

Health Behaviors Focus Group Findings

From a series of groups held Nov. 2002-August 2003

Cambridge Health Alliance Department of Community Affairs

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OVERVIEW OF FOCUS GROUP FINDINGS

Language spoken	Barriers to healthcare	Key Findings
Cantonese (65 and over years of age) Cantonese (<65 years of age)	 Long wait to get a doctor's appointment Long wait time at appointment to see the doctor and interpreter Long wait time to get appointment High cost of care 	 Knowledgeable about breast health Language not cited as a barrier to health care access as their physicians and hospitals are able to serve their language needs Slightly less knowledgeable about breast health than older counterpart Language was not cited as a barrier to access as
Vietnamese (Malden)	 High cost of care Lack of Vietnamese speaking interpreters Worried about proposed MassHealth cuts (2003) 	 Language was not cited as a barrier to access as their physicians and hospitals are able to serve their language needs Top health problems cited: TB, liver disease, peer-influenced drug abuse and smoking among children Participants indicated they were conscientious
English	 Long wait time to see PCP Brief clinical time 	 about their health Most had a PCP and were familiar with the PCP role Most understood importance of preventative care Belief that the privately insured receive better care than the publicly insured (MassHealth)
Haitian - Creole	 Lack of time Language barrier Lack of health insurance High cost of care Poor quality of care Past negative care experiences 	 Understand the importance of primary care but see doctor only when sick Positive patient / provider relationship key to better health and better communication with doctor
Portuguese (Brazilian)	 Language barrier Lack of interpreters Lack of health insurance Long wait to get a doctor's appointment Do not understand U.S. healthcare system 	 Exposed to the PCP model of care in Brazil Most did not have a PCP or saw doctor only when ill
Spanish	 Lack of health coverage High cost of care Language barrier 	 Although 'primary care physician' is a new term, many understood the importance of it Most would like to actively engage in their own primary care

INTRODUCTION

From November 2002 to August 2003 the **Department of Community Affairs** at the **Cambridge Health Alliance (CHA)** conducted eight in-depth focus groups in order to facilitate its program development efforts. The focus groups were conducted to better understand CHA client populations, including their ability to access primary care and their views on health care. The groups also explored specific health topics such as breast health.

Five focus groups were conducted to explore **primary care issues**:

- English-speaking The first focus group was conducted in English and was conducted by a consultant moderator. This focus group was also used as a training session on focus group moderation for Community Affairs staff.
- Spanish-speaking –This group was moderated by Community Affairs staff.
- Haitian Creole-speaking This group was moderated by Community Affairs staff.
- **Portuguese-speaking** These two focus groups with Brazilians were moderated by Community Affairs staff.

Two groups focusing on **breast health issues** were conducted with women in the **Cantonese-speaking** community. This effort was funded by an American Cancer Society grant, and the groups were moderated by volunteers from the American Cancer Society.

One focus group was conducted with **Vietnamese speakers** in Malden and was moderated by an intern from Tufts University's undergraduate Community Health Program. It centered on **health issues and concerns of the local Vietnamese-speaking community**.

To include both CHA patients and non-patients, participants were recruited via flyers posted throughout CHA's primary service communities (**Cambridge, Somerville, Malden and Everett**) and through phone calls to the clients of the community health workers in Community Affairs. All potential participants were told that their decision to participate or not in the focus group would have no effect on the health care services that they receive from CHA. Participants were given a \$30 stipend.

Before the guided discussion with participants, the moderator introduced the purpose and the format of the focus group, and informed the participants that the session would be taped. The moderator also discussed confidentiality issues with the participants. All participants were also asked to complete an anonymous survey collecting demographic information before the group started.

A report of each focus group has been compiled here in order to provide CHA staff and community members with a better understanding of some of the health issues affecting specific patient populations. Please remember that the information presented is general and was collected from a limited number of participants. The findings should be used as an aid to understand some of the populations who participated in the focus groups, not as a method of predicting the behavior of all members of a certain demographic group.

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FOCUS GROUP FAQs

What exactly is a focus group?

A focus group is an in-depth qualitative interview with a carefully selected group of individuals, facilitated by a moderator, designed for sharing insights, ideas, and observations on a topic of concern.

Why were these specific focus groups held?

These focus groups were held primarily to assist Department of Community Affairs staff in program development. The primary care focus groups were held in order to explore the best ways to connect individuals to primary care physicians, and to gather information that could be used to create wallet cards, videos and computer education modules that would help community members navigate the health care system. The women's health focus groups explored the health needs of Cantonese-speaking women in the Cambridge Health Alliance's service area, and gathered information needed to aid in promoting a discussion of breast health in this community. The focus group in the Vietnamese community was held as part of a larger needs assessment exploring health issues in Malden's Vietnamese community.

How many individuals were involved and how were they chosen?

A total of 81 individuals participated. The average group size was 12. Participants were recruited from local communities through flyers and word of mouth, as well as from among Community Affairs clients. Potential participants were then screened for eligibility.

Were focus group participants given an incentive for their participation?

Yes, all participants received a \$30 stipend for their participation in the group. Food was also served at all groups, and participants were provided with taxi vouchers, if transportation to and from the group was needed.

How were focus group questions written?

Focus group discussion guides were created by Community Affairs staff (PCP discussion guides were based on a guide created by Dr. Randi Cohen of Beetrix Research and Consulting, LLC), and translated by the Cambridge Health Alliance's in-house translation department.

Who moderated the different focus groups?

The groups were moderated by staff members and interns from the Department of Community Affairs in the Cambridge Health Alliance, volunteers from the American Cancer Society, and a professional consultant moderator.

How was the American Cancer Society involved?

A generous grant from the American Cancer Society helped to fund the two Cantonese-speaking women's focus groups focused on breast health. American Cancer Society volunteers moderated these two groups and wrote the corresponding reports.

FOCUS GROUP SUMMARIES

FOCUS GROUPS ON WOMEN'S HEALTH:

CANTONESE SPEAKERS (65 years old and over)

Summary Findings: (June 26, 2003) The objective of this focus group was to gain insight into the participants' general health care practices, perspectives on breast health, and knowledge about breast cancer and prevention. Feedback from these Chinese seniors revealed their ability to access medical resources and health care providers adequately. For this group, language was not a barrier to healthcare access, as participants chose primary care physicians and hospitals equipped to address their language needs. Most participants were knowledgeable about breast health and breast cancer. Only one participant had never had a mammogram. The two most frequently cited barriers to breast healthcare were the length of time it took to get an appointment, and the amount of time spent waiting for providers and interpreters during the clinical visit.

CANTONESE SPEAKERS (under 65 years old)

Summary Findings: (June 26, 2003) Similar to findings from the 65 years old and over group of Cantonese speakers, this group of younger Cantonese speakers were able to access medical resources and health care providers. They also revealed that language was not a large barrier, as the primary care physicians and hospitals they chose were equipped to address their language needs. This younger group seemed a little less knowledgeable about breast health issues than the older group. Although most participants, at the urging of their doctors, had had mammograms in the past, six out of the eight participants did not know how to conduct breast self exams, and only one conducted them regularly. Long waits and the high cost of health care were the most frequent barriers mentioned by this group.

FOCUS GROUP ON HEALTH ISSUES IN MALDEN'S VIETNAMESE COMMUNITY:

VIETNAMESE SPEAKERS

Summary Findings: (August 10, 2003) The main purpose of this focus group was to understand the perceptions of members of Malden's Vietnamese community on important health issues and problems facing their community. Most participants used health care resources, including doctors and hospitals, located outside of Malden. Some indicated that the lack of interpreters prevented them from getting the health care that they needed. Most participants worried about potential adverse effects of the recent MassHealth cuts on health benefits. Participants stated that some of the biggest problems facing the Vietnamese community in Malden were TB, liver disease, and peer influence on drug abuse and smoking in children. Many said that they take care of their health by doing exercise or other physical activity, and by watching what foods they eat.

FOCUS GROUPS ON PRIMARY CARE & ACCESS TO HEALTHCARE:

The purpose of these groups was to understand how some of the linguistic communities served by the Cambridge Health Alliance view the importance of primary care in their own health care, and what they perceive to be the role of a primary care provider. Further objectives were to learn what obstacles make it difficult to access primary care in these communities, and to gather information that would assist in developing programs and tools to help eliminate some of these obstacles.

ENGLISH SPEAKERS

Summary Findings: (March 13, 2003) Seven out of nine participants in the group had a primary care provider (PCP), and everyone seemed familiar with the role of PCPs. Their major motivations for getting regular checkups from their PCPs included influence from friends and family members, having 'peace of mind', and recognizing the importance of preventative care. The long wait time to see their PCP and the brief clinical time that their PCP spent with them were frequently cited as factors that discouraged their seeking care. Several participants believed that patients with private insurance receive better care than those with MassHealth or Free Care.

