Sarah Alger: Welcome to Proto. A podcast that explores the frontiers of medicine. I'm Sarah Alger.

Harry DeMonaco: And I'm Harry DeMonaco. Today we're exploring citizen science. What happens when everyday people contribute to medical research? We'll visit a community laboratory in Brooklyn that teaches cutting edge research techniques.

Ellen Jorgensen: When I heard about this movement where people were doing biology as a hobby, I thought, how can we possibly not support that? That's great.

Sarah Alger: And we'll look at how hospitals can find useful innovations being pioneered by their own patients.

Harry DeMonaco: Coming up on this episode of the Proto Podcast brought to you by Massachusetts General Hospital.

Sarah Alger: My co-host today is Harry DeMonaco, formerly the Director of the Innovation Support Center at Massachusetts General Hospital. Harry, welcome to the Proto Podcast.

Harry DeMonaco: Thank you, Sarah.

Sarah Alger: We usually imagine that medical innovation happens from the top-down. The government gives a grant to a research institution, the institution comes up with a new treatment, and then the treatment gets passed along to the patient. But do you see anything wrong with that approach?

Harry DeMonaco: There's really nothing wrong with that approach, but it's an incomplete vision of how the process really works. There's a large number of treatments, that are delivered by caregivers who find themselves without adequate resources, or without adequate solutions to an existing problem and have to innovate. So while the top-down approach is the traditional approach, it underestimates the innovation process by actual people in the field.

Sarah Alger: So when did you first find that there were different places in the system for innovation?

Harry DeMonaco: My introduction to the topic came back in around 2004, when I was introduced to a professor Eric Von Hippel from the Sloan school at MIT. Eric first described the concept of lead users as innovators.

Sarah Alger: Can you talk more about what you mean by lead users?

Harry DeMonaco: Sure. Lead users are folks who for a whole host of reasons, identify a solution to a common problem that has yet to be solved. So let me give you some mundane examples that I think are useful. Mountain bikes. Where did the concept of riding a bicycle through the woods, or in the mountains come from? The first assumption is, that that came from industry. And the reality is that's not the case. And the first mountain bikes were invented, not by a bicycle company, but by biking advocates and biking devotees.

It's a mundane example of the concept of lead user. They did that, not because they want it to sell bicycles, but because they had a problem, they wanted to solve. Physicians do this quite commonly. Roughly a third of all practicing physicians, have identified a new and effective treatment regimen for a troublesome condition. And our first exploration in the medical field, because I joined Eric as a researcher in this area, our first exploration was an examination of the source of new and effective drug therapy treatments with existing drugs.

Our sample strongly suggested that about 60% of new and effective uses of existing drugs, came from clinicians in the field and not from clinical researchers, or from scientists at the pharmaceutical industry.

Sarah Alger: So to switch to the patient perspective, can you give me some examples of new ideas that were generated by patients?

Harry DeMonaco: Sure. One of my favorites is that of Louis [Plant 00:03:41], who unfortunately passed away recently from complications of cystic fibrosis. For those who know about cystic fibrosis, thick tenacious sputum is a significant problem and they have to do chest physical therapy to get that sputum out of their lungs, to control breathing and reduce the likelihood of infection. Louis was an avid hard rock officiant Ottod, and recognize that when he sat too close to these very large speakers, he would cough up of large amounts of sputum.

Sarah Alger: Wow.

Harry DeMonaco: And recognized that there perhaps was something there to this vibration he was getting from the speakers. He went on to tinker with some low frequency amplifiers and eventually developed a commercial product that is actually commercially available at the moment, for the treatment of cystic fibrosis.

Sarah Alger: Wow, that's incredible. So it's kind of a strange time for science in the United States. On the one hand, you have climate change deniers, anti-vaxxers and even a resurgence in flat earthers who believe that the earth is not round. But on the other hand, you've got the March for science, which was a time when more than a million people around the world, marched in support of science funding. So given this environment, are you feeling optimistic, or pessimistic about popular views of science?

