

# EXECUTIVE SUMMARY

**Evaluation of the  
C. Everett Hoop Community Health Information Center  
(CHIC)**

**Contract No: 200-96-0598**

**by:**

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## EXECUTIVE SUMMARY

A significant part of the National Center for Chronic Disease Prevention and Health Promotion's (NCCDPHP) mission is to promote healthy personal behavior and to accomplish goals in partnership with health and education agencies, major voluntary associations, the private sector, and other Federal agencies. There are many channels through which individuals can obtain health information such as the Internet and Federal health information clearinghouses, but there is an urgent need to identify other ways to work in partnership with alternate groups to facilitate the dissemination of the effective and accurate health communication products produced by CDC and its partners.

Community health information centers have the potential to serve this purpose. Community health information centers provide individuals in their communities direct access to accurate health information as well as provide the added value of consultation with center staff. Additionally, community health information centers have the ability to establish networks and collaborative arrangements with regional organizations, corporations, public and medical libraries, and voluntary agencies that facilitate the dissemination of accurate health communication products.

Because of this potential, CDC's NCCDPHP has become interested in understanding the effectiveness of community health information centers in meeting the health information needs of the general public. One such case is the College of Physicians of Philadelphia. In 1995, the College created the C. Everett Koop Community Health Information Center (CHIC). The CHIC was developed by the College to provide individuals with a comprehensive resource for consumer-based health information.

In 1998, CDC contracted with Macro International Inc. to conduct an evaluation of the CHIC. The purpose of this project was to evaluate the effectiveness of the CHIC in serving as a national physician-based model for community health information centers by assessing (1) the effectiveness of the CHIC products and services from the users' perspective, (2) the use of the products and services as well as any barriers to use, and (3) the effectiveness of outreach with nonprofit organizations, corporations, libraries, government agencies, and voluntary health agencies. To accomplish these evaluations, Macro employed various data collection components such as an on-site survey of patrons, focus groups with people representing key intermediary organizations, phantom shopper surveys, and interviews with College staff and board members. The evaluation of the CHIC centered around three formal components: a Patron survey, key intermediary focus groups, and a phantom shopper survey.

## THE PATRON SURVEY

In order to ensure that users of the CHIC (Patrons) received the highest quality of services, from its inception the CHIC asked Patrons to complete a short survey evaluating their experience using the facility. Results from these surveys were used by the College administration to fine-tune the level and types of services provided to the Patrons. Under this evaluation, the Patron survey was

strengthened so as to provide the College and CDC with statistically valid and reliable results from which to make programmatic decisions and changes.

The survey instrument was administered to all Patrons who used the CHIC from April 1 through December 31, 1998. In total, 267 individuals completed the survey instrument. The survey instrument addressed four main areas:

1. The Patron's familiarity with or awareness of the CHIC
2. The type of information the patron was looking
3. How the CHIC can improve
4. Basic demographic information about the Patron

## Results

### Was Respondent Previously Aware of the CHIC?

To help assess the Patrons' previous awareness of the CHIC, respondents were asked to indicate if they had previously visited the CHIC, the College, or the Mutter Museum. Thirty-three percent (33%) of Patrons had visited the Museum in the past. Just over one third (35%) of Patrons had visited the College before, and 24% of Patrons also had obtained information from the College's library at some point, either that day or in the past. Patrons were also asked if they had visited the Mutter Museum on the same day that they had visited the CHIC. The majority of CHIC Patrons (58%) used the CHIC on the same day that they visited the Museum.

Respondents were then asked about how they became aware of the CHIC. The vast majority (39%) of Patrons became aware of the CHIC because of a Mutter Museum visit. During Museum tours, individuals are given an introduction to the College and its facilities, including the CHIC, and there is literature available at the Museum directing individuals to the CHIC. Approximately half as many became aware of the CHIC because of friends (21%) or from a library referral (20%).

### Where Do Patrons Go for Information and What Were They Looking For?

Patrons were given a list of nine possible sources of health information and asked to indicate on a scale of 1 "Rarely" to 3 "Most of the time" whether they go to any of the sources to find health information. The majority of Patrons turned to their health care providers for health information (value of 2.68 out of 3). In addition, Patrons asked their family members for health advice (1.99) and utilized the Internet to gain health information (1.96). Libraries were also a source of health information for Patrons, with the public library being the primary library used, followed by university and hospital libraries. Finally, respondents rarely contacted the health department or the CHIC for health information.

## Resources Utilized During the Visit

Patrons were asked what CHIC resources they utilized during their current visit. They were asked to check as many resources as applicable from a list of seven possible categories. The CHIC pamphlet collection and its collection of books were each used by 36% of respondents. In addition, Patrons utilized librarian services (28%) and the computers (25%). Fewer Patrons used the CHIC's magazine collection (16%), medical journals (10%), or video collection (4%).

## How Can the CHIC Improve?

Patrons were asked a series of four questions to assess their opinion about how the CHIC can better meet their needs. This series included questions about language preference, hours of access, and cost for services. Patrons were asked if they would be more likely to use the CHIC if it were open weekday evenings and Saturdays. Of the 206 Patrons who answered this question, 45% indicated that they would be more likely to use the CHIC if it were open weekday evenings. Significantly more Patrons indicated that Saturday hours would make them more likely to use the CHIC (68%). Patrons were also asked if they would be willing to pay to use the CHIC. Few Patrons are willing to pay an entrance fee (22%) or a membership fee (27%) to use the CHIC; however, Patrons are more likely to be willing to pay a fee for borrowing privileges.

## Experience with the CHIC

The survey also asked Patrons to comment on their experience using the CHIC by rating a series of 7 statements on a 4-point scale of "strongly disagree" (1) to "strongly agree" (4). Patrons felt that having a staff member available to them was very important. Specifically, 60% of Patrons "strongly agreed" and 35% "agreed" that having a staffperson was useful to them. Similarly, the vast majority of Patrons felt that the CHIC is a good resource for consumers. It is perhaps because Patrons felt that the CHIC was a good resource that they are also likely to tell others about the CHIC (95% "strongly agreed" or "agreed"). The CHIC was also seen as a place Patrons would come again to do medical research. In fact, 54% "strongly agreed" and 42% "agreed" that they would use the CHIC again.

## KEY INTERMEDIARY FOCUS GROUPS

The purpose of this portion of the evaluation was to (1) assess the health information needs of individuals who represent key audiences as defined by the CHIC (e.g., Arthritis Foundation, American Cancer Society), and (2) to act as a semi-marketing tool for the CHIC. It was felt that during the recruitment stage for the focus groups, the CHIC would have to contact additional organizations, thereby increasing these organizations' awareness of the CHIC.

## Methodology

Discussions were designed to elicit information about

- ▶ knowledge of the CHIC, its mission, and its role;
- ▶ attractiveness of the CHIC concept to constituency;
- ▶ barriers to access of the CHIC by constituency;
- ▶ other sources of health information;
- ▶ potential areas for collaboration; and
- ▶ best channels for promoting the CHIC with constituency.

Results presented below are from three focus groups conducted March 15-16, 1999, with 18 participants who were considered to be key intermediaries. Prior to conducting the focus groups, participants were provided with a 30-minute introduction to the CHIC and allowed to browse through the CHIC to help familiarize themselves with what the CHIC can offer.

## Results

### Knowledge of the CHIC, Its Mission, and Its Role

Most participants stated that they were not familiar with the CHIC and they did not believe that their clients were familiar with it. Only a few stated that they were “somewhat familiar” with the CHIC, but they also believed that their clients were not familiar with it.

### Attractiveness of the CHIC Concept

Participants seemed to believe that the CHIC concept was very attractive, particularly when compared to other sources of information. These other sources included the Internet, health care agencies, primary physicians, and bookstores. In terms of information **from** these sources, participants commented on the inadequacy of the information, in terms of either amount, type, and level of information or ease of obtaining the information. Several people talked about how overwhelming medical research can be, particularly when most places that house the most accurate and complete information are impersonal and too technical for the average person. The suggestion, it seemed, was that having a CHIC or similar facility, where information is available, easily accessed, and user friendly, is a much better alternative to all other existing sources of information.

## Barriers to Access of the CHIC

Participants thought there were several factors that might hinder potential users **from** accessing the CHIC. These included the following:

- ▶ Potential users feel disempowered.
- ▶ Potential users are **afraid** of answers.
- ▶ Hours of operation are inconvenient.
- ▶ Parking or transportation issue.
- ▶ Language barriers and low literacy levels among potential users.

Participants believed that improving parking, expanding the hours of operation, and targeting materials to non-English speaking or low-literate persons would make it easier for potential users to access the CHIC. But when asked if having to pay either an annual membership or borrowing fee would affect their clients' ability to use the CHIC, most said it would make it harder for their clients.

## PHANTOM SHOPPER SURVEY

One of the strong selling points of the CHIC is that it is the only place in Philadelphia where average citizens can research various medical conditions and issues. Moreover, the information that the **CHIC** houses is purposely geared toward consumers, not medical professionals. Thus, the CHIC asserts that it is the only location well-suited to serve consumers and that it has distinctive competencies such as providing consumer-centered health information and helpful resource staff. The purpose of this component was to determine if in fact the CHIC is positioned as it claims, and to help determine how the CHIC can enhance its services in order to reduce competition from other libraries in the metropolitan Philadelphia area.

To accomplish the phantom shopper study, four different types of libraries were visited. These included the CHIC, the main Free Library of Philadelphia, a local branch of the Free Library, and a university library (either the Penn Biomedical library or the Temple Medical School library). It was believed that these libraries covered the broad spectrum of locations where consumers might go to research medical conditions and issues.

Four phantom shoppers were recruited **from** the university communities through word of mouth. One shopper was a medical researcher, another shopper was a public health researcher, the third shopper was a graduate student in health, and the final shopper was a senior undergraduate. Each shopper visited each location. The shoppers visited these locations at various times during the day and on various days during November and December 1998. Shoppers were asked to assess the following issues, among others, when "shopping" for information about their disease/medical issue:

- ▶ Accessibility and ease of access: hours, days, evenings, parking, location

- ▶ Helpfulness of staff and role of staff (i.e., librarian model with lots of hands-on help, versus self-guided Museum model.)
- ▶ Amount of information available
- ▶ Complexity of information: simple booklets for general public, more complex material, etc.
- ▶ Currency: Were the collections up to date?
- ▶ Cost to use services, if any
- ▶ Other referrals: Where else are patrons referred for more information if they ask for it? In particular, are they referred to the CHIC?

## Results

### Accessibility and Ease of Access

The shoppers were asked to assess the accessibility and ease of access to the four types of libraries. Of key interest were the hours of operation, availability of parking, and accessibility by public transportation. The CHIC is open to the public Tuesday through Saturday, 10 a.m. until 4 p.m.<sup>1</sup> The Free Library of Philadelphia is open: Monday through Wednesday, 9 a.m. until 9 p.m.; Thursday and Friday 9 a.m. until 6 p.m.; Saturday, 9 a.m. until 5 p.m.; and Sunday, 1 p.m. until 5 p.m. Local branch libraries had hours of operation either a few weekdays from 1 p.m. until 9 p.m. or a few weekdays from 10 a.m. until 5 p.m., and then Saturday afternoon hours. Finally, university medical libraries had the most extensive hours of any of the visited locations; in some cases, they were open **24** hours per day.

Location proved to be important to shoppers. Shoppers felt that the CHIC's location was a bit problematic. Parking was either difficult to find or expensive (paid parking lots). **However**, access to public transportation was available. The Free Library is easily accessible by foot, public transportation, or car. The branch libraries were less accessible by public transportation than the main Free Library, but most offered free parking. Finally, the university libraries were all easily accessible by foot or public transportation, and all offered convenient paid parking. To use Temple's library, however, users must either be affiliated with or escorted by a Temple-affiliated person.

### Helpfulness of Staff

All the shoppers commented on the helpfulness of the CHIC librarian staff. The staff were **friendly**, informative, and "almost too eager" to help. Only a few problems were reported about the CHIC librarians. The shoppers found the reference librarian staff at the Free Library to be very helpful, although some shoppers had difficulty getting the attention of librarian staff. Branch librarians were also found to be very helpful. University medical librarians were viewed as being less helpful.

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<sup>1</sup> It is important to note that during the time of this study, the CHIC suspended Saturday hours. This situation was found out by one shopper who went to the CHIC on a Saturday and was told that they **were** closed.

Shoppers reported that the library staff was helpful in showing patrons how to use the medical databases but left the shoppers to do all the searching.

### **Amount of Information**

Shoppers agreed that the information housed by the CHIC was far more extensive than that of any other facility (except the Biomedical Library at Penn). This information was current, broad reaching, and well organized on the shelves. The public libraries, while having the information organized, had slightly less information, especially at the Branch locations. More importantly, the CHIC had additional information from other sources of consumer health information such as support groups, national research associations, and CDC 24-hour hotlines. In addition, the CHIC had contact information for other national organizations and Federal health agencies so that the shoppers could contact them on their own to request more specific information. All the libraries provided patrons with extensive access to the Internet and online medical databases, such as Medline.

### **Complexity, Readability, and Currentness of Information**

The information collection of the CHIC was viewed by the shoppers as being the most appropriate for general health consumers. The shoppers also found that the CHIC had a good balance between literature aimed at general audiences and more technical information. The information housed by the CHIC was seen as very readable, and it included several pamphlets geared toward low-literacy audiences. In addition, the CHIC has some information in languages other than English.

The Free Library and the branch libraries also had information geared toward general health information consumers, although there was some concern that the holdings were dated (e.g., 1980s). There also was some concern among the shoppers that the public librarians urged consumers to collect information by searching such databases as “Infotrac.” Despite this, the information available at the Free Library and its branches was also seen as very readable, but there were few materials aimed at low-literacy or non-English-speaking audiences.

Finally, all the shoppers agreed that the library collections of the university medical libraries were too technical for the general public. The information was the most current, but it was written at a level far too complex for the non-medically trained or non-academically trained individual.

### **Referrals for More Information**

One potential source of patrons for the CHIC is referrals from other libraries. To assess the extent to which this occurs, shoppers were told to ask librarians from non-CHIC libraries for referrals to other institutions that might have more information on the diseases they were researching.

When shoppers at the Free Library asked for suggestions about where they could find additional information, the shoppers were always referred to the Biomedical Library at Penn. A few shoppers were referred to the College of Physicians, but most felt the referral was to the **College** and not to the CHIC. Shoppers at branch libraries were most often referred to the main Free Library branch

and the Penn Biomedical library. No branch library referred shoppers to the CHIC. Finally, when shoppers at the medical libraries asked for referrals, most shoppers were referred to the main Free Library of Philadelphia.

## **CONCLUSIONS AND RECOMMENDATIONS FOR THE CHIC**

### **Marketing, Promotion, and Visibility**

#### **Awareness of the CHIC**

Most Patrons did not know about the CHIC prior to visiting the College. Only a few reported that they had been to the CHIC more than once. Key intermediaries also reported being unfamiliar with the CHIC and did not believe that their clients were familiar with it.

