“Empowering Cancer Patients: Navigating the Complexities of Diagnosis and Care” (Ari Akerstein and Brad Power) [#130]

Brad Power
February 5, 2025

“Our thesis is that diagnostics are the key to getting the best outcomes. Another observation is that the diagnostic technologies are exploding in what's available today. Tissue analysis and scans are used. DNA sequencing is still pretty low, but increasing. Things like liquid biopsies, functional testing, and RNA, are not utilized.” – Ari Akerstein

“The approach that we're taking is in thinking about what it would look like to design a system that's built around the patient, rather than having the patient contort to the medical system… Could you build a better thing that patients, in aggregate, are able to pull toward a better thing, whatever that ends up looking like, and bend the [access to innovation] curve that way?” – Ari Akerstein

“There's the report. There's that thing that's written down, and then there’s what does it mean? The one question on the mind of the patient is: Is this bad news? Should I be concerned, or is this good news, and I should not be concerned? The only way you get that, typically, is from talking to an expert who's seen a lot of cases to put it in context.” – Brad Power

“What are the characteristics if we were trying to design something that maximizes trust? Who do you trust? What do you trust? What does trust mean to you when you're getting test results when the confidence around them is not 100%, let's say, or the interpretation isn't. What does trust mean to you, and what is trustworthy?” – Brad Power

Meeting Summary

For patients and their loved-ones, a cancer diagnosis can feel like being dropped into a war zone without a map. You are bombarded with complex medical terminology, an avalanche of information, and a fragmented healthcare system that often feels impersonal and overwhelming. This can lead to feelings of helplessness and anxiety, hindering your ability to make informed decisions and actively participate in your care.

Specific challenges include:

- **High diagnostic errors**: One estimate suggests at least 40,000 cancer patients die each year in the US as a result of misdiagnosis or delayed diagnosis.
- **High variance in care**: Academic centers and community clinics offer vastly divergent experiences for patients. Household income is a large predictor of the care one will receive.
- **Missed opportunities to capitalize on emerging diagnostic technologies**: While tissue analysis and scans are commonly used, and DNA sequencing is increasing, many doctors don't prescribe emerging technologies such as liquid biopsies, functional testing, transcriptomics (RNA sequencing), proteomics, and other newer tests, missing opportunities to guide treatment decisions.
- **Disjointed patient experience**: Even the most proactive and informed patients struggle to navigate the complexities of the healthcare system.

“Empowering Cancer Patients: Navigating the Complexities of Diagnosis and Care” (Ari Akerstein and Brad Power) [#130]

- **Inadequate personalized support**: Cancer care is not one-size-fits-all. Each patient's needs, values, and treatment goals are unique. You deserve a healthcare system that recognizes and supports your individuality, providing tailored guidance and resources to empower you throughout your cancer journey.

Solution: Empowering Patients with Diagnostics, Community, Knowledge, and Support

The future of cancer care is rapidly evolving, with AI agents, personalized medicine, targeted therapies, and immunotherapies playing an increasingly important role. You need a platform to help you navigate this new landscape, providing you with the information and support you need to make informed decisions about your cancer care. To address these problems, you need access to:

- **Concierge testing guidance**: Selecting the latest diagnostic tests and technologies tailored to your individual needs, such as whole-genome sequencing, blood panels (liquid biopsies), and proteomics.
- **Personalized navigation**: Having a health navigation service to streamline the process of finding and accessing the right tests and the best providers and relevant/local services that match your particular needs, combined with a health data vault to manage your records and preferences.
- **Education**: Including curated information and expert guidance to help you understand your options, make informed decisions, and navigate your cancer journey with confidence.
- **Community**: Linking you to other patients that have traveled down similar paths you are on to ask questions, feel emotionally supported, and get recommendations.

Ari Akerstein and Brad Power are uniquely qualified to lead a discussion about the design and development of a "one stop shop" for diagnostic and navigation services for cancer patients and caregivers. Ari is a software product manager with experience at Meta/Facebook, Walmart Labs, and Included Health, and a cancer survivor. Brad is a process innovation consultant, the co-founder of the Cancer Patient Lab, and a cancer survivor. Together they hosted an accelerator (cancerhackerlab.com) for a dozen cancer diagnostics and navigation startups at the end of 2024. They learned that few startups try to serve consumers (patients and caregivers) directly. The incentives in healthcare drive founders to pursue a business model where they sell to pharmaceutical companies or providers.

What are the challenges patients and caregivers faced in getting diagnostic tests and interpreting them?

- **False positives**: Patients who get more tests will have to deal with false positives.
- **Noise**: Some of these tests have gotten so good at finding stuff that they pick up noise, things that your immune system is going to deal with just fine.
- **Interpretation**: Patients need help from trusted experts to interpret test results and provide context.
- **Education**: Patients need a glossary and other education materials to understand test results. They don't know what they don't know, and they don't know how to find out.
- **Retesting**: Retesting is useful to confirm results and increase confidence.

“Empowering Cancer Patients: Navigating the Complexities of Diagnosis and Care” (Ari Akerstein and Brad Power) [#130]

- **Guidelines**: Getting doctors to try new tests is hard enough; they don’t consistently follow the testing guidelines. Everyone should get basic tests, like DNA sequencing. Some doctors don’t prescribe the recommended tests because of a lack of education and inertia.
- **Test results concordance**: How to interpret apparent contradictions between test results.
- **Advice concordance**: You're going to have competition from online search engines, what people like to call “Dr. Google”. You can get good advice, you can get bad advice, and you can get the full range in between, and there is no easy way to tell the difference.
- **Useful long-term, but not now**: Some tests will not change the course of your therapy now, so there's no point in wasting time, attention, and money on tests that are going to give you background information.

How should you decide when to try a new test, especially one that’s not standard?

- **Skepticism**: When science uncovers technologies or insights that are new, it's really hard to figure out if they are useful. Skepticism is a natural reaction. When innovations first come out, people have reservations about whether they are true. In healthcare there is a built-in system to generate evidence that a new approach is worthwhile, the prospective, controlled, randomized clinical trial, and that is put into practice through medical practice guidelines, called “the standard of care”. It is effective, but extremely slow and expensive.
- **Safety**: To go off of the standard of care is dangerous. It's the safe decision at a certain point to stay on the standard of care, and then at a certain point, as the acceptance of the value of a new test increases, it probably becomes the safest decision to go beyond the standard of care.
- **Tipping point**: Figuring out when to switch between those two “safeties” is very difficult. How can you acquire the wisdom to evaluate the potential flood of information that you can get from all of these diagnostics, some of which are going to have good information, and some of which are going to have bad information?
- **Diagnostics vs. treatments**: Treatment decisions have serious impacts. Deciding whether to get a test to get information is and should be held to a lower standard. As Bryce Olson said, “Mo’ data is mo’ bettah.” There are costs to tests, and tests need to be interpreted correctly, but these problems can be solved.

How can test results and advice be trustworthy?

- **Multiple sources**: Get multiple tests and triangulation of multiple sources, from multiple oncologists in different specialties, like pathologists, smart generalists, and community.
- **Experts**: Find an expert whose advice you trust, usually a doctor, someone with a beginner's mindset who is looking for potential solutions.
- **Engaged patients**: Talk to other patients and see what their experience was, especially people that attend events like this and probably have seen quite a lot.

