

“Why Tell Me Now?” The Public and Healthcare Providers Weigh in on Pandemic Influenza Messages

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As scientists closely watch avian influenza A (H5N1) or “bird flu” as a potential progenitor of an influenza pandemic, researchers from the Department of Health and Human Services, Centers for Disease Control and Prevention, and Oak Ridge Institute for Science and Education conducted with focus groups with the public and interviews with healthcare providers to test pandemic influenza messages. General public findings include variable awareness of pandemic influenza, subtle changes in terms (eg, flu or influenza), and challenged communication; and “vaccine priority group” opposition to the term priority group because it meant they could be left out. Healthcare providers reported Google and local infectious disease specialists as dominant sources of pandemic information. The results of the study provide specific guidance for those who will develop messages about pandemic influenza for the public and healthcare provider audiences.

KEY WORDS: influenza, messages, pandemic

As scientists closely monitor what could be the birth of a new and potentially deadly global influenza pandemic, social sciences researchers have embarked on a quest to discover what types of messages about pandemic flu will be most well understood and used by the public and healthcare providers.

From August 2–11, 2005, researchers from the Department of Health and Human Services, Centers for Disease Control and Prevention (CDC), and Oak Ridge Institute for Science and Education (ORISE) jointly conducted group and individual interviews with members of the public and with healthcare providers on messages that had been developed about pandemic influenza. The study was conducted in four cities in four

regions of the United States: New York City, New York; Wichita, Kansas; Portland, Oregon; and San Francisco, California.

The Department of Health and Human Services, the CDC, states, and others are preparing communication materials to inform stakeholders about pandemic influenza and issues associated with preparing for a potential outbreak.¹ In this study, materials were drafted and tested with some of the intended target audiences—the public and healthcare providers—to learn how to best address stakeholder needs and concerns. The results of the study provide specific guidance for those who will develop messages about pandemic influenza.

● Methods

The primary objective of the research was to test selected draft communication materials about pandemic influenza for understandability, believability/credibility, level of interest in the subject, perceived importance of the information, likelihood of action after being exposed to the information, and unanticipated consequences of the information.

Along with testing the pandemic influenza messages, the participants were asked several questions

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to explore their understanding of the influenza pandemic issues and concerns. Specifically, participants were asked their knowledge of pandemic influenza, perceived likelihood of a pandemic, anticipated seriousness of a pandemic, perceptions of personal risk, credibility of various information sources, possible responses to likely public health actions, and other expectations.

The messages were developed on the basis of the following formative research process. First, we conducted a content analysis of the CDC's electronic system that reviews 4,000 newspapers and other publications daily for articles regarding vaccines and vaccine-preventable diseases and then stores these articles in a media library. We looked for all articles during 2004 through June 2005 that contained questions pertaining to pandemic influenza; 2,879 pandemic influenza news reports were identified (1,592 in 2004 and 1,287 through June, 2005); and 175 questions or concerns about pandemic influenza were identified. Next, the questions were reviewed by influenza and communication subject-matter experts. Overlap was noted among the questions; some were specific to particular geographic areas, and some were considered too complex for this initial test: these questions were removed from consideration for the study. The remaining 80 questions were categorized according to topical areas: pandemic awareness; H5N1 avian influenza; influenza; antiviral medications; and preparedness. Multidisciplinary teams composed of communication and disease experts prepared responses, using standardized answer sheets.

From the pool of messages they prepared, 14 responses were selected to be tested. We deemed these 14 to address the most basic questions likely to be asked—questions that when answered would essentially form the foundation of understanding of the pandemic flu issue and the foundation for further questions, discussions, or debates:

1. What is an influenza pandemic?
2. What are the chances there will be another influenza pandemic?
3. What numbers of people (by age, medical condition, and socioeconomic class) are likely to get influenza in a pandemic? How many will die? What are the assumptions from which these expected numbers are derived?
4. If pandemic influenza comes to the United States, who is likely to get it first?
5. Is the United States prepared for an influenza pandemic?
6. Why are public health officials worried about an influenza pandemic?
7. Can a vaccine be made to protect against pandemic influenza?
8. How long will it take to make enough influenza vaccine for everyone?
9. Who should get pandemic influenza vaccines if there is not enough for everyone?
10. Who decides who will get vaccine first and how will they decide?
11. Are there medicines that can prevent or treat influenza if a pandemic breaks out? How effective are they?
12. What should people do in the event of an influenza pandemic?
13. Will the measures that people were told to take during the flu vaccine shortage in 2004–05 protect people from pandemic influenza (hand-washing, covering your mouth when you cough)?
14. Why aren't young children and critical service workers higher on the list of priority groups for pandemic influenza vaccination?

