

“Who Can You Trust” MPHA Policy Forum

November 3rd, 2017...in making health care decisions?

Welcome- Lindsey Fabian, Past-President

Welcome to the first MPHA Policy Forum of this academic year. I am filling in for the new President, Becky Sechrist, who is at the APHA conference in Atlanta.

Moderator- Janny Brust

Janny worked for years in the public health world and recently retired. She is a past-president of MPHA and has been active for years. “My involvement in MPHA really enriched my life.” Janny became a member when she was fresh out of grad school and learned skills in a supportive environment that she was able to apply to her career.

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“Who Can You Trust?” Theme: In the olden days you believed your doctors and did whatever “he” said (they were all male). You also believed and trusted your mother and her knowledge of what to do when you’re sick. Today we’re inundated with information in healthcare. Some of the information is just plain wrong such as in the case of vaccinations. Sometimes people who are in power discuss these issues and then there is a tendency to believe them and it seems like a fact. You really can’t just take the information at face value. Also, information is more of an art than a science with multiple sets of risks, costs, and potential problems that have to be weighed. It really comes down to “Who Can You Trust?” to give you the best information.

Dr. Rebekah Nagler, Hubbard School of Journalism, University of Minnesota

I am a health communications researcher. Specifically tending to look more at the health information environment and how it may influence our beliefs, behaviors, and decision-making. My focus is mostly in the cancer prevention space- a function of training and funding. I will use some examples, but they really apply across the board. What we’re seeing in the health information/ communication landscape is a huge amount of information publically available. Has increased with the rise of the Internet. In the past you had to rely on gatekeepers such as the physician, but now we have information at our fingertips. When I say information environment, I mean everything- what you see on screens, print, and the physical environment (outdoor advertising, point of sale communication). We are also asking the public to play a more active role in their healthcare. This is creating a bit of a struggle for some patients; figure out how to negotiate this space. We are seeing that classic public health message is creating both positive and negative influence. Exposure can create adverse effects in that the more often people are exposed to adverse or contradicting information, or ever-changing recommendations, people are not sure what to do (e.g. recommendations for nutrition, or screening recommendations). People are becoming unsure of what to do and some adverse effects include:

confusion, backlash, decreased trust, not just about recommendations, but also more generally. This could be creating a climate of distress more broadly. The trust of science is at a bit of an all time low and it's a pivotal moment to mitigate negative messages and better equip people to make healthcare decisions. Additionally, healthcare literacy is crucially important. In communication and equalities (step under communication) we see differences among social groups, in processing, ability to obtain, and also what is done with the information. Differences in domains are seen and this can absolutely affect the decision-making.

Cira Sanchez, Director of Family Services, CLUES-Comunidades Latinas Unidas En Servicio

CLUES is the largest organization serving the Latino community and has many services including, but not limited to, mental health and case management. We serve 10,000 individuals and I'm here today to talk about the challenges that the Latino community faces in accessing the healthcare system.

Aubrey Stetter-Hesselberg, MS-CHE, CHES, Regional HPV Educator, Scenic Rivers Area Health Education Center

Based out of WI, part of a national HPV grant to assure all 50 states are represented (4/5 year grant- educate providers in 3 states). We attend forums, conduct webinars, lunch and learn and try to provide new viewpoints. Most people in their life will contract HPV and about 90% will clear in from their bodies. We don't know yet why that happens and there is research being done to figure out who are at the risk populations. Vaccinations are currently the best way to prevent HPV-related cancers. HPV came out in 2006. A ton of testing has been done on the vaccine. It is the most widely studied vaccine due to concerns and accusations when it came out. It's a really safe vaccination and is recommended for boys and girls around 11/12 years old (as early as 9). Tdap and Mening are also offered at this age and therefore the target population is already regularly coming into the doctors. In 2015 in MN Tdap was over healthy people goal of 80% at just under 91% and Mening was just under 84%, but HPV for females was not even 45% and for males was less than 23%. They're coming in to the clinic, but there is a concerning trend of not getting HPV at as high of rates. Where this all started was with the marketing as an anti-cancer vaccination, but also as sexually transmitted. Solely prevention should have been the focus in retrospect. HPV protects against cervical cancer and other cancers in both men and women. The US overall is lagging behind. A few states that require the vaccination for school, such as Rhode Island, are doing better with vaccination rates. The conversation of how HPV is attracted verse what it is preventing has really weighed heavy on the divided general community and also providers. Messaging behind this vacation has been key behind where this vaccination is.