What was the feedback on the early design concepts that Ari and Brad are building?

“Empowering Cancer Patients: Navigating the Complexities of Diagnosis and Care” (Ari Akerstein and Brad Power) [#130]

- **Good questions**: The quality of the answer is going to depend on the quality of the question, so help them design good questions.
- **Access**: Consider how to address the potential elitism and access issues in paying out-of-pocket for advanced diagnostic services
- **Present and future information value**: Help patients justify a test (to their doctor or their insurance company) that is going to provide information that won’t be useful in a treatment decision now, but may be useful longitudinally or in the future.

How can you learn more?

- Sign up to be part of a user test group to help review and develop services - contact Ari at ari@cancerhackerlab.com or Brad at bradpower@cancerpatientlab.org.
- Develop your principles about your profile on when to pursue novel diagnostic tests versus staying within the standard of care.

“Empowering Cancer Patients: Navigating the Complexities of Diagnosis and Care” (Ari Akerstein and Brad Power) [#130]

Meeting Notes

KEYWORDS

Cancer diagnostics, patient advocacy, diagnostic errors, patient trust, diagnostic tests, standard of care, precision medicine, diagnostic navigation, expert guidance, patient experience, diagnostic adoption, healthcare costs, patient empowerment, diagnostic accuracy, patient support.

SPEAKERS

Ari Akerstein (35%), Rick Davis (22%), Richard Anders (12%), Roger Royse (12%), Brad Power (10%), David Plunkett (6%), Mike Harris (3%), Alane Watkins (0%)

SUMMARY

Roger Royse introduced the Cancer Patient Lab Weekly Webinar Series, emphasizing the importance of cancer diagnostics. Ari Akerstein and Brad Power discussed their new initiative to improve diagnostic accuracy and patient outcomes. They highlighted issues like high diagnostic errors, lack of patient trust, and the underutilization of advanced diagnostics. Akerstein and Power proposed a patient-centric system that integrates expert guidance, community support, and a marketplace for diagnostic tests. They stressed the need for better diagnostic trust and the potential of a subscription model to provide affordable access to expert advice. The discussion also touched on the challenges of accessing advanced diagnostics due to cost and systemic barriers.

OUTLINE

Introductions and Overview

- Roger Royse introduced Brad and Ari, who discussed the importance of cancer diagnostics.
- Ari Akerstein described his consumer technology background and experience with diffuse large B cell lymphoma.
- There is a shift towards more engaged and informed patients who want access to their medical information.
- Diagnostics enable the best patient outcomes.
- Diagnostic technologies are advancing rapidly.
- Adoption of diagnostics faces challenges of diagnostic errors and a lack of patient trust in the system.

Diagnostic Technologies and Patient Trust

- Many new tests, such as liquid biopsies, functional testing, and RNA sequencing are underutilized in cancer care.
- Diagnostic errors affect treatment decisions.
- Many doctors are unaware of new diagnostic tests, which are particularly valuable for Stage IV patients.

“Empowering Cancer Patients: Navigating the Complexities of Diagnosis and Care” (Ari Akerstein and Brad Power) [#130]

Designing a Patient-Centric System

- Patients and caregivers need a system that puts the patient at the center, rather than the medical system.
- A trusted diagnostic guide can help select and order tests outside the provider network.
- AI agents and community connections can provide useful guidance.

Challenges and Solutions in Diagnostic Testing

- Roger Royse shared his experience with false positives and the importance of having trusted experts interpret test results.
- David Plunkett discusses the challenges of understanding diagnostic reports and the importance of having a glossary for patients.
- Brad Power and David Plunkett emphasize the need for expert interpretation of diagnostic tests and the role of oncologists in providing context.
- Rick Davis highlights the importance of retesting for cancer patients and the challenges of getting doctors to follow guidelines.

Trust and Expertise in Diagnostic Decisions

- Rick Davis discussed the importance of trust in diagnostic tests and the role of oncologists in providing accurate information.
- Ari Akerstein and Brad Power shared their design of a subscription model to provide diagnostic consultation and advice.
- You need to evaluate the quality of diagnostic information.
- There are challenges in going off standard of care.

Economic and Accessibility Concerns

- Rick Davis raised concerns about the elitist nature of some diagnostic tests and the challenges of accessibility for patients without financial resources.
- If patients pay out-of-pocket for diagnostic tests they can have more influence in decisions about their care.
- There are challenges in accessing basic testing for patients who can’t afford them. Centers of excellence can do a better job of helping get access.

“Empowering Cancer Patients: Navigating the Complexities of Diagnosis and Care” (Ari Akerstein and Brad Power) [#130]

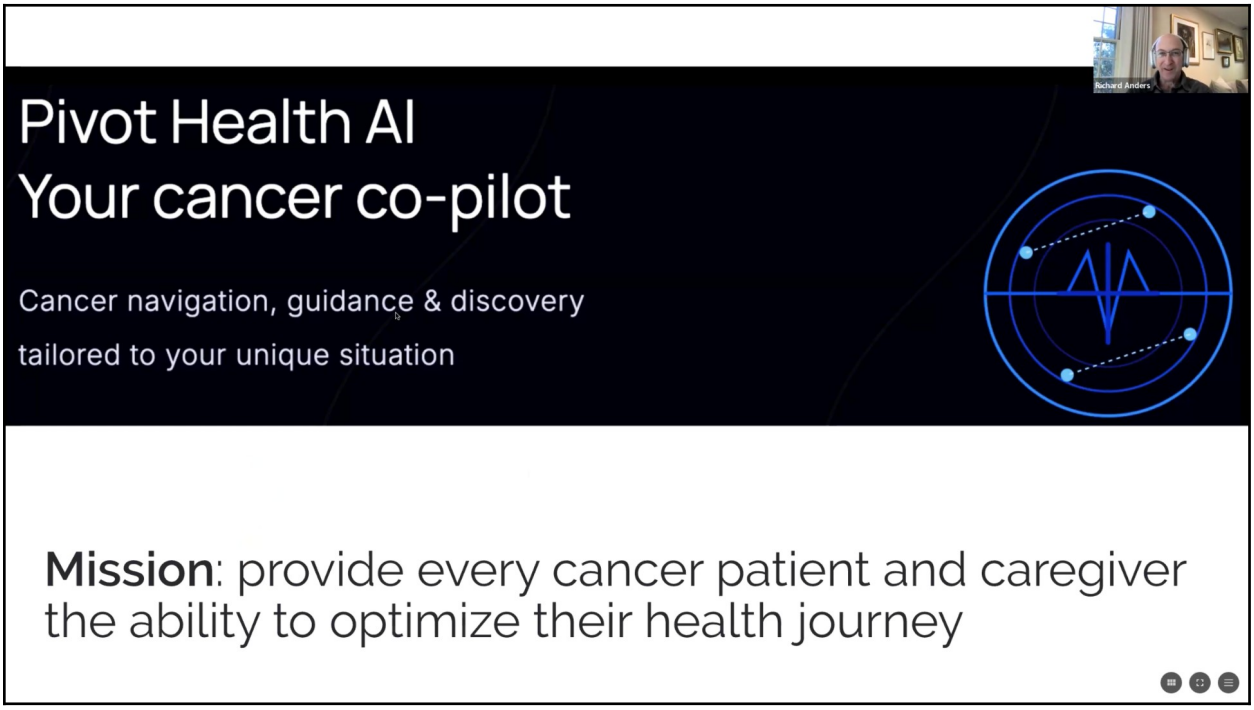
TRANSCRIPT

Roger Royse
Welcome to the Cancer Patient Lab weekly webinar series. I'm on the board of the Cancer Patient Lab.

