

**EVALUATION OF NIOSH NOTIFICATIONS, TASK II**  
**DEVELOPMENT OF AN APPROACH FOR ROUTINELY EVALUATING**  
**CURRENT NIOSH NOTIFICATIONS**

**Report on Trial #2**  
**September 1996**

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## Report on Trial #2

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**PART I: INTRODUCTION**

This report is part of a two-tiered project designed to help the National Institute for Occupational Safety and Health (NIOSH) evaluate its programs related to high-risk worker notification. Task I of the project, which examines the long-term impact of a notification/ screening program carried out by NIOSH in the early 1980s, is being reported separately.

Task II, the focus of this report, deals with the agency's current notifications. Task II aims not at research per se, but rather at developing a practical tool for routinely monitoring the notification process. NIOSH presently provides the research subjects in worker health studies with information about study results as a matter of routine policy. The purpose of Task II is to develop and test procedures and instruments for evaluating these current NIOSH notifications, focusing in particular on those that involve the sending of individual letters to study subjects.

The agency's present method of monitoring its current notifications relies on "bounceback" cards -- brief evaluation survey forms printed on postage-paid postcards included with the notification materials. This approach is low-cost and convenient, but like all subject-initiated feedback, it unavoidably suffers from selection bias and may fail to reflect the full range of responses. In addition, it gives no insight into the reactions of other stakeholder groups (for example, employers and union officials) involved in the notification. The picture emerging from subject-initiated bounceback cards is a very partial one, likely to omit exactly the information that would help most for quality control and program improvement.

Task II aims to develop and test a practical way for agency staff to cast a somewhat wider net in getting feedback related to current notifications. The goal is to strengthen the evaluation approach, while remaining realistic about the amount of staff time and effort actually available to carry out evaluations. The evaluation approach needs to be modest in terms of the time and resources required; sharply focused on issues of programmatic concern to the agency; and suited to use by the agency's own staff on a routine basis.

As explained in an earlier report, Task II has been planned as a multi-stage project with three separate data-gathering efforts, referred to in this report as "trials." Each trial centers on a different notification effort, selected by the NIOSH Project Officer from among the letter notifications recently carried out by the agency.

Trial #1 dealt with a notification related to talc exposure at Gouverneur Talc Company (GTC) in New York. Preceded by a period of planning and consultation with agency notification staff, this effort represented an exploratory pilot of the proposed evaluation methodology. It allowed the contractor to try out and refine working drafts of the instruments to be used in telephone interviews; to test how well NIOSH's contact information lends itself to doing random telephone surveys; to gather interview data from 25 randomly selected workers in the notified cohort, with attention to any problems that arise in data collection logistics or worker cooperation; to contact representatives of selected stakeholder groups so as to discover the best procedures and any issues or problems associated with getting their input; and to experiment with different formats for reporting the results succinctly. Results of Trial #1 (described in a Report dated May 1996) have been discussed with the NIOSH Project Officer and other agency staff.

Trial #2, the subject of this report, reflects some changes suggested by the experience of Trial #1. Trial #2 serves as an opportunity for the contractor to test these modified procedures; to work out any further rough spots in the methodology for gathering the evaluation data; and to develop clear guidelines for analyzing and reporting the evaluation findings. As before, the results will be discussed by the contractor and agency personnel. If the results of Trial #2 show a need for further changes in procedures, these will be made in preparation for Trial #3.

The plan is then for Trial #3 to test the evaluation methodology as used by agency staff, with only indirect support from the outside contractor. The forms and procedures will be used by Trial #3's notification officer exactly as they would be applied in routine practice, with the outside contractor's role limited to monitoring this process and documenting any problems or concerns that arise. Based on this experience, possibly reflecting further changes, a final version of all forms and procedures will then be recommended to the agency as a standard tool for routine evaluation of all letter notifications in the future.

## PART II: PROCESS USED IN TRIAL #2

Several notifications were considered by the Project Officer as possible focal points for Trial #2. The case finally selected -- a letter notification on Halowax exposure at a Habirshaw (Phelps Dodge Corporation) plant in Yonkers, NY -- was chosen in part because its differences from the Trial #1 case would help in making the evaluation procedures broadly applicable. In contrast to Trial #1, the Trial #2 notification involved a very large cohort of workers, many of whom are now separated from the plant. Also, the Trial #2 notification used a different array of materials, and was carried out by a different NIOSH notification officer than Trial #1.

In summer of 1996 the Halowax notification was designated as the target for Trial #2, and the cohort list (with addresses but not telephone numbers) supplied to the contractor. Worker interviews and stakeholder interviews for Trial #2 were carried out by telephone primarily during July and August 1996.

This section of the present report focuses on the process used in collecting and analyzing the Trial #2 data. The findings from the Trial #2 data are presented separately in a later section of this report, in a format that might serve as a model for the agency's routine evaluation reports.

### A. Process of Interviewing Stakeholders

In Trial #1, one of the key stakeholders (representing the employer) had been very distressed that he was not informed about the evaluation prior to the worker interviews. Building on this experience, we made certain to contact the stakeholders first in Trial #2 -- not for permission to interview the notified workers (NIOSH policy is clear on that point) but as a courtesy. Introductory letters were sent to the stakeholders identified by NIOSH as participants in the tripartite review, followed up within two weeks by telephone calls from the contractor.

This process seemed to work very well in terms of diplomacy, with the employer representatives in particular expressing appreciation for the early contact. However, we did encounter some other complications that will probably be common in these stakeholder contacts.

For example, both Trial #1 and Trial #2 suggest that some difficulty in locating and securing interview time with stakeholder informants is to be expected, and should be considered normal. Almost by definition, these are people with very busy schedules; simply establishing a time for the telephone interviews takes considerable perseverance.

Also, some of those on the list may turn out to have played marginal roles in the notification. This is actually an important finding to note, since it gives NIOSH a reality

check on whether the tripartite review process is serving as an effective means of stakeholder participation in notification.

As in Trial #1, the Trial #2 stakeholder interviews were built around a set of guiding questions used in a very flexible fashion, taking varying amounts of time. One interview lasted well over an hour because of the respondent's enthusiasm for communicating his ideas. If the discussion is kept narrowly focused on the stakeholder's opinions on the particular notification in question, as it probably should be for routine evaluation purposes, these interviews should run about fifteen minutes each.

In terms of reporting format, some careful consideration is needed. The present report presents the stakeholder interview content in considerable detail, in the form of narrative summaries developed from notes taken during the telephone conversation. This approach -- used by the contractor because the interview content is interesting and potentially useful -- seems too time-consuming to be practical for NIOSH staff on a routine basis.

The contractor recommends a much simpler approach for stakeholder interviews in Trial #3:

- a. **Treat the contact not as a structured interview, but simply as a conversation** aimed at getting the stakeholder's overall reaction to the process used in the notification and any problems that were observed. This should help in keeping the contact short and to the point. The pre-structured guide prepared for Trials #1 and #2 is not really needed. The interview can be built around a simple starting point such as "Please tell me what you think about the process used in NIOSH's notification on \_\_\_\_\_," followed by conversational probes as needed to get a full reaction.
- b. **Record the respondent's comments as notes taken during the interview, and immediately afterwards condense these into a very short (one paragraph) summary sharply focused on reactions to the notification process itself.** If there are interesting general comments that go beyond the evaluation of the particular notification, these could be written up separately and used for other purposes -- but need not be included in the evaluation itself.
- c. **Because of the potential sensitivities involved, calls to the stakeholders should be made by senior NIOSH staff only.** Respect seems to be a big issue here. The stakeholder calls definitely should not be made by secretarial staff.
- d. The issue of whether a notification officer should make these stakeholder calls on his/her own notifications has been raised, as a possible problem of asking for your own work to be evaluated. The contractor would argue that asking for feedback

on your own work is not a bad thing, and communicates an openness to constructive criticism that is in fact very healthy in an organization. It's done all the time in other organizational contexts. In any case, it's the process rather than the individual notification officer that is being evaluated, so it shouldn't really matter if a staff member gathers the stakeholder feedback on his/her own project.

However, there may be other advantages in having the stakeholder calls made by appropriate agency administrators rather than by notification staff. The stakeholder interviews do tend to have broader policy implications that go beyond the particular evaluation, that would be of administrative interest; it would in part answer concerns that might still be raised about objectivity; and it would help with stakeholder sensitivity about being treated with due respect. So in general, my advice would be to **consider having all stakeholder interviews done by an appropriate NIOSH administrator**. There aren't very many of these calls in terms of numbers, so the time involved is not major -- and it would be good internal quality control as well as helping NIOSH administrators monitor the complicated climate of public opinion surrounding the agency's work.

- e. **However much the procedures may be streamlined and modified, do not drop the stakeholder input or leave it out of the final notification report.** This input represents a critically important part of the overall evaluation; without the full range of interest groups represented, assessment of the notification would be very incomplete. In particular, critical reactions from employers need to be noted -- not as a weakness in the notification, but as part of full documentation and a source of potential ideas for better protecting worker health in future notification efforts.

## **B. Process of Interviewing Workers**

As in Trial #1, in Trial #2 we oversampled considerably from the worker cohort list in order to end up with the desired 25 telephone contacts. However, this time the need for oversampling proved to be even more extreme.

We (i.e., the contractor and research assistants) started out by randomly selecting 50 names from the list of 9028 notified individuals. Telephone numbers were then sought for these individuals by calling the information operator in the locations indicated for each worker -- an approach that Trial #1 had showed to be the quickest and most practical. Excluding those for whom no telephone number could be found reduced the sample size to about 40. Introductory letters (see Appendix C) were sent out to these 40 individuals. This more or less paralleled the process used in Trial #1, except that we deliberately made the numbers larger to allow for the higher attrition anticipated in this elderly cohort.

As the interviewing got underway, however, some surprises emerged. For one thing, it became clear that we had still not oversampled enough. Many individuals on the list had disconnected phones or could not be reached by telephone despite at least 8 attempts at different calling times. Refusals were much more numerous in this cohort, amounting to 7 (19% of those we called) as compared to only 2 in Trial #1. We also found several individuals willing but too ill to grant an interview, and one sample member had died since the notification -- something not encountered in Trial #1. We went back to the cohort list and randomly drew additional names as needed, eventually ending up with a total of 75 required to yield the desired 25 contacts.

Thus Trial #2 reinforces one of the lessons of Trial #1: **In aiming for 25 worker interviews, oversample to start with and expect about half of the names selected to be non-reachable by telephone.** Among older cohorts where refusals are more likely, it would be prudent to randomly select even more names (in this case, we needed three times as many as the 25 desired).

