

Rating the Raters: How the Informed Patient Institute Assesses Health Care Quality Reports

Moderator: Lise Rybowski, Consultant, TalkingQuality; President, The Severyn Group

Speaker:

Carol Cronin, Executive Director, Informed Patient Institute

Lise Rybowski

From the Agency for Healthcare Research and Quality, welcome to a podcast from Talking Quality, a Web site about communicating comparative information on health care quality to consumers. I'm Lise Rybowski from the Severyn Group and I manage the TalkingQuality project.

Today I'm here with Carol Cronin, Executive Director of the Informed Patient Institute. The Informed Patient Institute, sometimes referred to as IPI, is an independent non-profit organization that helps consumers and patients get access to credible, online information on quality and patient safety.

Like a few other Web sites, including the Report Card Compendium that's part of TalkingQuality, the Informed Patient Institute lists the health care report cards that are available in each State. But then it does something that no one else is doing right now: it evaluates each of those reports against a set of specific criteria, gives them a grade, and says what's good or not-so-good about the report. The Web site's available at www.informedpatientinstitute.o-r-g [www.informedpatientinstitute.org].

Carol, thanks for being here today. Can you tell us a little bit about where you get the funding to do this work?

Carol Cronin

Thanks, Lise, for having me. The original funding for IPI came from a charitable trust called the Fine Schneider Charitable Fund and then we got subsequent funding from a variety of foundations, non-profits, and government agencies, including the California HealthCare Foundation, the Community Health Foundation of Western and Central New York, the Maine Health Management Coalition, AARP, and government agency called AHRQ. So we have had a variety of funding over the last couple of years.

Lise Rybowski

So when you create these report cards, tell me a little bit about how you assess them as you're looking at them.

Carol Cronin

We use a set of five or six different criteria. And they include the content of the site, what's the breadth of the types of information that's in it. Secondly, we look at the timeliness: was information provided, is it from the last two years? Are there multiple years of information? Does the site readily indicate when the information was last updated?

Third is presentation and we're looking there for things like: is it very clear whether better performers and poorer performers are differentiated? The fourth area of criteria are ease of use, can users find information in a reasonable amount of time? Fifth is information to help make decisions; do they have contextual information that helps people understand what the various performance measures are? Is there decision support about how to use it?

And then finally the sixth area is that we have the ability to add some points that they do a particularly good job or take them away if we see that they do something particularly poorly or if they used to something and now they don't do it anymore. So we apply these criteria consistently using kind of yes or no: yes the criteria is present, or no it's not. And we do this all online so we're rating online and then there's an algorithm that basically leads to a grade and then on top of the grade we also write a quick little review, short little sentences about what we liked about the site and a couple of things that we didn't like, so that what appears on the site is an overall grade and then a quick review of pluses and minuses.

And we do this annually. Every site gets looked at annually on the date a year after we looked at it and then we also, if we know that it changed, something comes to our attention that it changed, we'll actually look at it then. So it's a fairly elaborate process.

Lise Rybowski

It sounds like it. So how did you come up with all of these criteria?

Carol Cronin

I've worked for a variety of organizations looking at the whole issue of how Web sites are credible. I've done some work for AARP and the Markle Foundation, so I'm somewhat familiar with the whole area of credibility of health Web sites. And then [I] have also been somewhat steeped for quite a few years in the whole area of health care report cards, so I'm pretty knowledgeable about both usability issues and then also the content. In developing these criteria, so I kind of drew on that knowledge.

But I also did vet the criteria with other experts in the field. And also we tested them with regular folks to see if they work and fine tuned them, but they've really held up pretty well over a couple of years.

Lise Rybowski

Well, so far I'm seeing the Web site has information about reports on nursing homes and physicians so I'm interested in hearing about your general impression of all of the reports you've seen. Let's start with the nursing home one.

Carol Cronin

I think on the nursing home side that there really are some pretty good sites out there now, which is really useful because nursing home sites, I think, are particularly relevant for patients and families. This is a decision that families may have to make, you know, suddenly they have to make a decision, it's a pretty high stakes decision so I think that there is a lot of interest in nursing homes. And in our nursing home category, we have a couple of sites that really do rate an "A", which is our top grade.

One, for example, is CalQualityCompare, which is sponsored by the California Healthcare Foundation. And they have a lot of information, both the breadth of information about quality and other types of information. But it's also very well organized in terms of the ways they've conveyed it. They use words like superior down to poor, which is kind of a high-level rating and then they allow you to dig deeper and get more details. They also have a really nice way of helping people in a decision support fashion. You can answer some questions about your particular situation and then it gives you back the types of long-term care facilities you might consider.