An example of the messages tested in response to the questions is found in Box 1. To reduce the introduction of messenger bias, the 14 messages were placed in the form of individual written fact sheets, eliminating influences that could be introduced using other presentation methods. Each fact sheet was designed similarly to include a question regarding pandemic influenza, three key messages addressing the question, the reiteration of those key messages in supporting information, referral to a site on the World Wide Web, and a toll-free number to call for additional information for each of the key points (Box 1).

Thirty-nine healthcare professionals (eg, physicians and nurse specialists) and 97 members of the general public were selected by market research companies, using a standardized screener that selected persons from existing consumer panel groups to attempt to achieve national representation.

Healthcare professionals were defined as physicians specializing in infectious diseases ($n = 6$), nurses specializing in infectious diseases ($n = 10$), emergency department physicians ($n = 10$), and family practice physicians ($n = 13$). The demographics of the healthcare professionals were as follows: 59 percent men; 82 percent White; 9 percent Asian; 6 percent Black; and 3 percent Hispanic.

The demographics of the consumer respondents were as follows: 49 percent men; 67 percent White; 12 percent Black; 7 percent Hispanic; 7 percent Asian or Pacific Islander; and 7 percent other. The healthcare professionals were interviewed in 1-hour in-depth individual interviews. The members of the general public were interviewed in 90-minute minigroup sessions with 3–5 participants at each session. Participants were asked to respond a predetermined set of questions, using a standardized format providing both written

BOX 1 ● What is pandemic influenza**Pandemic influenza is a global outbreak caused by a new influenza virus.**

- The virus may spread easily, possibly causing serious illness and death.
- Because so many people are at risk, serious consequences are possible.
- Historically, pandemic influenza has caused widespread harm and death.

Pandemic influenza is different from seasonal influenza (or “the flu”).

- Seasonal outbreaks of the flu are caused by viruses that are already among people.
- Pandemic influenza is caused by an influenza virus that is new to people.
- Pandemic influenza is likely to affect many more people than seasonal influenza.

Timing and consequences of pandemic influenza are difficult to predict.

- Pandemic influenza has occurred three times in the last century.
- Flu viruses are constantly changing.
- The most serious was the 1918 pandemic, which killed tens of millions of people worldwide.

Preparing now can limit the effects of pandemic influenza.

- The World Health Organization, the US Department of Health and Human Services, and countries throughout the world have developed emergency plans for pandemic influenza.
- Informed public participation and cooperation is needed for effective public health efforts.
- Individuals should stay informed about pandemic influenza and prepare as they would for any emergency.

For more information

- See Fact Sheets*
 - 105. What are the chances that there will be pandemic influenza again?
 - 202. Is the United States prepared for an influenza pandemic?
 - 215. What can individuals do to prepare for pandemic influenza?
- Call the CDC hotline at 1-800-CDC-INFO (1-800-232-4636).
- Go to <http://www.pandemicflu.gov> on the Internet.

*The message maps are located in the “Risk Communication” section of the www.pandemicflu.gov web site.

and verbal comments on the communication materials. The protocol and content of the sessions were reviewed, and the research was conducted in accordance with CDC and ORISE human subjects review requirements.

All participants were conversant in English, and all sessions were conducted in English; however, the moderator for the Hispanic groups could perform simultaneous Spanish translation if needed. Individual and minigroup interviews were led by professional moderators with a minimum of 5-year experience. Up to six observers from the Department of Health and Human Services (DHHS) Regional offices, DHHS National Vaccine Program Office, CDC, ORISE, and the US Department of Homeland Security, along with state and local health departments, observed the proceedings from behind one-way mirrors; representatives of all organizations were not present at all sessions. Observers provided written comments, evaluating each session, and proceedings were audiotaped for further analysis. All participants were debriefed by content specialists following each session to answer participant questions. At the conclusion of the minigroup and individual interviews sessions, observers and moderators identified and recorded qualitative findings that were significant for that session. Significant qualitative findings are reported in the results.

