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### Title

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### Permalink

<https://escholarship.org/uc/item/8gm1165k>

### Journal

The Permanente journal, 20(2)

### ISSN

1552-5767

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### Publication Date

2016

### DOI

10.7812/tpp/15-123

Peer reviewed

# The Language of Engagement: “Aha!” Moments from Engaging Patients and Community Partners in Two Pilot Projects of the Patient-Centered Outcomes Research Institute

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Perm J 2016 Spring;20(2):89-92

<http://dx.doi.org/10.7812/TPP/15-123>

## ABSTRACT

Compared with people living in the community, researchers often have different frameworks or paradigms for thinking about health and wellness. These differing frameworks are often accompanied by differences in terminology or language. The purpose of this commentary is to describe some of our “Aha!” moments from conducting two pilot studies funded by the Patient-Centered Outcomes Research Institute. Over time, we came to understand how our language and word choices may have been acting as a wedge between ourselves and our community research partners. We learned that fruitful collaborative work must attend to the creation of a common language, which we refer to as the *language of engagement*. Such patient-centered language can effectively build a bridge between researchers and community partners. We encourage other researchers to think critically about their cultural competency, to be mindful of the social power dynamics between patient and physician, to reflect on how their understanding might differ from those of their patient partners, and to find ways to use a common language that engages patients and other community partners.

## INTRODUCTION

Community-based participatory research involves collaboration. All partners (such as researchers, administrators, health care providers, patients, elected officials, community leaders, and ordinary citizens) are equally involved in the research process, and everyone has a unique strength and contribution to a research project.<sup>1</sup> Both of the pilot studies discussed in this commentary are examples of participatory research, and both are examples of the importance of finding a language of engagement for working with patients and community partners. In a study of mental health needs in the Mississippi River Delta Region,<sup>2</sup> funded by the Patient-Centered Outcomes Research Institute (PCORI), our team of researchers learned the importance of word choice in building relationships with community partners, often referred to as stakeholders. The purpose of this pilot project was to compare

and to contrast the use of focus groups and community forums to gather information from community leaders and ordinary citizens on their perspective of the mental health needs in their community. It was clear that differences in language signaled substantial differences in knowledge, attitudes, and underlying beliefs. For example, when we asked about their opinions on mental health, one of the community stakeholders replied:

“No one is going to talk to you about mental health. When people hear mental health they think of crazy... . I don't know how to help you help crazy people ... . If you want my expertise, you have to ask me about things I know about.”

In another PCORI project, aimed at creating a zone of openness to increase patient-centered communication between patients and primary care physicians,<sup>3</sup> we engaged with patients and clinicians in the San Francisco Bay Area to co-create an intervention with us. On the basis of our previous research that found patients to be uncomfortable about disagreeing with their physicians,<sup>4,5</sup> we invited patient stakeholders to react to our plan to help patients and clinicians get better at *disagreeing* with each other. One patient stakeholder told us, “You wouldn't want to encourage patients to disagree with their doctors,” and a physician stakeholder said, “I am uncomfortable about encouraging patients to disagree with their doctors.”

The Patient Protection and Affordable Care Act established PCORI to fund comparative clinical effectiveness research to assist patients, clinicians, and other health care decision makers in making informed health decisions.<sup>6</sup> As of August 2015, PCORI had approved more than one billion dollars in research funding since its inception, starting with 50 pilot projects to support the collection of preliminary data on methods that can be used to advance the field of patient-centered clinical effectiveness research. “Research done differently” has been PCORI's approach in its first 3 years. PCORI requires significant engagement with stakeholders, patient and community stakeholders in particular, in all stages of the research effort. Some investigators have questioned the value of engagement or the need for such an explicit requirement. Typically, the

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response to such questioning offers points related to the big picture; for example, interventions or treatment approaches developed in partnership may increase the chance of producing culturally appropriate, effective, and sustainable interventions.<sup>7</sup>

Our engagements with diverse stakeholder groups supported by PCORI and other funders have prompted us to critically analyze how our enculturation into biomedical theory and practice has shaped the language we use. As we have come to realize, we learn what Putsch and Joyce<sup>8</sup> refer to as “the language of biologically based and somatically focused health care.” This language is rooted in the scientific tradition, which is characterized by objectivity and rational thought. Biomedical language, similar to other languages, is complex, has its own jargon and specialized terminology, and conveys authority and power. Our work has taught us that patient and community members use diverse language to describe their health and ascribe meaning to their experience of illness. This language is shaped by cultural beliefs about illness and healing, by philosophies of self-actualization, and, in varying ways, by biomedical understandings of disease and curing.<sup>9</sup> For those health conditions that are stigmatized, such as mental illness, the language can be shaped by stigma, which has long been known to be pervasive and powerful.<sup>10-12</sup> Thus, the language we learn through our academic and medical training can limit our understanding of patients’ subjective experiences of health, which extend beyond the absence of disease and encompass a broader, more holistic sense of well-being.

