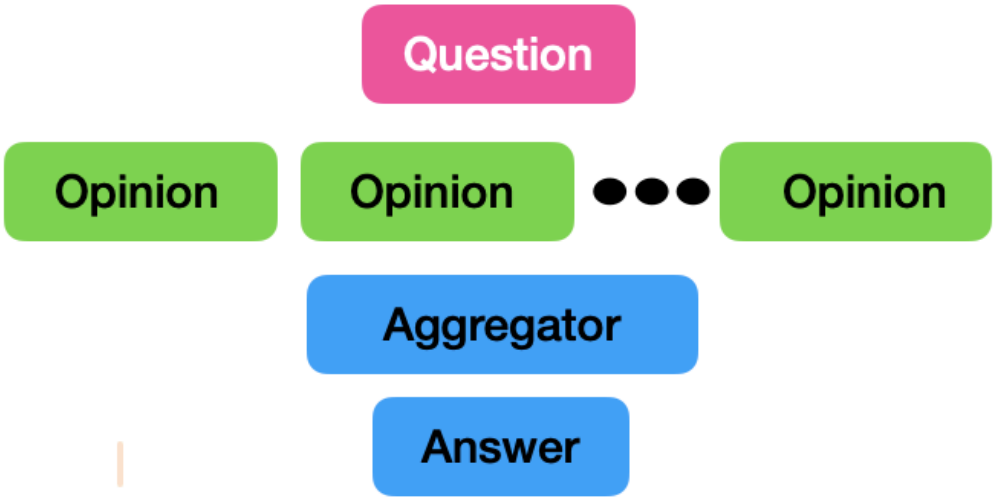


Crowd Wisdom

Caregiver Agent

17.04.2025

Bill Paseman
rarekidneycancer.org
–
Saratoga, Ca 95070

Rare Disease: a Patient's Perspective

As a Rare disease Patient, I needed to understand

- "Standard of Care", "Clinical Trials", "Post Clinical Trials" and Statistics
- The need for self-advocacy
- The need for a process to answer my questions.

"Standard of Care", "Clinical Trials", "Post Clinical Trials" and Statistics

Standard of Care: Most usual Medical conditions can be treated in a hospital or doctor's office using the so-called "Standard of Care" (widely taught and widely accepted treatments). Such treatments have a success rate of 30-80%.

Clinical Trials: But for many conditions, there is no "Standard of Care". In this case, the patient may be directed to a "Clinical Trial". Oncologic Clinical trials have a success rate of only 3.5%, making the patient's risk/reward calculation difficult. What's more, the "success" of such trials is often of short duration: usually measured in months, not years.

Post Clinical Trial: And when Clinical Trials are exhausted, and in the case of rarer conditions which have no trials, the patient is in a tough situation, and any choice is likely to have less than a 3.5% success rate. Unfortunately, even though the patient's situation is difficult, they still need a way to make decisions.

The Need for Self Advocacy

Patients are conditioned to trust their PCP (Primary Care Physician) to answer treatment questions. However, when asked about a clinical trial at a competing hospital, a physician recently said "If you want to know about their trial, talk to them."

This is a valid response from a BMW salesman about a question on a Mercedes car, but not particularly helpful to a patient examining cancer treatment options, especially since once a patient participates in their first trial, they are no longer "treatment naive". I.e they can't switch "cars" (treatments) easily. Getting rare disease patients to understand that we, not our PCP, are responsible for our own care is difficult.

The Process

Once the patient understands that they need to look beyond their PCP for answers, they need a process.

- **Questions:** What questions do I ask, and in what order?
- **Opinions:** How many people should I ask and where do I find them?
- **Aggregation**: How do I weigh their answers?

A Solution

Tumor Boards

One typical solution to this problem is a "tumor board", where a team of oncologists, surgeons, radiologists, and other specialists, gather to discuss challenging and complex cancer cases. However, tumor boards typically form within a single institution, whereas rare disease specialists are spread among multiple institutions.

Wisdom of Crowds

This dispersed expertise actually presents an opportunity to aggregate opinions that are decentralized, diverse and independent. An opportunity to tap into the "Wisdom of Crowds", which is the idea that larger groups of people can be smarter than just a few, better at solving problems, fostering innovation and coming to wise decisions. However, where and how these opinions are solicited and acted upon (aggregated) is important. Key process characteristics include:

- Diversity - Each person should have private information.
- Independence - People's opinions are not determined by the opinions of those around them.
- Decentralization - Specialists draw on local knowledge.
- Aggregation - Ability to turn private judgements into a collective decision.

This approach is not new. It is used in jury selection (12 jurors) and in financial portfolio management. Note that the aggregation approach differs in these two examples. Juries must reach a consensus. In a financial portfolio (Generally a collection of stocks and bonds), the hope is that the sum of the securities' returns is above average, so that at least one member makes up for the average returns (or losses!) from all the others.

Here, we use "Wisdom of Crowds" concepts to answer questions such as:

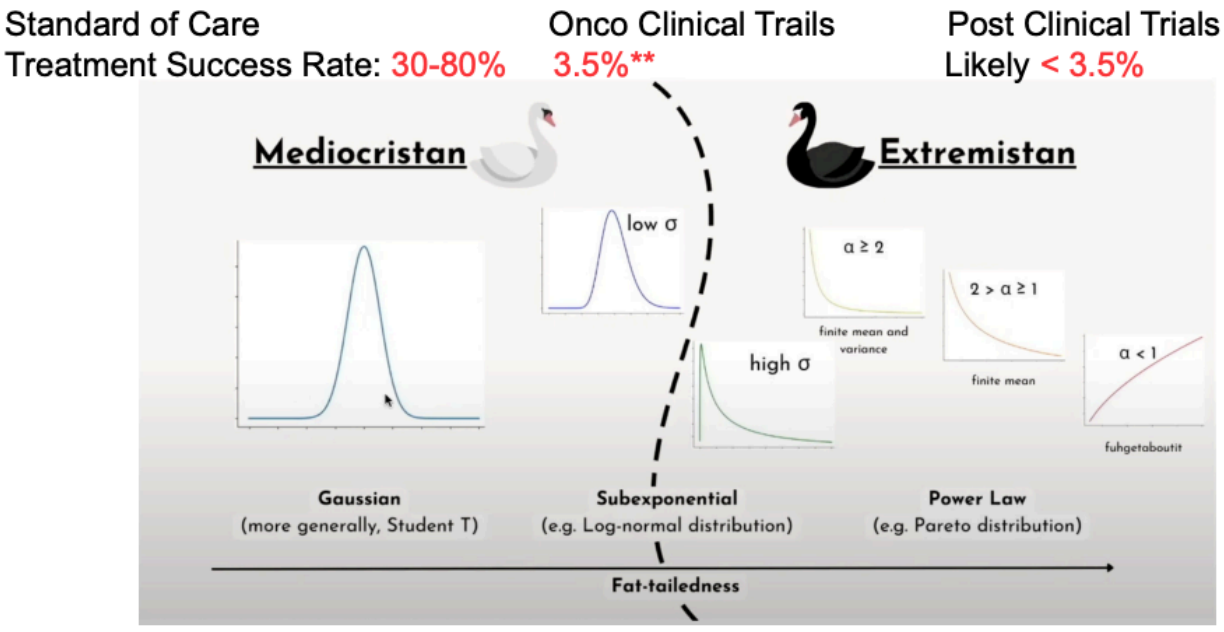
- Should I enroll in this clinical trial?
- Should I treat my brain meningioma with proton or photon radiation?
- What "genes of interest" are in my tumor, and what treatment(s) do they indicate?

I've incorporated this approach's workflow into a "Caregiver Agent" to allow the patient to

- Formulate a question
- Solicit opinions
- Judge and aggregate the opinions using several metrics
- Provide several answers based on the metrics and aggregation approach

How many Opinions do I need?

The number of independent opinions is important. Two opinions are OK when the success rate is 80%. When it is below 3.5%, my examples indicate that twelve or more opinions are better. Think of it this way. As you proceed from "Standard of Care" to "Oncological Clinical Trials" to "post Clinical Trials" in the figure below[1], you have less and less data. Doctors get less and less certain. Drugs for your condition become fewer and fewer. And the "Treatment Success Rate" falls. For you math heads out there, opinions are no longer "normally" (Gaussian) distributed, but rather form a long tail, and so rare disease patients need more than just a single "Second Opinion" to select a good answer.



[1] Image Courtesy of Youtube - Shaw Talebi - Pareto Power Laws and Fat Tails

Getting Opinions

"Wisdom of Crowds" helps ensure that the opinions you get are decent. But you need to get the opinions to begin with. There are two sources: Machines and People. In general, qualified people make many fewer mistakes, but consider fewer "out of the box" options. Machines make more mistakes, but also consider ideas that humans may "rule out". Here is an example.

From a Machine

Here is a question I asked chatGPT and Claude.io and their responses.

Question: What adjuvant clinical trial is more promising for papillary RCC and why?

- chatGPT
    - KEYNOTE-564 Trial: This trial focused on pembrolizumab in high-risk RCC after surgery. The trial demonstrated a significant improvement in disease-free survival compared to placebo. While this trial predominantly involved clear cell RCC, the success of immune checkpoint inhibitors in RCC provides a strong rationale for their use in other subtypes like pRCC.
- claude.io
    - 1. Immunotherapy approach: KEYNOTE-564 uses pembrolizumab, an immune checkpoint inhibitor. Immunotherapy has shown promise in various RCC subtypes, including papillary RCC.

But here is what Toni Choueiri said about KEYNOTE-564: "patients with nonclear cell RCC were not included". Papillary RCC **is** a nonclear cell RCC. Now, the machines did not directly say that KEYNOTE included papillary patients, but it did infer that this trial provided evidence for including them. Does it? That is a matter for discussion with humans.

From Humans

I need to solicit opinions from rare kidney cancer specialists. Rarekidneycancer.org lists rare kidney cancer specialists from around the world. I originally identified them by attending GUASCO and meeting doctors personally. I then convinced one (Dr. James Hsieh) to co-found rarekidneycancer.org with me. We then met at the next GUASCO (2016) to formulate our goals and write a paper. Participation is spotty. However, besides publishing, another way to get participation is to get a referral and enter a particular doctor's system. This allows them to bill and they are then willing to answer questions. However, in the role of an advocate, when I ask questions on behalf of another patient in need via email, I have a high response rate. After all, the overwhelming number of doctors

I am in contact with want to help people. That is why they became doctors. All this communication is open.

Machines and Humans Working Together

This process discussed here is automated. Humans and Large Language Models can opine on questions and the patient can aggregate opinions together or separately. And when aggregated together, I look at points of disagreement as much as points of consensus. E.g. KEYNOTE-564 was brought up by two different LLMs. Each made the argument that since immunotherapy is used to treat papillary RCC, I ought to look at using a particular immunotherapy: pembrolizumab. In fact, pembrolizumab IS currently used in treating papillary RCC in conjunction with other drugs. Maybe it makes sense to get my doctors to look more closely at KEYNOTE-564 protocols when making my treatment choices.

Examples Overview

EVEREST trial.

