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foundation

empowerment and engagement among low-income Californians: enhancing patient-centered care

2012 blue shield of california foundation survey

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Langer Research Associates

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introduction

Beyond the expansion of health insurance to millions of Americans, the Affordable Care Act also offers new challenges and opportunities to reshape the way that we deliver health care. Recognizing the need for improvement in the current health care system and the demands of health reform, there have been concerted efforts in the public and private sectors to more fully engage patients in their own care. Many advances have already been made toward achieving a health system in which patients are active participants. Much of this work to date has been driven by providers' notions of high-quality care and system-level interpretations of administrative data. While it is important to engage physicians and the broader health care system in the conversation around the transformation of care, we must also include the patients themselves.

The primary goal of this survey was to bring the voices of low-income Californians into these conversations, to hear – and share – their perspectives on some of the key tenets of patient-centered care. The results provide new empirical data to evaluate the relationships between patients and their providers, and help us understand how they can lead to a patient population that is more involved in their own health and well-being. Building upon findings from our previous survey of low-income Californians, this report dives deeper to provide meaningful insight into the kind of care that underserved populations want, and deserve.

The results of the survey underscore not only the value of a strong patient-physician connection, but also the role of effective communication in empowering and engaging patients. Among patients who say they are well-informed about their health, more than two-thirds report that they feel comfortable asking questions and very confident in their ability to make healthcare decisions. By engendering a sense of involvement and providing useful, accessible information, safety net providers can count on improved patient experiences and, ultimately, better health outcomes for some of our most vulnerable residents.

As the American health care system continues to transform, it is only by listening to those we aim to serve that we can ensure that changes will produce the desired outcomes. We will continue to ask relevant questions of key audiences to bring us closer to our shared goal of accessible, effective, and affordable health care for all Californians. Thanks to the team at Langer Research Associates – Gary Langer, Julie Phelan, Greg Holyk, and Damla Ergun. They are a delight to work with. Thank you to Cecilia Echeverría and Christine Maulhardt as well, for their tireless efforts to shepherd this project.

In partnership,
Peter V. Long, Ph.D.
President and CEO
Blue Shield of California Foundation

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executive summary

Slightly fewer than six in 10 low-income Californians overall want an equal say in their healthcare, leaving a substantial number who prefer instead to leave decisions mainly to their care providers. But if guidance about treatment options is offered, that recalcitrance fades: Given clear information, many more – eight in 10 – say they'd like an equal role.

That result is one of several in this Blue Shield of California Foundation (BSCF) survey that underscores the central role of information and communication in achieving the goals of patient-centered care. Among other outcomes, well-informed patients are much more likely than others to be confident about taking an active role in their care decisions, to feel comfortable asking questions of their care providers, and to report that they understand their providers' explanations.¹

Those elements – clear health information, confidence, comfort asking providers questions, and comprehension of providers' medical explanations – are the tools with which patients are empowered to take an active role in their health care. In turn, the product of that empowerment, this study finds, is greater self-reported engagement in healthcare decisions.

Empowerment and engagement are central aims of patient-centered care, the paradigm that seeks both more efficient care models, and improved health outcomes, in large part through a focus on the patient as an active participant in his or her care. This survey tested some of the basic principles of patient-centered care from the patient's perspective, producing empirical data with which to evaluate how these concepts may lead to a more engaged patient population. Results reveal the extent to which healthcare providers and facilities can encourage empowerment and engagement by providing patients – across the socioeconomic spectrum – with full, clearly explained information about their health conditions and choices for care.

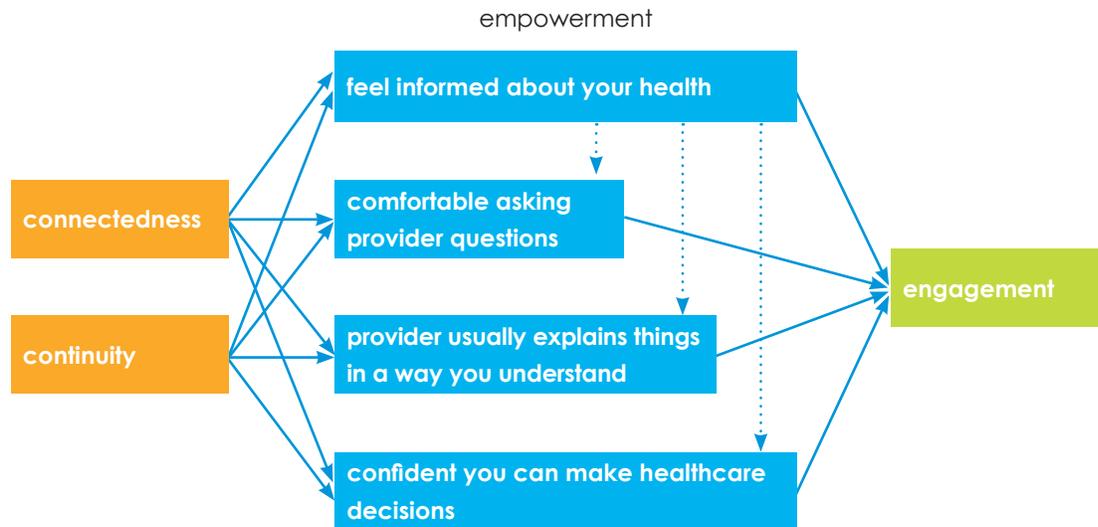
The role of information and communication described in this study builds upon findings from [Connectedness and Continuity: Patient-Provider Relationships Among Low-Income Californians](#), a BSCF report earlier this year. That report found that many patients desire closer personal relationships with providers and staff at their care facilities than they have now, and that, when present, such relationships produce greater patient self-efficacy and satisfaction alike.

Reinforcing and extending that finding, this report shows that continuity (seeing the same care provider regularly) and connectedness (thinking that someone at the care facility knows you well) foster the relationships

Well-informed patients are substantially more likely to be confident taking an active role in their care.

that help to empower and engage patients – improving the flow of information, increasing the comfort patients have asking questions of their providers, increasing the chances patients will find the information they are given to be clear and understandable and, ultimately, engaging them in their care decisions. These findings produce a model of patient engagement, based on a series of statistical analyses of the results of this survey, describing a continuum from connectedness and continuity to empowerment and then engagement.²

a model of patient engagement



Controlling for other factors, the results of this survey show that connectedness and continuity predict "empowerment" outcomes – feeling well-informed, being comfortable asking questions of care providers, understanding providers' answers and being confident in the ability to make healthcare decisions. Feeling well-informed also independently predicts the other three empowerment items. And each of the empowerment measures predicts "engagement," that is, taking a role in healthcare decisions – a key goal of patient-centered care.

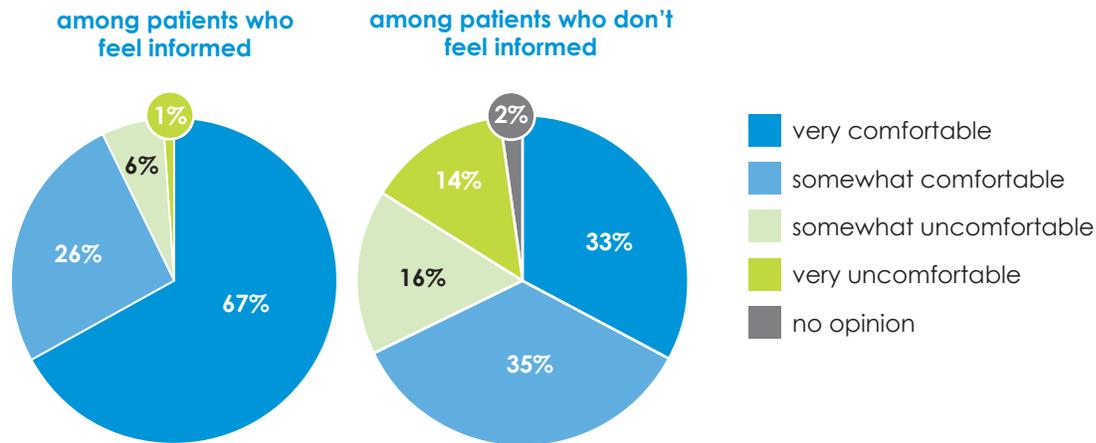
The data are striking: In terms of information, patients who see the same provider at least most of the time are 21 percentage points more apt than those with less continuity in a care provider to feel very informed about their health. And those who say someone at their care facility knows them well are more apt to be very informed, by 27 points, than those who lack that personal connection.

The fundamental role of information in enhancing empowerment also shows clearly in the survey results:

- Among patients who feel informed about their health, 67 percent say they're very comfortable asking questions of their provider. Among those who feel less informed, comfort asking questions drops by half, to 33 percent.
- Nearly seven in 10 of those who feel very informed about their health also feel very confident in their ability to make healthcare decisions. Strong confidence falls to 44 percent among those who feel less than very well-informed.

- Among patients who feel highly informed about their health, 61 percent say they always understand their providers' advice and treatment plans. That declines to 34 percent of those who feel just "somewhat" informed, and 18 percent of those who feel less informed about their health.

comfort asking provider questions



The next step, from empowerment, is to engagement in care decisions, and there the results are equally compelling:

- Among patients who report trouble understanding their providers' instructions, 51 percent are involved in decisions about their care. Among those who report higher levels of understanding, however, many more, 79 percent, are involved in their care decisions.
- Among patients who say they're less than fully comfortable asking questions of their care providers, 59 percent are involved in their care. Among those who are very comfortable asking questions, instead, 81 percent are involved.
- Involvement in care is 19 points higher among patients who are very confident in their ability to make health decisions than among the less confident, 81 percent vs. 62 percent.
- Information, in addition to enhancing empowerment, also directly impacts engagement. Among patients who feel they lack information about their health, just 55 percent also say they have a role in their healthcare decisions. Among those who are very informed, by contrast, the number who report involvement jumps to 83 percent.

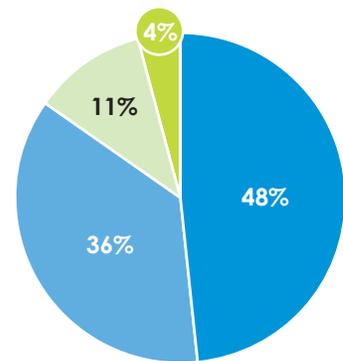
Notably, the extent to which patients feel informed about their health and confident about taking a role in their care decisions predicts their engagement independently of – and more strongly than – their education, income, gender, race/ethnicity, language spoken at home, and the type of care facility they use. That suggests that clear information can help level the healthcare playing field across population groups.

Still, there are socioeconomic barriers in current access to some forms of health information. Specifically, low-income Californians are substantially less apt than Americans more broadly to use the internet for healthcare information, reflecting the “digital divide” that disadvantages the poor and near-poor in the information age. Fifty-six percent in this population never have used the internet to obtain health information, and most of the rest do so only infrequently.

The survey was conducted by landline and cellular telephone interviews among a random statewide sample of 1,024 Californians age 19 to 64 with household incomes less than 200 percent of the federal poverty level. Among other results:

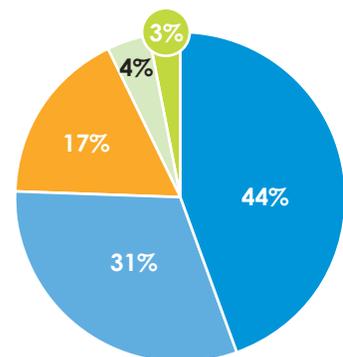
- Information is not absent; 84 percent feel at least somewhat informed about their health and any health problems they may have. But many fewer, 48 percent, feel “very” informed, a significant shortfall in this uniquely important indicator.
- Communication suffers similar challenges. Just 44 percent say their healthcare provider always explains things to them in a way they can understand. And one in five says there have been times when they didn't follow a care provider's advice or treatment plan because they didn't understand what they were supposed to do.
- Misunderstanding providers' instructions is especially prevalent among low-income Californians who feel less than fully comfortable asking questions about their care, marking the need for providers to encourage patients to speak up when they feel instructions are unclear. Patients with chronic conditions, and those who rate their health as less than very good, also are particularly vulnerable to failing to follow treatment plans because they haven't understood their instructions.
- Helpfully, 73 percent say they themselves, rather than their care providers, are chiefly responsible for managing their own health. This acceptance of personal responsibility may constitute a useful first step as providers seek to move patients down the path to greater engagement in their care.
- There's substantial desire for new information about healthcare options. More than eight in 10 express interest in learning about the pros and cons of tests or treatments, the training and experience of health professionals in their area, patient satisfaction ratings of local facilities, and quality ratings of care providers. The first is especially compelling, with 58 percent “very” interested in information on potential tests and treatments.

informed about health



- very informed
- somewhat informed
- not so informed
- not informed at all

provider explains things in a way patients can understand



- every time
- most of the time
- some of the time
- rarely
- never

- Fewer, albeit nearly half (47 percent), say a “seal of approval” from a national healthcare association would make them more likely to go to a particular facility. That ranges from 53 percent of patients of community clinics and health centers (CCHCs) to a low of 40 percent among Kaiser Permanente patients.
- Cultural, community and linguistic competence also receive broad interest. Two-thirds of poor and near-poor Californians say it’s important for their healthcare provider to understand their ethnic or cultural background. Three-quarters prefer that their provider know what’s going on in their community (including 86 percent of CCHC patients). And among those who mainly don’t speak English at home, more than nine in 10 want a provider who can speak with them in the language of their choice.

In combination with the *Connectedness and Continuity* report, results of this survey lend themselves to an action plan for California’s safety net healthcare providers. The previous study laid out approaches – including team-based care, healthcare navigators, group health programs, and use of technology – that can enhance the personal connection patients feel with their healthcare facility. This report explores the value of using those personal connections to provide clear information, thus empowering and engaging patients in their own care.

endnotes

- 1 Phrases such as “feeling informed,” “being informed,” and “having health information” are used interchangeably throughout this report to describe respondents who report feeling well-informed about their health and any health problems they may have. For question wording and full topline results, see Appendix B, question 37.
- 2 The model of patient engagement we present in this report is based on empirical results of our study – specifically, on mediation models in which we produced a series of regression analyses examining underlying processes in the relationships among the variables of interest. While our survey questions are based on some of the theoretical principles of patient-centered care, our model was independently derived from the data collected for this study. See Appendix A for full details of the mediation models predicting patient engagement. Separately, for a theoretical, literature-based model of relationships among patient-centered medical home concepts, see Agency for Healthcare Research and Quality Publication No. 10-0083-EF, http://pcmh.ahrq.gov/portal/server.pt/community/pcmh__home/1483/PCMH_HTMLConversion_10-0083-EF_v2.

project overview

This study is the second of two reports based on a 2012 Blue Shield of California Foundation survey of poor and near-poor Californians. The project extends a course of research initiated by BSCF with its 2011 study, [*On the Cusp of Change: The Healthcare Preferences of Low-Income Californians*](#). Identical in sample design, this year's survey focuses on two key findings of the 2011 report: Expressed interest in a traditional doctor-patient relationship, and hesitancy in some patient groups to embrace the concept of shared decision making in healthcare matters.

The first 2012 report, *Connectedness and Continuity: Patient-Provider Relationships Among Low-Income Californians*, measured experience and interest among patients in seeing the same care provider on a regular basis, and the prevalence of having someone at their healthcare facility who "knows you pretty well." It explored alternative paths to achieving this connectedness, and analyzed their positive impacts on patient satisfaction and efficacy, the capacity and confidence of patients to take an active role in their care.

This second report extends that research by examining low-income Californians' interest in having an equal role with the provider in decisions about their care specifically, and their empowerment and engagement more broadly, within the context of connectedness and continuity. Among the questions:

- Why would some patients rather leave health decisions up to their providers, and would additional information move the needle?
- How are confidence in making healthcare decisions, comfort in asking questions, and comprehension of providers' instructions supported by information? To what extent do these, in turn, relate to patients' engagement in their own care?
- How are connectedness and continuity – two key concepts from this year's first report – related to patient empowerment and engagement?
- How much health information do patients feel they have, how much would they like, and in what areas?
- What are patients' preferences for cultural, community, and linguistic competence in their healthcare providers?

This study, like last year's, was produced and analyzed by Langer Research Associates after an extensive review of relevant literature, listed in Appendix D, and discussions on questionnaire development with a group of prominent researchers and practitioners in the field: Carol Beasley, director of strategic projects, Institute for Healthcare Improvement; Susan Dentzer, editor, *Health Affairs*; Rushika Fernandopulle, co-founder and CEO, Iora Health; Ed O'Neil, former director, Center for the Health Professions at University of California, San Francisco; Dr. Sunita Mutha, interim director, Center for the Health Professions at University of California, San Francisco; Lyn Paget, director of policy and outreach, Informed Medical Decisions Foundation; Julia Paradise, associate director, Kaiser Commission on Medicaid and the Uninsured; Jane Stafford, managing director, Community Clinics Initiative; and Isabelle Von Kohorn, program officer, Institute of Medicine. We are grateful for their insights.

Blue Shield of California Foundation, long a thought leader in safety net healthcare services, has sponsored this research as part of its mission to improve the lives of Californians, particularly underserved populations, by making health care accessible, effective, and affordable for all Californians. BSCF in particular has a long history of support for the state's community clinic and health centers (CCHCs) through its Community Health Center Core Support Initiative and Clinic Leadership Institute offerings.

This survey was conducted among a representative, random sample of 1,024 Californians age 19 to 64 with household incomes less than 200 percent of the federal poverty level (approximately \$46,000 a year for a family of four). Interviews, averaging 22.6 minutes in length, were conducted by both landline and cellular telephone, in English and Spanish, from March 12 to April 8, 2012; see details in the methodology section of this report. Results for the full sample have a margin of sampling error of plus or minus 3.5 percentage points.

Sampling, fieldwork and data tabulation were carried out by SSRS/Social Science Research Solutions of Media, Pa. SSRS has performed similar services in a range of prominent healthcare studies, including surveys for the Harvard School of Public Health under the sponsorship of the federal Centers for Disease Control and Prevention, the Massachusetts Division of Health Care Finance and Policy (via the Urban Institute), the Minnesota Department of Health (through the University of Minnesota and the State Health Access Data Assistance Center), the Oregon Department of Human Services, the Colorado Health Institute, The Commonwealth Fund, and the Henry J. Kaiser Family Foundation.

sections guide

Key results are outlined in the executive summary. The full report provides extensive details, presented as follows:

part a: information and engagement

- section i: shared decision making. Whether or not patients prefer taking an equal role in health decisions, and the effect of information on that preference. Differences in initial preference for an equal say and shifting preference among groups.
- section ii: current and desired patient involvement. Current level of patient engagement in care decisions, and whether they desire more involvement or not. The relationship between patient empowerment and engagement.
- section iii: personal responsibility. Patient perceptions of who's most responsible for their own health – the patients themselves or their care providers.

part b: empowering healthcare consumers

- section iv: impacts of information. How informed patients feel they are about their own health, overall and among groups. The central role information plays in empowering patients and how connectedness and continuity in healthcare relationships foster empowerment, and through it, patient engagement.
- section v: miscommunication and its consequences. The number of patients who have not followed a provider's advice or treatment plan due to misunderstanding, and differences in doing so among groups.
- section vi: information and the internet. A look at the groups most likely to have used the internet to search for health information, including a brief discussion of the “digital divide” in internet usage.
- section vii: fostering empowerment. Patient confidence in making health-related decisions, comfort in asking questions of their care providers, and how frequently providers explain things in a way that patients can understand. An examination of the key independent predictors of each of these three elements of patient empowerment.

part c: additional information and cultural competence

- section viii: desire for greater information. Interest in more information on the pros and cons of tests or treatments, the training and experience of health professionals in the area, patient satisfaction ratings of local facilities, and quality ratings of care providers. The effects of a national seal of approval on patients' choice of facility.

- section ix: cultural competence and community understanding.
A look at the importance patients place on provider knowledge of their communities, understanding of their cultural and ethnic backgrounds, and for non-English speakers, their ability to communicate in the language of their choice.

part d: conclusions

methodology

A detailed description of the survey's sampling methodology, field work, data processing, weighting, response rate information, and procedures for healthcare facility identification.

The report concludes with appendices explaining the statistical modeling used in this study, and presenting the topline results for questions included in this report, the full questionnaire, and source references.

Questions on any aspect of this study, and requests for further data analysis, should be directed to Cecilia Echeverría, Blue Shield of California Foundation, 50 Beale Street, 14th Floor, San Francisco, Calif., 94105-1819, tel. (415) 229-6147, cecilia.echeverria@blueshieldcafoundation.org.

part a: information and engagement

section i: shared decision making

Patient-centered care envisions a range of services that enhance patients' involvement in their health care and ownership of their well-being. One prime element is shared decision making, in which patients are encouraged to take an equal role with their providers in medical decisions.

Fifty-nine percent of low-income Californians age 19 to 64 say they'd like that equal say – meaning that nearly four in 10, 39 percent, instead would rather leave decisions mainly to their healthcare providers. At first blush, having an equal say earns less than the overwhelming interest that might be expected, given the presumed appeal of a strong role in such personal matters – “nothing about me without me,” as it's phrased in the patient-centered care literature.

