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Cognitive Aspects of Reporting Cancer Prevention Examinations and Tests

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This report explores the cognitive process used by women 50 years of age and over to answer questions about their experiences during the past 5 years with three cancer screening procedures: Pap smears, mammograms, and clinical breast examinations. Focus groups and think-aloud interviews were conducted to examine the cognitive processes used by respondents.

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Preface

Symbols

- - - Data not available

. . . Category not applicable

— Quantity zero

0.0 Quantity more than zero but less than 0.05

Z Quantity more than zero but less than 500 where numbers are rounded to thousands

* Figure does not meet standard of reliability or precision (more than 30-percent relative standard error in numerator of percent or rate)

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Cognitive Aspects of Reporting Cancer Prevention Examinations and Tests

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Introduction

Background

As part of the initiative Healthy People 2000, the U.S. Department of Health and Human Services has the goal of significantly increasing national health promotion and disease prevention (1). Among these goals is the reduction of mortality from several cancers, including breast and cervical cancer, by detecting them in the earliest stages when treatment is most likely to be effective (2).

Papanicolaou (Pap) smears, mammograms, and breast physical examinations are widely accepted screening procedures commonly used to detect cancer at an early stage. These procedures have been shown to reduce cervical and breast cancer mortality (3,4). Currently, a majority of all adult women are screened with a Pap test at regular intervals (5). Only a minority of adult females, however, currently receive screening mammograms (6).

Knowledge of cancer-screening practices in the general population, of course, is based in large measure on self-reports collected in survey interviews, such as the National Health Interview Survey (NHIS). There are, however, continuing questions about the accuracy of self-reports of cancer detection tests obtained by interview, particularly in the absence of validation by medical records. For example, several investigators have validated self-reports of these early detection procedures using information from patient medical records as the standard.

Much of this material has focused on Pap smears. Data from 11 of these published studies have been summarized in table A. As the third, fourth, and fifth columns in this table show, these studies vary along several important dimensions. For example, subjects have been identified from a variety of sources, including random community samples (7–9), health maintenance organization (HMO) membership rolls (10,11), public health clinics (12), cancer tumor registries (13), and case-control studies (14), and across a variety of geographic locations. Consequently, the demographic profile of the subjects in these studies also varies in age, ethnicity, socioeconomic status, and urban-rural status. In addition, subjects were asked to recall their screening histories across a variety of intervals that ranged from immediately after a medical encounter up to the previous 5 years. Sufficient information was nonetheless available to calculate a comparable set of measures (defined in the section "Results of phase I") for each study. Gross accuracy of respondent reports of Pap smear history ranged from 0.39 through 0.80 (weighted average = 0.59). Although sensitivity was high (range = 0.71–0.97; weighted average = 0.88), specificity was only moderate (range = 0.21–0.65; weighted average = 0.52). Report-to-records ratios indicate that receipt of Pap smears was overreported in each study (range = 1.21–3.32; weighted average = 1.95). Additional reports of Pap smear validation are available that do not contain information necessary for inclusion in table A (15–18). The general findings reported in these studies are nonetheless consistent with those being summarized here.

Table A also summarizes findings from five studies that verified mammography reports. Note that these study populations were far more homogeneous in nature than were those examined for Pap smears. Four of the five mammography studies selected subjects from HMO rosters (10,11,19,20), with one (21) coming from a random community survey. These studies also examined a shorter range of recall intervals (6 months–2 years), compared with the Pap studies reviewed, and all were published during the 1990's. Overall, these studies report higher degrees of gross accuracy (range = 0.81–0.97; weighted average = 0.86), sensitivity (range = 0.92–1.00; weighted average = 0.91), and specificity (range = 0.58–0.94; weighted average = 0.74), compared with the Pap smear validation studies. Although overreporting was also a problem with mammography self-reports, report-to-records ratios were smaller than among the Pap smear studies (range = 1.06–1.76; weighted average = 1.29).

Only two studies were identified in which attempts were made to validate clinical breast examinations (table A). Gordon (10) reported a gross accuracy rate of 0.70 for this procedure, with high sensitivity (0.97) but low specificity (0.22). Because medical records validation data for this procedure are generally derived from physician notes rather than pathology or radiology reports, as is the case with Pap smears and mammograms, true reports for this procedure may have a greater likelihood of being labeled as "false positives." Consistent with the findings for the other two screening procedures, clinical breast exams were also likely to be overreported.

Cognitive aspects of survey research

One approach to improving the accuracy of self-reports in surveys that has received considerable attention in recent years is using the theories and methods of cognitive psychology

(22). The cognitive approach seeks to identify respondents' errors in understanding and answering questions and to design questions that minimize such errors.

It is now generally agreed by most researchers who use cognitive methods to study survey methods that there are four steps in the response process (23–25). Not every step is equally important for all questions.

The first step is interpreting the question. Questions dealing with specific screening procedures may well be subject to linguistic and interpretative difficulties. As examples, not all respondents, especially those with less education, may be sure of what a "Pap smear test" or a "blood stool test" is. This may lead to incorrectly reporting either that a test occurred when it did not or that it did not occur when it did. The researcher can improve reporting by choosing the most meaningful wording or possibly alternative wordings for different respondents.

The second step is retrieving either the answer to the question or relevant information that will be used to construct an answer. Here there has been substantial work reported recently about the effects of different question wordings that act as cues to improve retrieval (26).

Among the important findings are two: the use of schemas and the effectiveness of using alternative aspects of an event to recall it. Most cognitive psychologists believe that many repetitive activities are not easily retrieved as individual events but rather as schemas, which are generalizations. Thus, an older woman who gets an annual physical examination might remember months later that a Pap smear and stool sample are part of that examination and how these are usually conducted, without remembering the specifics of a particular test on a specific day (27). The accuracy of information obtained from schemas depends on the regularity of the behavior (28). Researchers may influence response accuracy by asking questions that deliberately evoke or discourage the use of schemas.

Brewer (29) has made a strong case that the date of an event is the least well remembered attribute of that event, relative to such other aspects as where the event occurred, who was present, and what happened (see also Wagenaar [30] and Means et al. [31]). The researcher may influence the accuracy of reports by a question order that postpones asking about the date until other better remembered aspects of the event are reported.

A well-recognized problem in recalling when an event occurred is called "telescoping." This is remembering that an event occurred but misremembering when it happened (32–35). For a variety of reasons, forward telescoping (remembering that an event has occurred more recently than it actually did) is more common than backward telescoping. This is also a possible explanation for overreporting of diagnostic procedures. There have been studies of telescoping of health-related activities (36) but apparently no studies of telescoping of reported diagnostic tests such as Pap smears and mammography. The records checks for this study will make such an analysis possible.

The third step in the response process is judgment formation. Computing judgments based on data retrieved from memory is an important aspect of attitude formation and the reporting of behavioral frequencies. Of particular interest in this context is the question of whether respondents attempt to count specific examinations or estimate based on a stored or computed rate.

Finally, the fourth step involves the editing of answers by respondents if they see certain answers as being more socially desirable than others (37). Socially desirable information is overreported, whereas undesirable behavior is underreported. There do not appear to be any studies indicating whether questions about specific disease prevention procedures are seen as threatening or not, and, if threatening, whether that is because having the tests done is seen as desirable or undesirable.

In the remainder of this report, findings are presented from an exploration of the cognitive processes that older (50 years of age and over) female respondents employ in answering questions related to their experiences with several cancer-screening procedures.

Table A. Data on validation studies of previous Pap smear, mammogram, and clinical breast exams

Study	Number	Sample	Location	Recall period	Gross accuracy	Sensitivity	Specificity	False negative	False positive	Report-to-records ratio
Pap smears										
Sawyer (7)	98	Random/ referred[1]	North Carolina	3 years	0.80	0.95	0.47	0.05	0.53	1.21
Bowman (8)	111	Random	Australia	3 years	0.78	0.93	0.55	0.07	0.45	1.21
Gordon (10)	352	HMO	Northern California	2 years	0.78	0.97	0.35	0.03	0.65	1.25
Walter (14).	212	Cervical dysplasia study control	Ontario	1 year	0.75	0.89	0.65	0.11	0.35	1.44
McKenna (13).	125	Tumor registry[1]	Chicago	3 years	0.65	0.96	0.41	0.04	0.59	1.72
Walter (14).	218	Cervical cancer study controls	Ontario	1 year	0.59	0.72	0.45	0.08	0.55	2.22
Michielutte (12)	318	Sexually transmitted disease clinic	Los Angeles	After exam	0.47	0.97	0.32	0.03	0.68	3.32
Warnecke (9)	544	Random[1]	Buffalo	5 years	0.39	0.71	0.21	0.29	0.79	2.10
Loftus (11)	173	HMO	Washington State	6 months	– – –	– – –	– – –	– – –	– – –	1.78
Mammograms										
King (20)	199	HMO	Pennsylvania	1 year	0.97	1.00	0.94	0.00	0.06	1.06
Brown (19).	380	HMO	Massachusetts	1–2 months	0.87	0.92	0.85	0.08	0.15	1.16
Gordon (10)	386	HMO	Northern California	2 years	0.84	0.98	0.58	0.02	0.42	1.21
Degnan (21).	456	Random	North Carolina	1 year	0.81	0.99	0.71	0.01	0.29	1.49
Loftus (11)	84	HMO	Washington State	6 months	– – –	– – –	– – –	– – –	– – –	1.76
Breast exams										
Gordon (10)	371	HMO	Northern California	2 years	0.70	0.97	0.22	0.03	0.78	1.42
Loftus (11)	172	HMO	Washington State	6 months	– – –	– – –	– – –	– – –	– – –	2.07
Weighted means[2]										
All exams	3,770	– – –	– – –	– – –	0.70	0.92	0.47	0.08	0.53	1.68
Pap smears	1,978	– – –	– – –	– – –	0.59	0.88	0.32	0.22	0.68	1.95
Mammograms.	1,421	– – –	– – –	– – –	0.86	0.97	0.74	0.03	0.26	1.29

[1]Black persons only.
[2]Means for report-to-record ratios include results from Loftus (11).

NOTES: HMO is health maintenance organization. Numbers in parentheses refer to entries in the reference list.

Phase I

Based on a review of the cognitive literature, four major issues were identified, corresponding to the four cognitive stages previously discussed:

- Comprehension: Do older women know what the terms "Pap smear," "mammogram," "breast examination," and "blood stool test" mean? Do they confuse procedures? Are any of the questions planned prone to substantial misinterpretation?
- Information retrieval: How do older women retrieve information on medical screening examinations? Are tests stored in discrete memory or do respondents use schemas? If they use schemas, what are the schemas used?
- Judgment formation: How do older women form a judgment about the frequency of screening tests? Do they count or estimate? How do they arrive at their count or estimate?
- Editing responses: How comfortable are older women discussing their experiences with various screening procedures? Are they motivated to withhold sensitive personal information or overreport socially prescribed behavior?

Focus group methodology

The use of focus groups has now become widespread as part of the process of designing good questionnaires. Focus groups enable researchers to learn how respondents think about an issue, so that researchers can avoid imposing their perspectives on respondents. Focus groups are also cost-effective because much useful information is obtained at a low cost. Although it is very dangerous to generalize from a focus group with special sample characteristics to a broader population, experience has indicated that the use of such groups at the beginning of the questionnaire-design process greatly improves the final questionnaire. For this reason, two focus groups were used to begin this research.

Sample selection

The first focus group was with black women and the other was with white women 50 years of age and over. Eighteen respondents were recruited from two sources: a health maintenance organization (HMO) that was collaborating in the study (RUSH-Anchor HMO) and University of Illinois employees who were not faculty members. Persons currently employed by health care facilities were specifically excluded from participation. Selected respondents were reimbursed $50 for participating.

The first focus group was held on Monday, December 16, 1991, in the Behavioral Laboratory of the University of Illinois at Chicago. Of the 10 black women who had been recruited, 8 attended. The second focus group was held on Tuesday, December 17, 1991. Of the 11 white women who had been recruited, 10 attended. Almost all the participants at both focus groups were staff members of the University of Illinois. About half of these were members of an HMO. Both focus groups were observed by all members of the project team.

Discussion guide and conducting of groups

A discussion guide for the focus groups was prepared and is included in appendix II of this report. The major issues covered in the discussion guide were:

- Healthy practices
- Relationships with providers
- Physical examinations and early detection
- Information retrieval
- Question threat

For the second focus group, it was decided to cut the section on healthy practices because it consumed a substantial amount of time and did not add much to the discussion of health screening procedures. Instead, the moderator asked what prompted participants to see a doctor and then proceeded to the section on relationships with their health care providers.

Both groups found the topic very interesting, and vigorous, lively discussions took place. The information provided resulted in significant changes in the way the think-aloud interviews were conducted. Within the first group, almost all of the women reported having regular, annual physical exams that included Pap smears and mammograms. They remembered the tests as components of the physical examination and not as individual events. In contrast to the first group, many more women in the second group did not consistently report having annual physicals that included Pap smears and mammograms. In fact, a few had not had a physical or any of the tests for 3–5 years. One of the women had never had a mammogram. It was also mentioned that irregular timing might be caused by how providers schedule physical examinations and screening tests. One woman who had recently

called to make an appointment for a mammogram was scheduled for one 6 months later. These results suggested experimenting with the content of questions in the think-aloud interviews, with one version asking about physical exams and the procedures that were included and the second asking about the procedures separately as in the existing National Health Interview Survey (NHIS). A detailed discussion of the results from the focus groups is given in the section "Results."

Think-aloud interview methodology

Think-aloud interviews are widely used to understand the processes used by respondents to answer questions and to improve questionnaire quality. Essentially, respondents are asked to think aloud as they answer a question and to say everything that comes to mind. If they just answer the question without reporting their thought processes, they are then asked a question such as, "How did you come up with that answer?" Respondents may also be asked to describe a question in their own words so that the researcher can determine how words in the question are being interpreted. For this reason, think-aloud interviews were conducted after the focus groups.

Sample selection

The respondents for the think-aloud interviews were selected from the computer files of the RUSH-Anchor HMO. Eligible women were those 50 years of age and over who had been members of the HMO for at least 5 years. Some of the initial sample contacted were ineligible because they worked in a medical facility or were no longer members of the HMO. No effort was made to control for the race of respondents in the sampling. Ultimately, the sample consisted of more black than white women, reflecting the composition of the HMO membership in that office.

Interviewers attempted to contact 74 women for the think-aloud interviews. Of these 74, interviews were scheduled with 17, 16 were ineligible (most worked at a health care facility), 11 could not be reached, and 30 were either unwilling to participate or unavailable on the days scheduled. Nevertheless, the proportion willing to cooperate was substantially higher than in a general population sample asked to participate in such groups. Of the 17 interviews scheduled, 1 was canceled because the respondent had the flu. The other 16 were completed. Respondents who participated were reimbursed $50.

Administration of think-aloud interviews

The think-aloud interviews were conducted in the offices of the Survey Research Laboratory in Chicago on January 22, 23, 25, 27, and 28, 1992. Interview times ranged from 9:00 a.m. until 6:30 p.m., and 17 time slots were filled. The interviews were conducted by the members of the project team and by the manager of field operations. In addition to the interviewer, another member of the team was in the room to assist by taking notes and asking additional questions at the end of the interview. Other members of the team were in an adjacent room where they could hear the interviews, as the

rooms were separated by only a partition that did not extend to the ceiling. All interviews were tape-recorded with the permission of the respondents. After two interviews it was decided that it would be useful to check the RUSH-Anchor medical records of think-aloud respondents to validate their responses. All the remaining 14 respondents gave written permission to have their HMO records checked.

Think-aloud questionnaires

For the purpose of these interviews, two questionnaires were developed. The first, based on the current NHIS supplements, asked about each of the four screening tests one at a time; the other asked about health events, physical checkups, and gynecological examinations during which the screening tests were conducted. These are shown in appendix II as version 1 and version 2, think-aloud interview questionnaires. As is common in the use of think-aloud methods (38), the questionnaires were modified continuously as new issues and problems arose. Although not every change is mentioned here, some of the major changes that resulted from the think-aloud interviews are presented.

Version 1 (appendix II), which is based on the NHIS supplements, contained questions that had been tested earlier, and no major problems arose with it. For this reason, only four of the think-aloud interviews used this version. Initially, there had been a problem with question 2 of the original version, which asked about how much a person can do to control a range of diseases. Most respondents who were asked this question had serious problems understanding what it meant and keeping the scale in mind. The question was revised, and a show card was developed to aid respondents. Comprehension improved, but there continued to be misunderstanding about whether the question was asking about disease prevention or about controlling the disease after one got it. Finally, it was decided to replace this question with a series of questions about the usefulness and painfulness of the specific procedures. These new questions worked very well, and no one had trouble with them.

Initially, question 29 in version 1 asked respondents about how threatening the questions were. This question, which formerly had been used in asking about the threat of questions dealing with drug and alcohol use (37), did not discriminate among respondents in the think-aloud interviews. None of the respondents reported that the questions would make them very uneasy, and only a few mentioned being a little uneasy. In the end, this question was omitted.

For each of the screening procedures except breast examination, respondents were asked how they found out their results. At this point, every respondent not only revealed how she found out, but what the result was. It was concluded that it does not make cognitive sense to ask respondents how they found out the results without also asking what the results were. This question was added for each screening test.

Version 2 was more complex than version 1, and 12 think-aloud interviews were conducted, until no new problems arose. Respondents who only had screening tests as part of a regular physical or gynecological checkup had no trouble with the initial draft. However, there were respondents who had

screening tests because of a health condition who wanted to talk about this after the initial question on health status. For this reason, a section was added asking about continuing health problems, major illnesses, or conditions. If the conditions were breast-related, questions were asked about whether respondents received mammograms and breast examinations for reasons related to the conditions. If respondents had gynecological or urinary problems, they were asked about any Pap smears received related to those conditions.

For respondents who reported screening examinations in different sections of the questionnaire, it was necessary to determine whether the exams were being reported twice. This was accomplished by adding a summary sheet to the back of the questionnaire where the total number of each kind of test received and the date of the last test were recorded. At the end of all the sections, these results were confirmed with the respondent. This method worked well.

It should be pointed out that although version 2 looks much longer than version 1, most respondents skipped several sections so that the interview averaged only about 20–25 minutes, a few minutes more than version 1.

Initially, respondents were asked whether they received a pelvic examination as part of their physical. There was some concern that respondents would confuse Pap smears and pelvic examinations. It turned out that all the respondents knew exactly what a Pap smear was, but several were unsure about what was meant by a pelvic examination. Pelvic examinations were dropped from the latest version because it seemed clear that asking this question did not improve reporting of Pap smears but simply added confusion.

There was also some confusion between mammograms and breast examinations. Some respondents thought that when they were asked about breast examinations, they were being asked about mammograms. In the final version, instead of just being asked about breast examinations, respondents were asked, "Besides the mammogram, do you ever have a breast examination by a doctor or medical assistant when the breast is felt for lumps?"

The initial version said, "As part of your physical exams, do you usually have . . . (screening test)?" A yes answer, however, still did not reveal how many tests respondents had had in the past 5 years. In the revised version, respondents were first asked, " . . . do you ever have . . .?" and if the answer was yes, as it most often was, they were then asked, "How often do you get . . .?" and then, "In what month and year was the last one?"

Initially it was asked whether any of the tests done as part of a physical or gynecological checkup were done at a different location or time. This obviously requires a lot of retrieval by respondents and caused difficulties. In the final version, these questions were asked at the end of the interview only for the last Pap smear and mammogram.

Results

Comprehension

Of the four screening procedures, Pap smears and mammograms are very well understood by women 50 years of age and over. There were no cases in which these terms were misinterpreted or not known. Although there is no wish to generalize to other populations, especially younger women, there was really no reason to explain these two terms to respondents or to be concerned about comprehension.

There was some confusion about the term "breast examination," as previously mentioned. Many women in the focus group and think-aloud samples thought first of mammograms when the term "breast examination" was used, rather than about a physical examination of the breast by a physician. Mammograms also appeared to be more distinctive, as they were taken at a different location and many women reported at least some discomfort. Some of the confusion about breast examinations may be reduced by a more careful definition of the term.

There was little confusion about the term "blood stool test," but some respondents had never heard of this test. It is unlikely that these respondents had ever had such tests. Those respondents who claimed to have heard of the test knew what it was.

As one might expect, respondents had different interpretations about the term "physical examination." Some defined this to include only the comprehensive examinations in which a broad range of tests are performed. Others included the briefer examinations they received when they came in for periodic checkups of their high blood pressure or diabetes. For the version 3 questionnaire, the aim was to exclude these briefer examinations unless for a breast or gynecological condition, because screening tests are not usually done then. For this reason, the phrase "physical examination" in the think-aloud questionnaire was changed to "complete physical checkup." This certainly helped, but it is not certain that the problem was totally solved. Note that there was no attempt in this study to measure how well women report getting physicals; however, if the woman considered physicals as more comprehensive checkups, she would report them less frequently and on a more regular basis so that her frequency judgments would be expected to be better. Some women were uncertain about the phrase "gynecological examination." This phrase was changed to "gynecological or female examination" in the last version of the think-aloud interviews. Perhaps because of the policies of RUSH-Anchor and other HMO's, most women reported complete physical checkups of which a gynecological examination was a part, while only a few reported separate gynecological examinations. It is unlikely that women who have had separate gynecological examinations do not know the term. The term "pelvic examination," on the other hand, was unclear to a number of women who, from other evidence, had had such examinations. The use of this term was discontinued.

Retrieval

From the focus groups and from the think-aloud responses to both versions of the questionnaire, it was clear that only a few respondents were retrieving isolated individual screening examinations. Instead, almost all respondents were relying on schemas. The reasons for this are fairly clear. First, a majority

of respondents reported the behavior being studied as very regular, with tests being done on an annual basis. (An examination of the records indicated that actual behavior was less regular than what was remembered.) Second, 5 years is a long period, which makes it difficult to retrieve individual events (some tables in this report show data for 6 years because the data collection period extended over 6 months). Both regularity (28) and long time periods (39) have been shown to lead to the retrieval of schemas rather than of individual episodes.

By far the most common schema used, even when unprompted, was to associate screening tests with annual complete physical checkups. Another major schema was associated with serious illnesses or conditions. Respondents who had had such events in their lives wanted to talk about them, but it was usually possible to limit the discussion to the past 5 years. If screening tests had been part of the detection of these conditions or as part of followup procedures, it appeared easy for respondents to remember that they had had such tests and to count the number of tests. Gynecological examinations were much less frequent than complete physical checkups, but when such exams did occur, Pap tests, breast exams, and mammograms were usually part of the process. Another schema that was mentioned involved tests for which the results were inconclusive. In this case, another test, and sometimes even more tests, were required.

Although respondents appeared to have little trouble retrieving schemas related to screening tests, there were some indications of possibly faulty retrieval. Several respondents reported getting regular annual checkups but in later discussion indicated that the time period between checkups varied from 12 to 15 and sometimes even 18 months. A few reported that they knew they were supposed to get the test annually but skipped 1 or more years out of 5 for a variety of reasons. This could, of course, have happened to others who no longer remembered the exceptions. Even in such cases, however, the schemas provided the basic structure for estimating frequencies.

Judgment formation

Obviously, respondents use the schemas to make their judgments. Thus, nearly all judgments are based on estimation and not on counting. The easiest and most common estimate that was made was by women who reported an annual physical every year without exception and who reported having a Pap smear or mammogram each time. They simply reported getting five tests in the 5 years. A few women used this rate-estimation procedure but then adjusted for exceptions. Thus, one woman reported that she had just recently reached 50 years of age and before that had not had a mammogram. Another woman reported that she typically had had an annual breast examination but that for some reason, her doctor had not given her one the previous year. Thus, she reported four breast examinations.

For the less common procedures, such as the blood stool test, counting was more common, especially when there had been only one or two tests. By far the most complicated situation for a respondent involved summing over different schemas that involved both counting and rates based on schemas. Thus, one of the think-aloud respondents had had a complete physical checkup annually but had also had breast cancer, which resulted in another series of mammograms. As she tried to report how many mammograms she had had in the past 5 years as well as the dates, she had considerable trouble keeping it all straight. Similar stories were heard in the focus groups. It was for this reason that version 3 was developed, to reduce the cognitive burden on respondents.

Editing

Respondents edit responses if they are concerned about the social desirability of their answers. In neither the focus groups nor the think-aloud interviews was there any evidence that respondents found screening tests difficult to discuss and report. On the contrary, almost all reported finding the topic very interesting and involving. There was no behavioral or oral indication of uneasiness when respondents were asked directly whether the questions about screening tests would make most women uneasy. A typical response was given in one of the focus groups by a woman who said that these questions might make teenage girls uneasy, but women who have had children would not find any of the questions threatening.

Finally, it must be recognized that screening tests for these women are seen as something that is socially desirable, so respondents may be reluctant to report not getting these tests. Thus, overreporting of tests could occur.

Comparison with records

After the think-aloud interviews and a pilot test (described on page 11) were completed, record checks were conducted with 26 respondents. This was done as a test of the record-retrieval methods as well as to get a first sense of how reported events compared with data from the medical records. Medical records personnel at RUSH-Anchor were paid to abstract from patient records the dates on which four cancer-screening procedures were conducted or reported by the provider. (The four procedures were Pap smear, breast examination by physician or other medical professional, mammogram, and fecal occult blood test.) Abstractors were blind to respondents' self-reports. Results were compared by project staff at Survey Research Laboratory. In the process of doing this record check, it became clear that fecal occult blood tests were not well reported in the records. It was decided to omit these tests from the comparisons.

This comparison of self-reports with medical records had several goals. The first was to assess the accuracy with which respondents recalled the number of times they had received each screening procedure during the past 5 years (since January 1, 1987) and the most recent date on which each test had been received. A second goal was to identify potential problems that might be encountered in matching records from RUSH-Anchor with survey responses. Also, because this was the first attempt at using the abstracting form planned for use in Phase II, it was important to learn how to improve its design.

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Table B. Phase I comparison of number of self-reported screening procedures with medical records: 1987–92

Type of statistic	Pap smear	Mammogram	Breast exam
Average number of screenings self-reported	3.6	4.3	4.0
Average number of screenings in records	2.4	3.3	3.3
Average difference	1.2	1.0	0.7
Percentage agreement	34.6	11.5	19.2

NOTE: Number of patients = 26.

