



**engaging California patients
in major medical decisions**

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SURVEY RESEARCH DESIGN • MANAGEMENT • ANALYSIS

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executive summary

One of the best opportunities to enhance patients' involvement at a critical stage of their healthcare experience is when they are facing major medical decisions. But California healthcare providers often skip recommended steps to inform and engage low-income patients at that key point.

This Blue Shield of California Foundation study suggests that the shortfall can be addressed – with substantial benefits of doing so. As decision-support activities rise, so do patients' self-reported engagement and their satisfaction with the decision-making process.

Continuing a series of survey-based reports on patient engagement sponsored by the Foundation, this study focused on support given to low-income Californians who say they've faced a major medical decision in the past year. It measures the number of decision-support activities their care providers initiated, their self-assessed involvement in the ultimate decision, their satisfaction with the process and, through statistical modeling, an evaluation of the independent predictors of that involvement and satisfaction.

Decision support is tested in a series of questions asking patients about ways in which their care providers may have encouraged their involvement in major medical decisions. These decision-support activities were drawn from the literature on shared decision making, where they appear repeatedly as recommended elements of patient support. They are:

- Asking about patients' goals
- Listening to patients' preferences and concerns
- Offering additional information sources
- Discussing the possibility of taking no action
- Offering multiple treatment options, and, if multiple options are offered:
 - Discussing best options in light of patients' goals and preferences
 - Discussing the risks of each option
 - Discussing the benefits of each option
 - Giving patients time to consider their preferences in light of their goals and options

Experience of these nine activities was tested among low-income Californians who said they had faced a major medical decision within the previous 12 months – 19 percent of the 1,018 respondents interviewed, for a sample of 211.^{1,2} The nature of the respondents' decision was not explored; what patients themselves regard as having been a major medical decision was accepted as such.

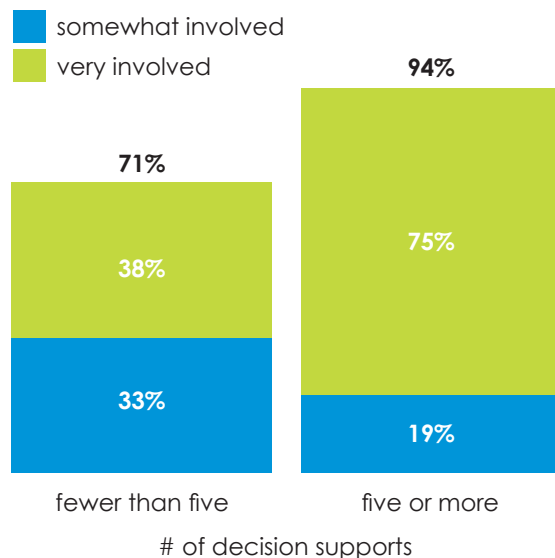
As decision supports rise, so do patient engagement and satisfaction with the decision-making process.

Among the key findings:

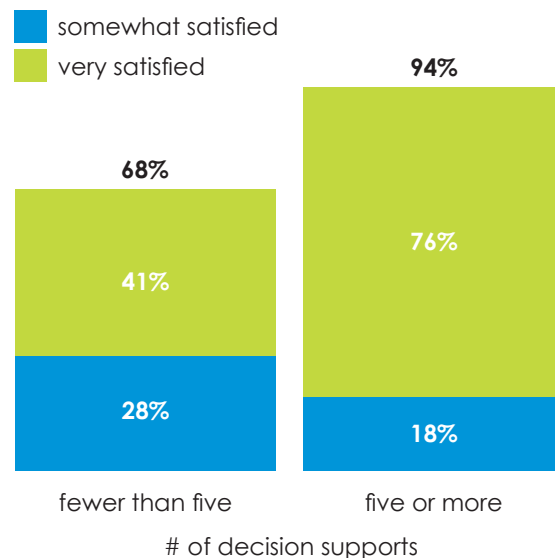
- These patients say their caregivers initiated, on average, 4.9 of the nine decision-support activities tested. Barely more than a quarter, 27 percent, say their caregivers engaged in all nine activities. Thirty-three percent experienced two or fewer support activities, with the rest in a range from three to eight. These results echo findings in the literature that important conditions for shared decision making are not fully being met.
- Among patients who reported experiencing five or more decision support activities, three-quarters report feeling “very involved” in the decision and “very satisfied” with the process. That level of involvement and satisfaction drops dramatically, to just four in 10, among those who received less decision-making support.

Seventy-five percent wanted to be very involved in the decision-making process. Fifty-seven percent feel they were.

involvement in the decision-making process



satisfaction with the decision-making process



- Many patients desire more involvement than they received. Seventy-five percent say they wanted to be very involved in the decision-making process. Many fewer, 57 percent, say they actually were very involved.
- In statistical modeling, the number of decision supports patients have experienced is the top predictor of their involvement in the decision and satisfaction with the process. This result validates the literature suggesting that these decision-support activities are important, by demonstrating their relationship with subjective outcomes even when controlled for other key variables.

It should be noted that shortfalls in decision support are not exclusive to low-income patients. Among a separate sample of higher-income Californians who've faced a major medical decision in the past year, the average number of reported decision-support activities is 5.2, almost exactly the same as among their low-income counterparts.³

involvement in decision making and satisfaction with the process

As detailed in Part A, more than eight in 10 low-income Californians report being at least somewhat satisfied with the decision-making process they experienced, and as many say they were involved in the decision. These include six in 10 who were "very" satisfied and 57 percent who feel they were "very" involved.

As noted, however, more say they *wanted* to be very involved – 75 percent. And, in a related result, just 30 percent say they received a great deal of information from their providers to help inform the decision.

