

APPENDIX 1

ICD and SEER Codes

Table 1. International Classification of Diseases (ICD) Code Disease Definitions

DISEASE CODE	DIGESTIVE DISEASE	ICD-9-CM Codes for Morbidity	ICD-9 Codes for Mortality (1979–1998)	ICD-10 Codes for Mortality (1999–2004)
1	Gastrointestinal Infections	001–009	001–009	A00–A09
2	Hepatitis A	070.0, 070.1	070.0, 070.1	B15
3	Hepatitis B	1991–PRESENT: 070.42, 070.52 ALL YEARS: 070.2, 070.3	070.2, 070.3	B16, B17.0, B18.0, B18.1
4	Hepatitis C	1991–PRESENT: 070.41, 070.44, 070.51, 070.54, 070.7 BEFORE 1991: 070.4, 070.5	070.4, 070.5	B17.1, B18.2
5	Other Viral Hepatitis	1991–PRESENT: 070.43, 070.49, 070.53, 070.59 ALL YEARS 070.6, 070.9	070.6, 070.9	B17.2, B17.8, B18.8, B18.9, B19
2–5	All Viral Hepatitis	—	—	—
6	Esophageal Cancer	150, 151.0	150, 151.0	C15, C16.0
7	Gastric Cancer	151.1–151.9	151.1–151.9	C16.1–C16.9
8	Cancer of Small Intestine	152	152	C17
9	Colorectal Cancer	153, 154.0–154.1	153, 154.0–154.1	C18–C20
10	Primary Liver Cancer	155.0	155.0	C22.0, C22.2–C22.7
11	Bile Duct Cancer	155.1, 156.1–156.9	155.1, 156.1–156.9	C22.1, C24
12	Gallbladder Cancer	156.0	156.0	C23
13	Pancreatic Cancer	157	157	C25
14	Other Digestive Cancers	154.2–154.3, 154.8, 155.2, 158, 159.0, 159.8, 159.9, 196.2, 197.4– 197.8	154.2–154.3, 154.8, 155.2, 158, 159.0, 159.8, 159.9, 196.2, 197.4–197.8	C21, C22.9, C26.0, C26.8, C26.9, C45.1, C48.0–C48.8, C77.2, C78.4–C78.8

Table 1. International Classification of Diseases (ICD) Code Disease Definitions (continued)

DISEASE CODE	DIGESTIVE DISEASE	ICD-9-CM Codes for Morbidity	ICD-9 Codes for Mortality (1979–1998)	ICD-10 Codes for Mortality (1999–2004)
6–14	All Digestive Cancers	—	—	—
15	Hemorrhoids	455	455	I84
16	Gastroesophageal Reflux Disease	530.1–530.3, 530.81	530.1–530.3	K20, K21, K22.1, K22.2
17	Peptic Ulcer Disease	531–534	531–534	K25–K28
18	Chronic Constipation	564.0	564.0	K59.0
19	Irritable Bowel Syndrome	564.1	564.1	K58
20	Other Functional Disorders	536, 564.2–564.9	536, 564.2–564.9	K30, K31.0, K59.1–K59.9, K91.0, K91.1, K91.8
18–20	All Functional Disorders	—	—	—
21	Appendicitis	540–543	540–543	K35–K38
22	Abdominal Wall Hernia	550, 551.0–551.2, 551.8, 551.9, 552.0–552.2, 552.8, 552.9, 553.0–553.2, 553.8, 553.9	550, 551.0–551.2, 551.8, 551.9, 552.0–552.2, 552.8, 552.9, 553.0–553.2, 553.8, 553.9	K40–K43, K45, K46
23	Crohn's Disease	555	555	K50
24	Ulcerative Colitis	556	556	K51
23–24	All Inflammatory Bowel Diseases	—	—	—
25	Diverticular Disease	562	562	K57
26	Liver Disease	570–573	570–573	K70–K76
27	Gallstones	574	574	K80
28	Pancreatitis	577.0, 577.1	577.0, 577.1	K85, K86.0, K86.1
29	Other Digestive Diseases	014, 017.8, 021.1, 022.2, 032.83, 040.2, 060, 072.3, 072.71, 075, 086.1, 091.1, 091.62, 095.2, 095.3, 098.7, 098.86, 099.52, 099.56, 112.84, 112.85, 120–129, 130.5, 176.3, 211, 230.1–230.9, 235.2–235.5, 239.0, 251.4–251.9, 271.3, 273.4, 275.0, 275.1, 277.01, 277.03, 277.1, 277.4, 279.01, 280.8, 281.0, 286.0–286.5, 286.7, 289.2, 306.4, 307.7, 452, 453.0, 286.7, 289.2, 306.4, 307.54, 307.7, 452, 453.0, 456.0–456.2, 530.0, 530.4–530.7, 530.82–530.89, 530.9, 535,	014, 017.8, 021.1, 022.2, 040.2, 060, 072.3, 075, 086.1, 091.1, 095.2, 095.3, 098.7, 120–129, 130.5, 176.3, 211, 230.1–230.9, 235.2–235.5, 239.0, 251.4–251.9, 271.3, 273.4, 275.0, 275.1, 277.1, 277.4, 280.8, 281.0, 286.0–286.5, 286.7, 289.2, 306.4, 307.7, 452, 453.0, 456.0–456.2, 530.0, 530.4–530.9, 535, 537, 538, 551.3, 552.3, 553.3, 557, 558, 560, 565–569,	A18.3, A21.3, A22.2, A51.1, A54.6, A56.3, A60.1, A74.8, A95, B25.1, B25.2, B26.3, B27, B46.2, B57.3, B58.1, B65–B83, B94.2, D00.1, D00.2, D01, D12, D13, D19.1, D20, D37.1–D37.9, D48.3, D48.4, D50.1, D51.0, D66, D67, D68.0–D68.4, D80.2, E16.3–E16.9, E73, E74.3, E80, E83.0, E83.1, E84.1, E88.0, F50.5, F98.1, I81, I82.0, I85, I86.4, I88.0, I98.2, K22.0, K22.3–K22.9, K23, K29, K31.1–K31.9, K44,

Table 1. International Classification of Diseases (ICD) Code Disease Definitions (continued)