HAITIAN CREOLE SPEAKERS

Summary Findings: (June 11, 2003) Participants in this focus group were aware of the need for primary care but seemed to seek their PCP primarily when they were sick. This group emphasized that a satisfying patient-provider relationship is a way to improve health and a way to improve communication and participation with providers in the health care setting. Common obstacles to accessing primary care included lack of time, language barriers, lack of health insurance, high cost of health care, poor quality of care, and previous negative experiences when seeking care.

PORTUGUESE SPEAKERS

Summary Findings: (November 19 & 21, 2002) Most participants in these focus groups had recently immigrated to the US from Brazil. They said that the role of the PCP in Brazil is more limited than in the U.S. While many participants did see their PCPs regularly when they lived in Brazil, many either did not have a PCP in the US or only saw their doctor when they were ill. Participants cited language and interpreter issues, lack of health insurance, the time it took to make and go to appointments, and the lack of a clear understanding of the American health care system as the main barriers to accessing healthcare.

SPANISH SPEAKERS

Summary Findings: (June 4, 2003) Participants in this focus group were aware of the need for primary care. Although the term 'primary care provider' was new to many participants, most were aware of the role of a primary care provider and its importance. Although participants said they would like to become more actively engaged in their own primary care, several key barriers exist, including communication issues and the lack of health care coverage due to cost.

FULL REPORTS

WOMEN'S HEALTH FOCUS GROUPS

CANTONESE SPEAKERS (65 + years old)

Summary Findings

(June 26, 2003) This focus group sought to understand both the participants' general health care beliefs and practices and their perspectives on breast health, including their knowledge about breast cancer and its prevention. Feedback received from these Cantonese speaking Chinese seniors indicated their ability to access medical resources and health care providers adequately, and showed that language did not pose a barrier for this group due to the fact that the participants chose primary care physicians and hospitals equipped to address their language differences. The majority of participants were quite knowledgeable about breast health and breast cancer, and all but one of the participants had had a mammogram in the past. The barriers to receiving breast health care most frequently mentioned by participants were the length of time it takes to get an appointment, and the amount of time they have to spend waiting for providers and interpreters once at the appointment.

Group Composition (N = 15, all female)

# of participants	 7 participants lived in Boston, 5 in Malden, 2 in Reading and 1 in Salem
1	 13 lived with their husbands, 2 lived with their children
1	 14 were Cantonese speaking, 1 Mandarin speaking but understood Cantonese
5	 13 had MassHealth, 1 had Tufts Health plan, 1 had no health coverage
1	 All 15 stated that they had a primary care physician (PCP)
	■ 14 reportedly had had mammograms, 1 had never had
	 one 12 stated they have had clinical breast examinations, 3 had not
	1

Media

All participants accessed information through Chinese media sources such as radio, cable television programs broadcast in Cantonese, and local Chinese newspapers such as *Sampan* and *World Journal*. Frequency of usage of radio and TV varied from occasionally to all the time.

Views on Health

Participants were asked to talk about their general views of health, including what does health mean, and how does one take care of their health. Most participants agreed that health means staying active, eating well, not being sick, and thinking positively. Participants stated that it is important to visit your doctor for routine physical exams. All of the participants mentioned that they go to physicians for medical care. Most of the participants prefer Chinese-speaking health care providers. The age and gender of the provider do not appear to be of concern.

All participants indicated that they are comfortable communicating with their primary care physician and/or specialists through interpreter services. Preferred hospitals are New England Medical Center and Beth Israel Hospital. Comments were made about the resourcefulness of social workers in helping the participants obtain MassHealth and other benefits such as free care.

Focus Group Questions

Focus Group Questions What does health mean to you?	 No sickness Our age should reflect our attitudes towards illnesses accordingly Positive thinking Routine daily schedules Feeling good emotionally, being able to exercise Engage in physical activities Participate in a variety of activities Sufficient sleep, stay away from smoking and alcohol Live, eat and do things in moderation Visit doctor(s): can find problems if you have any or otherwise get peace of mind if it is a clean bill of health The most precious thing in life
How do you take care of your own health?	 Physical and mental check-ups Routine physical exams Sense the physical changes [when] going through menopause
What types of health providers do you get health advice from?	Doctors
How do you select your health care provider(s)?	 Language, choose one who can accommodate The availability of Chinese-speaking interpreters is important Doctors who are responsible and have good bedside manners Doctors who are competent Geographic location Doctor's age does not matter Doctor's gender does not matter
Do you feel comfortable talking to your doctor about breast health issues?	All stated they feel comfortable talking about breast health with their PCPs. Many participants stated that their doctors took the initiative in discussing the subject.

Views on Breast Cancer and Breast Health

When asked what they know about breast cancer, including its causes and how it can be prevented, participants gave a variety of responses, many of which focused on living a healthy lifestyle. Participants also mentioned genetic inheritance as a factor involved in breast cancer, and said that

Caucasians are more susceptible to breast cancer than are Chinese. Participants in this group appeared to have few fears about breast cancer.

The majority of participants were aware of the need to have regular breast exams and mammograms, and most had done both in the past. Participants stated that they would take a combination of Chinese medicine and Western medicine if they had breast cancer. The general feeling appeared to be that breast exams, mammograms and surgery, if needed, are not pleasant, but are necessary. The main barrier to getting clinical breast exams and mammograms seemed to be the waiting time required to get an appointment, and the amount of time that the participants have to wait for their health care provider and interpreter once they have arrived at the appointment.

The participants gave collective answers regarding what breast health means to them and their experiences with mammograms or clinical breast exams (14 have had mammograms, 1 has not and 12 have had clinical breast exams, 3 have not). Common themes included:

- Need to have routine check-ups
- Doctors taught me how to do a self exam, you can do it yourself
- My PCP did not ask me to do a breast exam
- My PCP offered me the exam
- You can take the initiative to ask the doctor for the exam
- No difference than any other organ, it's part of your body
- I will take Chinese medicines
- Should be treated with a combination of both Western and Eastern interventions
- Must accept surgery
- Mammogram is uncomfortable, it hurts but it's worth it
- Feel embarrassed to be unrobed in front of male doctors (2 feel uneasy; others feel OK)
- None of the participants feel religion plays a role in influencing their decisions or views in managing their breast health

What do you know about breast cancer? Who do you think can get breast cancer?	 Breast-feeding makes you less vulnerable to develop it Genetic inheritance Caucasians are more prone to have it Influenced by alcohol and lifestyle habits
What do you think causes breast cancer?	 Smoking Eating B.B.Q. or deep fried food Drinking too much coffee Irregular lifestyle and routines Has to do with your emotions Side effect from taking hormone replacement pills
What fears and anxieties do you have about breast cancer?	 No fear, have lived long enough No fear, it is treatable if detected early enough Might affect other family member(s)

What reasons discourage or keep you from going to get a clinical breast exam or a mammogram?	 Wait too long for an appointment (2-3 months) The wait is too long for an interpreter Might be referred to a specialist, wait too long for a specialist Wait too long if going through the ER
Can you think of any ways that we could change some of these issues and problems, and get more people to go to see a doctor?	Make the wait shorter

Observations of the moderator and reporter

Out of 15 participants, 5 are from Malden, seven are from Boston, one from Reading, and one from Salem. The majority of participants have lived in the United States for more than 10 years and 3 have been here for over 20 years. Participants were outspoken and eager to express their thoughts. The moderator needed to use little effort to solicit their opinions. The participants appeared quite familiar with medical resources.

CANTONESE SPEAKERS (under 65 years old)

Summary Findings

(June 26, 2003) Feedback received from the participants of this group, similar to that gathered in the focus group with Cantonese speakers 65 + years old, indicated their ability to access medical resources and health care providers, and showed that the language barrier was not a pressing concern, as the primary care physicians and hospitals they chose were equipped to address their language needs. This younger group seemed a little less knowledgeable about breast health issues than the older group, and although the majority had had mammograms in the past at the urging of their doctors, six out of the eight participants did not know how to conduct breast self exams, and only one conducted them regularly. Long waits and the high price of health care were the most frequent barriers mentioned by this group.

Group Composition (N = 8, all female)

Age range	# of participants	 All participants lived with their family, spoke
20-29	1	Cantonese as a first language, and reported
		having primary care physicians (PCPs)
30-39	1	 4 participants lived in Malden, 1 in Reading, 1
		in Stoneham, 1 in Charlestown, and 1 in Quincy
40-49	5	 3 had MassHealth, 4 had private HMO plans,
		and 1 had no healthcare coverage
50-59	1	 5 reportedly had had mammograms
		 7 stated they had had clinical breast
		examinations, 1 had not
		• 6 people had been in the United States for more
		than 10 years, and two for less than 3 years

Media

Participants stated that they accessed information through both Chinese and English media, mostly from TV (especially cable news) and Chinese newspapers like the World Journal, North America News, Sin Tao Daily or Sampan. Radio reportedly was rarely listened to. Frequency and time of watching TV programs and reading newspapers varied from occasionally, to randomly, to all the time.

