



Health Communication Evaluation Services

Task 927650
Formative Evaluation of Proposed Campaign Materials
to Reduce Birth Defects

Folic Acid and Birth Defects Prevention: Focus Group Research with Health Care Providers

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Section

1

**BACKGROUND AND
PURPOSE OF STUDY**

**1.1
Background**

Neural tube defects (NTDs) affect about 4,000 women each year in the United States. NTDs occur when the fetal brain, spinal cord, or their coverings do not form normally during the early stages of pregnancy. These malformations generally occur in the first 2-4 weeks of gestation and lead to debilitating physical abnormalities or death of the infant.

Two major types of NTDs are spina bifida and anencephaly. Spina bifida occurs when the spinal tissue protrudes outside of the body. As a result, the infant can experience paralysis of the leg, lack of bladder and bowel control, mental retardation, and even death. In addition to the physical complications caused by spina bifida, the lifetime economic expenses can have a strong impact on a family. Several operations and lifetime services are needed which can accumulate medical bills up to \$500 million annually. Anencephaly occurs when the brain and head do not form completely. Babies who develop this defect are either stillborn or die soon after birth (ACOG, 1995).

An accumulation of research has found that folic acid, a B vitamin, can reduce the chances of a baby being born with these defects. Folic acid is a B vitamin that is required for the body to make DNA and RNA, the building blocks of all cells. B vitamins also help safeguard the embryo's brain and nervous system so that normal development can occur. This is especially important to a developing embryo because of the rapid cell division that occurs. The mechanism by which folic acid prevents spina bifida and anencephaly is still unknown.

The first evidence of the benefits of folic acid was published in July 1991 when the British Medical Research Council (MRC) conducted a



randomized control trial. The results demonstrated a 70 percent reduction in the risk of neural tube defects in pregnancies among women who received 4.0 mg. of folic acid daily and who had a previous NTD-affected pregnancy (MRC Vitamin Study Research Group, 1991).

The release of those findings prompted the Centers for Disease Control and Prevention to release an interim policy recommendation in August 1991. The recommendation was that women who had a previous neural tube defect-affected pregnancy should take 4.0 mg. of folic acid daily when planning a subsequent pregnancy (CDC, 1991).

Furthermore, in 1992, findings from Czeizel's Hungarian randomized control trial demonstrated complete protection from NTDs in pregnancies of women taking 800 micrograms (0.8 mg.) of folic acid who had not had a previous NTD-affected pregnancy (CDC, 1992).

Following these findings, the U.S. Public Health Service (PHS) published "Recommendations for the Use of Folic Acid to Reduce the Number of Cases of Spina Bifida and Other Neural Tube Defects" in 1992 (CDC, 1992). Unlike the previous recommendations, the PHS recommendation targeted all women capable of becoming pregnant, as opposed to only women who had an NTD-affected pregnancy. Albeit this expansion to all women, the PHS upheld the recommendation that 0.4 mg. of folic acid should be consumed everyday.

The reason for extending the recommendation to all women of childbearing age was due to the small window of time in which the neural tube, specifically the spinal cord and brain, begins to develop and the time it takes for folic acid to manifest its protective effects. The neural tube begins to form in the first two to four weeks after conception, usually before a woman knows she is pregnant. For folic acid to prevent NTDs, women need to start taking it at least 3 months prior to conception. The expansion of this recommendation will help every woman to protect herself from having an NTD-affected



pregnancy, especially since 50 percent of U.S. pregnancies are unplanned.

There are two ways to obtain the recommended amount of folic acid: foods containing folic acid and a multivitamin or folic acid supplement. Previous recommendations were based upon how much folic acid from food, also known as folate, was required to cure anemia due to folate deficiency. Folate can be found in green, leafy vegetables, orange juice, and fortified foods such as grains, bread, and cereals.

It has been discovered that it is very difficult for diet alone to provide the recommended daily amount of folic acid that would reduce the chances of having a pregnancy affected by a NTD. Large amounts of food would have to be consumed to obtain 0.4 mg. of folate. For example, one would have to eat 4½ cups of broccoli, 4 cups of orange juice, or 17 bananas daily. To counter the necessity of eating such large amounts of food, in March 1992 the Food and Drug Administration issued an order that folic acid be added to specific types of flour, breads, and other grains. However, this would typically only add 100 : g to a woman's daily diet. Conveniently, the recommended daily amount of folic acid can be found in multivitamins or a separate, individual folic acid supplement.

Cuskelly et al. found that at least 400 : g of folic acid plus the usual diet is required to achieve blood folate levels sufficient for full prevention of birth defects (Oakley, 1998). This idea of combining food and diet to reach recommended blood folate levels has recently been supported by the National Association of Sciences, Institute of Medicine. In April 1998, a report entitled "Dietary Reference Intakes: Folate and Other B Vitamins and Choline" supported the above findings with the recommendation to consume 400 : g of synthetic folic acid per day, in addition to food folate, to minimize the risk of an NTD (IOM, 1998).



1.2 CDC's Planned Communication Effort

Due to the difficulties of obtaining folate from food, the Centers for Disease Control and Prevention (CDC), Birth Defects and Developmental Disabilities (BDDD) recommends that all women take a multivitamin or a folic acid supplement daily, in addition to eating a healthy diet. A communication effort is underway to disseminate the following message:

All women of childbearing age in the United States who are capable of becoming pregnant should consume 0.4 mg. of folic acid per day for the purpose of reducing their risk of having a pregnancy affected with spina bifida or other NTDs (CDC, 1992).

Since the 1992 PHS recommendation was issued, several educational efforts targeting women of childbearing age about the importance of folic acid have been spearheaded by BDDD and other agencies. BDDD participates in birth defects surveillance, prevention, and intervention programs through cooperative agreements with individual states. CDC has also initiated its own health communication efforts as well as partnered with the March of Dimes and the Spina Bifida Association. A folic acid clearinghouse to facilitate the sharing of state and local folic acid materials has been developed, as well as others.

Despite these efforts, recent studies have found low knowledge levels of folic acid among the target audience. The March of Dimes sponsored two Gallup polls in 1995 and 1997. Comparing these two surveys, results revealed consistently low awareness of the PHS recommendation and of folic acid. Awareness of the PHS recommendation increased between 1995 and 1997 by 7 percent (22 percent in 1997 compared to 15 percent in 1995) among women surveyed. The study also found that more women had heard or read about folic acid in 1997 than in 1995 (66 percent in 1996 compared to 52 percent in 1995). However, there was a only a modest increase reported for folic acid consumption: 30 percent of nonpregnant women reported taking a multivitamin containing folic acid daily in 1997 compared with 25 percent in 1995 (MOD, 1997, 1995).



The findings from past surveys, polls, and educational efforts point to the need for additional efforts to increase knowledge about folic acid among women of reproductive age by tailoring messages to this group. CDC/BDDD's future efforts in this area will include a national health communication campaign to disseminate the PHS folic acid recommendation to all women of childbearing age. The national campaign, planned for kickoff in January 1999, will be multifaceted and include education, demonstration, and evaluation projects. The ultimate goal is to increase the proportion of women who consume the PHS recommended level of folic acid from 25 percent to 50 percent.

BDDD's proposed stages of formative research in designing this national health communication campaign include the following:

Exploratory research to help inform campaign development:

- 1) Analyses of existing data from market research and other research databases to form a profile of the target audience. This includes data from the Healthstyles and Lifestyles survey databases, results from the March of Dimes telephone interview surveys, numerous focus group study findings, and data from a National Health Interview Survey.
- 2) Focus groups with women at risk to learn about their knowledge levels, attitudes, and behaviors surrounding folic acid and neural tube defects (the results of which are detailed in a previous report entitled *Folic Acid and Birth Defects Prevention: Focus Groups with Women at Risk*).
- 3) Focus groups with health care providers to obtain their advice on communicating the PHS recommendation to women of childbearing age and their perception of their own role in the process (the results are detailed in this report).
- 4) Informal discussions with persons affected by spina bifida to gain their insight into the development of the campaign.

Campaign pretesting to obtain reactions to proposed campaign concepts/messages:

- 1) Concept-testing focus groups with women of childbearing age to glean their reactions to concepts/messages that have been



1.3 Purpose of Study

developed from information learned in the exploratory focus groups.

- 2) Informal discussions with persons affected by spina bifida to learn their reactions to developed concepts/messages.

During April and May of 1998, seven focus groups with health care providers were conducted. The purpose of conducting exploratory focus groups with health care providers was three-fold:

- To gather information on health care providers' knowledge, attitudes, perceptions, and behaviors relative to folic acid, and perceived barriers to and opportunities for counseling women at risk about folic acid;
- To obtain health care providers' reactions to research findings from the previous set of exploratory focus groups with women at risk; and
- To explore ways in which health care providers would prefer to receive information about the benefits of folic acid and how CDC can best provide this information.

