

Measuring the mortality burden of diabetes: Assessing the value of a death certificate checkbox

Introduction

Given the recent growth in the prevalence of diabetes, there is a great interest in knowing the true health burden of this disease (Nayaran et al, 2006; Tierney, Gregg, and Narayan et al, 2006). With respect to mortality, there is a widespread belief that the burden of diabetes is underestimated. The ranking of leading cause of death from death certificate data is based on the underlying cause, which is defined as the disease or injury leading to the sequence of events causing death. Since many diabetics do not have diabetes listed as a cause of death, the full impact of diabetes status on mortality is unknown. This has been confirmed in a number of analyses of linked datasets, such as the National Health Interview Survey/National Death Index (NHIS/NDI) file in which the cause of death codes are analyzed for decedents who had previously reported diabetes. This analysis suggests that approximately sixty percent of diabetics do not have diabetes listed on their death certificates as a cause of death (Heron and Anderson, 2006). An earlier study found that only ten percent of diabetics have diabetes listed as an underlying cause of death (Bild and Stevenson, 1992).

One response to this under-measurement of the mortality burden of diabetes has been to add a checkbox to the death certificate, which would indicate whether or not the decedent had diabetes. The purpose of a checkbox on the death certificate is to improve measurement of mortality among diabetics. This can occur in two ways: 1) by increasing the reporting of diabetes as an underlying or contributing cause of death, and 2) by providing a measure of the prevalence of diabetes among decedents regardless of cause of death, which would allow the calculation of mortality rates from all or selected causes for diabetics and non-diabetics.

Background

In 1992, North Dakota was the first to add a checkbox for diabetes to their death certificate. Kentucky added one in 2002, and New Jersey added a checkbox in 2004. Currently several other states have legislation pending that would add checkboxes to their death certificates. Advocates for diabetics argue that the diabetes checkbox should be used nationally and added to the U.S. Standard Certificate of Death. Yet this position is not unopposed. There are general concerns about adding excessive numbers of checkboxes to the death certificate, as there are currently checkboxes for tobacco use and pregnancy status. Additionally, it is possible that the diabetes checkbox may not actually improve the quality of information about the mortality burden of diabetes. This could occur if the presence of a checkbox leads to increased inaccuracies in cause of death coding for diabetes (e.g., if the checkbox is mistakenly used in lieu of coding diabetes as a cause of death), or if the diabetes checkbox is not an accurate measure of the prevalence of diabetes among decedents. To determine whether a checkbox for diabetes is a desirable addition to death certificates, it is necessary to consider both its impact on cause of death reporting as well as its accuracy as a measure of the prevalence of diabetes among decedents. It is also important to examine whether the effect on cause of death reporting and the accuracy of the checkbox varies significantly by race, ethnicity, age or

gender, to assess whether the addition of a checkbox is likely to enhance or distort understanding of disparities in diabetes.

Due to the homogenous nature of the North Dakota population and potential problems with the implementation of the check box in Kentucky (discussed below), New Jersey provides the first good opportunity to assess whether the diabetes checkbox may be a valuable addition to the death certificate. The purpose of this study is to provide an initial assessment of the diabetes checkbox in New Jersey by 1) examining the effect of the checkbox on cause of death coding, 2) estimating the accuracy of the checkbox, and 3) documenting variations in use of the checkbox by characteristics of decedents and physicians certifying the cause of death. This analysis will provide fundamental information about cause of death coding for future epidemiological studies of the diabetic decedent population. Specifically, we will identify for factors that may influence the accuracy of the checkbox and its effect on cause of death coding. It will also add useful information to the debate about whether the diabetes checkbox should be added death certificates in other states and, ultimately, nationwide.

One major argument in favor of adding a checkbox is the belief that diabetes is under-reported as a cause of death. The presence of the checkbox would function to remind physicians filling out the death certificate to record whether the decedent had diabetes. This could lead physicians in some cases to list diabetes as either an underlying or a contributing cause of death, when they otherwise may have otherwise failed to do so. An expected result of adding a diabetes checkbox, therefore, would be an increase in the number of deaths where diabetes is listed as an underlying or contributing cause. Another purpose for adding the diabetes checkbox to the death certificate is that it allows the calculation of death rates from various causes for diabetics. Using prevalence information estimated from surveys such as the Behavioral Risk Factor Surveillance System (BRFSS) or the NHIS as a denominator, it would be possible to see whether rates of death from a variety of causes are higher among diabetics than non-diabetics. Such studies could lead to new understandings about the more general impact of diabetes on health. For example, in North Dakota the checkbox has been used to analyze mortality among diabetics in several studies (Tierney et al., 2001; Tierney et al., 2004). While rates of death for many causes were found to be higher among diabetics, the difference has declined somewhat over time.

