THE REMAINING **UNINSURED IN MASSACHUSETTS: EXPERIENCES OF INDIVIDUALS LIVING** WITHOUT HEALTH **INSURANCE COVERAGE**

FEBRUARY 2016





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Acknowledgments

The authors would like to thank Nancy Esparza, Martha Benitez, Rita Hoskins, Adrianna Lira, and Vanessa Dacunha from Central Massachusetts Area Health Education Center; and Priscilla Vasquez from the University of Massachusetts Medical School for their important contributions to this project including their expertise with speakers of languages other than English.

In addition, the authors would like to thank Kim Prendergast of the MetroWest Free Medical Program, Ilana Steinhauer of Volunteers in Medicine Berkshires, Matilda Correia of the Brockton Neighborhood Health Center, Ann Poole of the Holyoke Health Center, Sandra Silva of the Greater Lawrence Family Health Center, and Caronanne Procaccini, Kelly Hewitt, and Sandra Dos Anjos of the Community Action Committee of Cape Cod & Islands for their assistance in helping to connect the report's authors with individuals who lack health insurance.

Photographs were taken by Kara Delahunt.

The findings and views expressed in this report are the authors' own and do not reflect the official positions of the Commonwealth Health Insurance Connector Authority or the University of Massachusetts Medical School.

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EXECUTIVE SUMMARY

Although Massachusetts has successfully achieved the lowest rate of uninsurance in the nation, an estimated 200,000 individuals in Massachusetts did not have health insurance coverage in 2015. Thousands of individuals and families in Massachusetts live with the potential adverse health effects and financial impacts of not having health insurance. This study conducted interviews with 33 uninsured individuals in Massachusetts with the aim of building a better understanding of the reasons they were uninsured and informing future strategies that might effectively minimize the barriers to coverage that some residents experience.

Key findings include:

1. Individuals are uninsured for a variety of reasons, including the following:

- Inability to afford health insurance.
- Changes in circumstances that result in loss of employer-sponsored insurance (ESI), such as losing or changing jobs, or reducing work hours and therefore becoming ineligible for job-based insurance.
- Loss of eligibility for subsidized insurance.
- Missing a renewal date for subsidized insurance.
- Difficulties with the process of applying for health insurance and completing application materials.

2. Most uninsured individuals valued and wanted health insurance coverage:

• Although a minority of the uninsured were not highly motivated to apply for insurance because they felt that they were in good health, the large majority of uninsured individuals highly valued health insurance and wished that obtaining coverage was easier or more affordable.

3. There are a wide variety of reasons why some uninsured individuals had not attempted to apply for health insurance, including the following:

- Not eligible for ESI.
- Not eligible for subsidized health insurance.
- Unable to afford health insurance, even if subsidized.
- Challenges with the application process.
- Satisfaction with health services, such as those obtained through the Health Safety Net, that can be obtained without health insurance.
- Concern that applying would affect their immigration status or that of someone they know.

4. The possibility of penalties for being uninsured was not a major factor influencing the majority of those who were without health insurance:

- Although most respondents affirmed their awareness of the requirement to have health insurance coverage, they differed in the degree to which they understood key details.
- The possibility of penalties for not having health insurance did influence a minority of respondents to apply for health insurance, but for the vast majority it did not appear to be a major factor.

5. Uninsured individuals voiced common themes regarding their experience applying for health insurance, including the following:

- Both past and future in-person assistance from Navigators and other Enrollment Assisters was highly valued by uninsured individuals.
- There was a strong preference for in-person assistance over applying by phone or online, which was generally regarded as frustrating, tedious, or confusing.

6. Uninsured individuals had suggestions for how to help people applying for coverage, including the following:

- Application information is confusing and complex, and needs to be made more understandable. Support and guidance that would streamline and clarify the process would be highly beneficial.
- The availability of in-person assistance should continue or be increased at convenient locations such as community health centers, nonprofit organizations, unemployment offices, and local businesses.
- Enrollment Assisters who speak different languages are critically important to meet the needs of those whose first language is not English.
- Having more affordable insurance options would make gaining coverage much more likely.

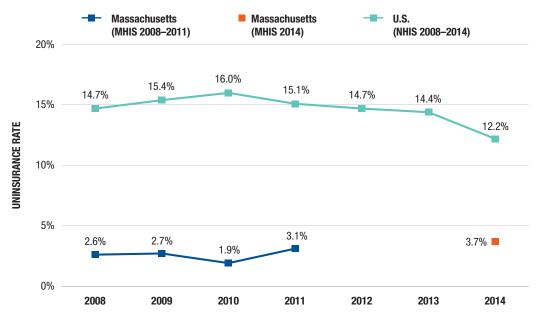
A further key finding of this study is that the remaining uninsured are a diverse group. They vary in their basic characteristics (e.g., gender, age, immigration status, income level, language spoken) and in the duration of their being uninsured. They vary in their reasons for being uninsured, in what insurance options are available to them, and in their capacity to navigate the health coverage landscape.

Because of this diversity, there is likely no single outreach strategy or policy that will lower the uninsurance rate in Massachusetts. Many options will be needed, and to be effective they should be designed and implemented while taking into consideration the experiences of the currently uninsured.

INTRODUCTION

Despite having the lowest uninsurance rate in the nation at approximately three percent in 2015, Massachusetts has over 200,000 residents who do not have health insurance coverage. Achieving the current uninsurance rate is partly a result of the state's 2006 landmark health care reform law: the proportion of the state's population that was uninsured in 2006 was approximately eight percent, and in 2008 it was three percent. While the 2010 Affordable Care Act (ACA) was successful in lowering the uninsurance rate on a national level, in Massachusetts the number of those without health insurance has not measurably decreased in the last seven years (Figure 1).^{1,2}

FIGURE 1. UNINSURANCE AT THE TIME OF THE SURVEY FOR ALL MASSACHUSETTS RESPONDENTS AND THE NATION AS A WHOLE, 2008–2014



Sources: 2014 Massachusetts Health Insurance Survey (MHIS) for 2008–2011 Massachusetts estimates; National health Interview Survey (NHIS) for 2008–2014 national estimates.

Note: Due to a change in survey design for the MHIS in 2014, Massachusetts estimates for 2014 are not directly comparable to estimates for 2008–2011. The 2014 national estimate from the NHIS is for the first two quarters of 2014.

