Summary Report:

A Review of NCI-Sponsored Pilot DES Education Programs

and Recommendations for the DES National Education Campaign

Marsha L. Vanderford, PhD
Penelope McMullan Johnson, MEd
National Center for Environmental Health
Centers for Disease Control and Prevention
4770 Buford Highway
MS F-29
Atlanta, GA 30341

May 23, 2000
# Table of Contents

- **Background** .......................................................................................................................... 1

- **Introduction: Brief Descriptions of Five NCI Pilot Studies** .................................................. 2
  - California ................................................................................................................................. 2
  - Massachusetts ......................................................................................................................... 3
  - New York ............................................................................................................................... 3
  - Texas ....................................................................................................................................... 4
  - Wisconsin .............................................................................................................................. 4

- **Lessons from the Five Site Studies** ....................................................................................... 5

- **Lessons from the Campaigns for Physicians** ...................................................................... 5

- **Lessons from the Campaigns for Consumers** .................................................................... 12

- **General Lessons for Health-Care Provider and Consumer Campaigns** .......................... 18

- **Recommendations for the National Education Campaign** ................................................ 19

  - **Recommendations for Formative Research** .................................................................... 20

  - **Recommendations for the Campaign for Providers** ....................................................... 22

  - **Recommendations for the Campaign for Consumers** .................................................... 25
Background

In 1999, Congress directed the National Institutes of Health to fund the Diethylstilbestrol (DES) National Education Campaign, expanding on five regional pilot educational efforts conducted by the National Cancer Institute (NCI) during 1993-1997. The Women's Health Research and Prevention Amendments of 1998 and the 1999 Appropriations Report direct NCI to contract with and provide funding to the National Center for Environmental Health (NCEH) at the Centers for Disease Control and Prevention (CDC) to "carry out a national program for the education of health professionals and the public with respect to DES.@

A national campaign was mandated because DES, prescribed for an estimated five million pregnant women during 1938-1971, was subsequently found to cause a rare vaginal cancer in DES daughters (women who were exposed to DES in utero) and abnormalities in the reproductive organs of the daughters and sons born to women who took DES while pregnant (DES mothers). Studies published as early as 1953 disproved the initial belief that DES decreased the risk of miscarriage. The Food and Drug Administration (FDA) issued a recommendation that DES not be prescribed for pregnant women in 1971, but the DES legacy lives on in the mothers who took it and in the sons and daughters they bore. The need for both consumers and their health-care providers to be vigilant in health-care screening and to have access to current DES information continues as exposed persons grow older. Much is still unknown about the long-term effects of exposure to DES. NCI supports continuing cohort studies to capture disease trends and health outcomes of exposed persons. Ongoing research has found additional health risks for third-generation DES-exposed mice.

The DES National Education Campaign will build on the results of the coordinated consumer/physician interventions developed by the NCI-sponsored regional pilot programs. Because no report was available that summarized the combined results of the NCI projects, the first task of CDC/NCEH staff was to describe the NCI pilot studies and compare the findings from the projects to derive lessons on which to base a national campaign. The CDC/NCEH staff have read the reports of all five pilot projects; carried out on-site interviews; and studied methods, messages, messengers, media, and materials to identify strategies and tactics most likely to optimize the efficiency and impact of a scaled-up nationwide campaign. (See Appendix A for the sources upon which this report is based.)
Introduction: Brief Description of Five NCI Pilot Studies

During 1993-1997, NCI funded five collaborative regional pilot studies designed to educate physicians and consumers about health risks and screening for DES exposure. The five studies developed a common set of questions for consumers and physicians for use in pre-intervention surveys to determine baseline information about DES knowledge, attitudes, and behaviors (see Appendix B for list of physician questions, and Appendix C for consumer questions). The pilot study teams collaborated on the development of seven educational booklets for consumers produced by the California site (see Appendix A for the titles of the consumer education booklets). All sites except Texas used these booklets as part of their consumer education programs. The Texas team developed an educational booklet for physicians, and all of the pilot study sites, except Massachusetts and California, distributed the booklet. Except for the pre-intervention questionnaires and the booklets, however, most of the strategies and materials that the pilot projects employed were unique and unrelated to the other projects.

Below are brief overviews of the pilot education studies. See Appendix A for information about individual study reports.

California

The California study was designed to identify and overcome barriers to the identification, diagnosis, and treatment of DES-related health problems and to disseminate educational material to as many DES-exposed persons as possible. The campaign involved three communities in which one community was the target for a consumer and a physician campaign, a matched community was the site for a physician-only campaign, and a third community served as a control. The physician study targeted 25 health-care providers in each community. The majority of the providers included in the study were physicians; 22 nurses, nurse practitioners, and physician assistants were also enrolled. Intervention site providers were invited to DES grand rounds and asked to schedule a DES Academic detailing visit. (Academic detailing is an educational process in which physicians have individual sessions with a credible expert in an attempt to influence the clinicians’ practice behaviors.) California providers received educational materials, DES office posters, and a DES office manual as a part of academic detailing visits.

Using the same matched communities as the provider campaign, the consumer campaign included a social network intervention called TalkDES, which educated 100 female opinion leaders about how to spread DES information to their friends and families. Opinion leaders received training, periodic updates about the campaign, and newsletters to motivate their activities. A consumer hotline was established to provide up-to-date DES information. TalkDES volunteers and targeted health-care providers were encouraged to refer women to the hotline for

1Although a small number of non-physician health care providers were included in several of the studies, the provider interventions focused on educating and motivating physicians.
further information on DES.

The social network campaign was supported by a background media campaign on DES, including dissemination of fact sheets in public settings, press releases to local newspapers, a local theater production, and cable television programming.

Massachusetts

The Massachusetts health-care provider campaign was designed to improve screening, treatment, and support for persons at risk for DES-related health risks. The project was conducted in the obstetrics/gynecology and internal medicine departments at 13 freestanding health centers at Harvard Pilgrim Health Care-New England, a Boston-area health maintenance organization (HMO). Sites were matched and assigned control or intervention status. Intervention sites received a comprehensive DES office systems intervention, including a DES tool kit \( \text{(DES Office System Manual)} \) to facilitate screening and appropriate follow-up for DES exposure and the clinical and administrative education necessary to use the tools effectively. The program involved both clinical (physicians, nurse practitioners, and physician assistants) personnel and office support staff. In control sites, health-care providers received an introductory letter from the local medical society, DES guidelines, and a reply card to receive recommendations for identification and care of DES-exposed patients.

The Massachusetts consumer study was designed to inform consumers about screening and prevention guidelines for individuals potentially exposed to DES. The project included a low-intensity public education campaign in which multiple reinforcing media and information channels delivered DES messages statewide through print, television, radio, and community outreach activities over a 10-month period (June 1995 through March 1996). Specifically, consumer messages encouraged the public to call a DES hotline for further information. Pre-intervention focus groups identified messages to move individuals from current stage of knowledge and behaviors to the next level of action. On the basis of focus group results, hotline callers were given steps to take to confirm DES exposure, strategies for initiating dialogue with family members about DES, and access to up-to-date prevention and screening information and free consumer education booklets.

New York

The New York campaign for physicians was designed to encourage physicians to ask about and record DES exposure in medical history, to conduct appropriate exams, to recognize patient concerns, and to provide patients with information. The New York team conducted a high-intensity intervention with 113 physicians who received not only DES academic detailing from a visiting physician but also an office tool kit, an invitation to apply for DES continuing medical education (CME) credits, educational materials, invitations to DES grand rounds, and calls from a registered nurse. A low-intensity campaign was conducted with 129 physicians who received the national guidelines for identifying and treating DES exposure and a letter of endorsement from the Nassau County Medical Society.

The consumer intervention focused on two audiences: individuals who were unaware of DES exposure status and persons who had confirmed exposure. The goals for the general public were to raise awareness of and knowledge about DES and the potential health effects of
exposure. A media campaign was designed to reach individuals who were unaware of exposure including press kits to 72 media outlets, special DES theater programs and speakers, and DES billboards. Newspaper articles, media inserts, mailings to community organizations, and DES flyers were all used to inform the public.

The campaign for DES-exposed daughters was designed to encourage daughters to get appropriate pelvic examinations, to encourage mothers to get regular breast exams, and to answer the public’s questions about exposure and care. The project drew subjects from the DES Screening Center patient list, local DES Action members, and local members of the DES Cancer Network. Based on concerns that DES-exposed women were experiencing barriers to appropriate care, the project included telephone counseling for DES mothers and daughters. Local telephone counselors were trained to solicit obstacles and employ algorithms with specific responses dependent upon the particular obstacle reported by the DES mother or daughter. In each case callers were provided with specific action steps.

Texas

The goals of the Texas campaign were to increase health information about DES exposure and to improve the early detection, diagnosis and treatment of several medical conditions associated with DES exposure.

The provider study solicited participation from a random sample of 1000 physicians by mail. The research team received 264 responses to their invitation. An additional 132 health-care providers were recruited through nomination of hotline callers who identified their providers as potential subjects for the provider study. Half of the mail recruits and all of the hotline recruits were assigned to a high-intensity intervention: a four-stage process including mailed booklets on patient care, algorithms, chart stickers, patient education materials, a videotape on patient care, and a newsletter with recent DES studies and references for future reading. The low-intensity intervention participants received the same materials as the high-intensity intervention, except for patient education booklets, algorithms, and chart stickers.

The Texas study team created a custom set of campaign materials. All identified the source of messages as the Southwest DES Center. Included were paid print ads; press kits for television, radio, and print features; and an educational videotape. Texas designed and distributed a single, comprehensive booklet for consumers, rather than using the collaboratively produced materials. Consumers were recruited to the study from three groups: DESAD cohort members; 800 line callers; and corporate health and wellness programs. Individuals who agreed to participate in the study received educational materials, including a fact sheet, an instructional shower card for breast and testicular self-examinations, and a newsletter with abstracts of the most current DES studies available. In addition to its use as a recruiting tool, the toll-free phone line provided access to a trained information specialist who was available to answer DES questions.

Wisconsin

The goals of the Wisconsin intervention were to increase public awareness and knowledge of DES and to increase attempts to confirm DES exposure-status. The campaign was designed to increase physicians’ DES-related knowledge and use of recommended screening procedures. The
Wisconsin campaign included outreach to four states (Wisconsin, Minnesota, Illinois, and Iowa), with matched communities as intervention and control sites. Physicians were target audiences in Peoria, Ill.; Cedar Rapids and Sioux City, Iowa; Alexandria and Mankato, Minn.; and Green Bay, La Cross, and Madison, Wisc.