There are some concerns that the diabetes checkbox can result in increased inaccuracies in the reporting of diabetes as a contributing or underlying cause of death. The purpose of adding a diabetes checkbox is to remind the certifier to report whether or not the decedent had diabetes. However, a somewhat paradoxical result is that the presence of a diabetes checkbox may lead certifiers to substitute the checkbox for the listing of diabetes as a cause of death, particularly in Part II of the death certificate, where contributing causes are listed. This appears to have been the experience in Kentucky, where a checkbox was added that had two questions, one which asked whether the decedent had diabetes, and a second which asked whether diabetes should be listed in either Part I or Part II of the death certificate. In Kentucky, after introduction of the check box in 2003, overall reporting of diabetes as a cause of death declined. Deaths reported in Part I

increased slightly from 2002 to 2003 (1,487 to 1,562), while deaths reported in Part II declined quite a bit (1,711 to 1,488). This seems largely due to the inclusion of the second question of the check box. In North Dakota, where a diabetes checkbox was introduced in 1993, but without the second question used in Kentucky, the reporting of diabetes as a contributing cause of death increased.

The benefit of a diabetes checkbox on the death certificate also depends upon its accuracy in measuring the prevalence of diabetes among decedents. While we have many estimates of the population prevalence of diabetes, it is difficult to know what the prevalence might be among decedents. One source of data which is relevant for comparison is the linked NHIS/NDI file, which provides data on cause of death among decedents who had previously self-identified as diabetics. This linked file provides important information on both the prevalence of diabetes among decedents, as well as the potential under-measurement of diabetes on death certificates.

In the North Dakota studies, which are the only examples of analyses of mortality among diabetics using information from a diabetes checkbox, there is no assessment of the accuracy of the checkbox in measuring the prevalence of diabetes among decedents. The value of these analyses depends on the accuracy of this checkbox measure. An examination of accuracy has not been done in any of the states which have included checkboxes on their death certificates, but is an important aspect of assessing the usefulness of a checkbox for diabetes.

An evaluation of the accuracy of the diabetes checkbox may also yield recommendations about ways in which the death certificate can be formatted so as to increase accuracy. For example, the implementation of an electronic death registration system, with the inclusion of appropriate quality checks, can reduce or eliminate certain inconsistencies between the check box and cause of death coding, such as cases where a decedent has diabetes listed as an underlying or contributing cause of death, yet the check box is checked “no”. In addition, thorough analysis of differences in diabetes coding across characteristics of decedents (e.g., race/ethnicity, gender, place of death) or certifiers (e.g., specialty, practice setting, foreign/US trained) can help states target educational strategies for physicians and health care facilities to improve the quality death certificate coding.

Data and methods

Some preliminary analysis of the diabetes checkbox in New Jersey has been conducted. The trend in diabetes mortality has been examined briefly, although the analysis only uses one year of death data since the checkbox was implemented (2005 data to be available soon), and little analysis has been done by subgroups. Additionally, some initial exploration of potential accuracy issues with the checkbox is described in this section. This largely consists of examining the frequency and characteristics of what is called the “false negative” error – i.e. decedents who did not receive a “yes” response to the diabetes checkbox even though they have diabetes listed as an underlying or contributory cause of death. Although this error is relatively easy to correct, an analysis of subgroup patterns is suggestive of more widespread errors in the diabetes checkbox which may exist.

A. Trend in diabetes mortality in New Jersey

1. Deaths where diabetes is the underlying cause

One way to examine the impact of the diabetes check box on cause of death coding is to compare trends in diabetes mortality in New Jersey to the U.S. as a whole. The checkbox was used for the first time in New Jersey in 2004. In 2004, there were 2595 deaths in New Jersey for which diabetes was the underlying cause. This represents an increase of 111 deaths from 2003. Table 1 shows age-adjusted mortality rates from diabetes by race and ethnicity in New Jersey between 1990 and 2004. As can be seen, the total age-adjusted rate in 2004 is slightly higher than for the previous year, but this difference is not statistically significant. The increase in the age-adjusted rate in New Jersey between 2003 and 2004 was 2.6 percent. For the U.S. as a whole, the age-adjusted death rate from diabetes decreased by 3.6 percent between 2003 and 2004, from 25.3 to 24.4.