- ▶ The CHIC must do more to increase its visibility in the community. This can be accomplished primarily by developing relationships with other organizations that can serve as referral agents and by successful advertising and marketing of the CHIC's resources. For example, physicians, libraries, community-based organizations, the general media, and gyms and fitness centers can serve as referral agents.

#### **Referral Agents/Agencies**

Key intermediaries believed that health care providers, libraries, and the Internet would serve as perfect vehicles for marketing the CHIC to potential patrons. In fact, the Patron survey revealed that Patrons typically go to their health care provider first for health information, a fact that was supported by the key intermediaries' reports about their clients.

- ▶ The CHIC should work with local health providers to provide patients easy access to consumer health information. The CHIC should improve its marketing effort within its own membership.

Key intermediaries thought that libraries would be a significant source of information for their clients. This may be true, but it cannot be expected that libraries serve as referral agents for the CHIC. In fact, the shoppers in the phantom shopper study were rarely referred to the CHIC when they asked for referrals to places where they could get more health information.

- ▶ If the CHIC wishes to increase traffic resulting from referrals, it will have to expand its marketing, especially to the branch and main Free Libraries.

## Resources

### Materials

Patrons reported using pamphlets and books more than any other resource at the CHIC. According to the phantom shopper survey, the CHIC was the only location visited by shoppers that provided patrons with brochures about health issues published by the government and/or the medical community. Perhaps the single most important and distinguishing aspect of the CHIC is its distribution of medical brochures and leaflets. This was, in fact, seen by the shoppers as a great benefit.

- ▶ It is, therefore, very important for the CHIC to continue to acquire and distribute current reference books as well as pamphlets for patrons to take with them as they leave the CHIC.

The majority of Patrons surveyed were 25 years old or older, and low or middle income. Not surprisingly, they all preferred materials in English. However, key intermediaries seemed to agree that offering materials in different languages as well as ensuring that publications are understandable for the low-literate would make it easier for their clients to use the CHIC. According to the phantom shopper survey results, the CHIC already houses materials for the low-literate and non-English-speaking audiences.

- ▶ To capture a broader base of patrons, the CHIC should continue to include in its collections materials for the low-literate and non-English-speaking audiences. These efforts to accommodate these audiences should be maintained to the extent that it is required by the educational and national/ethnic diversity of Philadelphia residents.

### Staff and Atmosphere

Key intermediaries and phantom shoppers talked about the overwhelming nature of conducting medical/health research, particularly when most places that house the most accurate and complete information are impersonal and too technical for the average person. Their suggestion was that having an intimate setting with accessible, helpful staff and user-friendly, consumer-oriented materials would be greatly beneficial to their clients.

- ▶ It is likely that the more satisfied patrons are with their experience at the CHIC, the more likely they are to tell others about the CHIC. The CHIC should continue to emphasize staff quality, layout, and user **friendliness** to ensure that all of its patrons are able to find information easily and accurately about the topic(s) they are researching.

## **Accessibility**

### **Hours of Operation**

Patrons' responses indicated a definite interest in seeing the CHIC offer Saturday hours and weekday evening hours. Key intermediaries tended to believe that current hours may serve as a barrier for some of their clients who work during those hours. Shoppers in the phantom shopper study also found the limited weekday hours to be a problem and desired to have the CHIC hours extended to include evening hours. The Free Library of Philadelphia was seen by the phantom shoppers as a better alternative to the CHIC, in this regard, because of its convenient extended hours.

- ▶ The CHIC should consider extending its hours to include weekends and weekday evenings. This will enable the public to come to the center during non-working hours, which will be particularly beneficial to those with long travel times or other transportation barriers.

### **Cost**

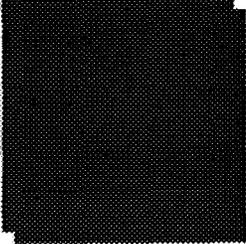
The income distribution of the Patrons surveyed may explain why many were willing to pay for services at the CHIC, especially for borrowing privileges. A smaller yet significant number of Patrons stated that payment for entrance or membership would make it more difficult to use the CHIC. Key intermediaries agreed that payment for any service would serve as a barrier for their clients. With regard to this issue, the phantom shoppers saw the Free Library as being more advantageous than the CHIC because the Free Library is truly free for use of all library services except photocopying.

- ▶ The CHIC should continue to be a free library and research facility for its patrons, and only charge for borrowing privileges if necessary.

## IMPLICATIONS FOR NATIONAL MODELS

One of the primary goals of this evaluation was to determine what lessons can be learned from the CHIC's experiences to help inform a national model. Results from the Patron survey, the key intermediary focus groups, and the phantom shopper survey offer the following lessons. Health information centers should

- ▶ be centrally located, with easy access to transportation and parking;
- ▶ have extended hours that fit the schedules of general users (this includes night and weekend hours);
- ▶ have adequate and helpful staff, including resource librarians;
- ▶ have health information brochures that patrons can take home with them;
- ▶ have information readily available on national health organizations that consumers can contact for additional condition-specific information;
- ▶ be as **free** as possible;
- ▶ provide a comfortable and well-laid-out environment for patrons to research their information;
- ▶ conduct outreach to other local libraries and health care providers so that they can become a source of referrals;
- ▶ consider linking the center with another resource so that patrons have more than one reason to visit (e.g., the Mutter Museum and the CHIC);
- ▶ work with the central public library to develop effective strategies for collaboration so that duplication of services is minimized and consumers can get current information quickly and easily;
- ▶ ensure that the collection of information is broad, comprehensive, medically accurate, current, and comprehensible to the average consumer; and
- ▶ make as much information about the center as possible available on a **website**.

# FINAL REPORT

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## **Results**

### **Knowledge of the CHIC, Its Mission, and Its Role**

Most participants stated that they were not familiar with the CHIC and they did not believe that their clients were familiar with it. Only a few stated that they were “somewhat familiar” with the CHIC, but they also believed that their clients were not familiar with it.

### **Attractiveness of the CHIC Concept**

Participants seemed to believe that the CHIC concept was very attractive, particularly when compared to other sources of information. These other sources included the Internet, health care agencies, primary physicians, and bookstores. In terms of information from these sources, participants commented on the inadequacy of the information, in terms of either amount, type, and level of information or ease of obtaining the information. Several people talked about how overwhelming medical research can be, particularly when most places that house the most accurate and complete information are impersonal and too technical for the average person. The suggestion, it seemed, was that having a CHIC or similar facility, where information is available, easily accessed, and user friendly, is a much better alternative to all other existing sources of information.

## Barriers to Access of the CHIC

Participants thought there were several factors that might hinder potential users from accessing the CHIC. These included the following:

- ▶ Potential users feel disempowered.
- ▶ Potential users are **afraid** of answers.
- ▶ Hours of operation are inconvenient.
- ▶ Parking or transportation issue.
- ▶ Language barriers and low literacy levels among potential users.

Participants believed that improving parking, expanding the hours of operation, and targeting materials to non-English speaking or low-literate persons would make it easier for potential users to access the CHIC. But when asked if having to pay either an annual membership or borrowing fee would affect their clients' ability to use the CHIC, most said it would make it harder for their clients.

## PHANTOM SHOPPER SURVEY

One of the strong selling points of the CHIC is that it is the only place in Philadelphia where average citizens can research various medical conditions and issues. Moreover, the information that the CHIC houses is purposely geared toward consumers, not medical professionals. Thus, the CHIC asserts that it is the only location well-suited to serve consumers and that it has distinctive competencies such as providing consumer-centered health information and helpful resource staff. The purpose of this component was to determine if in fact the CHIC is positioned as it claims, and to help determine how the CHIC can enhance its services in order to reduce competition **from** other libraries in the metropolitan Philadelphia area.

To accomplish the phantom shopper study, four different types of libraries were visited. These included the CHIC, the main Free Library of Philadelphia, a local branch of the Free Library, and a university library (either the Penn Biomedical library or the Temple Medical School library). It was believed that these libraries covered the broad spectrum of locations where consumers might go to research medical conditions and issues.

Four phantom shoppers were recruited **from** the university **communities** through word of mouth. One shopper was a medical researcher, another shopper was a public health researcher, the third shopper was a graduate student in health, and the final shopper was a senior undergraduate. Each shopper visited each location. The shoppers visited these locations at various times during the day and on various days during November and December 1998. Shoppers were asked to assess the following issues, among others, when "shopping" for information about their disease/medical issue:

- ▶ Accessibility and ease of access: hours, days, evenings, parking, location

- ▶ Helpfulness of staff and role of staff (i.e., librarian model with lots of hands-on help, versus self-guided Museum model.)
- ▶ Amount of information available
- ▶ Complexity of information: simple booklets for general public, more complex material, etc.
- ▶ Currency: Were the collections up to date?
- ▶ Cost to use services, if any
- ▶ Other referrals: Where else are patrons referred for more information if they ask for it? In particular, are they referred to the CHIC?

## Results

### Accessibility and Ease of Access

The shoppers were asked to assess the accessibility and ease of access to the four types of libraries. Of key interest were the hours of operation, availability of parking, and accessibility by public transportation. The CHIC is open to the public Tuesday through Saturday, 10 a.m. until 4 p.m.<sup>1</sup> The Free Library of Philadelphia is open: Monday through Wednesday, 9 a.m. until 9 p.m.; Thursday and Friday 9 a.m. until 6 p.m.; Saturday, 9 a.m. until 5 p.m.; and Sunday, 1 p.m. until 5 p.m. Local branch libraries had hours of operation either a few weekdays **from** 1 p.m. until 9 p.m. or a few weekdays from 10 a.m. until 5 p.m., and then Saturday afternoon hours. Finally, university medical libraries had the most extensive hours of any of the visited locations; in some cases, they were open **24** hours per day.

Location proved to be important to shoppers. Shoppers felt that the CHIC's location was a bit problematic. Parking was either difficult to find or expensive (paid parking lots). However, access to public transportation was available. The Free Library is easily **accessible** by foot, public transportation, or car. The branch libraries were less accessible by public transportation than the main Free Library, but most offered free parking. Finally, the university libraries were all easily accessible by foot or public transportation, and all offered convenient paid parking. To use Temple's library, however, users must either be affiliated with or escorted by a Temple-affiliated person.

### Helpfulness of Staff

All the shoppers commented on the helpfulness of the CHIC librarian staff. The staff were friendly, informative, and "almost too eager" to help. Only a few problems were reported about the CHIC librarians. The shoppers found the reference librarian staff at the Free Library to be very helpful, although some shoppers had difficulty getting the attention of librarian staff. Branch librarians were also found to be very helpful. University medical librarians were viewed as being less helpful.

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<sup>1</sup> It is important to note that during the time of this study, the CHIC suspended Saturday hours. This situation was found out by one shopper who went to the CHIC on a Saturday and was told that they were closed.

Shoppers reported that the library staff was helpful in showing patrons how to use the medical databases but left the shoppers to do all the searching.

### **Amount of Information**

Shoppers agreed that the information housed by the CHIC was far more extensive than that of any other facility (except the Biomedical Library at Penn). This **information** was current, broad reaching, and well organized on the shelves. The public libraries, while having the information organized, had slightly less information, especially at the Branch locations. More importantly, the CHIC had additional information from other sources of consumer health information such as support groups, national research associations, and CDC 24-hour hotlines. In addition, the CHIC had contact information for other national organizations and Federal health agencies so that the shoppers could contact them on their own to request more specific information. All the libraries provided patrons with extensive access to the Internet and online medical databases, such as Medline.

### **Complexity, Readability, and Currentness of Information**

The information collection of the CHIC was viewed by the shoppers as being the most appropriate for general health consumers. The shoppers also found that the CHIC had a good balance between literature aimed at general audiences and more technical information. The information housed by the CHIC was seen as very readable, and it included several pamphlets geared toward low-literacy audiences. In addition, the CHIC has some information in languages other than English.

The Free Library and the branch libraries also had information geared toward general health information consumers, although there was some concern that the holdings were dated (e.g., 1980s). There also was some concern among the shoppers that the public librarians urged consumers to collect information by searching such databases as "Infotrac." Despite this, the information available at the Free Library and its branches was also seen as very readable, but there were few materials aimed at low-literacy or non-English-speaking audiences.

Finally, all the shoppers agreed that the library collections of the university medical libraries were too technical for the general public. The information was the most current, but it was written at a level far too complex for the non-medically trained or non-academically trained individual.

### **Referrals for More Information**

One potential source of patrons for the CHIC is referrals **from** other libraries. To assess the extent to which this occurs, shoppers were told to ask librarians from non-CHIC libraries for referrals to other institutions that might have more information on the diseases they were researching.

When shoppers at the Free Library asked for suggestions about where they could **find** additional information, the shoppers were always referred to the Biomedical Library at Penn. A few shoppers were referred to the College of Physicians, but most felt the referral was to the College and not to the CHIC. Shoppers at branch libraries were most **often** referred to the main Free Library branch

and the Penn Biomedical library. No branch library referred shoppers to the CHIC. Finally, when shoppers at the medical libraries asked for referrals, most shoppers were referred to the main Free Library of Philadelphia.

## **CONCLUSIONS AND RECOMMENDATIONS FOR THE CHIC**

### **Marketing, Promotion, and Visibility**

#### **Awareness of the CHIC**

Most Patrons did not know about the CHIC prior to visiting the College. Only a few reported that they had been to the CHIC more than once. Key intermediaries also reported being unfamiliar with the CHIC and did not believe that their clients were familiar with it.

- ▶ The CHIC must do more to increase its visibility in the community. This can be accomplished primarily by developing relationships with other organizations that can serve as referral agents and by successful advertising and marketing of the CHIC's resources. For example, physicians, libraries, community-based organizations, the general media, and gyms and fitness centers can serve as referral agents.

#### **Referral Agents/Agencies**

Key intermediaries believed that health care providers, libraries, and the Internet would serve as perfect vehicles for marketing the CHIC to potential patrons. In fact, the Patron survey revealed that Patrons typically go to their health care provider first for health information, a fact that was supported by the key intermediaries' reports about their clients.

- ▶ The CHIC should work with local health providers to provide patients easy access to consumer health information. The CHIC should improve its marketing effort within its own membership.

Key intermediaries thought that libraries would be a significant source of information for their clients. This may be true, but it cannot be expected that libraries serve as referral agents for the CHIC. In fact, the shoppers in the phantom shopper study were rarely referred to the CHIC when they asked for referrals to places where they could get more health information.

- ▶ If the CHIC wishes to increase traffic resulting from referrals, it will have to expand its marketing, especially to the branch and main Free Libraries.

## Resources

### Materials

Patrons reported using pamphlets and books more than any other resource at the CHIC. According to the phantom shopper survey, the CHIC was the only location visited by shoppers that provided patrons with brochures about health issues published by the government and/or the medical community. Perhaps the single most important and distinguishing aspect of the CHIC is its distribution of medical brochures and leaflets. This was, in fact, seen by the shoppers as a great benefit.

