NEXCARE COLLABORATIVE, INC.

Go Local Los Angeles
FEASIBILITY REPORT

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Section 1
Executive Summary

Section 1 provides an overview of the Feasibility Report. A goal of the National Library of Medicine (NLM) is to learn how regionally based Go-Local programs can link the health information on MEDLINEplus with appropriate, local resources. By 2003, Go Local programs had been executed in two states – North Carolina and Missouri. Now NLM is interested in learning how a Go Local program could be implemented in states with much larger populations and vastly more community based resources. In response, NLM has partnered with NexCare Collaborative, Inc. to implement a similar solution for Los Angeles County.

Section 2 provides further background on the Los Angeles Go Local Program sponsored by Nexcare Collaborative and the request for a feasibility study. NexCare Collaborative is a not-for-profit organization created with a major contract from the First 5 Los Angeles Commission (Proposition 10) in Los Angeles County to create and operate First 5 LA's resource "hub" in the County. This system supports web-based searching and retrieval and is the ideal platform to support a Go-Local application in the vast geographical and cultural County of Los Angeles. The NexCare telephone call center complements web-based searches, thus providing an added resource to consumers seeking additional information or requiring assistance to navigate the services identified through a web-based interface. Through an NIH-funded Evaluation Express Award, the NLM has contracted with NexCare to design a process evaluation plan presented in Section 7.

Section 3 summarizes the Go Local Los Angeles implementation strategy, which consists of four phases: (1) proof of concept and testing, (2) countywide implementation, (3) MEDLINEplus implementation, and (4) on-going maintenance. Additionally, Appendix A provides a more detailed work plan, time schedule and budgetary considerations for developing, testing, and implementing the Go Local Los Angeles Program.

Section 4 describes the unique characteristics of the Go Local Los Angeles target population, one of the largest, most diverse, consolidated metropolitan areas in the United States. Meeting the medical and social services information needs will require sensitivity to the extraordinarily diverse ethnic, linguistic, socioeconomic and cultural landscape. Additionally, the design team describes three major elements of the Go Local infrastructure and its development: (1) the information creation component, (2) the information delivery component, and (3) the nine major usability goals that will guide infrastructure design. The section concludes by emphasizing the importance of advanced planning for building in devices and capabilities for promoting and marketing the Go Local Los Angeles website.

Section 5 proposes a formula for estimating disease specific population-based estimates for determining the number of providers that should be accessible through a Go Local Los Angeles search. The section on user interface suggests the specifications for the entrance page and fields to assist users in conducting an effective search. Supplemental information is provided in the Appendices: (C) disease rates and physician specialties, (D) a sample table for matching MEDLINEplus topics to providers and taxonomy, and (E) NexCare's Agency Verification Module, the updating process used to maintain consistently accurate information on the thousands of agencies in NexCare's database.

Section 6 highlights a unique feature of the NexCare/ First 5 LA Connect/ Go Local partnership, the value-add of the Call Center. For many consumers, contact with a live agent to sort through complex information will be a value added, one which NexCare's current call center and web-based systems can readily provide. Language is an issue that cannot feasibly be completely addressed over the internet. Although it is entirely reasonable for the web-based interface to encompass several languages with reasonable competence, a metropolitan center such as Los Angeles County must be served with nearly every language spoken on Earth. This capacity already exists at the call center operated by NexCare and will serve as a valuable resource to web users who reach the limits of their language proficiency and would prefer to speak with

someone of their own language. Currently, over 70% of the calls handled by NexCare staff are handled in Spanish. The recent flu epidemic provided an instructive example of how a call center can serve as a vital addition to the web site by providing live health information as well as referral to sites offering the flu vaccine, information and referral that includes directions to the administration site and up-to-date cost information for the vaccine.

Section 7 presents a comprehensive plan for the process evaluation reflecting the relevant phases of design, development, and implementation of a Go Local Program for Los Angeles County. Because of the significant scale of the California program, this is an important time to complete a feasibility study and to develop a strategy for evaluating this particular program. The proposed process evaluation will be conducted in parallel with the 4 phases of the implementation strategy outlined in Section 3. This includes an evaluation of each of the usability goals outlined in Section 4. Each phase of the process evaluation plan is discussed and summarized in Table 7.1.

Section 2
Background & Feasibility Study

Background

The National Library of Medicine (NLM) is the world's largest medical library. MEDLINEplus, a Web-based resource attracting over 2 million unique visitors per month, serves as an authoritative and trusted source of health information for medical professionals and consumers, especially patients, their families and the general public. NLM's MEDLINEplus program houses up to date information on over 600 diseases and conditions, including links to the Web sites of virtually all NIH ICs.

"Go-Local" is a complementary service under development by NLM that links MEDLINEplus health topics to information about local health services and resources. The "Go-Local" model was initiated as a pilot project in North Carolina, where web links on MEDLINEplus health-topic pages transport the consumer to pages containing information about local health services in that state. These links are to area hospitals, physicians, nursing homes, support groups, health screening providers, and others. For example, the MEDLINEplus breast cancer page may link the North Carolina user to cancer clinics in the area, nearby oncologists, accessible support groups, and other relevant information on the chosen topic.

A goal of NLM now is to learn how other regionally based Go-Local programs could link the health information on MEDLINEplus with appropriate, local resources, especially in states with much larger populations and vastly more community based resources. The NLM will mentor regional organizations as they create, manage, and maintain new Go-Local programs. The local organizations must build, manage, and review a database capable of addressing the needs of MEDLINEplus users. They must build and maintain links and ensure web-accessibility. They must further be able to deliver appropriate information in a manner sensitive to the linguistically and culturally diverse communities that they serve.

NLM has partnered with NexCare Collaborative, Inc. (Sherman Oaks, California) to implement a similar solution for Los Angeles County. NexCare Collaborative is a not-for-profit organization created with a major contract from the First 5 Los Angeles Commission (Proposition 10) in Los Angeles County to develop and operate First 5 LA's resource "hub" in the County. NexCare has implemented and manages a multilingual website and call center that provides a unique service to the county's residents with accurate and relevant information on the thousands of Los Angeles County resources, with a particular focus on those that are relevant to the needs of mothers and children in the first five years of life.

The First 5 LA Connect program helps them navigate the complex health and social services systems of the county. In the database supporting this Information and Referral program, the county's thousands of resources have been geographically mapped and a taxonomy of services has been developed to link users with resources relevant to their search topics and proximate to their location. This system supports web-based searching and retrieval and is the ideal platform to support a Go-Local application in the vast geographical and cultural County of Los Angeles. The NexCare telephone call center complements web-based searches, thus providing an added resource to consumers seeking additional information or requiring assistance to navigate the services identified through a web-based interface. Fully trained Information and Referral Specialists and Health Advisors with the capability to provide this service in any language, convey needed information on the resources available to consumers.

A recent study examined the web usage of Californians as compared to that of other Americans. According to a new report from the Pew Internet & American Life Project, low-income Californians are more likely to search for health information online than other low-income U.S residents. The survey was funded by the California HealthCare Foundation. It was reported that 84% of low-income California Internet users have

searched online for at least one health topic. Of these users, 66% said that the Internet has improved the medical information and services they receive. Seventy-four percent of English-speaking Latino Internet users in California said that online information has improved the health and medical information and services they receive. Overall, 31% of California residents have used the Internet to search for information on health insurance, compared with 24% of other U.S. Internet users. The implementation of MEDLINEplus Go-Local will be a welcome addition to the armamentarium of Californians from all walks searching for health information and referrals.

Request for Feasibility Study

During the development of the North Carolina Go-Local program, there was no mechanism in place for a systematic process evaluation of its implementation. Through an NIH-funded Evaluation Express Award, the NLM has contracted with NexCare to design a process evaluation plan reflecting the relevant phases of design, development, and implementation of a Go Local program for Los Angeles County. Because of the significant scale of the California program, this is an important time to complete a feasibility study and to develop a strategy for evaluating this particular program. This implementation evaluation will have further utility as the needs of the remainder of California are addressed and as other states plan and implement future Go-Local programs in their regions. The designed process evaluation will appraise the implementation of the Go-Local California program through each phase of program execution, allowing it to have a meaningful impact on the final program interface and function.

Section 3
Implementation Strategy and Testing

Go Local LA: Mission, Goals, & Objectives

This program is the next phase of the national roll-out of the Go-Local program for National Library of Medicine's MEDLINEplus. Go-Local efforts are managed by partners with extensive knowledge of local community resources and risk factors to ensure each implementation reflects the specific needs of that community. With a mandate to serve Los Angeles County's culturally diverse population, 9.8 million residents strong, the LA County Go Local program will be the largest effort to date, and will provide an example for future efforts, particularly characterized by large urban areas and diverse populations.

The mission of Go Local LA is to design, build and maintain an easy to use website to help people find local resources for topics researched on MEDLINEplus. The goal of the program is to provide a state-of-the art service characterized by ease of use, accuracy, depth and breadth of coverage, and with up to date and verified data. The objectives of the Go-Local LA program are to:

1. Create an easy to use web site that accepts links from MEDLINEplus;
2. Allow site visitors to search for resources based on geographic distance from their location and the MEDLINEplus topic;
3. Augment the First 5 LA Connect database with additional medical and public health resources to provide appropriate coverage of Medline topics and Los Angeles geography and resources;
4. Enhance the existing First 5 LA Connect web site by allowing users to access MEDLINEplus content for topics relevant to their searches; and
5. Determine the advantages of an affiliated call center and assess its utility in future Go-Local programs.

Implementation Strategy & Testing

The implementation strategy consists of four phases: (1) proof of concept and testing, (2) countywide implementation, (3) MEDLINEplus implementation, and (4) on-going maintenance. Feasibility Report Appendix A provides a detailed work plan, time schedule, and budgetary considerations for developing, testing, and implementing the Go Local Los Angeles Program.

Phase 1: Proof of Concept and Testing

A proof of concept website has been created featuring the following capabilities:

- Two MEDLINEplus topics have been created in the MEDLINEplus test site. The selected topics can be reached through a link in the prospective Go-Local website,
- The user is then prompted to enter a start point and a search radius,
- This proximity-filter is used to construct a database query,
- The results are displayed to the user, sorted by type and proximity.

To complete Phase 1, this website will be used to solicit feedback from the Expert Advisory Group on the site's workflow, look, and feel. This feedback will be used in the development of the fully functional pilot site.

Once complete, the fully functional pilot site will continue its searches based on the topics available in the First 5 LA Connect version of System 211 ("Sys211") and will incorporate the dual database query structure to access information from the Provider Database.

Phase 2: County-Wide Test Implementation

Data compiled from the North Carolina website show that "physician specialists" were the most highly sought out information among users in the state. Initially, the Go-Local Los Angeles database will be expanded to cover physicians, hospitals, nursing homes, support groups, health screening providers, agencies, resources, and other services in Los Angeles County. The initial expansion will be based on the top 20 topics researched on MEDLINEplus (Appendix 2).

The procedures to add and modify records will be piloted, as will the quality assurance procedures to ensure ongoing accuracy and currency. During this phase, the site will be available over the web for internal testing, but will not be available on a published public site. An internal advisory group and users group will test the County-wide site and will provide continued feedback on workflow, look and feel, coverage, accuracy and currency. At the culmination of Phase 2, 100% of topics will be mapped. Otherwise, similar to the North Carolina program, Go Local Los Angeles will explicitly state when gaps exist in the database, making users aware of the search limitations.

Phase 3: MEDLINEplus Implementation

Incorporating feedback from the second Phase, the Go-Local LA program will be made available over the web for remote testing and review. Once cleared for release, the site will be made available *via* a link from the MEDLINEplus site and will be actively promoted to the public. The Advisory Panel will convene on-going meetings to review and report on usability and technology process measures.

Phase 4: Maintenance

After the live release of Go-Local LA, Nexcare and Harbor will continue to provide on-going maintenance and support. This will include:

- Routine checking of links,
- Maintenance of technology platform and access,
- On-Going database maintenance to ensure up to date information,
- On-Going database development to increase the number of agencies and topics covered, and
- Routine user testing and enhancements.

Section 4
Target Audience, Usability Requirements, Promotion & Marketing

Target Audiences

MEDLINEplus is an authoritative and trusted source of health information for medical professionals and consumers of medical services. Go Local Los Angeles is intended for individuals who are seeking health care services for themselves or their families, and for providers of health and social services who may need additional information for making appropriate referrals to patients and clients. Additionally, because Go Local Los Angeles will be closely affiliated with Nexcare/ First5 LA Connect, the service will be made available to all First5 LA Connect callers and website users. The vast majority of the top 100 medical conditions resulting from MEDLINEplus searches are also relevant to the families and caregivers of children zero to five years of age as well as to the children themselves (Appendix 2).

The Go Local Los Angeles program will connect this wealth of high quality medical information to the local setting, healthcare providers, and resources that can make a difference in the lives of its users. The Go Local Los Angeles program is targeting one of the largest, most diverse, consolidated metropolitan areas in the United States:

- Nearly ten million people live in Los Angeles County;
- The LA Unified School District has identified 92 languages spoken among its students;
- UCLA Professor V. Ivanov has counted at least 224 languages spoken in Los Angeles County;
- According to the U.S. Census (1990) approximately 5% of LA County's population was hearing impaired;
- According to the Braille Institute, there are nearly 192,000 blind and visually impaired individuals living in Southern California.
- Los Angeles' income distribution is extensive and characterized by some of the wealthiest persons in the country with a large subgroup living below the federal poverty level and a substantial immigrant population.

This diversity means that Go Local Los Angeles must address the medical and social needs of the citizens of Los Angeles County with sensitivity to an extraordinarily diverse ethnic, linguistic, socioeconomic, and cultural landscape.

Usability Goals

The proposed Go Local LA project includes an information creation component (the creation of content to be delivered to the users) and an information delivery component (a web-based interface that allows users to access the content). Because the usability of the system relies on the quality of both components, the proposed usability goals reflect quality targets for both the content provided and the web-based interface. The purposes of the implementation evaluation (Section 7) are for providing feedback to improve information creation and delivery and for assessing progress towards achieving the usability goals described below:

Usability Goal 1. The information displayed should be accurate, complete, and up-to-date. This includes valid contact information, low rates of missing data (i.e., omitted providers), and accurate descriptions of the services provided by each provider / agency or valid links to these descriptions.

Usability Goal 2. Searches should result in the display of the "hits" most appropriate for the user. This means a large proportion of the physicians or agencies displayed on the first page of results can actually provide the services targeted by the user (i.e., they have the appropriate credentials to provide the services, are located within a practical distance from the user, are appropriate for the user's income / insurance status, and can communicate with the user). In addition, virtually all search term / location combinations should result in some hits. This can be accomplished by broadening the search radius until there are results for a given topic.

Usability Goal 3. The site should not make unusual educational demands on users. The presentation of materials on the site will parallel the presentation of information on the MEDLINEplus web site. Use of the website should not require knowledge of medical jargon or specialized computer terms. Whenever possible, the program should map colloquial terms, common misspellings, and partially completed terms onto appropriate medical terms when searching the database.

Usability Goal 4. The program should have minimal hardware and software requirements, as follows:

- Use standard, validated code (HTML 4 or earlier) to ensure compatibility with a wide range of commonly available browsers (Explorer, Netscape, Safari, Opera, Lynx, etc.)
- Functionality on low-resolution monitors
- Compatibility with common adaptive technology devices (see Goal 4).
- Moderate bandwidth requirements and adequate server / internet capacity (headroom) to ensure minimal delays in loading site for users of high-speed and low speed (56kbps) connections.

Usability Goal 4. The website will be designed to be maximally useful for individuals with disabilities (see guidelines at: http://www.w3.org/WAI/gettingstarted/). Our audience includes people with vision, hearing, and mobility impairments, and making health information accessible to this group via the Web is especially important. It should also be noted that conformance to accessibility specifications (specifically, US Section 508 and to the WCAG10 Guidelines) is increasingly valued by government and private funding agencies, and has become in many cases a requirement (see www.Section508.gov). Moreover, the cost of retrofitting a nonconforming website to accessibility standards is significantly greater than the cost of designing accessibility into the site.

Usability Goal 6. The site should be easy to find on the web. This includes relatively high placement in popular search engines for likely search strings such as: "Los Angeles Pediatrician", "Santa Monica HIV", or "Reseda California Doctor". Additionally, reciprocal links to other sites should be included that might attract individuals searching for an appropriate service provider or agency (e.g., LA County health websites, local hospital websites).

Usability Goal 7. The web interface should be easy to navigate. Ninety-five percent (95%) of the users should be able to identify all hyperlinks on each page (including any linked images or image maps). A large percentage of users should be able to accurately anticipate the effect of clicking on each link and be able to understand their current location in the search process / page hierarchy.

Usability Goal 8. The web interface should have an appearance that users find pleasant and professional, utilizing a graphic style that is complementary with the MEDLINEplus website.

Usability Goal 9: The site should be designed with the multi-lingual Los Angeles County audience in mind. Once a MEDLINEplus topic has been selected, the results, while in English, are usually in the form of standard names and addresses. Because the Go Local site itself will have relatively little descriptive text, it may be feasible to create several language templates to fit over the data. Because the MEDLINEplus

Spanish language interface is in an advanced stage of development, the Go Local Los Angeles site should develop the capability for addressing the information needs of Spanish speakers. Because the MEDLINEplus search terms are at present offered in English and Spanish only, the Go Local site will, for now, offer interfaces in English and Spanish, and will direct users whose English or Spanish competence is limited (i.e. all other languages) to the multi-lingual information specialists at Nexcare.

Promotion & Marketing

Once the site architecture has been articulated, reviewed, and designed, the Team will devote attention and resources to the promotion of the site. It is vital to consider promotion long before the site actually rolls out. This is because some promotional "devices" can be built into the site itself. The structure of the pages as well as the metadata tags can influence the relative position of the site in search engines. With reference to the MEDLINEplus portal these issues have been carefully tested and systematically addressed. With advance planning the Go Local Los Angeles home page could largely promote itself.

