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What is This?

Collecting Race, Ethnicity, and Language Data to Identify and Reduce Health Disparities: Perceptions of Health Plan Enrollees

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Abstract

Collection of race, ethnicity, and primary language data of health plan members is a recognized important step in addressing disparities in health care. The authors conducted six focus groups to examine perceptions of Massachusetts consumers about collection and use of race/ethnicity and language data by health plans, preferences for how and when the data should be collected, and preferences for racial/ethnic categories. Consumers understood the utility of collecting primary language data from members but expressed concerns about the collection of race/ethnicity data. Despite these concerns, they provided suggestions for using the data to improve care. Their preferences for racial/ethnic categories suggested that they wanted a balance between simplicity and reasonable granular detail. Ultimately, consumers wanted to be assured that the information they provided to health plans would be used to improve quality, and they wanted to be able to provide this information without undue burden and with assurances of confidentiality.

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A fundamental step to achieving the goal of a more equitable health care system is the systematic collection and use of patients' race/ethnicity and primary language information. Experts, accreditation bodies, the Institute of Medicine (IOM), and policy makers note that these data create the underlying foundation for identifying where and why disparities exist (Ver Ploeg & Perrins, 2004; IOM, 2009).

Health care involves a diverse set of public and private data collection systems, and no one set of organizations, such as hospitals, health plans, and federal or state agencies, currently has the capacity to collect race, ethnicity, and language data for the entire population. For example, these data are not commonly collected in doctors' offices, though this setting could provide a trusting environment to gather such information, (Nerenz, Hunt, & Escarce, 2006; Wynia, Ivey, & Hasnain-Wynia, 2010). Hospitals often have the staff and information systems to collect these data, but they serve only a small percentage of the overall population each year. Federal and state agencies administer surveys to estimate the health of populations and future health services needs, but these are generally population data that cannot be integrated into specific health care delivery sites (IOM, 2009).

Health plans manage health benefits for the majority of the U.S. population and play a central role in health care delivery. They are uniquely positioned to collect and use race, ethnicity, and primary language data captured from encounters across multiple settings. However, unlike hospitals, clinics, and physician practices, they rarely have direct contact with their members/enrollees. This lack of direct contact (and other factors) might diminish trust, which would create a barrier to data collection. In fact, Boulware, Cooper, Ratner, LaVeist, and Powe (2003) found that a majority of Black and White individuals reported that they trusted their physicians and hospitals but far fewer trusted their health plans. Reflecting the presumed importance of direct contact in collecting demographic data, those health plans that collect race/ethnicity and language data generally do so during one of their few moments of contact with members, although these are not necessarily in person: at enrollment, within disease management programs, during inbound customer service calls, on health risk assessments, and through voluntary member web portals (Angeles & Somers, 2007). However, it is not known whether direct contact is necessary to collect these data.

Another important and unexplored question is how many racial and ethnic categories to include and whether members have preferences for the level of detail they provide about their racial/ethnic background. As the National Health Plan Collaborative (2009) points out,

> Having every possible racial and ethnic category available in a data collection tool may be quite cumbersome and require sophisticated information technology. On the other hand, collecting data using very broad categories may not be useful for organizations serving very diverse populations.

Previous studies have examined patients' perceptions about health care providers (e.g., hospitals, clinics, physician practices) collecting race/ethnicity and language data

(Baker et al., 2005; Baker, Hasnain-Wynia, Kandula, Thompson, & Brown, 2007; Hasnain-Wynia & Baker, 2006). But health plans differ from providers in a number of important aspects that could affect their ability to collect reliable data. No studies, to date, have examined members' perceptions and comfort with health plans collecting race/ethnicity/language data, their preferences for how or when to collect the information, or their preferences for the level of detail in the racial/ethnic categories provided.

New Contribution

While organizational barriers to collecting race, ethnicity, and primary language data by health plans have been identified in previous studies (Nerenz et al., 2002), to our knowledge no studies have examined health plan members' perceptions about and preferences for data collection. California and Massachusetts recently mandated the reporting of member race/ethnicity/language data by health plans. In July 2009, the Massachusetts Health Care Quality and Cost Council promulgated regulations requiring all health plans in the Commonwealth to report race/ethnicity data. This article examines members' perceptions of data collection in Massachusetts and provides recommendations that should prove helpful for health plans nationwide.