Conducting focus groups with health care providers can yield valuable information about ways to reach a target population with health information, as well as ways to communicate health information to the health care team itself. Many research studies have found that health care providers are viewed by the public as one of the most credible sources of health information. One of the major findings from BDDD's exploratory groups with women was that participants said they would take a multivitamin if a doctor suggested it. This illustrates the importance of including discussions with health care providers into the formation of health communication efforts.

For the purpose of this research, health care providers were defined as the following:

- Physicians (Internists, Family Practice/Primary Care Physicians, Obstetricians/Gynecologists, Pediatricians);
- Nurses, Nurse Practitioners (working in the areas of Internal Medicine, Family Practice/Primary Care, Obstetrics, Gynecology, Pediatrics);



- Pharmacists; and
- Nutritionists.

These specific health care providers were chosen because of their medical specialties and their regular contact with women of childbearing age. Health care providers in these professions have unique opportunities to engage in counseling activities with women of childbearing age on a variety of health issues, and can specifically educate women about the benefits of folic acid.

1.4 Rationale for Conducting Focus Groups With Health Care Providers

While health care providers are viewed as credible sources and have the opportunity to communicate with women about folic acid benefits, past studies have identified several factors that may influence whether or not health care providers counsel women about folic acid supplementation.

- *Most women do not see a doctor before they become pregnant.*

Fifty percent of all pregnancies are unplanned and most women do not see a doctor before becoming pregnant, whether the pregnancy is planned or not. Thus, health care providers may have little opportunity to discuss folic acid with women of childbearing age before pregnancy.

According to a 1996 March of Dimes study, almost three-fourths (72 percent) of women who have had children or are currently pregnant said they waited to see their doctor to discuss pregnancy after they thought they were pregnant. Only twenty-seven percent of those women who have children reported seeing their doctor before they conceived. Among women currently pregnant, only 40 percent said they visited their doctor to discuss pregnancy before they conceived (MOD, 1997).



- *Most health care professionals do not discuss the benefits of folic acid with women of childbearing age.*

In the same study cited above, of those women who have had children or are currently pregnant, 84 percent said their doctor discussed behaviors that they could engage in to help them increase the likelihood of having a healthy baby. However, only 4 percent of those who said that their doctor discussed this indicated that one of the doctor's suggestions was to take folic acid. (MOD, 1997)

- *Many health care providers have low knowledge levels about the benefits of folic acid or the correct timing for taking folic acid.*

A recent Canadian study (Forman et al., in press) found that 25 percent of the pharmacists in the Toronto area were unaware of the importance of taking folic acid before conception. Thus, pharmacists did not recommend folic acid supplementation or give advice about the importance of folic acid.

Another recent study in Toronto surveyed a random sample of 35 family physicians; 43 percent did not mention folic acid supplementation as a topic for discussion with women of childbearing age, either with women actually planning pregnancies or with women in their first trimester of pregnancy. Only 14 percent knew the correct timing of folate supplementation (Perelman et al., 1996).

These studies show that there is a deficiency in health care providers' knowledge of folic acid and its role in the prevention of NTDs. Through focus group discussions, BDDD wanted to explore more about the knowledge and awareness levels of health care providers as well as channels through which information can be distributed to them. In addition, the focus groups were designed to learn more about the barriers to and opportunities for health care providers to counsel women about the benefits of folic acid and the prevention of neural tube defects. This report details the findings of seven exploratory focus groups conducted with health care providers.



Section **2** **METHODS**

2.1 Overview of Focus Group Research

Focus groups are used to elicit a target audience's beliefs, attitudes, awareness, and motivation around a chosen topic. In a focus group, a moderator facilitates an interactive discussion among 8-10 participants about selected topics. The moderator ensures that the group fully covers the selected topic, that all group participants are heard, and that unexpected relevant topics are explored.

Focus groups generate more in-depth information than can be learned using surveys and provide the opportunity for people to clarify and/or expand on their responses to questions. Characteristics of focus group participants usually reflect those of a larger population, although findings are not statistically representative due to the use of convenience samples and small sample sizes. A written summary of findings from a set of focus groups contains a synthesis of the findings from all groups, identifies general themes and patterns, and discusses any contrasts in responses from group to group. These findings can make a valuable contribution to planning effective health communication programs by providing insight into the knowledge levels, attitudes, and behaviors of the target audience.

Focus groups are a primary method of qualitative research.



2.2 Participant Recruitment and Research Design

For the present study, a total of seven focus groups were held with health care professionals from diverse health fields: internal medicine, family practice/primary care, obstetrics, gynecology, pediatrics, pharmacy, and nutrition. Physicians, nurses, nurse practitioners, pharmacists, and nutritionists were the targeted groups. A total of three focus groups were held with physicians from internal medicine, family practice/primary care, obstetrics/gynecology, and pediatrics. Two focus groups were held with nurses and nurse practitioners combined from all of the targeted medical specialties. One focus group was held with pharmacists and one with nutritionists.

Health care providers were recruited on the basis of their serving the target population for BDDD's planned campaign. The target population is as follows:

- African American, white, and Hispanic (both English-speaking and Spanish-speaking);
- Women between 18 and 35 years of age;
- Women in lower to middle income brackets (less than \$50,000), with emphasis given to women with annual household incomes of less than \$30,000.

The research team selected health care providers who serve these segments of the population in order to learn how health care providers interact with patients/customers and specifically how they counsel women about folic acid. The goal was to gain perspective on opportunities available to disseminate information about folic acid to women of childbearing age.

To ensure that focus group participants were representative of health care providers who have the opportunity to counsel women of childbearing age, BDDD and Westat created a series of screening questionnaires to use during the recruitment process. See Appendix A for the screeners developed.



Participants had to meet the following criteria:

- have regular contact with a patient population consisting of at least one-third women of childbearing age;
- at least one-third of the patients/customers have a racial/ethnic background of African-American, Hispanic, white, or Asian/Asian Pacific Islander;
- spend at least half of their time in direct contact with patients/customers;
- the majority of their patient/customer population is in the lower to middle income bracket.

BDDD also felt it was important to talk with health care providers who work in various community settings. These settings included:

- health clinics (including Women, Infants, and Children (WIC) clinics, public health clinics, university/college health clinics);
- private practice clinics;
- community-based pharmacies; and
- hospitals with outpatient clinics.

Health care providers who worked primarily in in-patient hospital settings or settings other than those listed above were excluded.

2.3 Focus Group Sites and Schedule

Professional focus group facilities, chosen because of their experience recruiting health care providers, used pre-existing databases to recruit participants. The facility that recruited participants for the nutritionists' group, however, used the membership directory of the Atlanta Dietetic Association and recommendations from the Georgia State Office of Nutrition (provided to them by Westat).

The seven focus groups with health care providers were held in two geographic locations in the United States: Atlanta, Georgia and Bethesda, Maryland. These locations were chosen based on the demographic characteristics of the target audience for the health



communication campaign, as well as the convenience and cost effectiveness of convening groups there.

All groups were held at professional market research facilities. At each facility, observers were seated behind a one-way mirror, and participants were informed that observers were present in an adjacent room.

Each group lasted approximately 2 hours. All groups were audiotaped and videotaped to aid researchers in recollection of the discussion; this activity was also disclosed to participants at the beginning of each discussion. Table 1 shows the dates, times, locations, and composition of each group.

Table 1. Schedule for Health Care Provider Focus Groups

Group	Practice Setting*	Place	Date	Time
Physicians	Ob/Gyn	Atlanta	April 14, 1998	6:00 p.m.
	IM/FP/PC	Atlanta	April 14, 1998	8:00 p.m.
	Pediatrics	Atlanta	April 15, 1998	6:30 p.m.
Nurses, Nurse Practitioners	Ob/Gyn; IM/FP/PC	Bethesda	May 11, 1998	6:00 p.m.
	Pediatrics	Bethesda	May 11, 1998	8:00 p.m.
Pharmacists	n/a	Bethesda	May 12, 1998	6:30 p.m.
Nutritionists	n/a	Atlanta	May 15, 1998	12:00 p.m.

*Abbreviations for medical specialties are as follows: IM= Internal Medicine; FP = Family Practice; PC= Primary Care; Ob/Gyn= Obstetrics/Gynecology.



2.4 Participant Characteristics

Table 2 provides a summary of participant characteristics in each group as well as across all groups. Information was obtained from a brief demographic questionnaire participants filled out before the group ended (see Appendix B).

Physicians

Three focus groups with physicians were conducted. Physicians were divided by their medical specialty in order to have like specialties within the same group. Group 1 consisted of physicians who specialized in obstetrics/gynecology. Physicians in Group 2 included doctors who work in internal medicine and family practice/primary care. Group 3 included pediatricians only.

A total of 27 physicians participated in the three focus groups. Half of the participants worked in a private practice setting and about one-third worked in a health clinic. A majority of the physicians (74%) worked in settings where African Americans make up one-third of their patient population. Almost 40 percent of the physicians also served Hispanics. All physicians received an incentive of \$175 for their participation.

Nurses, Nurse Practitioners

Two groups of nurses and nurse practitioners were selected to participate based upon the criteria described previously. Both types of providers were combined in the groups. One group was held with nurses and nurse practitioners from internal medicine, family practice, and obstetrics/gynecology settings. The second group was held with nurses and nurse practitioners in pediatric settings.

