

# When Patient Engagement Matters and When It Does Not

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So thank you very much. I'm taking a little bit of a different tactic on this, but I want to say I'm in agreement with both Dr. Hibbard and Dr. Fagerlin. I think we just take different approaches to the same information, which is what makes this literature and this area of research so rich.

## Patient Engagement

- **When it matters, getting it right is critical.**
- **When it does not matter, getting it right is critical as well.**



So my proposal today is that patient engagement does matter, or activation, or whatever you want to call it on this given day. But sometimes it matters less than others, and I think we have to be very careful to decide when it's important and when do we push for it -- and I think this point's come up a little bit today -- and when do we back off a little bit and use things, like defaults, to allow a little bit of cognitive relief for patients, particularly those dealing with chronic or critical diseases that are inundated by having to make lots and lots of choices that is -- has some biological basis in the fact that it's exhausting to do that. I don't know if any of you in the room have ever dealt with a serious condition, but it is -- it takes over your life for a while, and it gets very, very overwhelming, and you have the rest of your life to live at the same time. Your kids still need to be fed, the mortgage still has to be paid, you still have to go to work, and make lots of decisions around your health. So I know everyone that came here today wanted to talk about economic theory, so let's talk about that.

I'm a sociologist by training, so I got to have lots of theory. I spent six years in theory classes, so you got to put that to good use. So in economic theory, the concept of Homo economicus, or the economic man, is probably one of the most steadfast theories out there, and this portrays humans as consistently rational and narrowly self-interested agents who usually pursue and subjectively define ends optimally. Generally speaking then, they will look very carefully at all the evidence. They'll decide, "What is the best decision for me?" So you'll think about what's the financial cost, what's the emotional cost, how much pain am going to endure, put all of that data together -- like we have a big computer in our head -- and spit out the best decision. I haven't actually met that person. So you have Mr. Spock on "Star Trek," but that's not -- the reason that you had Mr. Spock on "Star Trek," because he's not normal. It was kind of interesting to see that. So this concept stands in almost complete opposition to how human beings actually work. So not so much Mr. Spock, maybe a little more Homer Simpson. So this is more looking at behavioral sciences, and more specifically, in behavioral economics, which looks at actual behavior that people do, not conceptual behavior around rationality -- and so things like cognitive biases, heuristics -- just basic irrationality comes into play here, and this is how people actually operate, even us, a bunch of smart people in the room. We all behave irrationally a lot of the time.

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## ***Homo economicus?* What We Have Learned Over the Past 250 Years**

- **Patient engagement is ongoing and sustained (almost never).**
- **Patients need to be engaged for good outcomes (sometimes).**
- **Good environmental design trumps patient engagement (almost always).**

Nease RF, Frazee SG, Zarin L, et al. Choice architecture is a better strategy than engaging patients to spur behavior change. *Health Aff (Millwood)*. 2013 Feb;32(2):242-9. PMID: 23381516.

Simon HA. Rational choice and the structure of the environment. *Psychol Rev*. 1956 Mar;63(2):129-38. PMID: 13310708.



So I'd like to propose three principles to consider around patient engagement, the first being that patient engagement itself is almost never ongoing and sustained, when you think about active engagement. The second is that sometimes patients do need to be engaged, but it needs to be for a finite period of time and you have to have breaks in between. And this is important in order to achieve good outcomes and for people to make good decisions. And lastly, that we have to consider environmental design, more than just buildings but in how we convey information, and that we've talked about a little bit. It's almost always more effective at improving outcomes and improving decision-making than relying strictly on patient engagement.

## Patient Engagement as Ongoing and Sustained

- Cognitive limitations and human nature
- Intent-behavior gap
- Is sustained engagement really possible or even desirable?

Kahneman D. Thinking, Fast and Slow. New York: Farrar, Straus and Giroux; 2011.

Nease RF, Frazee SG, Zarin L, et al. Choice architecture is a better strategy than engaging patients to spur behavior change. *Health Aff (Millwood)*. 2013 Feb;32(2):242-9. PMID: 23381516.

Pai CW, Edington DW. Association between behavioral intentions and actual change for physical activity, smoking, and body weight among an employed population. *J Occup Environ Med*. 2008 Sep;50(9):1077-83. PMID: 18784556.



