

*“Using formative research methods in the development of the
North Carolina Study of Home Healthcare and Hospice Nurses.”*

by

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Using formative research methods in the development of the North Carolina Study of Home Care and Hospice Nurses.

Abstract

There are approximately 200,000 nurses providing home healthcare in the United States. Through the potential exposure to patients' blood, these nurses are at risk of transmission and subsequent infection from human immunodeficiency virus (HIV), hepatitis B virus (HBV), and hepatitis C virus (HCV). Very little is known about the extent to which home healthcare nurses (HHN) are exposed to blood, factors contributing to their exposure, or current prevention practices in this population. As part of a larger study to reduce blood exposure among home healthcare nurses, we conducted formative research to: 1) identify the factors in the HHN work environment that might be relevant to understanding blood exposure and prevention practices for this population and 2) determine the optimal method of recruitment and data collection including techniques to maximize response rates. The formative research methods included interviewing key informants, shadowing HHN in the field and conducting focus groups with practicing HHN. Both quantitative and qualitative data were analyzed. The research findings yielded valuable information on possible risk factors for exposure and current prevention practices specific to this population. Information about data collection methods that appeal to this population and ways to improve response rates were incorporated into the study design. Information about potential risk factors and prevention practices was used as a basis for constructing a population-based survey that quantifies the risk of blood exposure and ultimately will be used to develop a prevention program to reduce blood exposure in HHN.

Introduction to Formative Research

Formative research is typically utilized in the program planning or social marketing fields as a basis for helping researchers identify and understand the characteristics of a target population. Formative research allows researchers to explore general knowledge, attitudes, and behaviors of the target population to establish a baseline for their efforts. This information can then be used to better understand decisions and actions of the target population. Qualitative data, gathered during formative research activities, is appropriate for situations where in-depth information is needed or when there is limited information on a specific population. In the present study, we utilized formative research to better understand the risk factors and motivations of an understudied population - home healthcare and hospice nurses. This information has been used to guide the study design, as well as the development of data collection instruments.

Background on the North Carolina Study of Home Healthcare and Hospice Nurses

The purpose of the North Carolina Study of Home Healthcare and Hospice Nurses is to reduce blood-borne infections among home healthcare and hospice nurses by preventing occupational blood exposure. Data for this study will come from a state-wide survey of home healthcare and hospice nurses. The specific aims of the overall study are as follows:

- 1. Estimate incidence rates of occupational blood exposure among HHN in North Carolina.** Currently, there are no national or regional estimates of blood exposure rates among home healthcare and hospice nurses in the United States. Perry et al. (8) reported 252 needlestick injuries among an unknown number of hospital-based home healthcare workers over a five year period. Backinger and Koustenis (2) surveyed a national sample

of directors of home healthcare agencies about needlestick injuries among their workers. Fifty eight percent of the respondents reported no needlestick injuries, whereas 22 percent reported more than 60 needlesticks per 100,000 needles purchased by the agency. Rates for nurses or total workers were not given. In contrast to these higher rates, one large home healthcare agency, where due to supportive management higher reporting was expected, experienced a rate among nurses of 1 needlestick per 225,000 home visits in 2003. This agency implemented needle-less devices in 2002. Before 2002, the needlestick rate among nurses was approximately 1 per 22,000 visits (personal communication, K. Utterback). Although the risk of exposure among HHN is not known, the nature of their work suggests that it may be high.

2. Identify risk factors for blood exposure among HHN.

HHN are increasingly required to perform procedures that involve potential exposure to blood and bloody body fluids (6, 7, 11). Unlike nurses who work in highly structured hospital environments, HHN provide patient care in homes where working conditions vary widely from one venue to the next (conducive to exposure) and they have little control over the work environment (unfavorable to preventive actions). These working conditions exacerbate the potential for blood exposure, especially from percutaneous injury from contaminated needles or sharp instruments. Prevention programs are most effective when they target known risk factors as risk factor mitigation leads to a reduction of exposures. However, current understanding of factors that increase the risk of healthcare workers' exposure to blood is based primarily on studies of hospital healthcare workers. Because of differing work environments, data from hospital workers may not be generalizable nor provide a sound basis for designing interventions aimed at home

healthcare workers. Studies of risk factors among home healthcare workers are needed for this purpose.

3. Quantify the availability and use of medical safety devices and other exposure prevention measures, and identify and quantify their determinants.

Universal Precautions are a set of procedures promulgated by CDC to prevent transmission of bloodborne pathogens (3). These procedures include the use of personal protective equipment (PPE) (e.g., gloves, goggles, facemasks and shields, and fluid-impermeable clothing), steps to prevent injury from sharp instruments, and related hygienic procedures (e.g., hand washing). Current efforts to prevent blood exposure comprise three major strategies: attaining full compliance with Universal Precautions; provision and correct use of PPE; and provision and correct use of safety devices (e.g., needles and lancets that have been engineered to reduce the risk of exposure). There is evidence that the vast majority of needlesticks are preventable by the use of safety devices and proper disposal of sharps; and that safety devices reduce exposures in healthcare workers (7).

Formative Research Plan

Although our research team is comprised of experts in occupational blood exposure, we recognize that the target population of Home Healthcare and Hospice Nurses is unique and faced with a distinctive set of challenges. Therefore extensive formative research was conducted to inform both the study design and development of specific survey questions. The specific objectives of the formative research were to:

Objective #1: Inform development of questionnaires items and response options. In order to collect valid survey data, it is necessary to utilize appropriate terminology in the data collection tools. Each target population has their own experiences and language, therefore, including familiar terminology in the data collection tool not only increases comprehension of the survey but also increases the validity of the data collected. Key informant interviews and shadowing of home healthcare and hospice nurses were conducted to inform the study team of population specific terminology, procedures, and medical devices.

