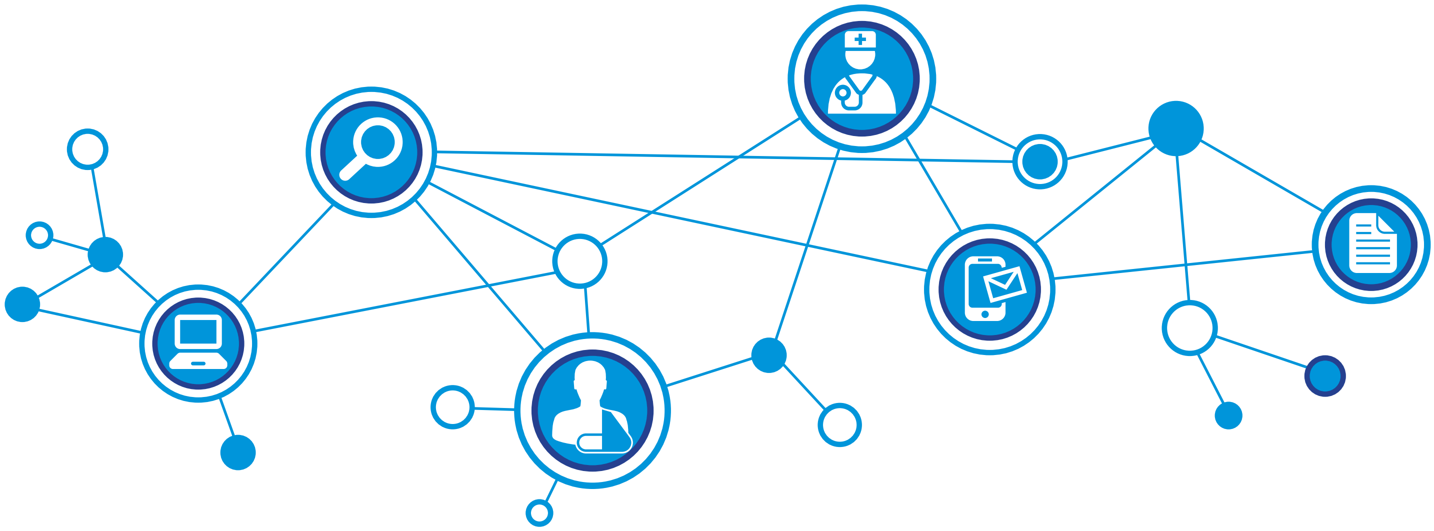
blue of california
foundation



building better health care for low-income Californians

October 2013

Langer Research Associates
SURVEY RESEARCH DESIGN • MANAGEMENT • ANALYSIS

introduction

The state of health care in America is changing very quickly. Appropriately, there are myriad efforts already underway around outreach, enrollment, and new health insurance coverage. Yet, while all this work takes place on the surface, underneath there are significant changes being made to the very architecture of our system. Prevailing provider shortages, calls for cost containment, and a broader and more varied patient population are forcing us to rethink and reshape the way that care is provided at the most basic level.

As we continue to make necessary adjustments in care delivery, the one constant we must not lose sight of is the patient. Input and engagement from patients will be critical at every step as we shift our system into 2014 and beyond.

Currently, we're seeing an emerging understanding of what patients want. However, there is still limited data to inform continued transformation based on true patient preferences, rather than predictions. We know that patients today are more technologically savvy, more empowered to seek information, and have more tools to access that information than ever before. The type of patient is also changing, with a diverse set of previously-underserved individuals entering into coverage, many for the very first time.

Yet, despite an increasingly dynamic patient population, very little – if any – of our health system's transformation to date has been informed by their experiences and expectations. This research contributes a deeper understanding of the healthcare needs of low-income Californians. Bringing a voice to these patients as "co-creators" in our redesign process will be vital to achieving a more substantive, affordable, high-quality system here in California and across the country.

Building upon previous surveys, this report goes further, and comes at a critical time of inevitable change in American health care. If we're going to deliver on our goals to lower costs while simultaneously improving health outcomes and the patient experience, we must commit to human-centered innovation and redesign. That means engaging, empowering, and ultimately understanding patients.

This may yet be the greatest test of our healthcare system – whether we can effectively bring patients into the conversation, instead of leaving the debate to politics, payers, and providers. We hope this report's findings bring us closer to this goal, and help illuminate the way forward.

Thanks to the team at Langer Research Associates for their time and effort in making this body of work possible.

In partnership,
Peter V. Long, Ph.D.
President and CEO

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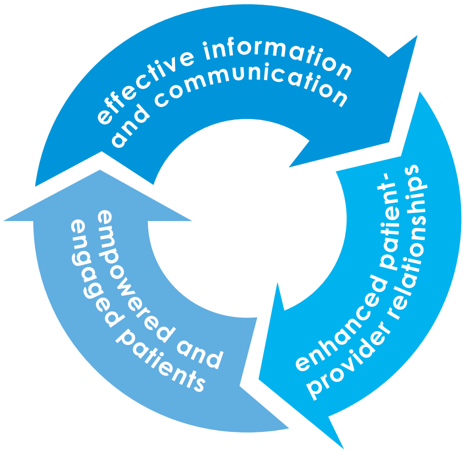
executive summary

Understanding patients' perspectives is a critical element of healthcare redesign. The "triple aim"[1] of enhancing care experiences, improving health outcomes and reducing costs relies on nurturing patients' engagement in their care and their openness to new care approaches. Those in turn require understanding how patients gather and use information and communicate with their providers – the foundation of successful healthcare experiences.

This report, the latest in a series from Blue Shield of California Foundation, focuses particularly on the experiences and attitudes of low-income patients in California.[2] It seeks to add their voices to the discussion, examining how these patients feel about their current communication with their healthcare providers, how they obtain health information, their interest in new information sources and communication methods – and how these inform their relationship with their providers and their care facilities more broadly, and their interest in new models of care.

The time is ripe for this research. Patient advocates and practitioners are focused ever more intently on realizing the ideals of patient-centered care and informed decision making. Advances in technology offer new opportunities for contact between patients and caregivers. And, as found in previous research, engaged patients are more apt to be satisfied and loyal ones – a key concern for safety net clinics[3] adjusting to the changes brought about by the Patient Protection and Affordable Care Act (ACA), as well as for the healthcare system overall in the transformation now under way.

This study's findings indicate ample room for healthcare facilities to improve the ways in which patients obtain and act upon information and communicate with their providers. And it finds that, when such efforts are present, they hold forth the prospect of sharply improved patient-provider relationships, a crucial milestone on the road to successful patient engagement.



Among the major findings:

- Successful communication between patients and providers produces a wide range of positive outcomes, including bolstering patients' satisfaction, trust in medical professionals, confidence and engagement in care decisions. Patients who have a stronger bond with their providers are a vast 43 percentage points more likely to feel they have a voice in their care, 35 points more likely than others to rate their quality of care positively and 26 points more strongly confident in their decision-making ability.

Information levels soar among patients enrolled in team-based care or healthcare navigator programs.

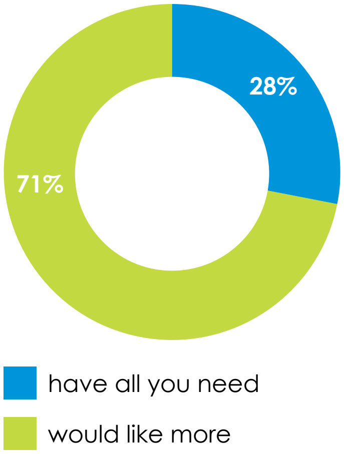
- A broad gap currently exists between the information patients possess and what they desire in order to make good medical decisions. Fifty-five percent of low-income Californians say they'd like more information for decision-making purposes – and if that information is clear and easily accessible, interest jumps to 71 percent.

- Self-reported information levels soar, and the perceived need for additional information declines, among patients who are enrolled in team-based care or healthcare navigator programs, indicating strong positive impacts of these emerging care models.[4] Patients enrolled in team-based care, for example, are a broad 19 points more likely than others to report feeling very informed about their health and 15 points less likely to feel they need more information in order to make good healthcare decisions.

- While current use is limited, there is broad interest in decision aids and internet-based patient portals alike – and when used, these resources are highly successful. Patient portal and decision aid users are more apt than non-users to feel very informed about their health, by 22 and 13 points, respectively. Among those who have and use portals, a nearly unanimous 92 percent find them useful. And among those who've been given a decision aid, a similarly high nine in 10 would use one again.

- Fewer than half of low-income Californians currently rely primarily on their care providers for their health information; as many rely on media sources (printed materials, television or the internet). Providers, however, are much more highly trusted.

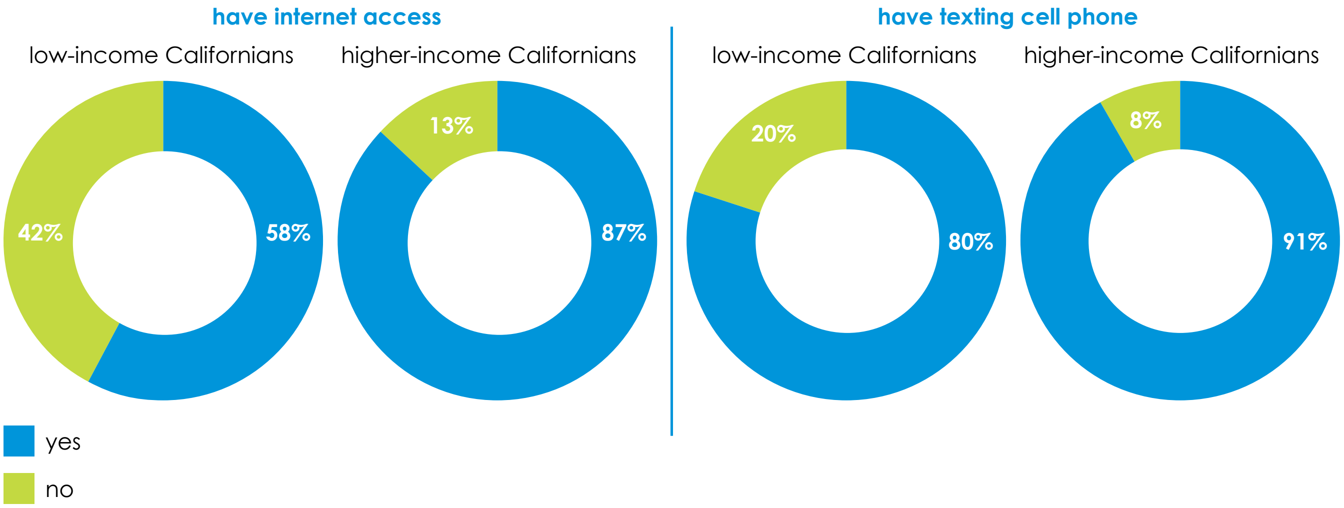
desire for clear, accessible information



- Alternative means of communication and information-gathering can enhance the role of care providers, rather than supplanting them. Use of a variety of technologies including the internet for health information, health-related smartphone applications and e-mailing or texting with care facilities are positively associated with successful patient-provider relations.

- Although relatively few low-income patients currently can communicate with their providers by text or e-mail (16 and 23 percent, respectively), 87 percent of those who do so find it useful – most of them, "very" useful. And among those who don't have these communication options, sizable majorities are interested.

There are challenges. The well-documented digital divide continues: Forty-two percent of low-income Californians lack access to the internet (compared with just 13 percent of higher-income residents). The divide narrows for cell-phone use, but still one in five lacks a text-messaging capable cell phone. The benefits of healthcare communication technology – smartphone applications, interactive websites, text or e-mail reminders and more – are lost to these offline or non-texting patients.



Yet in the areas available for improvement, the potential payoffs are substantial. Previous research has found that the extent to which patients feel well-informed about their health and health care largely predicts their broader healthcare experience, their empowerment (e.g., confidence and comfort asking providers questions), their engagement in their own care and their openness to team-based care and other alternative care models. This report moves the discussion ahead by offering insights on how the goals of well-informed patients and successful patient-provider relationships can be achieved.

health information, sources and trust

Well-informed decision making is still far from a reality for most low-income Californians; just 28 percent feel they have all the health information they need to make good medical decisions, assuming additional information is clear and easily accessible. Yet there are key differences across groups. As detailed in Part A of this report, patients are more likely to feel they have the information they need when they feel connected with their care facility, regularly see the same provider, use (or have used) alternative care models and tools or report a strong relationship and good communication with their provider.

It also helps, simply, for providers to be committed to patient involvement. Low-income Californians who say their healthcare provider encourages them to take an active role in their care are substantially more apt than others to feel very informed about their health generally and to say they have adequate information to make good healthcare decisions.

Medical professionals face competition in their traditional role as primary information sources. As noted, the survey finds that well fewer than half of low-income patients, 38 percent, rely on their providers as their top source of health information; as many primarily rely instead on media sources including the internet, television, books or magazines. And among those younger than age 40, the internet, TV and printed media supplant medical professionals as the primary source of health information by a substantial margin, 45 vs. 33 percent.

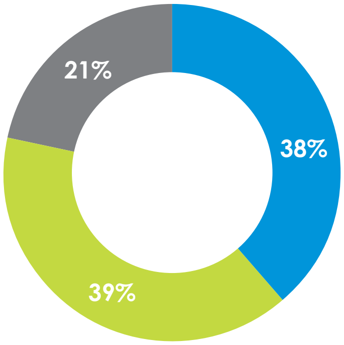
That's a potential problem, since trust in information is far higher when it comes from a medical professional than from other sources. The outcome, then, may be more patients getting information from sources they trust less – a potential obstacle to achieving the goal of well-informed, confident, participating patients.

Again, though, there are opportunities for progress. Both team care and health coaches bolster reliance on providers as primary sources of health information. So do continuity and connectedness, both shown previously to be key predictors (along with information) of patient empowerment and engagement. Patients who usually see the same healthcare provider (i.e., those with continuity of care) are 22 points more likely to rely on that provider as their primary source of health information, compared with those who see the same provider less often. Patients also are more apt to rely on their provider for information when they feel someone at their healthcare facility knows them (the definition of connectedness), as well as when providers explain things clearly, invite questions and encourage patients to be involved in their own care.

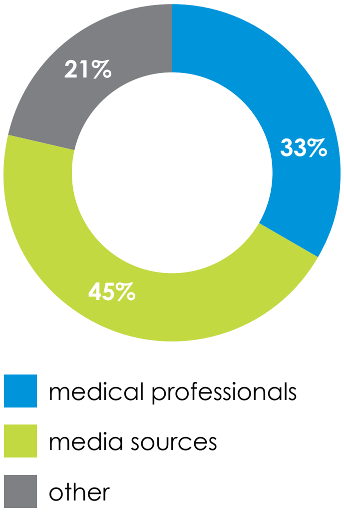
Team-based care and the use of health coaches bolster patients' reliance on providers as their primary sources of health information.

top source of information among

all low-income Californians



those age 19-39



communication, patient-provider relationships and health technology

While information is a necessary component of the shared decision-making process, communication and trust between providers and patients is key to making the relationship work.

As presented in Part B of this report, low-income Californians tend to have a positive relationship with their provider overall, although again with important differences among groups. The quality of patient-provider relationships suffers, for example, among those who don't primarily speak English or who lack insurance.

The importance of the quality of this relationship can hardly be overstated. As mentioned, those who report having a strong rapport with their providers are more likely than those with weaker bonds to feel very informed about their health, to be satisfied with the quality of care they receive at their facility and to trust the information provided by their doctors – all by more than 30-point margins. Indeed, there are almost no key outcomes that are not impacted by patients' perceived bonds with their provider.

Virtually every key outcome in terms of patient empowerment and engagement is predicted by the quality of patient-provider relationships.

Factors that contribute to a high-quality relationship between patients and providers include patients' perceptions that their provider encourages them to take an active role in their care, having as much of a say in health decisions as they desire and self-reported information levels. All three, therefore, should be areas of focus for community health centers and other care facilities.

Alternative communication approaches also show great promise in helping to improve patients' relationships with their providers. These models and tools – such as team-based care, decision aids, health coaches and online or smartphone-accessible health sites – enhance, rather than diminish, the critical connection between patients and their providers.

The digital divide, however, poses a problem – particularly in specific groups. While four in 10 low-income Californians overall lack internet access, that soars to 67 percent of Spanish-speakers, 63 percent of non-citizens, 62 percent of Latinas and 59 percent of those in only fair or poor health.

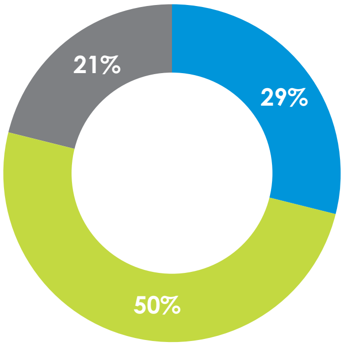
Further, among those age 50 and up, 59 percent lack internet access and 41 percent lack a text-capable cell phone – leaving this more vulnerable population particularly hard to reach with technology-based information and communications.

Among low-income Californians who do have internet access, 56 percent have used the internet for health-related reasons in general – 14 points lower than the number of higher-income residents who use the internet this way. Specific health-related uses, moreover, drop sharply. Anywhere from just 6 to 17 percent of low-income Californians with internet access have used websites or smartphone applications to look for information about a medical problem, find or track health data, obtain or share support or advice on a health experience or sign up for automated messages or reminders.

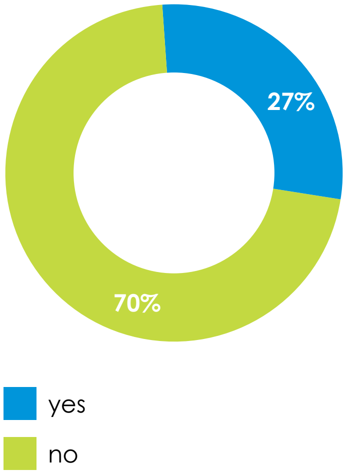
Direct, technology-based communications between patients and providers also are not yet widely in use. Among low-income Californians with text-capable phones, 11 percent receive text messages from providers or staff at their care facility; among those with internet access, 22 percent receive e-mails. More but still well short of most, 18 and 32 percent, respectively, say they can get their health questions answered via text or e-mail. (The percentages are much smaller when all low-income Californians are included, not just those with internet access or text-capable phones.) For comparison, 72 percent say their provider or care facility staff calls them by phone.

In terms of other information items, levels of use again are fairly low: Twenty-nine percent overall say their facility has a patient portal and 27 percent have been given decision aids (which can be delivered in printed, video or online formats).

facility has a patient portal



been given a decision aid



new healthcare models, resources and strategies

While use of technology-based information and communication tools is low, results detailed in Part C of this report reveal high levels of interest in these and other alternatives. Among those with online access, anywhere from 56 to 84 percent are interested in using (or already use) websites or smartphone applications for a range of health-related purposes.

There's broad interest, as well, in patient portals (i.e., secure, facility-run websites with patient information and communication tools) and in communicating with providers via text or e-mail. For example:

- While just three in 10 report that their facility has a patient portal, even fewer, 13 percent, can and do access it. Still, three-quarters of internet users are interested in using a patient portal, and among those who have done so, virtually all find it useful.

Anywhere from 56 to 84 percent of those with internet access are interested in using (or already use) websites or smartphone applications for health-related purposes.

- Just 11 and 22 percent of those with texting or internet access, respectively, say they currently receive text messages or e-mails from their provider, and only slightly more – 18 and 32 percent, respectively – say they can get questions answered via text or e-mail. Accounting for the widespread lack of internet and (to a lesser extent) texting access, this means that very few low-income Californians use such communication methods. That's unfortunate given that among those who do, 87 percent find them useful.

- Seven in 10 or more low-income Californians who have the necessary resources (i.e., internet access or a texting phone) but can't currently communicate with their provider via text or e-mail express interest in being able to do so.

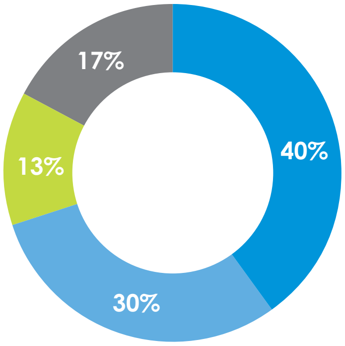
Each of these approaches represents a clear opportunity to engage patients in a way that enhances communication and information, thereby improving patient-provider relationships and, ultimately, increasing patient empowerment and engagement. It's worth noting, for example, that interest in communicating with providers by text or e-mail peaks among those who currently seek better communication, more information and greater clarity from providers than they now experience.

The desire for more health information is among the single strongest predictors of interest in alternative approaches including team-based care, health coaches and decision aids, as well as texting and e-mailing with providers. Those who have a strong relationship with their healthcare provider or who already use a variety of online health information resources, moreover, also are more open to trying new care paradigms.

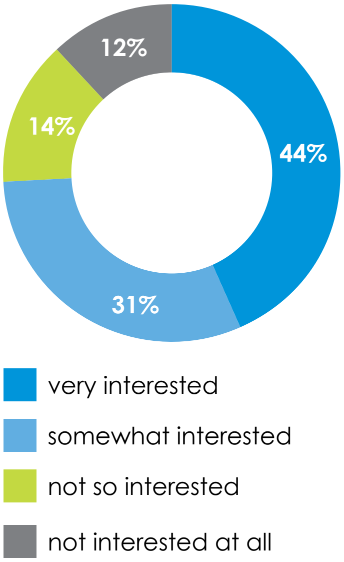
The success or failure of safety net clinics, and the healthcare system more broadly, depends as never before on empowering and engaging patients to be active, informed partners in their own health care. The route to that goal requires the adoption of alternative care, communication and information strategies by facilities and patients; it also requires seeking patients' input in the redesign process itself, an aim this survey seeks to advance. The end result is no less than greater cost-effectiveness and better health outcomes alike.[6] This report finds that patients are ready and eager for a range of new approaches – and that adopting them will help pave the way to a far more patient-engaged model of healthcare delivery.

% interested in getting health questions answered by: [5]

texting with provider



e-mailing with provider



endnotes

1 For details on the Triple Aim framework, developed by the Institute for Healthcare Improvement, see: http://www.ihi.org/offerings/Initiatives/TripleAim/Pages/default.aspx

2 Low-income patients are defined as those with household incomes of 200 percent or less of the federal poverty level. A statewide sample of higher-income Californians also was interviewed, for comparative purposes.

3 The term “safety net clinics” in this report refers to community, hospital and private clinics focused on serving the low-income population.

4 A health coach or healthcare navigator was defined as follows: “…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.” Team-based care was defined as follows: “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.” See questions 8 and 10, respectively, in the full questionnaire, Appendix E.

5 Results in these charts are among respondents with texting or internet access who cannot currently text or e-mail their providers, respectively.

6 See, e.g., the Institute of Medicine’s summary of its February 2013 Roundtable on Value & Science-Driven Health Care: “Prepared, engaged patients are a fundamental precursor to high-quality care, lower costs, and better health.” http://www.iom.edu/Activities/Quality/VSRT/~/media/Files/Report%20Files/2013/Partnering-with-Patients/PwP_meetingsummary.pdf

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 factors that best inform successful patient-provider relationships.

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 community health centers identify the most effective ways of encouraging patients and providers alike to embrace primary care redesign and ultimately move closer toward the goal of patient empowerment, as envisioned in 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*.

Like those studies, this year's survey is based on telephone interviews with a representative, random statewide sample of Californians age 19 to 64 with household incomes less than 200 percent of the federal poverty level (FPL), or about $47,000 a year for a family of four. For the first time this year, the survey also includes a representative sample of higher-income Californians, for comparative purposes.

As in past years, sampling, survey field work and data tabulation 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 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, the first of three in 2013, builds on results in the 2012 reports showing the strong role of patient information in predicting critical aspects of empowerment (e.g., confidence and comfort asking questions) and engagement (i.e., the amount of say patients have in their healthcare decisions). Among the research questions addressed in this study:

- Do low-income Californians feel that they have the information they need to make good healthcare decisions, or do they desire more? Where do they obtain their health and healthcare information now, and what additional information sources are of interest? How much trust do they have in different information sources?

- What role does communication technology, such as texting and e-mailing, play in enhancing patient information and patient-provider communication? How well do patients and providers communicate now, and what are the most important predictors of successful patient-provider relationships? How interested are patients in being able to communicate with providers and staff via e-mail or text when they have a non-urgent health question?

- How much interest is there in new communication strategies and information sources, including internet-based resources and smartphone applications that can help answer questions about medical problems, provide advice on dieting and nutrition, allow patients to share or read about similar health experiences, find support from others with similar health problems, automatically send patients reminders or information and/or track health, exercise or nutrition information? What experience do patients have with other new approaches such as patient portals and decision aids?

- Beyond its impact on information and patient-provider communication, how might technological advancements impact primary care redesign? Finally, how can the big three factors of information, patient-provider communication and information technology help promote openness to alternative strategies for care delivery?

While some comparisons of the healthcare experiences and attitudes of low- and higher-income Californians are included, most of those results will be explored in a second report. A third report will examine respondents' recent experiences with major medical decision making.

The study also allows for differentiation among low-income Californians on the basis of where they receive their care, e.g. from community clinics, private clinics, Kaiser Permanente or other private doctors' offices. Few differences by facility type were relevant to this report, but others will be explored in the forthcoming report on experiences of care.

The study was produced and analyzed by Langer Research Associates of New York, N.Y., after an extensive review of the relevant literature, reported in Appendix A and listed in Appendix F, as well as discussions with a group of prominent researchers and practitioners in the field. They include 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 Interim 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 and Veenu Aulakh, M.S.P.H., Managing and Associate Directors of the Center for Care Innovations. We are grateful for their insights.

Blue Shield of California Foundation (BSCF), 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 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 adheres to 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.

endnotes

7 See Appendix C for full methodological details, Appendix B for the topline data report and Appendix E for the full questionnaire.

sections guide

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

part a: health information

- section i: interest in information. How informed patients feel about their health and whether or not they feel they have the information they need to make good health decisions. The roles of health status, quality of care, frequency of visits and socioeconomic status in feeling informed and wanting more information.

- section ii: information and alternative care models. The ability of alternative care models – health coaches, team-based care, decision aids and online- and phone-based tools – to positively impact patients' information levels.

- section iii: primary sources of health information. Where patients get most of their health information and the degree to which they rely on healthcare providers vs. media sources. Differences in health information sources by demographic groups, quality of care and patient-provider relationships.

- section iv: trust in information sources. Trust in doctors, health websites, friends/family and other sources of health information. The divergence between use of sources and trust in them. Influences on trust in information from healthcare providers.

part b: communication and technology

- section v: current patient-provider relationships. Patients' perceptions of the quality of their relationship and communication with their providers.

- section vi: the importance of patient-provider communication. The central role of patient-provider communication in patients' health information needs, desires and trusted sources and the reciprocal importance of communication in quality patient-provider relationships.

- section vii: differences in the patient/provider index. Demographic patterns in patient-provider relationships. An examination of the key independent predictors of the quality of these relationships.

