

“Patient Influencers: The next frontier of direct-to-consumer pharmaceutical marketing”

Erin Willis, University of Colorado, Boulder

Daniel Garza, Lilmesican Productions, Inc.

International Disability Rights Affirmation Conference 2023

November 10

[2023/11/10 07:33] LV (LoriVonne Lustre): Hello everyone.

Today's presentation is being transcribed so those without audio or who require text only can participate in real time.

Some speakers may be using a text teleprompter tool for some or all of their presentation.

Transcriptionists will fill in any gaps and support the Question & Answer section at the end.

A little explanation about this service.

Voice-to-text transcriptionists provide a translation of the key ideas discussed, NOT a word for word transcription.

Voice-to-text services provide an in-the-moment snapshot of ideas and concepts, so that those who are unable to hear or to understand the audio program are able to participate in real-time.

You will see the transcription in local chat.

Transcription is provided by Virtual Ability, Inc.

The transcriptionists are:

Carolyn Carillon

Lorivonne Lustre

The speakers will be identified by initials as they speak.

The following initials in the transcription record will identify the speakers:

EW: Erin Willis

DG: Daniel Garza

[2023/11/10 07:31] Pecos Kidd: Our next presenters are an unlikely pair of a professor and a stand-up comedian!

Attica, the floor is yours to introduce them!

[2023/11/10 07:31] Attica Bekkers: Welcome

Today it is my pleasure to introduce Doctor Erin Willis and Daniel Garza

I'm a learning disabled woman in my 60s. I have been SL for a long time and I love the social aspect.

Dr. Erin Willis is an Associate Professor in the College of Media, Communication and Information

at the University of Colorado, Boulder.

Dr. Willis's research interest

is how health messages influence people's behaviors,

particularly in how personal health behavior is shaped by everyday information and technology.

Daniel Garza is an actor, stand up comic, host, patient leader, and energy worker. He is the co-founder of Lilmesican Productions, Inc. and the author of Grumpy Bunny and the Colors Game.

The topic of this session is Patient Influencers: The next frontier of direct-to-consumer pharmaceutical marketing.

[2023/11/10 07:33] LV (LoriVonne Lustre): <<transcription begins >>

[2023/11/10 07:32] ErinWillisPhD Resident: Hello! My name is Erin Willis, and I'm an associate professor in advertising and public relations at the University of Colorado Boulder. I am here to discuss what is shaping up to be the future of pharmaceutical advertising – patient influencers.

Joining me here today is Daniel G. Garza, a patient influencer and advocate who will help to bring this research to life.

.
With the proliferation of information and communication technology, using the internet to seek health information is a prevalent behavior around the world.

A 2020 survey conducted by Eurostat shows that 55% of Europeans aged 16 to 74 have looked for health-related information online.

That's a 21% increase since 2010. In other countries like Finland, Netherlands, Denmark, and Germany – that number has increased to be 70% of the population.

(See <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8701665/>)

According to the Pew Research Center, the percentage in the United States is similar.

[2023/11/10 07:35] ErinWillisPhD Resident: In some Asian countries, the percentage is closer to 80% like in the Philippines, or 85% like in Hong Kong and Indonesia, according to a study by Wang, Shi, and Kong published in the Health Communication.

Seeking health information online allows consumers to obtain knowledge about their health problems, and make health decisions, and have behavior change.

Last year in Healthcare, an article written by Jia, Pang, and Liu, and titled, "Online health information seeking behavior," described a systematic review of work done in this area.

The authors report that 83% of health information consumers searched using a general search engine such as Google or Yahoo.

Many consumers reported looking for health information on social media platforms, user-generated online information sites such as Quora and Reddit.

Jia, Pang, and Liu also found that the health topics consumers searched for vary.

The most popular searched topics include diet and nutrition, exercise and fitness, certain health diseases, specific health treatments, mental health issues, and sexual/productive health information.

This reflects data previously reported by the Pew Research Center.

.
We don't need a slide to tell us that consumers are on social media. Social media is ubiquitous with everyday life.

