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Session 2 – Invited paper

## ISSUES IN MEASURING THE HEALTH STATUS OF AUSTRALIANS.

Submitted by Australian Bureau of Statistics\*

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# ISSUES IN MEASURING THE HEALTH STATUS OF AUSTRALIANS

# Australia and its people

- 1. Australia's 20 million people live in a country of close to 8 million square metres, most living in cities and coastal areas, around the southern and eastern states. The more remote areas in the centre of Australia are much more sparsely settled, although a significant proportion of Australia's 460,000 Aboriginal and Torres Strait Islander peoples live in these areas.
- 2. With health expenditure increasing in recent years, and most recently measured as 9.3% of GDP there is significant policy and research interest in measuring many aspects of the health of Australia's population. Significant issues being addressed include prevention of illness and health risk factors in our children and youth and the future demands for health services as Australia's population ages. Health information is essential to inform future policy about population health, the health system and the planning and delivery of health services.
- 3. The Australian health system has a diversity of arrangements for planning, funding, delivering and regulating health services which feature a mix of private and public sector involvement. The health system is primarily driven by the national and State/Territory levels of government, represented by the Australian Government Department of Health and Ageing and the State and Territory health authorities. Further information about the different levels of government in Australia, and provision of health services is described in the Australian Year Book, available from www.abs.gov.au.

## **Australia's health information environment**

- 4. Australia has a comprehensive and well used set of health statistics, resulting from a high level of collaboration and cooperation between several government agencies, and the health care delivery sector. While there are many aspects of the national system where health statisticians are keen to see further developments, Australia has a relatively rich and effective health information system. This paper considers the measurement of health status in the major health surveys and administrative collections in Australia. It also considers infrastructure and activities directed at improving the standardisation and integration of health statistical sources.
- 5. Together with the Australian Institute of Health and Welfare (AIHW) and the Australian Bureau of Statistics (ABS), these government agencies play leading roles in the collection and reporting of information on health and wellbeing. Under the National Health Information Agreement, a National Health Information Development Plan sets out agreed national priorities for health information to be considered by the Australian Health Ministers' Advisory Council. A governance structure of health information committees oversees progress against the National Health Informaton Development Plan, and the broad range of health information development activities in Australia. These committees include representatives from the different levels of government, as well as industry groups and private sector service providers.
- 6. The ABS is responsible for a broad range of economic and population statistics. Within it's population and social statistics work program, it conducts a five-yearly population census, compiles statistics of vital events and causes of death from registration systems administered by State/Territory Registrars of Births, Deaths and Marriages, and conducts an extensive range of

household interview surveys, including a number on health and related issues. These include a three yearly National Health Survey, and six yearly surveys of Disability, Ageing and Carers, and Indigenous Health, and a four yearly General Social Survey. ABS undertakes analys is of broad health outcomes such as life expectancy and mortality and morbidity. It also collects and publishes economic performance data from businesses, including those in the health industry.

- 7. The ABS has established national units focusing on statistics related to the Indigenous population, Ageing, and Children and Youth. While these units take a broad scope, health issues feature for all of these population groups.
- 8. The Australian Institute of Health and Welfare is responsible for providing an extensive set of health and welfare statistics and information. It compiles data from systems involved in the delivery of health and welfare services, disease registers, and a wide range of other sources, makes extensive use of health data collected by the ABS, and conducts some surveys. AIHW prepares a major report on Australia's Health every two years for presentation to the Australian Parliament.
- 9. The AIHW and ABS work collaboratively to maximise the consistency, coverage and use of the data that they each produce, to avoid duplication in the activities of the two agencies and where possible, to agree on common priorities.

