Using social media to find great sources

Roxanne Khamsi @rkhamsi
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Who the heck am I?

Science writers needs to reach highly specialized sources

1. i.e. do you need to reach an infectious disease researcher or evolutionary virologist?

2. is this source familiar with the niche experiment and/or related methods?

3. do you need to reach a patient with an ultra-rare medical condition?

Traditional ways to find sources

1. PubMed (or Google Scholar)
2. Research paper references (related to step 1, but this is a deeper dive)
3. Press releases
4. Patient advocacy groups
5. Professional societies
6. University media teams
7. Also… don’t forget: ClinicalTrials.gov

A new way to find sources: social media

POLL 1: Do you currently use social media as a way to find sources?

- Yes
- No

A new way to find sources: social media

POLL 2: If you DO use social media to find sources, which one do you use most?

- Twitter
- LinkedIn
- Instagram
- Facebook
- YouTube
- Other (TikTok, Snapchat, Reddit?)

Reporting on medical foods for Phenylketonuria (PKU)

- an inborn error of metabolism where individuals don’t metabolize the amino acid phenylalanine well
- Expensive “medical foods” made without phenylalanine given to avoid harm
- But not always covered by insurance, especially for adults
- Looking for an adult with PKU

YouTube: How I found Katie

Photo: Jane Hu

The outcome

Rethinking the formula

Camino Foods

Health insurance covers drugs approved by regulatory agencies, but it often doesn't pay for the products known as 'medical foods' needed to keep individuals alive and well. This lack of reimbursement means that many who cannot afford these life-saving diets suffer brain deterioration and disability—or worse. **Roxanne Khamsi** reports on the battle for medical foods and how it could affect the treatment of diseases as diverse as osteoporosis and Alzheimer's.

Katie Maguire does her best to explain the kind of sandwich she wants. Looking up from her seat at Balthazar, a bustling restaurant amid the cobblestone streets of Manhattan's trendy SoHo district, she smiles at the waiter and asks for a chicken club—one without any chicken or bacon. "Can I just have a sandwich, just lettuce and tomato?" she asks. Some confusion ensues, and ultimately she tries a different description: "A BLT with no bacon." The waiter finally nods his head and scribbles down the order.

Although Maguire eats like a vegetarian, she does not do so for philosophical reasons. Her reason for skipping meat is a genetic condition whereby her body cannot tolerate more than a few grams of proteins each day. At age 28, Maguire has never eaten a hamburger.

Because Maguire can't process protein normally, she travels with a stash of special products to keep her well fueled. They contain carefully formulated mixtures of the protein building blocks known as amino acids that her body can tolerate. Without these special formulas, adults who have the disorder that affects Maguire, known as phenylketonuria, or PKU, develop cognitive problems ranging from short-term memory loss to hallucinations. Women with her disorder who forgo these tailored sources of amino acids give birth to babies with permanent developmental handicaps, including severe mental retardation.

Yet, even though Maguire relies on amino acid formulas to avoid cognitive deterioration, the US Food and Drug Administration (FDA) does not classify such products as drugs. Instead, they are considered 'medical foods.' That key distinction has made it much harder for Maguire, and others like her, to obtain insurance coverage for these expensive products, which can cost upward of $10,000 a year.

Michael Watson, executive director of the American College of Medical Genetics and Genomics (ACMG) in Bethesda, Maryland, describes the realm of medical foods as a "regulatory no-man's land," a confusing gray zone of peculiar rules. For example, the FDA does not ask for a new drug application, or NDA, for medical foods, nor does it require the extensive clinical trials necessary for drug approvals. But the agency does stipulate that medical foods should be made according to guidelines known as good manufacturing practice and obtained with the consent of a doctor. (A third product category, known as 'dietary supplements,' requires no such physician supervision.)

Whether an item gets classified as a drug or a medical food is not always predictable—or permanent. "It's a mess," Watson says. "The FDA doesn't know where to draw the line."

The ambiguity around the regulation and reimbursement of medical foods is a growing problem—and not just for the tens of thousands of people in the US living with so-called 'inborn errors of metabolism,' including the estimated 14,500 individuals with PKU. There are now medical foods available for conditions ranging from heart disease to osteoporosis to HIV/AIDS. And the list of products is increasing: in 2009, the FDA gave the green light to a new medical food known as Axona for people with Alzheimer's disease.

Maguire, a first-grade teacher, ultimately prevailed in obtaining reimbursement for the formula she needs thanks to the help of the staff of then–New York attorney general Andrew Cuomo (now governor of New York). But others aren't as lucky. They give up on fighting their insurance companies or lack coverage to begin with, and they simply cannot pay out of pocket. "A lot of people can't afford these special diets," says Alex Kemper, a pediatrician at the Duke University Medical Center in Durham, North Carolina.

Those who are earning too much to receive government assistance yet are too poor to pay out of pocket suffer the most, according to Cynthia Le Mons, executive director of the National Urea Cycle Disorders Foundation, who lost both a sister and a son to a metabolic disorder known as ornithine transcarbamylase deficiency, which can prove particularly lethal in infants. "If you're a family where you fall into that donut hole, your child does not have a good outcome," she says. "And that just should not happen in the United States of America."

Jorge Rio

Teaching hope: Katie Maguire has fought for reimbursement and won.