- ▶ It is, therefore, very important for the CHIC to continue to acquire and distribute current reference books as well as pamphlets for patrons to take with them as they leave the CHIC.

The majority of Patrons surveyed were 25 years old or older, and low or middle income. Not surprisingly, they all preferred materials in English. However, key intermediaries seemed to agree that offering materials in different languages as well as ensuring that publications are understandable for the low-literate would make it easier for their clients to use the CHIC. According to the phantom shopper survey results, the CHIC already houses materials for the low-literate and non-English-speaking audiences.

- ▶ To capture a broader base of patrons, the CHIC should continue to include in its collections materials for the low-literate and non-English-speaking audiences. These efforts to accommodate these audiences should be maintained to the extent that it is required by the educational and national/ethnic diversity of Philadelphia residents.

### Staff and Atmosphere

Key intermediaries and phantom shoppers talked about the **overwhelming** nature of conducting medical/health research, particularly when most places that house the most accurate and complete information are impersonal and too technical for the average person. Their suggestion was that having an intimate setting with accessible, helpful staff and **user-friendly**, consumer-oriented materials would be greatly beneficial to their clients.

- ▶ It is likely that the more satisfied patrons are with their experience at the CHIC, the more likely they are to tell others about the CHIC. The CHIC should continue to emphasize staff quality, layout, and user friendliness to ensure that all of its patrons are able to find information easily and accurately about the topic(s) they are researching.

## **Accessibility**

### **Hours of Operation**

Patrons' responses indicated a definite interest in seeing the CHIC offer Saturday hours and weekday evening hours. Key intermediaries tended to believe that current hours may serve as a barrier for some of their clients who work during those hours. Shoppers in the phantom shopper study also found the limited weekday hours to be a problem and desired to have the CHIC hours extended to include evening hours. The Free Library of Philadelphia was seen by the phantom shoppers as a better alternative to the CHIC, in this regard, because of its convenient extended hours.

- ▶ The CHIC should consider extending its hours to include weekends and weekday evenings. This will enable the public to come to the center during non-working hours, which will be particularly beneficial to those with long travel times or other transportation barriers.

### **Cost**

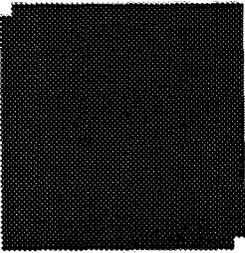
The income distribution of the Patrons surveyed may explain why many were willing to pay for services at the CHIC, especially for borrowing privileges. A smaller yet significant number of Patrons stated that payment for entrance or membership would make it more difficult to use the CHIC. Key intermediaries agreed that payment for any service would serve as a barrier for their clients. With regard to this issue, the phantom shoppers saw the Free Library as being more advantageous than the CHIC because the Free Library is truly **free** for use of all library services except photocopying.

- ▶ The CHIC should continue to be a free library and research facility for its patrons, and only charge for borrowing privileges if necessary.

## IMPLICATIONS FOR NATIONAL MODELS

One of the primary goals of this evaluation was to determine what lessons can be learned from the CHIC's experiences to help inform a national model. Results from the Patron survey, the key intermediary focus groups, and the phantom shopper survey offer the following lessons. Health information centers should

- ▶ be centrally located, with easy access to transportation and parking;
- ▶ have extended hours that fit the schedules of general users (this includes night and weekend hours);
- ▶ have adequate and helpful staff, including resource librarians;
- ▶ have health information brochures that patrons can take home with them;
- ▶ have information readily available on national health organizations that consumers can contact for additional condition-specific information;
- ▶ be as free as possible;
- ▶ provide a comfortable and well-laid-out environment for patrons to research their information;
- ▶ conduct outreach to other local libraries and health care providers so that they can become a source of referrals;
- ▶ consider linking the center with another resource so that patrons have more than one reason to visit (e.g., the Mutter Museum and the CHIC);
- ▶ work with the central public library to develop effective strategies for collaboration so that duplication of services is minimized and consumers can get current information quickly and easily;
- ▶ ensure that the collection of information is broad, comprehensive, medically accurate, current, and comprehensible to the average consumer; and
- ▶ make as much information about the center as possible available on a **website**.



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# **FINAL REPORT**

## INTRODUCTION

A significant part of the National Center for Chronic Disease Prevention and Health Promotion's (NCCDPHP) mission is to promote healthy personal behavior and to accomplish goals in partnership with health and education agencies, major voluntary associations, the private sector, and other Federal agencies. There are many channels through which individuals can obtain health information such as the Internet and Federal health information clearinghouses, but there is an urgent need to identify other ways to work in partnership with alternate groups to facilitate the dissemination of the effective and accurate health communication products produced by CDC and its partners.

Community health information centers have the potential to serve this purpose. Community health information centers provide individuals in their communities direct access to accurate health information as well as provide the added value of consultation with center staff. Additionally, community health information centers have the ability to establish networks and collaborative arrangements with regional organizations, corporations, public and medical libraries, and voluntary agencies that facilitate the dissemination of accurate health communication products.

Because of this potential, CDC's NCCDPHP has become interested in understanding the effectiveness of community health information centers in meeting the health information needs of the general public. One such case is the College of Physicians of Philadelphia. In 1994, they conducted a preliminary feasibility study, "Survey of Librarians and Physicians for the Development of a Consumer Health Information Center." The College used the results of the study to guide the creation of the C. Everett Koop Community Health Information Center (CHIC) in 1995. The CHIC was developed by the College to provide individuals with a comprehensive resource for **consumer-**based health information.

In 1998, CDC contracted with Macro International Inc. to conduct an evaluation of the CHIC. The purpose of this project was to evaluate the effectiveness of the CHIC in serving as a national physician-based model for community health information centers by assessing (1) the effectiveness of the CHIC products and services from the users' perspective, (2) the use of the products and services as well as any barriers to use, and (3) the effectiveness of outreach with nonprofit organizations, corporations, libraries, government agencies, and voluntary health agencies. To accomplish these evaluations, Macro employed various data collection components such as an **on-**site survey of patrons, focus groups with people representing key intermediary organizations, phantom shopper surveys, and interviews with College staff and board members.

Results presented in this report reflect the three formal components of the evaluation — the Patron survey, the key intermediary focus groups, and the phantom shopper survey.

## THE PATRON SURVEY

In order to ensure that users of the CHIC (Patrons) received the highest quality of services, **from** its inception the CHIC asked Patrons to complete a short survey evaluating their experience using the facility. Results from these surveys were used by the College administration to fine-tune the level and types of services provided to the Patrons.

Under this evaluation, the Patron survey was strengthened so as to provide the College and CDC with statistically valid and reliable results from which to make programmatic decisions and changes.

### Methodology

Prior to the commencement of this evaluation, the CHIC had already undertaken the task of conducting a survey of its users. Consequently, Macro staff worked with the CHIC and CDC to strengthen and fine-tune the survey instrument (see Attachment A for the instrument).

The survey instrument addressed four main areas:

1. The Patron's familiarity with or awareness of the CHIC
2. The type of information the patron was looking
3. How the CHIC can improve
4. Basic demographic information about the Patron

The survey instrument was then administered to all Patrons who used the CHIC. "Patrons" were distinguished by the CHIC staff **from** "Browsers" by the amount and type of activity the individual undertook when entering the CHIC. "Patrons" were defined by CHIC librarian staff as any person who was seen as doing more than walking through the collection. More specifically, if a person was seen reading or doing research, s/he was asked to complete the survey instrument. "Browsers" were not asked to complete the survey.

The survey instrument was displayed in a prominent place within the CHIC, along with a placard describing the purpose of the survey. CHIC staff then approached the individuals identified as "Patrons" toward the end of their visit to the CHIC and asked them to complete the survey instrument and deposit it in a survey collection box.

Results presented below are from surveys collected **from** April 1 through December 31, 1998. In total, 267 individuals completed the survey instrument.

### Results

Results will be presented below in order of the questions on the survey instrument.

## Was Respondent Previously Aware of the CHIC?

To help assess the Patrons' previous awareness of the CHIC, respondents were asked to indicate if they had previously visited the CHIC, the College, or the Mutter Museum. Thirty-three percent (33%) of Patrons had visited the Museum in the past. Just over one third (35%) of Patrons had visited the College before, and 24% of Patrons also had obtained information from the College's library at some point, either that day or in the past. Patrons were also asked if they had visited the Mutter Museum on the same day that they had visited the CHIC. The majority of CHIC Patrons (58%) used the CHIC on the same day that they visited the Museum. In addition, 14% of Patrons were repeat clients of the CHIC.

Respondents were then asked about how they became aware of the CHIC. Table 1 presents these results. The vast majority (39%) of Patrons became aware of the CHIC because of a Mutter Museum visit. During **Museum** tours, individuals are given an introduction to the College and its facilities, including the CHIC, and there is literature available at the Museum directing individuals to the CHIC. Approximately half as many became aware of the CHIC because of **friends** (21%) or fi-om a library referral (20%). The remaining Patrons heard about the CHIC **from** a brochure, their health care provider, a newspaper advertisement, a self-help or advocacy group, or the television.

**Table 1: How Patrons Heard About the CHIC**

<b>Respondent could check all that apply</b>	<b>Percent</b>
Heard from: Museum visit	39
Heard fi-om: Friend	21
Heard from: Library	20
Heard <b>from</b> : Brochure	11
Heard <b>from</b> : Provider	5
Heard from: Newspaper	3
Heard from: Self-help/advocacy group	3
Heard <b>from</b> : Television	2
Heard <b>from</b> : Radio	0

Those Patrons who became aware of the CHIC because of a brochure were then asked where they received the brochure. Of these 29 individuals, 28% received the brochure from their workplace and 28% **from** a library. The remaining Patrons received the brochure **from** their friends (10%), place of residence (6%), hospital (7%), or a physician (3%).

## Mode of Transportation

Patrons were asked how they got to the CHIC that day. The majority of respondents arrived at the CHIC by car (38%). Other significant forms of transportation included “by foot” (28%) and public transportation (23%). Far fewer people arrived at the CHIC by bicycle (5%) or other modes of transportation, such as “organized trip” (3%).

## Where Do Patrons Go for Information and What Were They Looking For?

Patrons were asked a series of four questions to determine where they typically go for health information, the type of information for which they were looking, the person for whom they needed the information, and the CHIC resources they used.

Patrons were given a list of nine possible sources of health information and asked to indicate on a scale of 1 “Rarely” to 3 “Most of the time” whether they go to any of the sources to find health information. Table 2 presents the average values for Patron responses. From this table, we see that the majority of Patrons turned to their health care providers for health information (value of 2.68 out of 3). In addition, Patrons asked their family members for health advice (1.99) and utilized the Internet to gain health information (1.96). Libraries were also a source of health information for Patrons, with the public library being the primary library used, followed by university and hospital libraries. Finally, respondents rarely contacted the health department or the CHIC for health information.

**Table 2: Where Patrons Go for Health Information**

	<b>N</b>	<b>Mean*</b>
Get information from: Provider	240	2.68
Get information from: Family/friends	194	1.99
Get information from: Internet	179	1.96
Get information from: Other	17	1.88
Get information from: Public library	184	1.77
Get information from: University library	160	1.66
Get information from: Hospital library	160	1.48
Get information from: Health department	152	1.43
Get information from: CHIC	151	1.31

\* Note: Respondents were able to choose **from** a scale of 1 to 3, representing the range from “rarely” (1) to “most of the time” (3).

Patrons were also asked to identify the types of health information they were researching. Patrons responded that they were looking for disease/condition information (52%), wellness information (26%), other information (21%), information on alternative medicine (10%), physician information (7%), and information on medications (5%). When aggregated, 58% of Patrons came into the CHIC to research just one issue, 14% were collecting information on two issues, and 6% of Patrons collected information on three to five types of information.

Patrons were next asked to indicate the person for whom they were collecting information. The majority were obtaining the information for themselves (56%). Others were obtaining information for family members (21%), other reasons (usually related to school – 19%), and friends (8%). Over 80% of Patrons information for only one person, either themselves, friends, or family, but not a combination of categories of people.

### Resources Utilized During the Visit

Patrons were asked what CHIC resources they utilized during their current visit. They were asked to check as many resources as applicable from a list of seven possible categories. Table 3 presents results for the most utilized CHIC resources. The CHIC pamphlet collection and its collection of books were each used by 36% of respondents. In addition, Patrons utilized librarian services (28%) and the computers (25%). Fewer Patrons used the CHIC’s magazine collection (16%), medical journals (10%), or video collection (4%). The vast majority of Patrons (51%) utilized only one resource, 29% utilized two resources, and the remaining 20% utilized three or more resources.

**Table 3: CHIC Resources Utilized**

	N*	Percent
Used: Pamphlets	96	36
Used: Books	96	36
Used: Librarian	75	28
Used: Computer:	68	25
Used: Magazines	44	16
Used: Journal	28	10
Used: Videos	10	4

\*Base N = 276

If Patrons indicated that they had used the CHIC's computer resources, they were then asked to indicate which resources were used. Of the 68 Patrons who used the computer resources, 40% used the CHIC's access to the Health Reference Center Database, 28% searched Medline, 24% used the computers for access to the Internet, 16% used the Online Library Catalogue, and 7% used various CD-ROM programs.

### How Can the CHIC Improve?

Patrons were asked a series of four questions to assess their opinion about how the CHIC can better meet their needs. This series included questions about language preference, hours of access, and cost for services. When asked for a language preference for materials, the overwhelming number of respondents preferred materials in English (93%), 2% of Patrons wished for materials in Spanish, and 2% of respondents wanted materials in other languages.

Patrons were then asked if they would be more likely to use the CHIC if it were open weekday evenings and Saturdays (Table 4). Of the 206 Patrons who answered this question, 45% of Patrons indicated that they would be more likely to use the CHIC if it were open weekday evenings. Twenty-four percent said they would not be more likely to use the CHIC if open weekday evenings and 31% of respondents said they were unsure if it would make a difference to them. Significantly more Patrons indicated that Saturday hours would make them more likely to use the CHIC (68%), while 10% of Patrons indicated that Saturday hours would not make them more likely to use the CHIC, and 22% of Patrons were unsure if Saturday hours would matter.

Next, Patrons were asked if they would be willing to pay to use the CHIC. Table 4 presents Patron responses. Few Patrons are willing to pay an entrance fee (22%) or a membership fee (27%) to use the CHIC; however, Patrons are more likely to be willing to pay a fee for borrowing privileges. Conversely, 56% of Patrons explicitly said they would not be willing to pay an entrance fee or a membership fee (43%) and fewer Patrons (26%) were against a borrowing charge. However, between 20% and 30% of Patrons were unsure if fees (under any circumstances) would change their willingness to use the CHIC.

