

MEETING REPORT

for

Contract Number 200-98-0102

**DES NATIONAL EDUCATION CAMPAIGN FOR CONSUMERS AND HEALTH CARE
PROVIDERS MEETING, JANUARY 27, 2000**

to

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February 10, 2000

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REVIEW OF LESSONS FROM THE 5 NCI PILOT STUDIES

| LESSONS FROM THE CAMPAIGN FOR PHYSICIANS | |
|---|---|
| Lessons | Discussion |
| The most successful campaigns relied upon local sources of influence. | There was agreement on this point. One-on-one education did seem to have the most impact on physician learning. However, there was discussion of whether the NCI studies with targeted physician groups would be generalizable to other providers. |
| Involvement of physician's office staff as part of the DES campaign increased the effectiveness of campaigns. | There was agreement on this point. Lessons one and two are thought to be interrelated in that the office staff can serve as important local sources of influence over a physician's practice. |
| Education materials and support systems are most effective when crafted specifically for particular physicians' practices. | There was agreement on this point. Participants agreed that mailed materials that did not fit into the office system were ineffective. However, participants also thought that crafting materials for each practice setting would not be feasible for the national education campaign. |
| Educating and motivating physicians to learn about and screen for DES-related health risks requires that campaigns overcome inconsistencies between physicians' attitudes and behaviors | There was agreement on this point. However, there was no agreement on what factors would affect physician attitude and behavior or how to overcome inconsistencies. Not all of the sites used the same variables to analyze the data for physicians. Some sites showed more motivation among physicians based on physician age (older age), gender (female), or specialty (OB/GYN) but these differences were not found across sites. |
| Most physicians do not perceive DES information to be relevant to their practices. | There was agreement on this point. Physicians do not realize the magnitude of DES exposure (10 million individuals), or the ongoing nature of health concerns for DES-exposed individuals. One of the most difficult things about this issue is that it is harder to change misinformation than to give new information. |

LESSONS FROM THE CAMPAIGN FOR PHYSICIANS

| Lessons | Discussion |
|--|--|
| Pilot studies that created patient demand were more successful in heightening physician's receptivity to DES information. | There was agreement on this point. Participants believe that physicians will be more receptive to DES education messages if their patients are concerned about this issue. This lesson may have implications of which providers to target. In order to capitalize on this effect, the national education campaign may want to target physicians who see more of the patients/consumers that the campaign would like to reach (i.e., the 80/20 rule: 80 percent of patients are seen by 20 percent of providers). Therefore, if the campaign wants to reach DES daughters it should also target OB/GYN providers. |
| 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. | There was some disagreement with this point. First, participants pointed out that obstetrician-gynecologists were also primary care physicians so the end of the statement should read "than are <i>other</i> primary care physicians." Second, while the scores on post tests were higher for obstetrician-gynecologists than other primary care physicians, the scores were still low and did not reflect all of the information that participants would want providers to know. Therefore the campaign cannot assume that any provider, even a subspecialist, would have all of the necessary knowledge and practice the correct behaviors. |
| Educational materials to physicians must be drawn from sources that are respected in the medical field. | There was agreement on this point. Currently, the Internet is not a good way to reach physicians other than for accessing more respected sources such as journal articles via MEDLINE, or NCI practice guidelines. |
| The use of CME conferences and mailed distribution of educational materials in isolation have little impact. | There was agreement on this point. CME credits are no longer enough to encourage physician attendance at special events when many hospitals now offer CME programs as a regular part of physician activities. Including DES in grand rounds may be the most effective way to ensure physician attendance. Mailings |

LESSONS FROM THE CAMPAIGN FOR PHYSICIANS

| Lessons | Discussion |
|---|--|
| | alone also have little impact particularly when they do not come from respected sources. |
| . Combinations of lessons are associated with the achievement of campaign objectives. | ere was agreement on this point. rticipants agreed that a multi-pronged approach would be necessary. |