Could we even accomplish our day without social media or without information technology?
How often do you check email on your cell phone? Or use GPS to find your way?
Or start a load of clothes in your washing machine with the Samsung app. Did you know that's a thing now?

How often do you use social media for clients or just for keeping touch with family members or friends?

In Colorado, we haven't ditched the QR codes at restaurants yet – remember when the idea didn't become popular after the initial launch in 1994, or even a reboot in 2011?

And now in 2022 after the COVID-19 pandemic, QR codes are here to stay for a while.

According to the Pew Research Center, in a report from 2021 on social media use, Americans are online and on social media sites like Facebook and Instagram.

That number increases as age decreases – which is on track with previous research conducted by the Pew Research Center.

The growth seen across individual sites and apps has remained steady for sites like LinkedIn, WhatsApp, Twitter, and Facebook.

What is interesting, however, is that sites like YouTube and Reddit both saw statistically significant growth since 2019 when the last Pew Research Center survey was conducted.

Instagram, TikTok and Snapchat are the most popular among young adults, ages 18 to 29.

Survey participants report visiting these sites at least once per day, and more than half say they visit several times per day.

.

Not long ago, Paris Hilton and Kim Kardashian were vying for coverage on entertainment news sites and in weekly gossip magazines. It was common to hear that these influencers were “famous for nothing.”

Skip to today, and social media influencers are common in marketing communication plans. Addison Rae, for instance, is a 21-year-old TikTok influencer. Last year, she made the Forbes “30 under 30” list for social media influencers.

According to TikTok, she has over 87 million followers on TikTok which makes her the fourth most-followed person on the platform.

Forbes reported that Addison Rae earned \$5 million in 2020 by means of endorsements with brands such as Reebok, L'Oréal, Hollister, and American Eagle.

A recent report by eMarketer noted that consumer response is highest when messages are delivered from social media influencers compared to brand-owned channels.

Since this is a relatively new marketing strategy, academics are still debating on the industry practice and its related definition.

So – here are a few definitions pulled from the literature.

When studying the effects of social media influencers, it has been found that consumers have stronger connectedness toward them and they perceive them as more authentic.

The perceived realness of influencers and the deep connectedness result in higher purchase intention of the products they endorse, because consumers personally identify with them and try to imitate them.

The brands of these influencers are perceived as real and relatable, so they become more approachable and compelling to imitate.

.

These two definitions are almost conceptually identical, and share the following [pause]: large number of followers, active engagement, and promotion of products or brands.

[2023/11/10 07:42] LV (LoriVonne Lustre): Erin will share the definitions of these later

[2023/11/10 07:42] ErinWillisPhD Resident: Influencer Marketing Hub conducts an annual survey about influencer marketing since 2017 – monitoring the state of the industry. The market grew from \$1.7 billion in 2016 to \$9.7 billion in 2020. In 2021, influencer marketing soared to \$13.8 billion, and is on track to be \$16.4 billion this year. This growth is attributed to the increasing popularity of short video formats like on TikTok or Instagram reels.

Social media platforms are viable avenues for consumers to learn about new products and services. Instagram, for example, is a popular platform for influencers, and has a wide global reach. 83% of users report using the app to find something new. After seeing posts with product information on Instagram, 87% took a specific action like following a brand, visiting its retail store, or making a purchase.

According to the Digital Marketing Institute, 49% of consumers depend on influencer recommendations, and 82% trust the opinions they see on social media channels shared by family, friends, and influencers, and they use these comments to drive purchase decisions.

Consumers don't trust pharmaceutical companies. Period.

That sentiment of distrust has prevailed among consumers for decades – not just in recent times related to the COVID-19 vaccine.

Trust is a complicated matter in prescription drugs, especially when the majority of Americans are dependent on them.

Almost half of all Americans take at least one prescription drug, the CDC reported in 2020. The legalization of direct-to-consumer marketing has permitted pharmaceutical companies to engage directly with patients.

Direct-to-consumer marketing is the promotion of prescription drugs directly to consumers as patients, instead of targeting only doctors and physicians.

Medical marketing reached \$30 billion in 2016 – up from \$18 billion in 1997.

