

Uninsured in West Virginia

A 50-64 Year Old Perspective

WV HRSA State Planning Grant Pilot Planning Project
Focus Groups

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The West Virginia University Institute for Health Policy Research conducted a total of six focus groups around the state with uninsured West Virginians ages 50 to 64 during the month of September 2005. This work was undertaken as part of a subcontract with the West Virginia Health Care Authority for a State Planning Grant from the Health Resources and Services Administration. The groups were taped and the tapes transcribed by Brown Reporting out of Beckley, West Virginia.

I. Methodology

The goal of this series of focus groups was to learn more about the needs and the problems of the uninsured age 50 to 64. The purpose was to enable the State Planning Grant leadership and its advisory group to identify the best health insurance product(s) for this population and choose one or more communities in which to pilot the product. All contact with the participants including the process for enrolling them into the groups, gaining their consent for participation and for audio taping, and the actual script for conducting the groups were reviewed and approved by the Institutional Review Board at the West Virginia University Morgantown campus in August 2005. (Appendix A – IRB Documents)

The focus group was selected as the method for data collection based on its utility for exploration of people’s knowledge and experience.

a. Recruitment

Participants for the focus groups were recruited using various methods: 1) Flyers were posted at area primary care centers and free clinics, 2) Flyers were sent to the area Family Resource Network members (FRNs) for posting in their communities, 3) Press releases were distributed to daily newspapers around the state, 4) Sally K. Richardson, Executive Director of the WVU Institute and Co-Principal Investigator for the West Virginia State Planning Grant, and Dr. Gail Bellamy, Principal Investigator for the focus group activity, were interviewed about the project by the Associated Press for an article published in the Charleston Saturday Gazette-Mail, and by West Virginia Public Broadcasting, and Metro News Statewide Radio for radio broadcast across the state. (Appendix B - 2005 Publicity Campaign)

Interested parties were asked to call a 1-800 number, staffed by the Health Care Authority. Individuals were screened to determine their eligibility (Appendix A – IRB Documents). Eligible participants received a letter confirming their participation and providing the directions to the location for their group. One to two days before the event, recruited participants received a reminder phone call. Each person was paid \$50 for his or her participation in the group. Free refreshments (coffee, soda, snacks, etc.) were also provided to the participants.

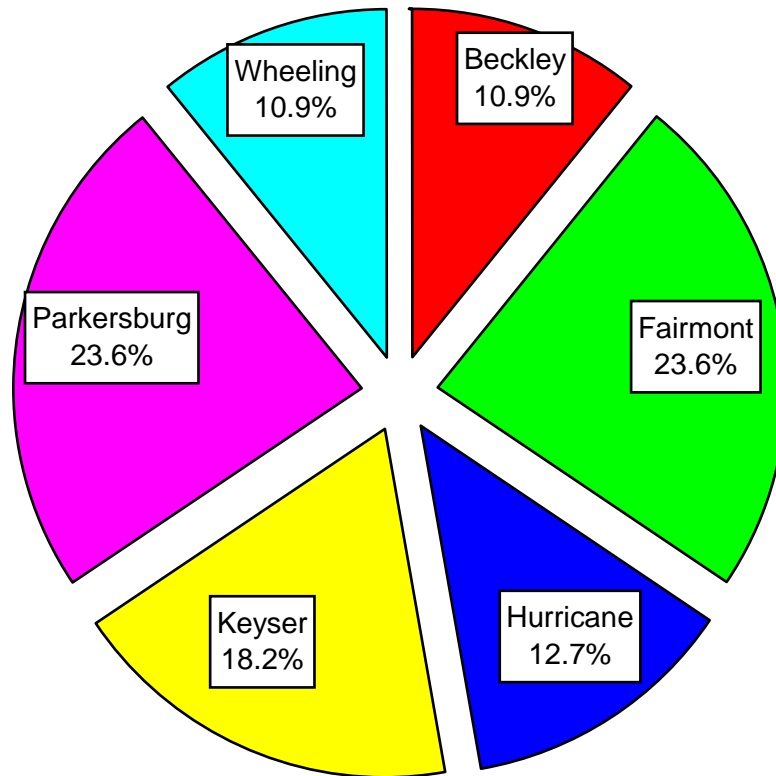
b. Site Selection

Originally, five sites and four alternate sites were recommended to the State Planning Grant advisory group (Appendix C). Sites were recommended based on 1) their location in a region of the state with high numbers of uninsured 50 to 64 year olds, 2)

c. Participant characteristics

Fifty-five people participated in the focus groups.

Participation by Region



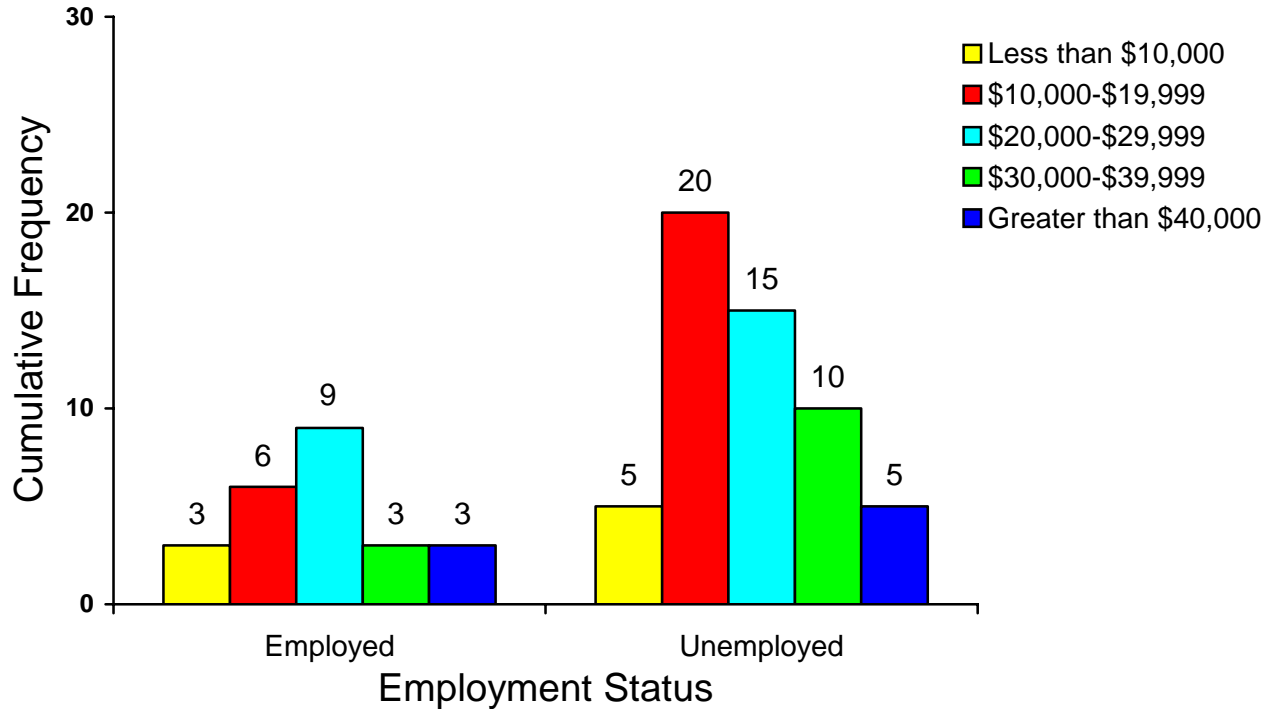
Although those participating in the focus groups represent a self-selected population, (i.e., they called the 1-800 number and met the minimum requirements), they provided a demographically diverse group from which to learn about the uninsured experience of this population.

Demographics: Overall, the groups were evenly distributed by age group: 33% were ages 50-54; 31% were ages 55-59; and 36% were ages 60-64. Four of the participants were African American, one was Latina, and the remainder was Caucasian. Another interesting characteristic was that ten married couples participated in the groups.

Just over 43.5% of participants were employed, while 56.4% were unemployed. Of the unemployed, about a third were disabled, 22% were retired, 25% were homemakers, one-third were homemaker/caretakers, and 13% had been laid-off by employers. Income is minimally correlated with employment in this group of participants (i.e., those who are employed have higher incomes). This anomaly is probably the joint function of

the representation of young retirees and homemaker/caretakers for relatives receiving disability and the low per capita income of West Virginia.

Employment Status by Income



II. Short Survey

A short survey (Appendix A – IRB Documents) was distributed to participants at the close of the focus group to assess what they saw as the most important services to be covered by a health insurance product, and what they felt they could afford to pay as a monthly premium for health insurance. This survey was administered at the close of each session recognizing that the discussion preceding the survey might, and probably would, effect how participants rated the importance of services based on what they had learned about the needs of others

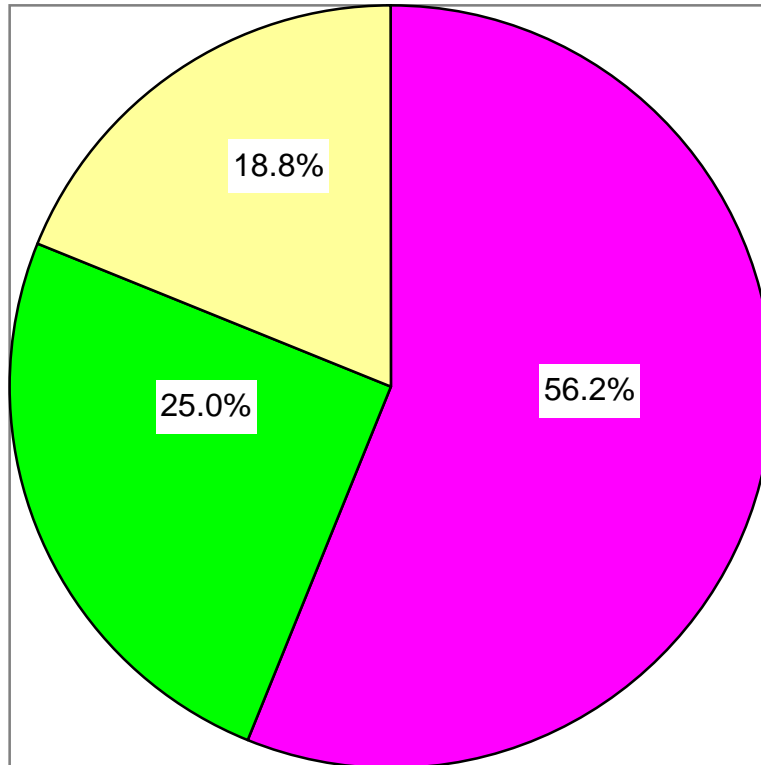
a. The Benefit Package

Services that were rated as very important by the participants were: Doctor Visits (72.2%), Specialists (81.5%), Drugs (79.6%), and Inpatient Hospital (89.1%). Services that were rated as very or somewhat important were: After hours/Urgent care (92.3%), Vision (83.6%), Dental (88.7%), and Durable Medical Equipment (75.5%).

b. Affordable premium

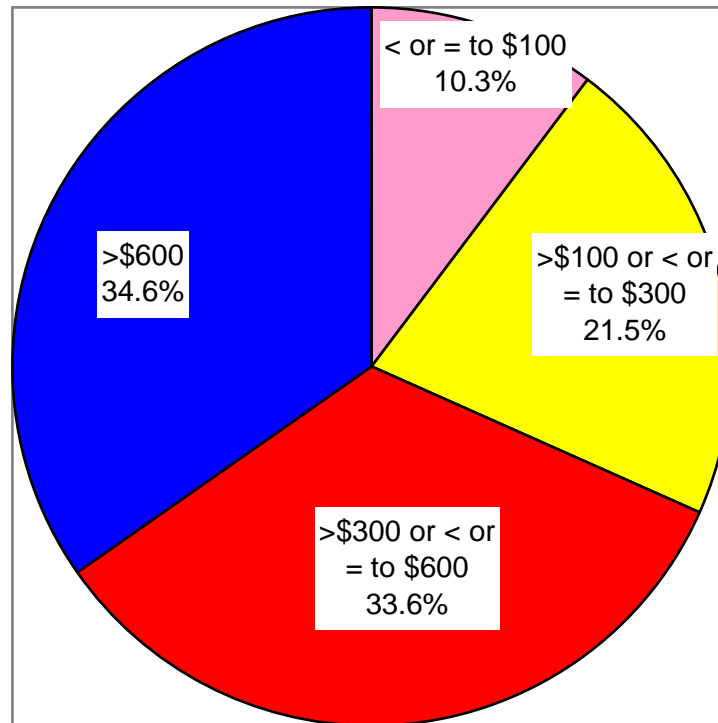
The questions relating to premiums did not ask what was reasonable to pay for health insurance with the desired coverage; rather it asked what individuals felt they could afford to pay for themselves or their families.

Affordable Individual Premium Amount



Excludes non-responses

Affordable Family Premium Amount



Excludes non-responses

III. Discussion

Health insurance, or the lack thereof, is a very emotional subject for these participants. There is considerable fear associated with losing their job, their homes, and their assets if they were to become severely ill. There is tangible concern among husbands and wives about what happens to the other if one of them becomes ill. There were expressions of distrust and anger directed toward insurers. In a few cases there was anger toward the Department of Health and Human Resources for treating them as “less than” those who have insurance or for making them jump through what they perceived to be unnecessary hoops. The Insurance Commission was also criticized for not affording them protection against frauds. Finally, anger and frustration was expressed toward some health care providers that participants felt gouged them (i.e., assessed higher charges for services than those charged to people with insurance), who recommended treatments knowing that participants could not afford them, or who treated them differently than those with insurance. A few participants questioned the quality of care they receive now that they are uninsured.