Table 1. Age-adjusted diabetes death rates, NJ residents, 1990-2004

Year	Total	White NH	Black NH	Hispanic	API NH	Male	Female
1990	27.4					29.2	25.8
1991	25.8					28.9	23.8
1992	27.3					31.7	24.1
1993	27.3	25.4	51.1	21.5	8.0	29.5	25.1
1994	27.5	24.8	52.8	23.1	16.9	29.2	25.8
1995	30.1	26.3	62.3	27.7	11.9	32.7	27.9
1996	29.1	25.3	62.4	29.5	13.8	31.8	27.2
1997	28.7	25.0	57.9	25.3	12.7	32.5	25.9
1998	27.4	24.9	50.1	28.3	17.2	32.1	24.0
1999	28.0	25.4	53.8	28.7	19.6	33.1	24.1
2000	28.2	25.8	54.6	29.7	20.3	34.0	24.1
2001	28.5	25.4	59.1	31.7	19.4	33.1	25.3
2002	27.8	25.4	52.0	27.1	17.7	31.4	24.9
2003	26.9	23.6	56.9	31.9	13.8	31.1	23.8
2004	27.6	25.0	54.5	26.3	17.4	31.9	24.4

Note: 1990-1998 rates have been comparability-modified because of the change from ICD-9 to ICD-10.

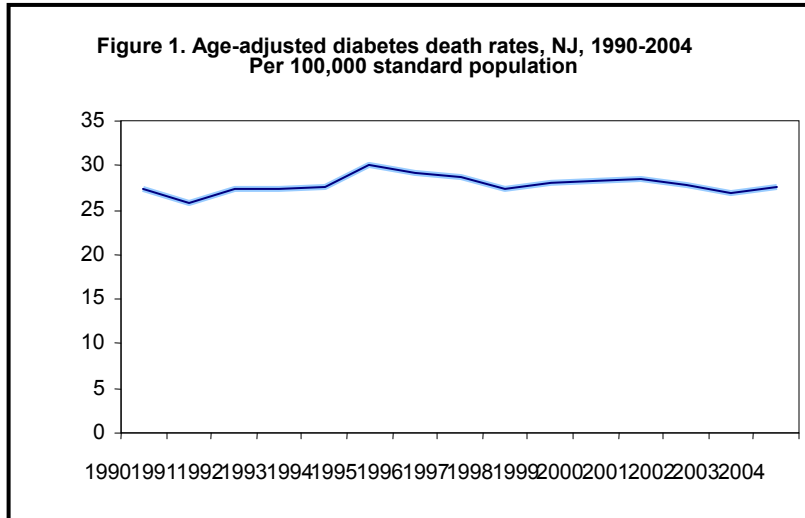
Comparability ratio = 1.008167

* Rates for API do not meet standards of reliability or precision; based on fewer than 20 deaths.

Bridged race data used for 2004 so it is comparable to 1990-2003 race/ethnicity classifications.

For individual race/ethnicity groups, there is an increase in the age-adjusted rate among whites and Asians in 2004, but a decrease in the 2004 rate for blacks and Hispanics. Death rates in 2004 are higher for both males and females as compared to the previous year. But none of these differences are statistically significant, except the decline in the rate for Hispanics in 2004.

Figure 1 shows that the trend in age-adjusted death rates from diabetes in New Jersey has been fairly flat over the past decade, and then rose slightly in 2004. However, as noted, this rise was not great enough to constitute a statistically significant difference.



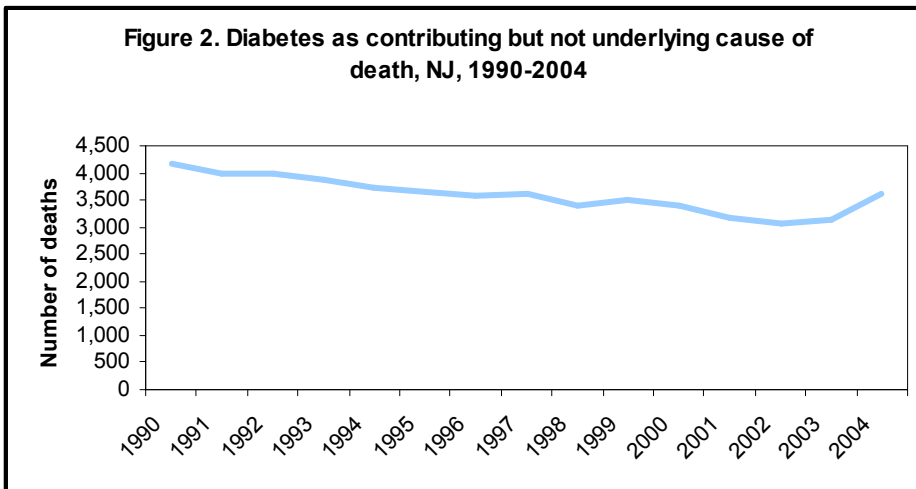
2. Deaths where diabetes is not the underlying cause

