Appendix 1

NHPA indicators for diabetes

Diabetes in Australia: indicator-based reporting

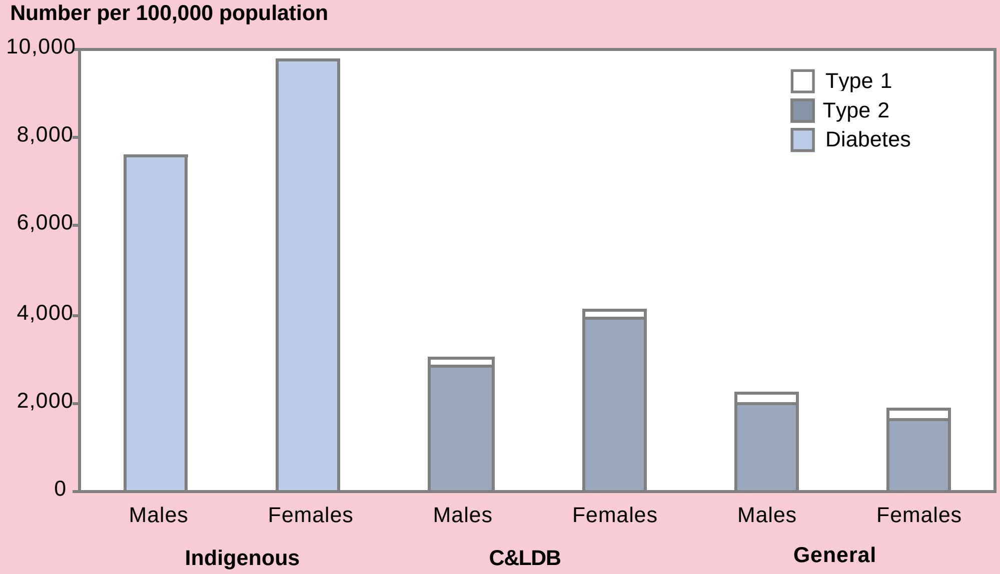
This appendix brings together national data for the purpose of reporting progress against NHPA indicators of diabetes. The appendix has been developed by the AIHW with input and support from various individuals and organisations, in particular Dr Jeff Flack, Director of the Diabetes Centre at Bankstown-Lidcombe Hospital in Sydney.

The format used for indicator-based reporting aims to provide information in a succinct manner. While the statistical information presented is confined to meeting the data requirements for each indicator, the interpretation offered is somewhat broader than the design of the indicator would suggest. This is in accordance with the basic tenet of indicator-based reporting.

Every attempt has been made to use the best available data, health service clinic-based or population-based, for reporting. Where available, time-series or other collateral information has been included to enhance interpretation. No attempt has been made to provide a comprehensive overview of the health issue in question. It is recommended that this appendix be read in conjunction with the epidemiological overview of diabetes given in Chapter 1.

While considerable progress has been made in developing and reporting indicators for other NHPAs, this is the first time that information has been put together for diabetes indicators in this format. The quality and comparability of much of the data presented here is variable. These problems, with appropriate caveats, are discussed throughout the appendix. Data issues specific to each indicator have also been discussed. For detailed statistical and data issues, see Appendix 2.

Indicator 1.1: Prevalence rates for Type 1 and Type 2 diabetes in the general population, Indigenous population, and among persons from culturally and linguistically diverse backgrounds



	Indigenous population	People from C&LDB		General population	
Population	Diabetes	Type 1	Type 2	Type 1	Type 2
Males	7,597	146	2,627	223	1,846
Females	9,763	158	3,609	210	1,508
Persons	8,767	149	3,103	218	1,662

Notes: Data not available by diabetes type for the Indigenous population.
Rates, age standardised to the 1991 Australian population, are given as prevalence per 100,000 persons.
C&LDB = Culturally and linguistically diverse backgrounds.

Sources: ABS (1997b; 1996).

- The prevalence of diabetes varies considerably among population groups in Australia. Many different factors contribute to this variation, including differences in incidence, management, treatment, mortality and population structure.

Operational definition

- This indicator provides a comparative picture of the prevalence of Type 1 and Type 2 diabetes in the general population and two specific population groups — Indigenous Australians and people from culturally and linguistically diverse backgrounds.
- Available national statistics to report against this indicator are not based on diagnostic criteria. Self-reported information, generated through various national surveys, has therefore been used as proxy data. It is expected that this indicator will be tracked with the national Biomedical Risk Factor Survey.

Prevalence rates

General population

- Based on the 1995 NHS self reports, the prevalence rate for Type 1 diabetes is estimated to be 235 per 100,000 persons in the general population.
- The prevalence rate for Type 2 diabetes is much greater (almost eight times the rate for Type 1 diabetes) at 1,794 per 100,000 population.
- Males show higher prevalence of both types of diabetes than females.

Indigenous population

- The prevalence of diabetes is significantly higher among people of Indigenous origin. According to 1994 NATSIS (ABS 1996a), the self-reported prevalence rate among Indigenous people is five times that in the general population.
- The prevalence rate is almost 30 per cent higher among Indigenous females than among Indigenous males.
- Estimation of prevalence rates by type of diabetes is not possible from the NATSIS collection. Nor is it possible to determine the correction factor for undiagnosed diabetes at this stage.

Persons from culturally and linguistically diverse backgrounds

- Diabetes is also more commonly prevalent among persons from culturally and linguistically diverse backgrounds, at almost twice the rate in the general population. Type 2 diabetes accounts for this difference. In contrast, Type 1 diabetes is less prevalent among this group.
- As is the case for Indigenous people, females from culturally and linguistically diverse backgrounds have higher prevalence of diabetes (both Type 1 and Type 2) than do their male counterparts.
- At this stage, it is not possible to determine the correction factor for undiagnosed diabetes among persons from this group.

Time trends and projections

- Several studies have indicated that the prevalence of diabetes is on the rise worldwide, including in Australia. It is projected that diabetes will affect about 950,000 Australians by the year 2010 (Amos et al 1997).
- While some of this rise may be attributed to improved management of the disease over the past several decades, rising incidence, ageing of the population and changing ethnic composition of the population may have also contributed to this trend.
- Due to the lack of a regular time series, it is not possible to quantify trends in diabetes prevalence at a national level.
- A comparison of self-reported prevalence rates, estimated from 1989–90 and 1995 NHS datasets, reveals a 30 per cent increase in prevalence. While some of this may be attributed to increase in incidence, better detection, management and awareness of the disease may have contributed to increased reporting during the 1995 NHS.

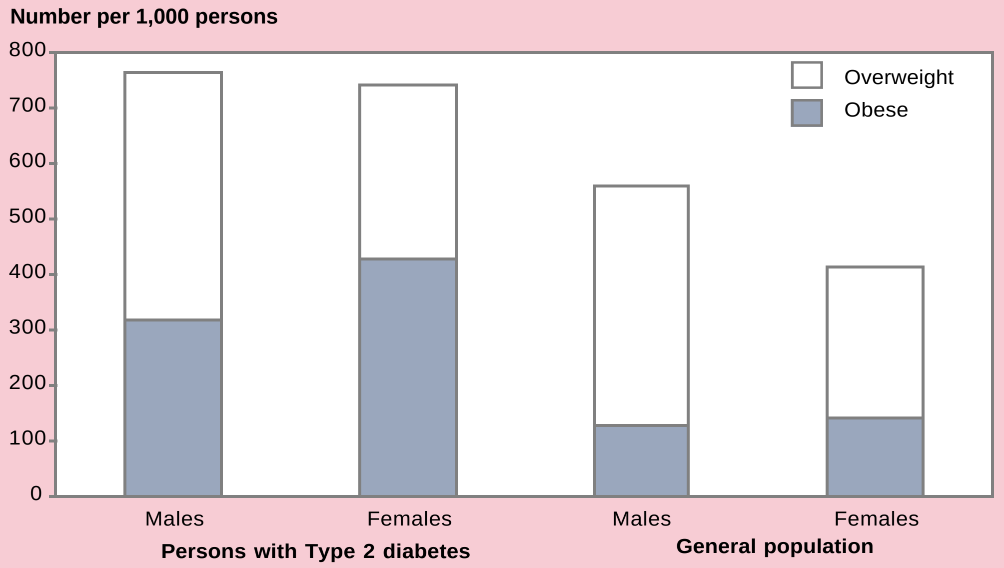
Data sources

- The NHS, conducted by the ABS, provide self-reported information on diabetes prevalence in the general population, as well as among persons from culturally and linguistically diverse backgrounds. Several State-based surveys also collect this information.
- Self-reported national information on diabetes among Indigenous Australians was collected through the 1994 NATSIS (ABS 1996a). An oversampling of the Indigenous population during the 1995 NHS has also provided a reliable estimate of the disease in the Indigenous population.

Data issues

- No national information based on diagnostic criteria is available on the prevalence of diabetes in Australia. The information provided here is therefore based on self reports.
- Estimates based on self reports are known to substantially underestimate the prevalence of diabetes in the community since a large proportion of Type 2 diabetes remains undiagnosed.
- It has been suggested that for every known case of Type 2 diabetes there is a person in the population whose diabetes has not been detected. Under-reporting may occur for diagnosed cases as well.
- Attempts to correct for some of these underestimations have yielded prevalence estimates of up to 4,300 per 100,000 persons, a total of 780,000 persons with diabetes in Australia in 1995 (Colagiuri et al 1998). Other similar corrections yield much lower estimates.
- Since the rising prevalence of diabetes has strong implications for health resources, accurate information on prevalence by type of diabetes is crucial to developing a clear strategy. A National Biomedical Risk Factor Survey that includes diagnostic tests will help obtain a more reliable estimate of the prevalence of diabetes in Australia.

Indicator 2.1: Prevalence rates for obesity and being overweight (as measured by BMI) among persons with Type 2 diabetes and in the general population



Population group (aged 30 years and over)		Crude rates		Age-standardised rates	
		Overweight	Obese	Overweight	Obese
Persons with Type 2 diabetes	Males	476	256	445	317
	Females	339	372	313	428
General population	Males	434	132	430	129
	Females	275	139	274	139

Note: Rates, age standardised to the 1991 Australian population, are given as prevalence per 1,000 persons.

Source: ABS (1997b).

- Overweight/obesity increases the risk of developing Type 2 diabetes and its complications. In particular, it increases predisposition of persons with diabetes to cardiovascular disease.

- The prevalence of overweight/obesity is on the rise in Australia. This may have implications for the population at risk of developing diabetes — those aged 40 years and above, and those belonging to certain population groups.

Operational definition

- This indicator provides a comparison of the prevalence rates for obesity and being overweight among persons with Type 2 diabetes and in the general population. The indicator focuses both on the population at risk of developing diabetes, and those who are at increased risk of developing diabetes-associated complications. In view of the age distribution of Type 2 diabetes, this indicator monitors only those aged 30 years and over.
- Overweight and obesity are determined using BMI, expressed as weight/height squared. No account is taken of excessive amount of body fat for a given body weight in this definition.
- Overweight is defined as a BMI score between 25 kg/m^2 and 30 kg/m^2. A BMI score of more than 30 kg/m^2 is termed obese (WHO 1998). For details on calculating BMI, see Appendix 2.
- Available national strategies for this indicator are not based on measurements. Self-reported heights and weights have been used for calculating BMI. The diabetes status of the person is also self reported.

Prevalence rates

- According to the 1995 NHS (ABS 1997b), more than three-quarters of males (aged 30 years and over) with Type 2 diabetes are overweight or obese, with an age-standardised prevalence rate of 762 per 1,000 persons. The rate is slightly lower among females with diabetes in that age range (741 per 1,000).
- Corresponding estimates for their counterparts in the general population are 559 and 413 per 1,000 persons.

Overweight (BMI = 25–30 kg/m^2)

- A much larger proportion of males with diabetes is overweight in comparison to females (445 against 313 per 1,000 persons). The difference between the two sexes is much larger in the general population.
- No significant difference is noted in the proportion of overweight males with diabetes and those in the general population (445 and 430 per 1,000 persons respectively). The proportion of overweight females with diabetes in comparison is 14 per cent higher than that in the general population.

Obesity (BMI ≥ 30 kg/m^2)

- In contrast to the pattern observed for being overweight, among people with diabetes obesity is more commonly prevalent among females than among males (428 versus 317 per 1,000 persons). The difference in prevalence rates between the two sexes is lower in the general population.
- Obesity is more commonly prevalent among persons with diabetes than in the general population. Males with diabetes are almost two-and-a-half times more likely to be obese than males in the general population. The ratio is more than three times between the two female groups.

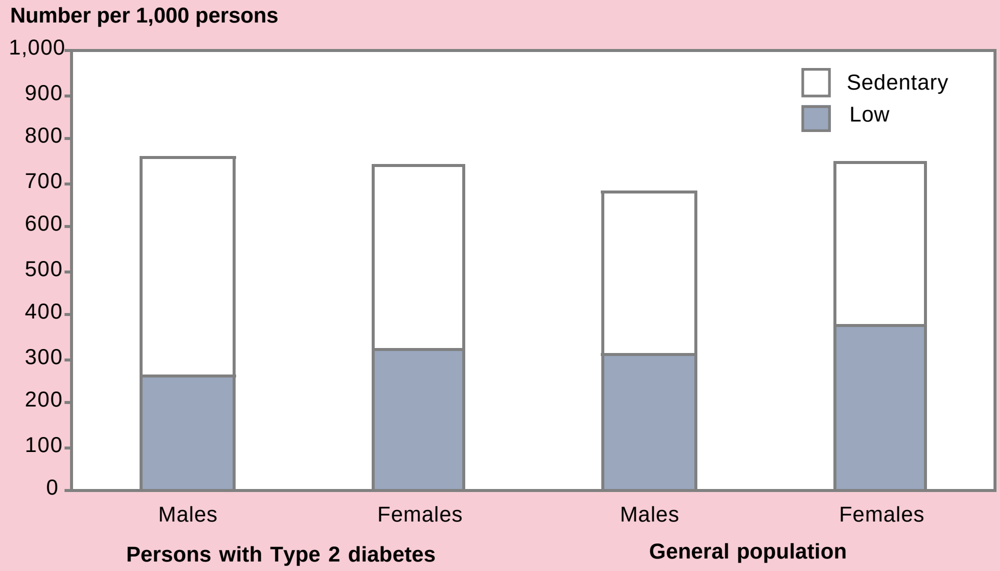
Time trends

- There has been a steady increase in the proportion of overweight/obese persons in Australia. The proportion of overweight/ obese among those aged 18 years and over increased by almost 7 per cent points between the 1989–90 NHS and 1995 NHS among males, and by about 5 per cent points among females.
- Assessment of changes in the proportion of overweight/obese persons with diabetes is not possible from the NHS data for technical reasons. However, comparisons of overweight/ obesity rates among those with diabetes and in the general population reveal that the gaps may have widened further between the 1989–90 and 1995 surveys.