Participants held Registered Nurse, Licensed Practice Nurse, or Nurse Practitioner degrees. Originally, the intention was to include physician assistants in these groups as well, but due to recruitment difficulties, physician assistants were not included.



Table 2. Focus Group Participant Characteristics

	Medical specialty *	Gender		Race/ethnic background of group participant **	Primary work setting	Patient population served ***	Number of providers with at least one-quarter medicaid patients
		M	F				
Group 1 Physicians (N=9)	Ob-Gyn (N=9)	8	1	3 AA 5 W 1 H	Private Practice (n=6) Unknown (n=3)	6 AA 2 H 2 - DA	6
Group 2 Physicians (N=9)	IM (n=3) FP/PC (n=6)	7	2	4 AA 3 W 1 H 1 API	Private Practice (n=6) Health Clinic (n=3)	7 AA 4 H 1 API 1 DA	5
Group 3 Physicians (N=9)	Pediatrics (N=9)	5	4	4 AA 3 W 2 H	Private Practice (n=5) Health Clinic (n=3) Mgd Care Org. (n=1)	7 AA 2 H 1 - DA	7
Group 4 Nurses/Nurse Practitioner (N=5)	FP/PC (n=3) Ob/Gyn (n=2)	0	5	3 AA 1 W 1 H	Private Practice (n=2) Health Clinic (n=3)	4 AA 1 W 4 H 1 API	2
Group 5 Nurses/Nurse Practitioners (N=9)	Pediatrics (n=8) Adolescent Medicine (n=1)	1	8	1 AA 7 W 1 H	Private Practice (n=5) Health clinic (n=2) Mgd. Care Org. (n=2)	9 AA 5 W 7 H 1 API	4
Group 6 Pharmacists (N=8)	n/a	5	3	4 AA 2 W 2 API	Pharmacy/Drug Store (n=5) Grocery/Drug Store (n=2) Univ. Health clinic (n=1)	7 AA 4 W 1 API	n/a
Group 7 Nutritionists (N=9)	n/a	0	9	3 AA 6 W	Private Practice (n=5) Health Clinic (n=3) Hosp. Outpatient Clinic (n=1)	5 AA 2 W 2 H	n/a
Total Group Participants (N=58)	Ob/Gyn=11 IM= 3 FP/PC=9 Ped= 17 Adol. Med. = 1 Pharm = 8 Nutrition = 9	M=26	F= 32	AA=22 W= 27 H=6 API= 3	Private Practice = 29 Health Clinic = 14 Managed Care Organization = 3 Pharmacy = 5 Grocery/Drug Store = 2 Hosp. Outpatient = 1	AA= 45 H= 21 W=12 API=4	24

* Sometimes participants chose more than one specialty on the questionnaire due to settings with multiple practice specialties.

Please see Table 1 for a list of medical specialty abbreviations.

** AA= African American; H= Hispanic; W= White; API= Asian/Asian Pacific Islander.

*** Participants were asked if 1/3 or more of their patients were African American (AA); Hispanic (H); Asian/Asian Pacific Islander =API; White =W; DA (Did not Answer). More than one race/ethnicity could be chosen by participants.



A total of 14 nurse practitioners and nurses from the metropolitan Washington DC area participated in the groups. As with the physician groups, a large proportion (92%) of the nurses and nurse practitioners saw at least one-third African Americans in their practice settings and 78 percent saw at least one-third Hispanics. Half of the nurses and nurse practitioners worked in private practice settings; one-third worked in private practice; one-third worked in a public health clinic setting. Participants received as much as \$100 for their participation.

Nutritionists

A total of nine nutritionists from the metropolitan Atlanta area participated in the focus group. Over half of the nutritionists worked in public health clinics. The remaining one-half were private nutrition counselors. Over half of the participants saw at least one-third African Americans as their clients; the remaining half of the participants saw at least one-third Hispanics and/or whites. Group participants received \$75 as an incentive for their participation.

Pharmacists

A total of eight pharmacists from the metropolitan Washington DC area participated in the focus group. The pharmacists were licensed, practicing pharmacists who worked in a retail pharmacy (62%), such as a drug store chain or a clinic. Twenty-five percent of the participants worked in a pharmacy within a grocery store. Twelve percent worked in a university health clinic. Eighty-seven percent of the participants served at least one-third African Americans, 50 percent saw at least one-third white customers, and 12 percent saw at least one-third Asian/Asian Pacific Islander. Participants received an incentive of \$100 for their participation.



2.5 Focus Group Moderator

A white female with over 20 years of experience moderating focus groups was chosen to moderate all seven focus groups. The moderator was chosen based upon her vast experience moderating focus groups with health care providers on a variety of topics.

Her relevant experience includes:

- Conducting telephone focus groups with pharmacists on ulcer disease to obtain input for planning communication programs to alert patients and health professionals about new treatments for ulcers.
- Conducting focus groups with nephrologists, dialysis center administrators, hospital administrators, nurses, and social workers about a variety of issues regarding kidney disease, including technical features of hemodialysis equipment, practice guidelines, and economic and clinical aspects of hemodiafiltration.

It was important to use the same moderator that was used to conduct some of the folic acid exploratory groups with women at risk because of her familiarity with the project and to provide consistency in the research process.

2.6 Discussion Guides

Six distinct discussion guides were developed for the focus groups (Appendix C). Separate guides were written for each of the following groups:

- Physicians in Internal Medicine, Family Practice/Primary Care, and Obstetrics/ Gynecology;
- Pediatricians;
- Nurses/Nurse Practitioners in Internal Medicine, Family Practice/Primary Care, and Obstetrics/Gynecology;
- Nurses/Nurse Practitioners in Pediatrics;
- Pharmacists; and
- Nutritionists.



All discussion guides were developed by Westat in conjunction with BDDD and the moderator. Separate guides were developed for each type of health care provider group in order to address specific issues that may arise in each practice setting. For example, a health care provider who works in a family practice setting may have more opportunities to counsel women of childbearing age pre- and post-pregnancy about general health issues including folic acid, whereas a health care provider who works in pediatrics may have a different type of encounter with a woman of childbearing age because the provider treats the child as opposed to the mother. The opportunity is, however, available for the pediatric health care provider to give advice on women's health issues to the mother of the child.

Despite minor differences addressing specific issues, a core set of questions was included in all of the guides so that comparisons could be made across groups. A brief discussion of each section of the guides follows.

2.6.1 Background and Introductions

Background and Introductions (10 minutes)

The moderator introduced herself and thanked everyone for coming. She briefly mentioned the background and purpose of why the groups were being conducted. She also informed the participants that the groups were sponsored by the CDC and not a vitamin company. Participants introduced themselves and told the group which medical specialty or in what type of setting they worked.

2.6.2 Topical Discussion

Perspectives on Folic Acid/Birth Defects Research (20 Minutes)

Participants were read the following statement:

Since 1992, the U.S. Public Health Service recommends that all women of childbearing age who are capable of becoming pregnant consume .4 mg. of folic acid daily to reduce the chance of spina bifida and other neural tube defects. Consuming this amount of folic acid 1-3 months before pregnancy reduces the risk of neural tube defects by 50-75 percent.



Participants were asked if they were familiar with this information and if they had any concerns or reservations about the recommendation. They were also asked if they had heard about the recent Institute of Medicine report that was released in April 1998.

***Profile of Patient Education/Counseling in Practice
(20 minutes)***

Participants were asked about opportunities for and barriers to patient education/counseling. The moderator explored with participants their priority topics for discussion with women of childbearing age, how those priorities are decided, and opportunities to discuss how/if a folic acid discussion fits into different practice settings.

***Response to Research with Women Regarding Folic Acid
(20 minutes)***

Participants were given a list of selected research findings from the exploratory focus groups conducted with women at risk. Participants were asked to respond to the findings, specifically whether the findings were indicative of their practice settings and the health care provider-patient relationship. Participants were also shown findings that specifically applied to their medical specialty. As a result, some of the groups were given a different list of findings from the exploratory group with women at risk. See Appendix D for the Selected Findings used in each group.

Communication Channels (15 minutes)

Participants were asked for suggestions on which materials and/or channels could be used to help health care providers disseminate information on folic acid to women of childbearing age. Participants were shown a picture of a baby with spina bifida and a drawing of a baby with anencephaly and asked if they should be shown in literature on folic acid (See Appendix E). In addition, participants were asked for recommendations for the best channels to reach health care providers with information about folic acid.



2.6.3

Closing and Departure

Wrap Up and Closing (10 minutes)

The moderator gave a demographic sheet to each participant and excused herself to check on incentives for respondents as well as check with observers to see if there were any additional questions that needed to be asked of the participants. Upon conclusion of the group, a CDC/BDDD employee debriefed participants about CDC's planned activities, and answered any questions.



Section **3** FINDINGS

3.1 Process for Analysis and Interpretation of Findings

A consistent and systematic methodology is used to analyze focus groups. The procedures used to analyze focus groups are not standardized, therefore an emphasis on using a uniform approach is important.

