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## HISTORICAL NOTES FROM THE HANFORD HEALTH AND MORTALITY STUDY

- 1965 Identification of operations cohort begins
- Identification of sib controls begins
- SSA trial to obtain sib SSN begins
  - Staff reported that records for separated employees had been destroyed as specified by federal government record disposal policies and that there was no way to identify where people worked at a given point in time. (Prog. Report 1, 1965, p. 5-1).
- 1966 First SSA submission
- 15,000 operations employees
  - 25,000 same sex sibs as controls for genetic and early environment
  - Attempt to identify two additional matched controls from SSA continuous work history sample (CWHS) records, who never worked at an AEC facility
- 1967 Reported that 2/3 of the sib controls had no date of birth. This hindered finding their SSN.
- 1968 5,000 records shipped to duPont when GE took over (these were recalled from the "duPont Hall of Records" and then returned).
- 1969 Historical identification of operations cohort complete
- 35,000 operations employees including nonstart control group
- Prospective enrollment begins
- Suggest inclusion of the 6,500 construction workers
- Job codes and organizational data collection completed
- SSA Commissioner authorized release of disability data and wage history data for cohort and all control subjects. Required strict audit procedure by SSA. (Data not available.)
- 1970 First death certificates ordered from individual states and the V.A.
- Test of SSA with known Hanford deaths
- Estimate 7% missed by SSA
- SSA authorizes release of more detailed data on disability, illness, and premature withdrawal from workforce. (Data not available.)

- 1971 Noted that PSQs had been selectively destroyed  
SSA could not identify 24% of sib controls.  
Mancuso, Sanders and Brodsky present first study of longevity to AEC staff in May. Mancuso announced members of his advisory committee: K.Z. Morgan, A. Stewart, W. Snider, A. Brues, H. Parker, H. Shulte, Hubler, and Elston. (AEC May 12, 1971 Meeting in Germantown).  
At the May 12 meeting it was stated that Sanders recommended sampling SSA tax return to assess the completeness of the cohort roster.
- 1972 Noted that sibs were never intended to be the only controls  
Concerned that internal controls were not a good choice  
Study reviewers concerned about selection of external controls
- 1973 SSA selects matched controls from CWHS
- 1974 Planning of hospital validation of selected causes of death begins then is deferred to 1975. (Never done)  
Second suggestion for inclusion of construction workers (first suggestion 1969)  
Suggest collection of off-site dosimetry (done)  
Suggest validation of roster using SSA reports (based on problems at Oak Ridge) (Never done)
- 1975 Ascertainment of deaths among SSA matched controls begins  
Stewart begins new analysis in May because of 'problems' with earlier analyses
- 1976 First analysis of sibs and one set of SSA (CWHS) matched controls completed  
■ MSK present analysis at DOE-HQ

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- 1977 Decision to drop second SSA (CWHS) matched control because of sampling problems
- 7000 death certificates on hand with another 14,000 notices of deaths. The 1985 mortality file shows only 5,657 on hand (must include sibs?)
- Cause of death available for 97% of known Hanford deaths
- Stewart completes and publishes first analysis
- ORAU ships certificates for sibs and SSA (CHWS) controls
- 1978 Transition
- PNL analysis complete
- 1979 PNL analysis published (Gilbert & Marks)
- K. Heid begins identification of construction sub-contractor employees from dosimetry files
- National Advisory Committee formed
- 1980 Sibling control file sent to storage
- files incomplete and SSA no longer provides SSN numbers for persons whose names are submitted
- Updated analysis published (Gilbert & Marks)
- 1981 Request for all file copies of weekly reports of hired and terminated JAJ employees. Lists found back to the late 1950's. New lists from 1981 forward become routine accessions.
- 1983 Updated analysis published (Tolley, Marks, Buchanan & Gilbert)
- 1985 Neverstarts removed from OHH master file, tape to storage and printed list to Research
- 1987 Updated analysis submitted to journal (Gilbert, Petersen & Buchanan)
- Analysis of lung cancer case-cohort study completed (Petersen, Gilbert, Stevens & Buchanan)
- DOE pooling projects were assigned. HEHF is the lead investigator for a case-control study of multiple myeloma.

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- 1987      Probability linkage and clerical processing of JAJ hire and Term records was completed. The project began in 1981. Recall of all A&R records confirmed the completeness of the Heid construction cohort created in 1979. The overlap study yielded 169 subjects not previously in the cohort. This represented 0.61% of the full cohort membership.
- 1988      Lung cancer case-cohort manuscript to Dr. Breslow for review prior to journal submission.

