Find Value: Keys Lost in Dark Alley. Look Under Streetlight? #140

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Proem

Value propositions can be vague, aspirational, and ethics remote. Think: Uber – The Smartest Way to Get Around; Apple iPhone – The Experience IS the Product; Walmart – Everyday Low Prices; Google – Search Engine for the World.

Imagine these:

XYZ Hospital – Money back guarantee Acme Specialty Services – On-time appts or we pay you We Wish Think Tank – Research for patients People's Pharmacy – Medications you can afford

I've heard people in healthcare say value equals quality + patient experience/cost.



All of this makes me crazy. We have no idea of what cost means anywhere in healthcare. We spend too little time understanding quality to whom - individuals when they're patients, caregivers, or clinicians OR groups of people – communities, OR companies – insurers, employers, healthcare providers?

Before we go any further, let me thank Joey van Leeuwen who creates the amazing music for my podcast, and Kayla Nelson, who serves as my web/social media coach and produces the video trailers for my podcast. You transform my podcast from good to great. You add value.

Introducing Jennifer Bright 02:38

Sara Traigle van Geertruyden from the <u>Partnership to Improve Patient Care</u> introduced me to Jennifer Bright back in May while we schmoozed about value in healthcare. I called Sara because of my floundering to define value. I wanted to stop complaining and sink my teeth into something inspiring, possible, and grounded. Sara sent me an article Jennifer wrote in StatNews, <u>It's time to get healthcare</u> value assessment right. I read her article and had a list of questions in five minutes.

- How can we motivate measure development experts to test value measures for patients, caregivers, and payers that promote positive agency of diverse communities of patients? We can say what we don't want, but what do we want?
- How can we keep our fingers on the pulse of iterative improvement of partnership with patients and caregivers?
- How can we better align the creation and funding of evidence-informed guidance (sometimes known as research) to answer people's questions?

Jennifer Bright is passionate about prevention, access to care, and patient and family involvement in research and care delivery. She's Executive Director of the Innovation and Value Initiative. IVI seeks to advance the science, practice, and use of value assessment in healthcare to make it more meaningful to those who receive, provide, and pay for care. IVI builds community to create rigorous, innovative, and relevant methods and translational research that facilitates patient-centered value.

Let's meet Jennifer Bright.

Health Hats: Thank you so much for joining me. I appreciate this. Sure. It's great. When did you first realize that health was fragile?

Jennifer Bright: Oh, my goodness. I think I shared with you that I came to this early on in my life. When I was 18, both of my parents were diagnosed with stage four cancers within four months of each other. Suddenly my entire family was plunged into the unknown world of surgery and pathology reports and drug regimens and chemotherapy and radiation therapy and things that we just had never heard. My father was in the army. We were lucky to be in what was de facto, the single-payer system that the US



has. And so, they were able to access immediate care, surgical care. Whatever was needed was taken care of. The problem was neither of them was diagnosed early enough. We had as a family a very rude awakening over the next five years. Ultimately my parents both passed away at the age of 50 from really devastating cancers. We didn't know what hit us, to be honest. At a very early age learned things, learned about the role reversal that happens. I learned what it means to be a caregiver to someone dealing with an acute and chronic illness. I learned about advanced directives. I learned about pathology reports. I've learned all kinds of things that I never thought I would understand.

Who's in charge here? Patient agency. 06:20

Jennifer Bright: The big takeaway for me is a lifelong passion for patient agency in healthcare, observing my parents, how they approach their care, and how they were without even being instructed. They were strong activists for themselves. My mother never had a meeting in which she didn't have a notebook, and she was asking questions, taking down notes, and challenging even what the doctors were telling her. And that left an impression on me. It also left an impression on me that little the family had a role or was told or incorporated into decision-making, and the entire episode was happening to us. It wasn't something in which we were on a journey. We weren't acknowledged that we had opinions, fears, anything. And the other thing that it impressed upon me was the importance of prevention and thinking about the problem that we're trying to solve in healthcare. I can't tell you the number of times doctors were writing scripts or suggesting traumatizing interventions; I guess that is the right word without really understanding the impact on the family, on the individual? I watched my mother be talked down to by several doctors who were diminishing her pain, her experience of pain, which turned out to be metastatic breast cancer in her spine. So, she was feeling pain, but several doctors told her that it was all in her head before we got it sorted. These are all things that have stayed with me throughout my life cycle. And it's led to a 30 plus year career focusing on health policy. What's the intersection with patients and with families, and with their experience? Mostly, I'm an agent for how do we make it better? How do we think about health policy and delivery and how we measure what health does for us in ways that matter to real people that's been foundational for me?

