



Survey of Organizations about Health Care Reform Resources to Assist California Health Care Consumers

A Report of Findings

Health Research for Action, August 2012

Contents

Highlights

Introduction

Summary of Survey Results

Detailed Survey Results

- The Participating Organizations
- Preferred Resources and Formats
- Barriers, Challenges, and Gaps
- Materials and Campaigns Related to Health Care

Reform

Limitations of the Survey

Appendix A: Survey Questions and Responses

Appendix B: Survey Instrument

Highlights

Health Care Reform Resources to Assist California Consumers

Health Research for Action (HRA), a center in the School of Public Health at the University of California, Berkeley, sent an electronic survey to 205 organizations serving California's health care consumers, in July 2012. The survey was conducted for the California Office of the Patient Advocate (OPA) and the Department of Managed Health Care (DMHC) to assess the needs for resources to help consumers navigate the changes and opportunities under Health Care Reform/the Affordable Care Act.

- 77 people responded, representing a wide variety of organizations providing advocacy, education, assistance, and other services to consumers.
- The clients of these organizations are primarily those with low incomes and the uninsured.
- 74% of organizations were currently educating consumers about Health Care Reform.
- 32% had been or were currently involved in campaigns related to Health Care Reform.

The need for easy-to-read materials

- 85% of respondents said that "Easy-to-read" was a main consideration when selecting information resources for clients.
- 72% said that "Writing and vocabulary are too complex" was a main barrier for clients in understanding Health Care Reform information.
- Making sure information is easy to understand was one of the main challenges facing organizations in educating their clients about Health Care Reform.
- The lack of information that was short and easy to use was a main gap in existing materials.

The need for targeted resources

- Explaining the relevance of Health Care Reform was one of the main challenges facing organizations in educating their clients about Health Care Reform.
- Practical information for consumers was a main gap in existing information.
- 69% said that "Community-specific or local" was a main consideration when selecting information resources for clients.
- 42% said that "Information is not relevant to the person's needs" and "Information is not relevant to the person's experience" were main barriers for clients in understanding Health Care Reform information.
- 43% said that "Focused on one main topic" was a main consideration when selecting information resources for clients.

The need for information in many languages

- 86% of respondents' organizations needed information in Spanish.
- Many organizations needed multiple additional languages. After Spanish and Chinese, the next most needed languages were Vietnamese, Hmong, and Korean.
- The lack of materials in multiple languages was frequently cited as an access barrier and as a gap in existing resources.

The need for print information

- 83% of respondents cited lack of Internet access as a barrier for their clients in accessing information on health care reform.
- The lack of easy-to-read, one-page materials was a main gap in existing information.

Introduction

Health Research for Action (HRA), a center in the School of Public Health at the University of California, Berkeley, conducted an electronic survey of organizations serving California's health care consumers. The survey was conducted in July 2012, for the California Office of the Patient Advocate (OPA) and the Department of Managed Health Care (DMHC) to assess the needs for resources to help consumers navigate the changes and opportunities under Health Care Reform/the Affordable Care Act.

HRA has over 25 years of experience conducting research and developing resources to meet the health literacy needs of consumers and to create healthier, more empowered communities.

The survey was conducted using the Qualtrics web-based survey software program. Approximately 205 people were invited to fill out the 25-question online survey, and the response rate was 38%. This is higher than average for an online survey. Seventy-seven people completed all or most of the survey.

This report presents the most salient results of the survey and recommends appropriate materials to develop through this project. Complete results can be found in the Appendix A of this report.

Summary of Survey Results

About the organizations. Most respondents represented organizations that provide health care advocacy, direct consumer assistance on health insurance benefits and rights, and/or outreach and education. Three quarters of respondents' organizations were currently educating consumers about Health Care Reform. Their activities in education and outreach included community events, one-on-one assistance, and presentations and trainings for clients, constituency groups, and health care providers; distributing fact sheets and other print materials; and using electronic media such as their own websites as well as e-mail, listservs, and blogs.