In 2014, I had my cancerous left kidney removed. Pathology determined that I had a rare (papillary) kidney cancer. I was offered an opportunity by my surgeon to participate in an adjuvant (preventative) clinical trial called EVEREST. So I consulted 13 clinicians and researchers.

- The first 3 said I ought participate
- 5 said I needed to make up my own mind
- 5 said I ought not participate

One "No" had run a clinical trial where Everolimus, the drug used in EVEREST, was used as first line (initial) therapy. The drug had not worked because papillary is so different from "normal" kidney cancer. I chose not to participate.

Proton vs. Photon

I let a meningioma grow for 9 years. I was then told I needed to treat it with radiation or surgery. I chose radiation. There were two types: Proton and Photon. Protons are nice because they don't exit the tumor. Photons are more prevalent. I asked 13 physicians. This was rather like talking to BMW and Mercedes dealers about the best car to buy. Each institution had already decided and recommended their equipment. However, one Institution in the Netherlands had both and recommended photon. Another clinician said "You're asking the wrong question. When you get a car repaired, you don't ask what wrench the mechanic uses, you ask how many cars they have successfully repaired". Using that advice, I was treated using photon at UCSF.

Hackathon for a Metastasis Treatment

Eventually, my kidney cancer may recur. And there are no treatments. So in 2018 and 2020, Pete Kane and I created a "Hackathon", where 80 researchers formed 17 teams examining my Blood/p1RCC tumor DNA in parallel for "Genes of Interest" and an associated treatment. Of the 17, one team scored very highly.

How many Opinions do I need - REDUX?

To Summarize numbers from the prior section,

- 1/13 people gave a credible answer in the "EVEREST Trial" case
- 2/13 people gave a credible answer in "Proton vs. Photon" case
- 1/17 people gave a credible answer in the "Hackathon" case

I've seen these ratios before in Finance. Two Examples:

Example 1: I formed a portfolio for my kids in 1997. I did not touch it. Here is how it has grown.

- INTC 47%
- CSCO 103%
- PYPL 128%
- EBAY 209%
- MSFT 2105% <- 10x better than the next best. 44x better than the worst.

Example 2: Kleiner IX, a 1999 fund had 38 investments: 37 were OK, #38 was named GOOG.

These two examples illustrate what Peter Thiel said in his book, "Zero to One": "The biggest secret in venture capital is that the best investment in a successful fund equals or outperforms the entire rest of the fund combined."

Now, collections of data are often counted and grouped. IQs are one example. The average IQ in the US is around 100. But some are higher and some are lower. If you put all the IQ scores in the US in 100 bins, labeled 50-149, and created a graph with 50-149 on the x-axis and the number in the associated bin on the y-axis, you would get a Bell shaped curve. This Bell curve is also called a "Normal" or "Gaussian" distribution. Weight, Height, Blood Pressure, all these have Gaussian distributions.

Wealth, Company Sizes, City populations and, as shown above, financial portfolios are not normally distributed. The biggest members are bigger than most of the others combined. Why is this important? Because (my three examples above) experience indicates that opinions **outside of "Standard of Care"** are not normally distributed. This means you need to sort through a lot of opinions to get a reasonable answer[2].

How many opinions do you need? Well, another type of distribution is "long tailed". That means it looks like a descending ski slope. Gaussian distributions have an average (100 in the case of IQ). Often, long tailed distributions do not. The more you look, the more "good ones" you find. For example, Microsoft was a good choice for my kids portfolio. Amazon or Nvidia would have been better.

So, again, How Many? I don't know. Certainly more than two. Twelve is what I use.

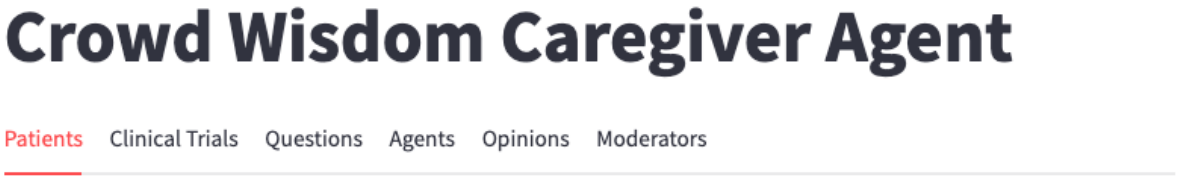
[2] Or, "You have to kiss a lot of frogs to find a prince."

Examples Detail

The boilerplate for exploring clinical trials, entering Patients, Questions, Agents (Doctors and LLMs), and soliciting opinions is largely the same for all examples. I will go through that once and explore opinion moderators in more depth for the EVEREST and Hackathon examples.

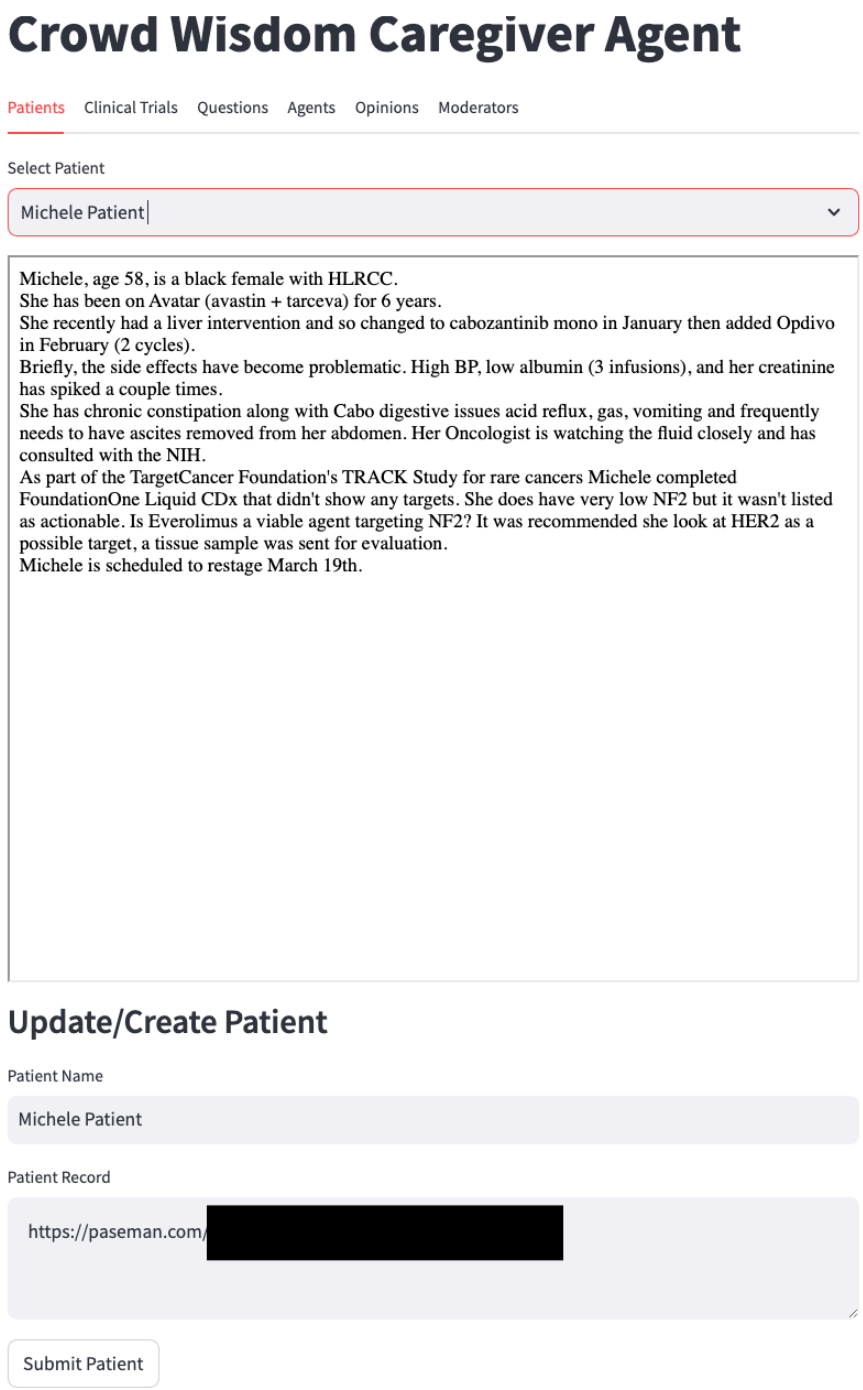
Overview

The application is written in Python and uses a Streamlit UI generated by chatGPT. The tab layout is shown below and the user works the tabs from left to right.



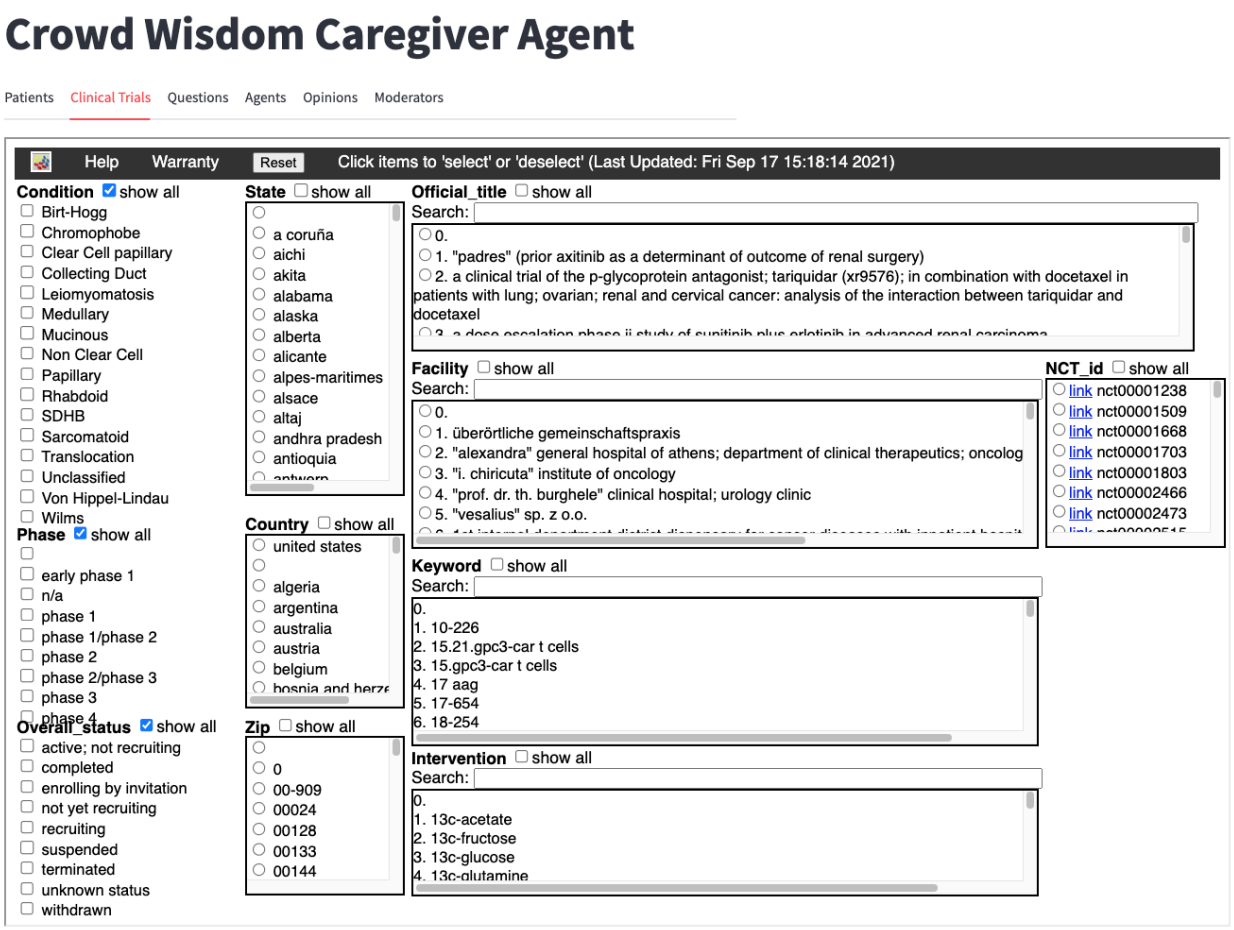
- Patients Tab - is used to enter the patient name, and a link to patient history.
- Clinical Trials Tab - Is used to find a clinical trial for the patient's condition.
- Questions Tab - Is used to enter Questions to ask the agents.
- Agents Tab - is used to enter the Agents (Doctors or LLMs).
- Opinions Tab - gathers all the Agent's opinions.
- Moderators Tab - Moderators are Questions specific. For Example:
    - Question: Should I participate in the Everest Clinical Trial?
        - "Return Strongest Answer" - If you ask an LLM which answer is the strongest, it will return "ask your doctor". So this prompt says compare each opinion pairwise and state which is strongest.
    - Question: What are my Tumor's Genes of Interest? This question came from my hackathon. 17 teams were given my DNA and asked to find a "Gene of Interest" plus an associated Treatment. Here are the aggregators.
        - Has anyone else chosen this answer? - If two independent groups discover the same gene, it is worth looking at.
        - Have any experts chosen this answer? - If this is common wisdom (e.g. Most type 1 papillary kidney cancers express the MET gene), it is good to know.
        - What is the RNA-seq expression level of this choice? - RNA-seq (The tumor RNA levels - the healthy kidney RNA levels) was NOT given to the participants, but was used as a "holdout set" to rank the submissions.