Objective #2: Determine the best method of data collection for the HHN population. Possible data collection methods included mail survey, telephone survey, web survey, and in-person interview. For this objective, we sought to identify the data collection method that would lead to the highest response rate while allowing us to collect the data necessary to meet the study objectives. In order to determine the best method for data collection, we conducted focus groups with home healthcare and hospice nurses.

Objective #3: Gather information on barriers, incentives, and general motivations for participating in the study. For reasons of validity, reliability, and cost, it is important to obtain high response rates to surveys. Lower response rates increase the potential for non-response bias that could potentially invalidate survey findings. Smaller numbers of responses reduce the precision of the findings which may limit their usefulness. In order to achieve the highest response rate possible, our team was interested in identifying barriers to participation and potential motivators such as incentives. We conducted focus groups with home healthcare and hospice nurses to understand these issues.

Formative Research Methods

Key Informant Interviews. The information gathered from practicing HHN provided a valuable frontline perspective on day-to-day activities. A total of seven interviews were conducted with home healthcare and hospice nurses employed at four types of home healthcare/hospice agencies (hospital based, private-freestanding, health department, and hospice). The interviews lasted sixty to ninety minutes each. All respondents were provided with a \$25 American Express Gift Check or \$25 Target Gift Card. The content of the key informant interviews focused mainly on information needed to develop questionnaire items and response options (Objective 1). (See Appendix A for Home Health Key Informant Interview Guide) Topics covered in the key informant interviews were:

- Shift structures and working patterns of nurses in home healthcare
- Types of procedures performed
- Steps taken to prevent blood exposure
- Provisioning and use of personal protective equipment / safety devices
- Perceived risk factors for blood exposure
- Training received to prevent blood exposures
- Reporting / documentation / recall of past blood exposures

Shadowing. Shadowing involved a member of the study team accompanying a home healthcare or hospice nurse during his/her shift to directly observe their work environment and daily activities. In all, three nurses were shadowed from a variety of home healthcare settings (hospice, private agency, and county health department) for the formative research. The nurses were provided with a \$25 American Express Gift Check

or \$25 Target Gift Card. A total of eight home visits were observed. The length of the home visits ranged from twenty to fifty-four minutes with the average home visit lasting thirty-six minutes. The majority of patients observed had a companion in the house during the time of the visit. The information gathered during shadowing aided with questionnaire development (Objective 1). (See appendix B for Home Health Observation Form) Actions and behaviors observed were similar to those being addressed in key informant interviews and include:

- Shift structures and working patterns
- Procedures performed
- Steps taken to prevent blood exposure
- Provisioning and use of personal protective equipment / safety devices
- Interaction with patients
- Nurses' work environment

Focus Groups. Focus groups were conducted in order to obtain information on the feasibility of various data collection methods (Objective 2) and possible barriers and incentives to participation in the study (Objective 3). The study team conducted two focus groups with practicing HHN. All focus group participants were provided with a \$50 Target Gift Card as an incentive. A trained focus group moderator facilitated the group discussions while a co-moderator took notes. The discussion was audio recorded and the moderator guided the discussion by presenting a topic or question to the group. The discussion proceeded primarily among focus group members, with the moderator joining in to keep the discussion on course and probe for additional information. (See Appendix C for Home Health Focus Group Moderator's Guide) Group members were

assured that their participation was voluntary and that their confidentiality would be protected. Each session lasted approximately 60 minutes. General topics that were discussed during the focus groups were as follows:

Motivation/ Barriers/Incentives to participation:

- Nurses interest in occupational blood exposure
- Nurses' interest in participating in this study
- Length of time a nurse would spend filling out the survey
- Possible incentives
- Concerns about participation (i.e., confidentiality)
- Effectiveness of having a professional group, agency endorse the study

Feasibility of various data collection methods:

- Nurses' thoughts and opinions of different modes of data collection (e.g., mail, web-based, telephone, in-person interviews)
- Nurses' accessibility to internet
- Nurses' proficiency using the internet
- Nurses' thoughts on being contacted via phone

Formative Research Findings

Objective 1: Inform development of questionnaires items and response options.

To address objective one, formative research activities included key informant interviews and shadowing. To estimate the incidence rates of occupational blood exposure among HHN in North Carolina, appropriate denominator information needed to be collected.

The information necessary to calculate a denominator varies by occupational setting. For

example, in a hospital setting the denominators might be the number of Full-Time Equivalents (FTE), patient admissions, patient beds, or patient days (1). Potential denominators investigated included the number of home visits per week, number of hours worked per week, and the number and type of procedures performed per week.

The majority of HHN indicated that they work between forty and forty-five hours per week, however this includes paperwork and travel time. Therefore, the number of working hours a home healthcare or hospice nurse reports does not equal the number of direct patient care hours. The number of direct patient care hours spent with a patient each week depends on a multitude of factors. All nurses indicated that they could recall the number of patients they visited yesterday, but could not easily calculate the number of patients visited in the last week. All nurses expressed that they could not accurately report the number of hours/minutes spent with each patient over the last week as they do not routinely capture information at this level of detail. Yet, when asked about the amount of time they spent with each patient yesterday, they suggested minutes would be the appropriate time measurement. Some nurses said they could accurately provide the number of minutes and others said they would estimate or provide a “best guess.” When we inquired about the specific number and types of skilled medical procedures performed yesterday, all but one nurse could recall this information. In order to calculate the specific number and type of medical procedures performed last week, nurses would have to refer to their clinical notes, which could be perceived as an additional burden and may lead to the provision of inaccurate data.