- section viii: communication and information tools. Current use of online and text-based communication and information tools including websites, applications, e-mails and texts for health-related purposes.

part c: openness to new care models and communication strategies

- section ix: interest in internet and smartphone application resources. Current levels of interest in using online and application-based health information and communication tools. A summary of the key drivers of interest in using health-related technological tools. A look at patient portals: access, perceived utility and interest.

- section x: interest in texting and e-mailing care providers. Interest in communicating with care providers via e-mails and texts. The demographic, attitudinal and experiential factors that influence these preferences.

- section xi: interest in alternative care and communication approaches. Key predictors of openness to alternative care and communication strategies, including team-based care, healthcare navigators, patient portals, decision aids and e-mail- and text-based communications with providers.

In addition to conclusions and recommendations, the report includes appendices presenting a review of the relevant literature consulted for this project; topline results for the questions included in this report; a detailed description of the survey's sampling methodology, field work, data processing, weighting, response rate information and procedures for healthcare facility identification; statistical modeling used in this study; the full questionnaire; and references.

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, tel. 415-229-5628, e-mail crispin.delgado@blueshieldcafoundation.org.

part a: health information

Healthcare providers increasingly are seeking to encourage a sense of partnership in patient-provider relationships, in which each side contributes valuable insights, preferences and goals, that, when fully discussed, optimize healthcare decisions.

This process of informed decision making envisions patients taking shared responsibility for their well-being. Less simple than it sounds, it requires bolstering patients' confidence, providing them with clear and reliable health information and taking advantage of communications technology to deliver that information efficiently, effectively and in ways they wish to receive it.

The potential rewards are great. In addition to the goal of improved outcomes at the heart of patient-centered care, previous research has found that informed and efficacious patients express greater satisfaction with their care and greater loyalty to their care provider.[8] And promising paths to increased patient engagement offer the additional benefit of increased efficiency in healthcare services and potentially improved health outcomes.

But there are difficulties in producing engaged, informed and invested patients – and they're heightened among the low-income safety net patients who are the focus of this report. Socioeconomic factors limit their access to healthcare providers and technology-based health information resources; cultural norms and language barriers also are among the obstacles to patient-provider communication.

Regardless, as described in the literature review,[9] easily accessible and understandable health information is essential to achieving active full participation of patients in their care. The first part of this report therefore focuses on patients' desire for greater information, their self-assessed current information levels, where they get information, their trust in information sources and their feelings about seeking out information on their own.

section i: interest in information

Despite widespread recognition among healthcare professionals of its importance, clear, easily accessible information has yet to make its way into the hands of many low-income patients. This survey finds that just 44 percent of low-income Californians feel they have all the information they need to make good health decisions.[10] And among the 55 percent who'd like to know more, more than half would like "a lot" more information about their health.

Moreover, even among those who feel they already have sufficient information, a substantial number would be interested in more health information if it were easier to find and understand than it is now. That leaves just 28 percent of low-income Californians who feel that, regardless of its accessibility, they have all the health information they need.

the role of health status and quality of care

Health status and healthcare experiences play a prominent role in low-income Californians' interest in more information. Patients who report being only in good, fair or poor health are more apt than those in excellent or very good health to want more information to aid their decision making (58 vs. 49 percent), likely because they face additional, or more complicated, health decisions.[11] Those in worse health also are 18 points less likely than others to feel very informed about their health, 37 vs. 55 percent, again likely because of their greater information needs.

Another sharp difference in the desire for greater information rests on patients' perceived quality of care. Among those who rate their care as excellent or very good, fewer than half (47 percent) think they need more information to aid their decision making. Among those who rate their facility less positively, that rises to 62 percent, including to 79 percent among the few who say the care they receive at their healthcare facility is not so good or poor.[12]

Connectedness and continuity, previously found to be key predictors of patient engagement and efficacy,[13] also relate to interest in information. Patients who usually see the same provider are 18 points more apt than others to feel informed about their health, and it's 15 points among those who say someone at their facility knows them well. Both of these better-connected patient groups also are more apt than others to say they have the information they need to make health decisions.

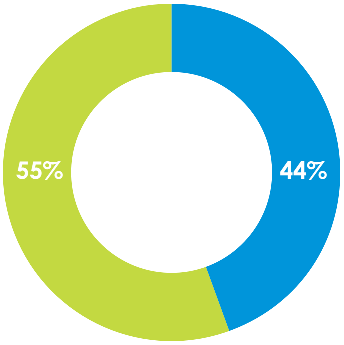
Continuity and connectedness serve as proxies for the nature of the relationship patients have with their provider. Patients who have a strong, positive healthcare relationship are more apt to feel informed about their health in general and to feel they possess the information they need to make medical decisions. As explored in Part B of this report, this, in turn, reflects the greater flow of information that occurs in trusted relationships.

feeling informed

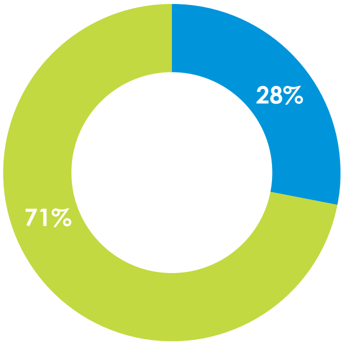
It should be noted that interest in greater health information to assist in medical decision making operates separately, to some extent, from current, self-assessed information levels. As was the case in a previous study,[14] 82 percent of low-income Californians feel very or somewhat informed about their current health, including 43 percent who feel "very" informed – even while, as noted, far fewer feel they have all the information they need to take the right action.

desire for more health information

overall



if information were clear and easily accessible



🟦 have all the information you need

🟩 would like more information

Thus feeling informed and feeling prepared to make the best health decisions are different constructs, albeit related ones – with the latter a far higher bar to meet. Even among low-income Californians who report being "very" informed about their health in general, 36 percent also feel that having more information would help them make better decisions. That nearly doubles to 64 percent of those who report feeling "somewhat" informed, and rises to 83 percent of those who feel not so or not at all informed about their current health.

In addition, feeling informed and equipped to make the right medical decisions, and actually being informed and capable to do so, are not precisely the same. While the two are related, feeling informed is an imperfect proxy for actual information levels; patients may be over- or under-confident in their self-assessments. As the literature review details, studies suggest that patients may be making important decisions with incomplete information (a possibility we will explore in a subsequent report). Regardless, as previous studies have shown, and this report confirms, subjective perceptions of information levels and the desire for greater health information clearly are important in their own right.

frequency of patients' medical appointments and its impact on information

Among other factors, self-assessed information levels increase in step with the number of medical appointments a patient has had in the past year (with a doctor, nurse or other healthcare provider). However, compared with their counterparts, just a third of those who've had one or no visits report feeling "very" informed about their health, but that rises sharply to 57 percent among those who've seen providers six or more times. In a related result, given their greater use of the system, women are more likely than men and people with a chronic medical condition are more likely than those without chronic conditions to feel very knowledgeable about their health. (Women report having seen a healthcare provider about 6 times on average in the past year, vs. 3.6 visits for men).[15]

Compared with their counterparts, there's no significant difference among frequent patients, women and those with chronic conditions in their desire for additional health information.

The desire for greater information to aid healthcare decision making is similar across socioeconomic lines.

socioeconomic status and interest in greater information

The desire for greater information to aid healthcare decision making is similar across socioeconomic lines, despite other differences among these groups. While 56 percent of low-income Californians with a high school degree or less say they could use more information, so do 57 percent of those with a college degree. Racial and ethnic gaps are negligible, with 52 percent of whites and 56 percent of non-whites (including 57 percent of Latinos) expressing the belief that more information would help their decision making.

In income groups, more information to aid decision making is sought by 55 percent of low-income Californians, as noted, but also by 50 percent of their higher-income counterparts. Also, if additional information were easier to find and understand than it is now, similarly few in either group feel they already have all the information they need, 27 and 30 percent, respectively.

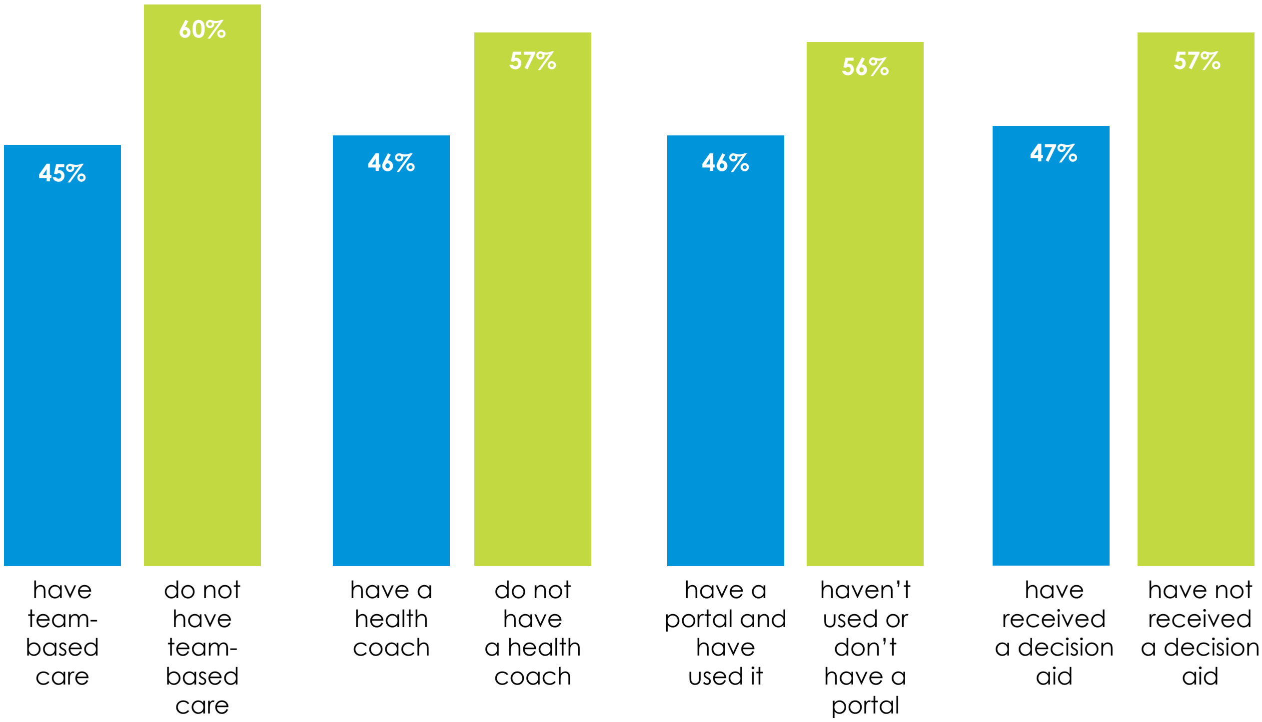
section ii: information and alternative care models

Echoing the 2012 survey, this year's results show that alternative care models hold promise as ways to provide patients with the information they want and need. The three in 10 low-income Californians who are enrolled in team-based care programs are 19 points more likely than those without team care to feel very informed about their health (57 vs. 38 percent) and 15 points less apt to feel they need more information to make good healthcare decisions (45 vs. 60 percent) – sizable gaps.

Similarly, those with a health coach are 16 points more likely to report feeling very informed than those without one (57 vs. 41 percent) and 11 points less likely to want more information to aid their decision making (46 vs. 57 percent). The extent to which team care and health coaches appear able to help bridge the information gap is striking.

the impact of alternative care and communication models

% who feel they need more information to make the right care decisions:



Other results further suggest the promise of innovative healthcare tools in creating a more-informed patient population. Patient portals, discussed in greater detail in Section VII, are websites that allow patients to interact online with the providers and staff at their facility, e.g. scheduling appointments, asking questions and viewing test results and medical records. Those who report having such a portal at their facility (three in 10 low-income Californians overall) and having used it (13 percent) are a wide 22 points more likely than those who haven't used[16] or don't have a portal to feel very informed about their health, and 10 points less likely to feel they need more information to help them make better health decisions.

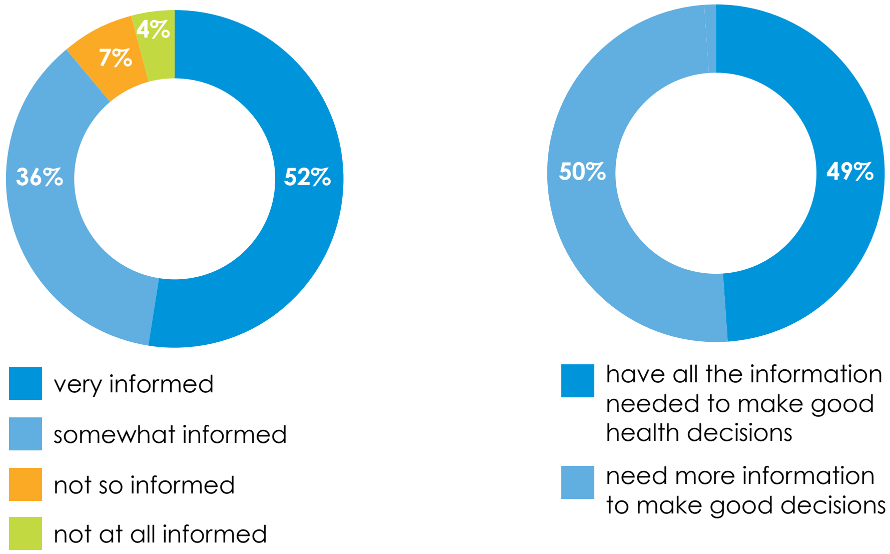
The use of decision aids, another relatively new effort, also shows promise. Examined in more detail in Section X, decision aids are pamphlets, videos or internet-based tools that provide patients facing a specific health problem with clear, detailed and balanced information about their options. Those who say they've been presented with a decision aid when they've faced a decision in the past (27 percent of all low-income Californians) are 13 points more likely than others to feel very informed about their health in general and 10 points less apt to feel they need more information to make better health decisions (47 vs. 57 percent).

In tandem, these results indicate the power of emerging healthcare tools and strategies to equip patients with the information they need to feel confident they can make the right decisions about their health. Notably, statistical modeling finds that alternative approaches also are significant independent predictors of strong patient-provider relationships and communications, as detailed in Section V.

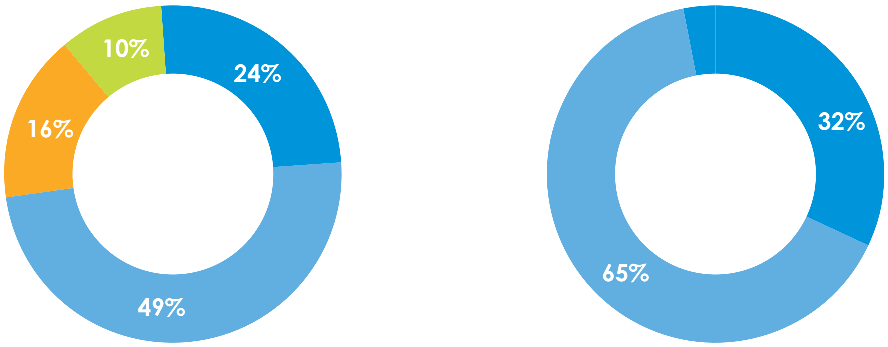
More generally, providers who encourage their patients to take an active role in their care – a fundamental goal of alternative care models – appear to be successful at actually engaging patients and motivating them to become more informed. Among patients who say their provider encourages their involvement, nearly nine in 10 report feeling informed about their health, with more than half saying they're "very" informed. Among those who feel instead that their provider does not encourage an active role,[17] those numbers drop by 15 and 28 points, respectively (to 73 and 24 percent). Patients who feel encouraged to take an active role also are 15 points less likely than their counterparts to feel they need more information than they have now to make good health decisions (50 vs. 65 percent).

the impact of encouraging patients to take an active role

provider encourages an active role:



provider does not encourage an active role:



Engagement in one's own care can include searching for health information online or e-mailing or texting questions to providers,[18] and indeed both are closely tied to information levels; low-income Californians who've used the internet to access health or wellness websites are 16 points more likely to feel very informed about their health.

Further, feeling very informed about one's health reaches two-thirds among those who find it very useful to be able to communicate by text or e-mail with their care providers and staff, compared with just 39 percent of those who don't or can't communicate with their providers in this way, or who find it less useful. Those who find texting or e-mailing with their provider to be very useful also are 11 points less likely to feel they need more information to make better health decisions.

There are, of course, challenges in implementing these approaches. As detailed in Part B, in further evidence of the well-documented digital divide, 42 percent of low-income Californians lack internet access and 20 percent don't own a text-capable cell phone. Until internet and cell phone access become more widely available, the benefits of many of the new healthcare approaches documented in this report – especially the technology advancements aimed at facilitating patient-provider communication – are largely beyond their reach.

Low-income Californians with internet access are more likely to depend on it for their health information and less apt to rely on their providers.

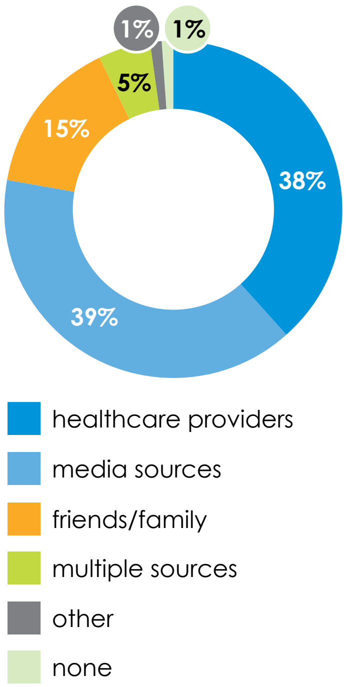
section iii: primary sources of health information

Where do low-income Californians currently get most of their information about their health? Medical professionals have competition: Well fewer than half of patients, about four in 10, rely primarily on their providers as their primary source of health information. As many rely chiefly on media sources including the internet, television, books or magazines, and 15 percent rely mainly on friends and family.[19]

Notably among groups, low-income Californians with internet access are 17 points more likely than those without it to depend chiefly on media sources for their health information (46 vs. 29 percent), and correspondingly are 13 points less apt to rely most on their healthcare providers (33 vs. 46 percent).

Partially because low-income Californians younger than age 40 are more likely than their elders to have internet access, they also are 13 points more likely to mainly rely on media sources for their health information (45 vs. 32 percent).[20] Conversely, older patients are 12 points more apt to rely on healthcare providers as their key information source (45 vs. 33 percent). These results raise the question of whether the internet increasingly is supplanting care providers as a primary source of health information – a potentially problematic result, especially given the much lower levels of trust in sources other than healthcare professionals, as detailed below.

primary sources of health information



In another difference, women are 10 points more likely than men to rely on healthcare providers as their primary source of information (43 vs. 33 percent); as with their greater self-reported information levels, this gap is due at least partially to the fact that women see their care providers more frequently than do men,[21] and so have more opportunities to obtain information from them.

More directly, those who've had two or more medical appointments in the past year are 15 points more likely to say care providers are their primary information source compared with those who've had fewer appointments (44 vs. 29 percent). Relying chiefly on providers for information peaks, at 54 percent, among those who've had more than 10 medical appointments in the past year, compared with 37 percent of those who've seen their providers less frequently.

Those who have a health coach or team-based care also are more apt to report that their care providers are their primary information source, by 15 and 14 points respectively, suggesting that these approaches may bolster the use of medical professionals as go-to information sources, perhaps by easing patients' ability to communicate with them when necessary.

Not surprisingly, those who primarily rely on emergency rooms for their care are the least apt to say healthcare providers are their principal source of information (26 percent, compared with about four in 10 patients of other facilities). Low-income Californians who lack insurance also are significantly[22] less likely to use healthcare providers as their primary information source (31 percent, vs. 42 percent of those with insurance coverage).

Again connectedness and continuity are important. Those who report that they see the same provider infrequently if at all, or who feel that no one at their facility knows them well, are 23 and 13 points, respectively, less likely than their counterparts to rely on healthcare providers as their primary source of information. Just more than half of patients who rarely or never see the same care provider primarily rely on printed publications, TV or the internet for their information. That drops to 34 percent of those who usually do see the same care provider.

primary source of health information

	healthcare provider	media sources
low income Californians overall	38%	39%
have internet access	33	46
no internet access	46	29
age 19-39	33	45
age 40-64	45	32
usually see same provider	45	34
sometimes see the same care provider	40	37
rarely/never see same provider	22	51
feel very informed about your health	48	34
somewhat informed	35	40
not so/not at all informed	20	52
provider encourages patient involvement	44	35
provider does not encourage this	26	50
have at least as much say as you want	42	34
lack the say you want	32	47
someone at facility knows you well	47	30
no one there knows you well	34	44
rate care as excellent	52	29
less than excellent	34	42

Patients who are satisfied with the care they receive are much more apt to rely on providers as their top information source. Of those who rate their care as excellent, 52 percent say providers are their primary source of information, compared with a third of those who rate their care less positively. Indeed, just 29 percent of those who rate the care they receive at their facility as "excellent" primarily turn to internet and other media sources, compared with 42 percent of those who are less satisfied with the care they receive.

Also notably, patients whose providers encourage them to take an active role in their care are 18 points more likely than others to rely on those providers for information. Patients who are not encouraged to take an active role, meanwhile, are more apt to turn to media sources (50 vs. 35 percent). Likewise those who have at least as much say in their care as they want are 10 points more likely to rely on their providers for information, while those who have less involvement than they want are more likely to rely on books, TV and the internet (47 vs. 34 percent).

Not relying chiefly on information from (or at least approved by) healthcare providers is potentially problematic from an information accuracy standpoint. While this survey does not attempt to measure participants' actual knowledge about their health,[23] there is a clear difference in trusted sources by self-reported information levels. Those who report feeling the most informed about their health are 13 points more likely to say their provider is their primary source of information, compared with those who are just "somewhat" informed. That grows to a 28-point gap when compared with those who say they are "not so" or "not at all" informed.

Similarly, among those who rely on healthcare providers for their information, 46 percent would like more information to make better decisions. Among those who instead mainly rely on media sources or their friends and family that rises by 13 and 16 points, respectively. Information from healthcare providers thus appears particularly effective in providing patients with the knowledge and confidence they need.

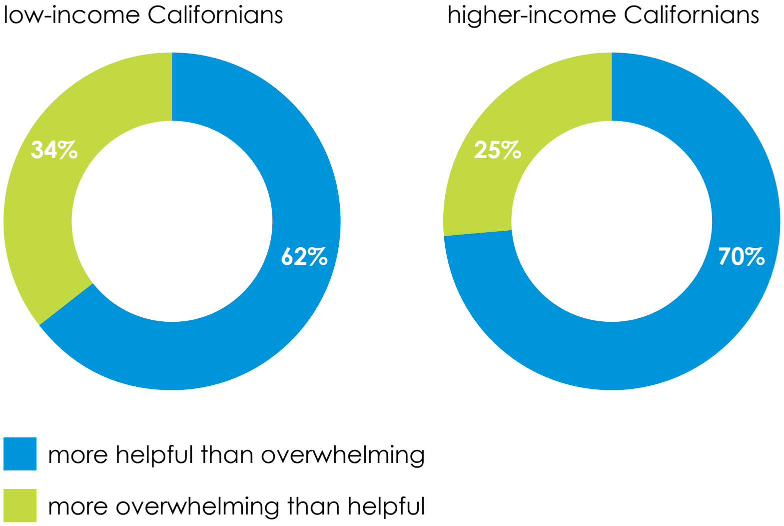
Among all potential information sources tested, healthcare professionals are by far the most trusted.

information overload?

Regardless of their preferred source, most Californians seek out health information on their own. Such searching allows people to find basic information without spending time and money on a medical visit; at the same time, given the abundance of information, conflicting advice and difficulty checking reliability, the experience can be challenging.

On balance, most find that the effort pays off: Just more than six in 10 low-income Californians find searching for health information on their own more helpful than overwhelming (including 31 percent who feel that way strongly). Still, a third of patients find solo information seeking more overwhelming than helpful (though far fewer, just 13 percent, feel this way strongly). And low-income Californians are significantly more likely than their higher-income counterparts to report feeling overwhelmed (34 vs. 25 percent).

comfort looking for health information



Perhaps surprisingly, there are no differences in finding the search for health information helpful vs. overwhelming by variables including education, race, citizenship, language or health status. That suggests it would be wise to avoid stereotypical assumptions about who may or may not need encouragement in using information resources. Safety net providers may be well-served by assessing individual patients' use of out-of-office information and providing instructions, assistance or resources directly, in particular to those most challenged by the process.

section iv: trust in information sources

Despite roughly equal numbers of low-income Californians relying on healthcare providers or media sources as their primary source of health information, there are huge differences in patients' ratings of the trustworthiness of these sources.

Among all potential information sources tested, healthcare professionals are by far the most trusted. Seven in 10 patients say they completely (29 percent) or mostly (42 percent) trust information they receive from the doctors they see. Essentially the same number, 71 percent, completely or mostly trust information from healthcare coaches (among those who have one). And six in 10 trust the "nurses, physician assistants or other medical staff you see."

Trust in other resources plummets dramatically. Among Californians who have used the internet for health information, well fewer than half, 41 percent, trust the health websites they've visited, and only 39 percent of smartphone users trust health-related smartphone applications. Just 8 percent in each of these groups "completely" trust health websites and applications, respectively.

Trust is lowest in information from friends and family or from other people with similar health conditions; just a third of low-income Californians express high levels of trust in information from the former, three in 10 from the latter.

level of trust in information sources

	completely/mostly	somewhat	not much/not at all
doctors you see	70%	19%	10%
healthcare coaches	71%	20%	8%
nurses/staff	61%	25%	13%
health websites	41%	51%	8%
smartphone applications	39%	41%	18%
friends/family	33%	40%	26%
others w/similar conditions	31%	42%	25%

It's problematic that more than half of low-income Californians rely chiefly on sources of health information in which they hold low levels of trust. Further, the results suggest that at least some patients may be turning to less-trusted sources out of necessity, not by choice – a possibility supported by the fact that those without insurance are significantly more likely than others to turn to non-provider sources.

trust in doctors among groups

Doctors' communication skills improve trust in the information they provide. Among low-income Californians who say their healthcare provider only sometimes, rarely or never explains things clearly, just 42 percent trust information from doctors, as do 48 percent of those who say their provider infrequently asks if they have any questions or concerns. Trust increases sharply – to just shy of eight in 10 – among patients whose doctors explain clearly and invite questions.

Trust increases sharply among patients whose doctors explain clearly and invite questions.

Trust in doctors is low in some other groups as well. Just half of low-income Californians who report feeling ill-informed about their health trust their doctors' information. That starkly contrasts with those who feel very informed, among whom more than eight in 10 trust the information they receive from their doctors.

