

The following idea is from 10 Ideas for Improving Patient Care by James L. Reinertsen, M.D., and Wim Schellekens, M.D.

## IDEA 1

# Put the Patient in the Room

*Put the patient in the room—on every board, committee, task force, improvement project, and design group in your organization.*

**H**ealthcare leaders should see to it that patients are full participants on all improvement teams, board committees, cross-disciplinary task forces, and other groups that work on improving patient care. In other words, put activated, articulate patients (and family members) in the rooms in which decisions are being made about the design of their care processes and systems.

*Put the patient in the room* is not about focus groups or other similar methods by which healthcare leaders ask patients to react to improved care designs that doctors, ▶

nurses, and administrators have created. Neither is the idea about including patient preferences during the actual delivery of care, such as the setting of goals in a plan for chronic disease. Both of these are important practices, but they are not the primary focus of this idea.

Rather, this idea is about including patients in the process of redesigning care systems and bringing their input, concerns, and values into the improvement process from the beginning. The underlying belief here is that results will be better if patients are involved. It lies within the core principles of the Institute of Medicine's blueprint for a transformed healthcare system as outlined in *Crossing the Quality Chasm* (Corrigan, Donaldson, and Kohn 2001).

This method is an open and direct way of sharing control—shifting some power, if you will, from us to our patients and their families. As such, it raises a number of questions such as, “Whose room is it, anyway?” and “Why do we state the idea in such a controlling, paternalistic way?” If one way of framing the overall practice of patient-centeredness is to consider ourselves to be guests in our patients' lives, rather than patients to be guests in our organizations, should

the idea be rephrased to something like “put ourselves in our *patients'* rooms?” In other words, should we instead think of ourselves as guests on our patients' design teams, rather than the other way around? (Garrett 2004).

These are provocative questions, and they surface important tensions that need to be addressed. Let's see the ideas in action first, and return to the tensions later. Following are examples of how putting the patient in the room works in practice.

### **EXAMPLE: SHARED CARE PLAN AT ST. JOSEPH**

St. Joseph PeaceHealth, a 250-bed hospital in Whatcom County, Washington, is leading a communitywide effort to redesign chronic disease care (see <http://www.ihl.org/IHI/Programs/pursuingperfection/>). The leadership board for this effort includes all the members you would expect: CEOs; medical directors; and executives from various clinics, physician practices, and health plans. It also includes someone you would not expect: Rebecca Bryson, an informed, activated, articulate patient with several chronic diseases, including diabetes and congestive heart failure.

Ms. Bryson is cared for by 11 physicians in 5 different organizational settings, and she is on an average of 10 medications. When one physician changes a medication dose, or stops one to start another prescription, Ms. Bryson informs the other 10 physicians of her new drug regimen. (Otherwise, she has learned that she will suffer the consequences of adverse drug events and other problems.) Early on, she asked the healthcare administrators on the leadership board, “Why can’t you do this for me, and for yourselves?”

This heartfelt, reasonable question broke through interorganizational rivalries that are common in communities like Whatcom County. It also allowed the leaders of otherwise independent entities to commit to the development of a communitywide, electronic Shared Care Plan for patients with chronic disease. Not surprisingly, a critical requirement of the plan specified by the leadership board was a common medication list, which is updated for all caregivers.

Ms. Bryson describes her role on the leadership board this way: “Patients can help to lead transformational change, even though we have no power or authority. We are the great levelers. When it comes to setting the direction or breaking

through the ties, they all yield to me as if I were the boss. That’s what becoming ‘patient-centered’ really means” (Bryson 2003).

The actual design process of the Shared Care Plan involved patients with chronic disease, which was critical to the outcome. As Dr. Marc Pierson (2003) states, “There is no way that information technology experts, physicians, and nurses would have come up with the designs that the patients wanted, if they hadn’t been in the room with us.”

An example of patient input is evident in the opening page of the Shared Care Plan record (see Figure B). This first page contains what patients believe is important for their care team to know, such as their personal long-term goals and the location of their advance directives. Normally, billing and demographic information opens any health record.

## **Results**

With the Shared Care Plan at the core, and a number of other patient-centered designs in its chronic care system, hundreds of St. Joseph PeaceHealth’s diabetics are starting to see real results. Nearly 50 percent of these patients now have glycosylated hemoglobin levels less than 7 percent.

**Figure B. Shared Care Plan Record**

Shared Care Plan for: **Doe, John**

Personal Profile | **Goals** | Next Steps | Care Team | Diagnoses | Medications | Reactions

**Personal Profile**

Birthdate: 1/1/1900  
 Phone Number: 360-999-9999 (Home - Telephone)  
 Email Address: johndoe@email.com

I want the person working with me to know...

