Forty Years of Progress in Monitoring Cancer Control

Nancy Breen and Tracy M. Layne
National Cancer Institute, National Institutes of Health

1. Introduction

The National Center for Health Statistics (NCHS) and the National Cancer Institute (NCI) have collaborated on groundbreaking ways to use the National Health Interview Survey (NHIS) to monitor trends and patterns, answer key research questions, and provoke further scientific inquiry into cancer prevention and control. Selected examples demonstrate how the cancer control and core survey have evolved over time to meet the needs of the cancer surveillance community. Three longstanding areas critical to national surveillance--tobacco control, cancer screening, and diet and nutrition, have been monitored. Though limited in scope, all have led to significant analytical and methodological advances.

Key innovations to NHIS data collection have resulted from careful surveillance planning combined with creative and timely analysis of resulting data. The large sample size and range of covariates make the NHIS an outstanding vehicle to which questions can be added to accomplish a range of complementary surveillance goals. A major advance to the design occurred in 1985, when the NHIS began over sampling African-Americans and Latinos. In 2006 it began over sampling Asians (1). The cancer control supplement was first translated into Spanish in 1987 (2) and the entire NHIS has been administered in Spanish as well as English since 2000 (1).

The long-term collaboration between NCHS and NCI has led to outstanding cancer control data from the NHIS. These publicly available data offer an opportunity to evaluate various aspects of our national population health. Over 100 articles have been published in the cancer control literature using the NHIS.

2. A Congressional Mandate for Cancer Control Data

Since 2000, NCI has collaborated on screening and other cancer control questions with the Division of Cancer Prevention and Control (DCPC) at the Centers for Disease Control and Prevention (CDC). Advances that resulted from this collaboration on the 2000 NHIS and subsequent surveys included narrowing the intent of questions to behaviors, updating the questions on colorectal cancer screening, adding questions on prostate-specific antigen (PSA) screening, and adding first-degree family history of cancer. In 2000, the split-sample design was traded for the full adult sample so that estimates would be more robust.

In 1987 NCI initiated regular cancer control questions in response to a Congressional mandate to understand patterns and trends in incidence, survival and mortality. At that time NCI sponsored cancer registries throughout the US that monitored patterns and trends in incidence, survival and mortality through the Surveillance, Epidemiology and End Results (SEER) program (for details: http://seer.cancer.gov); however, little was known about risk factors or cancer screening,.

The first Healthy People objectives were targeted to be met by the year 2000. NHIS data is used to monitor more of these objectives, including cancer objectives, than any other data source. Monitoring cancer control objectives for the next Healthy People target to be met by the year 2010 established a continuing need for NHIS data (1).

3. Tobacco Control Was First

The NHIS was first fielded in 1957. Tobacco control monitoring occurred for the first time with cigarette monitoring in response to the Surgeon General's report in 1965. Since 1965, questions to elicit whether respondents ever smoked and whether they are current or former smokers have appeared on the NHIS (for details: http://www.cdc.gov/nchs/about/major/nhis/tobacco/nhis_tobhoma.htm). The NHIS has provided data on the percentage of adults who have ever smoked and quit by gender since 1965.

