Infodemiology. Too much. Not enough.

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Proem 00:53

Looking at my brain scan creeps me out – fascinated, but creepy. My neurologist prefers that I get a scan every other year, but I ask, ‘what will you do differently depending on the results?’ “Nothing really to do’ he says, ‘you’re on the strongest infusion.’ So, I put it off. A few weeks ago, I relented and lay in that crashingly loud, claustrophobic cylinder for a scan. Last week he shared his screen on the virtual visit comparing the two most recent scans—definite progress in cervical spine lesions. No surprise, I know I’m progressing. My left leg is weaker; my balance deteriorates; I need to keep my brain engaged in walking for more than five minutes. Now I can see the culprit. Yuck. My neurologist spent almost an hour with me. Did I want to continue the twice-yearly infusions ($100,000 per dose)? What if I get COVID-19? Will the immunosuppressant effect my disease course? What impact will the infusion have on the effectiveness of a vaccine? He’s OK with either decision: continue or stop. I couldn’t make a decision. I don’t understand the pathophysiology. I hate researching myself. Some ePatient I am. I trust my neurologist. He would continue the infusion. My brain hasn’t shrunk, I have minor side effects, my insurance pays, we’ll manage the vaccine when we know more. So, I’ll continue the current course. We collaborated, I made an informed decision based on the information he shared, and I didn’t vet anything. I trust him; I’m doing what he recommends, full stop. That said, he suggested I take a muscle relaxant to reduce my leg cramping. No way - more fatigue, less mental acuity – no way. Thanks, but no thanks. I don’t need to research anything. Making medical, health choices – tough in the best of circumstances. My life of privilege, clinical background, collaborative, bright team, set me up for success. Informed, shared decision-making isn’t this easy for most.

Introducing Janice McCallum 03:32

My dear friend, Janice McCallum, is a marketing strategist and management consultant to healthcare publishers, digital health companies, and investment firms in the health and life sciences sectors. With a varied background in product marketing, economics, market research, information design, and digital publishing, her specialization is developing and assessing business models that leverage the value of information/data. Improving access to information to enable informed decision making has been a core objective throughout her career. Enhancing the utility of medical information and the quality of information used by clinicians and patients represents her current passion. Janice serves as an independent board member for the Journal of Bone & Joint Surgery (JBJS) and is a past board member of The Society for Participatory Medicine (S4PM). She has an MBA in Marketing from the University of Chicago, Booth School of Business, and a BA in Economics and French from Simmons University. I called on Janice to talk with us about infodemiology. What a cool sounding word. I'll let her explain what that is.

Health Hats: Janice, thank you so much for joining me. I love seeing you. One of the things I miss is that we don't get together.

Janice McCallum: Same here, Danny.

Health Hats: How do you introduce yourself when you're in a social situation?

Janice McCallum: It depends on the audience. With a general audience, not in my business community, I'm a consultant to publishers with a current emphasis on healthcare publishers. In a business gathering, I'm a marketing strategist for companies that produce healthcare content or data products. Often they don't understand the full breadth of what marketing constitutes.

Find a drop in the firehose 04:47

Health Hats: It's a perfect time to be talking with you because I've been working on this explosion of dreamlike unsatisfying information. When I was a kid, I would dream that I had an ice cream cone but could only taste my dry mouth. Disappointing. With COVID-19, the information needed can be tough to find. Plus, it doesn't answer the questions that people have. And I don't trust anything. I wanted to talk to you about this information dilemma that we're facing. What do you think about that? Just open-ended?

Janice McCallum: First, it's not a new problem - the fire hose of information – what's important to me? Finding the information you're looking for is an art and a science - information science. I don't see librarians brought into conversations about how we select quality information often enough. That's their specialty. Consumer health information is a subspecialty. I always recommend that people go there first if they want to know the basics. If you have a local library with a librarian with knowledge about healthcare information, use that person. The pandemic has brought this whole issue to the forefront. New clues about the coronavirus and how it spreads are coming out daily. People all over the world in different specialties study it. We're getting information in dribs and drabs, and it's confusing. Even among the experts, we first heard about large droplets, wear a mask, stay six feet away. More recently, we hear it may be smaller droplet aerosol, so don't do anything indoors. People say we can't trust those experts; they were wrong. Well, no, they advised based on the information they had then. Now we're in a unique situation that magnifies the challenge of weeding out the good from the bad information. How do you keep the information current?

