the EVALUATION@HSRI CENTER

Linking Mental Health Consumer Files with State Death Records

A Guide to Obtaining and Using Mortality Information to Evaluate the Needs and Outcomes of Consumer Populations.

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We have included the following items on a CD ROM*:

Appendix A – Additional Resources

- Text Only
- WORD 6.0/95
- WORD 2000
- Web page

Underlying Cause of Death Codes Only - UCREF

- UCREF.XPT - SAS (Export format)
- UCREF.SAV - SPSS
- UCREF.XLS - Excel
- UCREF (Tab delimited)

All Valid Multiple Cause of Death Codes Which Appear as Record Access Conditions - RAREF

- RAREF.XPT - SAS (Export format)
- RAREF.SAV - SPSS
- RAREF.XLS - Excel Format
- RAREF (Tab delimited)

* We have provided these resources on a CD ROM, these files are also available on diskette if needed, for more information contact *the Evaluation Center*@HSRI.

This Toolkit is one of a series of such kits commissioned by the Evaluation Center@HSRI. The Center is a grant of the Substance Abuse and Mental Health Services Administration, Center for Mental Health Services. The mission of the Evaluation Center is to provide technical assistance related to the evaluation of adult mental health system change.

The Center offers six programs, all of which are designed to enhance evaluation capacity.

- **The Consultation Program** provides consultation tailored to the needs of individual projects.
- **The Topical Evaluation Networks Program** maintains a forum for ongoing dialogue via electronic conferencing.
- **The Toolkit Program** develops manuals that provide evaluators with tested methodologies and instruments related to specific topics.
- **The Materials Program** is an evaluation materials program which supplies evaluators with original papers on selected topics and identifies relevant literature in the field.
- **The Conferences and Training Program** is designed to enhance the evaluation skills of producers and consumers of evaluations.
- **The Multicultural Issues in Evaluation Program** focuses on evaluation issues related to culturally, racially and ethnically diverse populations.

The Toolkits are designed to provide evaluators with complete descriptions of methodologies and instruments for use in evaluating specific topics. Based on information from a needs assessment study conducted by the Center and on feedback from evaluators in the fields, we have identified a number of important topics that evaluators are frequently interested in examining. Expert consultants have been engaged to review the background of these topics and to compile Toolkits that provide evaluators with state-of-the-art evaluation techniques to use in their own work.

The Evaluation Center@HSRI is also interested in supporting "user groups" for its Toolkits. These groups will provide a forum for Toolkit users to share their expertise and experiences with the Toolkits. If you would like to participate in a user group, please complete the postcard enclosed and return it to the Evaluation Center@HSRI.

We hope that this Toolkit on ***Linking Mental Health Consumer Files with State Death Records*** will be helpful to those evaluators who are interested in assessing the impact of system changes on the life circumstances of persons with severe mental illness.

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I. INTRODUCTION

State death records are a valuable health policy resource that have not been fully exploited by mental health clinicians, planners, and evaluators. Data from individual death certificates can help clinicians understand the risks faced by their clients, and in aggregate the same data can help state

mental health authorities (SMHAs) and others, (i.e. payers, providers, and regulators) assess the needs and outcomes of their target populations over time.

As part of its technical assistance to states, the Evaluation Center at the Human Services Research Institute (HSRI) developed this toolkit to help you link consumer files with state death records and use the results to evaluate the needs and outcomes of your consumers. The intended audience includes planners, statisticians, and researchers working in SMHAs, large providers, or insurers that maintain patient registries.

Use of this toolkit requires substantial computing resources. It is assumed that you already maintain a central unduplicated registry of consumers identified by name, birth date, and sex. Additional data such as social security numbers and addresses may also be necessary to verify record linkages. It is also assumed you have access to software, hardware, and manpower needed to process large files. If not, the initial data matching steps described below may have to be performed off-site and the resulting consumer files returned to the SMHA for analysis. If you have any problems in this regard, please contact the Evaluation Center@HSRI.

This document covers the technical aspects of processing computer files, and does not address the interpretation of medical conditions found on death certificates. Additional guidance from medical specialists, epidemiologists, and published literature will usually be needed to understand the significance of specific disease conditions associated with death. A Bibliography of Recommended Readings has been included for this purpose.

Before initiating this project it may be helpful to answer the following questions:

1. ***Will my state vital records agency allow batch searches for research purposes?***

   States vary in their rules and application procedures. National Center for Health Statistics (NCHS) has a contact list for each state at:
   http://www.cdc.gov/nchs/howto/w2w/alphabet.htm

2. ***If batch searches are allowed, will I be permitted to perform this in-house with my resources, or will the vital records agency only perform the search?***

   The cost and labor as well as precision will depend on who manages the matching process.

