KOS Design for Healthcare Decision-making Based on Consumer Criteria and User Stories

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Consumer Health Care Taxonomy background

- Designed to support types of queries a consumer health care information service such as a website might get from a wide variety of consumers in a wide variety of care conditions.
- Project sponsor:
  - U.S. Centers for Medicare and Medicaid Services (CMS)
- Users:
  - Medicare/Medicaid beneficiary*
  - Caregiver

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* Medicare is the U.S. government single payer health insurance for seniors over 65 years old. Medicaid is the U.S. jointly funded federal and State health insurance program for low-income people.

Related research: Information seeking

- Critique of social science qualitative methods (Davenport). Scientificity – consumer decision making is very different from studies of students, engineers and scientists.
- Most consumers search for health information on the Internet, usually starting with an organic search engine. The most commonly researched topics are diseases or conditions, treatments or procedures, and doctors or other health professionals. Half of online health information research is on behalf of someone else. (Pew)

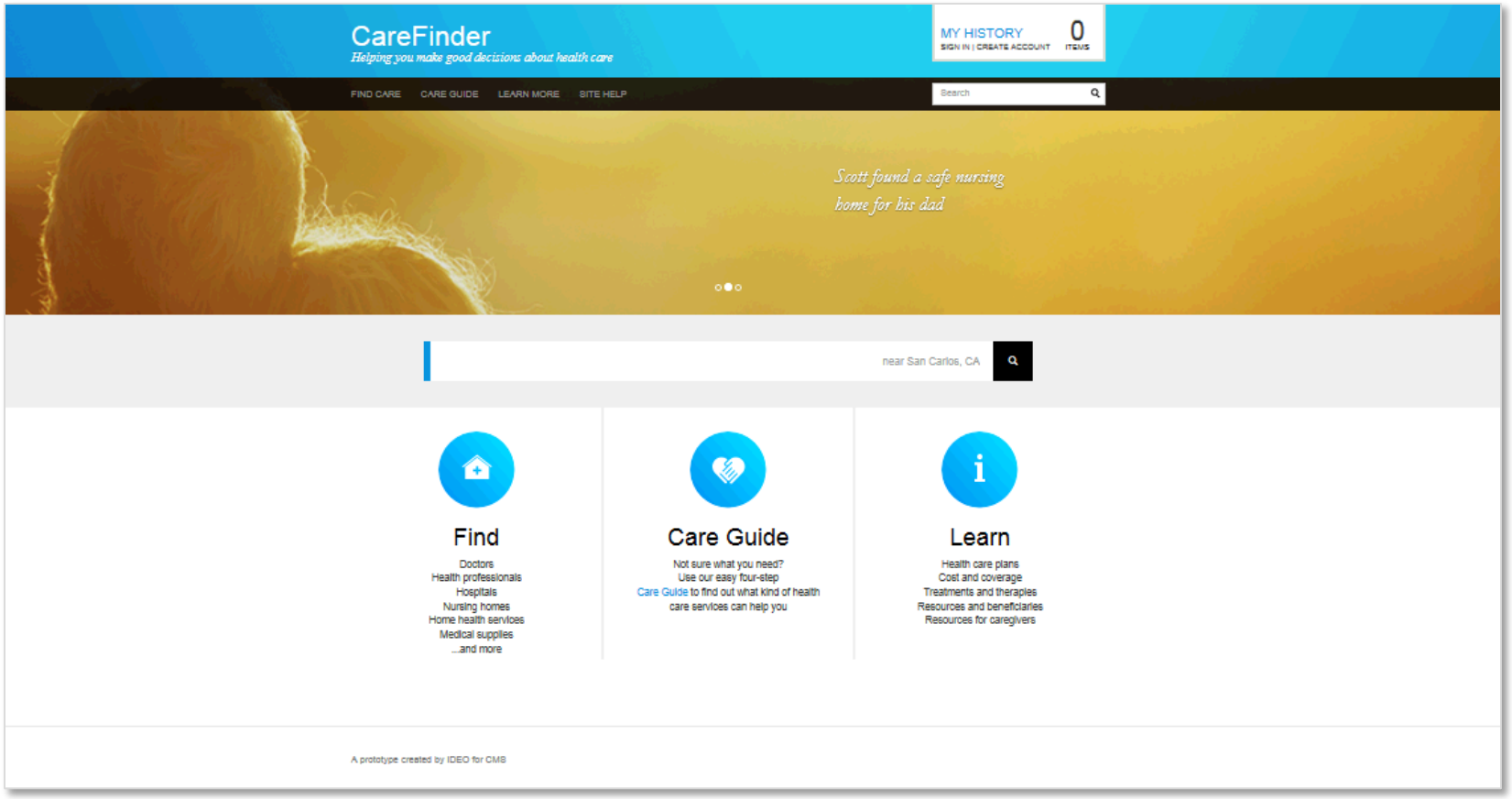
Related research: Quality of care

- Evidence-based decision-making by clinicians vs. factors that patients identify as most important such as cost, qualifications and accessibility of care. (Hibbard & Sofaer)
- Patient narratives are of more interest to consumers, and easier for them to understand. (Schlesinger)

Related research: KOS development

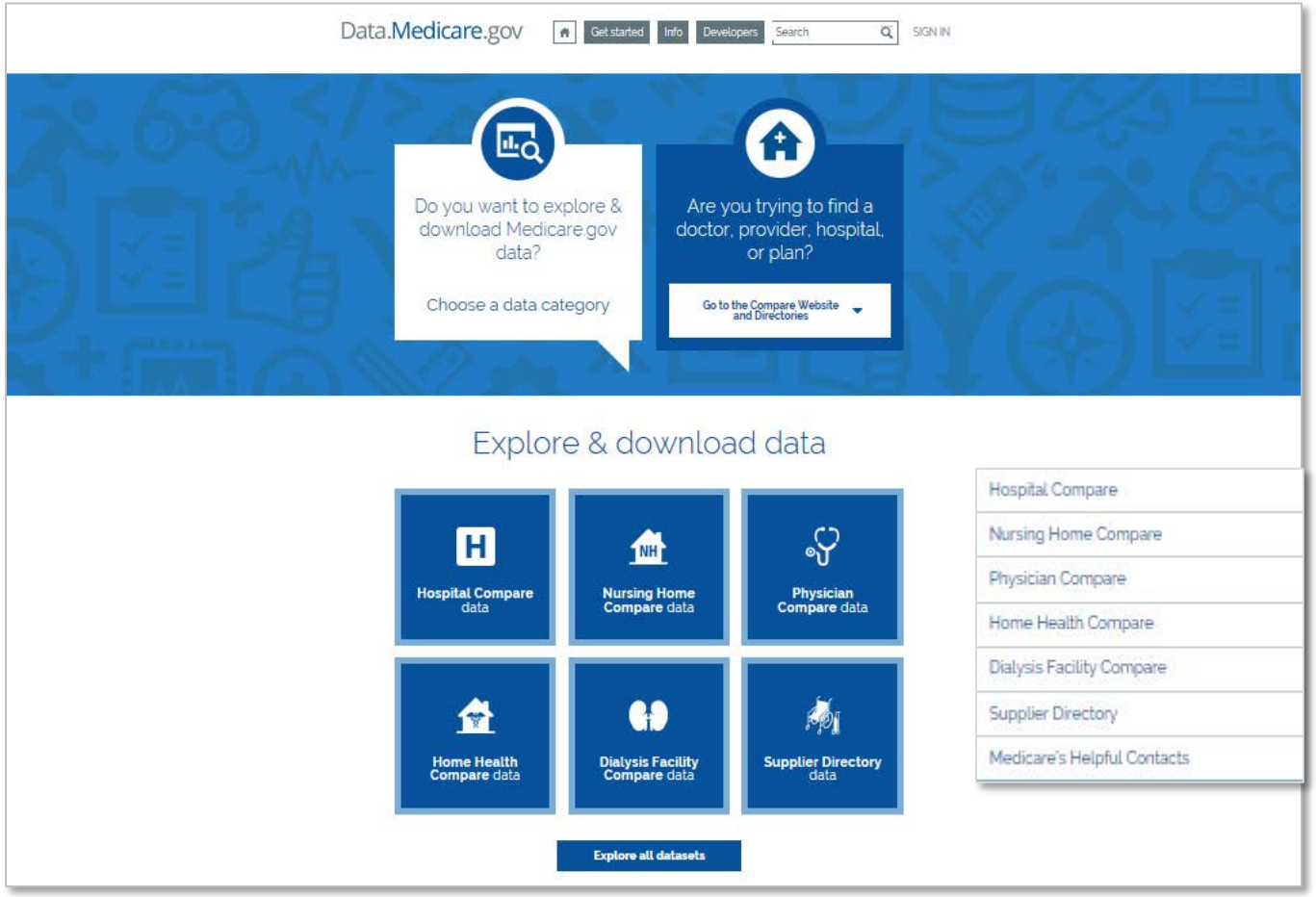
- Most health care KOS were originally designed to support researchers, clinicians and health insurers. But they can be useful sources to build consumer-oriented health care KOS, rather than starting from scratch. (Hyvönen)
- Consumer terminology used in health care related activities can be useful to improving existing health care KOS. (Doing-Harris)

