

Transcript: Could this AI tool make health insurance “suck less”?

Dan: Hey there--

Let's start with introductions.

Carolyn: My name is Carolyn DeSimone, and I have a super cute dog. His name is Professor Timbit. He's a professor because he's always researching something.

Holden Karau: My name is Holden Caro, and I'm trying to make health insurance suck a little bit less

Dan: Carolyn and Holden are married, and I talked with them in September because listeners had been sending me links to a story in the San Francisco Standard, with the headline “‘Make your health insurance company cry’: One woman’s fight to turn the tables on insurers.”

That woman was Holden. She works in tech, and the story was about a tool she'd built, to help people fight health insurance: It writes appeal letters, using AI of course.

She's made it available at a web site, "fight health insurance dot com"

I lose count of how many of you sent me that link, but *thank you*, SO much.

Holden and Carolyn live in San Francisco. I talked to them on Zoom. A local reporter, Lee Romney, helped set up mics for the two of them in their living room.

The bookshelves in the background had -- along with books --lots little stuffed creatures. When I squinted, I could see a pikachu.

Holden Karau: So there's a few Pikachu's actually. Um, and we have a, we have a stuffed poop. Um, it's a wombat poop. That's why it's square. Here.

Dan: And Lee can't help commenting when she sees the wombat poop because it's a brown, plushie cube with a face.

Carolyn: Let me go grab it. I'll show you.

Dan: Lee can't help commenting when she sees the wombat poop: it's a brown, plushy cube, with a face.

Lee Romney: That's a very regular looking turd.

Carolyn: Wombats have square poops so they don't roll away.

Lee Romney: Oh, I didn't know that.

Carolyn: Yeah, they have like special muscles in their buttocks to make square poops.

Dan: This is the most fun zoom I've ever been on, actually.

Dan: And we were just getting started.

This is An Arm and a Leg, a show about why health care costs so freaking much, and what we can maybe do about it.

I'm Dan Weissmann. I'm a reporter, and I like a challenge.

So the job we've chosen here is to take one of the most enraging, terrifying, depressing parts of American life, and bring you a show that's entertaining, empowering, and useful.

As you might imagine, Holden's decision to create Fight Health Insurance draws on both her significant professional expertise -- she's worked for Google, IBM, Apple, and now Netflix, and has written several technical books about programming --

and her personal experience fighting health insurance-- also significant.

And the reserves of anger and cussedness she got from those experiences.

Holden Karau: I try and be a nice person, but health insurance does not bring out the best in me.

Carolyn: I don't think it brings out the best in anyone.

Holden Karau: Certainly, certainly no one that I know.

Dan: Holden's gender transition provided lots of experience.

Holden Karau: **Being a trans person in America, you have to navigate health insurance.**

Dan: For instance, early on, Holden says she learned something that I didn't understand until I'd been working on this show for a while:

If you get health insurance from your employer, it's pretty likely that your state's insurance laws don't apply to your plan.

Instead, your plan gets regulated by the federal department of Labor, under a federal law called ERISA. Holden knows a LOT about ERISA and had to think for a minute about when she picked it up.

Holden Karau: **When did I learn about ERISA? I think I knew what an ERISA plan was from IBM.**

Carolyn: **Oh yeah, cause IBM got you boobs.**

Holden Karau: **Yeah. IBM paid for my boobs. Originally I was going to get a tattoo saying like sponsored by, but – I – no.**

Dan: Holden says her fighting-insurance game -- and those reserves of anger-- leveled up in 2019.

Holden Karau: **Yeah. When I got hit by a car is when I like started reading health insurance regulations because I didn't have a lot else to do and it was also really important that I figure it out.**

Dan: Holden had been riding a brand-new Vespa. She was on 16th Street in San Francisco's Mission District. Carolyn picks up the story here...

Carolyn: **A woman pulled out of the parking lot of the Safeway to turn left without looking.**

Holden Karau: **Yeah, across four lanes of traffic.**

Dan: Holden says she had two broken wrists, and some broken bones in her legs. It didn't take long for her to start thinking about medical bills. Even though she was on very strong painkillers.

Holden Karau: I think while I was still on fentanyl, I was thinking about insurance.

Dan: She was thinking, this is gonna be... a lot.

Carolyn: Out of the trauma bay, but possibly not when you were out of the ER, was the first time we thought about, what's this gonna cost?

Dan: But they say the actual haggling with insurance didn't start for a few days, when it was time for Holden to leave the hospital. And head to rehab. Her insurance, she says, had a place in mind.