Section 5

Provider Coverage Requirements and User Interface

Provider Coverage Requirements

Ideally, a formula will be developed to determine the number of providers required based on the population's need for medical services. To create a population-based estimate, assumptions must be made about the resource requirements per capita for a given medical care condition, service and-or provider. A review of existing measures led to the section of the California Code Regulations, Title 8, section 9773 (Treatment Standards). In this code, the Department of Industrial Relations (DIR) specifies the number of care givers a managed care program must offer per expected injury or illness:

> "At least one primary care giver within 30 minutes or 15 miles...for every 1200 expected injuries or illnesses."

Based on this guideline, the following assumptions are made: (1) The DIR regulation is a relevant calculation of the number of providers for a particular area and a particular number of cases; (2) A particular Go-Local implementation has enough providers in any given area to service; and (3) Driving times in Los Angeles are worse than they are throughout most of California, so a 30 minute drive is closer to 10 miles.

Using these assumptions, a formula is proposed for each of the expected injuries and illnesses sought on the MEDLINEplus site. For every search at least one provider should present for every 10 mile area and for every 1,200 people likely to experience the disease. To calculate the number of providers for a disease (MD_d), the following measures are required:

- The number of people in a 400 (20 mile X 20 mile) square mile area (POP_{10})
- The incidence rate for the particular disease (I_d)

Using these factors, the following calculation will be used to estimate provider requirements for any given disease in a 400 Sq Mile radius:

$MD_d = Cases/1200 = POP_{10} \text{ X } I_d/1200$
$POP_{10} = (Total\ Population / Total\ Square\ Miles) \text{ X } 400$
$MD_d = POP_{den} \text{ X } I_d / 3$

So for Los Angeles, where the population density is 2373 people per sq. mile, the calculation should be:

$MD_d = 791 \text{ X } I_d$

This means any given search within a 10 mile radius would generate MD_d providers of care. Also, a calculation of the total number of providers by disease would be found as:

$MD\ (total) = Total\ Population \text{ X } I_d / 1200$

With these formulas, the total number of providers for each topic in the database can be calculated, and the average number of providers that should be listed in a 10 mile radius search. Doing so reaffirms results derived from assumptions and calculations and on which key decisions will be made.

For instance, the incidence rate of Prostate Cancer, one of the top topics, is roughly 77 cases per 100,000 people (.077%).

Therefore, the total number of urologists to cover prostate cancer in Los Angeles should be:

MD (total) = (9,800,000 X.00077)/1200 = 6.28 (six or seven doctors)

But if you calculate the number of providers that need to come up in the 10 mile radius, the result would be:

= 791 X.00077 = .6

The results for all diseases that a provider would be associated are then added up to provide an "all topics" coverage number. For example, a target number of urologists to cover the top 100 topics would equate to the requirement for Prostate Cancer (.6) plus the requirement for Kidney Failure and any other topics to which they are attached.

Fractions will be rounded to the next integer (e.g., if the total is 2.6 MDs, the minimum number of MDs in a 10 mile radius in LA would be rounded to 3.0). If you calculate the number of 10 mile radius areas in LA you would get 4,061 / (π *100) = 13. This means that for any given type of provider there must be a minimum of 1 provider in any 10 mile radius, and a minimum of 13 providers total in LA County for a disease with a low incidence. If a specialty requires 3 providers in a 10 mile radius, the ideal minimum for LA County would be 3 X 13 or 39 providers.

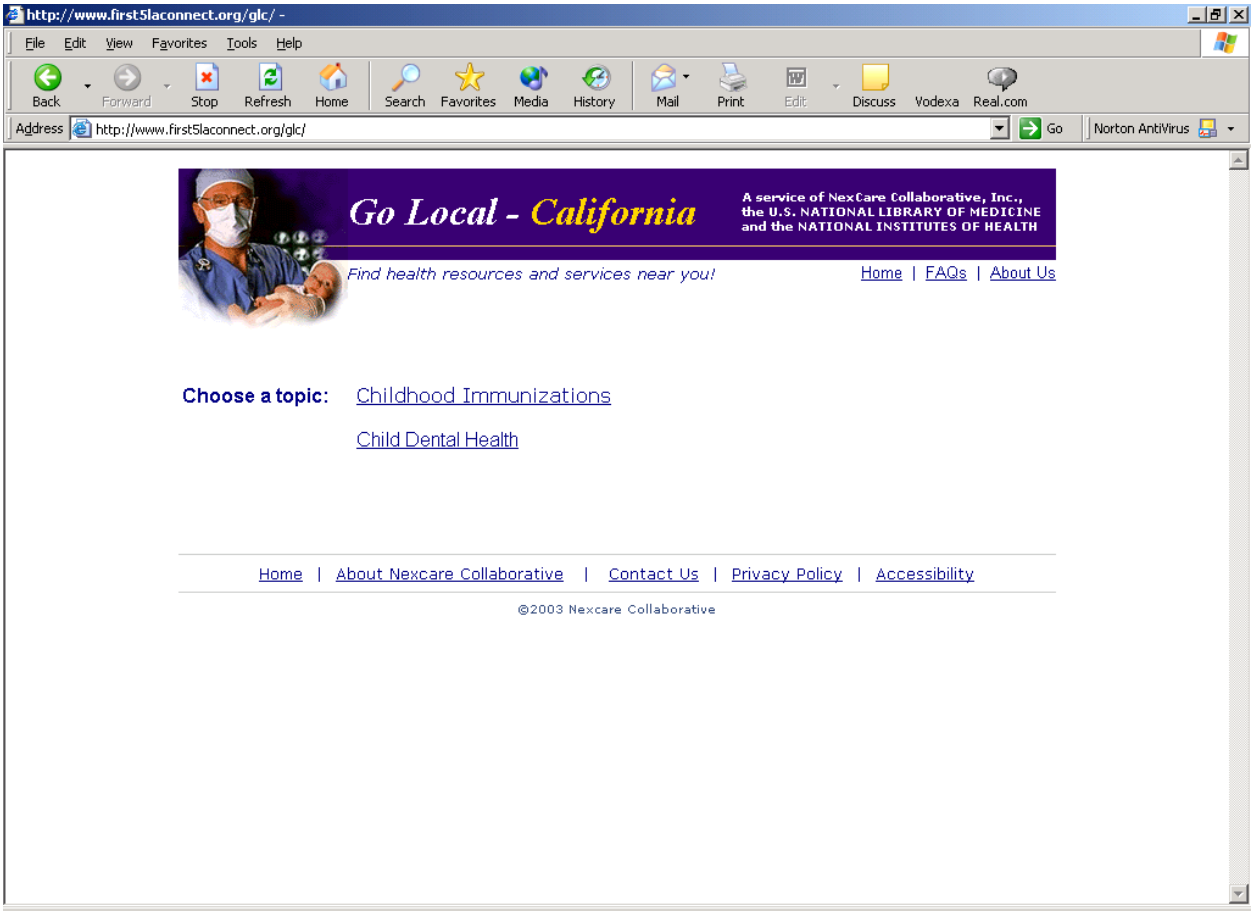
Appendix C provides information on calculating disease rates and identifying the appropriate physician specialists. Appendix D provides a sample table for matching MEDLINEplus topics to providers and taxonomy.

User Interface

The entrance page should include a field for a search string (disease name, symptom, service required, practitioner type, etc.) as well as fields to identify the user's location. Users should be able to access this page either directly or after entering the search string at the MEDLINEplus web page and clicking on a Go Local LA link. The initial search should provide a single page of results ordered by geographic distance. When more than one service provider / agency is found, the program should encourage users to refine the search using additional search terms, insurance / income requirements, or languages spoken / translated. Clearly labeled assistance should be available for selecting good search terms and defining the terms used in the fields.

On any results page, the user should be able to click on a provider / agency and obtain additional information. This should include: contact information for the provider / agency, links to their web site (if applicable), brief description of their services, information about insurance acceptance (or income eligibility for free or low cost services), and information about translation services available.

Some screen shot examples from the initial phase of this program are provided below. Updated versions of this approach with significant additions and improvements will be available within the first few weeks of 2004. The web site address of the test screen is http://www.first5laconnect.org/glc/.


