

# INDEX

- Accountability principle, 15
- Accountable Care Organizations (ACOs), 19
- Advance Care Planning, 20
- Advocacy, 120
- Affordable Care Act (ACA), 19, 100
- Agency for Healthcare Research and Quality (AHRQ), 2
- Allscripts, 80
- Alteryx Designer Product, 35
- American Community Survey (ACS), 27, 29, 125
  - data, 64
  - data profile, 31–32
  - wrangling ACS data, 30–32
- Anderson-Darling Goodness of Fit, 92
- Annual Homeless Assessment Report, 28
- Anticipatory grieving, 7
- Application programming interfaces (APIs), 23, 30, 126, 140
  - usage, 140–145
- Architecture, 138
- Behavioral Risk Factor Surveillance System (BRFSS), 28, 32–35
- Bias, 6, 32, 80
- Biomedical ethics, 152
- Body Mass Index (BMI), 35, 71
- Bundled payments, 20
- Bureau of Economic Analysis, 4
- Bureau of Economic Data (BEA), 62
- Bureau of Labor Statistics, 4, 62
- California Consumer Privacy Act of 2018 (CCPA), 13
- Care group, 99, 101, 120
- Center to Advance Palliative Care (CAPC), 6
- Centers for Disease Control (CDC), 6, 28, 62
  - BRFSS, 4, 70–77, 112
- Centers for Medicare and Medicaid Services (CMS), 6
- Cerner, 80
- Certificate Authority (CA), 138
- Children’s Health Insurance Program (CHIP), 19
- Chronic care management, 20
- Chronic conditions, 71
- Client, 112
- Client–server model, 137
- Clinical decision support (CDS), 19
- Collection limitation principle, 14
- Comma separated values (CSV), 80
- Comorbidity count distribution, 92–94
- Comprehensive care for joint replacement (CJR), 20
- Comprehensive Primary Care Plus program (CPC+ program), 20
- Consumer Assessment of Healthcare Providers and Systems (CAHPS), 19
- Consumer privacy law in US, 13
- Contingency table, 87
- Continuum of Care Programs (CoCs), 28
- Cross-Agency Priority (CAP), 62
- Cross-reference data base definition, 126–128
- Cumulative Distribution Functions (CDFs), 87
- Current procedural terminology (CPT), 19

- Data mapping to characteristics of care, 112–113
- Data privacy, 82
  - API, 140–145
  - architecture, 138
  - dataset generation, 148–149
  - installation of client components, 139–140
  - Kaplan-Meier curve generation, 149
  - Kaplan-Meier data, 148
  - Palliative Patient Web Pages, 145–148
  - security, 138
  - subscription, 138
- Data profiles (DPs), 30, 125
  - ACS, 31–32
  - DP02, 37–43
  - DP02001E, 30
  - DP02001ME, 30
  - DP02001P, 30
  - DP02001PM, 30
  - DP03, 44–49
  - DP04, 50–55
  - DP05, 56–59
- Data quality principle, 14
- Data repository design
  - cross-reference data base definition, 126–128
  - cross-reference example, 131
  - data base tables for storing targeted ACS five-year data, 132–133
  - populating cross-reference data, 128–131
  - retrieving ACS five-year data, 131–132
  - storing ACS five-year data, 134
- Data science
  - address disparities in access to palliative care, 8
  - concerns in palliative care, 7
  - facilitating transition to palliative care, 7
- Database, 126
- Death Anxiety, 7
- Decision support, 3
- Decryption, 138
- Demographic, 28
- Denial of Need for Care, 120
- Digital certificates, 138
- Digital Imaging and Communications in Medicine (DICOM), 4
- Digital privacy, 10
- E-Government Act of 2002, 13
- Education, 68–69, 98–99
- Electronic Communications Privacy Act (ECPA), 12
- Electronic Health Records (EHR), 4, 17–18, 80
  - addition popular EHRs, 89
  - data privacy and accuracy, 81–82
  - primary characteristics, 81
  - systems, 80
- Electronic Medical Record (EMR), 80
- Electronic Palliative Care Coordination Systems (EPCCS), 19
- Emergency room (ER), 22
- Employment, 69, 99
- Encounter Notification Services (ENS), 22
- Encryption, 138
- Epic, 80
- Ethics, 152
  - additional observations, 154
  - assiduous cultivation of data sources, 155
  - avoid imposing non-clinical risks, 153
  - common good, 154
  - conduct responsible activities, 154
  - informed consent, 155
  - LHSs and, 152
  - medical decision-making, 155
  - optimal clinical care, 153
  - reduce health inequalities, 154
  - respecting clinician judgment, 153
  - respecting rights and dignity of patients, 152–153
- Evaluation and management (EM), 21