Patients Tab



The patients tab is where patients are added and paired with their records. These will be sent to the Agents who, in turn, submit back opinions.

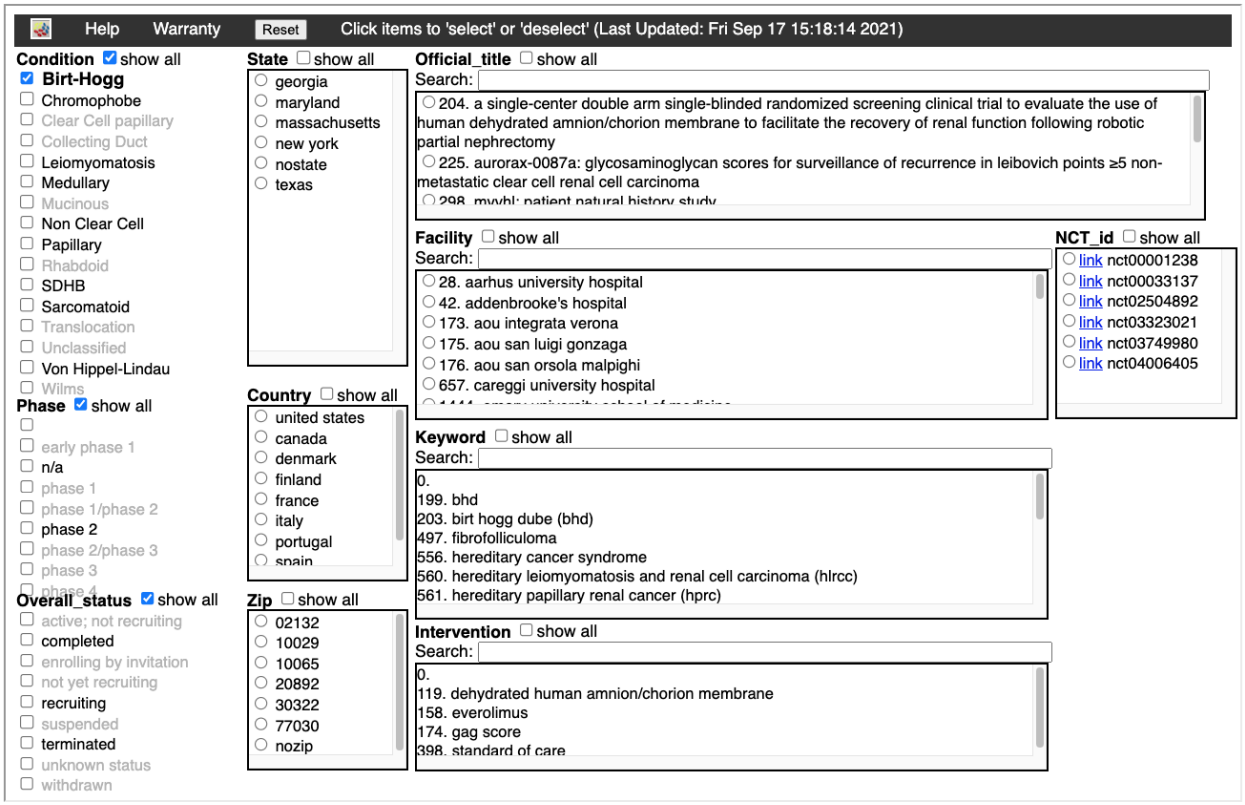
Clinical Trials Tab



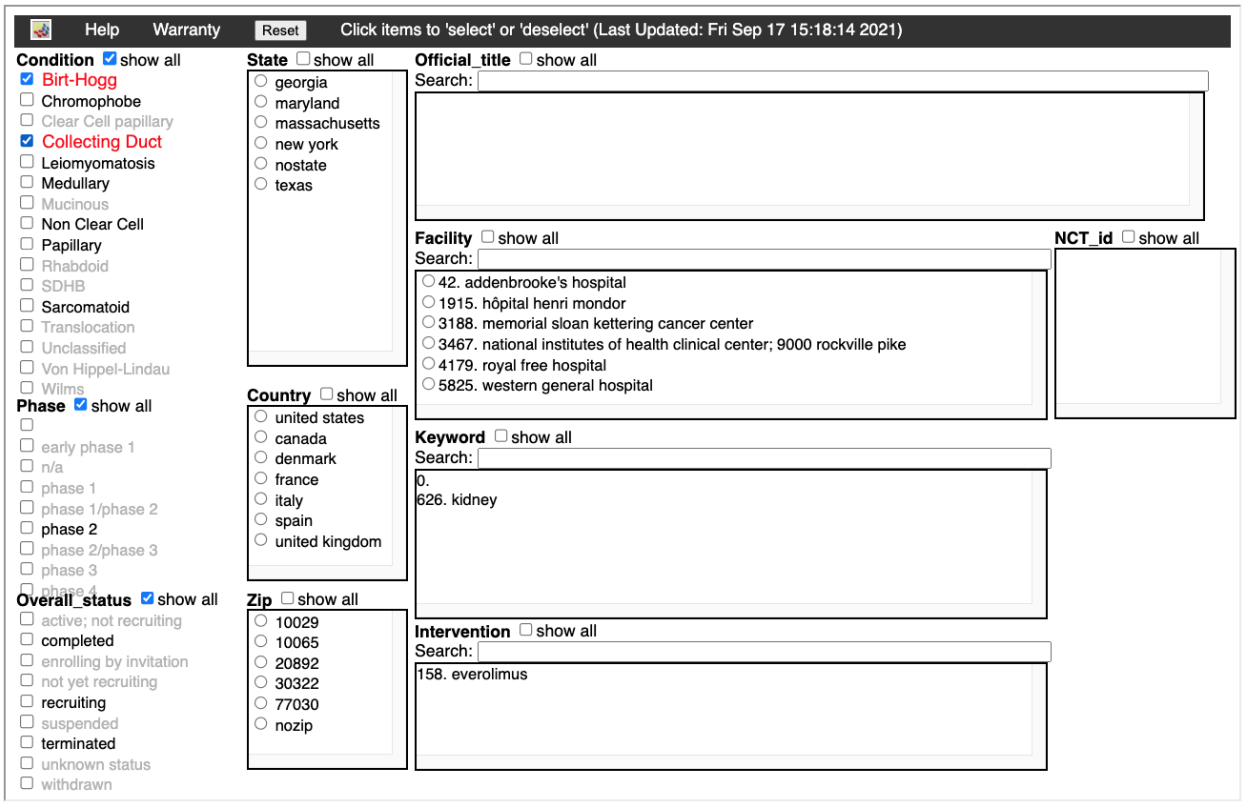
This is the initial Clinical Trial Tool Screen. Multiple Select options are denoted by boxes and Single select options are denoted by circles.

The Gist

This Clinical Trial tool will help you narrow down your choice of rare kidney cancer clinical trials listed on clinicaltrials.gov in a short period of time using only 'clicks'.



Initially, all text is 'selectable' (displayed in black. e.g. 'Birt-Hogg'). Clicking on selectable text 'selects' it. (displaying it in bold. e.g. **'Birt-Hogg'**). Once you select something, most likely other items will become incompatible with that selection. The tool 'eliminates' such items. In long lists, eliminated items disappear. (e.g. most states disappear if you select 'Birt-Hogg'). In short lists, 'eliminated' items are shown explicitly. (displayed in gray font. e.g. 'Collecting Duct')



'Eliminated' items can be selected as well. This produces a 'contradiction' (displayed in red 'strike through' font. e.g. ~~'Collecting Duct'~~). This means that there is no trial which meets all the selected criteria. Note that there are fewer countries. That is because only the displayed countries have trials for both conditions. 'Contradictions' can be removed by clicking them. This removes the selection and the item is again displayed as eliminated.

Some lists are quite long. For example 'Facilities' has 3800 items. You can scroll through the items or use the 'autocomplete' box above the list to search through the list's contents via entered text.

Some list entries have a link beside them (e.g. NCT_id, the Clinical Trial ID). Clicking the link will take you to the clinicaltrial.gov description of the clinical trial.

Note that all the data comes directly from clinicaltrials.gov. As such, it is LIMITED by how the researchers entered their data. In particular, researchers may use another term instead of "papillary", even if their trial admits papillary patients. The categories are created automatically, looking at the intersection of all the terms submitted for kidney cancer trials.

Some Clinical Trial Tool Detail

This tool interrelates 400 interventions, 1600 keywords and 3800 facilities. It will take several seconds to load.