We learned that the number of home visits made by a home healthcare or hospice nurse ranged from twenty to thirty-five visits per week. The number of patients visited each

day ranged from three to six (average number of patients five). In addition, the number of patients a nurse visits per week fluctuated due to changes in the patient census, patient needs (not all patients were visited everyday), administrative responsibilities, nurse turnover at agency, etc. Home healthcare and hospice nurses also indicated that the number of home visits is influenced by seasonal trends in agency patient census. For example, one nurse indicated that the number of patients she cared for increased in the fall and winter months due to flu season. The number of home visits was the denominator selected for the calculation of occupational blood exposure incidence rates in home care and hospice nurses ("Currently, how many home visits do you make in a typical week?"). To capture seasonal variation in patient census, we will include questions regarding the number of visits in a typical week at three points throughout the year ("Last summer, how many home visits did you make in a typical week? Last winter, how many home visits did you make in a typical week?").

Numerous skilled medical procedures including, wound care, intravenous therapy, injections, phlebotomy procedures, blood glucose testing, catheter care, ostomy care, ventilator care, and sectioning patients with tracheotomies, put home healthcare and hospice nurses at risk for occupational blood exposure. . Additional nursing tasks comprising of patient education, a patient's mental status, and moving/lifting patients also place a HHN at risk for blood exposure. To adequately assess a nurse's risk of occupational blood exposure, the study questionnaire included items regarding the frequency of which these procedures/tasks are performed in the home setting.

Situational factors in the home environment also influence occupational blood exposure. Cluttered homes, unrestrained pets, and unsupervised children were identified as environmental factors that increase the risk for occupational blood exposure. To investigate how nurses mitigate the risks associated with these home environmental factors, we inquired about this in the questionnaire.

The manner in which occupational blood exposure occurs in home healthcare and hospice nurses includes needlesticks, mucocutaneous exposure (i.e., blood in eyes, nose, or mouth), and blood on non-intact (broken) skin. In other healthcare populations, patient bites are a common route of exposure (5), yet are very rare in this population. Therefore, the study team decided to not investigate occupational blood exposure through patient bites on the questionnaire.

The provision of PPE and safety engineered medical devices are associated with a significant decrease in the incidence of occupational blood exposure in healthcare workers (13) (9). All nurses indicated that their employer provided the necessary PPE, safety-engineered medical devices, and sharps disposal containers. Types of PPE routinely provided to home care and hospice nurses include gloves, surgical-type facemasks, fluid impermeable gowns, HEPA masks, CPR masks, foot coverings, TB masks, and aprons. The utilization of safety-engineered devices has been shown to reduce percutaneous injury rates across occupations, activities, times of injury, and devices (10). Routinely provided safety engineered medical devices include retracting syringes, safety butterfly needles, needless IV systems, retractable or hinged capped or shielded straight needles, safety lancets, and safety pre-filled syringes. As a result of

these findings, questions regarding the provision of safety engineered devices and PPE by employers were included on the questionnaire.

Objective 2: Determine the best method of data collection for the home healthcare nurse population.

Focus group findings were used to determine the best method of data collection. A mail survey, telephone survey, internet-based survey, and face-to-face personal interview were the four methods of data collection discussed during the focus groups. There was a general consensus that a telephone survey would be unacceptable, as this method would need to be completed during non-work hours. Many nurses indicated that they didn't want to be bothered/disturbed in the evenings by a phone survey. Nurses consistently mentioned that they were very busy and had little to no "free-time." When asked their initial thoughts on a telephone survey, responses included, "I would hang up," "I don't answer calls from numbers that I don't recognize," "No, no, not a phone survey," and "there is never a good time to reach us."

Nurses unanimously agreed that face-to-face interviews were an impractical method of collecting occupational blood exposure data in home healthcare and hospice nurses.

Nurses would not feel comfortable being interviewed in their homes because of personal safety concerns. Even though, HHN are required to report occupational blood exposures to their supervisors or infection control practitioner, numerous reasons prevent a nurse from reporting a blood exposure to the appropriate authority. Reasons provided during the focus groups included, "I thought I might be blamed or get in trouble for having the exposure (by employer)," "I didn't think it was a significant exposure," "I didn't know

the reporting procedure,” “I was concerned about confidentiality,” and “I thought the source patient was low risk for HIV and/or hepatitis B or C.” Concerns about confidentiality of blood exposure status were mentioned as a reason for not conducting face-to-face interviews at their workplace. In sum, concerns of personal safety, confidentiality, and logistical impracticality terminated the idea of in-person interviews.

We discovered that an internet-based data questionnaire was an inappropriate method of data collection from home healthcare and hospice nurses. Surprisingly, many of the nurses did not have Internet access or were not interest in completing a questionnaire online. Concerns about the security of the data transmitted via the Internet were cited as a negative aspect of this method of data collection. Additionally, numerous nurses were not familiar with how to use the Internet or personal computers. Therefore, we decided to not pursue internet-based data collection.

Focus group participants consistently agreed that a mail survey would be the most appropriate way to collect data. A mail survey would allow the nurse to complete the questionnaire at a convenient time of their choice. Nurses suggested mailing the survey to their home address. One nurse said, “I don’t check my mailbox at work.”

