“Review of Services for Glioblastoma Navigation” (Mike Pyne) [#92]

Brad Power, Gabrielle Ruvinsky
April 10, 2024

“He couldn't believe how difficult it was for him to understand the information, understand what he was eligible for, and then even find the doctors that offer that treatment or clinical trial as a service.” – Mike Pyne

“People spend so much time online looking for answers about treatment or about a topic they learned about. We're trying to incorporate all that into one platform. It's marrying the digital platform with artificial intelligence with educational content.” – Mike Pyne

Meeting Summary

Navigating brain cancer is a daunting challenge for patients and their loved ones, marked by shock, overwhelming choices, and the urgency to make informed decisions about treatment options. The medical team provides initial guidance, but the plethora of choices in doctors, treatment locations, tests, and clinical trials demands that patients quickly educate themselves to make rational decisions. Understanding the landscape of brain tumors, including information on medical experts, treatment options, and support sources, becomes crucial for navigating this difficult journey.

In April 2024 Mike Pyne led a discussion about the navigation challenges faced by glioblastoma patients and caregivers and shared a prototype software application that he was building to address those needs. Mike was motivated by the challenges a friend of his had in dealing with his glioblastoma diagnosis, so he set out to develop tools that would support people in a similar situation. His ambition was to revolutionize how glioblastoma patients access treatments and clinical trials, simplifying their search based on genetic mutations and disease stages. There are many apps that can help cancer patients and their caregivers navigate and automate some of these tasks, but none that were specifically designed for glioblastoma. However, Mike hit a wall in creating content, and in June of 2024 decided to shift the focus of his work from glioblastoma to orthopedics. Nevertheless, this conversation delivered useful information for glioblastoma and other cancer patients, their loved ones, and software developers building similar tools.

What are the navigation challenges facing people with glioblastoma?

- Understanding the information about your disease and your testing and treatment options
- Understanding what you are eligible for
- Finding the doctors that offer that treatment or clinical trial as a service
- Deciding whom to trust on testing and treatment advice
- Making sure you have the latest information

What are the navigation services that patients and caregivers need?

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- Allow patients and caregivers to filter options based on genetic mutations, disease stages, and location
- Provide clear, unbiased information about treatments and clinical trials
- Offer a tool incorporating AI to answer patient questions
- Facilitate connecting patients with doctors who offer relevant treatments and clinical trials.
- Trusted and neutral presentation of testing and treatment options.

What is needed to deliver these navigation services?

- Develop an automated process to continuously update clinical trial listings; check which ones are still active by integrating a clinical trials API or directly contacting trial providers
- Partner with advocacy groups and patient navigators to get updated information on clinical trials and include them in the platform ecosystem
- Consider ranking clinical trials and treatment options by predicted success based on large language models, once AI is improved
- Add a filter section to allow searching by multiple mutations or locations
- Incorporate more information on ketogenic diet as a treatment option
- Consult medical professionals like pathologists to review platform content and terminology for medical accuracy
- Develop a beta testing community for review and feedback
- Develop a reliable source for education content

How can you learn more about glioblastoma and navigating treatment?

- See Al Musella’s discussion on navigating brain cancer here.
- See Ari Akerstein and Brad Power on empowering patients to navigate cancer care here.
- See Samira Daswani on helping patients navigate cancer here.
- See Vanessa Liu on illuminating the path of cancer care with a chatbot here.
- See Berries on introducing an app for navigating cancer care here.

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Meeting Notes

KEYWORDS

clinical trials, information, treatments, patients, questions, glioblastoma, works, metal, doctors, answers, understand, platform, people, gbm, good, website, create, wanted, filter, options

SPEAKERS

Mike Pyne (77%), Allen Morris (7%), Misha Mehta (6%), Al Musella (3%), John Powers (3%), Brian McCloskey (2%), Amit Gattani (2%)

OUTLINE

1. Misha's introduction. (0:00)
2. Steps of how Medoh works. (4:23)
3. Breaking down information into different categories. (9:06)
4. How do you figure out the order of the information? (15:36)
5. How does bias creep into the selection process? (20:09)
6. Finding a clinical trial provider. (24:23)
7. Yes no or unsure by clicking yes. (29:07)
8. How do you handle clinical trials for natural treatments? (35:12)
9. A quick suggestion for clinical trials. (40:48)
10. The most common type of brain tumor. (46:52)

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TRANSCRIPT

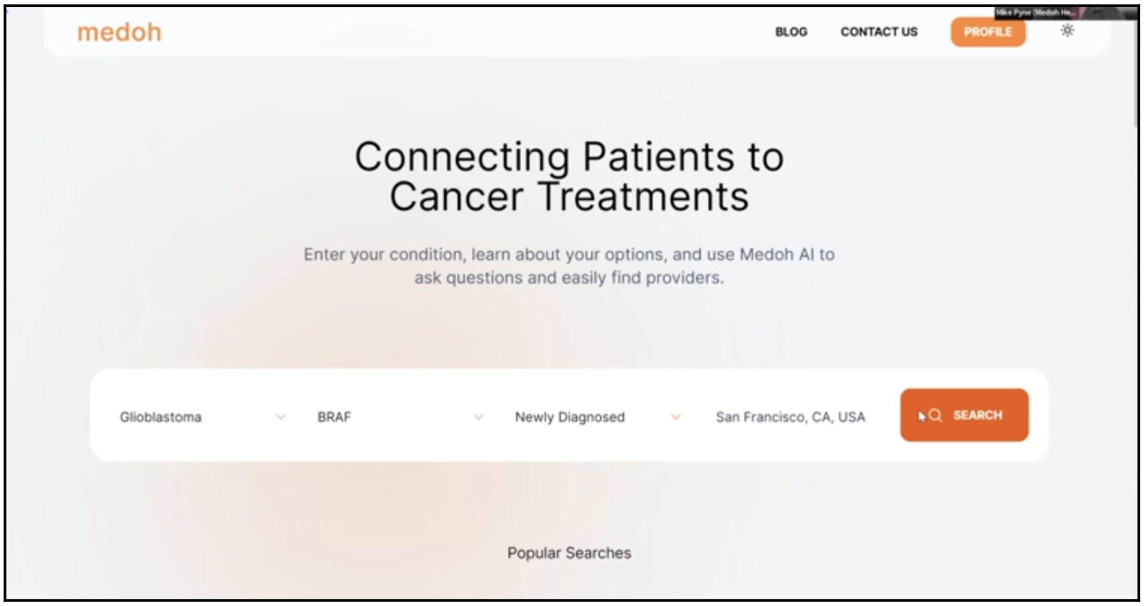
Misha Mehta
I am the mother of Neev Kolte who was diagnosed with a pediatric brain tumor called DIPG. He battled for 15 months.

It gives me great pleasure to introduce Mike Pyne today. Mike is uniquely qualified to talk about the navigation challenges of glioblastoma patients and his caregivers. When he first saw his friend's challenges upon being diagnosed with GBM (glioblastoma), he set out to develop tools that would help support people in similar situations. Medoh Health revolutionizes how GBM patients access treatments and clinical trials. Simply find the search based on genetic mutations and disease stages. There are many apps that are currently in the market that would help cancer patients and their caregivers to navigate and automate some of these cancer journey tasks. But none that is specifically made for GBM, and this tool is specific for GBM. Medoh Health is at an early stage of design, and Mike is working on a second iteration of a prototype. That's what he's going to be talking about with us today.

Mike Pyne 1:50
Thank you very much, Misha. Thanks, everyone. My name is Mike. I'm one of the cofounders of Medoh Health, which is a digital health platform that helps glioblastoma patients search, find, and understand treatments and clinical trials that are available today.

As most people have probably experienced on this call, when you are diagnosed with cancer, time is of the essence. I noticed that one of my friends who was diagnosed with glioblastoma wanted to understand and find what treatments and clinical trials options were available to him other than what his doctor was offering him. He said he couldn't believe how difficult it was for him to understand the information, understand what he was eligible for, and then even find the doctors that offer that treatment or clinical trial as a service.

He asked me to help him navigate it because I have nearly ten years experience of working in the medical device space. I basically did sales, marketing, product development for innovators of orthopedic treatment options. But I also created a lot of content around educating patients on the options they had available. When I tried to help him, I couldn't believe how difficult it was. I knew there were some platforms out there that you could easily just try and search the different clinical trials that are available. But the information was extremely difficult to understand because there was so much medical jargon. Then from that I even found he had so many questions about all of these treatments. And none of them could be answered from different websites and trying to navigate the web. So what I decided to do was just create a simple platform that allows patients to search by filtering out what options they have based on their genetic mutation, where they live, and the stages of the disease, if they're newly diagnosed or a reoccurrence. Because we didn't want to give them too many options, we wanted to be more specific. What I also wanted to do is help them understand. I just didn't want to give them a clinical trial. I didn't want to give them a treatment. I wanted them to have their questions answered by basically incorporating an AI tool that allows them to ask questions about the treatment or clinical trial they're looking at. The next step was easily helping find the doctors that offer that treatment in their local area or close by. And then the last part is their eligibility: help them understand if they're highly eligible, or not eligible at all by asking them a few simple questions about their condition about their experiences in layman's terms that they will be able to answer themselves. And those are basically the four steps of how Medoh works. So what I would like to do is basically show you how it works. Each stage, I'm going to pause and ask for any feedback. I am open to answering any questions you guys may have, and I want to keep it as informative and engaging as possible. So I'm just going to share my screen now. And I'm going to start with just showing you and giving you an overview of exactly how Medoh works. And in each stage, I'll pause and I'd be willing to answer any questions any of you may have.



