National Institutes of Health National Heart, Lung, and Blood Institute National Center on Sleep Disorders Research

Guide to Selected Publicly Available Sleep-Related Data Resources

July, 2006

This Page Intentionally Blank

Table of Contents

Introduction	1
Methodology	3
Key to Summary Matrix Coding	4
Summary Matrix of Sleep Questionnaires	4
Population-Based Studies	5
Selected Large-Sample Sleep Studies	6
Sleep Scales and Questionnaires	6
I. Population-Based Studies	7
A. American Time Use Survey Questionnaire	9
B. Behavioral Risk Factor Surveillance System State Questionnaire	10
C. CDC Pregnancy Risk Assessment Monitoring System 1999 Surveillance Report	. 11
D. Fatality Analysis Reporting System	. 11
E. Framingham Heart Study	. 12
F. Global School-Based Survey 2004 Core Questionnaire	. 13
G. National Asthma Survey, 2003	. 13
H. National Comorbidity Survey, 1990–1992	. 14
I. National Health Interview Survey, 2002	. 15
J. National Health and Nutrition Examination Survey	16
K. National Household Survey on Drug Abuse	. 17
L. National Sleep Foundation, Sleep in America Poll	. 18
M. National Survey of Children's Health, 2003	. 19
N. National Survey of Early Childhood Health	. 19
O. Nurses' Health Study	
P. United Nations General Social Survey, Cycle 12: Time Use	
Q. U.S. Department of Labor, Bureau of Labor Statistics: National Longitudinal Surveys	
R. Department of Veterans Affairs Databases	
S. National Hospital Discharge Survey	23
T. National Vital Statistics System	23
U. Women's Health Initiative	
V. Sleep Heart Health Study (SHHS)	25
W. National Ambulatory Medical Care Survey	. 26
II. Selected Large-Sample Sleep Studies	. 27
A. Corporate British Health Questionnaire	. 29
B. Chronic Fatigue Syndrome and Sleep Assessment	
C. Daytime Sleepiness and Hyperactive Children	
D. Nursing Home Quality Initiative	. 30
E. Older Adults and Arthritis	31
F. Pediatric Sleep Medicine Survey	31
G. Reduction in Tinnitus Severity	
III. Sleep Scales and Questionnaires	. 33
A. A.P.N.E.A. Net: The Apnea Patient's News, Education & Awareness Network—Sleep	
Apnea Questionnaire	35

B. Epworth Sleepiness Scale	35
C. Exempla Healthcare Sleep Disorders Laboratory: Patient Education and Screening	
Questionnaire	35
D. Infant Screening Questionnaire	35
E. Leeds Sleep Evaluation Questionnaire	
F. Maternal Child Supervision Questionnaire, 1961	
G. Parental Interactive Bedtime Behavior Scale	
H. Pediatric Sleep Questionnaire	
I. Sinai Hospital Sleep Disorder Assessment Questionnaire	
J. Sleep Apnea—The Phantom of the Night Questionnaire	
K. Pittsburgh Sleep Quality Index	
L. Stanford Sleepiness Scale	
M. Functional Outcomes of Sleep Questionnaire	

Appendices

- Appendix I. Relevant Questions From Population-Based Studies
- Appendix II. Relevant Questions From Selected Large-Sample Sleep Studies
- Appendix III. Relevant Questions From Sleep Scales and Questionnaires
- Appendix IV. Quick Links to Population-Based Studies, Questions from Large-Sample Sleep Studies, Questions From Sleep Scales and Questionnaires

Introduction

This Page Intentionally Blank

This document summarizes publicly available data resources for sleep-related variables. The majority of the data sources are large, usually random sample surveys conducted by Government agencies. Among these, most are health-related surveys, allowing for analyses of sleep-related variables in relationship to health behavior, health risk factors, and, in some cases, nutrition and certain comorbidities. The resources were obtained through extensive searches of the Internet and medical literature. The document summarizes each data source in terms of type of sleep variables, possible covariates, and data access. It also synopsizes and presents a brief background statement about each survey, as well as specific sleep-related questions. It does not provide data or survey results or analyses.

Methodology

Search Criteria: Using the search terms "sleep," "sleep disorder," "apnea," and others, we queried Web-based search engines, as well as online search engines for scholarly publications (e.g., PubMed, EBSCO, JSTOR, and Science Direct). In addition, all known Government and academic Web sites that contain publicly available data were searched. The references of articles obtained from searches of scholarly publications were reviewed for possible leads to data sources, other publications, or sleep-related questionnaires.

Inclusion Criteria: Any database that had at least one question pertaining to sleep (e.g., amount or self-reported quality), or sleep disorder (e.g., apnea, snoring) were included in the guide. In addition, databases with any sleep-related topic appearing as a possible response to a question (e.g., "treatment of insomnia" as a response to a question asking for reason for seeking alternative medicine therapy) were included. Databases that use International Classification of Disease (ICD) codes for diagnosis were automatically included (e.g., National Ambulatory Study). Typically, most of the databases indexed here are multiyear cross-sectional studies with nationally representative samples.

Recent studies with large sample sizes were also included in a separate section. Typically, these were one-time investigations focusing on specific populations.

This guide also contains questionnaires and scales that were specifically designed to measure sleep-related issues (e.g., quality of sleep, or self-reports of sleep disorders). We did not include instruments that touch on the issue of sleep but are not sleep-specific (e.g., Beck's Depression Inventory, in which lack of sleep appears as one of the symptoms).

The instruments, links to Federal and non-Federal Web sites, citations, and other information contained in this document do not necessarily reflect the official policies of the National Institutes of Health or the Department of Health and Human Services; nor does mention of trade names, organizations, commercial practices, products, or inclusion of any specific survey, questionnaire or instrument imply endorsement of the U.S. Government. Inclusion or reference to any website, survey or questionnaire does not imply endorsement by the National Heart, Lung, and Blood Institute, the National Institutes of Health and U.S. Department of Health and Human Services or imply fitness or applicability for a particular use. The inclusion or reference to any website, survey, or questionnaire does not represent the official views of the Government. Individuals interested in the use of any questionnaire are cautioned to contact the source to determine whether or not the instrument is proprietary or has any restrictions or caveats as to its use.

Key to Summary Matrix Coding

Characterist	tic Code	Description
Groups		Description
A. Sleep	1.	Sleep duration (e.g., number of hours slept on average night, last night, etc.)
Variables	2.	Sleep quality and satisfaction (slept well, did you get enough sleep?)
	3.	Sleep disorder diagnosis (ICD9 or ICD10 codes)
	4.	Self-reported sleep disorder symptoms (snoring, restless legs)
	5.	Self-reported sleep disorder (insomnia, Restless Legs Syndrome [RLS],
	6.	narcolepsy, apnea, etc.) Factors interfering with sleep (asthma)
	7.	Daytime symptoms associated with poor sleep (fatigue, tiredness, etc.)
	7. 8.	Reports of sleep-related problems as reasons for medication/therapies
	9.	Reports of sleep-related problems as reasons for substance abuse
	10.	Sleepiness, fatigue, drowsiness associated with traffic fatalities
	11.	Bedtime (when you go to sleep)
	12.	Sleeping position for infants
B. Risk Facto		Body Mass Index (BMI)
	2.	Smoking, alcohol abuse, substance abuse
	3.	Comorbid medical diagnosis (cardiovascular disease [CVD], hypertension,
		dialysis, diabetes, stroke, asthma, Chronic Obstructive Pulmonary Disease
		[COPD])
	4.	Stress, depression, and other mental health conditions
	5.	Physical activity
	6.	Nutrition
	7.	Work schedules
C. Data Type	1.	Random sample
	a.	National
	b.	State
	C.	Community
	d.	International
	2.	Administrative or discharge data
D. Data Assaul	3.	Convenience sample
D. Data Acces		Public (free open access or nominal charge) Proprietory (including Endore) data acts that must be purchased)
	2. 3.	Proprietary (including Federal data sets that must be purchased)
	ა.	Limited or restricted (including data distribution agreements, e.g., Sleep
		Heart Health Study [SHHS])

Summary Matrix of Sleep Questionnaires

Following is a matrix of the resources found and the characteristics identified. Each resource is addressed individually in the body of the document.