Data issues

- Both age and overweight/obesity are independent risk factors for diabetes. The older age distribution of those with diabetes compared with the general population is likely to account for part of the difference in overweight/obesity prevalence between the groups. However, adjustment for differences in age distributions in estimation has removed some of this effect.
- The accuracy of self-reported body weight and height has been questioned. Using measured weights and heights, ABS (1998) has determined that a large proportion of respondents under-reports bodyweight and over-reports height, resulting in lower BMI scores.
- The definition of overweight/obesity based on body weight and height alone is inadequate because it does not take into account body composition of the individual. It has been suggested that excessive amount of total body fat, in particular the presence of excessive abdominal (visceral) fat, is an important risk factor for diabetes in some populations.

Indicator 2.2: Rates for non-participation in regular, sustained, moderate aerobic exercise among persons with Type 2 diabetes and in the general population



Population group (aged 30 years and over)		Unadjusted rates by level of exercise: Low	Unadjusted rates by level of exercise: Sedentary	Age-standardised rates by level of exercise: Low	Age-standardised rates by level of exercise: Sedentary
Persons with Type 2 diabetes	Males	353	410	259	496
	Females	347	471	323	418
General population	Males	308	372	307	373
	Females	375	375	377	370

Note: Rates, age standardised to the 1991 Australian population, are given as number per 1,000 persons.

Source: ABS (1997a).

- Lack of physical activity is one of the known modifiable risk factors for Type 2 diabetes. Physical activity is also an important adjunct to the maintenance of body weight which is central to the management of diabetes.
- Physical activity not only protects against the development of diabetes but also improves insulin and glucose homeostasis. It can also appropriately reduce the levels of blood pressure and cholesterol, thus minimising the risk of cardiovascular disease.
- It has been shown that increased physical activity reduces the risk of developing diabetes between 30 and 50 per cent (Spelsberg & Manson 1995).
- No reliable estimates of the effect of increased physical activity in reducing heart, stroke and vascular disease are available.

Operational definition

- The operational definition for this indicator is the proportion of adults, with or without diabetes, who do not participate in vigorous or moderate levels of physical activity for recreation or fitness.
- Based on self-reported information, this indicator measures the proportion of people who have not undertaken that level of activity over a two-week period.
- Two different levels are identified — those who do not participate in any physical activity, referred to here as sedentary, and those who undertake low level of activity. People with a sedentary lifestyle, or undertaking only low levels of physical activity, fail to gain the health benefits that moderate intensity physical activity can confer. For details on physical activity type and level, see Appendix 2.
- A comparative perspective is sought between people at risk of developing diabetes and those who already have the condition, using lack of physical activity as an indicator.
- The indicator may also be interpreted as an indirect measure of the success of diabetes education and management programs that include physical activity as an integral component.

Non-participation rates

- According to the 1995 NHS, almost one-half of males with diabetes do not participate in any physical activity. Another 26 per cent undertake only low levels of activity.
- The proportion of females not undertaking any physical activity is reported to be lower among those with the condition, but is higher for low level physical activity.
- The proportion of males not participating in any physical activity is much higher among those with diabetes than among those in the general population.
- Data from the cross-sectional surveys do not enable us to establish if people are not participating in physical activity because they have diabetes, associated risk factors, or poor health, or if indeed lack of physical activity has contributed to the development of diabetes.

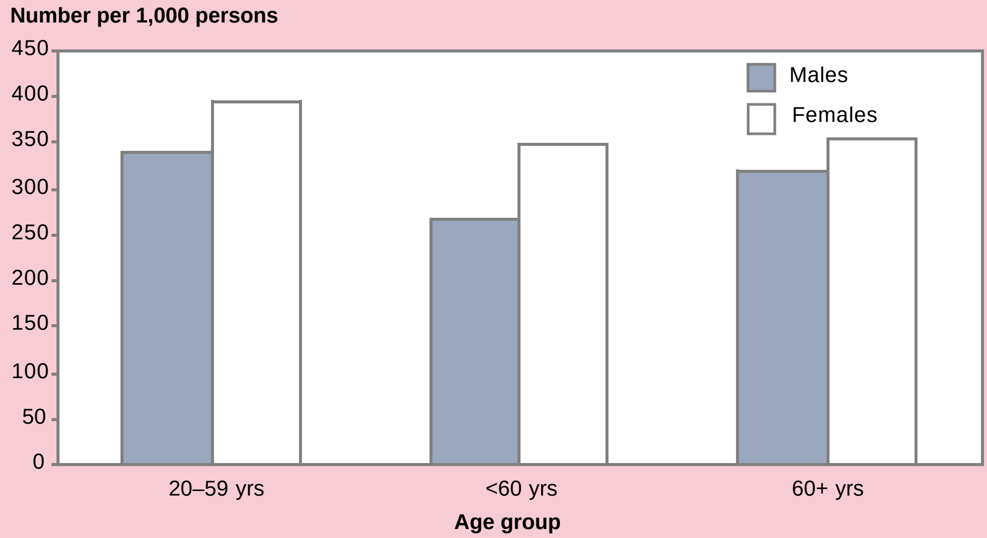
Time trends

- There is some evidence that Australians are now participating in physical activity more often. The proportion of those not engaged in physical activity decreased by around 6 per cent between 1989–90 and 1995.
- The increase in physical activity was mainly due to an increase in participation among people aged 35–54 years. Walking, a moderate physical activity recommended for health, increased in popularity during the 1990s with 45 per cent of males and 53 per cent of females walking for recreation or exercise in 1995 compared with 41 per cent and 49 per cent respectively in 1989–90.
- However, no time series is currently available on physical activity among persons with diabetes to provide a comparative picture.

Data issues

- Physical activity that reduces the risk of developing diabetes and its complications does not require a structured or vigorous exercise program. Because the majority of benefits of physical activity can be gained by performing moderate-intensity activities outside of formal exercise, this indicator has been designed to determine the rates for non-participation in regular, sustained, moderate aerobic exercise.
- However, data from the NHS do not provide validated information on the frequency or duration of the activity performed to assess this indicator as defined. Participation in any moderate or vigorous physical activity has been used as the proxy indicator.
- Self-reported data reflect the respondent's perception of the activity undertaken, its intensity, and his/her level of fitness. The AIHW is undertaking a validation study of moderate physical activity to reduce the effect of this problem in future surveys. Further validation of these data is required to assess the role of physical activity in preventing diabetes and improving outcomes of diabetes management.
- Currently, the AIHW is developing a physical activity questionnaire that will enable future surveys to collect the type of data needed to inform the indicator as defined above.
- Several variables influence the adoption of a physically active lifestyle by various population groups. These factors should be taken into consideration in comparing rates.

Indicator 2.3: Prevalence rates for high blood pressure among persons with Type 2 diabetes, aged less than 60 years or aged 60 years and over



Population group	Age group 20–59 years	<60 years	60+ years
Males	340	266	319
Females	395	347	354
Persons	382	328	335

Note: Rates, age standardised to the 1991 Australian population, are given as prevalence per 1,000 persons.

Source: NADC (1998).

- High blood pressure is known to be associated with diabetes, presenting often with central (upper body) obesity and dyslipidaemia.
- High blood pressure may be a risk factor for diabetes. High blood pressure could be present for up to 10 years before the detection of diabetes. The evidence is accumulating that the two may have a common aetiological factor.
- High blood pressure is an independent risk factor for cardiovascular disease, as well as renal disease. But in combination with hyperglycaemia and other risk factors such as hyperlipidaemia, it becomes more powerful a factor for diabetes-associated complications.

Operational definition

- The indicator has been designed to provide a comparative picture of the prevalence of high blood pressure in association with diabetes. In view of the strong association of high blood pressure with age, two different age-based cut-off points have been set up.
- High blood pressure for the purpose of this indicator is defined as:
  - — ≥ 140 mmHg systolic and/or 90 mmHg diastolic for people aged less than 60 years; and
  - — ≥ 160 mmHg systolic and/or 90 mmHg diastolic, for people aged 60 or more years.
- Since the indicator has been designed to determine prevalence rather than management outcomes for high blood pressure among persons with diabetes, those on treatment for high blood pressure are included in estimating the prevalence rates.

- Although the indicator has been designed to cover all age ranges, separate information is also provided for the age range 20–59 years, for more focused tracking of trends over time.
- It is expected that this indicator will be tracked with the National Biomedical Risk Factor Survey. Proxy data from the NADC will be used until that data becomes available.

Prevalence rates

Clinic-based data

- Based on the NADC survey, the prevalence rates for high blood pressure are estimated as 266 per 1,000 males and 347 per 1,000 females with Type 2 diabetes and under the age of 60 years. The proportions are slightly higher among those aged 20–59 years.
- The prevalence rates for high blood pressure among persons with diabetes and over the age of 60 years are similar to those noted for persons under the age of 60 years. Although blood pressure is age associated, the higher cut-off point for systolic pressure may have offset some of the difference.

Population-based data

Measured

- No population-based, national estimates of prevalence of high blood pressure among persons with diabetes, based on actual measurements, are available. However, in a survey in South Australia, Phillips et al (1998) have found that:
  - — almost one in three persons with Type 2 diabetes (321 per 1,000) have blood pressure ≥ 160/95 mmHg; and
  - — the proportion of those with blood pressure ≥ 140/90 mmHg is 597 per 1,000.
- The two cut-off points in the South Australian survey are not age specific. However, the population-based survey reveals slightly higher prevalence rates than the clinic-based data if the cut-off point of 140/90 mmHg is applied.

Self-reported

- The proportion of people with diabetes who reported high blood pressure during the 1995 NHS is 441 per 1,000. This figure has not been age and sex standardised because of the relatively small number of people with diabetes in the NHS sample.
- As both Type 2 diabetes and high blood pressure are associated with age, these prevalence rate ratios must be carefully interpreted.
- Also, the information is based on self reports, rather than actual measurement, which may lead to underestimation of the prevalence rate.

Diabetes-related risk factors and high blood pressure

- Almost one out of three respondents (310 per 100,000) at high risk of developing diabetes — over the age of 40 years and overweight or obese — reported high blood pressure during the 1995 NHS (ABS 1997a).
- This compares with a rate of 441 per 1,000 among persons with Type 2 diabetes and 100 per 1,000 persons without diabetes.
- Again, these figures are not age and sex standardised and therefore should be used carefully.

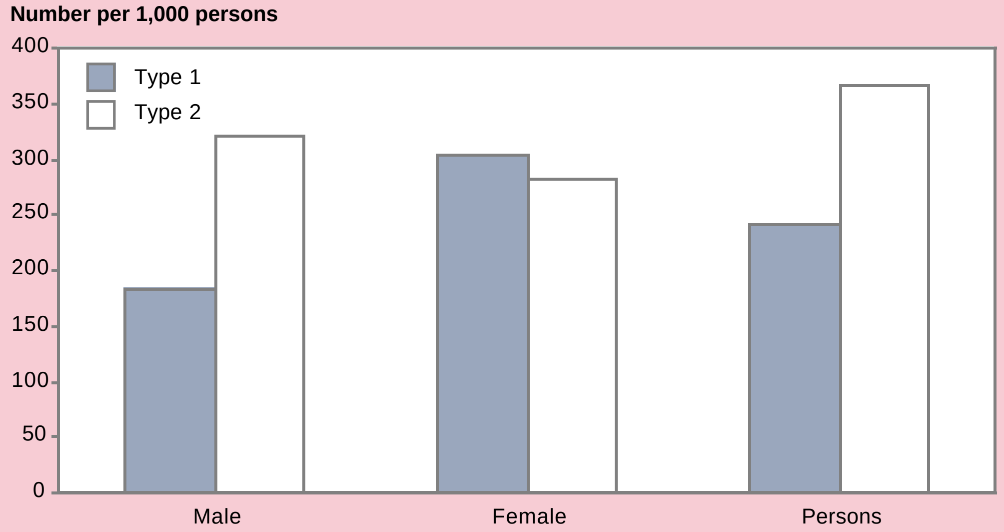
Time trends

- During the 1980s, average blood pressure levels in Australia declined significantly. The trend has continued into the 1990s (HEALTH & AIHW, in press).
- This trend has positive implications for diabetes outcomes. Evidence has long existed that managing blood pressure reduces diabetes-related complications, in particular cardiovascular disease and renal outcomes.

Data issues

- No direct comparison of the prevalence rates for high blood pressure among persons with diabetes, as estimated from three different types of survey, is possible. While the NADC survey included patients under the clinical care of specialist diabetes services, the other two surveys were population based. The two population-based surveys also used different methodologies.
- No reliable measurement-based benchmarks are currently available for self-reported blood pressure among persons with diabetes. Although, the 1995 National Nutrition Survey collected measured information on blood pressure to benchmark 1995 NHS self reporting, these results are not extendable to persons with diabetes.
- The NADC survey is based on an audit of patients attending specialist diabetes centres. It includes persons with diabetes requiring specialist clinical management, in particular those who have had poor control of their diabetes. A major limitation of the sample is that it does not accurately reflect the conditions prevailing in the general community.
- A more appropriate national dataset would be based on a population-based study. The proposed National Biomedical Risk Factor Survey is likely to provide suitable information.

Indicator 2.4: Prevalence rates for high levels of lipoproteins among persons with Type 1 and Type 2 diabetes



Population group (ages 20 years and over)	Prevalence of high cholesterol levels	
	Type 1 diabetes	**Type 2 diabetes**
Males	182	319
Females	303	282
Persons	242	366

Note: Rates, age standardised to the 1991 Australian population, are given as prevalence per 1,000 persons.

Source: NADC (1998).

- High levels of lipoproteins, or dyslipidaemia, and diabetes are known to be associated. There is some evidence that dyslipidaemia may precede abnormal glucose tolerance. Hyperglycaemia on the other hand is known to contribute to high levels of lipoproteins. Resistance to insulin action is considered to act as a common aetiological factor.
- The presence of lipoproteins at high levels constitutes a strong risk factor for atherosclerosis that may be intensified by diabetes. The impact of dyslipidaemia and diabetes may be even greater in combination with other cardiovascular disease risk factors such as high blood pressure and overweight/obesity.
- Although high levels of lipoproteins promote atherosclerosis in a similar manner in both types of diabetes, higher prevalence of overweight/obesity among persons with Type 2 diabetes may augment the risk for cardiovascular disease complications differently from that for Type 1 diabetes.

Operational definition

- The indicator has been designed to provide a comparative picture of the prevalence of dyslipidaemia in association with two major forms of diabetes, Type 1 and Type 2.
- Two different compounds, cholesterol and high-density lipoproteins, are measured and monitored with the following cut-off points:
  - —total plasma cholesterol ≥ 5.5 mmol/L; and
  - —high density lipoproteins < 1.0 mmol/L.
- It is expected that this indicator will be tracked using population-based biomedical risk factor data. However, in the absence of these data, information collected by the NADC survey will be used as proxy data.

Prevalence rates

Clinic-based data

- According to the NADC survey, age-standardised prevalence rate for high blood cholesterol (≥ 5.5mmol/L) among persons with Type 1 diabetes is 182 per 1,000 males and 303 per 1,000 females with Type 1 diabetes.
- The rates are respectively 319 and 282 per 1,000 among persons with Type 2 diabetes.

Population-based data

Measured

- In South Australia, more than half of the respondents (523 per 1,000 persons) with Type 2 diabetes had cholesterol levels ≥ 5.5 mmol/L (Phillips et al 1998).
- In more than one out of three persons with high cholesterol, the level was ≥ 6.5 mmol/L.
- High density lipoprotein was present at levels < 1.0 mmol/L in almost 46 per cent of persons with diabetes.