DISEASE CODE	DIGESTIVE DISEASE	ICD-9-CM Codes for Morbidity	ICD-9 Codes for Mortality (1979–1998)	ICD-10 Codes for Mortality (1999–2004)
29 (cont.)	Other Digestive Diseases (cont.)	537, 538, 551.3, 552.3, 553.3, 557, 558, 560, 565–569, 575, 576, 577.2, 577.8, 577.9, 578, 579, 643, 646.7, 671.8, 750.3–750.9, 751, 772.4, 773.4, 774.2–774.7, 776.0, 777, 779.3, 782.4, 787, 789.0, 789.1, 789.3–789.9, 792.1, 793.3, 793.4, 793.6, 794.8, 862.22, 862.32, 863, 864, 868.02–868.04, 868.12–868.14, 935.1, 935.2, 936–938, 947.2, 947.3, 973, 988.1, 996.82, 996.86, 996.87, 997.4, V01.0, V02.0–V02.3, V02.6, V03.0, V03.1, V04.4, V05.3, V06.0, V10.00, V10.03–V10.09, V12.7, V16.0, V18.5, V42.7, V42.83, V42.84, V44.1–V44.4, V45.3, V45.72, V45.75, V45.86, V47.3, V53.5, V55.1–V55.4, V58.75, V59.6, V73.4, V74.0, V75.5–V75.7, V76.41, V76.5, E858.4, E870.7, E879.5, E943	575, 576, 577.2, 577.8, 577.9, 578, 579, 643, 646.7, 671.8, 750.3–750.9, 751, 772.4, 773.4, 774.2–774.7, 776.0, 777, 779.3, 782.4, 787, 789.0, 789.1, 789.3–789.9, 792.1, 793.3, 793.4, 793.6, 794.8, 863, 864, 935.1, 935.2, 936–938, 947.2, 947.3, 973, 988.1, 997.4	K52, K55, K56, K60–K63, K65–K67, K81–K83, K86.2–K86.9, K87, K90, K91.2–K91.5, K91.9, K92, K93 O21, O22.4, O26.6, P53, P54.0–P54.3, P57, P59, P75–P78, P92.0, P92.1, Q39–Q45, R10.0, R10.1, R10.3, R10.4, R11–R15, R16.0, R16.2, R17–R19, R93.2, R93.3, R93.5, R94.5, S36.1–S36.9, T18.1–T18.9, T28.1, T28.2, T28.6, T28.7, T47, T62.0, T85.5, T86.4, Y53, Y60.7, Y84.5, Z11.0, Z11.6, Z12.0, Z12.1, Z20.0, Z20.5, Z22.0, Z22.1, Z22.5, Z23.0, Z23.1, Z24.3, Z24.6, Z27.0, Z43.1–Z43.4, Z46.5, Z52.6, Z80.0, Z83.7, Z85.0, Z87.1, Z90.3, Z90.4, Z93.1–Z94.4, Z98.0
1–29	All Digestive Diseases	—	—	—

SOURCE: ICD-9-CM: <http://www.cdc.gov/nchs/icd9.htm>
 ICD-9: <http://www.cdc.gov/nchs/about/major/dvs/icd9des.htm>
 ICD-10: <http://www.cdc.gov/nchs/about/major/dvs/icd10des.htm>

Table 2. Surveillance, Epidemiology, and End Results (SEER) Program Site Recodes With SEER Morphology Codes (ICD-0-3) for Digestive Cancers

DISEASE CODE	CANCER	SEER SITE RECODES (Morphology Codes in Parentheses)
1	Esophageal Cancer, Squamous Cell	21010 (805–808)
2	Esophageal Cancer, Adenocarcinoma	21010 (814–838)
3	Esophageal Cancer, Other	21010 (all other 0 codes)
1–3	All Esophageal Cancer	—
4	Gastric Cancer	21020
5	Cancer of Small Intestine	21030
6	Colorectal Cancer	21041–21049, 21051, 21052
7	Primary Liver Cancer	21071
8	Bile Duct Cancer	21072, 21090
9	Gallbladder Cancer	21080
10	Pancreatic Cancer	21100
11	Other Digestive Cancers (Other III-Defined)	21060, 21110, 21120, 21130
1–11	All Digestive Cancers	—

SOURCE: Fritz A, Percy C, Jack A, Shanmugaratnam K, Sobin L, Parkin DM, Whelan S, eds. *International Classification of Diseases for Oncology*. 3rd ed. Geneva: World Health Organization; 2000.

APPENDIX 2

Summary of Surveys Used in *The Burden of Digestive Diseases in the United States*

Constance E. Ruhl, M.D., Ph.D.; and Bryan Sayer, M.H.S.

National Ambulatory Medical Care Survey (NAMCS)

Sponsor	<p>Ambulatory Care Statistics Branch Division of Health Care Statistics National Center for Health Statistics Centers for Disease Control and Prevention U.S. Department of Health and Human Services 3311 Toledo Road Hyattsville, MD 20782 301-458-4600</p> <p>http://www.cdc.gov/nchs/about/major/ahcd/ahcd1.htm</p>
Design	<p>The National Ambulatory Medical Care Survey (NAMCS) is a continuing series of nationally representative sample surveys of office-based physicians in the United States. The survey includes all non-Federal office-based physicians who are primarily engaged in direct patient care. Anesthesiologists, pathologists, and radiologists are excluded. The design is a multistage stratified probability sample of geographically defined areas, physician practices within these areas, and patient visits within physician practices. Physicians are asked to complete a patient encounter form for a systematic sample of office visits occurring during a randomly assigned 1-week reporting period.</p> <p>The study design is described in: National Center for Health Statistics, Bryant E, Shimuzu I. <i>Sample design, sampling variance, and estimation procedures for the National Ambulatory Medical Care Survey</i>. Hyattsville, Maryland: Public Health Service, 1988; DHHS Publication No. (PHS) 88-1382. (<i>Vital and health statistics</i>, Series 2, No. 108.)</p>
Timeframe	<p>Data were collected annually from 1974 through 1981, and in 1985; data have been collected annually since 1989. Data from 1992 through 2005 were used in this report.</p>
Sample Size	<p>Through 1981, the sample included 3,000 total physicians, about 1,925 responding physicians, and about 51,000 patient visits. The 1985 sample included about 5,000 total physicians, 2,900 responding physicians, and 70,000 patient visits. Beginning in 1989, the sample included 2,500 total physicians, about 1,600 responding physicians, and about 42,000 patient visits.</p>
Content Relevant to Digestive Diseases	<p>Demographic data, reason for visit, physician's diagnostic and therapeutic services ordered or provided, diagnosis and disposition decision, and drugs prescribed are included. International Classification of Diseases (ICD) codes are given for the first four physician diagnoses. The reason for office visit is the principal reason given by the patient, which in the physician's judgment is the most appropriate one. Two additional symptoms or other reasons for visit can be coded.</p>
Strengths	<p>The survey form is completed from provider records. Trend data are available for about 30 years. Visits can be compared with those of the National Health Interview Survey, in which the conditions are similarly defined. Since 1980, data have been collected on the number and names of specific drugs prescribed in office-based practice. The sample allows estimates for specific physician subspecialties. ICD codes are used for diagnoses.</p>

Limitations	The sample is limited to office-based physicians, a group that has become a less inclusive source for ambulatory care. There may be more than one report per person, because the report reflects a visit rather than an individual. The sample size is small, so estimates of fewer than 200,000 are statistically unreliable. Because ambulatory care in Federal facilities is not included, ambulatory care rates based on the U.S. population are underestimates.
Availability of Data	Published data are found in the National Center for Health Statistics <i>Vital and health statistics</i> , Series 13 (http://www.cdc.gov/nchs/products/pubs/pubd/series/ser.htm#sr13) and in <i>Advance data</i> (http://www.cdc.gov/nchs/products/pubs/pubd/ad/ad.htm). Data are available for public use on the National Center for Health Statistics Web site in an easy-to-use form with input statements.