LESSONS FROM THE CAMPAIGN FOR CONSUMERS

| Lessons | Discussion |
|--|---|
| <p>Media coverage of DES prior to the NCI pilot studies shaped the quantity and quality of consumer's DES awareness and knowledge at baseline and confounded media campaign effects measurement.</p> | <p>There was agreement with this point. Participants also wanted it recognized that the sites for the NCI pilots were areas of the country that had a great deal of prior exposure to DES messages as these were major centers where DES was given. Other parts of the country that will be included in the national education campaign will probably not have had as much prior exposure. Also, it is important to reach other areas of the country as many people who were exposed to DES no longer live in areas of peak exposure. For instance, DES Action has a large membership in Florida where many DES mothers have retired.</p> |
| <p>Increases in awareness, knowledge, and behavior were constrained by intervention timing and duration.</p> | <p>There was agreement on this point. This lesson makes it important to have some sustainable efforts such as including DES in intake forms. This allows the national campaign to leverage past DES awareness/education campaigns in relation to changing patterns of care. For instance, the message "Tell your doctor" is effective if there is continuity of care by having the same physician or more commonly providing any physician access to previous records (e.g., as in an HMO).</p> |
| <p>Press relations efforts aimed at general and local news media coverage are productive means of arousing interest, as measured by calls to the DES information line.</p> | <p>There was agreement on this point. Having a national DES screening day or "hooking on" to another health issue (e.g., January is National Cervical Cancer Month) may be another avenue to generate on-going interest in the issue. While the California site sponsored a "DES day" it is difficult to get the press interested in such an event, as they are very common now.</p> |
| <p>The primary consumer education materials were useful in reinforcing and expanding education among the confirmed exposed population.</p> | <p>There was agreement on this point. It was not possible to measure the effect of the consumer education materials on public education.</p> |
| <p>Media coverage and paid advertising stimulate attempts to seek information.</p> | <p>There was agreement on this point. While both types of media generated interest, earned media coverage (e.g., news articles, etc.) were more effective than paid advertisement and may be more cost-effective for this campaign. Also print media coverage may be</p> |

LESSONS FROM THE CAMPAIGN FOR CONSUMERS

| Lessons | Discussion |
|---|---|
| | more effective in stimulating attempts to seek information than is television based on differences in the types of people who read versus watch television. |
| . DES messages targeted to the general public can also elicit response from those who know they are DES exposed and from providers. | ere was agreement on this point |
| . Networks can amplify media campaigns | ere was some disagreement on this point. e California pilot site that used this approach found it very labor intensive and suggested that it may not be feasible on a national level. Also the type of network arrangement used by DES Action and the DES Cancer Network is not comparable to what would be needed in a national campaign as they are working with individuals who are already motivated to contact the network. However, another way to utilize Anetworks@in a media campaign is to stimulate ecologically existing networks to raise awareness through word-of-mouth. |
| . Provider education alone appears to be insufficient to increase DES awareness among the public. | ere was agreement on this point |
| . Self-efficacy of DES exposed individuals can be enhanced by addressing specific barriers to health care. | ere was a question on this point. rticipant=s thought that incorporating the types of barriers that face DES-exposed individuals would strengthen this lesson. |

GENERAL LESSONS FOR PHYSICIAN AND CONSUMER CAMPAIGNS

Isolated, time-limited efforts usually have small and often short-lived effects. Participants were asked to respond to the following questions on how to enhance the sustainability of a National Education Campaign for DES.¹

What venues are the most fruitful for sustaining this effort?

- ⌘ Including DES education in provider education. Since this is a long-term goal, in the short-term, find out what barriers exist to including DES in current curricula or residency programs.
- ⌘ Including men in the campaign is an important goal. Perhaps an issue like osteoporosis, where early messages were solely aimed at women and then men were included, may serve as a model for how to do this for DES.
- ⌘ Providing a central information source for providers and consumers is important for the sustainability of the effort. The source must be respected among providers. For consumers a web-based information source may be necessary. DES Action is concerned that the source chosen to offer DES information will have to commit to providing such information for the long term. Otherwise, in the future, DES information may not be available.
- ⌘ Institute an annual DES awareness day rather than on-going projects. This approach may make it easier to gain attention for DES rather than trying to sustain a constant campaign.

What seeds can the communication campaign plan that consumer groups can nurture and sustain?

- ⌘ Disseminate easy to reproduce materials. The current consumer materials are too expensive for community groups to reproduce.
- ⌘ Identify or develop local sources of expertise in each community (e.g., an obstetrician-gynecologist) so that providers will have one expert to contact in their local area.

