Improving Decision Support Tools for the Long Term Care Consumer

ISSUE BRIEF

Introduction

The CalNHS.org Site

In 2002, the California HealthCare Foundation (CHCF) launched the CalNHS.org Web site, a free, public service. The site's primary purpose is to help meet the growing consumer need for assistance in deciding on the appropriate level of long term care for an individual, and in determining the quality of care among available long term care options. CalNHS.org provides comprehensive, consumer-friendly, comparative information on nursing facilities, home health agencies, and hospice programs operating in California. The site also provides information on congregate living, residential care facilities, continuing care retirement communities, and adult day care services in California.

Consumers can use the site's resources and practical information to assess options and to compare specific facilities and services, in order to make an informed choice for themselves or for loved ones. The site includes information on a number of factors shown to have an impact on quality of care, including:

- Staffing levels, turnover, and wages;

- Quality measures;

- Complaint, deficiency, and citation rates; and

- Costs and financing.

All of the data that appear on CalNHS.org come from state and federal government sources or accrediting agencies. Updated quarterly, the site benefits consumers, health professionals, quality watchdogs, and long term care providers by offering an independent, reliable source of quality information.

Nature of the CalNHS.org Site Review

As part of its ongoing efforts to improve CalNHS.org, in 2007 CHCF partnered with Howard Degenholtz, Ph.D. of the University of Pittsburgh Graduate School of Public Health, Sam Boonin Consulting, and the HMS Group, Ltd., to perform an extensive review of the site. The purpose of the review was to delve into the selection criteria used by consumers and providers with regard to long term care services, and thereby to help CHCF develop a strategy for refining the site. In particular, the researchers sought to explore the existing landscape of long term care decision tools, to review the type and quality of information available to Californians with regard to long term care decisions, and to specify potential improvements in CalNHS.org's usefulness to decision-makers.

To accomplish these goals, the research partners embarked on five separate project elements:

1. Focus groups with long term care consumers and professionals;

2. Focus group surveys;

3. On-site meeting with residents of a residential care facility;

4. Interviews with long term care administrators, as well as with individual experts and with representatives of organizations focused on long term care issues; and

5. Comprehensive overview and comparative analysis of Web-based long term care decision resources, as well as other health care and well-known consumer product Web sites.

Research was conducted during the first half of 2007, with findings presented to CHCF in June 2007 under the title "Choosing Long Term Care Services in California: Supporting Consumers and Providers."

Aims of this Report

Out of the research project's findings and analysis, this report seeks to extrapolate lessons that can be applied not only by CalNHS.org but also by other online sites that seek to guide consumers and professionals through the thicket of information concerning long term care options. The primary lessons taken from the research include the need for site producers to:

■ Identify primary and secondary audiences;

■ Understand the nature and extent of information currently sought—and what is ignored—by consumers;

■ Attend to additional types of information wanted or needed by consumers;

■ Restructure sites in order to better meet consumer-support goals; and

■ Recognize the efficacy of marketing strategies to build demand.

Recognizing Consumers as the Primary Audience for Online Long Term Care Sites

Many online long term care decision-support sites try simultaneously to serve different segments of the long term care universe: family caregivers doing advance planning; caregivers in crisis; consumers of both short term and long term care; referring professionals; facility intake personnel and other facility or agency administrators; and public and private organizations that assess long term care services and providers. Evidence

from this research project, however, indicates that out of all these potential audiences it is overwhelmingly consumers who use the sites, and that the primary audience within the consumer category is family caregivers. In both content and design, then, sites must focus their attention on the needs of this audience.

"Consumers and professionals have different levels of sophistication with regard to information needs and cannot be easily served by the same Web site."

— "CHOOSING LONG TERM CARE SERVICES IN CALIFORNIA: SUPPORTING CONSUMERS AND PROVIDERS"

Family Caregivers as Primary Audience

All aspects of project research that addressed the issue of usage indicated that consumers, rather than professionals or organizations, are the most frequent users of long term care online sites. And of these consumers, it is family caregivers more than actual recipients of care who make up the bulk—by some estimates 80 to 90 percent—of online site visitors.