Even more surprising, we found many individuals who had worked in the plant and were willing to be interviewed, but who had no recollection of ever receiving the notification materials. In fact, among the 25 randomly selected workers we contacted, 11 of them (44%) fell into this category. This unexpected finding is in fact quite useful for evaluation purposes, where the purpose is to assess the notification process rather than to get a certain amount of "complete data" from subjects. Therefore, rather than dropping out these non-remembering individuals and replacing them with others, we considered them an important part of the 25 worker contacts.

Whether or not to consider non-remembering workers as part of the 25 contacts may need further discussion. In the Trial #1 calls we encountered only one person in this category, and at that time (as explained in the Trial #1 report) we chose to drop that individual from the sample as an anomaly. However, the large proportion of such individuals showing up in Trial #2 casts a different light on the issue. The contractor now recommends that such individuals be retained in the sample, even if (actually, especially if) they constitute a large part of the total. Discovering such surprises is exactly what the evaluation is supposed to do. Tempting as it might be to keep going with new names in order to get 25 completed interviews, to do so would disguise a possible problem with the notification's mailing coverage and thereby defeat the whole purpose of evaluation. It seems more responsible (as well as more realistic in terms of agency resources) for the guideline to be: **limit the telephone contacts to 25 reachable and willing respondents, and simply report the results whatever they turn out to be.**

**In Trial #3 (and in subsequent routine evaluations), the contractor recommends keeping a log of all calls made to workers, and including in the evaluation report a summary of contact and attrition patterns similar to the one in this report (see page 13).**

The actual process of interviewing workers for Trial #2 proved smooth and uneventful. As in Trial #1, each interview took only about 15 minutes to complete (although a number of time-consuming callbacks were sometimes needed to connect in the first place). In both trials so far, the worker interviews have been carried out by graduate-level social workers with considerable experience both in field research and in human services. However, the interview questions and format seem fairly easy to use and hopefully would work for interviewers without this background. Trial #3 will serve as a test of whether available NIOSH staff encounter any problems with the instrument.

One area that might need some practice or training is exactly how much the NIOSH staff member should try to jot down by way of worker comments, in addition to marking the pre-structured responses. Brief comments are very helpful in terms of interpreting the coded responses, but only relevant comments should be written down (workers are likely to offer much broader commentary than is needed).

### C. Analyzing the Evaluation Data

Once the telephone data have been collected, they need to be condensed into a clear, concise format for presentation in a brief Evaluation Report on the notification, to accompany (or become part of) the Final Report on a routine basis. This section describes how the analysis was done in Trial #2, and gives some suggestions for Trial #3 where the procedures are to be tested for practicality in regular agency practice.

#### Stakeholder Data

The reporting format used in Trial #2 (**and recommended for Trial #3**) is a brief description of stakeholder contact attempts and outcomes in terms of process, followed by a short "Summary of Stakeholder Feedback" outlining the main substantive points that emerged in the content of the stakeholder interviews. The content summary is intended to be an interpretation, not a raw account of everything that was said. Therefore the summary emphasizes the points with the most use-value, and does not attempt to include or enumerate every point made by those interviewed.

In the Trial #2 report, as in the earlier Trial #1 report, detailed narrative notes from the stakeholder interviews themselves are also provided in the Appendix section in order to give a flavor of the discussion. While it would be nice to have detailed narratives of this kind in the routine reports, they are very time-consuming to reconstruct from the notes jotted down during the interview. **In Trial #3, it's probably more realistic to have the interviewer simply take rough notes during the interview and then prepare the brief summary of stakeholder feedback directly from these notes.** Preparing elaborate narrative versions of the interviews should be considered optional, to be done only if time allows and if the content was important enough to justify the extra effort.

## Worker Data

As mentioned earlier, an unexpected and very interesting finding in Trial #2 was that almost half the randomly selected workers we contacted did not remember ever receiving the NIOSH notification materials. The evaluative report on the worker data begins by describing this pattern, which seems quite important for evaluation purposes.

Next, the Trial #2 worker data were analyzed separately for the non-remembering workers and for the workers who completed the interview.

It seems likely that the Halowax cohort had an unusually high proportion of non-remembering workers, more than would be found in the typical notification, because their exposures occurred over 50 years ago; the cohort is by now quite elderly and unlikely to regard the exposure as an urgent health concern. However, whatever the proportion of non-rememberers might turn up in future evaluations, the two-part analysis format seems useful; we recommend its use for Trial #3. Organizing the data this way gives a clearer picture of the notification's coverage, serving as a valuable reality check for the agency on how well the notification actually reached the cohort it was sent to.

Data from the non-remembering workers is reported in list format, giving the circumstances of each respondent as recorded by the interviewer, in order to shed some light on what may have happened to the notification materials originally sent to them. This information is presented in raw form in an Appendix, with a brief interpretations incorporated into the evaluative summary.

The data from the completed interviews take a little more processing. In Trial #2 we report these data in three ways:

- (1) As "raw data" in the form of question-by-question response tabulations along with transcribed comments, used as a base to develop (2) and (3) and included in the report as an Appendix.
- (2) As a brief narrative evaluative summary of the main response patterns, along with some interpretations.
- (3) As an evaluative scorecard showing how the workers' modal responses match up with the desired response patterns (i.e., those responses that would suggest a successful notification).

**These three formats seem useful in different ways. The contractor recommends keeping all three as part of the routine evaluation report.**

In Trial #3, the NIOSH staff member should first develop the "raw data" report from the completed interview forms, using something like the analysis tools and guidelines supplied in Appendix B of this report. This becomes the basis for the rest of the analysis.

The NIOSH staff member should then carefully review this raw data report for overall patterns and anything especially interesting or worth noting, and write up the brief narrative evaluative summary of worker feedback. The summary should not repeat every detailed finding, since that is available in the raw data report. Instead, the summary should be more interpretive, briefly assessing how well this notification worked and discussing any useful ideas or insights suggested by the interviews.

The next step, the evaluative scorecard, is an attempt to take the evaluation somewhat beyond simple description in order to maximize its usefulness. What the scorecard does is to match up the modal responses actually given by the interviewed workers with the pattern of responses desired by the agency in terms of intended outcomes. This allows for a quick assessment of where the notification was strongest and where the notification process might need improvement. Because of the (necessarily) small sample size, the scorecard should not be seen as quality control -- merely as a source of evaluative ideas that might be useful.

**Step by step, here is the procedure for analyzing the completed worker interviews, as used in Trial #2.**

First, prepare the "raw data" report:

- a. Using the "Analysis Grid" supplied in Appendix B of this report, go through the stack of completed interviews and **tally the pre-coded response items marked for each question.** (It's quicker to work through each interview form from start to finish, rather than going through the whole stack question by question.)
- b. Use another copy of the "Analysis Grid" to **convert the tally marks into numerical frequencies** for the pre-coded response items on each question.
- c. Using yet another copy of the "Analysis Grid," for each question **compute the percentage that the frequency for each pre-coded response item represents of total responses** for that question.
- d. **Transcribe all comments recorded by the interviewer, question by question.**
- e. **Then transfer the frequencies, percentages, and comments on to a single copy of the interview schedule. On each question, circle the frequency that indicates the modal response(s).** Once completed, this consolidated form constitutes the "raw data" part of the evaluative report. In the routine evaluations this should go as an

appendix to the evaluation report, so as not to swamp the body of the report with too much undigested detail.

Second, prepare the evaluative summary:

- a. Based on the consolidated "raw data" form, **develop a brief narrative summary of worker feedback to go into the body of the evaluation report.** In addition to noting main patterns and highlighting any interesting or unexpected responses, the summary might include some worker comments if they raise substantive suggestions or ideas. The brief summary is meant to be interpretive, and should not simply duplicate the descriptive "raw data" on worker feedback.

Third, prepare the evaluative scorecard:

- a. Based on the consolidated "raw data" form, **use the modal responses on each question to fill out the Evaluative Scorecard** using the form supplied in Appendix B of this report. The scorecard organizes workers' responses in terms of how closely they match the desired pattern (the response pattern that would appear in a "successful" notification). Marking whether the modal responses from the worker interviews do or do not conform to the desired pattern ("yes" they fit or "no" they don't fit) gives a sense of where that particular notification was strongest, and where improvements in the notification process might be most useful in the future.
- b. Remember: Because of the (necessarily) small sample size, **the scorecard should not be seen or used as quality control** -- merely as a source of evaluative ideas that might be useful.

Keep in mind that in order to be useful, the overall evaluation report needs to **stay short, focused, and easy to prepare.**

## **PART III: EVALUATION FINDINGS FROM TRIAL #2**

The findings from Trial #2 are presented here in a format that could serve as a model for Trial #3 and subsequent routine evaluations.

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### **Halowax Notification: Evaluation Report**

#### **A. Background**

This report gives evaluation results for NIOSH's worker notification on Halowax exposure at a Habirshaw (Phelps Dodge Corporation) plant in Yonkers, NY. The Halowax notification follows from NIOSH's investigation of possible associations between exposure to chlorinated naphthalenes (CNs) and certain types of cancer and liver disease. The research in question was a records-based mortality study of 9,028 males and females employed at the Yonkers plant during the period 1940 to 1944, where they were potentially exposed to Halowax (the trade name of the CN product being used to insulate electrical cable at the plant). This was not a participatory study. However, because the data showed a sharply elevated risk of cirrhosis of the liver and some increase for certain cancers, individual letters were chosen as the appropriate method for worker notification of the study results.

Notification materials in this case consisted of the following items:

1. A four-page letter describing the findings of the relevant NIOSH research. The letter came in two versions, one for cohort members known to have had chloracne, and one for cohort members not known to have had chloracne. Both versions contained a toll-free NIOSH telephone number with an invitation to call with any questions.
2. Five color-coded enclosures:
  - a. A one-page (front and back) information sheet containing the following action advice to protect health: talk to your doctor, consider reducing or ending alcohol use, avoiding other liver toxins, quitting use of tobacco products, and dental exams for oral cancer.
  - b. A one-page (front and back) information sheet describing the Halowax study and its major findings, written in non-technical language using a question and answer format.

- c. A four-page information sheet with more detailed information on the study and its health implications, again written in non-technical language.
  - d. A list of Occupational and Environmental Clinics located around the country.
  - e. A four-page technical information sheet intended for the worker's doctor, giving details on the health effects of CN exposure; a summary of the NIOSH study results; and suggested procedures for evaluation, treatment and screening of patients with possible CN exposure.
3. A postage-paid postcard with a check-off survey and space for comments, to be mailed in as a "bounceback" response.