Happy anniversary

The fact that Katie Maguire is a healthy adult today is in large part thanks to Robert Guthrie, a physician-scientist with a love of sailing and a penchant for sleeping in the lab, who developed the newborn screening test for PKU in 1957. This year marks the fiftieth anniversary of the passage of state laws in Oregon and Massachusetts to mandate this test for all babies—the first such requirements of now-widespread newborn screening in the US.

The assay works by gauging the levels of the amino acid phenylalanine in the blood. At some point soon after she was born, a doctor or nurse pricked Maguire's heel to take a blood sample. A lab analysis based on Guthrie's method then showed that her phenylalanine levels fell above the normal range of 0.5 to 2.0 milligrams per deciliter of blood, indicating a malfunction in her body's version of the liver enzyme known as phenylalanine hydroxylase (PAH).

About 1 in 50 people in the US carry a mutation in the gene for this enzyme, but a second, functioning version keeps them healthy. By contrast, individuals with PKU have two faulty copies of the *PAH* gene, meaning that they have no working enzyme to convert phenylalanine into tyrosine, another amino acid. Here's the rub: tyrosine is a precursor for neurotransmitters such as dopamine—crucial for normal brain maturation and mood regulation. If untreated, a baby born with PKU will suffer severe mental retardation and other developmental problems.

Virtually every known protein in food contains a phenylalanine component. So doctors must immediately start babies born with PKU on a phenylalanine-free formula made up of other amino acids, including tyrosine. Evidence is emerging that individuals need to stick to this regimen for their entire lifetimes. One study has found that people with PKU who discontinue the special diet by age 10 have a 12-point drop in their IQ by adulthood, on average[1]. These individuals are also at risk of developing delusions and other symptoms similar to schizophrenia or bipolar disorder, often necessitating antipsychotic drug treatments or tranquilizers.

Staying on the diet is no easy task, though. For one thing, the smell of the formula is pungent, and it has the tang and consistency of sour milk. The liquid, and the foods modified to be low in protein for people with PKU, leave a long-lasting bitter taste at the back of the tongue that water does not quickly wash away. It's no surprise why people like Maguire drift off of the diet in their early teens, when the frustration of carrying and consuming the unpalatable and odorous formulas interferes with the pressures and norms of high school (never mind matters related to cost).

In the teenage years during which Maguire gave up on consuming formula, her family watched as her mood—and her grades—deteriorated. She was prone to emotional outbursts and struggled to achieve Bs on her report cards. Just before heading to college, her doctor gave her a tough talk, urging her to get back on the diet. The conversation shook Maguire out of her complacency, and as a college freshman she transitioned back onto the formula regimen.

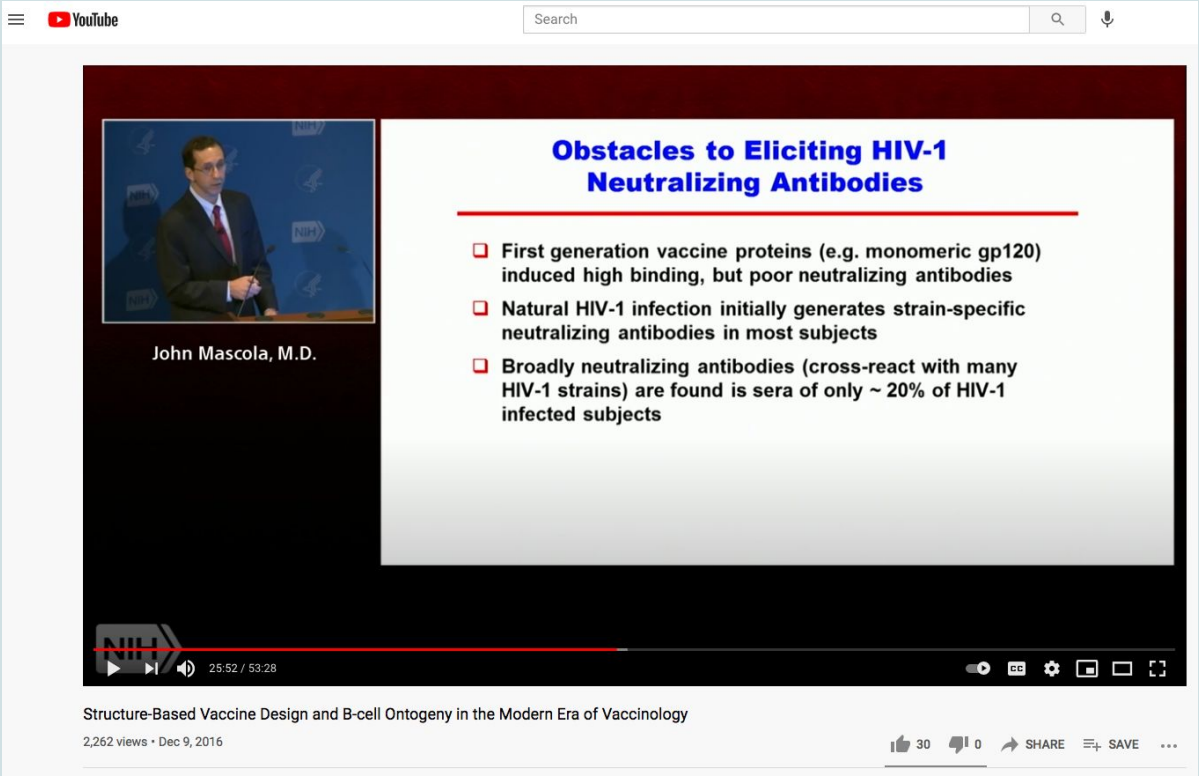
As the physician had predicted, her grades started to improve. "I started feeling better. I was able to think back and be like, 'Oh my God, I was like *that*?'" recalls Maguire, her eyes widening. "You know, once you're out of that fog, you realize what it was like to be off diet. When you're going through it, you don't have any idea."