Infodemiology 08:28

Health Hats: When you responded to an episode that I had published a week or two ago, you referred to *infodemiology*. I had never heard that before. Can you say more about that?

Janice McCallum: Absolutely. In 2009 I first used the term in comments to a Society of Participatory Medicine blog post-Susannah Fox wrote. At the time, our definition was *the study of information usage patterns to glean clues about how a disease may be spreading, where it's prevalent, where it's spreading.* Googling *flu trends* was a prime example. Then some other product products came along. I hadn't heard the term used; it didn't seem to catch on. So, I stopped using it. Recently, I signed up for a World Health Organization (WHO)-sponsored conference on infodemiology. They were defining it a bit differently, but before I get into that, I'm going to read a couple of definitions I came across in 2009. Still, the earlier, the first use was probably a decade before that from Gunther Eysenbach, who you may know.

Health Hats: Yes. The executive editor of the Journal of Medical Informatics and the Journal of Participatory Medicine.

Janice McCallum: He says he originated the term back in about 2000 in an editorial he wrote in 2002. I'm going to read his definition. *A new research discipline and methodology has emerged, the study of the determinants and distribution of health information and misinformation, which may be useful in guiding health professionals and patients to quality health information on the internet. Information epidemiology or infodemiology identifies areas where there is a knowledge translation gap between best evidence, what some experts know, and practice, what most people do, or believe as well as markers for high-quality information.* That's a little bit different from the way I was using.

Health Hats: That's a mouthful

Janice McCallum: Yes. WHO has a longer definition? I won't put you through the whole three paragraphs. I'll read the final one which is one sentence in the context of this meaning, and the meaning was similar to the way I define it, WHO defines infodemiology *as the science of managing infodemics*. They were more specific about saying it applies to times when we're having an epidemic.

Health Hats: OK. So, wait a minute. I hear both epidemic and epidemiology.

Janice McCallum: Right.

Health Hats: So, help me. I don't think I'm clear yet.

Janice McCallum: I was going more with the epidemiology route. I liked that you can identify in Boston that there were a lot of people searching for *body aches and fever*. So, you can see that search, and know maybe there's some other public health information that gives you a clue. You can follow where things are spreading, so public health applications.

Health Hats: OK. So, it's the use and distribution of information?

Janice McCallum: I think of it more as gleaning clues about outbreaks of disease based on information usage.

Health Hats: So, if people are searching *mosquito bite and a rash*, then you can look at the geographic distribution of that search and think maybe there's Lyme disease or encephalitis or other insect-borne, mosquito-borne disease? Oh, that's different than I was thinking.

Janice McCallum: Well, that's the way I like it.

Health Hats: Well, I had no idea. I was just making it up.

Janice McCallum: Gunther and the WHO are modifying that definition a bit to say, it's all about how to identify good sources and manage misinformation. To me, that's library science.

Finding information: PubMed and search engines 13:23

Health Hats: I've been focusing on how people find information. A librarian or academic might use PubMed and plug in some keywords, and hope articles are going to come up. A layperson is going into their favorite browser and type whatever they're thinking. Then some kind of algorithm chooses what sources to put on the top.

Janice McCallum: Right. If you recall the early days of Google and the other big search engines, you did depend on the words you put in. Now they do a lot more behind the scenes work to try to put quality sources at the top, especially in healthcare. So I would say, for things like basic disease information, putting it putting a few words into Google isn't a bad idea. You're going to get Mayo Clinic and maybe Healthline or WebMD toward the top. For that type of information, they're all pretty reliable unless it's something more nuanced, such as Lyme disease. I had an anecdote about Lyme disease in my notes that I prepared before our conversation. I got Lyme disease ten years ago.

Health Hats: OK.

