

CENTERS FOR DISEASE CONTROL AND
PREVENTION

DES National Education Campaign
Campaign Development Plan

Submitted by:
Porter Novelli
April 26, 2000

Introduction

An issue that many think is no longer relevant, DES continues to affect millions of Americans. For DES mothers it means an increased risk of breast cancer B along with the emotional devastation of having put their children at risk; for DES daughters and sons it means an increased risk of genital abnormalities, cancer, and/or fertility problems. As research on the effects of DES exposure continues to be conducted and as the population of exposed continues to age, additional negative impacts may be uncovered, such as the impact on menopause, the implications of hormone replacement therapy, and potential third generation effects.

The Centers for Disease Control and Prevention (CDC) is expressing its commitment to this issue by taking action. In partnership with the National Cancer Institute (NCI), DES advocacy organizations, and medical professionals, CDC is developing a national education campaign designed to provide current information about DES and ensure that DES mothers, sons, and daughters as well as health care providers have access to the latest information about DES exposure.

Each day, more DES daughters and sons lose the ability to determine their exposure status as their mothers' old health records become more difficult to access. Therefore, there is an urgency to this issue; a campaign must be developed quickly. However, the desire to do something quickly must be tempered with the need to do it well. Creating an effective, long-lasting and sustainable educational program involves taking stock of what we know, testing our key assumptions or hypotheses, and following a planning process that ensures the program is based on an understanding of the needs and perceptions of the intended audiences. This document is in essence a Blueprint® for the DES National Education Campaign (DES NEC) and will serve as a foundation upon which to build support for the campaign.

Objectives of the Campaign Development Plan

- ❑ To describe the process for developing an effective, sustainable DES National Education Campaign
- ❑ To present the key learnings and assumptions that will drive the campaign

Two Hypotheses On Who We Talk To, And What We Say

Building on the learning and wisdom we have accumulated to date, we begin this campaign with two basic hypotheses. The first involves the categories of audiences we will approach; the second how we will frame our messages to them. These hypotheses are based on learnings from the NCI pilot studies as well as extensive situation analysis. They also are in keeping with the campaign goal and desired outcomes articulated by the DES NEC Working Group:

Goal

To construct sustainable communication processes and programs that promote information-seeking action and that enhance DES-specific encounters between the general public and the medical professionals and organizations which serve their health care needs.

Desired Outcomes Specified by the DES NEC Working Group for General Public Awareness

- \$ Heightened awareness of the conditions under which DES exposure might have occurred and its possible consequences
- \$ Increased motivation and ability among the general public, both men and women, to query their own and/or family members' DES exposure status
- \$ Enhanced ability to apprise the primary health care physician of possible DES exposure and to expect DES-specific screening and/or treatment from appropriate specialists

Desired Outcomes Specified by the DES NEC Working Group for Health Care Community Awareness

- \$ An increase in current and accurate knowledge about DES, its health effects, screening and treatment guidelines
- \$ The development of a bias to action with respect to identifying, screening, treating, and referring patients to a range of current DES information and appropriate treatment resources

We believe the hypotheses presented to be sound. However, we will continually challenge these approaches throughout the formative research process, to confirm their value and to modify and adapt as necessary.

1. *Rather than focusing on all consumers and health professionals, we will focus our messages on those who are predisposed B through knowledge, experience or attitude B to care about the DES issue.*

In constructing a target audience, we balanced two somewhat competing criteria: the need to inform a broad-based public about a health issue that could affect a wide range of people, and the need to identify those members of the public and providers who will be most open to receiving those messages. Our approach is designed to recognize and address every member of the public and health professional audiences who are predisposed to DES messages. Specifically, we have selected three categories of consumer audiences.

- ❑ Those who are open to DES messages because they *know* they have been exposed to DES;
- ❑ Those who are likely to be receptive to DES messages because they are *experiencing* symptoms consistent with DES (although they are unaware of potential exposure);
- ❑ Those who fit the age profile (born or pregnant between 1938 and 1971) and have the *attitude* that indicates openness to health-related messages such as DES. This is an audience identified in the PorterNovelli *Healthstyles* research as being particularly *A*health information seeking.[@] (See Appendix A for a description of these audiences.)

For the health professional audience, we propose beginning our outreach efforts with ob/gyn physicians, physician assistants, nurse practitioners, and nurse midwives. The NCI pilot program indicated that these are the health professionals who, because of expertise and orientation, are most receptive to DES messages. Other primary care providers (family practice and internal medicine physicians, nurse practitioners, and physician assistants) will be secondary target audiences.

2. We can increase the impact of DES messages by integrating them into other health campaigns and into stable educational environments.

There is no doubt that the DES message is an important public health issue, with potential relevance to millions of Americans. However, the fact remains that today's health information environment is cluttered with competing, compelling health messages. Health-related public service announcements flood in to television stations at the rate of literally hundreds per week; every morning mail brings a pile of drug announcements and health collateral into the local physician's office. Unless a health issue is considered a primary part of the nation's current health agenda B on the level of AIDS or breast cancer, for instance B it can be extremely difficult to cut through the clutter.