Westat researchers employ a notes-based process for analyzing focus group findings. This is similar to the process recommended by Krueger (1994), who emphasizes that any process for analyzing focus group findings must be systematic and verifiable. He recommends processing each group briefly at its conclusion, then developing an overall picture of all groups, and finally considering particular groups' responses to specific questions. The following steps were carried out in order to identify key themes and findings for this report.

Step 1

Once the seven groups were completed, all records from each of the groups were gathered together. This included observers' notes, topline summary reports prepared by the moderator (included in Appendix F), and transcripts of each group discussion (included in Appendix G). All records were then carefully reviewed by the Westat research team. Trends across and contrasts between groups were noted and discussed.

Step 2

Following this overall assessment, the findings from *each group* were more closely considered to discern how they reflected, differed from, or illuminated the tentative observations made during Step 1. The examination of individual groups was designed to continue the overview process while adding more in-depth detail.



Next, findings were examined one discussion topic at a time. Summaries of the findings on each topic across groups were compiled and compared. Participant quotes were extracted from transcripts and used to illustrate key points made by the health care providers in all groups.

Step 4

The last step in this process involved developing the research conclusions and implications (Section 4) to assure they flow logically from the actual findings of the groups and that they are presented in terms of implications for health communication strategies.

Sections 3.2 through 3.9 present the findings from the seven focus groups conducted with the health care providers. In each section, overall findings and similarities are discussed first. A discussion of differences between the groups then follows, if applicable. Throughout the following discussions, acronyms will be used in the participant quotes to indicate which type of health care provider is speaking as follows:

- ob/gyn= obstetrics/gynecology,
- im/fp/pc= internal medicine/family practice/ primary care,
- ped= pediatrics,
- nurse/np= nurse/nurse practitioner,
- pharm= pharmacist, and
- nutr= nutritionist.

Step 3

3.2 Awareness of and Reaction to Folic Acid/Birth Defects Research

In the early part of the discussion, participants were read the following information and asked to respond.

Since 1992, the U.S. Public Health Service has recommended that all women of childbearing age who are capable of becoming pregnant consume 0.4 mg. of folic acid daily to reduce the chance of spina bifida and other neural tube defects. Consuming this amount of folic acid 1-3 months before pregnancy reduces the risk of neural tube defects by



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50-75 percent. You may also have heard about the Institute of Medicine's report confirming this recommendation.

Most of the health care providers were aware of the role of folic acid in the prevention of birth defects. However, many participants were not aware that folic acid must be taken 1-3 months **prior** to pregnancy. Others thought information regarding taking folic acid prior to pregnancy had been publicized only in the last few years and that it was new for the lay public. The following comments illustrate this:

To me there has not been a push until recently for women of childbearing age to take folic acid. The push was when you became pregnant. It's more recently the push is women of childbearing age . . . but we have not been pushing it prior. (im/fp/pc)

To me it's not really new. What's new is to bring it out to the lay public. I think we're all aware as physicians about the importance in the diet especially [for women] of childbearing age. (im/fp/pc)

I think it began to trickle into my practice about 10 years ago and the initial recommendations were coming from fertility specialists. I was sending someone over to one of those fertility doctors and the first thing they do is put them on folic acid. (ob/gyn)

It's not new to me . . . We've been recommending folic acid to our clients for some time with patient education . . . (nurse/np in ob/gyn, im/fp/pc)

Participants who were aware of this information heard it from a variety of sources including television, CNN Headline News, professional journals, information gathered at CDC sponsored workshops, posters and magnets received at their office, personal experience in treating patients with spina bifida, or a spouse's (or their own) experience with pregnancy.

Some of the nurses and nurse practitioners working in pediatric settings and several of the pharmacists were unaware that folic acid



should be taken prior to pregnancy. Moreover, a few of the pharmacists were completely unaware of the role folic acid had in the reduction of NTDs. Participants in these two groups had the following initial reactions:

Quite honestly, I didn't know anything about this. (nurses/np in ped)

. . . we do a great deal of teaching in our [clinic]. I would say in all the teaching we've done, this subject has never come up. (nurse/np in ped)

I did know that folic acid was important in pregnancy, but this 3 months prior to [is] news to me . . . and that's hard . . . How did they come up with that? (nurse/np in ped)

I'm not sure about the 3 months before getting pregnant. I don't think anybody's aware of that. (pharm)

I'm a little bit familiar with spina bifida but I didn't have the correlation with folic acid being one of the primary causes of that problem . . . I absolutely had not heard it at all. (pharm)

There was a lot of people that came in just to get folic acid. I personally thought it was to help their circulation. (pharm)

3.3 Opportunities for General Patient Education

Health care providers were asked to give a profile of how patient education fit into their practice settings. Opportunities for patient education were dependent upon the setting (i.e., managed care, private clinic, public health clinic) in which the provider worked, the health specialty (e.g., obstetrics/gynecology, pharmacy, family practice, nutrition), and the particular role of the provider (i.e., physician, nurse, nurse practitioner, pharmacist, nutritionist).

3.3.1 Health Care Setting

A provider's work setting shapes how patient education is conducted due to the administrative policies and the mission of the health care setting. For instance, in a public health setting, the policy and mission of providers is to educate, prevent, and treat patients on a variety of health problems. Whereas in other settings, the focus may be simply to treat the patient rather than provide patient education.



According to some physicians, nurses, and nurse practitioners, there appears to be more opportunity to provide counseling in a public health clinic or a private clinic setting, compared to a clinic in a managed care setting.

I work in a free clinic . . . We're not constrained by insurance and worrying about getting somebody through in an hour. (nurses/np in ped)

I think that is something with public health that differs from the private sector, the public health nurses, I mean that's what they do, patient education is the public's health so . . . this is their job, so they would have more time I think. (nurse/np in ob/gyn, im/fp/pc)

In Medicaid managed care we have to do health checks, physicals on kids and that's about the one opportunity that I do have to educate adolescents. (im/fp/pc)

Some physicians mentioned they use innovative techniques to help them tailor information to a patient's needs, especially if time is limited. Some physicians have created their own intake forms to help them remember to educate patients on a variety of health topics. Some examples are:

- One pediatrician gives a confidential questionnaire to adolescents about sexuality, suicidal depression, headaches, etc. He then identifies problem areas and talks with teens about them.
- Another physician created her own intake sheet with topics to cover with patients. If there is not enough time during the visit to cover all of the topics, she notes where the discussion stopped so she will know where to pick up in the next visit.

Some physicians, depending upon staff availability and time, count upon their nursing staff or use print materials to supplement patient education.

. . . it's a wonderful idea to have your nursing staff do a lot of the education. I think maybe nursing education guidelines that nurses could read . . . in addition to the ACOG book that's out already might help. (ob/gyn)



ACOG has a wonderful book called 'Preconceptual Planning.' We take [it] off the shelf and we hand it to them. (ob/gyn)

Sometimes the nurse may be the first one they come to . . . because they can relate to them. (ped)

A lot of the phone calls are handled by the nurse. They do a lot of counseling. (ped)

3.3.2 Role of Health Care Provider and Specialty

In addition to practice setting, opportunities to counsel women are affected by the role of the health care provider and his/her health specialty. Physicians typically counsel women of childbearing age when they visit for an annual exam, to get a new prescription for birth control pills, or because of other health problems.

I think most women of childbearing years get an annual Pap smear. I think if you focus on physicians that's a great one-on-one opportunity to say maybe it would be a good idea to take a multiple vitamin. (im/fp/pc)

Pediatricians typically see adolescent females when they come in for a sports physical exam or because of some other health problem. At these visits, the pediatrician will counsel the teen on several health issues, including smoking, multivitamins, drinking, and exercise. Pediatricians will also sometimes use this visit to counsel the mothers of the patients, if they bring up specific health issues.

As mentioned previously, the nursing staff is sometimes depended upon to counsel patients. Usually, a patient sees the nurse before and after seeing the physician or nurse practitioner. At the beginning of each visit, the nurse records vital signs and health information. The patient will then see the physician or the nurse practitioner. If time is limited, the nurse practitioner or physician tells the nurse which health topics the patient needs more information about and the nurse will address them.



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If someone is having a medical problem you have to take the time, but if it's something the nurse can deal with, usually that information or that problem is dealt with by the nurse, it's delegated. (nurse/np in ob/gyn, im/fp/pc)

Nurses and nurse practitioners said that patient education is a very important component of their work, therefore they use any opportunity they can to counsel patients. Opportunities to educate patients about multivitamins and other health issues usually occur when the mother brings her child in for care, during triage, or when patients call to ask questions in followup to their recent visit or about their medication.