Paying the price

The annual wholesale cost of basic formula for an adult on a 2,000-calorie-a-day diet is more than $8,500 (ref. 2). However, this amount excludes the cost of their other dietary needs, and price markups of as much as 300% at the point of distribution are common. What's more, foods modified to be low in protein—so that they are safer for people with PKU to eat—are generally priced two to eight times higher than their regular supermarket counterparts, and they usually have associated shipping costs. Whereas a run-of-the-mill loaf of bread costs less than $3, the same amount of bread specially manufactured for people with PKU can cost more than $13.

Nutritionists and doctors have numerous stories of paying out of pocket to help families that cannot afford formula or modified foods. "I've walked to the drugstore to buy supplemental formula for patients in the past," says Jerry Vockley, chief of medical

YouTube: An update - how lectures lead you to sources



(and Vimeo….) - using videos to see the experiment

The outcome

A year ago, in January, when John Mascola heard that a new coronavirus had been detected in an animal market in Wuhan, China, he left everything at his desk on the fourth floor of the US government's Vaccine Research Center and walked up one flight of stairs to the office of a longtime colleague, Nicole Doria-Rose. Felicitously, Mascola, who is the center's director, had been working on ways to immunize people against coronaviruses. A vaccine against this new bug, soon to be known as SARS-CoV-2, was the first priority, the only surefire way of halting the growing pandemic. Mascola and Doria-Rose, an immunologist, go way back. And they hoped there was another approach that might also contribute to the cause, one they'd been chasing for more than a decade. They wanted to find a monoclonal antibody.¶ Everybody knows about vaccines, which train the immune system to fight invaders, but monoclonal antibody drugs are less familiar. To develop them, scientists must generally find a person whose body has done better than most at fighting a disease; scour their immune system, needle-in-a-haystack style, to locate the most effective antibody; and use it as a blueprint to fashion a drug for people who are sick. When former New Jersey governor Chris Christie came down with Covid-19 in early October, he was given an experimental monoclonal antibody drug made by Eli Lilly. That treatment—with the exceedingly unpronounceable name bamlanivimab—can be traced directly back to the conversation Mascola had with Doria-Rose at the start of the pandemic. The Food and Drug Administration approved it for emergency use on November 9. Similarly, a combination of two other antibody drugs, made by the company Regeneron, was given to then-president Donald Trump when he contracted the virus. Like the vaccines made by Pfizer and Moderna, these monoclonals were deployed in record time.

Mascola became interested in monoclonal antibody treatments in the early 2000s, not long after he joined the Vaccine Research Center in Bethesda, Maryland. Back then, if you studied infectious diseases, as Mascola did, you were probably trying to understand HIV. It had killed an estimated 22 million people and seemed unstoppable. HIV wasn't as easy to contract as a respiratory illness—bodily fluids such as blood or semen, not the air you breathe, are the media for transmission—but once the virus took hold, its passage through the body was relentless. Patients suffered an array of painful symptoms, including mouth ulcers, skin sores, and pneumonia, before succumbing to a total collapse of the body's defenses. But there was a small percentage of people who held out longer; they made stronger antibodies against the virus.

Other researchers had shown it was possible to isolate one of those superpowered antibodies, and starting in 2006, Doria-Rose joined Mascola in setting out to catalog the immune systems of exceptional HIV fighters. They first had to find HIV patients who had been infected for years but had remained relatively healthy; then, from each of those people, they had to collect and analyze samples of blood to know if the donors were among the estimated 1 percent of people with the virus who made highly effective antibodies. The blood was processed through machines that quickly separated out antibody-producing cells, called B cells, which were then deposited into the tiny wells of a tray resembling a Keebler elf's muffin tin. From there, Mascola's team would capture the antibodies produced by each cell cocooned in the individual wells.

Next, they tested the antibodies for strength. They took a line of specially engineered human cells, designed to glow green when infected with an HIV-like virus, and bathed them in antibodies. Then they exposed the cells to the virus. If the antibody was a dud, the infected cells would glow; if it had superpowers, they wouldn't. Most of the time the mixture glowed. This went on for months; hundreds of samples failed.

But one day in 2009, while Mascola was sitting in the laboratory break room about to eat a sandwich, one of his scientists bounded toward him with a big smile on her face: They'd found the no-glow they'd been looking for.

That antibody came from a man known as Donor 45. Doria-Rose, who met with study participants when they came in for their regular checkups, says that Donor 45 was an exceedingly private gay Black man in his sixties from the Washington, DC, area. They dubbed the antibody VRC01—the first from the Vaccine Research Center.

It took almost a decade to develop a drug from this antibody and set up a clinical trial to make sure it was safe and effective. Other HIV researchers going down different roads came up with antiretroviral drugs—the famous "triple cocktail"—that effectively treat and prevent HIV infections by interfering with the virus's ability to make copies of itself. The crisis wasn't over. People still contracted HIV, but with the antiretrovirals they could live mostly normal lives. As access to those drugs expanded, the effort to use antibodies to make HIV drugs became less urgent. It plugged along, a clinical trial was started, but not as many people were paying much attention.

