

## Medical Source Refusals in the 1980 National Natality and Fetal Mortality Surveys

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Researchers utilizing mail surveys are frequently anxious about response rates. In an ongoing survey such as the 1980 National Natality Survey (NNS) and National Fetal Mortality Survey (NFMS) where a source may be contacted repeatedly, an individual's reply, "I do not want to participate and do not bother me again," raises serious concerns. In the 1980 NNS and NFMS, Questionnaires were mailed to mothers, physicians, and hospitals for each case in the sample. In these surveys, one case in the sample referred to one pregnancy outcome, one live birth or one fetal death; thus, a medical source may have been associated with several cases. Unfortunately, some medical providers refused to participate in the 1980 NNS and NFMS and indicated that they did not want to receive any more questionnaires. These sources were placed on a HOLD -DO NOT CONTACT AGAIN list. Since these surveys represented a national sample of live births and fetal deaths, and since hospitals and physicians often accounted for several births or fetal deaths in the sample, these refusing medical sources had an important impact on the survey response rates.

The purpose of this paper is to answer some questions about these refusing medical sources, and to make some recommendations to improve response rates for similar surveys in the future. Who were these medical sources? Did they affect response rates? What reasons did they give for refusing to participate?

### METHOD

The survey methodology for the 1980 NNS and NFMS have been described in detail by Placek (1984) and Weinberg and Placek (1984). The data sources for these surveys included mothers, physicians, and hospitals. This paper will deal only with hospitals and physicians named on the birth certificate or report of fetal death.

One new technique employed in these surveys was the use of a consent statement from the mother authorizing the release of her medical records. Married mothers were asked to sign and date a consent statement (CS) at the end of the mail questionnaire. When a CS was available, a copy of it was mailed to the mother's medical source. The use of these CS's was found to be significantly related to the medical source response rates (Simpson, 1983).

Data Collection began in May 1980 and ended in February 1982. Questionnaires were mailed to mothers as soon as their addresses were encoded from the certificates.

There were two sets of mailing procedures for medical sources. Medical sources for married mothers were mailed questionnaires as soon as a CS was received from the mother, or after all followups for the mother were exhausted. Medical sources for unmarried mothers were mailed questionnaires as soon as the addresses were received.

Although most medical sources returned completed questionnaires, some of them indicated that they did not want to participate in these surveys, and that they did not want to receive any more questionnaires. Since this type of response had not been anticipated, there was no method of identifying all the cases associated with an individual hospital or physician on the computer. The names could have been complete, incomplete or even misspelled when taken from the vital records, and existing computer programs could only search for exact matches. Since these data were continuously forwarded from the states, a HOLD -DO NOT MAIL TO AGAIN list was established. This list was used by mailers who manually checked it against all outgoing mailing labels which sometimes numbered in the thousands. Whenever a mailer identified a label as representing a source on the HOLD list, the case was not mailed, but was closed out as a refusal. This procedure was time consuming and subject to error.

Soon another problem developed with the medical sources. When the mother did not respond, or if the mother was unmarried, her medical sources were mailed to without a CS. Some medical sources began replying that they would only provide data when the questionnaire was accompanied by a CS. They requested NCHS not mail to them without a CS. These medical sources were placed on a second HOLD list - MAIL TO ONLY IF ACCOMPANIED BY A CONSENT STATEMENT (CS). Mailers also checked these sources against outgoing mailing labels and were instructed not to mail to these cases unless a CS was available.

Before being placed on either HOLD list, each case was assessed individually. When a source was added to one of the HOLD lists, the list was updated and distributed to the mailing staff.

Furthermore, when a source was assigned to the HOLD list, there was no established procedure to record the reason. Some of the letters and notes from medical sources were filed. These records provide the reasons for refusals given in this report. Although these data are incomplete, they are valuable because they may indicate the reasons other sources failed to respond.