## Measuring health status - defining what we are measuring

- 10. Before health status can be measured, the concepts and the context for what is being measured need to be defined. Of interest are definitions for health status, determinants of health such as behavioural and biomedical risk factors, and the need for comparison over time, and across population groups.
- 11. Health status can be defined as the presence or absence of disease and disability, or it can be a broader measure of the wellbeing of an individual, or group of individuals. Question modules, which seek information about health conditions and self-reported health status can be used to measure these concepts. In Australian surveys, respondents are often asked if they have ever been told by a doctor or nurse that they have a particular condition. This approach addresses concerns that respondents may self diagnose particular conditions, or be less inclined to report others leading to over and under reporting. Other surveys ask respondents to self-report health conditions, and level of functioning and disability. Data from administrative collections, including data on cause of death and diagnoses while hospitalised are based on information about conditions recorded by clinicians.
- 12. Determinants of health are also important in understanding future changes in health status for individuals, and for population groups. These include behavioural risk factors, such as smoking, alcohol consumption, nutrition and exercise and physical activity, as well as biomedical risk factors such as blood pressure and cholesterol. While difficult to measure in surveys, question modules have been developed which collect information from respondents about each of the behavioural risk factors.
- 13. Change over time, and comparison across population groups are two important areas of analysis that can inform and direct future policy, so it is also important to have consistent

measures of health status for this purpose. There is also a challenge in collecting similar information through different modes and methods and maximising its potential for comparison across different sources. In Australia a wealth of information is collected in surveys and through administrative systems, and considerable efforts are made to ensure that consistent standards are applied to enable comparison wherever possible.

# **Surveys - Australia's approaches**

National Health Surveys

- 14. The Australian Bureau of Statistics has conducted National Health Surveys in respect of 1989/90, 1995 and 2001. Similar surveys were also conducted in the late 1970s and earlier 1980s. With the next survey, which will go into the field in August 2004, the ABS is moving to a program of three yearly National Health Surveys. In developing its health surveys, like its other social surveys, the ABS consults with its users about priorities for topics to be included in the survey. New topics are tested through focus groups, cognitive testing and survey pilot testing, to ensure data reliability, before being included in the survey proper. There are also constraints in terms of survey budgets, and the load that will be imposed upon respondents selected to participate, as well as topic sensitivity.
- 15. Input on content priorities from government policy makers and researchers ensures the relevance of the information collected. Current policy focuses are reflected in the design of the surveys. For example, since the mid 1990s the Australian government has identified National Health Priority Areas (NHPAs), which focus national collaboration on the chronic diseases and conditions that have potential for health gains and improved outcomes for consumers, and that have the support of all jurisdictions. The current National Health Priority Areas are asthma, arthritis, cancer, cardio-vascular disease, diabetes, injuries and mental health.
- 16. The National Health Survey includes tailored questions aimed at collecting information for each of these topics including information about whether the person has ever been told by a doctor or nurse that they have a particular condition, whether the condition is now present, and what medications and treatments are used where relevant. An example of the questions used to collect information on diabetes is included in Attachment A.
- 17. To supplement the specific questions focusing on National Health Priority Areas, additional questions are included to collect information on all other long term conditions. All conditions collected are coded to the International Classification of Diseases, so that prevalence estimates for the widest range of conditions can be produced from the survey.
- 18. As well as self-reported information used to generate prevalence estimates of particular conditions, the ABS also includes specific modules to collect information about general health and well-being. The SF1 has been collected in past and current surveys, and is also used in other social surveys, such as the Survey of Disability, Ageing and Carers (last conducted in 2003), and the General Social Survey (first conducted in 2002). This question asks 'In general would you rate your health as excellent, very good, good, fair or poor'. In the 1995 National Health Survey the longer 36 question module, SF 36, was collected to produce national benchmarks for researchers who include this instrument in their studies. Other questions of this kind include those on health transitions and satisfaction with life.