In our effort to activate patients and physicians to fully engage in shared medical decision making, we recognized that our mindset and the language we use can act as a wedge between ourselves and the patient populations we serve. It is critical that researchers be sensitive and make the effort to understand whether a language gap exists and, if so, to agree upon a language that is acceptable to community members, patients or other partners, and researchers.

The cases presented above, each from PCORI pilot projects conducted in different institutions, emerged from the engagement experiences of investigators and can be seen as “Aha!” moments related to language for each of the research teams. We aim to describe the observations that illustrate the need for a more fine-grained understanding of the advantages of partnering with the patient populations we serve. We wish to share the importance of creating a language of engagement across stakeholder groups and heightened mindfulness among ourselves as researchers.

## METHODS AND RESULTS

### Assessing Mental Health Needs among Rural African Americans

The PCORI project Assessing Mental Health Needs compared two methods for obtaining community perspectives on the mental health needs of rural African Americans in the Arkansas Delta Region. The researchers on our team engaged the community stakeholders through focus groups, a common method researchers use to collect qualitative data from preselected participants of a specific group—for example,

with clergy and with members of faith communities. At the same time, our community partner conducted deliberative democracy forums, a method used to obtain informed public opinion and input from “ordinary citizens.” As a grassroots organization, they have used this method to better understand community perspectives and mobilize the community for social change. Whereas one objective of the study was to compare the process and outcomes of the two methods of engaging stakeholders in the research process, the other was to generate ideas for interventions to address the mental health needs in the community.

In developing the interview guide for the focus groups and the issue book for the forums, we sought input from our Community Advisory Board (CAB), a 12-member group consisting of community advocates, members of the clergy, community-based clinicians, local college students, and persons living with mental illness. We asked the CAB to help us write a definition of *mental illness* that would be understood by community members. CAB members told us we needed to step back and consider the term *mental illness* itself. CAB members considered *mental illness* a negative term and preferred the more positive term *emotional wellness*. CAB members pointed out that *mental* carries a negative, stigmatizing connotation, even when used to refer to good mental health. The CAB felt that *emotional wellness* implied a more holistic state of health that could speak to the community’s view of physical, spiritual, and mental health as interconnected. After engaging in this discussion and agreeing on a common terminology, we then were able to move on to define the term *emotional un-wellness*. Had we not understood and been sensitive to the language of the community, we would have risked alienating rather than engaging community members. From this pilot study, we learned that community members and leaders 1) understand that stress from poverty and racism are directly related to mental health, 2) are concerned about widespread stigma with mental illness, and 3) feel that community members do not effectively identify mental health problems requiring treatment.

### Creating a Zone of Openness to Increase Patient-Centered Communication (Open Communication)

Our other PCORI-funded study, the Open Communication study, was designed to address several key gaps in patient-physician communication initially gleaned from patient focus groups and subsequently confirmed in a large survey.<sup>4,5</sup> The findings from these studies suggested that although patients reported feeling generally comfortable about raising questions and expressing their preferences, they were much less comfortable about disagreeing with their physicians, indicating a substantial barrier to shared medical decision making.<sup>4,5</sup>

The Open Communication study engaged 12 research partners with equal representation of patients, physicians, and clinical staff, including a nurse, two medical assistants, and a clinical department manager. Following user-centered design principles,<sup>13</sup> we engaged in extensive discussions with the patient and physician partners about communication challenges in real-life clinical practice to design intervention tools

that would be acceptable to all stakeholders. We also leveraged insights from the scientific literature on patient-physician communication to guide our efforts to create an environment that could enable patients to feel comfortable asking questions<sup>14</sup> and expressing their preferences even when they were contrary to the clinician’s recommendation. Adopting the “deep-dive” technique used to rapidly immerse a group into a situation for problem solving or idea creation, we engaged our research partners in a series of 2-hour workshops. It was in these workshops that we learned that the language we had intended to use to encourage patients to speak up when they disagree with their physicians—for example, “I respectfully disagree”—could be counterproductive. Upon hearing several patients and clinicians advising against the use of the word disagree, we decided to invite our patient and physician partners to brainstorm with us on how we might best support patients in expressing their views that can be different from those held by their physicians. After multiple iterations, we were able to develop a 1-page Visit Companion Booklet, a communication tool that enables patients to state what is important to them and jointly set an agenda with their physicians. We also designed a short (2.5 minutes) animated video. Rather than encouraging patients to disagree with their physicians when their opinions differ, the narrator in the video reassured: “We want to know when you are uncomfortable about a treatment. It’s okay to interrupt. If something makes you feel uncomfortable, there are often other options we can try.” The video then portrayed a conversation between a patient and a physician in which the patient asked, “Is there something else I can try?”

