

INNOVATIVE APPROACHES TO OBTAINING COMMUNITY FEEDBACK IN THE WITNESS FOR WELLNESS EXPERIENCE

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Background: Awareness of the need for innovative approaches to obtaining feedback in community-based participatory research (CBPR) is increasing. These innovative approaches should incorporate the core principles of CBPR, including equity and co-learning. Additionally, the methods should be culturally appropriate and inclusive of the community and academic partners.

Objective: To develop and implement two separate methods of obtaining community feedback for two activities in a CBPR initiative: 1) discussion of three work-group plans during a leadership council meeting; and 2) feedback from the work groups to the target community in a public setting.

Methods: In order to facilitate a feedback process for the discussion of 3 separate group action plans, an adapted version of the modified Delphi technique was used during which 42 community and academic partners voted and evaluated each plan both before and after group discussion. Results were immediately posted on a projection screen for the group to process. The second community feedback method incorporated the use of an audience response system (ARS) in order to obtain responses from 187 community participants after hearing summaries of the Witness for Wellness work-group action plans. More than 60% of the respondents added that the use of the handheld device made research seem more relevant and less intimidating.

Conclusions: Both the use of the adapted modified Delphi process and ARS were effective in capturing community feedback related to two group activities in the Witness for Wellness initiative. Both methods also allowed participants to understand the role of research in a community setting. (*Ethn Dis.* 2006;16[suppl 1]:S1-35-S1-42)

Key Words: Assessment, Community, Delphi, Feedback, Participatory, Research

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INTRODUCTION

Recent clinical and public health research experts have emphasized the importance of an expanded role for public participation and use of community-based participatory research (CBPR) to achieve more relevant clinical research overall and more effective research on health disparities in particular.¹⁻³ Public participation may foster the adoption of research findings and tools within communities, while CBPR methods offer an approach to generate research of greater relevance to diverse communities that participate directly in it. Community-based participatory research (CBPR) also allows for communities that are historically underrepresented in research to gain more trust and understanding of the research process. Communities of color have rarely had an opportunity to voice their preferences for research methods and techniques in evaluation. In a recent Agency for Healthcare Research and Quality-sponsored review by Viswanathan et al, the importance of community participation and partnership in all phases of research was cited as the defining feature of CBPR initiatives.⁴ But what are the methods of facilitating and documenting community participation in agenda setting or goal formulation, a step that indicates whether a partnership has existed from the outset of an initiative? Additionally do innovative methods comfortably give the community tools that capture the consensus-building process?

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This paper describes two methods of facilitating and documenting community participation in agenda setting for a CBPR project. One method, adapted from the modified Delphi consensus process, is a familiar paradigm within health-services research. The other method, a computerized audience response system (ARS), is more familiar within communities, as it is similar to audience feedback mechanisms used on television game shows. The two unique methods offered a chance to explore the feasibility of structured methods for obtaining feedback on issues germane to community-academic partnerships as well as an understanding of the acceptability of technology-related research methods by the community members themselves.

Additional examples of social engagement include establishing an equitable partnership,⁵ empowering community members for leadership and action according to their own priorities,⁶ and establishing a collaborative process of feedback among community and academic partners.⁷ Communities need to feel that the research can give them a voice that will be acknowledged and respected throughout the collaboration. Since this can pose a formidable challenge, the literature describes strategies to evaluate group satisfaction,

CBPR methods offer an approach to generate research of greater relevance to diverse communities that participate directly in it.

cohesion, and productivity for health coalitions,^{8,9} descriptions of the evolution of community participation in specific projects (eg, Minkler and Wallerstein,¹⁰ Travers et al¹¹), and strategies to enhance participation of specific under-served communities (eg, Zambrana et al¹²). While the two methods we describe are not explicitly aimed at evaluation, they offer opportunity and insight into the development of participatory evaluation strategies that build on social engagement models.

