This is a question that I get very often: What's the difference between patient engagement and patient activation? Are they the same? Are they different?

Agenda

- **What are patient engagement and patient activation? How are they different or the same?**

  - ❑ How is patient activation linked with the use of information?
  - ❑ What is the evidence that patient activation is predictive of outcomes: behaviors, health, quality of care, utilization, costs?
  - ❑ How can patient activation be increased?
  - ❑ What are the implications for supporting the use of information in health care decisions?

I think I'll address that first. But we'll also talk about how patient activation is linked with the use of information; what is the evidence that activation is predictive of outcome, such as behaviors, utilization, costs; and what do we know about how to increase this in patients. I'll spend just a minute talking about how delivery systems are using this kind of measurement in innovative ways and then, finally, end u   with what the implications of all of this is for supporting the use of information in healthcare decisions among consumers.

What Is Patient Engagement?

■ **People use the term loosely and to mean different things:**

- ❑ Interventions to increase participation or involvement when they use the term "engagement"
  - OR
- ❑ The resulting participation or involvement
  - OR
- ❑ Both the efforts to increase meaningful participation and the resulting involvement and participation
  - OR....

What is patient engagement? As you all know, this term is used pretty loosely. People all say the same thing, but they mean different things. A common way it is used is to describe interventions to increase involvement or participation; or the resulting participation or involvement; or both; or something else. When we started the work on patient activation we spent a lot of time on definitions to be very clear what it was we were trying to measure.

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What Is Patient Activation?

An activated consumer: has the motivation, knowledge, skill, and confidence to take on the role of managing his or her health and health care

- Seek the full range of activation in any population group.

- Demographics tend to account for 5% to 6% of variation in the Patient Activation Measure (PAM) score.

The definition that we came u with after working with a national expert consensus panel, with patients, and going to the literature is that an activated consumer or patient is one who has the motivation, knowledge, skill, and confidence to take on the role of managing their health or their healthcare. That is, an individual who understands what their role is and feels competent and able to do it. This was one of the first things that we learned after working on measurement in this area is in almost any population group that we have looked at you see a full range. You see people who are very passive about their health and people who are very proactive. And that doesn't matter if they are eighty-five year olds you're looking at or if it is Medicaid; you'll see that full distribution. What you do see is that the mean will move a bit. For some groups the mean will be lower and for some groups the mean will be higher. But the point is that you don't know. Just because someone is maybe disadvantaged in certain ways, that doesn't mean that they aren't proactive about their health. And, in fact, demographics - age, education, income, gender - account for about five or six percent of the variation in patient activation scores. But it is there. it is just not very powerful. We looked at the same question per health literacy and it is about twenty-five percent of the variation is accounted for by those same variables.

Activation Measure Items

1.	When all is said and done, I am the person who is responsible for taking care of my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
2.	Taking an active role in my own health care is the most important thing that affects my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
3.	I know what each of my prescribed medications do	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
4.	I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
5.	I am confident that I can tell a doctor concerns I have even when he or she does not ask.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
6.	I am confident that I can follow through on medical treatments I may need to do at home	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
7.	I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
8.	I know how to prevent problems with my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
9.	I am confident I can figure out solutions when new problems arise with my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
10.	I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A

NA = not applicable

Here's the measure. A as you can see there are just declarative statements about-- and they're very general-- that people might make about their health and they respond with degrees of agreement or disagreement.