3. ***Are my patient registry data sufficiently clean to match person level with certainty?***

   This usually requires several elements used for successive matching routines, e.g. names, social security number, full birth date, sex. Addresses are also useful for sorting out false matches. None of these alone are error-free, but using several keys is a good idea.

4. ***Do I have data storage and staff resources to handle all death records?***

   You can estimate these at about 0.9% of your state general population per year, and each record at approximately 500 bytes. If you plan to compare patient mortality with non-patient mortality you will need access to death records in the comparison group. If you limit analysis to patient records, assume 1.0% of your patient registry will die each year.

5. ***Is there substantial migration in my consumer population?***

   This problem affects many states with interstate metro areas. The state where the death occurs 'owns' the death certificate; they may or may not have interstate agreements to share data. This complication may bias your analysis. Use your knowledge of the consumer population to judge this.

6. ***Will I need a "protection of human subjects" signoff to store identified death data with other clinical data?***

   If you are allowed to keep the death record along with other clinical data it becomes much more valuable than use in aggregate alone. Assuming you already have authorization to store patient data, the question is whether your vital records agency wants any additional review. Again, states will vary. Federal rules do not consider a deceased person as a 'human subject', however there are privacy laws regarding medical records in each state that may require some review.

II. DATA ACQUISITION

1. Importance to State Mental Health Authorities

Mortality patterns are a traditional and straightforward indicator of the health status of populations (Grob, 1983; Zopf, 1992). Investigators of mentally ill populations have focused on the clinical determinants of specific causes of death, especially suicide (Vogt, Pope, Mullooly, & Hollis 1994; Black, 1989). Recent improvement in the quality and sophistication of death records has also led to their use to assess the aggregate social and economic costs of mental disorders (Cruze, Harwood, Kristiansen, Collins, & Jones 1981; Harwood, Napolitano, Kristiansen, & Collins 1984; Rice, Kelman, Miller, & Dunmeyer, 1990). A prominent example of the strategic use of mortality

data is found in *Healthy People 2000*, where mortality rates are used as national performance targets in many key health areas (DHHS, 1990). A state level example is described in a working paper by the Evaluation Center@HSRI (Critical Incident Reporting Task Force, 1996). If mortality rates are valid indicators of the social and economic costs of mental illness, then reduced mortality attributable to the effects of services would be a strong measure of the value of such services. Conversely, mortality rates which remain stable or worsen in the long run may indicate service system failure, after controlling for other explanatory variables. Mortality data would thus seem to be a valuable performance indicator for policy makers.

Death certificates were initially meant to establish legal facts, especially the identity of decedents and their manner of death. The use of death certificates for medical and epidemiological purposes is a relatively recent development, which has been achieved through standardization of disease nomenclature, extensive training, and data processing initiatives by NCHS and the states in the 1980s. The International Classification of Diseases (ICD-9) was used as the basis for coding causes of death from 1979 through 1998. In 1999 the US implemented ICD-10, which increases the number of disease entities, changes the coding scheme, and results in some discontinuity with previous classifications. These changes should be reviewed to understand how they will affect data processing and interpretation of your results *(See Appendix A, Items 5 & 6).*

2. State and National Data

Mortality data are maintained by each state and the federal Centers for Disease Control, National Center for Health Statistics (NCHS). The three relevant data sets are:

Table 1: Maintenance of Mortality Data

Data set	Source
State multiple cause of death files	State
National multiple cause of death public use files	NCHS
National Death Index	NCHS