Additionally, mailing surveys to nurse’s home address would alleviate the possibility of the nurse employers uncovering non-reported occupational blood exposure. Based on these focus group findings, the study team decided on mail survey data collection methodology. The survey was mailed to the home address of the nurses. The North Carolina Board of Nursing provided the home addresses of home healthcare and hospice

nurses to the study team. The Dillman Tailored Design mail survey methodology was followed (4).

Objective 3: Gather information on barriers, incentives, and general motivations for participating in the study.

In addition to investigating an appropriate data collection method, focus groups discussed barriers, incentives, and general motivations for participating in the study. Nurses expressed numerous motivational factors associated with participation in this study including empowerment, the potential for exposure of the issue, and the hope that results will reduce future occupational blood exposures. In addition, this study would bring recognition to North Carolina home healthcare and hospice nurses. Numerous nurses indicated that the regional focus of the study was appealing. One nurse said, "It is great that information will be gathered on *our* state." The study was named the "North Carolina Study of Home Care and Hospice Nurses" to spotlight the regional focus and population being studied.

The appearance of the mail survey materials (outgoing envelopes, cover letters, questionnaire layout and cover, return envelopes) was noted to be tied directly to the perceived credibility of the study. Nurses suggested that mailing the survey in a large, eye-catching envelope would increase the likelihood of opening the materials as nurses generally look at the return address to see if the materials are "worth opening." Nurses suggested using the study name as the return address as opposed to the company name (Constella Group). Materials sent with the return address of Constella Group would be confused for direct marketing materials and most likely disposed of prior to opening. The manner in which an envelope is addressed to the recipient can influence whether or

not it is opened. Nurses recommended including RN after their names on the mailing label as this inclusion would alert the recipient that the envelope content has something to do with their profession.

A visually appealing mail survey would be easy to read, include space to write comments, easy to follow, and be no more than two pages in length. The study team worked in collaboration with a graphic designer and professional printing company to design the study materials. The purpose of the study, length of time to complete the survey, topic being studied, and the number of nurse participants are issues that nurses would use to determine participation. The cover letter accompanying the survey addressed each of these issues.

Focus group participants consistently mentioned two barriers for participation, 1) lack of time and 2) concerns about the confidentiality of the exposure data. To address these concerns the survey was designed to ensure it could be completed in less than ten minutes, was mailed to the nurses' home address, and confidentiality was assured by stating directly in the cover letter that nurses' employers would not be notified of their responses.

Nurses suggested that the inclusion of an incentive would increase participation in the study. All nurses agreed that an incentive should be included with the questionnaire. The most frequently mentioned incentive was cash; however, non-cash incentives were also suggested. The monetary value of incentive ranged greatly, from a dollar to thousands of dollars. The list below presents a list of the suggested incentives mentioned during the focus groups. Suggested incentives are not listed in any particular order.

Suggested Incentives:

- Gift cards/gift certificates to stores and restaurants
- Cash
- Label Pin that says "Home Health RN"
- Mosby Drug Consultant (textbook)
- Pre-paid Gas Cards
- Massage/Day at the spa
- Movie Tickets
- Magnets
- Insulator Bags
- Nursing Software
- Weekend at the beach or mountains
- Year of Profession House Cleaning Service
- Pen
- Vein finding machine
- Keychain
- Travel Mugs
- Stethoscope
- Year supply of Gas
- PDA
- Year of Lawn Care
- Car or Truck
- Payment of Board of Nursing Licensing Fee

During the pilot study, the study team tested the effectiveness of two different incentives during the pilot study. A one-dollar bill and a lapel pin with the study logo were the two incentives evaluated.

Pilot Study

A pilot study was conducted in the fall of 2005 to evaluate three objectives, 1) the feasibility of the proposed data collection method, 2) identification of flaws in the data collection instrument, and 3) evaluation of techniques to influence response rate. Two factors were tested to investigate their effects on response rate; 1) the inclusion of either a one dollar bill or a lapel pin with the study logo, and 2) the outgoing envelope type. Surveys were mailed in one of two different envelope types; one had a return address (study name and logo), while the other had the return address (study name and logo) and the inclusion of an image of nurse with a patient in a home setting (See Appendix D for return address/study logo). The sample size for the pilot study was 400. The North Carolina Board of Nursing provided the home addresses of the selected nurses. The overall response rate for the pilot study was 65%. Response rates by different incentive type were 67.5% for the lapel pin and 62% for the one-dollar bill. Response rates by outgoing envelope type were 64% for the envelope with the image and 65.5% for the envelope with no image. The differences in response rates by incentive and envelope type are not statistically significant.

Conclusion

Formative research activities (key informant interviews, shadowing, and focus groups) allowed our study team to address the three formative research objectives and intimately learn about the home healthcare and hospice nursing population of North Carolina.

Formative research provides a valuable opportunity to learn more about a target population thus develop better data collection instruments and increase the validity of data collected. Utilizing formative research methods to develop a knowledge base on a target population could be applied to a variety of studies to increase response rates and

validity of the responses. Specifically, formative research allows epidemiologists to become intimately knowledgeable of potential target populations, thus broadening their ability to study new populations.

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APPENIX A: Home Health Key Informant Interview Guide

Thank you so much for taking the time to talk with me. Information gathered during this interview will be used to write a survey to estimate the incidence of blood exposure among home health nurses. This interview should take 90 minutes of your time. Topics to be covered include skilled nursing procedures performed in the home, training, management structure, use of Personal Protective Equipment and safety devices, etc. If at anytime I am not using the proper terminology please correct me. If there are questions you cannot answer or don't feel comfortable answering please let me know, and we will move on to the next section.