Within the family caregivers category, however, there are significant distinctions. Among these consumers seeking online assistance are:

■ "48 hours" caregivers, so designated because they seek information in the immediate aftermath of a family member's health crisis;

■ "Six months" caregivers, engaged in advance planning for a family member's approaching but not immediate long term care needs;

■ People seeking relatively short term skilled nursing facility care, rehabilitation facility care, and/or home health care for a family member about to be discharged from the hospital; and

- Those seeking long term custodial care, or long term home health and/or community care.

Each of these types of caregiver seeks somewhat different information, within different time frames. These differences have implications for both the content and structure of an online site, as neither one set of data nor one path to information can serve each of these caregiver categories equally well.

People in Need of Care Less Frequent Site Users

People who are themselves in need of care, or soon will be, are another set of consumers who use online decision-support tools. The project researchers found, however, that those in need of care use these tools much less frequently than family caregivers do. There are several main reasons why actual care recipients visit online sites much less than do their adult children and grandchildren, who make up the greatest proportion of family caregivers. One reason is generational: Older people are less familiar, comfortable, and capable with online tools than are their younger family members. Another major reason is that information about care options is often sought only after the person needing care is in crisis, which renders that person unable to engage in online investigation. Similarly, by the time many people need or consider long term care,

they are physically or cognitively impaired, and thereby less capable of conducting an online search.

Considering Long Term Care Professionals as a Secondary Audience

Research for this project revealed that the number of long term care professionals who make significant use of online decision-support sites is small compared to the number of consumers. Moreover, different categories of professionals use different aspects of the sites, and for different purposes. Therefore, site developers need to assess how their sites serve these secondary audiences. One approach might be to collect and present certain information intended to meet the specific needs of professionals, but to present it along a separate pathway from information primarily intended for consumers. This separate presentation might simultaneously serve two purposes: making a site more useful to professionals, while making it simpler for consumers to navigate toward the different information they seek.

Referring Professionals Rely on Their Own Information Circuits

One element of the secondary audience is referring professionals: hospital and skilled nursing facility discharge planners and ombudsmen, geriatric care

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Referring Professionals Seek Different Information

Professionals who make placement referrals to long term care facilities and agencies tend to look for different kinds of online information than do consumers, and at present do not find that information on most decision-support sites. Referring professionals reported that they would make more extensive use of sites that presented information directly useful to them. Placement professionals are most interested in:

- Number and availability of beds;
- Aspects of ownership (e.g., non-profit status, corporate culture, ownership philosophy);
- Staffing, including types, qualifications, tenure, and turnover of on-site staff (as opposed to mere staff-to-patient ratio);
- Special services and amenities;
- Types of insurance accepted;
- Types of patients accepted (e.g., psychiatric, dementia, "difficult");
- Specialized medical services (e.g., IV antibiotics, wound care, rehabilitation); and
- Specific contact information, including names of intake staff.

managers, and long term care referral agencies. As a group, these professionals make a high percentage of referrals to long term care facilities and home care agencies. From this it might be inferred that they would make extensive use of online information about long term care facilities and services. To the contrary, however, research for this project disclosed that this group tends to rely almost exclusively on established, direct relationships with local long term care providers, and so make little use of online sites.

Other Professionals Use Sites for Information Monitoring

Another segment of the secondary audience for online sites is long term care facility and home health care agency administrators and intake staff. They use the sites to keep themselves informed about public and professional perceptions about their facility or service. They also use site information for comparison purposes with other, similar facilities and services. In some instances, these administrators and staff use this information when making facility or service adjustments.

A final segment of this professional audience is public and private agencies and organizations that study, synthesize, and present data and other information regarding long term care, sometimes offering that information to decision-making consumers but not making direct referrals. These organizations gather data from online sites for their own information-presenting purposes.

Consumers Currently Seek Only Limited Information from Online Sites

Designing an online long term care decision-support site requires an understanding not only of what information could be offered but also of what the primary audience is looking for. They are not necessarily the same. The researchers in this project found that consumers used existing online sites in only limited ways. In particular, consumers did not pay nearly as much attention to quality of care data as site developers expected.

