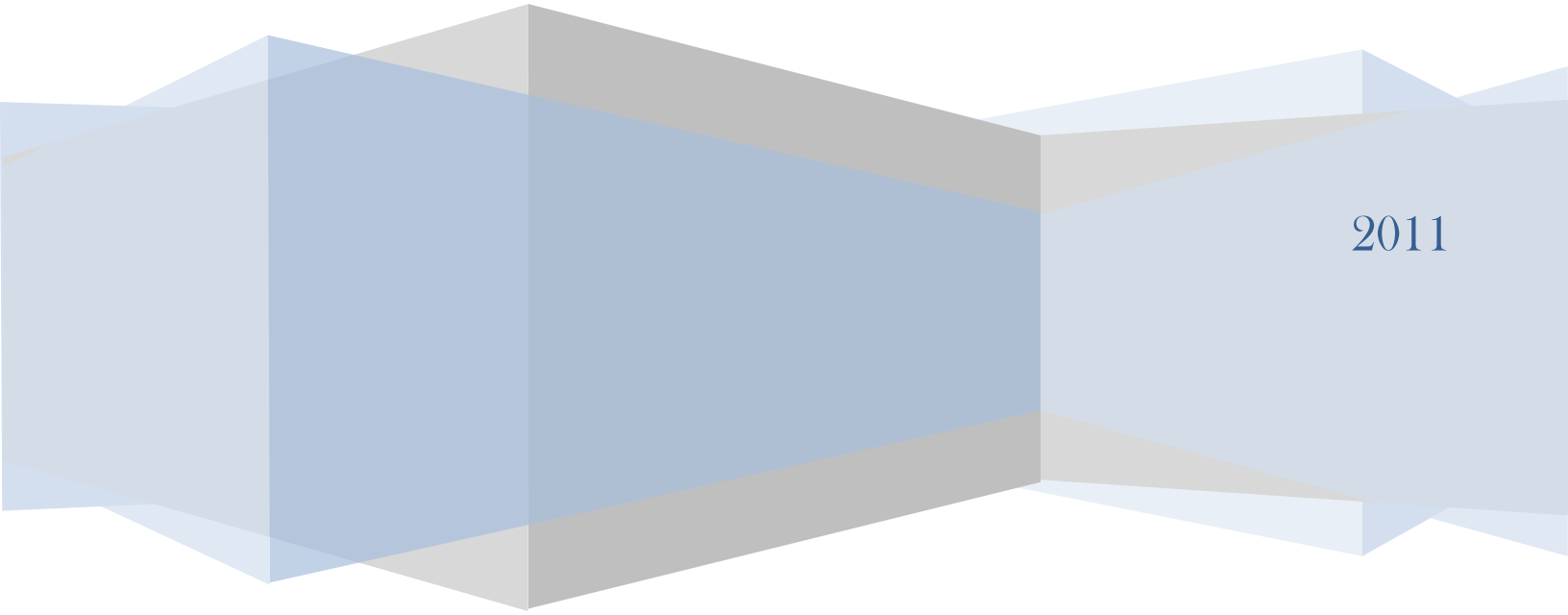
NIOSH Radiation Dose Reconstruction Program

Ten Year Review – Phase I Report

Quality of Service

Chia-Chia Chang



2011

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Submitted By

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Ten-Year Review of the NIOSH Radiation Dose Reconstruction Program

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Executive Summary

In 2009, the National Institute for Occupational Safety and Health (NIOSH) initiated a review of its program supporting the role of the Secretary of Health and Human Services under the Energy Employees Occupational Illness Compensation Program Act of 2000 (EEOICPA or the Act). As stated in the NIOSH Docket #194, Phase I of the review is a data-driven assessment of the dose reconstruction program, which will be used in Phase II of the review by NIOSH leaders to offer recommendations for improving the program. This report is the Phase I report on the customer service provided by NIOSH in the program. This report was based on comments from those who received services, as well as analysis of reports and communication documents. The report looked at the incorporation of information provided by claimants, petitioners, and their representatives; the understandability of NIOSH information; and other issues raised by comments to the docket and during nine interviews.

Incorporation of information provided by claimants, petitioners, and their representatives

Comments received from interviews and the public docket discussed the issues of incorporation of information provided by workers, affidavits, DOE information and worker information, incorporation of information provided by others, program integrity and claimant favorability, criteria for evaluating worker statements, deadlines for NIOSH response to worker-provided information, and program assumptions.

The author of this report reviewed the 2005 and 2009 NIOSH procedures for worker outreach meetings, as well as an external evaluation report on the 2009 procedures, observed and concluded the following:

- The 2009 procedures focus on activities before and during outreach meetings and provide less guidance than the 2005 procedures regarding capturing of worker comments and follow-up.
- Without specific procedures, there is no observed NIOSH policy requiring that worker comments be recorded and action taken on the comments.
- Developing criteria for following up on worker information, policies on following up, and deadlines could be useful steps toward ensuring that worker concerns are addressed and that worker information is taken into consideration.
- It may be useful for NIOSH to highlight the changes that have been made since the SC&A evaluations and take further actions as needed to improve worker outreach procedures and actions.

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The author of this report conducted of a sample of 100 dose reconstruction reports and Section 6 Incident Information from computer-assisted telephone interview (CATI) reports. The results of the analysis were as follows:

- Thirteen of the dose reconstruction reports did not mention the information provided in Section 6 of the CATI reports. Unlike the other dose reconstruction reports, these 13 dose reconstruction reports do not summarize the incident information provided by the claimant during the CATIs.
- Of the 85 cases in which claimant-provided information was fully acknowledged in the dose reconstruction report, in none of the records did NIOSH indicate that a change was made to the dose estimate based on claimant-provided information.
- In none of the 100 cases reviewed did NIOSH mention other kinds of follow up, such as talking to coworkers.
- There was little explanation of how the claimant-provided incident information was addressed by NIOSH.
- There were four cases in which NIOSH stated that it is not possible to know whether there was exposure, yet NIOSH believes that the dose estimate accounted for any potential dose.
- In most of the cases reviewed, NIOSH stated that the employee had a dosimetry record or monitoring. However, there was little indication that NIOSH had confirmed that the employee was monitored before, during, and after the reported incidents.

Understandability of NIOSH Information

Comments received from interviews and the public docket discussed the issues of the understandability of the processes of dose reconstruction and SEC petition, the understandability of scientific information, professional assistance sought, helpfulness of NIOSH assistance, impact on trust, and suggestions for NIOSH.

A readability evaluation was performed on a sample of NIOSH documents and webpages. The evaluation found the following:

- The six sampled dose reconstruction reports were written at grade levels four to six years beyond the high school education level.
- Of 29 webpages evaluated, only four were at or below the 12.0 grade reading level.
- Of the 12 printed educational materials, seven were at the 12.0 grade reading level or below.

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Other Issues Identified in Interviews and the Public Docket

Comments received from interviews and the public docket covered a few other topics:

- Burdens: preparation for dose reconstructions, barriers faced by workers and survivors, workers' access to information, survivors' access to information, reducing information requests, reducing the number of dose reconstructions, and "burden of proof";
- Access to information: specificity and clarity of citations and reports, availability of information, access to information used by NIOSH to make decisions, Freedom of Information Act (FOIA) requests, and transparency;
- Communications: communications with staff, responsiveness of staff, mistakes in oral and written communications, communications with the Department of Labor (DOL);
- Assistance to claimants and petitioners: program procedures, assistance during CATIs, attendance at meetings, role of others, recommendations for NIOSH;
- Trust and conflict: trust in the program and the government and potential conflicts of interest; and
- Issues addressed in other sections of the Phase I review: science, decisions, and timing

Conclusions

Comments of interviewees and docket submissions identified issues which NIOSH may wish to consider for improving customer service of the dose reconstruction program. Analysis of data indicates that there are opportunities for strengthening NIOSH communication of its use of information from workers and for increasing the understandability of NIOSH information. These issues, as well as others raised by respondents, should be considered during Phase II of the ten-year review.

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Background

In 2009, the National Institute for Occupational Safety and Health (NIOSH) initiated a review of its program supporting the role of the Secretary of Health and Human Services under the Energy Employees Occupational Illness Compensation Program Act of 2000 (EEOICPA or the Act). As stated in the NIOSH Docket #194, Phase I of the review is a data-driven assessment of the dose reconstruction program, which will be used in Phase II of the review by NIOSH leaders to offer recommendations for improving the program. Both phases cover the following five issues:

- The quality of science practiced in the program at the current time as well as throughout the evolution of the program (quality of science).
- The timing of the accomplishment of NIOSH program tasks (timing).
- The appropriateness and the consistency of decisions regarding petitions to add groups of claimants to the Special Exposure Cohort (SEC) established under the statute
- The appropriateness and the consistency of individual dose reconstructions
- The quality and timing of service provided to claimants and petitioners, and their representatives (customer service).