And then came Covid-19. That day in January 2020, Mascola immediately saw that everything he and his colleagues had learned from studying HIV antibodies could be mobilized to treat the new pathogen. It would be "the culmination of a life's work," he says.

Mascola is a restrained kind of guy. He communicates with economy. "When he puts one exclamation point in an email, you know you have done something phenomenal!" Doria-Rose wrote to me. So when he came to her office, they got straight down to business. Doria-Rose began asking team members to fire up the cell-sorting machines and fill the tiny muffin tins and engineer test cells that glowed. They overhauled their work schedules and went all in.

Getty Images (all images source)

YouTube as a way to find sources - tips

1. Find patients’ stories and learn their point of view
2. If appropriate, follow up with online research to find their contact information
3. Explore topics to find lectures with articulate scientific sources
4. Verify the scientific authority of the sources on YouTube (on PubMed)
5. If you are having trouble picturing an experiment, find it on YouTube/Vimeo

Reporting positive tests for Covid-19 months out

- some people continuously test positive for Covid-19 many weeks out from their first positive test
- But it is rare
- As a reporter, it’s difficult to find a person with this situation

Facebook: How I found Natalie

Facebook: Reach out to group moderators

The outcome

The Mystery of Why Some People Keep Testing Positive for Covid-19

Inside the debate over how long the coronavirus lasts in the body

Roxanne Khamsi Jul 28, 2020 · 15 min read

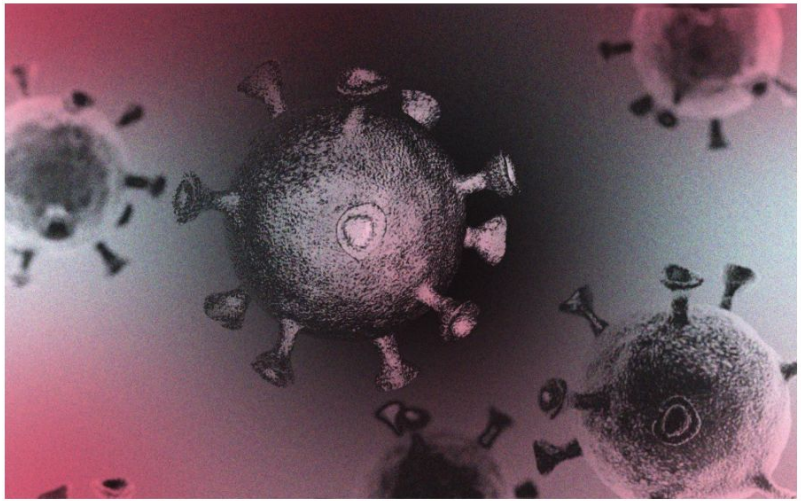


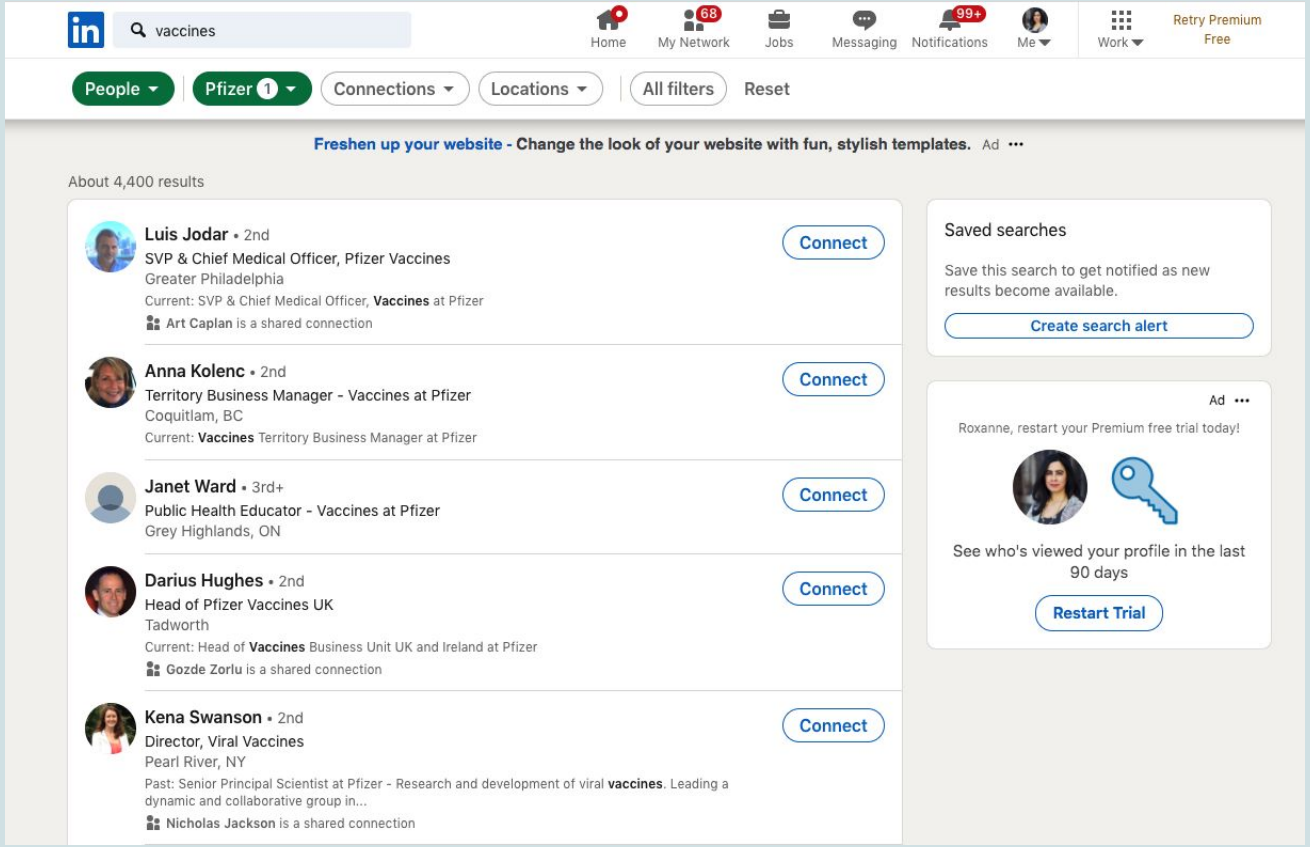
Photo illustration, source: Dowell/Getty Images