- 19. In the 2001 National Health Survey a measure of psychological distress was collected using the Kessler 10 module, and this will be retained in the 2004/5 survey. This measure was originally developed by Professors Ron Kessler and Dan Mroczek, for use in the US Health Interview Survey, and was initially used by the ABS in a survey specifically focused on Mental Health and Well-being of Adults which was conducted in 1998<sup>1</sup>. Collecting it in the 2004/5 survey will enable comparison across time, because testing has shown the Kessler 10 to be a stable and robust module for measuring non-specific psychological distress. Further information about the Kessler 10 is provided at Attachment B.
- 20. As well as measuring disease, the National Health Survey also measures key determinants of health such as information about high blood pressure and high cholesterol, exercise levels, tobacco, alcohol, and some indicators of nutrition. Again these modules are tested to ensure that they produce appropriate measures, and are suitable in a self-report survey. There are some limitations in terms of the populations for particular questions. Smoking behaviour is collected for persons aged 18+ only, because of concerns about reliability of responses from persons 15 -17 answering in the presence of a parent, or the ability of respondents to give consistent answers. (It is illegal to supply cigarettes or tobacco products to any person aged less than 18 in Australia.)
- 21. The full forms used to collect information in the 2001 NHS, as well as other information about the survey, are available on the ABS website at www.abs.gov.au/Themes/Health.
- 22. With the move to a three yearly program of National Health Surveys, the ABS is consulting with users to determine the best ways to schedule topics into the surveys. This consultation is focused on how best to expand the range of topics included, taking account of the extent to which measures might change in three years, and including topics that are best measured together. As well consideration is being given to better aligning, where possible, the content collected in the National Health Survey with other topic specific collections run by the AIHW, as well as with health surveys run by individual States and Territories using computer assisted telephone interviews (CATI).
- 23. The ABS also conducts a six yearly Survey of Disability Ageing and Carers, which focuses on activity limitations and participation restrictions resulting from health conditions, and generates the Australian estimates of disability prevalence, as well as use of formal and informal services. Results from the 2003 survey are due for release in mid 2004. Further information about this survey is available on the ABS website at www.abs.gov.au/Themes/Disability.

## Other related Australian surveys

24. To provide information to monitor specific policy objectives AIHW has conducted surveys focusing on particular risk factors, such as drug and alcohol use, including selected illicit drugs (National Drug Strategy Household Surveys) and physical activity (Active Australia

<sup>&</sup>lt;sup>1</sup>Kessler, R.C., Andrews, G., Colpe, L., et al. (2002). Short Screening Scales to Monitor Population Prevalence and Trends in Non-specific Psychological Distress, Psychological Medicine, 32, 959-976.

- surveys). The trends observed in these surveys are generally consistent with those observed over time in the National Health Surveys, although the prevalence levels have varied, partly due to differences in survey scope as well as the survey instrument and methodology. For example, the National Drug Strategy Household Survey covers teenagers aged 14 to 17 years, below the 18 year age cut-off for the National Health Survey.
- 25. Several States and Territories conduct their own regular surveys, using Computer Assisted Telephone Interviews (CATI). These surveys are designed to give broad information on a timely basis. The ABS is working with the jurisdictions, the AIHW and the Australian Government Department of Health and Ageing to develop a set of survey module manuals which can be used to better integrate the information collected, and allow for comparison across states.
- 26. Other related ABS collections include the Household Expenditure Survey (HES), and the General Social Survey(GSS). The 1998-99 HES also collected information on a number and type of disability/health conditions, their severity and the tasks that people required help or supervision with, and onthe range of health and personal insurance cards that people held. In addition it collected information on the tasks that a person had difficulty with even though help was not required, and the severity of restrictions resulting from disability/health conditions. The earlier HES conducted in 1993/94 collected a wider range of information about health conditions and activity restrictions. In 2002 the ABS conducted its first GSS which included a short module on disability, as well as the SF 1 question which asks how people rate their health.

## *Limitations of self reported health status information*

- 27. There are some limitations to the interpretation of self-report data on health status and determinants of health. We know from comparison of objective measures with self-reported data, for example, that people generally underestimate their weight, and overestimate their height. There is also a propensity for people to self diagnose some conditions, such as arthritis, leading to the potential for overstated prevalence estimates for some conditions. This is in part addressed by using questions which ask 'Have you ever been told by a doctor or nurse that you have....', rather than asking simply whether a condition is prevalent. Testing has shown that this produces more accurate prevalence estimates.
- 28. Some conditions and risk factors could perhaps be better measured by collecting physical measures and samples. There have been limited collections of this kind in Australia. Measured height and weight was collected for a sub-sample of the 1995 National Health Survey, along with information in a 24 hour recall nutrition diary. The Australian Diabetes, Obesity and Lifestyle Study (Ausdiab) was conducted from May 1999 through to Nov 2000. This included the collection of physical measurements and samples with a particular focus on the potential risk of diabetes. Response rates for the biomedical measures were low at 27.5%; although 55.2% of eligible adults agreed to have physical measurements. These results indicate the potential for significant non-response bias. Similar response rates were achieved in a 2003 pilot test of an Australian Health Measurement Survey, which was conducted with the involvement of the ABS, the AIHW and the Australian Government Department of Health and Ageing. There are no current plans in Australia to conduct a collection of this kind in the near future.