The findings and conclusions expressed in this report are exclusively those of the author(s) and do not necessarily represent the views or position of the National Institute for Occupational Safety and Health (NIOSH), the Centers for Disease Control and Prevention (CDC), or the Department of Health and Human Services (HHS). This document is only one of many inputs that the NIOSH Director may consider in the ten-year review of NIOSH's performance under the Energy Employees Occupational Illness Compensation Program.

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The following is the Phase I report on the last issue, customer service provided by NIOSH in the program. This report looks at the following issues:

I. **Incorporating Information Provided by Claimants, Petitioners, and Their Representatives**

   A. Comments from Interviews and the Public Docket
   B. Procedures for Worker Outreach Meetings
   C. Incident Information from the Computer Assisted Telephone Interview (CATI)

II. **Understandability of NIOSH Information**

   A. Comments from Interviews and the Public Docket
   B. Readability Evaluation

III. **Other Issues Identified in Interviews and the Public Docket**

   A. Burden
   B. Access to Information
   C. Communications
   D. Assistance to Claimants and Petitioners
   E. Trust and Conflict
   F. Science, Decisions, and Timing

Introduction

As part of the Phase I report, this section assumes a working knowledge of NIOSH activities under EEOICPA. Information for this section was based on comments from those who received services, as well as analysis of data from reports and communication documents. Comments were gathered from the public docket (discussed in other sections of the Phase I report), website feedback, and key informant interviews.

Feedback was collected on the website of NIOSH Division of Compensation Analysis and Support (DCAS), the NIOSH arm which carries out responsibilities under EEOICPA, during the period of August-November 2010. Initially, 3% of website visitors received a pop-up box to provide feedback; the percentage was increased to 14% to increase the opportunity for feedback. Starting in October, the top of every DCAS webpage included a link to the website feedback for all visitors. By November, five comments were received, which are listed in Appendix A. [Although the survey has been removed for the purposes of

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the ten-year review, the DCAS website still provides a link for visitors to offer feedback for continuous improvement of the site and program.]

To learn about the first-hand experience of claimants, petitioners, workers, survivors, and advocates with the program, nine phone interviews were conducted. The aim was to obtain feedback from people who had not submitted comments to the docket and who had experienced either the dose reconstruction process and/or the SEC petition process**.** The key informant interviews were based on suggestions from Lewis Wade, Special Assistant to the NIOSH Director; Laurie Breyer, SEC Petition Counselor[1]; Denise Brock, NIOSH Petitioner/Claimant Ombudsman; and follow-ups from the interviewees. The people interviewed were the following:

Andrew Evaskovich, petitioner and advocate
Laurence Fuortes, petitioner and advocate
Karen Johnson (joined by Mary Johnson, survivor), petitioner and advocate
Jan Lovelace, claimant and survivor
Hugh Stephens, advocate
Loretta Valerio, advocate
Anthony Windisch, claimant
Kathy Wolf, claimant and survivor
Anonymous, advocate (did not wish for name to be released)

Notes from the interviews were sent to the interviewees for review to ensure accuracy. Appendix B provides all the interview notes after redactions for compliance with the Privacy Act.

Comments to the docket are available at http://www.cdc.gov/niosh/docket/archive/docket194.html

[1] Joshua Kinman currently serves in the role of NIOSH SEC Petition Counselor.

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I. Incorporating Information Provided by Claimants, Petitioners, and Their Representatives

Claimants, petitioners, and their representatives may provide information to NIOSH to support their dose reconstruction or SEC petition evaluation. Information may be provided through different channels, including but not limited to the following:

- Documents such as SEC petitions and those of the claims process,
- Meetings such as NIOSH-sponsored worker outreach meetings or the public comment periods of the Advisory Board on Radiation and Worker Health,
- Computer assisted telephone interviews (CATIs) with claimants, and
- Other communications with NIOSH, such as emails, postal mail, and phone conversations.

One aspect of customer service is the degree to which NIOSH listens to or pays attention to comments from claimants, petitioners, and their representatives. This may be reflected in the extent to which claimants and petitioners feel that their information has been incorporated into dose reconstruction reports, site profiles, SEC petition evaluations, and other reports. Following is a review of the way that NIOSH follows up on information received from workers and survivors during CATIs and NIOSH worker outreach meetings.

A. Comments from Interviews and the Public Docket

Below are topics raised in the docket and during interviews regarding NIOSH incorporation of information from workers and survivors.

Incorporation of information provided by workers

> "If an individual works at a facility that has a spill every day, but the spills aren't big enough to be investigated or reported to DOE, those small, constant exposures could be looked at." [Valerio]
>
> "…we ask that the review of the program will…Review all public comments to determine if worker or worker advocates provided NIOSH with oral history or documents that were not reflected in NIOSH technical documents…we ask for fair treatment of workers and acceptance of the information they have shared or will share in the future. In most instances, the only real way to evaluate earlier periods of time is through worker histories. Historical records often were not kept or have been destroyed." [Alliance of Nuclear Worker Advocacy Groups (ANWAG) comments to the docket, March 2010]
>
> "Two separate NIOSH representatives gave conflicting accounts as to whether worker oral histories, offered during the CATI interviews, are given any consideration when reconstructing dose….ANWAG

questions whether NIOSH accepts and subsequently investigates work histories provided by workers/claimants during CATI interviews or whether such accounts are ignored when reconstructing dose?" [ANWAG comments to the docket, April 2010]

Affidavits

"Five years ago, NIOSH started requiring signed affidavits to verify claimants and their stories. NIOSH gets information without affidavits from health and safety officers…don't know if they're also put in private rooms and intimidated like workers are…NIOSH doesn't require affidavits when they talk to health physicists or program administrators or other sources of history." [Fuortes]

"Worker affidavits do not appear to be acknowledged, ever, whether for dose reconstructions or petitions. I've had many people say they've sent multiple affidavits in, but when they talk to the Department of Labor (DOL) or NIOSH, they're basically ignored. I've been told by a NIOSH health physicist that worker affidavits are usually not used, probably because NIOSH claims to use overestimates, so they don't need it I guess, but that's never explained." [Johnson]

"One of the affidavits pointed out that that his badge changed color when it was dipped in a solution; they never said anything about it and just gave him a new badge the next day. That wasn't acknowledged in the denial letter." [Johnson]

DOE information and worker information

"NIOSH relies on the records at the site, even though they're supposed to take into account the claimants' statements." [Evaskovich]

"Whatever the workers say in the computer assisted telephone interview is ignored by the claims examiner unless it's corroborated in the record…the blanket tendency of NIOSH to ignore testimony of a claimant in the event it is not corroborated by site records should be adjusted." [Stephens]

"In general, NIOSH appears to endorse a low weighting to eyewitness worker outreach and interview testimony and affidavits. Interview information is used selectively without adequate justification in technical reports." [McKeel comments to the docket, June 2010]

Incorporation of information provided by others

"I've never heard of any coworkers being contacted. I would like to see them do that, especially for the elderly who don't remember. It would be good to contact coworkers or others who work in the same general areas." [Valerio]

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> "We had somebody – an operator who worked for [energy employee]– write a letter on our behalf on the kind of work that [energy employee] did...We're not sure the kind of hands on work he did was taken into account." [Wolf]

> "We submitted letters from coworkers…None of [energy employee's] coworkers' statements have been taken into consideration…For DOL or NIOSH to not accept statements from supervisors is wrong. They didn't even accept statements from the [medical providers]." [Lovelace]

> "If the claimant has a letter from a physician saying that it's a work-related cancer, then NIOSH should at least address the letter from the physician." [Valerio]

The ANWAG March 2010 submission to the docket included comments from McKeel regarding NIOSH and the NIOSH contractor, Oak Ridge Associated Universities (ORAU):

> "NIOSH and ORAU should make better use of claimant information from the CATI interviews and outreach meetings in creating and revising their technical documents."

