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ABSTRACT

Twenty health and literacy professionals (predominantly National Work Group on Cancer and Literacy members) were interviewed by telephone regarding communicating with low-literate audiences. Most respondents reported using census data, state statistic', and the Wide Range Achievement Test to help them target and identify low-literate individuals. After citing a number of reasons why it is difficult to recruit low-literate individuals for research, most respondents stated that recruiting was more successful if the research project was linked to individuals' personal goals and if research- and medical/social service-related visits were paired. When asked to evaluate low literacy health communication strategies and materials, most respondents favored formative research and health education strategies that were interactive and had limited objectives. Most respondents favored including health messages in literacy curricula and reported doing so. There was general agreement that health professions need to be aware that many patients are low literate and that they should keep their verbal and written communications simple and clear. The major challenge mentioned in relation to collaborating on health and literacy projects was building a consensus between literacy organizations and health organizations with different agendas and territorial issues. (Appended are the prenotification letter and questionnaire.) (MN)

NATIONAL WORK GROUP ON CANCER AND LITERACY

INTERVIEW REPORT

Low Literacy Cancer Education Program
Office of Cancer Communications
National Cancer Institute

November 1993

CONTENTS

I. EXECUTIVE SUMMARY

Background and Purpose

The National Cancer Institute's (NCI) Low Literacy Cancer Education Program is charged with communicating cancer prevention, early detection, and treatment information to individuals with limited literacy skills. One activity to support these efforts began in May 1992 when NCI and the AMC Cancer Research Center convened the first meeting of the National Work Group (NWG) on Cancer and Literacy.

The purpose of the meeting was to identify effective strategies for communicating cancer information to low-literate audiences and to diffuse that information to the national cancer control community. The twenty-two NWG meeting participants included representatives from the fields of cancer communications, cancer control research, medicine, literacy, international health communications, health education, and the media.

The NCI conducted individual interviews with NWG members to capture their expertise as researchers, physicians, educators, and communicators who work with limited literacy audiences. The goal of this qualitative research project was to contribute to the existing knowledge base about communicating with limited literacy audiences. The following fundamental topic areas were addressed in the interviews:

- Identifying low-literate individuals (methods used).
- Recruiting low-literate individuals for qualitative and quantitative research (methods used and lessons learned).
- Evaluating low literacy health communication strategies and materials.
- Using health messages in literacy curriculums.
- Training health professionals on low literacy issues.
- Collaborating on health and literacy efforts.

Research Methodology

Telephone interviews were conducted with twenty health and literacy professionals, predominantly NWG members, to obtain information about the fundamental topics related to communicating with low-literate audiences. Possible participants were informed about the project via letter and interviews were scheduled from April 19, 1993 to May 7, 1993. Selection of respondents was based on their experience with the

priority topics listed above. Some respondents were interviewed on more than one topic. The interviews lasted between 45 minutes and 1 hour and were tape recorded. Please note that this is a qualitative research project with a small sample size and is not intended to represent the entire area of low literacy health communication efforts.

Key Findings

- Identifying Low-Literate Individuals

  --Respondents' definitions of low literacy ranged from a reading level of "less than fourth grade" to an "eighth-grade level or less."

  --Most respondents reported that the Wide Range Achievement Test (WRAT) was used more than any other instrument to verify that an individual has low literacy skills. Other methods included asking general questions about reading skills and examining demographic information such as education level, income, or employment status.

  --Most respondents reported using census data and state statistics to help them target low-literate individuals. Other sources included Adult Basic Education maps that plot areas where people have not finished high school and a national database of the medically underserved.

- Recruiting Low-Literate Individuals for Research

  --Respondents said that recruiting low-literate individuals for research was more successful if the research project was linked to the individual's personal goals. They also said that it was successful if participating in the project was made easy for an individual by pairing their visits with other medical or social service scheduled visits, for example, cholesterol screening or picking up a welfare check.

  --Most of the respondents said it was difficult to recruit low-literate individuals for a variety of reasons, including time, cost, mobility of the population, the social stigma of illiteracy, and lack of accessibility to the population. They said the lack of access was due to several factors, including no telephone in the low-literate individual's home, their mistrust of recruiters, and because these individuals often were located in hard-to-reach rural areas.