The difference in trust of doctors between those who are satisfied vs. dissatisfied with the care they receive at their healthcare facility is similarly stark. Among those who rate their care as excellent or very good, 83 percent trust the information they get from their doctors; that drops by 24 points, to 59 percent, among those who rate their care less positively. It falls especially low, to 41 percent, among those who give their care facility just a "not-so-good" or poor rating.[24]

trust doctors' information

	completely or mostly
doctor explains clearly	78%
does not explain clearly	42%
doctor invites questions	78%
does not invite questions	48%
satisfied with care	83%
not satisfied	59%
feel very informed	82%
feel somewhat informed	67%
feel not informed	50%

Many of the factors that influence information levels and primary information sources also impact trust in information provided by doctors. Low-income Californians who have continuity and connectedness in their care, have a healthcare provider who encourages an active role, are in good health, have a healthcare navigator, go to a private doctors' office or Kaiser Permanente or have frequent medical appointments all express higher levels of trust in information from their doctor. Conversely, trust is lowest among patients who lack insurance, are non-citizens, don't primarily speak English, have less of a say in healthcare decisions than they'd like, are patients of clinics, have less formal education or are non-white.

For their part, higher-income Californians are 17 points more trusting in information from doctors than are low-income Californians (87 vs. 70 percent). Higher-income Californians also are 12 points more trusting of nurses and other medical staff members (73 vs. 61 percent). Though low-income Californians' trust in healthcare professionals is still quite high, this income gap suggests they have a greater apprehension about the medical establishment – a problem that safety net providers may need to overcome before they are able to fully reach the ideals of patient-centered care and shared decision making.

endnotes

8 See BSCF's 2012 survey report, *Empowerment and Engagement among Low-Income Californians: Enhancing Patient-Centered Care.*

9 See Appendix A.

10 Here and elsewhere, the percentages for those who "feel they have all the information they need" also includes the fewer than 1 percent of low-income Californians who volunteer that they have more information than they need to make the right decisions about their health.

11 Unless otherwise noted, group differences in desire for more information refer to the question assessing interest in more information to aid decision making overall, not the follow-up asking about information that is easier to find and understand.

12 The sample of low-income Californians who rate their care as "not so good" or "poor" is low, 89; we report the result because it's so striking, as well as statistically significant.

13 See BSCF's 2012 survey report, *Connectedness and Continuity: Patient-Provider Relationships among Low-Income Californians.*

14 Ibid.

15 Five patients reported having been to a doctor 300 or more times in the past year. Extreme deviations from normative responses can unduly influence analyses involving the affected variable. We therefore capped the maximum number of visits at 150. This had the effect of reducing the overall average number of doctor visits among low-income Californians from 5.4 to 4.8. The median is 2, the mode 1.

16 This includes low-income Californians who have a portal but lack internet access, as well as those who volunteered that they have never used the portal when asked how useful they find it.

17 This includes those who say their provider discourages them from taking an active role as well as those who say their provider neither encourages nor discourages them from doing so.

18 Both of these are discussed in greater detail in Part B.

19 Results were very similar among higher-income Californians: Forty-two percent rely primarily on providers for their health information, 36 percent on media sources and 13 percent on friends and family.

20 To confirm that access to the internet partially explains the age differences in low-income Californians' primary information sources, we conducted a mediation analysis. A Sobel's z-test confirms that internet access is a significant mediator of the effect, $z = 3.36$, $p < .001$. See Appendix D.

21 As above, mediation analysis confirms that frequency of doctor visits in the past year is a significant partial mediator of this effect, $z = 2.14$, $p < .05$.

22 The term "significantly" in all uses in this report refers to statistical as well as practical significance.

23 Attempting to use surveys to measure knowledge is fraught, as discussed in the literature review, Appendix A.

24 The sample of those rating their facility as "not so good" or "poor" is small ($n = 89$). However the difference in trust in doctors' information in this group, vs. patients who rate their facility as "good," is statistically significant at $p < .05$.

part b: communication and technology

As noted in the executive summary, while information is a necessary component of shared decision making, communication and trust between providers and patients are critical for the relationship to work.

Shared decision making necessitates that healthcare providers trust their patients enough to allow them to have a say (i.e., to relinquish absolute control) and are willing to expend the time and effort to listen to patients' preferences and concerns, ask about their healthcare goals and answer their questions. Patients, for their part, need a willingness to engage; confidence in their information; and comfort talking, sharing ideas and even disagreeing with their provider.

In the traditional physician-driven model of care, staffing realities and time constraints work against this goal. But, as our 2012 report showed, alternative healthcare models – such as team-based care and the use of health coaches – are promising avenues for building patient-provider bonds within existing resources. This study finds that technology-based communication strategies also may serve this goal.

Given its critical importance in achieving optimal patient-centered care, the second part of this report focuses on the patient-provider relationship, including the current state of low-income Californians' relationship and communication with their providers, the ways in which the quality of the patient-provider bond impacts healthcare experiences and the factors that best predict successful patient-provider relations.

section v: current patient-provider relationships

Patient-provider relations can be especially complicated. Health care is extremely important, intensely personal, often complex, typically fragmented, sometimes anxiety-provoking and frequently delivered via a highly unbalanced power relationship. Yet, as discussed in Section VI, establishing a true partnership between providers and patients is essential. Therefore examining the current state of these relationships and potential ways to improve them within available resources is a central goal of this report.

We start with an index created to capture the quality of Californians' current relationships and communication with their providers.[25] The patient-provider index includes questions assessing the following:

- The extent to which patients feel their providers care about them personally;
- The frequency with which they feel their providers explain things to them in a way they can understand and ask them if they have any questions or concerns;
- How comfortable or uncomfortable they feel asking providers 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 in the past has been; and
- How much of a say they feel they currently have in decisions about their health care.[26]

The index can range from a score of 1, indicating the most negative responses to all eight questions, to 4, when all responses indicate strong patient-provider rapport. The average score is 3.16, meaning that most low-income Californians' perceive their relationship with their provider to be positive overall.

At the same time, a third of low-income Californians score below 3 on the index, indicating less than positive communication and rapport with providers, on average. In addition, just 6 percent score a "perfect" 4 on the index, showing an excellent relationship across the board. So while patient-provider relationships overall are rated relatively positively, there is clear room for improvement.

While patient-provider relationships overall are rated relatively positively, there is clear room for improvement.

section vi: the importance of patient-provider communication

While the literature establishes that the quality of a patient's relationship and communication with her or his provider is important, the patient-provider index allows us to pinpoint how critical it is, and in what ways. Specifically, comparing patients who have a more negative relationship with their provider (i.e., the 45 percent of low-income Californians who score below the average on the index) with those with more positive patient-provider rapport (the 55 percent scoring above the mean) shows just what aspects of care are most influenced by the bond between patients and providers.

As can be seen in the next table, one of the largest effects of patient-provider communication is on patients' health information needs, desires and trusted sources. Low-income Californians who score above the average on the patient-provider index are a remarkable 43 points more likely to feel very informed about their health than those who score below the mean. They also are 24 points more apt to feel they have all the information they need to make informed decisions about their health[27] and 17 points more likely to rely on healthcare providers as their primary source of health information.

Breaking the index further into quartiles reveals that 55 percent of those above the 75th percentile (indicating a particularly strong relationship with their provider) rely on healthcare providers for their information. Among those at or below the 25th percentile (indicating a particularly weak relationship with providers), that falls to just two in 10.

Low-income Californians who score above the average on the patient-provider index are a remarkable 43 points more likely to feel very informed about their health than those who score below the average.

benefits of successful patient/provider relationships

	strength of relationship with healthcare provider		
	weak	**strong**	**difference**
information:			
feel "very" informed about your health	20%	63%	43 points
have all information needed to make informed decisions	30%	54%	24
reliance and trust:			
healthcare providers are top information source	30%	47%	17
trust doctors you see	54%	85%	31
trust nurses/other medical staff	47%	74%	27
overall healthcare experience:			
have a great deal or good amount of say in care decisions	43%	86%	43
rate care received at facility as excellent or very good	30%	65%	35
provider encourages you to take an active role in your care	52%	82%	30
current amount of say matches desired amount of say	35%	62%	27
very confident in healthcare decision-making ability	47%	73%	26

Similarly, trust in doctors as sources of health information is significantly weaker among those with less positive relationships with their care provider. Just more than half of those who score below average on the patient-provider index trust the information they receive from doctors, and that slips to 44 percent among those scoring in the lowest quartile on the index. By contrast, among those with above-average scores, nearly twice as many – 85 percent – trust the health information they receive from the doctors they see.[28]

Mistrust of medical professionals among those with a less-positive relationship with their provider extends to the information they receive from nurses, physician's assistants or other medical staff they see. Low-income Californians who score above the mean are 27 points more likely to trust medical staff than those who score below the mean. Once again, the gap becomes even wider – 39 points – when comparing those in the lowest quartile on the patient-provider index to those in the top quartile. Although the sample size of patients with health coaches is too small to break into subgroups, the same trend occurs, albeit less strongly. Those who report having a stronger relationship with their provider are significantly more apt to trust information from their healthcare coach.[29]

Beyond information, other key variables are strongly impacted by the quality of patients' relationships with their providers. Not surprisingly, patients who have a better bond with their provider are more likely to rate the quality of care they receive at their facility positively – by a 35-point margin – compared with those with a less-positive patient-provider rapport. They're also a vast 43 points more likely to report having at least a good amount of say in decisions about their care, 27 points more likely to say that their current amount of say matches their desired involvement and 26 points more likely to feel very confident in their healthcare decision-making abilities.[30]

In sum, as expected, the quality of a patient's relationship with her or his provider is related to an array of important outcomes, ranging from satisfaction with one's care to self-reported information levels to trust in medical professionals. Enhancing the patient-provider bond is an area on which community health clinics and other facilities must focus if they wish to attract and retain patients in the shifting healthcare landscape. The next section provides insight into possible effective and efficient ways of achieving this goal.

Enhancing the patient-provider bond is an area on which community health clinics and other facilities must focus if they wish to attract and retain patients in the shifting healthcare landscape.

section vii: differences in the patient/provider index

Given the substantial impact the patient-provider relationship can have on nearly every aspect of a patient's healthcare experience, it's useful to know whether patient-provider rapport suffers among certain demographic groups, and – even more critically – what attitudinal, behavioral and demographic factors best predict the quality of this bond.

Insurance coverage is one factor; those without health coverage score significantly lower on the patient/provider index compared with those who have some form of coverage. Additionally, scores on the index are higher among Kaiser Permanente and other private doctors' patients, and among those who see their provider frequently.

As suggested by the literature, because so many healthcare providers are white English-speakers, non-white patients, especially those who do not speak English fluently, often have a hard time forming a relationship with their providers. In line with this suggestion, the index is lower among non-English speakers, non-whites (including Latinos, African-Americans and members of other non-white groups) and non-citizens.

The following table shows the index by some demographic groups; asterisks indicate a significantly higher average score.

	patient-provider index [31]
overall	**3.16**
insurance status:	
insured	3.23*
no insurance	2.98
facility type:	
kaiser/private doctor	3.32*
clinic (all)	3.09
hospital ER	3.00
medical appointments in the last year:	
at least one	3.20*
none	3.03
race/ethnicity:	
white	3.27*
latino	3.11
other	3.15
language spoken at home:	
english	3.26*
not english	3.04
citizenship:	
u.s. citizen	3.22*
non-citizen	3.03

predictors of positive patient/provider communication

Although information on demographic differences can be useful for facilities wishing to target certain groups for interventions, they provide an incomplete picture of the factors that most drive differences in patient-provider relationships. The insurance status and racial/ethnic differences, for example, may actually be due to other, underlying behavioral or attitudinal factors. Therefore it is important to isolate the variables that best explain the differences in the quality of patient-provider relationships overall in order to identify the root causes of disparities and devise potential solutions. To this end we computed a regression model with the patient-provider relationship index as the outcome variable.[32]

Regression modeling is a statistical technique that assesses the independent relationship between each predictor and the outcome (in this case, the index). It identifies the variables that explain the most unique variance in patient-provider relationships (i.e., by statistically controlling for, or holding constant, other potentially related variables). These models, therefore, offer key insights into how providers may most effectively connect with their patients.

The model shows three critical predictors of patient-provider relationships: self-reported information levels about one's health, whether or not healthcare providers encourage patients to take an active role in their care and whether or not patients feel they have as much say in their care as they desire.

Key predictors of positive patient-provider relationships

- Feeling informed about one's health
- Having care providers who encourage an active role
- Having as much of a say in health decisions as desired

The vast majority of mismatches between desired and actual say reflect patients desiring more say than they currently have.

As noted, feeling informed may help patients feel they are on more equal footing with providers, addressing real or perceived inequality in status, education and expertise. For providers, having a well-informed patient may make it easier to relax their control over the decision-making process. It also means that more complex, higher-level information can be conveyed rather than a lengthy discussion of the basics, an especially important consideration given the time constraints under which many healthcare professionals operate.

Further, by encouraging patients to take an active role, care providers may signal confidence in their patients' ability to participate. As with feeling informed, this may help to break down the patient-provider power differential.

Separately, having actual and desired levels of involvement in care decisions align is critical. The vast majority of mismatches between desired and actual say reflect patients desiring more say than they currently have. Potential causes may include, for example, restricted time, language barriers or simply a provider's unwillingness to relinquish control. Regardless of the reason, it's clearly damaging for patients to feel their input is not as valued as they'd like.

Additional predictors of the patient-provider index also are instructive. Connectedness is one; low-income Californians who report a personal connection with someone at their care facility (i.e., saying someone there "knows you pretty well") report significantly better relationships with their providers than those lacking a personal connection.

There's much room for improvement here, given that just 38 percent of low-income Californians report such a connection with someone at their facility. Its impact on patient-provider relations is another strong reason to seek to expand connectedness, which was found in last year's BSCF survey also to be a fundamental building block of patient empowerment and engagement.

In an equally important finding, alternative approaches to health care also positively predict better patient-provider relationships. These include having team-based care or a health coach, as well as using a variety of communication and information strategies such as decision aids (see Section X), health websites and applications and texting or e-mailing with providers. In fact, the model suggests that current use of each of the alternative approaches measured in this survey is linked to better patient-provider rapport.

Additional predictors of successful patient-provider relationships[33]

- Connectedness
- Having team-based care
- Extent of current health technology use
- Having used a decision aid
- Having a healthcare coach

Among these:

- Team-based care, another significant positive predictor of the patient-provider index, was shown in Part A of this report to be linked to higher self-reported information levels, and our June 2012 report found that team-based care positively predicts patient satisfaction and efficacy. The results of this analysis expand the promise of this care model to the patient-provider relationship itself. Those who have a care team have a better relationship, including improved communication, with their providers.

- As the literature review describes, decision aids are intended to enhance patients' baseline information, making them better-informed decision makers. Also, because these aids can be reviewed at home, they preserve valuable face time with providers for higher-level discussions. The regression results support these suggestions: Having used a decision aid has a significant positive impact on patient-provider relationships.
- An index assessing current use of emerging technology-based communication and informational tools, such as using the internet or smartphone applications for health reasons or text messaging/e-mailing with providers, also is linked to better communication and relationships with healthcare providers. (See Section VIII for more information about the current health technology-use index.) This suggests that contrary to concerns that these technologies may be off-putting or encourage information overload, they can help advance patient-provider communication, not detract from it.[34]
- A health coach or healthcare navigator is an individual assigned to help patients get the appointments, information and services they need, to make sure their questions have been addressed and even to call to check in with them between visits. Even though these coaches are not themselves healthcare providers, having a healthcare coach is a positive predictor of successful patient/provider relationships.

It's important to note that all these results take into account the level of information patients report having. This means that the effects of team care, decision aids, healthcare coaches and information technology reflect more than simply their role in making patients feel more informed, but operate independently of that factor as well.

Finally, one demographic predictor of the index is particularly noteworthy. Even after controlling for all of the other attitudinal and behavioral factors described above, language spoken at home is a statistically significant, unique predictor of the quality of the patient-provider relationship, with this bond lower among those who do not primarily speak English. This result underscores the advantage for healthcare providers and staff being fluent in languages spoken by their non-English-speaking patients, something for which community health centers may be particularly well-placed given their traditional focus on cultural sensitivity.

Team-based care, decision aids, healthcare coaches and use of health information technology all significantly predict successful patient-provider relationships.

section viii: communication and information tools

Technological advances have encouraged the increasing dissemination of health-focused information and communication tools. Websites and smartphone applications aid an individual's ability to obtain health information and advice; track their own health and wellness; and communicate with providers, people with similar conditions and support networks, among other services. In addition to vastly increasing information opportunities, text, e-mail and secure websites and smartphone applications provide new avenues for medical professionals to stay connected with their patients, monitor their compliance, answer non-urgent questions and be apprised of emergency situations.

Such tools remain in their infancy. Many approaches are in development without a clear sense of what patients actually want and will use. Few healthcare facilities have formal strategies in place, in part because few health insurers and public programs, such as Medicare and Medicaid, reimburse providers for the use of these tools. Such resources therefore are little-used.

Despite their newness, this study finds that these alternative communication and information tools hold the promise of reducing burdens on providers while enhancing patient care.

Alternative communication and information tools hold the promise of reducing burdens on providers while enhancing patient care.

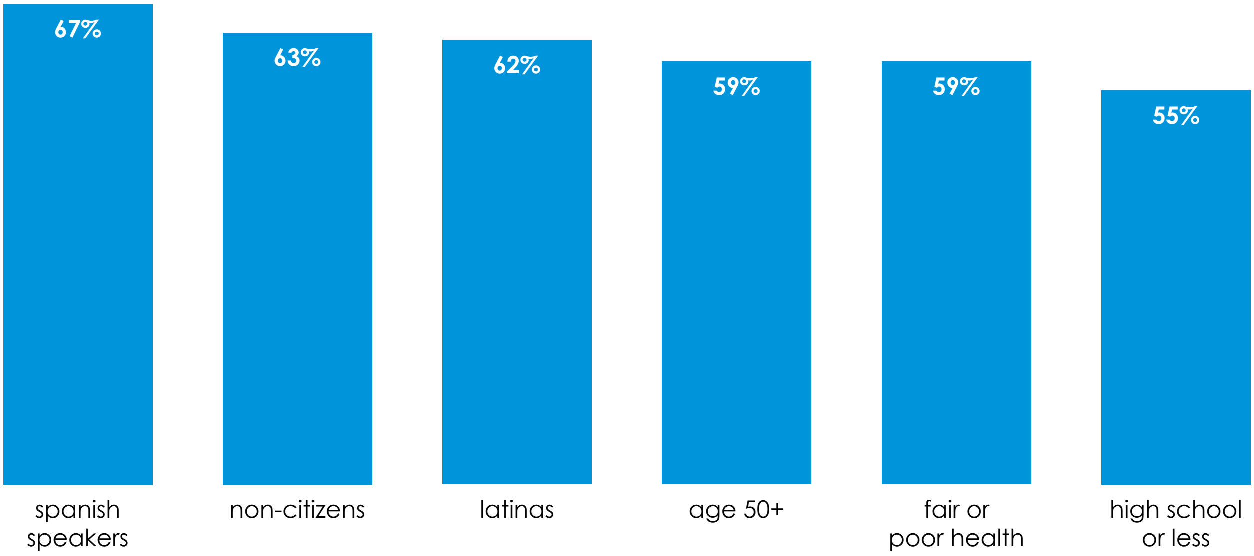
current use of online resources

A challenge for safety net providers is that many in their service population lack the access required to make use of online or text-based communication and information tools. This survey finds that six in 10 low-income Californians do not have a smartphone, more than four in 10 lack internet access entirely and two in 10 lack a cell phone that can send and receive text messages. Clearly there are portions of the safety net population who are excluded from the benefits of a more technology-friendly approach to health information.

For comparison, technology access among higher-income Californians is dramatically higher. Nearly nine in 10 Californians at or above 200 percent of the federal poverty level have access to the internet, 29 points greater than the rate among those with lower incomes. Seven in 10 higher-income Californians have a smartphone, compared with 39 percent of low-income Californians. And almost no higher-income Californians (8 percent) lack a cell phone that at least can send and receive text messages.

Some groups within the low-income Californian population are especially unlikely to have internet access, including 72 percent of those who also lack a texting cell phone, 63 percent of non-citizens, 61 percent of those who primarily speak a language other than English at home (including 67 percent of Spanish speakers), 59 percent of those age 50 and older, 59 percent of those in fair or poor health, 57 percent of Latinos (including 62 percent of Latinas, vs. 52 percent of Latino men) and 55 percent of those who have no more than a high-school education.

% lacking internet access (among low-income Californians)



On the flip side, groups most apt to have internet access include low-income Californians with more than a high-school education (78 percent, including 89 percent of college graduates), whites (78 percent, including 81 percent of white women and 74 percent of white men), those under 30 (75 percent), those who primarily speak English (73 percent), those in excellent or very good health (73 percent) and Kaiser Permanente or other private doctors' office patients (70 percent).

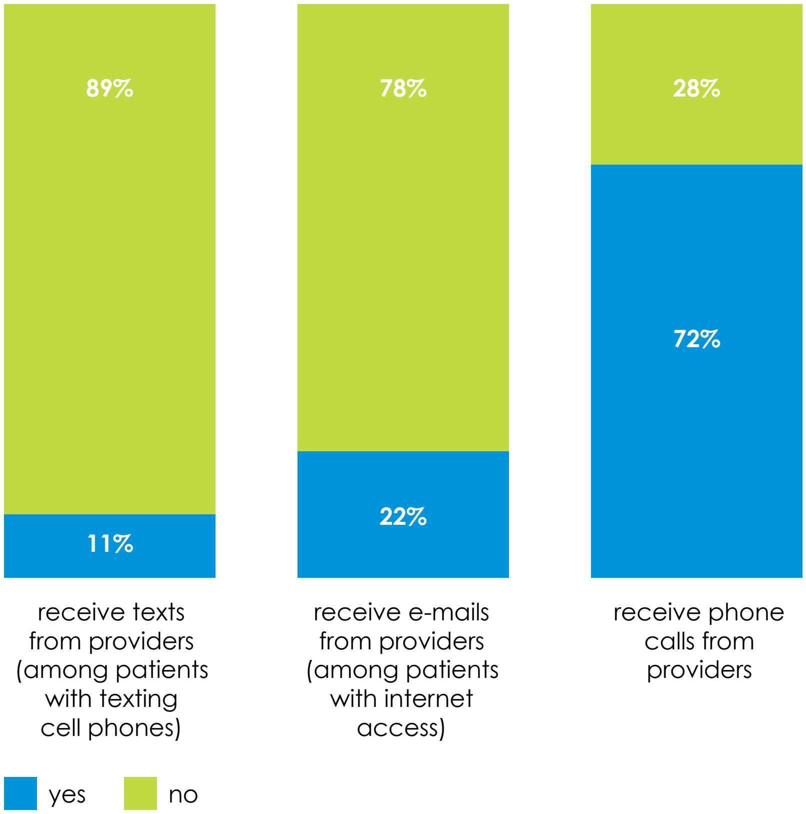
While significantly more Californians have a cell phone with texting capabilities than have internet access (80 vs. 58 percent, as noted), there are a few gaps in access to texting phones as well. For example, four in 10 older low-income Americans lack a texting phone, as do 44 percent of those who lack internet access and 31 percent of those who primarily speak Spanish at home. Other gaps in possession of a phone with texting capabilities are far less stark than the differences among groups in internet access described above.

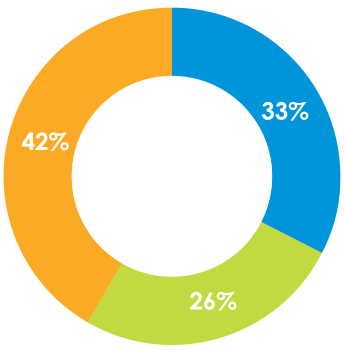
use of information/communication technology for health purposes

Beyond access, the survey assessed whether Californians have used the internet or their phones specifically for health-related purposes. For example, overall 56 percent of low-income Californians with internet access have visited health or wellness websites; among higher-income internet users, that jumps to 70 percent. When accounting for the income disparity in access to the internet in general, that means just a third of low-income Californians have used the internet for health reasons, compared with six in 10 higher-income residents.

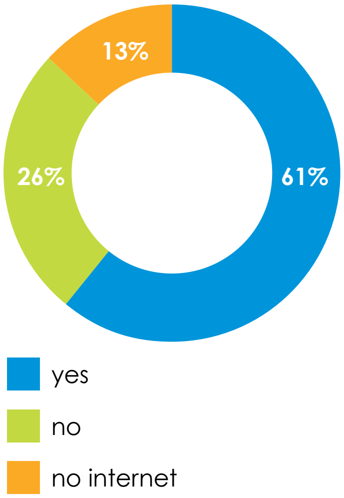
Further, just 17 percent of low-income Californians with internet access report that they have used a website or smartphone application to look for information about a medical problem; 14 percent apiece have used either of these methods to look for dieting, nutrition or exercise information or to track their own health, exercise or nutrition; and 8 percent have used these tools to find support or advice from other people with similar health issues. Finally, 6 percent each say they've either shared or read about a personal health experience online or signed up to receive automatic health messages or reminders. Again, accounting for the lack of internet access among many low-income Californians means the overall usage rates are between just 3 and 10 percent.

Texting and e-mailing for health reasons also are fairly rare for patients and providers alike. Among low-income Californians who own a phone with texting capabilities, just one in 10 say the providers or staff at their care facility send them text messages and 18 percent say they can have a health question answered via text. Among those with internet access, 22 percent say the staff or providers at their facility send them e-mails and a third say they can get health questions answered via e-mail. By contrast, 72 percent say their care providers or staff call them by phone.




have used the internet for health information

low-income californians


higher-income californians

All 12 relevant variables were combined into an index summarizing the extent to which low-income Californians use health information technology. The health information technology index can range from 0, indicating no use of technology tools whatsoever, to 12, indicating use of each of the 12 types of tools tested. The average score among low-income Californians overall is just 1.94, meaning, on average, respondents have used approximately two of the 12 technology tools.[35] Higher-income Californians, by contrast, have used an average of three technology tools (average = 3.14).

health information technology index

- use of the internet or a smartphone to access health or wellness websites or applications
- using websites or applications to:
  - look for information about a medical problem
  - look for information or advice about dieting, nutrition or exercise
  - track health, exercise or nutrition information
  - find support or advice from other people with similar health issues
  - share a personal health experience with others, or read about someone else's experiences
  - receive automatic health messages or reminders
- receiving phone calls, e-mails or text messages from your care facility
- being able to e-mail or text care providers

A regression analysis was performed with this index as the dependent variable in order to identify key demographic differences in who is most apt to use these tools. Not surprisingly, the top predictor by far is having internet access. But even low-income Californians with internet access have used, on average, fewer than three types of these 12 information and communication tools. (That drops to fewer than one, on average, among those without internet access, and almost to zero when phone calls from facilities are dropped from the index.)

Additional predictors of current technology use include being a patient of Kaiser Permanente,[36] likely a reflection of its technology-oriented approach. Patients who go to facilities with a patient portal also are more likely to use technology tools – which may again be a reflection that such facilities (and by extension, their patients) are more technology-focused.

Among groups, Latinos are particularly unlikely to have used technology-based tools (even controlling for their lower likelihood of having internet access). Those more apt to use such tools include patients who feel connected to someone at their care facility, have received a decision aid from a provider in the past or say their doctor encourages them to take an active role in their care. These, especially the latter, suggest that when patients are encouraged to become more actively informed about their health, at least some are turning to technology to do so.