**Table 4: Respondents' Likelihood to Use Chic If: (N = 206)\***

	Yes	No	Not Sure
Open evenings	45%	24%	31%
Open Saturday	68%	10%	22%
Willing to pay: Entrance fee	22%	56%	22%
Willing to pay: Borrowing fee	54%	26%	20%
Willing to pay: Membership fee	27%	43%	30%

\* Note: 61 Patrons did not answer this question.

**Experience with the CHIC**

The survey also asked Patrons to comment on their experience using the CHIC by rating a series of 7 statements on a 4-point scale of “strongly disagree” (1) to “strongly agree” (4). Table 5 presents the average values for Patron responses. Patrons felt that having a staff member available to them was very important. Specifically, 60% of Patrons “strongly agreed” and 35% “agreed” that having a staffperson was useful to them. Similarly, the vast majority of Patrons felt that the CHIC is a good resource for consumers. Four percent of Patrons “disagreed” or “strongly disagreed” with this statement. It is perhaps because Patrons felt that the CHIC was a good resource that they are also likely to tell others about the CHIC (95% “strongly agreed” or “agreed”). Five percent of Patrons indicated that they would not tell others about the CHIC. The CHIC was also seen as a place Patrons to which would come again to do medical research. In fact, 54% “strongly agreed” and 42% “agreed” that they would use the CHIC again. Finally, Patrons felt that the information was helpful and that it was easy to understand. Perhaps the only area in which Patrons had a slight concern with the CHIC was related to finding all the information they needed. Fourteen percent of Patrons felt that they did not find all the information they needed.

**Table 5: Patron Experience with CHIC**

	<b>N</b>	<b>Mean*</b>
Having staff available was useful	228	3.50
CHIC is a good resource	235	3.49
I will tell others about CHIC	235	3.47
I would use the CHIC again	233	<b>3.45</b>
Information was helpful	236	3.34
Information was easy to understand	230	3.34
Found all information I needed	225	3.20

\* Note: Respondents were able to choose from a scale of 1 to 4, representing the range **from** “strongly disagree” to “strongly agree.”

**Patron Demographics**

Patrons were asked five demographic questions: age, race, income, home ZIP code, and whether they work within walking distance of the CHIC. Table 6 presents the age breakdown of Patrons. Few Patrons were under the age of 18 (4%) or over the age of 65 (9%). Slightly more Patrons were between the ages of 19 and 24 (16%). The majority of CHIC Patrons were between the ages of 25 and 44 (**43%**), and a large number of Patrons were between the ages of 45 and 64 (28%).

**Table 6: Patron Age (N = 257)\***

<b>Age</b>	<b>Percent</b>
Under 18	4%
19-24	16%
<b>25 - 44</b>	<b>43%</b>
<b>45 - 64</b>	<b>28%</b>
65 and over	9%

\* Note: 10 Patrons did not answer this question.

As is evidenced in Table 7, most CHIC Patrons were white (78%), while the remaining respondents consisted primarily of African Americans (17%).

**Table 7: Patron Race (N = 245)\***

<b>Race</b>	<b>Percent</b>
White	78
Black	17
Hispanic	2
Asian	2
Native American	1

\* Note: 22 respondents did not answer this question.

The CHIC Patrons represented a broad spectrum of household income. Twenty-three percent of respondents reported an income of under \$20,000; 27% reported an income of between \$20,000 and 40,000; 21% reported an income of between \$40,000 and \$60,000; and the remaining 30% of respondents reported an income of over \$60,000 (Table 8). Looking at cross-tabulation of income and race (Table 9), it is evident that similar income distributions of Patrons exist within the various racial strata. This suggests that, for the most part, the Patrons of various racial backgrounds do not vary by income.

**Table 8: Patron Household Income (N = 233)\***

Household Income	Percent
Under \$20k	23
\$20k - \$40k	27
\$40k - \$60k	21
\$60k - \$75k	9
Over \$75k	21

\* Note: 34 Patrons did not answer this question.

**Table 9: Race X Household Income Cross-tabulation % Within Race**

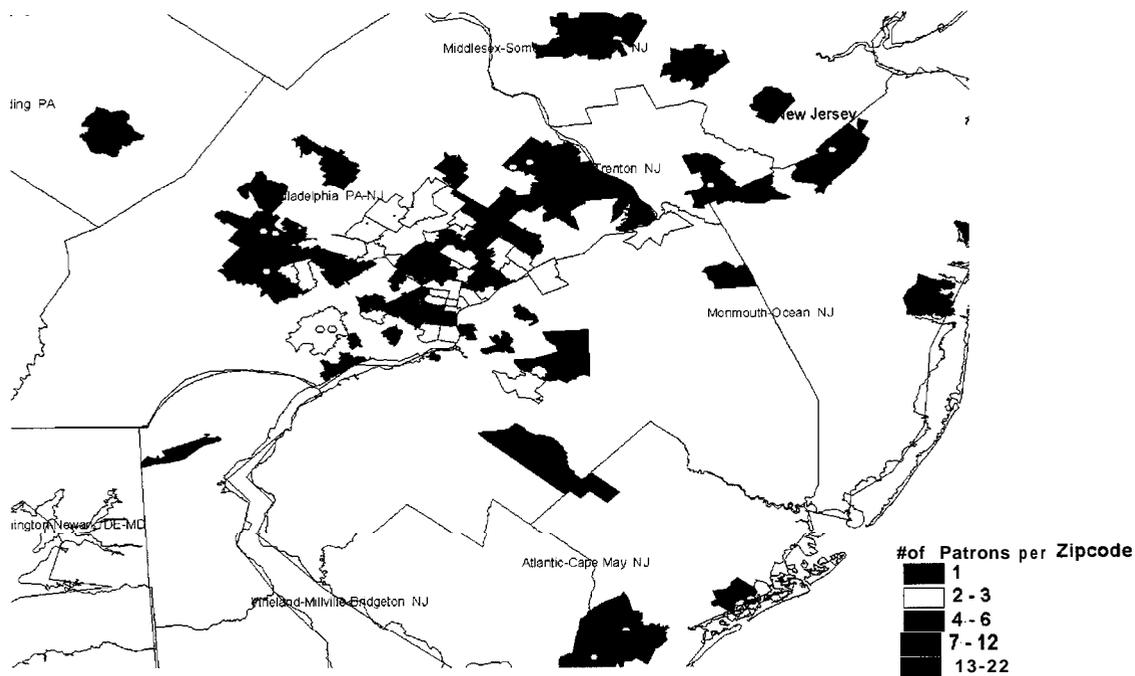
Race	Household Income					Total
	Under \$20k	\$20k - \$40k	\$40k - \$60k	\$60k - \$75k	Over \$75k	
White (N = 190)	21.6%	25.1%	19.9%	9.9%	23.4%	100.0 %
Black (N = 41)	24.3%	37.8%	24.3%	5.4%	8.1%	100.0 %
Hispanic (N = 5)	40.0%	20.0%	20.0%		20.0%	100.0 %
Asian (N = 6)	20.0%	20.0%	40.0%		20.0%	100.0 %
Native American (N = 3)	100.0%					100.0 %
Total (N = 245)*	23.2%	26.8%	20.9%	8.6%	20.5%	100.0 %

Note: 22 Patrons did not answer the question about race, and 34 did not answer the question about income.

Figure 1 presents a map, by ZIP code, capturing the home ZIP codes for CHIC Patrons. As is evident, the CHIC has attracted a broad audience for its services. The CHIC had Patrons visiting from as far away as Alexandria, Virginia, and as close as a few blocks away. However, the vast majority of CHIC Patrons reside within the greater Philadelphia region, including suburban New Jersey and the Delaware Valley.

**Figure 1**

**Home Location of CHIC Patrons - By Zipcode**



**Summary**

A small number of Patrons surveyed for this study were repeat clients of the CHIC, although a few more had visited the College or Museum before. More than half of CHIC Patrons reported using the CHIC on the same day they visited the Museum. In fact, the majority of them became aware of the CHIC because of a Museum visit, during which they were introduced to the College and the CHIC. A smaller but substantial number of Patrons became aware of the CHIC from friends and library referrals. Health care providers and media were reported by some Patrons as referral sources, but were not significant sources of information about the CHIC.

The majority of respondents reported turning to their health care providers for health information, A considerable number also sought advice from their family members, used the Internet, or visited various libraries. Not surprisingly (since many of the Patrons surveyed were first-time visitors to the CHIC), most respondents stated that they rarely contacted CHIC for health information.

Patrons sought health information on a variety of issues, primarily disease/condition information and, to a lesser but significant extent, **wellness** information, and reported obtaining the information primarily for themselves or family members. To obtain this information at the CHIC, respondents reported using pamphlets and books more than any other resource, although a considerable number also used librarians and computers. Magazines, journals, and videos were used by Patrons to a lesser degree.

Although transportation could be a problem for potential patrons, it did not seem to be a problem for the Patrons surveyed. They reported using a variety of modes of transportation to and **from** the CHIC, including walking, taking public transportation, or driving their own cars. In terms of the hours of operation, many Patrons suggested that extending hours to include Saturday and weekday evening hours, especially the former, would make it easier to use the CHIC. In terms of fees, most Patrons stated that they would not be willing to pay an entrance fee or a membership fee, but would be willing to pay for borrowing privileges. Even though most Patrons were unwilling to pay fees for entrance or membership, the Patrons surveyed were slightly more willing to pay a membership fee than an entrance fee.

In terms of the demographics of the Patrons surveyed, the majority were 25 years old or older, white, and low or middle income. Non-white Patrons, however, did not differ drastically from whites in their overall income distributions.

## KEY INTERMEDIARY FOCUS GROUPS

The purpose of this portion of the evaluation was to (1) assess the health information needs of individuals who represent key audiences as defined by the CHIC (e.g., Arthritis Foundation, American Cancer Society), and (2) to act as a semi-marketing tool for the CHIC. It was felt that during the recruitment stage for the focus groups, the CHIC would have to contact additional organizations, thereby increasing these organizations' awareness of the CHIC.

### Methodology

Focus group participants were recruited from organizations regarded as key constituencies that the CHIC viewed as being a potential source of referrals (see Appendix B for a list of participants). Among others, these included

- ▶ elementary/middle/high schools,
- ▶ public/hospital/university/medical school libraries,
- ▶ social workers/case managers,
- ▶ home health workers,
- ▶ geriatric workers,
- ▶ corporate **wellness** programs, and
- ▶ local businesses.

The discussions were designed to elicit information about

- ▶ knowledge of the CHIC, its mission, and its role;
- ▶ attractiveness of the CHIC concept to constituency;
- ▶ barriers to access of the CHIC by constituency;
- ▶ other sources of health information;
- ▶ potential areas for collaboration; and
- ▶ best channels for promoting the CHIC with constituency.

Participants were also given a short OMB-approved survey to ascertain

- ▶ their knowledge of the CHIC,
- ▶ the types of information needed by clients and sources of that information,
- ▶ factors that might influence ability to use the CHIC, and
- ▶ marketing suggestions.

Results presented below are from three focus groups conducted March 15-16, 1999, with 18 participants who were considered to be key intermediaries. Prior to conducting the focus groups, participants were provided with a 30-minute introduction to the CHIC and allowed to browse through the CHIC to help familiarize themselves with what the CHIC can offer.

## **Results**

Results will be presented below by topic area (listed above).

### **Knowledge of the CHIC, Its Mission, and Its Role**

Most participants stated that they were not familiar with the CHIC and they did not believe that their clients were familiar with it. Only a few stated that they were “somewhat familiar” with the CHIC, but they also believed that their clients were not familiar with it.

### **Attractiveness of the CHIC Concept**

Participants seemed to believe that the CHIC concept was very attractive, particularly when compared to other sources of information. These other sources included the Internet, health care agencies, primary physicians, and bookstores. In terms of information from these sources, participants commented on the inadequacy of the information, in terms of either amount, type, and level of information or ease of obtaining the information. Several people talked about how overwhelming medical research can be, particularly when most places that house the most accurate and complete information are impersonal and too technical for the average person. The suggestion, it seemed, was that having a CHIC or similar facility, where information is available, easily accessed, and user **friendly**, is a much better alternative to all other existing sources of information.

## **Barriers to Access of the CHIC**

Participants thought there were several factors that might hinder potential users **from** accessing the CHIC. These included the following:

- ▶ Potential users feel disempowered.
- ▶ Potential users are afraid of answers.
- ▶ Hours of operation are inconvenient.
- ▶ Parking or transportation issue.
- ▶ Language barriers and low literacy levels among potential users.

Participants believed that improving parking, expanding the hours of operation, and targeting materials to non-English speaking or low-literate persons would make it easier for potential users to access the CHIC. But when asked if having to pay either an annual membership or borrowing fee would affect their clients' ability to use the CHIC, most said it would make it harder for their clients.

## **Other Sources of Health Information**

Other sources of health information mentioned by participants were

- ▶ health care agencies,
- ▶ physicians,
- ▶ the Internet,
- ▶ television, and
- ▶ libraries.

## **Potential Areas for Collaboration**

- ▶ Local health care providers and medical community
- ▶ Registry of motor vehicles
- ▶ Department of Health
- ▶ Colleges and universities
- ▶ Other libraries

## **Best Channels for Promoting the CHIC**

- ▶ Brochures in medical offices
- ▶ Advertisements in health or health agency newsletters and community newspapers

One other suggestion is that the CHIC market by medical concern and rotate concerns.

## Summary

Results of the key intermediary focus groups lend support to some of the findings of the Patron survey. In addition, the key intermediaries revealed some barriers to using the CHIC that would not have been found by Patrons nor Browsers. Furthermore, the key intermediary focus groups were able to elicit ideas about how to market the CHIC to potential Patrons as well as to other individuals or agencies that might serve as referral agencies or intermediaries.

Although most intermediaries thought the CHIC concept was attractive, they were not familiar with the CHIC and did not expect that their clients were familiar with the CHIC. The most important reason given for finding the CHIC concept attractive is the fact that it is rare to find a source of information that is designed for the average health consumer. In the absence of such a place, the key intermediaries believed that their clients sought health information from health care agencies, physicians, libraries, and the media. They felt that these represented potential collaborators for the CHIC to improve the marketing and reach of their offerings.

The key intermediaries believed that there were several factors that might hinder their clients from using the CHIC, including cost of services, hours of operation, and transportation problems. However, in general, it seemed that the primary hindrance at this point (**from** the perspective of the key intermediaries) is the lack of awareness of the CHIC among the lay, health, and medical communities.

## PHANTOM SHOPPER SURVEY

This portion of the report specifically details the phantom shopper survey of the CHIC and three other libraries in Philadelphia. One of the strong selling points of the CHIC **is that** it is the only place in Philadelphia where average citizens can research various medical conditions and issues. Moreover, the information that the CHIC houses is purposely geared toward consumers, not medical professionals. Thus, the CHIC asserts that it is the only location well-suited to serve consumers and that it has distinctive competencies such as providing consumer-centered health information and helpful resource staff. The purpose of this study was to determine if in fact the CHIC is positioned as it claims, and to help determine how the CHIC can enhance its services in order to reduce competition from other libraries in the metropolitan Philadelphia area.