Populations served. Organizations primarily served populations with low incomes. The main other groups served are the uninsured, families, children, immigrants, and seniors. Non-English speakers were a major clientele; the overwhelming majority of these were Spanish speaking. Nearly all organizations needed information in English and Spanish, and many requested additional languages. The next most commonly needed languages were Chinese, Vietnamese, Hmong, and Korean.

Needs for information. The highest-rated needs for consumer information about Health Care Reform were for information on changes to Medi-Cal, the California Health Benefits Exchange, finding coverage, and health care rights. The highest rated video topics were consumer assistance, getting preventive care, using translation services, and understanding health care costs.

Barriers and challenges. The main barriers for clients in understanding information about Health Care Reform were that the language is difficult to read, the information itself is complex, the presentation is not engaging, and the relevance to their needs or experience is not clear. A large number of their clients do not speak English and/or lack Internet access. Access for the visual or hearing impaired is a challenge. Organizational challenges included providing clear and relevant information, the lack of funding and resources, the complexity of the law, and the need to provide information in many languages.

Considerations for choosing resources. Respondents' main considerations when selecting informational resources were that the materials should be easy to read and understand, free, community-specific, and visually attractive. Respondents noted that their clients would prefer resources with bright color schemes and photos of real people.

Most useful formats. Respondents chose fact sheets and brochures as the most useful types of print resources for their clients. The most useful resources in other media were the organization's website, videos, PowerPoints, and Facebook.

Detailed Survey Results

See Appendix A for complete responses and Appendix B for the survey instrument.

A note on how to read the charts: The charts list the responses in order of frequency. Many questions allowed the respondent to “Check as many as you like.” The column labeled “Responses” lists the number of responses for each answer and the total respondents for the question. The column labeled, “%” lists the percent of the total number of people who answered a question who checked that item. For example, in the first chart below, a total of 85 people answered the question, and 60 of these, or 71%, said that their organization engaged in advocacy.

Survey Results: The Participating Organizations

- 205 representatives from a variety of health care, non-profit, community, advocacy, government, and private agencies and organizations were invited to participate in the 25-question electronic survey; 96 people opened the survey and 77 answered most or all the survey questions, for a response rate of 38%. *(See Question 1 in Appendix A for a list of the organizations responding.)*
- Over half of the respondents were senior managers, such as CEOs, presidents, executive directors, and program directors. *(See Question 5 in Appendix A.)*
- 74% are currently educating consumers about health reform; 32% have been or are currently involved in campaigns related to health reform. *(See Questions 6 and 21 in Appendix A.)*
- The survey asked how many people the organization served in a year. The median response among those who gave a numerical response was 10,000. Two organizations had over a million members. Some organizations provided no direct services. *(See Question 3 in Appendix A.)*

Services provided

Respondents' organizations provided a wide range of services. *See Table 1.*

- The main services checked were advocacy, education about health insurance and rights, consumer assistance, and events.
- The most often mentioned Other services related to analysis and policy, health education, and community development.

Table 1. Services Provided

Question 2. What kind of services does your organization provide? (Check all that apply.)

Answer		Responses Total=85	%
Advocacy		60	71%
Education about health insurance and rights		50	60%
Consumer assistance		46	55%
Events		42	50%
Other (specify)		32	38%
Case management		22	26%
Legal aid		15	18%
Health care (direct services)		13	15%
Mental health care (direct services)		7	8%

Populations served

The organizations served a wide variety of populations, primarily people with low incomes, the uninsured, families, children, and immigrants. *See Table 2.*

- 62% of respondents said that their organization served immigrants, and 33% said they served specific language and cultural groups. These were primarily Spanish-speakers, but also include a wide variety of other groups.
- In comments, five said that they served people with disabilities, and four said that they served professionals (doctors, pharmacists, and others) who serve patients.