National Hospital Ambulatory Medical Care Survey (NHAMCS)

Sponsor	<p>Ambulatory Care Statistics Branch Division of Health Care Statistics National Center for Health Statistics Centers for Disease Control and Prevention U.S. Department of Health and Human Services 3311 Toledo Road Hyattsville, MD 20782 301-458-4600</p> <p>http://www.cdc.gov/nchs/about/major/ahcd/ahcd1.htm</p>
Design	<p>The National Hospital Ambulatory Medical Care Survey (NHAMCS) is a continuing series of nationally representative sample surveys of physicians in hospital emergency departments and outpatient departments in the United States. The survey includes all non-institutional, non-Federal, general, and short-stay hospitals with at least six beds staffed for patient use. The design is a multistage stratified probability sample of geographically defined areas, hospitals within these areas, clinics within the outpatient departments and emergency service areas within the emergency departments of these hospitals, and patient visits to these clinics and emergency service areas. Physicians are asked to complete a patient encounter form for a systematic sample of visits occurring during a randomly assigned 4-week reporting period.</p> <p>The study design is described in: National Center for Health Statistics, McCaig LF, McLemore T. <i>Plan and operation of the National Hospital Ambulatory Medical Care Survey</i>. Hyattsville, Maryland: Public Health Service, 1994; DHHS Publication No. (PHS) 94-1310. (<i>Vital and health statistics</i>, Series 1, No. 34.)</p>
Timeframe	<p>Data have been collected annually since 1992. Data from 1992 through 2005 were used in this report.</p>
Sample Size	<p>A fixed panel of 600 hospitals was selected for the sample. A special supplement of 66 hospitals was added in 2003 to increase reliability of emergency department estimates for rural and proprietary hospitals. In 1992, the sample included about 36,000 emergency department visits and about 35,000 outpatient department visits.</p>
Content Relevant to Digestive Diseases	<p>Demographic data, reason for visit, physician's diagnostic and therapeutic services ordered or provided, diagnoses and disposition decision, drugs prescribed, types of health care professionals seen, causes of injury where applicable, expected sources of payment, and characteristics of the hospital such as type of ownership are included.</p>
Strengths	<p>This survey complements the NAMCS, to provide more complete data on ambulatory care. The survey form is completed from provider records. Trend data are available for more than 10 years. International Classification of Diseases (ICD) codes are used for diagnoses.</p>
Limitations	<p>There may be more than one report per person, because the report reflects a visit rather than an individual. The sample size is small, so estimates of fewer than 200,000 are statistically unreliable. Because ambulatory care in Federal facilities is not included, ambulatory care rates based on the U.S. population are underestimates.</p>
Availability of Data	<p>Published data are found in the National Center for Health Statistics <i>Vital and health statistics</i>, Series 13 (http://www.cdc.gov/nchs/products/pubs/pubd/series/ser.htm#sr13) and in <i>Advance data</i> (http://www.cdc.gov/nchs/products/pubs/pubd/ad/ad.htm). Data are available for public use on the National Center for Health Statistics Web site in an easy-to-use form with input statements.</p>

Healthcare Cost and Utilization Project Nationwide Inpatient Sample (HCUP NIS)

Sponsor	<p>Agency for Healthcare Research and Quality U.S. Department of Health and Human Services 540 Gaither Road, Suite 2000 Rockville, MD 20850 301-427-1364 866-290-HCUP</p> <p>http://www.hcup-us.ahrq.gov/</p>
Design	<p>The Healthcare Cost and Utilization Project Nationwide Inpatient Sample (HCUP NIS) is a database of hospital inpatient stays. It utilizes a stratified sample of hospitals drawn from the subset of hospitals in the States that make their data available to HCUP. Hospitals are stratified by region, location/teaching status, bed-size category, and ownership. All discharges from sampled hospitals are included. The 2004 HCUP NIS includes all discharges from more than 1,000 hospitals, an approximate 20 percent stratified sample of U.S. community hospitals. HCUP NIS data are weighted to represent the annual discharges from non-Federal hospitals in the United States.</p> <p>Several revisions have been made to the HCUP NIS sampling design since its inception. First, the sampling frame changed over time as more States made their data available to HCUP. The 1988 HCUP NIS was drawn from a sampling frame of eight States, representing 31 percent of all hospital discharges in the United States. In contrast, the sampling frame in recent years included 37 States, representing 85 to 90 percent of all hospital discharges in the United States. Second, in 1998, the sampling method was changed to better reflect the cross-sectional population of hospitals. The hospital stratification variables were redefined, short-term rehabilitation facilities were dropped from the target universe, and sampling preference was no longer given to prior-year NIS hospitals.</p>
Timeframe	Data have been collected annually since 1988. Data from 2004 were used in this report.
Sample Size	The sample size is approximately 8 million hospital stays each year.
Content Relevant to Digestive Diseases	Data for each hospital stay include patient demographics (gender, age, race, median income for ZIP Code), admission and discharge status, length of stay, total charges, expected payment source, up to 15 diagnoses and 7 surgical procedures coded using International Classification of Diseases (ICD)-9-CM codes, and hospital characteristics (ownership, size, teaching status).
Strengths	The HCUP NIS is the largest all-payer inpatient care database in the United States. Data are weighted to be nationally representative of non-Federal hospitals in the United States. The HCUP NIS is the only national hospital database containing charge information on all patients, regardless of payer.
Limitations	Not all States participate. Not all participating States collect data on race-ethnicity; in 2004, race-ethnicity data were not collected by 11 participating States: Georgia, Illinois, Kentucky, Maine, Minnesota, Nebraska, Nevada, Ohio, Oregon, Washington, and West Virginia. The charge information is for the facility only; no information on physician fees is available. Data on medications are not supplied, although medication costs are included in the charge total.
Availability of Data	Summary statistics are published by the Agency for Healthcare Research and Quality (http://www.hcup-us.ahrq.gov/reports.jsp). An online database, HCUP-Net, allows users to generate certain statistics easily (http://hcupnet.ahrq.gov/). Selected data sets can be purchased for analysis.