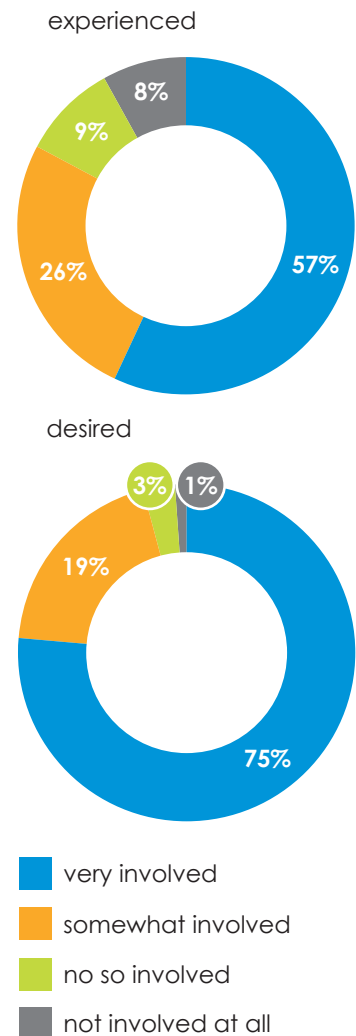
Ultimately, 40 percent of patients say they personally made the major medical decision they faced; as many say they shared equally in it with their provider, while two in 10 say it was the provider's decision alone. That suggests a comparatively low level of unilateral decision making by providers, a positive result within the framework of shared decision making. At the same time, other results show that even among patients who say they made or shared in the decision, many say it didn't chiefly reflect their own preference.⁴

Specifically, 26 percent of low-income patients overall say the decision was based chiefly on their personal preference. Three in 10 mainly relied on their provider's recommendation, with the rest dividing between financial considerations and the advice of family and friends. Further, even among those who say the decision was theirs or was shared, just 28 percent say it was based chiefly on their own preferences.

Shared decision making is a central element of the broader concept of patient-centered care. It envisions a process in which care providers and patients work together in aligning evidence-based clinical approaches with patients' individual preferences to arrive at informed decisions. This applies most fully to cases in which decisions are "preference-sensitive," meaning no treatment option is objectively superior to another and patients should be encouraged to consider the tradeoffs among them.

Even among patients who say they made or shared in the decision, many also say it didn't chiefly reflect their own preference.

levels of involvement in major medical decision making



Clearly a mix of factors can and should influence this process, including the provider's clinical judgments and the patient's preferences alike. Regardless, results of this study demonstrate that whether or not they feel actively involved in the decision, most patients, when confronted with a major decision, did not bring their personal preferences to the fore.

supporting successful decision making

Other results underscore the positive impacts of decision support. As noted, among patients who report that their provider engaged in five or more of the decision-support actions, three-quarters say they felt very involved in the decision and very satisfied with the process. That falls to four in 10 of those who had fewer support activities – dramatic gaps in involvement and satisfaction alike.⁵

Involvement in decision making and satisfaction with the process are predicted most strongly by the number of decision-support activities initiated by providers.



Statistical analyses were used to identify the strongest predictors of patient satisfaction and self-assessed involvement in major medical decisions. The results, detailed in Part B, find that involvement in decision making and satisfaction with the process are predicted most strongly by the number of decision-support activities that providers initiated – key results because they validate the importance of these activities in successful decision making.

The number of decision-support activities initiated by caregivers is not the only factor in the equation. Involvement in decision making also is predicted by providers' simply encouraging patients to take an active role in their care, as well as by patients' connectedness, that is, their sense that someone at their healthcare facility knows them well.

Patients' satisfaction with the decision-making process also is independently predicted by other factors in addition to the level of decision support provided. These include the strength of the patient-provider relationship, as measured by factors such as whether patients think their providers care about them personally, the quality of their communication and how much of a say patients feel they have in decisions about their care; as well as by the extent of patients' use of communication technology for health-related purposes, which includes text-messaging and e-mail communication with providers and use of the internet to seek health information.

These findings suggest ways forward. Supporting patients with multiple options and clear information about risks and benefits, eliciting their preferences, making room to discuss these goals and enhancing patient-provider relationships and communication more generally all pave the way to greater patient involvement at the critical point of major medical decisions.

endnotes

- 1 Respondents were asked: "In the past 12 months have you faced a major medical decision, or not?"
- 2 All differences in results described in this report have been tested for statistical significance.
- 3 Low-income Californians are defined as those with incomes less than 200 percent of the federal poverty level (FPL). Higher-income Californians are those with incomes of 200 percent of the FPL or more. This survey included a total of 498 respondents in the higher-income group, of whom 98 had made a major medical decision in the previous 12 months.
- 4 It should be noted, as well, that previous studies have suggested that patients tend to over-report their actual involvement in decision making. See, e.g., Zikmund-Fisher et al. (2010) and Institute of Medicine (2012).
- 5 No statistically significant differences in satisfaction were observed based on whether or not a specialist was involved.

project overview

This Blue Shield of California Foundation survey extends research initiated by the Foundation in 2011 to study the healthcare experiences and preferences of low-income Californians, identify the motivators of patient satisfaction and engagement, explore receptiveness to alternative care models and uncover the key factors that contribute to successful patient-provider relationships.

The Foundation commissioned this research to better inform public policy and the implementation of the Patient Protection and Affordable Care Act (ACA). Specifically, two aims have motivated this project: First, to help healthcare facilities – particularly California's community health centers – successfully navigate the changes brought about by the ACA; second, to help identify the most effective ways of encouraging low-income patients and providers alike to embrace primary care redesign and ultimately move closer toward the goal of patient empowerment, based on the principles of patient-centered care and shared decision making.

The research produced *On the Cusp of Change: The Healthcare Preferences of Low-Income Californians* in 2011, followed by a pair of reports in 2012, *Connectedness and Continuity: Patient-Provider Relationships among Low-Income Californians* and *Empowerment and Engagement among Low-Income Californians: Enhancing Patient-Centered Care*. Most recently, in October 2013, the Foundation published *"Building Better Health Care for Low-Income Californians"* and *"Health Care in California: Leveling the Playing Field,"* the first two reports from the 2013 survey. The former focused on the role of information and communication in low-income Californians' relationships with their providers and their interest in alternative care and communication strategies; the latter, on strategies to bridge the gap in healthcare experiences between low-income and higher-income residents.⁶

Sampling, field work and data tabulation for the survey were carried out by SSRS/Social Science Research Solutions of Media, Pa. Interviews were conducted in English and Spanish on landline and cellular telephones from May 2 to June 8, 2013, among 1,018 Californians with household family incomes below 200 percent of the federal poverty level (FPL) and 498 with incomes at 200 percent of the FPL or more. The margin of sampling error is plus or minus 3.5 percentage points for the sample of low-income

respondents and 5 points for the higher-income sample, accounting for design effects.⁷ This report focuses on the subset of respondents who report having faced major medical decisions in the past year, including 211 low-income and 98 higher-income Californians. The error margins for these samples are 8 and 12 points, respectively.