It might be expected that the diabetes checkbox would have a greater impact on cause of death coding in cases where the underlying cause of death is something other than diabetes, but where diabetes contributed to the death in some way. If diabetes were the primary cause of death, it is unlikely that the physician would need to be reminded of this by the diabetes check box. It is more likely that the check box would serve as a reminder in cases where the cause of death is something else and diabetes plays a contributory role.

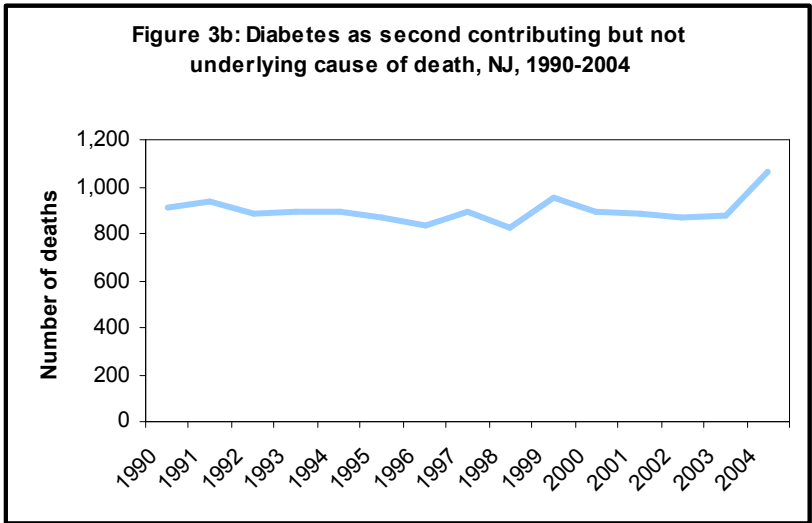
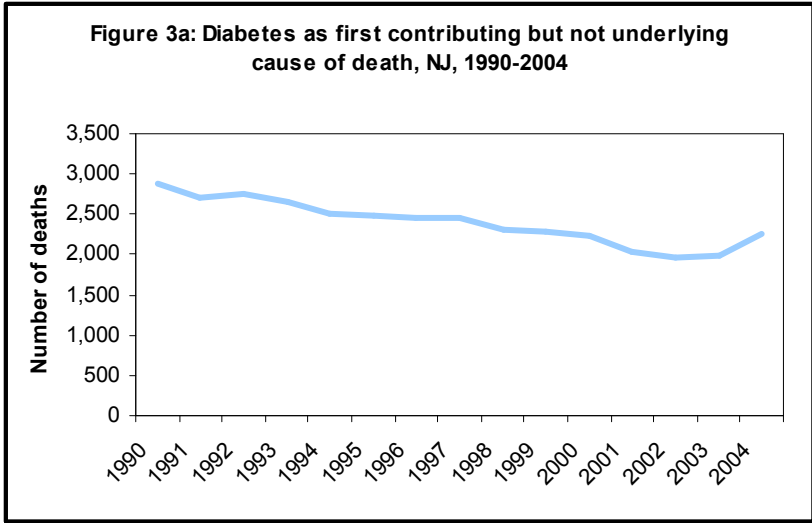
Looking at deaths where diabetes is the contributory but not the underlying cause of death, we can see the impact of the check box more clearly. As Table 2 shows, there was an increase in 500 deaths overall between 2003 and 2004 where diabetes was listed as a contributory but not underlying cause of death, representing an increase of nearly sixteen percent. This increase was greatest among Blacks, Hispanics, and Asians, and for these three groups, the change was statistically significant.