As noted in Section V, use of these tools positively predicts stronger patient-provider relationships, which ultimately leads to a better healthcare experience. In addition, the extent to which patients have used health technology information and communication tools, and the extent to which they find communicating with their provider via technology useful, both are associated with greater self-reported information levels. The lack of internet access among a wide swath of the low-income population thus has pervasive negative implications for patients' information-levels, their relationships with their providers and their overall healthcare experience.[37]

endnotes

25 Relationships and communication are highly related (conceptually and empirically), and therefore we include both in our index evaluating patients' bonds with their provider. In discussing this index we use the terms "relationship" and "communication" interchangeably.

26 This report focuses on results of the full index. Individual items, especially in terms of differences in these measures between low- and higher-income Californians, will be explored in a subsequent report.

27 Where possible, we also computed the correlation between the full patient-provider index and continuous versions of each of the measures reported in the table. Overall, the index has a strong positive correlation with self-reported information levels ($r = .49$, $p < .001$) and a moderate positive correlation with the extent patients feel they have all the information they need to make informed decisions ($r = .26$, $p < .001$).

28 The index and trust in doctors have a positive linear relationship, $r = .44$, $p < .001$.

29 Among low-income Californians with a healthcare coach, the patient-provider index and trust in information from healthcare coaches correlate at $r = .28$, $p < .001$.

30 The full patient-provider index correlates with healthcare facility ratings, patients' reports of their current amount of say in their care and their confidence in their ability to make decisions about their care at $r = .46$, $r = .55$, and $r = .32$, respectively ($ps < .001$ in each case).

31 The standard deviations for these items range from .53 to .66.

32 See Appendix D for details.

33 See Appendix D for a full list of significant predictors.

34 As noted in Appendix D, this and next predictor are marginally significant at $p < .10$.

35 Note that the index is based on all low-income Californians, not, e.g., just those who have a regular place of care or who have internet access or text-capable cell phones.

36 For the full list of predictors of the health technology use index see Appendix D.

37 As recently reported, in recognition of this digital divide, the Obama administration has spent more than $7 billion to extend broadband internet access. Yet much remains to be done, with an estimated 60 million Americans still lacking high-speed connections to the internet.

part c: openness to new care models and communication strategies

While the digital divide is a serious barrier in bringing health information technology to low-income Californians, it should be noted that 58 percent do report having personal access to the internet, four in 10 have smartphones and 80 percent have a text-capable cell phone. Progress therefore is possible, and the opportunities are substantial.

While the digital divide is a serious barrier, progress is possible, and the opportunities are substantial.

As the previous section reports, use of information technology depends not only on internet access, but also factors such as connectedness with a care facility and encouragement from care providers to take an active role. Another factor is important as well: personal interest in using these resources. This survey finds high levels of interest across many modes, including using websites on the internet, smartphone applications and patient portals for health information, as well as texting or e-mailing with care providers.

Openness to new approaches, moreover, extends beyond information technology to interest in new care models such as team-based care, health navigators and the use of decision aids. And interest in these, as with information technology, largely is driven by the desire among patients for more information to aid their health decision making.

section ix: interest in internet and smartphone application resources

As noted above, current use of technology-based information and communication tools by low-income Californians is relatively uncommon. Fewer than two in 10 of those who have internet access currently use it to look for medical information, share health experiences or track their own exercise or nutrition information, among other items. Regardless, many more express interest in using it for these purposes.

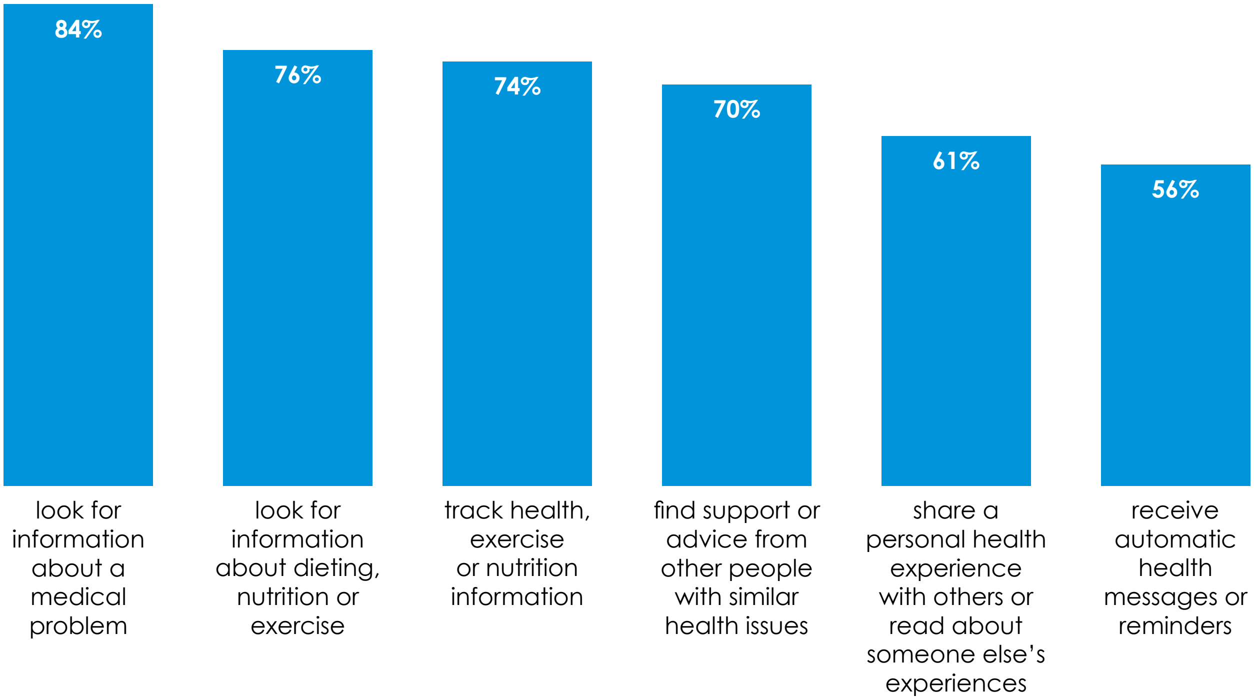
Two-thirds of those with internet access are very or somewhat interested in using the internet or a smartphone application to look for information about a medical problem. Six in 10 or more of those with internet access are likewise interested in using the internet to find support or advice from other people with similar health issues (63 percent); look for information or advice about dieting, nutrition or exercise (62 percent); or track health, exercise or nutrition information (60 percent). Fifty-five percent are interested in sharing a personal health experience with others or reading about someone else's experience online. Half express interest in signing up to receive automatic health messages or reminders.

Encouragement and guidance may boost increased use of health communication technology.

Clearly many low-income Californians are interested in trying technology-based health information and communication tools and have the resources to do so – yet don't. One possible reason is that expressing interest is easier than acting on it; providing encouragement or other motivation could boost uptake. Unfamiliarity could be an issue as well; guidance on which health-based websites or applications to use and assistance using them most efficiently and effectively also could help. Workshops helping patients learn how to find and use reliable resources could provide the additional bonus of steering them toward trustworthy sources.

Adding those who already use health technology resources (and can therefore be assumed to be interested in them) means that the overall rates of low-income Californians with internet access who are open to using these technology-based tools ranges from a low of 56 percent (for automated reminders or health messages) to a high of 84 percent (for seeking information about a medical problem).

% interested in using (or use) the internet/smartphone applications



We created an index to summarize the groups with internet access who are most interested in these online health information and communication resources. Scores can range from 1, indicating no interest at all in any of the six technology-based health tools tested, to 5, indicating that the respondent already uses all six of the resources. The average score on the index is 3.03, meaning that low-income Californians with internet access are, on average, somewhat interested in these technology-based health tools.

index of interest in online information and communication tools

assesses amount of interest in using the internet/smartphone applications to do the following:

- look for information about a medical problem
- look for information about dieting, nutrition or exercise
- track health, exercise or nutrition information
- find support or advice from other people with similar health issues
- share personal health experiences with others or read about someone else's experiences
- sign up to receive automatic health messages or reminders

A regression predicting interest in these six information and communication resources reveals that the strongest independent predictor, by a wide margin, is patients' desire for more health information. Cross-sectional data clearly illustrate this result. Among low-income Californians with internet access who feel they have all the information they need, the average score on the index is 2.70 (where 3 approximates "somewhat" interested). Among internet users who feel that having more information would help, the index rises to 3.26, a statistically significant difference that suggests internet resources are more attractive to those who want to be better informed.

Not surprisingly, low-income Californians who are more trusting of non-provider sources (including health websites and applications, as well as friends and others with similar health problems) also are more likely to express interest in these health information technology tools.

Among other significant predictors, those who have received a decision aid from their provider when facing a medical decision, as well as Kaiser Permanente patients, are significantly more likely than others to be interested in these six tools. The former suggests that facing a medical decision coupled with encouragement to be better informed encourages greater interest in one's health in general. The latter may again be a reflection of Kaiser Permanente's more technology-centric approach.

Also, low-income men with internet access are less interested than women in online health information and communication tools, even controlling for current self-assessed information levels and desires for more (or less) information.

There are a few unique predictors of some of the individual tools. Among them:[38]

- Having a disability or chronic condition positively predicts interest in using the internet to look for information about a medical issue and to find support or advice from others with similar health issues. Separately, Latinos are significantly less interested than non-Latinos in using the internet or smartphone applications to find support or advice from others.
- Self-reported health status is a positive predictor of interest in dieting, nutrition or exercise advice, as is having a healthcare provider who encourages patients to take an active role in their health. Education is a positive predictor of interest in using the web to track health, exercise or nutrition information.
- Perhaps being better attuned to reminders from others, patients who have a healthcare navigator are significantly more likely to be interested in automated health messages or reminders than those without a health coach. Those who find searching for health information on their own to be particularly overwhelming also are more interested in receiving health information or reminders than those who find searching for information to be more empowering.
- As noted, even when controlling for other potentially related factors, men are significantly less interested in using online tools than women. This gender difference is especially apparent on three tools: looking for information about a medical problem, finding advice about dieting, nutrition or exercise and receiving automated health information or reminders. Women, in each case, are more interested in using the internet for these purposes than are men.

patient portals: access, perceived utility and interest

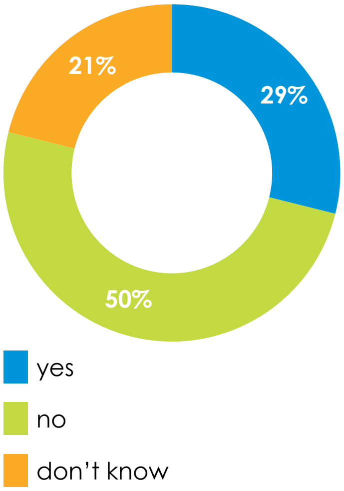
Regardless of whether or not they have internet access, low-income Californians were asked whether their care facility has a patient portal – a centralized website where patients can make medical appointments, find health information and view their medical records or test results, among other activities. Overall, three in 10 report having a patient portal available. Among those with a patient portal and internet access, seven in 10 find it useful, just 5 percent say it's not useful and a quarter report never having used it. Excluding those patients who report that they've never used the portal, this means a near-unanimous 92 percent say it's helpful.

Among those with internet access who do not have a patient portal, interest is high. Three-quarters express interest in using one, and strong interest outstrips strong disinterest among internet users without a portal by more than three to one (44 percent "very" interested vs. 12 percent "not at all" interested).

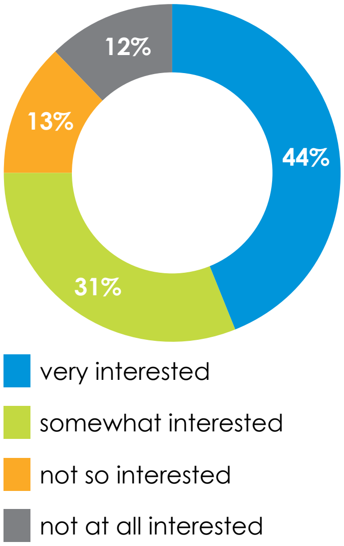
Interest in various potential portal features is high across the board. Among those with internet access who either have a portal or who have at least some interest in one,[39] six common features of portals were tested to determine which is most valued. The test revealed a close race:

- Ninety-two percent express interest in being able to view test or lab results on a patient portal, including seven in 10 who are strongly interested in this feature.
- Nine in 10 would like to be able to find health information their healthcare provider recommends on a portal, including 53 percent who are very interested in having a portal as a source of provider-approved information.
- Eighty-nine percent are interested in being able to view their medical records, and as many are interested in being able to us the portal to ask questions of the doctor or nurse, with 64 and 57 percent very interested in these options, respectively.
- Eighty-seven percent would like to be able to ask for a referral to a specialist on a portal and 85 percent are interested in being able to schedule appointments online, with six in 10 strongly interested in each of these capabilities.

have a patient portal



% interested in a patient portal (among internet users without one)



section x: interest in texting and e-mailing care providers

E-mailing and texting with healthcare providers is still a relatively new phenomenon. As mentioned, just 11 percent of low-income Californians who have a phone with texting capabilities say they receive texts from their providers, while slightly more, 18 percent, believe they can get an answer to a health question by texting the providers or staff at their facility.[40] E-mailing is more common, but still just 22 percent of low-income Californians with internet access say their facility sends them e-mails and 32 percent believe they can get questions answered by e-mailing their providers.

Among those who have communicated with their provider via text or e-mail, almost all – 87 percent – say such communications were either somewhat (34 percent) or very (53 percent) useful, underscoring their potential. Moreover, among those who have the ability to communicate with their provider in these ways (i.e., who have a texting phone or internet access) but cannot currently do so, there is strong interest. Seven in 10 who can't currently text their provider express interest in doing so, and it's 75 percent for e-mailing.[41]

Interest in being able to text healthcare providers is especially high among low-income Californians under age 40, with 74 percent interested, vs. 61 percent of those 40 and older. There also is a wide difference by facility type: Patients of private doctors' offices who can't currently get health questions answered via text are far less interested in being able to do so than patients at all other facility types (58 vs. 75 percent). That's likely because those who go to a private doctor have greater existing levels of continuity, information and confidence.

Interest in being able to text healthcare providers is especially high among low-income Californians under age 40.

Those who only sometimes, rarely or never see the same doctor when they have an appointment also are far more interested in being able to text their provider when they have a question than those who see the same doctor on each visit (75 vs. 61 percent). They may see texting as a way to establish a form of continuity that's currently lacking.

Desires for greater information and a greater role in one's health care are related to interest in texting. As with interest in the technology-based resources described in Section VIII, patients who'd like more information about their health for decision making express substantially greater interest in being able to text their provider for answers to questions, compared with those who feel they have all the information they need (81 vs. 56 percent). Those who'd like more of a say in decisions about their care also are more apt to want to text their providers than those whose desired say matches their actual say (79 vs. 64 percent).

Poor communication between providers and patients is another factor influencing patients' interest in communicating via text. Those who feel their providers' explanations are sometimes, rarely or never clear are more interested in being able to text (likely with follow-up questions) than those who say their providers' explanations are usually clear (82 vs. 67 percent). Similarly, those who feel that overall the information they've received from providers has been more complicated than it should be are 10 points more interested in being able to text their provider to ask questions, compared with those who feel the information they've received has been as simple as it can be.

Many of the same patterns apply to interest in being able to e-mail providers or medical staff. The desire for continuity, for more information and the need for greater clarity all seem to drive interest in communicating with providers through alternative means. In addition, younger low-income Californians are much more interested in texting and e-mailing their providers, suggesting that interest in these technology-based tools should expand along with the share of the population that's grown up with these technologies.

interest in communicating with providers via…

	e-mail	text messaging
age: 19-39	79%	74%
age: 40+	65%	61%
see same provider:		
sometimes/rarely/never	83%	75%
always	61%	61%
more info would help	82%	81%
have all info I need	63%	56%
health info. from providers:		
complicated	84%	78%
simple as it can be	70%	68%

section xi: interest in alternative care and communication

One of the goals of this survey is to examine how patient-provider communication and patient information might inform primary care redesign, especially patients' willingness to try new care models and methods of communication. In particular, we examined interest in using team-based care, having a healthcare navigator, having a patient portal, using a decision aid when facing a healthcare decision and finally, as discussed immediately above, being able to communicate with a provider via text and e-mail.

For each of these, (with the exception of texting and e-mail, covered above) the current status is as follows:

- A third of low-income Californians have team-based care. Among those who do not, more than seven in 10 express interest in trying it, including a third who are "very" interested. That means that eight in 10 overall either currently use team-based care or are interested in trying it.

- Two in 10 report having a health coach to help them navigate their care needs, make appointments and get answers to questions. Interest is lower than in having team care: Among those who don't currently have a healthcare navigator or coach, half are interested. In total that means six in 10 low-income Californians overall either have a healthcare coach or express interest in having one, while four in 10 are uninterested.

- As previously noted, three in 10 low-income Californians say their healthcare facility has a patient portal; of the rest, those with internet access express broad interest in having a one. Three-quarters are interested, including 44 percent "strongly" interested.

- Decision aids are not necessarily technology-based (they can be delivered in printed or video formats as well as online) and therefore are accessible regardless of internet or cell-phone access. Though not yet widely used, the literature review suggests they hold great promise in quickly and effectively providing critical information to patients and therefore allowing them to have a greater say in decisions about their care.

Just over a quarter of low-income Californians say they've been given a decision aid when facing a medical decision, and nearly all of them – 90 percent – would be interested in using one again. Among those who have not received a decision aid previously, three-quarters express interest in trying one, including a third who are "strongly" interested. Just 10 percent of low-income Californians overall say they're not interested at all in using a decision aid if faced with a medical decision.

predicting interest in care and communication approaches

We computed regression models predicting each of the six items measuring openness to alternative care and communication strategies – again, interest in using team-based care, having a healthcare navigator, having a patient portal, using a decision aid, being able to communicate with a provider via text and being able to do so via e-mail. These regressions show which predictors are important across the board, compared with which are key for only one or a few of the alternative approaches. They also reveal a few unique predictors that may be important to consider when implementing specific new care or communication strategies.

Perhaps the most important finding is that the desire for more health information drives interest in all of the six alternative approaches tested,[42] to varying degrees. Those who seek greater information to improve their health decisions are more interested in trying new care models (i.e., a health coach and team care) and in using new information and communication strategies (i.e., patient portals, decision aids and communicating via text and e-mail),[43] suggesting that these tools are perceived as a means of filling the information void many patients currently feel.

Common predictors of interest in alternative strategies[44]

					Communicate via:	
	Health coach	**Team care**	**Portal**	**Decision aid**	**Text**	**E-mail**
Desire for more information	✓✓	✓✓	✓✓	✓✓	✓✓	✓
Patient-provider index	✓✓	✓✓		✓✓		✓✓
Gender: Male	✓✓	✓✓		✓✓		✓✓
Current health technology usage			✓✓	✓✓	✓✓	✓✓
Employed: Full-time			✓	✓✓	✓✓	✓✓

Double checkmarked items are significant at $p < .05$, single checkmarked items at $p < .10$.

While the desire for more information is important across the board, the patient-provider relationship is especially important in four approaches: interest in having a healthcare coach, trying team-based care, using a decision aid when faced with a health decision and communicating with healthcare providers via e-mail. Those who report having a strong relationship and good communication with their provider are more open to these approaches than those with a weaker connection with their provider. Feeling that someone at the facility knows you well, another important bond, is an important driver of interest in trying a patient portal and texting with providers or staff.

Patients' gender also consistently emerges in many of the models predicting openness to alternative strategies. Men are less open than women to trying team-based care or a healthcare coach, and less interested in using a decision aid. On the other hand, men are more interested in being able to e-mail their health provider than are women. While speculative, this may suggest that men are resistant to new approaches that they believe will take more time or effort on their part, but are open to those, such as e-mailing, that can make their care experience easier.

The extent to which patients currently use health technology tools, such as websites or smartphone applications to find information, share health experiences or find advice (see Section VII for details), also is a common predictor of openness to alternative models. Although low-income Californians currently use few online health tools, those who use more also are more likely to be open to texting or e-mailing with their care provider, using a patient portal and using a decision aid when next faced with a major medical decision. "Early adopters" appear more open to new technology-based health resources and alternative care strategies alike.

A few other patterns emerge:

- Being employed full-time is a positive predictor of openness to e-mailing and texting with providers, using a patient portal and trying a decision aid, likely because each approach may be perceived as a quick and efficient way to get health questions answered, and one that does not involve missing work for an appointment.

- Having faced a major medical decision in the past year is a significant positive predictor of openness to a healthcare coach, team-based care and decision aids. Approaches that facilitate communication and the transfer of knowledge may be particularly attractive to those who have recently faced a major health decision of their own.

- Having less say in healthcare decisions than desired drives interest in texting with providers, using a decision aid and trying team care. Each of these approaches may be seen as ways to increase one's say in healthcare decision making; promoting them as such may increase interest.

- Patients who report seeing the same provider infrequently express greater interest in having a patient portal and in being able to e-mail with their providers – perhaps seeing each as tools to stay organized and connected despite their lack of continuity.

Targeting different services based on ethnicity, age and education may prove effective. Latinos are especially open to healthcare navigators and team-based care, but less interested in being able to e-mail their providers. Likewise, older respondents are more interested in having a healthcare navigator, while younger patients express greater interest in e-mailing with their provider. Finally, low-income Californians with less formal education are more apt to be interested in e-mailing or texting with their healthcare providers than are patients with more education.[45]

endnotes

38 Each of the models described below was conducted only among low-income Americans who currently have internet access.

39 Specifically, internet users without a portal who said they were "not at all" interested in one were not asked this question.

40 This indicates that among those who say their healthcare providers have never sent them a text message, there are some who still believe they can get an answer to a question by texting their providers. This is also true for e-mailing.

41 Interest in texting/e-mailing with providers was only asked of those who have the technology available to them to do so (i.e., who have a texting-capable phone or internet access, respectively), but whose facility does not currently allow them to do so. For brevity, we do not make this distinction in each of the descriptions below.

42 Models predicting openness to team care, health care navigators and decision aids include all low-income Californians. Those predicting interest in patient portals and e-mailing with providers are among low-income Californians with internet access, and models assessing openness to texting with providers are among those with text-capable cell phones.

43 The desire for more health information is only a marginally significant predictor of interest in emailing providers ($p < .10$). In all other cases, it is statistically significant at at least $p < .05$, see Appendix D for details.

44 Double checkmarked items are significant at $p < .05$; single checkmarked items at $p < .10$. Table shows only predictors that were significant in four or more models.

45 See Appendix D for a full list of the significant predictors of each of the six models.

part d: conclusions and recommendations

At a time of upheaval in the provision of healthcare services in the United States, opportunities are at hand to reshape the system with a focus that is at once patient-centered, efficient and highly effective in its impacts. This study explores those opportunities from the perspective of patients themselves, examining their information sources, relationships with providers and openness to alternative care models and information technology.

Key takeaways include the positive potential impacts of internet and smartphone technology, the promise of new models of caregiving in enhancing information sharing and the profound benefit of caregivers actively and meaningfully encouraging patient engagement. Each of these enhances the quality of patient-provider relationships, the precursor to empowering patients to take an active role in their care.

Many low-income Californians are open to trying new methods of learning about their health and health care and participating in alternative care models. Information and communication play a critical role in this interest. Patients who desire more information with which to improve their decision making, and those who report having successful communication with their provider, are especially open to new models of care.

The results of this survey usefully inform the healthcare system transformation now under way, suggesting a range of effective yet cost-efficient methods to improve patient experiences, patient engagement and, in turn, health outcomes. These include:

- Increasing the use of alternative care models such as team-based care and healthcare navigators and broader adoption of technology-based communication and information tools, all of which can improve the quality of patient-provider relationships.

- Encouraging patients to take an active role in their care and giving them a greater say in decision making. Results of this survey find, simply, that such encouragement works – patients who feel encouraged to engage in their care are more apt actually to do so. They also report strong relationships with their providers, as well as the many positive outcomes those relationships predict.

- Improving patients' access to high-quality, accurate and easily understood health information. This step should both increase patients' confidence in decision making and, at the same time, help to balance the power differential between patients and providers, a leveling of the playing field that can help improve communication between patients and providers, enhance patients' trust in the medical establishment and strengthen their bond with providers overall.

To that end, there are many concrete ways for community health centers and other safety net providers to work on better informing their clientele, including:

- Incorporating validated decision aids as a standard element of the decision-making process, an approach that should at once free up critical staff resources while enhancing patient information.

- Creating a patient portal or adding functionality and usability to existing ones, in order to provide internet-ready patients with approved information as well as communication resources. This should both ease information-gathering for patients and help care providers focus their attention on reliable sources.

- Increasing patients' ability to ask healthcare questions via text or e-mail. Opening these lines of communication can allow providers to direct patients to trustworthy information sources, as well as enhance their relationship with their healthcare providers.

With thoughtful strategies tailored to their patient populations, these results point the way for community health centers and other facilities to revitalize healthcare delivery. Communication technology and alternative care models can bolster the critical relationship between patients and their care providers – producing, as a result, the prospect of significant progress in achieving the triple aim of better patient experiences, better health outcomes and greater cost efficiency alike.

appendix a – literature review

introduction

This review presents a detailed synthesis of existing studies, reports and surveys on the role of information and communication in patient-provider relationships and primary care redesign. We summarize research on the healthcare information people currently have, how informed and knowledgeable they feel, their communication with health professionals and their experience with and interest in medical decision aids and health information technologies.

The research suggests that many Americans lack important healthcare knowledge, desire to be better informed and more involved in their care and are open to a variety of sources of information to accomplish this goal. The literature also indicates that current communication with providers often falls short of the ideal. But there is great potential for improvement; intervention studies suggest that outcomes can be greatly enhanced even by fairly simple efforts to educate medical professionals and patients alike on better approaches to effective communication.

The 2012 Blue Shield of California Foundation survey of low-income Californians established the critical role of information in patient empowerment and engagement. As described in a model of patient engagement derived from the data in that survey, information is supported by the connectedness and continuity patients feel with their care providers, but also independently predicts other elements of patients' engagement, including their comfort asking questions, comprehension of answers and confidence in their ability to participate in healthcare decisions. Information also is associated independently with the extent to which patients report that they take an active role in their health care, a fundamental goal of patient-centered care.

This review was produced to explore existing knowledge on information and communication from other sources, in order to inform the questionnaire and analytical design of the 2013 BSCF survey.

Understanding the role of information in enhancing patient-provider communication and shaping primary care redesign is especially critical and timely in light of several provisions within the Patient Protection and Affordable Care Act (ACA). Specifically:

- Section 3506 of the ACA aims to facilitate shared decision making by requiring the development of a program that will establish a standardized accreditation process for patient decision aids and work to create, test and disseminate such aids; and

- Section 3013 of the ACA authorizes the secretary of health and human services to award contracts and funds for developing quality-of-care measures that focus on the role of information in shared decision making and the extent to which care is patient-centered.

i. overview

High-quality health care is not only medically appropriate and safe, but also ensures that each procedure, treatment, medication and test aligns with patients' goals and preferences. It thus requires patients to be informed and involved in the decision-making process (Fowler, Levin, & Sepucha, 2011).