The majority of the uninsured in the state are working-age adults (ages 19 to 64), and the uninsured are disproportionately young adults, male, single, Hispanic, and low-income. However,

¹ Center for Health Information and Analysis. *Findings from the 2014 Massachusetts Health Insurance Survey.* May 2015. http://www.chiamass.gov/assets/docs/r/pubs/15/MHIS-Report.pdf.

² For 2014 and 2015, the uninsurance rate in Massachusetts is reported to have been between 3 percent and 5 percent in different state and federal surveys. The uninsurance rates vary among different sources as a result of different methodologies. The uninsurance rates in the various sources and the total population of Massachusetts imply that over 200,000 individuals in Massachusetts do not have health insurance.

it is also true that there are uninsured individuals of every age, gender, family size, and ethnicity, located in all parts of the Commonwealth. In Massachusetts, Hispanic persons make up 20 percent of the uninsured but only 11 percent of the state's residents.^{1, 3}

Individuals gave a wide variety of reasons for being uninsured, including the high cost of health insurance, not knowing how to get insurance coverage, and losing access to health insurance (Figure 2).⁴ Underlying these high-level findings are a number of questions about what kind of assistance might help them to obtain insurance coverage and why individuals are losing eligibility or access to health insurance. This study sought to address these questions in order to build a better understanding of the reasons for being uninsured and to inform future strategies—in terms of both outreach and policy—that might help to minimize the barriers to coverage that some residents experience.

To address our study aim, we conducted interviews with 33 residents across seven counties of Massachusetts who were uninsured. Semistructured interviews and qualitative data analysis were used to determine how the individuals become uninsured in the first place, the experiences they'd had if they'd previously tried to gain insurance coverage, the barriers that prevented them from gaining insurance, and the factors that might facilitate their gaining coverage in the future.

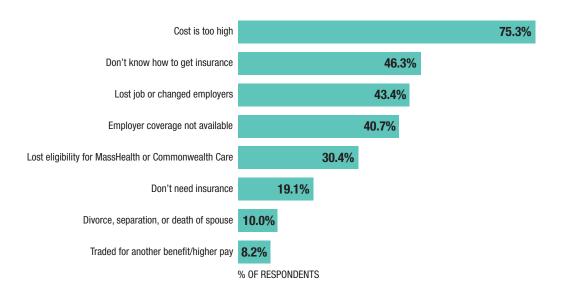


FIGURE 2. REPORTED REASONS FOR BEING UNINSURED IN MASSACHUSETTS IN 2014

Source: 2014 Massachusetts Health Insurance Survey. Note: The categories listed above are not mutually exclusive. Respondents were asked to select all applicable options.

4 Center for Health Information and Analysis. *Findings from the 2014 Massachusetts Health Insurance Survey*. May 2015. http://www.chiamass.gov/assets/docs/r/pubs/15/MHIS-Report.pdf.

³ U.S. Census Bureau. March 2014 Current Population Survey.

METHODS

The criteria used to select the respondent sample included being uninsured at the time of agreeing to participate in this study (May 2015 to July 2015), currently living in Massachusetts, and being age 19 or older. Within these criteria, we sought a sample that represented a mix of the three most commonly spoken languages in the Commonwealth, English, Spanish, and Portuguese; duration of being uninsured; and different regions of the state. Respondents were recruited via community-based agencies that help individuals access health care, including Brockton Neighborhood Health Center, Community Action Committee of Cape Cod & Islands, Holyoke Health Center, Greater Lawrence Family Health Center, MetroWest Free Medical Program, and Volunteers in Medicine Berkshires. In collaboration with the Blue Cross Blue Shield of Massachusetts Foundation, the research team developed an outreach flyer for the sites to assist in recruitment efforts. The flyer, which was available in English, Spanish, and Portuguese, briefly described the study and provided a phone number for people to call if interested. The research team from the University of Massachusetts Medical School (UMass) contracted with Central Massachusetts Area Health Education Center (Central MA AHEC) to screen and obtain the consent of individuals who called the screening line. A \$50 gift card was offered to all individuals who participated in the study.

To ensure data comparability across respondents, the research team developed an interview guide specifically for this study. The guide included a mix of closed- and open-ended interview questions (see Appendix A for the complete interview guide). All interviews were conducted by phone, and respondent answers were captured via detailed handwritten and typed notes. Interviews were also audio-recorded when spoken consent was secured from interviewees. Researchers from UMass conducted the interviews with respondents whose preferred language was English. Central MA AHEC conducted the interviews with respondents whose preferred language was Spanish or Portuguese and translated interview notes into English. In total, 34 interviews were conducted, and one was excluded from the analysis because it was difficult to understand the participant since the participant's primary language was not English, Spanish, or Portuguese.

Following the interviews, all notes and audio recordings were converted to Microsoft Word files and uploaded into ATLAS.ti, a qualitative data analysis program. Content analysis was used to identify emergent themes in the interview data. Two members of the team independently coded transcriptions and reviewed each other's coded documents to assure consistent code application. Any coding disagreements were addressed through discussion until consensus was reached. A third member of the team reviewed all coding and checked for consistency. Code reports were generated from software and reviewed by the evaluation team to identify subcodes and themes. In addition, respondent answers to the closed-ended questions in the interview guide were entered into an Excel spreadsheet and analyzed to assess variation within and across subgroups of respondents.

RESULTS

STUDY SAMPLE OVERVIEW

The final sample of respondents consisted of 33 individuals, of whom 14 were interviewed in English, nine in Spanish, and 10 in Portuguese. Across these groups, 64 percent of the respondents were female, and almost half (45%) were 50 to 64 years old. Most respondents were employed (79%), and these respondents were fairly evenly split between full-time and part-time workers. Three respondents reported working both a full-time and a part-time job. Respondents drew from seven different counties: Barnstable (18%), Berkshire (24%), Essex (9%), Hampden (9%), Middlesex (27%), Norfolk (3%), and Plymouth (9%). Regarding duration of uninsurance, 14 respondents (42%) reported never having had health insurance, 12 (36%) reported having been without insurance for more than one year, and seven (21%) reported having been uninsured for less than one year. (See Appendix B for a summary of the characteristics of the study sample.)

Among the 26 interviewees who were employed, seven indicated that insurance was available to them through their employer. Two respondents did not know if their employer offered employer-sponsored insurance (ESI), and several respondents reported that they were ineligible for ESI due to part-time work status. The main reason the seven respondents with access to ESI gave for not enrolling in that insurance was that it was too expensive.

Although the interview guide did not ask respondents specifically about their immigration status, respondents' answers to questions provided some information and insight regarding their status. We estimate that 13 respondents (39%) were undocumented immigrants and therefore are not eligible for certain subsidized programs, including plans offered through the Health Connector, the state's health insurance marketplace.