Method

Data Source and Study Design

Six focus groups were conducted between October 1 and October 31, 2008, with a total of 54 individuals in Massachusetts. Focus group participants' characteristics are provided in Table 1. Each group consisted of 8 to 10 individuals from Caucasian/White, African American/Black, Asian (e.g., Chinese), Portuguese-speaking (e.g., Portuguese, Brazilian, Cape Verdean), Hispanic/Latino Spanish-speaking, and Hispanic/Latino English-speaking groups. Because a more homogenous focus group composition can help promote the comfort of participants (Halcomb, Gholizadeh, DiGiacomo, Phillips, & Davidson, 2007), each focus group was homogenous, comprising participants with similar racial, ethnic, or language backgrounds. All focus group members were either privately insured or insured through Medicaid/Medicare plans. Participants were recruited via telephone by a focus group firm, which works with local and regional community centers and advocacy groups. Participants completed a brief screening questionnaire that included questions about race/ethnicity, age, education, marital status, employment, income, and nativity. Individuals participating in the 90-minute focus groups received $75. Sessions were conducted in Massachusetts locations convenient for the participants. The study protocol was approved by the institutional review board of Bentley University.

Focus group sessions. A trained moderator conducted each session, using a moderator's guide and starting with broad questions about the topic of interest and then focusing on targeted questions about race/ethnicity and language data collection. Participants

Table 1. Participants' Demographic Characteristics

	White (N = 8)	African American (N = 8)	Portuguese (N = 10)	English- Speaking Hispanic (N = 9)	Spanish-Speaking Hispanic (N = 9)	Asian (N = 10)
Gender						
Male	5	4	5	2	6	5
Female	3	4	5	7	2	5
n/a	0	0	0	0	1	0
Age (years)						
Median	57	50.5	35	31	47.5	32
Range	40-68	43-59	29-50	24-45	45-66	23-63
n/a	0	0	1	0	1	0
Marital status						
Single	2	5	2	7	1	5
Married	3	3	6	1	6	5
Divorced	2	0	1	1	1	0
Widowed	1	0	0	0	0	0
n/a	0	0	1	0	1	0
Country of birth						
Born in the United States	8	7	0	4	0	4
Foreign born (including those born in Puerto Rico)	0	1	9	5	8	6
n/a	0	0	1	0	1	0
Education						
College graduate	4	5	2	2	2	4
n/a	0	0	1	0	1	0
Employment status						
Employed	3	6	8	7	5	9
Retired	3	0	0	0	0	1
Unemployed	2	2	1	2	3	0
n/a	0	0	1	0	1	0

(continued)

Table 1. (continued)

	White (N = 8)	African American (N = 8)	Portuguese (N = 10)	English- Speaking Hispanic (N = 9)	Spanish-Speaking Hispanic (N = 9)	Asian (N = 10)
Income ($)						
<15,000	0	2	0	1	2	0
15,000-25,000	2	1	0	4	2	0
25,000-35,000	1	0	1	3	2	0
35,000-50,000	0	0	2	1	2	1
50,000-75,000	1	3	6	0	0	0
75,000+	4	2	0	0	0	1
Insurance						
Medicaid/Medicare	1	3	5	5	7	0
Private	7	5	5	4	2	10

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Table 2. Statements Regarding Health Plans' Intentions for Collecting and Using Race/Ethnicity

- Race/ethnicity information would be used to ensure everyone gets high quality care.
- Race/ethnicity information would be used to create health programs for specific groups.
- Race/ethnicity information would be used to ensure that patient education materials are culturally appropriate.
- Race/ethnicity information would be used to promote services to specific groups.
- Race/ethnicity information would be used to understand if specific groups have varying levels of satisfaction with the care they receive.
- Racial/ethnic information would not be used to determine coverage level.
- Racial/ethnic information would not be used to determine benefits packages.
- Racial/ethnic information would not be used to determine premiums.