Figure 1

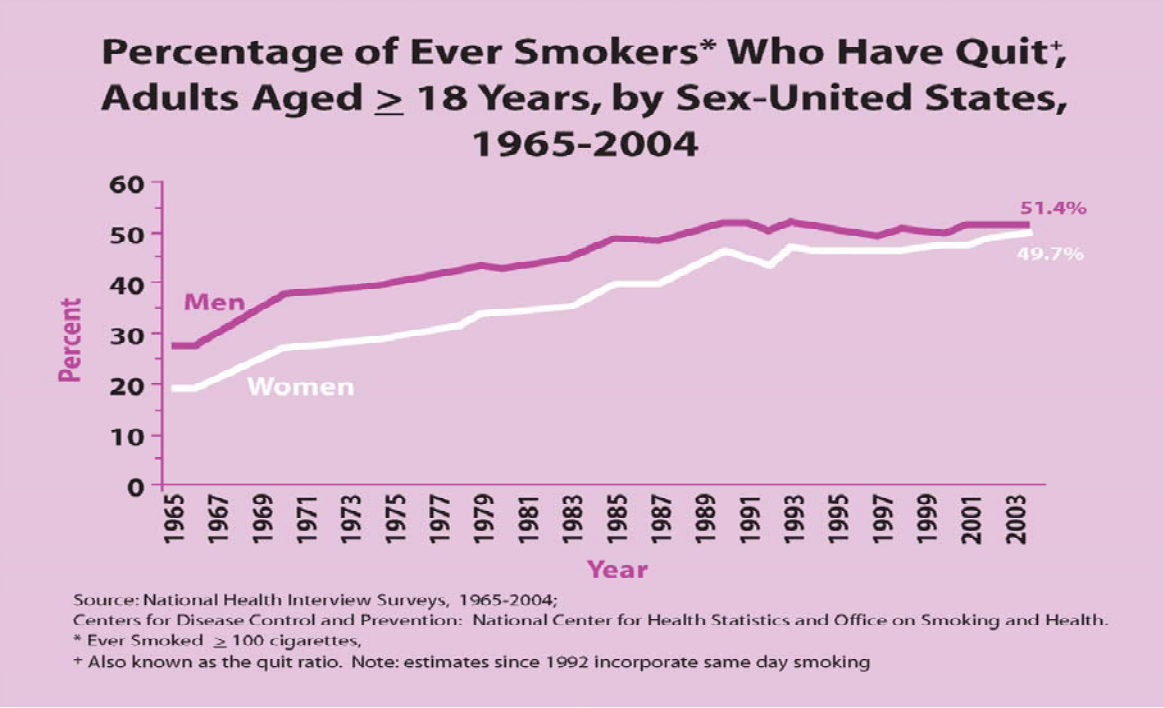
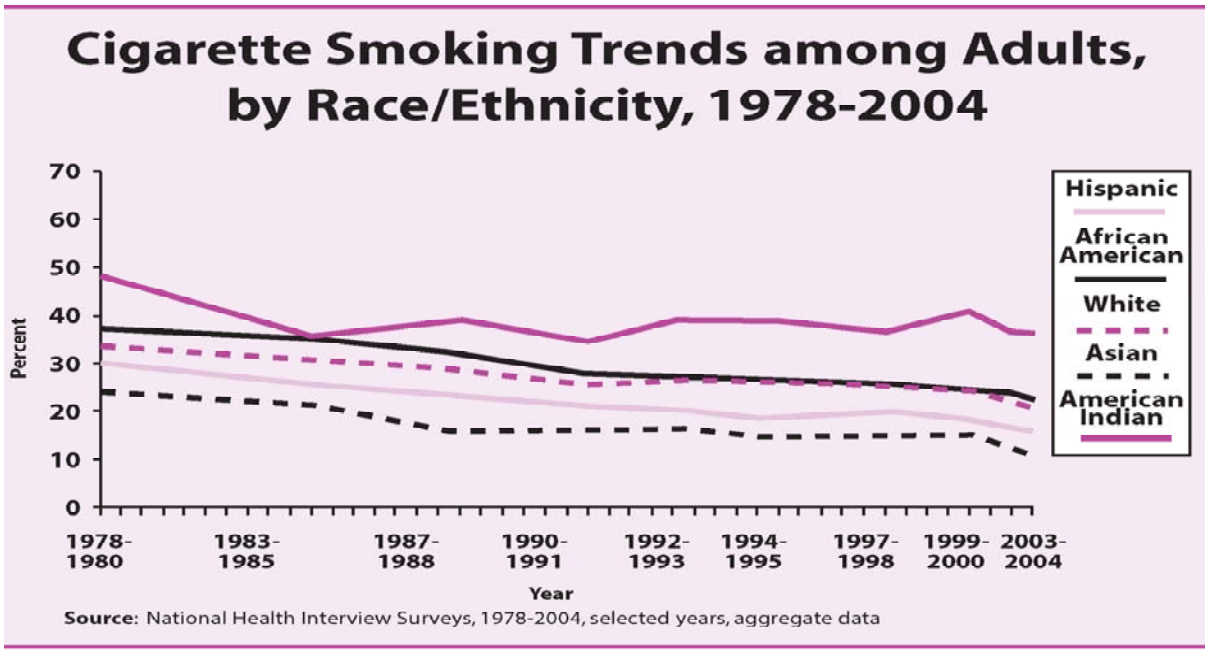


Figure 1 shows that quit rates for both men and women rose dramatically since 1965 but only recently have women's quit rates caught up to men's. About 50% of men and women had quit smoking by 2003. Trends in cigarette smoking among adults are available by race since 1978, when detailed race categories were first included on the NHIS (for details: **http://www.cdc.gov/nchs/about/major/nhis/rhoi/history_rho.htm**).