Janice McCallum: I didn't recognize it as Lyme Disease at first. I had been in my backyard, and I had a bunch of mosquito bites. My next symptoms were chills and body aches. There was a lot of news about West Nile diseases at the time. So I'm thinking, Oh dear, I've got West Nile disease. Maybe a week later, I saw the telltale bullseye rash. I knew right away that it was Lyme disease, and went to the doctor, got the test, took doxycillin and all as well, at least as far as I know. But without that rash, I probably never would have identified it. To go a step further, there were symptom checkers out there, but I haven't seen one that works very well. Ten years ago, for fun, I went into some of the symptom checkers and put my symptoms in. They worked when you had an anchor on your first symptom. In my mind, that was rash. Lyme disease never came up, though. I remember that jock itch came up. Perhaps I had jock itch, but it didn't allow the multiple symptoms. They weren't very sophisticated.

Health Hats: OK. Those are the early symptom trackers.

Janice McCallum: I'm not convinced they've improved that much.

Absorbing the information found 16:34

Health Hats: This glut of information is too much to take in even if we could select the information we needed. Finding information is not a given, but even if we could, it's too much to take in. Is infodemiology also about providing the information in a manner that people can integrate into their lives, into their experience?

Janice McCallum: I don't know that it's defined that way. WHO is trying to manage disinformation. That brings in some other issues about why people believe certain things. I had some problems if infodemiology is striving to become the science of how you determine good information and manage information. They better get together with information science because they're both trying to solve the same problem. I see that so often in many contexts that Person X over here doesn't know person Y over here is working on the same thing. If they collaborated, they could make more progress.

Health Hats: Makes sense. But this issue of mis- and disinformation is enormous. It seems like there's certainly room for many different brains to weigh in and problem-solve together. Different brains like library science, ethics, I suppose?

Janice McCallum: Publishers choose a topic that interests a specific audience and do the culling, curating, and distilling to report on the essential pieces.

Health Hats: So, when you say publishing, are you talking about publishing books or journal articles, or are you talking about Twitter and Facebook?

Janice McCallum: I wouldn't put Twitter and Facebook in the category of publishers. But every other format, newsletter, journal, podcast series, video information I see as potentially trusted sources. I am going to go to this source because I trust them to provide me updates on a particular topic, so I don't have to go out there and start from scratch.

What do you trust? 19:64

Health Hats: OK. So, who do you, or what do you trust?

Janice McCallum: Because I do a lot of research?

Health Hats: Yes. You start with a base. I'm interested in how you decide what's trustworthy?

Janice McCallum: There are brands I trust, well-known journals. However, it depends on the query because medical journals aren't trying to solve consumer health problems. They're geared toward a professional audience. I like the Merck Manual for consumer health information. I don't see people referencing that often.

Health Hats: No, I used the Merck Manual when I was in nursing school quite a bit, but never since.

Janice McCallum: Both the consumer and the professional versions are online for no charge. I think they're really well done.

Health Hats: I didn't even know there was a consumer version of the Merck Manual. That's how old I am. It's 45 years since I became a nurse. I probably stopped looking at the professional version and was not aware. OK. Merck Manual. What else?

Janice McCallum: For basic disease information, I'll go to any of the consumer health sources. I like Mayo Clinic. But it's just like HealthLine and WebMD. They all have a lot of information, but for certain things, not everything.

Health Hats: There's nothing like blanket trustworthiness. Does it depend on what information you want?

Trust but verify. Follow the money. 21:36

Janice McCallum: That's true. My mantra is trust but verify. I very rarely depend on a single source. I always want to look at multiple sources. If it's a source I'm not familiar with, I'll want to know about the people who publish it. How do they make their money, who's writing the articles?

Health Hats: How do they make their money? Meaning, is this an industry-supported or an academic supported?

Janice McCallum: Absolutely. One of the most critical questions I ask is 'where does the revenue come from?' It's one of the biggest problems with quality information right now.

Health Hats: So, what part of it is, publishers like to publish new stuff. When you say trust, but verify - verify to me means that somebody else did a study that maybe not exactly the same study, but they got the same results. That doesn't happen that often.