Recalling numbers of screening procedures

The comparisons of reported numbers of screening procedures are presented in table B. On average, respondents tended to overreport the number of times they had received each screening test during the previous 5 years (average overreporting ranged from 0.7 for breast exams to 1.2 for Pap smears). The proportion of respondents who were able to correctly recall the number of times they had received each procedure varied considerably, from about 35 percent for the number of Pap smears to about 12 percent for the number of mammograms received. Distributions of the differences between self-reports and medical records data for each screening procedure are presented in table C (definitions of each measure can be found in the response-quality outcome measures beginning on page 12). There is some indication that mammograms are

Table C. Percent differences between self-reports and medical record data, by test and type of statistic: 1987–92

Statistic	Pap smear	Mammogram	Breast exam
		Percent	
Gross accuracy	72.9	76.3	69.3
Matched data	30.3	42.1	29.4
No test	42.6	34.2	39.9
False reports	23.2	17.8	22.9
Omissions	3.9	5.9	7.8
		Number	
Reporting years	6	6	6
Reports	155	155	153

NOTE: Number of patients = 26.

better reported than Pap smears and breast examinations (gross accuracy for mammograms is 76.3 percent, compared with 72.9 percent and 69.3 percent for Pap smears and breast exams, respectively). Table D shows the results by year for all tests combined. No clear trends were observed.

Potential problems

Several potential problems were identified during both the medical records abstraction and the matching phases of this project. During records abstraction, the major problem reported by the RUSH-Anchor staff concerned the availability of test results from fecal occult blood examinations. Apparently, large numbers of test result slips are never filed properly in the medical records. Because patient identification number is not routinely recorded on the fecal test cards that patients mail back to the clinic, it often becomes difficult to properly file result slips once test results are known. When examining patient charts, physician references to the results of fecal tests (for example, "fecal test negative," "fecal okay") were nonetheless found in the progress notes. In this study, such references were classified as evidence the test had been conducted, even if actual test results were not available. Physician notes that the patient had been given the fecal occult card to take home and return with specimen smears were not by themselves considered evidence that the test had been done, as the cards were often not returned by the patient. Also, recent research has indicated that this procedure is not effective in detecting colorectal cancer (40). For these reasons, fecal tests were excluded from additional analyses.

After the initial abstracting test, the records abstractors also expressed concern about their ability to accurately identify all instances in which a breast examination had been conducted by the physician or medical assistant. Abstractors believed that the degree to which this information was recorded varied with the health professional conducting the exam, and they were somewhat frustrated by the requirement that there be specific written documentation in the record that the examination had been conducted. In contrast, abstractors remained confident that they were able to identify all Pap tests and mammograms that were performed in their facility.

During records-report matching, a serious concern was correctly identifying the total number of mammograms that

Table D. Percent distribution of Phase I response-outcome measures for all exam types, by year and type of statistic: 1987–92

Statistic	1987	1988	1989	1990	1991	1992
			Percent distribution			
All measures	100.0	100.0	100.0	100.0	100.0	100.0
Gross accuracy	82.1	53.8	71.4	75.3	70.3	84.2
Matched data	8.9	25.6	54.6	43.3	48.6	23.6
No test	73.1	28.2	16.9	32.0	21.6	60.5
False reports	12.8	43.6	23.4	19.5	17.6	10.5
Omissions	5.1	2.6	5.2	5.2	12.2	5.3
			Number			
Reporting years	6	6	6	6	6	6
Reports	78	78	77	77	74	76

NOTES: Figures may not add to 100.0 because of rounding. Number of patients = 26.

had been performed. Because abstractors recorded dates when these tests had been ordered or recommended as well as the dates of lab results, instances arose in which there were more lab results than referrals recorded in the record and there were more referrals than test results available in the record. Although these two sets of dates usually correlated very well, these findings demonstrated that some information clearly was not making its way into the medical records. Some of this may be accounted for by the observation that reports of very recent tests were not corroborated by the medical record, suggesting that these test results may not yet have been filed in the records. RUSH-Anchor staff indicated that results normally are filed in patient records 1–2 weeks after the test. Other instances were discovered in which the most recent reported date for a mammogram matched well with the most recent referral date found in the medical records but not with the most recent date for which test results were available (using decision criteria, these cases were classified as a mismatch). Where there were more results than referral dates, the problem appeared to have been physician failure to record that the procedure had been recommended. In practice, this was less of a concern, given the coding criteria for having received a mammogram, which required evidence of test results (or reference to them).

Changes in abstraction form

In preparation for the next phase of the study, the RUSH-Anchor abstractors indicated that it would not be difficult to provide counts of the total number of patient visits made on an annual basis. They also indicated that it would be fairly easy to identify the individual health care providers who had seen each patient. Both of these items were included in a revised draft of the abstracting form.

In terms of other changes in the abstracting form, the RUSH-Anchor staff indicated that it was easier, given the structure of their medical records, to record screening procedures beginning with the earliest event and moving forward. Previously, they had been asked to begin with the most recent event and code backward.

Finally, the abstracting form was restructured so that space was provided for remarks to be included along with each date recorded. During this initial test, abstractors were asked to record relevant information in the margins next to referral and screening dates. This information often proved critical in making final matching-related decisions.

Better understanding of the survey process

This research had as its main purpose the improvement of questionnaires dealing with health-screening procedures. It also had the aim of improving the general understanding of the cognitive processes that underlie surveys.

Two important general contributions were derived from Phase I. The first was an added understanding of how the regularity of behavior affects the process of reporting its frequency. It is now fairly widely known that respondents use estimation when the number of events to be recalled goes much above five. Many researchers, including members of this team, might have expected that respondents would usually count fewer than five events. The results from Phase I of this study sharply contradicted this expectation.

What was observed was that regardless of the number of events, for highly regular and similar routine events, almost all respondents estimated based on schemas. These results agree with those found by Menon (28), but in her study, the events (for example, washing one's hair, brushing one's teeth) were much more frequent, and a much shorter time period (1 week) was used. These results are also consistent with results from Lessler, Tourangeau, and Salter (41) on reporting of dental visits. The results of this study indicate that even for few events over a much longer time period, regular and similar activities are estimated. Menon also found that regular, similar events were estimated with good accuracy. The results of Phase II also support this.

This research was also an illustration of the process by which focus groups and think-aloud interviews can be used to develop a questionnaire whose flow matches the actual retrieval methods of most respondents. Many researchers have proposed that questionnaires be tailored to individual respondents to improve data quality, but the mechanisms for doing this have not typically been specified. Some anthropologists (42) have pointed out problems that respondents have with traditional questionnaires and have proposed unstructured questionnaires that better match respondent needs. Unstructured questionnaires have not been widely adopted, however, because of concerns about interviewer variability and the major difficulties of processing questionnaires for large-scale samples.

The final version 3 (see appendix II) was developed entirely from the focus groups and think-aloud interviews. Version 3 is a structured questionnaire that attempts to be responsive to different individual cognitive processes. It appears longer and more complex than the traditional questionnaire because it tries to follow the different retrieval paths that focus group respondents reported using. The actual length of the interview was not significantly longer, however, because most respondents skipped many of the branching paths.

It was expected that this version would help respondents for whom the retrieval task was complex, and this hypothesis was tested in Phase II. Some respondents may also have used retrieval methods that did not fit the organization of version 3. The focus group and think-aloud samples were small and possibly nonrepresentative. It was expected, however, that most of the RUSH-Anchor HMO sample would use retrieval methods that were mentioned in the focus groups or think-aloud interviews and were covered in version 3.

One major concern with respondents' use of schemas is that they may forget exceptions to the schemas and falsely remember events. For this reason, version 4 was developed to force respondents to adopt a counting strategy.

Phase II

Introduction

After Phase I was completed and the results analyzed, a field study was designed and executed to test the methods that had been suggested and developed. As in Phase I, the RUSH-Anchor HMO provided access to medical records for validation and for sample selection.

Objectives and scope

Cognitive methods were investigated to improve responses to questions about health promotion and disease prevention, focusing on predictors of accuracy in the reporting of three early detection procedures: the Pap smear, mammography, and breast physical examinations.

Research objectives

The objectives of this research were to measure how well the experience of receiving cancer-screening procedures is recalled by respondents and to determine what methods of questioning are most likely to elicit accurate recall and reporting of having received these procedures.

Hypotheses

Based on the results of Phase I and the literature review mentioned in the previous section, five hypotheses were formulated:

1. More accurate reporting will be found for diagnostic tests that were conducted separately rather than as part of a physical exam because separate events will be more salient and easier to retrieve.
2. Controlling for frequency, more accurate reporting (less over- and underreporting) will be found for respondents for whom the diagnostic tests are conducted regularly rather than irregularly because regular events are easier to schematize accurately.
3. More accurate reporting will be found among respondents using a questionnaire form that activates schemas relating to health events, physical checkups, and gynecological examinations, compared with a questionnaire that asks about each of the screening tests separately.
4. For questionnaires that ask about each screening test separately, more accurate reporting will be found for

respondents of whom questions are asked about the details of the procedure (for example, who performed it, where it was performed, what happened) before questions about when it happened.
5. For questionnaires that evoke schemas by asking about health events, physical checkups, and gynecological examinations, more accurate reporting will be found if respondents are required to count individual episodes rather than to give a rate.

Hypotheses 1 and 2 were based on characteristics of the diagnostic procedures and the context in which they occur. The method of delivery and its regularity cannot be directly manipulated by researchers. However, both regularity and the context in which such procedures are delivered can be ascertained from existing data. Hypothesis 1 was based on ideas that respondents will be more aware of and better able to retrieve irregular diagnostic tests when they are performed separately because the way such tests are stored in memory will more closely relate to the way that the question is asked than if the tests are parts of a more general diagnostic procedure. When the event occurs sporadically rather than as part of a familiar process, recall is likely to be enhanced. The respondent must have been specifically made aware that the event occurred distinctly from other events that occurred at the same time.

Hypothesis 2 was based on the work of Menon (28) and others who suggest that the formation and use of schemas to make estimates of one's behavior is facilitated by the regularity of the behavior. In other words, when the behavior is performed regularly, the regularity itself promotes and enhances recall. In such cases, the context in which the event occurs facilitates the recall. Note that hypotheses 1 and 2 are not contradictory, because hypothesis 1 relates to irregular behavior and hypothesis 2 to regular behavior.

Hypotheses 3 through 5 relate to procedures for questionnaire development that are under the control of the investigator. Hypothesis 3, which also is derived from the ideas of schema formation, asserts that schemas will be easier to retrieve and to use in estimation if they have already been previously activated by questions that parallel the schemas that most respondents use.

Hypothesis 4 was based on works of Brewer (29), Means, Swan, Jobe, and Esposito (31), Herrmann (43), and Wagenaar (30), who strongly suggest that time is the least well remembered aspect of an event. Asking about the better remembered

aspects first may provide additional cues as to when the event occurred.

Hypothesis 5 was developed by observing that respondents sometimes remember events as being more regular than they really were and forget the exceptions. For such cases, getting respondents to count rather than using a rate should increase accuracy.

Methodology

Target population

The population was women 50 years of age and over who were members of the RUSH-Anchor HMO. Women in this age group were selected because they are the group most likely to misreport having received a Pap smear (17,18,44). Moreover, women over 50 years of age are the primary target population for mammograms and breast physical examinations. Screening for women under this age is controversial, and data conflict as to the value of these tests in routine case finding (45). After careful consideration of the sample characteristics of the RUSH-Anchor population, it was decided to sample the list at random and not stratify. Because the stratifying variables were not computerized, stratification would have required individual record abstraction, which would have increased costs significantly.

Pretest

Before the main data collection began, a small pretest was conducted of the data collection procedures as well as of the revised questionnaires. Using a recruitment script, interviewers telephoned a small number of women from the target population to solicit cooperation and set up appointments for face-to-face interviews in their homes. After 13 interviews were conducted, a debriefing session was held with the interviewers to discuss how the procedures and questionnaires worked. It was decided that for the main data collection, advance letters on RUSH-Anchor stationery would be sent out prior to calling for interview appointments. In addition to containing information about the project, the letter included the name and telephone number of a person at the HMO who could be called if the potential respondent wanted to confirm the study's authenticity.

As expected, the most difficult interviewing task was obtaining dates for tests that had been taken. Although the questionnaires asked for the month and year that each test was taken, a complete answer was not typically volunteered by the respondent until the interviewer probed. Most survey researchers agree (see, for example, Fowler and Mangione [46]) that probing is the hardest interviewing skill to learn because it cannot be completely standardized. The pretest experience confirmed this problem, and as a result, specific probes were built into the final questionnaires for questions asking about dates.

Face-to-face interviews

To obtain an approximately equal number of interviews with each of the four questionnaire versions, each interviewer was given a stack of blank questionnaires in rotating version order (different for each interviewer) and told to use the top questionnaire for each subsequent interview. One-half of the sample was interviewed with a questionnaire based on schemas related to health events, physical checkups, and gynecological examinations. The other half used a questionnaire that asked about each screening test separately.

Within the schema questionnaire, one-half of the respondents were asked questions that encouraged the use of a rate, with possible adjustment for missed examinations (version 3, final questionnaire). The other half were encouraged to count individual events (version 4, final questionnaire).

Within the sample in which screening tests were asked about separately (that is, episodically), one-half of the respondents were asked first about details of the diagnostic procedure before being asked about when it occurred (version 2, final questionnaire); the other half were asked first for when it occurred, then about the details (version 1, final questionnaire). The new wordings developed in the cognitive laboratories were used for all respondents. The four alternative forms that were used can be found in appendix II.

At the end of the interview, respondents were asked for permission to examine their medical records at RUSH-Anchor; 178 of 211 granted permission. These respondents' interviews were then compared with the abstracted records. The analyses are based on this sample of 178 respondents for whom validation information was available. The demographic characteristics of these 178 women are shown in table E.

Medical records abstraction

Table F lists the specific data collected from each eligible patient record. Within each patient record, the following

Table E. Demographic characteristics of study respondents: 1987–92

Characteristic	Percent
Age[1]	
50–59 years	57.9
60–69 years	33.7
70 years and over	8.4
Race	
Black	87.6
White	8.4
Hispanic	3.4
Asian/Pacific Islander	0.6
Education	
Less than high school graduate	15.2
High school graduate	34.8
Some college	25.8
College graduate	24.2
Employment status	
Employed full-time	71.9
Employed part-time	5.6
Not employed	22.5

[1]Mean age was 59.6 years.

NOTE: Number of respondents = 178.

Table F. Data abstracted from medical records

Data item	Information sought
Medical visits during previous 5 years	Total number
Occurrence of full or partial hysterectomy.	Yes or no
Pap tests done during previous 5 years.	Dates
Results of Pap tests	Normal or abnormal
Mammograms recommended during previous 5 years . .	Dates
Mammograms completed during previous 5 years	Dates
Results of mammograms	Normal or abnormal
Breast examinations done during previous 5 years	Dates
Results of breast examinations	Normal or abnormal

sources were reviewed for information regarding these variables: physician progress notes, cytology reports, laboratory reports, and radiology reports.

Reliability

The generally accepted procedure of validating self-reports by relying on medical records was used. However, in so doing, it was recognized that many of those who rely on records have reported that records are an incomplete and not totally reliable source (47–49). A record reabstraction study was undertaken to evaluate the reliability of information derived from these medical records. The goal of the reabstraction study was to assess the degree to which complete information was abstracted from medical records. A credentialed medical records technician employed by the contractor reabstracted 20 records, and the data were compared with the data initially abstracted. Overall, 98 percent of the reports showed consistency between the initial and reabstracted data, indicating a very high level of reliability.

The matching between the record and the questionnaire was done by a medical records specialist. Initially, matching was done regardless of discrepancies by date. The matching protocol is included in appendix II. Once a match was established, the difference in months between the record date

and the interview date was computed if a date was given on the interview.

Results

Analysis

To test all the hypotheses, it was necessary to specify what is meant by "accuracy." There is no single measure because accuracy is a multidimensional concept. Although screening test information was collected for all tests reported in a year, for the purposes of this report, only the first test was used. Few respondents reported two or more tests a year, and respondents had difficulty distinguishing between two distinct tests as opposed to the redoing of a single test because the initial test was not performed properly or followup studies were required.

Tables G–K show the statistics defined in the next section, and more detailed tables are found in appendix II.

Response-quality outcome measures

The following four response-outcome measures are reported:

- Matched data: The respondent reported receiving a screening test, and the test was verified in the medical records (verified reports divided by total sample).
- False reports: The respondent reported receiving a screening test and no matching test was found in the records (unverified reports divided by total sample). This measure is different from and should not be confused with traditional epidemiologic measures of false positive and false negative rates, also defined in this section.
- Omissions: The respondent reported no test but a test was found in the records (unreported tests divided by total sample).
- No test: The respondent reported no test and no evidence

Table G. Percent distribution of response-quality measures, by test and type of measure: 1987–92

Statistic	All tests	Pap smears	Breast exams	Mammograms
		Percent distribution		
All measures	100.0	100.0	100.0	100.0
Matched data	31.8	27.9	29.8	37.9
False reports	16.2	18.9	18.5	11.1
Omissions	5.3	3.0	8.4	4.5
No test	46.7	50.2	43.3	46.5
		Percent		
Reporting test.	48.0	46.8	48.3	49.0
Test in records	37.1	30.9	38.2	42.4
Ratio	1.29	1.51	1.26	1.16
Gross accuracy	0.79	0.78	0.73	0.84
Sensitivity	0.86	0.90	0.78	0.90
Specificity	0.74	0.73	0.70	0.81
False negatives.	0.14	0.10	0.22	0.11
False positives	0.26	0.27	0.30	0.19
		Number		
Respondents	178	178	178	178
Reports.	3,168	1,059	1,058	1,051

Table H. Percent distribution of response-quality measures, by year and measure: 1987–92

Measure	1987	1988	1989	1990	1991	1992[1]
			Percent distribution			
All measures	100.0	100.0	100.0	100.0	100.0	100.0
Matched data	16.9	34.9	40.5	43.2	40.8	15.2
False reports	14.1	17.4	19.7	17.2	21.3	7.5
Omissions	11.1	8.4	5.0	3.4	2.1	1.9
No test	57.9	39.3	34.8	36.1	35.8	75.4
			Percent			
Reporting test	31.0	52.3	60.2	60.5	62.1	22.7
Test in records	28.0	43.3	45.5	46.6	42.9	17.1
Ratio	1.11	1.21	1.32	1.30	1.45	1.33
Gross accuracy	0.75	0.74	0.75	0.77	0.77	0.91
Sensitivity	0.60	0.81	0.89	0.93	0.95	0.89
Specificity	0.80	0.69	0.64	0.68	0.63	0.91
False negatives	0.40	0.19	0.11	0.07	0.05	0.11
False positives	0.20	0.31	0.36	0.32	0.37	0.09
			Number			
Respondents	178	178	178	177	178	178
Reports	532	524	522	523	534	533

[1]Partial year.

NOTES: Figures may not add to 100.0 because of rounding. Data shown are for all procedures combined.

Table J. Percent distribution of response-quality measures, by type of test, test regularity, and measure: 1987–92

Measure	Pap smears		Breast exams		Mammograms	
	Regular	Irregular	Regular	Irregular	Regular	Irregular
			Percent distribution			
All measures	100.0	100.0	100.0	100.0	100.0	100.0
Matched data	67.1	20.1	52.8	24.7	63.9	30.3
False reports	11.0	23.2	6.9	23.2	7.1	14.0
Omissions	5.2	2.7	20.2	5.4	7.7	3.5
No test	16.7	54.0	20.1	46.7	21.3	52.2
			Percent			
Reporting test	78.1	43.3	59.7	47.9	71.0	44.3
Test in records	72.3	22.8	73.0	30.1	71.6	33.8
Ratio	1.08	1.90	0.82	1.59	0.99	1.31
Gross accuracy	0.84	0.74	0.73	0.71	0.85	0.83
Sensitivity	0.93	0.88	0.92	0.82	0.89	0.90
Specificity	0.60	0.70	0.75	0.67	0.75	0.79
False negatives	0.07	0.12	0.28	0.18	0.11	0.10
False positives	0.40	0.30	0.25	0.33	0.25	0.21
			Number			
Respondents	35	129	39	131	50	117
Reports	210	765	233	777	297	688

of a test was found in the records (verified absences of tests divided by total sample).

Note that each of these measures was calculated using the total sample ($N = 178$) as the denominator.

Using these response-outcome measures, the following response-quality measures were estimated to summarize respondent reports:

- Gross accuracy (matched data plus no test): also commonly referred to as an indicator of "concordance" (50) or as the "raw agreement rate" (51)

- Report-to-records ratio (percent reporting divided by percent records): a measure of net bias in test reporting; a similar measure has been previously used by Brown and Adams (51)

- Sensitivity (matched data divided by [matched data plus omissions]): the number of correctly recalled tests divided by the number of cases in which tests were found in medical records; in previous research, measures that are operationally identical to sensitivity have been referred to as a "measure of completeness" (52,53) and as a "medical records confirmation rate" (51)

Table K. Percent distribution of response-quality measures, by form and measure: 1987–92

Measure	Form 1[1]	Form 2[2]	Form 3[3]	Form 4[4]
		Percent distribution		
All measures	100.0	100.0	100.0	100.0
Matched data	31.3	32.7	34.0	30.2
False reports	14.4	16.8	18.0	16.2
Omissions	5.1	4.5	6.5	5.3
No test	49.2	46.0	41.5	48.3
		Percent		
Reporting test	45.7	49.5	52.0	46.4
Test in records	36.4	37.2	40.5	35.5
Ratio	1.26	1.33	1.28	1.31
Gross accuracy	0.81	0.79	0.76	0.79
Sensitivity	0.86	0.88	0.84	0.85
Specificity	0.77	0.73	0.10	0.75
False negatives	0.14	0.12	0.16	0.15
False positives	0.23	0.27	0.30	0.25
		Number		
Respondents	51	41	37	48
Reports	306	246	221	286

[1]Episodic question format; date of test occurrence requested first.
[2]Episodic question format; details of test requested first.
[3]Schema question format; encouraged use of rates and adjustments to estimate number of events.
[4]Schema question format; encouraged to count individual events.

NOTE: Data are for all tests and years combined.

- Specificity (no test divided by [no test plus false reports]): the number of correctly reported "no tests" divided by the number of cases in which no test was found in the medical records

- False negatives (1 minus sensitivity): the number of tests not reported divided by the number of cases in which tests were found in medical record

- False positives (1 minus specificity): the number of tests reported divided by the number of cases in which no test was found in the medical records

- Percent reporting (matched data plus false positives): the number of respondents who reported during the interview that they received the test in question

- Percent records (matched data plus false negatives): the number of respondent medical records that indicated that they received the test in question

Hypothesis 1 proposes that tests conducted separately will be better remembered. For this sample, almost all Pap smears and breast examinations appeared to have been conducted as parts of the physical or gynecological examination. The exceptions were too few to analyze. Mammograms were conducted at a separate location across the street from the clinic, and there was some variation in when this test was done. For hypothesis 1, mammograms that were done elsewhere were compared with Pap smears and breast examinations usually done at the time of the physical. Differences in accuracy of reporting of these procedures may have been related, however, to factors other than separateness.

For hypothesis 2, it was necessary to define what was meant by "regularity." Based on the results, respondents were classified as regular if there was evidence in the medical

records that they were tested every year, every other year, or if they received examinations during 4 of the 5 years included in the study. Other respondents were classified as irregular, except those with no medical record evidence of cancer-screening examinations during the 5-year study period, who were excluded from the comparison of regular and irregular respondents.

For hypotheses 3 through 5, the analysis compared the accuracy measures just described. Sampling errors were also computed and tests of significance were performed.

Overreporting of screening tests

The basic finding of this study is that respondents generally overreport having received screening tests. As may be seen in table G, which summarizes the data over the entire 6-year period (see section entitled "Objectives and scope"), the relative overreporting averages 29 percent for all three procedures and ranges from 16 percent for mammograms to 51 percent for Pap smears. To put this another way, the percent of false reports averages 16 percent, and the percent of omissions averages only about 5 percent (table G). Detailed data by year are given in table II in appendix II.

The null hypothesis that memory errors are unbiased would lead to a test of whether the percentages of false reports do not differ significantly from the percentages of omissions. To test this hypothesis, the McNemar test for related samples was calculated for each type of examination for each reporting year shown in table II (54). Overreporting (false reports) was found to be significantly greater ($p < 0.05$) than underreporting (omissions) for 6 of the 6 reporting years for Pap smears and

for 3 of the 6 reporting years both for clinical breast exams and mammograms.

Effects of time

Table H shows the response-quality measures separately by year for all three tests combined (detailed results are given in table II in appendix II). The results differ between the false reports and the omissions. There appears to be no effect of time on the false reports (range = 14.1–21.3, excluding partial 1992 data). It appears that the false reports occur because most respondents are using a schema (that they get the tests on a regular, yearly basis) and forgetting possible exceptions. If such schemas are used, and exceptions are not related to time, then one would expect a consistent level of false reports, and this is what was observed.

Respondents who did not get screening tests regularly were forced to attempt to remember individual tests. It has long been known that the rate of forgetting increases with increased time (33). This is exactly what was seen with the omissions. There was a steady increase of omissions from 2.1 percent in 1991 to 11.1 percent in 1987.

Gross accuracy remained relatively constant between 1987 and 1991 (range = 0.74–0.77), increasing only for 1992 (0.91). Most respondents were interviewed during the second quarter of 1992, so reports for that year were based on a shorter time interval, which likely accounts for their higher accuracy.

Tests of hypotheses

Of the five hypotheses, two are related to the characteristics of the events and three are based on form manipulations. In testing these hypotheses, both intuitive interpretation of the measures presented in tables G–K and random-effects logistic regression models were relied upon (55). This statistical procedure was employed to adjust for the fact that all obser-

vations in these analyses were not independent of one another. In fact, most of the 178 respondents contributed 18 self-reports (three screening procedures for each of 6 years) to the analysis. The clustered nature of these data therefore requires an analytic approach capable of testing these hypotheses while simultaneously modeling this dependency. The model does this by including random person-specific effects and then estimating the variability associated with these random effects. Note that this is similar to the way repeated-measures ANOVA accounts for the dependency in the data resulting from repeated observations of the same individuals across time; the logistic regression model was used here because the dependent variables were dichotomous rather than continuous. For testing the hypotheses in these regression analyses, gross accuracy was selected as the dependent variable of interest. The null model is presented in column 1 of table L. This model estimates two parameters, one for reporting year and a second for the variability (standard deviation) associated with the random person-specific effect. Both of these terms are significant, indicating that gross accuracy improves with time (resulting in large part from the inclusion of partial data for 1992; estimate = 0.16, standard error = 0.02, $p < 0.001$) and that there is a clustering effect within these data (the intraperson correlation observed in this model is 0.10; estimate = 0.60, standard error = 0.07, $p < 0.001$). This model was employed as a baseline for evaluating each of these hypotheses.

