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## Interview

## Interview with Carolyn M. Clancy, MD

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**Brian Powers: You have led AHRQ for almost a decade. What do you consider to be the Agency's greatest accomplishments during that time?**

**Carolyn Clancy:** There are a few I would like to highlight. First, I am very proud of the work we have done to make sure that the patient voice is a key part of how we assess quality of care. Compared to the early days of the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAPHS), it is remarkable that we are now at a time when 25–30% of value-based purchasing is based on those data. It is a real sea change. I am also proud of several initiatives we have launched over the past decade such as the National Health Care Quality and Disparities reports and the AHRQ Innovations Exchange. We have also become much more transparent in everything that we do. From U.S. Preventive Services Task Force recommendations to policy analysis, our deliberations and processes are more open than they were a decade ago. Finally, as a nation, we are really starting to make important and sustained progress in making care safer. And that has been particularly gratifying to see.

**BP: Is there anything you wished had gone differently?**

**CC:** I wish the nation had made more headway in reducing disparities. That being said, I was excited to hear about a recent study that found that from 2005 to 2010 disparities for black and Latino populations in CMS Hospital Compare data narrowed. This suggests that increased transparency is changing behavior, but that is only part of the solution.

**Katy B. Kozhimannil: Continuing on the topic of AHRQ's commitment to reducing disparities, how does patient-centered research integrate with AHRQ's focus on priority populations?**

**CC:** In our work on patient engagement we have learned a lot about engaging individual patients, but we have also learned about the importance of engaging communities of patients. This has a very big impact on the research that we do, especially for our priority populations. One example is our campaign with the AdCouncil to

encourage patients to take a more active role in their care. Based on focus groups and message testing, we found that different messages are effective for different groups. The only way to know how to best reach a community is to engage with that community and ask them. That process continues to shape our work.

**KBK: How has AHRQ been working to incorporate the patient perspective into its research and implementation efforts?**

**CC:** AHRQ does an enormous amount of work in patient engagement; it is an integral component for all of our Centers. One of the biggest changes we have made is to always bring articulate, informed consumers in the room for our discussions. It is a complete game changer. We have learned a lot about how best to present research, and how to structure discussions in a way that promotes meaningful dialogue for all stakeholders, but we still have not perfected it.

**KBK: What challenges have you faced when trying to better incorporate the patient perspective into health care quality and decisions?**

**CC:** Both physicians and patients are enthusiastic about patient-centered care, but they have different perspectives about boundaries. For complex and chronic conditions, providers understand the importance of patient engagement and the value of patient preferences and patient-reported outcomes. But providers are not sure about whether they should be assessed based on patient perspectives. And whether patients should be able to judge clinical quality is far more controversial. Patients, too, have a guarded enthusiasm. They value shared decision-making and being part of the discussion, but want to be careful not to anger physicians on whom they depend for their care.

**BP: AHRQ is tasked by Congress to disseminate research findings to patients and providers. How have you been approaching this mandate and what challenges have you encountered?**

**CC:** We have a wide variety of dissemination activities. Some dissemination efforts are practical, such as the AdCouncil work I spoke about earlier. These involve dedicated work with experts in communication and decision sciences. Through this work, we have

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learned that disseminating research findings to the public goes beyond simply providing results. Patients may not have reliable access to comprehensive health care resources, so they have been particularly interested in guidance, materials, and products. In addition to summarizing research findings, we include questions for patients to consider for the next stage of their health care journey with the hope that they can plan a more active role in their care.

Much of our other work centers on studying strategies for dissemination. And this is where more improvement is needed. We funded the study that found it takes 17 years to turn 14% of original research findings to the benefit of patient care. But we have not been particularly successful in learning how to accelerate the timelines of adoption. We are starting to gain a better understanding, and I have been particularly impressed by how much health care professional organizations want to be part of the solution.

**KBK: How is the work of the Patient-Centered Outcomes Research Institute (PCORI) integrating with that already underway at AHRQ? Are you discovering any tensions or redundancies?**

**CC:** When creating PCORI, Congress was incredibly wise to require that the heads of NIH and AHRQ sit on the board of governors and methodology committee. Both sides recognize that in a time of increasing worry about the economy and debt, we cannot spend one dollar for work that is already being done. The federal government has an infrastructure to track current and ongoing research. But, as an independent entity, PCORI does not have that same knowledge. So we have been working closely together to help prevent duplication.

Occasionally there is a bit of creative tension, in cases where we are both doing similar things and struggle to articulate how initiatives are synergistic. But PCORI has made great progress in patient engagement and helping to discern which practices actually engage patients better than others. By and large, the whole enterprise works really well. A challenge for PCORI is to build a research infrastructure from scratch. We want to be as

helpful as we can in allowing PCORI to utilize our existing infrastructure where that makes sense so that their work can be as efficient as possible. For example, the data infrastructure work we started with funds from the Recovery Act has built an infrastructure that can be leveraged by PCORI and many others.

Ultimately, the work of PCORI fits in to our broader mandate to disseminate all research findings on comparative effectiveness and health care quality. We will have to contextualize results from PCORI studies, and help explain how they fit in to existing research.

**KBK: How do you see the role of AHRQ evolving as the Affordable Care Act (ACA) is implemented and nationwide efforts at reform continue?**

**CC:** For years I have been really excited about the work we have done on improving quality and safety. But we always faced a key challenge: how does a science agency actually partner with others to promote change? Fortunately, the ACA sets the stage for AHRQ to engage with others. For example, the Partnership for Patients has effectively created a nationwide distribution network for our dissemination efforts. And the National Quality Strategy has provided a framework to structure our work with the Centers for Medicare & Medicaid Services, the Office of the National Coordinator for Health IT, and the private sector.

The ACA does a lot to ensure that Americans have access to quality health care coverage. I think AHRQ and the rest of the field need to take the ball home in terms of making sure that the promise of expanded coverage can be maintained through work to create a more sustainable and reliable delivery system.

**KBK: As you transition to the next stage of your career, what are the key challenges you will focus on addressing?**

**CC:** There's no question that I'll remain deeply involved in quality and safety, and in figuring out what exactly patient-centered and patient-driven really mean. One thing I have come to realize is that the closer we come to bringing our information to where clinicians make their decisions, the more eager I have been to move to the other side. So you can watch that space!