answered key questions individually and were encouraged to interact and talk with each other to explore and clarify individual and shared perspectives. Following a brief ice-breaker, the moderator asked several broad questions about participants' perceptions about their health plans (e.g., "Do you think your health plan tries to give you the best quality care possible for you and your family?"). The next set of questions focused on trust (e.g., "Let's talk about how much you trust your health plan?"). The moderator then asked members to rank health plans, doctors, nurses, and hospitals in order of trust from most to least. Finally, the moderator asked a series of focused questions about participants' perceptions about race/ethnicity and language data collection by their health plans. Specific questions asked were the following:

- If someone from your health plan or hospital asks you what your race/ethnicity is, what would you say? Do you have any concerns or worries about health plans collecting race/ethnicity or language information from you?
- How important is it to you that health plans tell you why they are asking you to provide information about your race/ethnicity and language? Do you think health plans should be required to tell you why the information is being collected and used? With this question participants were also given eight "explanations" regarding health plans' intentions for collecting and using race/ethnicity/language information to assess participants' responses to each. Five statements used positive reinforcement messages, while three used negative reinforcement messages. The statements are provided in Table 2. Participants did not see a positive/negative descriptor for each statement.
- When do you think is the best time for health plans to collect information about your race, ethnicity, and language? What is the best way of getting this information from you? Would you feel more comfortable if you gave this information directly to a person or via the Internet or paper form?
- How would you respond to the following lists of categories, and which option would you be most likely to choose? How would you respond to

an option where race/ethnicity are presented together? How would you respond to questions with more detailed ethnic categories? (Table 3 shows the three options presented.) To assess preference for race/ethnicity categories, participants were given print-outs of different formats for asking race/ethnicity questions: the One Question Format, the Two Question Format, and the Granular Format (Table 3). The One Question Format combined Hispanic/Latino ethnicity with race (National Quality Forum, 2008). The Two Question Format followed the Office of Management and Budget (1997) Guideline and asked Hispanic/Latino ethnicity first and race second. The Granular Format consisted of very specific ethnic categories from the Census that were deemed most relevant to the Massachusetts population (IOM, 2009).

Data Analysis

The focus group sessions were recorded and transcribed. The data were analyzed with NVivo software (NVivo Qualitative Data Analysis Software, 2008). Using the moderator guide as an initial framework, each of the authors independently reviewed all transcribed focus group sessions to extract themes and develop a draft coding scheme. These drafts were then reconciled by consensus, and a final coding scheme was used to extract data from the transcripts. Our analysis was guided by a grounded theory perspective, which enabled us to assess the information from participants' perspectives rather than testing a priori assumptions or hypotheses (Glasser & Strauss, 1967). We used grounded theory rather than hypothesis testing to avoid developing hypotheses based on previous studies on patients' perceptions related to data collection in hospitals or doctor's offices, because of the unique nature of health plans as described above.

Results

We identified several themes that occurred frequently across all focus groups, as well as some that were interesting because they arose in only specific groups. These themes of interest, with illustrative quotes, follow.

Language Data Collection Is Not Worrisome

Across all groups, participants expressed few or no concerns about health plans collecting language data. Participants believed health plans should know the languages their members prefer to speak to facilitate communication, which is important in health care. Since there was near unanimous agreement about this point, we focus our findings on the collection of race and ethnicity data, where there was much greater discussion and concern.

Table 3. Race/Ethnicity Categories

Two Question Format
  Do you consider yourself Hispanic/Latino?
    ☐ Yes
    ☐ No
  Which category best describes your race?
    ☐ American Indian/Alaska Native
    ☐ Asian
    ☐ Black or African American
    ☐ Native Hawaiian/Other Pacific Islander
    ☐ White
    ☐ Multiracial
One Question Format
  Please tell us what you consider your race/ethnicity.
    ☐ African American/Black
    ☐ Asian
    ☐ Caucasian/White
    ☐ Hispanic/Latino/White
    ☐ Hispanic/Latino/Black
    ☐ Hispanic/Latino/Declined
    ☐ Native American
    ☐ Native Hawaiian/Pacific Islander
    ☐ Multiracial
Granular Format
  Please tell us what you consider your race/ethnicity:
    ☐ American Indian/Alaska Native