Replicating results from the 2011 Blue Shield of California Foundation survey, *On the Cusp of Change: The Healthcare Preferences of Low-Income Californians*, having an equal say appears almost as intimidating as it does appealing to some specific groups within the poor and near-poor population. This is particularly true among individuals – such as those who are less educated, noncitizens, or who don't primarily speak English – who may be less accustomed to having their voices heard (or, for some, may have cultural reasons for preferring a less active role).

But information shifts the playing field. A follow-up question in this survey asked respondents who prefer to leave decisions to their care provider whether they feel that way mainly because they don't think they have enough information to make the right decisions, or because they feel it is the doctor's responsibility, not theirs. Well fewer than half in this group, 40 percent, said it's because they feel it is the doctor's role. In sum, this means that a mere 16 percent of low-income Californians reject shared decision making simply because they see it as the doctor's job.

In another follow-up, moreover, patients who expressed reluctance about taking an equal role in care decisions were asked how they would feel about it “if the doctor has selected treatment options for you – a choice of things you might do, any of which is medically appropriate – and you've been given information that you understand about these options.” Under these conditions, interest in shared decision making jumps from 59 percent overall to 81 percent – key evidence of how clear information can increase patient involvement.

Having an equal say appears almost as intimidating as it does appealing to some groups within the poor and near-poor population.

decision making among groups

There are significant group differences in initial interest in shared decision making (i.e., before asking about the inclusion of clearly explained options).³ As noted, interest in an equal say is lowest among the least-educated adults; fewer than half of those without a high school diploma find shared decision making appealing, compared with more than seven in 10 college graduates. And about half of Latinos, non-English speakers, and noncitizens initially prefer to leave decisions up to the care provider, compared with a third or fewer of non-Latinos (whites and other racial groups alike), English speakers, and citizens.

An important finding is that initial preference for an equal role in decision making is higher among more empowered patients. As explored in part b, this study finds four major indicators of patient empowerment – feeling informed about your health, being comfortable asking questions of a care provider, having confidence in your ability to make healthcare decisions, and understanding your provider's explanations and advice. When these are present, patients tend to be more interested in taking an active role in their health care.

key elements of patient empowerment

- informed about your own health
- understand the information you're given
- comfortable asking questions of your providers
- confident making decisions regarding your health

Specifically, interest in shared decision making is higher by 24 percentage points among patients who feel comfortable asking their healthcare provider questions, by 12 points among those who feel informed about their health, by 11 points among those who are very confident in their ability to make care decisions, and by 8 points among those who say their care provider always explains things in a way they can understand, compared, in each case, with their opposites.⁴

In evidence of the power of personal connections, initial preference for an equal say also is 11 points higher among individuals who have a regular personal doctor, and, in a related result, rises to 70 percent of those with private insurance (vs. 53 percent among the uninsured, who are less likely to have a doctor or a personal relationship at their care facility).

Initial preference for an equal role in decision making is higher among more empowered patients.

initial preference for an equal say in care decisions

all	59%
race/ethnicity	
white	75
latino	49
other	65
citizenship	
citizens	66
non-citizens	47
education	
< high school	47
h.s. diploma/some college	65
college graduate	72
personal doctor	
have personal doctor	65
lack personal doctor	54
insurance status	
private insurance	70
government insurance	56
no insurance	53

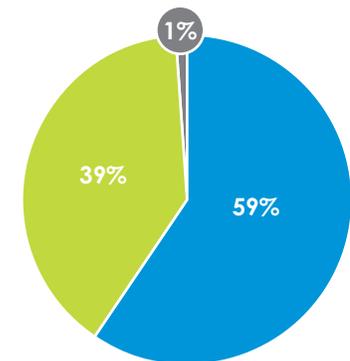
the impact of information on shared decision making

There are two informative differences in who shifts their preference from leaving decisions to their caregiver to wanting an equal say, after it's been specified that clear, well-explained options will be provided. Those who see the same care provider on every visit are more likely to move than are those with less continuity of care (63 vs. 51 percent).⁵ Similarly, those who feel someone at their healthcare facility knows them well are more likely to shift their preference toward greater involvement than are those who lack a personal connection, 62 vs. 51 percent. These suggest that even among those who are initially resistant to having an equal say, continuity and connectedness – two key aspects of care relationships – can encourage more active participation in shared decision making once clear information is in the mix.

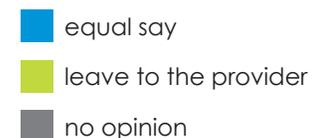
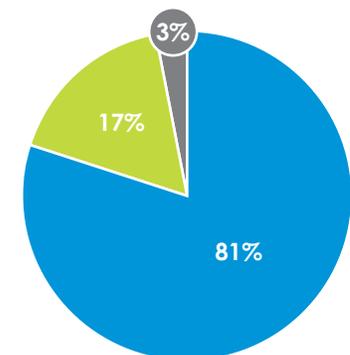
There are few other group differences in the impact of information on interest in shared decision making. Indeed, the takeaway from these results is how universally high interest rises when accompanied by clear information. For example, what started as a stark 25-point education gap in initial preferences for an equal say shrinks to a non-significant 7-point difference when information is provided: Eighty-three percent of those with a college education express interest in having an equal say, but so do 76 percent of those who lack a high school diploma.

Moreover, racial or ethnic, language, and citizenship differences in preference for an equal say all are greatly reduced when information is provided. A 26-point gap in initial interest in an equal say between whites

initial shared decision making preferences



shared decision making preferences when clear information is provided



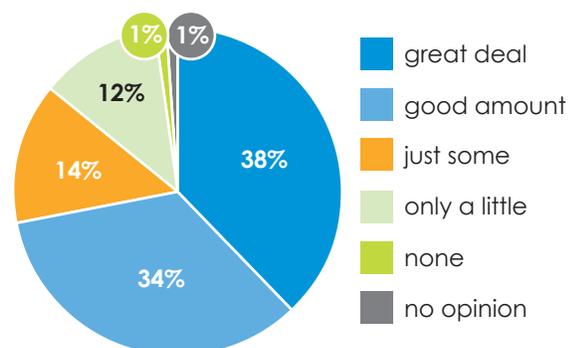
and Latinos is cut in half, with nine in 10 whites expressing a desire to take an active role in their care and 77 percent of Latinos saying the same. Likewise, despite their initial reluctance to embrace shared decision making, seven in 10 non-English speakers and three-quarters of noncitizens express desire for a say in their care when clearly explained options are offered.

section ii: current and desired patient involvement

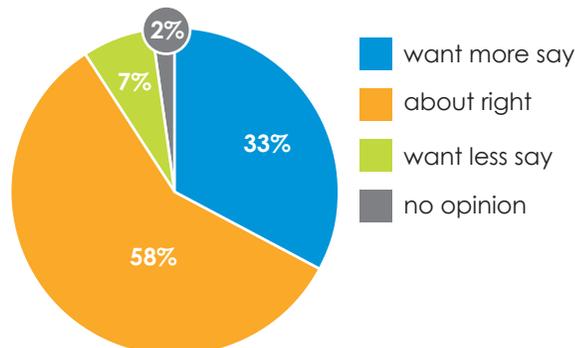
Currently more than seven in 10 low-income Californians say they do have at least a good amount of involvement in decisions about their health care. But many fewer, 38 percent, report having a “great deal” of input, marking patient involvement as an area ripe for improvement.

Another question measures whether patients feel their current involvement is sufficient; a majority (58 percent) rates it as “about right.” One in three, though, wants more of a say, and that rises to 47 percent among those who feel they lack at least a good amount of involvement now.

current say in care decisions



desired say in care decisions



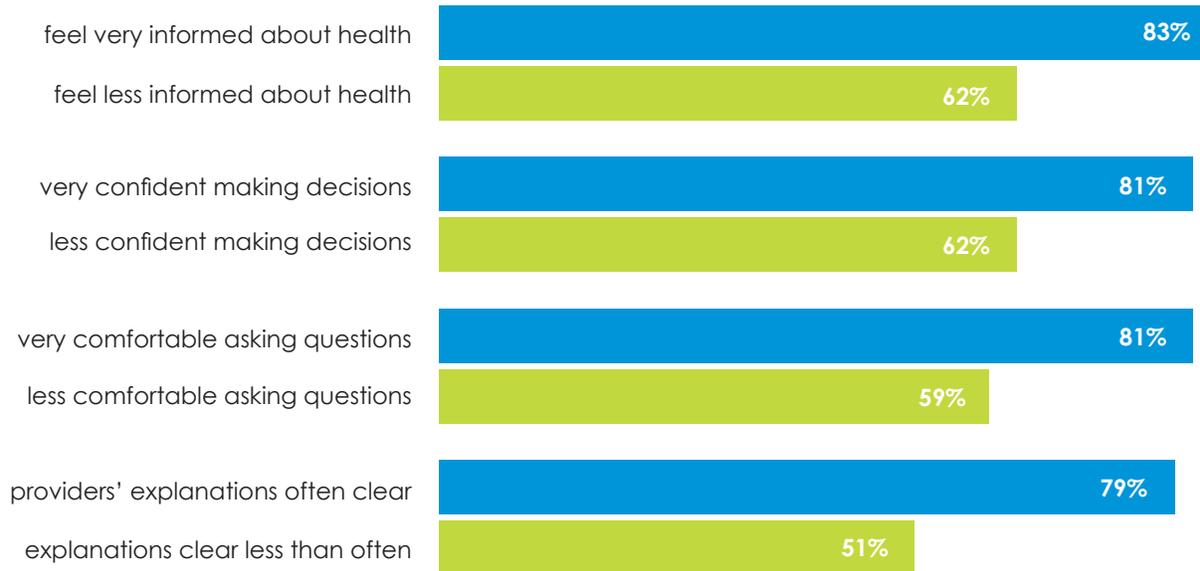
Statistical modeling shows that the four components of empowerment – feeling informed, being comfortable asking questions, being confident in decision making, and understanding providers' explanations – are the strongest independent predictors of patient involvement in healthcare decisions, controlling for other factors including health status, having a personal doctor or personal point of connection, and a variety of demographic variables.⁶

In one example, 83 percent of low-income Californians who feel very informed about their care also say they have a great deal or good amount of say in their healthcare decisions. That sense of involvement falls to 65 percent among those who report being just somewhat informed about their health, and to 55 percent of those who feel less informed.

Similarly, those who say their provider often explains things in a way they can understand are 28 points more apt to report being involved in their care decisions than are people who understand their provider less often, 79 percent vs. 51 percent. Among patients who are very comfortable asking

questions, 81 percent say they're involved in care decisions, compared with 59 percent of those who are less comfortable asking questions of their provider, a 22-point gap. And patients who are very confident in their ability to make healthcare decisions are 19 points more likely to feel involved in those decisions than those with less confidence, 81 vs. 62 percent.⁷

% currently involved in care decisions

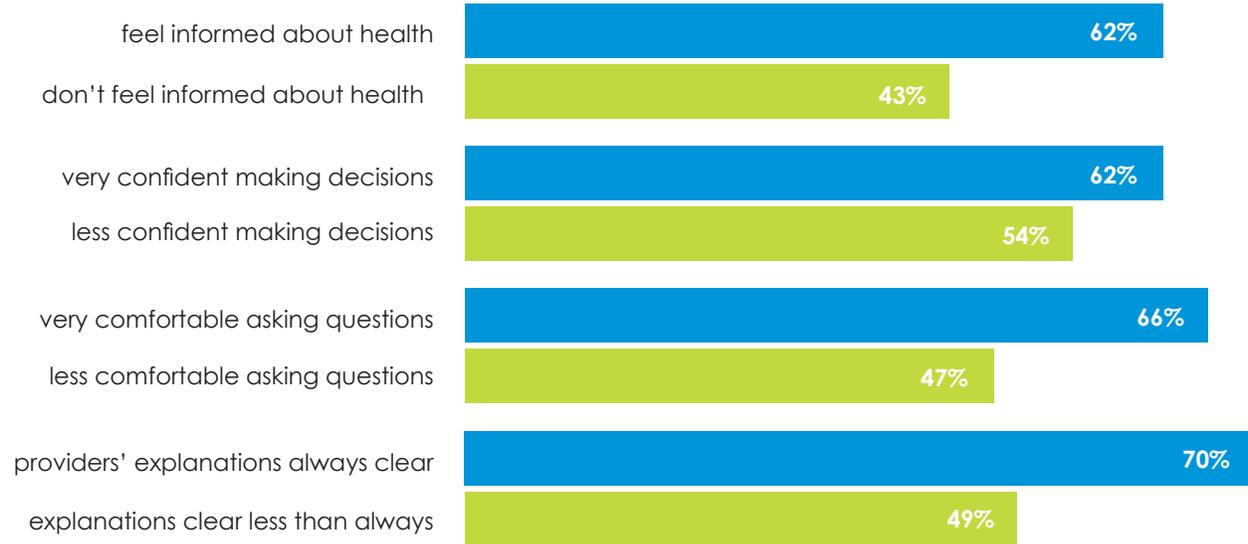


As noted, lacking current say is, predictably, a strong factor in patients wanting more of a say in their care than they have now. Desire for more say is 23 points higher among those who report having little or no current say, compared with those who have at least a good amount of input.

That's also expressed in other results. Desire for more say in medical decisions tops out among people who currently use hospital emergency rooms as their primary care facility (they're also more apt to say they lack input now).⁸ And desire for more involvement is 10 points higher among those who rarely or never see the same care provider when they have a medical appointment, compared with those who see the same provider on each visit.

Perhaps not surprisingly, more empowered low-income Californians express greater satisfaction with their current level of say than do less empowered groups. Sixty-two percent of patients who feel informed about their health say they have about the right amount of input, compared with 43 percent of patients who feel less informed. Patients who feel their provider always explains things in a way they can understand, who are very comfortable asking their provider questions, and who are very confident in their ability to make care decisions are 21, 19, and 8 points more likely to be satisfied with the amount of say they have now than their less-empowered peers.

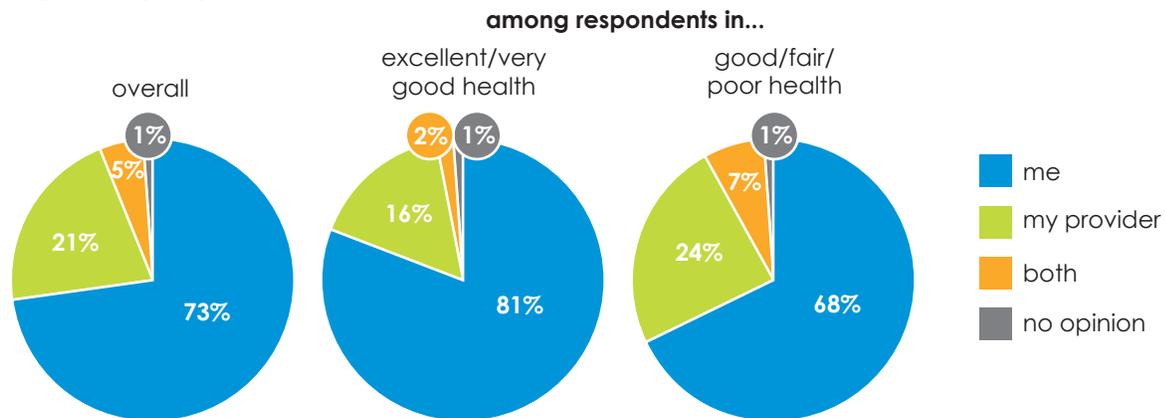
% satisfied with their current amount of say



section iii: personal responsibility

Another result illuminates personal responsibility for one's health as a pathway by which healthcare providers can approach patients about taking a greater role in their care decisions. When asked whom they feel is more responsible for managing their health, 73 percent of low-income Californians say it's their own responsibility, many more than the 21 percent who place the onus on their healthcare providers.

responsibility for patient health



Health status is one important differentiator. Among people who say their health is very good (or better), 81 percent take personal responsibility for managing their health; that declines to 68 percent of those in just good health, or less. Patients who need more care, then, are more apt to delegate prime responsibility for their health management. It's a result for providers to keep in mind: As complexity rises, information overload may reduce patients' self-reliance, marking the need for a more concerted effort to convey even the most complex health information in ways that are easily understandable. Of course, certain health problems themselves may reduce patients' capacity to manage their own health.

It follows that young adults (who tend to be in better health) are 11 points more apt than those 40 and older to take personal responsibility. There also is a racial and ethnic gap; 85 percent of whites say they're responsible for managing their own health, vs. 69 percent of Latinos and a very similar 67 percent of other racial and ethnic groups.

Perhaps most useful is the finding that patients who take personal responsibility for their care are more likely than others to express initial interest in shared decision making, as well as more apt to move to that position if clear information about healthcare options is provided. That suggests that providers can encourage patients to take a more involved role in their health care by appealing to their existing sense of personal responsibility.

endnotes

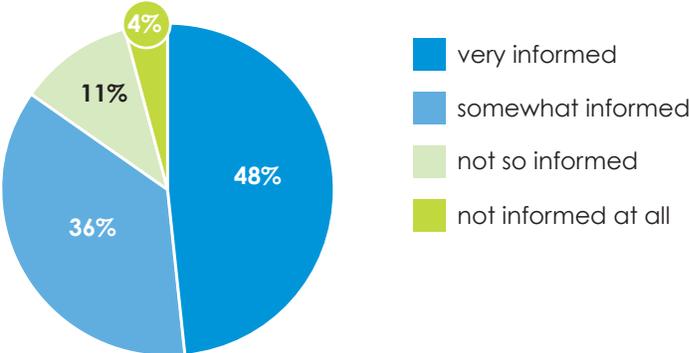
- 3 Unless otherwise indicated, all differences described in this report are statistically significant at the 95 percent confidence level.
- 4 The sample size of those who report feeling uncomfortable asking questions is small, 92. Nonetheless, given the magnitude of the difference, the result is statistically significant at the 95 percent confidence level.
- 5 Here and in the paragraphs below, desire to have most of the say is netted with desire to have an equal say.
- 6 See Appendix A, Model 1 for details of the regression model predicting patient involvement in care decisions.
- 7 Regression models do not establish causality. While it is likely that comfort asking a provider questions impacts the amount of involvement patients have in decisions about their care, it's also possible that the amount of say patients have impacts their comfort asking questions, or that the causal arrow points both ways.
- 8 The sample size for hospital emergency room patients is small (N=94), however this difference is statistically significant at the 95 percent confidence level.

part b: empowering healthcare consumers

section iv: impacts of information

While a broad majority of poor and near-poor patients, 84 percent, feel at least somewhat informed about their health, that doesn't mean care providers can rest in their efforts to improve patient information. Many fewer patients – 48 percent – feel “very” informed. And information is uniquely critical. As indicated above, being well-informed on health issues is a key predictor of patient engagement. It also is a fundamental precursor of empowerment.⁹

informed about health



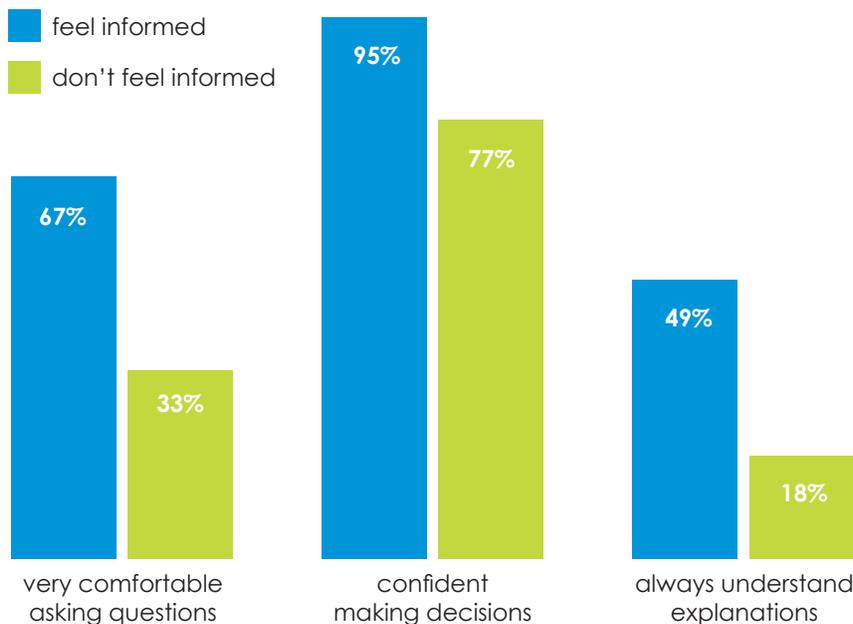
Specifically, statistical modeling finds that how informed patients feel about their health independently predicts three of the basic aspects of patient empowerment identified in this study – comfort asking questions of care providers, confidence in making healthcare decisions, and understanding of providers' explanations and advice.¹⁰

Regression models such as those used in this study do not establish causality.¹¹ Regardless, the very consistent importance of health information, as well as its clear influence on interest in shared decision making, mark it as essential in advancing patient-centered care.

The very consistent importance of information marks it as essential in advancing patient-centered care.