Sources: CMS health care website prototype



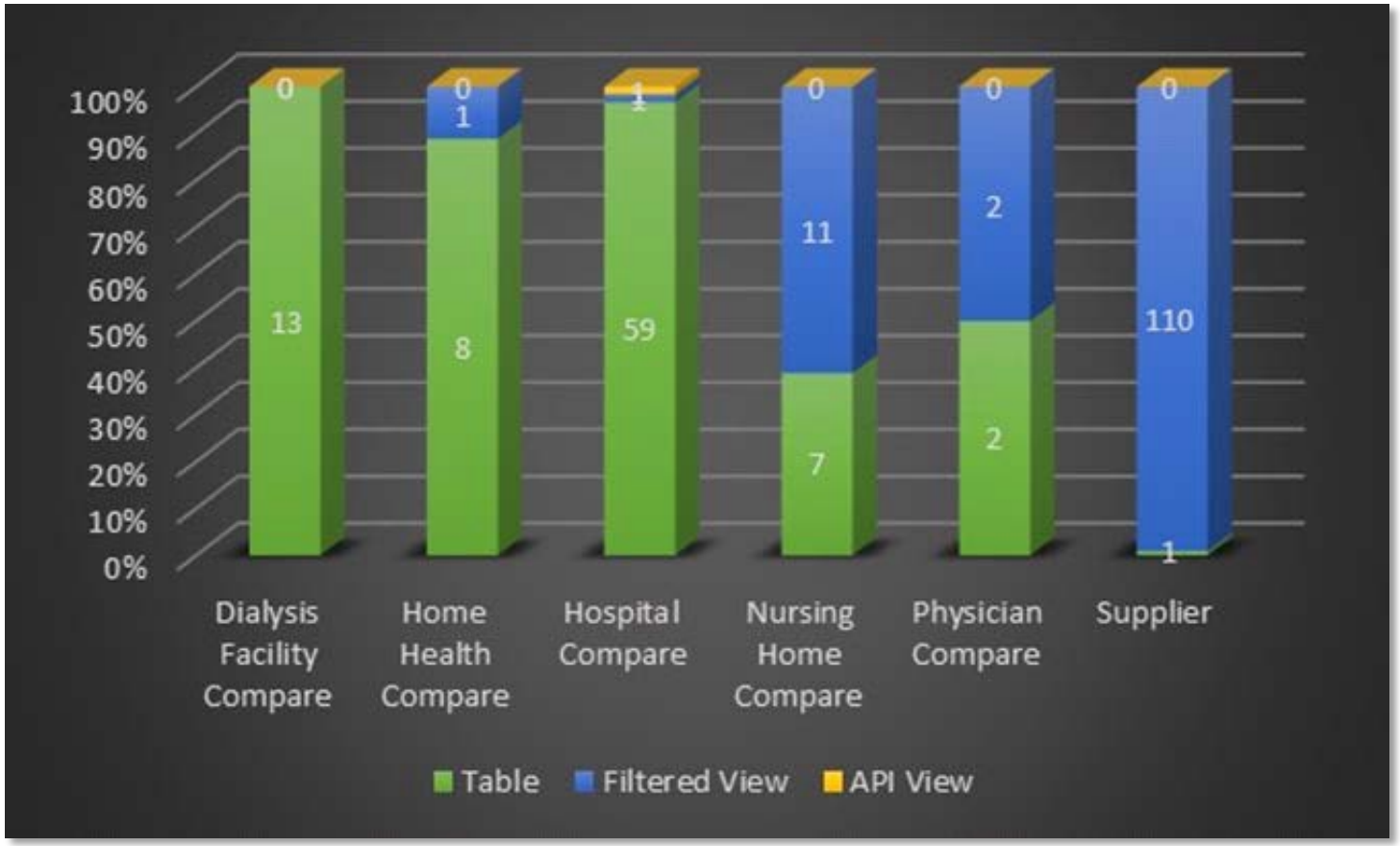
CareFinder prototype envisions leveraging Medicare's massive datasets to support consumers in making better health care decisions.