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### SOCIAL SECURITY ADMINISTRATION

#### What are some of the biases of the system?

In 1935 when the Social Security Act was passed, it did not include federal employees, farmers, self-employed professionals and the military. Many of these were covered in the 1950's. In 1958, dependents of deceased or disabled members became eligible for benefits. These changes increased reporting of death. Prior to 1981, funeral directors and estates received a lump-sum death benefit. This was changed in 1981 and resulted in a decrease in reported deaths (Aziz and Buckler, 1984) (Arellano et al, 1985).

Several SSA researchers have examined the completeness of reporting deaths to the SSA. They compared deaths known to the SSA by year, sex and age with published information on all deaths within the United States (Aziz & Buckler, 1984). Between 1950 and 1977, the completeness went from about 20% to nearly 100%. A similar pattern was seen for white males and females.

The social security system is designed to keep track of members' payments into the system and the system's payments out to beneficiaries and members. The information that is collected and where it is kept within the system is determined by legislative mandate and managerial choice. These laws and administrative decisions changed over time. The system was not designed to provide information for researchers outside the Social Security Administration. System users need to be aware of the system's history and limits.

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### How does SSA find out about deaths among members and beneficiaries?

From its inception in 1935 up through the 1970s, the only way it found out about deaths was when survivors of members applied for benefits or when funeral directors applied for a burial fee. In 1981, the burial fee was discontinued. In the 1970's and early 1980's, considerable effort was made to use other programs administered by the SSA and other federal sources of death data. These include routine death reporting from the Railroad Retirement system, Medicare since the mid 1960's, and the Veterans Administration. Recently, it was reported that the Office of Personnel Management and the Department of Defense would be used as sources of death information.

The SSA system historically has underreported deaths and has been biased. For long term industrial workers, the system has been relatively complete.

### Why have epidemiologic studies relied on the SSA?

The potential of the system was recognized in the 1940's by persons interested in looking at employment and health, particularly causes of death among well defined industrial cohorts where all employees were enrolled in Social Security (Mancuso and Coulter, 1959). The limitations of the system for conducting health studies were pointed out by Myers in 1965.

Prior to 1981, there was no alternative at the national level (Beebe, 1983).

### FOLLOW-UP OF FORMER HANFORD SITE EMPLOYEES

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### Background

Follow-up is the process engaged in to determine if some prespecified event has occurred to specific employees. The event of interest is death and the medical events thought to have caused it.

There are two general types of follow-up. These are active and passive. Active follow-up requires direct communication between the investigator and the specific employee, his relatives or health care providers. It attempts to establish positively that a person is alive or deceased and the date. This is done through mass mail campaigns or telephone surveys. It requires good information about the residence of each person. It is time consuming and very expensive relative to passive methods. Passive follow-up attempts to look for indicators of a person's vital status using available information collected by others for purposes not related to the investigation. This information is usually found in files of accessible government and employer records. It may indicate a person was alive at some date, such as the fact that they were receiving social security benefits or a corporate pension.

Researchers must assume that persons receiving benefits are alive. For those who are thought to be dead, the process of verification of death follows. This requires identifying when and where a person died and then successfully obtaining a copy of the death certificate. This is not an easy task and will be discussed in the section of the Death Certificate Retrieval Office. One

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result of passive follow-up is the creation of a group of employees whose status is unknown for various reasons. Because of the high cost of resolving these, assumptions about them are made when the statistical analyses are done. The techniques of dealing with these are described in many articles and books dealing with life-table analysis.

Since passive follow-up has been the major type used in the Hanford mortality study, it is important to describe the efforts made to determine if the method works and how well it works.

Passive Social Security follow-up was chosen for the AEC study because of investigator preference (Mancuso and Coulter, 1959) and on the basis of being the best available method at that point in time.

The vital status search used the various records maintained by the Social Security Administration (SSA). Through the 1970s, the SSA supported recognized medical investigators. The name, sex, race and date of birth along with the social security number of former employees were sent to the SSA and search results were returned. The data included indicators that a person was alive in a specific year, and if dead the date and presumed place of death were provided. A status report is provided for each name submitted. In addition to being alive (paying into SSA or receiving benefits), persons whose accounts are inactive or persons whose SSNs do not match the name on file (nonmatch) are so indicated. Our information indicates that inactive persons are about 10 years younger than the active workers and that the nonmatched are older,

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resembling the birth year distribution of deceased workers. This suggests that the nonmatched workers should be monitored closely for deaths. The use of SSA also created a means of exploiting other information about workers siblings (sibs) and selection of other workers, not in the AEC system, for use as comparison groups (see Control selection). Even with the adoption of a passive approach using the SSA there are various levels of effort that can be applied with different costs.

