



UNIVERSITY OF
LOUISVILLE
SCHOOL OF MEDICINE

Office of Community of Engagement
2301 South Third Street
209F Grawemeyer Hall
University of Louisville
Louisville, KY 40218
Attn: Susan Rhodes

Department of Neurology
Division of Movement Disorders

Irene Litvan, MD
Division Chief

David J. Houghton, MD, MPH
Assistant Professor

Joseph M. Ferrara, MD
Assistant Professor

Dear Signature Partnership Faculty Award Committee:

Please find the enclosed report from our Signature Partnership Grant titled "Development of a Questionnaire to Study Barriers to Healthcare Access and Impediments to Participation in Medical Research in Residents of West Louisville." Through this project, we have successfully obtained necessary pilot data to be used for an NH grant proposal. In addition, this project has provided us the opportunity to develop relationships with several Community-Based Organizations and medical providers in the West Louisville community. We would like to thank the committee for allowing the Division of Movement Disorders the opportunity to explore this important issue faced by residents of West Louisville through financial grant support.

Sincerely,

Irene Litvan, M.D.
Raymond Lee Leiby Professor
University of Louisville,
Division of Movement Disorders
220 Abraham Flexner Way, Ste 1503
Frazier Rehab Institute
Louisville, KY 40202

Development of a Questionnaire to Study Barriers to Healthcare Access and Impediments to Participation in Medical Research in Residents of West Louisville

Whitney T. Rogers, M.A.
Ramona E. Stone, Ph.D.
David J. Houghton, M.D.
Irene Litvan, M.D.

January 31, 2011

A Technical Report in Fulfillment of Signature Partnership Grant

SIGNATURE PARTNERSHIP PROJECT

EXECUTIVE SUMMARY

The purpose of this community-based project was to identify perceived barriers and impediments to healthcare access and participation in medical research as experienced by residents of West Louisville. Through a process called concept mapping, we have successfully captured the data necessary to develop a questionnaire to study the social, economic, geographic and cultural challenges encountered by this medically underserved community. This qualitative approach has enabled us to achieve a comprehensive understanding about these issues by comparing responses that reflect the attitudes and beliefs of the stakeholders most invested in the community (healthcare professionals and community leaders). It is hoped that the results of this study will be used to design a population study of the prevalence of Parkinson disease and essential tremor in West Louisville.

INTRODUCTION

In view of the under-representation of residents of West Louisville at the University of Louisville Division of Movement Disorders (DMD), despite that all residents of the Louisville Metro area can have access to its care, our Division proposed to conduct a community-based project to identify perceived barriers and impediments to healthcare access and participation in medical research as experienced by residents of West Louisville.

To better study the social, economic, geographic and cultural challenges that residents of West Louisville experience to access healthcare as well as the minority population's reluctance to participate in medical research, we proposed to use group-oriented concept mapping methodology (Trochim and Kim, 2005) when conducting structured focus groups with: (1) providers of healthcare services in the community, and (2) community leaders and (3) residents of the area. If recruitment was low, we planned for individual interviews. The results of the focus groups and individual interviews were to be used to develop a questionnaire that will be tested in Family Health Centers and other community settings.

METHODOLOGY

Identification of Community Liaisons

To identify key stakeholders in the West Louisville community, the first step in this study was to form a partnership with the Northwest Area Health Education Center (N.W.A.H.E.C.). This partnership was successfully executed and a working relationship with the Northwest AHEC has been established. Through this partnership, the director of the N.W.A.H.E.C. identified a well-respected and highly visible community leader (Kim Mapp) to serve as a community liaison between the community and the University of Louisville DMD for this Signature Partnership project. The primary role of the

community liaison was to identify community leaders and healthcare professionals within the West Louisville community for participation in the focus group and concept mapping exercises. Key stakeholders identified included administrators and healthcare professionals from Family Health Centers, the Grassroots Alliance for Community Empowerment (GRACE), area health education centers, Louisville Metro Health Department, Neighborhood Associations, health ministers and community activists.

Community-Based Focus Groups

Following identification of key stakeholders, two community-based focus groups were conducted to better understand the barriers and impediments to medical care and participation in research as experienced by individuals working directly with the community. Focus group sessions were co-led by Whitney Rogers, Drs. Irene Litvan and Ramona Stone. All sessions were audio taped and later transcribed.

The *first focus group* comprised of healthcare professionals was conducted on October 29th, 2010 at the Catholic Enrichment Center. In this focus group, 3 out of the 8 healthcare professionals (38%) invited to participate attended and participated in the group. Such a large number of no-shows for the first focus group was unexpected and prompted us to reevaluate our strategy for retaining identified stakeholders.

Our community liaison identified several barriers to participation and strategies such as reminder calls and frequent contact were implemented to ensure better turn out at subsequent focus groups. Although not ideal, healthcare professionals who were unable to attend the initial meeting were invited to attend the second focus group. Despite this modification, we still encountered difficulties in getting key stakeholders to show up for the second focus group session.