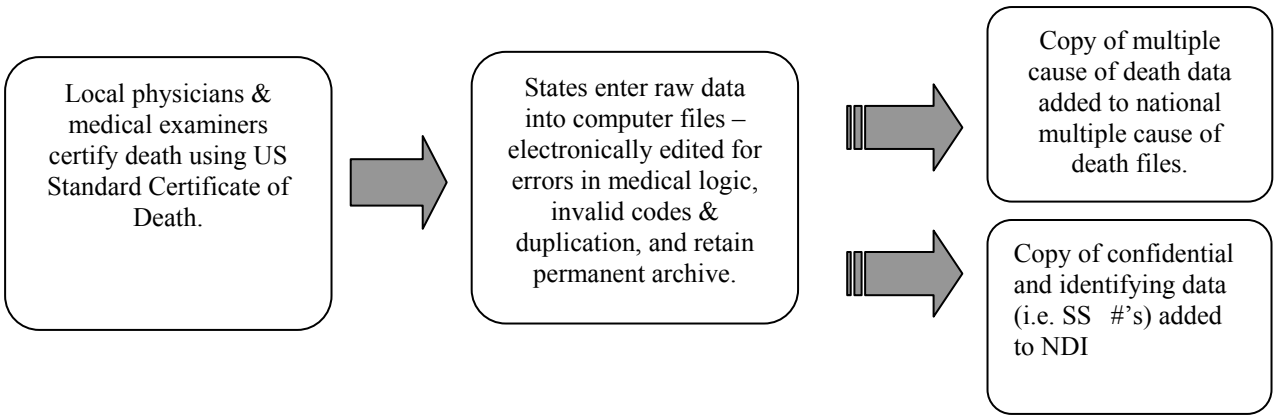
3. State Multiple Cause of Death Files

Death data originate when local physicians and medical examiners certify over 2 million

deaths annually using the US Standard Certificate of Death (SCD) (*See Appendix B*). States[1] enter raw data from the SCD into computer files, which are then electronically edited for errors in medical logic, invalid codes, and duplication. This editing is generally performed by the state using standard software programs designed specifically for this purpose. This editing assures a high level of reliability across states for items such as assignment of underlying cause of death (DHHS, 1993). States differ in the extent of other personal data contained in the electronic files, but they all conform to a standard core of medical data which is subsequently added to the national multiple cause of death files. State and federal mortality files are generally available about 12 months after the close of the calendar year.

[1]States include each of the 50 states and the District of Columbia. In addition, New York City maintains vital records independent of New York State, the only exception to state management of death certificates.

Table 2: Flow of Death Certificate Data



4. National Multiple Cause of Death Public Use Files

After processing state death certificates for the year, electronic copies are submitted to NCHS to become part of the national mortality archive. This archive has been maintained by NCHS as the sources of public-use tapes since 1968. By 1989 all states were using the US Standard Certificate of Death and participating in the uniform reporting of multiple cause of death data. A copy of core demographic and medical elements, minus any identifying data is used to create the annual multiple cause of death public use file. Except for the omitted identifiers, the files are identical to those archived by the state.

The medical data are recorded in two ways: all ICD coded conditions as originally appearing on the death certificate, called 'entity axis conditions', followed by the electronically edited version, the 'record axis conditions' assigned by NCHS software. A single underlying cause of death is also assigned during this editing process. Thus it is possible to compare the certifier's original judgment about cause of death, with the edited version.

While NCHS files are not useful for linked studies, they do provide baseline measures of mortality for state and county populations. In cases where your state vital records agency will not grant access to the complete state death files, the national files can be used to construct appropriate comparison groups for the general population.

5. National Death Index

A second extract of state death records, the National Death Index (NDI) contains only data identifying the decedent and the state of death. The NDI is a national registry of all US decedents maintained by NCHS since 1979. The purpose of the NDI is to identify and trace individuals who have died, but *not* to provide medical information on cause of death. The NDI is extracted from the same SCD records as the multiple cause files, but includes name, birth date, social security number, state of death, certificate number, and various other elements helpful in identifying the date and state of death.

The NDI is appropriate for tracking out-of-state deaths when verification of individual deaths is important. For example, in longitudinal studies with small samples, these deaths may be crucial to the validity of outcome findings. In large scale studies, use of the NDI will generally not be necessary unless there is reason to believe there is a high rate of out-migration that would bias your findings. Since there is a charge for each record matched through the NDI, cost should be considered when submitting large batch files.

Persons wishing to use the NDI must complete an application and upon approval investigators typically submit an electronic list of names and are charged fees for search results (*See Appendix C*). The investigator must then refer to the appropriate state for the full death record.

III. DATA PROCESSING

1. Step 1: Human Subjects Protection

Persons who have died are technically not human subjects for research purposes, however their death records and treatment records may be protected in some states. Living persons identified in patient registries are human subjects, and research involving their records must be conducted under authorization of an appropriate review committee. Since you will be processing files containing data on living clients your work will have to be authorized accordingly. If you do not plan any follow-up contact with family members or surviving patients, then a waiver from informed consent can be granted, assuming no disclosure of identifying data will be made. If follow-up contact will be made, such as interviews with family members or providers, then informed consent procedures must be followed. In either case, your plans should be reviewed by an appropriate committee for the protection of human subjects.