Do you have any questions before we get started?

I am going to start by asking you more about your experience as a home health nurse.

- How long have you worked as a home health nurse?
 - What do you like most about being a home health nurse?
 - What do you like the least?
- What type of home health agency do you work for? By type, I mean a hospital based agency, a freestanding home health agency (not affiliated with any other institution such as a hospital, health department, or nursing home), health department based agency, hospice, etc.
 - Do you currently work for more than one home care agency?
 - How often do home care nurses work for more than one agency?
 - Have you worked for other types of home care agencies? *(Refer to the different types of agencies above if they ask for clarification)*
If yes, what other types of agencies?
- Do you have a nursing specialty?
- Do you focus on certain types of home health patients?
- Do you work in more rural, suburban, or urban areas?

We are going to get the names of nurses to participate in our study through the Board of Nursing.

- If you move, do you tell the Board of Nursing of your new address?
- If you, how do you inform them?

To help me better understand home health nursing, I have some basic questions about the type of work you do and your work environment.

- How many hours did you work last week?
- Was this a normal work week for you in terms of hours?

- How many patients do you generally visit per week, per day?
 - Does the number of patients you visit per week fluctuate?
If so, what causes this fluctuation?
- Are there seasonal variations in the number of patients you visit?
For example, do you visit more patients in the summer as opposed to the winter?
- Could you tell me the number of patients you visited yesterday?
 - How about the number you visited last week?
 - How would you calculate the number of patients you visited last week?
 - How about yesterday?
- Could you tell me the amount of time you spend (in minutes) with each patient yesterday?
 - How about in hours?
 - How about the amount of time you spent with each patient last week?
 - How would you calculate this number?
- What types of skilled nursing procedures do you routinely perform during home visits? (*Probe if you do not understand the procedure.*)
 - If respondent mentions phlebotomy: Probe: Are glass or plastic tubes used for phlebotomy?
- Could you tell me the specific number and type of procedures you performed yesterday?
 - How about last week?
 - How would you obtain this information?
 - Would this information be difficult to obtain?
- How do you document what has been done during each visit?
 - Do you document care in the patient's home, in the office, at your home, car, etc.?
 - Do you use a laptop or PDA to chart?
 - How is this information shared with your agency?
- Could you share with me some of the different types of home environments you visit? (*Probe on cleanliness, clutter, running water, lighting, etc*)

The next set of questions focuses on Personal Protective Equipment (PPE) and safety devices.

- Can you list the different types of PPE that home care nurses use during a home visit? (*Probe: gloves, goggles, masks, etc*)
 - Of these items, which ones do you routinely use during home visits?
 - When would a home care nurse not use provided PPE?

- Who provides the PPE?
- Do you ever need to provide your own PPE?
If so, when?
- How have you been trained on how to use the PPE?
- Can you list the different safety engineered devices you use?
 - What types of procedures do you do with each type of device?
 - Do you have a preference on the type of device you use?
 - Do you ever feel at risk for blood exposure when using a safety engineered device?
If so, which device and why?
 - Who is responsible for providing you with the safety engineered devices?
 - How are you trained on how to use these devices?
 - How is the training documented?
 - How are you monitored for compliance in using safety devices and PPE?
 - Do you think other nurses in your agency use the safety device correctly?

Now I would like to talk about disposal of sharps and other items contaminated with blood.

- What is the usual procedure for disposing of a sharp?
 - What type(s) of sharps disposal container(s) are you using in the home?
 - Who is responsible for providing the sharps disposal containers?
 - Who is responsible for disposing of the sharps disposal containers?
- How do you dispose of other contaminated items such as dirty dressing changes, bandages, etc.?
 - How do you dispose of used PPE?
 - What would you do if your uniform/clothes becomes soiled with blood during a patient visit?

Now I have some general questions about blood exposure in home care. To help you answer these questions let me define what I mean by blood. For this study we define blood as blood or any body fluid visibly contaminated with blood.

- In your opinion, how common do you think blood exposure is among home health nurses?
- Of all the skilled nursing procedures that you perform, which ones do you think contribute most to blood exposures?

In a similar study we conducted with paramedics, we found that other factors contributed to blood exposure besides medical procedures. For example, the environment where care is being provided or combative patients contributed to the blood exposure.

- Can you think of any factors that contribute to blood exposure among home health nurses besides skilled nursing procedures? (*Probe on environmental, nurse and patient factors*)
- When would blood exposure be considered traumatic?
- When would blood exposure not be considered traumatic?
 - How far back in time would a home health nurse be able to remember their last blood exposure?
 - Would this depend on the type of exposure?
 - Would they be able to recall the events surrounding the exposure such as the procedure they were performing, environmental surroundings, etc.?
- How would a home health nurse feel about sharing information on the circumstances surrounding his/her exposure to a patient's blood with researchers?
 - How could we put them at ease about sharing this information?

For our study we are focusing on five ways that nurses can be exposed to patient blood. I would like to hear your thoughts on each of the five ways.

The first way is needle or lancet sticks from a needle or lancet that had been used on a patient.

- Do you consider a needle or lancet stick a blood exposure? (If no, ask why not?)
 - What types of skilled nursing procedures could lead to a needle or lancet stick?
 - Do you think using PPE could reduce the likelihood of having a needlestick? If so, which type of PPE could be used?
 - What do you think about using safety devices to prevent needlesticks?
 - Are there certain devices that you think work better than others to prevent needlesticks?
 - What other factors do you think contribute to needlestick injuries? (*Probe on patient factors, nurse factors, environmental factors if necessary*)

The second way is a cut from a scalpel, razor, or scissors that have blood or body fluid visibly contaminated with blood on them.