On July 22, Natalie Forouzad was dreaming of finally leaving the basement of her parents' house in North Carolina. She used to begin most days with a six-mile run, but for the last 43 days, she hadn't ventured much past the basement walls. Her ordeal began in early June

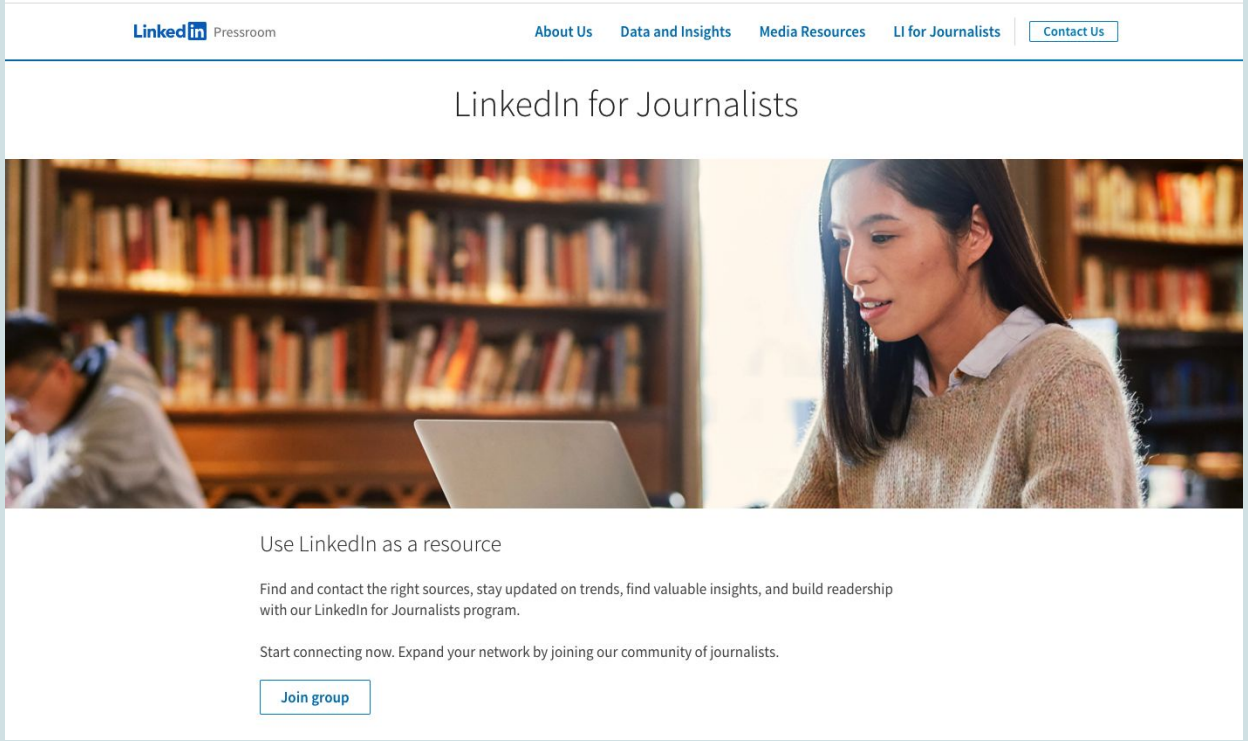
Facebook as a way to find sources - tips

1. Be conscious that people might not expect to hear from a reporter this way
2. Approach with respect
3. There are many collective groups to tap into
4. Moderators of closed Facebook groups can help you reach their members
5. Reach out to moderators with direct messages

LinkedIn: Using “People Search”



LinkedIn — special resources for journalists



LinkedIn — special resources for journalists

Save the date: LinkedIn for Journalists webinar

Our introductory webinars happen in March, June, September, and December.