Since the 1950s, the SSA has been used more and more often for research of large industrial cohorts. An appreciation of the limitations and the evolution of the SSA record systems is useful when evaluating research results (Myers, 1965).

Social security records do not fully cover all U.S. citizens. The original list of persons not eligible for the system were federal employees, many state employees, farmers, self-employed professionals and the military. In addition, dependents were not eligible for death benefits. Over the time the eligibility increased, the inclusion of dependents became manifest and the special payments upon death was terminated. These changes over time affected the reporting of death to the SSA (Aziz and Buckler, 1984). The steady progress in improved completeness of the system up to 1981 and the loss of funeral directors as a source of death reporting after this time are documented (Beebe, 1983).

Since 1966, the SSA has been the administrator of Medicare through the Health

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Care Finance Agency (HCFA). Notifications of deaths are available to the SSA from the HCFA.

### **The Death Certificate Retrieval Office**

The Center for Epidemiologic Research at the Oak Ridge National Laboratory (ORNL) manages the Death Certificate Retrieval Office (DCRO). The purpose is to have a single DOE contractor interfacing with the Social Security Administration (SSA). The other functions of the DCRO include actual searches of the lists of deaths from many states to locate persons declared dead by the SSA. In addition, the DCRO will provide other services to DOE epidemiologists on an ad hoc basis.

Historically, the AEC studies were all managed out of the ORNL. The most complete component in the AEC series of studies had been the one at the Hanford site. The Hanford site was split from the main study and transferred to the Hanford site. At the same time, the Los Alamos-related studies were transferred to Los Alamos National Laboratory. These transfers took place in the late 1970s.

Until 1980 the only source of death information came from the SSA through the DCRO. The underlying cause of death was assigned by the office. Anecdotal information indicated that there was an unknown level of error in the coding of the underlying cause of death. Since the results of the analysis were so

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important and required the highest level of confidence in their content it was decided to recode all death certificates.

Arrangements were made with the National Center for Health Statistics (NCHS) in North Carolina to privately contract with their senior coders to code all medical conditions on the death certificate. The NCHS would then run this data through their software to assign the underlying cause of death. This has become a routine aspect of our work. The ICD-9 is used and is converted to ICD-8 prior to using standard analysis programs that do not use ICD-9.

As of 1987, the DCRO handles the Hanford cohort in a special way. They store our master roster and each year we provide them with a list of all active employees. They purge the master file of the active workers and send the remainder to the SSA. This approach was designed to reduce the time and expense of preparing master tapes on site.

The DCRO does not search for deaths occurring in Washington state and California because we do that ourselves. Deaths occurring in these states are sent to the DCRO on a lagged schedule. In 1987, deaths we know about through 1983 are provided to the DCRO. In 1988, the 1984 deaths will be provided.

The DCRO also searches for deaths identified through the National Death Index. This is described elsewhere.

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### Ascertaining Deaths

The history of the SSA has revealed weaknesses and uncertainties that we explored beginning in 1980. Our exploration was intended to accomplish two goals. The first was to determine how complete the SSA death reporting was over time and the second was to improve our death ascertainment program. It was important to us that we not alter the traditional SSA mechanism while at the same time extending our passive follow-up activities.

The extensions involved comparing our roster of employees with other available and appropriate death reporting systems. We established a close tie with California to compare their death records from 1960-1983 with ours. In Washington state, we compared the list of employees with two systems. The first included all deaths among Washington residents for 1968-1986. The second included male deaths in Washington 1950-1985 that were included in the Washington State Occupational Mortality Surveillance System. (Department of Social and Health Services, Epidemiology Section).

Traditionally, files are compared name-by-name using clerks or some simple computer program that finds names that match exactly and may use other pieces of information such as date of birth, sex and race. The California (1960-83) and Washington state (1968-83) vital statistics tapes were compared to the list of workers using a special computer program based on probability theory (Arellano et al, 1984). This system allows an efficient and optimal way of identifying people common to both files using different pieces of information of variable completeness and accuracy.

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### Ascertaining Living Persons

The goal of follow-up is two-fold: positively identify the dead and the living. We have mentioned the death ascertainment program. Here we focus on the establishment of the "alive" status.

Four categories of response are provided by the SSA: dead, alive, inactive and unknown. Those assumed to be alive were actively paying into SSA or receiving benefits from it. Those persons with unknown vital status represent persons not covered by the Social Security System and the inactives represent persons whose accounts have not been active for many years.

