

**Recommendations for Formative Research for Health Care Providers:
Gaps and Lessons from the NCI Pilot Studies= Baseline Data
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The principal investigators of the NCI pilot studies attempted to compile their baseline data. Deborah Wingard, Ph.D. (a co-investigator in the California project) asked each of them to submit their data in comparable tables and divided between obstetrician-gynecologists and other primary care providers (almost all physicians). Even though the data is incomplete (Texas did not submit their data in the desired format; they did not analyze ob-gyns and other physicians separately), there are some consistencies indicating conclusions about health care providers= levels of DES awareness, knowledge, and behaviors. In addition, analysis of the baseline data is helpful in pointing to areas where the formative research can fill in the gaps.

A. Caveats:

It is important to consider this baseline data as noncomparable; the P.I.s have explicitly indicated that the data should not be added together and generalized. In addition, the data reported in these tables is sometimes inconsistent with the numbers reported in individual pilot study final reports. We have not been able reconcile the differences. In addition, the surveys were administered between 1994 and 1996, making the data 4-6 years old. DES knowledge, attitudes, and behaviors might have changed since then (although the impact of the DES pilot studies appears to have little influence on physicians). However, recent news concerning DES in beef might have rekindled interest and awareness of DES among physicians.

Below are highlights from the baseline data and areas of suggested implications for formative research.

B. Nonphysician Health Care Providers

1) None of the data should be used to form conclusions about nurse-practitioners, physician assistants, or nurses relative to DES knowledge, awareness, and behaviors or other information seeking behaviors. Only two of the pilot studies reported including any health care providers except physicians: California and Massachusetts. The numbers of nonphysician health care providers was small:

California

- 4 Nurse/nurse-practitioner in general practice
- 16 Nurse/nurse-practitioner in ob-gyn specialities
- 2 Physician assistants in general practice

Massachusetts

- 73 Nurses/nurse practitioners in general practice
- 40 Nurses/nurse practitioners in ob-gyn
- 22 Physician assistants in general practice

14 Physician assistants in ob-gyn

Texas's patient nomination subject pool could have included other health care providers, but the investigators did not analyze their data by type of health care provider.

2) Issues for formative research:

Though not reported in the baseline data, cumulative knowledge scores on DES in the California study indicated that nurses and physician assistants in their sample were initially less well informed in pre-intervention tests about DES issues (5.80 total knowledge score for nurses; versus 7.33 for physicians). The sample is too small to generalize, however, we can probably assume that nonphysician health care providers know no more than physicians about DES. As a result, topics for formative research might include the following topics:

A. Awareness of DES exposure as a health risk for women who took DES during pregnancy and those exposed in utero

DES moms: breast cancer

DES daughters: clear cell cancer of the vagina or cervix (and ages of possible diagnosis)
high risk pregnancies
ectopic pregnancies
infertility
miscarriages
premature births
structural abnormalities of genital organs

DES sons structural abnormalities of genital organs
epididymal cysts

B. Source of current information on DES

C. Do they (or the office staff in which they work/or the in-take form in the office) routinely ask about DES exposure?

D. How often they encounter DES exposed patients

E. Current process for screening DES exposed patients

Referral to physician

Referral to specialist

F. Current steps to educate/counsel DES exposed patients

Current educational materials used

Referrals to external sources (consumer groups, websites)

G. Where do they go to learn about unfamiliar health issues when patients ask questions or present with complaints that health care providers have little information about?

H. What are routine sources of information to keep up-to-date on new health problems, treatments and screening?

Journals (which)

Newsletters (which)

Conferences

Local Grand Rounds

CEU courses:

Self-study print courses

On-line/web based courses

Local hospital/clinic sponsored CEUs

Other _____

I. What professional organizations do they belong to?

J. Do they screen mail (their own or for physicians)?

If so, what filters do they use?

What mail gets routinely thrown away?

What mail usually finds its way on to their/ the physicians= desks?

K. What is their role in patient in-take?

L. What is their role in patient counseling/education?

What are the barriers to fulfilling this role?

M. What role do they play in creating in-take forms for their offices?

N. What kinds of patient education information is routinely displayed and given to patients in their offices?

Sources?

Formats? (Pamphlets, videos, tv shows, posters)

O. What type of office practice?

P. Do answers to A-N vary

By office practice type?

By speciality?

By age?

C. Physicians: Obstetrician-gynecologists and other Primary Care Physicians:

The baseline results included some useful conclusions for formative research and campaign planning. Listed below are data consistent across all the sites reporting. Although derived from very different campaign samples, these conclusions represent findings that do not have to be reconfirmed through subsequent formative research.

1) Ob-gyns and other primary care physicians represent two distinct audiences with different levels of DES awareness and different patterns of behavior relevant to DES.

Ob-gyns are roughly twice as likely to have read DES practice guidelines as have other primary care physicians.

Ob-gyns are two to seven times more likely to routinely ask patients if they have been exposed to DES.

Not reported in the baseline data, but in pilot study reports, ob-gyns had higher cumulative scores on DES knowledge than did other primary care physicians.

2) All physicians surveyed knew the most about some health risks/screening for DES daughters:

DES daughters= increased risk of vaginal cancer.

86-94% of primary care physicians agreed there was an increased risk
(Although 13% of New York primary care physicians surveyed did not know of this risk)

94-100% of ob-gyns agreed there was increased risk.

The second most commonly known DES related health risk was genital structure abnormalities in DES daughters.

58-78% of primary physicians knew about this health effect

96-100% of ob-gyns knew about this health effect.