On the other hand, many participants talked about their doctors and dentists who continued to see them even after the provider was aware that they were uninsured. Participants spoke of their gratitude toward the doctors, the dentists, and the clinics (primary care clinics, public health clinics, and free clinics) that provide them with services.

Participants came to be uninsured in a number of ways including choosing to drop their health coverage when the costs became too high or exceeded the perceived benefits, losing coverage as a function of divorce, a spouse being laid-off from a job with benefits, a spouse becoming disabled and losing health benefits, or losing benefits as a function of losing a job. All but one or two individuals have had insurance before.

The following is intended to give the reader a greater sense of these participants, an opportunity to “hear” their voices through select quotes that are illustrative of the issues and concerns they raised during the six group sessions.

Health Status: Sixty-eight percent of respondents reported that their health was “good,” including those who reported having some chronic illnesses that were “under control.” Eleven percent rated their health as very good or excellent. Approximately twenty percent rated their health as poor, experiencing multiple disabling chronic problems, including COPD, arthritis, black lung, and others.

Last saw provider: With 2-3 exceptions everyone had seen a medical provider within the preceding 2-3 months.

Reason for visit: The majority had seen a provider for a problem, followed by a follow-up visit, or for tests related to a chronic illness.

Provider-type: The majority of respondents go to a doctor’s office (a family doctor) when they need medical care. Some go to a local clinic, a couple of respondents are eligible for veteran’s benefits, and few go to the E.R. Use of the E.R. for respondents who lived in less urbanized areas was a function of the limited availability of other medical care alternatives after normal work hours or on weekends. The other E.R. usage was attributable to the person perceiving their situation as needing urgent medical attention.

a. Themes and Select Quotes

The topic of health insurance, or the lack thereof, is very emotional.

- Many respondents felt they were treated rudely or abruptly. After years of working and paying for insurance, now that they do not have it, they are perceived as somewhat undeserving of care.
- A number of people commented they would let themselves die rather than end up destitute.
- Respondents commented that providers show lack of awareness or understanding of patient circumstances, prescribing drugs or behaviors (e.g. testing their blood sugar 2-3 times per day) that are impossible for the patient to fulfill.

A relationship with a provider, a physician, or a dentist mitigates the difficulty of receiving care but does not eliminate all of the difficulties, specifically, paying for care.

- “When I was losing my medical coverage, I discussed with my doctor, who I had been going to for a long time and I said, look, you know, I don’t have the coverage that I had before. And he said, you’ll always be my patient, so I’m blessed...even though I have to pay, you know, out of my pocket, and so I don’t use it very often.”
- “Today it’s not been hard to find a place to get healthcare, people will treat you if you don’t have insurance, but the financial burden gets tough, you know, it’s not being able to find a place that will take care of you, it’s being able to pay the bills is the problem.”
- “Because most of physicians are private practice and they won’t take you without insurance or some kind of healthcare coverage... there’s just not that many people that practice that take people that have no insurance or health care. .We have no 330 clinic in our area at this time.”
- “The Sutton Hospital is a small hospital. It has a clinic, a woman’s clinic; well actually, anybody can go to it. And as long as you pay upfront, they take anybody.”

Having a free clinic or a 330-funded clinic¹ mitigates the difficulty associated with payment for care.

- “Well I knew I was going to be leaving my job so with the health plan, I had found a primary care physician. So, I maintained my relationship with him, but I also knew that there was a free clinic in town. My main doctor helped me out with samples of medication that he could help me out with, but he couldn’t send me for tests, so I had to go to the free clinic.”
- Some have found ways to navigate the system – either programs to assist them in paying for or receiving care and they also spoke of the “cash and carry discount” that is sometimes available if they tell the provider they are paying cash.

When and where available respondents take advantage of existing programs for prevention:

- “I go to Planned Parenthood, who sets me up for my mammograms and they do the cancer screening there. But it’s still \$20 an office visit.”
- “We would go to Saint Joe whenever they offer their free flu shots, which they haven’t done for, you know, a couple of years now.”
- “I go to Health Right and they’re really good about that with me so...because I never did have a pap—well, I hadn’t had a pap smear since my youngest child was born and a mammogram, I never did have until I went to Health Right, so they had...”
- Others budget to pay for a preventive screenings; one spreads the annual physical out over several months so she can afford to pay a little at a time; another calls ahead to the provider and completes the lab work in advance so there is only one office visit to pay.

¹ Primary care clinic that receives special federal funding, also known as a federally quality health center (FQHC).

And for pharmaceuticals:

The majority of participants who have a relationship with a provider receive sample medications from that provider although it is not without some difficulty. Many respondents participate in pharmaceutical assistance programs. Everyone, however, still experiences some difficulty accessing prescription drugs.

- “Sometimes they don’t have them {free samples} and you have to wait for your medications.”
- “...we’ve had a problem with being able to get them because the doctor is out or because the drug dealers haven’t made their rounds yet.”

However, some respondents can’t afford to pay even a small amount on multiple prescriptions and don’t have a connection for samples:

- “I took myself off my medication because I can’t afford it because I don’t have any medical care. So what my doctor prescribed, I can no longer afford so I’m only taking an aspirin a day.”
- “I don’t take any medications, I just take a lot of vitamins and drink ice water and walk slow. I’m sorry, when you’re living on the edge, what else can you do?”

When it is important, respondents try to keep follow-up appointments but many skip appointments:

- “I had an appointment...for a colonoscopy. And when I got down there, it was really sort of a consultation and I was to call back and try to set it up. And the gas prices and since he’s been out of work, I’m having to...the work I do, my shift runs three hours each and I’m trying to do two a day. And, you know, with gas prices and everything, I just can’t afford to go back.”

What concerns them about being uninsured?

- For the great majority of participants catastrophic expenses, i.e. those that result in bankruptcy and/or losing everything they have worked a lifetime for is a major concern.
- “I was unable to work because I got sick, and in six months my IRA was gone, my 401K was gone, so everything I have for retirement is gone.”
- “I’ve learned to stop worrying about it and I accept it... if I had a fairly minor condition requiring surgery or radiation or something like that, it would simply be fatal. Whereas, I have friends who have health insurance and it is just an incident in life. So I’m not going to worry about it but I know that I’m potentially not going to live as long because I don’t have access to medical care.”

With one to two exceptions, everyone had health insurance at some point in their life.

- “Any company that I’ve ever worked for has never offered it, even my ex-husband, they didn’t offer it with him so I’ve just never had any.”
- “I had health insurance for many years. When I first got it, the premium was less than \$1,000 per year and when it got to \$8,000, I just dropped it. I couldn’t do it anymore.”
- “I got laid off with a job that had insurance in 1993, and it’s been all we could do to pay the house insurance, the car insurance, and the life insurance, you know, to get those bills paid every month. I’ve always joked, joked all these years, I’ve always said, well, if they ever tell me I have something catastrophic wrong with me, I’ll just have to get in the car and run into a tree...”

A major complaint about the cost of insurance relates to the value for money.

- Not cost effective. Better to put money away and pay for things as they come up versus paying premiums plus deductibles, etc.
- Exclusions from coverage due to preexisting conditions or very high deductibles preclude people of getting needed care.

Affordability was listed repeatedly as the primary reason they did not have health insurance.

- Lost job, couldn't afford COBRA²
- Part-time, couldn't afford premium
- Self-employed, couldn't afford premiums
- Being able to make payments
- “They {Employer} dropped it and I wasn’t able to get insurance”

The lack of availability of care in rural areas after hours and weekends was noted as a reason for using the emergency room and/or not receiving care.

- There are no 330³ clinics in our area.
- The clinics do not have after hour services.
- My doctor doesn't have admitting privileges to the local hospital.

The perceived lack of sensitivity of providers and sometimes the quality of care they are receiving is a source of frustration:

- Having to make multiple long distance trips
- “I’ve been in the hospital three times this last year and when I had insurance, they treated me differently than when I didn’t have insurancethe way the nurses acted on the floor and the emergency room...I’ve had it {insurance} and then didn’t have it and then had it”

² The Consolidated Omnibus Budget Reconciliation Act (COBRA) of 1986 amends the Employee Retirement Income Security Act, the Internal Revenue Code and the Public Health Service Act to provide continuation of group health coverage that otherwise might be terminated.

³ Federally Qualified Health Center

How do we cover the uninsured age 50-64? How do we get people enrolled?

Universal healthcare was mentioned by participants in each group although not necessarily a system that was free to everyone. Healthcare versus health insurance was an issue for some.

- "...there has to be something for those of us that are in the room all have different circumstances, different income levels, a couple of us work part-time, ...we just need some kind of universal coverage so we don't live in fear."
- "When you lose your job and you've got to apply for unemployment, then you ought to get some kind of basic coverage"
- "If you're not eligible for something or other, why can't you buy into Medicaid, pay so much to Medicaid, to qualify yourself for some coverage."
- CHIP⁴ for adults
- Many cannot pay even a small monthly premium, for them we need socialized insurance.
- A box on your taxes that puts a small sum into a fund for the uninsured.
- Everyone should have insurance. It should be required and it should be, like I say, on a sliding scale. As you go through your life, you would, you know, increase salary hopefully and you would pay more."
- "Some kind of understanding of what people can afford. How can you do that? By their income statement, you know."
- I guess I would really like to see a high deductible catastrophic insurance policy available for people that, you know, they could get at a reasonable price."
- System needs to be refocused on prevention.
- Why don't we freeze research until everybody has access to everything we already know how to do?

What have we forgotten to ask? What do you want readers to know?

- "Eliminate superfluous appointments, superfluous testing."
- "The system for the DHHR⁵...they don't give you a hint if you're eligible for it. They knew exactly up front how much money we made, yet they put us through all of the hours of painstaking paperwork, research...."
- "As long as I wasn't sick I had insurance. When I got sick and couldn't work, I didn't have health insurance."
- To be eligible for some government programs "Your assets cannot be over \$3,000. That's ridiculous. Who wants an automobile that is a pile of junk and you can't get around in it."
- Physicians prescribe a course of action they know cannot be acted on, it covers the provider, but doesn't help the patient.
- A physician in a hospital sending a patient home after they learn he/she has no insurance.

⁴ Children's Health Insurance Program

⁵ Department and Health and Human Resources

- “I wish, really, that there was a department of the government, a segment that looked at us as not statistics, not as people that are getting older and are getting ready to really impact the healthcare system of this country, but we’ve all worked and paid taxes, we’ve been good citizens, we’ve given our sons and our daughters, we’ve educated them, we’ve tried our best and we’re at that point now through – maybe no fault of our own – and they’re just – they don’t even want to....”

IV. Summary

The age group 50 to 64 is often described as the sandwich generation; sandwiched between children and parents. This description was true for many in this group of participants. They are sandwiched between their children, even if they are grown, and their parents or older relations. Many in this group live with a spouse who suffers from a chronic or disabling condition.

With few exceptions, all the respondents have had health insurance at some point in their lives. They no longer have health insurance because they’ve

- lost their job,
- gotten a divorce,
- retired early, and/or
- can’t afford the premiums (self-employed and employer-based).

Some participants have multiple chronic illnesses; some have a chronic condition that is currently under control, and some are healthy. The majority works at staying well, and staying healthy so they can work, and take care of their loved ones. They all pay their bills on time, particularly when providers will work with them. Being required to pay upfront for care is difficult for many of the participants. However, they are willing and expect to pay something toward their health.

Many expressed concern and even fear in seeking the preventative services that they know they should be getting. They said they are “afraid” of what will be found during the preventative check-ups for fear of what they would do with the results, either for treatment or in case of the possibility of being able to have insurance again. The issue of findings from preventative services being listed as pre-existing conditions in the future was mentioned in different areas of the state.

Participants who have found ways to navigate the system are still upset with providers, government agencies, etc., that exacerbate the problems of care for the uninsured. They have found that discounts exist for the uninsured but are mad that they have to ask for it; they feel providers should offer help as soon as the provider knows they are uninsured and not after the fact when the bill is due. Some have become their own best advocate in maneuvering through the healthcare services and billing systems and are now well informed, educated healthcare consumers. Still others communicated a lack of understanding on some issues and did not feel there was a place to help them get the information they needed.

Without exception, what participants are asking for and what they want is an insurance product that

- meets their health care needs, and is
- affordable according to their financial circumstance.

APPENDICES

Appendix A: IRB Approved Documents

Appendix B: 2005 Publicity Campaign

Appendix C: Original Recommendations for 5 Focus Group Sites and Alternates

Appendix D: Select Participant Comments by Question by Site

Appendix E: Frequency Tables from Short Survey

APPENDIX A:
IRB Approved Documents

Approval Date: August 25, 2005
West Virginia University Institutional Review Board
Protocol #: 16477

**Consent and Information Form
Authorization to Use or Disclose Protected Health Information (PHI)**

**Title of Project:
West Virginia's State Planning Grant
Uninsured Focus Groups Ages 50-64**

Introduction

I, _____, have been invited to participate in this research which has been explained to me by _____. This research is being conducted by the West Virginia University Institute for Health Policy Research. Gail R. Bellamy, Ph.D., Johnna Beane, B.A. and Melissa McCormick, M.A. are the investigators of this study. This project is being funded by the West Virginia Health Care Authority, through a grant from the Health Resources and Services Administration (HRSA).

Purposes of the Study

The purpose of this study is to learn more about health and health insurance issues of West Virginians aged 50-64.

Description of Procedures

This study involves me participating in a focus group discussion and answering a short informational survey at the end of the discussion. I will be asked to talk about my health and health care issues that affect me and my family. I understand that this discussion is being audio taped in order to make sure that everyone's answers and the entire discussion can be analyzed. A transcript of this session will reflect my gender and city of residence ONLY. My participation will take approximately two hours for me to complete. Approximately 90 subjects are expected to participate in this study.