Connecting Patients to Cancer Treatments

Enter your condition, learn about your options, and use Medoh AI to ask questions and easily find providers.

Glioblastoma | BRAF | Newly Diagnosed | San Francisco, CA, USA

Popular Searches

I just want to also state that we're in the early stages of the development of Medoh. So there might be a few little mistakes or it might be perfect, but that's why I wanted to do this call. So we can get a little bit of feedback and make little improvements on areas that might not be perfect or areas that can be improved. So as you can see here, what I noticed was there's definitely a few different companies out in the market that do something similar to Medoh, but Medoh differentiates in two very different ways. The first one is, we wanted to give patients options without them having to fill out hundreds of questions. The way I thought about it is anytime someone's looking for a house, they go to Zillow to look at the different options they have first. Once they find a house, they contact a realtor and then all the work behind it actually goes on to make sure they can buy the house or rent it. I wanted to do the same thing with Medoh. I wanted to make it as easy as possible by filtering down some of the options by giving patients treatments that they can actually learn and understand about their potential potentially eligible for. I didn't want to create any barriers to entry. The second thing is, I wanted to filter out the ones that weren't going to be applicable from the start without asking for too much information. So as you can see here in the search bar, we basically asked for four pieces of information:

their condition, the variation or mutation that the patient has. As you can see, we have hundreds of different mutations that we just put in. And again, only some of these are relevant, but we want to try and include them all. The reoccurrence. Are you newly diagnosed? Or is this a reoccurrence? And then the location you are in. The reason why we thought it was important to put the location is because we thought it'd be a lot easier just to filter down the options that are within 100 mile radius or a 200 mile radius of where you currently live. That would just give the patient less choice. And it would also just help them understand: this is what's local to me. But if they wanted to find the options that are outside them, they can always use a filter. So all you pretty much have to do from that is enter generic pieces of information and press the search bar. If you don't know your mutation, if you don't want to put it in a location, and you just want to try the whole of the US, you can literally remove those pieces of information and it will just give you more options across the whole of the United States for clinical trials and treatments. And then when you press search, it basically goes to the next stage. So that is the basic search function. And I know that's really simple. But does anyone have any questions about those particular things that I just spoke about?

Brian McCloskey 7:45
What if you have multiple mutations?

Mike Pyne 7:53
A really good point. What we're trying to do, and what we're going to do is, on this particular part of the page, we're going to add a filter section. And basically, that filter will allow you to edit or add more filters to it. So for example, if you have more than one mutation, or you want to try a number of different cities across the United States, we're going to have a little pop up bar here that's going to allow the patient just to change the filters, so they can actually get more accurate results. Again, very similar to how Zillow works, it doesn’t ask for a small piece of information first, and then it gives you filter options the further you go down. We're also going to do the same thing because we know that's going to be an important part because each person is slightly different, they're going to want to filter certain pieces of information. So that's something that we're going to build in, we just don't have it done yet. Because the way we look at it is we want to basically walk before we can run, build the basics. And then once we have the basics, build the features that make a bigger difference and make it a better experience. And you'll probably hear me say that a lot over the next hour when I'm talking about this.

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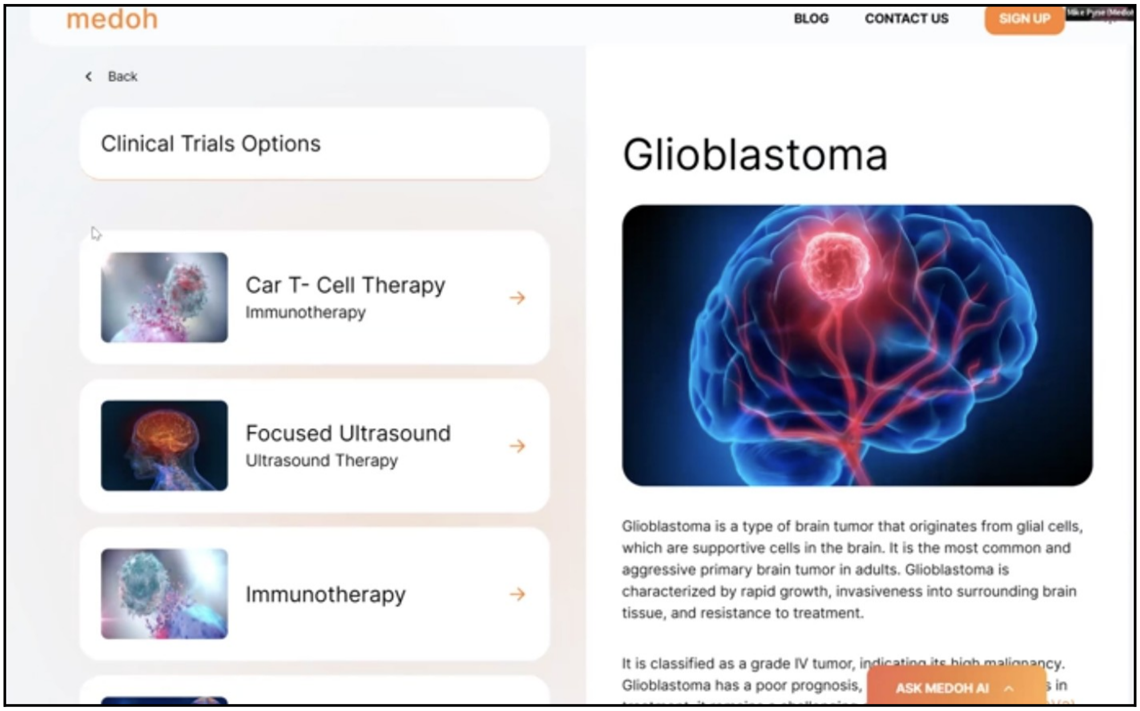

Glioblastoma

Glioblastoma is a type of brain tumor that originates from glial cells, which are supportive cells in the brain. It is the most common and aggressive primary brain tumor in adults. Glioblastoma is characterized by rapid growth, invasiveness into surrounding brain tissue, and resistance to treatment.

It is classified as a grade IV tumor, indicating its high malignancy. Glioblastoma has a poor prognosis,

The next stage is breaking down information into different categories. What I noticed with my friend is also that there were a lot of clinical trials sites to help patients find clinical trials, but they offered no other types of treatments. So what I wanted to do is basically create a system that was easily interactive, so that your patients and users could easily interact with Medoh and could clearly understand what treatments are approved, what's in clinical trials, what's off label, depending on all the clinical trials around. We just wanted to break it down. And for example, one thing I noticed from a lot of feedback from patients is that the clinical trials you’re learning about are actually only focusing on the clinical trials, the structure of it and have very little information about the actual treatment as the primary focus.

I wanted to explain the treatment first to the patient, because that's what the patient has the most questions about. If you don't explain the treatment, the patient doesn't really understand why the clinical trial is being conducted. So what we decided to do is focus on just the treatment first, and then help them find doctors, and then help them find the clinical trial.

When we go into clinical trials, it will filter out the clinical trials based on the information that you've given and filter out the treatments. But what we wanted to do before we just jumped straight to the clinical trial and explaining it in depth, we wanted to explain what the primary focus of the treatment was. Because like I mentioned, from the feedback we got, patients wanted to understand about the treatment first, because that's usually considered the most experimental part. That's where they have the questions. And that's where we're trying to differentiate ourselves.