. . . nurses are teachers, they are health educators . . . so that means that [the] nurse who sees the patients first is giving patient health education all the way, even [during] the drawing of the blood . . . so it's kind of like you can't really separate yourself from being a nurse and a health educator, they're just too intertwined. (nurse/np in ob/gyn, im/fp/pc)

I guess the best opportunity for me to do any teaching is when we're checking in the patient. If it's a newborn, while the mom's getting the baby undressed and when we're weighing, things like that. I'll ask them questions; they'll ask me questions. (nurse/np in ped)

[When she brings a child] in sometimes a mother comes in looking so tired that I ask her what is she doing for herself . . . I recommend she take a multivitamin. (nurse/np in ped)

I think the biggest time I have with someone . . . is when I'm taking someone in for a PE and then the moms are asking questions That's when we get into nutrition and we start talking about the vitamins and some moms are pretty young so you ask her about hers. (nurse/np in ped)

Some nurses mentioned that an ideal time to counsel patients is over the phone. Patients are usually more receptive to information because they had time to think about their recent visit with the health care provider and have thought of questions.



I get phone calls all day long from teens and yes that's a good opportunity. (nurse/np in ob/gyn, im/fp/pc)

By telephone . . . they call . . . I think it's more effective when they call because they want to know. (nurse/np in ped)

Nurses and nurse practitioners sometimes use alternative methods that enable them to educate their patients. One nurse in obstetrics/gynecology makes home visits with her patients during and after pregnancy, which she discovered is a good opportunity to counsel women about preconceptual issues. Another nurse uses the “buddy” system and partners older women with younger women so they can learn from each other.

Most of the times I take the time to . . . put together a young lady with an older one so they share experiences because the younger [ones] listen a little bit more sometimes than the older ones. (nurse/np in ob-gyn, im/fp/pc)

Opportunities for pharmacists to counsel customers are shaped by a federal law called the Omnibus Budget Reconciliation Act (OBRA) 1990. This law mandates that all pharmacists offer consultation to patients for their medications and various conditions, which could affect or be affected by the use of those medications. Usually, the process entails obtaining a signature from the customer stating that he/she would like/not like to see the pharmacist.

Pharmacists felt that education was an important part of their job and mentioned specific opportunities for educating customers. For example, it was mentioned that they have more time to counsel customers when patient volume is low. One participant in the pharmacist group mentioned that she writes a special note for the technician to tell the customer that he/she needs to see the pharmacist if she notices that the customer is taking two medications that could have a negative interaction. Some other comments by pharmacists about customer education were as follows:



Right now, business is slow, I have the time. (pharm)

I mean it's an important aspect of being a pharmacist, communication with the patient about the medication or whatever and you try to alleviate their anxieties or doubts about whether they should take it to completion or whatever. I strongly make an effort especially if it's an original prescription. (pharm)

If I know there is an interaction or something that I want to discuss with the patient I will write on the bag cause I'll forget- 'Please ask the pharmacist to talk to patient.' (pharm)

We actually ring the register, which gives me more time. I like to ask client about new medications: Is it working? (pharm)

Pharmacists mentioned that sometimes their customers trust their advice about medications more than they do their physicians. A few of the pharmacists had been working in their pharmacies for a long time and had developed relationships with some of their customers. This relationship created a sense of trust between the customer and the pharmacist, such that some customers would often ask them for their advice on medications.

I have people saying I'm not going to the doctor, tell me what to do. (pharm)

Nutritionists said they have many opportunities for patient education and a variety of methods are used to reach clients. Some of those methods for counseling clients include the following:

- One-on-one counseling sessions,
- Nutritional analysis,
- Group education sessions,
- Nutrition education sessions at high schools,
- Cooking classes, and
- Counseling women with eating disorders.



3.4 Barriers to General Patient Education

3.4.1 Health Care Setting

Participants identified a number of barriers to conducting patient education. Limitations due to the practice setting and to the role of the health care provider were two main barriers mentioned across all groups and will be discussed in detail below.

Physicians, nurses, and nurse practitioners strongly voiced that their opportunities to educate patients were limited in a managed care setting or in private practice because of other administrative duties, tight scheduling, and patient volume.

It seems . . . there's less and less time with direct patient care and more and more time doing paperwork or on the phone with the HMO trying to get something, so there's less time for education. (im/fp/pc)

With managed care and everything else, patients are scheduled tighter than it used to be. There used to be more time allowed but nobody's getting the reimbursements they used to get. (nurse/np in ob/gyn, im/fp/pc)

Well, I think it's very difficult in [a] relatively high volume primary care practice to be much of an educator and unfortunately it's getting more difficult. (im/fp/pc)

Pharmacists said that customer volume could limit the amount of time available to counsel customers about medications. Although OBRA mandates customers be offered counseling, as mentioned in Section 3.3.2, pharmacists are not always able to do so, especially if many customers are waiting. The customer will often see a technician rather than a pharmacist for information on over-the-counter products as well as prescription medicine. If the customer has specific questions, then he/she can see the pharmacist.

In our setting we fill 300 [prescriptions] plus a day, it's very hard for us to break away from the filling station and talk to them. (pharm)



*It is difficult to give the customer the time you want to.
(pharm)*

3.4.2 Role of Health Care Provider and Specialty

Some physicians felt they did not have the opportunity for extensive patient education in addition to diagnosis and treatment, completing their paperwork, and administrative duties. A few physicians felt that patients came to see them for treatment of a particular problem and that patient education was secondary.

In pediatric settings, mothers or caregivers would sometimes mention their own health problems when they brought in their kids for care. However, pediatricians felt restricted to give advice only to their younger patients and not the mother/caregiver because of liability issues.

The problem is you're not far away from treating them [mothers] which you're not allowed to do. Your insurance doesn't cover you to do that. (ped)

. . . people start saying 'I'm sick' and 'I'm having trouble'. . . I tell them you need to go ask your doctor and talk to them about that. (ped)

Two potential barriers noted by the pharmacists were that women are sometimes reluctant to talk with a male pharmacist about sensitive health issues or there may be language barriers in some communities, which prevent communication.

They don't come and talk to me most of the time . . . I'm a male. They probably want to talk to a female . . . so most of the questions I get on something like that is from a phone call. (pharm)

Actually . . . because they are Hispanic, pure Spanish, they don't speak English at all. I have to talk through my clerk and so I did not really go into why [they're] taking it. (pharm)

Pharmacists also mentioned they felt a little uncomfortable suggesting nonprescription medications to their customers because of past conflicts with doctors. A few pharmacists said they had encountered



tense situations if, after seeing the prescribed medication, they called the doctor and questioned if the medication type or dosage was appropriate for the patient. These types of situations make it difficult to counsel patients about both nonprescription and prescription medication. Pharmacists recognized that a better relationship was needed with physicians before they could really educate their customers.

3.5 If/How Folic Acid Fits into Patient Education

Participants were asked if and how they could fit folic acid information into their existing patient education practices. This section will discuss opportunities for and barriers to counseling patients specifically about folic acid.

3.5.1 Opportunities for Folic Acid Education

Many health care providers said that women do ask them about multivitamins or folic acid during their visits. Many physicians said that their patients sometimes bring in several bottles of vitamins, herbs, and minerals and ask which one is best. These situations can give the provider an opportunity to counsel about folic acid because patients are already interested in different vitamins. When asked by patients, most health care providers reported suggesting the cheapest brand of multivitamin because they are all the same. However, nutritionists said that they felt compelled to recommend a particular brand of multivitamin so that their patients will go and buy a bottle. Pharmacists also said that their customers often inquire about multivitamins when they felt tired or stressed.

Most of these people work 2-3 jobs, male and female, and they always complain of fatigue and of course when you work all the time you cannot eat a balanced diet . . . so you need a vitamin . . . (pharm)



Some pediatricians and obstetricians/gynecologists said they take the opportunity to advise mothers or caregivers on prenatal issues if the woman asks about multivitamins or if future pregnancy is mentioned.

I always recommend a multivitamin to all patients in their childbearing age who mention that they are planning to become pregnant. (ob/gyn)

It doesn't happen a lot but very commonly people will tell me or I'll ask them . . . 'are you going to expand our practice any' and they'll tell me 'we're working on it,' so it's not a bad idea to think about mentioning to those people, . . . 'go ahead and start your prenatal vitamins now.' (ped)

The only time I really discuss nutrition with a patient is . . . for an annual exam, or . . . for pre-natal care . . . or she initiates the conversation, then we discuss nutrition. (ob/gyn)

I do a lot of internal medicine, also, so a lot of times I'm just taking care of the whole family so it's not 'oh by the way' it's actually . . . when I'm finished talking about that child even if the mother is not asking for an appointment. She will voice some of her own concerns. (ped)

A lot of times you'll get it too from the moms that are nursing. They'll ask you 'should I continue to take my prenatal vitamins or how's my diet?' So I do a lot of nutritional counseling to the moms that are nursing because they'll just start asking questions. (ped)

In a public health setting, some patients have an opportunity to talk with a nutritionist and/or to receive free multivitamins. Physicians in obstetrics/gynecology mentioned that if there is not a nutritionist on staff, they probably would not address nutritional issues because of a lack of time. Some other comments were as follows:

. . . with the County [health department] . . . Every new patient has an opportunity to talk with a nutritionist where she would do the counseling on the vitamins and minerals, and what foods were high in certain vitamins, minerals, and folic acid. (nurse/np in ob-gyn, im/fp/pc)



We give a lot of vitamins out in general to the [patient] under 21 years. Medicare pays for that. (im/fp/pc)

One physician mentioned that another prime opportunity for counseling is if the woman has had a miscarriage.

