

# Nationwide monitoring and surveillance question development: Diabetes mellitus

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## Introduction

Diabetes is the seventh leading cause of death in Australia (1), contributing significantly to premature mortality, morbidity, disability and potential years of life lost (2). From the 1995 National Health Survey (NHS), it was estimated that 430,700 individuals (2.4 per cent of the total population) reported having been diagnosed with diabetes at some stage in their life, and that a further 300,000 (1.5 per cent of the population) have undiagnosed diabetes (1). In 1996, the Australian Health Ministers declared diabetes as the fifth National Health Priority Area (NHPA), as several of the criteria for priority national attention were met (2). These included:

- high overall burden of the disease in terms of mortality, morbidity and disability;
- potential for health gain through prevention of the disease or lessening its impact
- existence of cost-effective interventions; and
- disproportionate impact upon certain segments of the population.

There are three main types of diabetes:

- Type 1 diabetes – Insulin dependent diabetes, occurs when the pancreas gland no longer produces enough insulin to convert glucose into energy. This type represents approximately 15 per cent of all cases of diabetes.
- Type 2 diabetes – represents approximately 85 per cent of all cases of diabetes and is known to be promoted by lifestyle factors such as lack of exercise, and unhealthy diet contributing to obesity. Occurs when the pancreas is not producing effective insulin.
- Gestational diabetes – it occurs in at least six per cent of pregnancies, increasing the risk of pregnancy complications (6).

Diabetes is the most common cause of end-stage renal disease, of new onset blindness in the working age population, and of lower limb amputations, and a noted risk factor for cardiovascular disease (10). Diabetes and its complications (cardiovascular, kidney and eye diseases) were estimated to contribute to 2.2 per cent (approximately \$681 million per annum) of the total health system costs in the period from 1993-1994 (2).

This discussion paper examines a number of issues related to diabetes and the instruments that have been used to measure diabetes in the population. In particular, the paper looks at health surveillance data collection.

## **What Should Be Measured?**

The measurement of diabetes and the detail included in any data collection clearly relate to the purpose of the collection. A number of issues are related to this, including:

- Should we be including all six National Health Priority Areas Indicators for diabetes?
- Should coverage of the population be restricted to adults only (over 18 years) or expanded to cover young people, adolescents and children?
- Is diabetes worth measuring without conjoint information on physical activity or obesity?
- Can point-in-time measurement be enhanced to give incidence, providing some data towards pictures of peoples' lifetime management of diabetes?
- What kind of comparability is required of the measuring instruments (intra-population, international, cross-cultural, over time)?

## **Purpose of Measuring Diabetes**

A number of questions related to diabetes measurement need to be answered.

- What is the purpose of measuring diabetes in a population survey?
- What is it we want to measure?
- With what do we want to compare the answers?

The answers to these questions include the following:

- To assess population risk factor prevalence over time.
- To provide evidence for outcomes-based research into diabetes.
- Using internationally agreed questionnaires and other instruments and measures to provide international comparability.
- To document the effect of health promotion activities (and other items such as changes in the built environment) directed at changing population behaviours.
- To improve population benchmarking.
- For longitudinal tracking as the population moves through different age cohorts.
- To keep the issues in the public eye.
- To allow targeting of sub-populations.
- To assist in tailoring intervention materials or programs aimed at behavioural change.
- To monitor specific population-wide goals.
- To provide information to professionals (eg, General Practitioners) on health promotions and/or interventions that work.

- For monitoring the relationship with other key risk factors (such as overweight, physical inactivity).
- To identify areas to invest in (eg, physical activity).
- To better predict populations at high risk.
- To examine environmental factors that may enhance or impede peoples' ability or desire to engage in (more) physical activity or maintain a good nutritional status.

## **Population Surveillance Concepts**

Public health surveillance of diabetes and its complications is critical for increasing the recognition of the disease, identifying high-risk groups, developing strategies to reduce the economic and human cost of this disease, formulating health care policy, and evaluating progress in disease prevention and control (4).

