Health Terminologies and Vocabularies

Environmental Scan findings as of September 1, 2017

Findings from June 21 hearing, research, and interviews

NCVHS Charges Related to Data Standards

- "Study the issues related to the adoption of uniform data standards for patient medical record information and the electronic exchange of such information and report to the Secretary of Health and Human Services (HHS) recommendations and legislative proposals for such standards and electronic exchange."
- "Advise the Department on health data collection needs and strategies; review and monitor the Department's data and information systems to identify needs, opportunities, and problems."

Health Terminologies and Vocabulary Project Goals, Scoping document, 6/20/17

Take a contemporary look at the health terminology and vocabulary landscape in order to advise the Secretary regarding

1. The changing environment and implications for timing and approach to health terminology and vocabulary standards adoption,
2. Needs, opportunities, and problems with development, dissemination, maintenance, and adoption of health terminology and vocabulary standards,
3. Actions that HHS might take to improve development, dissemination, maintenance, and adoption of standards.

National Committee on Vital and Health Statistics

Advising the Secretary of Health and Human Services on health information policy since 1949.

NCVHS Terminology and Vocabulary Milestones

1998

Principles for guiding choices for the standards to be adopted by the Secretary.
https://www.gpo.gov/fdsys/pkg/FR-1998-05-07/pdf/, p. 25274

2000

Report: *Uniform Data Standards for Patient Medical Record Information* (2000) https://www.ncvhs.hhs.gov/wp-content/uploads/2014/08/hipaa000706.pdf

2001

Report: *Information for Health: A Strategy for Building the National Health Information Infrastructure* (2001)https://aspe.hhs.gov/report/information-health-strategy-building-national-health-information-infrastructure

2003

Letter to Secretary recommending that HHS initiate the regulatory process for the concurrent adoption of ICD-10-CM and ICD-10-PCS
https://www.ncvhs.hhs.gov/recommendations-reports-presentations/november-5-2003-letter-to-the-secretary-icd-10-recommendations/

2003

Letter to Secretary recommending adoption of PMRI Standards.
https://www.ncvhs.hhs.gov/wp-content/uploads/2014/05/031105lt3.pdf

2012-14

Letters to the Secretary pertaining to ICD-10 implementation
https://www.ncvhs.hhs.gov/wp-content/uploads/2014/05/120302lt4.pdf
https://www.ncvhs.hhs.gov/wp-content/uploads/2014/05/130920lt.pdf
https://www.ncvhs.hhs.gov/wp-content/uploads/2014/05/140515lt3.pdf

Health Terminologies and Vocabularies Defined

*(NCVHS, 2000)**

- **Terminology** - a collective term used to describe the continuum of code set, classification, and vocabulary.
- **Code** - a representation assigned to a term so that it may more readily be processed. In general, most terminologies incorporate a coding system for computer processing.
- **Classification**- arranges or organizes like or related terms for easy retrieval (e.g. ICD-10)

- **Vocabulary** - a set of specialized terms that facilitates precise communication by minimizing or eliminating ambiguity. (e.g. SNOMED-CT)
  - "Controlled vocabulary" indicates only the set of individual terms in the vocabulary.
  - "Structured vocabulary" or "reference terminology," relates terms to one another (with a set of relationships) and qualifies them (with a set of attributes) to promote precise and accurate interpretation. These relationships and attributes may be represented in some type of an information model.
  - Vocabularies are mapped to standard terminologies
- **Nomenclature** – synonym of vocabulary

*NCVHS "Uniform Data Standards for Patient Medical Record Information (PMRI) as required by the Administrative Simplification Provisions of the Health Insurance Portability and Accountability Act of 1996" July 6, 2000, p. 24

Terminologies and Vocabularies Developed, Maintained and/or Disseminated by the Federal Government

CDC/National Center for Health Statistics

- The Collaborating Center for the WHO Family of International Classifications for North America
  - ICD-10-CM
  - ICF (International Classification of Functioning, Disability and Health
  - Classification of Death and Injury Resulting from Terrorism
  - ICD-O

CMS

- ICD-10-PCS
- HCPCS – Levels I and II

National Library of Medicine

- Designated as the central coordinating body for PMRI (Patient Medical Record Information) Terminology Standards
  - SNOMED CT
  - LOINC
  - RxNorm
- UMLS