[when a woman miscarries], that's when they're most concerned about what they can do to prevent any further occurrences of this nature. (ob-gyn)

Nutritionists have many opportunities to fit in education about folic acid. For example, two of the participants work with adolescents with eating disorders. Since these patients are concerned with returning back to good health, there is an open opportunity to counsel women about folic acid within the framework of healthy eating and a healthy lifestyle.

[There are opportunities] with the disordered eating population, younger women who are wanting to get pregnant and that's one of the motivations to improve their eating . . . and get their body . . . able to conceive. (nutr)

3.5.2 Barriers to Folic Acid Education

The biggest barrier to patient education cited by most participants is that they do not have a chance to talk to women about pregnancy issues until after pregnancy has occurred. Although providers encourage women to visit them preconceptionally, women still do not follow their advice. Many providers said that most women do not plan their pregnancies and usually come to see them because they think they are pregnant or because of some other health problem.

Women rarely come to discuss pregnancy, which I think is the biggest factor of all this. Most of it is unplanned and those who seek are probably ones who have had trouble conceiving or they're older women and they're usually pretty well informed . . . [they] usually seek medical advice, the younger women . . . either in or out of marriage or whatever it's not planned. (nurse/np in ob/gyn, im/fp/pc)



We've been talking about preconception . . . for 20 years . . . We haven't made a dent in it because people don't think that [they] need to see someone before [they] get pregnant, so we see them, they're already pregnant and some of the things that could be prevented you've missed because they didn't come and even a lot of your highly educated people won't go for preconceptual care. (nurse/np in ob/gyn, im/fp/pc)

The problem is . . . when mothers come with babies and they're thinking about becoming pregnant, even in the OB office they don't think about what they should do prior to or sometimes they're only thinking to stop the pill, those kinds of things. (ped)

You have a lot of different patients from a lot of different countries who pregnancy to them is a normal occurrence so as long as they're not having any problems [in] early pregnancy they're not going to come first trimester. (nurse/np in ob/gyn, im/fp/pc)

Some health care providers expressed reluctance about recommending a multivitamin because they were unsure of its benefits since this topic was not a part of their medical training. Also they felt that there is not enough research confirming the benefits of taking a multivitamin. This is potentially a large barrier to educating patients about sources of folic acid, since multivitamins contain the recommended daily amount of folic acid.

There was confusion in some of the groups because some participants had previously been taught that vitamins are not necessary if one is eating a healthy diet. Also, some group participants thought that conflicting messages about the benefits of vitamins presented in the mass media cause even more confusion.

The medical community . . . has been against vitamins in general . . . but this folic acid seems to be pretty much mainstream now and you're trying to get us into different gear that we haven't been doing for probably 50 years. (im/fp/pc)



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. . . go back 10 years . . . there was a lot of literature for awhile putting down prenatal vitamins, saying how unnecessary they were. (ob/gyn)

I have a little trepidation about giving multivitamins because I know iron is in multivitamins and I know if you don't need iron you shouldn't be taking [multivitamins]. (im/fp/pc)

I think most of that is really unnecessary and it's just a multi-billion dollar industry and our illnesses are getting worse since the 40-50 years most people have been taking multivitamins and minerals and not getting better. (im/fp/pc)

I think nutrition is so important to health in general and I used to not be such a huge proponent of telling people to take vitamins because in a lot of cases it just makes expensive pee. (nurse/np in ped)

One of the problems with vitamins is that the research has been slow coming about because there's not a whole lot of profit in it. We don't know [about multivitamins]. (im/fp/pc)

I feel a little bit leery about telling someone they should be taking folic acid because I feel like I'm only putting in one piece. (nutr)

As dietitians we've all been beaten over the head, you should never take a supplement, always do it with your diet. It's really hard for us to make this leap of faith even into discussing the fact that we're giving people a supplement. (nutr)

Although most health care providers knew the importance of taking folic acid and were aware of its ability to reduce the risk of a NTD-affected pregnancy, there was a lot of discussion about the importance of taking folic acid prior to pregnancy. Some participants wondered if there had been an increase of babies born with birth defects or if NTDs were affecting certain racial or ethnic populations more than others. Furthermore, participants found it hard to believe that there had been a substantial increase in NTDs since they had only seen one or two children with spina bifida in their practice settings or perhaps had only seen pictures during their medical training. The following are some of their reactions.



I haven't had any parents come in to me and say, boy I had an unlucky pregnancy. My kid has spina bifida or [a] neural tube [defect]. (im/fp/pc)

I've been in practice since 1983 and I had one patient with that disease. I don't know what the incidence is but I don't think it's very high. (im/fp/pc)

In the Oriental population, I hardly see the problem. (pharm)

We have the largest satellite clinic and we have one child [with spina bifida]. (im/fp/pc)

Is this a Caucasian ailment more than Afro-Americans? (im/fp/pc)

I didn't even know there was a precipitous increase of incidence of spinal defects. I read a lot, I wasn't aware of that. (im/fp/pc)

I'm kind of ashamed to think I'm not as well educated about [folic acid] because I never perceived it to be a big issue and I would be very interested in . . . what group of patients and how do they estimate, I'd like to see data. (im/fp/pc)

Health care providers who serve female adolescents said they feel uncomfortable counseling them about taking folic acid before pregnancy for fear of sending a mixed message about sexual activity. Providers expressed extreme discomfort discussing sexuality issues with adolescents, especially in front of the parent, because they did not want parents to think they were promoting sexual activity to their children.

We're more into prevention of pregnancy, not helping them plan. (ped)

. . . preventive medicine during adolescence is really not part of the equation of primary care. (im/fp/pc)

To tell you the truth I can never discuss with my teenagers about folic acid because you tell a 15-year-old 'if you get pregnant,' I could never discuss [it] even with mothers. (ped)



You can't send them a mixed message to getting pregnant. (ped)

You start telling adolescents 'if you get pregnant this is going to help you,' the parents are going to be very upset. (ped)

It's also a major problem doing all the sports physicals with adolescent girls and it's like the mothers come in and sit there and watch me like a hawk and it's hard to get a sexual history to talk about these problems in front of the mother . . . you know they take it the wrong way. (im/fp/pc)

'Your child's 13 years old and maybe it's a good idea you start taking this folic acid now because she may be pregnant at 14' which is probably the reality but I don't think parents are going to like that. (im/fp/pc)

3.5.3 Other Barriers

The following barriers are ones that may not be an impediment to patient education per se, but health care providers perceive them as having a potential impact on whether a provider will recommend a multivitamin or a folic acid supplement to patients and whether or not women will comply with the provider's recommendation.

Some participants mentioned that women are apprehensive about taking pills because of possible side effects, such as weight gain and digestive problems. Participants also questioned if women would take a folic acid supplement or a multivitamin daily if they did not perceive an immediate benefit. Some providers found it hard to believe that women at risk would take a multivitamin when they often do not adhere to providers' recommendations about taking calcium to prevent osteoporosis or taking birth control pills to prevent pregnancy. Providers also thought that women would not see any reason to take folic acid if they were not planning to become pregnant. For all of these reasons, participants did not think there would be high patient compliance with taking folic acid.

They're worried about gaining weight. Some of them have a misconception that if they take the vitamin they will gain weight. (ped)



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It's tough enough to get women to take calcium for this epidemic called osteoporosis. (ob-gyn)

The hardest part about getting people to take folic acid as well as to eat well . . . in terms of prevention is that there's no immediate benefit. (nurse/np in ped)

According to the participants, compliance is shaped by education level, socio-economic status, age, and race. Some of the providers said that less educated patients/customers are less likely to ask health care providers questions and are less likely to comply with providers' recommendations.

Research indicates that if you interview 100 people when they leave the office 60-70 percent can't say what went on about one thing in the office, yet you want to in addition to smoking or contraceptives; cholesterol; get some exercise; you're going to add folic acid? (im/fp/pc)

. . . prenatal is generally when I come in contact with my patients. It may not be in depth because we're dealing with a lot of different educational levels. (nurse/np in ob-gyn)

Most participants felt that adolescents are unlikely to comply with a health care provider's advice about folic acid because of their inability to comprehend the consequences of becoming pregnant and absorb a lot of information at one time.