Harry DeMonaco: I guess I'm both. Sort of pessimistic that significant numbers of people across this country and probably across the world, have a somewhat dim view of science and what its capabilities are. It confuses and mystifies me to be quite honest. But by the same token, I'm rather optimistic that this democratization of science will in fact yield some rather large results, so that as long as we can maintain a political effort to maintain funding for cutting edge science, I think my optimism will remain that and the democratization process seems to be the right mix in my mind.

Sarah Alger: That's fascinating. Thank you. Coming up, we'll visit a laboratory in Brooklyn at the cutting edge of the citizen science movement.

Harry DeMonaco: You're listening to the Proto Podcast, a production of Massachusetts General Hospital.

Sarah Alger: Medical research has always been one of those fields restricted to the very few. Researchers have to go through years, sometimes more than a decade of specialized schooling. And the laboratories where they do their work, are filled with complicated and expensive machines that aren't easy to come by.

Harry DeMonaco: But there's a movement underway, to make the spirit of inquiry and the hardware at the heart of biomedical research, more widely available. Community laboratories allow anyone with a healthy curiosity about the frontiers of medical science, to learn about them.

Sarah Alger: Genspace in Brooklyn was the very first of these spaces. The nonprofit lab offers hands-on classes about biomedical research. And they make their equipment available to everyday people for a small fee, so that they can work on their own research projects. Last year we featured one of the Genspace projects in Proto magazine. Volunteers fanned out across New York City and swapped the surfaces of the streets and subways. They sequenced the DNA they found they're, creating a citywide genomic portrait. We send producer Bradley Klein to Genspace to hear more.

Bradely Klein: Genspace is upstairs in a nondescript industrial building, near one of the busiest intersections in Brooklyn, where Flatbush Avenue meets Atlanta. It seems an unlikely spot for a laboratory, but then Genspace is unusual in a lot of ways. This so-called community lab, is open to anyone. A place to teach the public how to conduct cutting edge science right here with their own hands. Walking inside, Ellen Jorgensen meets me in an entryway that is dusty and crowded with old building materials. Jorgensen co-founded the lab seven years ago.

Ellen Jorgensen: Well, we can actually go into the lab space. And this is really the first lab space that we set up, is this little.

Bradely Klein: And it is a little room built into the middle of the enormous open loft space. The lab proper is about 12 by 20 feet and all the walls are see-through.

Ellen Jorgensen: Our very eccentric and lovable building owner asked us, "What kind of space do you need?" And we said, "Well, we want to reassure everyone that the biotech that we do here, is for useful, peaceful purposes. And so the more transparent we are, even literally the better." And we came back three days later and he and a friend of his, who I call the kamikaze carpenter, had put together this glass rectangular space out of old sliding glass doors and windows that they'd salvaged from somewhere.

Bradely Klein: So you're actually living in a glass house?

Ellen Jorgensen: Yes. And the lab benches are all repurposed stainless steel restaurant counters.

Bradely Klein: The lab space is clean and tidy, but crowded with equipment. Experiments are in progress all around. And just outside of the lab in the main loft space, a barely controlled chaos reigns. The basic kitchen and the furniture, would look at home in a college dorm. And in every free corner, there is the machinery of biological research.

Ellen Jorgensen: So we have all the equipment that you would need for molecular biology. So this device here is called an incubator shaker. We have an analytical balance. We have a clean hood for doing work that we don't want to get contaminated. These are autoclave. This is what steam sterilizes things. It probably started life in a dentist's office. And we got it on eBay a long time ago.

Bradely Klein: Jorgensen says that Genspace began with four people sitting down in 2009, each with slightly different goals.

Ellen Jorgensen: Myself, a career molecular biologist, a science journalist, and two students. The students' motivation was, they couldn't find a professor that would take them into their lab and let them do their own project, not just do something that was the professor's work.

Bradely Klein: And Jorgensen says, she had been thinking about how to counteract what she saw as a growing skepticism about science, among the general public.

