

Acronyms and Glossary

Below are terms that University of Florida Citizen Scientists may need to be familiar with as part of their work. Feel free to add any to this list, as it is meant to be a living document and a useful resource for you.

Acronyms

ACA: Affordable Care Act
AHCA: Agency for Health Care Administration
CAD: Coronary Artery Disease
CCD: (also called CCR) Continuity of Care Document/Record
CKD: Chronic Kidney Disease
CDM: Common Data Model
CDRN: Clinical Data Research Network
CER: Comparative Effectiveness Research
CPF: Community Practice Facilitator
CPT: Current Procedural Terminology
CRC: Clinical Research Center
CS: Citizen Scientist
CTSA: Clinical and Translational Science Award through NIH
CTSI: Clinical and Translational Science Institute at UF
CVAD: Cardiovascular Arterial Disease
CVD: Cardiovascular Disease
DMD: Duchenne Muscular Dystrophy
DUA: Data Use Agreement
EHR: (also called EMR) Electronic Health/Medical Record
FDoH: Florida Department of Health
HBP: High Blood Pressure (also referred to as HTN which is hypertension)
HCPCS: Healthcare Common Procedure Coding System
HCV: Hepatitis C Virus
HIPAA: Health Information Portability and Accountability Act
I2B2: Informatics for Integrating Biology and the Bedside
ICD: International Classification of Diseases
IDR: Integrated Data Repository
IGNITE: Implementing Genomics in Practice
IOM: Institute of Medicine
IRB: Institutional Review Board
ISP: Implementation Science Program
MoA: (also called MOU) Memorandum of Agreement/Understanding
MOC: Maintenance of Certification
NCATS: National Center for Advancing Translational Sciences at NIH
NHLBI: National Heart, Lung and Blood Institute

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NIDCR: National Institute of Dental and Craniofacial Research
NIH: National Institutes of Health
NINDS: National Institute of Neurological Disorders
PBRN: Practice-Based Research Network
PPRN: Patient-Powered Research Network
PCOR: Patient Centered Outcomes Research
PCORI: Patient Centered Outcomes Research Institute
PCORnet: Patient Centered Outcomes Research Network
PFA: PCORI Funding Announcement
PheKB: Phenotype Knowledge Base
PHI: Protected Health Information
PI: Principal Investigator
PMS: Phelan-McDermid Syndrome
PROs: Patient Reported Outcomes
QI: Quality Improvement
QoL: Quality of Life
REDCap: Research Electronic Data Capture
RED-I: REDCap Importer
SAS: Statistical Analysis Software

Glossary

Algorithm: A step-by-step set of operations (mathematical equations) that are used to perform reasoning, or a set of rules that defines a sequence of operations.

Bioinformatics: biomedical informatics; information and data related to a patient and their medical records. This information is typically used to improve outcomes and patient health care quality.

Common Data Element: Standardized pieces of data that are expected to be collected and are then used across networks.

Common Data Model: Standardizes the definition, content, and format of data across networks to enable a single standardized view that can be used for querying. The PCORI Common Data Model is a list of data tables with the patient elements of interest; a set of rules on how to properly format them.

Comparative Effectiveness Research: The direct comparison of existing health care interventions to determine which work best for which patients and which pose the greatest benefit or harm.

Computable Phenotype: An electronic algorithm used to identify certain conditions or characteristics. This process can be used to identify cohorts of individuals for studies.

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Consent2Share: A database of people who are willing to have their medical records flagged as someone who is interested in hearing about research opportunities, and then allow UF Health to share their name and contact information with UF researchers when their medical records show they might qualify for a future research study.

Continuity of Care Document: An electronic document exported to summarize patient care (Same as a Continuity of Care Record)

Claims Data: Payment information provided by your insurance carrier for payable medical, dental, and prescription (and other) benefits.

Empirical evidence: Information acquired by observation or experimentation. This data is recorded and analyzed by scientists and is a central process as part of the scientific method.

False-Positives: Data showing up as true/positive when test and experiences prove it as false. Example is that there are more kids with asthma diagnoses than kids who actually have asthma. This is due to one episode of some sort of respiratory distress, which gets diagnosed as asthma when there is no established pattern of respiratory distress.

Genotype: The inherited genetic instructions of an organism.

Heterogeneity: How treatments effect different populations

Honest Broker: An appointed entity that keeps private information, but distributes parts of those sets of data to other entities (researchers) who do not need all of the information. The purpose of this is to protect identity, and this person (or persons) is also a decision maker in whether to allow use of the existing data or materials.

Hypertension: Constant High Blood Pressure is the symptom for a hypertension diagnosis

Incidence: The rate of occurrence of something, especially of something unwanted. For example: The rate of new cases (the incidence) of diabetes in 2012 was 1.7 million new diagnoses.

I2B2: NIH funded National Center for Biomedical Computing. This scalable informatics framework enables researchers to use existing clinical data for discovery research and facilitate designs of targeted therapies.

Memorandum of Agreement/Understanding: A written document between parties to cooperate on an agreed upon project or objective.

Morbidity: Refers to having a disease or a symptom of disease, or to the amount of disease within a population. Morbidity also refers to medical problems caused by a treatment.

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Mortality: In medicine, this term refers to the death rate, or the number of deaths in a certain group of people in a certain period of time. Mortality may be reported for people who have a certain disease, live in one area of the country, or who are of a certain gender, age, or ethnic group.

n: Number of participants. In a research study $n=100$ means that 100 individuals participated in the research study.

Obfuscate: To make something more difficult to understand. For instance, when identifying the possible number of people, using i2b2 for cohort discovery, the results will come back as ± 3 in order to make it unclear exactly how many people have a specific disease. This is used to protect the identity of people with a specific disease.

Personalized Medicine: The customization of healthcare based on individual traits such as genetics, and other information that guides medical decision making, practices, and/or products being tailored to the individual patient are the basis for personalized medicine. Also called precision health care.

Pharmacogenetics: Pharmaceutical treatments that are personalized through genetic information.

Phenotype: An organism's observable characteristics or traits resulting from the expression of genetic material coupled with the environmental factors the organism is exposed to.

Pragmatic Clinical Trials: Pragmatic trials are designed to evaluate the effectiveness of interventions in real-world settings and routine practice conditions, whereas explanatory trials aim to test whether an intervention works under optimal situations.

Prevalence: The proportion of individuals in a population having a disease or characteristic. Prevalence is a statistical concept referring to the number of cases of a disease that are present in a particular population at a given time, whereas incidence refers to the number of new cases that develop in a given period of time. For instance, as of 2012, 29.1 million Americans, or 9.3% of the population had diabetes (prevalence).

Query: The mechanism for getting information from a database. They are questions that are asked of the database in a predefined format, written in a language that the computer understands in order to produce.

Randomized Clinical Trial: A study in which the participants are assigned by chance to separate groups that compare different treatments; neither the researchers nor the participants can choose which group. Using chance to assign people to different groups means that the groups will be similar and that the treatments they receive can be compared objectively. At the time of the trial, it is not known which treatment is best. It is the patient's choice to be in a randomized trial.

State Agency Directors: The Directors of the Agencies of the Department of Health, FL Medicaid, etc.

Steering Committee: A steering committee is a body within an enterprise that supports the steering of its actions. Its main concern is making strategic concerning future realization of the enterprise's projects.