- Evaluating Low Literacy Health Communication Strategies and Materials

  --Most of the respondents reported using formative research, including focus groups, one-on-one interviews, and comprehension and readability tests. Very little outcome research has been conducted by the respondents.

  --Respondents reported that the most successful health education strategies targeting low-literate individuals were those developed from a solid knowledge of the target audience, included the target audience in the development process, were interactive, and had limited objectives.

  --Respondents felt that the best materials were those that were clear and simple, used realistic visuals, and were well designed.

- Using Health Messages in Literacy Curriculums

  --Respondents reported that breast cancer, cervical cancer, AIDS, heart disease, first aid, diabetes, domestic violence, nutrition, and cholesterol have been included in literacy curriculums. Respondents said that the inclusion of health topics in literacy curriculums was primarily based on the students' interest in such topics.

  --The respondents had a positive reaction to including health messages in literacy curriculums because they felt the information had relevance for students and empowered students.

  --Respondents reported that many of the women were very interested in learning about their bodies and their children's health. They wanted to know how to be better parents and learn how nutrition, smoking, and violence affect the health of their families.

- Training Health Professionals on Low Literacy Issues

  --Respondents felt that health professionals need to be aware that many of their patients are low-literate and that health professionals should be able to empathize with their patients.

  --Respondents also suggested that health professionals need to recognize that their verbal and written communications should be simple and clear.

- Collaborating on Health and Literacy Projects

  --In describing challenges faced when developing health and literacy collaborations, respondents reported that individuals in higher level positions sometimes lacked an understanding of the needs of low-literate individuals and the types of materials that effectively reach this population. They said that conflict often arises between direct service providers and administrators/executives.

  --One major challenge expressed by respondents was building a consensus between literacy organizations and health organizations that had different agendas and territorial issues.

II. DETAILED FINDINGS

A. Identifying Low-Literate Individuals (Methods Used)

Ten NWG members with experience testing individuals to measure literacy levels were interviewed. They included cancer control researchers and educators, literacy professionals, health educators, health and literacy experts, oncologists, physician researchers, and Cancer Information Service Project Directors.

Operational Definition of Low Literacy

Respondents were asked how they operationally defined low literacy. Their definitions ranged from a reading level of "less than fourth grade" to an "eighth- grade level or less" to people who had difficulty reading materials necessary for daily living. There was clearly a lack of consensus regarding a single definition of low literacy. For example:

- ". . . lack or deficiency of reading skills that is so bad that people can't read the things that confront them in their daily life that they need to read . . . I often think of people who read at less than a fourth-grade level as so functionally illiterate that they are not going to be able to meet that definition."

- "I define it as the ability to read at about the eighth-grade level. But the real test is the ability to process information relating to the reasonably complex world we live in with the ability to process health information, behavior modification messages, taking pills, learning about appointments, things like that."

Respondents also were asked if they had looked at different categories of low-literate individuals. Most of the respondents reported working exclusively with native English speakers. A few, however, said they worked with individuals with reading disabilities and had compared functional versus marginal literacy.

Procedures for Low Literacy Verification

Respondents were asked what tests they use to verify that an individual has limited literacy skills. Most respondents reported using the Wide Range Achievement Test (WRAT) more than any other instrument to verify that an individual has limited literacy skills. Several respondents used the last grade of school completed, the Test of Adult Basic Education (TABE), the Rapid Estimate of Adult Literacy in Medicine (REALM), or a comprehension/listening test. Other tests mentioned included the Cloze, Mott, Test of Adult Literacy Skills (TALS), and the Adult Basic Learning Examination (ABLE). The respondents reported that they administered the various tests either at the beginning or the end of the screening or in-depth interview.