The *second community-based focus group* was conducted on November 11, 2010 at the

Louisville Metro Health Department's Center for Health Equity. In this second focus group, which consisted of a mix of healthcare professionals and community leaders, 8 out of the 15 (53%) invited stakeholders attended and participated in the focus group. Overall, we succeeded in recruiting and consenting 48% (11/23) invited focus group participants. The final breakdown of the 11 attendees was as follows: 6 Healthcare professionals and 5 Community Leaders.

Community Residents

To better understand the health behaviors, beliefs and attitudes in the West Louisville community, we proposed to conduct focus groups and concept mapping exercises with community residents. Our ultimate goal in conducting this exercise with residents was to better understand the reasons, specific to West Louisville, why residents who were actively experiencing medical problems did not seek medical care. To identify this specific population of community residents, we partnered with the Parkinson Support Center of Kentuckiana to hire staff to routinely attend community events (e.g. health fairs, church events) and conduct free Parkinson's disease (PD) health screenings on behalf of the University of Louisville, DMD. As part of our partner's screening tool, individuals were asked in advance and consented to the sharing of their screening information with the DMD. We designed a screening tool based on prior validated ones that would identify PD/Parkinsonism (e.g. tremor at rest, shaking, decreased sense of smell, balance and walking difficulties, slowness, etc) or essential tremor (ET) symptomatology (e.g. postural tremor) (see Appendix).

Over the course of 12 months our partner attended 28 community events and screened over 316 people. Out of the 316 people screened, 60 (19%) screened positive for PD/Parkinsonism/ET. To confirm the diagnosis of PD/Parkinsonism/ET, DMD movement disorder specialists Drs. Irene Litvan and David Houghton, offered a free neurological examination at the Catholic Enrichment Center, in West Louisville to all individuals screening positive on the screening tool. Individuals with a positive

screening were contacted by our community partner, both on-site at the community event or by telephone, and scheduled for an appointment at the Catholic Enrichment Center. Initially, our community partner dedicated numerous hours trying to contact previously screened individuals by telephone and encountered a many challenges such as disconnected phones, repeated unanswered messages and individuals who had no recollection of their participation in the initial screening. To circumvent these obstacles, our community partner started scheduling individuals for evaluations immediately following completion of the screening tool while on-site at the community event. Out of the 60 individuals identified for further neurological screening, our community partner was able to reach and schedule 27 (45%) individuals.

Free neurological screenings were conducted over the course of several months. The first screening took place on May 21st, 2010 and 4 out of the 6 (67%) individuals scheduled for an evaluation showed up for their appointments and were evaluated. From this screening 2 individuals received a confirmed diagnosis; one individual was diagnosed with an Atypical Parkinsonian disorder called Dementia with Lewy Bodies (DLB) and one with an Essential Tremor. The second screening took place on July 17th, 2010 and 3 out of the 6 (50%) individuals scheduled showed up for their appointments and were evaluated. From this screening 2 individuals were diagnosed as having Parkinson's disease. The third screening took place on October 8th, 2010 and 4 out of the 15 (27%) individuals scheduled showed up for their appointments and were evaluated. From this screening 2 individuals received a confirmed diagnosis; one individual was diagnosed with Parkinson's disease and one with an Atypical Parkinsonian disorder called Multiple System Atrophy (MSA).

These community-based neurological screenings resulted in Drs. Litvan and Houghton evaluating a total of 11 out of the 27 (41%) individuals scheduled; overall, there were 6 individuals diagnosed with PD/Parkinsonism/ET out of the 11 who kept their appointment (see Figure 1). All individuals diagnosed were referred to appropriate providers for care.

These six individuals were then invited to participate in a community focus group and concept mapping exercise by a DMD staff member. After repeated attempts at contact, 4 out of the 6 individuals agreed to participate in the study. Only 1 individual was agreeable to coming to the University to participate in the study. Two individuals indicated their participation was contingent upon the DMD staff member coming to their residence to conduct the study. The fourth individual agreed to participate but stated the DMD staff member needed to come to their place of employment due to a demanding 6-day, 12-hr shift work schedule. An attempt was made to honor all requests in order to complete this study. Unfortunately, due to unforeseen problems (e.g. hospitalization, home infestation of bed bugs), only one community resident was able to complete the study. The study and procedures were explained to the individual and informed consent was obtained. During the first part of the interview, the DMD staff member observed the study participant falling asleep repeatedly. After several attempts to help the participant maintain alertness (e.g. offering juice or soda) were unsuccessful, it was determined that the participant was excessively tired and could not continue participation in the study. It was concluded that the participant would contact the DMD staff member at a later time to resume study participation.