As specified in the agency's procedural guidelines, a tripartite review took place prior to the notification itself. Drafts of the notification materials were sent to representatives of management and representatives of the workers' union, and some comments were received back. The notification materials themselves were sent out in August of 1995. As noted in the Notification Officer's final report, the worker responses received through bounceback cards and telephone calls to NIOSH were generally quite positive.

The present evaluation is based on telephone interviews carried out in summer of 1996 with 25 workers selected randomly from the notified cohort and two stakeholder representatives.

### **B. Worker Responses**

From the notification cohort list of 9028 workers, 75 names were randomly selected (in waves, as needed) to yield 25 telephone contacts with workers willing to be interviewed. Clearly a random sample this small has little claim to representativeness in a scientific sense. However, it is a practical approach to gaining evaluative feedback from notified workers in a form less biased by self-selection than the feedback from bounceback cards.

The worker sample in Trial #2 proved relatively hard to reach and had higher refusal rates than encountered in Trial #1. Unexpectedly, a large proportion (11, or 44%) of the 25 workers willing and able to grant an interview claimed they had no recollection of ever receiving the notification materials. These reactions may in part be a reflection of the unusually advanced age and health infirmity of the cohort. While the NIOSH studies on Halowax were fairly recent, the exposures themselves had occurred some 50 years earlier during World War II. The surviving cohort members are therefore all quite elderly; workers in their 20s at the time of exposure would now be in their 70s.

Because of the long time lapse, the notified workers do not seem to regard their Halowax exposures as an urgent health concern.

Overall, the sampling and attrition patterns for the workers in Trial #2 were as follows:

- 75 = total number of names drawn from cohort list
- 39 = unreachable
  - 23 = telephone number unavailable or disconnected
  - 15 = no answer after 8 attempts to call
  - 1 = deceased
- 11 = reached but no interview
  - 3 = willing but too ill
  - 7 = refused
  - 1 = claimed never worked in the plant
- 25 = reached and willing to grant interview
  - 14 = interview completed
  - 11 = reported never receiving notification

### **Summary of Worker Feedback**

The raw data on which the following summary is based can be found in the Appendix section.

Based on the completed interviews, the Halowax notification appears to have been very well received by workers. In terms of the content and format of the materials, they really liked this notification. This dimension of notification effectiveness -- worker satisfaction -- has historically been the main focus of NIOSH evaluative effort and constitutes the core of the content on the bounceback cards.

However, looking at other dimensions of effectiveness, the notification had some problematic areas. For example, workers' understanding and retention of the factual information given them was poor, and in general they neither remembered nor acted on the preventive advice contained in the material. (This pattern also showed up somewhat in Trial #1, where workers failed to remember the notification's advice for disease prevention; they had a better retention of the hazard information, but the reason is probably that most of the Trial #1 workers reported already knowing about the hazard from other sources before being notified by NIOSH.)

This aspect of NIOSH's notification -- impact on knowledge and health behavior -- has rarely been examined. In any case, it is hard to say what level of information retention should be considered "success." Judging from health education literature, expectations should not be set unrealistically high. Still, the low level of information retention found in Trial #2 suggests that more thought needs to be given to the underlying purpose of NIOSH's worker notification. Is the point only to present information in a way that the study subjects find satisfactory and non-alarming, thereby meeting the agency's obligation to disclose research findings? Or is it to communicate information and advice for secondary disease prevention in a way that sticks in the worker's mind and might motivate behavior with an actual health payoff?

If the goal is even partially to have a public health impact, thought needs to be given to ways of making the critical secondary disease prevention information contained in the notification stand out more clearly. As suggested in the report on Trial #1, this might be done by making the notification letter itself more sharply focused on such information, using a checklist format for the prevention advice, using graphics, and highlighting key items with color or in boxes. Enclosing a wallet-sized card containing the key health-relevant information and advice, along with the NIOSH telephone number, might also be considered. By roughly monitoring the "impact" dimension of effectiveness, the routine notification evaluations could become a very useful tool for assessing the relative utility of these different approaches.

Another problematic dimension of effectiveness in the Trial #2 notification was coverage. Almost half (44%) of the randomly selected workers did not recollect ever receiving the NIOSH notification materials. Given the advanced age and relative infirmity of the cohort, this may reflect the workers' own attitudes about not opening their mail. However, some of those who could not remember being notified were honestly baffled as to why -- since they were very interested, routinely opened all their mail, and had been reached by the evaluation letter at the same address used for the original notification. Whether the letter failed to reach them or they simply failed to open it, there may be a better approach for getting fuller coverage in future notifications -- either by solving the NIOSH mailing problem if there is one, or by making the letter more appealing to open by using colored envelopes or printing something eye-catching on the outside.

None of the workers reported any problems caused by the notification. All who received the materials were glad to have gotten them, and several who had not received the materials requested a copy. While the workers clearly liked the idea of the bounceback cards and NIOSH information number, the majority made no use of either.

### Evaluative Scorecard Based on Worker Responses

What follows is a tentative attempt to develop a notification "success" rating.

EVALUATIVE SCORECARD BASED ON WORKER RESPONSES

	<u>Desired Response</u>	<u>Modal Response</u>	<u>Do they Match?</u> <u>YES NO</u>	
<u>DID THE NOTIFICATION CONNECT?</u>				
% who report receiving info	> 80%	<u>56%</u>	<u>  </u>	<u>  </u> ✓
Q1: Info seen as important	1 or 2	<u>  1  </u>	<u>  </u> ✓	<u>  </u>
Q2: Risk info was new	2	<u>  2  </u>	<u>  </u> ✓	<u>  </u>
Q3: Was read carefully	1 or 2	<u>  1  </u>	<u>  </u> ✓	<u>  </u>
<u>WAS THE CONTENT RETAINED AND/OR USED?</u>				
Q4: Remembers health effects	1	<u>  2  </u>	<u>  </u>	<u>  </u> ✓
Q5: Remembers action advice	1	<u>  2  </u>	<u>  </u>	<u>  </u> ✓
Q6: Could retrieve material	1	<u>  1  </u>	<u>  </u> ✓	<u>  </u>
Q18: Gave info to doctor	1	<u>  2  </u>	<u>  </u>	<u>  </u> ✓
<u>WERE THE MATERIALS WELL REGARDED?</u>				
Q7: Rated high overall	1 or 2	<u>  1  </u>	<u>  </u> ✓	<u>  </u>
Q8: Easy to understand	1 or 2	<u>  1+2  </u>	<u>  </u> ✓	<u>  </u>
Q9: Length was appropriate	3	<u>  3  </u>	<u>  </u> ✓	<u>  </u>
Q10: Factual info appropriate	3	<u>  3  </u>	<u>  </u> ✓	<u>  </u>
Q11: Sensitivity appropriate	1 or 2	<u>  1  </u>	<u>  </u> ✓	<u>  </u>
Q12: Info considered complete	2	<u>  2  </u>	<u>  </u> ✓	<u>  </u>
Q19: Glad info was sent?	1	<u>  1  </u>	<u>  </u> ✓	<u>  </u>
Q14: Did not cause problems	2	<u>  2  </u>	<u>  </u> ✓	<u>  </u>

Worker Interview Scorecard -- page 2

	<u>Desired Response</u>	<u>Modal Response</u>	<u>Do they Match?</u> <u>YES</u> <u>NO</u>
<u>OVERLAP WITH OTHER FEEDBACK TO NIOSH</u>			
Q16: Redundant to postcards?	2	<u>2</u>	<u>✓</u> <u>—</u>
Q17: Redundant to call-ins?	2	<u>2</u>	<u>✓</u> <u>—</u>

POTENTIALLY USEFUL SUGGESTIONS

Selected comments from interviews, particularly on questions Q 13, 15, and 20;  
substantive suggestions only.

- "I don't even know what a Halowax is."
- "Explain what the word 'Halowax' means. You assume we all know that word, but we never called it that. It should be explained better."  
[Apparently the workers were not all familiar with Halowax as a trade name, as assumed in the materials.]
  
- "Include more factual information and less garbage. More facts and figures. Where exactly was Halowax used in the operation?"
- "They should have described the manufacturing process more specifically so that people would be able to tell more quickly if they were likely to have been exposed."  
[High-risk areas of the plant should probably be identified, if this is possible.]
  
- "I assume a good many have passed on by now, so there's nothing to be done."
- "I'm not sure they should send out letters to people about something that happened 50 years ago. What's the point?...By this time a lot of the people involved are really old, and some of them are out to lunch, to put it in plain English."
- "If nothing happens to you in 50 years, why worry about it now?"
- "If I lived this long, after 50 years, could it really make any difference?"
- "I did read it, but I don't remember half the stuff. Give me a break, I'm 84 years old!"  
[Elderly cohorts may tend to disregard the preventive health advice because they

are fatalistic about ill health and death. The importance of measures for secondary disease prevention even at an advanced age might be addressed directly in the letter: "Even in your older years, it can still make an important difference to your health and wellbeing if you...."]

-- **"My son just cleaned my house and I think he threw it out."**

-- **"My children helped me understand it and went over it with me."**

[Family members may be important influences, especially for older cohort members. The letter might suggest discussing the information with one's family.]

-- **"There's so little a lay person can do. They need to be alerted, then move on to a medical professional. There was too much there. It diluted the basic message."**

-- **"Make it more brief and to the point."**

-- **"My advice would be to put down only the most important facts, no more than 20 items, then mention areas where it was used, and maybe make the whole thing about 3 to 4 pages."**

[Food for thought. A much shorter letter with very strong advice on preventive measures, including consulting a doctor, might ultimately be more effective in terms of public health impact.]

-- **"I liked the highlighter they used to show which part would apply to me."**

[Visual interest and personalization got a good response here.]

-- **"Do something to speed this up. The principal drawback with this is the time element."**

-- **"The fact that such a long time passed did negate some of the usefulness of this."**

-- **"Getting this news after fifty years does seem a little ridiculous."**

-- **"The number of government people assigned to this effort should be increased so it wouldn't take so long."**

[These are common sentiments; maybe the reasons for the delay should be explained briefly in the letter.]

-- **"One thing I did wonder about: I was there for 2 years, and worked with other dangerous materials besides Halowax. Are any of those others likely to cause long-term health problems?"**

[Again, a common concern. The letter might say: If you would like more information about the health effects of this or any other potentially harmful substances you were exposed to at work, please call the NIOSH toll-free number.]

### C. Stakeholder Responses

Unfortunately, we were unable to talk with the union official most centrally involved; he had since retired and moved to Colorado, and declined to be interviewed. Other union officials named on the NIOSH stakeholder list were cooperative and very positive about the Halowax notification, and assured us that the union had felt adequately involved; however, they were unable to comment in any detail on the process and materials used. While more detail would have been desirable, it seems reasonable to conclude that the union was satisfied with the opportunities provided for input and saw no major problems with the way this notification was carried out.