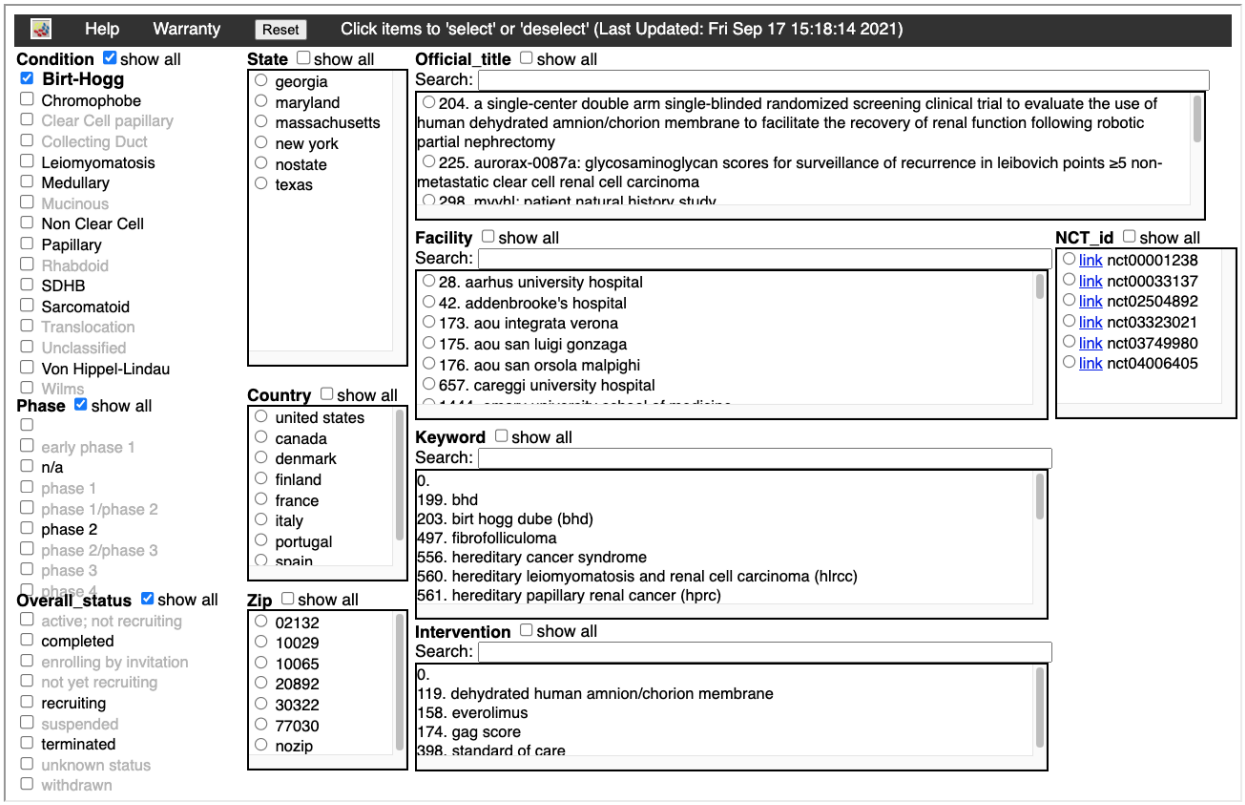
A newcomer to clinical trials is unlikely to know all the important categories in a clinical trial (Phase, Condition, Interventions (e.g. 'Drugs'), Keywords, etc.). So we list them explicitly.

A newcomer is also unlikely to know all the names of category members as well (Papillary, Chromophobe, Foretinib, Bevacizumab, etc.) So we list them ALL explicitly as well.

Unfortunately dealing with long lists is a pain, so we provide several mechanisms to help.

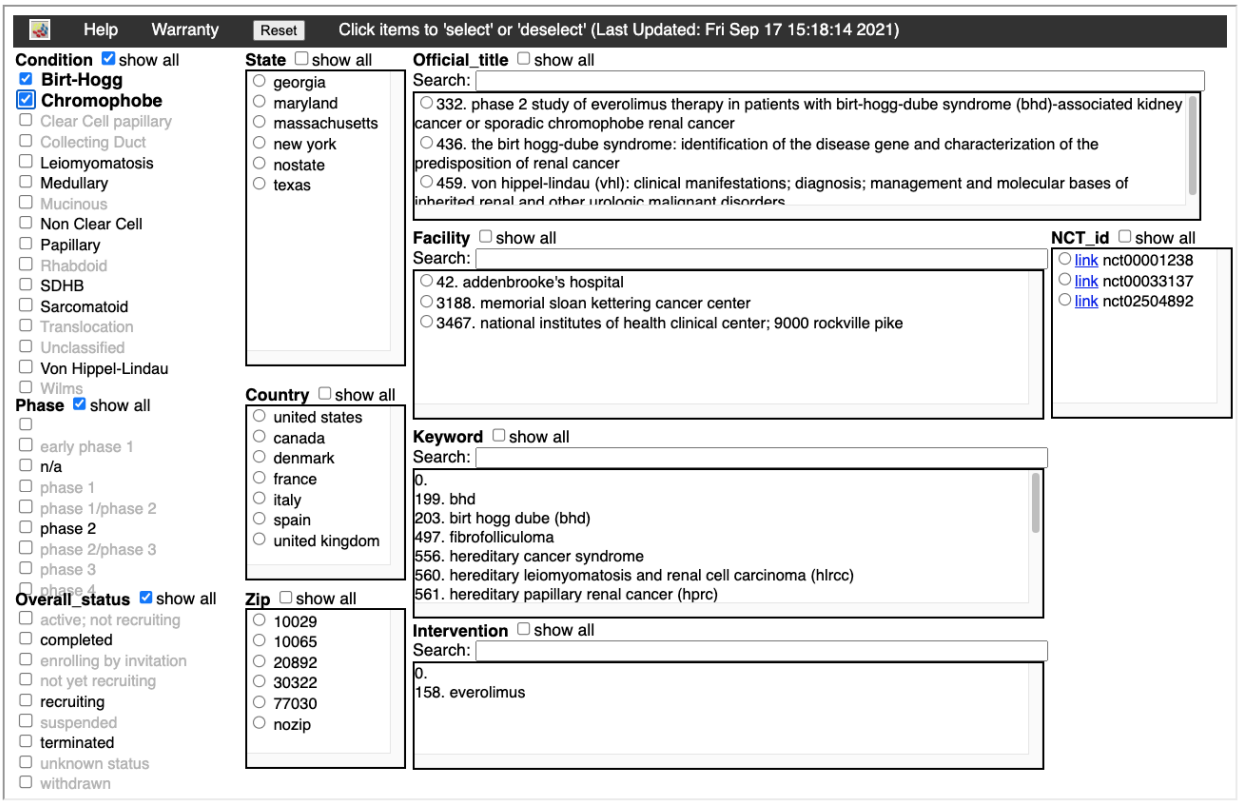
1. 'show all' - if checked, all items are shown. If unchecked, all eliminated items disappear.
2. 'search' - an autocompletion field that searches all entries in the category. E.g. 'Facilities' contains 4000 or so entries. You can enter 'memorial sloan kettering' to see all the msk facilities participating in clinical trials. You can then select an item from the drop down
3. Hyperbolic text - the text changes size as you mouse over it. (This was removed from the clinicalTrials tool by popular demand.)

Clinical Trials Tab Tutorial

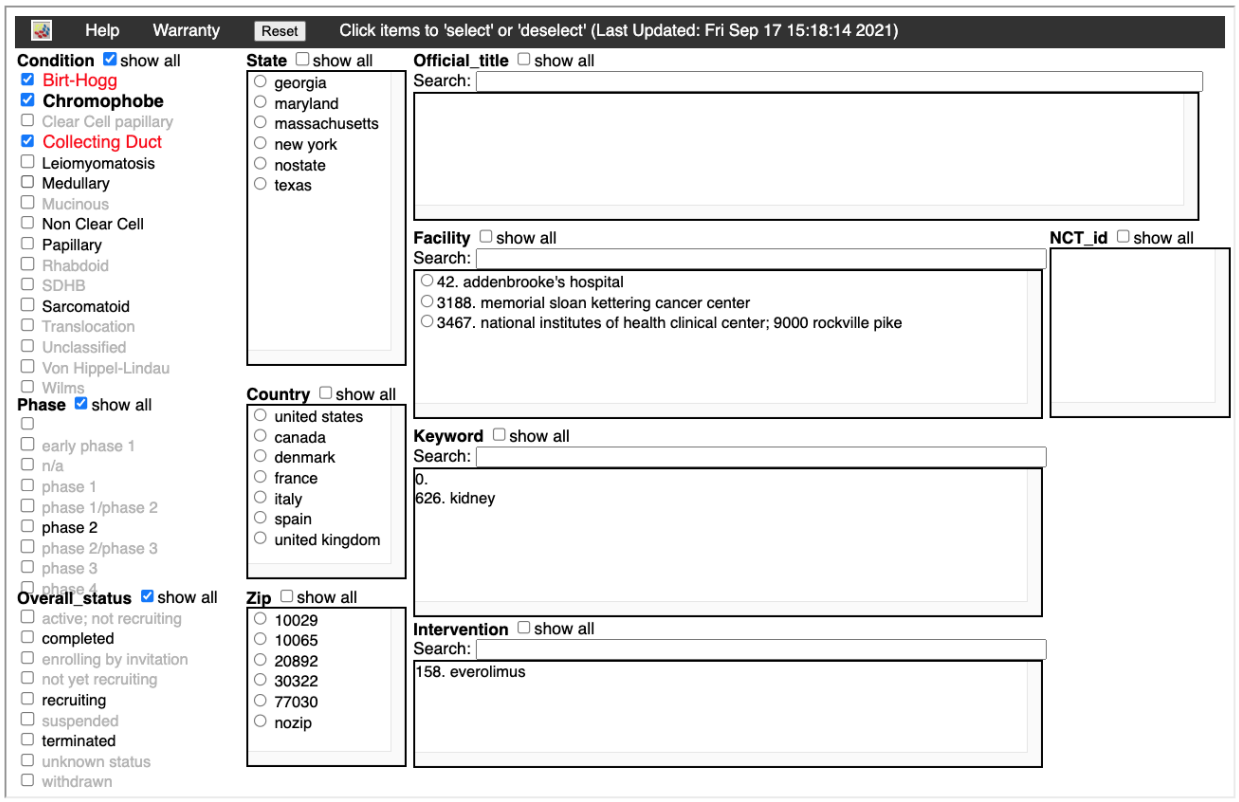


Let's illustrate tool features by continuing the above example.