Program integrity and claimant favorability

> "I understand there needs to be some sort of corroboration…NIOSH needs to prevent fraud, so it can't base decisions on the uncorroborated testimony of a worker where that worker is in a position to make things up to allow him/her to qualify. But the record keeping is insufficient, and in a claimant favorable program, exceptions need to be made." [Stephens]

Criteria for evaluating worker statements

> "...is it possible that one dose reconstruction team considers these histories while other teams consider them suspect? What criteria have been established by NIOSH to determine and/or assess the credibility of workers' statements during CATI interviews? Have the dose reconstruction teams developed any site specific metric to evaluate workers' statements to initiate subsequent data capture efforts to verify workers' statements?" [ANWAG comments to the docket, April 2010]

> "What steps will be taken by NIOSH to review the process by which ORAU evaluates worker statements/affidavits in the SEC evaluation process to ensure that ORAU is investigating any and all potential exposure issues raised by workers?" [American Federation of Labor and Congress of Industrial Organizations (AFL-CIO) Building and Trades Department comments to the docket]

Deadlines for NIOSH response to worker-provided information

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"A NIOSH policy that states when site related e-mails, faxes, and letters will be answered from workers, site experts, claimants, and SEC petitioners would be very helpful to limit the number of separate communications." (McKeel comments to the docket, June 2010)

Program assumptions

"NIOSH staff has overtly stated the following bias BEFORE obtaining worker histories…'We start with the assumption that this was a safe workplace and there were no errors or missing information. We trust our information. You have to provide & prove any conflicting information.'…should be the opposite…All it indicates is evidence of lack of good record keeping…Decisions should be weighted in the context of worker histories, i.e., what workers tell NIOSH, if there is no data." [Fuortes]

Author Observations and Conclusions

1. Two respondents noted that workers and survivors may have information that is not in DOE records which could be useful. One respondent believed that NIOSH does not incorporate information from workers even when there are signed affidavits. Two respondents questioned the criteria or process for evaluating information submitted by workers for incorporation by NIOSH.

2. Three respondents believed that NIOSH seems to place more weight on information from DOE than on information from workers. One respondent questioned whether signed affidavits are required from all data sources or only workers.

3. Two respondents suggested that NIOSH take into consideration information from supervisors and medical professionals. Other information from claimants, including letters from coworkers, were also suggested as information which NIOSH should address and/or accept.

4. These comments indicate that there should be more explanation of NIOSH policies on how it evaluates, corroborates, and incorporates information from different sources. This could foster more accurate expectations of how the information will be used and reduce misunderstandings about use of information from DOE, workers and survivors, and others.

5. When there is a lack of data, one respondent believed that it seems as if though the burden is on claimants/petitioners to provide data and proof of exposure. Another respondent suggested that while NIOSH needs to prevent fraud, claimant favorability needs to be considered.

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6. One respondent recommended setting policies regarding when NIOSH would respond to information provided by workers.

B. Procedures for Worker Outreach Meetings

To obtain information for dose reconstructions and SEC petition evaluations, NIOSH holds worker outreach meetings. Procedures for the worker outreach program were originally developed in 2005 (Appendix C). In 2009, a new document outlining procedures was approved (Appendix D). The following briefly summarizes both procedures.

The 2009 procedures were reviewed by SC&A, a contractor tasked by the Designated Federal Official to conduct work for the Outreach Work Group of the Advisory Board on Radiation and Worker Health. A brief summary of the findings from the SC&A report (Appendix E) is below.

The 2005 and 2009 procedures and the 2010 SC&A review are Appendices C, D, and E, respectively.

Procedures

ORAUT-PROC-0097, the procedures approved in 2005, outlined the following steps, including deadlines as appropriate for each procedure:

1. Arranging Worker Outreach Meetings
2. Preparing and Distributing Meeting Materials
3. Conducting the Worker Outreach Meeting
4. Preparing Meeting Minutes
5. Extracting Comments and Determining Which Comments Require a Response
6. Selecting Comment Recipients
7. Generating and Reviewing Comment Responses
8. Reporting Scheduled Actions and Follow up

The records generated may include notifications about the meetings, the Worker Input to Site Profile Revisions (WISPR) database, as well as "draft meeting minutes sent to labor organizations and meeting attendees for comment; final meeting minutes; formal comments on draft meeting minutes provided by labor organizations and meeting attendees; and other input (hardcopy and electronic) received from individual workers, unions, and other parties."

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OCAS-PR-012, the procedures approved in 2010, outlined the following steps with no deadlines specified:

1. Identifying the Need for Outreach Effort
2. Identifying the Need for Outreach Support Contractor (OSC) Team Support for Outreach Efforts
3. Arranging Outreach Efforts
    - Initiating support
    - OSC activities
    - Preparing Meeting Materials
    - DOL notification as appropriate

The Outreach Tracking System (OTS) database tracks information such as "correspondence… issue tracking, etc." The procedure lists three types of records that may be generated: "meeting minutes, sign-in sheets, and formal letters to claimants and stakeholders."

Appendices included the "General Meeting Structure and Discussion Points" and "Outreach Meeting Process Activities." The process activities during meetings include noting or identifying issues/needs; after meetings, process activities include reviewing minutes and identifying, inputting, and tracking issues. No details were provided on these activities.

SC&A Findings

Major findings of SC&A regarding the 2010 procedures were that it did not resolve the original issues and "eliminated many of the positive elements" of the 2005 procedures. SC&A found that the 2009 procedures:

- did not "provide direction for tracking, trending, evaluating, or responding to worker input;"
- did not "specify criteria for identifying action items or for evaluating the adequacy and timeliness of response/resolution;"
- did not have the "majority of expected documentation" in the OTS database;
- did not "define processes or requirements for several venues of worker outreach" and seemed to give "site expert interview records more weight than worker input obtained through outreach meetings;" and
- did not ensure "that worker feedback is accurately and completely documented."

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SC&A also recommended that NIOSH ensure that recordings, minutes, notes, and worker information captured during meetings are submitted for classification review as appropriate; notify participants that the purpose of the meetings is to solicit information that is not classified for national security and provide alternate, private venues if requested by workers; provide a call-in number for those who cannot physically attend meetings; and communicate conflict of interest and bias disclosures at the beginning of meetings.

Author Observations and Conclusions

1. The 2009 procedures focus on activities before and during outreach meetings and provide less guidance than the 2005 procedures regarding capturing of worker comments and follow-up.
2. Without specific procedures, there is no observed NIOSH policy requiring that worker comments be recorded and action taken on the comments.
3. Developing criteria for following up on worker information, policies on following up, and deadlines could be useful steps toward ensuring that worker concerns are addressed and that worker information is taken into consideration.
4. It may be useful for NIOSH to highlight the changes that have been made since the SC&A evaluations and take further actions as needed to improve worker outreach procedures and actions.

C. Incident Information from the CATI

To examine the extent to which NIOSH follows up on information provided during CATIs, the author of this report reviewed a sample of CATI reports and compared them to the final dose reconstruction reports. The review looked specifically at the CATI Section 6 Radiation Incidents, which asked "Was the Covered Employee ever involved in an accident involving radiation exposure or contamination?" and the dose reconstruction report section entitled, "Dose from Radiological Incidents." 100 CATI reports were chosen at random from the population of interviews which had entries in Section 6 and had completed dose reconstructions which had a probability of causation (POC) of less than 50%.

Findings are discussed below.

Thirteen of the dose reconstruction reports did not mention the information provided in Section 6 of the CATI reports. Unlike the other dose reconstruction reports, these 13 dose reconstruction reports do not summarize the incident information provided by the claimant during the CATIs.

Typical language from the thirteen dose reconstruction reports was the following:

> "No radiological incidents were reported during the interview…"
>
> "No incidents were discussed in the interview or were found in the dosimetry records. Additionally, no information was raised in the interview to suggest that the doses estimated in this dose reconstruction are not claimant favorable."
>
> "The record of the telephone interview was evaluated carefully by the dose reconstructor. No additional information affecting the dose reconstruction was identified."

In addition, there were two dose reconstruction reports which noted some of the information provided during the phone interview, but not all.

Of the 85 cases in which claimant-provided information was fully acknowledged in the dose reconstruction report, in none of the records did NIOSH indicate that a change was made to the dose estimate based on claimant-provided information.

In none of the 100 cases reviewed did NIOSH mention other kinds of follow-up, such as talking to co-workers.

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It was not evident in the dose reconstruction reports' discussions on dose from incidents that any action was taken. In one dose reconstruction report, the only NIOSH response to the CATI incident information was the following statement:

> "A search of the site records and those provided by the Department of Energy [for employee] did not produce records of radiological incidents, or personal exposures due to radiological incidents [at site]."

There were no explanations of how NIOSH determines when worker or survivor provided information is insufficient and that substantiation is needed.

There was little explanation of how the claimant-provided incident information was addressed by NIOSH.

Two examples of NIOSH responses are below:

> "Although no monitoring records were available, the claimant-favorable assumptions applied in this dose reconstruction would take into account any potential radiation doses received during this incident."

> "The maximizing assumptions applied in this dose reconstruction would account for any exposure [to employee] during his employment [at site]."

There were six cases in which such statements regarding claimant favorability were the entirety of the dose reconstruction reports' response to incident information provided during CATIs.

In another 12 cases, the NIOSH response consisted of only stating that no information was found in the DOE records and that overestimates were made.

There were four cases in which NIOSH stated that it is not possible to know whether there was exposure, yet NIOSH believes that the dose estimate accounted for any potential dose.

There was little explanation of how the estimated dose addressed the claimant-provided incident information, given the lack of information.