The data used for this report are from a preliminary 1980 NNS and NFMS data tape and not from the final 1980 NNS and NFMS data tape. Individual hospitals were identified by their American Hospital Association (AHA) number. Those with no AHA number and physicians were identified by their name and address. Computer programs were run to identify the number of cases for each hospital by state. For more detailed analysis, medical sources on the HOLD lists were matched manually to the individual survey cases using zip codes to narrow identification. Response and CS status were recorded on data sheets and calculated manually for these cases.

It is important to understand the difference between the number of hospitals or physicians and the number of cases. A case refers to one pregnancy outcome, one live birth or one fetal death in the sample. Thus, one hospital may represent several cases since more than one live birth or fetal death in the sample may have occurred there. This paper discusses both the number of hospitals and physicians, and the number of cases involved in the surveys.

## FINDINGS

### Hospitals

As shown in Table 1, there are 97 hospitals on HOLD list 1 (DO NOT CONTACT AGAIN). These hospitals represent 2.7 percent of all surveyed hospitals, but they include 1027 or 6.0 percent of the hospital cases in the surveys. HOLD list 2 (MAIL TO ONLY IF ACCOMPANIED BY A CS) contains 95 hospitals representing 2.6 percent of the hospitals in the surveys and accounting for 1008 cases or 5.9 percent of all cases in the surveys. Hospitals on HOLD list 1 and 2 account for a total of 11.9 percent of the cases in the surveys; thus, almost 12 percent of the cases were involved in these HOLD lists and may have required special manual and time consuming procedures.

The majority of medical sources were placed on the HOLD lists toward the end of the surveys. Three hospitals and four physicians were placed on HOLD list 1 in

1980. HOLD list 2 was not needed until January 1981. Over one-half of all of the medical sources on the HOLD lists were placed on the list between July and December 1981.

Table 2 shows the number and percent of hospitals and the cases they represent on HOLD list 1. In only a few states were there more than 4 percent of the hospitals on HOLD list 1: Rhode Island, Maryland, the District of Columbia, Mississippi, Nevada and California.

There are greater differences among the states in the proportion of cases on HOLD list 1. These differences range from 0 for states where there are no hospitals on the HOLD list to 24.8 percent of all cases in Mississippi where 5 hospitals are on the HOLD list. In the Northeast, one hospital on Hold list 1 in Connecticut represents 15.7 percent of all cases for that state. Iowa and Michigan, in the North Central region, have 2 and 4 hospitals respectively on the HOLD list 1 representing 9.3 and 10.3 percent of the cases for their respective states. In the South, states with a high proportion of cases represented on this list beside Mississippi, include Maryland, the District of Columbia, Georgia, and Tennessee. Also, three western states have a high proportion of cases represented on this HOLD list: Idaho, Nevada, and California. Thus, some of these hospitals represent a disproportionately large number of cases for their states.

Hospitals on HOLD list 1 may have received more questionnaires than other hospitals. According to Table 3, the average number of cases per hospital on HOLD list 1 is more than twice as high as the average number of cases per sample hospital, that is 10.6 versus 4.7. Once these hospitals were placed on the HOLD list, they should not have received any more questionnaires; thus, while the hospitals on HOLD list 1 represented more cases than the survey hospitals, not all of these cases represent mailed questionnaires.

The most common reason for refusing, given by 45.4 percent of the hospitals that were placed on HOLD list 1, was that they

**Table 1**  
**Total Number of Delivery Hospitals and Delivery Hospital Cases**  
**on HOLD list 1 and 2 for the 1980 NNS and NFMS**

	Number of hospitals	Percent of hospitals	Number of cases	Percent of cases
Total in Survey	3637	100.0	17096	100.0
HOLD list 1	97	2.7	1027	6.0
HOLD list 2	95	2.6	1008	5.9
<b>Total</b>	<b>192</b>	<b>5.3</b>	<b>2035</b>	<b>11.9</b>

**Table 2**  
**Number and Percent of Hospitals and their Cases in the 1980**  
**NNS and NFMS on HOLD list 1 by Region and State**