In addition to the message concept testing, health-care providers were also presented with two draft al-

gorithms for the diagnosis of pandemic influenza; one algorithm designed for use during an interpandemic period and one for use during a pandemic period were tested. These algorithms were developed by physicians of infectious disease and influenza in consultation with communication experts. Some of these persons had recent experience in the development of the CDC’s algorithm for the diagnosis of smallpox.

Testing was performed in each of the four locations according to the following schedule: New York City, New York, August 2, 2005; Wichita, Kansas, August 4, 2005; Portland, Oregon, August 9, 2005; and San Francisco, California, August 11, 2005.

At the conclusion of all the in-depth interviews and minigroup sessions, the moderators and observers presented their observations and conclusions at a wrap-up session. Those observers who were not in attendance at the wrap-up session were asked to provide written comments about the sessions they observed.

● Findings and Comments

Qualitative findings and comments that were consistently made by several observers are presented in this section. Observations that were seen in both healthcare and public groups are reported as crosscutting issues, whereas the findings specific for each of the two groups are presented separately.

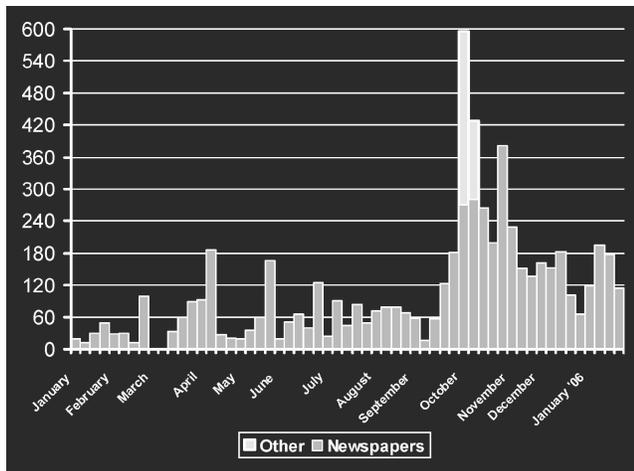


FIGURE 1. Weekly pandemic news stories frequency trend (January 2005 to January 2006).

Crosscutting issues

The draft communication materials elicited some similar responses from both public and healthcare providers.

1. Awareness regarding pandemic influenza varied across participants but was generally very low. Few participants from the general public recalled ever hearing the term *before*. Knowledge as to its definition and characteristics was correspondingly low. When asked what they thought it meant, one imaginative participant said it was combination of the words “panic” and “epidemic.” Numerous others expressed similar ideas; most recognized it as “something bad.”

Among healthcare providers, knowledge was also variable but somewhat better. Verbal comments from participants indicated that their concern about a pandemic was generally low (especially among the 13 family practitioners), although some recognized the potential seriousness. Health providers reported no instances of patients asking questions related to the topic.

The avian influenza virus H5N1 was not generally associated with the possibility of a pandemic. While a number of participants recalled hearing something about “bird flu,” it was seen as geographically remote, and not immediate, concern.

References to previous pandemics had little or no resonance with participants. Few, if any, recalled the influenza pandemic of 1968–69 and the special conditions that year. When the term *Hong Kong flu* was presented in discussion, it produced recognition among middle-aged and older participants but no association with “pandemic” or especially serious conditions. A few participants made passing reference to the pandemic of 1918–19. Comments typically addressed the fact that they had heard something about it, or that their

parents had talked about it, and that it was very bad. Only one participant mentioned the swine flu episode of the 1970s. It was a passing remark and only mildly negative.

After reviewing the draft communications fact sheet, there was general recognition of the global significance of a pandemic. Some participants from the public raised the issue of human immunodeficiency virus/acquired immunodeficiency syndrome as an example of a global pandemic.

2. The term *priority groups* had strong negative connotations. Many participants saw this as an elitist term—a euphemism for the wealthy, the famous, and politically powerful—potentially creating the appearance of a social justice issue. When the term was explained as referring to medical personnel, police, and firefighters, the strategy was readily accepted. Yet, the idea of also vaccinating the families of those groups first was not as well accepted.