> "Without additional information or an approximate date, it would be difficult to address this potential incident. Additionally, no information was found in the records provided by the Department of Energy that would indicate involvement in an explosion. The claimant-favorable overestimates of external and internal dose applied in this dose reconstruction would account for

any potential radiological exposures that [employee] may have received while employed at the [sites]."

"The available records do not contain information about this event so it cannot be determined if it involved exposure to radiation or radioactive materials. The doses applied in this dose reconstruction are overestimates and should account for incidental radiation exposure that may have occurred."

"No incident information was provide[d] by the DOE for [employee] so it is not known if he was involved in any incidents where one of these machines found significant contamination."

"Without details such as location, date and likely activities being performed, no adjustment to [employee's] dose can be made based on this comment. As previously described, only radiation dose from occupationally related medical X-ray procedures has been evaluated in this dose reconstruction; therefore, this incident information has not been evaluated."

In most of the cases reviewed, NIOSH stated that the employee had a dosimetry record or monitoring. However, there was little indication that NIOSH had confirmed that the employee was monitored before, during, and after the reported incidents.

An example of such language is below:

"Based on the time frame [employee] worked at the site [years] and the fact that he was monitored for external exposure periodically, assumptions noted in this report account for recorded exposure and potential unmonitored exposure, both internally and externally, and are considered claimant favorable."

There is no confirmation that the periodic monitoring included the time periods mentioned in the incident information.

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Author Observations and Conclusions

1. The number of cases (15) in which claimant-provided incident information was not fully acknowledged in the dose reconstruction report suggests both a need to better capture information, and quality control to ensure that interviewee comments are noted in dose reconstruction reports.

2. Follow-up on the incident information seemed to consist of only searching for DOE information. It would be informative to discuss any other follow-up that was conducted, such as interviewing coworkers and using information from those interviews.

3. Not making changes to the dose because no DOE records were found seems to indicate that DOE records are more accurate than worker comments. NIOSH may wish to consider providing information on the validity and reliability of DOE recordkeeping and how decisions are made regarding which source to use when there is conflicting information.

4. The NIOSH response to most information was to state that dose estimates were overestimates and were claimant-favorable. This does not seem to directly respond to claimant comments. Customer service would be improved by providing more detailed, case-specific responses.

5. In none of the 100 cases reviewed did NIOSH indicate that a change was made to the dose estimate based on claimant-provided incident information. There could be more clarity if the reports highlighted any changes that were made to dose reconstruction reports based on information provided by workers or survivors.

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II. Understandability of NIOSH Information

Information that NIOSH provides to claimants, petitioners, and their representatives include the processes of the program (i.e., dose reconstruction and SEC petition evaluation processes), the findings of NIOSH (dose reconstruction reports, SEC petition evaluation reports, technical information bulletins, site profile documents, etc.), the status of a claim or petition, and more.

Such information is shared by NIOSH in different ways, including but not limited to the following:

- the NIOSH website,
- personal communications (email, postal mail, phone, in-person meetings),
- written documents,
- public meetings to disseminate program information, including revisions of site profiles,
- educational dose reconstruction workshops for invited advocates,
- meetings requested by the public, such as those to discuss the SEC process, and
- meetings held by DOL to which NIOSH is invited.

Following is a review of the understandability of the information provided by NIOSH.

A. Comments from Interviews and the Public Docket

Below are topics raised in the docket and during interviews regarding the understandability of NIOSH-provided information.

Understandability of the processes of dose reconstruction and SEC petition

> "The complexity of the key process, namely Dose Reconstruction, is well beyond the average claimant, and no meaningful attempts have been made by NIOSH to clarify in detail how the dose reconstructions are done on a case by case basis and how the percentages were derived…While the scientific detail NIOSH provides is impressive, it is simply unreasonable to expect claimants to understand this process, or to be able to respond to NIOSH in cases where claims have been denied based solely on this information." [Bennett comments to the docket]

> "NIOSH presents its decisions in language a majority of people do not understand… NIOSH fails to keep SEC petitioners informed about the process." [AFL-CIO Building and Trades Department comments to the docket]

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"The basic stuff is on the web, you can look it up. But at the Board meetings, most of the petitioners don't know what the next step is --they don't even know what a Board meeting is, what the protocol is." [Johnson]

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Understandability of scientific information

"Are reports sent to claimants being prepared in such a way that they can be understood by a high school graduate, as is specified in both the 2002 and 2009 ORAU contracts?" [AFL-CIO Building and Trades Department comments to the docket]

"I've helped with claimants, explaining the dose reconstruction reports. I don't think most of the claimants understand them. The structure of the reports, the long introduction –I can understand why it's there, but it takes a number of pages to get to the meat of the report." [Evaskovich]

"The dose reconstruction reports are lengthy and language can be very overwhelming to read. They're technical documents, so I know that this may be unrealistic." [Valerio]

"We received a letter saying NIOSH was going to be over the 180 days for completing the evaluation report. The letters were wordy, not simplistic, not clear. Seemed like they were written in a biased viewpoint. Somebody needs to write these from the viewpoint of a petitioner." [Johnson]

"As an environmental attorney, I run into this type of thing all the time –complicated science I'm not familiar with, and I can generally do that, but I haven't been able to do that in the context of the dose reconstruction." [Stephens]

"…their explanations of what they've done-- is very complicated for most claimants…I'm capable of understanding anything that makes sense. I've spoken with many claimants, and the DRs do not make sense to most." [Lovelace]

"It was very difficult for [energy employee]…he had a rough time reading and writing…If I wasn't there, he wouldn't have been able to…understand the pages and pages of dose reconstruction reports and the response deadlines…I'm an engineer, I worked in the industry, so it wasn't that difficult to understand the information. But to call and ask questions, you had to go through a phone tree, and he had trouble doing that on his own." [Wolf]

"On a scale of 1 to 10, 10 being the most difficult to understand, I'd have to place the information as a 9 or 9.5, extremely complex." [Anonymous interviewee]

Professional assistance sought

"Weldon Spring has gotten extremely technical…The site expert we had helping us –if we didn't have that, we really wouldn't understand." [Johnson]

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Quality of Service

"We feel like eventually, we'll be able to find a health physicist to help us make compelling arguments to attack the dose reconstruction." [Stephens]

Quality of Service

Helpfulness of NIOSH assistance

"Something that NIOSH did that I think is very favorable: Claimants get a packet of materials. It includes a handout with the 14 steps, with a check mark showing the step you're at." [Anonymous interviewee]

"For the most part, I believe that people understand the dose reconstruction process... Again, as far as them explaining to us the process and being available to assist petitioners, they've been wonderful." [Valerio]

"Some ANWAG advocates recently attended the NIOSH two-day workshop in Cincinnati which explained the dose reconstruction and SEC programs. The workshop was very helpful and informative." [ANWAG comments to the docket, April 2010]

"I've met the NIOSH people at the Board meetings --they will help you when you talk to them. But not everyone can go to the Board meetings. I just call and talk to the NIOSH people I know –not everyone knows can do that. Normally, during the CATIs, it's just someone calling to ask them questions." [Anonymous interviewee]

"The NIOSH annual DR workshops do allow time for Q&A and direct, nearly one on one, interactions with DCAS staff…However, access to these sessions is by invitation and is weighted towards union representatives at large DOE sites. DOE sites get better service from NIOSH than AWE sites" [McKeel comments to the docket, June 2010]

Impact on trust

"There's a lack of communication with the petitioners, no real guidance. So I have a lack of trust in NIOSH and their ability." [Johnson]

Suggestions for NIOSH

"A petitioner should have someone assigned to them to hold their hand through the process. I know a lot of agencies don't like to hold someone's hand, but this is a very important process. We're talking about workers –even attorneys would have a hard time. A worker deserves better treatment….Something needs to be provided to us, maybe a list of independent health physicists who could consult for free with us." [Johnson]

"I think the program benefits from the participation of advocates…DOL should make available a list of licensed, certified advocates –it's better if there's no relationship with the program…Now that the

fee limits are part of the program's legislation, that's enough to prevent claimants from being taken advantage of." [Stephens]

"Put it in layman terms. Spell it out to me so I can help the claimants. Generate an online tutorial for representatives, an explanation of dose reconstruction, or at least give them a number to call. Make the dose reconstruction more open to the needs of the claimants. Some people can understand and could appreciate the trainings. Go a step further. There could be some form of instructional tool, maybe a CD…" [Anonymous interviewee]

"There wasn't a disable-friendly process…It would help to have a contact who could sort of walk you through these things if you do have disabilities or somehow take into account people who have difficulty reading and writing if you have a disability." [Wolf]

Author Observations and Conclusions

1. Most of the respondents consider the processes and program information to be complicated and difficult to understand. This may be due to the complexity of the information as well as the way the information is communicated.
2. Two respondents, including an environmental attorney advocate, said that they sought professional experts to help with the scientific and technical information.
3. Four respondents believed that assistance from NIOSH has been helpful, although it is not always available to everyone.
4. Respondents suggested that NIOSH provide tutorials, workshops available to all, and access to independent health physicists or advocates.
5. NIOSH should explore ways in which the process and information can be more disability friendly to better address the needs of the claimant and petitioner population.