This is from an article in the Journal of the American Medical Association by Woloshin and Schwartz, published in 2019.

Much of that money is spent on direct-to-consumer marketing, focused on disease-awareness advertising.

Pew Research Center in 2009 reported that more than 77% of patients use search engines to learn about prescription drugs that treat specific conditions.

This presents pharmaceutical companies the opportunity to communicate with patients online.

Documented scholarship notes that recent direct-to-consumer marketing efforts by pharmaceutical companies have focused on digital advertising and engagement tactics to connect with patients and build relationships.

We won't spend too long here, just a quick stop over to note that since the legalization of direct-to-consumer advertising in the U.S.

in 1985, a debate has unfolded with experts arguing the benefits and consequences of this type of marketing communications.

For decades, pharmaceutical companies have modified direct-to-consumer strategies, even being early adopters of digital communication platforms.

Proponents of direct-to-consumer advertising say that ads are a legitimate sources of quality patient information, and ways to increase patients' health literacy.

Arguments against direct-to-consumer advertising center on concerns about the pharmaceutical industry's ability to produce unbiased information.

Given the nature of market economics, the primary aim of direct-to-consumer advertising is to increase market share and profit rather than enhance patient well-being.

.
In June of 2014, the Food and Drug Administration (FDA) issued guidance for industry on social media platforms.

There have not been any further updates to this guidance, to my knowledge.

The Federal Trade Commission (FTC), in June 2022, proposed changes to its Guides Concerning the Use of Endorsements and Testimonials in Advertising.

This relates to disclosures and endorsements by influencers.

.
Now. Let's talk about patient influencers.

It was the Vox article that initially piqued my interest, and then a conversation with an industry professional in pharmacy communications that confirmed – patient influencers are working with pharmaceutical companies.

Now, maybe you all know that already, and I'm the one who is late to dinner.

Why the silence in the academic literature, and in industry publications?

There's so little about this phenomenon.

.
To explore this topic, we conducted in-depth interviews with patient influencers.

The question then became, how do we recruit patient influencers?

The way we thought about patient influencers for this research is someone who has a homogeneous following in a specific disease category.

Disease category being like the brand category, and homogeneous following being others with the same disease or illness.

HealthUnion is a marketing agency who works as an intermediary between pharmaceutical brands and patients.

We wanted our research to be reliable, so – we thought HealthUnion was a viable jumping off point, so we asked for a list of patient influencers who might be interested in participating in our research study.

Using that initial list, we conducted in-depth interviews using snowball sampling. When we interviewed a patient influencer, we asked for a referral. Participants were paid \$50 for their time.

Inclusion criteria was that participants had to be at least 18 years old, and have a social media following of more than 1,000.

Participants had a wide range of illness and disease, from HIV/AIDS to fibromyalgia to prostate cancer.

In total, we conducted 37 interviews by phone or through Zoom that averaged 87 minutes in length.

Interviews were recorded and transcribed, and are being analyzed back in Colorado, as I talk to you today.

What I'm going to show you now are some initial findings.
We are working on a few papers now for publication.

Ultimately, it was said time and time again by participants that patients are interested in other patients' experiences.

Being able to see how life looks while living with – for example – fibromyalgia allows patients to evaluate their own selves and what their future prognosis might look like. Some of the participants started their social media platforms with the intention of being a patient influencer.

To them, that meant sharing about living their life with the disease to show others what it is like, and allow them to ask questions or engage with other patients.

When we use the term influencer, many people think of Kylie Jenner or Kim Kardashian, and many of the participants interviewed felt the term had a negative connotation, despite describing their work.

Kyle Jenner and Kim Kardashian are mega-influencers, and are very costly and difficult to secure.

In contrast, patient influencers most frequently are micro- or nano-influencers.

Participants interviewed for this study had less than 20,000 followers.

What is special about patient influencers is that a large percentage of their following has the same illness or disease, providing a direct avenue for health communication and health education.

That's what you would say if you worked in public health. If you worked in marketing, however, that is not what you would say.

There was debate if the term patient influencer is an appropriate term, or if patient advocate would be better to describe the work that they do.