Views on Health

Participants were asked about their general views on health, including what health means, and how they take care of their own health. Most participants agreed that health means eating well, and being in good mental and physical condition. Participants said that causes of illness include unhealthy lifestyle choices, such as a bad diet and lack of exercise, as well as stress and genetic inheritance. Participants stated that they take care of their health by getting regular physical exams, exercising, and taking both Western and Chinese herbal medicines. Participants generally chose their health care providers based on the health insurance that they have. The majority seemed to prefer Cantonese-speaking doctors, and they also said that it is important for health care providers to be patient and have a good attitude. Participants felt strongly about the importance of medical insurance in preventing financial disaster in case of accident or illness.

What does health mean to you?	 Eat and sleep well Eat healthy diet (i.e. vegetarian) In good spirits Have good moral character, be in good physical condition and have wisdom
What are the causes of illness?	 Work Stress Diet Lack of exercise Insufficient rest Genetic inheritance Nature of the body
How do you take care of your own health?	 Talk out the stress (might work both ways, what if people gossip about you!) Routine physical exams Jogging, exercise Take Chinese herbal tonic Take advantage of both Eastern and Western medicines
What types of health providers do you get health advice from?	 Doctors
How do you select your health care provider(s)?	 Your health insurance dictates who you might have as doctors Use less expensive coverage plan Employer dictates what coverage plan you might have Doctor's attitude, will change PCP if I don't like his/her attitude Doctor needs to be patient Detail-oriented doctors Language, preferably Chinese Doctor's gender; 2 prefer female doctors over male doctors Have Chinese PCPs, but does not matter for ER doctors or specialists
Why is health care coverage necessary?	 One participant talked about how important it is to have sufficient health coverage. She told a story about a couple she knew who were involved in a car crash and accrued a medical bill of 4 million dollars during a 2-month hospital stay. In conclusion, all participants felt strongly about having some coverage to prevent financial disaster from happening if catastrophic medical services are ever needed. Participants also commented that MassHealth might be considered if one meets the income guideline

How do you feel about asking your doctor questions about your health?	 Language differences can be a challenge (interpreter is needed, sometimes) Sometimes do not feel like going along with doctor's intervention or treatment plan
Do you feel comfortable talking to your doctor about breast health issues?	All stated they are at ease talking about breast health with their PCPs.

Views on Breast Cancer and Breast Health

When asked what they know about breast cancer, including its causes and how it can be prevented, participants gave a variety of responses, many of which were focused on living a healthy lifestyle. Participants also cited genetic inheritance as playing a role in breast cancer, and said that Caucasians are more prone to getting it than are Chinese. Participants stated that early detection of breast cancer is critical, and some stated that they have fears about breast cancer, while some do not. Participants said that breast cancer is preventable through lifestyle changes. Only one out of the 8 participants regularly conducted self-breast exams, while 6 did not know how to do them. Five out of eight of the participants had had mammograms at their PCP's request.

The main barriers to getting clinical breast care seemed to be:

- Long waits (both to get an appointment, and in the waiting room when at the appointment)
- High cost of health care

Some of the other key points that emerged out of this discussion were:

- Self exam can be learned.
- 2 participants knew how to do a breast self exam, 1 of the 2 did it routinely, 6 did not know how to do it
- Medically compliant because of "fear to die"

What do you think causes	 Genetic inheritance
breast cancer?	 Caucasians are more prone to have it
	 Influenced by alcohol and lifestyle habits
	 Improper diet (i.e. fried food) and smoking can be causes
	 Higher risk if not breast-feeding
	 Single, unmarried women are at higher risk, as women
	who do not give birth have higher chances
	 Birth control pill users are at a higher risk
	 Using cell phone makes one more prone to develop cancer
	(breast cancer included)
	 Have fears about it
Is breast cancer	 Yes, monthly self exam
preventable? If so, how?	 Vegetarian diet, avoid food additives, preservatives,
	canned goods
	■ Diet

	Adjust your moodLifestyle and habits can be modified
What fears and anxieties do you have about breast cancer?	 No fear Don't feel it will bother family members No concern about breast disfiguring, cosmetic surgery is readily available
What reasons discourage or keep you from going to get a clinical breast exam or a mammogram?	 Wait too long for an appointment Wait too long in the waiting room Co-payment too high for office visit Medications are too costly
Can you think of any ways that we could change some of these issues and problems, and get more people to go to see a doctor?	Hope to not need to wait that long and cost is more affordable.

Observations of the moderator and reporter

Out of 8 participants, 4 are local from Malden, one is from Reading, one from Stoneham, one from Charlestown and one from Quincy. Six out of the eight participants have lived in the States for more than 10 years, and the other two are newcomers, having been here for less than 3 years.

Seven (7) participants were very expressive and verbally forthcoming in sharing their thoughts. A newcomer was quiet but would answer questions when given the opportunity. Another newcomer who does not have health coverage stated that she exercises "self care" by taking vitamins that are reportedly high in antioxidants while boosting up her immune system with high vegetable intake.

Participants were observed to be outspoken and eager to express their thoughts. The moderator needed to make little effort to solicit opinions. Like the senior group, this group appeared to know how to seek and utilize medical resources. This group, however, had less to say re: "what does health mean to you?" as compared to the senior group. Some of the participants appeared to know each other or the recruiter prior to the meeting. Answers to the questions given by this group of participants seemed to be quite homogeneous.

FOCUS GROUP ON HEALTH ISSUES IN MALDEN'S VIETNAMESE COMMUNITY:

VIETNAMESE SPEAKERS

Summary Findings

(August 10, 2003) The main purpose of this focus group was to understand the perceptions of members of Malden's Vietnamese community on important health issues and problems facing their community. Many of the participants used health care resources located outside of Malden, including doctors and hospitals. According to some of the participants, the lack of interpreters sometimes prevented them from getting the health care that they needed. Most of them worried about the recent MassHealth cuts and how they could affect their health benefits. According to the participants, some of the biggest problems facing the Vietnamese community in Malden included TB, liver disease, and peer influence on drug abuse and smoking in children. Most of the participants said that they take care of their health by doing some form of exercise or physical activity, and watching what foods they eat.

Group Composition (N = 14, 5 males and 9 females)

(11 – 14, 5 maies and 9 females)		
Age	<u># of</u>	■ 13 Malden residents, and 1 Everett resident
Range	<u>participants</u>	 When asked what language they speak most often at home,
		all 14 participants said Vietnamese
30-39	1	 All participants lived with family members
		 Most of the participants shared their time between caring for
40-49	1	their husbands, grandchildren, and their own children;
		tending to household chores; eating; walking; and gardening.
50-59	1	2 participants work in factories
		 Participants' length of residence in Malden ranged from 2 to
60-69	6	13 years
		 Health Coverage: 7 participants had MassHealth, 1
70-79	5	participant had Mass Health/Free Care, 1 participant had
		Blue Cross Blue Shield, 3 participants had Free Care, 1
		participant did not have insurance, and 1 participant did not
		respond to the question
		 Primary Care Physician (PCP): 6 participants had a PCP, 3
		participants did not have a PCP, and 5 participants did not
		answer the question

Best Ways to Reach the Vietnamese Community in Malden with Health Information:

All of the participants accessed information through Vietnamese newspapers such as *Tieng Chuong*, which they obtained from Vietnamese markets. Most of the participants agreed that their children inform them of current events. In terms of radio usage, one participant listened to the news via a Vietnamese station broadcast by the BBC. In regards to television usage, several of the participants watched ABC, CBS, NBC and CNN. There is a Vietnamese newscast from California, which unfortunately comes on at 12 am, limiting many of the participants from viewing the program. One participant used the internet to learn about current events.

When asked about the best ways to reach people with health messages and information about the Cambridge Health Alliance in the future, many of the participants agreed that there is a lot of written news in Vietnamese, but there are not many visual news outlets on television networks. Some of the participants suggested that it would be wonderful to have a news program, or a segment geared towards the Vietnamese on Malden's Channel 3. Channel 3 is a locally based station that already has some programs geared towards the Cambodian community in Malden.

A suggestion was made to have a monthly pamphlet written in Vietnamese distributed at the Sacred Heart Church. All of the participants agreed that this method would be the easiest way to deliver information since having a Vietnamese program or segment on Channel 3 would be difficult to obtain. Another suggestion made was to have pamphlets written in Vietnamese left at Vietnamese markets and restaurants, since many of these businesses have large numbers of Vietnamese customers.