Analyses and assessments of health are moving into whole-of-population models and including information on non-medical factors (ethnicity, gender) and 'health related behaviour' (20). The population risk factor surveillance model implies that personal behaviours can influence peoples' health status. A number of lifestyle risk factors are known to increase the risk of developing diabetes, including obesity and physical inactivity. The risk of developing Type 2 diabetes is approximately five to ten times greater in obese individuals than in those with an acceptable weight, and the risk of developing diabetes is 30 to 60 per cent lower among regular exercisers (2). Additional modifiable risk factors include income inadequacy, smoking and hypertension (10). There is strong evidence that diabetes could be prevented by reducing or preventing cardiovascular risk factors (4). This can be achieved through the promotion of physical activity, weight control, smoking prevention and cessation, hypertension prevention and blood pressure control, and lipid and glycaemic control.

## **Scope**

As with any self-reported data there are limitations. Survey data based on self-reported diabetes are limited as about half of persons with diabetes do not know they have the disease (9). This can have major implications when planning diabetes services. Survey data do not detect people with undiagnosed diabetes unless a blood sample is taken (10).

A study, undertaken in Finland, assessed the agreement and validity of a self-administered questionnaire on selected chronic diseases with information documented in medical records. The

results showed there to be substantial agreement on the occurrence of diabetes. However, the prevalence of diabetes based on questionnaire responses was lower than that recorded in medical records when based on both definite and possible diagnosis and higher when based on definite diagnosis alone. This high level of agreement was shown for a number of chronic conditions/diseases that have clear diagnostic criteria and are easily communicated to patients (22).

For a large proportion of individuals that had been diagnosed with Type 1 diabetes, answering questions concerning their disease are often straightforward. Type 1 diabetes affects the life of the individual considerably, unlike Type 2 diabetic patients who often have less pronounced symptoms, have an easier treatment and their mean age is greater (16). For these individuals the risk of misunderstanding or answering questions concerning diabetes incorrectly is increased. A number of diabetic patients who's condition is managed by diet often believe that they no longer have the disease, thus in order to avoid this misunderstanding the question that is often used is 'Do you have or have you had diabetes?'

A number of frequently asked questions in national health surveys are interpreted differently across cultural groups (5) and even among cultures. A study undertaken by Johnston et al. looked at label preferences for the disease diabetes mellitus across cultures. The study revealed, that overall 88.3 per cent of Americans preferred the term "diabetes" and the remaining 11.7 per cent selected other labels, including "sugar diabetes", "sugar", or "high sugar". **Table 1** shows that African Americans were more likely to prefer labels other than "diabetes" than non-Hispanic whites. A similar analysis was conducted for the term "hypertension". From this analyses the label "high blood pressure" was endorsed 78.8 per cent of the time, while the term "hypertension" was preferred 17.3 per cent of the time (11.3 per cent for Mexican Americans compared with 18.8 per cent for non-Hispanic whites).

**Table 1. Responses to disease label probes by cultural group (percentages)**

Probes	African American	Mexican American	Puerto Rican	Non-Hispanic white
[a] “Next I’d like to ask you about a disease that is referred to by many names. Please look at this card and tell me which name you would call it. [diabetes, sugar diabetes, sugar, high sugar, something else (specify)].”				
[b] “Now please look at this card and tell me which name you would actually call this problem. [high blood pressure, hypertension, high blood, something else (specify)].”				
[a] Selected “diabetes”	81.7	90.3	87.6	93.6
[b] Selected “hypertension”	25.7	11.3	13.1	18.8

Source: Centres for Disease Control and Prevention, 1996

In South Australia, there is evidence to suggest that diabetes has been underreported in surveys such as the SERCIS and Health Omnibus Surveys due to label preferences (14). Rather than diabetes, some people believe they have ‘a touch of sugar’ or ‘high blood sugar’. As a consequence of label preferences, an additional question on diabetes was included in the 1998 Health Priority Areas Survey. This question asked respondents who did not answer yes to having been told they have diabetes as to whether they had been told by a doctor that they had ‘high blood sugar’ or ‘a touch of sugar’. It was estimated that the ‘high blood sugar’ prevalence rates for males and females (outside of pregnancy) was 1.7 per cent, indicating that there may be nearly 50 per cent more cases of diabetes in South Australia than previously estimated.

A study undertaken in Pu-Li to compare the prevalence of diabetes in two surveys, suggested that in areas where health awareness and the widespread use of traditional medicine is an issue, it is better to include treatment history of diabetes rather than depending on self-reporting alone (23).