While only a few of these patient influencers participated in our study, there are hundreds, if not thousands of patients sharing their stories on social media platforms.

The participants reported using hashtags so that their content could be easily found by others who might be searching for information.

A lot of the patient influencers we interviewed for this study either currently worked, or have worked, with pharmaceutical companies in some way.

That might be – speaking at an event, participating in focus groups, serving on a patient panel, etc.

In a few instances, patients worked with a pharmaceutical company and posted social media content promoting a specific brand or raising disease awareness.

In other instances, participants felt it was inappropriate for patient influencers to work with pharmaceutical companies, or to discuss prescription medication with other patients online.

It was common for patient influencers to say they wanted to help others avoid the experience that they had when first diagnosed.

Many reported a lack of information, especially people of color and culturally appropriate health information.

Many patient influencers felt it was their calling to help others, or to empower other patients to take care of their health.

All of the patient influencers were motivated by helping others and being a reliable information source.

Pharmaceutical companies leverage the patient journey or the lived disease experience of patient influencers to build trust with patient populations.

The findings the slide refers to is about health literacy, and how influencers communicate about prescription medications on social media.

It was agreed among the sample that drug information should only be shared if the patient influencer has direct experience with the prescription medication.

When patient influencers communicated about a particular medication, it was usually related to side effects they experienced, or how it worked for them.

Patient influencers spoke to other patients as experts in disease management after having lived with their condition for a long time.

Often, patients are seeking other patients' experiences and knowledge.

Pharmaceutical companies collaborate with patient influencers for their specialized knowledge, but also for their influence on their community of followers.

The patient influencers who did share their experiences with pharmaceutical medications with their community of followers all agreed that transparency was key.

They did not want to work with a pharmaceutical company if their messaging would be restricted in any way.

The patient influencers wanted to be an accurate, trustworthy source for their followers and did not ever want to mislead other patients.

Many of the patient influencers interviewed conducted research on disease topics, new pharmaceutical medications, and research trials.

Patient influencers wanted to share this type of information so that other patients could become educated and make positive health decisions.

Followers develop an emotional connection through the influencer's shared content.

A lot of the patient influencers received training about the federal regulations related to pharmaceutical drugs – this is a service provided by HealthUnion.

Despite having different approaches to discussing pharmaceutical medications online, the patient influencers interviewed all deferred to physicians, telling followers that they should “talk to their doctor.”

Depending on the disease or condition, there is a range of plausible treatments in different disease categories, and in others – there are no pharmaceutical options.

Patient influencers' knowledge about pharmaceutical medications differs greatly, as does consumers'.

Unanimously, all patient influencers agreed that they would not give any medical advice but instead prompt the patient to contact their physician with questions.

In the interviews, it was heard repeatedly that the patient influencers wanted to help others be better patients, to take control of their health, and their attitude – and to use information to advocate for what they need.

The patient influencers discussed wanting to help other patients overcome their own challenges and “to live a good life with this disease.”

All of the patient influencers wanted to help their followers and to raise awareness about disease.

Despite enduring many health challenges, these patient influencers expressed self-efficacy to engage in self-management and “take care of my health.”

By sharing their success, patient influencers may be increasing their followers' self-efficacy to practice self-management, including medication adherence.

.
(pause for Daniel's presentation)
.

[2023/11/10 08:03] LV (LoriVonne Lustre): DG: My name is Daniel G Garza. I am very nervous. But this is super cool! I would rank this as one of the top 3 presentations I have every done

I am going to talk to you today about Advocate vs. Influencer and Stigma in culture

Advocate vs. Influencer.

Advocate: A person who actively supports and promotes the interests of another person

Influencer: someone who can persuade a large group of people to do, buy, or use the same things that they do.

As an advocate I get to represent people in the HIV, anal cancer, and ostomy community as well as those affected by PTSD due to health issues.

I became the ostomy champion this year

My job is to speak to health care professionals, policymakers, and law makers that work with the community and tell them about the needs of the community.

To help the community I get to share my story. I get to be vulnerable. I get to ask them to do better for the community. I have the responsibility to reflect the image of the community I am serving.