Population-Based Studies

Survey Name	Sleep Variables (A)	Risk Factors (B)	Data Type (C)	Data Access (D)
A. American Time Use Survey Questionnaire, 2004 (p. 9)	11	3,4,5,7	1a	1
B. Behavioral Risk Factor Surveillance System State Questionnaire (p. 10)	2,6,10	1,2,3,4,5, 6,7	1a	1
C. CDC Pregnancy Risk Assessment Monitoring System (PRAMS) 1999 Surveillance Report (p. 11)	12	1,2,3,4	1a	1
D. Fatality Analysis Reporting System (p. 11)	10	N/A	2	1
E. Framingham Heart Study (p. 12)	2,6,8	1,2,3,4,5,6	3	3
F. Global School-Based Survey 2004 Core Questionnaire (p. 13)	10	1,2,3,4,5, 6,7	1d	1
G. National Asthma Survey, 2003 (p. 13)	6	1,2,3,5	1a	1
H. National Comorbidity Survey, 1990–1992 (p. 14)	1,2	2,3,4,5,6	1a	1
I. National Health Interview Survey, 2002 (p. 15)	5,7,8	1,2,3,5	1a	1
J. National Health and Nutrition Examination Survey (p. 16)	2,5,6,7	1,2,3,4,5, 6,7	1a	1
K. National Household Survey on Drug Abuse (p. 17)	2,4,8,9,10	1,2,4	1a	1
L. National Sleep Foundation, Sleep in America Poll (p. 18)	1,2,4,5,7, 10,11	1,2,3,4,7	1a	3
M. National Survey of Children's Health, 2003 (p. 19)	2	1,3,4,5,6	1a	1
N. National Survey of Early Childhood Health (p. 19)	2,6,12	3,6	1a	1
O. Nurses' Health Study (p. 20)	1,2,4,7	1,2,3,4,5, 6,7	1a	2
P. United Nations General Social Survey, Cycle 12: Time Use (p. 21)	1,2,4,5,7, 10,11	4,7	1a	2
Q. U.S. Department of Labor, Bureau of Labor Statistics: National Longitudinal Surveys (p. 22)	2,11	3,4,5	1a	1
R. Department of Veterans Affairs Databases (p. 22)	3	2,3,5,6	2	3
S. National Hospital Discharge Survey (p. 23)	3	N/A	2	1
T. National Vital Statistics System (p. 23)	10	N/A	1a	2
U. Women's Health Initiative (p. 24)	1,2,4,6,7,8	1,2,3,4,5	1a	1
V. Sleep Heart Health Study (SHHS) (p. 25)	1,2,3,4,5,6, 7,8,10,11	1,2,3,4,5	1a	3
W. National Ambulatory Medical Care Survey (p. 26)	3,4,6	1,2,3,4	1a	1

Selected Large-Sample Sleep Studies

Survey Name	Sleep Variables (A)	Risk Factors (B)	Data Type (C)	Data Access (D)
A. Corporate British Health Questionnaire (p. 29)	1,2,7	1,2,3,4,5,6	3	1
B. Chronic Fatigue Syndrome and Sleep Assessment (p. 29)	1,2,3,4,5,7,8	1,7	1c	1
C. Daytime Sleepiness and Hyperactive Children (p. 30)	7,8	4	1c	1
D. Nursing Home Quality Initiative, 2004 (p. 30)	2	4,5,7	1a	1
E. Older Adults and Arthritis (p. 31)	2	3,4	1b	1
F. Pediatrics Sleep Medicine Survey (p. 31)	2,6,7,8,10	N/A	1b	1
G. Reduction in Tinnitus Severity (p. 32)	6	N/A	2	1

Sleep Scales and Questionnaires

Survey Name	Sleep Variables (A)	Risk Factors (B)	Data Type (C)	Data Access (D)
A. A.P.N.E.A. Net: The Apnea Patient's News, Education & Awareness Network—Sleep Apnea Questionnaire (p. 35)	2,4,5,6,7	3,4	N/A	N/A
B. Epworth Sleepiness Scale (p. 35)	7,8	N/A	N/A	N/A
C. Exempla Healthcare Sleep Disorders Laboratory: Patient Education and Screening Questionnaire (p. 35)	1,2,4,5,7,8	2	N/A	N/A
D. Infant Screening Questionnaire (p. 35)	1,2,11	N/A	3	1
E. Leeds Sleep Evaluation Questionnaire (p. 35)	2,7,8	N/A	1a	1
F. Maternal Child Supervision Questionnaire, 1961 (p. 36)	2	N/A	1a	1
G. Parental Interactive Bedtime Behavior Scale (p. 36)	8	N/A	1d	1
H. Pediatric Sleep Questionnaire (p. 36)	2,4,5,6,7,8,11	1,2	N/A	N/A
I. Sinai Hospital Sleep Disorder Assessment Questionnaire (p. 36)	4,5,7	3	N/A	N/A
J. Sleep Apnea—The Phantom of the Night Questionnaire (p. 36)	4,5,6,7	2,3	N/A	N/A
K. Pittsburgh Sleep Quality Index (p. 36)	1,2,4,6,11	N/A	N/A	N/A
L. Stanford Sleepiness Scale (p. 36)	7	N/A	N/A	N/A
M. Functional Outcomes of Sleep Questionnaire (p. 36)	7	N/A	N/A	N/A

I. Population-Based Studies

This Page Intentionally Blank

The instruments, links to Federal and non-Federal Web sites, citations, and other information contained in this document do not necessarily reflect the official policies of the National Institutes of Health or the Department of Health and Human Services; nor does mention of any trade names, organizations, commercial practices, products, or inclusion of any specific survey, questionnaire, or instrument imply endorsement of the U.S. Government. Inclusion or reference to any website, survey, or questionnaire does not imply endorsement by the National Heart, Lung, and Blood Institute, the National Institutes of Health and U.S. Department of Health and Human Services or imply fitness or applicability for a particular use. The inclusion or reference to any website, survey, or questionnaire does not represent the official views of the Government. Individuals interested in the use of any questionnaire are cautioned to contact the source to determine whether or not the instrument is proprietary or has any restrictions or caveats as to its use.

A. American Time Use Survey Questionnaire

Survey Summary			
A. Sleep Variables	11. Bedtime (when you go to sleep)		
B. Risk Factors	 Comorbid medical diagnosis (CVD, hypertension, dialysis, diabetes, stroke, asthma, COPD) 		
	4. Stress, depression, and other mental health conditions		
	5. Physical activity		
	7. Work schedules		
C. Data Type	1. Random sample		
	a. National		
D. Data Access	Public (free open access or nominal charge)		
E. Source	Homepage: http://www.bls.gov/tus/		
	Questionnaire: http://www.bls.gov/tus/tuguestionnaire.pdf		

The American Time Use Survey (ATUS) is a Computer Assisted Telephone Interview (CATI) conducted by the Bureau of Labor Statistics to collect information on how people use their time. It is a nationally representative sample drawn from households completing the Current Population Survey (CPS). The survey asks respondents to report their activities during the 24 hours prior to the interview. Since the respondents are drawn from the sample frame of CPS, demographic and labor force information collected by CPS is added to ATUS.