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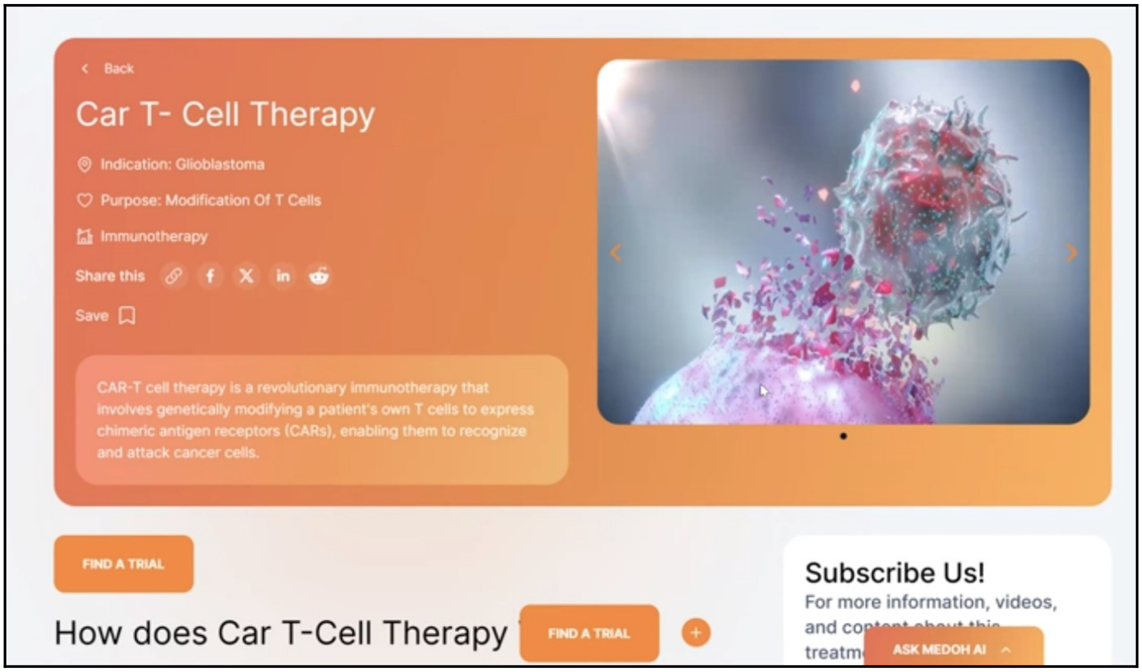

Car T- Cell Therapy

Indication: Glioblastoma

Purpose: Modification Of T Cells

Immunotherapy

CAR-T cell therapy is a revolutionary immunotherapy that involves genetically modifying a patient's own T cells to express chimeric antigen receptors (CARs), enabling them to recognize and attack cancer cells.

How does Car T-Cell Therapy

Subscribe Us!

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treatm

What we want to do is try to break down and explain the treatment by using two different things. One, by using AI, which we've incorporated into Medoh Health. And the other is by using video content, which we're trying to create. The whole idea is if a patient has a specific question, they can get it answered without actually having to speak to a doctor, or at least go to a different website. Because patients become really empowered with the more information they have. And a lot of the information right now is on a number of different websites. You might find a clinical trial or a treatment on one particular website, but it doesn't answer any questions you have about it. And you have to go to a number of different websites and try to play a guessing game on where to find information and how to get your questions answered. Because if you can't empower the patient with information, they don't feel as educated or as informed in the decision making process. Again, everyone's always very aware, it's the patient and the patient's loved one that is going to make a decision. So the whole idea is we break down how all these different treatments work by giving a little piece of information, breaking it down, but then also by asking AI a series of questions.

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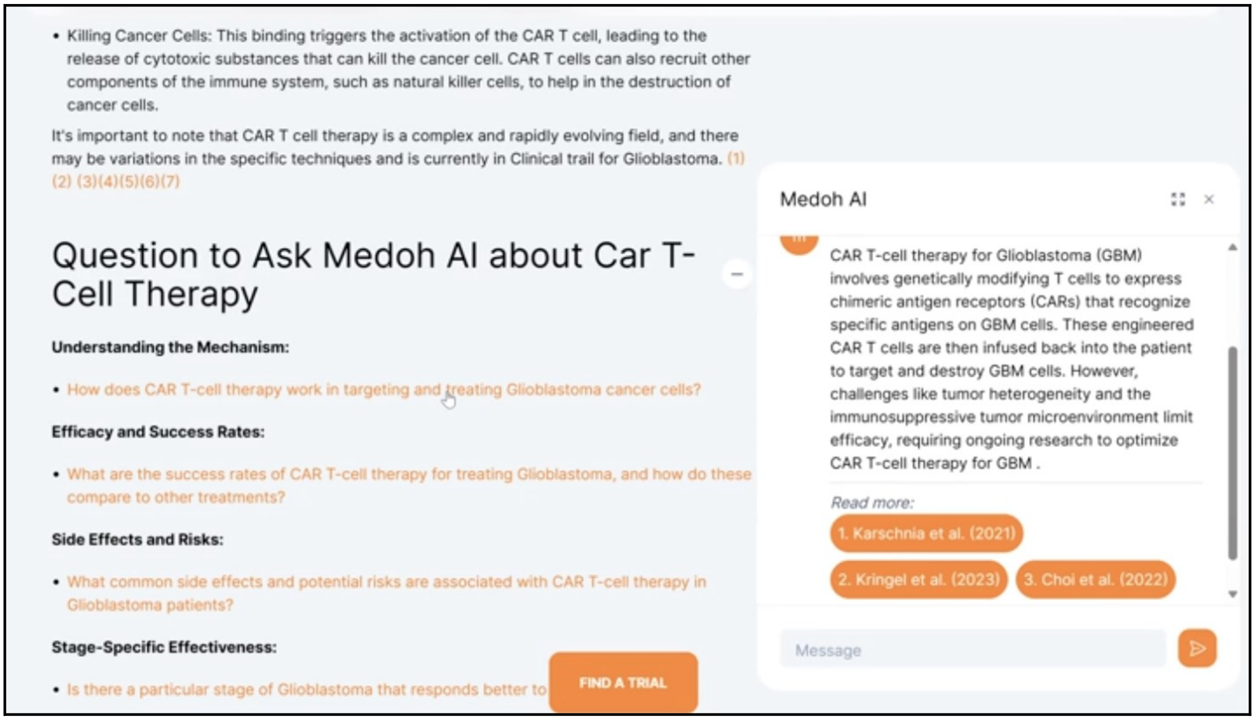


- Killing Cancer Cells: This binding triggers the activation of the CAR T cell, leading to the release of cytotoxic substances that can kill the cancer cell. CAR T cells can also recruit other components of the immune system, such as natural killer cells, to help in the destruction of cancer cells.

It's important to note that CAR T cell therapy is a complex and rapidly evolving field, and there may be variations in the specific techniques and is currently in Clinical trail for Glioblastoma. (1) (2) (3)(4)(5)(6)(7)

Question to Ask Medoh AI about Car T-Cell Therapy

Understanding the Mechanism:

- How does CAR T-cell therapy work in targeting and treating Glioblastoma cancer cells?

Efficacy and Success Rates:

- What are the success rates of CAR T-cell therapy for treating Glioblastoma, and how do these compare to other treatments?

Side Effects and Risks:

- What common side effects and potential risks are associated with CAR T-cell therapy in Glioblastoma patients?

Stage-Specific Effectiveness:

- Is there a particular stage of Glioblastoma that responds better to

CAR T-cell therapy for Glioblastoma (GBM) involves genetically modifying T cells to express chimeric antigen receptors (CARs) that recognize specific antigens on GBM cells. These engineered CAR T cells are then infused back into the patient to target and destroy GBM cells. However, challenges like tumor heterogeneity and the immunosuppressive tumor microenvironment limit efficacy, requiring ongoing research to optimize CAR T-cell therapy for GBM .

Read more:

We developed this AI to answer questions that patients have. What we do is we create our own frequently asked questions. Then the AI takes the question, pulls all the information from a number of different credible sources, and it gives you an answer. But the answer is given in two ways. One, that a patient understands, and two, in a non-biased fashion. A lot of the tools that I see being used when it comes to answering patients' questions are very, very biased. The whole idea of Medoh is to create a platform that's not biased to specific treatments or to specific clinical trials. Because what we're trying to do is give general information about the topic that people are interested in learning more about, and try to find a doctor or a provider for.

As you can see, if you can ask the question: ‘How does CAR T-cell therapy work in targeting and treating glioblastoma cancer cells?’ Here's the answer. It's produced in a way that makes it really, really simple for patients to understand. Because if the answer is too complex, they're not going to understand it. And then as you can see, you have ‘Read more’ here. We only take the answers from clinical papers that have been published, because we feel like they're actually extremely credible sources. And if you want to actually find these papers, all you have to do is click and it brings you to it here. If you want to share it with your doctor, if you want to look through or read a little bit more, you know exactly where the source of the information is coming from. So that's pretty much how Medoh works when it comes to understanding the treatments that are available for the information you put in. The next step would be finding a doctor and understanding a little bit more about the clinical trial. But I'd like to open it up to anyone that might have any questions they’d like to ask about this particular topic, or anything that I've shown?

Al Musella 15:43
How do you figure out the order of these items [under Clinical Trial Options]?

Mike Pyne 15:47
Good question. Right now it's actually run alphabetically, as you can see there. But the more information you put in, the less options you get. We're not trying to promote or put a treatment on a scale because we partner with a life science company or anything, we're just trying to make it as non-biased as possible without pushing one particular one because we have a partnership with them. Right now, it's just alphabetical, which we think is the fairest order for us to do it.

Al Musella 16:20
We do a similar type of thing. We're trying to get it in order of how good they are, basically.

Mike Pyne 16:30
That's actually a great idea.

Al Musella 16:34
Especially if you have already looked for all the research behind the publications, you could probably ask a large language model (a type of AI designed for human language generation) to rank these by success.