National Hospital Discharge Survey (NHDS)

Sponsor	<p>Hospital Care Statistics Branch Division of Health Care Statistics National Center for Health Statistics Centers for Disease Control and Prevention U.S. Department of Health and Human Services 3311 Toledo Road Hyattsville, MD 20782 301-458-4321</p> <p>http://www.cdc.gov/nchs/about/major/hdasd/nhds.htm</p>
Design	<p>The National Hospital Discharge Survey (NHDS) is a continuing series of nationally representative sample surveys of hospitals in the United States. The survey includes all short-stay, non-Federal non-institutional hospitals having six or more beds for patient use and, before 1988, those in which the average length of stay for all patients was less than 30 days. In 1988, the scope was altered slightly to include all general and children's general hospitals regardless of the length of stay. The design is a two-stage stratified probability sample of hospitals and discharges within hospitals. Beginning in 1985, two data collection procedures have been used: (1) a manual system in which data are abstracted from hospital records by the hospital staff or U.S. Census Bureau staff on behalf of the National Center for Health Statistics, and (2) an automated system in which machine-readable medical record data are purchased from commercial organizations, State data systems, hospitals, or hospital associations.</p> <p>The study design is described in: National Center for Health Statistics, Dennison CF, Pokras R. <i>Design and operation of the National Hospital Discharge Survey: 1988 redesign</i>. Washington, D.C.: U.S. Government Printing Office, 2000; DHHS Publication No. (PHS) 2001-1315. (<i>Vital and health statistics</i>, Series 1, No. 39.)</p>
Timeframe	Data have been collected annually since 1965. Data from 1979 through 2004 were used in this report.
Sample Size	Approximately 270,000 stays from about 500 hospitals each year constitute the sample.
Content Relevant to Digestive Diseases	Data in medical records for hospital discharges are collected for patient demographics (age, sex, race, ethnicity, and marital status), disposition, length of stay, expected source of payment, and for up to seven diagnoses and four surgical procedures coded to the International Classification of Diseases (ICD)-9-CM.
Strengths	The NHDS includes patients who die in the hospital and admissions from nursing homes, thereby producing more accurate estimates of utilization, diagnostic, and procedure data than those produced by household, self-reported interview surveys such as the National Health Interview Survey. Data are obtained directly from hospital records, thus minimizing underreporting. Data include up to seven discharge diagnoses and four procedure codes. ICD codes are used for diagnoses. Trend data are available for about 40 years.
Limitations	The data, which are based only on the factsheet of the hospital discharge record, may contain incomplete or inaccurate information, because there is no validation of condition. Extensive demographic and other health-related information is not available from hospital records. Recorded data reflect a discharge, not a person, so there may be more than one discharge per person for the same condition. Race is not coded on approximately 10 percent of records. Because hospitalizations in Federal facilities are not included, hospitalization rates based on the U.S. population are underestimates.
Availability of Data	Published data are found in the National Center for Health Statistics <i>Vital and health statistics</i> , Series 13 (http://www.cdc.gov/nchs/products/pubs/pubd/series/ser.htm#sr13) and in <i>Advance data</i> (http://www.cdc.gov/nchs/products/pubs/pubd/ad/ad.htm). Data are available for public use on data tapes, data diskettes, CD-ROMs and downloadable files from the National Center for Health Statistics Web site in an easy-to-use form with input statements.

Vital Statistics of the United States: Multiple Cause-of-Death Data

Sponsor	<p>Mortality Statistics Branch Division of Vital Statistics National Center for Health Statistics Centers for Disease Control and Prevention U.S. Department of Health and Human Services 3311 Toledo Road, 7th floor Hyattsville, MD 20782 301-458-4666</p> <p>http://www.cdc.gov/nchs/deaths.htm</p>
Design	<p>Multiple cause-of-death mortality data from the National Vital Statistics System provide mortality data by multiple cause of death for all deaths occurring within the United States. Each record in the microdata is based on information abstracted from death certificates filed in vital statistics offices of each State and the District of Columbia. Causes of death were coded according to the International Classification of Diseases (ICD)-9 for 1979 through 1998, and according to ICD-10, beginning in 1999.</p> <p>The study design is described in: National Center for Health Statistics, <i>Data systems of the National Center for Health Statistics</i>. Hyattsville, Maryland: Public Health Service, 1981; DHHS Publication No. (PHS) 82-1318. (<i>Vital and health statistics</i>: Series 1, No. 16.)</p>
Timeframe	Data have been collected annually since 1968. Data from 1979 through 2004 were used in this report.
Sample Size	The sample is a 100 percent count of deaths in the United States.
Content Relevant to Digestive Diseases	Demographic data (age, sex, race, residence) and underlying and contributing causes of death are included.
Strengths	A complete count of deaths in the United States is included, along with 18 diagnoses. Trend data are available for more than 35 years. For digestive diseases with high mortality rates, such as cirrhosis, death records are the most comprehensive data source. Mortality statistics may be the only reliable data source for uncommon fatal conditions. Annual age-adjusted mortality rates are useful for examining trends over time, assuming case-fatality rates do not change significantly. Mortality rates for diseases that are usually fatal are often used as estimates of incidence rates when the latter are not available.
Limitations	Quality is dependent on the accuracy of death certificates, which may vary, according to condition. Chronic diseases that contribute to mortality are frequently underreported.
Availability of Data	Published data are found in: National Center for Health Statistics. <i>Vital statistics of the United States</i> , Vol. II, Mortality, Parts A and B (http://www.cdc.gov/nchs/products/pubs/pubd/vsus/vsus.htm); <i>National vital statistics reports</i> (http://www.cdc.gov/nchs/products/pubs/pubd/nvsr/nvsr.htm); and <i>Vital and health statistics</i> , Series 20 (http://www.cdc.gov/nchs/products/pubs/pubd/series/ser.htm#sr20). Data are available for public use on the National Bureau of Economic Research Web site (http://www.nber.org/data/multicause.html) in an easy-to-use form with input statements.

United States Population Estimates

Sponsor	<p>Division of Population Projections U.S. Census Bureau From CDC Wonder Centers for Disease Control and Prevention (CDC) U.S. Department of Health and Human Services 1600 Clifton Road Atlanta, GA 30333 404-639-3311 404-639-3534 and 800-311-3435 (public inquiries)</p> <p>http://wonder.cdc.gov/census.html</p>
Design	<p>The population estimates are mid-year (July 1) population counts by age, sex, and race. The counts are used with all national samples as the denominator for all estimates of rates. The year 2000 estimates are also used for age adjusting. These estimates are not used for cancer statistics from the Surveillance, Epidemiology, and End Results (SEER) program, which has its own population counts.</p>
Timeframe	<p>Estimates for 1979 through 2005 were used in this report.</p>
Sample Size	<p>The U.S. population is the sample.</p>
<p>Content Relevant to Digestive Diseases</p>	<p>Denominators are provided for calculating rate per 100,000 persons by age, race, and sex.</p>