B. Behavioral Risk Factor Surveillance System State Questionnaire

		Survey Sur	nmary
A.	Sleep Variables	Sleep quality and satisfac	tion (slept well, did you get enough sleep?)
		actors interfering with sl	eep (asthma)
		Sleepiness, fatigue, drow	siness associated with traffic fatalities
B.	Risk Factors	Body Mass Index (BMI)	
		Smoking, alcohol abuse,	substance abuse
		Comorbid medical diagno troke, asthma, COPD)	sis (CVD, hypertension, dialysis, diabetes,
		Stress, depression, and o	ther mental health conditions
		hysical activity	
		lutrition	
		Vork schedules	
C.	Data Type	Random sample	
		. National	
D.	Data Access	Public (free open access	or nominal charge)
E.	Source	epage: http://www.cdc.g	ov/brfss/
Questionnaires: http://www.cdc.gov/brfss/questionnaires/index.htm			dc.gov/brfss/questionnaires/index.htm

The Behavior Risk Factor Surveillance System (BRFSS) is a State-administered survey sponsored by the Centers for Disease Control and Prevention (CDC). It is designed as a primary prevalence monitoring system for a number of risk factors. Typically, the BRFSS is a random sample of State population that therefore tends to overrepresent larger urban centers.

In addition, States are free to add modules to the core survey and add their own questions. Complete historical documentation of modules used by States is provided on the BRFSS Web site. Sleep-related questions appear in Healthy Days, Quality of Life, Quality of Life and Care Giving, and Asthma History modules. Note that Healthy Days is essentially the Quality of Life module renamed. In 2002, "difficulties with sleep" was one of the choices in the Effects of September 11th module. Note that data on sleep is limited by the States that used the module.

C. CDC Pregnancy Risk Assessment Monitoring System 1999 Surveillance Report

	Survey Summary			
A.	Sleep Variables	12. Sleeping position for infants		
B.	Risk Factors	1. BMI		
		2. Smoking, alcohol abuse, substance abuse		
		3. Comorbid medical diagnosis (CVD, hypertension, dialysis, diabetes, stroke, asthma, COPD)		
		4. Stress, depression, and other mental health conditions		
C.	Data Type	1. Random sample		
		a. National		
D.	Data Access	Public (free open access or nominal charge)		
E.	Source	Homepage: http://www.cdc.gov/reproductivehealth/PRAMS/		
		Questionnaire: http://www.cdc.gov/PRAMS/PDFs/1999PRAMSsurv.pdf		

The Pregnancy Risk Assessment Monitoring System (PRAMS) generates statewide estimates of important perinatal health topics among women who have delivered a live infant. The sample is drawn from birth certificates, and samples approximately 100 to 250 women per month. PRAMS covers a number of topics pertaining to pregnancy risk factors, prenatal and followup care, family dynamics, and so forth. The only question relevant to sleep is the position in which a new mother puts the new baby down to sleep.

Please see appendix I for sleep-related questions in this survey.

D. Fatality Analysis Reporting System

	Survey Summary				
A.	Sleep Variables	10. Sleepiness, fatigue, drowsiness associated with traffic fatalities			
B.	Risk Factors	N/A			
C.	Data Type	2. Administrative or discharge data			
D.	Data Access	Public (free open access or nominal charge)			
E.	Source	Homepage: http://www-fars.nhtsa.dot.gov/main.cfm			

Fatality information derived from the Fatality Analysis Reporting System (FARS) includes motor vehicle traffic crashes that result in the death of an occupant of a vehicle or a nonmotorist within 30 days of the crash, based on State accident reports and other State data. The National Highway Traffic Safety Administration (NHTSA) has a contract with an agency in each State to provide information on fatal crashes. FARS analysts are State employees who extract the information and put it in a standard format. The FARS file contains descriptions of each fatal crash reported. Each case has more than 100 coded data elements that characterize the crash, the vehicles, and the people involved. "Being drowsy, sleepy, asleep, or fatigued" is coded as one of the Driver Related Factors. The data are available through an interactive query system. The interface allows for single year tabulations and cross-tabulations. Note that interpretation of the results is somewhat tricky. For instance, "being drowsy, sleepy, asleep, or fatigued" was reported as a driver factor in 1,140 fatal crashes in 2004, out of 54,317 cases, where cases represent drivers involved in 38,253 fatal crashes. FARS-published data files are available in SAS or ASCII formats from ftp://ftp.nhtsa.dot.gov.

Please see appendix I for sleep-related questions in this survey.

E. Framingham Heart Study

			Survey Summary
A.	Sleep Variables	2.	Sleep quality and satisfaction (slept well, did you get enough sleep?)
		6.	Factors interfering with sleep (asthma)
		8.	Reports of sleep-related problems as reasons for medication/therapies
B.	Risk Factors	1.	BMI
		2.	Smoking, alcohol abuse, substance abuse
		3.	Comorbid medical diagnosis (CVD, hypertension, dialysis, diabetes, stroke, asthma, COPD)
		4.	Stress, depression, and other mental health conditions
		5.	Physical activity
		6.	Nutrition
C.	Data Type	3.	Convenience sample
D.	Data Access	3.	Limited or restricted (including data distribution agreements, e.g., Sleep Heart Health Study [SHHS])
E.	Source	Но	mepage: http://www.nhlbi.nih.gov/about/framingham/index.html
		Qu	estionnaire: http://www.nhlbi.nih.gov/about/framingham/ex_forms.htm

The Framingham Heart Study is a longitudinal study of causes of cardiovascular disease. The National Heart, Lung, and Blood Institute (NHLBI) initiated the study in 1948. Originally, 5,209 men and women were recruited from the town of Framingham, Massachusetts, and committed to extensive physical examination and lifestyle interviews every 2 years. In 1971, original participants' children and spouses were recruited for a similar study. Currently, a third cohort (grandchildren of the original participants) is being recruited. The study's Web site outlines procedures for requesting genetic data

(http://www.nhlbi.nih.gov/about/framingham/policies/index.htm) and for conducting ancillary studies (http://www.nhlbi.nih.gov/about/framingham/ancpolicy.htm). Secondary data analysis appears to fall under the latter jurisdiction.

F. Global School-Based Survey 2004 Core Questionnaire

	Survey Summary				
A. B.	Sleep Variables Risk Factors	 Sleepiness, fatigue, drowsiness associated with traffic fatalities BMI Smoking, alcohol abuse, substance abuse Comorbid medical diagnosis (CVD, hypertension, dialysis, diabetes, stroke, asthma, COPD) 			
		 4. Stress, depression, and other mental health conditions 5. Physical activity 6. Nutrition 7. Work schedules 			
C.	Data Type	Random sample d. International			
D. E.	Data Access Source	Public (free open access or nominal charge) Homepage: http://www.cdc.gov/gshs/index.htm Questionnaire: http://www.cdc.gov/gshs/questionnaire/index.htm			

The Global School-Based Student Health Survey samples students ages 13–15 in several countries, and is conducted jointly by the World Health Organization and CDC. It primarily collects data on risk behaviors such as alcohol and drug use, sexuality, and violence, in addition to mental health, hygiene, and physical activity. According to the CDC Web site, data for each country will be made public within 2 years of survey administration, specifying how these data will be disseminated. It appears that the stated 2-year window is unique to each country. The questionnaire is available in both English and French.