Sources: Medicare “Compare” websites and datasets



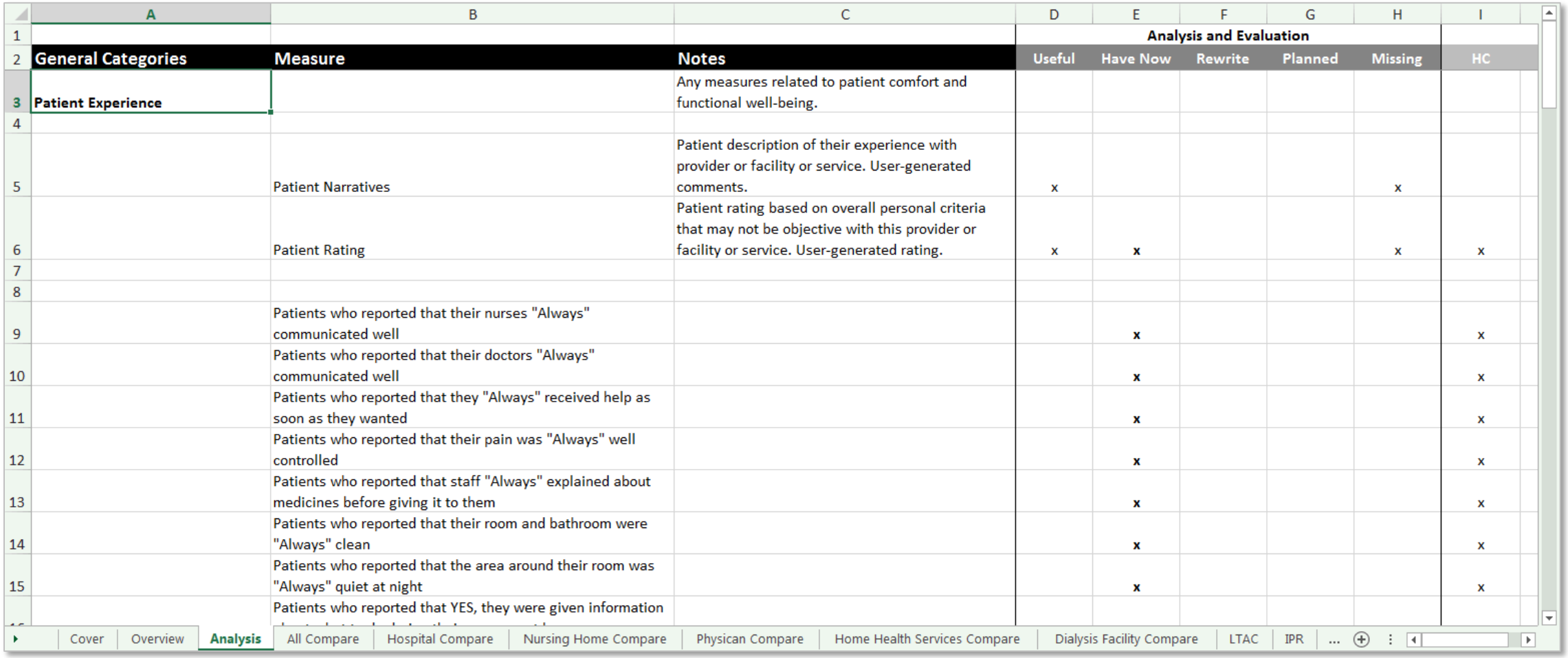
Compare websites and datasets provide directory information about CMS-registered service providers and suppliers, and reported quality measures.