Named Standards

Name	Purpose	Ownership/Governance	Development and Maintenance	Release
SNOMED-CT (Systematized Nomenclature of Medicine -- Clinical Terms)	Clinical terminology with global scope enabling automation of reasoning and analytical approaches to process EHR data ***Named standard for Meaningful Use***	Owned and maintained by the SNOMED International (IHTSDO); NLM is the US member.	International Advisory Groups for editorial, terminology releases, and content; Clinical reference groups expand dialogue with specialists and address emerging uses such as precision medicine. Extensive partnerships and collaborations with AMA, LOINC, WHO, LOINC, etc. Formal change request process; Mappings to ICD-10- CM, ICD-10, LOINC, ICPC and others; US releases available through UMLS;	US Editions released in March and September; Mapping files and other derivatives throughout the year
LOINC (Logical Observation Identifiers Names and Codes)	Universal standard for identifying health measurements, observations and documents. ***Named standard for Meaningful Use***	Owned and maintained by Regenstrief Institute, Inc.	LOINC Committee defines overall naming conventions and policies for the development process; Committee has laboratory, clinical, and nursing subgroups. Change request process; Each release contains about 1,400 new terms. To advance use, RELMA software helps users map their local terms or lab tests to LOINC codes. Apps aid use of LOINC by developers.	June and December releases
RxNorm	Drug terminology for the US that presents drugs from prescribers' point of view (ingredient + strength + dose form) ***Named standard for Meaningful Use and electronic exchange in government systems***	Developed and maintained by NLM.	Derived from other commonly used public and private drug terminologies including FDA structured product labeling (NDC); major editorial policy changes informed by user feedback. Changes compiled from data sources received monthly except FDA NDC codes which are updated daily.	Full release each month for UMLS licensees and in May and November through UMLS Metathesaurus; new drug updates weekly; API queried over 800 million times in 2016 by 20K unique users.

Named Standards

System	Purpose	Ownership/Governance	Development and Maintenance	Release
ICD-10 (International Classification of Diseases and related health problems, 10th rev)	Cause of death coding from death certificates; in use in US since 1999 (statutory basis)	World Health Organization holds copyright.	WHO Update and Revision Steering Committee (URC) assesses the need to update ICD and the need to revise particular areas of the classification. Once the plan is approved, the URC oversees the revision effort. Changes must be sponsored by one of the WHO Collaborating Centers for Classification of Disease. NCHS serves as US Center.	URC responsible for revisions annually or less frequently; Major revisions approximately every decade.
ICD-10-CM (International Classification of Diseases, clinical modification, 10th revision)	Classification of Diseases and Related Health Problems Named HIPAA standard for morbidity in outpatient, inpatient and other care settings.	World Health Organization holds copyright. CDC/NCHS develops and maintains Clinical Modification for use in the U.S.	CDC/NCHS participates in development of ICD versions and develops conforming Clinical modification (CM) for US use. Maintenance through the Coordination and Maintenance (C & M) Committee which receives and considers code change proposals through an open process. CDC/NCHS is final authority for changes to ICD-10-CM. The Cooperating Parties comprised of NCHS, CMS, AHA and AHIMA advise on changes and develop coding guidelines. Cooperating Parties serve as Editorial Advisory Board (EAB) to Coding Clinic sponsored by AHA. AHA maintains the central office on ICD-10-CM for handling coding questions from the field.	Annual updates effective October 1 of each year; Official output files posted on NCHS and via NLM UMLS.
ICD-10-PCS (ICD-10 Procedure Coding System)	Classification of inpatient procedures Named HIPAA standard for inpatient procedures	Centers for Medicare and Medicaid Services	10-PCS is a totally redesigned system for coding procedures developed by CMS as a complete replacement for ICD-9-CM Volume 3. CMS co-chairs C & M Committee with CDC/NCHS as described above and CMS has final authority for changes to PCS. Public comments and requests for changes are handled by C & M process. CMS serves as a member of the Cooperating Parties for guideline development and the EAB to oversee coding questions from the field.	Annual updates effective October 1 of each year; official output files posted on CMS and via NLM UMLS.