The first hypothesis was that more accurate reporting would be found for respondents for whom the diagnostic tests were conducted separately, rather than as part of a physical examination, because separate events would be more salient and easier to retrieve. Because of the special HMO population used in this study, virtually all breast examinations and Pap smears were given as part of a physical examination, while mammograms were performed in a different location across the street.

Table L. Random effects logistic regression estimates and standard errors for report year, procedure type, test regularity, and questionnaire form effects on gross accuracy

[1 = yes]

Item	Model			
	(1)	(2)	(3)	(4)
Intercept	***1.00 (0.08)	***1.42 (0.11)	***1.23(0.12)	***1.21 (0.12)
Random effect standard deviation	***0.60 (0.07)	***0.62 (0.07)	***0.54 (0.08)	***0.52 (0.07)
Report year	***0.16 (0.02)	***0.17 (0.02)	***0.17 (0.02)	***0.17 (0.02)
Pap smears	. . .	***−0.45 (0.11)	***−0.45 (0.12)	***−0.45 (0.12)
Breast exams	. . .	***−0.74 (0.11)	***−0.70 (0.11)	***−0.70 (0.11)
Test regularity	. . .	. . .	**0.28 (0.12)	**0.30 (0.12)
Question form contrasts				
Form 1 versus form 2	. . .	. . .	. . .	−0.04 (0.09)
Form 3 versus form 4	. . .	. . .	. . .	0.12 (0.09)
Forms 1 and 2 versus 3 and 4	. . .	. . .	. . .	−0.17 (0.07)
Log L	−1,604.30	−1,582.50	−1,539.79	−1,538.22
Δx^2	—	***43.6	***81.4	3.1
Degrees of freedom	—	(2)	(1)	(3)

**p < .01
*** p < .001

NOTE: Standard errors are in parentheses.

Thus the hypothesis would suggest that mammograms should be better reported than Pap smears and breast examinations, and, as seen in table G, this hypothesis was confirmed using bias (report-to-records ratio), gross accuracy, or specificity measures. These results were consistent over time, as seen in table H. Another difference is in the percentage of false reports, which averaged 18.9 percent for Pap smears and breast examinations and 11.1 percent for mammograms. This hypothesis was tested in the random-effects logistic regression model presented in column 2 of table L. For this analysis, dummy variables representing Pap smear and breast exam reports were added to the null model in order to contrast these procedures with reports of mammograms. These two coefficients confirm the information in table G, in that mammograms were reported with greater accuracy than either Pap smears (estimate = -0.45, standard error = 0.11, $p < 0.001$) or clinical breast exams (estimate = -0.74, standard error = 0.11, $p < 0.001$). Additional analyses (not shown) found similar results for the specificity of these reports .

As previously noted, however, some of the better reporting of mammograms may have been related to other characteristics of the test, such as the pain of the procedure for some women, in addition to test location. To test this alternative hypothesis, respondents were asked whether or not they thought mammograms were very painful, somewhat painful, or not very painful. There were no differences between respondents who thought the procedure was very or somewhat painful and those who thought it was not painful (data not shown). Similarly, there was no difference in accuracy of reporting Pap smears by those who thought the procedure was painful versus those who did not.

Hypothesis 2 was that more accurate reporting would be found for respondents for whom the diagnostic tests were conducted regularly rather than irregularly because regular events are easier to schematize accurately. This hypothesis was partially supported.

Table J reveals that the major difference between regular and irregular test recipients was that the percentage of false reports was higher among irregular test recipients (11.0 percent compared with 23.2 percent for Pap smears; 6.9 percent compared with 23.2 percent for breast exams; and 7.1 percent compared with 14.0 percent for mammograms). The cognitive explanation of this finding makes it almost tautological. Many respondents use regularity schemas in reporting about these tests. Those respondents whose records indicated that indeed the tests were received regularly would certainly have had a lower level of false reports than respondents who had not received the tests regularly but who thought they had.

There is no cognitive reason to have expected that the percentage of omissions would have been significantly different for regular than for irregular test recipients, but it was for breast examinations. One practical reason for this finding could be the lower validity of the medical records for this procedure. Although the record checks for Pap smears and mammograms relied heavily on pathology and radiology reports, respectively, evidence of breast examinations relied solely on the notes of the physicians. It is possible that in some cases, the physician checked off "breast examination" on the

physical examination form although one was not done. It is also possible that if one was done, the patient did not recognize or recall it as such. Given the speed with which some physical examinations are conducted, both possibilities are feasible.

Net reporting bias is shown in table J. Overall, the net biases are far smaller for respondents who received tests regularly for each procedure. Biases range from +8 percent for Pap smears to -18 percent for breast examinations, with mammograms reported with a net bias of only 1 percent for those getting tests regularly. On the other hand, the net biases for those getting the tests irregularly range from a low of +31 percent for mammograms to +90 percent for Pap smears. Review of gross accuracy measures suggests, though, that regularity is most strongly associated with reports of Pap smears.

Column 3 of table L provides an overall test of the effect of test regularity, controlling for test type, on gross accuracy. Both the regression estimate for this variable (estimate = 0.28, standard error = 0.12, $p < 0.001$) and the difference in likelihood ratio chi-square for the overall model ($\Delta\chi^2 = 81.4$, degrees of freedom = 1, $p < 0.001$) indicate that test regularity improves the accuracy with which cancer screening tests are reported.

Hypothesis 3 proposed that more accurate reporting would be found for respondents using a questionnaire form that activates schemas related to health events, physical checkups, and gynecological examinations compared with a questionnaire that asks about each of the screening tests separately. The results, shown in table K, do not support this hypothesis.

One problem in examining this hypothesis was that the sample sizes for each of the four treatments were small, ranging from 37 to 51 cases. Thus, it is not surprising that there is substantial variability by year and between the three screening tests. The most stable measure is simply the total across all years and across all tests, which is shown in table K. The more detailed results are given in table IV in appendix II.

It may be seen in table K that the report-to-records ratios by form range from 1.26 to 1.33. There thus appears to be no consistent pattern of superiority of any form over all three screening tests or over years. In retrospect, it appears that the treatment was ineffective because most respondents used schemas in answering the questions regardless of the form. To put it another way, schemas did not need to be activated by the form of the question; they were already activated simply by the topic.

Hypothesis 4 was also not supported. It stated that more accurate reporting would be found on version 2, which asked details about the procedure before asking about the date, than on version 1, in which the date was asked first. As can be seen in table K, there were no practical differences. The retrospective explanation is that because respondents were using schemas to report events, the details of specific events were not used in retrieval as they would have been if the respondents had been attempting episodic recall.

Hypothesis 5 predicted that version 3, which asked respondents to count individual physical examinations first before giving a total and specifically asked respondents whether they

had missed having a physical exam in any of the past 5 years, would result in more accurate reporting (that is, a reduction in the positive bias), compared with version 4, which simply evoked a regularity schema.

Again, it may be seen that there were no significant differences between forms 3 and 4 (table K). It is evident that neither of the forms changed the process respondents used in retrieving their schemas. In retrospect, this result is not too surprising, because others (39,56) have also found it difficult to change the retrieval procedures that respondents use.

Menon (28) found that it was possible to reduce overreporting by specifically asking respondents about exceptions to regularity. Her questions, however, asked about a very short time period. In this study, it is much more likely that respondents forgot about the nonoccurrence of a perceived regular event several years earlier.

Hypotheses 3 through 5 were also tested using logistic regression analysis with random effects (column 4, table L). This analysis confirms that questionnaire form had no significant effect $(\Delta)C^2 = 3.1$, degrees of freedom $= 3$, not significant) on the gross accuracy of reports. Additional analyses (not shown) also failed to identify any effects of questionnaire form on sensitivity and specificity.

Event dating

To this point, the analysis has simply consisted of looking at whether the events reported by the respondents and in the records could be matched at all. To look further, one can now turn to a comparison of the dates reported by respondents and in the records for the subsample of events that were matched. The data are presented in tables M and N. More detailed data are given in tables V and VI in appendix II.

It may be seen in table M that the net biases are small (range = 0.8–1.3), averaging less than 1 month, but are consistently positive, meaning that there is a slight tendency for respondents to remember the test as having occurred more recently than the date given in the records. Many respondents, however, date the procedure as having occurred earlier than the date given in the records. The gross error averages about 3.5 months.

There appear to be no meaningful differences in dating errors by procedure, year, or form. The sampling errors for the

Table M. Net bias and gross error in reporting of dates of test procedures for matched data: 1987–92

Type of test or form	Net bias	Gross error	Number
Test		Months	
Total.	0.8	3.5	767
Pap smears	0.8	3.4	208
Breast exams	1.1	3.7	234
Mammograms.	0.6	3.8	325
Form			
Version 1.	1.3	3.2	216
Version 2.	0.9	3.0	180
Version 3.	0.6	4.3	189
Version 4.	0.8	2.8	182

total sample in table M are about 5 months. Many women reported getting their examinations during the same season each year, and thus, should have been able to use this information in reporting dates. The results suggest that there was not much additional error in dating if the test had been remembered correctly. Table N presents information on the precision with which respondents reported dates. Although women were asked for month and year, only about 19 percent of them reported month and year for all tests. The most common method used was to give the exact month for some tests, and a season of the year when the exact month could not be remembered. Consistent with the earlier information on data accuracy, more women reported an exact month for mammograms compared with Pap smears and breast examinations. Also, there was a greater likelihood for the exact month to be reported on the most recent test than on tests from earlier years.

Discussion and recommendations

It was noted based on the Phase I focus groups that most women appeared to use schemas such as, "I get a mammogram every year" or "I get a Pap smear along with my annual physical." This same heavy use of schemas was noted in the Phase II interviews. It was thought that this use of schemas could by affected by revising the forms used, but that was unsuccessful.

Schemas do not necessarily provide poor estimates. For very regular behavior, schemas may provide better estimates than efforts to remember individual episodes. Schemas can result in overstatements of behavior when respondents forget occasions when the regular behavior was interrupted. That is the case for all of the health care behaviors studied in Phase II. As was seen in table G, respondents, on average, overstated receiving health care procedures by 29 percent, compared with records. The overstatement was lowest for mammograms (16 percent) and highest for Pap smears (51 percent) but was found for all procedures. One consequence of using schemas is that there is little difference in the level of false positives by year, as there is with trying to recall individual events. Researchers typically observe sharp increases in underreporting caused by forgetting for longer time periods. Such differences in false negatives are observed in table H. Because the number of false positives is far larger, they dominate the net results.

Based on the findings from this study, it is not possible to recommend any changes in the questions currently used in the NHIS to obtain information about Pap smears, mammograms, and breast examinations. These procedures are overreported because many women use the schema of an annual checkup at which time they always get these procedures. The assumption of a complete annual checkup, however, is not correct and may become an increasing problem as the U.S. health care system becomes more competitive and pressed for time. Some of the HMO physicians in the study noted that they have become more likely to conduct physical examinations and preventive services over several visits. This will create additional obstacles for accurate patient recall. None of the new

Table N. Percent distribution of level of reporting precision, by test and response pattern: 1987–92

Response pattern	All tests	Pap smears	Mammograms	Breast exams
		Percent distribution		
All patterns	100.0	100.0	100.0	100.0
Always gave month and year	19.3	35.3	46.4	43.9
Some month and year, some season and year	32.4	19.2	13.9	12.2
Some month and year, some season and year, some year	17.6	3.9	2.4	3.7
Some month and year, some year	7.4	6.4	6.6	4.9
Some month and year, some don't know	6.8	4.5	5.4	3.0
Always gave season and year	6.8	16.0	14.5	13.4
Some season and year, some year	4.0	1.9	2.4	1.8
Some season and year, some don't know	2.3	5.8	1.2	4.9
Always gave year only	1.1	4.5	3.0	4.9
Some year, some don't know, or all don't know	2.3	2.5	4.2	7.3
		Number		
Number reporting tests	176	156	166	164
Number reporting no tests	2	22	12	14
Mean number of tests (all women)	11.2	3.1	3.3	3.4
Mean number of tests (if had one or more)	11.3	3.6	3.6	3.6

NOTE: N = 178 respondents.

forms tested appeared to change the way that women retrieved this information.

Pap smears were the most overreported procedure, possibly because some women may have them regularly every 2 years. It might be possible to test a question on Pap smears that made this explicit in the introduction. It had been speculated that women who had had hysterectomies would report Pap smears more accurately, but that did not occur. Although of course they reported fewer tests, the percentage of false positives and negatives did not differ between women who had and had not had hysterectomies.

It has been assumed that the major cause of overreporting was the way information is retrieved. It should be pointed out, however, that nothing in this study could rule out the possibility that some of the overstatement is caused by the perceived social desirability of preventive care behavior. This does not mean that many respondents deliberately falsified their answers. Rather, respondents who may have been uncertain about whether they had a procedure every year said that they did because they knew that this was what they should have done.

This sample was a desirable one because of the ability to validate information from records. It may not be representative of the general public, however, as HMO patients are more likely to receive cancer-screening procedures than are patients receiving care from fee-for-service physicians (57–59). It is also possible that membership in an HMO results in more regular behavior and greater use of schemas than is found in the general population of women over 50 years of age. It would be useful to replicate this study with a general population sample.

Broader implications for cognitive research on survey response

Aside from a better understanding of how women report on these three cancer-screening tests, the results also have implications for future research on cognitive aspects of survey response. First, these results strongly suggest that respondents are likely to use schemas in reporting about behavior, even when the total number of events is small, if they perceive the events as regular. The use of schemas is even more likely as respondents are asked about less recent events.

The use of schemas can lead to highly accurate reporting if indeed the events are very regular. Schemas, however, will lead to overreporting of behavior if respondents forget to exclude exceptions. One might expect that the likelihood of forgetting exceptions would increase with longer time periods, but there was no evidence of this in this study. If schemas are used, then the results would suggest that the order in which questions are asked about details of an event would have no effect on the accuracy of reporting that the event occurred.

Obviously, it would be desirable to tell respondents what retrieval method they should use for greatest accuracy, but this research is in agreement with past efforts that indicate that it is enormously difficult to get respondents to change the way they find easiest to retrieve information. This is not to say that it is impossible to do so, but it was not possible in this study, even though the focus groups and think-aloud interviews had given a good understanding of what methods respondents were actually using.

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Appendixes

Appendix tables

Appendix I
Questionnaires and
supplementary information

DISCUSSION GUIDE

<u>MINUTES</u>   1. <u>Introduction</u>
5-10

Welcome
Discussion of focus group procedures
Observation
Read consent and ask for signature

10-15   2. <u>Healthy Practices</u>

Discuss life style patterns related to risk and for seeing
a physician.
What can people do to keep healthy?
    (Lists) Things to do.
        Things not to do
For each practice on list, do they follow the practice?
Sum up with discussion of where their ideas about healthy
life-style come from. Family, friends, interaction with
health care providers?

10-15   3. <u>Relationship with their providers</u>

What kinds of health education do they get from their
contacts with the health care system?

How regular is the contact?
What kinds of contact do they have?
Are they likely to see a provider to get a check-up when
they are not ill?
    Why? Why not? (Note: probe for ease of getting these;
    time required; expenses uncovered--i.e. baby-sitting,
    transportation)

20-30   4. <u>Physical Examination and Early Detection</u>

What happens in a physical examination?

How complicated is getting a physical?
    <u>Probes:</u>
        Length of time?
        Number of separate visits for all procedures?
        (Reaction?)
        Location for procedures?
        Discomfort or embarrassment?

What kinds of things might the doctor do to see if you
have cancer?

List kinds of early detection that might be done.
Who should get procedures?
Which procedures are best for detecting cancer early?
Which are best for you?
Which are usually done in a physical exam?
    Performed by regular doctor or someone else?

Do they feel the doctor/provider <u>explains</u> what is happening?

Does the provider specifically discuss early detection?
Does provider describe procedures?
Explain what they are for?
Do they feel they can ask questions?
Do they ask?
Do they understand what they are told?

Do they feel they can influence what happens in their physical exam? Do they?
    <u>Probes:</u>
        Do they ask for early detection procedures?
        Does the provider tell them what they need and why they need it?
        Probe for understanding of what they are told.

Communication following physical.
    <u>Probes:</u>
        Do they hear about results whether positive or negative?
        How long do they wait for results?
        How are they communicated?
        Satisfaction with information provided?
        Do they feel they receive adequate explanation of what results mean?

15-20   5.   <u>Information Retrieval</u>

Who do they think is responsible for keeping track of when it is time for a physical or early detection procedures to be done?

How do they know when it is time to see a health care provider?

Do they have special reminders for physical exam/early detection?

    <u>Probe:</u>
        Can they remember when they had their last physical?
        Can they remember when they had their last Pap?
        Mammogram? Rectal exam? Fecal Occult Blood?

<u>General probe for comfort level with discussion about what early detection procedures they get and in how they describe them.</u>

COGNITIVE ASPECTS OF REPORTING HEALTH
PROMOTION AND DISEASE PREVENTION
THINK-ALOUD

University of Illinois
Survey Research Laboratory

Case ID # _____	
Study #___707___	
Version #___1___	
Intvr _____	

1. Would you say that your health, in general, is excellent, very good, good, fair, or poor?

Excellent 1

Very good 2

Good 3

Fair 4

Poor 5

2a. Have you had a health problem at any time in the past five years, since January 1987, for which you consulted or are still consulting a doctor on a regular basis?

Yes 1

No . . . . 2 --> (SKIP TO Q.3a)

2b. What was the problem?

Breast related (SPECIFY) 1

_____

Gyne or urinary related (SPECIFY). 2

_____

Other (SPECIFY). 3

_____

3a. Have you had any major illnesses or conditions at any time in the
     past five years, since January 1987, for which you consulted a
     doctor?

                          Yes 1

                          No . . . . 2 --> (SKIP TO Q.4a)

  3b. What was the problem?

       Breast related (SPECIFY). 1

       _____

       Gyne or urinary related (SPECIFY) 2

       _____

       Other (SPECIFY) 3

       _____

4a. Have you ever heard of a Pap smear test?

                          Yes 1

                          No . . . . 2-->(SKIP TO Q.5a)

                          DON'T KNOW . . . . 8-->(SKIP TO Q.5a)

  4b. In your own words, what happens during a Pap smear test?

       _____

       _____

       _____

  4c. How useful do you think Pap smear tests are for early detection of
       disease? Would you say . . .

                          Very useful, ... 1

                          Somewhat useful, or . . 2

                          Not very useful? 3

                          DON'T KNOW 8

                                    -2-

5a.   (A Pap smear is a routine test, often part of a pelvic examination, where the doctor uses a swab to take a sample from the mouth of the womb or cervix.) Have you ever <u>had</u> a Pap smear?

Yes 1

No . . . . 2-->(SKIP TO Q.9)

DON'T KNOW . . . . 8-->(SKIP TO Q.9)

5b.   How many Pap smears have you had in the <u>past five years,</u> since January 1987?

_____ Pap smears

DON'T KNOW 8

6a.   In what month and year did you have your <u>last</u> Pap smear?

6b.   How did you come up with that answer?

a. Last Pap	b. How answered
_____	_____
_____	_____

(KEEP ASKING FOR ALL PAPS IN PAST 5 YEARS -- NUMBER IN Q.5b)

6c.   How about the one before <u>that</u>?

6d.   How did you come up with that answer?

Pap #	c. When	d. How answered
2.	_____	_____
	_____	_____
3.	_____	_____
	_____	_____
4.	_____	_____
	_____	_____
5.	_____	_____
	_____	_____

7.   Why did you get your <u>last</u> Pap smear?

       Part of a routine checkup 1

       Because of symptoms 2

       As followup to previous problem 3

       Other (SPECIFY) 4

8a.   How did you find out the results of the Pap smear?

At next doctor's visit 1

By letter 2

Doctor's office phoned R 3

R phoned doctor's office 4

Was told would not hear unless there
was a problem 5

Never found out results 6

Other (SPECIFY) 7

8b. Was everything OK or did they find a problem?

       Everything was OK 1

       There was a problem 2

9.   How painful do you think Pap smear tests are? Would you say they
are . . .

       Very painful, ... 1

       Somewhat painful, or 2

       Not very painful? 3

       DON'T KNOW 8

10a. Have you ever <u>heard</u> of a mammogram?

            Yes 1

            No . . . . 2-->(SKIP TO Q.11a)

            DON'T KNOW . . . . 8-->(SKIP TO Q.11a)

   10b. In your own words, what happens during a mammogram?

   _____

   _____

   _____

   10c. How useful do you think mammograms are for early detection of
        disease? Would you say . . .

            Very useful, ... 1

            Somewhat useful, or . . 2

            Not very useful? 3

            DON'T KNOW 8

11a. (A mammogram is an x-ray taken only of the breasts by a machine that
     presses the breast against a plate.) Have you ever <u>had</u> a mammogram?

            Yes 1

            No . . . . 2-->(SKIP TO Q.16,P7)

            DON'T KNOW . . . . . . 8-->(SKIP TO Q.16,P7)

   11b. How many mammograms have you had in the <u>past five years</u>, since
        January 1987?

            _____ Mammograms

            DON'T KNOW 8

12a. In what month and year did you have your <u>last</u> mammogram?

   12b. How did you come up with that answer?

                 a.   b.
          <u>Last Mammogram</u>   <u>How answered</u>

        _____   _____

        _____   _____

(KEEP ASKING FOR ALL MAMMOGRAMS IN PAST 5 YEARS -- NUMBER IN Q.11b)

12c. How about the one before <u>that</u>?

12d. How did you come up with that answer?

<u>Mammo- gram #</u>	c. <u>When</u>	d. <u>How answered</u>
2.	_____	_____
	_____	_____
3.	_____	_____
	_____	_____
4.	_____	_____
	_____	_____
5.	_____	_____
	_____	_____

13. Why did you get your <u>last</u> mammogram?

      Part of a routine checkup 1

      Because of symptoms/lump 2

      As followup to previous problem 3

      Other (SPECIFY) 4

      _____

14. <u>Where</u> did you get your last mammogram?

      _____

      _____

      _____

15a. How did you find out the results of the mammogram?

At next doctor's visit 1

By letter 2

Doctor's office phoned R 3

R phoned doctor's office 4

Was told would not hear unless there
was a problem 5

Never found out results 6

Other (SPECIFY) 7

_____

15b. Was everything OK or did they find a problem?

Everything was OK 1

There was a problem 2

16. How painful do you think mammograms are? Would you say they
are . . .

Very painful, ... 1

Somewhat painful, or 2

Not very painful? 3

DON'T KNOW 8

17a. Have you ever <u>heard</u> of a breast exam by a doctor or medical assistant?

Yes 1

No . . . . 2-->(SKIP TO Q.18a)

DON'T KNOW . . . . 8-->(SKIP TO Q.18a)

17b. In your own words, what happens during a breast exam?

_____

_____

_____

18a. (A breast examination is when the breast is felt for lumps by a doctor or medical assistant.) Have you ever __had__ a breast exam by a doctor or medical assistant?

Yes 1

No . . . . 2-->(SKIP TO Q.22a,P9)

DON'T KNOW . . . . . . 8-->(SKIP TO Q.22a,P9)

18b. How many breast examinations have you had in the __past five years,__ since January 1987?

_____ breast exams

DON'T KNOW 8

19a. In what month and year did you have your __last__ breast examination?

19b. How did you come up with that answer?

a. Last breast examination	b. How answered
_____	_____
_____	_____

(KEEP ASKING FOR ALL BREAST EXAMS IN PAST 5 YEARS -- NUMBER IN Q.18b)

19c. How about the one before __that__?

19d. How did you come up with that answer?

Breast exam #	c. When	d. How answered
2.	_____	_____
	_____	_____
3.	_____	_____
	_____	_____
4.	_____	_____
	_____	_____
5.	_____	_____
	_____	_____

20. Why did you get your <u>last</u> breast examination?

  Part of a routine checkup 1

  Because of symptoms/lump 2

  As followup to previous problem 3

  Other (SPECIFY) 4

_____

21. How did you find out the results of the breast exam?

  At next doctor's visit 1

  By letter 2

  Doctor's office phoned R 3

  R phoned doctor's office 4

  Was told would not hear unless there
  was a problem 5

  Never found out results 6

  Other (SPECIFY) 7

_____

22a. Have you ever <u>heard</u> of a blood stool test?

      Yes 1

      No . . . . 2-->(SKIP TO Q.23a)

      DON'T KNOW . . . . 8-->(SKIP TO Q.23a)

 22b. In your own words, what is a blood stool test?

   _____

   _____

   _____

22c. How useful do you think blood stool tests are for early detection of disease? Would you say . . .

Very useful,. 1

Somewhat useful, or . . 2

Not very useful? 3

DON'T KNOW 8

23a. (A blood stool test is where the stool is smeared on a card that is mailed back to the doctor and examined to determine whether it contains blood.) Have you ever <u>had</u> a blood stool test?

Yes 1

No . . . . 2-->(SKIP TO Q.27,P12)

DON'T KNOW . . . . . . 8-->(SKIP TO Q.27,P12)

23b. How many blood stool tests have you had in the <u>past five years</u>, since January 1987?

_____ blood stool tests

DON'T KNOW 8

24a. In what month and year did you have your <u>last</u> blood stool test?

24b. How did you come up with that answer?

a. <u>Last blood stool test</u>	b. <u>How answered</u>
_____	_____
_____	_____

(KEEP ASKING FOR ALL BLOOD STOOL TEST IN PAST 5 YEARS -- NUMBER IN Q.23b)

24c. How about the one before _that_?
24d. How did you come up with that answer?

Blood stool test #	c. When	d. How answered
2.	_____	_____
	_____	_____
3.	_____	_____
	_____	_____
4.	_____	_____
	_____	_____
5.	_____	_____
	_____	_____

25. Why did you get your _last_ blood stool test?

    Part of a routine checkup 1

    Because of symptoms/blood 2

    As followup to previous problem 3

    Other (SPECIFY) 4

    _____

26a. How did you find out the results of the blood stool test?

    At next doctor's visit 1

    By letter 2

    Doctor's office phoned R 3

    R phoned doctor's office 4

    Was told would not hear unless there
    was a problem 5

    Never found out results 6

    Other (SPECIFY) 7

34

26b. Was everything OK or did they find a problem?

    Everything was OK 1

    There was a problem 2

27. How painful do you think blood stool tests are? Would you say
    they are . . .

    Very painful, ... 1

    Somewhat painful, or . . . 2

    Not very painful? 3

    DON'T KNOW 8

29. Now that we are almost through with this interview, I would like to ask
    your feelings about it. As I mention groups of questions, please tell
    me whether you think those questions would make most women very uneasy,
    somewhat uneasy, or not at all uneasy. How about questions about . . .