☐ Asian	☐ Filipino	☐ Pakistani
☐ Asian Indian	☐ Hmong	☐ Sri Lankan
☐ Bangladeshi	☐ Indonesian	☐ Thai
☐ Bhutanese	☐ Japanese	☐ Vietnamese
☐ Burmese	☐ Korean	☐ Iwo Jiman
☐ Cambodian	☐ Laotian	☐ Maldivian
☐ Chinese	☐ Malaysian	☐ Nepalese
☐ Taiwanese	☐ Okinawan	☐ Singaporean
☐ Madagascar		
☐ Black or African American	☐ Ethiopian	☐ Barbadian
	☐ Liberian	☐ Dominican
☐ Black	☐ Namibian	☐ Dominica Islander
☐ African American	☐ Nigerian	☐ Haitian
☐ African	☐ Zairean	☐ Jamaican
☐ Botswanan	☐ Bahamian	☐ Tabagoan
☐ Trinidadian		
☐ West Indian	☐ Belearic Islander	☐ Mexican
☐ Hispanic/Latino	☐ Gallego	☐ Mexican American
☐ Spaniard	☐ Valencian	☐ Mexicano
☐ Andalusian	☐ Canarian	☐ Chicano
☐ Asturian	☐ Spanish	☐ La Raza
☐ Catalonian	☐ Basque	☐ Mexican

(continued)

Table 3. (continued)

☐ American Indian
☐ Central American
☐ Criollo
☐ Latin American
☐ Puerto Rican
☐ Cuban
☐ Costa Rican
☐ Guatemalan
☐ Honduran
☐ Salvadoran

☐ Samoan
☐ Tahitian
☐ Tongan
☐ Tokelauan
☐ Micronesian
☐ Guamanian or
☐ Chamorro
☐ Guamanian
☐ Chamorro
☐ Mariana Islander

☐ Central American
   Indian
☐ Canal Zone
☐ South American
☐ Argentinean
☐ Bolivian
☐ Chilean
☐ Colombian
☐ Ecuadorian
☐ Paraguayan

☐ Marshallese
☐ Palauan
☐ Carolinian
☐ Kosraean
☐ Pohnpeian
☐ Saipanese
☐ Kiribati
☐ Chuukese
☐ Yapese

☐ Peruvian
☐ Uruguayan
☐ Venezuelan
☐ South American
   Indian
☐ Dominican
☐ Native Hawaiian/Other
Pacific Islander
☐ Polynesian
☐ Native Hawaiian

☐ Melanesian
☐ Fijian
☐ Papua New
   Guinean
☐ Solomon Islander
☐ New Hebrides
☐ White
☐ European
☐ Armenian

☐ English
☐ French
☐ German
☐ Irish
☐ Italian
☐ Polish
☐ Scottish
☐ Middle Eastern or
☐ North African
☐ Assyrian
☐ Egyptian
☐ Iranian
☐ Iraqi
☐ Lebanese
☐ Palestinian
☐ Syrian
☐ Afghanistani
☐ Israeli
☐ Arab
☐ Multiracial

Race/Ethnicity Data Collection Poses
Perceived Risks to Minority Groups

Most participants (67% across all groups) expressed concern, skepticism, and confusion about a health plan collecting and using their race/ethnicity data. In particular, they suggested that this information could be used to target and marginalize minority groups by raising their premiums or denying them care.

> If it was up to my health plan, I wouldn't have gotten to see my specialist. (Multiracial female)

> Depending on the statistics they will not provide certain services. (English-speaking Hispanic/Latino male)

Many individuals stated that their health plan should provide care irrespective of a person's race/ethnicity and expressed confusion about how this information would be useful, especially when compared to knowing a person's language, which has obvious utility. Many also compared health plans with others whom they might trust more with this information or whom they perceived to have a more legitimate medical use for the information.

> A provider, I could understand, but not your health care carrier. I think they are just looking to skew premiums. (White male)

> Mainly, you see your doctor, right? And you have a one-on-one with your doctor, isn't it? With your health plan you just . . . put down your information, and they tell you what they cover or what they won't cover. (English-speaking Hispanic/Latino male)

> Why should you collect this information at [the] health plan? Shouldn't you collect this information at the time when I see the doctor? That is the information that is needed at that time. At the health plan stage, why do you need all this information about me? (Asian female)

Participants in the Hispanic/Latino Spanish-speaking and Asian groups expressed particular concern about privacy and confidentiality compared with members of other groups.