When asked how they would describe their health, roughly three in four respondents (73%) reported being in good or excellent health. At the same time, more than one-third (39%) had one or more chronic conditions, including high blood pressure, depression, diabetes, high cholesterol, chronic migraines, and neck and back problems. The majority of individuals interviewed (88%) had seen a doctor or other health care provider within the past 12 months. Of these, almost half said the visit was for a routine medical exam or test. Other respondents reported that their last doctor's visit was for nonroutine care to treat specific symptoms, an injury, or an illness. Most received these services at a health center or free clinic, and four respondents indicated that their last doctor's visit took place outside the U.S.

HOW INDIVIDUALS BECOME UNINSURED IN THE FIRST PLACE

A sizable share (42%) of individuals interviewed reported that they had never had health insurance coverage. Many of these respondents described coming to the U.S. from another country (some more than 10 years ago; two within the previous month) and never having had insurance in either their home country or the U.S. Many also noted receiving services through the Health Safety Net (HSN), though some said they had not received HSN services for several years. A majority of these respondents are likely undocumented immigrants. The remaining respondents (58%) had health insurance coverage at some point in their adult lives. Among these respondents, 26 percent had been uninsured for less than six months, 11 percent for between six and 12 months, 37 percent for one to two years, and 26 percent for three or more years. With this group of respondents, we explored the reasons they had become uninsured. Four main reasons were cited:

- Some respondents decided to let their insurance lapse, mainly because it was too expensive to maintain. Some respondents in this group also noted that they had not used their insurance, or had not used it enough to justify the cost.
- Some respondents' circumstances changed such that they were no longer eligible for the insurance they'd had. For example, respondents lost their ESI because they were laid off, changed jobs, or experienced a reduction in work hours that made them ineligible for ESI. At least one respondent lost MassHealth eligibility because her income increased slightly but she was unable to afford the premiums for the available insurance options. By the time she had the money to pay, it was past the two-month window for enrolling, and she perceived that she was "locked out" until the next open enrollment period.
- Some respondents experienced an involuntarily lapse of insurance because they missed the renewal form submission date for subsidized

"I stopped paying [for health insurance] because I never really used it. At the time it was superexpensive and I couldn't afford to pay it.... If it wasn't really expensive, I might have really used it. It was 40 percent of my income."

"On prior years, I receive by mail the form to fill out by myself but was too complicated. I need to talk to someone to translate for me. I need help, and it was really hard to find someone to help me, so the most of the time I would miss the renewal due date."

coverage. In some cases, respondents did not know they needed to take action to renew their insurance; in other cases, respondents needed help to complete the form (mainly help with translating and understanding the form) but were unable to get it. Some respondents had not received or had misplaced their insurance renewal notice.

• Two respondents reported having difficulty completing the online insurance application. These respondents tried to enroll online but were unable to complete the enrollment process.

REASONS FOR NOT APPLYING FOR HEALTH INSURANCE

Close to half the individuals interviewed (45%) had not tried to get health insurance coverage within the previous 12 months. Respondents in this group were more likely to have experienced a persistent lack of insurance: about half had never had insurance coverage, and the other half had been uninsured for at least one year, some for as long as eight years. Most were employed (87%), and many appeared to be undocumented immigrants (73%).

Respondents often cited multiple reasons for why they had not applied for insurance. Their reasons for not applying fell into four broad categories. The first and by far most frequently cited reason was that the respondent could not afford insurance. Among this group, some noted that

they were not eligible for their employer's insurance, and others noted that they were not eligible for insurance subsidies. A second reason for not applying for insurance was problems with the health insurance application process that compromised the respondent's ability and/or desire to apply. These problems included application forms not being available in the respondent's language, the application process itself being too complicated, lack of information about insurance and how to apply, and not having time to apply. A third reason, noted by two respondents, was being satisfied with access to services that were available to them through the HSN. A fourth reason, given by some respondents who were estimated to

"First of all, I could never afford paying for health insurance, because it's very expensive and I am selfemployed, working part-time making \$300 per week."

"I am worried that applying for health insurance may interfere with citizenship status.... The system required legal status.... I am willing to pay; however, the insurance should have a reasonable fee."

be undocumented immigrants, was concern that applying for health insurance would negatively affect their immigration status or the status of someone they knew.

EXPERIENCE APPLYING FOR HEALTH INSURANCE

Approximately half of the individuals interviewed (55%) had applied for health insurance within the past 12 months. Some sought assistance from community-based agencies, others applied (or tried to apply) through the Health Connector website, and yet others relied on a combination of the two. The time period in which respondents had applied for insurance coincided with the unique challenges associated with the implementation of the ACA. Massachusetts encountered delays and difficulties implementing new procedures for application and eligibility determination in the period leading up to and immediately following January 2014, when major components of the ACA took effect. Since then, the Health Connector and the state Medicaid program (MassHealth) have been working to improve their application and enrollment processes, as well as customer service functions. Therefore, some of the difficulties that respondents encountered may have already been addressed. With this context in mind, respondents' efforts to apply for insurance can be summarized in four types of experiences:

- Some respondents applied for insurance in person at community-based sites including health centers, unemployment offices, and hospitals. Some of the respondents in this group were already receiving services at these locations; others were referred by a friend. At these locations, respondents received assistance from staff who were trained to help individuals apply for and renew health insurance coverage. These staff members, who are referred to as "Enrollment Assisters" or "Assisters" in this report, included Navigators and Certified Application Counselors, who receive training and certification to be able to assist clients in the application and renewal process. Respondents were very pleased with the assistance they received and appreciated the opportunity to ask questions and have the application process explained to them.
- Other respondents who applied for insurance with help from an Assister at a communitybased agency noted challenges in accessing in-person assistance, including a lengthy wait

time to get an appointment (up to two weeks) and limited availability of people who can assist in languages other than English. Some of these respondents also noted that they had to take time off from work to attend the appointment; others said that it was essential to have a car or some form of transportation to get to the locations where the assistance was available.

- Some respondents tried but failed to apply online or via a customer service phone line. Respondents in this group were fairly consistent in describing the process as frustrating and tedious. Respondents experienced a range of problems including the online link not working properly; trying but failing to complete an application on a cell phone; the online application not being set up for individuals who do not have a Social Security number; and long wait times on the customer service phone line. Some respondents also acknowledged their own lack of experience and skills with computers. These individuals eventually sought in-person assistance.
- Three respondents were able to successfully apply for insurance online. Two of them reported that their online experience was good; the third respondent was able to successfully complete his application online and send requested documents, but he never heard back regarding his insurance status.