Efforts to interview the two management representatives on the NIOSH stakeholder list were more successful. Both were very forthcoming, although it took numerous callbacks to find a convenient time to carry out the interviews. Both expressed appreciation that NIOSH was taking the trouble to secure their opinions.

#### Summary of Stakeholder Feedback

The raw data on which the following summary is based can be found in the Appendix section.

Based on two complete stakeholder interviews from management informants and brief comments from several union officials, this notification appears to have gone fairly smoothly, without major problems. However, two important issues were raised that bear consideration for the future.

First, one of the employers reported that this notification roughly coincided with the parent corporation's decision to close down his plant. He was, in fact, presiding over a skeleton operation and expected to lose his own job once the phase-out process was complete. He felt that under the circumstances, management's engagement with the notification had been minimal and that any notified workers employed by the plant at the time probably didn't pay much attention to the NIOSH information because they were so preoccupied with the prospect of being laid off. This problem would not affect workers already retired (which in this cohort was a large proportion because of their age). However, it serves as a reminder that NIOSH notification messages go out into a social context of extreme concern over job security, and that should be taken into account. If the workers are facing large scale downsizing, it might be wise to make the notification information briefer and more to the point than is usually done. Assuming that the tripartite review stage provides opportunity for discussions with employers and union officials, getting this kind of background information on the cohort prior to finalizing the notification materials would not involve much extra effort by NIOSH staff.

Second, one of the stakeholders (the employer's industrial hygienist) reported that he took considerable trouble to prepare written comments on the draft notification materials that were sent to him, with the intent of supporting and improving the accuracy and effectiveness of the notification. After sending in his comments, he never got any response from the agency. He was highly incensed about this, as it seemed to him that his technical input was not being taken seriously, his time was wasted, and NIOSH's invitation for his comments was probably insincere in the first place. He claimed that he didn't mind if his suggestions could not be used for some reason, but he felt that NIOSH owed him at least a call from someone with appropriate technical expertise to discuss his input. As it was, he felt that his comments may have been thrown away unread, or dismissed by someone without the technical training to make an informed judgment about them. He described himself as one of the rare "friends of NIOSH" in the corporate world, noting sadly that this experience had shaken his support for the agency. In this instance, it seems that the tripartite review process backfired.

#### **PART IV: CONCLUSIONS, TRIAL #2**

Trial #2 has reaffirmed that the calls to 25 randomly selected workers represent a promising approach to evaluation. While this sample size is small, it does seem to pick up a wider range of responses than the subject-initiated bounceback cards, which tap only the dimension of worker satisfaction and are potentially biased (apparently toward positive responses) because of the self-selection involved. By reflecting more diversity and identifying more problem areas, the telephone interviews seem likely to yield more useful information for improving the notification process. The bounceback cards should definitely be kept as a vehicle for inviting worker input, but evaluation will be on firmer ground if based on agency-initiated calls to randomly selected cohort members.

The large proportion of the worker sample reporting no recollection of ever receiving the NIOSH materials is particularly interesting. The reason may be the advanced age and related ill health of this particular cohort, which is atypical in those respects. However, comments from the non-remembering workers suggest that there may also be some unrecognized problems occurring in NIOSH's mailing procedures. More than half the non-remembering workers reported no reason why the NIOSH mailing should not have reached them, and claimed they would not have failed to notice it and remember it. Adding to the puzzle, the letters sent to them in advance of the evaluation study reached them successfully at the same addresses used for the original NIOSH mailing.

As for the stakeholder interviews, one point of special interest is the fact that written input from one of the tripartite review participants received no agency response. It is not clear that a simple "thank you for your comments" would have sufficed for this participant, as he apparently was assuming he had been invited to enter into a dialogue with NIOSH scientists whose technical training was equivalent to his own. It may be that his expectations about the purpose of the tripartite review were inflated or in error. However, he was quite outraged about the situation, which is clearly undesirable from an agency public relations point of view. NIOSH administrators should probably give some further thought to ways of keeping the tripartite review process from inadvertently insulting the very participants it was meant to reassure.

In terms of evaluation procedures, the worker interview instrument seems to be working out fairly well. A version suitable for use in Trial #3 appears in Appendix C. As explained earlier, oversampling from the cohort list is necessary -- but this must be done in waves, as needed, so as to avoid sending out far too many introductory letters and leaving the "extra" letter recipients wondering why they never got a follow-up phone call.

Sending out explanatory letters before calling the worker respondents is an important step which should be retained. Appendix C contains the form letter used in Trial #2 (which would need to be re-worded for Trial #3 because the caller will be from NIOSH).

Stakeholder interviews should definitely be done first, before any letters are sent out to the worker sample. The stakeholder interview guide used in Trials #1 and #2 seems unnecessarily structured and ended up not being all that useful. For Trial #3, the contractor recommends that the stakeholder interviews should take the form of unstructured conversations, built around simple open-ended questions such as suggested in Appendix C.

For a variety of reasons discussed earlier, it would be advantageous if the stakeholder calls were made by an appropriate NIOSH administrator rather than by regular staff. They should not be made by clerical staff. Calls should be preceded by an introductory letter to stakeholders a week or two in advance, along the same general lines as the sample letter in Appendix C.

In the reports for Trials #1 and #2, stakeholder interviews have been presented in considerable detail because of their interesting content. However, this level of detail would be unrealistic as a routine agency evaluation procedure. In Trial #3, aimed at testing procedures in terms of practicality for routine use, the contractor strongly recommends that stakeholder responses be reported much more briefly. Notes should be taken during the telephone conversation, and a short report should then be written up for each stakeholder immediately after the call (while the discussion is fresh in memory), covering the stakeholder's overall reaction and any important insights or problems

relevant to the evaluation. After the stakeholder interviews are done, a brief summary covering all stakeholder responses (major points only) should be prepared for use in the evaluation report.

In addition to refining the techniques for routine evaluation, Trial #2 has turned up several issues that call for deeper consideration by NIOSH administrators. One is the issue of coverage: why is it that almost half of the workers called in Trial #2 reported never receiving the NIOSH notification materials? Another issue concerns the basic goal of notification. If the goal is to disclose NIOSH study results in a way that gets a positive reaction from workers, notification seems to be succeeding. On the other hand, if the goal is to use notification to advance public health, some modifications may be needed because workers do not seem to be remembering either the facts about the hazard or the advice for secondary prevention of disease. Thirdly, how can the tripartite review process be used to promote a meaningful sense of openness to stakeholder input? NIOSH procedures at present may be having the opposite effect, convincing some tripartite review participants that their involvement is essentially window dressing.

To maximize its usefulness, evaluation should involve judgments that go somewhat beyond simple description. For Trial #2, the worker responses were organized into a "scorecard" in a tentative effort to facilitate this level of analysis. What the scorecard does is to match up the modal responses given by the interviewed workers with the pattern of responses desired by the agency in terms of intended outcomes. This allows for a quick assessment of where the notification was strongest and where the notification process might need improvement. The scorecard approach as used in Trial #2 is only a rough start, but it does seem to yield additional insight and some interesting food for thought. The contractor welcomes discussion with NIOSH staff about it, and recommends that it be tried again in Trial #3.

Trial #3, planned for fall of 1996, offers a chance to explore all of these issues further, as well as to test the evaluation approach for practicality in routine agency use.

## **APPENDICES**

### **A. Attachments to Trial #2 Evaluation Findings (Raw Data)**

1. Circumstances of Workers Who Did Not Remember Being Notified
2. Raw Data on Worker Interviews
3. Detailed Narratives from Stakeholder Interviews

### **B. Tools for Analyzing Worker Interview Data**

1. Analysis Grid
2. Evaluative Scorecard

### **C. Forms and Instruments Suggested for Trial #3 Data Collection**

1. Introductory Letter to Stakeholders
2. Introductory Letter to Workers
3. Revised Interview Guide for Stakeholders
4. Revised Worker Interview Instrument

## Appendix A

### **ATTACHMENTS TO TRIAL #2 FINDINGS**

1. **CIRCUMSTANCES OF WORKERS WHO DID NOT REMEMBER BEING NOTIFIED**

Interviewer's comments on workers in the evaluation sample who reported they did not receive the notification materials

2. **RAW DATA ON WORKER INTERVIEWS**

Responses from completed worker interviews reported as frequencies and percentages, with worker comments included and modal responses marked

3. **DETAILED NARRATIVES FROM STAKEHOLDER INTERVIEWS**

[Reported in Trial #2 as a matter of general interest, but probably not needed in Trial #3 and subsequent routine evaluations]

## Appendix A(1)

### INTERVIEWER'S COMMENTS ON WORKERS IN THE EVALUATION SAMPLE WHO REPORTED THEY DID NOT RECEIVE THE NOTIFICATION MATERIALS (N = 11, or 44% of the sample of 25)

Among those with no recollection of receiving notification materials, circumstances varied widely -- as shown in the following notes taken by the interviewer for these eleven individuals:

1. This woman is 80 years old. Says she never received information sent 1 year ago. She's blind and lives with her daughter. She said her daughter told her about my letter 3 days ago but she has no memory of the initial Halowax mailing.
2. This respondent (female) reports "I never got nothing. I don't know what it's about. Never heard of it."
3. Respondent (female) received my letter but had no memory of Halowax notification. Said she worked there many years ago and wasn't in the section that used Halowax or asbestos. "I worked with cotton." She had no interest in receiving any materials on Halowax.
4. Wife answered. She said she and her husband look at all mail without exceptions, and this is the first time they've heard about NIOSH or Halowax. She asked what we were doing and what health problems might be associated with Navy cable work. Interested, but did not wish to have information packet.
5. Respondent (male) says "I don't even know what a Halowax is." I explained the issue to him and he stated he never had chloracne. He said he never was in the room with the powder. "Everyone stayed away. People told each other not to go near there." He was very nice and wants information. He can't understand why he never received a packet last year. "The mail here is terrible." He's been living in the same house in Yonkers for 48 years and has never had mail stopped, so it's a mystery.
6. Respondent says "I read it in the paper but I never got anything in the mail." She was very confused because they've lived in this house for two years and she should have received it. She's quite sure she didn't get the notification letter but truly believes she did read something about this in the newspaper in Florida during the last 6 months to a year. She thinks she saved the article from the paper but doesn't know where it is. She wasn't sure if she knew the word Halowax; I clarified the name twice. She said "I had been working with it. Thank God nothing is wrong."