Risks and Discomforts

There are no known or expected risks from participating in this study. I may find some of the questions and/or discussion uncomfortable but if I do, at all times, I will have the option to not answer the question or to not participate in the discussion of the particular topic/question.

Alternatives

I understand that I do not have to participate in this study.

_____ Initials _____ Date

Page 1 revised on 7/25/2005

Pages 1, 2 & 3 revised on 7/6/2005

Title of Project: West Virginia's State Planning Grant Uninsured Focus Groups Ages 50-64

Benefits

I understand that this study is not expected to be of direct benefit to me, but the knowledge gained may be of benefit to others. I also understand that I will be paid \$50 for my participation in the focus group discussion.

Contact Persons

For more information about this research, I can contact Johnna Beane, at 304-347-1258, or Dr. Bellamy at 304-347-1353. For information regarding my rights as a research subject, I may contact the WVU Office of Research Compliance at 304-293-7073.

Confidentiality

I understand that any information about me obtained as a result of my participation in this research will be kept as confidential as legally possible. The recording of this session will be destroyed once the content has been described. The transcripts will include my gender and city of residence ONLY and the informational survey will include some basic demographic information but not any information from which I might be identified. I understand that my research records, just like hospital records, may be subpoenaed by court order or may be inspected by the study sponsor or federal regulatory authorities without my additional consent. In any publications that result from this research, neither my name nor any information from which I might be identified will be published without my consent.

Voluntary Participation

Participation in this study is voluntary. I understand that I am free to withdraw my consent to participate in this study at any time. Refusal to participate or withdrawal will involve no penalty to me. I have been given the opportunity to ask questions about the research, and I have received answers concerning areas I did not understand.

Upon signing this form, I will receive a copy.

I willingly consent to participate in this research and to be recorded during this focus group discussion.

_____ Initials _____ Date

Title of Project: West Virginia's State Planning Grant Uninsured Focus Groups Ages 50-64

Authorization to Use or Disclose Protected Health Information (PHI)

West Virginia University

I hereby voluntarily authorize the use or disclosure of my individually identifiable health information as described below.

Name: _____

Date of Birth: _____

IRB Protocol #: 16477

Persons/organizations providing the protected health information (e.g. hospitals):

I understand that I will be providing my protected health information as part of the focus group discussion and the short informational survey that I will be asked to complete at the end of the discussion.

Persons/organizations receiving the information (e.g. investigators, clinical coordinators, sponsor, FDA):

Copies of the focus group transcripts, that will include city of residence, and the short informational survey, that will include age and race information, will be available to West Virginia University Institute for Health Policy Research investigators and research staff. In addition, staff from the sponsors (the West Virginia Health Care Authority and the Health Resources and Services Administration) will have access to the transcripts and short informational survey.

The following information will be used:

City of residence, Age, and Race

The information is being disclosed for the following purposes:

West Virginia's State Planning Grant Uninsured Focus Groups Ages 50-64 is collecting the city of residence, age, and race for each focus group participant in order to fully describe the persons and communities that are represented in the focus group discussion.

_____ Initials _____ Date

Title of Project: West Virginia's State Planning Grant Uninsured Focus Groups Ages 50-64

Authorization to Use or Disclose Protected Health Information (Contd.)

I may revoke this authorization at any time by notifying the Principal Investigator in writing at:

Dr. Gail R. Bellamy WVU Institute for Health Policy Research 3110 MacCorkle Ave., SE Charleston, WV 25304
--

If I do revoke my authorization, any information previously disclosed cannot be withdrawn. Once information about me is disclosed in accordance with this authorization, the recipient may redisclose it and the information may no longer be protected by federal privacy regulations.

I may refuse to sign this authorization form. I may not be allowed to participate in the focus group if I do not sign the form.

This authorization will have no expiration date.

I will be given a copy of this authorization form.

Signature of Subject

Date

Time

Signature of Investigator or Co-Investigator

Date

Time

APPENDIX A: continued

West Virginia's HRSA State Planning Grant

**Focus Group Discussion Guide
Uninsured Ages 50-64**

Introduction & Description of the project

Welcome, My name is _____ and I'd like to thank you for taking the time to share your opinions with me today. We will be talking about healthcare and health insurance issues for West Virginian's who are between the ages of 50 & 64.

I am from the West Virginia University Institute for Health Policy Research and we are conducting this discussion as part of a federal grant called the State Planning Grant. The purpose of this discussion is to better understand the issues facing uninsured West Virginian's in this age group.

Focus group intro, taping, confidentiality

Your responses tonight will be kept anonymous and your name will not be reported in any document. Any time we cite something from the discussion it will be labeled as either man or woman from the city/town you live.

My colleague(s) _____ is/are in the room to take notes of what is being said. We are also recording this to make sure that we have everyone's comments. This way we will have an accurate transcript of our discussion. Again, we will never use your name in any way. If we quote you, we will just say, "a man/woman from [city]".

[Hand-out consent] If you are comfortable with the recording, please read and sign this release form that we are handing out.

[Hand out payment form] In order to receive the \$50 for participating today, the West Virginia Health Care Authority needs your contact information. Please complete and sign the form I am sending around now and provide it to us when you leave today. The Health Care Authority will mail the check directly to you in approximately (2) weeks.

Ground rules

Focus group discussions are open discussions, so please feel free to say whatever you think. We want to hear from every one of you. There are no right or wrong answers; it is your opinion that matters to us.

A few things that I need to go over:

First, please speak up; if your voice is too soft we will not be able to hear what you say.

Also, please speak one at a time so everyone's comments can be recorded and try to not have any side conversations.

We want to hear from everyone so I may call on quiet people or ask for your views specifically. Since we only have a limited amount of time to finish, I may interrupt so we can move on.

So that we stay on time, we will not have a scheduled break but there are refreshments in the room. Please feel free to take a bathroom break if you need it, but I just ask that we not have more than one person away from the table at a time, as much as possible. Also, if you have a pager or cell phone, please turn it off during our discussion so that no one is distracted.

Participant introductions

INTRO QUESTION: I'd like for you to go around the room and say only your first name, the city/town where you live, and describe who lives in your household?

[Note to moderator: if necessary reiterate confidentiality]

Questions/Discussion:

General Healthcare Discussion (15 minutes)

1. How is your health these days?
2. How about the health of your family?
3. When was the last time you saw a health care provider (either for an office visit, or to the hospital)?
 - a) Was this for a health problem or a regular check-up?
4. If you got sick or needed medical care, where do you usually go for care, to a doctor's office or a clinic, hospital, emergency room? *[Probe to clarify the type/location]*
 - a) If emergency room - why? Why not alternatives?
5. What about when your spouse/children become sick or need care, where do they go? *[Probe to clarify the type/location]*
 - a) If emergency room - why? Why not alternatives?
6. Who usually pays the bill for these visits? *[Probe]*
7. Would you say that you have a regular doctor? What about your family members, do they have a regular doctor?

Impact of Not Having (20 minutes)

8. Did it take you a long time to find a place you could get health care without health insurance? Why/why not?

9. Since you've been uninsured, has it been difficult or easy for you to get medical care if you needed it? [*Probe: for examples how it may be difficult*]
10. How does the lack of insurance affect you getting preventive care such as mammograms, physicals, a flu shot, colorectal screenings, etc?
11. How does the lack of insurance affect filling your prescriptions?
12. Do you skip tests or follow-ups because of lack of insurance?
13. How does the lack of insurance affect your dental care?
14. What most worries you and your family about not having health insurance?

Health Insurance Issues (15 minutes)

15. Have you ever had health insurance?
 - a) IF NO: Have you ever tried to get it? What happened that you didn't get it?
 - b) IF YES: What are the main reason or reasons that you do not have health insurance now?

[Listen/probe for: costs too much; not important – I am healthy; can get all the medical care I need without insurance; don't know how to get it; too much trouble/too complicated; employer doesn't offer; not eligible]

16. Does anyone in your immediate family have health insurance?
 - a) Who? What kind of coverage (through work, private, Medicaid, CHIP, Medicare, etc)
17. Have any of you ever been offered insurance and turned it down? If so, why?
18. How many of you work or have a spouse that works?
19. If you or your spouse works, does your employer offer insurance?
 - a) IF NO - Why do you think your employer does not provide health insurance?
 - b) IF YES – Why do you not have this coverage? [*Listen/probe for costs too much; not important – I am healthy; can get all the medical care I need without insurance; not eligible*]
 - c) IF NOT Eligible – Do you mind sharing why you aren't eligible?

Importance and Willingness to Pay (10 minutes)

20. How much do you think it would cost each month to buy basic health insurance?

Community Situation

Ending Questions (20-30 minutes)

21. Are there any other comments that you would like to make at this point? Have we missed anything?

Summarize key themes and ideas

22. Now, I would like to go around the room and ask you to give your suggestion on how to increase health insurance coverage of people age 50-64 or how we might help you get health insurance?

THANK YOU for your participation – *provide instructions for handing in the incentive/stipend form and remind that the incentive will be received in the mail according to the address listed on the form.*

APPENDIX A: continued
Screening Questionnaire

Potential Enrollees

Hello. My name is (WHOEVER IS COVERING THE 1-800 LINE). How may I help you?

[IF CALLER IS RESPONDING TO ADS REGARDING FOCUS GROUP READ:]

Thank you for calling. The West Virginia University Institute for Health Policy Research is conducting focus groups with uninsured West Virginians ages 50 to 64 to identify barriers to health care coverage for this group. We are inviting 12-15 individuals from your area to participate in a focus group, and paying \$50 to participants. All information will be held strictly confidential.

To see if you qualify for one of our groups, I need to ask you a few questions.

CIRCLE ALL RESPONSES

[DO NOT ASK, RECORD GENDER RECRUIT A MIX.]

Female 1
Male 2

1. Are you between the ages of 50 and 64?
 - a. Yes CONTINUE
 - b. No TERMINATE, THANK THEM FOR THEIR INTEREST

2. Would you tell me your race? **[DO NOT READ CATEGORIES]**
 - a. White CONTINUE
 - b. Black/AA CONTINUE
 - c. Asian/Oriental/Chinese CONTINUE
 - d. Hispanic/Latino (Puerto Rican, Mexican-American, etc.) CONTINUE
 - e. (Other) CONTINUE
 - f. (Don't know/refused) TERMINATE, THANK THEM FOR THEIR INTEREST

3. Right now, are you personally covered by health insurance?
 - a. YES TERMINATE, THANK THEM FOR THEIR INTEREST
 - b. NO CONTINUE
 - c. Don't know/refused

4. Are you employed or self-employed **[RECRUIT 30 UNEMPLOYED TOTAL FOR ALL LOCATIONS]**
 - a. YES
 - b. NO

If NO, are you

 - a. Homemaker
 - b. Retired

- c. Unemployed due to lay-off
 - d. Unemployed due to disability
 - e. Other (SPECIFY) _____
5. Was your household income from all sources, before taxes for 2004...(RECRUIT A MIX)
- a. Less than \$10,000
 - b. \$10,000-\$19,999
 - c. \$20,000-\$29,999
 - d. \$30,000 to \$39,999
 - e. \$40,000 or more

IF NOT QUALIFIED READ:

I am sorry you do not meet the eligibility criteria for participation. Thank you for calling and for your interest in this important research.

IF QUALIFIED READ:

I would like to invite you to participate in one of our group discussions. The group will be held on **(INSERT DATE)** at **(INSERT TIME)** and at **(INSERT LOCATION AND FACILITY NAME/ADDRESS)**.

You will be paid \$50 for your participation in the group and we will provide light refreshments and drinks.

You must arrive no later than **(INSERT TIME & GIVE TIME 15 MINUTES BEFORE THE GROUP STARTS AS ARRIVAL TIME)**.

You will receive a confirmation letter with directions to the group. Please bring some sort of photo identification card such as a driver's license. We will not be recording the information; we just need to verify your identity. We will be reading some things so be sure to bring glasses if you need them.

The groups will last about 2 hours. Please arrive no later than **(GIVE TIME 15 MINUTES BEFORE GROUP STARTS AS ARRIVAL TIME)**.

NAME _____

STREET _____

CITY/TOWN _____

ZIP _____

DAY PHONE _____

EVENING PHONE _____

EMAIL & FAX # _____

DATE RECRUITED _____

LOCATION RECRUITED TO _____

RECRUITER _____

APPENDIX A: continued
Short Survey Tool

**West Virginia's HRSA State Planning Grant
Focus Group Short Informational Survey
Uninsured Ages 50-64**

Now we would like to know a little more about you in order to accurately describe the participants in the focus groups. **Please remember your responses will be kept confidential. You will not be identified and information will only be reported about all of the participants as a group.**

1. What is your age _____ ?
2. What is your race?
 - a. White
 - b. Black/African-American
 - c. Asian/Oriental/Chinese
 - d. Hispanic/Latino (Puerto Rican, Mexican-American, etc.)
 - e. Other, please specify _____
 - f. Don't know/refused
3. Are you currently employed or self-employed?
 - a. YES
 - b. NO
4. If NO, are you:
 - a. Homemaker
 - b. Retired
 - c. Unemployed due to lay-off
 - d. Unemployed due to disability
 - e. Other; Please specify _____
5. What was your household income, from all sources, before taxes for 2004?
 - a. \$10,000-\$19,999

- b. \$20,000-\$29,999
- c. \$30,000 to \$39,999
- d. \$40,000 or more

We would also like to gather some additional information about you and your views on health insurance. We'd like to know what types of coverage would be important to you in a health insurance plan.