Surveillance, Epidemiology, and End Results (SEER) Program

Sponsor	<p>Cancer Statistics Branch Surveillance Research Program Division of Cancer Control and Population Sciences National Cancer Institute National Institutes of Health U.S. Department of Health and Human Services 6116 Executive Boulevard Suite 504, MSC 8316 Bethesda, MD 20892-8316 301-496-8510</p> <p>http://seer.cancer.gov/</p>
Design	<p>A total of 17 population-based registries in the United States provide data on all residents diagnosed with cancer and follow-up information on all previously diagnosed patients. Data are compiled twice a year. Cancer mortality data are obtained from vital statistics for the entire United States.</p>
Timeframe	<p>Data have been collected annually since 1975. Data from 1979 through 2004 were used in this report.</p>
Sample Size	<p>Surveillance, Epidemiology, and End Results (SEER) program data for trends are 100 percent counts from Atlanta, Georgia; Connecticut; Detroit, Michigan; Hawaii; Iowa; New Mexico; San Francisco/Oakland, California; Seattle/Puget Sound, Washington; and Utah. SEER data for 2004 are 100 percent counts from the 9 registries above, plus Los Angeles, California; San Jose-Monterey, California; Rural Georgia; the Alaska Native Tumor Registry; Greater California; Kentucky; Louisiana; and New Jersey. National Center for Health Statistics mortality data are 100 percent counts from the entire United States.</p>
Content Relevant to Digestive Diseases	<p>Data regarding cancer incidence and mortality, including current and projected trends, are collected for selected sites, such as esophagus, stomach, colon, rectum, liver, and pancreas. Demographic data include age, sex, and race.</p>
Strengths	<p>SEER data are verified for quality and completeness. Data are estimated to be 99 percent complete from the registry sites. Mortality data are 100 percent counts of the United States. Trend data are available for about 30 years.</p>
Limitations	<p>SEER data represent only 17 areas of the country (and only 9 for trend data). Although the data are weighted to provide national estimates, these data are not statistically representative of the United States. Accuracy of cause of death coding for some gastrointestinal cancers is unknown.</p>
Availability of Data	<p>Data are published by the National Cancer Institute (http://seer.cancer.gov/publications/). Certain statistics can easily be generated online (http://seer.cancer.gov/statistics/). Selected data sets are available for analysis.</p>

Verispan

Sponsor	<p>Verispan 800 Township Line Road, Suite 125 Yardley, PA 19067 267-685-4300 (telephone) 267-685-4400 (fax)</p> <p>http://www.verispan.com/</p>
Design	<p>The Vector One®: National (VONA) is a national-level prescription and patient tracking service that provides data on the numbers of prescription drugs dispensed by retail pharmacies. Data on nearly half of retail prescriptions dispensed in the United States are collected each month and are projected to be nationally representative through methods that stratify by geography, pay type, and class of trade.</p> <p>The Physician Drug & Diagnosis Audit (PDDA) collects national-level disease state and associated therapy data from more than 3,100 office-based physicians representing 29 specialties. Physicians report all patient activity during one typical workday each month. Data collected are projected by region and specialty to be nationally representative of office-based physicians.</p> <p>Diagnosis data from the PDDA and prescription data from the VONA are utilized by the Factor Processor to segment the number of prescriptions, units dispensed, or retail sales by disease state or diagnosis, to estimate total number of prescriptions and total costs for specific diseases.</p>
Timeframe	The PDDA was established in 1990. Data from 2004 were used in this report.
Sample Size	Each month, data are captured on approximately half of all retail prescriptions dispensed in the United States. More than 3,100 office-based physicians report all patient activity during 1 typical workday each month.
Content Relevant to Digestive Diseases	The database includes International Classification of Diseases (ICD) codes for physician diagnoses that can be used to generate data on drugs prescribed for specific digestive diseases of interest.
Strengths	Data are nationally representative. Drug data are available for specific diseases defined by ICD codes.
Limitations	Estimates of total numbers of prescriptions and total costs for specific diseases are based on a factoring method applying information on physician prescribing practices to pharmacy data, rather than direct measurement. Number of prescriptions written by physicians may not be equivalent to number of prescriptions filled. Retail value of drugs may not be equivalent to the cost actually paid by patients. Prescription drugs from mail-order pharmacies are not included. Over-the-counter medications are not included.
Availability of Data	Summary statistics can be purchased through a contract with Verispan.

National Endoscopy Database (NED)/Clinical Outcomes Research Initiative (CORI)

Sponsor	<p>Clinical Outcomes Research Initiative 3303 Southwest Bond Avenue, Suite 15C Portland, OR 97239 888-786-2674 (toll-free telephone) 503-494-7401 (local telephone) 503 494-2699 (fax) 503-494-6522 (research services fax)</p> <p>http://www.corl.org/index.asp</p>
Design	U.S. endoscopy sites that voluntarily participate in the Clinical Outcomes Research Initiative (CORI) submit data on all endoscopic procedures performed at the sites.
Timeframe	CORI began in 1995 and is ongoing. Data from 2001 through 2005 were used in this report.
Sample Size	Currently, more than 275,000 procedure reports are received annually from 86 practice sites and more than 400 physicians in the United States. More than 1.7 million reports exist in the National Endoscopic Database (NED). Data used in this report came from 77 practices with 101 sites that performed a total of 542,650 colonoscopies, 270,957 esophagogastroduodenoscopies (EGD), 55,708 flexible sigmoidoscopies, 9,333 endoscopic retrograde cholangiopancreatographies (ERCP), and 6,945 endoscopic ultrasonographies (EUS), from 2001 through 2005.
Content Relevant to Digestive Diseases	Data collected include site and patient characteristics, indications for procedures, findings from procedures, completion rates, and unplanned event rates.
Strengths	The NED is the only U.S. national endoscopy database. Trends can be studied using data from a subset of “stable sites” that have participated for multiple consecutive years.
Limitations	Participation in CORI is voluntary; therefore, data from participating sites are not nationally representative.
Availability of Data	Through a contract with CORI, summary statistics can be purchased by persons outside the participating endoscopy sites.

National Nursing Home Survey (NNHS)

Sponsor	<p>Long-Term Care Statistics Branch Division of Health Care Statistics National Center for Health Statistics Centers for Disease Control and Prevention U.S. Department of Health and Human Services 3311 Toledo Road Hyattsville, MD 20782 301-458-4747</p> <p>http://www.cdc.gov/nchs/nnhs.htm</p>
Design	<p>The National Nursing Home Survey (NNHS) is a continuing series of nationally representative sample surveys of nursing homes in the United States. The survey includes all nursing homes with at least three beds that are either certified (by Medicare or Medicaid) or have a State license to operate as a nursing home. The design is a two-stage stratified probability sample of nursing homes and of current residents, persons discharged (deceased or alive) in the past year, and staff members within nursing homes. Data on residents and discharges are collected by interviewing a nurse who obtains the needed information from the medical records and the next of kin. The redesigned 2004 survey was administered using a computer-assisted personal interviewing (CAPI) system.</p> <p>The study design is described in: Shimizu I. The 1985 National Nursing Home Survey design. <i>Proceedings of the section on survey research methods, 1986 Annual Meeting of the American Statistical Association</i>. Chicago: American Statistical Association, 1987.</p>
Timeframe	<p>Data have been collected in 1973–74, 1977, 1985, 1995, 1997, 1999, and 2004. Data from 2004 were used in this report.</p>
Sample Size	<p>In 2004, 1,500 facilities were selected from a sampling frame of 16,628 nursing homes, and 1,174 facilities participated. A total of 14,017 residents were sampled from the responding facilities, and 13,507 participated.</p>
Content Relevant to Digestive Diseases	<p>Prevalence of chronic conditions by primary diagnosis, medications taken, functional status, receipt of services (medical, nursing, and therapeutic), discharge health status and length of stay by diagnosis, cost of providing care by diagnosed condition, and sources of payment are available. Information on fecal incontinence is specifically gathered. Also included are demographic characteristics of residents, health and functional status before nursing home admission, lifetime use of nursing home care, and amount of Medicaid spending. Ostomy patients and patients with alcohol abuse or dependence can be identified. Bowel and bladder incontinence was also recorded.</p>
Strengths	<p>The survey provides a source of health status data on the subgroup of the population residing in and discharged from all types of nursing homes for whom health care data are otherwise difficult to obtain. Primary and secondary diagnoses by International Classification of Diseases (ICD) code, which include the diseases of the digestive system, are available for residents at admission and discharge. Reasons for admissions from short-stay hospitals by selected diagnostic-related groups for age 70 years or older include esophagitis, gastroenteritis and miscellaneous digestive disorders, and gastrointestinal hemorrhage.</p>
Limitations	<p>Residents with a primary diagnosis of digestive disease make up a small percentage of the nursing home population. The survey is of limited use for examining specific conditions, which tend to be coded only broadly.</p>
Availability of Data	<p>Published data are found in the National Center for Health Statistics <i>Vital and Health Statistics</i>, Series 13 (http://www.cdc.gov/nchs/products/pubs/pubd/series/ser.htm#sr13) and in <i>Advance data</i> (http://www.cdc.gov/nchs/products/pubs/pubd/ad/ad.htm). Data are available for public use on the National Center for Health Statistics Web site in an easy-to-use form with input statements.</p>