In intervention sites, physicians were invited to special DES grand rounds and received a videotape of a DES education lecture, as well as NIH practice guidelines for DES, patient education booklets for distribution, cards to request a DES office management kit, and an opportunity for CME credit through the University of Wisconsin. A DES information phone line for physicians was established for the duration of the campaign.

The consumer intervention was carried out in four of the communities: Alexandria, Minn; Green Bay, Wisc; Peoria, Ill; and Mankato, Minn. The campaign included three paid public service announcements broadcast on local television in each treatment area. Two of the messages focused on DES exposure; the third focused on early detection of testicular cancer. In addition, printed consumer booklets were distributed through libraries and HMOs in each treatment area. A toll-free line, 800 DES-News was established for the period of the consumer intervention and was staffed by DES Action in California.

**Lessons from the Five Site Studies**

Because of the diversity of tactics, sampling techniques, analytic procedures, and assessment measures, no generalizable findings can be identified by comparing the five studies. In addition, several of the studies focused on small samples of target audiences. All of the studies found some statistically significant effects from their interventions. However, most of the intervention results were small. Nevertheless, several themes can be gleaned by comparing and contrasting the pilot studies to identify common tactics and characteristics among campaigns achieving campaign objectives.

**Lessons from the Campaigns for Physicians**

The pilot studies demonstrate the power of local sources of influence in which specific contexts, institutional practices, and professional networks have the most impact on physicians= actions, knowledge, and attitudes. The incorporation of other health-care providers, in addition to physicians, increased the effectiveness of education projects. Educating physicians about DES requires overcoming a disjuncture between stated attitudes and professional behaviors. Traditional forums for physician education--printed materials and CME meetings--can have an impact on providers= knowledge, but they are not usually sufficient to move physicians to change practice. Finally, obstetrician-gynecologists are the least in need of DES education; primary-care physicians are the least knowledgeable and least likely to provide appropriate DES screening.

Although the California, Massachusetts, and Texas pilot studies included non-physician health-care providers in their studies, most of the results focused on physicians. Few of the studies identified knowledge, attitudes, or behaviors of nurses, nurse practitioners, physician assistants, or office staff. As a result, the lessons and recommendations to follow focus on physicians, unless specifically identified as related to non-physician health-care providers.
1. The most successful campaigns relied upon local sources of influence.

Three tactics fall within this category: a) The existence of a local champion for DES education within a practice organization or other campaign community, b) a regionally/locally respected medical school or research institution as sponsor for the campaign, and c) the incorporation of the campaign within the physicians’ practice institution and routine.

The Massachusetts pilot study had the most success in influencing physicians to learn about DES and to screen for related health risks. A comparison of pre- and post-intervention measures of intervention site physicians showed large and statistically significant increases in physicians’ familiarity with DES, reading of the national guidelines on DES health risks and treatment, inclusion of DES on intake forms, routine questioning about DES exposure, knowledge about health risks for DES mothers and daughters, and recording of DES information on medical charts and to computer data banks.

The Massachusetts campaign was unique; it included two of the three characteristics of local influence—endorsement of the physician’s practice unit and a local champion for DES education. The DES education project was adopted as unitwide projects of the Departments of Internal Medicine and Obstetrics-Gynecology at Harvard Pilgrim Health Care-New England (HPHC-NE); therefore, the campaign had the endorsement and resources of the physicians’ local practice organization. HPHC-NE held DES education sessions during regularly scheduled meeting times, added DES on unitwide intake forms and computer systems, and provided back-up support for physicians in the form of office staff reinforcement for DES screening and follow-up.

The Massachusetts study also had two local champions, a physician-liaison between the research team and the health-care organization and a nurse practitioner. These insiders served as physically present reminders, points of information, and resources about DES during the campaign at the providers’ work sites.

The research team and the lead physician from HPCH-NE reported that the use of regularly scheduled meeting time for DES education was critical to the success of the intervention. Saving time is one of the highest values in health care. Incorporating DES education into already scheduled meeting times avoided the ever-present time barrier that prevents physicians from attending to many health promotion tasks. In addition, incorporation of DES education in regular daily business signals that the issue is not a one-time special event, but a part of daily practice issues.

The need to incorporate DES education into regularly scheduled meetings and educational programs is reinforced by a comparison with the New York project. In New York, a special DES lecture/dinner was sponsored by the pilot study in conjunction with the Nassau County Medical Society. Although the New York educational content was similar to that presented at HPHC-NE, the New York events were not a part of an established CME program or ongoing institutional education program that physicians attended regularly. The difference in attendance is compelling. In comparison to participation by the entire department in Massachusetts, only eight physicians (of 113 invited) attended the New York sessions.

Although the Massachusetts campaign had the greatest success in meeting campaign goals for physicians, other campaigns that relied on local influence also were effective. The California campaign team effectively used local endorsement for DES grand rounds. The Medical Chiefs of
Staff at the three hospitals where DES grand rounds were held cosigned letters of invitation to DES programs. Attendance at the education programs ranged from 43% to 100% of the targeted physicians. The highest level occurred at the Kaiser Permanente site, where the obstetrics-gynecology department adopted DES education as a unitwide goal. In Texas, Dr. Raymond Kaufman’s involvement in the Texas project was visible and direct. As an internationally renowned DES expert and Director of the DES Baylor DESAD cohort, Kaufman was principal investigator for the Texas project and reported that he knew most of the obstetrician-gynecologists in the study area. Kaufman reported calling physicians personally as part of the recruiting and follow-up process. Because about 70% of physicians in the Texas study were obstetrician-gynecologists, Kaufman’s personal involvement, local influence, and reputation probably played a motivational role in physicians’ response to the Texas study (where effects included statistically significant increases in reading guidelines, asking about DES, and adding DES to intake forms).

The use of local influence was supported in interviews with research partners for the pilot studies. Allen Dietrich, M.D. (Dartmouth College), expert on physicians’ office systems and designer of the HPHC-NE system intervention, explained that to get physicians’ attention, a letter or request must come from someone the physician knows personally and respects. Otherwise, letters and materials—even those from professional organizations and agencies such as the American Medical Association—are likely to be discarded. This view was reinforced by Dr. Kaufman. According to Kaufman, “Your best way to reach physicians is to have someone the recipient knows and respects to individually sign the letter endorsing the program.”

2. Involvement of physicians’ office staff as part of the DES campaign increased the effectiveness of campaigns.

Several physicians involved in the pilot studies explained that most mailed material, requests for appointments (including academic detailing), and announcements of events (such as CME programs) do not reach physicians. In his studies of office systems, Allen Dietrich, M.D., has found that office staff are trained to be gatekeepers, filtering less important mail from higher priority items. His conclusions are supported by the Wisconsin study, in which only 38% of physicians responded post-interview that they had received mailed DES educational material that was sent to all physicians. More successful campaign efforts incorporated these office staff gatekeepers into the campaign.

Both California and Massachusetts had successes as a result of involving office staff in the campaign. In Massachusetts, office staff were instructed about DES screening and health risks and were trained to use an office system DES manual with special codes and chart stickers. In California, when physicians failed to respond to requests for patient names, to respond to reminders about returning surveys, or to schedule DES academic detailing appointments, the campaign team contacted office staff and provided incentives for nurses and receptionists to encourage the physicians’ cooperation. Periodic study newsletters were sent to intervention site office staff to motivate them to help with the study. The California team was able to schedule 86% (double intervention targets) to 65% (single intervention targets) of their academic detailing visits and to obtain 100% of patient names requested for pre- and post-intervention surveys. Both of these tasks required the cooperation of office staff.
These results indicate that physicians' office staff influences physicians' attentiveness to campaign messages. In addition, the incorporation of non-physician health-care professionals into DES education campaigns increases the probability of reaching campaign goals.

3. Educational materials and support systems are most effective when crafted specifically for particular physicians' practices.

All the pilot sites received copies of the *DES Office Systems Manual* developed by Allen Dietrich, M.D. The tool kit included DES medical journal reprints, diagnostic algorithms, chart stickers, and DES routing forms. The manual was specifically crafted for HPHC-NE, and its contents were divided between physicians, nurses, and office staff, depending upon their professional functions and roles in the DES campaign.

The tool kit was carefully crafted to meet practice patterns at HPHC-NE. In that context, the manual was introduced to physicians and office staff, and each staff member used manual information to fulfill role-specific elements of their jobs. The results of the Massachusetts campaign, detailed earlier in this document, clearly demonstrate the power of context-specific educational materials and a systems approach to interventions.

The cooler reception accorded the *DES Office System Manual* at other sites demonstrates the importance of making materials context specific. In Wisconsin, the manuals were offered to physicians without contextualization or incorporation of the tool kits into office practice by staff members. Only 31 of 1,552 enrolled in the Wisconsin study requested office manuals. In both Texas and Wisconsin, coinvestigators reported that physicians in their study areas ridiculed the manuals as unwieldy and inconsistent with their practices. In New York and California, the academic detailing physician used pieces of the *Manual* in their discussions with physicians, incorporating only those materials designed for physicians' use. No records were kept of the responses to the materials as a part of academic detailing visits.

4. Educating and motivating physicians to learn about and screen for DES-related health risks requires that campaigns overcome inconsistencies between physicians' attitudes and behaviors.

Survey data from all five sites consistently revealed that physicians believed that DES was an important health issue. However, their knowledge and screening behaviors contradicted their stated attitudes. Ninety-four percent (Massachusetts) to 58% (Texas) agreed that DES exposure in utero is a continuing health concern. In Wisconsin pre-intervention results indicated that 75% of physicians believed that it was important to obtain a history from DES-exposed female patients, and 50% agreed that such a history was important for exposed males.

Yet, the physicians' knowledge and screening behaviors failed to support these positions. In California, baseline scores for physician knowledge averaged 6.35 to 7.53 out of a possible 24 points. In New York, physicians at baseline averaged knowledge scores of 4.5 (out of 11 possible). In Wisconsin, physicians who rated themselves *very* familiar with DES answered less than one-half the questions on the knowledge survey correctly.

Physicians' behaviors also failed to support the importance of DES screening. In Texas, physicians who routinely ask about DES exposure ranged from 22% (physicians over 55 years old) to 9% (physicians who are 26-35 years old). At the Pleasanton, Calif., site, 5% reported that they routinely ask about DES exposure. Few physicians reported having DES exposure as a
question on their intake form. Fifteen percent to 20% of Wisconsin physicians reported having DES on their intake form at baseline. Baseline responses from Massachusetts revealed that 30-35% of physicians included DES on their encounter forms.

Reports from patients in California confirmed the physicians' self-report. Eighty-eight percent of DES mothers reported that their current provider has never asked them whether they were DES exposed, and 92% said their current provider has never given them a form containing a question about DES exposure.