Mike Pyne 16:48
The way the large language model works, and we're still trying to get a few kinks out of it, but the idea of Medoh AI is to summarize information and explain information rather than give biased opinions on what's the best and what's the worst. I think it's really important that Medoh stays as neutral as possible. What we're trying to do is give people basic information without actually saying ‘this is the best, this is the worst,’ because that looks biased. The whole idea is, for example, there's 10 people using Medoh. One person might want to look for a particular type of treatment or clinical trial, and another might want to look for another one. The less biased we are, the better the user experience. We think it's best for us to just give people the information based on what they're looking for. But then also let a doctor decide, by us connecting you to them, if it's the best thing for you or not. I personally think bias is a really important thing. Because as soon as you start partnering with companies, your opinions shift dramatically, to your own pocket. I really want to try to keep it as unbiased as possible with all the information we give. That's why I'm trying not to particularly rank them at this moment of time. This is why it's a very good learning curve for us, because we're just trying to figure out what works and what doesn't, so we could create a better product from it, too. And that might be the best way to go eventually.

Al Musella 18:27
I would say most people would assume, like even just from a Google search, that the first item is the most important one. To randomly list it by what they happen to title the treatment by seems kind of strange.

What is your business model? How are you going to fund this?

Mike Pyne 18:48
How Medoh works is, if a patient comes to the platform, and they apply for a clinical trial or treatment, basically we get all their information, ask them a series of questions. And then they create a profile for us. The clinical trial provider, or the treatment provider that they want to speak to, we will contact them and say, ‘Hey, we have a patient that's interested in applying for your clinical trial. Do you want to accept this patient? Here's some basic information about their medical record without seeing any other personal information’. And if they accept the information, they pay a small fee. If they don't, we help them find someone else. That's what I'm going to explain a little further later in this call, is about what we're currently building and why we're building it.

The whole idea is to connect patients to eligible treatments and clinical trials, but then also reduce the cost dramatically for life science companies and doctors that are trying to recruit patients to speed up the recruitment process, but also save them money because we know those are two things that cost so much of the resources that they have when it comes to clinical trials.

Amit Gattani 20:07
We are focused on brain cancer here, of course, but from an AI training perspective, or what AI can do in this space, is this trained to focus on more brain cancer stuff? Or can the same engine be used to ask questions for prostate cancer, or pancreatic cancer, or anything else?

Mike Pyne 20:55
Right now, the platform only helps you find treatments for glioblastoma. The reason is, we wanted to start with one, get it right, and then start going into other areas where we feel like there's a need for this. With Medoh AI, you can ask it any question about any health condition. You can get any answers you want by using this particular tool. But the flow of the website is specifically designed for glioblastoma right now.

Amit Gattani 21:31
You said this is a public website? How long ago was it launched? What's the maturity status?

Mike Pyne 21:46
I launched version one 8 months ago in August of 2023. Then we had a very simple website. I'll show you a little more what the next steps are and how it works. But it was a very simple website that basically brought you to this page. You could go no further. We would have links to some of the clinical trial providers that had CAR T-cell therapy for glioblastoma. It’ll bring you externally to another website. We've built it out the back end, which helped patients find providers, and then apply through our platform. It makes it a lot more streamlined and a lot more efficient in a number of different ways.

Brian McCloskey 22:40

How does bias creep into the selection process? Or the presentation process? And how do you mitigate it?

Mike Pyne 22:55
I think it's really hard to have a perfect system when it comes to bias. But as soon as life science companies, or hospitals that are trying to recruit for clinical trials come into the picture, you can very easily get sideswiped by bias. I really want to try and stay away from that as much as possible. Because the less bias there is, the more trust you can build between a person using Medoh and the platform itself.

Brian McCloskey 23:27
Does it show up in SEO (search engine optimization)? How does the search engine pick up that hospitals are recruiting really hard for patients?

Mike Pyne 23:39
On our platform Medoh or on Google?

Brian McCloskey 23:42
Through your platform.

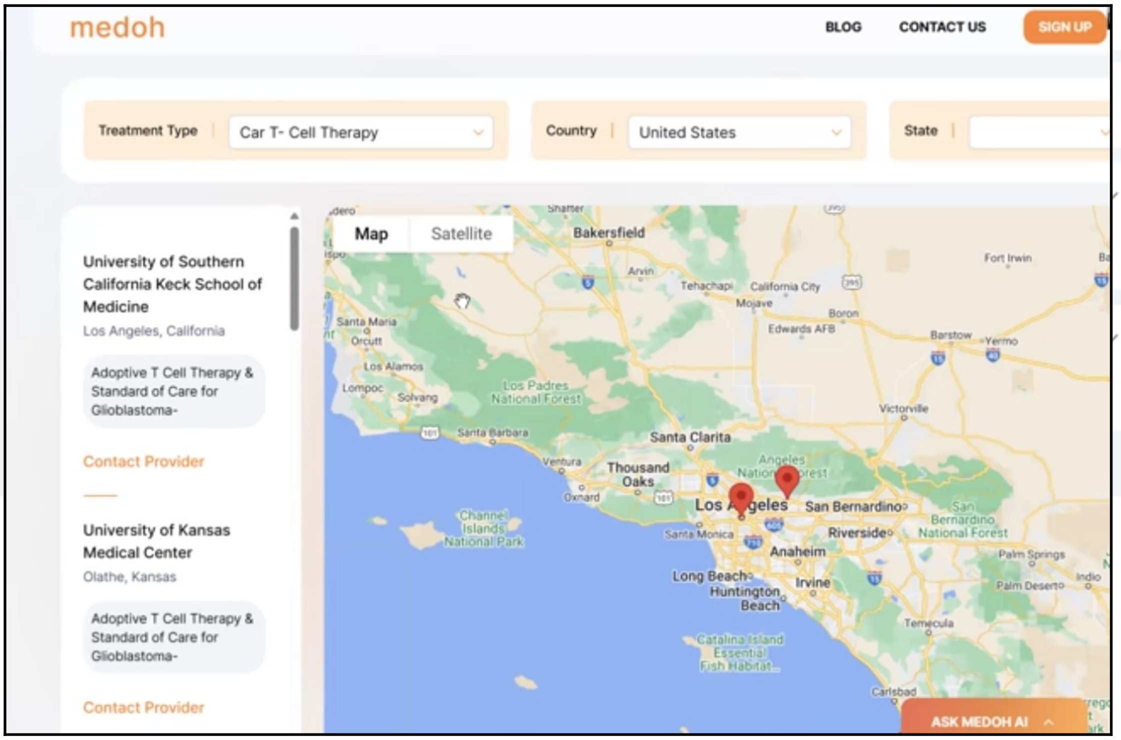
Mike Pyne 23:46
So it's all done manually, between myself and Michael. Basically, we keep an eye on everything that is currently being published in a number of different channels that have clinical trials, and we keep up-to-date with it. We use different APIs (application programming interfaces), which are little pieces of technology that connect information from loads of individual websites to Medoh. It constantly gets kept up-to-date with the information that's been published in other websites. It's not through SEO. It's just aggregating all the information that's out there and pulling it to one particular place.

Mike Pyne 24:31
The third stage to this is basically finding a provider. The whole idea of Medoh, like we mentioned, is to help people search, help people understand, like I just showed you, but then also help them find the doctors and healthcare providers in their local area that offer this treatment or clinical trial as a service.

Let's say the user or patient has asked Medoh a series of questions about CAR T-Cell therapy. They want to understand and find a little bit more information about it. They’ve asked a number of questions, they've gotten a lot more information, they're a little bit more educated. They want to understand ‘where do I find doctors?’

And in order to do that, it basically will show you the doctors in your local area that offer all of the clinical trials for CAR T-cell therapy, based on the filtering that you've done in the search bar initially. So as you can see here, for CAR T-cell therapy, there was none in San Francisco, but it automatically brought you down to Los Angeles, where there are two facilities that have a CAR T-cell therapy treatment. All you have to do in order to get there is click on this link.

It shows you the clinical trials for CAR T-cell therapy. As you can see here, there are two



Treatment Type | Car T- Cell Therapy

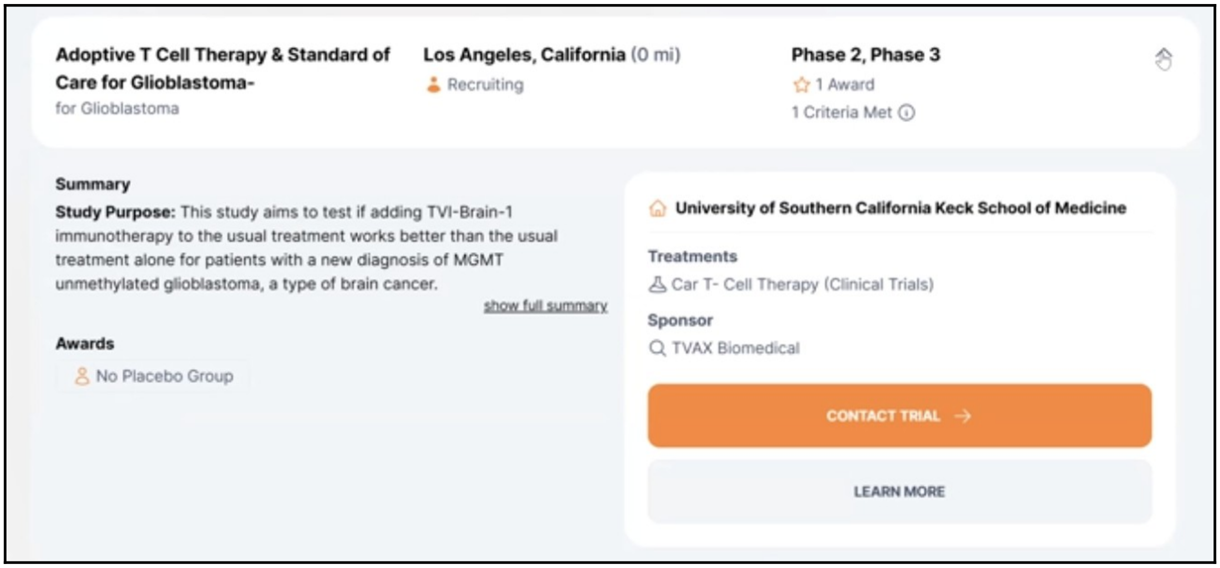
Country | United States

State |

University of Southern California Keck School of Medicine
Los Angeles, California
Adoptive T Cell Therapy & Standard of Care for Glioblastoma-
Contact Provider

University of Kansas Medical Center
Olathe, Kansas
Adoptive T Cell Therapy & Standard of Care for Glioblastoma-
Contact Provider

options.