National Home and Hospice Care Survey (NHHCS)

Sponsor	<p>Long-Term Care Statistics Branch Division of Health Care Statistics National Center for Health Statistics Centers for Disease Control and Prevention U.S. Department of Health and Human Services 3311 Toledo Road Hyattsville, MD 20782 301-458-4747</p> <p>http://www.cdc.gov/nchs/nhhcs.htm</p>
Design	<p>The National Home and Hospice Care Survey (NHHCS) is a continuing series of surveys of home and hospice care agencies in the United States. The survey includes all agencies that are licensed or certified (Medicare or Medicaid). The design is a two-stage stratified probability sample of home health and hospice agencies and of current patients and discharges within agencies. Data are collected through personal interviews with administrators and staff.</p> <p>The study design is described in: National Center for Health Statistics, Haupt BJ. <i>Development of the National Home and Hospice Care Survey</i>. Hyattsville, Maryland: Public Health Service, 1994; DHHS Publication No. (PHS) 94-1309. (<i>Vital and health statistics, Series 1, No. 33.</i>)</p>
Timeframe	Data were collected in 1992, 1994, 1996, 1998, and 2000. Data from 2000 were used in this report.
Sample Size	In 2000, 1,800 agencies were selected from a sampling frame of 15,451 home health and hospice care agencies, and 1,425 agencies participated. The patient sample consisted of approximately 14,000 total patients, split between home health and hospice, and between current patients and discharged patients.
Content Relevant to Digestive Diseases	Admission and discharge diagnoses, referral and length of service, number of visits, patient charges, health status, reason for discharge, and types of services were provided.
Strengths	This survey provides a source of health status data on the subgroup of the population receiving care from, or discharged from, all types of home and hospice care agencies for whom health care data are otherwise difficult to obtain. Primary and secondary diagnoses by International Classification of Diseases (ICD) code, which include the diseases of the digestive system, are available for residents at admission and discharge.
Limitations	The exact coverage of the current patients is unclear. The weighted total may underestimate or overestimate the number of patients enrolled in a given year due to the rolling nature of the survey and the length of stay of patients. In addition, cost data represent billed amounts and not paid amounts.
Availability of Data	Published data are found in the National Center for Health Statistics <i>Vital and health statistics, Series 13</i> (http://www.cdc.gov/nchs/products/pubs/pubd/series/ser.htm#sr13) and in <i>Advance data</i> (http://www.cdc.gov/nchs/products/pubs/pubd/ad/ad.htm). Data are available for public use on the National Center for Health Statistics Web site in an easy-to-use form with input statements.

Medical Expenditure Panel Survey (MEPS)

Sponsor	<p>Agency for Healthcare Research and Quality U.S. Department of Health and Human Services 540 Gaither Road, Suite 2000 Rockville, MD 20850 301-427-1364</p> <p>http://www.meps.ahrq.gov/mepsweb/</p>
Design	<p>The Medical Expenditure Panel Survey (MEPS) is a set of national surveys. The Household Component (HC) provides data from individual households and their members, which are supplemented by data from their medical providers. The HC collects data from a nationally representative subsample of households that participated in the prior year's National Health Interview Survey (NHIS). The selected subsample undergoes several rounds of interviews during 2 full years of follow-up. A new sample of households is included in the survey each year.</p> <p>The Medical Provider Component (MPC) surveys hospitals, physicians, home health care providers, and pharmacies identified by HC respondents to supplement and/or replace information received from the HC respondents.</p> <p>The Insurance Component (IC), also known as the Health Insurance Cost Study, is a separate survey of a sample of private and public sector employers that collects data on employer-based health insurance plans.</p>
Timeframe	Data have been collected annually since 1996. Data from 2004 were used in this report.
Sample Size	The 2004 HC surveyed 32,737 individuals from 13,018 families.
Content Relevant to Digestive Diseases	<p>Data collected in the HC on each person in the household include demographic characteristics, health conditions, health status, use of medical services, charges and source of payments, access to care, satisfaction with care, health insurance coverage, income, and employment.</p> <p>Data collected in the IC include the number and types of private insurance plans offered (if any), premiums, contributions by employers and employees, eligibility requirements, benefits associated with these plans, and employer characteristics.</p> <p>Data utilized in the current report were from the HC and consisted of counts of the number of days of work missed due to illness, injury, or hospitalization.</p>
Strengths	The sample is nationally representative of the U.S. population. Household data are supplemented by health care provider data. The survey includes data on number of days of work missed due to illness, injury, or hospitalization, which are unavailable from other data sources.
Limitations	Household data on medical conditions are by self-report.
Availability of Data	Summary data tables are published by the Agency for Healthcare Research and Quality on the MEPS Web site. An online database, MEPSnet, allows users to generate certain statistics easily (http://www.meps.ahrq.gov/mepsweb/data_stats/meps_query.jsp). HC data files are available for public use. IC data files are not released publicly. MPC data files are not available for public release; information from these files is incorporated into the HC data files.

APPENDIX 3

Methodology for Tables and Figures

Bryan Sayer, M.H.S.

This appendix provides information on the sources and computations for the tables and figures used in the chapters on digestive diseases.