	Very uneasy,	A little uneasy,	or	Not at all uneasy?	DK
a. Pap smears? Would these questions make most women . .	1	2		3	8
b. Mammograms?	1	2		3	8
c. Breast examinations? . . .	1	2		3	8
d. Blood stool tests? .	1	2		3	8

29. Do you think it would make a difference to most women if they were asked
    these questions by a man instead of a woman?

    Yes 1

    No 2

30. How much trouble do you have finding the time to go to the doctor and get tests done? Do you have . . .

        A lot of trouble, ... 1

        Some trouble, or 2

        Not much trouble? 3

31. How hard is it for you to travel to the doctor when you need to go? Is it . . .

        Very hard, ... 1

        Somewhat hard, or 2

        Not very hard? 3

1/28/92

COGNITIVE ASPECTS OF REPORTING HEALTH
PROMOTION AND DISEASE PREVENTION
THINK-ALOUD

University of Illinois
Survey Research Laboratory

1.   Would you say that your health, in general, is excellent, very good, good, fair, or poor?

Excellent 1

Very good 2

Good 3

Fair 4

Poor 5

2a. Have you had a health problem at any time in the past five years, since January 1987, for which you consulted or are still consulting a doctor on a regular basis?

Yes 1

No . . . . 2 --> (SKIP TO Q.3a)

2b. What was the problem?

Breast related (SPECIFY) 1

_____

Gyne or urinary related (SPECIFY) 2

_____

Other (SPECIFY) 3

_____

3a. Have you had any (other) <u>major</u> illnesses or conditions at any time in the past five years, since January 1987, for which you consulted a doctor?

Yes 1

No . . . . 2-->(SKIP TO BOX A)

3b. What was the problem?

Breast related (SPECIFY) 1

_____

Gyne or urinary related (SPECIFY) 2

_____

Other (SPECIFY) 3

_____

(IF BREAST PROBLEM IS MENTIONED):
4.   In what month and year did the (BREAST CONDITION) occur?

_____

5a.   Did you have any mammograms that were directly related to diagnosing or treating this condition?

Yes 1

No . . . . 2-->(SKIP TO Q.7a)

5b.   How many mammograms did you have in connection with this condition?

_____ mammograms

6a.   In what month and year did you have your <u>last</u> mammogram that was directly related to this condition?

_____

6b.   How did you come up with that answer?

a.	b.
Last Mammogram	How answered
_____	_____
_____	_____

(KEEP ASKING FOR ALL OTHER MAMMOGRAMS RELATED TO THAT CONDITION)

6c.   How about the one before <u>that</u>?

6d.   How did you come up with that answer?

Mammo-gram #	c. When	d. How answered
2.	_____	_____
	_____	_____
3.	_____	_____
	_____	_____
4.	_____	_____
	_____	_____
5.	_____	_____
	_____	_____

7a.   In treating or diagnosing this breast condition, did you have any breast examinations besides the mammogram?

Yes 1

No . . . . 2-->(SKIP TO BOX B)

7b.   How many breast examinations did you have in connection with this condition?

_____ breast examinations

8a. In what month and year did you have your <u>last</u> breast examination in connection with this problem?

_____

8b. How did you come up with that answer?

<table>
<tr><td align="center">a.
<u>Last breast examination</u></td><td align="center">b.
<u>How answered</u></td></tr>
<tr><td>_____</td><td>_____</td></tr>
<tr><td>_____</td><td>_____</td></tr>
</table>

(KEEP ASKING FOR ALL OTHER BREAST EXAMINATIONS RELATED TO THAT CONDITION)

8c. How about the one before <u>that</u>?

8d. How did you come up with that answer?

<u>Breast</u> <u>exam #</u>	c. <u>When</u>	d. <u>How answered</u>
2.	_____	_____
	_____	_____
3.	_____	_____
	_____	_____
4.	_____	_____
	_____	_____
5.	_____	_____
	_____	_____

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B:
> IF THE RESPONDENT HAD A GYNECOLOGICAL OR URINARY
> TRACT PROBLEM, CONTINUE WITH Q.9.
>
> IF NOT, SKIP TO Q.12.,P.8.

9.   In what month and year did the (GYNE/URINARY PROBLEM) first occur?

_____

10a.   Did you receive any pap smears that were directly related to that condition since it was diagnosed?

Yes 1

No . . . . 2-->(SKIP TO Q.12)

10b.   How many pap smears related to this condition have you had?

_____ pap smears

11a.   In what month and year did you have your last pap smear in connection with this problem?

_____

11b.   How did you come up with that answer?

a. Last Pap	b. How answered
_____	_____
_____	_____

(KEEP ASKING FOR ALL OTHER PAPS SMEARS RELATED TO THAT CONDITION)

11c.   How about the one before <u>that</u>?

11d.   How did you come up with that answer?

Pap #	c. When	d. How answered
2.	_____	_____
	_____	_____
3.	_____	_____
	_____	_____
4.	_____	_____
	_____	_____
5.	_____	_____
	_____	_____

12. Have you had a complete physical checkup in the past five years, since January 1987? (IF BY OB/GYN, CODE UNDER Q.19--GYNE CHECKUP.)

Yes 1

No . . . . 2-->(SKIP TO Q.19, P.11)

13a. Do you get checkups on a regular basis, or only when you have a health problem?

Regular basis 1

Only for health problem . . . . 2--(SKIP TO Q.15)

13b. How often do you get a checkup?

_____

14. Have you ever skipped getting a checkup during the past five years?

Yes 1

No 2

DON'T KNOW . . . . 8-->(SKIP TO Q.16a)

15. How many complete physical checkups have you had during the past five years?

_____ checkups

DON'T KNOW 8

16a. In what month and year did you have your __last__ checkup?

16b. How did you come up with that answer?

a. Checkup	b. How answered
_____	_____
_____	_____

(KEEP ASKING FOR ALL CHECKUPS IN PAST 5 YEARS -- NUMBER IN Q.15)

16c. How about the one before __that__?

16d. How did you come up with that answer?

Checkup #	c. When	d. How answered
2.	_____	_____
	_____	_____
3.	_____	_____
	_____	_____
4.	_____	_____
	_____	_____
5.	_____	_____
	_____	_____

17a. As part of your complete
physical checkups, since 1987
do you _ever_ have . . .

(IF YES TO Q.17a):
17b. How often do you get a (TEST)?

	Yes	No	Every year	Other (How many times?) (SPECIFY)	In what month and year was the last one?
1. A Pap smear? (A Pap smear is a routine test, often part of a pelvic examination, where the doctor uses a swab to take a sample from the mouth of the womb or cervix.)	1	2	1	2_____	_____ _____
2. A mammogram? (A mammogram is an x-ray taken only of the breasts by a machine that presses the breast against a plate.) . . .	1	2	1	2_____	_____ _____
3. (Besides the mammogram,) A breast examination by a doctor or medical assistant when the breast is felt for lumps?	1	2	1	2_____	_____ _____
4. A blood stool test where a stool sample is put on a card mailed back to the doctor, and checked for blood?	1	2	1	2_____	_____ _____

18. <u>Where</u> was your <u>last</u> checkup done?

Rush Presbyterian Hospital 1

Professional Building 2

Anchor HMO 3

Other (SPECIFY) 4

_____

19. (Aside from your complete physical checkup(s)), have you had a (separate) gynecological or female checkup in the <u>past five years</u>, since January 1987?

Yes 1

No . . . . 2-->(SKIP TO Q.26a,P14)

20a. Do you get gynecological checkups on a regular basis, or only when you have a health problem?

Regular basis 1

Only for health problem 2-->(SKIP TO Q.22)

20b. How often do you get a gynecological checkup?

_____

21. Have you ever <u>skipped</u> getting a gynecological checkup during the past five years?

Yes 1

No 2

DON'T KNOW . . . . . . 8-->(SKIP TO Q.23a)

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22. How many complete gynecological checkups have you had during the past five years?

_____ gynecological exams

DON'T KNOW 8

23a. In what month and year did you have your last gynecological checkup?

_____

23b. How did you come up with that answer?

a. Last Checkup	b. How answered
_____	_____
_____	_____

(KEEP ASKING FOR ALL GYNECOLOGICAL CHECKUPS IN PAST 5 YEARS—NUMBER IN Q.22)

23c. How about the one before that?
23d. How did you come up with that answer?

Gyne/CU #	c. When	d. How answered
2.	_____	_____
	_____	_____
3.	_____	_____
	_____	_____
4.	_____	_____
	_____	_____

24a. As part of your gyneco-
logical checkups since 1987,
do you _ever_ have . . .

(IF YES TO Q.24a):
24b. How often do you get a (TEST)?

	Yes	No	Every year	Other (How many times?) (SPECIFY)		In what month and year was the last one?

1. A Pap smear? (A Pap smear
is a routine test, often
part of a pelvic examination,
where the doctor uses a
swab to take a sample from
the mouth of the womb
or cervix.)   1   2   1   2_____   _____   _____

2. A mammogram? (A mammogram
is an x-ray taken only of
the breasts by a machine
that presses the breast
against a plate.) . . .   1   2   1   2_____   _____   _____

3. (Besides the mammogram,)
A breast examination by a
doctor or medical assistant
when the breast is felt
for lump?   1   2   1   2_____   _____   _____

4. A blood stool test where a
stool sample is put on a
card mailed back to the
doctor, and checked for
blood?   1   2   1   2_____   _____   _____

25. Where was your last complete gynecological checkup done?

      Rush Presbyterian Hospital 1

      Professional Building 2

      Anchor HMO 3

      Other (SPECIFY) 4

_____

26a. (In addition to the Pap smear(s) you already mentioned) have you had any (other) Pap smears in the past five years, since January 1987?

        Yes 1

        No . . . . 2-->(SKIP TO Q.29a)

26b. How many (other) Pap smears have you had?

      _____ Pap smears

27a. In what month and year did you have your last (other) Pap smear?

_____

27b. How did you come up with that answer?

a. Last Pap	b. How answered
_____	_____

-14-

27c.   How about the one before <u>that</u>?

27d.   How did you come up with that answer?

Pap #	c. <u>When</u>	d. <u>How answered</u>
2.	_____	_____
	_____	_____
3.	_____	_____
	_____	_____
4.	_____	_____
	_____	_____

28.   NOT ASKED

29a.   (In addition to the mammogram(s) you already mentioned,) have you had any <u>(other)</u> mammograms in the <u>past five years</u>, since January 1987?

Yes 1

No . . . . . 2-->(SKIP TO Q.32a,P17)

29b.   How many (other) mammograms have you had?

_____ mammograms

30a. In what month and year did you have your <u>last</u> (other) mammogram?

_____

30b. How did you come up with that answer?

<table>
<tr><td align="center">a.
<u>Last Mammogram</u></td><td align="center">b.
<u>How answered</u></td></tr>
<tr><td>_____</td><td>_____</td></tr>
<tr><td>_____</td><td>_____</td></tr>
</table>

(KEEP ASKING FOR ALL OTHER MAMMOGRAMS IN PAST 5 YEARS -- NUMBER IN Q.29b)

30c. How about the one before <u>that</u>?

30d. How did you come up with that answer?

<u>Mammogram #</u>	c. <u>When</u>	d. <u>How answered</u>
2.	_____	_____
	_____	_____
3.	_____	_____
	_____	_____
4.	_____	_____
	_____	_____

31. NOT ASKED

32a. (In addition to the breast exam(s) you already mentioned,) have you had any (other) breast exams in the past five years, since January 1987?

                              Yes 1

                              No . . . . 2-->(SKIP TO Q.35a)

    32b. How many (other) breast exams have you had?

                              _____ breast exams

33a. In what month and year did you have your last (other) breast exam?

    _____

    33b. How did you come up with that answer?

              a.   b.
          Last Breast Exam   How answered

    _____   _____

    _____   _____

(KEEP ASKING FOR ALL BREAST EXAMS IN PAST 5 YEARS -- NUMBER IN Q.33b)

33c. How about the one before _that_?

33d. How did you come up with that answer?

Breast Exam #	c. When	d. How answered
2.	_____	_____
	_____	_____
3.	_____	_____
	_____	_____
4.	_____	_____
	_____	_____

34. NOT ASKED

35a. (In addition to the blood stool test(s) you already mentioned,) have you had any (other) blood stool tests in the _past five years_, since January 1987?

Yes 1

No . . . . . . 2-->(SKIP TO BOX C, P20)

35b. How many (other) blood stool tests have you had?

_____ blood stool tests

-19-

36a. In what month and year did you have your **last** (other) blood stool test?

_____

36b. How did you come up with that answer?

a. Last Blood Stool Test	b. How answered
_____	_____
_____	_____

(KEEP ASKING FOR ALL OTHER BLOOD STOOL TESTS IN PAST 5 YEARS--NUMBER IN Q.35b)

36c. How about the one before **that**?

36d. How did you come up with that answer?

Blood Stool Test #	c. When	d. How answered
2.	_____	_____
	_____	_____
3.	_____	_____
	_____	_____
4.	_____	_____
	_____	_____

37. NOT ASKED

C:

> CHECK SUMMARY SHEET FOR PAPS.
>
> IF NO PAPS, ASK Q.38a.
>
> IF 1 OR MORE PAPS, SKIP TO Q.39.

38a. Just to confirm, you've said that you have <u>not</u> had a pap smear in the last five years. Is that correct?

Yes . . . . 1-->(SKIP TO BOX F,P22)

No 2

38b. In what month and year did you have your <u>last</u> Pap smear? _____

38c. How did you come up with that answer?

b.	c.
<u>Last Pap</u>	<u>How answered</u>
_____	_____
_____	_____

> SKIP TO Q.40a

39. Just to confirm, you've said that in the last five years, since January 1987, you have had the following pap smears: (READ NUMBER FOR EACH TYPE AND DATE OF LAST TEST.) Is that correct?

Yes 1

No . . . . 2-->(MAKE CORRECTIONS ON
SUMMARY SHEET)

40a. How did you find out the results of this last pap smear?

At next doctor's visit

Doctor told R (PROBE) 1

R asked doctor/nurse 2

By letter 3

Doctor's office phoned R 4

R phoned doctor's office 5

Was told would not hear unless there was
a problem 6

Never found out results . . . . 7 --> (SKIP TO Q.40x)

Other (SPECIFY) 8

40b. Was everything OK or did they find a problem?

Everything was OK 1

There was a problem 2

40x. Where was this pap smear done?

Rush Presbyterian Hospital 1

Professional Building 2

Anchor HMO 3

Other (SPECIFY) 4

D:

> IF PART OF A COMPLETE PHYSICAL
> EXAM, ASK Q.41a.
>
> IF NOT, SKIP TO BOX F.

41a. Was this pap done on a different day than the rest of the checkup?

Yes 1

No . . . . 2 --> (SKIP TO BOX E)

41b. When was it done?

_____

E:

> CHECK SUMMARY SHEET FOR MAMMOGRAMS.
>
> IF NO MAMMOGRAMS, ASK Q.42a.
>
> IF 1 OR MORE MAMMOGRAMS, SKIP TO Q.43.

42a. Just to confirm, you've said that you have __not__ had a mammogram in the last five years. Is that correct?

Yes . . . . 1-->(SKIP TO BOX G,P25)

No 2

**42b. In what month and year did you have your <u>last</u> mammogram?

_____

42c. How did you come up with that answer?

b. <u>Last Mammogram</u>	c. <u>How answered</u>
_____	_____
_____	_____

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┌─────────────────┐
│                 │
│  SKIP TO Q.44a  │
│                 │
└─────────────────┘
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43. Just to confirm, you've said that in the last five years, since January 1987, you have had the following mammograms: (READ NUMBER FOR EACH TYPE AND DATE OF LAST TEST.) Is that correct?

Yes 1

No . . . . 2-->(MAKE CORRECTIONS ON
                             SUMMARY SHEET)

44a. How did you find out the results of this mammogram?

At next doctor's visit

Doctor told R (PROBE) 1

R asked doctor/nurse 2

By letter 3

Doctor's office phoned R 4

R phoned doctor's office 5

Was told would not hear unless there was
a problem 6

Never found out results . . . . 7 --> (SKIP TO Q.40x)

Other (SPECIFY) 8

_____

44b. Was everything OK or did they find a problem?

Everything was OK 1

There was a problem 2

45. Where was this mammogram done?

_____

-25-

IF PART OF A COMPLETE PHYSICAL
EXAM OR GYNE EXAM, ASK Q.46a.

IF NOT, SKIP TO BOX I.

46a. Was this mammogram done on a different day than the rest of the checkup?

Yes 1

No . . . . 2 -->(SKIP TO BOX I)

46b. When was it done?

_____

I:

CHECK SUMMARY SHEET FOR BREAST EXAMS.

IF NO BREAST EXAMS, ASK Q.47a.

IF 1 OR MORE BREAST EXAMS, SKIP TO Q.48.

47a. Just to confirm, you've said that you have not had a breast exam in the last five years, since January 1987. Is that correct?

Yes . . . . 1-->(SKIP TO BOX J)

No 2

47b. In what month and year did you have your <u>last</u> breast exam?

_____

47c. How did you come up with that answer?

b.	c.
<u>Last breast exam</u>	<u>How answered</u>

_____   _____

_____   _____

```
┌─────────────────┐
│   SKIP TO BOX J │
└─────────────────┘
```

48.   Just to confirm, you've said that in the last five years, since January 1987, you have had the following breast exams: (READ NUMBER FOR EACH TYPE AND DATE OF LAST TEST.) Is that correct?

Yes 1

No . . . . 2-->(MAKE CORRECTIONS ON
SUMMARY SHEET)

J:

```
┌──────────────────────────────────────────────┐
│ CHECK SUMMARY SHEET FOR BLOOD STOOL TESTS.    │
│                                               │
│ IF NO BLOOD STOOL TESTS, ASK Q.49a.           │
│                                               │
│ IF 1 OR MORE BLOOD STOOL TESTS, SKIP TO Q.50. │
└──────────────────────────────────────────────┘
```

49a. Just to confirm, you've said that you have not had a blood stool test in the last five years, since January 1987. Is that correct?

Yes . . . . 1-->(SKIP TO Q.52a,P29)

No 2

**49b. In what month and year did you have your <u>last</u> blood stool test? _____

49c. How did you come up with that answer?

b. <u>Last Blood stool test</u>	c. <u>How answered</u>
_____	_____
_____	_____

<div style="border:1px solid">SKIP TO Q.51a</div>

50. Just to confirm, you've said that in the last five years, since January 1987, you have had the following blood stool tests: (READ NUMBER FOR EACH TYPE AND DATE OF LAST TEST.) Is that correct?

Yes 1

No . . . . 2-->(MAKE CORRECTIONS ON SUMMARY SHEET)

K:

CHECK BLOOD STOOL TESTS.

PUT A * NEXT TO MOST RECENT ONE AND SAY: "SO YOUR LAST BLOOD STOOL TEST WAS (DATE)."

51a. How did you find out the results of this blood stool test?

At next doctor's visit

Doctor told R (PROBE) 1

R asked doctor/nurse 2

By letter 3

Doctor's office phoned R 4

R phoned doctor's office 5

Was told would not hear unless there was
a problem 6

Never found out results . . . . 7 --> (SKIP TO Q.52a)

Other (SPECIFY) 8

51b. Was everything OK or did they find a problem?

Everything was OK 1

There was a problem 2

52a. How useful do you think Pap smear tests are for early detection of disease? Would you say . . .

Very useful, ... 1

Somewhat useful, or. . . 2

Not very useful? 3

DON'T KNOW 8

52b. How painful do you think Pap smear tests are? Would you say they are . . .

Very painful, ... 1

Somewhat painful, or . . 2

Not very painful? 3

DON'T KNOW 8

53a. How useful do you think mammograms are for early detection of disease? Would you say . . .

Very useful, ... 1

Somewhat useful, or . . 2

Not very useful? 3

DON'T KNOW 8

53b. How painful do you think mammograms are? Would you say they are . . .

Very painful, ... 1

Somewhat painful, or . . 2

Not very painful? 3

DON'T KNOW 8

54. How useful do you think blood stool tests are for early detection of disease? Would you say . .

Very useful, ... 1

Somewhat useful, or . . 2

Not very useful? 3

DON'T KNOW 8

55. How much trouble do you have making an appointment to see the doctor? Do you have . .

A lot of trouble, ... 1

Some trouble, or 2

Not much trouble? 3

56. How much trouble do you have finding the time to go to the doctor and get tests done? Do you have . .

A lot of trouble, ... 1

Some trouble, or 2

Not much trouble? 3

57. How hard is it for you to travel to the doctor when you need to go? Is it . . .

Very hard, ... 1

Somewhat hard, or 2

Not very hard? 3

PAPS

Conditions _____ _____

Checkups _____ _____

Gyne _____ _____

Other _____ _____

MAMMOGRAMS

Conditions _____ _____

Checkups _____ _____

Gyne _____ _____

Other _____ _____

BREAST EXAMS

Conditions _____ _____

Checkups _____ _____

Gyne _____ _____

Other _____ _____

BLOOD STOOL TESTS

Conditions _____ _____

Checkups _____ _____

Gyne _____ _____

Other _____ _____

4/28/92

COGNITIVE ASPECTS OF REPORTING HEALTH
PROMOTION AND DISEASE PREVENTION ACTIVITIES

Survey Research Laboratory
University of Illinois

This study is being conducted under authority of Section 306 of the Public
Health Service Act (42 USC 242k). Every reply is treated with the strictest
confidence and will only be heard by professionals involved in questionnaire
design research. The results of this study will be presented only in the form
of statistical tables that do not contain the identity of any respondents.

TIME INTERVIEW BEGAN ____ ____ : ____ ____   (24-hour clock)

1. Would you say that your health, in general, is excellent, very good, good, fair, or poor?

> Excellent 1
>
> Very good 2
>
> Good 3
>
> Fair 4
>
> Poor 5

2a. Have you had a health problem at any time in the past five years, since (MONTH) 1987, for which you consulted a doctor on a regular basis?

> Yes 1
>
> No . . . . 2 -->(SKIP TO Q.3a)

2b. What was the problem?

Breast-related (SPECIFY) 1

_____

Gynecologic or urinary-related (SPECIFY) . 2

_____

Other (SPECIFY) 3

_____

_____

3a. Have you had any (other) <u>major</u> illnesses or conditions at any time in the past five years for which you consulted a doctor?

Yes 1

No . . . . 2 -->(SKIP TO Q.4a)

3b. What was the problem?

Breast-related (SPECIFY) 1

_____

Gynecologic or urinary-related (SPECIFY) . 2

_____

Other (SPECIFY) 3

_____

_____

4a. A Pap smear is a routine test, often part of a pelvic examination, where the doctor uses a swab to take a sample from the mouth of the womb or cervix. Have you ever <u>had</u> a Pap smear test?

Yes 1

No . . . . 2 -->(SKIP TO Q.9, P.5)

DON'T KNOW . . . . 8 -->(SKIP TO Q.9, P.5)

4b. How many Pap smear tests have you had in the <u>past five years</u>, since (MONTH) 1987?

_____ Pap smear tests
(IF "0" SKIP TO Q.9, P.5)

DON'T KNOW 98

5a. In what month and year did you have your <u>last</u> Pap smear test?

> (IF UNABLE TO GIVE YEAR): Would you say that it was early in the last five years--1987 or '88, later than that--1989 or '90, or more recently--1991 or '92?
> (IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the spring, the summer, or the fall?
> (IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle, or the end of (those months/that season)?

_____

5b. How did you remember that date?

_____

_____

(KEEP ASKING FOR ALL PAPS IN PAST 5 YEARS -- NUMBER IN Q.4b)

5c. What about the one before <u>that</u>? In what month and year was it?

> (IF UNABLE TO GIVE YEAR): Would you say that it was early in the last five years--1987 or '88, later than that--1989 or '90, or more recently--1991 or '92?
> (IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the spring, the summer, or the fall?
> (IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle, or the end of (those months/that season)?

<u>Pap #</u>

2) _____

3) _____

4) _____

5) _____

6) _____

<u>(IF R MENTIONS MORE DATES THAN PAP SMEAR TESTS)</u>:
5d. You said that you had (NUMBER IN Q.4b) Pap smear test(s) in the past five years, but you gave me the dates for (NUMBER OF LINES FILLED IN Q.5c.) Which number is correct?

> (NUMBER IN Q.4b) . . . . 1 -->(CORRECT DATES ABOVE)
>
> (NUMBER OF DATES IN Q.5c) . . . 2 -->(CORRECT Q.4b)

6. Why did you get your <u>last</u> Pap smear test? (IF NECESSARY): The one in (DATE OF LAST PAP IN Q.5a).

                    Part of a routine checkup 1

                    Because of symptoms 2

                    As followup to previous problem . . 3

                    Special event 4

                    Other (SPECIFY) 5

                    _____

7a. How did you find out the results of this last Pap smear test? (CIRCLE ONLY ONE.)

                    At next doctor's visit . . .

                        Doctor told R (PROBE)   1

                        R asked doctor/nurse 2

                    By letter 3

                    Doctor's office phoned R 4

                    R phoned doctor's office 5

                    Was told would not hear unless
                    there was a problem . . . . 6 -->(SKIP TO Q.9)

                    Never found out results . . . . . 7 -->(SKIP TO Q.9)

                    Other (SPECIFY) 8

                    _____

    7b. Was everything OK or did they find a problem?

                    Everything was OK 1

                    There was a problem 2

8. NOT ASKED

9. How <u>useful</u> do you think Pap smear tests are for early detection of disease? Would you say . . .

<div style="margin-left: 4em;">

Very useful, ... 1

Somewhat useful, or 2

Not very useful? 3

DON'T KNOW 8

</div>

10. How <u>painful</u> do you think Pap smear tests are? Would you say they are . . .

<div style="margin-left: 4em;">

Very painful, ... 1

Somewhat painful, or 2

Not very painful? 3

DON'T KNOW 8

</div>

11a. A mammogram is an x-ray taken only of the breasts by a machine that presses the breast against a plate. Have you ever <u>had</u> a mammogram?

Yes 1

No . . . . 2 -->(SKIP TO Q.17, P.9)

DON'T KNOW . . . . 8 -->(SKIP TO Q.17, P.9)

11b. How many mammograms have you had in the <u>past five years</u>, since (MONTH) 1987?

_____mammograms
(IF "0" SKIP TO Q.17, P.9)

DON'T KNOW 98

12a. In what month and year did you have your <u>last</u> mammogram?

(IF UNABLE TO GIVE YEAR): Would you say that it was early in the last five years--1987 or '88, later than that--1989 or '90, or more recently--1991 or '92?
(IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the spring, the summer, or the fall?
(IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle, or the end of (those months/that season)?

_____

12b. How did you remember that date?