Figure 2



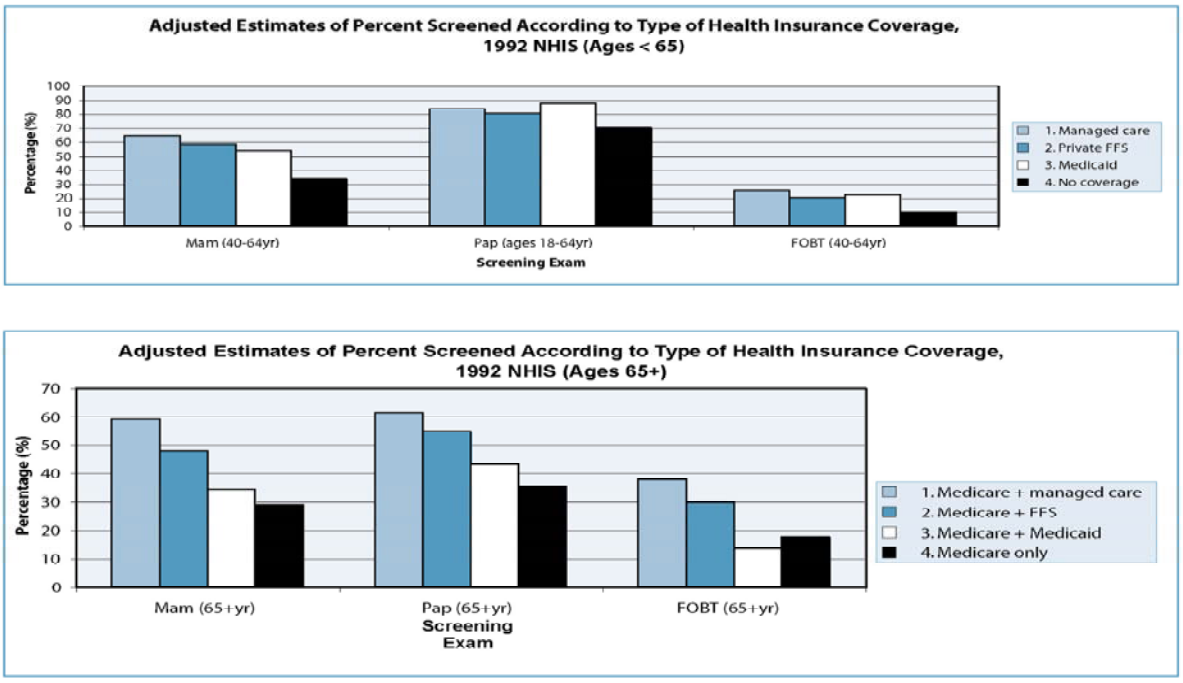
Data on Figure 2 show a continued steady drop in cigarette smoking among all racial-ethnic groups except American Indians. This finding indicates a health disparity that needs to be addressed.

4. Advances in Cancer Control Surveillance Research Using the NHIS

4.1 Health Insurance

In response to findings that less extensive health care coverage and greater out-of-pocket payments were associated with lower use of preventive services, NCI and NCHS staff collaborated on questions to obtain detailed health insurance coverage information on the 1992 NHIS. NHIS is a household survey administered in-person by Census field representatives. Thus respondents can be asked to present their insurance documentation to improve accuracy and detail. The 1992 insurance data was used for the first estimates of men and women screened for breast, cervical and colon cancer by type of health insurance coverage and age. Potosky et al. (3) examined how receipt of screening is related to type of health insurance while taking into account differences by age, educational attainment, race, income, marital status, self-reported health, and gender where applicable. The article presented logistic regression results, using predictive margins for greater accuracy and intuitive appeal. Figure 3 provides the adjusted percent estimates for selected cancer screening tests, assessed separately for respondents under 65 years old who are not eligible for Medicare and those 65 years and above who are. Highlights from this article displayed in Figure 3 include the new finding that cancer screening among respondents between the ages of 40 and 64 years was not higher for those with private Fee For Service (FFS) than those with Medicaid (public FFS), as the authors had expected based on earlier research (4-6). For older respondents, screening rates were higher among individuals with private supplemental insurance to Medicare than among those with only Medicare and/or Medicaid.

Figure 3

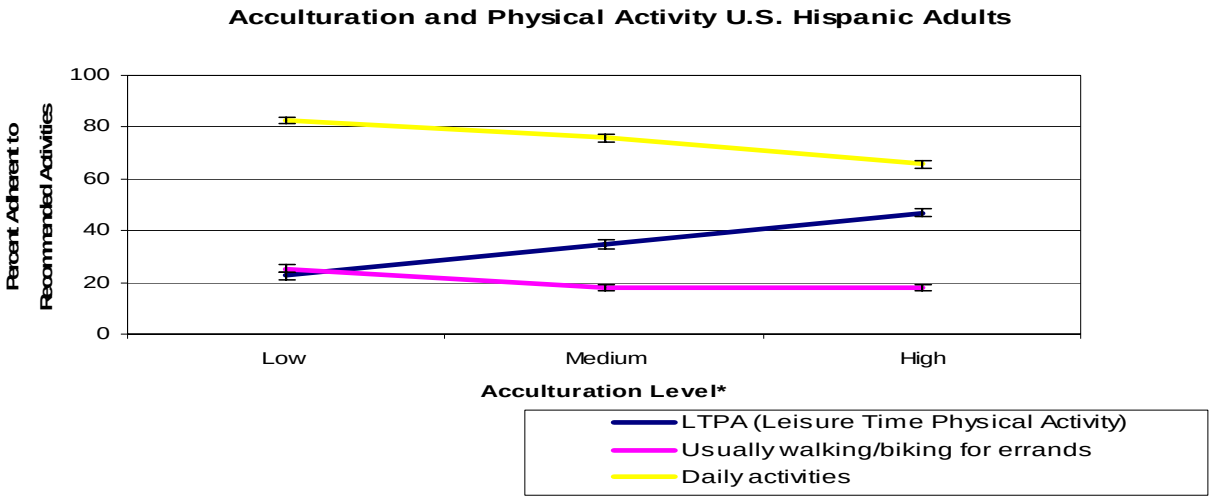


Source: Potosky A et al. Med Care 1998; 36(3): 257-70

4.2 Physical Activity

Another important advance occurred in measuring and monitoring leisure time physical activity (LTPA). The NHIS core routinely measures LTPA. *Health US* reported a gradient showing a direct relationship with LTPA and income **(7).** The 2000 NHIS cancer control data added questions on acculturation and non-leisure time physical activity. Berrigan et al. **(8)** collaborated with other NCI researchers to examine a sample of approximately 5000 Hispanic adults from the NHIS. The NCI researchers examined whether the slopes for different types of physical activity and acculturation were consistent. As Figure 4 shows, they are not. Daily activities are indirectly associated with acculturation while leisure time physical activity is directly associated with it.