I. DATA SOURCES

The number of ambulatory care visits, hospital discharges, and deaths in the tables and figures came from four sources (see Appendix 2 for descriptions):

1. Ambulatory care visits data in tables and figures came from the combined National Ambulatory Medical Care Survey (NAMCS)/National Hospital Ambulatory Medical Care Survey (NHAMCS) years 1992–2005 (<http://www.cdc.gov/nchs/about/major/ahcd/ahcd1.htm>).
2. Data on hospital discharges in the figures came from the National Hospital Discharge Survey (NHDS), years 1979–2004 (<http://www.cdc.gov/nchs/about/major/hdasd/nhds.htm>).
3. Hospital data in the tables came from the Healthcare Cost and Utilization Project Nationwide Inpatient Sample (HCUP NIS) for the year 2004 (<http://www.hcup-us.ahrq.gov/nisoverview.jsp>).
4. Mortality data came from the National Vital Statistics System Multiple Cause Mortality data years 1979–2004, as prepared by the National Bureau of Economic Research (<http://www.nber.org/data/multicause.html>).

For digestive cancers (Chapters 4–12), cancer incidence and survival were derived from the Surveillance, Epidemiology, and End Results (SEER) program of the National Cancer Institute (NCI) (<http://seer.cancer.gov/data>). Data in the tables for 2004 came from the 17 registry sites that SEER used at that time. Data in the figures for 1979–2004 were from the nine sites in operation during the entire period. Population data corresponding to the definition of the SEER sites were provided by SEER.

II. DISEASE DEFINITIONS

Digestive diseases were coded into 1 of 29 digestive disease categories based on the International Classification of Diseases (ICD)-9 CM (Clinical Modification) (<http://www.cdc.gov/nchs/icd9.htm>) code for morbidity, and either ICD-9 (1979–1998) or ICD-10 (1999–2004) for mortality. See Appendix 1 for the complete list of codes for each of the 29 diseases. The first-listed diagnosis was considered the primary diagnosis for tables and figures for primary digestive disease. All remaining diagnoses were considered secondary and were included under the category “All-Listed Diagnoses.” In the tables and figures for ambulatory care visits, hospital discharges, and mortality, diagnoses were counted only once under the all-listed category, irrespective of the number of actual diagnoses. For example, in the chapter on all digestive diseases, only one digestive disease diagnosis was counted, even though more than one could have been listed on a medical record or death certificate.

While the coding for digestive disease mortality is generally consistent between ICD-9 and ICD-10, the World Health Organization (WHO), which produces the ICD code definitions, advises that series are not necessarily comparable across versions of the ICD code book. This change was portrayed as a vertical line at 1999 on the mortality figures.

III. DEMOGRAPHIC CATEGORIES

For the purpose of calculating rates for the U.S. population, population data were derived from the national population estimates program of the U.S. Census Bureau and the Centers for Disease Control and Prevention (CDC) (<http://wonder.cdc.gov/population.html>). Population counts were specific for each of the demographic subgroups shown in the tables.

DEMOGRAPHIC SUBGROUP		POPULATION COUNT, 2004
AGE (Years)	Under 15	60,806,159
	15–44	125,824,714
	45–64	70,692,944
	65+	36,333,025
RACE	White	238,285,011
	Black	38,608,953
SEX	Female	149,121,439
	Male	144,535,403
TOTAL		293,656,842

Race was coded as “White” or “Black”; or “Other,” if another category was specified. Missing race data were not considered “Other.” The HCUP NIS data combine Hispanic origin with race, so it was impossible to know whether Hispanics were white or black. In order not to undercount the totals, we assumed all Hispanics were white. As a result, discharges for whites were slightly overstated and for blacks slightly understated.

HCUP NIS data came from the individual States, and 11 States did not report race in 2004. To adjust for this limitation, we created a separate weight for race, based on the existing weight times the inverse of the proportion of each race in the States that did report race to the total for the United States. Note that these are counts of persons, based on the 2004 mid-year population estimate, and not the proportion of discharges. We did not report separate counts for “Other” race, because the definition in the HCUP NIS and the population counts may not be the same.

IV. AGE-ADJUSTMENT

Age-adjustment through direct standardization allowed for comparisons across race, sex, and time that were not influenced by differences in age distribution for the groups being compared. Year-specific population data in 19 age groups, plus the National Center for Health Statistics (NCHS) standard year 2000 population, were

used for age-adjusting. (http://www.cdc.gov/nchs/data/nvsr/nvsr47/nvs47_03.pdf). Age-specific rates were calculated for each of the 19 age groups (age 0, age 1–4, 5-year age groups through age 84, and age 85 and older), and the results were multiplied by the year 2000 standard population proportion in each of the age groups. These results then were summed to arrive at the age-adjusted population rate estimate. Further details can be found in Anderson and Rosenberg.¹

V. TABLES

MORBIDITY ESTIMATES

1. **Ambulatory Care Visits** Estimates in the tables for ambulatory care visits in 2004 were from combined NAMCS/NHAMCS files for the years 2003–2005. Multiple years were combined in order to have sufficient observations to meet the minimum threshold for reporting and for more stable estimates. The 3 years of data were averaged by dividing the sampling weight by 3, in accordance with the general instructions from NCHS. The combined file included visits to freestanding physician offices and physician offices at hospitals, and emergency room visits that did not result in an overnight stay in the hospital.

First-Listed Diagnosis The primary diagnosis for an outpatient visit was the first diagnosis listed in the record. A visit was considered to have been for 1 of the 29 digestive diseases if the first of the diagnoses listed on the record fell into the subject category. Estimates for first-listed diagnosis for digestive diseases included the number of visits and the rate of visits per 100,000 of the population. The rate per 100,000 was the number of visits, not the number of individuals with a visit, divided by the number of persons (in 100,000s) in the population in the specific subgroup.

The weighted count of visits with a first-listed diagnosis of each of the digestive diseases was the count (in thousands) listed in the table under “Ambulatory Care Visits,” “First-Listed Diagnosis,” “Number in Thousands.” The “Rate per 100,000” was calculated by dividing the count of visits by the

number of persons (in 100,000s) in the population in the specific subgroup.

All-Listed Diagnoses Each outpatient record could have multiple diagnoses listed. A visit was considered to have been for a specific digestive disease if any of the diagnoses listed on the record fell into the subject category. Therefore, any individual record could be counted for more than one digestive disease. However, a given record was not counted more than once for a specific disease. For example, a record having the ICD-9-CM diagnostic codes of “001” and “002” was only counted once in the category of Gastrointestinal Infections. The weighted count of visits with all-listed diagnoses of each of the digestive diseases was the count (in thousands) listed in the table under “Ambulatory Care Visits,” “All-Listed Diagnoses,” “Number in Thousands.” The “Rate per 100,000” was calculated by dividing the count of visits by the number of persons in the population (in 100,000s) in the demographic subgroup.

- Hospital Discharges** Hospital discharges were based on inpatient stays of at least 1 night. Emergency room visits that did not result in an admission to the hospital with an overnight stay were not counted. Data in the tables came from the 2004 HCUP NIS file of hospital discharges from participating States. Sampling weights inflated the discharges to the U.S. total, based on information from the American Hospital Association. Data in the figures showing age-adjusted hospital discharges over time were based on the NHDS, 1979–2004.