_____

_____

(KEEP ASKING FOR ALL MAMMOGRAMS IN PAST 5 YEARS -- NUMBER IN Q.11b)

12c. What about the one before <u>that</u>? In what month and year was it?

      (IF UNABLE TO GIVE YEAR): Would you say that it was early in the
         last five years--1987 or '88, later than that--1989 or '90,
         or more recently--1991 or '92?
      (IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter,
         the spring, the summer, or the fall?
      (IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the
         middle, or the end of (those months/that season)?

<u>Mammogram #</u>

2) _____

3) _____

4) _____

5) _____

6) _____

<u>(IF R MENTIONS MORE DATES THAN MAMMOGRAMS)</u>:
12d. You said that you had (NUMBER IN Q.11b) mammogram(s) in the past
     five years, but you gave me the dates for (NUMBER OF LINES FILLED
     IN Q.12c). Which number is correct?

        (NUMBER IN Q.11b) . . . . 1 -->(CORRECT DATES ABOVE)

        (NUMBER OF DATES IN Q.12c) . . . 2 -->(CORRECT Q.11b)

13. Why did you get your <u>last</u> mammogram? (IF NECESSARY): The one in (DATE
    OF LAST MAMMOGRAM IN Q.12a).

        Part of a routine checkup 1

        Because of symptoms/lump 2

        As followup to previous problem 3

        Special event 4

        Other (SPECIFY) 5

        _____

14. Where was this mammogram done?

   RUSH Presbyterian Hospital 1

   Professional Building 2

   Anchor HMO 3

   Other (SPECIFY) 4

   _____

15a. How did you find out the results of this mammogram? (CIRCLE ONLY ONE.)

   At next doctor's visit . . .

    Doctor told R (PROBE) 1

    R asked doctor/nurse 2

   By letter 3

   Doctor's office phoned R 4

   R phoned doctor's office 5

   Was told would not hear unless
   there was a problem . . . . . . 6 -->(SKIP TO Q.17)

   Never found out results . . . . 7 -->(SKIP TO Q.17)

   Other (SPECIFY) 8

   _____

15b. Was everything OK or did they find a problem?

   Everything was OK 1

   There was a problem 2

16. NOT ASKED

17. How <u>useful</u> do you think mammograms are for early detection of disease?
     Would you say . . .

>   Very useful, ... 1

>   Somewhat useful, or 2

>   Not very useful? 3

>   DON'T KNOW 8

18. How <u>painful</u> do you think mammograms are? Would you say they
     are . . .

>   Very painful, ... 1

>   Somewhat painful, or 2

>   Not very painful? 3

>   DON'T KNOW 8

19a. A breast examination is when the breast is felt for lumps by a doctor or medical assistant. Have you ever <u>had</u> a breast examination by a doctor or medical assistant?

        Yes 1

        No . . . . 2 -->(SKIP TO Q.23a, P.12)

        DON'T KNOW . . . . 8 -->(SKIP TO Q.23a, P.12)

19b. How many breast examinations have you had in the <u>past five years</u>, since (MONTH) 1987?

        _____ breast exams
        (IF "0" SKIP TO Q.23a, P.12)

        DON'T KNOW 98

20a. In what month and year did you have your <u>last</u> breast examination?

    (IF UNABLE TO GIVE YEAR): Would you say that it was early in the last five years--1987 or '88, later than that--1989 or '90, or more recently--1991 or '92?
    (IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the spring, the summer, or the fall?
    (IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle, or the end of (those months/that season)?

_____

20b. How did you remember that date?

_____

_____

(KEEP ASKING FOR ALL BREAST EXAMS IN PAST 5 YEARS -- NUMBER IN Q.19b)

20c. What about the one before that? In what month and year was it?

> (IF UNABLE TO GIVE YEAR): Would you say that it was early in the last five years--1987 or '88, later than that--1989 or '90, or more recently--1991 or '92?
>
> (IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the spring, the summer, or the fall?
>
> (IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle, or the end of (those months/that season)?

Breast Exam #

2) _____

3) _____

4) _____

5) _____

6) _____

(IF R MENTIONS MORE DATES THAN BREAST EXAMS):

20d. You said that you had (NUMBER IN Q.19b) breast exam(s) in the past five years, but you gave me the dates for (NUMBER OF LINES FILLED IN Q.20c.) Which number is correct?

(NUMBER IN Q.19b) . . . . 1 -->(CORRECT DATES ABOVE)

(NUMBER OF DATES IN Q.20c) . . . . . . 2 -->(CORRECT Q.19b)

21a. Why did you get your last breast examination? (IF NECESSARY): The one in (DATE OF LAST BREAST EXAM IN Q.20a).

Part of a routine checkup 1

Because of symptoms/lump 2

As followup to previous problem 3

Special event 4

Other (SPECIFY) 5

_____

21b. Was everything OK or did they find a problem?

Everything was OK 1

There was a problem 2

79

22. NOT ASKED

23a. A blood stool test is one where the stool is smeared on a card that is mailed back to the doctor and examined to determine whether it contains blood. Have you ever <u>had</u> a blood stool test?

> Yes 1
>
> No . . . . 2 -->(SKIP TO Q.28, P.14)
>
> DON'T KNOW . . . . 8 -->(SKIP TO Q.28, P.14)

23b. How many blood stool tests have you had in the <u>past five years</u>, since (MONTH) 1987?

> _____blood stool tests
> (IF "0" SKIP TO Q.28, P.14)
>
> DON'T KNOW 98

24a. In what month and year did you have your <u>last</u> blood stool test?

> (IF UNABLE TO GIVE YEAR): Would you say that it was early in the last five years--1987 or '88, later than that--1989 or '90, or more recently--1991 or '92?
> (IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the spring, the summer, or the fall?
> (IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, middle, or end of (those months/that season)?

_____

24b. How did you remember that date?

_____

_____

(KEEP ASKING FOR ALL BLOOD STOOL TESTS IN PAST 5 YEARS -- NUMBER IN Q.23b)

24c. What about the one before <u>that</u>? In what month and year was it?

(IF UNABLE TO GIVE YEAR): Would you say that it was early in the last five years--1987 or '88, later than that--1989 or '90, or more recently--1991 or '92?
(IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the spring, the summer, or the fall?
(IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle, or the end of (those months/that season)?

<u>Blood Stool Test #</u>

2) _____

3) _____

4) _____

5) _____

6) _____

(<u>IF R MENTIONS MORE DATES THAN BLOOD STOOL TESTS</u>):
24d. You said that you had (NUMBER IN Q.23b) blood stool test(s) in the past five years, but you gave me the dates for (NUMBER OF LINES FILLED IN Q.24c). Which number is correct?

(NUMBER IN Q.23b) . . . . 1 -->(CORRECT DATES ABOVE)

(NUMBER OF DATES IN Q.24c) . . . . . 2 -->(CORRECT Q.23b)

25. Why did you get your <u>last</u> blood stool test? (IF NECESSARY): The one in (DATE OF LAST BLOOD STOOL TEST IN Q.24a).

Part of a routine checkup 1

Because of symptoms/blood 2

As followup to previous problem . . . 3

Special event 4

Other (SPECIFY) 5

_____

26a. How did you find out the results of this blood stool test?   (CIRCLE ONLY ONE.)

> At next doctor's visit . . .
>
> > Doctor told R (PROBE) 1
> >
> > R asked doctor/nurse 2
>
> By letter 3
>
> Doctor's office phoned R 4
>
> R phoned doctor's office 5
>
> Was told would not hear unless
> there was a problem . . . . 6 -->(SKIP TO Q.28)
>
> Never found out results . . . . . 7 -->(SKIP TO Q.28)
>
> Other (SPECIFY) 8
>
> _____

26b. Was everything OK or did they find a problem?

> Everything was OK 1
>
> There was a problem 2

27. NOT ASKED

28. How <u>useful</u> do you think blood stool tests are for early detection of disease? Would you say . . .

> Very useful, ... 1
>
> Somewhat useful, or 2
>
> Not very useful? 3
>
> DON'T KNOW 8

29a.   Have you had a complete physical checkup or gynecological or female examination in the past five years, that is since (MONTH) 1987?

                    Yes   1

                    No . . . .   2 -->(SKIP TO Q.30)

      29b.   How many have you had during the past five years?

                    _____ checkups

                    DON'T KNOW 98

30.   How much trouble do you usually have making an appointment to see the doctor? Do you have . .

                    A lot of trouble, ...   1

                    Some trouble, or   2

                    Not much trouble?   3

31.   How much trouble do you usually have finding the time to go to the doctor or get tests done? Do you have . .

                    A lot of trouble, ...   1

                    Some trouble, or   2

                    Not much trouble?   3

32.   How hard is it for you to travel to the doctor when you need to see one? Is it . . .

                    Very hard, ...   1

                    Somewhat hard, or   2

                    Not very hard?   3

33. Do you keep any of the following kinds of records of your visits to the doctor? What about . . .

		Yes	No
a.	A datebook or calendar?	1	2
b.	A separate listing of medical dates?	1	2
c.	Bills, checks or other financial records?	1	2
d	Any other kinds of records? (SPECIFY)	1	2

_____

34a. Are you currently . . .

Employed full time, ... 1 -->(SKIP TO Q.35a)

Employed part time, or . . . . . . 2 -->(SKIP TO Q.35a)

Not employed at all? 3

34b. Are you . . .

Retired, ... 1

Disabled, ... 2

Temporarily unemployed, ... 3

A student, ... 4 -->(SKIP TO Q.36)

Keeping house, or . . . . 5 -->(SKIP TO Q.36)

Not employed and not looking for paid employment? . . . . 6 -->(SKIP TO Q.36)

Other (SPECIFY) 7

_____

_____

(IF "RETIRED," "DISABLED," OR "TEMPORARILY UNEMPLOYED," ASK ABOUT MOST RECENT OCCUPATION):

35a. What (is/was) your main occupation or job title?

_____

_____

35b. What kind of work (do/did) you do, that is, what (are/were) your most important duties on the job?

_____

_____

35c. In what type of business or industry (is/was) this; that is, what product (is/was) made or what service (is/was) given?

_____

_____

36.   What is the highest grade or year of school you have completed?

      None 00

      Elementary . . 01 02 03 04 05 06 07 08

      High school 09 10 11 12

      College 13 14 15 16

      Some graduate school 17

      Graduate or professional degree 18

37. What race do you consider yourself?

        American Indian or Alaskan Native . . . 1

        Asian or Pacific Islander 2

        Black, not of Hispanic origin 3

        White, not of Hispanic origin 4

        Hispanic 5

        Other (SPECIFY) 6

_____

38. In what year were you born?   19 _____ _____

(SHOW RESPONDENT THE RELEASE CONSENT FORM.)

39. As part of our research, we would like your permission to review your records at the HMO. We will only be looking at the dates of various tests that you have had, to see how they match your recall of them. The information will be strictly confidential and we will never report any information in connection with your name.

    Please sign this consent form, print your name, and fill in today's date and your social security number. If any of your records might be listed under another name, please fill in that information on the lines provided.

Thank you very much for your cooperation.

TIME INTERVIEW ENDED: _____ _____ : _____ _____ (24-hour clock)

40. DID THE RESPONDENT USE ANY OF THE FOLLOWING TO HELP HER REMEMBER INFORMATION?

		<u>Yes</u>	<u>No</u>
a.	A datebook or calendar	1	2
b.	A separate listing of medical events	1	2
c.	Bills, checks or other financial records	1	2
d.	Anything else (SPECIFY)	1	2

_____

_____

INTERVIEWER COMMENTS:

_____

_____

_____

_____

_____

_____

4/28/92

COGNITIVE ASPECTS OF REPORTING HEALTH
PROMOTION AND DISEASE PREVENTION ACTIVITIES

Survey Research Laboratory
University of Illinois

TIME INTERVIEW BEGAN ____ ____ : ____ ____ (24-hour clock)

1. Would you say that your health, in general, is excellent, very good, good, fair, or poor?

                    Excellent 1

                    Very good 2

                    Good 3

                    Fair 4

                    Poor 5

2a. Have you had a health problem at any time in the past five years, since (MONTH) 1987, for which you consulted a doctor on a regular basis?

                    Yes 1

                    No . . . . 2 -->(SKIP TO Q.3a)

   2b. What was the problem?

   Breast-related (SPECIFY) 1

   _____

   Gynecologic or urinary-related (SPECIFY) . 2

   _____

   Other (SPECIFY) 3

   _____

   _____

3a. Have you had any (other) <u>major</u> illnesses or conditions at any time in the past five years for which you consulted a doctor?

> Yes 1
>
> No . . . . 2 -->(SKIP TO Q.4a)

3b. What was the problem?

> ' Breast-related (SPECIFY) 1
>
> _____
>
> _____
>
> Gynecologic or urinary-related (SPECIFY) . 2
>
> _____
>
> _____
>
> Other (SPECIFY) 3
>
> _____
>
> _____

4a. A Pap smear is a routine test, often part of a pelvic examination, where the doctor uses a swab to take a sample from the mouth of the womb or cervix. Have you ever <u>had</u> a Pap smear test?

> Yes 1
>
> No . . . . 2 -->(SKIP TO Q.9, P.5)
>
> DON'T KNOW . . . . 8 -->(SKIP TO Q.9, P.5)

4b. How many Pap smear tests have you had in the <u>past five years</u>, since (MONTH) 1987?

> _____ Pap smear tests
> (IF "0" SKIP TO Q.9, P.5)
>
> DON'T KNOW 98

5.   NOT ASKED

6. Why did you get your <u>last</u> Pap smear test?

                    Part of a routine checkup 1

                    Because of symptoms 2

                    As followup to previous problem . 3

                    Special event 4

                    Other (SPECIFY) 5

                    _____

7a. How did you find out the results of this last Pap smear? (CIRCLE
    ONLY ONE.)

                    At next doctor's visit . . .

                        Doctor told R (PROBE) 1

                        R asked doctor/nurse 2

                    By letter 3

                    Doctor's office phoned R 4

                    R phoned doctor's office 5

                    Was told would not hear unless
                    there was a problem . . . . 6 -->(SKIP TO Q.8a)

                    Never found out results . . . . . 7 -->(SKIP TO Q.8a)

                    Other (SPECIFY) 8

                    _____

    7b. Was everything OK or did they find a problem?

                    Everything was OK 1

                    There was a problem 2

8a. In what month and year did you have your <u>last</u> Pap smear test?

    (IF UNABLE TO GIVE YEAR): Would you say that it was early in the last five years--1987 or '88, later than that--1989 or '90, or more recently--1991 or '92?
    (IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the spring, the.summer, or the fall?
    (IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle, or the end of (those months/that season)?

_____

8b. How did you remember that date?

_____

_____

(KEEP ASKING FOR ALL PAPS IN PAST 5 YEARS -- NUMBER IN Q.4b)

8c. What about the one before <u>that</u>? In what month and year was it?

    (IF UNABLE TO GIVE YEAR): Would you say that it was early in the last five years--1987 or '88, later than that--1989 or '90, or more recently--1991 or '92?
    (IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the spring, the summer, or the fall?
    (IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle, or the end of (those months/that season)?

<u>Pap #</u>

2) _____

3) _____

4) _____

5) _____

6) _____

<u>(IF R MENTIONS MORE DATES THAN PAP SMEAR TESTS)</u>:
8d. You said that you had (NUMBER IN Q.4b) Pap smear test(s) in the past five years, but you gave me the dates for (NUMBER OF LINES FILLED IN Q.8c). Which number is correct?

    (NUMBER IN Q.4b) . . . . 1 -->(CORRECT DATES ABOVE)

    (NUMBER OF DATES IN Q.8c) . . . 2 -->(CORRECT Q.4b)

9. How <u>useful</u> do you think Pap smear tests are for early detection of disease? Would you say . . .

        Very useful, ... 1

        Somewhat useful, or 2

        Not very useful? 3

        DON'T KNOW 8

10. How <u>painful</u> do you think Pap smear tests are? Would you say they are . . .

        Very painful, ... 1

        Somewhat painful, or 2

        Not very painful? 3

        DON'T KNOW 8

11a. A mammogram is an x-ray taken only of the breasts by a machine that presses the breast against a plate. Have you ever <u>had</u> a mammogram?

        Yes 1

        No . . . . 2 -->(SKIP TO Q.17, P.8)

        DON'T KNOW . . . . 8 -->(SKIP TO Q.17, P.8)

    11b. How many mammograms have you had in the <u>past five years</u>, since (MONTH) 1987?

           _____ mammograms
           (IF "0" SKIP TO Q.17, P.8)

           DON'T KNOW 98

12. NOT ASKED

13. Why did you get your <u>last</u> mammogram?

        Part of a routine checkup 1

        Because of symptoms/lump 2

        As followup to previous problem 3

        Special event 4

        Other (SPECIFY) 5

        _____

14. Where was this mammogram done?

        RUSH Presbyterian Hospital 1

        Professional Building 2

        Anchor HMO 3

        Other (SPECIFY) 4

        _____

15a. How did you find out the results of this mammogram? (CIRCLE ONLY ONE.)

        At next doctor's visit . . .

          Doctor told R (PROBE) 1

          R asked doctor/nurse 2

        By letter 3

        Doctor's office phoned R 4

        R phoned doctor's office 5

        Was told would not hear unless
        there was a problem . . . . 6 -->(SKIP TO Q.16a)

        Never found out results . . . . 7 -->(SKIP TO Q.16a)

        Other (SPECIFY) 8

        _____

    15b. Was everything OK or did they find a problem?

        Everything was OK 1

        There was a problem 2

16a. In what month and year did you have your <u>last</u> mammogram?

> (IF UNABLE TO GIVE YEAR): Would you say that it was early in the last five years--1987 or '88, later than that--1989 or '90, or more recently--1991 or '92?
>
> (IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the spring, the summer, or the fall?
>
> (IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle, or the end of (those months/that season)?

_____

16b. How did you remember that date?

_____

_____

(KEEP ASKING FOR ALL MAMMOGRAMS IN PAST 5 YEARS -- NUMBER IN Q.11b)

16c. What about the one before <u>that</u>? In what month and year was it?

> (IF UNABLE TO GIVE YEAR): Would you say that it was early in the last five years--1987 or '88, later than that--1989 or '90, or more recently--1991 or '92?
>
> (IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the spring, the summer, or the fall?
>
> (IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle, or the end of (those months/that season)?

<u>Mammogram #</u>

2) _____

3) _____

4) _____

5) _____

6) _____

<u>(IF R MENTIONS MORE DATES THAN MAMMOGRAMS)</u>:

16d. You said that you had (NUMBER IN Q.11b) mammogram(s) in the past five years, but you gave me the dates for (NUMBER OF LINES FILLED IN Q.16c). Which number is correct?

(NUMBER IN Q.11b) . . . . 1 -->(CORRECT DATES ABOVE)

(NUMBER OF DATES IN Q.16c) . . . . 2 -->(CORRECT Q.11b)

17. How <u>useful</u> do you think mammograms are for early detection of disease? Would you say . . .

> Very useful, ... 1
>
> Somewhat useful, or 2
>
> Not very useful? 3
>
> DON'T KNOW 8

18. How <u>painful</u> do you think mammograms are? Would you say they are . . .

> Very painful, ... 1
>
> Somewhat painful, or 2
>
> Not very painful? 3
>
> DON'T KNOW 8

19a. A breast examination is when the breast is felt for lumps by a doctor or medical assistant. Have you ever <u>had</u> a breast examination by a doctor or medical assistant?

> Yes 1
>
> No . . . . 2 -->(SKIP TO Q.23a, P.10)
>
> DON'T KNOW . . . . 8 -->(SKIP TO Q.23a, P.10)

19b. How many breast examinations have you had in the <u>past five years,</u> since (MONTH) 1987?

> _____breast exams
> (IF "0" SKIP TO Q.23a, P.10)
>
> DON'T KNOW 98

20. NOT ASKED

21a. Why did you get your <u>last</u> breast examination?

> Part of a routine checkup . . . 1
>
> Because of symptoms/lump 2
>
> As followup to previous problem 3
>
> Special event 4
>
> Other (SPECIFY) 5
>
> _____

21b. Was everything OK or did they find a problem?

> Everything was OK 1
>
> There was a problem 2

22a. In what month and year did you have your <u>last</u> breast examination?

> (IF UNABLE TO GIVE YEAR): Would you say that it was early in the last five years--1987 or '88, later than that--1989 or '90, or more recently--1991 or '92?
> (IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the spring, the summer, or the fall?
> (IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle, or the end of (those months/that season)?

22b. How did you remember that date?

(KEEP ASKING FOR ALL BREAST EXAMS IN PAST 5 YEARS -- NUMBER IN Q.19b)

22c. What about the one before <u>that</u>? In what month and year was it?

> (IF UNABLE TO GIVE YEAR): Would you say that it was early in the last five years--1987 or '88, later than that--1989 or '90, or more recently--1991 or '92?
> (IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the spring, the summer, or the fall?
> (IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle, or the end of (those months/that season)?

<u>Breast Exam #</u>

2) _____

3) _____

4) _____

5) _____

6) _____

<u>(IF R MENTIONS MORE DATES THAN BREAST EXAMS)</u>:
22d. You said that you had (NUMBER IN Q.19b) breast exam(s) in the past five years, but you gave me the dates for (NUMBER OF LINES FILLED IN Q.22c). Which number is correct?

> (NUMBER IN Q.19b) . . . . 1 -->(CORRECT DATES ABOVE)
>
> (NUMBER OF DATES IN Q.22c) . . . . . 2 -->(CORRECT Q.19b)

23a. A blood stool test is one where the stool is smeared on a card that is mailed back to the doctor and examined to determine whether it contains blood. Have you ever <u>had</u> a blood stool test?

      Yes 1

      No . . . . 2 -->(SKIP TO Q.28, P.12)

      DON'T KNOW . . . . 8 -->(SKIP TO Q.28, P.12)

23b. How many blood stool tests have you had in the <u>past five years,</u> since (MONTH) 1987?

      _____ blood stool tests
      (IF "0" SKIP TO Q.28, P.12)

      DON'T KNOW 98

24. NOT ASKED

25. Why did you get your <u>last</u> blood stool test?

      Part of a routine checkup 1

      Because of symptoms/blood 2

      As followup to previous problem 3

      Special event 4

      Other (SPECIFY) 5

      _____

26a. How did you find out the results of this blood stool test? (CIRCLE ONLY ONE.)

      At next doctor's visit . . .

        Doctor told R (PROBE) 1

        R asked doctor/nurse 2

      By letter 3

      Doctor's office phoned R 4

      R phoned doctor's office 5

      Was told would not hear unless
      there was a problem . . . . 6 -->(SKIP TO Q.27a)

      Never found out results . . . . 7 -->(SKIP TO Q.27a)

      Other (SPECIFY) 8

      _____

26b. Was everything OK or did they find a problem?

      Everything was OK 1

      There was a problem 2

27a. In what month and year did you have your <u>last</u> blood stool test?

(IF UNABLE TO GIVE YEAR): Would you say that it was early in the last
five years--1987 or '88, later than that--1989 or '90, or more
recently--1991 or '92?
(IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the
spring, the summer, or the fall?
(IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle,
or the end of (those months/that season)?

_____

27b. How did you remember that date?

_____

_____

(KEEP ASKING FOR ALL BLOOD STOOL TESTS IN PAST 5 YEARS -- NUMBER IN Q.23b)

27c. What about the one before <u>that</u>? In what month and year was it?

(IF UNABLE TO GIVE YEAR): Would you say that it was early in the
last five years--1987 or '88, later than that--1989 or '90,
or more recently--1991 or '92?
(IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter,
the spring, the summer, or the fall?
(IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the
middle, or the end of (those months/that season)?

<u>Blood Stool Test #</u>

2) _____

3) _____

4) _____

5) _____

6) _____

<u>(IF R MENTIONS MORE DATES THAN BLOOD STOOL TESTS)</u>:
27d. You said that you had (NUMBER IN Q.23b) blood stool test(s) in the
past five years, but you gave me the dates for (NUMBER OF LINES
FILLED IN Q.27c). Which number is correct?

(NUMBER IN Q.23b) . . . . 1 -->(CORRECT DATES ABOVE)

(NUMBER OF DATES IN Q.27c) . . . . . 2 -->(CORRECT Q.23b)

28. How <u>useful</u> do you think blood stool tests are for early detection of disease? Would you say . . .

        Very useful, ... 1

        Somewhat useful, or 2

        Not very useful? 3

        DON'T KNOW 8

29a. Have you had a complete physical checkup or gynecological or female examination in the past five years, since (MONTH) 1987?

        Yes 1

        No . . . . 2 -->(SKIP TO Q.30)

    29b. How many have you had during the past five years?

        _____ checkups

        DON'T KNOW 98

30. How much trouble do you usually have making an appointment to see the doctor? Do you have . .

        A lot of trouble, ... 1

        Some trouble, or 2

        Not much trouble? 3

31. How much trouble do you usually have finding the time to go to the doctor or get tests done? Do you have . .

        A lot of trouble, ... 1

        Some trouble, or 2

        Not much trouble? 3

32. How hard is it for you to travel to the doctor when you need to see one? Is it . . .

        Very hard, ... 1

        Somewhat hard, or 2

        Not very hard? 3

33. Do you keep any of the following kinds of records of your visits to the doctor? What about . . .

		Yes	No
a.	A datebook or calendar?	1	2
b.	A separate listing of medical dates?	1	2
c.	Bills, checks or other financial records?	1	2
d	Any other kinds of records? (SPECIFY)	1	2

_____

34a. Are you currently . . .

Employed full time, ... 1 -->(SKIP TO Q.35a)

Employed part time, or . . . . . 2 -->(SKIP TO Q.35a)

Not employed at all? 3

34b. Are you . . .

Retired, ... 1

Disabled, ... 2

Temporarily unemployed, ... 3

A student, ... 4 -->(SKIP TO Q.36)

Keeping house, or . . . . 5 -->(SKIP TO Q.36)

Not employed and not looking for paid employment? . . 6 -->(SKIP TO Q.36)

Other (SPECIFY) 7

_____

_____

(IF "RETIRED," "DISABLED," OR "TEMPORARILY UNEMPLOYED," ASK ABOUT MOST RECENT OCCUPATION):

35a. What (is/was) your main occupation or job title?

_____

_____

35b. What kind of work (do/did) you do, that is, what (are/were) your most important duties on the job?

_____

_____

35c. In what type of business or industry (is/was) this; that is, what product (is/was) made or what service (is/was) given?