http://www.first5laconnect.org/glc/ -
File Edit View Favorites Tools Help
Back Forward Stop Refresh Home Search Favorites Media History Mail Print Edit Discuss Vodexa Real.com
Address http://www.first5laconnect.org/glc/
Go
Norton AntiVirus
Go Local - California
A service of NexCare Collaborative, Inc., the U.S. NATIONAL LIBRARY OF MEDICINE and the NATIONAL INSTITUTES OF HEALTH
Find health resources and services near you!
Home | FAQs | About Us
Choose a topic:
Childhood Immunizations
Child Dental Health
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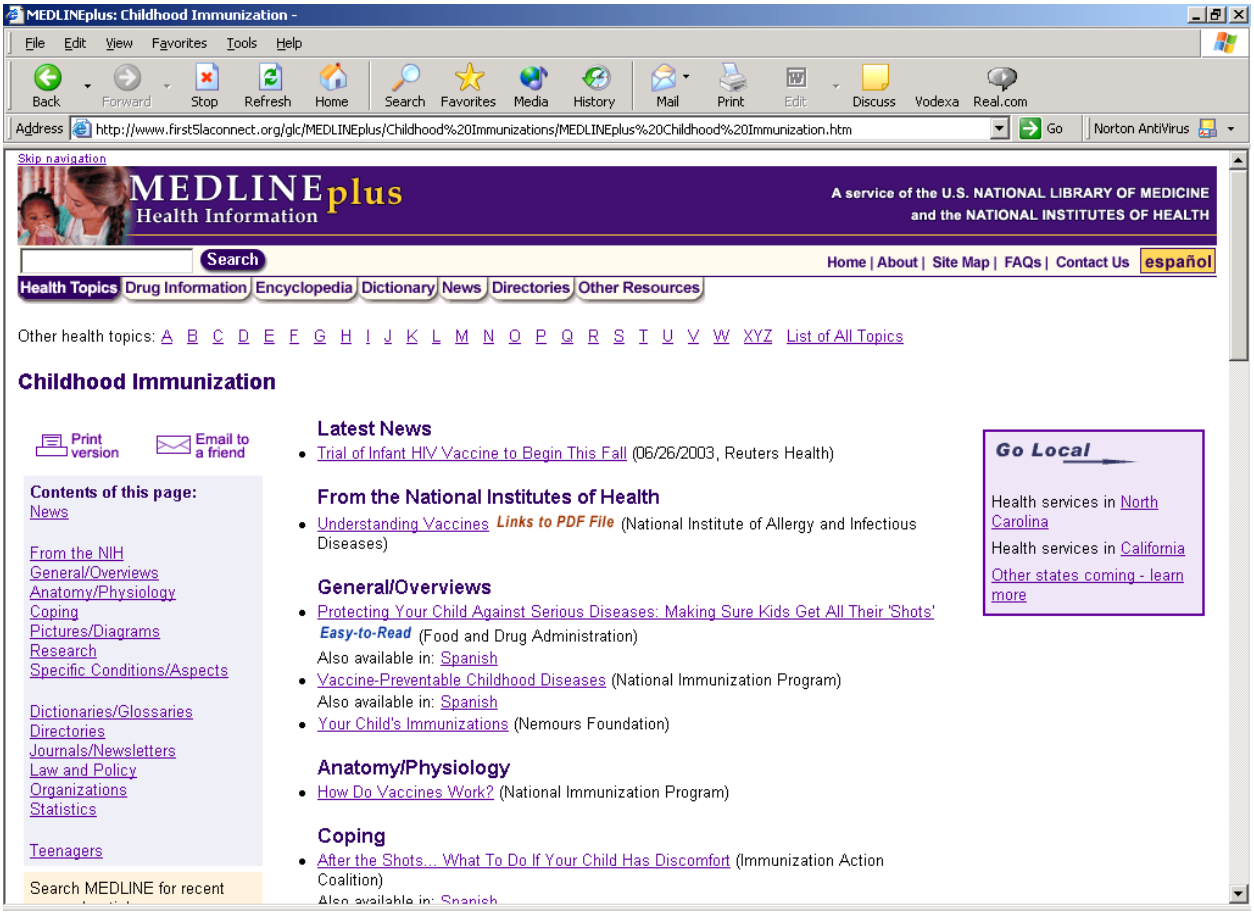
MEDLINEplus: Childhood Immunization -
File Edit View Favorites Tools Help
Back Forward Stop Refresh Home Search Favorites Media History Mail Print Edit Discuss Vodexa Real.com
Address http://www.first5laconnect.org/glc/MEDLINEplus/Childhood%20Immunizations/MEDLINEplus%20Childhood%20Immunization.htm
Go Norton AntiVirus
Skip navigation
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Other health topics: A B C D E F G H I J K L M N O P Q R S T U V W XYZ List of All Topics
Childhood Immunization
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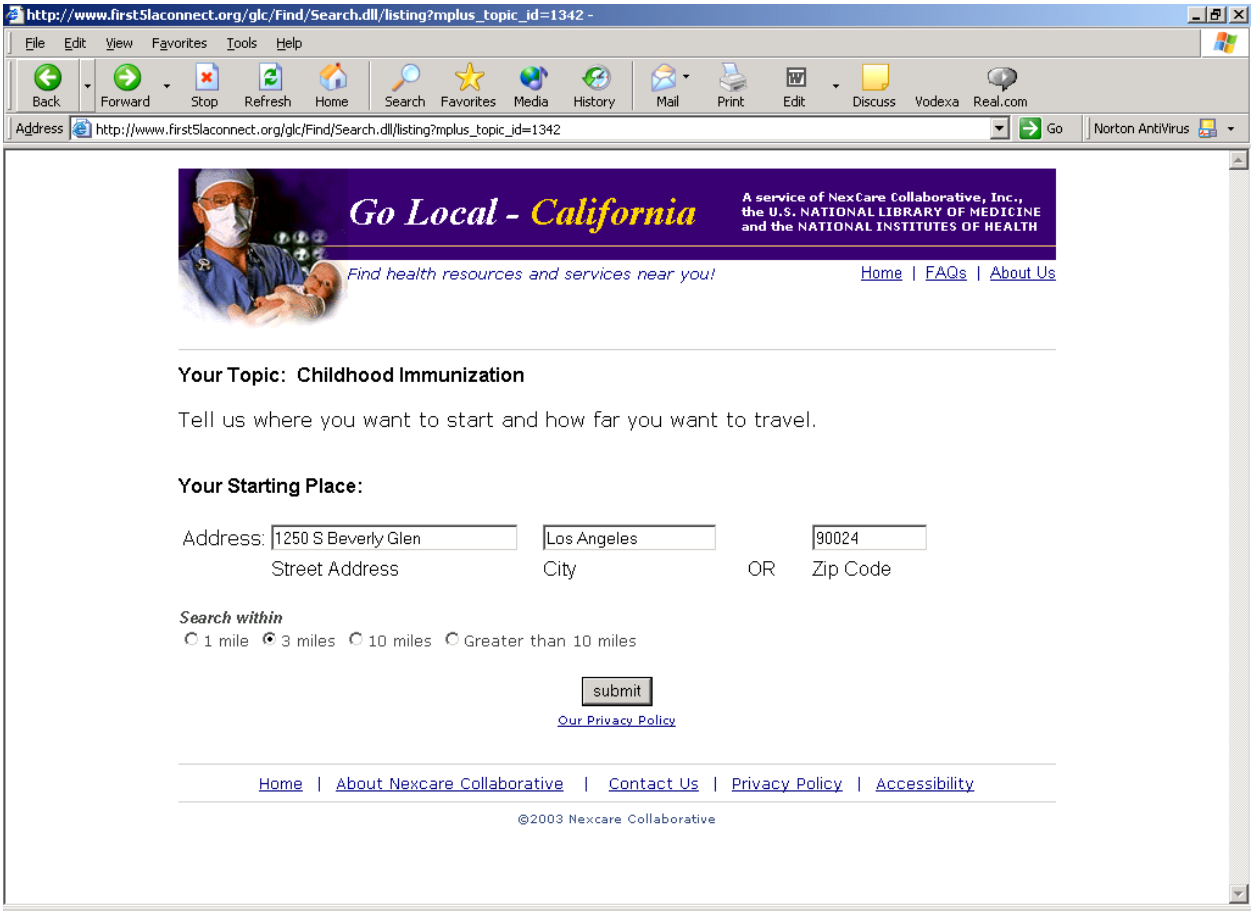
Trial of Infant HIV Vaccine to Begin This Fall (06/26/2003, Reuters Health)
From the National Institutes of Health
Understanding Vaccines Links to PDF File (National Institute of Allergy and Infectious Diseases)
General/Overviews
Protecting Your Child Against Serious Diseases: Making Sure Kids Get All Their 'Shots' Easy-to-Read (Food and Drug Administration)
Also available in: Spanish
Vaccine-Preventable Childhood Diseases (National Immunization Program)
Also available in: Spanish
Your Child's Immunizations (Nemours Foundation)
Anatomy/Physiology
How Do Vaccines Work? (National Immunization Program)
Coping
After the Shots... What To Do If Your Child Has Discomfort (Immunization Action Coalition)
Also available in: Spanish
Go Local
Health services in North Carolina
Health services in California
Other states coming - learn more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File Edit View Favorites Tools Help
Back Forward Stop Refresh Home Search Favorites Media History Mail Print Edit Discuss Vodexa Real.com
Address http://www.first5laconnect.org/glc/Find/Search.dll/listing?mplus_topic_id=1342
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Tell us where you want to start and how far you want to travel.
Your Starting Place:
Address: 1250 S Beverly Glen
Street Address
Los Angeles
City
OR
90024
Zip Code
Search within
1 mile 3 miles 10 miles Greater than 10 miles
submit
Our Privacy Policy
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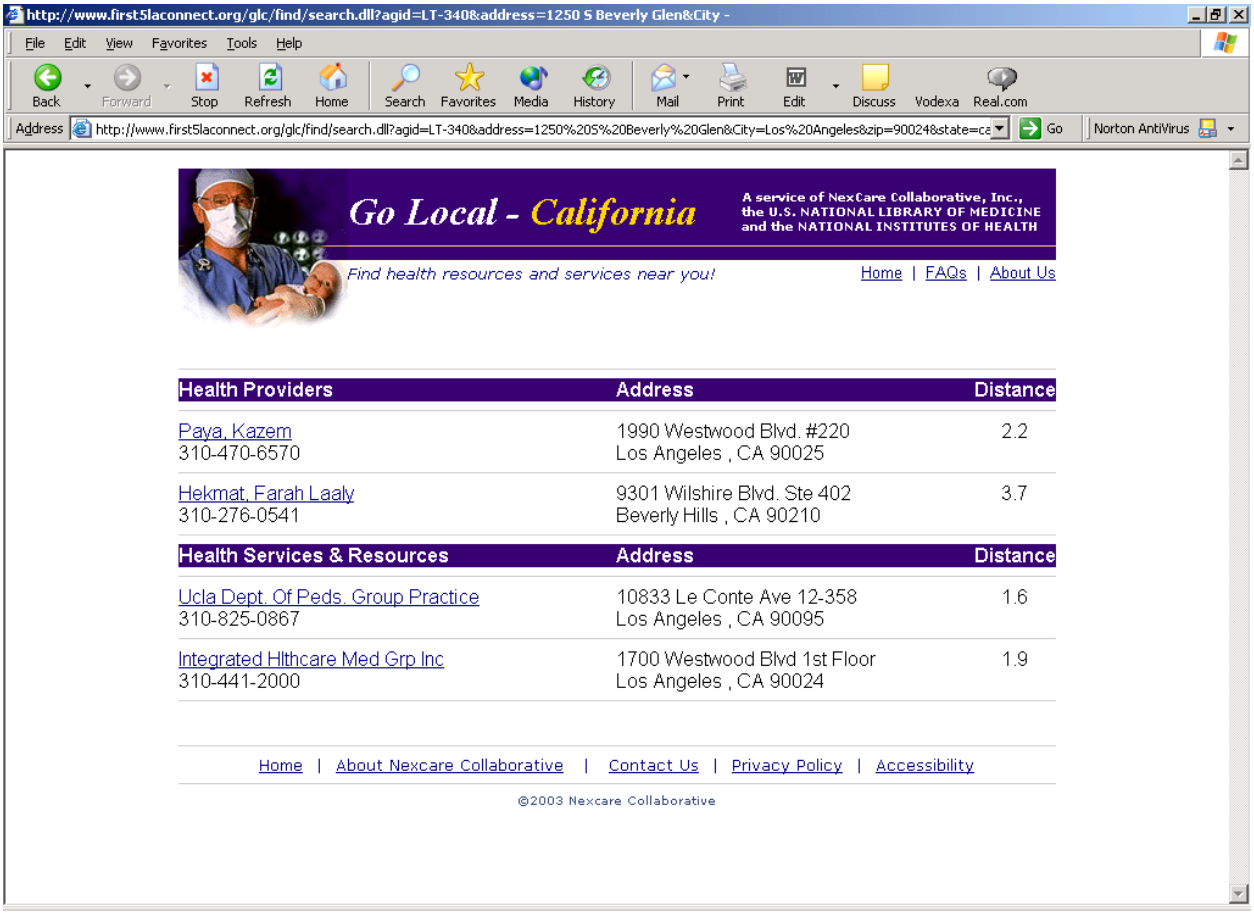
http://www.first5laconnect.org/glc/find/search.dll?agid=LT-340&address=1250 S Beverly Glen&City -
File Edit View Favorites Tools Help
Back Forward Stop Refresh Home Search Favorites Media History Mail Print Edit Discuss Vodexa Real.com
Address http://www.first5laconnect.org/glc/find/search.dll?agid=LT-340&address=1250%20S%20Beverly%20Glen&City=Los%20Angeles&zip=90024&state=ca
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Los Angeles , CA 90025
2.2
Hekmat, Farah Laaly
310-276-0541
9301 Wilshire Blvd. Ste 402
Beverly Hills , CA 90210
3.7
Health Services & Resources
Address
Distance
Ucla Dept. Of Peds. Group Practice
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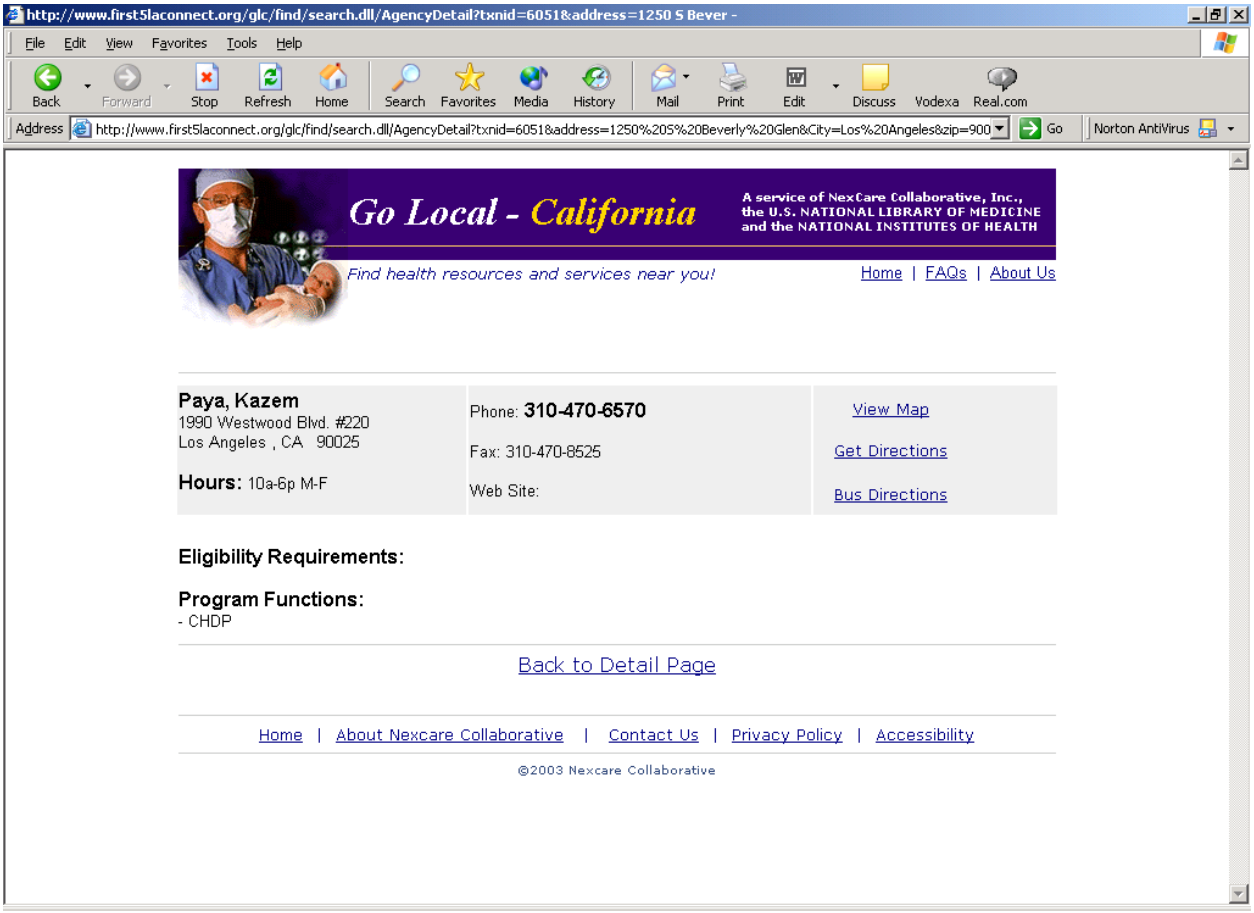
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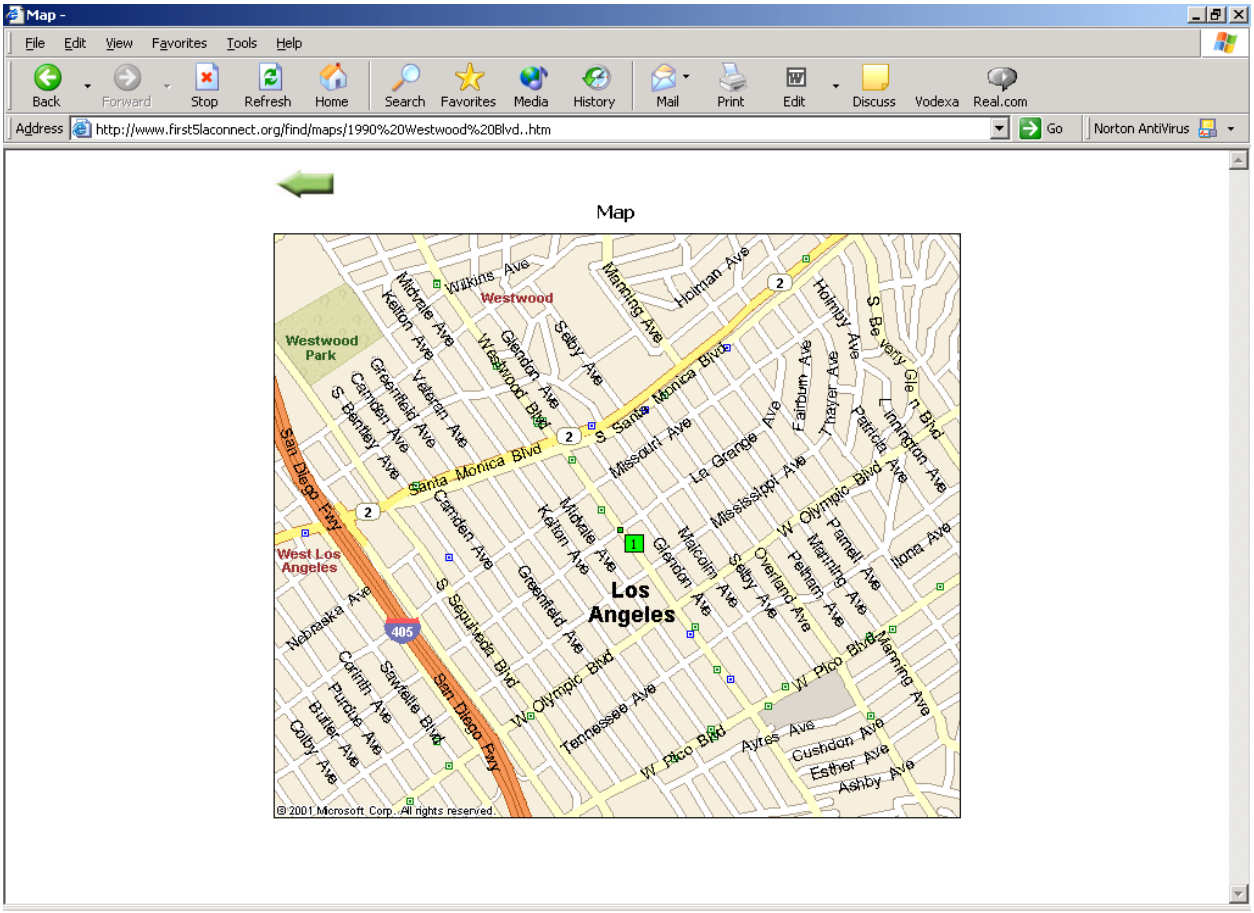
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Section 6

Value-Add of a Call Center

MEDLINEplus is solely a web based interface. The Go-Local program offers a unique addition to MEDLINEplus by offering local resources relevant to the researched information on the MEDLINEplus site. But for some consumers this additional information may become overwhelming in scale and scope. The additional depth and breadth of information may require live contact for clarification and prioritization of information. Contact with a live agent, including an Information and Referral Specialist, Nurse, Nurse Practitioner, or Social Worker may be in the form of telephone, instant messaging, or e-mail.

MEDLINEplus has shouldered the ambitious task of offering its web based services in two languages, English and Spanish. The MEDLINEplus Go-Local site will mirror this language capacity by offering clients the ability to search for information in both of these languages. The NexCare call center is equipped to further assist callers in English and Spanish as upwards of 70% of the tens of thousands of calls currently handled by the call center are capably processed entirely in Spanish.

For clients on the MEDLINEplus Go-Local web site who reach the limits of their proficiency in the two languages offered by the web based interface, the call center stands ready to assist web users in any language in the world. The availability of a live agent to help address concerns or issues as well as to help prioritize and clarify information gathered on the website may be an added value and preferable to the singular use of a web based interface for addressing the concerns of MEDLINEplus users.

Process monitoring will be used to detect the point at which consumers ask for live assistance. Routine quality assurance questions currently in place at the NexCare call center can monitor the referral source of the call. This process can in addition document the approximate length of time spent on the web site prior to asking for call center support. Questions raised by the web based search that are not answered directly through the web can thus be monitored and addressed through the quality assurance process and updates to the web site.

This process, already operational at NexCare, will be a key component of learning about the needs of clients, as well as improving systems to better serve consumers via a web-based interface. The process currently in place utilizes a three layered system of quality assurance, internal evaluation, and external evaluation to monitor client satisfaction with the manner in which information is provided, the information that is provided, effectiveness of programs, and the usefulness of the referral agency to the client. There is a continual feedback mechanism in place for system and process improvement based on this evaluation data.

A recent study conducted by an external evaluator examined the first five months of operation of the NexCare/ First 5 LA Connect Call Center. The evaluation results indicated 98% of those responding to the survey would call the center again and 98% would refer the call center as a valuable resource to others. A majority of respondents would not change anything to improve the call center – they ranked themselves as "very satisfied." Of the 28% offering suggestions for improving the services, a recurring theme emerged: 33% were interested in receiving calls back from the center to make sure the services or application materials requested were satisfactorily received and completed.

The data indicate the call center can serve in a capacity that a solitary web based interface cannot. The call center's capacity to "call back" clients, either by telephone or through the internet, is a service callers are requesting even though they have live information and referral specialists to speak with on the initial call. The information and referral specialist whose career is dedicated and whose extensive training has included resource search and identification is more adept at filtering through the several thousands of available

resources via computer than an average resident of Los Angeles County. Still, the number one issue raised by consumers was a request that they be called back to ensure the appropriate service requirements were met. MEDLINEplus searches through a lone web based interface encompassing thousands of agencies will likely introduce queries that cannot be responded to as easily without the help of a specialist. This concern is amplified further when one considers the diverse range of cultures and languages spoken by Angelinos.

Language is an issue that cannot feasibly be completely addressed over the internet. Although it is entirely reasonable for the web based interface to encompass several languages with reasonable competence, a metropolitan center such as Los Angeles County must be served with nearly every language spoken on Earth. This capacity already exists at the call center operated by NexCare and will serve as a valuable resource to web users who reach the limits of their language proficiency and would prefer to speak with someone of their own language.

To illustrate the complexity of a web-based search, consider that an initial search on pregnancy information on the MEDLINEplus site may result in information on several physician choices, information on the timing of prenatal visits, prenatal vitamins, medicines that should be discontinued during pregnancy, smoking cessation programs, advocacy groups for working mothers, domestic violence prevention programs, health insurance issues during pregnancy and beyond, health insurance for the infant, car seats, breast feeding counseling, the availability of free food for moms and babies, and other specific questions on parenting, diet, stress, health, child care, continuing education, housing, and legal concerns.

In the best case scenario, the client will identify all of the needed resources and identify, in order of priority, those services that are most suited to her current requests and those most urgently needed. An example of such an urgent need during the course of pregnancy is that of prenatal visits to an obstetrician. Since visits to a doctor require payment that is often too burdensome to handle in an out-of-pocket fashion, the need for health insurance inevitably arises. For many pregnant women, this requirement may delay the first prenatal visit and put her health and the health of the unborn child at great risk. As such, the ability to identify a doctor within a reasonable distance from the Go Local client's current residence or place of work simply is not an adequate response to the predicament. And it is unlikely that a web-based interface can in and of itself serve the function of identifying the needs of the client, to qualify her for the appropriate health insurance program, and to successfully enroll her in the program. Such a level of service, undoubtedly needed by a great many of the residents of Los Angeles County, currently can only be supported through a call center. And the NexCare call center, currently operational and quite adept at addressing needs such as health insurance enrollment, will without question be a great addition to the web user with needs that reach beyond that which can be achieved through a singular web based interface.

It may prove useful to refer once again to the study conducted by the external evaluators of the call center. In a focus group format, the external evaluation team questioned participants on their expectations of the call center and web site currently offered by NexCare. Comments reflected the need for services that reached beyond simple referral, "What if I already have the applications and don't know how to fill them out?" And "How will they know if the referral helped?" The focus group participants wanted the website to provide the same information as that provided by the call center. However, they were concerned that the web site and call center should extend beyond the scope of a simple referral source. What was deemed necessary was the ability to provide detailed service provider information as well as counseling and crisis intervention services, services that reach beyond those possible through a web based interface.

The recent Flu epidemic serves as an example of the detailed service provider data and information that reaches beyond simple referral that web based users seem to consider most useful. California was not immune to the flu epidemic that hit the United States this winter. NexCare, five months into its official operations was recognized by the English as well as Spanish speaking media as a trusted source for not only accurate and up-to-date health information that is understandable by the public, but as well, as a

source of actionable information, providing added value to televised newscasts. During a four day period at the start of the month of December, NexCare was on-the-air fourteen times, reaching an estimated audience number of 2.5 million within and surrounding Los Angeles County. This exposure led to thousands of telephone calls about the flu; this call volume was handled successfully in English, Spanish, as well as several of the other languages spoken within the vast expanse of Los Angeles County.

The circumstances that the residents of this county and NexCare were in were instructive for the following reasons: The county's nearly 10 million residents found themselves exposed to an apparently new disease with no apparent prior immunity; there were news reports from other Western states that identified otherwise healthy children who had died as a result of exposure to this flu virus strain; parents were confused by information regarding what age group children and what adults should receive the vaccine; there were reports that called on "high-risk" populations to receive the vaccine without providing clear and concise information on what criteria could be used to conclude that one was or was not "high-risk"; there was an apparent shortage of the vaccine – this was confirmed as thousands scrambled to get the vaccine but could not reach administration sites in time; the population was inundated with information leading them to stay clear of already overcrowded hospital emergency rooms; there was no central location within the county that provided up to date information on the many questions families had about this health crisis.