Holden Karau: They really wanted to send me somewhere really, really shitty.

Carolyn: We looked at the reviews of them.

Holden Karau: Yeah. And it's like, they're actively being investigated by the state...

Carolyn: ...for like hitting their patients with things.

Holden Karau: Yeah. It was like, no, I don't want to go there.

Dan: Carolyn said she pitched in to help get Holden to a better rehab, but then they say there were battles over how much treatment she'd actually get. By that time, Carolyn says, Holden was ready to go right at it.

Carolyn: Once you got to the rehab, I think you started reading the forms for fun.

Holden Karau: I didn't have a lot going on at that point, and I was still on opiates, but the opiates were less strong, so my brain was starting to work again.

Carolyn: You got bored.

Holden Karau: Yeah.

Dan: Holden says her brain was working, but not her body. She couldn't hold a laptop, or really type. Or get out of bed to pick up her phone if it fell to the

floor. But even with broken wrists, she was ready to fight for the rehab treatment she needed.

Holden Karau: it ended up working out okay, and part of that was my willingness to just, like, take things to an unreasonable length. I was like, really, I have nothing to lose here, so I will sue you. I am bored.

Dan: Holden says it helped that she could afford a good lawyer.

Especially because there were more fights ahead. She says she had to fight for special crutches – cause she couldn't use regular ones with broken wrists -- and for more physical therapy when she got home.

And there was an epic fight to make sure medical bills didn't completely devour any settlement from the driver's car insurance. This was a next-level legal education.

Holden says it took three years to get all the legal issues resolved. And, Meanwhile, she discovered that she'd developed a super-power -- or call it a special interest.

She noticed: If someone at a party, say, started talking about a problem they were having with health insurance, she was ready -- eager-- to take them down the rabbit hole.

Holden Karau: they'd be like, complaining about a thing, and it's like, oh no, like, yeah, yeah, yeah, this sucks, and they totally do that, but like, there's actually a thing that you can do, it was like, okay, like, this is a thing that I know how to do. I like helping people

Dan: But conversations at parties weren't much of an outlet.

Holden Karau: Like, I don't get invited to a lot of parties, because not a lot of people are like, I would love to hang out with that lady that keeps talking about ERISA regulations or the Affordable Care Act.

Dan: And then, in January of 2023, Holden was talking with a friend at a tech conference.

Holden Karau: He has family that also has perhaps a non standard level of experience with insurance, and so like we were talking about generative AI...

Dan: Generative AI. Chat GPT had been released less than two months before.. Holden and her friend ended up thinking.. .

Holden Karau: You know what, we could use this to actually, like, make the world suck a little less.

Dan: Could use these new generative-AI tools to fight health insurance. Like by having it write appeal letters when claims got denied. An idea was one thing. Making something would take more. Holden used what she knew about herself to make that happen.

Holden Karau: There's, there's different kinds of motivation, right? There's like, uh, deadline driven, uh, programming, which is like when you agree to give a talk at a conference, you're like, okay, I need to do this by this date. Otherwise I'm going to look really bad in front of a bunch of people. Uh, so I'll do that a lot, but the other equally strong motivation, I think, is hate. And I hate insurance companies. Because they've just like, they've been so mean to me and my friends.

Dan: Then, a few months later, another conference provided an opportunity to combine those motivations: A hackathon -- a competition where engineers and developers get a limited amount of time to put a project together. .

Holden Karau: I was like, okay, I'm gonna work on this for the hackathon.

Dan: That gave her a deadline: 30 days. Her project came in third.

Holden Karau: which, not fantastic, but, like, not terrible, you know.

Dan: Third out of more than 50. Plus, it worked! Kind of.

Holden Karau: So like it would say things like, this procedure should be covered because of the llama llama virus, and it's just like, oh, well that, that's not a real thing, but like, good try, good try, right? And it was like, you know, like, it's interesting, and like, it kind of sort of works, but it's also, it's not great, right?

Dan: Getting to the next stage would require a new approach, and some motivation — more rage — which came from a surprising source.. That's next...

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health issues. Their reporters do amazing work -- and win all kinds of awards every year. We're honored to work with them.

So Holden came out of that hackathon with something that kind of worked. Kind of.

Then she says she found herself in a fight on behalf of someone else in her household.

Holden Karau: Timbit, our dog, who's amazing, I love him, had a bunch of dental work done and the pet health insurance people were jerks about that.

Carolyn: They said he didn't need anesthesia to have teeth pulled. They rejected the anesthesia. He's 11 pounds. He can't be awake during...

