“The Advanced Cancer Navigator - Helping Patients Shop for Services” (Brad Power) [#31]

Brad Power
October 26, 2022

“This is a battle that ultimately has to be won and will be won because we're building a system here which is fundamentally better for patients, and they will vote with their feet.” – Marty Tenenbaum

“We're setting up a place where someone who has questions can post them, and hopefully someone else will either have the answer or will want to try to run the experiment.” – Marty Tenenbaum

Meeting Summary

A community of advanced cancer patients, diagnosticians, scientists, researchers, bioinformaticians, molecular biologists, modelers, and clinicians has come together to help with advanced cancer patient testing and treatment decisions. To increase the value of the community to patients and other participants, we are defining and building a bundle of precision oncology services and a platform to continuously learn from patients using those services – The Advanced Cancer Navigator.

The purpose of this meeting and these notes is to get feedback on this venture. Please contact us with your thoughts.

Here is a summary of the key arguments and services in our pitch deck:

Navigating the cancer maze is a nightmare for patients with metastatic disease. *(Why/The problem we are addressing)*

- No one knows the optimal way to treat advanced cancer because every patient’s tumor is unique and must be treated with an individualized combination of therapies in cocktails or over time. There are far more rational regimens than can be tested in clinical trials.
- Precision oncology can help inform treatment decisions, but requires frequent clinic visits for blood draws, imaging, and biopsies, and careful management of scarce tumor tissue. Picking the right tests can be hard, and interpreting test results is often challenging,not to mention Integrating results across tests and time to provide a comprehensive view.
- Every patient taking every drug is an experiment that could provide insight on which tests and therapies work and which don’t. However, only the patient experiences that are being captured and reviewed are those in clinical trials, about 5% of the total.
- The bureaucracy of academic medicine and misaligned incentives impede the free flow of data, specimens, and information. This adversely affects clinical decisions. Patients pay the price.

The Advanced Cancer Navigator solves these problems by providing four essential services absent in the current system. *(What/Our solution to the problem)*

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1. **A One-Stop-Shop for patients seeking services beyond the standard of care.** A services guide identifies vetted “best of breed” providers for services such as molecular profiling and ex vivo drug screens that reduce guesswork and increase confidence in treatment decisions. Navigation, trial matching, and virtual tumor board services help patients and physicians make more informed decisions. Agreements with preferred providers and specimen management partners streamline access to their services and provide for return of raw data to facilitate integration of services into workflows, as well as research collaborations.
2. **A transformative platform for clinical oncology that tightly integrates research and care to continually learn from every patient.** The platform aggregates medical records in real time and transforms them into structured,regulatory-grade, real world data. The data is used to recommend treatment and trial options to patients and physicians, and to run decentralized trials and exploratory signal seeking studies for under $1000 per patient, with no startup costs or delays. Studies that show signals can be rapidly replicated, seamlessly scaling from an n-of-1 case study to a case series, and ultimately to an open label trial with synthetic controls. This approach encourages continuous refinement of multi-therapy regimens before locking down the protocol for inexpensive pivotal trials.
3. **A global data commons where patients consent to share their data with each other and the research community.** The data is routinely mined for clinical insights that could benefit both participating and future patients. It is also used to evaluate the comparative effectiveness of new tests and treatments and accelerate their development by steering patients to the stuff that works.
4. **Educational forums where leading researchers, bioinformaticians and clinicians are invited to pitch their latest precision oncology services and therapy options.** Patients and physicians evaluate these innovations in n-of-1 studies on our platform. If successful, they are incorporated into the services catalog and our standard workflows. Patient forums enable patients with similar conditions to learn from each other’s experiences.

Ideas for implementing these services came out of our discussion:

We must build a testing and treatment system that will provide the best personalized approach for each patient and continuously learn from every patient. *(How/Architecture)*

Every advanced cancer patient's disease has evolved through many mutations that make it unique. Their cancer must therefore be treated with an equally unique personalized combination of therapies, administered in a strategic sequence, with personalized dosing. To answer the treatment decision, we should first have a database where we can bring all the patient cases together and try to find a good match for this patient. But the uniqueness of each personalized treatment means there may be no detailed data or evidence to support the decision in advance. The opportunity then is to run each treatment decision as a prospective experiment and see the outcome. We must create a platform to manage the flow of data.

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These services represent a disruptive shift for healthcare. *(Implementation/Call to action)*

This venture will accelerate the disruptive shift from the batch standard of care to personalized treatments, from evidenced-based (randomized clinical trials) to evidence-informed (real world evidence), and from power in large, legacy institutions to patients. It will unfold like other grassroots social movements, such as the Homebrew Computer Club, which was a small group of hobbyists and hackers that came together in the 1970s and led to Apple Computer, or the advocates who drove the FDA to accelerate adoption of new HIV/AIDS drugs. We will grow with an empowered patient here, a doctor there, and a researcher there. It won't happen in a day. This is a change that will happen because we're building a system which is fundamentally better for patients, and they will vote with their feet.

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Meeting Notes

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SUMMARY KEYWORDS

patients, cancer, services, data, people, dana farber, drug, institutions, question, add, treatment, interested, run, experiment, organization, tests, treatment options, clinical trials, find, clinicians

SPEAKERS

Brad Power (56%), Marty Tenenbaum (17%), Saed Sayad (14%), Richard Anders (12%), Jeff Waldron (2%)

Brad Power:

This discussion is on the Advanced Cancer Patient Research Navigator. The genesis of this venture is that we have wanted to scale the work that we've been doing in “hackathons” (diverse crowds that come together) to address patient testing and treatment decisions. There have been three or four patient hackathons, depending on how you count, and then the Prostate Cancer Lab, which currently has seven patients. We want to grow the size of the community, especially to grow the number of patients. We have a goal, which looks very ambitious now, to find 100 patients by the end of the year.

I'm going to review our pitch deck for this venture, which is scaling up the things we've been doing, providing services for testing and treatment decisions, treatment strategy, and other services for advanced cancer patients. The goal that I have in presenting this today is that hopefully all of you will give me great feedback to make this better.

The target audience is advanced cancer patients, but there are multiple stakeholders, as there always are in healthcare. We'd like to grow the number of advanced cancer patients. We've identified funders who might provide grants to us. This could be pharmaceutical companies, or could be patient foundations, like the Prostate Cancer Foundation, or it could be other philanthropies.

We want to attract more patients, clinicians, diagnosticians, molecular biologists, bioinformaticians, and so on, to this effort. We have a flavor of being a community and being open source. Our philosophy is, where possible, to make things free for everyone so that everyone can join, like Wikipedia.

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There are multiple stakeholders in our community, but I tend to start with patients. That's an array of patients across the top of the slide. They are advanced cancer patients Steven Aldrich, Bryce Olsen, Linnea Olson, Brian McCloskey, Kasey Altman, Rick Stanton, Shirley Pepke, me, and Ricardo Salgado. These are all people for whom we've run hackathons or who have actively participated. These are the people we have in mind as we are trying to offer ideas and services and help. Many of those people have passed, so we are doing this in their honor as well.

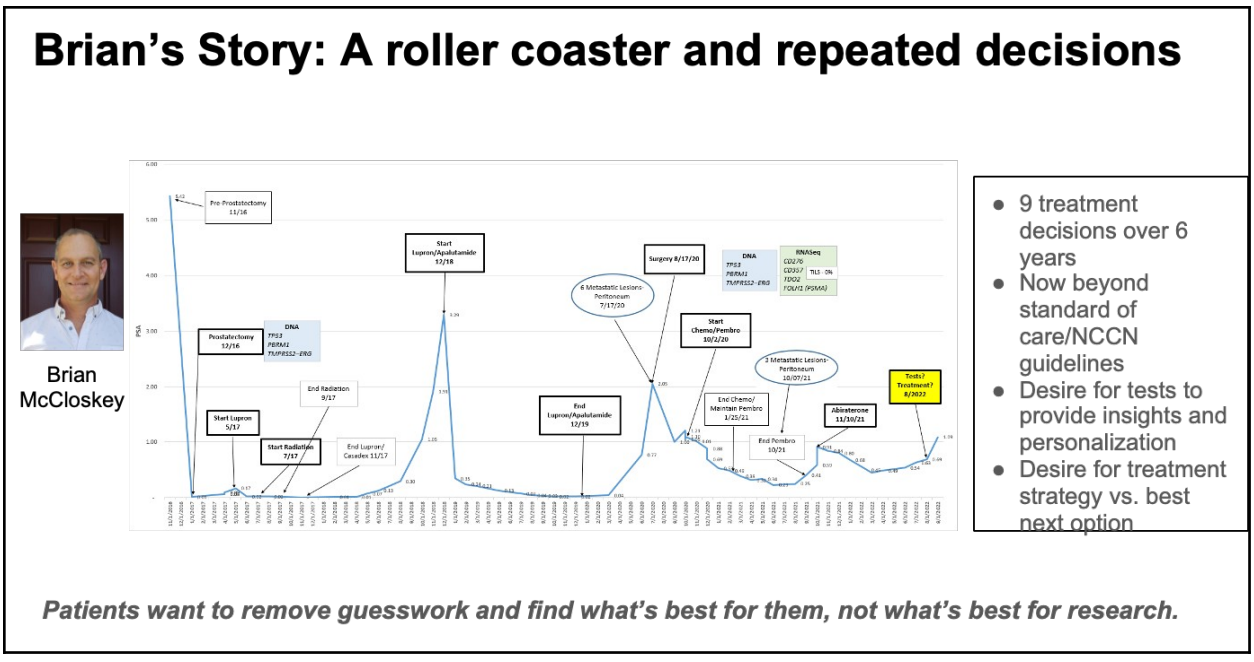
Every one of the words in the title “Advanced Cancer Patient Research Navigator” has meaning. We're talking about advanced cancer patients, meaning those who are beyond the standard of care or metastatic, who are advanced. I have always liked the word “advanced” because it also means they're advanced, like smart. It's about patients with cancer. It's not all diseases. It's patient-focused, for those patients who are researching their disease and researchers coming the other way doing research. “Navigator” meaning that it has to do with finding your way and being a guide.