Table 2. Deaths where diabetes is a contributory but not underlying cause, New Jersey 1990-2004

	All N	White NH N	Black NH N	Hispanic N	Asian NH N	Other NH N	Male N	Female N
1990	4150	3487	484	146	32	1	1969	2181
1991	3981	3287	510	166	18		1840	2141
1992	3989	3299	523	137	27	3	1925	2064
1993	3889	3155	582	119	31	2	1912	1977
1994	3711	3017	541	118	31	4	1743	1968
1995	3653	2932	550	134	36	1	1683	1970
1996	3594	2881	540	127	41	5	1691	1903
1997	3618	2886	557	128	41	6	1737	1881
1998	3399	2668	527	147	55	2	1592	1807
1999	3505	2725	556	162	58	4	1726	1779
2000	3393	2618	550	177	46	2	1671	1722
2001	3167	2411	543	154	55	4	1505	1662
2002	3077	2341	494	174	64	4	1499	1578
2003	3120	2371	527	162	57	3	1550	1570
2004	3623	2725	595	204	74	25	1805	1818



This increase in deaths where diabetes is listed as contributory but not underlying is concentrated in deaths where the first and second positions on the multiple cause field are used. The increase is sharpest among those where diabetes is listed as the second contributing cause. There were 874 such deaths in 2003 and 1060 in 2004, an increase of over twenty percent.

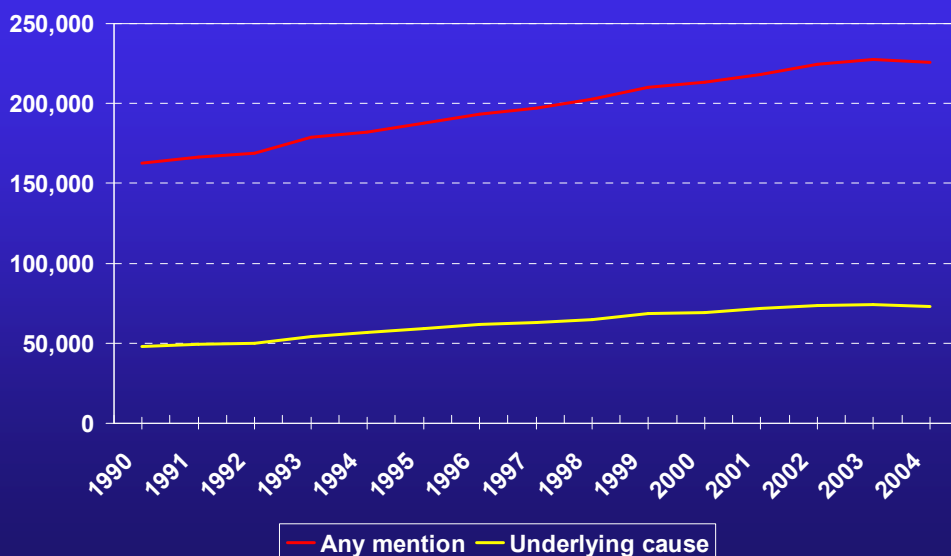


Figures 3a and 3b show the increase in numbers of deaths by position on the death certificate, and reflect the fact that the increase was sharpest for deaths listed in the second position. Table 3 shows deaths where diabetes is a contributory but not underlying cause, by position on the death certificate. As can be seen, the increase in deaths was greatest in cases where diabetes was listed in the first or second positions.

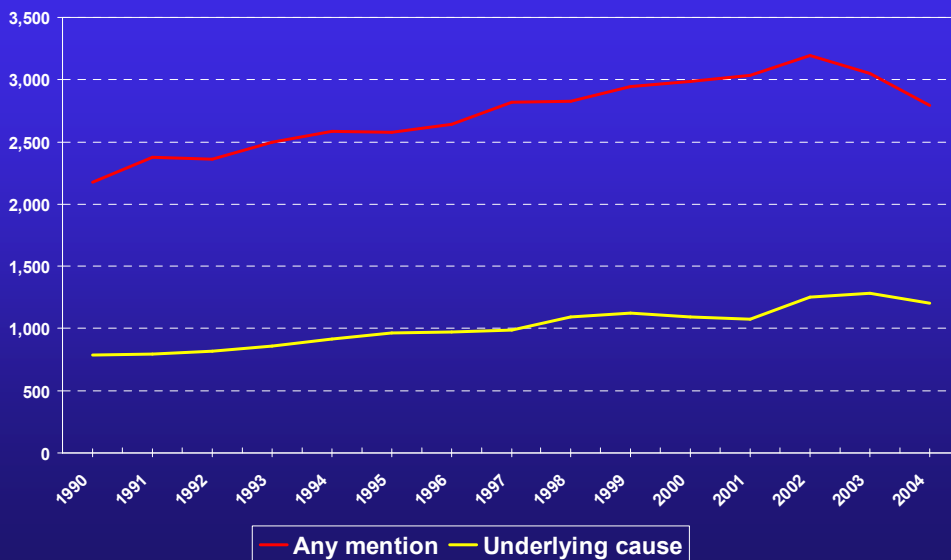
year	Position on death certificate								Total
	1	2	3	4	5	6	7	8	
1990	2887	907	270	67	13	5	1	0	4150
1991	2697	937	265	66	13	1	1	1	3981
1992	2766	887	260	60	12	4	0	0	3989
1993	2646	895	278	57	11	0	2	0	3889
1994	2519	891	236	52	9	4	0	0	3711
1995	2489	867	242	37	18	0	0	0	3653
1996	2463	830	249	38	10	4	0	0	3594
1997	2459	890	225	36	6	1	1	0	3618
1998	2308	822	216	46	6	1	0	0	3399
1999	2282	949	218	46	8	1	1	0	3505
2000	2233	893	216	42	7	1	1	0	3393
2001	2041	881	191	43	9	2	0	0	3167
2002	1954	865	211	33	11	3	0	0	3077
2003	1980	874	213	39	13	1	0	0	3120
2004	2268	1060	230	54	10	1	0	0	3623
Total	35992	13448	3520	716	156	29	7	1	53869