Most physicians know that DES daughters= screening should include palpation of the complete vaginal walls

70-75% of primary care physicians agreed

86-95% of ob-gyns agreed

3) Physicians are much less likely to know about:

DES daughters ectopic pregnancies

The majority of primary care physicians did not know or thought it was questionable (54-68%)

Most ob-gyns were aware of ectopic pregnancies as a health risk (47-64%)

Even so, 15-28% of ob-gyns said ectopic pregnancies were not a risk

24-28% didn't know or thought it was questionable.

DES daughters= high risk pregnancies

6-20% of primary care physicians agreed they should always be considered high risk

33-38% of ob-gyns agreed

DES mothers= increased risk of breast cancer

61-67% of primary care physicians didn't know or found it questionable

More ob-gyns answered that moms were at increased risk, but only 11-21% said yes.

DES sons epididymal cysts (lumps in testicles@)

66-84% of primary care physicians said they didn't know or it was questionable

58-81% of ob-gyns said didn't know or questionable

Only 14-27% of any group knew about epididymal cysts

4) The majority of physicians agree that most men don't know if they are DES exposed

57-75% of primary care physicians

55-76% of ob-gyns

5) Large majorities of physicians indicate that they always record DES exposure and charts (above 80% for both primary care and ob-gyn) and that they always counsel about risks.

However only 7-20% of primary care physicians routinely ask patients about DES exposure (between ob-gyns the range is 24-72%).

6) The baseline data doesn't provide accurate assessments of physicians' knowledge of several health risks related to DES exposure. Several questions on the baseline surveys had the potential to be misinterpreted.

DES guidelines.

The surveys asked physicians if they had read DES guidelines. There was no indication of which guidelines. Our interviews indicated that many physicians didn't know there were any guidelines. A survey of NCI website and discussion with their outreach staff failed to find national guidelines on DES treatment and screening. As a result, even though the majority of ob-gyns indicated they had read DES guidelines, we don't know the content or source these guidelines.

DES awareness.

Although the surveys asked how familiar physicians were with DES, the question did little to identify the content of the awareness. Physicians might well have been aware of initial concerns over DES discovered in the 70's, but not aware of current research. Agricultural uses of DES might have been reflected in responses to this item as well.

Age of vaginal cancer diagnosis.

Although the survey asks about DES daughters' risks of vaginal cancer, the survey did

not ask about the physician's awareness of age at diagnosis. Since many physicians were aware of early research findings when cancers were thought to occur only in girls and young women exposed to DES in utero, it is possible that many are unaware of the later findings that women are being diagnosed with clear cell cancer into their early 50s.

Questions with no answers.

Several of the questions asked physicians to answer questions to which there are no correct answers.

Physicians were asked about screening DES daughters. Three of their questions focused on practices for which there are no clear answers:

Colposcopy: Many experts agree that this procedure is necessary if there is an abnormality noted in the routine exam, but not otherwise. Others believe that physicians should do a colposcopy for the first exam of the DES daughter but not for ever exam.

Iodine Staining: Same controversy as for colposcopy

Pap smear of vaginal fornices: Most physicians agree this is necessary for DES daughters, but not all experts believe it is necessary.

Implications for Formative Research

The areas of omission and ambiguity suggest the following as topics for formative research for physicians

1. Knowledge of DES screening and treatment

- a) Level and content of awareness regarding DES
- b) Knowledge of age of diagnosis of vaginal cancers in DES daughters
- c) Awareness of controversies surrounding DES screening guidelines for DES daughters
- d) If unaware of DES screening/treatment, what are referral patterns?

2. Sources of information on DES:

- a) Sources of DES guidelines physicians have read
- b) Contents of DES guidelines physicians have read
- c) Although many physicians indicated they learned about DES from professional societies or government agencies, ob-gyn's were much more likely to use these as sources (86-89%) than were other primary care physicians (31-5%). Many indicated that medical literature and lectures were their sources of DES information, but Massachusetts physicians indicated a reliance on consumer groups. Need to explore sources of information for variations/preferences among specialities.
- d) Content of medical school curricula on DES

3. Sources of medical knowledge

What sources do they turn to when patients bring complaints for problems about which the physician has little information or education?

How do physicians stay informed on low prevalence diseases and health risks?

Attitudes and uses of internet for medical information.

Which, if any web sites they use?

What web sites are credible?

Are they more likely to pick up the phone and call an 800 # for information?

What medical journals are they most likely to read?

How do they read the journals? Do they pay attention to the ads?

Where are they most likely to go to fulfill CME requirements?

Conferences?

On-line formats?

Self-study (print/audio recordings)?

At their conventions, is there a kind of Abook fair@room, for information technologies?

4. Since the DES campaign is likely to be a two-tiered approach to health care providers (1st tier ob-gyn, 2nd tier other primary care providers), how do 2-tiered approaches work for changing medical professional behavior (gatekeepers vs. specialists) on other issues?
5. Since the campaign will employ a consumer-booster element, how do physicians react when patients come in asking for specific screening? With lists of questions?
6. Medical Intake Forms - how are they developed, who creates them, how can they be changed, who uses them and how are they used?
7. How is mail screened in physicians=offices? What kind of mail is likely to be tossed out?
What is most likely to reach physicians=desk?
8. What role do other health care providers (nonphysicians) play in educating and counseling patients about health risks and prevention?
9. What kinds of patient education materials are displayed distributed in physicians=offices? Who makes those decisions?
10. Do the answers to 1-9 vary by age groups? By specialty?