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Activation Is Developmental

STARTING TO TAKE A ROLE · BUILDING KNOWLEDGE AND CONFIDENCE · TAKING ACTION · MAINTAINING BEHAVIORS

Increasing Level of Activation

Hibbard JH, Mahoney E, Stockard J, et al. Development and testing of a short form of the Patient Activation Measure (PAM). Health Serv Res. 2005 Dec;40(6 Pt 1):1918-30. PMID: 16336556.
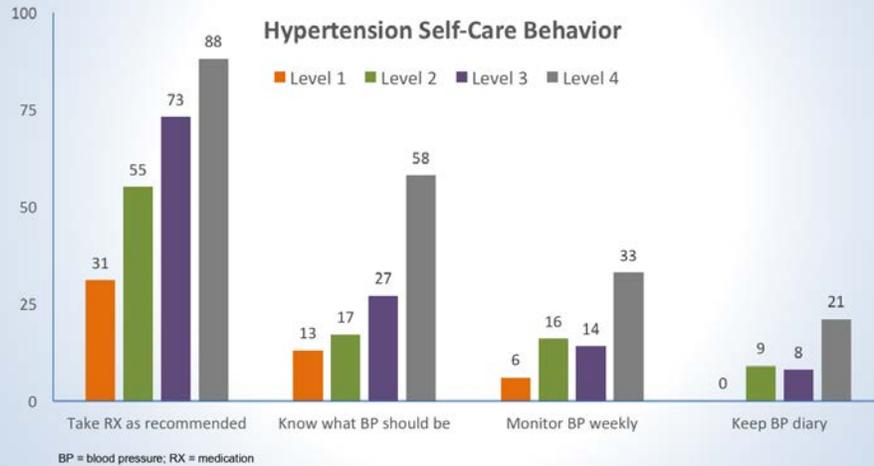
We were able to see that there appears to be levels or stages that people go through on their way to becoming effective self-managers. And very early on we did in-depth interviews with people along this dimension who understand how do they understand their role, how do they cope and respond. And it was quite informative. We saw that people who measured low on this scale they had much more experience with failure; they were much more likely to say things like, "It doesn't really matter what I do. I can't have a positive impact on my health." They were discouraged. They were overwhelmed with the task of managing their health. They had very poor or low competence and many had poor problem-solving skills. And then the other surprising thing was many of them didn't really understand what their role was. They thought it was to be passive in the medical encounter. All of that has   lot of implications, which I'll talk about at the end-- about what does that mean for engaging people with information. We ended up using a Rasch analysis to create the measure. There are two characteristics I want to just mention here. One is that it is interval-level measurement. So it is more like   ruler with equal distance between the marks on the ruler and that means that the measure is more precise and consistent than most social-science-based measures. The math of it tells us that we're actually tapping into one underlying idea. The math doesn't tell us what that idea is, but what we're measuring is a person's self-concept as a manager of their own health. And it may not be conscious on the individual's part, but that's kind of what they're telling us in answering these questions. At this point the measure's been translated into twenty-three different languages and we have been able to evaluate the psychometric properties of about half of those translations. And so what we see is that concept itself is robust and seems to work across culture and language.

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Why Is Patient Activation Important?

- Findings from over 200 studies that quantified patient activation were reviewed.
- Higher activated individuals are more likely to engage in positive health behaviors and to have better health outcomes.

At this point there are over 200 public studies that quantify patient activation and what we see, generally, is that prior activated individuals are more likely to engage in positive behaviors and have better health outcomes.

Activation and Behavior

Hypertension Self-Care Behavior

Level 1 Level 2 Level 3 Level 4

Take RX as recommended: 31, 55, 73, 88
Know what BP should be: 13, 17, 27, 58
Monitor BP weekly: 6, 16, 14, 33
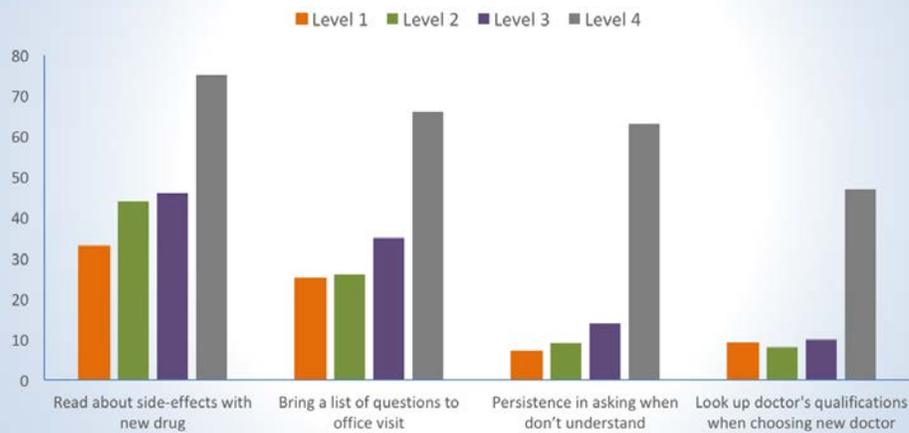**Keep BP diary:** 0, 9, 8, 21

BP = blood pressure; RX = medication

Hibbard JH. Using systematic measurement to target consumer activation strategies. Med Care Res Rev. 2009 Feb;66(1 Suppl):9S-27S. PMID: 19052169.