Holden Karau: I don't even know if like, don't, I don't know anyone can be awake for that. And so I was like, okay, cool, how can I put the screws to them? Because you were mean to my dog. I'm used to health insurance companies being mean to me to the extent that I'm almost numb to it at this point. But like, my dog is precious and perfect. I read the plan documents because I'm a nerd. And like, this is not, Your obligation, like, you are obligated to do more. You would have to prove that this is not necessary, and I don't think you can do that.

Dan: Holden says she also read up on state regulations for pet insurance, and let the company know she'd found grounds for some potentially-serious challenges.

Holden Karau: and that, along with, uh, some other, perhaps less than polite words, did result in them changing their opinion about whether or not he should be awake for getting his teeth pulled out.

Dan: Well done. Well done.

Holden Karau: And then it s was like, okay, you know what? Yeah, I should put in the time to finish this, right?

Dan: Finish the tool to fight insurance companies.

Holden Karau: Like, I've got this thing that's like kind of half baked, but I should, I should take this over the finish line. Like, screw these insurance companies.

Dan: To do that, she was going to need some data to train her AI -- the technical term is "large language model" -- or "model" for short.

Holden Karau: Because the big problem, and part of why we got this like, llama llama virus thing, is like when you don't have data to train a model, it's bad, right? It's like garbage in, garbage out. And this is also part of why like, a lot of large models on the internet are bad, they're like trained on Reddit..

Dan: Yeah, so they learn HOW people use language. But they don't learn facts. They're like a really smart 18 year old who hasn't done the reading but is good at bullshitting. Because they know what "an answer" sounds like in this context.

Holden needed to train her model on a bunch of factual data for health insurance appeals and denials. And she found it. Thanks to the California Department of Insurance. If your insurance denies a claim, and it's regulated by the state of California, you can request an independent medical review from the Department of Insurance.

Which decides whether your procedure was medically necessary. Every decision gets published online. Describing the facts. The diagnosis. The procedure. And the reasoning behind the decision.

Holden Karau: And, like, that's the information that you want, right? You want to know, like, for a diagnosis and procedure, why is this necessary? Why should the insurance company have to cover this?

Dan: And all that information was in this data -- for many thousands of appeals, many thousands of decisions.

Holden Karau: I found the independent medical review data. And I was like, okay, cool. I can use this to make the model better.

Dan: Holden started whipping the model into shape. After about six months, she paid a developer to work up a web version -- something that you don't have to be a tech person to actually use. She bought hardware -- servers. All told, she thinks she spent maybe ten thousand dollars, plus a year of nights and weekends.

In August of this year, she had something ready to show the world.

She emailed a local reporter who had been writing about health insurance.

Holden Karau: I'm like, this local kid who's been working on this thing. It seems like it might be, like, kinda on your beat. If not, like, absolutely no stress, but, like, let me know. And if you wanna chat about it, like, I'm happy to jump on my Vespa and like, swing over and I can talk with you about it and show it to you. And, um, and she emailed me back and was like, yeah, that sounds cool.

Dan: What Holden showed that reporter -- pretty much what you see now at fight health insurance dot com -- isn't a magic wand. It doesn't do EVERYTHING for you.

You've gotta make a scan of the denial letter from your insurance company, and run it through "optical character recognition" -- turn it from an image of text into actual text. Oh, and zap personally-identifiable information -- like your name and address -- from the document. So none of that gets captured by any machines.

You can also write up a narrative with any details -- that's optional, but seems like a good idea. And you can upload your documents from your insurance company that describe your benefits. That also seems smart.

You feed it everything, and it gives you back a draft of an appeal letter -- actually, more than one, so you can pick and choose, and make edits.

So, there's some homework. And it all still looks kinda early-stage. The site isn't super-pretty. And you know how early, not-quite-officially-released software gets called a "beta" release? This one says "alpha" -- earlier than that.

So, no guarantees. But it's something.

Holden showed it to that reporter, and the result was the article that a bunch of listeners started sending me.

By the time I talked with Holden and Carolyn, about three weeks later, Holden said about three hundred people had used it. She'd been keeping an eye on how it performed.

Holden Karau: It seems to generate things that look good, right? Which, this is important to me. Um, I also get emails from people saying like, cool, thank you, thanks for doing this, um, so that's pretty rad.

But like, I assume that you get some of the same stories there's some people where they reach out, they're like, Hey, this is my specific situation. Like, what can I do? And it's often just like, I wish I could help you. But like, this is just completely fucked.