Janice McCallum: The reputation of the publisher. You can't verify every article. Publishers work hard to build a brand to say 'this is what we stand for. We fact check. We have good writers.' That type of thing. So, you learn to trust a brand.

Health Hats: So, if a brand that you trust, ends up saying, 'we withdraw this', do you trust them more or less?

Janice McCallum: I'd have to look at the record, but probably more.

Health Hats: Because they're straightforward and they're saying, well, we blew it. We learned this since, and it made us question our original decision. That's a sign of integrity.

Janice McCallum: It's tricky. I don't want to go into this in too much detail, but you can't know everything that happened in the course of a research study. So, they're relying on the researchers and authors of the draft. Publishers can't go through and work through all the data. It's only recently that datasets accompany some of the medical journal articles. In the past, at best, they just included little tables. So, we're making progress, but medical research is complicated.

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Never trust a headline 25:16

Janice McCallum: One thing I want to say in terms of identifying and weeding out useful information is ‘never trust a headline.’

Health Hats: Oh, that makes sense. Say more.

Janice McCallum: I was going to say that Twitter is planning to chastise or punish people who retweet articles without reading the article behind the headline or linking through at least. I'm not sure exactly how they're going to do that and when. But I think that's a good thing. Headlines are designed to attract. They're clickbait. And they don't know necessarily represent what's the conclusions of an article.

Health Hats: OK. They could say, ‘amazing new finding’ yet the study's not done; it hasn't been peer-reviewed; the data isn't available. So, it’s a stretch to say, ‘amazing new findings.’

Janice McCallum: Yes, certainly in this COVID era, ‘looks like it's very effective’ that was a phase two result, and we haven't tested it in a large population. If an article is written about the results of a survey or a clinical trial, I want to know more details. How many people were involved? What was the demographic and mix of people studied - that type of thing?

Information from patient communities 26:48

Health Hats: That brings up another thing. I remember when I first went to the first neurologist who diagnosed me with MS. And, he said, I know a lot about therapeutics and how they affect groups of people. And I don't know crap about you. And my job is to learn more about you, and your job is to learn more about these different therapeutics. And besides thinking I died and gone to heaven, it made me appreciate the difference between a research result and how the findings affect me.

Janice McCallum: Right.

Health Hats: Now, in our hopefully full state of more health equity awareness, it seems like we're looking for what might work for people who are like me. And that's hard to pull out of either an article or a research paper.

Janice McCallum: Yes. So, this would be an excellent time to talk a little bit about patient communities. I don't know if I mentioned them as when I was talking about sources for disease information, patients, patient communities, and patient advocacy organizations are good places to consider checking.

Health Hats: Then, how do you check them? Say more about that. Some people have lived with whatever it is that I'm going through, and the likelihood that I might learn about something that I haven’t heard before, or my doctor might not have heard before, is possible. And then if you're lucky and you have a doctor who's open to that kind of stuff, like this neurologist would say when I would talk to him about acupuncture. I felt like acupuncture help with neuropathy. He said, ‘I don't know anything about acupuncture, but I'm open to anything that works for my patients. So why don't you tell me about your experience?’

Janice McCallum: We've all heard stories of how people have found useful information in patient communities. We've all heard ePatient Dave's story. I'm not a heavy user of patient communities. I've done work for some of them. It's not like a Google search. It may take more time. It's almost like forming relationships with people. One of the issues I'm going to bring up again, the general business model, how are patient communities going to carry on, how did they make money? I think they're valuable, and I'd love to see them progress, but it's not easy; there's no easy answer to that. The business model we've mostly seen or the revenue model that has taken hold has been well; we'll help find participants for clinical trials. So, pharma is funding them.

Health Hats: OK. So, then there is some bit of a peer community, but their basic purpose is to recruit.

Janice McCallum: Well, I don't know about basic. You have to be careful when that becomes your primary objective. If that's where the money's coming from. That's the line we have to tow.