For example, patients who feel informed about their health are 34 points more likely than those who feel less informed to say they're very comfortable asking questions of their provider, 67-33 percent; 31 points more likely to say they always understand their providers' explanations and advice, 49-18 percent; and 18 points more likely to express confidence in their ability to make healthcare decisions, 95-77 percent.

engagement by level of information



connectedness and continuity

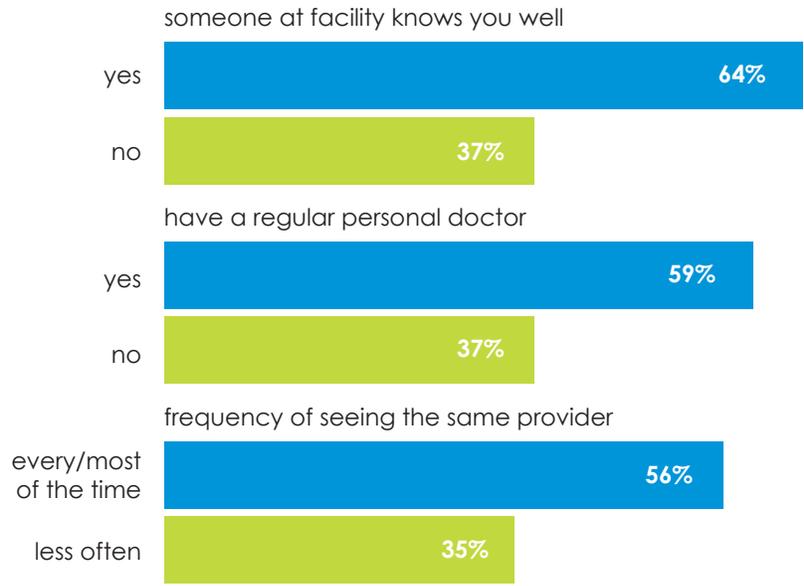
An earlier report from this survey found that patients' involvement and satisfaction with their care are positively impacted by their seeing the same provider on a regular basis (continuity) and by the sense that someone at their care facility knows them well (connectedness). This report, in turn, finds that connectedness and continuity also are basic contributors to patient empowerment, and through it, engagement.

Connectedness and continuity can come from a variety of sources, whether it's a traditional doctor-patient relationship; another personal and consistent connection with someone at the care facility; or alternative care relationships through health teams or coaches, group programs, or technology-based communication via phone, texting, or the internet.

Those who see the same provider at least most of the time, or say there's someone at their facility who knows them well, are 21 and 27 points, respectively, more apt to feel very informed about their health than are patients who lack these kinds of relationships. Similarly, those who have a regular personal doctor, a healthcare coach, or team-based care all are more likely to feel very informed than are those who do not, by 22-, 14-, and 10-point margins, respectively.

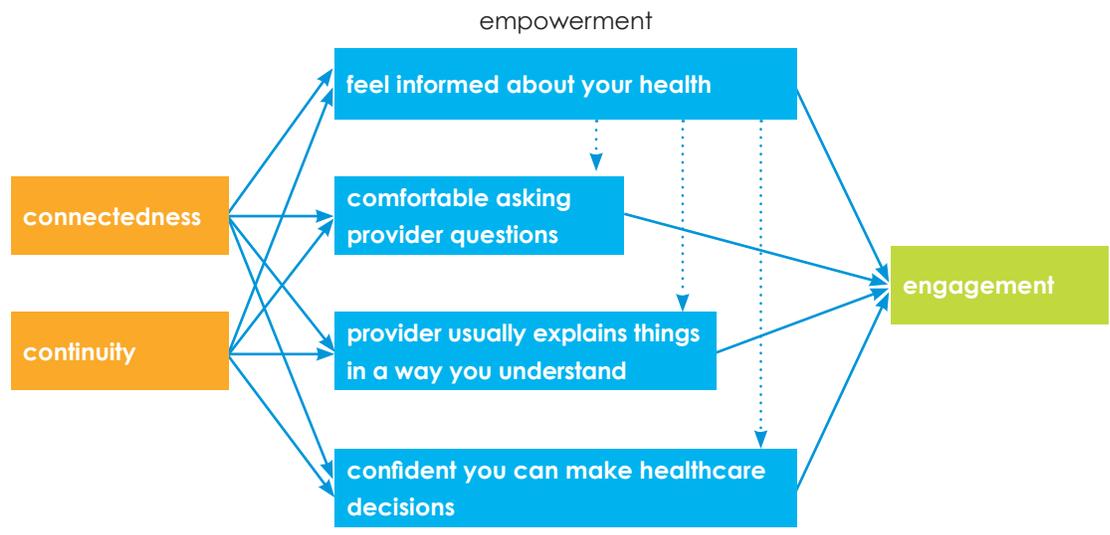
Continuity and connectedness also have positive impacts, ranging from 10 to more than 20 points, on comfort asking questions, on confidence in making healthcare decisions, and on understanding care providers.

% very informed about their health



Mediation analyses extend these results, showing a progression from connectedness and continuity to patient empowerment and on to engagement. In other words, greater connectedness and continuity significantly impact patient engagement, not directly, but by increasing health information, confidence, comfort and comprehension. (As noted in the Executive Summary, and detailed in Appendix A, this model of patient engagement was independently produced in statistical analyses of the results of this study.)

a model of patient engagement



Controlling for other factors, the results of this survey show that connectedness and continuity predict "empowerment" outcomes – feeling well-informed, being comfortable asking questions of care providers, understanding providers' answers and being confident in the ability to make healthcare decisions. Feeling well-informed also independently predicts the other three empowerment items. And each of the empowerment measures predicts "engagement," that is, taking a role in healthcare decisions – a key goal of patient-centered care.

information among groups

If connectedness and continuity can get the ball rolling, information keeps it in play. Indeed, even when connectedness and continuity are absent, information remains a primary driver of empowerment and engagement. Close examination of self-assessed health information levels among groups thus is warranted.¹²

By facility type, rates of feeling very informed are highest among patients of private doctors' offices and Kaiser Permanente, at 58 percent and 53 percent, respectively, and lower among those who rely on hospital emergency rooms for their care (36 percent). CCHC and non-CCHC clinic patients fall between these groups in their levels of information, with 47 and 43 percent, respectively, feeling very informed about their health.

The uninsured report lower levels of health information (just a third in this group feels very informed, compared with more than half of those with insurance). And there are significant gaps by income, with those worse off – even within the already-restricted population of poor and near-poor Californians – reporting less information than those with not-quite-so-low incomes. In addition, whites are roughly 10 points more likely than Latinos and members of other racial/ethnic groups to report feeling very informed about their health.

feel very informed about health

facility type	
private doctors' offices	58%
Kaiser Permanente	53
CCHCs	47
non-CCHC clinics	43
hospital E.Rs.	36
insurance status	
Medi-Cal	58
private	52
none	34
race/ethnicity	
white	55
other	46
latino	45
age	
30+	53
<30	36
gender	
women	53
men	42

There also are gender and age differences: Women are more likely to report feeling very informed than are men, 53 to 42 percent. And while just 36 percent of younger low-income Californians (i.e., those age 19-29) feel very informed about their health, that rises to more than half of their elders.

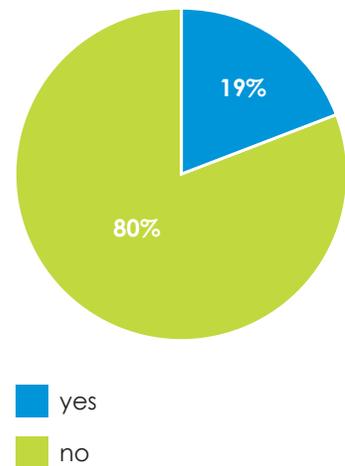
section v: miscommunication and its consequences

Health information is effective only if clearly communicated, and here there are significant challenges. Fewer than half of poor and near-poor Californians, 44 percent, say their care provider always explains things to them in a way they can understand (as detailed in section vii). And nearly one in five, 19 percent, says there have been times when they didn't follow a care provider's advice or treatment plan because they didn't understand what they were supposed to do.

The likelihood of misunderstanding medical advice can be reduced by providers and care facilities making their messages clear – and also by developing relationships in which patients feel at ease asking questions.¹³ Among patients who are uncomfortable asking questions, a third say that at times they have not followed a provider's advice or treatment plan because they didn't understand what to do. Among those who are very comfortable asking questions, fewer than half as many, 14 percent, report instances in which they didn't follow instructions.

Another result points to a particular need for clarity among people with chronic conditions or who rate their health as less than very good. These individuals may have more opportunities to misunderstand their care providers, and indeed they do: A quarter of those in less-than-good health, and 31 percent of those with chronic conditions, report times they didn't follow instructions because they didn't know what to do. That drops to 15 percent both among those without chronic conditions, and whose overall health is excellent or very good.

did not follow provider's advice due to misunderstanding



% who have misunderstood medical instructions

disability/chronic condition	
yes	31%
no	15
health status	
fair/poor	25
good	19
excellent/very good	15

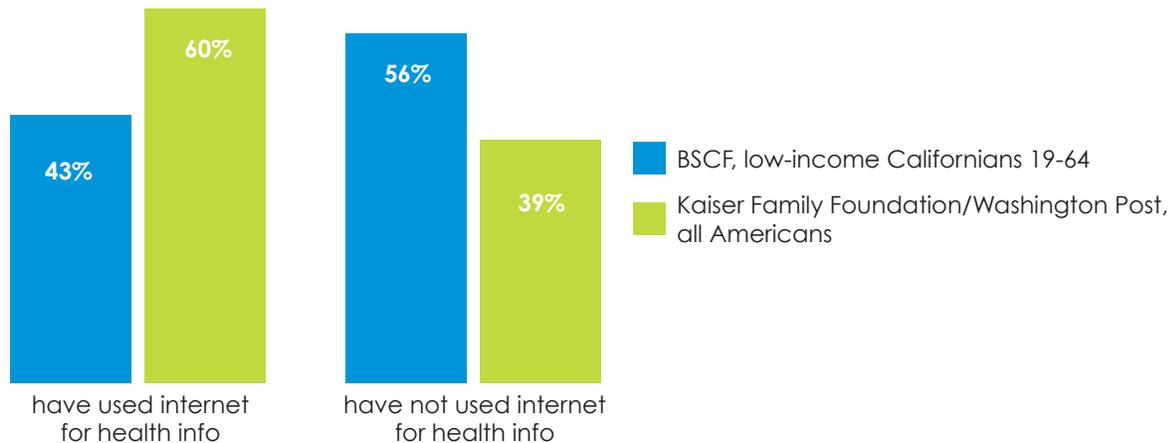
There's one difference in miscommunication across care facilities: Among people relying on emergency rooms for care, 26 percent report having not followed instructions because they didn't understand them; that compares with 14 and 15 percent, respectively, of Kaiser Permanente and CCHC patients. (Users of other facility types fall in between.)

It's also notable that poor and near-poor African-Americans in California are twice as likely as low-income whites and Latinos alike to say they haven't followed a physician's advice or treatment plan because of a lack of understanding.¹⁴

section vi: information and the internet

If communication is one challenge, information access is another. Most low-income Californians, 56 percent, never have used the internet to obtain health information, and most of the rest do so only infrequently. Use of the internet for health information was 17 points higher among all adults nationally in a Kaiser Family Foundation/Washington Post poll in 2011; its lower level in this survey likely reflects the so-called "digital divide," in which adults with lower socioeconomic status are less apt to have easy access to technology, including high-speed internet service.

use of internet to access health information



This divide occurs even within the low-income California population.¹⁵ College graduates are twice as likely as non-graduates to say they've used the internet to access health information (77 vs. 39 percent), by far the biggest gap in usage. Young adults, citizens, whites, and non-Latino respondents also are more likely to have done so than are older people, noncitizens, and Latinos. Indeed nearly seven in 10 poor and near-poor Latinos in the state say they never have used the internet for gathering health information.

Kaiser Permanente patients and those with private insurance are more likely than others to have searched for health information on the internet, 62 and 56 percent, respectively. On the lowest end of the usage spectrum are patients of CCHCs and non-CCHC clinics alike (34 and 37 percent, respectively) and those who lack private health insurance (38 percent).

Those who take sole responsibility for their health, who desire an equal say in shared decision making, or who have at least some input in their current care all are more likely to have used the internet to access health information than those who do not – again underscoring the relationship between information (whatever its source) and engagement.¹⁶

internet use by groups

education	
college grad	77%
non-college grad	39
race/ethnicity	
white	57
latino	31
other	59
age	
19-29	57
30-39	41
40-64	34
citizenship	
citizen	53
noncitizen	25

Results suggest untapped potential to use the internet to enhance health information more generally, and through it empowerment and engagement.

As noted in the previous report from this survey, use of the internet may be a way to improve the connectedness patients feel with their care facility, and substantial numbers express interest in online resources for activities such as scheduling medical appointments and renewing prescriptions. The results in this report further suggest untapped potential to use the internet to enhance health information more generally, and through it empowerment and engagement – to the extent that the digital divide can be bridged.

section vii: fostering empowerment

Whether by clearer delivery of health information, internet resources, or other means, unquestionably there's room for greater patient empowerment. While more than nine in 10 low-income Californians are at least somewhat confident in their ability to make healthcare decisions, fewer, 56 percent, are "very" confident. Although nine in 10 express comfort asking questions about their care, fewer, 62 percent, are very comfortable in this role. And while three-quarters say their provider explains things in a way they can understand at least most of the time, only 44 percent, as noted, say this happens "every time."

confidence can make healthcare decisions		comfort asking provider questions		frequency provider explains things in a way you understand	
very confident	56%	very comfortable	62%	every time	44%
somewhat confident	36	somewhat comfortable	28	most of the time	31
not so confident	6	somewhat uncomfortable	7	some of the time	17
not confident at all	2	very uncomfortable	3	rarely	4
		no opinion	1	never	3

As described above, improving continuity and connectedness in patients' healthcare experiences is one means of improving patient empowerment. The following section examines additional predictors of each of these elements, including the common factor of information in each one.

confidence

Regression modeling shows that the most important predictors of self-confidence in making healthcare decisions are feeling informed, having clear explanations from providers, and taking responsibility for one's own health.¹⁷

Cross-sectional data illustrate those results. As noted previously, patients who feel very informed about their health are 24 points more apt than those less informed to be very confident making healthcare decisions. And among those who say their provider often explains things in a way they can understand, strong confidence is 15 points higher, 59 percent, than it is among those who report more trouble understanding their care provider, 44 percent.¹⁸

Moving beyond modeling, there's a gender gap in confidence among whites: While 65 percent of white women report being very confident in their ability to make decisions about their care, this declines to 49 percent of white men. There's no such division among Latinos, 56-55 percent, women-men.¹⁹

Patients of all facility types report being very confident at relatively equal rates. But broader confidence ("very" and "somewhat" combined) peaks among patients of private doctors' offices, Kaiser Permanente facilities and CCHCs, at 96, 95, and 94 percent, respectively. That's significantly higher than it is among emergency room users, 79 percent. (It falls in between, 88 percent, among non-CCHC clinic users.)

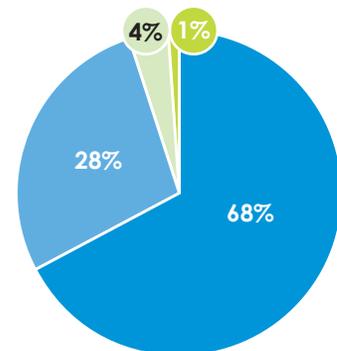
comfort asking questions

Confidence itself predicts patients' comfort level asking questions of their care providers, as does respondents' sense that their providers give clear explanations, and, again, health information levels.²⁰

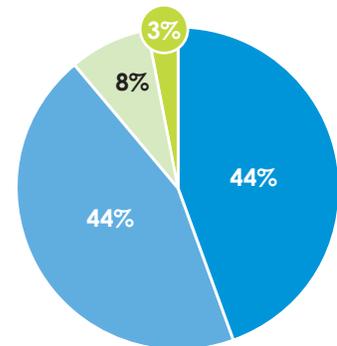
The quality of provider explanations is chief among these predictors. Patients who say their provider often explains things in a way they can understand are more than twice as apt to feel very comfortable asking questions, compared with those whose providers are less clear, 71 percent vs. 32 percent.²¹ Additionally, patients who feel well-informed about their health show a 26-point advantage in comfort asking their provider questions vs. their less-informed peers. And patients who are very confident making decisions are 26 points more apt than those who are less confident to be comfortable asking questions, 73 percent vs. 47 percent.

confidence can make healthcare decisions

among those who feel very informed



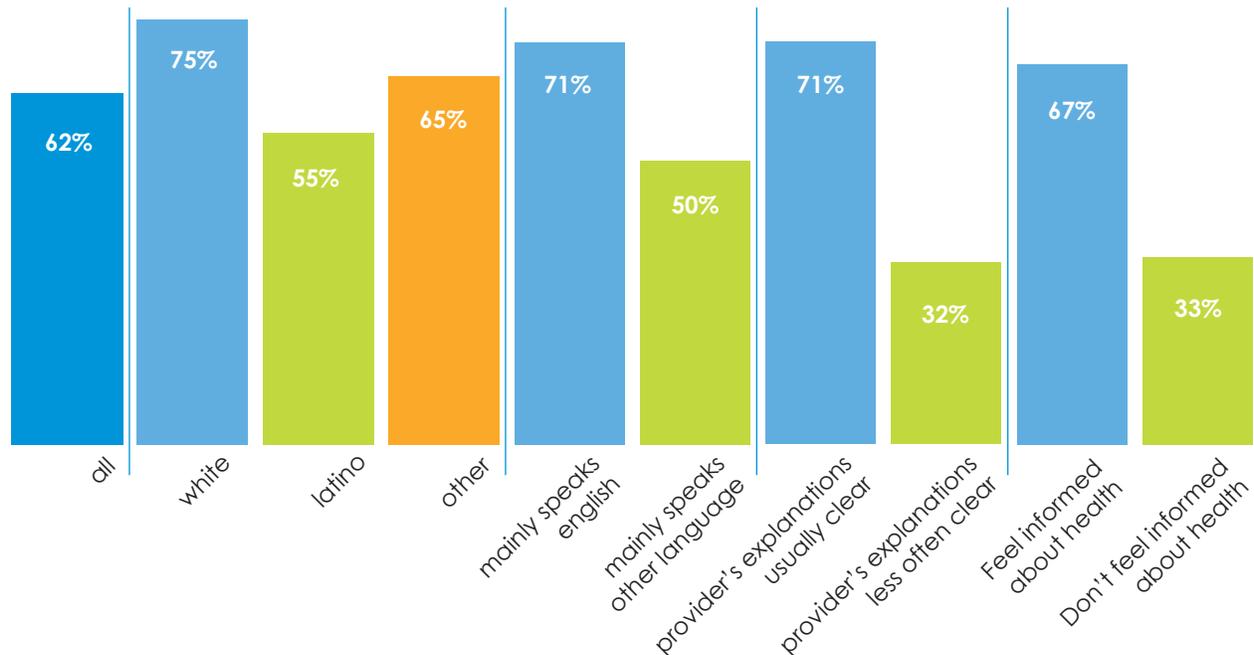
among those who feel less informed



- very confident
- somewhat confident
- not so confident
- not confident at all

Comfort asking questions also varies by race and ethnicity. Three-quarters of whites in this low-income population are very comfortable asking questions of their providers, compared with 55 percent of Latinos, with other groups in the middle (65 percent).²² Strong comfort asking questions also is comparatively low, 50 percent, among those who don't primarily speak English.

very comfortable asking questions



By facility type, patients at Kaiser Permanente or private doctors' offices are more likely to say they feel "very" comfortable asking questions than non-CCHC clinic and hospital emergency room patients (69 vs. 56 and 55 percent, respectively). CCHC patients fall in between these groups (63 percent report feeling very comfortable).

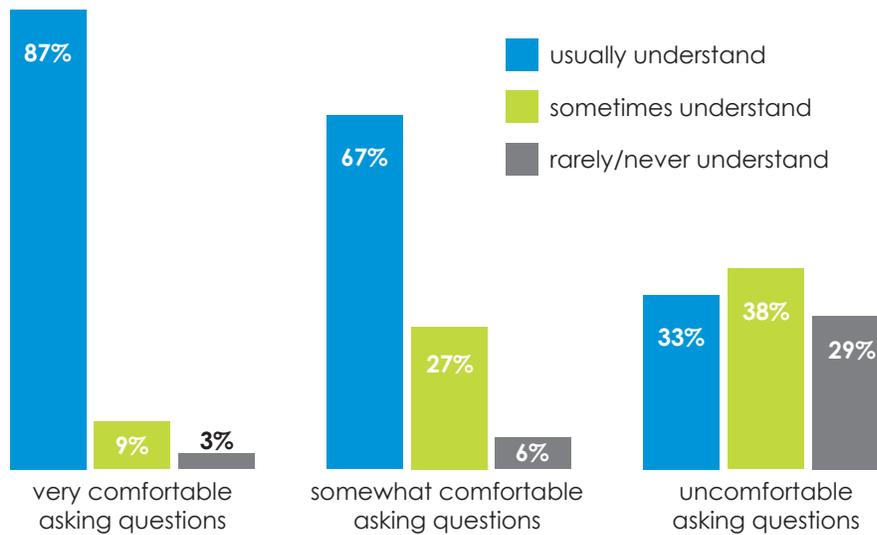
understanding providers

Statistical modeling finds that understanding of providers' explanations is best predicted by patients' comfort asking questions, how informed they feel about their health, and how much continuity they have in a care provider.²³

Some of the data on this measure are particularly striking. Among patients who feel informed about their health, 81 percent say their provider's explanations are clear at least most of the time, including 49 percent who say they always understand those explanations. Among those who feel less informed, these drop to 44 and 18 percent, respectively.