## Methodology

To accomplish the phantom shopper study, four different types of libraries were visited. These included the CHIC, the main Free Library of Philadelphia, a local branch of the Free Library, and a university library (either the Penn Biomedical library or the Temple Medical School library). It was believed that these libraries covered the broad spectrum of locations where consumers might go to research medical conditions and issues.

Four phantom shoppers were recruited from the university communities through word-of-mouth. One shopper was a medical researcher, another shopper was a public health researcher, the third shopper was a graduate student in health, and the final shopper was a senior undergraduate. Each shopper visited each location.

The shoppers visited these locations at various times during the day and on various days during November and December 1998. The shoppers went to the libraries to research the following diseases and situations:

- ▶ Grandmother with Alzheimer's
- ▶ Person with Chronic Fatigue Syndrome
- ▶ Father with colorectal cancer
- ▶ Person concerned about breast cancer, e.g., mother and sister has/had it

Shoppers were asked to assess the following issues when "shopping" for information about their disease/medical issue:

- ▶ Accessibility and ease of access: hours, days, evenings, parking, location
- ▶ Helpfulness of staff and role of staff (i.e., librarian model with lots of hands-on help, versus self-guided Museum model.)
- ▶ Amount of information available
- ▶ Format of information (written versus electronic versus audio and video tape)
- ▶ Complexity of information: simple booklets for general public, more complex material, etc.
- ▶ Readability level: Was the shopper able to understand the literature, or was it only scientific?
- ▶ Was information available in languages other than English? --
- ▶ Currency: Were the collections up to date?
- ▶ Does the library have information on medications?
- ▶ Does the library have information on surgery and treatment options (where appropriate)?
- ▶ Does the information include references to alternative/complimentary medicine?
- ▶ Cost to use services, if any
  - If free, is there also a paid option where the library will do more for someone if that person pays for the service?
- ▶ Other referrals: Where else are patrons referred for more information if they ask for it? In particular, are they referred to the CHIC?

## Results

Results will be presented **below** by topic area. Additional summaries for each of the four library types is presented in Appendix B.

### Accessibility and Ease of Access

The shoppers were asked to assess the accessibility and ease of access to the four types of libraries. Of key interest were the hours of operation, availability of parking, and accessibility by public transportation.

The CHIC is open to the public Tuesday through Saturday, 10 a.m. until 4 **p.m.**<sup>1</sup> The Free Library of Philadelphia is open: Monday through Wednesday, 9 a.m. until 9 p.m.; Thursday and Friday 9 a.m. until 6 p.m.; Saturday, 9 a.m. until 5 p.m.; and Sunday, 1 p.m. until 5 p.m. Local branch libraries had hours of operation either a few weekdays from 1 p.m. until 9 p.m. or a few weekdays **from** 10 a.m. until 5 p.m., and then Saturday afternoon hours. Finally, university medical libraries had the most extensive hours of any of the visited locations; in some cases, they were open 24 hours per day.

Location proved to be important to shoppers. Shoppers felt that the CHIC's location was a bit problematic. Parking was either difficult to find or expensive (paid parking lots). However, access to public transportation was available. The Free Library is easily accessible by foot, public transportation, or car. The branch libraries were less accessible by public transportation than the main Free Library, but most offered free parking. Finally, the university libraries were all easily accessible by foot or public transportation, and all offered convenient paid parking. To use Temple's library, however, users must either be affiliated with or escorted by a Temple-affiliated person.

### Helpfulness of Staff

All the shoppers commented on the helpfulness of the CHIC librarian staff. The staff were friendly, informative, and "almost too eager" to help. Only a few problems were reported about the CHIC librarians. One shopper indicated that the librarian **left** the CHIC for half an hour and the shopper was unable to access CD-ROM technology during that time. Also, the librarians were unable to solve a computer problem; thus, one shopper was unable to print some information.

The shoppers found the reference librarian staff at the Free Library to be very helpful, although some shoppers had difficulty getting the attention of librarian staff. Branch librarians were also found to be very helpful. Most shoppers commented on the willingness **of branch** staff to help. In fact, in one case, the librarian sat with the shopper and searched for information about the disease. During that

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<sup>1</sup> It is important to note that during the time of this study, the CHIC suspended Saturday hours. This situation was found out by one shopper who went to the CHIC on a Saturday and was told that **they were** closed.

time, the shopper did not feel that the librarian was bothered by having to help; instead, the librarian was very sorry that s/he could not help the shopper much more.

University medical librarians **were** viewed as being less helpful. Shoppers reported that the library staff was helpful in showing patrons how to use the medical databases but **left** the shoppers to do all the searching. In addition, librarians at the medical libraries were less willing to “hand-hold” the patrons. Thus, some level of sophistication is required by patrons in order to fully benefit **from** the resources at university medical libraries.

## **Amount of Information**

Shoppers agreed that the information housed by the CHIC was far more extensive than that of any other facility (except the Biomedical Library at Penn). This information was current, broad reaching, and well organized on the shelves. More importantly, the CHIC had additional information **from** other sources of consumer health information such as support groups, national research associations, and CDC 24-hour hotlines. In addition, the CHIC had contact information for other national organizations and Federal health agencies so that the shoppers could contact them on their own to request more specific information. The CHIC also provided patrons with extensive access to the Internet and online medical databases, such as Medline.

The information that shoppers found at the Free Library was extensive, although one shopper was concerned that it was outdated. Most of the medical information he found in printed form was from the early 1980s. The library did not have brochures for the shoppers to take, but had numerous books per topic. Shoppers reported that the library had a reference area with “a wall of shelved books dedicated to health.” In addition, the library had an entire section dedicated to alternative medicine, with over 30 books ranging in topics from American homeopathy to Chinese herbal medicine.

The Free Library also provided shoppers with extensive access to the Internet and medical search engines, and each shopper reported using these tools to gain current information. In fact, this library was the only location of the ones visited by phantom shoppers that allows patrons to print an unlimited number of pages from their computer searches for free.

Most of the information available at the local branch libraries came from online sources, such as Infotrac. The online databases had full-text articles that covered all the information for the various diseases. However, most of these articles were found in popular magazines such as *Self*, *Mademoiselle*, and *The Ladies Home Journal*. Not all of the articles were available online. Most of the references for journal articles found in the database could be retrieved at the main library branch at 19<sup>th</sup> and Vine Streets. The regional branches housed mostly popular magazines.

The medical libraries had the most extensive collection of information compared to any of the other locations. However, this amount of information also had its drawbacks. Shoppers commented on how overwhelmed they felt when trying to research their diseases. In short, these libraries house abundant current information, but it is too much for the average person.

## **Format of the Information**

The CHIC provided shoppers with the broadest collection of materials. Not only did they provide shoppers with access to books, journals, magazines, and the Internet, but they also provided shoppers with access to CD-ROM, video tapes, and, more importantly, brochures from various public health organizations, including health newsletters from institutions such as Johns Hopkins and Harvard.

The Free Library and branch libraries also provided shoppers with access to books, journals, magazines, and the Internet, but they provided less access to videotapes and did not provide access to health brochures. Similarly, the medical libraries provided shoppers with access to books, journals, and the Internet, but they did not provide access to magazines, newsletters, nor videotapes.

## **Complexity, Readability, and Currentness of Information**

The information collection of the CHIC was viewed by the shoppers as being the most appropriate for general health consumers. The shoppers also found that the CHIC had a good balance between literature aimed at general audiences and more technical information. The information housed by the CHIC was seen as very readable, and it included several pamphlets geared toward low-literacy audiences. In addition, the CHIC has some information in languages other than English.

The Free Library and the branch libraries also had information geared toward general health information consumers, although there was some concern that the holdings were dated (e.g., 1980s). There also was some concern among the shoppers that the public librarians urged consumers to collect information by searching such databases as "Infotrac." While the databases housed a wealth of information, some of it might be too complex for the average reader. Despite this, the information available at the Free Library and its branches was also seen as very readable, but there were few materials aimed at low-literacy or non-English-speaking audiences.

Finally, all the shoppers agreed that the library collections of the university medical libraries were too technical for the general public. The information was the most current, but it was written at a level far too complex for the non-medically trained or non-academically trained individual.

## **Information on Medications, Treatments, and Alternative Medicines**

Of the four locations, the CHIC was seen as having the most extensive collection of materials regarding medications and complementary treatments (aimed at the general health consumer). For example, when a shopper researched Alzheimer's disease, the shopper found about a dozen books on complementary medicine of which about a fourth had sections on the disease. Some treatments offered include: nutritional supplements, vitamin therapy, acupuncture, herbal medicines, and self-care/ hydrotherapy. Two books in particular offered additional information about where to find help and other recommended reading materials.

The Free Library had several books specifically related to medications, and also offered easy access to the Internet. Like the CHIC's collection, many of the books had sections dealing with treatments and surgery, although one of the shoppers was unable to find information on surgical options for his/her disease. The Free Library also had an extensive collection of books (about 30) on homeopathy and alternative medicine.

Branch libraries had fewer books on medications, treatments, and alternative medicines, but each branch relied heavily on Infotrac or the Internet to help patrons find information. In addition, each branch library had a collection of reference materials (e.g., PDR, Merck, Mayo Clinic) that were fairly standard across all the locations and provided general and specific information on many diseases, conditions, and treatments.

The university medical libraries also housed collections on medications, treatments, and alternative medicines. The medical libraries excelled in their collections on medications (both experimental and prescribed), having many journals and books dedicated to these topics. Similarly, they also housed extensive collections on surgical and treatment options. However, these collections were aimed at the medical community, not the general public. Finally, the medical libraries also contained several resources devoted to complementary treatment options.

## **Cost of Services**

All the libraries are "free." Some are just more free than others. None of the libraries charges an entrance fee, and all but the CHIC allow patrons to borrow books for free. However, to borrow books from these libraries, one has to be affiliated with their institutions (either as a student/staff/faculty for university libraries, or as a registered patron for the public libraries). At the Free Library, not only can individuals use the library for free, but, according to the shoppers, patrons can print as many pages as necessary from the Internet or other online sources for free. Services such as interlibrary loans or the use of translator services are also free at the **Free Library**, but there is a charge for photocopying pages from books. At the CHIC and branch libraries there is a cost to print pages from the Internet or from computer searches. At the university libraries, patrons can print information from online searches for free.

## **Referrals for More Information**

One potential source of patrons for the CHIC is referrals **from** other libraries. To assess the extent to which this occurs, shoppers were told to ask librarians from non-CHIC libraries for referrals to other institutions that might have more information on the diseases they were researching.

When shoppers at the Free Library asked for suggestions about where they could find additional information, the shoppers were always referred to the Biomedical Library at Penn. A few shoppers were referred to the College of Physicians, but most felt the referral was to the College and not to the CHIC. Shoppers at branch libraries were most often referred to the main Free Library branch and the Penn Biomedical library. No branch library referred shoppers to the CHIC. Finally, when shoppers at the medical libraries asked for referrals, most shoppers were referred to the main Free

Library of Philadelphia. The College of Physicians was mentioned once, but the librarian did not seem to think a referral was necessary. She said, “. . . after all, the Penn library is the most comprehensive medical library in the area.”

It must be noted that shoppers reported that, when the CHIC was mentioned, it was only after shoppers repeatedly asked for more referrals. In other words, the CHIC was not a front-line referral.

## Summary

It is clear that the CHIC has the best collection of medical research and health information for consumers in the greater Philadelphia area. Its collection of medical information is only surpassed by the Penn Biomedical library, which does not contain much consumer-oriented information. Shoppers found the CHIC facility to be the best designed of all the libraries. All the information was easily accessible and well categorized. Shoppers felt the size and intimacy of the CHIC made it much more accessible than the health section of the Free Library. In addition, the library staff were seen as extremely helpful and knowledgeable. Moreover, the CHIC was the only location that provided patrons with brochures about health issues published by the government and/or the medical community. This was seen by the shoppers as a significant benefit. It was also the only location that provided the shoppers with information on how to contact other health groups and associations.

These strengths notwithstanding, the CHIC did have its drawbacks. Parking is a serious problem around the College of Physicians. In addition, shoppers indicated that there is no external sign advertising the CHIC at the College, which makes it easy for the CHIC to go unnoticed. Also, during this study, weekend hours were suspended, leaving only limited weekday hours for patrons to visit the CHIC. All the shoppers commented on the difficulty in visiting the CHIC during weekday work hours. Each shopper wished that the CHIC were open in the **evening**. Finally, the CHIC is the only location of those visited by the phantom shoppers that charged for borrowing privileges.

Health information consumers in this area do have a good alternative to the CHIC—the main Free Library of Philadelphia. While this library was not seen as being as “user friendly” as the CHIC, it does house a collection of books pertaining to various health issues that is **almost** as extensive as the CHIC’s. In fact, most of the shoppers reported a duplication in books between the CHIC and the Free Library. In addition, the primary benefits of the Free Library were seen as twofold: 1) the library is easily accessible and has extended hours convenient to most of the public, and 2) the library provided **free** access to many Internet-based resources, including free printing of online material and full-text articles.

Local branch libraries and the university libraries were viewed as a distant last place in their ability to provide health information to the public. Most of these branches have smaller collections and more restricted hours than the main library. On the other hand, the university libraries were seen as being more comprehensive in their collections than the CHIC or the Free Library, but not **useable**

by a general health information consumer. In both locations, shoppers were referred to the main Free Library's reference area for more information.

Finally, when shoppers at locations other than the CHIC asked for referrals to local institutions where they would be able to get more information, seldom was the CHIC recommended as a resource. In only a few cases, after significant prompting, was the CHIC mentioned. In order to increase the number of persons and agencies who are aware of the CHIC's resources, shoppers suggested that the CHIC might want to do outreach to physicians, libraries, community-based organizations, the general media, and gyms and fitness centers.

## **CONCLUSIONS AND RECOMMENDATIONS FOR THE CHIC**

### **Marketing, Promotion, and Visibility**

#### **Awareness of the CHIC**

Most Patrons did not know about the CHIC prior to visiting the College. Only a few reported that they had been to the CHIC more than once. Key intermediaries also reported being unfamiliar with the CHIC and did not believe that their clients were familiar with it.

- ▶ The CHIC must do more to increase its visibility in the community. This can be accomplished primarily by developing relationships with other organizations that can serve as referral agents and by successful advertising and marketing of the CHIC's resources. For example, physicians, libraries, community-based organizations, the general media, and gyms and fitness centers can serve as referral agents.

#### **Affiliations**

The Patron survey showed that the majority of Patrons visited the CHIC on the same day as they visited the Mutter Museum.