> You have to guarantee me that my information is going to stay here in a confidential way. (Spanish-speaking Hispanic/Latino male)

> Are they just going to use it for health care or are they going to share it with everybody. (Spanish-speaking Hispanic/Latino female)

Race/Ethnicity Data Could Also Be Useful

Despite these initial concerns, when participants were asked to consider ways that race/ethnicity data could potentially be useful for them and their health plans, many could develop arguments for the utility of collecting these data (31% of those expressing concern also understood the potential importance of the information). For example, some noted the information could be used to provide targeted care to specific groups.

> I think you can actually get some good information from the ethnicity part; because people from Brazil, for example, are going to have certain types of diseases than people from China. So if you know, you probably can better care for them. (Portuguese-speaking female)

Others discussed how health plans could use this information to see whether people were receiving the care they need, to provide culturally competent services, to develop educational health materials for members, and to ensure that the physicians serving the health plan were representative of the health plans' members. Members of the Asian, Black, and the Portuguese-speaking groups, in particular, thought it was important for health plans to use the information to contact physicians who look like members of their ethnic community and could relate to them culturally.

> I would like to know that they apply it. If they are going to tell me that they are going to send me patient education materials that are culturally relevant, send them to me. That would work. (Asian female)

> They should recruit more people of color. They should recruit doctors that look like the people that they are serving. (Black male)

Health Plans Should Explain Why They Are Collecting These Data

Regardless of participants' general attitudes about whether health plans should be collecting and using race/ethnicity data, the vast majority of participants (90%) indicated that it was very important for health plans to provide a clear explanation to members, both verbally and in writing, about why they were collecting the data and how it would be used. Participants suggested that plans communicate this information to their members using various means, such as the Internet, by mail (e.g., newsletter), email, or through signs posted in a doctor's office. Opportunities for verbal communication could take place during enrollment or disease management discussions, but many noted that if information is conveyed verbally, members should also be told where they can obtain it in writing. Some participants also

suggested the use of television and radio as means for relaying this information to the broader community to increase peoples' comfort level in providing it.

When participants reviewed sample explanations that plans could provide members reasons for collecting race/ethnicity data, more than half (54%) found the explanation that race/ethnicity information is being collected to ensure that everyone gets high-quality care to be the most convincing (Table 2). The Portuguese-speaking group preferred a variation on this theme: Race/ethnicity information is being collected to understand if specific groups have varying levels of satisfaction with the care they receive.

Demographic Information Should Be Collected at Enrollment

A majority of the participants (92%) indicated that, if health plans are to collect this information, they should do so at enrollment, though a small number (8%) believed that collection should only occur after enrollment because they perceived that collecting this information at enrollment could influence coverage or benefits decisions.

Participants discussed a number of methods that health plans could use to collect race/ethnicity/language data: phone, Internet, filling out a form, mail, and data transferred from physicians to the health plan. Half of the participants indicated a preference for filling out a form and sending the information by mail, 20% preferred the phone, 16% preferred the Internet, and 4% suggested that their physician transfer the information to the health plan. All participants indicated that, when forms were used, they should be kept simple and the form should provide a number that they could call with questions.

Members' Preferences for Race/Ethnicity Categories

The OMB two question format (Table 3: Two Question Format), which asks about Hispanic/Latino ethnicity first and then race second, was easily answered by each group except for the Hispanic/Latino participants. They expressed confusion over separate questions for race and ethnicity and found that the race question excluded them, because there was no choice for them to identify as Hispanic/Latino in the race response options. Most participants preferred the format where race/ethnicity choices were combined into one question rather than two (Table 3: One Question Format). Overall, participants found this format to provide a balance of both simplicity and greater inclusion of Hispanic/Latino groups.

Even though Hispanic/Latino groups (both English and Spanish speaking) preferred the one question over the two question format, they also preferred the format that provided granular ethnicities (Table 3: Granular Format). Participants from the other groups, however, found the granular ethnicity categories to be too complicated and cumbersome. Few saw any benefit from this level of specificity and many found it confusing. No participants in the White group could see the value in providing their White ethnic heritage; the Asian group found it to have too much detail; and the

Portuguese-speaking group stated that, in addition to being extensive and confusing, it still did not address their heritage.