Just to give you an example of how it translates into behaviors, we have looked at the percentage of people at each level of activation engage in behaviors. This is the behavioral domain of managing hypertension: "Do you take your medication as recommended, know what your blood pressure should be?" as taking more ownership; monitoring, that is, being more proactive; and keeping a diary, even more so. Looking at lots of behavioral domains we see this kind of stair-step approach where the higher activated are more likely to engage in the behavior and the less activated, less likely to. But we also saw that as the behaviors become more difficult, require sustained action, less people in all the levels actually down then.

Behavior in the Medical Encounter

Level 1   Level 2   Level 3   Level 4

Hibbard JH. Using systematic measurement to target consumer activation strategies. Med Care Res Rev. 2009 Feb;66(1 Suppl):9S-27S. PMID: 19052169.

Here's how people behave in the medical encounter. How do you get a new prescription? Do you read about side effects? Do you bring a list of questions to your office visit? When you don't understand, are you persistent in asking until you do? And do you look at the doctors' qualifications when choosing a new doctor?

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Insights

- Many of the behaviors we are asking of people are only done by those in the highest level of activation.

- When we focus on the more complex and difficult behaviors, we discourage those who are the least activated.

- When we give people too much information or suggest too many changes, we discourage those who are the least activated.

- When we start with behaviors that are more feasible for patients to take on, we increases the opportunity for each to experience success.

What we saw was that the higher activated did most of these behaviors, but the others were more of a stair-step approach. So after looking at lots of these behavior maps and looking at who does what, what we came away with was the insight that a lot of the behaviors that we're asking people to do are only done by this highest level of activation. So when we focus on complex and difficult behaviors, first and only, maybe we're discouraging those who are less activated. And when we give people too much information or suggest too many changes are we discouraging the least activated and, essentially, are we setting them up for failure. What we want to do, really, is set people up for success. So what we took away from this was let's start with behaviors that are more feasible for people to take on, and that might mean breaking them down into small steps, and in doing so we can increase the opportunity for people to experience success. And what we have observed is that when people do experience success, even if there're just small steps, their motivation goes up. And then they're more ready to take on that next challenge. So this was all sort of empirical, looking at the data and thinking about what does this mean? How should we proceed? I am going to jump ahead here to some of the research on how this relate to outcomes.

Higher Activated Patients Have Better Outcomes:
Correlation between PAM scores and clinical outcomes (within normal range), from electronic health records

|	Baseline		Baseline
Prevention Colon Mammograms Pap smears	 *** **	*Clinical Indicators in Normal Range* Systolic Diastolic	 **
Healthy Behaviors Not obese Not smoking *Costly Utilization* Lower hospitalizations Lower emergency room use	*** *** *** ***	High-density lipoprotein Triglycerides Hemoglobin A1c	*** *** *

Controlling for age, income, gender, and chronic diseases: *p<.05; **p<.01; ***p<.001.

Greene J, Hibbard JH. Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. J Gen Intern Med. 2012 May;27(5):520-6. PMID: 22127797.

This is a study that was published a few years where we were working at the large delivery system, where they were collecting patient activation scores from patients that went into the electronic medical record. We had the opportunity to see how does the patient activation score relate to all of the quality metrics and the electronic medical record? This is controlling for age, income, gender and chronic illness. It is only telling us what was statistically significant. It is not telling us the magnitude of the relationship. But everything is in the expected direction. So people who are more activated are more likely to get screenings, they're less likely to be obese, less likely to be smokers, less likely to have costly utilization and to have their clinical indicators within range for most of these measures. Later we had the opportunity to follow people over time in the same delivery system and here we can see a little bit more about the magnitude of the relationship.