Dan: I do get those, of course. It never gets easier. [And, I should say: If you've written me and I haven't responded, don't assume it's because your situation is completely fucked. It's just as likely that I can't keep up with my email, but I REALLY APPRECIATE you writing to me, no matter what. I learn so much. Including things that don't suck, like when a bunch of you wrote to me about Holden and her project.]

When we talked, Holden said she hadn't gotten much information about whether these appeals were working. Insurance companies generally give themselves a month to respond to appeals. And it hadn't been that long.

Meanwhile, there was the question of where this project could go next.

Holden Karau: Do I do it for like, more than evenings and weekends? Or do I do it for evenings and weekends? And I don't, I don't know what the answer to that is yet.

Dan: Holden had ideas about ways it could earn income -- maybe by charging doctors and other providers, but keeping the service free for patients?

When I asked how much it would cost to take Fight Health Insurance to the next level, make it available and useful to -- you know, everybody who might need it-- and keep it up to date, and keep it reliable and stable -- she started thinking, and the numbers kept going up: a hundred thousand, two, four, five, more.

A few weeks later, Holden came to Chicago, where I live, for a conference. I went to meet her! And I got an update from her.

Holden Karau: there's some people who, who like sent in their appeals and, and things got approved, and that's pretty awesome. I'm, I'm pretty stoked with that. I guess the, the other thing is like, people seem generally positive and happy. So yeah...

Dan: Thank you for this thing that didn't exist before.

Holden Karau: when the alternative is just giving up hope, like, this is so much better than just going, like, God damn it.

Dan: She was still puzzling over how Fight Health Insurance could grow. She said when she asked a friend with experience in the startup world for advice about talking with business or venture capital folks, the friend's response was pretty immediate.

Holden Karau: What are you doing? No, no. They are gonna like, they're, hm... they're gonna lead you down the path that you are trying really hard to avoid.

Dan: Charge patients money, maybe harvest their data for who-knows-what icky purposes. Basically turn into another shark.

Holden Karau: This is probably just my naivety, but I really I have this belief that the consumer version should be free always. And so one of the tricks is finding someone that agrees with that, who's willing to give us money. Because, otherwise, It's like, nah, it's cool. But then the second question is, like, is there a way to shift the economics of denials, such that, like, insurance companies, like, it just costs them more to be dicks, right?

Dan: Assuming she finds the right kind of partner, there's a question of how Fight Health Insurance would earn income to keep itself going.

She's still interested in the idea of selling a paid version to doctors and other practitioners, and when we talked she'd heard from some folks in that world.

Holden Karau: Of the professionals reaching out, a lot of them were from the mental health field. That's something where, that's an area that I feel strongly about. Like, I would not be here if it was not for access to mental health.

Dan: Meanwhile, she says she's squeezing in about a day a week for the project, in between her full-time job and the rest of her life.

Holden Karau: It's probably not super healthy. Um, yeah. There's this whole trading sleep thing, which is, in the long run, not a great bargain.

Dan: So you've been thinking, at some point, there'll be some choices to make.

Holden Karau: Yeah, I mean realistically probably January will be when I know if I can like work on this more full time or not. Otherwise it'll

continue to exist as the thing that I do when I have free time and no one's looking too closely.

Dan: For now, Holden's taking things one step at a time.

Holden Karau: **One of the other things that I'm reminded of what one of my therapists reminds me of so frequently is that we are not responsible for fixing the world, but we must participate in the world's healing.**

Dan: Yep.

I think that for some of us, our existence is enough, but when we can, I think it's good to find the small things we can do because otherwise we would do nothing.

Dan: Can I please say, Amen.

If you give Holden's tool a try, I am SUPER curious to hear how it turns out.

If you do, I should mention: The privacy policy on Holden's site says that if the enterprise ever, say, gets sold, then whoever buys it could end up with any data you give it.

So Holden actually suggests: maybe create a temporary email address for working with her site. Just in case some shark ends up with this stuff. (It needs AN email to send you its results. The site asks for a name too. You could consider using a fake one.)

We'll have links to fight health insurance -- and to instructions for creating a temporary email address -- wherever you're listening to this.

And we'll be back in a few weeks with a brand-new episode.

Till then, take care of yourself.

This episode of An Arm and a Leg was produced by me, Dan Weissmann, with help from Emily Pisacreta -- and edited by Ellen Weiss.

Adam Raymonda is our audio wizard. Our music is by Dave Weiner and Blue Dot Sessions. Gabrielle Healy is our managing editor for audience.

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