Please see appendix I for sleep-related questions in this survey.

G. National Asthma Survey, 2003

	Survey Summary			
Α.	Sleep Variables	Factors interfering with sleep (asthma)		
B.	Risk Factors	BMI		
		Smoking, alcohol abuse, substance abuse		
		Comorbid medical diagnosis (CVD, hypertension, dialysis, diabetes, stroke asthma, COPD)		
		Physical activity		
C.	Data Type	Random sample		
		a. National		
D.	Data Access	Public (free open access or nominal charge)		
Ε.	Source	mepage: http://www.cdc.gov/nchs/about/major/slaits/nsa.htm		
		uestionnaire:		
		p://www.cdc.gov/nchs/data/slaits/revised_nas2003_national_specs.pdf		

According to the National Center for Health Statistics (NCHS) National Asthma Study Web site (http://www.cdc.gov/nchs/about/major/slaits/nas.htm), the study "examines the health, socioeconomic, behavioral, and environmental predictors that relate to better control of asthma. This study explores the content of care and health care experiences of persons with asthma." There are two related studies. The first was a national sample fielded from February 2003 to February 2004, and the second was a four-State sample, fielded from March 2003 to March 2004. In accordance with CATI logic, the sample included households in which someone has asthma and households in which no members have asthma. The study addresses sleep only in relation to asthma interfering with sleep.

Please see appendix I for sleep-related questions in this survey.

H. National Comorbidity Survey, 1990–1992

		Survey Summary
A.	Sleep Variables	 Sleep duration (e.g., number of hours slept on average night, last night, etc.)
		2. Sleep quality and satisfaction (slept well, did you get enough sleep?)
B.	Risk Factors	2. Smoking, alcohol abuse, substance abuse
		3. Comorbid medical diagnosis (CVD, hypertension, dialysis, diabetes, stroke, asthma, COPD)
		4. Stress, depression, and other mental health conditions
		5. Physical activity
		6. Nutrition
C.	Data Type	1. Random sample
		a. National
D.	Data Access	Public (free open access or nominal charge)
E.	Source	Homepage: http://www.hcp.med.harvard.edu/ncs
		Questionnaire:
		http://www.hcp.med.harvard.edu/ncs/ftpdir/Baseline%20NCS.pdf

The stated purpose of National Comorbidity Survey (NCS) is to provide nationally representative prevalence and correlates of the disorders in the American Psychiatric Association's *Diagnostic* and Statistical Manual of Mental Disorders (DSM-III-R). As such, it uses structured research diagnostic interviews to assess the mental health of the respondents. The baseline data were collected from 1990 to 1992 using face-to-face interviews with respondents ranging in age from 15 to 54. The second survey was conducted with the same 10,000 respondents in 2001 to 2002. In 2001, a similar survey (NCS-A) was conducted with a nationally representative sample of adolescents (13–17 years old).

I. National Health Interview Survey, 2002

Survey Summary			
A. Sleep	Variables 5.	Self-reported sleep disorder (insomnia, RLS, narcolepsy, apnea, etc.)	
	7.	Daytime symptoms associated with poor sleep (fatigue, tiredness, etc.)	
	8.	Reports of sleep-related problems as reasons for medication/therapies	
B. Risk F	actors 1.	BMI	
	2.	Smoking, alcohol abuse, substance abuse	
	3.	Comorbid medical diagnosis (CVD, hypertension, dialysis, diabetes, stroke, asthma, COPD)	
	5.	Physical activity	
C. Data	Гуре 1.	Random sample	
		a. National	
D. Data A	Access 1.	Public (free open access or nominal charge)	
E. Sourc	e Ho	omepage: http://www.cdc.gov/nchs/nhis.htm	
	Fa	mily questionnaire:	
	<u>ftp</u>	://ftp.cdc.gov/pub/Health_Statistics/NCHS/Survey_Questionnaires/	
	NI	HIS/2002/qfamilyx.pdf	

The National Health Interview Survey is intended to provide information about the health of the American public. Its sampling unit is a household, from which one adult and one child are interviewed. The survey oversamples African American and Hispanic households. The 2004 survey consisted of over 36,000 households, yielding 94,460 individual respondents.

Since 1996, the survey has consisted of a core module and variable supplements. The core module itself consists of three components: family core, adult core, and children core. Family core collects information about all family members, such as socio-demographic characteristics, activity limitations, basic health indicators, insurance coverage, and access and utilization of health care services. Adult and children cores collect information about individual health issues of sampled individuals. For instance, the adult core questionnaire collects information about health behaviors such as smoking, alcohol use, and sleep.

The variable supplements vary from year to year. In 2002, the National Interview Survey included a battery of questions on use of alternative medicine and therapies. In addition to core questions pertaining to insomnia, sleep-related items were among choices for each alternative medicine/therapy question, specifically on whether an individual uses alternative medicine/therapies for excessive sleepiness during the day or for insomnia/lack of sleep.

J. National Health and Nutrition Examination Survey

	Survey Summary		
A.	Sleep Variables	2.	Sleep quality and satisfaction (slept well, did you get enough sleep?)
		5.	Self-reported sleep disorder (insomnia, RLS, narcolepsy, apnea, etc.)
		6.	Factors interfering with sleep (asthma)
		7.	Daytime symptoms associated with poor sleep (fatigue, tiredness, etc.)
B.	Risk Factors	1.	BMI
		2.	Smoking, alcohol abuse, substance abuse
		3.	Comorbid medical diagnosis (CVD, hypertension, dialysis, diabetes, stroke, asthma, COPD)
		4.	Stress, depression, and other mental health conditions
		5.	Physical activity
		6.	Nutrition
		7.	Work schedules
C.	Data Type	1.	Random sample
			a. National
D.	Data Access	1.	Public (free open access or nominal charge)
E.	Source	Но	mepage: http://www.cdc.gov/nchs/nhanes.htm

The most recent version of the National Health and Nutrition Examination Study (NHANES) ran from 1999 through 2004. The study was a population-based survey designed to provide information on the health and nutrition of the U.S. population. NHANES was a two-part data collection effort consisting of physical examinations of participants and an at home interview. The content of the NHANES questionnaires, type of physical examinations, and target ages of participants are summarized on the NCHS document Web site (http://www.cdc.gov/nchs/data/nhanes/comp3.pdf). There were three previous iterations of NHANES prior to the current version; however, the previous versions contained very few sleep-related questions.

K. National Household Survey on Drug Abuse

		Survey Summary
A.	Sleep Variables	 Sleep quality and satisfaction (slept well, did you get enough sleep?) Self-reported sleep disorder symptoms (snoring, restless legs) Reports of sleep-related problems as reasons for medication/therapies Reports of sleep-related problems as reasons for substance abuse Sleepiness, fatigue, drowsiness associated with traffic fatalities
B.	Risk Factors	 BMI Smoking, alcohol abuse, substance abuse Stress, depression, and other mental health conditions
C.	Data Type	Random sample a. National
D.	Data Access	Public (free open access or nominal charge)
E.	Source	Homepage: http://www.oas.samhsa.gov/nhsda.htm Questionnaire: http://www.oas.samhsa.gov/nhsda/2k1CAI/2001_CAI_Specs_W.pdf

The National Household Survey on Drug Abuse is a representative national sample of U.S. citizens over age 12, yielding a sample size of 68,929. The survey's focus is to assess prevalence of drug use in the United States; however, the survey also collects data on alcohol and tobacco use, mental health, and mental health treatment. Sleep disorders appear in this survey primarily as symptoms of withdrawal, as well as choices for diagnostic questions for mental disorders.