Discussion

While collecting data on enrollee race, ethnicity, and primary language has been widely recommended, and is now the law in Massachusetts, little has been known about how health plan enrollees view the idea of their health plans asking them to report their race, ethnicity, and language data. In a series of focus groups with health plan enrollees in Massachusetts, we found that virtually none had any concerns about reporting their primary language to health plans, but many expressed significant qualms about reporting race or ethnicity. In particular, many participants are concerned that health plans could use race or ethnicity data to marginalize specific groups, keep them from getting certain services, or for setting higher premiums.

The high level of comfort with collecting language data versus race/ethnicity appears to reflect the participants' ability to readily see how collecting language information can improve quality and lead to better service delivery, whereas it was more difficult for them to understand how collecting race/ethnicity data might serve this purpose—a finding that has been noted in prior work outside the health plan setting (Baker et al., 2007). With minimal prompting, however, many participants (some in every group) were able to describe potentially constructive uses of the data, such as for monitoring care, developing educational materials, and providing culturally competent care. Perhaps reflecting on this brief, but important, learning process, all participants consistently and clearly expressed that health plans collecting these data would need to explain, verbally and in writing, how the data would be used.

From an operational standpoint, where to collect and how to use demographic data poses challenges for health plans, because there are a number of opportunities to collect the information (e.g., enrollment forms, customer service calls, disease management programs, member surveys, health risk appraisals), multiple options for how to ask questions about demographics, and multiple potential databases for storage. The vast majority of focus group participants (92%) indicated that health plans should collect their demographic data at enrollment, a recommendation that, if adopted, would streamline the data collection process.

With regard to how to ask about race and ethnicity, we found that Hispanic/Latino individuals prefer more granular choices that offer the opportunity to more specifically identify one's heritage. Participants in other groups, however, often found the granular ethnicity choices cumbersome, irrelevant, and confusing. This finding suggests that providing granular ethnicity options will require health plans to consider local circumstances and offer only those categories needed to understand the populations in a given region or community (IOM, 2009).

This study has some important strengths. We conducted multiple focus groups, with a diverse array of racial, ethnic, and language populations; we used skilled and culturally sensitive moderators; and our coding scheme and analysis plan were carefully

developed to avoid a priori biases. Yet our study has some important limitations. Focus group participants were not selected randomly and most were aware of the topic of discussion prior to choosing to participate, which could have created a selection bias. In addition, none of the Portuguese or Hispanic/Spanish focus group participants were born in the United States by virtue of how individuals were selected. Some of our findings are specific to certain ethnic groups, yet we had a single focus group from each race/ethnicity/language, making these findings more tenuous. As with all focus groups, despite our skilled moderators, the highly interactive setting increases the possibility of bias toward socially desirable responses or conversational capture by certain dominant participants. Finally, our study was conducted only in the state of Massachusetts. Perceptions of plan members may differ by geography.

Conclusions

There is broad agreement that to address inequities in health care quality, there is an urgent need for better data on the demographics of health plan enrollees. Massachusetts has recently mandated the reporting of these data by health plans, so the lessons learned there should prove useful in other states and even nationally. Our results provide an early and important window into understanding the perceptions of individuals in Massachusetts about health plan requests for race, ethnicity, and primary language data. As indicated earlier, our study is exploratory in nature. The findings should be interpreted in light of this context and should also be used to generate hypotheses for future studies, which may be more definitive in their conclusions.

The significant early concerns of these enrollees about health plans collecting race and ethnicity data were balanced by their relatively quick ability to understand and articulate constructive uses for these data. This suggests the need for broad-based, consumer-oriented education on the importance of race and ethnicity data collection and use in improving care and reducing disparities. Enrollees want to be assured that the information they provide will be used to improve quality. They also want to be able to provide this information without undue burden and with assurances of confidentiality.

Finally, health plans play a central role in health care delivery and in reducing disparities in care, but they cannot be the only entities responsible for collecting these data. High member turnover rates make it difficult to track long-term quality improvement and even the best data collection efforts by plans to date have achieved only moderate success. Nationally and regionally, therefore, it will be important to encourage the development of data exchange and transfer protocols between different plans as well as hospitals, other providers, and employers.

Declaration of Conflicting Interests

Funding

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