Table 2. Populations Served

Question 4. What specific population(s) does your organization serve? (Check all that apply.)

Answer		Responses Total=82	%
Low income		63	77%
Uninsured		54	66%
Families		52	63%
Children		52	63%
Immigrants		51	62%
Seniors		46	56%
Various/all		42	51%
Young adults		42	51%
Insured		42	51%
Employees		28	34%
Specific ethnic/language groups (specify)		27	33%
Other (specify)		19	23%

Survey Results: Preferred Resources and Formats

Preferred print resources and tools

Respondents were asked to rate a variety of print resources and tools from 1 (most useful to their clients) to 7 (least useful to their clients). *See Table 3.*

- Fact sheets were by far the highest-rated print resource, followed by brochures.
- The main Other resources and tools mentioned were presentations and trainings, and one-on-one consultation.

Table 3. Most Useful Resources

Question 7. Which of the following resources and tools are most useful to your clients? (Rank order of importance, 1 being most useful.)

Answer	1	2	3	4	5	6	7	Responses
Fact sheets	31	19	6	3	1	3	4	67
Brochures	14	14	10	5	5	5	0	53
Other (specify)	11	4	2	0	0	2	3	22
Newsletters	5	6	5	21	12	4	4	57
Quizzes	3	1	7	2	10	14	11	48
Booklets	2	7	17	13	12	0	3	54
Worksheets	1	10	6	10	10	18	5	60
Totals	67	61	53	54	50	46	30	

Preferred multi-media and social media tools

The survey asked which multi-media and social media tools were most useful.

- Respondents' main preferred resources were their own websites, followed by videos, PowerPoints, e-newsletters, and webinars. *See Table 4.*
- The main social media tools used were Facebook and YouTube.
- Other tools mentioned included bilingual videos, Vlog in sign language & captioning, PSA's, and TV ads.

Table 4. Most Useful Multi-Media and Social Media Tools

Question 8. What multi-media and social media tools are most useful for your clients about Health Care Reform? (Check all that apply.)

Answer		Responses Total=78	%
Your organization's website		44	57%
Videos		38	49%
PowerPoints		37	48%
Webinars		34	44%
E-newsletters		34	44%
Facebook		28	36%
Links to other resources/websites		22	29%
YouTube		21	27%
Interactive self-instruction tutorials		15	19%
Twitter		11	14%
Phone apps		9	12%
Other		5	6%
Other video media		4	5%
Wikis		1	1%

Considerations when selecting information resources

- All the criteria listed in *Table 5* were rated fairly high. Most important were: Easy-to-read, no cost, and community-specific or local.
- Other considerations included disability access, language access, clear language, cultural sensitivity, and actionable tips.

Table 5. Considerations When Selecting Health Care Reform Materials

Question 9. Which of the following are your main considerations when selecting information resources for your clients?

Answer		Responses Total=74	%
Easy-to-read		63	85%
No cost		57	77%
Community-specific or local		51	69%
Visually attractive		35	47%
Focused on one main topic		32	43%
Interactive, promotes action		19	26%
Other (specify)		16	22%

Design considerations

The survey asked several questions related to design:

- 66% of the respondents said that their clients found charts, tables, or diagrams useful. In comments, many added that the charts should be simple. (Question 11 in Appendix A).
- Most respondents (80%) wanted a blank space on the materials developed, for the organization to put its contact information and logo on. (Question 20 in Appendix A.)
- For Table 6, respondents were asked to check the design elements that would make a resource visually attractive for their clients; 76% checked photos of real people, and 70% checked bright colors such as those used for OPA’s materials.
- In comments, respondents mentioned: simple, plain language; easy-to-read layout; checklists, simple tables, charts, and other graphics; and photos of people with ethnic diversity/age diversity. Several respondents mentioned issues for people with vision impairments, including universal design principles and alternative formats. They specifically mentioned the need for high contrast and large type.