Ellen Jorgensen: It was very disturbing to me to see that science funding was being cut. And that I didn't think that scientists had the same status as they did when I was growing up in the '60s. And we would all go into a room and watch the rockets get launched and everything. And it was yey science. And this profound kind of anti-science, anti-tech attitude, it was very scary to me. And so, when I heard about this movement where people were doing biology as a hobby, I thought, how can we possibly not support that? That's great.

Bradely Klein: Jorgensen describes herself as the kind of person who likes to make things happen. And things are happening at Genspace. Individuals have their own research projects underway. Classes meet regularly. They include the slime mold workshop, the biotechnology crash course, and genome editing with CRISPR- CAS9.

Will Shindel: And then we'll take both of those and put them into our yeast.

Bradely Klein: That last class, teaches techniques on the very cutting edge of biotech, which allows scientists to modify the genes of a living organism, in this case, yeast.

Will Shindel: And so, everybody is going to claim your cultures. And you're going to transfer one and a half milliliters of culture into one of the-

Bradely Klein: Will Shindel teaches the CRISPR class. He's also the lab manager at Genspace. and he says, he feels right at home in the do-it-yourself ethic that's at work here.

Will Shindel: A lot of the community labs do have this sort of rugged feel that they've sort of been put together using what was available. Especially because a lot of community labs just don't have a lot of funding. And so, we sort of have to make do.

Bradely Klein: This evening's class is made up of about a dozen students, mostly in their 20s and 30s with an even split between men and women. They came to the class with a wide range of scientific training. From post-doc, to no science since high school. And their motivations for taking the class, are just as diverse.

Will Shindel: It is always a wide range and I'm always a little bit surprised by their range. I've had teams of people who were sent from work, to learn these skills for their job and who paid on corporate credit cards. I've had high school students, who just were really excited about biology and couldn't learn about CRISPR in their schools. I've had a fair number of DIYers and just people from the general public, who are interested and just want to understand what this buzz word they keep hearing about is.

Bradely Klein: It's nearing 10:00 PM on a weeknight and many of the students work full-time jobs.

Will Shindel: So we're actually going to go ahead and plate our staff.

Bradely Klein: If all goes to plan, the students will remove their Petri dishes of yeast from the incubator in a couple of days, and find that they now glow under fluorescent light. The genome of the yeast, now contains jellyfish DNA added using CRISPR.

Ellen Jorgensen: I really like the idea of people participating hands-on. And the word I like to use, is demystifying the technology.

Bradely Klein: Jorgensen says, that providing people with this kind of experience, helps to balance the science's scary scenarios in the media. When people see a movie about a lone bio terrorist, or read about genetically engineered designer babies. The pictures they conjure she says, are often incomplete.

Ellen Jorgensen: These technologies, often you'll hear people say, "Well, I can't understand them." It's like somebody is doing something that's highly technical that you don't understand, and it's out of control, your control and it affects you. And that's always a scary thing. So this is a way of people at least being able to understand it better.

Bradely Klein: And genetic engineering in particular, will continue to be at the center of a global debate. A better grounding in the science. Including the kind of learning happening at Genspace and labs like it around the world, may help people make more informed decisions. For the Proto Podcast. I'm Bradley Klein.

Sarah Alger: I'm joined again by Harry DeMonaco, the former Director of the Innovation Support Center at Massachusetts General Hospital. In the short time since we produced our profile of Genspace, the nonprofit community lab has undergone a few changes. Ellen Jorgensen remains involved, but has stepped down as Executive Director. And her co-founder Daniel Grushkin has moved into that role. Also, the lab has moved from its original space, but remains in Brooklyn, New York. So Harry, what do you think of places like Genspace?

Harry DeMonaco: I think they're a fascinating idea. Probably an outgrowth from the DIY experiences and other domains. But what they're really doing, is linking people with an idea or people searching for a solution, with domain experts. They're also linking the domain expert with available technology. And that's likely to yield very great results downstream. Not just from the philosophical perspective, or not from the educational perspective, but simply from the innovation perspective.