PAM in 2010 Predicts Outcomes 2 Years Later: Odds Ratios
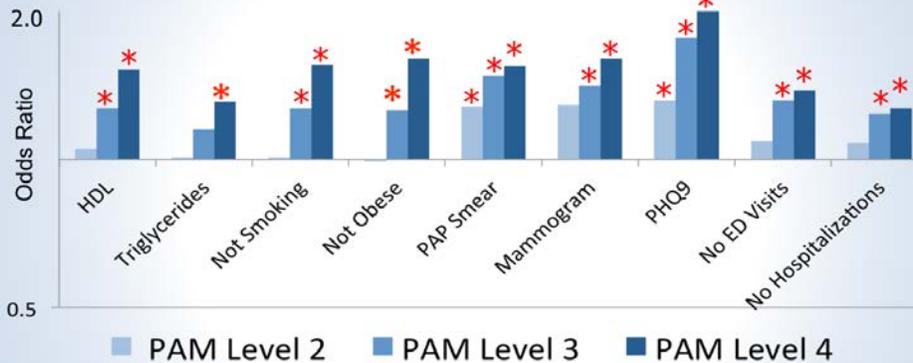
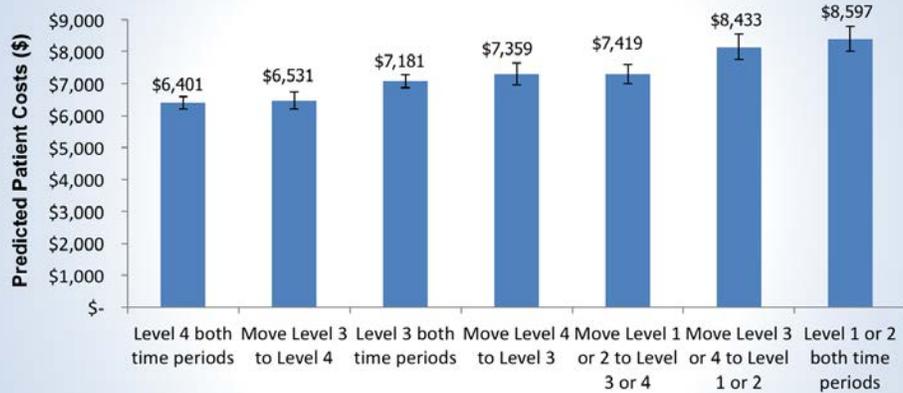ED = emergency department; HDL = high-density lipoprotein; PHQ9 = Patient Health Questionnaire-9

- Models included controls for age, sex, number of chronic conditions, natural logarithm of income, and percentage of care that was received in network. Insignificant results for hemoglobin A1c, low-density lipoprotein, diastolic blood pressure, and systolic blood pressure not shown.
- The asterisks indicate results that are statistically significantly different from PAM Level 1 at $p<0.05$.

Greene J, Hibbard JH, Sacks R, et al. When patient activation levels change, health outcomes and costs change, too. Health Aff (Millwood). 2015 Mar;34(3):431-7. PMID: 25732493.

We're looking at that 2010 PAM score predicting outcomes at two years later It is comparing people who are at level one to the other three levels. And, for example, if you look at the PHQ-9-- that is, are people in normal range in the PHQ-9, they were about two times more likely to be in the normal range two years ago that had a PAM score that was a level four. So that's how you would interpret this. So you still see that kind of stair-step even though this is multivariate analysis we're controlling for all the things I mentioned before.

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Predicted Average Per-Capita Costs 2 Years Later by Change in PAM Level

Predicted Patient Costs ($)

- Level 4 both time periods: $6,401
- Move Level 3 to Level 4: $6,531
- Level 3 both time periods: $7,181
- Move Level 4 to Level 3: $7,359
- Move Level 1 or 2 to Level 3 or 4: $7,419
- Move Level 3 or 4 to Level 1 or 2: $8,433
- Level 1 or 2 both time periods: $8,597

Predicted costs are based upon regression models with log-transformed costs that control for age, sex, chronic conditions, natural logarithm of income, and percentage of care that was received in network. Costs were retransformed from log dollars using the Duan smear factor.

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Then we were able to actually link this with cost. This analysis is a little bit different. Here we looked at changes in PAM score related to changes in cost and we saw people who were moving u   in their PAM level and people were moving down. Their dollar amount costs were moving in the same direction as their PAM score was moving. So this is a 2-year time frame and, basically, what you see is that if they were at level four both time periods and if they were at level one or two both time periods, those are their cost differences. And all of the groups in between were moving up or they were moving down and their costs were consistent with that direction. And, again, this is a multivariate controlling for all the variables that were in the previous analysis.