Named Standards

Name	Purpose	Ownership/Governance	Development and Maintenance	Release
CDT (Code on Dental Procedures and Nomenclature)	Achieve uniformity, consistency and specificity in documenting dental treatment; used to process dental claims, and populate an EHR. Named HIPAA standard	American Dental Association. Council on Dental Benefit Programs (CDBP)	Multi-stakeholder Code Maintenance Committee accepts, amends, or rejects code change requests.	Annual update, effective January 1 of each year
CPT (Current Procedural Terminology)	Terminology used to uniformly and consistently report ambulatory and hospital outpatient medical procedures and services by physicians and other health care professionals. Named HIPAA Standard as HCPCS Level I	American Medical Association (AMA) Board of Trustees appoints the CPT Editorial Panel who has final authority for updates.	Work of the CPT Editorial Panel aided by CPT Advisory Committee medical specialty and health professional advisors; a public request process for changes suggested by medical specialty societies or individual practitioners. Agenda and reports of Editorial Panel meetings are publically available; a formal process in place for public comments and appeals of Panel decisions.	Annual update, effective January 1. Early fall release to support implementation planning and training. Certain category I codes are "early released" to become effective 6 months subsequent to release date (e.g., vaccine products, Molecular Pathology); other category codes may be early released to capture reporting for evaluation.
HCPCS–Level II (Healthcare Common Procedure Coding System)	National codes used to identify products, supplies, and services such as ambulance and durable medical equipment and supplies when used outside a physician's office. Named HIPAA Standard	CMS with participation from other federal agencies and private health plans.	CMS HCPCS Workgroup responsible for decisions about additions, revisions, and deletions. Workgroup comprised of representatives of CMS, CMS contractors, consultants from Federal agencies and Medicaid, private insurance, and the Department of Veteran's Affairs. Codes used by all private and public health insurers.	Quarterly with annualized compilation

Named Standards

System	Purpose	Ownership/Governance	Development and Maintenance	Release
NDC (National Drug Codes)	A universal product identifier for drugs intended for human use. Code denotes labeler, product and packaging. ***Named HIPAA Standard***	Product labeler/manufacturer assigns two segments of the code and FDA assigns one.	FDA publishes electronic NDC Directory. RxNorm also includes NDC codes and they are available via FDA and UMLS. Also available via mobile apps. CMS's 11-digit NDC derivative format adopted by data standards selected pursuant to HIPAA regulation.	NDC Directory is updated daily.

Other WHO International Classifications

Name	Purpose	Ownership/Governance	Development and Maintenance	Release
ICPC (International Classification of Primary Care)	Classification of primary care problems and related conditions; captures reason for encounter, symptoms, relevant social problems; episode based; interoperable with standard terminologies and classifications	World Organization of Family Physicians (WONCA); a related classification within the WHO Family of International Classifications	International Classification Committee, 2nd revision (1998) ICPC-2nd revision updated in 2015; 3rd revision under development but experienced challenges of a largely volunteer effort	
ICD-O-3 (International Classification of Diseases for Oncology, 3rd Ed.	Used in tumor or cancer registries for coding the site (topography) and the histology (morphology) of neoplasms, usually from a pathology report. Used in NIH research.	WHO; A derived classification within the WHO Family of International Classifications.	The classification is based on ICD-10 but provides greater site detail for some types of tumors. Last update is 2000; Work is underway on version 4 with no published release date.	
ICF (The International Classification of Functioning, Disability & Health)	Classification for measuring health and disability at both individual and population levels. A version for children ICF-CY is also available	WHO; A reference classification within the WHO Family of International Classifications	WHO adopted a standardized method for measuring health and disability across cultures based on the ICF that can be applied before and after intervention to measuring the difference made by a given intervention.	
ICHI (International Classification of Health Interventions)	Under-development and intended as a common tool for reporting and analyzing health interventions for statistical purposes.	WHO; to be a new reference classification	Based on ICD-9 Volume 3 so less complex than ICD-10-PCS. Includes public health related procedures.	