Value - what, for who? Magic math. 08:11

Health Hats: That's great; thank you for that. This leads to the reason we're talking because I've been thinking a lot about value in healthcare. What is valuable, and how do we measure value and value to whom? When I think about myself as a person with chronic illness, I have specific goals, and value to me is meeting those goals. I wanted to talk to you more about what you've learned about the different ways that people measure value in healthcare, in life, in technology. There's just so much I don't know. What I know is I'm not satisfied. But I can't take it much farther.

Jennifer Bright: I think one of the biggest problems right now is value is an overused word. And it's one that we've used so much that we don't quite know what we mean when we say it. To quote you, it's value to whom, and value is in that eye of the beholder. We hear that often. That's usually used to dismiss and minimize perspectives that fall outside this very pristine kind of mathematical calculation of



benefit versus risk and equals value. And that's where I think we find ourselves most stuck in this country is we're focused on it from the standpoint of dollars and cents. And we are trying to overlay that viewpoint over top of a human experience. That values first and foremost, what you've talked about, can I play with my kids? Can I play my horn? Then I go to work every day. Can I live without pain, or can I minimize the pain I'm experiencing? And those things are valuable to us as humans, as families, people, but they're not the thing that's getting measured. They're not the thing that is top of mind. Why? Because it's more complicated because it's more individualized because it's harder to measure.

Value from a person point of view, Measurable? 10:32

Jennifer Bright: As a measurement field, thinking of NQF, we've straight to what are the easy things to measure? We've measured the heck out of processes. We can mathematically measure something, think functioning - the six-minute walk test. Those measures become the primary and then everything else is a surrogate endpoint or a contextual consideration, or some other diminutive terminology. Still, it's not held at the same level of importance as the concept of value. Over the last three and a half years, I've been leading the Innovation and Value Initiative. And I got involved in it because when I first learned about it, the first thing I thought it was, this is fascinating. I wonder how they're looking at patient perspectives on value. What's essential to the patient, and how do we measure it from a costeffectiveness economic modeling standpoint? It turns out they were the only ones trying to ask why and how do we do it better? And so that's why I've been at this table for the last three and a half years. And believe me, it is not an easy business. We're talking about identifying what's important and those qualities of life that are important to patients because we can't measure everything. We will die under that burden. And then, once we've decided what's important to measure, how do we go about measuring it in a replicable way, that's scientific, that people can do? How can we do it in a way that's easier because we know that we're burdening healthcare providers, clinicians, hospitals with all this measurement that's happening? And then probably the trickiest part is what I call the magic math, which is all the calculations and the formulas and the black box theory that goes on in determining what picture we get when we talk about values? Yes, there's the business side of value, which is the dollars and cents. But I would argue right now that's probably too much in the driver's seat about the conversation about value. We need to swing the pendulum a little bit and talk about qualities that matter to patients and families and make sure that we acknowledge and bring those factors into the discussion and the measurement of value. Because if we don't take the opportunity to do that, I think we may come out with an economical answer that says this is the lowest cost option, which might serve our purposes from a business model standpoint. Still, it isn't necessarily going to lead to better health outcomes or better satisfaction within patients and families about the quality of their treatment.

Balance - cost, quality, outcomes 13:17

Jennifer Bright: I think we can achieve better balance. I'll give you one example from my mother's treatment. So, this was 30 years ago. She was taking oral morphine, and it has an enormous impact on people's ability to interact, wakefulness, and ability to move their bowels and be mobile. All of it. Yeah. It was horrible. It was debilitating. It changed her as a person and. She was on it and on it. And we



happened to be, at least this is my understanding at the time. Because she was being treated at Walter Reed Army Medical Center, there was a study going on utilizing a port -an innovative port for delivery of morphine straight into your bloodstream, and it wasn't oral. After many weeks of complaining about this, her oncologist got her into this study, and she was able to get the port, and it was transformative. And I will tell you from the context of this conversation, that port and that technology costs more than oral morphine. So if you put that in the context of today's decision-making, what patients are up against often is the difference between technology that can truly transform their life, not just from a pain management standpoint, but from a family interaction allowing our final weeks with that person to be lucid and memories and laughter and not a comatose patient. Versus it's cheap, it's ready, and we will give you access to this option only.

