WASHINGTON—At a time when oncology leads U.S. health care in molecular diagnostics and targeted therapies, new survey data from the Personalized Medicine Coalition (PMC), show that two-thirds of Americans have never even heard of personalized medicine. However, when personalized medicine—i.e., also variously called precision medicine or individualized medicine—is explained, the survey showed that 65 percent of Americans do indicate that they recognize the potential benefits to patients and want to learn more.

As one survey respondent put it, what is most compelling is “that meds and treatments will be customized to my personal needs. Meds and treatments will be more targeted, thus reducing excess and unnecessary meds and treatments.”

According to figures cited by PMC in the 2014 edition of its “The Case for Personalized Medicine” report, the percentage of cancers driven by genetic mutations that could be drug targets include:
- Melanoma, 73 percent;
- Thyroid, 56 percent;
- Colorectal, 51 percent;
- Endometrial, 43 percent;
- Lung, 41 percent;
- Pancreatic, 41 percent; and
- Breast, 32 percent.

Speaking at the National Press Club here at a news briefing to release the findings, Mark Richards, PhD, Senior Vice President and Management Supervisor at KRC Research, which conducted the survey for the PMC, explained that the data come from a 25-minute nationally representative telephone survey (landline and mobile phone) of 1,024 American adults age 18 and older, which was conducted in English in March of this year.

He said that while the proportion of survey respondents who know about personalized medicine is lower than four in 10, when the definition was explained to them, “most people reacted to the idea very positively.” He added, “Their goal is to get well...This is something that is not a dream any more.” So anything that can help patients set priorities in their health care decision-making process is valuable to them.

The survey sample was “in proportion to U.S. census data,” he said, and was roughly 50/50 in gender representation.

Specific Findings
The data from the new PMC survey show that:
- Among respondents who have heard the term “personalized medicine,” only 16 percent feel very informed about what it is.

Access and affordability are the chief concerns of respondents when they understand what personalized medicine is. Some 69 percent said they feared insurers would not cover personalized therapies and 67 percent said they feared patients could not afford them.

Patient advocate Donna Cryer, JD, President and CEO of the Global Liver Institute, said that she had benefited personally from personalized medicine.

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as a patient with multiple autoimmune diseases. Still, she did not hear about it from her physician, she noted. “As a patient I think there’s a lot of work for us to do” in consumer education, she said.

‘Exploding’
Consumers need to understand the benefits of personalized therapies because tools for genetic sequencing and testing “are exploding at the present time,” said another speaker, Raju Kucherlapati, PhD, the Paul C. Cabot Professor in the Department of Genetics at Harvard Medical School and Professor in the Department of Medicine at Brigham and Women’s Hospital.

He said that largely because of the sequencing of the human genome and the increasing affordability of genetic testing, he considers this “the golden age of discovery.” Patients need to know about these new discoveries so they can become excited: “We need to be able to show the public where we are.”

Kucherlapati, along with Richards, noted that the general public responds best to specific examples of personalized medicine at work—such as, for instance, the story of a cancer patient who was treated with a targeted therapy and experienced a remission.

Upcoming Study
Looking ahead, the PMC plans to commission a study on the number of personalized therapies in the pipeline and issues relating to them, said PMC President Edward Abrahams, PhD.

The new survey data also underscore how important it is for the pharmaceutical industry to demonstrate its commitment to the science undergirding personalized medicine, noted Randy Burkholder, Vice President for Policy at the Pharmaceutical Research and Manufacturers of America (PhRMA). There was a phase in the past where the pharmaceutical industry was not seeing the fruit of personalized medicine in its research pipeline and thus was not as enthusiastic as it could have been, he acknowledged. But, he said, the measure of the industry’s commitment to targeted therapies was its willingness to accept the fact that there would be a lag time between a scientific breakthrough and its translation into patient care.

Burkholder cited oncology as having a high number of targeted drugs today, especially for melanoma and lung cancer. Indeed, targeted therapeutics are being approved by the U.S. Food and Drug Administration “in steady succession,” notes the PMC, and hundreds of targeted therapies are in Phase I, II, and III trials worldwide. “These are significant steps forward,” Burkholder said. “I think we’re going to see more and more.”

He predicted that in a few years there would be an even greater number of new targeted therapies entering the medical marketplace. In recognition of the growth of personalized therapeutics, FDA released a 60-page report in October 2013 called “Paving the Way for Personalized Medicine: FDA’s Role in a New Era of Medical Product Development.” The agency has stated its intention to support rapid advancements in genomic medicine.

Insurance Coverage
Another PMC report shows that respondents to the survey who expressed concern about insurance coverage of personalized tests and therapies are right to be concerned. The new report, “The Future of Coverage and Payment for Personalized Medicine Diagnostics,” released in July, cites the following as potential future problems for personalized medicine:

• Imminent federal pricing of highly innovative molecular tests, which could result in lower reimbursement levels, especially for Medicare;
• Inconsistent standards and paradigms for evaluating diagnostic, prognostic, and predictive genomic tests, since assessment of “clinical utility” for such tests is “neither clear nor predictable,” according to the report; and
• A lack of incentives for the development of genomic medicine, since traditional funding, pricing, or reimbursement systems are not geared to genomic medicine.

In order for molecularly targeted genomic medicine to move forward and fulfill the “golden age of discovery” cited at the briefing, the PMC report recommends funding the education of physicians and patients in personalized medicine; funding allied health professionals such as genetic counselors; and creating incentives to develop new tools that have the potential to revolutionize some therapeutic areas—for example, understanding the role of a gene in human drug metabolism and clinical outcomes.