Likewise, a vast 87 percent of patients who are very comfortable asking questions also say their providers often explain things in a way they understand. Among those who are somewhat comfortable, 67 percent report frequent understanding; among those who are uncomfortable, it's just 33 percent. Patients are well-served when providers put them at ease in asking questions – achieved, to some extent, by those providers giving clear answers and advice.

% who understand providers' explanations



There's also differentiation in clear communication across care facilities. Among patients of Kaiser Permanente and private doctors' offices, 89 and 81 percent, respectively, say their providers' explanations are usually clear; that compares with 79, 72, and 69 percent, respectively, among patients of public clinics, private/other clinics and CCHCs. The lowest rates, again, are among hospital emergency room users, 59 percent of whom say they generally receive clear information from their care providers, and just 28 percent of whom say they always do.

Related to this result, those who lack insurance entirely are less likely than those with Medi-Cal to usually understand their care provider – 63 vs. 75 percent. Comprehension rates are highest among low-income Californians with private insurance, with 85 percent saying they usually understand their care provider, including 54 percent who say they always do.

In one other difference, understanding is higher among patients who report being in better health – 83 percent among those who describe their health as excellent or very good, vs. 71 percent among those who say they're in good, fair or poor health; this again may reflect the greater amount and complexity of information needed by patients in less robust health as well as the possibility that some health problems can reduce patients' cognitive capacity.

Those with a college degree are 12 points more apt to say they usually can understand their providers' explanations than are low-income Californians with a high school diploma or less. In addition, citizens and English speakers are 13 and 12 points more likely to say they usually understand care providers' instructions, compared with noncitizens and non-English speakers, respectively. In tandem, these findings suggest the need for clear instructions that can overcome educational and language barriers.

endnotes

- 9 There are cultural differences in norms about empowerment, and while patient empowerment is an essential component of patient-centered care, it may not be universally desired by all patients.
- 10 While health information is directly related to greater patient engagement in making care decisions, it takes an important indirect role as well. Specifically, involvement in care decisions is predicted by confidence, comfort, and comprehension – three items that, as noted, all are enhanced by greater information. See Appendix A, Model 3, 4 and 5 for details of the model predicting how informed respondents feel about their own health.
- 11 It's logical, for instance, that the clarity of explanations given by providers will affect how informed patients feel about their health, just as the amount of information patients have about their health will impact their ability to understand their providers. See Section VII for further details of the predictors of comfort, confidence and comprehension.
- 12 See Appendix A, Model 2 for details of the model predicting how informed respondents feel about their own health.
- 13 A review of effective patient-provider communication methods is beyond the scope of this report. Specific strategies have been demonstrated to improve patients' understanding of medical explanations, such as the teach-back method. See Schillinger, D, Piette, J., Grumbach, K., et al. (2003). Closing the loop: physician communication with diabetic patients who have low health literacy. *Archives of Internal Medicine*, 163, 83-90. Other resources include <http://www.nchealthliteracy.org/toolkit/tool5.pdf> and http://pilot.train.hrsa.gov/uhc/pdf/module_02_job_aid_teach_back_method.pdf.
- 14 The sample size of African-Americans in this survey is too small for precise population estimates (N = 87), however, this difference is statistically significant at the 95 percent confidence level.
- 15 See Appendix A, Model 7 for details of the model predicting the frequency patients use the internet for health information.
- 16 The difference between those who have little or no say in current decisions compared with those with at least some say is statistically significant at the 90 percent confidence level. The other differences reported in this paragraph are statistically significant at 95 percent confidence.
- 17 See Appendix A, Model 3 for details of the model predicting patient confidence in making decisions about their own health.

- 18 As with other regressions presented in this report, causality is not assured; having confidence and understanding the provider's instructions, for example, may be self-reinforcing.
- 19 The sample size among other ethnic/racial groups is too small to separately analyze results by gender.
- 20 See Appendix A, Model 5 for details of the model predicting patient comfort in asking questions of their care provider.
- 21 Again, this is a case in which the causal arrow likely points both ways. Providers who explain things well may invite questions from the patient to ensure clarity (as noted in Model 5), but comfort asking the provider questions also may improve the clarity of the advice and instructions of the provider (as seen in Model 4).
- 22 The sample sizes of other racial/ethnic groups (e.g., African-Americans, Asian-Americans) are too small for precise population estimates.
- 23 See Appendix A, Model 4 for details of the model predicting how frequently the provider explains things in a way patients understand.

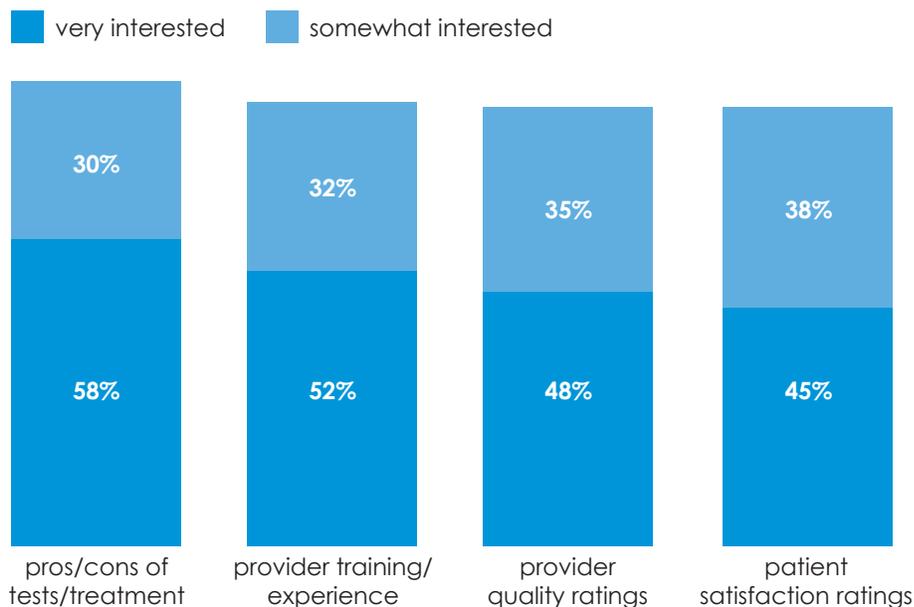
part c: additional information and cultural competence

section viii: desire for greater information

Helpfully, whatever the level of information patients feel they currently possess about their health, there is substantial desire for more information about treatments and healthcare providers alike. Anywhere from 83 to 88 percent of low-income Californians express interest in a variety of information resources: learning about the pros and cons of relevant tests or treatments, the training and experience of health professionals in their area, patient satisfaction ratings of local facilities, and quality ratings of care providers in their community.

Encouragingly, this includes considerable high-level interest, with 45 percent or more “very” interested in each option. At the top end, 58 percent are very interested in information on potential tests and treatments.

interest in more information

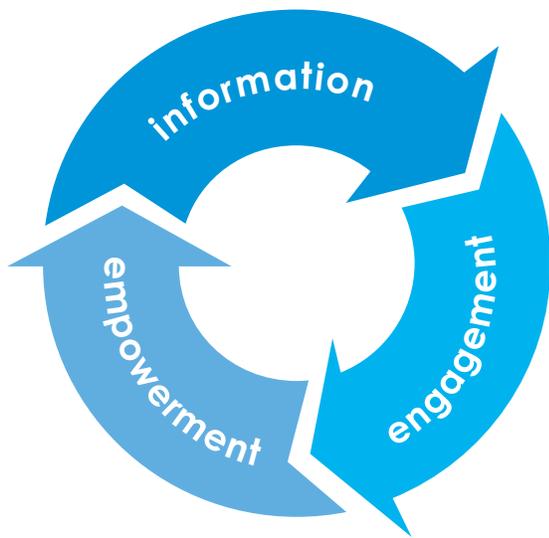


Strong interest peaks among patients who feel they currently have at least a good amount of say in care decisions, but would still like to have more. Anywhere from 61 to 69 percent in this group are very interested in each of the information options tested, much greater than the interest levels among patients who either don't feel involved, or who don't seek greater involvement.

Because interest in one item is related to interest in another, all four were combined in an index of interest in health-related information. Higher scores on this index strongly relate to indicators of patient empowerment and engagement alike – that is, having confidence, being comfortable asking questions, current involvement in care decisions, and desire for more involvement in care decisions all predict greater interest in additional health-related information.²⁴

This finding points to a positive feedback loop: Poor and near-poor Californians who feel more confident, comfortable, and involved are more likely to be interested in obtaining further information, which in turn can lead to still greater empowerment and engagement.

the cycle of patient engagement



In this survey, information about one's health leads to greater patient empowerment and engagement; these, in turn, predict a desire for more health-related information.

Modeling shows that connectedness and continuity, or if they are lacking, a desire for more of each, also relate to interest in more information; it rises among those who have a regular personal doctor, or don't have but want one; as well as among those who would like to see the same provider more consistently than they do now. Additionally, more educated low-income Californians are more interested in greater information about treatments and providers, likely reflecting their confidence using information effectively.

Women are more likely than men to say they're interested in information on the pros and cons of treatments, training and experience of providers, and patient satisfaction ratings, by small but statistically significant margins. (The difference is smaller on the fourth item, quality ratings of care providers in the area.)

Interest in more information is high across patients of different facility types for the most part, albeit generally lower among hospital emergency room patients. And CCHC patients are particularly interested in information about patient satisfaction ratings of healthcare facilities – 91 percent.

Poor and near-poor Californians who feel more confident, comfortable, and involved are more likely to be interested in obtaining further information.

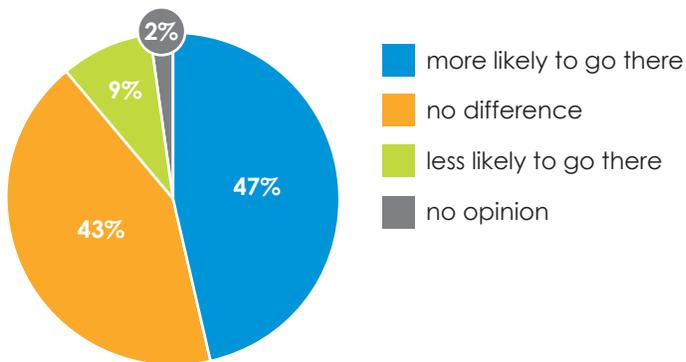
It's 85 percent among non-CCHC clinic patients, 82 percent of Kaiser Permanente or private doctors' office patients, and 76 percent of hospital emergency room users.

seal of approval

Given interest in information on satisfaction and quality ratings, a substantial number of low-income Californians – though not a majority – say their choice of facility could be positively influenced by its having received a “seal of approval” from a national healthcare association.

Forty-seven percent say they'd be more likely to go to a particular facility in their area if it had a rating of this type; 43 percent say it would make no difference and 9 percent actually say they'd be less likely to use such a facility. Other factors – price, location, and personal recommendations – may simply be more important, and the result also may indicate some reluctance to accept ratings that are produced by a national group rather than locally.

effect of seal of approval on choice of healthcare facility



While further research on this question could be useful, it's clear that a general desire for more information is related to patients saying they'd consider a seal of approval. Among those who are interested in more information on health treatments and healthcare providers and facilities in their area, roughly half indicate they'd be positively persuaded by a seal of approval, compared with just over a quarter of those who are not interested in more health information.

Fifty-three percent of CCHC users say a seal of approval would increase their likelihood of using a particular facility, compared with a low of 40 percent among Kaiser Permanente users. Patients of other facility types fall in between these two.

section ix: cultural competence and community understanding

Beyond information, low-income Californians also express interest in other elements of patient-centered care – cultural competence and community awareness. Two-thirds say it's important for their healthcare providers to

A substantial number of low-income Californians – albeit not a majority – say their choice of a facility could be positively influenced by a national “seal of approval.”

understand their ethnic or cultural background. More, three-quarters, prefer that their providers know what's going on in their community. And among those who mainly speak a language other than English at home (44 percent overall), a vast 92 percent want a provider who can speak with them in the language of their choice.

% who see cultural, community and linguistic competence as important

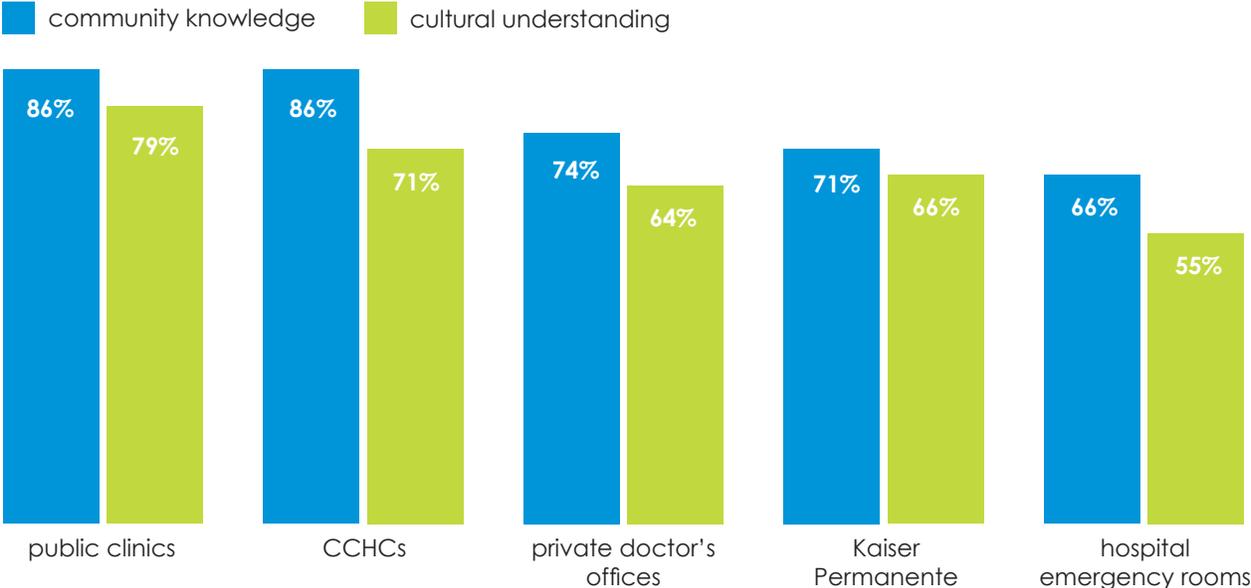


Knowing the community and the patient's ethnic and cultural background matters far more to people who say it's important that someone at their facility knows them well (80 vs. 59 percent and 70 vs. 52 percent, respectively). In this way, knowledge of the community and understanding of patients' ethnic and cultural backgrounds and linguistic needs, can be viewed as specific examples of ways providers can get to know their patients better, and with that increased connectedness improve patient empowerment and engagement.

Low-income Californians who already have a close relationship with their caregiver or facility are more apt to view these competencies as important. Those who have a health coach, team-based care, or who see the same care provider at least some of the time are all more likely than their counterparts to think it's important for providers to know what's going on in the community (by 15-, 14-, and 11-point margins, respectively) and to understand their cultural or ethnic background (by 12-, 15-, and 13-point margins). Non-English speaking respondents who have a personal connection at their care facility or who have team-based care are 12 and 11 points more apt to view a provider's ability to speak with them in the language they prefer as very important, vs. non-English speakers who do not.

Clinic patients are especially interested in community and cultural competence. Eighty-one percent of clinic-goers overall, including 86 percent of CCHC patients, say a provider's knowledge of the community is important to them. This falls to 74 percent of people who go to private doctors' offices, 71 percent of Kaiser Permanente patients, and 66 percent of those who use hospital emergency rooms for their care. Understanding of their cultural and ethnic background, similarly, is more important for public clinic patients (79 percent) than it is for Kaiser Permanente and private doctors' patients (66 and 64 percent, respectively). And CCHC patients (71 percent) and non-CCHC clinic patients (72 percent) alike show more interest in cultural understanding than do hospital emergency room patients (55 percent).

importance of cultural competence and understanding of the community by facility type



The broad interest expressed in cultural competence differs from a result in the 2011 Blue Shield of California survey, in which just 20 percent of respondents indicated that they would rather go to a facility that has a focus on “serving people of similar backgrounds as your own.” This year’s measurement instead focuses more on the personal – whether the facility understands the patient’s own ethnic and personal background, rather than catering to others with similar backgrounds.

Attention to cultural and community details is more important to Latinos, other racial or ethnic minorities, and noncitizens than it is to whites and citizens. Nearly three-quarters of Latinos and nonwhites alike say cultural understanding is important, compared with half of whites. Eighty-two percent of Latinos say knowledge of the community is important, falling to 65 percent of whites (other racial or ethnic groups fall in between, at 72 percent). In addition, 78 percent of noncitizens say it’s important that a provider understands their ethnic and cultural background, and 84 percent want their provider to know about their community, exceeding citizens on these measures by 18 and 14 points, respectively.

These results underscore the important relationship aspect of patient-centered care, in which community and cultural awareness are of value to majorities of individuals across population groups, and particularly appealing to some.

endnotes

24 See Appendix A, Model 6 for details of the model predicting the index of interest in more health information.

part d: conclusions

Results of this survey lend themselves to specific actions by healthcare providers and facilities in California to engage and involve their low-income patients. First, as laid out in the separate report on continuity and connectedness, is to recognize the critical value of ongoing, personal relationships, and to implement new models to achieve those aims – for example, through the use of team-based care, as well as via healthcare navigators, group care programs and the enhanced use of communication technology.

This report adds details on the equally critical role of clear health information in empowering patients to have confidence in their decision-making abilities, to feel comfortable asking questions and to be better equipped to understand providers' answers.

One important finding is that information empowers patients regardless of socioeconomic background; it helps level the playing field. Another is that while information can be enhanced by continuity and connectedness, it also independently predicts empowerment even in the absence of such connections. Current information that patients understand, then, is a uniquely powerful tool in achieving the goals of patient-centered care.

As described above, information needs can vary across groups. Patients with chronic conditions or lower health status are more likely to have failed to follow providers' instructions because they didn't understand what to do – pointing to a particular need for concerted information delivery to these groups. Clear instructions also need to be devised to cross language and education barriers, marking the value of cultural, community and linguistic competence, an area in which many CCHCs have particular expertise.

More broadly, the survey shows that fostering an environment in which patients feel comfortable asking questions decreases the chance of misunderstanding. And it shows that appeals to self-responsibility – already widely valued by patients – may be effective in encouraging patients to take a greater role in their own care.

In sum, continuity and connectedness improve the flow of information. Information enhances empowerment. Empowerment in turn leads to engaged patients who are more active in their care decisions, more likely to desire an even greater role, and more likely as well to step up to the ultimate aim of shared decision making. It's a promising pathway to patient-centered care.

Information is a uniquely powerful tool in achieving the goals of patient-centered care.

methodology

This Blue Shield of California Foundation survey was conducted March 12 to April 8, 2012, via telephone interviews with a representative statewide sample of 1,024 Californians between the ages of 19 to 64 with family incomes below 200 percent of the federal poverty level (FPL).²⁵ The sample was comprised of 618 landline and 406 cell phone interviews, with 719 interviews conducted all or mostly in English and 305 in Spanish. The survey was produced, managed and analyzed by Langer Research Associates of New York, N.Y., with sampling, fieldwork and data tabulation by SSRS/Social Science Research Solutions of Media, Pa.

sample design

Samples from landline and cell phone telephone exchanges were generated by Marketing Systems Group (MSG). The landline sample was designed to reach the target population as efficiently as possible, accounting for the high-incidence of Latino families within the low-income California population and addressing the regional distribution of low-income households in the state. Three main strata were identified: (1) the *High Latino* stratum, comprised of landline telephone exchanges associated with Census-block groups in which Latinos were at least 57.5 percent of the population; (2) a *High Low-Income* stratum, which consisted of all remaining landline phone numbers whose exchanges were associated with Census-block groups in which more than 40 percent of the population had annual household incomes less than \$35,000; and (3) a *Residual* stratum, which included all exchanges other than those in the first two strata. In addition, a separate phone stratum was constructed of all phone numbers associated with households whose records in the infoUSA database indicated there was at least one household resident between the ages of 19 and 64 with household annual income less than \$23,000. These numbers were removed from their respective telephone strata and considered a fourth, *Listed Low-Income*, stratum. Thus the four landline strata were mutually exclusive.

Within each of these strata, the sample was broken down by geographical designations: (1) Los Angeles area: phone numbers whose 6-digit NPA-NXX exchange was associated with numbers in the Los Angeles metropolitan statistical area (MSA); (2) San Francisco/San Diego/Sacramento areas: phone numbers whose exchanges were associated with these MSAs; and (3) Other areas: All remaining California landline exchanges.