2. Step 2: Contact Your State Vital Statistics Agency

Contact your state vital records agency and ask for their protocols covering access to death records for research purposes. These rules vary from state to state. The state SMHA may have better access than other applicants, but some formal application procedures and potential fees should be expected. If you do not already have routine access to death records, you should establish an interagency relationship with your vital records agency. Appendix A, Item 3 contains information on locating appropriate state agencies.

If you are likely to proceed with an application, you should immediately request a computer file layout and data dictionary specifying the form of the electronic file and the definition of each variable. While the medical portions of death data conform to national standards, other data will vary from state to state. For example, some states may carry complete addresses of decedents and information about family members. Some states add

geographic codes called 'geocoding', such as census tract, as an aid to performing epidemiological research.

In addition to the file description, you will need to know the physical medium of the file to

be transferred to you. You may be offered files on tape, compact disk, diskette, or directly on-line. The size of these files and your software/hardware capability will determine the best way to transfer, store, and process them.

3. Step 3: Estimating Consumer Death Count

It is assumed that you have acquired a death file, loaded it onto a computer containing consumer records, enlisted data processing support, and are now ready to link them. You can estimate that about 1% of your client population dies each year. If your consumer file is contemporary with, or predates the period of your death records, you should expect to find about N*.01 cases for each year of mortality. For example, if you have an unduplicated population of consumers totaling 50,000, and two years of subsequent mortality records, you should expect about (50,000)*(.01)*(2yrs)=1,000 deaths.

4. Step 4: Linking Records

The state vital records agency may deny direct access to the full death file, and offer instead to perform the match for you. In this case they will already have an established matching routine, and will usually advise you of its limitations. You will be asked to submit a file of names and other identifiers to their specifications containing all cases you wish to match, and they will return death records that match yours. Usually name, sex, birth date, and social security numbers are used in this matching process.

On the other hand, if the vital records agency provides you with access to the full death files, you will have to create your own electronic matching routine. To generate valid matches your client files must at minimum contain full name, sex, and birth date. Social security numbers and address are also helpful, since these are also carried in state death files, but because typographical errors occur in these fields you should not expect perfect matching. Success depends on the quality of data in each source file and the amount of time you allocate to inspecting the results. As a rule the quality of death records is high with regard to the identification of decedents and the cause of death codes.

Linkage involves creating a temporary ID for each case using elements from the name, birth date, and sex. This ID can be between 10 and 12 characters long. If the ID field is too long it will

result in false negatives (i.e. false non-matches) due to typographical errors in the source files. If it is too short, the ID will generate a large number of false positive matches requiring lengthy secondary editing. Assuming resources are available to perform secondary screening, it is generally better to include false positives that are eliminated through subsequent editing (Banks & Pandiani, 1999).

An example of a constructed ID is the ten character constructed ID used in the Massachusetts study that was defined as follows (Dembling, Chen, & Vachon, 1999):

Table 3: Example of a Constructed ID

Position	Description
1	sex: M or F
2	first initial of first name
3-4	first two letters of last name
5-6	birth month
7-8	birth day
9-10	birth year

In the Massachusetts study this ID resulted in a 6% rate of false matches, which were subsequently eliminated through manual inspection. The rate of false non-matches was not known and can only be estimated through a controlled simulation.

Assuming you have generated a list of IDs from each source file, these can be matched using your data management or statistical software. You will be making several passes through the data depending on how successful your first attempts appear. After the initial match process, a visual inspection of records should be performed. Since duplicate and false matches (i.e. false positives) are inevitable in very large samples, you should incorporate the social security number, address, or some other field that can easily distinguish these errors. Scan the output from the initial test to get an impression of how much error there appears to be.

It is important to note that false non-matches, or false negatives, are not detected by this process. This is why you do not want to make the initial matching criteria too stringent. If you know in advance the year of death of a particular client, you can test for the presence of that case in the matched set. Otherwise it may not be feasible to detect false negatives or estimate their rate.

After the initial match is made, you will have to determine how "*clean*" your data need to be. There is no set rule for this, though ideally you will want to eliminate obvious false-positives. The inclusion of false-positives in your analysis will tend to bias findings toward mortality patterns in the

general population, while false-negatives should introduce little or no bias. If your data set is relatively small (up to a few hundred cases) you may choose to edit errors manually. If you need to make additional edits electronically, you should rematch the files using the social security number alone. After trying aspects of name, sex, birth date, and social security number there is little alternative to manual editing to correct false matches.

The effort you make in cleaning data will depend on your purpose. If you intend to make the death record a part of the clinical record, great care must be taken to make sure the match is valid. If your purpose is primarily to generate aggregate statistics, individual errors may generally be treated as random and ignored. The exception here is if the errors are systematically biased with regard to any of the dimensions of the analysis you expect to perform. Consult your house statistician for advice on the size of this problem.