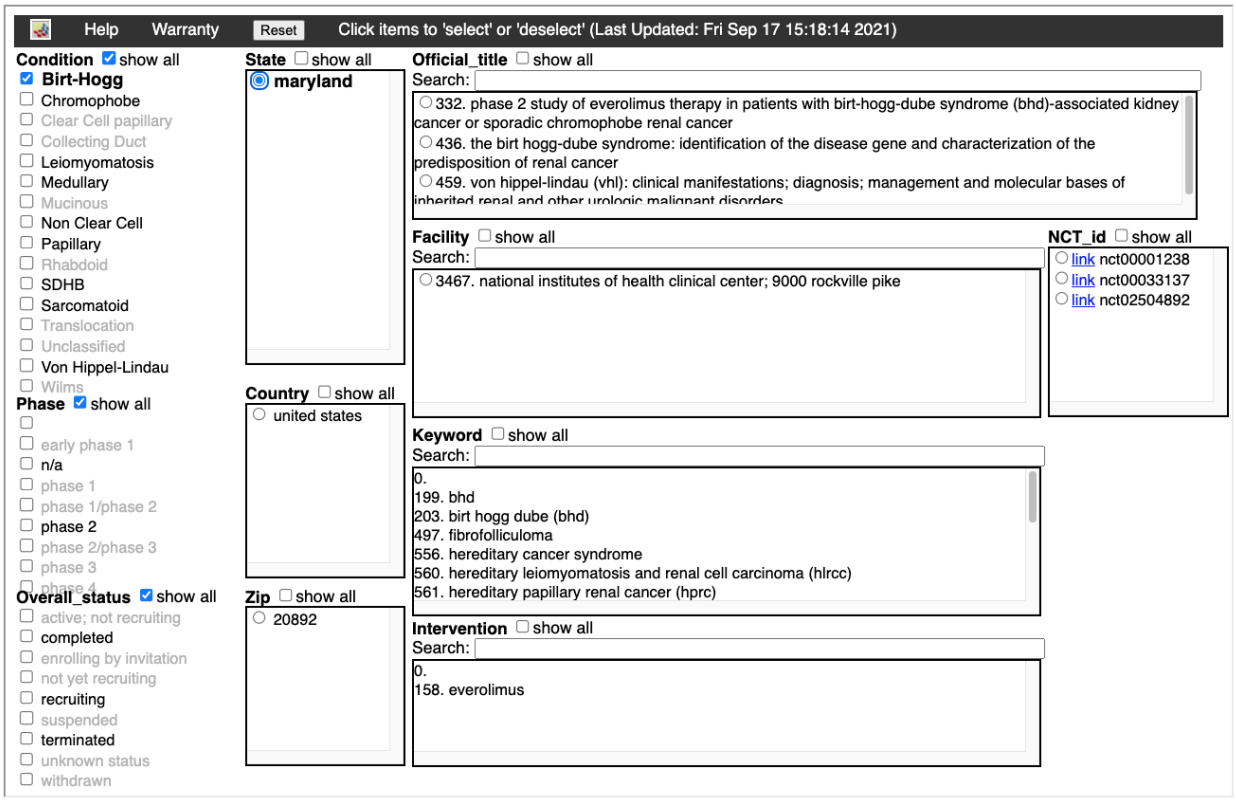
1. Click on Condition - 'Birt-Hogg'
    1. Notice that **'Birt-Hogg'** is displayed in bold font. This means that it has been selected.
2. Click on Condition - 'Birt-Hogg'
    1. Notice that 'Birt-Hogg' is displayed in plain black font. This means that it has been de-selected.
3. Click on Condition - 'Birt-Hogg'
    1. **'Birt-Hogg'** is again displayed in bold font since it has been re-selected.
    2. Notice that 'Collecting Duct' is displayed in gray font. This means that it has been eliminated, i.e. that there are no clinical trials that are treating both 'Birt-Hogg' and 'Collecting Duct'.
    3. However, there are trials that treat both 'Birt-Hogg' and 'Chromophobe'. That is why 'Chromophobe' is still in plain black.



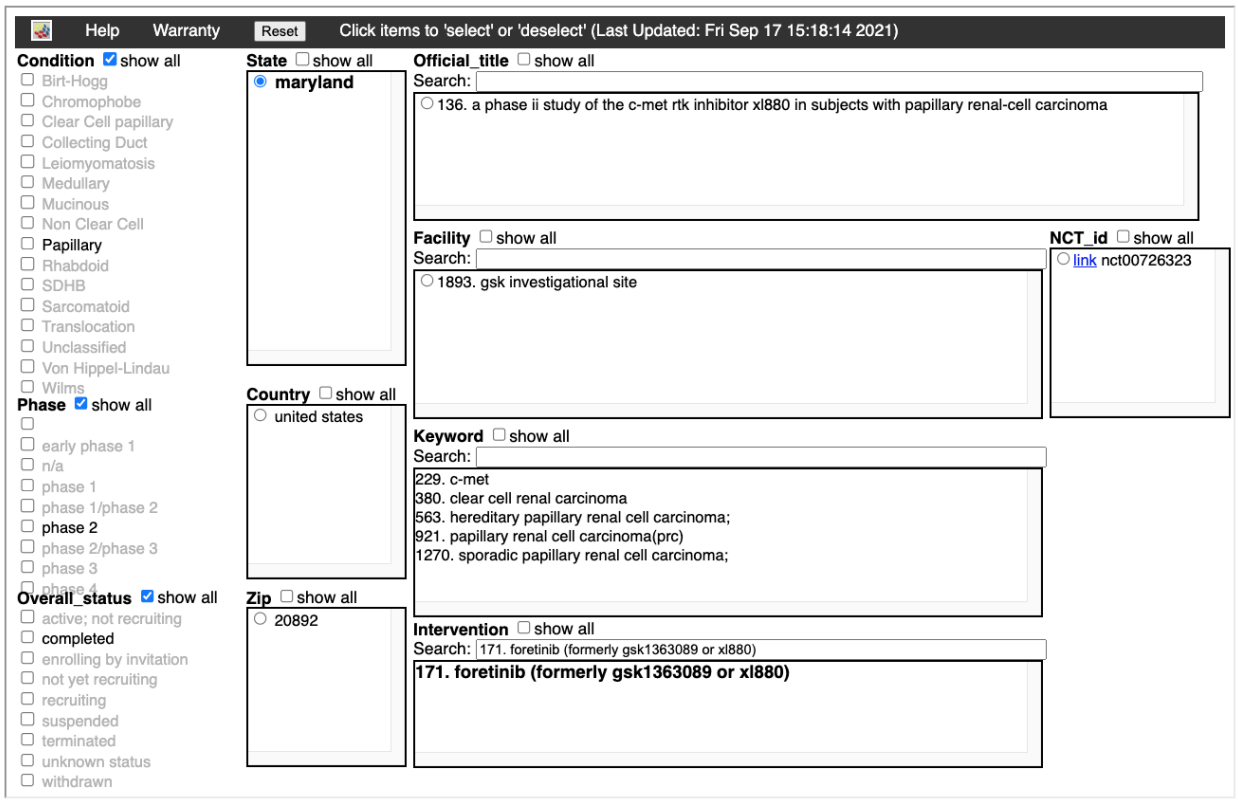
4. Click on Condition - 'Chromophobe'
    1. Notice that **'Chromophobe'** is now displayed in bold font. This means that it has been selected.
    2. Notice also that the number of clinical trial IDs displayed in the NCT_ID field has been reduced. (As before you can deselect and reselect 'Chromophobe' to notice this.) This means that there are fewer trials that treat both 'Birt-Hogg' and 'Chromophobe' than trials that treat 'Birt-Hogg' alone.



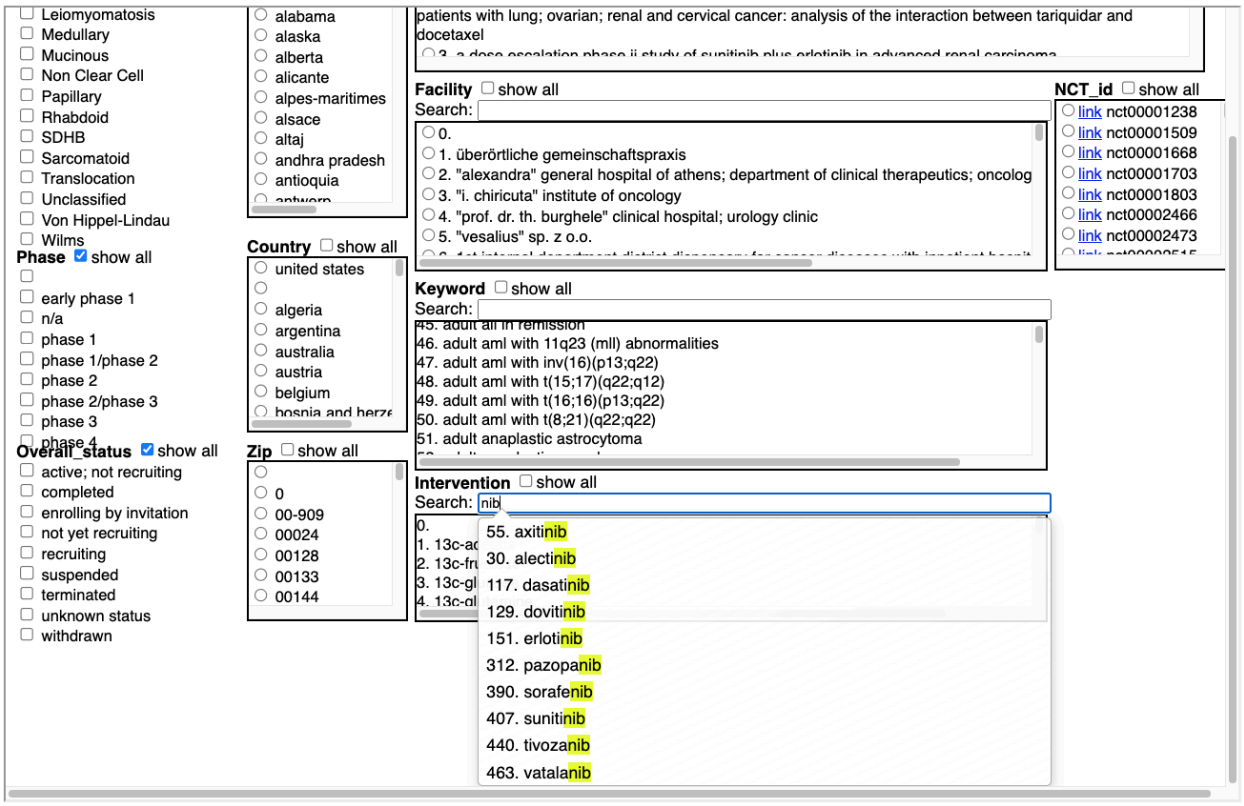
5. Click on (eliminated) Condition - 'Collecting Duct'
    1. Notice that **'Chromophobe'** is still displayed in plain black font, but ~~'Collecting Duct'~~ and ~~'Birt-Hogg'~~ are displayed in red 'strike through' font. That is because there are no clinical trials that are treating both 'Birt-Hogg' and 'Collecting Duct'.
6. Click on Condition - 'Chromophobe' and ‘Collecting Duct’- deselecting them