Other Specialized Systems Available through UMLS*

Name	Purpose	Ownership/Governance	Development and Maintenance	Release Schedule
DSM (Diagnostic and Statistical Manual of Mental Disorders, 5th ed)	Defines and classifies mental disorders that also defines disorders in order to improve diagnoses, treatment, and research	American Psychological Association	Thirteen (13) workgroups including representatives from 16 countries participated in this edition. Scientific review and Clinical and Public Health Committees oversaw the workgroups. National Institutes of Mental Health, Drug Abuse and Alcoholism and Alcohol Abuse and the American Psychiatric Institute for Research and Education supported underlying research. Corrections and additions through web portal.	5th edition is first full revision since 1994; no published schedule for updates
ICNP (International Classification of Nursing Practice)	A terminology for nursing practice and a framework into which existing vocabularies and classifications can be cross-mapped to enable comparison of nursing practice. Limited use in US.	International Council of Nurses (ICN); a related classification within the WHO Family of International Classifications	Participation open to individuals and groups; Individual researchers and organizations, such as ICN accredited ICNP R&D Centers, are encouraged to collaborate closely with ICN through their national nurses associations. "at risk conditions"	
MedDRA (Medical Dictionary for Regulatory activities, v20)	Standardized medical terminology to facilitate sharing of regulatory information internationally for medical products used by humans.	International Council for Harmonization (ICH) of Technical Requirements for Pharmaceuticals for Human Use (ICH) is the convener)	MedDRA Maintenance and Support Services Organization (MSSO) manages the maintenance process	Twice a year, March and September

*UMLS includes a number of other systems relating to nursing practice, drugs, devices, clinical research and genomics.

Other Specialized Systems Available through UMLS*

Name	Purpose	Ownership/Governance	Description	Release Schedule
The Gene Ontology (GO)	The GO Project is a collaborative effort to address the need for consistent descriptions of gene products in different databases. Intended for use by system developers who need consistent descriptions of gene products in different databases.	Produced by the GO Consortium. Vocabularies and gene product annotations available to all public and private sector users with no licensing requirements.	Three structured, controlled vocabularies (ontologies) that describe gene products in terms of their associated biological processes, cellular components and molecular functions in a species-independent manner. GO includes cross-links between the ontologies and the genes and gene products in the collaborating databases, and tools that facilitate the creation, maintenance and use of ontologies.	Updated regularly throughout the year
MEDCIN	An electronic medical record engine for entry, retrieval and correlation of clinical information at the point of care, and to store medical information and produce narrative reports from the same data.	Created and is maintained by Medicomp Systems, Inc.,	MEDCIN contains more than 300,000 clinical data elements encompassing symptoms, history, physical examination, tests, diagnoses, and therapies. Includes concepts, descriptions, a hierarchy, and SNOMED CT® mappings.	Updated files are released at least twice per year.
CDISC Terminology	The goal of CDISC is to develop platform independent standards that aid interoperability of healthcare information systems to support clinical research.	The Clinical Data Interchange Standards Consortium (CDISC) is an international non-profit organization that develops data standards for medical research and other healthcare areas.	The CDISC consists of a series of standards to support the research process such as Study Data Tabulation Model (STDM), Questionnaire (QS) and Functional Test (FT) Terminology, Clinical Data Acquisition Standards Harmonization (CDASH) and Analysis Data model (ADaM). In addition, CDISC maintains a Clinical Data Element Glossary, a controlled terminology to support the therapeutic area standards of CDISC.	The CDISC Terminology is updated annually as part of the NCI Thesaurus.