5. Step 5: Classifying Cause of Death Codes

In their raw form death records are of limited use. You will want to classify cases based on key characteristics (i.e., sex and race) in your consumer files and causes of death from the death file. Cause of death codes must also be translated in order to proceed with analysis. With the included electronic files (*See CD*) you can build translation tables for cause of death codes. The file UCREF contains all the underlying cause of death codes. The file RAREF contains all valid contributing cause of death codes which appear as record access conditions, or multiple cause of death, in ICD-9 codes. Examples of these files can be seen in Tables 4 and 5.

Table 4: Underlying Cause of Death Codes (ucref files)

UC	UNAME	DX5	DCCHPR	DXCLASS
0019	CHOLERA NOS	00190	135	9
0020	TYPHOID FEVER	00200	135	9
0021	PARATYPHOID FEVER A	00210	135	9
0022	PARATYPHOID FEVER B	00220	135	9
0023	PARATYPHOID FEVER C	00230	135	9
8108	MV-TRAIN COLL-PERS NEC	E8108	261	161
8109	MV-TRAIN COLL-PERS NOS	E8109	261	161
8110	REENTRANT MV COLL-DRIVER	E8110	261	161
8111	REENTRANT MV COLL-PASNGR	E8111	261	161

Table 5: Contributing Cause of Death Codes (raref files)

RA	RNAME	DX5	DCCHPR	DXCLASS

00100	CHOLERA D/T VIB CHOLERAE	00100	135	9
00110	CHOLERA D/T VIB EL TOR	00110	135	9
00190	CHOLERA NOS	00190	135	9
84990	ACCIDENT IN PLACE NOS	E8499	261	161
850 1	CONCUSSION W/O COMA	N8500	233	16
85000	ACC POISON-HEROIN	E8500	261	161
85001	CONCUSSION W/O COMA	N8500	233	16
85010	ACC POISON-METHADONE	E8501	261	161
85011	CONCUSSION-BRIEF COMA	N8501	233	16

The translation tables are based on the Agency for Health Care Policy and Research, Clinical Classification for Health Policy Research, Version 2. It has been modified to match all ICD-9 cause of death codes used through 1998. Alternative classification systems can be found in the NCHS documentation for the Multiple Cause of Death Files (DHHS, 1993). Through 1998 cause of death codes are numeric only. They do not contain 'E' or 'N' prefixes found in the ICD-9 reference manuals.

The underlying cause of death and up to 20 contributing conditions are assigned by computer programs that check several related fields (sex, age, other ICD codes). In practice you will rarely find more than three to five contributing conditions listed on a record. The underlying cause, *UC*, is a four digit code with leading zeros and no decimal places. It corresponds to the first four digits of the ICD-9 code system. As of 1998 there were 5533 possible UC codes (*See CD – UCREF file*). The *UNAME* and *RNAME* are brief text descriptions of the disease condition; the *DX5* is the standard ICD-9 form of the underlying cause code, and the *DCCHPR* and *DXCLASS* are alternative classification schemes that collapse diagnosis into clinically related groups.

Record axis conditions, *RA*, are all possible contributing causes of death, including the underlying cause, however these are five digits in length with leading zeros and no decimal places. As of 1998 there were 6664 possible RA codes (*See CD, RAREF file*). RA codes are similar to UC codes with the addition of nature of injury codes, N codes, which provide more specificity of injury sites. N codes are never used as underlying cause codes, and always end with the digit '1'. These are useful for obtaining detail on poisonings, fractures, and other injuries. V codes are not used as contributing cause of death.

6. Step 6: Analyzing Mortality Patterns

If you do not intend to make comparisons between consumers and the general population,

you will not need access to all state death records. In this case you will probably want to perform descriptive analyses within the consumer population. These analyses will depend on your objectives and the nature of the data contained in your client files.

IV. DATA ANALYSIS

1. Comparing Populations

Often you will want to compare consumer mortality patterns with those observed in the general population or some other selected reference group. Such comparisons should always correct for differences in the age and sex distributions of the living populations (*See Appendix A, Item 9*). The standardized mortality ratios described below make this correction, however other methods require computation of an analysis weight, also described below. Choice of analysis will be determined partly by your local interests and the extent to which you have access to all state death records. You should also be cognizant of other standard methods for analyzing mortality data. Two basic methods are covered here, and you are encouraged to pursue citations in the Bibliography of Recommended Readings for other applications.