Consumers Use Sites as Entry Point into Search for Long Term Care

The most common use of online sites by consumers is simply as a starting point in the search for long term care. Geography, more than level of care or services offered, was most often consumers' initial subject of entry. That is, usually the first and often the only question consumers asked of the site was "What is available near where I (or my parent or family members) live?" Consumers also commonly used sites to find out about the cost of, and availability of insurance coverage for, particular facilities and services. Through this combination of information about geography and cost, consumers used the sites as first-line filters to rule out many potential facilities and services, and thereby to narrow their choice to a small set of alternatives. At that stage, most consumers believe that the usefulness of online sites gives way to the need for personal visits to facilities or agencies under consideration, and for other more informal kinds of information.

Online Information on Quality Is a Secondary Consideration for Consumers

Once they get past questions of geography and cost, some consumers use online sites for secondary considerations. This includes information concerning quality of life in residential facilities, such as:

- Nature of the accommodations;
- Appearance of the facility and its residents;
- Food quality and choice;
- Amenities offered by the facility; and
- Recreation opportunities.

Some consumers also look for site information pertaining to staff: ratio, qualifications, turnover. And some seek information regarding the languages and ethnicities of residents and staff, seeking compatibility for the person in need of care.

Quality of care is also identified by some consumers as an important second-line consideration. But consumers

usually consider this issue by looking at the specific medical and therapeutic services offered by a facility or agency rather than by examining comparative quality of care data.

Consumers Use Little Quality of Care Data

Health care monitoring and advocacy groups have expended considerable energy in recent years gathering and disseminating quality of care data regarding health care institutions and services, including long term care facilities. One of the significant findings of this research project, however, is how little consumers pay attention to such quality data, including statewide comparative surveys, as presented by online decision-support sites. Hardly any of the people in need of care consider quality of care data, and only a small number of (usually younger) family caregivers refer to this data online. These findings point to the futility of simply piling more and more comparative quality data onto sites intended primarily for consumers, at least as those data are currently presented.

Information Consumers Want or Need Added to Online Sites

This project's research included direct engagement with consumers—both family caregivers and facility residents—to determine the types of information they would want to see added to online decision-support sites. The project also sought out assessments by long term care professionals of the types of additional information they believe would be useful to consumers, as well as types of information they would not recommend be prominently offered on the sites.

Types of Information Identified by Consumers to Improve Online Sites

When asked—in focus groups, focus group surveys, and meetings with facility residents—what types of new information they would welcome at online decision-support sites, a number of consumers named facility and agency reviews by other consumers. Reading the experiences of actual residents and family caregivers could give prospective consumers a quality of information not otherwise available. Moreover, consumers believed that such reviews could also alert them to issues or experiences that they had not considered. However, their enthusiasm for such reviews was tempered by certain concerns. Some consumers were worried about the "subjectivity" of such opinions, and others were concerned that the consumers who posted such reviews would tend to be only those expressing the most extreme—positive or negative—opinions about their experiences.

Another type of information consumers identified as potentially helpful is an assessment tool that could guide them to the appropriate search criteria specific to their family member's particular care needs. This is congruent with the opinions of long term care experts (see below), almost all of whom express concern that consumers have little understanding about the different levels of care available, and about how to match their family member's needs to an appropriate level.

Professionals' Assessment of Information to Be Added for Consumers

There is no consensus among experts in the long term care field about the potential for consumers to make use of extensive quality of care information at online sites. However, the experts interviewed for this project did identify a number of areas in which they believe online decision-support sites might provide more extensive information to consumers.

Introduction to levels of care. A number of experts asserted that most consumers lack awareness of the different types and levels of available long term care: skilled and custodial nursing facilities; assisted living and other residential facilities; home care; and community-based care. At a minimum, this lack of information results in considerable waste of time and energy during the search for care; worse, it can mean an inappropriate or unnecessarily costly care choice for a family member. One of the early entry points for consumers, therefore,

should be information on the different types and levels of care that exist, and the needs and conditions that each type of care addresses. This might be abetted by a tool than can match the consumer's specific needs with the appropriate type and level of care available within a specific geographic area.