- Are there any other sharp devices that I may have missed that can cut a home health nurse?
 - Do you consider a cut from a scalpel, razor, or scissors that have blood or body fluid visibly contaminated with blood on them a blood exposure? (*If no, ask why not?*)
 - What types of skilled nursing procedures could lead to a cut from a sharp?

- Do you think using PPE could reduce the likelihood of having a cut from a sharp?
If so, which type of PPE could be used?
- What do you think about using safety devices to prevent a cut from a sharp?
Are there certain devices that you think work better than others to prevent cuts?
- What other factors do you think contribute to cuts from sharps? (*Probe on patient factors, nurse factors, environmental factors if necessary*)

The third type of exposure is getting blood or body fluid visibly contaminated with blood in your eyes, nose, or mouth.

- Do you consider getting blood or body fluid visibly contaminated with blood with your eyes, nose, or mouth a blood exposure? (*If no, ask why not?*)
 - What types of skilled nursing procedures could lead to blood in your eyes, nose, or mouth?
 - Do you think using PPE could reduce the likelihood of getting blood in your eyes, nose, or mouth?
If so, which type of PPE could be used?
 - What do you think about using safety devices to prevent blood from getting in your eyes, nose, or mouth?
Are there certain devices that you think work better than others to prevent blood from getting in your eyes, nose, or mouth?
 - What other factors do you think contribute to getting blood in your eyes, nose, or mouth? (*Probe on patient factors, nurse factors, environmental factors if necessary*)

The fourth type of exposure is getting blood or body fluid visible contaminated with blood on non-intact skin.

- How do you define non-intact skin? Is there another phrase or term that is used to describe non-intact skin?
 - Do you consider getting blood or body fluid visibly contaminated with blood on non-intact skin a blood exposure? (*If no, ask why not?*)
 - What types of skilled nursing procedures could lead to blood on non-intact skin?
 - Do you think using PPE could reduce the likelihood of getting blood on non-intact skin?
If so, which type of PPE could be used?
 - What do you think about using safety devices to prevent blood from getting on non-intact skin?
Are there certain devices that you think work better than others to prevent blood from getting on non-intact skin?

- What other factors do you think contribute to getting blood on non-intact skin? (*Probe on patient factors, nurse factors, environmental factors if necessary*)

The last type of exposure is getting bitten by a patient.

- Do you consider a patient bite a blood exposure? (*If no, ask why not?*)
 - What types of skilled nursing procedures could lead to a patient bite?
 - Are there certain situations in which a patient bite is likely to happen?
 - Do you think using PPE could reduce the likelihood of getting bitten by a patient?
Is so, what type of PPE could be used?
 - What other factors do you think contribute to patient bites? (*Probe on patient factors, nurse factors, environmental factors if necessary*)
- Can you think of any other types of blood exposure that home health nurses experience that I may have missed?

Now let's talk about management and blood exposure reporting procedures.

- What is the management structure at your agency?
 - Who do you report to in your agency?
 - Are you given enough training on how to use PPE and safety devices?
 - Do you think other home health nurses are given enough training on how to use PPE and safety devices?
 - What are the consequences for not following safety procedures or correctly using safety devices?
- Have you received your Hepatitis B vaccination series?
 - In no, ask why they haven't been vaccinated for Hep B.
- How are blood exposures reported?
 - Who is the exposure reported to in your agency?
 - How complete is this reporting?
 - When wouldn't an exposure be reported to the appropriate authority?
 - Would a home health nurse be reprimanded by their employer if they received a blood exposure?
 - What type of reprimand would this be?
 - Is there a stigma attached to being exposed?

That is all the questions I have for now. Thank you so much for taking the time to share your knowledge on home health nursing.

APPENDIX B: HOME HEALTH OBSERVATION FORM

Home Health Observation Form

| | |
|-----------------|----------------------|
| Today's Date: | Observer's Initials: |
| Arrival Time: | Nurse's Initials: |
| Departure Time: | Nurse Employer Type: |

Home Environment

| | |
|--|---|
| Setting of home: | <input type="checkbox"/> Rural <input type="checkbox"/> Urban <input type="checkbox"/> Suburban |
| Type of home: | |
| Were other people present during the visit? | <input type="checkbox"/> No <input type="checkbox"/> Yes How many: Relationship to patient: |
| Was the area in the home that treatment was delivered clean? | <input type="checkbox"/> No <input type="checkbox"/> Yes |
| Overall description of the home setting: (things to look for include lighting, cramped spaced, pets, infestations of rodents/fleas/roaches/etc.) | |
| Potential risk factors observed in regard to the home environment: | |

Type of Visit/setting

| | |
|---|--|
| Is the patient: | <input type="checkbox"/> Pediatric <input type="checkbox"/> Adult <input type="checkbox"/> Geriatric |
| Location of the patient in the home during the visit: | |

| | |
|--|--|
| | |
| Patient's health status: | <input type="checkbox"/> Chronically Ill <input type="checkbox"/> Acute Illness <input type="checkbox"/> Hospice <input type="checkbox"/> Other: |
| Patient's demeanor during visit: | <input type="checkbox"/> The patient was alert and cooperative <input type="checkbox"/> The patient was unconscious and unaware that the procedure was being performed <input type="checkbox"/> The patient was anxious and agitated but did not require restraint <input type="checkbox"/> The patient was anxious and agitated and had to be restrained <input type="checkbox"/> The patient was anxious and agitated but no effort to restrain was made <input type="checkbox"/> Not observed/Not applicable |
| Potential risk factors observed in regards to patient characteristics: | |