Figure 4



Source: Physical activity and acculturation among adult Hispanics in the United States.Res Q Exerc Sport. 2006 Jun;77 (2):147-57.

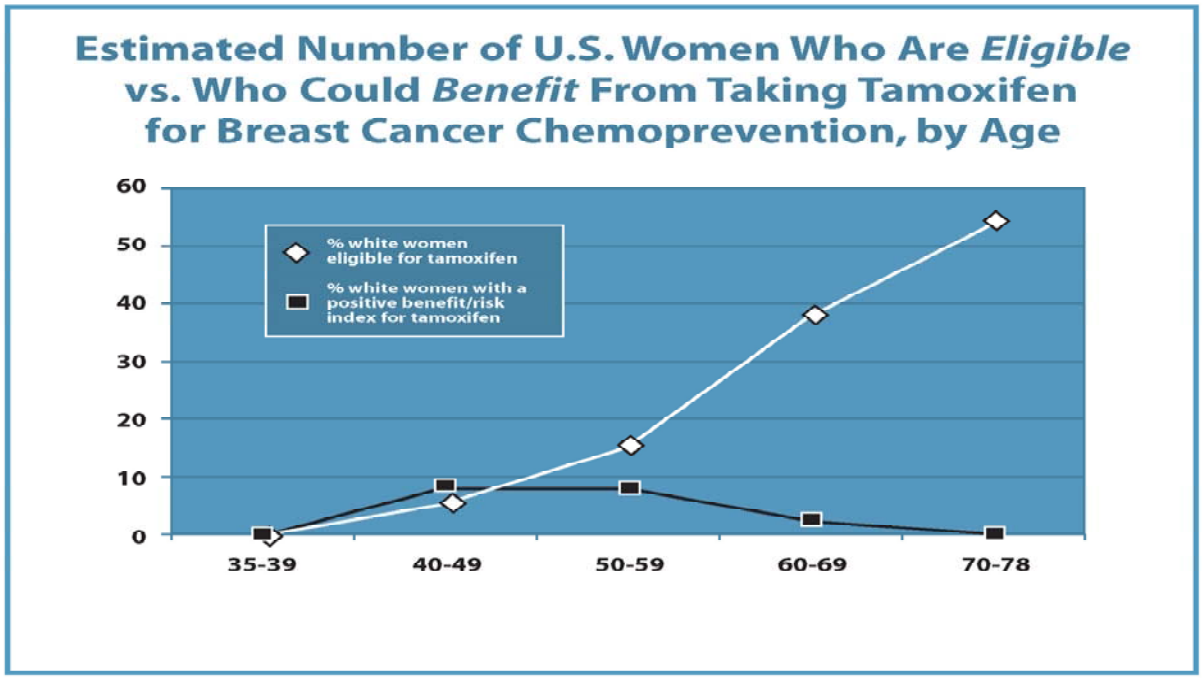
The authors defined adherence to physical activity or exercise recommendations as a combination of activities resulting in either 60 minutes of vigorous activity or 150 minutes of light or moderate activity per week, or a combination of both types totalling 150 minutes. Acculturation level was determined by summed scores from a series of eight questions on language usage. Respondents were defined as having low acculturation if they reported that they spoke only Spanish. Both Spanish and English were defined as medium acculturation respondents, and only English was defined as high acculturation.

4.3 Risk Assessment and Chemoprevention

An innovative research application using comprehensive health data from the NHIS applied cancer risk assessment models and chemoprevention drug benefit/risk indices to the NHIS data **(9)**. Questions were added to the 2000 NHIS to assess breast cancer risk using the Gail Model **(10)**. These questions allowed for the estimation of the 5-year risk of developing breast cancer for women ages 35 to 79 years old who completed the 2000 NHIS. Questions included information on age at first live birth, number of first degree relatives with breast cancer, and family history of breast cancer. Using this model, Freedman et al. calculated the number of U.S. women eligible for tamoxifen breast cancer chemoprevention, based on FDA criteria. They found that over 10 million women in the U.S. would be eligible.