Concept Mapping

Two focus group sessions were conducted with community leaders and healthcare professionals using the group-oriented concept mapping methodology described in 2005 by Trochim and Kim. Focus groups were conducted in a group setting at community-based organizations located in the West Louisville community. The project was explained to the participants and informed consent was obtained from all attendees. After consenting, focus group participants were provided with two focus prompts and asked to generate single-concept statements starting with the most important issue to that prompt. The first focus prompt was “Specific reasons that people in my community don’t get medical

care are...?”. The second focus prompt was “Specific barriers to participation in medical research are...?”. Immediately following the statement generation exercise, focus group participants were invited to engage in a round table discussion. The discussion portion of the focus group was audio taped and later transcribed.

Following completion of the two focus groups, all written statements to the focus prompt were consolidated into one master list. The orders of the statements were recorded across all subjects as well as the frequency at which statements were endorsed. All duplicate statements were eliminated and statements that contained more than one concept were separated out into single-concept statements. Audio taped recordings of the round table discussion were transcribed and single concept statements were extracted and combined with statements in the master list.

Study participants were then asked to participate in a sorting/rating exercise. This exercise was conducted by mail. Single-concept statements were transferred onto 3X5 index cards and participants were asked to group statements in a commonsensical manner and provide a label to each group created. Participants were provided with instructions and rules for the sorting exercise as well as post-it notes, rubber bands and a pre-addressed, stamped envelope to return the study materials (See Appendix). The second part of this exercise was a ranking exercise. In the same mailing, study participants were provided the same single-concept statements in a survey format. They were asked to rate the questions according to their importance using a Likert scale (1-5) rating system. A total of 11 packets were assembled and mailed to study participants. To ensure timely study completion, participants were kindly requested to return study materials within a 2-week window. Study participants with outstanding packets after the 2-week period received a telephone call by the DMD staff member. The purpose of the phone call was to identify and address any barriers to completion of the study exercises. After 4 weeks, study participants received one additional call to further prompt the return of any outstanding materials. These efforts resulted in a final return rate of 36% (4 out of 11). Such a low return rate by the

key stakeholders in this community was an unexpected finding in this study and warrants further exploration.

RESULTS

Data analyses were conducted using qualitative methodologies. There were a total of 11 people who participated in the two focus groups. The number of individuals who scored the statements derived from the focus groups are presented below. The statements were selected for inclusion on the concept mapping scorecards based on them being mentioned in the focus groups. Further, they will be included in the questionnaire based on rankings of importance. Individual statements were entered into Excel and sorted in two ways: a) by the number of individuals who chose the issue as being important, no matter the degree of importance assigned to it (table 1), and b) by the average importance score (table 2). The mean importance score was obtained by averaging the importance scores assigned by respondents.

Table 1 shows that the issues chosen by most people were transportation, trust, and cost of care. Table 2 shows that top importance scores were assigned to the cost of care (ex, insurance), financial problems, culture of poverty, lack of knowledge/ awareness/ education regarding health care system and health care in general, lack of trust. The categories in Table 3 could also be classified in the following four topics that we will further use in the development of the questionnaire:

- a) *Access/geographic barriers* (i.e. transportation, time away from job, child-care),
- b) *Socio-economic barriers* (i.e. un- or under-insured, cost of travel and other secondary costs),
- c) *Cultural barriers* (i.e. mistrust of medical community, preference for non-Western medical treatment, limited value placed on own health), and
- d) *Health literacy barriers* (i.e. limited knowledge of medical conditions, lack of appropriate referral by primary care physicians).

The questionnaire will include measures for all of these four topics, along with demographic measures (See Appendix A2 for Preliminary Draft of Questionnaire).

Table 1. Single Concept Statement by Frequency

Rank	Issue	N	Mean Score*
1	Transportation	11	2
2	Mistrust/distrust of providers	11	2.25
3	Parking	11	2.75
4	Cost	9	1.25
5	Financial Problems	9	1.25
6	Difficulty taking time off work	9	2
7	Lack of insurance	8	1
8	Fear concerning risk	8	2
9	Literacy issues	8	2
10	Intimidation of research	7	2.5
11	No people of color doing the research	7	2
12	Unethical History of research in community	5	2.25
13	Misuse of data	5	2.5
14	Unemployment	4	1.5
15	No sense of accountability	4	2.5
16	Wait times	3	1.5
17	Disjointed "system" of care	3	1.75
18	Other priorities	3	2.5
19	People not feeling sick	3	1.5
20	Don't know we exist	3	1.25
21	Lack of understanding of chronic issues/diseases	3	1.5
22	Do not see the importance of annual exams	3	1.5
23	Lack of private practice physicians	2	1.75
24	Daycare issues	2	2
25	Perception re quality of care	2	1.25
26	Culture of poverty	2	1.25
27	No primary care physician/ No true medical home, may be in the same building but not see the same time each time one goes	2	1.5
28	Location	2	2.25
29	Not willingness to change lifestyle	2	1.75
30	Don't know what we do/lack of knowledge re: health care providers	2	1.75
31	Fear that doctors in their community (West End) are not real doctors and will not give good care	2	2.25
32	Feelings of being disrespected by doctors when asking extra questions or talking about other health issues during a visit	2	1.5
33	Fears of being diagnosed/misdiagnosed	1	2.5