Medical Procedures

| | |
|--|--|
| Medical procedures performed during visit: | |
| Was a needle used? | <input type="checkbox"/> No <input type="checkbox"/> Yes Type of Needle: <input type="checkbox"/> Butterfly (non-safety) <input type="checkbox"/> Butterfly (safety) <input type="checkbox"/> Straight Needle (non-safety) <input type="checkbox"/> Straight Needle (safety) <input type="checkbox"/> Phlebotomy system(non-safety) |

| | |
|--|---|
| | <input type="checkbox"/> Phlebotomy system(safety) <input type="checkbox"/> Other: |
| Was a sharp used? | <input type="checkbox"/> No <input type="checkbox"/> Yes What kind of sharp? Did it have a safety feature? |
| Other medical devices used during visit: | |
| Was there an approved sharps disposal container in the home? | <input type="checkbox"/> No <input type="checkbox"/> Yes |
| Location of approved sharps disposal container: | |
| Was the container overfilled? | <input type="checkbox"/> No <input type="checkbox"/> Yes |
| Where was biohazard waste disposed of? | |

| |
|--|
| Overall description of medical procedures/use of medical devices/disposal of sharps/biohazard waste: |
| Potential risk factors observed in regards to medical procedures: |

Nurse Information

| | |
|---|--|
| Did the nurse use any PPE during the visit? | <input type="checkbox"/> No <input type="checkbox"/> Yes If yes, what type of PPE: <input type="checkbox"/> Gloves <input type="checkbox"/> Mask <input type="checkbox"/> Gown <input type="checkbox"/> Other: |
| Did the nurse wash their hands during the visit? | <input type="checkbox"/> No <input type="checkbox"/> Yes If yes, when: |
| Did the nurse get blood on them during the visit? | <input type="checkbox"/> No <input type="checkbox"/> Yes If 'Yes', briefly describe: |
| Other activities performed by the nurse (aside from medical procedures) | |
| Was the nurse.... | <input type="checkbox"/> Rushed <input type="checkbox"/> Distracted <input type="checkbox"/> Uncomfortable <input type="checkbox"/> Other: |

Overall description of nurse information:

Potential risk factors observed in regards to nurse behavior/information:

Summary of Visit

Did anything unexpected happen during the visit?

☐ No

☐ Yes

If yes, what:

Summary of visit procedures:

Additional Notes:

APPENDIX C: HOME HEALTH FOCUS GROUP MODERATOR'S GUIDE

INTRODUCTION (*15 minutes with intros*)

- Hello, my name is _____ I work for Constella Health Sciences. Thank you for taking the time to speak with us today. This is (assistant moderator) who also works for Constella Health Sciences. She will be taking notes and assisting with the discussion.
- Constella Health Sciences is working with the Centers for Disease Control and Prevention, or CDC, on a project to estimate the incidence rate of occupational blood exposure among home health and hospice nurses. The purpose of our discussion is to hear your thoughts and opinions on the best way to gather information from home health and hospice nurses in NC regarding occupational blood exposure. We are also interested in hearing your opinions on reasons why home health or hospice nurses might not take part in the survey and how to encourage nurses to respond to the questionnaire.
- You have been selected to participate in this focus group because you are a home health or hospice nurse.
- This focus group should take about 90 minutes of your time. Your participation in this discussion is voluntary. You may leave at any time and you do not have to give a reason why. Although we would appreciate it if you would stay for the entire session.
- The session will be audio taped. We need to make sure we capture your words, not just a summary of them. The taped information will be used to refresh our memories as to what was said during the discussion. Your last name and other personal information will not be used in any report. All information will be kept in strict confidence. Information you share will be combined with information

from other people in other groups. The recordings will be destroyed once we have summarized all focus groups.

- We ask that you respect each others' privacy. Please do not share any information you hear during the focus group.
- Before we get into the details of this activity, let me explain how the focus group will work. As the moderator of this discussion, I ask that you:
 - Respect each other during this process.
 - Talk one at a time and do not interrupt.
 - Feel free to comment on each other's remarks.
 - Avoid side conversations
- I want you to know that there are no right or wrong answers; we are simply interested in your opinions. Not everyone has to answer every single question but I would like to hear from each of you at least once or twice during the session.
- My role here today is simply to guide the discussion and make sure we cover all of the topics we need to cover today. I am not a nurse so your perspective is very valuable to us.
- Before we get started, let's go around the table and have each of you introduce yourself by telling us your first name, how long you have worked in home health or hospice, and one thing about yourself. (ALLOW ALL FOCUS GROUP PARTICIPANTS TO INTRODUCE THEMSELVES)

B. DISCUSSION

Before we start our discussion, let me tell you a little bit more about the study we plan to conduct. We have been hired to gather information on how often occupational blood exposures are happening to home health and hospice nurses in NC. The study

team is going to write a survey that will ask home health and hospice nurses about a variety of topics including their current employment setting, use of safety devices and PPE, and whether they have experienced an occupational blood exposure. For example, we might ask, "In the last 12 months, have you had a needlestick?" Home Health and Hospice nurses will be asked to fill out one survey.

Does anyone have questions before we get started?

B.1 MOTIVATION (5 minutes)

Before we get into the details of the study, what are some of the reasons a study like this might be important? Why might home care and hospice nurses be motivated to participate in this study? (RECORD RESPONSES ON FLIPCHART)

- Might lead to better safety precautions
- Might prevent future injuries
- Want to help "science"
- Sheds light on home care and hospice nursing profession
- No one currently knows how "at-risk" HHNs are
- Brings recognition to NC nurses

Ok now we know why we're collecting this data, let's get into some of the details. Next, we're going to talk about all the different ways or modes that we could administer this questionnaire.