5. Most physicians do not perceive DES information to be relevant to their practices.

One reason for the discrepancy between physicians' attitude—that DES is an ongoing health concern—and their failure to act on that belief may be the perception that DES is irrelevant to the doctor's patients and practice.

Survey data across the five sites indicated that physicians thought they had few DES patients. At baseline, fewer than 1% of Texas physicians surveyed reported having a DES-exposed patient. In Wisconsin, only 4% responded that they had any male patients who were DES exposed. Although baseline data for California physicians indicated that the majority (50% of primary care physicians and 68% of obstetrician gynecologists) had at least one DES-exposed patient, practitioners who declined to participate in the DES study indicated that DES education was irrelevant for their patient population.

In addition, DES-related health problems are low prevalence. With the likelihood of clear cell cancer being 1.4 in 1000, (or, more conservatively, 1.4 in 10,000) for DES daughters, many physicians expressed the belief that finding a clear cell cancer among their patients was very small. There is a higher prevalence of other DES-related problems, but they do not require special screening practices. Many of the preventative measures for DES exposure are the same as for nonexposed patients: testicular self-exam for DES sons and breast exams for DES mothers. As a result, physicians are unlikely to believe that knowledge of and screening for DES health risks produces any practical advantage in their practices. Physicians provide only 20%-60% of recommended health promotion counseling for very common problems such as smoking and hypertension. They are unlikely to attend to something perceived as having little practical impact on patient health outcomes. As one physician asked a co-investigator in the Wisconsin study, 

What does this have to do with my practice?

6. Pilot studies that created patient demand were more successful in heightening physicians' receptivity to DES information.

When physicians become aware that their patients are concerned about DES, physicians are more likely to respond by learning more about the drug and its health effects. For example, Texas used a system of patient referral to recruit physicians for high-intensity intervention participation. When consumers called a DES hotline, they were asked to nominate their health-care provider for the provider study. In turn, when the research team contacted the provider, they indicated that the provider's patient was in the DES study and had nominated the provider for inclusion in the study. This tactic achieved a 100% success rate in gaining physicians' participation in the study.

Two other studies revealed that educating consumers has a booster effect on physicians—
knowledge and behaviors. In California’s double-intervention site (which included education for physicians and consumers), the increases in knowledge, reading DES guidelines, and asking patients about DES exposure were significantly higher than in the single-intervention site (where there was only a physician intervention). In Wisconsin, physicians who saw the consumer television spots (as consumers in their own homes) were more likely to have read national DES guidelines on care and management (84% versus 67% of those who didn’t see the ads) and more likely to ask patients about their DES exposure status than physicians who did not see the television spots (33% of those who saw the ad versus 14% for those who did not see the ad).

Consistent with the idea that patients’ concerns about DES increase physicians’ attention to the issue was Wisconsin’s finding that physicians who had DES-exposed patients were twice as likely to say that they were very familiar with the drug (35% versus 15%), twice as likely to have DES on their intake forms (32% versus 13%), and twice as likely to routinely ask about DES exposure (28% versus 15% of all physicians) as were physicians who did not have DES-exposed patients.

7. As a group, obstetrician-gynecologists are more knowledgeable about DES-related health risks, more receptive to DES education, and more responsive to DES education programs than are primary-care physicians.

Because DES has historically been identified as a problem for DES daughters and has been related to gynecologic cancers and abnormalities, obstetrician-gynecologists are most likely to perceive DES exposure as relevant to their practices. Across the pilot studies, obstetrician-gynecologists achieved higher knowledge scores, included DES on their intake forms, and asked about DES more routinely than did other physicians. Obstetrician-gynecologists in California had baseline knowledge scores that were significantly higher than those of other physicians and showed the largest increase in knowledge scores of any group (10.60 versus 8.38). In Wisconsin, obstetrician-gynecologists scored more than two points higher than all other physicians on DES knowledge. In Massachusetts, being an obstetrician-gynecologist (compared with other primary-care physicians) was significantly associated with higher scores in both knowledge and awareness of DES. Wisconsin’s baseline data indicated that obstetrician-gynecologists were more likely than other specialties to record exposure and counsel patients.

Obstetrician-gynecologists also were more likely to participate in DES educational activities. In both California and Massachusetts, obstetrics-gynecology departments embraced the DES education projects as departmentwide efforts. In Texas and in California’s double-intervention site, physicians who were successfully recruited for participation in the DES intervention where overwhelmingly obstetrician-gynecologists (70% in Texas and 67% in Pleasanton).

In contrast, primary-care physicians were the least attentive to DES health issues. The majority of physicians in each pilot study were primary-care physicians (internists or family medicine) or obstetrician-gynecologists. The final reports did not consistently analyze data to single out results for primary-care physicians. However, based on the effects reported for specialists, the sample that remains was almost all primary-care physicians. The non-obstetrician-gynecologists were consistently reported as less knowledgeable about, less familiar with, and less likely to ask about DES. Where primary-care physicians were a subject category, baseline surveys
indicated that primary-care physicians were the least likely to report being familiar with DES, least likely to ask about DES exposure (11%), and least knowledgeable about DES (knowledge scores were 6.93 out of a possible 22). In New York, generalists were least likely to distribute DES information to their patients and to enroll in the DES study.

8. Educational materials to physicians must be drawn from sources that are respected in the medical field.

Pilot studies that attended to the hierarchy of medical knowledge were more effective than those that neglected that principle. Across the pilot studies, physicians responding to baseline surveys reported that the medical journals were the sources physicians relied upon most to learn about DES health risks and treatment. In interviews, physicians consistently identified published medical research on humans as the basis for their practice decisions. As a result, the sources of information used in the pilot studies seemed to be critical to physicians.

The Texas campaign provides a good example how source credibility works. The materials in the campaign were consistently identified with Dr. Raymond Kaufman (as author or spokesperson). The Texas campaign materials included booklets edited by Dr. Kaufman, a video featuring him, and a letter signed by him. Materials were distributed by mail. The higher-intensity campaign group reported statistically significant increases in reading DES national guidelines, adding DES to their intake forms, and asking about DES exposure. No other campaign realized the same level of intervention effect by relying solely on mailed materials. A combination of local influence and source credibility in Texas were probable causes of the campaigns’ impact.

Experiences at other sites add weight to this argument. California’s higher attendance at grand rounds and greater intervention effects (significantly increased level of reading national guidelines and asking about DES) may well have been influenced by the credibility of the physicians who delivered the grand rounds at the California sites: Kenneth Noller, M.D., and Raymond Kaufman, M.D. Both are internationally known for their DES research.

Less effective interventions had less credible sources for their messages. In New York, a semiretired obstetrician-gynecologist performed the academic detailing with area physicians. The detailer was a respected physician but not an acknowledged DES expert. The pilot study team reported that the physician was treated politely, but the intervention had no measured impact on physician knowledge or awareness of DES. Similarly, the source of Wisconsin’s educational materials was listed as the Department of Agricultural Journalism. The research team at Wisconsin attributed low response rates and poor enrollment in CME programs, in part, to the dissemination of medical information from a nonmedical source. For example, one physician attending DES grand rounds announced that he had thrown the DES videotaped lecture away because the return address label created confusion; he did not expect medical information from an agricultural journalism department.

9. The use of CME conferences and mailed distribution of educational materials in isolation have little impact.

Long employed as a primary means to educate practicing physicians, CME credits alone failed to motivate physicians to attend DES educational sessions. Although physicians had only to attend the New York dinner lecture and send in a form to obtain CME credits, only eight attended
(of 131 invited). Of these eight, only one physician applied for the credit. In Wisconsin, CME credits were offered for attendance at grand rounds or watching a videotape. Physicians had to only answer 12 questions based on the videotape to achieve a CME credit. Of 1,552 physicians, only 13 applied for CME credits; 12 of them passed the test.

Mailing single sets of educational materials did not achieve desired effects either. The research team in Wisconsin sent educational materials to 3,000 physicians; of the 775 who responded to the post-intervention survey, only 38% (300) reported receiving the materials. In New York, post-intervention physician reports indicated significant increases in reading the mailed national guidelines for DES identification and care. Yet the same respondents demonstrated no change in knowledge, behavior, or familiarity with DES or its health risks. Although the Texas campaign also relied upon mailed educational materials, it resulted in significant effects for physicians. The Texas campaign different from other mail campaigns, however, by delivering its message over a four-stage period, reinforcing the original message in different ways by a strong local champion who was also an internationally recognized DES researcher.

Previous studies on physician receptivity to messages (Davis et al. 1995, Kosecoff et al. 1987, and Lomas et al. 1989) support conclusions about the limited impact of isolated mailed print or CME education. Reinforcements of campaign messages are necessary through booster calls, follow-up visits, and other related activities and materials (Davis 1998).

10. Combinations of lessons are associated with the achievement of campaign objectives.

More successful physician campaigns incorporated multiple lessons from the nine previous lessons. No single cause can be isolated as the antecedent to changes in physicians' knowledge, attitudes, or actions regarding DES. Instead, combinations of tactics appear to work in concert when physicians are influenced to learn about and act on DES health risks.

The Texas campaign employed local influence. Its subject pool was primarily obstetrician-gynecologists (for whom DES exposure is perceived as more relevant than for other physicians), the campaign materials were drawn from a highly regarded medical source, recruiting tactics created patient demand as a motivator for physicians, and the intervention was developed in four reinforcing stages. The Massachusetts study employed local DES champions, incorporated the DES education program within providers' practice institution, created consumer demand, and included reinforcement materials supported by office staff involvement and education. Other campaigns with fewer effects were associated with fewer of the previous lessons.

Lessons from the Campaigns for Consumers

The five pilot site consumer campaigns shared the overarching objectives to raise DES awareness at the population level, to convert that awareness into motivation to act, and to increase the quality and quantity of encounters with physicians among DES-exposed individuals. All five studies were implemented in the same time frame, during 1993-1997, and all included pre- and post-intervention consumer surveys with common questions at the core. All study sites developed teams composed of expert
medical research, and DES consumer advocates. All study sites were located in regions rich in DES history. The five campaigns also shared elements, such as a companion physician stimulus and education campaign, toll-free DES-specific information lines, and the NCI consumer education booklet series, elements of which were widely regarded as necessary and valuable to the campaigns.

The studies diverged on points such as theoretical bases, sample selection, and recruitment. Some teams included marketing communication specialists who were charged with executing a deliberate public relations and media outreach strategy to gain campaign coverage and message dissemination. In New York, Massachusetts, and Texas, custom press kits played a major role in gaining coverage of messages intended for the general public.