Views on Health

Participants were asked about their general views on health including what health means to them, what especially interests them about their health, whether they had specific health concerns, and how they take care of their own health. Most of the participants agreed that health is the lack of illness. Health was considered very valuable because it allows the participants to carry on their daily lives.

Cuts in MassHealth were of great concern for many of the participants. MassHealth was used by many of the participants to obtain routine health care and to purchase prescription drugs. From the responses that were given, it seems that several of the participants who had Mass Health had recently lost specific benefits that they had in the past, while other participants seemed to worry about losing all of their MassHealth benefits. All of the participants agreed that staying active, exercising regularly, and eating a healthy diet are important to maintaining one's health.

rocus Group Questions	
What does health mean to you?	 Health is more valuable than gold; it is very important If you have health, you can help your children and grandchildren, and your children don't have to worry about you Health is when you don't have to worry about dying, which allows you to have a better life Health is what is maintained when you have MassHealth and medicine. If you are sick, MassHealth or Medicare can help, but if the benefits are cut, then you won't be able to take care of yourself.
What especially concerns you regarding your health?	 Intestinal problems Inability to eat and sleep Weak heart Ulcers Hearing problems Coughing problems High cholesterol, getting appropriate treatment High blood pressure Aches and pains in joints

	 Diabetes, genetic diseases Fear of dying Poverty Language barriers, the need for interpreters Children disobeying a parent, which causes many worries, leading to health issues High cost of medication cannot take medication that a doctor prescribes because of the high cost If the state provides financial coverage, there is less worry than if the state did not provide coverage MassHealth cuts—worries about the future of their health and the ability to pay for health care
How do you take care of your health?	 I don't know how or what to do to take care of my health Refrain from eating fatty and salty foods, eating healthy Stay active to keep the body healthy. If one cannot do strenuous work, one does light work. Walking Doing housework Taking grandchildren out to play
What comes easily when taking care of one's health?	Eating healthyKeeping active
What's more difficult when taking care of one's health?	 For men, giving up cigarettes For women, limiting consumption of salty foods
What do you think are some of the causes of illness?	 God Consuming a lot of fatty foods Too many worries, which affects the state of one's health, leaving one susceptible to illness Lack of exercise
Where do you go for health care?	 Vietnamese family doctor in Malden Boston Medical Center Dr. Le Chinh in Dorchester American doctor at New England Medical Center American doctor in Burlington Chinese doctor in Malden Family doctor in a hospital in Everett Two doctors, an American doctor and a Vietnamese doctor at Dorchester House ** Those that use American doctors use interpreters. However, when interpreters are not available, they usually miss their appointments because they cannot communicate in English.

	It was not clear from the responses given what the participants use as their mode of transportation to get to their appointments.
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Health in Malden's Vietnamese Community

According to the participants, some of the health problems facing the Vietnamese community in Malden included TB, liver disease, drug abuse among youth, joint pain, and poor eyesight in the elderly. Liver disease was expressed to be particularly serious and quite common. Other specific health problems mentioned include alcohol consumption in men and cancer in women.

Some of the participants mentioned general problems that prevent them from seeking the health care they need, including the cost of health care and prescription drugs that have risen as a result of MassHealth cuts. Moreover, language problems are a concern for many. Some of the participants miss their doctor appointments because an interpreter is not available. Other barriers included time, transportation, and childcare.

To improve the health of the Vietnamese community, participants suggested that there be a health education resource center, a free vaccination program, financial aid to help with the high costs associated with health care, and an increased number of interpreters in healthcare facilities.

Focus Group Questions	
What are some of the health problems or issues facing the Vietnamese community in Malden?	 TB Liver disease Drug/marijuana abuse in children Heart disease Lack of a free, community vaccine program such allergy shots Availability of medication for treating joint aches and pains in the elderly Poor eyesight among the elderly, cost associated with lenses
What are some issues specific to men's health?	 Drinking alcohol, beer Cigarette smoking Worry associated with the notion that men have a shorter lifespan than women do
What are some issues specific to women's health?	 Aches and pains Cancer for older women Vaginal discharge High cholesterol
What are some issues specific to children's health?	 High school peer influence which can lead to drug abuse and smoking

	 High fever Fear of young children transmitting diseases to each other
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Wallet Card as a Tool to Communicate with Health Providers

Many of the participants said they would use a wallet card to remind them of important questions to ask their health care provider. However, all of the participants agreed that the questions on the card should depend on the individual's circumstances. Most of the participants stated that they already bring along a sheet of paper with a list of questions to ask during their appointment. When asked what type of questions they would like to see on the wallet card, the following were suggested:

- Questions concerning medications that one is already taking.
- What is the cause of the illness?
- What are the symptoms?
- How do you treat it?
- What medicine do you take?
- How long do you take it?
- Is the illness serious, or dangerous?

Observations of the Moderator

The focus group was held in the meeting room in the lower rectory of Sacred Heart Parish in Malden. No more than ten participants were expected, but it was very difficult for the moderator to turn the extra four who showed up away. For this reason, 14 participants participated in the focus group.

Out of the 14 participants, 13 were from Malden. One participant was from Everett. The majority of the participants had lived in the US for more than 10 years, with two individuals having been in the US for more than 20 years. Another two participants had arrived in the US 3 years ago and one woman had arrived 2 years ago.

MassHealth cuts have clearly left many of the participants worried about their health care. A majority of the participants were very vocal on this particular issue.

FOCUS GROUPS ON PRIMARY CARE & ACCESS TO HEALTHCARE:

ENGLISH SPEAKERS

Summary Findings

(March 13, 2003) 7 out of 9 participants in the group had a primary care provider (PCP), and everyone in the group seemed familiar with the role of PCPs. Main motivators for the group in getting regular checkups from their PCP included influence from friends and family members, having 'peace of mind', and the importance of preventative care. The amount of time they had to spend waiting to see their PCP, and the brief amount of time that their PCP spends with them, were mentioned frequently by participants as factors that discourage them in getting care. There was also the perception from several of the participants that patients with private insurance receive better care than those with MassHealth or Free Care.

Group Composition (N=9, 4 male, 5 female)

Age range: 26 - 48	 Participants were from Cambridge, Somerville, Everett and Melrose, MA. Most had lived in the Boston area their whole lives. The majority of the participants were Caucasian. One of the participants was Brazilian, and said she spoke both English and Portuguese at home, while the other participants said that they only spoke English at home. Health Coverage: Five participants had MassHealth, two participants had Free Care, one participant had private insurance, and one participant was uninsured. Primary Care Physicians (PCPs): Two participants did not have a PCP, but the rest of the group did. Of those who did have a PCP, six participants had last seen their PCP one year ago or less and one participant had seen his PCP two to three years ago.
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Views on Health

Participants generally agreed that it is very important to be healthy. Several people said that getting older had made them focus more on their health. It was also a common theme for people to have become interested in certain aspects of health because they had friends or family members with those conditions. There was a discussion among several people who said that they didn't want to know what was wrong with them; as one participant noted, "I just want to wake up and be in heaven." Participants also mentioned that they felt it was hard to deal with doctors and diagnoses when they had MassHealth, Free Care, or were uninsured.

Focus Group Questions

What does health mean to you?	 Everything. If you don't have your health you don't have anything. Mental health is very important. Healthy mind, healthy body. You have to take care of yourself before anything [else]. Health is feeling good, a good sense of physical well-being.
What is it about your health that especially interests you?	 All of it. There isn't one part of it that's more important than another. Osteoporosis—sees what friend with osteoporosis goes through Cancer Healthy eating/dieting—need to change eating habits because heart disease runs in the family Getting in shape/exercising Maintenance of current health and becoming healthier Stopping smoking Knee and back problems
What is difficult for you in taking care of your health?	Participants had already mentioned that eating right, exercising, and giving up smoking was difficult for them.
What comes easily?	 Sports Walking Slow, small exercises. Have to do something that's not too hard in order to finish. Eating right Holistic healing, alternative medicines
How do you get information about your health? How do you decide what to choose to do or what's not for you?	Several people said that they use the Internet. They go to search sites and search for topics. Already know a lot Word of mouth Don't think about health until something's wrong. When something's wrong, go to the hospital.

Primary Care Providers

There was a general agreement that participants were familiar with the phrase "PCP," and knew that it stood for primary care physician/provider. Participants expect their PCP to have time for them, but a lot of complaints were made regarding the typically long wait time for a doctor and the feeling that doctors try to rush through appointments.

Two of the participants were twin brothers. One had a PCP, and the other did not. The one who did not said that he hates going to the doctor. The other twin got his PCP after being hospitalized for bipolar disorder.