Value to a caregiver? lost wages, burnout, illness 14:58

Health Hats: That's a great example. When I can't solve a problem, I try to go at it totally differently. And sometimes, when I think about value, I think about family caregivers instead of the patient. And I think about even if you're want to focus on money. It's like lost wages, increased illness. It helps me reorient myself. I guess the COVID has made me want to think. I'm a nurse. So, I think about the point of care clinicians as well. And I think about burnout and mental health and illness of our professional caregivers, and I want that stuff to be part of value too.

Jennifer Bright: We do not measure any of that. I'll give you some thoughts. A study I read this morning that a colleague shared with me looked at the career impact of three different mental health conditions: bipolar disorder, depression, and schizophrenia. And it found that there was a measurable suppression of career growth. So wages a 34% that's with the depression diagnosis and it went all the way I think the range went all the way up to 74% with a diagnosis of schizophrenia. That's huge. Think about what we're doing to the economic longevity of people by not diagnosing them early. By not focusing on preventative mental health care. We wait until stage four or, frankly, treat people with mental illness because it makes no economic sense when we're talking about value. If you want to get down to dollars and cents, that is a huge case that nobody has been able to explain. And family caregivers. We've done a lot with rheumatoid arthritis patient communities with other caregiver communities that talk about lost wages and change. I chose my career path, or I chose this job, and I've stayed in this job with little growth because it's where I can get health insurance that will cover my medications. I had an RA patient say they had to leave for disability because their condition was so debilitating. They effectively lost 12 years of career wages in their profession due to not having adequate treatment for their illness. And this is the kind of stuff that gets under our skin, Danny, and makes us say how do we make it better?

Person-first problem solving – listen 17:36

Health Hats: Okay. How do we make it better? I'm on this NQF Cost and Efficiency Standing Committee. And I bring up these issues, and I say things like we're looking for the keys we lost under the streetlight when we lost them in the dark alley because that's where the light is. But I don't feel like I have anything



to offer to inform movement away from how we do it now. So that's your business, right? That's what you're trying to figure out.

Jennifer Bright: Yeah, exactly. I mentioned that I joined IVI because they had such a strong Innovation and Value Initiative or IVI. I joined the organization because I was intrigued and impressed that they were taking seriously the notion that a patient-centered focus needed to guide us out of the woods, if you will. And so, involvement of patient communities in our research, participation in our governance involvement, and helping us think through the most essential types of work for this organization to be working on, we take very seriously. But I think I have a couple of specific examples of things we're doing and where I think the field needs to improve. One example is something that we often say, which is start with the patient and the family. Suppose you want to be, by extension. In that case, we need to do a better job in the research community of understanding what is important to patients and families living with these conditions, whether it's an acute episode or a chronic illness, or something rare. We are not doing a good job in the research community, writ large of gathering information about what's essential to those. What are the problems we're trying to solve?

Health Hats: So that's listening. You're talking about listening to those communities. Okay.

Commonalities: fatigue, function, loneliness, pain, angst 19:47

Jennifer Bright: That is going to yield a whole host of issues. But I think what then we need to be listening for is what the signals are? There are common things across all kinds of disease states that we need to listen for and prioritize. For example, fatigue is a pervasive experience in all types of disease states, but it varies. It varies in magnitude. And it varies in how we measure it. And it isn't always the most critical factor. So, it's finding that cross-section of what's important to patients. How important is it? And are there connect points across disease where we can make maximum impact. If we measure this across all conditions, do we learn something that improves our conceptualization of value?

Health Hats: Okay. So, like loneliness, like pain, I'm just trying to think of what are some of those?

Jennifer Bright: Fatigue is one that I hear often. Another is functioning. But of course, that will differ depending on disease states about what that means and how would you measure it? But for example, some criticism we've heard from patient communities is often functioning is measured in a clinical trial. But, it's not measured by using any standard that's relevant to the patient community.

Health Hats: So, standards, oh my goodness.