A focus on patient engagement and care that reflects and matches the informed preferences of patients is not new. In 1982 the President's Commission for the Study of Ethical Problems in Medicine proposed a model of informed medical decision making that was flexible and collaborative, providing patients with information on their condition and treatment options as well as uncertainties, risks, benefits and costs associated with each option, thereby allowing them to decide whether or not to pursue a treatment, medication or test.

Since then, patient involvement in decision making has been a central concept in the healthcare field and has been advocated for by many prominent organizations. For example, in a 2001 report, the Institute of Medicine noted the wide chasm between the current state of health care and the one we should and could have. It recommended redesigning care delivery in a way that emphasizes patient preferences, needs and values at every step of the process.

While some situations (e.g., emergency care) may make it nearly impossible for a high-quality patient-provider dialogue to occur, almost every other healthcare decision likely would benefit from such discussions (Krumholz, 2010). Indeed, many medical decisions are "preference-sensitive," meaning that no treatment option clearly is superior to others and the patient should be allowed, even encouraged, to consider the tradeoffs in each. For example, Lee et al. (2010) discuss the many reasonable treatment alternatives in the case of a diagnosis of early-stage breast cancer. Fowler et al. (2011), do the same in the case of a patient with a herniated disk.

Despite the ideal of an informed patient as the source of control in medical decisions, patients often receive care that does not reflect their preferences (Lee & Emanuel, 2013). This is undoubtedly a function of the complicated nature of the task at hand combined with the resource constraints on the healthcare delivery system.

In terms of patients' role in medical decisions there are three essential conditions that need to be met for decision making truly to be shared (Fowler et al., 2011): (1) Patients need to be provided with clear information about the pros and cons of the options under consideration in an unbiased, objective and complete manner; (2) patients need to consider how each option fits with their values, goals and concerns; and (3) patients need to have an interaction with their providers to identify the options that best incorporate their preferences into the final decision.[1]

This is a complicated task given both the cognitive burden it presents for the patient and the demands of time and resources on providers and the healthcare system overall. The process can fall apart from either side at multiple points, e.g., in how and exactly what kind of information is provided to patients, during patients' consideration of how each option fits best with their goals and/or in discussion among patients and care providers.

ii. main findings

Research summarized in this review includes investigations of what kind of information patients have access to; how they interact with their providers and how they want to; and to what extent medical decisions reflect what is best for individual patients' needs and desires alike. The main findings are summarized below, with details in the sections that follow.

- People trust their healthcare providers first and foremost for support and information for making healthcare decisions, but when asked specifically, often report that most providers have not shared information or directed them to resources to help make these decisions.

- Actual levels of knowledge often are not assessed, but the few studies that do so suggest patients may be making important decisions with incomplete information. We note, however, that measurements of knowledge generally are problematic in a survey context.

- Having specific health knowledge and feeling informed are not always related and therefore may not be useful proxies for each other. Nonetheless, self-assessments of being informed are important in their own right as a predictor of empowerment and engagement.

- Decision aids – tools designed to help prepare patients for discussions and decisions with their providers – are associated with increased knowledge, including more accurate risk perceptions, less conflict between patient values and medical decisions and, typically, more conservative treatment decisions.

- Although many people use the internet to find health information, it is consistently ranked as a secondary source compared with healthcare professionals.

- Fewer patients have engaged in other online health behaviors such as tracking information on exercise and nutrition, looking up medical records or exchanging e-mails with providers. The extent to which these online behaviors are growing in popularity and how willing people are to try them remain open questions.

- Americans desire more access to their medical records; available evidence tentatively suggests that such access may improve patients' experiences without creating an additional burden for providers.

- Decisions in the healthcare setting often fall short of being fully "informed" and "shared." While doctors frequently recommend treatments and describe their advantages, risks of treatments rarely are covered and the option to pursue no treatment seldom is mentioned. Most patients nonetheless report having shared the decision with their providers, suggesting that researchers should ask about details of the decision process rather than relying solely on self-reports of shared decision making.

- Providers' doubts about their patients' knowledge and potential as capable participants in their care may jeopardize effective communication.

- Providers and patients alike benefit from communication skills training, even ones of limited duration. Patients become more engaged and providers (often, physicians) become more patient-focused.

- Alternative models of care such as disease self-management programs and peer groups provide information and support that can help improve patient outcomes by encouraging patients to take a more active role in their care and become more engaged in managing their conditions.

iii. methodological limitations and unexplored topics

Unfortunately, many previous studies and surveys on this subject depart from best practices in survey research, and as such produce results that lack a solid empirical foundation. Some rely on non-probability samples, the results of which are not reliably generalizable to a broader population (AAPOR, 2010). Others use suboptimal questionnaire design; common in our review are a lack of the alternative proposition and the use of agree/ disagree or yes/no formats, all of which have been shown to be inherently biasing (e.g., Saris et al., 2010); and the use of both overlong and only partially labeled number scales, which often compromise internal validity.

Given these and many other problems, the findings of most of the studies cited in this report can be viewed as tentative only, and in need of confirmation by more rigorous research. Nonetheless, the literature provides testable insights and hypotheses, identifies gaps in current knowledge and points to important directions for further research.

Separately, we note that a variety of topics relating to patient-provider information and communication have been explored insufficiently, if at all. These include in-depth examination of the sorts of information sources and formats patients prefer, the amount of information they want, their interest in and use of decision and behavioral support aids and health information technologies (e.g., portals and apps), their perceptions of providers' willingness to cede control of information sources and whether and to what extent some patients feel empowered vs. abandoned or overburdened when asked to share in their healthcare decision making.

iv. information

Easily accessible and understandable information is essential to achieve the ideal of patients as the source of control in their health care (Institute of Medicine, 2001). While the content and knowledge required to be "informed" may depend on the specific decision under consideration, it is universally required that patients possess good-quality information that's unbiased and balanced (Zikmund-Fisher et al., 2010).

Many surveys have assessed levels of trust in healthcare information sources, but fewer have delved into important underlying constructs, including actual levels of information patients possess, how much information and responsibility they in fact want, what kinds of information they find most useful and how they'd like to receive it.

The few studies that have assessed patients' interest in more information suggest that most desire greater access to resources on a broad variety of topics. For example, BSCF's 2012 survey of low-income Californians[2] found that 83 to 88 percent expressed interest in 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, with 45 percent or more "very" interested in each option. At the top end, 58 percent were very interested in information on potential tests and treatments.

In a study by the California Healthcare Foundation (2009), roughly six in 10 Californians with incomes less than $20,000 a year and chronic health conditions expressed interest in learning how to take better care of themselves, learning exactly what to do to improve their health and attending community events for healthcare support and information. About seven in 10 Californians with chronic conditions (regardless of income) were interested in learning how to realistically improve their nutrition and exercise habits, set health goals with others and balance their work, family and health needs as well as get practical tips from other people like themselves, with interest especially high among lower-income Californians.

A 2012 Institute of Medicine (IOM) survey found that two-thirds or more of adults who had seen at least one care provider in the previous 12 months "strongly" agreed that they wanted their provider to tell them the full truth about their diagnosis, risks associated with each treatment option and how each would affect their quality of life. Nearly half strongly agreed that they wanted their provider to help them understand the costs of each option, always to offer treatment choices and always to discuss the option not to pursue treatment.

Healthcare professionals are the central source of information on health-related matters for most people, with friends and family consistently ranking second. A recent Pew Research Center study (2013) found that 70 percent of American adults got information and support from physicians and other providers the last time they had a serious health issue. Sixty percent said they received support and information from their friends and family and 24 percent said they turned to others with similar conditions.[3]

Other studies align with these findings. The 2010 DECISIONS survey by the University of Michigan examined health information sources and knowledge among English-speaking Americans age 40 or older who had faced one of nine major medical decisions in the previous two years.[4] Regardless of the clinical decision, patients consistently viewed healthcare professionals as their most important source of health information, followed by family and friends and the media (Couper et al., 2010).

Likewise, in the California Healthcare Foundation's (2009) study, low-income Californians with chronic health conditions were most interested in receiving information and health-management support from care professionals (85 percent) and people they know around them (75 percent).

Despite the central role of healthcare professionals, a 2012 IOM survey found that only a quarter of American adults who had seen a healthcare provider in the past year had been directed by their provider to an external information resource to help with a decision; only 5 percent had been directed to an electronic resource (Alston et al., 2012).[5] This suggests that most information is coming directly from the doctors themselves, a suboptimal process given the limited amount of time doctors are able to spend with patients and the inherent power differential between the two.

Although preferred and actual sources of health information routinely are assessed, there is an especially notable absence in the literature of research into the nature and quantity of information patients desire and how they wish to receive it.

v. knowledge

In addition to documenting trusted sources, the DECISIONS study sought to assess respondents' actual knowledge about the specific health decisions they faced. Assessing knowledge in a survey instrument, however, is a challenging task. Opportunities for measurement-based error are vast, given the difference between the lighter cognitive burden of expressing opinions and the heavier, often context-activated process of accessing factual knowledge. Knowledge itself often is ill-defined; we suggest that it should reflect the ability to reach informed judgments from a variety of information sources, not merely to recite disassociated facts accurately. Accurate survey responses may reflect superior recall or expert test-taking ability rather than true knowledge; inaccurate responses may reflect weak recall or reluctance to engage in cognitive burden, rather than lack of actual knowledge. The DECISIONS survey, moreover, asked about health decisions made as many as two years previously, a very long period for respondents to be expected to retain specific facts.

Although conclusions should be tentative given these limitations, results from the study did suggest vast shortfalls at least in recall, if not knowledge. Only 4 percent of men who had decided whether or not to have a prostate cancer screening answered incidence and mortality risk questions correctly; 7 percent of women who had made a decision about breast cancer screening answered two breast cancer knowledge questions correctly. Recall among those who considered a colorectal cancer screening was higher, but still just 31 percent of men and 23 percent of women answered those questions correctly (Fagerlin et al., 2010).

Further, 30 percent of men overestimated the risk for prostate cancer by threefold; for colorectal cancer, 55 percent did. Forty-four percent of women overestimated the risk of breast cancer by threefold and 65 percent did the same for colorectal cancer (Hoffman et al., 2010). An open question, if these overestimations in fact exist, is the extent to which they may drive ill-informed cancer screening decisions.

Factual recall among respondents who had decided whether or not to take medication or have surgery also was lacking, but varied by condition. Respondents who faced a decision about blood pressure medication were better able to recall information about their health condition than were those who had made decisions about cholesterol or depression medication.

In addition to the challenges in defining and measuring knowledge, it's important to note that this study classified answers as accurate only if they were within 5 percentage points of actual mortality risk and within 10 points of actual incidence risk, a high standard given both the elapsed time and the fact that people are notoriously bad at reasoning about probabilistic information (Kahneman, Slovic, & Tversky, 1982). Further, patients may have been reporting their own risk, which may have differed from the risk levels of the general public.

Other studies, mostly focusing on single conditions and one patient population or limited geographical areas, have found that patients often lack crucial information for making medical decisions regarding hypertension, oral coagulants, cataracts, prostate cancer and breast cancer (e.g., Alexander et al., 2003; Fagerlin et al., 2006; Partin et al, 2004; Roche-Nagle et al., 2003; Volk et al., 2003).

vi. being informed and feeling informed

The relationship between feeling informed and being informed likely is not straightforward; decades of psychology research suggests that people tend to overestimate their abilities,[6] meaning many may feel more informed about their health than they actually are. The DECISIONS study suggested that feeling informed and being informed (according to the study's definition) may not always be related (Sepucha et al., 2010). Thirty-six percent of participants felt extremely well-informed about their health and an additional 30 percent felt well-informed, while far fewer were able to recite risk factor estimates accurately, with no correlation between the two.[7]

While conclusive data are lacking, if patients do overestimate their own information, the results could be problematic: People facing major health decisions may erroneously think they don't need additional information to make an informed choice.

Nonetheless, subjective perceptions of being informed are important in their own right, whether or not they're an accurate proxy for health knowledge. As noted, BSCF's 2012 survey of low-income Californians found that patients who consider themselves well-informed about their health were much more likely than others to be confident in taking an active role in their care decisions, to feel comfortable asking questions of their providers, to report that they understand their providers' explanations and actually to take an active role in their health care. Feeling informed is a powerful predictor of patient empowerment and engagement regardless of whether or not it's a true measure of information or recall.

The 2012 BSCF study showed that feeling connected to healthcare providers and having continuity in care were important precursors to feeling informed. But the kind of tools, resources and communication styles most likely to empower patients – vs. those likelier to overwhelm them – remains an open question.

vii. decision aids

Decision aids are informational tools to help prepare patients to participate with their providers in making medical decisions. Typically focused on a particular medical situation, they are designed to present evidence-based information in an unbiased, complete and clear manner. Decision aids can come in many different formats, including pamphlets, videos, in-person presentations and internet-based resources (Lee & Emanuel, 2013; Stacey et al., 2011).

Patients' time with the doctor often is limited, so decision aids can give providers a way to share critical information with their patients without cutting into precious face time. These aids also may reduce the possibility that doctors' recommendations or biases will have an undue influence on patients' thinking (Fowler et al., 2011). The ultimate goal of decision aids is to put patients on a more level playing field with their providers and to facilitate discussion of patients' preferences regarding the medical decision they are facing.

A systematic review of 86 studies using decision aids and comparing their effectiveness in randomized controlled trials involving actual medical decisions suggests that, compared with patients under usual care, patients using decision aids had more knowledge, more accurate risk perceptions, more consistency between their values and the medical decision and less decisional conflict (Stacey et al., 2011). They also were less passive and less likely to remain undecided.

Further, this study, known as the Cochrane review, reported that patients facing major surgical decisions who used decision aids typically chose less invasive surgical options and more conservative approaches. (This finding encompasses 11 studies on procedures including surgery for removal of uterine fibroids, back surgery and surgery for breast and ovarian cancer.) Likewise, a recent observational study in a large health system in Washington state found that the introduction of video-based decision aids among patients with hip and knee osteoarthritis resulted in 26 percent fewer hip replacement surgeries and 38 percent fewer knee replacements compared with a control period (Arterburn et al., 2012). (Success, of course, is best measured by the perceived match between the patients' preferences and the care they receive.)

There is some concern that decision aids may make patients feel as if the burden of responsibility has been shifted from the doctor to them. The 20 studies included in this review that measured patient anxiety found no significant differences between those who used decision aids and those who did not.

While there were sampling and methodological problems with the studies included in the review,[8] the general consensus across studies suggests that decision aids have great promise to inform patients, help clarify their values and improve communications and interactions with providers. But clearly more research is needed to assess actual uptake and effectiveness among the general population, as well as interest in and readiness for such materials among those who have not been exposed to them.

Unlike decision aids, which neutrally lay out two or more viable options for a specific medical decision, behavioral support aids are resources that "describe, justify, and recommend actions that, over time, lead to predictable outcomes" (Elwyn, Frosch, & Rollnick, 2009). These aids may not to be specific to a single medical decision, but instead attempt to teach patients behaviors (e.g., how to reduce stress or eat better) that may improve their health overall. Our review of the literature did not find any systematic studies investigating the uptake of, interest in or effectiveness of these resources.

viii. internet and health information technologies

Online resources and electronic communications promise a vast transformation in the movement of health information between patients and healthcare providers – a process that in turn may spur patients' transition from passive recipients to active participants in their own care management. Among others, electronic health records (EHRs), patient portals and smartphone applications can equip all involved with greater information, interactivity and data management alike.

Use of the internet in general to obtain health information is widespread, though it varies greatly by groups and by purposes. Overall, more than six in 10 Americans (including eight in 10 internet users) report having used the internet to search for health information in the past (Pew, 2013). However, many fewer, 35 percent of adults, have gone online specifically to try to figure out a medical condition they or someone else might have and just more than one in 10 have accessed medical test results online. Moreover, just a quarter of patients facing a specific healthcare decision reported using the internet to find information to help them with that decision (Mathieu, 2010).

A California Healthcare Foundation survey in 2010[9] found that 30 percent of Americans had searched for information about doctors online; about two in 10 had tracked information about chronic illness, weight or exercise online; and 15 percent had renewed a prescription online. Rates were even lower (in the single digits) for exchanging e-mails with a doctor, looking at test results online, using tools that connect to a computer (e.g., blood glucose meters, heart rate monitors or blood pressure monitors) or participating online in a health forum or group. A 2009 study by the same foundation, among low-income Californians with chronic conditions, found that nearly half said they'd be interested in using the internet for information and support, although only 16 percent said they already relied on the internet at least some for help.

Health-related internet usage is higher among those facing a major health decision (e.g., surgery or cancer screening; Mathieu, 2010). It's also greater among younger and more educated Americans (who are more likely to be internet users in general); in an example of the socioeconomic "digital divide," the 2012 BSCF survey found that among low-income Californians, just 43 percent reported having ever used the internet to access health information.

Still, internet resources can be useful even among individuals who do not want, or cannot use, the technology themselves, because it can provide critical information to sources the patient does trust, such as friends, family and health coaches. A 2013 Pew report showed that more than half of internet users have looked for information related to someone else's medical situation. Therefore in addition to assessing direct interest in and access to health technology, it is important to assess the extent to which people have support from others to help them get the information they want and need.

It should be noted that internet resources are not seen as a replacement for healthcare providers (see Couper et al., 2010; Mathieu, 2010). Instead, patients see the internet as an important secondary source of information. In fact, Lee (2008) found that health information seeking on the internet was related to greater physician contact and communication. Though the causal arrow of this relationship is unclear, at the very least this suggests that patients are not using the internet to bypass their providers.

However, Diaz et al. (2002) found that 59 percent of those who had accessed health information online did not discuss it with their physicians. One reason for this lack of communication may be that doctors are not asking patients about information they find elsewhere. Indeed, unless explicitly encouraged, patients may feel that their doctors do not want them to seek out additional information about their health.

The same study found that 62 percent of those who had used the internet to search for information rated it as "excellent" or "very good," and six in 10 thought that the information was the "same as" or "better" than the information they received from their doctor (Diaz et al., 2002). Whether this perception aligns with reality is an open question – there are no standards for health information freely available on the internet, and we have found no research investigating whether those who have obtained information from the internet appear more or less knowledgeable.

There is little research available on other health information technologies. A recent quasi-experimental study conducted in healthcare institutions based in three states (Massachusetts, Pennsylvania and Washington) focused specifically on patients' access to electronic medical records (Delbanco et al., 2012). It suggests that this access may be beneficial to patients without significantly increasing the workload for providers.

Although problematic because of self-selection of physicians and patients alike, the study revealed potentially important insights. First, at the outset, physicians were less likely than patients to think that access to medical notes would benefit patients' treatment adherence, self-care or understanding of health conditions, and more likely to think that access to the notes would create confusion, worry and concerns about privacy, and might offend patients.

At the end of the year, among patients with notes available, more than eight in 10 had read the notes in two sites, but that declined to just less than half in the third site, an urban safety-net hospital. A majority of patients who opened at least one note and completed the post-intervention questionnaire reported that having access to their notes helped them feel more in control of their care and almost none reported that the notes caused confusion, worry or offense. Almost all wanted access to their notes continued.

Meanwhile physicians' concerns about workload diminished and most who answered an open-ended question reported that the process helped strengthen their relationships with their patients. When physicians at two institutions were given the option to discontinue their participation, none did. While the results are tentative given design challenges, patient interest in greater electronic access to medical records (including full medical notes) should be further investigated.

Additionally, a 2009 survey by the Kaiser Family Foundation, Harvard School of Public Health and National Public Radio found that three-quarters of Americans thought it was important for healthcare providers to keep electronic, rather than paper-based, healthcare records and two-thirds thought that the adoption of a system of electronic records that could be shared online would likely improve the overall quality of medical care in the country. Roughly six in 10 felt such a system would improve the quality of care their own family received and would reduce the number of people receiving unnecessary medical care.

Research into interest, usage and effectiveness of other health technology tools is even sparser. The 2012 BSCF study found broad interest among low-income Californians in tools that would allow them to receive reminders and health information via text message and to renew prescriptions, schedule appointments and review their medical records online. Interest in these resources among the broader population likely is even higher.[10]

At the same time, current usage of such resources appears fairly low.[11] A 2013 Pew report found that just 9 percent of cell phone owners who text message report having received text updates or alerts about health or medical issues from a doctor or pharmacist. But there is some evidence to suggest that such texts can be useful; a review of 20 randomized controlled trials and five controlled studies suggested that voice and text message interventions to provide care and disease management support were effective in improving compliance, symptoms, stress levels and self-efficacy (Krishna, Boren, & Balas, 2009). Whether these effects generalize beyond the specific populations studied remains an open question.

In sum, while a vast array of patient portals, health-related apps and other internet-based tools are under development, we find very little research investigating the specifics of what patients (and providers) actually want and need from these tools. Many open questions remain, including: What resources would be of most value to patients? What tools actually work (i.e., empower patients, give them critical information they can understand and/or allow them to communicate effectively with the provider)? Are health information technology preferences generally common, or is there wide individual variation? What aspects of healthcare delivery do patients not want to be replaced by technology? Can these resources become more overwhelming than empowering, and what can be done to prevent that outcome?

ix. information and the decision making process

Patient-centered care involves decisions that are reached collaboratively by doctors and patients, are informed by best available evidence and incorporate patients' preferences and values. Yet research suggests that most patients' experience falls short of one or more of these criteria.

For example, a content analysis of over a thousand clinical encounters between patients and primary care physicians or surgeons found that only 9 percent of decisions met the researchers' conditions for informed decision making (Braddock et al., 1999). The specific criteria assessed were whether or not there was a discussion of the patient's role, the clinical issue, alternatives, pros and cons of each alternative, uncertainties associated with options and patients' understanding and preferences.

The number of criteria that had to be met in order to be coded as an "informed" decision varied by the complexity of the decision. Basic decisions, such as whether or not to have a routine lab exam, were considered informed if they met at least two of the criteria (a discussion of the clinical issue and either a discussion of the patient's role or their preferences); only 17 percent did. Complex decisions, such as whether or not to get a screening test for prostate cancer, were only coded as "informed" if they met all the criteria. Almost none did.

Because the study used audiotaped interactions from patients of selected physicians recruited on a convenience-sample basis in Colorado and Oregon, it's impossible to estimate to what extent the results would generalize. Nonetheless, the findings are worrisome.

The DECISIONS study investigated similar questions, but using a self-report format (Zikmund-Fisher et al., 2010). Across the nine common medical decisions examined, 80 percent or more of respondents felt that they personally had made the decision or that they had shared in the decision-making process with their provider. Responses to specific questions about the decision-making process, however, suggested a less rosy picture.

Roughly eight in 10 patients reported that the provider made a recommendation, mostly in favor of taking action (i.e., taking medication, being screened or having surgery) as opposed to taking no action.

While the pros of the treatment or test were discussed in 90 percent of all decisions, a discussion of cons was less prevalent, reported in roughly half of medication and surgery discussions and fewer than three in 10 screening decisions.

A majority of respondents considering five of the six non-surgical decisions also indicated that they had not been asked their preferences for treatment (the exception was medication for depression). Still, 65 percent of participants felt extremely confident that their chosen option was the right decision, choosing "10" on a scale from 0-10.

The 2012 IOM survey found other disconnects between actual and ideal medical decision making. While eight in 10 patients strongly agreed that they wanted their provider to listen to them, just six in 10 strongly agreed that this is what they experienced. There were double-digit discrepancies between patients' desires and experiences of their providers' explanations of risks, discussions of no treatment as an option and coordination of care. Only 59 percent were extremely comfortable asking questions of their provider and only 57 percent said they felt comfortable telling their provider if they didn't understand something.

Although the researchers measured important dimensions such as explicit communication of not taking action as an option, other potentially informative aspects of the decision-making process seem to be unassessed.[12] These include the use of decision aids, the extent to which respondents felt like they received enough information, how they experienced this information (e.g., whether it was useful or overwhelming), precisely what kind of information they actually want to receive and in what format. Each is important because information that matches the needs of patients has the unique potential to improve their healthcare behaviors and outcomes alike (Tulsky, 2005).

Regardless, these results underscore the importance of measuring process variables, in addition to outcome variables such as satisfaction or belief that a decision was informed, which may reflect low expectations (Sepucha et al., 2004). Useful avenues for further research include measuring details of the decision-making process; the extent to which patients felt their values, preferences and desires for involvement were achieved; and their comfort with the ultimate decision.

There have been efforts to develop short survey instruments to assess the extent to which decisions reflect what's most important to a patient (Lee et al., 2010; Sepucha et al., 2008).

Using one such measure developed with a convenience sample of patients diagnosed with breast cancer in the last five years, researchers found striking differences in what patients and providers considered important (Lee et al., 2010). Only 7 percent of patients listed saving the affected breast as a top goal for them, compared with 71 percent of doctors.[13] For 86 percent of patients doing what doctors thought was best was a top goal; 14 percent of doctors said the same. Differences also were present, albeit not as starkly, in consideration of reconstructive surgery and hormone vs. chemotherapy.

Despite sampling issues, the findings suggest how priorities may substantially differ between the two groups and thus highlight the importance for patients to be able to communicate their preferences to their providers. Among other results, patients' inclination to rely on their providers' opinions suggests that not only doctors but also patients need experience and education in developing shared decision-making skills.

Reliance on providers may, at least in part, reflect emotional factors not typically assessed in the healthcare literature. Fear of outcomes, anger at one's own situation, being overwhelmed with options and information or being afraid that one will regret the decision may lead people to delegate some of their decision-making power to their providers. As developed in social psychology research, these emotional and psychological factors may further influence how people attend to and process information (Bodenhausen, Sheppard, & Kramer, 1994; Cottrell & Neuberg, 2005; Forgas, 2003; Small & Lerner, 2008; Tiedens & Linton, 2001).

x. communication

To participate in their health care meaningfully, patients need high-quality interactions and communication with their providers as well as high-quality, evidence-based information about their options and potential outcomes (Fowler et al., 2011). But practical and attitudinal barriers may make optimal communication difficult to achieve.

In terms of practical barriers, many healthcare facilities struggle with demand for doctors' time. Patients may be limited to briefer visits than they desire and may not see the same provider on each visit, both factors that can inhibit quality patient-provider communication.

The 2012 BSCF study showed that many low-income Californians lack continuity and connectedness in their care; while 86 percent felt that it was important to have someone at their healthcare facility who knows them well, just 38 percent actually had such a connection. And just a third reported seeing the same provider on every visit. The impact on patient-provider communication is clear – both continuity and connectedness are key predictors of patients' comfort asking the provider questions and their understanding of providers' explanations.

Further, a 2009 California Healthcare Foundation study found that low-income[14] Californians with at least one chronic health problem were more than 25 points more likely than higher earners to say they wished their doctor had more time to talk with them, they often leave medical appointments feeling confused, they feel like they are on their own in managing their health and they don't believe their providers understand what their experiences are like at home. Moreover, nearly half said their providers don't make plans to contact them after visits, don't refer them to support services, don't talk to them about self-care strategies and don't ask if they need help managing their health at home.