So that's probably one of our top-rated sites, and there are other very good nursing home sites in Maryland, New York, in Ohio. Some of them even include family satisfaction surveys, which is something you don't see that much in the nursing home. So I would say there's some very good sites on the nursing home side.

Lise Rybowski

What about on the physician and medical group side, could you say the same thing?

Carol Cronin

I think there's much less content on the physician side. In contrast to nursing homes, we don't have any "A" sites, you know, top sites on the physician's side. There's just a lot fewer measures on the physician side in the first place so the sites that do have some measures, there's not a real breadth of measures.

Another problem with the physician sites, I think, from the perspective of consumers is that a lot of the measurement is done at the level of the group as opposed to at the level

of the individual physician, with some exceptions but mostly there. And there's little effort in many of the sites to help people understand overall which particular groups, or individuals, are better. So there's not any higher level rating like using stars or other types of icons to quickly help users know which sites overall are the best. So I think the physician sites have a long way to go. Although, they're getting better but they're not as good as the nursing home sites.

Lise Rybowski

Will you be evaluating more reports? What's coming next to the sites?

Carol Cronin

The next category we're looking at right now is actually the largest category that we have in our database and that's hospitals. There are probably over a 100 hospital sites. There's some that cover every hospital and then there's quite a few state-specific, so hospitals is what we're looking at next.

Lise Rybowski

So given all of your work in this area, what advice can you offer the organizations that develop reports on health care quality so that they do get an "A" from you?

Carol Cronin

I think it's a combination of both the content of the site and the usability of the site. And on the content we do see, there are increasingly sites that have some type of clinical quality information, albeit it's still relatively narrow in terms of the types of conditions and procedures it covers. But what you see less of, particularly on the nursing home side and the physician side, are satisfaction information. People understand satisfaction information and yet that's one area that you don't see that much, particularly on doctors and nursing homes.

Another type of information in terms of content which I think would be useful to see more of is the cost and charge information. People, I think, increasingly understand that a lot of health care is going to come out of their own pocket, even possibly more than it does now. So having more information about cost would be useful. And it would also be useful to see more efforts on the site sponsors to make the information more easily accessible to users by summarizing or aggregating the information and giving those higher level scores which quickly give people the ability to understand which health provider is doing better than another. So it differentiates providers quickly at a glance.

So those are some ideas on the content side, and on the usability side, I think the key here is that simpler is better than more complicated and possibly less is more. And having said that, there are users of these sites that are going to be interested in the details, so the opportunity to have high-level summary information that you can quickly, at a glance, get a sense of how these providers relate to one and other, but then also

the opportunity to drill down and get to more granular information for those users who want to do it.

Now having said that the tough part of doing this is that you also, in framing your whole site, you can't assume that the users will understand anything about quality or performance measurement or any of the content. So at the same time that you're trying to be simple and less complicated, you can't necessarily assume that people will know what you're talking about when you use words like quality or performance measurement.

So the trick, I think, is to really figure out how to convey some of those concepts that are fairly complicated but do it in a fashion that you know comes across as being relatively simple and uncomplicated. So I recognize it's not an easy thing to do; this is hard and I think we're learning and I can see the sites that are coming on now as opposed to a couple of years ago are really starting to learn those lessons. So I'm optimistic that they'll get better and better, but I want to recognize those folks that are doing this; this is not an easy task.

Lise Rybowski

Well I think that's really great advice for them. It certainly is a challenge for everybody who's working on these reports to do what you're describing.

Carol Cronin

Right.

Lise Rybowski

Now I understand that IPI has a new project; I wanted to ask you a little bit about that. You're developing tip sheets, right, for consumers to help them understand what they can do if they have a problem or a concern about quality and that's in a nursing home, hospital, or a doctor's office. So can you tell me a little more about these tip sheets?

Carol Cronin

Sure. The genesis of this set of activities was that I've been interested to think about a scenario where we can actually see the patients or family members or residents in the case of a nursing home actually recognize that quality varies, they kind of understand that message, and they're in a situation, in a nursing home or in a hospital or in a doctor's office, and they see something happen either to themselves or to a loved one. And the light bulb goes off in their head and they said that's, that's probably a quality issue. I'm seeing that right in front of my eyes.

So the question in my mind, which these tip sheets are trying to answer, is what are they supposed to do if they do see that quality concern. So they are written from a very

kind of practical question and answer format using as plain English simple terms as possible again, bearing in mind that this isn't an area that people know a lot about, and they really try and take you through a set of action steps which you can take if you do have a concern about quality: who you call, what you should do, what's the process look like, and so forth.