NexCare's web site and call center were operationally prepared. A button linking to information on the flu was posted on the front page of the web site and additional information and referral clarification in English and Spanish as well as any other language in the world were offered by the call center trough Information and Referral Specialists and Family Health Advisors. Thousands called. NexCare stood prepared with information on the flu including risks of exposure, contagion, and symptoms; information on the flu vaccine including qualification criteria, possible side effects, and effectiveness; up-to-date and verified information on all of the facilities in Los Angeles County that continued to offer the flu vaccine; and confirmed information on the cost of the flu vaccine at each facility offering its administration. This contact opportunity was as well utilized by NexCare to assist callers who did not have health insurance with application, qualification, and procuring health insurance for themselves and their families. The lessons learned as a result of exposure to this epidemic can be applied to other situations where rapid response with accurate health information is vital. Such situations include possible population exposures to SARS or a terrorist attack with a transmissible agent.

It is thus feasible and reasonable to assume that for many consumers, contact with a live agent to sort through complex information will be a value added to the MEDLINEplus Go-Local web site, one which NexCare's current call center and web-based systems can readily provide in English and Spanish as well as nearly any other language spoken on Earth. The telephone call center may as well serve as a portal of entry to the MEDLINEplus Go Local program for those consumers without immediate access to the web. By making the MEDLINEplus Go Local information available to information and referral (I&R) specialists, clients can access the same information by contacting the call center by telephone. This essentially provides access to the MEDLINEplus Go-Local web site for clients without access to the web.

The telephone call center can in addition function as a referral source for the web site itself. It may be quite preferable for clients to further research a particular topic or continue to read on an issue through MEDLINEplus. Thus, the telephone client can be referred to the web site at the conclusion of the call for further information. And the MEDLINEplus Go Local client may be referred to a live agent for further clarification or help with prioritization. The complementary nature of a call center and web-based system and the synergy of assistance they may offer clients seeking health related information in Los Angeles County is unique and the potential, exciting.

The idea of a call center in addition to a web-based interface is derived from the notion that the business of serving clients and empowering them to overcome problems through access to resources is not achieved by

programming rules alone. Rather this function is best served through the additional application of human principles. It is reasonable to project that for the residents of Los Angeles County, access to the Go Local web site will be an excellent step toward reaching the services they need. And that the Call Center can serve as an additional portal through which the scale and scope of these services can be refined to best serve the needs of the Go Local client.

Section 7
Work Plan, Time Schedule & Budget Requirements For Conducting Implementation (Process) Evaluation

The goal of the Go Local LA evaluation is to provide feedback that will improve the overall effectiveness of the program. Because the overall usability of the system is limited by the quality of the data created by the project, the technical performance of the web site, and the quality of the web interface accessing the data, the proposed analysis plan includes an assessment of all of these components. The proposed process evaluation will be conducted in parallel with the 4 phases of the implementation strategy outlined in Section 3. This includes an evaluation of each of the usability goals outlined in Section 4. Each phase of the process evaluation plan is discussed below, and summarized in Table 7.1.

Table 7.1 Evaluation Tasks for each Implementation Phase

Task	Phase I	Phase II	Phase III	Phase IV
Market Research Survey	X			
Expert Functionality Review	X			
Data Completeness Assessment		X		
Data Accuracy Assessment		X	X	X
Expert Search Algorithm Review		X		
Internal Heuristic Review of Design		X		
Accessibility Standards Compliance		X		
External Expert Review		X		
Lab-Based Usability Testing		X		X
Log-Based Search Algorithm Review			X	
Solicited Community Feedback			X	
Online User Survey			X	X
Unsolicited User Feedback			X	X
External Testing of Performance			X	X
General Server-Log Abstraction			X	X
Special Populations Focus Groups				X
Web Site Linkage Monitoring				X
Search Engine Placement Testing				X

Evaluation Phase I

The primary goal of this evaluation phase is to analyze the market for the Go Local LA program. This information will inform the design and implementation of the program by: (a) identifying the features / functionality that are necessary for Go Local to meet the needs of potential users, (b) identifying the characteristics of individuals who could benefit from information delivered by Go Local (desired target

audience), and (c) identifying any instances in which Go Local LA might provide information that is counterproductive to high-quality medical care (e.g. by increasing patient costs, failing to identify the appropriate point-of-entry to a service provider, making an inappropriate referral, etc.).

Two research methods are proposed to conduct this market evaluation: (1) a representative survey of LA county residents using a web-enabled research panel, and (2) a review of the proposed Go Local LA functionality by experts who currently perform most referrals to social service agencies and physicians. The marketing survey would assess respondents' current methods for health or social services referrals, their perceived barriers to additional services (with particular emphasis on the barriers that might be mitigated by Go Local LA – e.g., distance), their evaluation of the web as a means to locate a service provider, and the information they would like / need to have prior to contacting a provider. The answers to these questions would be used to identify the features / functionality that are necessary for Go Local to meet the needs of potential users, and they would provide empirical evidence of demand for this service, information that may be important for securing operational funding.

In addition, responses can be broken down by the demographic and health insurance characteristics of the respondents to provide an empirical "market segmentation" that would identify the characteristics of individuals who could most benefit from the information provided by Go Local Los Angeles. Knowledge Networks, Inc. maintains a nationwide, web-enabled research panel with approximately 450 participants located in the LA metropolitan area. The primary use of this panel is market research for private-sector clients; however a range of academic and governmental research projects have also made use of the panel. Conducting a 15-minute marketing survey of 450 LA County residents would cost approximately $35,000 for data collection. The analysis and preliminary write up of these results would cost an additional $10,000 to $20,000 (Estimated 160 person hours).

There are several unique features about healthcare in Los Angeles County that could impact the effectiveness of the Go Local Program, and should be considered in the design. Los Angeles has one of the highest rates of HMO penetration of any metropolitan area in the country (Kominski, Davidson, Keeler, Razack, Becerra, and Sen 2003), approximately 60% of those are with private insurance, according to the American Association of Health Plans. Los Angeles also has one of the nation's highest rates of uninsurance (Brown, Ponce, Rice, & Lavarreda 2002). The health care needs of these uninsured are primarily served by the county's public health system, the largest county or municipal system in the nation. For these reasons, the majority of Los Angeles County residents have highly constrained choices regarding their health care providers, and conversely, many providers have exclusive contracts with health plans and cannot treat most other residents. This health care environment complicates the physician and services referral process because the closest qualified provider may not be an appropriate referral for the majority of residents. To address this complexity, expert reviewers will be used to assess how the proposed functionality compares to the existing methods of referring individuals to physicians or social services. The goal of these expert interviews would be to answer three questions:

1. What are the important criteria for determining an appropriate referral to a physician or social services agency?
2. What characterizes individuals who are poorly served by the current system of connecting individuals with physicians or social service agencies -- and might, therefore, benefit from Go Local?
3. Under what circumstances might Go Local LA provide information that is counterproductive to high-quality and efficient medical care, e.g. by increasing patient costs, failing to identify the appropriate point-of-entry to a service provider, failing to list important service providers, reducing visits to primary care providers, etc.

This panel of expert reviewers would consist of nine to fifteen individuals from three groups: primary care physicians (PCP's), health insurance / health policy researchers, and social workers. The former two groups would answer these questions with respect to physician referrals, while social workers would provide insight about referrals to social services agencies. These interviews would be conducted by telephone, with all participants receiving a modest stipend. Participants would be selected to reflect a diverse array of perspectives including ethnicity, region, and insurance plan participation. The expected research cost would be $1,500 in expert stipends, 32 person hours of interview development and interviewer training, 16 person hours for interviews, 48 person hours to abstract and summarize the results of the interviews.

Evaluation Phase II

The primary goals of evaluation Phase II are to assess (a) the accuracy and completeness of the database, (b) the appropriateness of the distance-based search algorithm used to select providers from the database, and (c) the usability of the prototype web-interface, developed during the prior phase.

These three goals correspond to three types of research that will be conducted during implementation Phase 1. Trained data validators will assess the accuracy of the database information. These individuals will draw a random subset of the providers listed in the database and contact those providers to ensure the accuracy of the information. This will include verifying that: (1) the name, phone number and address displayed in the database are accurate and provide the appropriate point-of-contact for new clients / patients, (2) the provider accepts new clients without a special referral, (3) someone is available at that phone number who can speak the languages claimed, and (4) the information about services provided is accurate. The completeness of the database can be tested against other publicly available lists of doctors and social services agencies (e.g., the phone book). These tests will be used to ensure data quality prior to public release of the service. An error rate above 15% is considered unacceptable for release to the general public. To ensure that the data released to the public meets our accuracy criterion, a random sample of 196 providers from the database must contain at least 90% of all providers listed in the phone book, and 90% of the entries must be verified as completely accurate prior to public release of Go Local LA. This sample would allow the rejection of the hypothesis that the true error rate is greater than 15% with p=.05. The labor required for validating the data is built into the implementation budget of Go Local, which includes data validation procedures. The evaluation will require that error rates discovered by the validation process be monitored over time. This function could be built into the software designed for data validation; costs would be approximately 16 hours of programming.

The suitability of the distance-based search algorithm will also be assessed. The primary goal is to ensure that this method of selecting providers displayed to the users does not omit important referrals. For example, an individual searching Go Local under "infant nutrition" may have several pages of childcare centers, pediatricians, etc. displayed before the first WIC (Women, Infants, and Children) office because those providers are geographically closer. Similarly, a search that should result in referrals to both a family practice physician and an oncologist may result in no oncologists listed on the first several pages of results due to their relative scarcity. An assessment will be conducted to determine if our database query system actually provides the important referrals in the first several pages of search results, and will modify the programming to address any problems discovered. This assessment will use experts who currently handle most referrals to social service agencies and physicians (e.g., social workers and PCP's). The goal will be to elicit from these experts the types of referrals most appropriate for each of several search terms that we anticipate will be common (Appendix B). The programmers can then test the software to ensure that these referrals actually appear in our first 2 pages of search output, and are not "crowded out" by less relevant or redundant providers that happen to be closer to the search location. Regular failures to display the medically appropriate referrals in the first few pages of output will require changes to the search algorithm. The expected research cost would be $500 in expert stipends, 16 person hours of interview development and

interviewer training, 8 person hours for interviews, 24 person hours to abstract and summarize the results of the interviews. More labor will be required if the simple distance-based algorithm requires modification.

During this phase we also perform usability testing to ensure the web design is functional and easy to use for the target user group. This testing will include an initial heuristic analysis of the prototype, review to ensure compliance with accessibility standards, an expert design review, and lab-based user testing. "Research-Based Web Design and Usability Guidelines" recently released by NIH will be used as the guide to an internal heuristic analysis of the site (http://usability.gov/pdfs/guidelines.html). The internal web development team will create an evaluation in which the Go Local site is assessed against recommendations contained in this guideline. A document will be produced evaluating each guideline, indicating if the site is currently following, partially following, not following, or not applicable. The team can then determine the necessary steps to improve compliance with the guidelines, or to justify the guideline discrepant aspects of the site. We expect that this effort will take 40-120 person-hours.

In addition, project staff will use a similar procedure to ensure compliance with the accessibility standards set forth by US Section 508 and WCAG10. These guidelines are designed to make information on the web maximally accessible to people with vision, hearing, and mobility impairments. The internal web development team will compare the site prototype to the recommendations contained in these guidelines. A document will be produced evaluating each guideline, indicating if the site is currently following, partially following, not following, or not applicable. The team can then determine the necessary steps to improve compliance with the guidelines. Similarly, we should ensure that all prose used on the site are written to minimize education requirements (e.g., the Flesch-Kincaid Grade level of the writing is lower than 8.0). Several computer programs can perform the Flesch-Kincaid Analysis for the English version of the web site. The Spanish version will be based on a translation of the English version. We will assess the quality of this translation by comparing a back-translated version to the original English text. We expect that these accessibility evaluations will require 32 person-hours.

We will also contract with a human factors engineering or user-interface testing firm to perform expert consultation on the design and to perform lab-based usability testing. Expert review can occur using an "expert user" methodology in which usability experts use your site to perform predetermined functions. A recent study conducted by the American Institutes for Research (AIR) used this method to examine the two existing Go Local prototypes developed in North Carolina and Missouri. Conducting an expert review of both websites, AIR reported a list of 20 findings and recommendations for developing a prototype Go Local Program (AIR 2003). Due to recent experience with this approach and immediate expertise in the area, we will solicit assistance from the National Library of Medicine to obtain cost estimates for an AIR study for the Go Local LA program.

The expert review as well can follow a "parallel design" methodology, in which web-developers are given the usability requirements and desired functionality thereby mocking-up a proposed site design without having used the existing prototype. The web development team can then reconcile the differences between the existing prototype and the newly proposed design. Recent research suggests that this methodology is highly effective at avoiding subsequent usability problems (Macbeth, Moroney & Biers, 2000; McGrew, 2001). For most complex web sites, a parallel design method is prohibitively expensive. However, the proposed Go Local web site is likely to have only a few different types of pages and will not be graphic-intensive. In this case, the parallel design method may be comparable in cost to an expert review. (These costs vary widely depending on who is asked to carry out the design. As a practical matter this task could be budgeted at the same level as the expert review and decisions regarding which method to use could be made at a later date.)

Finally, we propose to conduct lab-based usability testing during this phase, as recommended in Siegel & Wood (2002). These tests would be conducted by having individuals who meet our "target user"

characteristics (Defined in evaluation Phase I). The tests require the target users to perform a predetermined series of tasks on the web site. The keystrokes and timing would be recorded, and users' evaluations would be assessed using both standardized instruments and expert debriefing. (Costs here also vary widely. Three human factors labs in Southern California were consulted. Resulting estimates varied widely. Costs depend on sample selection and the extent of quantitative analysis to be performed.)

Evaluation Phase III

The goals of evaluation phase III are to incrementally improve the database and search algorithm, to solicit and measure community feedback, and to assess the technical performance of the service.

The proposed Go Local Los Angeles software and web site are designed as a specialty search engine, similar in form to Google, Alltheweb, Yahoo, or MSN search, but searching a specialty database. These search engines rely very heavily on server log data to improve their performance. Specifically, they use "click-through" rates to modify the order in which results are displayed, i.e., web sites that are more frequently clicked on when displayed in search results are displayed more prominently in subsequent searches. (The only major exception to this is Google, which uses click-through rates as a performance benchmark of their algorithm but does not use it to determine sort order. Instead, Google uses "link-to" rates to order results.) Once Go Local Los Angeles is publicly available, web log abstraction should begin to assess the performance of the data query algorithm by monitoring which providers are selected by users. The search algorithm needs to be modified to ensure the most sought after providers are displayed prominently, and specific performance benchmarks should be monitored (e.g., the percentage of searches in which a provider on the first results page is selected). The web development team will need to create a server log abstraction macro to monitor these click-through rates broken down by position in the results pages, as well as several other useful pieces of information: popular search strings, proportion of visitors who initiate a search, common user computer configurations, length of time viewing results, and usage maps. A gross estimate for programming that will accomplish collecting and monitoring performance data is $10,000 - $15,000.

The accuracy of the database will also be reassessed in Phase II using the methodology in Phase I above, however the accuracy criterion will be raised to 95%. To ensure that the data released to the public meets our accuracy criterion, 97% out of a random sample of 203 providers must be verified as completely accurate. This sample would allow the rejection of the hypothesis that the true error rate is greater than 5% with p=0.05. The labor for this task is already included in the database maintenance costs, however some small amount of additional work is required to monitor accuracy information recorded during verification.

We also intend to solicit community feedback in three ways beginning in this Phase. First, we will initiate a mailing to community agencies and physicians (i.e., those in the database) to announce the launch of the service and request that they (a) review their information for accuracy, (b) explore the functionality of the web site, and (c) give online feedback about the service. We expect that a direct mail campaign to 12,000 providers will cost approximately $7,000. The second method for feedback will be a brief "pop-up" survey and comment solicitation for users to provide feedback. During this phase – the initial launch to the public – we expect to request online feedback from all first-time users (this requires cookies and java script capable browsers) including those directed to the site by the direct mail campaign. Survey programming costs are anticipated, compiling descriptive summaries of survey responses will require approximately 80 person-hours for the first 6-months, then 40 person-hours every 6 months thereafter. In addition to these requests for user feedback, we will also collect unsolicited user feedback. This can occur using a "contact us" or "feedback" link on the web page as well as documentation of any web-related contacts to the NexCare call center.

Finally, the website will be tested to monitor technical performance benchmarks. These tests will be based on automated processes that will continue throughout the life of the project. These include server-side monitoring of search latencies and downtime. It also includes client-side (application) monitoring of performance (e.g., total time, downtime, and packet loss). Several firms offer daily or hourly client-side server monitoring for less than $100/year. Alternatively, a script can be run on computers at NLM or UCLA that would collect this data on an hourly basis.

Evaluation Phase IV

This evaluation phase corresponds to the maintenance phase (Phase IV) of the Go Local Los Angeles implementation plan. The evaluation plan for this phase includes the continuation of several evaluation methods used in earlier phases, including: randomized internal user surveys, compilation of unsolicited user feedback, monitoring technical performance, additional lab-based usability testing, and testing of database accuracy. Once an accurate database has been developed, the costs of ongoing testing of database accuracy are minimal because the testing is a by-product of the ongoing database maintenance procedures The scope and target audience for additional lab-based usability testing will depend on two factors: the extent to which prior testing and user feedback indicate usability problems, and the extent to which we made changes to the interface subsequent to the last round of testing. These costs will likely be similar to earlier testing.

In addition to these ongoing evaluation efforts, Phase IV will include three new or expanded evaluation methods. First, the server log abstraction will be expanded to assess the overall use of the site. Key statistics for monitoring the usefulness of the web site will include monitoring the number of searches (more appropriate than visitors or unique visitors), the number of providers who have been "clicked" to display the full record, and the time spent viewing the search results pages. The costs for this assessment are minimal.

In addition, we propose to use focus group methods to improve the Go Local Los Angeles website's ability to serve special populations. The precise populations tested will depend on the results of the previous phases of the evaluation, although we expect special efforts will be required to meet the needs of lower-income minorities and residents who do not speak English. These focus groups will assess the services referral needs in targeted communities, the current methods used to gather information about services, and the usability of the Go Local Los Angeles web site. The costs of obtaining an experienced firm to conduct three group sessions with 8-12 participants are in the $5000-$20,000 range. Actual costs vary considerably as a function of the method used to recruit participants, and the level of documentation / data analysis provided (these range from one page summaries of group consensus, to full transcripts with formal content analysis).