*Ranking scores are on a Likert scale 1-5: 1=most important issue to 5=least important issue

Table 2. Single Concept Statement by Importance Score (lower= higher importance)

Ran k	Issue	N	Mean Score*
1	Lack of insurance	8	1
2	Cost	9	1.25
3	Financial Problems	9	1.25
4	Don't know we (health care providers) exist	3	1.25
5	Perception re: quality of care	2	1.25
6	Culture of poverty	2	1.25
7	Unemployment	4	1.5
8	Wait times	3	1.5
9	People not feeling sick	3	1.5
10	Lack of understanding of chronic issues/diseases	3	1.5
11	Do not see the importance of annual exams	3	1.5
12	No primary care physician/ No true medical home, may be in the same building but not see the same time each time one goes	2	1.5
13	Feelings of being disrespected by doctors when asking extra questions or talking about other health issues during a visit	2	1.5
14	Disjointed "system" of care	3	1.75
15	Lack of private practice physicians	2	1.75
16	Not willingness to change lifestyle	2	1.75
17	Don't know what we do/lack of knowledge re: health care providers	2	1.75
18	Transportation	11	2
19	Difficulty taking time off work	9	2
20	Fear concerning risk	8	2
21	Literacy issues	8	2
22	No people of color doing the research	7	2
23	Daycare issues	2	2
24	Mistrust/distrust of providers	11	2.25
25	Unethical History of research in community	5	2.25
26	Location	2	2.25
27	Fear that doctors in their community (west end) are not real doctors and will not give good care	2	2.25
28	Intimidation of research	7	2.5
29	Misuse of data	5	2.5
30	No sense of accountability	4	2.5
31	Other priorities	3	2.5
32	Fears of being diagnosed/misdiagnosed	1	2.5
33	Parking	11	2.75

*Ranking scores are on a Likert scale 1-5: 1=most important issue to 5=least important issue

The statements presented in tables 1 and 2 were further categorized in the following themes:

Table 3. Identified Themes

Theme	Categories
Lack of trust in providers (Cultural barrier)	Feelings of being disrespected by doctors when asking extra questions or talking about other health issues during a visit Perception re quality of care Disjointed “system” of care Mistrust/distrust of providers Don’t know we [health care providers] exist Don’t know what we do Fears of being diagnosed/misdiagnosed Fear of not getting good care Fear that doctors in their community (west end) are not real doctors and will not give good care
Lack of knowledge /awareness (Health Literacy barrier)	Lack of understanding of chronic issues/diseases Do not see the importance of annual exams Lack of private practice physicians No primary care physician/ No true medical home, may be in the same building but not see the same time each time one goes
Lack of access/ barriers: * geographical * socioeconomic	Lack of insurance Wait times Transportation Parking Location Daycare issues Literacy issues Not willingness to change lifestyle Financial Problems Cost
Culture of poverty	No sense of accountability Other priorities Fear concerning risk People not feeling sick Culture of poverty Difficulty taking time off work Unemployment
Lack of trust of researchers	Unethical History of research in community Intimidation of research No people of color doing the research Misuse of data

Discussion and Future Directions

There were many lessons learned from conducting this Signature Partnership project in the medically underserved community of West Louisville. Barriers to participation were much greater than expected in respect to both key stakeholders and community residents. To address the difficulties encountered with recruiting and retaining community resident, future studies utilizing the PD screening tool as a method of identifying study participants will incorporate on-the-spot neurological evaluations to increase participation. Future studies incorporating a concept mapping-type exercise will be conducted in-person, rather than by mail. Minimizing the time commitment needed for participation in these types of community-based projects will be crucial to future successes. Despite the unforeseen difficulties encountered conducting this study, our team was still able to accomplish our primary goals.