1. Please rate each of the following on a scale of 1 to 5 with 5 being Very Important and 1 being not at all important.

- a) Dr. visits either for sick or for check-ups
- b) Access to specialists for chronic illnesses (diabetes, asthma, high blood pressures or other long-term conditions)
- c) Prescription Drugs
- d) Hospitalization
- e) After-hours urgent care
- f) Maternity care – prenatal care, delivery and post natal for mother
- g) Vision benefits – eye exams and glasses
- h) Dental care
- i) Outpatient substance abuse or mental health treatment
- j) Durable medical equipment such as wheelchairs, oxygen equipment, etc
- k) Are there any other care or services you would want or need?

2. How much, if anything, would you be willing to pay each month out of your own pocket for a health plan that provides basic coverage for doctor visits, hospitalization and prescription drugs for just yourself?

- a. How much would you be willing to pay for a plan to cover your entire family?**

APPENDIX A: continued
Media Releases and Flyer

**West Virginia's State Planning Grant Uninsured Focus Groups
Ages 50-64 (Protocol #16477)**

News Press Release Text – VERSION 1

FOR IMMEDIATE RELEASE

*[INSERT CONTACT NAME]
[INSERT CONTACT NUMBER]
[INSERT CONTACT EMAIL]*

Health Insurance Focus Groups Being Held Across The State

Charleston, WV ---[INSERT DATE] West Virginia University Institute for Health Policy Research is conducting health insurance focus group sessions across several communities throughout West Virginia in **[INSERT MONTHS – anticipated August and September]**. The West Virginia Health Care Authority through a grant from the Health Resources and Services Administration (HRSA) is funding this project. Gail R. Bellamy, Ph.D., Johnna Beane, B.A. and Melissa McCormick, M.A. with the Institute are the investigators of this study, with Dr. Bellamy leading as the Principal Investigator.

The purpose of the study is to learn more about health and health insurance issues of West Virginians aged 50-64. The discussions are intended to identify barriers to health care coverage for this age group. Residents of West Virginia between the ages of 50-64 without health insurance coverage are being asked to volunteer to participate in the focus group sessions. Each participant will receive \$50 for providing their opinions about healthcare and insurance issues that affects them, their family and their community.

If you are interested in participating, please contact the West Virginia Health Care Authority at 1-888-558-7002.

News Press Release Text – VERSION 2

FOR IMMEDIATE RELEASE

*[INSERT CONTACT NAME]
[INSERT CONTACT NUMBER]
[INSERT CONTACT EMAIL]*

Health Insurance Focus Groups Being Held Across The State

Charleston, WV ---[INSERT DATE] West Virginia University Institute for Health Policy Research is conducting health insurance focus group sessions across several communities throughout West Virginia in **[INSERT MONTHS – anticipated August and September]**. The purpose of the study is to learn more about health and health insurance issues of West Virginians aged 50-64. The discussions are intended to identify barriers to health care coverage for this age group. Residents of West Virginia between the ages of 50-64 without health insurance coverage are being asked to volunteer to participate in the focus group sessions. Each participant will receive \$50 for providing their opinions about healthcare and insurance issues that affect them, their family and their community.

This project is funded through a grant from the federal Health Resources and Services Administration (HRSA) in partnership with the West Virginia Health Care Authority. Gail R. Bellamy, Ph.D., Johnna Beane, B.A. and Melissa McCormick, M.A. are the investigators of this study for the Institute, with Dr. Bellamy as the project's principal investigator

If you are interested in participating, please contact the West Virginia Health Care Authority at 1-888-558-7002.

Radio Ad TEXT – Version 1

Health Insurance Focus Groups

Are you 50-64 years old without health insurance coverage? If so, you can receive \$50 to participate in one of the important focus groups being held throughout the state. Provide your opinion and share information about healthcare and insurance issues that affect you, your family and your community. West Virginia University Institute for Health Policy Research is conducting focus groups during **[INSERT MONTHS – anticipated August and September]** with uninsured West Virginians ages 50-64 to identify barriers to healthcare coverage for this age group.

Your participation *can* make a difference and help the state work toward reducing the number of uninsured West Virginians.

If you are interested in participating, please contact the West Virginia Health Care Authority at 1-888-558-7002.

Radio Ad TEXT – Version 2

Health Insurance Focus Groups

Are you 50-64 years old and have no health insurance coverage? If so, you can receive \$50 to participate in one of the important focus groups being held throughout the state. West Virginia University Institute for Health Policy Research is conducting focus groups

during ***[INSERT MONTHS – anticipated August and September]*** with uninsured West Virginians ages 50-64 to identify barriers to healthcare coverage for this age group. Help the state work toward reducing the number of uninsured West Virginians by providing your opinion about healthcare and insurance issues that affect you, your family and your community!

If you are interested in participating, please contact the West Virginia Health Care Authority at 1-888-558-7002.

Radio Ad TEXT – Version 3

Health Insurance Focus Groups

Are you 50-64 years old without health insurance coverage? If so, participate in one of the important focus groups being held throughout the state and receive \$50 to provide your opinions about healthcare and insurance issues that affect you, your family and your community!

West Virginia University Institute for Health Policy Research is conducting focus groups during ***[INSERT MONTHS – anticipated August and September]*** with uninsured West Virginians ages 50-64 to identify barriers to health care coverage for this age group. Your participation can help the state work toward reducing the number of uninsured West Virginians.

If you are interested in participating, please contact the West Virginia Health Care Authority at 1-888-558-7002.



Health Insurance Focus Group

**Are you between the ages of 50 & 64
and have NO health insurance
coverage?**

Participate in an important focus group. Make a difference – provide your opinions and have fun.

Each person will receive \$50 for participating
in the focus group.

If you are interested in participating, please contact
the West Virginia Health Care Authority at 1-888-
558-7002.

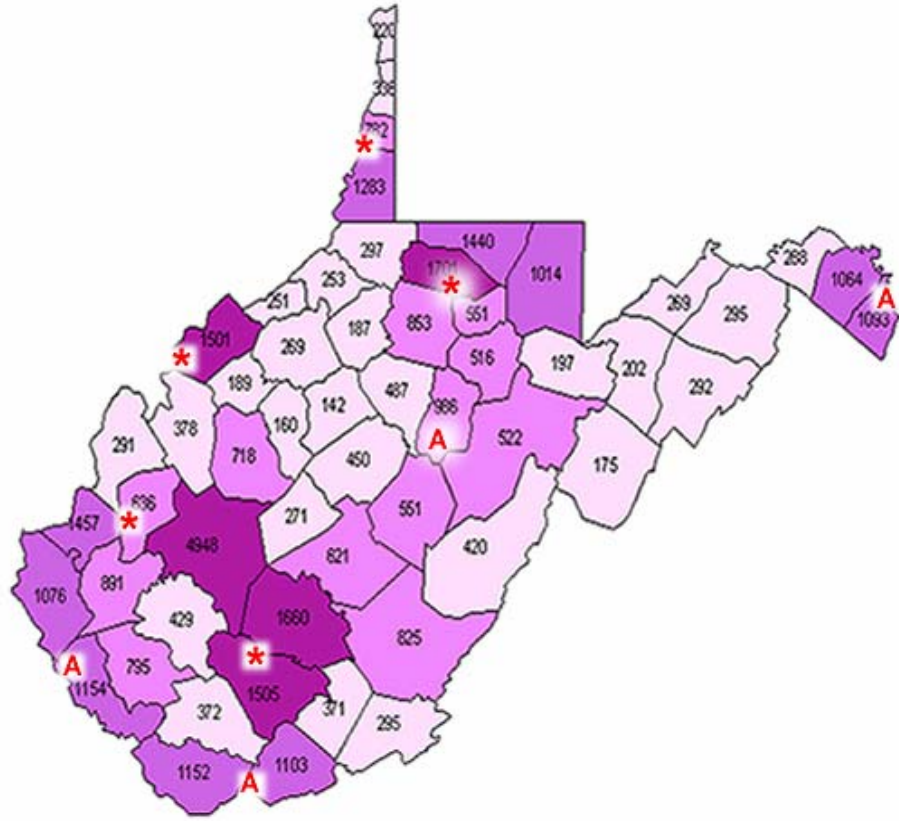


APPENDIX B:
2005 Publicity Campaign: Focus Groups for Uninsured Ages 50-64

1. Press Release Distributed: (August 24-26)
 - Robert C. Byrd Health Sciences Center (HSC), West Virginia University. Press Office, Morgantown, WV (Bill Case, Communications Manager)
 - HSC News List (80 newspaper, radio, and television stations statewide).
 - WCHS-TV News (Charleston and Tri-state area)
 - Parkersburg News and Parkersburg Sentinel, Mineral County News Tribune, and Cumberland Times-News
2. Focus Group Flyer and Press Release Distributed for Posting (August 24-26)
 - West Virginia Dept. of Health and Human Resources (statewide)
 - West Virginia Family Resource Networks (newsletters, advocacy agencies)
 - Counties: Boone, Cabell, Fayette, Kanawha, Lincoln, Marshall, Marion, Mingo, Mineral, Monongalia, Ohio, Putnam, Raleigh, Wirt, and Wood
 - West Virginia Primary Care Association
 - Community Health Systems, Beckley, WV
 - Hygeia Facilities Foundation, Charleston, WV
 - Lincoln Primary Care Center, Hamlin, WV
 - Monongahela Valley Association of Health Centers, Fairmont, WV
 - Valley Health Systems, Huntington, WV
 - Women Care/Family Care, Scott Depot, WV
 - Women's Health Center of WV, Charleston, WV
 - Affordable Insurance Workgroup (clinics, hospitals, pharmacies, grocers)
3. Associated Press Interview for News Article
 - Sally K. Richardson – Charleston Saturday Gazette-Mail (August 27 issue)
4. Radio Interviews (preferred over radio ad text, broadcast throughout the state)
 - Sally K. Richardson – WV Public Broadcasting, FM station (August 26)
 - Dr. Gail Bellamy – Metro News Statewide Radio, AM station (September 7)

APPENDIX C:

a. Original Recommendations for 5 Focus Group Sites and Alternates



APPENDIX D:
Select Participant Comments by Question by Site

BECKLEY

1. How is your health these days?
 - 3 – Fine/good
Things are starting to fall apart
 - 1 – Excellent
 - 2 – Poor

2. How about the health of your family?

No other family members living with anyone.

3. When was the last time you saw a health care provider (either for an office visit, or to the hospital)?
 - 3 weeks
 - 4 months
 - 2 months
 - 6 months
 - Annual
 - 3 months
 - a) Was this for a health problem or a regular check-up?
 - Follow-up
 - Regular
 - 3 – Check-up

4. If you got sick or needed medical care, where do you usually go for care, to a doctor's office or a clinic, hospital, emergency room? [*Probe to clarify the type/location*]
 - 2 – Clinic
 - Family practitioner
 - Treat myself
 - Rural area, don't really have a place to go
 - a) If emergency room - why? Why not alternatives?

"...we live in a very rural area. ...it is very hard to [know] where would I go if I would get suddenly sick. I don't know. We had a problem when [name] was sick. He had no---he had never been to a doctor before and the local hospital was backed up. It was just because a friend was a physician heard that he was sick. Same day. And called back and said, I'll take you even if I'm overbooked

because if you're sick, something is wrong. So if you live in a very rural area, you don't have much access to healthcare."

5. What about when your spouse/children become sick or need care, where do they go? *[Probe to clarify the type/location]*

None

6. Who usually pays the bill for these visits? *[Probe]*

Self-pay

7. Would you say that you have a regular doctor? What about your family members, do they have a regular doctor?

5 – Yes

1 – No

8. Did it take you a long time to find a place you could get health care without health insurance? Why/why not?

9. Since you've been uninsured, has it been difficult or easy for you to get medical care if you needed it? *[Probe: for examples how it may be difficult]*

"Because most of the physicians are private practice and they won't take you without insurance or some kind of healthcare coverage. And you use the emergency room, but then you have to pay twice the cost because you have no insurance or you have no health coverage of any kind. So you get – I have to pay the full bill. And there's just not that many people that practice that take people that have no insurance or health care. And we have no clinic. We have no 330 clinic in our area at this time.

"The Sutton Hospital is a small hospital. It has a clinic, a woman's clinic; well actually anybody can go to it. And as long as you pay upfront, they take anybody."

"I have used the Greenbrier Valley Medical Center and the physicians at Greenbrier Physicians...they all know that, you know, I'd sell my cat to pay the bill if I had to, so they let me in. Well, I'd take them the cat."

10. How does the lack of insurance affect you getting preventive care such as mammograms, physicals, a flu shot, colorectal screenings, etc?

"...I do that at the health department because nobody else wants to treat you because I don't have the insurance. And even though they're a collaborative partner with the health department, they're supposed to do that because they honor West Virginia Breast and Cervical Cancer Program. They don't really honor it when it really comes down to it unless they're forced to do so. And if I had not have known that I could demand it because I had the appointment card and all that and they said

that I didn't have one. But see, if I had not kept that, then I would not have been able to have been seen because they would have said it would have been my word against theirs."

"I had health insurance until two years ago when the premium went up to \$8,000 a year. And I decided rather than paying the \$8,000, I would take whatever that I could afford and put it into preventive care. And so that's what I do, I pay for my own rather than have health insurance. ...I'm at some fairly significant risk for colon cancer and so every other year, I have a colonoscopy. Three years ago, it cost \$4,200, last year it cost \$5,600. I have no idea how much to save for the one that I need next fall. But my health insurance didn't cover that anyway, so I couldn't afford that and preventive care and health insurance, so that's when I dropped the health insurance and said let me put my dollars to care."