Let me tell you, it can be confusing at times!

Then I go back to the community and share what I have learned. I create workshops, collaborate with other organizations, and gather more information. And the cycle starts all over again.

It is so fulfilling to be able to use my diagnosis and conditions as fuel to push me to follow my passion, help others, and give my life purpose. When I could sit back and feel sorry for myself, I chose to take my situation and make a career out of it.

I get to be an influencer as well. With my production company, Lilmesican Productions Inc, a social enterprise, we create shows that reflect the community we live in; Latinx, LGBTQIA+, and those with health conditions.

Through our main show, The Christian & Daniel Show, we can talk about businesses, projects, or events that are of interest. We can help shape our community while entertaining, educating, and energizing our viewers.

As an influencer in the community, I am responsible for making sure that I do my homework. It is easy to pass along information that can hurt the community.

The Advocate and The Influencer must work together to make sure that they are providing the best information, work on building up the community, and hold each other accountable.

Stigma in Culture

Stigma is a negative attitude, prejudice, or false belief associated with specific traits, circumstances, or health. Stigma in culture varies depending on the group that I am representing.

HIV, Cancer, and Mental Health carry different degrees of stigma. Being Gay, Latino, and an immigrant carries another level of stigma. Alone, each one, is hard, when combined it can be hard to succeed.

It is like combining playdough and trying to separate the colors later

When I was starting my career, it was suggested that I work on my accent. Working in the corporate world would be easier if I did not have such a strong accent.

As a Gay man in the Latino community that are certain cultural rules that must be followed to belong. Coming out came with assumptions that are ingrained in our culture and create more stigma.

I did not realize until I was diagnosed with cancer that even in health there are levels of social acceptance. In my case they range in this order; Cancer, Diabetes, Ostomy, Mental Health, HIV.

Cancer is more acceptable, until I say Anal Cancer than that creates some looks and comments. Colorectal Cancer is more acceptable than Anal. Breast Cancer is more acceptable but in the Latino community any cancer conversation can be a cause for shame.

Social Norms and Prevention

Social norms are shared values, beliefs, attitudes, and behaviors that are considered acceptable in a particular social group or culture. These can become overwhelming when they work against you.

I made a choice when I came out in 1988 that I would not hide my identity. I was open about my HIV status when I was diagnosed in 2000, and anal cancer in 2015.

When Latino social norms dictated that I should keep those things to myself, keep them a secret, and not act on them I decided to walk away from the traditions that were normal in my community.

When I decided to work in HIV advocacy it was hard to break through the social norms to be able to talk about HIV and Anal Cancer prevention.

Not everyone is ready or willing to listen and break through cultural and religious barriers. These are norms that have been held for generations. I will admit that even for me it was hard when I was first diagnosed.

I thought it was a punishment from God. That the Universe was making me pay for my past. That Karma was coming to make things even. I had a lot of time to process and analyze my life.

Working through my issues has helped me be a better advocate, influencer, and person. I have experience in breaking through cultural, religious, and social norm barriers.

I appreciate your time and attention, again my name is Daniel G Garza, thank you.

Back to Erin.

[2023/11/10 08:12] ErinWillisPhD Resident: Patient influencers are already being used by pharmaceutical companies to promote both prescription and over-the-counter medications. So little is known about this practice.

More research needs to be done to understand the effects of patient influencers' recommendations on patients' prescription requests.

There is so little up-to-date regulation related to this practice. Obviously, no one wants to get in trouble.

However, the current FDA and FTC regulations do not consider the updated platforms nor their functionality like Instagram Stories or direct messages.

Perhaps there should be “best practices” created to guide professional behavior.

Little is known about pharmaceutical companies’ relationships with patient influencers due to non-disclosure agreements, and secrecy within the advertising industry.

From the outside, this practice is shrouded in secrecy and therefore breeds suspicion.

If no rules are being broken, why isn’t more being said or written about this common practice?

Marketing agencies like HealthUnion are third-party organizations that are connecting patient influencers with paid opportunities.

Lastly, and perhaps the most concerning point – patient influencers, in some essence, are interactive direct-to-consumer advertisements, just with less regulation.