Engagement with physician stakeholders enabled us to design a communication coaching program delivered by standardized patient instructors.<sup>15</sup> The standardized patient instructor portrayed a patient who resisted an approach that her physician had prescribed and asked about other options. The standardized patient instructor also provides a safe space for the physician to practice communicating with empathy and patience when a patient wants something different from what the clinician would prescribe—that is, other *options*. This multidimensional approach addresses *disagreement* without using language that could introduce friction in the patient-physician relationship. By discussing *options*, we focus on the choices available from which the patient and physician can choose collaboratively.

## DISCUSSION

These two research projects illustrate how important language is to building relationships between various stakeholder groups. In some ways, each stakeholder group is embedded in its own culture that is reflected in the language and terminology commonly used by that group. We did not initiate either of our pilot projects with an intention to address language per se, but we learned that agreement on specific words or terms was an important first step in engaging patients and community stakeholders.

Many of us had been speaking in the community for years and using the term *mental illness* without recognizing that we

may have been, at the very best, having little impact, and at the very worst, alienating our audiences and acting as a wedge between ourselves and our community research partners. Had we not had this input from our community advisors, the Assessing Mental Health Needs study would have proceeded to use the term *mental illness* in the study. Likewise, had the Open Communication study not solicited the insights from patients and clinicians, it could have given the impression that the project encourages patients to disagree with their physicians. Using these terms (*mental illness* and *disagree*) could have placed a wedge between us and our community partners, therefore decreasing the likelihood of our being able to engage with community members and groups and producing meaningful study findings. When agreement on terminology is reached in a mutual way, this can effectively build a bridge between researchers and stakeholder groups.

## CONCLUSION

The goal of this commentary is to encourage researchers to carefully consider the language and terminology used in their work with communities. We encourage researchers to think critically about their own mindset and how their understanding of health and wellness might differ from that of their patients, to incorporate patients’ subjective understanding of illness and disability into treatment programs, and to find ways to build bridges that lead to improved patient-physician interactions and to enhance patient well-being.

By allowing patients, physicians, and community partners to be equal participants in the design of our projects and the language of our projects, we were reminded of the obvious: that patient and community stakeholders and researchers often have different frameworks or paradigms for thinking about health, wellness, and their relationship with health care providers. These differing frameworks are often accompanied by different terminology or language. Fruitful collaborative work needs to attend to the creation of a common language, which we refer to as the *language of engagement*. More importantly, through engagement with our patient and community stakeholders, changes were made in our research approach that enhanced our ability to work in partnership with our respective communities or stakeholders.

## Implications for Policy or Practice

Health care services are undergoing fundamental transformations. Engaging stakeholders in all phases of research has led to patient-centered design processes that have the potential to develop interventions that could empower both patients and clinicians to communicate more openly and more effectively.

It is time to transform our mindset from “the researcher knows a lot” to “the research partners know a lot.” We must be open to adaptive learning; we must be curious and courageous

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enough to ask questions whose answers we do not already know or think we may already know, and to respond to questions at times by indicating we do not know the answers. Being aware of our own mindsets formed from our training and from our experiences interacting with patient and community stakeholders in previous research, we can learn to leave our preconceived notions (including outdated language) behind.

The lessons learned from these studies are also applicable beyond the research community and into health care operations. Careful choice of language is definitely needed in communicating with patients and community members who serve as advisors on executive and clinical operations groups of health care delivery organizations. ❖

#### Disclosure Statement

*These 2 projects were funded by Contract Numbers 11P2PI000055-01 and IP2PI000338-01DS from the Patient-Centered Outcomes Research Institute (PCORI). All statements in this report, including its findings and conclusions, are solely those of the authors and do not necessarily represent the views of PCORI, its Board of Governors or Methodology Committee, or the views of any other funding agency.*

*The author(s) have no conflicts of interest to disclose.*

#### Acknowledgments

*We are deeply grateful to our stakeholder partners for the value their experience and insights can bring to our collaboration. Showing our appreciation for their value in the language we use and the action we take can put us on a different trajectory. The downstream benefit of this paradigm shift can be research that is more meaningful to patients and communities, potentially enabling us to conduct research that garners greater interest among patients and communities, thereby improving external validity and public impact.*

*Mary Corrado, ELS, provided editorial assistance*

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## The Pale Shadows

Words are the pale shadows of forgotten names. As names have power,  
words have power. Words can light fires in the minds of men.

Words can wring tears from the hardest hearts.

— Patrick Rothfuss, b 1973, American writer of epic fantasy