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Study of Dementia in Swedish Twins, 1990-1999

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User Guide

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RESOURCE BOOK OF THE STUDY OF DEMENTIA IN SWEDISH TWINS

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The Study of Dementia in Swedish Twins was designed to study the relative influence of genetic and environmental risk factors for Alzheimer's disease and other dementias and to test the role of specific environmental exposures that might constitute risk or protective factors for dementia. This archive is restricted to the first seven years of the Study of Dementia in Swedish Twins, sometimes referred to as "SALZA", with clinical data updated during the next five years through an extension of the Study of Dementia in Swedish Twins.

Participants in SALZA are from the population defined by the Swedish Adoption/Twin Study of Aging (SATSA). SATSA consists of a subset of same-sex twins from the population-based Swedish Twin Registry, specifically, all pairs from the twin registry who indicated having been reared apart and a matched sample of pairs who were reared together, drawn from the twin registry to correspond in sex, year of birth, and county of birth to the reared apart twins. At baseline in 1984, 2845 of these individuals were alive (1223 pairs and 399 singletons), defining the SATSA population. SATSA administrative files are based on an N of 3838 individuals (or 1919 complete pairs) which corresponds to the sample of pairs that was drawn from the Swedish Twin Registry. For data analytic purposes, it is helpful to have a file with complete pairs, even though the deceased partners are not part of the baseline population.

Dementia-related data collection by SALZA entailed the following sample: Individuals were included if they were alive in 1987 and if they were in the SATSA population as originally drawn, whether or not they had ever responded to any SATSA data collection effort, and whether or not their twin sibling was alive. Due to the low prevalence of dementia in middle age, only individuals born in 1935 or earlier were included in the dementia study. The resulting base sample for SALZA consisted of 2394 individuals.

The structure of SATSA comprises the framework for data collection for the Study of Dementia in Swedish Twins. Therefore it is helpful to have an overview of the SATSA design. SATSA is a longitudinal study that began in 1984. Both mail-out questionnaire and in-person testing components were included, with a rolling three-year interval between measurement occasions. There were four mailed questionnaires in 1984, 1987, 1990, and 1993, called Q1, Q2, Q3, and Q4, respectively. The first in-person testing, IPT1, took place over the years 1986-1988. The second in-person testing, IPT2, took place over the years 1989-1991, with participants visited three years after IPT1. Similarly, IPT3 took place over the years 1992-1994, with participants again seen three years after their prior visit. At the time of each IPT visit, another copy of the most recent questionnaire was sent to the twins participating in in-person testing waves one week prior to the in-person testing session; this questionnaire is called an IPTQ. [Questionnaire and in-person testing data from SATSA are archived separately in NACDA as Study No. 3843.]

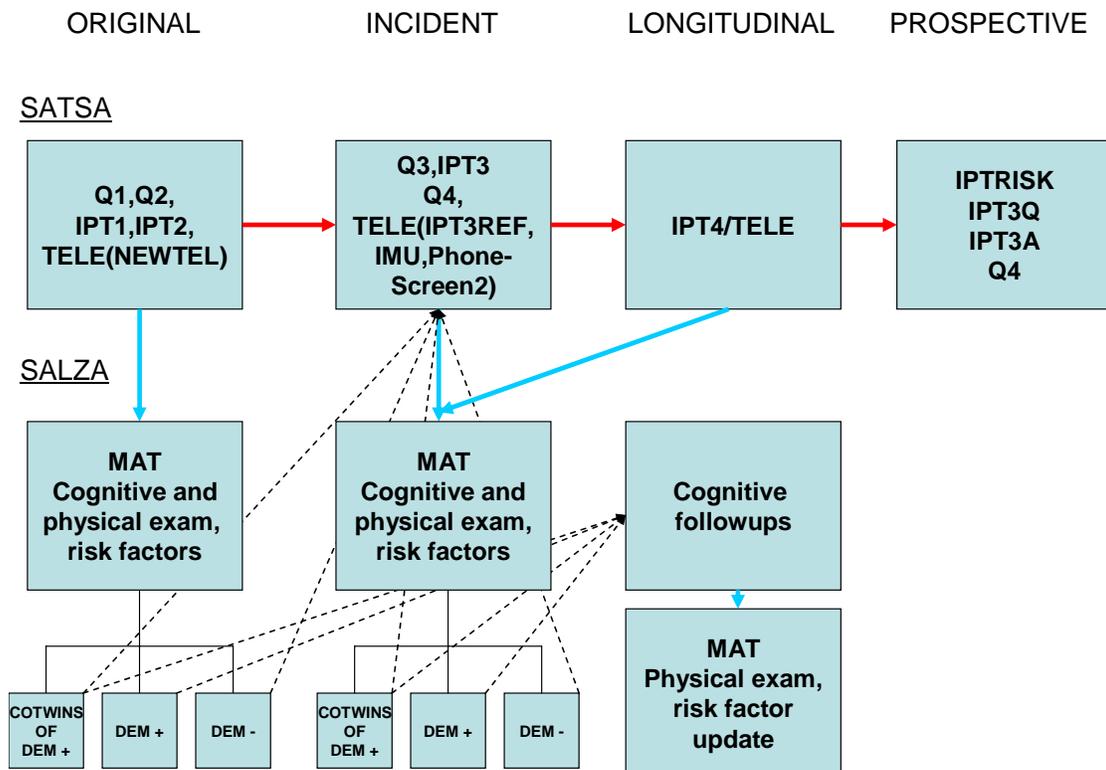
The Study of Dementia in Swedish Twins was funded for an additional seven years during which all twins in the Swedish Twin Registry were screened and evaluated for dementia, with a small subset followed longitudinally. Any SALZA twins who were still alive were included in this evaluation, which is called HARMONY [Hälsa (health), ARv (genes), Miljö (environment), Och (and), NY (new)]. Furthermore, longitudinal SATSA data collection has continued. Thus, clinical dementia diagnoses for SALZA participants have been updated via

the HARMONY study (1998-2001), HARMONY-Longitudinal (3 years after HARMONY baseline), SATSA IPT5 (1999-2001), and SATSA IPT6 (2002-2004). That information is included in the present archive.

This resource book has four parts: A. a description of the data collection, organized by phases; B. a description of the data files; C. notes to assist in data analysis; D. scale and methodology references.

A. PHASES

The goal of SALZA was to identify all cases of dementia in SATSA, to work up the cases and their twin partners, and to collect information about possible risk and protective factors. We describe SALZA below in four phases: (a) the original or baseline phase in which we identified all possible cases of dementia in SATSA up until the time that SALZA began; (b) the incident phase in which we identified new cases of dementia from new waves of SATSA; (c) the longitudinal phase in which we identified new cases of dementia from those who participated in baseline or incident work-ups; (d) and the prospective risk information phase in which we collected data from SATSA twins who had not yet been identified as potential dementia cases. The sections below elaborate each of these phases.



A.1. ORIGINAL PHASE

A1.a SCREENING

The SALZA study began in the spring of 1990, during SATSA IPT2, by screening the SATSA population for cognitive dysfunction sufficient to warrant evaluation for dementia. Screening used whatever SATSA data were available:

(a) The SALZA team developed a telephone mental status instrument called the TELE (Gatz, Reynolds, Nikolic, Lowe, Karel, & Pedersen, 1995). Any SATSA twin who did not complete one of the standard SATSA evaluations—Q1, Q2, IPT1, or IPT2—was contacted for an interview using the TELE protocol. An informant form of the TELE interview was available when preferred. Twins who had requested to be removed from future twin studies (n=194) were not contacted. Based on the results of this phone screen, individuals who were suspected of dementia and their co-twins were invited to participate in a full clinical evaluation.

(b) Any SATSA twin who participated in in-person testing was screened as part of the in-person visit. The IPT protocol included the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975), modified to include recognition questions for missed recall items (each scored 0.5 points). If there was any suggestion of dementia from the IPT (MMSE<24.5, drop in MMSE between IPT1 and IPT2, or report by family informant that the twin had memory problems), the twin pair was referred to the SALZA team for further evaluation.

The outcome of this original evaluation phase for each twin has been recorded in an administrative data file (see ADSAL: OUTSCREN).

A.1.b. EVALUATION

If a twin screened positive, s/he was labeled a “suspect” or “possible proband”. It was possible for a twin pair to be doubly ascertained if both screened positive. Once a twin was marked as a dementia suspect, the individual and his/her cotwin were invited to participate in a full in-person clinical evaluation. The evaluation was conducted by a mobile assessment team, or MAT, comprised of a psychologist and a physician. If during the scheduling of the visit or during the visit itself, it was determined that the individual had a psychiatric disorder or was mentally retarded or had suffered a stroke or had some other explanation for the cognitive dysfunction that did not involve dementia, the in-person evaluation was discontinued (see ADSAL:REFMAT). Possible probands or their co-twins could also refuse a MAT visit. If the suspected proband was excluded or refused a MAT visit, the presumptively intact cotwin was not visited by MAT for evaluation. Participation or lack of participation in SALZA did not affect on-going participation in SATSA.