After identifying this subset of eligible women, Freedman et al. took the analysis a step further by applying a tamoxifen risk/benefit index developed by Gail et al. **(11)** to the data. This index evaluates the benefits of tamoxifen chemoprevention against the risk of adverse events. Figure 5 illustrates some the key findings of this analysis. This figure shows that benefits vary with age among eligible white women but are most evident between 40 and 59 years. Freedman et al. estimated that overall, more than 2 million eligible white women in the U.S. would have an estimated positive net benefit if they were to take tamoxifen to reduce their risk of breast cancer. This analysis represents the first time national prevalence estimates have been obtained for women at high risk for breast cancer who could potentially benefit from the chemopreventive effects of tamoxifen.

Figure 5



Source: Freedman et al. J Natl Cancer Inst. 2003 Apr 2;95(7):526-32

4.4 Food Intake Assessment

A major surveillance advance occurred with the diet and nutrition section of the cancer control questions. In 1987 and 1992, the NHIS Food Frequency Questionnaire (FFQ) took 40 minutes to administer. The length of the FFQ required using a split-sample design for the cancer control questions. This design limited the ability of analysts to obtain robust statistical estimates for cancer screening and risk factors. Development of a Multifactor Food Screening Instrument (MFSI) provided an efficient means for estimating some key aspects of diet. First fielded on the 2000 NHIS, items included fruits and vegetables and percentage of energy from fat and fiber. A key objective of this tool was to create a simple instrument to avert the split sample design required by food frequency questionnaires used on previous cancer supplements.

In order to develop the multifactor screener, NCI staff analyzed a range of foods to determine which ones were associated with key sources of energy such as fat, fiber, and sweets. Using regression analysis, staff found a few foods in each category for the MFSI. Replacing the FFQ by the MFSI reduced the length of the diet and nutrition section of the survey from 40 minutes to 4 minutes and maintained a basic food intake covariate. Table 1 lists the questions from the MFSI asked on the 2000 CCM to assess dietary intake, as reported by Thompson et al **(12)**. In addition, MFSI items can be fielded on specialized surveys and compared to national estimates.

Table 1

Questions asked in Multifactor Food Screener: NHIS 2000

How many times per day, week, or month did you USUALLY eat (or drink):

- cold cereals?
- bacon or sausage, not including low-fat, light, or turkey varieties?
- hot dogs made of beef or pork?
- whole-grain bread including toast, rolls, and in sandwiches? Whole-grain breads include whole wheat, rye, oatmeal, and pumper nickel.
- 100% fruit juice such as orange, grapefruit, apple, and grape juices? Do NOT count fruit drinks such as Kool-Aid,® lemonade, cranberry juice cocktail, Hi-C, band Tang.®
- fruit? COUNT fresh, frozen, or canned fruit. Do NOT count juices.
- regular-fat salad dressing or mayonnaise, including on salad and sandwiches?
- lettuce or green leafy salad, with or without other vegetables?
- french fries, home fries, or hash brown potatoes?
- other white potatoes? COUNT baked potatoes, boiled potatoes, mashed potatoes, and potato salad.
- cooked dried beans, such as refried beans, baked beans, bean soup, and pork and beans?
- not counting what you just indicated (about lettuce salads, white potatoes, cooked dried beans), and not counting rice …OTHER vegetables?
- any kind of pasta? COUNT spaghetti, noodles, macaroni and cheese, pasta salad, and any other kind of pasta.
- peanuts, walnuts, seeds, or other nuts, not including nut butters.
- regular fat potato chips, tortilla chips, or corn chips? Do NOT include low-fat chips.

What kind of milk did you usually use?

- milk, either to drink or on cereal?
- Response categories were: whole milk, 2% fat, 1% fat, 1/2% milk, non fat or skim milk, or other.

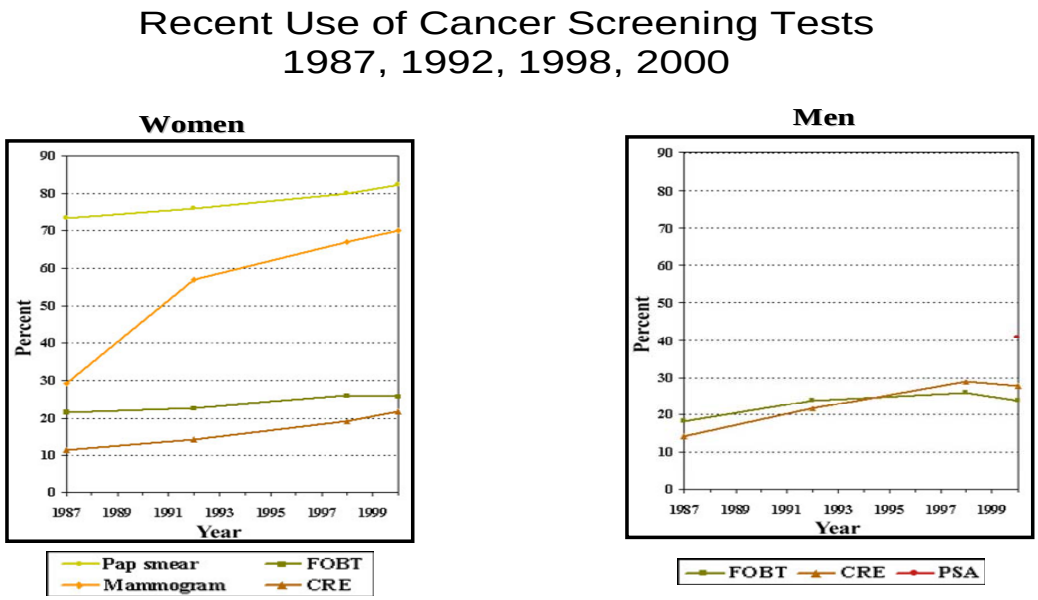
(Additional help was given for individual questions as the need arose.)
Response categories were recorded for 1) Number of times (0 to 94; 95=95+) and 2) Time period (day, week, month, year)