"If you would like to have again, health insurance, because what are you going to do if you have something catastrophic coming on, that's what we are talking about. I cannot get preventive care because everything I mentioned to my doctor and she writes it down, is going to be preexisting condition. If I want to get health insurance, they will not cover anything before that. For that reason, I have had a fibroid when I, you know, 20 years ago, no problem. It's looked at every year and there's no problem. But all my ailments is not covered if I want health insurance...I had some kind of rash that was caused by boots. We work in a farm. It was the annual visit and asked her, what it could be. She said, I don't know. You're getting old and blood vessels on the surface. It happened when changed boots. It disappeared. So it must have been the boots, I didn't notice it. But my legs are excluded...I can never tell her that I have some kind of a problem because if I have any kind of a problem...this will be also a preexisting condition. So can't have preventive care."

11. How does the lack of insurance affect filling your prescriptions?

I was on a prescription for depression that costs \$80 a month and first of all, I never particularly agreed with the diagnosis. And I just decided it's not worth it and revoked the prescription."

"I don't get them filled because I can't afford them because I just lost my job in June and, you know, I just don't get it done because there's no money and you don't qualify for assistance because you don't...you're in between. You don't have anything but yet you don't have a job but you have the possibility of getting a job, so there's nothing to help catch that safety net in between because you can't qualify for reduced medication at all."

"I'm letting a lot mine go until I at least get this social security where I can get the money to fill it."

12. Do you skip tests or follow-ups because of lack of insurance?

Don't skip follow-up appointments as a rule.

"I had an appointment...for a colonoscopy. And when I got down there, it was really sort of a consultation and I was to call back and try to set it up. And the gas prices and since he's been out of work, I'm having to...the work I do, my shift runs three hours each and I'm trying to do two a day. And, you know, with gas prices and everything, I just can't afford to go back."

"Because I had to go to the emergency room in Charleston because I wasn't admitted by a doctor who worked at the hospital....I got there at 8:30, the doctor showed up at 11:00 and by then I was feeling a lot better. And he said, I don't think you have appendicitis and [we] said we want to know something for sure. So I travel an hour and half back home and then have something happen overnight or we can stay in the hospital, that's \$1,000 or we can stay in a motel. And is there anyway of really knowing? We'll I'm sure you're okay, but if you want to have a CAT scan done, that would tell you for sure. So I said okay. You know, we had looked at it before. We could do a CAT scan and that would tell you. Didn't know exactly how much it was going to cost, I knew it was going to be expensive, but at that point, you know, you don't care about it. And then, you know, went and got the scan, 15 minutes later he came with the IV. We're going to operate."

"But they [providers] don't stop to understand where the patient may be coming from unless they really are very good friends of yours, you know, then they can understand your situation. But most physicians, they just say, I provide a service, you're in need of this, either you want it or you don't because, you know we're expecting payment no matter what."

"The doctor says to test your sugar two or three times a day and you're sitting there looking at him, okay, okay. All right. He knows you're going to walk out of the office and not get those strips because you cannot afford those strips. And he tells you, he's off the hook because it's on his papers there he told you to test that sugar two or three times a day. I can't afford the strips."

13. How does the lack of insurance affect your dental care?

Most go.

"Laughing is good medicine. Dental care, you know, again, I don't believe there's that much unless you break something."

"I've been with the same dentist for 30 years for very routine cleaning and care and I have a fortune in my mouth but it's working so far. And I don't dare stop because he knows me and knows where I live and would come and fuss at time. Sometimes he does say, you've been here a couple of times recently. This one's on the house because he understands my financial circumstances."

14. What most worries you and your family about not having health insurance?

Catastrophic.

“What worries me the most right now is that you don’t have access to healthcare and if you get really sick, where would you go....I have no one. Who would take care of me? Even if I sold my house and all that, how would you pay the bills?”

“I’ve learned to stop worrying about it and I accept it. But if I had a fairly minor condition requiring surgery or radiation or something like that, it would simply be fatal. Whereas, I have friends who have health insurance and it’s just an incident in life. So I’m not going to worry about it but I know that I’m potentially not going to live as long because I don’t have access to medical care.”

“I worry about not having coverage for preventive, you know, to prevent us from getting to that point.”

15. Have you ever had health insurance?

a) IF NO: Have you ever tried to get it? What happened that you didn't get it?

b) IF YES: What are the main reason or reasons that you do not have health insurance now?

“I had health insurance for many years. When I first got it, the premium was less than \$1,000 per year and when it got to \$8,000 I just dropped it. I couldn’t do it anymore.”

“I had health insurance until my husband divorced me and that left me without any backup whatsoever because I was declined for coverage through him. And secondly, when I got employed on my own and I had a job, that was one of the things that was required under sub agency contract was that we pay for our health insurance, which I did. But then when I was terminated along with some other people in June, I lost my health insurance at midnight on the 30th of June and I have no coverage.”

16. Does anyone in your immediate family have health insurance?

a) Who? What kind of coverage (through work, private, Medicaid, CHIP, Medicare, etc)

Not applicable, no other family members other than spouses who were also in the group

17. Have any of you ever been offered insurance and turned it down? If so, why?

“When I first got a private health insurance policy, I was extremely healthy. And then there came a time when I had kidney stones which knowing my health insurance wasn’t going to pay for anything, I got a stick and passed them at my house. But I did see a doctor to get the diagnosis that that’s what they were and they were small

enough that I could pass them if I were willing to do that alone. Well, once that was on my record and they had submitted that to my health insurance, I now have a preexisting condition. And I was told by the agent who sold me the policy that I could never change insurance companies. I had to keep that policy, it was that policy or nothing forever...”

18. How many of you work or have a spouse that works?

19. If you or your spouse works, does your employer offer insurance?

a) IF NO - Why do you think your employer does not provide health insurance?

b) IF YES – Why do you not have this coverage? [Listen/probe for costs too much; not important – I am healthy; can get all the medical care I need without insurance; not eligible]
Too expensive.

c) IF NOT Eligible – Do you mind sharing why you aren't eligible?

20. How much do you think it would cost each month to buy basic health insurance?

\$400

\$850

\$1000

\$4000 per year

\$8000 per year

“Sliding scale according to a person's income and whatever, you know, you can't afford it, the actual cost should be made up in taxes or those who can afford it.”

“Well, what I'm willing to put up with, at the end, they kept changing the coverage. In the beginning I had no outpatient, no diagnostic, no mental, no dental, but sort of a catastrophic, you know, if something really huge happened, they would pay 80 percent after a \$5,000 deductible which is not much insurance but you can sleep better at night. They kept changing it, so that at the end when I finally dropped it, the things they used to cover at 80 percent, now, they're only going to cover at 50 percent. I have a \$10,000 deductible and \$8,000 a year premium. I only make about \$25,000. I mean, this is like more than half my income and I don't think that's fair. I really think that a fair health primary, you know, basic health policy ought to be based on some proportion of minimum wage because those are the only jobs that we're bringing into West Virginia.”

“I make \$7 an hour and my shift runs three hours at a time. I'm trying to take care of two shifts a day. So how much does that come to, \$42. How can a person pay any kind of a premium? If it's even \$100 a month, with a house payment, utilities and everything, gas, medical. We couldn't begin to pay anything. And I'm one of the lucky ones to get \$7 an hour.”

"I think we should pay because whenever something is free, you don't appreciate it."

21. Are there any other comments that you would like to make at this point? Have we missed anything?
22. Now, I would like to go around the room and ask you to give your suggestion on how to increase health insurance coverage of people age 50-64 or how we might help you get health insurance?

"Everybody should have health insurance. It should be required and it should be, like I say, on a sliding scale. As you go through your life you would, you know, increase our salary hopefully and you would pay more. And those who don't would still be covered because they're being subsidized by those who pay more. It's a community. It's healthcare. It's a national problem. I think it's the only way...it's the same thing as car insurance."

"Health care should be for everyone from the start, i.e., as children. Today you are afraid to go in for screening because they may find something. It should not be free because some free is not appreciated."

"Educate population about why they need healthcare coverage. Work with children who are covered today, then they can understand why it's important to the preventive care and they will participate as they grow older. We grew up not going to the doctor."

"We're paying for other people's health insurance you know. We're not useless people. We've led very productive and we still lead productive lives. We still help make our communities better and yet when we need help in return by way of taking care of medical costs, the community doesn't turn around and help us back. ...Why don't we freeze research until everybody has access to all the things we already know how to do. ...You know if we're going to be greedy and individualistic about this, let's stop using tax money to subsidize part of the population and not the other part. The healthcare system it costs too much in part because there are too many fingers that aren't providing healthcare getting wealthy off it."

Fund programs that work, e.g., the CAP grants

FAIRMONT

- 1) How is your health these days?
 - 8 – Good
 - 3 – Good but commented had problems under control
 - 1 – Problems under control
 - 1 – Decent

- 2) How about the health of your family?
 - Not many have other family members living at home
 - Not so good, husband
 - Daughter excellent
 - Son decent health, in college
 - Son, traumatic brain injury

- 3) When was the last time you saw a health care provider (either for an office visit, or to the hospital)?
 - Last month
 - Yesterday, discharged from hospital
 - 3 – January (8-9 months)
 - June (3-4 months)
 - March (6-7 months)
 - August (1-2 months)
 - This month
 - Longer
 - a) Was this for a health problem or a regular check-up?
 - Follow-up
 - 2 – check-up
 - 8 – health problem

- 4) If you got sick or needed medical care, where do you usually go for care, to a doctor's office or a clinic, hospital, emergency room? [*Probe to clarify the type/location*]
 - 1 – Emergency Room
 - 3 – Clinic
 - 3 – Doctor's office
 - 2 – Free Clinic
 - 1 – VA
 - 1 – Quick Care

a) If emergency room - why? Why not alternatives?

"I could go to the VA but they didn't know what was wrong, so I had to go to the emergency room and there was no way I can get to Clarksburg from Morgantown right away."

"An ER has been the only way that I – I'm just under the ER, the limit to get assistance from the ER where they pay like 100 percent or something, and having a problem right now, this bill was \$6,000 for just three days I was in there, you know, and it's the work."

5) What about when your spouse/children become sick or need care, where do they go? *[Probe to clarify the type/location]*

1 – Emergency Room

3 – Doctor's office

1 – Provider in Pittsburgh for traumatic brain injury

a) If emergency room - why? Why not alternatives?

Accessibility – open all the time.

6) Who usually pays the bill for these visits? *[Probe]*

4 – Out-of-pocket

3 – Hospital assistance

7) Would you say that you have a regular doctor? What about your family members, do they have a regular doctor?

5 – Yes

6 – No

8) Did it take you a long time to find a place you could get health care without health insurance? Why/why not?

9) Since you've been uninsured, has it been difficult or easy for you to get medical care if you needed it? *[Probe: for examples how it may be difficult]*

6 – Yes

4 – No

"We've been fortunate that we haven't had to seek healthcare since we lost our insurance, so I don't know how hard it would be, but I've got a doctor that's very understanding."

"Today it's not been hard to find a place to get healthcare, people will treat you if you don't have insurance, but the financial burden gets tough, you know, it's not being able to find a place that will take care of you, it's being able to pay the bills is the problem."

“A lot of places want clinics, places like that want prepaid....A lot of problem is the fact that doctors aren't billing anymore, they've got billing agencies doing it for them, which is almost just one step away from being a collection agency.” “it isolates them from having to deal with it and they're not the bad guy then, the person trying to collect is, and that's what we're looking at a lot of here in West Virginia.”

“I think that we don't have a problem getting health care, it's in your own mind deciding when you need it. In other words, you know, when you had insurance, you go to the doctor if you thought you needed to go. That doesn't happen anymore.”

10)How does the lack of insurance affect you getting preventive care such as mammograms, physicals, a flu shot, colorectal screenings, etc?

“I went to get my physical and they told me, the doctors told me that you've got congestive heart failure. Okay. So I, you know, driving a truck and being under DOT regulations and stuff, which are federal regulations, I have 72 hours to call my company and tell them why I failed my physical. Okay. They enter that in on my record and I can never drive a truck again. Okay. Now, I run the test and they find out I've got asthma, which I could drive the truck, I could drive the truck. I lost a job that I owned my own truck, just because somebody made a misdiagnosis.”

“But the only thing she does the routine things is she'll say can we afford it, you know. She'll look at it and say, can we afford it. And I don't know about anybody else here, can we not afford it, I mean....”

“You know, if you have, say diabetes or high blood pressure, you definitely have to keep treating it, you have to stay on your medication, in order to get your medication, you have to go to a doctor, so you know, in a sense of the word, that's preventive maintenance.”

11)How does the lack of insurance affect filling your prescriptions?

Free samples. Without free samples many people say they would be unable to get their meds.

“Sometimes they don't have them {free samples} and you have to wait for your medications.”

“...we've had a problem with being able to get them because the doctor is out or because the drug dealers haven't made their rounds yet.”

“There's a new program....you can get on the Internet....And if you can get the doctors to fill out the paperwork, you can get your medication free, as long as you're low income and you need it. But the problem has been with me, a lot of times, is getting the doctors or somebody in the doctor's office to fill out the paperwork. I went in to get one filled out.And I took the paperwork in and asked them if they could fill the paperwork out and the lady in the office, the nurse said, well, yeah, we can do it, but you know, gee, this is not really a high priority item. It's going to be six

to eight weeks before we get around to doing it. And then sometimes when the medicine professionals come into the office, it sits there three or four days before we get a chance to open it.”

“...if I need my medicine, I just cut a bill in half or do without something to get those pills.”

12) Do you skip tests or follow-ups because of lack of insurance?

Many have skipped follow-up visits.

13) How does the lack of insurance affect your dental care?

About half go to the dentist.

“I go; I just pay them \$10 a month, \$5 a month, whatever I can do.”

14) What most worries you and your family about not having health insurance?

Catastrophic.