March 18, 2021

Our next webinar will take place on
March 18, 2021 8:00 AM PT / 11:00 AM ET

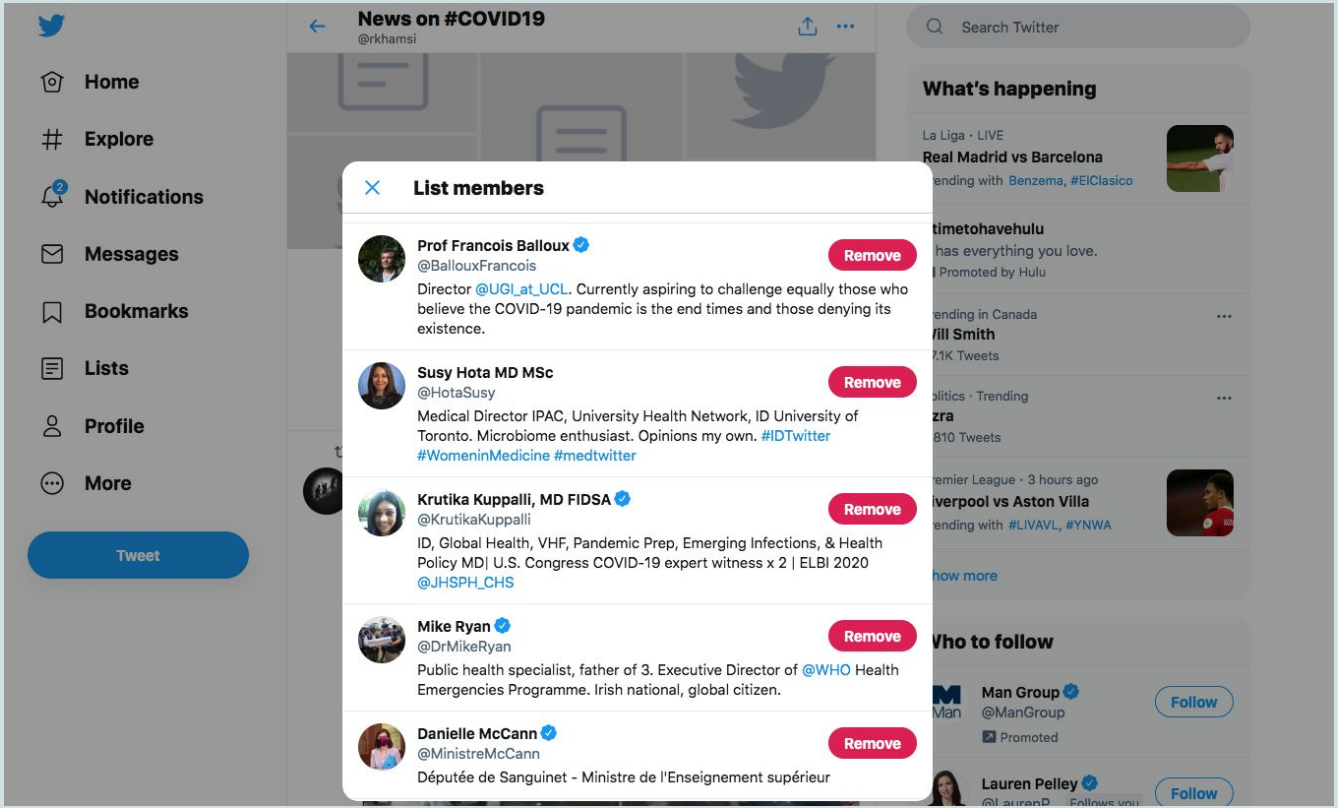
Applications are closed.

LinkedIn as a way to find sources - tips

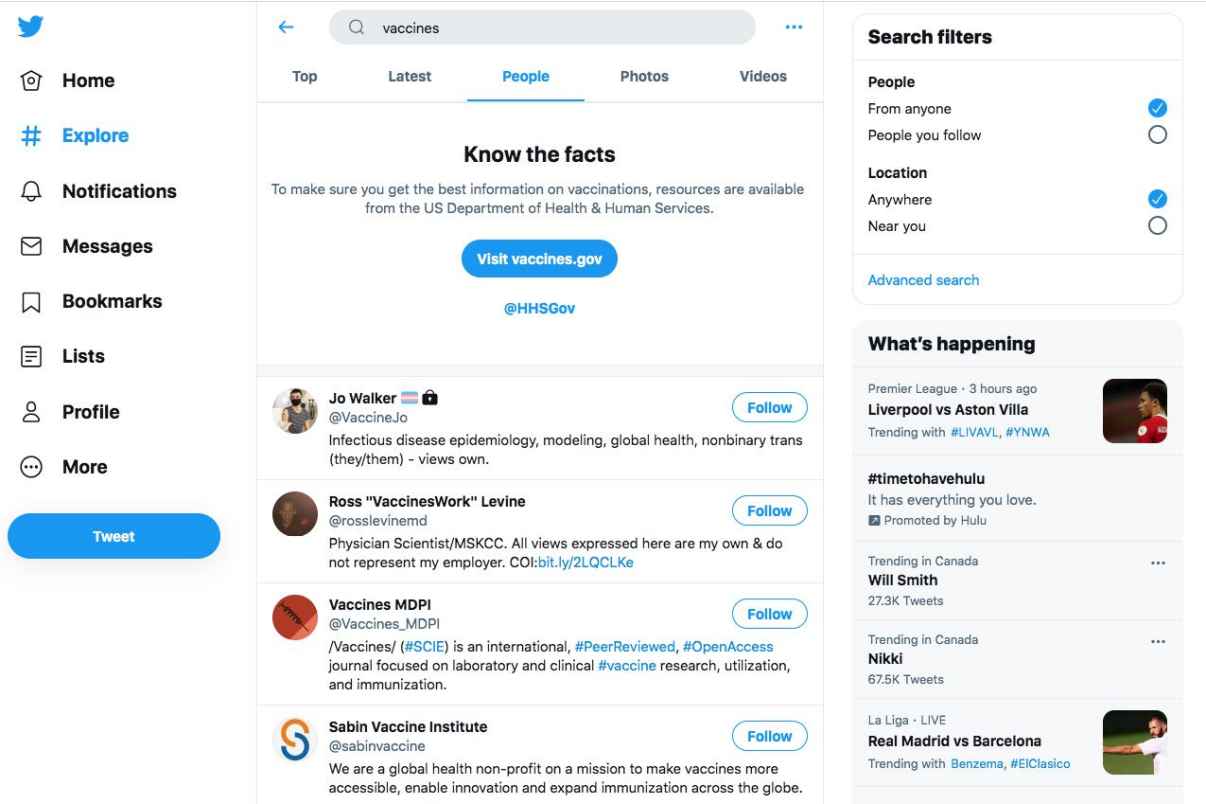
1. Don’t just ‘connect’ with a source you want to reach, message them.
2. Use the ‘people search’ to find individuals, especially in industry
3. LinkedIn is a great way to find *former* employees who can say more
4. Consider attending seminars for journalists held by LinkedIn for more info