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Online Information Is Heavily Weighted Toward Nursing Facilities

Many consumers begin their search unaware of the various types and levels of long term care that might be available to them, or of how to determine which might be most appropriate. Information that introduces them to and explains these various types of care is crucial. So is supporting information that helps them decide among the facilities or agencies that offer the appropriate level of care.

Unfortunately, online decision-support sites tend to have far more information concerning custodial care nursing facilities than about any other level or type of care. This may leave consumers adrift in their search for home- or community-based care, or for assisted living or other residential care. It may even unwittingly edge consumers toward choosing a nursing facility when another type or level of care may be both more appropriate and more affordable.

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Staffing information. Long term care facility administrators report that consumers frequently express interest in staffing issues but do not necessarily know what questions to ask. They tend to focus on staff-to-patient ratios. In the context of at-home care, staff-to-patient ratios are not comprehensible to consumers. According to experts interviewed for this project, online sites should also provide consumers with information on types and qualifications of on-site staff, tenure of the facility or agency administrator and director of nursing, and turnover rate for the general staff.

Cost and coverage information. In addition to the cost of specific facilities and agencies, experts believe that consumers need clearer explanations about payment mechanisms and coverage. Many consumers have misperceptions about Medicare coverage for nursing

facility and home health care, both short and long term. Consumers are also generally unfamiliar with complicated Medicaid (Medi-Cal in California) rules concerning eligibility and coverage for long term care. And of those consumers who have long term care insurance, many are uncertain about how benefits become activated and what they would pay.

State/federal evaluation results. Experts are doubtful about presenting consumers with too much detailed quality data. In particular, the experts believe that such data is often too difficult or overwhelming for consumers. However, they do believe that consumers should be informed about reports of specific deficiencies regarding a facility or care agency, and about what the facility or agency has done in response to them.

Global rating scored by experts. Many experts interviewed for this project believed that consumers both wanted and could benefit from global ratings or other indicators that compared facilities and agencies. Moreover, they believed that consumers would respond positively to ratings evaluated by experts, though a site should also permit a consumer to drill down to the detailed facility or agency ratings on which the expert evaluation is based.

Structural Site Changes to Better Meet Consumer-Support Goals

A significant part of this site review project focused on the ways in which online information is presented. Focus groups and resident interviewees were asked for their responses to navigating CalNHS.org and other long term care Web sites, as well as selected sites for other services and products. Similarly, long term care experts were asked about consumer experience navigating their own Web sites. And project investigators undertook a comparative analysis of long term care consumer-support Web sites. The results of this research led to recommendations, intended to facilitate consumer use, regarding structural changes to online decision-support sites.

Reducing the Cognitive Load for Consumers

One of the project's overarching lessons concerning decision-support site structure was the need to reduce the "cognitive load" for consumers. That is, research showed that too often consumers were overwhelmed by a given page. This was due either to the page carrying more information than they could easily process in one step, or to information being presented in a way that was too difficult for them to sort through. The consequences of this cognitive overload included consumers misreading information, missing important information, or turning away from the site altogether.

To address the problem of cognitive overload, project researchers made several recommendations:

Progressive access to information. Researchers found that consumers prefer to begin with broad information categories. This might seem to some site designers as an unnecessary step, but consumers appear to be more comfortable beginning with such a preliminary stage before moving progressively down to more detailed and need-specific information.

Clearer displays and explanations. Many consumers have trouble understanding or interpreting graphic displays of available services, comparative ratings, and benchmarks. This stems in part from differences among various ratings within the same site, even within the same dataset, as well as from site to site. It also results from poor explanation of the rating system being used. Experts counsel that consumer testing can be of great value in overcoming these problems.

Adjustments in pitch of language. Sites must be careful to match their language to consumer levels of long term care literacy. Researchers propose that sites use a health literacy expert to help avoid industry jargon in favor of common, consumer-friendly terminology.