As we proceed through formative research, in speaking with members of the public and providers, we will explore a wide range of potential opportunities to get the public interested in and motivated about DES messages to the point where it could stand on its own B we are not closing that door. However, the experience of the NCI pilot programs B which required great effort and had minimal impact B indicated this will be an uphill battle. Therefore, we start with the hypothesis that there is another way to tell the DES story: by integrating DES messages into health stories and campaigns that are currently on the forefront of the nation's public health agenda and by placing DES messages in stable educational environments B such as medical curricula, the Cancer Information Service, and patient brochures B that will have a longer-lasting effect.

This approach could be effective for a number of reasons. First, one of the key objectives of the DES initiative is to create the framework for a sustainable DES platform. By integrating DES messages into ongoing health messages B such as infertility problems, gynecologic examinations, breast cancer screening, and testicular self examination B we could significantly increase the chances of DES becoming a lasting part of the public health agenda. Second, from a medical perspective, this allows us to target health issues that have the most potential relevance to DES: breast cancer in women over 60, for instance, or genital abnormalities in middle-aged men. And finally, integrating our messages allows us to *stand on the shoulders of giants* B rather than beginning our efforts from the ground up, we can leverage the infrastructure and experience of those in the breast cancer arena, for instance, to make our voices heard. This can be particularly effective in reaching out to providers and other health professionals. Experience has shown that attracting their interest

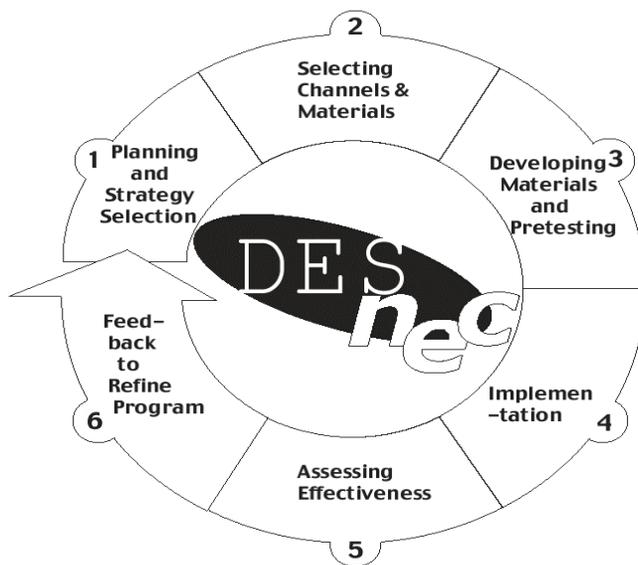
in a new health issue is quite difficult; this approach, however, offers them a new angle (the impact of DES exposure) on issues they perceive as important (breast cancer, gynecologic cancers, etc). We foresee B and research will confirm or deny B that this could have a greater impact on their behavior.

The Health Communication Process

In this section we outline the phases of campaign development in the context of what is known about DES and the findings from the NCI pilot programs. The model we are applying to the DES National Education Campaign is the NCI's six-stage Health Communication Process (described in NCI's publication *Making Health Communication Programs Work: A Planner's Guide*).

The Health Communication Process is one of the most respected and widely used planning tools in the health communication field. The process is based upon time tested health communication principles which makes it well-suited for programs large or small as well as complicated or straightforward health issues. A fundamental principle of this planning process is that to be viable, health communication programs must be based on an understanding of the needs and perceptions of their target audiences. It encourages tailored vs. Acookie cutter® approaches to program planning. For this reason, we recommend using the Health Communication Process for a complex issue like DES that requires a unique approach.

The diagram below illustrates how the process incorporates target audience feedback (e.g., an assessment of their needs and perceptions) at critical points in program development and implementation. The six stages constitute a circular process, in which the last stage feeds back into the first in a continuous process of planning and improvement. The following sections describe the six stages of the Health Communication Process as they relate to the DES National Education Campaign.



NCI's Health
Communication
Process

Stage 1: Planning and Strategy Selection

Understanding the Process

The planning stage of a program provides the foundation for the entire health communication process. This stage is critical to a campaign because decisions made during this phase affect the development of messages and materials and selection of communication channels. Faulty decision-making at this point in the process can lead to campaign materials and channels that are ineffective. To ensure that all elements of the campaign are on target, by the end of the planning stage the following will be in place:

- \$ *Campaign goals and objectives* B what we want to accomplish with the campaign
- \$ *Target audiences* B who we want to reach and affect with our campaign messages
- \$ *Strategies and Tactics* B how we will get there (i.e., the approach we will use for the campaign) and what activities will be done

Setting Campaign Goals and Objectives

CDC and the DES NEC Working Group are no strangers to the steps involved in this first stage of the health communication process. Over the past year, the Working Group has actively engaged in laying out what is currently known about DES exposure and who is most affected. Significant progress has been made in defining the salient issues for the campaign and outlining the goals and desired outcomes of the program (as described in the previous section of this plan).