15) Have you ever had health insurance?

a) IF NO: Have you ever tried to get it? What happened that you didn't get it?

b) IF YES: What are the main reason or reasons that you do not have health insurance now?

Yes

Costs, unemployed couldn't afford COBRA, costs associated with preexisting condition

16) Does anyone in your immediate family have health insurance?

Mixed responses – Yes and No

a) Who? What kind of coverage (through work, private, Medicaid, CHIP, Medicare, etc)

“The son that I have in college, this summer, fell and cracked his head open, split it open on the back and I looked at him, I said, well, we'll put a Band-Aid on it and pull it together. He said, well, the EMT said I ought to go have it looked and get a couple of stitches and I said, well, the EMT's not paying the bill. You know, and we pulled it together, but, I mean, that's the decisions you make.....if I'd have had insurance, I'd have had him at the emergency room and got stitches. But, you know, you make those decisions.”

17) Have any of you ever been offered insurance and turned it down? If so, why?

"You get sick and you go into the hospital. Now, what they pay, they pay all they're going to pay and you're responsible for the rest and they go in there and they say, well, on this we only pay \$500 and on this we only pay \$25 and on this, we only pay \$15, okay, and you've got a \$10 - \$15,000 hospital bill, and you end up --- now, you paid all this money out, you paid \$1000 a month for 12 months, that's \$12,000, you end up with a \$12,000 hospital bill. Now, they've only paid, just say \$75 of that, you're responsible for the rest of it. They don't pay anything. I don't care what kind of insurance they say, they don't pay."

18) How many of you work or have a spouse that works?

19) If you or your spouse works, does your employer offer insurance?

a) IF NO - Why do you think your employer does not provide health insurance?

"I work two part-time offices, but even if I worked fulltime at either of those offices, those offices do not provide that, because they have spouses who have medical insurance on them. One office has two dentists. They both have wives who have insurance through the state of West Virginia, you know, teachers, and federal. The other one also has it through his wife's business, so they don't need it for themselves, therefore, they don't get it for the whole office because they don't have to have it."

b) IF YES – Why do you not have this coverage? [Listen/probe for costs too much; not important – I am healthy; can get all the medical care I need without insurance; not eligible]

c) IF NOT Eligible – Do you mind sharing why you aren't eligible?

20) How much do you think it would cost each month to buy basic health insurance?

\$500

\$600

\$1000

\$1200-\$1400

\$2000

21) Are there any other comments that you would like to make at this point? Have we missed anything?

22) Now, I would like to go around the room and ask you to give your suggestion on how to increase health insurance coverage of people age 50-64 or how we might help you get health insurance?

"... when you've got to go in these offices and fill these things out for this, it takes your dignity away, or can ask him, you can ask anybody over here. You've got to go in here and you're talking to some 19, 20, year old girl who just got out of high

school, that thinks she's about 15 times better than anybody..."it's the way they ask questions. They take your dignity away from you. It makes you not want to do it."

"We need something for the people that don't have Medicare, you know, we're caught in the crack."

"I think the state has some real good coverage available through DHHR. My thing is let us keep our dignity while we're getting it, you know..."

"...What if we took all that money and pooled it into some sort of a thing where people could participate and get credits for, you know, taking good care of themselves, instead of, you know, just trying to like market it, actually make it worth your while to eat right and not smoke and do whatever."

"I think that the State ought to somehow connect some kind of basic, even if it's just basic hospitalization coverage to unemployment....I'm not as concerned about the money I get from unemployment as I am of me having a heart attack tomorrow and she's left with nothing because all that we had to go to pay that bill."

"...But I'm not for socialized medicine and all, but there has to be something for...those of us that are in the room all have different circumstances, very different circumstances, different income levels, a couple of us work part-time, you know, for reasons of choice and, I don't know, we just need some kind of like you said, universal coverage or something so that we don't live in fear."

"...I really feel like what we need, and I don't know if it needs to be administered statewide, a federal program or what, but I feel like what we really need is some kind of universal healthcare, whether you pay a premium based on your income or what you're able to afford to pay. You know, I've not got a problem with paying a premium on a health insurance program that will cover my needs, if I could afford to pay it. And, you know, if you have more money and you can afford to pay more, you pay more. "

"Maybe the government or the governor will start a bill where a person can afford a health plan each month, without selling their home or cashing in their life insurance policy to pay medical bills or get the prescriptions each month, because a lot of people, I know my neighbors, they have lost their homes, they've cashed in their life insurance policy, everything, just to keep their medical bills and the prescription going for month after month..."

"...I was thinking about the unemployed, when we did have the truck, the programs that they have now look at our gross income, which doesn't really do us any good when more than half of it goes back to support the truck, you know, for fuel and tires and all that kind of thing that goes on a big truck, they don't care about that, they just want to know about your gross income, so it's really difficult for self-employed people."

"I have worked for several different companies and due to layoffs and shut downs and things like that, all I have to retire on, besides Social Security, is what I have in the bank, and if you base it on what you've got in the bank, no matter how little or how much it is, you know, some of that money is my future, so our future."

Pre-existing conditions: "Not eliminate it, but go back and check and if it's over a certain period of time, if you haven't had high blood pressure, or some other matter like that, for the last five or ten years, eliminate it then."

"...just as you have donations to a charity that's IRS, that's deductible, for corporate donations, maybe corporations or possibly even personal, you know, you can earmark, if you have a little square on your IRS saying I would like to have \$5 of my, you know, whatever, to go to help supplement medical insurance for a sliding scale program or however you want to word it...."

If you don't have children take property tax dollars and instead of going to the schools put it into a fund for people that have no insurance.

HURRICANE

- 1) How is your health these days?
 - 1 – Good with caution
 - 1 – Shaky
 - 2 – Fairly good
 - 1 – Excellent
 - 1 – Not too good
 - 1 – Poor

- 2) How about the health of your family?

Daughter, good health
Sister, questionable health. SSI.
3 daughters—depression
Sister, diabetes
Daughter, weight
Son Ulcerative colitis, high blood pressure, sugar drops
Mother, breast cancer survivor, ruptured disks in her back, difficulty walking

- 3) When was the last time you saw a health care provider (either for an office visit, or to the hospital)?
 - 2 – Last week
 - 3 years
 - 4 months
 - 3 months
 - a) Was this for a health problem or a regular check-up?
 - 3 – Problem
 - 1 – Check-up

- 4) If you got sick or needed medical care, where do you usually go for care, to a doctor's office or a clinic, hospital, emergency room? [*Probe to clarify the type/location*]
 - 3 – Clinic
 - Emergency room (asthma attack)
 - 2 – Regular doctor
 - a) If emergency room - why? Why not alternatives?

"It depends. If I have an asthma attack, I go to the emergency room. If I have allergy attacks or something other than that, I go to HealthPlus even though I have to pay, otherwise, I try to go to my regular doctor."

5) What about when your spouse/children become sick or need care, where do they go? *[Probe to clarify the type/location]*
None

6) Who usually pays the bill for these visits? *[Probe]*
Self-pay — all

7) Would you say that you have a regular doctor? What about your family members, do they have a regular doctor?

4 – No

4 – Yes

“He told me he would keep me even though I didn’t have insurance.”

8) Did it take you a long time to find a place you could get health care without health insurance? Why/why not?

9) Since you’ve been uninsured, has it been difficult or easy for you to get medical care if you needed it? *[Probe: for examples how it may be difficult]*

“When I was losing my medical coverage, I discussed with my doctor, who I had been going to for a long time and I said, look, you know, I don’t have the coverage that I had before. And he said, you’ll always be my patient, so I’m blessed...even though I have to pay, you know, out of my pocket, and so I don’t use it very often.”

“I’ve heard that doctors will not take you if you have no insurance on the outside chance that you may have something serious and you need to be hospitalized. And, therefore, there’s a state law or something that they have to see you in the hospital and they’re not sure they’re going to get their money so they won’t---they just say we aren’t taking new patients if you call and try to engage a doctor without insurance. I don’t know if this is true, I just heard this because I was contemplating getting an exam but...”

“The greatest thing I face, because I have so many health problems, is if you go to a clinic you’re getting residents. Residents don’t really know all the situations or anything else, just they have someone over them, but a head doctor, normally, never comes in to see you, even ask you follow-up questions from a resident. Another thing, the regular doctor I go to, it’s on a sliding fee scale, but if you were to ask me was he a good doctor, I’d have to tell you no..

“I’ve been needing surgery for carpal tunnel on both hands and I can’t---you know, even after applying, you know, for disability, I can’t get help.”

“I have called and done everything to try and get help paying for my oxygen. Nobody...they won’t do that at the clinic so I have to pay for that myself. I have a

concentrator I have to pay \$128.90 a month for that I use at night and when I'm home and those tanks are \$13.50 each." (tanks last 4-5 hours)

10) How does the lack of insurance affect you getting preventive care such as mammograms, physicals, a flu shot, colorectal screenings, etc?

"I let it go."

"I haven't had one since I lost my health insurance. I haven't had a mammogram or a... the other thing."

"I just haven't had an exam since I lost my job and my insurance."

"I did have a flu shot last year, yes, at the clinic."

"I go to the Health Department... It gets you mammogram and it gets you pap smears."

"I had breast cancer in 1988 so I have been able to get follow-up mammograms every six months for the first couple years and then every year, and pap smears. And, also, I've had a colorectal exam."

"After my mother was diagnosed, I did have a mammogram. But since then I haven't had another one."

11) How does the lack of insurance affect filling your prescriptions?

"I took myself off my medication because I can't afford it because I don't have any medical care. So what my doctor prescribed, I can no longer afford so I'm only taking an aspirin a day."

"I don't take any medications; I just take a lot of vitamins and drink ice water and walk slow. I'm sorry, when you're living on the edge, what else can you do?"

"The doctor I had, because my cholesterol was high, wanted to put me on, what is it statins?...and I declined. And I'm glad because I would have just had to forego it. So I exercise, I have a really healthy diet, I really do try to take very good care of myself. And the thing that really...if I had to have a medicine, I have some money in the bank that I would just have to tap, but I just hope I don't have to."

"I get mine on a sliding scale at the clinic."

12) Do you skip tests or follow-ups because of lack of insurance?

Skip follow-up visits unless it's covered by clinic or someone else.

"I've arranged it so I take my ...I do my blood work before I schedule my appointment with the doctor."

13)How does the lack of insurance affect your dental care?
Half and half.

14)What most worries you and your family about not having health insurance?
"That I'm not getting the care that I need."

"Just being able to pay for it if something does happen, you know, without getting wiped out for what you've worked for all your life."

15)Have you ever had health insurance?

a) IF NO: Have you ever tried to get it? What happened that you didn't get it?
I never has had insurance
"Any company that I've ever worked for has never offered it, even my ex-husband, they didn't offer it with him so I've just never had any."

b) IF YES: What are the main reason or reasons that you do not have health insurance now?
"I couldn't afford my premium. When I became disabled and had to leave work, the premium was going to be like \$600-some a month and that was more than my retirement check."

"I was offered COBRA with my exit plan, if you'd call it that, but it was \$400 a month. That's not doable."

16)Does anyone in your immediate family have health insurance?

a) Who? What kind of coverage (through work, private, Medicaid, CHIP, Medicare, etc)
Some have Medicare; most of their children do not have coverage including both those still living with them and those who are out of the house

17)Have any of you ever been offered insurance and turned it down? If so, why?

"I could have had on-campus insurance for students that's offered, but you have to pay something each semester to apply and then there's a huge premium. You just can't do it."

18) How many of you work or have a spouse that works?

19)If you or your spouse works, does your employer offer insurance?

a) IF NO - Why do you think your employer does not provide health insurance?

- b) IF YES – Why do you not have this coverage? [Listen/probe for costs too much; not important – I am healthy; can get all the medical care I need without insurance; not eligible]

Too expensive.

“And they ask you if anybody in your family --- what’s your family history? My father died of emphysema and lung cancer and my brother is living with lung cancer right now. He’s a Vietnam vet, he’s only 57 years old, and it’s inoperable because they didn’t it in time even though he was under a doctor’s care and they x-rayed him. But it was over a year before they told him that he had lung cancer and then by that time it was just raging. We don’t know why it’s so prevalent. But if they get that on my record, you’d better bet they’re not going to insure me, not without a huge premium.”

- c) IF NOT Eligible – Do you mind sharing why you aren’t eligible?

- 20) How much do you think it would cost each month to buy basic health insurance?

\$500, even if I got it through AARP or somebody like that.

\$625

Average \$600 to \$700 a month.

\$1000 a month

\$1000 for two

- 21) Are there any other comments that you would like to make at this point? Have we missed anything?

- 22) Now, I would like to go around the room and ask you to give your suggestion on how to increase health insurance coverage of people age 50-64 or how we might help you get health insurance?

"...there should be some plan we could buy into with co-payments and a maximum or a minimum with a deductible that we could...I mean, that was based on you and what you were really...you know, most people aren't going to try to hide a bunch of assets in a safety-deposit box someplace. Most of us are pretty honest, forward people and want to pay our way. We don't want somebody else to give us something. We've earned the right to be treated like human beings."

"It could be something that was offered by the federal government or the state government so that you could purchase. But it has to be reasonable, it can't be out of sight."

"You didn't go to the doctor when I was growing up. You didn't go unless it was an emergency or something, you know. You didn't go for any kind of checkup or healthcare other than emergencies so I think all of that stems from that."

"The government should do another assessment on the assets that people can have. We're in West Virginia; this is hills, a rural area. How many buses is going to run up a hollow? You know, how's people getting out? Vehicles here in WV are very important, especially for our age, our transportation is really poor here. I think when the government steps in, especially like in WV, and sees what we have to go through, what is a \$3000 car?"