Adoptive T Cell Therapy & Standard of Care for Glioblastoma-
for Glioblastoma

Los Angeles, California (0 mi)
Recruiting

Phase 2, Phase 3
1 Award
1 Criteria Met

Summary
Study Purpose: This study aims to test if adding TVI-Brain-1 immunotherapy to the usual treatment works better than the usual treatment alone for patients with a new diagnosis of MGMT unmethylated glioblastoma, a type of brain cancer.
show full summary

Awards
No Placebo Group

University of Southern California Keck School of Medicine

Treatments
Car T- Cell Therapy (Clinical Trials)

Sponsor
TVAX Biomedical

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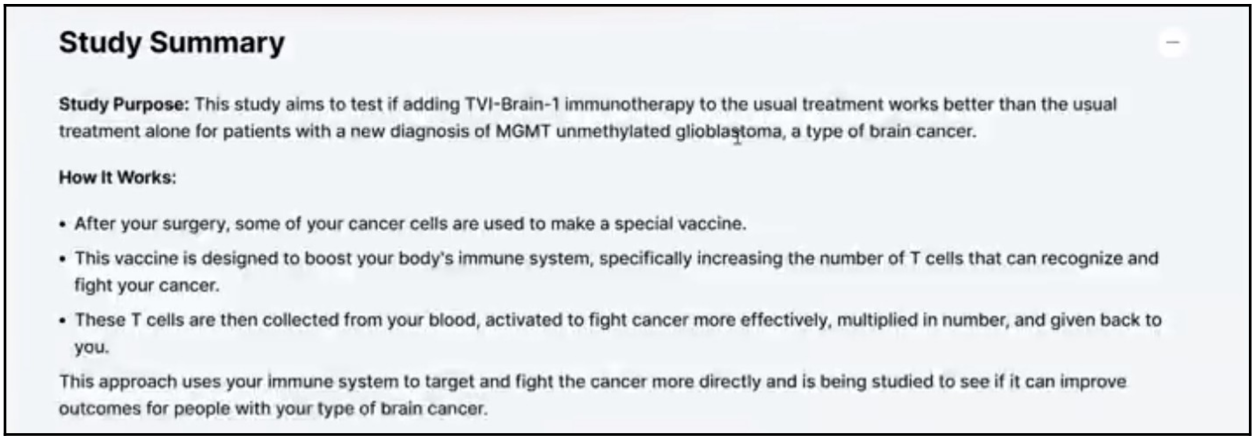
You can look briefly and get the information about the clinical trial. You can contact the clinical trial provider through this. Or what you could do to learn about the full clinical trial itself, you just click ‘Learn More’. It brings you to this website. We take all the information from clinical trials.gov. We've restructured the information to make it really easily understandable and lay it out in a way that patients can understand it and follow it. Because a lot of the websites use way too much medical jargon or don't have enough information on it.



Study Summary

Study Purpose: This study aims to test if adding TVI-Brain-1 immunotherapy to the usual treatment works better than the usual treatment alone for patients with a new diagnosis of MGMT unmethylated glioblastoma, a type of brain cancer.

How It Works:

- After your surgery, some of your cancer cells are used to make a special vaccine.
- This vaccine is designed to boost your body's immune system, specifically increasing the number of T cells that can recognize and fight your cancer.
- These T cells are then collected from your blood, activated to fight cancer more effectively, multiplied in number, and given back to you.

This approach uses your immune system to target and fight the cancer more directly and is being studied to see if it can improve outcomes for people with your type of brain cancer.

As you can see here, all of the information that's on clinical trials.gov is all repurposed onto this particular page. This is only if you want to learn more about the clinical trial itself. This is the specific clinical trial.

Misha Mehta 27:06
When you do that, does it also tell you the eligibility criteria? Because there's a lot of times that you like something, that you're excited about it, but you don't meet the eligibility criteria.

Mike Pyne 27:22
There are two ways of doing it. One is here.

We took all the eligibility criteria from clinical trials.gov. But we restructured it so it's really easy to understand for patients. As you can see here, it says eligibility criteria, and we actually show the original as well, because we think it's really important that we show the original criteria of it. But what we did is we broke it down so that it's really easy to understand for the patient. If you want to contact this trial, or contact the doctor or the location that you selected, you press ‘Contact Trial’.

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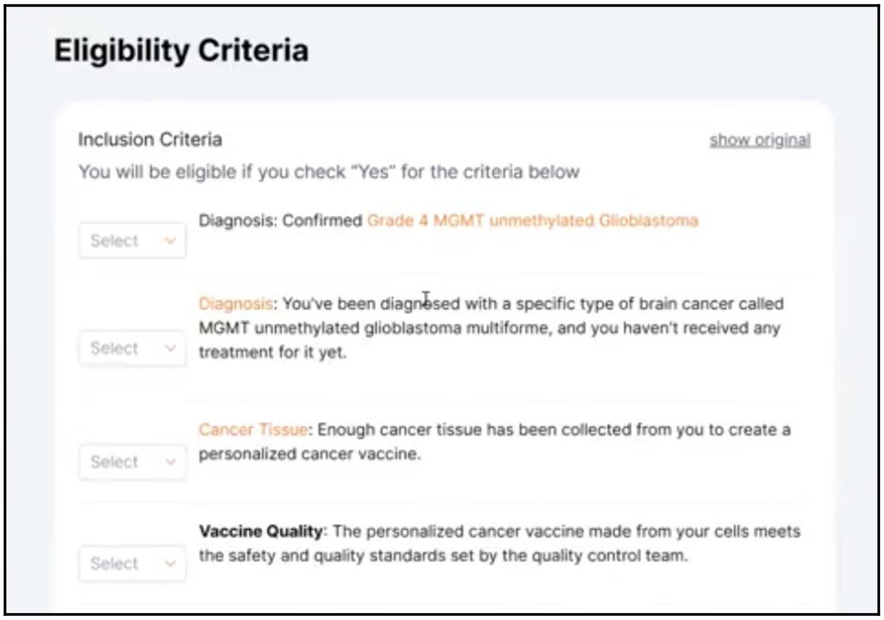


Eligibility Criteria

Inclusion Criteria

show original

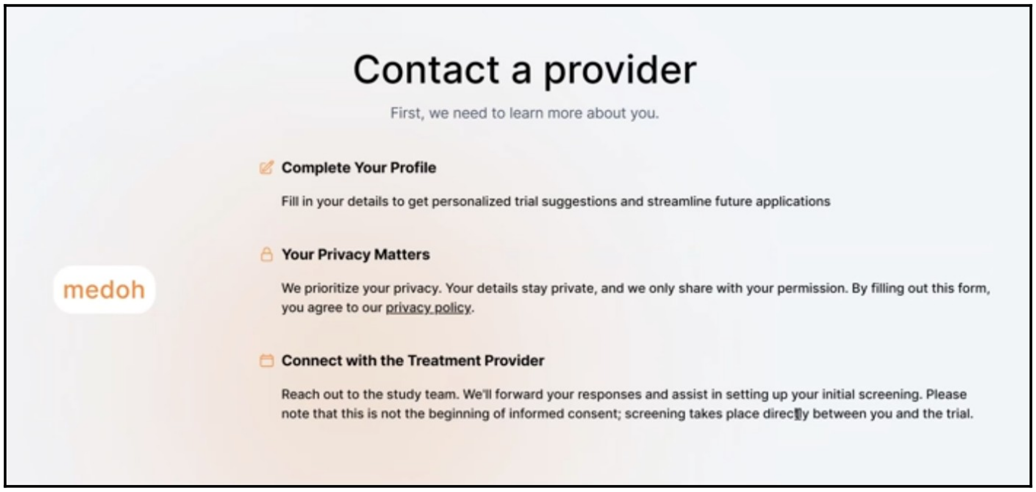
You will be eligible if you check “Yes” for the criteria below

Diagnosis: Confirmed Grade 4 MGMT unmethylated Glioblastoma

Diagnosis: You've been diagnosed with a specific type of brain cancer called MGMT unmethylated glioblastoma multiforme, and you haven't received any treatment for it yet.