While formal consensus-development methods such as the modified Delphi process have been used extensively in health-services research, for example, to establish practice guidelines,^{13,14} we do not know whether these methods would be acceptable for use with under-served communities. In general, fewer established procedures exist for conducting culturally competent and responsive participation research in community-based research when compared to the evaluation literature for traditional health-services research.¹⁵

The agenda-setting consensus methods explored in this project each hold some potential to capture the feedback of the community while attending to key principles of CBPR. Each method also has the potential to help the community incorporate research tools and principles into the day-to-day community structure so that they empower the participants to do their job. In this respect, these principles also represent a kind of conceptual framework or perspective that underlie their application in this study. The following terms were used in building the framework and processes of these methods. Inclusiveness: a fundamental tenet of participatory feedback in CBPR is that it attempts to involve all the people who have an interest in the outcomes of the research.¹⁶ Transparency: traditional research methods generally emphasize scientific objectivity by distancing investigators from other participants; re-

search in CBPR involves self-assessment and is transparent to members of the community. Equity: the use of participatory (including consensus) methods within CBPR has become an important part of the project itself, which suggests that the selection of methods should facilitate the same kind of equitable process and products as the underlying project.¹⁷ Documentation/Public and Scientific Transparency: documented, explicit processes within CBPR projects are important to achieve transparency of the process across project stakeholders as well as facilitating replication and funding for future work.¹⁸

Based on this framework, we thought that the two separate methods of capturing feedback (modified Delphi-based and ARS) would be seen as increasing the inclusiveness, equity, and documentation of the process.^{19,20} Each method also offers a unique insight into the emotional reactions, sentiments, and opinions about the process and objective of data aggregation.

DESCRIPTION OF THE WITNESS FOR WELLNESS PROJECT

The Witness for Wellness project is a collaborative initiative between Healthy African-American Families (HAAF, a community-based organization), Charles R. Drew University, University of California–Los Angeles (UCLA), and RAND aimed at addressing the recognition and treatment of depression among African Americans in the Los Angeles area. The initiative was based on an existing CBPR method developed by HAAF and the Centers for Disease Control and Prevention (CDC) for work on reducing infant mortality in communities of color.²¹ This method, called community-participatory partnered research (CPPR), features community groups that develop work plans and submit them to the community, respond to suggestions for revisions, and

present for consideration a final set of work plans. Building on this two-step feedback process, the Witness for Wellness initiative is a strong partnership that uses a community and academic evaluation committee within the initiative. The project is overseen by the Wellness Council, which serves as a community advisory board with members from academia and African-American community-based organizations. Under the structure of the Wellness Council, three working groups each have a different concentration: Supporting Wellness deals with policy and advocacy issues around depression, Building Wellness trains and educates healthcare providers on depression, and Talking Wellness is committed to increasing awareness about depression through arts and prose.

Nine months after the initial Witness for Wellness community conference, held in July 2001, all three of the Witness for Wellness work groups had developed work plans that were to be used as a guide for the activities and research in the project. The participants in the project wanted an opportunity to review all of the work-group plans in a group setting to provide internal feedback to each of the three groups. The overall goals of a review process were:

1. To develop a process of eliciting input that would be culturally appropriate and engaging to the community
2. To document the process
3. To build on well-documented approaches in the literature for facilitating differences in viewpoints but working toward a consensus
4. To ensure flexibility during the decision-making process
5. To make sure that any review process is transparent to the community
6. To allow community members to see that their input was received in real time by the members of the working groups.

USE OF THE ADAPTED MODIFIED DELPHI TECHNIQUE

In considering how to achieve these goals, the Witness for Wellness executive committee, consisting of several academic and community members, considered several options, all of which would be recorded by trained scribes. These included: 1) informal presentations of plans with discussions recorded by trained scribes; 2) voting on plans followed by a discussion; or 3) a formal modified Delphi process to arrive at consensus. A Delphi process involves review of materials, eliciting rankings, discussing differences, modifying materials, and re-voting with a statistical marker such as a median to represent the consensus.¹³ The technique has been used widely in the literature to capture a range of topics, including quality of clinical care and the development of educational curricula.²² It also involves careful selection of participants. Its use in CBPR has been documented as early as 1980, when Hancock et al used the process to identify key health issues in a community in Toronto.²³ The Delphi method posed particular appeal for the Witness for Wellness community because it provided an opportunity to capture the feedback of a group in a meaningful, scientific way that is also efficient. The resulting plan for eliciting initial feedback on the work plans (the adapted modified Delphi technique) blended both the informal and formal methods that the group felt were important to the process. In this adaptation, each work group briefly presented its plans to 42 work group members, academic researchers, and community members of the Witness for Wellness project. Any interested project participants were included in the process, which had no minimum requirements or exclusion criteria. Each group's action plan consisted of short-term and long-term goals with specific target audiences, interven-

tion activities, and potential collaborations. For example, the Supporting Wellness work group, which deals with policy and advocacy around issues related to depression, had an action plan consisting of short-term member-education initiatives related to the fundamentals of health policy. One of the overall long-term goals is to change the policy related to provision of mental-health services for uninsured African Americans in the south Los Angeles area.