- Federal Communications Act, 11
- Federal data strategy, 62
- Federal Information Processing System (FIPS), 132
- Federal Wiretap Act of 1968, 12
- Fourth Amendment's limitation of searches and seizures, 11
- Framingham Study, The, 2
- Freedom of Information Act (FOIA), 12
  
- Gehan-Breslow-Wilcoxin test, 117
- General Data Protection Regulation on Scientific Research (GDPR), 15
- Generic Module Framework (GMF), 82
- Geriatric Syndrome, 97
- Group, 2, 149
- Group assignment, 115–116
- GUID, 141, 143, 148
  
- Hazard rate, 118
- Health and Human Services (HHS), 19
- Health information exchange (HIE), 19
  - tapping into HIE services, 22–23
- Health Insurance Portability and Accountability Act of 1996 (HIPAA), 9–10, 12–13, 23, 80
  - Privacy Rule, 81
- Health Management Organizations (HMOs), 67
- Healthcare system, 17
- Heuristics in palliative care, 6–7
- Home movement, riding hospital at, 24
- Homeless Data Exchange (HDX), 28
- Homeless Research Institute, 6
- Housing and Urban Development Exchange (HUD Exchange), 4, 28, 64
  
- Illusion of control, 7
- Income, 70, 100
  - 0%–150% of poverty level by sex-race-age group, 109
  - 150%–250% of poverty level by sex-race-age group, 110
  
- Incomplete secondary education by sex-race-age group, 103
- Individual participation principle, 15
- Information blocking, updated rules regarding, 23–24
- Information technology, 19, 22, 24
- Informed consent, 155
- Instagram, 62
- Insurance, 67–68, 99–100
- International standards for privacy, 14–15
- Internet of Things (IoT), 5
  
- JavaScript Object Notation (JSON), 132
  
- Kaplan-Meier analysis, 117
- Kaplan-Meier curve, 113–115
  - generation, 117–118
  - generation, 149
  - mean and median output, 117
  - pairwise tests on, 118
  - use of, 118–120
- Kaplan-Meier data, 148
- Kaplan-Meier survival analysis, 94, 101
- Katz test, 11–12
- Katz v. The United States*, 11–12
  
- Learning activities, 152
- Learning Health Systems (LHSs), 1–2, 112, 137, 151
  - address disparities in access to palliative care, 8
  - ethical foundation for, 152
  - ethics and, 152
  - recommendations, 3
- Legal standards, 13
- Log-Rank test, 117
- Luxembourg data protection authority, 15
  
- Machine learning, 7
- Mantle-Cox test (*see* Log-Rank test)
- Medicaid, 18
- Medical decision-making, 155

- Medicare Access and the Children's Health Insurance Program Reauthorization Act (MACRA), 19
- Medicare beneficiaries and data, 18–19
- Medicare Shared Saving Programs (MSSP), 19
- Meditech, 80
- Merit-based Incentive Payment System (MIPS), 19
- Meta (Facebook), 62
- Metabolic Syndrome, 71
- Metadata, 125–126, 128
- Migration Policy Institute (MPI), 4, 6, 64
  
- National Health Interview Survey (NHIS), 6
- National Institutes of Health (NIH), 82
- Natural Language Processing (NLP), 7
- New York Senate Bill S6701, 13
  
- Olmsted v. The United States*, 11
- Openness principle, 14
- Oregon, 22
- Organization for Economic Co-operation and Development (OECD), 13–14
- Overall Health, 120
  