Focus Group Questions

How did you get your PCP?	Group members reported a number of different ways that they had obtained their PCP. Prior PCP was too busy, called to find new PCP Word of mouth Sent to PCP by MassHealth Can't remember if self-selected, or assigned Female participant wanted a male PCP; her PCP was the only man available. Randomly picked their PCP
What, personally, do you expect from a PCP?	There was a general consensus that participants expected that their PCP would have time for them. Many people felt that their PCPs were too busy, and tried to rush them through their appointments. We heard that people wanted their PCPs to give them their undivided attention while they were at the appointment. There were also a lot of complaints about having to wait at the doctor's office. Other responses included: PCPs should be knowledgeable. PCPs should be compassionate, a good listener, honest. PCPs should know their limits; know when to make referrals to another physician.

Motivations & Barriers

Several general themes emerged about what motivates or inspires participants to go to their PCP. One motivation was to obtain "peace of mind," while another was the experiences of friends and family members (e.g. pressure from a friend or family member to go or knowing someone who had experienced health problems). Another motivator mentioned by participants was preventative care, including having a regular check-up, or a pap smear. Most participants agreed that people should get a yearly physical. A few of the participants said that they have regular checkups in order to target possible health problems before they begin.

Additional responses about what motivates or inspires participants to go their PCP included:

- To stay healthy for their children and to set a good example
- Experiencing discomfort or pain
- Sports injuries
- Professional requirement (Needed to renew barber's license every two years)
- To get monthly medications, and find out about new treatments for pre-existing health problems
- Go before MassHealth and Free Care get cut

When asked what discourages or prevents participants from going to their PCP, waiting too long for the doctor was a very common theme. One participant said that she gets all of her care at the ER, because

she knows that she will have to wait at the ER, so she doesn't mind it, but she hates having to wait for an appointment. Some participants said that if they have to wait, they wouldn't mind it so much if they were kept updated on how long the wait would be, or if the physician or other staff members apologized. Many participants said that when it comes to waiting, they would like to be treated with more courtesy.

Some participants had the perception that people who have private insurance get treated better than those with public or no insurance. They also thought that the quality of care that people with MassHealth and Free Care receive is lower. Other participants disagreed. One participant said that she has had all types of insurance, and gets the best care she's ever had now that she has MassHealth. Another participant said that without MassHealth, she would never be able to go to the doctor.

A couple of other barriers that were mentioned by several participants were a fear of needles, and a feeling that doctors are overbooked, which causes the doctors to have to rush too much, which influences them to be too inattentive.

Other comments about what discourages or prevents participants from going to their PCP included:

- Don't want to know what's wrong
- Feel healthy, feel like there is no need to go
- Language barrier. All of the reading materials are in Spanish. People at the front desk do not understand her.
- One participant said that she gets labeled as pain medication-seeking based on her age, race, and appearance. She is questioned when she says that she is in pain, and feels that she is being profiled / stereotyped. She believes that there is a lack of empathy from physicians.
- Don't trust doctors / fear of inexperienced doctors
- Physicians don't have any compassion. They just want to make money.
- Hard to find time during the day, difficult to take off work, also too busy with other activities
- If you work far away from your doctor's office, this makes it harder
- Picked PCP based on location, but hard to get to specialists' offices.
- Fear of surgery—had it once, and didn't like it
- Don't like being passed between providers in practice—want to see the same provider every time they go to the doctor. "Nobody follows you."

Suggestions for Improvement

	 Extended hours, at least one day per week
What could be done to	 More doctors, so that doctors won't be overburdened and they
improve things?	can take more time with their patients
	 Need better accommodations for children. Nothing for kids to
	do if they are accompanying their parents.
	 Waiting room needs to be comfortable
	 More training for doctors on improving their bedside manner
	 If care was made equal for everyone, rich people wouldn't get
	better care, and so then everyone would go to the doctor
	 Patients will seek healthcare more often when they feel like the
	doctor is caring and listening.

	 Would be more willing to put up with delays if patients were treated better House calls
Have you ever told your PCP your complaints?	 Three or four participants said that yes, they had complained. One participant had complained to her physician and everyone else in the office. She felt that that she has been treated better because she has complained. One participant walked out of the PCP's office after feeling she had been waiting too long. One participant said that he has complained several times, and physicians' responses have varied. Some ignored him. Some apologized. He doesn't feel like anything changed after he made the complaints.
Have you ever filled out a patient satisfaction survey?	 Several people said that they have filled out surveys before. A couple of people said that they had never been offered surveys. In general, the participants thought that surveys should be handed out more often.

Mental Health Care

Several people regularly receive mental health care. One participant says that her clinician is great, and does not treat her differently because she has MassHealth. Another participant goes to Victims of Violence counseling. She mentioned, however, that programs often run out of funding and clinicians leave, forcing her to switch clinicians, which she finds unfortunate. She also thinks that the appointment times are too short. There was also a general discussion about the fact that insurance only allows you a limited amount of mental health care visits or hospitalization days per year—all of the participants thought that this is a problem. A couple also said that they think there's too much emphasis on giving people medication. Participants also said that they thought that mental health care should not be "such a business."

Other Comments

Several participants said that they thought Mass Health puts too many restrictions on doctors, thus limiting their ability to treat patients. One participant disagreed.

HAITIAN CREOLE SPEAKERS

Summary Findings

(June 11, 2003) The discussions generated by this focus group conducted in Haitian Creole indicate that participants are aware of the need for primary care. However, for the most part participants seemed to go to their PCP primarily only when they're sick. This group's discussions emphasized a satisfying patient-provider relationship as a way to improve their health as well as a way to improve communication and participation with providers in the health care setting. Common obstacles to accessing primary care included not enough time, language barriers, lack of health insurance, high cost of health care, poor quality of care, and previous negative experiences when seeking care.

Group Composition (N=8, 3 male, 5 female)

Group Composition (11–6, 5 maic, 5 remaie)	
Age range: 26 - 64	 The group consisted of two Cambridge residents, four Somerville residents, and two Malden residents When asked what language they speak most often at home, six participants said Haitian Creole, one said English and one said French and Haitian Creole. All participants lived with family members. All participants shared their time between work, home, and social activities such as church and school. Health Insurance: three participants did not have any type of health coverage, two participants had Free Care, one participant had MassHealth, one participant had private insurance, and one participant did not answer this question. Primary Care: three participants did not have a primary care provider, two had one, one was unsure, and two participants did not answer this question. Four participants said they had seen their primary care providers in the last year.

General Ideas about Health

Most participants agreed that a healthy person feels good and is able to function during daily activities. Important health issues mentioned included nutrition, physical activity, and access to health care. Specific health concerns included nutrition and physical activity as well as environmental concerns such as trash in one's neighborhood and exposure to cigarette smoke.

What does health mean to you?	 Health means a total well being Health is when you can go about your daily routine without any pain Health is when nothing bothers you; you have no pain whatsoever Health is when your body is in good shape and you can function
	 Health is when your body is in good shape and you can function normally Health is when you have nothing to complain about When you're healthy, you have no symptoms of disease

How do you take care of your own health?	 You can take care of yourself by the way you eat. I don't put much salt, spices and oil in my food. Going to the doctor when I feel sick You could be eating well and not feel healthy. The most important thing is that you should see a doctor when you don't feel well. I try to eat well and do what my doctor recommends. That's what keeps me going. I exercise and I feel good Sometimes, it's difficult to go to the doctor even if you want to go because of health insurance or language barriers Some people might want to go see a doctor but they don't have the necessary information. They might not know about the services available.
Do you have any specific concerns about health issues?	 Bad nutrition is a big issue in our community. What you eat and drink is responsible for how healthy you are. People don't eat well and they put too much oil in their cooking. This can't be good for our health. Environmental issues. Sanitation is a big concern for me. In my neighborhood, you can see trash on the street. For me, cigarette smoking is a big issue. I don't smoke, but too many people are smoking [around me] and I know that that can cause diseases. Exercise is something that most people don't do and it's a big concern. The way you dress or not dress can make you sick too. You can get cold from dressing too lightly.

Primary Care Providers (Definition, meaning and role)

Most participants indicated that they rely on their PCP only when they are sick or need certain tests, although one participant mentioned that a PCP is a good resource for learning about prevention. The provider-patient relationship appeared to be very important to participants; they wanted PCPs that spend time with their patients, make patients feel comfortable, and act as a counselor.

When asked for suggestions that could improve communication and involvement between patients and providers, participants thought that preparing a list of questions to ask a provider is a good idea. Other ideas included: spending more time with the provider, being more comfortable with the provider, and choosing a provider that speaks Haitian Creole.