7. Respondent (female) was quite surprised by my letter because "I'd never heard anything about this before; what's this all about?" I briefly filled her in and she asks that we send her the information that the other workers received.
8. Respondent (male) is disoriented, doesn't remember receiving the notification. "I'm 85, and I worked there before I went in the service. I think I might have a slight recollection of it. I heard of Halowax, maybe. I'm not really sure. I just get help from God and my religion."
9. "I've been having trouble with the mail. Sometimes things don't show up for 2 weeks." She also said, "I'm 84." She was one of a number of people who mentioned their age at the start of the conversation in order to explain why they don't want to or can't do an interview. She said she'd never seen the initial notification letter. She says she can't remember the name of the company.
10. I'm not sure I ever got the materials you're talking about. I can't read because my eyes are bad. I can't see to write anymore. People who send things, I wish they'd stop because I can't read now. Maybe I did get the information, but I'm 85. I'm not a young girl anymore with a good memory. As it happens, my liver is one of the few parts of my body that is still OK!"
11. He did receive my letter, but did not know anything about the NIOSH materials in question. He remembers working there before going into the service but doesn't care to know more about Halowax. He said he wanted to help but knows nothing of NIOSH. "You seem like good people and I wish I could help, but I can't."

Appendix A(2)  
RAW DATA ON WORKER INTERVIEWS

Responses from the 14 Completed Worker Interviews Reported as Frequencies and Percentages, with Worker Comments Included and Modal Responses Circled

1. **How much importance did you place on the material you received in the mail about the health effects of Halowax? Did you consider it very important, somewhat important, right in the middle, somewhat unimportant, or very unimportant?**

50% 7 **Very important**

I left there in 1995.

I was only 18 when I worked there. I remember trying to cover my hair and my head.

I wasn't aware of what was going on; this was news to me.

7% 1 **Somewhat important**

I say "somewhat" because I didn't see where I was personally involved in it. I worked 3 machines in 1942-43, and earned an award for production, but it wasn't a direct hazard to me personally. However, I could see other guys working a floor below us, and there were all kinds of powder in the air around them. For 6 months they were twisting asbestos around a cable machine; they would coat it with something like a hot tar. People would get an itch from this, rashes and so forth. They were definitely exposed. I'm sure it was very important for them. I'm sure people died. There was powder all over the place. I felt sorry for all of those guys.

7% 1 **Right in the middle**

I guess I would have felt it was more important if I had health problems from it!

29% 4 **Somewhat unimportant**

Some got sick and some didn't. I never gave a thought about it. I'm 84 now, and it just doesn't seem very important.

— 0 **Very unimportant**  
7% 1 **Don't know**  
— 0 **No answer**

2. Before getting the material, did you think there was any health risk from working with Halowax?

36% 5 Yes

Yes, that's why I moved out of that line of work. I originally went there to help the war effort, since I was too young to join up. We wouldn't have won that war without the homefront, you know! My brother and I both worked there, in different parts of the plant. He got covered with boils so that I couldn't even recognize him. He was so covered that he was rejected by the Army for it. Then they moved me to his section and wouldn't change me when I asked. I was scared to death. I left.

A lot of people complained.

I used to get a lot of it on my skin; I got a lot of pimples. I was only a teenager at the time, 18 or 19. It was a pro-war job. I didn't know anything about any danger. A lot of people got bad rashes. A friend of mine had his face covered with it, all over his face. The also polluted the Hudson. It was a very, very unhealthy job. After the war they asked me about coming back. I said "Hell, no."

I knew about the dangers of asbestos! But this other hazard and the terminology, I didn't know.

57% 8 No

Before getting the material, I didn't even know what Halowax was.

This was before asbestos was known to be bad.

I had never heard of it.

7% 1 Don't know

I knew people had gotten sick but I didn't know what caused it. I didn't know what Halowax was. Was it in the cables, or in the powder?

— 0 No answer

3. How thoroughly did you read the information that came in the mail? Please be completely honest; we really want to know.

58% 7 Very carefully (any part of it)

I read it twice.

36% 5 Fairly carefully

Well, I read it, but I go for yearly check ups so I already knew I was all right. At this age, I don't get scared by much of anything anymore.

I glanced over it all.

14% 2 Looked through it quickly

I figured it didn't concern me that much, because I never worked with it directly.

— 0 Did not read it at all

— 0 Don't know

To me, it was so long ago. I got the material and looked at it. It was about chemicals and I don't know anything about chemicals.

— 0 No answer

4. As far as you know, are there any specific health problems that may be linked to Halowax exposure?

29% 4 Yes

Boils -- people would get facial boils to the point they were unrecognizable. Also it can cause liver problems; that was in the newspaper.

Problems with lungs and liver.

I knew what they were when I read it, but I can't remember offhand now.

Most of them had facial blisters. I think it's an offshoot of asbestos.

43% 6 No

29% 4 Don't know

What is it? What is this stuff, anyway?

— 0 No answer

5. As far as you know, is there anything that workers who were exposed to Halowax in the past can do to protect their health now?

14% 2 Yes

It's best just to avoid it in the first place. We didn't know about it back then. Now they have heavier uniforms, mouth masks, rubber around the wires. We used to get the fumes all the time; it's kind of smelly.

Maybe to call in the details to their doctors? That might help.

57% 8 No

I assume a good many have passed on by now, so there's nothing to be done.

At this age, if something hasn't got you by now, you're just lucky! But seriously, once you're exposed and have it in your system, there's nothing you can do.

Maybe move to Arizona?

29% 4 Don't know

— 0 No answer

6. Did you keep any of the material sent to you, in some place where you could refer to it again in the future?

43% 6 Yes

I probably have it here somewhere, but I just get stacks and stacks of mail.

I had it for awhile. It's somewhere, but I'd have to dig for it.

Yes, but I'm not going to keep it forever.

My doctor has it.

29% 4 No

29% 4 Don't know

My son just cleaned my house and I think he threw it out.

    0 No answer

7. Overall, how would you rate this informational mailing? Was it very well done, somewhat well done, right in the middle, somewhat poorly done, or very poorly done?

79% 11 **Very well done**

Very interesting and very nice.

I understood it and appreciated it. I always had a hunch it was dangerous to work there.

I did think that for the lay person, all that detail was not needed.

7% 1 **Somewhat well done**

— 0 **Right in the middle**

— 0 **Somewhat poorly done**

— 0 **Very poorly done**

14% 2 **Don't know**

— 0 **No answer**

8. In your opinion, how understandable was the information sent to you? Was it very easy to understand, somewhat easy, right in the middle, somewhat difficult to understand, or very difficult to understand?

36% 5 Very easy

My children helped me understand it and went over it with me. They understood it and thought it was fine. They said it was just to make sure people knew about this.

36% 5 Somewhat easy

7% 1 Right in the middle

7% 1 Somewhat difficult

It could have been in more plain language.

7% 1 Very difficult

7% 1 Don't know

— 0 No answer

9. How about the length of the material? Was it much too short, somewhat too short, about right, somewhat too long, or much too long?

— 0 Much too short

27% 1 Somewhat too short

36% 5 About right

It didn't get too technical.

21% 3 Somewhat too long

14% 2 Much too long

There's so little a lay person can do. They need to be alerted, then move on to a medical professional. There was too much there. It diluted the basic message.

21% 3 Don't know

Length doesn't matter to me at all, as long as I was interested.

— 0 No answer

10. In your opinion, how appropriate was the amount of factual information contained in the material? Was it not enough information to be useful, not quite enough, about right, more than needed, or way too much?

— 0 Not enough

7% 1 Not quite enough

I would have liked information on the percentage of people who contracted cancer, and stuff like that.

43% 6 About right

I liked the highlighter they used to show which part would apply to me. I also have something I cut out of the paper, that has some facts in it.

14% 2 More than needed

— 0 Way too much

36% 5 Don't know

— 0 No answer

11. How about the way the material was worded? In your opinion, was it very sensitive to people's feelings, somewhat sensitive, right in the middle, somewhat insensitive, or very insensitive?

43% 6 Very sensitive

Very, very good. It didn't bother me at all. It was very nicely put, about the years, the results, the cancer -- explaining all the different kinds, oral cancer and sarcomas.

It made it very plain that you shouldn't get alarmed.

I thought it was really nice. Here I'm going on 75, and they took the trouble to track me down. If I hadn't been going to a doctor already, it might have been really important for me to get this.

21% 3 Somewhat sensitive

21% 3 Right in the middle

— 0 Somewhat insensitive

— 0 Very insensitive

14% 2 Don't know

I did read it, but I don't remember half the stuff. Give me a break, I'm 84 years old!

— 0 No answer

12. Was there any important information left out, that you think should have been included?

21% 3 Yes

They should have described the manufacturing process more specifically so that people would be able to tell more quickly if they were likely to have been exposed.

It's a wonder that there wasn't a warning sign all over the plant. You should explain why that didn't happen.

Add something about unions. Unions were powerless at the time; they didn't do anything about it. But are they doing anything now? Are they a source of help for the workers who were exposed?

79% 11 No

I wondered why after all these years we finally got this information in the mail.

One thing I did wonder about: I was there for 2 years, and worked with other dangerous materials besides Halowax. Are any of those others likely to cause long-term health problems?

    0 Don't know

    0 No answer

13. Other than sending information in the mail, is there anything else that you think should be done to notify workers who had possible exposure to Halowax in the past?

29% 4 Yes

I think it's been too long. We should have been notified years ago. If we had known earlier, maybe some of us would have quit smoking and so forth.

If they'd told us sooner, I would have gone to a doctor or something.

The workers should have been warned. Too bad they didn't say anything back then. I guess they didn't know.

I suppose that nowadays, the time span involved would be very different. The fact that such a long time passed did negate some of the usefulness of this.

50% 7 No

They're probably all gone by now. I'm 72 and I was one of the youngest guys there.

For years they've been trying to contact all these people, and now I finally got the notice. Keep doing it!

21% 3 Don't know

It's a long time ago. I was there in 1940, 56 years ago. Such a long time ago. It seems like water under the bridge. I don't think 99% of us knew what was going on, but it's so far back now.

— 0 No answer

14. Did sending the information cause you problems of any kind?

— 0 Yes

100% 14 No

When I first got it, I got really panic stricken, believe me. I hit the panic button. It sent me spinning, believe me. Then I said to myself, calm down. These guys are just trying to be thorough. I don't know any way to make it less distressing and still tell people the truth. The panic will eventually go away, and it's better to know than not to know.

No, but it did pique my curiosity, so I went to a doctor.

I was surprised to get it, but it was good. If I wasn't going to a doctor already, maybe I would have really needed it.