At the MAT visit, a clinical team visited the participant’s home for a full workup. The MAT visit included both assessments necessary to make a clinical diagnosis (cognitive tests, somatic exam, medical history, informant description of cognitive decline) and collection of risk factor information, including family history, medical risk factors, and environmental risk

factors, and a form asking twins to compare their exposures earlier in life to the exposures of their twin partner (comparative risk). See Table 1 for a listing of assessments, forms and datasets.

A.1.c DIAGNOSIS

For all twins who completed a MAT visit at this point, it is considered the ORIGINAL visit and concludes with an ORIGINAL consensus conference and an original diagnosis. All clinicians who participated in the assessment attended the consensus conference, which was chaired by a clinical psychologist who had not met the twin. The chair obtained the independent opinion of each clinician, then directed a discussion and consensus.

An independent clinician was given copies of complete clinical work-up data from 31 twins and asked to determine a diagnosis based on these records. There was agreement on 93.5% of individuals whether the twin was demented. For those twins where there was a disagreement as to dementia status or differential diagnosis, the disagreement was resolved by a third independent clinician. Wherever a diagnosis was changed due to additional review, it is flagged in ADSAL (See B.1.a).

In some instances, the MAT visit was not completed (due to intervening death of suspected proband, or due to the family's unwillingness to have a personal visit but willingness to be interviewed and to provide consent for medical record review). In such situations, a consensus conference was conducted using collateral reports (informant description of medical history and cognitive decline [NAVLIDEN]) and medical records. For SATSA participants who were diagnosed as demented but whose twin partner was not alive in 1987, medical records were used, where possible, to determine a diagnosis for the deceased twin. Both of these types of individuals were assigned an original diagnosis.

In the SALZA dataset, 173 individuals received an original consensus conference diagnosis. The data contained in this set of ORIGINAL variables were used to calculate a prevalence estimate, although data from the 18 individuals who were deceased prior to 1987 were excluded from the prevalence estimate.

A.2 INCIDENT PHASE

A.2.a SCREENING

After the original phase of SALZA, the full cohort of SATSA twins continued to receive SATSA questionnaires and visits (Q3 in 1990, IPT3 in 1992-94, Q4 in 1993). Those who failed to return a mailed questionnaire were telephoned using the TELE protocol to determine if they should be referred for a full MAT workup (IPT3REF and IMU). At Q4, respondents were also asked whether they needed assistance in completing the questionnaire. A positive response to this question also triggered a telephone screening. Incident dementia suspects were identified during IPT3 using the same procedures and criteria as IPT2. A small group of twins who had been identified as possible probands but not yet visited, was contacted for a second TELE phone screening to verify status before scheduling an in-person visit. This screen is referred to as Phone-Screen2.

An additional wave of SATSA in-person testing, IPT4, was discontinued due to lack of funding. Instead of the planned fourth in-person IPT4 visit, in 1995-97, each SATSA twin was telephoned with the TELE screening protocol. The results of this telephone cognitive interview constituted a comprehensive screening from which additional incident cases were identified and referred for diagnostic workup.

If, during any of these further SATSA evaluations, a twin screened positive who was not already visited by MAT in the ORIGINAL phase, both the twin and cotwin were referred for an incident MAT visit. Those who were screened as suspects in the original phase, but were visited and diagnosed as non-demented, continued to be followed and re-screened. However, if they became demented, they were coded as longitudinal rather than as incident (See A.3.)

A.2.b EVALUATION AND DIAGNOSIS

Any twin identified during this second stage who did not have an original MAT evaluation is considered a possible INCIDENT proband. The procedure for the MAT visit and consensus conference were the same as for the original phase, but the consensus conference and diagnosis are referred to as INCIDENT. Of the SALZA sample, 150 twins received an INCIDENT consensus conference.

A.3 LONGITUDINAL / FOLLOW-UP PHASE

All those who received a dementia diagnosis, as well as non-demented partners of cases, questionable cases, and partners of questionable cases were followed up at 18 month intervals. For those who were demented, this follow-up consisted of an in-person administration of the cognitive battery. These data are of interest for tracking the course of cognitive decline among the demented cohort. For those who were not demented, the intent of follow-up was to determine whether a previously intact co-twin showed signs of possible dementia and should thus be referred for a full clinical MAT evaluation. This follow-up consisted of a telephone interview at 18 months using the TELE form, an in-person visit at 3 years to administer the cognitive battery, a telephone interview at 4 ½ years (TELE), and an in-person visit at 6 years (cognitive battery). For twins also being seen longitudinally by SATSA, the two follow-ups were conducted concurrently, with a longitudinal cognitive battery being combined with a longitudinal SATSA IPT visit. The results were reviewed in a longitudinal mini-consensus conference with the psychologist who conducted the longitudinal evaluation and the chair of the consensus conference. The mini-consensus conference did not contain the input of a physician.

If the mini-consensus showed concern that there might be a change in status, a full follow-up visit by the MAT team was launched with complete assessment and a full longitudinal consensus conference using the same procedures as the original consensus conference. This is referred to as a longitudinal MAT. Any twin receiving a longitudinal MAT, by definition, has already completed either an original or incident MAT. Of the SALZA sample, 23 twins received a LONGITUDINAL consensus conference and diagnosis.

Additionally, if a twin died, who has previously been given an original or incident diagnosis (regardless of whether the person was demented), the informant was contacted and a mini-consensus conference was conducted using collateral reports (informant description of medical history and cognitive decline prior to death and medical records to determine whether the diagnosis had changed prior to death.

All twins and their partners were invited at the original visit to participate in brain donation. For twins who did agree to autopsy, once autopsy results were received, the diagnosis (whether demented and type of dementia) was again reviewed and changed if so indicated. (see ADSAL: AUTCONS)

A.4 PROSPECTIVE RISK INFORMATION PHASE--IPT3Q, IPT3A, IPTRISK, Q4—AND UPDATED CLINICAL DIAGNOSES--EPILOG

At IPT3, all SATSA participants were assessed for the same risk factors as had been included in the SALZA risk factor data collection. The purpose was to have prospective risk factor information for any individuals who might become demented during subsequent waves of SATSA longitudinal data collection. The questionnaire sent to in-person testing participants just prior to the visit included some basic risk factor questions (IPT3Q) and the comparative risk questions (IPT3A). An interview to elaborate on this information was included in the in-person visit itself (IPTRISK). At Q4, which took place in approximately the same timeframe, the questionnaire mailed to everyone in the SATSA sample included a few basic risk factor questions (Q4).

Updated clinical diagnoses are based on the continuation of the Study of Dementia in Swedish Twins (called HARMONY) and two additional waves of SATSA. Included in the EPILOG file are the most recent, cumulative, clinical diagnosis, age of onset (if demented), and age of last assessment, based on these sources.

B. DATAFILES

The complete set of datafiles for the SALZA study is detailed below. Data were collected and initially processed in Sweden. As a result, the datafiles were assigned names in Swedish. To aid the user of these files, we have assigned an English name equivalent by which we commonly refer to many of the files. However, the underlying Swedish naming convention has been maintained to ensure back-compatibility with the SALZA study. All open-ended answers recorded in Swedish have been translated to English, except for the names of medications. See Table 1 for a list of each datafile and the corresponding data collection form or coding form.

B.1. ADMINISTRATIVE DATAFILES

B.1.a. ADMINISTRATIVE FILE FOR SALZA

ADSAL is the administrative file for SALZA. It includes relevant demographic and zygosity data, apoe genotype, information from dementia screening, ages at assessments and

diagnostic outcomes. This information was compiled from various forms; thus, ADSAL does not correspond to a data collection instrument. However, there is a document by the same name that describes all variables in the datafile.

The variable CDIAGNOS contains the final/cumulative diagnosis assigned to a twin at the last time the twin was assessed throughout the course of the study. The source of the diagnosis varies over twins and may come from the ORIGINAL, INCIDENT, or LONGITUDINAL consensus conferences. A small number of diagnoses were updated following review by an independent clinician (as described in A.1.c). These are denoted in the VALCONS indicator variable. Diagnoses assigned at autopsy are contained in the variable DIAG_A; when DIAG_A was available, it became the final diagnosis.

The complete screening/evaluation process resulted in assigning clinical diagnoses to 323 twins. Of these, 158 twins were considered demented and given a differential diagnosis for dementia (CDIAGNOS =(1-6)).

