question:

What is your reaction to the description of personalized medicine?\*

- Mostly positive
- Neutral
- Mostly negative

\*See description at left

# SUPPORT FOR COVERAGE

## Seeing ‘Major’ Benefits, Most Americans Believe Insurers Should Cover Personalized Medicine

Most Americans believe health insurance companies should cover personalized tests and treatments. Two-thirds (67 percent) believe personalized tests and treatments should be covered. The other third believes payers should not cover personalized medicine because health care costs are already too high. Those who are over age 65 and those who have faced or had a loved one face a life-threatening disease are more likely to believe that the tests and treatments should be covered.

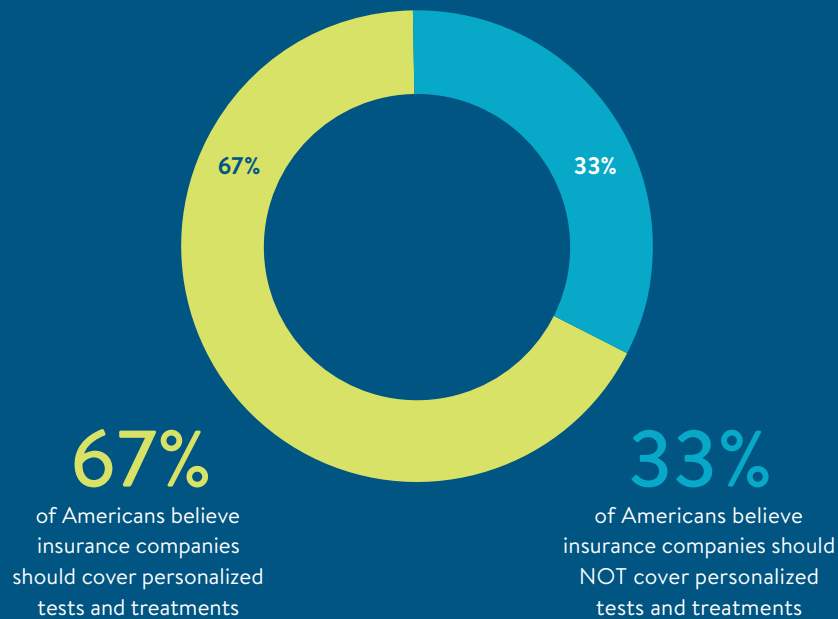
The support for coverage likely reflects the fact that most Americans are excited by the potential of personalized medicine. Survey respondents saw “major” benefits, for example, in opportunities to improve upon the trial-and-error treatment process (70 percent), reduce the need for invasive procedures (67 percent), reduce adverse side effects (65 percent) and shift the emphasis in medicine from reaction to prevention (64 percent).

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## Most Americans Believe Insurance Companies Should Cover Personalized Tests and Treatments



These results were derived from the following question:

Because personalized tests and treatments are targeted to a small number of patients, they are sometimes more expensive than conventional tests and treatments. With that in mind, read these two statements. Of the two statements, which one is closest to your own personal opinion?

- Personalized tests and treatments deliver more value to patients and may help control overall health care spending by avoiding the trial-and-error process currently used to find a treatment that works for each patient. Therefore, health insurance companies should cover these tests and treatments.
- 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 personalized tests and treatments.

# EMERGING CONCERNS

## Some Americans Have Coverage, Affordability and Privacy Concerns Related to Personalized Medicine

Although most Americans had no worries about personalized medicine when asked, 44 percent raised questions related to topics including side effects, safety and privacy of personal genetic information. When shown a list of known concerns, most said they have major concerns that a test might not be covered by their insurer (62 percent), they might not be able to afford personalized medicine (59 percent), or that test results could be used to deny coverage for a treatment (52 percent) or affect long-term care or life insurance policies (51 percent). Only 10 percent of Americans indicated that they are aware of the Genetic Information Nondiscrimination Act, which prohibits employers or health insurers from asking for genetic test results when making employment or coverage decisions.

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## Americans Cite ‘Major’ Concerns Related to Access, Cost and Privacy

The test might not be covered by my insurer.

62%

The test could be used to deny coverage for a treatment I want.

52%

I might not be able to afford a personalized approach to health care.

59%

Information about my risk for developing a disease in the future could be used to deny long-term care or life insurance that I need.

51%

### ■ Americans Expressing “Major” Concern

These results were derived from the following question:

Here are some reasons some people give for why they worry about personalized medicine. For each one, please indicate how much of a concern it would be for you personally.

[CHOICES: Major Concern; Minor Concern; Not a Concern; Not Sure]

- The test might not be covered by my insurer.
- The test could be used to deny coverage for a treatment I want.
- I might not be able to afford a personalized approach to health care.
- Information about my risk for developing a disease in the future could be used to deny long-term care or life insurance that I need.

# CONCLUSION

## Strong Public Support for Personalized Medicine

The survey results show strong public support for personalized medicine. Americans are quick to recognize the shortcomings of the trial-and-error processes by which most treatment decisions are made today, and see value in tools that can quickly identify which treatment is right for a patient. Influenced but undeterred by cost and privacy concerns, most Americans believe the benefits of personalized medicine warrant coverage of tests and treatments even when they are associated with higher up-front costs.

The results indicate that innovative efforts on behalf of policymakers to facilitate greater access to personalized medicine would be well-received by the American public. They also point to a need for public education about the field, particularly as new personalized medicines enter the market.

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## ABOUT US



**The Personalized Medicine Coalition (PMC)**, representing innovators, scientists, patients, providers and payers, promotes the understanding and adoption of personalized medicine concepts, services and products to benefit patients and the health system.



**GenomeWeb** is an independent online news organization based in New York. Since 1997, *GenomeWeb* has served the global community of scientists, technology professionals, and executives who use and develop the latest advanced tools in molecular biology research and molecular diagnostics.





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