When asked if they had compared the different literacy assessment tools, most respondents answered "no." The few respondents who had compared the tools compared the REALM to the: WRAT; Peabody Individual Achievement Test (PIAT); and SORT. Other respondents reported that the REALM was correlated with the PIAT (.97), the SORT (.96), and the WRAT (.88). One respondent compared two bilingual reading level tests, the Instrumento Para Diagnosticar Lecturas and the Estuval, which yielded a .90+ correlation. In explaining her experience using the different tests, one respondent said:

- "We found that patients don't like the WRAT; the words get too hard too fast. The SORT [has] 200 words, and they get tired of reading them, and the older patients find the words too small. The patients like the PIAT all right, but it was unwieldy and expensive and required the administrator to have a little more training than the other straight-up reading recognition. The REALM--we found that they liked; it was friendly, nonthreatening, and the health care providers and the patients immediately saw it was applicable to a medical setting because all the words are health related."

In addition to literacy assessment tests, respondents reported other ways to verify or assess that an individual has limited literacy skills. These methods included asking general questions about reading skills or examining demographic information such as education level, income, or employment status. Another method reported was to conduct a learner verification test; an individual reads written materials and then answers questions for reading comprehension. One respondent explained another method of verification:

- "We wait for verbal cues, like 'Can I take this form home and show it to my spouse?' or 'I left my glasses home,' or 'I'm not feeling well today. I can't do this.' We look if patients don't fill out medical histories. If we hand them a form and half of it is filled out and half of it isn't, there's a tip-off right there."

Many respondents reported using census data or state statistics to help them target low-literate individuals. Other sources included Adult Basic Education maps that plot areas where people have not finished school and a national database of the medically underserved. This database of 36,000 noninstitutionalized civilians includes information on the last year of school completed, income, health problems, and hospitalizations. A few of the respondents felt that the sources mentioned tended to give a global view of the literacy situation and very little detail regarding local communities.

B. Recruiting Low-Literate Individuals for Research (Methods Used and Lessons Learned)

The 10 NWG members who were interviewed for the previous section also were interviewed for this section. Again, they included cancer control researchers and educators, literacy professionals, health educators, health and literacy experts, oncologists, physician researchers, and Cancer Information Service Project Directors.

Successful Recruitment Strategies

Respondents were asked how they recruited low-literate individuals for focus groups, one-on-one interviews, and/or quantitative research projects. They said that, for the larger scale quantitative projects, individuals were randomly selected to receive a prenotification letter and then telephoned by the researcher for an interview. In one case, a census track was identified and a telephone study conducted to find individuals for a focus group. For smaller scale qualitative projects, individuals were approached on site and personally recruited.

Once individuals were recruited, many of the respondents reported conducting screening tests to verify reading levels. They said the WRAT was the standard test used in screening procedures. The respondents reported recruiting low-literate individuals for research from medical, educational, and social service settings, including:

- Medical Settings:

  --Hospitals/Veteran Administration hospitals.
  --Clinics.
  --Medicaid lists.

- Educational Settings:

  --Adult Basic Education programs.
  --Other literacy programs.

- Social Service Settings:

  --Head Start programs.
  --Child development centers.
  --Senior and community centers.
  --Social service sites (i.e., Welfare to Work sites).
  --County health departments.
  --Churches.
  --Public health departments.
  --Public housing projects.

Respondents said that recruiting low-literate individuals for research was more successful if the research project was linked to the individual's personal goals. They also said that it was successful if participating in the project was made easy for an individual by pairing their visits with other medical or social service scheduled visits, for example, going for a cholesterol screening or picking up a welfare check. One respondent shared her experience in recruiting participants from public housing projects. She said, "The managers of public housing [have] not been approached the way other intermediaries have been . . . so they're not burned out, they're extremely helpful."

Incentives

Some respondents said they gave low-literate individuals incentives for participating in their research study. Incentives included monetary rewards, free transportation, refreshments, or special medical attention such as spending longer periods of time with health professionals. The respondents reported that many of the low-literate individuals were willing to participate in the research studies that offered no specific incentive in order to "help out" and improve health education materials.

- "We were just in a waiting room and the only incentive we used to get them to participate was that we said we were going to be rewriting patient education information, and asked them if they would be willing to help . . . and most of the time we got positive responses to that."