Less-Activated Patients Have Higher Total Health Care Costs

- After controlling for demographics and health status, there was a $1,987-per-patient annual cost differential between those patients who stay high in activation and those who stay low in activation over a 1-year period. This represents a 31% difference.

Greene J, Hibbard JH, Sacks R, et al. When patient activation levels change, health outcomes and costs change, too. Health Aff (Millwood). 2015 Mar;34(3):431-7. PMID: 25732493.

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After controlling for these things we saw almost a $2,000 cost differential between patients who stayed high and those who stayed low. That's a 2-year period. And this represents a 31% percent cost differential. People always ask me, "Well, why do you have all those controls and then you can't tell what the real difference is?" Well, the real difference is much bigger because we removed the effects of health status, et cetera. We also know that it is possible to increase activation level, but it takes a kind of different approach.

Increases in Activation Are Possible

- **If we want patients to take ownership, we have to make them part of the process.**
  - Listen, problem-solve, and collaborate.
  - Help them gain the skills and confidence they need.
- **This approach represents a major paradigm shift.**
  - We are moving away from simply "telling patients what to do" and seeking their "compliance."
  - The focus now is on developing confidence and skills and not just the transfer of information.

If we want patients to feel ownership and to be part of the process, then we have to make them part of the process. And we have to think about this as a kind of capacity building effort. Because that's what's happening over these different levels. So it represents a paradigm shift. it is not just telling patients what to do and looking for their compliance. The focus is on developing competence and skills and not simply the transfer of information.

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Intervention Studies

- 50 published studies have used PAM as an outcome measure.
- Randomized trials show that different interventions increase activation and improve outcomes.
  - ❑ Stanford Chronic Disease Model (clinical outcomes)
  - ❑ Tailored coaching (clinical outcomes)
  - ❑ Participatory decisionmaking (only behavioral outcomes)
  - ❑ Worksite interventions (only behavioral outcomes)

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At this point there are 50 published studies that used the PAM as outcome measure with the intervention studies. And we do see that many of them do result in increases in activation. And I will talk a little bit about those.

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Tailoring Support to the Patient's Activation Level

- Identify appropriate starting points.
- Address realistic and achievable behavior goals.
- Customize action steps, mediums, and frequency.

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One of the more effective ways is just simply to tailor support to the patient's level of activation. So essentially, meet them where they are and work with them to find goals that they care about that are realistic for them to achieve. So I am going to say a few words about what delivery systems are doing here, because they're doing some pretty innovative things.

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Innovative Delivery Systems

The PAM score is a vital sign that:

- Uses tailored coaching/support
- Uses both a behavioral lens and a clinical lens to manage patient populations
- Is a more efficient use of resources because it targets those who need more help
- Is used as an intermediate outcome of care measure
- Is used as a way to assess provider performance

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Many are looking at the PAM scores as kind of a vital sign that you need to understand where the patient is coming from and then you can tailor your support and the way that you provide education and coaching. We always look at a population through a clinical lens, but some are adding kind of a behavior lens to this clinical lens in the form of the patient activation measure. The point is to think about more efficient use of resources by targeting those who actually need more help and it is not always because of their disease, but it is often because they don't have the self-management skills that they need. Some are looking at this as an intermediate outcome of care. That is, patients who are getting good care should actually be gaining in their ability to self-manage and we can measure that and we should be paying attention to that. And now some are using it as a way to assess provider performance. And, in fact, the New York State district program says they're going to use it as a performance metric. So are they moving the needle on patient activation for the clinic or the provider level? And they haven't said exactly how they're going to do that, but that's what they're saying.

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Segmenting the Population

PAM Level	Disease Burden	
	Low	High
High	ELECTRONIC RESOURCES	PEER SUPPORT ELECTRONIC RESOURCES
Low	TEAM MEMBERS	TEAM MEMBERS More Active Outreach

Source: Judith H. Hibbard, DrPH, Health Policy Research Group, University of Oregon, Eugene, OR

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Here is a very simplified version of segmenting the population using that clinical and behavioral lens. We have just four cells -- disease burden, high and low, and PAM level. We dichotomize, "high" and "low" to think about how do you use your resources more effectively. So, people with high disease burden and low PAM scores: if they're not already in trouble, they're going to be in trouble soon. They're more passive about their health, so they may not come in. So we need to use more active outreach and more contact. For those who are higher activated, use other kinds of resources because these patients are more ready to use information -- electronic resources and other kinds of community supports. There are several groups that are doing this now. We don't have the results of their work, but it is a way to think about being more targeted in your resources. There are many, like the National Health Service in England that are trying this approach.