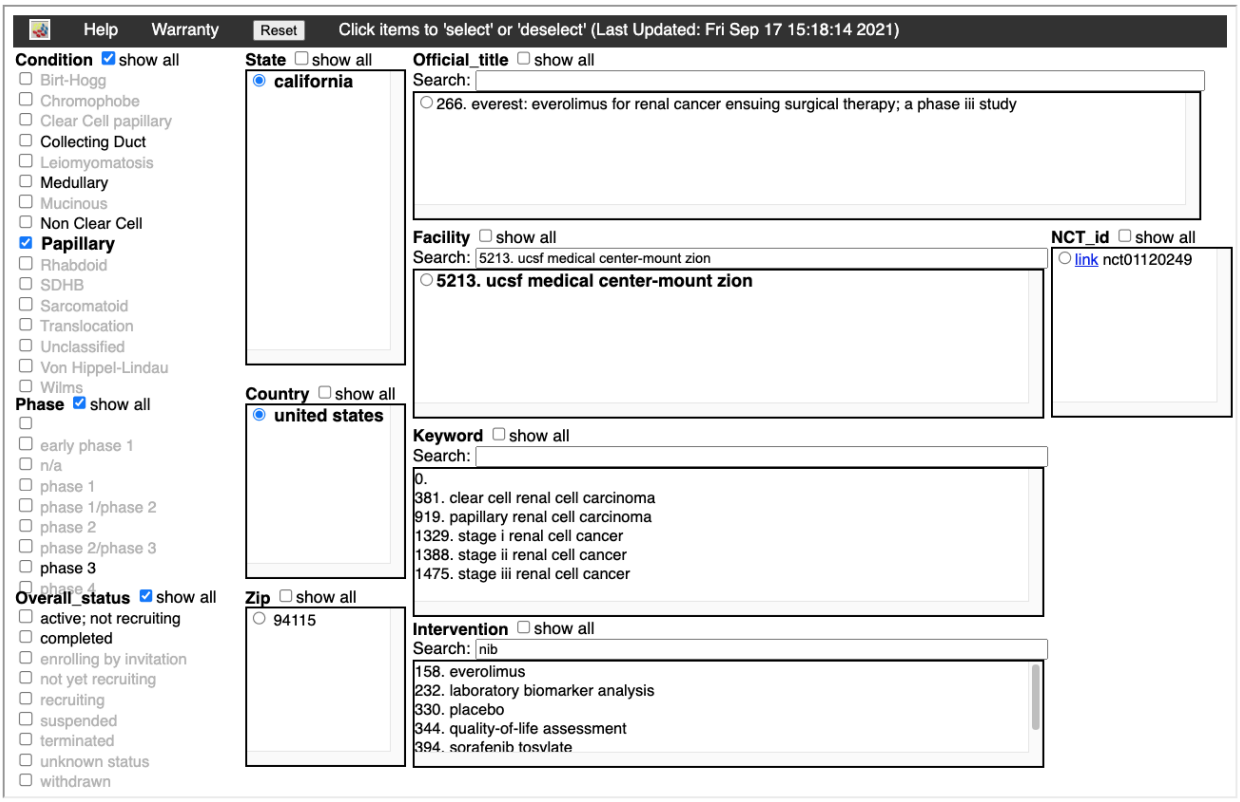
7. Look at the list of States
    1. Several states, including 'Maryland', are still selectable.
    2. Many others have disappeared since 'show all' is not selected.
    3. Select Maryland
    4. 'Maryland' is consistent with the facilities listed since 'national institutes of health clinical center' is in Bethesda Maryland.
8. Look at the list of Drugs
    1. Note that all the drugs have also disappeared except everolimus.
    2. As such, it is likely that everolimus is the drug being used
9. Look at the list of Clinical Trial IDs (NCT_id)
    1. NCT_id shows that there are several clinical trials dealing with Birt Hogg.
    2. Clicking on the 'link' entry to the left of the NCT_id takes you directly to the clinical trial description.



10. Deselect Birt-Hogg and Enter "foretinib" in the Intervention search field and click on the single dropdown entry.
    1. Under condition, we see that there is one condition that it is used for: papillary kidney cancer.
    2. It is being tested only in the US in one clinical trial in one state.



11. Enter "nib" (or "mab" or "olimus") in the Intervention search field and click on the single dropdown entry.
    1. These are three common suffixes for kidney cancer treatments. So these queries help you discover all the clinical trials using these treatments.



Let's continue using Bill as an example. Bill has papillary kidney cancer, lives in California and picks USF Mount Zion as his hospital. They are only running one trial for his cancer type. Bill is able to access information on this trial by clicking the blue link nct01120249.

S0931, Everolimus in Treating Patients With Kidney Cancer Who Have Undergone Surgery (S0931)

ClinicalTrials.gov ID NCT01120249

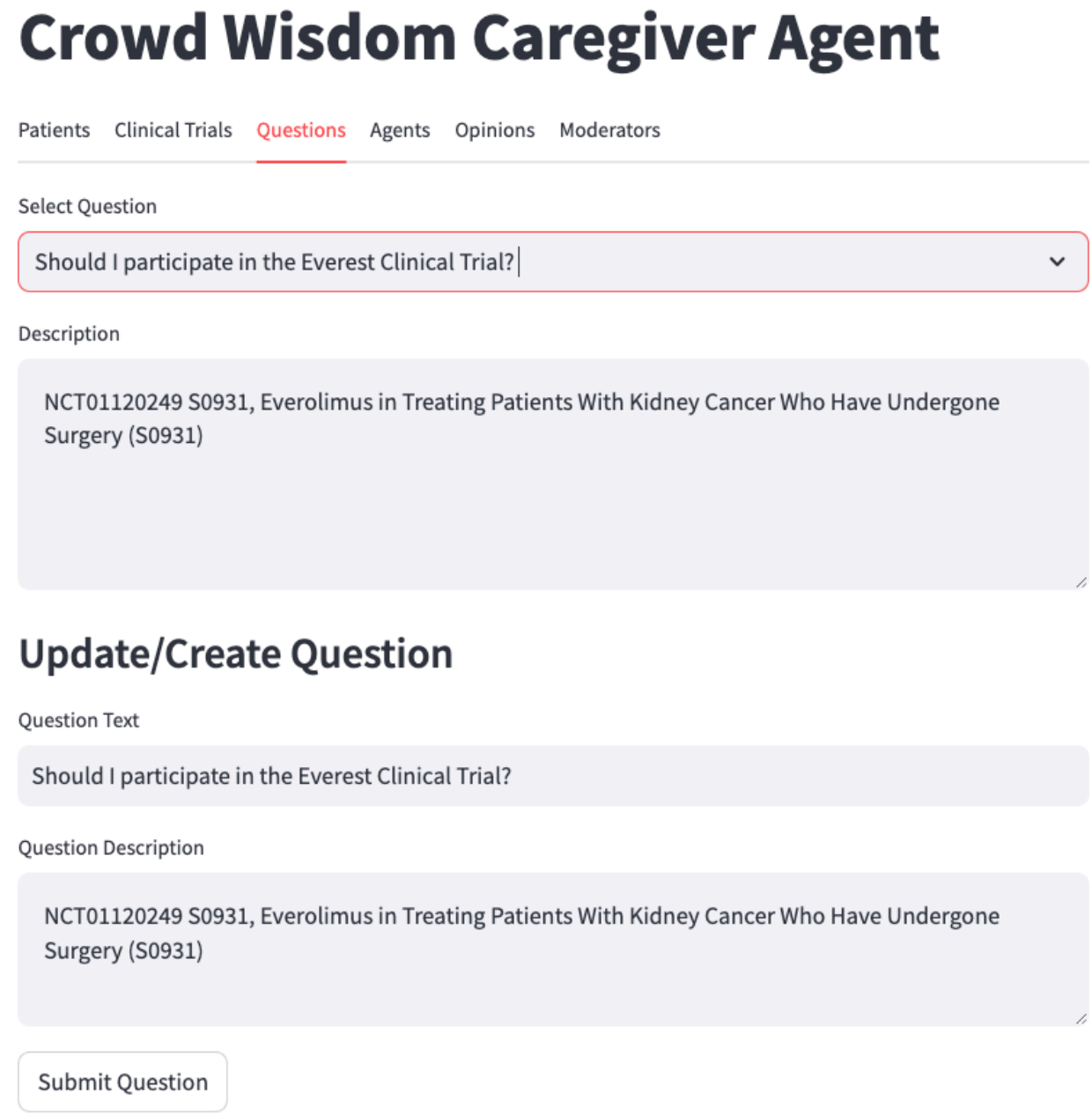
Sponsor SWOG Cancer Research Network

Information provided by SWOG Cancer Research Network (Responsible Party)

Last Update Posted 2024-08-29

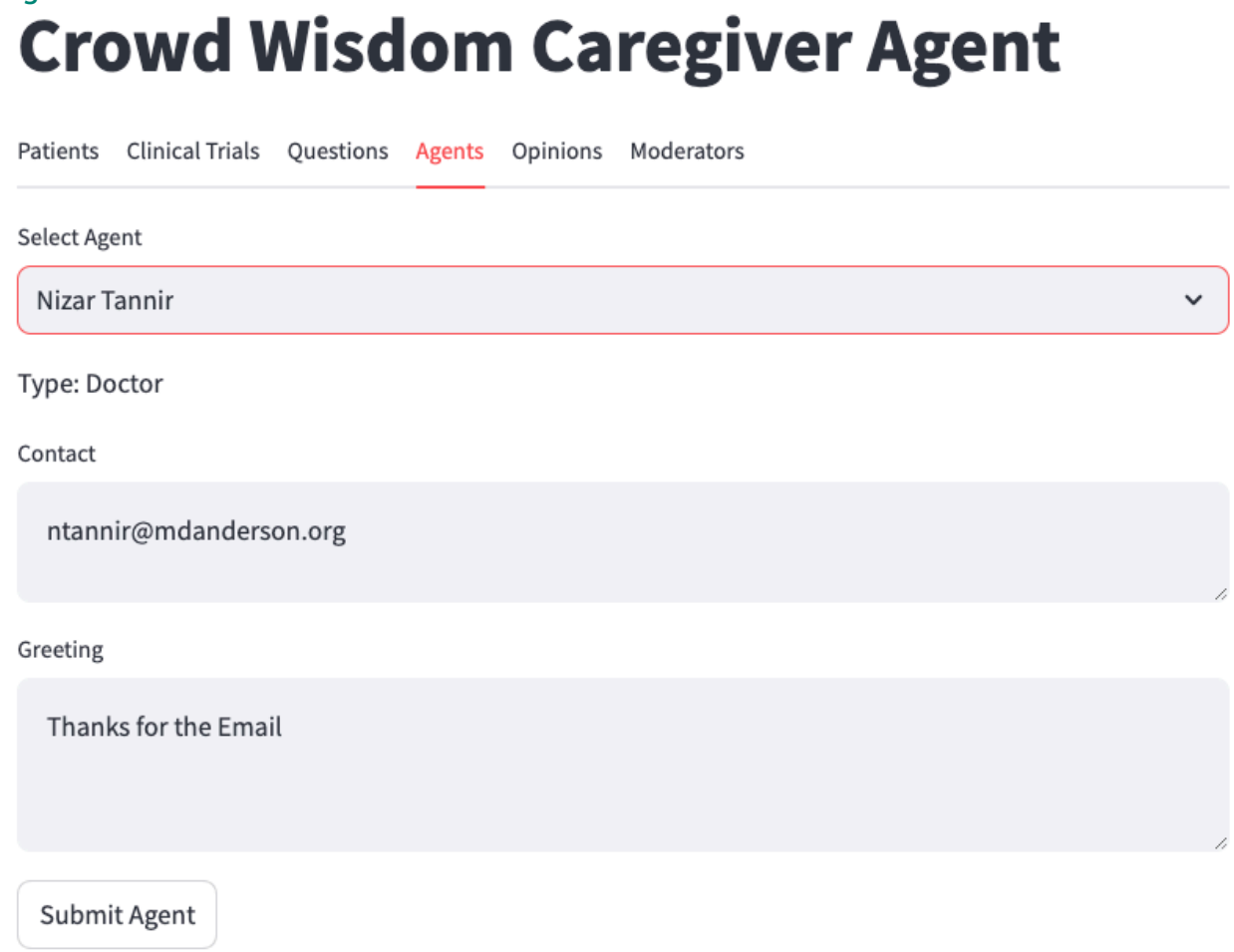
This trial is popularly known as EVEREST.