	Total number of hospitals in the survey	Percent of hospitals on HOLD list 1	Total number of cases in the survey	Percent of cases for hospitals on HOLD list 1
<b>Northeast</b>				
Massachusetts	56	1.8	304	1.3
Rhode Island	9	11.1	64	3.1
Connecticut	34	2.9	172	15.7
New York	190	2.1	1234	6.0
New Jersey	75	4.0	330	6.4
Pennsylvania	177	3.9	816	8.8
<b>Total Northeast</b>	<b>602</b>	<b>2.8</b>	<b>3085</b>	<b>6.5</b>
<b>North Central</b>				
Ohio	143	2.8	842	4.3
Indiana	92	1.1	393	.5
Illinois	172	3.5	967	3.8
Michigan	115	3.5	427	10.3
Wisconsin	96	2.1	348	3.2
Minnesota	92	1.1	293	1.7
Iowa	80	2.5	226	9.3
Missouri	94	2.1	410	.9
Kansas	61	1.6	195	5.1
<b>Total North Central</b>	<b>4359</b>	<b>3.9</b>	<b>170</b>	<b>3.9</b>
<b>South</b>				
Maryland	37	8.1	233	15.5
Dist. of Columbia	10	20.0	107	17.8
Virginia	67	1.5	263	2.3
South Carolina	62	3.2	301	4.0
Georgia	103	3.9	557	15.1
Florida	115	2.6	647	3.9
Tennessee	80	2.5	404	10.9
Alabama	82	3.7	358	8.9
Mississippi	69	7.2	274	24.8
Arkansas	55	3.6	209	6.2
Louisiana	81	3.7	406	6.4
Oklahoma	71	1.4	258	1.2
Texas	266	1.5	1239	4.0
<b>Total South</b>	<b>1299</b>	<b>2.7</b>	<b>6218</b>	<b>6.7</b>
<b>West</b>				
Idaho	31	3.2	72	13.9
Colorado	57	3.5	255	2.0
Utah	27	3.7	198	8.6
Nevada	9	11.1	68	10.3
Washington	61	1.6	266	7.5
Oregon	47	2.1	197	5.1
California	321	4.7	1830	9.3
<b>Total in West</b>	<b>695</b>	<b>3.2</b>	<b>3434</b>	<b>7.0</b>
<b>Total in survey</b>	<b>3637</b>	<b>2.7</b>	<b>17096</b>	<b>6.0</b>

\*Totals in Columns 1 and 3 include states where no hospitals are on HOLD list 1.

lacked the resources (time, staff, money) to participate. Other reasons given were:  
 policy - do not participate in surveys  
 doubt value, purpose of the survey  
 questionnaire is too long  
 tired of receiving questionnaires

#### Hospitals on HOLD list 2

Similar to the hospitals on HOLD list 1, only a few states have over 4 percent of

their survey hospitals on HOLD list 2. (These figures are shown in Table 4.) These include Delaware, where one hospital represents 20 percent of the sample of hospitals for the state, and the District of Columbia, where four hospitals equal 40 percent of the sample hospitals.

There is again, however, greater variation in the percentage of cases represented by the hospitals on HOLD list 2

**Table 3**  
Average Number of Cases per Hospital for Survey Hospitals in the 1980 NNS and NFMS and for those on HOLD list 1 by Region

	Average number of cases per survey hospital	Average number of cases per HOLD list 1 hospital
Northeast	5.1	11.8
North Central	4.2	7.4
South	4.8	11.9
West	4.9	10.9
<b>Total</b>	<b>4.7</b>	<b>10.6</b>

by state. This percentage ranges from 0 for states with no hospitals on list 2 to 68.3 percent for the hospital in Delaware. Other states with a high percentage of cases represented by hospitals on HOLD list 2 include Vermont, Ohio, Illinois, Missouri, the District of Columbia, Tennessee, Louisiana, Idaho, Nevada, and Washington.