I have challenges with:  Vision  Hearing  Mobility  Other  
 My primary language is: Croatian  Translator needed:

Comments: Deaf in left ear

I have special diet needs:

Comments: No red meat

My religion/spirituality impacts my health care:

Comments: Hanging on my fridge

I have:  Advance Directives  POLST  Power of Attorney

Shared Care Plan for: **Doe, John**

Personal Profile | **Goals** | Next Steps | Care Team | Diagnoses | Medications | Reactions

**Long Term Goal** Add New

Goal Description	Function
See my daughter graduate from college	<input type="button" value="Edit"/> <input type="button" value="Remove"/>

**Completed Long Term Goals**

Goal Description	Function
See my son get married	<input type="button" value="Edit"/> <input type="button" value="Remove"/>

**Health Indicators** Add New

Indicator	Goal	Comment	Function
HbA1c	8	Currently at 10	<input type="button" value="Monitor"/> <input type="button" value="Edit"/> <input type="button" value="Remove"/>
Ejection Fraction	60%	EF% on 1/2/2003: 40%	<input type="button" value="Monitor"/> <input type="button" value="Edit"/> <input type="button" value="Remove"/>

[Personal Profile](#) | [Goals](#) | [Next Steps](#) | [Care Team](#) | [Diagnoses](#) | [Medications](#) | [Reactions](#)

[Libraries](#) | [Shared Care Plan](#) | [Patient Website](#) | [Pursuing Perfection](#)  
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 Project participants: Center for Senior Health, Community Health Plans of Washington, Family Care Network, Group Health Cooperative, North Cascade  
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## EXAMPLE: PULMONARY REHABILITATION AT KING’S COLLEGE

The Pursuing Perfection team at King’s College Hospital in London, England, set itself the challenge of improving care for patients with chronic obstructive pulmonary disease (COPD). One of the team’s major obstacles was to redesign the system of pulmonary rehabilitation, which had long wait times, high costs, and low patient satisfaction levels. A key strategy in the redesign effort was to enlist patients with COPD in the design process from the

outset. COPD patients were not only delighted to participate, they also came up with a number of significant “breakthrough” ideas.

For example, the COPD patients noted that each patient was unique in level of knowledge, desire for self-management, severity of disease, and other characteristics. With the guidance of the patient-run Breathe Easy group, the rehabilitation team redesigned its service from a one-size-fits-all eight-week course to a menu of education and rehabilitation options tailored to the needs and wishes of individual patients. Patients with high self-management skills and

mild disease now can choose a much more streamlined, lower-cost program, whereas more dependent, severely ill patients receive the intense, full 12-week course (see Table 1).

## Results

Twice as many COPD patients now start the process of rehabilitation, and three times as many complete the entire process. Wait times are down, as are the overall costs of the rehabilitation service. Most importantly, the early going shows a nice improvement in level of pulmonary function for this COPD population. Almost half the patients have moved to a higher level of self-management and/or pulmonary function.

## WHY IS THIS IDEA FIRST ON OUR LIST?

1. *It is a powerful driver of cooperation.* Organizations have learned that when patients are sitting at the same table as doctors, nurses, pharmacists, and CEOs, their presence tends to stifle self-serving and organization- or profession-centric discussions.
2. *The presence of patients brings the whole system of care out into the open.* They experience care across multiple departments, physician

offices, and institutions. Their presence on design teams opens the eyes of those responsible for those systems to new ways in which cooperation can drive improvement. Ms. Bryson's question about communitywide medication lists ("Why can't you do this for me?") rings constantly in the ears of the physicians and administrators who have heard it. After a few meetings with patients like Ms. Bryson present, many administrative leaders simply cannot go back to viewing their responsibilities as separate from the larger community care system. And that's a good thing.

3. *Patients have innovative ideas that get results.* The designs and outcomes of the Shared Care Plan for Whatcom County and the pulmonary rehabilitation system in South London would never have been as successful if patients had not stopped the designers and said, "No, that's not going to work for us. Why don't we try it *this way*?"
4. *The experience of being part of these committees helps patients to understand the science of medicine and the strengths of the care system as well as its weaknesses.* Patients who are so informed can serve an enormously useful "linking" role to other patients and the broader community, educating and