_____

_____

36. What is the <u>highest</u> grade or year of school you have completed?

None 00

Elementary   01 02 03 04 05 06 07 08

High school 09 10 11 12

College 13 14 15 16

Some graduate school 17

Graduate or professional degree 18

37. What race do you consider yourself?

American Indian or Alaskan Native 1

Asian or Pacific Islander 2

Black, not of Hispanic origin 3

White, not of Hispanic origin 4

Hispanic 5

Other (SPECIFY) 6

_____

38. In what year were you born?   19 _____ _____

(SHOW RESPONDENT THE RELEASE CONSENT FORM.)

39. As part of our research, we would like your permission to review your
     records at the HMO. We will only be looking at the dates of various
     tests that you have had, to see how they match your recall of them. The
     information will be strictly confidential and we will never report any
     information in connection with your name.

     Please sign this consent form, print your name, and fill in today's date
     and your social security number. If any of your records might be listed
     under another name, please fill in that information on the lines
     provided.

Thank you very much for your cooperation.

TIME INTERVIEW ENDED: _____ _____ : _____ _____ (24-hour clock)

40. DID THE RESPONDENT USE ANY OF THE FOLLOWING TO HELP HER REMEMBER
    INFORMATION?

		<u>Yes</u>	<u>No</u>
a.	A datebook or calendar	1	2
b.	A separate listing of medical events	1	2
c.	Bills, checks or other financial records	1	2
d.	Anything else (SPECIFY)	1	2

_____

_____

INTERVIEWER COMMENTS:

_____

_____

_____

_____

_____

_____

_____

4/28/92

COGNITIVE ASPECTS OF REPORTING HEALTH
PROMOTION AND DISEASE PREVENTION ACTIVITIES

Survey Research Laboratory
University of Illinois

VERSION 3
SUMMARY CHART

Case ID #_____

Study # _____707___

Interviewer # _____

<u>Number</u>   <u>Last Date</u>

CHECKUPS

(Q.7)_____   (Q.8a)_____

PAPS

Checkups . . .   (Q.9b1)_____   (Q.9d1)_____

Other . . . . .   (Q.11b)_____   (Q.12a)_____

Confirmation
add-on . . . .   (Q.14c/15)_____   (Q.14b/15)_____

MAMMOGRAMS

Checkups . . .   (Q.9b2)_____   (Q.9d2)_____

Other . . . . .   (Q.18b)_____   (Q.19a)_____

Confirmation
add-on . . . .   (Q.21c/22)_____   (Q.21b/22)_____

BREAST EXAMS

Checkups . . .   (Q.9b3)_____   (Q.9d3)_____

Other . . . . .   (Q.26b)_____   (Q.27a)_____

Confirmation
add-on . . . .   (Q.29c/30)_____   (Q.29b/30)_____

BLOOD STOOL TESTS

Checkups . . . .   (Q.9b4)_____   (Q.9d4)_____

Other . . . . . . (Q.32b)_____   (Q.33a)_____

Confirmation
add-on . . . . .   (Q.35c/36)_____   (Q.35b/36)_____

TIME INTERVIEW BEGAN _____ _____ : _____ _____   (24-hour clock)

1. Would you say that your health, in general, is excellent, very good, good, fair, or poor?

                    Excellent 1

                    Very good 2

                    Good 3

                    Fair 4

                    Poor 5

2a. Have you had a health problem at any time in the past five years, that is since (MONTH) 1987, for which you consulted a doctor on a regular basis?

                    Yes 1

                    No . . . . 2 -->(SKIP TO Q.3a)

    2b. What was the problem?

    Breast-related (SPECIFY) 1

    _____

    Gynecologic or urinary-related (SPECIFY) . 2

    _____

    Other (SPECIFY) 3

    _____

    _____

3a. Have you had any (other) <u>major</u> illnesses or conditions at any time in the past five years for which you consulted a doctor?

        Yes 1

        No . . . . 2 -->(SKIP TO Q.4)

3b. What was the problem?

Breast-related (SPECIFY) 1

_____

Gynecologic or urinary-related (SPECIFY) . 2

_____

Other (SPECIFY) 3

_____

_____

4. Have you had a complete physical or gynecological (female) checkup in the <u>past five years</u>, since (MONTH) 1987?

          Yes 1

          No . . . . 2 -->(SKIP TO Q.11a, P.8)

5a. Do you get checkups on a regular basis, or only when you have a health problem?

          Regular basis 1

          Only for health problem . . . 2 -->(SKIP TO Q.7)

5b. How often do you get a complete physical or gynecological checkup?

          Annually/Once a year 1

          Other (SPECIFY) . . . . 2 -->(SKIP to Q.6)

          _____

5c. Does the time between checkups ever stretch out to <u>more</u> than a year, because of any reason, including problems with making an appointment?

          Yes 1

          No 2

6. Have you ever <u>skipped</u> getting your regular checkup during the past five years?

          Yes 1

          No 2

          DON'T KNOW 8

*7. How many complete physical or gynecological checkups have you had during the past five years? (ENTER NUMBER HERE AND ON CHART.)

_____ checkups
(IF "0" SKIP TO Q.11a, P.8)

DON'T KNOW 98

*8a. In what month and year did you have your <u>last</u> checkup?

(IF 'UNABLE TO GIVE YEAR): Would you say that it was early in the last five years--1987 or '88, later than that--1989 or '90, or more recently--1991 or '92?
(IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the spring, the summer, or the fall?
(IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle, or the end of (those months/that season)?

_____

8b. How did you remember that date?

_____

_____

(KEEP ASKING FOR ALL CHECKUPS IN PAST 5 YEARS -- NUMBER IN Q.7)

8c. What about the one before <u>that</u>? In what month and year was it?

(IF UNABLE TO GIVE YEAR): Would you say that it was early in the last five years--1987 or '88, later than that--1989 or '90, or more recently--1991 or '92?
(IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the spring, the summer, or the fall?
(IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle, or the end of (those months/that season)?

<u>Checkup #</u>

2) _____

3) _____

4) _____

5) _____

6) _____

(<u>IF R MENTIONS MORE DATES THAN NUMBER OF CHECKUPS</u>):

8d. You said that you had (NUMBER IN Q.7) checkup(s) in the past five
     years, but you gave me the dates for (NUMBER OF LINES FILLED IN
     Q.8c). Which number is correct?

                   (NUMBER IN Q.7) . . . . 1 --> (CORRECT DATES)

                   (NUMBER OF DATES) . . . . . . 2 --> (CORRECT Q.7
                                                         AND CHART)

9a. As part of your (NUMBER IN Q.7) complete physical
or gynecological checkup(s) in the past five years,
have you had . . .

9b. How many times since
1987 have you had a
(TEST) as part of your
checkup(s)? (ENTER
NUMBER HERE AND ON
CHART.)

	Yes	No	DK

1) A Pap smear test--which
is a routine test, often part
of a pelvic examination, where
the doctor used a swab to take
a sample from the mouth of the
womb or cervix? 1   2   8   _____ *

2) A mammogram--an x-ray
taken only of the
breasts by a machine that
pressed the breast against
a plate? 1   2   8   _____ *

3) (Besides the mammogram,) A
breast examination by a doctor
or medical assistant when the
breast was felt for lumps? . . . 1   2   8   _____ *

4) A blood stool test where a
stool sample was put on a card,
mailed or taken back to the
doctor, and checked for blood? . 1   2   8   _____ *

(ASK QS.9b-e, IF APPLICABLE, BEFORE GOING ON TO NEXT TEST.)

```
┌─────────────────────┐                              ┌─────────────────────┐
│ IF NUMBER OF TESTS IS│                              │ IF DATE OF TEST IS  │
│ GREATER THAN NUMBER OF│                             │ MORE RECENT THAN MOST│
│ CHECKUPS ON CHART    │                              │ RECENT CHECKUP ON   │
│ (Q.7), ASK Q.9c.     │                              │ CHART (Q.8a) ASK Q.9e.│
└─────────────────────┘                              └─────────────────────┘
```

9d. In what
month and year
was the last
(TEST) that was
part of a checkup?
(SEE PROBES BELOW.)
(ENTER DATE HERE
AND ON CHART.)

9c. You said you've had
(NUMBER IN Q.7)
checkups and (NUMBER
IN Q.9b) (TESTS). Why
was that?
(IF INCORRECT, CHANGE
ANSWERS.)

9e. You said your last
checkup was in (DATE
IN Q.8a) but this
(TEST) was in (DATE IN
Q.9d). Why is that?
(IF INCORRECT, CHANGE
ANSWERS.)

_____   _____ *   _____

_____   _____

_____   _____ *   _____

_____   _____

_____   _____ *   _____

_____   _____

_____   _____ *   _____

_____   _____

PROBES:

(IF UNABLE TO GIVE YEAR): Would you say that it was early in the last five years--
     1987 or '88, later than that--1989 or '90, or more recently--1991 or '92?
(IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the spring, the summer,
     or the fall?
(IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle, or the end of
     (those months/that season)?

10. Where was your <u>last</u> checkup done?

        RUSH Presbyterian Hospital 1

        Professional Building 2

        Anchor HMO 3

        Other (SPECIFY) 4

        _____

11a. [In addition to the (NUMBER IN Q.9b1) Pap smear test(s) you already mentioned] have you had any <u>(other)</u> Pap smear tests in the <u>past five years</u>, since (MONTH) 1987?

        Yes 1

        No . . . . 2 -->(SKIP TO BOX A, P.10)

*11b. How many (other) Pap smear tests have you had?
     (ENTER NUMBER HERE AND ON CHART.)

       _____Pap smear tests

*12a. In what month and year did you have [this test/the most recent of the (NUMBER IN Q.11b) tests]?   (ENTER DATE HERE AND ON CHART.)

      (IF UNABLE TO GIVE YEAR): Would you say that it was early in the last five years--1987 or '88, later than that--1989 or '90, or more recently--1991 or '92?

      (IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the spring, the summer, or the fall?

      (IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle, or the end of (those months/that season)?

_____

(KEEP ASKING FOR ALL OTHER PAPS IN PAST 5 YEARS -- NUMBER IN Q.11b)

12b. What about the one before <u>that</u>? In what month and year was it?

      (IF UNABLE TO GIVE YEAR): Would you say that it was early in the last five years--1987 or '88, later than that--1989 or '90, or more recently--1991 or '92?

      (IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the spring, the summer, or the fall?

      (IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle, or the end of (those months/that season)?

<u>Pap #</u>

2) _____

3) _____

4) _____

5) _____

6) _____

13. Why did you get the Pap smear test in (DATE IN Q.12a)?

        Part of a routine checkup 1

        Because of symptoms 2

        As followup to previous problem . . 3

        Special event 4

        Other (SPECIFY) 5

_____

```
┌─────────────────────────────────────┐
│ CHECK SUMMARY SHEET FOR PAPS.        │
│                                      │
│ IF NO PAPS, ASK Q.14a.               │
│                                      │
│ IF 1 OR MORE PAPS, SKIP TO Q.15.     │
└─────────────────────────────────────┘
```

A:

14a. Just to confirm, you've said that you have <u>not</u> had a Pap smear test in the last five years. Is that correct?

Yes . . . . 1 -->(SKIP TO Q.18a, P.12)

No 2

*14b. In what month and year did you have your <u>last</u> Pap smear test? (ENTER DATE HERE AND ON CHART.)

_____

*14c. How many Pap smear tests have you had in the <u>past five years</u>, since (MONTH) 1987? (ENTER NUMBER HERE AND ON CHART.)

_____ Pap smear tests

DON'T KNOW 98

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┌──────────────────┐
│ SKIP TO Q.16a.   │
└──────────────────┘
```

15. Just to confirm, you've said that in the last five years, since (MONTH) 1987, you have had the following Pap smear tests: (READ NUMBER FOR EACH TYPE FROM CHART) for a total of (SUM) and the <u>last</u> one was (READ DATE OF LAST PAP). Is that correct?

Yes 1

No . . . . 2 -->(MAKE CORRECTIONS ON SUMMARY CHART)

16a. How did you find out the results of your last Pap smear test?
(CIRCLE ONLY ONE.)

At next doctor's visit . . .

Doctor told R (PROBE) 1

R asked doctor/nurse 2

By letter 3

Doctor's office phoned R 4

R phoned doctor's office 5

Was told would not hear unless
there was a problem . . . . 6 -->(SKIP TO BOX B)

Never found out results . . . . 7 -->(SKIP TO BOX B)

Other (SPECIFY) 8

16b. Was everything OK or did they find a problem?

Everything was OK 1

There was a problem 2

B:
```
IF LAST PAP WAS PART OF A CHECKUP,
ASK Q.17a.

IF NOT, SKIP TO Q.18a.
```

17a. Was this Pap smear test done on a different day than the rest of the checkup?

Yes 1

No . . . . 2 -->(SKIP TO Q.18a)

17b. How long before or after the checkup was it done?

18a. [In addition to the (NUMBER IN Q.9b2) mammogram(s) you already
     mentioned,] have you had any _(other)_ mammograms in the _past five years,_
     since (MONTH) 1987?

                              Yes 1

                              No . . . . 2 -->(SKIP TO BOX C)

    *18b. How many (other) mammograms have you had?
          (ENTER NUMBER HERE AND ON CHART.)

                              _____ mammograms

*19a. In what month and year did you have [this mammogram/the most recent of
      the (NUMBER IN Q.18b) mammograms]? (ENTER DATE HERE AND ON CHART.)

      (IF UNABLE TO GIVE YEAR): Would you say that it was early in the last
           five years--1987 or '88, later than that--1989 or '90, or more
           recently--1991 or '92?
      (IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the
           spring, the summer, or the fall?
      (IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle,
           or the end of (those months/that season)?

      _____

      (KEEP ASKING FOR ALL OTHER MAMMOGRAMS IN PAST 5 YEARS -- NUMBER IN Q.18b)

    19b. What about the one before _that?_ In what month and year was it?

         (IF UNABLE TO GIVE YEAR): Would you say that it was early in
              the last five years--1987 or '88, later than that--1989 or
              '90, or more recently--1991 or '92?
         (IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the
              winter, the spring, the summer, or the fall?
         (IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the
              middle, or the end of (those months/that season)?

Mammogram #

  2) _____

  3) _____

  4) _____

  5) _____

  6) _____

20. Why did you get the mammogram in (DATE IN Q.19a)?

Part of a routine checkup 1

Because of symptoms 2

As followup to previous problem . . 3

Special event 4

Other (SPECIFY) 5

_____

C:

CHECK SUMMARY SHEET FOR MAMMOGRAMS.

IF NO MAMMOGRAMS, ASK Q.21a.

IF 1 OR MORE MAMMOGRAMS, SKIP TO Q.22.

21a. Just to confirm, you've said that you have __not__ had a mammogram in the last five years. Is that correct?

Yes . . . . 1 -->(SKIP TO Q.26a, P.16)

No 2

*21b. In what month and year did you have your __last__ mammogram? (ENTER DATE HERE AND ON CHART.)

_____

*21c. How many mammograms have you had in the __past five years__, since (MONTH) 1987? (ENTER NUMBER HERE AND ON CHART.)

_____ mammograms

DON'T KNOW 98

SKIP TO Q.26a, P.16.

22. Just to confirm, you've said that in the last five years, since (MONTH) 1987, you have had the following mammograms: (READ NUMBER FOR EACH TYPE FROM CHART) for a total of (SUM) and the <u>last</u> one was (READ DATE OF LAST·MAMMOGRAM). Is that correct?

> Yes 1
>
> No . . . . 2 -->(MAKE CORRECTIONS
> ON SUMMARY CHART)

23a. How did you find out the results of your last mammogram? (CIRCLE ONLY ONE.)

> At next doctor's visit . . .
>
> > Doctor told R (PROBE) 1
> >
> > R asked doctor/nurse 2
>
> By letter 3
>
> Doctor's office phoned R 4
>
> R phoned doctor's office 5
>
> Was told would not hear unless
> there was a problem . . . . 6 -->(SKIP TO Q.24)
>
> Never found out results . . . . 7 -->(SKIP TO Q.24)
>
> Other (SPECIFY) 8

23b. Was everything OK or did they find a problem?

> Everything was OK 1
>
> There was a problem 2

24.   Where was this mammogram done?

RUSH Presbyterian Hospital 1

Professional Building 2

Anchor HMO 3

Other (SPECIFY) 4

_____

D:

| IF LAST MAMMOGRAM WAS PART OF A CHECKUP EXAM, ASK Q.25a. |
| IF NOT, SKIP TO Q.26a. |

25a.   Was this mammogram done on a different day than the rest of the checkup?

Yes 1

No . . . . 2 -->(SKIP TO Q.26a)

25b.   How long before or after the checkup was it done?

_____

26a. [In addition to the (NUMBER IN Q.9b3) breast examination(s) you already mentioned,] have you had any (other) breast examinations in the past five years, since (MONTH) 1987?

Yes 1

No . . . . 2 -->(SKIP TO BOX E)

.*26b. How many (other) breast examinations have you had?
(ENTER NUMBER HERE AND ON CHART.)

_____ breast examinations

*27a. In what month and year did you have [this breast exam/the most recent of the (NUMBER IN Q.26b) breast exams]? (ENTER HERE AND ON CHART.)

(IF UNABLE TO GIVE YEAR): Would you say that it was early in the last five years--1987 or '88, later than that--1989 or '90, or more recently--1991 or '92?
(IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the spring, the summer, or the fall?
(IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle, or the end of (those months/that season)?

_____

(KEEP ASKING FOR ALL BREAST EXAMS IN PAST 5 YEARS -- NUMBER IN Q.26b)

27b. What about the one before that? In what month and year was it?

(IF UNABLE TO GIVE YEAR): Would you say that it was early in the last five years--1987 or '88, later than that--1989 or '90, or more recently--1991 or '92?
(IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the spring, the summer, or the fall?
(IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle, or the end of (those months/that season)?

Breast Exam #

2) _____

3) _____

4) _____

5) _____

6) _____

28. Why did you get the breast examination in (DATE IN Q.27a)?

> Part of a routine checkup 1
>
> Because of symptoms 2
>
> As followup to previous problem . . 3
>
> Special event 4
>
> Other (SPECIFY) 5

E:

> CHECK SUMMARY SHEET FOR BREAST EXAMS.
>
> IF NO BREAST EXAMS, ASK Q.29a.
>
> IF 1 OR MORE BREAST EXAMS, SKIP TO Q.30.

29a. Just to confirm, you've said that you have not had a breast exam in the last five years. Is that correct?

> Yes . . . . 1 -->(SKIP TO Q.32a)
>
> No 2

*29b. In what month and year did you have your last breast exam? (ENTER DATE HERE AND ON CHART.)

---

*29c. How many breast examinations have you had in the past five years, since (MONTH) 1987? (ENTER NUMBER HERE AND ON CHART.)

> _____ breast exams
>
> DON'T KNOW 98

> SKIP TO Q.32a.

30. Just to confirm, you've said that in the last five years, since (MONTH) 1987, you have had the following breast exams: (READ NUMBER FOR EACH TYPE FROM CHART) for a total of (SUM) and the last one was (READ DATE OF LAST BREAST EXAM). Is that correct?

        Yes 1

        No . . . . 2 -->(MAKE CORRECTIONS
                                       ON SUMMARY CHART)

31. Was everything OK with your last breast exam or did they find a problem?

        Everything was OK 1

        There was a problem 2

32a. [In addition to the (NUMBER IN Q.9b4) blood stool test(s) you already mentioned,] have you had any (other) blood stool tests in the past five years, since (MONTH) 1987?

        Yes 1

        No . . . . 2 -->(SKIP TO BOX F, P.20)

*32b. How many (other) blood stool tests have you had?
      (ENTER NUMBER HERE AND ON CHART.)

        _____ blood stool tests

*33a. In what month and year did you have [this test/the most recent of
the (NUMBER IN Q.32b) tests]? (ENTER DATE HERE AND ON CHART.)

    (IF UNABLE TO GIVE YEAR): Would you say that it was early in the
        last five years--1987 or '88, later than that--1989 or '90, or
        more recently--1991 or '92?
    (IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter,
        the spring, the summer, or the fall?
    (IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the
        middle, or the end of (those months/that season)?

(KEEP ASKING FOR ALL OTHER BLOOD STOOL TESTS IN PAST 5 YEARS
--NUMBER IN Q.32b)

33b. What about the one before <u>that</u>? In what month and year was it?

    (IF UNABLE TO GIVE YEAR): Would you say that it was early in
        the last five years--1987 or '88, later than that--1989 or
        '90, or more recently--1991 or '92?
    (IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the
        winter, the spring, the summer, or the fall?
    (IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the
        middle, or the end of (those months/that season)?

<u>Blood Stool Test #</u>

2) _____

3) _____

4) _____

5) _____

6) _____

34. Why did you get the blood stool test in (DATE IN Q.33a)?

        Part of a routine checkup 1

        Because of symptoms 2

        As followup to previous problem . . 3

        Special event 4

        Other (SPECIFY) 5

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┌─────────────────────────────────────────────────┐
│ CHECK SUMMARY SHEET FOR BLOOD STOOL TESTS.       │
│                                                  │
│ IF NO BLOOD STOOL TESTS, ASK Q.35a.              │
│                                                  │
│ IF 1 OR MORE BLOOD STOOL TESTS, SKIP TO Q.36.    │
└─────────────────────────────────────────────────┘
```

F:

35a. Just to confirm, you've said that you have not had a blood stool test in the last five years. Is that correct?

Yes . . . . 1 -->(SKIP TO Q.38)

No 2

*35b. In what month and year did you have your last blood stool test? (ENTER DATE HERE AND ON CHART.)

_____

*35c. How many blood stool tests have you had in the past five years, since (MONTH) 1987? (ENTER NUMBER HERE AND ON CHART.)

_____ blood stool tests

DON'T KNOW 98

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┌─────────────────────┐
│ SKIP TO Q.37a.      │
└─────────────────────┘
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36. Just to confirm, you've said that in the last five years, since (MONTH) 1987, you have had the following blood stool tests: (READ NUMBER FOR EACH TYPE FROM CHART) for a total of (SUM) and the last one was (READ DATE OF LAST BLOOD STOOL TEST). Is that correct?

Yes 1

No . . . . 2 -->(MAKE CORRECTIONS
                                    ON SUMMARY CHART)

37a. How did you find out the results of your last blood stool test?

At next doctor's visit . . .

    Doctor told R (PROBE) 1

    R asked doctor/nurse 2

By letter 3

Doctor's office phoned R 4

R phoned doctor's office 5

Was told would not hear unless
there was a problem . . . . 6 -->(SKIP TO Q.38)

Never found out results . . . . 7 -->(SKIP TO Q.38)

Other (SPECIFY) 8

37b. Was everything OK or did they find a problem?

Everything was OK 1

There was a problem 2

38. Now I'd like to go back to Pap smear tests for a moment. How <u>useful</u> do you think Pap smear tests are for early detection of disease? Would you say . . .

Very useful, ... 1

Somewhat useful, or 2

Not very useful? 3

DON'T KNOW 8

39. How <u>painful</u> do you think Pap smear tests are? Would you say they are . . .

Very painful, ... 1

Somewhat painful, or 2

Not very painful? 3

DON'T KNOW 8

40. How <u>useful</u> do you think mammograms are for early detection of
disease? Would you say . . .

> Very useful, ... 1
>
> Somewhat useful, or 2
>
> Not very useful? 3
>
> DON'T KNOW 8

41. How <u>painful</u> do you think mammograms are? Would you say they
are . . .

> Very painful, ... 1
>
> Somewhat painful, or 2
>
> Not very painful? 3
>
> DON'T KNOW 8

42. How <u>useful</u> do you think blood stool tests are for early detection of
disease? Would you say . .

> Very useful, ... 1
>
> Somewhat useful, or 2
>
> Not very useful? 3
>
> DON'T KNOW 8

43. How much trouble do you usually have making an appointment to see the
doctor? Do you have . .

> A lot of trouble, ... 1
>
> Some trouble, or 2
>
> Not much trouble? 3

44. How much trouble do you usually have finding the time to go to the
doctor or get tests done? Do you have . .

> A lot of trouble, ... 1
>
> Some trouble, or 2
>
> Not much trouble? 3

45. How hard is it for you to travel to the doctor when you need to see one? Is it . . .

> Very hard, ... 1
>
> Somewhat hard, or 2
>
> Not very hard? 3

46. Do you keep any of the following kinds of records of your visits to the doctor? What about . . .

	Yes	No
a. A datebook or calendar?	1	2
b. A separate listing of medical dates?	1	2
c. Bills, checks or other financial records?	1	2
d. Any other kinds of records? (SPECIFY)	1	2

47a. Are you currently . . .

> Employed full time, ... 1 -->(SKIP TO Q.48a)
>
> Employed part time, or . . . . . 2 -->(SKIP TO Q.48a)
>
> Not employed at all? 3

47b. Are you . . .

> Retired, ... 1
>
> Disabled, ... 2
>
> Temporarily unemployed, ... 3
>
> A student, ... 4 -->(SKIP TO Q.49)
>
> Keeping house, or . . . . 5 -->(SKIP TO Q.49)
>
> Not employed and not looking for paid employment? . . . . . . 6 -->(SKIP TO Q.49)
>
> Other (SPECIFY) 7

(IF "RETIRED," "DISABLED," OR "TEMPORARILY UNEMPLOYED," ASK ABOUT MOST RECENT OCCUPATION):

48a. What (is/was) your main occupation or job title?

_____

_____

48b. What kind of work (do/did) you do, that is, what (are/were) your most important duties on the job?

_____

_____

48c. In what type of business or industry (is/was) this; that is, what product (is/was) made or what service (is/was) given?

_____

_____

49. What is the highest grade or year of school you have completed?

None 00

Elementary   01 02 03 04 05 06 07 08

High school 09 10 11 12

College 13 14 15 16

Some graduate school 17

Graduate or professional degree 18

50. What race do you consider yourself?

American Indian or Alaskan Native 1

Asian or Pacific Islander 2

Black, not of Hispanic origin 3

White, not of Hispanic origin 4

Hispanic 5

Other (SPECIFY) 6

51. In what year were you born?   19_____ _____

<u>(SHOW RESPONDENT THE RELEASE CONSENT FORM.)</u>

52. As part of our research, we would like your permission to review your records at the HMO. We will only be looking at the dates of various tests that you have had, to see how they match your recall of them. The information will be strictly confidential and we will never report any information in connection with your name.

    Please sign this consent form, print your name, and fill in today's date and your social security number. If any of your records might be listed under another name, please fill in that information on the lines provided.

                    Thank you very much for your cooperation.