Also, as with the hospitals on HOLD list 1, the hospitals on HOLD list 2 were eligible to receive more questionnaires than the other survey hospitals. The overall average number of cases per hospital in the surveys is 4.7; the average number of cases per hospital on HOLD list 2 is 10.6.

### Physicians

Overall, physicians were the poorest responders in the surveys with final response rates of 64.3 percent in the NNS and 57.9 percent in the NFMS. (See Table 6.) Seventy-three physicians on HOLD list 1 represent 122 cases. The average number of cases for physicians on HOLD list 1 is 1.7. There is no method of identifying cases associated with individual physicians in the survey, other than what would be an extremely time consuming process of individually matching physicians with thousands of cases.

The most common reason recorded for physicians being placed on HOLD list 1 is "lack of time," followed by "wanted payment". Physicians also gave the following reasons:

- doubt value and purpose of survey
- tired of receiving questionnaires
- data are confidential -do not want to release it

There are only 8 physicians on HOLD list 2 representing 11 cases with an average of 1.4 cases per physician.

**Table 4**  
Percent of Hospitals and their Cases in the 1980 NNS and NFMS on HOLD HOLD list 2 by Region and State

	Percent of hospitals on HOLD list 2	Percent of cases for hospitals on HOLD list 2
<b>Northeast</b>		
Vermont	8.3	9.7
Massachusetts	1.8	4.3
Rhode Island	11.1	6.3
New York	3.7	8.7
New Jersey	2.7	2.1
Pennsylvania	4.5	7.6
<b>Total Northeast</b>	<b>3.3</b>	<b>6.4</b>
<b>North Central</b>		
Ohio	3.5	9.7
Indiana	3.3	3.8
Illinois	5.2	9.6
Michigan	2.6	2.6
Wisconsin	2.1	2.3
Minnesota	1.1	2.1
Iowa	1.3	1.3
Missouri	6.4	18.5
Kansas	1.6	3.1
<b>Total North Central</b>	<b>3.0</b>	<b>6.9</b>
<b>South</b>		
Delaware	20.0	68.3
Maryland	2.7	5.2
Dist. of Columbia	40.0	57.0
Virginia	3.0	3.8
South Carolina	1.6	2.7
Georgia	2.9	7.0
Florida	.9	1.7
Kentucky	2.9	7.1
Tennessee	2.5	17.1
Mississippi	4.3	6.9
Arkansas	1.8	2.9
Louisiana	6.2	12.3
Texas	3.0	5.6
<b>Total South</b>	<b>2.6</b>	<b>6.5</b>
<b>West</b>		
Idaho	6.5	15.3
Nevada	11.1	23.5
Washington	3.3	9.0
Oregon	2.1	8.1
California	1.3	2.2
<b>Total in West</b>	<b>1.4</b>	<b>3.1</b>
<b>Total in Survey</b>	<b>2.6</b>	<b>5.9</b>

### DISCUSSION AND CONCLUSIONS

While there is no way of knowing the percentage of physician cases involved on the HOLD lists from the surveys, approximately 12 percent of the hospital cases were related to the HOLD lists. Thus, 12 percent of the cases may have required special time consuming manual procedures for the mailing staff. Six percent of the cases were related to HOLD list 1 in which the hospital refused to participate at all. The

**Table 5**  
**Average Number of Cases per Hospital**  
**for Survey Hospitals in the 1980 NNS and NFMS**  
**and for those on HOLD list 2 by Region**

Region	Average number of cases per survey hospital	Average number of cases per hospital on HOLD list 2
Northeast	5.1	9.8
North Central	4.2	9.7
South	4.8	11.9
West	4.9	10.7
<b>Total</b>	<b>4.7</b>	<b>10.6</b>

hospitals on HOLD list 2 said they would respond when they were sent a CS. These hospitals had an important impact on the overall response rates of the 1980 NNS and NFMS.

For the most part, state and regional differences among the hospitals on HOLD list 1 are minimal.