With respect to the outcome of their efforts to apply for insurance, at the time of our interviews most respondents had recently completed the application process and were still waiting to hear about their eligibility status. The outcome for other respondents, however, was that they remained uninsured and did so for one of two reasons:

- Some were not eligible for MassHealth, and when they learned how much insurance for which they were determined eligible cost, they realized they could not afford it.⁵
- Others experienced frustration with the application process and reported that difficulty with the application process was the main reason they had remained uninsured. One respondent tried to apply by phone but gave up after being unable to get through on repeated attempts. Another respondent completed the online application process, learned that she was not eligible for MassHealth, and was advised that she might be eligible for other kinds of assistance but would need to seek in-person assistance. She gave up trying to get coverage after she was told that in-person assistance was available at locations that were difficult for her to get to, since they were one to two hours away from where she lived.

"In Weymouth, it's hard to get appointments, especially because they only have appointments on Wednesday and Friday mornings with a person that speaks Portuguese. So I had to go to Brockton they have lots of people that are fluent in Portuguese, and it's easier to get appointments and help."

"The [online] system is tedious and complicated. I expend two hours filling out forms in the computer, and the system keeps sending me to the same spot. I felt I was going in circles."

⁵ In these cases, in which a respondent reported not being eligible for MassHealth and being unable to afford the premiums for available insurance, the interview protocol did not explore the details of the respondent's eligibility for other subsidized programs. Therefore, it was not determined whether these respondents were eligible, through the Health Connector, for ConnectorCare plans, Qualified Health Plans with Advance Premium Tax Credits, or unsubsidized Qualified Health Plans.

SUGGESTIONS FOR FUTURE ASSISTANCE

Respondents were queried as to what would be helpful if they were to apply for health insurance in the future. Four main suggestions were made:

- Many respondents indicated that having detailed and accurate written information about insurance, in the language that they were most fluent in, would be very helpful during the application process. Respondents asked for information to be put in simple terms, with less use of acronyms, which they found confusing.
- Respondents wanted to receive help directly from an Assister at convenient locations throughout the community, including health clinics, hospitals, nonprofit organizations, unemployment offices, and local businesses. They also proposed offering evening/weekend hours, additional appointment times, and more staff members able to assist.
- More than half of the respondents said it was important to receive assistance from a person who speaks their native language.
- Three individuals indicated that health insurance options, including ESI, need to be more affordable.

"I would like a person that speaks Spanish, with an office close to my area and with services after 4:00 p.m., since we all work. It would be helpful to have printed materials in Spanish."

"I would appreciate to get assistance from an organization such as a church or community group.... that would be familiar with the process and also would expedite the application. And since it would be in the community, I would feel comfortable dealing with people that would speak my language."

VIEWS ON HEALTH INSURANCE

All respondents perceived the importance of having health insurance. Many recognized the benefits of health insurance coverage for their physical health; some emphasized the value in terms of their financial well-being. Respondents also described how insurance provides a sense of security, or peace of mind, by facilitating ready access to routine and preventive care and minimizing the financial risk associated with illness and injury.

The themes of access to and cost of care were echoed in respondents' observations about how being uninsured affects their health. Many individuals reported that being uninsured limits *when* they can get care, *where* they get care, and *what* type of care they receive. Nearly a third said they were unable to get care when they needed it and that not having insurance limited their access to specialty care, routine tests, and preventive screenings. A few also mentioned that being uninsured restricted their choice of providers and health facilities. One in three respondents also indicated that it was essential to maintain their health and rely on home remedies since they don't have insurance coverage. These individuals try to engage in healthy behaviors to stay well and avoid having to seek care.

UNDERSTANDING OF POSSIBLE PENALTIES FOR NOT HAVING HEALTH INSURANCE

Most respondents (77%) said they were aware that some individuals may face a fee if they do not have health insurance. Awareness was higher among respondents who were U.S. citizens or estimated to be documented immigrants (90%) than among those estimated to be undocumented immigrants (46%). Although most respondents said they were aware of possible fees, they differed in the degree to which they understood key details. Some confused the penalty with health care bills or insurance premiums/deductibles, while others said they did not have to worry about paying the penalty because they were unemployed or earned too little for it to apply to them. In general, documented respondents tended to know more about how and when the tax penalty applies. The threat of paying a penalty on their taxes was what prompted a few of these respondents to apply for health insurance in the first place, although they remained uninsured. But at least one respondent said that paying the penalty was less expensive than purchasing insurance.

"Yes, I heard recently about a law that says that everybody has to have health insurance. I am not certain how it works, but I heard that when you do your taxes you need to inform them about your insurance."

"I've been paying a penalty every year I do my tax return.... it's better off paying whatever they charge me because I am not going to be paying \$80 to \$100 a week as a part-time employee when sometimes I am not even earning \$400. I'm not going to pay that amount for health insurance."

DISCUSSION

After initial gains in the statewide rate of insurance coverage in the two years after enactment of the 2006 Massachusetts health care reform law, there remain over 200,000 uninsured individuals in the Commonwealth. The 2010 federal ACA has not yet translated into a significant decrease in the uninsurance rate in the Commonwealth. This study interviewed uninsured residents of Massachusetts about the experience of being without health insurance in an attempt to better understand the remaining barriers to coverage. Study findings can inform strategies aimed at reducing the number of uninsured in the state.

Affordability: As health care costs continue to rise in Massachusetts, affordability of health insurance and health care is a problem for both those with and those without health insurance. For individuals not eligible for MassHealth, the cost of health insurance is a significant perceived or actual barrier to gaining health insurance, and this is the case even for individuals eligible for other subsidized health insurance programs, such as those available through the Health Connector.

Providers who serve the uninsured populations: Uninsured individuals rely on providers such as community health centers, free clinics, and community-based organizations for help with applying for health insurance, as well as for care when they are uninsured. These organizations provide essential health care and other services to both uninsured and insured populations and are especially crucial to undocumented immigrants who have few insurance options. Continued support for organizations whose mission includes serving uninsured populations is important to help the uninsured in Massachusetts.

Outreach and enrollment assistance: Previous work has suggested possible outreach strategies to help the uninsured in Massachusetts.⁶ One of these is in-person assistance—a strategy that this study especially supports. Since health insurance and the process of applying for it can be complex, the uninsured were overwhelmingly in favor of in-person assistance. Broadening access to it by increasing support for in-person Assisters, offering evening and weekend hours, and holding outreach events in the community can be of high value in helping those without health insurance.