Strained patient-provider communication severely limits the likelihood that truly informed shared decision making can occur, but it also has a profound impact on patients' overall satisfaction with their care.[15] As the 2012 BSCF report documented, continuity and connectedness are primary predictors of overall satisfaction ratings. Further, the 2012 IOM report found that patients who feel that their provider listened to them, used clear language, explained their condition, discussed the risks and benefits of their options, mentioned the option of not taking action and provided medical evidence to help them make their decision were far more satisfied with their care than those who did not report such high-quality communication behaviors.

There may be ways to improve patient-provider communication (and, by extension, informed decision making and satisfaction) even in the absence of increased resources. The BSCF study found that clinic patients with team-based care[16] reported having as much connectedness with their facility as patients at private doctors' offices. Even if time and resource constraints on doctors restrict the amount of time they can spend with patients, improving patients' connection with other medical staff offers an alternative route to improved communication.

In terms of attitudinal barriers, patients must want to take on the responsibility of shared decision making, of course, but providers also must be willing to give up some of their power in order to give patients that role. A 2009 report by the Informed Medical Decisions Foundation describes some physician beliefs that must be overcome for this to happen. (The study, however, was conducted via a nonprobability opt-in online panel, so the results are not generalizable.)[17]

Nine in 10 or more physicians who participated in the study agreed that shared decision making was important for a variety of behaviors such as managing chronic conditions, taking medications and changing lifestyle behaviors; and about eight in 10 or more said they actually engaged in shared decision making with respect to the same behaviors. But 73 percent also said that the fact that they want their patients to rely on their recommendations was a barrier to engaging in more shared decision making. When asked to pick the most important barrier, 45 percent mentioned time constraints and 38 percent mentioned patients' lack of education and understanding.

Further, roughly eight in 10 or more said it was "very" important for patients to be well-informed about a variety of healthcare decisions from screenings to changing lifestyle behaviors, while just 20 percent or fewer thought their patients were very well-informed about each of these options. Nearly eight in 10 reported that patients brought with them information they gathered on their own, but those physicians were divided on whether this made their job easier or harder (four in 10 said each).

From 43 to 53 percent said that shared decision making would make it more likely for patients to request unnecessary tests, request costly imaging tests and opt for surgical procedures. However, as noted, a systematic review of decision aids suggests the opposite, finding that engaged and informed patients make more conservative decisions (Stacey et al., 2011).

These findings suggest that physicians may underestimate the ability and potential for patients to meaningfully engage in their care, barriers to shared decision making that may be communicated through non-verbal cues as well as by what is discussed and what is omitted.

Still, there's reason for optimism. As reviewed below, cross-sectional and intervention studies, albeit with shortcomings, indicate that communication styles and skills improve with training.

xi. cross-sectional studies and interventions

Communication is not only important to achieving the goals of patient-centered care, but also has been linked to increased patient satisfaction, treatment adherence, recall of information and health status (e.g., BSCF, 2012a, 2012b; Stewart, 1995; Zolnierek & DiMatteo, 2009).

In a review of randomized controlled trials and cross-sectional studies, Stewart (1995) found that asking patients questions in order to understand their problems and feelings, showing support and empathy, providing clear information and showing willingness to share decision making were associated with patients' reduced psychological distress and improved health status. But patient factors also played a role. Expressing oneself fully; conveying feelings, opinions and information; and asking questions also were associated with alleviated symptoms and less distress.

A more recent meta-analysis of 106 correlational studies and 21 experimental interventions found that better physician communication was associated with increased adherence (Zolnierek & DiMatteo, 2009). Measurement of physician communication varied across studies and included verbal, task-measured and nonverbal communications, and was operationalized in 10 of the studies via a measure of patients' trust in their providers.

Despite measurement shortcomings, across correlational studies, patients were more than twice as likely to adhere to treatment and prevention recommendations if their providers were better communicators than not. And studies assessing outcomes of communication skills interventions indicated that patients of providers who received training were nearly twice as likely to adhere to treatments as those of untrained providers.

The literature on this topic continues to expand (e.g., Tarn et al., 2013), often with randomized trial designs with small treatment and control groups. This work typically shows that even short (e.g., one-hour), single sessions result in improved ratings of physician communications.

Other studies have tested communication interventions using small-sample pre/post-test designs. Neeman et al. (2011) found that patients' self-confidence about communicating with their physicians, and perceptions that their problems and questions were effectively addressed, were improved simply by training doctors to use a short worksheet on which they can write notes in specific sections covering problems and symptoms, possible causes, treatment recommendations, timelines and patient questions and concerns.

Notably, most studies focus on the communication between patients and their physicians, lacking explorations of communication with other members of the care staff, who might have equally important roles in patient care and often spend more time with patients.[18]

There also has been some research on interventions targeting patients' communication skills. Kinnersley et al. (2009) identified 33 randomized trials aimed at encouraging patients to ask questions and gather information (in most cases, using written material provided to patients immediately before the visit, though some involved verbal coaching). A meta-analysis of these studies found that interventions led to small but statistically significant increases in the number of questions patients asked during appointments, as well as overall patient satisfaction.

Other research, albeit conducted with small convenience-based samples, also suggests that communication skills training for patients results in limited enhancements to their physicians' engagement style (Cegala, McClure, Marinelli, & Post, 2000; Cegala & Post, 2009). That is, patients who were either trained in communication skills or who were already skilled were apt to engage in more information seeking, assertive utterances and expression of concerns, which in turn elicited different communication styles from their physicians than did patients whose skills in communication were more limited.

Audiotaped interactions, coded by trained staff, indicated that as they interacted with patients with more developed skills, physicians' responses to patients' ideas, feelings and expectations were more exploratory and validating. However, physicians were not significantly more likely to facilitate agreement with the treatment plan by trying better to understand the patient's family, work situation, important beliefs and personal struggles.

While clearly more work is necessary on interventions for improving provider and patient communication skills, available research is encouraging. Physicians, and surely other healthcare providers, can be trained in communication skills, and improvements in communication patterns are likely to be associated with improved patient outcomes. Available research suggests that patients also can benefit from skills training. Nonetheless, what's noticeably lacking from the literature is good-quality research that better assesses what types of specific communication behaviors are associated with what types of outcomes.

xii. alternative models of care and patient activation

Not all health care takes place in the confines of an office visit. Alternative forms of care such as groups and self-management programs can provide much needed support for patients while helping to alleviate the time and financial pressures of an already over-stretched system.

One example is the Chronic Disease Self-Management Program developed at Stanford University (Lorig et al., 1999; Lorig et al., 2001), a weekly six-week workshop that trains individuals with chronic diseases in health maintenance strategies, confidence and self-efficacy. The highly participatory sessions, each taught by two trained leaders, focus on dealing with frustration and pain; exercise and nutrition; medications; communication skills for interacting with family, friends and healthcare staff; decision making; and evaluating treatments.

Randomized, controlled tests of the program suggest that participants have better health outcomes (e.g., fewer days of hospital stays); improvements in self-reported health, distress and fatigue; and better communication with healthcare professionals.

Other research also finds that such programs focusing on skill development, problem solving and peer support are related to increased patient activation, a concept that refers to patients' willingness and confidence that they can take actions to manage their own health (Frosch, Rincon, Ochoa, & Mangione, 2010; Hibbard & Greene, 2013; Lorig & Alvarez, 2011).

Typically, patient activation is measured with a 13-item scale that consists of statements with which respondents are asked how much they agree or disagree (Hibbard et al., 2005), as noted a suboptimal format (Saris et al., 2010). The activation scale assesses agency and feelings of responsibility in taking charge of one's health, confidence that one can carry out novel and maintenance health behaviors and perceived levels of information. One item specifically covers communication behaviors (confidence that one can tell his/her provider of any concerns even when not asked).

Patient activation itself is associated with a variety of important outcomes, including increased preventative behaviors, decreased health-compromising behaviors (e.g., smoking and drug use) and increased patient engagement in clinical settings (e.g., preparing questions, knowing more about treatment options, seeking out health information; Fowles et al., 2009; Greene & Hibbard, 2012; Hibbard & Cunningham, 2008; Hibbard & Greene, 2013; Salyers et al., 2009). Further, patients with higher activation scores are less likely to require costly care such as hospitalization and their annual costs of care overall are lower than those with lower scores (Hibbard et al., 2013).

xiii. recommendations

This review of the academic literature and major public opinion studies suggests content areas for new research on the topic and points to a range of unanswered questions, among them:

- Health information needs of low-income individuals more broadly, including how much information they desire, in what format and from what sources.

- Experiences with information sources that patients currently use; whether or not it meets their needs, the extent to which it eases their concerns or overwhelms them, and whether they find information from care providers accessible or confusing.

- The extent to which patients feel informed about their health, any conditions they may have, expected effects of medications or treatments and where to go for help or more information.

- The amount of information patients say providers have given to them, including sharing pros and cons of each treatment approach (including the option of no treatment).

- Comfort asking questions of providers, disagreeing with recommendations, sharing information obtained from other sources and expressing preferences to wait to make a decision or to seek a second opinion.

- Perceptions that providers welcome and encourage patient participation, don't act defensively when patients disagree, and will support the patient's decision.

- Satisfaction with or confidence in previous health decisions and the extent of patients' involvement in decision making, including, beyond whether the decision was shared or not, whether it matched their desired level of involvement and whether their needs, values and preferences were elicited, heard and reflected in the decision.

- The extent to which patients have been exposed to decision and behavioral support aids, their ratings of such tools and perceptions of their usefulness. Prevalence of discussion with providers after reviewing decision aids. Interest in using decision aids among patients who have not been exposed to them in the past.

- Experience with various positive provider behaviors including maintaining contact with patients outside of visits, addressing self-care strategies, referring patients to support resources, and investigating what help patients feel they need to manage their care.

- Experience with and desire for access to medical records, online self-management, and communication tools and other health information technology from providers, insurers or other sources.

- The aspects of healthcare delivery patients are most and least interested in having replaced or augmented by technology.

- Amount of (desired and actual) support from others in taking care of one's health, including help with technology and obtaining necessary information.

- Exposure to, experience with and openness to alternative care models including team care, health coaches, peer support groups and self-management programs.

- Connectedness and continuity, both of which were shown in our 2012 BSCF survey to be important predictors of feeling informed, empowered and engaged.

endnotes

1 Often, researchers note the need to honor the preferences of the patient's family as well (e.g., Alston et al., 2012).

2 Defined as those with household incomes less than 200 percent of the federal poverty level.

3 Note that while the Pew report was released in 2013, the data were collected in 2012.

4 This survey was limited to adults who possessed landline home telephone service, a potentially problematic restriction. Interviews were conducted only among those who made a recent decision on whether or not to take medication for hypertension, hypercholesterolemia or depression; to undergo a screening test for colorectal, breast, or prostate cancer; or to have surgery for knee/hip replacement, cataracts or lower back pain. Questionnaire design was problematic, e.g., partially labeled number scales.

5 While full methodological details are lacking, the 2012 IOM survey used a probability-based sample, but appeared to rely on suboptimal questionnaire design, including agree/disagree questions.

6 For example, studies have shown that students overestimate their performance on exams and physicians overestimate the accuracy of their diagnoses (Christensen-Szalanski & Bushyhead, 1981; Clayson, 2005).

7 Less-educated and lower-income respondents were more likely than their counterparts to report feeling extremely well-informed, suggesting the result may have been an artifact of the cognitive burden imposed by the survey's questionnaire design, in this case, a partially labeled 11-point number scale. The 2012 BSCF survey, using a four-point verbal scale, found no such pattern.

8 In addition to using convenience samples, many of the scales used to assess the key dependent variables (e.g., knowledge, how informed respondents feel and how certain they are about their decision) suffered from psychometric shortcomings such as true/false questions, which can encourage guessing; and unbalanced agree/disagree or yes/no questions, which can artificially inflate agreement.

9 The survey items have many measurement problems, including yes/no items, agree/disagree questions and scales with unlabeled options. But the question topics remain useful.

10 Indeed, many convenience-sample studies have found broad interest among patients in communicating with their physicians, requesting medication refills, obtaining test results and making appointments via email (see, for example, Couchman, Forjuoh, & Rascoe, 2001; Kleiner et al., 2002; Sittig, King, & Hazlehurst, 2001). Moreover, Liederman and Morefield (2003) suggest that when patients do have access to electronic communication tools they highly value them. Their convenience-sample study investigated a web messaging system used in a UC Davis clinic and found that more than three-quarters of users reported the system was easy to use, gave better access to their provider and was better than using the phone to reach their doctor.

11 Again, available evidence about current usage of these types of online resources comes from studies using convenience samples, which make it impossible to generalize to the broader population. For example, Moyer et al. (2002) found that despite broad interest, just 10 percent of e-mail users reported e-mailing with their doctors (see also Sittig et al., 2001). Lacher et al. (2000) found that just 7 percent of physicians reported exchanging e-mail with their patients.

12 Because of the incomplete disclosure of research findings, assertions are tentative.

13 Providers were asked their most important goals for each treatment option, not what they felt the patients' top goals were. It's possible goals would have aligned more if providers were asked what they felt patients wanted. Still, it's noteworthy that providers' and patients' goals were so different.

14 Defined in this study as those with household incomes less than $20,000 a year.

15 Several studies utilizing convenience samples also suggest that strained patient-provider communication can be detrimental to patient adherence and health outcomes (e.g., Beach, Keruly, & Moore, 2006; Schneider et al., 2004; Schoenthaler et al., 2009; Wroth & Pathman, 2006), though due to methodological limitations of these studies the results are only suggestive.

16 Team-based care is an alternative model for care in which a team of medical professionals, including doctors, nurses and health coaches, among others, work together to provide patients care.

17 Questionnaire construction is another problem with this study. Among other challenges, questions include biased or unbalanced wording and vague descriptions of key constructs.

18 Although most interventions are targeted towards physicians (Tulsky, 2005), some investigators have included nurses (e.g., Ferrell et al., 2005; Maguire & Pitceathly, 2003).

appendix b – topline data report

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

		Excellent/very good				**Fair/poor**			
		NET	Excellent	Very good	Good	**NET**	Fair	Poor	No opinion
6/18/13	All	52	20	32	29	19	15	4	*
	<200% FPL	35	12	22	34	31	25	7	*
	200%+ FPL	61	24	37	26	13	11	2	*

1. About how many times in the past year have you seen a doctor, nurse or other healthcare provider?

		None	**Once**	**2-5 times**	**6+ times**	**No opinion**	**Mean**	**Median**
6/18/13	All	16	23	42	17	1	4.55	2
	<200% FPL	19	21	40	18	2	4.83	2
	200%+ FPL	15	25	44	16	*	4.38	2

2/2a/3/4. 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? [Follow-ups specified – see questionnaire.]

6/18/13 – Summary Table

	All	**<200% FPL**	**200%+ FPL**
Kaiser Permanente	19	9	24
Private doctor's office	41	25	50
Clinic NET	**27**	**48**	**17**
Community clinic or health center	8	16	5
Public hospital clinic	5	11	2
Private/religious hospital clinic	4	3	4
Hospital clinic other/unknown type	*	1	-
County/city clinic	1	3	1
Private clinic	4	6	3
Clinic other/unknown type	5	8	3
Hospital emergency room	5	9	3
Hospital unspecified	1	1	1
Someplace else	5	6	4
Never have gone for health care*	1	1	*
No opinion	1	1	*

*Asked 1z, Q2-4, 7, 16-25, 27-29, 42-44, 55-59, 1z2 and demographics.

5/5a. 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?

		Excellent/very good				**Not so good/poor**			
		NET	Excellent	Very good	Good	**NET**	Not so good	Poor	No opinion
6/18/13	All	63	36	27	30	6	5	2	*
	<200% FPL	49	26	23	41	9	6	3	1
	200%+ FPL	69	40	29	25	5	4	1	*

*If no usual place: "the last time you received health care"

6. 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?

		Yes	**No**	**No opinion**
6/18/13	All	47	52	1
	<200% FPL	38	61	1
	200%+ FPL	52	48	1

7. 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?

		Usually				**Rarely/never**			
		NET	Every time	Most of the time	Some of the time	**NET**	Rarely	Never	No opinion
6/18/13	All	66	39	27	14	19	13	6	1
	<200% FPL	53	29	24	21	25	16	9	1
	200%+ FPL	72	44	28	11	16	11	5	*

Q8-11 held for release.

12. To what extent, if at all, do you feel that the healthcare providers at the facility you (usually go/last went) to care about you as a person, not just a patient – do you think they care about you personally a great deal, a good amount, just some, not so much or not at all?

		Care a lot				**Care less**			
		NET	A great deal	A good amount	Just some	**NET**	Not so much	Not at all	No opinion
6/18/13	All	59	26	33	24	15	10	5	1
	<200% FPL	56	23	34	25	16	10	6	2
	200%+ FPL	60	28	32	24	15	10	5	1

Q13-15 held for release.

16. On another topic, do you personally have access to the internet or e-mail, or not?

		Yes	No	No opinion
6/18/13	All	77	23	0
	<200% FPL	58	42	0
	200%+ FPL	87	13	0

17. (IF HAS INTERNET ACCESS, Q16) Does that include internet or e-mail access through a smartphone, or not?

		Yes	No	No opinion
6/18/13	All	76	24	*
	<200% FPL	67	33	*
	200%+ FPL	79	21	*

16/17 NET:

		Has internet access				
		NET	Smartphone	No smartphone	No internet	No opinion
6/18/13	All	77	59	18	23	0
	<200% FPL	58	39	19	42	0
	200%+ FPL	87	69	18	13	0

18. (IF DOES NOT HAVE INTERNET ACCESS, Q16) Do you have a cell phone that can send and receive text messages, or not?

		Yes	No	No opinion
6/18/13	All	88	12	*
	<200% FPL	80	20	*
	200%+ FPL	91	8	*

19. (IF HAS INTERNET ACCESS, Q16) Have you ever used (the internet/the internet or your smartphone) to access any health or wellness websites or applications, or not?

		Yes	No	No opinion
6/18/13	All	67	33	*
	<200% FPL	56	44	0
	200%+ FPL	70	29	*

16/19 NET:

		Has internet access				
		NET	Used for health info.	Hasn't used for health info.	No internet	No opinion
6/18/13	All	77	52	25	23	0
	<200% FPL	58	33	26	42	0
	200%+ FPL	87	61	26	13	0

20. (IF HAS INTERNET ACCESS, Q16) Please tell me how interested you are in using a website or app to do each item I name. First is using a website or app to [ITEM] – are you very interested in doing that, somewhat interested, not so interested or not interested at all? If you already do this, please just say so.

6/18/13 - Summary Table

	Interested				Not interested			
	NET	Do now	Very	Smwt	**NET**	Not so	At all	No op.
a. Look for information about a medical problem for yourself or someone else								
All	85	19	42	25	15	7	8	*
<200% FPL	84	17	36	31	16	7	9	*
200+% FPL	86	19	43	23	14	7	7	*
b. Look for information or advice about dieting, nutrition or exercise								
All	76	19	26	32	23	11	13	*
<200% FPL	76	14	31	31	24	11	14	0
200%+ FPL	77	20	25	32	23	11	12	1
c. Find support or advice from other people with similar health issues								
All	68	9	22	37	32	14	17	*
<200% FPL	70	8	26	37	29	15	15	*
200%+ FPL	67	10	20	37	32	14	18	1
d. Share a personal health experience with others, or read about someone else's experiences								
All	57	9	17	32	43	20	22	*
<200% FPL	61	6	19	37	39	18	21	0
200%+ FPL	56	9	16	30	44	21	22	*
e. Sign up to receive automatic health messages or reminders								
All	53	11	19	24	46	17	29	*
<200% FPL	56	6	21	29	44	19	25	0
200%+ FPL	53	12	18	23	46	16	30	*
f. Track health, exercise or nutrition information								
All	72	17	26	30	27	14	13	*
<200% FPL	74	14	29	30	26	12	14	*
200%+ FPL	72	17	25	30	28	14	13	*

21. (IF HAS SMARTPHONE, Q17*) In general, would you be more interested in doing the things I just mentioned using (an app), using (a website), or both equally?

		App	Website	Both equally	No opinion
6/18/13	All	11	26	60	3
	<200% FPL	11	21	67	1
	200%+ FPL	11	28	59	3

*Respondents with a smartphone who said they were not interested at all in any of the items in Q20 (n = 17) were not asked Q21.

22. 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			Not informed			
		NET	Very	Somewhat	NET	Not so	At all	No opinion
6/18/13	All	89	51	38	10	7	3	1
	<200% FPL	82	43	39	17	10	6	1
	200%+ FPL	93	55	38	7	6	2	*

23. (Do you feel like you have all the information you need to make informed decisions about your health), or (do you feel that having more information than you have now would help you make better decisions about your health)?

		Have all I need	More info. would help	Have more than need (vol.)	No opinion
6/18/13	All	47	51	*	1
	<200% FPL	43	55	1	2
	200%+ FPL	49	50	*	1

24. (IF FEELS LIKE MORE INFORMATION WOULD HELP, Q23) How much more information about your health would you like to have – a lot more, just some or only a little more?

		A lot	Some	A little	No opinion
6/18/13	All	49	37	14	*
	<200% FPL	56	30	14	1
	200%+ FPL	46	41	13	0

23/24 NET:

		Want more health info.						
		NET	A lot	Some	A little	Have all I need	Have more than need (vol.)	No op.
6/18/13	All	51	25	19	7	47	*	1
	<200% FPL	55	30	16	8	43	1	2
	200%+ FPL	50	23	20	7	49	*	1

25. (IF HAS ALL INFORMATION NEEDED, Q23) Imagine if more information about your health was easier to find and to understand. In that case would you (like to have more information than you have now), or would you (still say you already have enough information)?

		Like more	Have enough	No opinion
6/18/13	All	38	61	1
	<200% FPL	37	63	*
	200%+ FPL	39	60	1

23/25 NET:

		Want more health info					
		NET	In general	If easier to find/und.	Have all I need	Have more than need (vol.)	No op.
6/18/13	All	51	29	18	47	*	1
	<200% FPL	55	27	16	43	1	2
	200%+ FPL	50	30	19	49	*	1

Q26 held for release.

27. Do you find searching for health information on your own more (helpful) or more (overwhelming)? Do you feel that way strongly or somewhat?

		Helpful			Overwhelming				
		NET	Str.	Smwt.	NET	Smwt.	Str.	Haven't tried (vol.)	No op.
6/18/13	All	67	38	29	28	17	11	2	2
	<200% FPL	62	31	32	34	21	13	2	2
	200%+ FPL	70	42	28	25	15	10	2	3

28. Where do you get most of the information you have about your health – (from healthcare providers), (from friends and family), or (from sources like books, magazines, television or the internet)?

		Providers	Family	Books/TV	Other (vol.)	Multiple (vol.)	Don't get info.(vol.)	No op.
6/18/13	All	41	14	37	1	7	1	*
	<200% FPL	38	15	39	1	5	1	1
	200%+ FPL	42	13	36	1	8	1	0

29. Thinking about different sources of health information, how much do you think you can trust health information you can get from [ITEM] – can you trust it completely, mostly, somewhat, not much or not at all?

6/18/13 - Summary Table

	More trust				**Less trust**			
	NET	Completely	Mostly	Somewhat	**NET**	Not much	Not at all	No op.
a. Doctors you see								
All	81	33	48	14	4	3	1	*
<200% FPL	70	29	42	19	10	6	4	1
200%+ FPL	87	35	51	12	1	1	0	*
b. Nurses, physician assistants or other medical staff you see								
All	69	21	47	23	8	5	3	1
<200% FPL	61	19	42	25	13	8	5	1
200%+ FPL	73	23	50	22	5	4	1	*
c. (IF HAS HEALTHCARE COACH, Q8) Your healthcare coach								
All	73	32	41	18	6	4	2	4
<200% FPL	71	25	46	20	8	5	3	1
200%+ FPL	74	37	37	17	4	4	1	5
d. Friends and family								
All	31	8	23	46	23	16	6	*
<200% FPL	33	10	23	40	26	17	9	1
200%+ FPL	30	8	23	49	21	16	5	*
e. Other people with health issues like yours								
All	30	6	23	46	23	15	7	2
<200% FPL	31	10	21	42	25	16	9	2
200%+ FPL	29	5	25	48	21	15	6	1
f. (IF HAS USED INTERNET/APPS FOR HEALTH REASONS, Q19) The websites you personally have used on the internet								
All	44	8	36	48	7	6	1	1
<200% FPL	41	8	33	51	8	7	*	1
200%+ FPL	46	8	37	47	7	6	1	1
g. (IF HAS SMARTPHONE, Q17) Health-related apps you can get on your smartphone								
All	32	4	28	43	21	10	10	5
<200% FPL	39	8	31	41	18	10	8	2
200%+ FPL	30	3	27	44	21	11	10	6

30a. (IF HAS SMART OR TEXTING PHONE, Q16/17) Do the healthcare providers or staff at the place you (usually go/last went) for health care ever send you text messages, or not?

		Yes	No	No opinion
6/18/13	All	15	85	*
	<200% FPL	11	89	0
	200%+ FPL	16	83	*

30b. (IF GETS TEXT MESSAGES FROM PROVIDERS, Q30a) Are these mainly (automated messages) or mainly (individual messages to you personally)?

		Automated	Individual	Both (vol.)	No opinion
6/18/13	All	44	46	8	1
	<200% FPL	35	53	5	7
	200%+ FPL	47	44	9	0

30a/30b NET:

		Receives texts from providers					
		NET	Automated	Individual	Both (vol.)	No texts	No opinion
6/18/13	All	15	7	7	1	85	*
	<200% FPL	11	4	6	1	89	0
	200%+ FPL	16	8	7	2	83	*

31a. (IF HAS INTERNET ACCESS, Q16) Do the healthcare providers or staff at the place you (usually go/last went) for health care ever send you e-mails, or not?

		Yes	No	No opinion
6/18/13	All	36	64	0
	<200% FPL	22	78	0
	200%+ FPL	40	60	0

31b. (IF GETS E-MAILS FROM PROVIDERS, Q31b) Are these mainly (automated e-mails) or mainly (individual e-mails to you personally)?

		Automated	Individual	Both (vol.)	No opinion
6/18/13	All	33	39	26	2
	<200% FPL	32	38	25	5
	200%+ FPL	33	39	26	2

31a/31b NET:

		Receives e-mails from providers					
		NET	Automated	Individual	Both (vol.)	No e-mails	No opinion
6/18/13	All	36	12	14	9	64	0
	<200% FPL	22	7	8	6	78	0
	200%+ FPL	40	13	16	10	60	0

32a. Does the place you (usually go/last went) for health care ever call you by phone, or not?

		Yes	**No**	**No opinion**
6/18/13	All	74	26	*
	<200% FPL	72	28	*
	200%+ FPL	75	25	0

32b. (IF GETS PHONE CALLS FROM FACILITY, Q32a) Are these mainly (automated calls) or mainly (individual calls to you personally)?