The tag line here is about helping advanced cancer patients and their caregivers. We shouldn't forget the caregivers, such as parents taking care of their kids or family members who are taking the lead in the care for their friends or family. Our focus is largely on complex testing and treatment decisions, but we include everything that patients would like to know. For example, our next discussion is going to be on palliative care, and we have future ones on finance and nutrition.

On “shopping for services”: Most people don't shop when it comes to health care. They have a primary care provider, they have references or referrals, they get to specialists, but they don't really shop. But we're thinking of this in terms of shopping and finding providers for a variety of

services, sort of disaggregating what's usually all bundled together in what you would get through your hospital or through your doctor or through your clinic.
The companies across the bottom are the founding organizations who are collaborating and contributing to the development of this, with an intention that we will add others.

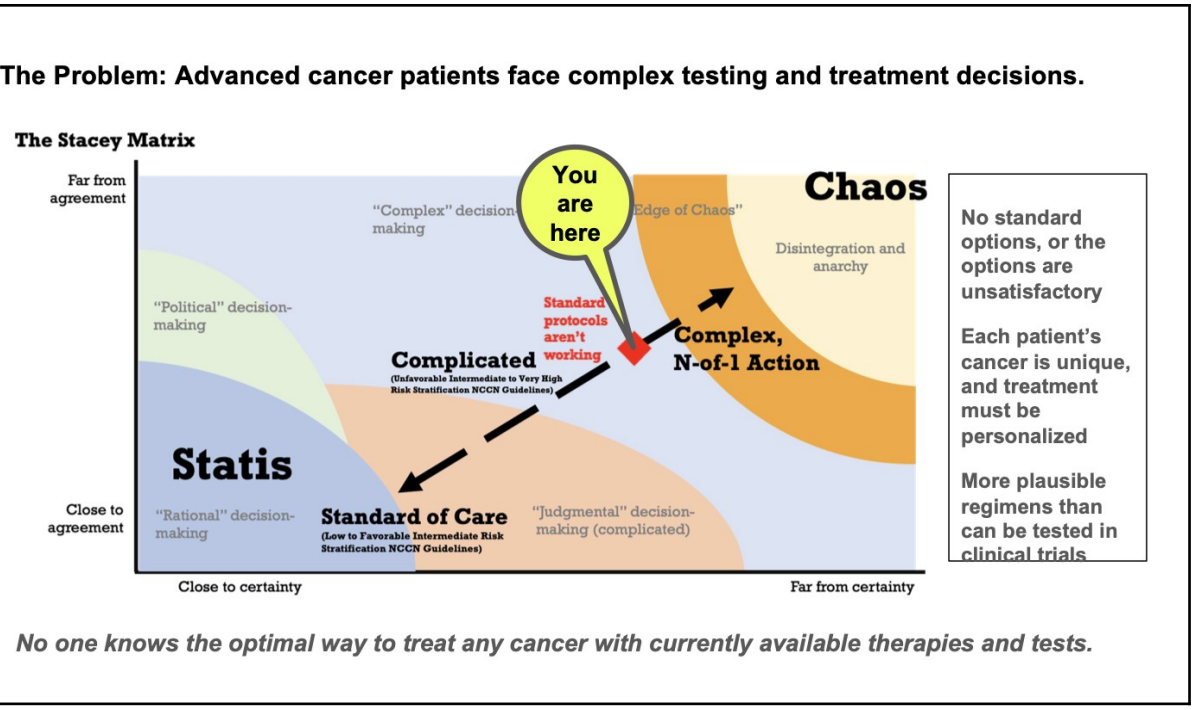
- **Cancer Commons**: Marty Tenenbaum is participating in this meeting. He's the founder of Cancer Commons, which provides online second opinions for free, as well as running virtual tumor boards. Cancer Commons works closely with xCures, which provides the infrastructure for the tumor boards, the registry, and access for patients.
- **CancerHacker Lab** is the group that I founded that is convening events like this and building community and a guide for consumers and related services.
- **The Prostate Cancer Lab** is the group I co-founded with Rick Stanton and Brian McCluskey. We have seven advanced prostate patients who are at the core of Prostate Cancer Lab and a whole community.
- **Stanton Biosciences** is Rick Stanton's business, where he's doing matching based on deep analysis of molecular biology.
- **TGen** is a research institute associated with the City of Hope, an academic research medical center. Our colleague Nik Schork, a close friend of Rick's, has been actively involved in bringing their services to the table. “TGen” stands for “Translational Genomics”. So they're conducting research, and they're able to do complicated assays and tests, then interpret those tests and bring them to market.



I always like to start with the patient perspective. This is Brian’s story. We could do Bryce's story, or we could do any number of patient stories. But the main idea here is that Brian has been on a roller coaster with repeated decisions, which is typical for advanced prostate cancer patients. It's not easy.

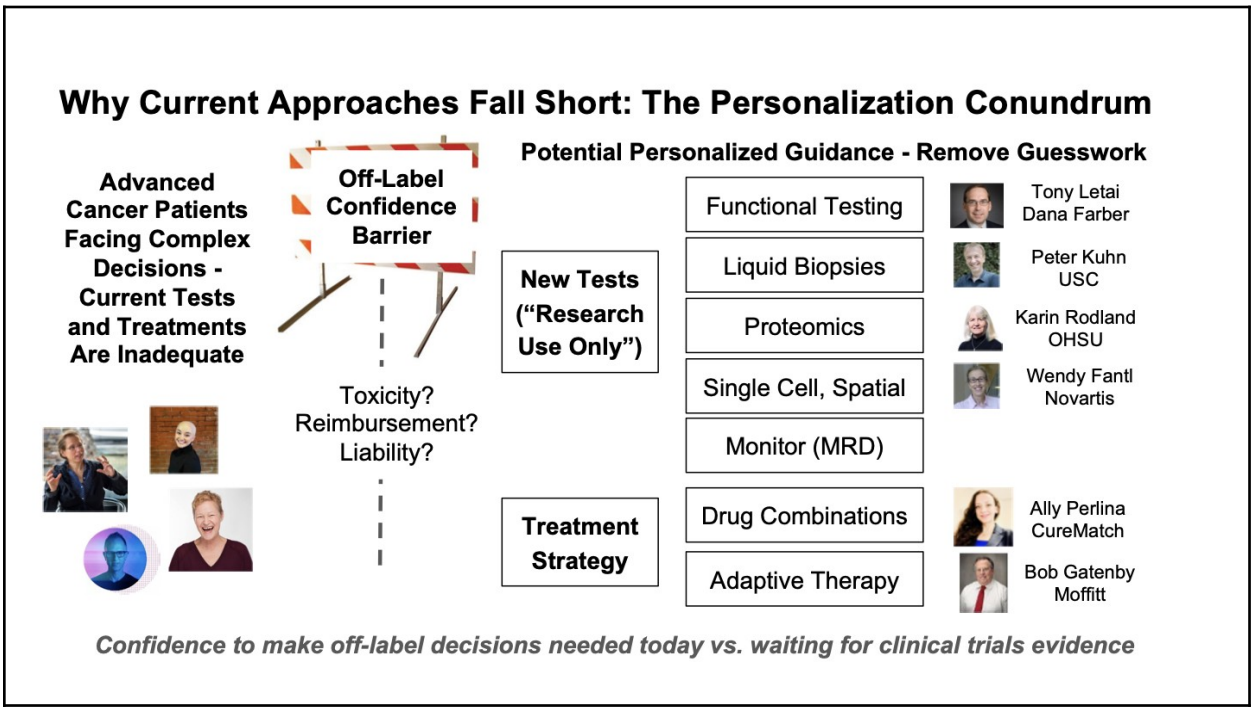
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Over time, there's some degradation of the quality of life. For example, being on androgen deprivation therapy for long periods of time is unpleaasant. Brian is a former executive in marketing at Hewlett Packard and understands tech, ecommerce, and personalization. He's always leaning into more tests. More data is better, providing more guidance for his treatment. He is always trying to both get access to more testing, as well as help that information guide more novel treatment options and uncover new treatment options through that testing. He's about to undergo a surgery where he's going to get more tissue for more testing, so that he can do functional testing and send the tissue all over the place to get more information. To guide his treatment, he could have gotten radiation to attack and remove and debulk some of his metastatic lesions, but he chose to do surgery, in part because it'll give him tissue for more guidance.