. . . an adolescent [is] only going to comply with one or two things. (nurse/np in ob/gyn, im/fp/pc)

. . . the adolescent population is probably one of the most non-compliant population [s] that exists. (ped)

It's just an information overload and you wonder how much [adolescents] really get. It goes in one ear and out the other. (im/fp/pc)

Responsibility is the issue. I mean teens aren't responsible. They won't take a birth control pill. (nurse/np in ped)

A few obstetricians/gynecologists and nurses felt that some women are unwilling to take multivitamins because they are perceived as



unnatural and would rather spend their money on more “natural” products:

People today under the current managed care environments are not going to go out and spend out of their own pocket \$15 for a pre-natal vitamin, but they'll go out and spend out of their pocket 100 bucks for ginseng root, because medicine is supposed to be paid for by someone else . . . but if it's a natural herb product, then it's good for them and they're willing to pay. (ob/gyn)

They're not going to put anything unnatural in their body. They're going au natural. (nurses/np in ob/gyn, im/fp/pc)

Cost of supplements can be a potential barrier for patients. A few nurses and nurse practitioners in public health settings said that since their patients are primarily of lower socioeconomic status, buying multivitamins is not a priority. Often women of low socioeconomic status are preoccupied with other issues (e.g., buying food, paying bills) that are perceived to be more important than getting their daily folic acid.

Their lights are going to be turned off or they're about to get evicted, that takes precedence over the pre-natal portion and I do have the resources for all of those things so a lot of times that's why I don't even get to folic acid. (nurse/np in ob/gyn, im/fp/pc)

Vitamins cost a lot of money for a lot of people and it's not covered by insurance. (im/fp/pc)

A lot of the HMOs won't pay for vitamins after 21 years of age. (im/fp/pc)

Health care providers in private practice clinics and clinics in managed care networks are also affected by cost issues. Reimbursement by managed care organizations and insurance companies for counseling patients is perceived to be insufficient. Physicians, in particular, felt that they had so many health topics to cover in short amount of time, that adding folic acid to their list would be too much.



It costs me \$150 an hour to run my office and when a managed care company is paying you \$22.81 for a visit . . . they've stripped away the ancillary income we used to pick up from Pap smears . . . you don't have time to sit there and talk to someone for a half hour . . . economically it doesn't match. (im/fp/pc)

I got one recently from the HMO and they're sending out all preventive guidelines that they want you to do for their patients . . . it's like they're paying you less and you have to do more paperwork and you're expected to do more for that patient. I don't know where the opportunity is. (im/fp/pc)

Very few insurances will reimburse for the dietitian. (im/fp/pc)

3.6 Priority Topics in Counseling Women of Childbearing Age

One of the major barriers mentioned by providers was that counseling about folic acid was not a high priority. Participants were asked to list priority topics for health education and counseling for women of childbearing age and how those priority topics were chosen.

Focus group participants mentioned the following priority areas for education and counseling women of childbearing age:

- smoking
- mammograms
- cancer
- alcohol
- obesity
- STDs, including HIV
- drug use
- osteoporosis
- prenatal care
- hypertension
- tetanus shots
- over-the-counter medication

Participants in the physicians' groups said that counseling women about folic acid would be a difficult task in light of all these other priority topics.

The smoking, the drinking, the cholesterol, . . . trying to get a person to take their birth control pills everyday or come in for the Depo shot in 3 months is difficult enough. I don't know how and where I could work that in. (im/fp/pc)



issues is a big topic, but I think most of them are associated more with osteoporosis, breast cancer, coronary heart disease, things like that [more] than neural tube defects. (im/fp/pc)

For adolescents, in addition to the priority topics listed above, nurses and nurse practitioners mentioned pregnancy prevention, anorexia, and psychological problems.

[topics usually include] ‘Are you sexually active?’ talking about drugs, avoidance of violence, prevention of violence, and covering those basic survival issues, I’m trying to figure where the hell am I going to get in folic acid? (nurse/np in ped)

Our thing is to prevent [pregnancy] cause most of my patients are teens. I’m not trying to promote them into thinking about [doing] it again. (nurse/np in ob/gyn, im/fp/pc)

Pharmacists mentioned that customers usually dictate the priority topics for discussion by the questions they ask. Customers usually ask them about birth control pills, herbal products, and interaction of medications, or they want opinions about advertised drugs.

The only thing we do is with the birth control pills; we tell them [to] take the iron. (pharm)

If they were on antibiotics we tell them it might decrease the effectiveness of their oral contraceptives, but at the same time if they’re not pregnant we try to . . . give them information on STDs, and preventive type things that they need to be aware of just in case they become pregnant or just for their own safety. (pharm)

[we talk with them about] drinking, interaction with things, medication. (pharm)

[Folic acid] is not a focus. Women’s health



Herbals are becoming very popular now so we got an herbalist that works 3 times a week. There is a big increase of questions about advertised medications, like Claritin. (pharm)

Nutritionists mentioned that priority topics are usually shaped by their practice setting and that folic acid was not a high priority topic. Their clients were more concerned with how nutrition affects weight loss, diabetes, and heart disease.

. . . even though a lot of them are of childbearing age, folic acid is not important to them. The nutrient that they're most interested in is knowing if they get enough calcium. (nutr)

That sits low on my priority list because most of the people I see want weight loss, they have diabetes, they have heart disease... some of the athletes, I see . . . they're more interested in making sure their diets are nutritionally complete because they're an athlete and they want to perform optimally. (nutr)

There are so many deficiencies in diet that folate would be down on the list . . . energy, protein malnutrition are such issues that is the priority for the first several sessions. (nutr)

3.7 Recommended Sources of Folic Acid

When participants were asked what sources of folic acid they would recommend to patients/customers, providers said they would recommend a multivitamin, an individual folic acid supplement, or getting folic acid through a healthy diet. It is important to note that providers would sometimes recommend multivitamins to all women, especially those with an unbalanced diet and to those who are anemic, but would not necessarily mention multivitamins as a source of folic acid.

There was a mix of responses as to which source, multivitamins or food, was most often recommended. Overall, participants correctly identified green leafy vegetables, orange juice, and broccoli as sources for folic acid. However, they also said people, in general, are living a “fast” life and do not eat properly because they are always eating fast food. Multivitamins were mentioned as a good alternative, but some



participants felt that some people would try to substitute a multivitamin for healthy food.

Vitamins are great but they still don't take the place of good food. (nurse/np)

We don't really push folic acid and say well you need to take this folic acid along with these vitamin tablets. We don't really push that. We usually tell them about eating the green leafy vegetables and the meats that have all these vitamins and things in there. (nurse/np)

Get from your balanced diet first unless you're on a special diet and can't eat anything like that. Vitamins to me come as a nutritional supplement and supplement what you don't get from your regular diet, some people think if they pop a pill like that, they don't need to eat. (pharm)

Fortified foods were mentioned frequently as a source for folic acid. Many participants mentioned that the foods adolescents typically eat should be fortified with folic acid, such as Coca Cola, potato chips, pizza, and water. Other participants mentioned that folic acid should be included in birth control pills or in the Depo Provera shot.

Most providers reported recommending a multivitamin if they are asked about it. Pediatricians may recommend multivitamins if the young patient comes in for a sports physical exam or if the mother mentions her child being fatigued or not eating properly.

. . . we do recommend a lot of vitamins in adolescents especially if they do sports and we do a lot of sports physicals... because most of the time they don't eat right.. (ped)

. . . Usually it's the mother that will come and ask about vitamins because the teenager is tired.. the mother will come right up and ask about vitamins. What kind of vitamin can I give to give her more energy or make her eat more? (ped)



3.8 Suggestions for Communicating with Women

Participants were asked to give suggestions for the best ways to reach women with information about folic acid. The following were suggested:

- brochures
- videos
- bookmarks
- lapel buttons for providers
- magnets
- placards on public transit systems
- tapes
- PSAs
- schools
- magazines
- internet
- television

Health care providers said it was important for any materials to be provided to them free of cost. Some physicians mentioned that cost can have an influence on which materials are purchased and how they are distributed. Participants said that materials should be in clear, simple language, and available in English and Spanish.

Participants were also shown two pictures of babies affected by NTDs (See Appendix E). Most participants said that including pictures of a NTD-affected baby in educational materials provides a good opportunity to show women how NTDs can impact a child. There was also a suggestion that a picture of an older child in a wheelchair should be shown so women could see how a NTD affects older children's lives. Some participants felt that the pictures should be restricted from certain areas, such as a pediatric office for fear of young children seeing them.

3.9 Suggestions for Communicating with Health Care Providers

Health care providers mentioned the following as the best channels for communicating with them about folic acid:

- Professional journals
- Consumer news
- Mass mailings from CDC, PHS



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Several participants suggested that two other ways to remind health care providers to counsel women about folic acid are to include a question on health history forms and to make it a standard practice to include counseling about folic acid when prescribing birth control methods.



Section **4** CONCLUSIONS AND IMPLICATIONS FOR COMMUNICATION ACTIVITIES

Findings from this series of focus groups with health care providers have several implications for enhancing the role of providers in persuading women of childbearing age to increase their intake of folic acid even if they are not specifically planning a pregnancy. This section of the report discusses key findings in the context of such implications and is based on the assumption that at the current time, BDDD is not planning a separate communication campaign for health care providers. Since health care providers have access to the target audience and are viewed as highly credible sources of information about folic acid by the target audience, BDDD's intention is to utilize health care providers as a potentially effective channel for disseminating campaign messages to women, both directly and through its partnership with the National Council on Folic Acid.