The trend data for New Jersey suggests that check box may have functioned to increase coding of diabetes as a contributory cause of death, but had relatively little effect on the coding of diabetes as an underlying cause of death. This experience is unlike that of Kentucky, where, as previously described, the introduction of the checkbox seemed to result in a decline in coding of diabetes as a cause of death, a paradoxical result. The difference between the experience of New Jersey and Kentucky seems to be attributable to the presence in Kentucky of a second checkbox question, which asks whether or not diabetes ought to be listed in either Part I or Part II of the death certificate. The three slides below, created by Melonie Heron and Robert Anderson of CDC, succinctly illustrate the different effects on mortality coding for New Jersey and Kentucky, as compared with the United States as a whole.

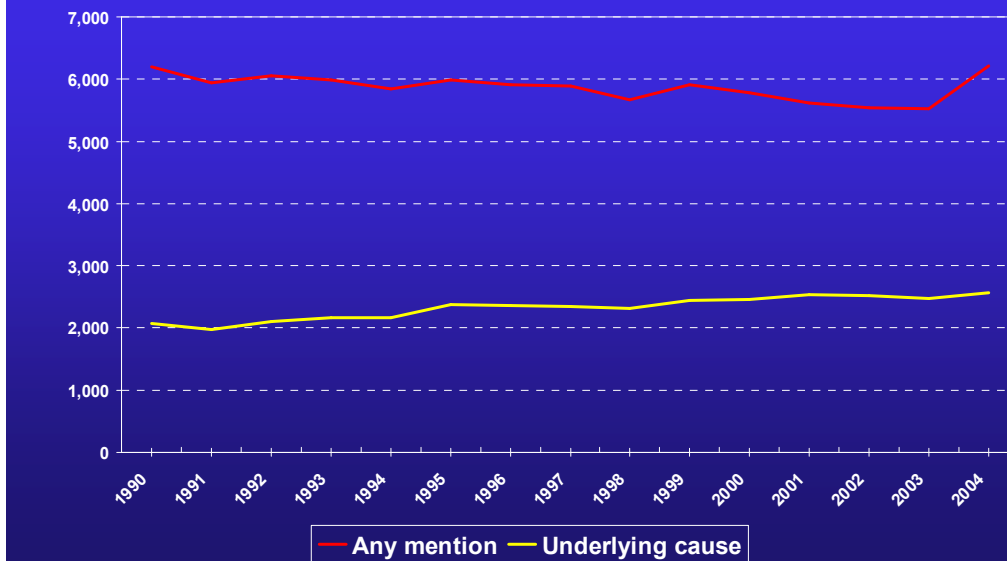
Diabetes Deaths: US, 1990-2004



Diabetes Deaths: Kentucky, 1990-2004



Diabetes Deaths: New Jersey, 1990-2004



B. The accuracy of the check box in New Jersey, 2004

1. Checkbox status and cause of death

Overall, the checkbox was checked “yes” in about eighty-eight percent of deaths where the underlying cause was diabetes, and in eighty-nine percent of deaths where diabetes was a contributing but not underlying cause. When “yes” was not checked, it was more likely that the unknown category was checked or the checkbox was left blank than that “no” was checked. These data are shown in Table 4.