The study was produced and analyzed by Langer Research Associates of New York, N.Y., after an extensive review of the relevant literature as well as discussions with a group of prominent researchers and practitioners in the field. They include Veenu Aulakh, M.S.P.H., Executive Director of the Center for Care Innovations; Rushika Fernandopulle, M.D., co-founder and CEO of Iora Health; Dominick Frosch, Ph.D., Professor of Medicine, University of California at Los Angeles and Associate Staff Scientist at the Palo Alto Medical Foundation's Research Institute; Boris Kalanj, Director of Programs at the California Health Center Safety Net Institute at the California Association of Public Hospitals and Health Systems; Sunita Mutha, M.D., Professor of Medicine, University of California at San Francisco (UCSF) and Director of the Center for the Health Professions; Ed O'Neil, M.P.A., Ph.D., F.A.A.N., Professor, Family and Community Medicine, USCF, and former Director of the Center for the Health Professions; Lyn Paget, M.P.H., Director of Policy and Outreach at the Foundation for Informed Decision Making; David Quackenbush, former Vice President of Member Services and Val Sheehan, M.P.H., Director of Development and External Relations at the California Primary Care Association; Ron Spingarn, Deputy Director of the California Office of Statewide Health Planning and Development; and Jane Stafford, former Managing Director of the Center for Care Innovations. 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. The Foundation in particular has a history of support for the state's community health centers through its Community Health Center Core Support Initiative and Clinic Leadership Institute offerings.

This research was directed by Gary Langer, president, and Julie E. Phelan, Ph.D., senior research analyst, of Langer Research Associates, with the assistance of Gregory Holyk, Ph.D., and Damla Ergun, Ph.D., research analysts. Data analysis was conducted by Phelan, and Phelan and Langer wrote the report. All comparisons of data have been tested for statistical significance. Langer Research Associates complies with the Code of Professional Ethics and Practices of the American Association for Public Opinion Research and the Principles of Disclosure of the National Council on Public Polls.

Questions on any aspect of the this study, and requests for further data analysis, should be directed to Crispin Delgado, Blue Shield of California Foundation, 50 Beale Street, 14th Floor, San Francisco, Calif., 94105-1819.

endnotes

- 6 See the “Building Better Health Care” report for four appendices that are not duplicated in this third report in the series: the literature review conducted for this study (Appendix A), a detailed description of the survey methodology (Appendix C), the full formatted survey questionnaire (Appendix E) and a list of references (Appendix F).
- 7 See Appendix A of this report for a topline data report and Appendix B for details of statistical modeling.

part a: shared decision making

This study is based on a subset of a random statewide sample of low-income Californians: The approximately two in 10 who say they've made a major medical decision in the past year.

For this group, the precepts of patient-centered care, particularly its focus on shared decision making, are particularly important. As the literature review associated with this study reports,⁸ while some situations (e.g., emergency care) may make dialogue difficult, almost every other healthcare decision likely would benefit from greater shared decision making,⁹ a process in which care providers and patients work together in aligning evidenced-based clinical approaches with patients' individual preferences to arrive at informed decisions. Indeed, many decisions are "preference-sensitive," meaning no treatment option is clearly superior to others and the patient should be allowed, even encouraged, to consider the tradeoffs among them.

Three essential conditions are recommended for patients to be able take a meaningful role in decision making. They need:

- To be provided with clear information about the pros and cons of the options under consideration in an unbiased, objective and complete manner;
- To consider how each option fits with their values, goals and concerns; and
- To have an interaction with their providers to identify the options that best incorporate their preferences into the final decision.¹⁰

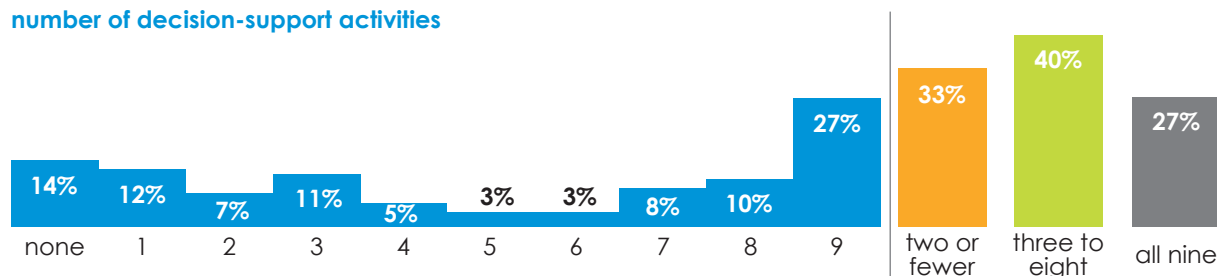
As with previous studies cited in the literature review, this study finds that in many cases these conditions are only partially being met.

section i: levels of decision support initiated by healthcare providers

Drawing from the literature, nine individual decision-support activities central to shared decision making were developed and tested in this survey: Whether providers asked patients about their goals, listened to their preferences and concerns, offered them additional information sources, discussed taking no action, gave them multiple options, described the benefits of these options, described the risks, gave patients time to consider the options in light of their preferences and goals and talked with patients about which option best aligned with their goals.¹¹

Among low-income Californians who report having faced a major medical decision in the past year, 27 percent report that their provider initiated all nine of these decision support activities. An additional 18 percent say their provider met seven or eight of the nine items on the list. Across the spectrum, 33 percent report two or fewer decision-support actions, including 14 percent who say their provider did not meet any of the shared decision-making criteria at all.

number of decision-support activities



Among individual items, 56 percent of those who faced a major decision report that their healthcare provider gave them multiple treatment options to consider. This is perhaps the most fundamental of the shared decision-making precepts tested, but for more than four in 10 low-income Californians, just one treatment option was presented, making the ultimate decision seem all but preordained.