Because of these variables, generalization about media campaigns is not prudent, although several common principles and threads can be identified. Media coverage of DES before the NCI pilot studies shaped the quantity and quality of consumers’ DES awareness and knowledge at baseline, and confounded media campaign effects measurement. Increases in awareness, knowledge and behavior were constrained by intervention timing and duration. Press relations efforts were productive: media coverage and paid advertising stimulated consumer information seeking. DES messages targeted to the general public elicited response from DES exposed persons and from providers, and networks amplified media campaign tactics. The primary consumer education materials consolidated information and expanded education. Provider education alone appears to be insufficient to increase DES awareness among the public. Finally, addressing specific barriers to health care increased self-efficacy.

1. Media coverage of DES before the NCI pilot studies shaped the quantity and quality of consumers’ DES awareness and knowledge at baseline and confounded media campaign effects measurement.

All study sites were located in regions where DES had been widely prescribed. The five pilot studies measured awareness and knowledge before the start of the interventions through random-digit dial or random mail surveys. Results ranged from 38% in Wisconsin’s treatment communities to 69.3% in Massachusetts. California’s intervention and control communities each measured awareness at 60% among women. In Texas, awareness scores of 64% among females and 21% among males were recorded, but included members of the DESAD group (93% awareness). A subsegment more representative of the general population, the Texas corporate group, yielded awareness level of 33% across all five companies. The two New York study sites measured 42.8% and 47.6% awareness levels where multiple regression analysis demonstrated that the strongest predictor of baseline values of awareness were (more) education, (older) age and (female) sex.

Across the five pilot studies, newspapers or magazines were cited as DES knowledge sources by 58%-61%; radio or television were cited by 36%-53%. Less frequently mentioned sources were health-care providers at 7%-24%, family or friends at 20%-30%, and pamphlets at 28%-43%.

Post-intervention evaluation of the consumer campaigns revealed small, if any, increases in awareness levels and sources of knowledge. The bases of awareness for the 1994-95 baseline
surveys emanated from the same sources that continue to be identified as dominant sources of DES awareness--newspapers, magazines, radio, and television. Significant changes attributable to campaign efforts were difficult to register, absent a paradigm shift in the way consumers obtain DES knowledge, or a new set of scientifically supported facts about DES risks.

In addition, it is difficult to separate the awareness that may have resulted from the pre-intervention survey itself from prior learning or intervention effect. In New York, the comparison site showed a larger increase in awareness (42.8% to 53.8%) than did the intervention site (47.6% to 48%); the comparison site also recorded a decrease in attempts to confirm exposure (44.2%-39.3%)

Much of consumer DES awareness at baseline probably came from press reports about DES effects, first broadcast in the early 1970s, by trusted icons on networks with large and loyal followings. It was not until the end of 1977 that Ralph Nader's consumer organization demanded that the FDA require all physicians to warn patients of the possibility of DES related cancers. National press covered issues such as DES use as a morning-after pill, its use in cattle and chickens, and lawsuits brought against pharmaceutical companies who made and sold DES, further intruding on information directly related to DES taken during pregnancy. Major newspapers and publications also wrote about DES. Absent was notification by the pharmaceutical/medical community to women who had taken DES. Therefore, consumers who self-reported awareness of DES, as measured by the NCI pilot study surveys, may have based their responses on old, discomfiting impressions garnered from the media. (A similar circumstance seems to exist in the medical community where the early association of DES with vaginal cancer in young girls continues to form the nucleus of physician knowledge about DES.)

2. Increases in awareness, knowledge and health promotion behavior were constrained by intervention timing and duration.

The pilot studies occurred shortly after the national health-care reform debate and during a period of rapid changes in health-care delivery systems. A major part of the health-care reform debate focused on the tension between economic incentives and the quality of patient care. A key consumer issue in that debate centers on the physician-patient relationship that has been at greater risk for interruption under managed care than with traditional private practice. This issue has clear implications for DES-exposed consumers who depend on continuity of care for regular and proper health care. A behavioral change sought by the campaign--asking consumers to inform doctors about DES exposure--implies that the consumer regularly sees the same physician. The Texas intervention is an excellent illustration of that principle in which some of the success of the study may be attributed to the longstanding relationship between Dr. Kaufman and his patients.

Other sites provide insights for how managed care can provide continuity of care. Both Massachusetts and California included intervention sites in HMO practices: Harvard Pilgrim Health Care-NE and Kaiser Permanente. The Massachusetts study demonstrated how a health systems computerized recordkeeping system can enhance the probability that the health-care provider has access to the patient’s complete records, including notation of DES exposure status, without regard to the specific physician involved in the encounter.

The Massachusetts study collected data through chart review, which provided unique ability to confidently measure changes in patient/provider interactions within the prescribed study time frame. More typical were sites without systems interventions, and where the campaign
The implementation period was shorter than the interval between typical well-patient visits (e.g. 1 year or more). The Wisconsin consumer (television) intervention ran for 5 months, from October 1995 to February 1996. Baseline was measured in January 1995, and post-test surveys were conducted in March 1996. The New York community intervention, targeted to the unaware, was implemented for 10 months, from June 1995 through March 1996. The Texas pre-intervention survey was completed in April 1995, with post-test survey in January 1996. These sites were at a disadvantage when collecting post-intervention data, in terms of recency and consumers’ ability to accurately recall details of the last visit to their physicians. These consumer surveys relied on patient recall about questions such as whether the provider asked about DES exposure during past pregnancies or DES exposure in utero and whether the physician’s health history form included questions about DES. This issue may be more salient among the unaware consumers, especially those who are not seen in managed-care settings or lack a sense of urgency about a separate visit solely to discuss DES, or those who may forget to initiate discussion of DES at a future visit.

3. Press relations efforts aimed at general and local news media coverage are productive means of arousing interest, as measured by calls to DES information lines. Sixty-three percent of DES daughters surveyed in California reported becoming aware of DES through newspaper or magazine articles. Callers who were aware of the DES exposure status before calling the hotline and those who were hearing about it for the first time almost evenly matched in number, based on actual measures and estimates from advocacy leaders. Among study sites that tracked and measured response to local media, Massachusetts consumer hotline recorded 267 callers who identified a single article in the Boston Globe as the source that prompted their calls, accounting for 22% of all calls. Print media in general accounted for 40% of all calls in the Massachusetts area during the study period. A single item on a local TV channel resulted in 156 calls. A spot on one local radio station prompted seven calls. Metropolitan daily newspapers had the largest impact, with smaller community papers producing only 3% of the calls (41). The Massachusetts project made two separate mailings to 194 small community papers, resulting in only eight printed DES articles. Smaller papers may have appeared less receptive to DES messages during the study period, in light of the major Boston Globe article.

Consumer advocacy leaders reported that newspaper or magazine feature articles were followed by increases in calls to hotlines. Michael Freilick (Vice President, DES Action/DES Sons Network) reports that he receives increased calls after DES-related media events (appearances on Good Morning America and local TV talk shows), often from mothers or wives who may have known of DES but seek more information about the impact on DES sons.

4. The primary consumer education materials were useful in reinforcing and expanding education among the confirmed exposed population. All sites, except Texas, used a core group of common patient education booklets. The collaborative development of these materials from the NCI project represents an important and unique contribution to DES education. Led by the California study site team, the series of tightly targeted booklets resulted from consultation with all members of the
cooperative agreement, thus incorporating both medical and consumer viewpoints into content and style, a nexus of physician and patient. The booklets were used as counseling resources, community distribution materials, and as hotline response mailouts. Although each constituency expressed mixed personal evaluation of the booklets, they agreed on the more important point that the booklets worked for the targeted audience and were the first consolidated recommendations for patient education and action.

The booklets were described by advocates and health-care providers as serving the needs of individuals who are motivated to seek information on DES. They allow the reader to learn about DES in private. In addition, print materials serve as enduring references. Physicians and nurses appreciate having a dependable and time-saving device that enhances and confirms patient-provider discussion. New York pilot study partners reported sending out hundreds of the booklets. Consumer advocacy groups ran out of some of the brochures because of consumer demand.

The pilot teams reported that some booklets were used more extensively than others. The comprehensive yellow booklet, *Were You Born Between 1938-1971: Or Pregnant Then?* and the purple booklet *DES Daughters* were in the most demand. Because the booklet *DES Sons* was not available until the end of the campaign, it was not a part of the pilot study interventions. Although the *Clear Cell Cancer* booklet was not widely distributed, the DES Cancer Network indicated that the book was important for the small (about 15 per year), but needy group of women in whom cancer had been newly diagnosed. Finally, several research teams reported that the condensed version (blue) of the *Were You Born?* booklet was redundant and not widely distributed. Most agreed that the content of *Talking About DES* could be incorporated into other brochures without diluting its message.

Even though the booklets were distributed at different sites in clinics, work places, and libraries, they seem to have contributed little to raising awareness among the general public. As indicated in the final reports of the NCI studies, the five pilot sites were situated in locations where DES awareness was high because of high levels of DES use. General media reporting of the issue and physicians notifying patients of DES health consequences drove awareness in prior years. The booklet series—style and content are more appropriate for use by DES-exposed persons who want to learn more about health risks and treatment (people well along in the hierarchy of communication effects).

5. Media coverage and paid advertising stimulate attempts to seek information.

The Wisconsin study report notes, *Just getting the word out* is the main mission of the program, more reliance on media alone is called for. On the other hand, if goals are more complex
attitudinal or behavioral changes, as is the case with DES, those are apt to be accelerated by more direct forms of citizen contact and intervention. Wisconsin's television campaign consisted of three separate 30-second paid television announcements. Wisconsin attempted to isolate its campaign effects through cable stations with signals that reached only the viewing areas contained in the study. Although the percentage of residents in communities where DES advertising was shown reported increased awareness of DES (38% at baseline and 55% post-intervention), the same group of residents also reported that they had heard of DES from magazines (23%), newspapers (20%), and educational materials (18%) in addition to television. The media campaign-exposed population did have a heightened awareness that problems could result from DES exposure and of the importance of knowing one's personal DES exposure status. However, the 165 calls to Wisconsin's 800 line were answered in California by DES Action, further confounding the measurement of the source of campaign effects. The Texas study placed a paid advertisement in Texas Monthly magazine, which resulted in recruitment of 550 persons. An unanticipated outcome included responses from Florida and from countries outside the United States. Migration patterns might point to the need for message distribution to DES mothers in states with high retirement populations. Press relations programs employed by New York and Massachusetts, without paid media, produced 2,137 and 1,215 responses, respectively, to 800 lines during their respective study periods. Calls to 800 lines are a measurable consumer action that can be attributed to media coverage. Other actions, such as calling a physician, talking to friends, or telling children about in utero exposure, may have occurred but were not measured.