## Administrative collections - Australia's approaches

- 29. A wealth of information is collected through A ustralia's health administrative systems, usually administered at the State/Territory level of government. With the cooperation of States and Territories, the AIHW coordinates the development of National Minimum Datasets on a range of topics such as hospital morbidity and mental health. These datasets define a minimum number of fields and the classifications which should be used to collect and code these fields, so that national datasets can be compiled. As well, the AIHW collects and manages data from National Disease Registers, such as the National Cancer Register and the National Diabetes Register.
- 30. To support the consistent collection of health data from both administrative sources and household surveys, a National Health Data Dictionary is maintained by the AIHW, with a range of demographic and health data items defined to enable consistency across State/Territory datasets. Where appropriate, health status is coded to similar classifications to those used in the NHS, such as the International Classification of Diseases. Where other classifications, such as the International Classifications on Primary Care (ICPC), and the Australian Diagnostic Related Groups (AN-DRG) are used, generally they can be concorded back to the ICD. The use of standard classifications assists in comparison across collections.
- 31. These datasets provide information about both program performance and the health status of people interacting with different parts of the health system, enabling analysis of service costs, and incidence (new cases) of particular conditions. Although administrative data often have limited demographic information, and are sometimes incomplete in terms of disease history or patterns of service use, they provide a significant amount of information to analyse the health status of Australians.
- 32. Data from such government administrative collections are an important, and at times crucial, source of information about the circumstances of Indigenous peoples interacting with service providers. However, the quality of the information about Indigenous Australians derived from these collections depends, in part, on the quality of the identification of Indigenous people in those systems. One project supported by the ABS and the AIHW is targeting improved administrative data sets. It focussed initially on births and deaths registrations and hospital separations, but has widened in scope to work with a range of agencies on a larger number of important datasets. The work involves encouraging and facilitating the implementation of the ABS standard Indigenous identifier in priority datasets, negotiation on data collection and reporting on the practices and processes utilised by collection agencies.

# National Aboriginal and Torres Strait Islander Surveys

In 2004/5 the ABS will conduct the first National Aboriginal and Torres Strait Islander Health Survey (NATSIHS), with content that overlaps with the 2004/05 NHS and a 2001 Indigenous supplement to the NHS. NATSIHS will have a sample of approximately 10,000 Indigenous adults and children across remote and non-remote Australia. For the 2001 survey Indigenous results were compiled from information for 3,700 Indigenous adults and children across remote and non-remote Australia. They are also available from the 1995 NHS from information for 1,800 Indigenous adults and children across non-remote Australia only.

- 34. National advisory groups on Indigenous information (such as the National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data, NAGATSIHID) advise on ABS's Indigenous statistics work program (including the NATSIHS). Advice is also sought from Indigenous survey reference groups, comprising Indigenous experts, and representatives from government, academia and Indigenous organisations.
- 35. The development of ABS Indigenous surveys also involves substantial and wide consultation with Indigenous peoples so that their values and priorities are reflected in the methodology and content of the surveys. Information papers are sent to hundreds of organisations (the majority being Indigenous organisations such as land councils, medical and legal services, Aboriginal and Torres Strait Islander Commission Regional Councils, special interest groups such as Stolen Generations NT Inc, Indigenous women's groups, and Indigenous local government councils). A range of consultation meetings are held across Australia to discuss the ABS proposals and seek feedback.
- 36. Focus group discussions, involving hundreds of Indigenous A ustralians, are used in further refining survey content, followed by survey testing in both urban and remote areas. Only those questions to which Indigenous people have shown an ability and willingness to provide good quality information are carried into the final survey. Field testing and surveying conducted in discrete Indigenous communities involves consultation with the community councils, and the employment of local community people as facilitators. Some Indigenous Australians have been recruited to the permanent ABS household interviewer panel, with opportunities being pursued to increase those numbers.
- 37. Surveys of the Indigenous population in the non-remote areas of Australia have traditionally used the Census distribution of Indigenous persons across collection districts as a stratified sampling frame. Problems with this frame have included: the dispersion of the relatively small Indigenous population across non-remote areas; the high cost of screening for potential Indigenous residents; the high mobility of the Indigenous population (ie no longer living in the CDs in which they were enumerated on census night); and some tendency (anecdotally reported) for Indigenous residents to decline to acknowledge their Indigenous origin to survey takers as a way of avoiding the respondent burden. The experience in the field has been that the lowest success rate in finding expected Indigenous residents has been in those CDs with the largest numbers of Indigenous residents.
- 38. The potential for bias in areas where there has been less success in finding Indigenous residents has been analysed for the 2001 Indigenous supplement to the NHS, with no bias discernible. A similar analysis will be undertaken for future Indigenous surveys.
- 39. Apart from the high cost of getting to Indigenous communities in remote areas, there are a number of requirements for success in their enumeration, and risks to enumeration. Good liaison with community organisers is essential to obtain support for the surveys, and it has been found that returning to the same communities (with different households being surveyed) maximises the effectiveness of establishing and observing appropriate protocols for collecting information, including the recruitment of local facilitators. However, enumeration can be interrupted, postponed, or cancelled by events such as community violence or a death in the community.