Finally, the long-term impact of Go Local Los Angeles depends on the ability of people who want such a service to find it on the Internet. Users most commonly find web sites through two mechanisms: hyperlinks to well-known or commonly used sites and results displayed by Internet search engines. As part of Phase IV evaluation we will formally track and assess the ability to find Go Local Los Angeles on the web. This will include using search engines to "link search" your site (e.g., using the "link:" operator in a Google search). This will allow Go Local Los Angeles to monitor how many websites -- and what types of websites -- contain links to the Go Local site or the NLM page that links to Go Local Los Angeles. These results will inform our marketing effort to improve Go Local's integration into the web.

In addition, we propose a formal process of monitoring search results placement over time. Search engine placement will be particularly challenging for Go Local as the website is dynamic, i.e., the search results pages that contain many possible search terms cannot be indexed by search engines. Engineering superior search results placement has become increasingly challenging over the last 5 years as all major search engines have downgraded or eliminated their reliance on meta data. At the same time, search engines

have increased to the extent that placement is determined by fees. We propose to periodically test the major web search engines (Google, Alltheweb, Yahoo, MSN search, AOL search, and Hotbot) for Go-Local LA's placement using a range of search strings that indicate a desire for Go Local's service (e.g., Los Angeles Pediatrician, Santa Monica HIV, or Reseda California Doctor). For each search engine, we will monitor the placement of the Go-Local web page in these search results, as well as any sites that link directly to Go-Local. Problems associated with directing traffic to the Go Local site can be noted and a strategy developed to improve placement. This may include working with the advertising department at each search engine to improve placement (possibly pro bono), modifying the web site, or more actively encouraging other web sites to link to Go-Local. The costs of this will depend on how well Go-Local is picked up by the search engines. The testing itself would cost very little, likely eight person-hours per month, and much of it may be automated. Repairing problems can prove more costly. An in-house employee will continually follow up with search engines to encourage web links from prominent web sites, accounting for eighty person hours in the first year after release. Paying for placement may prove less costly depending on price structures of individual search engines.

Table 7.2 provides a cost breakdown for the evaluation component. Most tasks are calculated with the burdened hourly rate for employees at a rate of $50; at this juncture, this is an estimate and a recalculation may provide a more accurate figure. The labor required will involve a mix of programmers, researchers, research assistants, and other hourly wage employees.

Table 7.2: Approximate Costs of Proposed Evaluation Activities.

Evaluation Task	One-time Costs	Recurring Costs
Market Research Survey	**$51,000**	
Expert Functionality Review	**$6,300**	
Data Completeness Assessment	**$1,200**	
Data Accuracy Assessment	**$1,200**	**$1,200***
Expert Search Algorithm Review	**$3300**	
Internal Heuristic Review of Design	**$4,000**	
Accessibility Standards Compliance	**$1,600**	
External Expert Review	**$12,000**	
Lab-Based Usability Testing	**$30,000**	**$30,000** †
Log-Based Search Algorithm Review	**$15,000**	
Solicited Community Feedback	**$7,500**	
Online User Survey	**$6,000**	**$2,000 ***
Unsolicited User Feedback	**$400**	**$4,00 ***
External Testing of Performance	**$500**	**$5,00 ***
General Server-Log Abstraction	**$800**	**$8,00 ***
Special Populations Focus Groups	**$17,500**	**$17,500** †
Web Site Linkage Monitoring	**$1,200**	**$1,200 ***
Call-Center Evaluation	**$1,200**	**$1,200 ***
Search Engine Placement Testing	**$3,200**	**$3,200 ***

* annual reoccurring costs; † costs per additional study.

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Section 8
Feasibility Report Appendices

A. Work Plan, Time Schedule & Budget Requirements for Developing, Testing, and Implementing Go Local Los Angeles

B. MEDLINEplus Top 100 Topics (June – October 2003)

C. Disease Rates & Physician Specialties

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Appendix A
Work Plan, Time Schedule & Budget Requirements
For Developing, Testing, and Implementing Go Local Los Angeles

The redesigned NexCare Collaborative homepage will provide links to First 5 LA Connect, National Library of Medicine MEDLINEplus, and Go Local Los Angeles. By displaying each logo and providing links to each home page, the collaborating organizations will be prominently recognized. The new provider database created for Go Local Los Angeles will be separate from the existing First 5 LA Connect agency database, but it will be accessed through a unified interface and will interoperate seamlessly. By expanding the existing web site infrastructure, economies of scale can be utilized.

The project's work plan, time schedule, and estimated budget are organized according to the following phases (see Section 3):

Phase 1: Proof of Concept and Testing
Phase 2: County-Wide Test Implementation
Phase 3: MEDLINEplus Implementation
Phase 4: Maintenance

Non-recurring costs

Phase of Project	Cost (in dollars)
Proof of Concept and Testing	
Initial Development of the Go Local Los Angeles & Development of the Demonstration Website	18,000
County-Wide Test Implementation	
Expansion of NexCare Database Expansion of the NexCare database to include resources beyond the scope of First5LA can and should begin as soon as possible. The Design Team estimates that 1.5 FTE of a verification specialist will be necessary for several months to revise the procedures and expand the database. It would be valuable and prudent to hire a Database Administrator (DBA) to oversee and manage the technical aspects of this process. The budgeted amount is for a .25 FTE DBA to oversee the expansion.	12,000
Initial Development of Provider Database Configuring the Harbor Provider Database to include those data required by Go Local, including insurance and health plan information will also require approximately .25 FTE of the DBA. It will additionally require time from the Website designer and the developer of the database hooks.	24,000
Initial Development of User Interface	12,000
Initial Development of Term Matching Database Developing and adapting the schemata for matching terms, and populating these tables.	8,000
Initial Populating, Validating Data	8,000
Initial Setup of Database Hosting	6,000
MEDLINEplus Implementation	

Setup of Maintenance Procedures	4,000
Setup of Ongoing Data-entry, Data Validation Procedures	4,000
Setup of Hosting of Database NexCare's web server and Harbor's hosted server will provide sufficient resources through Phase 2. After NexCare's database expansion and the determination of the new systems architecture, we will be able to more accurately estimate the server and bandwidth requirements. This figure is allocated for the migration and installation of the databases in their permanent "homes".	2,000
TOTAL	98,000

RECURRING COSTS (Dollars per month)

Maintenance	
Ongoing Data-entry, Data Validation Procedures	6,000
Hosting of Database	1,000

Appendix B

Top 100 MEDLINEplus Topics (June - September 2003)

1. High Blood Pressure
2. West Nile Virus
3. Fibromyalgia
4. Back Pain
5. Shingles (Herpes Zoster)
6. Lupus
7. Sexually Transmitted Diseases
8. Insect Bites and Stings
9. COPD Chronic Obstructive Pulmonary Disease
10. Lyme Disease
11. Gastroesophageal Reflux/Hiatal Hernia
12. Gallbladder and Bile Duct Diseases
13. Dizziness and Vertigo
14. Thyroid Diseases
15. Cholesterol
16. Vitamin and Mineral Supplements
17. Diabetes
18. Skin Cancer
19. Gout and Pseudo gout
20. Knee Injuries and Disorders
21. Parkinson's Disease
22. Menopause
23. Prostate Cancer
24. Birth Control/Contraception
25. Ovarian Cysts
26. Psoriasis
27. Multiple sclerosis
28. Skin Diseases General
29. About Your Medicines
30. Herpes Simplex
31. Severe Acute Respiratory Syndrome
32. Liver Diseases General
33. Heart Diseases General
34. Anemia
35. Diverticulosis and Diverticulitis
36. Breast Cancer
37. Low Blood Pressure
38. Colorectal Cancer
39. Hormone Replacement Therapy
40. Infectious Mononucleosis
41. Obesity
42. Alzheimer's Disease
43. Hives
44. Stomach Cancer
45. Ulcer Active Colitis
46. Osteoarthritis
47. Spinalstenosis
48. Peptic Ulcer
49. Anatomy
50. Varicose Veins
51. Cellulitis
52. Depression
53. Cystic fibrosis
54. Pregnancy
55. Hemorrhoids
56. Bone Cancer
57. Irritable Bowel Syndrome
58. Sinusitis
59. Osteoporosis
60. Weight Loss Dieting
61. Laboratory Tests
62. Kidney Diseases General
63. Dermatitis
64. Exercise Physical Fitness
65. Rheumatoid Arthritis
66. Stroke
67. Bipolar Disorder
68. Crohn's Disease
69. Impetigo
70. Scabies
71. Carpal Tunnel Syndrome
72. Hernia
73. Attention Deficit Disorder with Hyperactivity
74. Ovarian Cancer
75. Dementia
76. Lung Cancer
77. Herbal Medicine
78. Hysterectomy
79. Eye Diseases General
80. Appendicitis
81. Kidney Failure and Dialysis
82. Arthritis
83. Candidiasis
84. Aids
85. Teen Age Pregnancy
86. Ear Infections
87. Alcoholism
88. Polymyalgiarheumatica
89. Smoking
90. Sports Injuries
91. Chickenpox
92. Spleen Diseases
93. Hepatitis C
94. Celiac Disease
95. Nutrition
96. Tick Bites
97. Seizures
98. Heart Attack
99. Diarrhea
100. Brain Cancer

Appendix C
Disease Rates and Physician Specialties

Disease Rates

About prevalence and incidence statistics: The term 'prevalence' of Parkinson's Disease usually refers to the estimated population of people who are managing Parkinson's Disease at any given time. The term 'incidence' of Parkinson's Disease refers to the annual diagnosis rate, or the number of new cases of Parkinson's Disease diagnosed each year. Hence, these two statistics types can differ: a short-lived disease like flu can have high annual incidence but low prevalence, but a life-long disease like diabetes has a low annual incidence but high prevalence.

- California has a population of approximately 34.5 million, about 12 percent of the total U.S. population, and is composed of a variety of ethnic backgrounds including white (59.5 percent), black (6.7 percent), Hispanic (32.4 percent), Asian (10.9 percent) and Native American (1.0 percent).

- Approximately 10.6 percent of the state's population is over the age of 65.

- The average household income in California is $47,493.

- Of California's total population, 14.2 percent live below poverty level.

Data Source: U.S. Bureau of Census, 2001
Estimated on 1/1/03 the population of LA County is 9,979,600
US Census population of the USA, 2002: 284,796,887
Endocrinology, Gastroenterology, Infectious Disease, Nephrology, Oncology, Pulmonary, and Rheumatology specialists are usually Internal Medicine specialists. Primary Care Physician is interchangeable with Family Practice and General Practice

Glossary of Physician Specialties

Allergist/Immunologist - manages patient in a state of hypersensitivity induced be exposure to a particular antigen (allergen)

Anesthesiologist - putting patients under the influence of drugs or agents used to abolish the sensation of pain

Cardiologist - diagnoses and treats heart disease

Child and Adolescent Psychiatrist - detects, treats and prevents mental disorders in children and adolescents

Colon-Rectal Surgeon - manages disorders of the colon and rectum

Dermatologist - diagnoses and treats diseases of the skin

Electrophysiologist - manages the consequences of electrical phenomena in the body; specifically the electrical activity of the heart

Endocrinologist - understands the endocrine system of the body and diagnoses and treats disorders of the glands of internal secretion (endocrine glands)

Family Practitioner - treats any or all members of the family for illness and injury, teaches preventive medicine to keep entire family healthy, and refers patients to specialized physicians when necessary

Gastroenterologist - diagnoses and treats diseases of the stomach and intestines

General Surgeon - treats diseases, injuries and deformities of all kinds by manual operative methods

Hematologist/Oncologist - treats diseases of the blood, blood-forming tissues of the body and tumors

Infectious Diseases Specialist - manages diseases communicated or capable of being communicated by infection

Internist - diagnoses and medically treats diseases of adults

Maternal-Fetal Medicine Specialist - manages high-risk pregnancy and the fetus

Neonatologist - diagnoses and treats disorders of the newborn infant

Nephrologist - diagnoses and treats diseases of the kidney

Neurologist - diagnoses and treats disorders of the nervous system

Obstetrician/Gynecologist - manages pregnancy, labor and post-labor, as well as treats diseases of the female genital tract

Oncologic Surgeon - treats tumors through operative methods

Ophthalmologist - diagnoses and medically or surgically treats diseases and defects of the eye and related structures

Oral and Maxillofacial Surgeon - diagnoses and surgically treats diseases, injuries and defects of the mouth and dental structures

Orthopedic Surgeon - corrects deformities of the musculoskeletal system

Otolaryngologist - medically or surgically treats the head and neck, including the ears, nose and throat

Pediatrician - treats the child, his or her development and care, as well as the diseases of children

Pediatric Ophthalmologist - diagnoses and medically or surgically treats diseases and defects of an infant or child's eye and related structures

Peripheral Vascular Surgeon - treats diseases and deformities of the peripheral blood vessels through operative methods

Plastic Surgeon - surgically restores, reconstructs, corrects or improves the shape and appearance of body structures that are defective, damaged or misshapen by injury, disease or growth and development

Psychiatry - detects, treats and prevents mental disorders

Pulmonologist - diagnoses and treats diseases of the lungs

Radiation Oncologist - uses energy transmitted by waves (radiation) to treat tumors

Radiologist - uses radiation to diagnose and treat disease

Rehabilitation/Physical Medicine Specialist –(Physiatrist) the functions of the body and its parts, and the physical and chemical factors and processes involved

Rheumatologist - diagnoses and treats disorders marked by inflammation, degeneration or metabolic derangement of the connective tissue structures of the body, especially the joints and related structures

Thoracic and Cardiovascular Surgeon - treats diseases and deformities of the heart and surrounding blood vessels through operative methods

Urologist - diagnoses and treats disorders of the male and female urinary tracts and the male genital organs

**Resource:* 27th Edition Dorland's Illustrated Medical Dictionary, W. B. Saunders Company, Philadelphia, 1988

West Nile Virus – as of Sept 26, 2003 there have been 5,005 cases of WNV in the US (44 states). 2 confirmed cases in California. (California DHS Web Site)
Physicians: Internal Medicine/Infectious Disease, Family Practice

Sexually Transmitted Disease – Total of all sexually transmitted diseases are appx. 1.2 million cases diagnosed each year in California – Number of cases of: Chlamydia-– 101,944, Gonorrhea, 23,296, Syphilis 3,050. These are reportable STD's. (STD Surveillance 2001, Division of Sexually Transmitted Diseases, National Center for HIV, STD and TB Prevention, Centers for Disease Control and Prevention, Department of Health and Human Services, September 2002)
Physicians Primary Care Physicians, Internal Medicine/Urology

Diabetes – 6.5% of population has diabetes (increase prevalence with age) Age adjusted prevalence rates is 6.2 per 1,000 (National Center for Health Statistics) 1,642,000 –Prevalence rate: total number of adults diagnosed with diabetes in California as of the end of 2001 (Prevalence of Diagnosed Diabetes," Diabetes Surveillance System, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, Department of Health and Human Services)
Physicians Internal Medicine/Endocrinology, Primary Care Physicians, Internist, Podiatry, Cardiologist

COPD (Emphysema and chronic bronchitis) - Prevalence rates per 1,000 is 54.9 for chronic bronchitis and 14.6 for emphysema (total 69.5 per 1,000) (American Lung Assoc and CDC)
Physicians Internal Medicine/Pulmonology, Primary Care Physicians, Internist

High Cholesterol (defined as increase over 240) –20% of the population (CDC booklet)
Physicians Internal Medicine, Primary Care Physician

High Blood Pressure (over 140 or over 90) – 23% of the population (CDC booklet) has high blood pressure
Physician Internal Medicine, Primary Care Physician, Cardiologist

Shingles (Herpes Zoster) approx. 500,000 cases will be diagnosed this year (5-6 weeks to recover) US Dept. of Health and Human Services. 215 per 100,000 person-years
Physician Internal Medicine/Dermatologist, Primary Care Physician, Internist

Low Back Pain: In the United States, back pain is reported to occur at least once in 85% of adults below the age of 50. Nearly all of them will have at least one recurrence. It is the second most common illness-related reason given for a missed workday and the most common cause of disability. Work-related back injury is the number one occupational hazard. Nearly everyone has low back pain sometime in his or her lies.
Physician Primary Care Physician, Orthopedic Surgeon, Physiatrist, Anesthologist (pain mgmt)

Fibromyalgia - 3-6 million people in the USA suffer from Fibromyalgia (American College of Rheumatology) or 1 in 73 people (NIAMS)
Physician Internal Medicine/Rheumatologist, Primary Care Physician

Contraception – 64% of more than 60 million women age 15-44 use contraception in the USA (CDC)
Physician Obstetrics/Gynecology, Primary Care Physician, Internal Medicine,

GERD – Gastro esophageal Reflux Disease /Hiatal Hernia-2% of the adult population is diagnosed with GERD (GERD information Resource Center). Recent statistics from the US Department of Health and Human Services indicate that about seven (7) million people in the US alone suffer from GERD. Source: Digestive Diseases in the United States: Epidemiology and Impact, National Digestive Diseases Data Working Group, James E. Everhart, MD, MPH, Editor, US Department of Health and Human Services, Public Health Service, National Institutes of Health, NIH Publication No. 94-1447, May 1994)
Physician Primary Care Physician, Internal Medicine/Gastroenterology, General Surgeon

Parkinson's disease Parkinson's disease is a serious disorder that affects nerve cells (neurons) in the part of the brain controlling muscle movement. Nearly one million Americans currently live with Parkinson's and approximately 50,000 more receive a diagnosis of the disease every year (Mayo Clinic Web Site)
Physician Neurologist, Internist, Neurosurgeon, Primary Care Physician

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Arthritis or chronic joint symptoms affect nearly 70 million Americans (about 1 in 3 adults), making it one of the most prevalent diseases in the USA. .Arthritis is the leading cause of disability among U.S. adults. It limits everyday activities for more than 7 million Americans
Physician Internal Medicine/Rheumatologist, Internist, Primary Care Physician,

Gout and Pseudo gout Gout occurs in 840 out of every 100,000 people in the USA. Pseudo gout occurs in about 3 percent of people in their 60s and as many as half of people in their 90s.
Physician Internal Medicine/Rheumatologist, Internist, Primary Care Physician, Podiatrist