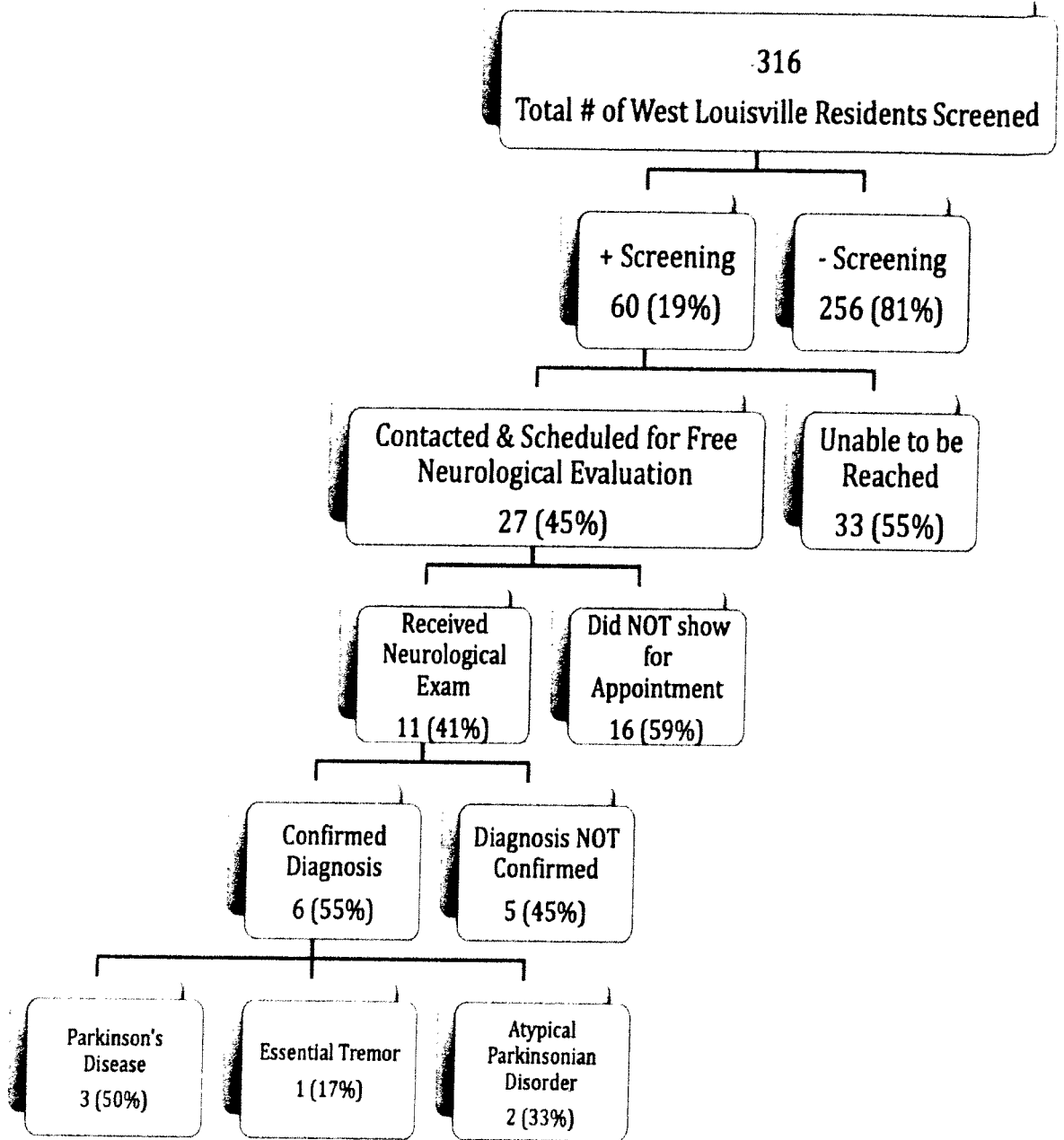
This project was successful in developing relationships of trust with the key stakeholders and community leaders in the West Louisville community. Through this collaborative partnership grant, the University of Louisville, Division of Movement Disorders (DMD), has become a contributing partner in a network of community-based organizations and will begin providing training and education for health ministers and wellness coaches serving at numerous congregations throughout the community. These partnerships will be crucial in demonstrating feasibility of conducting a large epidemiological study such as LUNA in this underserved community. Through this project we successfully obtained necessary pilot data to be used in an NIH R01 research project application. This Signature Partnership project has allowed us to demonstrate that, although somewhat challenging, gaining access to this study population is feasible.

The deliverable result of this study is the development of a culturally sensitive questionnaire to assess barriers to medical care and impediments to participation in medical research in residents of West Louisville. This questionnaire captures the key issues as experienced by residents and individuals working directly with this community. Our next step beyond this project is to have the questionnaire

reviewed by our community liaisons for cultural appropriateness and sensitivity. Once this is completed, all study participants will be invited to attend a brief meeting to disseminate the study results and make additional suggestions. All suggestions made by the study participants will be taken into consideration in the final version of the questionnaire.

Once finalized, our multidisciplinary academic-community research partnership group plans to test the questionnaire in Family Health Centers and community settings in West Louisville. We will also validate this questionnaire in a door-to-door study that will allow us to determine as well if there is feasibility for an epidemiologic study of PD/Parkinsonism/ET in West Louisville. This will result in a standardized and validated instrument and provide feasibility data to be used in the Louisville Underserved population Neurological Assessment (LUNA) project to ascertain prevalence estimates of Parkinson's disease and Essential Tremor residents of West Louisville. The use of this culturally appropriate instrument in a large sample is hoped to provide information that can be used to design healthcare policy models to improve healthcare delivery and participation in medical research.

Figure 1: Ascertainment of Undiagnosed PD/ET/Parkinsonism in West Louisville Residents



APPENDIX

Appendix 1. Screening tool for parkinsonism (English).