So the idea that patient engagement is ongoing and sustained is something that I'd like to believe is true, but I know it's not. And this goes back to some of the work by Daniel Kahneman and some of the other people before him, again, in the way that we think -- and I'm not going to reiterate some of the same information that's been talked about already -- but if you think about System 1 thinking, which is what most of us do most of the time, versus System 2 thinking, which is hard, so we can only do that a little bit at a time -- you have to think about how that actually works in your brain and why we have cognitive limitations around how much System 2 thinking we can do. A lot of that has to do with the amount of energy -- I mean, we're talking about pure biology, glucose consumption here -- to engage in System 2 thinking. So your brain makes up 5 percent of your body mass, on average. It consumes 20 percent of the calories you take in, at least from your resting metabolic heart rate. We know from the obesity epidemic right now that there's lots of people who exceed that, but your brain is basically the giant SUV organ of your body, and it is taking a ton of energy. And so in order for us to survive as human beings -- because remember, we've evolved from cavemen and whatever -- your brain had to learn to conserve energy. You had to learn to conserve energy for sheer survival, because if you were using up all of your glucose all of the time trying to do this active thinking, then you would have nothing left for times of emergency and that sort of thing. Also you have to remember as human beings that it wasn't that long ago where famine was a pretty regular occurrence. And so we became very good as human beings at conserving energy, and your brain does that almost naturally. So it will try not to work very hard. That's why habits are so important in improving health behavior. You get people to do things without having to expend any energy doing it, and they will do it, and I think that's where some of the work that others have presented here today on being able to present small pieces of information, so that people can build on that, so that you no longer have to engage the System 2 thinking, to do things like take your medication -- you just do it -- is really important. Then you have enough energy to go on to the next thing. So it kind of goes way back to also what we can pay attention to with cognitive limitations. So I would like to think that I'm always rational -- again, I know I'm not. I also know that I, like every other human being on the planet, pay attention to basically two types of things: things that are either pressing or things that are pleasurable. Again, that goes back to where we evolved from. So consider that you're a caveman walking around in nature, and if you've ever sat out and gone into a forest, there's a lot of stimuli there. If you're going to think deeply about all of that -- every sound, every smell, everything touching you -- you're going to get worn out. So the things that you had to learn to pay attention to were things that were either pressing -- "There's this large animal coming to try to eat me!" -- or that were pleasurable. "Oh, there's this great bush of berries that are ripe and ready to eat." So now as evolved human beings, we're not that much different, right? We pay attention to things that are either fun, food -- lots of us like that -- or that scare us -- losing your job, or that sort of thing. That's no different when you're dealing with chronic illness. You're going to pay attention to the kinds of things in your life -- not just your condition -- that are either pressing or pleasurable. Thinking about your health is neither, most of the time. When you're first diagnosed with, say, breast cancer, that's pressing. Right? You go through this period of time of crisis where you're thinking out a lot. Well, a couple of weeks go on, and you still have to pay the mortgage, and your kids still have to get ready for school, and you find out that your 15-year-old is smoking marijuana, and the transmission goes out on your car. It no longer becomes kind of the thing you think about all the time because you can't, because you have to do other things. So the other issue that comes in with the ongoing and sustained engagement or an engagement in and of itself is what some researchers and I that worked together at Express Scripts called the "intent-behavior gap." And that goes to some of the work Dr. Fagerlin and Dr. Hibbard shared about what patients say they want, but then what they actually do. We measured this in a number of ways, as have some other researchers before, and in this particular instance we asked patients whether or not they would prefer to take a lower-cost medication when one's available. Eighty-two percent of people who said, "Yes, I would rather take a generic," were still taking a brand-name medication. Even though they say they want something, the follow-through often doesn't happen because that requires something other than inertia, which most of us are prone to do. How many of you drive to work the same way every single day? Is there a better way? Have you ever tried to find a better way? But that's just -- it's how I go to work. It takes less effort to do it the same way. Patients are the same on that respect. So we did this in a number of things, asking people about home delivery versus retail, asking them about whether or not they should stop medications even when they weren't medically necessary anymore -- say statins for people that are 80 years old -- it was often inertia. "Well, I've always taken this." So they just continue to do it. So with that being said, because of some of these limitations, we have to consider whether or not sustained engagement is really possible, and if it's even desirable a lot of times. I think about whether or not our healthcare system as it stands right now is truly ready to deal with huge masses of fully engaged patients. So a fully engaged patient is a real pain. They have lots of questions. They call their doctor every day. Doctors love that. Who's going to answer their questions? Who is going to keep them engaged? Because what happens with engagement is that if you're not getting the feedback you need, you're going to become less engaged finally. You're going to get discouraged. And so we have to think about when it's necessary, and then what we can actually handle.