When you hear the phrase primary care provider (PCP), what comes to mind?	 A Primary Care Provider is someone who takes care of you when you're sick It's someone you can call when you're sick A PCP is someone to whom you can tell everything about yourself, your health. You can't hide things from that person. It's someone you should feel comfortable with in order for him to be able to help you find a solution to your health problems Someone who can help you take prevention measures, giving you information regarding staying healthy. For example, HIV is something that can destroy your family, your community and even society. Your doctor would give you advice on how to behave in order to protect yourself and your family.
What does a primary care provider do for you?	 The doctor gives you a check up. They can check your blood pressure, vision, heart, ears, and lungs. This doctor sends you for blood tests to check your glucose level, cholesterol, etc. When I go to the health center, they usually check my blood pressure and weight. Then, I wait for the doctor. The doctor asks me questions about my health. Sometimes you think you have a specific problem, but when you go to the doctor, he finds something else. He will prescribe medications for you to take and you will feel better.
Who do you consider to be a primary care provider?	 I think that people who work at the health centers are primary care providers. Doctors, nurses, nurse practitioners are primary care providers.
What is the role of a primary care provider in Haiti?	I don't think the role of a primary care provider is any different in Haiti or any other country. They all do the same thing. The only difference is that the providers here have access to better material and they speak a different language.
For those of you who do not have a PCP, how do you think you would go about getting one if you wanted one?	 I can go to a health center and apply for free care and people there will refer me to a PCP. You have to have health insurance in order to have a PCP. I think in a group setting like this people can get advice from [each other] in terms of how to get a PCP. I'm assuming your department can help me find one. Listening to the radio and TV, you hear people talking about how to get a PCP, also by talking to friends who have a PCP. You can get a PCP by listening to what other people say about the person.

For those of you with a primary care provider, how did you get yours?	 I got my PCP from a group education done at St. Ann Church. The hospital referred me to my PCP.
If you have a primary care provider, how often should you go?	 You should see your PCP every month. (Said 3 participants) I see my PCP every 3 months because I'm not so healthy. A person should visit his PCP twice a year. It depends on your health and your provider. I usually go to my provider when I feel sick and get new prescriptions.
For those of you with a primary care provider, what do you personally expect from your PCP?	 It has to be someone who is in close collaboration with me; I must have his address and phone number, his schedule. Someone I can call whenever I need him. He has to be working for me, for my advantage. Someone who likes what he is doing, who likes his patients and makes you feel comfortable. No matter what kind of a health problem I have, I would feel comfortable telling him. You don't want to feel awkward when talking to your PCP. A PCP should be a good counselor, someone you can trust A PCP should be a friend and a counselor Your PCP should be as close to you as your parents; you should be able to tell him anything.

Motivations & Barriers

Focus Group Questions For those of you who have seen a PCP, can you remember why you saw him or her?	 Sickness Headaches and other kinds of pains High blood pressure Dizziness Heart disease Pregnancy Fever and cold Cuts and burns Pain in general
What has stopped you from going, or what has kept you from going in the first place?	 Fear: syringes, anesthesia, injections, blood drawing, etc. Language barrier No health insurance No money Bad treatment (past treatment) Time: no time because of work schedule or knowing that you will spend too much time at the appointment.

How can we improve	 More evening and weekend hours in the clinics
things?	 More health centers with Haitian providers in Malden, Everett, and Lynn. We have a good Haitian doctor at North Cambridge, but it's too far for many people. A daycare center at the hospital Make sure front desk people are friendly with patients Group education for the community More free ESL classes Inform people about Free Care and how to obtain it

Participants were also asked if any of the following issues were of concern to them when accessing primary care:

Focus Group Questions	_
Insurance	 Insurance can be a big problem because if you don't have insurance you can't see a doctor Sometimes, you would like to have insurance, but your job does not offer it I know Cambridge Hospital offers Free Care, but not everybody knows about it
Childcare	 I have two children. When I go to the doctor, I have to take them with me most of the time. I can't even focus on my visit because of them. I would like to leave them somewhere, but you have to have the money for that. Babysitting is a big problem. I'm here tonight with my kids. That's a big example.
Interpreters	 An interpreter being around is both good and bad but sometimes you don't have much of a choice. Sometimes, you have a problem that you don't want a third person to know about. Yes, you don't want people passing judgment on you. If you don't speak the language, you have no choice. Sometimes, only you can explain what you want to say.
Transportation	 That's not an issue. If someone doesn't have a car, you can always catch a bus or take a train.
Time	 Time is one of the biggest [barriers]. You can't be late or call in sick to work when you have an appointment. It's not very possible to get an appointment on your day off. A doctor sees too many people per day. That's why you have to wait so long when you go to the appointment. We need more doctors.

Religion	 Yes, some people believe in natural medicine and that stops them from seeing the doctors Some religions don't believe in certain health practices such as blood transfusion
Quality of Care	 Quality of care is a concern for some people depending on where they go for care and who the provider is. Sometimes, your own people treat you worse. I remember once I went to a clinic, and I saw a Haitian provider. I knew he was Haitian, but he did not speak Creole with me. I had to struggle to talk to him. He did not want people to know he was Haitian. Front desk people can be rude.

Communication with Primary Care Providers

Participants were asked to talk about their own experiences with primary care providers. How do they feel about actively participating in their health care? How could they become more involved and engaged in their own health care? Participants agreed that preparing a list of questions to ask a provider is a good idea. They also agreed that having a friend or a family member there could help in many ways, but sometimes they don't want the person to be in the exam room with them. Other things suggested to improve communication and involvement included spending more time with the provider, being more comfortable with the provider, and choosing a provider that speaks Haitian Creole.

How do you feel about asking your PCP questions about your health? Do you feel comfortable explaining your symptoms to your PCP?	 Everyone should feel comfortable to ask questions to their PCP, I do. I think it's important to ask questions
Do you understand the information your PCP gives you about medications you are taking?	 My PCP usually explains everything to me Sometimes my doctor explains about the medications" My doctor always gives me details about any medication he gives me. If I don't understand something, I ask him.
What do you think about preparing and bringing a list of questions to your PCP?	Everyone agreed that's a good idea to bring a list of questions when they are going to the PCP visit.
Do you use the internet to learn about a particular health issue before you visit your PCP?	Only 3 people used the Internet to learn about health issues before they go to their PCP visit.

Do you feel capable of making decisions about your health care?	The majority of participants said that they feel confident to make their own decisions, although two patients said: I have the doctor to make decisions for me. It depends on the decision and how healthy I am when I need to make it.
What do you think would help you to become more actively involved in your health care?	 Spending more time with the doctor might help me get more engaged. Doctors don't spend enough time with patients. Be comfortable with the provider. Having a provider who speaks Haitian Creole could
	definitely help me.

Technologies for Health Education

Participants were asked about computer ownership and use, and their preferred ways to learn health information. They were also asked how they would like to receive health information (e.g.: newsletter, internet, etc.). Most participants preferred learning technologies that patients can both look at (read and/or see pictures) and hear at the same time. They feel that computer-based learning has a lot of potential but will work best only for the most literate people in the community.

Three participants owned a computer, and said they use it every day for various purposes, including general internet search, word documents, games, e-mail, etc. Those three participants liked the idea of the use of a CD-ROM to learn about health issues. None of the participants used a computer at work. All participants owned a VCR and three participants had DVD players, and they all thought that it would be a great idea to have information on specific health issues available on video/DVD.

When asked about the types of community settings that would be suitable to introduce a computer program that provides health information, participants suggested clinic or hospital waiting rooms. They thought that putting such a program in a church, particularly in locations that are dedicated to such activities, could be successful as well. They do not recommend implementing the computer program in areas for religious services. Beauty salons could also be a great location, but the information has to be very brief or else customers will not be able to finish viewing the entire program. Other places suggested included libraries, schools, pharmacies, and malls. Participants stated that grocery stores would not be a great location to present the computer program because people will not take the time to use it at a grocery store.

Participants indicated that a group talk or discussion was their preferred way to receive information, but thought that the radio and TV are also good sources of information. They maintained that the idea of computer programming or DVDs would not necessarily work for all members of their community.

PORTUGUESE SPEAKERS

Summary Findings

(November 19 & 21, 2002) The majority of participants in this group had recently immigrated to the US from Brazil. In general, participants said that the role of the PCP in Brazil is more limited than it is here. Although many participants saw their PCPs regularly when they lived in Brazil, many did not have one in the US, or only saw one when they were sick. Some of the main barriers to receiving health care mentioned by participants included language and interpreter issues, health insurance, the time it takes to make and go to appointments, and the lack of a clear understanding of the American health care system.