Sources: Inventory of data.medicare.gov datasets



Each Medicare dataset has a different structure and number of tables.

Sources: Inventory of quality measures



	A	B	C	D	E	F	G	H	I
1				Analysis and Evaluation					
2	General Categories	Measure	Notes	Useful	Have Now	Rewrite	Planned	Missing	HC
3	Patient Experience		Any measures related to patient comfort and functional well-being.						
4									
5		Patient Narratives	Patient description of their experience with provider or facility or service. User-generated comments.	x				x	
6		Patient Rating	Patient rating based on overall personal criteria that may not be objective with this provider or facility or service. User-generated rating.	x	x			x	x
7									
8									
9		Patients who reported that their nurses "Always" communicated well			x				x
10		Patients who reported that their doctors "Always" communicated well			x				x
11		Patients who reported that they "Always" received help as soon as they wanted			x				x
12		Patients who reported that their pain was "Always" well controlled			x				x
13		Patients who reported that staff "Always" explained about medicines before giving it to them			x				x
14		Patients who reported that their room and bathroom were "Always" clean			x				x
15		Patients who reported that the area around their room was "Always" quiet at night			x				x
		Patients who reported that YES, they were given information							

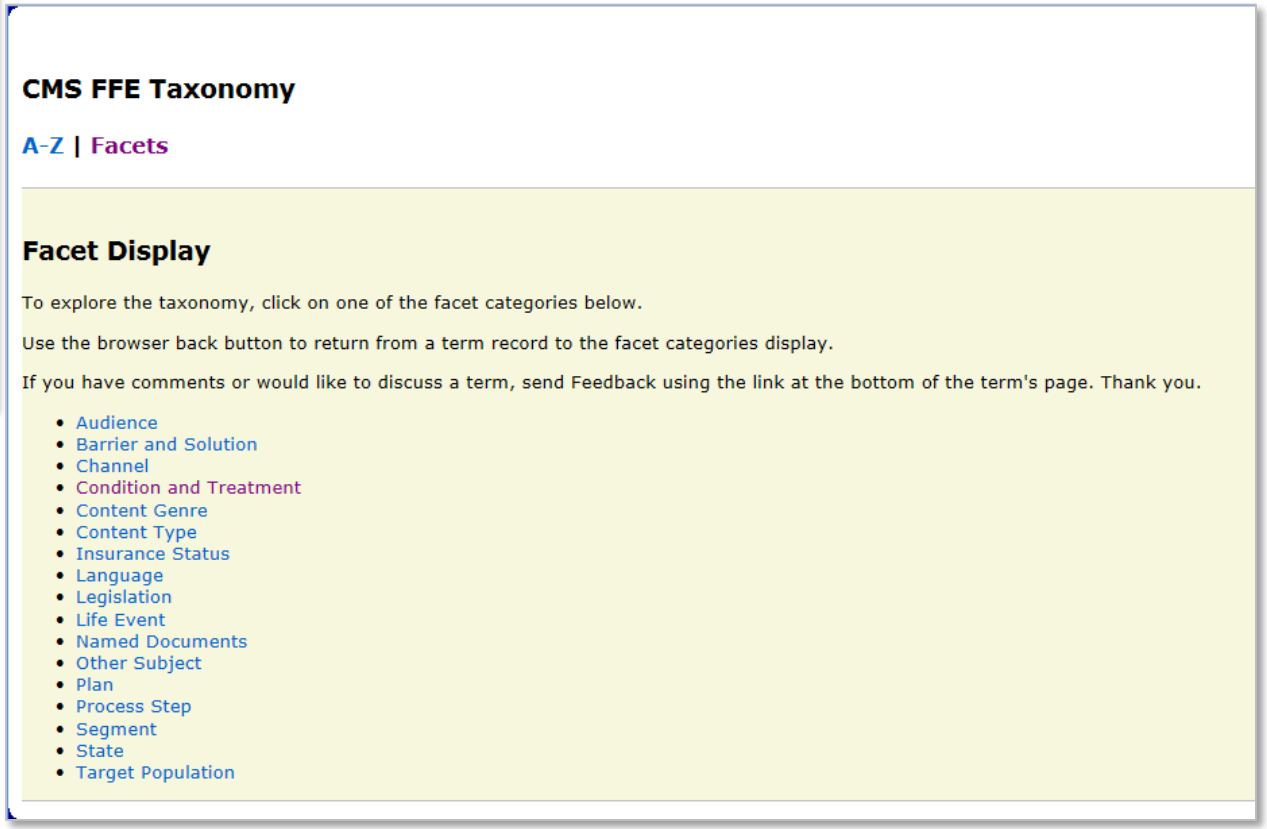
Cover | Overview | Analysis | All Compare | Hospital Compare | Nursing Home Compare | Physican Compare | Home Health Services Compare | Dialysis Facility Compare | LTAC | IPR | ...