The services we are exploring are for patients who are beyond the standard of care. When you look at the NCCN guidelines, they take you through prescribed steps. In prostate cancer, if you aren't metastatic, you get a prostatectomy. If you're metastatic, you go immediately into androgen deprivation therapy, radiation, and chemotherapy. It's all very structured, until you get into unstructured land after you go through those programmed lines of therapy for prostate cancer. There are other diseases where you end up in this zone of complex decision-making from the moment you're diagnosed. For example, in pancreatic cancer or glioblastoma, from the moment of diagnosis you're very quickly in the zone of complex decision-making. And as it says at the bottom, no one knows the optimal way to treat any cancer. There's no evidence. There are no easy answers, no one knows. It's really an opportunity for patients to get involved to influence the course of their treatment. But it gets complicated because as soon as you get to this advanced cancer zone, where there aren't obvious decisions, almost everything tends to be “off label”.

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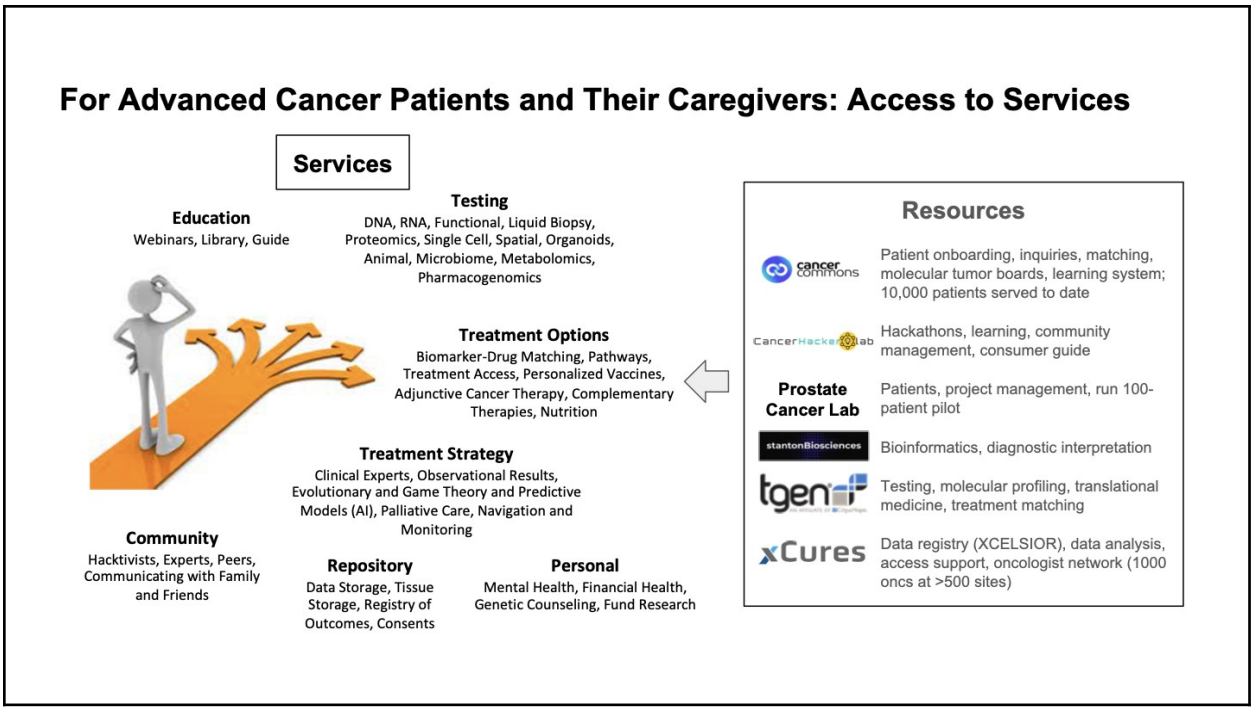


“Off label” means that it's not going to be applied the way that the drug was approved. For example, you have a genetic mutation, e.g., ALK, as Eric has, which is more typically seen in lung cancer. Therefore, the ALK drugs are approved in lung cancer, but any application of an ALK drug for prostate cancer is going to be off label. Immediately, clinicians are concerned about off label uses of drugs due to concerns about toxicity, reimbursement, and liability.

We're big proponents of combination therapies, drug combinations, and most drug combinations have not gone through the randomized clinical trial process. Then if you personalize dosing, there are so many combination options that they can't run randomized clinical trials for all of them. Clinicians are concerned about toxicity, whether they can get reimbursement, and liability.

We're looking into things like whether there is a personalized dosing strategy. Is there a way to do this that gives clinicians confidence to make these off label decisions? Because advanced cancer patients can't wait for the clinical trials evidence, much as they'd like to, because those things take years, even a decade. And they have decisions to make in days, weeks or months.

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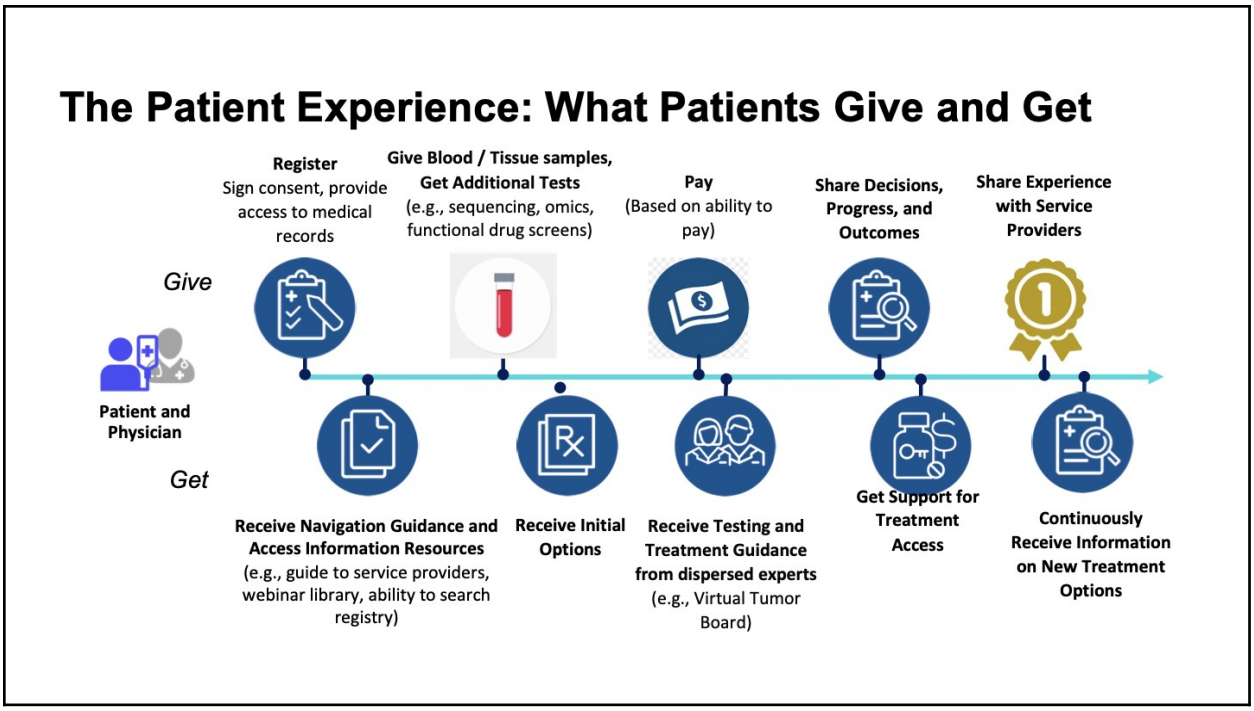


This slide shows the kinds of services that patients may be interested in and need to shop for. For example, they may be looking for education. Most people get a cancer diagnosis out of the blue. They had no anticipation. When I was diagnosed with lymphoma, I didn't know what it meant. I had no idea. Patients need to get educated. They need to find out about testing, testing options, treatment options, and treatment strategy.

Patients and caregivers may want to search for a community of people who have gotten their disease and may be able to offer advice because they're further down the road. They may want a repository for their data for their tissue samples, so they can shop without having to repeat the same questions and sources every time. There are personal services that people need, for example for mental health, financial health, and genetic counseling.

On the right are the service organizations that have already come to the table to help patients and to help guide this. We're also looking to add other service providers. The obvious candidates for us are Massive Bio, which has been helping our patients find clinical trials, and CureMatch, which is an expert in finding and recommending drug combinations.