"It's just about like trying to put a band aid on a surgical wound, that's what the State's trying to do with all these little clinics here and there. There's just a little bit here, a little bit there, and not enough to go around for everybody. We're not getting the quality, the quantity, the preventative or the maintenance. Are we all in agreement?"

KEYSER

- 1) How is your health these days?
 - 7 – Fine/good/pretty good
 - 2 – Super/very good
 - 1 – Lousy

- 2) How about the health of your family?
 - Daughter, chronic bronchitis, asthma
 - Husband disabled, 2 heart attacks, and dialysis
 - Son, healthy
 - Husband, heart surgery, diabetes
 - Husband, closed head injury, diabetes
 - Husband, heart, stroke

- 3) When was the last time you saw a health care provider (either for an office visit, or to the hospital)?
 - 3 – 1 month
 - 3 – 2 months
 - 21 years
 - This morning
 - Week and a half
 - Medieval
 - a) Was this for a health problem or a regular check-up?
 - 3 – Regular, underlying problem (rheumatologist, diabetes)
 - 2 – Problem
 - Colonoscopy

- 4) If you got sick or needed medical care, where do you usually go for care, to a doctor's office or a clinic, hospital, emergency room? [*Probe to clarify the type/location*]
 - 5 – Doctor's office (mentioned Cumberland Maryland, Tri-State Medical Center)
 - a) If emergency room - why? Why not alternatives?
 - ER – on weekends, evenings, rural area no other options

- 5) What about when your spouse/children become sick or need care, where do they go? [*Probe to clarify the type/location*]
 - None

- 6) Who usually pays the bill for these visits? [*Probe*]
Payment plan

“...If I can, I’ll put my flashers on and take my husband to Cumberland because the rescue squad, and especially if you have to be transferred, I mean, that is overwhelming, the payment right there, for the rescue squad alone. It’s amazing.”

- 7) Would you say that you have a regular doctor? What about your family members, do they have a regular doctor?
2 – NO

- 8) Did it take you a long time to find a place you could get health care without health insurance? Why/why not?
9) Since you’ve been uninsured, has it been difficult or easy for you to get medical care if you needed it? [*Probe: for examples how it may be difficult*]
Yes

“It is unless you have it on a weekend, which mine end up being.”

- 10) How does the lack of insurance affect you getting preventive care such as mammograms, physicals, a flu shot, colorectal screenings, etc?
Majority of people don’t go

“I go to the health department for my flu shot, I can do that, and you...here in Keyser, at least, you can do that.”

“That’s my last colonoscopy.” (had procedure just prior to ending health insurance)

- 11) How does the lack of insurance affect filling your prescriptions?

Free samples.

Barter: “I do quilting for the PAC in the doctor’s office, and she veers the samples in my direction.”

“First I ask is there generic, because very often there is, for my daughter. I go alternative; I use herbal medication, teas and stuff. If I’m really pushed and it gets expensive. She had emergency surgery. I’m still writing bills and I’m still getting bills for this stuff. When we get these things, my daughter and I, we’ll look and we’ll say, do you think we really need to do this, and sometimes we fill it and sometimes we don’t.”

"I have some relatives that have insurance, but I find, like you say, I think it's crazy the way they get prescriptions. I mean, they get prescriptions for one thing and then they have to get another prescription to counteract what's happening on that first prescription and then another prescription to counterbalance the other two. I wouldn't touch pharmaceuticals."

"...we were fortunate enough to get Plavix, which my husband has to be on forever now, through the pharmaceutical company itself. They granted that, you know, so you have to reapply depending on your income. Then I have a pharmacist who is just very understanding again and there have been months when I couldn't pay everything all off and then he would just be patient and wait until I got it all paid off. I've never not paid but sometimes it just takes a while..."

"I do get them from the VA and I do have to pay co-payments for them, but you know if people don't know anything about VA services that's only available to you when you're at that place, so if I were traveling somewhere and something were to happen to me, I'm just like everybody else who has no insurance."

12) Do you skip tests or follow-ups because of lack of insurance?

Some skip follow-up; depends on what it's for. If it's important they try to go.

"Well, I'd go for blood work when they have these clinics around here every six months or so and I'd do my blood work and have them send it to me and it tells me any problem and if I need to, I'll follow-up with my thyroid doctor."

13) How does the lack of insurance affect your dental care?

"I go when there's a problem."

"And I worked for a dentist for eight years, but I haven't been for a while. It's just too expensive."

"I had to make a decision and weigh out the costs of \$5,000 to get the necessary work done or \$2,000 for upper dentures, so I had to take the dentures."

14) What most worries you and your family about not having health insurance?

Catastrophic

"I'd say the catastrophic, a heart attack or something really, really bad, a major whatever and then being strapped with this, you know, bill that's in the thousands of dollars, and then losing your home."

"It's the fear of being a burden to my family. That's there's nothing to show for my life if it all goes to the nursing home or something like that."

15) Have you ever had health insurance?

a) IF NO: Have you ever tried to get it? What happened that you didn't get it?

b) IF YES: What are the main reason or reasons that you do not have health insurance now?

Can't afford it

"Well, they have AFLAC where I work right now and it's not worth it."

"My COBRA from BCBS was \$300 and something a month and now they want...I wanted to transfer because it ran out, and they want \$1,500 and something per month."

16) Does anyone in your immediate family have health insurance?

a) Who? What kind of coverage (through work, private, Medicaid, CHIP, Medicare, etc)

Most responded Yes – through school, employer, Medicare

17) Have any of you ever been offered insurance and turned it down? If so, why?

"Because it was so expensive and they wouldn't cover this, that and the other thing and with the cost, even with a \$5,000 deductible and health savings account, it was still over \$800 per month. And they wanted exclusions and just plain not pay for certain things."

18) How many of you work or have a spouse that works?

19) If you or your spouse works, does your employer offer insurance?

a) IF NO - Why do you think your employer does not provide health insurance?
Self-employed

b) IF YES – Why do you not have this coverage? [Listen/probe for costs too much; Not important – I am healthy; can get all the medical care I need without insurance; not eligible.

c) IF NOT Eligible – Do you mind sharing why you aren't eligible?
Pre-existing; Previous health

20) How much do you think it would cost each month to buy basic health insurance?

\$349

\$400

\$500

\$1200 for the two of us

\$1500 a month

21) Are there any other comments that you would like to make at this point? Have we missed anything?

Superfluous appointments, superfluous testing.

Waiting period for Medicare after you go on disability.

Uninsured paying top dollar.

DHHR is not helpful, put people through hours and hours of paperwork and forms when it know you're not eligible at the start.

"...you know, if you've got money or you're lucky enough to have healthcare, you're in good shape. If you don't, God bless you and hope you make it."

22) Now, I would like to go around the room and ask you to give your suggestion on how to increase health insurance coverage of people age 50-64 or how we might help you get health insurance?

Drug companies will "pursue a certain drug if they think it's going to be a high money-maker. I have seen them drop other things, which would still deal with the same problem, but it'd be less of a moneymaker for them and they'll go with the high return income." "If the drugs cost less, then maybe the insurance could be less and it would be that block after block after block that would tumble down and you'd be able to afford something."

"I've had a doctor look at me and say, well, if you had insurance, and I look at him and say, if I had insurance it would be different. It's not that I don't want insurance. That ain't the issue. The issue is I can't afford the price they want me to pay.....They forget that you pay your electric bill, your phone bill, your heat, your water if you live in a city, car insurance, other costs see they don't take any of that into consideration just the insurance bill."

"What is missing is a group plan for the uninsured and it can be on a state by state basis. People who have no insurance such as all of us sitting here. Blue Cross or somebody like that could say, hey, what we could do here for \$300 a month, this is just a hypothetical figure, we will insure every family that does not have insurance in WV, we'll give them decent coverage, prescriptions care with some co pays and deductibles on stuff, just like traditional insurance. This is the gap that exists and until someone is willing to fill that gap, it'll get worse."

"Again, I'd like to emphasize that instead of health insurance, which is a business to make money, we talk about healthcare."

MINERAL WELLS

- 1) How is your health these days?
 - 3 – Okay/fair
 - 4 – Good
 - 4 – Not good
 - 2 – Excellent (one, one step below excellent)

- 2) How about the health of your family?
 - Son, seizures
 - 2 boys, excellent

- 3) When was the last time you saw a health care provider (either for an office visit, or to the hospital)?
 - 2 – 1-2 months
 - 3 – 3-4 months
 - 2 weeks
 - Years
 - Yesterday
 - a) Was this for a health problem or a regular check-up?
 - 1 – Check-up
 - 1 – Problem
 - Follow-up
 - “We don’t go unless it’s just really bad. He had an appendicitis and it had almost ruptured at the house and I think I had pneumonia, but that’s been years ago. But, I mean, it’s really serious before we go.”

- 4) If you got sick or needed medical care, where do you usually go for care, to a doctor’s office or a clinic, hospital, emergency room? [*Probe to clarify the type/location*]
 - 7 – Family doctor
 - 2 – Good Samaritan Clinic
 - Health food clinic

- 5) What about when your spouse/children become sick or need care, where do they go? [*Probe to clarify the type/location*]
 - 1 – Good Samaritan
 - 3 – Family doctor
 - 1 – Emergency Room (bad cut and broken ankle)
 - VA

- 6) Who usually pays the bill for these visits? *[Probe]*
Self-pay all

"I've found that, at least in my situation, without healthcare, there's a discount if you pay cash, which has become, I guess, a new thing for the doctors and it really saves them a lot of time because, from my experience is they have to like send the billing to insurance and they might send it back because one question wasn't answered, or you know, there's a couple minds of things there, so if they lower their fee or rate a little bit, it's basically the same difference, you know, the money comes in quicker, they don't have to do as much paperwork and everything."

"So even when I go to the doctor, his discounted fee is \$70 an office visit, so big discount."

- 7) Would you say that you have a regular doctor? What about your family members, do they have a regular doctor?

Yes

"I have a regular doctor and health insurance until I got sick, and then I couldn't work, so now I don't have insurance, so now I don't have a doctor."

"Well, I had a regular doctor and I just had a flu shot and it was like \$15 and I haven't been there the rest of the year because I couldn't afford it, so they let me go..."

"I have a regular doctor but losing my insurance is new and I'm not sure how long I'll be able to afford to go. And so I've had insurance for about 25 years and was cut back to part time and lost my insurance so it's..."

- 8) Did it take you a long time to find a place you could get health care without health insurance? *Why/why not?*
9) Since you've been uninsured, has it been difficult or easy for you to get medical care if you needed it? *[Probe: for examples how it may be difficult]*

"...you just don't go."

"Well I had surgery in 1999 and I ended up having to file bankruptcy because of the medical bills. I paid my bills all my life, good credit, and it's wiped out in one three or four-day visit to the hospital for surgery, very devastating."

- 10) How does the lack of insurance affect you getting preventive care such as mammograms, physicals, a flu shot, colorectal screenings, etc?

"I go to Planned Parenthood, who sets me up for my mammograms and they do the cancer screening there. But it's still \$20 an office visit."

“We would go to Saint Joe whenever they offer their free flu shots, which they haven’t done for, you know, a couple of years now.”

“Whatever we get, we have no trouble getting it. We don’t get all those things; no.....We pay for any care we get. We have no insurance to pay for anything so we just pay for it.”

In the Parkersburg area “Camden Clark and the mall have gone together to support a group called Lifetime Partners and Soul Mates. And matter of fact that’s how we found out about this group. If you’re a member, which membership’s free, they offer a lot of either free or low cost tests and we get like the multiphasic blood test once a year for, I think its \$30.” But you have to be 55.

11)How does the lack of insurance affect filling your prescriptions?

Pharmaceutical assistance programs.

“Well, I don’t take out of the probably six or seven pills I’m supposed to take, I only take two.”

“I’m only on one prescription medication. I feel fortunate about that. And by going to Wal-Mart and using my Golden Mountaineer Discount Card that the State of West Virginia furnished and the fact that the prescription drug just when on generic about a year ago, and I get a very reasonable price on it.”

“I just haven’t been taking, like I say, I’m a diabetic and I haven’t taken diabetes medicine for quite a few years, because I just couldn’t afford it. And I didn’t know what the long-term effects is. Like I say, yesterday I failed a stress test and I hope the diabetes hasn’t caused this.”

12)Do you skip tests or follow-ups because of lack of insurance?

Don’t keep – in general

13)How does the lack of insurance affect your dental care?

Don’t go (dentures or expense)

“WE don’t go to the dentist at all but I make sure that our boys have went ever since they’ve been three years old twice a year. And then if they get a cavity, then they have to mow lawns and whatever, they have to pay for their own cavities, but I pay for the checkups and the x-rays.”

14)What most worries you and your family about not having health insurance?

Catastrophic

“I’m on my own and if something happens to me and I can’t work because...then I’ll lose everything.”

“I was unable to work because I got sick, and in six months my IRA was gone, my 401K was gone, so everything I have for retirement is gone.”

15) Have you ever had health insurance?

a) IF NO: Have you ever tried to get it? What happened that you didn't get it?

b) IF YES: What are the main reason or reasons that you do not have health insurance now?

Costs

The company cut us back to save them money.”

“The cost benefit ratio is unacceptable. We feel that our health is such that we can get by without health insurance for a while and we used to have it and the cost was just so high and when the company would not pay a claim we had, we just looked at the costs and thought, what’s the benefit of this insurance and we just...we decided to let it lapse and that’s been 14 years ago, 13 something like that....And we’ve been lucky. We’ve had to pay for some procedures since then out of our own pocket, but what we have paid is way less than what we would have paid had we had insurance...”

“I got laid off with a job that had insurance in 1993, and it’s been all we could do to pay the house insurance, the car insurance, and the life insurance, you know, to get those bills paid every month. I’ve always joked, joked all these years, I’ve always said, well, if they ever tell me I have something catastrophic wrong with me, I’ll just have to get in the car and run into a tree...”