After each workgroup's presentations, 42 members were each asked to rate the group's plan on the basis of six items: clarity, feasibility, impact, reach, appropriateness, and feeling. "Clarity" referred to whether or not the respondent understood the plan itself. "Feasibility" referred to the respondent's perception of the group's ability to carry out the action plan. "Impact" is the perception of the overall effect that the plan will have on the Witness for Wellness project. "Reach" referred to the scope of the project and whether or not the action plans were consistent with the objectives of the working groups. "Appropriateness" is the level of cultural and community sensitivity that each plan encompasses. Finally, "feeling" is the respondent's "gut reaction" to the overall plan. All of the responses for the items, with the exception of feeling, were on a Likert scale of 1 to 5 (very weak, weak, okay, strong, very strong). The responses to feeling were also on a five-point Likert scale with different rating values (I don't like and shouldn't be carried out, I don't like it but won't stand in the way, I have no opinion, I basically like it, I really like it). The findings were then entered into a computer with some time allowed for the computer operator to enter the data and display them on a projection screen to show the degree of agreement and distribution of opinion. The ease with which the results were displayed and the transparency in which it was done (no editing before

viewing, etc) was well received by the community members.

Pursuant to the ratings and overall ranking of the work plans, community and academic moderators co-facilitated a discussion of the entire group, focusing on clarifying one or two priorities for modification. Then the entire group re-rated the work plans with the same scales that were previously used. This process was repeated for the next two work-group plans so that the Supporting, Building, and Talking Wellness plans were all reviewed. The revised ratings were not available until shortly after the meeting because of the time necessary to collate the data.

The response rate for the items was 99%. The pre- and post-discussion mean, median, standard deviation, and number of responses were available immediately for the respondents. Mean responses on the five-point Likert scales were used to compare the pre- and post-discussion responses (Table 1). For most of the items, the discussion resulted in higher ratings, with the exception of the action plan for the Building Wellness working group whose main objective is to oversee the development of training for community mental-health volunteers and providers. The mean ratings for clarity, feasibility, reach, appropriateness, and feeling were all lower than the pre-discussion ratings, but only the rating of the "feeling" item (How do you feel about this action plan?) was statistically significant (Table 2). Since the before and after comparisons were not available until after the meeting, the Witness For Wellness members responded to the initial ratings and offered the specific work groups additional feedback based on the initial ratings.

During the adapted modified Delphi process, the co-facilitators noted that the structured sequencing of presentations and ratings seemed to cause initial discomfort in the community, and some participants felt that they were being graded or evaluated during the

Table 1. Summary of Community Responses: Witness for Wellness Work-Group Meeting (3/12/2004)

Group	Item	Pre-Discussion				Post-Discussion			
		n Rating	Mean Rating	SD	Median Rating	n Rating	Mean Rating	SD	Median Rating
Talking Wellness	Clarity	42	3.83	.85	4	31	4.00	.68	4
	Feasibility	42	3.62	.76	4	31	3.94	.68	4
	Impact	42	3.74	.99	4	31	3.97	.71	4
	Reach	42	3.40	1.23	3.5	31	3.71	.82	4
	Appropriateness	42	3.90	.93	4	31	3.97	1.02	4
	Feeling	41	4.27	.90	4	30	4.37	.61	4
Building Wellness	Clarity	41	3.76	.92	4	30	3.57	.73	4
	Feasibility	41	3.68	.85	4	30	3.53	.82	4
	Impact	41	3.85	.82	4	30	3.97	.68	4
	Reach	41	3.83	.89	4	30	3.80	.81	4
	Appropriateness	41	3.88	.87	4	30	3.70	.95	4
	Feeling	40	4.33	.66	4	30	3.87	1.07	4
Supporting Wellness	Clarity	38	4.29	.69	4	29	4.34	.61	4
	Feasibility	38	4.18	.73	4	29	4.24	.64	4
	Impact	38	4.05	.80	4	29	4.28	.70	4
	Reach	38	4.16	.86	4	29	4.31	.71	4
	Appropriateness	38	4.26	.69	4	29	4.34	.67	4
	Feeling	37	4.57	.50	5	30	4.50	.57	5