¹ Note: Isolated, time-limited campaigns may be appropriate for some aspects of the National Education Campaign (e.g., the American Red Cross has a constant need for blood supplies but only periodically has blood drives.®)

RECOMMENDATIONS FOR THE CAMPAIGN FOR HEALTH CARE PROVIDERS

RECOMMENDED TARGET AUDIENCES

| Recommendations | Discussion |
|---|---|
| <p>Primary Care Physicians: Recommendations 4 B The national education campaign should broaden its target group of providers to include nurses, nurse practitioners, physician's assistants, and nurse-midwives as segmented target audiences.</p> <p>Goal: We advocate formative research as a foundation for targeting advanced care professions (nurse-practitioners, nurse midwives, physician's assistants) and nurses for DES education.</p> | <p>Participants questioned whether we would learn anything from formative research that would be a change from what we already know.</p> <p>The formative research would not be conceptual in nature, rather it would allow the national campaign to: Assess awareness of DES in different sub-groups Discover what counseling and educational opportunities these providers have with patients Determine what materials these providers use Operationalize recommendations for these groups.</p> |
| <p>Primary Care Physicians: Recommendations 5 B Target primary care physicians as the primary physician audience for DES education.</p> <p>Goal: The goals of the campaign for primary care physicians would be to make them responsive to patient inquiries (and referrals from advanced care professionals), rather than initiators of DES inquiry, counseling, and screening.</p> | <p>Participants wanted to make it clear that primary care physicians encompassed four main groups: Pediatricians Primary Care Internists Family Physicians Obstetrician-Gynecologists</p> <p>As such, the term primary care provider may be the more encompassing term. Also, while primary care internists and family physicians may be the least knowledgeable about DES and serve in a gatekeeper role, obstetrician-gynecologists need to receive educational messages to correct misinformation.</p> <p>The goal for primary care providers should include some type of action step. At a minimum, providers should be expected to include a DES screening question on their intake form. This approach emphasizes the importance of the issue. DES is included on some standard intake forms, (e.g., ACOG, Kaiser), however, it will never be included on 100% of intake forms used by OB/GYN. Changing intake forms may also require targeting nurses who develop these forms.</p> |

RECOMMENDATIONS FOR THE CONSUMER CAMPAIGN

RECOMMENDED TARGET AUDIENCES

| Recommendations | Discussion |
|---|--|
| <p>DES Sons - The DES National Education Campaign should make sons a target audience and provide support for mothers to enable them to talk with their sons.</p> | <p>What is known about DES exposure in sons? Based on animal studies there is the potential for: Non cancerous urogenital abnormalities Cancer of the urogenital tract Fertility problems At this point, results on health outcomes from men in the Chicago cohort study, which includes 1400 exposed and 1400 unexposed men, are premature. Preliminary analysis shows that urogenital defects are rarely reported in men.</p> <p>What can and should the DES National Education Campaign say to men who know they are exposed about DES exposure? Conduct regular testicular self-exams for your whole adult lifetime (the recommendation now is only for ages 16-40) Get PSA exams as currently recommended. There is no consensus on the need for regular urinalysis.</p> <p>What to tell sons who do not know they are exposed. Sons are at risk too Sons are being studied If you were born between 1938-1971, try to find out whether you are exposed. Ask your mother or sister about possible exposure.</p> <p>What kinds of topics should be covered in formative research to best achieve these goals? Focus groups with sons would help to determine the messages to give to sons Compare the views of DES sons who know they are exposed versus those who do not know they are exposed. What will motivate the unknown exposed to seek information about DES? Ways to encourage discussions between brothers and sisters about DES exposure. What motivates men to seek regular health care? Who takes care of the health in your family? (Many health education campaigns have found that men are not good targets for health messages. See models from heart disease/hypertension)</p> |

CAMPAIGN MATERIALS

| Recommendations | Discussion |
|---|---|
| <p>Consumer Education Booklets B Recommendation 3 BThe DES National Education Campaign should explore effective and credible ways to use new communication technologies and formats for the distribution of DES education materials</p> | <p>Besides the use of the Internet, what are the most cost-effective ways for consumer advocates and local health agencies to disseminate DES information?</p> <p>A flyer or a postcard as a primary contact. Only those who request more information would receive the booklet. A one-page brochure (fact sheet) would help to raise awareness. Target magazines like Men's Health to reach DES sons. Add DES sections to published health books (DES information is included in some popular health series). Wallet cards to record next physician appointment. Incorporate DES exposure questions (risk assessment) into a portable Ahealth passport@ (possible one already distributed by other organizations).</p> |
| <p>Recommendation 4 B The NCI consumer booklet series should be updated (including decreasing the number of consumer booklets)</p> | <p>What would be lost/gained from such a move?</p> <p>Many of the consumer education materials have information that overlaps. Having only one comprehensive book (Ayellow book@) and several targeted books (e.g., DES daughters with cancer Awhite book,@ and providers Abrown book@) would help to reduce the redundancy. The information from the comprehensive booklet could also be put on a web site. The booklet could be distributed through public libraries as well as through consumer organizations.</p> |

DES EDUCATION PRIORITIES

PRIORITIES FOR THE DES NATIONAL EDUCATION CAMPAIGN

Which of the goals can best be met by the DES National Education Campaign?