Self-reported

- The proportion of people with diabetes who reported the presence of high cholesterol during the 1995 NHS is 165 per 1,000 persons. This rate is over three times as high as the rate among those without diabetes (49 per 1,000 persons).
- No distinction was made between persons with Type 1 or Type 2 diabetes in this analysis.

Time trends

- No clear time trends were observed in the plasma cholesterol levels in Australia in 1980s. No new information on this important risk factor — to track the trend further — has become available in 1990s.

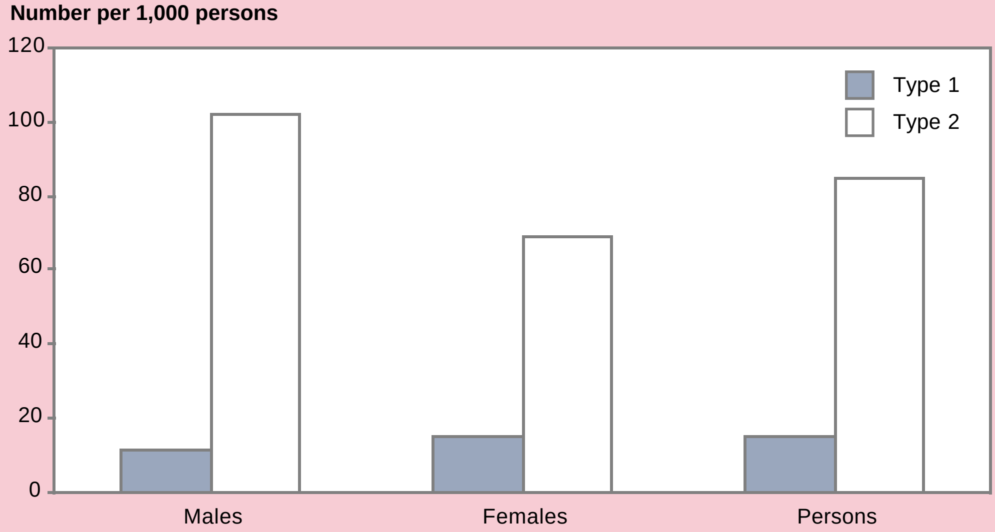
Data sources

- Information on the prevalence of dyslipidaemia among those attending diabetes centres was collected in 1998 through an NADC survey. The NADC survey is based on an audit of patients attending specialist diabetes centres. The survey included 1,681 persons, aged 20+ years, presenting at 32 specialist diabetes service centres in the country. Of these, 83 per cent have Type 2 diabetes.
- Self-reported information on high cholesterol levels in the general population and among persons with diabetes was collected during the 1995 NHS. This information was not backed up by a laboratory-based test.
- No national benchmark, population-based information on cholesterol levels based on laboratory measurements, among persons with diabetes or in the general population, has become available since the 1989 Risk Factor Prevalence Survey by the NHF.
- Population-based, regional information on the prevalence of cholesterol and high density lipoproteins among persons with Type 2 diabetes has been generated through a survey in South Australia (Phillips et al 1998). No comparable regional information from another State/Territory is currently available.

Data issues

- No direct comparisons of lipid levels between the NADC and South Australian data are possible because of different sampling strategies. While the former includes patients under clinical care, the latter survey is population based. The two estimates were also generated using different standard populations for age adjustments.
- An order of magnitude difference has been noted in the estimates of prevalence rates for high cholesterol among males based on self reports during 1989–90 NHS and measurement of cholesterol during the 1989 Risk Factor Prevalence Study.
- The NHS data are based on self reports, rather than measured levels of cholesterol, which may lead to the underestimation of prevalence rates. While some of this discrepancy may result from the recent lowering of the cut-off point for high cholesterol from 6.5 mmol/L to 5.5 mmol/L, the awareness of this risk factor in the general population may not be high.
- The cholesterol cut-off point of 5.5 mmol/L, used here, is in accordance with the recommendations of the NHF.
- The NHS estimates are not age and sex standardised because of the relatively small number of people with diabetes in the NHS sample (ABS 1997a).
- The NADC survey is based on an audit of patients attending specialist diabetes centres. It includes persons with diabetes requiring specialist clinical management, in particular those who have had a poor control of their diabetes. A major limitation of the NADC sample is that it does not accurately reflect the conditions prevailing in the general community.
- A more appropriate national dataset would be based on a population-based study.

Indicator 2.5: Prevalence rates for fasting hypertriglyceridaemia among persons with Type 1 and Type 2 diabetes



	Type of diabetes	
Population group	**Type 1**	**Type 2**
Males	11.8	102.3
Females	15.4	69.2
Persons	15.0	84.8

Note: Rates, age standardised to the 1991 Australian population, are given as prevalence per 1,000 persons.

Source: NADC (1998).

- Hypertriglyceridaemia, or high triglyceride levels, represents an increase in both circulating chylomicrons and very low density lipoproteins in blood. Elevated triglyceride levels have been consistently associated with Type 2 diabetes, impaired glucose tolerance and Syndrome X.
- Increased triglyceride levels might possibly induce insulin resistance through interference with peripheral insulin binding and action. Conversely, persistent hyperglycaemia in combination with obesity may lead to high levels of triglycerides. Often it is impossible to determine which of the two metabolic disorders in this relationship has primacy.
- Hypertriglyceridaemia is also an independent risk factor for cardiovascular disease. It is considered that elevated levels of triglycerides play an important role in the pathogenesis of macroangiopathy.

Operational definition

- This indicator has been designed to provide a comparative picture of hypertriglyceridaemia in persons with Type 1 and Type 2 diabetes. Since insulin therapy is known to be highly effective in reducing triglycerides, a comparison of triglyceride levels would be useful for monitoring the management of the two forms of diabetes.
- Hypertriglyceridaemia for the purpose of this indicator is defined as fasting triglyceride levels above 4.0 mmol/L.
- It is expected that this indicator will be tracked using population-based biomedical risk factor data. However, in the absence of these data, information collected by the NADC survey will be used as proxy data.

Prevalence rates

Clinic-based data

- According to the NADC survey, the age-standardised prevalence rate for high triglycerides was estimated to be 15 per 1,000 among persons with Type 1 diabetes. The rate is much higher among individuals with Type 2 diabetes, almost 85 per 1,000 persons.
- The prevalence rate for hypertriglyceridaemia is much higher among males with Type 2 diabetes when compared to females, with a rate ratio of 1.5. However, the numbers are too small to make an objective assessment of triglyceride levels among persons with Type 1 diabetes.

Population-based data

- No population-based, national information on the distribution of triglycerides by type of diabetes is available. However, a regional study conducted in South Australia by Phillips et al (1998) included laboratory measurement of triglycerides among persons with Type 2 diabetes.
- According to this study, triglyceride levels above 4.0 mmol/L are prevalent at a rate of 136 per 1,000 persons. But almost half of the persons with Type 2 diabetes (478 per 1,000 persons) have triglycerides above 2.0 mmol/L.
- These prevalence rates are slightly higher than the rates estimated from the NADC study. The lower rates in the NADC study may partly reflect the clinical setting of the sample and regular diabetes care it offers.

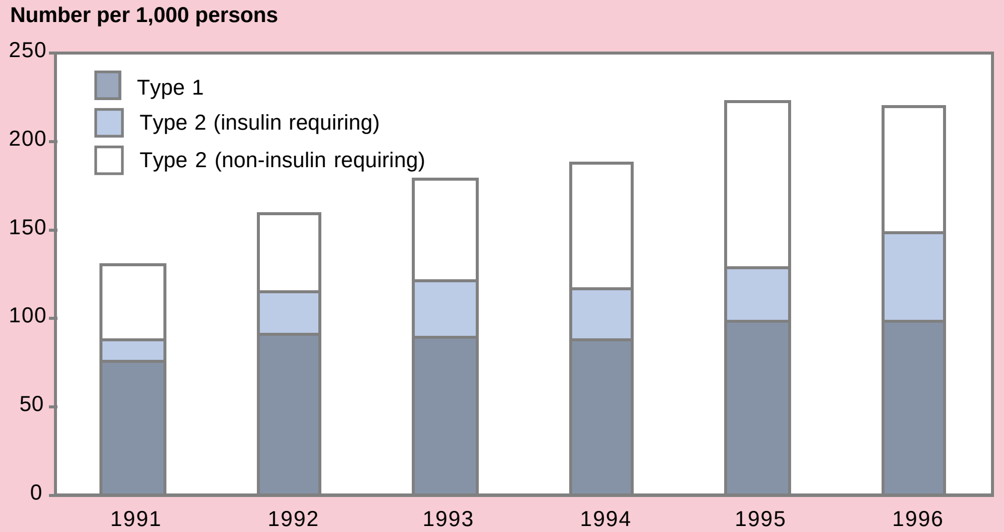
Data sources

- No national benchmark, population-based information on triglyceride levels, self-reported or based on laboratory measurements, has become available since the 1989 NHF Risk Factor Prevalence Survey.
- Population-based, regional information on the prevalence of triglyceride levels among persons with Type 2 diabetes has been recently generated through a survey in South Australia (Phillips et al 1998). The study was based on a sample of 173 persons.
- Information on the prevalence of hypertriglyceridaemia among those attending diabetes clinics has been recently collected through an NADC survey. The NADC survey is based on an audit of patients attending specialist diabetes centres. The survey included 1,681 persons, aged 20+ years, presenting at 32 specialist diabetes service centres in the country. Of these, 83 per cent have Type 2 diabetes.

Data issues

- No direct comparison of lipid levels between the NADC and South Australian data is possible because of different sampling strategies. While the former includes patients under clinical care, the latter survey is population based. Besides, the two sets of estimates have been obtained using different standard populations for age adjustments.
- A population-based study of the prevalence of hypertriglyceridaemia among persons with and without diabetes is required for generating baseline information.

Indicator 3.1: Proportion of persons with end-stage renal disease with diabetic nephropathy as a causal factor



	Year					
Type of diabetes	**1991**	**1992**	**1993**	**1994**	**1995**	**1996**
Type 1	76.0	91.0	90.0	88.0	97.7	97.9
Type 2 (insulin requiring)	11.5	24.0	31.0	29.0	30.8	50.0
Type 2 (non-insulin requiring)	42.0	44.0	57.0	70.9	94.9	71.0
All types	130.0	158.8	178.5	188.0	223.5	219.1

Note: Rates, age standardised to the 1991 Australian population, are given as number per 1,000 persons.

Source: Estimates based on data derived from the 1996 and 1997 ANZDATA Registry Annual Reports (Disney 1996; Disney et al 1997).

- Diabetic microvascular complications include disorders of the kidney. Some aspect of diabetic state (possibly hyperglycaemia) contributes directly to nephropathy that progresses to end-stage renal disease. In several cases, this necessitates transplantation or regular dialysis for survival.
- Several other factors contribute to end-stage renal disease. These include analgesic nephropathy, glomerulonephritis, high blood pressure, polycystic kidney and reflux, the effect of some of which may be accentuated further by the presence of diabetes.
- During the 1995 NHS, about 7 per cent of persons with diabetes reported the presence of kidney disease, more than four times the rate noted among persons without diabetes (ABS 1997a). More than one out of three persons with Type 2 diabetes in a South Australian survey were found to have poor glomerular filtration rate (Phillips et al 1998).

Operational definition

- This indicator measures the proportional contribution of diabetic nephropathy to the incidence of end-stage renal disease in Australia.
- Since the natural history of nephropathy in persons with Type 1 is known to differ from the course among persons with Type 2 diabetes, the contributions from two forms of the disease are presented separately.

Number of cases

- A total of 260 persons registered with Australia and New Zealand Dialysis and Transplant Registry in 1996 for end-stage renal disease had diabetes (Disney 1996).
- Persons with diabetes as the primary cause of renal disease account for almost one in five new registrants in the age group 25–84 years. The proportion declines from one in four among those aged 25–34 years to less than one in sixteen among those aged 75–84 years.
- More than a quarter of new end-stage renal disease registrants in 1996 — with diabetes as the primary cause of renal disease — had Type 1 diabetes. Another third of the registrants that year had Type 2 diabetes, but were on insulin treatment.
- The proportion for persons with Type 1 diabetes — with diabetes as the primary cause of renal disease — changes from 75 per cent in the age group 25–34 years to almost nil among those aged 75–84 years.

Time trends

- Concomitant with increases in new end-stage renal disease registrants over the last several years (from 982 in 1991 to 1,405 in 1996), new cases of end-stage renal disease with diabetes as the primary cause of renal disease also increased over five years (1991–1996). The proportional increase was however much higher — more than two-fold, from 123 in 1991 to 260 in 1996.
- In comparison, the number of new cases of end-stage renal disease without diabetes as the primary cause of renal disease increased by only 33 per cent during the same period, from 859 to 1,145.
- The proportion of end-stage renal disease cases with diabetes has increased from around one in seven cases in 1991 to more than one in five in 1995. This proportion however declined slightly in 1996. This proportional increase has been noted in all three groups of persons with diabetes identified here.
- A large part of this proportional increase is accounted for by increases in the number of persons with Type 2 diabetes, by almost 60 per cent between 1991 and 1996. The proportional rise for Type 1 diabetes was 29 per cent during this period.
- As the population ages further, this shift in relative contribution to end-stage renal disease from diabetes, in particular Type 2 diabetes, is likely to continue.

Data issues

- When age standardised, the relative contributions of various forms of diabetes to end-stage renal disease changes significantly. This is mainly because the age structure of persons with Type 1 diabetes and end-stage renal disease is very different from that for persons with Type 2 and end-stage renal disease.
- Age adjustment can sometimes produce bizarre results, in particular when two disparate distributions are pooled. Therefore, the results presented in the Figure and the accompanying Table should only be used for following time trends for each form of diabetes separately.

Indicator 3.2: Incidence rate for eye disease among clinically diagnosed persons with diabetes

Population group	Incidence of blindness
Males	NA
Females	NA
Persons	8

Note: Rates, age standardised to the 1991 Australian population, are given as incidence per 1,000 persons.

Source: NADC (1998).

- Diabetic retinopathy is a common, though largely preventable, cause of blindness in Australia. Cataracts and glaucoma, two other major causes of blindness, are also more common among persons with Type 2 diabetes.
- The appearance and progression of diabetic retinopathy, and the resultant visual loss, is known to be associated with hyperglycaemia. High blood pressure, early age of onset of diabetes and duration of disease are other known risk factors.

Operational definition

- This indicator has been designed to monitor the incidence of eye disease among clinically diagnosed persons with diabetes.
- The diseases/conditions to be covered include vision-threatening retinopathy, cataracts, glaucoma and blindness.
- The indicator does not include persons who already have had vision-threatening retinopathy or blindness at the time of diagnosis of diabetes.
- The indicator is based on four hard end points. No account is taken of progression to various intermediate stages.

Incidence rates

- No information is available on the national incidence of vision-threatening retinopathy, cataracts and glaucoma.
- The NADC data suggest an annual incidence rate for technical blindness of 8 per 1,000 persons.