Table 4. Check box status and cause of death, New Jersey, 2004

Check box status	Cause of death			Total
	Diabetes Underlying	Diabetes Contributing only	Neither	
Yes(N)	2278	3233	6660	12171
%	87.78	89.24	10.22	17.05
No(N)	56	61	38197	38314
%	2.16	1.68	58.63	53.68
Unknown(N)	138	155	14550	14843
%	5.32	4.28	22.33	20.8

Blank(N)	123	174	5746	6043
%	4.74	4.8	8.82	8.47
Total(N)	2595	3623	65153	71371

As can be seen in Table 4, it is interesting to note that of those decedents for whom the checkbox is checked “yes”, more than half do not have diabetes listed as either an underlying or contributing cause of death. This is similar to the experiences of North Dakota and Kentucky, the other two states with diabetes check boxes. And is also roughly similar to the results from the analysis of the NHIS/NDI linked file described previously. The comparative results for the three states can be seen in Table 5.

Table 5. Cause of death when the diabetes check box is checked "yes", three states

	Diabetes Underlying	Diabetes Contributing only	Neither	Total
New Jersey				
N	2278	3233	6660	12171
%	18.7	26.6	54.7	100
North Dakota (%)	15	28	57	100
Kentucky (%)	15	19	66	100

Source: Heron and Anderson, CDC; New Jersey mortality data, 2004

2. Decedents with diabetes as a cause of death – the “false negative” error

When considering differences by race, ethnicity and gender, some interesting patterns emerge. Table 6 shows the proportion of decedents with a mention of diabetes as a cause of death for whom the diabetes checkbox was checked “yes”. In general, non-hispanic whites were more likely than other groups to receive a “yes” on the checkbox. For decedents for whom diabetes was contributing but not underlying, Asians were most likely to receive a “yes”. Due to the relatively small numbers of Asians decedents in New Jersey, however, this number may not be particularly stable, and overall these figures only reflect the first year of data from New Jersey’s implementation of the checkbox.

Table 6. Percent with checkbox="Yes", by race and ethnicity, New Jersey, 2004

Diabetes as COD	White	Black	Hispanic	Asian	Total	Chi-Sq
Any mention	89.2	87.5	85.3	86.7	88.6	0.1845
Underlying cause	88.9	85.2	84.2	79.6	87.8	0.0329 *
Contributing only	89.4	89.2	86.3	91.9	89.2	0.5205

Note: Hispanics can be of any race.

Source: New Jersey mortality data, 2004. Center for Health Statistics, New Jersey
Department of Health and Senior
Services

Table 7 shows results of a similar analysis by gender. While gender differences are not very large, overall females are more likely than males to receive a “yes” on the checkbox, given that they have a mention of diabetes as a contributing or underlying cause of death. The differences are greater when diabetes is an underlying rather than contributing cause.

Table 7. Percent with checkbox="Yes", by gender, New Jersey, 2004

Diabetes as COD	Male	Female	Total	Chi-Sq	
Any mention	87.8	89.4	88.6	0.0388	*
Underlying cause	86.6	88.9	87.8	0.0749	
Contributing only	88.6	89.9	89.2	0.2097	

Source: New Jersey mortality data, 2004. Center for Health Statistics,
New Jersey Department of Health and Senior Services

A look at geographical variation in the use of the check box for decedents with a mention of diabetes as a cause of death of diabetes revealed some variation but no clear spatial pattern. There are no significant differences by age in checkbox status for decedents with a mention of diabetes. Differences by place of death, however, were significant. Overall, decedents who died at home, in a hospice, or in a long term care facility were most likely to receive a “yes” on their diabetes checkbox, given a mention of diabetes as a cause of death. Those who were dead on arrival, died in other and unspecified locations, and those who died as inpatients were less likely than average to receive a “yes”. These differences are more pronounced when diabetes is a contributing but not underlying cause of death. These results are summarized in Table 8.

Table 8. Percent with checkbox="Yes", by place of death, New Jersey, 2004

	Any mention	Underlying	Contributing
Inpatient	87.4	85.6	88.6
Outpatient/ER	88.7	89.3	88.3
Dead on arrival	82.1	84.6	80.5
Home	90.5	90.2	90.8
Hospice	93.2	91.4	94.1
Nursing Home/LTC	89.5	88.8	90.0
Other	84.1	82.8	84.9
N/S	83.8	85.3	82.5
Total	88.6	87.8	89.2
Chi-Square(p=)	0.0047*	0.1248	0.0852

Source: New Jersey mortality data, 2004. Center for Health Statistics, New Jersey Department of Health and Senior Services

These statistics describe one issue related to the accuracy of the diabetes checkbox. Assuming that certifiers are correct in listing diabetes as a contributing or underlying cause of death, it would seem that the diabetes checkbox should be filled in as “yes”. A failure to do so would appear to be an error. The preliminary analyses described in tables six through eight show that this error is not random, but is more likely to occur when decedents are male, black or Hispanic, and when death occurs in places other than home, a hospice, or long term care facility. Within certain racial and ethnic groups, there are significant differences by gender. For example, more than fifteen percent of black males with a mention of diabetes as a cause of death did not have a “yes” on the diabetes checkbox, as compared with less than ten percent of black females. This difference is statistically significant ($p < .01$). A multivariate logistic regression (not shown), which estimates the probability of the “false negative” error (i.e. not receiving a “yes” when there is a mention of diabetes as a cause of death) has significant coefficients for males, blacks, Hispanics, and several places of death.