L. National Sleep Foundation, Sleep in America Poll

		Survey Summary
A.	Sleep Variables	 Sleep duration (e.g., number of hours slept on average night, last night, etc.)
		2. Sleep quality and satisfaction (slept well, did you get enough sleep?)
		4. Self-reported sleep disorder symptoms (snoring, restless legs)
		5. Self-reported sleep disorder (insomnia, RLS, narcolepsy, apnea, etc.)
		7. Daytime symptoms associated with poor sleep (fatigue, tiredness, etc.)
		10. Sleepiness, fatigue, drowsiness associated with traffic fatalities
		11. Bedtime (when you go to sleep)
B.	Risk Factors	1. BMI
		2. Smoking, alcohol abuse, substance abuse
		3. Comorbid medical diagnosis (CVD, hypertension, dialysis, diabetes, stroke, asthma, COPD)
		4. Stress, depression, and other mental health conditions
		7. Work schedules
C.	Data Type	1. Random sample
		a. National
D.	Data Access	3. Limited or restricted (including data distribution agreements, e.g. SHHS)
E.	Source	Homepage: http://www.sleepfoundation.org/hottopics/index.php?secid=16
		Questionnaire: http://www.sleepfoundation.org/_content/hottopics/
		2005_summary_of_findings.pdf

The Sleep in America Poll is conducted by the National Sleep Foundation. It is a random sample survey of approximately 1,900 individuals residing in the United States that focuses exclusively on sleep behavior, sleep disorders, and factors affecting sleep, such as medical comorbidities or work schedules. Currently, only summary reports of the data collected are available.

M. National Survey of Children's Health, 2003

		Survey Summary
A.	Sleep Variables	2. Sleep quality and satisfaction (slept well, did you get enough sleep?)
B.	Risk Factors	1. BMI
		3. Comorbid medical diagnosis (CVD, hypertension, dialysis, diabetes, stroke, asthma, COPD)
		4. Stress, depression, and other mental health conditions
		5. Physical activity
		6. Nutrition
C.	Data Type	1. Random sample
		a. National
D.	Data Access	Public (free open access or nominal charge)
E.	Source	Homepage: http://www.cdc.gov/nchs/about/major/slaits/nsch.htm
		Questionnaire: http://www.cdc.gov/nchs/data/slaits/NSCH_Questionnaire.pdf

The National Survey of Children's Health (NSCH) was designed to produce national and state-specific prevalence estimates for a variety of physical, emotional, and behavioral health indicators as well as measures of children's experiences with the health care system. The survey also includes questions about the family (e.g., parents' health status, stress and coping behaviors, family activities) and about respondents' perceptions of the neighborhoods in which their children live. A total of 102,353 interviews was completed from January 2003 to July 2004. Parents most familiar with children's health issues served as respondents. The survey was a module of the State and Local Area Integrated Telephone Survey (SLAITS), a data collection mechanism developed by NSCH and CDC to supplement existing national health data collection systems.

Please see appendix I for sleep-related questions in this survey.

N. National Survey of Early Childhood Health

	Survey Summary		
A.	Sleep Variables	2. Sleep quality and satisfaction (slept well, did you get enough sleep?)	
		6. Factors interfering with sleep (asthma)	
		12. Sleeping position for infants	
B.	Risk Factors	3. Comorbid medical diagnosis (CVD, hypertension, dialysis, diabetes, stroke, asthma, COPD)	
		6. Nutrition	
C.	Data Type	1. Random sample	
		a. National	
D.	Data Access	Public (free open access or nominal charge)	
E.	Source	Homepage: http://www.cdc.gov/nchs/about/major/slaits/nsech.htm	
		Questionnaire: http://www.cdc.gov/nchs/data/slaits/survey_sech00.pdf	

The National Survey of Early Childhood Health was sponsored by the American Academy of Pediatrics and was collected using the SLAITS system. The sample size was 2,068 children ages 4–5 months. African American and Hispanic children were oversampled to permit more precise estimates for these groups. The main focus of the survey is on the parent-health care provider interaction and access to care.

Please see appendix I for sleep-related questions in this survey.

O. Nurses' Health Study

	Survey Summary
A. Sleep Variables	 Sleep duration (e.g., number of hours slept on average night, last night, etc.)
	2. Sleep quality and satisfaction (slept well, did you get enough sleep?)
	4. Self-reported sleep disorder symptoms (snoring, restless legs)
	7. Daytime symptoms associated with poor sleep (fatigue, tiredness, etc.)
B. Risk Factors	1. BMI
	2. Smoking, alcohol abuse, substance abuse
	 Comorbid medical diagnosis (CVD, hypertension, dialysis, diabetes, stroke, asthma, COPD)
	4. Stress, depression, and other mental health conditions
	5. Physical activity
	6. Nutrition
	7. Work schedules
C. Data Type	1. Random sample
	a. National
D. Data Access	Proprietary (including Federal data sets that must be purchased)
E. Source	Homepage: http://www.channing.harvard.edu/nhs/index.html
	Questionnaire:
	http://www.channing.harvard.edu/nhs/questionnaires/pdfs/NHSII/2001.PDF

The Nurses' Health Study, established in 1976 by Dr. Frank Speizer, and the Nurses' Health Study II, established in 1989 by Dr. Walter Willett, are among the largest prospective investigations into the risk factors for major chronic diseases in women. The content of questionnaires varies from year to year. For instance, sleep-related questions appear in 2001, 2002, and 2004 on the standard questionnaire. Furthermore, in 2001, three questions assessed self-satisfaction with amount of sleep, snoring, and whether activities interfere with sleep. The 2002 questionnaire collected data on amount of sleep and snoring. In 2004, "my sleep was restless" appeared as one of the dimensions of a diagnostic scale for depression. Data are available, but use requires permission of the research team (see http://www.channing.harvard.edu/nhs/questionnaires/nhs-data-use.doc).

Questions from the Nurses' Health Study are copyrighted and could not be included here. Please see appendix I for a list of relevant questions across the years of study implementation.

P. United Nations General Social Survey, Cycle 12: Time Use

		Survey Summary
A.	Sleep Variables	 Sleep duration (e.g., number of hours slept on average night, last night, etc.)
		2. Sleep quality and satisfaction (slept well, did you get enough sleep?).
		4. Self-reported sleep disorder symptoms (snoring, restless legs)
		5. Self-reported sleep disorder (insomnia, RLS, narcolepsy, apnea, etc.)
		7. Daytime symptoms associated with poor sleep (fatigue, tiredness, etc.)
		10. Sleepiness, fatigue, drowsiness associated with traffic fatalities
		11. Bedtime (when you go to sleep)
B.	Risk Factors	4. Stress, depression, and other mental health conditions
		7. Work schedules
C.	Data Type	1. Random sample
		a. national
D.	Data Access	2. Proprietary (including Federal data sets that must be purchased)
E.	Source	Homepage:
		http://unstats.un.org/unsd/demographic/sconcerns/tuse/default.aspx
		Questionnaire: http://unstats.un.org/unsd/methods/timeuse/
		tusresource_instruments/canada_instr.pdf

Time use surveys were conducted under the U.N. General Social Survey mechanisms in several countries, notably in Canada and Mexico in 1998 and in Australia in 1997. Each survey was conducted by each country's agencies (e.g., Statistics Canada and Australian Bureau of Statistics). All surveys were random samples of the population, although methodologies differed somewhat. In general, the sampling unit was a household and data were collected from household members 15 years old and older.