B. Readability Evaluation

The author of this report analyzed the readability of a sample of NIOSH dose reconstruction reports, webpages, and educational materials using Microsoft Word 2007 grammar check function readability evaluation tool, which calculated the Flesch Kincaid Grade Level. The Flesch Kincaid Grade Level is

Quality of Service

based on the number of words per sentence and the number of syllables per word. Only the text of the reports was evaluated; tables, references, cover pages, and footnotes were omitted.

Quality of Service

Dose Reconstruction Reports

An evaluation of the grade level of dose reconstruction reports was conducted. As noted by the AFL-CIO Building and Trades Department comments to the docket, the following is in the ORAU contract language:

> "3.2 The contractor will collect and analyze all available information relevant to dose estimation/reconstruction for each individual claim and produce and transmit to NIOSH a draft report providing dose estimates, methods, and the factual basis upon which the doses were estimated, including a narrative explanation of this information understandable by claimants with a high school education." http://www.cdc.gov/niosh/ocas/pdfs/orau/drcntrt2.pdf

Below is an analysis of the readability of dose reconstruction reports numbers 5000, 10000, 15000, 20000, 25000, and 30000. The six reports were written at grade levels four to six years beyond the high school education level.

Document	Grade Level
Dose reconstruction report 5000	17.1
Dose reconstruction report 10000	17.6
Dose reconstruction report 15000	16.8
Dose reconstruction report 20000	18.2
Dose reconstruction report 25000	16.3
Dose reconstruction report 30000	17.7

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Quality of Service

Webpages

Twenty-nine webpages with substantive content were analyzed. Not included were the 22 webpages that consisted mostly of links to other pages or documents; 42 archived historical pages, and 110 pages of links about specific work sites.

Of 29 webpages evaluated, only four were at or below the 12.0 grade reading level.

Page	Grade Level
About DCAS http://www.cdc.gov/niosh/ocas/ocasabt.html	17.3
Advisory Board http://www.cdc.gov/niosh/ocas/ocasadv.html	15.9
Conflict or Bias Policy and Disclosure Statements http://www.cdc.gov/niosh/ocas/ocascobs.html	16.3
DCAS Home http://www.cdc.gov/niosh/ocas/	15.8
Dose Reconstruction http://www.cdc.gov/niosh/ocas/ocasdose.html	15.6
General Activities on Atomic Weapons Employer (AWE) Cases http://www.cdc.gov/niosh/ocas/ocasawe.html	15.6
General Activities on Department of Energy (DOE) Cases http://www.cdc.gov/niosh/ocas/ocasdoe.html	14.8
How to Submit an SEC Petition http://www.cdc.gov/niosh/ocas/how2add.html	13.7
Phone Interview Information http://www.cdc.gov/niosh/ocas/phone.html	13.6
Probability of Causation –NIOSH IREP http://www.cdc.gov/niosh/ocas/ocasirep.html	15.8
Program Evaluation Reports (PERs) and Program Evaluation Plans (PEPs) http://www.cdc.gov/niosh/ocas/ocaspers.html	16.6
Quality Assurance/Quality Control Activities http://www.cdc.gov/niosh/ocas/ocasqaqc.html	14.6
SEC Home http://www.cdc.gov/niosh/ocas/ocassec.html	14.3
Submissions not Qualifying for Evaluation http://www.cdc.gov/niosh/ocas/noqual.html	15.4
Technical Documents Used in Dose Reconstruction http://www.cdc.gov/niosh/ocas/ocastbds.html	15.9
FAQs The Act http://www.cdc.gov/niosh/ocas/faqsact.html	12.6
FAQs Case Concerns http://www.cdc.gov/niosh/ocas/faqscp.html	11.0
FAQs Claimant Correspondence http://www.cdc.gov/niosh/ocas/faqscc.html	11.6

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Quality of Service

FAQs Conflict or Bias (COB) Policy http://www.cdc.gov/niosh/ocas/faqscob.html	13.1
FAQs Dose Reconstruction http://www.cdc.gov/niosh/ocas/faqsdr.html	13.7
FAQs Freedom of Information Act (FOIA) http://www.cdc.gov/niosh/ocas/faqsfoia.html	10.1
FAQs National Defense Authorization Act http://www.cdc.gov/niosh/ocas/faqsdaa.html	13.7
FAQs NIOSH-Interactive RadioEpidemiological Program http://www.cdc.gov/niosh/ocas/faqsirep.html	12.7
FAQs Probability of Causation http://www.cdc.gov/niosh/ocas/faqspoc.html	13.4
FAQs Residual Contamination Report http://www.cdc.gov/niosh/ocas/faqsrc.html	15.2
FAQs Responsibilities under Subtitle B of EEOICPA (The Act) (Agency, Advisory Board, and Contractor)http://www.cdc.gov/niosh/ocas/faqsar.html	14.4
FAQs Technical Documents http://www.cdc.gov/niosh/ocas/faqstd.html	12.2
FAQ SECs http://www.cdc.gov/niosh/ocas/faqssec.html	14.0
FAQs Telephone Interviews http://www.cdc.gov/niosh/ocas/faqsint.html	11.6

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Quality of Service

Printed Educational Materials

Of the 12 printed educational materials, seven were at the 12.0 grade reading level or below.

Document	Grade Level
Fact Sheet: A Closer Look Behind Your Claim: Dose Reconstruction http://www.cdc.gov/niosh/ocas/pdfs/misc/2005-144.pdf	12.3
Fact Sheet: A Closer Look Behind Your Claim: Probability of Causation http://www.cdc.gov/niosh/ocas/pdfs/misc/2005-141.pdf	12.2
Fact Sheet: A Closer Look Behind Your Claim: Residual Contamination http://www.cdc.gov/niosh/ocas/pdfs/misc/2005-142.pdf	14.2
Fact Sheet: A Closer Look Behind Your Claim: Special Exposure Cohort http://www.cdc.gov/niosh/ocas/pdfs/misc/2005-143.pdf	10.5
Fact Sheet: A Closer Look Behind Your Claim: Technical Basis Documents http://www.cdc.gov/niosh/ocas/pdfs/misc/2005-140.pdf	11.1
Brochure: Let's Talk About Your Claim http://www.cdc.gov/niosh/ocas/pdfs/misc/2005-145.pdf	11.4
Brochure: Office of Compensation Analysis and Support http://www.cdc.gov/niosh/ocas/pdfs/misc/2002-137.pdf	11.4
What a Claimant Should Know About Radiation Dose Reconstruction http://www.cdc.gov/niosh/ocas/pdfs/misc/2002-138.pdf	13.1
Overview of the Dose Reconstruction Process under the Act http://www.cdc.gov/niosh/ocas/pdfs/misc/overview.pdf	9.5
Detailed Steps in the Dose Reconstruction Process http://www.cdc.gov/niosh/ocas/pdfs/misc/detailedsteps.pdf	11.1
Glossary of Terms http://www.cdc.gov/niosh/ocas/pdfs/misc/glossary.pdf	12.3
Frequently Asked Questions http://www.cdc.gov/niosh/ocas/pdfs/misc/drfaqs.pdf	11.3

Author Observations and Conclusions

1. The six sampled dose reconstruction reports were written at grade levels four to six years beyond the high school education level. Of 29 webpages evaluated, only four were at or below the 12.0 grade reading level. Of the 12 printed educational materials, seven were at the 12.0 grade reading level or below.

2. To be better understood by a greater number of people, dose reconstruction reports, webpages, educational materials, as well as other documents (SEC petition evaluation reports, etc.) should be written at or below the 12th grade reading level. It may be helpful to provide short, easy to read summaries.

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Quality of Service

III. Other Issues Identified in Interviews and the Public Docket

Other issues identified in public comments and during the interviews were the burden on claimants and petitioners to provide information, access to information used by NIOSH to make decisions, written and oral communications by NIOSH, the assistance provided by NIOSH to claimants and petitioners, and trust or conflict of interest.

[Also mentioned were the issues addressed in other sections of the report regarding the science, decisions, and timing; since they are covered by other sections of this ten-year review, they will be only briefly mentioned below.]

A. Burden

Topics raised in the docket and during interviews are discussed below.