The big one… Twitter

Twitter tips: Make lists to aggregate sources on topics



Twitter tips: Use the ‘people’ function in search (but vet!)



Twitter tips: Drop in a link of a paper — reverse search

nejm.org/doi/full/10.1056/NEJMoa2104840

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Thrombotic Thrombocytopenia after ChAdOx1 nCov-19 Vaccination

Andreas Greinacher, M.D., Thomas Thiele, M.D., Theodore E. Warkentin, M.D., Karin Weisser, Ph.D., Paul A. Kyrle, M.D., and Sabine Eichinger, M.D.

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27 References

April 9, 2021
DOI: 10.1056/NEJMoa2104840

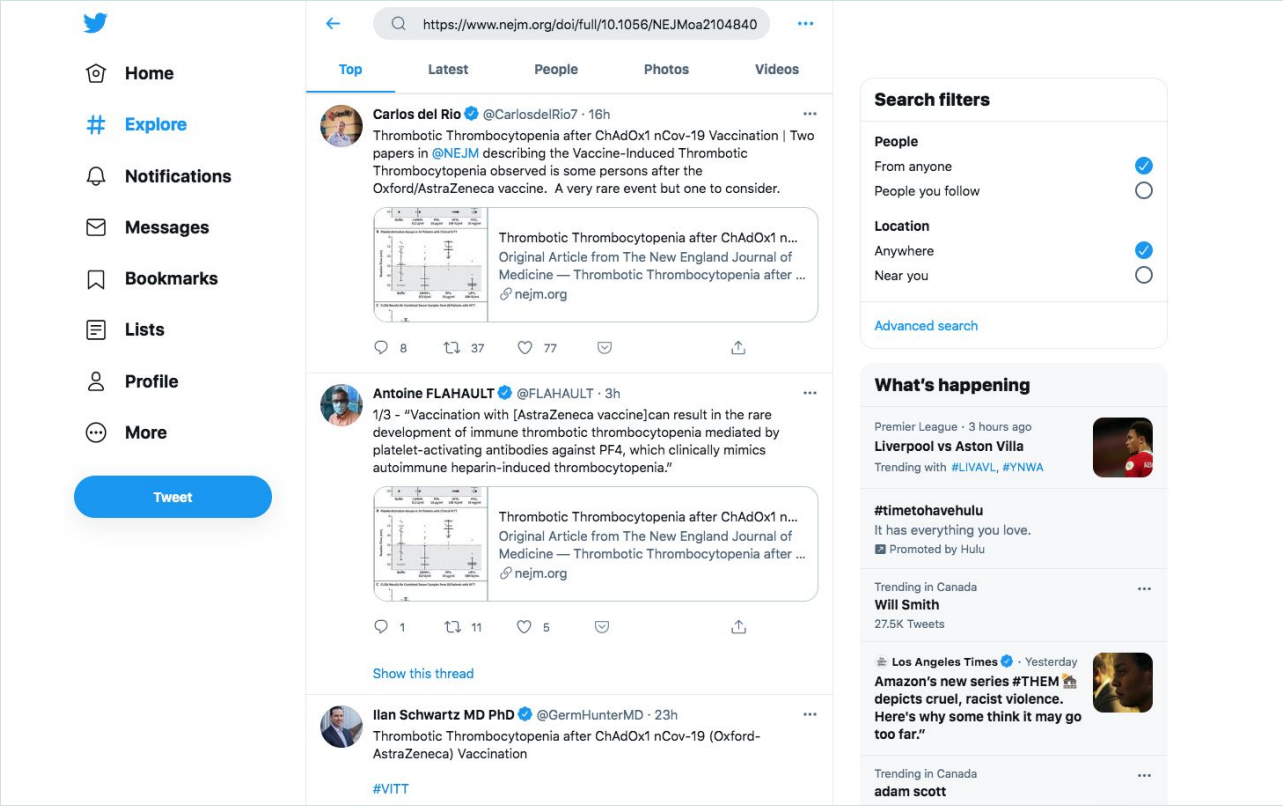
Abstract

BACKGROUND
Several cases of unusual thrombotic events and thrombocytopenia have developed after vaccination with the recombinant adenoviral vector encoding the spike protein antigen of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) (ChAdOx1 nCov-19, AstraZeneca). More data were needed on the pathogenesis of this unusual clotting disorder.