Aligning measurement and innovation with what people need 21:19

Jennifer Bright: So, in the process of trying to standardize our measurement and how we measure quality, what we've done is find the least common denominator. And usually, it's a process measure,



and it isn't necessarily one that's even correlated to what patients expect. And then when patients have the audacity to the point that out, what they get told is, but this is how we've always done it. It's a validated measure, and it's scientifically replicable, and all the other terminology we use to kind of cut patients out of the conversation. And I think we're at a point here in the US where we need to just wholly, not start from scratch, but we need to lose that this is the way we've always done it thinking. And one thing you'd see, for example, FDA has this patient-focused drug development project, which they've been doing, and they just did a report where they self-evaluated themselves. And they said this had been significant work. I think they need to go to the next step. Take all that information they've gathered across 20 some odd conditions and find the signals like what's unique among all these disease groups. But then what are some of the themes that cut across all those reports, and where does that lead us in terms of feedback to the health innovation complex? Not just drugs- devices, diagnostics, all of it. Where do we give them marching orders that say, if you want to make a dent in health outcomes, here materially are the five things that your research should include and should be able to demonstrate impact? If we had started with that with a drug in COVID, for example, or if we had started with that with a drug in the Alzheimer's space, would we be having a different conversation now about the first therapy that's been available in the Alzheimer's space? And everybody has been waiting for so long, and families and patients are desperate for options. But we didn't take the time and go back and make sure that the things we were measuring and the targets for that innovation aligned with what patients needed. That's a mistake. And that's not an indictment of any actor in this whole chain. Still, if we're genuinely going to have a patient-centered health system, and if we're genuinely going to get to value, it's my fervent belief that we have got to start listening to the patient communities that have expertise and experience in these disease categories and ask them what the top five commonalities are? I know that that sounds very pat and simple, but it is an enormous amount of work.

Health Hats: The golden rule is pat and simple and a bitch to do. Yeah. Yes.

Leadership voice from patients and patient communities 24:15

Jennifer Bright: It requires that everybody acknowledge that the room's authentic leadership voice needs to be the patient community. And I'm not saying one patient, and I'm not saying just a prominent professional, nonprofit patient organization. There are ways to make sure there's representative participation from within a patient community. And the way you know that you've achieved it is when you push, go to different groups and stretch and do the necessary outreach. And when you start to hear the same thing from all those other groups that you've triangulated, then you've found the representative sample. But it takes a lot of work, and it takes a lot of revenue. And unfortunately, I think we are much more comfortable funneling all the revenue to academic centers that are well-established in research methodology and everything else. And no disrespect to any of them. But they're not the ones with the experience. People like you, who are living with decision-making about your condition every day, are the ones we should be listening to. How's that for a solution? I don't know.



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IVI Business Model 26:18

Health Hats: Tell me more about this membership model of your organization. Are individuals members? Are organizations members? Communities?

Jennifer Bright: We've set up that we have set up the membership structure such that organizations can be members, but individuals can also be members.

Health Hats: So, what about communities? What if Chicago wanted to join?

Jennifer Bright: No, that's interesting. We haven't come across government agencies or cities, but I think there's room for that under the organizational umbrella or even an individual. Someone within the Medicaid department in a city or a state was interested in becoming a member, or they could join as an individual. And that allows for that. Because they may not be able to represent their organization inside a member, but because of their personal interests or skill set or things like that, they have a personal interest in being a member of the organization. So, we deliberately made both options. We have corporate. We have medical centers. We have device companies. We have drug companies we're hoping to have some insurance companies come to the tables, employer organizations. That's how we roll. That said, we also engage with organizations that aren't necessarily members.

Multi-stakeholder advisory groups 27:35

Jennifer Bright: The first thing we did was build an advisory group that brought together experts in the field. So we have five patient organizations at the table who help us with outreach on patient side research that we want to do. They helped us connect with patient communities and individuals that could feed into this research. We have clinicians at the table, both the significant guilds we have employer groups. We have insurers. We have clinicians all it's like a 22-member advisory group. Maybe a couple of them are de facto members of IVI, but they've all shown up to every call that we've had, where we talk about, this is what we're trying to build. What do we need to be thinking about? What's your perspective about the problem we're trying to solve? If we could do this way of measuring, would it be useful? Yes or no. These are the questions we put to this advisory group, and they are all in. It's been a pleasure to be a part of that. But that's another way that IVI the Innovation and Value Initiative engages with multiple stakeholders to bring this multi-dimensional view of value into the world. You started by saying the value is dollars and cents or is quality of life. We're trying to develop models that



allow you to look at it from different angles. Suppose you want to think about it that way because it's not a flat proposition, and it's not black and white either. We have to shift to say if we're looking at the population with major depressive disorder, but what we want to understand is the outcomes and the factors that are important to black women living with depression? Can we pivot the model to be able to look at that? The answer should be yes.