Know the source 30:45

Health Hats: Oh, my goodness. It's sort of amazing that there's any trust at all. This does relate but one of the things, so I've been married 45 years, and one of the things that I only realized in the last few years is that when I would say something to my wife, she would have to think it through and verify it for herself. I thought for 40 years that she didn't trust me. Then finally we had a conversation about that, and she said, ‘that's the way I'm wired. I have to come to it for myself.’ Then I could say, ‘OK, this makes sense.’ I didn't have to be hurt about it anymore after 40 years. I bring it up because of your saying, ‘verify for yourself,’ even when there's the trust of 45 years.

Janice McCallum: Yes. I like your wife's approach. Somebody tells you something, or somebody tells me something I'm going to get online to learn more or go to the source. I always want to see a reference to the source. Another piece of advice I would have is if somebody goes on Facebook, sees something that says, ‘copy this to all your friends, share widely,’ and there's no citation or anything like you can be guaranteed that’s a problem.

Health Hats: Its sort of a nice thing about Wikipedia is the referencing. In a way, when I go to Wikipedia to look at something, it's overwhelming how many references there are, but it seems like that's the model that they're supporting. Where'd you get this, whatever it is you're putting on there, like where'd it come from?

Janice McCallum: Right. I like the Wikipedia model, but again they have an issue with funding. The conclusion we can come to is that there's not enough funding for information. That's public health use. We need more public health funding. We need more funding for information and health literacy. Those areas that have been defunded for quite a few years.

Trusted information, trusted sources, Twitter 33:21

Health Hats: So, let me ask you a different question. When people search the internet, how do they filter so that they can like maximize getting a return of answers that they're more likely to trust? It sounds like too big of a question but give it a stab.

Janice McCallum: OK. I want to tie it back at first to your comment about ‘you told me something, you're a person I trust, but I'm still going to go online to get more.’ You're going to get some information from experts, maybe your doctor or a community health leader, a good place to start. If it's not top of mind and you get online, which is what most people do, I recommend checking multiple sources and see if they agree. If something's way out there I'd question it. It's not to say that it's not accurate or trustworthy, but I'd put a higher level of verification on that. But I think we do need to depend on experts, and I think Twitter is a good platform, a useful resource for finding experts.

Health Hats: Meaning that you identify specific people who you generally trust? I follow Dr. Lena Wen, a former Baltimore public health commissioner. I also follow Dr. Aaron Carroll from the University of Indiana. I like that they're very free to say, 'I don't know.' That is so big, and then they say, 'here's how to think about it.' They'll talk about your risk tolerance, or they'll give me ways that I can think about what they're recommending or what somebody else is recommending. That makes me trust them more.

Janice McCallum: Right. But your preferences may be a little different from other people. With Twitter from the very start, I've recommended people create Twitter lists or maybe find a Twitter list and subscribe to that. So, I have one list of MDs, a few allied health professionals, and perhaps I may have snuck into medical professionals. I have a list of epatients. I have a list I call projects, which is things related to the stuff I'm working on, but that's sort of grown out of control, but it's a good list. I like that list.

Health Hats: Say more about that. I just subscribe. It sounds like you're talking about groups of lists, several lists.

Janice McCallum: Yes. I couldn't live without one of the dashboards. I use both TweetDeck and HootSuite.

Health Hats: Then you create a list of Lena Wen and Aaron Carroll and two or three other medical professionals, and then I might have Susannah Fox or you (Janice McCallum) or Casey Quinlan, or people in the advocacy world. I do like to follow people who agree with me, who I know have values that I'm sympatico.

Janice McCallum: Absolutely, I think that's true of almost everybody. Unfortunately, that's also how misinformation grows. I'm not saying you're a candidate for that.

Health Hats: Oh, I'm sure I am. I'm as gullible as the next person.

Janice McCallum: I would go further to say, there are certain groups that to be part of a group, you have to subscribe to their way of thinking and watch only certain TV stations and only read a certain type of thing or listen to certain things.

Health Hats: I see.

Janice McCallum: That's when things get dangerous, conspiracy theory or theorists, and that type of thing. Tackling that problem is outside of my area of expertise

Health Hats: Who labels themselves, but I'm a progressive, equity-focused person. I do like to pepper what I read with stuff that I don't necessarily agree with, but they seem pretty smart. I follow The Bulwork because these are conservatives who, in this time of misinformation, they approach it differently than I do. I don't always agree with them, but they make me think.