However, some of the hospitals on HOLD list 1 are key hospitals because they represent a large portion of cases for their state. Also, overall, the hospitals on HOLD list 1 average more cases per hospital, and thus, potentially could have received more questionnaires than the other hospitals in the survey. The main reason given by these hospitals for their refusal is lack of resources (time, staff, money); however, hospitals on HOLD list 1 represent an average of almost 11 cases or questionnaires each (not counting followup questionnaires). It may be that hospitals with limited resources willing to respond to 1 or 2 questionnaires were overwhelmed by 6 or 7 questionnaires to the point where they declined to participate further. The same patterns appear for the hospitals on HOLD list 2 (MAIL TO ONLY IF ACCOMPANIED BY A CONSENT STATEMENT (CS)). In general, state and regional differences do not exist among the number of hospitals, but some of the hospitals represent a large proportion of the sample of births or fetal deaths for their state. For example, one hospital in Delaware represents 68.3 percent of the cases for the state, and four hospitals in the District of Columbia have 57.0 percent of the cases there.

There are fewer physicians than hospitals on both HOLD lists. The two most important reasons stated by physicians on HOLD list 1 are lack of time and lack of monetary compensation. Private physicians may not have the staff available to respond. Also, the average number of cases per physician on HOLD list 1 is only 1.7 compared with an average of almost 10.6 cases per hospital. Since the physicians were not overwhelmed

**Table 6**  
**Final Response Rates from the 1980 NNS and NFMS**

	NNS	NFMS
Mothers	79.5	74.5
Hospitals	77.6	76.3
Physicians	64.3	57.9

Note: This data is from final 1980 NNS and NFMS tape.

with questionnaires, they may not have felt that the surveys warranted an explanation for refusing.

Also, physicians do not appear to be as concerned about consent statements as the hospitals are. There are only 8 physicians on HOLD list 2. However, the use of the consent statement was significantly related to higher physician response rates (Simpson, 1983).

The following are recommendations or alternative considerations to improve future survey response rates:

1. Establish some control or measure to limit the number of cases per hospital. This would have to be incorporated in the sample design of the survey. An average of 11 cases per hospital places a heavy burden on the hospital.

2. If the number of cases per hospital can not be limited, investigate the possibility of monetary compensation. The Department of Health and Human Services prohibits financial compensation to respondents, but exceptions are allowed if the data collection requires significant work and effort on the part of the respondents, and equity would justify reimbursement.

3. Mail all cases to all medical sources at the same time. Medical providers would know from the beginning the total participation expected from them. Since the medical data is taken from medical records, there would be no loss due to lack of recall. Also, hospitals accounting for a large number of cases could be identified before mailing questionnaires, and if approved, could be offered monetary reimbursement.

4. After the data collection is completed and some analysis has been done, contact medical sources that participated in the surveys by letter, and thank the hospitals that participated. Give references of published reports and emphasize important findings from the data.

5. If possible, contact unmarried mothers for a CS. Many states did not allow contact with unmarried mothers; thus, they were excluded from the surveys and their medical sources were contacted without CS's.

Perhaps these mothers could be contacted simply to sign a consent for a national health survey for medical data for a given time period without mention of any pregnancy or pregnancy outcome.

6. In planning future surveys, include important findings from the 1980 NNS and NFMS with publication references in or with the cover letter. Also mention endorsements from professional associations.

7. Try to give the illusion of a shorter questionnaire. The hospital questionnaire had 3 pages which were only answered if the patient had certain tests or x-rays. Make pages for additional information clearly stand out as such, for example, by marking clearly FOR ADDITIONAL INFORMATION ONLY.

These findings are bound by limitations. First, the data used for this report are from a preliminary data tape. Also, there were no formal procedures to record the reasons for refusals, and these findings do not deal with the possible effects of the birth outcome (live birth or fetal death) or marital status of the mother on the medical sources' decision not to participate. However, hopefully these data provide some insight into the problem of medical source refusals and implementation of some of the above ideas will reduce the need for HOLD lists in the future.

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