Table 6. Preferred Design Features

Question 10. What do you think would make a resource visually attractive for your clients? (Check all that apply.)

Answer		Responses Total=74	%
Photos of real people		56	76%
Bright colors, like those used in the Office of the Patient Advocate's materials		52	70%
Symbols and icons		29	39%
Other (specify)		22	30%
Drawings		19	26%
Another color scheme (specify)		6	8%

Languages

Language access was a recurring need throughout the survey responses. The main languages in which organizations need information are listed in *Table 7*.

- Regarding spoken Chinese, 32% needed materials in Mandarin and 26% Cantonese. For written Chinese, 28% needed Simplified characters and 25% Traditional. After Spanish and Chinese, the next most needed languages were Vietnamese, Hmong, and Korean.
- Other languages that were specifically mentioned were: Burmese, Caldean, Ethiopian, Hindi, Japanese, Laotian, Punjabi, Somalian, Thai, Ukranian.
- Comments also mentioned large print, ASL, sign language (DVD-Vlog), s, and audio.

Table 7. Language Needs

Question 19. In which languages do you need information? (Check as many as you like.)

Answer	Responses Total=72	%
English	67	93%
Spanish	62	86%
Vietnamese	31	43%
Hmong	26	36%
Korean	23	32%
Chinese: spoken Mandarin	23	32%
Russian	22	31%
Tagalog	21	29%
Chinese: written Simplified	20	28%
Cambodian	19	26%
Chinese: spoken Cantonese	19	26%
Chinese: written Traditional	18	25%
Farsi	16	22%
Arabic	16	22%
Armenian	15	21%
Other	15	21%
Khmer	11	15%

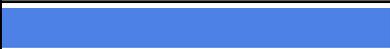
Useful topics for printed materials

Organizations expressed many needs for information on many different Health Care Reform topics. See Table 8. The top topics were Medi-Cal changes and the California Health Benefit Exchange. However, each of the 19 topics listed was checked by 27% or more of the respondents.

Only 15% of the respondents suggested additional topics. These included women's health, patient rights to accessible care, and the "medication therapy management" benefit under Medicare Part D.

Table 8: Prioritized Topics for Printed Materials

Question 14. On which Health Care Reform/consumer assistance topics do you need information for consumers? (Check all that apply.)

Answer		Responses Total=71	%
Medi-Cal changes		58	82%
California Health Benefit Exchange		52	73%
Finding coverage if you do not have insurance		48	68%
Patient rights, including new rights		47	66%
Medicare changes		46	65%
Preventive care		46	65%
Prescription drug coverage		45	63%
Language access		41	58%
Health care costs		41	58%
Health insurance basics		40	56%
Adults with pre-existing conditions		40	56%
Mental health care		39	55%
Coverage for young adults under 26		33	46%
Children with pre-existing conditions		32	45%
Quality of care		30	42%
Complaints, grievances, and appeals		29	41%
Dental care for children		27	38%
Employee health benefits in small businesses		20	28%
Electronic medical records		19	27%
Other (list as many as you like)		11	15%

Useful video topics

All video topics were rated fairly high. Sixty eight percent of respondents checked *Using consumer assistants and navigators*. This was clearly the top rated video topic, but all six topics listed were checked by 39% or more of the respondents. *See Table 9.*

Fifteen percent of the respondents checked Other. Several suggestions echoed the theme of consumer assistance. Medi-Cal changes were also mentioned.

Table 9: Prioritized Topics for Videos

Question 15. Please select the topics below (or suggest other topics) that you think would be most useful to address in a video. (Check as many as you like.)