Language support: Providing outreach and enrollment assistance in multiple languages is also a need that the uninsured recognized clearly. This study intentionally interviewed people who use the three most commonly spoken languages in Massachusetts, and both Spanish and Portuguese speakers emphasized how important it was to have materials and Assisters that speak the language in which they were most fluent.

Transitions and changes of circumstances: The uninsured often cite transitions and changes of circumstances as major barriers to gaining or keeping health insurance. For those who have had access to ESI, transitions include losing employment, changing jobs, and moving from full-time employment to part-time employment that results in loss of ESI eligibility. For those who have had subsidized coverage, transitions include loss of Medicaid eligibility or missing the date for renewing Medicaid coverage. Targeted interventions could provide additional support to individuals who find themselves in these transitional periods that make residents vulnerable to becoming uninsured. MassHealth held outreach events in 2015 with a particular focus on providing members with opportunities to get in-person assistance with the renewal process, and these events could be repeated or expanded in future years. Additional strategies that stakeholders might consider include partnering with employers or unemployment offices to host outreach and enrollment events, and efforts to help people who are seeking insurance outside open enrollment periods.

It is understandable that decreasing the uninsurance rate in Massachusetts below its nationleading levels is challenging. However, Massachusetts can continue its leadership in health care reform and in helping vulnerable populations by learning from the experiences of its residents who are currently uninsured. The remainder of this report is devoted to the stories of a few Massachusetts residents who have struggled with acquiring or maintaining health insurance.

⁶ Sharon Long, et al. *Reaching the Remaining Uninsured in Massachusetts: Challenges and Opportunities.* BCBSMA Foundation. March 2013.

UNEMPLOYED MAN POSTPONES MEDICAL TESTS BECAUSE HE CAN'T AFFORD TO CONTINUE INSURANCE

Losing the job he held at a local newspaper for 25 years broke Winslow Thayer's heart. But not being able to afford health insurance while unemployed almost literally stole his breath.

One month after the 54-year-old South Yarmouth man was laid off and lost his health insurance, he was forced to postpone several medical tests recommended by doctors to find out why he was having trouble breathing.

"I told the doctor I can't do any more tests. I have to wait," Winslow said, knotting his hands at his dining room table as he remembered making that hard decision. "I didn't want to go to the hospital and have them bill me and have, I don't know, hundreds of dollars billed."

It was May 2015 when the breathing trouble began for Winslow. He was short of breath and getting winded easily. Even though he had no insurance, he paid out of pocket to visit his primary care doctor. The physician ordered an echocardiogram. Winslow went ahead and had the test. His out-of-pocket cost was \$200, a \$300 discount the hospital offered because he did not have health insurance.

The doctor ordered more tests. Winslow knew it would be impossible to pay for the rest of the tests out of pocket, so he told his doctor to hold off until he got new insurance. "I said I can't afford it, I gotta wait," Winslow said.

Winslow was without health insurance because he lost his employer-sponsored plan in April 2015 when he was part of his employer's large-scale lay-off. His last day of work as a supervisor in the production facility was his last day of coverage.

He would have liked to continue his health insurance, but none of the available options worked for Winslow and his family. He did some research that led him to believe he would not qualify for MassHealth because his income was too high, in part because of a severance package he received from his former employer. Winslow said he could not continue his employer-sponsored insurance through the COBRA program because the monthly premium was too high.

"I didn't have the money to pay COBRA. They wanted \$1,400 a month, and that was more than my severance," said Winslow, who also received a small amount of unemployment compensation. "It's out of the question. I don't know how people do it." Losing health insurance also meant Winslow had to pay \$60 out of pocket each month for his prescription medications. And it had an effect on his live-in partner Sandra Cohrs, who was diagnosed seven years ago with an autoimmune disorder that has resulted in her becoming a paraplegic who uses a wheelchair and oxygen. She must be covered by two insurance plans because she has hundreds of thousands of dollars in medical bills each year. Before Winslow was laid off from his job, she was on his insurance plan and one held by her ex-husband. When Winslow lost his insurance, she scrambled to sign up for MassHealth.

Winslow wasn't happy about going without health insurance, but he decided to do so when he was in good health. Once he faced unexplained medical issues and a list of tests he knew he could not afford on his own, Winslow set out to sign up for health insurance.

> A few days after telling his doctor to hold off on more tests, Winslow went online and made some phone calls, but he couldn't figure out what health insurance he qualified for, or how to sign up. So he walked into a Hyannis unemployment office desperate for help in understanding his options, and worked with a staff member who explained that to Winslow's surprise, his income level qualified him for MassHealth. The staff member helped Winslow fill out paperwork, and he became fully covered on June 1, 2015.

Once his insurance was in place, Winslow went back to the doctor and underwent more testing. After a CT scan, electrocardiogram, stress tests, and endoscopy in June 2015, he was diagnosed with pulmonary fibrosis and a deviated trachea. On October 1, 2015, Winslow began pulmonary rehabilitation to train his body how to breathe more efficiently and understand its limits.

Winslow is upset that he had to go without insurance for two months and put off dealing with a major health crisis. He wishes there were more options for individuals who lose a job and then find themselves in a position where COBRA is too expensive and state-subsidized insurance seems out of reach.

"I'm hard-working. I pay my taxes," Winslow said. "Too bad there's no program for people like myself—in between."

WORKING WOMAN REMAINED UNINSURED UNTIL A COMMUNITY-BASED ORGANIZATION HELPED HER APPLY FOR INSURANCE

In her native country of Jamaica, health insurance is a luxury only available to the wealthy or well connected. An immigrant who frequently moved to find employment, Carlin Usher didn't know that publicly subsidized health insurance was an option here or that she would qualify. A main reason that she has not had health insurance is that "I didn't know how to go about it," the South Yarmouth resident said.

When Carlin initially came to the U.S. in 1999, she arrived in Tennessee and took a housekeeping job. She moved to various locations for work, spending time in Florida and Maine before moving to Massachusetts in the spring of 2015 to work at a hotel on Cape Cod.

Her health always took a back seat to working hard and earning a paycheck so that Carlin could send money to her husband and three grown children who live in Jamaica, where they struggle with the cost of living in the face of limited job opportunities. There, the family has no health insurance, and care is obtained at health clinics with long wait times. Her husband, a taxicab operator who was diagnosed with colon cancer, receives his treatment from one of these clinics.