— 0 Don't know

— 0 No answer

15. If the government sends out information like this in the future, do you have any suggestions to make it more useful?

437 6 Yes

Explain what the word "Halowax" means. You assume we all know that word, but we never called it that. It should be explained better.

Include more factual information and less garbage. More facts and figures. Where exactly was Halowax used in the operation? It should be more simple.

Make it more brief and to the point. The number of government people assigned to this effort should be increased, so it wouldn't take so long.

The quicker, the better. For people like me, basically in good health, it's OK to take so long. But for someone who has already come down with a disease related to work, this might be too late to do any good. Getting this news after fifty years does seem a little ridiculous.

I'm not sure they should send out letters to people about something that happened 50 years ago. What's the point? It just gives people something depressing to think about. Besides, by this time, a lot of the people involved are really old, and some of them are out to lunch, to put it in plain English.

I suggest that the government should go after them for money, and get the workers some kind of remuneration. Our health was put at risk and we should get some kind of compensation.

297 4 No

— 0 Don't know

I just think too much is covered up. Look at Agent Orange. That was a cover-up for sure.

— 0 No answer

16. The material sent to you included a postcard for comments. Did you send back that postcard?

14% 2 Yes

50% 7 No

36% 5 Don't know

— 0 No answer

17. The material sent to you included a toll-free telephone number to call NIOSH (the government agency that mailed the information) if you had any questions. Did you use that telephone number at all?

7 1 Yes

I thought the biopsy I had might be of interest, so I called them. I had this rash a long time ago, maybe 10 years ago. It was a rare skin disease, a type of lymphoma, mycosis fungoid. Very rare. They did a biopsy and I had chemo. It was red, itchy, all on my stomach, where I used to work on the machines and be standing against them. I gave the [notification] information to my doctor but she says she doesn't know if the exposure caused the disease.

93 13 No

— 0 Don't know

— 0 No answer

18. The material sent to you included some information for your doctor about the health effects of Halowax. Did you pass that along to your doctor?

36% 5 Yes

I gave it to my doctor. I called him on the phone and he had me bring in the letter. He had me call him and he said it's not anything I need to worry about now. If nothing happens to you in 50 years, why worry about it now?

64% 9 No

If I lived this long, after 50 years, could it really make any difference?

No need to. I'm in excellent health. I walk 5 mile a day.

No need to tell him, everything is perfect.

    0 Don't know

    0 No answer

19. Overall, are you glad the information was sent to you, or do you wish it had not been sent to you?

79% 11 **Basically glad**

I felt as if I wasn't there long, so it might not apply to me. But it wasn't for old timers who worked with it for a long time; they'd all be dead by now.

It's OK.

Absolutely a good thing to do.

I was enlightened.

You can never have too much knowledge! It's always better to know.

14% 2 **Neutral or mixed feelings**

At first I wished they hadn't sent it but after I talked to my doctor it was OK.

— 0 **Basically wish not**

7% 1 **Don't know**

— 0 **No answer**

20. Is there anything else you think NIOSH should know about workers' response to getting that in the mail?

21% 3 Yes

They just shouldn't make people work with dangerous stuff in the first place. You'd come home and you'd be covered with it. I was just lucky, I never got rashes or anything.

My advice would be to put down only the most important facts, no more than 20 items, then mention areas where it was used, and maybe make the whole thing about 3 to 4 pages.

Do something to speed this up. The principal drawback with this is the time element.

You guys are slow, but you're pretty darn thorough, and that's good.

57% 8 No

It's a good idea, but it's hard to say if this is really much help at this point. There's so few of us left. You can only reach whoever is still standing.

21% 3 Don't know

The main target should be people who are sick from it. It's a fine thing to send it to them. I didn't need it that much myself.

— 0 No answer

Appendix A(3)

DETAILED NARRATIVES FROM STAKEHOLDER INTERVIEWS

[Reported in Trial #2 as a matter of general interest, but probably not needed in Trial #3 and subsequent routine evaluations]

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INTERVIEW #1: EMPLOYER REPRESENTATIVE

Interviewed 7/11/96

(Reconstructed from notes, not recorded verbatim)

(Telephone number on NIOSH contact list was disconnected. Fortunately, the company's current telephone number was obtainable from the information operator for Yonkers, NY.)

Yes, I got your letter [about evaluating the NIOSH notification for Halowax] -- but I don't know what it is you're referring to. I don't know about any notification project going on recently for Halowax.

[Explanation of the NIOSH notification] Well, your letter was the first I've heard of it. I do remember some people going through old records awhile back. I assumed it had to do with asbestos.

In terms of what connection we might have had with the recent notification? Cablec used to be Phelps Dodge, which was a big manufacturer of asbestos cable. The company changed names in 1984. It was Phelps Dodge and then one split second later it was Cablec. The product and production processes kept going. Of course, I don't remember anything about the period when you say these exposures took place [1940-1944]; I was born in 1936. I guess the workers being notified are pretty old now. I guess they're not around -- for one reason or another.

At this point, the plant is closed. We're in the process of shutting it down -- stopping production, making transition plans, eventually we'll do demolition. We just happened to be a one product plant and our product was an environmental problem with lots of oil, lead, asbestos and so forth. Our customers stopped ordering, and we couldn't keep going. We're going the way of the horse & buggy, out of date.

It's a sad process. When I came to Yonkers in the 1960's, there were 4 Phelps Dodge plants here. Now we're down to just this one, and it's closing. At its peak, this plant employed 200 people. Right now we're down to 30 people, as a transition team. Our unionized workers were let go in February 1996. Some have found other work, I guess; lot's haven't.

I'm as puzzled as you are about why I didn't hear about the notification. Maybe I

got something in the mail and just threw it away. I do that sometimes, just glance at the return address and throw things away without opening them if they don't seem important. I get so much mail it's the only way I can deal with it. But something from OSHA or NIOSH, I would certainly open. If it was just last summer, I think I would remember -- things may be stressful here, but I'm not that far gone! If you said it was 10 years ago, I might possibly have forgotten it, but not something from just a year ago.

No, I didn't hear any of our workers talking about it. They had a lot on their minds, with the plant closing and all. It might have seemed secondary compared to the job loss they were facing.

I really wonder, with all this downsizing, who's going to pick up the tab for all the people out of work. Without work, they can't buy other consumer items like washing machines and cars, and then the whole economy suffers. It's such an enormous problem that it pretty much overshadows other concerns.

---

**INTERVIEW #2: EMPLOYER REPRESENTATIVE**

Interviewed 7/12/96

(Reconstructed from notes, not recorded verbatim)

Well, I have your letter and survey guide here somewhere. A follow up of a worker notification, wasn't it? It's a really old exposure; none of us now in management were around then.

I'm a little concerned about you telephoning the workers. My perception is that if you call them, they'll say "I don't remember," or "I tossed it out." If they don't remember, are you going to explain the risks again? If you do that, won't you just be raising their anxieties all over again?

[Explanation that the planned telephone survey simply evaluates the NIOSH materials and imparts no new risk information; assurance that his concern is valid and understood, and great care is being taken to avoid raising workers' anxieties; assurance that the interviewers are well trained and experienced; note that without this kind of evaluation, NIOSH won't know how well its notification process is working.]

OK, I see why it's necessary. It makes sense. How else can I help you?

What do I think of the procedures used in this notification? Put it this way: I've been in the industrial hygiene profession for 15 years. I'm one of the people in the field who strongly supports NIOSH. Industry as a whole sometimes says "Let's do away with

NIOSH. They don't serve our research needs. It's a waste of taxpayers' money." I've been one who says, "We need NIOSH as an agency, whether what it's doing is good or bad. If it's bad, let's improve it."

So, having said that, here's my reaction to NIOSH's process in the Halowax notification. It felt to me like they made up their mind first what they were going to do, then they asked for our comments because they felt they had to, but they didn't really take them into account. They were sort of going through the motions as window dressing. It's like they said -- without ever actually saying it -- "We have to get your comments, but we don't have to take them seriously." I know people in NIOSH and I respect them professionally. I just don't feel that in this case we had any meaningful exchange on a professional level.

How might they do it differently? For one thing, they should not come in with such rigid agendas. They say that industry has agendas. My god, it's nothing compared to the agendas they have.

Here's how they could improve the process. At present it goes like this: They call us about the notification they're planning, send us the information, we review it and send them comments -- and then we never hear anything back. Eventually we get the final materials, and maybe (as in this case) our comments weren't used. We don't know why. Was it a matter of professional disagreement, or were our comments just dismissed by someone in the bureaucracy without professional training? Were our comments just thrown away?

I feel like I am a key player in the situation, and I was willing to take the time to give serious thought to my comments on the NIOSH materials. I'm a reasonable person. After I sent my comments in, if someone in NIOSH who was my professional peer called me up, we could discuss why my comments could or couldn't be included. We could say to each other, "Look, we both want to help these workers. Here's why it should get stated this way or that way." We might agree or we might not, but at least I would understand that professional judgement was entering into the discussion.

So this is one thing I'd suggest very strongly: Add a step to the process, whereby someone from NIOSH with professional expertise calls the people who sent in comments and discusses with them how the agency will or will not use the input. This isn't an issue of control. It's a matter of making the review input meaningful, instead of merely symbolic.

Please understand, I'm talking about the process in general. In this particular notification I don't have any major concerns about the materials that were sent out. If I did, I would have called up people in NIOSH, or gotten our lawyers on it. If I saw a real problem, I would have made a big stink. To be honest, I can't even remember what kind of changes I was suggesting in my comments. But they were significant enough that I did take the time to write them up, so I must have thought they would be improvements. Believe me, with my work schedule I would have been happy to let it go

without comments if I thought it didn't need any changes. So having taken the trouble to do the comments, I would have liked to have some followup from NIOSH and some explanation of why they weren't used. Even just as a courtesy.

In terms of other observations about NIOSH's approach? Remember, I'm speaking as an IH who's been around a long time and someone who sees NIOSH as a critically important agency. Here's what I have to say, based on that perspective.

NIOSH's research agenda is badly out of focus. If NIOSH were to toss out their current technical research agenda, the entire occupational safety and health profession would stand up and cheer. In my opinion, the agency should be giving high priority to the following four issues, now being neglected:

1. The psychological aspects of behaviorally based safety programs. There's real prevention potential here. What keeps it from being addressed by NIOSH? Habit? Ideology?
2. The cost effectiveness of occupational safety and health interventions. Industry is trying to develop information on this. It's a strong argument in favor of such interventions. Why isn't NIOSH doing more studies to show the cost savings involved? It's the agency that ought to be doing this research. At present, there's no good basis for the numbers being presented by OSHA, for example, or the National Safety Council.
3. Methods for measuring industrial hygiene effectiveness -- how much disease is being prevented. Again, NIOSH is the agency that should be doing this. It's ironic that DOE is actually doing more of this kind of basic research than NIOSH is.
4. Documenting the population demographics of health and safety educational programs, and evaluating the availability and quality of such programs. We don't know nearly enough about this, and it's critical to worker protection. Who is being trained, as workers and as professionals, and how good is the training?