The Hanford site cohort of operations workers through 1984 was seen to have a distinct pattern among those lost to follow-up. The distribution of birth year for the inactive is similar to the active workers in its shape. The unknown to SSA group have a year of birth distribution nearly identical to the deceased workers. We concluded that those persons not known to SSA have the highest likelihood of being deceased and require a closer look. Persons who were not dead or alive were examined by checking them against Medicare files and Federal Personnel files in 1986. About 28 per cent of those persons looked for were located (17 per cent in Medicare and 11 per cent in personnel files).

It is curious that 17 per cent were found in Medicare files since Social Security administers the system. The 11 per cent represent people who were never covered by SSA because they were federal workers that in the past were

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not covered by SSA. The 72 per cent not located are the subjects of more intense searches. Many of these persons are very short term workers; most without radiation exposure. The effort expended to determine their status depends on the level of other more important projects.

### CONTROL SELECTION

#### Comparison Populations

The results of every epidemiologic study are relative. Every study requires a reference group for comparison. The appropriateness of the reference group is a key consideration when interpreting results.

The early AEC study intended to use several control groups for the Hanford workers. The first group was comprised of same sex siblings ascertained from security clearance records. The purpose was to control for genetic and work place factors. This group was difficult to ascertain. The study designers never reported on evaluating the completeness of sibling identification. In addition, the SSA was responsible for providing a SSN for each sib. This is currently illegal. In the project reports it was also mentioned that about 1/4 of the sibs had no date of birth and thus were not identifiable in SSA records.

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The second set of controls selected was a sub-sample of persons registered in the SSA Continuous Work History Sample (CWHS) who had never worked at an AEC site. This file contains the long-term job, industry and wage and benefit records for those selected. This was a clear recognition of the importance of using an employed comparison group rather than the entire population. This sub-sample selection process was difficult at best. The reports mention that purging this SSA file of all persons who ever worked at an AEC site was a problem resulting in the abandonment of the second SSA (CWHS) control. The SSA/CWHS data is not available.

In the early 1980's scientists had requested that the SSA use the CWHS as the basis of a reference population for industrial cohorts. This has not been done as of 1987. In the late 1980's the National Institute of Occupational Safety and Health (NIOSH) began pooling all their industrial cohort data bases in an attempt to create a synthetic reference group to replace general population mortality rates generally used in industrial studies. As of summer 1987, this reference group is not available.

The AEC investigators were not certain that using internal controls would be a valid approach, thus they did not pursue this route. By contemporary standards, the internal (unexposed or very low exposure group) control is well accepted.

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### NATIONAL DEATH INDEX

The National Death Index (NDI) was operational in 1981 (Beebe, 1983) about 20 years after it was first suggested. The need for the NDI was felt by medical researchers who had to trace study subjects years after some event. Social Security could often provide an indication of when some persons died but not where. In the early years of the AEC project, the principle investigator suggested a "national alphabetic index of deaths" to aid in obtaining death certificates for former nuclear workers (Progress Report No. 2). He also suggested access to the certificates in a single location.

The NDI provides a way to compare computer files and obtain lists of possible deaths among some groups of people. Due to legal agreements with various states the death certificates are not available from the NDI. We must rely on the willingness of each state to provide copies of the death certificates. This willingness is not universal and in some cases agreements are required stipulating that we may not give any information from the certificate to persons outside the DOE.

The Hanford group applied to use the NDI in 1981 and approval was granted in 1983. For a time, the NDI did not think they could grant us use of the system.

We have used the files for the period 1979 through 1983. The NDI is about two years behind in releasing data.

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Deaths ascertained using all methods have been compared to the NDI valid deaths. This provides one picture of the completeness of death ascertainment at Hanford. For the period 1979-1981, agreement is very good giving a measure of confidence in the acquisition of death information.

The NDI provided indications of one or more possible deaths for 4,295 former Hanford employees. Review of all the possible matches resulted in identification of 299 'best bets'. The agreement between what we knew and what NDI found was 87%. For operations workers only, the agreement was 85%, i.e., 204 we already knew about, and 30 found by NDI we had not known about.

This experience with the very large list of false positives indicated to us that the output from the NDI was cumbersome and expensive in terms of personnel time. We were fortunate that our specialist consultant at Advanced Linkage Technologies of America, Inc. in California had solved the problem. He used probability theory to select the best candidate deaths and provides easy to use products. This system was used for the 1982 and 1983 NDI returns with great ease. Our experience at Hanford is summarized in Arellano et al.