## Population Coverage

Most population-based instruments have focussed on adult populations *per se*, despite the fact that diabetes Type 1 is one of the most common chronic conditions of childhood. Diabetes Type 1 (juvenile diabetes) is likely to have a higher incidence in children under 20 years of age than cancer, cystic fibrosis, multiple sclerosis, juvenile rheumatoid arthritis and muscular dystrophy (19).

The 1995 Australian National Health Survey, however, interviewed persons aged 18 years or over personally, those aged 15-17 years with the consent of a parent or guardian, and obtained

information for persons aged less than 15 years from a person responsible for the child (3). Nationally, diabetes has been measured in the Australian Bureau of Statistics (ABS) National Health Survey (Attachment A), and at a State level it has been measured in South Australia, Queensland, Victoria, Western Australia and New South Wales.

## **Relationship to Other Factors**

Evidence is increasing that in some populations, non-insulin dependent diabetes shares common causal factors with cardiovascular disease and in particular with coronary heart disease (15). In a number of studies from selected populations, an inverse relationship between physical activity level and the risk of subsequent non-insulin dependent diabetes (reported by patients to have been diagnosed by a doctor), has been described (12, 17, 18). It is also well documented that physical inactivity is a risk factor for cardiovascular disease (21). Likewise, obesity is a well-known risk factor for both diabetes and coronary heart disease. These findings emphasize the interrelations between risk factors for non-insulin dependent diabetes and coronary heart disease and the potential value of an integrated approach to the prevention of these conditions based on the prevention of obesity and the promotion of physical activity (13).

## **Diabetes Indicators**

The National Health Information Management Group (NHIMG) Working Party on Health Outcomes Activities and Priorities developed a set of priority indicators for monitoring and reporting diabetes. These indicators (shown in **Table 2**) are likely to be influential, valid and reliable measures for monitoring progress towards better health outcomes in Australia (2).

**Table 2: NHPA Indicators**

Indicator	1998 reporting
<i>1 Disease incidence and prevalence</i>	
1.1 Prevalence rates for Type 1 and Type 2 diabetes in: a) general population; b) indigenous population; and c) among people from culturally and linguistically diverse background.	✓
1.2 Incidence rates for Type 1 and Type 2 diabetes in: a) general population; b) indigenous population; and c) among people from culturally and linguistically diverse background.	✗
1.3 Gestational diabetes among women aged 20-44 years	✗
<i>2 Risk factors for diabetes and associated complications</i>	
2.1 Prevalence rates for obesity and being overweight (as measured by BMI) in: a) general population; and b) among persons with Type 2 diabetes	✓
2.2 Rates for non-participation in regular sustained, moderate aerobic exercise in: a) general population; and b) among persons with Type 2 diabetes	✓
2.3 Prevalence rates for high blood pressure among persons with Type 2 diabetes: a) ≥ 140 mmHg systolic and/or 90 mmHg diastolic and aged <60 years; b) ≥ 160 mmHg systolic and/or 90 mmHg diastolic and aged ≥60 years; and/or c) those on medication for high blood pressure	✓
2.4 Prevalence rates for high levels of lipoproteins among persons with Type 1 and Type 2 diabetes: a) total cholesterol above 5.5 mmol/L; and b) high density lipoproteins below 1.0 mmol/L	✓
2.5 Prevalence rates for fasting hypertriglyceridaemia among persons with Type 1 and Type 2 diabetes	✓
<i>3 Diabetes complications</i>	
3.1 Proportion of persons with end-stage renal disease with diabetic nephropathy as a casual factor	✓
3.2 Incidence rate for eye disease among clinically diagnosed persons with diabetes	✓
3.3 Prevalence rate for foot problems among clinically diagnosed persons with diabetes	✓
3.4 Incidence rates for coronary heart disease and stroke in: a) general population; and b) among clinically diagnosed persons with diabetes	✓
<i>4 Hospital separations for diabetes complications</i>	
4.1 Hospital separation rate for end-stage renal disease where diabetes is an additional Diagnosis	✓
4.2 Hospital separation rate for coronary heart disease or stroke where diabetes is an additional diagnosis	✓
4.3 Hospital separation rate for conditions other than end-stage renal disease and coronary heart disease/stroke among: a) persons with diabetes as primary diagnosis or an additional diagnosis; and b) persons without diabetes as a reported diagnosis	✓