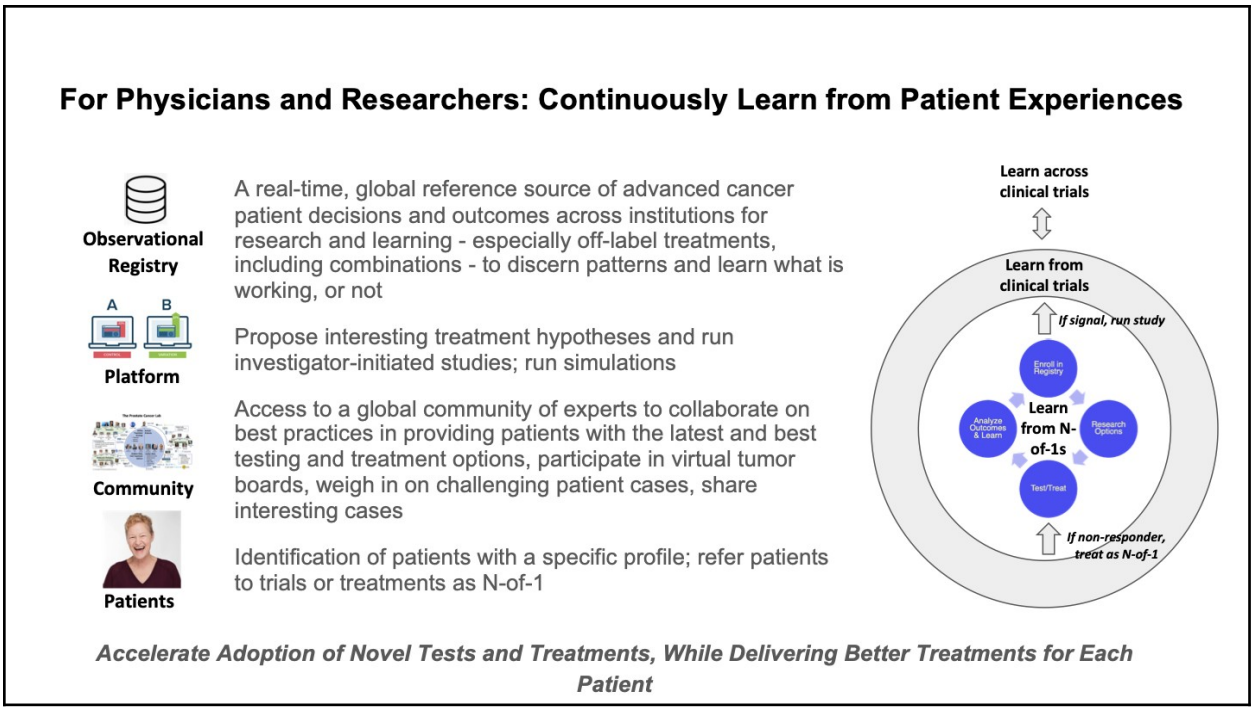
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This is a description of the patient process and experience with “gives” and “gets”. This is modified from something that Cancer Commons already does, but added a few wrinkles. The idea is that every patient should get a standard battery of tests, and those would include, for example, a blood test as the blood vial there.

We would ask the patients to pay. The best way to align a service like this with the target audience of patients is to have patients pay. We're also looking at other sources for money. The idea here is that patients will both give their data and donate it for others to see their decisions and outcomes. Every patient is an experiment. There are results and outcomes from those experiments. Whatever works and doesn't work for them would become resources for those who follow. It would also mean that with their profile information publicly available, drug companies could come and say, “Hey, we've got a clinical trial we think would be just right for you.” It's a way for patients to get lots of information: advice on treatment options, guidance and support for accessing treatments, and continuously being updated on new developments. It's not a “once and done” thing, but as new tests become available, as new treatments become available, as the patient's situation evolves, which it does continuously, they will continue to get updated advice, new ideas, and new information.

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This is the value proposition for physicians and researchers. They can learn from real-time patient experience. This is basically an argument for real world evidence, for those of you who know the distinction between that and randomized clinical trials. We will have all the patients contributing their data to this observational registry. We'd have a platform that would allow researchers to run experiments. There's a community, both for peers to learn from, and also to identify patients with a specific profile. Again, pharmaceutical companies are always looking for patients to fit a specific profile to recruit to their clinical trials. It's a win for patients too if there's a fit that would help them.

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Value Proposition for Physicians and Researchers

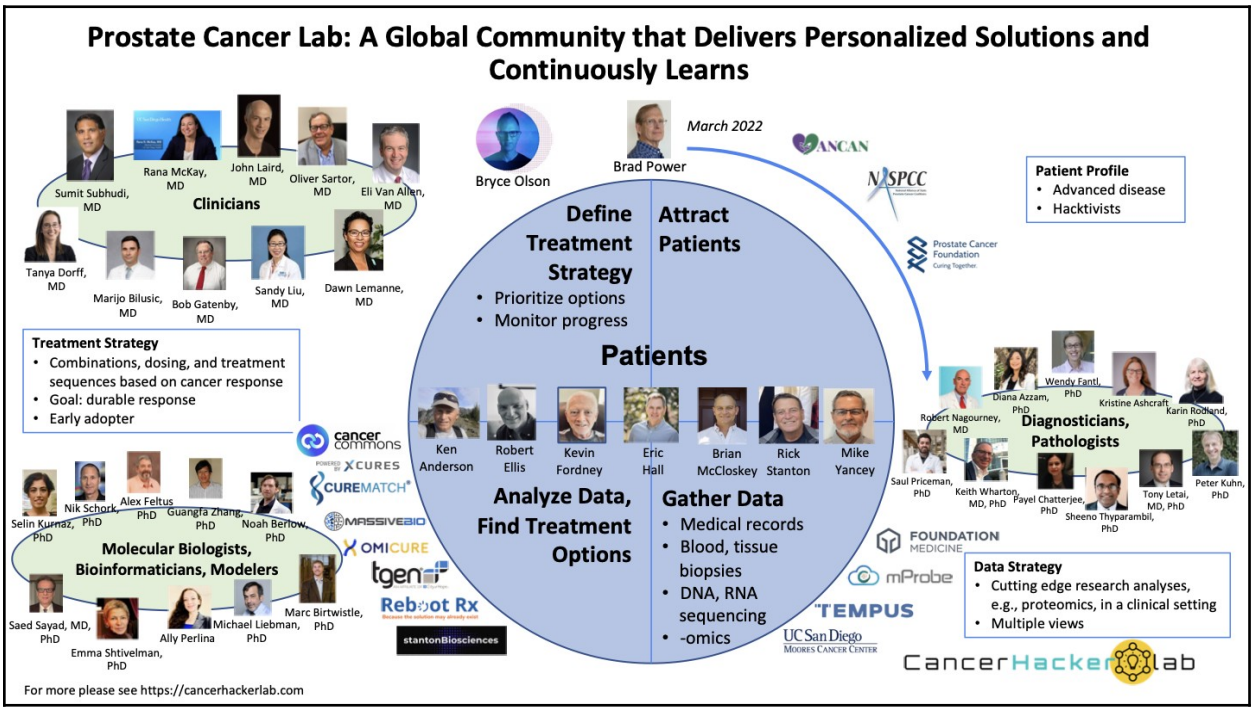
Give (What you bring)

- Seasoned experience in translational application of science (we saw it the lab, we saw it in a mouse, how would it apply in a clinical situation?); tumor board experience; precision medicine experience
- Rationale for something off label, e.g., drug combinations
- Provocation to mix and match, stir the pot, think differently, encourage creativity

Get (What’s in it for me and my institution?)

- Use the platform to capture regulatory-grade real world data on every patient, and run clinical studies at a fraction of the time and cost of traditional trials
- Access activist patients who are interested in participating in studies and being early adopters
- Use the real world registry data to inform treatment decisions and learn in real-time from all patients on innovative treatments (not just those in trials)
- Share ideas and experiences with peers on new tests, targets, and treatments/regimens and collaborate to accelerate clinical application
- Influence the care of patients beyond your practice and contribute to the development of a better standard of care
- Network with professional peers and develop new relationships

This slide breaks out the “gives” and “gets” for the physicians and researchers.



This is our community. This slide is continuously updated. Every time we have someone speak at one of our sessions, I add their mugshot. For example, I just added Robert Nagourney, who was our presenter last week. You see him over under diagnosticians and pathologists. He's a

practicing MD, so I could have put him over with the clinicians, but his claim to fame is functional profiling, so I put him with the diagnosticians.