First-Listed Diagnosis The primary diagnosis for a hospital discharge was the first diagnosis listed in the record. Inpatient estimates for first-listed diagnosis for digestive diseases included the number of discharges and the rate of discharges per 100,000 of the population. The weighted count of hospital discharges with a primary diagnosis of each of the digestive diseases was the count (in thousands) listed in the table under “Hospital Discharges,” “First-Listed Diagnosis,” “Number in Thousands.” The “Rate per 100,000” was the number of discharges, not the number of individuals

with an inpatient stay, divided by the number of persons (in 100,000s) in the population in the specific subgroup.

All-Listed Diagnoses Each hospital discharge record could have multiple diagnoses listed. A discharge was considered to have been for a specific digestive disease if any of the diagnoses listed on the record fell into the subject category. Therefore, any individual record could be counted for more than one digestive disease. As with ambulatory care visits, a given record was not counted more than once for a specific disease. For example, ICD-9-CM diagnostic codes of “001” and “002” were only counted once in the category of Gastrointestinal Infections. The weighted count of hospital discharges with all-listed diagnoses of each of the digestive diseases was the count (in thousands) listed in the table under “Hospital Discharges,” “All-Listed Diagnoses,” “Number in Thousands.” The “Rate per 100,000” was calculated by dividing the count of hospital discharges by the number of persons in the population (in 100,000s) in the demographic subgroup.

MORTALITY

Counts for 2004 for deaths from digestive disease were derived from the Multiple Cause-of-Death data files from the Division of Vital Statistics, CDC. These data are a complete accounting of all deaths in the United States (although not necessarily for all U.S. citizens). Cause of death is organized on a record axis, with a specific underlying cause of death and contributing causes for each decedent.

- Underlying Cause of Death** The underlying cause of death was determined from the list of all causes on the death certificate by professional coders. Underlying cause is analogous to a first-listed diagnosis for morbidity. The “Number of Deaths” column for “Underlying Cause” was a count of the number of records in the file with each digestive disease as the underlying cause of death.

The “Rate per 100,000” column was determined by dividing the number of deaths with the underlying cause by the population (in 100,000s) in the

demographic subgroup. The race- and sex-specific estimates were age-adjusted, while the age-specific rates and the total were not age-adjusted.

“Years of Potential Life Lost” assumed life expectancy of 75 years, had individuals not died before that age. Because age at death is reported in full years, we added 0.5 years to each age at death. Thus, for the purpose of calculating years of life lost, a person whose age at death was listed as 65 was counted as having been 65.5 years old. The age 65.5 represented the average age of all persons who died at age 65, and each contributed 9.5 years of potential life lost ($75 - 65.5 = 9.5$). The tables showed the total number of years of life lost to age 75 in thousands.

2. Underlying or Other Cause of Death The record axis of the death certificate can contain up to 20 contributing causes in addition to the underlying cause. A recording of any of the 29 unique digestive diseases was noted for each of the 21 total possible causes, and any duplicate digestive diseases were eliminated. A death was attributed to one of the digestive diseases if any of the unduplicated digestive diseases were recorded. Therefore, a death could appear under more than one of the digestive diseases in the “Underlying or Other Cause” column of the tables. Unlike the underlying cause, only the “Number of Deaths” and the “Rate per 100,000” were shown for “Underlying or Other Cause.” “Years of Potential Life Lost” were irrelevant.

“Number of Deaths” (in 100,000s) was the count of all deaths that had the specified digestive disease listed in any position on the record axis. A death could appear under more than one disease if any of the diagnoses were listed; however, no death appeared more than once for a given disease.

The “Rate per 100,000” column was determined by dividing the number of deaths for underlying or other cause by the population (in 100,000s) in the demographic subgroup. The race- and sex-specific estimates were age-adjusted, while the age-specific rates and the total were not age-adjusted.

CANCER INCIDENCE

Cancer incidence and 5-year survival rates in Chapters 4–12 were derived from SEER registry data. The registries did not cover the entire United States, nor necessarily represent the entire population. Instead, each registry covers a specific set of counties, usually statewide, across diverse sections of the country. (For more information on registries, see SEER.^{2, 3}) Population counts used for rates and age-adjustment were also restricted to the counties covered by the registry. Only estimates based on unweighted counts of 17 or more cases were shown, following the reporting standard set by NCI.

Cancer incidence was estimated for the entire country from the rates for the 17 registries in 2004, multiplied by the 2004 U.S. population. This yielded an estimated number of new cases for the United States in 2004. The unadjusted and age-adjusted incidence rates were based only on the 17 registry areas. Unadjusted rates were calculated from the number of new cases in 2004 divided by the population in the demographic subgroup. Age-adjusted incidence rates were calculated from the age-specific rates within the demographic subgroup multiplied by the U.S. standard 2000 population as described in section IV. Age-Adjustment.

VI. FIGURES

MORBIDITY ESTIMATES

The figures showing trends in ambulatory care visits and hospital discharges for the period 1979–2004 used the all-listed diagnoses. The all-listed diagnoses were defined the same as for the tables. However, the data source for hospital discharges was the NHDS because HCUP NIS data were unavailable over the entire timeframe. Because of the smaller sample size for the ambulatory care surveys, estimates derived from NAMCS/NHAMCS files were 3-year averages, except for the 1992 estimates, which were averages of 1992 and 1993 data. This approach provided more stable estimates across time. The year 1992 was the starting point, because this was the first year of the NHAMCS. All rates were age-adjusted.

MORTALITY

The figures showing mortality data for the period 1979–2004 used the multiple cause-of-death data for each year. Because these were observed counts for the United States and not samples, they were not considered estimates. The age-adjusted mortality rates were shown for both underlying cause and underlying or other cause for the total population per year. The vertical line at 1999 represented the change from ICD-9 to ICD-10.

CANCER INCIDENCE AND 5-YEAR SURVIVAL

For digestive cancers (Chapters 4–12), the figures for age-adjusted cancer incidence and 5-year survival were derived from data obtained by the nine registries that SEER used through the entire period 1979–2004. Five-year survival was the proportion of those diagnosed in a given year who were still known to be alive 5 years later. Five-year survival ended at 1999, because it was impossible to know the 5-year status of patients diagnosed after that year. Absolute survival is shown in these figures, whereas SEER typically publishes relative survival. Relative survival takes into account

the expected survival of the population as a whole and is higher than absolute survival, especially for cancers that concentrate in groups with high underlying mortality, such as the elderly.

¹ Anderson RN, Rosenberg HM. Age standardization of death rates: implementation of the year 2000 standard. 3:1-20. October 7, 1998. *National Vital Statistics Reports*. Hyattsville Maryland: National Center for Health Statistics.

² *Surveillance, Epidemiology, and End Results (SEER) Program Limited-Use Data (1973–2005)* (www.seer.cancer.gov). National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch. Released April 2008, based on the November 2007 submission.

³ *US Population Data 1969–2005*. Downloaded from *SEER Program Populations (1969–2005)* (www.seer.cancer.gov/popdata). National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch. Released April 2008.

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