"Sometimes you suffer a lot," Carlin said, describing the health care system in Jamaica. "If I was sick, I wouldn't know because I have never really gone to the doctor. I would just suffer."

Carlin's only medical care for the last several years has come from pre-employment examinations that she has received when she's looked for work through employment agencies, since "they want to know if you are fit to go work." These examinations would typically happen when she returned from visiting family in the winter months, when work is slow in the hotel industry here in the U.S.

It wasn't until Carlin was having significant seasonal allergies in April 2015 that she even considered applying for health insurance. A co-worker suggested that she look into MassHealth and brought her to the office of a local communitybased organization on Cape Cod that provides assistance with applying for health insurance. Carlin's friend had encouraged her to apply for insurance coverage, saying that medical expenses can quickly add up, and "if you get sick here, you're going to be in trouble."

An enrollment worker at the community-based organization spoke with Carlin, determined that she likely would qualify for MassHealth, and helped her fill out the paperwork.

The 52-year-old received confirmation of her MassHealth enrollment in the fall of 2015. It was the first time in her life that Carlin was covered by health insurance. She immediately reached out to find a primary care doctor and made an appointment for a month later. A mammogram was scheduled, since the last one she had was over 15 years ago. In light of her husband's cancer diagnosis, she was happy that having health insurance would allow her to get properly screened for breast cancer.

> A visit with Carlin's new primary care doctor helped her manage her allergies, which had been causing sinus headaches. In addition, she finally had the chance to talk to a medical provider about her symptoms.

Follow-up appointments have been scheduled to discuss her concerns in more detail, and Carlin is extremely grateful.

"I'm healthy. Everything is okay so far," she said with relief. Carlin feels that she can breathe a little easier now that she has health insurance coverage and a primary care provider. "You never know when something will come up," she said. "I am really glad for the insurance. I appreciate it."

LACK OF HEALTH INSURANCE CONTRIBUTES TO MEDICAL DEBT AND POSTPONING NEEDED CARE

Even though it is less than a thousand dollars, Rosalia Reyes expects that it may take her several more years to pay off the debt that came as a result of receiving care in July 2015 when she was uninsured. She had sought medical treatment at a local hospital for severe weakness in one hand when she was incapable of completing simple tasks such as brushing her teeth or washing the dishes. She was also unable to care for her four-year-old child, and safety became an issue. Although she was granted a personal payment plan for her debt, the unanticipated bill remains a significant burden for her and her family.

Rosalia legally immigrated to Lawrence, Massachusetts, from the Dominican Republic in 2009. For several years, she worked odd jobs for minimal wages and no health insurance benefits. In June of 2015, she was let go from her most recent job because business had slowed down, and since then she has yet to find another source of income. While fortunate to have a husband who can pay for the family's housing and put food on the table, she is unable to afford health insurance through his company.

After receiving the medical bill in July, Rosalia knew it was time to investigate her options for health insurance coverage. This turned out to be no easy task. Utilizing the resources she was aware of, she sought out insurance options at the local community health center. The 44-year-old recounted her experience, explaining that "the forms were complicated, but the social worker at the clinic helped me fill them out." Rosalia believes that the process of obtaining health insurance could be improved by receiving clear information about the steps that happen after someone completes an application. "I submitted my paperwork three months ago, and I still haven't heard anything," she said. Not being fluent in English, Rosalia has found navigating the insurance application process confusing. She feels insecure in her knowledge of the system, and worries that she will not be able to afford the premiums if she does obtain health insurance.

Rosalia has twice paid a penalty for not having health insurance coverage: the fee was approximately \$700 each year. She hadn't been aware that there might be a penalty until the first time she had to pay it when she filed her annual tax return. The following year, despite wanting to gain coverage, she and her husband couldn't afford the premiums for insurance, and therefore they reluctantly paid the penalty a second time.

Rosalia describes her health as "fair" and explained that "I don't know what is wrong with my hand. The weakness and pain started getting worse again last week. I can't go to see a doctor because it will cost me money that I don't have." She recalls that the medicine prescribed to her when she visited the hospital cost \$27 without insurance coverage, so she has not filled the prescription in order to pay for other expenses for her family.

> In addition to concerns about her hand, Rosalia has other apprehensions about her health. Over the past month her ability to hear has decreased and she has noticed swelling around her left ear. Due to her concerns over accumulating more debt, she has not sought out medical advice, and is left hoping that nothing serious is causing her symptoms. In addition, it weighs on her mind that high blood pressure and heart disease run in her family, but she has not yet been screened to see if she has

these conditions.

Rosalia tries to take matters into her own hands and spends time at the gym almost every day. "I use the exercise machines to stay healthy. Diabetes is killing us here in Lawrence. I want to keep myself healthy, insurance or no insurance," she said. Her aspiration is to be a health coach in order to improve the health of her community. "I would like to bring people to the gym and show them how exercise can keep them healthy." Rosalia hopes that someday gaining access to health insurance won't be a hurdle to overcome but instead will be a tool for obtaining good health.

YOUNG WOMAN CHOSE TO GO WITHOUT HEALTH INSURANCE COVERAGE TO PAY HER STUDENT LOANS

Renata Bussadori lived without health insurance for seven years, receiving no routine physicals or other preventive health care and putting off eye exams despite vision difficulties. The 22-year-old called it a calculated risk born of economic necessity.

"Thank God I'm healthy. Had I not been, I don't know what I would have had to give up to get health insurance," said Renata, who looked into obtaining health insurance for the first time through the Health Connector in 2014. She applied for health insurance, but "considering I had school loans, car loans, and all that to pay, I just couldn't afford it."

Renata moved from Brazil to the U.S. with her mother when she was 11 years old. Soon after, they got coverage from MassHealth. That changed when Renata was 15 and her mother remarried. The new family income was too high to qualify for MassHealth, and Renata's stepfather enrolled in health insurance that covered only him and his new wife. "I was just left out," Renata said.

Soon after her insurance lapsed, Renata started to suffer from migraines. Thanks to the Health Safety Net program, she was able to receive care at a community health center in Worcester, where the providers found that she needed corrective lenses to see clearly. Over the seven-year period that she was uninsured, Renata returned once more to the community health center for a viral illness.

Once she graduated from high school, Renata enrolled in a training program to become a medical assistant and worked at a local granite company. The health insurance plan offered by her employer was limited, with premiums of approximately \$300 a month. It was more than the Marlborough resident could afford.