Gallbladder According to the National Institutes of Health, as many as one in 12 Americans has gallstones.
Physician Primary Care Physician, Internal Medicine/Gastroenterology, Internist, General Surgeon

Bile Duct Diseases – not descriptive enough
Physician Internal Medicine/Gastroenterology, Internist, General Surgeon

Knee injuries and Disorders – About 10.8 million visits are made to physicians' offices because of a knee problem. It is the most often treated anatomical site by orthopedic surgeons. There is no statistical data regarding injury to the knee.
Physician, Orthopedist, Physiatrist, Internist

Lupus The Lupus Foundation of America estimates that approximately 1,500,000 Americans have a form of lupus. 1 in 85 (NWHIC). 1 in 2,000 Americans (NIAID); 1 in 250 young African-American women
Prevalence Rate: approx 1 in 194 or 0.51% or 1.4 million people in USA
Prevalence of Lupus: Lupus occurs in 1 out of 2,000 Americans and in as many as 1 in 250 young, African-American women.[1] ... Lupus affects 1.4 million people in the United States (1 in 85).
Physician Internal Medicine/Rheumatologist, Primary Care Physician, Internist, Dermatologist

Prostate Cancer In California 20,500 new cases of Prostate Cancer will be diagnosed this year. Prostate cancer is the most common cancer in American men. By age 50, up to one in four men have some cancerous cells in the prostate gland. By age 80, the ratio increases to one in two. As you age, your risk of prostate cancer increases. In the United States, the average age at diagnosis is 72. In 1995 incidence rate in California was 121.5 cases per 100,000.(California DHS website)
Physician Internal Medicine/Oncologist, Urologist, Internist, Radiation Oncology

Skin Cancer Nonmelanoma skin cancer is the most common type of cancer that affects humans. This year, there will be over 1,000,000 cases diagnosed and treated in the United States alone. This exceeds the number of all other cancers combined. 20,403 melanomas were diagnosed in 2000 (CDC statistics) There are two main forms of nonmelanoma skin cancer, basal cell carcinoma (BCC) and squamous cell carcinoma (SCC). The number of new melanomas diagnosed in the United States is increasing. Since 1973, the incidence rate for melanoma (the number of new melanomas diagnosed per 100,000 people each year) has more than doubled from 5.7 to 14.3 (American Cancer Society). The American Cancer Society estimates that about 53,600 new melanomas will be diagnosed in the United States during 2002. About 7,400 people in the US are expected to die of melanomas during 2002 (American Cancer Society). In 2003, it is estimated that about 54,000 Americans will be diagnosed with melanoma, the deadliest form of skin cancer, which is expected to account for 7,700 deaths (CDC)
Physician Dermatologist, Internal Medicine/Oncologist, Primary Care Physician

Thyroid Diseases Your thyroid gland tells every cell in your body the rate at which it should function. Having too little hormone, called hypothyroidism and this is a problem for more than 10 million Americans-of whom 8 million don't know it. Having too much hormone, called hyperthyroidism, is a problem affecting 4.5 million Americans, but at least 600,000 of them have yet to be diagnosed.
Thyroid Cancer – It is estimated that 22,000 new cases of Thyroid Cancer will be diagnosed in 2003.
Physician Internal Medicine/Endocrinologist, Ob/Gyn, Primary Care Physician, Oral & Maxillofacial Surgeon, General Surgeon

Vitamin and Mineral Supplements
Physician Internist, Primary Care Physician, Osteopath

Insect Bites and Stings
Physician Primary Care Physician, Infectious Disease, Allergist

Lyme Disease 23,760 cases reported to the CDC in 2002 U.S. statistic (CDC) 97 cases in California.
Physician Dermatologist, Infectious Disease, Internist, Primary Care Physician

Menopause - In the US in 2000, three were an estimated 42.19 million women over the age of 50. About 33.21 million women are over the age of 55. A woman's life expectancy is estimated at 79.7 years. Today a woman who reaches 54 can expect to reach the age of 84.3 years. NAMS has estimated that natural menopause in the Western world is 51 years. The US census bureau estimates in the year 2000 that 8.89 million women would be aged 50-55 on July 1, 2000. One can assume that 50% of 51 year olds have reached menopause and that percentage would increase to 90% at 55 years of age, allowing the overall percentage over the 5-year span to be approximately 75%. Thus 75% of 8.98 million is 6.73 million – the number of women who have reached menopause in this age group. This number is added to 33.21 million, the number of women aged 55 plus. Therefore, 39.94 million US women had experienced spontaneous menopause as of 2000 (excludes early menopause and surgical menopause) (North American Menopause Society).
Physician Gynecologist, Primary Care Physician, Internist

Ovarian Cysts – Occur in most women of childbearing age at some time in their lives. Usually last less than 3 months and goes away spontaneously. No hard data on the exact numbers (Mayo Clinic Web Site).
Physician Gynecologist, Primary Care Physician, Internist

Psoriasis Psoriasis is a persistent, chronic disease that tends to flare periodically and may go into remission, but usually remains active for years. Researchers estimate that up to seven million people in the U.S. have psoriasis, about 1% to 2% of the population. Unfortunately, there isn't a cure for this condition, but there are a number of effective treatments that can help keep psoriasis under control
Physician Dermatologist, Primary Care Physician, Internist

Multiple Sclerosis An estimated 400,000 Americans have MS. It generally first occurs in people between the ages of 20 and 50. The disease is twice as common in women as in men. This estimate suggests that approximately 200 new cases are diagnosed each week in the US. (MayoClinic.com and National MS Society).
Physician Neurologist, Internist, Primary Care Physician

Skin Disease – To generic/broad topic
Physician Dermatologist, Internist, Primary Care Physician

About your Medicines – To broad a subject
Physician Pharmacist Internist, Primary Care Physician

Herpes Simplex . 1 in 5 people are infected with the Herpes virus (I and II) (web MD Also, between 200,000 and 500,000 people "catch" genital Type II) herpes each year and the number of Type 1 infections is many times higher.(American Academy of Dermatology)
Physician Dermatologist, Primary Care Physician, Internist

Sever Acute Respiratory Syndrome (SARS) According to the World Health Organization (WHO), during the SARS outbreak of 2003, a total of 8,098 people worldwide became sick with SARS; of these, 774 died. In the United States, there were 192 cases of SARS among people, all of whom recovered. Through July 2003, laboratory evidence of SARS-CoV infection had been detected in only eight U.S. cases. Most of the U.S. SARS cases were among travelers returning from other parts of the world with SARS
Physician Internal Medicine/Infectious Disease, Internal Medicine/Pulmonology

Liver Diseases Prevalence of Chronic liver disease: Prevalence Rate: approximately 1 in 679 or 0.15% or 400,000 people in USA (Digestive Diseases Statistics/NIDDK)
Physician Hepatologist, Internal Medicine/Gastroenterologist, Internist, Primary Care Physician

Breast Cancer An estimate of 21,100 new cases of breast cancer will be diagnosed in 2003 in California (NCI California Population and Cancer Statistics and the American Cancer Society)
Physician Internal Medicine/Oncologist, Internist, General Surgeon, Plastic Surgeon, Primary Care Physician

Low Blood Pressure Low blood pressure isn't a specific disease. It's usually a sign of an underlying problem. Management of low blood pressure depends on the symptoms and cause. There are no valid statistics on this disorder
Physician Primary Care Physician, Internist

Colorectal Cancer 13,000 new cases of colorectal cancers are estimated to be diagnosed in 2003 (NCI California Population and Cancer Statistics and the American Cancer Society). 64,967 cases were diagnosed in 2000 in the United States (CDC statistics).
Physician Internal Medicine/Gastroenterology, Internal Medicine/Oncology, Internist, Primary Care Physician

Hormone Replacement Therapy Almost half of the postmenopausal women in the US have taken HRT (National Center for Health Statistics). But, with the new findings regarding the dangers of HRT many of these women will be seeking alternative remedies. May want to combine this with Menopause.
Physician OB/Gyn, Internist, Internal Medicine/Endocrinologist, Primary Care Physician

Mononucleosis In the United States, as many as 95% of adults between 35 and 40 years of age have been infected with the Epstein-Barr virus that causes Mononucleosis. Infants become susceptible to EBV as soon as maternal antibody protection (present at birth) disappears. Many children become infected with EBV, and these infections usually cause no symptoms or are indistinguishable from the other mild, brief illnesses of childhood. In the United States and in other developed countries, many persons are not infected with EBV in their childhood years. When infection with EBV occurs during adolescence or young adulthood, it causes infectious mononucleosis 35% to 50% of the time.
Physician Internist, Internal Medicine/Infectious Disease, Primary Care Physician

Obesity 57% of Californians are considered overweight. Overweight is defined as having a body mass index greater than or equal to 25.0 kg/meters squared. . (Behavioral Risk Factor Surveillance System, 2001, unpublished data. National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services).
How many adults are obese? Nearly one-third of U.S. adults are obese (BMI $\geq$ 30)
All adults (20+ years old): 61.3 million (30.5 percent)
Women (20+ years old): 34.7 million (33.4 percent)
Men (20+ years old): 26.6 million (27.5 percent)
Physician Primary Care Physician, Internist, Internal Medicine/Endocrinology

Hives Hives are very common. Urticaria is the medical word for hives. Approximately 25% of the U.S. population will experience an episode of hives at least once in their lives (Medline Plus – American Academy of Allergy, Asthma and Immunology). Incidence (annual) of Hives: about 15% Americans each year (NWHIC) Incidence Rate: approx 1 in 6 or 15.00% or 40.8 million people in USA
Physician Allergist, Dermatologist, Primary Care Physician, Internist

Stomach Cancer Incidence (annual) of Stomach Cancer: Incidence Rate: approx 1 in 12,592 or 0.01% Incidence of Stomach Cancer: Each year, about 24,000 people in the United States learn that they have *cancer* of the stomach.
Physician Internal Medicine/Gastroenterologist, Internal Medicine/Oncologist, General Surgeon, Internist, Primary Care Physician

Ulcerative Colitis
Physician Internal Medicine/Gastroenterologist, Internist, Primary Care Physician, General Surgeon

Osteoarthritis
Physician Internal Medicine/Rheumatologist, Internal Medicine, Primary Care Physician

Alzheimer's Disease An estimated 4.5 million Americans have Alzheimer's disease. By 2050, the estimated range of the disease prevalence will be 11.3 million to 16 million Americans, with a middle estimate of 13.2 million unless a cure or prevention is found. In a 1993 survey, 19 million Americans said they had a family member with Alzheimer's and 37 million said they knew someone with Alzheimer's. One in 10 persons over 65 and nearly half of those over 85 have Alzheimer's. A small percentage of people as young as their 30's and 40's get the disease (Alzheimer's Society web page)
Physician Neurologist, Gerontologist, Internist

Spinal Stenosis
Physician Orthopedic Surgeon, Physiatrist, Primary Care Physician

Peptic Ulcer

Physician Internist, Internal Medicine/Gastroenterologist, Primary Care Physician

Varicose Veins

Physician Primary Care Physician, Internist, Peripheral Vascular Surgeon

Cellulitis

Physician Primary Care Physician, Dermatologist, Internist

Depression According to a report from the National Institutes of Mental Health, nearly 18.8 million Americans over the age of 18 suffer from major depression. Suicide, closely linked to depression, is the third leading cause of death in10- to 24-year-olds. Unfortunately, most people never seek treatment. Left undiagnosed and untreated, depression can worsen, lasting for years and causing untold suffering, and possibly even result in suicide (Web MD web site) estimated 5.3% adults (USSG); 17 million people; approximately. Appx. 4% of adolescents get seriously depressed (NIMH); annually 12% of women ; 7% of men; lifetime risk of an episode for women 20%. 3-4 million men

Prevalence Rate: approx 1 in 18 or 5.30% or 14.4 million people in USA

Prevalence of Depression A number of epidemiological studies have reported that up to 2.5 percent of children and up to 8.3 percent of adolescents in the U.S. suffer from depression

Physician Psychiatry, Psychologist, Internist, Primary Care Physician

Mental Disorders (All) Mental disorders are common in the United States and internationally. An estimated 22.1 percent of Americans ages 18 and older—about 1 in 5 adults—suffer from a diagnosable mental disorder in a given year.[1] When applied to the 1998 U.S. Census residential population estimate, this figure translates to 44.3 million people. [2] In addition, 4 of the 10 leading causes of disability in the U.S. and other developed countries are mental disorders-major depression, bipolar disorder, schizophrenia, and obsessive-compulsive disorder. [3] Many people suffer from more than one mental disorder at a given time (National Institute of Mental Health).

Physician Psychiatry, Psychologist, Internist, Primary Care Physician

Crohn's Disease/ Prevalence of Crohn's disease: 500,000 Americans Prevalence Rate: approx 1 in 544 or 0.18% or 500,000 people in USA It is estimated that as many as one million Americans have IBD-with that number evenly split between Crohn's disease and ulcerative colitis. Males and females appear to be affected equally. Crohn's disease may occur in people of all ages, but it is primarily a disease of adolescents and young adults-affecting mainly those between 15 and 35 (Crohn's and Colitis Foundation of America). About 7 out of every 100,000 people will develop Crohn's disease (Medline NIH)

Physician Internal Medicine/Gastroenterologist, Internist, Primary Care Physician, General Surgeon

Impetigo Impetigo accounts for approximately 10% of skin problems observed in pediatric clinics. Because it occurs more frequently in a warm humid environment, impetigo is more common in the southeastern US than in the cooler northern states. The prevalence of impetigo varies seasonally; however, in regions that remain warm and humid throughout the year, seasonality may not occur. True prevalence statistics were not located.

Physician Pediatric Dermatologist, Pediatrician, Primary Care Physician

Diverticulosis and Diverticulitis About 10 % of Americans over the age of 40 have diverticulosis. There are appx. 300,000 new cases per year diagnosed in the US. The condition becomes more common as people age. About half of all people over the age of 60 have diverticulosis. When the pouches become infected or inflamed, the condition is called diverticulitis. This happens in 10 to 25 percent of people with diverticulosis. Diverticulosis and diverticulitis are also called diverticular disease (National Digestive Disease Information Clearinghouse 1983-1987

Physician Internal Medicine/Gastroenterologist, Internist, Primary Care Physician

Heart Disease

Physician Cardiologist, Internist,

Anemia

Physician Hematologists, Internist

Cystic Fibrosis Each year approximately 3,200 white babies are born in the United States with CF. Two-thirds of the infants born with CF will be diagnosed in the first year of life. In all, about 30,000 American adults and children are living with the disorder in the USA

Physician Pediatric Pulmonologist, Pediatric Gastroenterologist, Internal Medicine/Pulmonologist (adult), Internal Medicine/Gastroenterologist (adult)

Pregnancy

Physician OB/GYN, Midwife, Family Practice (very rare)

Hemorrhoids

Physician Primary Care Physician, Internist, General Surgeon

Bone Cancer In 2003, about 2,400 new cases of cancer of the bones and joints will be diagnosed, and about 1,300 deaths from these cancers are expected (USA). Primary cancers of bones account for less than 0.2 percent of all cancers. Osteosarcoma is the most common primary bone cancer (35% of cases), followed by chondrosarcoma (26%), Ewing's tumor (16%), chordoma (8%), and malignant fibrous histiocytoma / fibrosarcoma (6%). Several rare types of cancers account for the remainder of cases.

Physician Internal Medicine/Oncology, Internist, General Surgeon, Radiation Oncologist

Irritable Bowel Syndrome
Physician Internal Medicine/Gastroenterologist, Internist, Primary Care Physician

Sinusitis
Physician Otorhinolaryngology (ENT), Allergist, Internist, Primary Care Physician

Osteoporosis
Physician Primary Care Physician, Internist, Ob/GYN

Weight Loss / Dieting
Physician Internist, Primary Care Physician, Surgeon

Kidney Diseases
Physician Internal Medicine/ Nephrologist, Internist

Dermatitis
Physician Dermatologist, Primary Care Physician, Allergist

Exercise/Physical Fitness In California 46% of the adult population meets the recommended level of physical activity. But 27% report no physical activity Subjects classified as inactive reported no leisure time activities that cause increases in heart rate and or breathing (e.g., running, calisthenics, golf, gardening, or walking). (Prevalence of Physical Activity, Including Lifestyle Activities Among Adults --- United States, 2000--2001, Mortality and Morbidity Weekly Report, Volume 52, Issue 32, August 15, 2003, Centers for Disease Control and Prevention)
Physician Primary Care Physician, Physiatrist

Rheumatoid Arthritis Prevalence, 2.1 million Americans have RA (MayClinic.com).
Physician Internal Medicine/Rheumatology, Internist, Primary Care Physician

Stroke Stroke strikes about 700,000 Americans each year, but the vast majority of people survive. Close to 5 million stroke survivors are managing their health today. (web Md) About Stroke is our nation's No. 3 killer and a leading cause of severe, long-term disability (The American Stroke Association) The American Stoke Association spends more on stroke-related research and stroke-related programs than any other not-for-profit organization, second only to the federal government
Physician Neurologist, Internist

Bipolar Disorder/manic depression According to the National Institute of Mental Health, over 2.3 million American adults have bipolar disorder. Bipolar disorder usually begins in early adulthood, appearing before age 35. Children and adolescents, however, can develop this disease in more severe forms and often in combination with attention deficit hyperactivity disorder (ADHD)
Physician Psychiatry, Psychologist, Internist, Primary Care Physician

Scabies
Physician Dermatologist, Pediatrician, Pediatric Dermatologist

Carpal Tunnel Syndrome Carpal tunnel syndrome affects approximately 3 percent of adults in the United States.
Physician Neurologist, Electrodiagnostic Medicine, Physical Medicine and Rehabilitation , Primary Care Physician

Hernia
Physician Primary Care Physician, Internist, General Surgeon

Attention Deficit Disorder with Hyperactivity
Physician Pediatrician, Psychiatry, Psychologist, Neurologist

Ovarian Cancer 26,700
Physician OB/GYN, Oncologist Surgeon, Internist, Primary Care Physician