Answer		Responses Total=71	%
Using consumer assistants and navigators		48	68%
Getting preventive care		38	54%
Requesting and using an interpreter		37	52%
Figuring out health care costs		34	48%
Calling member services or government help lines like DMHC about a problem		30	42%
Filing a grievance or appeal		28	39%
Other (many as you like)		11	15%

Survey Results: Barriers, Challenges, and Gaps

Barriers to understanding

The survey asked respondents to rate a list of text, content, and design barriers. *See Table 10.*

- The two main barriers to consumers’ understanding of resource content were the complexity of the writing and vocabulary, and of the concepts and information. The third was lack of engaging presentation.
- The fourth was lack of relevance. This was also the main theme of the Other comments: “(Health Care Reform is) still not clearly linked to everyday options just yet.”
- Other issues mentioned were language barriers, complex writing, the cost of insurance, and the evolving nature of the information.

Table 10: Prioritized Barriers to Understanding

Question 12. What are the main barriers for your clients in understanding Health Care Reform information? (Check all that apply.)

Answer		Responses Total=74	%
Writing and vocabulary are too complex		53	72%
Concepts and information are too complex		51	69%
Information is not presented in an engaging manner		44	59%
Information is not relevant to the person’s needs		31	42%
Information is not relevant to the person’s experience		31	42%
Other (list as many as you like)		21	28%

Barriers to access

Respondents were asked about barriers to access. *See Table 11.*

- 83% of respondents said that lack of Internet access was a barrier for their clients.
- 27% cited access for the visually impaired and 20% cited access for the hearing impaired. The lack of materials in alternative formats was mentioned several times in the survey.
- The main other barriers mentioned include language access and literacy barriers.

Table 11: Prioritized Barriers to Access

Question 13. Are there any barriers for your clients in accessing Health Care Reform information?
(Check all that apply.)

Answer		Response Total=60	%
Client does not have Internet access		50	83%
Other (list as many as you like)		23	38%
Information cannot be read by the visually impaired		16	27%
Information is not accessible to the hearing impaired		12	20%

Other challenges and gaps

The survey asked three open-ended questions about barriers, challenges, and gaps in information. The main themes are summarized here.

Challenges facing organizations in educating clients about Health Care Reform

Question 16. What are the biggest challenges facing your organization in educating your clients about Health Care Reform?

- Making sure information is relevant, clear, and easy to understand
- Funding and time to train staff and to reach consumers
- Complexity of law and timing of implementation

Health Care Reform topics that are most difficult to explain to clients

Question 17. Which Health Care Reform topics are most difficult to explain to your clients?

- The Exchange and its details
- Medi-Cal changes
- Eligibility and enrollment issues

Gaps in existing consumer health information resources

Question 18. What, in your opinion, is missing from existing consumer information on Health Care Reform?

- Great to have talking points and guides to help real people navigate a new world, post 2013.
- Easy to read one pager materials
- The essential health benefits
- Materials in different languages
- Basic information about health insurance

Survey Results: Materials and Campaigns Related to Health Care Reform

We asked about campaigns and resources related to Health Care Reform. *See Questions 21, 22, and 23 in Appendix A.* We reviewed the materials shared, as well as many other national, state, and local resources.

While 32% of respondents said their organization had been or is currently participating in a campaign related to Health Care Reform, 74% said that their organization was currently educating consumers about Health Care Reform. As there was much overlap among the sample materials shared in response to these questions and the question about other useful materials, we have combined them in this section of the report.

Types of education and outreach

The focus and breadth of educational outreach and campaign efforts varied widely, from providing a brochure on the Affordable Care Act to conducting numerous campaigns as part of national advocacy efforts. A number of organizations host or participate in health fairs, community events, or town halls.

In general, organizations incorporated Health Care Reform/Affordable Care Act general themes and/or specific topics as they relate to the organization's primary mission. For example, a family planning clinic distributed a fact sheet on the Affordable Care Act and reproductive rights in its waiting rooms. And an organization that serves people with disabilities distributed a fact sheet on pre-existing conditions and Health Care Reform.

Some organizations conducted campaigns when the law was initially passed, or on its anniversary. Some conducted campaigns in collaboration with other community organizations, with state agencies such as DMHC, or with state and national organizations.