- 1) Do you have trouble rising from a chair?
 - 2) Is your handwriting smaller than it once was?
 - 3) Do people tell you that your voice is softer than it once was?
 - 4) Is your balance poor when walking?
 - 5) Do your feet suddenly seem to get stuck on the floor or freeze in doorways?
 - 6) Does your face seem less expressive than it used to?
 - 7) Do your arms and legs shake?
 - 8) Do you have trouble buttoning buttons?
 - 9) Do you shuffle your feet and take tiny steps when you walk?
- A) Has anyone ever told you that you have Parkinson's disease?
- B) Have you ever taken drugs like carbidopa/levodopa, Sinemet®, Stalevo®, pramipexole, Mirapex®, ropinirole, Requip®, selegiline, Eldepryl®, Zelapar®, rasagiline, Azilect®, amantadine, or Symmetrel®?

Appendix 2. Screening tool for parkinsonism (Spanish).

- 1) Tiene Ud. problemas para levantarse de una silla?
 - 2) Ha notado si su escritura es mas pequeña que antes?
 - 3) Le han comentado si el volumen de su voz es menos potente que antes?
 - 4) Ha notado si su equilibrio esta alterado?
 - 5) Ha notado que los pies se le quedan pegados al suelo al cruzar el umbral de las puertas?
 - 6) Le parece que su cara es ahora menos expresiva?
 - 7) Le tiemblan los brazos y las piernas?
 - 8) Tiene dificultad para abrocharse los botones?
 - 9) Arrastra los pies y da pasitos cortos al andar?
- A) Le han dicho a Ud. alguna vez que Ud. tiene la Enfermedad de Parkinson?
- B) Ha tomado Ud. medicaciones como carbidopa/levodopa, Sinemet®, Stalevo®, pramipexole, Mirapex®, ropinirole, Requip®, selegiline, Eldepryl®, Zelapar®, rasagiline, Azilect®, amantadine, o Symmetrel®?

Appendix 3: Concept Mapping Study Materials

Hello Study Participants,

Thanks for participating in our focus group on “Barriers to Medical Care and Research in Residents of West Louisville”. The second part of this study is a short sorting and ranking activity. This will conclude your participation in this study.

The packet you received should contain the following items:

1. A stack of colored index cards. The cards have statements written on them that were generated through our focus groups. These statements are worded exactly how they were written during the statement generation portion of the focus groups.
2. On the back on the cards there are random numbers. These numbers are random and don’t mean anything.
3. Also included in your packet are some post-it notes and rubber bands.
4. You will additionally find a piece of paper with _ statements written in a questionnaire format. This paper will be used for the ranking exercise and will be returned to U of L.
5. A self-addressed, stamped envelope is also provided for you to return the study materials.

Here are the instructions:

Sorting Exercise

1. **Step 1:** Sort the cards into piles based on a common theme.
 - a. **Rules:**
 - i. You must have more than one pile.
 - ii. Piles must contain more than one card (i.e. one card does not make a pile)
2. **Step 2:** Once the cards are sorted, place a rubber band around the piles and label the piles with a post-it note. Come up with a name or “theme”. This label is whatever title/name/theme you can come up with that best describes the issue or concept represented by all the cards in one pile.
3. **Step 3:** Place the rubber banded and labeled piles of note cards in the self-addressed stamped envelope.

Ranking Exercise

1. **Step 1:** Take the piece of paper in your packet that lists all the concept statements in a questionnaire format. Beside each statement is a blank line. Using a Likert-scale ranking system, rank each statement as to how important you think this particular issue is to “Barriers to Medical Care and Research in Residents of West Louisville”.
2. **Step 2:** Place the paper with the ranked statements back in the self-addressed stamped envelope (with the index cards).
3. **Step 3:** Place the packet in the mail. **Done!**

Ranking Exercise:

The following statements were generated through our focus group discussions and reflect reasons and barriers to medical care and participation in medical research for residents of West Louisville. These statements are identical to the statements that are written on the index cards.

Instructions:

Please rank the following questions according to their importance using a Likert scale rating system from 1-5, where 1 is the most important issue and 5 is the least important issue. An example is provided below to help distinguish the difference in ranking levels

(Ex.)

- 1- Most Important issue
- 2- Important issue
- 3- Neutral
- 4- Somewhat important
- 5- Least Important Issue

-
- 1. Lack of private practice physicians _____
 - 2. Transportation _____
 - 3. Parking issues _____
 - 4. Lack of insurance _____
 - 5. Mistrust/distrust of providers _____
 - 6. Daycare issues _____
 - 7. Cost _____
 - 8. Other financial problems _____
 - 9. Wait times _____
 - 10. Perception of quality of care _____
 - 11. Disjointed "system" of care _____
 - 12. Other priorities _____
 - 13. Fear concerning risk _____
 - 14. Do not see the importance of annual exams _____
 - 15. Lack of knowledge about chronic diseases _____
 - 16. Literacy issues _____
 - 17. Culture of poverty _____
 - 18. No primary care physician/
No true medical home _____
 - 19. Location _____
 - 20. Employment issues
(taking time off from work) _____