The patient influencer has the ability to engage with consumers, or in this instance, that would be – patients.

This interaction most frequently happens in the privacy of a direct message and therefore, cannot be regulated.

This interaction could be misleading or contain misinformation, or persuade/dissuade from a specific medication, etc.

More research must be conducted in this area to know if patient influencers are a marketing practice worth concern.

.

I added a slide to make one quick point, and that’s in relation to patient influencers’ reach and impact.

Within these disease categories, there’s only so many patients.

For instance, according to the CDC, 30,000 people in the United States have cystic fibrosis.

Only so many of those cystic fibrosis patients would be online, and on social media.

Thus, the reach and impact of social media influencers should be thought about differently than lifestyle influencers or other niche market influencers.

Social media also has a reach outside of the countries where direct-to-consumer marketing is legal.

.

There are several notable practical implications from our work on patient influencers.

Patient influencers may be especially useful in the areas of health education and teaching self-management behaviors.

Influencers have shown to be especially influential among young adults.

Research should test to see if this is also true in regards to patient influencers and health behaviors.

These interviews showed that many patients want to collaborate with pharmaceutical companies, and patient influencers think of themselves as advocates for other patients and for the disease category.

Not one participant was motivated to be a patient influencer because of money or financial gain.

Pharmaceutical marketers should consider what is offered by patient influencers, and what could increase the value of strategic communication to target patient populations.

Defining this phenomenon is important, especially as “best practices” are created to guide the pharmaceutical-patient relationship.

It’s important for more research to be conducted in the area of patient influencers and the various stakeholders involved in this process.

More must be known about these relationships, the players involved, and the key performance indicators.

More research also needs to consider “best practices” for the industry practice, whether that is pharmaceutical companies, marketing and advertising agencies, patient influencers, etc.

Additionally, it should be considered if there is equity in the process, and how to expand the opportunity to more diverse patient populations.

This study has limitations. The interviews cannot be generalized, and snowball sampling is limited in that participants are from the same network.

Questions?

Erin.Willis@Colorado.edu

DanielGGarza@Hotmail.com

[2023/11/10 08:16] Eme Capalini: great job!

[2023/11/10 08:16] Pecos Kidd: Fascinating presentation - thank you both!!!

[2023/11/10 08:16] Gemma (Gemma Cleanslate): lovely

[2023/11/10 08:16] Mook Wheeler: QUESTION: You said that: "Not one participant was motivated to be a patient influencer because of money or financial gain". Did you find that this tendency *changed* or distorted with time or increase in influencer follower numbers? Social media monetisation, endorsements and corporate product freebies (in return for 'mentions'), is now an entrenched reality of social media. But because 'patient influencers' deal with people's health and treatments, this is obviously concerning. I do understand that the snowball sampling would bear upon your findings.

[2023/11/10 08:17] Carolyn Carillon: EW: great question

It's a difficult conversation

If you look at Daniel's Instagram

He's a patient influencer

Or advocate

But there are others who influence more than advocate

It feels good to make money but some can't make money or relied on the pharmaceutical relationship to survive

So it's a grey area

I think you'll see more patients try to get those opportunities

It's a slippery slope

I hope that answered your question

[2023/11/10 08:19] Mook Wheeler: thank you and I agree it's very gray

[2023/11/10 08:19] Gentle Heron: QUESTION- Daniel, your part of the presentation was so powerful. What advice would you give to people who are thinking of becoming an advocate or influencer? You showed us it takes courage.

[2023/11/10 08:19] Carolyn Carillon: DG: good question
What advice would I give?
Be mentally, physically and spiritually ready
It takes mental power to work through info
Physically, it's stressful
You have to do homework
Sometimes I put out information
Like today
I woke up early or stay up at nights
I ask, am I doing the right thing for the community?
And spiritually, your condition is about to be public knowledge
I talked with my family
Especially about HIV
I had people to consider
Sit down and have an honest conversation with yourself
Ask, am I ready to take this journey
Once it's out there, it's out there
You can't take it back
If you're ready mentally, physically and spiritually, then move forward

[2023/11/10 08:21] Pecos Kidd: Do you know if any courts have started to determine liability responsibility for influencers/advocates who provide incorrect or damaging advice?