B.2 MODES (40 minutes)

You have probably responded to many different types of questionnaires over the past few years. Someone might have asked you to fill out a questionnaire to tell them if you were happy with your new car purchase, whether you liked the burger you just ate or even to answer some questions aimed at determining whether you are eligible for a new credit card. What are the different ways or modes in which someone has asked you to fill out a survey? (LET THE GROUP BRAINSTORM DIFFERENT MODES)

- Has anyone ever been asked to complete a questionnaire by ... (fill in here what wasn't mentioned: web-based, mail, telephone, face to face interviews)?

Which of these do you think would be a good way to administer a questionnaire to home health and hospice nurses? (PLACE A STAR NEXT TO THE MODES INDICATED)

Let's talk about the pros and cons of each of these ways (START A NEW SHEET FOR EACH MODE)

Mail Survey/Pen and Paper survey

- When I mention this type of survey what thoughts come to mind?
(RECORD RESPONSES)
 - PROBE: Why did you say ____?, Tell me about that., Does anyone disagree?
- Suppose we decided to go with this mode, how could we make the envelope more attractive to you so that you would open it to see what's inside? Probe: Color, Text that says "open immediately" or "important information enclosed"
- Suppose we had a sponsor for the study and the letter arrive from this organization. What organization's return address would make you more likely to respond to the survey?
- How could we create the layout of the survey so that it is more appealing?
 - E.g., would you rather see all of the questions condensed to 4 pages so it doesn't seem so long or the same number of questions spread out so they are easier to read?
- Would you fill out and return a survey if it were mailed to your home address (as opposed to your work address)?
 - If not, why wouldn't you answer the survey?

Telephone Survey

- When I mention this type of survey what thoughts come to mind?
(RECORD RESPONSES)
 - PROBE: Why did you say ____?, Tell me about that., Does anyone disagree?
- Suppose we decided to administer this survey as a telephone questionnaire, what could we do to make you more interested in completing the survey?
 - POSSIBLE PROBES: Pre-survey letter, Caller-ID says "Home Health Study", Affiliate with organization, State up front how long survey will take to complete, ability to schedule interview for a different time, have a nurse administer survey.
- When is the best time of day or week to reach you?
- Suppose we provided you with an 800 number to call us at your convenience instead of us calling you. Would this work? Why or Why not?

Web Based Survey

- For a Web-based survey, we would send you a letter asking you to visit a website to fill out the survey. When I mention this type of survey what thoughts come to mind? (RECORD RESPONSES)
 - PROBE: Why did you say ____?, Tell me about that., Does anyone disagree?

- Do you have access a computer with web access?
- Would you feel comfortable using the web?
- Would the computer have dial-up, cable, or DSL connection?
- Do you think other home health and hospice nurses would have access to the web and feel comfortable answering a survey on the web?

Face to Face Interviews

- What comes to mind if you think about having the interview conducted in person? (RECORD RESPONSES)
 - PROBE: Why did you say _____?, Tell me about that., Does anyone disagree?
- Where should the interview take place?
- What do you think would be the best way to set up the interview?
- When would be the best time for the interview to take place (at night, on the weekends)?

Seeing that we will only have the name and home addresses of the home health and hospice nurse, the first contact we make with them will probably be through a letter or postcard. I would like to discuss this letter or postcard.

- What are your thoughts on being contacted by a letter or postcard to be informed of the study?
- What type of information would you need to decide whether or not to participate in the study?
- Would you be likely to participate if the letter included a story about a home health or hospice nurse that has had a blood exposure? What if the letter came from a nurse that had been exposed?
- Would you be more likely to read a letter or a postcard?

B.3 INCENTIVES (10 minutes)

Now I would like to discuss incentives that could be used to help encourage home health and hospice nurses to participate in our study.

- What types of incentives do you think would encourage a nurse to participate in the study? (WRITE ON FLIP CHART)
 - PROBE: What types of incentives have you seen or received for other types of surveys you've completed?

In a similar study, we conducted with paramedics we found that including a token incentive increased participation compared to a lottery incentive. The token incentive was a sticker with the study logo on it. All participants who completed the survey were entered into a lottery to win a palm pilot programmed with paramedic software.

- Can you think of any token incentives that home health and hospice nurses would find appealing? Token incentives are items that cost less than a few dollars.
- Can you think of any lottery incentives that home health and hospice nurses would find appealing?

B.4 BARRIERS (10 minutes)

This next section is on barriers to participation. We've discussed a number of barriers as they relate to the specific modes but not to the specific survey items themselves. If you recall, we'll be asking about use of PPE, past blood exposures, and perceptions of an agency's commitment to safety.

- Can you think of any reason's why a home health or hospice nurse would not participate in the study?
 - PROBES: Not important, too long, won't change anything, nurse hasn't personally experienced a needlestick, etc.
- How can we address these reasons?
- Do you think home health and hospice nurses would feel comfortable answering these questions honestly?
- Do you think home health and hospice nurses would be willing to share occupational exposures with researchers?

B.5 WRAP-UP (5 minutes)

- Summary
- Any closing remarks? Have we missed anything?
- That is all the questions I have. You have provided us with a great deal of information and we appreciate your honesty. Once again, thank you for your time today.

APPENDIX D: STUDY LOGO/RETURN ADDRESS