Before we get started, none of this is medical advice. Please consult your own doctor for any advice specific to your situation.

The Cancer Patient Lab is a 501(c)(3) nonprofit organization, so it depends on contributions from the public. If you'd like to make a contribution, please go to our website and use the “Donate” button.

I want to introduce you to Brad and Ari, who are going to talk about the importance of cancer diagnostics. We've had a lot of sessions here, and I've been beating the drum forever about the importance of diagnostics because, believe it or not, there's a movement out there that, gee, patients shouldn't have so much information. They don't need to know. Let's wait until they get wheeled into the emergency room before we tell them what's wrong with them. That's changing. We're getting more engaged patients and more informed patients, and people are starting to say, “I do want to know, myself. I want my information.” Brad and Ari are working with an accelerator and a new company with a program that promotes those technologies.

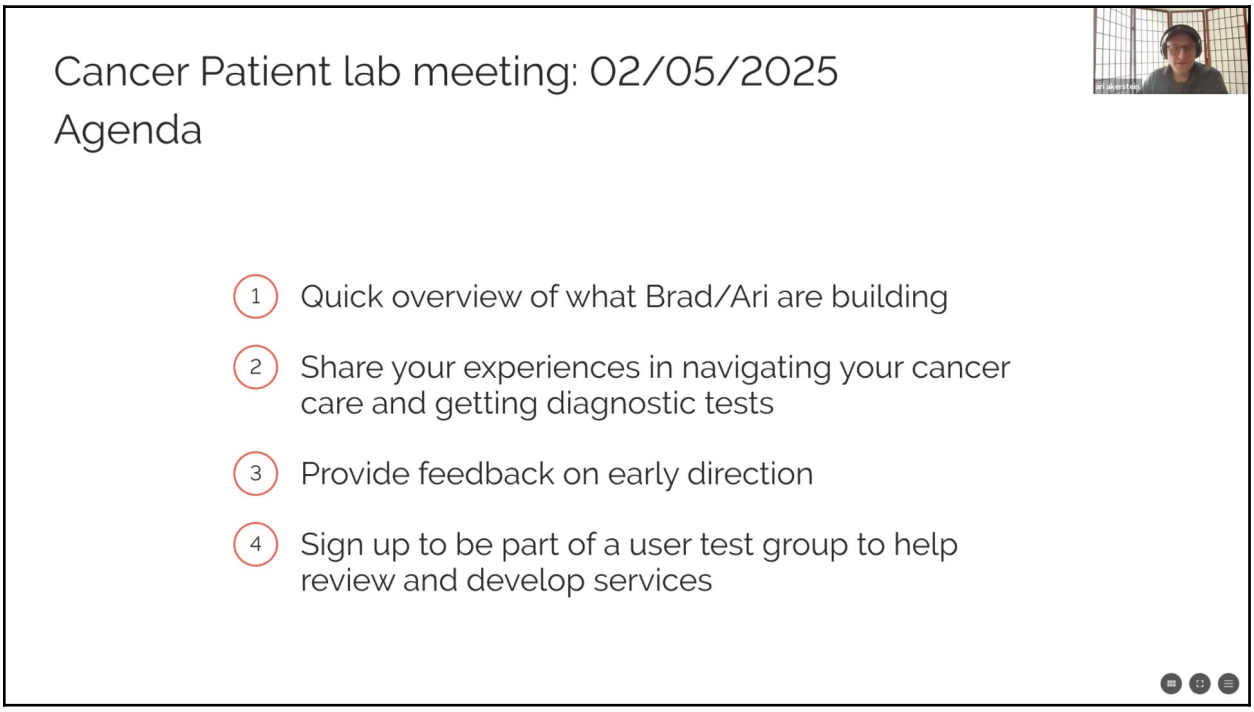


Ari Akerstein 1:57
By way of a quick intro, I gave a talk here a few months ago. A brief background on me: I’m coming from a consumer technology background. I’m a cancer survivor. I went through diffuse

“Empowering Cancer Patients: Navigating the Complexities of Diagnosis and Care” (Ari Akerstein and Brad Power) [#130]

large B cell lymphoma a few years ago, and that was my entry point into the wonderful world of patient self advocacy, as it were, diagnostics, and all the fun that that comes from that.

You all know Brad, so I don't think he needs any intro.

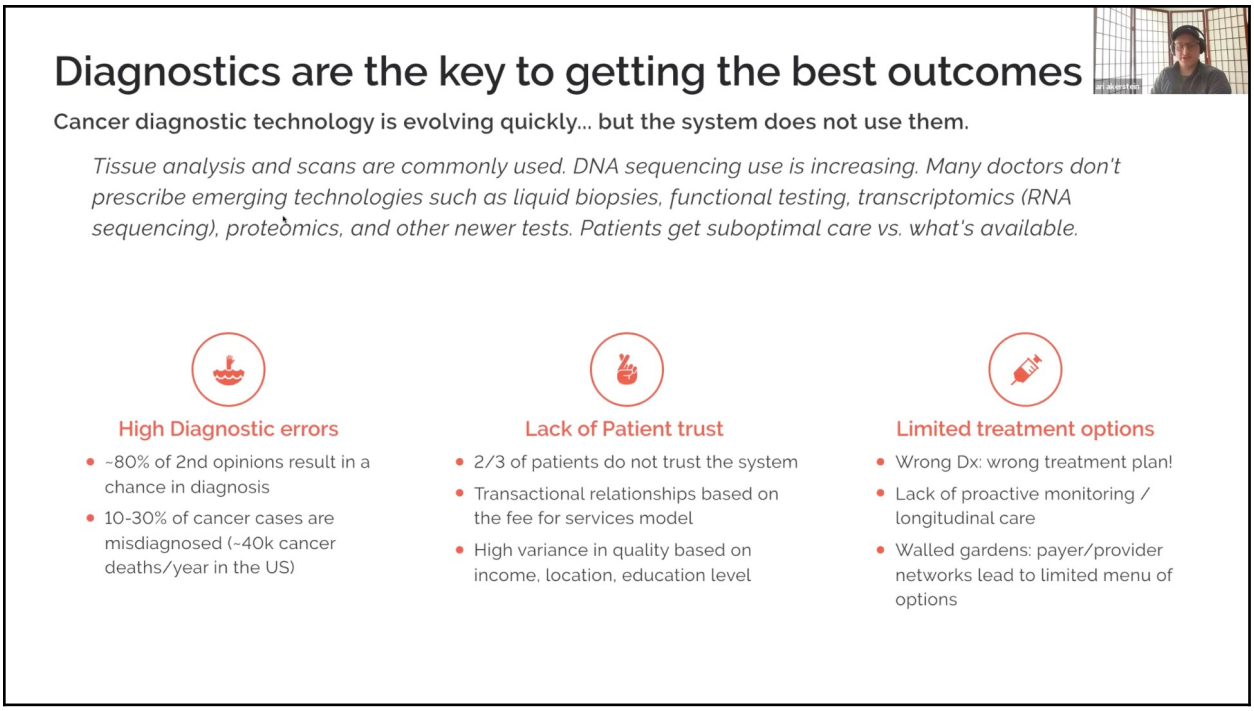


What we'd like to go through here is to provide a quick overview of what Brad and I have been working on with respect to a new initiative in terms of addressing some of the problems that we see in the industry. Roger, to your point, this is maybe somewhat adjacent to the accelerator. We certainly can talk about that, but we'll be talking more about the approach that we're taking with this new company initiative.