6. DES messages targeted to the general public can also elicit response from those who know they are DES exposed and from providers. All sites included messages encouraging the public to call a toll-free DES information telephone number to gain more information about DES exposure. In Massachusetts, the toll-free line received 1,215 calls over a 10-month period, with 53.8% coming from mothers and daughters who already knew they were exposed. Other site studies confirmed that most of the calls received by hotlines were from persons who knew or suspected DES exposure: Texas (67%), New York (50%-27% mothers and 23% daughters) The Massachusetts hotline recorded 10 calls from providers. Wisconsin physicians who saw the consumer announcements on television reported greater reading of DES guidelines and making changes in their DES practices.

7. Networks can amplify media campaigns The California study combined media messages about DES with a social network approach. The TalkDES Opinion Leader Training project had a small but significant impact on public awareness. The study suggested that women rely on networks for health information and found that opinion leaders played a central role in the diffusion of information by increasing DES discussions and DES confirmations. Findings from California opinion leaders showed a significant increase in correctly answered questions from average of 16% to 44%. However, the percentage of incorrectly answered questions also increased significantly, from 15% to 24%.

When measured by increased opportunities to disseminate DES information, the network approach was even more successful. As a result of involving community opinion leaders, Nora Cody (Executive Director, DES Action USA) was invited to speak on behalf of the campaign on a local television station. Numerous local papers covered the DES campaign, one of the research
communities declared a DES Awareness Day, and a physician influenced an entire obstetrics and gynecology department to become involved in the health-care provider intervention. The combination of media and social network approaches is consistent with recommendations from the 1992 Designing Health Communication Campaigns and research stemming back to the 1960s and 1970s identified the important role of interpersonal communication networks in encouraging health promotion behaviors.

8. **Provider education alone appears to be insufficient to increase DES awareness among the public.**

   In Wisconsin, no significant differences existed in public DES awareness levels between control and intervention sites (38%) during pre-intervention assessment. In post-intervention measures, communities in which both physicians and the public were target audiences reported statistically significant increases in consumer awareness of DES. Communities in which providers were the only targeted audiences did not report the same level of change. Similar results were found in the California study, where provider education alone had no significant impact on the number of consumers who tried to confirm DES-exposure status. In California, the sample size was insufficient to demonstrate that the consumer intervention boosted the provider intervention, but the pilot study reported that the provider intervention by itself was not sufficient to reach consumers at the community level.

9. **Self-efficacy of DES-exposed persons can be enhanced by addressing specific barriers to health care.**

   In New York, the research team took advantage of Nassau County’s high level of public awareness of DES exposure and targeted DES-exposed persons as a separate audience. Based on concerns that DES-exposed women were experiencing barriers to appropriate care, the project included telephone counseling for DES mothers and daughters. Local telephone counselors were trained to solicit obstacles that women experienced when attempting to get DES information and appropriate health care. Each counselor had an algorithm with specific responses dependent upon the particular obstacle that the DES mother or daughter reported. In each case, callers were given specific steps they could take to obtain appropriate care.

   Through this method of barrier-specific counseling, callers were empowered with options to use in future interactions with physicians or in other situations when they were seeking information about DES exposure and screening. The results of the New York campaign demonstrate that such an approach increases women’s perceptions of self-efficacy to a statistically significant degree. Health communication research has linked perceptions of self-efficacy to probability of performing health promotion behaviors. In Texas, significant differences in general self-efficacy and social self-efficacy emerged for both exposed and non-exposed females, but not among males, who responded to the 800-DES-NEWS line. DES-exposed females in the corporate group also showed significant increases in self-efficacy.

**General Lessons for Health-Care Provider and Consumer Campaigns**

All five site studies included multiple persuasive goals for physicians and consumers, from increased awareness to performance of specialized medical tests. These goals vary widely in
the means and exposures necessary to achieve each. Research in health communication, notably McGuire’s hierarchy of effects model (McGuire, 1984), identify the achievement of diverse campaign goals as dependent upon the audiences’ initial predispositions and readiness to change (see also Prochaska, Norcross, & DiClemente, 1994). The possibility of moving an audience from lack of concern and awareness (the position of most of the public and physicians regarding DES) to specific health promotion behaviors in a single campaign is probably impossible.

The five site studies are consistent with other studies in this regard. Even though several sites registered statistically significant changes in awareness, knowledge, and health information-seeking, most results were small. Few projects realized large-scale changes in action. Instead, as might be expected, smaller, preliminary changes occurred. For physicians, increased reading of DES national guidelines was common. Fewer realized changes in knowledge or screening behaviors. Even Massachusetts, which achieved significant and large changes in physician screening and knowledge, had diminished effects over time. The use of DES computer codes, one of the biggest impacts of the Massachusetts campaign, has now been discontinued at the intervention sites. The five pilot studies demonstrated the need for sustained efforts to educate the public and physicians and the need to use the audience’s stages of readiness to change as a beginning point for influencing target groups to take the next step in health promotion.

Recommendations for the National Education Campaign

The goal of DES National Education Campaign is to construct sustainable communications processes and programs that promote information-seeking action and that enhance DES-specific encounters between the general public and the medical professionals and organizations that serve their health-care needs. Rather than approaching the education project as a campaign that denotes a specific period of time, this effort should focus on sustainability, embedding DES education into stable educational structures that will last over time. Emerging research concerning DES cohorts and health risks indicate that periodic updates and information will be necessary as the cohort of DES-exposed persons ages and as third-generation possibilities are explored.

The desired outcomes among the general public include:

- 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 providers of possible DES exposure and to expect DES-specific screening and/or treatment from appropriate specialists.
The desired outcomes among the health-care community include:

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.

Recommendations for Formative Research

Several areas of formative research are recommended before moving to the creative stage of the campaign because important questions relevant to the DES National Education Campaign remain unanswered and invite further exploration.

Additional baseline data must be gathered before laying the foundation for a sustained social marketing effort to monitor its progress and to measure results in a meaningful way. The pilot studies collected baseline data on physicians and public awareness, knowledge, and screening behaviors, but the full results of those surveys were not available, and the partial data provided in the pilot study reports were not comparable. In addition, several years have elapsed since those data were collected, and the pilot studies were all conducted in areas of the country where DES had been heavily prescribed. As a result, little is known about a range of topics necessary to develop a national campaign of DES education (for example, the level of DES knowledge among rural populations, how consumers use the internet to find DES information, the level of DES awareness among urologists, or the barriers faced by consumers trying to confirm DES exposure).

A range of activities can be useful in filling gaps left by pilot study baseline data. Secondary data, such as the Healthstyles database, should be reviewed for findings applicable to the DES National Education Campaign. In addition, opportunities to insert DES questions on repeatable national health surveys should be explored. Large population surveys of selected target audiences, sufficient in size and structure to detect and measure changes in behavior, may be necessary to set a sound foundation on which to build and measure campaign activities. Research to inform campaign development should include qualitative techniques involving first person interaction, such as focus groups and individual interviews. Such methods should explore DES knowledge, attitudes, and behaviors among participants to enhance message delivery. To account for geographic differences in DES usage and regional variations in medical practice patterns and communication channels, research should be conducted in at least four
regions of the nation. Sites should be selected to include urban, suburban, and rural populations.

Audiences identified in the pilot studies should be further segmented and augmented. To encourage a wider array of health-care professionals to educate consumers about DES, formative research must include health-care professionals who were not widely included in NCI studies: nurses, nurse practitioners, physician assistants, and nurse-midwives. Formative research to determine the awareness, knowledge, and behaviors of these groups regarding DES is necessary. In addition, these populations should be canvassed to determine the best means of reaching them with DES information, the most credible sources of educational materials, and the most effective avenues for incorporating nurses, nurse practitioners, physician assistants, and nurse-midwives in DES care and patient education.

Office staff members should be interviewed with regard to their role as gatekeepers for physicians’ offices. These individuals are primary sources of information about variables and patterns in physicians’ professional practice. Their input can shed light on how physicians prioritize information and requests they receive from patients and medical agencies. Office staff should be important sources of information about the best ways to penetrate physicians’ offices with DES information through mailed materials, telephone contact, or academic detailing.

Variations in physician characteristics seem to influence receptivity to DES messages and practice patterns and need further investigation. The pilot studies suggest such variations are based on age, specialty, practice type, and geographic location. Physicians involved in formative research should be screened for age (years in practice can be a proxy), specialty (primary care, obstetrics-gynecology, urology, geriatrics) and office model (HMO, network practices, centralized practices, and solo practices) with representation from men and women. Regional practice patterns should be accounted for by conducting research in at least four geographic locations.

Additional up-to-date information about the patient-provider relationship is needed. Among consumers, formative research should explore the emotional factors and knowledge that nourish patient self-efficacy and readiness to practice preventative health behaviors. Emphasis should be placed on discovering any systemic characteristics that make consumers feel more or less capable of asking questions and bringing information to their health-care providers. Researchers should explore consumer perceptions of what elements enhance or diminish their relationships with providers and whether those elements vary depending upon the physician’s type of practice.

Expanded consumer segments should be described and targeted for behavior change with differentiated action messages. About 10 million
mothers, daughters, and sons were exposed to DES during pregnancy or in utero. Half of exposed persons are estimated to know about their DES exposure status. DES-related consumer groups estimate that about 70% of those who know are women. Messages targeted to that group should enable, reinforce, and reward regular and proper screening for DES sequelae. The remaining five million (estimated) exposed mothers, daughters, and sons who are not aware of their DES exposure or of possible health risks associated with the drug should receive messages that stimulate curiosity and attention to DES as a health risk. Men who fall within the relevant age groups for DES exposure and their families should be included in the formative research. The pilot studies did not target men as primary audiences for DES education, and little information was gathered about their DES knowledge, attitudes, or behaviors. Family and friends can be effective conduits of health information and effective motivating agents for DES sons.

Formative research should explore the repertoire of health information sources that consumers consider useful and reliable. Consumers should be asked how they make judgements about a variety of health information sources, channels, and formats: family, friends, nurses, pharmacists, worksite programs, for-profit and nonprofit hospital/clinic outreach, wellness/fitness programs, television, radio, newspaper news/features, Internet, support groups, and nonprofit organizations (such as those concerned with health issues that match DES sequelae). Research should compare similarities and differences in consumers' perceptions of messages that arrive through mass media or other outreach efforts compared with information resulting from purposeful research or information gathering.

**Recommendations for the Campaign for Providers**

For maximum effectiveness, the physician campaign should be based on principles of immediacy, recency, medical hierarchy, and sustainability. In addition, the National Education Campaign must expand the type of clinicians targeted for education.