Q. U.S. Department of Labor, Bureau of Labor Statistics: National Longitudinal Surveys

		Survey Summary
A.	Sleep Variables	2. Sleep quality and satisfaction (slept well, did you get enough sleep?)
		11. Bedtime (when you go to sleep)
B.	Risk Factors	3. Comorbid medical diagnosis (CVD, hypertension, dialysis, diabetes, stroke, asthma, COPD)
		4. Stress, depression, and other mental health conditions
		5. Physical activity
C.	Data Type	1. Random sample
		a. National
D.	Data Access	Public (free open access or nominal charge)
E.	Source	Home Page: http://www.bls.gov/nls/
		Time use questionnaire: http://www.bls.gov/nls/quex/y97r3timeuse.pdf
		Health questionnaire: http://www.bls.gov/nls/79quex/r19/y79r19health.pdf

The National Longitudinal Surveys currently comprise four surveys with different cohorts.

The National Longitudinal Survey Year 1979 (NLSY79) follows men and women born between 1957 and 1964, who were 14 to 22 years old when first interviewed in 1979. NLSY97 follows young men and women born in the years 1980 to 1984, who were ages 12 to 17 in 1997. National longitudinal surveys of young women and mature women (NLSW) survey women who were between ages 14 and 24 in 1968 (young women survey) and those who were ages 30 to 44 in 1967 (mature women). The NLSY for Children and Young Adults follows children of women from the 1979 cohort. The National Longitudinal Surveys of young men and older men were discontinued in 1981 and 1990, respectively. Since the surveys are longitudinal, sleep questions appear in different rounds of the survey.

Please see appendix I for sleep-related questions in this survey.

R. Department of Veterans Affairs Databases

	Survey Summary			
Α.	Sleep Variables	3.	Sleep disorder diagnosis (ICD9 or ICD10 codes)	
B.	Risk Factors	2.	Smoking, alcohol abuse, substance abuse	
		3.	Comorbid medical diagnosis (CVD, hypertension, dialysis, diabetes, stroke, asthma, COPD)	
		5.	Physical activity	
		6.	Nutrition	
C.	Data Type	2.	Administrative or discharge data	
D.	Data Access	3.	Limited or restricted (including data distribution agreements, e.g., Sleep Heart Health Study [SHHS])	
E.	Source	Но	mepage: http://www.virec.research.med.va.gov/	

The Department of Veterans Affairs (VA) maintains an extensive documentation of patients' inpatient and outpatient treatment as well as pharmacy use. The datasets are described on the VA

Information Resource Center (VIREC) Web site at http://www.virec.research.med.va.gov/. In brief, every episode of care (identified by admission date or visit date) for each patient has a record that contains the primary and several secondary diagnosis codes. Episodes of care for sleep-related disorders can be abstracted using ICD10 codes. Each patient is uniquely distinguished by an identifier, so various data sources can be linked. Data can also be linked historically using the unique patient identifier. Some of the files date back to the 1970s. The VIREC Web site provides initial points of contact for obtaining the data for non-VA researchers (http://www.virec.research.med.va.gov/Support/Training-NewUsersToolkit/ACRSrequest.htm), advising that access to the data is governed by multiple regulations.

Because sleep-related disorders must be searched by ICD9 codes, questions are not presented in the appendix.

S. National Hospital Discharge Survey

	Survey Summary					
A.	Sleep Variables	3. Sleep disorder diagnosis (ICD9 or ICD10 codes)				
B.	Risk Factors	N/A				
C.	Data Type	2. Administrative or discharge data				
D.	Data Access	Public (free open access or nominal charge)				
E.	Source	Homepage: http://www.cdc.gov/nchs/about/major/hdasd/nhdsdes.htm				
		Data description: http://www.cdc.gov/nchs/data/series/sr_01/sr01_039.pdf				

The National Hospital Discharge Survey (NHDS), which has been conducted annually since 1965, is a national random sample of discharge records from non-Federal hospitals. The NHDS collects data from a sample of approximately 270,000 inpatient records acquired from a national sample of about 500 hospitals. Only hospital stays under 30 days in duration are included. Sleep disorders and comorbidities can be derived by examining diagnostic codes. The data file includes principal diagnosis and up to six secondary diagnoses. Principal procedure and up to three other procedures are also recorded.

Because sleep-related disorders must be searched by ICD9 codes, questions are not presented in the appendix.

T. National Vital Statistics System

Survey Summary				
A.	Sleep Variables	10. Sleepiness, fatigue, drowsiness associated with traffic fatalities		
B.	Risk Factors	N/A		
C.	Data Type	2. Administrative or discharge data		
D.	Data Access	Public (free open access or nominal charge)		
E.	Source	Homepage: http://www.cdc.gov/nchs/nvss.htm		

Part of the National Center for Health Statistics (NCHS), the National Vital Statistics System (NVSS) includes mortality data that may include primary causes of death information as well as contributing comorbidities that did not directly cause death, including sleep-related deaths. This information is coded from original death certificates, and medical conditions are coded as ICD10

codes. Previous data were coded into ICD8 and ICD9 codes, depending on the year they were recorded. The available data range from 1968 to 2002, however, only data from 1968 through 1988 are publicly available. More recent data can be obtained by submitting a written request to NCHS (http://www.cdc.gov/nchs/products/elec_prods/subject/mcompres.htm). Simple analyses for the later data are available on CDC Wonder (http://wonder.cdc.gov/mortSQL.html).

Because sleep-related disorders must be searched by ICD9 codes, questions are not presented in the appendix.

U. Women's Health Initiative

	Survey Summary					
A.	Sleep Variables	 Sleep duration (e.g., number of hours slept on average night, last night, etc) 				
		2. Sleep quality and satisfaction (slept well, did you get enough sleep?).				
		4. Self-reported sleep disorder symptoms (snoring, restless legs)				
		6. Factors interfering with sleep (asthma)				
		7. Daytime symptoms associated with poor sleep (fatigue, tiredness, etc)				
		8. Reports of sleep-related problems as reasons for medication/therapies				
B.	Risk Factors	1. BMI				
		2. Smoking, alcohol abuse, substance abuse				
		3. Comorbid medical diagnosis (CVD, hypertension, dialysis, diabetes, stroke, asthma, COPD)				
		4. Stress, depression, and other mental health conditions				
		5. Physical activity				
C.	Data Type	1. Random sample				
		a. National				
D.	Data Access	Public (free open access or nominal charge)				
E.	Source	Homepage: http://www.whiscience.org				
		Variable list: http://www.whiscience.org/data				

The Women's Health Initiative (WHI) is a long-term national health study that has focused on strategies for preventing heart disease, breast and colorectal cancer, and osteoporotic fractures in postmenopausal women. These chronic diseases are the major causes of death, disability, and frailty in older women of all races and socioeconomic backgrounds.

The WHI has two major parts: a randomized Clinical Trial and an Observational Study. The randomized controlled Clinical Trial (CT) enrolled 68,132 postmenopausal women between the ages of 50 and 79 into trials testing three prevention strategies.