- 21. Unemployment _____
- 22. Willingness to change lifestyle _____
- 23. Lack of knowledge _____
- 24. Unethical History of
research in community _____
- 25. Misuse of data _____
- 26. Don't know we exist _____
- 27. Misdiagnosis _____
- 28. Don't know what we do _____
- 29. Intimidation of research _____
- 30. Don't feel sick _____
- 31. Lack of understanding about
chronic issues/diseases _____
- 32. Fear that doctors in their community (west end) are not
real doctors and will not give good care _____
- 33. Feelings of being disrespected by doctors when asking extra questions or talking about other health
issues during a visit _____
- 34. No people of color doing the research _____
- 35. Fear of being diagnosed _____
- 36. No sense of accountability _____

Appendix 4. DRAFT – PRELIMINARY QUESTIONNAIRE-

Respondent ID# _____ Respondent Name: _____
 Address: _____ Telephone # _____

		Y	N	N A
Is English the primary language spoken at home? If, other, specify:				
Employment and Education	Are you currently employed?			
	Are you able to work?			
	Do you have a high school diploma or GED?			
Transportation	Do you have a valid driving license?			
	Do you own or have access to a car that runs?			
	Are you familiar with public transportation?			
	Do you use public transportation?			
Childcare	Do you need childcare in order to work?			
	Do you have any children in daycare?			
	Do any of your children attend Head Start programs?			
	Do any of your children participate in after-school programs?			
	Are you currently in need of medical services?			
Health	Do you have health insurance?			
	Do you have a primary care physician?			
	Do you have a dentist?			
	Are you in need of medical services?			
Is anyone in your household currently receiving...?	Food Stamps			
	KTAP (cash assistance)			
	Unemployment benefits			
	Social Security			
	SSI (Disability) for the adults			
	Worker's Compensation			
Access to electronic information	Do you have a home computer?			
	Do you have access to e-mail?			
	Do you have access to the internet?			

	Would you say that you are:				
	Very satisfied	Somewhat satisfied	Somewhat dissatisfied	Dissatisfied	D K / N A
Overall, how satisfied are you with					
your living conditions?					
your neighbors?					

your neighborhood in general ?					
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SN1. How far away is the nearest bus stop?

1. Less than 15 min 2. 16 to 30 minutes 3. more than 30 minutes away 8. DK 9. NA

SN2. How far away is the nearest grocery store?

1. Less than 15 min 2. 16 to 30 minutes 3. more than 30 minutes away 8. DK 9. NA

SN3. How long it takes you to go to the doctor/clinic you use most of the time?

1. Less than 15 min 2. 16 to 30 minutes 3. more than 30 minutes away 8. DK 9. NA

ES1. Do you currently work for pay? 1. Yes 2. No (skip to ES2) 9. NA

ES1a (IF employed) What type of employment do you have?

1. Full-time
2. Part-time
3. Temporary
4. Odd/Seasonal
5. Other: _____

ES1b. Do you currently have more than one job? 1. Yes 2. No 9. NA

ES2. (IF unemployed) Have you ever worked for pay?

1. Yes 2. No 9. NA

ES2a. How many years has it been since you were last employed?

1. _____ # years 2. Less than one year 3. Never worked 8. DK 9. NA

ES2b. What is the main reason you are NOT working?

1. Ill/Sick
2. Disabled and unable to work
3. Retired
4. Taking care of home or family
5. Going to school
6. Cannot find work
7. A strike, bad weather, or a temporary lay-off
8. Temporarily not working (specify why _____)
9. Other (specify) _____

ES3. Think about your own experience when looking for jobs or working during the past 12 months.

Please tell me whether any of the following factors made it difficult for you to look for a job, or to keep a job.

1. Not having work experience
2. Not having child care
3. Not having GED/HS diploma
4. Not speaking English well
5. Lack of transportation
6. Having a disability
7. Discrimination
8. Lack of jobs in the neighborhood

9. Having a drug or alcohol problem
10. Having a criminal record
11. Other (specify)

ES4. How difficult is it for (you/your family) to meet the monthly payments on your (family's) bills? Would you say extremely difficult, very difficult, somewhat difficult, slightly difficult or not difficult at all?

1. Extremely difficult
2. Very difficult
3. Somewhat difficult
4. Slightly difficult
5. Not difficult at all

ES5. Would you mind giving the letter from page 46 in your booklet, which comes closest to the total income you had in 2010 before taxes?