Variation within diversity 29:27

Jennifer Bright: We should be able to look at different perspectives and angles on the same question and get an answer. Suppose all we're doing and talking about value is saying a plus B equals X answer, and that's what's used to guide our thinking about everything from benefits design to whether something comes to market. In that case, we are making a massive mistake, in my opinion, and no, COVID and everything else over the last year has shown us that people are different and respond differently to disease. They respond differently to interventions. They react differently to vaccines. And if we have not learned as a society that we can't just come up with a one-size-fits-all answer, then we have been asleep for the last year.

Health Hats: I think that dilemma of the balance of appreciating tremendous diversity yet thinking about themes that run through that diversity. That you've hit a home run when you look at something from many perspectives. And you hear similar themes across all those perspectives, then, okay, now we're onto something. This is worth investing in and developing the science of measuring. And then we have all these groups that we can now go and test. It's brilliant.

Finding IVI 31:03

Health Hats: So how can people I know you're going to send me stuff so I can put it in the show notes but say just a bit of there is five people who are going to listen to this who are going to go, oh my God, I want to be part of this. What should they do?

Jennifer Bright: We have a website it's www.thevalueinitiative.org. And there is information about our membership. We have one of my colleagues, Erica Malik. Her passion is to help connect people and bring people into the organization in whatever capacity fits them. So, we have lots of opportunities there. We have a newsletter that goes out to interested parties. If you go to our website, you can sign up for that, even if you're not a member, that's just a general here's what's going on and what we're working on here are published here as a webinar series that we're getting ready to do that kind of thing. And then obviously people can contact me directly. But we are on Twitter. We are on LinkedIn. We publish our series called Value Blueprints, which you can access on our website. These are a couple of pages of research briefs that kind of try to synthesize things that we're learning. Because I think one of the things that we take very seriously is that this is a significant proposition and there's a lot of technical aspects to it that people don't understand. And so, one of the things is we want to share learning as we go. For example, I mentioned the major depressive disorder model, that's a multi-year proposition, it's a big animal, but there are points at which we are publishing what we learn because it's it stands on its



own. So, for example, we just published a paper about our patient engagement strategy and what we were learning about how to involve patients in our research. That's just as important to the field as the results of the model that we eventually built. And I would say personally, as a non-economist, it's more important because that's where change happens when we show people that, yes, it's complex. Yes, it takes a lot of time. Yes. You have to spend a lot of time talking to people. But we're showing how. So that fewer voices are saying no can't be done. Or it's too complex. That's just not a reason not to do it. It just isn't when we've got people living with complex co-occurring health disorders that are not being well-treated. They're ending up in hospitals or worse. And all we're doing is collecting the statistics about a poor outcome, about suicide, about opiate disorders. These are the metrics that we're spending all our money and energy on when what we should be spending it on is figuring out what kind of treatment, what kind of diagnostics, what kind of interventions can stop that outcome from happening? That, to me, will tell me when we've learned as a health system.

Strategy and tactics. Inspire and motivate 34:05

Health Hats: I think you and I need to have more tactical and strategic conversations. The tricky part for me is that as an advocate, the first thing, and usually the most time, is spent getting people to drink the Kool-Aid. I don't mean that. I don't like how I said that. The Kool-Aid part is okay. Getting people, it's like people wanting to drink the Kool-Aid. But once people have drunk the Kool-Aid, then it's okay, now what? Drinking the Kool-Aid is essential. But, what do you do with that is that's what's hard.