Dementia
Physician Primary Care Physician, Internist, Neurologist, Gerontologist

Lung Cancer 14,400 cases of lung and bronchial cancer are estimated to be diagnosed in 2003 (NCI – California Population and Cancer Statistics). 89,489 cases of lung cancer was diagnosed in 2000 in the U.S. (CDC statistics)
Physician Internal Medicine/Pulmonologist, Internal Medicine/Oncologist, Internist, Primary Care Physician

Herbal Medicine
Physician Primary Care Physician, Osteopath, Alternative Medicine (CAMS)

Hysterectomy
Physician OB/GYN, General Surgeon, Primary Care Physician, Internist

Eye Diseases
Physician Ophthalmologist

Appendicitis
Physician Internist, Primary Care Physician, General Surgeon (Emergency Room)

Kidney Failure and Dialysis
Physician Internal Medicine/Nephrologist, Urologist, Urogynecologist (Gyn specialty)

Candidiasis (Thrush) mild infection caused by the *Candida* (*KAN-di-duh*) fungus, which lives naturally in the gastrointestinal tract. Infection occurs when a change in the body, such as surgery, causes the fungus to overgrow suddenly (mouth or genital). Common in children and older adults. Common in people suffering with AIDS. Nearly 75% of all adult women have had at least one genital "yeast infection" in their lifetime.
Physician Pediatrician, Primary Care Physician, Ob/Gyn, Internist

AIDS/HIV – 800,000 – 900,000 currently living with HIV in the USA 128,064 total cumulative cases in California have AIDs in 2002. Appx. 4,000 new cases diagnosed each year.12.5 AIDS case rate per 100,000 in California (2001 statistic- Kaiser Family Foundations). 49,411 persons in California living with AIDS at the end of 2001)
Physician Internal Medicine/Infectious Disease, Internist, Dermatology, Ophthalmology

Teenage Pregnancy In 2001 there were 53,000 teenage births (Special Data Request. Division of Vital Statistics, National Center for Health Statistics, Centers for Disease Control and Prevention . 45.2 teen birthrate per 1,000 in 2001 California (Births: Final Data for 2001, National Vital Statistics Report, Vol. 51, No. 2, December 18, 2002, Division of Vital Statistics, National Center for Health Statistics)
Physician Ob/Gyn, Primary Care Physician (rarely)

Ear Infections
Physician Pediatrician, Primary Care Physician, Otolaryngologist/ENT, Internist

Alcohol abuse Chronic alcohol abuse is defined as 60 or more drinks during the past month by self report is 7.1 % of the California population (California DHS web site)
Physician Internist, Primary Care Physician, Psychologist (Addictive Medicine)

Polymyalgia Rheumatica
Physician Internal Medicine/Rheumatologist, Primary Care Physician, Orthopedist, Internist

Smoking Adult smoking rate for total population in California is 17.2 % (Behavioral Risk Factor Surveillance System, 2001, unpublished data. National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services)
Physician Primary Care Physician, Internist

Sports Injuries
Physician Primary Care Physician, Orthopedist, Physiatrist, Internist

Chickenpox
Physician Primary Care Physician, Pediatrician, Infectious Disease, Internist

Spleen Disease (Includes Mononucleosis, Epstein Barr virus and rupture (trauma)
Physician Primary Care Physician, Internal Medicine/Infectious Disease, General Surgeon

Hepatitis C A national U. S. survey found that 1.8 percent of Americans – about 3.9 million – have been infected with HCV, of whom most about 2.7 million – are chronically infected with HCV, with many showing no signs or symptoms.
Physician Hepatologist, Internal Medicine/Gastroenterologist, Internal Medicine/Infectious disease, Internist

Celiac Disease Celiac Disease Celiac Disease is most commonly found in genetically susceptible Caucasians. Recent studies suggest that at least 1 in 250 persons in the United States is affected. Many cases go undiagnosed or are asymptomatic for years. CD occurs in 5 - 15 % of the offspring and siblings of the celiac. In 70% of identical twin pairs, both twins have the disease It is suggested that family members be tested (Ciliac Disease Foundation). An estimated 1 in 4,700 Americans have been diagnosed with celiac disease. Some researchers question how celiac disease could be so uncommon in the United States since it is hereditary and many Americans descend from European ethnic groups in whom the disease is common. A recent study in which random blood samples from the Red Cross were tested for celiac disease suggests that as many as 1 in every 250 Americans may have it. Celiac disease could be under diagnosed in the United States for a number of reasons (Medline Plus National Digestive Diseases Information Clearinghouse)
Physician Pediatrician, Pediatric Immunology and Allergy, Internal Medicine/Gastroenterologist, Internist, Primary Care Physician

Nutrition
Physician Internal Medicine/Gastroenterologist, Internist, Primary Care Physician

Tick Bites In 1998 in California was 0.4 per 100,000 population overall. With the incidence higher in the North Coastal Counties(California DHS web site).
Physician Internal Medicine/Infectious Disease, Primary Care Physician, Internist,

Seizures Disorder Seizures Disorder – Epilepsy More than 2 million people in the U.S. are diagnosed with epilepsy. Epilepsy is a disorder of brain function that results in repeated seizures. Epilepsy can affect as many as 5 to 10 people in every 1,000—

that's as many as 2 million people in the United States. Approximately two-thirds of the 125,000 persons who are newly diagnosed each year are adults..(epilepsy foundation of America)
Physician Neurologist, Internist, Primary Care Physician

Myocardial Infarction – Heart Attack It is estimated that approximately 1 million patients visit the hospital each year with some type of MI as their principal diagnosis
Physician Cardiologist, Internist, Primary Care Physician

Chronic Diarrhea Most Americans suffer from some form of diarrhea sometime in their lives. Chronic diarrhea is defined as lasting 2 or more weeks and can be chronic in nature (reoccurring) It is not a disease in itself but rather a symptom of various diseases. The prevalence of diarrhea varies according to the definition of diarrhea used and the population being studied. In the United States the estimated prevalence is 3%. In the United States, diarrhea causes from 300 to 400 deaths a year in children, almost 200,000 hospitalizations, 1.5 million outpatient visits, and more than 1 billion dollars in medical costs (EBM Solutions Web Site)
Physician Internist, Internal Medicine/Infectious Disease, Internal Medicine/Gastroenterologist

Brain Cancer
Physician Internal Medicine/Oncologist, Neurologist, Internist, Primary Care Physician

Stress
Physician Internist, Primary Care Physician

Hiatal Hernia
Physician Internist, General Surgeon, Internal Medicine/Gastroenterologist

Asthma (missing from list but should be included) 7.2% diagnosed with Asthma in the U.S. (adults) (Self-Reported Asthma Prevalence and Control Among Adults --- United States, 2001," Division of Environmental Hazards and Health Effects, National Center for Environmental Health, Centers for Disease Control and Prevention, Department of Health and Human Services, 2002)
Physician Allergist and Immunologist, Pediatrician, Pulmonologist, Internist, Primary Care Physician

ADDITIONAL RELIABEL STATISTICS

Brain Impairment

The following tables estimate the incidence and prevalence of the major causes of brain impairment in adulthood in the United States in general and in California in particular. The estimates are conservative, excluding rare disorders for which reliable data are not available.

- Table 1 shows an estimated 1.2 million people aged 18 years and older who are diagnosed annually with adult onset brain disease/disorders in the United States (i.e., the incidence).
- Table 2 estimates that between 13.3 and 16.1 million individuals age 18 and over are afflicted with common brain disorders and diseases (i.e., the number of people currently living with the impairment, or prevalence).
- Table 3 looks at the data in comparison to the overall population of the United States and California. An estimated 13% - 16% of the United States and California households may be dealing with the burden of caring for a loved one with an adult-onset brain disease/disorder.

TABLE 1: Incidence of Adult Onset Brain Disorders

DIAGNOSIS/CAUSE	*People Diagnosed Annually*
Alzheimer's Disease	250,000[2]
Amyotrophic Lateral Sclerosis	5,000[3,4]
Brain Tumor	33,039[5]
Epilepsy	135,500[6,7]
HIV (AIDS) Dementia	1,196[8]
Huntington's Disease	N/A
Multiple Sclerosis	10,400[9]
Parkinson's Disease	54,927[10]
Stroke	600,000[11]
Traumatic Brain Injury	80,000[12]
TOTAL ESTIMATED INCIDENCE	170,312

- More than one million adults in the U.S. are diagnosed annually with a chronic brain disease or disorder. The need for both long-term care and support for family caregivers is dramatic. Many of these conditions, for example Alzheimer's, Stroke and Parkinson's, are associated with increasing age. Given the aging of the United States population, figures will increase proportionately in the coming decades.

TABLE 2: Prevalence of the Major Causes of Adult-Onset Brain Disorders		
	People Currently Living with Disorder:	
DIAGNOSIS/CAUSE	*Low Estimate*	*High Estimate*
Alzheimer's Disease	4,000,000[1]	4,000,000[2]
Amyotrophic Lateral Sclerosis	20,000[3]	30,000[4]
Brain Tumor	N/A	N/A
Epilepsy	1,984,000[5,6]	2,000,000[7]
HIV (AIDS) Dementia	14,537[8]	58,150[9]
Huntington's Disease	30,000[10]	30,000[11]
Multiple Sclerosis	250,000[12,13]	350,000[14]
Parkinson's Disease	500,000[15]	1,500,000[16]
Stroke	4,000,000[17]	4,400,000[18]
Traumatic Brain Injury	2,500,000[19]	3,700,000[20]
TOTAL ESTIMATED INCIDENCE	13,298,537	16,068,150

- Table 2 dramatically illustrates the long-term nature of care giving for many of these conditions. While it is estimated that one quarter of a million people are diagnosed with Alzheimer's annually in the United States, there are an estimated four million people living with the disease, many of whom require 24-hour care.

TABLE 3: Selected Population Characteristics: United States and California		
	United States	*California*
Total Population	274,634,000[1]	34,336,091[2]
Total Population 18+	203,852,000[3]	30,000[4]
Total Households	101,041,000[5]	12,242,576[6]
Total Estimated Adults with Brain Impairment		
a. Low Estimate	13,298,537	1,622,422[7]
a. High Estimate	16,068,150	1,960,314[8]
Percentage of Adult Population Affected by Brain Impairment		
a. Low Estimate	6.5%	6.5%
a. High Estimate	7.9%	7.9%
Percentage of Households Affected by Brain Impairment		
a. Low Estimate	13.2%	13.3%
a. High Estimate	15.9%	16.0%

- The 16% figure for the number of households affected by brain impairment only begins to elucidate the impact of brain impairment upon family caregivers and the long-term care system. With many individuals requiring 24-hour care, there are often several family members from different households involved in the care giving process including spouses, adult children, siblings and friends. Often these caregivers are juggling the responsibilities of care giving, child rearing and employment simultaneously.

Footnotes/Overview:

[1] Federal Interagency Forum on Aging-Related Statistics (2000). *Older Americans 2000: Key Indicators of Well-Being*.

[2] California Health and Human Services Agency (January, 1999). Report on Long-Term Care Programs and Options for Integration. Sacramento, CA.

Table 1:

[1] Due to differences in reporting and data collection, estimates vary and in some cases the figures are for slightly different populations (e.g. aged 13+ or aged 15+) as noted.

[2] Alzheimer's Disease Education & Referral Center, Personal Communication, October 10, 2000 based on figures from 1991. Silver Spring, MD.

[3] Amyotrophic Lateral Sclerosis Association (1999) *ALS and the ALS Association*, Calabasas Hills, CA

[4] National Institute of Neurological Disorders and Stroke (2000), *Amyotrophic Lateral Sclerosis, Bethesda*, MD.

[5] American Brain Tumor Association (2000). *Facts and Statistics*, Des Plaines, IL.

[6] Epilepsy Foundation (2000). *Cost Study Shows Divide in Treatment Effect*, Landover, MD.

[7] Persons 15 years of age and older.

[8] Centers for Disease Control and Prevention (1999), *HIV/AIDS Surveillance Report, 1997 Vol. 9 Number 2*, Atlanta, GA. [Note: Includes ages 13 and above.]

[9] National Institute of Neurological Disorders and Stroke (2000), *Multiple Sclerosis: Hope Through Research*, Bethesda, MD.

[10] American Parkinson's Disease Association, Personal Communication October 10, 2000. Figure derived from an incidence of 20 cases/100,000 and an estimated population of 274,634,000 from U.S. Census Bureau (1999). *Statistical Abstract of the United States: 1999.* [Note: Projections for the year 2000.]

[11] American Heart Association (2000), *2000 Heart and Stroke Statistical Update*, Dallas, TX

[12] Centers for Disease Control and Prevention (2000), *Epidemiology of Traumatic Brain Injury in the United States*, Atlanta, GA [Note: Estimate includes all age groups and only those who have TBI-related disabilities. Estimates are based on provisional data.]

Table 2:

[1] Alzheimer's Disease and Related Disorders Association, Inc. (2000), *General Statistics/Demographics*, Chicago, IL.

[2] ibid.

[3] National Institute of Neurological Disorders and Stroke (2000), *Amyotrophic Lateral Sclerosis*, Bethesda, MD.

[4] Amyotrophic Lateral Sclerosis Association (1999) *ALS and the ALS Association*: Calabasas Hills, CA.

[5] Epilepsy Foundation (2000), *Cost Study Shows Divide in Treatment Effect,* Landover, MD.

[6] Persons 15 years of age and older.

[7] National Institute of Neurological Disorders and Stroke (2000), *Seizures and Epilepsy: Hope Through Research*, Bethesda, MD.

[8] Centers for Disease Control and Prevention (1999), *HIV/AIDS Surveillance Report, 1997 Vol. 9 Number 2*, Atlanta, GA. [Note: Includes ages 13 and above. Estimated from 1997 data on % of individuals developing AIDS-Indicator conditions multiplied by the estimated of number of adults/adolescents currently living with AIDS. Overall the CDC reports that the incidence of HIV dementia is decreasing.]

[9] Berghuis, J. P., Uldall, K. K. and Lalonde, B. (1999). Validity of Two Scales in Identifying HIV-Associated Dementia, *Journal of Acquired Immune Deficiency Syndromes*, Volume 21, pp. 134-140. [Note: Based on the high end of their estimate of 7–20% of HIV/AIDS patients developing dementia times the CDC estimate of individuals currently living with AIDS.]

[10] National Institute of Neurological Disorders and Stroke (2000), *Huntington's Disease Hope Through Research*, Bethesda, MD.

[11] An estimated 150,000 additional persons are at risk of inheriting Huntington's disease from a parent.

[12] National Institute of Neurological Disorders and Stroke (2000), *Multiple Sclerosis: Hope Through Research*, Bethesda, MD.

[13] The National Multiple Sclerosis Society Information Resource Center and Library (2000), *Multiple Sclerosis Information Sourcebook*, New York, NY.

[14] National Institute of Neurological Disorders and Stroke (2000), Multiple Sclerosis: Hope Through Research, Bethesda, MD.

[15] National Institute of Neurological Disorders and Stroke (2000), *Parkinson's Disease Hope Through Research*, Bethesda, MD.

[16] National Parkinson Foundation (1998), *What the Patient Should Know,* Miami, FL.

[17] National Stroke Association (1999), *Brain Attack Statistics*, Englewood, CO.

[18] American Heart Association (2000), *2000 Heart and Stroke Statistical Update*, Dallas, TX.

[19] National Institutes of Health (1998) NIH consensus statement on rehabilitation of persons with traumatic brain injury: Bethesda, MD. [Note: Estimate includes all ages.]

[20] Thurman, D. J. (1999) Preliminary estimate of prevalence for adults age 18+ living with an acquired brain injury. Personal communication, January 8, 1999. National Center for Injury Prevention and Control Centers for Disease Control, Atlanta, GA.

Table 3:

[1] U.S. Census Bureau (1999). *Statistical Abstract of the United States: 1999*. [Note: Population figures for the U.S. and California are projections for the year 2000.]

[2] State of California, Department of Finance (May, 2000). *City/County Population and Housing Estimates*, 1991-2000, with 1990 Census Counts. Sacramento, CA.

[3] U.S. Census Bureau (1999). *Statistical Abstract of the United States: 1999.* [Note: Population figures for the U.S. and California are projections for the year 2000.]

[4] State of California, Department of Finance (December, 1998). *Race/Ethnic Population with Age and Sex Detail, 1970-2040*. Sacramento, CA. [Note: Based on projections for the year 2000.]

[5] U.S. Census Bureau (1999). *Estimates of Housing Units, Households, Households by Age of Householder and Persons per Household: July 1, 1998*.

[6] State of California, Department of Finance (May, 2000). *City/County Population and Housing Estimates, 1991-2000, with 1990 Census Counts*. Sacramento, CA.

[7] These estimates are based on the percentage of population age 18+ years residing in CA.

[8] These estimates are based on the percentage of population age 18+ years residing in CA. 9 Assumes one brain impaired individual per household.

Resources

FAMILY CAREGIVER ALLIANCE WEBSITE

Appendix D
Sample Table for Matching MEDLINEplus Topics
To Providers and Taxonomy

Frequently Requested Topics:	Primary Care 1	Primary Care 2	Specialty 1	Specialty 2	Taxonomy 1	Taxonomy 2	Taxonomy 3	Taxonomy 4
High Blood Pressure	Internal Medicine	Family Practice / Primary Care	Cardiologist		LV-330	LV-260	LV-330.150	
West Nile Virus	Family Practice / Primary Care	Pediatrician	Pulmonary Medicine	Infectious Disease	LV-260	LV-680	LV-680.690	LV-330.315
Back Pain	Family Practice / Primary Care	Chiropractor	Neurologist / Pain Specialist	Orthopedic Surgeon	LV-260	LT-050.150		LV-830.650
Shingles (Herpes Zoster)	Family Practice / Primary Care	Internal Medicine	Infectious Disease	Dermatologist	LV-260	LV-330	LV-330.315	LV-180
Insect Bites and Stings	Family Practice / Primary Care	Pediatrician	Infectious Disease	Allergist	LV-260	LV-680	LV-330.315	LV-050
Lyme Disease	Family Practice / Primary Care	Pediatrician	Infectious Disease	Internal Medicine	LV-260	LV-680	LV-330.315	LV-260
Gastroesophageal Reflux / Hiatal Hernia	Internal Medicine	Pediatrician	Gastroenterologist		LV-330	LV-680	LV-330.280	
Dizziness and Vertigo	Internal Medicine	Family Practice / Primary Care	ENT-Otolaryngology	Cardiologist	LV-330	LV-260	LV-640	LV-330.150
Vitamin and Mineral Supplements	Family Practice / Primary Care	Pediatrician	Holistic Medicine	Nutritionist	LV-260	LV-680	LT-050.310	LH-270.600
Diabetes	Family Practice / Primary Care	Pediatrician	Endocrinologist		LV-260	LV-680	LV-330.180	

The Alliance of Information and Referral Services Taxonomy of Human Services is a classification system used to index community resources based on the services they provide. The coding system incorporates terminology that is accepted in the human services field; using a structure that is straightforward and comprehensive in approach.