Identifying and Defining the Target Audiences

We begin the planning process with a general understanding of the goals and objectives (based on the work of the DES NEC Working Group and the results of the NCI pilot programs). The next important component of this first stage is to identify the target audiences. At this stage of the process we know who is affected by DES, but not specifically who is best targeted for the campaign. Often in a campaign, we can define the health problem and who is affected, but information about that population may be unavailable or outdated. For the DES National Education Campaign, we know that the populations affected include women who were pregnant between 1938 and 1971 who were prescribed DES, and their sons and daughters. Identifying and reaching this population, however, is extremely difficult because many do not know if they were exposed to DES.

Clearly, a more defined set of target audiences is needed. However, before final decisions about the target audiences for this campaign can be made, additional information needs to be gathered. Formative research with the proposed audiences will help us confirm decisions about who to target for the campaign, and will describe their concerns, issues, and needs regarding information about DES. Without hearing directly from the affected population, we risk planning a program with incomplete information. Speculating how a daughter will react to finding out she has been exposed to DES or how a DES mother may feel about telling her son that he has been exposed can lead to unfounded and potentially dangerous assumptions. For this reason, it is critical that we engage in formative research.

The Formative Research Proposal describes in detail who will be included in the research and what types of information we will gather from them. Critical to this process is input from Working Group members who have personal experience with the topic and/or have studied it extensively. However, hearing directly from the target audience is also of critical importance.

Based on the results of the formative research, we will be able to confirm our recommendations for which audiences to target and describe their knowledge, attitudes, behaviors, and perceptions of DES. Given the diverse interests, needs, concerns and priorities among different segments of the public, trying to reach everyone with the same message is a difficult task. Specifically defining the audiences we want to reach and influence with our messages will help in developing messages and materials and identifying channels most likely to reach them.

In addition to defining the target audiences, we must prioritize them. For example, the primary audiences for the general public component of the campaign may be the DES mothers, sons and daughters who *know* they are exposed and those people who are experiencing symptoms consistent with DES exposure but do not know they have been exposed. The secondary audience would then be the health information seekers (see Appendix A for a description of this audience).

For the health care community, the primary audiences may be ob/gyn physicians, nurse practitioners, physician assistants, and nurse-midwives. The secondary audience would then be other primary care providers (both physician and non-physician). The formative research will inform our final decisions about which audiences should be primary, secondary, or complementary.

In addition, the results of the research will help to refine the campaign objectives to make them more audience specific. In addition, the evaluation contractor will create audience tracking mechanisms such as a baseline survey and periodic follow up surveys. Results from the baseline will help us create measurable objectives.

Provider Campaigns Require Consumer Support, and Vice Versa

Challenge: *Neither a consumer education program nor a provider education program alone is sufficient: each audience must be addressed, and each campaign reinforces the other.*

Response: *Utilize a push/pull strategy which encompasses both the consumer audiences and health care professionals.*

Based on findings from the pilot program, the Working Group has agreed that a push/pull strategy approach may be most effective in generating results for the DES campaign. This includes a targeted program to consumers, to drive their interest and push them to their doctors' offices, as well as a program to health care providers, to educate them on issues, and pull the consumer into necessary action.

The Communication Plan and Timetable

The communication plan builds upon all of the research and planning done during this first stage of the Health Communication Process. The communication plan will include an explanation and discussion of who we're reaching, strategic considerations that affect how we're reaching them, specific tactics to reach them most effectively, and a strategic framework under which all activities will be conducted. This document will enable all parties working on the campaign to clearly understand what we're doing, why we're doing it, and what we expect the results to be. The strategic communication plan will crystallize and encapsulate all

the learning from the formative research, and tie them together with our most creative ideas on how to execute.

To ensure that all campaign activities are completed in a timely fashion, a program timetable will be developed that outlines key dates and tasks and who is responsible for completing them. (See Appendix B for a tentative timeline for the DES National Education Campaign.)

Stage 2: Selecting Channels and Materials

Understanding the Process

Once the groundwork for the program has been established we can focus our attention on developing the right communication tools. In Stage 2 of the planning process, we will decide what kinds of materials are appropriate for the target audience and which channels will work the best.

Identifying Existing Materials

Materials development and production can be a time consuming and costly process. Many see this as the key developmental step for a campaign; however, creating new materials is not always necessary. For this reason, it is important to first review existing materials to determine if they can be used or adapted for the campaign. CDC and the DES Working Group have already begun this process by compiling and reviewing the materials used in the NCI Pilot Studies. (See Appendix C for a selected list of DES materials used in the pilot studies with potential for updating and adaptation to the national campaign.)