Cancer Tissue: Enough cancer tissue has been collected from you to create a personalized cancer vaccine.

Vaccine Quality: The personalized cancer vaccine made from your cells meets the safety and quality standards set by the quality control team.



Contact a provider

First, we need to learn more about you.

Complete Your Profile

Fill in your details to get personalized trial suggestions and streamline future applications

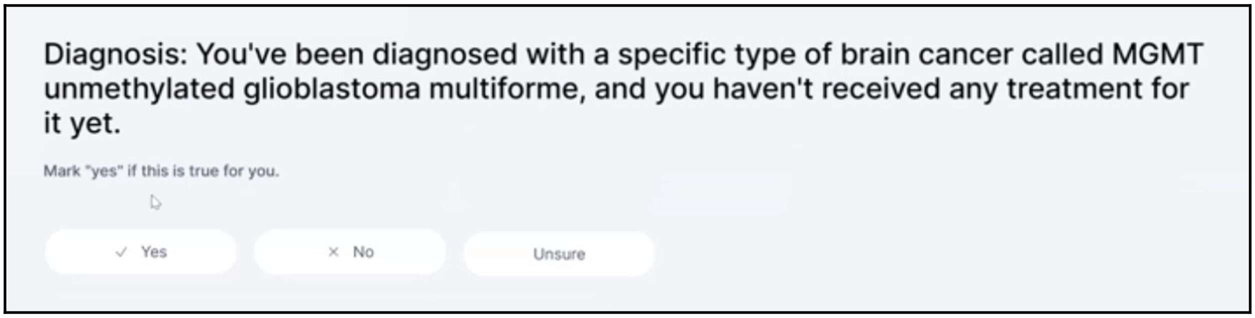
Your Privacy Matters

We prioritize your privacy. Your details stay private, and we only share with your permission. By filling out this form, you agree to our privacy policy.

Connect with the Treatment Provider

Reach out to the study team. We'll forward your responses and assist in setting up your initial screening. Please note that this is not the beginning of informed consent; screening takes place directly between you and the trial.

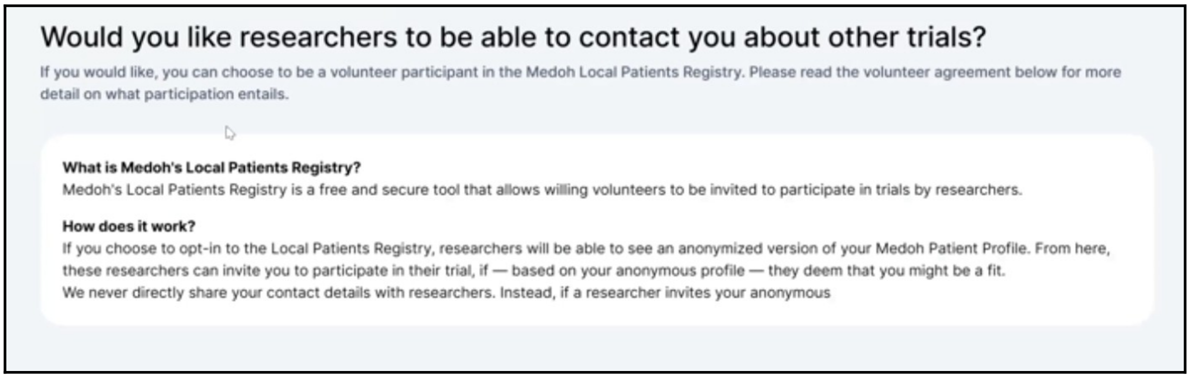
This is where you complete a profile. We ask you a series of questions. From this, it asks for a number of different generic things. It asks your name, where you were born, all the generic information you can think of, basic information about you. This is just all generic pieces of information. Then it brings you to a section where it asks about your condition. What condition do you have? What genetic markers apply to you? Then what previous treatments have you had? This is where it asks eligibility questions. These are specific to the clinical trial that you've clicked on, or that you're interested in applying for. And as you can see, we just have some simple questions with answers like “Yes”, “No”, or “Unsure”.



Diagnosis: You've been diagnosed with a specific type of brain cancer called MGMT unmethylated glioblastoma multiforme, and you haven't received any treatment for it yet.

Mark "yes" if this is true for you.

By clicking ‘Yes’, it gives you an idea if you're highly eligible for this particular clinical trial, based on the questions that you've answered.



Would you like researchers to be able to contact you about other trials?

If you would like, you can choose to be a volunteer participant in the Medoh Local Patients Registry. Please read the volunteer agreement below for more detail on what participation entails.

What is Medoh's Local Patients Registry?

Medoh's Local Patients Registry is a free and secure tool that allows willing volunteers to be invited to participate in trials by researchers.

How does it work?

If you choose to opt-in to the Local Patients Registry, researchers will be able to see an anonymized version of your Medoh Patient Profile. From here, these researchers can invite you to participate in their trial, if — based on your anonymous profile — they deem that you might be a fit.

We never directly share your contact details with researchers. Instead, if a researcher invites your anonymous

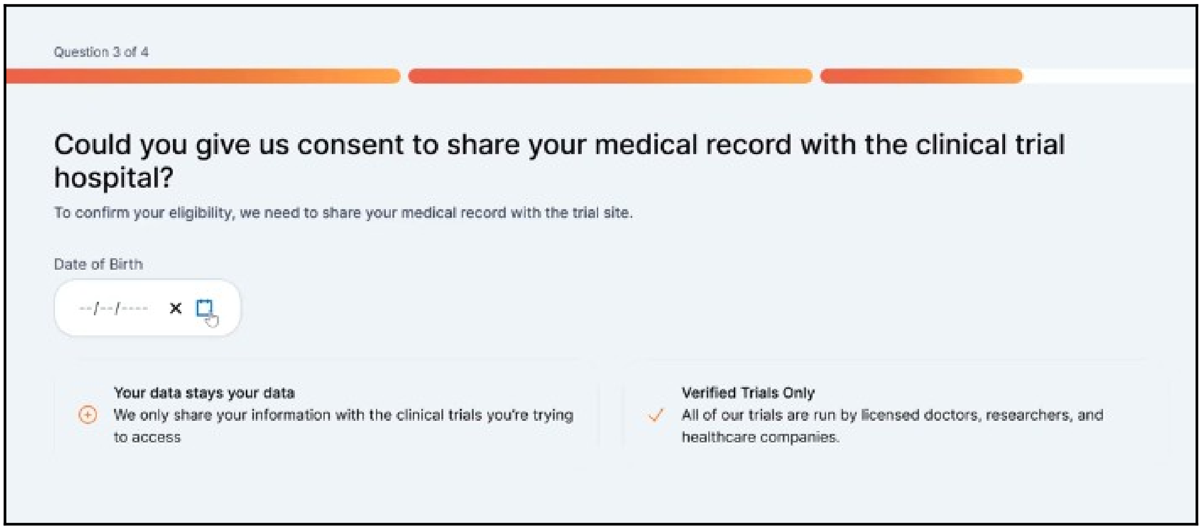
If you answered “No” to a question, we're trying to have this warning sign come up, which should be actually implemented over the next few weeks, where it says, ‘Based on your information, or information you gave from the eligibility questions, you're extremely uneligible for this clinical trial.’ That helps patients know and understand based on information they gave if they're highly eligible or if they're if they're not eligible at all. These are just by answering simple “yes” or “no" questions that are already out there on a number of sites. But it also doesn't just help the patient. It also helps the provider on the other end, because they know the patient has answered a few questions that helps them understand what their eligibility is like before the provider even speaks with them. We're working on this a lot more and building out a few interesting tools that will make this a lot more efficient moving forward, which I can talk about in a few minutes.

Misha Mehta 30:31
Does it also mean that you have to fill out the basic information for every trial that you want to see the eligibility criteria for?

Mike Pyne 30:42
This is where it gets interesting. I'll show you that, after you create a profile, which is what we're currently doing right now, it will have all your information based in a profile. And then from that, we'll be able to help you understand which trials you are more eligible for on the back end. And

as well, if you've already filled out some of the questions, you know if you're highly eligible for them. So it makes it a lot easier for the patient. Once you fill out the information, every clinical trial, every treatment, is going to have slightly different eligibility criteria. So it very much depends on how different the eligibility questions are. But the more information we get on patients, the more we can help them understand and find the options that are best suited to them. That's something I'll speak about in a minute with the technology that we're building currently, which streamlines that significantly.

As you can see here, everything is about consent. There's two pieces of consent we asked for. One is, “would you like other researchers that have treatments or clinical trials that you potentially are eligible to contact you?” You can say “yes”, and your information goes into a database that clinical trial providers and doctors can see. They can see your profile, none of your personal information, but your profile based on some of the questions that you have already answered on Medoh when you're creating a profile. If you say “no”, it doesn't happen. It's very much up to the patient on what they would like to do. This is to help people automate the process so that they don't have to find options themselves. This just gives them more options. For a potential healthcare professional or an expert in the field, they could say, ‘Hey, based on your profile, it looks like you might be eligible for a clinical trial that we're holding for immunotherapy.’ It's just another way to give patients more hope of getting more options without having to do it all themselves. It also asks if you're registering on behalf of yourself.