		Automated	**Individual**	**Both (vol.)**	**No opinion**
6/18/13	All	19	71	10	*
	<200% FPL	20	73	6	*
	200%+ FPL	18	69	13	*

32a/32b NET:

		Receives phone calls from facility					
		NET	Automated	Individual	Both (vol.)	No calls	No opinion
6/18/13	All	74	14	52	8	26	*
	<200% FPL	72	14	53	5	28	*
	200%+ FPL	75	14	52	9	25	0

33. (IF HAS SMART OR TEXTING PHONE, Q17/18) As far as you know, when you have a question, can you get an answer by texting the healthcare providers or staff at the place you (usually go/last went) for care, or not?

		Yes	**No**	**No opinion**
6/18/13	All	15	73	12
	<200% FPL	18	75	8
	200%+ FPL	15	72	14

34. (IF HAS INTERNET ACCESS, Q16) As far as you know, when you have a question, can you get an answer by e-mailing the healthcare providers or staff at the place you (usually go/last went) for care, or not?

		Yes	No	No opinion
6/18/13	All	42	45	12
	<200% FPL	32	57	10
	200%+ FPL	45	42	13

35. (IF RECEIVES OR CAN SEND TEXT AND/OR EMAILS TO PROVIDERS, Q30a/31a/32a/33/34) How do you feel about the ability to communicate by (text message/e-mail/text message and e-mail) with the people where you (usually go/last went) for care – do you find this very useful, somewhat useful, not so useful or not useful at all?

		Useful			Not useful					
		NET	Very	Smwt.	**NET**	Not so	At all	Haven't done (vol.)	Dep.	No op.
6/18/13	All	89	52	37	8	4	4	2	1	*
	<200% FPL	87	53	34	10	5	6	2	0	*
	200%+ FPL	89	52	37	7	4	3	2	1	*

36. (IF CANNOT TEXT PROVIDERS, Q33) Assuming they respond, how interested would you be in being able to text the healthcare providers or staff at the place you (usually go/last went) for care when you have a question – very interested, somewhat interested, not so interested or not interested at all?

		Interested			Not interested			
		NET	Very	Somewhat	NET	Not so	Not at all	No opinion
6/18/13	All	66	35	30	34	15	19	*
	<200% FPL	70	40	30	29	13	17	1
	200%+ FPL	64	34	31	35	16	19	*

37. (IF CANNOT E-MAIL PROVIDERS, Q34) Assuming they respond, how interested would you be in being able to e-mail the healthcare providers or staff at the place you (usually go/last went) for care when you have a question – very interested, somewhat interested, not so interested or not interested at all?

		Interested			Not interested			
		NET	Very	Somewhat	**NET**	Not so	Not at all	No opinion
6/18/13	All	73	44	30	26	9	16	1
	<200% FPL	75	44	31	25	14	12	0
	200%+ FPL	73	43	30	26	7	18	1

38. Some healthcare facilities have a website where patients can go to do things like (make appointments), (view their medical records and test results), (ask doctors or nurses questions) and (find health information). It's sometimes called a patient portal. As far as you know, does the place where you (usually go/last went) for care have such a website or patient portal, or not?

		Yes	**No**	**No opinion**
6/18/13	All	37	44	19
	<200% FPL	29	50	21
	200%+ FPL	40	41	19

39. (IF HAS INTERNET ACCESS, Q16, AND FACILITY DOES NOT HAVE PORTAL, Q38) How interested would you be in using a patient portal as I've described it – very interested, somewhat interested, not so interested or not interested at all?

		Interested			**Not interested**			
		NET	Very	Somewhat	**NET**	Not so	Not at all	No opinion
6/18/13	All	76	42	34	24	9	15	*
	<200% FPL	74	44	31	25	13	12	*
	200%+ FPL	76	41	36	23	7	17	*

40. (IF HAS INTERNET ACCESS, Q16, AND FACILITY HAS A PORTAL, Q38) How useful do you find this portal – very useful, somewhat useful, not so useful or not useful at all? If you've never used it, just say so.

		Useful			**Not useful**				
		NET	Very	Somewhat	**NET**	Not so	At all	Haven't used it (vol.)	No opinion
6/18/13	All	78	53	25	2	1	1	18	2
	<200% FPL	69	50	19	5	2	3	25	*
	200%+ FPL	81	54	27	2	1	1	16	2

41. (IF HAS INTERNET ACCESS, Q16, AND [FACILITY HAS A PORTAL OR EXPRESSES INTEREST IN PORTAL*, Q38/Q39]) I'll name some possible features of a patient portal. For each, please tell me how interested you'd be in doing this using a patient portal – very interested, somewhat interested, not so interested, or not interested at all. First is being able to [ITEM] – is that something you'd be very interested in doing using a patient portal, somewhat interested in doing, not so interested or not interested at all in doing?

6/18/13 - Summary Table

	Interested				Not interested			
	NET	Do now (vol.)	Very	Smwt.	**NET**	Not so	At all	No op.
a. Schedule appointments online								
All	87	2	66	19	12	6	7	*
<200% FPL	85	1	60	23	15	8	7	0
200%+ FPL	89	3	69	17	11	4	7	*
b. View your medical records								
All	90	2	70	18	10	4	6	*
<200% FPL	89	1	64	23	11	6	5	*
200%+ FPL	91	2	73	16	9	3	6	-
c. Ask the doctor or nurse questions								
All	91	1	65	25	9	4	5	*
<200% FPL	89	1	57	31	12	7	4	0
200%+ FPL	92	2	67	23	7	2	5	*
d. Find health information your healthcare provider recommends								
All	91	1	59	31	9	4	5	*
<200% FPL	90	*	53	37	9	6	4	*
200%+ FPL	91	1	62	28	9	4	5	0
e. View your test or lab results								
All	92	2	74	16	8	3	5	*
<200% FPL	92	1	69	21	8	4	5	*
200%+ FPL	92	2	76	14	7	2	5	0
f. Ask for a referral to a specialist								
All	89	1	65	23	11	5	6	*
<200% FPL	87	*	59	28	13	8	5	*
200%+ FPL	90	1	68	20	10	4	6	0

*Only those who say they are "not at all interested" in a portal were excluded from this question.

Q42-56 held for release.

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

		Yes	**No**	**No opinion**
6/18/13	All	22	78	*
	<200% FPL	23	76	*
	200%+ FPL	21	79	*

58. (IF HAS DISABILITY OR CHRONIC CONDITION, Q57) At what age were you first diagnosed with a disability or chronic condition?

		<29	30-39	40-49	50-64	Not diagnosed (vol.)	No opinion	Mean	Median
6/18/13	All	38	19	26	14	*	2	32.9	35
	<200% FPL	43	20	21	13	1	2	31.3	33
	200%+ FPL	37	19	28	15	0	2	33.8	35

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

6/18/13 – Summary Table

	All	<200% FPL	200%+ FPL
Private NET	**65**	**33**	**81**
Employer-purchased insurance	55	25	71
Self-purchased insurance	10	9	10
Government subsidized NET	**16**	**35**	**9**
MediCal, also known as Medicaid	10	24	3
Any other state health insurance program	3	5	2
V.A., Tri-Care, military, federal	3	3	3
Indian Health Service	*	*	0
Medicare	1	1	1
Medicare and MediCal	*	1	*
None, you are uninsured	17	30	10
No opinion	1	2	1

Selected demographics:

6/18/13 – Summary Table

	All	<200% FPL	200%+ FPL
Sex			
Male	49	47	50
Female	51	53	50
Age			
19-29	25	33	22
30-39	22	23	22
40-49	22	21	23
50-64	30	23	33
Relationship status			
Married	47	34	54
Living with a partner	13	17	10
Widowed	2	2	2
Divorced	6	7	6
Separated	3	5	2
Single	28	35	25

6/18/13 – Summary Table

	All	<200% FPL	200%+ FPL
Employment status			
Employed, full-time	53	34	63
Employed, part-time	18	26	15
Not employed NET	**28**	**40**	**22**
Retired	4	4	4
Homemaker	7	9	5
Student	5	6	4
Unemployed	9	13	6
Disabled	4	6	2
Other	1	1	*
No opinion	*	1	*
Education			
Less than high school NET	**17**	**32**	**9**
8th grade or less	7	13	4
Some high school	10	18	6
High school graduate	21	26	19
Some college/associates degree	33	31	34
College graduate NET	**29**	**12**	**37**
Graduated college	19	9	23
Post graduate	10	2	14
Race/Ethnicity			
White, non-Latino	42	27	49
Black, non-Latino	6	7	6
Latino NET	**36**	**53**	**28**
White Latino	24	34	20
Black Latino	7	13	4
Latino unspecified	5	7	4
Asian	12	9	13
Multiracial	2	2	3
Other	1	2	1
Income			
<$16,000	10	29	0
$16,000-$30,999	18	46	4
$31,000-$52,999*	22	16	25
$53,000+ NET	**45**	**2**	**68**
$53,000-$99,999	24	2	35
$100,000+	21	0	33
No opinion	5	7	4

appendix c – methodology

This Blue Shield of California Foundation survey was conducted May 2 to June 8, 2013, via telephone interviews with a representative statewide sample of 1,530 Californians between the ages of 19 to 64, including 1,018 with household family incomes below 200 percent of the federal poverty level (FPL) and 498 with household family incomes at 200 percent of the FPL or more.1,2 The sample was composed of 819 landline and 711 cell phone interviews, with 1,196 interviews conducted all or mostly in English and 334 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 simultaneously reach the lower-income population as efficiently as possible, while reaching a representative sample of the higher-income population. The design accounted for the high incidence of Latino families within the low-income California population and addressed 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 FPL). 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.[3]

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 50 percent of the qualifying population was estimated to be CPO, the estimated number of people in each of the unlisted cells was reduced by 50 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.

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 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 and project staff provided feedback to interviewers throughout the survey period.

A live pretest of the survey instrument was conducted April 23-24, 2013. In all, 26 pretest interviews were completed during this time period (six in Spanish). 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 live interviews, along with SSRS project managers. Additional interviews were digitally recorded and placed on a secure FTP site for review.

The questionnaire screened for eligible households by establishing the respondent's family size and annual family income,[4] then selecting only respondents between the ages of 19 and 64, with an oversample of respondents with family incomes under 200 percent FPL.[5] In households that were reached by landline, respondents were randomly selected from the qualifying household residents by asking for the male or female 19 to 64 years old 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 busy signals) 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.

weighting procedures

A multi-stage weighting design was applied to ensure an accurate representation of the target population(s). Weighting was done separately for each income group (less than 200 percent FPL and 200 percent-plus FPL) and involved the following stages:

1. *Sample design correction*. In order to correct for over- or under-sampling 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, low-income cases in the *Residual-LA* cell received a weight equal to their estimated share among low-income households (21 percent of low-income households) divided by their share among the landline low-income interviews (10 percent). Using more exact values, the calculation for the weight for this cell ($W_{\text{resid-LA}}$) is:

   $W_{\text{resid-LA}} = .20532/.09765 = 2.10261$

   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 and higher-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 base weight.

3. *Post-stratification weighting.* With the base weight applied, the low-income and higher-income samples were put, separately, 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 and those with family incomes of 200 percent FPL or more, respectively. 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);[6] citizenship status 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.

5. *Income-group proportionate adjustment.* The sample design called for a minimum of 1,000 interviews with respondents with household incomes less than 200 percent FPL and 500 with respondents with household incomes at or greater than 200 percent FPL. However, among 19- to 64-year-old Californians, only 33.5 percent are low-income. To create

an accurate estimate of the state of California overall, the low-income sample weights were multiplied by approximately 0.5, while the higher income weights were multiplied by approximately 2.0. The sum of weights for the 14 cases who refused income remained 14.

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 and rounding.)

table 1a. acs estimates and unweighted and weighted sample percentages – less than 200 percent FPL

	ACS	Unweighted sample	Weighted sample
Race			
White non-Latino	27.9%	26.5%	27.5%
Black non-Latino	7.3	7.8	7.2
Latino	52.4	56.0	53.0
Other non-Latino	12.4	9.6	12.4
Sex/race			
Male, non-Latino	22.4	18.4	21.9
Female, non-Latino	25.2	26.0	25.3
Male, Latino	25.1	25.4	25.2
Female, Latino	27.3	30.3	27.6
Education			
Less than high school	31.6	30.3	31.6
High-school education	26.1	29.4	26.2
Some college	30.9	26.3	30.7
College graduate-plus	11.4	13.9	11.5
Age			
19-29	32.8	25.6	32.6
30-39	23.1	20.0	23.0
40-49	21.0	20.1	21.0
50-64	23.0	34.4	23.4
Region			
Sierra/Northern Counties	4.2	5.3	4.1
Greater Bay Area	14.3	10.8	13.7
Sacramento Area	5.6	5.4	5.4
San Joaquin Valley	13.2	14.0	12.7
Central Coast	5.4	7.1	5.4
LA County	30.1	29.4	29.0
Other Southern CA	27.2	24.8	26.6
Phone status			
Cell phone only	55.6	36.7	55.1
Some landline use	44.4	63.3	44.9

table 1b. acs estimates and unweighted and weighted sample percentages – 200 percent FPL or more

	ACS	Unweighted sample	Weighted sample
Race			
White non-Latino	49.0%	57.4%	48.8%
Black non-Latino	5.5	6.3	5.5
Latino	28.2	23.2	28.0
Other non-Latino	17.3	13.0	17.8
Sex/race			
Male, non-Latino	35.8	38.8	36.1
Female, non-Latino	36.0	38.2	36.1
Male, Latino	14.8	13.7	14.6
Female, Latino	13.4	9.2	13.2
Education			
Less than high school	9.4	5.2	9.3
High-school education	19.0	17.3	19.0
Some college	34.4	27.4	34.1
College graduate-plus	37.3	50.0	37.5
Age			
19-29	22.1	12.9	21.8
30-39	21.8	17.4	21.9
40-49	23.6	21.4	23.6
50-64	32.5	48.3	32.7
Region			
Sierra/Northern Counties	3.3	4.0	3.2
Greater Bay Area	22.9	23.3	22.4
Sacramento Area	5.8	4.6	5.7
San Joaquin Valley	8.2	7.4	8.0
Central Coast	6.1	6.6	6.0
LA County	25.3	21.9	24.4
Other Southern CA	28.5	29.7	27.9
Phone status			
Cell phone only	40.3	29.0	40.2
Some landline use	59.7	71.0	59.8

table 1c. acs estimates and unweighted and weighted sample percentages – California (19-64)

	ACS	Unweighted sample	Weighted sample
Race			
White non-Latino	42.0%	36.8%	41.7%
Black non-Latino	6.1	7.3	6.1
Latino	36.3	45.2	36.4
Other non-Latino	15.7	10.6	15.8
Sex/race			
Male, non-Latino	31.3	25.2	31.4
Female, non-Latino	32.4	29.8	32.4
Male, Latino	18.2	21.6	18.1
Female, Latino	18.0	23.4	18.1
Education			
Less than high school	16.8	22.1	16.8
High-school education	21.4	25.5	21.5
Some college	33.2	26.7	32.9
College graduate-plus	28.6	25.7	28.8
Age			
19-29	25.7	21.5	25.5
30-39	22.3	19.2	22.3
40-49	22.7	20.3	22.5
50-64	29.3	39.0	29.7
Region			
Sierra/Northern Counties	3.6	4.8	3.5
Greater Bay Area	19.9	15.0	19.5
Sacramento Area	5.7	5.2	5.6
San Joaquin Valley	9.9	11.8	9.6
Central Coast	5.8	7.0	5.8
LA County	26.7	26.9	25.8
Other Southern CA	27.9	26.0	27.5
Phone status			
Cell phone only	45.5	34.1	45.1
Some landline use	54.5	65.9	54.9
Income status			
Less than 200% FPL	33.5	67.2	33.4
200% FPL or more	66.5	32.8	66.6

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 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 (3 percent) were asked where they last went for care (using the same options listed above), and whether it was in California or not. Those who said they went for care to a nonprofessional 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 900 California community clinics and health centers (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 CCHCs 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 or not. 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 clinic codes 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."

For a breakdown of facility usage for the full sample, as well as those with family household income below 200 percent FPL and 200 percent FPL and above, see the table for Q2/2a/3/4 of the topline data report.

text-enabled cell phones

Because of an error in programmed instructions, 324 respondents who lack internet access were not asked in initial interviews if they have a text-enabled cell phone (Q18), and as a result those who lack internet access but have a text-enabled cell phone were not asked questions 31a, 33, 35 and 36, pertaining to e-mail and text communication. The programming was corrected, and of the 324 missing cases, 177 respondents were recontacted and their data added. Close analysis of these data indicated that the remaining missing cases would not meaningfully impact the results for these questions.

response rate

The response rate for this study was calculated at 25 percent for the landline sample and 23 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	819	711	1,530
Eligible, non-interview (Category 2)			
Refusal (Eligible)	583	196	779
Answering machine household	50	79	129
Physically or mentally unable/incompetent	3	1	4
Language problem	56	4	60
No interviewer available for needed language	0	3	3
Unknown eligibility, non-interview (Category 3)			
Always busy	307	88	395
No answer	22,019	13,943	35,962
Technical phone problems	868	22	890
Call blocking	9	24	33
No screener completed	2,623	4,518	7,141
Housing unit, unknown if eligible	4,477	3,740	8,217
Not eligible (Category 4)			
Fax/data line	2,729	289	3,018
Non-working number	53,667	1,962	55,629
Business, government office, other organizations	5,137	1,140	6,277
No eligible respondent	1,370	1,974	3,344
Total phone numbers used	94,734	28,864	123,598

design effect and margin of sampling error

The survey has a design effect due to weighting of 1.4 for each of the income groups and 2.1 for the entire California sample. The margin of sampling error is 3.5 percentage points for the full sample and the low-income sample and 5 points for the higher-income sample. Error margins are higher for subgroups within these populations.

endnotes

1 Fourteen respondents did not provide enough information to determine their household family income.

2 The federal poverty level is calculated on the basis of family size and the combined income of family members.

3 These numbers were then adjusted based on the actual share of qualifying households found in each stratum during the course of the survey.

4 If respondents were uncertain about their annual income, they were asked about the corresponding monthly income.

5 Families were defined in accordance with the definition applied by the U.S. Census bureau and FPL was based on the 2013 HHS Poverty Guidelines.

6 Regions were defined following the California Health Interview Survey (CHIS) operationalization of regions. Each county was assigned to one of the seven regions. County was derived from respondents' self-reported ZIP code. When respondents declined to identify their ZIP code, 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 d – 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-provider relationships, use of communication and information resources for health purposes and interest in alternative care and communication strategies. This appendix details 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., having team-based care) and the dependent variable (e.g., the quality of the patient-provider relationship), 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 outcome variables used in each regression analysis reported in this study, followed by details of the results.[1]

model 1: predicting the patient-provider index

The patient-provider index assesses the strength of the relationship and quality of communication between patients and their providers. See Section VII for details.

	Standardized coefficient (β)	**Significance test (*t*)**
Feel informed about your health/health problems	.29	9.81***
Healthcare provider encourages patient to take an active role	.24	8.50***
Have as much say in care decisions as desired	.18	6.61***
Connectedness with healthcare facility	.12	4.00***
Has team-based care	.09	2.95**
Has faced a major medical decision in the past year	-.08	2.72**
Language spoken at home: English	.08	2.05*
Self-reported health status	.07	2.23*
Current health technology usage index	.07	1.89+
Citizenship	-.07	1.77+
Have received a decision aid	.06	2.20*
Employed: Full-time	.05	1.82+
Has a healthcare navigator	.05	1.66+

Model $R^2 = .47$, $p < .001$

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

model 2: predicting the health information technology index

The health information technology index assesses the extent to which patients currently use a variety of technology-based tools for information and communication. See Section VIII for details.

	Standardized coefficient (β)	**Significance test (*t*)**
Has internet access	.38	9.31***
Facility: Kaiser Permanente	.14	4.56***
Have received a decision aid	.12	4.26***
Facility has a patient portal	.12	3.98***
Race/ethnicity: Latino	-.11	2.68**
Household size	.08	2.40*
Connectedness with healthcare facility	.07	2.25*
Income	-.07	2.23*
Healthcare provider encourages patient to take an active role	.06	2.17*

Model $R^2 = .44$, $p < .001$

models 3-9: predicting interest in online information and communication tools

The index of interest in online information and communication tools assesses interest in using the internet or smartphone applications for a variety of health-related purposes. In addition to predicting interest in the tools overall, we assessed interest in each tool to identify any unique predictors. These models were conducted only among low-income Californians who currently have internet access. See Section IX for details.

	Standardized coefficient (β)	**Significance test (*t*)**
Model 3: Overall index, $R^2 = .33$, $p < .001$		
Desire for more health information	.41	9.24***
Trust in non-provider sources of information[2]	.13	2.94**
Gender: Male	-.11	2.57*
Have received a decision aid	.10	2.36*
Facility: Kaiser Permanente	.10	1.96*
Model 4: Looking online for information about a medical problem, $R^2 = .28$, $p < .001$		
Desire for more health information	.32	7.10***
Has a disability or chronic condition	.16	2.84**
Have received a decision aid	.14	3.32***
Has a texting-capable phone	.11	2.42*
Gender: Male	-.09	2.15*
Trust in non-provider sources of information	.09	1.98*
Helpfulness of searching for health information alone	.08	2.02*

	Standardized coefficient (β)	Significance test (*t*)
Model 5: Looking online for advice about dieting, nutrition and exercise, R^2 = .25, $p < .001$		
Desire for more health information	.32	6.97***
Self-reported health status	.15	2.98**
Healthcare provider encourages patient to take an active role	.13	2.72**
Income	-.12	2.18*
Gender: Male	-.10	2.27*
Have less say in healthcare decisions than desired	.09	2.00*
Model 6: Finding online support from others with similar health issues, R^2 = .25, $p < .001$		
Desire for more health information	.31	6.64***
Trust in non-provider sources of information	.17	3.71***
Race/ethnicity: Latino	-.13	2.23*
Has a disability or chronic condition	.12	2.03*
Model 7: Sharing health experiences online, or reading about others', R^2 = .19, $p < .001$		
Desire for more health information	.24	5.04***
Have not had to make a medical decision in the past year	-.09	2.01*
Model 8: Receiving health reminders online or a smartphone, R^2 = .24, $p < .001$		
Desire for more health information	.28	5.98***
Helpfulness of searching for health information alone	-.17	4.00***
Marital status: Married/living as married	.16	2.21*
Gender: Male	-.14	3.03**
Has a healthcare navigator	.14	2.95**
Facility: Kaiser Permanente	.11	2.10*
Trust in non-provider sources of information	.10	2.11*
Have not had to make a medical decision in the past year	-.09	2.05*
Model 9: Tracking health, exercise or nutrition information online, R^2 = .22, $p < .001$		
Desire for more health information	.29	6.18***
Income	-.17	3.09**
Have received a decision aid	.10	2.25*
Education	.10	2.01*

models 10-15: predicting interest in alternative care and communication strategies[3]

We assessed openness to alternative care and communication strategies by computing regression models for each of the alternative care models and strategies mentioned in Section XI, and described below.

	Standardized coefficient (β)	Significance test (*t*)
Model 10: Interest in having a healthcare navigator, $R^2 = .13, p < .001$		
Patient-provider index	.17	3.66***
Rating of healthcare facility	-.13	3.36***
Insurance: None	-.13	3.26**
Race/ethnicity: Latino	.12	2.30*
Desire for more health information	.10	2.78**
Have faced a major medical decision in the past year	.10	2.84**
Age	.11	2.58*
Facility: Private doctor's office	-.09	2.19*
Gender: Male	-.08	2.21*
Model 11: Interest in team-based care, $R^2 = .15, p < .001$		
Patient-provider index	.14	2.95**
Race/ethnicity: Latino	.12	2.35*
Have less say in healthcare decisions than desired	.11	2.99**
Gender: Male	-.10	2.98**
Desire for more health information	.09	2.55*
Facility: Hospital ER	.09	2.34*
Have faced a major medical decision in the past year	.08	2.44*
Citizenship	-.08	1.75+
Extent patient finds searching for health info overwhelming	.07	1.91+
Model 12: Interest in patient portals (among internet users), $R^2 = 26, p < .001$		
Current health technology usage	.19	3.87***
Continuity of care at healthcare facility	-.19	3.62***
Desire for more health information	.17	3.49***
Marital status: Single	-.15	2.08*
Has a smartphone	.13	2.52*
Facility: Kaiser Permanente	.11	2.09*
Connectedness with healthcare facility	.11	2.08*
Insurance: None	-.10	1.95+
Facility: Hospital ER	-.09	1.79+
Employed: Full-time	.08	1.75+

	Standardized coefficient (β)	Significance test (t)
Model 13: Interest in using decision aids, $R^2 = .17$, $p < .001$.		
Desire for more health information	.24	6.97***
Patient-provider index	.13	2.95**
Citizenship	-.13	2.94**
Have never searched for health information alone	-.11	3.06**
Gender: Male	-.09	2.61**
Have faced a major medical decision in the past year	.09	2.60**
Have less say in healthcare decisions than desired	.09	2.57*
Extent of current health technology usage	.09	2.21*
Income	-.09	2.20*
Insurance: None	-.08	1.93+
Employed: Full-time	.07	2.12*
Extent patient finds searching for health info. overwhelming	.06	1.74+
Model 14: Interest in texting with healthcare providers (among those with texting-capable cell phones), $R^2 = .20$, $p < .001$.		
Extent of current health technology usage	.25	5.32***
Desire for more health information	.21	4.86***
Education	-.13	2.74**
Facility: Private doctors' office	-.13	2.64**
Connectedness with healthcare facility	.11	2.46*
Have less say in HC decisions than desired	.10	2.32*
Employed: Full-time	.08	2.05*
Have never had to make a medical decision	-.08	2.05*
Model 15: Interest in e-mailing with healthcare providers (among those with internet access), $R^2 = .24$, $p < .001$.		
Extent of current health technology usage	.26	5.38***
Patient-provider index	.15	2.35*
Employed: Full-time	.13	2.97**
Facility: Kaiser Permanente	.12	2.41*
Age	-.12	2.17*
Gender: Male	.11	2.48*
Continuity of care at healthcare facility	-.11	2.20*
Race/ethnicity: Latino	-.11	1.83+
Education	-.10	2.22*
Desire for more health information	.08	1.78+

Summary Table of Models 10-15: Common predictors of interest in alternative strategies

					Communicate via:	
	Health coach	**Team care**	**Portal**	**Decision aid**	**Text**	**E-mail**
Desire for more information	**	*	***	***	***	+
Extent of current health technology usage			***	*	***	***
Patient-provider index	***	**		**		*
Gender: Male	*	**		*		*
Employed: Full-time			+	*	*	**
Have faced a major medical decision in past year	**	*		**		
Have less say in healthcare decisions than desired		**		*	*	
Continuity of care			***			*
Education					**	*
Race/ethnicity: Latino	*	*				*
Insurance: None	**		+	+		
Facility: Doctor's office	*				**	
Citizenship		+		**		
Age	*					*
Connectedness			*		*	
Facility: Kaiser Permanente			*			*
Facility: Hospital ER		*	+			
Extent patient finds searching for health info. overwhelming		+		+		

Note. ***p < .001, **p < .01, *p < .05, +p < .10 . Bolded blue indicates a positive relationship, red indicates a negative relationship.

endnotes

1 All models control for region and whether or not respondents were asked Q18 (see Appendix C for details), as well as other demographic variables

2 Trust in non-provider sources of information is a simple average of trust in "friends and family," "other people with health issues like yours," "websites that you personally have used on the internet" and "health-related apps you can get on your smartphone," with each recoded so that 1 = no trust at all and 5 = complete trust. The latter two measures are based on subsamples of patients who indicate they have used the internet for health-related reasons or who have smartphones, respectively. See Appending B, Q29d-g for details..