Population figures for each of the 12 stratum-by-area sampling cells were estimated through MSG's GENESYS system, and a sampling design was implemented oversampling those cells with an estimated higher incidence of respondents matching the survey criteria for eligibility (that is, family income below 200 percent of the federal poverty level). An initial estimate

of the eligible population was created based on the percentage in each one of these cells who, according to the GENESYS data, had an annual household income of less than \$35,000.²⁶ In estimating the size of the eligible population in each cell, two adjustments were made: (1) Correction for the proportion of non-working numbers in the listed sample. Because the size of the unlisted sample in each stratum was calculated as the total population minus the number of listed records, the size of the listed sample in each stratum was decreased by the percentage of non-working numbers found among the listed numbers; and (2) Correction for the cell phone only (CPO) population. The initial total estimated number of unlisted households in each stratum included any household that did not have a listed landline number. However, since about 40 percent of the qualifying population was estimated to be CPO, the estimated number of people in each of the unlisted cells was reduced by 40 percent.

Cell phone numbers were not stratified, but generated from all numbers corresponding with California cell phone exchanges. Each record was labeled based on the exchange's geographic affiliation with the three sampling areas used for the landline (LA; SF/SD/Sac; Other). CPO California residents with non-California phone numbers could not be included.

In Table 1 we compare the (adjusted) estimated population in each of the landline sampling cells and their share among the landline interviews. "SF/SAC/SD" (second row) refers to the sample in the San Francisco, Sacramento and San Diego metropolitan statistical areas. Data in the third and fourth columns represent original estimates of the number and percentage of low-income households in the cell. The fifth column represents each cell's share among landline households based on the observed incidence of those meeting survey eligibility.

table 1. estimated and observed share of low-income households compared with number of landline interviews, by stratum and area

Stratum	Area	Low-Income Households			Interviews	
		Estimated #	Estimated %	Observed %	%	#
Residual	Los Angeles	746,365	20%	22%	10%	62
Residual	SF/SAC/SD	777,174	20	21	10	60
Residual	Other	279,040	7	7	7	44
High Latino	Los Angeles	471,844	12	13	18	109
High Latino	SF/SAC/SD	41,028	1	1	4	24
High Latino	Other	76,052	2	2	3	21
High Low Income	Los Angeles	387,198	10	11	15	95
High Low Income	SF/SAC/SD	79,447	2	3	4	27
High Low Income	Other	260,109	7	8	8	50
Low Income Listed	Los Angeles	297,607	8	5	7	46
Low Income Listed	SF/SAC/SD	161,027	4	5	5	29
Low Income Listed	Other	217,477	6	3	8	51
Total		3,794,367	100%	100%	100%	618

Sample numbers were generated within each sampling cell using an *epsem* (equal probability of selection method) from active blocks (area code + exchange + two-digit block number) that contained three or more residential directory listings ('3+ listed RDD sample'). The cell phone sample was not list-assisted, but was drawn through a systematic sampling from dedicated wireless 100-blocks and shared service 100-blocks with no directory-listed landline numbers. Following generation, the landline RDD sample (excluding the Listed-Low Income sample) was prepared using MSG's GENESYS IDplus procedure, which not only limits sample to non-zero banks, but also identifies and eliminates approximately 90 percent of all non-working and business numbers. (At present, there is no capability to scrub such a sample or to run it through listed databases.)

field preparations, fielding and data processing

Before the field period SSRS programmed the study into CfMC Computer Assisted Telephone Interviewing (CATI) software. Extensive checking of the program was conducted to assure that skip patterns followed the questionnaire design. The questionnaire was translated into Spanish so respondents could choose to be interviewed in English or Spanish, or to switch between the languages according to their comfort level.

In advance of interviewing, CATI interviewers received both formal training on the survey and written materials including an annotated questionnaire containing information about the goals of the study as well as the meaning and pronunciation of key terms. Additional written materials detailed potential obstacles to overcome in obtaining meaningful responses, potential respondent difficulties and strategies for addressing them.

Interviewer training was conducted both prior to the study pretests and immediately before the survey was officially launched. Call-center supervisors and interviewers were walked through each question in the questionnaire. Interviewers were given instructions to help maximize response rates and ensure accurate data collection. Interviewers were monitored throughout the study and project staff provided feedback to interviewers throughout the survey period.

A live pretest of the survey instrument was conducted on March 5, 2012. In all, 18 pretest interviews were completed throughout the afternoon and evening. Pretest interviews were scheduled prior to the live pretest and respondents were offered a \$20 incentive to participate. Langer Research Associates and BSCF representatives monitored the interviewing live, along with SSRS project managers, for approximately two hours. Additional interviews were digitally recorded and placed on a secure FTP site for review. Several questions were reworded or removed altogether based on the pretest results.

The questionnaire screened for eligible households by establishing the respondent's family size and annual family income,²⁷ then selecting only respondents between the ages of 19 to 64 with family incomes lower than

200 percent of the FPL.²⁸ In households that were reached by landline, respondents were randomly selected from the age-qualifying household residents by asking for the male or female with the most recent birthday.

Interviews in the *High Latino* and *Listed Low-Income* strata were initiated by bilingual interviewers. All interviews were conducted using the CATI system, ensuring that questions followed logical skip patterns and that complete dispositions of all call attempts were recorded.

In order to maximize survey response, SSRS enacted the following procedures during the field period:

- Each non-responsive number not already set up with a callback (answering machines, no answers and busies) was called approximately eight times, varying the times of day and days of the week that callbacks were placed using a programmed differential call rule.
- Interviewers explained the purpose of the study and offered to give the respondent the name of the sponsor at the completion of the interview.
- Respondents were permitted to set the schedule for a return call.
- The study offered reimbursement of \$5 for any cell phone respondent who mentioned concerns with the costs of cell phone usage.
- Respondents who initially refused to participate in the survey but were considered 'soft' refusals (respondents who simply hung up the phone, stated the timing was bad or expressed disinterest in participating) were contacted at least once more and offered a \$10 participation incentive.

procedures for identifying healthcare facility usage

The survey included a highly detailed effort to identify usage of various types of healthcare facilities. Respondents were asked if they usually go for health care to a Kaiser Permanente facility, a private doctor's office, a community clinic or health center, a hospital or someplace else. (These options were offered in randomized order, with "someplace else" always last.)

Those who said they have no usual place of care (5 percent) were asked where they last went for care (using the same options listed above), and whether it was in California. Those who said they went for care to a non-professional location (e.g., a relative or friend) were asked where they go for professional care.

Respondents who said they see a doctor were asked if that was a private doctor's office or a doctor at one of the other listed facility types. Respondents who said they use a hospital for care were asked if that was a hospital clinic or a hospital emergency room. If a hospital clinic, they were asked the type of hospital, county or private/religious.

The CATI program included codes for more than 800 CCHCs or hospital-based clinics. Those who said they use a clinic were asked the clinic's name and location. These were compared with a list of California community clinics and health centers compiled by the California Primary Care Association (CPCA) and a list of California public hospital clinics compiled by the California Association of Public Hospitals and Health Systems (CAPH).

For clinics not initially matched to the lists, respondents were asked if the clinic was operated by a hospital. If yes, they were asked the type of hospital, county or private/religious. If the clinic was not operated by a hospital, they were asked if it was run by a county/city, or privately.

All clinics that did not match to the CPCA and CAPH lists during the interview were later back-checked to ensure the lack of match wasn't due to a misspelling or the respondent's use of a shortened version of a clinic name. Clinic type was further confirmed for ambiguous coding by internet searches or by directly calling the clinics named.

Some facilities were not subcategorized, either because the respondent provided insufficient information or because their facility type did not fall into any of the other categories. These were coded, using available information, as "clinic, other/unknown type," "hospital clinic, other/unknown type," "hospital, unspecified" or "someplace else."

This procedure produced the following breakdown of facility usage: Clinics, 43 percent; private doctors' offices, 27 percent; Kaiser Permanente, 13 percent; and hospital emergency rooms, 10 percent. Remaining categories were hospital, unspecified, 1 percent; someplace else, 4 percent; never have received health care, 1 percent; and no opinion, 1 percent.

Clinics were subcategorized as follows: CCHCs, 17 percent; public hospital clinics, 9 percent; clinic, other/unknown type, 7 percent; private clinics, 4 percent; private/religious hospital clinics, 4 percent; county or city clinics, 2 percent; and hospital clinic, other/unknown type, 1 percent.

CCHC estimates

The 2011 BSCF survey estimated that 11 percent of the population used CCHCs, vs. the 2012 estimate of 17 percent. Given this difference, SSRS and Langer Research undertook a highly detailed review of all procedures related to this measurement – sampling, questionnaire, field work, coding protocols and weighting – in comparison to the 2011 survey. SSRS took the additional step of re-contacting 49 clinic patients, all of whom confirmed their clinic type.

There was essentially no change in overall provider-type classifications. Clinic users overall were 43 percent of the sample in 2012, 44 percent in 2011; private doctors' office patients, 27 vs. 28 percent; Kaiser Permanente patients, 13 vs. 12 percent; hospital ER, 10 percent both times. The only change of any size was in the clinic subgroup of CCHC users, with slight numerical declines in use of other clinic types.

3/3a/4/4a. Where do you usually go when you are sick or need health care for any reason – (Kaiser), (a private doctor's office), (a community clinic or health center), (a hospital) or someplace else? (IF NO USUAL PLACE) Where's the last place you went?

	4/08/12	4/25/11	Difference
Kaiser Permanente	13%	12%	+1
Doctor's office	27	28	-1
Clinic NET	43	44	-1
Community clinic/health center	17	11	+6
Public hospital clinic	9	10	-1
Private hospital clinic	4	5	-1
Hospital clinic – other/unknown type	1	1	=
County/city clinic	2	5	-3
Private/other clinic	4	5	-1
Clinic – other/unknown type	7	8	-1
Hospital emergency room	10	10	=
Hospital unspecified	1	2	-1
Someplace else	4	2	+2
Never have gone for health care	1	2	-1
No opinion	1	1	=

Numerical increases in CCHC use was found across almost all groups in 2012 vs. 2011; they were largest in three related populations: Spanish speakers, noncitizens and the lowest-income respondents.

Differences did appear in other estimates in 2012 vs. 2011, e.g., -7 points in non-employment, +5 in full-time employment, -6 in ratings of personal health as “good” and +5 in “strong” preference not to have an equal say. Other figures matched closely; net provider type, ratings of current care provider, overall interest in an equal say, prevalence of a disability or chronic condition, insurance type, marital status and education all were within 2 points year-to-year.

Nothing was identified in the survey design or execution that created the change in the CCHC estimate. Some of it may reflect an actual increase in CCHC usage, albeit presumably not at this level; the rest seems attributable to sampling variation.

personal doctor estimate

There was a deliberate change in approach to measurement of the prevalence of having a personal doctor, resulting in a 47 percent estimate in the 2012 survey vs. 57 percent in 2011.

In 2011, during field work pretests, some respondents who said they went to a private doctor's office were confused or annoyed when asked if they had a regular personal doctor. We elected to automatically code those who said they went to a private doctor as having a personal doctor.

Upon reconsideration in 2012, the autocode was dropped. There were no trouble reports from the field, indicating the 2011 adjustment had been unnecessary. Moreover, 32 percent of private doctors' office patients in 2012 said they did not have a regular personal doctor.

Had the autocode been retained, the 2012 estimate of individuals with a regular private doctor would have been 55 percent overall, essentially the same as 2011's 57 percent. We conclude, however, that 47 percent is the better estimate.

weighting procedures

A multi-stage weighting design was applied to ensure an accurate representation of the target population. Weighting involved the following stages:

1. Sample design correction. In order to correct for over- or undersampling of each of the 12 stratum-by-area landline cells, each landline case was assigned a weight equal to the estimated percentage of the cell among landline-qualifying households divided by the percentage of the cell among completed landline interviews. For example, cases in the *Residual-LA* cell received a weight equal to their estimated share among low-income households (22 percent) divided by their share among the landline interviews (10 percent). Using more exact values, the calculation for the weight for this cell ($W_{\text{resid-LA}}$), is:

$$W_{\text{resid-LA}} = .21783 / .10032 = 2.17131.$$

Cell phone design weights were based on the three sampling areas. The estimated share of target cell phone completes was based on the percent of CPO households in each area. The percent of qualifying low-income households was then estimated based on the actual data (qualified households divided by qualified+unqualified). Weights were then assigned to each cell phone case equal to the estimated percent of qualifying households in the area divided by the area's percentage of cell phone interviews.

2. Within-household selection correction. This stage corrected for the unequal probabilities caused by some households having more qualified adults than others. Households with a single adult age 19 to 64 received a weight of 1, whereas households with two or more qualifying adults received a weight of 2. Cases were adjusted so that the sum of this weight totaled the unweighted sample size. Cell phone respondents were given the mean landline weight (1).

The product of these two corrections (design weight, within-household correction) was then calculated as the sampling weight, or baseweight.

3. Post-stratification weighting. With the baseweight applied, the sample was put through iterative proportional fitting (IPF, or 'raking'), in which the sample was balanced to reflect the known distribution of the target population along specific demographic parameters. These parameters were based on the 2011 American Community Survey (ACS) for the state of California, based on residents age 19 to 64 and members of families with incomes less than 200 percent FPL. In addition, a balancing target was set for the CPO population, based on an estimate provided by Dr. Stephen Blumberg of the Centers for Disease Control and Prevention, a leading CPO researcher.

The weighting parameters used were age (19-29, 30-39, 40-49 and 50-64); education (less than high school, high school, some college and college or more); race (white non-Latino, African-American non-Latino, other non-Latino and Latino); sex by Latino status (i.e., Latino-male, Latino-female, non-Latino-male, non-Latino-female); region (Northern and Sierra counties, Greater Bay Area, Sacramento area, San Joaquin Valley, Central Coast area, Los Angeles County and other Southern CA);²⁹ and percent CPO.

4. Weight truncation ('trimming'). In order to minimize the influence of outlier cases on the data and to contain variance, the weights were truncated so that no one case received a weight greater than 4.0 or smaller than .25.

The design effect is 1.4.

ACS estimates and unweighted and weighted sample percentages are listed below. (Percentages for several parameters do not add to 100 percent because of “don’t know” responses.)

table 2. acs estimates and unweighted and weighted sample percentages

	ACS	Unweighted Sample	Weighted Sample
Race			
White non-Latino	28.0%	29.0%	27.3%
Black non-Latino	7.1	8.8	7.0
Latino	52.8	51.3	53.9
Other non-Latino	12.1	9.4	11.6
Sex/race			
Male, non-Latino	21.1	24.5	21.6
Female, non-Latino	25.3	23.1	24.8
Male, Latino	25.1	23.2	25.4
Female, Latino	27.3	29.3	28.1
Education			
Less than high school	33.3	33.0	33.1
High-school education	26.0	25.6	26.1
Some college	29.9	25.2	29.9
College graduate +	10.9	12.0	10.9
Age			
19-29	33.5	23.6	33.3
30-39	23.4	18.3	23.2
40-49	21.0	21.1	21.0
50-64	21.2	37.0	22.6
Region			
Sierra/Northern Counties	4.4	7.1	4.5
Greater Bay Area	14.4	10.6	13.7
Sacramento Area	5.4	5.9	5.4
San Joaquin Valley	12.9	13.4	12.4
Central Coast	5.6	6.2	5.5
LA County	30.4	27.9	29.2
Other Southern CA	27.0	27.1	25.7
Phone status			
Cell phone only	43.2	31.8	43.1
Some landline use	56.4	68.1	56.7

response rate

The response rate for this study was calculated at 27.6 percent for the landline sample and 22.1 percent for the cell phone sample using the “Response Rate 3” formula of the American Association for Public Opinion Research.

Following is a full disposition of the sample selected for this survey:

	Landline	Cell	Total
Eligible, Interview (Category 1)			
Complete	704	301	1005
Eligible, non-interview (Category 2)			
Refusal (Eligible)	303	57	360
Answering machine household	32	20	52
Physically or mentally unable/incompetent	6	1	7
Language problem	13	86	99
No interviewer available for needed language	0	3	3
Unknown eligibility, non-interview (Category 3)			
Always busy	532	1632	2164
No answer	8696	3866	12562
Technical phone problems	144	20	164
Call blocking	8	0	8
No screener completed	2634	2126	4760
Housing unit, unknown if eligible	2623	4085	6708
Not eligible (Category 4)			
Fax/data line	1814	409	2223
Non-working number	28517	6865	35382
Business, government office, other organizations	947	609	1556
No eligible respondent	1930	1311	3144
Total phone numbers used	48903	21304	70294

endnotes

- 25 The federal poverty level is calculated on the basis of family size and the combined income of family members.
- 26 These numbers were then adjusted based on the actual share of qualifying households found in each stratum during the course of the survey.
- 27 If respondents were uncertain about their annual income, they were asked about the corresponding monthly income.
- 28 Families were defined in accordance with the definition applied by the U.S. Census bureau and FPL was based on the 2012 HHS Poverty Guidelines.
- 29 Regions were defined following the California Health Interview Survey (CHIS) operationalization of regions. Each California county was assigned to one of the seven regions. County was derived from respondents' self-reported ZIP code. When respondents refused to identify their ZIP codes, region was derived from the ZIP code associated with their landline exchange. Cell phone respondents who declined to provide their zip code were considered region-unknown.

appendix a – statistical modeling

Several sections of this study refer to regression analyses used to measure the relationships among various attitudes, demographic variables, and predicted outcomes, such as patient engagement, confidence in healthcare decision making abilities, and feeling informed about one's health. This appendix provides details of these statistical analyses.

A regression is a form of statistical modeling that measures the independent strength of the relationship between each predictor with the posited outcome, known as the dependent or outcome variable. While it does not establish causality, a regression reveals the strength of the relationship between a predictor (e.g., feeling informed about one's health) and the dependent variable (e.g., patient engagement), with other predictors in the model held constant.

Many variables may be related to a given outcome. A regression identifies which of them explain the most unique variance in the dependent variable, after adjusting for these other relationships. Below we describe the variables used in the regression analyses reported in this study, followed by details of the regression results.

key variables

Overall health (W1): A continuous variable reflecting respondents' self-reported health status, with 1 = poor health and 5 = excellent health (Mean = 3.1, Standard Deviation = 1.2).

Prioritize health (Q1): A binary variable indicating whether or not respondents say that taking care of their health is their top priority (0 = not health, 1 = health).

Number of medical appointments in the past year (Q2): A continuous variable indicating the number of times respondents have had a medical appointment in the past year ($M = 4.3$, $SD = 7.6$).²⁸

Facility type (Q3-4): The type of facility used by each respondent was coded using a series of binary variables indicating, separately, whether he or she received care at a community clinic and health center (CCHC), or not; a Kaiser Permanente facility, or not; a private doctors' office, or not; a public clinic, or not; some other type of clinic (not CCHC or public) or not; and a hospital emergency room (ER), or not. For each facility type, respondents were coded 1 if a patient, 0 if not.

Has a personal connection (Q7): A binary variable indicating whether or not respondents say there is someone at their healthcare facility who knows them well (0 = no, 1 = yes).

Has a personal doctor (Q10): A binary variable indicating whether or not the respondents have a regular personal doctor (0 = no personal doctor, 1 = personal doctor).

Want a personal doctor (Q10-11): A binary variable indicating whether or not respondents desire a personal doctor (0 = have a personal doctor already or lacks one, but say having one is not important to them, 1 = does not have a personal doctor but wants one).

Continuity in a care provider (Q13): A continuous variable reflecting how frequently respondents see the same healthcare provider when they have an appointment on a scale from 1 = never to 5 = every time ($M = 3.66$, $SD = 1.28$).

Desire for continuity in a care provider (Q14): A binary variable indicating whether or not respondents would like to be able to see the same healthcare provider more often (0 = do not think seeing the same provider more often is important or already see the same provider every visit, 1 = would like to see the same provider more often).

Usually see a doctor for care (Q15): A binary variable indicating whether respondents normally see a doctor or usually see a non-physician provider (e.g., a nurse or physician's assistant) for routine care (0 = usually see a non-physician provider for routine care, 1 = usually see a doctor, or both a doctor and a non-physician provider for routine care).

Has a health navigator (Q20): A binary variable indicating whether or not respondents currently have a health navigator or health coach (0 = do not have a health navigator, 1 = have a health navigator).

Has team care (Q23): A binary variable indicating whether or not respondents currently have team-based care (0 = do not have team-based care, 1 = have team-based care).

Impact of national seal (Q31): A continuous variable reflecting the impact a seal of approval from a national healthcare association would have on respondents with 1 = less likely to go there, 2 = make no difference and 3 = more likely to go there ($M = 2.39$, $SD = .64$).

Patient engagement in care decisions (Q35): A continuous variable reflecting how much say the respondent feels they currently have in decisions about their health care on a scale from 1 = no say to 5 = a great deal of say ($M = 3.98$, $SD = 1.04$).

Desire for greater say (Q36): A binary variable indicating whether or not respondents want more of a say in their healthcare decisions (0 = current say is about right, or would like less of a say, 1 = want more of a say in healthcare decisions).