3. There was little geographic variation in response. Some participants in San Francisco recognized their area as one with much travel to and from Asia, as well as immigration. They therefore deemed it more likely that H5N1 would occur in their area earlier than in other parts of the country. Respondents in Portland and Wichita did not communicate this sense of immediacy and in fact expressed belief that their localities would have some time to prepare before an epidemic reached them. Participants in New York City occupied an intermediate position.

These perceptions had no apparent effect on the sense of urgency or other aspects of response to the materials.

4. The most commonly cited sources of information were Google, followed by the CDC. When asked where they would seek additional information about pandemic flu, virtually all healthcare providers responded, “I’d Google™ it.” Many member of the public responded similarly.

Healthcare providers also cited several subscriptions services (eg, Medline) as sources they would use. Journals were mentioned infrequently.

The CDC continued to be regularly cited as a credible source of information by healthcare providers. Members of the public also had substantial name recognition for CDC and commonly described it as a source of objective information.

Healthcare providers responses

1. There was little sense of urgency among healthcare providers regarding pandemic influenza. Healthcare providers were primarily concerned with daily concerns and time limitations of each patient visit. This was especially noted among the six infectious disease specialists in New York City, where their focus is

care of patients with human immunodeficiency virus/acquired immunodeficiency syndrome.

A commonly held sentiment among healthcare providers was “When it’s important, tell me what to do and I’ll do it.”

2. Most reported they would contact an infectious disease specialist in their community or call CDC for more information. As previously noted, virtually all healthcare providers reported that they would use Google to find information on pandemic influenza. When asked who they would call for more information, they universally cited a local specialist.

3. The diagnostic algorithm was perceived as standard material, usable, and effective for its purpose. On the basis of the 13 family practitioners interviewed, family practitioners would likely have a high dependency on the algorithm. There were relatively few suggestions for substantive changes, and they will be addressed in the next iteration of the algorithm.

General public responses

1. Initial exposure to the information generally produced strong negative reactions and a strong desire to learn personal protective actions. Many described the information as “scary” or some equivalent. Participants demonstrated a strong desire to know actions that would protect themselves and their families during an influenza pandemic. Those who reviewed messages involving personal action (eg, respiratory etiquette) exhibited a sense of relief that they could do something. There was less interest in action they could take now, when a pandemic was neither present nor imminent.

Participants who received little or no information about protective actions they could take expressed helplessness and frustration. Some focused on self-help methods by professing their intent to “build up their immune systems” through various available means (better health habits, homeopathy, having their children wash their hands more frequently, avoiding travelers). Others professed aversion (“I don’t want to think about it.”). Still others chose to “shoot the bearer of bad news,” discounting the value of information by linking it to “duct-tape,” the “shortage-then-surplus” of influenza in the 2004–05 season, and other events that cast doubt on the credibility of the information. While these reactions were widespread among the respondents in public groups, some of this appeared to reflect a general distrust of government for some participants.

Respondents’ desire for actions they could take during a pandemic was exacerbated by both the unpredictability of pandemics and the strong negative language used in materials (eg, catastrophic, severe, shortages). The perceived contradiction (eg, between stockpiling medicines and expected shortages), as described in materials, also contributed to this.

International cooperation was perceived as very positive by many respondents, as was the involvement of the World Health Organization.

2. Members of the public anticipated that vaccine allocation in a pandemic would be as it is for seasonal influenza. Most respondents, in discussing the allocation of a vaccine if there was a shortage, expressed their belief or desire for medical workers, children, and the elderly to receive the vaccine.

3. The challenges of communication about pandemic influenza were enhanced by the number and subtlety of distinctions people are being asked to make. Consumers of the information were observed to make an effort to discriminate among a number of things and work to learn new terms:

- Influenza *versus* flu
- Flu *versus* other viruses
- Seasonal flu *versus* pandemic influenza
- H5N1 (“bird flu”) *versus* pandemic influenza
- Vaccine *versus* medication
- “regular” flu vaccine *versus* the vaccine against a pandemic strain
- vaccine specificity *versus* the broadness of antivirals
- antivirals *versus* antibiotics

Substantial confusion was observed as learning took place.