- "We did give meal tickets to individuals who came back to complete some of the questionnaire. It worked fairly well. My gut feeling is if we are asking patients to come back, we probably need to include something, whether it's a bus ticket, meal ticket, some type of incentive."

- "A good incentive if you know you are going to be working with a population would be to get them involved right up front before you develop anything at all . . . ask them how they would recruit their own peers."

Difficulties in Recruiting

Most of the respondents said it was difficult to recruit low-literate individuals for a variety of reasons, including time, cost, mobility of the population, the social stigma of illiteracy, and accessibility to the population. For example:

- "It's very labor intensive. We may go out to a location and interview maybe 12 individuals where we need a total pool of 200 to make it statistically significant. It takes a lot of time because it's a very rural state and 12 people in one place at one time is [considered] a large number."

- "[Low-literate individuals are] difficult to keep track of. The staff costs for working with the lowest [reading] level population are astronomical because you can't depend on print; they need a lot of attention, they move a lot and don't leave forwarding addresses, they don't have phones."

- "One of the difficulties is that there is a great social stigma to being illiterate or functionally illiterate, or being a poor reader or whatever you want to call it, and so people who lack literacy skills wish to hide that fact."

Topics To Avoid

Some respondents reported that some low-literate individuals found it difficult to discuss questions regarding income and citizenship. One respondent explained, "[If I asked] a citizenship question . . . all of a sudden you could see antennas going up . . . are we really with the immigration service?"

Others said that participants were reluctant to answer questions about their income for fear that they might lose their food stamps and/or other entitlements. Some respondents recommended avoiding the word "literacy" because people often associate it with "illiteracy."

C. Evaluating Low Literacy Health Communication Strategies and Materials

Ten NWG members were interviewed for this section. They included cancer control researchers and educators, literacy professionals, health educators, health and literacy experts, oncologists, physician researchers, and Cancer Information Service Project Directors, international health communicators, and visual communication specialists.

Type of Research

Respondents were asked if they had evaluated their health communications efforts targeted to people of limited literacy. Most of the respondents reported conducting formative research through focus groups, one-on-one interviews, and comprehension and readability tests.

Very little outcome research has been conducted by the respondents. Several respondents expressed interest in conducting outcome research but were hampered by lack of time, budget, or evaluation designs. Others were in the process of conducting outcome research.

One respondent described outcome research she had conducted with pregnant smokers. In this study, some pregnant smokers were exposed to a booklet and/or a videotape, and others were exposed to a nursing intervention. Women were monitored several times during their pregnancy for any smoking behavior change. After delivery, they were asked if they cut down on smoking or stopped smoking.

Effective Educational Strategies and Materials

Respondents were asked if they found any particular strategy, materials, and/or combination of strategies and materials that worked best when educating low-literate individuals about health. They reported the strategies that worked best were those that were developed from a solid knowledge of the target audience, included the target audience in the development process, were interactive, and had limited objectives.

- "By getting to know the target group -- their characteristics, their psychographics, demographics, reading skills -- that's a critical piece to developing educational pieces that will be useful . . . For instance, in our videotape, we included patients that would normally go to that clinic; we had pictures from the clinic, health care professionals and nurses that you would normally see at that clinic. It really was a very realistic visual for the target group."

An international health communications respondent described how a community had decided it needed better health communications on family planning. Working with the community, a project using beads was developed for women to track their menstrual

cycle. Print materials also were distributed with very simple illustrations, diagrams, and text in the indigenous languages. The women's understanding of their fertility increased. As one respondent said, these materials were effective because "they were for and of the communities themselves."

Respondents said that the materials that worked best were those that were clear and simple, used realistic visuals, and were well designed. One respondent said that if print materials were written at an appropriate level, they were just as good for knowledge enhancement as video materials. Another respondent reported that, in Thailand, mothers were inspired to have healthier, well-fed babies when given well-designed materials using realistic visuals to chart their babies' growth. The following describes other respondents' views on materials:

- "Audiotape has the opportunity to communicate in voice and give emotional feeling as well, as it's much more likely to be conversational in style and enable the person to get the message very quickly without having to decode print."