- 40. Some issues are particularly sensitive when surveying Indigenous peoples, with "lead in" questions needed about whether it is satisfactory for the interviewer to proceed with a particular line of questioning. Measuring social and emotional wellbeing is one example, both in terms of the application of western measures to Indigenous peoples, and in a context where these ideas are related to notions of invasion and dispossession and can be distressing for people to talk about with interviewers. No questions on mental health were included in the 2001 Indigenous supplement to the National Health Survey, although they were an important component of the NHS. For the 2004/5 NATSIHS, a module on Social and Emotional Wellbeing (SEWB) is being considered. The development of a SEWB module was initiated after a workshop with a number of key stakeholders, including Indigenous individuals and organisations. That workshop focussed primarily on progress being undertaken by the National Aboriginal Community Controlled Health Organisation (NACCHO) in collaboration with the National Health and Medical Research Council. A module has progressed to dress rehearsal stage through collaboration between NACCHO, ABS and AIHW, and includes 5 'negative' questions from Kessler 10 (including impact measurement), together with positive aspects of well-being derived from the Short Form 12 module (SF12), anger questions drawn from a native American Indian survey, as well as questions about stressors in peoples lives. Indigenous community controlled health services and state/territory health services provide on-demand support for survey respondents who may wish to talk to someone as a result of the feelings raised by answering certain questions about social and emotional wellbeing.
- 41. Particular attention is required to ensure that the concept being sought is interpretable in a remote context, and that the form of language expression is appropriate to capture that concept. Some mainstream concepts, such as western notions of family and household, are not relevant in the context of many Indigenous Australian's lives. Attachment A provides an example of the type of modification that can be required by comparing some of the questions used to collect information on diabetes in the NHS and in the NATSIHS for remote communities.
- 42. Some information about the health status and risk factors for the Indigenous population is also collected in ABS National Aboriginal and Torres Strait Islander Social Surveys (NATSISS). These are six yearly surveys with data content particularly relevant to Indigenous persons. The 2002 NATSISS collected self assessed health status, disability status (level of activity restriction and type of restriction), smoking and alcohol consumption, and the non-medical use of other substances (petrol sniffing and drug use). The 1994 NATSIS (conducted before any national Indigeous health survey had been conducted in Australia) also collected health and disability status, smoking and alcohol use, information on illnesses, types of health conditions, access and attitudes to health services, relative weight, diet and breastfeeding.

# **Issues for other population groups**

*Older people* 

43. ABS social surveys are generally limited in scope to private dwellings. People in institutions, military and diplomatic personnel are generally excluded. As well, because many older people may live in non-private dwellings such as nursing homes, or may be admitted to hospitals for extended periods, they can be underrepresented in social surveys. To address this the ABS includes some Aged Care accommodation in the sample for the Survey of Disability,

Ageing and Carers. Strategies to collect similar information for the National Health Survey may need to be developed in the future.