V. Sleep Heart Health Study (SHHS)

	Survey Summary					
A.	Sleep Variables	1.	Sleep duration (e.g., number of hours slept on average night, last night, etc)			
		2.	Sleep quality and satisfaction (slept well, did you get enough sleep?).			
		3.	Sleep disorder diagnosis (ICD9 or ICD10 codes)			
		4.	Self-reported sleep disorder symptoms (snoring, restless legs)			
		5.	Self-reported sleep disorder (insomnia, RLS, narcolepsy, apnea, etc).			
		6.	Factors interfering with sleep (asthma)			
		7.	Daytime symptoms associated with poor sleep (fatigue, tiredness, etc)			
		8.	Reports of sleep-related problems as reasons for medication/therapies			
		10.	Sleepiness, fatigue, drowsiness associated with traffic fatalities			
		11.	Bedtime (when you go to sleep)			
В.	Risk Factors	1.	BMI			
		2.	Smoking, alcohol abuse, substance abuse			
		3.	Comorbid medical diagnosis (cardiovascular disease [CVD], hypertension, dialysis, diabetes, stroke, asthma, Chronic Obstructive Pulmonary Disease [COPD])			
		4.	Stress, depression, and other mental health conditions			
		5.	Physical activity			
C.	Data Type	1.	Random sample			
			a. National			
D.	Data Access	3.	Limited or restricted (including data distribution agreements, e.g., Sleep Heart Health Study [SHHS])			
E.	Source	Но	mepage: http://www.jhucct.com/shhs/default.html			
		Qu	estionnaire: http://www.jhucct.com/shhs/manual/documen.htm			

The Sleep Heart Health Study is a multi-center cohort study implemented by the National Heart, Lung, and Blood Institute to determine cardiovascular and other consequences of sleep-disordered breathing. The study was motivated by the increasing recognition of the frequent occurrence of sleep-disordered breathing in the general population, and mounting evidence that sleep-disordered breathing may increase risk for cardiovascular diseases, including coronary artery disease and stroke, as well as hypertension, and may reduce quality of life generally.

Approximately 1,000 participants will be enrolled from the parent cohorts of each of the seven Investigative Centers. Recruitment approaches will be tailored for the requirements of the specific Field Centers. All participants will be at least 40 years of age, and all minority members of each of the parent cohorts will be recruited.

Each participant in the parent studies will be asked to complete the Sleep Habits Questionnaire, which covers usual sleep pattern, snoring, and sleepiness. Combining these responses with the ongoing outcome assessment of the full parent cohorts will permit the testing of hypotheses concerning the consequences of self-reported snoring and sleepiness in a combined sample of approximately 20,000 persons.

W. National Ambulatory Medical Care Survey

Survey Summary

A.	Sleep Variables	3.	Sleep disorder diagnosis (ICD9 or ICD10 codes)
		4.	Self-reported sleep disorder symptoms (snoring, restless legs)
		6.	Factors interfering with sleep (asthma)
B.	Risk Factors	1.	BMI
		2.	Smoking, alcohol abuse, substance abuse
		3.	Comorbid medical diagnosis (CVD, hypertension, dialysis, diabetes, stroke, asthma, COPD)
		4.	Stress, depression, and other mental health conditions
C.	Data Type	1.	Random sample
			a. National
D.	Data Access	1.	Public (free open access or nominal charge)
E.	Source	Ho	mepage: http://www.cdc.gov/nchs/about/major/ahcd/namcsdes.htm

The National Ambulatory Medical Care Survey (NAMCS) is a national survey designed to meet the need for objective, reliable information about the provision and use of ambulatory medical care services in the United States. Findings are based on a sample of visits to non-federally employed, office-based physicians who are primarily engaged in direct patient care. Physicians in the specialties of anesthesiology, pathology, and radiology are excluded from the survey. The survey was conducted annually from 1973 to 1981, in 1985, and annually since 1989.

Because sleep-related disorders must be searched by ICD9 codes, questions are not presented in the appendix.

	~		~ :	O
Ш.	Selected	Large-Sample	Sleep	Studies

II. \$	Selected	Large-S	Sample	Sleep	Studies
--------	----------	---------	--------	-------	----------------

This Page Intentionally Blank

The instruments, links to Federal and non-Federal Web sites, citations, and other information contained in this document do not necessarily reflect the official policies of the National Institutes of Health or the Department of Health and Human Services; nor does mention of any trade names, organizations, commercial practices, products, or inclusion of any specific survey, questionnaire, or instrument imply endorsement of the U.S. Government. Inclusion or reference to any website, survey, or questionnaire does not imply endorsement by the National Heart, Lung, and Blood Institute, the National Institutes of Health and U.S. Department of Health and Human Services or imply fitness or applicability for a particular use. The inclusion or reference to any website, survey, or questionnaire does not represent the official views of the Government. Individuals interested in the use of any questionnaire are cautioned to contact the source to determine whether or not the instrument is proprietary or has any restrictions or caveats as to its use.

A. Corporate British Health Questionnaire

Mills, P. R.(2005). The development of a new corporate specific health risk measurement instrument, and its use in investigating the relationship between health and well-being and employee productivity. *Environmental Health: A Global Access Science Source*, 4(1), 1

Source: http://www.ehjournal.net/content/4/1/1

Objective: Researchers describe the use of the 20-item health and well-being (HWB) assessment in assessing the impact of employee health on productivity and performance.

Methodology: Researchers report on the development and validation of the health and wellbeing (HWB) assessment, a free-to-use health-risk appraisal questionnaire that has been specifically developed for use in the corporate setting. The HWB assessment focuses upon modifiable health issues that directly affect business drivers. Development involved interviews with business leaders to ascertain their key areas of focus, reviews of scientific and general literature to find evidence for health status that affects these areas, and end-user testing. Three UK-based organizations in the insurance, telecommunications, and consumer goods sectors participated in the research. A total of 2,224 employees completed the HWB assessment, Short Form 36 (SF-36), and the World Health Organization Health and Work Performance questionnaire (WHO-HPQ) as part of the validation process. This methodology allows the study of relationships between sleep and various health risk factors.

Please see appendix II for sleep-related questions in this survey.

B. Chronic Fatigue Syndrome and Sleep Assessment

Unger, E. R., et al. (2004). Sleep assessment in a population-based study of chronic fatigue syndrome. *BMC Neurology*, 4(6).

Source: http://www.biomedcentral.com/1471-2377/4/6

Objective: The purpose of the study was to describe sleep characteristics of persons with chronic fatigue syndrome (CFS) identified in the general population of Wichita, Kansas.

Methodology: The study included 339 subjects identified through telephone screening in a previously described population-based study of CFS in Wichita, Kansas. Subjects completed questionnaires to assess fatigue and wellness and two self-administered sleep questionnaires. Scores for five of the six sleep factors (insomnia/hypersomnia, nonrestorative sleep, excessive daytime somnolence, sleep apnea, and restlessness) in the Centre for Sleep and Chronobiology's Sleep Assessment Questionnaire® (SAQ®) were dichotomized on the basis of threshold. The Epworth Sleepiness Scale score was used as a continuous variable.

Please see appendix II for sleep-related questions in this survey.

C. Daytime Sleepiness and Hyperactive Children

Melendres, C. S., et al. (2004). Daytime sleepiness and hyperactivity in children with suspected sleep-disordered breathing. *Pediatrics*, 114(3), 768–76.

Objectives: Excessive daytime sleepiness (EDS) is seen less frequently as a presenting complaint in children with sleep-disordered breathing than in adults. Instead, symptoms of hyperactivity are often described. Researchers hypothesized that children with suspected sleep-disordered breathing (S-SDB) were both sleepier and more hyperactive than control subjects. Furthermore, researchers hypothesized that overnight polysomnographic parameters correlated with sleepiness and hyperactivity.

Methodology: A cross-sectional study was conducted at a university-affiliated hospital and a community-based pediatric clinic. A total of 108 patients with S-SDB (mean age=7, SD=4) and 72 control subjects (mean age=8, SD=4) were recruited. A modified Epworth Sleepiness Scale (ESS) and the Conners Abbreviated Symptom Questionnaire were administered. Polysomnography was performed in patients with S-SDB.

Please see appendix II for sleep-related questions in this survey.