Note: The rating values for items "Clarity," "Feasibility," "Impact," and "Reach," are: 1=very weak; 2=weak; 3=okay; 4=strong; 5=very strong. The rating values for item "Feeling" are: 1=I don't like and shouldn't be carried out; 2=I don't like it but won't stand in the way; 3=I have no opinion; 4=I basically like it; 5=I really like it.

process. However, the researchers who were more familiar with the process eased the discomfort by acknowledging the fact that most community members have never heard or used this type of process. Toward the end of the feedback session, the community participants were very satisfied with the process.

USE OF THE ARS

The adapted modified Delphi process gave the Witness for Wellness executive committee an opportunity to reflect on the use of technology in community participatory research. The group felt that a different process which would allow for timely feedback would be appropriate for the next Witness for Wellness event, which was an external community feedback meeting called the Report Back Conference.²⁴ In contrast to the first meeting, which was an internal feedback process, the second session was meant to serve as a report to and from the community and was held in a large south Los Angeles movie

theater in July 2004. The community and academic members thought through the various options for capturing feedback including surveys and focus groups, but an opportunity to use an ARS made the decision much easier for the group. The ARS provided a timely system that was suitable for individual responses in the setting of a movie theater.

Once the availability of a technician and an adequate number of handheld units was confirmed, community and academic members worked to develop the questions to be used with the ARS. It was the first time that some of the participants had developed questions for others to answer, and a sense of responsibility was attached to the task. The community members of each group also paid particular attention to the need and use of culturally appropriate language and terms that would be familiar to community members. Each group engaged in lively discussions in person, over email, and via telephone to finally arrive at 39 questions that both conveyed a sense of work-group purpose

and succinctly asked the community for their viewpoints. These questions ranged in scope depending on the objective of the work group. Responses were either dichotomous (yes/no), on a five-point Likert scale (I really like it, I basically like it, I have no opinion, I don't like it but won't stand in the way, I don't like it and don't think it should be carried out as designed), or a choice of four options. The questions were submitted to the ARS technician one week before the Report Back Conference in order to program the handheld response units.

Approximately 167 people attended the Report Back Conference in response to a snowball mechanism of recruitment. All of the Witness for Wellness workgroup members were asked to disseminate flyers and news about the conference to other community-based organizations and mental-health service offices. Of the attendees, 63 (40.1%) were affiliated with community-based organizations, 26 (16.6%) were government officials, 30 (19.1%) held an academic affiliation, 17 (10.8%) were

Table 2. Comparison of Before and After Responses: Witness for Wellness Work-Group Meeting (3/12/2004)

Group	Item	Pre-Discussion			Post-Discussion			Differences			
		n	Mean	SE	n	Mean	SE	Mean (post-pre)	SE (post-pre)	t Stat	P Value
Talking Wellness	Clarity	42	3.8333	.1316	31	4	.1227	.1667	.186	.90	.3734
	Feasibility	42	3.619	.1178	31	3.9355	.1221	.3164	.1727	1.83	.0711
	Impact	42	3.7381	.1526	31	3.9677	.1269	.2296	.2086	1.10	.2746
	Reach	42	3.4048	.1899	31	3.7097	.1481	.3049	.2553	1.27*	.2096*
	Appropriateness	42	3.9048	.1438	31	3.9677	.1825	.063	.2293	.27	.7844
	Feeling	41	4.2683	.1398	30	4.3667	.1123	.0984	.1897	.55*	.5850*
Building Wellness	Clarity	41	3.7561	.1431	30	3.5667	.1329	-.189	.2023	-.94	.3524
	Feasibility	41	3.6829	.1327	30	3.5333	.1496	-.15	.2011	-.74	.4595
	Impact	41	3.8537	.1286	30	3.8667	.1244	.013	.1843	.07	.9439
	Reach	41	3.8293	.1393	30	3.8	.147	-.029	.2058	-.14	.8873
	Appropriateness	41	3.878	.1361	30	3.7	.1739	-.178	.2178	-.82	.4164
	Feeling	40	4.325	.1037	30	3.8667	.1961	-.458	.2076	-2.07*	.0446*
Supporting Wellness	Clarity	38	4.2895	.1126	29	4.3448	.114	.0554	.1629	.34	.7351
	Feasibility	38	4.1842	.1184	29	4.2414	.118	.0572	.1703	.34	.7382
	Impact	38	4.0526	.1304	29	4.2759	.1303	.2232	.1878	1.19	.2388
	Reach	38	4.1579	.1387	29	4.3103	.1323	.1525	.1965	.78	.4405
	Appropriateness	38	4.2632	.1111	29	4.3448	.1243	.0817	.1673	.49	.6271
	Feeling	37	4.5676	.0826	30	4.5	.1045	-.068	.1314	-.51	.6087