Targeted education to death certificate certifiers in different health care facilities may improve accuracy in completion of the diabetes checkbox. Additional years of data from New Jersey may show improvement in use of the checkbox and a reduction in this error. The implementation of the Electronic Death Reporting System in New Jersey, a web-based death certificate currently in pilot stage, which will contain quality control checks, may reduce or even eliminate this error, as it could be made impossible to provide a response other than “yes” to the diabetes check box when the decedent has diabetes listed as a cause of death.

While the “false negative” error may be easily corrected through hard-coding quality control checks in a web-based death certificate, it raises questions about the overall accuracy of the diabetes checkbox. More than eleven percent of decedents with a cause of death of diabetes did not receive a “yes” on the checkbox. It is possible that the checkbox does not provide an accurate measure of the prevalence of diabetes among decedents. An assessment of the accuracy of the diabetes checkbox is critical, so that its value as a method for estimating the burden of mortality among diabetics can be better understood.

3. Decedents without diabetes as a cause of death

Overall, approximately 6,600 decedents in New Jersey received a “yes” on the diabetes checkbox but did not have diabetes listed as a cause of death. An examination of the distribution of underlying causes of death for these decedents reveals a distribution of leading causes which is very similar to the overall ranking of leading causes of death, aside from the absence of diabetes. Considering differences by race, ethnicity, gender, age, and place of death, it would be expected that differences in the prevalence of diabetes would affect the likelihood of a “yes” on the checkbox, given no mention of diabetes as a cause of death.

Table 9. No mention of diabetes and checkbox = "Yes", by gender, New Jersey, 2004

	Male	Female	Total	Chi-Sq	
Total	10.5	10.0	10.2	<i>0.0651</i>	*
Non-Hispanic White	10.3	9.2	9.7	<i><.0001</i>	
Non-Hispanic Black	11.4	14.38	12.5	<i><.0001</i>	*
Hispanic	9.0	14.53	11.45	<i><.0001</i>	
Asian	11.6	10.87	11.3	<i>0.7264</i>	

Source: New Jersey mortality data, 2004. Center for Health Statistics, New Jersey Department of Health and Senior Services

The data in Table 9, therefore, are somewhat contrary to expectations. The overall difference by gender is minimal, which is similar to the overall difference in the

prevalence of diabetes by gender. Differences by race and ethnicity, however, do not reflect differences in population prevalence of diabetes. According to BRFSS data, in New Jersey for the years 2003-2005, for example, more than twelve percent of blacks reported that they had diabetes, as compared with less than five percent of whites. Hispanics and Asians had prevalence levels in between those of whites and blacks. Further, while the overall difference in receipt of a “yes” by gender is not significant, within racial groups, particularly blacks and Hispanics, there is a large difference by gender, which is statistically significant. In particular, Black males are far less likely than females to have a “yes” checkbox, a pattern which is similar to the differences by gender in the “false negative” error for blacks.

Population prevalence of diabetes is a very crude proxy for what might be expected among decedents, and it is not necessarily the case that the same gender and race/ethnicity patterns of diabetes prevalence would be observed in the population and among decedents. One would expect the prevalence of diabetes among decedents to be considerably higher than in the population. A study of patients in the V.A. system estimated the prevalence of diabetes to be approximately twenty percent in 2000, using information from hospital discharge data, prescription information, and Medicare claims data (Miller et al, 2004). Yet the overall proportion of New Jersey decedents with a “yes” on the diabetes checkbox was seventeen percent. Additionally, the percent with a “yes” is approximately ten percent among white decedents without a mention of diabetes as a cause of death, nearly fifty percent higher than the population prevalence of diabetes for this group. However, among blacks, the proportion with a “yes” is approximately the same as the population prevalence, about twelve percent. Additionally, there is a large difference by gender among blacks, which does not reflect differences in the population prevalence of diabetes. These findings suggest that it is possible that the diabetes checkbox may be underestimating the prevalence of diabetes, particularly among black male decedents, although this of course cannot be confirmed by this observation alone.