B.1.b. INFORMANT LIST

This form (Inform.List) was completed by the MAT concerning each informant who provided information about a SALZA twin. It details the relationship of the informant to the twin as well as a measure of how well the informant knows the twin. Because more than one informant may have provided information about a twin, the datafile (INFLIST) contains more than one record per twin id. By cross-referencing this file with the “informant” variable present in other files, it can be determined which informant is providing information on any particular form.

B.1.c. POST-MORTEM SCREENING

This is a phone instrument (Avliden-Tele) that was administered to an informant in lieu of TELE whenever it was learned that the twin had died. It assesses the status of the twin’s memory, personality, functioning and mental status during his/her last year of life. The data are stored in the file NAVLIDEN.

B.1.d. SCREENING OUTCOMES

OUTSCREEN is the administrative file that details the longitudinal aspects of SALZA. It contains the telephone screening information (NEWTEL, IMU, IPT3REF, IPT4, Phone-Screen2) and additional SATSA contacts (IPT3, Q3, Q4) used to update the cognitive screening status of the SALZA twins over the course of the study. It includes ages at assessments, scores on mental status and memory tests, as well as informant reports where available. This information was compiled from various forms; thus, OUTSCREEN does not correspond to a data collection instrument. However, there is a document by the same name that describes all variables in the datafile.

B.2 MAT DATAFILES

These files are comprised of data collected by the mobile assessment team or MAT.

B.2.a CODELIST

These files (KODLISTA, KODLIST_INF) are abstractions of risk/exposure data from the twin and informant interviews, respectively. Both medical and environmental risks are included. History of exposure as well as age and duration data, where collected, are recorded in these files. There is a kodlista abstraction form and a Risk Exposure Coding Instruction sheet for detailed information on this abstraction process.

B.2.b COGNITIVE

This file (NEWMATV5) contains the cognitive data from the initial visit to the dementia suspects and their partners by the Mobile Assessment Team (MAT) using the Tvilling-Psyk form for the twins, and the Inform-Psyk form for informants. The data from twins include a neuropsychological interview consisting of scales such as the Mini Mental State Examination and the Short Portable Mental Status Questionnaire as well as neuropsychological tests such as the WAIS Information Test and the CERAD Word List.. A complete list of interview forms and tests along with references can be found in Section D. Total scores for tests are corrected. Not all individual items can be assumed to be correct. For individuals who were very impaired, a shortened test battery was used. In turn, some of the simplest items were skipped for those who were not impaired. The data from informants includes Blessed Dementia Rating scale items and ratings of Activities of Daily Living. In addition, the MAT rated degree of aphasia and completed a CDR. Data from both the twin (Tvilling-Psyk) and informant (Inform-Psyk) are included in the same data file.

B.2.c COMPARATIVE RISK

This datafile (PARRSK) contains the twins' assessments of the twins' relative contact to purported risk factors and exposures using the Par-Risk form. During the MAT visits, each twin was asked questions of the type "who had more...?"

B.2.d DRUGS

This file (DRUGS) contains current medication data from all available sources for the 298 people who had been assessed by SALZA at the time of the drug review process. Reports of medication use were obtained from medical record review, twin and informant interviews and a nurse's extraction of drug data taken at the time of the MAT workup. Since many people take more than one drug and sometimes the drug is taken at different points in time by a person, there are multiple records per id. This file should not be considered complete, as it was compiled before all participants had been visited by MAT. Additional drug data may exist in the Medrisk datafiles.

Drugs are recorded using the Anatomic Therapeutic Chemical (ATC) Classification system. For information related to decoding these values, see the following websites:

<http://www.whooc.no/atcddd/> and <http://www.fass.se/LIF/home/index.jsp>

B.2.e FAMILY HISTORY

This datafile (FAMHX) contains family history data obtained using the Par-Familj form during the MAT visit. As data for the entire family is recorded on a single form, the form refers to Twin A and Twin B. Twin A is always identified as the record ID. Information may have been obtained from more than one member of the family but are combined in the

same informant form. All those who contributed are noted in the informant variables. Discrepant responses were resolved by the MAT interviewer, and the “best” answer recorded.

The form assesses family history of dementia, medical disorders, miscarriages, and Down’s syndrome. A detailed Dementia History was taken for each member of the family indicated by the Par-Familj interview to be affected. This information is included in this data file.

(As described in C.2.c., if a twin had completed a prospective family history interview prior to the MAT visit, a shorter interview was used to avoid burdening the twin with redundant items.)

B.2.f MEDICAL HISTORY/RISKS

These files (MEDRISK, MEDRISK_INF) contain the medical history and medical risk factor data obtained using the Tvilling-Med form for each twin visited by the MAT team. Self-report data are stored in MEDRISK. Informant data are stored in MEDRISK_INF. Risk factors assessed include fever, head injury, exposure to radiation (e.g. CTs, xrays), anesthesia, antacids, pain relievers, foods, and aluminum exposure. In addition, the Smell Survey (Gilbert & Wysocki , 1987) was administered. For purposes of excluding reversible causes of dementia, a detailed medication history was taken and blood was drawn for lab analysis of folate, cobal aminos, HbA1c, and the markers TSH, T3 and T4.

B.2.g RISKS-ENVIRONMENTAL

These files (LIVRISK, LIVRISK_INF) contain responses from the Inform-Risk interview form administered during the MAT visits to twins and informants. The same variables are available for both twins and informants. The form assesses life-time risks and exposures related to residential history, presence of well water at residences and vacation homes, travel, work, hobbies, sports activities, animals, deodorant usage, and smoking. A list of common environmental risk factors referred to as the “Big Six” was referenced during this assessment. (see Table 5). Detailed information from this form was abstracted and can be found in the Kodlist and Work-Hobby datafiles. (As described in C.2.c., if a twin had completed a prospective risk interview prior to the MAT visit, a shorter risk interview was used to avoid burdening the twin with redundant items.)

B.2.h WORK_HOBBY

These files (WORK_HOBBY, WORK_HOBBY_INF) are an abstraction of the work and hobby risk/exposure data from the twin and informant Yrkeliv risk interview questions. The same variables are available for data supplied by both twins and informants. History of exposure as well as age, frequency and duration data, where collected, are recorded in this file.

Jobs are coded according to the occupational classification from NYK 78 (Nordic Occupational Classification), which was used in the 1980 Swedish Census (FoB 80). See Table 2 for the NYK 78 occupational codes and category titles and corresponding codes for the 1970 US Census categories. The matching was performed by Ross Andel as part of his dissertation. [See Andel, R., Crowe, M., Pedersen, N.L., Mortimer, J., Crimmins, E.,

Johansson, B., & Gatz, M. (2005). Complexity of work and risk of Alzheimer's disease: A population-based study of Swedish twins. *Journals of Gerontology: Psychological Sciences*, 60, P251-P258.]

Swedish socio-economic classification (SEI) is coded according to the categories defined and published in Reports on Statistical Co-ordination 1982:4, Statistics Sweden. See Table 3 for a description of the SEI categories used in these data and Table 4 for the commonly used SEI groupings to define social classes. (SCB Meddelanden i samordningsfragor. 1982:4 Nytryck 1995)

B.3 LONGITUDINAL DATAFILES

B.3.a COGNITIVE

This file (MATLONG) contains the follow-up cognitive data collected during the series of 18-month followup visits using the Tvilling-Psyk-Longitudinal form. Data come from follow-ups conducted at 18, 36 54, and 72 months after the original MAT was completed. Total scores for cognitive tests are corrected. Not all individual items can be assumed to be correct. Data from both the twin and informant are included in the same file, primarily cognitive test scores from twins and Blessed Dementia Rating and ADL items from informants.

The file is constructed with one record per respondent. This record contains data collected during all followups in which the respondent participated. Data collected during the 18 month followup are contained in the variables with a prefix of 'x', the 36 month followup in variables with a prefix of 'y', 54 month with a prefix of 'z', and 72 month with a prefix of 'w'.

B.3.b IPT4

These files (IPT4, IPT4_INF) contain responses from the Tvilling-Tele-IPT4 screening interview for twins and Inform-Tele-IPT4 (IPT4_Inf) for informants. The TELE is a revised version of the same dementia screener used at all waves of SALZA. The form includes a mental status test and associated questions about change in memory and how it may have affected functioning. The Inform-Tele is the informant version, designed to identify whether the twin has memory problems and if the memory problems likely are dementia.

B.4 PROSPECTIVE DATAFILES

B.4.a IPT3A

This file (IPT3A) contains the subset of items from the SATSA IPT3 interview form that parallel the items in the comparative risk (Par-Risk) form assessed at the first MAT visit. A one-to-one correspondence does not exist across the SALZA and SATSA forms, so care must be taken when matching items across the forms.