* The null hypothesis of equal variances are rejected and the calculations are based on the "Satterthwaite" approximations, while in the case of equal variances, the pooled t tests are used.
SE=standard error.

health professionals, and the remainder had no formal affiliations. These demographics are consistent with other partnership projects and outreach interventions involving health professionals.²⁵ The Wellness Council, which is an at-large group tasked with overseeing the activities of the three work groups, coordinated the scheduling for the conference activities. The morning opened with an overview of the Witness for Wellness project, followed by a series of presentations by each of three work groups. Each group spent ≈20–30 minutes giving a Power-Point presentation that went over their purpose, action plan, and future initiatives.

Before each of the work-group presentations, individual handheld units were distributed to each audience member. In order to ensure that each participant understood how to use the device, a brief orientation was conducted upon distribution of the units. Additionally, the audience was given an overview of how to interpret the results so that when the responses were tallied and projected on the movie screen,

individual members of the audience could understand how their answers compared with others and what the researchers might do with that information. The conference co-facilitators and other work-group leaders noted an air of excitement as the keypads were handed out, which highlighted the eagerness to use innovative technology to capture community sentiment. Assistance from two research assistants was available if needed. The ARS has previously generally been used as a teaching tool for house staff and physicians.^{19,26} The use of ARS has been shown to improve retention rates of factual information in educational settings but has not been used in this type of forum for community-based participatory research.^{20,27}

After each workgroup gave their presentations, the audience responded to a series of questions related to the workgroup. Each question was projected on the movie screen, and a moderator read the entire question and all of the response choices out loud to facilitate any literacy needs. Then the audience was given a fixed amount of time (one minute) to key in their

response. After all of the questions related to the particular workgroup were answered, a distribution graph of all the responses was projected for each question. This method immediately provided the audience with an opportunity to see how their individual responses were aggregated with other responses.

Response rate for the questions ranged from 36% for one question to almost 95% for the remainder. The poor response rate was in answer to the following question: "If we want to make it safer to talk about depression, what would be the best starting point?" The lower response rate may have been related to the complex nature of the questions and the brief period in which people had to respond (approximately one minute per question). Five questions at the end dealt with the overall process of the day. When asked whether the work plans were clear and easy to understand, 62.4% (n=98) responded "agree" or "strongly agree." In response to the final question, "Having the community vote in this way is an excellent way of giving them a voice," 83% (n=132) indicated that they

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strongly agreed with the statement; 98.7% ($n=151$) found the voting procedure to be very comfortable.

Finally, any potential monotony of being asked a series of questions that could seem quite detailed was alleviated with intervals of hip-hop music provided by the ARS technical programmer who also displayed the results on the theater movie screen. Audience participants commented on how the ARS process was “therapeutic” in and of itself because it allowed for people to be anonymous, which was important for a stigmatized issue such as depression. Some members later expressed that it was the first time that research really echoed the sentiment of the community. The ease with which the collective responses were displayed on a movie screen also excited both academic researchers and community members, reinforcing the importance placed on transparency and co-learning.