Organizations also provided Health Care Reform education as part of enrollment campaigns for Healthy Families, Medi-Cal, the low-income Medi-Cal pilot program, the 100% Campaign, and the Children's Health Initiative.

Six organizations reported that they train professionals or Promotores/peer educators.

The main general types of education and outreach mentioned included:

- Presentations, community forums, campaigns, and other outreach
- Training and education for providers and organizations that serve consumers
- Providing print and web-based resources

Specific campaigns, activities, and resources mentioned by respondents

- 100% Campaign is a joint effort of California groups to enroll children in health care. Their website posts several brochures on Health Care Reform and children and families.
- AARP's California page gives consumers information on Health Care Reform in this state.
- Asian Pacific American Legal Center's Health Access Project and Health Justice Network, a collaborative of API organizations, posts news, commentary, and briefs on many aspects of Health Care Reform.

- California Consortium for Indian Health has an attractive summary of Health Care Reform for consumers.
- California Endowment's WeConnect Campaign is a website that connects consumers to community services, including health care and new services under Health Care Reform.
- California Family Resource Association's website has a page on Health Care Reform and posts a Health Reform Toolkit.
- California Health Care Foundation has extensive ongoing reporting and analysis on Health Care Reform in California. Its brochure, *What Californians Should Know*, is a one-page overview of the Affordable Care Act.
- California Medical Association developed a brochure on Health Care Reform, in English, Spanish, and Chinese, which physicians can use with their patients.
- Californians for Patient Care has a web page on Health Care Reform.
- Center for American Progress produced a video: *Illustrating the Success of Health Reform*.
- Children's Health Initiative is a campaign to enroll children in health coverage.
- Consumer Health Alliance has developed and posted fact sheets for consumers and briefs for professionals/assistants/navigators on many aspects of Health Care Reform. The fact sheets explain the provisions most relevant to health care consumers, in plain English and in 12 languages.
- Consumers Union has an attractive PDF booklet: "The Affordable Care Act: What You and Your Family Need to Know" and a similar booklet for seniors.
- FAIR Health is a consumer-friendly website on health care costs.
- First 5 LA held a panel discussion on *Children's Health: Obesity Prevention Under Health Care Reform*.
- Health Access posts ongoing briefs and reports on Health Care Reform. The Year 2 Report summarizes California's accomplishments and the impact of the Affordable Care Act in California in the two years since the Affordable Care Act was passed.
- Health Care for America Now (HCAN) a national coalition of more than 1,000 groups in 50 states representing 30 million people. HCAN advocates for the Affordable Care Act (Affordable Care Act).
- HICAP created a one-page summary of Medicare preventive services.
- Kaiser Family Foundation is the go-to site for many organizations seeking information on Health Care Reform. Health Reform Source and the video, *Health Reform Hits Main Street*, and Kaiser Health News are specific resources.

Limitations of the Survey

Because of the rapid timeline to implement the Affordable Care Act in California, it was necessary to conduct the survey during a very short time period. For this reason a web survey design was selected. Web surveys have the advantage that they are fast to conduct and much less costly than telephone surveys with multiple follow-up calls. The disadvantage is that response rates are typically much lower for web compared to telephone surveys. The response rate of 38% in this survey is above average web survey. However, without a higher response rate, it is not possible to generalize the survey results to the entire sample of respondents. Despite this limitation, the similarity of responses, leading to several key findings, suggest that the survey has a good degree of convergent validity. Further, the respondents represented a good cross-section of the types of organizations the survey intended to include. There does not appear to be an obvious “response bias.”

The sample of respondents had a special focus on organizations that support low-income and uninsured clients, given that these populations have the greatest needs and will benefit most from healthcare reform. Therefore, although the sample included organizations that also support currently insured populations, additional information will be needed in the future about the communication needs of these populations, including those who routinely use the Internet. However, the principle of “universal design,” provides strong scientific support that communication for *all* populations, not just those with lower health literacy, should be easy to access and understand.