On the Trail Less Traveled

By Cheryl L. Reed

Researchers track down the most elusive South Side residents in a pilot study about health care

The sign on the door reads: Private Property. No Trespassing.

Inside, a plastic strip secured with masking tape leads a path through the dark, twisting hallway. The trail ends at a bulletproof window. There, a hotel clerk raises her eyebrows at the red clipboard in Ramya Iyer’s arms and the Nextel phone box in Billy Jackson’s hands.

“We’re from the University of Chicago’s South Side Health and Vitality Studies, and we have a couple of people from our survey in this building,” announced Iyer, a 26-year-old Social Services Administration graduate student. “We don’t have names, just numbers of their rooms.”

The clerk buzzes the two field researchers through a side door. They climb a set of stairs and knock on the doors that correspond to the numbers derived from a database back at the University of Chicago Survey Lab. But no one responds. The researchers hang tags on the doors, offering $15 for a 15-minute interview.

Had someone answered, he or she would have had the option of taking a cell phone, with free texting, so researchers could follow up in six weeks and then in three months.

The incentives are part of the Recruitment and Retention Survey, a pilot study tracking residents from six South Side neighborhoods: Kenwood, Grand Boulevard, Washington Park, Woodlawn, Roseland and Pullman. A separate sampling includes people from those neighborhoods who are especially difficult to track — those who live in single room occupancies (SROs), who move frequently, don’t have land-lines or are known to the post office as difficult to track down for mail delivery.

The South Side Studies, which includes building community partnerships, research and education, are part of the broader South Side Health and Vitality Studies, a longitudinal analysis of 5,000 randomly selected South Side residents. These studies are slated to begin in three years.

“These are the broad brush strokes of what will be a complicated study of the South Side,” said John Schneider, MD, instructor of medicine and epidemiology and director of global health programs at the Medical Center. Schneider, who designed the pilot study and is part of the team devising the larger study, spends up to three months a year in India tracking down men susceptible to contracting HIV. He understands the complications of tracking elusive populations.

The South Side Studies will monitor the health of the sample for 20-plus years and will be patterned after Boston University’s Framingham Heart Study, which started in 1948 and now has tracked three generations of residents from that Boston suburb. Just as the Framingham study focused on heart disease and stroke, the South Side Studies will likely focus on rates of obesity and diabetes, the health effects of violence and mental health issues of South Side residents — issues that were ranked as the most pressing among community leaders.

“People talk about food deserts on the South Side, but there are health care provider deserts too,” explained Schneider. “Part of the secondary objectives of this pilot study is to ask the greater questions about residents’ access to health care. A lot of people are telling us that they don’t know where to go to see a dentist or to get HIV care.”

The hope is that the long-term study will be able to establish a baseline picture of health for South Side residents which, in turn, will inform specific programs to target those health problems down to the neighborhood or even block. The studies would track the efficiency of health programs and how well they are addressing problems. Information collected would be used to attract federal and state funds by documenting the needs of the community.

Funding for the South Side Studies, though, remains an obstacle. Because of its breadth and depth, the longitudinal study is estimated to cost anywhere from $8 million to $15 million, turning researchers into salesmen as they try to convince major donors, government entities and foundations to support the project.

“We need to find philanthropists who are passionate about this issue,” explained Stacy Tessler Lindau, MD, assistant professor of obstetrics and gynecology and principal investigator for the South Side Studies. “Those sources of support are going to be very important in securing funding from the federal government.”

Currently, the Resource and Retention pilot study and another pilot study last summer that mapped every non-residential building in six South Side neighborhoods have cost the university about $200,000, not including faculty and staff time and overhead expenses. The Medical Center has committed an initial $1.5 million for development of the pilot studies, which includes building community partnerships and fundraising to extend the mapping project to all 34 South Side neighborhoods. The funding came from the studies’
On the Trail Less Traveled

By Cheryl L. Reed

Researchers track down the most elusive South Side residents in a pilot study about health care

The sign on the door reads: Private Property. No Trespassing.