Informed about health (Q37): A continuous variable reflecting how informed the respondents feel about their health and any health problems they may have on a scale in which 1 = not informed at all and 4 = very informed (M = 3.28, SD = .83).

Frequency use the internet for health information (Q38-39): A continuous variable reflecting how frequently the respondents use the internet to access health information on a scale in which 0 = never have used the internet to access health information and 5 = use the internet very often to access health information (M = 2.09, SD = 1.41).

Index of interest in more health information (Q40a-d): A composite measure of interest in having more information about the pros and cons of different tests or treatments, the training and experience of local health professionals, patient satisfaction ratings for local healthcare facilities, and quality ratings for local healthcare providers. These four items were recoded so that 1 = not interested at all and 4 = very interested and then averaged to form the index ($\alpha = .83$), which ranges from 1 (indicating no interest in more information on any of the four topics) to 4 (indicating strong interest in more information on all four topics). The average index value is M = 3.28, SD = .74.

Confidence can make healthcare decisions (Q41): A continuous variable reflecting how confident respondents are in their ability to make decisions about their health care on a scale where in which 1 = not at all confident and 4 = very confident (M = 3.45, SD = .70).

Responsible for health: Me (Q42): A binary variable indicating whether or not respondents think they are ultimately responsible for managing their health, rather than the care provider (0 = provider or both provider and me responsible for health, 1 = me responsible for health).

Frequency provider explains things in a way you can understand (Q43): A continuous variable reflecting how often respondents feel their healthcare provider explains things in a way they can understand on a scale ranging from 1 = never to 5 = every time (M = 4.10, SD = 1.02).

Comfort asking provider questions (Q44): A continuous variable reflecting how comfortable respondents feel asking the healthcare provider questions about their health or treatment on a scale in which 1 = very uncomfortable and 4 = very comfortable (M = 3.49, SD = .75).

Has misunderstood care provider (Q45): A binary variable indicating whether or not there has been a time when the respondents didn't follow a healthcare provider's advice or treatment plan because they didn't understand what they were supposed to do (0 = have not misunderstood care provider, 1 = have misunderstood care provider).

Has a disability (Q48): A binary variable indicating whether or not respondents have a disability or chronic medical condition (0 = do not have a disability or chronic condition, 1 = have a disability or chronic condition).

Demographic variables: In addition to the variables listed above, the following demographic variables were included in all models unless otherwise indicated: insurance status, employment status, gender, age, household size, relationship status, education, race/ethnicity, language mainly spoken at home (English vs. not English), income, and citizenship status. All models also controlled for regional differences. All demographic variables were coded as binary variables by category except for age, household size, income, and education, which were coded as continuous variables.

modeling details and results

model 1: patient engagement in care decisions

To determine what factors independently predict patients' involvement in their medical care, we performed a regression with patient engagement in care decisions entered as the outcome variable and the following variables included as predictor variables (see above for definitions): overall health, prioritize health, number of medical appointments in the past year, facility type, has a personal connection, has a personal doctor, continuity in a care provider, usually see a doctor for care, has a health navigator, has team care, informed about health, frequency use the internet for health information, confidence can make healthcare decisions, responsible for health: me, frequency provider explains things in a way you can understand, comfort asking provider questions, and has a disability. All demographic variables listed above also were included. Table 1 shows the results of this model (Model 1).

table 1. key predictors of patient engagement in care decisions

	Standardized coefficient (β)	Significance test (t)
frequency provider explains things in a way you can understand	.16	4.19***
confidence can make healthcare decisions	.13	3.75***
informed about health	.12	3.24**
comfort asking provider questions	.10	2.64**
age	.08	1.80+
has a personal connection	.06	1.80+

Model $R^2 = .19, p < .001$

Here and below: *** $p < .001$, ** $p < .01$, * $p < .05$, + $p < .10$

model 2: informed about health

To determine what factors independently predict feeling informed about one's health, we performed a regression with informed about health as the outcome variable. Model 2 used the same predictors as Model 1, with the exception that confidence can make healthcare decisions and informed about health were both omitted as predictors. See Table 2 for the results.

table 2. key predictors of informed about health

	Standardized coefficient (β)	Significance test (t)
frequency provider explains things in a way you can understand	.23	6.61***
comfort asking provider questions	.20	5.87***
income	.12	3.23**
has a personal connection	.10	2.96**
continuity in a care provider	.09	2.47*
race/ethnicity: white	.08	1.87+
prioritize health	.06	2.00*

Model $R^2 = .32, p < .001$

model 3: confidence can make healthcare decisions

A similar model was performed to determine what factors independently predict respondents' confidence that they can make healthcare decisions. Model 3 was identical to Model 2, with the exception that comfort asking provider questions was removed as a predictor variable while informed about health and has misunderstood care provider were both added as predictors. Table 3 shows the results of this regression.²⁹

table 3. key predictors of confidence can make healthcare decisions

	Standardized coefficient (β)	Significance test (t)
informed about health	.22	5.95***
frequency provider explains things in a way you can understand	.16	4.40***
responsible for health: me	.12	3.66***
health status	.11	2.69**

Model $R^2 = .19, p < .001$

model 4: frequency provider explains things in a way you can understand

To determine what factors independently predict the frequency respondents feel the provider explains things in a way they can understand, we performed a model similar to Model 3. Frequency provider explains things in a way you can understand was entered as the outcome variable, and all predictors used in Model 3 were used in Model 4 (except, obviously, frequency the provider explains things in a way you can understand). Comfort asking questions was also entered as a predictor in Model 4. Results are shown in Table 4.

table 4. key predictors of frequency provider explains things in a way you can understand

	Standardized coefficient (β)	Significance test (t)
comfort asking provider questions	.35	10.93***
informed about health	.22	6.62***
continuity in a care providerr	.14	4.22***
facility: hospital ER	-.11	3.43**
gender: male	.06	2.11*
has team-based care	.06	1.85+

Model $R^2 = .35, p < .001$

model 5: comfort asking provider questions

The model predicting respondents' comfort asking their healthcare provider questions was similar to Model 4, but added informed about health, confidence can make healthcare decisions, and frequency provider explains things in a way you can understand as predictors. Results of this model are shown in Table 5.³⁰

table 5. key predictors of comfort asking provider questions

	Standardized coefficient (β)	Significance test (t)
frequency provider explains things in a way you can understand	.34	10.34***
confidence can make healthcare decisions	.10	6.21***
informed about health	.16	4.60***
race/ethnicity: white	.11	2.46*
has a personal connection	.06	1.87+

Model $R^2 = .35, p < .001$

model 6: index of interest in more health information

To determine what factors independently predict interest in more health-related information, we entered the index of interest in more health information as the outcome variable and all the variables entered in Model 1 as predictors. In addition, the following variables were also included as predictors: impact of national seal, patient engagement in care decisions, desire for greater say, and have misunderstood care provider. Table 6 shows the results of this model.

table 6. key predictors of the index of interest in more health information

	Standardized coefficient (β)	Significance test (f)
confidence can make healthcare decisions	.17	4.99***
desire for greater say	.16	4.95***
want a personal doctor	.16	3.81***
impact of national seal	.14	4.48***
has a personal doctor	.14	2.96**
household size	.12	3.25**
patient engagement in care decisions	.11	3.20**
frequency use the internet for health information	.11	3.20**
education	.10	2.67**
comfort asking provider questions	.10	2.55*
desire for continuity in a care provider	.09	2.58*
gender: male	-.08	2.59*

Model $R^2 = .28, p < .001$

model 7: frequency use the internet for health information

To determine the independent predictors of the frequency respondents use the internet to access health information, we repeated Model 6, only with frequency use the internet for health information as the outcome variable. Key predictors are shown in Table 7.

table 7. key predictors of frequency use the internet for health information

	Standardized coefficient (β)	Significance test (f)
education	.28	7.28***
has a disability	.13	3.59***
facility: Kaiser Permanente	.12	3.00**
have misunderstood care provider	.11	3.28**
race/ethnicity: latino	-.10	2.10*
age	-.09	2.13*
speak english	.08	1.75+
impact of national seal	-.07	2.11*
health status	.07	2.00*

Model $R^2 = .26, p < .001$

mediation models

A mediation model is a series of regressions that can clarify the relationship between an independent or predictor variable and a dependent variable by examining potential underlying processes. Essentially, mediation analyses help to answer the question of how variable x influences variable y.

Simple linear regression reveals the direct relationship between an independent variable and an outcome variable (e.g., that having a

personal connection is related to increased patient engagement in care decisions). But there may also be an indirect relationship between the independent variable and the outcome variable through a third variable. For example, having a personal connection might be related to respondents feeling more informed about their health which, in turn, predicts increased patient engagement in care decisions. Mediation analyses allow us to explore these potential indirect relationships.³¹

Specifically, we hypothesized that even though having a personal connection has only a weak positive relationship with patient engagement in care decisions in Model 1, it might have an indirect relationship with engagement by increasing how informed respondents feel about their health, their confidence they can make healthcare decisions, their comfort asking providers questions, and their understanding of the provider's explanations and advice (i.e., the four indicators of patient empowerment). Since these variables, in turn, predict increased engagement (see Model 1) – this would show the importance of connectedness in increasing patient engagement, albeit by indirect means. We further hypothesized that continuity might operate in the same way – that is, even though it has no direct effect on engagement in Model 1, it might be indirectly associated with engagement by increasing the four indicators of empowerment.

To test the mediation models, we followed Baron and Kenny's (1986) steps for mediation, which include the following:

1. Regressing the outcome variable on the independent variable ($x \rightarrow y$) to confirm that the independent variable (IV) does in fact predict the outcome of interest when no other variables are included (e.g., that connectedness predicts engagement when no other variables are entered).
2. Regressing the mediator on the independent variable ($x \rightarrow m$) to confirm that there is a significant relationship between the two variables (e.g., that connectedness predicts feeling informed about one's health).
3. Regressing the outcome variable on both the mediator and the independent variable (x and $m \rightarrow y$) to confirm that the mediator is a significant predictor of the outcome, and that the relationship between the IV and the outcome variable assessed in Step 1 is reduced once the mediator is included (e.g., to show that feeling informed is a significant predictor of engagement, and that the effect of connectedness on engagement is less than it was in Step 1).

We then computed a Sobel t-test, which tests whether the indirect effect of the IV on the outcome through the mediator is statistically significant. If a statistically significant mediation is confirmed, it means that the effect of the IV on the outcome variable (shown in Step 1) is at least partially (or entirely) due to the fact that the IV influences the mediator, which in turn influences the outcome variable. In other words, the mediator or mediators explain the process through which the IV influences the outcome.

The table below shows the results for each step of the mediation separately for each of the two independent variables (continuity and connectedness) and the four potential mediators (informed about health, confidence can make healthcare decisions, comfort asking provider questions, and frequency provider explains things in a way you can understand), a total of eight mediation models. As can be seen, in each case the indirect effect of connectedness and continuity through the mediator is statistically significant.

The final model, shown at the end of the table, combines each of the individual mediations to show the collective effect. Specifically, the first step shows that when connectedness and continuity alone are regressed on patient engagement, each is a statistically significant predictor. However when the four empowerment variables are also included in the model, the effect of continuity is eliminated and the effect of connectedness is cut in half. This shows that connectedness and continuity have a significant impact on patient engagement in large part because they increase patients' feelings of empowerment.

table 8. mediation models

	standardized coefficient (β)	significance test (f)
mediation model 1: connectedness → information → engagement		
step 1: connectedness → engagement	.18	5.75***
step 2: connectedness → information	.26	8.53***
step 3: connectedness + information → engagement		
connectedness	.11	3.50***
information	.27	8.69***
Sobel test of indirect effect		6.08***
mediation model 2: Continuity → Information → Engagement		
step 1: continuity → engagement	.15	4.76***
step 2: continuity → information	.27	8.96***
step 3: continuity + information → engagement		
continuity	.07	2.34*
information	.28	8.89***
Sobel test of indirect effect		6.30***
mediation model 3: connectedness → confidence → engagement		
step 1: connectedness → engagement	.18	5.75***
step 2: connectedness → confidence	.12	3.90***
step 3: connectedness + confidence → engagement		
connectedness	.15	4.92***
confidence	.24	7.96***
Sobel test of indirect effect		3.51**

mediation model 4: continuity → confidence → engagement		
step 1: continuity → Engagement	.15	4.76***
step 2: continuity → Confidence	.10	3.16**
step 3: continuity + Confidence → Engagement		
continuity	.12	4.08***
confidence	.25	8.14***
Sobel test of indirect effect		3.01**
mediation model 5: connectedness → understanding → engagement		
step 1: connectedness → Engagement	.18	5.75***
step 2: connectedness → Understanding	.18	5.88***
step 3: connectedness + Understanding → Engagement		
connectedness	.13	4.12***
understanding	.30	9.75***
Sobel test of indirect effect		5.04***
mediation model 6: continuity → understanding → engagement		
step 1: continuity → Engagement	.15	4.76***
step 2: continuity → Understanding	.27	8.71***
step 3: continuity + Understanding → Engagement		
continuity	.07	2.21*
understanding	.30	9.62***
Sobel test of indirect effect		6.51***
mediation model 7: connectedness → comfort → engagement		
step 1: connectedness → engagement	.18	5.75***
step 2: connectedness → comfort	.19	5.98***
step 3: connectedness + comfort → engagement		
connectedness	.13	4.24***
comfort	.26	8.55***
Sobel test of indirect effect		4.92***
mediation model 8: continuity → comfort → engagement		
step 1: continuity → engagement	.15	4.76***
step 2: continuity → comfort	.15	4.74***
step 3: continuity + comfort → engagement		
continuity	.11	3.54***
comfort	.27	8.82***
Sobel test of indirect effect		4.11***

combined models predicting patient engagement

step 1: connectedness and continuity alone		
connectedness	.15	4.44***
continuity	.10	3.11**
step 2: connectedness and continuity with the four empowerment variables		
connectedness	.07	2.36*
continuity	.02	.54
informed	.13	3.97***
confidence	.13	4.27***
understanding	.16	4.69***
comfort	.10	2.83**

Note. Because of space constraints we use shortened variable names. "Connectedness" = has a personal connection, "information" = informed about health, "engagement" = patient engagement in care decisions, "continuity" = continuity in a care provider, "confidence" = confidence can make healthcare decisions, "understanding" = frequency provider explains things in a way you can understand, and "comfort" = comfort asking provider questions.

endnotes

- 28 The mean was skewed by one respondent who indicated he/she had had more than 300 medical appointments in the past year. This response was removed.
- 29 "Confidence can make healthcare decisions" had a significant negative skew. We transformed the variable to eliminate this skew, reran the regression and found nearly identical results. Since the same predictors were statistically significant, we present the results of the non-transformed regression for ease of interpretation.
- 30 "Comfort asking provider" questions had a significant negative skew. We transformed the variable to eliminate the skew and reran the regression using the transformed variable. The results were essentially the same; all significant predictors shown in table 5 remained so using the transformed variable. We present the results of the non-transformed regression for ease of interpretation.
- 31 As with regression analyses more broadly, mediation analyses cannot conclusively establish causality.

appendix b – topline data report

This appendix provides complete question wording and topline results for data included in this report on the 2012 Blue Shield of California Foundation survey of low-income Californians. Some material was previously released in the first report from this survey, entitled *Connectedness and Continuity: Patient-Provider Relationships Among Low-Income Californians*.

*= less than 0.5 percent

1-28, 46-47 previously released or held for release.

29. How much does it matter to you that the healthcare provider and staff at your healthcare facility [ITEM] – is that very important to you, somewhat important, not so important or not important at all?

	Important		NET	Not Important		NET	No opinion
	Very	Somewhat		Not so	At all		
a. know what's going on in your community	41%	34	75	13	11	24	*
b. understand your cultural or ethnic background	39	28	67	15	18	33	1
c. (asked if not primarily an english speaker) are able to speak with you in the language you prefer	76	16	92	2	6	8	*

30 previously released.

31. If a healthcare facility in your area had a seal of approval from a national healthcare association would that make you (more likely) to go there, (less likely) to go there, or wouldn't it make a difference?

More likely	No difference	Less likely	No opinion
47%	43	9	2

32. Thinking about healthcare decisions, is it your preference to (leave decisions about your health care mostly up to the doctor or nurse), or would you prefer to (have an equal say with the doctor or nurse in decisions about your health care)? Do you feel that way strongly, or somewhat?

Leave to the doctor		NET	Have an equal say		NET	No opinion
Strongly	Somewhat		Somewhat	Strongly		
29%	10	39	10	48	59	1

33. (IF LEAVE TO THE DOCTOR, Q32) Is that more because (you feel you don't have enough information to make the right decision) or more because (you feel that making care decisions is the doctor's responsibility, not yours)?

Not enough information	Doctor's responsibility	Both (vol.)	Other (vol.)	No opinion
51%	40	4	1	3

32/33 NET:

Prefer to leave decisions to the doctor				NET	Prefer equal say	No opinion
Not enough information	Doctor's responsibility	Both (vol.)	Other (vol.)			
20%	16	2	1	39	59	1

34. (IF DOESN'T WANT EQUAL SAY, Q32) Now imagine the doctor has selected treatment options for you – a choice of things you might do, any of which is medically appropriate – and you've been given information that you understand about these options. In this situation, would you prefer to (leave the decisions mostly up to the doctor or nurse) or would you prefer to (have an equal say with the doctor or nurse in the decisions)?

Leave to the doctor	Have an equal say	Have most of the say (vol.)	No opinion
42%	54	1	3

32/34 NET:

Prefers equal say or more		NET	Prefer to leave to the doctor	No opinion
Always	If given options			
59%	22	81	17	3

35. How much of a say do you feel you currently have in decisions about your health care – a great deal of say, a good amount, just some or only a little?

Has more say		NET	Has less say			NET	No opinion
Great deal	Good amount		Some	Little	None (vol.)		
38%	34	72	14	12	1	27	1

36. Regardless of whether or not you want an equal say, would you like more of a say in decisions about your health care than you have now, less of a say, or is it about right?

More say	About right	Less say	No opinion
33%	58	7	2

37. In general, how informed do you feel about your health and any health problems you may have – very informed, somewhat informed, not so informed or not informed at all?

Informed		NET	Not informed		NET	No opinion *
Very	Somewhat		Not so	At all		
48%	36	84	11	4	16	

38. Have you ever used the internet to access health information, or not?

Yes	No	No opinion
43%	56	*

Compare to Kaiser Family Foundation/Washington Post national sample:

	Yes	No	No opinion
02/09/11	60%	39	*

39. (IF HAS USED THE INTERNET TO ACCESS HEALTH INFORMATION, Q38)
Do you do that very often, somewhat often, just occasionally or rarely?

Often		NET	Not often		NET	No opinion *
Very	Somewhat		Occasionally	Rarely		
23%	21	44	40	16	56	

38/39 NET:

Have used internet to access health information								
Often		NET	Not often		NET	NET	Have not 56	No opinion *
Very	Somewhat		Occasionally	Rarely				
10%	9	19	17	7	24	43		

40. How interested, if at all, would you be in having more information about [ITEM] – very interested, somewhat interested, not so interested or not interested at all?

	Interested		NET	Not interested		NET	No opinion
	Very	Somewhat		Not so	At all		
a. the pros and cons of different tests or treatments you might need	58%	30	88	4	8	11	*
b. the training and experience of the health professionals in your area	52	32	84	8	7	15	1
c. patient satisfaction ratings for the healthcare facilities in your area	45	38	83	7	9	16	1
d. quality ratings for providers in your area – like with more stars for the better ones	48	35	83	8	8	16	1

41. How confident are you in your ability to make decisions about your health care – very confident, somewhat confident, not so confident or not confident at all?

Confident		NET	Not confident		NET	No opinion
Very	Somewhat		Not so	At all		
56%	36	92	6	2	8	*

42. Overall, who do you feel is most responsible for managing your health – (you yourself) or (your healthcare provider)?

Me	My provider	Both (vol.)	No opinion
73%	21	5	1

43. When you go for medical care, how often does the healthcare provider explain things in a way you understand – every time, most of the time, some of the time, rarely or never?

Often explains		NET	Some of the time	Rarely explains		NET	No opinion
Every time	Most of the time			Rarely	Never		
44%	31	76	17	4	3	7	*

44. How comfortable or uncomfortable do you feel asking the healthcare provider questions about your health or treatment – very comfortable, somewhat comfortable, somewhat uncomfortable or very uncomfortable?

Comfortable		NET	Uncomfortable		NET	No opinion
Very	Somewhat		Somewhat	Very		
62%	28	89	7	3	10	1

45. Has there ever been a time when you didn't follow a healthcare provider's advice or treatment plan because you didn't understand what you were supposed to do, or has that not happened?