Group Composition: (N=21; two groups were held, with a roughly equal male to female ratio)

<u>Age range</u> : 27 - 44	 All group participants were Brazilian. They had been living in the US for a relatively short period of time, ranging from three months to five years. About half of the participants had lived in the US for less than a year. One participant had been alternating between Brazil and the US for 15 years. Most of the participants were married and lived with their families; however, several mentioned that their immediate families were living in Brazil.
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Media & Communication

When participants were asked how they prefer to access information, the most popular response was newspapers. Newspaper preferences included: Brazilian Times, A Noticia, Diario Brasil, Jornal do Brasil, Boston Globe, Boston Herald, and Metro. Participants read the newspapers at all times throughout the day. One participant said it helps that some of the newspapers are free. Other popular sources of information included the radio and television. In terms of radio usage, participants listened to 106.7 FM, 1030 AM, NPR, and various other FM stations. They listened to the radio during the workday, in the evening and in the car. Regarding television usage, the participants liked to watch news and informational programs (Telemundo, Univision, CNN, Animal Planet, and Discovery), cartoons (Cartoon Network), and shows on leisure/cultural information (e.g. gardening programs). The participants watched TV primarily in the evenings.

Views on Health

Most of the participants agreed that health is essential and important. There was a general consensus that eating well, watching what one eats, getting enough sleep, and preventative measures are important methods in maintaining health.

When asked how often they visit a PCP, participants agreed that they go to the doctor more often in Brazil than they do here. The group ranged from those who seemed to understand the concept of prevention and go to a PCP once a year (in Brazil) to those who only see their physicians when they are sick. Most of the participants fit the latter description.

While one participant stated that there is an abundance of health information available, the majority of participants described a lack of health information.

Focus Group Questions	
What does health mean to you?	 An opportunity to live well Living a healthy life. Everything in life (<i>Tudo na vida</i>) Something important to keep an eye on The most important thing in life First God, then your health My asset/wealth (<i>meu patrimonio</i>) My security so I can keep working (<i>Minha seguranca no trabalho</i>) Without health, you endanger those close to you. Tranquility Just having a health plan gives you tranquility.
Why do you see a PCP less often here than you do when you're in Brazil?	 Language barriers. (One participant noted that she had heard about interpreters being offered, but wasn't sure about this). Health insurance Haven't needed it or felt there was a need Lack of information in the Brazilian community on how to find a doctor/enter the system. Time
Do you have any specific health concerns?	 Cancer (e.g. breast cancer), especially with family history. Heart attacks and stress Knowing about illnesses, especially being in a new country with "different diseases" Prevention
How do you take care of your health?	 Not drinking Not smoking Eating well Getting enough sleep Taking natural antibiotics (propolis) Drinking orange juice and milk to prevent osteoporosis Going to the doctor
What comes easily when taking care of your health?	 Eating well (both easy and difficult) Getting enough sleep Prevention in general Having a sense of humor Doing one thing a day that is enjoyable Walking
What's difficult when taking care of one's health?	 Exercise, because of weather and lack of time Eating well

Primary Care Providers

Participants generally agreed that a PCP is a physician who treats illnesses and provides individuals with specialists if he or she cannot treat those illnesses. There were many participants who had not lived in the US for very long and for whom the concept of the PCP was unfamiliar. These participants believed that a PCP would become available as soon as they become sick or visit the emergency room to get care. Most of the participants expected a PCP to be considerate, be able to treat their illnesses, and provide preventive care in a professional way.

Focus Group Questions	
What do you think of when you hear the word PCP (Clinico Geral)?	 Helps us to get a specialist See once a year Professional from the health area who helps you get a specialist if needed Doctor who studies the whole body in general, providing a general diagnosis Treats basic (superficial) illnesses Does triage
How would you explain role of PCP to someone not familiar with the system here in the US?	 PCPs do your first diagnosis to see if situation can be resolved; if not, they send you to a specialist. PCP has a broader role in the US than in Brazil. Participants had difficulty with this question; some of them had not lived in the US very long and had had little contact with the US health care system. Some did not have a PCP in the US.
	For those who had not been to a PCP in the US, when asked what they would do if they needed a PCP, participants noted: They would go to the ER and be assigned a PCP. One participant noted that he would only get a PCP if he got sick. Another would get insurance and a PCP if needed.
	For those who had not been to a PCP in the US, when asked why they did not have a PCP, participants noted: Can go to emergency room when sick Lack of confidence Lack of knowledge about body Got check-up in Brazil before coming here For those who had PCPs, the participants sought them out when they had specific issues (e.g. pregnancy, gynecological problems, and blood pressure concerns). One participant sees a PCP when she is not feeling well.

Expectations of PCPs	 They will direct treatment
	 Issues will be well attended to and resolved
	Treat them well and help them to be well
	 Talk about prevention and family history
	 Are good professionals

Motivations & Barriers

Some of the main barriers to obtaining health care mentioned by participants included a lack of insurance, language/communication problems, and the notion that if one saw a doctor in Brazil before arriving in the US, one does not have to seek health care here unless they are sick. To mitigate the insurance problem, participants suggested increasing awareness of the Free Care program and encouraging people to apply for benefits. Some of the participants were not familiar with interpreter services, and thus, one participant recommended promoting the use of interpreter services in the health care facilities and identifying that there are health care providers who speak Portuguese. Finally, in response to the belief that one does not need health care unless one is sick, the participants proposed that education should be improved by informing people about the benefits of practicing prevention rather than only seeking treatment when health issues arise.

One participant commented that he is afraid to go to doctors because he heard that they are expensive. Even with Free Care, he heard that a person may still receive a bill. Concerning time issues, one participant said that going to a PCP when he is well would be taking time to do something that is not necessary. However, if a PCP were needed, time would not be an issue. Regarding quality issues, some participants made comparisons to the system in Brazil.

Transportation and religious concerns were generally not barriers for participants.

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Focus Group Questions	
What are some of the barriers to health care?	 Language/no awareness of interpreter services Just went to a doctor in Brazil, no need to go now No insurance No time: lose a day of work Not getting a Free Care card Never had an issue or need to go Not having been in the US long and thus had no need for it Transportation (for a few participants)
What are some of the ways to reduce those barriers to health care?	 Facilitate applying for/access to Free Care Inform/educate the community that prevention is better than treatment Information to address fear of discrimination/poor treatment based on immigration status More information about interpreter services Identify Brazilian professionals who know the situation for immigrants Provide information about PCPs Reminder calls for appointments

SPANISH SPEAKERS

Summary Findings

(June 4, 2003) Findings from this focus group, which was conducted in Spanish, indicate that participants were aware of the need for primary care. Although the term itself ("primary care provider") was new to many participants, most were aware of the role of a primary care provider and its importance. Participants said they would like to become more actively engaged in their own primary care, but several barriers exist. The most significant barriers mentioned were communication issues and the lack of health care coverage due to cost.

Group Composition (N=6, 3 males and 3 females)

Age range: 22 - 45	 Two men were single (one lived with his mother and was in school), one woman lived with her husband and two sons, and another woman was a single mother with two daughters. The length of time that group members had lived in the US ranged from almost 2 years to 22 years, with the majority of participants having lived here for about 10 years. Three participants lived in Cambridge, one in Somerville, and two in Stoneham. Five participants said that they speak Spanish in their homes; one participant responded "Spanglish." Health Coverage: Three participants did not have any health insurance, two had Free Care, and one woman had both Mass Health and private insurance. Primary Care: Two participants had a primary care physician (PCP), three did not, and one participant was unsure. The two participants with PCPs had both have seen their PCPs within the year.
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Media & Communication

Participants were asked what forms of media they used, how often they used them, and which they think would be useful for receiving health-related information. Although the group members preferred different types of media, most participants read a daily newspaper, and preferred *Univision* and PBS to mainstream TV networks. Several participants used the internet to obtain news and other information.

Views on Health

Participants were asked to talk about health in general. They agreed that health is a mental as well as physical state of well-being and that having good health is related to being financially stable. Participants said they stay healthy by eating nutritious meals, practicing good hygiene (washing hands, etc.), and relying on their doctors' advice. Participants were especially concerned about the cost of health care coverage and access to such coverage.

What does health mean to	Health is a fundamental human right
you?	 Physical state and the system of feeling well; being comfortable both spiritually and mentally Health is complicated by monetary issues Low-income people are not as healthy To take care of your body, be well, not only physically, but mentally Natural state of not being sick, physically and mentally
How do you take care of your health?	 Access to education in general, because health and education are inter-related One participant had information about healthy cooking, which foods have what vitamins, etc. This led to a discussion about how education is related to good nutrition and healthy eating habits. Some participants thought that health information and resources are not useful if you still have no access to the medical system. For example, one participant's wife uses the internet to learn about health concerns but he says it is useless knowledge because she cannot see a doctor about it. Good food, good nutrition habits Exercise, weight management Hygiene: hand-washing, etc. Two participants said the most difficult thing about taking care of their kids' health is teaching their children how daily activities affect their health. They agreed that television often encourages poor health habits, especially because it promotes unhealthy foods such as chips and fast food. One young male participant said he takes his health for granted and that he's too busy to really take care of himself. Taking care of his health was not a priority for him because he is rarely sick.
Do you have any specific concerns about health issues?	Participants agreed that the community needs to know about health issues such as nutrition and disease prevention. They said there seems to be information and resources available, but the community has trouble accessing them. • Worry about people who are not US citizens, the least healthy are often immigrants and people of lower-income groups • One participant felt that the US is such a rich country that there should be universal health care • Lack of government support of health care

	 One participant worried because she did not know where to go if she gets sick. She said that health care is very expensive and her fear is that she or a family member would get sick and wouldn't be able to pay for medical care. Her husband was employed but didn't have comprehensive insurance.
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Primary Care Providers

Participants were asked to share their thoughts about primary care providers: who they are, what they do, and participants' experiences with them. For most participants, the term "primary care provider" was new, although the role that they play was familiar. Of those participants with a PCP, most felt that they didn't have a highly positive relationship with them or the health care system in general because of certain issues and obstacles. Several participants mentioned that they had seen a PCP only to be referred to another health care provider or health care site. This system of referrals generally does not exist (unless a specialist is required) in the participants' native countries.