Determining the extent to which existing materials can be used will depend in large part on the results of the formative research. Once more about the target audiences is known, we can determine how well the materials fit our campaign objectives. Also, when considering the materials needed for the DES National Education Campaign, we should

consider both the content and the format. Print materials (e.g., brochures, fact sheets), Web pages, TV and radio spots, and videotapes are all types of material formats that could be used for the campaign.

The following will determine the most appropriate formats:

- \$ The message (e.g., its complexity, sensitivity, style, purpose)
- \$ The audience (e.g., will they want read about the subject, or would they rather watch a videotape)
- \$ The channels (e.g., whether you will be most likely to reach the audience through a physician, community organization, family member, media, or a combination of these)
- \$ The budget and other available resources

Engaging Those Who Are Unaware

Challenge: *Primary consumer education materials, developed during the pilot program, are useful in reinforcing and expanding education among the confirmed exposed population B but will not draw in those who are not currently engaged in the DES world.*

Those who are currently exposed to DES are the easiest audience to educate, of course, as they are most motivated to learn about DES. Other audiences are less likely to read ADES Information® pamphlets, as they do not see DES as relevant to their own lives or situations. For these audiences, a different kind of outreach is required.

Response: *Detailed DES information can be supplemented with A call to action® materials to stimulate awareness among audiences unaware of DES exposure.*

DES messages and materials should include a A call to action® B convincing the public to make a phone call, visit a web site, or talk to their health care professional on the next visit. Once this initial contact is made, we can follow up with more detailed DES information, such as the DES brochures developed during the pilot programs.

Choosing Channels

As discussed previously, for the DES National Education Campaign, we propose using existing health information channels to disseminate our messages. For example, the National Cancer Institute's Cancer Information Service provides credible, up-to-date information about cancer prevention, screening, and treatment and would be an important place to include DES messages. In addition, DES messages could be included on health and medical information Web sites, such as WebMD. Progress is already being made in this area as partnerships are being developed with agencies and professional organizations that have offered to include DES information on their Web sites.

Interpersonal channels put health messages in a more familiar context. These channels are more likely to be trusted and influential. Physicians, friends and family members of the target audiences are usually very credible sources and will most likely play an important role in the DES National Education Campaign.

Community and organizational channels (including community organizations and professional organizations) can reinforce and expand upon media messages.

Using a variety of channels will increase the repetition of DES information, raising the chance that the audience will be exposed to the messages a sufficient number of times to absorb and remember it.

When choosing channels, the following questions should be considered:

- \$ Which channels are most appropriate for the health problem/issue and message?
- \$ Which channels are most likely to be credible to and accessible by the target audience(s)?
- \$ Which channels fit the program purpose? (e.g., inform, change behavior)

Depending upon what we learn about our target audiences through the formative research and based on the results of the NCI pilot studies, we may choose a different mix of channels for each audience based on what they consider credible information sources and how they are most likely to be reached.

Convincing Physicians to Respond to DES

Challenge: *Physicians—even those who comprise our selected target audience—are unlikely to read most health communications materials they receive.*

Healthcare providers are bombarded with the latest and greatest health care information daily: the best new drug, the newest critical public health issue, new scientific findings and research. By targeting those who are closest to DES (ob/gyns), we lower the barriers to capturing their interest. However, targeting alone, as was demonstrated in the pilot study, is not enough: the channels and materials themselves must work to differentiate DES from the competitive clutter.

Response 1: *Collaborate with experts and partners nationally, and potentially in certain local geographic areas, to stimulate interest and attention in DES.*

Healthcare providers are more likely to support an issue if someone that they respect and know endorses the issue. In the Massachusetts pilot program, physicians were more likely to attend grand rounds or use the campaign materials when they were endorsed by someone they knew and respected. Local champions were also used to stimulate interest in DES. These champions distributed DES education materials and monitored physician practices to ensure that the DES materials were being used. Therefore, in partnership with the DES NEC Working Group, we can identify local experts in selected markets to help push the DES story through to our target physicians.

Response 2: *Engage physician office staff members to stimulate campaign effectiveness.*

As has been demonstrated in past campaigns (such as CDC's own *H. pylori* initiative), physicians' staffs can serve as gatekeepers in disseminating materials. In the California pilot study, office staff was shown to be extremely effective in disseminating campaign materials to reach physicians.

Stage 3: Developing Messages and Materials and Pretesting

Understanding the Process

We enter this stage having taken great care to make sure we fully understand both the issues surrounding DES and how our audiences think and feel about DES. Armed with this information, we are ready to take three key steps:

- (1) Developing message concepts and materials,
- (2) Testing those concepts and materials with target audiences, and
- (3) Making changes based on what we learn.

We will develop message concepts (i.e., messages in rough draft form) using input from the Working Group, audience research conducted to date, and principles of effective health communication. These messages will be designed to help us achieve our communication objectives.