<b>Indicator</b>	<b>1998 reporting</b>
<i>5 Mortality</i>	
5.1 Death rates for diabetes in: a) general population; b) indigenous population; and c) among people from culturally and linguistically diverse backgrounds	✓
5.2 Death rates for coronary heart disease and stroke among persons with diabetes in; a) general population; b) indigenous population; and c) among people from culturally and linguistically diverse backgrounds	✗
<i>6 Health Status</i>	
6.1 Self-assessed health status of persons with and without diabetes	✓
<i>7 Screening and management</i>	
7.1 Proportion of persons with diabetes tested for glycosylated haemoglobin level at least every six months	✗
7.2 Proportion of pregnant women being tested for gestational diabetes	✗

Source: Australian Institute of Health and Welfare, 1998

## **Indicators Suitable for CATI Surveys**

### *1 Disease incidence and prevalence*

Indicators 1.1, 1.2 and 1.3 are suitable for CATI surveys.

Self-reported prevalence rates of diabetes in the general population and among those from culturally and linguistic diverse backgrounds was collected by the ABS in the 1995 NHS. In the 1994 NATSIS, self-reported prevalence rates were collected for Indigenous Australians (2). This information has also been collected from a number of State-based surveys.

Incidence rates have been collected in South Australia from the Health Goals & Targets Health Priorities Area Survey in 1998.

In a number of surveys, to determine the prevalence of gestational diabetes, women are asked whether or not they were pregnant when they were first diagnosed with diabetes.

## *2 Risk factors for diabetes and associated complications*

Indicators 2.1 and 2.2 are suitable for CATI surveys.

The NHS, along with a number of other surveys, collects self-reported height and weight measurements. An individual with a Body Mass Index (BMI, expressed as weight/height squared) of 30 kg/m<sup>2</sup> or more is considered obese.

Questions regarding regular, sustained and moderate aerobic exercise are frequently asked in health related surveys. These questions usually indicate participation levels in physical activity for recreation or fitness purposes over a two-week period.

There are currently no population-based, national estimates of prevalence of high blood pressure among persons with diabetes, based on actual measurements (2). Neither can this information be collected in a CATI based survey, therefore measurements on high blood pressure must rely on self-reports.

## *3 Diabetes complications*

Indicators 3.2 and 3.3 are suitable for CATI surveys.

Eye diseases or conditions that are related to diabetes include vision-threatening retinopathy, cataracts, glaucoma and blindness (2). Currently this information is only being collected by the National Association of Diabetes Centres (NADC) Survey. The NADC survey includes diabetic patients requiring specialist clinical management, therefore it may not give a true picture of eye diseases/conditions in the general community.

Foot problems, including ulcers, gangrene and loss of sensitivity to pain and trauma, along with lower leg amputation are used as the two end-points for monitoring persons with clinically diagnosed diabetes. This information has been collected in the 1995 NHS for lower leg amputation and estimates of foot ulcers are based on the NADC data.

## *6 Health Status*

Indicator 6.1 is suitable for a CATI survey

Respondents of the 1995 NHS and SF-36 were asked how they would say their health is: Excellent, very good, good, fair or poor? This indicator therefore compares people with and without diabetes in the general population as to whether they rate their health as 'good, very good or excellent' or 'fair or poor'.

## International Surveys

The following table outlines a number of international surveys that have included questions on diabetes.

**Table 3: International Surveys**

<b>United States</b>					
<b>Survey</b>	<b>Year</b>	<b>Sample size (weighted pop. Estimates)</b>	<b>Geographical/ population coverage</b>	<b>Age (years)</b>	<b>Definition of diabetes</b>
National Health Interview Survey	1998	107,000	non-institutionalized United States residents	All	Have you EVER been told by a doctor or health professional that you have diabetes or sugar diabetes?
Behavioral Risk Factor Surveillance System	Ongoing	200/month	non-institutionalized United States residents	18+	Have you ever been told by a doctor that you have diabetes?
National Health and Nutrition Examination Survey	Ongoing	5,000 annually	15 U.S. locations a year		{ Other than during pregnancy, { have you/has SP }/{ Have you/Has SP } } ever been told by a doctor or health professional that { you have/{ he/she/SP } has } diabetes or sugar diabetes?
Wisconsin Family Health Survey	1998	2,463 hh annually/ 6,560 persons	stratified random sample of households in Wisconsin	All	.....please tell me whether you or anyone in your household has ever been told by a doctor that they have.....Diabetes?
<b>Canada</b>					
General Social Survey	1985	11,200 (19,669,000)	10 provinces	15+	Do you have diabetes?
General Social Survey	1991	11,924 (20,980,862)	10 provinces	15+	Do you have diabetes?