Participants were asked to talk about their personal experiences with primary care providers. Most participants agreed that their health care providers didn't listen to them or encourage questions. They attributed these problems to language differences and the health care providers' unwillingness to get more involved with their patients. Participants stated that one way to make the clinical encounter more of a participatory process would be to write a list of questions and concerns before seeing the doctor.

The moderators of the focus group pressed participants to identify specific tools that would help them to become more engaged in their own health care. One example the moderators gave was a wallet card – a card that can be carried in a purse or pocket that reminds patients of important information for their appointment. Participants stated that useful information on such a card would include a reminder to the patient to have a list of symptoms ready, as well as a list of questions to ask the doctor. Although a few participants said that taking out a prepared list of questions in front of the doctor is sometimes embarrassing, all participants agreed that it depends on the doctor. Participants also agreed that the provider must encourage questions and then spend time answering them.

What word / title do you use for a primary care provider?	 Doctor, medico Doctor primario – this term seemed appropriate to everyone Medico de cabecera – this term is commonly used in Mexico Medico familiar
What does a PCP do?	 A doctor with whom you have a consistent, long-term relationship A doctor you see for regular check-ups, physical examinations, colds You see them for common illnesses, things that are not very complicated One participant said he did not know because he does not have a PCP.

How did you get your PCP?	 I chose my PCP randomly from a book that my insurance company sent me I don't have a PCP in the US, but in Mexico we choose doctors by friends' recommendations I don't have one I received a packet with a list of doctors in my area, I chose one randomly There should be info for people who don't speak English (in mailings). When I get information at home (like from Mass Health), it's in English and I don't understand it
How often do you see your PCP?	 When my kids were younger, whatever the pediatrician said every 6 months, whatever Once a year, my kids once a year too 2 to 3 times a year Once a year, but now that I don't have insurance, I go to health fairs or ambulatory clinics that announce free screening in the newspapers I only go when I'm really sick
How is the role of your PCP here in the US different than a similar physician in your native country?	 In my home country, I didn't have someone to go to once a year; I only went for vaccinations and things like that. Now I go to the doctor more often. Here it is very difficult to see a doctor because you need health insurance. In Mexico, there is a social health care system for everyone who works, although it isn't very good. If you have a little money, it's easy to get a private doctor. Here you also need a lot of time to get an appointment. You can't see the doctor right away unless it's an emergency. In my country, communication is better with the doctors because you speak the same language – and even if you speak English very well, the culture is different here. In my country, I don't go to a doctor only to get sent to another doctor The system here is very decentralized in that you get sent to many doctors and places for one thing
How do you feel about actively participating in your health care?	 My doctor doesn't give me the opportunity to ask questions; I can't express myself The doctors don't want to get involved with patients, "te sueltan" [they dismiss you] in 2-3 words People here feel inferior to the doctors; they don't feel confident and comfortable. Sometimes its something subtle, like racism or discrimination Doctors have too many patients and there is no connection between the doctor and individual patients

	 It all depends on the way the doctor treats you Sometimes the language that the doctor uses is impossible to understand, even though I speak English, because he uses words that I don't use, and he uses a lot of medical words I appreciate it when a doctor tries very hard to communicate with me I let the doctor make decisions about my health for me, as long as I can afford the medicines or whatever he recommends
How do you think you can become more involved and engaged in your own health care?	 Take notes before my visit. Sometimes I leave the doctor and I realize that I forgot to ask something important. It would be helpful to be reminded. When you change doctors, you should be reminded to bring a copy of your previous medical records. I would like a record of my medications – something to keep track of what I take and when I should take them, and also something to keep track of symptoms.
What type of information and questions would be useful to have on a wallet card?	 List of symptoms along with frequency, location, and intensity. Also, what makes symptoms better? Worse? Lifestyle issues and what influences such symptoms (diet, etc.) What should be avoided, if anything? For example, what to avoid if you have an ulcer, or a heart condition.
What are some advantages and disadvantages to using a wallet card?	 People forget things sometimes because of time – you have limited time with the doctor and at the end if he asks you if you have any questions, you're rushed and you forget. The doctor has to have his own list, he has to know this is good practice, to have patients ask questions I would be embarrassed to have a list. I would rather memorize it. People need to be educated not to be embarrassed because the doctor is there to help, to offer solutions. We need to empower patients because "la salud no es un juego" [health is not a game] – and it should be a priority.

Motivations & Barriers

This discussion focused on identifying barriers to primary medical care, and how to break down these barriers. Common obstacles to accessing primary care included lack of child care, linguistic issues, feeling uncomfortable around interpreters because of confidentiality issues, and cost. Participants generally felt that having health insurance would be of tremendous help in obtaining primary care.

Identified barriers included:

- Child care is a big problem
- Sometimes there is a lack of interpreters
- With interpreters, I feel uncomfortable when discussing personal things, even though I know they are there to help
- Not having direct communication with the doctor
- Money
- Religion can sometimes be a barrier, but it depends on the religion. I know some people for whom it is a problem. For example, they think that for some sicknesses you shouldn't take medicine, you should let God take care of you.
- Everything with health here (in the US) is very complicated the paperwork, the referral process – nothing is efficient. You have to explain your situation over and over to different people.
- We could remove some obstacles if everyone had health insurance.

Authorware Computer Modules

The Department of Community Affairs is developing interactive computer-based education tools that are particularly suited for low-literacy populations including patients for whom English is not a first or preferred language. At this point in the focus group, the participants were introduced to the computer program, shown a brief example of the program about primary care, and asked their opinions about what they saw. Most participants responded positively to the computer program and said it could be improved by making it more interactive or offering other health topics that may be more relevant to different individuals. Also, some participants felt that using the computer program before their appointment with the primary care provider would help them to prepare for the visit.

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Focus Group Questions	
What did you like/dislike	• "Me encanto!" [I loved it!]
about the computer-based	 The suggestions were very useful
about the computer-based education tool?	 The suggestions were very useful When people go to the doctor, they may be nervous saying private things, so this is helpful It is helpful because it gives the patient some language and vocabulary to use with the doctor More interactive, things need to be interactive for me to learn This would be helpful for someone who needs basic information Doesn't tell you where you can get more information I thought this was very helpful; I usually read anything I see related to health It's important for the public to know about symptoms, etc. I liked the part about lab questions. Particularly, what tests does the doctor perform? How much do they cost? I
	hadn't thought of asking these questions before.
	 It reminded me to write my questions down.
	 I learned how I can work on getting the doctor to understand me
	One participant said he wouldn't watch it and asked what age group the program had been designed to reach.

	One participant felt that the program was too slow and too
	shallow (not enough detail), but he understood that for some people this was appropriate.
	A younger participant said that what is important is the type of information and interaction that the program can offer. This participant said that he would not use this to learn about any topic in general. The content has to be relevant to his health and his needs.
	3 respondents said that they would use it, 1 respondent said that he wanted something more specific
What topics would be interesting in a computer program like this one?	 Things that tend to cause panic/fear like HIV and SARS, because there is a lot of incorrect information out there Nutrition Physical activity Clean air and water Vitamins Prevention and health
Would you use a computer program like this one if you had the chance?	 I would use this before seeing the doctor I would definitely use this— especially if I am waiting half an hour to see my doctor. I would use the information to help me prepare for my appointment and to help me think of questions for my doctor It's better to do this than to just sit there waiting Some people are scared of technology; not everyone has the capacity to use a computer or has a computer at home. This is great for young people who have computers Need to offer the same information in a brochure or something to patients who don't want to use a computer. People need to have that option.

Other Comments

Participants were asked if they had any other questions, comments, or suggestions. No new issues were introduced at this point, but participants emphasized again their worries about the cost of medical care and lack of health care coverage. It is clear that this was a major concern and source of stress for the participants.