B.4.b IPT3Q

This file (IPT3Q) contains the subset of items from the SATSA IPT3q questionnaire that are similar to the risk/exposure items in the Inform-Risk and Tvilling-Med forms. These include

antacid and pain reliever use, deodorant use, depression medications, work and hobby exposures, aluminum exposure and presence of well water at residences.

B.4.c Q4

This file (Q4) contains the subset of items from the SATSA Q4 questionnaire that are similar to the risk/exposure items in the Inform-Risk and Tvilling-Med forms. These include pain reliever use, depression medications, anesthesia, deodorant use, work and hobby exposures, head injury, sports, well water, and aluminum exposure.

B.4.d IPT3RISK

This file (IPT3RISK) contains the IPT-Risk data that were collected from intact SATSA twins in conjunction with the IPT3 assessment visit. It assesses life-time risks and exposures related to presence of well water at residences and vacation homes, travel, work, hobbies, sports activities, and animals. It also contains medical history and medical risk factor data similar to that in MEDRISK and family history of dementia data similar to that in FAMHX.

B.4.e. EPILOG

This file (EPILOG) is compiled from various sources and does not correspond to a data collection instrument. However, there is a document by the same name that describes all variables in the datafile. It includes the final clinical diagnosis based on IPT5, IPT6, HARMONY, and HARMONY-Longitudinal evaluations, all of which occurred after the conclusion of the SALZA study. The variable E_DIAGNOS is the cumulative diagnosis. E_ONSET is the age of onset if demented, while E_LASTAGE is the last time that the twin was seen and determined to be non-demented.

C. DATA ANALYSIS

CAUTION NOTE: Publications using these data were completed at various times throughout the course of data collection and data cleaning. As a consequence, results of analyses with the archived data may not exactly reproduce a specific published analysis.

C.1 DIAGNOSIS

C.1.a CROSS-SECTIONAL

The variable DIAGNOS contained in the ADSAL datafile records the dementia diagnosis assigned at the original consensus conference and was used to calculate a cross-sectional prevalence estimate at beginning of the study. The sample for this estimate included all those who were alive when the SALZA study was established. The variable CDIAGNOS (also in ADSAL) provides a cumulative diagnosis and can be used—in combination with other information—in incidence studies to identify who became demented over the course of the seven-year study period.

C.1.b CASE-CONTROL

The variable CASE (ADSAL) can be used to determine who is eligible to be defined as a baseline control in a case control design. These are the twins who were confirmed as non-

demented during the Original phase of the study, either through a complete in-person dementia evaluation or based on cognitive screening results (sometimes including SATSA in-person testing results; sometimes relying on telephone cognitive screening).

The variable PREVCASE (ADSAL) was used to help calculate the baseline cross-sectional prevalence of dementia. There are more twins coded non-demented in this variable than in CASE. These additional twins are those who could be reasonably assumed non-demented based on their on-going participation in SATSA. This variable should not be used to determine the dataset in a case control design.

C.1.c ASCERTAINMENT

It is possible to use the variables ASMAT (ADSAL) and ASMATI (ADSAL) to determine which of the twins referred to MAT were primarily ascertained. This variable will only be coded for those twins who were alive at the time of screening and thus available to receive a MAT. ASMAT reflects the ascertainment status during the Original phase. Because a thorough screening was completed of all twins, it is possible to determine if a cotwin is referred to MAT as a possible proband or as a cotwin(partner) of a possible proband. If both twins in a pair have a code of 1, this means they were doubly ascertained.

ASMATI is a similar variable that reflects the Incident phase. However, because not all twins and cotwins were simultaneously screened during the Incident phase, ASMATI does not include a partner code. In this phase, if a twin was identified as a possible proband, the cotwin was automatically referred to MAT without completing a cognitive screening interview.

C.2 QUESTIONNAIRE VERSIONS

Several of the instruments used to collect information from and about the twins had multiple versions. The following describes situations where multiple versions exist and provides any information needed during analysis to appropriately handle these versions.

C.2.a MAT-Cognitive

Three versions of the Tvilling-Psyk questionnaire were administered. The version used can be identified with the TVPSYK variable.

Tvpsyk=1: Standard Tvilling-Psyk

Tvpsyk=2: Tvilling-Psyk-SATSA-Formular. This version was administered to twins (N=15) who had recently received a SATSA evaluation (e.g. IPT2/3). Because of overlap in the assessments, SALZA scales that were asked during the SATSA evaluation were not repeated during the SALZA visit. However, the final score for such a scale was transferred from the SATSA form to the SALZA form. In this group of twins, the record will not have item level data for the scores – only the final score. When carrying out analyses incorporating both SATSA and SALZA data, one must be careful to note that there are not two separate

administrations of the scale – just one administration that was recorded in two separate places. The set of scales handled in this manner include: Information, Block Design, Digits Forward, Digits Backward, Symbol Digit-A, Symbol Digit-B, Figure Logic, Synonyms, Figure Identification, Thurstone Picture Memory.

Tvpsyk=3: Tvilling-Psyk –Impaired. This is a short version of the Standard Tvilling-Psyk that was administered to twins who were too impaired to complete all items in the survey. There is not a separate questionnaire. Rather, skip instructions throughout the Tvilling-Psyk form show which path the impaired respondents took based on their ability to answer certain items. (N=18)

C.2.b Longitudinal Followup-Cognitive

Three versions of the Tvilling-Psyk-Longitudinal questionnaire were administered. The version used can be identified with the XINFO variable. There is only one Tvilling-Psyk-Longitudinal form; the tests to be administered are listed on the face page, where it is also indicated whether the twin was in the SATSA IPT sample.

XINFO=1: SATSA

In this situation, a twin was scheduled to receive a SALZA phone interview. He/she was simultaneously scheduled for a SATSA IPT visit. As a result, the phone interview not performed but the SATSA visit took place. SATSA data that overlap with SALZA Tvilling-Psyk-Longitudinal form were copied into SALZA longitudinal data file. When carrying out analyses incorporating both SATSA and SALZA data, one must be careful to note that there are not two separate administrations of the scale. Scale items were asked only once and recorded in two places. It is possible that additional longitudinal data may be available in the SATSA files if not all overlap items were copied. SALZA specific items in the Tvilling-Psyk-Longitudinal questionnaire will be missing for these records since they were not administered in the SATSA interview.

XINFO=2: SALZA

These twins were scheduled for a SALZA interview only. The complete Tvilling-Psyk-Longitudinal questionnaire was administered and data are recorded only in the SALZA files.

XINFO=3: BOTH

In these situations, a SATSA staff member and a SALZA staff member visited the twin together. Tests were administered once, but recorded in both data files. All items that are in both questionnaires were assessed with the SATSA questionnaire and the SALZA unique items were then asked and recorded. Note that in a very few instances where items are scored differently by the SATSA and SALZA studies, recorded data will differ (e.g., on the WAIS information test, the question about the main political parties was scored in the traditional manner by SATSA but updated to reflect the actual current situation by SALZA).

C.2.c MAT-Risk factors

In some instances, a twin who was scheduled to receive a MAT visit during the Incident phase of the SALZA study, had recently completed a SATSA risk assessment entitled IPT3-

Risk. This questionnaire collected self-report exposures similar to those elicited in the SALZA MAT protocol of Inform-Risk and Tvilling-Med questionnaires. To reduce interviewee burden, items that were common between the two surveys were not repeated. Only those items unique to the SALZA questionnaire were administered during the MAT visit using a form entitled “Kort Version for Incidenta.” As a result, to obtain complete risk information for this set of twins, it is necessary to merge the SATSA IPT3RISK data with the SALZA risk data.

Similarly, the IPT-Risk interview included family history questions similar to the SALZA Par-Familj protocol. Consequently, only those family history items unique to the SALZA questionnaire were administered during the MAT visit using a form entitled “Kort Version for Incidenta.” To obtain complete family history information for this set of twins, it is necessary to merge the SATSA IPT3RISK data with the SALZA family history data.