<b>Survey</b>	<b>Year</b>	<b>Sample size (weighted pop. Estimates)</b>	<b>Geographical/ population coverage</b>	<b>Age (years)</b>	<b>Definition of diabetes</b>
National Longitudinal Survey of Children and Youth	1994/95	22,831 (4,673,390)	Provinces and territories; diabetes question asked of only women with children under 2 years of age	NA (mothers)	During pregnancy, did you suffer from pregnancy diabetes?
National Pop. Health Survey Institutional	1995	2,287 (227,842)	10 provinces; all long- term residents of selected health care institutions	12+	Do you have diabetes that has been diagnosed by a health care professional?
National Pop. Health Survey-cross- sectional	1994/95	17,011 (23,948,603)	10 provinces; no Indian reserves	12+	Do you have diabetes that has been diagnosed by a health care professional?
<b>Hawaii</b>					
Hawaii Health Survey	1996	12,923	Statewide households (4,382), the respondent was the person who was most knowledgeable about their household	18+	Has anyone in the household been told by a physician or medical professional that they have diabetes?
<b>Norway</b>					
The Nord-Trondelag health survey	1984-86	76,885	all inhabitants	20+	Do you have any of the following diseases.....Diabetes?
<b>England</b>					
The Health Survey for England	1993 onwards	19,654 (1998)	representative sample living in private households in England.	2+	Do you now have or have you ever had Diabetes?
National Survey of Physical Activity and Health	1991	4200	112 parliamentary constituencies	adults	Have you ever had any of the following....Diabetes?
<b>Wales</b>					
The Welsh Health Survey	1995	50,000	Electoral role	adults	Do you have Diabetes/

In addition to the core questions asked in the Behavioural Risk Factor Surveillance System (BRFSS), an optional module (see **Attachment B**) on diabetes can be asked at each states discretion. The National Health and Nutrition Examination Survey (NHANES) (see **Attachment C**) also ask additional questions on diabetes that covers most of the indicators that are suitable in CATI surveys.

## **International Surveillance**

The Centres for Disease Control and Prevention (CDC) has established an ongoing surveillance system that collects, analyses and disseminates national data on diabetes and its complications. The data, although representative, tends to be insufficient for analysing national trends among minority groups (4). This is of particular concern, as many studies show that minority populations are disproportionately affected by diabetes (7, 8, 10, 24, 26).

Since 1996, the National Diabetes Surveillance System (NDSS) has been committed to improving surveillance of diabetes at the national, provincial/territorial, and community levels (including Aboriginal people) to monitor the human and economic burden of diabetes in the Canadian population. The data will be used to provide accurate baseline data on the prevalence and incidence of diabetes and its complications, identify high risk groups/areas and to identify change, to assist health professionals in the planning of diabetes prevention and control programs. Through the partnerships with Aboriginal groups and government, the NDSS has the potential to provide diabetes information concerning Aboriginal Peoples living off-reserve or using health services off-reserve, and to be coordinated or integrated with other Aboriginal data information systems (11).

## **Current Data Limitations**

- about half the people with diabetes are not aware that they have the disease
- most samples do not include persons in institutional settings, however it is these people that are more likely to have diabetes
- information collected is not verified
- respondents may not remember essential information
- the same question may not mean the same thing to different respondents

- proxy respondents are likely to underreport diabetes
- the sample does not include any households without telephones
- prevalence data is based on self-report, which may lead to over or under reporting
- there is no standardisation of diabetes data collected from different sources in Australia (2)

## **Improving Data Development and Information Systems**

The NHPA Report outlines several ways in which national data concerning diabetes could be improved in order to assist in the development of health planning and resource allocation. These include:

- Development of standard definitions for each aspect of monitoring would enable consistent information to be collected by the various diabetes health service providers, and outcomes to be evaluated in relation to health service utilisation.
- Inclusion of agreed diabetes fields into existing national minimum datasets is essential to obtain timely and accurate data.
- Surveys and other data collection instruments are required to determine and monitor the incidence and prevalence of diabetes in the general population and in special population groups.
- A mechanism that promotes data linkage across service settings has the potential to increase efficiency and improve diabetes health outcomes and should be investigated in the short term. National coordination of record linkages is desirable as currently there is some duplication of effort across jurisdictions.