**Table 1. Designing Pulmonary Rehabilitation to Fit Patients' Characteristics**

	<b>Mild Disease</b>	<b>Medium Severity</b>	<b>High Severity</b>
<b>High Self-Management</b>	<ul style="list-style-type: none"> <li>• Leisure card</li> <li>• Smoking cessation</li> <li>• COPD booklet/disk</li> <li>• Breathe Easy</li> <li>• Cost: \$120</li> </ul>	<ul style="list-style-type: none"> <li>• Leisure card</li> <li>• Exercise on referral/walks</li> <li>• Self-help management course</li> <li>• Smoking cessation</li> <li>• Cost: \$300</li> </ul>	<ul style="list-style-type: none"> <li>• 4/52 pulmonary rehab in leisure center</li> <li>• Exercise on referral/walks</li> <li>• Self-help management course</li> <li>• COPD booklet/disk</li> <li>• Referred to buddy patient</li> <li>• Cost: \$460</li> </ul>
<b>Medium Self-Management</b>	<ul style="list-style-type: none"> <li>• Leisure card</li> <li>• Exercise on referral/walks</li> <li>• Self-help management course</li> <li>• Smoking cessation</li> <li>• COPD booklet/disk</li> <li>• Breathe Easy</li> <li>• Cost: \$300</li> </ul>	<ul style="list-style-type: none"> <li>• Leisure card</li> <li>• Exercise on referral/walks</li> <li>• Self-help management course</li> <li>• Smoking cessation</li> <li>• Referred to buddy patient</li> <li>• Cost: \$450</li> </ul>	<ul style="list-style-type: none"> <li>• 7/52 pulmonary rehab in leisure center</li> <li>• Breathe Easy</li> <li>• Smoking cessation</li> <li>• Crisis management</li> <li>• COPD booklet/disk</li> <li>• Referred to buddy patient</li> <li>• Cost: \$650</li> </ul>
<b>Low Self-Management</b>	<ul style="list-style-type: none"> <li>• 4/52 pulmonary rehab in leisure center</li> <li>• Exercise on referral/walks</li> <li>• Breathe Easy</li> <li>• Self-help management course</li> <li>• Smoking cessation</li> <li>• COPD booklet/disk</li> <li>• Referred to buddy patient</li> <li>• Cost: \$580</li> </ul>	<ul style="list-style-type: none"> <li>• 7/52 pulmonary rehab in leisure center</li> <li>• Exercise on referral/walks</li> <li>• Breathe Easy</li> <li>• Smoking cessation</li> <li>• COPD booklet/disk</li> <li>• Referred to buddy patient</li> <li>• Cost: \$580</li> </ul>	<ul style="list-style-type: none"> <li>• 7/52 pulmonary rehab in hospital</li> <li>• PLUS 4/52 in leisure center</li> <li>• Breathe Easy</li> <li>• Smoking cessation</li> <li>• Crisis management</li> <li>• COPD booklet/disk</li> <li>• Referred to buddy patient</li> <li>• Cost: \$880</li> </ul>

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informing them about what’s really going on.

5. *Physicians and nurses have found that patients on design teams bring an enormous reservoir of emotional support for healthcare professionals.* Patients want those who care for them to feel good about their work, and they will do everything in their power to ensure the success of the professionals to whom they are entrusting their lives.

If you are a CEO looking for a radical transformational strategy for your organization—one that will drive fundamental, deep changes in your culture, organizational design, core processes of care, and relationships with the rest of the community—we can think of no idea stronger than this: put the patient in the room—on every board, committee, task force, improvement project, and design group in your organization.

## **AVOID THE PITFALLS OF THIS IDEA**

*Put the patient in the room* is strong medicine and can backfire if you do not use it well. Among the early lessons are as follows:

1. Be as thoughtful about which patients you choose to put on

boards, task forces, and design teams, as you would about which administrators, physicians, and nurses you put on those design and decision-making groups. People, including patients, are not equally gifted in their ability to see beyond the boundaries of their own experiences; to speak articulately for the needs of others; or to bring a positive, can-do attitude to the group.

2. Patients (and parents, in the case of pediatrics) tend to have more good improvement ideas, and more long-term engagement on design teams, when the design problem revolves around chronic illness rather than around an acute problem or one-time diagnostic service.

3. No doubt that this idea raises some potentially awkward power and control issues for professionals and for patients. In practice, however, patients’ ideas about how to design care (e.g., Ms. Bryson’s request for a system that would keep track of chronic disease patients’ medication lists) are seldom wacky or scientifically unsound. Although there are times when “doctor knows best” and a patient’s suggestion needs to be trumped by medical science, those occasions appear to be far less frequent than expected. In other words, we can consider ourselves “guests on our patients’

design teams” without sacrificing the science of medicine.

4. It seems prudent to place several patients on any design team, rather than to count on a single patient’s voice to bring the full range of ideas and concerns forward, especially in such a potentially intimidating environment.

One last note: be prepared for consequences, because once you start down this road, there is no going back. As Dennis Malloy, COPD patient and chair of the Lambeth Breathe Easy group in South London says, “You’ve given us the lollipop, and we’re not giving it back.”

## WHERE TO LEARN MORE

There are a number of resources to which you might turn, over and above

the chapters on patient-centeredness in *Crossing the Quality Chasm*. If you wish to see truly innovative work being done in patient-centered information systems design for chronic disease, go to [www.patientpowered.org](http://www.patientpowered.org). This web site describes the Shared Care Plan as it continues to develop in Whatcom County.

For anyone wishing to understand an overall framework for engaging activated patients, an important resource is the web site [www.improvingchroniccare.org](http://www.improvingchroniccare.org). It is devoted to sharing the chronic disease model first articulated by Wagner and colleagues (2001).

An entire section is dedicated to chronic disease on the superb web site [www.ihi.org](http://www.ihi.org). This section is full of good ideas on and approaches to putting the patient in the room.

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