About half of low-income Californians facing a major decision say their healthcare provider gave them clear information about the risks and benefits of multiple treatment options (52 and 48 percent, respectively). Half say they were given time to consider how these options fit in with their preferences and treatment goals; fewer than half, 44 percent, say their provider actually had a discussion with them about which of the options best matched their health goals.

decision-support activities

provider listened to patient's preferences/concerns	73%
provider asked about patient's goals	59%
provider explained how to get more information	55%
provider discussed taking no action	53%
provider gave multiple options	56%
if yes,	
clearly described benefits	48%
provider discussed best option given patient's goals	44%
clearly described risks	52%
gave time to consider preferences and goals	50%
average across items	54%
average # of decision-support items	4.9



Four in 10 of those facing a major medical decision say their provider did not ask about their healthcare goals.

Among the other decision-support activities tested:

- Nearly three-quarters, 73 percent, say their providers listened to their preferences and concerns before a decision was made, making this the single most-reported type of decision support. However, that leaves 27 percent of low-income Californians who faced a major medical decision without having this kind of basic discussion. Moreover, a third of those who report that their preferences and concerns were heard also say they were not provided with multiple treatment options to consider, suggesting these patients may have been less than fully informed when speaking with their provider.
- Six in 10 report that their healthcare provider asked them their healthcare goals before the decision was made. That leaves a substantial four in 10 whose goals were not explored.
- Fifty-five percent say their provider told them how to get more information. Again, though, 25 percent of these patients were not given multiple treatment options to consider in the first place – perhaps rendering information seeking a more daunting and less fruitful task.
- Fifty-three percent say their provider explicitly discussed the possibility of not taking any action at all. As the literature suggests, this option often is overlooked when major medical decision discussions take place. This research finds that for 45 percent of patients, providers did not present such a possibility.

Each of these nine steps advances a fully informed, patient-focused decision-making process. Yet none of the individual support actions is universally provided, and relatively few patients, as noted, report that their

provider has taken all of them. Working to increase the number of decision-support activities undertaken by healthcare providers not only can result in patients making more informed decisions that align with their overall healthcare goals, but, as described below, also can have a sizable impact on patients' ultimate assessment of their decision-making experience.

section ii: satisfaction, information and involvement in decision making

Despite substantial shortfalls in decision-support activities, more than eight in 10 patients report having been involved in the decision with their providers and being satisfied with the process. That result echoes previous research, in which patients paint a rosier picture of their involvement than the level of their decision support suggests.¹²

This divergence – substantial overall satisfaction and self-assessed involvement, despite low actual support and engagement – need not be seen as contradictory, nor is it comforting. Patients' unfamiliarity with the precepts of patient-centered care and shared decision making may mean that their expectations for the decision-making process are low. If it's outside their experience to be given multiple treatment options to consider, to be informed of the risks and benefits of each option and to have discussions with their providers about their healthcare goals and preferences, patients may simply be unaware of what they're missing.

Further, positive ratings are broad, but could be deeper. Eighty-one percent of low-income patients who faced a major medical decision in the past 12 months report that, regardless of the medical outcome, they were at least somewhat satisfied with the decision-making process. Fewer, six in 10 were “very” satisfied; the rest, “somewhat” satisfied, indicating (along with the 18 percent dissatisfied) room for improvement.

Eighty-three percent say they were at least somewhat involved in the decision, including 57 percent who report being “very” involved – again leaving many for whom feelings of involvement can be increased.

Clearly there is a desire for even greater involvement than currently is self-reported. A nearly unanimous 94 percent of these patients say they wanted to be involved in the decision-making process. That includes 75 percent who wanted to be very involved, compared with the 57 percent who say they actually had that level of involvement.

Underscoring that result with crosstabulated data, a less-than-ideal 63 percent of low-income patients report having had the amount of involvement that they desired in their major medical decision. Three in 10 wanted to be more involved; 8 percent, less so.

An assessment of how much information patients received to support their decision suggests the desirability of greater effort here as well. Thirty percent report having received a great deal of information from their providers to help inform the decision. Thirty-two percent received “a good amount” of information; more than another third, 37 percent, were given less information.

section iii: the role of patients’ own preferences

Patients who recently faced a major medical decision were asked what influenced their decision the most and who they felt made the ultimate decision. Both results provide further insight into the current state of shared decision making among low-income Californians.

From a list of options – personal preferences, recommendations from providers, suggestions from friends or family, financial considerations or something else – just 26 percent said their personal preferences were the determining factor in the decision. Thirty-two percent mainly relied on the recommendation of their providers; 17 percent relied on the advice of family or friends, and as many say financial considerations were the main factor.

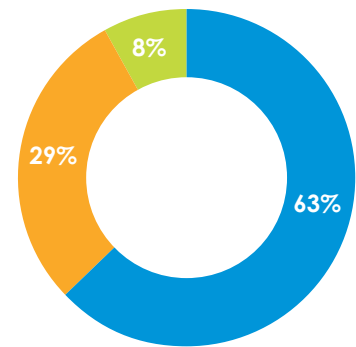
A related question asked patients whether they felt they ultimately made the decision (40 percent say so), they shared in the decision making equally (39 percent) or their providers ultimately made the decision (21 percent).

Notably, among those who say they had input into the final decision (either alone or in tandem with their providers) just 28 percent also say their final decision was most influenced by their personal preferences. More than three in 10 instead say their providers’ recommendation influenced their decision the most, and an additional three in 10 say either family and friends, or financial considerations, weighed most heavily on their decision. Even when patients say they have a role in the ultimate decision, personal preferences rarely are the driving force.

In sum, most patients feel they made or shared in the ultimate decision and feel satisfied and involved in the process – yet at the same time far fewer report that their personal preferences drove the decision, and most describe a decision-making process that strays from the ideal.