At NexCare, we use the taxonomy system for three levels of identification:

1. Facility Type (such as hospital)
2. Services Types (such as emergency room (ER) or Intensive Care Unit (ICU))
3. Target Population (such as shelters whose target population is Battered Women; in this case, "Battered Women" would be the Target Population.)

Using the Top Ten Frequently Requested Topics as an example of the Taxonomy Coding System used, the system can be illustrated through the use of "high blood pressure" as a case in point:

High Blood Pressure

A) Physician Codes:

Internal Medicine; Family Practice/Primary Care; Cardiologist

B) Taxonomy Codes & Human Services Definitions:

LV-330 - Internal Medicine - Programs that are staffed by physician specialists who provide comprehensive preventive, diagnostic, and treatment services for individuals who have diseases or injuries which affect the internal organs and require non-surgical intervention. General internists provide continuing comprehensive care for common and complex multi-system illnesses in ambulatory care as well as hospital settings. Internists often function as primary care physicians who are the patient's initial point of contact with the health care system and who assume ongoing responsibility for maintaining the health of their patients and for providing treatment in case of illness, including consultation with specialists when required.

LV-260-Family Practice - Programs that are staffed by specialists who provide comprehensive medical care including preventive services with particular emphasis on the family unit, in which the physician's continuing responsibility for health care is not limited by the patient's age or gender, nor by a particular organ system or disease entity.

LV-330.150 Cardiovascular Medicine - Programs that are staffed by specialists who provide comprehensive medical management including preventive, diagnostic and treatment services for individuals who have diseases or other conditions that affect the heart, lungs, and blood vessels. Cardiologists manage complex cardiac conditions such as heart attacks and life threatening abnormal heart beat rhythms in settings such as coronary care units of hospitals.

Appendix E
Agency Verification Module

Agency Verification Module

The Agency Verification Module (AVM) is the heart of the Nexcare CRM. The Agency Verification Module's sole purpose is to maintain verified agencies in the database.

The maintenance of an agency (referred to as Verification) is the actual update process of the information about an agency. It is performed when the user is talking to an agency on the phone or has received feedback from an agency in writing and needs to apply the changes to the agency record.

It is also in this module that the user assigns taxonomy codes to an agency or the agency to taxonomy codes.

Ease of use is important, since any member of the staff at anytime may be assigned to Verify agencies. The layout for agency searches and results is designed for minimal keystrokes and quick location of agencies:

Agency Verification Process

The process for verifying agencies is an essential one. Updates are completed at regular intervals, with the system designed to programmatically organize call data and transmit automated inquiries to agencies that provide e-mail addresses and fax numbers. The process for verifying agency records for updating current information is as such:

- Regular updates sent/completed via:
  - e-mail
  - Fax
  - U.S. Postal Mail
  - Telephone

At minimum annual phone calls are made to:

- Each of the agencies for verbal update
- All non-responses to automated update processes
- Any new agencies

The information collected and maintained through the Agency Verification Module is utilized by the Information and Referral Module (I&RM) to provide appropriate services to the caller.

AGENCY VERIFICATION MODULE

Objective: By verifying services and programs that agencies offer in the LA County area, we enhance our database; provide accurate information to our callers, such as hours of operations, requirements they need to meet to receive services, agency's address, and phone numbers.

First Screen/Tab 1

General: This tab has the general information on the agency, which will be displayed on the I&RM (Information & Referral Module). This will be provided to the caller/web user after the

search is conducted by the I&RS, therefore it is very important to gather accurate information on such agencies.

Second Screen/Tab 2
Operations: This tab is for internal purposes only, it important to gather this information so that we can communicate and create a relationship with the agencies and organizations we are verifying.

Third Screen/Tab 3
Programs: Programs offered by the organizations or agencies, each program will be assigned a Taxonomy code base on this Taxonomy code the program will be displayed in the I&R Module as the I&RS enters the term and searches for it.

Fourth Screen/Tab 4
Services: This screen displays the areas of services by the agency, taxonomy codes are also assigned on this tab, once a Taxonomy code is assigned to the agency based on the Programs, the completed information will be display on the I&R Module/Web Site.

Fifth Screen/Tab 5
Payment: Agencies have a different form of payment; most of the agencies in the database are a low-cost, or no-cost for services, at times some of them do charge a first time visit or monthly fee therefore, during the verification process these questions are required to be asked.

Sixth Screen/Tab 6
Eligibility: Requirements callers have to meet in order to get services provided by the agency. This information is provided to the caller/web user.

Seventh Screen/Tab 7
Verification: This tab is the record profile, any changes or updates are recorded on record properties. This tab is for internal purposes only and not provided to the caller/web user.

Eight Screen/ Tab 8
Research: Captures the information on any member that has had access to the record and outreach information. This is internal information and it is not provided to the caller/web user

Ninth/Screen/Tab 9
Activity: This tab reports any activity conducted to the record. This tab is for internal purposes only and the information is not provided to the caller/web user.

~ Agency Verification Protocol ~

This protocol has been created to conduct 2 types of calls

1. Add and verify new agencies and organizations that offer low cost, no cost services,
2. Verify agencies and organizations that already exist in the AVM (Agency Verification Module),

The information found in the AVM was retrieved from a variety of sources

During the call tabs 1- 3, 5, and 6, have to be verified, including all changes on services or programs. All questions are mandatory to be asked during a verification session.

It is better to not to say your name at the beginning of the greeting, this will prevent you from sounding like a sales representative. (if the person inquires your name, give it to them)

I&RS: Good morning, I'm calling on behalf of First Five LA Connect. We are a not-for-profit referral service, funded by the State of California via Prop. 10. Basically, what we do here Sir/Meme is "**We refer people in need, to services that can help them get back on there feet, such as clinics, health care providers, housing, job training, food providers and medical insurance".**

We have you in our database as one of those organizations that can help these people. If you can give me just a few minutes of your time, I would like to verify what programs you have now, so we can better assist our clients. (Please review very closely instructions in the boxes)

- If the individual is receptive to this greeting, go straight to the programs screen/tab and start reading off the programs (don't ask him/her for the programs) This will make the individual more at ease with you.

-If the programs are incorrect or not complete, he/she will let you know right away (make the necessary changes).

- If the individual can not provide you with the information, ask for the H.R Department or Administrative services.

- If they say they don't have the time;

- **I&RS should explain: these services will help a great deal of people and the questions will not take long.**

- If they asked the Question: Why should I give this information to you?

- **I&RS should answer: "We are funded by the state, we have hundreds of agencies at our disposal and we, as a unit, can funnel a lot more information to a lot more people, through our services with your help".**

- If they do not respond positively or they do not have the time:

- **I&RS should ask: what is the best time to call you? (Proceed to set up an appointment with the person on the phone and noted on the AVM report, NOT on data base).**

(Usually they will respond. It all depends on your presentation)

Third Screen

Programs- (Follow the next example when verifying services).

- If it is an agency that offers different programs:

I&RS:
I see here that the (mention the name of the agency) provides (mention services listed) as well as (mentioned other services) is that correct? Great! Do you still provide (read the more services If there are still some more), are there any other programs that you have that I have missed?

To ensure that we classify you correctly, what type of facility would you consider your agency to be (examples: Hospital, clinic, shelter)

- If they have support groups listed under programs:

I&RS:
I also have here that you have language support groups as well as weekend support groups. Is that correct?

(Once you have established the programs, go to the first screen).

First Screen

General- (Information will be displayed on I&R Module and website when providing referrals to the caller therefore you have to make sure to spell everything right, check boxes: check mark means **yes**, blank box means **no**

I&RS:
- The name of your agency is? (Verify spelling of the agency name)
- You are located at? (Repeat address)

- Is your address confidential? (check box if **YES**, blank if **No**)
- Is your mailing address the same as the business? (If **YES** check box, if **NO** proceed to get the mailing address)
- The nearest street/cross St. is? (mention street if available, if not ask for the right street)
- I have your business number as (repeat number you are calling)
- Your fax number is? (read it off the screen)
- Do you have a hot line?
- Do you have a total free number
- Do you have TTY services?
- Do you have a web-site? (make sure to repeat back the web-site)

Second Screen

Operations (This information is for internal purposes)

I&RS: **"**Just a few more questions and I can let you get on with your day"

- Can I have your name?
- Can I have your title? Or your title is?
  - Do you have a direct phone number or is it the same as the agency?
  - Do you have an e-mail address?
  - Your director's name and his/her extension? (If name is not displayed, ask the following). Can I have the Director's name and extension?
  - Does he/she (Director) have a private/direct phone number?
  - Are you affiliated with any organizations?
  - I see here that your hours of operation are?(repeat hrs of operation, make sure to capture the right information, it will be distributed to the callers)
  - Refer to the reference guide to find out if they are a Collaborator (**Do not ask the question**)
  - Are you funded by Prop 10?
  - Are you a not for profit? **(pay close attention)**
  - Do you have the FEIN? (Federal Employer's Identification Number), or we will need proof of not-for-profit status could you please send us your 501c or letter of certification from the IRS?
  - How large is your staff? (optional answer)
  - More importantly, what is your client capacity? (optional answer)

Fifth Screen

Payment (Information will be provided to the caller/web user)

I&RS:

- I see here that your services are free; is that correct?
- Do you accept any type of Health Insurance? (see procedures for QA below)

Sixth Screen

Eligibility (information will be provided to the caller/web user)

I&RS:

- And you do accept referrals and walk-ins?

- Do you provide transportation to your clients?
- Do you provide services in any other language than English? (If languages listed on AVM then verify them).

I&RS:

- Are their any other eligibility requirements? (note any extra information on the notes field)
- What is your main Target Population (example: youth, elderly adults)?

Closing: "Thank you very much for your help, I just want to let you know that we are open 7 days a week from 7am-7pm. have wonderful day"

Procedure for QA of Agencies

Agency Verification Module

Tab 1: General

1. **Agency Name:**
   a. System programmatically uses upper/lower case, there will be clean-up in this area
   b. Upper Lower Case properly used (ex.: La should be L A)
   c. Check that all Spelling is correct

2. **Agency Status**

   Note: The only acceptable criteria for assigning the status is through a phone call to the agency and confirming that it is in business and currently providing service to the public.

   a. Look in the "**Remarks**" tab and "**Programs**" tab to see if there are any notes related to the agency being "**Active/Inactive.**" You may also need to update the notes (remember to date the notes)

Note: The above 2 fields will always remain visible as you switch between tabs

3. **Addresses**
   a. Address is Confidential
      - If the agency says their address is confidential, the check the empty box next to the "**Confidential**" field MUST be checked. e.g., Domestic Violence shelter. Revealing the address to this type of agency can put the customers in jeopardy.
        i. Look in "**Remarks**" Tab and "**Programs**" tab to see if there are any notes related to a confidential address.
        ii. If you believe the agency may have a confidential address, but the status is not checked, ask the person on the line immediately. Keep the Address Confidential box unchecked until information is verified.

   b. Business
      - Is the Main address a Business (physical) address? If not move address to Tab 2-Mailing

- Check for correct spelling of information
- Use standard Address abbreviations as shown below:
  i. Ave
  ii. St
  iii. Blvd
  iv. Rd

c. Mailing
   - If Mailing and Business address are the same, check the empty box to the right of the **"Same as Business"** field.

d. Cross Streets

4. Agency "**Contact"** Information (phone numbers)

a. **Business—**enter the phone numbers with hyphens as shown in the following format: 323-222-2593
b. **Fax**
c. **Hotline**
d. **Toll-Free**

Use the same format as above

   - Make sure toll free numbers begin with: 800, 888, 877 or 866
   - If the number does not include on of the numbers above,
     i. Look in the "**Remarks**" Tab and "**Programs**" tab to see if there are any other phone numbers listed—if so verify if they are valid.
     ii. If they are the same agency with a different location, create a new agency record so that location can be called for verification. Once you create the new record, delete the phone number from the Remarks/Programs field.
     iii. If the number is not another location and there is no field to which the number relates, make a note indicating what the phone number is for.

e. **TTY**—*Use the same format as above.*

1. Website

a. Proper website address format www.address.com
b. The website address is not an email address (which contains the @ sign).

Tab 2: Operations

1. Personnel

a. Make sure contact all information looks correct
b. Names are spelled correctly
c. Position, employee titles are accurate
d. Phone numbers are entered correctly and correspond to the correct individuals
e. Emails are entered correctly, no spaces.

Affiliations

- Separate affiliation types that you enter with a comma
- Types of affiliations are:

1. County
2. Government
3. Church/Temple
4. Hospital

2. Hours of Operation

a. The "Hours of Operation" field should include days open and times
   - If there are only time, and get days open
   - Information should read with hours first, then days and use commas to separate
     1. ex. 8a-5p M & W , 9a-6p T & Th, 6a-2p F OR 8a-5p M-F

3. Misc (1)

a. **<u>* Collaborator</u>**–Is the agency one of our Collaborators?—If yes, check the empty box to the right of the "Collaborator" field.
   - Check the List (located in the introduction of the Reference Guide) to see if the agency is a Collaborator.
   - Consider the 10 Child Care R&R's as Collaborators—in Reference Guide (Child Care Resources)

b. **<u>Funded by Prop 10</u>**—If yes, check "Prop10 Funded" status field
   - The list of Prop 10 funded establishments is located in the introduction of the Reference Guide
   - Check the list for Prop 10 Funded establishments- Search for Agency in Sys211, if agency is part of the Database, check the Prop10 Funded Status. If they are not in the database note the agency name to possibly be added and verified at a later date.

c. **<u>*Non-Profit</u>**—If agency is a non-profit, check the empty box next to the "Not for Profit" status

4. FEIN (Federal Employer's Identification Number)—if the agency is not-for-profit, ask the contact person for the form. (they need to faxed it immediately)

5. Misc (2)

a. Staff size—attempt to get an estimate of the number of employees that are staffed at that particular location.
b. Client capacity—Ask if there is a limit to the number of clients (customers) they are able to serve at any given time.
   - If yes, ask for the maximum number and enter it in the space provided.
   - If no, leave the space blank.

Tab 3: Programs

Pay special attention to this tab. Do not hesitate to ask questions if you are not certain.

1. **Programs Formatting**
   a. Make sure all spelling is correct, check for proper grammar
   b. Use "-" (dash) as the bullet
   c. Clean up any narratives by making them brief and to the point.
   d. Put any information that doesn't belong in this section in the appropriate section (ex. Eligibility requirements notes field)
   e. Ask if you are not sure.
      - Ask the person on the line if something looks incorrect or inconsistent
   f. Delete any repetitive information.

Tab 4: Services

1. **Area**
2. **Zip Code**—enter the zip codes that the agency serves and separate multiple entries with commas.
   a. After entering all the zip codes, click on the "Insert" button to transfer them to the grid below.
3. State, State and City, Area Code, Area Code and Exchange, and Unrestricted (National)
4. **Area of Service**
   - Look in the "Remarks" tab and "Programs" tab for Areas Served related information
5. **Taxonomy**—for now, unless you are assigned to taxonomy coding, you will not need to do anything in this tab.

Tab 5: Payment

1. **Payment Options**
   Check the boxes that apply to the payment options offered by the agency.
   a. **Free**
   b. **Sliding Scale**
   c. **Fees** (a fee may be required for certain services)
      - Briefly specify the fee and the corresponding service in the blank space located next to the "Fees" field.
      - Call the agency to verify the fee for service information if there is any doubt.
2. **Supplemental**
   a. Check all the boxes that apply with respect to the types of health insurance programs that are accepted by the agency.
   b. **Other**
      - This space is provided to specify any other health insurance programs the agency accepts that are not listed above.
      - If there is information not related to insurance/payment in this field and it applies to another field, put it in the appropriate field (or check the appropriate box)
      - If the information does not apply, verified the information and place it in the "Remarks" or "Programs" tabs, accordingly.

Tab 6: Eligibility

1. **Requirements**
   a. **Call for Referral, Accept Walk-ins, Provides Transportation**
      - Make sure appropriate boxes are checked, if applicable
      - Enter only relevant and brief notes in the fields to the right
      - Remove any notes unrelated to or redundant (ex. If call for referral is checked, there is no need to have a note that says, "call # for referral")
2. **Languages**
   - The boxes are checked if the agency is able to provide service in those languages.
   - If the **"Other"** field is checked, you MUST specify the language in the space provided to the right. If the field is empty, remove the check from the "Other" field.
3. **Misc**
   a. **Access to ATT Trans**—This box is checked if the agency is able to provide service using ATT Translation services.
4. **Eligibility** Notes—Pay special attention to this tab. The information will be used later on to include the "drop and drag" function.
   - Make sure all spelling is correct, check for proper grammar
   - Use "-" (dash) as the bullet
   - Clean up any narrative and make bullet points
   - Put any information that doesn't belong in this section in the appropriate section (ex. Program Main Function info in Programs tab)

   Note: Ask if you are not sure!
   - Call agency if any information looks incorrect
   - Delete any repetitive information

Tab 7: Verification

1. **Verification expires in ___ Days**
   - If you assigned and/or verified taxonomy codes leave 365 days
   - If you did not assign and/or verify taxonomies change to 14 days
2. **Verification Completed**
   - Check this box once you have verified the record.

Tab 8: Research

1. **Notes**
   a. Enter any additional information that is not appropriate to enter in any other field, but that is important to save in the record.
   b. Use the same processes used in the "Program" and "Eligibility" Tabs to format any information that is staying with the record

Please make sure to ask questions when you are unsure.
It is important to make the information as accurate as possible.
This information will also be used on our website.