- ▶ It is important that the CHIC be open during primary Museum visiting hours and that Museum staff continue to advertise the CHIC and suggest that Museum users visit the CHIC.
- ▶ In addition to the role of the Mutter Museum, the CHIC must pay attention to what else and who else attracts patrons to it. These places and persons should serve as key collaborators and marketing outlets.

## **Referral Agents/Agencies**

Key intermediaries believed that health care providers, libraries, and the Internet would serve as perfect vehicles for marketing the CHIC to potential patrons. In fact, the Patron survey revealed that Patrons typically go to their health care provider first for health information, a fact that was supported by the key intermediaries' reports about their clients.

- ▶ The CHIC should work with local health providers to provide patients easy access to consumer health information. The CHIC should improve its marketing effort within its own membership.

According to the Patron survey, the Internet has surpassed libraries as a place Patrons turn for health information.

- ▶ The CHIC should improve its **website** to include links to its holdings, as well as links to other sites, where patrons can go for further information. Once the CHIC has expanded its **website**, it should also market the **website**.

Key intermediaries thought that libraries would be a significant source of information for their clients. This may be true, but it cannot be expected that libraries serve as referral agents for the CHIC. In fact, the shoppers in the phantom shopper study were rarely referred to the CHIC when they asked for referrals to places where they could get more health information.

- ▶ If the CHIC wishes to increase traffic resulting from referrals, it will have to expand its marketing, especially to the branch and main Free Libraries.

## **Resources**

### **Materials**

Patrons reported using pamphlets and books more than any other resource at the CHIC. According to the phantom shopper survey, the CHIC was the only location visited by shoppers that provided patrons with brochures about health issues published by the government and/or the medical community. Perhaps the single most important and distinguishing aspect of the CHIC is its distribution of medical brochures and leaflets. This was, in fact, seen by the shoppers as a great benefit.

- ▶ It is, therefore, very important for the CHIC to continue to acquire and distribute current reference books as well as pamphlets for patrons to take with them as they leave the CHIC.

According to the results of the Patron survey, most Patrons were researching information on diseases or health conditions for themselves. One of the advantages of the CHIC, as found by phantom shoppers, is that its information is often more current than that at other libraries (with the exception of university medical libraries).

- ▶ The CHIC must continue to maintain a collection focused on diseases and health conditions, and expand the number of diseases and health conditions on which their materials focus
- ▶ In addition to focusing on making its collection comprehensive, the CHIC should continue to house materials that are current.

The majority of Patrons surveyed were 25 years old or older, and low or middle income. Not surprisingly, they all preferred materials in English. However, key intermediaries seemed to agree that offering materials in different languages as well as ensuring that publications are understandable for the low-literate would make it easier for their clients to use the CHIC. According to the phantom shopper survey results, the CHIC already houses materials for the low-literate and non-English-speaking audiences.

- ▶ To capture a broader base of patrons, the CHIC should continue to include in its collections materials for the low-literate and non-English-speaking audiences. These efforts to accommodate these audiences should be maintained to the extent that it is required by the educational and national/ethnic diversity of Philadelphia residents.

### **Staff and Atmosphere**

Key intermediaries and phantom shoppers talked about the overwhelming nature of conducting medical/health research, particularly when most places that house the most accurate and complete information are impersonal and too technical for the average person. Their suggestion was that having an intimate setting with accessible, helpful staff and **user-friendly**, consumer-oriented materials would be greatly beneficial to their clients. The phantom shopper survey proved this to be one of the strengths of the CHIC, particularly when compared to other sources of comprehensive medical information in the Philadelphia area.

- ▶ It is likely that the more satisfied patrons are with their experience at the CHIC, the more likely they are to tell others about the CHIC. The CHIC should continue to emphasize staff quality, layout, and user friendliness to ensure that all of its patrons are able to find information easily and accurately about the topic(s) they are researching.

## **Accessibility**

### **Hours of Operation**

Patrons' responses indicated a definite interest in seeing the CHIC offer Saturday hours and weekday evening hours. Key intermediaries tended to believe that current hours may serve as a barrier for some of their clients who work during those hours. Shoppers in the phantom shopper study also found the limited weekday hours to be a problem and desired to have the CHIC hours extended to include evening hours. The Free Library of Philadelphia was seen by the phantom shoppers as a better alternative to the CHIC, in this regard, because of its convenient extended hours.

- ▶ The CHIC should consider extending its hours to include weekends and weekday evenings. This will enable the public to come to the center during non-working hours, which will be particularly beneficial to those with long travel times or other transportation barriers.

### **Transportation**

A variety of modes of transportation were used by Patrons surveyed to get to the CHIC. However, key intermediaries tended to believe that some of their clients would have transportation barriers. This was believed to be particularly true for clients wishing to drive themselves because parking is difficult at the CHIC. The phantom shopper survey corroborated the problem of parking.

- ▶ To avoid hindering those wishing to drive from using the CHIC, the CHIC and the College may need to consider alternatives to current parking arrangements in order to accommodate all visitors as much as possible.

A significant number of Patrons reported arriving at the CHIC by foot, but a smaller number said they work within walking distance of the CHIC.

- ▶ The CHIC must market themselves within the small corridor surrounding the College.

### **Cost**

The income distribution of the Patrons surveyed may explain why many were willing to pay for services at the CHIC, especially for borrowing privileges. A smaller yet significant number of Patrons stated that payment for entrance or membership would make it more difficult to use the CHIC. Key intermediaries agreed that payment for any service would serve as a barrier for their clients. With regard to this issue, the phantom shoppers saw the Free Library as being more advantageous than the CHIC because the Free Library is truly free for use of all library services except photocopying.

- ▶ The CHIC should continue to be a **free** library and research facility for its patrons, and only charge for borrowing privileges if necessary.

## IMPLICATIONS FOR NATIONAL MODELS

One of the primary goals of this evaluation was to determine what lessons can be learned **from** the CHIC's experiences to help inform a national model. Results **from** the Patron survey, the key intermediary focus groups, and the phantom shopper survey offer the following lessons. Health information centers should

- ▶ be centrally located, with easy access to transportation and parking;
- ▶ have extended hours that fit the schedules of general users (this includes night and weekend hours);
- ▶ have adequate and helpful staff, including resource librarians;
- ▶ have health information brochures that patrons can take home with them;
- ▶ have information readily available on national health organizations that consumers can contact for additional condition-specific information;
- ▶ be as free as possible;
- ▶ provide a comfortable and well-laid-out environment for patrons to research their information;
- ▶ conduct outreach to other local libraries and health care providers so that they can become a source of referrals;
- ▶ consider linking the center with another resource so that patrons have more than one reason to visit (e.g., the Mutter Museum and the CHIC);
- ▶ work with the central public library to develop effective strategies for collaboration so that duplication of services is minimized and consumers can get current information quickly and easily;
- ▶ ensure that the collection of information is broad, comprehensive, medically accurate, current, and comprehensible to the average consumer;
- ▶ depending on the national/ethnic and educational diversity of the community, ensure that the collection accommodates non-English-speaking and low-literate audiences;
- ▶ make as much information about the center as possible available on a **website**; and
- ▶ if sponsored by another medical society, begin marketing the center's services to the society's membership.

**Appendix A**  
**Patron Survey Instrument**

## Do you know who we are?

1. Have you ever: [Check all that apply]
- |  | Yes                      | No                       |
|--|--------------------------|--------------------------|
| Visited the Koop CHIC before? .....                      | <input type="checkbox"/> | <input type="checkbox"/> |
| Visited the College of Physicians of Philadelphia? ..... | <input type="checkbox"/> | <input type="checkbox"/> |
| Obtained information from the College's Library? .....   | <input type="checkbox"/> | <input type="checkbox"/> |
| Visited the Mütter Museum? .....                         | <input type="checkbox"/> | <input type="checkbox"/> |
| Visited the Mütter Museum TODAY? .....                   | <input type="checkbox"/> | <input type="checkbox"/> |

2. How did you hear about the Koop CHIC? [Check all that apply]

- Self-help/Advocacy group:   
 Health care provider: .....   
 Library: .....   
 Friend .....   
 Television: .....   
 Newspaper: .....   
 Brochure: .....

Personnel Office: <input type="checkbox"/>	Library: <input type="checkbox"/>
Doctor's Office: <input type="checkbox"/>	Hospital: <input type="checkbox"/>
Apartment Bldg.: <input type="checkbox"/>	Friend: <input type="checkbox"/>

3. How did you get to the Koop CHIC today?

- Car:  Bike:   
 Public Transit:  On foot:   
 Other: (Specify: \_\_\_\_\_)

## What were you looking for today?

4. When you need health information, do you go to:

	Rarely	Sometimes	Most of the time
Family/friends .....	<input type="checkbox"/>	<input type="checkbox"/>	0
Doctor/health professional .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Koop CHIC .....	<input type="checkbox"/>	<input type="checkbox"/>	0
Public Library .....	<input type="checkbox"/>	<input type="checkbox"/>	0
Hospital Library .....	<input type="checkbox"/>	<input type="checkbox"/>	0
University Library .....	<input type="checkbox"/>	<input type="checkbox"/>	0
Public Health Department/Public Agency .....	<input type="checkbox"/>	<input type="checkbox"/>	0
Internet .....	<input type="checkbox"/>	<input type="checkbox"/>	0
Other (Specify: <input type="checkbox"/> _____) .....	<input type="checkbox"/>		0

5. What kind of health information are you looking for today? [Check all that apply]

- Wellness Information: .....  Alternative Medicine: .....   
 Physician Information: .....  Medication Information: .....   
 Disease/Condition Information:  → (Specify: \_\_\_\_\_)  
 Other: .....  → (Specify: \_\_\_\_\_)

6. Do you need information for:

- Yourself: .....  Friend: .....   
 Family Member: .....  Other: (Specify: \_\_\_\_\_)

(PLEASE TURN OVER . .)

**Appendix B**  
**Shopper Summary Reports**

## THE CHIC

The CHIC is open to the public from Tuesday - Saturday, 10am - 4pm.<sup>2</sup> There was a wish among all shoppers that the CHIC be open in the evening. Shoppers felt that the CHIC's location was a bit problematic. Parking was either difficult to find or expensive ( parking lots). One shopper commented that:

“I drove to the CHIC and had to drive around a little to find parking. There is no parking lot so I had to park at a meter and put quarters in every two hours. This was a bit inconvenient.”

However, the CHIC is accessible by public transportation and several shoppers availed themselves of public transportation.

All the shoppers commented on the helpfulness of the CHIC librarian staff. The staff were friendly, informative, and “almost to eager” to help. One shopper indicated that the librarian stepped out of the CHIC for half an hour and thus the shopper was unable to access CD-ROM technology during that time. Also, the librarians were unable to solve a computer problem, thus not allowing one shopper to print some information.

Shoppers agreed that the information that the CHIC contained was far more extensive than that of any other facility (except the Biomedical Library at Penn). This information was current, broad reaching, and well organized on the shelves. All of the holdings were written for the lay person, and there were a few pieces of information in Spanish. More importantly though is the fact that the CHIC had additional information from other sources of consumer health information such as: support groups, national research associations, the CDC 24-hour hotline, etc.. In addition, the CHIC had contact information for other national organizations and Federal health agencies so that the shoppers could contact them on their own and request more specific information.

The CHIC also carried the most extensive collection of materials regarding medications and complementary treatments. For example, when a shopper researched Alzheimer's disease, the shopper found about a dozen books on complimentary medicine of which about a quarter had sections dealing with the disease. Some treatments offered include: nutritional supplements, vitamin therapy, acupuncture, herbal medicines, and self care - hydrotherapy. There were two books in particular that offered where to find help and other recommended readings.

In addition, their video collection was also found to be thorough covering not only disease information for the patient and family, but also coping strategies for the caregiver. For example, one of the shoppers was able to find three videos related to Alzheimer's disease.

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<sup>2</sup> It is important to note that during the time of this study, the CHIC suspended Saturday hours. This situation was found out by one shopper who went to the CHIC on a Saturday and was told that they were closed.

“Of the three videos to select from, I viewed two, one about living with a loved one with Alzheimer’s (1995) and the Time Life Medical Series (1996). The third video was about using coping strategies for family members (mainly testimonials about sharing thoughts and experiences). While the time Life video was the mostly informative, clearly explaining the disease in terms of biology and medical practices the video about “living with one you love...” was more concerned with dealing with emotional support and practical advise for caregivers.”

Perhaps the following quote best sums up the experience of the shoppers at the CHIC:

“Compared to the information I found at the Chestnut Hill library with regard to Chronic Fatigue Syndrome, CHIC is truly amazing. I found myself wanting to research things related to my own health and that of my family than my assigned research topic! Had I known this library existed, I probably would have visited a long time ago.”

Issue	Experience
Amount of Info	<ul style="list-style-type: none"> <li>◆ over the top; CHIC caters completely to the consumer’s needs</li> <li>◆ same access to Infotrac as Chestnut Hill library branch, yielding same search results</li> <li>◆ approximately 40 general reference books with c.f.s. entries (signs, symptoms, prevention, what you can do, when to call the doctor); recognizable names such as World Book Encyclopedia, Merck, Consumer Reports, AMA</li> <li>◆ 3 books geared specifically to chronic fatigue syndrome (please see photocopied tables of content)</li> <li>◆ librarian pulled out a manilla folder from a filing cabinet filled with pamphlets of which they have only one copy; I was able to photocopy them if I wanted to; approximately 20 pamphlets from CDC, DHHS, National Chronic Fatigue Syndrome and Fibromyalgia Association, and NIH</li> </ul>
Diversity of Info	<ul style="list-style-type: none"> <li>◆ 99% of the c.f.s. information I found was geared toward the consumer; information giving overview of the disease, organizations you can contact for more information and help, pamphlets with information about school children &amp; c.f.s., suicide and c.f.s., understanding the emotions surrounding c.f.s., support groups, the Americans with Disabilities Act and c.f.s.; Compared to the information found at my first visit, the info. at CHIC is extremely diverse</li> </ul>
Readability of Info	<ul style="list-style-type: none"> <li>◆ the readability of the majority of the information is definitely at the high school diploma level</li> </ul>
Ease of finding info	<ul style="list-style-type: none"> <li>◆ very easy – the librarian pointed me in the right direction</li> <li>◆ I think it was easy also because of the size of the library – small, and all of the information is medically and health related so you aren’t jaunting all over a large library looking in different sections for different information</li> <li>◆ the bookshelves are well marked; I only had difficulty finding the books, and the librarian had to help</li> </ul>

Issue	Experience
Did they have computers and Web access/online journals	<ul style="list-style-type: none"> <li>◆ 2 computers – one with Internet and CD-rom access, the other with online catalogs for the College of Physicians library as well as the libraries of Hahnemann, Penn, Pitt, and Jefferson</li> <li>◆ OVID</li> <li>◆ Medline</li> <li>◆ CD-ROMS: AMA Family Medical Guide, Health Reference Center, Mayo Clinic Family Health Book, Bodyworks 5 .0, My Amazing Human Body, Pharm-assist</li> </ul>
Format of info	<ul style="list-style-type: none"> <li>◆ electronic and written</li> <li>◆ no videos or audio tapes</li> </ul>
Were you give brochures or articles	◆ there were no brochures on the wall, but as stated earlier, the librarian pulled out a folder of brochures that I could photocopy
Multilingual info	◆ only English for this topic, although I did see brochures and books for other topics in Spanish displayed
Was location convenient (bus, car - parking)	◆ I was dropped off and then took the bus back to my apartment, so it was very accessible. I chose not to drive because the only street parking nearby the College of Physicians is meter parking or lot parking, and both are a bother and very expensive, In this case, I think public transportation is the best choice for me.
Were hours convenient	◆ 10 - 4, Tues. - Sat. I was pleasantly surprised to <b>find</b> that CHIC has Saturday hours, but evening hours would make it even more convenient for someone who works full-time
Did you have to pay	◆ I paid for photocopies, .15/each
Did they have a pay option	
Did they refer you for more info (where)	◆ no
Could you <b>find</b> info on medications	◆ yes, but the information is limited to one or two drugs. Again, due to the cryptic nature of the disease, treatment is limited
Could you <b>find</b> info on treatment and surgery	◆ yes – treatment; because of the nature of the disease, there really is no surgery available, but I found a good amount of information on drugs that are used, treatment in the way of lifestyle changes, and alternative therapies
Could you <b>find</b> information on complementary treatment	<ul style="list-style-type: none"> <li>◆ yes – see photocopies</li> <li>◆ 20 manuals on alternative/complementary medicine as a whole, half of those had entries related to <b>c.f.s.</b></li> <li>◆ Andrew Wiel's book was the only name I recognized</li> </ul>
Amount of Info	<b>There</b> was a good amount of material on the disease. A total of 10 books (9 in English, 1 in Spanish) specifically on Alzheimer's and 5 books with sections devoted to the disease. The breadth of information ranged greatly including topics of <b>concerns</b> for the one afflicted and for those caring for someone with the disease.