C.3 ALGORITHMS

C.3.a CDR algorithm (MAT)

A global Clinical Dementia Rating score is calculated following Morris, Ernesto, Schafer, Coats, Leon, Sano, Thal & Woodbury (1997). Clinical Dementia Rating training and reliability in multicenter studies: The Alzheimer’s disease cooperative study experience. *Neurology*, 48, 1508-1510.] using scores from each of the six scale categories (memory, orientation, judgment and problem solving, community affairs, home and hobbies, and personal care). In deriving the score, Memory is considered the primary category. If at least three other categories are assigned the same rating as Memory, then CDR=the Memory rating. If three secondary categories are scored on one side of Memory and two secondary categories are scored on the other side of Memory, then CDR=Memory. Otherwise, CDR=the score of the majority of secondary categories. If Memory=0.5 and at least 3 other categories>0.5, then CDR=1. If Memory=0.5, CDR cannot=0; it can only be 0.5 or 1. If Memory=0, CDR=0 unless 2 or more secondary categories>0, in which case CDR=0.5. The scale scores can be interpreted as follows:

0=none

0.5=questionable dementia

1=mild dementia

2=moderate dementia

3=severe dementia

C.3.b FAMHX algorithm (HX)

Two variables (FAMHX, FAMHX2) assessing family history of dementia using data from the Family History questionnaire have been constructed and included in the FAMHX dataset. These variables are available only for individuals interviewed by the MAT. FAMHX is the preferred variable. It classifies family history as negative only if parents are known to have lived to age 65 without dementia. FAMHX2 can be used as an alternative if it is not feasible to use FAMHX. The categories for each variable are as follows:

FAMHX=0 negative- no first degree relatives had dementia and parents lived to >=65
=1 positive- >=1 first degree relative with dementia
=2 uninformative- parents died <65
=. Missing- key information not known

FAMHX2=0 negative- no first degree relatives had dementia
=1 positive- >=1 first degree relative with dementia
=. Missing- key information not known

C.3.c Smell data (Medical Risk)

A Smell Test as described in Gilbert & Wysocki (1987) was administered to all twins as part of the Medical Risk protocol. The odors administered were as follows: 1. sweat- androstenone; 2. banana- isomyl acetate; 3. musk- galaxolide; 4. cloves- eugenol; 5. natural gas warning scent- mercaptans; 6. rose- synthetic rose scent. The following pre-coded response categories were considered by the SALZA team to be “correct” identification of each smell: 1.musky or urine; 2. fruity; 3. musky; 4. spicy; 5.foul; 6.floral. Open-ended responses that were unaccompanied by a pre-coded category need to be considered on a case-by-case basis.

C.4 MISSING VALUE CODES

Table 6 provides details on the missing value code system utilized in the cognitive portion of the MAT assessment (datafile: Newmatv5). An attempt was made to determine and record the reason for a missing response to any particular question. Reasons for missingness were then incorporated into the algorithms for the scoring of tests and scales as described in the table.

D. SCALE AND METHODOLOGY REFERENCES

Age of Onset (questions included in Inform-Psyk)	Bayles, K. A. (1991). Age at onset of Alzheimer's disease. <i>Archives of Neurology</i> , 48, 155-159.
Blessed Dementia Rating Scale	Blessed, G., Tomlinson, B.E., & Roth, M. (1968). The association between quantitative measures of dementia and of senile change in the cerebral grey matter of elderly subjects. <i>British Journal of Psychiatry</i> , 114, 797-811.
Clinical Dementia Rating (CDR)	Morris, J.C., Ernesto, C., Schafer, K., Coats, M., Leon, S., Sano, M., Thal, L.J., Woodbury, P., & the Alzheimer's Disease Cooperative Study. (1997). Clinical Dementia Rating training and reliability in multicenter studies: The Alzheimer's disease cooperative study experience. <i>Neurology</i> , 48, 1508-1510.
Clock Test	Johansson, B. (1988/89). The MIR- Memory-in-Reality Test. Psykologiforlaget AB, Stockholm, Sweden.
Coin Test	Johansson, B. (1988/89). The MIR- Memory-in-Reality Test. Psykologiforlaget AB, Stockholm, Sweden.
Comprehension (WAIS)	Jonsson, C.O., & Molander, L.(1964). Manual till CVB-skalan [Manual of the CVB-Scales]. Stockholm: Psykologi Forlaget.
Depression	Kessler, R.C., Andrews, G., Mroczek, D., Ustun, B., & Wittchen, U.L. (1998). The World Health Organization Composite International Diagnostic Interview Short Form (CIDI-SF). <i>International Journal of Methods in Psychiatric Research</i> , 7, 171-185.
Digit Span (forward and backward)	Jonsson, C.O., & Molander, L.(1964). Manual till CVB-skalan [Manual of the CVB-Scales]. Stockholm: Psykologi Forlaget.
Figure Copying (CERAD)	Morris, J.C., Heyman, A., Mohs, R.C., Hughes, J.P., van Belle, G., Fillenbaum, G., Mellits, E.D., & Clark, C. (1989). The consortium to establish a registry for Alzheimer's disease (CERAD): I. Clinical and neuropsychological assessment of Alzheimer's disease. <i>Neurology</i> , 39, 1159-1165.
Figure Identification	Dureman, I., Kebbon, L., & Osterberg, E. (1971). Manual till DS-Batteriet [Manual of the DS-Battery]. Stockholm: Psykologi Forlaget.
Figure Logic	Dureman, I., Kebbon, L., & Osterberg, E. (1971). Manual till DS-Batteriet [Manual of the DS-Battery]. Stockholm: Psykologi Forlaget.

Information (WAIS)	Jonsson, C.O., & Molander, L.(1964). Manual till CVB-skalan [Manual of the CVB-Scales]. Stockholm: Psykologi Forlaget.
Informant Interviews (NAVLIDEN protocol to determine cognitive status of a deceased individual)	Davis, P. B., White, H., Price, J. L., McKeel, D., & Robins, L. N. (1991). Retrospective postmortem dementia assessment. <i>Archives of Neurology</i> , 48, 613-617.
Koh's Block Design	Arthur, G. (1947). A point scale of performance tests (Rev. Form II). New York: Psychological Corporation.
Logical Memory	Wechsler, D. (1945). A standardized memory scale for clinical use. <i>Journal of Psychology</i> 19: 87-93. Johansson, B., & Zarit S.H. (1991). Dementia and cognitive impairment in the oldest old: a comparison of two rating methods. <i>International Psychogeriatrics</i> , 3,29-38.
Memory-in-Reality(MIR)/Apartment Test	Johansson, B. (1988/89). The MIR- Memory-in-Reality Test. Psykologiforlaget AB, Stockholm, Sweden. Johansson, B., & Zarit S.H. (1991). Dementia and cognitive impairment in the oldest old: a comparison of two rating methods. <i>International Psychogeriatrics</i> , 3,29-38.
Mini-Mental State Examination (MMSE)	Folstein, M., Folstein, S., & McHugh, P. (1975). "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. <i>Journal of Psychiatric Research</i> , 12, 189-198.
Mental Status Questionnaire (MSQ)	Kahn, R.L., Pollack, M., & Goldfarb, A.I. (1961). Factors related to individual differences in mental status of institutionalized aged. In P. Hoch & J. Zubin (Eds.), <i>Psychopathology of aging</i> (pp. 104-113), New York: Grune & Stratton.
Serial Threes (SPMSQ)	Duke University Center for the Study of Aging and Human Development (1978). <i>Multidimensional functional assessment: The OARS methodology</i> . Durham, NC: Duke University.
Similarities/Differences	Hughes, C.P., Berg L., Danzinger, W.L., Cohen, L.A., Martin, R.L. (1982). A new clinical scale for the staging of dementia. <i>British Journal of Psychiatry</i> , 140, 566-72. Jonsson, C.O., & Molander, L.(1964). Manual till CVB-skalan [Manual of the CVB-Scales]. Stockholm: Psykologi Forlaget.
Short Portable Mental Status Questionnaire (SPMSQ)	Duke University Center for the Study of Aging and Human Development (1978). <i>Multidimensional functional assessment: The OARS methodology</i> . Durham, NC: Duke

	University. Pfeiffer, E. (1975). A short portable mental status questionnaire for the assessment of organic brain deficit in elderly patients. <i>Journal of the American Geriatrics Society</i> 23: 433-441.
Smell Survey	Gilbert, Wysocki (1987). The Smell Survey Results. <i>National Geographic</i> , 122:514-525.
Swedish Naming	Goodglass, H., & Kaplan, E. (1972). <i>Assessment of aphasia and related disorders</i> . Philadelphia: Lea & Febiger.
Symbol Digit	Smith, A. (1982). <i>Symbol digit modalities test (SDMT). Manual (revised)</i> . Los Angeles: Western Psychological Services.
Synonyms	Dureman, I., Kebbon, L., & Osterberg, E. (1971). <i>Manual till DS-Batteriet [Manual of the DS-Battery]</i> . Stockholm: Psykologi Forlaget.
TELE	Gatz, M., Reynolds, C., Nikolic, J., Lowe, B., Karel, M. & Pederson, N.L. (1995). An empirical test of telephone screening to identify potential dementia cases. <i>International Psychogeriatrics</i> , 9, 429-437.
Three Item Recall (MMSE)	Folstein, M., Folstein, S., & McHugh, P. (1975). "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. <i>Journal of Psychiatric Research</i> , 12, 189-198.
Picture Memory	Thurstone, L.L. (1938). <i>Primary mental abilities</i> . Chicago: University of Chicago Press.
Verbal Fluency (CERAD)	Morris, J.C., Heyman, A., Mohs, R.C., Hughes, J.P., van Belle, G., Fillenbaum, G., Mellits, E.D., & Clark, C. (1989). The consortium to establish a registry for Alzheimer's disease (CERAD): I. Clinical and neuropsychological assessment of Alzheimer's disease. <i>Neurology</i> , 39, 1159-1165.
Word List Recall/Recognition (CERAD)	Morris, J.C., Heyman, A., Mohs, R.C., Hughes, J.P., van Belle, G., Fillenbaum, G., Mellits, E.D., & Clark, C. (1989). The consortium to establish a registry for Alzheimer's disease (CERAD): I. Clinical and neuropsychological assessment of Alzheimer's disease. <i>Neurology</i> , 39, 1159-1165.