## Do Patients Need To Be Engaged for Good Outcomes?

- **Increased patient engagement improves outcomes?**
  - Mixed results
  
- **Engagement or behavior?**
  - Concordance not guaranteed
  
- **Sometimes patient engagement matters and sometimes it does not.**

Nease RF, Frazee SG, Zarin L, et al. Choice architecture is a better strategy than engaging patients to spur behavior change. *Health Aff (Millwood)*. 2013 Feb;32(2):242-9. PMID: 23381516.

Rask KJ, Ziemer DC, Kohler SA, et al. Patient activation is associated with healthy behaviors and ease in managing diabetes in an indigent population. *Diabetes Educ*. 2009 Jul-Aug;35(4):622-30. PMID: 19419972.

Remmers C, Hibbard J, Mosen DM, et al. Is patient activation associated with future health outcomes and healthcare utilization among patients with diabetes? *J Ambul Care Manage*. 2009 Oct-Dec;32(4):320-7. PMID: 19888008.



So let's move on to "Do patients need to be engaged for good outcomes?" I don't want to dismiss it, because I think it is important. I think the research has shown that it is important, sometimes. That being said, engagement does not always lead to behavior, and so my focus in my last ten years of research has really been on driving actual behavioral change rather than worrying as much about whether or not people were engaged, where the rubber meets the road. And then sometimes, again, it matters if they're engaged and sometimes it doesn't. So I'm going to talk a little bit about that.

## Engagement Matters Less

- **When the default choice is both in the patients' best interest and what most patients would choose**
  - Use choice architecture and do not fight the human tendency toward inattention and inertia.
- **When you can piggyback on other healthy habits**
  - Small steps become part of the patients' "work flow" and do not need sustained active engagement.

Carroll GD, Choi JJ, Laibson D, et al. Optimal defaults and optimal decisions. *Q J Econ.* 2009 Nov;124(4):1639-74. PMID: 20041043.

Kahneman D. *Thinking, Fast and Slow.* New York: Farrar, Straus and Giroux; 2011.

Nease RF, Frazee SG, Zarin L, et al. Choice architecture is a better strategy than engaging patients to spur behavior change. *Health Aff (Millwood).* 2013 Feb;32(2):242-9. PMID: 23381516.



So when does engagement matter less? So a couple of instances where it matters less is when the default choice is both in the patient's best interest and is what patients would choose -- most patients would choose. You have to be very careful about that to make sure that you handle it ethically, but things like scheduling your next mammogram -- most patients who get mammograms believe they should get them regularly. You don't have to get the patient to do anything to do that. You could just schedule it for them. Just schedule it. Most people will go. My dentist has done that for me for 20 years. They schedule my cleanings twice a year. Ninety-nine percent of the time I show up. Once in a while I'll change it because of a conflict, but, if I depended on myself to schedule that, it'd be like the once-every-18-months cleaning because I just wouldn't get around to it because inertia gets into play. The other area where you don't have to count on engagement so much is where you can piggyback on other healthy habits, where you can say, "When you do this, do this other thing as well." So we've all done piggybacking. It's how you teach your children to brush their teeth and do everything else. So you have a routine, you wash up, you put on your pajamas, you brush your teeth. I've never seen a child who on their own gets engaged in brushing their teeth at the very beginning. Usually it's something you have to kind of force them to do. The parent's engaged, the child is not. But most of you, today I bet, brushed your teeth, and you weren't engaged in that, you just did it. It's in your workflow. It's how all of us operate.

## Engagement Matters More

- When specific skill or information learning is required
- When critical treatment or health decisions must be made that require patient choice and input
- When ongoing behavior must be performed by the patient

Harvey L, Fowles JB, Xi M, et al. When activation changes, what else changes? The relationship between change in patient activation measure (PAM) and employees' health status and health behaviors. *Patient Educ Couns*. 2012 Aug;88(2):338-43. PMID: 22459636.  
Nease RF, Frazee SG, Zarin L, et al. Choice architecture is a better strategy than engaging patients to spur behavior change. *Health Aff (Millwood)*. 2013 Feb;32(2):242-9. PMID: 23381516.