## **Conclusion**

Public health surveillance on diabetes provides an opportunity to examine which population groups are most at risk, thus providing a basis for the development of timely and appropriate preventive and treatment programs. This information is also used to provide guidance in allocating resources to satisfy current and future needs for diabetes-related health services (25).

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## Attachment A

### National Health Survey Questions on diabetes

417. HAVE YOU EVER BEEN TOLD BY A DOCTOR OR A NURSE THAT YOU HAVE -
- DIABETES? ..... 1
- HIGH SUGAR LEVELS IN YOUR BLOOD OR URINE? ..... 2
- Neither ..... → Q. 435 3
418. DO YOU CURRENTLY HAVE (DIABETES/HIGH SUGAR LEVELS)?
- Yes ..... 1
- No ..... 2
- Don't know ..... 3
419. Sequence Guide
- . If '2' in Q. 417 ..... → Q. 421 1
- . Otherwise ..... → Q. 420 2
420. WHAT TYPE OF DIABETES WERE YOU TOLD YOU HAVE?
- Insulin Dependent Diabetes Mellitus (Type 1) ..... 078
- Non-Insulin Dependent Diabetes Mellitus (Type 2) ..... 079
- Diabetes Mellitus Type Unknown ..... 093
- Other (*Specify*) ..... 990
- ..... 990
- Don't know ..... 093
421. AT WHAT AGE WERE YOU FIRST TOLD THAT YOU HAVE (DIABETES/HIGH SUGAR LEVELS)?
- Years .....
- Less than 1 year old ..... 98
- Don't know ..... 99

422. HAVE YOU EVER BEEN GIVEN DIETARY ADVICE FOR THIS CONDITION?

- Yes ..... 1
- No ..... → Q. 425 2

423. HOW OLD WERE YOU WHEN YOU WERE FIRST GIVEN THIS ADVICE?

- Years .....
- Less than 1 year old ..... 98
- Don't know ..... 99

424. ARE YOU CURRENTLY TRYING TO FOLLOW DIETARY ADVICE MOST OF THE TIME?

- Yes ..... 1
- No ..... 2

425. (APART FROM DIETARY ADVICE) HAVE YOU EVER RECEIVED ANY (OTHER) TREATMENT FOR (DIABETES/HIGH SUGAR LEVELS)?

- Yes ..... 1
- No ..... → Q. 438 2

426. (APART FROM DIETARY ADVICE) HOW OLD WERE YOU WHEN YOU FIRST RECEIVED ANY (OTHER) TREATMENT?

- Years .....
- Less than 1 year old ..... 98
- Don't know ..... 99

427. (INCLUDING DIETARY ADVICE) WHAT TREATMENT OR ADVICE WERE YOU FIRST GIVEN WHEN YOUR CONDITION WAS FIRST DIAGNOSED?

- Insulin .....a 1
- Tablets .....b 2
- Diet .....c 3
- Exercise .....d 4
- Lose weight .....e 5
- Other .....f 6

428. (APART FROM DIETARY ADVICE/EXERCISE/LOSING WEIGHT) ARE YOU CURRENTLY ON ANY TREATMENT FOR (DIABETES/HIGH SUGAR LEVELS)?