TIME INTERVIEW ENDED: _____ _____ : _____ _____ (24-hour clock)

53. DID THE RESPONDENT USE ANY OF THE FOLLOWING TO HELP HER REMEMBER INFORMATION?

		<u>Yes</u>	<u>No</u>
a.	A datebook or calendar	1	2
b.	A separate listing of medical events	1	2
c.	Bills, checks or other financial records	1	2
d.	Anything else (SPECIFY)	1	2

    _____

    _____

INTERVIEWER COMMENTS:

_____

_____

_____

_____

_____

_____

4/28/92

COGNITIVE ASPECTS OF REPORTING HEALTH PROMOTION AND DISEASE PREVENTION ACTIVITIES

Survey Research Laboratory
University of Illinois

Survey Research Laboratory
University of Illinois
Cognitive Aspects

VERSION 4
SUMMARY CHART

<u>Number</u>   <u>Last Date</u>

<u>CHECKUPS</u>

(Q.8e)_____   (Q.8a)_____

<u>PAPS</u>

Checkups . . .   (Q.9b1)_____   (Q.9d1)_____

Other . . . . .   (Q.11b)_____   (Q.12a)_____

Confirmation
add-on . . . .   (Q.14c/15)_____   (Q.14b/15)_____

<u>MAMMOGRAMS</u>

Checkups . . .   (Q.9b2)_____   (Q.9d2)_____

Other . . . . .   (Q.18b)_____   (Q.19a)_____

Confirmation
add-on . . . .   (Q.21c/22)_____   (Q.21b/22)_____

<u>BREAST EXAMS</u>

Checkups . . .   (Q.9b3)_____   (Q.9d3)_____

Other . . . . .   (Q.26b)_____   (Q.27a)_____

Confirmation
add-on . . . .   (Q.29c/30)_____   (Q.29b/30)_____

<u>BLOOD STOOL TESTS</u>

Checkups . . . .   (Q.9b4)_____   (Q.9d4)_____

Other . . . . . . (Q.32b)_____   (Q.33a)_____

Confirmation
add-on . . . . .   (Q.35c/36)_____   (Q.35b/36)_____

133

TIME INTERVIEW BEGAN _____ _____ : _____ _____   (24-hour clock)

1. Would you say that your health, in general, is excellent, very good, good, fair, or poor?

                    Excellent 1

                    Very good 2

                    Good 3

                    Fair 4

                    Poor 5

2a. Have you had a health problem at any time in the past five years, that is since (MONTH) 1987, for which you consulted a doctor on a regular basis?

                    Yes 1

                    No . . . . 2 -->(SKIP TO Q.3a)

     2b. What was the problem?

          Breast-related (SPECIFY) 1

          _____

          Gynecologic or urinary-related (SPECIFY) . 2

          _____

          Other (SPECIFY) 3

          _____

          _____

3a. Have you had any (other) <u>major</u> illnesses or conditions at any time in the past five years for which you consulted a doctor?

               Yes 1

               No . . . . 2 -->(SKIP TO Q.4)

3b. What was the problem?

Breast-related (SPECIFY) 1

_____

Gynecologic or urinary-related (SPECIFY) . 2

_____

Other (SPECIFY) 3

_____

_____

4. Have you had a complete physical or gynecological (female) checkup in the <u>past five years</u>, since (MONTH) 1987?

               Yes 1

               No . . . . 2 -->(SKIP TO Q.11a, P.8)

5-7.   NOT ASKED

*8a. In what month and year did you have your <u>last</u> checkup?

    (IF UNABLE TO GIVE YEAR): Would you say that it was early in the last five years--1987 or '88, later than that--1989 or '90, or more recently--1991 or '92?
    (IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the spring, the summer, or the fall?
    (IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle, or the end of (those months/that season)?

_____

8b. How did you remember that date?

_____

_____

    (KEEP ASKING FOR ALL CHECKUPS IN PAST 5 YEARS)

8c. What about the one before <u>that</u>? In what month and year was it?

    (IF UNABLE TO GIVE YEAR): Would you say that it was early in the last five years--1987 or '88, later than that--1989 or '90, or more recently--1991 or '92?
    (IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the spring, the summer, or the fall?
    (IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle, or the end of (those months/that season)?

<u>Checkup #</u>

2) _____

3) _____

4) _____

5) _____

6) _____

8d. NOT ASKED

```
┌─────────────────────────────────────────┐
│                                         │
│   INTERVIEWER:  HAS R MENTIONED THE     │
│        NUMBER OF CHECKUPS YET?          │
│                                         │
│         Yes  . . . . .   1              │
│                                         │
│         No . . . . . .   2              │
│                                         │
└─────────────────────────────────────────┘
```

*8e.   (Then to confirm) How many complete physical or
         gynecological checkups have you had during the past five
         years? (ENTER NUMBER HERE AND ON CHART.)

         _____ checkups
         (IF "0" SKIP TO Q.11a, P.8)

         DON'T KNOW 98

9a. As part of your (NUMBER IN Q.8e) complete physical or gynecological checkup(s) in the past five years, have you had . . .

9b. How many times since 1987 have you had a (TEST) as part of your checkup(s)? (ENTER NUMBER HERE AND ON CHART.)

	<u>Yes</u>	<u>No</u>	<u>DK</u>
1) A <u>Pap smear test</u>--which is a routine test, often part of a pelvic examination, where the doctor used a swab to take a sample from the mouth of the womb or cervix?	1	2	8
2) A <u>mammogram</u>--an x-ray taken only of the breasts by a machine that pressed the breast against a plate?	1	2	8
3) (Besides the mammogram,) A <u>breast examination</u> by a doctor or medical assistant when the breast was felt for lumps? . . .	1	2	8
4) A <u>blood stool test</u> where a stool sample was put on a card, mailed or taken back to the doctor, and checked for blood? .	1	2	8

9b. answers:

_____ *

_____ *

_____ *

_____ *

(ASK QS.9b-e, IF APPLICABLE, BEFORE GOING ON TO NEXT TEST.)

| IF NUMBER OF TESTS IS GREATER THAN NUMBER OF CHECKUPS ON CHART (Q.8e), ASK Q.9c. | | IF DATE OF TEST IS MORE RECENT THAN MOST RECENT CHECKUP ON CHART (Q.8a) ASK Q.9e. |

9c. You said you've had (NUMBER IN Q.8e) checkups and (NUMBER IN Q.9b) (TESTS). Why was that? (IF INCORRECT, CHANGE ANSWERS.)

9d. In what month and year was the last (TEST) that was part of a checkup? (SEE PROBES BELOW.) (ENTER DATE HERE AND ON CHART.)

9e. You said your last checkup was in (DATE IN Q.8a) but this (TEST) was in (DATE IN Q.9d). Why is that? (IF INCORRECT, CHANGE ANSWERS.)

_____ _____ * _____
_____

_____ _____ * _____
_____ _____

_____ _____ * _____
_____ _____

_____ _____ * _____
_____

PROBES:

(IF UNABLE TO GIVE YEAR): Would you say that it was early in the last five years--
    1987 or '88, later than that--1989 or '90, or more recently--1991 or '92?
(IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the spring, the summer,
    or the fall?
(IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle, or the end of
    (those months/that season)?

10. Where was your <u>last</u> checkup done?

     RUSH Presbyterian Hospital 1

     Professional Building 2

     Anchor HMO 3

     Other (SPECIFY) 4

_____

11a. [In addition to the (NUMBER IN Q.9b1) Pap smear test(s) you already mentioned] have you had any <u>(other)</u> Pap smear tests in the <u>past five years</u>, since (MONTH) 1987?

             Yes 1

             No . . . . 2 -->(SKIP TO BOX A, P.10)

*11b. How many (other) Pap smear tests have you had?
     (ENTER NUMBER HERE AND ON CHART.)

     _____ Pap smear tests

*12a. In what month and year did you have [this test/the most recent of the (NUMBER IN Q.11b) tests]? (ENTER DATE HERE AND ON CHART.)

(IF UNABLE TO GIVE YEAR): Would you say that it was early in the last five years--1987 or '88, later than that--1989 or '90, or more recently--1991 or '92?
(IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the spring, the summer, or the fall?
(IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle, or the end of (those months/that season)?

(KEEP ASKING FOR ALL OTHER PAPS IN PAST 5 YEARS -- NUMBER IN Q.11b)

12b. What about the one before <u>that</u>? In what month and year was it?

(IF UNABLE TO GIVE YEAR): Would you say that it was early in the last five years--1987 or '88, later than that--1989 or '90, or more recently--1991 or '92?
(IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the spring, the summer, or the fall?
(IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle, or the end of (those months/that season)?

<u>Pap #</u>

2) _____

3) _____

4) _____

5) _____

6) _____

13. Why did you get the Pap smear test in (DATE IN Q.12a)?

Part of a routine checkup 1

Because of symptoms 2

As followup to previous problem . . 3

Special event 4

Other (SPECIFY) 5

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┌─────────────────────────────────────────┐
│ CHECK SUMMARY SHEET FOR PAPS.            │
│                                          │
│ IF NO PAPS, ASK Q.14a.                   │
│                                          │
│ IF 1 OR MORE PAPS, SKIP TO Q.15.         │
└─────────────────────────────────────────┘
```

A:

14a. Just to confirm, you've said that you have <u>not</u> had a Pap smear test in the last five years. Is that correct?

      Yes . . . . 1 -->(SKIP TO Q.18a, P.12)

      No 2

*14b. In what month and year did you have your <u>last</u> Pap smear test? (ENTER DATE HERE AND ON CHART.)

_____

*14c. How many Pap smear tests have you had in the <u>past five years</u>, since (MONTH) 1987? (ENTER NUMBER HERE AND ON CHART.)

    _____ Pap smear tests

    DON'T KNOW 98

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┌─────────────────────┐
│  SKIP TO Q.16a.     │
└─────────────────────┘
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15. Just to confirm, you've said that in the last five years, since (MONTH) 1987, you have had the following Pap smear tests: (READ NUMBER FOR EACH TYPE FROM CHART) for a total of (SUM) and the <u>last</u> one was (READ DATE OF LAST PAP). Is that correct?

      Yes 1

      No . . . . 2 -->(MAKE CORRECTIONS ON SUMMARY CHART)

16a. How did you find out the results of your last Pap smear test?
(CIRCLE ONLY ONE.)

        At next doctor's visit . . .

           Doctor told R (PROBE) 1

           R asked doctor/nurse 2

        By letter 3

        Doctor's office phoned R 4

        R phoned doctor's office 5

        Was told would not hear unless
        there was a problem . . . . 6 -->(SKIP TO BOX B)

        Never found out results . . . . 7 -->(SKIP TO BOX B)

        Other (SPECIFY) 8

_____

16b. Was everything OK or did they find a problem?

        Everything was OK 1

        There was a problem 2

B:

IF LAST PAP WAS PART OF A CHECKUP, ASK Q.17a.
IF NOT, SKIP TO Q.18a.

17a. Was this Pap smear test done on a different day than the rest of the checkup?

        Yes 1

        No . . . . 2 -->(SKIP TO Q.18a)

17b. How long before or after the checkup was it done?

_____

18a. [In addition to the (NUMBER IN Q.9b2) mammogram(s) you already mentioned,] have you had any (other) mammograms in the past five years, since (MONTH) 1987?

Yes 1

No . . . . 2 -->(SKIP TO BOX C)

*18b. How many (other) mammograms have you had?
(ENTER NUMBER HERE AND ON CHART.)

_____ mammograms

*19a. In what month and year did you have [this mammogram/the most recent of the (NUMBER IN Q.18b) mammograms]? (ENTER DATE HERE AND ON CHART.)

(IF UNABLE TO GIVE YEAR): Would you say that it was early in the last five years--1987 or '88, later than that--1989 or '90, or more recently--1991 or '92?
(IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the spring, the summer, or the fall?
(IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle, or the end of (those months/that season)?

_____

(KEEP ASKING FOR ALL OTHER MAMMOGRAMS IN PAST 5 YEARS -- NUMBER IN Q.18b)

19b. What about the one before that? In what month and year was it?

(IF UNABLE TO GIVE YEAR): Would you say that it was early in the last five years--1987 or '88, later than that--1989 or '90, or more recently--1991 or '92?
(IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the spring, the summer, or the fall?
(IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle, or the end of (those months/that season)?

Mammogram #

2) _____

3) _____

4) _____

5) _____

6) _____

144

20. Why did you get the mammogram in (DATE IN Q.19a)?

              Part of a routine checkup 1

              Because of symptoms 2

              As followup to previous problem . . 3

              Special event 4

              Other (SPECIFY) 5

              _____

C:

```
┌─────────────────────────────────────────────┐
│  CHECK SUMMARY SHEET FOR MAMMOGRAMS.          │
│                                               │
│  IF NO MAMMOGRAMS, ASK Q.21a.                 │
│                                               │
│  IF 1 OR MORE MAMMOGRAMS, SKIP TO Q.22.       │
└─────────────────────────────────────────────┘
```

21a. Just to confirm, you've said that you have <u>not</u> had a mammogram in the
     last five years. Is that correct?

              Yes . . . . 1 -->(SKIP TO Q.26a, P.16)

              No 2

     *21b. In what month and year did you have your <u>last</u> mammogram?   (ENTER
           DATE HERE AND ON CHART.)

           _____

     *21c. How many mammograms have you had in the <u>past five years</u>, since
           (MONTH) 1987?   (ENTER NUMBER HERE AND ON CHART.)

                      _____ mammograms

              DON'T KNOW 98

```
┌──────────────────────────┐
│   SKIP TO Q.26a, P.16.    │
└──────────────────────────┘
```

22. Just to confirm, you've said that in the last five years, since (MONTH) 1987, you have had the following mammograms: (READ NUMBER FOR EACH TYPE FROM CHART) for a total of (SUM) and the <u>last</u> one was (READ DATE OF LAST MAMMOGRAM). Is that correct?

Yes 1

No . . . . 2 -->(MAKE CORRECTIONS
                                                ON SUMMARY CHART)

23a. How did you find out the results of your last mammogram? (CIRCLE ONLY ONE.)

At next doctor's visit . . .

   Doctor told R (PROBE) 1

   R asked doctor/nurse 2

By letter 3

Doctor's office phoned R 4

R phoned doctor's office 5

Was told would not hear unless
there was a problem . . . . 6 -->(SKIP TO Q.24)

Never found out results . . . . 7 -->(SKIP TO Q.24)

Other (SPECIFY) 8

_____

23b. Was everything OK or did they find a problem?

Everything was OK 1

There was a problem 2

24. Where was this mammogram done?

        RUSH Presbyterian Hospital 1

        Professional Building 2

        Anchor HMO 3

        Other (SPECIFY) 4

D:
> IF LAST MAMMOGRAM WAS PART OF A CHECKUP EXAM, ASK Q.25a.
>
> IF NOT, SKIP TO Q.26a.

25a. Was this mammogram done on a different day than the rest of the checkup?

        Yes 1

        No . . . . 2 -->(SKIP TO Q.26a)

25b. How long before or after the checkup was it done?

26a. [In addition to the (NUMBER IN Q.9b3) breast examination(s) you already mentioned,] have you had any (<u>other</u>) breast examinations in the <u>past five years</u>, since (MONTH) 1987?

Yes 1
No . . . . . . 2 -->(SKIP TO BOX E)

*26b. How many (other) breast examinations have you had?
    (ENTER NUMBER HERE AND ON CHART.)

    _____ breast examinations

*27a. In what month and year did you have [this breast exam/the most recent of the (NUMBER IN Q.26b) breast exams]? (ENTER HERE AND ON CHART.)

    (IF UNABLE TO GIVE YEAR): Would you say that it was early in the last five years--1987 or '88, later than that--1989 or '90, or more recently--1991 or '92?
    (IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the spring, the summer, or the fall?
    (IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle, or the end of (those months/that season)?

_____

(KEEP ASKING FOR ALL BREAST EXAMS IN PAST 5 YEARS -- NUMBER IN Q.26b)

27b. What about the one before <u>that</u>? In what month and year was it?

    (IF UNABLE TO GIVE YEAR): Would you say that it was early in the last five years--1987 or '88, later than that--1989 or '90, or more recently--1991 or '92?
    (IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the spring, the summer, or the fall?
    (IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle, or the end of (those months/that season)?

<u>Breast Exam #</u>

2) _____

3) _____

4) _____

5) _____

6) _____

28. Why did you get the breast examination in (DATE IN Q.27a)?

> Part of a routine checkup 1
>
> Because of symptoms 2
>
> As followup to previous problem . . 3
>
> Special event 4
>
> Other (SPECIFY) 5
>
> _____

E:
> ```
> CHECK SUMMARY SHEET FOR BREAST EXAMS.
>
> IF NO BREAST EXAMS, ASK Q.29a.
>
> IF 1 OR MORE BREAST EXAMS, SKIP TO Q.30.
> ```

29a. Just to confirm, you've said that you have not had a breast exam in the last five years. Is that correct?

> Yes . . . . 1 -->(SKIP TO Q.32a)
>
> No 2

*29b. In what month and year did you have your last breast exam? (ENTER DATE HERE AND ON CHART.)

_____

*29c. How many breast examinations have you had in the past five years, since (MONTH) 1987? (ENTER NUMBER HERE AND ON CHART.)

> _____ breast exams
>
> DON'T KNOW 98

> ```
> SKIP TO Q.32a.
> ```

30. Just to confirm, you've said that in the last five years, since (MONTH) 1987, you have had the following breast exams: (READ NUMBER FOR EACH TYPE FROM CHART) for a total of (SUM) and the <u>last</u> one was (READ DATE OF LAST BREAST EXAM). Is that correct?

        Yes 1

        No . . . . 2 -->(MAKE CORRECTIONS
                                      ON SUMMARY CHART)

31. Was everything OK with your last breast exam or did they find a problem?

        Everything was OK 1

        There was a problem 2

32a. [In addition to the (NUMBER IN Q.9b4) blood stool test(s) you already mentioned,] have you had any (<u>other</u>) blood stool tests in the <u>past five years</u>, since (MONTH) 1987?

        Yes 1

        No . . . . 2 -->(SKIP TO BOX F, P.20)

*32b. How many (other) blood stool tests have you had?
(ENTER NUMBER HERE AND ON CHART.)

        _____ blood stool tests

*33a. In what month and year did you have [this test/the most recent of the (NUMBER IN Q.32b) tests]? (ENTER DATE HERE AND ON CHART.)

> (IF UNABLE TO GIVE YEAR): Would you say that it was early in the last five years--1987 or '88, later than that--1989 or '90, or more recently--1991 or '92?
>
> (IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the spring, the summer, or the fall?
>
> (IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle, or the end of (those months/that season)?

(KEEP ASKING FOR ALL OTHER BLOOD STOOL TESTS IN PAST 5 YEARS --NUMBER IN Q.32b)

33b. What about the one before that? In what month and year was it?

> (IF UNABLE TO GIVE YEAR): Would you say that it was early in the last five years--1987 or '88, later than that--1989 or '90, or more recently--1991 or '92?
>
> (IF UNABLE TO GIVE MONTHS OR SEASONS): Was it during the winter, the spring, the summer, or the fall?
>
> (IF UNABLE TO GIVE ONE MONTH): Was it toward the beginning, the middle, or the end of (those months/that season)?

Blood Stool Test #

2) _____

3) _____

4) _____

5) _____

6) _____

34. Why did you get the blood stool test in (DATE IN Q.33a)?

    Part of a routine checkup 1

    Because of symptoms 2

    As followup to previous problem . . 3

    Special event 4

    Other (SPECIFY) 5

```
┌─────────────────────────────────────────────────────┐
│  CHECK SUMMARY SHEET FOR BLOOD STOOL TESTS.           │
│                                                       │
F: │  IF NO BLOOD STOOL TESTS, ASK Q.35a.               │
│                                                       │
│  IF 1 OR MORE BLOOD STOOL TESTS, SKIP TO Q.36.        │
└─────────────────────────────────────────────────────┘
```

35a. Just to confirm, you've said that you have not had a blood stool test in the last five years. Is that correct?

Yes . . . . 1 -->(SKIP TO Q.38)

No 2

*35b. In what month and year did you have your last blood stool test? (ENTER DATE HERE AND ON CHART.)

---

*35c. How many blood stool tests have you had in the past five years, since (MONTH) 1987? (ENTER NUMBER HERE AND ON CHART.)

_____ blood stool tests

DON'T KNOW 98

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┌─────────────────────┐
│  SKIP TO Q.37a.      │
└─────────────────────┘
```

36. Just to confirm, you've said that in the last five years, since (MONTH) 1987, you have had the following blood stool tests: (READ NUMBER FOR EACH TYPE FROM CHART) for a total of (SUM) and the last one was (READ DATE OF LAST BLOOD STOOL TEST). Is that correct?

Yes 1

No . . . . 2 -->(MAKE CORRECTIONS
ON SUMMARY CHART)

37a. How did you find out the results of your last blood stool test?

        At next doctor's visit . . .

            Doctor told R (PROBE) 1

            R asked doctor/nurse 2

        By letter 3

        Doctor's office phoned R 4

        R phoned doctor's office 5

        Was told would not hear unless
        there was a problem . . . . 6 -->(SKIP TO Q.38)

        Never found out results . . . . 7 -->(SKIP TO Q.38)

        Other (SPECIFY) 8

        _____

37b. Was everything OK or did they find a problem?

            Everything was OK 1

            There was a problem 2

38. Now I'd like to go back to Pap smear tests for a moment. How <u>useful</u> do
    you think Pap smear tests are for early detection of disease? Would you
    say . . .

                Very useful, ... 1

                Somewhat useful, or 2

                Not very useful? 3

                DON'T KNOW 8

39. How <u>painful</u> do you think Pap smear tests are? Would you say they
    are . . .

                Very painful, ... 1

                Somewhat painful, or 2

                Not very painful? 3

                DON'T KNOW 8

40. How <u>useful</u> do you think mammograms are for early detection of disease? Would you say . . .

                    Very useful, ... 1

                    Somewhat useful, or 2

                    Not very useful? 3

                    DON'T KNOW 8

41. How <u>painful</u> do you think mammograms are? Would you say they are . . .

                    Very painful, ... 1

                    Somewhat painful, or 2

                    Not very painful? 3

                    DON'T KNOW 8

42. How <u>useful</u> do you think blood stool tests are for early detection of disease? Would you say . .

                    Very useful, ... 1

                    Somewhat useful, or 2

                    Not very useful? 3

                    DON'T KNOW 8

43. How much trouble do you usually have making an appointment to see the doctor? Do you have . .

                    A lot of trouble, ... 1

                    Some trouble, or 2

                    Not much trouble? 3

44. How much trouble do you usually have finding the time to go to the doctor or get tests done? Do you have . .

                    A lot of trouble, ... 1

                    Some trouble, or 2

                    Not much trouble? 3

45. How hard is it for you to travel to the doctor when you need to see one?
Is it . . .

        Very hard, ... 1

        Somewhat hard, or 2

        Not very hard? 3

46. Do you keep any of the following kinds of records of your visits to the
doctor? What about . . .

		Yes	No
a.	A datebook or calendar?	1	2
b.	A separate listing of medical dates?	1	2
c.	Bills, checks or other financial records?	1	2
d.	Any other kinds of records? (SPECIFY)	1	2

_____

47a. Are you currently . . .

        Employed full time, ... 1 -->(SKIP TO Q.48a)

        Employed part time, or . . . . . 2 -->(SKIP TO Q.48a)

        Not employed at all? 3

47b. Are you . . .

        Retired, ... 1

        Disabled, ... 2

        Temporarily unemployed, ... 3

        A student, ... 4 -->(SKIP TO Q.49)

        Keeping house, or . . . . 5 -->(SKIP TO Q.49)

        Not employed and not looking
for paid employment? . . . . . . 6 -->(SKIP TO Q.49)

        Other (SPECIFY) 7

_____

_____

(IF "RETIRED," "DISABLED," OR "TEMPORARILY UNEMPLOYED," ASK ABOUT MOST RECENT OCCUPATION):

48a. What (is/was) your main occupation or job title?

_____

_____

     48b. What kind of work (do/did) you do, that is, what (are/were) your most important duties on the job?

     _____

     _____

     48c. In what type of business or industry (is/was) this; that is, what product (is/was) made or what service (is/was) given?

     _____

     _____

49. What is the <u>highest</u> grade or year of school you have completed?

     None 00

     Elementary   01 02 03 04 05 06 07 08

     High school 09 10 11 12

     College 13 14 15 16

     Some graduate school 17

     Graduate or professional degree 18

50. What race do you consider yourself?

     American Indian or Alaskan Native 1

     Asian or Pacific Islander 2

     Black, not of Hispanic origin 3

     White, not of Hispanic origin 4

     Hispanic 5

     Other (SPECIFY) 6

51.   In what year were you born?   19_____ _____

(SHOW RESPONDENT THE RELEASE CONSENT FORM.)

52.   As part of our research, we would like your permission to review your
       records at the HMO. We will only be looking at the dates of various
       tests that you have had, to see how they match your recall of them. The
       information will be strictly confidential and we will never report any
       information in connection with your name.

       Please sign this consent form, print your name, and fill in today's date
       and your social security number. If any of your records might be listed
       under another name, please fill in that information on the lines
       provided.

                   Thank you very much for your cooperation.

TIME INTERVIEW ENDED: _____ _____ : _____ _____ (24-hour clock)

53.   DID THE RESPONDENT USE ANY OF THE FOLLOWING TO HELP HER REMEMBER
       INFORMATION?

	Yes	No
a. A datebook or calendar	1	2
b. A separate listing of medical events	1	2
c. Bills, checks or other financial records	1	2
d. Anything else (SPECIFY)	1	2

       _____

       _____

INTERVIEWER COMMENTS:

_____

_____

_____

_____

_____

_____

Medical Record Coding Instructions

General Instructions

* all sections of the medical record, including consultant reports, should be reviewed. Consultant reports are especially important if the patient has a breast lump, discharge from the breast, abnormal mammogram results, or undergoes a breast biopsy.

* please indicate if record appears to be incomplete for any time period since January 1, 1987.

* references to stool guaiac and hemocult tests, where stool samples are taken in the clinic, should <u>not</u> be counted as fecal blood tests, in which the patient is given a card to take home, place samples on, and mail back to the clinic.

Eligibility

* only patients who: (1) are females, (2) aged 50 or older, and (3) who have been enrolled with RUSH Anchor HMO since January 1, 1987 are eligible for this study.

* only patients meeting the above criteria have been sampled and interviewed. However, if you find evidence in the medical record that any patient has <u>not</u> been enrolled at the HMO since <u>at least</u> January 1, 1987, this record should be reported before any abstraction of it is done.

Examination Dates

* for each type of examination, both test reports (i.e., from Cytology or Radiology) and references to test results (i.e., "pap negative.") in physician notes, should be considered evidence a test was done. Record MD notes of test results verbatim. Do for all tests, regardless of whether findings are normal, abnormal, or inconclusive.