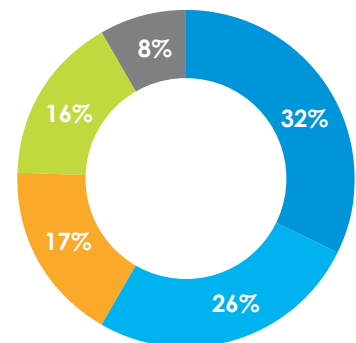
Many patients who have yet to experience substantial decision support see a less collaborative process as satisfactory, if not strongly so. Therefore, while the process can benefit from efforts to encourage providers to engage in more decision support, patients also may benefit from greater information about what they can and should expect of their providers when faced with a major medical decision.

involvement vs. desired involvement



- had desired level of involvement
- wanted more involvement
- wanted less involvement

main factor in decision making



- provider's recommendation
- personal preference
- family/friends
- financial considerations
- something else

section iv: differences by income in the decision-making process

The survey sampled higher-income Californians as well as low-income residents for purposes of comparison. It finds that those with higher incomes (200 percent or more of the federal poverty level, or about \$47,000 a year for a family of four) are equally likely as low-income Californians to have faced a major medical decision in the past year, and experienced about the same number of decision-support activities – 5.2, on average, of the nine tested in this survey.



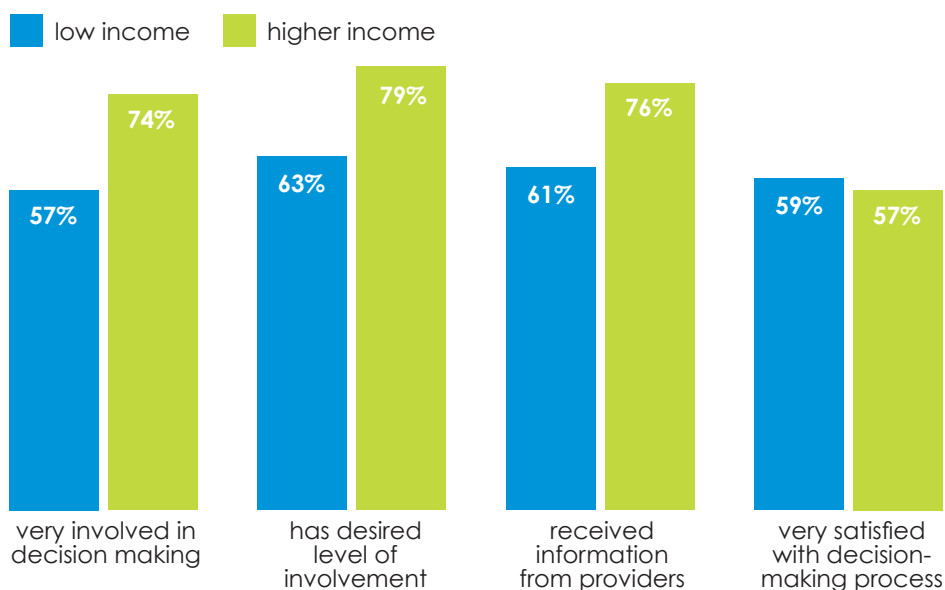
Even when patients say they have a role in the ultimate decision, personal preferences rarely are the driving force.

While the number of decision-support activities is the top predictor of patient engagement and satisfaction with decision making, other factors also independently predict these outcomes, as detailed in Part B. Those include positive patient-provider relationships and connectedness, defined as the sense that someone at your care facility knows you pretty well. Both of these are more prevalent among higher-income Californians than they are among low-income patients.¹³

It follows that higher-income Californians can be expected to be more engaged in the decision-making process, even with their comparable lack of decision supports. This is the case: Higher-income patients are 17 percentage points more likely to report being very involved in the decision (74 vs. 57 percent), 16 points more likely to report that their involvement matched their desired involvement (79 vs. 63 percent) and 15 points more likely to feel they received at least a good amount of information from their provider to help inform their decision (76 vs. 61 percent).

Higher-income patients also are 10 points more likely to be satisfied with the decision process overall – but no more likely to be “very satisfied” with it, indicating that this group, too, stands to benefit from increased use of decision-support activities.

differences by income group



endnotes

- 8 See the literature review, Appendix A of "Building Better Health Care for Low-Income Californians," Blue Shield of California Foundation, October 2013.
- 9 See Krumholz, H. M. (2010). Informed consent to promote patient-centered care. *Journal of the American Medical Association*, 303, 1190-1191.
- 10 See Fowler Jr., F. J., Levin, C. A., & Sepucha, K. R. (2011). Informing and involving patients to improve the quality of medical decisions. *Health Affairs*, 30, 1-8.
- 11 Providing multiple options is of particular importance, given its role as a precursor to discussing and considering those options in a way that advances the decision process.
- 12 Zikmund-Fisher et al. (2010), for example, reported that across nine common medical decisions examined, 80 percent or more of respondents felt that they had made the decision or shared in the decision-making process with their provider. At the same time, many fewer reported having had a discussion of the cons of a given treatment, and in five of six non-surgical decisions, majorities indicated that they had not been asked their preference. A 2012 Institute of Medicine discussion paper, *Communicating with Patients on Healthcare Evidence*, reported double-digit discrepancies between patients' desires and their experiences in various items, including having providers explain risks and discuss no treatment as an option.
- 13 See "Health Care in California: Leveling the Playing Field," Blue Shield of California Foundation, November 2013.

part b: predicting satisfaction and engagement in decision making

Understanding the factors that most strongly predict involvement and satisfaction with major medical decision making offers insights into how practitioners can best achieve these outcomes. This is evaluated through regression modeling, a statistical technique used to evaluate the independent predictors of an outcome while holding other factors constant.