We want to talk about peoples’ experiences in navigating your own cancer care and getting diagnostic tests, in particular – The Good, the Bad, and the Ugly. We would love to get some early feedback on our direction, and the approach that we're taking. The other thing is that we're starting to shift from visioning to putting pen to paper, or pixels on the screen, however you want to think about it, workflows in motion, and thinking about partnering with folks you know that would benefit from this kind of service. That's a call to sign up to learn more.

The approach that we're taking overall is in thinking about what it would look like to design a system that's built around the patient, rather than having the patient contort to the medical system.

“Empowering Cancer Patients: Navigating the Complexities of Diagnosis and Care” (Ari Akerstein and Brad Power) [#130]



Our thesis is that diagnostics are the key to getting the best outcomes. Another observation is that the diagnostic technologies are exploding in what's available today. Tissue analysis and scans are used. DNA sequencing is still pretty low, but increasing. Things like liquid biopsies, functional testing, and RNA, are not utilized.

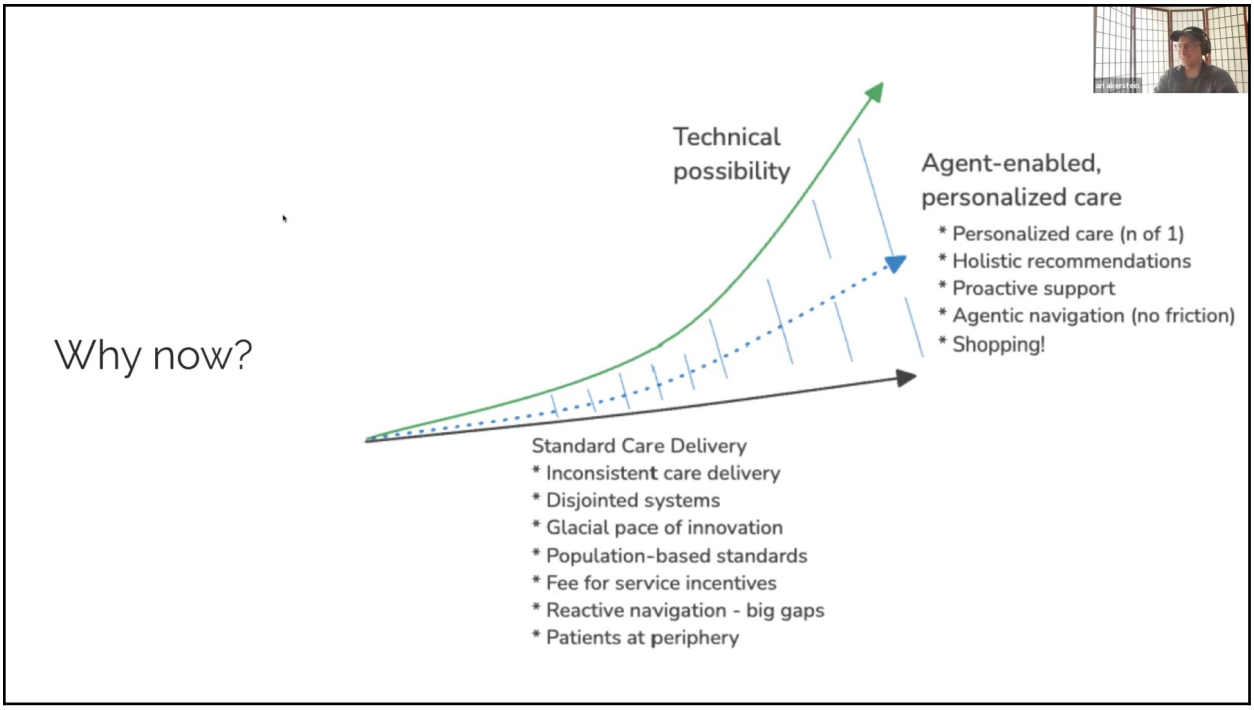
An anecdote: I went to Dana Farber for a checkup just the other day. I asked the question, “Why are we doing just standard panels for monitoring follicular lymphoma?” “I wouldn't know what to do with the liquid biopsy. It's not part of the standard of care, etc.” The downstream impact on patients – I’m not saying that this is directly causal, but certainly contributing – is that you see clear trends of a lack of patient trust. Something like two-thirds of patients do not trust the system. We have a transactional “fee for services” system that introduces really warped incentives. Patients see through that very clearly.

In terms of the diagnostics themselves, we have high diagnostic errors. I saw a crazy statistic from Mayo that something like 80% of second opinions result in a material change in diagnosis, which is fascinating. One of our close collaborators, Tony Magliocco, who many of you may know, shared that as we pull on the thread, we find the diagnostic error rate is worse than we suspected.

When you think about the importance of a diagnostic and then map that into a treatment decision, with a wrong diagnosis, you're off on the wrong foot on the treatment path. Many of the folks here may have experienced that with changes in diagnosis.