Simplifying the Navigation System

Consumers using online decision-support tools are likely to be familiar with relatively simple site navigation systems, such as those found on retail commercial sites. But they are probably neither experienced nor comfortable with the kinds of search systems that health care professionals regularly use. Therefore, decision-support site designers should consider navigation systems that permit consumers to follow the path of their needs and concerns as they actually consider them, rather than asking consumers to grasp a logic pattern that is unfamiliar to them.

"Consumers who use the Internet are familiar with Web sites that permit them to flexibly sort and filter search results based on their specific needs. Such a feature would facilitate complex searches [on long term care sites]."

— "CHOOSING LONG TERM CARE SERVICES IN CALIFORNIA: SUPPORTING CONSUMERS AND PROVIDERS"

The project's researchers identified a number of structural elements that address the specific needs and capabilities of consumers searching for long term care decision support:

Sequential disclosure. Most long term care decision-support sites use a linear structure, with a wide array of information on each page. This makes it difficult for many consumers to easily access the specific information they seek; having to drill deeper and deeper into the site to find what they are looking for increases the chance that they will get "lost" along the way. Instead of this linear design, information should be hierarchically organized in a "trunk/branches" structure that more closely resembles the cognitive map people use to organize large amounts of complex information.

Flexible filtering search engine. A long term care decision-support search engine should permit multiple entry points to the data. This would permit users to access the particular information they want from any level on the site, and at any stage of the search process. Each page should incorporate graphic elements and contrasting colors that both engage users and facilitate differentiation.

Different opening paths. Experts have identified two distinct sets of consumers who seek assistance from online decision-support sites: "48 hours" emergency decision-makers who must find care during a crisis, and "six months" planners who have a longer lead-time for their decisions (see "Family Caregivers as Primary Audience," on page 2). Because the needs and processes of these two groups can be quite different, researchers suggest that from the site's topmost level a different search path be offered to each.

Consumer feedback function. Current long term care sites do not encourage or permit discussion among consumers of long term care decisions or of individual providers. Yet this type of consumer feedback is relatively common in other domains, both retail and public service (e.g., school selection). Despite some reservations, consumers interviewed for this project expressed interest in having comments from other consumers available on a decision-support site. Such a feedback function might be enhanced by a system that vetted the comments to minimize inappropriate use.

"Key Words" Search Function

Some consumers arrive at decision-support sites looking for information about only one kind of facility or service, or about one particular issue. Others are interested in care options but have little information about types of facilities and providers. A broad key words search function can help both sets of consumers. The key words function can permit consumers to go directly to the material they seek without having to search through the site. And the function can locate the correct information paths for consumers who know only vaguely what certain facilities or services are called within the field of long term care.

Marketing Campaign to Build Demand

The old expression "All dressed up and nowhere to go" has a parallel in the virtual world: a comprehensive, easy-to-use Web site that no one visits. This can happen if the site is constructed or written in such a way that search engines do not prominently display it. But even addressing that problem has little effect on consumers who do not frequently use the Internet. A site can suffer inattention from these consumers if the site's sponsors fail to make good use of advertising and marketing avenues beyond the world of virtual searching.

Site sponsors thus need to invest in a comprehensive marketing campaign that includes various types of media. And the effort must be sustained—in order to influence behavior, exposure to a message must be repeated. Also, consumer turnover is constant, with new people entering the search for care as others conclude theirs.

Search Engine Optimization

Commercial sites are well versed in trying to optimize the likelihood that Internet search engines will prominently feature them. Given the proliferation of health care related sites, search engine optimization is becoming increasingly important for long term care decision-support sites as well. This requires attention, through optimization experts, to both site language and structure.

Web Advertising to Build "Equity"

Advertising and other vehicles for garnering a mention on other related, trusted Web sites can be extremely effective in reaching consumers who regularly use the Internet. Such linking may send to the decision-support site some consumers who might otherwise not find it. And based on the original site's willingness to provide the link, the decision-support site imports the consumer's sense of trust in that original site.