Questions Tab



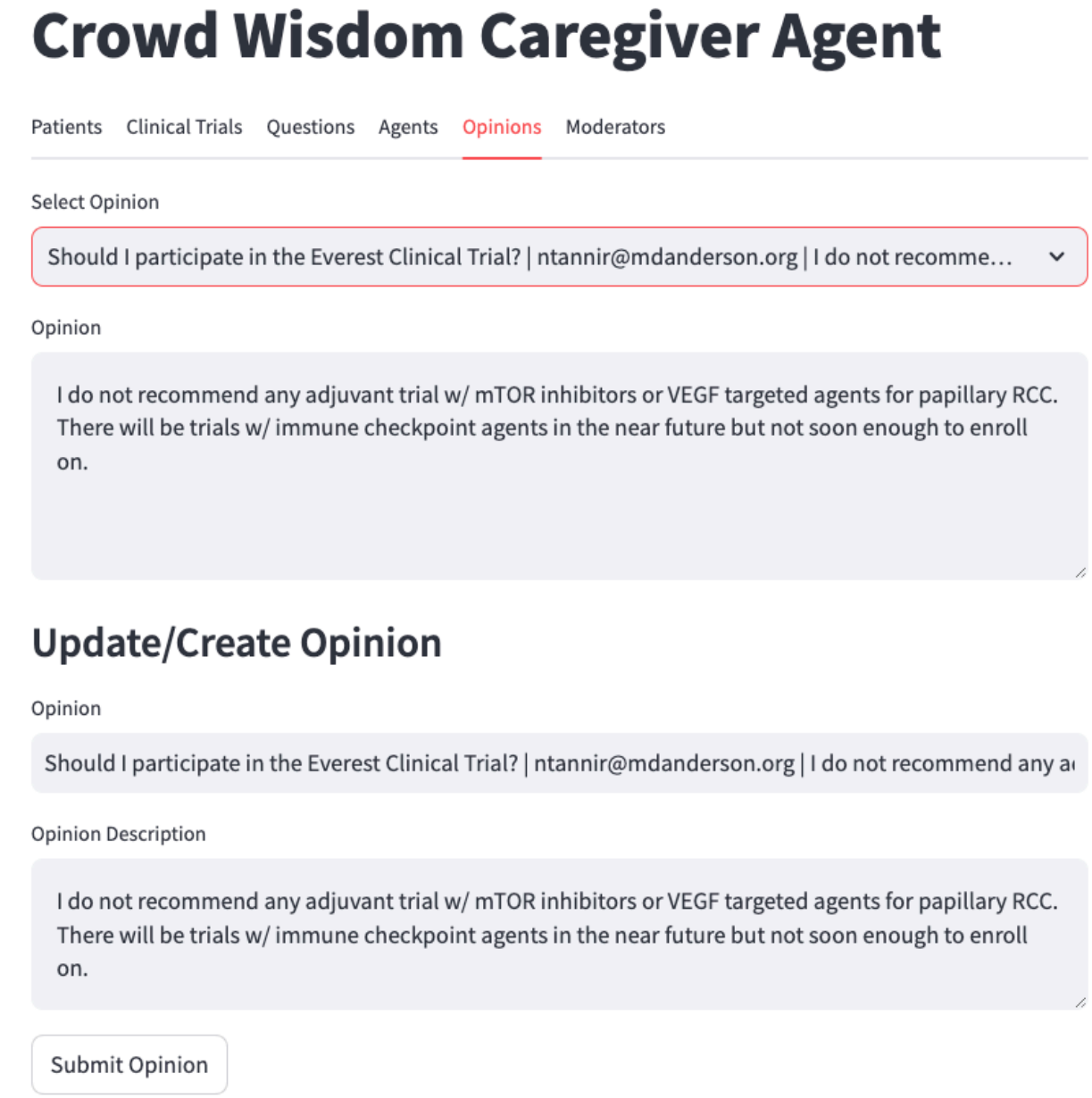
Bill has questions about Everest, so he posits the question plus some detail.

Agents Tab



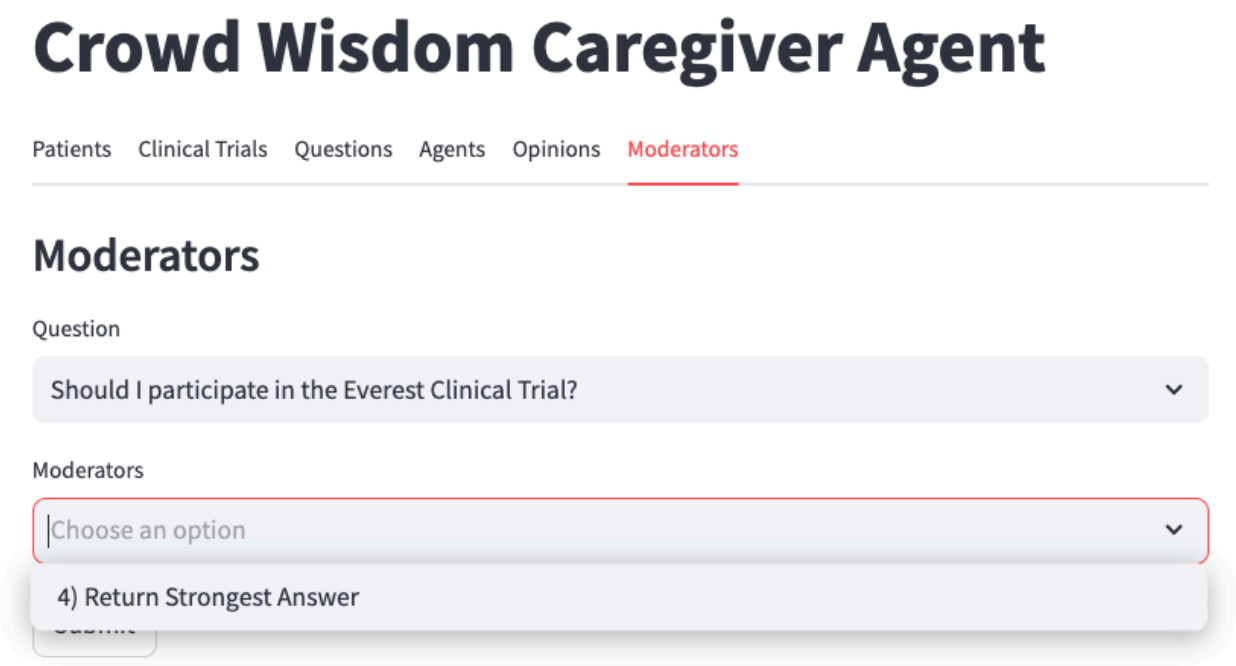
Nizar Tannir from MD Anderson specializes in this type of Cancer. Bill has communicated with him previously, so Bill sends him an email with a Greeting, the question and a pointer to his record.

Opinions Tab



After a period of time, Dr. Tannir responds and Bill submits the Opinion to be evaluated.

Moderators Tab - Everest Clinical Trial Example



I once tried loading 13 opinions into chatGPT and asked it to pick the Best one.

Prompt: I am considering participation in the EVEREST clinical trial after a full left nephrectomy for papillary kidney cancer. I created a “tumor board” of 13 physicians to determine if this is a good idea. Their (numbered) responses are below. The number is a physician id. This is followed by a “yes” or “no” as to whether I ought to participate. Next is the physician “label”. Finally, their rationale is included. Given this data, Please act as a tumor board moderator and tell me if I ought to participate in the trial. Please include your rationale.

Answer: Recommendations: I encourage you to have a detailed discussion with your primary oncologist or a specialist familiar with your case.

So I tried this instead..

Prompt: Create a playoff with physicians 1-5 and 7. Pair one of the 3 "yes" physicians with one of 3 "no" physicians into 3 matchups (pairs). Compare each yes/no pair and choose a winner based on how convincing their argument is. If the result is unanimous (3 "yes" or 3 "no"), report it. If it is not, create two more playoffs between the minority opinion and each of the majority opinions. Report the results from each step.

Answer: The “Don’t do the trial” contingent won unanimously.

Crowd Wisdom Caregiver Agent

Patients Clinical Trials Questions Agents Opinions Moderators

Moderators

Question

Should I participate in the Everest Clinical Trial?

Moderators

4) Return Strong… ×

Submit

Opinions

	Moderator 4	Answer	ID	Argument
0	No	Yes	Sutter	"Minimal Downside"
1	No	Yes	Stanford	"If you are eligible always a good idea to partake on trials"
2	No	Yes	Davis	"No cons other than ending up in the placebo arm or having to deal w
3	No	No	Los Gatos	"Kidney cancer has had no successful treatment (e.g. radiation, chem
4	No	No	MD Anderson	Nizar Tannir: "I do not recommend any adjuvant trial w/ mTOR inhibit

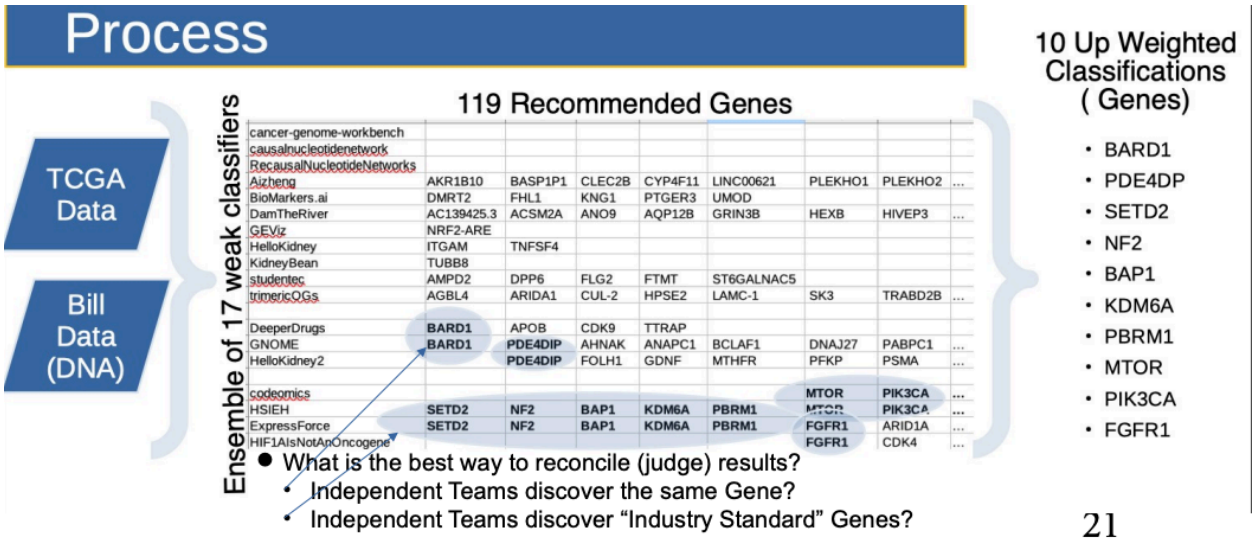
Answers

	Moderator	Answer	IDs	Argument
0	4	No	MD Anderson	Nizar Tannir: "I do not recommend any adjuvant trial w/ mTOR inhibitor

"Opiniions" show three doctors who encouraged participation (Answer="Yes") and two who discouraged participation (Answer="No").