Related Articles

ORIGINAL ARTICLE APR 9, 2021
Thrombosis and Thrombocytopenia after ChAdOx1 nCoV-19 Vaccination
N.H. Schultz and Others

Twitter tips: Drop in a link of a paper — reverse search

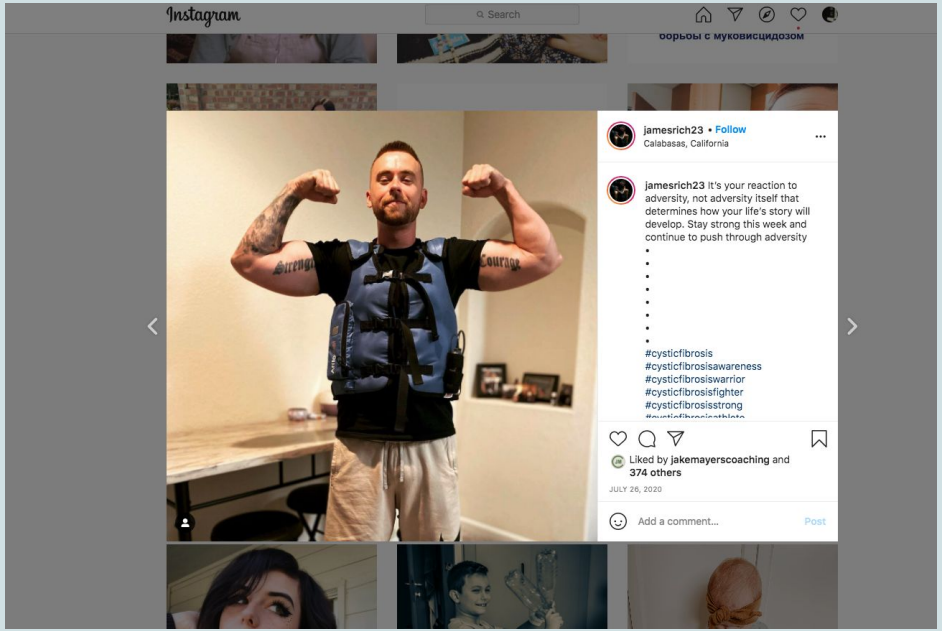


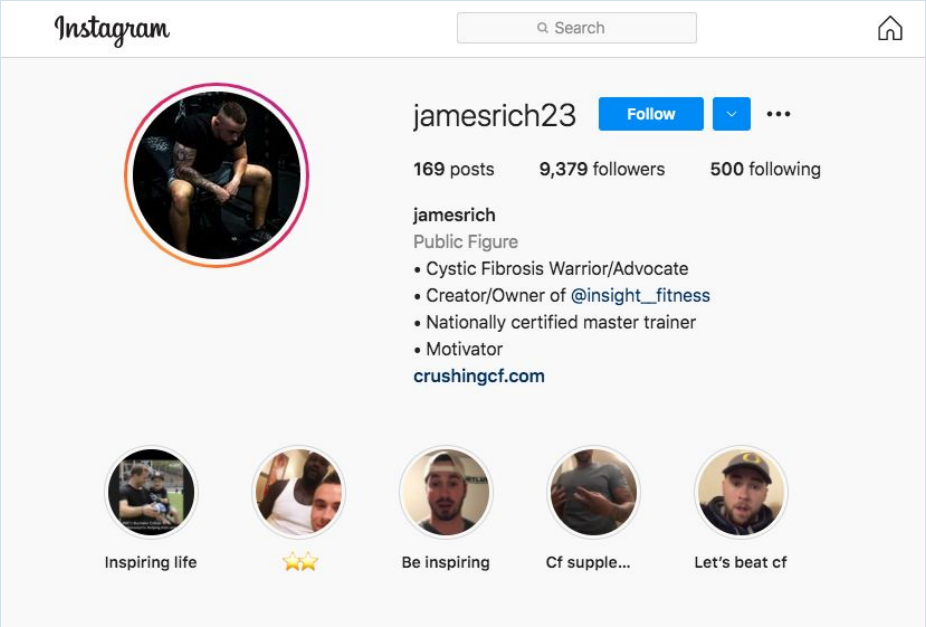
Twitter as a way to find sources - tips

1. Make lists of people — lots of them — on topics you are reporting
2. Look at the lists of the people on the lists you are making (meta!)
3. Search the topic you are reporting on and look at ‘people’ search result
4. Drop in the URL of a paper you are writing about to see who is discussing it
5. Not everyone on Twitter has the credentials to be a source — vet carefully!

Coda… Instagram

Instagram and the power of hashtags (#) #cysticfibrosisfighter





A new way to find sources: social media

POLL 3: After listening to these examples, which social media tool are you now most likely to try for the first time in the next year to find sources:

- Twitter
- LinkedIn
- Instagram
- Facebook
- YouTube
- Other (TikTok, Snapchat, Reddit?)

Final points

1. Supplement your traditional sourcing tools with social media tools
2. Social media can be a great way to find patients eager to share their stories
3. When searching on social media look at ‘people’ search result
4. Use specific hashtags to narrow your search; or combined search terms
5. Vet carefully, and try to find sources who are most specifically qualified

Thank you! Questions? Comments?

Let’s talk.

And if you need to find me on Twitter, I’m at **@rkhamsi**...