When does engagement matter more? And I think this is where it becomes really thoughtful and you have to be careful. When there's specific education or skills that have to be learned -- take the patient who's living with diabetes that needs to learn to be able to test their blood sugar and maybe titrate their insulin dose. You have to pay attention when you're doing it because you can really have some seriously negative outcomes if you don't do it right. At least for a period of time, you have to pay attention. Secondly, when there's a critical treatment or health decisions that have to be made and require patient choice or input, or at least should require patient choice and input. If you've just been diagnosed with cancer, as a patient, you need to be engaged in that decision-making so that the healthcare system isn't doing things to you, but for you. And I think a lot of patients, because they're often not engaged in the process, feel like things are being done to them. So true collaborative decision-making requires engagement and it requires a level of resources that I think most of you are cognizant of, but I think a lot of people in the healthcare community in general, they just think, "Oh, patient engagement. We'll do that. We'll have this app. It'll be simple." It's not. It's resource-intensive. But you only have to use it in some circumstances. So if you focus on it when it's really important, it saves the resources for that, instead of trying to make sure that every single person is engaged all of the time. And then a third instance where it matters is when ongoing behavior must be performed by the patient, but here you only need engagement long enough for it to become part of the patient's workflow. I'm going to give a personal example of this, just because I have permission from my husband. My husband has heart disease. He's had a few heart attacks. He's terrible at taking his medication. Absolutely terrible. He's a smart person, he knows he should take it; he doesn't think about it. So we had to get involved in a way to get him engaged in the short-term to develop a solution. "How do we do some problem-solving around this?" So our problem-solving behavior ended up being a big, ugly, clear pillbox that sits on the breakfast table, and had to do surveillance on him for a while to make sure he took it, and now he knows -- he sits down to eat breakfast, he takes his pills before he takes his first bite of food, and it's now something he never thinks about, as long as that pillbox is sitting on that table. But for a while, both of us had to get very engaged in the process. Now, 9 to 10 years beyond the fact, he's at about 99 percent compliant on his medication. track his data on a spreadsheet -- he loves that when we sit down and we talk about all his stats -- and it's usually when I'm traveling that he falls off, because it changes that routine a little bit.

## Important Considerations

- Ethics
- Practical implications
- Designing for patient choice

Nease RF, Frazee SG, Zarin L, et al. Choice architecture is a better strategy than engaging patients to spur behavior change. *Health Aff (Millwood)*. 2013 Feb;32(2):242-9. PMID: 23381516.  
King D, Greaves F, Vlaev I, et al. Approaches based on behavioral economics could help nudge patients and providers toward lower health spending growth. *Health Aff (Millwood)*. 2013 Apr;32(4):661-8. PMID: 23569045.  
Smith NC, Goldstein DG, Johnson EJ. Choice without awareness: ethical and policy implications of defaults. *J Public Policy Marketing*. 2013 Fall;32(2):159-72.



So, and last but not least, we have to consider several other things that I know that all of us think about regularly, but we can't forget about them. First is ethics. Are we designing things in a way that is ethical and respectful for patients? Are we preserving patient choice for patients? Second is practical implications, and this is probably the area that -- although I think ethics are extremely important, it's the practical implications of things that really get me excited about things. How do you actually deliver this to large numbers of patients in a way that's scalable and affordable? As much as we've expanded access to healthcare, the dollar pool has not expanded that much for what we have to pay. So what is practical? What can you deliver to huge numbers of people in a way that will work over time? What is sustainable? Ask a physician to do something new with a patient for a short period of time. did a research study earlier this year where we had an inpatient clinic and the physicians were doing about a 15-minute assessment on every single patient for a month. They were part of this study; they were pretty compliant; you had to harass them a little bit. But if we expected them to do that forever with no extra remuneration, no decrease in their patient load, how long would it last? So how practical is it? Will it fit in the workflow, not only of the patient but of the healthcare providers that are in the system? And then last but not least, we have to design for patient choice. Patients are individuals, they always have to be in the driver's seat -- you have to present things in a way that patients can actually choose. Give them the information in a way that they can understand it. Give them enough time to process it so that there is a choice made and not just, "Well, my doctor said this, to go there." So in closing, I just propose that patient engagement is important, but there are other things that we have to consider, and sometimes there are other things you can do other than rely on engagement.