Inside, a plastic strip secured with masking tape leads a path through the dark, twisting hallway. The trail ends at a bulletproof window. There, a hotel clerk raises her eyebrows at the red clipboard in Ramya Iyer’s arms and the Nextel phone box in Billy Jackson’s hands.

“We’re from the University of Chicago’s South Side Health and Vitality Studies, and we have a couple of people from our survey in this building,” announced Iyer, a 26-year-old Social Services Administration graduate student. “We don’t have names, just numbers of their rooms.”

The clerk buzzes the two field researchers through a side door. They climb a set of stairs and knock on the doors that correspond to the numbers derived from a database back at the University of Chicago Survey Lab. But no one responds. The researchers hang tags on the doors, offering $15 for a 15-minute interview. Had someone answered, he or she would have had the option of taking a cell phone, with free texting, so researchers could follow up in six weeks and then in three months.

The incentives are part of the Recruitment and Retention Survey, a pilot study tracking residents from six South Side neighborhoods: Kenwood, Grand Boulevard, Washington Park, Woodlawn, Roseland and Pullman. A separate sampling includes people from those neighborhoods who are especially difficult to track — those who live in single room occupations (SROs), who move frequently, don’t have landlines or are known to the post office as difficult to track down for mail delivery.

Learning how to keep in contact with the most elusive population will inform researchers about how to conduct the larger South Side Health and Vitality Studies, a longitudinal analysis of 5,000 randomly selected South Side residents. These studies are slated to begin in three years.

“These are the broad brush strokes of what will be a complicated study of the South Side,” said John Schneider, MD, instructor of medicine and epidemiology and director of global health programs at the Medical Center. Schneider, who designed the pilot study and is part of the team devising the larger study, spends up to three months a year in India tracking down men susceptible to contracting HIV. He understands the complications of tracking elusive populations.

The South Side Studies will monitor the health of the sample for 20-plus years and will be patterned after Boston University’s Framingham Heart Study, which started in 1948 and now has tracked three generations of residents from that Boston suburb. Just as the Framingham study focused on heart disease and stroke, the South Side Studies will likely focus on rates of obesity and diabetes, the health effects of violence and mental health issues of South Side residents — issues that were ranked as the most pressing among community leaders.

“People talk about food deserts on the South Side, but there are health care provider deserts too,” explained Schneider. “Part of the secondary objectives of this pilot study is to ask the greater questions about residents’ access to health care. A lot of people are telling us that they don’t know where to go to see a dentist or to get HIV care.”

The hope is that the long-term study will be able to establish a baseline picture of health for South Side residents which, in turn, will inform specific programs to target those health problems down to the neighborhood or even block. The studies would track the efficiency of health programs and how well they are addressing problems. Information collected would be used to attract federal and state funds by documenting the needs of the community.

Funding for the South Side Studies, though, remains an obstacle. Because of its breadth and depth, the longitudinal study is estimated to cost anywhere from $8 million to $15 million, turning researchers into salesmen as they try to convince major donors, government entities and foundations to support the project.

“We need to find philanthropists who are passionate about this issue,” explained Stacy Tessler Lindau, MD, assistant professor of obstetrics and gynecology and principal investigator for the South Side Studies. “Those sources of support are going to be very important in securing funding from the federal government.”

Currently, the Resource and Retention pilot study and another pilot study last summer that mapped every non-residential building in six South Side neighborhoods have cost the university about $200,000, not including faculty and staff time and overhead expenses. The Medical Center has committed an initial $1.5 million for development of the pilot studies, which includes building community partnerships and fundraising to extend the mapping project to all 34 South Side neighborhoods. The funding came from the studies’
parent program known as the Urban Health Initiative, the Medical Center’s major, long-term commitment to help improve the health status of the surrounding communities. (See adjoining article.)

Finding incentives

By mid-October, the Recruitment and Retention pilot study had reached 168 people out of an initial computerized sample of 640, and researchers were beginning to apply a full-court press to reach the stragglers before re-contacting respondents for six-week and three-month follow-ups.

Standing in an unseasonably chilly downpour, Iyer and Jackson, a 23-year-old South Side freelance artist who lives near the survey lab, waited for someone to answer an apartment call button. The wind whipped across their jackets as they huddled together outside the brick building protected by an ominous steel gate. Though no one stirred in the building, the Grand Boulevard neighborhood was alive with activity. Church bells sounded across the street and an elderly woman passed by, pushing a cart of groceries.