No decision has been made to use the NDI for 1984 and later years because it detects very few unknown deaths.

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### WASHLINK

This is a short procedural history of the project called WASHLINK. This effort was directed at using probability linkage software to assess completeness of death reporting in Washington state.

In January 1980, the idea was formally presented to a large group of staff from the Washington State Department of Health and Human Services (WSDSHS) in Olympia. At that time, they were not sure about sharing the vital statistics. They did mention that the Fred Hutchinson Cancer Research Center (FHCRC) had a historical file they used and that we might work with them. In December 1980, the FHCRC was visited and they were not willing to share this data. Our request was considered again in 1981 when WSDSHS circulated a memo among their staff. The contacts continued via phone over the period 1982-1984. Some of the unresolved concerns were release of the SSN, who would process the data and where, as well as a general question about confidentiality. In early 1984, Dr. Breitenstein made a few calls to Olympia and by September we had received mortality data for the years 1968-1983. Each year in the spring the death tape for the previous year is received and processed by Information Design Technology in California. As of August 1987, we have processed deaths through 1986.

The tapes are received and copied immediately. The original tape is returned to DSHS and the copy is sent to California. The reports of the linkage are processed directly. Results are received on paper and on a diskette.

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The benefit is nearly complete death reporting for about half of all those dying in the cohort within a few months of occurrence.

### **CALINK: A BRIEF PROCEDURAL HISTORY**

Ten per cent of the deaths among Hanford employees occur in California. This is the largest proportion after deaths occurring in Washington state.

We decided to become actively involved in the project to implement the California Automated Mortality Linkage System (CAMLIS) for two reasons: First, to assess the completeness of death ascertainment using California as the surrogate and second, to prepare the way for future linkage in Washington state.

In February 1981, we received permission to access the vital statistics data base for California. This preceded HEHF's support of the preparation of the California death tapes for use in the linkage system that were available for the years 1966-1978 in March 1981.

As a prelude to using CAMLIS, we were required to standardize race and place of birth codes on our files to be compatible with those on the California death tapes.

By January 1982, two more years of deaths had been added and we were ready to

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conduct the linkage. Late in 1983 the deaths for 1960-1965 and 1981 were available for linkage.

Annual death tapes are available about one year following the end of the year of interest. To date, we have processed data for 1960 through 1985.

## OCCUPATIONS AND EXPOSURES

One aspect of the original AEC study was to create a qualitative list of exposures and stresses commonly found among 54 selected occupational groups. The special project was completed in the early 1970's. Recently we have been able to obtain the services of the engineer who was responsible for some aspects of the project. He has agreed to go through the files and other historical materials with us and prepare a procedural history.

Although conditions have changed, the exposures represent the prevailing situation up to the early 1970's. This period is the most important in terms of the cohort. We are interested in assessing jobs that were not included in the original study, and we are exploring ways to accomplish this.

The product will be a dictionary of exposures by job and historical period. It will be used to explore the relationship of general exposures to any observed differences in the patterns of mortality between occupational groups. The successful application of the exposure histories assumes that each worker can be classified by occupation.

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There are several steps required to achieve this classification for work that is not trade-related. Trade-related work is classified in a straight forward manner, vague job titles must be clarified.

Assuming that the classification is accomplished, then we must find ways to deal with multiple jobs for the same person. It is relatively simple for the trades and complicated for other configurations.

One phase, which is several years away, is to compare our records from the contractors' accounting departments with what the workers tell us at the time of their physical examination.

Given that we successfully classify and summarize the jobs while at Hanford we will not know what a person did before or after Hanford. It is possible to use the death certificate statement of occupation and industry in concert with our records. Although possible, we have to exercise extreme caution.

As for work before Hanford, some workers have job histories in their personnel folders or in security clearance documents. Starting in 1983, we will obtain a job history for work lasting a year or more.

If we find different patterns of death or different rates for some causes of death between occupations, we will then enter the exposure data file by occupation and see if there are differences there.

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The way in which we proceed, then, becomes important. The matrix of exposures and stresses with a qualitative expert judgment as to the frequency and intensity of the exposure needs to be reduced to a manageable level. We think that the present scale of 0-9 could be simplified, i.e., no exposure, potential exposure and definite exposure.

We are aware that people change jobs and occupations concomitantly with changes over time in technologies and processes. Given all of these factors, and our relatively small population size, we cannot become detailed if we are to glean any useful information out of it.

We know there is important information in the work histories and exposure file. We are committed to revealing and reporting it. The time-frame is a function of funding for people and computer time.

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