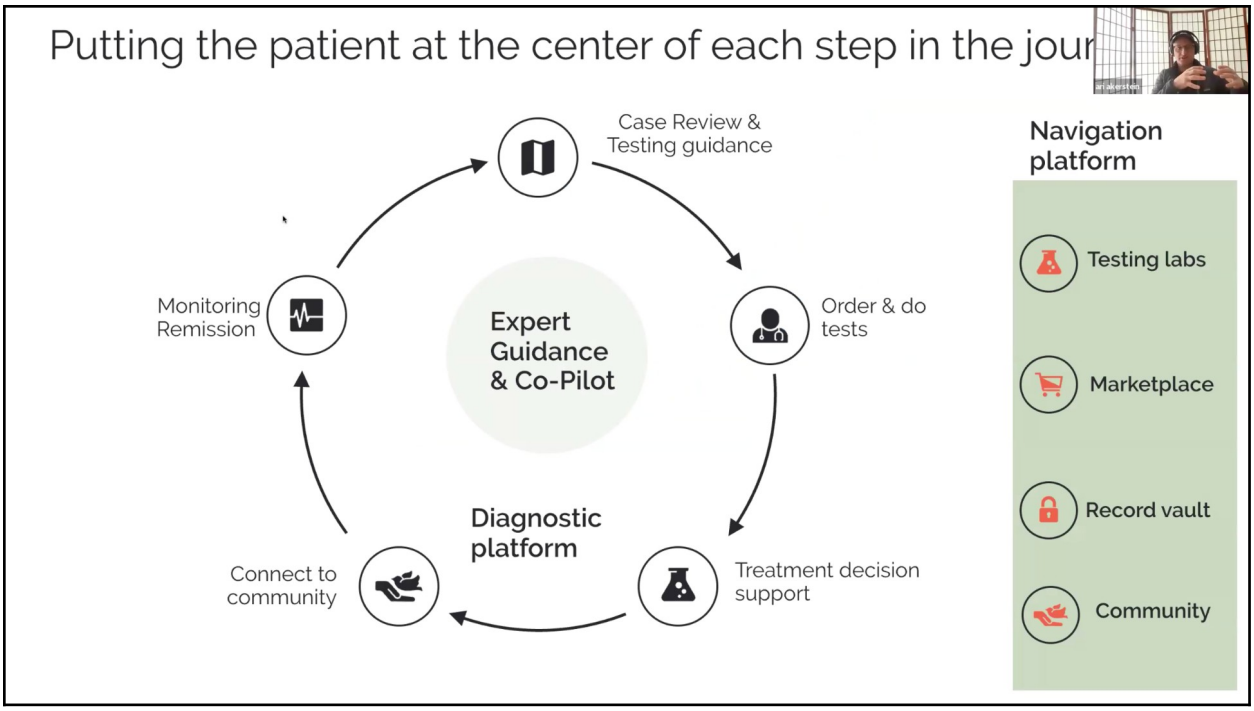
There's also a lack of proactive monitoring over time, longitudinally. Again, back to that transactional system and that menu of options that is available to patients, is limited based on the payer-provider network and for other reasons regarding reimbursement and other things.

Brad Power 8:43
Doctors don't know about the full range of possible tests. They're not standard, and yet those tests could be very valuable, particularly for Stage IV patients and patients beyond the standard of care. That's a really big gap.



Ari Akerstein 9:01
We think about the green line being the curve of technical possibilities, which are moving very quickly. I was just reading about Alpha Fold 3 or 4 the other day. It's astonishing. On the bottom is the black line, which would be what you might think of as a standard of care. You have the best in class standard of care at the Centers of Excellence. You have variants inside of that, where you could have a bar on how much that is. Our aspiration would be to think about, how do you bend that curve from what the baseline adoption might actually be, which is to say a factory model, treating on averages, all the things that I've listed out here. But the pace of adoption of innovation is slower than it needs to be, and that directly impacts patients. The nerd in Brad, mathematician, is how do we increase the integral, the area under the curve of that blue dotted line? How do we increase that in terms of impacting patient outcomes and patient experiences? And so that's what we're after here.

“Empowering Cancer Patients: Navigating the Complexities of Diagnosis and Care” (Ari Akerstein and Brad Power) [#130]



In thinking about what it might look like to put the patient at the center, we think of this in two parts. You have diagnostics on the one hand, which is this circuit that you're seeing in this circular chart, and navigation. We've been working pretty closely with Tony Magliocco in thinking about getting that diagnostic trust locked in. That would start with a case review and ability to not only order the tests that are inside your provider network, but surveying the entire landscape of what makes sense, given a person's history and a deep understanding of their biomarkers. What do we need to make the most informed decision? Do those tests, and make an informed decision and then do the treatment. Connect with the treating location.

An interesting part of this is that if a patient has diagnostic trust and confidence, then you can point them into different provider networks or treating locations, as is useful. When I think about my own particular experience with this: You're diagnosed with something. You are disoriented. You really don't know where to begin. What's up and down. As you learn more, you realize, “Huh, it doesn't actually matter where you get particular types of treatment.” The treatment regime that I got was six rounds of R-CHOP chemotherapy. The advice I got from UCSF was that it doesn't matter where you get that treatment, because it's the same everywhere. The part that actually mattered and had high variance in terms of interpretation and completeness was on the diagnostic side. It's interesting to tease those two elements apart in terms of how it can impact what a patient actually needs.

We've put expert guidance and co-pilot in the middle here. Over time, AI agents are getting better. You can imagine a world where you start with experts. Sometimes we think of tumor panels or tumor boards as a way of co-locating multiple experts to inform a particular treatment path, but anchoring on what a patient needs, and mapping that set of options into that.

“Empowering Cancer Patients: Navigating the Complexities of Diagnosis and Care” (Ari Akerstein and Brad Power) [#130]

On the navigation platform, we have several elements that I'll briefly fly over: things like connecting to a community, finding patients like you, patients that have gone down the path. In terms of engendering trust, that's a really important element, not only getting the best experts, but also patients that may have some experience in going down the various rabbit holes relative to a diagnosis.

A marketplace is something that we've been talking about that is quite interesting, which is: what would it look like to break out of the provider system and provide a menu of options that are like a Costco model, priced cheaper than retail, and do that discovery for patients that are looking for navigation services, different diagnostic tests. What might that look like: a records vault, community connection? That would be the foundational platform.

That's a very brief flyover of how we're thinking about approaching this problem.

What we wanted to spend the bulk of the time on was talking with you all and understanding number one: when you're thinking about your own diagnostic journey from the first time you were diagnosed to monitoring and remission and that whole landscape, and what that looks like. We would really love to get some thoughts from folks on what the pain points are that you see when you're dealing with that. We've also put up a few other conversational bullets up here, but that's the big one that we were hoping to Round Robin and just get some feedback from folks. Does this sound like a problem that you all have faced? We would love to hear from you about what the pain points are that you all have experienced as you go through this.

Roger Royse 15:47

“Empowering Cancer Patients: Navigating the Complexities of Diagnosis and Care” (Ari Akerstein and Brad Power) [#130]

Let me start, because I'm the diagnostics king here. I get every test that comes along, and a lot of them are startups and unproven and unheard of.

One of the issues is that you get false positives. I've been through that a few times, and that's that's a little bit concerning.

Secondly, it feels to me like some of these tests have gotten just so good at finding stuff that they pick up noise, and they pick up things that your immune system is going to deal with just fine. I'm wondering how you're going to deal with that if you're entering a diagnostic, because that seems to me to be the biggest problem with diagnostics. Maybe it's not, but at least it's a problem. How are you dealing with that issue?

Ari Akerstein 16:48
The answer is triangulating on opinions and backstopping on experts that know the diagnostic space. Our mutual friend Tony Magliocco at Protean BioDiagnostics is a world expert in understanding the pathology reports, not only which tests, but interpreting the tests. If you pull the thread a little more on your story, Roger, because I think you're talking about the one on New Year's where you had that false positive. Tony was the one that suggested that it was noise, and kind of flagged that as the issue,

Roger Royse 17:29
It was late on New Year's Eve, and I get this report that says, “You've got this new mutation. P13 or something.” I talked to him at 7am on New Year's Day, and he said, “Yeah, don't worry about it. That's noise. But you need to do follow up tests.” So we did follow up tests with some other companies, and they didn't find anything. He didn't trust the test. You're going to get that sometimes.

Ari Akerstein 18:08
Was the recommendation to get that particular test? Did it originate from your oncologist, from Tony, from you, or from the community?