She chose to remain uninsured but grew concerned about meeting her health needs because diabetes and thyroid issues run in her family. "I thought, at some point I need to do a checkup. I had not had a physical or anything in a while, so that was something that had worried me," Renata said.

Keeping up with her vision needs also made Renata uneasy. A trip to Brazil to visit her ill grandmother in February 2014 also served as an opportunity to see a family friend to get a new prescription and eyeglasses. It had been five years since Renata had seen an eye doctor.

Plagued by worries about her health and eyesight, Renata visited the community health center in mid 2014 to meet with staff members who could help her enroll in health insurance. She learned that her income from the granite company was too high to qualify for MassHealth, and she was told to visit the Health Connector website.

"I remember thinking, I'm better off without it," Renata said, explaining how she felt after visiting the website and learning that health insurance would cost her more than \$150 a month. She was frustrated that the application process did not take into account some of her major expenses, such as the debt from her medical assistant training program, a car loan, rent, and tuition to

> attend a nursing program at a community college. "The car I needed to go to work. The school I just couldn't put a stop to it," Renata said. "It was very tight. There was nothing I could really cut back."

Renata gave up hope on obtaining health insurance. But things turned in her favor in October 2015, when she started a new job as a medical assistant in a doctor's office. At orientation she received a welcome packet with benefits information. The materials said it would cost Renata a little more than \$23 a week to receive both health and

vision insurance.

"It ended up being affordable," she said with a smile. "I'm already looking at primary care doctors, and I've been to the eye doctor."

Thinking back on her experience, Renata said that she hopes health care plans and government programs can consider not just a person's income but also their major expenses such as debt, student loans, and tuition.

The cost of health insurance, even when partially subsidized, is more than many people can afford, especially young people who are students or are just getting started on their career. "They need options that they can afford," she said. "It's very expensive. At the end, you barely have anything left in your paycheck."

WORKING WOMAN AND CAREGIVER HOPES FOR A LESS COMPLICATED APPLICATION AND ENROLLMENT PROCESS

For over 25 years, Francisca Ynoa has worked full-time in Massachusetts as a skills instructor helping individuals who have intellectual disabilities. In October 2014 she was surprised to find out that she was no longer eligible for MassHealth. Since then she has remained without health insurance, and still finds it unclear why she lost access to the coverage that she would be very willing to pay for.

Francisca immigrated to the U.S. over 30 years ago, and when she proudly became a U.S. citizen in 2011, she hoped that her opportunities and benefits might improve. She does currently have the option to purchase private health insurance through her fulltime employer, but she cannot afford the least expensive option, which costs over \$200 per month. Despite working hard helping others both in her full-time job and as a caregiver for her ailing mother, she feels that her life is not as secure as she had hoped it would be, and she is anxious about living without the protection of health insurance.

From 2007 to 2010, Francisca had purchased subsidized health insurance through the Health Connector, paying \$85 per month in premiums. Then in 2011, for reasons that she didn't find to be clear, she qualified for MassHealth and no longer had to pay a monthly premium. From 2011 to 2013 she was very happy with her MassHealth coverage, and in early 2014 she completed her annual renewal paperwork as she had done in previous years. However, when she went to an eye doctor in October 2014 for a problem

with her vision, the doctor's office told her that she no longer had health insurance coverage. She was surprised by this news, since she had not received any follow-up information after completing the renewal paperwork, and she had believed that her insurance coverage had continued.

Francisca went to the eye doctor in October 2014 because she was experiencing worsening vision related to eye trauma that she had sustained during a childhood accident. She decided to pay for the visit out of pocket; the bill was \$95. At the visit, she was given a prescription for new glasses, which, because of her eye condition, would cost \$500. This was more than she was able to afford. As a result, for the past year she has delayed filling the prescription for new glasses, hoping that she'll be able to gain insurance to offset some of the cost. In the meantime, she has

been wearing an old pair of glasses, and suffering with worsening headaches.

As Francisca reflected on her experience trying to keep her health insurance, she recalled that the application and enrollment process has been confusing and overwhelming. She does speak and understand English very well, but she prefers Spanish for complex topics such as health care and health insurance. She is extremely thankful to her local community health center, and sees them as her trusted source of information and assistance, since they have staff to help her in either English or Spanish. Over the past several years she has found it very easy to complete applications for health insurance coverage with the in-person assistance available at the community health center. Despite this service being available, she was frustrated by losing her coverage for reasons that still are unclear to her. She felt

> that "if someone had called me and explained the reasons that I didn't qualify for MassHealth, I wouldn't be confused right now.... I don't care if I have to pay more, just tell me. For my health, it's worth it." She plans to set up an appointment at the local community health center to try to understand why she lost her eligibility for subsidized insurance, and to see what options are available to her.

"I am very lucky that I don't have very many chronic medical problems," Francisca said. She has a history of chronic sinusitis and would like to see an otolaryngologist

to discuss her worsening pain. However, she knows that without insurance this will cost more than she can afford. She is extremely grateful for the state's Health Safety Net program, which helps her receive primary care at the community health center. However, she still wishes to have health insurance coverage, and she reported that the Health Safety Net program "really only covers me to see my primary care physician. If I go to the hospital or see a specialist, I will have to pay a lot of money."

Francisca reflected, "If I didn't work for a living, I might qualify for better health insurance benefits." She worries that, ironically, her full-time employment is preventing her from obtaining health insurance. However, with her mother gravely ill, she must continue to support her family.

APPENDIX A: INTERVIEW GUIDE

INTRODUCTION:

Thank you for agreeing to participate in this study.

This study aims to better understand some of the reasons why people don't have health insurance.

The information you provide will be kept confidential. When we write our report about the interviews, we will not use your name, or the name of the other people who will be interviewed. With your permission, we would like to audio-record the interview to ensure that we capture the information that you provide accurately. We will destroy the recording as soon as we complete our report.

Do you agree to being recorded? Yes / No

If you complete the full interview, then you will receive a \$50 gift card to Target. The gift card will be sent to you by mail.

Before we begin the interview, I want to confirm the information that you previously provided when you called our research team. You told us that you live in Massachusetts and you do not have health insurance coverage. Is this correct? **Yes / No**

If the respondent indicates that they have insurance, ask when they obtained this insurance.

If a person obtained health insurance between the time of the screening call and the interview, then you may proceed with the interview.

Do you have any questions before we begin?

Let's begin with the interview.