Yes	No	No opinion
19%	80	*

48. Do you have any disability or chronic medical condition that requires ongoing health care, or not?

Yes	No	No opinion
29%	71	*

49. What is your main source of health insurance coverage, if any?

Private health insurance through an employer	22%
Private health insurance that you buy on your own	11
Medi-Cal, also known as Medicaid	25
Any other state health insurance program	5
The V.A., Tri-Care, military, federal insurance	2
Indian Health Service	*
Medicare	2
Medicare and Medi-Cal	2
None, you are uninsured	29
No opinion	3

selected demographics:

Sex	
Male	47%
Female	53

Age	
19-29	33%
30-39	23
40-49	21
50-64	23

Relationship status	
Married	39%
Living with a partner	15
Widowed	3
Divorced	6
Separated	4
Single	33

Employment status	
Employed, full-time	36%
Employed, part-time	21
Not employed NET	41
Retired	4
Homemaker	8
Student	9
Unemployed	14
Disabled	6
Other	*
No opinion	2

Education	
Less than high school NET	33%
8th grade or less	12
Some high school	21
High school graduate	26
Some college/associates degree	30
College graduate NET	11
Graduated college	10
Post graduate	1

Race/Ethnicity	
White, non-Latino	27%
Black, non-Latino	7
Latino NET	54
White Latino	36
Black Latino	13
Latino unspecified	5
Asian	8
Multiracial	1
Other	2

Income	
< \$16,000	30%
\$16,000-\$30,999	47
\$31,000-\$51,999	15
\$52,000+	2
No opinion	6

appendix c – full questionnaire

This appendix reproduces the full, formatted questionnaire for Blue Shield of California Foundation's 2012 survey of low-income Californians.

[CONFIRM LANGUAGE AT THE BEGINNING OF THE INTERVIEW]

INTRO [ALL SAMPLE]: Hello. My name is _____. I'm calling from SSRS and we're conducting research on important issues concerning healthcare in California. We're not selling anything – just getting opinions on how to make health care better for more people. Our questions are for research only and your answers are strictly confidential.

(IF CELL SAMPLE)

CELL1. May I please ask if I've reached you on a cell phone, or on a regular landline phone?

INTERVIEWER NOTE: IF RESPONDENT ASKS, WHY DO YOU NEED TO KNOW CELL VS. LANDLINE PHONE? SAY, "So we can make sure all people are included whatever phone they use."

- | | | |
|---|-----------------------|-----------------|
| 1 | Cell phone | |
| 2 | Landline phone | THANK AND TERM. |
| R | (DO NOT READ) Refused | THANK AND TERM. |

(IF CELL SAMPLE)

CELL2. Before we continue, are you driving or doing anything that requires your full attention right now?

- | | | |
|---|-----------------------------------------------|-------------------|
| 1 | Yes, respondent is driving/doing something | SET UP CALLBACK |
| 2 | No, respondent is not driving/doing something | CONTINUE TO CELL3 |
| R | (DO NOT READ) Refused | THANK & TERM. |

(IF CELL SAMPLE AND IF RESPONDENT ASKS ABOUT OR OBJECTS TO COST OF CALL OR LOSS OF MINUTES DURING ANY PART OF THE INTERVIEW, TYPE "CELL" AT PROMPT TO REACH THE FOLLOWING SCREEN): We are able to offer you five dollars as reimbursement for the use of your cell phone minutes for this call. If you complete the full survey, I will ask for your mailing address at the end of the survey so we can send you a check. Is this OK? (CONTINUE TO CELL3 OR TO NEXT QUESTION)

(IF CELL SAMPLE)

CELL3. So we can ask you the right questions, could you please tell me if you are 18 or younger, older than 18 but younger than 65 or are you 65 or older?

- 1 18 or younger THANK & TERM.
- 2 19 to 64
- 3 65 or older THANK & TERM.
- R (DO NOT READ) Refused THANK & TERM.

(IF Q.CELL3 =2)

CELL4. In what state do you currently live?

- 1 California
- 2 Not California THANK & TERM.
- R (DO NOT READ) Refused THANK & TERM.

W1. I'd like to ask about your overall health. In general, would you say your health is excellent, very good, good, fair, or poor?

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

INSERT "this household" IF LL SAMPLE

INSERT "the same house as you" IF CELL SAMPLE

S1. To ask the right questions we need to know how many people in your family usually live in (this household/the same house as you). By family we mean any blood relatives or people related to you by birth, marriage or adoption. Including yourself, how many people in your family live there?

(INTERVIEWER NOTES:

- THIS INCLUDES ANY FAMILY MEMBER THAT LIVES IN THE SAME HOME. FAMILY MEMBERS WHO NORMALLY LIVE IN THE HOUSEHOLD BUT ARE TEMPORARILY LIVING SOMEPLACE ELSE (e.g. hospital or school) SHOULD BE COUNTED
- UNMARRIED COUPLES DO NOT COUNT AS FAMILY MEMBERS. IF THERE ARE ANY CHILDREN FROM THIS RELATIONSHIP, THEY DO COUNT AS FAMILY MEMBERS
- INTERVIEWER NOTE: IF HH SIZE MORE THAN 15, PLEASE CONFIRM BEFORE ENTERING RESPONSE.)

_____ (valid: 1-100)

- RRR (DO NOT READ) Refused THANK & TERM.

(ASK Q.S2a IF Q.S1=1 AND LL SAMPLE)

S2a. And are you 18 or younger, older than 18 but younger than 65 or are you 65 or older?

- | | | |
|---|-----------------------|---------------|
| 1 | 18 or younger | THANK & TERM. |
| 2 | 19 to 64 | |
| 3 | 65 or older | THANK & TERM. |
| R | (DO NOT READ) Refused | THANK & TERM. |

(ASK Q.S2 IF Q.S1=2+ AND LL SAMPLE)

S2. And how many of these family members, including you are older than 18 but younger than 65?

_____ (RANGE = 1- RESPONSE IN Q.S1)

- | | | |
|----|-----------------------|---------------|
| NN | None | THANK & TERM. |
| RR | (DO NOT READ) Refused | THANK & TERM. |

(ASK EVERYONE; READ ITEM IN PARENS IF S1=2+)

S3. To ask the right questions, we need to know whether in 2011, your (family's) total annual income from all sources, before taxes, was more or less than (INSERT Y*)?

(IF NEEDED: Family income includes income from you and any family members living with you. Income can be pay for work or any other money coming in.)

(IF NEEDED: Your income makes it easy or hard to take care of healthcare costs. We need to know that to ask the right questions.)

[INTERVIEWER: IF RESPONDENT REFUSES: Your responses are strictly confidential and are not attached to any identifying information. It is important for us to know this information to ask you about your healthcare.]

[INTERVIEWER: IF RESPONDENT IS UNSURE, PROBE: Can you estimate?]

- | | | |
|---|--------------------------------|---------------|
| 1 | More than (AMOUNT) | THANK & TERM. |
| 2 | Less than (AMOUNT) | |
| 3 | (DO NOT READ) Exactly (AMOUNT) | THANK & TERM. |
| D | (DO NOT READ) Don't know | GO TO Q.S3b |
| R | (DO NOT READ) Refused | GO TO Q.S3b |

VALUES FOR Y*

IF S1=1	\$23,000	IF S1=6	\$62,000
IF S1=2	\$29,000	IF S1=7	\$70,000
IF S1=3	\$36,000	IF S1=8	\$78,000
IF S1=4	\$46,000	IF S1=9+	\$93,000
IF S1=5	\$55,000		

(ASK Q.S3b IF Q.S3 = D OR R)

(READ ITEM IN PARENS IF S1=2+)

S3b. How about average monthly income? Can you estimate whether your (family's) average monthly income from all sources was more or less than (INSERT M*)?

(IF NEEDED: Family income includes income from you and any family members living with you. Income can be pay for work or any other money coming in.)

(IF NEEDED: Your income makes it easy or hard to take care of healthcare costs. We need to know that to ask the right questions.)

[INTERVIEWER: IF RESPONDENT REFUSES: Your responses are strictly confidential and are not attached to any identifying information. It is important for us to know this information to ask you about your healthcare.]

[INTERVIEWER: IF RESPONDENT IS UNSURE, PROBE: Can you estimate?]

- | | | |
|---|--------------------------------|---------------|
| 1 | More than (AMOUNT) | THANK & TERM. |
| 2 | Less than (AMOUNT) | |
| 3 | (DO NOT READ) Exactly (AMOUNT) | THANK & TERM. |
| D | (DO NOT READ) Don't know | |
| R | (DO NOT READ) Refused | |

VALUES FOR M*

IF S1=1	\$2,000	IF S1=6	\$5,100
IF S1=2	\$2,400	IF S1=7	\$5,800
IF S1=3	\$3,000	IF S1=8	\$6,500
IF S1=4	\$3,800	IF S1=9+	\$7,800
IF S1=5	\$4,500		

(ASK Q.S3c IF LL SAMPLE AND Q.S3b = D OR R AND Q.S1>1)

S3c. Is there someone else there you can ask?

- | | | |
|---|--------------------------------|------------------------------|
| 1 | Yes, coming to phone | RE-READ INTRO & GO TO Q.S3 |
| 2 | Yes, but presently unavailable | GET NAME & SCHEDULE CALLBACK |
| 3 | No | THANK & TERM. |
| R | (DO NOT READ) Refused | THANK & TERM. |

(IF CELL SAMPLE OR Q.S2a = 2 GO TO Q.S5)

(ASK Q.S4 IF LL SAMPLE AND Q.S1 = 2+)

(IF Q.S2 = 1, DO NOT INSERT ANY OF THE VERBIAGE IN PARENS)

S4. To complete our survey we need to speak with the (male/female) family member living in your household, who is between the ages of 19 and 64 and had the last birthday. Is that person at home right now?

(INTERVIEWER NOTE: IF RESPONDENT ASKS WHY DO YOU NEED TO TALK TO THE MALE/FEMALE WHO HAD THE LAST BIRTHDAY? SAY, "Our research experts set it up that way so that all types of people will be represented.")

- 1 Yes, respondent on the phone
- 2 Yes, respondent coming to the phone REPEAT INTRO & GO TO Q.S5
- 3 Person is unavailable GET NAME & SCHEDULE CALLBACK
- 4 No one in the HH of that gender
- R (DO NOT READ) Refused THANK & TERM.

(ASK Q.S4a IF Q.S4 = 4)

S4a. Then may I please speak with the (female/male) (INSERT OPPOSITE GENDER FROM Q.S4) family member living in your household, who is between the ages of 19 and 64 and had the last birthday?

- 1 Yes, respondent on the phone
- 2 Yes, respondent coming to the phone REPEAT INTRO AND GO TO Q.S5
- 3 Person is unavailable GET NAME & SCHEDULE CALLBACK
- R (DO NOT READ) Refused THANK & TERM.

S5. What language do you mainly speak at home? (DO NOT READ.)

- 1 English
- 2 Spanish
- 3 Chinese/Mandarin/Cantonese
- 4 Korean
- 5 Filipino/Tagalog
- 7 Other
- R (DO NOT READ) Refused

S6. RECORD GENDER OF RESPONDENT

- 1 Male
- 2 Female

main questionnaire

S7. And just to confirm, what is your age?

_____ (19-64)

- LL 18 or less THANK AND TERM.
- 65 65 OR MORE THANK AND TERM.
- RR (DO NOT READ) Refused

(ASK Q.S7a IF Q.S7 = RR)

S7a. Could you please tell me if you are...? (READ LIST.)

(INTERVIEWER NOTE: IF RESPONDENT SAYS "YOUNGER THAN 19" OR "OLDER THAN 65" – PLEASE CONFIRM BEFORE ENTERING RESPONSE)

- 1 Younger than 19 THANK AND TERM.
- 2 19 to 29
- 3 30 to 39
- 4 40 to 49
- 5 50 to 64, or
- 6 65 OR OLDER THANK AND TERM.
- R (DO NOT READ) Refused

(ASK Q.S7b IF Q.S7a = R)

S7b. Can you just confirm that you are older than 18 and younger than 65?

- 1 Yes
- 2 No THANK AND TERM.
- R (DO NOT READ) Refused THANK AND TERM.

(SCRAMBLE LIST)

1. Of the items I name please tell me which one is the single biggest concern for you right now – is it ...?

(READ LIST.)

- 1 Housing issues
- 2 Being able to pay for basics like food
- 3 Getting or holding a job
- 4 Immigration or legal issues
- 5 Or, taking care of your health
- 7 (DO NOT READ) Other
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

2. About how many times in the past year have you seen a doctor, nurse or other healthcare provider? (IF NEEDED: Just your best guess)

_____ NUMBER OF TIMES

NN None

DD (DO NOT READ) Don't know

RR (DO NOT READ) Refused

(ROTATE VERBIAGE IN PARENS)

3. Where do you usually go when you are sick or need health care for any reason – (Kaiser), (a private doctor's office), (a community clinic or health center), (a hospital) or someplace else?

(INTERVIEWER NOTES:

– IF MULTIPLE PLACES, ASK “Which one usually?”

– IF RESPONDENT SAYS “DOCTOR” ASK: IS THAT A PRIVATE DOCTOR'S OFFICE OR A DOCTOR AT [REPEAT OTHER CHOICES]?

– IF RESPONDENT SAYS NON-PROFESSIONAL, I.E., “PARENT, FAMILY, HOME”, SAY “I mean for professional healthcare.” AND RE-ASK QUESTION.)

- 1 Kaiser
- 2 A private doctor's office
- 3 A community clinic or health center
- 4 A hospital
- 5 Someplace else
- 6 (DO NOT READ) No place I usually go
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ASK Q.3a IF Q.3 = 6, D, OR R)

3a. OK, where's the last place you went when you needed health care?
(ENTER ONE ONLY)

(INTERVIEWER NOTES:

– IF RESPONDENT SAYS “DOCTOR” ASK: IS THAT A PRIVATE DOCTOR'S OFFICE OR A DOCTOR AT [REPEAT OTHER CHOICES]?

– IF RESPONDENT SAYS NON-PROFESSIONAL, I.E., “PARENT, FAMILY, HOME”, SAY “I mean for professional healthcare.” AND RE-ASK QUESTION.)

- 1 Kaiser
- 2 A private doctor's office
- 3 A community clinic or health center
- 4 A hospital
- 5 Or, someplace else
- 6 (DO NOT READ) Never have gone to doctor/nurse/healthcare provider
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(IF Q.3a = 1, 2, 4, 5)

3b. Was this in California, or not?

- 1 Yes
 - 2 No
 - D (DO NOT READ) Don't know
 - R (DO NOT READ) Refused
- THANK & TERM.
THANK & TERM.
THANK & TERM.

(ASK Q.4 IF Q.3 = 3 OR Q.3a = 3)

4. What's the city or town where your clinic is located?

(ENTER 1ST LETTER OF CITY/TOWN FOR LIST OF AVAILABLE CITIES/TOWNS)

096	Fresno	259	San Francisco
158	Los Angeles	263	San Jose
201	Oakland	330	Ventura
213	Oxnard	997	Other answer given (SPECIFY) _____
254	Sacramento	DDD	(DO NOT READ) Don't know
255	Salinas	RRR	(DO NOT READ) Refused
258	San Diego		

(ASK Q.4aa IF Q4 = 096, 158, 201, 213, 254, 255, 258, 259, 263, OR 330 OR 997)

4aa. What's the name of the street where your clinic is located?

(ENTER 1ST LETTER OF STREET FOR LIST OF AVAILABLE CLINICS)

001	Answer given (SPECIFY) _____
DDD	(DO NOT READ) Don't know
RRR	(DO NOT READ) Refused

(ASK Q.4a IF Q.3 = 3 OR Q.3a = 3)

4a. What's the name of that clinic?

(ENTER 1ST LETTER OF CLINIC FOR LIST OF AVAILABLE CLINICS)

(INTERVIEWER NOTE: IF 2+ CLINICS WITH SAME NAME, VERIFY STREET NAME IF AVAILABLE)

997	Answer given (SPECIFY) _____
DDD	(DO NOT READ) Don't know
RRR	(DO NOT READ) Refused

(ASK Q.4b IF Q.4a = 997, DDD, OR RRR)

4b. As far as you know, is that a clinic that's operated by a hospital, or not?

(ENTER ONE ONLY)

1	Yes, operated by a hospital
2	No, not operated by a hospital
D	(DO NOT READ) Don't know
R	(DO NOT READ) Refused

(ASK Q.4c IF Q.4b = 1; ROTATE VERBIAGE IN PARENS)

4c. Is this clinic run by a (county hospital) or a (private or religious hospital)?

(ENTER ONE ONLY)

1	County hospital
2	Private or religious hospital
3	(DO NOT READ) Other
D	(DO NOT READ) Don't know
R	(DO NOT READ) Refused

(ASK Q.4d IF Q.4b = 2)

(ROTATE VERBIAGE IN PARENS)

4d. Is this clinic run by a (county or city), or by a (private company)?

(INTERVIEWER NOTE: IF "COLLEGE OR UNIVERSITY-RUN STUDENT CLINIC"
CODE AS 3 "OTHER")

- 1 County or city
- 2 Private company
- 3 (DO NOT READ) Other
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ASK Q.4e IF Q.3 = 4 OR Q.3a = 4)

(ROTATE VERBIAGE IN PARENS)

4e. Is that a (hospital clinic), or is it a (hospital emergency room)?

- 1 Hospital clinic
- 2 Hospital emergency room
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ASK Q.4f IF Q.4e = 1)

(ROTATE VERBIAGE IN PARENS)

4f. Is this clinic run by a (county hospital) or a (private or religious hospital)?

- 1 County hospital
- 2 Private or religious hospital
- 3 (DO NOT READ) Other
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ASK Q.5 IF Q.3 = 1-5)

5. Thinking about the place where you usually go for health care, how would you rate the health care you receive – excellent, very good, good, not so good or poor?

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Not so good
- 5 Poor
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ASK Q.5a IF Q.3a = 1-5, D OR R)

5a. Thinking about the last time you received health care – was the health care you received excellent, very good, good, not so good or poor?

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Not so good
- 5 Poor
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ASK Q.6 IF Q.3 = 1-5 OR Q.3a = 1-5, D OR R)

6. Apart from the health care they provide, what about the kind of assistance they offer to help you get the support services you may need, such as information, referrals, transportation and other assistance – would you rate this as excellent, very good, good, not so good or poor?

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Not so good
- 5 Poor
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ASK Q.7 IF Q.3 = 1-5 OR Q.3a = 1-5, D OR R)

INSERT 1ST VERBIAGE IN PARENS IF Q.3 = 1-5; INSERT 2ND VERBIAGE IN PARENS IF Q.3a = 1-5, D, OR R)

7. Thinking about the people working at the place where you (usually go/ last went) for care, do you feel there's a person there who knows you pretty well, or not really?

(IF NEEDED: I mean someone who has a pretty good idea of what's going on in your life that may affect your health. This can be anyone you see there, not necessarily the doctor.)

- 1 Yes, there is someone that knows you pretty well
- 2 No, there is no one that knows you pretty well
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ASK Q.8 IF Q.7 = 1)

(SCRAMBLE 01-04)

8. Who is that person – I mean their job?

(IF NEEDED: Could be a (INSERT CODES 01-04), or so forth?)

(READ LIST.)

INTERVIEWER NOTE: healthcare navigator also can be “healthcare coach” or similar

- 01 Doctor
- 02 Nurse
- 03 Healthcare navigator (Spanish: Promotores de salud)
- 04 Someone at reception
- 05 (DO NOT READ) Nurse's aide
- 06 (DO NOT READ) Physician's assistant (PA)
- 07 (DO NOT READ) Pharmacist
- 08 (DO NOT READ) Nutritionist
- 09 (DO NOT READ) Case worker/social worker
- 10 (DO NOT READ) Billing clerk
- 97 (DO NOT READ) Other (SPECIFY) _____
- DD (DO NOT READ) Don't know
- RR (DO NOT READ) Refused

(ASK Q.9 IF Q.3 = 1-5 OR Q.3a = 1-5, D OR R)

INSERT “Is that” IF Q.7 = 1

INSERT “Would that be” IF Q.7 = 2, D, OR R

9. How much does this matter to you – having someone there who knows you well? (Is that/Would that be) very important to you, somewhat important, not so important or not important at all?

- 1 Very important
- 2 Somewhat important
- 3 Not so important
- 4 Not important at all
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

10. Do you have a regular personal doctor, or not?

[IF NEEDED: I mean one you would regularly see if you need a checkup, want advice about a health problem, or get sick or hurt.]

- 1 Yes, do
- 2 No, do not
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ASK Q.11 IF Q.10 = 2)

11. Would you like to have your own personal doctor, or is it not that important to you?

- 1 Yes, would like to
- 2 No, not that important
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ASK Q.12 IF Q.10 = 1)

12. Do you like having your own personal doctor, or is it not that important to you?

- 1 Yes, like it
- 2 No, not that important
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

13. Regardless of whether or not you have a personal doctor, how often do you see the same healthcare provider when you have a healthcare appointment – every time, most of the time, some of the time, rarely or never?

- 1 Every time
- 2 Most of the time
- 3 Some of the time
- 4 Rarely
- 5 Never
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ASK Q.14 IF Q.13 = 2, 3, 4, 5, D, OR R)

14. Would you like to be able to see the same healthcare provider more often than you do now, or is that not that important to you?

- 1 Yes, would
- 2 Not that important
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ASK Q.15 IF Q.3 = 1-5 OR Q.3a = 1-5, D OR R)

(ROTATE VERBIAGE IN PARENS)

15. Thinking about when you go in for routine care or a checkup, not for a special problem – (do you usually see a doctor), or (do you usually see a care provider who is not a doctor, like a nurse or a physician's assistant)?