On a more fundamental level, my advice to the agency boils down to this: Take more seriously the comments of the agency's "worst enemies" -- i.e., industry. Maybe some of our suggestions could actually help NIOSH, if they would listen. I'm really concerned about this, because NIOSH is important for worker health and I don't want to see the agency's political opponents succeed in abolishing it. But frankly, some of the Republican criticism is well deserved. The agency's off target. They need to be working on issues that are centrally important, not piddling around with minor research issues that don't meet anybody's real needs. I'm in a Fortune 200 industry at present, but I also used to do a lot of consulting with small business; so I have a sense of what kind of health and safety research is needed on both levels of business -- and when we're talking about businesses, we're also talking about the workers who earn their living there. The

needs of real employers and real workers should be the research starting point for a tax-supported agency like NIOSH. Frankly, it's hard to say whose needs are being met by NIOSH's current research agenda.

Yes, I do know that industry input was invited in the recent development of the National Occupational Research Agenda. I guess what I think is needed is a different level of dialogue.

If someone from NIOSH wanted to explore the idea of an informal give-and-take workshop with sympathetic health and safety professionals from industry, just to clarify common concerns and areas for collaborative effort, here's who they might contact as a start:

Frank White  
Organizational Resource Councilors (ORC)  
Washington, DC  
202-293-2980

As an organization, the ORC represents large U.S. industries and is sympathetic in principle to the kind of work NIOSH does (or could be doing) to protect worker health. Frank White, a prominent member, is an active voice on occupational safety and health issues; his input and support would be particularly valuable.

As I said, I'm a strong supporter of NIOSH and I have a lot of respect for people in the agency. My remarks to you should be taken in that spirit. I'm just trying to put in words what other industry friends of NIOSH may be thinking but don't have a chance to say quite so openly and honestly. Please make that clear in your report.

## **APPENDIX B**

### **TOOLS FOR ANALYZING WORKER INTERVIEW DATA**

1. **Analysis Grid**

Form for use in reducing data (tallying frequencies and computing percentages) from worker survey forms

2. **Evaluative Scorecard**

Form for use in interpreting the match between the interviewed workers' modal responses and the pattern of responses desired for a successful notification.

Appendix B(1)

ROUTINE EVALUATION OF NOTIFICATIONS

GRID FOR ANALYZING  
WORKER INTERVIEW RESPONSES

Q#	1	2	3	4	5	DK	NA
1							
2			XXX	XXX	XXX		
3					XXX		
4			XXX	XXX	XXX		
5			XXX	XXX	XXX		
6			XXX	XXX	XXX		
7							
8							
9							
10							
11							
12			XXX	XXX	XXX		
13			XXX	XXX	XXX		
14			XXX	XXX	XXX		
15			XXX	XXX	XXX		
16			XXX	XXX	XXX		
17			XXX	XXX	XXX		
18			XXX	XXX	XXX		
19				XXX	XXX		
20			XXX	XXX	XXX		

ROUTINE EVALUATION OF NOTIFICATIONS

GRID FOR ANALYZING  
WORKER INTERVIEW RESPONSES

*Responses tallied from Survey Forms*

Q#	1	2	3	4	5	DK	NA
1	<del>///</del> //	1	1	////	-	1	
2	<del>///</del>	<del>///</del> ///	xxx	xxx	xxx	1	
3	<del>///</del> //	<del>///</del>	//	-	xxx	-	
4	////	<del>///</del> 1	xxx	xxx	xxx	////	
5	//	<del>///</del> ///	xxx	xxx	xxx	<del>///</del>	
6	<del>///</del> 1	////	xxx	xxx	xxx	////	
7	<del>///</del> <del>///</del> 1	1	-	-	-	//	
8	<del>///</del>	<del>///</del>	1	1	1	1	
9	-	1	<del>///</del>	///	//	///	
10	-	1	<del>///</del> 1	//	-	<del>///</del>	
11	<del>///</del> 1	///	///	-	-	//	
12	///	<del>///</del> <del>///</del> 1	xxx	xxx	xxx	-	
13	///	<del>///</del> //	xxx	xxx	xxx	///	
14	-	<del>///</del> <del>///</del> ///	xxx	xxx	xxx	-	
15	<del>///</del> 1	////	xxx	xxx	xxx	////	
16	//	<del>///</del> //	xxx	xxx	xxx	<del>///</del>	
17	1	<del>///</del> <del>///</del> ///	xxx	xxx	xxx	-	
18	<del>///</del>	<del>///</del> ///	xxx	xxx	xxx	-	
19	<del>///</del> <del>///</del> 1	//	-	xxx	xxx	1	
20	///	<del>///</del> ///	xxx	xxx	xxx	///	

SAMPLE USAGE  
 (use for filling out  
 scorecard -  
 see p. 15)

ROUTINE EVALUATION OF NOTIFICATIONS

GRID FOR ANALYZING  
 WORKER INTERVIEW RESPONSES

*Tablled Responses Converted to Frequencies*

Q#	1	2	3	4	5	DK	NA
1	(7)	1	1	4	-	1	
2	5	(8)	xxx	xxx	xxx	1	
3	(7)	5	2	-	xxx	-	
4	4	(6)	xxx	xxx	xxx	4	
5	2	(8)	xxx	xxx	xxx	5	
6	(6)	4	xxx	xxx	xxx	4	
7	(11)	1	-	-	-	2	
8	(5)	(5)	1	1	1	1	
9	-	1	(5)	3	2	3	
10	-	1	(6)	2	-	5	
11	(6)	3	3	-	-	2	
12	3	(11)	xxx	xxx	xxx	-	
13	4	(7)	xxx	xxx	xxx	3	
14	-	(14)	xxx	xxx	xxx	-	
15	(6)	4	xxx	xxx	xxx	4	
16	2	(7)	xxx	xxx	xxx	5	
17	1	(13)	xxx	xxx	xxx	-	
18	5	(9)	xxx	xxx	xxx	-	
19	(11)	2		xxx	xxx	1	
20	3	(8)	xxx	xxx	xxx	3	

*(Modal responses are circled)*

ROUTINE EVALUATION OF NOTIFICATIONS

GRID FOR ANALYZING  
WORKER INTERVIEW RESPONSES

*Frequencies Converted to Percent of Responses*

Q#	1	2	3	4	5	DK	NA
1	50	7	7	29	-	7	
2	36	57	xxx	xxx	xxx	7	
3	50	36	14	-	xxx	-	
4	29	43	xxx	xxx	xxx	29	
5	14	57	xxx	xxx	xxx	29	
6	43	29	xxx	xxx	xxx	29	
7	79	7	-	-	-	14	
8	36	36	7	7	7	7	
9	-	7	36	21	14	21	
10	-	7	43	14	-	36	
11	43	21	21	-	-	14	
12	21	79	xxx	xxx	xxx	-	
13	29	50	xxx	xxx	xxx	21	
14	-	100	xxx	xxx	xxx	-	
15	43	29	xxx	xxx	xxx	-	
16	14	50	xxx	xxx	xxx	36	
17	7	93	xxx	xxx	xxx	-	
18	36	64	xxx	xxx	xxx	-	
19	79	14		xxx	xxx	7	
20	21	57	xxx	xxx	xxx	21	

Appendix B(2)  
EVALUATIVE SCORECARD BASED ON WORKER RESPONSES

	<u>Desired</u> <u>Response</u>	<u>Modal</u> <u>Response</u>	<u>Do they</u> <u>Match?</u> <u>YES</u> <u>NO</u>
<u>DID THE NOTIFICATION CONNECT?</u>			
% who report receiving info	> 80%	—	— —
Q1: Info seen as important	1 or 2	—	— —
Q2: Risk info was new	2	—	— —
Q3: Was read carefully	1 or 2	—	— —
<u>WAS THE CONTENT RETAINED AND/OR USED?</u>			
Q4: Remembers health effects	1	—	— —
Q5: Remembers action advice	1	—	— —
Q6: Could retrieve material	1	—	— —
Q18: Gave info to doctor	1	—	— —
<u>WERE THE MATERIALS WELL REGARDED?</u>			
Q7: Rated high overall	1 or 2	—	— —
Q8: Easy to understand	1 or 2	—	— —
Q9: Length was appropriate	3	—	— —
Q10: Factual info appropriate	3	—	— —
Q11: Sensitivity appropriate	1 or 2	—	— —
Q12: Info considered complete	2	—	— —
Q19: Glad info was sent?	1	—	— —
Q14: Did not cause problems	2	—	— —

Worker Interview Scorecard -- page 2

	<u>Desired</u>	<u>Modal</u>	<u>Do they</u>	
	<u>Response</u>	<u>Response</u>	<u>Match?</u>	
			<u>YES</u>	<u>NO</u>
<u>OVERLAP WITH OTHER FEEDBACK TO NIOSH</u>				
Q16: Redundant to postcards?	2	—	—	—
Q17: Redundant to call-ins?	2	—	—	—

POTENTIALLY USEFUL SUGGESTIONS

Selected comments from interviews, particularly on questions Q 13, 15, and 20;  
substantive suggestions only.

## APPENDIX C

### FORMS AND INSTRUMENTS SUGGESTED FOR TRIAL #3 DATA COLLECTION

1. Introductory Letter to Stakeholders  
[as used in Trial #2; needs recasting for Trial #3]
2. Introductory Letter to Workers  
[as used in Trial #2; needs recasting for Trial #3]
3. Revised Interview Guide for Stakeholders
4. Revised Worker Interview Instrument

Appendix C (1)

INTRODUCTORY LETTER TO STAKEHOLDERS

[On letterhead]

[Date]

[Address]

Dear \_\_\_\_\_:

You will be getting a telephone call from me within a few days. This letter is just to let you know what it's about.

As I'm sure you'll remember, last year the National Institute for Occupational Safety and Health (NIOSH) sent notification letters to a group of workers with possible exposure to Halowax, informing them of findings from the agency's research on such exposures.

NIOSH is very interested in knowing whether the information was effective and useful from the viewpoint of those involved. They want to gather some workers' opinions and reactions by telephone, and have asked me to make these calls on their behalf as an independent evaluation researcher. The survey deals only with the effectiveness of the NIOSH materials themselves, and does not involve any additional risk information or advice to the worker. I'm enclosing a copy of the questionnaire we'll be using. The calls will be made during the next few weeks to a randomly selected sample of the notified workers. While the name list and all information gathered are confidential, I wanted you to know that these calls are taking place, and what their purpose is.