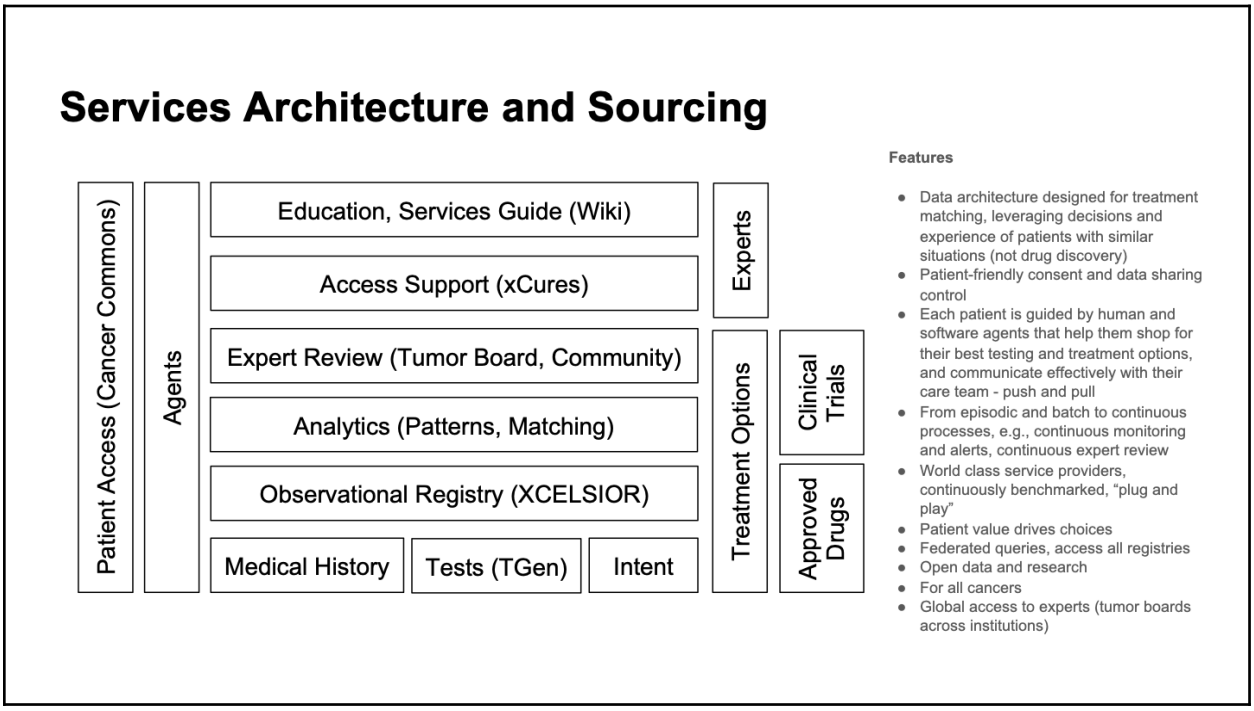
This is a circular process flow for patients, starting with attracting patients. We currently have seven patients, who are in the middle.

We then gather data through a standard battery of tests. We're very interested in whole genome sequencing, RNA sequencing, and proteomics.

The third step is analyzing the diagnostic data and finding treatment options. For example, Rick Stanton and I spoke yesterday to Shepherd Therapeutics, which is doing transcriptomic interpretation, and we might be adding them to that group.

The fourth step is review and guidance by our clinicians. We encourage everyone to provide recommendations for clinicians; for example, if you have a treating oncologist you think might be interested in participating. The clinicians we have in our group are willing to answer email questions. They're on call. If we have a request to them, we can send them an email, and usually we'll get a response.

We're always looking to grow all of the aspects of this community. This is the basis that we are building on as we try to scale up.



This slide shows an internal perspective. What are the services that we provide? You have patients coming in on the left, you have agents, both human and eventually AI, onboarding them. There's our education and services guide, access support, expert review – a virtual tumor

board, and the analytics that are finding patterns and doing treatment matching. The observational registry (XCELSIOR) comes from xCures. Patients will be contributing their medical tests, medical history, and their intent.

On the right, we have experts and treatment options from both approved drugs and clinical trials.

How we identify, review, and onboard service providers

1. Identify a service need and find service providers and include them on our list of possible options
2. Invite the service provider to pitch their services at one of our Wednesday meetings
3. One or two of our patients try the service and report results
4. Incorporate the service into our standard workflow
5. Continuously compare the service with others, and swap -- plug and play
6. Look for service combinations across service providers

We have a process for deepening relationships with service providers. First of all, we identify service needs. I have a working document that has over 30 services for advanced cancer patients. For each of the services, we've identified service providers as you would for a consumer's guide, or as you would if you went to Amazon to search for services. For those that look promising, we invite the service provider to pitch their service at one of our Wednesday meetings, which again, many of you have probably seen before. Then we have one or two of our patients try the service and report results.

For example, consider Shepherd Therapeutics. Rick Stanton is going to take his RNA seq data and send it off to them and kick the tires and see what he thinks of their response. And then if it's good, we will incorporate that service into our standard workflow and say to all patients that come through our pipeline, “You should send Shepherd Therapeutics your RNA seq data and get their interpretation and see what biomarkers they identify and what treatments they would recommend.”

We will continuously compare the service with others and swap if others are better.

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This is a services architecture. This is a modular, componentized services model with “APIs” (automated programming interfaces) that define the boundaries of those services. Then we can “plug and play.” As new ones come out better, we will swap them in and others out. For example, we like Tempus a lot, but Willy Hoos says that Boston Gene is a better source for whole genome sequencing, so we might say Tempus is our currently preferred provider, but we also like Boston Gene. And we might steer things to Boston Gene as things evolve.

We'll also be looking for service combinations across service providers so that we can put together bundles; whatever is right to help patients streamline their work. We will try to make it a “one stop shop” and “once and done”, so that once a patient is entered into our system and their medical history, they can easily go to different service providers without having to re-enter all their information.

What’s Distinctive (Our Beliefs, Biases, and Process)

- **Patient-led**: organization leaders are patients
- **Patient-centered**: help advanced cancer patients make better decisions and achieve better outcomes (versus help researchers develop new drugs), citizen science
- **Advanced, activated cancer patients**: facing complex decisions (beyond standard of care), highly activated and engaged
- **Openness**: open data/data commons, open communication, open source organization
- **More data**: lean into advanced testing and algorithms to inform, predict, and monitor response to therapy
- **Strategic**: employ dynamic treatment strategies based on evolutionary and game theory (beyond single best next treatment), favor drug combinations
- **Continuous**: analyze data in real-time (not batches, as in RCTs)
- **Global**: globally coordinate treatment recommendations across patients to maximize collective learning (across institutions and countries)
- **Innovative**: novel organization (avoid resources), business, and funding models (open)

Increased patient engagement, more data, and an explicit strategy based on evolutionary and game theory will improve outcomes for advanced cancer patients and learning for all.

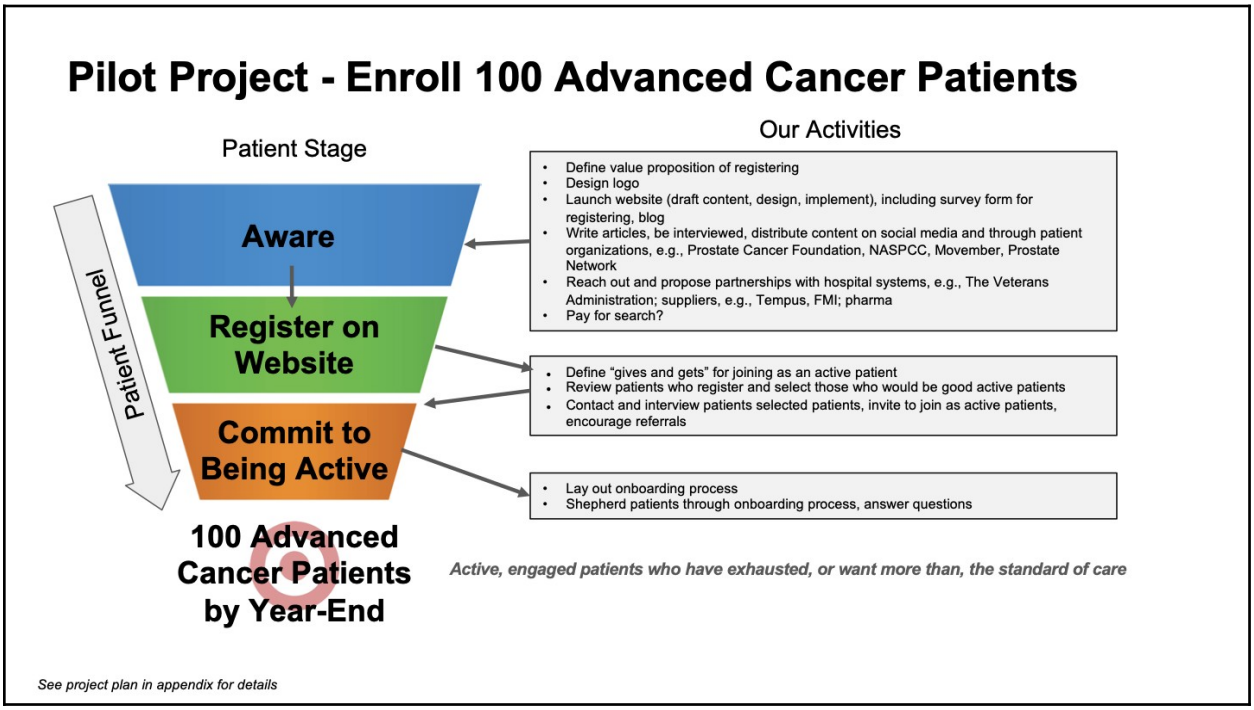
These are some of our key attributes that make us distinctive.
I want to pull out two or three things here.