- "It seems that illustrations work or enhance their ability in a couple of ways: it increases their interest in what's being read and they have two different sources to figure something out."

Measuring Change in Knowledge, Attitudes, Behavioral Intent, and Actual Behaviors

When asked how they measured change in knowledge, attitudes, behavioral intent, and actual behaviors, respondents listed focus groups, one-on-one interviews, telephone interviews, and quantitative surveys.

Most of the respondents could not verify that changes were entirely due to their strategies and materials. They could measure the change in awareness and knowledge, but not change in behavior. Respondents remarked that there must be long-term studies to determine behavior change.

Recommendations for Evaluation Strategies

Several respondents expressed a need for effective evaluation designs to determine causal relationships between their materials and behavior change. Respondents suggested the following evaluation strategies:

- Involve the target audience in all phases of evaluation.

- Consult professionals regarding marketing, research, and literacy.

- Conduct one-on-one interviews instead of focus groups, because people are afraid of expressing their opinion in front of others.

- Conduct a baseline evaluation at the beginning of a project and follow up with comparative studies at midpoint and the end.

D. Using Health Messages in Literacy Curriculums

Two literacy teachers/tutors and a literacy specialist were interviewed to determine how health messages were used in literacy curriculums. It was difficult to locate individuals who had actually taught cancer or health information in literacy classes.

Health Topics in Literacy Curriculums

Respondents were asked which health topics they have seen included in literacy curriculums. They reported the following: breast cancer; cervical cancer; AIDS; heart disease; first aid; diabetes; domestic violence; nutrition; and cholesterol.

Respondents explained that the inclusion of health topics in literacy curriculums was primarily based on the students' interest in such topics. One respondent said that if a student expressed an interest in a particular topic, the student's tutor would usually get outside materials to include in his or her curriculum.

Another respondent said that her literacy organization had extensive experience working in other countries on the connection between health and literacy; therefore, it was a natural fit to include health topics in literacy curriculums on the domestic front and also to apply some of the techniques that worked in other places.

Responses to Health Messages in Literacy Curriculums

The respondents were asked how they felt and how the students felt about using health materials in literacy curriculums. As teachers, they reported a positive reaction to including health messages in literacy curriculums because the information had relevance to the students' lives and empowered them. One respondent commented that, as teachers, "we take on sort of an empowerment model of health education."

The respondents observed that the students were very enthusiastic and comfortable using health materials in their learning. In addition, they observed that multicultural and gender-mixed groups of students also seemed to be comfortable discussing health-sensitive topics. They also reported that many of the women were very interested in learning about their bodies and their children's health. They wanted to know how to be better parents and learn how nutrition, smoking, and violence affect the health of their families.

The respondents thought that students were interested in additional health information on topics including smoking, prenatal care, women's health, stress reduction, sexually transmitted diseases, sickle cell anemia, environment, diabetes, cancer, and vitamins.

E. Training Health Professionals on Low Literacy Issues

Three NWG members were interviewed who had extensive experience training health professionals on low literacy issues. They represented health education, international health communications, and health and literacy fields.

Health Professionals' Greatest Training Needs

Respondents were asked about health professionals' greatest needs for training on low literacy issues. They reported that health professionals need to be made aware that many of their patients are low-literate, and health professionals also need to be able to empathize with their patients. In addition, they said that health professionals need to realize that their verbal and written communications should be simple and clear. One respondent stated that many health professionals "don't need to be taught much, just limit their sentences to 10 words each and take out the words that have three to four syllables." Respondents felt that many health professionals were unaware of the problem and, therefore, resistant to solving it.

Types of Training

The trainers interviewed were very involved in trying to meet the needs of health professionals. For example, to meet the staff needs within a large rural health center, one respondent trained a core team of health professionals and they, in turn, trained every employee in their health network. Nearly 400 people, including physicians, physicians' assistants, nurses, and secretaries were trained in the organization to meet the needs of low-literate individuals.

Respondents reported that effective strategies for training health professionals included raising their awareness of the low literacy problem, sharing personal experiences of working with low-literate individuals, and providing tools and developing skills for communicating with low-literate individuals.