Existing quality measures were categorized by type, usefulness, availability and source.

Sources: Existing CMS and HHS taxonomies

Substance Abuse and Mental Health Services Administration (SAMHSA)

Healthcare.gov →



The methods and learnings from earlier projects helped inform the Consumer Health Care Taxonomy approach.

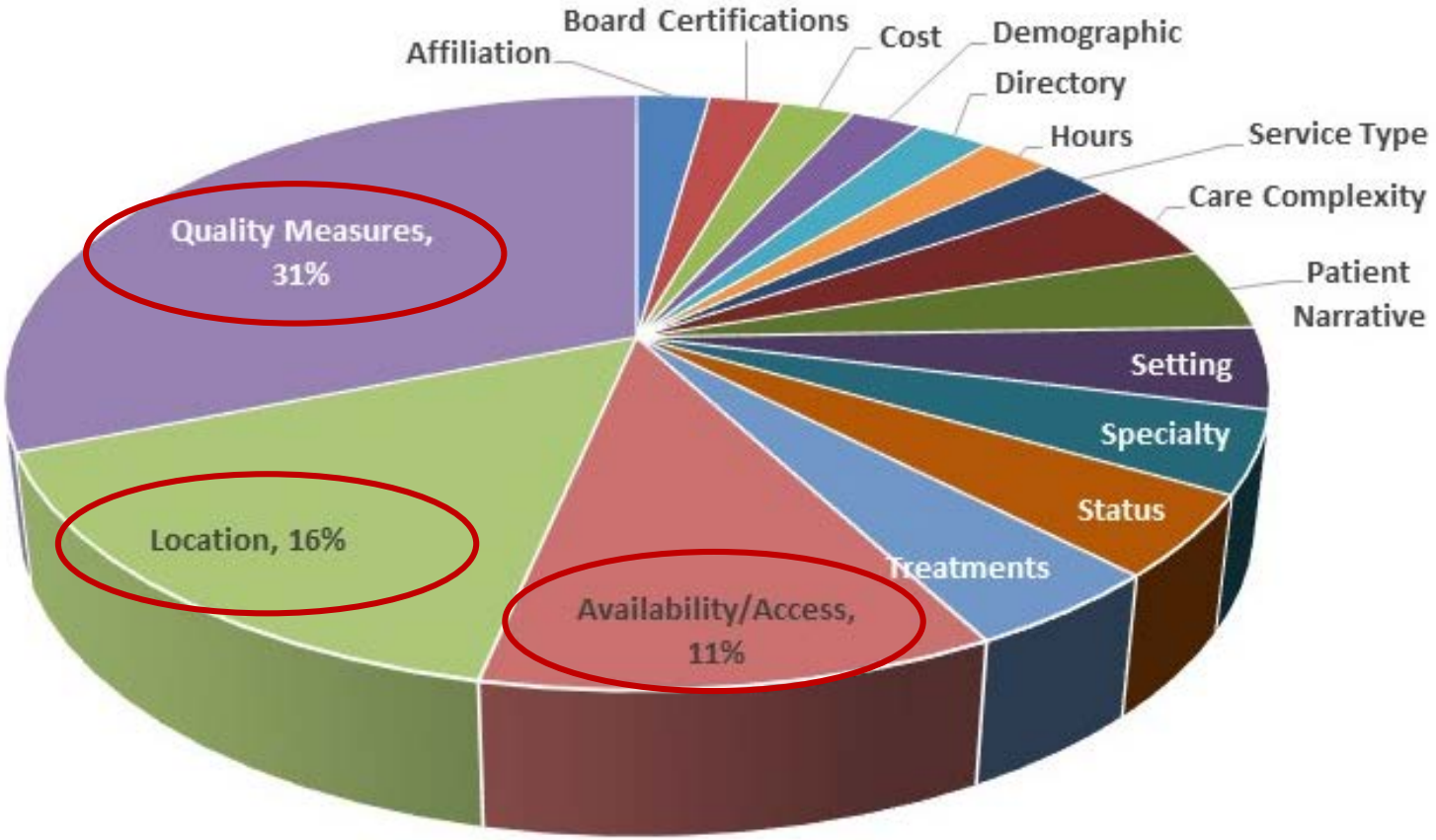
Sources: Authoritative sources, websites and query logs