- | | | |
|-------------------------|------------------------|---------------------------|
| A) Less than \$0 (loss) | M) \$10,000 - \$10,999 | Y) \$30,000 - \$34,999 |
| B) \$0 (None) | N) \$11,000 - \$11,999 | Z) \$35,000 - \$39,999 |
| C) \$1 - \$999 | O) \$12,000 - \$12,999 | AA) \$40,000 - \$44,999 |
| D) \$1,000 - \$1,999 | P) \$13,000 - \$13,999 | BB) \$45,000 - \$49,999 |
| E) \$2,000 - \$2,999 | Q) \$14,000 - \$14,999 | CC) \$50,000 - \$74,999 |
| F) \$3,000 - \$3,999 | R) \$15,000 - \$15,999 | DD) \$75,000 - \$99,999 |
| G) \$4,000 - \$4,999 | S) \$16,000 - \$16,999 | EE) \$100,000 - \$149,000 |
| H) \$5,000 - \$5,999 | T) \$17,000 - \$17,999 | FF) \$150,000 - \$199,999 |
| I) \$6,000 - \$6,999 | U) \$18,000 - \$18,999 | GG) \$200,000 - \$299,999 |
| J) \$7,000 - \$7,999 | V) \$19,000 - \$19,999 | HH) \$300,000 - \$499,999 |
| K) \$8,000 - \$8,999 | W) \$20,000 - \$24,999 | II) \$500,000 - \$999,999 |
| L) \$9,000 - \$9,999 | X) \$25,000 - \$29,999 | JJ) \$1,000,000 or more |

RH1. In general, would you say your overall health is...?

1. Excellent
2. Very good
3. Good
4. Fair
5. Poor
8. DK
9. NA

RH2. Do you currently have any illness or chronic health condition that requires regular, ongoing care?

1. Yes
2. No
9. NA

RH3. Did you have any illness or chronic health condition that required regular, ongoing care within the past three years?

1. Yes
2. No
9. NA

RH3a. If YES, please specify conditions _____

RH4. Next we're interested in whether you've experienced any major health problems. Some examples are cancer, ulcers, chronic pain, stomach problems, or migraines. Have you experienced any major health problems in the past 12 months?

- 3 new to area
- 4 usual place not available
- 5 like >1 place
- 6 too far away
- 7 can't afford
- 8 distrusts drs
- 9 dk where to go
- 10 rel/frn is PCP
- 11 dr retrd/left

AH5. During the past 12 months, did you or a family member **not get** or **postpone** getting *medical care* or *surgery* when you/they needed it?

- 1. Yes
- 2. No (skip to AH6)

AH5a. What was the main reason why you/they did not get the medical care or surgery you needed?

- 1. Lack of insurance or money
- 2. Don't know where to get medical care
- 3. Other reason (specify)_____

AH6. During the past 12 months, did you/they not get or postpone getting *dental care* when you needed it?

- 1. Yes
- 2. No (skip to AH7)

AH6a. What was the main reason why you/they did not get the dental care you needed?

- 1. Lack of insurance or money
- 2. Don't know where to get dental care
- 3. Other reason (specify)_____

AH7. During the past 12 months, did you/they not fill or postpone filling a *prescription* for drugs when you needed them? 1. Yes 2. No

AH7a. What was the main reason why you/they did not get the drugs you needed?

- 1. Lack of insurance or money
- 2. Don't know where to fill prescription
- 3. Other reason (specify)_____

Social or Interpersonal Support

	1. No, definitely not	2. No, probably not	3. Yes, possibly	4. Yes, probably	5. Yes, definitely
SS1. Is there someone who would help to take care of you if you were confined to bed for several weeks?	1	2	3	4	5
SS2. Is there someone you could turn to if you needed to borrow \$10, a ride to the doctor, or some other small, immediate help?	1	2	3	4	5
SS3. Is there someone you could turn to if you needed to borrow several hundred dollars for a medical emergency?	1	2	3	4	5

RD2. What is your current marital status? (Circle one)

1. Married
2. Widowed
3. Divorced
4. Separated
5. Single
6. Unmarried/Living with partner

RD3. What is the highest school grade completed? _____

RD4. Have you received a High School Diploma or GED?

1. Received a H.S. Diploma
2. Received a GED
3. Has not received either 8. *D* 9. *NA*

RD5. What is your age as of July 1, 2011?

RD6. Gender 1. Male 2. Female 3. Other

RD7. Race/Ethnicity (choose all that apply)

1. White 2. Black 3. Asian 4. Hispanic 5. Other

INTERVIEWER OBSERVATIONS

IO1. Was R suspicious about the study before the interview?

- 1 - Yes, very suspicious
- 3 - Yes, somewhat suspicious
- 5 - No, not at all suspicious

IO2. The respondent's attitude at the beginning of the interview was:

- 1 - Cooperative, helpful
- 2 - Neutral, relaxed
- 3 - Nervous, uncertain
- 4 - Antagonistic

IO3. The respondent's attitude at the end of the interview was:

- 1 - No change from the beginning of the interview
- 2 - More cooperative, more helpful
- 3 - Less cooperative, less helpful

IO4. Did R seem to rush (his/her) answers, hurrying to get the interview over?

- 1 - Yes 0 - No

IO5. During the interview, did R ever ask how much longer the interview would take?

- 1 - Yes 0 - No

IO6. Did the respondent seem to want to talk a lot during and after the interview?

- 1 - Yes 0 - No