Prevalence rates

Retinopathy

- No national estimates of the prevalence of diabetic retinopathy are available.
- According to a South Australian survey, almost one in five persons with Type 2 diabetes (190 per 1,000 persons) have retinopathy. This includes both non-proliferative and proliferative retinopathy (Phillips et al 1998).
- The Newcastle study on the other hand reveals a prevalence rate for vision-threatening retinopathy of 130 per 1,000 among persons with clinically diagnosed diabetes (Mitchell 1985).
- Wide variation occurs in the prevalence of diabetic retinopathy among different populations. Several different factors contribute to this variation including genetic susceptibility and differences in prevalence rates for diabetes.

Cataracts and glaucoma

- According to the 1995 NHS, the prevalence rate for cataracts among those with diabetes is 99 per 1,000 persons in comparison to 16 per 1,000 persons among those without the disease.
- Glaucoma is also reported to be prevalent almost five times more often among those with diabetes during the 1995 NHS. The prevalence rates among persons with and without diabetes are 34 and 7 per 1,000 respectively.

Blindness

- According to the 1995 NHS, blindness is present in almost 57 out of 1,000 persons with diabetes, more than six times the rate among persons without diabetes.

Time trends

- No information on trends in the incidence of vision-threatening diabetic retinopathy is available. However, with increasing prevalence of diabetes and ageing of the population, the rates are likely to rise further.

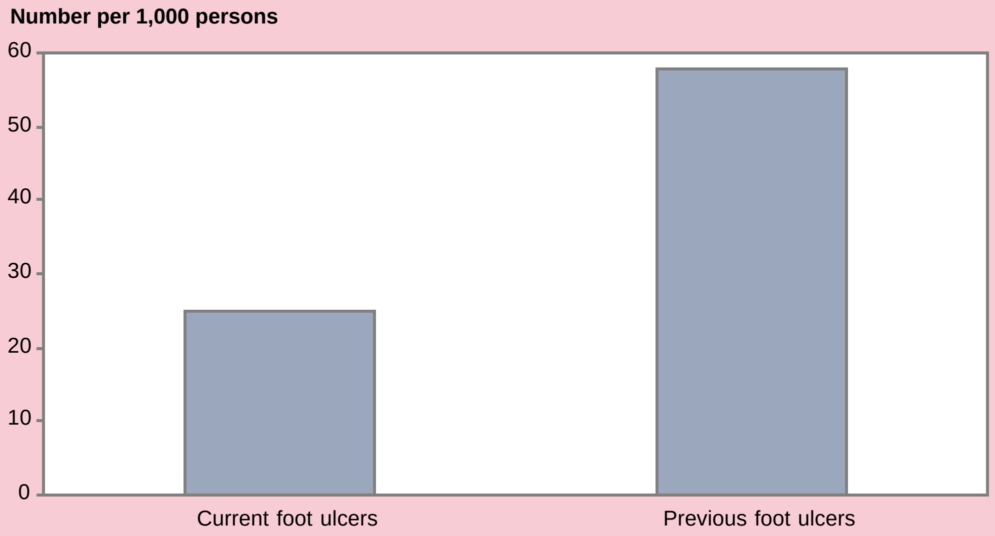
Risk factors

- Increasing duration of diabetes and age over 40 years are two major predictors of diabetic retinopathy. The four-year relative risk of blindness among persons with diabetes has been estimated to be almost 29 times that in the general population.
- Retinopathy is much more common among persons with Type 1 diabetes than among those with Type 2 diabetes, reflecting mostly differences in the mean duration of the disease. However, persons with Type 2 diabetes are more likely to have an eye complication at the time of diagnosis.
- Large clinical trials in the United States (DCCT) and the United Kingdom (UKPDS) have demonstrated the benefits of good diabetes care and control in reducing the risk of retinopathy. These trials have also established the efficacy of laser photocoagulation in preventing visual loss from proliferative retinopathy and maculopathy.

Data issues

- Data to monitor eye diseases among persons with diabetes are highly variable in quality and content.
- The NADC survey is based on an audit of patients attending specialist diabetes centres. It includes persons with diabetes requiring specialist clinical management, in particular those who have had a poor control of their diabetes. A major limitation of the NADC sample is that it does not accurately reflect the conditions prevailing in the general community.
- A more appropriate national dataset would be based on a population-based study.
- Further work is required to develop a suitable operational definition. Since retinopathy progresses over time through various grades, the incidence rate may be computed on the basis of progression to the next stage of the disease (see, for example, Mitchell 1985).

Indicator 3.3: Prevalence rate for foot problems among clinically diagnosed persons with diabetes



	Prevalence of foot ulcers	
Population group	**Current**	**Previous**
Males	NA	NA
Females	NA	NA
Persons	25	58

Source: NADC (1998).

- Diabetic foot problems include ulcers, gangrene and loss of sensitivity to pain and trauma. Peripheral neuropathy or vascular disease are usually the underlying complications. It is estimated that more than one in seven persons with diabetes will develop foot problems.
- Progression of these conditions often leads to amputations. Diabetes accounts for approximately half of all non-traumatic amputations.
- Most of the amputations are of lower level, that is amputations of toe, foot and ankle. Secondary amputations are also not uncommon.
- Mortality among persons with diabetes who develop foot problems, in particular if ulceration, infection, or gangrene occurs, is known to be high. Three-year survival rates of less than 50 per cent have been reported among diabetic amputees.

Operational definition

- This indicator has been designed to monitor the prevalence of foot problems among clinically diagnosed persons with diabetes. Presence of foot ulcers and lower leg amputations are used as the two endpoints for monitoring.
- Prior history of foot ulcers is an important indicator of the presence of undercurrent neuropathic or vascular complications. Information on previous foot ulcers is therefore important and included here for comparisons.

Prevalence rates

Foot ulcers

- Based on the 1998 NADC data, the prevalence rate for current foot ulcers is estimated to be 25 per 1,000 among persons with clinically diagnosed diabetes. In addition, almost 58 persons (using 1,000 as the denominator) had ulcers on previous occasions.
- The above estimates are based on persons with diagnosed diabetes, and attending a diabetes clinic regularly. A large proportion of persons with diabetes in the general population may be under less regular care for their condition than those included in the NADC survey.
- Health care factors and diabetic history are important in the development of foot problems. The prevalence of diabetic foot problems therefore could be more common in the general population. Conversely, the NADC sample may represent a more severe end of the spectrum of the disease.

Amputations

- Absence of limbs was reported at a rate of 18 per 1,000 persons with diabetes during the 1995 NHS. Despite the higher mortality of diabetic amputees, the rate was more than three times greater than that among persons without diabetes.
- Most of the amputations among persons with diabetes are those of toe, foot and ankle. However, more disabling amputations, including those above the knee, are equally common among those with and without diabetes.
- The incidence of lower limb amputations is estimated to be 1.1 per 1,000 persons among persons attending the NADC clinics.

Risk factors

- A variety of risk factors have been identified for foot problems among persons with diabetes. These include age, sex, ethnic background, peripheral neuropathy, peripheral vascular disease, diabetes type, glycaemic control and clinical duration of diabetes.
- A positive history of retinopathy is also a factor in increased risk of foot problems.

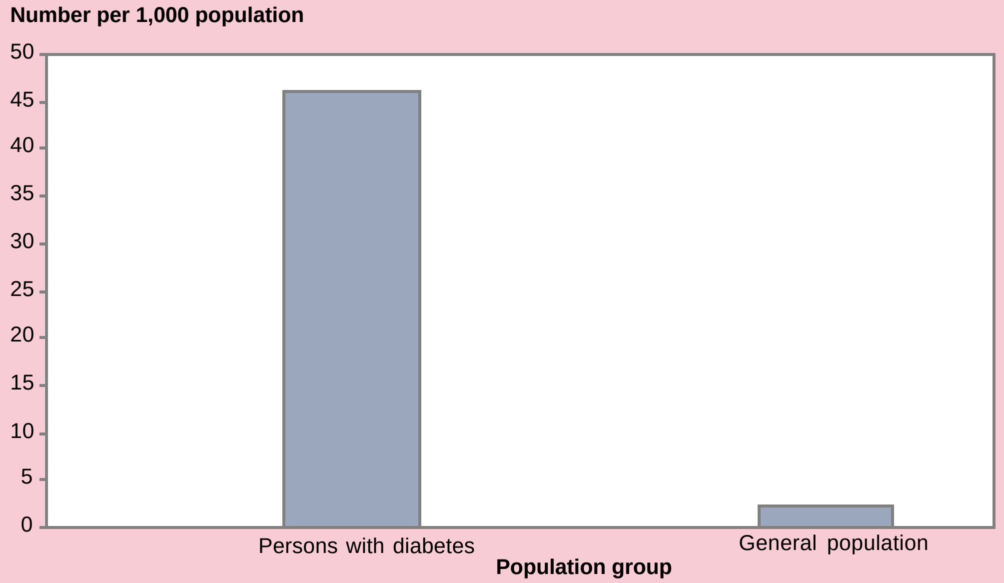
Data sources

- 1995 NHS for lower limb amputations data; self-reported.
- Estimates for foot ulcers are based on the NADC data, which is an audit of patients attending specialist diabetes centres.

Data issues

- The majority of foot ulcers are treated in outpatient settings, which limits effective surveillance of the problem. Some information on the extent of the foot problems however may be obtained from hospital separations data.
- There are no population-based, national data on foot problems among persons with diabetes. The information obtained through the NHS is less specific since it pertains to lower limb amputation in general than to specific parts of the foot.
- The NADC survey includes persons with diabetes requiring specialist clinical management, in particular those who have had a poor control of their diabetes. Its major limitation is that it does not accurately reflect the conditions prevailing in the general community.
- A more appropriate national dataset would be based on a population-based study.

Indicator 3.4: Incidence rate for coronary heart disease and stroke in clinically diagnosed persons with diabetes and the general population



Population group (aged 35–69 years)	Heart attack* Persons with diabetes	Heart attack* General population	Stroke Persons with diabetes	Stroke General population
Males	NA	3.5	NA	NA
Females	NA	1.2	NA	NA
Persons	42	2.3	24	NA

* Estimated rates for fatal and non-fatal heart attacks, age group 35–69 years, financial year 1995–96, not age standardised.

Sources: AIHW (unpublished data); NADC (1998).

- People with diabetes have a higher risk of coronary heart disease and stroke. Along with renal disease, coronary heart disease and stroke are two of the major causes of death among persons with diabetes, accounting for more than half of the deaths.
- In contrast to persons without diabetes, coronary heart disease occurs at younger ages among persons with diabetes. Furthermore, persons with diabetes are known to have relatively poor prognosis following a heart attack or stroke.
- Hospitalisation statistics also reveal diabetes as a co-diagnosis with coronary heart disease and stroke in almost 19 per cent of separations.
- During the 1995 NHS, about 15 per cent of persons with diabetes reported the presence of heart disease, at almost six times the rate reported by persons without diabetes. An additional 4 per cent reported having suffered a stroke, again at a higher rate (ABS 1997b).

Operational definition

- Disease prevalence rates are a function of disease incidence and its management. This indicator has been designed to follow the incidence of diabetes among persons with clinically diagnosed diabetes, in comparison to the rate in the general population.
- The indicator provides a proxy for treatment and management of hyperglycaemia and other cardiovascular disease risk factors present among persons with diabetes.
- No distinction is made between Type 1 and Type 2 diabetes. Persons among whom diabetes is diagnosed at the time of or following a coronary heart disease or stroke event are not covered by this definition as this may inflate the rate of ascertainment.
- No data are available for the incidence of coronary heart disease. Information on non-fatal, first heart attack has been presented here instead.
- In correspondence with Indicator 2.1 for NHPA Cardiovascular Health (HEALTH & AIHW, in press), the age range for the indicator is set at 30–79 years. However, the data are currently available for ages 35–69 years only, and have been reported as such.

Incidence rates

- Based on the NADC data, the incidence rate for heart attack is estimated as 42 per 1,000 persons with clinically diagnosed diabetes. In comparison, the incidence of heart attack in the general population has been estimated to be 2.3 per 1,000 persons, at one-twentieth the rate noted among persons with diabetes.
- The incidence of stroke among persons with clinically diagnosed diabetes, based on the NADC data, has been estimated as 24 per 1,000 persons. No comparable information is available on the incidence rate in the general population but the rate is likely to be much lower.

Risk factors

- Persons with Type 2 diabetes suffer exceptionally high rates of coronary heart disease because they share many of the risk factors for heart disease, including central obesity, high blood pressure, hypertriglyceridaemia and high cholesterol (McCarty et al 1996). The excess risk of heart disease occurs with Type 1 diabetes as well.
- Persons with diabetes who have had a heart attack are at an increased risk of having another (potentially fatal) heart attack or stroke.

Time trends

- Trends in incidence of coronary heart disease and stroke among persons with diabetes may be influenced by a variety of factors. These include, besides ageing of the population and mean duration of diabetes, management of hyperglycaemia and other common risk factors such as overweight/obesity, hyperlipidaemia and high blood pressure.
- No data are currently available to determine trends in the incidence of coronary heart disease and stroke among persons with diabetes in Australia.

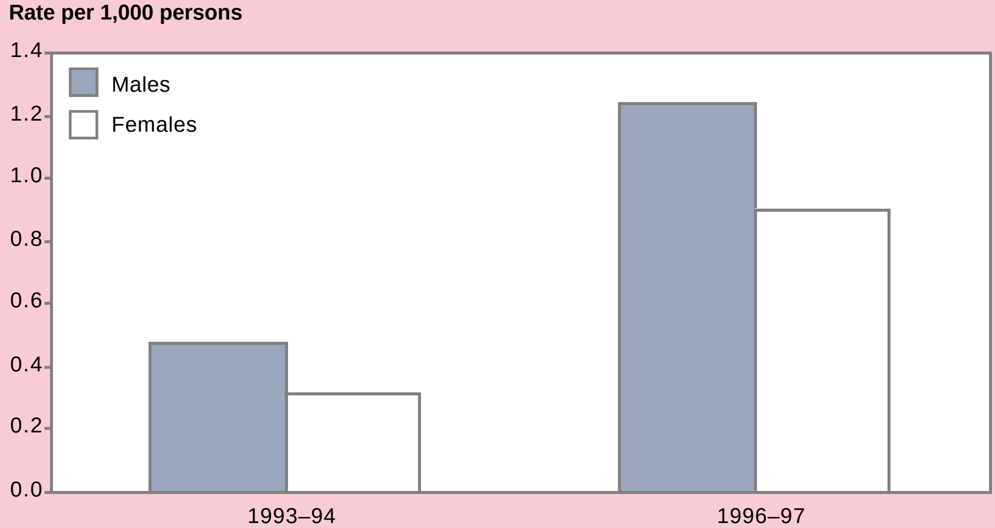
Data sources

- No national data are available on the incidence of coronary heart disease and stroke among Australians with diabetes. The information reported is based on a survey of those attending specialist diabetes clinics (the NADC survey).
- Information on the incidence of heart attack in the general population was obtained using methodology developed by the Universities of Newcastle and Western Australia, and Queensland Health. No information is currently available on the incidence of stroke.