A Cautionary Note: *It is important to recognize the range of emotional responses that people have to the DES issue, and to prepare messages and materials accordingly.*

DES exposure is unlike many other public health issues in that it was 100% caused by the actions of another person or a healthcare provider and was continued long after it should have been stopped. This leads to a range of emotions about being DES exposed that can have a significant impact on the audience. All materials should be carefully tested with DES audiences to ensure that they are respectful of the DES experience. Similarly, materials developed for those who are unaware of DES exposure should be informative but not alarmist or inflammatory, to avoid causing unnecessary pain to those who cannot confirm their DES exposure.

But first, what is a *message*? In its purest form, a message contains key information you want to convey. But, most importantly, messages are imbued with qualities such as emotional or motivational qualities that help your target audience to take notice or start to think differently about an issue. We cannot emphasize enough how important it is to get the message right. Failure to develop a clear, effective message will result in first failing to have an impact on the target audiences or if they do not understand the message and/or do not see the issue as relevant, they are not likely to respond to it. Of even greater concern, however, is that a poorly developed message will create unnecessary anxiety among the audiences. Should this happen, our attempts to demonstrate caring and commitment to the victims of DES exposure through this campaign would be outweighed by the amount of emotional harm caused. Getting firsthand feedback from audiences on message concepts will help us ensure that the messages are effective and appropriate. Specifically, we will learn more about issues such as the audience's emotions about the information the messages convey, the words they prefer, and whether some messages are likely to be more important or more motivational than are others.

In addition to making sure that message concepts reflect audience research and the input of the Working Group, some key principles of

communication will guide our message development. For example, based on what we understand about health communication, we can predict that some of our challenges may include:

- \$ Ensuring that DES exposure is seen by our target audiences as relevant (given the cacophony of new health information in our environment currently)
- \$ Helping individuals understand how the risk of exposure applies to them (as correctly grasping one's own relative risk can be difficult)
- \$ Describing clearly and simply what steps people can take to learn whether they have been exposed to DES (because it is critical that the *call to action* we make is easy to understand and implement)

And we know that our messages must be constructed to be:

Clear	<ul style="list-style-type: none"> • Messages should be easy to understand and free from jargon.
Consistent	<ul style="list-style-type: none"> • The National Education Campaign must be able to convey both what science tells us about the risks of DES exposure and what we do not yet understand about DES exposure without confusing or frightening our audiences.
Focused on main points	<ul style="list-style-type: none"> • It is a common urge to render simple messages complex by filling them with information, clauses, caveats and the like because so much of what we wish to convey is important. We must stay focused on what matters most. The details will be conveyed, but core messages must be focused on the most important main points.

<p>Constructed with the appropriate tone and appeal</p>	<ul style="list-style-type: none"> The DES National Education Campaign messages may, for example, strive to create a sense of urgency for action while also reassuring our audiences.
<p>Responsive to audience concerns</p>	<ul style="list-style-type: none"> In order to even pay attention to the issue of DES exposure, our audiences will first need to recognize that our messages are relevant and important to them

Messages will be incorporated into draft materials for testing. A materials audit and Working Group input will help inform decisions about what materials will be useful for the DES National Education Campaign. Potential materials include brochures, kits for health care providers and media, and fact sheets.

Once message concepts and draft materials are developed, they will be tested with our target audiences, the most important people of all. The evaluation contractor will conduct communication product pretesting with audience members and ask questions like the following:

- \$ Which of these messages gives you the most important *new* information? (to explore how attention-getting and how helpful the message is)
- \$ What is this message trying to say? (to explore whether the message is understandable)
- \$ Do you feel as if these messages are meant for you or for someone else? What about them makes them relevant/not relevant to you?
- \$ Will this message motivate you to take action? (e.g., find out about your DES exposure status)

- \$ Do you read anything in these messages that you find difficult to believe? How about easy to believe?
- \$ When you look at these materials, what is your gut reaction?
- \$ How could the materials be made more visually attractive?

The responses to these questions will be analyzed and shared among the key individuals working on the campaign. Together, we will refine the campaign messages so that they are easy to understand, reflect the appropriate emotions, and convey the key issues identified in our communication objectives.

Stage 4: Implementing Your Program

Understanding the Process

With our target audiences defined, channels selected, and messages and materials in hand, we are ready to implement the program. While there are numerous ways to implement a program, we will describe here an approach that is consistent with the findings from the NCI pilot programs and the campaign strategy B to embed DES messages in stable educational structures. In essence, this implementation approach focuses on intensive one-on-one relationship building with key organizations, established health information structures, medical school curricula developers, and health media reporters and editors.

As opposed to a flash in the pan publicity, working to get our messages in a variety of health and medical contexts may be the strongest, most effective way to reach our target audiences. This approach may sound simple but requires intensive relationship building with key organizations and individuals who have the capacity to reach thousands of consumers and health care providers.

Getting on the Public Health Agenda

Challenge: *Today's health information environment is extremely cluttered and competitive, making it difficult for less known public health issues to attract the attention they deserve.*

As discussed in the hypotheses section of this plan, the health information environment is extremely competitive. For example, CNN estimates that they're pitched on dozens of Acritical@ health stories per day. Breaking through the clutter can be difficult for even the most well-known public health topics.