We're obviously patient-led, which makes us different from other service providers. For example, Brian McCloskey recently found a service provider that is coming out of Weill Cornell that has a one stop shop for sequencing, interpretation, organoids, and so on. It's a very nice service, Brian's very interested in it. But it's always going to be proprietary. And the data that the patient contributes, is going to be owned and controlled by that organization.

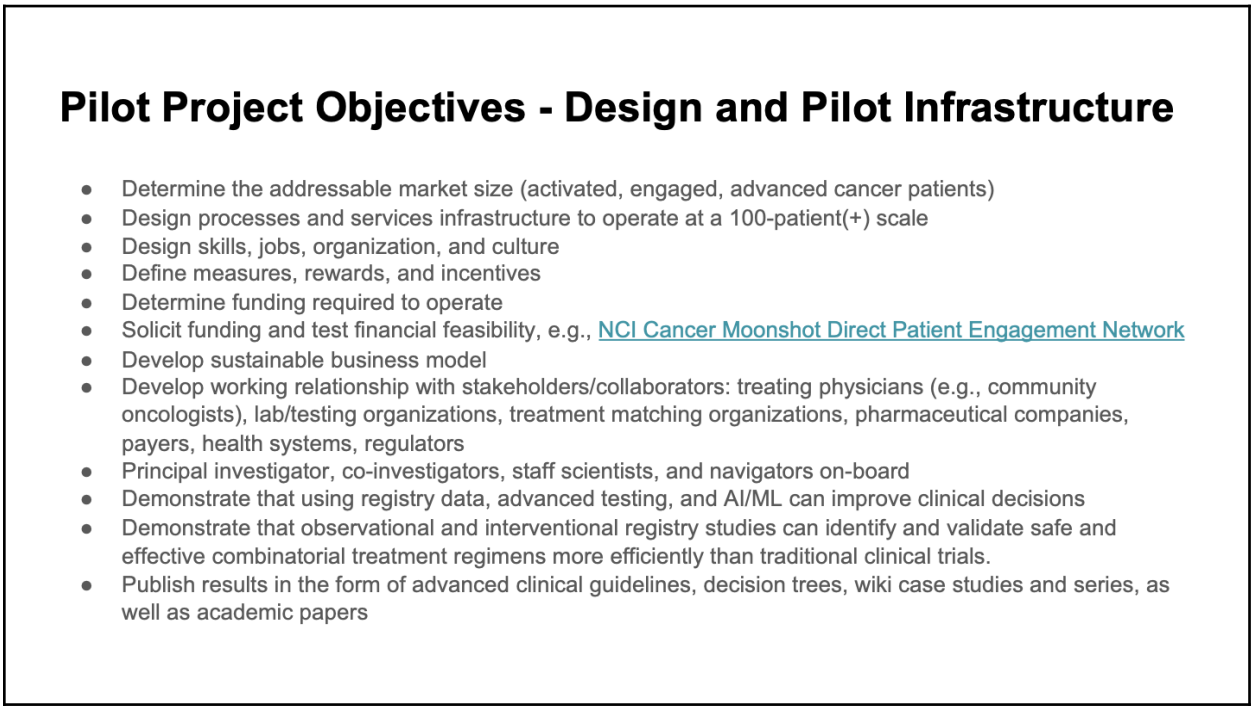
Openness and being open source (like Wikipedia) are very important.

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We're innovative. Whenever we're looking at things, we're trying to lean into new tests, new treatments, new organization forms. We're trying not to follow the industry standard medical, industrial, complex business models or ways of thinking about how we do things.

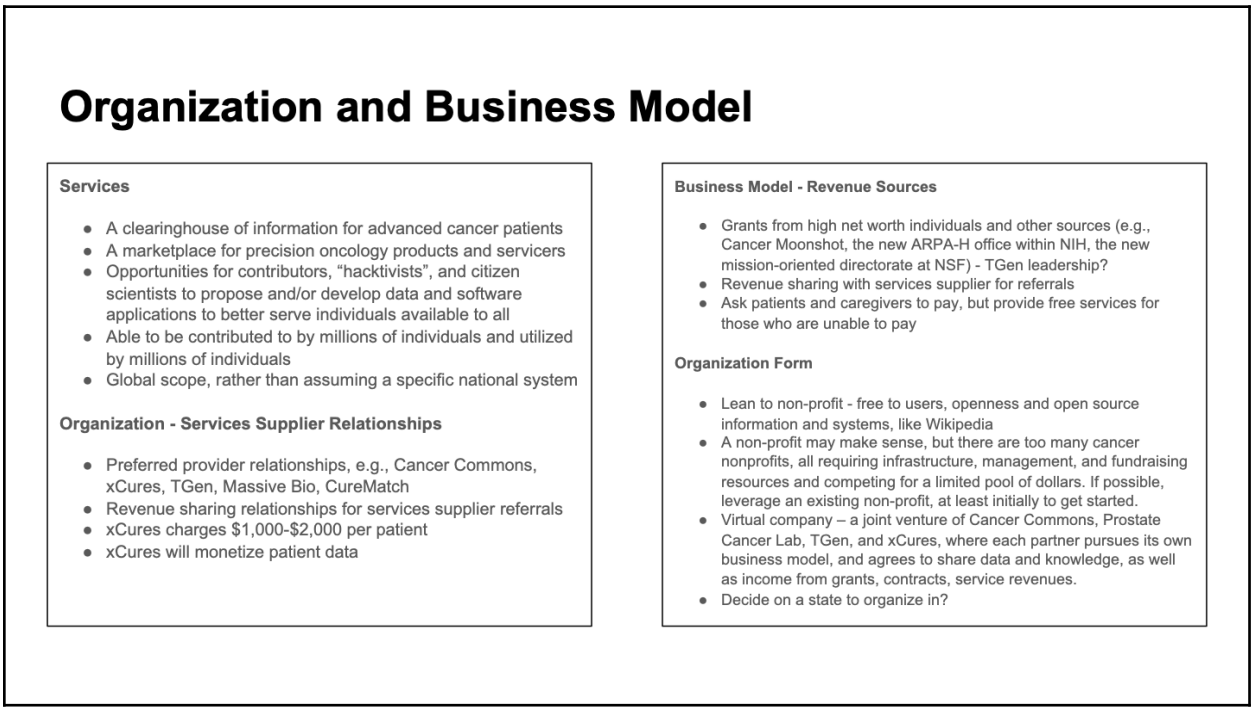


I mentioned we're trying to grow from the current seven patients to 100. It's going to force us to build some infrastructure.



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We are working on our organization and business models. We are trying to figure out, “Is this a traditional startup, that's a for-profit? Is this a not-for-profit? Is it a not-for-profit and a for-profit? Is it a web3 organization? What is it? How do we get money? How do we get paid?” It's all open. That's part of what we need to do. The basic logic is that if we were currently working free and as a virtual entity, but if we scale up, then we need people to do the onboarding and manage the patients. They need to be paid. We need to get money to pay them.



We're being pushed as we grow into questions about our organization and business model.

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Key Barriers and How to Overcome Them

Barrier	Description	Countermeasure
Money, Business Model	Work requires people, which requires money; for-profit models corrupt incentives; patients won’t pay	Solicit grants, request payments from patients tied to ability to pay, provide referrals
Physician Protection	Liability concern by clinicians about what they are recommending (liability, Hippocratic Oath)	A robust IRB that includes provider protections in the patient consent form
Data Cleaning	Medical records are notoriously laborious to clean (Flatiron example)	Develop AI for data cleaning, e.g., PClean (MIT: Lew, Agrawal, Sontag, and Mansinghka)
Privacy	Bad actors may use patient data for nefarious purposes; Patients don’t want others to know	Be transparent and let those patients and caregivers who are comfortable opt in
Real World Evidence	Resistance to be guided by anything other than randomized clinical trial evidence	For patients for whom there are no good options; additional information and testing increases confidence in decisions
Predicting Response and Resistance	Lack of models and computer systems that predict patient response to personalized treatments	Repurpose pharma drug response and trial matching systems to match patients with the best individualized regimens for them

There are a number of other issues we need to address. For example, physician engagement is a challenge. Physicians are very comfortable working in the system as they know it, but finding ways to engage them is hard. Data cleaning is an ongoing issue that many have run into. Privacy. Real world evidence competing with randomized clinical trials. Finding ways to predict response and resistance.