Issue	Experience
Diversity of Info	The information was pretty extensive in content. Covered topic included: symptoms, causes, theories, ongoing research, diagnosis, behavioral and emotional changes one goes through, medications, living with the disease, ways of coping daily, how to <b>find</b> support groups for people caring for an afflicted person, and financial implications.
Readability of Info	All of the material in the library pertaining to the disease was written for the layman. All terms were <b>define</b> in a clear and concise manor. There were no medical journals or medical jargon used in any of the books, pamphlets, or videos.
Ease of finding info	It was very easy to <b>find</b> all the information they have. It's a very small library (one room) and the shelves were easily marked. The librarian was very eager to help me <b>find</b> all the information for which I requested.
Did they have computers and Web access/online journals	There was one computer with access to the Internet and their Health Reference Center, which offered overviews of the disease, reference books, and pamphlets you can get (not necessarily at CHIC).
Format of info	Information was available in Pamphlets ( <b>2</b> ), books ( <b>15</b> ), video ( <b>3</b> ), and on-line via Internet connections to <b>Medline</b> and their Health Reference Center.
Were you give brochures or articles	I was given two brochures on Alzheimer's Disease, invited to make copies of anything I found in the library (15 cents a copy), and allowed to print up to 10 pages off of the computer for free (after 10 pages there is a charge of 10 cents per page).
Multilingual info	There was one book in Spanish. No other languages were offered.
Was location convenient (bus, car parking)	I drove to CHIC and had to drive around a little to <b>find</b> parking. There is no parking lot so I had to park at a meter and put quarters in every two hours. This was a bit inconvenient.
Were hours convenient	<b>The</b> hours of operation are Tuesday through Saturday, <b>10am</b> to 4pm. Since they have weekend hours I had no problems with having enough time in the library. Evening <b>hours</b> certainly would make it more easily assessable since I work Monday through <b>Friday, 8:30am to 4:30pm.</b>
Did you have to pay	I paid to use the copy machine, not to have access to the materials. I was told that if I wanted to borrow a book or video I would have to become a member ( <b>\$20/year</b> ).
Did they have a pay option	<b>They</b> do offer a pay for Online Search option for acquiring information on a specific <b>opic</b> . The cost is \$50.
Did they refer you for more info (where)	<b>The</b> librarian suggested I try to <b>find</b> more information at the Free Library or other local hospital/medical libraries. She did not refer me to the local Alzheimer's Association.
Could you <b>find</b> info on medications	I did <b>find</b> information on 'varying types of medications commonly used for Alzheimer's patients including: their names, side effects, and reasons used (i.e. lepression, anxiety, hallucinations, sleep).
Could you <b>find</b> info on treatment and surgery	I found one section in a report from the Harvard Medical School Health Publications <b>Group</b> that suggested tissue implant as a treatment, but not a cure for Alzheimer's. <b>In</b> the rest of the information I read I found no options for surgery. The treatment <b>seems</b> to be only intended to make the afflicted person's life as comfortable as <b>ossible.</b>

Issue	Experience
Could you <b>find</b> information on complementary <b>treatment</b>	In a section of the library dedicated to complimentary medicines, I found about 6 books with sections dedicated to Alzheimer's. The alternative treatments ranged <b>from</b> vitamin therapy to acupuncture to hydrotherapy.

## Free Library of Philadelphia

This library is centrally located in downtown Philadelphia. It is easily accessible by foot, public transportation, or car. They are open: Monday-Wednesday 9am-9pm, Thursday-Friday 9am-6pm, Saturday 9am-5pm, and Sunday 1pm-5pm.

The shoppers found the reference librarian staff very helpful, although some shoppers had difficulty getting the attention of librarian staff. The following quotes typifies shopper experiences with librarian staff:

“All of the staff seemed to be very knowledgeable about their library. They provided a lot of hands on help.”

“The staff was helpful and pleasant when I was able to talk to them.”

“Although it was a busy weeknight, the number of librarians working could not seem to manage the demands of the crowds. I found it very difficult to get a librarian to help me find the information I was looking for.”

The information that shoppers found was extensive, although there was concern among one shopper that it was dated. Most of the medical information he found in printed form was **from** the early 1980's. The library did not have brochures for the shoppers to take, but had numerous books per topic. Shoppers reported that the library had a reference area with “a wall of shelved books dedicated to “health.” In addition, the library had an entire section dedicated to Alternative medicine. There were over 30 books ranging in topics **from** American homeopathy to Chinese herbal Medicine.

The library also provided shoppers with extensive access to the Internet and medical search engines, and each shopper reported using these tools to gain current information. In fact, the library was the only location that allows patrons to print as many pages as they want from these services for **free**. There was some concern, though, that some of this information was too complicated for the average reader.

The library also did not have materials in languages other than English, however, they did offer a **free** translator service if needed. Finally, the library does have a collection of medical video-tapes, which patrons can borrow for **free** for up to two weeks. However, it is interesting to note that one of the shoppers was unable to find these resources, even after asking many librarians.

I suspect the following shopper's comment sums up their impression of the Free Library: "I felt that the amount of information fell somewhere between the branch library I first visited and the CHIC."

When the shoppers asked for suggestions on where they could find additional information, the shoppers were always referred to the Bio Medical Library at Penn. A few shoppers were referred to the College of Physicians, but most felt the referral was to the College and not the CHIC.

Issue	Experience
Amount of Info	<ul style="list-style-type: none"> <li>◆ approximately 30 books</li> <li>◆ same number of Infotrac Health Database entries as CHIC and Chestnut Hill library</li> <li>◆ reference materials-Diseases <i>series</i>, just like Ch. Hill; The Marshall Cavendish Encyclopedia of Family Health, 1991; <b>Magill's</b> Medical Guide – Health and Illness; Macmillan Health Encyclopedia, Vol.3 – Noncommunicable diseases and disorders (3 very short paragraphs)</li> </ul>
Diversity of Info	<ul style="list-style-type: none"> <li>◆ I would estimate that about 75% of the information shown to me last night was geared toward the consumer.</li> </ul>
Readability of Info	<ul style="list-style-type: none"> <li>◆ Just as above, most of the information was not too difficult to understand because of the intended audience</li> </ul>
Ease of finding info	<ul style="list-style-type: none"> <li>◆ compared to other two visits, the Free Library falls in between CHIC and Chestnut Hill. Not quite as easy as CHIC but certainly easier than Chestnut Hill</li> </ul>
Did they have computers and Web access/online journals	<ul style="list-style-type: none"> <li>◆ At least 4 online catalog computers in each room</li> <li>◆ At least 15 computers with access to Internet</li> </ul>
Format of info	<ul style="list-style-type: none"> <li>◆ both print and electronic (the full text articles in Infotrac)</li> </ul>
Were you give brochures or articles	<ul style="list-style-type: none"> <li>◆ no brochures, but ability to print full text Infotrac articles for. fee</li> </ul>
Multilingual info	<ul style="list-style-type: none"> <li>◆ not that I saw</li> </ul>
Was location convenient (bus, car - parking)	<ul style="list-style-type: none"> <li>◆ convenient for walking/bus because it is only about 5 blocks <b>from my</b> apartment</li> <li>◆ parking – only street or paid lot; no <b>free</b> parking</li> </ul>
Were hours convenient	<ul style="list-style-type: none"> <li>◆ Monday • Wednesday <b>9am</b> • 9pm</li> <li>Thursday • Friday <b>9am</b> • 6pm</li> <li>Saturday <b>9am</b> - <b>5pm</b></li> <li>Sunday 1pm • 5pm</li> </ul>
Did you have to pay	<ul style="list-style-type: none"> <li>▶ to <b>borrow</b> – no, to photocopy – yes</li> </ul>
Did they have a pay option	<ul style="list-style-type: none"> <li>▶ no</li> </ul>
Did they refer you for more info (where)	<ul style="list-style-type: none"> <li>▶ No, it seemed in the librarian's opinion that everything I could ever want would be there, or I could contact specific organizations where they deal with CFS directly</li> </ul>

Issue	Comments
Could you <b>find</b> info on medications	♦ there were several books on medications available, but as has been the case with the other sites, CFS is rarely treated with drugs due to the enigmatic nature of the , disease
Could you <b>find</b> info on treatment and surgery	♦ information on treatment was found within some of the books, but nothing on treatment specifically
Could you <b>find</b> information on complementary treatment	♦ Deepak Chopra – <i>Boundless Energy: The Complete Mind/Body Program for Overcoming Chronic Fatigue</i> ♦ William Collinge – <i>Recovering from Chronic Fatigue Syndrome: A Guide to Self-Empowerment</i>
Amount of Info	I was able to <b>find</b> a good amount of information at the Free Library of Philadelphia. There were only two books dedicated strictly to Alzheimer’s Disease, but I found an extensive amount of <b>information</b> on their Infotrac system.
Diversity of Info	The information I found was very diverse in content. Topics covered included: analysis, causes, different types of therapies, research development and progress, laws and regulations, genetic components, media coverage, and imaging techniques used (e.g. MRI).
Readability of Info	Most of the information I read was written for the layman. I found some scientific journal articles that were a bit more difficult to read, but not completely impossible to digest.
Ease of finding info	This is where the Free Library fell short. While the librarians were all very helpful in assisting my search, the library is sectioned off into departments throughout a large multi-level building and I had to go from department to department or all the information. I visited a total of three areas to <b>find</b> all the information on AD.
Did they have computers and Web access/online journals	There were 8 computers with access to the Internet in the department of Business, Science and Industry, which is where the Health section is located. There was also one computer with Infotrac, a computer based system for accessing more scholarly types of research.
Format of info	Information was available in books, video, Online and through Infotrac.
Were you given brochures or articles	There were no brochures offered on the disease, however I was allowed to print as many pages of articles off of Infotrac as I needed free of charge. See enclosed.
Multilingual info	There was no multilingual material available, however, I was told that they did have a number I could call for a translator if needed.
Was location convenient (bus, car - parking)	The Free Library is very conveniently located and is easily assessable by car and public transportation. I had no problems finding a meter to park at while I conducted my searches.
Were hours convenient	The hours are very convenient. Monday through Wednesday: <b>9am - 9pm</b> , Thursday, Friday: <b>9am - 6pm</b> , Saturday: <b>9am - 5pm</b> , and Sunday: <b>1pm - 5pm</b> .
Did you have to pay	I did not have to pay for any of my searches.
Did they have a pay option	They did offer a pay option for specific topics. I was given the number of the database search line.

Issue	Experience
Did they refer you for more info (where)	I was referred to the College of Physicians (CHIC) and given there location and hours. I was also referred to the Thomas Jefferson medical library.
Could you <b>find</b> info on medications	All the information I found on medication was on the Internet and Infotrac.
Could you <b>find</b> info on treatment and surgery	Again, the information I found on treatment options was on the Internet and Infotrac. I found no information on surgery as a treatment option.
Could you <b>find</b> information on complementary treatment	There were about 30 books on Homeopathy and Alternative Medicine. Of the 30, I found sections related to Alzheimer's in 10 of the books.

## Local Branch Library

Three different branch libraries were visited for this study: Chestnut Hill, West Philadelphia, and Southwark Park. Most libraries had hours in the variation of a few weekdays from 1 PM - 9 PM, a few weekdays from 10 AM - 5 PM, and then Saturday afternoon hours. The libraries were less accessible by public transportation than the main Free Library, but most offered free parking.

Shopper's assessments of the community libraries can be summarized as such:

“It's a very small community library located in the heart of South Philadelphia and seems to cater mostly to the neighborhood schools with a majority of the sections (and computer programs) geared toward children.”

Librarians were found to be very helpful. Most shoppers commented on the willingness of staff to help. In fact, in one case, the librarians sat with the shopper and searched for everything they could about the disease. All the time, the librarians never made the shopper feel like the shoppers were bothering them and moreover, they were very sorry that they could not help the shopper much more.

Most of the information available at the local libraries came from online sources such as Infotrac. The online databases had full text articles that covered all the information for the various diseases. The articles were typically written in a very readable format and they addressed common concerns about the diseases. For example, the people most at risk, possible treatment alternatives and the latest medications. Most of the online articles were found in popular magazines like Self, Mademoiselle, and The Ladies Home Journal. For a charge of 15 cents one could print the articles. However, not all the articles were available online. Most of the references found on the database for journal articles could be retrieved at the main library branch on 1 9<sup>th</sup> and Vine Streets. The regional branches housed mostly popular magazines.

Branch libraries also housed various videotapes related to health issues. For instance, Shoppers were able to find tapes from the Time Life Medical series. The tapes cannot be viewed at the library but they can be checked out. Other videos and electronic books were housed at the main branch. No

brochures were available and most of the information was in English. Shoppers did indicate that the database did list some articles in Spanish.

Finally, in most cases, when shoppers asked for referrals to other sources of information, the two most mentioned were the main Free Library branch, and the Penn Biomedical library. In no branch library were shoppers referred to the CHIC.