- "I give [trainees] something to read that is written backwards . . . I'm trying to communicate what it feels like to have to decipher any kind of text word by word and what it feels like to be frustrated to lose the meaning of the sentence even though you might be able to decipher the individual words."

- "One of the things that's most important is to recognize that it is possible to bring about change in a relatively short period of time with the current skills and equipment that you've got on hand."

Determining the Success of Training

When asked how they assess how well training was implemented, respondents gave various examples. One respondent explained that at the close of a training session, trainees identified one or two things they would do differently in their work. The participants were contacted in the next 90 days to see if they had implemented those changes. They discovered that roughly one-third had made, or were currently making, the changes.

Another respondent felt that followup from participants indicated success in implementation. He said:

- "To me the most successful measure of how successful a training was, [are] the followup activities that occur . . . . If I do a training in Costa Rica for health professionals on HIV prevention and subsequent to that training receive calls or letters for more information, or learn that individuals are really applying the skills, I think that is the most effective evaluation technique for those trainings."

F. Collaborating on Health and Literacy Projects

Ten NWG members with experience collaborating on health and literacy projects were interviewed. Those interviewed included media specialists, literacy professionals, Cancer Information Service Project Directors, health and literacy experts, health educators, cancer control researchers, and physician researchers.

Developing Health and Literacy Collaborations

When asked to describe challenges they faced in developing health and literacy collaborations, the respondents discussed bureaucratic roadblocks to developing and disseminating low literacy materials. They said that the individuals in higher level positions sometimes lacked an understanding of the needs of low-literate individuals and the types of materials that can reach them. They added that conflict often arises because direct service providers are exposed to these needs whereas administrators or executives are not often directly exposed. The respondents felt that many problems could be solved by educating the managers of such programs.

One major challenge expressed by the respondents was building a consensus between literacy organizations and health organizations that had clearly delineated agendas and territorial issues. A respondent explained:

- "Health educators and literacy teachers have pretty different agendas. The health educator's point is to get a message out. The literacy teacher's work is to help learners use their new skills in reading, writing, thinking, and speaking; to think critically about whatever issues are coming up; and not be the one to give answers. They are not comfortable telling people what to do."

To enhance collaborations, another respondent suggested adding a research component to Cancer Information Service (CIS) contracts that would focus on research with low-literate audiences.

Current Collaborations

Respondents shared many names of organizations or programs that they were aware of, or had been involved with on collaborative projects. They included: American Academy of Family Physicians; Society of Teaching and Family Medicine; American Cancer Society; Rand Corporation; Literacy Commission; Adult Basic Education departments; Family Resource Centers that cater to General Equivalency Diploma (GED) programs; state health departments; Department for Health Services; Kentucky Educational Television (training tutors on television); cable television (those airing public service announcements); American College of Obstetricians and Gynecologists

(Baby Talk Magazine); Department of Public Health; National Governors' Association; Cancer Information Service; extension agents (state and county); NCI-designated cancer centers (e.g., Massey Cancer Center); West Virginia Library Commission; Literacy Coalition in West Virginia; and a refugee group in Boston. Some respondents did not clarify whether organizations or programs were local, state, or national.

Dissemination of Information

Many of the respondents suggested ways that collaborations between health and literacy professionals could be shared with a larger audience. Suggestions included:

- Publishing information in newsletters or developing a newsletter for this purpose.
- Asking people involved in collaborative efforts to spread the word.
- Publishing collaborative efforts in professional journals.

III. APPENDIX

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

National Institutes of Health
National Cancer Institute
Bethesda, Maryland 20892

April 5, 1993

2~ 3~
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Dear 9~:

We will begin interviewing National Work Group on Cancer and Literacy members in the next few weeks. The purpose of this interview project is to gather information from health and literacy professionals on the following subjects:

- Identifying low-literate individuals (what methodologies are used to identify people of limited literacy).
- Recruiting low-literate individuals for qualitative and quantitative research (methods used and lessons learned).
- Health and literacy networking/collaborative opportunities.
- Training for health professionals on low literacy issues.
- Evaluation of low literacy health communication strategies and materials.