Sarah Alger: So to get to CRISPR specifically, there's an important update on the CRISPR research we heard about. Gene editing kits are widely available to the public, but other CRISPR kits have targeted people who would like to try to modify their own human DNA. In late November, the FDA put out a strongly worded statement warning against any kind of kit that promotes human experimentation. They said, "The sale of these products, is against the law. FDA is concerned about the safety risks involved."

The lab manager at Genspace told us that they do not advocate self-medication, or allow self- experimentation. But I think this brings up the broader question of risks. What are the risks of untrained scientists and how do we manage that?

Harry DeMonaco: Innovation by definition, is a messy and chaotic process and is as likely to produce negative, as well as positive results. So it's not sufficient simply to provide people with technology. Here's a CRISPR kit, go play with it. People need to understand that science is complicated. Innovation is messy. And that combination can result in really negative outcomes. So I don't have any issues with people doing DIY anything, but they need to do it with wide open eyes.

And I think part of the role of the scientist, should be to make sure that people understand both the positive and negative aspects of any technology. And if you're going to make technology available to the public, you better make well sure that people understand the positive and negative attributes of that technology.

Sarah Alger: So to bring it back to the medical arena, how can physicians and hospitals promote more education and involvement in research?

Harry DeMonaco: I think there're two levels to this. The first is, institutions promoting the innovation process among their staff, whether they be clinical, or nonclinical staff promoting the concept of innovation. Lots of organizations put innovation somewhere in their logo, in their mission statement, but very few actually follow up on the concept of promoting innovation. So I think organizations need to make it clear, that innovation is a priority and that they to democratize the process that is, the innovation process is open to anyone within the organization.

The second part of that is, innovation on the part of patients. Patients with chronic illness innovate, the literature strongly supports that fact, but most clinicians don't understand it. And I think simply asking patients, how is it that you're doing well, is a very simple question and it can be asked. To identify what the public health people would call, the positive deviance. The people who are doing better than you would expect them to be doing.

Because many of those people are doing sort of interesting things. Let me give you a mundane example. Folks with obstructive sleep apnea, have a breathing problem at night. They need to use a continuous airway pressure device, to keep the airways open at night, to prevent airway collapse and hypoxia and anoxia. A group of folks with obstructive sleep apnea, is now using something called the didgeridoo. An Australian Aboriginal instrument, to improve their obstructive sleep apnea.

I doubt that most physicians would ever ask their patients, who seem to be doing well with their sleep apnea, whether they're playing the didgeridoo or not. That's not ... And I doubt that most patients would in fact admit to playing the didgeridoo as a treatment for sleep apnea. So I think the simple answer is, ask people.

Sarah Alger: So I have to ask, what is it about the didgeridoo that helps?

Harry DeMonaco: In order to play the didgeridoo, there's something called circular breathing. So they're inhaling and playing the instrument simultaneously. This circular breathing process, strengthens the musculature in the back of the throat, so that it doesn't collapse.

Sarah Alger: Well, who knew?

Harry DeMonaco: Apparently people with ... Some people with sleep apnea did.

Sarah Alger: So can you tell us more about what you're doing now? You're looking for innovators right?

Harry DeMonaco: Since retiring from the MGH, I've gone back to the Sloan School at MIT as a visiting scientist. And along with a host of folks from Europe and within the United States, conducting research around the lead users, my interest is primarily in the medical field. I've become fascinated, not only with lead users as innovators in the medical field, but now lead users as researchers. And I think that represents a new frontier for the innovation process.

Sarah Alger: Well, that sounds like fascinating work. And thank you for joining us today, Harry.

Harry DeMonaco: Thank you. It was a great pleasure.

Sarah Alger: And listeners, thank you for tuning in to the Proto Podcast.

Harry DeMonaco: Today's podcast was produced by Jason Anthony, Bradley Klein and Emily Silver.

Sarah Alger: Thanks also to our technical director, Adam Keller. You can find the Proto Podcast on iTunes and Stitcher. Please subscribe. And can also follow Proto on Facebook and Twitter. See you next time.