Response: *Integrate DES messages and materials into other public health issues in order to Apiggy back@ coverage of DES.*

DES has relevance to a number of public health issues that are currently on the nation's public health agenda: reproductive health, breast care, fertility, and cancer. Rather than attempting to create a DES campaign from scratch Bfacing the competition and clutter of so many other campaigns B we propose partnering with existing public health initiatives to disseminate DES messages. This will not only sidestep the challenge of gaining media attention for a Alow profile@ issue, but also establishes a framework for a sustainable campaign.

Who are these organizations and individuals? You are quite familiar with many of them because they are represented on the DES NEC Working Group. The American Medical Association, the Office of Women's Health, the American Academy of Physician Assistants, the National Association of Nurse Practitioners for Women's Health, the Association of Reproductive Health Professionals, and the American College of Nurse-Midwives provide powerful voices to carry the DES message to health care providers. In addition, the dozens of other medical professional associations CDC has relationships with provide opportunities to embed DES messages in professional newsletters, medical school curricula, conferences, etc.

Medical schools and colleges designated by the Office of Women's Health as Centers of Excellence for Women's Health will be involved in the development and implementation of educational materials for health care providers (physicians, nurse-practitioners, and physician assistants). The Centers include the University of Wisconsin, Yale University, Harvard, Magee Women's Hospital, Boston University Medical Center, University of CaliforniaBLos Angeles, University of CaliforniaBSan Francisco, MCP Hahnemann University, University of Illinois at Chicago, and Indiana University School of Medicine. Guided by the formative research findings

the Centers of Excellence will develop materials targeted toward health care providers.

Educational materials developed by the Centers of Excellence would likely include 1) Development of DES courses: free-standing, multiple-unit programs for use as CME's CEUs, provider workshops, and/or self-study. 2) On-line resources (including materials designed for a DES National Education Campaign web site and appropriate to health care providers), 3) Development of single-unit DES Lectures/Grand Rounds Presentations, and/or Professional Education Seminars, 4) Development of materials to integrate DES education into ongoing medical, nurse practitioner, and physician assistant training. 5) Development of ABench to Bedside® essays on DES--reviews of current research on DES which identify practice implications for specific provider audiences to be published in specialty provide-type journals.

The Centers of Excellence will incorporate the programs and materials developed in their own medical curricula and training programs. In addition, they will assist in the dissemination of materials through established and appropriate grand rounds programs, educational seminars, and training channels. Although the Centers are recognized for their excellent programs in women's health, they are committed to the development of effective materials for educating primary care physicians about DES effects, screening, and treatment in DES sons.

The advocacy groups B including DES Action, DES Cancer Network, DES Sons Network, and the National Women's Health Network B as well as government health agencies like NCI are credible resources for disseminating the latest information about DES exposure. These sources of information are particularly important for the men and women who know they have been exposed to DES and for those who are searching for answers because they have been experiencing symptoms consistent with DES exposure. Reaching out to other groups who have access to the many men and women suffering from symptoms of DES exposure B

and are as of yet unaware of why B provides additional opportunities to place DES messages. This covers two of our three consumer audiences.

For those audiences who are not yet aware of DES or have not been experiencing problems like infertility or high-risk pregnancies, we can best reach them through channels they are likely to use already B such as health and medical information Web sites, doctors= offices, health and wellness magazines, and popular consumer health books. By building relationships with the health and medical reporters/editors of Web sites, magazines, newspapers, and TV/radio shows, we can encourage them to include DES messages. The goals of this outreach would include having DES messages included in articles about fertility issues, or women=s health risks, or lists of top things you should know about your health.

This approach B embedding health messages in a variety of health and medical contexts B allows for a long-lasting, sustainable program. The relationships established early on in the program can be expanded and messages about the latest DES research can be provided on a continuous basis.

Stage 5: Assessing Effectiveness

Understanding the Process

Naturally, the DES National Education Campaign will need to know how well it has conveyed its messages, changed the thinking of target audiences, and perhaps even influenced some key behaviors such as doctors talking with patients about DES exposure. We will assess effectiveness at several stages:

- \$ During the research phase through **formative evaluation** to understand our audiences and assess our message concepts and materials;

- \$ During campaign implementation through **process evaluation** to assess how well our activities are working (and make any needed adjustments); and,
- \$ At a predetermined time far into the campaign to assess through **outcome evaluation** short-term results (such as knowledge, attitude, and behavior changes among target audiences or policy changes in physicians= offices).

To assess the effectiveness of the DES National Education Campaign, the evaluation contractor will be asking questions like the following:

- \$ Were campaign objectives met?
- \$ How well was each stage of program planning and implementation handled? How can program activities be improved?
- \$ What changes in target audiences= knowledge, attitudes, and behaviors did the program achieve?