This section first describes a model conducted to predict patients' self-reported involvement in decision making, then a separate regression predicting their satisfaction with the process. These and other models are detailed further in Appendix B of this report.

section v: predicting involvement in decision making

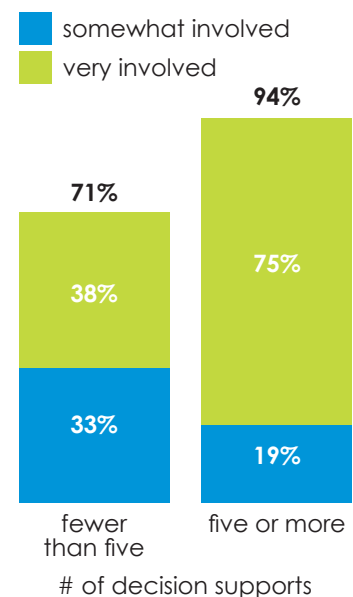
Patients' assessments of their involvement in the decision-making process are strongly predicted by the number of decision-support activities that their providers initiated. The differences are sharp: As noted in the executive summary, those whose providers engaged in at least five of the nine decision-support activities are 23 points more likely to say they were involved in the decision-making process and a broad 37 points more likely to say they were "very" involved, compared with those who were provided with fewer decision supports.

Self-reported involvement in decision making also is predicted by providers encouraging patients to take an active role in decisions about their care. Holding other factors constant, patients who say this occurs also are more likely to have been involved in their major medical decisions. As found in previous reports, this result confirms that simple encouragement effectively increases patients' engagement in their care.

key predictors of self-assessed involvement in decision making

- » number of decision-support activities caregivers provide
- » providers' encouragement of patients to take an active role

involvement in the decision-making process



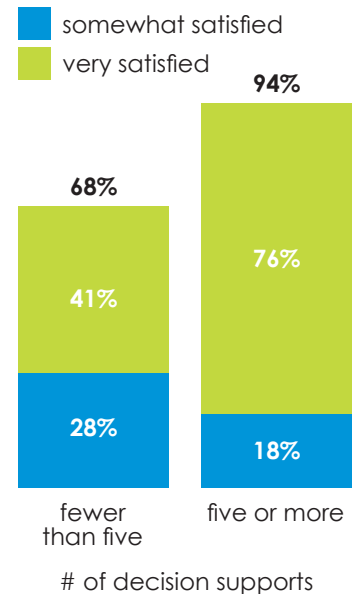
Among less-strong predictors,¹⁴ a notable factor is connectedness, meaning the patient's feeling that someone at his or her healthcare facility "knows you pretty well." Among patients who report this sense of connection, seven in 10 felt they were very involved in their major medical decision. Among those who lack connectedness, that falls to fewer than half, 46 percent.

section vi: predicting satisfaction with the decision-making process

After the evaluation of involvement, a separate regression predicts patients' satisfaction with the decision-making process. The two key predictors of satisfaction are the number of decision-support actions the provider initiated and the quality of the patient-provider relationship.¹⁵ Providers who meet these criteria can substantially improve patients' satisfaction with major medical decision making.



satisfaction with the decision-making process



key predictors of satisfaction with major medical decision making

- » number of decision-support activities
- » strength of the patient-provider relationship

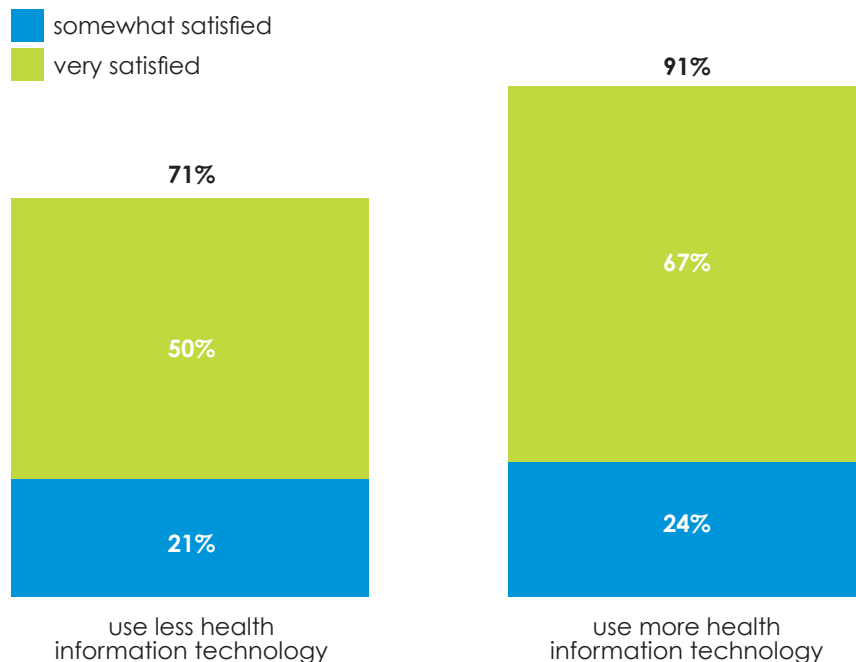
Crosstabulated data clearly illustrate the effect of decision-support activities. Among low-income patients who say their providers met at least five of the nine shared decision-making criteria, satisfaction is a near-universal 94 percent, and 76 percent report being "very" satisfied with the decision-making process. Among those who say their provider met four or fewer of these criteria, this drops sharply – by 26 and 35 points, respectively, to 68 and 41 percent.

As noted, having a strong patient-provider relationship also predicts satisfaction with the decision-making process. This finding underscores the importance of clear communication, accessible information and provider encouragement in patient engagement, confirming the findings of previous Foundation reports.

There are additional, albeit less strong, predictors of satisfaction with the decision-making process.¹⁶ The most informative of these is the extent to which patients currently use health information and communication technology, such as communicating with their providers via text-messaging or e-mail or using the internet to obtain health information or advice.¹⁷ While these activities are uncommon in general among low-income Californians, those who report having used more health information and communication technology tools report greater satisfaction with the decision-making process.