Janice McCallum: Yes. I wouldn't want to sound as though I'm saying only restrict your information input to a small group. I like to look at a lot of different sources, as you said, it makes you think, and it also gives you insight into how they're manipulating.

Good information crowding out bad information 38:57

Health Hats: What should I be asking you that I'm not in this wide-ranging conversation we're having about information?

Janice McCallum: I haven't touched on that I wanted to bring up is the concept of good information crowding out bad information. That's something I would like to see happen more frequently. For people who aren't extreme conspiracy theorists but tend to get limited information and don't have a good understanding of medical topics. If people shared more good information with them, if they received it from somebody they trusted, that will help drive out the bad.

Health Hats: I think you need to talk more about that. So, give me an example of how you might have done that.

Janice McCallum: I point people to Snopes.com, a fact-checking website. Somebody they trust has to send them to the site, maybe a relative or a medical professional of some sort. Although I don't think that happens enough, I would like to see medical professionals encouraging people to find good information on their own more frequently.

Health Hats: In this COVID world, the big fear that I have is that, Oh my God, vaccination will be successful and there will be so much mistrust from any perspective, and people will take advantage of something that is overhyped, or they'll dismiss it out of hand. How can good information drown out misinformation in those situations?

Janice McCallum: Yes, that's a tough, complicated topic. I'm very pro-vaccine, yet I'm concerned that we're going to rush something out. Suddenly, we're going to do things five times faster, ten times faster than we've ever done before, that raises some questions in my mind. I would want to see more detail. Show me. I would love to see instead of how many vaccines are in the research phase. I don't want to say there's too many. But instead of collaborating, we have a lot of people competing. I think that's a problem. But I'll go back to wanting more detail - show the steps, show some narrative of how this has been tested, or there are very few side effects. You might need a booster, but this is going to help you—more good information.

Health Hats: Is selective retweeting part of what you're saying?

Janice McCallum: Yes. If somebody's a trusted expert or someone who knows how to follow trusted experts, consistently shares reliable information, as you said Aaron Carroll, you like him because he explains, OK, here are the risks and here's how you should think about that. We need some more of that now. Not everybody's going to be prepared for that. Are enough people who have a trusted brand, and they share the good that will help.

Health Hats: This is a thorny problem.

Janice McCallum: Yes, yes. Especially in a time when things are moving so fast, and it's such a big, scary, dangerous issue.

Health Hats: Janice, thank you.

Janice McCallum: You're welcome. There's so much that could be touched on. I feel like we just scratched the surface, but I'll just leave with we really need more resources put into public health.

Health Hats: I'm with you. Yes, I'm totally with you on public health.

Janice McCallum: It's a big problem, trying to find a silver lining in the horrific cloud over us right now, perhaps there'll be more focus on prevention and public health in the future.

Health Hats: All right. Thank you so much.

Janice McCallum: You're very welcome.

Reflection 44:15

Infodemiology, infodemics: I like the definition: an overabundance of information that makes it difficult for people to find trustworthy sources and reliable guidance when they need it. Access to the right information, at the right time, in a manner, context, and format that's useful to me. *Knowing ourselves seems essential with overabundant information, misinformation, and life uncertainty. I liken it an eye exam with those adjustable optician frames that take and rotate different lenses. The eye chart looks different depending on the lens and the rotation—same chart, different impression on the brain. The lenses through which we view information could be the perceived reputation of the source, the trust in science, life experience, the relative value of value individual rights over community. Perhaps risk tolerance is the rotation of the lenses. Tolerance for physical, financial, emotional, spiritual safety - keeping a job, preventing infection, learning, socializing? So complicated! I can't pretend to advise people on what choices to make. I can only share my metaphor of the adjustable optician frames and consider their unique tolerance for risk.*

I need to add one more thought, not related to the story in this episode. I read a report from The Guardian and Kaiser Health News about More than 900 US healthcare workers have died of COVID-19- and the toll is rising. Please read it. Help the helpers. We need them well, not dead.