Increase awareness of the link between folic acid and birth defects.

Increasing awareness among health providers, especially nurses and pharmacists, of the link between folic acid and reducing the risk of birth defects is important to facilitating dialogue with patients/customers that will heighten women's awareness and influence their actions.

Most participants in this series of focus groups were familiar with the connection between folic acid and reducing the risk of birth defects. However, there were exceptions. Some pediatric nurses and pharmacists were unfamiliar with the importance of folic acid. These two groups of professionals have opportunities to counsel women that will clearly be missed if they are unaware of folic acid's importance. Especially in the case of nurses, since they view patient education as their role, it is important to inform them about issues like folic acid



In contrast, generally, nutritionists and providers who work in obstetrics/gynecology, well as nurses and nurse practitioners in public health settings, seemed likely to be aware of folic acid's importance and to have more regular opportunities for education and counseling on this topic than other providers.

and birth defects.

Increase awareness of the role of folic acid *before* pregnancy.

Increasing awareness among health care providers of the vital importance of women having enough folic acid in their body *before* pregnancy is critical. Even among providers who were aware of folic acid's importance, there were participants who did not realize that maximum benefits are only derived from obtaining enough folic acid *before* conception. For example, some family physicians and pediatricians were under the misperception that sufficient folic acid can be obtained from prenatal vitamins taken during pregnancy. This finding, considered in light of findings from previous groups with women that indicated that provider advice significantly affects their behavior, underscores the importance of provider awareness of both the general recommendation to take folic acid and in particular, the need to take it before conception. Without such increased awareness, it remains unlikely that providers will regard folic acid counseling as significant enough to make it a priority for patients who do not specifically indicate that they are planning a pregnancy, let alone with women throughout their childbearing years.

Increase awareness of the incidence and severity of NTDs.

Through the media campaign targeted at consumers and through partnerships with various health professional associations, BDDD's planned campaign can increase health care providers' awareness of the incidence and severity of NTDs.

Many of the participants were unsure of the incidence of NTDs and some expressed the sense that the problem must not be very widespread because they had not seen it in their practice or been otherwise exposed to it. Their perception of NTDs as a rare occurrence likely affects the priority health care providers give this topic in patient education and counseling.



Through its partners on the National Council on Folic Acid, BDDD can disseminate information about the incidence of NTDs in different populations, emphasizing that spina bifida in particular is one of the most common types of neural tube defects and largely preventable through adequate folic acid consumption prior to conception and during the early weeks of pregnancy. CDC can also work with professional associations to encourage incorporation of folic acid education into practice protocols (e.g., including questions about pregnancy intention and vitamin consumption on intake forms).

Increase knowledge of sources of folic acid.

Increasing health care providers' knowledge of sources of folic acid, and in particular, of the limitation of reliance on food sources, is also important. Many providers did not seem comfortable about what to recommend to patients as good sources of folic acid. There was general awareness about the types of foods that provide folate, but not of the amounts needed to serve as a sufficient source, except among nutritionists. Providers, including nutritionists, were also divided about multivitamins and supplements as a source because of concerns about cost, efficacy, and women's reservations (e.g., upset stomach, weight gain) about taking them. Confusion on the part of providers about what sources to endorse or recommend could contribute to limited concern and compliance among women, who, in earlier research, indicated that they would be likely to follow a provider's advice about this issue.

Educate providers about barriers to vitamin use.

Many health care providers were not sufficiently aware of the barriers women perceive to taking multivitamins. Educating providers about women's perspectives regarding vitamins will increase their effectiveness in patient counseling and education. While some participants were aware of the perceived barriers to consumption of multivitamins or folic acid supplements, many were surprised by the research findings from the women's groups regarding barriers. In particular, many had not heard the myth that multivitamins cause weight gain, which is a significant obstacle to multivitamin consumption for some women.



Health care providers can more effectively counsel women if they are aware of such perceived barriers. They can correct misinformation and suggest ways to overcome common barriers (e.g., they can recommend taking a folic acid supplement alone for women with concerns about taking multivitamins, chewable or coated vitamins for women who object to the taste, and vitamins without iron for women concerned about constipation as a side effect of multivitamins).

Involve all types of providers in disseminating the folic acid message.

All of the health care providers who participated in the focus groups described some level of opportunity to counsel and educate women about the importance of folic acid, whether through face-to-face counseling or through dissemination of patient education materials in their practice settings. In order to reach as many women as possible and because women perceive health care providers to be a credible source of health information, the campaign should partner with all levels of health care providers (physicians, nurse practitioners, nurses and others) in obstetrics/gynecology, pediatric, and primary care settings.

The kinds of opportunities for patient education and counseling ranged from some public health nurses describing extensive contact with patients including, in many cases, home visits, to pharmacists occupied primarily with filling prescriptions who have minimal contact with customers. Even those health care providers describing little opportunity for face-to-face contact with patients felt that print materials and other consumer education materials could be disseminated in their practice settings.

The findings underscore the importance of CDC, working through the National Council on Folic Acid, involving all types of health care providers (physicians, nurse practitioners, nurses, and others) working in obstetrics/gynecology, pediatric, and primary practice settings as partners in the effort to get the word out about folic acid.



Equip providers with materials for women.

Equipping health care providers with materials to facilitate dialogue with their female patients would increase the likelihood that providers could communicate information about why folic acid is important for all women in their childbearing years and about ways to get more folic acid.

As indicated, most providers identified at least some opportunities for patient education and counseling on various issues. Although the nature of opportunities to provide counseling about folic acid varied for different professionals in the groups (e.g., obstetricians, family physicians, pediatricians, nurses, nurse practitioners, pharmacists, and nutritionists) and in different work settings (e.g., clinic, private practice, pharmacy, health department), all providers expressed a desire for low-cost, simple materials, ideally in English and at least Spanish (if not other languages also) to facilitate communication with women on this topic.

Suggested materials included those that could be used directly with women such as print handouts, as well as content or questions for providers to include on health assessment or intake forms to remind them to address folic acid during dialogue with patients about nutrition, birth control, or other related topics.

Include explicit illustrations depicting spina bifida and NTDs in materials.

Most providers were comfortable with including pictures or illustrations in patient materials of how neural tube defects affect babies and, in particular, how they affect the lives of older children with spina bifida (such as a picture of a child in a wheelchair.)

In focus groups with women, most participants were supportive of featuring some type of picture or illustration to show what spina bifida is or what it is like to live with it. Providers were similarly supportive and said that pictures would aid comprehension of the severity of these birth defects.



However, both women and providers expressed some concern about the pictures being readily accessible to young children and, as a result, recommended that depictions be used only in print materials that are handed to women rather than in display or mass media materials.

Use providers as one of many channels to reach the target audience.

Most providers reported barriers to counseling and education either in general or on this topic specifically that underscore the need for the communication campaign aimed at women to include strategies to augment, not just rely upon, provider efforts.

Significant barriers to counseling and education about folic acid mentioned by the providers included limited time in many of the settings that the various providers work in (due to constraints such as patient load, managed care-dictated appointment limits); higher priorities with the patient populations many providers see (e.g., illness or acute problems, smoking, obesity, screening tests); no contact (often the case with pharmacists); no opportunity for preconceptual counseling because many women come to the provider only after they are already pregnant; or no appropriate opportunity (such as pediatricians' concerns about sending a mixed message if they recommend folic acid while discouraging pregnancy).

Some barriers could be reduced with increased awareness of the importance of folic acid generating greater concern among both providers and women. Other barriers may impede some providers from addressing folic acid or making it a regular or high priority. Accordingly, other communication strategies and channels must also be used.

Promote the credibility of providers.

In general, providers in these focus groups were not surprised by the findings from focus groups with women. However, quite a few providers were skeptical about the finding that women would be more likely to take a multivitamin for folic acid if a health care provider recommended it. Provider participants in most groups cited examples of patients refusing to take birth control pills or medicines for pain or infections. Therefore, participants said they doubted



multivitamins that provide no immediate benefit, cost money, and generate complaints about side effects. Providing compelling evidence for health care providers that women are influenced by their advice may make them more inclined to address folic acid.

With greater confidence that their advice about folic acid will actually encourage women to take a multivitamin or supplement, health care providers will be more likely to cover this topic in the limited time available for patient education and counseling. It will be important to demonstrate that providers' recommendations can make a difference in women's behavior.

Through its partners, the National Council on Folic Acid and CDC can disseminate these encouraging findings about health care providers' potential influence on folic acid consumption and suggest ways to incorporate the topic of folic acid into provider's current patient education and providers' counseling practices.

that women would take

**Communicate to providers
through professional and
consumer media.**

Professional and consumer media are both important means of communicating with health care providers on this topic. Many of the providers indicated that they learn from both their professional media and from consumer media.

For this campaign, many providers seemed anxious to be reassured that efforts other than their own contact with women would be employed to disseminate the folic acid message. A strong media campaign targeted to women will document for providers that CDC does not intend for them to be solely responsible for communicating with women about folic acid and convincing them of its importance.



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Section

6

APPENDICES

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