Source: Thompson et al. J Am Diet Assc. 2005 Mar; 105(3); 352-63; quiz 487

5. Cancer Screening

NCI has monitored cancer screening since 1987. Pap tests, mammograms, breast clinical and self exams, colorectal endoscopy, fecal occult blood testing, digital rectal exams and prostate-specific antigens have been monitored over the years. As studies and clinical guidelines have refined our understanding of cancer screening, NHIS questions have been modified to reflect them. Trends can be constructed for most cancer screening tests since 1987**(13)**. (See Figure 6)

Figure 6



Source: Swan J et al, *Cancer*, 2003, Volume 97(6):1528-1540.
National Health Interview Survey data. Percentages are standardized to the 2000 Projected U.S. Population by 5-year age groups.
PAP smear: Within the last 3 years, age 25+. **Mammogram**: Within the last 2 years, age 40+. **FOBT**: Fecal Occult Blood Test within the last year, age 50+. **CRE**: Colorectal endoscopy within the last 3 years, age 50+. **PSA**: Prostate Specific Antigen test within the past year, age 50+.

Among women, Figure 6 shows consistently high rates of Pap testing, a rapid increase in mammogram use between 1987 and 1992 which slowed between 1992 and 2000. Colorectal cancer screening for women, whether using endoscopy or Hemoccult, has risen slowly –especially given the strength of evidence for a mortality benefit for these screening tests. Among men, Figure 6 shows an increase in endoscopy use which, by 1998, exceeded use of FOBT (a trend not yet observed among women). The first population-based measure of Prostate-specific Antigen (PSA), collected in 2000, indicated high rates of use for a test with uncertainty associated with its use and follow up.

5.1 Health Disparities

Lack of health insurance or a usual source of care, and time in the United States was associated with health disparities in cancer screening practices in 2000, shown in Table 2. NCI and CDC researchers collaborated on a study of progress in cancer screening over the years **(13).** This table underscores screening gaps based on socio-demographic characteristics. Of particular interest is the change in cancer screening usage between 1987 and 2000: NHIS data revealed that disparities in cancer screening among those with no usual source of care continued to widen.

Table 2 also shows a total of 82% of women ages 25 and older who reported having a Pap test in the 3 years prior to their interview. These figures dropped to 62% of women with no health insurance, 58% with no usual source of care, and 61% who had immigrated to the U.S. within the last 10 years of the survey. Women ages 40 years and older were asked if they had a mammogram in the previous 2 years. Seventy percent reported having had one, but only 38% of those with no health insurance, 35% of those with no usual source of care, and 39% of women who immigrated to the U.S. in the last 10 years reported having a mammogram. For colorectal cancer screening, reported for men and women ages 50 years and older, 18% of women and 20% of men with no health insurance reported having either a Fecal Occult Blood Test (FOBT) in the last year or a colorectal endoscopy in the past 5 years.

Table 2

Cancer Screening in the U.S.: Where Are the Disparities?

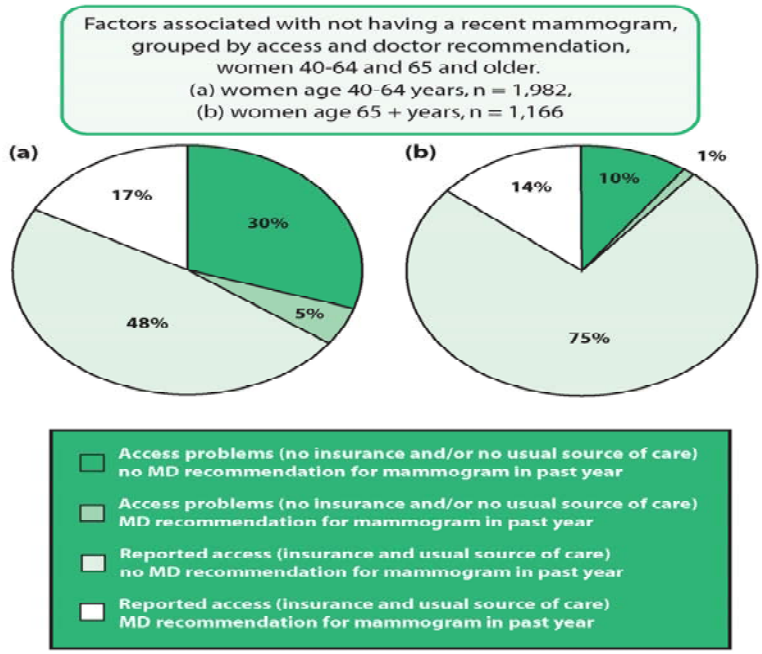
2000 National Health Interview Survey

	Pap Test	Mammogram	Colorectal (Women)	Colorectal (Men)
Total	**82%**	**70%**	**38%**	**41%**
No health insurance	62%	38%	18%	20%
No usual source of care	58%	35%	13%	14%
Recent immigration	61%	39%	16%	20%