DISCUSSION

Community-based participatory research (CBPR) is a growing set of principles to guide public health and clinical research, but the methods for engaging community members in decisionmaking have not always been explicit. In this article, we attempted to develop methods to support community participation in decisionmaking that were both culturally appropriate and inclusive. The first method, the adapted modified Delphi technique, was used

for an internal feedback process among project participants. The second method, the ARS, was used for an external feedback process with people from the community.

The two methods are unique but are responsive to the basic values and principles of CBPR. The literature currently offers a range of principles and some strategies to enhance the scope and depth of community participation in research. For example, two central principles of CBPR are the promotion of co-learning and the realignment of previous hierarchical relationships to enable an equal partnership. Such realignment may benefit from the use of communication strategies, group games, and other activities that promote the transfer of knowledge and experience across partners. Group activities can also be tailored to allow for cultural expression and allow for the community members to plan the specific details with academic partners, a process that is empowering. The ARS provides an opportunity for community and academic members alike to generate culturally sensitive, research-relevant questions. Similar strategies and mechanisms of social engagement should generate trust between partners and might benefit from written agreement on key principles of interaction.^{7,28–30} Hope and Timmel,³¹ for example, provide a comprehensive guide to engagement strategies for use with under-served communities. In turn, these written agreements can help document processes that work in particular community settings for future collaborations. In a similar fashion, the modified Delphi process offers an opportunity for written agreement and technological and social engagement.

Through co-learning and sharing in the responsibility of developing questions and implementation strategies, both of the resulting methods are also a reflection of the language and culture of the African-American community and the scientific background of the research

community. The result was a process that was transparent and meaningful to the community, which was reflected in verbal feedback from each of the community leaders present at one or both of the feedback events. Each community work-group leader (six in total) was given the opportunity to express his or her thoughts after each of the two sessions, and the consensus among the leadership was that both the adapted modified Delphi technique and the ARS were community-friendly and made community members feel like they were being told the truth about research. The two methods provided a fair way of incorporating feedback across participants (equitable) and facilitated public/scientific documentation.

At a debriefing meeting held after the Report Back Conference, several community members felt that the ARS feedback process “finally gave the community a voice” and helped people feel that Witness for Wellness is a “safe place.” Community members expressed the sentiment that the process of using the handheld units was therapeutic. Project work-group leaders also felt that both the adapted Delphi technique and the ARS taught them practical leadership and research skills that will be useful in future settings. Finally, one of the community members, a former African-American health professional, said that the methods made the project more credible and helped show the “importance of the project beyond a publication.”

Both the adapted modified Delphi system and the ARS have helped obtain community feedback on important issues in the Witness for Wellness experience. The adapted modified Delphi process was useful to facilitate discussion and prioritization and providing a fair process of incorporating and displaying community feedback, while also documenting that feedback explicitly and in real time. But this process may have been more stressful during initial implementation, and in this sense may have been less

meaningful to the community, than one based on more familiar paradigms. This problem might be improved by incorporating a more entertaining presentation style, greater explanation, or training of community facilitators. In contrast to the adapted modified Delphi system, the ARS was popular with the participants and did not seem to cause any initial discomfort or hesitation. Furthermore, it excited the community members to share knowledge with each other and the collaborators. The community was engaged in the process and even asked some of the research members how they could get involved in careers in academics. The ARS method was also nonthreatening, which may have helped ensure a wider range of responses from the audience. The success of the ARS method is tempered by the possibility that some of the richness may have been lost because it offered no opportunity for a post-discussion revision of opinions. In other words, we learned less in a formal way about the meaning of the project's goals to the community than with the Delphi-based method. In the future, we might consider follow-up small group discussions or tables with scribes to capture the depth of the community's opinions, but we have no assurance that this method would yield as inclusive or equitable a review of the opinion in the community as the more formal discussion process inherent to the Delphi method.

The use of the adapted Delphi process and ARS has not been previously described, to our knowledge, in the context of CBPR. Several lessons were learned from the two experiences. First, these techniques can be used to elicit sentiment and share knowledge between academia and the community and among community members and working partnership groups with diverse goals. Second, the process by which the questions for the ARS were developed was both community generated and community relevant. This aspect lends itself to the promotion of a true

community-academic partnership.^{4,32} Third, the methods of engaging community participation in CBPR are themselves a subject for future development and research.

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