Preparation for dose reconstructions

> "Sometimes, claimants don't understand what information they're being asked for…Stuff gets missed and you end up redoing the dose reconstruction." [Evaskovich]

> "People should be encouraged to understand what's going on when they're describing what they know, and it's just not fair for a NIOSH representative to be asking questions of the claimant without encouraging the participation of an advocate, without any incentive for a claimant to be somehow prepared for the interview…The burden on claimants is significant, but understandable." [Stephens]

Barriers faced by workers and survivors

> "The timing of the CATI is usually when people are getting treatment, radiation therapy --it's a lot more difficult for them to remember." [Evaskovich]

> "At Pantex, some are still working at the site. They don't want the employer to know who said what about historical exposures and risks. They're afraid for their well being and for their children. It's a relatively small community, so they're also concerned about their children's employment." [Fuortes]

Workers' access to information

> "So many workers weren't aware of what they were exposed to. But they know that they were in those areas." [Valerio]

Quality of Service

"…The site has been destroyed; there is no information. Unless we kept stuff, how would you know? It's a backward way of doing things. Individuals don't usually keep dose records and things like that." [Wolf]

"Workers were held under secrecy. Things that are almost classified information in some cases. They're very high tech questions. Some former workers can't even remember things themselves." [Anonymous interviewee]

"Workers had worked under 'need to know.' They don't know how many thousands of pounds of uranium or other substances were used. Their knowledge was limited." [Fuortes]

Survivors' access to information

"In some cases claimants were asked to provide specific dates where their Husband/Father worked at the plant. In other cases they were asked to provide the department where their Husband/Father worked, or they were asked to provide the clock number of their Husband/Father. How could anyone possibly expect that anyone would be able to provide this type of information when the events in question occurred over 60 years ago at a plant that in effect no longer exists." [Bennett comments to the docket]

"NIOSH demands too much evidence from claimants, especially survivors… NIOSH processes are never-ending." [AFL-CIO Building and Trades Department comments to the docket]

"There are so many questions asked of former workers, especially surviving spouses, siblings, etc.…unanswerable because there is no way they could know, they have no way of responding effectively…If the person doesn't have a subject matter expert on the site…the questions really can't be answered. That's something that needs to be looked at." [Anonymous interviewee]

"The CATIs for survivors are difficult, especially survivors who aren't familiar with the facility or the work. Survivors just don't have access to that information, especially if it's classified." [Valerio]

"In the interview, you go through the potential isotopes you were exposed to… if you were an operator or a spouse who never worked in the industry, how would you have a clue?" [Wolf]

Reducing information requests

"It had included a list of people to contact…When I asked about it, they said, 'We only contact them if we need to.'...There's a lot of up front paper work that wasn't ever used. If they aren't going to

use them, why bother?...a lot of the things took a lot of time, back & forth in the telephone interview…Only ask for the information that you need." [Wolf]

"Could make process more humane and more efficient…Shouldn't ask claimant questions just to check off a box in the process; should ask about things only if they are relevant to the decision making. The process is stalled because of this…Salaried scientists at NIOSH –not contractors-- could put some thought into what to do…Algorithms could be developed covering common scenarios to streamline the process and save time, money, and confusion." [Fuortes]

"For SEC members in part B who have a medical diagnosis and verified employment, the DOL resource center should not go over their work history and exposure, and NIOSH should not have to ask about duration of work/job titles/etc. Only the 250 days employment in a covered facility and covered cancer are at issue." [Fuortes]

"…Why does NIOSH do more interviews with survivors who have just lost a loved one after their initial claim was approved but who died before the claim process was finalized?...They can always provide comments; however, NIOSH and DOL should not hold up the claims process nor subject the claimant to additional questioning." [Fuortes]

Reducing the number of dose reconstructions

"People with six or seven skin cancers who worked for 20 years are likely to be compensated, but if people with only one skin cancer never get compensated, then why are dose reconstructions being done for them?" [Fuortes]

"...Why does NIOSH push for people to pursue dose reconstructions for things that claimants haven't brought up? If you already know that the data shows that the POCs will be less than 50%, then don't subject the person to the process…" [Fuortes]

"It's a little confusing that every time an individual is diagnosed with a new condition, they have to go through a new dose reconstruction. It doesn't seem cost effective." [Valerio]

"Burden of proof"

"The burden of proof is always on the person submitting the claim. It's always, 'Do you have more information?'" [Wolf]

Quality of Service

"I was told that I could attach the SC&A report to my petition, along with worker affidavits, but after I submitted it, I was notified that it wasn't acceptable –I needed to quote excerpts from the report." [Johnson]

"It's a time consuming process to challenge a dose reconstruction. We're probably not going to be successful most of the time." [Stephens]

Quality of Service

Author Observations and Conclusions

1. Although CATIs and submission of work history information are voluntary, there is concern that the program places on claimants and petitioners the responsibility of proving exposure.

2. Based on comments from respondents that NIOSH requested "specific dates" and "excerpts," better explanations could be provided regarding information requests, the mandatory information needed from claimants and petitioners, and the role of NIOSH in obtaining information for dose reconstructions and petition evaluations.

3. Two respondents suggested that NIOSH better explain CATIs and prepare claimants for the interviews and the information that will be requested of them.

4. NIOSH should take into consideration circumstances faced by workers and survivors, such as the passage of time, burdens of illness, lack of technical expertise, fear of retribution by current energy employers, and systematic lack of information sharing given national security concerns.

5. To reduce burden, it was suggested that NIOSH request information only if the information will be used. Two respondents believed that some dose reconstructions and interviews seem unnecessary. NIOSH should examine its procedures and eliminate any steps that are redundant or are barriers to timely, effective dose reconstructions and petition evaluations.

B. Access to Information

Topics raised in the docket and during interviews are discussed below.

Specificity and clarity of citations and reports

"The citation method is completely inadequate…the citation should be 'this document, this page.' Should give you enough information that if you're willing to do the work, you can find the document." [Stephens]

"Information that should be included in the report: the data that they applied and didn't apply to the dose reconstruction. Some reports explain, e.g., 'The dose reconstruction didn't apply ambient because this other data was used instead. We used missed dose for these specific years, etc.' All the reports should have this information. The dose reconstruction reports don't always say if they applied miss or ambient dose." [Evaskovich]

"NIOSH reports that represent second attempts (i.e., are DR "reworks") do not generally spell out exactly what parameters or assumptions were changed…" [McKeel comments submitted to the docket by ANWAG, March 2010]

"…the differences in parameters and assumptions used in both DRs are not stated clearly in the second DR report. Changing this policy would be immensely helpful to claimants. A table comparing DR1 and DR2 parameters and assumptions would greatly alleviate this problem…" [McKeel comments to the docket, June 2010]

"There is inadequate feedback to SEC petitioners on what site information was captured, apart from number of boxes and very general descriptions such as number of documents…The issues matrices I have seen have never included any entries under 'Board Action' to indicate current status of Findings…NIOSH and SC&A do not keep the SEC and TBD site profile issues matrices PA cleared versions up to date and distributed appropriately. There is continued confusion tracking the latest and last updated versions at work group meetings involving NIOSH discussants that impede progress. Valuable work time on crowded agenda items is wasted because of this factor…" [McKeel comments to the docket, June 2010]

Quality of Service

Availability of information

"The burden on the claimants is extremely hard when we can't have access to files." [Lovelace]

"In one case, they use a 1958 memo available on the DOE website, but the website has only 3 out of the 5 pages, and there are a lot of attachments to the memo that aren't available on the internet. This piece of evidence that has been cited is not available." [Stephens]

"It costs money to get the measurements and ICRP models --about $200 every time…NIOSH could buy and make available these ICRP models, but they're probably proprietary information…" [Stephens]

"…when I put in my authorized advocate form, I usually request the file, and I get the file very quickly. I think that's a very good thing. We don't have to pay for it –that's great. We almost never have to charge clients anything like in a typical personal injury." [Stephens]

"In accessing documents on websites (guidelines, TIBs), I've found that the website has been helpful. I check the website daily to see if any new information pertains to me…But not everyone is computer savvy or has access to internet as far as good downloads…A lot of workers are retired, senior citizens, and may not be into computers." [Evaskovich]

Access to information used by NIOSH to make decisions

"If individual wants a copy of whatever was used to do their dose reconstruction, there shouldn't be any privacy issues since it's part of their claim file. It has to go to DOE to be declassified and takes an act of Congress to get the information." [Valerio]

"NIOSH has health physicists and boxes of data and no transparency with community stakeholders about what is known or unknown from primary sources. Petitioners do not and did not have access to these data…Anything that's not affected by national security or confidentiality should be on a common website. NIOSH shouldn't be using information that's not available to petitioners (except security)." [Fuortes]

"I got a letter saying that even though mine didn't qualify, they found other reasons to make it qualify. The letter didn't say what those reasons were." [Johnson]

"The surrogate data issue came up. [NIOSH staff] says he has real data to replace the surrogate data. We don't know what that data is." [Johnson]