2. Standardized Mortality Ratios

The most commonly reported statistic in a study population is the standardized mortality ratio, SMR, the ratio of observed to expected deaths by sex at each age. In order to create the SMR you will need the following four elements:

1. an age by sex population table for your state,
2. the total death count by age and sex from your death files for a defined period,
3. an age by sex population table of your consumer population known to be living at the start of the risk period, and
4. the age by sex death count from your consumer population for the same risk period used in to determine the total death count in element 2.

The SMR is then derived in 3 steps:

Step 1: Compute the expected mortality rate (EMR) from the general population by dividing total deaths by total general population at each age and sex.

Step 2: Expected deaths in the consumer population are the product of the EMR times the consumer population at each age and sex.

Step 3: Divide the observed consumer deaths by the expected death, and this is the SMR.

Step 1: EMR

Expected Mortality Rate (EMR)=

$$\frac{\text{Total Deaths by sex at age x}}{\text{Total Population by sex at age x}}$$

Step 2: Expected Consumer Deaths

Expected Consumer Deaths = (EMR)*(Consumer Population by sex at age x)

Step 3: SMR

Standardized Mortality Ratio (SMR) =

$$\frac{\text{Observed Consumer Deaths}}{\text{Expected Consumer Deaths}}$$

The SMR method is not considered reliable if the expected number of deaths for a group is less than 20.

3. Age Standardization

If the SMR method is not used, some other age standardization procedures must be performed. For example, if a state's general population is the standard for comparison, one of the comparison groups, usually the smaller, must be adjusted using analysis weights. Since the living study and general populations usually have different age and sex distributions, valid comparisons could not be made without adjusting for this difference. The study population can be standardized by age and sex to the general population following the direct standardization procedure recommended by the Centers for Disease Control and Prevention, CDC (Curtin & Klein, 1995). An analysis weight can be computed for each decedent as:

$$\mathbf{W_{DMH/AS} = P_{GP/AS} \ / \ P_{DMH/AS}}$$

Where $W_{DMH/AS}$ is the final analysis weight for each case by age and sex, $P_{GP/AS}$ is the proportion of the total state general population at each age and sex, and $P_{DMH/AS}$ is the proportion of the total patient population at each age and sex. For example, young adults and males, which are usually over-represented in an SMHA population, receive weights of less than one, while females and the aged received weights greater than one. The weights so calculated can then be applied whenever comparative means and frequencies are reported.

4. Years of Potential Life Lost

To provide a metric for relative excess mortality, years of potential life lost (YPLL) relative to current life expectancy for each decedent can be computed. Unlike *life expectancy at birth*, which does not change, *current life expectancy* is the mean survival age for a living cohort at each age and sex. YPLL is thus always a positive value and approaches zero at advanced age. This method has been used routinely by the CDC since 1982 to report the relative burden of disease and injury (Center for Disease Control, 1986). In various forms YPLL has been adopted as an alternative to standardized

mortality rates to assess the impact of specific causes of death (Gardner & Sanborn, 1990; Murray & Lopez, 1996).

A current life expectancy table by age and sex can be obtained for each state and the nation (*See Appendix A, Item 10*).[2] These tables are prepared by the Bureau of Census from National Center for Health Statistics data. Since the Bureau does not estimate current life expectancy beyond age 85, you will have to extrapolate YPLL for cases older than this if necessary. In general, however, YPLL under age 65 is the most frequently published statistic.

To add YPLL to your consumer death files, the consumer file must first be sorted by sex and age. A new variable, YPLL, is then computed as the difference between expected life and consumer age at death. These years can then be used in aggregate to describe excess mortality by various consumer groups or causes of death. Table 6, on the following page, illustrates using life expectancy to compare differential mortality by underlying cause of death, in this case YPLL was derived for each decedent based on current life expectancy in the US in 1992, approximately mid-way in the study period (DHHS, 1996).

[2]Current life expectancy differs from life expectancy at birth since it is projected from the living cohort surviving at each age by sex. YPLL is therefore always a positive number, but approaches 0 at older ages.

Table 6: Example of Comparative Analysis of Underlying Cause of Death

Table 3 Difference in mean years of potential life lost by clinical class of underlying cause of death among male and female decedents age 18 and older who were served by the Massachusetts Department of Mental Health (DMH), 1989-1994.