QUESTIONS TO BE USED DURING THE INTERVIEW:

- 1. Work status and access to employer-sponsored health insurance: [~5 minutes]
 - a. Are you currently working? Yes / No IF "NO," THEN SKIP TO QUESTION #2
 - b. What type of work do you do? _
 - c. Are you working part-time or full-time? Part-time / Full-time
 - d. Is health insurance available to you through your employer? Yes / No If "no," then skip to Question #2
 - e. Why did you not enroll in that insurance?

2. Length of time without health insurance: [~5 minutes]

a. Approximately when was the last time you had any type of health insurance?

Alternate version of Question #2a that can be used if the interviewee already provided information about when they last had health insurance:

When you previously called our research team, you told us that the last time you had any type of health insurance was approximately ______ months ago. Is this correct?

Probe that can be used if the interviewee is uncertain when they last had insurance:

- Was it approximately 6 months ago? 1 year ago? 5 years ago?
- b. What was the name of that health insurance? _

Probes that can be used if the interviewee needs examples of "health insurance":

- MassHealth
- Commonwealth Care
- Blue Cross Blue Shield
- Neighborhood Health Plan
- BMC HealthNet

IF THE INTERVIEWEE DOES NOT ANSWER "MASSHEALTH" OR "COMMONWEALTH CARE," THEN ASK:

- c. Did you get that health insurance through your employer? Yes / No / Unsure
- d. How did that health insurance come to end?

3. Health status and health access: [~5 minutes]

- a. How would you describe your health: "poor," "fair," "good," or "excellent"? Poor / Fair / Good / Excellent
- b. Do you have any chronic health conditions such as diabetes or high blood pressure? And if you do, then what conditions do you have?
- c. When was the last time you saw a doctor or other health care provider?

4. Opinion & impact of not having health insurance: [~10 minutes]

- a. Is it important to you to have health insurance? Why or why not?
- b. How has not having health insurance affected your ability to get the health care you thought you needed?

5. Barriers to gaining health insurance: [~20 minutes]

- a. Have you tried to get health insurance within the last 12 months? Yes / No IF "NO," SKIP TO QUESTION #6
- b. What was your experience in trying to get health insurance (or what happened)?
- c. What were the reasons you were unable to get health insurance?

Probes that can be used if needed:

- Could not afford health insurance
- No longer eligible for assistance lowering the monthly cost of health insurance
- Application process difficult to understand
- Difficult to get information in a language most familiar with
- Worried that applying for health insurance may interfere with citizenship status
- · Could not find the time / process too time-consuming
- d. What kind of assistance did you get when you tried to get health insurance?
 - Probes that can be used if needed:
 - Customer service line
 - Health care provider (such as a hospital or community health center)
 - · Someone who works for a community organization or a faith-based organization
 - Friend or family
 - None
- e. How helpful was the assistance that you received?

Probes that can be used if needed:

- Why was the assistance helpful (or not helpful) to you?
- How satisfied were you with the assistance that you received?
- How could the assistance have been more helpful to you?
- f. If you try to get health insurance in the future, what would be helpful to you?

Probes that can be used if needed:

- Getting assistance from someone at an organization that I already know and trust (like a church, community group, or a clinic)
- Talking to someone who is a native speaker of the language you prefer
- Talking to someone on multiple occasions, not just once
- · Meeting with someone in person, instead of talking by phone
- A person or place that you can get assistance during evenings and weekends
- · Printed materials that are more understandable than ones you've seen before
- Online materials that are more understandable than ones you've seen before

AT THE END OF QUESTION #5, SKIP TO QUESTION #7

6. Barriers for those who haven't tried to get health insurance within 12 months: [~20 minutes]

a. What are the reasons that you haven't tried to get health insurance within the 12 months?

Probes that can be used if needed:

- Certain that could not afford health insurance
- Not eligible for assistance lowering the monthly cost of health insurance
- Application process difficult to understand
- Difficult to get information in a language most familiar with
- Worried that applying for health insurance may interfere with the citizenship status of you or someone you know
- Could not find the time / the process is too time-consuming
- b. If you try to get health insurance in the future, what would be helpful to you?

Probes that can be used if needed:

- Getting assistance from someone at an organization that I already know and trust (like a church, community group, or a clinic)
- Talking to someone who is a native speaker of the language you prefer
- Talking to someone on multiple occasions, not just once
- Meeting with someone in person, instead of talking by phone
- A person or place that I can get assistance during evenings and weekends
- Printed materials that are more understandable than ones you've seen before
- Online materials that are more understandable than ones you've seen before

7. Understanding of the individual mandate:

a. Are you aware that some individuals may be asked to pay a fee if they do not have health insurance? Yes / No

| APPENDIX B | B: CHARACTERISTICS | OF THE STUDY SAMPLE |
|-------------------|---------------------------|----------------------------|
|-------------------|---------------------------|----------------------------|

| LANGUAGE THAT THE INTERVIEWS WERE CONDUCTED IN | # | % |
|---|----|-----|
| English | 14 | 42% |
| Spanish | 9 | 27% |
| Portuguese | 10 | 30% |
| TOTAL | 33 | |
| AGE OF INTERVIEWEES | # | % |
| 19 to 26 | 4 | 12% |
| 27 to 39 | 9 | 27% |
| 40 to 49 | 5 | 15% |
| 50 to 64 | 15 | 45% |
| 65+ | 0 | 0% |
| TOTAL | 33 | |
| LOCATION WHERE THE INTERVIEWEES LIVE WITHIN MASSACHUSETTS | # | % |
| Barnstable County | 6 | 18% |
| Berkshire County | 8 | 24% |
| Essex County | 3 | 9% |
| Hampden County | 3 | 9% |
| Middlesex County | 9 | 27% |
| Norfolk County | 1 | 3% |
| Plymouth County | 3 | 9% |
| TOTAL | 33 | |
| GENDER OF THE INTERVIEWEES | # | % |
| Female | 21 | 64% |
| Male | 12 | 36% |
| TOTAL | 33 | |
| LENGTH OF UNINSURANCE | # | % |
| No insurance for less than 6 months | 5 | 15% |
| No insurance for 6 to 12 months | 2 | 6% |
| No insurance for less than 1 year | 7 | 21% |
| No insurance for 1 to 2 years | 7 | 21% |
| No insurance for 3 or more years | 5 | 15% |
| No insurance for more than a year | 12 | 36% |
| Never has had insurance | 14 | 42% |
| TOTAL | 33 | |
| EMPLOYMENT STATUS AT TIME OF INTERVIEW | # | % |
| Employed, with available ESI | 7 | 21% |
| Employed, without available ESI | 19 | 58% |
| Not employed | 7 | 21% |
| TOTAL | 33 | |