The unique nature of the DES issue B which has been described throughout this plan B calls for additional evaluation any possible unintended effects of the campaign (e.g., creating unnecessary anxiety among target audiences). Porter Novelli will develop an evaluation plan to monitor the ethical impact of this campaign, which may include:

- \$ periodic assessments of the emotional (e.g., fear) impact of DES-related information on consumer audiences;
- \$ periodic interviews with expert informants (e.g., members of DES advocacy groups) to assess ethical impact of the campaign; and
- \$ focus groups with DES-exposed mothers, sons, and daughters to learn more about their emotional reactions to knowing their status (and related health risks), and to learn how their health care providers dealt with the issue.

Stage 6: Feedback to Refine Program

Understanding the Process

This step can often be forgotten in the hustle and bustle of program work. But reflecting upon the information gathered and lessons learned helps us prepare for a new cycle of program development.

At this stage, we will

- \$ Reassess campaign objectives (to phase in any new objectives needed as we make progress toward achieving the campaign's initial objectives)
- \$ Determine any programmatic changes that should be made to increase our effectiveness (to establish new procedures if needed, adapt or abandon any strategies that have proven to be less effective than planned, etc.)
- \$ Reaffirm support (to reenergize partner groups if needed, ensure that key stakeholders feel that the program continues to move in the right direction)
- \$ Apply any other lessons we have learned over time.

This stage should also look at the bigger picture. Just as we have been fortunate to learn from other health and risk communication efforts, so too might future programs be able to learn from the DES National Education Campaign. At this stage we will have a wealth of information about how our audiences relate to the issues surrounding DES, what messages and outreach methods were most effective, and what processes helped us to make the campaign sustainable over time. Moreover, the qualities that make a campaign on this issue so different from some past public health campaigns may be especially helpful for others working on issues that bear similarities to DES. Therefore, this stage is a time for thinking about venues such as conferences, meetings of advocacy groups, web-based forums, professional journals or publications, etc. for sharing lessons learned. If indeed, a part of our mission is to right a past wrong then it is

our responsibility to share what we learn from our audiences and the experience of carrying out the DES National Education Campaign.

APPENDIX A

Porter Novelli's *Healthstyles* A Health Information Seeking® Audience Segments

Healthstyles is an audience segmentation database that provides information about the American public's health practices and the meanings of health to the American people. In addition, the database provides a wide range of general lifestyle information including media use, attitudes, perceptions of self, activities, and shopping patterns.

Healthstyles is based on the results of three mail survey questionnaires administered annually since 1995 -- the DDB Needham Life Style Survey & supplemental Life Style survey which contain most of the demographic and media use questions and the *Healthstyles* survey which contains the core *Healthstyles* instrument, a host of other health questions developed to support basic segmentation and profiling work, and questions that meet the information needs of specific clients. The most recent *Healthstyles* analysis examined the health-information seeking patterns of the American public and revealed five distinct audience segments: Moderates, Independent Actives, Doc-Dependent Actives, Doc-Dependent Passives, and Uninvolveds. A brief description of each segment is provided below. The first three segments (marked with an asterisk) which comprise two-thirds of the general population are proposed target audiences for the DES National Education Campaign.

Moderates*

Moderates are the largest group, making up 28% of the adult population. They have an age and ethnic distribution similar to that of the general population, although they are slightly more likely to be women (56%). Of all the groups, Moderates most closely reflect the general population.

They are neither active nor passive seekers of such information. They value such information, because they believe they need it to stay healthy.

Unlike other groups, Moderates prefer to get their information from a variety of sources rather than mostly doctors. They are moderately satisfied with the health information they obtain from their doctors, and they are somewhat proactive in seeking it from their doctors. Compared to the average person, Moderates are slightly more confident in their ability to understand the health information they receive from their doctors as well as other sources. They also have a somewhat stronger orientation toward health prevention.

Independent Actives■

Independent Actives comprise 19% of the adult population. They have an age distribution similar to that of the general population but are more likely to be women (68%). Although the majority is White (76%), Independent Actives have a higher proportion of Blacks than the population at large and lower Hispanic representation (7%). Of all the groups, Independent Actives are the most active seekers of health information. They highly value such information, both because they believe they need it to stay healthy and because they enjoy learning about health. Unlike Doc-Dependent Actives, Independent Actives prefer to get their information from a variety of sources rather than mostly doctors. They are the most proactive in seeking information from their doctors and highly satisfied with the information they receive, though less so than the Doc-Dependent Actives. In addition, they are the most confident in their ability to understand the health information they receive whether from their doctors or other sources. Along with Doc-Dependent Actives, Independent Actives are committed to living a long and healthy life.