J: "Why do you think that people have a hard time understanding health information?"

A: Generally, it's the way that we are now receiving information or are accepting to receive information. Social media is huge and can be super helpful, but can be hugely detrimental information. It's easy to spread bad information quickly.

C: From the Latino perspective, many people don't speak the language and all of the materials are in English.

J: "What about the cultural differences?"

C: In Latin America people don't have a primary doctor- they go to the pharmacy. When they come to this country they don't understand the mainstream health system. There are a lot of barriers including knowledge about services in the community, language, and cost to see the doctor. Also, some people don't believe in medicine and they only use home remedies.

R: For understanding, health literacy and understanding culture can be important-how information gets received and processed. Another one is numeracy, which is numbers and percentages. We often talk about numbers such as relative risk verse absolute risk. I teach a mass communications course at the U and administer a numeracy quiz. The scores are nowhere near perfect. People that even have quite a bit of education can still struggle to make calculations and really understand. When you look at information from a new study or even the CDC it's not something that may be easily understood even by someone that is well educated.

Another issue is trust and the influence of how we receive information. Science has become politicized, but has nothing to do with politics in a direct way. However it creates connections in people's mind.

J: "How do you combat some of this?" As we become polarized we tend to only believe the sources that we listen too, which is technically one side to an issue.

A: I'm by nature optimist. I try to see the best and do what I can. I think it's about being consistent and being open and honest with information and information sharing to humanely address someone's concern. Understanding that's it's really a concerned parent wanting what is best for their child. Ultimately it is about wanting what is best for the whole, not just the party.

R: Political scientists have called these "belief echoes" where false information gets out there and it's very hard to retract and correct it (e.g. vaccinations). Studies have shown that people have dug in more with corrective information- they understood, accepted, but do not change behavior. Humans have a complicated thought processing. It's important to find someone that is trusted, and an unexpected health source with aligned values that could be a way to pull people out of the belief echo. In short, we don't really know yet.

J: Only 1/10 Americans are able to make sense of and use information. Can you talk a little bit about this ability to understand and process this information? **"Do you**

know if there are any efforts to make sure that people understand what they are told?"

A: In a clinical system it's system-based. If there's a health educator, that would be the follow up person or if working with a caseworker they could be asked for further clarification. It's hard when resources are sent home to know that it's being understood.

C: When clients come out of the hospital they come to our agency and we have to translate all of those papers

R: One thing that people are working on is trying to figure out if we can do more in the clinical encounter such as by using visuals to help with decision-making and to better understanding risk-benefit tradeoff. It is a really tough challenge.

A: One hesitancy of patients is to ask providers questions. Be comfortable taking the provider's time and not feel bad as a consumer of your own health and healthcare.

J: It's good to bring a friend or relative with you when you have something complex going on- you can't always comprehend on the spot. It's one thing to take responsibility for you, **"What are some of the challenges that caregivers face around health information and trusting that information?"**

A: It is a different role that you play and you're responsible for someone else's choices and having an influence on their outcomes- it's a huge responsibility. There are multiple factors to consider such as sharing and understanding their values and ideas. Also being brave enough to slow down the provider and ask the right questions, take notes do your research, etc.

R: Information seeking relates to this. Some people enjoy this and some do not. For some a new diagnosis and lead to this information seeking, but for others a sort of paralysis can set in. Proxy seeking, where someone will seek information on your behalf is increasingly getting acknowledged, especially in cancer care.

C: We are the case manager, but are not related to the patient. Sometimes we have to make decisions for the patients. Many clients are here by themselves and are isolated.

J: "Do you think that people are getting more involved with their doctors visits? More compliance? Trust?"

A: Yes and no. There's research that shows that more affluent women are not taking the recommendation of their provider (e.g. vaccination), but rather are taking the more natural approach. This is fantastic when talking preventative, but with something like vaccinations- you can't eat enough to prevent HPV.- In these populations there is actually a bit more push back. Less educated individuals that trust their provider are more likely to take the information and recommendations. Right or wrong, it's an interesting dynamic. I am proud of people that take initiative

to be their own advocate and I hope for the providers' sake that there is system change and that they become better able to take more time to build relationship with patients.

C: Patient example- a woman went to see the doctor and was only seen for 3 minutes and was not able to actually share or feel comfortable to ask questions.