1. The DES National Education Campaign should create a sense of immediacy for physicians around DES health issues. Immediacy can be achieved by creating the perception that DES is an issue about which the physician=local peers and affiliated institutions are concerned and because it affects his/her patients. Such an approach takes advantage of physicians=priority on immediate patients= needs, trust of medical insiders, and accustomed ways of learning. Four sub-recommendations undergird the principle of immediacy: drawing upon local sponsorship for DES-education efforts, using extant programming venues for DES-education efforts, developing patient demand for DES information and screening, and creating accountability for DES knowledge.
Rather than using a broadly based national, single-source approach (e.g., AMA or CDC) for the dissemination of physician information on DES, the National Campaign should seek regional and local sites as sources through which to disseminate information and host educational programs. Where possible, local sponsorship of DES education should be encouraged and local champions nurtured.

The National Campaign should pursue the use of extant programming sources for DES education and embed DES programs in well-established physician education forums, such as CME schedules or other educational structures, such as American College of Obstetricians and Gynecologists (ACOG) bulletins or ACOG audio tape series. Since these programs seem ineffective in isolation, they should be part of a staged campaign in which DES messages are introduced and reinforced through multiple channels and messages. Since single-shot tactics are ineffective in promoting sustained behavioral change, the campaign should make DES education a part of routine provider education (rather than isolated, special events). Reinforcement strategies should be developed to increase and maintain educational impact.

The campaign should develop a sense of immediacy for physicians by creating patient demand for DES information and screening. Part of the campaign message to physicians is to inform them of the consumer campaign. The knowledge that patients will be showing up in the physician’s office asking about DES creates a sense of relevance for the provider that might be missing if no public campaign existed. Patient education should occur concurrently with the provider intervention ensuring that patients will have better-informed physicians to ask about DES health risks.

Finally, a sense of immediacy can be created if physicians know that they are accountable for attending to DES as a health issue. The incorporation of DES questions on licensing exams (such as the obstetrician-gynecologist AABC@test--required for recertification) and on standardized intake forms (such as those sold through the ACOG or computer software programs) would result in systemwide changes in physicians’ attention to this issue.

2. Focus on recency as a principle of the physician campaign.

Interviews with physicians indicated that they often respond to the topic of DES by asking What’s new? Because many physicians believe they are familiar with DES but score poorly on knowledge, they are probably basing their familiarity on information from the 1970s that did not include breast cancer risks for DES mothers, health risks for DES sons, pregnancy risks for DES daughters, later-age diagnosis of clear cell adenocarcinoma for DES daughters, nor concerns about possible third-generation health risks. Overcoming misinformation is more difficult than teaching when target audiences know they are lacking information. In addition, interviews with several principal investigators at the study sites indicated that physicians resent outsiders coming in to teach them something they should already know.

The principle of recency is particularly important when considering the history of DES medical research. Early and news-catching findings in the 1970s focused upon the connection between in utero exposure to DES and clear cell cancer of the vagina. Physicians in practice at the time received FDA bulletins outlining the health effects and banning the use of DES in pregnant women. As the majority of DES daughters reached
age 30 years and the numbers of clear cell cancers declined, many physicians perceived the health problems associated with DES to be over.

In the 1980s, ongoing studies of DES-exposed cohorts explored other effects of DES exposure: genital abnormalities and fertility in DES children and breast cancers in DES mothers. Many of these studies lacked the clear-cut results and compelling consequences of the clear cell cancer effects documented in the 1970s. In addition, some cohort studies were interrupted because of lack of funding, reinforcing a perception among physicians that DES health risks were no longer an issue. As a result, many doctors recognize the DES cancer risks for DES daughters in their teens and 20s but are unaware of other health risks.

Based on consumer advocacy, new funding became available for DES research in the 1990s. Since the NCI pilot studies began, new research--much of it confirming earlier studies--has been published, documenting a 20%-30% increased risk of breast cancer for DES mothers, identifying clear cell cancer in older women and confirming high-risk pregnancies for DES daughters.

As the DES-exposed population ages and becomes vulnerable to age-related cancers, new questions have emerged about how DES exposure will affect their cancer risks. These questions have been spurred by recent animal studies that have linked DES exposure to testicular cancer, prostate cancer, and reproductive tract tumors in third-generation DES mice. No clear extrapolation to humans can be made on the basis of the animal studies. However, the mouse studies have been predictive for much of the human sequelae resulting from DES exposure. In light of those parallels, health-care providers and the public should remain alert for possibilities. Awareness of DES exposure is necessary to continue to screen for known health risks and for the possibility of future risks should they emerge.

The health-care provider campaign should be tied to news from the most recently completed/published studies from the DES cohorts. Several studies have recently been published by Raymond Kaufman, M.D.; Arthur Herbst, M.D.; and Elizabeth Hatch, Ph.D., on fertility and cancer. According to Dr. Hatch, several studies from the combined DESAD cohorts are slated for publication. Focusing on the new studies as the springboard for current DES provider education can utilize the principle of recency, which may reach physicians without incurring resistance based on perceptions of previous familiarity with the drug. In addition, such information has the potential to correct perceptions that DES health problems are no longer relevant to provider practice.

3. Employ the most credible medical sources of information for messages for the DES National Education Campaign:

The National Education Campaign should draw materials, letters, and endorsements from the most highly regarded clinical researchers in the DES field. Where possible, these medical experts should be integrated into campaign planning. Because medical journals are considered by physicians to be the best source of DES education, the most recently published peer-reviewed journal articles on DES should form the foundation of the campaign. Where possible, DES educational information should be placed in the providers’ specialty journals.
4. The National Education Campaign should broaden its target group of providers to include nurses, nurse practitioners, physician assistants, and nurse-midwives as segmented target audiences.

The vast majority of health-care providers included in the NCI pilot studies were physicians. Only Texas and California included other health-care providers as part of their provider audiences, and these were few in number. The national campaign should target nurses, nurse practitioners, nurse-midwives, and physician assistants as part of the provider audiences. According to Dietrich, Cynthia Johnson, M.D. (HPHC-NE); and Candice Tedeschi (OGNP, Project Site Director for the New York pilot study), nurses, nurse practitioners, and physician assistants do much of the intake for many practices and so are in the best position to ask patients about DES exposure. In addition, they have more time to counsel patients than do physicians. According to Tedeschi, patients will often tell nurses and nurse practitioners what patients think physicians are too busy to hear.

In addition, nurses and nurse practitioners seemed to be interested in educational materials offered by the pilot studies. Kari Christianson (liaison to physician CME programs on the Wisconsin pilot study) reported that nurses took booklets with them after lectures and voluntarily attended Minnesota DES Grand Rounds. The California study used nurse practitioners and physician assistants to fill out their study when physicians weren’t willing. Even though nurse practitioners and physician assistants were initially less well informed in pre-intervention tests about DES issues (5.80 knowledge score for nurses pre-intervention; versus 7.33 for physicians at baseline), follow-up evaluations indicated that nurse practitioners and physician assistants in the intervention groups achieved higher scores on average than did physicians (9.0 versus 8.86 for physicians). Non-physician health-care providers need the correct information about DES and have the interest and motivation to learn about DES and educate patients.

5. Target primary-care physicians as the primary physician audience for DES education.

Although few physicians (including obstetrician-gynecologists) in the studies scored high ratings on the DES knowledge tests, primary-care physicians (family practice physicians and internists) scored the lowest across the pilot studies. In addition, primary-care physicians were the least likely to screen for DES exposure. Because primary-care physicians see more than any specialists and since they also serve as gatekeepers for more specialized referrals, primary-care physicians should be the primary provider target audience for the DES National Education Campaign. Campaign goals should include increasing primary-care physicians’ knowledge of resources for DES information, awareness of new DES research, inquiries to patients about DES exposure, and provision of appropriate DES-related care or referrals. Given the demands on primary-care physicians’ time and the multiple health counseling tasks they are asked to perform, our goals should be prioritized with this audience.

The highest priority should be to prepare the physician to receive patient inquiries about DES. The campaign should aim first to increase physicians’ awareness concerning ongoing health risks for DES-exposed patients. In addition, the provider should have on hand guidelines for screening, treatment, and/or referrals that can be used when such a patient
presents him/herself. The provider should also have information about where to call (or an Internet address) for further provider information about DES management. The second priority should be to motivate the physicians to initiate DES counseling and screening. These secondary goals include encouraging physicians and other health-care providers to routinely ask about DES exposure, include a question about DES on his/her intake form, and provide patients with educational material about DES health risks and how to confirm exposure.

Recommendations for the Campaign for Consumers

The DES National Education Campaign for consumers should develop a communication strategy of new and carefully crafted messages. Campaign materials for consumers should address DES-exposure as a risk factor, rather than as a disease; reach defined and expanded target groups; be based on new, cost-effective, and widely accessible information formats and sustainable distribution channels; and incorporate new information from recently published scientific research on DES.

1. The DES National Education Campaign should revise and expand target audiences

As the DES issue matures, expectations about changes in consumers’ knowledge and behavior change should be built into the campaign, and definitions of audience segments should be revised. Target audiences can be differentiated on the basis of whether they are aware of their DES exposure status. For example, among persons who have been aware of their DES exposure for a long time, some will have experienced and been treated for DES-related medical problems. A substantial portion of those who are aware of DES exposure have not experienced problems but remain highly motivated to continue screening and seek up-to-date DES information. This group may be subdivided into persons who are concerned for themselves and persons who are concerned about family or friends’ exposure status. For example, 50% of hotline callers to the Massachusetts pilot study hotline were DES mothers or daughters, aware of their exposure and seeking updated and additional information. Of 295 DES mothers who called, 50% specifically asked for information about health risks for their sons. Only 44 men called on their own behalf.

These results support the need for campaign materials targeted specifically for men. In addition, the DES National Education Campaign should offer DES mothers support to encourage them to talk with their sons about DES. Michael Freilick, founder of DES Sons Network, estimates that most callers to the DES Sons Network information line are mothers or spouses of sons rather than DES sons themselves. The DES National Education Campaign should be designed to enable DES sons to access regular and timely updates of DES news, to encourage DES sons to adopt preventive health practices, and to provide sons with information about appropriate health screening.

The campaign should incorporate a new approach to the unaware population. Many individuals who are concerned about DES exposure are unable to confirm their status. On average, three-fourths of the persons who were prompted to confirm exposure, and who subsequently reported results of their search, were unsuccessful. Similar numbers are
estimated for those who contacted the DES Cancer Network. Pilot study subjects reported difficulty confirming their exposure. Many pilot study messages encouraged audiences to ask their mother about DES exposure or to get medical records to confirm exposure. A new approach is necessary that reflects confirmation barriers. Because no medical test is available to confirm or exclude exposure to DES and its health risks, consumers may experience anxiety if they try and fail to confirm exposure status. A new approach for unaware persons should be explored by targeting individuals who are experiencing medical problems related to DES sequelae, such as infertility, genital abnormalities, and breast cancer. Support groups and organizations associated with these health issues offer potential for introducing DES exposure as a possible cause of a health problem. By disseminating information in terms of risk analysis, individuals could be motivated to research DES as a possible contributor to an existing problem or condition. Organizational alliances should be developed to enhance opportunities to reach salient audiences.