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What Are the Implications of Patient Activation Study Results for Supporting the Use of Information in Choice?

- In the clinical encounter?

- In promoting the use of evidence in choice?

- In implementing shared decisionmaking?

■One size does not fit all.

What are the implications for all of this for supporting the use of information and choice? You can think about it for the clinical encounter for promoting the use of evidence and implementing shared decision making. So let's just go back and review the less activated patients. We know that they're more passive. We do know they're less likely to seek out information on their own and I think part of this is related to how they understand their role. If they don't think this is their job, then they're not going to spend their energy looking for this.

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Less-Activated Patients

- Are more passive and less likely to seek out information on their own

- Are easily overwhelmed

- Have low confidence

- Often do not understand their role in the care process

- Have poor problem-solving skills

- May be in denial about their health

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And in interviews with people who are less activated, if you ask them something about how they manage their health, they're more likely to say, "Oh, my doctor handles that. it is not my job." So it is hard to interest people in information and new skills if they don't think it is their job. They are easily overwhelmed. They have low confidence and poor problem solving skills. They may be in denial of their health. People who are less activated are more likely to say, "They say I have diabetes." They don't actually own it.

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Tailoring Information for Less-Activated Patients

- **Do not overwhelm patients with too much information. Give them what they need to know right now.**
  - ❑ Think about parsing out information over time.
- **Help them prioritize.**
  - ❑ "If you can only do two things right now, focus on those two."
- **Help them see what their role is and what the role of the care team is.**
- **Focus on foundational issues that can be built upon over time.**
- **Use more "high touch" delivery modes with less-activated patients and more "high tech" modes with the more-activated patients.**

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So what does this mean? First of all, think about people transitioning out of the hospital and have reams of information they've been given about how to handle their condition in the post-hospital period. If they are overwhelmed, help them prioritize. Help them see what it is that they can do that's most important and that's maybe what's second-most important. I think, generally, in this process helping them to see how important their role is and also what the role of the caretaker is. Think about it kind of foundational issues that we can build on over time. I think about this as so many things, like learning to swim. You don't throw people into the deep end of the pool. For most it is not going to work out that well. It is a process. You know, you have to feel comfortable to put your face in the water before you can float. And so this too, is a building process. I think becoming an effective self-manager is like that. So we need to think about that and how we support people and one foundational issue is "Your role is important. You have something important to contribute here." So, think about a more high touch delivery mode with less activated patients and more high tech modes with less activated patients.

Shared Decisionmaking?

- A study conducted in the United Kingdom showed that patients with kidney disease all gained in activation after receiving a shared-decisionmaking intervention, expect those who measured low in activation.[1]

- Less-activated patients may not be ready for shared decisionmaking.
  - They do not see what they have to offer.
  - They may need some support to get "ready" for shared decisionmaking.

[1] Mukoro F. Summary of the Evidence on Performance of the Patient Activation Measure (PAM). London, England: National Health Service; March 2012. http://selfmanagementsupport.health.org.uk/media_manager/public/179/SMS_resource-centre_publications/PatientActivation-1.pdf.

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I got a call from someone in a large delivery system who said, "We're trying to roll out shared decision-making across our system," and then she said, "but, you know, I don't think the less activated patients are ready for it." And I thought about that and I said, "Oh, I bet that's right." And then the next week I was in the U.K. and I sat down with people from the NHS Kidney Foundation and they were showing me the results of their study where they looked at the impact of shared decision-making on activation scores. And they had actually broken it u   by levels of activation. And they said, "See, it really helped everyone. Oh, except the less activated." And I thought, "Oh, yeah. They're not ready," because they don't think they have something to offer here. And so maybe they just need some help to get ready.

Meeting Patients Where They Are and Tailoring the Provision of Information Can:

- Increase the likelihood of patients accessing and using evidence
- Improve patient experiences
- Increase the likelihood the patient will do his or her part in the care process

So if we think about how we tailor the provision of information, I think we can actually increase the likelihood that patients will access and use evidence and I think we can also improve patient experiences with that. And I think we can increase the likelihood that patients will do their part in the care process.