The young researchers had lucked out in their first contact that morning: A couple living in an SRO were eager to visit and opted for the phone over a Target gift card. Instead of being shooed away and having doors slammed in their faces, the researchers say their biggest problem is that residents like the company and keep talking outside the scope of the study.

“Some people are very lonely,” explained one of the field researchers, Jeff Bean, 23, who recently graduated from the University of Chicago. “Offering money has made it easier. One of the survey questions asks how likely they would be to do the study if we paid them $100 each time we talked to them. They just look at you and laugh and say: ‘Uh, very likely.’”

The pilot study is not only testing the best way to get someone to participate — is $2 or $5 a better incentive or will it require a $15 gift card or a walkie-talkie phone — but what methods are best to keep in contact: phone, e-mail or an in-person visit (no one has turned down $100 yet). The study also taps into respondents’ access to health care and technology. Currently, only 20 percent of households on the South Side have Internet access through a home computer. Researchers hope to use information from the mapping study to apply for stimulus money that would provide free Internet access through community centers and churches on the South Side. That way residents could get health information and stay in contact with doctors even if they don’t have a phone or a stable address.

Though the young researchers aren’t strangers to urban populations, they say they’ve been surprised by the divergent lifestyles and disparate housing they’ve encountered on the South Side. They’ve interviewed residents with high-ceiling apartments and grand pianos, but they’ve also encountered people who share boarded-up buildings.

“It’s informed my work as a therapist and given me a better understanding of the range of their environments,” Iyer said.

They’ve also been pleased by the number of people who have agreed to do the survey. “People are just surprised that the university is taking an interest in them,” Bean said.
Mapping neighborhoods

This past summer, Bean and Johnson were both field researchers in the mapping project that plotted everything but homes in six neighborhoods: Hyde Park, Kenwood, Woodlawn, Washington Park, Grand Boulevard and Eastside. That pilot study, called the Resource Mapping Project, was completed by summer’s end and the results were made available online in mid-October at www.southsidehealth.org. Visitors to the site can conduct precise searches of everything from car repair shops to health care clinics on the neighborhood level.

Although researchers are still fine-tuning the website and aspire to extend the project to include all 34 South Side neighborhoods, the data was made available to the public before it was picture-perfect — part of the Medical Center’s promise to community leaders to share findings quickly and to solicit feedback on how to tailor data for community use. “We have definitely heard people say: ‘We’re tired of researchers parachuting in and doing studies and never getting information back,’” explained Lindau. “We’re doing things differently now. We’re working with the community and putting our joint product out in an early phase. This gives community and university folks a chance to work with the data, tell us how they want to use it, and then we work together to ensure it translates.”

The information gathered in Woodlawn has already been handed over to community leaders like Arthur M. Brazier, bishop emeritus of the neighborhood’s mega church, Apostolic Church of God. Brazier has been working to revamp Woodlawn’s elementary school curricula to stress parent-teacher engagement and push the importance of college, starting from pre-school. Brazier is hoping the information from the mapping project will help make the case for a $25 million grant from the U.S. Department of Education that would enable them to change the curricula.

Part of the Medical Center’s motivation behind the mapping project was to prove to community members that the university could be an equal partner and would live up to its stated commitments. At the mapping website’s unveiling, dozens of community members packed into the DuSable Museum of African American History, near the Medical Center’s campus, to give their unbridled input. Some openly admitted they’d been skeptical in the beginning, but the project had helped them warm to partnering with the university.

“I was born and raised on the South Side and have a healthy skepticism about the university,” said Shirley Fleming, a member of the health ministry at Trinity United Church of Christ, also on the South Side. “We want to contribute to the process and to promote health in our community. This data allows us to apply for grants and be on the ground level. Let’s just say it’s made me hopeful.”

“One of the survey questions asks how likely they would be to do the study if we paid them $100 each time we talked to them. They just look at you and laugh and say: ‘Uh, very likely.’”

— Jeff Bean, Field Researcher