Moderator 4's ranking of the different answers. ("No" wins head to head everytime).

Moderators Tab - Hackathon "Genes of Interest" Example



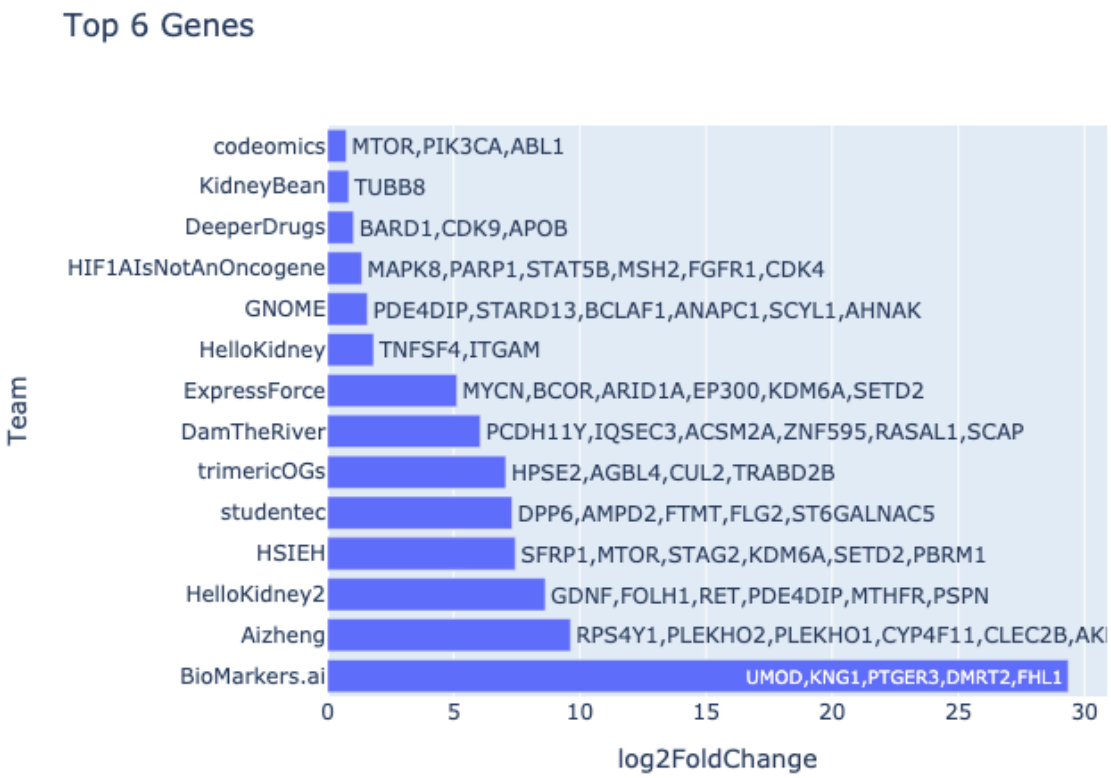
In 2018 and 2020, Pete Kane (researchtothepeople.org) and I collected 80 researchers to find "Genes of Interest" in my tumor. This was important to me since no original research into my condition had been done in 10 years. The 80 participants formed 17 teams (names listed on the row headers above) and were given a lot of genomic data about me. In addition to the teams, we were joined by my co-founder of rarekidneycancer.org: Dr. James Hsieh. He researches the disease, and his picks for "Genes of Interest" are listed to the right of his name. All the other participant's "Genes of Interest" are listed to the right of their names.

Some patterns immediately emerge. In several cases, independent researchers had identified the same gene (BARD1 and PDE4DP). This would seem to be important because there were lots of genes and this was a competition: no collaboration allowed. In addition, some teams had overlap with the expert (Dr. Hsieh). Is that important? Not clear. Perhaps they just googled his work.

However there was a third scoring mechanism. As you know, DNA is present in every organ in the body. And the reason that organs don't look the same is that the DNA is "expressed" (as RNA via the Genes) differently in each. RNA then creates proteins and enzymes that particularize the organ. Now, suppose we view tumors as just another organ! They start with the same DNA but express RNA differently than the organ from which they originate.

So one form of analysis is to measure RNA levels (called "RNA-seq") in the Organ and Tumor and subtract the healthy organ RNA-seq levels from the tumor RNA-seq levels. The assumption is that wherever there are surpluses and deficits from normal, the processes associated with those Genes are abnormal as well. Now RNA-seq levels vary wildly, so they

are measured using log2norm, which is a logarithmic compression of the value. In the hackathon, participants were given DNA, not RNA-seq. I used the RNA-seq as a holdout set to rank the proposed genes by their differential log2 norm values. This was my 3rd moderation approach and the scoring for that is shown below.

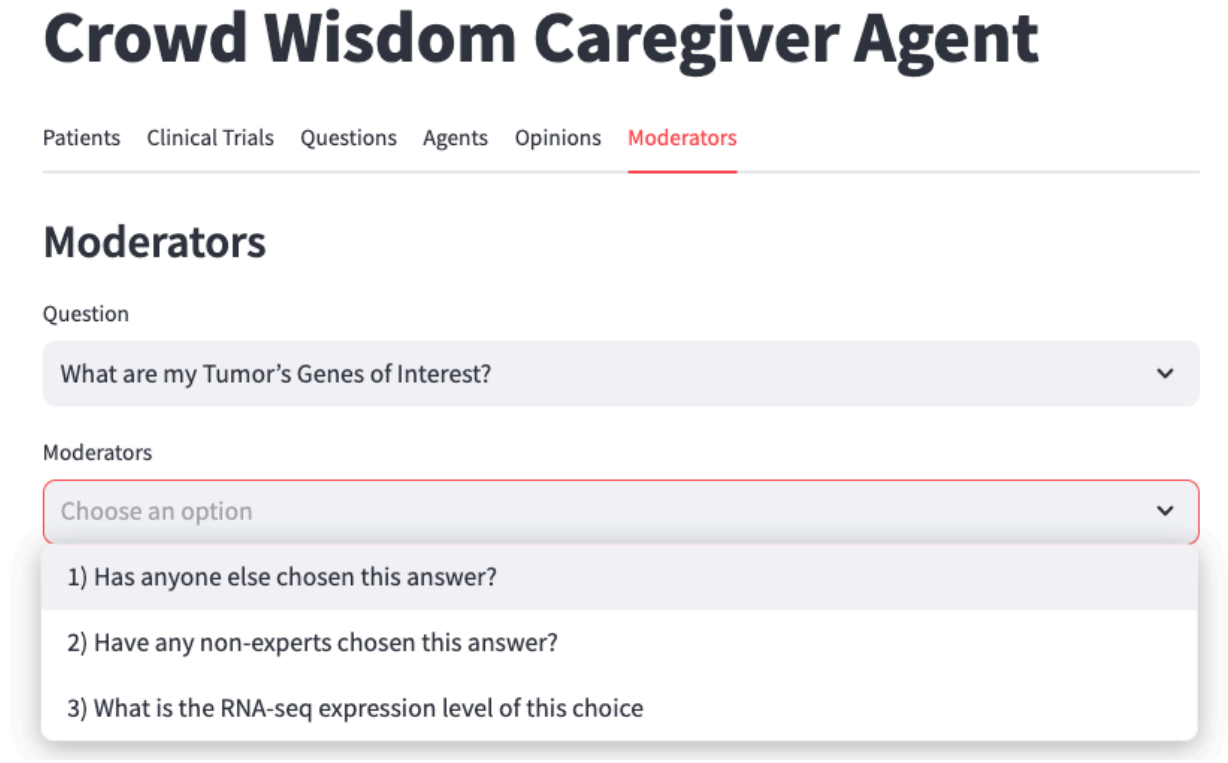


The x-axis is logarithmic, so the difference is especially stark.

So what did the BioMarkers.ai team (Saed Sayad) do differently? They knew that DNA provides a weak signal for genomic analysis and RNA is much better. So he "looked up" RNA data on NCBI GEO (Gene Expression) data) using my DNA data as a key. That is, by using other people's RNA (whose DNA matched mine), they got a stronger signal than by using my DNA data directly. And as the above chart shows, their approximation ultimately matched my RNA-seq data when it became available.

Many modern analysis techniques work on boosting weak signals. But Biomarkers.ai's signal was so strong that they were able to use a cluster separation technique from the 1930's, LDA- Linear Discriminant analysis, to get clean data separation and so make better predictions.

Why is this cool? Because it had never been done before. This "Wisdom of Crowds" approach produced a new research technique, as well as helping them figure out some repurposed molecular treatments for me.



Here are the moderators for the Hackathon Opinion.

Opinions

	Moderator 1	Moderator 2	Moderator 3	Answer	ID	Argument
0	No	No	-0.668831	KNG1	Biomarkers.ai	x
1	Yes	Yes	-0.0465753	BARD1	GNOME	x
2	Yes	Yes	-0.0465753	BARD1	DeeperDrugs	x
3	Yes	No	0.02846798	SETD2	ExpressForce	x
4	Yes	No	0.02846798	SETD2	HSIEH	x
5	No	No	0.37044632	FHL1	Biomarkers.ai	x

Answers

	Moderator	Answer	IDs	Argument
0	1	BARD1	GNOME, DeeperDrugs	Overlap, including Experts
1	1	SETD2	ExpressForce, HSIEH	Overlap, including Experts
2	2	BARD1	GNOME, DeeperDrugs	Overlap, excluding Experts
3	3	KNG1	Biomarkers.ai	Minimum Expression
4	3	FHL1	Biomarkers.ai	Maximum Expression

Above is the Opinions and Answers section of (a subset of) the results for Moderators 1,2 and 3.

1. Has anyone else chosen this answer? - This is the set of Genes including the ones selected by Dr. James Hsieh (SETD2) plus non-experts (BARD1)
2. Have any non-experts chosen this answer? - This is the set excluding Dr. Hsieh's choices. So only BARD1
3. What is the RNA-seq expression level of this choice? - This shows the top (most overexpressed) and bottom (most under expressed) Genes.

Summary

Congress has cut support for rare disease research this year. In particular, CDMRP, the kidney cancer research program I have lobbied for since 2020, has had its funding cut from $50M to $0 this year.

So it is up to the patient to find their own solutions and do their own research. Fortunately, patients do have access to their own data. And many rare disease patients are more interested in treatments than data privacy(HIPAA). So in a world where funding is being cut and data is hard to get, perversely, rare disease data is a nice bargaining chip to recruit bioinformatics help. This is the argument Pete Kane and I used to get 80 participants into my Genomics Hackathon. Time, food and venue were all donated (i.e. no government funding).

The methods described here and the supporting tool can help sort out clinical trial choices and research results for patients holding their own hackathons.

This approach helped me. I hope it helps you.