2. Develop a new set of information materials, based on contemporary messages for consumers and for the popular press.

DES and its effects should be described across all campaign materials in consistent and unified ways to build a clear campaign identity and to prevent unintended meanings and associations. As a low-prevalence health risk, DES can be confused through association with similar but more salient medical topics such as fertility hormones, estrogens, birth control pills, or other drugs taken during pregnancy. For example, it has been widely reported in news accounts and through anecdotal evidence that consumers confuse DES and its sequelae with thalidomide (see, for example, *Dallas Morning News*, 1998). The pilot studies attempted to circumvent the erroneous association in their baseline consumer surveys. Campaign materials for the DES National Education Campaign should be crafted to reduce chances of misinterpretation. This is especially important for materials used in press kits.

A good example of campaign unity and consistency can be found in the materials distributed by the Texas pilot study. Founded at Baylor College of Medicine, the Texas project employed a common identity through repeated use of a campaign logo, a photograph of an infant. A custom name, *Southwest DES Center,* was adopted and used consistently on campaign materials. By employing the center name and photograph-logo on all booklets, posters, and recruitment letters, all campaign materials were readily identifiable as members of the same family. Such consistency links the various elements to a central theme and promotes an air of organization, permanence, and authority.

3. The DES National Education Campaign should explore effective and credible ways to use new communication technologies and formats for the distribution of DES educational materials.

The pilot studies provided evidence that consumers of all ages accept and are ready to use newer information formats. In the Wisconsin study, older, higher income respondents used the same kinds of media to learn about health as younger and lower income participants: television, print, radio, and computer information sources (listed in
descending order of amount of learning derived). Since 1995, when the Wisconsin survey was completed, computer and Internet use has increased dramatically. Analysis of the use of new technologies reveals that one of the foremost uses of the Internet is to research health issues. The American Association of Retired People (AARP) reports that Internet use among its members is growing at double digit rates annually, suggesting that use by DES mothers as well as their exposed children could be increasing. Because Internet use tends to be private experience, men may be more likely to seek DES information through the Internet. Because access has also become widely available, placing DES information on the Internet would make DES information ubiquitous. Low or no-cost Internet access is available in libraries, senior centers, and educational institutions, making access to web-based DES information available to anyone. The AARP suggests on its website that Internet use can be a satisfying intergenerational activity. The possibilities of hotlinks could foster communication with strategic partner organizations and causes.

A DES website can be a resource for both consumers and providers, who would branch into respective areas of interest from the home page. Consumers would be led to further information on support groups, viewable and printable version of the brochures, and a video or a documentary of a personal story. Chat rooms and personal websites would be available to create a DES Community. Websites that are maintained by organizations dealing with allied conditions such as hormone replacement therapy, fertility, and cancer could have direct links. Both providers and consumers should have an opportunity to e-mail question and comments to a central source. Providers might link to the latest research reports and medical websites or log-on for a CME course. The website could be an access point to audio and video materials that are anticipated for use in other venues (e.g., documentary, video, print materials, and brochures).

4. The consumer booklet series originally developed by NCI should be updated.

Because the printed, multi-color booklets were expensive to develop and produce, the number of booklets should be decreased, and each volume should be updated to incorporate the newest findings of recent research on DES. The content of the seven separate booklets should be condensed and incorporated into the comprehensive yellow booklet, *Were You Born Between 1938-1971*, in a format that is easily updated and printed as necessary. Booklets should be created in a desktop publishing edition so consumer groups can reprint materials easily and inexpensively as needed. Additional outlets for this material must be developed as Internet sources and links to established health-care sites to address a growing interest and use of electronic media for health information.

5. Alternatives to the NCI booklets should be developed as educational materials for the general public.

New materials must be developed to raise awareness among at-risk audiences who are unaware of their DES exposure-status. Campaign materials should include a reminder-device for consumers to ask their health-care provider about DES and to stimulate discussions about DES with family/friends. Considerable time may elapse between the consumer's acquisition of DES information and his/her next medical encounter. A durable, attractive, inexpensive device, such as a wallet-sized card (similar to an vaccination
record) could be disseminated through multiple channels, from press events to community events. The card could list DES risk factors for both men and women (date of birth/pregnancy, fertility problems, epididymal cysts, etc.) with check-off boxes or radio buttons that the consumer can fill in as self-appropriate. The completed card would serve as a discussion guide during a patient/provider encounter or with family and friends.

6. Maintain a National 800 "warmline" toll free call-in number for local DES information and counseling.

Primary issues raised by callers to the DES Action 800 number concerned impact on risks associated with onset of menopause, decisions about hormone replacement therapy, effects among DES grandchildren, additional cancer risks, possible effects of DES exposure on the immune system, and the need for providers to be up-to-date on DES issues. In the Massachusetts study, more than half of 800 line callers already knew of their DES exposure.

Because DES is a low-prevalence health issue, it is possible that this line can be added to the services of an existing medical information line that handles other health issues. In this case, the DES number should ring to a specific line that staff can answer as the DES connection. During periods of intense media activity on DES (a nighttime documentary, for example), staff should be available immediately following the broadcast that advertises the warmline number.

7. Consider developing a national agenda-setting event targeted primarily to consumers and secondarily to providers.

In the context of the total package of DES materials, this is the most national in scope and broadest in reach. The purpose would be to stimulate word-of-mouth attention, similar to the goals of the opinion leader network intervention studied in California. Physicians in the pilot study who reported their sources of DES knowledge included consumer groups (2% -18%) and family or patients (7%-43%) as sources. In Wisconsin, physicians who viewed DES television media, as consumers, reported changes in their practices with respect to DES.

Airing the DES story on the Public Broadcast System network or special-interest channel might stimulate collateral local coverage of the broadcast by print and/or television health reporters or newspapers. Frontline included DES as part of a report on environmental concerns. The point of a new documentary would be to reach the general public and illustrate the DES legacy and its psychological and physical impact through the generations. The overarching concept would be the need for consumers to take responsibility for being informed and for getting regular preventive care.

8. Develop a press kit adaptable to local use

Press kits were successfully used in New York and Massachusetts. In each case, a press relations professional who was a member of the campaign team developed the contents and implemented a distribution plan. The impact of media coverage that resulted from the press relations efforts was measured by calls to local Massachusetts (n=1,215)
and New York (n=2,137) 800 lines. More callers responded to those hotlines than in Wisconsin (n=165) and Texas (n=550), which paid for advertising.

The DES National Education Campaign press kit should include electronically formatted material ready and suitable for use by health information distribution websites (such as ivillage.com; adam.com, drkoop.com, msnbc.com, cnn.com).

**Conclusion**

Next steps in the development of the DES National Education Campaign will include 1) feedback about the *Summary Report* from the Working Group, 2) selection of a contractor to conduct formative research and concept development/testing, 3) and convening of a mid-point Working Group meeting to guide the formation of campaign plans. The Working Group is a committee of partners comprising DES advocates, medical professionals (scientists and clinicians), and government agency personnel with interest and expertise in DES (see Appendix D for a list of committee members’ names). The CDC/NCEH staff will rely on all of their special areas of expertise to guide the formation of the campaign. Additional experts who are not members of the Working Group also will be asked for their input in the process.
Selected Bibliography


Appendix A
Resources Used in the Development of the Summary Report

Personal Interviews

Principal Investigator and Research Team for NCI Pilot Study in Wisconsin
Marion Brown, PhD (Principal Investigator, University of Wisconsin, Department of Agricultural Journalism)
Cynthia Laitman (Co-Investigator, Center for Health Policy and Program Evaluation)
Garret O’Keefe, PhD (Co-Investigator, University of Wisconsin, Department of Agricultural Journalism)
Paul Moberg, PhD (Co-Investigator, Center for Health Policy and Program Evaluation)
Heather Boyd, PhD (Research Assistant, University of Wisconsin, Department of Agricultural Journalism)
Melissa Phillips (Research Specialist, Center for Health Policy and Program Evaluation)

Principal Investigator and Research Team and Partners for NCI Pilot Study in California
Barbara Cohn, PhD (Principal Investigator, Center for Research on Women’s and Children’s Health, Public Health Institute)
Pat Cody (DES Action USA)
Nora Cody (DES Action USA)
Susan Helmrich, PhD (DES Cancer Network)
Elizabeth Adler (Elizabeth Adler Communications)
June Flora, PhD (Stanford Research Institute)

Principal Investigator and Research Team and Partners for NCI Pilot Study in New York
Nancy Avis, PhD (Principal Investigator, New England Research Institute)
Sarah McGraw, PhD (Co-Principal Investigator, New England Research Institute)
Kevin Smith (Project Statistician, New England Research Institute)
Candice Tedeschi, OGNP (Project Site Director)
Burton Krumholz, MD (Director, DES Screening Center: Nassau, Suffolk, and Queens Counties, New York)

Principal Investigator and Research Team and Partners for NCI Pilot Study in Massachusetts
Lydia O’Donnell, EdD (Principal Investigator, Educational Development Center)
Rebecca Jackson, PhD (Co-Investigator, Educational Development Center)
Cynthia Johnson, MD (liaison physician to Harvard Pilgrim Health Care of New England),
Cynthia Lang (Media Coordinator of the consumer campaign, Educational Development Center).
Allen Dietrich, MD (Dartmouth Medical School)
Andrea Goldstein RN (DES Action, Consultant to Educational Development Center)
Principal Investigator and Research Team and Partners for NCI Pilot Study in Texas
Raymond Kaufman, MD (Principal Investigator, Baylor College of Medicine)
Susan Kutzner, PhD (Co-Investigator, Baylor College of Medicine)
Erwin Adam MD (Baylor College of Medicine)
Elizabeth Barnard (Project Coordinator)

DES Scientist
Elizabeth Hatch, PhD (Co-Principal Investigator, NCI, Combined DES Cohorts Study)

Telephone Conference Calls
Michael Freilick (DES Sons Network)
Karen Fernandes, RN (DES Action, Consultant to the Texas Pilot Study)
Kari Christianson (DES Action, Minnesota Outreach to Physicians on the Wisconsin Project)
John McLachlan, PhD (Director, Center for Bioenvironmental Research, Tulane University)
Stephen McPhee, MD (University of California, San Francisco, Adviser and Collaborator, Physician Education, California Pilot Study)

Materials Reviewed

Final Reports of the NCI Pilot Studies:

*DES Core Consumer Hotline and Education Resource through Networks. (@California NCI DES National Education Project.