Source: Swan et al., Cancer 2003:1528-1540

In an effort to understand which women don't get screened and why, NCI and other researchers analyzed factors associated with not having a recent mammogram, grouped by access and doctor recommendation (**14**). Figure 7 shows that the vast majority of women age 40 and older who did not report a recent mammogram had a usual source of health care and health insurance but no doctor recommendation for this screening procedure. Non-screened respondents were categorized according to four factors associated with not having a mammogram. Figure 7 displays the distribution of these factors for women between the ages 40 and 64 and those 65 and older.

Figure 7



Source: Meissner et al. Cancer Causes Control. 2007 Feb; 18(1):61-70

NCI and other researchers used the wealth of screening data collected in the 2000 NHIS to highlight factors affecting screening behaviors among women who ever had an abnormal mammogram **(15).** Yabroff et al defined "at least some level of follow-up" as any subsequent additional tests or procedures received, including additional imaging; clinical exams/surgical consult; biopsy or fine-needle aspiration; or breast/lump removal. The investigators used bivariate and multivariate analyses to examine whether an abnormal mammogram is associated with socio-demographic, general health, health behaviors, breast cancer risk and health care utilization. Table 3 presents the odds that women with specific characteristics would have at least some level of follow-up. Among the women aged 30 and older who reported ever having an abnormal mammogram, lack of follow-up was directly associated with educational attainment, lack of health insurance coverage and delayed care due to high cost.

Table 3

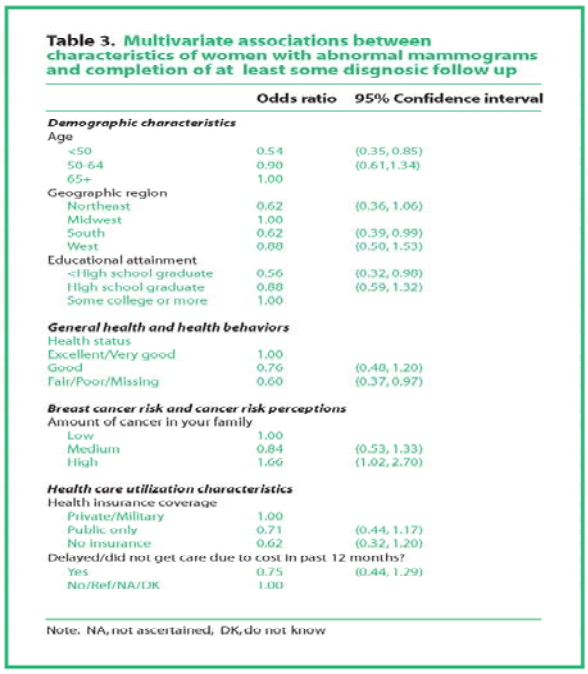


Table 3. Multivariate associations between characteristics of women with abnormal mammograms and completion of at least some disgnosic follow up

	Odds ratio	95% Confidence interval
Demographic characteristics		
Age		
<50	0.54	(0.35, 0.85)
50-64	0.90	(0.61,1.34)
65+	1.00	
Geographic region		
Northeast	0.62	(0.36, 1.06)
Midwest	1.00	
South	0.62	(0.39, 0.99)
West	0.88	(0.50, 1.53)
Educational attainment		
<High school graduate	0.56	(0.32, 0.98)
High school graduate	0.88	(0.59, 1.32)
Some college or more	1.00	
General health and health behaviors		
Health status		
Excellent/Very good	1.00	
Good	0.76	(0.48, 1.20)
Fair/Poor/Missing	0.60	(0.37, 0.97)
Breast cancer risk and cancer risk perceptions		
Amount of cancer in your family		
Low	1.00	
Medium	0.84	(0.53, 1.33)
High	1.66	(1.02, 2.70)
Health care utilization characteristics		
Health insurance coverage		
Private/Military	1.00	
Public only	0.71	(0.44, 1.17)
No insurance	0.62	(0.32, 1.20)
Delayed/did not get care due to cost in past 12 months?		
Yes	0.75	(0.44, 1.29)
No/Ref/NA/DK	1.00	

Note. NA, not ascertained, DK, do not know

Source: Yabroff et al. Cancer Epidemiol Biomarkers Prev. 2004 May; 13(5): 723-32.

6. Concluding Remarks

Significant progress in cancer control data has been made over the past 40 years by building on the foundation provided by the NCHS. NHIS data have been widely and creatively analyzed to further cancer control science and inform new research. When 2005 NHIS mammography rate estimates showing a slight, but statistically significant, decline in recent mammogram use were published (16), it generated considerable publicity. Reporters clamored for local results underlying the NHIS data. As currently designed, the NHIS cannot provide the state and local estimates required to provide a scientific evidence base for decision making at the state and local levels.