16) Does anyone in your immediate family have health insurance?

a) Who? What kind of coverage (through work, private, Medicaid, CHIP, Medicare, etc)

Yes – Medicare, some through employers, VA benefits, or retirement

Some children who do not have coverage

17) Have any of you ever been offered insurance and turned it down? If so, why?

“My company just recently, this year, offered health insurance coverage to part-time employees, but I would not have made enough working part-time to even begin to afford the premiums. And there was a cap on things, like \$5,000 for a hospital visit or whatever, and it just wasn’t feasible. And like I say, I wasn’t making enough money working part-time to even afford the premiums.”

18) How many of you work or have a spouse that works?

19) If you or your spouse works, does your employer offer insurance?

- a) IF NO - Why do you think your employer does not provide health insurance?
- b) IF YES – Why do you not have this coverage? [Listen/probe for costs too much; not important – I am healthy; can get all the medical care I need without insurance; not eligible]
Too expensive.
- c) IF NOT Eligible – Do you mind sharing why you aren't eligible?

20) How much do you think it would cost each month to buy basic health insurance?

- \$275
- \$100-\$300
- \$400-500
- \$600
- \$700-800
- \$1000

21) Are there any other comments that you would like to make at this point? Have we missed anything?

22) Now, I would like to go around the room and ask you to give your suggestion on how to increase health insurance coverage of people age 50-64 or how we might help you get health insurance?

"We took XXX to the E.R. for the cut that he got that time, well, the doctor didn't even see him it was just the nurse, and she put a couple stitches in him there or whatever, a nurse practitioner, it wasn't a doctor. Well, we got the bill and we were charged for the doctor's fee. So I called and I said my son never even got up on the bed of a thing that you've got there, you didn't even have to change the paper on it. We'll, we had to pay this outrageous amount of money for the use of their E.R. anyway. Of course, it was, you know, and so I asked for a payment plan, of you know, \$25 a month, \$50 a month, something like that. And no, they were going to turn it over to a collection fee.So I took the money out of their college fund, which was basically their money anyway, and I then paid them back. But the hospital wouldn't even work with you when you wanted to make a regular payment."

"Well, we already have in place a program for children in the state of WV that provides for this, there's procedures there, it's already going and why can't it just be expanded to adults.....when I tried to get help, there were like six different programs, with spend downs and all of this and whatever and I didn't qualify anything and like I say, my income was less than \$500 for seven months, you know. What are you going to have to take to qualify? And if the set-s already there for children why can't we just add adults to it?"

WHEELING

- 1) How is your health these days?
 - 2 – Lousy/terrible
 - 2 – Improving
 - 2 – Somewhat okay/good

- 2) How about the health of your family?
 - Husband, bad
 - Son, some problems, okay
 - Mother, back surgery and hip operation, she's on medication.
 - Aunt, 85 y/o osteoarthritis, can hardly walk

- 3) When was the last time you saw a health care provider (either for an office visit, or to the hospital)?
 - 2 – 2 months
 - 6 months
 - 1 month
 - 2 weeks
 - Yesterday
 - a) Was this for a health problem or a regular check-up?
 - 4 – Check-up
 - 1 – Follow-up, regular
 - 3 – Problem

- 4) If you got sick or needed medical care, where do you usually go for care, to a doctor's office or a clinic, hospital, emergency room? [*Probe to clarify the type/location*]
 - 2 – Family doctor
 - 3 – Emergency Room
 - 1 – Physician
 - a) If emergency room - why? Why not alternatives?

Excruciating pain from back; really bad state; fish hook in hand

- 5) What about when your spouse/children become sick or need care, where do they go? [*Probe to clarify the type/location*]
 - Emergency Room
 - 2 – Family physician

a) If emergency room - why? Why not alternatives?
Got severely dehydrated

- 6) Who usually pays the bill for these visits? *[Probe]*
3 – Self-pay (includes one on Medicaid spend-down)
1 – Charity
1 – Free Clinic
1 – Self-pay and Free Clinic-
1 – Worker’s Compensation

7) Would you say that you have a regular doctor? What about your family members, do they have a regular doctor?
5 – Yes

8) Did it take you a long time to find a place you could get health care without health insurance? Why/why not?

9) Since you’ve been uninsured, has it been difficult or easy for you to get medical care if you needed it? *[Probe: for examples how it may be difficult]*

“I went right to Health Right. I qualified for it because of raising my two children. They put me on in Wheeling Health Right....They are an excellent facility, especially with the problems they have and the people that are running in and out of there, some need to be there, some don’t need to be there. But they are a really good facility and they need to be complimented.”

“Well I knew I was going to be leaving my job so, with the health plan, I had found a primary care physician. So I maintained my relationship with him, but I also knew that there was a free clinic in town. My main doctor helped me out with samples of medication that he could help me out with, but he couldn’t send me for tests, so I had to go to the free clinic.”

“I’ve been in the hospital three times this last year and when I had insurance they treated me differently than when I didn’t have insurance, in the hospital.....they knew I was on Health Right, they treated me poorly, and it was like, you couldn’t get any help in the hospital...the quality of care went down.”

“...in the past year, I’ve been in the hospital a few times, several times, and both hospitals, they, you know, Weirton and Trinity West, and it was just like you wait or you’re there longer and, you know, even if you really feel like you’re sick and need to be admitted, you know, they still send you home, and you just didn’t know.”

10) How does the lack of insurance affect you getting preventive care such as mammograms, physicals, a flu shot, colorectal screenings, etc?

“...they’re not really sending you for anything preventive.”

“When I go see one doctor, my main doctor, he’ll say, when was your last pap smear. I can tell him a year ago. I could go see him every month, every three months, and tell him the same thing, and he’s not saying anything, but then, this last time, he said, you can go to the health department and get it done for free and he’s the doctor that’s doing it. So he can say go do it for free. But the clinic is not doing anything preventative, like with mammograms or I have fibroids or thyroid things, they’re not doing anything preventative. The only thing he’s helped me with is getting my sugar down, which I guess I can be thankful for that.”

“I do that (a physical), but anything that I think I’m going to dig into to open a can of worms, might be asking for trouble.”

“I go to Health Right and they’re really good about that with me so...Because I never did have a pap—well, I hadn’t had a pap smear since my youngest child was born and a mammogram, I never did have until I went to Health Right, so they had...”

“I’m prudent about that. When you get to a certain age, you should be, anyway, unless you’re living in a cave somewhere....I get my heart checked because I had a mild heart attack five years ago. I run a blood pressure now of 118 over 68, with a heart rate of 55, so I’m fine. But I still go every year to find out if I’m fine.”

11)How does the lack of insurance affect filling your prescriptions?

“I fill them and they’re cheaper at the clinic. But a couple times, the clinic didn’t have it and I had to pay \$82 for a bottle of insulin or \$113 for cholesterol medicine. It’s just not having the insurance, the co pay, you know, that was much better having the insurance.”

“My doctor gives out a lot of medicine. And then, if it’s a prescription that I don’t really need right away, I call the manufacturer and get that for that assistance program.”

“I take 12 different pills and if I didn’t have Health Right to get them through, I’d be in a lot of trouble.”

12)Do you skip tests or follow-ups because of lack of insurance?

Keep follow-up appointments – in general (unless not authorized by Worker’s Compensation)

13)How does the lack of insurance affect your dental care?

Don’t go, can’t afford the expense unless there’s a problem.

- 14) What most worries you and your family about not having health insurance?
“Prescriptions.”

“Having to pay a large bill and, just having the money to pay for it.”
- 15) Have you ever had health insurance?
a) IF NO: Have you ever tried to get it? What happened that you didn't get it?

b) IF YES: What are the main reason or reasons that you do not have health insurance now?
Unemployed, expense
“Like I said, my husband's the one that had it for us and when he got in that accident and lost it, because he had to lose his job, then he's got Medicare. He's got it, like I said, through Medicare, but I don't have any because I don't have any job or whatever so...” [caretaker for husband]
- 16) Does anyone in your immediate family have health insurance?
a) Who? What kind of coverage (through work, private, Medicaid, CHIP, Medicare, etc)
Most family members have some coverage but a few grown children who do not have anything
- 17) Have any of you ever been offered insurance and turned it down? If so, why?
“My employer advertises that they provide insurance and they don't. They make it available. The first year I worked for them, It was \$62 per month. The second year, it went up to \$126 a month with a \$500 deductible. And there's medication I have to have, but I couldn't afford it, so I had to turn it down.”
- 18) How many of you work or have a spouse that works?
- 19) If you or your spouse works, does your employer offer insurance?
a) IF NO - Why do you think your employer does not provide health insurance?

b) IF YES – Why do you not have this coverage? [Listen/probe for costs too much; not important – I am healthy; can get all the medical care I need without insurance; not eligible]
Too expensive.

c) IF NOT Eligible – Do you mind sharing why you aren't eligible?
- 20) How much do you think it would cost each month to buy basic health insurance?
Basic: eye, dental, whole health plan
\$75 to \$100 per month
Group \$126 plus a little less than \$200

\$150
\$250-300
\$585

Basic: prescription coverage, quality care, ability to go wherever I want with certain out-of-pocket expenses. Around \$50

“Basic policy \$5000 front end deductible, co pays on your RX, 90-day co pay mail order. \$20 to see doc, \$40 specialist. You pay out-of-pocket, your bill will be \$5000 a year, total, total out-of-pocket. And you could pay the hospital \$10 a month. Let’s face it guys, you know that. And then the rest of it is paid at 100 percent, so you don’t get these little bills that say the anesthesiology, \$300.”

“An individual policy shouldn’t cost...a basic, with Rx, should cost more than...again we go with age. If you’re female, 45 years old, it shouldn’t cost more than \$150 a month. If it’s male, same age, probably \$105 a month.”

21) Are there any other comments that you would like to make at this point? Have we missed anything?

22) Now, I would like to go around the room and ask you to give your suggestion on how to increase health insurance coverage of people age 50-64 or how we might help you get health insurance?

“...you’re a human being and they’re in the human being business....And they should not look at you differently.”

“And I don’t understand why they let businesses come into the state of West Virginia that don’t provide insurance for the employees.....Okay, the only other alternative, I think, would be to set up something like flood insurance, where everybody has insurance.”

“Preventative care. Make it mandatory wherever you work, that you go get your OB/GYN, that you must go get your physical.”

Premiums based on income

State run program to pool people who aren’t working

APPENDIX E:
Frequency Tables from Short Survey

Employment Status

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Employed	24	43.6	43.6	43.6
	Unemployed	31	56.4	56.4	100.0
	Total	55	100.0	100.0	

Income

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	LT \$10,000	5	9.1	9.1	9.1
	10,000-19,999	20	36.4	36.4	45.5
	20,000-29,999	15	27.3	27.3	72.7
	30,000-39,999	10	18.2	18.2	90.9
	GT 40,000	5	9.1	9.1	100.0
	Total	55	100.0	100.0	

Doctor Visits

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very Important	39	70.9	72.2	72.2
	Somewhat Important	13	23.6	24.1	96.3
	Little Importance	1	1.8	1.9	98.1
	Not Needed	1	1.8	1.9	100.0
	Total	54	98.2	100.0	
Missing	System	1	1.8		
Total		55	100.0		

Specialists

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very Important	44	80.0	81.5	81.5
	Somewhat Important	9	16.4	16.7	98.1
	Not Needed	1	1.8	1.9	100.0
	Total	54	98.2	100.0	
Missing	System	1	1.8		
Total		55	100.0		

Drugs

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very Important	43	78.2	79.6	79.6
	Somewhat Important	10	18.2	18.5	98.1
	Little Importance	1	1.8	1.9	100.0
	Total	54	98.2	100.0	
Missing	System	1	1.8		
Total		55	100.0		

Hospitalization

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very Important	49	89.1	89.1	89.1
	Somewhat Important	6	10.9	10.9	100.0
	Total	55	100.0	100.0	

After hours urgent care

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very Important	33	60.0	63.5	63.5
	Somewhat Important	15	27.3	28.8	92.3
	Little Importance	4	7.3	7.7	100.0
	Total	52	94.5	100.0	
Missing	System	3	5.5		
Total		55	100.0		

Maternity care

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very Important	20	36.4	37.7	37.7
	Somewhat Important	8	14.5	15.1	52.8
	Little Importance	1	1.8	1.9	54.7
	Not Needed	24	43.6	45.3	100.0
	Total	53	96.4	100.0	
Missing	System	2	3.6		
Total		55	100.0		

Vision

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very Important	26	47.3	47.3	47.3
	Somewhat Important	20	36.4	36.4	83.6
	Little Importance	6	10.9	10.9	94.5
	Not Needed	3	5.5	5.5	100.0
	Total	55	100.0	100.0	

Dental

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very Important	25	45.5	47.2	47.2
	Somewhat Important	22	40.0	41.5	88.7
	Little Importance	4	7.3	7.5	96.2
	Not Needed	2	3.6	3.8	100.0
	Total	53	96.4	100.0	
Missing	System	2	3.6		
Total		55	100.0		

Outpt SA & MH

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very Important	19	34.5	34.5	34.5
	Somewhat Important	17	30.9	30.9	65.5
	Little Importance	5	9.1	9.1	74.5
	Not Needed	14	25.5	25.5	100.0
	Total	55	100.0	100.0	

DME

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very Important	24	43.6	45.3	45.3
	Somewhat Important	16	29.1	30.2	75.5
	Little Importance	5	9.1	9.4	84.9
	Not Needed	8	14.5	15.1	100.0
	Total	53	96.4	100.0	
Missing	System	2	3.6		
Total		55	100.0		