## Chestnut Hill Library

Issue	Experience
Amount of Info	<ul style="list-style-type: none"> <li>◆ The computer card catalog system, searching for “chronic fatigue syndrome”, landed 3 books. Only two were available at that branch, and only one was actually on the shelf.</li> <li>◆ “Health reference center” of Infotrac magazine search engine (on same computer) yielded 179 articles, half of which were <b>full</b> text and could be printed out there on site; of those that were not full text, none were available from on site journals/magazines</li> <li>◆ tried using “chronic Epstein-Barr virus disease” as search topic = 158 articles, approximately 314 were <b>full</b> text. <b>HOWEVER</b>, since there were only 2 computers with which this search could be done, and it was a busy Saturday afternoon, lines were forming behind me and I could not investigate beyond that</li> <li>◆ 3 diagnostic manuals with short entries on chronic fatigue <b>syndrome/Epstein-Barr</b> = Current Medical Diagnosis and Treatment; Cecil Textbook of Medicine; The Merck Manual of Diagnosis and Therapy = all for health professionals</li> <li>◆ Johns Hopkins Medical Handbook = short entry on c.f.s., geared toward lay individuals</li> <li>◆ Merck Manual of Medical Information = totally geared toward lay individual; one 4 sentence paragraph on c.f.s.</li> <li>◆ “Symptoms -- Their Causes and Cures” = by editors of Prevention Magazine; short section on fatigue</li> <li>◆ Diseases (8 volume set by Grolier Education)- very helpful for lay individual; sections on cause/history/incidence, symptoms you see, symptoms doctors see, treatment options (no alternative), stages and progress</li> </ul>
Diversity of Info	<ul style="list-style-type: none"> <li>◆ medical information geared toward health professionals</li> <li>◆ information geared toward educating lay individuals on the basics of chronic fatigue syndrome (i.e., history, possible symptoms, treatments)</li> </ul>
Readability of Info	<ul style="list-style-type: none"> <li>◆ readability/complexity = geared toward the health professional; approximately three-fourths of the information I saw was geared toward health professionals, especially when using alternative Epstein-Barr search term</li> <li>◆ information geared toward lay people was still pretty complex, at minimum geared toward high school grad. if not college educated</li> </ul>
Ease of finding info	<ul style="list-style-type: none"> <li>◆ fairly easy, if you are not afraid to ask for help from librarians</li> </ul>

Issue	Experience
Did they have computers and Web access/online journals	<ul style="list-style-type: none"> <li>◆ 2 catalog search computers</li> <li>◆ 3 Internet/word processing computers (2 of which were out of order)</li> <li>◆ 1 multimedia computer for children</li> <li>◆ librarian did not offer computers/ online journals beyond the regular library search computers</li> <li>◆ GREAT OPTION- when doing article searches on Infotrac, you can e-mail the full text or single citation to whatever e-mail address you choose</li> </ul>
Format of info	<ul style="list-style-type: none"> <li>◆ mostly electronic; articles could be available in hard paper format (if not printed out as full text) through library ordering</li> </ul>
Were you give brochures or articles	<ul style="list-style-type: none"> <li>◆ no, although there were a couple of brochures listed on-line</li> </ul>
Multilingual info	<ul style="list-style-type: none"> <li>◆ all in English</li> </ul>
Was location convenient (bus, car - parking)	<ul style="list-style-type: none"> <li>◆ convenient through regional rail system and buses</li> <li>◆ located in Chestnut Hill community, used by Chestnut Hill, Mount Airy, and perhaps Germantown residents</li> <li>◆ street parking and small side lot</li> <li>◆ I had no problem parking on the street directly outside of library</li> </ul>
Were hours convenient	<ul style="list-style-type: none"> <li>◆ Monday and Wednesday - 1pm - 9pm</li> <li>◆ Tuesday, Thursday, and Friday - 10am - 5pm</li> <li>◆ Saturday - 1pm - 5pm</li> <li>◆ in my opinion, somewhat convenient; not uniform, so harder to remember</li> </ul>
Did you have to pay	<ul style="list-style-type: none"> <li>◆ if I were to make photocopies, yes</li> <li>◆ no charge for printing</li> </ul>
Did they have a pay option	<ul style="list-style-type: none"> <li>◆ no</li> </ul>
Did they refer you for more info (where)	<ul style="list-style-type: none"> <li>◆ I had to ask for a referral, and the librarian suggested that I visit the main Free Library branch downtown</li> </ul>
Could you find info on medications	<ul style="list-style-type: none"> <li>◆ in a few of the reference books</li> </ul>
Could you find info on treatment and surgery	<ul style="list-style-type: none"> <li>◆ yes</li> </ul>
Could you find information on complementary treatment	<ul style="list-style-type: none"> <li>◆ one reference book mentioned using herbs, but I could not find any additional information on alternative treatments</li> <li>◆ one thing I did learn is that doctors are at odds about how to treat this with traditional procedures, so I wouldn't expect more information on alternative medicines</li> </ul>

## West Philadelphia Branch

Issue	Experience
Amount of Info	There was a good amount of information available on breast cancer. Though not all the information was on site.
Diversity of Info	There was information on all the different topics related to breast cancer -treatment, medications, detection etc.
Readability of Info	The information was easy to read. Not highly technical
Ease of finding info	The information on the database was easily accessible. Most of the journals were not available at this branch, they were housed in the main library downtown.
Did they have computers and Web access/online journals	There were computers and Web access but a library card is required to use the computers
Format of info	There were magazine and journal articles, reference articles and an online database
Were you give brochures or articles	There were no brochures and the online articles could be printed at 15 cents a page.
Multilingual info	Most of the info was in English. The online database did have some articles in Spanish.
Was location convenient (bus, car • parking)	Location easily accessible by car or train. Parking is hard to <b>find</b> .
Were hours convenient	Hours were convenient, They have morning, afternoon and evening hours.
Did you have to pay	No
Did they have a pay option	No pay option
Did they refer you for more info (where)	Referred to Temple and University of Pennsylvania
Could you <b>find</b> info on medications	The database did have articles with info on medications.
Could you <b>find</b> info on treatment and surgery	The database did have articles with info on treatment and surgery.
Could you <b>find</b> information on complementary treatment	There was info on complementary treatment

## Southwark Branch

Issue	Experience
Amount of Info	There was very little material on Alzheimer's disease in this library. There was one book specifically on the disease. It was over 15 years old, was written in the first person, and read like a story. I did <b>find</b> two books with sections devoted to Alzheimer's. These books were also dated, 19 and 10 years old.
Diversity of Info	The information I found was very limited in scope. Other than via On-line access I could <b>find</b> no information on research, diagnosis, medications, ways of coping with living with someone afflicted with he disease, support networks, etc..
Readability of Info	The information I found was written for the layman and easy to read.
Ease of fmding info	It was relatively easy to <b>find</b> the information they had. It 's a small library and the medical section is very limited.
Did they have computers and Web access/online journals	There were 6 computers in the library, all with Internet access. There was a 30 minute time limit with one time slot allowed per day. One has to sign up for a time slot.
Format of info	Information was available in books, video (1), and On-line.
Were you give brochures or articles	There were no brochures or pamphlets.
Multilingual info	There were no books on Alzheimer's disease in any other language.
Was location convenient (bus, car ▪ parking)	The library was easy to get to and there was ample parking in the area (free of charge). I know of two bus routes that pass within one block of the library.
Were hours convenient	They had evening and weekend hours ▪ very convenient. Monday and Wednesday: 12pm - 8pm, Tuesday, Thursday, and Friday: 10am ▪ 5pm, Saturday: 1-5pm.
Did you have to pay	I did not have to pay to get the information. If I printed off of thecomputer I would be charged ten cents a page.
Did they have a pay option	They did not have a "pay for gathering information" option.
Did they refer you for more info (where)	They only referred me to the Main Branch of the Free Library upon my asking for suggestions of where I could look for more information. They never suggested CHIC.
Could you <b>find</b> info on medications	I only found information on medications in the alternative medicine book (1) and On-line.
Could you <b>find</b> info on treatment and surgery	Again, I only found information on treatment and surgery options On-line.
Could you <b>find</b> information on complementary treatment	There was one book on complimentary medicine (dated 1994). The book was the same as the one found in CHIC.

## The University Medical Libraries (Penn and Temple)

The university libraries are located on each campus. Both libraries had the most extensive hours of any of the visited locations; in some cases, they were open 24 hours per day. In addition, each of the libraries is easily accessible by public transportation, and paid parking is readily available. However to use Temple's library, users must either be affiliated with, or escorted by, a Temple-affiliated person.

The amount of information held by the Penn library, in particular, was noted by each shopper. Shoppers experiences can be summarized as such:

“The amount of information at this library was tremendous. It was at least a 9.5 on a scale of 1 to 10. I could have spent weeks in there and not have read half of the information that they had available.”

However, this amount of information also had its drawbacks. For example, each shopper commented that the information was written for a technical audience. They also commented on the overwhelming feeling they got trying to research their diseases. In short, these libraries house abundant information, that is current, but it is too much for the average person. For instance, shoppers found an abundance of information on medications, surgery and overall treatments in these libraries. However, “there was so much information that a non-medically trained individual would most likely be confused by it all.”

The libraries did not carry video or audio information. However, shoppers were informed that they could request the library to order such materials. Once the information was ordered, it could take between 48 hours to a week for the videotapes to arrive. On a positive note, the librarians made sure to point out that there was no charge for special ordering videos.

Finding the information in the library was reported as fairly easy, but shoppers found searching the databases as a long and tedious process. Shoppers reported that the library staff was helpful in showing patrons how to use the databases but they left the shoppers to do all the searching. When asked where to find additional information, the librarians did not refer shoppers to the CHIC. In fact, the librarians stressed that PENN had online access to all local libraries and if the shopper needed an article or a book that was not in one of PENN's libraries, the shopper could use the interlibrary loan option.

Shoppers noted that the university libraries did not have information written in languages other than English. However, once again, the libraries are more than willing to get you such materials at no cost. You can also search for articles written in other languages by using their computer system. There is no cost to use these libraries unless you want to make copies of articles to take out with you. The cost for that is \$.07/page. These libraries do not offer a paid research service. When asked for referrals, most shoppers were at best referred to the main Philadelphia Free Library branch. The College of Physicians was mentioned once, but the librarian couldn't understand why they wanted a referral... ‘after all the Penn library is the most comprehensive medical library in the area.’

## BioMedical Library - University of Pennsylvania

Issue	Experience
Amount of Info	Found a lot of information here. Had information on every aspect of breast cancer from detection to treatment options.
Diversity of Info	Information came in the form of journal articles, online journals and books.
Readability of Info	Some of the information was highly technical but less technical information was also available.
Ease of finding info	Finding the information was simple. The process of searching through all the references online was extremely tedious
Did they have computers and Web access/online journals	There is Web access and online journals. The computers were the first place the librarian told me to look
Format of info	The information came in journal articles and textbooks. There were no brochures
Were you give brochures or articles	There are articles but no brochures
Multilingual info	Some articles were written in other languages, for example French and Spanish. The majority of the information however, was written in English.
Was location convenient (bus, car - parking)	There is no special parking facilities for the <b>BioMedical</b> Library. There is parking at various locations around the campus.
Were hours convenient	The hours were convenient however, access is restricted after <b>6pm</b> to people with ID's from either the PENN community, or other organizations affiliated with the library.
Did you have to pay	I did not have to pay for the information
Did they have a pay option	There was no pay option
Did they refer you for more info (where)	I was not referred anywhere else. The librarian said if there was something that they did not have in the library, they would order it.
Could you <b>find</b> info on medications	There was information on medications in the articles, textbooks and online journals
Could you <b>find</b> info on treatment and surgery	There was information available on treatment and surgery.
Could you <b>find</b> information on complementary treatment	Yes, there was also information available on complementary treatment options.
Amount of Info	I found 24 listings for books/journal articles/symposium proceedings/papers on the disease in the card catalog.
Diversity of Info	The diversity of the information I found was a bit limited in that it focused strictly on the research and known "treatments." I found little information on surgery options, caring for a loved one with the disease, and alternative approaches to caring for one afflicted with AD.

Issue	Experience
Readability of Info	Most of the information was very technical and highly scientific, but there were two books that I considered would be easy to read for a generally educated person.
Ease of <b>finding</b> info	The information was difficult to <b>find</b> . The books seemed organized in a strange manner that I never quite figured out. The librarian helped me a bit, but there were many students also needing his assistance so his availability was limited.
Did they have computers and Web access/online journals	They had 10 computers, five with Internet access and five with online journals. I was told they had access to seven different medical databases ( <b>AIDSline, BioethicsLINE, CancerLIT, CINAHL, Current Contents Life Sciences/Clinical Medicine, and HealthSTAR</b> ). However, the night I visited the library the computer system was down.
Format of info	There were books, journals, and Online access. No pamphlets, videos or audio cassettes.
Were you give brochures or articles	No.
Multilingual info	There was no multi lingual information offered.
Was location convenient (bus, car - parking)	The library is very conveniently accessed by public transportation or by car. The library is not in a "good" part of town, but the area was very well lit by flood lights atop the building.
Were hours convenient	The hours were excellent. Monday - Thursday 7am - midnight, Friday 7am - <b>10pm</b> , Saturday <b>9am-6pm</b> , Sunday Noon - 6pm.
Did you have to pay	I did not have to pay, but I did need a Temple Univ. ID to get into the building. The library is not open to the general public.
Did they have a pay option	There is not a "pay for <b>info.</b> " <b>option</b> , but they will do free searches for you for a specific book or journal.
<b>Did they refer you for more info (where)</b>	I was referred to the Philadelphia Free library. I was not referred-to CHIC.
<b>Could you find info on medications</b>	There were many journals articles about medications (experimental and prescribed).
Could you <b>find</b> info on treatment and surgery	I found one article talking about the surgery option, but little was in laymen terms.
Could you <b>find</b> information on complementary treatment	The section of the library on alternative medications was complicated to maneuver through, but I did <b>find</b> a couple of books that offered some insight into dementia treatments (Alzheimer's disease was not specifically mentioned).

**Appendix C**  
**Focus Group Participants**

# FOCUS GROUP PARTICIPANTS

## Group 1

Patty Cooper, Consumer  
Cathi Christino, Red Cross  
Mark Katz, Mental Health Assoc. of SE PA  
Tammy Daley, SIDS Alliance, Bucks County  
Maria Weidinger, Alzheimer's Assoc. of SE PA  
Pat West, Exec. Committee, CPP Public Health and Prevention, Medical Section

## Group 2

Eugenia Juchimiuk, Consumer  
Madhuo Kothari, American Red Cross  
Judy Kleppel, Public Health Physicians Network  
Estela Juchimiuk, Community Healthcare

## Group 3

Annette Myarick, Arthritis Foundation  
Lori Curtis, The Wellness Community  
Ed Sfida, Arthritis Foundation  
Marilyn Arnott, Living Beyond Breast Cancer  
Bill Kurlans, Consumer