Data issues

- Population-based studies are required to determine the true incidence of diabetes-related complications such as coronary heart disease and stroke.
- Patients attending diabetes clinics are likely to represent the more severe end of the spectrum of the disease than those under less organised care, and therefore may yield biased estimates. But patients under regular care are likely to have better management of their disease and associated risk factors.
- Also, there is virtually no information available on non-fatal outcomes to determine the pattern of incidence of cardiovascular disease complications among persons diagnosed with diabetes. The study by Phillips et al (1995) however provides some information on this aspect for coronary heart disease.
- Self reports through NHS also provide a picture of the relative risk of heart disease and stroke among persons with and without diabetes. However, these studies do not readily yield incidence data.
- Several population-based studies have compared the risk of fatal heart attack or stroke among persons with and without diabetes. The suitability of this information to follow trends in the management of diabetes and its complications needs to be determined.

Indicator 4.1: Hospital separation rate for end-stage renal disease with diabetes as an additional diagnosis



	Year	
Population group	**1993–94**	**1996–97**
Males	0.5	1.2
Females	0.3	0.9
Persons	0.4	1.0

Note: Rates, age standardised to the 1991 Australian population, are given as separations per 1,000 persons.

Source: AIHW National Hospital Morbidity Database.

- Kidney-related problems including renal failure constitute the single largest cause of hospitalisation in Australia (AIHW 1998a). Hospitalisation for dialysis is the most commonly listed reason for hospitalisation.
- Diabetic nephropathy is one of the major contributors to renal failure. During the 1995 NHS, about 7 per cent of persons with diabetes reported the presence of kidney disease, more than four times the rate noted among persons without diabetes (ABS 1997a). More than one in three persons with Type 2 diabetes in a South Australian survey were found to have poor glomerular filtration rate (Phillips et al 1998).
- Because of the limitation of the hospital separation data — episode rather than individual based — it is not possible to generate information on the impact of diabetes on hospitalisation for renal failure on an individual basis. However, hospital-based information provides an indication of the extent of morbidity associated with a disease and impact on the community.

Operational definition

- This indicator tracks hospital separations where both renal failure (ICD-9-CM: 584–585) and diabetes (ICD-9-CM: 250) are listed as co-diagnoses, with neither of them necessarily the principal diagnosis.
- Although renal failure is much more prevalent among persons with Type 1 diabetes than those with Type 2 diabetes, no distinction is made between the two in this report.

Hospital separation rates

- In 1996–97, both renal failure and diabetes recorded as co-diagnoses for a total of 20,344 separations. These accounted for approximately 7.9 per cent of all separations with renal failure as a listed diagnosis.
- Almost one in thirteen males admitted to hospital with renal failure have diabetes as a co-diagnosis. The ratio is slightly higher among females. The proportion is markedly higher for patients over the age of 34 years with an upward trend all through the later age groups.
- Age-standardised hospital separation rate for diabetes and renal failure as co-diagnoses is estimated to be 1.0 per 1,000 persons in 1996–97. The rate is greater among males, almost 40 per cent higher than the rate among females.

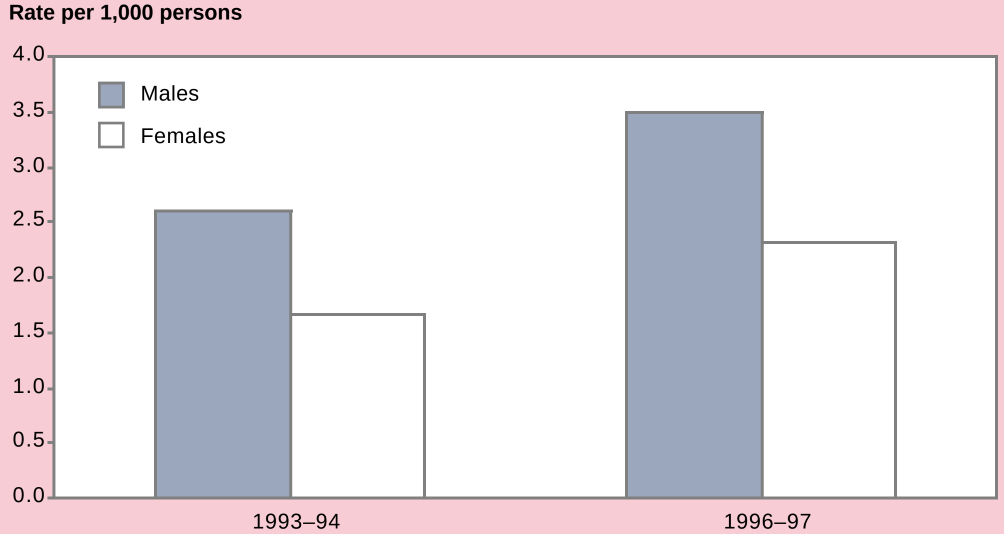
Time trends

- A large increase (34.6 per cent) in the rate of separations with diabetes and renal failure listed as co-diagnoses has been noted between 1993–94 and 1996–97. This increase partly reflects the upward trend noted in the relative proportion of persons with diabetes among end-stage renal disease patients (see Indicator 3.1).
- The number of separations with renal failure as a diagnosis increased by more than 160 per cent during the same period. This increase is attributed to increased inclusion of dialysis and dialysis catheter procedures as hospital separations.
- The gap between the change in hospital separation rates for renal failure as co-diagnosis, and renal failure as a diagnosis, between 1993–94 and 1996–97 is inexplicable. Over time, there has been a greater propensity to list diabetes as a diagnosis, however this increased propensity is not fully reflected in co-diagnoses for renal failure.

Data issues

- The validity of using hospital separations data to assess the burden of hospitalisation associated with diabetes has been questioned. This is mainly because the presumption that every hospitalisation for persons with diabetes should have the condition listed as a comorbid diagnosis is met varyingly.
- Accordingly, under-reporting of hospital separations of people with diabetes is likely to occur. In a large proportion, it is likely that diabetes is not listed as principal or as one of the diagnoses. The extent of this under-reporting in Australia has not been determined.
- The indicator has not been designed to provide information on the proportion of persons with diabetes who are hospitalised for renal failure. This is because of the limitation of the hospital separation data — it is episode rather than individual based. Nonetheless, this indicator, in combination with information derived from the NHS, provides a useful picture of the kidney-related morbidity among persons with diabetes.

Indicator 4.2: Hospital separation rates for coronary heart disease or stroke with diabetes as an associated diagnosis



	Year	
Population group	**1993–94**	**1996–97**
Males	2.6	3.5
Females	1.7	2.3
Persons	2.1	2.9

Note: Rates, age standardised to the 1991 Australian population, are given as separations per 1,000 persons.

Source: AIHW National Hospital Morbidity Database.

- Persons with diabetes are highly prone to coronary heart disease and stroke. Furthermore, they are also known to have worse prognosis following a stroke (Kuller 1995). Hospitalisation for the two problems is therefore common among persons with diabetes.
- Persons with Type 2 diabetes suffer exceptionally high rates of coronary heart disease because they share many of the traditional risk factors for heart disease including central obesity, high blood pressure, hypertriglyceridaemia and high cholesterol (McCarty et al 1996). The co-presence of diabetes and these risk factors accentuates the situation further. Persons with Type 1 diabetes are also at increased risk to develop cardiovascular disease problems.
- During the 1995 NHS, about 15 per cent of persons with diabetes reported heart disease, at almost six times the rate noted among persons without diabetes. In addition, more than 4 per cent of respondents have had a stroke, eight times more often than among those without diabetes (ABS 1997a).

Operational definition

- This indicator tracks hospital separations for which diabetes (ICD-9-CM: 250) is a comorbid diagnosis with coronary heart disease (ICD-9-CM: 410–414), or stroke (ICD-9-CM: 430–438), or both.
- Since persons with both Type 1 and Type 2 diabetes are at an increased risk for coronary heart disease and stroke, no distinction is made between the two types of diabetes.

Hospital separation rates

- In 1996–97, there were 272,227 hospital separations for which coronary heart disease or stroke was one of the listed diagnoses. For 56,256 separations, diabetes was listed as one of the diagnoses in combination with coronary heart disease or stroke. In comparison, a total of 267,449 hospital separations listed diabetes as a diagnosis.
- Almost one out of six males admitted to hospital with coronary heart disease or stroke as a diagnosis have diabetes. The proportion is slightly higher among females.
- Age-standardised hospital separation rate for the diagnosis of diabetes, in conjunction with coronary heart disease or stroke as additional diagnoses, is estimated to be 2.9 per 1,000 persons in 1996–97. The rate is higher among males than females.

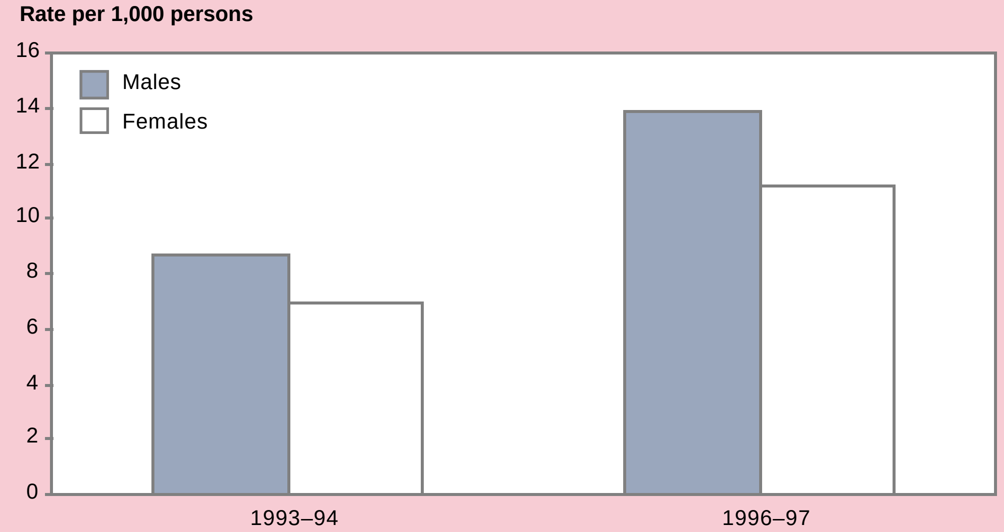
Time trends

- A significant increase (more than 38 per cent) has been noted in the proportion of separations with diabetes and coronary heart disease or stroke as co-diagnoses between 1993–94 and 1996–97. This contrasts with limited increase in separation rates during that period for coronary heart disease or stroke as listed diagnoses, irrespective of whether diabetes was a diagnosis or not.
- A greater propensity to code diabetes as one of the diagnoses may account for this trend. Changes in the pattern of incidence and prevalence of coronary heart disease and stroke, combined with population ageing, may have also contributed to increase in diabetes as an associated diagnosis.

Data issues

- The validity of using hospital separation data to assess the extent of morbidity associated with diabetes has been questioned. This is mainly because the presumption that every hospitalisation for persons with diabetes should have the condition listed as a comorbid diagnosis is met varyingly.
- Under-reporting of hospital separations of people with diabetes is likely to occur. In a large proportion of pertinent cases, it is likely that diabetes is not listed as a diagnosis. The extent of this under-reporting in Australia has not been established.
- The indicator has not been designed to provide information on the proportion of persons with diabetes who are hospitalised for cardio-vascular disease-related problems. This is because of the limitation of the hospital separation data — it is episode-based, rather than individual-based.
- Another major limitation of hospital separation data in respect of diabetes is the coding bias. For example, diabetes is likely to be classified as a principal diagnosis in less than one out of twelve hospital separations (8.6 per cent in 1996–97) that list diabetes as one of the diagnoses.
- In contrast, coronary heart disease or stroke are more likely to be listed as primary diagnosis, in more than three-quarters of hospital separations (76.3 per cent in 1996–97), if two conditions are listed as one of the diagnoses.
- Nonetheless, this indicator, in combination with NHS information, provides a useful profile of cardiovascular disease morbidity among persons with diabetes.

Indicator 4.3: Hospital separation rates for conditions other than end-stage renal disease and coronary heart disease/ stroke for persons for whom diabetes was reported as the principal diagnosis or an additional diagnosis



Population group	Year 1993–94	1996–97
Males	8.7	13.9
Females	6.9	11.2
Persons	7.7	12.4

Note: Rates, age standardised to the 1991 Australian population, are given as separations per 1,000 persons.

Source: AIHW National Hospital Morbidity Database.

- Persons with diabetes are hospitalised more often than those without diabetes. Both Type 1 and Type 2 diabetes lead to conditions that require hospitalisation more often.
- According to the 1995 NHS, respondents with diabetes are admitted to hospital, based on episodes during the two weeks prior to the interview, at a rate of 19 per 1,000 persons.
- This rate is almost three times the rate reported by those without diabetes, 7 per 1,000 persons (ABS 1997b). While a substantial proportion of this difference is caused by end-stage renal disease and cardiovascular disease problems, the rate is high in respect of several other conditions and problems as well.
- In addition, persons with diabetes visit a hospital day clinic at more than twice the rate. Most of this difference is accounted for by visits in relation to the management of diabetes and its complications.
- Because of the limitation of the hospital separation data — episode rather than individual based — it is not possible to generate hospital-based information on an individual basis. However, an indicator can be designed to indirectly capture information on morbidity associated with diabetes from hospital separation data where diabetes is a listed diagnosis.

Operational definition

- This indicator tracks hospital separations where diabetes (ICD-9-CM: 250) is a listed diagnosis, but excludes coronary heart disease, stroke and renal failure as co-diagnoses. Since persons with both Type 1 and Type 2 diabetes are at an increased risk for hospitalisation, no distinction is made between the two types of diabetes.
- For the purpose of this report, the indicator also does not cover the following diseases and conditions: infectious and parasitic diseases, neoplasms, mental disorders, congenital anomalies, injury and poisoning, factors influencing health status and contact with health services (V codes, including visits for dialysis).

Hospital separation rates

- In 1996–97, there were 241,146 separations where diabetes is listed as a co-diagnosis, accounting for 6.1 per cent of all separations for other conditions excluding end-stage renal disease and coronary heart disease/stroke.
- This proportion increases steadily from about 1 per cent for the 20–24 years age group, to about 12 per cent in the 60–64 years age group, and remains high. The female age-specific separation rates stagger the male rates by about a five-year cohort.
- Almost one out of twelve males admitted to a hospital had diabetes as an additional diagnosis. The proportion was much lower among females.
- Age-standardised rate for hospital separation in 1996–97 for diabetes listed as a diagnosis in conjunction with other diagnoses is estimated to be 12.4 per 1,000 persons. The rate is greater among males, more than 24 per cent higher than the rate among females.