Contributors and Collaboration Partners

Organizations: Contributions

- cancer commons — Patient onboarding, inquiries, matching, molecular tumor boards, learning system; 10,000 patients served to date
- CancerHackerLab — Hackathons, learning, community management, consumer guide
- Prostate Cancer Lab — Patients, project management, run 100-patient pilot
- stantonBiosciences — Bioinformatics, diagnostic interpretation
- tgen — Testing, molecular profiling, translational medicine, treatment matching
- xCures — Data registry (XCELSIOR), data analysis, access support, oncologist network (1000 oncs at >500 sites)

Prospects: American Cancer Society, AnCan, ARPA-H, Cancer Moonshot, Consuli, Count Me In, CureMatch, Hive Networks, Illumina, Massive Bio, Moffitt, NIH, Owkin, The Parker Institute, Prostate Cancer Foundation, Providence, Sema4, Stand Up to Cancer, Takeda, Tempus, US Oncology, Veterans Health Administration

Individuals: Contributions

Peter Kuhn (USC, Epic Sciences): Liquid biopsies

William Oh: Patient referrals, physician perspective

Jim Palma (Target Cancer): TRACK experience (navigation services and registry for rare cancers)

Ricardo Salgado: Patient perspective, ALK+

Stacey Tinianov: Patient perspective, patient groups

Prospects: Marijo Bilusic, Erika Hanson Brown, Lisa Butterfield, Jennifer Cayer, Andrea Downing, Bob Gatenby, Pete Kane, Rob Newson, Corrie Painter, Daryl Pritchard (PMC), Roberto Pugliese, Jason Sager, Eli Van Allen, Matt Vander Heiden, Dan Von Hoff, Nick Wagle

For more information on the Advanced Cancer Navigator, please contact Brad Power at bradfordpower@gmail.com

“The Advanced Cancer Navigator - Helping Patients Shop for Services” (Brad Power) [#31]

We have existing collaboration partners, and down below we have a list of prospects, organizations and individuals that we're reaching out to to see if they would be interested in joining us.

Brad Power:

Marty Tenenbaum has been very actively involved in helping build out this pitch deck. I have a primary focus on patients, and he's good at making sure that the other stakeholders' perspectives are represented and what they might get.

Marty Tenenbaum:

What we're talking about here is a natural evolution is what Cancer Commons has been doing for decades. We've been doing similar initiatives in specific cancers, brain cancer and pancreatic cancer, to be specific, with a desire to grow in two ways. One is to build this out to cover all cancers, and to be able to specifically exploit the economies of scale. Opportunities for cross learning would come from doing that. Everyone agrees that when a cancer gets sufficiently advanced, it doesn't behave in the way that traditional organ-specific cancer does. Metastatic cancer needs to be thought of in the same way that you would think about, for example, a cancer of unknown origin, a pan-cancer approach. That is where there are tremendous opportunities to speed learning; for example, from a drug that works in lung cancer, to other cancers that might share common mutations. But I'm very interested in building a network of networks, where this might be a network. And while Cornell might have their own network, learn from each other.

The key is to do this in a patient-centric way. Because if you get to the point where if you recognize that every patient's advanced cancer is going to have evolved through many mutations, that's going to make it unique, maybe unique on the planet. That cancer has got to be treated with a combination of therapies. Even an individual's cancer is heterogeneous. There's no way that you can do this in a traditional trial. The potential combinations exceed the number of patients in the universe. If you just think about the combinatorics, there are thousands of drugs that are available, and what's the right way to combine them? And that's just the combinatorics; it says nothing about what Brad talked about with the mode or process of administration. Do you give these drugs together as a cocktail, or in some sequence? What's the dosing? What's the order? What's the timing? There's no way you can do this in trials; the only way you can possibly do it, is first of all, to set up a system that continuously learns from every patient. And that's what we're trying to do here. And, secondly, to be able to do this in a way where we're not just observing what the patients are doing, but we're looking down with a “God's eye” view, trying to be a command and control layer that sees what's working, what's not, and try to get more people into the things that are working, or even to be able to plan prospective experiments that just look like they need to be run because the experts are disagreeing this versus that. Well, let's run the experiment. No one is doing this today. This is really an opportunity.

“The Advanced Cancer Navigator - Helping Patients Shop for Services” (Brad Power) [#31]

This audience brings many sources of expertise and disciplines to the table. So when Brad and I are struggling with what's the right organization and business model, we're wide open for input.

Jeff Waldron:

You listed all the organizations you're partnering with. It'd be good to list the academic medical institutions too. For example, you've been working a lot with Pete Kane and Fereshteh and the team at Stanford, and we've had Tony Letai from Dana Farber lead a discussion.

Marty Tenenbaum:

That's a great point, but we don't have relationships with academic institutions; we have relationships with very smart academics. That's a key difference because what we're doing is anathema to an organization that makes its money off of clinical trials.

Jeff Waldron:

You still have relationships with them. The reason I say “institutions" is because you want it to be based on more than one person since that person could leave that institution and go somewhere else.

Marty Tenenbaum (31:50):
I absolutely agree with you aspirationally. I'd love to do that. I'm just saying we do not at this time. And it's not for want of trying to have relationships. I've had my wrist slapped, and more. Seriously, the investigators have had their wrists slapped. They are asked, “Why are you working with these guys?”

Jeff Waldron (32:09):

If you look at Brad's speakers, they've often been from leading academic, medical or diagnostics institutions.

Marty Tenenbaum (32:18):

We work with the best people in the world. And many of them are academics. But try to talk to their institution about getting a formal relationship. It's not easy.

Brad Power (32:32):

That's the way I've thought about it. Every one of our patients is working with an institution through their clinician. I started putting all those on our community slide, and it got very cluttered very fast. Your point is well taken: we're would be happy to get the brand halo from those highly respected organizations. I agree with Marty, that the way that we relate to the institutions is we've got relations with, for example, Sumit Subhudi, who's at MD Anderson, or Rana McKay,

who is at UCSD. We access those institutions through the individuals, but they're participating as individuals. That's because we are a rogue group. We're looking for the mavericks, the iconoclasts, the people going outside the standard of care and willing to take risks, such as prescribing things off label.

Marty Tenenbaum (33:35):

Let me be more specific about an example of where the rubber meets the road on this issue. Number one is if you try to get the institutions to share data, as opposed to getting specific patients being treated at those institutions to give you a HIPAA release to share their data. One is easy, and the other is virtually impossible.

Another example is I've tried to get the tumor boards at different institutions to share their discussions with each other. It’s very, very hard. It's not impossible. We've had a few institutions that have said, “Our tumor boards are siloed. We would like to learn what our peers are recommending, because we can learn from that.” But most of the time it’s “take a hike”.

Brad Power (34:29):

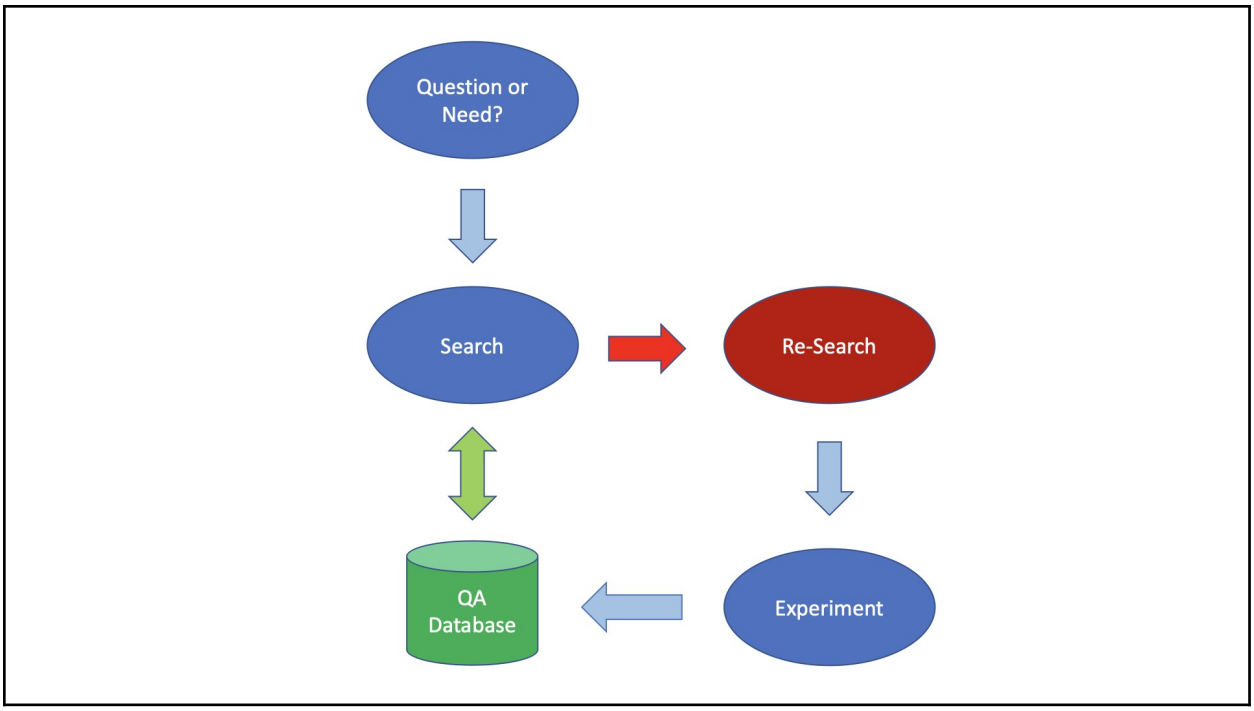
That comes back to the name Cancer Commons. One of the nice things about that brand is the “commons” name. And the idea that it's, as Marty said, a registry of registries, or you could say it's like a data clearinghouse or a network of networks. Aspirationally that's the way we're looking at it. The underlying theme is learning. And it's collective global learning and trying to be as open as possible by going cross-institutional. For example, Memorial Sloan Kettering, MD Anderson, Dana Farber, and UCSF are awesome. We're trying to see how we can collaborate across these institutions, which is often hard.