#### Children and Youth

44. The range of health information of interest for children and youth can vary from the topics of interest for the general population. Some diseases are less relevant to children and youth. And in ABS surveys parents or other guardians are asked to answer for children below 15, which may not always lead to accurate answers. For example, parents don't always know the current height and weight of their children, making it difficult to collect this information as reported in a survey. As well, as has been noted earlier, the collection of information about the illicit activities (such as smoking or alcohol consumption) directly from teenagers, or their parents can be difficult in a household interview situation. The ABS weights up its decision to collect such information, taking account of possible effects that seeking this information could have on the trust of our providers.

## CONCLUSION

- 45. Different measures of health status and determinents of health are collected and published in different ways in Australia, from surveys and administrative collections. This includes information about risk factors and other determinants of health, which may be indicators of the likely health status of the Australian population in the future. While there are some limitations to the self report nature of information collected in surveys, it is seen as fit for the analytical purposes for which it is collected, and can be seen to be consistent with information collected through Australia's administrative collections.
- 46. The ABS uses particular strategies to ensure that the best information is collected about the health of its Indigenous populations, and recent developments have included the development and testing of new modules to measure the social and emotional well-being of Indigenous peoples.

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# Other

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# ATTACHMENT A: EXAMPLE OF SOME DIABETES QUESTIONS

Questions used in National Health	Questions used in National
Survey, and National Aboriginal and	Aboriginal and Torres Strait Islander
Torres Strait Islander Health Survey - non	Health Survey - remote enumeration
remote enumeration	
The next few questions are about	The next questions are about
Diabetes and High Sugar Levels	diabetes or sugar problems
Have you ever been told by a doctor	Have you ever been told by a doctor
or nurse that you have diabetes?	or nurse that you have diabetes or sugar
1. Yes	problems?
2. No	1. Yes 2. No
(Have you ever been told by a doctor	2. 140
or nurse that you have) High Sugar Levels	
in your blood or urine?	
in your crood or urine.	
1. Yes	
2. No	
At what age were you first told that	How old were you when you were
you had Diabetes?	first told that you had (Diabetes or Sugar
	problems)?
1. Enter age in years	1. Enter years
2. Don't know	2. Less than 1 year
	3. Don't know
What type of diabetes were you told	
you had?	
1 Type 1 (Insulin dependent	
1. Type 1 (Insulin dependent Diabetes Mellitus/Juvenile onset	
Diabetes/Type A)	
2. Type 2 (Non Insulin dependent	
Diabetes Mellitus/Adult onset	
Diabetes/Type B	
3. Gestational (pregnancy)	
4. Diabetes insipidus	
5. Other (Specify)	
6. Don't know	
NB. This question is not asked at all	
in the Indigenous Health Survey	D (311 (311 )
Do you currently have diabetes?	Do you still have (diabetes or sugar
1 Vec	problems)?
<ol> <li>Yes</li> <li>No</li> </ol>	1. Yes 2. No
2. No 3. Don't know	2. No 3. Don't know
J. Don t know	J. Don t know

#### ATTACHMENT B: ABOUT THE KESSLER 10

## KESSLER 10

The K10 - is a 10 item scale of nonspecific psychological distress which asks about current negative emotional states. It was developed by Professors Ron Kessler and Dan Mroczek, as a short dimensional measure of nonspecific psychological distress in the anxiety-depression spectrum for use in the US Health Interview Survey. K-10 is not copyrighted so that any agency or organisation can use it for free.

The K-10 is a ten item questionnaire intended to yield a global measure of psychological distress based on questions about the level of anxiety and depressive symptoms in the last 30 days. It contains low through to high-threshold items. For each item there is a five-level response scale based on the amount of time (from none through to all) that a person experienced the particular problem. Each item is scored from 5 for "all the time" to 1 for "none of the time". The maximum possible score is 50 and the minimum possible score is 10, with high scores indicating high levels of distress and low scores indicating low levels of distress.

## **Kessler 10 Questions**

In the past 30 days( 1997 SMHWB used 'In the last 4 weeks'), about how often did you

feel

.... tired out for no good reason?

.... nervous?

.... so nervous that nothing could calm you down?

.... hopeless?

.... restless or fidgety?

.... so restless you could not sit still?

.... depressed?

.... that everything was an effort?

.... so sad that nothing could cheer you up?

.... worthless?

## **Answer Scale**

All of the time 5
Most of the time 4
Some of the time 3
A little of the time 2
None of the time 1

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