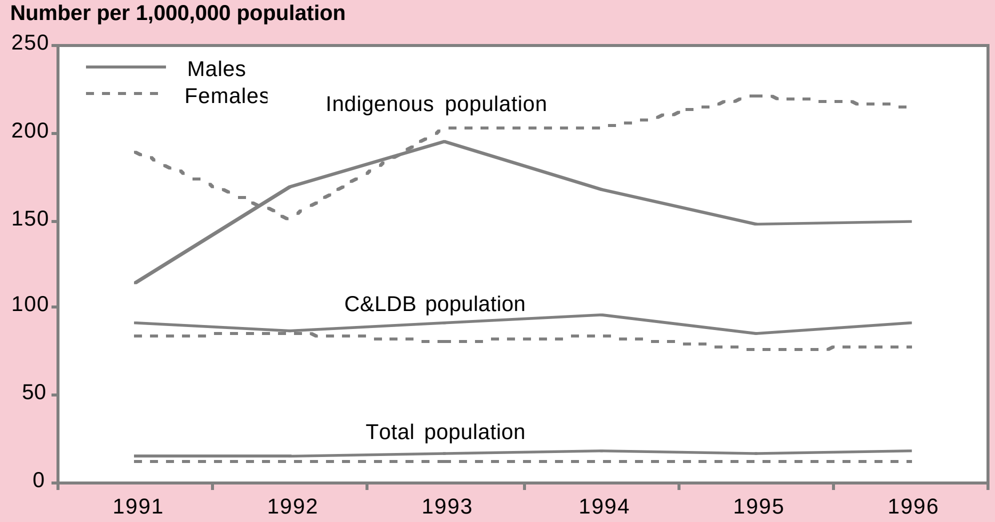
Time trends

- The number of separations where diabetes is a co-diagnosis increased by more than 60 per cent between 1993–94 and 1996–97. The rate of growth was much higher than for all diagnoses (excluding the ones listed earlier), less than 12 per cent during the same period. These differences in growth rates mostly reflect a changing propensity to code diabetes as one of the diagnoses.

Data issues

- The validity of using hospital separation data to assess the burden of hospitalisation associated with diabetes has been questioned. This is mainly because the presumption that every hospitalisation for persons with diabetes should have the condition listed as a comorbid diagnosis is met varyingly.
- Accordingly, under-reporting of diabetes hospital separations is likely to occur. In a large proportion of cases, it is likely that diabetes is not listed as one of the diagnoses. The extent of this under-reporting in Australia has not been established.

Indicator 5.1: Death rates for diabetes in the general population, Indigenous population and among people from culturally and linguistically diverse backgrounds



Population group		Year 1991	1992	1993	1994	1995	1996
Indigenous	Males	114.8	169.0	194.5	167.7	148.1	148.7
	Females	188.3	150.7	203.5	202.2	220.5	215.5
C&LDB	Males	91.7	87.0	91.1	95.9	85.4	91.3
	Females	84.1	85.9	81.2	83.7	75.9	77.1
General	Males	15.8	15.5	16.8	17.8	16.5	18.3
	Females	11.5	12.0	11.9	12.2	11.9	12.3

Note: Rates, age standardised to the 1991 Australian population, are given as number per 100,000 persons. C&LDB = Culturally and linguistically diverse backgrounds.

Source: AIHW National Mortality Database.

- Diabetes, with its complications, is one of the leading causes of death in Australia. It ranked seventh as the primary cause of death in 1996, a rank it has held for many years.
- It also contributes to deaths caused by several conditions and diseases. In particular, diabetes is known to contribute to deaths caused by cardiovascular disease and renal problems.
- Premature mortality is a hallmark of diabetes. Death rates among Australians with diabetes are more than twice as high as in comparison to the rate in the general population. The death rate ratios are in particular high among Indigenous people.
- Statistics suggest that more than one-seventh of persons with Type 1 diabetes will die by the age of 40 years, at which time the death rate ratio will be more than 20 in comparison to the rate in the general population (Portuese & Orchard 1995).
- Among middle-aged persons with Type 2 diabetes, life expectancy is estimated to be reduced by 5–10 years (Geiss et al 1995). Reduction in life expectancy is greater for those with complications, but decreases with increasing age at diagnosis.

Operational definition

- This indicator has been designed to generate a comparative picture of diabetes-associated mortality in Australia over time.
- Although death rate is an indicator of the net impact of diabetes and its associated complications, in the absence of reliable information on diabetes as an underlying cause of death, this indicator focuses on diabetes (ICD: 250.0–250.9) as the primary cause of death.
- Two major population groups covered by the indicator are the Indigenous population and persons with a culturally and linguistically diverse background, known to have high prevalence of the condition.
- Sex-specific information is also generated to emphasise differences in mortality patterns, in death rates between males and females with diabetes as well as in mortality ratios in comparison to those without diabetes.
- No distinction is made between the various forms of diabetes.

Death rates

General population

- In 1996, diabetes was cited as the underlying cause of 2,991 deaths in Australia, accounting for 2.3 per cent of deaths from all causes. It was the seventh leading cause of death that year, with an age-standardised rate of 16 per 100,000 persons (ABS 1997c). The rate is almost 50 per cent higher among males than females.

Indigenous population

- Death rates from diabetes are much higher among Indigenous people, with age-standardised rates of 149 per 100,000 males and 216 per 100,000 females, with rate ratios respectively of 8.1 and 17.5 in comparison to the total population in 1996.
- Diabetes is highly prevalent among Indigenous people, with rates varying between 10 to 30 per cent in some population groups (Colagiuri et al 1998), which contributes to higher death rates.
- The impact of diabetes on the Indigenous population is accentuated further by low survival. According to Phillips et al (1995), the eight-year survival rate among Indigenous people diagnosed with Type 2 diabetes is less than 56 per cent.

Persons from culturally and linguistically diverse backgrounds

- Death rates from diabetes are also much higher among people from culturally and linguistically diverse backgrounds, with age standardised rates of 91 per 100,000 males and 77 per 100,000 females, with rate ratios respectively of 5.0 and 6.3 to the total population in 1996.
- Diabetes is highly prevalent among Micronesians, Polynesians and certain Melanesian Pacific Islanders, migrant Asian Indians and Chinese, some Arab populations, and some European communities, especially those from Southern Europe (McCarty et al 1996).

Time trends

- Dramatic changes have been noted in the pattern of mortality from diabetes this century. After the introduction of insulin in 1920s, not only did the survival rates improve for persons with diabetes but a major shift also occurred in the causes of death, in particular among those with Type 1 diabetes.
- Availability of oral hypoglycaemic agents and other therapies has also contributed to improvement in the survival of persons with other forms of diabetes.
- The impact of the availability of improved therapies on diabetes-associated mortality may now be leveling off. Death rates for diabetes are instead on the rise in Australia. Between 1991 and 1996, the death rate for diabetes increased at a rate of 2.9 per cent annually among males although no change was noted among females.
- The reversal of the trend may be attributed to ageing of the population and increasing incidence of diabetes. An increasing propensity to identify diabetes as the primary cause of death may also contribute to this increase.
- Death rates from diabetes among Indigenous males peaked in 1994, but continue to rise 5.1 per cent annually among Indigenous females.
- The death rate decreased among females from culturally and linguistically diverse backgrounds at an annual rate of 2.2 per cent during 1991–1996 but was stable among their male counterparts during that period.

NHPA indicators for diabetes

Diabetes-associated mortality

- Diabetes contributes to a much larger proportion of deaths than the above figures suggest. The figures given above indicate only the number of deaths directly attributable to diabetes.
- In 1995, for example, there were 8,839 deaths where diabetes is mentioned on the death certificate but is not reported as the underlying cause of death. This number is in addition to 2,708 cases where diabetes is given as the primary cause of death.
- Thus, diabetes could have contributed to almost seven per cent of total deaths, with an age-standardised rate of 49 per 100,000 population that year (ABS 1997c), and even that may be an underestimate.
- Cardiovascular disease is the major cause of death among persons with diabetes (Phillips et al 1990). However, renal disease was the direct cause of death in more than 22 per cent of Indigenous persons with diabetes (Phillips et al 1995), followed by infections (21 per cent) and coronary heart disease (14 per cent).
- The death rate ratio for people with diabetes, in comparison to those without diabetes, is estimated to be around two-fold. For people with Type 2 diabetes, the death rate for people with diabetes has been estimated to be between 20 to 80 per cent higher than for the general population in Western Australia (Knuiman et al 1992; McCann et al 1994). The ratios are higher among people with Type 1 diabetes.

Data issues

- The validity of deaths data in the context of diabetes has been questioned because of problems with sensitivity and specificity of death certificates. The presumption that diabetes should be recorded as one of the causes of death for all persons with diabetes is met varyingly on death certificates. According to Phillips et al (1995), 44 per cent of death certificates in Central Australia make no mention of diabetes.
- The problem is accentuated further with only one underlying (previously known as primary) cause of death coded. Since diabetes contributes to many causes of death, albeit to a variable degree, lack of information on diabetes as an additional cause of death masks its overall contribution to mortality.
- Beginning with deaths reported in 1997, the ABS has commenced coding all underlying causes of death reported on death certificates. This will improve information on the cause-of-death patterns for persons with diabetes. Further improvement is also needed in listing underlying causes of death on certificates.

Indicator 6.1: Self-assessed health status of persons with and without diabetes

Health status	Population group (aged 30 years and over)	Self assessment: Persons with diabetes	Persons without diabetes
Good, very good or excellent	Males	543	827
	Females	626	834
	Persons	605	837
Fair or poor	Males	457	173
	Females	374	166
	Persons	395	163

Note: Rates, age standardised to the 1991 Australian population, are given as number per 1,000 persons.

Source: ABS (1997a).

- A positive feeling of health is linked to resilience and resistance to disease. In the context of a lifelong disease such as diabetes, it not only implies current well being but also presages future management of the disease.
- Several studies during the past decade have revealed negative psychosocial aspects of chronic diseases such as diabetes. Structured diagnostic interviews have revealed increased prevalence of depression among persons with diabetes. There is also evidence that anxiety disorders, in particular generalised anxiety disorder and simple phobia, are more common in this group (Lustman & Gavard 1995).
- It is a prevalent clinical belief that depression and other psychological problems in diabetes are secondary to psychosocial hardship brought on by the chronic nature of the disease and its complications. However, the nature of psychological problems in diabetes is complex, and a range of biological, genetic and environmental factors are likely to contribute to their occurrence.
- Self assessment of health in this context provides a window on an individual's ability to cope with chronic diseases, institute changes in health-related behaviours and react to the newly acquired health risk status. The information is highly relevant to under-standing health-related life-style behaviours and health service utilisation.

NHPA indicators for diabetes

Operational definition

- This indicator compares self-assessed health status of persons with and without diabetes in the general population, using a global measure of health status based on the question:

  In general would you say your health is: Excellent, very good, good, fair or poor?
- Two different categories are considered, namely those rating their health as: 'good, very good or excellent' and 'fair or poor'. In the absence of national data on assessed health status of children with diabetes, the indicator is limited to those aged 18 years and over.

Health profile

- Slightly more than 60 per cent of adults with diabetes, responding to the 1995 NHS question, rate their health as 'good to very good to excellent'. This contrasts with almost 84 per cent of persons who tend to rate their health in that category. While no difference is found between the two sexes, males with diabetes were more likely to report their health as 'fair or poor'.
- Self-assessed health status is age-related, both among persons with and without diabetes. Only five per cent of persons with diabetes aged 18–30 years, most of them with Type 1 diabetes report their health as 'fair or poor'. In comparison, one out of ten persons with diabetes in the age range 55–74 years, report their health as 'fair or poor'.
- SF-36 scores, also generated by the 1995 NHS, support the above results. Those with diabetes and aged 18 years or over had statistically significant lower standardised mean scores than those without diabetes across all eight SF-36 scales. General health and role limitations due to physical health problems reveal the largest differentials (ABS 1997a). For details on SF-36 scales, see Appendix 2.
- The self-assessed health status data are of a subjective nature, ie in the context of health as well-being. Any number of factors that may not be related to health may influence perceptions. However, the more objective assessment of health status using the SF-36 questionnaire confirms the health impact of diabetes.

Data issues

- The health self-assessment question has been included in several national health surveys, including the 1989–90 and 1995 NHS. It is also included in the SF-36 questionnaire. In due course, it may be possible to have time series information for this indicator at a national level.
- On account of small numbers, the NHS data have not been adjusted for several of the factors that may influence the responses. These include level of family income, family composition and other markers of social support.

Appendix 2

Data and statistical issues

Data and statistical issues concerning individual indicators have been described in relevant sections of the report. However, there are several common issues that need to be discussed more generally. These relate mostly to the nature and quality of data, their comparability, timeliness, gaps and deficiencies. Notes on statistical procedures for converting data into useful information, such as age standardisation, estimation of rates and ratios, and life tables, also need to be assembled.

The NHPA *goals and targets* approach has implications for the range of information collected, and its analysis. The adoption of a set of defined indicators requires the development of standard definitions and standardised data elements. The establishment of baselines and appropriate time series for regular reporting are equally important. The data collections may need to be tailored to meet the reporting requirements, or new data collections instituted.

As the diabetes indicators are being reported here for the first time, several data definition and collection issues need to be resolved. This appendix briefly describes some of these issues. For a general discussion of sources, developments and deficiencies in Australian health statistics, see *Australia's Health 1998* (AIHW 1998a).

Data issues

Data sources

Sources of data for monitoring diabetes are wide and varied. Many of the data collections that are used for diabetes monitoring are the by-products of administrative collections (eg deaths and hospital separations). Other collections are specifically designed to monitor the prevalence of diabetes and its complications. Most of the latter collections however are not national in scope or coverage at this stage.

Diabetes-related information for this report was extracted from several national and quasi-national data sources. These include the National Mortality and National Hospital Morbidity databases, the NHS, the National Nutrition Survey, NADC Surveys, ANZDATA and NATSIS. In addition, there are several other data sources that have the potential to yield useful information for diabetes monitoring.

National Mortality Database

Registration of deaths in Australia is the responsibility of the State and Territory Registrars of Births, Deaths and Marriages. Information on the cause of death is supplied by the medical practitioner certifying the death, or by a coroner. Other information about the deceased is supplied by a relative or other person acquainted with the deceased or by an official institution where the death occurred. Registration of death is a legal requirement in Australia, and compliance is virtually complete.

Information on deaths is provided by the Registrars to the ABS for coding of information and compilation into national statistics. AIHW maintains these data in a national database.

Data and statistical issues

Deaths data remain the most comprehensively collected national data pertaining to health. The reliability of these data depends principally on the information listed on the death certificate, or that available in coroners' records, as well as on the reliability of the application of ICD-9 codes by the ABS to that information. In particular, deaths relating to diabetes are substantially under-reported on death certificates as well as in ABS coding which, until 1996, was based on a single underlying cause of death (Phillips et al 1995). The latter issue is now being addressed through multiple cause-of-death coding by ABS (introduced in 1997).

The ABS has also introduced an automated coding system for deaths data.

A further difficulty encountered in using the mortality database is the poor identification of Indigenous people in New South Wales and Victoria, and (until recently) lack of information on Indigenous deaths in Queensland. Analysis of Indigenous mortality for diabetes has therefore been limited to the Northern Territory, Western Australia and South Australia where more than 90 per cent of Indigenous deaths are identified (ABS 1997c).

National Hospital Morbidity Database

The AIHW National Hospital Morbidity Database is a compilation of electronic summary records collected in admitted patient morbidity systems in public and private hospitals. Almost all hospitals in Australia are included. The exceptions are public hospitals not within the jurisdiction of a State or Territory health authority or the Department of Veterans' Affairs (that is, hospitals operated by the Department of Defence, for example, and hospitals located in offshore Territories). In addition, data were not able to be supplied for 1995–96 for the one private hospital in the Northern Territory, the private free-standing day hospital facilities in the Australian Capital Territory and the public psychiatric hospitals in Queensland (AIHW 1998b).