Brad Power (35:25):

For those of you who don't know, Said Sayad is an expert on data, especially public data, and learning things from publicly available datasets.

Saed Sayad (35:45):

“The Advanced Cancer Navigator - Helping Patients Shop for Services” (Brad Power) [#31]



The idea of your presentation was to answer a question or meet a need.

The first thing we need to do is search — maybe somebody has that answer.
I can give you one example. I was talking to the team at the UK Biobank, which we know is a big, multibillion-dollar project. They have clinical data, lab data, omics data, and images. I asked them, “Do you know about the Geo database or Array Express, which is also in Europe?” These two datasets have close to 1 million experiments. They didn't know about that.
The first thing we need is an infrastructure, maybe by crowdsourcing, to do the search, to see if we can find the answers for that question or need, then put it in the database. We need a QA database because otherwise we just get the answer and set it and forget it.

If there is no answer after searching, then we need to do research. This research might be finding somebody else who is doing the research, or we can have a website because we cannot do it by ourselves. We can have some sort of platform to share, for example, an equation we had where we couldn't find the answer. Can we share this with researchers? They love to have the word on a new idea and write papers. That's about the experiment. And it goes back to our QA database. We should focus on what we need, and then focus and talk about the infrastructure for those needs. As I said, the key here is we have a question, and we want to find an answer.

Marty Tenenbaum (38:38):

I love this slide. This is precisely what we're setting up the infrastructure to do – making a place where someone who has questions can post them and maybe someone else will either have the answer or will want to try the experiment.

There are many, many people who have invested a lot of money in big databases, and big data projects. It's helpful. If you have data, you may find the answer. But the dimensionality of the space we're talking about, where the combinatorics, the timing, the dosing, and all those things, will make it most likely that it's going to be very hard to find an answer to most of the questions people are going to have. What people don't realize is because the optimal treatments have probably not been tried anywhere. The answer is that there's zero data on them. I don't think the world really recognizes that. But the opportunity is where you say, run the experiment in a prospective way to get the answer that you want. That's the key. That's different from what has been done historically, which is investing a lot of money in big projects like Flatiron.

Saed Sayad (40:06):

The biggest issue I see in this field is that they start without a clear question.

Another problem on top of it is that they don't define success criteria. You will find some biomarkers, then what? Even after they find the answer, they don't know about the deployment, the use of that. They do experiments and research. For example, a patient comes to the site and he has a question. We cannot give him a 30-minute presentation about what we are doing on this map. He wants an answer. That's all he wants. The answer might come from a search from the same type of patient, if that patient uses drug x. There are many prostate cancer patients who are using drug x. Now I am a new patient, and I want to know if x is better than y. What's the best thing? You have it in the machine learning similarity function. We try to find a function to find similar cases. This is what we can do with the help of our patients. We need to find a good match, somebody who is one step ahead of myself as a patient, and that one is that can help me to see that patient got a good result. Or to say it didn't work for him, then finding the match. Then we can add on top of it. I have no doubt that there are huge amounts of data everywhere. But they are not organized. They are not based on the question. They just put the data together to create a database. That doesn't help. When they answer a question, I really like that decision-making process. Each node in the decision-making process is a question, Should I go down this path or that path? To answer this question, first, find similar cases, try to have a database where we can bring all these cases together and try to find a good match for it. Then on top of it, there is public data, and there are experiments in action. This is what we need to start to create – a platform to control the flow of the data. Otherwise, it's going to be very difficult. This is something that we're interested in academically working on. Right now, my focus is on my startup company, Bioda.

Brad Power (44:30):

Richard Anders, for those of you who don't know him, is connected with MIT. He is also an angel investor who has Mass Angels, an investor community that he works with.

Richard Anders (44:49):

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I taught at MIT for a number of years.

The notion that we don't know the optimal treatment is, of course, true. But “the optimal” is certainly the enemy of “the good”. The optimal treatment is a drug you take with no side effects, and the cancer is gone. Maybe that'll happen someday. But I don't think patients need optimal treatments; they need “good enough” treatments and treatments that are good enough relative to where they are and what their risk profile is. If you navigate between the shores of skill and Charybdis, it's a really difficult journey, because there are risks on both sides. Helping patients to understand the risk set, notwithstanding the fact that there are accepted standards of care, is important.

The profiles of the institutions are really frustrating. I was on an IRB at the Dana Farber for a number of years, and I regularly would say, “This is an approved drug for this trial. As part of the consent form, we should tell the patient that they might be able to get this drug without being randomized.” I thought that it was honestly the ethical thing to do to tell patients, and I didn't win one of those battles. From the institution's point of view, I get it, because how do you run a clinical trial if you don't have randomization? But there's another side to this, which is that there is a war going on. Data is totally balkanized. Every institution thinks that data is something that they can control. All the academic institutions seem to want to do that. Memorial Sloan Kettering got in a lot of trouble when they tried to monetize their set of data. There are institutions which are agglomerating their datasets so that they can. Everybody tries to balkanize the data. It's a very serious set of problems that we deal with on the institutional side.

This has got to be a subversive effort, like the Homebrew Computer Club. In the short run you are not going to go to the institutions, and they're going to fall over to partner with you. This is doctor here, doctor there, and if enough patient pull comes through the Homebrew Computer Club, you get Apple Computer and the microcomputer revolution. But it didn't happen in a day.

Marty Tenenbaum (47:50):

Richard, where is your current affiliation?

Richard Anders (47:55):

I run an angel group. That's my only affiliation.

Marty Tenenbabum:

I've been fighting the battles that you've described for two decades. I'm seeing thaws in the ice. It's certainly not easy. When I used to bring these things to Dana Farber or to Stanford, at the top of the executive suite, I was told, “We can't do that. We're Stanford with a reputation to protect.” Or at the top of Dana Farber, I was in the room where the CEO put his fist down and said, “We are not sharing data with other institutions in the Partners System.” Which was insane. All I can tell you is that this is a battle that ultimately has to be won and will be won

because we're building a system here which is fundamentally better for patients, and they will vote with their feet.

Among other things, you know, we didn't talk about the concept of decentralized trials, but there's no reason a patient should have to go to Boston or Houston or New York to be able to get access to the kinds of therapies that are today only available in a half dozen places. It doesn't make any sense.

I have one really telling question to ask you, which is, as the head of an angel group, would you invest in a company that said we are committed to trying to break the system by building a system that is fundamentally better for patients?

Richard Anders (49:38):

That wouldn't be the business proposition that would garner investment. That might be part of the strategy to do it. There's got to be a path to what is likely to work to be an investable proposition.

Marty Tenenbaum (49:57):

As an example, take a look at what xCures has accomplished, and what they're trying to do, in terms of the experience of raising the funding next year. It raised $17 million, a significant amount of money. It hasn't been easy. We wanted to get a big check to build a system that was going to learn from every patient.

Richard Anders:

Is it grant-funded?

Marty Tenenbaum:

No. It’s funded by smaller venture funds. The big venture funds that they would have expected to write checks for tens of millions of dollars, which is what it's going to take to do this, said, “This is very interesting. Come back when you derisk it.” That's unfortunate, but that’s reality.

Richard Anders (50:58):

VC is hard when you're talking about things that are unknown quantities. A very unknown quantity is how you make a social movement. Somehow the internet managed to galvanize people, and they invested in a social movement. The opportunity seems so big in the medical field. People look for targets. They look for drugs that seem effective. The idea of galvanizing a movement is a little bit harder for an industrial life sciences person to understand. That's the challenge.

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Marty Tenenbaum (51:37):

If you're interested in this topic, I get to Massachusetts frequently, and I would love to meet up with you.

Richard Anders (51:44):

That'd be great. I have this vague idea that we did meet once upon a time.

Marty Tenenbaum (51:52):

I hang out in Andy Lowe's circles.

Richard Anders (51:55):

I've been to a couple of those.

Marty Tenenbaum (51:59):

That may be where we met.