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TABLE 1: Form/Datafile Cross Reference

ASSESSMENT	FORM	RESPONDER	MODE	DATAFILE	N RECORDS
ADMINISTRATIVE/DX					
Administrative File for Salza			Constructed	Adsal*	2394
Informant List	Inform.List	Informant	In-person	Inflist	241**
Post-Mortem Screening	Avliden-Tele	Informant	Telephone	Navliden	80
Screening Outcomes			Constructed	Outscreen*	2394
MAT					
Codelist		Twin	Constructed	Kodlista*	59
		Informant	Constructed	Kodlist_inf	139
Cognitive	Tvilling-Psyk	Twin	In-person	Newmatv5	209
	Inform-Psyk	Informant	In-person	Newmatv5	
	Tvilling-Psyk-Satsa-Formular	Twin	In-person	Newmatv5	
Comparative Risk	Par-Risk	Twin	In-person	Parrsk	58
Drugs			Constructed	Drugs*	4392**
Family History	Par-Familj	Twin/Informant	In-person	Famhx	290
Medical History/Risks	Tvilling-Med	Twin	In-person	Medrisk	135
		Informant	In-person	Medrisk_inf	226
Risks- Environmental	Inform-Risk	Twin	In-person	Livrisk	126
		Informant	In-person	Livrisk_inf	232
Work-Hobby	Yrkeliv	Twin	Constructed	Work_hobby	73
		Informant	Constructed	Work_hobby_inf	227

* codebook is named to correspond to data file

**multiple records per ID

ASSESSMENT	FORM	RESPONDER	MODE	DATAFILE	N RECORDS
LONGITUDINAL FOLLOW_UP					
Cognitive	Tvilling-Psyk-Longitudinal	Twin	In-person	Matlong	79
IPT4	Tvilling-Tele-IPT4	Twin	Telephone	Ipt4	387
	Inform-Tele-IPT4	Informant	Telephone	Ipt4_inf	10
PROSPECTIVE					
EPILOG			Constructed	Epilog*	3838
IPT3A	Par-Risk-IPT	twin	In-person	Ipt3a	536
IPT3RISK	Ipt-risk	Twin	In-person	Ipt3risk	533
IPT3Q	IPT3Q(selected questions)	twin	questionnaire	Ipt3q	528
Q4	SATSA Q4 (selected questions)	Twin	questionnaire	Q4	1450

* codebook is named to correspond to data file

**multiple records per ID

Table 2: NYK78 (Nordic Occupational Classification)

Nyk	nyk_title	uscensus	uscensus_title
0	Professional, technical and related work		
00	<i>Engineering work</i>		
001	Architects	002	Architects
002	Electricians	012	Electrical and electronic engineers
003	Mechanical engineers	014	Mechanical engineers
004	Chemical engineers	010	Chemical engineers
005	Metallurgists	015	Metallurgical and materials engineers
006	Engineers and technicians from other industries	023	Engineers, n.e.c.
007	Surveyors, measurers	161	Surveyors
008	Technical assistants	173	Technicians, n.e.c.
009	Non-specified	99900	
01	<i>Chemical and physical work</i>		
011	Chemists, physicists	045	Chemists
012	Physicists	053	Physicists and astronomers
013	Geologists, meteorologists	051	Geologist
014	Lab technicians/assistants	151	Chemical technicians
019	Non-specified	99901	
02	<i>Biological work</i>		
021	Veterinarians	072	Veterinarians
022	Biologists	044	Biological scientists
023	Agri-,horticultural advisors	042	Agricultural scientists
024	Forestry researchers	025	Foresters and conservationists
025	Non-spec. biological work	99902	
029	Non-specific information	99902	
03	<i>Medical work</i>		
031	Physicians and surgeons	065	Physicians, medical and osteopathic
032	Dentists	062	Dentists
039	Non-spec. medical work		
04	<i>Health and nursing work</i>		
040	Registered nurses	075	Registered nurses
041	Midwives	924	Lay midwives
042	Attendants-psychiatric care	925	Nursing aids, orderlies, and attendants
043	Practical nurses	926	Practical nurses

044	Dental nurses	921	Dental assistants
045	Medical technicians	085	Health technologists and technicians, n.e.c.
046	Pharmacists	064	Pharmacists
047	Physio-, occup. therapists	076	Therapies
048	Other	99804	
049	Non-spec.	99904	
05	<i>Educational work</i>		
050	Principals, headmasters	240	School administrators
051	Higher ed. teachers	135	Miscellaneous teachers, college and university
052	Teachers in theoretical subjects	122	Social science teachers
053	Form-masters	142	Elementary school teachers
054	Teachers in painting	123	Art, drama, and music teachers
055	Teachers in vocational subjects	134	Trade, industrial, and technical teachers
056	Pre-primary ed. teachers	143	Prekindergarten and kindergarten teachers
057	Ed. methods advisors	174	Vocational and educational counselors
058	Other educ. work	99805	
059	Non-specified educ. work	99905	
006	<i>Religious work</i>		
061	Ministers, priests	086	Clergymen
068	Other	090	Religious workers, n.e.c.
069	Non-specified	99906	
07	<i>Legal work</i>		
071	Judges and public lawyers	030	Judges
072	Prosecutors, senior police officers	031	Lawyers
073	Private lawyers	031	Lawyers
074	Corporation lawyers	031	Lawyers
078	Other	99807	
079	Non-specified	99907	
08	<i>Literary and artistic work</i>		
081	Sculptors, painters, photographers	190	Painters and sculptors
082	Designers	183	Designers
083	Display artists	183	Designers
084	Authors	181	Authors
085	Journalists	184	Editors and reporters
086	Performing artists	194	Writers, artists, entertainers
087	Composers, musicians	185	Musicians and composers
088	Other	194	Writers, artists, entertainers
089	Non-specified	99908	
09	<i>Other professional, technical or related work</i>		
091	Accountants and auditors	001	Accountant
092	Social workers	100	Social workers

093	Librarians, archivists	032	Librarians
094	Economists, statisticians	091	Economics
095	Psychologists	093	Psychologists
096	Staff officers	220	Office managers, n.e.c.
097	Systems analysts	055	Operations and systems researchers and analysts
098	Other	99809	
099	Non-specified	99909	
1	Government legislative, administrative		
10	<i>Government legislative, administrative work</i>		
101	Government legislative, administrative work	222	Officials and administrators; public administration, n.e.c.
109	Non-specified (not in FoB)		
11	<i>Business administration and other work</i>		
111	General business managers	216	Managers and superintendents, building
118	Other business managers	220	Office managers, n.e.c.
119	Non-specified	99911	
2	Bookkeeping and clerical work		
20	<i>Bookkeeping and cashier</i>		
201	Bookkeepers, cashiers	305	Bookkeepers
203	Bank tellers	301	Bank tellers
204	Cashiers-retail, restaurants	310	Cashiers
208	Debt collectors	313	Collectors, bill and account
209	Non-specified	99920	
29	<i>Clerical and related work</i>		
290	Clerical and related	395	Not specified clerical work
291	Computer operators	343	Computer and peripheral equipment operators
292	Bank employees	301	Bank tellers
293	Travel agency employees	390	Ticket, station, and express agents
294	Forwarding and shipping	374	Shipping and receiving clerks
295	Property, store managers	231	Sales managers and department heads, retail trade
296	Insurance, claims adjusters	326	Insurance adjusters, examiners, and investigators
297	National insurance officers	326	Insurance adjusters, examiners, and investigators
298	Cost accountants	375	Statistical clerks
299	Non-specified	99929	
3	Sales work		
30	<i>Working proprietors, trade</i>		
301	Proprietors, wholesale	205	Buyers, wholesale and retail trade
302	Retail traders	205	Buyers, wholesale and retail trade