3 Respondents who indicate that they already use the alternative method in question are coded as having high interest in it.

appendix e – full questionnaire

This appendix reproduces the full, formatted questionnaire for Blue Shield of California Foundation's 2013 survey of 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 health care 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 SCEEEN): 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.

1z. 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)
2 Less than (AMOUNT)
3 (DO NOT READ) Exactly (AMOUNT)
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 $24,000
IF S1=2 $30,000
IF S1=3 $37,000
IF S1=4 $47,000
IF S1=5 $56,000
IF S1=6 $63,000
IF S1=7 $72,000
IF S1=8 $80,000
IF S1=9+ $95,000

(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)
2 Less than (AMOUNT)
3 (DO NOT READ) Exactly (AMOUNT)
D (DO NOT READ) Don't know
R (DO NOT READ) Refused

VALUES FOR M*
IF S1=1 $2,000
IF S1=2 $2,500
IF S1=3 $3,000
IF S1=4 $3,900
IF S1=5 $4,600
IF S1=6 $5,200
IF S1=7 $6,000
IF S1=8 $6,600
IF S1=9+ $7,900

(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	
R	(DO NOT READ) Refused	

(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.

(ASK EVERYONE)
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

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.

main questionnaire

(ASK EVERYONE)
1. About how many times in the past year have you seen a doctor, nurse or other healthcare provider?

(IF NEEDED: Just your best guess)

(INTERVIEWER NOTE: IF RESPONDENT SAYS 100+ TIMES, PLEASE CONFIRM BEFORE ENTERING RESPONSE.)

_________ NUMBER OF TIMES
NN None
DD (DO NOT READ) Don't know
RR (DO NOT READ) Refused

(ROTATE VERBIAGE IN PARENS)
2. 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 NOTE: IF MULTIPLE PLACES, ASK "Which one usually?")

(INTERVIEWER NOTE: IF RESPONDENT SAYS "DOCTOR" ASK: IS THAT A PRIVATE DOCTOR'S OFFICE OR A DOCTOR AT [REPEAT OTHER CHOICES]?)

(INTERVIEWER NOTE: IF RESPONDENT SAYS NON-PROFESSIONAL, I.E., "PARENT, FAMILY, HOME," SAY "I mean for professional health care." 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.2a IF Q.2 = 6, D, OR R)
2a. OK, where's the last place you went when you needed health care?

(RE-READ LIST IF NECESSARY)

(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 health care." 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.2a = 1-5)
2b. Was this in California, or not?

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

(ASK Q.3 IF Q.2 = 3 OR Q.2a = 3)
3. 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
158 Los Angeles
201 Oakland
213 Oxnard
254 Sacramento
255 Salinas
258 San Diego
259 San Francisco
263 San Jose
330 Ventura
997 Other answer given (SPECIFY) _______
DDD (DO NOT READ) Don't know
RRR (DO NOT READ) Refused

(ASK Q.3aa IF Q.3 = 096, 158, 201, 213, 254, 255, 258, 259, 263, 330 OR 997)
3aa. 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.3a IF Q.2 = 3 OR Q.2a = 3)
3a. 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.3b IF Q.3a = 997, DDD, OR RRR)
3b. As far as you know, is that a clinic that's operated by a hospital, or not?

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.3c IF Q.3b = 1)
(ROTATE VERBIAGE IN PARENS)
3c. 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.3d IF Q.3b = 2)
(ROTATE VERBIAGE IN PARENS)
3d. 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.4 IF Q.2 = 4 OR Q.2a = 4)
(ROTATE VERBIAGE IN PARENS)
4. 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.4a IF Q.4 = 1)
(ROTATE VERBIAGE IN PARENS)
4a. 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.2 = 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.2a = 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.2 = 1-5 OR Q.2a = 1-5, D OR R)
INSERT 1ST VERBIAGE IN PARENS IF Q.2 = 1-5; INSERT 2ND VERBIAGE IN PARENS IF Q.2a = 1-5, D, OR R)
6. 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 EVERYONE)
7. 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.8 IF Q.2 = 1-5 OR Q.2a = 1-5, D OR R)
INSERT "go" IF Q.2 = 1-5
INSERT "last went" IF Q.2a = 1-5, D, OR R
8. 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.9 IF Q.8 = 2, D, OR R)
9. 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.10 IF Q.2 = 1-5 OR Q.2a = 1-5, D OR R)
INSERT "go" IF Q.2 = 1-5
INSERT "last went" IF Q.2a = 1-5, D, OR R
10. 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.11 IF Q.10 = 2, D, OR R)
11. If it was available where you go for care, how interested would you be in having team-based care – 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.12 IF Q.2 = 1-5 OR Q.2a = 1-5, D OR R)
INSERT "usually go" IF Q.2 = 1-5
INSERT "last went" IF Q.2a = 1-5, D, OR R
12. To what extent, if at all, do you feel that the healthcare providers at the facility you (usually go/last went) to care about you as a person, not just a patient– do you think they care about you personally a great deal, a good amount, just some, not so much or not at all?

1 A great deal
2 A good amount
3 Just some
4 Not so much
5 Not at all
D (DO NOT READ) Don't know
R (DO NOT READ) Refused

(ASK Q.13 IF Q.2 = 1-5 OR Q.2a = 1-5, D OR R)
13. When you go for medical care, how often does the healthcare provider (INSERT) – every time, most of the time, some of the time, rarely, or never? And how often does the healthcare provider (INSERT NEXT ITEM) – 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

a. Explain things in a way you understand
b. Ask you if you have any questions or concerns

(ASK Q.14 IF Q.2 = 1-5 OR Q.2a = 1-5, D OR R)
(ROTATE VERBIAGE IN PARENS)
14. Overall, would you say the healthcare providers you see [(encourage you to take an active role in decisions about your care), (discourage you from taking an active role in decisions about your care)] or neither [(encourage) nor (discourage)] your taking an active role?

1 Encourage
2 Discourage
3 Neither encourage nor discourage
D (DO NOT READ) Don't know
R (DO NOT READ) Refused

(ASK Q.15 IF Q.2 = 1-5 OR Q.2a = 1-5, D, OR R)
(SCRAMBLE ITEMS b AND c; ITEM a SHOULD ALWAYS BE FIRST)
15. How comfortable or uncomfortable do you feel (INSERT) – very comfortable, somewhat comfortable, somewhat uncomfortable, or very uncomfortable? And how comfortable or uncomfortable do you feel (INSERT NEXT ITEM) – very comfortable, somewhat comfortable, somewhat uncomfortable or very uncomfortable?

(INTERVIEWER INSTRUCT ONLY FOR ITEMS B and C: IF R SAYS "NEVER HAVE DONE" SAY, "WELL, IF YOU HAD TO… AND REPEAT QUESTION.)

1 Very comfortable
2 Somewhat comfortable
3 Somewhat uncomfortable
4 Very uncomfortable
D (DO NOT READ) Don't know
R (DO NOT READ) Refused

a. asking the healthcare provider questions about your health or treatment
b. telling the healthcare provider about health information you've obtained from other sources
c. telling the healthcare provider that you don't want to do something they recommend

(ASK EVERYONE)
16. On another topic, do you personally have access to the internet or e-mail, or not?

(INTERVIEWER NOTE: IF RESPONDENT SAYS THEY GO ONLINE ON THEIR SMARTPHONE CODE AS "1")

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

(ASK IF Q.16 = 1)
17. Does that include internet or e-mail access through a smartphone, or not?

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

(ASK Q.18 IF Q.16 = 2, D, OR R)
18. Do you have a cell phone that can send and receive text messages, or not?

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

(ASK Q.19 IF Q.16 = 1)
INSERT 1ST VERBIAGE IF Q.16 = 1 AND Q.17 = 2, D, OR R
INSERT 2ND VERBIAGE IF Q.17 = 1
19. Have you ever used (the internet /the internet or your smartphone) to access any health or wellness websites or applications, or not?

(INTERVIEWER NOTE – READ ONLY IF RESPONDENT ASKS FOR EXPLANATION: This can include dieting, nutrition, exercise as well as health-specific websites and apps.)

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

(ASK IF Q.16 = 1)
(SCRAMBLE ITEMS)
20. Please tell me how interested you are in using a website or app to do each item I name. First is using a website or app to (INSERT) – are you very interested in doing that, somewhat interested, not so interested or not interested at all? If you already do this, please just say so.
What about using a website or app to [INSERT NEXT ITEM] – are you very interested in doing that, somewhat interested, not so interested or not interested at all? If you already do this, please just say so.

(INTERVIEWER NOTES:
-IF RESPONDENT SAYS "ALREADY DO IT", ENTER CODE 5; IF RESPONDENT SAYS "DOES NOT DO IT", SAY, "How interested would you be in…")
-FOR ITEM c IF RESPONDENT SAYS "HAVE NO HEALTH ISSUES" SAY, "WELL IF YOU DID…")

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

a. look for information about a medical problem for yourself or someone else
b. look for information or advice about dieting, nutrition or exercise
c. find support or advice from other people with similar health issues
d. share a personal health experience with others, or read about someone else's experiences
e. sign up to receive automatic health messages or reminders
f. track health, exercise or nutrition information

(ASK IF Q.17 = 1 AND IF ANY Q.20a-f = 1, 2, 3, 5, D, OR R)
(ROTATE VERBIAGE IN PARENS)
21. In general, would you be more interested in doing the things I just mentioned using (an app), using (a website), or both equally?

1 An app
2 A website
3 Both equally
D (DO NOT READ) Don't know
R (DO NOT READ) Refused

(ASK EVERYONE)
22. 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

(ASK EVERYONE)
(ROTATE VERBIAGE IN PARENS)
23. (Do you feel like you have all the information you need to make informed decisions about your health), or (Do you feel that having more information than you have now would help you make better decisions about your health)?

1 You have all the information you need
2 Having more information would help
3 (DO NOT READ) Have more information than I need
D (DO NOT READ) Don't know
R (DO NOT READ) Refused

(ASK Q.24 IF Q.23 = 2)
24. How much more information about your health would you like to have – a lot more, just some or only a little more?

1 A lot more
2 Just some
3 Only a little more
D (DO NOT READ) Don't know
R (DO NOT READ) Refused

(ASK Q.25 IF Q.23 = 1)
(ROTATE VERBIAGE IN PARENS)
25. Imagine if more information about your health was easier to find and to understand. In that case would you (like to have more information than you have now), or would you (still say you already have enough information)?

1 Like to have more information
2 Already have enough information
D (DO NOT READ) Don't know
R (DO NOT READ) Refused

(ASK Q.26 IF Q.2 = 1-5 OR Q.2a = 1-5, D OR R)
(ROTATE VERBIAGE IN PARENS)
26. Overall, have you found that the health information you've received from healthcare providers has been (as simple as it can be) to understand, or (more complicated than it should be)? Do you feel that way strongly or somewhat?

1 As simple as it can be, feel that way strongly
2 As simple as it can be, feel that way somewhat
3 More complicated than it should be, feel that way somewhat
4 More complicated than it should be, feel that way strongly
5 (DO NOT READ) Depends on the provider
6 (DO NOT READ) Have not received any information from a provider
D (DO NOT READ) Don't know
R (DO NOT READ) Refused

(ASK EVERYONE)
(ROTATE VERBIAGE IN PARENS)
27. Do you find searching for health information on your own more (helpful) (SPANISH: util) or more (overwhelming)? Do you feel that way strongly or somewhat?

1 Strongly helpful
2 Somewhat helpful
3 Somewhat overwhelming
4 Strongly overwhelming
5 (DO NOT READ) Haven't tried
D (DO NOT READ) Don't know
R (DO NOT READ) Refused

(ASK EVERYONE)
(SCRAMBLE VERBIAGE IN PARENS)
28. Where do you get most of the information you have about your health – (from healthcare providers), (from friends and family), or (from sources like books, magazines, television or the internet)?

1 From healthcare providers
2 From friends and family
3 From sources like books, magazines, television or the internet
4 (DO NOT READ) Other (SPECIFY) _______________
5 (DO NOT READ) Multiple options equally
6 (DO NOT READ) Don't get health information
D (DO NOT READ) Don't know
R (DO NOT READ) Refused

(ASK ITEMS a, b, d AND e OF EVERYONE)
(ASK ITEM c IF Q.8 = 1)
(ASK ITEM f IF Q.19 = 1)
(ASK ITEM g IF Q.17 = 1)
(SCRAMBLE ITEMS, BUT ITEM b SHOULD IMMEDIATELY FOLLOW ITEM a)
29. Thinking about different sources of health information, how much do you think you can trust health information you can get from (INSERT) – can you trust it completely, mostly, somewhat, not much or not at all? How about health information you can get from (INSERT NEXT ITEM)?

(INTERVIEWER NOTE: ON ANY ITEM, IF RESPONDENT SAYS THEY DON'T GET INFORMATION FROM THAT SOURCE SAY, "WELL IF YOU DID." ON ITEM e, IF RESPONDENT SAYS THEY HAVE NO HEALTH ISSUES, SAY, "WELL IF YOU DID.")

1 Completely
2 Mostly
3 Somewhat
4 Not much
5 Not at all
D (DO NOT READ) Don't know
R (DO NOT READ) Refused

a. doctors you see
b. nurses, physician assistants or other medical staff you see
c. your healthcare coach (Spanish: promotore de salud)
d. friends and family
e. other people with health issues like yours
f. the websites you personally have used on the internet
g. health-related apps you can get on your smartphone

(ASK Q.30a IF [Q.2 = 1-5 OR Q.2a = 1-5, D, OR R] AND [Q.17 = 1 OR Q.18 = 1])
INSERT "usually go" IF Q.2 = 1-5
INSERT "last went" IF Q.2a = 1-5, D OR R
30a. Do the healthcare providers or staff at the place you (usually go/last went) for health care ever send you text messages, or not?

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

(ASK Q.30b IF Q.30a = 1)
(ROTATE VERBIAGE IN PARENS)
30b. Are these mainly (automated messages) or mainly (individual messages to you personally)?

(INTERVIEWER NOTE: IF RESPONDENT SAYS "CAN'T TELL," ENTER CODE D.)

1 Automated messages
2 Individual messages
3 (DO NOT READ) Some of both
D (DO NOT READ) Don't know
R (DO NOT READ) Refused

(ASK Q.31a IF [Q.2 = 1-5 OR Q.2a = 1-5, D, OR R] AND Q.16 = 1)
INSERT "usually go" IF Q.2 = 1-5
INSERT "last went" IF Q.2a = 1-5, D OR R
31a. Do the healthcare providers or staff at the place you (usually go/last went) for health care ever send you e-mails or not?

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

(ASK Q.31b IF Q.31a = 1)
(ROTATE VERBIAGE IN PARENS)
31b. Are these mainly (automated e-mails) or mainly (individual e-mails to you personally)?

(INTERVIEWER NOTE: IF RESPONDENT SAYS "CAN'T TELL," ENTER CODE D.)

1 Automated e-mails
2 Individual e-mails
3 (DO NOT READ) Some of both
D (DO NOT READ) Don't know
R (DO NOT READ) Refused

(ASK Q.32a IF Q.2 = 1-5 OR Q.2a = 1-5, D, OR R)
INSERT "usually go" IF Q.2 = 1-5
INSERT "last went" IF Q.2a = 1-5, D OR R
32a. Does the place you (usually go/last went) for health care ever call you by phone, or not?

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

(ASK Q.32b IF Q.32a = 1)
(ROTATE VERBIAGE IN PARENS)
32b. Are these mainly (automated calls) or mainly (individual calls to you personally)?

(INTERVIEWER NOTE: IF RESPONDENT SAYS "CAN'T TELL," ENTER CODE D.)

1 Automated calls
2 Individual calls
3 (DO NOT READ) Some of both
D (DO NOT READ) Don't know
R (DO NOT READ) Refused

(ASK Q.33 IF [Q.2 = 1-5 OR Q.2a = 1-5, D, OR R] AND [Q.17 = 1 OR Q.18 = 1])
INSERT "usually go" IF Q.2 = 1-5
INSERT "last went" IF Q.2a = 1-5, D OR R
33. As far as you know, when you have a question, can you get an answer by texting the healthcare providers or staff at the place you (usually 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.34 IF [Q.2 = 1-5 OR Q.2a = 1-5, D, OR R] AND Q.16 = 1)
INSERT "usually go" IF Q.2 = 1-5
INSERT "last went" IF Q.2a = 1-5, D OR R
34. As far as you know, when you have a question, can you get an answer by e-mailing the healthcare providers or staff at the place you (usually 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.35 IF Q30a = 1 OR Q.31a = 1 OR Q.33 = 1 OR Q.34 = 1)
INSERT "text message" IF [Q.30a = 1 OR Q.33 = 1] AND [(Q.31a = 2, D, OR R) AND (Q.34 = 2, D, OR R)]
INSERT "e-mail" IF [Q.31a = 1 OR Q.34 = 1] AND [(Q.30a = 2, D, OR R) AND (Q.33 = 2, D, OR R)]
INSERT "text message and email" IF (Q.30a = 1 OR Q.33 = 1) AND (Q.31a = 1 OR Q.34 =1)
INSERT "usually go" IF Q.2 = 1-5
INSERT "last went" IF Q.2a = 1-5, D OR R
35. How do you feel about the ability to communicate by (text message/e-mail/text message and e-mail) with the people where you (usually go/last went) for care – do you find this very useful, somewhat useful, not so useful or not useful at all?

1 Very useful
2 Somewhat useful
3 Not so useful
4 Not useful at all
5 (DO NOT READ) Haven't done
6 (DO NOT READ) Depends
D (DO NOT READ) Don't know
R (DO NOT READ) Refused

(ASK Q.36 IF Q.33 = 2, D, OR R)
INSERT "usually go" IF Q.2 = 1-5
INSERT "last went" IF Q.2a = 1-5, D OR R
36. Assuming they respond, how interested would you be in being able to text the healthcare providers or staff at the place you (usually go/last went) for care when you have a question – 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.37 IF Q.34 = 2, D, OR R)
INSERT "usually go" IF Q.2 = 1-5
INSERT "last went" IF Q.2a = 1-5, D OR R
37. Assuming they respond, how interested would you be in being able to e-mail the healthcare providers or staff at the place you (usually go/last went) for care when you have a question – 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.38 IF Q.2 = 1-5 OR Q.2a = 1-5, D OR R)
INSERT "usually go" IF Q.2 = 1-5
INSERT "last went" IF Q.2a = 1-5, D OR R
38. Some healthcare facilities have a website where patients can go to do things like (make appointments), (view their medical records and test results), (ask doctors or nurses questions) and (find health information). It's sometimes called a patient portal. As far as you know, does the place where you (usually go/last went) for care have such a website or patient portal, or not?

1 Yes, has patient portal
2 No, does not have patient portal
D (DO NOT READ) Don't know
R (DO NOT READ) Refused

(ASK Q.39 IF Q.38 = 2, D, OR R AND Q.16 = 1)
39. How interested would you be in using a patient portal as I've described it – 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.40 IF Q.38 = 1 AND Q.16 = 1)
40. How useful do you find this portal – very useful, somewhat useful, not so useful or not useful at all? If you've never used it, just say so.

1 Very useful
2 Somewhat useful
3 Not so useful
4 Not useful at all
5 Have never used it
D (DO NOT READ) Don't know
R (DO NOT READ) Refused

(ASK Q.41 IF [(Q.39 = 1, 2, 3, D, OR R) OR (Q.38 = 1 AND Q.16 = 1)] AND [Q.2 = 1-5 OR Q.2a = 1-5, D OR R])
(SCRAMBLE ITEMS)
41. I'll name some possible features of a patient portal. For each, please tell me how interested you'd be in doing this using a patient portal – very interested, somewhat interested, not so interested, or not interested at all. First is being able to (INSERT 1ST ITEM) – is that something you'd be very interested in doing using a patient portal, somewhat interested in doing, not so interested or not interested at all in doing? How about being able to (INSERT NEXT ITEM) using a patent portal? Is that something you'd be very interested in doing, somewhat interested in doing, not so interested, or not interested at all in doing?

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

a. schedule appointments online
b. view your medical records
c. ask the doctor or nurse questions
d. find health information your healthcare provider recommends
e. view your test or lab results
f. ask for a referral to a specialist

Changing topics…

(ASK EVERYONE)
42. 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 OR INPUT.")

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

(ASK EVERYONE)
43. Regardless of your current amount of say, how much of a say would you LIKE to 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 OR INPUT.")

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

(ASK EVERYONE)
44. In general, 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

(ASK Q.45 IF Q.2 = 1-5 OR Q.2a = 1-5, D OR R)
45. In the past 12 months have you faced a major medical decision, or not?
(READ IF NEEDED: Anything you consider major)

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

READ: 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.

[INTERVIEWER INSTRUCT: READ FOR FIRST THREE QUESTIONS, THEN AS NEEDED: Thinking about the last major healthcare decision you faced…]

(ASK Q.46 – Q.53 IF Q.45 = 1; ALL OTHERS SKIP TO Q.54)
46. 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?

1 Very satisfied
2 Somewhat satisfied
3 Somewhat dissatisfied
4 Very dissatisfied
D (DO NOT READ) Don't know
R (DO NOT READ) Refused

47. How involved were you in the decision-making process – very involved, somewhat involved, not so involved or not involved at all?

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

48. 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?

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

49. 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?

1 A great deal
2 A good amount
3 Just some
4 Not much
5 (DO NOT READ) None at all
D (DO NOT READ) Don't know
R (DO NOT READ) Refused

(ALWAYS ASK ITEM a FIRST; SCRAMBLE OTHER ITEMS)
(ASK ITEMS b, c, f, AND h IF ITEM a = 1)
50. And again, thinking about the last major healthcare decision you faced. Before a decision was made, did a healthcare provider (INSERT), or not? Before a decision was made, did a healthcare provider (INSERT NEXT ITEM), or not?

(INTERVIEWER NOTE: REPEAT 1ST SENTENCE ONLY IF NEEDED.)

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

a. give you multiple options to consider
b. give you clear information about the benefits of these different options
c. give you clear information about the risks of these different options
d. discuss the possibility of not taking any action at all
e. ask you what your healthcare goals were
f. give you enough time to consider how each option fit in with your preferences and goals
g. listen to your preferences and concerns
h. have a discussion with you about which option best matched your preferences and goals
i. tell you how to get more information

(SCRAMBLE VERBIAGE IN PARENS)
51. 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?

1 Your personal preferences
2 The recommendations from healthcare providers
3 The recommendations from family or friends
4 Financial considerations
5 Something else (SPECIFY) ___________________
D (DO NOT READ) Don't know
R (DO NOT READ) Refused

INSERT "your usual place of care" IF Q.2 = 1-5
INSERT "the last place you went for care" IF Q.2a = 1-5, D OR R
52. 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?

1 Someone at your usual place of care/the last place you went for care
2 A specialist
3 Both equally
D (DO NOT READ) Don't know
R (DO NOT READ) Refused

(ROTATE VERBIAGE IN PARENS)
53. 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?

1 A healthcare provider
2 You
3 Shared in the decision making equally
D (DO NOT READ) Don't know
R (DO NOT READ) Refused

READ: Some patients facing a specific healthcare decision are given decision aids, which provide clear, detailed and balanced information about options for treatment. They can be printed, videos, or internet-based.

(ASK Q.54 IF Q.2 = 1-5 OR Q.2a = 1-5, D OR R)
54. When you have faced a specific healthcare decision at any time in the past, has a healthcare professional ever given or directed you to this sort of decision aid or not?

1 Yes, has
2 No, has not
3 (DO NOT READ) No such decision
D (DO NOT READ) Don't know
R (DO NOT READ) Refused

(ASK EVERYONE)
55. The next time you face a medical decision, how interested would you be in using a decision aid – do you think you would be very interested in this, 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 EVERYONE)
(SCRAMBLE VERBIAGE IN PARENS)
56. If you were given a decision aid, what format do you think would be most useful for you personally – (a printed decision aid, such as a booklet), (a video-based decision aid) or (an online decision aid)?

1 A printed decision aid, such as a booklet
2 A video-based decision aid
3 An online decision aid
4 (DO NOT READ) None would be useful
5 (DO NOT READ) All equally useful
D (DO NOT READ) Don't know
R (DO NOT READ) Refused

(ASK EVERYONE)
57. 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

(ASK Q.58 IF Q.57 = 1)
58. At what age were you first diagnosed with a disability or chronic condition?
(INTERVIEWER IF NEEDED: Just your best guess)

___________ AGE (valid: 1 – AGE GIVEN IN Q.38, Q.38a or Q.38b)
00 Less than 1 year old
99 (DO NOT READ) Not diagnosed
DD (DO NOT READ) Don't know
RR (DO NOT READ) Refused

(ASK EVERYONE)
59. 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 NOTES:
-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 (PRONOUNCE: Meda-CAL), 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

(ASK IF NOT ORIGINAL RESPONDENT – Q.S4 = 2 OR Q.S4a = 2)
1z2. 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

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

(ASK EVERYONE)
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

(ASK EVERYONE)
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 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

(ASK EVERYONE)
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

(ASK EVERYONE)
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

(ASK EVERYONE)
D6. Are you of Hispanic or Latino 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.D6a = 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

(ASK EVERYONE)
(IF FPLscreen=1:
-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.)
(IF FPLscreen=2.
-DO NOT DISPLAY CODE 01-03.
-DISPLAY CODES 04 AND 05 IF S1<3.
-DISPLAY CODE 06 IF S1<4
-DISPLAY CODES 07 AND 08 IF S1<5.
-DISPLAY CODE 09 IF S1<6.
-DISPLAY CODE 10 IF S1<7.
-DISPLAY CODE 11 for EVERYONE.)
(IF FPLscreen=9 DISPLAY ALL CODES.)
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 $37,000
06 At least $37,000 but less than $42,000
07 At least $42,000 but less than $48,000
08 At least $48,000 but less than $53,000
09 At least $53,000 but less than $63,000
10 At least $63,000 but less than $100,000
11 Or $100,000 or more
DD (DO NOT READ) Don't know
RR (DO NOT READ) Refused

(ASK EVERYONE)
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 – GO TO INST. ABOVE INT1

(READ IF INT0 = 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 f – references

The following references were consulted in preparation and analysis of Blue Shield of California Foundation's 2013 survey of Californians.

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Blue Shield of California Foundation
50 Beale Street
San Francisco, CA 94105

blueshieldcafoundation.org
email: bscf@blueshieldcafoundation.org