* for mammograms and fecal blood tests, all physician referrals for testing should be recorded, irrespective of whether there is evidence the test was ever completed.

* also for mammograms, read through all results to determine when the previous (if any) mammogram was performed. This often helps determine if any mammogram results are missing from the record.

* patient refusals to have tests done should also be recorded.

Number of Clinic Visits

* in counting number of visits per year to RUSH Anchor, stops in two or more clinics in the same day should be counted as a single visit.

* telephone calls should <u>not</u> be counted as clinic visits.

* regular visits for either chronic or acute conditions, and all follow-up visits after surgical procedures, should be counted as visits.

* instances in which the patient has an appointment but leaves before the physician sees her should <u>not</u> be counted as clinic visits.

* visits to pick up a prescription refill should <u>not</u> be counted as visits.

* psychiatric visits should also <u>not</u> be counted as visits.

revised: July 24, 1992.

General Matching

* There must be evidence in the chart, either a test result report (i.e., from Cytology or Radiology), or a references to the results in the physician's notes (i.e., "class II pap" of "mammogram okay"), before it can be assumed that a test was done. Evidence that the physician referred the patient for a test, in the absence of test results, is not sufficient (abstractors have been instructed to record referral dates as well as test dates). Only tests verified in this manner should be counted as part of the total number of tests done.

* When matching, differences between reported and actual test dates are to be recorded in months. When respondent reports are more recent than test results, the difference in months should be positive (i.e., if the chart says a test was done in August 1988, and the respondent says it was done in December 1988, the difference is +4 months). Likewise, when respondent reports are less recent than the test results, the difference in months should be recorded as negative (i.e., if the chart says test done in July 1991, and the respondent says January 1991, the difference is -6 months). An exact monthly match is codes as a difference of 0 months.

* When more than three tests or examinations are reported or abstracted for any given year, the first three tests received during that year should be matched and recorded on the matching form. All additional tests should be matched and recorded separately for future analyses.

* When a test is reported by the respondent, but there is no evidence of a corresponding test in the medical record, a "90" should be recorded.

* When a medical record provides the date of a test, and the respondent does not report a test that can be matched, a "91" should be recorded.

* When a test is reported by the respondent, but with the date unknown, and a possible matching test is found in the medical record, a "92" should be recorded.

* When a test is reported, but with the date unknown, and there is no potential matching test in the medical record, a "93" is recorded. This is recorded in the "floating" variable for the test in question, as the reference year (see below) is unknown.

* When both the respondent and the medical record agree that no tests of a particular type where done since January 1, 1987, a "94" is recorded in the "floating" variable for that test.

* When the respondent was <u>not</u> asked about a particular test, and no possible matching test is found, a "95" is recorded in the "floating" variable for that test.

* When a test is found in the medical record, and the respondent was <u>not</u> asked about having received such a test, then a "96" is recorded for the appropriate reference year.

* When respondent reports year of test only, a match should be coded as "97."

* If the respondent reports having a <u>specific</u> test/exam at a non-RUSH facility, delete reference to that test only.

* For patients that were discovered to have had <u>all</u> of their care provided at a facility other than Rush-Anchor, code "99" under each of the four floating variables.

<u>Reference Year</u>

* The reference year for matching is the year the respondent indicates an event took place. The only exceptions are when a test is recorded but there is no test report for that year. In such cases, the year of the test should be used as the frame of reference. For example, if a respondent reports a test in March 1991 and the record indicates that the test was done in December 1990, the match code (+3 months) is recorded for 1991, as the year reported by the respondent is considered the frame of reference. In contrast, if a medical record indicates a test done in 1989, but no tests are mentioned by the respondent that can be matched with this date, the frame of reference becomes the actual test date – 1989.

<u>Exact Dates Not Reported</u>

* when respondent provides season only, code Winter as January, Spring as April, Summer as July, and Autumn as October for purposes of matching.

* when respondent reports test as occurring "mid-year," code as July for purposes of matching.

* When a respondent gives a range of months during which a test or exam occurred, record the even-numbered month if a range of two months is given, and record the middle month if a range of three months is given.

Revised: September 9, 1992

Appendix II
Raw frequencies by outcome measures, tests, and year

Table I. Raw frequencies, by outcome measure, test, and year: 1987–92

Test	Matched data	False reports	Omissions	No test	Missing
			Number		
Pap smear					
1987–92	295	200	32	532	9
1987	34	30	13	100	1
1988	57	37	7	74	3
1989	60	43	7	64	4
1990	62	39	2	74	1
1991	58	41	3	76	0
1992	24	10	0	144	0
Breast exam					
1987–92	315	196	89	458	10
1987	27	28	27	96	0
1988	64	34	19	58	3
1989	67	36	16	56	3
1990	70	30	13	61	4
1991	66	46	7	59	0
1992	21	22	7	128	0
Mammogram					
1987–92	399	117	47	488	17
1987	29	17	19	112	1
1988	62	20	18	74	4
1989	84	24	3	62	5
1990	94	21	3	54	6
1991	94	27	1	56	0
1992	36	8	3	130	1

Table II. Percent distribution of response-quality measures and number and percent of respondents, by year, test, and outcome measure: 1987–92

Test and outcome measure	All years combined	1987	1988	1989	1990	1991	1992
Pap smears							
Number of respondents	1,059	177	175	174	177	178	178
				Percent distribution			
All measures	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Matched data	27.9	19.2	32.6	34.5	35.1	32.6	13.5
No test	50.2	56.5	42.3	36.8	41.8	42.7	80.9
False reports	18.9	16.9	21.1	24.7	22.0	23.0	5.6
Omissions	3.0	7.4	4.0	4.0	1.1	1.7	0.0
				Percent			
Reporting test	46.8	36.1	53.7	59.2	57.1	55.6	19.1
Test in records	30.9	26.6	36.6	38.5	36.2	34.3	13.5
Ratio	1.51	1.36	1.47	1.54	1.58	1.62	1.41
Breast exams							
Number of respondents	1,058	178	175	175	174	178	178
				Percent distribution			
All measures	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Matched data	29.8	15.2	36.5	38.3	40.2	37.0	11.8
No test	43.3	53.9	33.2	32.0	35.1	33.2	71.9
False reports	18.5	15.7	19.4	20.6	17.2	25.9	12.4
Omissions	8.4	15.2	10.9	9.1	7.5	3.9	3.9
				Percent			
Reporting test	48.3	30.9	55.9	58.9	57.4	62.9	24.2
Test in records	38.2	30.4	47.4	47.4	47.7	40.9	15.7
Ratio	1.26	1.02	1.18	1.24	1.20	1.54	1.54
Mammograms							
Number of respondents	1,047	173	174	173	172	178	177
				Percent distribution			
All measures	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Matched data	37.9	16.4	35.7	48.6	54.7	52.8	20.3
No test	46.4	63.3	42.5	35.8	31.4	31.5	73.4
False reports	11.1	9.6	11.5	13.9	12.2	15.2	4.5
Omissions	4.5	10.7	10.3	1.7	1.7	0.6	1.7
				Percent			
Reporting test	49.0	26.0	47.2	62.5	66.9	68.0	24.8
Test in records	42.4	27.1	46.0	50.3	56.4	53.4	22.0
Ratio	1.16	0.96	1.03	1.24	1.19	1.27	1.13
All procedures							
Number of respondents	3,164	528	524	522	523	534	533
				Percent distribution			
All measures	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Matched data	31.8	16.9	34.9	40.5	43.2	40.8	15.2
No test	46.7	57.9	39.3	34.8	36.1	35.8	75.4
False reports	16.2	14.1	17.4	19.7	17.3	21.3	7.5
Omissions	5.3	11.1	8.4	5.0	3.4	2.1	1.9
				Percent			
Reporting test	48.0	31.0	52.3	60.2	60.5	62.1	22.7
Test in records	37.1	28.0	43.3	45.5	46.6	42.9	17.1
Ratio	1.29	1.11	1.21	1.32	1.30	1.45	1.33

Table III. Percent distribution of response-quality measures and number and percent of respondents, by year, test, and test regularity: 1987–92

Test and outcome measure	All years combined	1987	1988	1989	1990	1991	1992
Pap smears received irregularly							
Number of respondents	765	128	126	125	128	129	129
Percent distribution							
All measures	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Matched data	20.1	13.3	23.8	24.0	27.3	24.0	8.5
No test	54.0	64.0	46.0	39.2	43.0	46.5	84.5
False reports	23.2	18.0	25.4	32.0	28.1	28.7	7.0
Omissions	2.7	4.7	4.8	4.8	1.6	0.8	0.0
Percent							
Reporting test	43.3	31.3	49.2	56.0	55.4	52.7	15.5
Test in record	22.8	18.0	28.6	28.8	28.9	24.8	8.5
Report-to-records ratio	1.90	1.74	1.72	1.94	1.92	2.12	1.82
Pap smears received regularly							
Number of respondents	210	35	35	35	35	35	35
Percent distribution							
All measures	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Matched data	67.1	48.6	77.1	85.7	77.1	77.2	37.1
No test	16.7	11.4	5.7	2.9	14.3	5.7	60.0
False reports	11.0	20.0	14.3	8.5	8.6	11.4	2.9
Omissions	5.2	20.0	2.9	2.9	0.0	5.7	0.0
Percent							
Reporting test	78.1	68.6	91.4	94.2	85.7	88.6	40.0
Test in record	72.3	68.6	80.0	88.6	77.1	82.9	37.1
Report-to-records ratio	1.08	1.00	1.14	1.06	1.11	1.07	1.08
Breast exams received irregularly							
Number of respondents	777	131	128	129	127	131	131
Percent distribution							
All measures	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Matched data	24.7	12.2	29.6	33.3	35.4	32.1	6.1
No test	46.7	59.5	36.7	36.4	37.0	34.4	75.6
False reports	23.2	19.1	25.8	25.6	23.6	30.5	14.5
Omissions	5.4	9.2	7.8	4.7	3.9	3.1	3.8
Percent							
Reporting test	47.9	31.3	55.4	58.9	59.0	62.6	20.6
Test in record	30.1	21.4	37.4	38.0	39.3	35.2	9.9
Report-to-records ratio	1.59	1.46	1.48	1.55	1.50	1.78	2.08
Breast exams received regularly							
Number of respondents	233	39	39	38	39	39	39
Percent distribution							
All measures	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Matched data	52.8	28.2	66.7	63.2	64.1	61.6	33.3
No test	20.2	25.6	7.7	2.6	15.4	15.4	53.8
False reports	6.9	7.7	2.6	7.9	0.0	15.4	7.7
Omissions	20.2	38.5	23.1	26.3	20.5	7.7	5.1
Percent							
Reporting test	59.7	35.9	69.3	71.1	64.1	77.0	41.0
Test in record	73.0	66.7	89.8	89.5	84.6	69.3	38.4
Report-to-records ratio	0.82	0.54	0.77	0.79	0.76	1.11	1.0
Mammograms received irregularly							
Number of respondents	688	116	113	114	112	117	116
Percent distribution							
All measures	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Matched data	30.3	14.6	26.5	35.1	44.6	48.7	12.9
No test	52.2	66.4	51.3	43.7	36.6	33.3	81.0
False reports	14.0	12.1	15.9	18.4	16.1	17.1	4.3
Omissions	3.5	6.9	6.2	2.6	2.7	0.9	1.7

Table III. Percent distribution of response-quality measures and number and percent of respondents, by year, test, and test regularity: 1987–92—Con.

Test and outcome measure	All years combined	1987	1988	1989	1990	1991	1992
				Percent			
Reporting test.	44.3	26.7	42.4	53.5	60.7	65.8	17.2
Test in record	33.8	21.5	32.7	37.7	47.3	49.6	14.6
Report-to-records ratio	1.31	1.24	1.30	1.42	1.28	1.33	1.18
Mammograms received regularly							
Number of respondents	297	50	50	48	49	50	50
				Percent distribution			
All measures	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Matched data	63.9	24.0	64.0	91.6	89.8	74.0	42.0
No test	21.2	54.0	10.0	2.1	4.1	12.0	50.0
False reports	7.1	0.0	4.0	6.3	6.1	14.0	6.0
Omissions	7.7	22.0	22.0	0.0	0.0	0.0	2.0
				Percent			
Reporting test.	71.0	24.0	68.0	97.9	95.9	88.0	48.0
Test in record	71.6	46.0	86.0	91.6	89.8	74.0	44.0
Report-to-records ratio	0.99	0.52	0.79	1.07	1.07	1.19	1.09

NOTE: Figures may not add to 100.0 because of rounding.

Table IV. Number and percent of respondents and percent distribution of response-quality measures, by test, questionnaire version, and year: 1987–92

Test, version, and outcome measure	All years combined	1987	1988	1989	1990	1991	1992
Pap smears							
Version 1:							
Number of respondents	306	51	51	51	51	51	51
			Percent distribution				
All measures.	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Matched data	27.7	19.6	31.4	31.3	37.2	31.4	15.7
No test	52.4	64.7	45.1	33.4	41.2	49.0	80.4
False reports.	17.3	13.7	19.6	29.4	19.6	17.6	3.9
Omissions	2.6	2.0	3.9	5.9	2.0	2.0	0.0
			Percent				
Reporting test	45.0	33.3	51.0	60.7	56.8	49.0	19.6
Test in record	30.3	21.6	35.3	37.2	39.2	33.4	15.7
Report-to-records ratio.	1.49	1.54	1.44	1.63	1.45	1.47	1.25
Version 2:							
Number of respondents	246	41	41	41	41	41	41
			Percent distribution				
All measures.	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Matched data	25.2	22.0	34.2	43.9	24.4	24.4	2.4
No test	52.4	51.2	46.3	22.0	48.8	56.1	90.3
False reports.	19.1	19.5	14.6	26.8	26.8	19.5	7.3
Omissions	3.3	7.3	4.9	7.3	0.0	0.0	0.0
			Percent				
Reporting test	44.3	41.5	48.8	70.7	51.2	43.9	9.7
Test in record	28.5	29.3	39.1	51.2	24.4	24.4	2.4
Report-to-records ratio.	1.55	1.42	1.25	1.38	2.10	1.80	4.0
Version 3:							
Number of respondents	221	37	37	36	37	37	37
			Percent distribution				
All measures.	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Matched data	29.4	16.2	37.8	41.7	29.8	35.2	16.2
No test	43.5	51.4	35.2	36.1	29.7	29.7	78.4
False reports.	23.9	21.6	24.3	22.2	37.8	32.4	5.4
Omissions	3.2	10.8	2.7	0.0	2.7	2.7	0.0
			Percent				
Reporting test	53.3	37.8	62.1	63.9	67.6	67.6	21.6
Test in record	32.6	27.0	40.5	41.7	32.5	37.9	16.2
Report-to-records ratio.	1.63	1.40	1.53	1.53	2.08	1.78	1.33
Version 4:							
Number of respondents	286	48	46	46	48	49	49
			Percent distribution				
All measures.	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Matched data	29.0	18.8	28.2	23.9	45.9	38.8	18.3
No test	51.4	56.2	41.4	54.3	45.8	34.7	75.6
False reports.	16.4	14.6	26.1	19.6	8.3	24.5	6.1
Omissions	3.2	10.4	4.3	2.2	0.0	2.0	0.0
			Percent				
Reporting test	45.4	33.4	54.3	43.5	54.2	63.3	24.4
Test in record	32.2	29.2	32.5	26.1	45.9	40.8	18.3
Report-to-records ratio.	1.41	1.14	1.67	1.67	1.18	1.55	1.33
Breast exams							
Version 1:							
Number of respondents	306	51	51	51	51	51	51

Table IV. Number and percent of respondents and percent distribution of response-quality measures, by test, questionnaire version, and year: 1987–92—Con.

Test, version, and outcome measure	All years combined	1987	1988	1989	1990	1991	1992
				Percent distribution			
All measures.	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Matched data	28.1	11.7	29.4	31.4	37.2	43.2	15.7
No test	45.1	60.8	45.1	35.3	54.3	31.3	58.8
False reports.	18.0	11.8	15.7	19.6	19.6	23.5	17.7
Omissions	8.8	15.7	9.8	13.7	3.9	2.0	7.8
				Percent			
Reporting test	46.1	23.5	45.1	51.0	56.8	66.7	33.4
Test in records.	36.9	27.4	39.2	45.1	41.1	45.2	23.5
Report-to-records ratio.	1.25	0.86	1.15	1.13	1.38	1.48	1.42
Version 2:							
Number of respondents	246	41	41	41	41	41	41
				Percent distribution			
All measures.	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Matched data	32.5	19.5	41.5	58.6	36.6	36.6	2.4
No test	41.1	48.8	31.6	14.5	29.3	39.0	83.0
False reports.	21.1	24.4	22.0	22.0	24.3	22.0	12.2
Omissions	5.3	7.3	4.9	4.9	9.8	2.4	2.4
				Percent			
Reporting test	53.6	43.9	63.5	80.6	60.9	58.6	14.6
Test in record	37.8	26.8	46.4	63.5	46.4	39.0	4.8
Report-to-records ratio.	1.42	1.64	1.37	1.27	1.31	1.50	3.04
Version 3:							
Number of respondents	220	37	37	35	37	37	37
				Percent distribution			
All measures.	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Matched data	32.8	13.5	40.6	37.1	45.9	35.1	24.3
No test	39.5	48.7	18.9	28.6	35.2	37.9	67.6
False reports.	17.7	18.9	18.9	25.7	10.8	27.0	5.4
Omissions	10.0	18.9	21.6	8.6	8.1	0.0	2.7
				Percent			
Reporting test	50.5	32.4	59.5	62.8	56.7	62.1	29.7
Test in record	42.8	32.4	62.2	45.7	54.0	35.1	27.0
Report-to-records ratio.	1.18	1.00	0.96	1.37	1.05	1.77	1.10
Version 4:							
Number of respondents	286	49	46	48	45	49	49
				Percent distribution			
All measures.	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Matched data	26.9	16.3	36.9	29.2	42.2	32.6	6.1
No test	46.2	55.1	32.7	45.8	35.6	26.6	79.7
False reports.	17.5	10.2	21.7	16.7	13.3	30.6	12.2
Omissions	9.4	18.4	8.7	8.3	8.9	10.2	2.0
				Percent			
Reporting test	44.4	26.5	58.6	45.9	55.5	63.2	18.3
Test in record	36.3	34.7	45.6	37.5	51.1	42.8	8.1
Report-to-records ratio.	1.22	0.76	1.29	1.22	1.09	1.48	2.26
Mammograms							
Version 1:							
Number of respondents	306	51	51	51	51	51	51
				Percent distribution			
All measures.	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Matched data	37.9	9.8	31.4	45.1	53.0	58.8	29.5
No test	50.3	76.5	56.9	41.2	31.3	31.4	64.6
False reports.	7.9	3.9	3.9	11.7	15.7	7.8	3.9
Omissions	3.9	9.8	7.8	2.0	0.0	2.0	2.0

Table IV. Number and percent of respondents and percent distribution of response-quality measures, by test, questionnaire version, and year: 1987–92—Con.

Test, version, and outcome measure	All years combined	1987	1988	1989	1990	1991	1992
				Percent			
Reporting test	45.8	13.7	35.3	56.8	68.7	66.6	33.4
Test in record	41.8	19.6	39.2	47.1	53.0	60.8	31.5
Report-to-records ratio	1.10	0.70	0.90	1.21	1.30	1.10	1.06
Version 2:							
Number of respondents	246	41	41	41	41	41	41
				Percent distribution			
All measures	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Matched data	40.3	26.8	34.2	58.6	56.1	51.2	14.6
No test	45.1	51.2	48.7	26.8	26.8	39.0	70.5
False reports	10.2	12.2	7.3	12.2	12.2	9.8	7.4
Omissions	4.4	9.8	9.8	2.4	4.9	0.0	7.4
				Percent			
Reporting test	50.5	39.0	41.5	70.8	68.3	61.0	22.0
Test in record	44.7	36.6	44.0	61.0	61.0	51.2	22.0
Report-to-records ratio	1.13	1.07	0.94	1.16	1.12	1.19	1.00
Version 3:							
Number of respondents	216	36	36	35	36	37	36
				Percent distribution			
All measures	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Matched data	39.8	13.9	52.8	42.8	61.1	43.3	25.0
No test	41.7	58.3	30.6	34.3	30.6	27.0	69.4
False reports	12.0	5.6	8.3	20.0	5.5	29.7	2.8
Omissions	6.5	22.2	8.3	2.9	2.8	0.0	2.8
				Percent			
Reporting test	51.8	19.5	61.1	62.8	66.6	73.0	27.8
Test in record	46.3	36.1	61.1	45.7	63.9	43.3	27.8
Report-to-records ratio	1.12	0.54	1.00	1.37	1.04	1.69	1.00
Version 4:							
Number of respondents	283	49	46	46	44	49	49
				Percent distribution			
All measures	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Matched data	34.6	16.3	28.2	47.9	50.0	55.1	12.2
No test	47.4	63.3	30.5	39.1	36.4	28.6	83.7
False reports	14.8	16.3	26.1	13.0	13.6	16.3	4.1
Omissions	3.2	4.1	15.2	0.0	0.0	0.0	0.0
				Percent			
Reporting test	49.4	32.6	54.3	60.9	63.6	71.4	16.3
Test in record	37.8	20.4	43.4	47.9	50.0	55.1	12.2
Report-to-records ratio	1.31	1.60	1.25	1.27	1.27	1.30	1.34
All tests combined							
Version 1:							
Number of respondents	918	153	153	153	153	153	153
				Percent distribution			
All measures	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Matched data	31.3	13.7	30.7	35.9	42.4	44.4	20.3
No test	49.2	67.3	49.0	36.6	37.3	37.3	67.9
False reports	14.4	9.8	13.1	20.3	18.3	16.3	8.5
Omissions	5.1	9.2	7.2	7.2	2.0	2.0	3.3
				Percent			
Reporting test	45.7	23.5	43.8	56.2	60.7	60.7	28.8
Test in record	36.4	22.9	37.9	43.1	44.4	46.4	23.6
Report-to-records ratio	1.26	1.03	1.16	1.30	1.37	1.31	1.22

Table IV. Number and percent of respondents and percent distribution of response-quality measures, by test, questionnaire version, and year: 1987–92—Con.

Test, version, and outcome measure	All years combined	1987	1988	1989	1990	1991	1992
Version 2:							
Number of respondents	738	123	123	123	123	123	123
				Percent distribution			
All measures.	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Matched data	32.7	22.7	36.6	53.7	39.0	37.4	6.5
No test	46.0	50.5	42.3	21.1	35.0	44.7	82.9
False reports.	16.8	18.7	14.6	20.3	21.1	17.1	9.0
Omissions	4.5	8.1	6.5	4.9	4.9	0.8	1.6
				Percent			
Reporting test	49.5	41.4	51.2	74.0	60.1	54.5	15.5
Test in record	37.2	30.8	43.1	58.6	43.9	38.2	8.1
Report-to-records ratio.	1.33	1.34	1.19	1.26	1.37	1.43	1.91
Version 3:							
Number of respondents	657	110	110	106	110	111	110
				Percent distribution			
All measures.	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Matched data	34.0	14.6	43.6	40.5	45.4	37.8	21.8
No test	41.5	52.7	28.2	33.1	31.9	31.6	71.8
False reports.	18.0	15.4	17.3	22.6	18.2	29.7	4.6
Omissions	6.5	17.3	10.9	3.8	4.5	0.9	1.8
				Percent			
Reporting test	52.0	30.0	60.9	63.1	63.6	67.5	26.4
Test in record	40.5	31.9	54.5	44.3	49.9	38.7	23.6
Report-to-records ratio.	1.28	0.94	1.12	1.42	1.27	1.74	1.12
Version 4:							
Number of respondents	855	146	138	140	137	147	147
				Percent distribution			
All measures.	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Matched data	30.2	17.1	31.2	33.6	46.0	42.2	12.3
No test	48.3	58.2	34.8	46.4	39.4	29.9	85.5
False reports.	16.2	13.7	24.6	16.4	11.7	23.8	1.5
Omissions	5.3	11.0	9.4	3.6	2.9	4.1	0.7
				Percent			
Reporting test	46.4	30.8	55.8	50.0	57.7	66.0	13.8
Test in record	35.5	28.1	40.6	37.2	48.9	46.3	13.0
Report-to-records ratio.	1.31	1.10	1.37	1.34	1.18	1.43	1.06

NOTE: Figures may not add to 100.0 because of rounding.

Table V. Net bias and gross error in reporting of dates of preventive care tests for matched events, by test and year: 1988–92

Test and year	Net bias[1]	Gross error	Number
		Months	
All tests combined			
1992	1.0	1.8	80
1991	0.8	3.3	187
1990	0.4	3.4	196
1989	0.7	4.2	161
1988	1.4	3.9	143
Average	0.8	3.5	767
Pap smears			
1992	0.8	1.3	23
1991	0.2	2.5	53
1990	0.1	3.4	51
1989	1.4	5.0	38
1988	1.8	4.1	43
Average	0.8	3.4	208
Breast exams			
1992	0.1	2.6	20
1991	1.5	4.0	48
1990	0.4	3.6	59
1989	1.0	4.1	56
1988	1.4	3.4	51
Average	1.1	3.7	234
Mammograms			
1992	0.9	1.6	37
1991	0.7	3.4	86
1990	0.6	3.2	86
1989	0.1	4.2	67
1988	1.1	4.1	49
Average	0.6	3.8	325

[1]A positive value indicates that respondents report test dates more recent than record shows.

Table VI. Net bias and gross error in reporting of dates of preventive care tests for matched events, by year and version of questionnaire: 1988–92

Year and version	Net bias	Gross error	Number
		Months	
All years combined:			
Version 1	1.3	3.2	216
Version 2	0.9	3.0	180
Version 3	0.6	4.3	189
Version 4	0.8	2.8	182
1992:			
Version 1	0.8	1.0	32
Version 2	−0.2	1.0	8
Version 3	2.1	3.7	23
Version 4	0.5	1.1	17
1991:			
Version 1	−0.4	3.0	52
Version 2	0.7	3.1	43
Version 3	1.2	3.5	41
Version 4	1.2	3.5	51
1990:			
Version 1	0.9	3.7	54
Version 2	−0.1	3.0	40
Version 3	−0.4	4.5	45
Version 4	1.2	3.5	43
1989:			
Version 1	1.3	5.7	41
Version 2	1.8	3.8	49
Version 3	−0.9	4.6	38
Version 4	0.1	2.8	33
1988:			
Version 1	2.2	4.3	37
Version 2	1.3	2.8	36
Version 3	1.2	5.2	42
Version 4	0.7	2.7	28

Vital and Health Statistics
series descriptions

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For answers to questions about this report or for a list of reports published in these series, contact:

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