Jennifer Bright: One thing we're doing that I didn't mention is that IVI is sponsoring. We have an annual method, what we call a method summit, and we are fortunate enough to have a PCORI engagement, a grant to help us put this on, and our first one was wildly successful, and thank God it happened right before COVID shut us all down. This next one is happening this October, and the focus of it is how do we measure patient perspectives on value? What's important to measure? How do we measure it, and how do we push forward an agenda that is a priority? It was not just for people like they sold it for payers, pharmaceutical companies, regulators, PCORI, and NIH. How do we make those? Can we define that subset? Small set where it's high impact, high relevance, and what we need is high resource. So that's our theme for this fall.

Health Hats: I'm interested. I'm really interested.

Jennifer Bright: Yeah, and I think there are some huge opportunities with PCORI's reauthorization, and there is a slightly expanded mandate. There's a huge opportunity there to begin to measure things that we haven't heretofore. So, the cost impacts like things like lost wages and caregiver burden. We haven't been able to put numbers on them in a way that's considered valid. We need to do that. That's a huge opportunity. The same for now NQF has new leadership in Dr. Dana Safron, and she brings enormous perspective from her prior experience. There's also an opportunity to make the NQF mandate more relevant to day-to-day decision-making, I think.



Health Hats: I so agree. At last, this one. Was it this week or last week? I can't even remember. This is Monday, so it must have been last week. I was on a call and, I'm the patient-caregiver representative on this standing committee. And my question is, how has this measure we're reviewing either motivated change or informed change. And I think the answer is it hasn't. And we're investing all this time and money in it if it doesn't inform or motivate, or should I say inspire?

What problem are we solving? 37:29

Jennifer Bright: But the purpose of quality measurement heretofore has been for two things accreditation and payment reimbursement. And that neither one of those things has to do with the health outcomes. Not first and foremost. And that's where I think we have an opportunity. I'm being. I'm really audacious now. I can't believe I'm saying this on camera. I think we need to look at all of these systems that we've built and take a hard look and say, Are we willing to keep throwing all this money and effort at something that materially is not changing lives. That's precisely what you just said. Yeah. And that's what, frankly, I think is at the heart of health equity, is this conversation about we cannot continue to do things the same way we've been doing them because we are poorly serving wide swaths of our population. And we are. We don't even know it in some instances because we do not measure it. But in many cases, we know exactly how badly we're doing. We're just not willing to do anything. And I think that part of the value conversation needs to be, what are we learning about patient experience, and why are we continuing to allow that to be the standard of the status quo? And that's where there's an opportunity in the conversation about the value, to be perfectly frank. I do care about the cost of things. I think we have gotten obsessed with the notion that arguing over the cost of something is a proxy for whether value is available to everybody. And I think we are missing the forest for the trees. It's a red herring to focus on the dollars and cents and not say, are we solving a problem that matters to patients living with this condition? That's the harder question, but that's the question we should be all looking at each other in the eye and saying yes or no, because if the answer is no, then we should undo everything that we've been doing and start over.

Health Hats: Let's leave it at that.

Jennifer Bright: Thank you so much. It's. Thank you. It's good to talk with you. We will speak again. I know. Take care. All right. Take care, Danny.

Reflection 39:43

So much said here. Who cares about value and measurement? At one point in my career as a quality management professional, I thought, *if you can't measure it, you can't manage it*. I don't subscribe to that now. Can't do without leadership and will, but we can do without measurement. On the other hand, measurement can help focus, guide adjustment, and make a statement about values. Values, as in principles, ethics, priorities, point of view. My activism focuses on *person-first*. *Person-first* starts with understanding individual variation in circumstances, history, preferences - lives - of the people making clinical decisions together (direct care clinicians, patients, and caregivers). These people make decisions



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within the context of institutional workflows, as well as community and personal life flows. Person-first means hearing the questions and concerns people have about safe living, well-being, and meaningful lives and then conducting research, developing guidelines, and digitizing solutions to inform their choices.

Person-first means recognizing that people vary in comfort with uncertainty, understanding of the messiness of science, tolerance of risk, and curiosity and empathy for their decision collaborators. These characteristics impact both the readiness and ability to make decisions together and follow-through to implement the decisions eventually made.

Jennifer spoke of starting with the person, aligning measurement with what people need, problem solving with the leadership of people making health decisions, balancing cost, quality, and outcomes, and finding commonalities across conditions. Check out IVI, the Innovation and Value Initiative. Consider joining. I did. Thanks.