Dividing the population into groups that have used fewer vs. more information technology tools demonstrates this effect. Patients who use little to no health information technology are 20 points less apt to be satisfied with the decision-making process than more avid users, 71 vs. 91 percent, including 17 points less apt to report being “very” satisfied, 50 vs. 67 percent.

satisfaction with the decision-making process



Health information technology tools facilitate information gathering or communication between patients and providers. The fact that their use predicts satisfaction with the decision-making process shows that technology can be used to aid patients facing major medical decisions, as well as to augment patient-provider relationships and the transfer of knowledge more generally.

endnotes

- 14 Here and below, “less strong” predictors are statistically significant at $p < .10$ rather than $p < .05$.
- 15 The patient-provider index, detailed in the Foundation’s “Building Better Health Care” report of October 2013, is based on measurements including the extent to which patients feel their providers care about them personally; the frequency with which they feel their providers explain things in a way they can understand and ask them if they have any questions or concerns; how comfortable they feel asking their provider questions, telling providers about health information they’ve obtained from external sources and telling providers when they disagree with their recommendation; how simple or complicated they feel the health information they’ve received from their providers has been; and how much of a say they feel they have in decisions about their health care.
- 16 Gender and health status are also less-strong predictors of satisfaction, with men and those in better health reporting greater satisfaction with the decision process than women and those in worse health.
See Appendix B.
- 17 Elements of the health information technology index include use of the internet or a smartphone to access health or wellness websites or applications; use of websites or smartphone applications to look for information about a medical problem; looking online for information or advice about dieting, nutrition or exercise; going online to track health, exercise or nutrition information; looking online for support or advice from other people with similar health issues; use of the internet to share a personal health experience with others or read about someone else’s experiences; use of the internet to receive automatic health messages or reminders; receiving phone calls, e-mails or text messages from a care facility; and being able to e-mail or text message care providers.

part c:

conclusions and recommendations

Many healthcare providers in California do not initiate all or even most of the steps recommended to encourage patient involvement in major medical decisions. Several reasons are possible. Providers may be unfamiliar with shared decision-making precepts, or (as the literature suggests) resistant to them. Limited time and resources may be a factor. So may a perception among providers that patients themselves are reluctant to take a more active role.

Regardless, the data show that many patients who've faced a major decision desired a higher level of involvement than they actually obtained. And the benefits of engagement are clear: As providers give their patients more information and opportunities to participate in major decisions, patient involvement and satisfaction sharply rise.

Satisfaction with the process also is bolstered by strong patient-provider relationships and the use of health information and communication technology, two factors previously identified as predictors of patient engagement overall.

This study adds to previous findings by establishing the benefits of greater efforts to provide decision-support activities to patients facing major medical decisions – offering multiple treatment options, discussing the risks and benefits of those options, introducing the possibility of taking no action, learning patients' concerns, asking about their goals, creating time for them to consider their preferences and discussing their best choices. These decision-support activities are shown here to be the single strongest predictor of patients' involvement in major medical decision making – and in their satisfaction with that critical process.

appendix a – topline results

This appendix provides complete question wording and topline results for data included in this report on the 2013 Blue Shield of California Foundation survey.

*= less than 0.5 percent

1z-44 previously released.

45. In the past 12 months have you faced a major medical decision, or not?

		Yes	No	No opinion
6/18/13	All	19	81	*
	<200% FPL	19	81	*
	200%+ FPL	18	82	0

For the next few items, we ask that you think about the last major health decision you faced and answer each question to the best of your ability. There are no right or wrong answers.

46. (IF FACED MAJOR DECISION IN PAST 12 MONTHS, Q45) Regardless of the medical outcome, overall, how satisfied or dissatisfied were you with the decision making process – were you very satisfied, somewhat satisfied, somewhat dissatisfied or very dissatisfied?

		Satisfied			Dissatisfied			No opinion
		NET	Very	Somewhat	NET	Somewhat	Very	
6/18/13	All	87	58	30	13	7	5	*
	<200% FPL	81	59	22	18	10	8	*
	200%+ FPL	91	57	34	9	5	4	0

47. (IF FACED MAJOR DECISION IN PAST 12 MONTHS, Q45) How involved were you in the decision-making process – very involved, somewhat involved, not so involved or not involved at all?

		Involved			Not involved			No opinion
		NET	Very	Somewhat	NET	Not so	At all	
6/18/13	All	88	69	20	12	8	4	0
	<200% FPL	83	57	26	17	9	8	0
	200%+ FPL	91	74	17	9	7	1	0

48. (IF FACED MAJOR DECISION IN PAST 12 MONTHS, Q45) Regardless of your actual level of involvement, how involved would you have liked to have been in the decision-making process – very involved, somewhat involved, not so involved or not involved at all?

		Involved			Not involved			No opinion
		NET	Very	Somewhat	NET	Not so	At all	
6/18/13	All	96	79	18	3	3	*	1
	<200% FPL	94	75	19	4	3	1	2
	200%+ FPL	97	80	17	3	3	0	0

49. (IF FACED MAJOR DECISION IN PAST 12 MONTHS, Q45) Overall, how much information did you receive from healthcare providers, if any, to help inform the decision – a great deal of information, a good amount, just some or not much?

		Lots of information			Little/no information				No opinion
		NET	Great deal	Good amount	NET	Just some	Not much	None (vol.)	
6/18/13	All	71	41	30	25	14	11	4	0
	<200% FPL	61	30	32	37	22	15	2	0
	200%+ FPL	76	46	30	20	11	10	4	0

50. (IF FACED MAJOR DECISION IN PAST 12 MONTHS, Q45) And again, thinking about the last major healthcare decision you faced. Before a decision was made, did a healthcare provider [ITEM], or not?

6/18/13 - Summary Table

	Yes	No	No opin.	Not given options
a. Give you multiple options to consider				
All	62	36	1	NA
<200% FPL	56	43	1	NA
200%+ FPL	65	34	1	NA
b. (IF GIVEN MULTIPLE OPTIONS) Give you clear information about the benefits of these different options				
All	49	14	1	36
<200% FPL	48	8	1	43
200%+ FPL	49	15	1	34
c. (IF GIVEN MULTIPLE OPTIONS) Give you clear information about the risks of these different options				
All	55	7	2	36
<200% FPL	52	4	1	43
200%+ FPL	56	8	3	34
d. Discuss the possibility of not taking any action at all				
All	57	41	1	NA
<200% FPL	53	45	2	NA
200%+ FPL	59	40	1	NA

	Yes	No	No opin.	Not given options
e. Ask you what your healthcare goals were				
All	55	45	1	NA
<200% FPL	59	40	1	NA
200%+ FPL	53	47	*	NA
f. (IF GIVEN MULTIPLE OPTIONS) Give you enough time to consider how each option fit in with your preferences and goals				
All	55	7	1	36
<200% FPL	50	6	1	43
200%+ FPL	57	7	1	34
g. Listen to your preferences and concerns				
All	79	21	1	NA
<200% FPL	73	27	*	NA
200%+ FPL	82	18	1	NA
h. (IF GIVEN MULTIPLE OPTIONS) Have a discussion with you about which option best matched your preferences and goals				
All	52	10	2	36
<200% FPL	44	12	1	43
200%+ FPL	55	8	3	34
i. Tell you how to get more information				
All	52	47	1	NA
<200% FPL	55	43	2	NA
200%+ FPL	50	50	1	NA

51. (IF FACED MAJOR DECISION IN PAST 12 MONTHS, Q45) Ultimately, what factor influenced this decision the most – was it (your personal preferences), (the recommendations from healthcare providers), (the recommendations from family or friends), (financial considerations) or something else?