These topics were selected to begin filling the information gaps on communicating to limited-literacy audiences.

During the week of April 12th, you will receive a telephone call from Allison Mobley at Prospect Associates, a contractor to the National Cancer Institute for this project. She will set up an appointment with you to conduct a telephone interview. The interview will take approximately 20-30 minutes. After the interviews are completed, we will compile the information in a report and share it with you at our June meeting.

Thank you in advance for your assistance. If you have any questions regarding this project, please contact Wendy at 301-496-6792, or Cathy at 303-239-3390.

Sincerely,

Wendy Mettger, M.A.
Low Literacy Program Coordinator
National Cancer Institute

Cathy Coyne, M.P.H.
Project Director
AMC Cancer Research Center

NATIONAL WORK GROUP ON CANCER AND LITERACY QUESTIONNAIRE

Name: _____ Date/Time: _____

Address: _____

_____

_____

_____

Telephone: _____

Hello _____ this is _____. First, I'd like to thank you for setting aside this time for our telephone interview. The purpose of this interview project is to gather information from health and literacy professionals on:

- **Identifying low-literate individuals,**
- **Recruiting low-literate individuals for qualitative and quantitative research,**
- **Health and literacy networking/collaborative opportunities,**
- **Training for health professionals on low literacy issues, and**
- **The evaluation of low literacy health communication strategies and materials.**

If any question is inappropriate or does not apply to the work you've done, please let me know and we'll move on to the next section. If it's alright with you, I will be tape recording our interview. This will expedite the process so I can refer to the tape instead of writing everything down.

I. Identifying Low-Literate Individuals

Let's start with a few questions on how you identify low-literate individuals. This section assumes that you've done work identifying low-literate individuals. If you have not done that work then we'll move on to the next section.

1. How do you operationally define low-literacy? (NOTE: May need further explanation for non-researchers, such as low literacy may be defined as reading between 5th and 8th grade reading level, or possessing less than an 8th grade education)

2. In your work, have you looked at different categories of literacy? (Probe for: native english speakers, non-native english speakers, reading disabilities, functional vs. marginal illiteracy)

3. a. What tests do you use to verify that an individual has limited literacy skills?

   ___ Wide Range Achievement Test (WRAT)
   ___ Cloze
   ___ Test for Adult Basic Education (TABE)

   Specially designed tools such as:
   ___ Rapid Estimate of Adult Literacy in Medicine (REALM)]
   ___ Other (Specify)

   b. When do you use these tests in the interview process?

   c. Have you compared the different literacy assessment tools? Please tell us about the results. What was the correlation between the tests?

   d. What other ways are you aware of that can be used to verify/assess that an individual has limited literacy skills?

4. a. Some people have mentioned that they used census data or state statistics to justify targeting low-literate individuals for research efforts or education programs. What information sources have you used? (Probe for: Adult Basic Education statistics, census data, state statistics)

   b. Do you sense that anything was missing from these sources? Did the sources give an accurate feeling of the literacy problem?

II. Recruiting Low-Literate Individuals for Qualitative and Quantitative Research

Once you have identified the low-literate individuals, we would like to know more about how you actually recruited low-literate individuals into your qualitative and/or quantitative research.

1. How have you recruited low-literate individuals for focus groups, one-on-one interviews, and/or quantitative research projects?

2. a. What recruitment strategies did you find to be most successful/least successful?

   b. What are the difficulties involved in recruiting these individuals? (Probe for: not accessible by phone, lack of transportation, no child care services)

3. a. Have you used any of the reading level tests (WRAT, REALM) mentioned earlier as a screening tool in your research?

   ____ Wide Range Achievement Test (WRAT)
   ____ Cloze
   ____ Test for Adult Basic Education (TABE)

   Specially designed tools such as:
   ____ Rapid Estimate of Adult Literacy in Medicine (REALM)]
   ____ Other (Specify)

   b. If you have developed your own test, could you send us a copy?

4. a. When you were recruiting low-literate individuals, did they find any of the screening questions to be offensive? If so, how did you address this problem?

   b. Would you please send me one of your screening questionnaires?