[2023/11/10 08:22] Carolyn Carillon: EW: y'all have such great questions!

I don't know

A lot of people refer to Kim Kardashian where she promoted medication for morning sickness

And didn't say it was a sponsored post

She was fined but it's laughable to fine her \$10k

That's the only famous example

Daniel, do you know?

DG: Symptoms go under the radar so there are no real consequences
if you've watched HIV commercials, they used to use actors to represent patients

Several years ago, they started using actual advocates

Who were living with HIV

For more transparency

Some of my friends are in those commercials

And that's exciting

To see actually people living with HIV in those commercials

[2023/11/10 08:24] Pecos Kidd: Thanks!

[2023/11/10 08:24] Mook Wheeler: Regulation and enforcement of social media influencers [activities] would take massive rewriting of current legislation, I imagine.

[2023/11/10 08:24] Huntress Catteneo: here some have been fined for COVID misinformation

[2023/11/10 08:24] Carolyn Carillon: EW: I think this area will only grow with misinformation

As people see that it could be financially lucrative
In our sample, none of them would discuss a drug that they have not taken
BUT that's 37 patients
I think as this area grows, there will be more people flooding the space
There's a growing feeling of competition
There are only so many opportunities
These patients want those opportunities
So that will complicate matters
That's why I'm an advocate for more legislation or best practices between agencies
Some talked about standardization of pay
If you don't know how to negotiate you could be doing this for less money
So there are lots of things to think about
[2023/11/10 08:26] Rhiannon Chatnoir: The FCC has a 101 for social media influencers regarding disclosing endorsements: <https://www.ftc.gov/business-guidance/resources/disclosures-101-social-media-influencers>

[2023/11/10 08:26] Faith Frances (Roxie Marten): I have a question. Knowing the past history of the drug companies, how can we trust influencers?
We know how drug companies would wine and dine doctors. How do we know they are not doing this again?

[2023/11/10 08:26] Carolyn Carillon: EW: during my interviews, these people are doing such great work
They're trying to help communities
So Faith's question about trusting influencers is tricky
There are people you can't trust
Patients have to do their homework
They need to doublecheck the info they're getting
The ones we interviewed are truly making things better
But it's separating the good influences from those who are motivated by money

DG: my avatar looks so mysterious and moody
I'm supposed to be a vampire
One of the things I've learned as an influencer
When someone says trust me
I won't say that
Anything I promote are things we've tried or done
The medications are ones we've been on
I shy away from talking about medications because everyone is different
You should talk to your doctor
I will say, this is my story with that product
If you hear me say, trust me
Run away
That's a joke, by the way :)
More questions?

[2023/11/10 08:30] Pecos Kidd: Great job both of you. Thank you!!

[2023/11/10 08:30] Gentle Heron: We probably need to wrap up so the next presenter can get set up

[2023/11/10 08:30] Carolyn Carillon: EW: thanks for the invitation
this is cool

[2023/11/10 08:30] Daisy Gator (TheGator Resident): Excellent presentation! Fascinating!

[2023/11/10 08:30] Gentle Heron: Thank you both so much!

[2023/11/10 08:30] ♡ Andee ♡ (Andee Cooper): YaY claps

[2023/11/10 08:30] Itico Spectre: Stick around!

[2023/11/10 08:30] Carolyn Carillon: DG: thanks everyone

[2023/11/10 08:30] Eme Capalini: thank you for the presentation

[2023/11/10 08:30] Elektra Panthar: 🎵🎵🎵 Applauds 🎵🎵🎵

[2023/11/10 08:30] ♡ Andee ♡ (Andee Cooper): awesome presentation

[2023/11/10 08:30] Lou Netizen: thanks very much for being here and presenting

[2023/11/10 08:31] Keif Denimore: thank you both, very interesting!

[2023/11/10 08:32] Lilmesican Resident: Thank you for having us!!!

[2023/11/10 08:30] Carolyn Carillon: <<transcription ends>>