Quality of Service

Freedom of Information Act (FOIA) requests

"Sometimes, FOIA requests aren't responded to in a timely manner or at all. I had a request denied because it was determined that I was using it for personal gain. Nothing could be further from the truth." [Anonymous interviewee]

"It is nearly impossible to access information. I have requested records under FOIA numerous times, and I've yet to get the papers I am asking for and get the same records as before. In the papers I did get, I've received five other people's files…DOE tells me they had no records. Well, it's law that they keep records." [Lovelace]

"We wanted to file a FOIA request –that was a huge roadblock…They said it could take up to two years…It's not clear which agency you're supposed to send it to…We refined our search --I still don't like it. I did get a packet from NIOSH. They said we could have it within a couple of weeks. I got it a couple of months later –three days prior to the Board meeting. I don't know if I got everything that I requested –how would I know?...They claimed that the NIOSH presentation interviewed nine people –I got three and haven't seen others…I later got a CD which was about 500 documents –and it wasn't necessarily documents that NIOSH had used…I haven't followed up because I was so aggravated the first time. I'm obviously not going to get anywhere." [Johnson]

"My experiences with the CDC FOIA office have been very unfavorable. In my opinion, they have practice censorship, caused delays, not found all responsive documents, have not always cited FOIA allowed exemptions, and have made inappropriate redactions…" [McKeel comments to the docket, June 2010]

Transparency

"Decisions should be independent and science based, not political…Discussions should be made transparent to the public…Scientific and financial arguments are going on behind the scenes…" [Fuortes]

"NIOSH is not being forthcoming with their evidence, so I don't trust it. Again, customer service goes a long way with trust. If they would call and explain why they haven't given me the information, that could go a long way." [Johnson]

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Quality of Service

Author Observations and Conclusions

1. Two respondents indicated that they believed that people should have access to information used for dose reconstructions or petition evaluations. Another respondent believed that claimant burden would be reduced if there is more access to information. There was also a mention of the importance of transparency and the decrease in trust caused by the lack of information.

2. Two respondents expressed satisfaction with some of their access to information, but both also provided examples of the limitations to the access to information.

3. Based on these comments, access to the information used by NIOSH to make decisions could be increased by addressing barriers such as cost, inconvenience, and lack of timeliness. NIOSH should provide the information in a manner that would facilitate use of the data/information by others.

4. Three respondents gave specific examples of information which NIOSH could provide which would help them better understand NIOSH reports. For example, an improved citation method could help claimants and petitioners follow up on dose reconstruction, SEC petition evaluation, and other reports.

5. Four respondents stated difficulties with the process of obtaining information under FOIA. An item for consideration is to better explain the FOIA process and to work with other offices to consider ways to increase timeliness and responsiveness.

6. Providing full, free, immediate, and convenient access to information may increase trust in the program and NIOSH. In making information more available, NIOSH would need to address issues related to the time it takes NIOSH to complete tasks, privacy protections, and the understandability of information.

Quality of Service

C. Communications

Communications with staff

"As an advocate, I assisted people with claims and sit in on CATI interviews. In that arena, I have nothing but praise: the people from NIOSH are very cordial, some have gone out of their way, actually stopped the interview because some things were missing in the file." [Anonymous interviewee]

"It's been my experience, whenever I'm dealing with the people at DCAS, they're always friendly and helpful; I've always had the ability to get my questions answered. I never talk to the health physicists, so I don't know if they've been helpful to claimants, but the people I meet at the Board meetings have always been very helpful. I personally can't say anything negative about customer service from that aspect." [Evaskovich]

"…[NIOSH staff] encouraged them to take a look at the petition again, and we did get it reversed" [Johnson]

"I've gone to the workshops, Board meetings, met with the people from NIOSH. They've been very cooperative and helpful. Every time I've talked to staff, personnel at NIOSH, they have all been very, very helpful. Very thorough in explaining things and responding." [Valerio]

"…my experience with NIOSH has been polite, businesslike, and dreadful. Beginning with the receipt of my NIOSH dose reconstruction on December 19, 2009, my continuing conversations with NIOSH have been evasive, non committal, and I thought a male representative was rude in his comments." [Windisch]

"You just talk to the interviewer, and most of them aren't technical people. I had one who you would think was a robot. He'd say 'yes,' 'no,' 'I do not know' just like a robot: short and abrupt." [Lovelace]

"We did the initial telephone interview back then, obviously with someone who didn't have a clue about the kind of work we did." [Wolf]

"The phone call with the health physicists and ORAU was itself adversarial. I was condescendingly reminded what a critical incident is." [Johnson]

Quality of Service

Responsiveness of staff

"…I was always given a short, canned answer that sounded like procedure: 'I haven't heard anything.' Or if I asked for a specific question, I would get a procedural answer: 'This is what normally happens.' Not my specific answer. And even the procedural answer wasn't always correct." [Johnson]

"There was a lot of wasted time where we got repeated status reports that were of no value…You can never get a straight answer." [Wolf]

"Customer service has been lacking since the beginning when I started filing SEC petition." [Johnson]

"We hear several repeated complaints from claimants…NIOSH staff does not listen to the claimants." [AFL-CIO Building and Trades Department commented to the docket]

Mistakes in oral and written communications

"I was told that I could attach the SC&A report to my petition, along with worker affidavits, but after I submitted it, I was notified that it wasn't acceptable…" [Johnson]

"There are a lot of mistakes. I was showing them: 'are' instead of 'area,' 'no' instead of 'not' –that makes a big difference." [Lovelace]

"We got the dose reconstruction report back; it had lots of errors, so we had to get it corrected." [Wolf]

Communications with DOL

"We deal with the claims examiners, who work for DOL...Our communication with NIOSH tends to be filtered by the DOL claims examiner." [Stephens]

"There are problems with the information reported by DOL to NIOSH: wrong type of cancer, etc. I would like for claimants to be able to give information directly to NIOSH (and copy DOL) so it can be faster instead of having to channel everything through DOL. If there's more than one cancer, maybe NIOSH could contact claimant to follow up, instead of DOL." [Valerio]

Quality of Service

"NIOSH gets a black eye because of wrong information from DOL…there's a certain degree of unfairness…NIOSH is doing the best with what they've got…Sometimes, things get lost. When someone refers to a certain document or something that should be in the file, it's not always there." [Anonymous interviewee]

Author Observations and Conclusions

1. There seems to be inconsistency in the personal communications by staff in terms of friendliness, helpfulness, and responsiveness. It may be useful to provide more staff training in risk communication and conflict resolution.
2. The quality of written communications can be improved to reduce errors, which may increase creditability and trust.
3. To address concerns from three respondents regarding DOL, NIOSH could try to work with DOL to consider ways to reduce mistakes.

Quality of Service

D. Assistance to Claimants and Petitioners

Program procedures

"I don't understand why ORAU or NIOSH wouldn't call a petitioner and ask for clarification…They could call the petitioner and help, saying, 'We don't think this is going to work, but here's what you could do.'" [Johnson]

"Instead of assisting people with SECs, DCAS had denied petitions, then being made to reverse the denials during administrative review." [Fuortes]

"The rationale of protecting national security interests and not being able to accept the history of workers is part of the pattern of obstruction of the SEC process and has intimidated workers…Examples of intimidation: 'Since you're going to be talking about potential national security issues, we need to take you to a private room.' It's tactless, a power ploy, intimidating. The process is clearly designed as 'We have authority; you guys don't.'" [Fuortes]

Assistance during CATIs

"The interviews follow the form, which is convenient, but not good interview technique –they don't try to involve the senses, emotions, to stir the memory. They tend to be pretty dry, which isn't a rich environment for extracting information, trying to get the workers to remember the places where they worked…The workers may consider something a small thing, but it may be beneficial to get credit for exposures. I'm not sure how to fix that to make it work for both sides. I know it takes a lot of time to conduct dose reconstructions. Maybe something we advocates need to work on to assist people." [Evaskovich]

Attendance at meetings

"Petitioners and the community are not advised in a timely fashion about Board meetings…There's no excuse for that to not be dramatically improved…Should give more notice when conveying to the public and the media." [Fuortes]

"More than a month out would be helpful, especially for advocates. I travel on my own time and expense. If NIOSH could get the contracts with the hotels sooner, that would be helpful. That would be a cost benefit for NIOSH as well, saving flight costs. But, I understand there are guidelines concerning procurement and dealing with hotels." [Evaskovich]

Quality of Service

"I'm told by more than one person at NIOSH that it's beneficial if petitioners can be at meetings in person, whether it's a workgroup or Board. Petitioners are doing this on our own time. It would be helpful if they could pay for something, even if it's just for travel to one Board meeting that you're on the agenda for or a workgroup meeting." [Johnson]