Question 3 of 4

Could you give us consent to share your medical record with the clinical trial hospital?

To confirm your eligibility, we need to share your medical record with the trial site.

Date of Birth

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Your data stays your data
We only share your information with the clinical trials you're trying to access

Verified Trials Only
All of our trials are run by licensed doctors, researchers, and healthcare companies.

Again, it asks for consent to share your information. This is where an electronic record is created with your signature, basically stating that you're okay for your information to be shared from Medoh to the healthcare provider you want to speak with. Again, it is very important that we do that because we need patient consent, or the user consent, in every aspect. Then it asks for a reason on why you applied. That is pretty much that section. I'm just going to log in to show you what happens on the back end.

Al Musella 33:23

“Review of Services for Glioblastoma Navigation” (Mike Pyne) [#92]

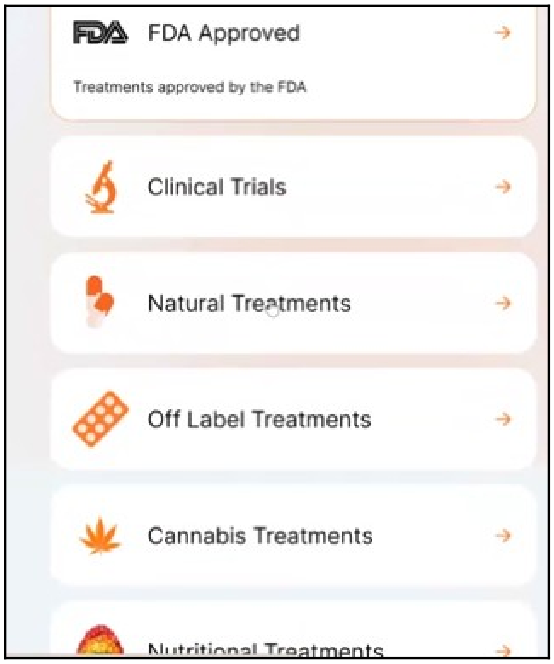
If somebody selects an off-label therapy, do you still connect them to doctors who are likely to use it?

Mike Pyne 33:34
Yes. There are a few different clinical trials that are studying off-label therapies. The whole idea is to give it to them first. But again, not trying to be biased, I want them to know the options on what doctors are out there that they can speak to about this off-label treatment. Because we know that there are a lot of people out there that have different opinions. Some people want to go for an off-label treatment because they've heard or gathered information on it. Some people want to look out for natural treatments, nutritional treatments, cannabis treatments. I'm not trying to be biased in any way. I'm trying to give people the information they want, and just point them in the right direction to a healthcare professional or an expert that can help them get more information about that particular topic.

Does anyone have any questions, any concerns? Please feel free to voice your opinion. You can give more in depth feedback if you'd like. I'm very open to suggestions or concerns, anything that you guys potentially feel.

John Powers 35:12
I work with a lot of folks with natural treatments. Yours is trial-based. It’s great, because the conventional medicine people are going to be onboard here. But from a food and diet standpoint, I have a good input for glial patients. How would you handle something like that?

Mike Pyne 35:39
At the start, I break down all the treatment options into different categories.



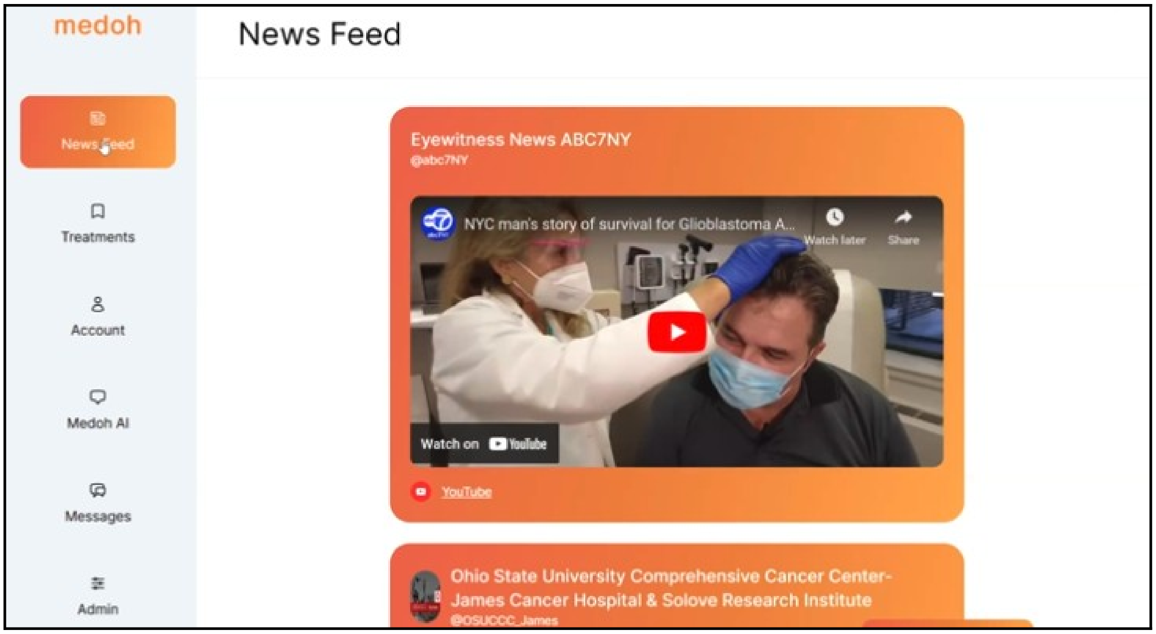
As you can see here, we have natural treatments. These are just like supplements you can take. There’s off-label treatments, just a list of the off-label treatments that are available for glioblastoma. Then we have cannabis treatments and nutritional treatments. The whole idea of Medoh again was, I know there's a lot of platforms out there that offer you clinical trials, but no one actually offers you the treatments that are in different categories. You can see that we have FDA-approved treatments. We've pretty much put everything in here and a lot of these are the standard of care. We wanted to try and create a platform that gives people all of their options. We don't have it perfectly designed yet. But we know we're getting there just by offering the right information and putting it in the right place that's easy for people to understand.

As you can see, like under ‘Nutritional’, for example, there are ketogenic diets there. And there are some little pieces of information that we're still missing. Keto doesn't have anything specific in it yet. But we're going to add that, because we know that the keto diet is very important to a lot of people with GBM, and a lot of people have had good success with it.

Mike Pyne 37:21
This is the profile that's created after you complete the application that you just saw for the particular clinical trial. We wanted to have all the treatments or clinical trials that you're interested in saved in a specific location so that you can always go back to them and learn more about them or ask any questions. Only a person's personal information is kept in a specific location. Any question you ask AI, it will automatically save here, so you can always go back to it and learn or read about the questions that you asked, because it's very easy to forget about.

This section is going to be messages that you have between you and the healthcare provider that you reached out to for any of the trials. Our content is going to be a huge part of how Medoh works. The reason is, patients have so many questions about so many topics. We want to provide them with content of doctors talking about frequently asked questions and on all the different treatments that they are potentially interested in. We're trying to incorporate that part into the earlier stages that I showed you in the treatment side. But we also want to try and incorporate it here. Right now we don't have any content recorded, just because it's probably something that I'm struggling with a little bit. One, because it's really difficult to get. And two, it's very, very expensive. We don't have that much money to spend on healthcare professionals recording content.

“Review of Services for Glioblastoma Navigation” (Mike Pyne) [#92]



We decided to create a simple news feed for the time being that constantly updates and gives you information from a number of different sources like YouTube, social media, Tik Tok, Instagram, or Twitter, on topics about glioblastoma. Every day this is updated with anything new. Then we easily give patients access to loads of different resources about glioblastoma that they can just get through the Medoh platform. The idea of what we're trying to do here though, in this particular location, is very similar to what Roon do, except Roon focuses on frequently asked questions for the condition of glioblastoma itself. What we're trying to do is have a lot of frequently asked questions about the treatments, and have doctors and patients that have done those treatments talk about it on this particular platform. Because like I mentioned earlier, educating patients is empowering patients. People spend so much time online looking for answers about treatment or about a topic they learned about. We're trying to incorporate all that into one platform. It's marrying the digital platform with artificial intelligence with educational content. We know that's going to be the winning factor that differentiates us massively to what other companies are doing out in America. Content and patient education and user education is the most important part to us. Because if we don't do that well, we're never going to be able to get people to come to the platform, because we want it to be resourceful. And that is pretty much the whole platform start to finish.

Al Musella 40:48
I noticed if you click on treatments, we see all the clinical trials that they were looking at. You might want to do a quick search on those clinical trials and see which ones are still active. Because you have one here that's not active anymore.

Mike Pyne 41:03
Very good point. Two, three weeks ago, Michael and I went through all of the clinical trials. I think, in total, we have 287. We went through all of them and tried to scan through

clinicaltrials.gov. We knew we probably missed one or two. You're spot on: there are a few things that we must change. And these are the little mistakes that we're making.

Al Musella 41:30
You could use the clinical trials API and quickly check those three different clinical trials just to avoid wasting time and energy.