Roger Royse 18:20
No, I did it. It was my fault. One of my clients is a friend who has a startup that has this test, and he contacted me and said, “You should do this.” So it did not come from Tony. It came from me, and I take full responsibility for that one. But the moral of the story is, you need to get an expert in this to read this stuff and separate the wheat from the chaff, as Brad would say back in Minnesota.

Brad Power 18:55
Roger's point is something really important, which is, there are the facts, and then there is the interpretation. There's the test result. There's the report. There's that thing that's written down, and then what does it mean? The one question on the mind of the patient, as it was in Roger’s case, is: Is this bad news? Should I be concerned, or is this good news and I should not be concerned? The only way you get that, typically, is from talking to, in my case, it was Emma

Shtivelman at Cancer Commons. It could be Tony. It could be my oncologist. I would trust him if he said, “This is not concerning.” But it does take an expert who's seen a lot of cases to put it in context.

It also takes someone who is knowledgeable about these tests, because my oncologist, who's very cutting edge at Dana Farber, when I said I can get an RNA Seq test through Tony Magliocco at Protean BioDiagnostics, he said, “That's great. But I wouldn’t know how to interpret it if you showed it to me.” Interpretation is an important step, and it's pretty much done by humans these days after the diagnostic group sends you that report and those facts.

Roger Royse 20:14
I got a proteomics report as well that I got through Cancer Patient Lab from mProbe, and it was this big, technical, single-spaced report. I gave it to my oncologist, and I should show you his email. He says, “What am I supposed to do with this? I don't even understand it.” Then I went to Kaumudi Bhawe, and she explained it. She said, “Go tell the oncologist to look at page three, line 26, and tell them to focus him on that.” I took it back to him, and he said, “Oh, now I get it.” So it really is important to have the right people in the room for sure.

David Plunkett 21:10
It puts me in mind of Harry Truman's complaint about his economic advisors, and they would tell him, “Well, on the one hand this, and on the other hand, that.” And Harry Truman said, “I wish I could find an economist with only one hand.”

I come at this more from the beginner's point of view, from the people in my support groups who come in not understanding the vocabulary. A glossary is really important. They don't know what they don't know, and they don't know how to find out.

I like to tell them that asking questions is good, but the quality of the answer is going to depend on the quality of the question, so helping them design good questions is a good thing.

You're going to end up with competition from online search engines, what people like to call “Dr. Google”. You can get good advice, you can get bad advice, you can get the full range in between, and no way to tell the difference.

The other thing that came to mind from what you said so far is when I brought up the idea of genetic testing with my oncologist, I was always already well into my treatment plan, and the response I got was, “Well, at this point, whatever results you get are not going to change the course of your therapy. So there's no point in wasting time, attention and money on tests that are going to give you background information, because we're just going to keep doing the same thing.” So I went ahead and arranged to get some genetic testing through the Promise program and Color testing, and I turned that over to my oncologist, and someday that might become useful, but it was something I had to go and figure out for myself. That is support for this being a good idea. It's just that people need to understand that sometimes it's going to provide background information or information that's only really useful in the future.

“Empowering Cancer Patients: Navigating the Complexities of Diagnosis and Care” (Ari Akerstein and Brad Power) [#130]

Brad Power 23:28
I had a similar experience. I had to ask five times to get my tumor tissue sequenced because I was already in a course of treatment of chemotherapy, and the test was not urgent. They eventually did it, but it wasn't going to affect my immediate treatment decision.

David Plunkett 23:45
It also means they're not likely to push against any financial restrictions placed on them by the insurance company. If the insurance company doesn't approve it, they're not going to want to try and persuade the insurance company otherwise or get you to pay for it yourself.

Brad Power 24:04
I want to come back to your first point, though, which is a key theme that runs throughout all of this, which is trust. You can get, as in Roger’s case or in your case, recommendations that you think are maybe fringe. Are they reliable? There's a question of confidence. What are the characteristics if we were trying to design something that maximizes trust? Who do you trust? What do you trust? What does trust mean to you when you're getting test results when the confidence around them is not 100%, let's say, or the interpretation isn't. I would ask this of everyone, what does trust mean to you, and what is trustworthy?

David Plunkett 25:00
I've got conflicting ideas on that. One is, I like to see multiple sources telling me the same thing. The danger is, when they're telling you different things, which one do you choose and whom do you trust? And that brings me to, I think it's called Segel's Law, which says, you know, “A man with one watch knows what time it is, and a man with two is never sure.”

Brad Power 25:32
Anyone else on trust and what they find trustworthy? What would cause you to trust someone or a recommendation or a result?

Richard Anders 25:45
That's really an interesting question, because it gets into what's endemic for our age and society now anyway. How do we know what to trust? We typically these days, like on the political front, we trust the people in the cohort that we feel ourselves aligned to, and we can pick and choose our information. To some extent, that may be what can happen in this world of diagnostics as well. If a diagnostic test gets adopted by the trade, the trade being oncologists, people still tend to trust their oncologist up to a point, but only up to a point, because the treatments work only up to a point, as long as they trust their oncologist and the treatments are working reasonably well, and the oncologist believes in a test, I think that test will be a trusted test.

It's when people get to the bleeding edge of where things start to work. They have to roll their own trust, because, by definition, the oncologist can't easily adopt things that take them out of the comfort zone of the standard of care. Maybe you have to find a trusted more bleeding edge oncologist, or you have to do your own research.

But if you do your own research, it's very, very difficult, because to do your own research, you all of a sudden have to start to become something like an expert. This is such narrow stuff that the decisions that an average person makes are not those of an expert, but somebody who rushes into something; which does close the circle a little bit to what you and Ari are doing.

I spoke to this group a few months ago about building a guide to diagnostic services. Maybe that's what in some ways you're wrapping around the sets of things that you want to do. But to the extent there is something that can be a trusted authority in the sense that people generally believe what it says and what it does, and that its recommendations are reasonable, then oncologists start to adopt it, then it could be something that an average person can start to trust, even if they don't fully understand it. But right now, whatever a company says is almost what you have to do, because it's really hard to get that.

I was wondering though, Roger, what motivated you to get the test that you got? Do you just get most of these tests to see what they say, or was there a particular reason you got the test that you got?

Roger Royse 28:37
I’m monitoring for recurrence. I'm at a high risk of recurrence, so I keep a close eye on it. The standard of care is: you come in every six months and get a scan. First of all, six months is too long. And secondly, by the time it shows up on a scan, it is too late. I wanted something better.

Getting back to the trust issue, for me it's two things. Number one, it's got to be a doctor that I trust, and I really like Tony. I think he really knows his stuff on a diagnostic side.

Then secondly, I want to talk to other patients and see what their experience was, especially people that attend events like this and probably have seen quite a lot.

Ari Akerstein 29:31
I anchor on that as well. As a naive patient, I trusted the brand of the institution that I went to. The more deeply immersed I got in the details I saw the lack of critical thinking. I don't know what to call it exactly. Once I went in under the umbrella of that particular brand, and then started talking to other experts, I realized, you have to go under the brand and dig into the details. How good is the oncologist? For most people, it's like, “Oh, they're at x, an awesome brand of place that has a good brand recognition, the Hutch, or whatever.” And they generally are good. But I was at Kaiser, and I thought the brand was good at Kaiser, and then I'd see how the oncologist approached things, and it was not so good. Then it ended up being a triangulation of multiple sources, from multiple oncologists to different specialties, like pathologists to smart generalists and community.