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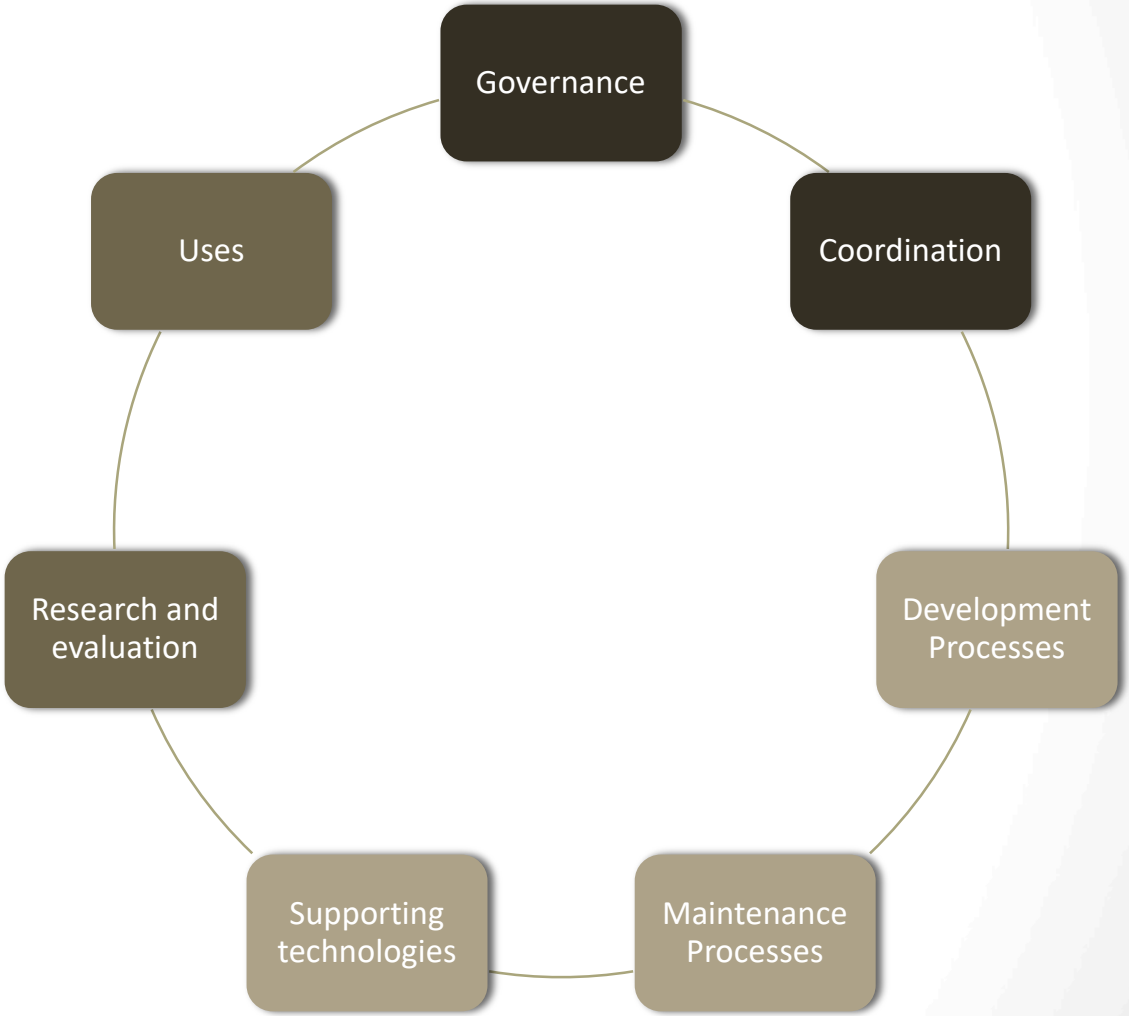
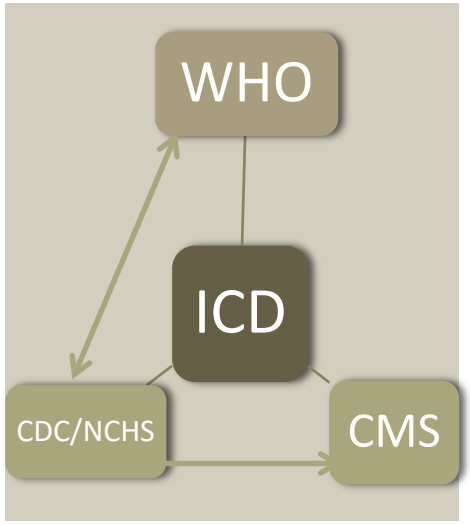
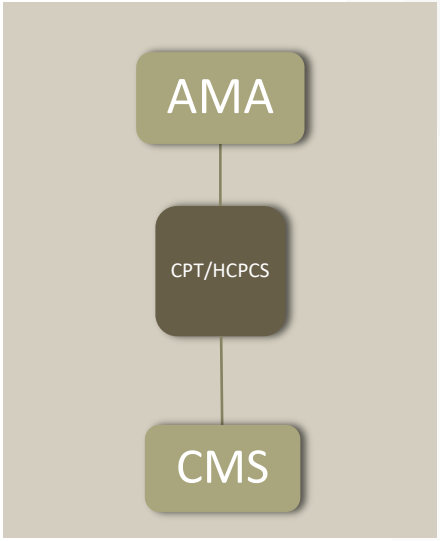
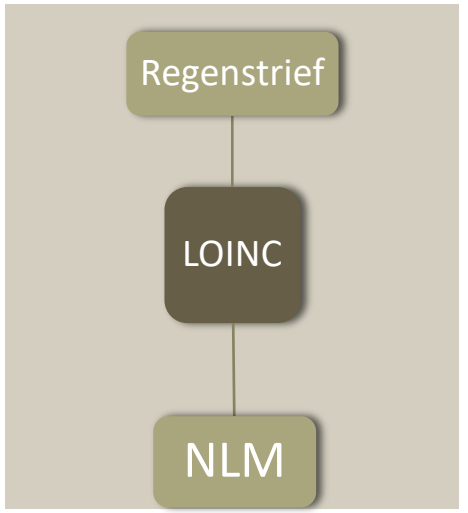
Key Issues