Role of others

"At least one…[client] was contacted by NIOSH after I put in my authorized representative notice. NIOSH shouldn't be contacting…without attempting to include me in the conversation. It's good for the integrity of the program for the advocate to appear as if the advocate is connected with the program and things aren't just happening out of the blue. " [Stephens]

"In an ideal world, there wouldn't be a perception of 'us versus them.' Personally I have repeatedly been made to feel like a persona non grata…People such as myself, Former Medical Worker Medical Screening Program Principal Investigators (FWP PIs), and other persons with professional expertise regarding workers' histories, exposures, health experiences and claims and SEC petition experiences would like to work 'with' rather than 'counter to' colleagues at NIOSH & DOL…Unless there is a collegial process, then it feels like you're just tossing in your two bits when and where they aren't wanted." [Fuortes]

Recommendations for NIOSH

"I think there should be some type of oversight board which checks into our complaints." [Lovelace]

"We should be working with DOL as coalitions of agencies and individuals figuring out what's the right thing to do…Could have a community review board which gets input from academics and former workers on science and other issues…In particular, when there are decisions to be made. If someone is being obstructionist or a cog in the administrative wheel, there should be someone who can facilitate the process to get on with it and change the status quo." [Fuortes]

Author Observations and Conclusions

1. Respondents provided examples of ways in which NIOSH could be more helpful to claimants and petitioners. One respondent expressed concern that NIOSH intimidates workers. New strategies could be developed to reach out to assist in identifying exposures.

The findings and conclusions expressed in this report are exclusively those of the author(s) and do not necessarily represent the views or position of the National Institute for Occupational Safety and Health (NIOSH), the Centers for Disease Control and Prevention (CDC), or the Department of Health and Human Services (HHS). This document is only one of many inputs that the NIOSH Director may consider in the ten-year review of NIOSH's performance under the Energy Employees Occupational Illness Compensation Program.

Quality of Service

2. Respondents recommended that NIOSH to make a greater effort to work collaboratively with advocates and others in the community.
3. Claimants and petitioners may be more able to attend meetings if NIOSH announced meeting dates and locations sooner and provided financial assistance.
4. It was suggested that a position or entity be developed to respond to complaints and obtain feedback from and communicate with the community.

E. Trust and Conflict

Trust in the program and the government

> "…had me shred records. I'm sure I've shredded some of the records that the men and women need right now. When you work in a DOE facility, you do what you are told to do…not realizing the consequences 30 years later." [Lovelace]
>
> "It seemed obvious that ORAU was told to find a reason to deny it…
>
> "…lack of trust with NIOSH…is valid and long standing…
>
> "…From the claimant side, it looks like they're buying our site experts..." [Johnson]
>
> "We are totally disgusted how our government has enacted this program. We will never trust them again." [Anonymous comment to the docket]
>
> "Compensation is not a reward –it is Symbolic of a country who is grateful to a patriotic American who would sacrifice his or her life for their country…But I sometimes wonder how people can continue to believe in government when it is so shamelessly corrupt." [Padilla comments to the docket]

Potential conflicts of interest

> "…Even though they're not working on individual claims, when they make programmatic decisions, that affects everyone...I know they called in top notch professionals, but there's conflict…It's not a level playing field...It's difficult for us to believe that there isn't some sort of bias…" [Anonymous interviewee]
>
> "It was confusing why NIOSH staff can do work on a site even though they had been there in the past, but if a claimant has a site expert, they're not allowed to work on the site if they've ever spoken a word on the claimants' favor." [Johnson]
>
> "Contractors presumably get paid based on the number of dose reconstructions done, so there could be pressure within the system to conduct dose reconstructions even if they are futile." [Fuortes]

Author Observations and Conclusions

Quality of Service

1. Comments during interviews and in the docket indicate that dissatisfaction in the program may have led to mistrust of the program and the government, including NIOSH and DOE. This lack of trust should be considered in communications and developing program policies.

2. NIOSH should examine and change the policies and actions which create conflicts of interest.

F. Science, Decisions, and Timing

During the telephone interviews conducted for this section on customer service, comments were also made about the quality of science, the appropriateness of decisions on SECs and individual dose reconstructions, and timeliness – topics addressed in other sections of this ten-year review. Below are excerpts on those topics. Since the topics are covered by other sections of this report of the ten-year review, only a few quotes are listed below. As mentioned previously, complete notes from the interviews are in the appendix of this report.

Quality of science

Incomplete or missing data:

"Some of the data sets have been very small: one sample for bioassay…six samples altogether." [Evaskovich]

"I felt I was sent on a wild goose chase…NIOSH says that if nothing can be found on it, then it wasn't used. The whole point of filing an SEC is because the data wasn't there. It contradicts the whole purpose." [Johnson]

"You see 'assumed' many times in dose reconstruction letters. When we file a claim, we can't assume that someone has a medical condition. We can't assume anything." [Anonymous interviewee]

"In the CATI Incidents section, some of the incidents weren't sufficient in magnitude to be reported, but they're nevertheless incidents." [Valerio]

"Why did they use a temporary dosage for my dose reconstruction rather than using my actual records?" [Windisch]

Unreliability of records:

"…there's an effort by the contractor to comply with regulations --and that need to comply provides the contractor with an incentive to downplay the incidents. So the likelihood that an

accident would've occurred that's not record in any detailed way and that an exposure occurred that's not part of the record is extremely significant…The incentive to underestimate a hazard is significant. How you use the report needs to be considered in light of the context, time period, incentives, that the report was written." [Stephens]

Quality of Service

> "The SEC petition used many documents from the Federal lawsuit case. It spelled out that the record keeping wasn't the best. The data NIOSH is using to do dose reconstruction is the same data that was not accurate and was frivolous. I'm can't challenge the methodology of the science, IREP, dose reconstruction, etc., but I can challenge the reliability of that data. The court document says this was bad information." [Anonymous interviewee]

Coworker or surrogate data:

> "[energy employee]…walked back and made sure his team was doing the work correctly; he had incidents at [site]…We're not sure the kind of hands on work he did was taken into account." [Wolf]

> "Even though we've presented his rad badges…He was given less probability of exposure than someone who was driving outside the gate… They said the coworker could have been a mechanic on the other end of the plant. It should've been the people that [energy employee] worked with." [Lovelace]

Appropriateness and consistency of decisions on individual dose reconstructions and SEC petitions

> "Claimant favorability is talked about a lot. When a technical document changes, it may not be favorable for the claimant." [Anonymous interviewee]

> "One of my criticisms is that you can't ever criticize their model. We were working with an epidemiologist…to revise the IREP model, which treats brain cancer the same as the nervous system…There needs to be more transparency on the model and how it works. If there's evidence the model is inadequate, they should take steps to adjust it." [Wolf]

Quality of Service

Probability of Causation:

> "I know they use efficiency measures because it speeds things up. You're encouraged to turn in more things because it helps the claim, but their next POC number is lower…It gives NIOSH a black eye because it's hard for people to understand…I've been to the IREP trainings where people are helping claimants…There needs to be a better explanation…The efficiency measures are almost taking away due process." [Anonymous interviewee]
>
> "The method for probabilities makes no sense…'" [Lovelace]

Timeliness

> "Some dose reconstructions are processed in a few weeks, so it makes you wonder why some take years. Seems like they're either taking too long or not enough." [Valerio]
>
> "SEC decisions should be made in a more timely manner. I understand there's a lot of reading, research involved. But usually, petitioners have it pretty well documented that people were not monitored…As an advocate, I feel that for the older claims that are still in process, if new information surfaces on these facilities, an SEC makes it so much more claimant favorable for the worker or the survivor." [Valerio]
>
> "NIOSH doesn't abide by the same rules that it imposes on SEC petitioners. NIOSH and DOL write letters giving times constraints for responses to petitioners and claimants, but they take all the time in the world to generate such letters. NIOSH gives little time for response from petitioners --some are widows going through recent loss or people dying of cancer." [Fuortes]

Author Observations and Conclusions

1. There is concern about the issues identified in other sections of the ten-year review: quality of science, decisions, and timeliness of the program.
2. Satisfaction with the quality of services delivered by the dose reconstruction program may increase if changes were made to the scientific and administrative procedures.

Conclusions

Comments of interviewees and docket submissions identified issues which NIOSH may wish to consider for improving customer service of the dose reconstruction program. Analysis of data indicates that

there are opportunities for strengthening NIOSH communication of its use of information from workers and for increasing the understandability of NIOSH information. These issues, as well as others raised by respondents, should be considered during Phase II of the ten-year review.

Appendices

Appendix A: Website Feedback

Appendix B: Phone Interview Notes

Appendix C: Conduct of the Worker Outreach Program, ORAUT-PROC-0097, 12/29/2005

Appendix D: Worker Outreach Program, OCAS-PR-012, 3/4/2009

Appendix E: Review of OCAS-PR-012, SCA-TR-PR2010-0002, 4/2010