Programs and policies are increasingly designed and implemented at the local level, and local data would make it possible to monitor these programs and policies. Increasing the sample size representing the US population could be done in several ways. For example, if state surveys were coordinated to collect data at the local level using the NHIS instrument and scientific sampling strategies, resulting data could improve the effective sample size of the NHIS and the granularity of estimates. The California Health Interview Survey (CHIS) (18) provides the only model for a large, population-based statewide local health survey in the US that administers questions comparable or identical to the NHIS. Administered biennially by telephone to about 50,000 Californians, the large CHIS sample provides estimates reflecting the diversity of the California population. The Random Digit Dial (RDD) design and telephone administration yields estimates that represents the California population (18) and make allows survey administration in multiple languages. The NHIS has been a critical source of inspiration and comparison for the CHIS.

Its large sample size and rich set of co-variates has made the NHIS the premiere national population-based public health survey in the US. NCI looks forward to continuing our collaboration with NCHS on this critical national resource in the next forty years.

Acknowledgements

The authors wish to thank Andrew Freedman, David Berrigan, Martin Brown, Rachel Ballard-Barbash, Amy Subar, Fran Thompson for their helpful suggestions and careful review.

References

1. National Center for Health Statistics. National Health Interview Survey (NHIS). Centers for Disease Control and Prevention, U.S. Department of Health and Human Services. Available at: http://www.cdc.gov/NCHS/nhis.htm

2. National Center for Health Statistics, C.A. Schoenborn and M. Marano. 1988. Current estimates from the National Health Interview Survey: United States. 1987. *Vital Health Statistics*. .Series 10, No. 166. DHHS Pub No.

(PHS) 88-1594. Public Health Service. Washington: U. S. Government Printing Office.

3. Potosky AL, Breen N, Graubard BI, Parsons PE. The association between health care coverage and the use of cancer screening tests: results from the 1992 National Health Interview Survey. *Med Care* 1998; 36(3):257-70.

4. Riley GF, Potosky AL, Lubitz JD, Brown ML. Stage of cancer diagnosis for Medicare HMO enrolees. Am J Public Health 1994;84:1598.

5. Bernstein AB, Thompson GB, Harlan LC. Differences in rates of cancer screening by usual source of medical care. Data from the 1987 National Health Interview Survey. Med Care 1991;29:196.

6. Retchin SM, Brown B. The quality of ambulatory care in Medicare health maintenance organizations. Am J Public Health 1990:80:411.

7. National Center for Health Statistics. Health, United States, 1998 with Socioeconomic Status and Health Chart book. Hyattsville, Maryland: 1998

8. Berrigan D, Dodd K, Troiano RP, Reeve BB, Ballard-Barbash R. Physical activity and acculturation among adult Hispanics in the United States.Res Q Exerc Sport. 2006 Jun; 77 (2):147-57.

9. Freedman AN, Graubard BI, Rao SR, McCaskill-Stevens W, Ballard-Barbash R, Gail MH. Estimates of the number of US women who could benefit from tamoxifen for breast cancer chemoprevention. J Natl Cancer Inst. 2003 Apr 2; 95(7):526-32.

10. Gail MH, Brinton LA, Byar DP, Corle DK, Green SB, Schairer C, et al. Projecting individualized probabilities of developing breast cancer for white females who are being examined annually. J Natl Cancer Inst 1989; 81:1879-86.

11. Gail MH, Costantino JP, Bryant DP, Croyle R, Freedman L, Helzlsouer K, Vogel V. Weighing the Risk and Benefits to Tamoxifen Treatment for Preventing Breast Cancer. J Natl Cancer Inst 1999;91:1829-46.

12. Thompson FE, Midthune D, Subar A, McNeel T, Berrigan D, Kipins V. Dietary intake estimates in the National Health Interview Survey, 2000: methodology, results, and interpretation. J Am Diet Assoc. 2005 Mar;105(3):352-63; quiz 487.

13. Swan J, Breen N, Coates RJ, Rimer BK, Lee NC. Progress in Cancer Screening Practices in the United States: Results from the 2000 National Health Interview Survey. Cancer. 2003 Mar 15;(6):1528-40.

14. Meissner HI, Breen N, Taubman M, Vernon S, Graubard B. Which women aren't getting mammograms and why? Cancer Causes Control. 2007 Feb;18(1):61-70.

15. Yabroff KR, Breen N, Vernon SW, Meissner HI, Freedman AN, Ballard-Barbash R. What factors are associated with diagnostic follow-up after abnormal mammograms? Findings from a U.S. National Survey. Cancer Epidemiology Biomarkers Prev. 2004 May;13(5):723-32.

16. Breen N, Cronin KA, Meissner HI, Taplin SH, Tangka FK, Tiro JA, McNeel TS. Reported Drop in Mammography: Is This Cause for Concern? Cancer. 2007;109:2405-9