In order to get a balanced view, I would also like to talk with individuals like yourself who were involved in NIOSH's "tripartite review" process in the initial stages of this notification effort. Your name has been given to me as someone whose opinions would be especially useful. I hope very much that you can spare about 15 minutes of your time to discuss the program from your own perspective.

I'll be calling you sometime within the next week or so. If the call comes at an inconvenient time, I'll gladly reschedule it for a better time. Your participation is voluntary, of course, but I do hope you'll help with this evaluation of NIOSH's notification procedures. Since the point of the research is to help NIOSH better understand the full range of reactions to their worker notification process, your input will be communicated to NIOSH staff in summarized form for internal agency use. In that sense your comments will not be entirely confidential. However, you will not be identified by name in any published report.

Thanks in advance. I look forward to talking with you.

Best wishes,

Carolyn Needleman, Ph.D.  
Professor and Director,  
Occupational and  
Environmental Health Program

Appendix C(2)  
INTRODUCTORY LETTER TO WORKERS

[On letterhead]

[Address]

[DATE]

Dear \_\_\_\_\_:

You will be getting a telephone call from us within a couple of weeks. This letter is just to let you know what it's about.

As you probably remember, last \_\_\_\_\_ you received some health information regarding workplace exposure to \_\_\_\_\_. The government agency providing the information was the National Institute for Occupational Safety and Health, usually called NIOSH.

NIOSH is very interested in knowing whether the information was effective and useful from the viewpoint of the workers who were notified. To find out, they want to gather some opinions and reactions by telephone. They have asked me to make these calls on their behalf as an independent evaluation researcher.

We took a random sample from the list of all workers who were given the information on \_\_\_\_\_, and your name came up by chance as one of the workers to be called. We hope very much that you can give about 15 minutes of your time to tell us your opinions.

Sometime within the next few weeks, you'll be getting a call either from me personally or from a co-worker named \_\_\_\_\_. If the call comes at an inconvenient time, we can arrange to call you back another time.

Your participation is voluntary, but we do hope you'll help with this study. It's for the purpose of improving services to America's workers. All information you give us will be kept completely confidential, and your name will not be used in any way.

Thanks in advance. We look forward to talking with you.

Best wishes,

Carolyn Needleman, Ph.D.  
Professor and Director,  
Occupational and  
Environmental Health Program

## Appendix C(3)

### REVISED INTERVIEW GUIDE FOR STAKEHOLDERS

Stakeholder interviews should take the form of conversations, not structured surveys. About 15 minutes of discussion should be enough, although they could run longer if the stakeholder wishes. The interviewer should jot down notes on main points expressed by the respondent, and consolidate these into a very brief summarized narrative immediately after the call. Lengthy, detailed narratives such as those in the Trial #2 report are probably not necessary.

Start out with a general open-ended question such as:

"We're trying to evaluate NIOSH's notification procedures and would welcome your opinions. As someone who was involved in the notification on \_\_\_\_\_, what do you think of the process used in that notification?"

Then where necessary, probe with:

"Was there anything that worked especially well?"

"Any particular problems?"

Appendix C(4)

TELEPHONE INTERVIEW GUIDE FOR WORKERS NOTIFIED BY LETTER

Notification Project: \_\_\_\_\_

Respondent ID \_\_\_\_\_ Interviewer: \_\_\_\_\_ Date of interview \_\_\_\_\_

INSTRUCTIONS:

Determine that the person on the line is the intended interviewee. Open with a natural-sounding paraphrase of the following script:

"Hello, my name is \_\_\_\_\_, and I'm calling on behalf of a government agency named NIOSH. We recently sent you a letter explaining that we would be calling you. Did you get that letter?"

["Good" or "Sorry, maybe it went to the wrong address."]

"Here's what it's about."

"Recently NIOSH sent letters to present and former employees of \_\_\_\_\_ about a study the agency did on the health effects of \_\_\_\_\_. We'd like to learn more about people's reaction to that information, so we're calling some of the workers to get their opinions."

"Do you remember getting some material in the mail recently about the health effects of \_\_\_\_\_?"

IF NOT, POLITELY TERMINATE & NOTE REASON BELOW.

"Your name came up just by chance, in a random sample of people who have worked at \_\_\_\_\_. If it's all right, I'd like to do a short, confidential telephone interview with you -- either right now, or at a later time if that's more convenient. The interview questions are not highly personal, and the whole thing takes about 15 minutes at most. Would that be all right with you?"

IF NO: Politely terminate, note refusal, and go on to next.

NOTE REASON FOR REFUSAL HERE:

---

IF YES, BUT LATER: Arrange a mutually convenient time.

NOTE TIME OF APPOINTMENT HERE:

---

IF YES, NOW: "Thanks very much; this will help us a lot. Before we do the interview, I'm required to read a brief consent statement, if you don't mind."

READ THIS CONSENT STATEMENT VERBATIM:

"You are being asked to participate in a NIOSH telephone survey. The purpose of the survey is to learn more about people's reaction to some government information they received in the mail. We will conduct an interview with you that takes about 15 minutes. The interview is completely voluntary. That is, you are not in any way required to participate, and if you want to, you can end the interview without penalty at any time. The information you give us will be treated in a confidential manner, and will not be released unless required by law under exemptions to the Privacy Act. Such releases are very rare. If you have any questions or complaints about the study, you should contact my supervisor, \_\_\_\_\_, at this number: \_\_\_\_\_.

Do I have your consent to do the interview?"

INTERVIEWER SHOULD SIGN THIS STATEMENT (do not read to respondent):

I, the interviewer calling on behalf of NIOSH, have accurately described this study to the participant and have secured his/her verbal consent to be interviewed.

\_\_\_\_\_  
(Signature of Interviewer)

THEN PROCEED WITH INTERVIEW.

## INTERVIEW QUESTIONS FOR WORKERS

(Circle appropriate response codes. Where relevant, jot brief comments on this form.)

1. How much importance did you place on the material you received in the mail about the health effects of \_\_\_? Did you consider it very important, somewhat important, right in the middle, somewhat unimportant, or very unimportant?

1 Very important  
2 Somewhat important  
3 Right in the middle  
4 Somewhat unimportant  
5 Very unimportant  
DK Don't know  
NA No answer

2. Before getting the material, did you think there was any health risk from working with \_\_\_?

1 Yes  
2 No  
DK Don't know  
NA No answer

3. How thoroughly did you read the information that came in the mail? Please be completely honest; we really want to know.

1 Very carefully (any part of it)  
2 Fairly carefully  
3 Looked through it quickly  
4 Did not read it at all  
DK Don't know  
NA No answer

4. As far as you know, are there any specific health problems that may be linked to \_\_\_ exposure?

1 Yes (What? \_\_\_\_\_)  
2 No  
DK Don't know  
NA No answer

5. As far as you know, is there anything that workers who were exposed to \_\_\_\_ in the past can do to protect their health now?

- 1 Yes (What? \_\_\_\_\_)
- 2 No
- DK Don't know
- NA No answer

6. Did you keep any of the material sent to you, in some place where you could refer to it again in the future?

- 1 Yes
- 2 No
- DK Don't know
- NA No answer

7. Overall, how would you rate this informational mailing? Was it very well done, somewhat well done, right in the middle, somewhat poorly done, or very poorly done?

- 1 Very well done
- 2 Somewhat well done
- 3 Right in the middle
- 4 Somewhat poorly done
- 5 Very poorly done
- DK Don't know
- NA No answer

8. In your opinion, how understandable was the information sent to you? Was it very easy to understand, somewhat easy, right in the middle, somewhat difficult to understand, or very difficult to understand ?

- 1 Very easy
- 2 Somewhat easy
- 3 Right in the middle
- 4 Somewhat difficult
- 5 Very difficult
- DK Don't know
- NA No answer

9. How about the length of the material? Was it much too short, somewhat too short, about right, somewhat too long, or much too long?
- 1 Much too short
  - 2 Somewhat too short
  - 3 About right
  - 4 Somewhat too long
  - 5 Much too long
  - DK Don't know
  - NA No answer
10. In your opinion, how appropriate was the amount of factual information contained in the material? Was it not enough information to be useful, not quite enough, about right, more than needed, or way too much?
- 1 Not enough
  - 2 Not quite enough
  - 3 About right
  - 4 More than needed
  - 5 Way too much
  - DK Don't know
  - NA No answer
11. How about the way the material was worded? In your opinion, was it very sensitive to people's feelings, somewhat sensitive, right in the middle, somewhat insensitive, or very insensitive?
- 1 Very sensitive
  - 2 Somewhat sensitive
  - 3 Right in the middle
  - 4 Somewhat insensitive
  - 5 Very insensitive
  - DK Don't know
  - NA No answer
12. Was there any important information left out, that you think should have been included?
- 1 Yes (What? \_\_\_\_\_)
  - 2 No
  - DK Don't know
  - NA No answer

13. Other than sending information in the mail, is there anything else that you think should be done to notify workers who had possible exposure to \_\_\_ in the past?
- 1 Yes (What? \_\_\_\_\_)
  - 2 No
  - DK Don't know
  - NA No answer
14. Did sending the information cause you problems of any kind?
- 1 Yes (What? \_\_\_\_\_)
  - 2 No
  - DK Don't know
  - NA No answer
15. If the government sends out information like this in the future, do you have any suggestions to make it more useful?
- 1 Yes (What? \_\_\_\_\_)
  - 2 No
  - DK Don't know
  - NA No answer
16. The material sent to you included a postcard for comments. Did you send back that postcard?
- 1 Yes
  - 2 No
  - DK Don't know
  - NA No answer
17. The material sent to you included a toll-free telephone number to call NIOSH (the government agency that mailed the information) if you had any questions. Did you use that telephone number at all?
- 1 Yes
  - 2 No
  - DK Don't know
  - NA No answer

18. The material sent to you included some information for your doctor about the health effects of \_\_\_\_\_. Did you pass that along to your doctor?

- 1 Yes
- 2 No
- DK Don't know
- NA No answer

19. Overall, are you glad the information was sent to you, or do you wish it had not been sent to you?

- 1 Basically glad
- 2 Neutral or mixed feelings
- 3 Basically wish not
- DK Don't know
- NA No answer

20. Is there anything else you think NIOSH should know about workers' response to getting that information in the mail?

- 1 Yes (What? \_\_\_\_\_)
- 2 No
- DK Don't know
- NA No answer

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"That's the end of the interview! Thanks so much. We really appreciate your help."