Non-Web Marketing

Many consumers continue to use and depend on non-Internet forms of communication for most if not all of their information. This is particularly true for older consumers, who make up a large part of those searching for long term care for themselves or family members. It is therefore important for sponsors of any long term care consumer decision-support site to use traditional media channels to develop awareness of the site. Such traditional marketing should follow two different paths:

Marketing to groups that influence consumers. One marketing avenue for a consumer site is to develop awareness of the site among individuals, groups, and organizations that influence long term care consumers. This would include nurses' groups, hospital discharge planners, care managers, geriatric clinics, state and local ombudsmen, area agencies on aging, and patient education centers.

Direct marketing to consumers. Sponsors of consumer decision-support sites should also consider direct marketing to consumers in community settings. This can include generating television, radio, newspaper, and magazine publicity through press kits, press releases, and other marketing tools, as well as advertising in these media. It can also include distribution of marketing materials to targeted organizations and locations such as senior centers, public libraries, volunteer agencies, and retail shopping centers.

Conclusion

Publicly available information concerning long term care facilities and services is rapidly proliferating. As the information becomes increasingly broad and complex, the need to carefully organize and present it becomes both more important and more difficult. Online long term care sites offer consumers and professionals access to large amounts of such information quickly, efficiently, and inexpensively. But unless carefully tailored, such sites can doubly miss their marks: Information aimed at professionals may have few takers, while a large spread of information may overwhelm consumers who are seeking specific decision support.

Research conducted for this project suggests several ways—some having to do with content, some with structure—for long term care online sites to address this double bind. The first concerns the issue of audience. The project confirmed that the primary audience for online long term care sites is consumers rather than professionals, and in particular the adult children of those needing care. Researchers suggest that site sponsors shape their information to fit the needs and capabilities of this audience, and that they further refine their presentation to offer different search paths for those consumers operating under crisis conditions and for those who are engaged in longer term planning.

Currently, consumers use online decision-support sites primarily as a starting point in their long term care search. Many consumers have little understanding of long term care options, and use online sites simply to find local facilities. They also look at information on costs, and some consider simple measures of quality of life and care, but they make very limited use of quality of care data. Based on this current use and on consumer needs remaining unfilled, the project's researchers propose that online sites offer more extensive information on: types of care; staffing; cost and coverage; and state/federal evaluation results, including deficiencies. The researchers also suggest global ratings scored by experts, as well as some form of consumer feedback.

Project researchers also pointed to structural changes that would improve consumer site use. These are aimed at reducing the cognitive load consumers face, and at simplifying site navigation systems to ease access and reduce the risk of consumers getting "lost" in a site. The proposed changes include progressive rather than linear access, broad beginning categories, multiple entry points, easily comprehensible benchmarks, and a reduced emphasis on quality of care databases. Researchers also

emphasize the importance of adjusting the pitch of site language to match consumer levels of long term care literacy.

Finally, researchers emphasized that having the best site in the world is small consolation if no one knows about it. Sponsors need to market their site, not merely upon its launch but as an ongoing part of its operation. Such marketing should include: search engine optimization; advertising on other related, trusted Web sites; traditional media channels to groups that influence long term care consumers; and direct marketing to consumers in community settings.

About the Research Partners

Howard B. Degenholtz, Ph.D., is associate professor of health policy and management, and associate director of research in the Center for Bioethics and Health Law, at the University of Pittsburgh. Dr. Degenholtz is a health services researcher who focuses on long term care and aging and whose work includes ongoing research on quality of life for nursing facility residents.

The HSM Group, Ltd., based in Scottsdale, Arizona, is a health care consulting business. It provides market research, training, economic models, consulting, and strategic planning to many areas of the health care industry, including managed care organizations, health systems and hospitals, pharmaceutical manufacturers, medical products manufacturers, and health care trade organizations. They can be reached online at www.hsmgroup.com.

Sam Boonin Consulting is an independent marketing consulting business in Oakland, California, that focuses on technology marketing. The company's services include business strategy, go-to-market planning, messaging, and positioning, marketing program management, competitive analysis, and website content development.

About the Foundation

The **California HealthCare Foundation,** based in Oakland, is an independent philanthropy committed to improving California's health care delivery and financing systems. Formed in 1996, our goal is to ensure that all Californians have access to affordable, quality health care. For more information about the foundation, visit us online at www.chcf.org.