Clinical Class of underlying cause of death	*Males*		*Females*	
	N years	p≤[1]	N years	p≤[1]
TOTAL	**14.1**	**.001**	**5.7**	**.001**
NATURAL	10.5	.001	4.2	.001
Infectious	8.5	.001	9.2	.001
Neoplasms	6.3	.001	1.5	.001
Endocrine	11.8	.001	6.8	.001
Blood	8.5	ns	.6	ns
Mental	16.9	.001	7.5	.001
Nervous System	18.0	.001	3.5	.01
Circulatory	9.7	.001	5.1	.001
Respiratory	6.7	.001	4.9	.001
Digestive	11.2	.001	6.2	.001
Genitourinary	2.9	.01	4.7	.001
Pregnancy	-	-	-	-
Skin	4.1	ns	-	-
Musculoskeletal	12.0	.001	10.7	ns
Congenital	12.2	.001	.8	ns
Ill defined	34.2	Ns	4.5	ns
Unclassified	4.7	.001	-2.5	ns
EXTERNAL	7.5	.001	10.2	.001
Accident	6.1	.001	2.4	.01
Suicide	8.4	.001	9.3	.001
Homicide	0.9	ns	10.8	.001
Undetermined	1.9	.001	-5.1	.001

[1] Based on the difference between weighted mean years of potential life lost for DMH decedents minus the mean for non-DMH decedents analyzed using Student's t test. The statistic was not computed where the number of cases was less than 2.

Dembling, B.P., Chen, D.T., & Vachon, L. *Life Expectancy and Causes of Death in a Population Treated for Serious Mental Illness*. Psychiatric Services, 50 (8),1039, 1999. Copyright 1999, the American Psychiatric Association. Reprinted by permission.

5. Multiple Cause of Death Conditions

Additional analysis can be made using multiple cause of death conditions. While most mortality statistics are reported based on the underlying cause of death, there is increasing interest in comorbidity associated with all contributing conditions. For example, mental disorders are rarely reported as an underlying cause of death, however they are more frequently cited as contributing causes.

Multiple causes can be processed in two ways. First, dummy variables representing conditions of interest can be added to each death record. Then a series of 'if then' statements would recode the variables as conditions present or absent. If the number of conditions of interest is small, this may be the most efficient approach.

A second alternative, where all possible disease conditions are to be analyzed, requires construction of a file with one record for every condition listed. On average this will mean three records per death. The frequency of specific conditions can then be compared among consumer groups or with non-consumer decedents using observed and expected counts and chi square tests of homogeneity. YPLL associated with various classes of conditions can also be analyzed. An example of analyzing multiple cause conditions from the Massachusetts study can be seen in Table 7.

Table 7: Example of Comparative Analysis of Multiple Contributing Cause of Death

Table 4 Clinical conditions significantly overrepresented among multiple causes of death of male and female descendents served by the Massachusetts Department of Mental Health.[1]

Clinical Conditions	*Males*				*Females*			
	Actual observed	Expected observed	Deviation	P≤	Actual observed	Expected observed	Deviation	P≤
INFECTIONS								
HIV Infection	59	22	37	.001	13	6	7	.01
MENTAL DISORDERS								
Alcohol-related disorder	25	9	17	.001	13	3	10	.001
Substance-related disorder	12	5	7	.01	-	-	-	-
Affective disorders	19	1	19	.001	21	1	20	.001
Schizophrenia and related disorders	44	2	42	.001	84	3	81	.001
Other mental conditions	-	-	-	-	35	8	27	.001
NERVOUS SYSTEM								
Epilepsy convulsions	40	10	29	.001	60	17	43	.001
Coma, stupor, brain damage	18	9	9	.01	28	11	17	.001
RESPIRATORY								
Pneumonia	-	-	-	-	229	149	80	.001
Chronic obstructive pulmonary disease	-	-	-	-	141	103	38	.001
Aspiration pneumonitis	-	-	-	-	51	25	25	.001
DIGESTIVE								
Alcohol-related liver disease	16	6	9	.001	-	-	-	-
EXTERNAL INJURIES								
Intracranial injury	21	9	13	.001	14	6	8	.01
Open wounds: head, neck, trunk	29	11	18	.001	-	-	-	-
Burns	-	-	-	-	11	1	10	.001
Poisoning, psychotropic agents	27	1	26	.001	23	2	21	.001
Poisoning, other medications	101	12	90	.001	51	8	43	.001
Poisoning, other	11	3	8	.001	-	-	-	-
Other injuries	147	32	115	.001	99	26	73	.001

[1] Cases were included in the analysis if observed counts were ten or higher and the p value for the chi square comparison of actual and expected observations was less than .01.