Governance
Coordination
Development Processes
Maintenance Processes
Supporting technologies
Research and evaluation
Uses

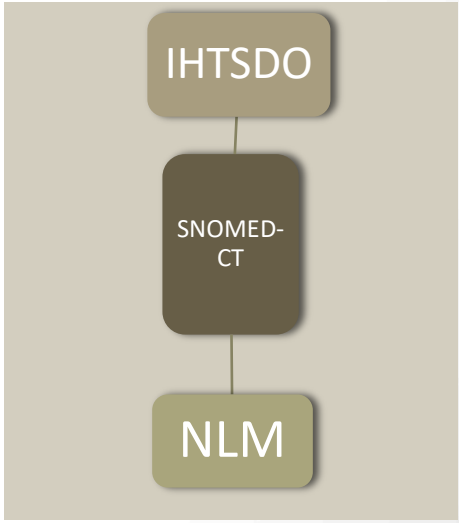
Governance and Coordination



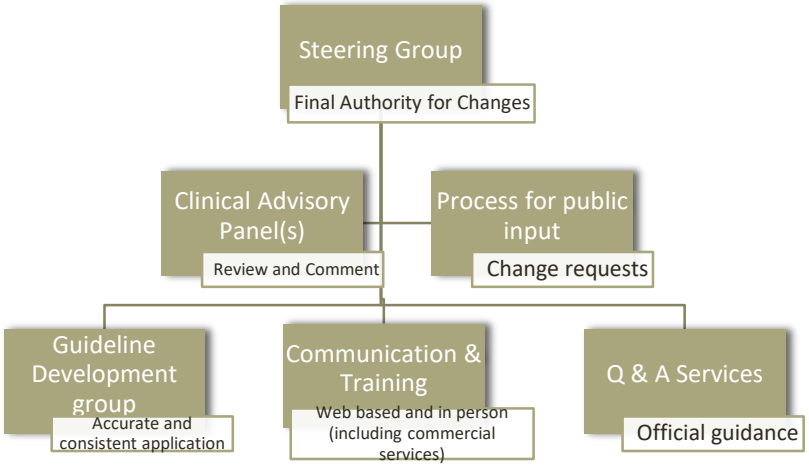




1. Is current level of directional and operational coordination across named standards adequate?
2. Are the paths for sustainability adequate?
3. Is there research on how best to measure validity and fitness for use?