Roger Royse 30:55
The bigger and more well known the institution, the less ownership they take. You're going to get the standard of care in all these places. And the standard of care doesn't do any of the stuff

we're talking about. I went to three different large institutions, and none of them told me to go out and get this. I got a standard report. I did get that, but nobody said, “Get a BostonGene, get a Tempus, get proteomics.” They just don't go that far. They can't. The system would be overwhelmed. The way it is to tell patients to start especially with stuff that's insured.

Rick Davis 31:55
Kaiser is a great system, Ari, and it has brand recognition. As long as you don't get sick,

Ari Akerstein 32:12
With bumps and bruises, they do a good job.

Rick Davis 32:14
It's perfect if you don't get sick, and you like changing your doctor and you want second opinions, but it's not the place to be if you have significant issues, and that's because their business model is based on the standard of care, and to get anything more than the standard of care is very difficult. I have the t-shirt because I was partially treated when I was diagnosed at Kaiser, and fortunately, partially treated at UCSF, because they didn't have a contract with UCSF at the time, and that made all the difference. That got me along the path where I am right now, and what I do.

The second thing I really wanted to say was that any doctor who says there's no point in doing testing because you're already on the treatment path and we're just going to stick with that, I personally would fire.

Ari Akerstein 33:22
To David's point earlier.

Rick Davis 33:26
This week we had a guy come in who's treated at the VA, and his medical oncologist, who wasn't a specialized medical oncologist, that he could handle it. He can do what anybody else does. Then the guy asked him for details of his tests. And the guy said, “You don't need that. You're already on a treatment path.” We said to him, “You go back and fire that guy.” If we as patients don't stand up and do that, the doctors will put themselves on a pedestal, and they will assume that that's okay to treat patients in that way. Many people will say, “Well, that's what the doctor said.” A doctor who says to you, you don't need a test because you're already on a treatment path, doesn't understand the way medicine has been going the last 15 years or so, which is the path of precision medicine. Yes, you may be on a treatment path, but if you have a certain biomarker that singles you out for a particular drug that may be a better drug than you may be on the wrong treatment path. David, I forget your details, but since you said that you did the Promise test, I assume you have a prostate cancer diagnosis. The rate of testing in prostate cancer is very poor. An article I just saw says that men with metastatic hormone sensitive prostate cancer only get retested at the rate of 9% for NGS. We tell people, you need to get retested every year, every two years, because the cancer changes. That's not for your germline test. That's not for the Promise test, that's for what your cancer makes itself. The fact that you

didn't show anything, or you may not have shown anything on the Promise test, doesn't mean you're not carrying a BRCA mutation in your tumor that the doctor won't know about unless he tests the tumor, which he can do with liquid, which is very simple, if you have enough of a tumor burden, or he can or a high enough CTC or CtDNA, or from a tumor sample itself. But I would say to anybody that a doctor who doesn't want to get basic testing, and by basic, I mean germline and somatic testing, and not a lot of these fancy tests that we talk about here, because I think those are out of the ordinary, and I don't think they should be available to everybody, because it would be just way too much of a burden on the medical system. These tests are expensive. You want to go get a Sage test from Chris Apfel. They cost a lot of money. If you can afford it, God bless you. But at the same time, we have to recognize that there are cost limitations, but we are entitled to basic information, and to me, basic information today means we know what mutations we're carrying.

Ari Akerstein 37:17
What do you think is the root cause? What I see is a failure of truth seeking. Perhaps one might interpret it from the oncologist’s point of view that fundamentally there's a lack of interest, a lack of time, a lack of reimbursement to getting that additional information. Is there an obvious answer to that question?

Rick Davis 37:52
There are two issues. Probably the most significant issue for oncologists overall is inertia and lack of education, because many of these docs were trained before the era of precision medicine, and they're being asked to adopt it, and they're not ready to adopt it. They live by the standard of care, and even then, they don't follow the guidelines. So the guidelines for prostate cancer say that any man who's metastatic should be somatically tested in practice. That doesn't happen. There was a paper by Neil Shoring and Illumina at last year's GU ASCO, that reported on the frequency of NGS testing, notwithstanding that if you look at the guidelines, if you're metastatic, you must be tested, but it isn't observed.

Ari Akerstein 39:04
You're pointing to another mechanic, which is just lack of execution against the guidelines themselves.

Rick Davis 39:12
You have a bunch of things. One is you have this lack of education. Two, you have this unwillingness to follow the guidelines because, unfortunately, it comes with the territory. A lot of these doctors have egos, and they don't want to be told what to do. In fact, they don't know what to do, but they don't accept it.

All of the issues around payers is huge, because these doctors don't want to be involved in having to apply for reimbursement. They don't want to get into that paperwork and so they reject.

We have to lower our standards of expectation if we're being treated in a community practice environment. We navigate in all of our groups, and Mike Harris has heard us in the pancreatic group. We do it in the prostate cancer group. We do it in the blood cancer group. Get yourself to a center of excellence. Not everybody can do that, but a lot of people don't even know to do that. They see a doctor who's a medical oncologist locally in a community practice, and they think that's the best they can get. Then they'll come to you and say, “Oh, I've got the best. My doctor is a world expert.” Most of the time, they're not even an expert in their own community,

Mike Harris 40:57
It may not be a lack of education. It may be the way that education is oriented. In my organization, TriCan Health, we come across PhDs and MDs and a gross oversimplification that I'm sure is unfair, but I'll say it anyway, which is, MDs are trained to narrow the path to a particular treatment path. They are eliminating options along the way to try and guide you toward the standard of care. But that diagnostic path is eliminating different options they can just end on one. The way that PhDs tend to be trained is more sort of opening, starting from one problem and finding what could be the multiple paths for potential solutions. So it's a beginner's mind. It's more curious. It's more trying to find what the root causes are. Perhaps there's a synergy, essentially between these. Can't these centers of excellence that have NCI designated centers and so forth, where you have the intersection of these two paths to constantly look for what could be the additional root causes? Coming across as a caregiver for several cancer patients, when I find those physicians who have an open mind, who are looking for potential causes rather than constantly narrowing things down, that's where I get back to your original question, which is, “Where would I find trust?” It's in that person who has that kind of beginner's mindset that's looking for potential solutions.

Ari Akerstein 42:30
That resonates, and that actually goes back to that chart I was showing. One of the sad realizations is that it's unlikely that the system writ large is going to change in our lifetimes of its own volition, getting to the synthesis of the PhD mindset and the MD mindset. You've got 20 million cancer patients in the US today, and like 50 million globally. That number is just going up as it becomes more manageable. It's not likely, I don't think to expect that. The profession of educating MDs to be more beginner's mind is not going to happen anytime soon. The question then becomes, and I think part of the reason that Brad and I are bullish on building some type of more technologically-enabled solution is because we don't think that change is going to happen on that black bottom line that we were talking about anytime soon. The question is: what would it look like to build, rather than pushing the system? Could you build a better thing that then patients, in aggregate, are able to pull toward a better thing, whatever that ends up looking like, and bend the curve that way? That’s the thinking here, and that's what we're trying to drive at.