Hospitals collect clinical and administrative information about the patients they treat, including socio-demographic, diagnostic, duration-of-stay data and the procedures performed.

This information is collated, on an inpatient basis, by the various State and Territory health authorities, and by the Department of Veterans' Affairs. The AIHW then receives the collections from these agencies, and maintains them without unique identifiers in a national hospital morbidity database.

A perceived deficiency in hospitalisations data is in the level of identification of Indigenous status on hospital records. This is likely to vary considerably. While the hospital separation rate in 1995–96 for the Indigenous population (440 per 1,000) was much higher than for the overall population (285 per 1,000), large variations among the States and Territories cast doubt on the coverage of Indigenous hospitalisations.

Hospital separations data also have the limitation that they cannot usually be used to identify multiple admissions for the same patient. The feasibility of addressing this problem by linking records is being investigated. The numbers and trends in hospital separations are also affected by differing admission practices, differing levels and patterns of service provision, and changes in coding practices over time.

Diabetes is considered to be under-reported in hospital separations. Not only is diabetes not always listed as the principal diagnosis, it is likely that it is not always recorded as an associated underlying condition. The extent of this under-reporting in Australia has not been determined.

National Health Surveys

The NHS conducted by the ABS provide self-reported information on health risk factors, complications, the use of health services, self-assessed health status, and a range of socio-demographic information. Data on diabetes, its risk factors and its complications are also collected.

Under the NHS, adults (aged 18 years and over) respond for themselves and children aged 15–17 years are interviewed with their consent and with the permission of a parent or responsible adult. A parent, guardian or close relative is interviewed on behalf of children aged 0–14 years.

A recall period of two weeks is mostly used in the NHS to get information on a range of topics including illness conditions, the use of health services, physical activity and smoking. Even with a short recall period of two weeks, some people, particularly older respondents, can under-report information owing to memory lapse.

During the 1995 NHS, recent illness conditions were ascertained using an 'actions-based' approach. The respondents were asked whether they had, in the two weeks before the survey, taken any actions (consultations with doctors and other health professionals, use of medications, hospitalisation, days away from school or work) in relation to their health. For each action taken, the respondents were asked to state the illness condition or the reasons for taking the action. While this approach has its own merits in capturing actions taken for dental and eye problems which are often not perceived as 'illness', many minor conditions for which no action was taken may not have been reported. It is very likely that the respondents only reported those conditions that had a greater effect on them.

Under-reporting of long-term conditions experienced by respondents may also have occurred, particularly in respect of those conditions which are controlled by treatment, recur infrequently or to which respondents have become sufficiently accustomed to no longer consider it an illness. Furthermore, illness conditions that the respondent was reluctant to discuss may have been omitted. Since no clinical tests were carried out to confirm the respondents' claims, the data reflects descriptions of conditions that are probably based on earlier medical diagnosis. Self-reported information is considered to considerably underestimate the true prevalence of certain conditions and illnesses. In particular, diabetes is considered to be highly under-reported in the NHS data, mainly because Type 2 diabetes often remains undetected in the community. The 1995 NHS self-reported information by type of diabetes is also not considered reliable. However, these biases have largely been minimised by the adjustments to assign those who did not know their type of diabetes to a specific category.[6]

6 The ABS designed a technique to incorporate additional self-reported information collected in the survey — ie age at diagnosis of diabetes, type of diabetes treatment and/or medication — to produce more reliable estimates of prevalence by type of diabetes. For example, those respondents who reported they had never been diagnosed with diabetes but currently had high sugar levels in the blood/urine and took insulin treatment for that condition, were included in the alternate estimate. People who reported insulin dependence but were overweight and commenced insulin treatment after the age of 40 were assigned to the category of Type 2 diabetes (ABS 1997b).

Self-reported information is of a subjective nature for many other aspects of diabetes as well. This is particularly the case in relation to collecting weight and height information. Momentary or short-term circumstances can influence the respondent's perception of health, particularly in relation to self-assessed health status. The discussions the respondents had with the interviewers on illnesses and the use of medication may have compelled them to alter their responses on health status (the SF-36 questionnaire was distributed to the respondents before the main interview to overcome the possible bias this could have had on the responses). The presence of others at the time of interview can also affect the responses.

National Aboriginal and Torres Strait Islander Survey

The 1994 NATSIS included about 15,700 Indigenous Australians. The survey collected information on people aged 13 years and over through self reports. For children younger than 13 years, the child's parent or guardian usually provided the information.

The NATSIS collection includes information on diabetes, its risk factors and some of the complications. As is the case with prevalence estimates derived from the NHS, self-reported NATSIS collection may yield lower estimates of the prevalence of diabetes and its complications in the Indigenous population.

National Nutrition Survey

The 1995 National Nutrition Survey obtained information on diet and nutrition of Australians. In addition, the survey collected measured data on body weight, height and blood pressure. The survey was based on a subsample of the 1995 NHS.

The National Nutrition Survey and NHS data can be linked to obtain relevant information on persons with diabetes. However, the National Nutrition Survey sample size for persons with diabetes is too small to yield reliable estimates for most of the indicators.

National Association of Diabetes Centres Survey

The NADC Survey provides annual cross-sectional data on disease incidence, prevalence, risk factors, complications and demographic information from persons attending specialist diabetes service centres. The collection provides a snapshot of the clinical condition of individuals and information on their current status. The data are not representative of all persons with diabetes.

The first data collection was undertaken for a one-month period in March 1998. A standardised dataset, developed by NDOQRIN (including demographic, clinical and biochemical data) was recorded by 30 diabetes centres and three specialist endocrinologists in private practice, in all States.

Integration SERU Survey of General Practitioners

This survey, initiated in 1998, assesses the extent and type of diabetes data collection being undertaken in general practice. Of those Divisions operating a diabetes program, 65 per cent have started collecting practice and patient outcome data, most using a Division-based patient register incorporating the NDOQRIN dataset.

The extent of GP coverage achieved within a Division is influenced by its size, the length of time the program had been operating, the method of data collection used and whether or not incentives for data collection were offered.

The proportion of people with diabetes registered on a Division of General Practice patient register depends on the extent of GP participation in the program and the length of time the program has been operating. Unless adequate GP involvement can be attained, there is likely to remain a large proportion of people with diabetes for whom there is no systematic collection of management or health outcome information.

Australia and New Zealand Dialysis and Transplantation Register

The ANZDATA Register collects data biennially from all dialysis and transplant units in Australia, and maintains records on people who are on dialysis treatment and/or await kidney transplantation or have undergone the operation. The Register dates back to 1977 when the previously separate dialysis and transplant registries were combined. The database contains information such as incidence, primary renal disease, comorbidity, duration of known renal failure, pubertal status and use of growth hormone in children, acute rejection, treatment given and response, quality of life, date and cause of death, and demographic data including country of birth and race.

National Diabetes Register

A National Diabetes Register, based at the AIHW, has been set up to collect information on diabetes in Australia. The register will initially focus on new cases of insulin-treated diabetes. It will keep records of persons using the National Diabetic Services Scheme and the Australian Paediatric Endocrine Group State-based registers as sources of ascertainment. Inclusion in the Register will be voluntary. The data from the register will be used for monitoring national diabetes indicators. The register will also provide information for epidemiological and clinical studies on the aetiology, prevention and complications of diabetes in Australia.

Quasi-national data

Population health surveys have been conducted in some jurisdictions, and are planned in others. These surveys yield estimates of the prevalence of diabetes, associated comorbidity, and those at risk of developing diabetes. A representative survey of adults, conducted by the South Australian Department of Human Services, for example, is a useful source of population-based information on diabetes-related complications and risk factors (Phillips et al 1998).

South Australia has also established a Diabetes Clearing House, to provide timely and relevant information about diabetes to help direct policy and program development. The role of the clearing house includes reviewing and evaluating literature, providing comprehensive epidemiological information and recommending, refining and developing descriptors of diabetes that will be useful in measuring and monitoring health outcomes.

Registers on children and adolescents with Type 1 diabetes exist in all States. A register of patients treated with insulin has existed in Tasmania since 1984.

Data gaps and deficiencies

There are large gaps and deficiencies in the national health information base in relation to diabetes. The existing data sources fail to provide sufficient information for assessing the impact of diabetes on the Australian community and comprehensive surveillance of diabetes nationally. These deficiencies include the following.

- There are currently no national data on screening for diabetes, its incidence, diabetes care, or long-term outcomes of care. Nor is information available by type of diabetes.
- There is a lack of national trend information about diabetes and its complications and a lack of trend data on diabetes-related disease costs.
- Information on disease incidence and prevalence is based on self reports alone. This information is not supported by laboratory-based, diagnostic criteria. In the absence of good quality incidence and prevalence data, it is not possible to reliably assess the magnitude of the problem.
- Information on risk factors is available from sources that fail to cover several important risk factors for diabetes. Little information has been collected on the biomedical aspects of risk factors for diabetes and its complications over the last decade.
- Few data collections are nationally representative, have sufficient numbers from priority populations, use nationally agreed instruments, undertake routine validation of self reports, or include biological measurements.
- There are no agreed definitions for diabetes data elements.
- No linking of records to generate profiles of diabetes management occurs.

This lack of relevant information makes it difficult to assess the effect of public health measures on the development of the disease, or the effect of health services and interventions on diabetes-related complications.

Data development activities

Several data development activities are now in progress, or are being planned, to address some of the issues mentioned above. These activities include the following.

- A set of diabetes indicators for priority reporting has been finalised, and indicators for routine monitoring are currently being developed and refined by the AIHW.
- The AIHW has also developed operational definitions for priority diabetes indicators. These definitions will be refined further following the development of standard definitions for diabetes-related data elements.
- A proposal for a national biomedical risk factor survey that includes blood sampling is being developed under the auspices of the National Public Health Information Working Group. The survey will help generate national estimates of diabetes prevalence.
- Work on monitoring diabetes mortality and morbidity has been initiated by the AIHW, and an outline for a national monitoring system for diabetes is being prepared.

- A Pre-Hospital Emergency Care Survey is being developed to combine State and Territory ambulance service emergency data into a national minimum dataset which will include identification of people with diabetes.
- A Disease Costs and Impact Study is being undertaken by the AIHW, to generate estimates of the direct costs of diabetes. The estimates cover hospital, home, medical, other health professionals and pharmaceutical costs.
- The University of Sydney and the AIHW are collaborating to undertake an annual audit of patients seen, problems managed and the management techniques provided in general practice in Australia. The survey, called BEACH (Bettering the Evaluation And the Care of Health), will also generate useful information on the primary care of diabetes.
- The International Diabetes Institute is planning to conduct a study on the prevalence of diabetes. The study will be conducted in three states — Victoria, New South Wales and Western Australia.
- There is growing support for the coordination of data collection for cardio-vascular disease and diabetes. In South Australia, a state-wide program for secondary prevention of cardiovascular disease and diabetes is under development through the Divisions of General Practice. A combined database, CARDIAB, will be available in early 1999 for Divisions undertaking data collection in both diabetes and cardiovascular disease programs.
- A current activity of the NDOQRIN Management Committee is development of standard definitions and measures for diabetes, for inclusion in the *National Health Data Dictionary*.
- Definitions and measurement standards for overweight and obesity have been developed, and standards for smoking and physical activity are being developed under the umbrella of the National Health Information Agreement.
- The process is commencing for developing data definitions of high blood pressure and high cholesterol for use in both epidemiological and health care settings.

Other initiatives to improve diabetes-related data quality

The National Diabetes Outcomes Quality Review Initiative

The National Diabetes Outcomes Quality Review Initiative (NDOQRIN, pronounced endocrine) aims to promote the collection and management of nationally standardised clinical diabetes information based on a core minimum dataset. The NDOQRIN dataset is being used by the NADC to collect and pool national data on diabetes care and complications in people attending specialist services. The NDOQRIN dataset has been disseminated to all Divisions through the National Divisions of Diabetes Program modules, and Divisions have been encouraged to include the dataset and definitions in their database/register. The indicators in the National Division of Diabetes Program Evaluation Module assume collection of the NDOQRIN dataset.

Indigenous data

Although diabetes is highly prevalent among Indigenous people, there is a lack of reliable information to obtain a national picture. The need to improve the quality of Indigenous health information, including diabetes-related data, has been identified as a national health information priority (AIHW & AHMAC 1995). A plan was presented to the October 1997 AHMAC meeting (AIHW & AHMAC 1998) to address the problem. The plan's major recommendations include:

- development of specific protocols for the sensitive handling of data concerning Indigenous peoples, with the active involvement of communities;
- establishment of permanent and long-term positions for Indigenous personnel, to facilitate substantial improvements in the quality of information;
- ensuring all major health and related collections in all jurisdictions have the capacity to differentiate between Indigenous and other Australians; and
- use of common identification classifications and collection protocols in all major collections.

Representatives from NHIMG and relevant Indigenous health organisations are working together to help implement the plan. The ABS and AIHW have accepted lead roles in working with organisations to implement Indigenous identification in priority information systems. The ABS has this role for vital statistics and AIHW for hospital separations, perinatal data and cancer registrations.

Incentives for data collection

A major issue to be addressed is the question of who collects the data and appropriate, standardised incentives for this collection. Some method of standardising payments for data collection is required. Payment for data collection is ad hoc across jurisdictions. The method used in the South Australian Coordinated Care Trial of providing a capped sum provides a model for wider application.

Minimum dataset for diabetes prevention and care

Data collection is inconsistent within service provider organisations, and within and across jurisdictions. Some diabetes services collect data consistent with the NDOQRIN minimum dataset, while others collect fewer or more data items. In addition, data collection in many diabetes outpatient services is paper-based which impedes analysis.

Among Divisions of General Practice, a range of registers and recall systems have been established. Through the National Divisions Diabetes Program, Divisions have been encouraged to include the NDOQRIN dataset and definitions in their registers. The National Divisions Diabetes Program will work with Divisions and their State-based organisations to facilitate the collation of de-identified data at a State/Territory and national levels. The funding of $50 million over three years for information technology announced as part of the Review of General Practice Strategy should facilitate this process.

Similarly, the commitment of the South Australian, Australian Capital Territory and Queensland Governments to the Community Health Information Management Enterprise (CHIME)[7] initiatives should facilitate the collection of standardised, computer-based diabetes-related data in community health services.

7 The CHIME project will deliver a client-focused operational information system for community-based and ambulatory health services.

Recall systems

Effective long-term care of people with diabetes requires systems for encouraging patients to have regular assessment and screening for complications. A recall system for annual complication screening is planned for Southern Tasmania (Tasmanian Department of Health). Of the 65 Divisions with a diabetes program surveyed by the Integration SERU in August 1998, 75 per cent used their patient registers to recall patients for review by their GP.

The use of pathology laboratories in the collection of data and recall of patients is being trialed in New South Wales by the Central Sydney Division of General Practice. A small number of other Divisions are keen to explore opportunities to collaborate with pathology laboratories in this regard.