4. In the current terrorism-aware environment, several respondents spontaneously raised the question of pandemic as a terrorist tool. Recent attacks on mass transit systems and increased surveillance regarding them were raised as incidents increasing awareness of the possibility of terrorism and a possible link with pandemic influenza.

5. Respondents wanted to know the signs and symptoms of pandemic influenza. In the absence of a specific pandemic influenza, the signs and symptoms are like those for many other diseases (“flu-like symptoms”). Associating flu-like symptoms with pandemic influenza, in the absence of a specific disease, is likely to be confusing and raise undue alarm. More definitive signs and symptoms of pandemic influenza infection will need to be disseminated following the emergence of a dominant pandemic influenza strain.

6. Presentation of new knowledge suggested immediacy and imminence to the public. A frequently heard remark from participants was “Why are you telling me this now?” The information was perceived by some respondents as a warning about events that are going to occur in the upcoming respiratory tract infection season.

● Recommendations

The revised messages developed on the basis of the findings of this study will form the basis for all federal

government print and other communications with the public and healthcare providers regarding pandemic influenza. For example, for media interviews, the messages are the foundation for responses. Similarly, for print materials such as posters or news releases, the message will be the foundation for development, with topic selection based on the communication need at hand.

The findings suggest that neither the general public nor healthcare providers are particularly familiar with the term *pandemic influenza*. This is interesting in light of the fact that another CDC study found that there was a total of 3,654 news stories on pandemic influenza during the period of January 1, 2000–May 27, 2005, across the United States, with a little more than 150 stories occurring daily in 2005.²

As respondents from the public came to understand the term and the potential seriousness of the consequences of a pandemic, their reactions were negative and many recognized it as “scary.” Some found relief in learning actions they could take to protect themselves.

Therefore, to the extent possible, it is important to pair positive actions the public can take to protect themselves and their families with the descriptions of pandemic influenza and its consequences. Also, extremely negative terms used in the fact sheets should be used sparsely or edited out. Minimal use of negative words or images in public information should be balanced with positive elements (eg, international cooperation, preparedness).

Using the terms *pandemic influenza* and *pandemic influenza preparedness* consistently would assist the public in making the distinction between pandemic influenza and seasonal flu.

Mention of past influenza pandemics does not produce significant recall or a meaningful context for understanding the present threat now. It is important to explicitly explain why pandemic influenza preparedness is receiving attention today.

Speculation about the signs and symptoms of pandemic influenza does not provide a benefit to the public. It may be useful to explain that the specifics of an influenza virus that results in a pandemic could influence the symptoms it manifests. If a pandemic breaks out or if a new strain of pandemic is detected, then inform people of the signs and symptoms.

The terms *vaccine* and *antivirals* are not readily understood by the public. Communication should make the clear distinction that vaccine is used to prevent influenza, and, in a pandemic, antivirals will likely be used for treatment. Using the brand name “Tamiflu” to describe antivirals rather than the generic name Oseltamivir would similarly reduce confusion, even though the use of a brand name is contrary to normal protocol.

Communications should also emphasize the differences between seasonal influenza and pandemic influenza and provide explicit information on who is to be vaccinated first and why. The potential delay in the supply of vaccine effective against pandemic influenza should be explained often, and efforts to develop new techniques for faster vaccine production should be emphasized.

Messages about the critical policy area of establishing “priority” groups needs further attention as they elicited strong negative responses from the members of the public and, interestingly, healthcare providers as well, although many are likely to be in top priority groups and members of the public expected prioritization similar to that for seasonal influenza vaccine when supplies are short or delayed. Using the term *priority groups* should be avoided altogether. Instead, list the groups and why they are included (eg, “The plan is for all persons to receive the vaccine, these groups will receive it first because. . .”). Policy makers and spokespersons should be prepared to address the issue of vaccination of family members of those who are expected to be vaccinated first if the vaccine is in short supply.

No matter how clear and understandable the information is made, respondents among both healthcare providers and the general public preferred to avoid having to think about pandemic influenza unless they had to or unless a pandemic was imminent or present. This suggests that “just in time delivery” of information is preferred by both the public and healthcare providers who often have other timely concerns. While significant efforts should be devoted to preparing the public for a pandemic, it is most likely that attention to messages will increase as the perceived likelihood of a pandemic increases.