But one of the themes that I'm hearing is: there's a range of options. Many of those options are for various reasons that Rick articulated are not adopted by the industry, by doctors. There's a bunch of issues there that are not likely to self correct. That leaves patients in a bit of a conundrum. You have people that are in this meeting, and people like all of us that are going to self advocate, really figure out what to do, what's the right thing, who to talk to. But then you

think about that's maybe 5% of the population, and then you've got a lot of people that the community clinic is awesome, and they have, Richard, like you like to say, the apparent trust that their oncologist, because they're an oncologist, knows the right thing. To do that leaves patients in a conundrum. I can go be like a Cancer Patient Lab kind of person, or I can unwittingly go with my local oncologist, because I don't know what I don't know. There is a set of options in the middle that could be helpful toward patients. How do we think about that?

Brad Power 45:32
There are issues around diagnostics adoption, and we could use an application to the extent that they maybe could and should be. What would you think of a subscription shopping offer where you would pay, like $40 a month, some number like your Netflix subscription to get diagnostic, consultation and advice and guidance?

Richard Anders 46:19
I was thinking about the thing that needs to be said that is very difficult to get one's hands around, but is really important. If you look at the transmission of any kind of knowledge, when the knowledge is new, it's really hard to figure out if it's good. You can look at every scientific discovery, practically. You can look at the skepticism around all sorts of things that people that we now know to be true, but when they were first coming out, people had great reservations about whether it was true. We're dealing with very, very important issues here. To go off of the standard of care is dangerous. It's the safe decision at a certain point to stay on the standard of care, and then at a certain point, it probably becomes the safest decision to go off the standard of care. Figuring out where that liminal zone is between those two safeties is very difficult. I would suggest that one of the really valued services that one could do, and you know what you're proposing, and maybe in a diagnostic guide, is to give people this wisdom, and I don't really know how to do it. It's probably a lot of discussion to think about it, give people the wisdom to help them evaluate at what point the flood of information that they can get from all of these diagnostics, some of which are going to have good information, some of which are going to have bad information, how to assess what to do with the flood of information, so that you are making the safest, best decision at each point. When you're first diagnosed, I'm not sure that the best decision is to go to a really novel test that prescribes something way off standard of care, but very late in the process, that may well be the wisest course. To help people understand how to make that transition is really, really important. I don't know quite how to do it, but I think it's really important.

Ari Akerstein 48:43
Consider a new diagnosis. Is that (following the standard of care) correct, given the misdiagnosis rates and things like that? That feels like pretty low hanging fruit.

The other thing that sticks with me is what I think, Rick, you were saying about the lack of execution against the guidelines or standards, and so there's almost a check that you can put in. “Well, I've got this diagnosis. Did my doctor do the right thing?” Which it sounds like, if that's not happening, that's a pretty obvious thing that you could empower a patient to just check that. I mean, that shouldn't be hard to figure out.

Richard Anders 49:29
Medical errors are a known source of serious adverse effects. There are studies that talk about that. Going off standard of care in that elementary way clearly borders on medical error, if not steps firmly into medical error. There are all sorts of things that you want to do. Your service might prevent medical errors. There's no doubt that that's in the safe zone. You want to prevent medical errors at every stage. There's certainly value in the service that does that. But as soon as you start to step off of standard of care, then you get into the transitional zone where the questions get hard.

Ari Akerstein 50:15
Richard, do you think maybe that's the right framework that you're pointing at, which is you've got a safe zone, and there's like a checking piece, and then there's an optimization piece, and you have to figure it out.

Brad Power 50:31
I want to push back on this argument a little bit, because I think we have mental models that come out of chemotherapy that don't apply that well to targeted therapies, and we have ideas that apply to therapeutics, but may apply less well to diagnostics. Diagnostics is information. If you get a 23andme report that says you're liable for BRCA, you might say, “Okay, I need to get another test to validate this.” It's information. It's when you don't interpret it well, and you then go into making decisions based on it, you can get into trouble. I just want to make a distinction: diagnostic information does not have the same evidence standards as therapeutic recommendations, and yet we might apply the same mental models to both.

Rick Davis 51:16
Can I raise something that really concerns me, and it's concerned me, Brad, from the inception of this platform? I've talked a little bit about this with Mike Harris: I feel that some of these tests and some of what you examine here, whilst certainly valuable and very interesting and beneficial to some, is part of a very elitist model. It bothers me, if you have the money to pursue it, you have every right to pursue it, and a platform like this helps to inform you, but it can be very expensive to pursue it.

We send people to centers of excellence because the centers of excellence are more likely to pursue what we discuss here and be open to it. If the patient cannot afford to do what is being offered privately, there's more chance they can get it through a Center of Excellence. They have very little if, no chance, at a community center.

It also takes me back to a dilemma, which I think few of us in this country appreciate. There are a lot of people who advocate for a single payer system, but Americans would never tolerate a single payer system. The reason is because they don't have a choice. We in this country insist on choice. We insist on the right to buy what we want to buy, if we have the money to buy it, which is an elitist healthcare situation. If we lived in Canada, we'd be tearing our hair out. The number of Canadians that we support in AnCan is considerable, and they come into the group,

and they cannot access the type of basic treatments that we're getting in the United States because they're in a single payer system. If they want to move out of that system, they have to come to the United States, and they have to pay for it out-of-pocket, and that's what a single payer system means. I grew up in the National Health Service. I'm raising a bunch of issues, and I'm not condemning what we do here, but I think we have to recognize that what we do is because we can afford to do it, and not because it should be available to everybody that's out there.

Richard Anders 54:16
There's a policy side to that, which is the flip of that, which is American medicine, for better or for worse, is known to be much more expensive. The drug side is much more expensive. But also most of the drug innovation, or at least a good deal of the drug innovation, comes from here. It could be that it's very elitist in the short run, but in the long run, some of this stuff gets proven through the elites and then trickles down into standard of care, and that's one way it happens. So that's a good spin off benefit to the extent it's true.

Brad Power 54:52
I was going to make a similar point, which is that we're focusing on diagnostics and information, and if patients would pay for that out-of-pocket, then they would be in control and could shop for the care delivery in a way that they don't shop today. We don't have a consumer mentality in healthcare. We go with the flow. We go with whatever our primary care physician offers. Everything is focused on the provider as the gatekeeper to everything, and so the patient, the consumer, has very little influence in the system.

Part of what we're doing is explicitly going at the very forces that you're describing, Rick, when you describe the national system, which is that people won't pay for things that are not reimbursed, and therefore they won't get that scan, and therefore they won't get that information. We're trying to push for the idea that if you could pay for that test that costs, who knows, $100 or $1,000, then you can save downstream in the care delivery, which is multiples of that cost.

Rick Davis 56:00
That means that you've got that $100 or $1,000 to spend right now. Not everybody does. We minister to a community for renal middle area carcinoma, which is a horrendous disease which is highly correlated with sickle cell. We have a lot of African Americans and a lot of Hispanics who are plagued by this disease, and it's a horrible, aggressive, nasty type of cancer. These people don't have two red cents to rub together. It's all well and good saying, “I can write a check for $1000. These people don't have it. We're fighting to get these guys NGS testing.