Record linkage

The integration or linkage of data across the health continuum is being considered by all jurisdictions in current strategic planning for diabetes. There is support across jurisdictions for the development of 'seamless' data systems that allow all service providers access to complete patient history (eg hospital admissions, medications prescribed, GP interventions, community-based interventions). Record linkage via smart cards or a unique patient identifier is commonly suggested, consistent with the recent recommendation of the Taskforce on Quality in Australian Health Care to pilot patient-held, portable, electronic smart cards (AHMAC 1996).

A number of jurisdictions have recognised the need to identify persons with diabetes, to ensure that they receive diabetes education and screening. There are activities to address this issue in all jurisdictions, raising questions about duplication of effort and whether national coordination would be more efficient.

In Western Australia, the Linked Database Project is a collaborative effort by the University of Western Australia's Centre for Health Services Research and the Health Department of Western Australia, to link health records from different databases from 1980 onwards. Similarly, the Australian Capital Territory is currently looking at developing a central system that all providers can access.

Data linkage is a principle underpinning the Coordinated Care Trials. For example, in the South Australian Coordinated Care Trial, Health Insurance Commission data have been provided by the Commission at the individual patient level. This information is linked to hospital admissions data and will also soon be linked to district nursing, domiciliary care, hospital outpatient and allied health data. Data is supplied to GPs and Care Mentors on a monthly basis on CD-ROM or as hard copy reports and also online through the real-time intranet-based Care Planning On-Line system. The key to this data linkage was a unique indentifier based on patient name, date of birth, gender, Medicare card number and/or Department of Veterans' Affairs number. A new Medicare number was only used for a small number of patients where there was more than one individual listed on the existing card.

There is support among clinicians for Health Insurance Commission data to be provided at patient level. Trials on this data provision are being established with Divisions in New South Wales. The Health Insurance Commission will provide information to GPs in selected Divisions on patients who have had HbA_{1c} tests. Divisions will use this information as the basis for diabetes recall registers.

Data and statistical issues

At the national level, the AIHW is responsible for undertaking a National Health Record Linkage Project. The AIHW's primary role in this project is to define and implement demonstration record linkage projects by acting as a broker for cross-jurisdictional record linkage activities and presenting these results to the community. The AIHW will test the feasibility of this role via a proposed record linkage project involving the Western Australian Linked Database Project, the Health Insurance Commission and the Commonwealth Department of Health and Aged Care. The proposed project will examine patterns of inpatient and community ambulatory care among people with diabetes in Western Australia.

Specifically the project will report on utilisation rates of services according to year and demographic factors, risk of hospital admission and death in relation to intensity of ambulatory care and pharmaceutical interventions and risk of readmission following hospitalisation for complications of diabetes and effects of community-based care. Results will be obtained from linking data from the Western Australian Linked Database (hospital morbidity, mortality) to the National Death Index and the Medicare and Pharmaceutical Benefits Scheme databases. Of particular importance will be an examination of the feasibility of undertaking a similar project in a national context by using the AIHW's National Hospital Morbidity Database.

While there is strong support among clinicians for data to be linked to patients, there is also significant concern among service providers (particularly Indigenous providers) about linking data at any level other than the local level. The benefit of data linkage at regional, jurisdictional or national levels needs to be justified before agreement can be reached on this issue. However, the impetus to link records should come from individuals and health providers, rather than from governments and regulators (Madden 1998).

Data analysis and dissemination

Use of data for decision support

There is strong support for analysed data to be provided to clinicians to inform their practice. This shifting emphasis from data collection to decision-support systems is evident in CHIME, which is underway in Queensland, New South Wales, South Australia and the Australian Capital Territory.

The South Australian Department of Human Services is investigating the broader application of data linkage to decision-support systems, and is embedding guidelines in data systems and including templates for scheduling appointments.

Definitions of terms and measures

Body mass index (BMI)

The BMI is calculated as weight in kilograms divided by the square of height in metres. The scores are grouped into four categories:

<20 kg/m^2 = underweight

20–24.9 kg/m^2 = acceptable weight

25–30 kg/m^2 = overweight

>30 kg/m^2 = obese

Physical inactivity

Information on physical activity is collected by asking the respondents whether, in the last two weeks, they did any walking for sport, recreation or fitness; moderate exercise (apart from walking); and vigorous exercise. Respondents are also asked the number of times they exercised in the reference period and the total amount of time spent on exercise.

The ABS defines, for the purpose of the survey, moderate exercise as exercise or other activities (undertaken for recreation, sport or fitness) that cause a moderate increase in the heart rate or breathing of the respondent. Vigorous exercise is defined as including exercise or other activities (as above) that cause the respondent to perspire and/or increase the respondent's heart rate or breathing.

These definitions of moderate and vigorous exercise levels reflect the respondent's perception of the activity undertaken, level of intensity and their level of fitness.

From the information on frequency, duration and intensity of exercise, an exercise level is derived for each person. The level is based on a score, derived from:

Number of times activity undertaken × Average time per session × Intensity

Intensity values of 3.5 for walking, 5.0 for moderate exercise and 9.0 for vigorous exercise are used to reflect more recent developments in the field of exercise statistics. The exercise level score ranges are:

<100 = sedentary;

100 < 1,600 = low exercise level;

1,600–3,200 or >3,200 and <2 hours vigorous exercise = moderate exercise level; and

>3,200 and 2 hours or more of vigorous exercise = high exercise level.

General health and well being (SF-36)

Indicators for eight dimensions of health are derived from responses given to the questions in SF-36 form the basis of this health assessment. The eight dimensions of health included physical functioning, role limitation due to physical problems, bodily pain, general health, vitality, social functioning, role limitation due to emotional problems, and mental health.

Items and scales for the eight dimensions of health are scored in three stages.

- *Item recoding*, for those eight items in the scale for which the response categories are listed in reverse order. This stage of scoring also incorporates imputation of missing values where possible. The SF-36 scoring rules allow for values of missing items to be imputed if at least 50 per cent of the items for a scale are present. The algorithm used in the imputation process substitutes a person-specific estimate for the missing item — the estimate is the average score across completed items in the same scale for that respondent.
- *Computing raw scores for each dimension*, by summing across component items.
- *Transforming the raw dimension scores to a 0–100 scale*. The formula converts the lowest and highest possible score to zero and 100 respectively; scores between these values represent the percentage of the total possible score which had been achieved (ABS 1996b).

Statistical methods

This section describes all the rates and ratios presented in this report and the methods used to calculate these measures. Most estimates in this report are age standardised to the 1991 Australian Population. However, in some instances both the crude rate and the standardised rate are given. Crude rates and age-specific rates are necessary precursors to deriving age-standardised rates, therefore, information on how to obtain these estimates is also mentioned in this section.

Crude rates

A crude rate is defined as the number of events (eg births, deaths, disease) occurring in a specified period (usually a year) divided by the total average population in the same period (usually 30 June that year). For example, crude death rate in 1998 is the total number of deaths in 1998 divided by the total population at 30 June 1998. The rates are generally expressed as per 1,000 or 100,000 population and can be calculated for males, females, persons or a subset of the population.

Age-specific rates

An age-specific rate is calculated by dividing the number of events occurring in a particular age by the total number of persons at that age. The size of age categories used varies according to the phenomenon studied, but five-year age groups are most common. The rates can be expressed either as per 1,000 or 100,000 population.

Rate ratio

Rate ratios are produced by dividing one number by another when the two numbers are not related in the way necessary for the calculation of a rate. This is useful for comparing the difference between two or more rates, using one as the index. For example, the ratio of diabetes prevalence between the Indigenous and the general population, using the general population as the index, is obtained by dividing the Indigenous rate by the general rate. The result can be expressed as the Indigenous rate being ‘n’ times higher or lower than that of the general population.

Age standardisation

To control for any effects of varying age structures of populations, direct age standardisation is applied to death rates, incidence rates, prevalence rates and hospital separation rates. The total estimated resident population of Australia at 30 June 1991 is used as the standard (Table A2.1).

The usual convention of using age-specific rates for five-year age groups, as shown in Table A2.1, is followed using the following formula:

$$SR = \Sigma \{R_i \times P_i\} / \Sigma P_i$$

where SR = the age-standardised rate;

R_i = the age-specific rate for age group *i*; and

P_i = the standard population in age group *i*.

It should be noted that trends in age-standardised estimates obtained using this standard population might differ from those obtained using another standard population.

Table A2.1 Age composition of the Australian population by sex, 30 June 1991

Age group	Males	Females	Total
0–4	652,302	619,401	1,271,703
5–9	652,418	619,790	1,272,208
10–14	638,311	603,308	1,241,619
15–19	698,773	665,301	1,364,074
20–24	707,124	689,640	1,396,764
25–29	702,728	696,935	1,399,663
30–34	713,784	711,951	1,425,735
35–39	664,228	664,159	1,328,387
40–44	655,138	639,133	1,294,271
45–49	526,498	502,647	1,029,145
50–54	433,762	413,172	846,934
55–59	367,302	358,648	725,950
60–64	366,779	370,089	736,868
65–69	320,142	351,248	671,390
70–74	228,494	282,261	510,755
75–79	158,993	225,502	384,495
80–84	84,413	145,415	229,828
85 and over	44,220	110,027	154,247
Total	**8,615,409**	**8,668,627**	**17,284,036**

Source: ABS.

Acronyms and abbreviations

ABS	Australian Bureau of Statistics
ACCO	Aboriginal Community Controlled Organisation
ACE	angiotensin converting enzyme
ADA	American Diabetes Association
ADEA	Australian Diabetes Educators' Association
AHMAC	Australian Health Ministers' Advisory Council
AIHW	Australian Institute of Health and Welfare
ANZDATA	Australia and New Zealand Dialysis and Transplantation Registry
BMI	body mass index
C&LDB	culturally and linguistically diverse backgrounds
CADS	Community Awareness of Diabetes Strategy
CHIME	Community Health Information Management Enterprise
DCCT	Diabetes Complications and Control Trial
DHHCS	Commonwealth Department of Health, Housing and Community Services
DHSH	Commonwealth Department of Human Services and Health
DHFS	Commonwealth Department of Health and Family Services
GP	general practitioner
HEALTH	Commonwealth Department of Health and Aged Care
HbA_{1C}	glycosylated haemoglobin
MACOD	Minsterial Advisory Committee on Diabetes
NACCHO	National Aboriginal Community Controlled Health Organisation
NADC	National Association of Diabetes Centres
NATSIS	National Aboriginal and Torres Strait Islander Survey
NDDP	National Divisions Diabetes Program
NDOQRIN	National Diabetes Outcomes and Quality Review INitiative
NHF	National Heart Foundation
NHIMG	National Health Information Management Group
NHMRC	National Health and Medical Research Council
NHPA	National Health Priority Areas
NHPC	National Health Priority Committee
NHS	National Health Surveys
NIDDM	non-insulin-dependent diabetes mellitus
NIH	National Institutes of Health (United States)
NPHP	National Public Health Partnership
OATSIH	Office for Aboriginal and Torres Strait Islander Health
RACGP	Royal Australian College of General Practitioners
SERU	Support and Evaluation Research Unit
UKPDS	United Kingdom Prospective Diabetes Study
WHO	World Health Organization

Glossary

Methodology terms

Additional diagnosis: diagnosis of conditions that affect a person's care in terms of requiring therapeutic treatment, clinical evaluation, diagnostic procedures, extended length of hospital stay or increased nursing care and/or monitoring. These include comorbid conditions (co-existing conditions) and complications.

Goal: a general statement of intent and aspiration describing outcomes that might be reasonably achieved in the light of current knowledge and resources. Goals apply to the broad population with priority populations identified when different strategies are required to achieve equitable outcomes.

Health outcome: a change in the health of an individual, a group of people or a population, which is wholly or partially attributable to an intervention or series of interventions.

Indicator: a specific measure for assessing progress towards goals. In terms of health outcomes, an indicator is a statistic or other unit of information which reflects, directly or indirectly, the performance of a health and welfare intervention, facility, service or system in maintaining or increasing the well being of its target population.

Meta-analysis: method used to combine the results of several independent studies to generate firm evidence. It effectively increases sample size and decreases sampling errors.

Patient-centred approach: an approach that requires the active involvement of the patient. It is different from patient education which in the context of this report refers to the one-way imparting of knowledge (eg from health service provider to patient).

Principal diagnosis: the diagnosis established after study to be that chiefly responsible for occasioning the patient's episode of care in hospital.

Randomised controlled trial: an experimental study in which subjects are randomly assigned to treatment and control groups.

Separation: the process by which a patient completes an episode of care that can be a total hospital stay (from admission to discharge, transfer or death) or a portion of a hospital stay beginning or ending in a change of type of care (eg from acute to rehabilitation).

Target: a specific and measurable amount of change in population health gain that could be expected within a given timeframe. Targets are specific to indicators of mortality, quality of life, disability, disease states, risk factors and other aspects of health.

Medical terms

Atherosclerosis: nodular thickening or hardening of the layers in the wall of an artery; characterised by irregularly distributed lipid deposits in the intima of large and medium sized arteries.

Cataracts: clouding of the lens of the eye or its capsule creating reduced vision.

Comorbidity: a concomitant but unrelated pathologic or disease process that indicates co-existence of two or more disease processes.

Coronary heart disease: conditions such as heart attack and angina caused by blockages in the coronary arteries that supply blood to the heart muscle.

Dialysis: a method of removing waste products from the blood when the kidneys are unable to work effectively.

Gangrene: death of body tissue due to a lack of blood supply.

Glaucoma: a group of diseases of the eye resulting in pathological changes in the optic disk and typical visual field defects and eventually blindness if not successfully treated.

Glucose: the main sugar that the body uses for energy. Glucose comes from the breakdown of carbohydrates as well as from the breakdown of glycogen (the storage form of glucose found in the liver and muscles) in the liver.

Glycosylated haemoglobin (HbA_{1c}): the binding of glucose to haemoglobin molecules. Levels of glycosylated haemoglobin provide an indication of the extent of glucose control over an extended period, say two to three months.

Hyperglycaemia: high blood glucose levels (ie above 10 mmol/L).

Hypoglycaemia: a low blood glucose level (ie 3.5 mmol/L or less) due to too much insulin or because not enough carbohydrates were eaten at the correct time. A hypoglycaemic reaction causes unpleasant symptoms of hunger, sweating and confusion.

Impaired glucose tolerance: an abnormality where fasting blood glucose levels and results of oral glucose tolerance tests fall between normal values and those that meet criteria for diabetes.

Insulin: a hormone produced by β cells in the pancreas that helps glucose molecules to enter body cells and be used for energy.

Ketoacidosis: uncontrolled blood glucose and ketone (chemical substances from the breakdown of fats) levels that cause dehydration, concentration of body fluids, build up of acids and coma. This condition mainly occurs in Type I diabetes. The excessive glucose is unable to be used for energy and the body starts breaking down stored fat as an alternative energy source, resulting in build up of ketones in the blood (ketosis) and urine (ketonuria).

Macrosomia: greater body size.

Oral glucose tolerance test: a two-step diagnostic test for diabetes. An initial fasting blood glucose test is followed by another test after a concentrated sugar drink.

Pancreatic β cells: insulin-producing cells in the pancreas.

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