Both sets of respondents would primarily use the Google search engine and seek out the CDC for information on pandemic influenza. Since the CDC is viewed as an especially credible and objective authority, the CDC should consider collaborating with Google and other search engines to ensure high placement in search results and find other ways to capitalize on the recognition of the CDC name brand.

In addition, the study underscores the importance of maintaining updated e-mail databases and readying them for electronic communication with healthcare providers through proprietary sites if there is a pandemic alert. Pandemic treatment algorithms and materials should be available through Web-based medical databases and through handheld information retrieval.

Also, because healthcare providers would likely seek out assistance from specialists of infectious disease in their community, channels of communication should reach them specifically. For example, collaborative efforts should be developed with infectious disease professional associations, such as the Infectious Diseases

Society of America, to reach their members in real time. A directory of specialists can be included in electronic communications to family practitioners so they know whom to call in their area. Since state and local health departments will have critical roles during a pandemic, a directory of these agencies should be included also.

Since geography was not a determinate in the respondents' sense of urgency or awareness of pandemic influenza, information during the current inter-pandemic interval need not be substantially tailored to specific geographic areas. If circumstances change, such as the issuance of a pandemic alert, likely ports of entry would benefit from increased levels of communication attention.

● Additional Considerations

If efforts to educate the nation about pandemic influenza are successful, the public will increasingly become engaged in discussions about a pandemic's troubling outcomes—illness, death, the pressure on health institutions, lost livelihood, and commerce. The social pressure for certainty and answers will likely grow.

While the study fact sheets accurately described what is currently known about pandemic influenza and pandemic influenza preparedness, implicit in this study's findings are fear and unfulfilled information needs among respondents who read the fact sheets.

While it is not possible to predict when an epidemic will arrive, the questions the public will ask once a pandemic is imminent or present can be anticipated. Some questions will be an urgent reprise of questions already expressed and some will emerge as the event unfolds. For example, is there enough medication and a vaccine? Is government offering all the protection it can? Will the government prepare adequately and quickly enough? How will the economy and the healthcare system hold up? What should I do to protect my family and myself? The answers to these questions may help shape their personal responses to a pandemic. Will they turn to self-destructive modes of behavior such as substance abuse? Will they isolate themselves emotionally? Will some people and places become stigmatized as contaminated or unhealthy? How will workers maintain wages, salaries, and other forms of income if they are ill, or stay home to care for a sick child, or their workplaces close? What will happen to the economy and needed goods and services such as groceries, banking, and other basics of human life if many workers are ill? To address such concerns, CDC/DHHS should work with existing and new partners in mental health, disaster preparedness, business, and other disciplines.

The inter-pandemic period we are in today provides an opportunity to use the results of this study to con-

tinue to develop and test informational materials to address an additional range of complex dilemmas—practical, emotional, and psychological—that could arise during a pandemic. Time should also be devoted to using a scientific process for updating materials if necessary based on recent events, such as the movement of infected birds closer to the United States.

A significant limitation of the study is that it was conducted in English with the ability to translate into Spanish if needed. Many people in the United States are homeless or undocumented who present outreach challenges to the public health emergency response system. Future communication efforts must focus on the development of materials for multiple language groups and other populations not reached through mainstream media, such as persons with disabilities, sensory, or mobility; persons with low literacy; the behaviorally ill; the elderly, whether in nursing homes, assisted living sites or living independently; the homeless; those in recovery or otherwise institutionalized (half-way homes, group homes, and the incarcerated); and cultural or traditional groups such as Native American tribes.

Leaders and spokespersons at all levels of government, healthcare, business, and community life will need training and support to incorporate tested information into their communications with stakeholders and the public. According to a report from The Center for Biosecurity of Pittsburgh Medical Center, in an epidemic "Leaders must tend to immediate life-and-death matters such as caring for the sick, ward off socially corrosive effects like ostracism of the afflicted, and stem dramatic economic effects for victims and affected locales."³ Training and support for leaders and potential spokespersons must be advanced along with the information they will need to communicate effectively in times of crisis and uncertainty.

The lack of immediacy of an influenza pandemic provides both the challenge of making the subject meaningful to the public and healthcare providers and the opportunity to anticipate and prepare for the fullest possible range of information needs. Today the central question is "Why are you telling me now?" In the future it will be, "Did the United States do all it could while it still had time?"

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