309	Non-specified	99930	
31	<i>Sales of insurance, properties</i>		
311	Insurance sellers	265	Insurance agents, brokers, and underwriters
312	Brokers, valuers	2457190	Finance, insurance, real estate
313	Advertising salesmen	260	Advertising agents and salesmen
318	auctioner, valuer	261	Auctioneers
319	Non-specified	99931	
32	<i>Sales of insurance, visit costumers, agencies</i>		
321	Solicitor	265	Insurance agents, brokers, and underwriters
33	<i>Other sales work</i>		
331	Commercial travelers	225	Purchasing agents and buyers, n.e.c.
332	Shop managers	231	Sales managers and department heads, retail trade
333	Shop assistants	283	Sales clerks, retail trade
338	Gas station attendants	2456480	Gasoline service stations
339	Non-specified	99933	
4	Agricultural, forestry, fishing work		
40	<i>Agricultural, forestry work</i>		
401	Proprietors	801	Farmers (owners and tenants)
402	Farm managers	802	Farm managers
403	Forestry managers	2456070	Lumber and building material, retail trade
404	Horticultural managers	802	Farm managers
405	Livestock breeders	821	Farm foremen
406	Breeders of fur animals	821	Farm foremen
407	Reindeer owners	740	Animal caretakers
409	Non-specified	99940	
41	<i>Agricultural, livestock work</i>		
411	Agricultural, livestock workers	822	Farm laborers, wage workers
412	Horticultural workers	822	Farm laborers, wage workers
413	petkeeper	822	Farm laborers, wage workers
414	Fur-bearing animal farm workers	822	Farm laborers, wage workers
415	Reindeer herdsman	822	Farm laborers, wage workers
418	Other	822	Farm laborers, wage workers
419	Non-specified	99941	
42	<i>Wildlife protection and hunting</i>		
421	Gamekeepers	740	Animal caretakers
43	<i>Fishing</i>		
431	Fishermen	752	Fishermen and oystermen
432	Fish-breeders	99843	
439	Non-specified	99943	
44	<i>Forestry</i>		
441	Forest workers, log drivers	6901070	Logging machine operatives

5	Mining and quarrying work		
50	<i>Mining and quarrying work</i>		
501	Miners, querymen	6400480	Coal mining
502	Well, diamond drillers	614	Drillers, earth
503	Ore dressers	614	Drillers, earth
504	Other	99850	
509	Non-specified	99950	
6	Transport and communications work		
60	<i>Ships' officers</i>		
601	Deck officers	221	Officers, pilots, and pursers; ship
602	Ship pilots	221	Officers, pilots, and pursers; ship
603	Ship engineers	455	Locomotive engineers
609	Non-specified	99960	
61	<i>Ships' deck and engine room crew</i>		
611	Deck and engineer room crew	661	Sailors and deck hands
62	<i>Aircraft officers</i>		
621	Aircraft officers	163	Airplane pilots
63	<i>Rail and road transport work</i>		
631	Railway engine drivers, assistants	455	Locomotive engineers
632	Railway guards	226	Railroad conductors
633	Car, tram drivers	6902190	Motor vehicles and motor vehicle equipment operatives
635	Delivery men	705	Delivery men and route men
636	Bus, tram conductors	704	Conduction and motormen
639	Non-specified	99963	
64	<i>Traffic supervision</i>		
641	Harbor masters	221	Officers, pilots, and pursers; ship
642	Air-traffic controllers	164	Air traffic controllers
643	Train station masters, train dispatchers	226	Railroad conductors
644	Road traffic supervisors	963	Marshalls and constables
649	Non-specified	99964	
65	<i>Post and telecommunications</i>		
651	Post-office clerks	361	Postal clerks
652	Telecommunications traffic officers	385	Telephone operators
653	Telephone operators	385	Telephone operators
654	Office phone operator	364	Receptionists
655	Telegraph, radio operators	171	Radio operators
659	Non-specified	99965	
66	<i>Mail distribution and messenger</i>		
661	Sorting clerks, postmen	361	Postal clerks
662	messengers	333	Messengers and office boys
669	Non-specified	99966	
67	<i>Other transport and communication work</i>		
671	Lighthouse, ferry operators	701	Boatmen and canalmen

678	Railway linemen	7804070	Railroads and railway express services
69	<i>Non-identifiable transportation and commun.</i>		
699	Non-identifiable	99969	
7	Production work		
70	<i>Textile work</i>		
701	Spinners, weavers, dyers	672	Spinners, twisters, and winders
709	Non-specified	99970	
71	<i>Sewing work</i>		
711	Tailors, dressmakers	551	Tailors
712	Fur tailors	551	Tailors
713	Milliners, hat makers	551	Tailors
714	Upholsterers	563	Upholsterers
715	Patternmakers, cutters	514	Pattern and model makers
716	Dressmakers and seamstresses	613	Dressmakers and seamstresses
718	Other	99971	
719	Non-specified	99871	
72	<i>Shoe work</i>		
721	Shoe makers, repairers	542	Shoe repairmen
722	Shoe cutters, lasters, sewers	542	Shoe repairmen
726	Leather goods makers	7803880	Tanned, curried, and finished leather workers
729	Non-specified	99972	
73	<i>Metal processing work</i>		
731	furnacemen	622	Furnacemen, smeltermen, and pourers
732	Metal annealers, temperers	446	Heat treaters, annealers, temperers
733	Rolling mill workers	7801390	Blast furnaces, steel works laborers
735	Smiths, forgers	403	Blacksmiths
736	Metal casters, moulders	503	Molders, metal
737	Wire, tube drawers	522	Plumbers and pipe fitters
738	Other	99873	
739	Non-specified	99873	
74	<i>Precision tool manufacturing</i>		
741	Precision tool makers	453	Jewelers and watchmakers
742	Watchmakers	453	Jewelers and watchmakers
743	Opticians	506	Opticians, and lens grinders and polishers
744	Dental technicians	426	Dental laboratory technicians
745	Gold-, silver smiths	453	Jewelers and watchmakers
749	Non-specified	99974	
75	<i>Engineering and building metal work</i>		
750	Toolmakers, tool operators	561	Tool and die makers

751	Machinery fitters, repair	495	Not specified mechanics and repairmen
752	Machine, motor repair	495	Not specified mechanics and repairmen
753	Sheet metal workers	535	Sheetmetal workers and tinsmiths
754	Plumbers, pipe fitters	522	Plumbers and pipe fitters
755	Welders, flame cutters	680	Welders and flame cutters
756	Heavy metal work	7801470	Other primary iron and steel industries
757	Metal platers, coaters	635	Metal platers
758	Other metal work	99875	
759	Non-specified	99975	
76	<i>Electrical and electronics work</i>		
761	Electrical fitters, wiremen	430	Electricians
764	Radio, tv assemblers, repair	485	Radio and television
765	Recording, sound, light operators	6902070	Radio, television, and communication equipment operators
766	Tele-installers, repairmen	552	Telephone installers and repairmen
767	linemen, electricians	433	Electric power linemen and cablemen
768	Other	99876	
769	Non-specified	99976	
77	<i>Woodwork</i>		
771	Construction carpenters, joiners	415	Carpenters
772	Bench carpenters, cabinet makers	413	Cabinetmakers
773	Laminated wood, fiberboard workers	415	Carpenters
774	Frame, circular sawyers	662	Sawyers
778	Other	99877	
779	Non-specified	99977	
78	<i>Painting work</i>		
781	Painters	510	Painters, construction and maintenance
782	Spray painters	510	Painters, construction and maintenance
79	<i>Other building and construction work</i>		
791	Bricklayers	410	Brickmasons and stonemasons
792	Masons	410	Brickmasons and stonemasons
793	Concrete, construction workers	751	Construction laborers
794	Insulators	601	Asbestos and insulation workers
795	Glaziers	445	Glaziers
797	Divers, pipe layers	522	Plumbers and pipe fitters
798	Other	99878	
799	Non-specified	99978	
8	Production work		
80	<i>Printing work</i>		