		Personal prefs.	Providers	Family	Finances	Other	No opin.
6/18/13	All	30	37	12	8	11	2
	<200% FPL	26	32	17	16	9	1
	200%+ FPL	33	40	8	4	12	2

52. (IF FACED MAJOR DECISION IN PAST 12 MONTHS, Q45) What healthcare provider was mainly involved in this decision – was it someone at (your usual place of care/the last place you went for care), a specialist or both equally?

		Usual/last place	Specialist	Both equally	No opinion
6/18/13	All	32	34	33	1
	<200% FPL	28	28	43	1
	200%+ FPL	33	38	28	1

53. (IF FACED MAJOR DECISION IN PAST 12 MONTHS, Q45) For the most part, who do you think ultimately made the decision – (a healthcare provider), (you) or did you share in the decision making equally?

		Provider	You	Both equally	No opinion
6/18/13	All	21	40	39	*
	<200% FPL	21	40	39	1
	200%+ FPL	21	41	39	0

54-59 previously released.

appendix b – statistical modeling

Part B of this study refers to regression models used to measure the predictors of key outcomes of the decision-making process among low-income Californians. This appendix details these statistical analyses.¹

A regression measures the independent strength of the relationship between predictor variables (such as attitudes and demographics) with a posited outcome, known as the dependent or outcome variable, such as, in the case of this study, self-reported involvement in decision-making process and satisfaction with this process.

While it does not establish causality, a regression reveals the strength of the relationship between a predictor (e.g., the number of decision supports provided) and the dependent variable (e.g., satisfaction with the decision-making process), with other predictors in the model held constant. While many variables may be related to a given outcome, a regression identifies the extent to which each predictor explains unique variance in the dependent variable after adjusting for these other relationships.

These models include a count of the number of decision-support activities that were initiated. Since four of the activities tested are dependent on a patient's having been offered multiple treatment options, we ran the models with and without those four items included. The results were essentially identical in both cases.

Below we provide the results of the involvement and satisfaction models reported in this study. Three other models, though not covered in the report's narrative, are included as well.²

model 1: predicting self-assessed involvement in decision making

This model predicts low-income Californians' self-reported involvement in the decision-making process.

	Standardized coefficient (β)	Significance test (f)
Number of informed decision-making criteria met	.25	2.65**
Healthcare provider encourages patient to take an active role	.23	2.76**
Race/ethnicity: Latino	.18	1.82+
Connectedness with healthcare facility	.16	1.84+

Model $R^2 = .38$, $p < .001$

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

model 2: predicting satisfaction with the decision-making process

This model predicts satisfaction with the decision-making process among low-income Californians who've faced a major medical decision in the past year. Two of the key predictors are indices. The patient-provider index assesses the strength of the relationship and quality of communication between patients and their providers. The health information and communication technology index assesses the extent to which patients use a variety of technology-based tools for health information and communication.

	Standardized coefficient (β)	Significance test (<i>t</i>)
Number of informed decision-making criteria met	.28	2.99**
Patient-provider index	.26	2.50*
Self-reported health status	.17	1.92+
Health information and communication technology index	.17	1.85+
Gender: Male	.13	1.69+

Model $R^2 = .40, p < .001$

model 3: predicting decision-support activities

This model predicts how many of nine individual decision-support activities were provided by caregivers. As noted, the patient-provider index assesses the strength of the relationship and quality of communication between patients and their providers.

	Standardized coefficient (β)	Significance test (<i>t</i>)
Patient-provider index	.27	2.59*
Feel informed about health/health problems	.21	2.23*
Age	-.18	2.03*
Education	-.18	1.72+
Has team-based care	.14	1.74+
Uses a patient portal	.14	1.70+

Model $R^2 = .40, p < .001$

model 4: predicting perceived amount of information

This model predicts the amount of information low-income Californians facing a major medical decision say they received from providers in order to help inform the decision. This assessment was made before questions asking about specific details of the decision-making process (see Appendix A). As noted, the patient-provider index assesses the strength of the relationship and quality of communication between patients and their providers. "Usual provider involved in the decision" is a binary variable that indicates whether the decision-making process occurred either solely or jointly with the patient's primary care provider, vs. solely with a specialist.

	Standardized coefficient (β)	Significance test (t)
Number of informed decision-making criteria met	.34	3.89***
Patient-provider index	.23	2.34*
Feel informed about health/health problems	.15	1.68+
Usual provider involved in the decision	-.12	1.78+

Model $R^2 = .49, p < .001$

model 5: predicting the perceived final decision maker

This model predicts who the patient feels ultimately made the decision: themselves (either alone or in equal partnership with their provider) or their provider.

	Standardized coefficient (β)	Significance test (t)
Continuity with the same healthcare provider	-.26	2.51*
Number of informed decision-making criteria met	.23	2.21*
Healthcare provider encourages patient to take an active role	.18	1.98*
Connectedness with healthcare facility	.18	1.79+

Model $R^2 = .24, p < .05$

endnotes

- 1 For a full report of the survey methodology see Appendix C of "Building Better Health Care for Low-Income Californians," Blue Shield of California Foundation, October 2013.
- 2 All models control for demographic variables including race/ethnicity, language spoken at home, gender, age, marital status, employment status, education, income, internet access, cell-phone access and insurance status.

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