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V. CONCLUSION

In conclusion, as Dembling, Chen and Vachon (1999) noted in a recent publication, "The reduced life expectancies and mortality differentials reveal a health gap faced by those with serious mental illnesses" (p.1041). Specific causes for this gap could be identified through additional studies from states such as yours with large patient registries that permit multivariate analyses. Comparing results from your state mental health system with other mental health systems may reveal whether variation in resource levels, insurance benefits, or the organization of care explain variation in life expectancy and cause of death.

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VIII. APPENDIX A

Additional Resources

The following table lists state and federal resources that can be accessed through the Internet. The disk included in the toolkit contains an HTML as well as a WORD version of this list.

	DATA SOURCE	LOCATION	INFORMATION AVAILABLE
1.	National Death Index (NDI)	http://www.cdc.gov/nchswww/about/otheract/ndi/ndi.htm	Computerized index of death record information on file in the State vital statistics office.
2.	Health Care Financing Administration (HCFA) Public Use Files (PFU's)	http://www.hcfa.gov/stats/pufiles.htm	Downloadable copy of ICD-9CM Codes
3.	Center for Disease Control & Prevention (CDC)and National Center for Health Statistics (NCHS)	http://www.cdc.gov/nchswww/default.htm	State Vital Records
4.	CDC, NCHS	http://www.cdc.gov/nchswww/about/major/dvs/medsof.htm	Information of how states process death records, the Mortality Medical Data System
5.	CDC, NCHS	http://www.cdc.gov/nchswww/about/otheract/icd9/abticd9.htm	ICD9 & 10* as used in Death Records
6.	CDC, NCHS	http://www.cdc.gov/nchswww/about/otheract/icd9/icd9hp2.htm	ICD9 & 10 as used in Death Records
7.	Government files	ftp://ftp.cdc.gov/pub/Health_Statistics/NCHS/Publications/ICD-9/	Codes used in Death Records
8.	US Census Bureau	http://www.census.gov/population/www/estimates/statepop.html	State Population Estimates 1990 Forward

	DATA SOURCE	LOCATION	INFORMATION AVAILABLE
9.	US Census Bureau	http://www.census.gov/population/www/estimates/stagesex.html	State Population Estimates: by age and sex, 1990 forward for age adjustments
10.	CDC, NCHS	http://www.cdc.gov/nchswww/products/pubs/pubd/lftbls/life/1966.htm	Life Tables (life expectancy) for each state
11.	CDC, NCHS	http://www.cdc.gov/nchswww/howto/w2w/alphabet.htm#m	State Vital Records Agencies
12.	CDC, NCHS	http://www.cdc.gov/nchswww/howto/w2w/w2welcom.htm	How to Obtain Death Records
13.	CDC, NCHS	http://wonder.cdc.gov/wonder/data/Mailtome.exe	Historical Mortality Data underlying cause only

* International Classification of Disease, Ninth Revision & Tenth Revision, Clinical Modification

IX. APPENDIX B

X. APPENDIX C

National Death Index

The National Death Index (NDI) is a central computerized index of death record information on file in the State vital statistics offices. Working with these State offices, NCHS established the NDI as a resource to aid epidemiologists and other health and medical investigators with their mortality ascertainment activities.

- Available to investigators **solely** for statistical purposes in medical and health research. **Not accessible to organizations or the general public for legal, administrative, or genealogy purposes.**

- Central computerized index of death record information (beginning with 1979 deaths) compiled from magnetic tapes submitted by State vital statistics offices. Death records are added to the NDI file annually, approximately 10 months after the end of a particular calendar year.

- Contains a standard set of identifying information on each death to be used in searches of the file to identify and locate death records in the State offices.

- Assists investigators in determining whether persons in their studies have died and, if so, provide the names of the States in which those deaths occurred, the dates of death, and the corresponding death certificate numbers.

- Investigators can then make arrangements with the appropriate State offices to obtain copies of death certificates or specific statistical information such as cause of death.

To use the system, investigators first must submit an NDI application form to NCHS. Applicants should allow about 2 months for their applications to be reviewed and approved. Once approved, users may submit their study subjects' names, social security numbers, dates of birth, and related information to NCHS on magnetic tape, floppy disk, or NCHS coding sheets.

As of January 1996 the fees for NDI searches consist of a $350.00 service charge plus $0.30 per user record for each year of death searched. For example, 1,000 records searched against 10 years would cost $350 + ($0.30 x 1,000 x 10) or $3,350. Fees are reduced for NDI searches involving more than 2,500 records.

To obtain a free NDI User's Manual and NDI application form and more information on NDI fees, write to:

National Death Index
Division of Vital Statistics
National Center for Health Statistics
6525 Belcrest Road, Room 840
Hyattsville, Maryland 20782
(301) 436-8951