Doc-Dependent Actives*

Doc-Dependent Actives account for 20% of the adult population, the same percentage as that of Doc-Dependent Passives. They are the oldest group, with 34% being ages 65 or older. Of all the groups, they have the most even gender distribution (53% female and 47% male). Compared to the other groups, they have the lowest percentage of Whites (69%) but higher percentages of Blacks (16%). Doc-Dependent Actives are one of two groups that are most active in seeking health information; they are not as active as Independent Seekers. They highly value health information, more because they believe they need it to stay healthy and less because they enjoy learning about health. As opposed to Independent Seekers, Doc-Dependent Actives prefer to get their information from a narrower range of sources, and as do Doc-Dependent Passives, they often turn to their doctors. Yet Doc-Dependent Actives are unlike Doc-Dependent Passives in that they rely even more heavily on doctors, are more proactive in seeking information from doctors, and are more satisfied with their relationship with doctors. Doc-Dependent Actives are less confident than most other people in their own ability to understand the health information they receive from their doctors as well as other sources. Regardless, they place a high value on health prevention, and slightly more so than Independent Seekers.

Doc-Dependent Passives

Doc-Dependent Passives account for 20% of the adult population. They have an age distribution similar to that of the general population. They are slightly more likely to be men (57%). Although the majority are White (74%), they are more likely than any other group to be Asian/Pacific Islander (5%). Doc-Dependent Passives are one of the least active seekers of health information, second only to Uninvolveds. They place little value such information, although they value it somewhat more than Uninvolveds. More than any other group, they claim that lack of time is a barrier. Similar to Doc-Dependent Actives, Doc-Dependent Passives prefer to get their information from a narrower range of sources, particularly doctors. Unlike their counterparts, they are somewhat dissatisfied with their relationship with their doctors, and they are much less proactive in seeking information from their doctors. Of all the

groups, Doc-Dependent Passives are the least confident in their ability to understand the health information they receive from their doctors as well as other sources. Doc-Dependent Passives have a weak orientation toward health prevention, which is only slightly stronger than that of Uninvolveds.

Uninvolveds

Uninvolveds make up 14% of the adult population. They are younger than any other groups (45% are 18-34 years old). Uninvolveds are more likely to be men (67%). Compared to any other group, they are most likely to be White (82%) and least likely to be Black (4%).

Uninvolveds are the least active seekers of health information, and they seldom value such information. Unlike Doc-Dependent Passives, they prefer to get their information from a broader variety of sources rather than mostly doctors. They have little satisfaction with the information they obtain from their doctors and are the least proactive in seeking information from their doctors. Compared to Doc-Dependent Passives, they have more confidence in their ability to understand the health information they receive from their doctors as well as other sources. Uninvolveds have the weakest orientation toward health prevention.

APPENDIX B

DES National Education Campaign

TENTATIVE TIMELINE

Activity	Key Dates
1) Develop Campaign Development Plan and Formative Research Proposal; Present to DES NEC Working Group	4/26/00
2) Revise plan and proposal based on DES NEC Working Group feedback	5/15/00
3) Conduct formative research	complete by 8/31/00
4) Develop creative briefs for target audiences	complete by 9/30/00
5) Create a strategic communication plan for DES National Education Campaign	complete by 10/31/00
6) Develop draft concepts of campaign messages and materials for each of the selected target audience segments	11/30/00
7) Develop a plan for concept testing	11/30/00
8) Conduct concept testing	1/31/01 (delay due to Holidays)
9) Product development and modification	Winter 2001

- | | |
|--|-------------|
| 10) Materials testing | Spring 2001 |
| 11) Develop a plan for campaign materials dissemination | Summer 2001 |
| 12) Develop a plan to monitor on-going progress and reach of the DES National Education Campaign | Summer 2001 |
| 13) Develop a plan to evaluate the ethical impact of the DES National Education Campaign | Summer 2001 |
| 14) Print materials | Summer 2001 |
| 15) Implement program | Fall 2001 |

APPENDIX C

**Existing Educational Materials with Potential for Use
In the DES National Education Campaign If Updated, Modified, and/or
Condensed**

Existing DES Consumer/Physician Materials	Mother s	Daughter s	Son s	Physician s
Clear Cell Cancer: Resource Guide for DES Exposed Daughters and Their Families		X		
DES Daughters: Women Born Between 1938 and 1971 Who Were Exposed to DES Before Birth		X		
DES Sons: Men Born Between 1938 and 1971 Who Were Exposed to DES Before Birth			X	
Talking about DES: A Family Guide for DES-Exposed Mothers, Daughters and Sons	X	X	X	
Were You Born Between 1938 and 1971 or Pregnant Then? If So, You Could Be Exposed to DES (two versions)	X			
Women Who Took DES: A Guide for Women Who Took DES During Pregnancy From 1938-1971	X			
Physician Information: How to Identify and Manage DES Exposed Individuals				X
Prenatal Diethylstilbestrol {DES} Exposure: Recommendations of the Diethylstilbestrol-Adenosis {DESAD} Project for the Identification and Management of Exposed Individuals				X
An Atlas of Findings in the Human Female After Intrauterine Exposure to Diethylstilbestrol				X