*DES Education for Health Professionals and the Public. (@Massachusetts NCI DES National Education Project.

*National DES Education Program for Health Professionals and the Public. (@The Southwest DES Center, NCI National Education Project.

*Educating Physicians and Consumers on the Effects of Diethylstilbestrol. (@Wisconsin NCI DES National Education Project.

*DES-Northeast Education and Outreach. (@New York NCI DES National Education Project.

Campaign Booklets for Physicians and the Public
Clear Cell Cancer: Resource Guide for DES-Exposed Daughters and Their Families
(National Cancer Institute Publication, January 1995).

DES Daughters: Women Born Between 1938 and 1971 Who Were Exposed to DES Before Birth
(National Cancer Institute Publication, January 1995).

DES Sons: Men Born Between 1938 and 1971 Who Were Exposed to DES Before Birth
(National Cancer Institute Publication, 1995)

Talking About DES: A Family Guide for DES-Exposed Mothers, Daughters, and Sons
(National Cancer Institute Publication, January 1995).

Were You Born Between 1938 and 1971 or Pregnant Then? If So, You Could Be Exposed to DES
(National Cancer Institute Publication, January 1995).


(National Cancer Institute Publication, January 1995).

Physician Information: How to Identify and Manage DES Exposed Individuals (Editor, Raymond H. Kaufman, MD, NIH Publication No. 81-2049, August 1996).
Appendix B

Common Core Questions from the Physician Campaigns
(Respondents were asked to respond to these questions on a Likert-type scale or yes-no responses).

Knowledge of DES
1. How familiar are you with DES?
2. Have you read the DES national guidelines?
3. Does your patient intake form ask if there is DES history?
4. Do you routinely ask about DES when taking a history?
5. In the past 12 months, about how many patients have asked you about DES?
6. Agreement/disagreement with the following:
   - Most women who are DES exposed know they are DES exposed.
   - Most men who are DES exposed know they are DES exposed.
   - It is important for people who are DES-exposed to know they are DES-exposed.
   - DES exposure in utero is a continuing health concern.
   - It is important to obtain a history of DES exposure from female patients.
   - It is important to obtain a history of DES exposure from male patients.
   - Once women who were exposed to DES in utero are past the age of 30, vaginal clear cell cancer is no longer a health threat.
   - Men exposed to DES in utero have no known increased health risk.
7. To what extent do you agree or disagree with the following reasons for not telling patients they have been exposed to DES?
   - Telling patients would create anxiety with no clear benefit.
   - If over age 30, a woman or man exposed to DES in utero is not likely to have problems.
   - Telling patients would not change the way I treat patients.
   - The risk for DES problems is so low that there is no need to mention it.
   - Unless patients are having problems, there is no need to mention it.
   - Litigation concerns.
8. Which of the following do you think are indicated on a routine gynecological examination for women exposed to DES in utero?
   - Palpation of the entire vaginal wall
   - Colposcopy of the cervix and vagina
   - Iodine staining of the cervix and vagina
   - Vaginal Pap smear
9. Should women exposed to DES in utero be treated as high-risk obstetric patients?
10. Which of the following do you think are indicated on a routine examination for men who were exposed to DES in utero?
    - PSA screening for prostatic carcinoma
    - Palpation of the testes
    - Rectal palpation for the prostate
    - Semen analysis
11. Are women who were exposed to DES in utero at increased risk for the following?
- Breast cancer
- Clear cell cancer of the vagina
- Ectopic pregnancy
- Ovarian cancer
- Structural abnormalities of the genital tract

12. Are women who took DES during pregnancy at increased risk for the following?
- Breast cancer
- Cervical or vaginal cancer
- Osteoporosis

13. Are men who were exposed to DES in utero at increased risk for?
- Epididymal cysts
- Prostate cancer
- Testicular cancer

14. How have you learned about DES and DES-related issues?
- American Cancer Society
- American College of Obstetricians and Gynecologists
- National Cancer Institute Cancer Information Service (CIS), Cancer Hotline, Cancer FAX
- DES consumer groups
- Medical literature
- Medical/nursing school
- Family or patients
- CME/conferences
- Other

15. Have you ever had any patients in your practice who you know were exposed to DES?

16. Do you now have any patients in your practice who you know have been exposed to DES?

17. Which of the following statements describe how you would provide care to female patients exposed to DES in utero?
- I do routine check-ups for DES-exposed patients, but I refer patients elsewhere if they need special DES-related procedures or treatment.
- I take care of DES-exposed patients for most or all of the care they need.
- I do not have female DES-exposed patients.

18. Which of the following statements describes how you provide care to male patients exposed to DES in utero?
- Do routine check-ups for DES-exposed patients, but I refer them elsewhere if they need special DES-related procedures or treatment.
- I take care of DES-exposed patients for most or all of the care they need.
- I do not have male DES-exposed patients.

19. For patients who have been exposed to DES do you:
- Record exposure in the medical record
- Counsel patient about risks
-Counsel women who took DES during pregnancy to tell children

20. Have any of the following kept you from providing screening or treatment to DES patients?
- Inadequate insurance coverage
- Insufficient scientific information on DES
- Lack of familiarity with management of DES-related problems
- Litigation concerns

21. How often have you referred DES-exposed men or women to the following?
- American Cancer Society
- National Cancer Institute Cancer Information (CIS), Cancer Hotline, Cancer FAX
- DES ACTION
- DES Cancer Network
- DES Sons Network
- RESOLVE

22. Which of the following best describes your practice?
- Private practice
- Freestanding clinic
- HMO
- Hospital
- Medical school
- Community clinic
- Other

Demographics:
23. Sex
24. Date of Medical Degree/Other
25. Medical Specialty (Family practice, General practice, Internal Medicine, OB/GYN, Oncology, Urology, Other)

Any comments about DES or this survey?
Appendix C

Common Core Questions from the Consumer Campaigns
(Respondents were asked to respond to these questions on a Likert-type scale or yes-no responses).

**Demographic Information**
1. Date of birth
2. Sex
3. Race
4. Education
5. Marital status
6. Living arrangement
7. Date since last routine health checkup
8. Health insurance coverage

**For Women Only:**
9. Ever been pregnant?
   - Number of times
   - Live births
   - Premature births
   - Miscarriages
10. Do you have a gynecologist or obstetrician?
11. Date of last ob-gyn examination
12. Ever had a mammogram
13. Date of last mammogram
14. Reason for last mammogram
15. Ever had a clinical breast exam?
16. Date of last clinical breast exam?
17. Reason for last clinical breast exam?
18. Ever had a Pap smear?
19. Date of last Pap smear?
20. Reason for last Pap smear?
21. Ever had a colposcopy?
22. Ever had infertility problems, tubal/ectopic pregnancy, breast cancer, cancer of the vagina, abnormal shape of uterus or cervix, or vaginal adenosis?

**For Men Only**
23. Ever had a PSA?
24. Date of last PSA?
25. Ever had a DRE?
26. Date of last DRE?
27. Reason for last DRE?
28. Ever had a testicular exam?
29. Date of last testicular exam?
30. Reason for last testicular exam?
31. Ever had cysts on testicles, infertility, prostate cancer, testicular cancer, or urinary tract abnormalities?

**Knowledge of DES**

32. Ever heard of DES?

**For Women Who Have Been Pregnant**

33. Did you take DES during pregnancy?
34. How did you find out whether you were given DES during pregnancy?
35. Ever tried to determine if you were given DES during pregnancy?
36. How did you try to determine exposure?
37. If you took DES, do you have daughters who were exposed?
38. Since you took DES during pregnancy, have you told your daughter that she was exposed?
39. If you have not told your daughter, is it because daughter does not have problem, don’t want to worry daughter, don’t think it affects girls/women, not sure how to tell her, daughters don’t need to know unless they want to have children, I feel guilty, I am embarrassed to talk about it, or other reason?
40. Do you have sons who were DES exposed?
41. Since you took DES, have you told your son that he is exposed to DES?
42. If you have not told son, is it because son does not have problems, don’t want to worry son, don’t think it affects boys/men, not sure how to tell son(s), men don’t need to know until they want children, I feel guilty, I am too embarrassed, or other?

**All Men and Women**

43. Was your mother given DES while pregnant with you?
44. If yes, how did you find out: mother, father, mother’s doctor, mother’s medical records, other
45. Have you ever tried to determine whether your mother was given DES while pregnant? How? Asked: mother, father, mother’s doctor, mother’s medical records, or other?
46. Do you have brothers/sisters?
47. Did your mother take or was she given DES while pregnant with any of your brothers or sisters?

**Discussed DES with Health-Care Provider**

48. Have any of your current health care providers ever asked if you were DES exposed?
49. Have you ever asked any of your current health care providers about DES?
50. Have any of your current health care providers ever given you a medical history form that asked if you were exposed to DES?

**Knowledge of DES Part 2:**

Asked for extent of agreement/disagreement with the following statements:

51. Prior exposure to DES is a continuing health concern.
52. It is important for DES-exposed people to know they are DES-exposed.
53. Does DES exposure cause any of the following in sons/daughters whose mothers took DES while pregnant with them?
- Deformed arms or legs
- Cleft palate
- Menstrual problems or endometriosis
- Miscarriages or ectopic pregnancies
- Ovarian cancer
- Vaginal cancer
- Colon Cancer
- Bladder cancer
- Lumps in the breasts that are not cancer
- Lumps in the testicles that are not cancer

54. Does DES exposure cause any of the following health problems in women who were given DES?
- Bladder cancer
- Breast cancer
- Ovarian cancer
- Vaginal cancer
- Osteoporosis
- Problems with menopause
- Lumps in the breast that are not cancer

**For Those Who Are DES-Exposed:**
55. Does your health-care provider carry out any special medical exam or screening procedures for you because you are DES-exposed?
56. Which of the following medical steps should DES daughters follow?
   - Pap smear from the vagina as well as the cervix
   - Vaginal palpation
   - As soon as pregnancy is suspected, an early pregnancy test by a physician
   - More frequent prenatal visits
   - Fertility evaluation

**Barriers to Care**
57. Indicate how much difficulty, if any, each of the following has ever caused you in obtaining DES-related health care.
   - Health-care provider did not think DES exposure was an important issue
   - Inadequate or no insurance coverage
   - Health-care provider lack of knowledge
   - Insufficient scientific information on DES

**Source of Knowledge on DES**
58. Have you received information about DES from any of the following?
   - Health-care provider
   - Mother
   - Other family member/friend
   - DES consumer group
- Pamphlets
- Newspaper or magazine articles
- Radio or television programs
- Other

**Additional Comments**

59. Would you like to know more about DES?
60. Do you have any comments?