5. a. What kind of incentives, if any, did you use when recruiting low-literate individuals?

   b. Which incentives worked best?

   c. Were there particular incentives which didn't work?

III. Evaluation of Low Literacy Health Communications' Strategies and Materials

Now, I would like to ask you a few questions on the evaluation of low literacy health communications' strategies and materials.

1. a. Have you evaluated your health communications efforts that were directed to people of limited literacy?

   YES --> GO TO c.

   NO --> b. Could you tell me why an evaluation of your health communications efforts hasn't been conducted?

   c. How did you determine if your health message was communicated effectively to low-literate individuals? (Probe for: evaluation procedures)

   d. Was your emphasis on formative or summative research?

   e. If your emphasis was on formative research, what pre-testing methods did you use and why?

2. a. Did you find any particular strategy/material or any combination of strategies/materials that work best when educating low-literate individuals regarding health? (Probe for: one-on-one education and video, print, audio, interactive video)

   b. Please explain why the strategy(ies) and/or materials were effective?

   c. What strategy(ies) and/or materials were ineffective and why is that?

3. a. Did you attempt to measure changes in knowledge, attitudes, behavioral intent, and actual behaviors?

   YES --> GO TO b.

   NO --> Why not?

   b. How did you measure those changes? (Probe for: surveys, interviews, activities)

4. a. Could you determine if the change in behavior was due to the strategies and/or materials?

b. How did you determine this causal relationship?

5. What would you recommend or not recommend as evaluation strategies based on your experience?

IV. Health Messages in Literacy Curricula

Today I would like to talk with you about your experience with health messages in literacy curricula.

1. What health topics have you seen included in literacy curricula?

2. What was the process that led to the inclusion of health topics in your literacy curricula?

3. How would you recommend improving the process of including health messages in literacy curricula?

4. What was your response as a teacher to the material? (Probe for: problems/challenges)

5. a. Do you think literacy teachers are interested in additional health information?

   b. What particular topics?

6. What was the response from students regarding health topics in literacy curricula? (Probe for: confused, comforted, apathetic)

7. a. Are the students interested in additional health information?

   b. What particular topics?

V. Training for Health Professionals on Low Literacy Issues

Now, let's talk about your experience in training health professionals on low literacy issues.

1. What are health professionals' greatest needs for training on low-literacy issues?

2. What efforts have been made to meet these needs?

3. What strategies have proved most effective in teaching people about the learning/information needs of low-literate populations?

4. What advice would you like to share with others who conduct training with health professionals on low literacy issues?

5. How do you assess how well your training was implemented?

6. Would you please send me a copy of your training curricula?

VI. Health and Literacy Networking Opportunities

And finally, let's talk about your experience with health and literacy networking/collaborative opportunities.

1. What specific organizations or individuals do you collaborate with in the development of health-related materials for limited literacy audiences? [Probe for: Adult Basic Education (ABE) and English as a Second Language (ESL) programs, literacy organizations, other health groups, statewide networks)

2. Could you describe any challenges that you faced in developing these cooperative health and literacy efforts?

3. How did you sustain the relationship over time?

4. What suggestions would you like to make on how to enhance networking efforts? [Probe for: what worked and didn't, limitations, different modus operandi (m.o.)]

5. Could you suggest any individuals that we should contact who are actively collaborating?

6. a. Based on your experience, could you suggest any groups that should be informed of actual products, such as literacy curricula that include cancer messages? (For example groups such as State Directors of Adult Basic Education)

   b. Do you have any suggestions for ways to disseminate information on literacy and health collaborations? For example, how should we get the word out that literacy and health collaborations are going on?

That concludes our interview, are there any other comments you would like to share with us?

Thank you very much for your time and willingness to participate in our interview.

Thank you for sending us a copy of your:

___ Own reading level test (II.3.b.)

___ Screening Questionnaire (II.4.b.)

___ Training Curricula (V.6.)

___ Other Information

Please send it to my attention, Allison Mobley, Prospect Associates, 1801 Rockville Pike, Suite 500, Rockville, MD 20852.

After all the interviews are completed, we will compile the information in a report and share it with you at the June meeting.