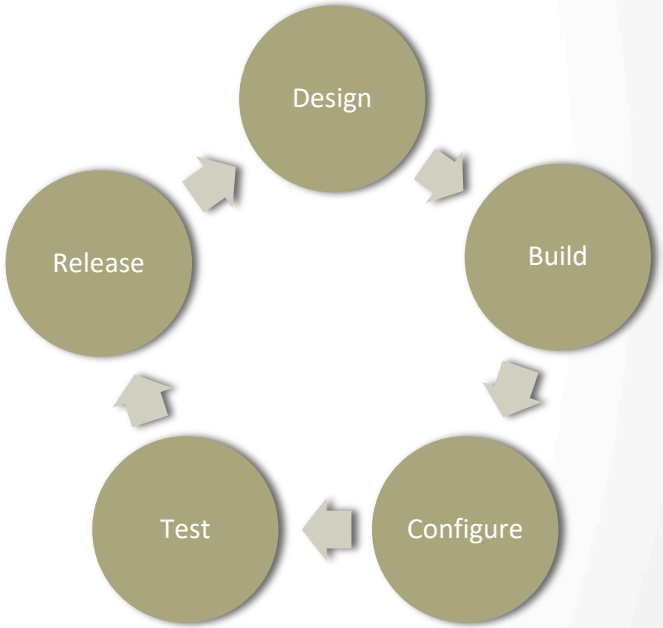


Maintenance Process



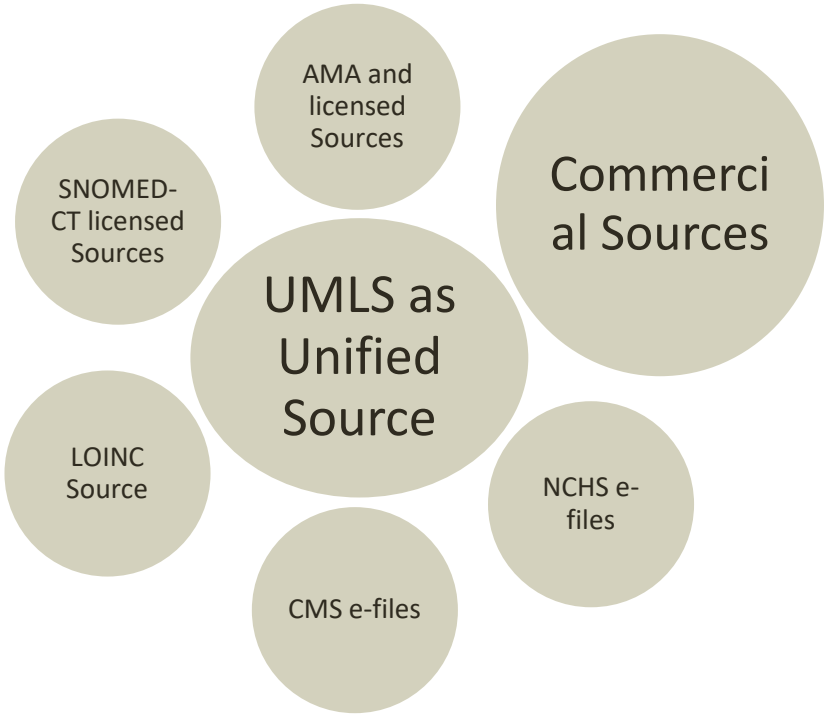
1. Are maintenance processes regularly reviewed for improvement?
2. Is use of technology and analytics optimized?
3. Are there any steps missing?

Development
(ICD-11 as example)



1. Is ICD-11 version being designed so that major redesign won't be needed for version 12?
2. What is the "predictability roadmap" for moving from ICD-10 to ICD-11?

Dissemination



1. Original intent of the UMLS Metathesaurus is to provide terminology standards from one place in a uniform format. Is there more that can be done to ensure UMLS is "the" distribution point for all named standards?
2. Could redundant channels for web dissemination by federal agencies be reduced?
3. Are there ways to optimize the use of technology for dissemination?

Next steps

January Committee Meeting	Q-1 & 2 2018	Q-3 & 4 2018, Q 1 2019
1. Deeper dive what we've learned about the ICD-10-CM and PCS results to date. 2. Deeper dive into design of ICD-11 and vision for its use in conjunction with SNOMED-CT. 3. Governance models from other countries.	1. Finalize environmental scan report as input for Stakeholder Roundtable 2. Host Stakeholder Roundtable to consider opportunity areas, frame models and recommendations. 3. Standards Subcommittee considers integration into Predictability Roadmap	1. Reserve possibility of one additional hearing in fall 2018 2. Draft final report and letter to the Secretary 3. Present to Committee for preliminary discussion in first meeting of 2019 4. Present for final approval in June 2019