So we received some funding from the California HealthCare Foundation to do this work first in California: what to do if you have a concern about quality in a California hospital, or a California nursing home, or a California doctor's office. And then we replicated it in New York and in Maine and in Pennsylvania.

Lise Rybowski

And is this work related to the report cards you're evaluating?

Carol Cronin

Yes, it's related in a couple of ways. One of the sections of the tip sheets, the last section in all of them, is where can you go for information about quality or complaints, other types of information. So in each of the tip sheets, there's links to sites -- both national sites and sites in those particular States that include information about quality.

But what's been interesting is I've worked in this in depth in each of these States -- is that there is a whole type of information that does emanate out of the licensing part of the health provider world, so the department of health licensing, nursing homes, and hospitals.

And then the medical licensing board, licensing physicians -- and there is in some cases information that comes out of those worlds that really has not been very well integrated into the traditional report cards as we thought about them that really focused more on clinical quality. And I think that's a type of information in terms of complaints and possibly other types of enforcement actions that consumers might be very interested in. So I'm hoping that possibly down the road the folks that work on the broader-based report cards that have quality and patient satisfaction and those types of things, might consider how to better integrate information from health departments and licensing boards of various types.

Lise Rybowski

That's an interesting point. Does it ever work the other way around? Do the report cards use these tips sheets at all? Have you seen any doing that?

Carol Cronin

Oh yes, in fact that's one other aspect of what we're seeing is that some of the folks that sponsored these tip sheets -- for example, in Maine and in Pennsylvania it will be also

available -- they are including the tip sheets as part of their overall report cards. In addition to providing information about hospitals and doctors, they also have a section on general health information for consumers and are including the tip sheets. So it's nice; it allows people to find these both in the State, in a non-profit in the State, as well as through the Informed Patient Institute Web site. So it's kind of a double opportunity for people to get access to the information.

Lise Rybowski

So now that you've done this four times now, what are your impressions of what patients are faced with when they do have a concern about quality?

Carol Cronin

Well it's not an easy thing to do. I've been struck by the fact that it takes a fair amount of strength to decide that you want to call someone and say that you're not happy with something that you've seen. And you have to be prepared to take the time to have to explain it in some detail; you might have to explain it quite a few times and ultimately people may not agree with you, the way you see the situation. So it's not an easy thing.

One of the things I'm interested in doing is trying to identify best practice in this area in terms of what it feels like as a patient to have to express a concern about quality to a State agency or to another non-profit agency like the Joint Commission or a QIO. So my eyes have been opened in terms of the fact that this isn't easy, this isn't easy for patients or for family members to do.

Lise Rybowski

Now are there -- is it any easier for hospitals or doctors or nursing homes? Or are they all about the same?

Carol Cronin

No, I think nursing homes is the one area where there does seem to be more attention paid to the experience of the resident or the family member. There is generally in the nursing home area, there's actually a function within the State called an ombudsman whose job it is, as an independent party, to take complaints and try to resolve them. So I think that's a function that makes it a little bit easier to complain in a nursing home.

The other thing I found in terms of nursing homes is that there's often levels of review, there's often appeal rights that allow you to keep going up the chain in case you are turned down. You have an appeal right and there's also usually more specific timeframes around a nursing home process, you know, you have to be responded to within X days. And I'm wondering if the reason that all those things happen is perhaps because of the greater focus on nursing homes in terms of policy advocates and

nursing home advocates and so forth -- that they're just paying more attention to this and making sure that the process is a little bit more resident and family friendly.

So I'm -- it'd be interesting to see if there are analogies from that process that we can apply in the area of hospitals and doctors because I think it does make a difference from the perspective of the patient or the resident or the family.

Lise Rybowski

Well, thanks so much Carol. This really has been interesting and I look forward to seeing more of these tip sheets for consumers in other States. I'm also glad we had this opportunity to talk about everything you've been doing to rate the health care report cards and I hope that will be helpful to the many folks who are developing those reports. There are definitely a growing number of them and I think they'll really benefit [from] knowing more about the criteria you use.

You can check out Carol's site at www.informedpatientinstitute.o-r-g [www.informedpatientinstitute.org]. I'd also like to encourage our listeners to visit the TalkingQuality Web site at www.talkingquality.a-h-r-q.gov [www.talkingquality.ahrq.gov] to read about strategies for designing and promoting reports that can help improve your grade on Carol's site. To hear about future podcasts, be sure to subscribe to the TalkingQuality e-mail list by clicking on the little red envelope at the top of our Web site.

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