- 1 Usually see a doctor
- 2 Usually see a care provider who is not a doctor, like a nurse or physician's assistant
- 3 (DO NOT READ) Usually see both
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ROTATE VERBIAGE IN PARENS)

16. For routine visits or checkups, would you prefer to see (a doctor), would you prefer to see (a nurse or physician's assistant) or does it not matter much to you either way?

(INTERVIEWER NOTE: If respondent says "both", say, "Well, if you had to choose...")

- 1 Prefer to see a doctor
- 2 Prefer to see a nurse or physician's assistant
- 3 Doesn't matter either way
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ASK Q.16a IF Q.16 = 1 OR 2)

INSERT "doctor" IF Q.16 = 1

INSERT "nurse or physician's assistant" IF Q.16 = 2

16a. Do you feel that way strongly or somewhat?

(IF NECESSARY: That you prefer to see a (doctor/nurse or physician's assistant))

- 1 Strongly
- 2 Somewhat
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ASK IF Q.16 = 1)

(ROTATE VERBIAGE IN PARENS)

(SCRAMBLE ITEMS)

17. What if (INSERT ITEM) – in that case would you (still prefer to see a doctor) for routine care, or would you (prefer to see a nurse or physician's assistant)?

- 1 Still prefer to see a doctor
 - 2 Prefer to see a nurse or physician's assistant
 - 3 (DO NOT READ) Either/Doesn't matter
 - D (DO NOT READ) Don't know
 - R (DO NOT READ) Refused
-
- a. It's harder to get an appointment with a doctor
 - b. The appointment with the doctor is shorter than it would be with a nurse or physician's assistant
 - c. The doctor doesn't know you as well as the nurse or physician's assistant

(ASK Q.17a IMMEDIATELY FOLLOWING Q.17 FOR EACH = 1 OR 2)

INSERT "still prefer to see a doctor" IF Q.17 = 1

INSERT "would prefer to see a nurse or physician's assistant" IF Q.17 = 2

17a. Do you feel that way strongly or somewhat?

(IF NECESSARY: That you (still prefer to see a doctor/would prefer to see a nurse or physician's assistant))

- 1 Strongly
- 2 Somewhat
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

- a. It's harder to get an appointment with a doctor
- b. The appointment with the doctor is shorter than it would be with a nurse or physician's assistant
- c. The doctor doesn't know you as well as the nurse or physician's assistant

18. For routine health questions, how would you feel about talking with a healthcare provider over the telephone instead of having an in-person appointment – would you be very willing to do this, somewhat willing, somewhat unwilling or very unwilling?

- 1 Very willing
- 2 Somewhat willing
- 3 Somewhat unwilling
- 4 Very unwilling
- 5 (DO NOT READ) Depends
- 6 (DO NOT READ) Already do this
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

19. How about using e-mail? For routine health questions, how would you feel about using e-mail instead of having an in-person appointment to communicate with a healthcare provider – would you be very willing to do this, somewhat willing, somewhat unwilling or very unwilling?

- 1 Very willing
- 2 Somewhat willing
- 3 Somewhat unwilling
- 4 Very unwilling
- 5 (DO NOT READ) Depends
- 6 (DO NOT READ) Already do this
- 7 (DO NOT READ) Do not use internet/e-mail and/or computer
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ASK Q.20 IF Q.3 = 1-5 OR Q.3a = 1-5, D OR R)

INSERT "you go" IF Q.3 = 1-5

INSERT "last went" IF Q.3a = 1-5, D, OR R

20. On another subject, some places have a person whose job it is to help people get the appointments, information and services they need, make sure their questions have been addressed, or may even call to check in on them between visits. There are different names for this kind of role, for example a healthcare navigator or healthcare coach [Spanish: promotores de salud]. Do you personally have a health navigator or health coach at the place (you go/last went) for care, or not?

- 1 Yes
- 2 No
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ASK Q.21 IF Q.20 = 1)

21. How do you like having this healthcare navigator – do you like it a great deal, somewhat, not so much or not at all?

- 1 A great deal
- 2 Somewhat
- 3 Not so much
- 4 Not at all
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ASK Q.22 IF Q.20 = 2, D, OR R)

22. How interested would you be in having a healthcare navigator providing these services – very interested, somewhat interested, not so interested or not interested at all?

- 1 Very interested
- 2 Somewhat interested
- 3 Not so interested
- 4 Not interested at all
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ASK Q.23 IF Q.3 = 1-5 OR Q.3a = 1-5, D OR R)

INSERT "you go" IF Q.3 = 1-5

INSERT "last went" IF Q.3a = 1-5, D, OR R

23. Some places have what's called team-based care. Each patient gets a healthcare team that includes a doctor, a healthcare navigator, a nurse or physician's assistant and a health educator. The same team always works with that patient. As far as you're aware do you personally have a healthcare team at the place (you go/last went) for care, or not?

- 1 Yes
- 2 No
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ASK Q.24 IF Q.23 = 1)

24. How do you like this team-based approach – do you like it a great deal, somewhat, not so much or not at all?

- 1 A great deal
- 2 Somewhat
- 3 Not so much
- 4 Not at all
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ASK Q.25 IF Q.23 = 2, D, OR R)

25. If it was available where you go for care, would you be very willing to have team-based care, somewhat willing, somewhat unwilling or very unwilling?

- 1 Very willing
- 2 Somewhat willing
- 3 Somewhat unwilling
- 4 Very unwilling
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ASK Q.26 IF Q.23 = 2, D, OR R)

26. The idea of team-based care is that while you may see a doctor less often, it's easier to see more types of healthcare providers who know you and can help in different ways. Knowing this, would you be very willing to participate in team-based care somewhat willing, somewhat unwilling or very unwilling?

- 1 Very willing
- 2 Somewhat willing
- 3 Somewhat unwilling
- 4 Very unwilling
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(SCRAMBLE a-e)

(IF CODE 6, ENTERED AT ANY TIME, THEN ALL OTHER INTERNET-RELATED ITEMS SHOULD BE AUTO-GEN'D A CODE 6 [ITEMS c, d, e]. IF CODE 7 ENTERED AT ANY TIME, THEN ALL OTHER TEXTING-RELATED ITEMS SHOULD BE AUTO-GEN'D A CODE 7 [ITEMS a,b])

27. There can be different ways to communicate with a healthcare provider. For each item I name, please tell me how interested you are in doing that, if at all. If you're already doing this, please just say so. The first is (INSERT ITEM) – are you very interested in doing that, somewhat interested, not so interested or not interested at all? How about (INSERT NEXT ITEM)?

- 1 Very interested
- 2 Somewhat interested
- 3 Not so interested
- 4 Not interested at all
- 5 Already doing this
- 6 (DO NOT READ) No e-mail/internet/computer access
- 7 (DO NOT READ) No cell phone/don't text message
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

- a. Receiving text messages reminding you to take medicine or come in for a test
- b. Receiving text messages with information about health issues you may be having
- c. Being able to schedule a medical appointment over the internet
- d. Being able to look at your health records over the internet
- e. Being able to renew prescription medicines over the internet

28. How concerned are you, if at all, about the privacy of your health information on the internet and in e-mails – very concerned, somewhat concerned, not so concerned or not concerned at all?

- 1 Very concerned
- 2 Somewhat concerned
- 3 Not so concerned
- 4 Not concerned at all
- 5 (DO NOT READ) Do not use internet/e-mail
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(SCRAMBLE ITEMS)

(ASK ITEM c IF Q.S5 = 2-7 OR R)

29. How much does it matter to you that the healthcare provider and staff at your healthcare facility (INSERT ITEM) – is that very important to you, somewhat important, not so important or not important at all?

(INTERVIEWER NOTE: IF R SAYS "NO FACILITY" SAY, "IF YOU HAD ONE...")

- 1 Very important
- 2 Somewhat important
- 3 Not so important
- 4 Not important at all
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

- a. Know what's going on in your community
- b. Understand your cultural or ethnic background
- c. Are able to speak with you in the language you prefer

30. Some places offer group programs on healthcare issues. There may be a program for people with diabetes, or for pregnant women, or for people trying to quit smoking, for example. These are places for people to share their experiences as well as get healthcare information. If there was a group program where you go that addressed a health issue you have, how willing would you be to participate in that – very willing, somewhat willing, somewhat unwilling or very unwilling?

(INTERVIEWER NOTE: IF R SAYS "NO HEALTH ISSUES" SAY, "WELL, IF YOU DID HAVE ONE...")

- 1 Very willing
- 2 Somewhat willing
- 3 Somewhat unwilling
- 4 Very unwilling
- 5 (DO NOT READ) Depends
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ROTATE VERBIAGE IN PARENS)

31. If a healthcare facility in your area had a seal of approval from a national healthcare association would that make you (more likely) to go there, (less likely) to go there, or wouldn't it make a difference?

- 1 More likely
- 2 Less likely
- 3 Wouldn't make a difference
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ROTATE VERBIAGE IN PARENS)

32. Thinking about healthcare decisions, is it your preference to (leave decisions about your health care mostly up to the doctor or nurse), or would you prefer to (have an equal say with the doctor or nurse in decisions about your health care)?

(INTERVIEWER NOTE: If respondent seems confused by the term "equal say" please say: "EQUAL SAY – LIKE AN EQUAL VOICE.")

- 1 Prefer to leave decisions mostly up to the doctor or nurse
- 2 Prefer to have an equal say with the doctor or nurse in decisions
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ASK Q.32a IF Q.32 = 1 OR 2)

32a. Do you feel that way strongly, or somewhat?

(IF NECESSARY: That you would [INSERT RESPONSE FROM Q.32])

- 1 Strongly
- 2 Somewhat
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ASK Q.33 IF Q.32 = 1)

(ROTATE VERBIAGE IN PARENS)

33. Is that more because (you feel you don't have enough information to make the right decision) or more because (you feel that making care decisions is the doctor's responsibility, not yours)?

- 1 You feel you don't have enough information to make the right decision
- 2 You feel that making care decisions is the doctor's responsibility, not yours
- 3 (DO NOT READ) Both
- 4 (DO NOT READ) Neither/other
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ASK Q.34 IF Q.32 = 1, D, OR R)

(ROTATE VERBIAGE IN PARENS)

34. Now imagine the doctor has selected treatment options for you – a choice of things you might do, any of which is medically appropriate – and you've been given information that you understand about these options. In this situation, would you prefer to (leave the decisions mostly up to the doctor or nurse) or would you prefer to (have an equal say with the doctor or nurse in the decisions)?

(INTERVIEWER NOTE: If respondent seems confused by the term "equal say" please say: "EQUAL SAY – LIKE AN EQUAL VOICE.")

- 1 Prefer to leave the decision mostly up to the doctor or nurse
- 2 Prefer to have an equal say with the doctor or nurse in the decision
- 3 (DO NOT READ) Prefer to have most of the say
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

35. How much of a say do you feel you currently have in decisions about your health care – a great deal of say, a good amount, just some or only a little?

(INTERVIEWER NOTE: If respondent seems confused by the term "say" please say: "SAY – AS IN VOICE.")

- 1 A great deal
- 2 A good amount
- 3 Just some
- 4 Only a little
- 5 (DO NOT READ) None
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

36. Regardless of whether or not you want an equal say, would you like more of a say in decisions about your health care than you have now, less of a say, or is it about right?

(INTERVIEWER NOTE: If respondent seems confused by the term "equal say" please say: "EQUAL SAY – LIKE AN EQUAL VOICE.")

- 1 More say
- 2 Less say
- 3 It's about right

- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

37. In general, how informed do you feel about your health and any health problems you may have – very informed, somewhat informed, not so informed or not informed at all?

(INTERVIEWER NOTE: IF R SAYS "NO HEALTH PROBLEMS", SAY "HOW INFORMED DO YOU FEEL ABOUT YOUR HEALTH IN GENERAL?")

- 1 Very informed
- 2 Somewhat informed
- 3 Not so informed
- 4 Not informed at all
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

38. Have you ever used the internet to access health information, or not?

- 1 Yes
- 2 No
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ASK Q.39 IF Q.38 = 1)

39. Do you do that very often, somewhat often, just occasionally or rarely?
(IF NEEDED: Use the internet to access health information...)

- 1 Very often
- 2 Somewhat often
- 3 Just occasionally
- 4 Rarely
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(SCRAMBLE ITEMS)

40. How interested, if at all, would you be in having more information about (INSERT ITEM) – very interested, somewhat interested, not so interested or not interested at all?

- 1 Very interested
- 2 Somewhat interested
- 3 Not so interested
- 4 Not interested at all
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

- a. The pros and cons of different tests or treatments you might need
- b. The training and experience of the health professionals in your area
- c. Patient satisfaction ratings for the healthcare facilities in your area
- d. Quality ratings for providers in your area – like with more stars for the better ones

41. How confident are you in your ability to make decisions about your health care – very confident, somewhat confident, not so confident, or not confident at all?

- 1 Very confident
- 2 Somewhat confident
- 3 Not so confident
- 4 Not confident at all
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ROTATE VERBIAGE IN PARENS)

42. Overall, who do you feel is most responsible for managing your health – (you yourself) or (your healthcare provider)?

- 1 You yourself
- 2 Your healthcare provider
- 3 (DO NOT READ) Both equally
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ASK Q.43 IF Q.3 = 1-5 OR Q.3a = 1-5, D OR R)

43. When you go for medical care, how often does the healthcare provider explain things in a way you can understand – every time, most of the time, some of the time, rarely, or never?

- 1 Every time
- 2 Most of the time
- 3 Some of the time
- 4 Rarely
- 5 Never
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ASK Q.44 IF Q.3 = 1-5 OR Q.3a = 1-5, D, OR R)

44. How comfortable or uncomfortable do you feel asking the healthcare provider questions about your health or treatment – very comfortable, somewhat comfortable, somewhat uncomfortable, or very uncomfortable?

- 1 Very comfortable
- 2 Somewhat comfortable
- 3 Somewhat uncomfortable
- 4 Very uncomfortable

- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ASK Q.45 IF Q.3 = 1-5 OR Q.3a = 1-5, D, OR R)

45. Has there ever been a time when you didn't follow a healthcare provider's advice or treatment plan because you didn't understand what you were supposed to do, or has that nothappened?

- 1 Yes, there has been a time
- 2 No, this has not happened
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

46. Changing subjects, as you may know, a health reform bill was signed into law in 2010. Given what you know about the health reform law, do you have a generally favorable or generally unfavorable opinion of it?

(GET ANSWER THEN ASK: Is that a very favorable/unfavorable or somewhat favorable/unfavorable opinion?)

- 1 Very favorable
- 2 Somewhat favorable
- 3 Somewhat unfavorable
- 4 Very unfavorable
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ROTATE VERBIAGE IN PARENS)

47. Do you think you and your family will be (better off) or (worse off) under the health reform law, or don't you think it will make much difference?

- 1 Better off
- 2 Worse off
- 3 Don't think it will make much difference
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

48. On another topic, do you have any disability or chronic medical condition that requires ongoing health care, or not?

- 1 Yes, do
- 2 No, do not
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

49. What is your main source of health insurance coverage, if any?

(READ LIST IF RESPONDENT DOES NOT IMMEDIATELY VOLUNTEER AN ANSWER FROM THE LIST)

(INTERVIEWER NOTE: IF RESPONDENT SAYS "Kaiser Permanente", "Anthem/Blue Cross or other insurance company" PROBE FOR WHETHER IT'S CODE "01" OR "02." IF RESPONDENT SAYS "COBRA", CODE AS "02;" IF RESPONDENT SAYS "SCHIP", CODE AS "04.")

- 01 Private health insurance through an employer
- 02 Private health insurance that you buy on your own
- 03 MediCal, also known as Medicaid
- 04 Any other state health insurance program
- 05 The V.A., military insurance through Tri-Care or any other federal government program
- 06 Indian Health Service
- 07 Medicare, which would only be if you are disabled
- 08 (DO NOT READ) Both Medicare and MediCAL (Medi-Medi)
- 00 Or none, you are uninsured
- DD (DO NOT READ) Don't know
- RR (DO NOT READ) Refused

READ: Now for classification purposes only...

(ASK CELL SAMPLE ONLY)

D1a. For personal calls do you only use a cell phone, or do you also have regular landline telephone service in your home on which I could have reached you?

- 1 Only use a cell phone
- 2 Have regular landline
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ASK LL SAMPLE)

D1b. For personal calls, do you only use a landline phone like this one, or do you also have a cell phone on which I could have reached you?

- 1 Landline phone only
- 2 Cell phone also
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

D2. Are you currently married, living with a partner, widowed, divorced, separated, or single, meaning never married and not living with a partner?

- 1 Married
- 2 Living with a partner
- 3 Widowed
- 4 Divorced
- 5 Separated
- 6 Single, meaning never married and not living with a partner
- R (DO NOT READ) Refused

D3. Currently, are you yourself employed full time, part time, or not at all?

- 1 Full time (SKIP TO Q.D4)
- 2 Part time (SKIP TO Q.D4)
- 3 Not employed (GO TO Q.D3a)
- R Refused (SKIP TO Q.D4)

(ASK IF Q.D3=3)

D3a. Are you: (READ LIST)?

- 1 Retired
- 2 A homemaker
- 3 A student, or
- 4 Temporarily unemployed
- 5 (DO NOT READ) Disabled/handicapped
- 7 (DO NOT READ) Other
- D (DO NOT READ) Don't Know
- R (DO NOT READ) Refused

D4. May I please have your zip code?

_____ ZIP CODE

- 99997 (DO NOT READ) Other (Specify)
- DD (DO NOT READ) Don't know
- RR (DO NOT READ) Refused

D5. What is the last grade of school you've completed?

(DO NOT READ LIST)

- 1 8th grade or less
- 2 Some high school
- 3 Graduated high school
- 4 Some college/associates degree
- 5 Graduated college
- 6 Post graduate
- R (DO NOT READ) Refused

D6. Are you of Hispanic origin or descent?

- 1 Yes
- 2 No
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ASK Q.D6a IF Q.D6 = 1)

D6a. Are you white Hispanic or black Hispanic?

- 1 White
- 2 Black

- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(ASK Q.D6b IF Q.D6 = 2, D, OR R)

D6b. Are you white, black, Asian or some other race?

- 1 White
- 2 Black
- 3 Asian
- 4 (DO NOT READ) Multiracial
- 7 Other (SPECIFY) _____
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

(DISPLAY CODES 01-03 FOR EVERYONE)

(DISPLAY CODE 04 IF S1>1)

(DISPLAY CODE 05 IF S1>2)

(DISPLAY CODES 06 AND 07 IF S1>3)

(DISPLAY CODES 08 AND 09 IF S1>4)

(DISPLAY CODE 10 IF S1>6)

(READ ITEM IN PARENS IF S1=2+)

D7. To help us describe the people who took part in our study, it would help to know which category describes your (family's) total annual income last year before taxes. That's income from all family members living in your household. Is it...? PROBE: Your best estimate is fine. (READ LIST.)

- 01 Less than \$16,000
- 02 At least \$16,000 but less than \$20,000
- 03 At least \$20,000 but less than \$24,000
- 04 At least \$24,000 but less than \$31,000
- 05 At least \$31,000 but less than \$36,000
- 06 At least \$36,000 but less than \$41,000
- 07 At least \$41,000 but less than \$47,000
- 08 At least \$47,000 but less than \$52,000
- 09 At least \$52,000 but less than \$62,000
- 10 Or \$62,000 or more
- DD (DO NOT READ) Don't know
- RR (DO NOT READ) Refused

D8. Confidentially and for statistical purposes only, are you a citizen of the United States, or not?

- 1 Yes, citizen
- 2 No, not a citizen
- D (DO NOT READ) Don't know
- R (DO NOT READ) Refused

FOR INTERVIEWER

INT0. DO NOT READ. Did respondent ask for sponsor information at intro?

- 1 Yes, asked for sponsor information
- 2 No, did not ask for sponsor information

(READ IF INTO =1)

The survey sponsor is the Blue Shield of California Foundation, a nonprofit group that works on healthcare issues in the state. The Foundation is a separate non-profit organization from the Blue Shield of California health plan. It has an independent Board of Trustees, which oversees its grant-making program. The Foundation is funded entirely by a contribution from the health plan.

FOR INTERVIEWER (CELL PHONE SAMPLE ONLY):

INT1. DO NOT READ. Did respondent request money for using their cell phone minutes?

- 1 Yes, requested money
- 2 No, did not request money – GO TO END OF INTERVIEW

(READ IF SAMPLE = CELL AND INT1=1)

That's the end of the interview. We'd like to send you \$5 for your time. Can I please have your full name and a mailing address where we can send you the money?

INTERVIEWER NOTE: If R does not want to give full name, explain we only need it so we can send the \$5 to them personally.

- 1 [ENTER FULL NAME] – INTERVIEWER: PLEASE VERIFY SPELLING
 - 2 [ENTER MAILING ADDRESS]
 - 3 [City]
 - 4 [State]
 - 5 CONFIRM ZIP from above
- R (VOL.) Respondent does not want the money

CLOSING: That completes our interview. Thank you very much for your time.

[end of questionnaire](#)

appendix d – references

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