801	Typographers	422	Pressmen and plate printers, printing
806	Bookbinders	405	Bookbinders
808	Other	99880	
809	Non-specified	99980	
81	<i>Glass, pottery, and tile work</i>		
811	Glass formers, cutters	7801370	Pottery and related products laborers
812	Potters	7801370	Pottery and related products laborers
813	Glass, ceramics kilnmen	7801370	Pottery and related products laborers
814	Glass painters, decorators	644	Painters, manufactured articles
818	Other	99881	
819	Non-specified	99981	
82	<i>Food processing work</i>		
821	Grain mill, oil press workers	501	Millers; grain, flour, and fee
822	Bakers, pastry cooks	402	Bakers
823	Chocolate workers	6902980	Non-specified food industries
824	Brewery, distillery workers	6902980	Non-specified food industries
825	Canning workers	6902780	Canning and preserving fruits, vegetables and seafoods
826	Butchers, meat preparers	633	Meat cutters and butchers, manufacturing
827	Dairy workers	7802690	Dairy products
828	Other	99882	
829	Non-specified	99982	
83	<i>Chemical, cellulose processing work</i>		
831	Chemical process workers	7803470	Industrial chemicals
834	Paper pulp workers	7803280	Pulp, paper, and paperboard mills
836	Paper, paperboard workers	7803280	Pulp, paper, and paperboard mills
838	Other	99883	
839	Non-specified	99983	
84	<i>Tobacco work</i>		
841	Tobacco workers	6902990	Tabacco manufacturers
85	<i>Other production work</i>		
850	Basketry weavers	673	Weavers
851	Rubber products workers	7803790	Rubber products
852	Plastic products workers	7809990	All other industries
853	Tanners, fur dressers	7803880	Tanned, curried, and finished leather
854	Photo lab workers	645	Photographic process workers
855	Musical instrument makers, tuners	575	Craftsmen and kindred workers, n.e.c.
856	Stone cutters, carvers	546	Stone cutters and stone carvers
857	Paper, paperboard products workers	7803280	Pulp, paper, and paperboard mills

858	Other	99885	
859	Non-specified	99985	
86	<i>Unskilled manual work</i>		
861	Unskilled manual work	785	Not specified laborers
87	<i>Operations monitoring, material handling</i>		
871	Stationary engine operators	461	Machinists
872	Crane, hoist operators	424	Cranemen, derrickmen, and hoistmen
873	Riggers, cable splicers	554	Telephone linesmen and splicers
874	Construction machine operators	6900990	Construction machine operatives
875	Truck, conveyor operators	715	Truck drivers
876	Greasers	642	Oilers and greasers, except auto
878	Other	99887	
879	Non-specified	99987	
88	<i>Packing, freight handling and storage</i>		
881	Packers	643	Packers and wrappers, except metal and produce
882	Dockers, freight handlers	753	Freight and material handlers
883	Store, warehouse workers	770	Warehousemen
888	Other	99888	
889	Non-specified	99988	
899	other manufacturing work	785	Not specified laborers
9	Service work		
90	<i>Civilian protective service work</i>		
901	Firefighters	961	Firemen, fire protection
902	Policemen	964	Policemen and detectives
903	Customs surveyance	962	Guards and watchmen
904	Prison officials	962	Guards and watchmen
908	Other	99890	
909	Non-specified	99990	
91	<i>Housekeeping and related services</i>		
911	Catering supervisors	916	Food service workers
912	Cooks	912	Cooks, except private household
913	Kitchen maids	913	Dishwashers
914	Nursemaids	925	Nursing aids, orderlies, and attendants
915	Housekeeping service	950	Housekeepers, except private household
916	Hotel receptionists	364	Receptionists
917	Pursers, stewards	933	Attendants, personal service
918	Other	99891	
919	Non-specified	99891	
92	<i>Waiters, waitresses</i>		
921	Waiters and waitresses	915	Waiters
93	<i>Caretaking, cleaning work</i>		

931	Building caretakers	903	Janitors and sexton
932	Cleaners	902	Cleaners and charwomen
933	Chimney sweepers	903	Janitors and sexton
939	Non-specified	99993	
94	<i>Other service work</i>		
941	Hairdressers, beauticians	944	Hairdressers and cosmetologists
942	Bath attendants	933	Attendants, personal service
943	Launderers, dry cleaners	630	Laundry and dry cleaning operatives
944	Pressers	611	Clothing ironers and pressers
945	Coaches, horse trainers	124	Coaches and physical education teachers
946	Photographers	191	Photographers
947	Undertakers	785	non-specified laborers
948	Other	99894	
949	Non-specified	99994	
98	<i>Armed forces</i>		
981	Members of armed forces	962	Guards and watchmen
99	<i>Unidentifiable occupations</i>		
999	Workers reporting unidentifiable or inadequately described occupations		

TABLE 3: Swedish socio-economic classification (SEI) ¹
 (SCB Meddelanden i samordningsfragor. 1982:4 Nytryck 1995)

Manual workers Occupations normally organised by LO (The Swedish Trade Union Confederation) 11-22

	Delineations
11 Unskilled employees in goods production	Less than 2 years of post-comprehensive school education
12 Unskilled employees in service production	Less than 2 years of post-comprehensive school education
21 Skilled employees in goods production	2 years or more of post-comprehensive school education
22 Skilled employees in service production	2 years or more of post-comprehensive school education

Non-manual employees Occupations normally organised by TCO (The Swedish Confederation of Professional Employees) or SACO (The Swedish Confederation of Professional Associations) 33-57

33 Assistant non-manual employees, lower level	Less than 2 years of post-comprehensive school education
34 Assistant non-manual employees, higher level, without subordinates ²	2 but not 3 years of post-comprehensive school education
35 Assistant non-manual employees, higher level, with subordinates ²	2 but not 3 years of post-comprehensive school education

¹ Published in Reports on Statistical Co-ordination 1982:4, Statistics Sweden

² Could be aggregated to 36 Assistant non-manual employees, higher level

44 Intermediate non-manual employees, without subordinates ³	3 but not 6 years of post-comprehensive school education
45 Intermediate non-manual employees, with subordinates ³	3 but not 6 years of post-comprehensive school education
54 Professionals and other higher non-manual employees, without subordinates ⁴	At least 6 years of post-comprehensive school education
55 Professionals and other higher non-manual employees, with subordinates ⁴	At least 6 years of post-comprehensive school education
57 Upper-level executives	Upper-level executives in private enterprises or organisations with at least 100 employees or in public service

Self-Employed 60-87

60 Self-employed professionals	At least 6 years of post-comprehensive school education
76 Self-employed without employees ⁵	Not including farmers or professionals
77 Small-scale entrepreneurs ⁵	Self-employed with 1-9 employees, not including farmers or professionals
78 Large-scale entrepreneurs ⁵	Self-employed with 10 or more employees or large-scale farmers
86 Small-scale farmers ⁶	Farmers with at most 20 hectares of arable land and at most 100 hectares of forest land

³ Could be aggregated to 46 Intermediate non-manual employees

⁴ Could be aggregated to 56 Professionals and higher non-manual employees

⁵ Could be aggregated to 79 Self-employed other than professionals

⁶ Could be aggregated to 89 Farmers

87 Medium-scale farmers ⁶

Farmers with 21–100 hectares
of arable land or 101– 400
hectares of forest land

Non –Active population

101-103 Students

201-287 Housewives (or male equivalents)

Last 2 digits indicate
husband's code

311-387 Old age pensioners

Last 2 digits indicate
previous occupation

TABLE 4: COMMON SOCIAL CLASS GROUPINGS

SEI_GROUP	SEI	
1	11-12	
2	21-22	
3	33-36	
4	44-46	
5	54-60	
6	76-78	
7	86-87	
8	97	
9	91,95,96,98,99	

TABLE 5: BIG 6 LIST

	EXPOSURE	
1	Metals	
2	Solvents	
3	Plastics/Synthetics	
4	Animal Products	
5	Radiation	
6	Welding	

TABLE 6: Scoring rules for missing codes in Newmatv5 datafile:

<u>Ej_jufort Codes</u>	<u>Scoring Rule</u>
0. Subject did not understand	Contribute zero points
1. Met Criterion for not administering the test.	Varies by test*
2. Attempted test but discontinued because couldn't do it.	Contribute zero points
3. Didn't attempt-seemed unlikely could do it (tester decision)	Call it missing for statistical purposes
4. Subject/Respondent refused	Varies by test**
5. Sensorimotor reason made it impossible.	Call it missing or prorate if possible
6. Other reason	Call it missing or prorate if possible
7. SATSA example-not coded	Score not available – call it missing
8. Subject/Respondent doesn't know.	Shouldn't be used in this file
9. Not asked, no reason given.	Call it missing or prorate if possible
10. Not motivated	

* Contribute zero points for cases where test not given because couldn't complete/do examples or previous test (e.g. Word List not given if subject couldn't do 3-item recall; If can't draw square subject not asked to draw cube). Sometimes items are skipped in a test where the earlier ones are easier (e.g. Information), if the starting point item is correct then subject gets points for easier items not given.

** If progressively more difficult, give zeros to unattempted items. Tests with increasing difficulty include: Information, Block Design, Mir apartment test (recognition & test placement), & Figure Copying. For tests of non increasing difficulty then prorate where possible (e.g. Word List trials, Judgment, Naming, Digit Symbol (i.e. if have part A and not part B). Call it missing if can't prorate or assign zeros.