Questions from the floor:

“Due to the overwhelming amount of information online, do you think that providers should do more to educate their patients on how to hunt for correct resources” “Is it the medical systems responsibility?”

R: I'm not sure that doctors know any better. Are they equipped to do so? Example- no nutrition requirement in most medical school curriculums.

A: It comes down to what does that mean in your life (e.g. a handout given) and what information is pertinent. Even clinicians have a hard time navigating side effects and therefore even with help and guidance it's difficult for a patient to navigate even with assistance from a provider and/or pharmacist. I don't really know if providers are the best people to put all of these pieces together.

J: Someone comes in and has cancer- you know there's a whole lot of options, but they're only given two because they're old and assumed to have limited understanding. **“How would you advise the patient or what sort of resource/ advice could be give?”**

R: How much information do people actually want? Too much information may be too much of a burden. There are complexities, but not everyone wants a lot of information.

“Are the 20 min provider visits a big part of the problem around the communication of visits?”

A: I think it's very important to understand that you can shop around and find a physician that fits well for you. It's a privileged choice, but you do often have choice to some extent and should not feel bad for taking extra time.

C: Many community members don't have a choice; even if the fee is only \$20 they don't have that.

“Celebrity health concerns become news, then the news expands the coverage”

R: One of my now graduated PhD students did her work around this. There is a long history of celebrity announcements and where misinformation can come in. Researchers are tying announcements with uptake, but its uncertain if there is a

causal relationship. Regardless they are strong claims and therefore this is a real concern. There can be both positive and negative affects of celebrity disclosures.

“Are there specific recommendations, good groups, events or resources, degrees in health communications, a follow up to this forum?”

A: One of many solutions with thinking about the voices of the anti-vax community, they are really loud and prevalent and utilize social medial to spread their messaging. It’s vital that we have equally loud voices on the other end. It takes courage on behalf of public health people. It’s important to be brave enough to address false information whether even replying to something on social media.

C: Develop partnerships with the university, community agencies, churches, etc. to educate.

R: The solutions are the hardest part. Partnerships are critical. How to go beyond basic messaging such as with anti-tobacco campaigns (funded by ClearWay MN). It’s important to test messages.

Public forums through the university, PH communications courses, working on developing center for health communication at the U.

“Why is the HPV only approved for a certain age range?”

A: The research that has been done so far and also considering the age of sexual debut. Also, it’s not covered by insurance after a certain age. You can still request it at any age.

J: We so many connections, but in some ways we are becoming more disconnected in our polarized environment.

Our Forum's Panelists

Rebekah H. Nagler is an assistant professor in the Hubbard School of Journalism & Mass Communication and affiliate faculty in the School of Public Health at the University of Minnesota. Her research examines the effects of routine exposure to health information in the media, with a particular focus on conflicting and often controversial information about cancer prevention and screening. Her work has been funded by the National Institutes of Health, the American Cancer Society, and ClearWay Minnesota.

Cira Sanchez, is the Director of Family Enrichment Services for CLUES-- Comunidades Latinas Unidas En Servicio. Ms. Sanchez has twenty years of experience in the field of domestic violence and child protection services and ten years of experience working with CLUES and the Twin Cities' Latino population. CLUES offers programs designed to provide access to resources and opportunities for Latino families and individuals to be healthier, prosperous and engaged. Ms. Sanchez provides strong leadership and direction at CLUES in best serving clients' needs. She earned a Bachelor's degree in Sociology from City College in New York City.

Aubrey Stetter-Hesselberg, is the Regional HPV Educator for the Scenic Rivers Area Health Education Center.

Aubrey has been with Scenic Rivers Area Health Education Center for just under two years and is responsible for coordinating provider education sessions throughout Iowa, Minnesota, and Wisconsin. She also currently teaches at Western Technical College in La Crosse, Wisconsin. Her past experiences include work in a myriad of health promotion positions in the fields of wellness coaching and worksite wellness.

Our Forum's Moderator

Janny Brust is a consultant, focused on public health and managed care projects. She recently retired after 30 years working in a variety of public health and private health care sector positions. Those positions included Director of Medial Policy and Community Affairs at the Minnesota Council of Health Plans, Vice President of Public Health at Allina Health System and Epidemiologist for the Minneapolis Health Department. Janny is a past president of the Minnesota Public Health Association (MPHA). She also served as the MPHA affiliate representative for APHA, worked on the policy forums, and chaired or co-chair MPHA committees.