- Palliative care, 2, 18–19, 91, 137
  - approaches to supporting palliative care data collection in real time, 21–23
  - data science address disparities in access to, 8
  - data science concerns in, 7
  - data science facilitating transition to, 7
  - heuristics in, 6–7
  - key barriers to, 3
  - providers, 2
- Palliative data, 4
  - validity, 5
  - variety, 4–5
  - velocity, 5
  - veracity, 5
  - volatility, 5
  - volume, 4
- Palliative Patient Web Pages, 145–148
- Personally Identifiable Information (PII), 13, 61
- Poverty level, 32, 64
- PRAXIS, 80
- Prescription Drug Monitoring Programs (PDMPs), 20
- Primary Care First Program, 20
- Privacy, 9
  - current understanding of privacy in US, 13–15
  - GDPR, 15
  - history of privacy in US, 10–13
- Privacy Act of 1974, 13
- Private insurance, 67
- Private key, 138
- Protected Health Information (PHI), 12, 80
  
- Public data sources, 27–29
  - BRFSS, 32–35
  - CDC BRFSS, 70–77
  - employment, 69
  - evolving nature of data, 62–63
  - federal data strategy, 62
  - income, 70
  - overall data aggregation, 35
  - population characteristics, 63
  - US Census ACS, 63–69
  - US census five-year ACS, 29–30
  - wrangling ACS data, 30–32
- Public key, 140
- Public key infrastructure (PKI), 138
- Public Use Microdata Sample (PUMS), 84–85
- Publicly available data, 79
- Purpose specification principle, 14
- Python script, 131
  
- Quality of life, 118
- Query, 146

- Referral process, 18
- Refugee Processing Center (RPC), 6
- Remote patient monitoring platforms, 17–18
- Right to privacy, 10
- Risk-based payment systems, intersecting with, 17–18
- Sampling, 148
- Secondary education by sex-race-age group, 104
- Security, 138
  - safeguards principle, 14
- Server, 12, 81
- Simulation, 82
- SQL, 128
- Stanford Encyclopedia of Philosophy online, 10
- Stratified random sampling, 149
- Subscriber, 138
- Survival analysis, 112
- Synthea, 82
  - augmenting Synthea data, 84–87
  - comorbidity count distribution, 92–94
  - conditions, 90
  - CSV, 83
  - data baseline, 91–92
  - data mapping process, 112
  - demographic characteristics, 95–98
  - demographic summary, 101
  - education, 98–99
  - employment, 99
  - identifying palliative patients, 94–95
  - income, 100
  - insurance, 99–100
  - output files, 83
  - output formats, 83
  - simulation, 82
- Synthetic patient records, 87
- Synthetic patients, 92
- Tarone-Ware Test, 117
- Telehealth services, 17–18, 21
- Text mining, 7
- Translation, 64–66, 120
- Twenty-first Century Cures Act, 23
- Twitter, 62
- Unconscious bias, 5–6
- Underemployed status by sex-race-age group, 106
- Underinsured by sex-race-age group, 108
- Unemployed status by sex-race-age group, 105
- Uninsured by sex-race-age group, 107
- United States (US), 2, 18, 27, 92, 152
  - current understanding of privacy in, 13–15
  - history of privacy in, 10–13
- United States Census Bureau, 6, 30, 62, 126
- United States Core Data for Interoperability (USCDI), 23
  - USCDI V2, 23
- Unstructured data analysis, 7
- US Census American Community Survey, 4, 28, 63, 112
  - education, 68–69
  - insurance, 67–68
  - translation, 64–66
- US census five-year ACS, 29–30
- US Department of HUD, 6
- Use limitation principle, 14
- Validity, 5
- Value-based care and data use incentives, 19–21
- Variety, 4–5
- VBA script, 130
- Velocity, 5
- Veracity, 5
- Volatility, 5
- Volstead Act, 11
- Volume, 4
- WhatsApp, 62
- World Health Organization (WHO), 2, 6
- Wrangling, 4, 30–32