- Yes ..... 1
- No ..... → Q. 438 2

429. WHAT TREATMENT ARE YOU CURRENTLY HAVING?

- Insulin .....a 1
- Tablets .....b 2
- Other .....c 3

430. Sequence Guide

- . If code '1' marked in Q. 429..... → Q. 431 1
- . Otherwise ..... → Q. 438 2

431. ARE YOU CURRENTLY HAVING INSULIN INJECTIONS DAILY?

- Yes ..... 1
- No ..... → Q. 438 2



## Attachment B

### Behavioural Risk Factor Surveillance System Optional Modules

#### Module 1: Diabetes

- |    |  |           |
|----|--|-----------|
| 1. | How old were you when you were told you have diabetes?   | (202-203) |
|    | Code age in years [ <b>97 = 97 and older</b> ]   | — —       |
|    | Don't know/Not sure  | 9 8       |
|    | Refused  | 9 9       |
| 2. | Are you now taking insulin?  | (204)     |
|    | a. Yes   | 1         |
|    | b. No  | 2         |
|    | Refused  | 9         |
| 3. | Are you now taking diabetes pills?   | (205)     |
|    | a. Yes   | 1         |
|    | b. No  | 2         |
|    | Don't know/Not sure  | 7         |
|    | Refused  | 9         |
| 4. | About how often do you check your blood for glucose or sugar? Include times when checked by a family member or friend, but do not include times when checked by a health professional. | (206-208) |
|    | a. Times per day   | 1 _ _     |
|    | b. Times per week  | 2 _ _     |
|    | c. Times per month   | 3 _ _     |
|    | d. Times per year  | 4 _ _     |
|    | e. Never   | 8 8 8     |
|    | Don't know/Not sure  | 7 7 7     |
|    | Refused  | 9 9 9     |

5. About how often do you check your feet for any sores or irritations? Include times when checked by a family member or friend, but do not include times when checked by a health professional. (209-211)
- a. Times per day 1 \_\_\_
  - b. Times per week 2 \_\_\_
  - c. Times per month 3 \_\_\_
  - d. Times per year 4 \_\_\_
  - e. Never 8 8 8
  - f. Not feet 5 5 5
  - Don't know/Not sure 7 7 7
  - Refused 9 9 9
6. Have you ever had any sores or irritations on your feet that took more than four weeks to heal? (212)
- a. Yes 1
  - b. No 2
  - Don't know/Not sure 7
  - Refused 9
7. About how many times in the past 12 months have you seen a doctor, nurse, or other health professional for your diabetes? (213-214)
- a. Number of times \_\_\_
  - b. None 8 8
  - Don't know/Not sure 7 7
  - Refused 9 9

8. A test for hemoglobin “A one C” measures the average level of blood sugar over the past three months. About how many times in the past 12 months has a doctor, nurse, or other health professional checked you for hemoglobin “A one C”? (215-216)
- |   |     |
|---|-----|
| a. Number of times [76 = 76 or more]        | — — |
| b. None                                     | 8 8 |
| c. Never heard of hemoglobin “A one C” test | 9 8 |
| Don’t know/Not sure                         | 7 7 |
| Refused                                     | 9 9 |

**If “no feet” to Q5, go to Q10**

9. About how many times in the past 12 months has a health professional checked your feet for any sores or irritations? (217-218)
- |                     |     |
|---------------------|-----|
| a. Number of times  | — — |
| b. None             | 8 8 |
| Don’t know/Not sure | 7 7 |
| Refused             | 9 9 |
10. When was the last time you had an eye exam in which the pupils dilated? This would have made you temporarily sensitive to bright light. (219)
- |   |   |
|---|---|
| a. Within the past month (0 to 1 month ago)   | 1 |
| b. Within the past year (1 to 12 months ago)  | 2 |
| c. Within the past 2 years (1 to 2 years ago) | 3 |
| d. 2 or more years ago                        | 4 |
| e. Never                                      | 8 |
| Don’t know/Not sure                           | 7 |
| Refused                                       | 9 |

11. Has a doctor ever told you that diabetes has affected your eyes or that you had retinopathy? (220)
- a. Yes 1
  - b. No 2
  - Don't know/Not sure 7
  - Refused 9
12. Have you ever taken a course or class how to manage your diabetes yourself? (221)
- a. Yes 1
  - b. No 2
  - Don't know/Not sure 7
  - Refused 9

## Attachment C

### National Health and Nutrition Examination Survey

#### DIABETES - DIQ

DIQ.010 The next questions are about specific medical conditions.

{Other than during pregnancy, {have you/has SP}/{Have you/Has SP}} **ever** been told by a doctor or health professional that {you have/{he/she/SP} has} diabetes or sugar diabetes?

CAPI INSTRUCTION:

IF SP AGE < 12, DISPLAY "HAVE YOU" FOR THE FIRST DISPLAY AND "SP HAS" FOR THE SECOND DISPLAY.

IF SP IS FEMALE AND AGE >= 20, DISPLAY "OTHER THAN DURING PREGNANCY, {HAVE YOU/HAS SP}".