Mike Pyne 41:47
This is where I must do a little bit more improvement. We know that this part is imperfect. There are a few different things that we must add. So thank you for that. I'm really glad to get this information, because I know I'm missing little things here or there. The more feedback we get, the better we can make this platform. So please anyone that has any other suggestions, feel free to keep it coming, because we're very, very open to suggestions and ways we can improve it and find things that we're missing, just so we can make it a better overall experience.

Misha Mehta 42:30
There is a comment in the chat: Vanessa says that clinicaltrials.gov is not always updated in a timely manner. Do you have any alternate sources that you get your clinical trials information from, like talking to the doctors directly that are running the trials?

Mike Pyne 42:50
As of now, no, because we don't have the relationships built up with any of the life science companies or hospitals or doctors that are offering these clinical trials. Eventually, yes, we'd like to keep a very close tab of this and be informed once we have those relationships built. But we don't yet. That's one of the pitfalls of, like Vanessa mentioned, with a number of these websites, they're a little bit lagged or a little bit delayed. That's something we want to try and change. But we don't have the answers to that yet. This isn’t an excuse. We're trying to focus on so many things. We know where we want to go with it and what things we need to do in order to make them really perfect. But it might take us a little bit of time to get there. So that's something we know. Because I think Vanessa mentioned that to me in the past, as well as that is something that we have a pulse on. But we probably won't be able to get there until we have all the relationships built with a number of different providers, hospitals, and doctors.

John Powers 43:54
Are you doing anything with advocacy groups?

Mike Pyne 43:58
We tried to partner with a few different nonprofits to get feedback. Because we knew that if we partner with nonprofits who are dealing with glioblastoma and helping patients navigate the care pathway, it would be a really good way to give people the platform and get some feedback about what improvements we can make, how we can make it better and find out what is missing from it.

John Powers 44:24

Including them in your ecosystem, like you're talking about, is good because they usually have really good updated information on all the trials as well.

Mike Pyne 44:34
We're currently in the process of doing that. I spoke with Vanessa and Adrienne Nugent at Cancer Commons as well. We have spoken with a few other nonprofits as well. We need to do a better job of partnering with them as much as possible because I feel like they have so much knowledge. Honesty is great because I know if I get honest opinions, I can make it better. The whole idea is to make it as good as possible by getting brutal, anonymous feedback, because that's what's going to make this platform a lot better. There's a long way for us to go as well.

Misha Mehta 45:16
We usually have patient navigator coordinators. They are up-to-date on the clinical trials. In case you want to get in touch with any of the navigators for the adult side.

Mike Pyne 45:30
I know I am speaking with one lady from a nonprofit today that I met a few weeks ago. I think it's called Brain Bank. She's going to give me some feedback on how I can make improvements on the clinical trial aspect, and how I can keep it more up-to-date, and what patients really want to see. Because a lot of the information that I have is just from feedback from some patients, but we also want to get the opinion of the experts and people who are well equipped in this particular space.

Misha Mehta 46:08
Why the name Medoh?

Mike Pyne 46:14
Medoh stands for Medical Options in Healthcare. It was just something I put together that I thought was a little easy, but I think it's a little hard for some people to understand. So I want to get the best name, but I thought that abbreviation was nice at the time.

Allen Morris 47:01
I'm a community hospital pathologist. You stated that you are focusing on GBM, is that correct?

Mike Pyne 47:20
Yes.

Allen Morris 47:21
In some sense I’m taking a step backwards. The term is brain tumors. As you know, there are many brain tumors, not just GBM. I presume you picked GBM because it's the most common, the most primary brain tumor, is that correct?

Mike Pyne 47:39

The reason I chose it is just more coincidence that my friend has been diagnosed with it. I knew from speaking with him and him being in the community, that a lot of other people have this problem. So that's why I decided to start with one type of brain cancer, which is the one my friend had.

Allen Morris 48:00
There's this semantics of “uncommon” and “rare" and all that stuff. You said that you met several people with GBM, and that affected you personally. From a community hospital pathologist viewpoint, I wouldn't call it rare, but it's uncommon. Where am I going with this? The second most common one is IDH mutant astrocytoma (a type of brain tumor with a mutation in the isocitrate dehydrogenase gene), which can be graded 2, 3, and 4 also. I take it, you're not focusing on that, is that right?

Mike Pyne 48:38
Initially, it will just be glioblastoma with any genetic viewed mutations associated with that. We will be expanding it to other brain cancers and other cancers. But the whole idea for me is, I've seen a lot of companies who tried to do all clinical trials at once, and it just doesn't work. The way I look at it is you have to do something really well for a really small group of people and make it perfect, or get what we call product-market fit. Once you have product-market fit, and you have a system that works well and people like the product, then you can start expanding it to other areas. The whole idea is to just really have a laser focus on one particular area, do a really good job with that. And once we have a system, we know that we can start expanding into other types of brain cancers or other types of deadly cancers that are common throughout the world that people have a similar issue with when it comes to looking for information.

Allen Morris 49:42
You've led me up to my $64,000 point that I want to make. I have the article right in front of me. It's called 2021 WHO Classification of Tumors. It's dated August 2021. The reason I'm bringing this up is because everybody that is a cancer patient starts with a name like prostate cancer or pancreatic cancer. Everybody just runs with it like it's a given. But there's actually a human being called a pathologist that makes that determination. It turns out the classification of brain tumors changed radically in 2021. Everybody has to remember if they want to be a citizen scientist, and a very educated cancer patient, any research paper that predates 2021 has to be looked at with a very jaundiced eye. In other words, you almost have to throw it out, because you're dealing with a completely different disease set when it's reclassified because everybody runs with the diagnosis, like, ‘I have GBM’, they just assume that everything that existed before 2021 applies to them. And guess what–it does not. Because GBM has, I shouldn't say it, a shorter course, and since there aren't as many tools in the toolbox for it, the current research probably is getting the truth of what the disease is now. But that happened in prostate cancer, and in almost all cancers. It's just a profound thing that's lost on everybody that's not a pathologist, I think, or the researchers. The less than 1% of clinicians that do research, it's lost on them. It's really important, actually, this 2021 thing changed what everything is.

Mike Pyne 51:59

A very good point. It's something that, not specifically what you said, but I notice a lot of the times patients, depending on how much patients research and try to understand themselves. I noticed that the only true way to get accurate results when it comes to patients and our understanding of someone's actual diagnosis, because like you mentioned, a pathologist is the one that is going to give those answers from doing pathology work.

On the backend we are creating a simple tool that allows people to upload electronic medical records. From that, we summarize and scan it and pull out all the main most important pieces of information that are on that record from that, and it actually automatically goes into the profile. We're not allowing patients to try to search, find, and understand the options themselves, we’re creating technology in the backend that if they create a profile, based on information they upload into it, we're able to link them to the most eligible types of treatments and clinical trials. Because we want to think that maybe it's easy to access the information on Medoh, but the further down the road you go, it will actually be able to be a lot more accurate with matching them to the right clinical trials and treatments that are available.

It's a very good point, because we know the further down the road we go, we want to make sure that the more information we can collect, the more efficiently we're able to match them with the right treatments and clinical trials. It just takes a little bit of simple technology to do that. That's something we're about to be able to do on our end too.

If there are any mistakes or any areas of improvement you think you could see on the website or on the platform, please let us know. Because the more feedback we get, the better understanding we have, and we'll be able to fix those mistakes, but we'll also be able to make a better platform moving forward. Please feel free to comb through it. Anything that you see doesn't work, please feel free to highlight them. And we'd really greatly appreciate as many people's feedback.

John Powers 54:56
I have one more suggestion that goes back to Allen's comment. I want to thank Allen for chiming in. Because a lot of times what you'll see is some simple things in terms of your semantics and your description, you’re going to turn off medical professionals and you really need a pathologist consultant, or make sure there are doctors looking at this. Because people who go to sites are going to go ask their doctors. If there's anything that you know, I mean, doctors are busy. If there's one thing that's turns them off, it could hurt people actually getting good information. So it'd be great to have someone reviewing it. I thought it was great that he chimed in and said that because there are things you’re just not going to know.

Mike Pyne 55:42
Absolutely. Very, very true.

Brian McCloskey 55:50
Mike, I would just offer as you continue to build this, feel free to reach out to us. You can reach out to me personally, if you want to get any feedback that can help you to improve your product,

because it's exciting to see where you're going and what you've built so far. We know you're in the early stages, but I'm sure this will be useful to some of our patients.

“Review of Services for Glioblastoma Navigation” (Mike Pyne) [#92]

CHAT DISCUSSION

00:14:07 Vanessa Hugo: Reacted to "Hello, posterity!" with 👍
00:19:53 Brad Power at Dana-Farber: Why the name “Medoh”?
00:30:47 Brad Power at Dana-Farber: How do you make it non-biased?
00:56:09 Vanessa Hugo: Also, clinicaltrials.gov is not always updated in a timely manner!
01:03:33 David Plunkett: "Perfect is the enemy of good."
01:07:18 Al Musella: Some trials report results broken down by idh mutations. For the older trials that do so you can trust them and just use the idh- results