Simultaneously conduct provider and consumer campaigns.

Providers and consumer can help to educate one another and provide one another with information about DES.

Narrow the consumer list.

Consumers to target include:

- ☞ The unknown exposed with health problems consistent with DES exposure
- ☞ The known exposed with misinformation.

Messages for consumers.

Messages for men who do not know they are exposed but have health problems consistent with DES exposure:

- ☞ Men can be affected by DES exposure.
- ☞ Ask your mother or sister about your exposure.
- ☞ Men should perform testicular self-exams for their entire lifetime.
- ☞ Follow current guidelines for prostate cancer screening.

Messages for men who know they are exposed are the same except they do not have to ask about their exposure.

Note: messages for men may also work for gatekeepers (mothers, wives, girl friends) as well as for men themselves.

Messages for daughters who do not know they are exposed but have health problems consistent with DES exposure:

- ☞ These (problems) may mean you were exposed to DES.
- ☞ Ask your mother/family member if you were exposed.
- ☞ There is a lifelong cancer risk. Get appropriate screening.

- ☹ It's not just cancer.
- ☹ Know where to go for more information.
- ☹ Tell your health care provider

Messages for daughters who know they are exposed are the same except they do not have to ask about their exposure.

Narrow the provider list.

Possible provider groups to target include:

- ☹ Family Physicians
- ☹ Primary Care Internists
- ☹ Obstetrician-Gynecologists
- ☹ Gynecological oncologists
- ☹ Urologists
- ☹ Nurse Practitioners, Nurse Mid-Wives, Physician's Assistants (those involved in primary care)
- ☹ Nurses (are office staff for all of the above providers)

Participants voted on the most important group to target in the campaign. The criterion used was the group of providers who would see the largest number of potentially exposed consumers. The results of the vote were:

- ☹ Obstetrician-gynecologists (10 votes)
- ☹ Urologist (0 votes)
- ☹ Primary care providers (family physicians and primary care internist and the nurse practitioners and physician assistants who work with them) (6 votes)
- ☹ Gynecologist oncologists (0 votes)

Messages for Providers.

It was not clear how many messages you need for providers, however, no matter how many messages you have; they should be distributed through appropriate channels and relevant sources. The messages to give to obstetrician-gynecologists are:

- ☹ The cancer risk continues.
- ☹ Here is where you can get information about DES.
- ☹ It's not just cancer (fertility, high-risk pregnancy, menopause, autoimmune disorders, etc.).

The messages to give to primary care providers are:

- ⌘ You have DES-exposed individuals (both male and female) in your practice. Ask their status. Be aware of risk factors.
- ⌘ The cancer risk continues.
- ⌘ Here is where you can get information about DES.
- ⌘ It's not just cancer in young women (fertility, high-risk pregnancy, menopause, autoimmune disorders, known abnormalities in men, breast cancer, etc.).
- ⌘ Know the cancer risk and screening practices for male and female patients.
- ⌘ Refer appropriately.

PRIORITIES FOR CONSUMER ACTION GROUPS OR OTHER AGENCIES

Which remaining goals might be pursued through other channels?

- ⌘ Including DES education in initial provider education such as the curricula of medical schools and nursing schools. There are some existing curricula developed during the pilot studies. DES Action has one for nursing schools. The Wisconsin pilot project developed one for physicians, complete with videos. There is also a course on the computer. Pre-packaged materials are likely to be the most useful. The Office of Women's Health (OWH) has existing agreements with 18 academic medical centers designated as National Centers for Excellence. These centers will work with OWH to include women's health issues into their training in a variety of ways. DES may be one topic that can be included in this effort. While it is not likely that DES will become a part of every school's curriculum, these centers serve as models for other academic medical centers so effects could spread beyond these 18 schools.
- ⌘ Changing intake forms.
- ⌘ Taking policy, insurance, or legislative action.
- ⌘ Disseminating a provider referral list.
- ⌘ Influencing Healthy People 2010.
- ⌘ Preparing peer reviewed journal articles about the latest research or reviews articles with practice implications (although publications could be timed with the media campaign to coordinate with press releases, or reprints of articles could be included in media packets).

NEXT STEPS

20. CDC will hire a contractor to develop the creative portions of the communication campaign.
 21. In April the contractor will come before the group and present (1) a plan for carrying out the campaign and (2) plans for formative research to fill in gaps.
 22. Formative research will be completed by June.
 23. Concept development and testing will be completed before Thanksgiving.
 24. Product development will be done over the winter.
 25. Feedback from the meeting and dates for the April meeting will be communicated over the listserv.
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