YES ..... 1  
NO ..... 2 (DIQ.050)  
BORDERLINE ..... 3 (DIQ.050)  
REFUSED ..... 7 (DIQ.050)  
DON'T KNOW ..... 9 (DIQ.050)

DIQ.040 How old {was SP/were you} when a doctor or other health professional **first** told {you/him/her} that {you/he/she} had diabetes or sugar diabetes?

CAPI INSTRUCTION:

IF SP AGE < 12, DISPLAY "YOU" FOR THE SECOND DISPLAY.

ENTER AGE IN YEARS

LESS THAN 1 YEAR ..... 666  
REFUSED ..... 777  
DON'T KNOW ..... 999

DIQ.050 {Is SP/Are you} **now** taking insulin?

YES ..... 1  
NO ..... 2 (BOX 0)  
REFUSED ..... 7 (BOX 0)  
DON'T KNOW ..... 9 (BOX 0)

DIQ.060 For how long {have you/has SP} been taking insulin?

\_\_\_\_|\_\_\_\_|\_\_\_\_|  
ENTER NUMBER (OF MONTHS OR YEARS)

LESS THAN 1 MONTH ..... 666  
REFUSED ..... 777  
DON'T KNOW ..... 999

ENTER UNIT

MONTHS ..... 1  
YEARS ..... 2  
REFUSED ..... 7  
DON'T KNOW ..... 9

**BOX 0**  
**CHECK ITEM DIQ.065:**  
  
IF 'YES' (CODE 1) IN DIQ.010, CONTINUE.  
OTHERWISE, GO TO BOX 2.

DIQ.070 {Is SP/Are you} **now** taking diabetic pills to lower {{his/her}/your} blood sugar?  
These are sometimes called oral agents or oral hypoglycemic agents.

YES ..... 1  
NO ..... 2  
REFUSED ..... 7  
DON'T KNOW ..... 9

**BOX 1**  
**CHECK ITEM DIQ.075:**  
  
IF SP AGE >= 20, CONTINUE.  
OTHERWISE, GO TO END OF SECTION.

DIQ.080 Has a doctor **ever** told {you/SP} that diabetes has affected {your/his/her} eyes or that {you/s/he} had retinopathy?

YES ..... 1  
NO ..... 2  
REFUSED ..... 7  
DON'T KNOW ..... 9

**BOX 2**

**CHECK ITEM DIQ.085:**

IF SP AGE >= 40, CONTINUE.

OTHERWISE, GO TO END OF SECTION.

DIQ.090 {Have you/Has SP} **ever** had an ulcer or sore on {your/his/her} leg or foot that took more than **4 weeks** to heal?

YES ..... 1  
NO ..... 2  
REFUSED ..... 7  
DON'T KNOW ..... 9

DIQ.100 During the **past 3 months**, {have you/has SP} had numbness or loss of feeling in {your/his/her} hands or feet, other than from {your/his/her} hands or feet falling asleep?

YES ..... 1  
NO ..... 2 (DIQ.120)  
REFUSED ..... 7 (DIQ.120)  
DON'T KNOW ..... 9 (DIQ.120)

DIQ.110 Has the numbness or loss of feeling been in {your/SP's} hands, feet, or both?

HANDS ..... 1  
FEET ..... 2  
BOTH ..... 3  
REFUSED ..... 7  
DON'T KNOW ..... 9

DIQ.120 During the **past 3 months**, {have you/has SP} had a painful sensation or tingling in {your/his/her} hands or feet? Do not include normal foot aches from standing or walking for long periods.

YES ..... 1  
NO ..... 2 (DIQ.140)  
REFUSED ..... 7 (DIQ.140)  
DON'T KNOW ..... 9 (DIQ.140)

DIQ.130 Has the painful sensation or tingling been in {your/his/her} hands, feet, or both?

HANDS ..... 1  
FEET ..... 2  
BOTH ..... 3  
REFUSED ..... 7  
DON'T KNOW ..... 9

DIQ.140 {Do you/Does SP} **ever** get pain in either leg while {you are/s/he is} walking?

- YES ..... 1
- NO ..... 2 (END OF SECTION)
- REFUSED ..... 7 (END OF SECTION)
- DON'T KNOW ..... 9 (END OF SECTION)

DIQ.150 Does this pain include pain in {your/SP's} calf or calves?

- YES ..... 1
- NO ..... 2
- REFUSED ..... 7
- DON'T KNOW ..... 9