D. Nursing Home Quality Initiative

Minimum Data Set (MDS) For Nursing Home Resident Assessment and Care Screening

Source: http://www.cms.hhs.gov/NursingHomeQualityInits

Instrument: http://www.cms.hhs.gov/NursingHomeQualityInits/downloads/MDS20MDSAllForms.pdf

Funding: National Long-Term Care Center, University of Minnesota School of Public Health; sponsored by the Health Care Financing Administration, U.S. Department of Health and Human Services.

E. Older Adults and Arthritis

Dominick, K. L., et al. (2004). Health-related quality of life among older adults with arthritis. *Health and Quality of Life Outcomes*, 2(5).

Source: http://www.hqlo.com/content/2/1/5

Objectives: The purpose of the study was to examine the relationship of health-related quality of life (HRQOL) among a statewide sample of older adults with osteoarthritis (OA) or rheumatoid arthritis (RA) and to investigate the relationship of demographic characteristics of HRQOL among older adults with OA and RA.

Methodology: Older adults in Pennsylvania completed a mail version of the Centers for Disease Control and Prevention (CDC) HRQOL modules. The response rate was 57.6 percent, with 83,471 questionnaires returned. Respondents and nonrespondents were similar with respect to demographic characteristics, including age, gender, race, residential status, marital status, and annual income. Medicare data were used to identify subjects with a diagnosis of OA, RA, or no arthritis. Researchers compared HRQOL responses among these groups and also examined the relationship of demographic characteristics to HRQOL among subjects with arthritis. The survey can be found on the next page.

Sample Characteristics: 23.6 percent male, mean age 79.1 years, \$11,108 mean income, 93.6 percent white, 16.9 percent married, 96.3 percent community-dwelling, 2.1 mean Charlson Comorbidity Score.

Please see appendix II for sleep-related questions in this survey.

F. Pediatric Sleep Medicine Survey

Owens, J. A. (2001). The practice of pediatric sleep medicine: Results of a community survey. *Pediatrics*, 108(3),51.

Source: http://pediatrics.aappublications.org/cgi/reprint/108/3/e51

Objectives: The Pediatric Sleep Medicine Survey sought to assess knowledge, screening, evaluation, treatment practices, and attitudes regarding sleep disorders in children and adolescents in a large sample of community-based and academic pediatricians.

Methodology: A 42-item questionnaire was mailed to a random sample of 2,740 practicing pediatricians in Southern New England. The questionnaire assessed the knowledge of clinical screening, diagnostic and treatment practices for common sleep disorders, and practitioner attitudes regarding the impact of sleep disorders. The response rate was 37.9 percent, with 828 completed, usable surveys.

Sample Characteristics: Participants were the providers themselves, not the patients whom they served. Mean age was 46.6 years, 49.7 percent were female, 16.1 percent (n=101) had a second specialty, 86.7 percent were community-based (group or managed care practice, private office, or

health center), and 13.4 percent were academic or hospital-based. A total of 61 percent had sleep problems themselves.

Please see appendix II for sleep-related questions in this survey.

G. Reduction in Tinnitus Severity

Folmer, R. L. (2002). Long-term reductions in tinnitus severity. *BMC Ear, Nose and Throat Disorders*, 2(3).

Source: http://www.biomedcentral.com/1472-6815/2/3

Objectives: The purposes of the study were: 1) to assess long-term changes in tinnitus severity exhibited by patients who completed a comprehensive tinnitus management program; 2) to identify factors that contributed to changes in tinnitus severity within this population; and 3) to contribute to the development and refinement of effective assessment and management procedures for tinnitus.

Methodology: Detailed questionnaires were mailed to 300 consecutive patients prior to their initial appointment at the Oregon Health & Science University Tinnitus Clinic. All patients were then evaluated and treated within a comprehensive tinnitus management program. Followup questionnaires were mailed to the same 300 patients 6 to 36 months after their initial tinnitus clinic appointment.

III. Sleep Scales and Questionnaires

This Page Intentionally Blank

The instruments, links to Federal and non-Federal Web sites, citations, and other information contained in this document do not necessarily reflect the official policies of the National Institutes of Health or the Department of Health and Human Services; nor does mention of any trade names, organizations, commercial practices, products, or inclusion of any specific website, questionnaire or survey instrument of the U.S. Government. Inclusion or reference to any website, questionnaire or survey instrument does not imply endorsement by the National Heart, Lung, and Blood Institute, the National Institutes of Health and U.S. Department of Health and Human Services or imply fitness or applicability for a particular use. The inclusion or reference to any website, questionnaire or survey does not represent the official views of the Government. Individuals interested in the use of any questionnaire are cautioned to contact the source to determine whether or not the instrument is proprietary or has any restrictions or caveats as to its use.

Please see appendix III for sleep-related items from each instrument.

A. A.P.N.E.A. Net: The Apnea Patient's News, Education & Awareness Network—Sleep Apnea Questionnaire

Source: http://www.apneanet.org/question.htm

B. Epworth Sleepiness Scale

Source: http://www.cdc.gov/nasd/docs/d000701-d000800/d000705/d000705.pdf

C. Exempla Healthcare Sleep Disorders Laboratory: Patient Education and Screening Questionnaire

Exempla is a not-for-profit hospital network that runs a sleep disorder clinic. The Exempla Patient Education and Screening Questionnaire combines the Epworth scale with questions on medical history and the Severity of Daytime Sleepiness scale.

Source: http://www.exempla.org/care/services/sleep/docs/PtQuestionnaire.pdf

D. Infant Screening Questionnaire

Sadeh, A. (2004). A brief screening questionnaire for infant sleep problems: Validation and findings for an internet sample. *Pediatrics*, 113(6), 570–77.

Source: http://pediatrics.aappublications.org/cgi/content/full/113/6/e570

E. Leeds Sleep Evaluation Questionnaire

Laudon, M. (2003). Subjective assessment of the effects of CNS-active drugs on sleep by the Leeds Sleep Evaluation Questionnaire. *Human Psychopharmacology: Clinical and Experimental*, 18(1),1–20.

F. Maternal Child Supervision Questionnaire, 1961

Robertson, W. O. (1961). An investigation of Maternal Concerns by Mail Survey. *Child Development*, 32(3), 423–36.

Source: http://www.jstor.org/view/00093920/ap030118/03a00010/0

G. Parental Interactive Bedtime Behavior Scale

Morrel, J., et al. (2002). The developmental change in strategies parents employ to settle young children to sleep, and their relationship to infant sleeping problems, as assessed by a new questionnaire: The Parental Interactive Bedtime Behavior Scale. *Infant and Child Development*, 11, 17–41.

H. Pediatric Sleep Questionnaire

Source: http://www.saintpatrick.org/images/sleep_questionnaire.pdf

I. Sinai Hospital Sleep Disorder Assessment Questionnaire

Source: http://www.lifebridgehealth.org/pdf/inst1.pdf

J. Sleep Apnea—The Phantom of the Night Questionnaire

Johnson, S.T., et al. (2003). *Sleep apnea—The phantom of the night*. Onset, MA: New Technology Publishing.

Source: http://www.healthyresources.com/sleep/apnea/question/quiz.html

K. Pittsburgh Sleep Quality Index

Source:

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=2748771 &dopt=Abstract

L. Stanford Sleepiness Scale

Source: http://www.stanford.edu/~dement/sss.html

M. Functional Outcomes of Sleep Questionnaire

Source:

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=9415942 &dopt=Abstract

Links to appendices for selected images of the surveys and questionnaires cited in this document can be accessed electronically at http://www.nhlbi.nih.gov/about/ncsdr/research/research-a.htm