- More than 100 vocabulary sources for Consumer Health Care concepts including:
  - National Library of Medicine's Medical Subject Headings (MeSH).
  - International Classification of Diseases (ICD) used by CMS and other health insurance providers to classify diseases and conditions.
  - Unified Medical Language System (UMLS), a mapping of more than 100 vocabularies and classification systems including MeSH and ICD.
- Query logs from Physician Compare and MedLine Plus to help identify unique facets, relevant terms, and synonyms for the Taxonomy.
- Semantic relationships between Consumer Health Care Taxonomy concepts were made based on trusted sources such as:
  - Online symptom checkers from the Mayo Clinic, Cleveland Clinic, NHS UK, and HealthDirect Australia.
  - Physician Compare mappings of conditions and symptoms to medical specialties.
  - Google medical search.

Sources: Interviews with SMEs and key stakeholders

- More than 30 CMS staff working on the various Compare websites.
- CMS Compare website data contractors.
- IDEO team that built the CareFinder prototype.
- CMS user research staff.
- External health care professionals.
- Friends and family who have health care stories.

What do consumers want or need to make choices about where to get care?



Sources: User stories

Jim

Jim returns

Mike

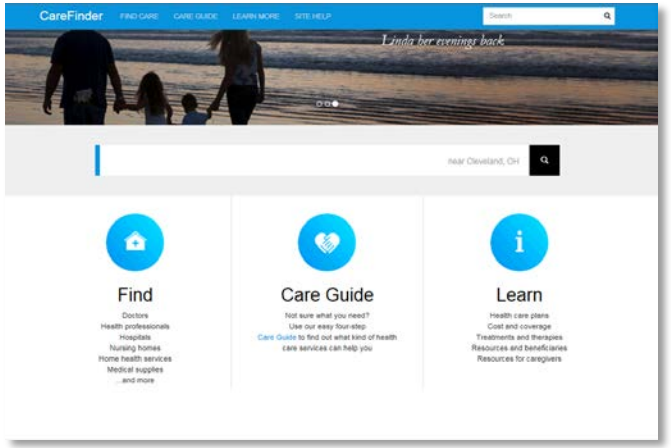
Carol

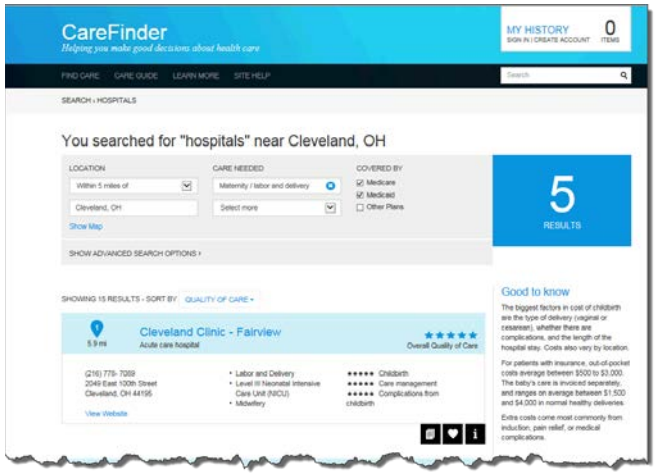
Maria

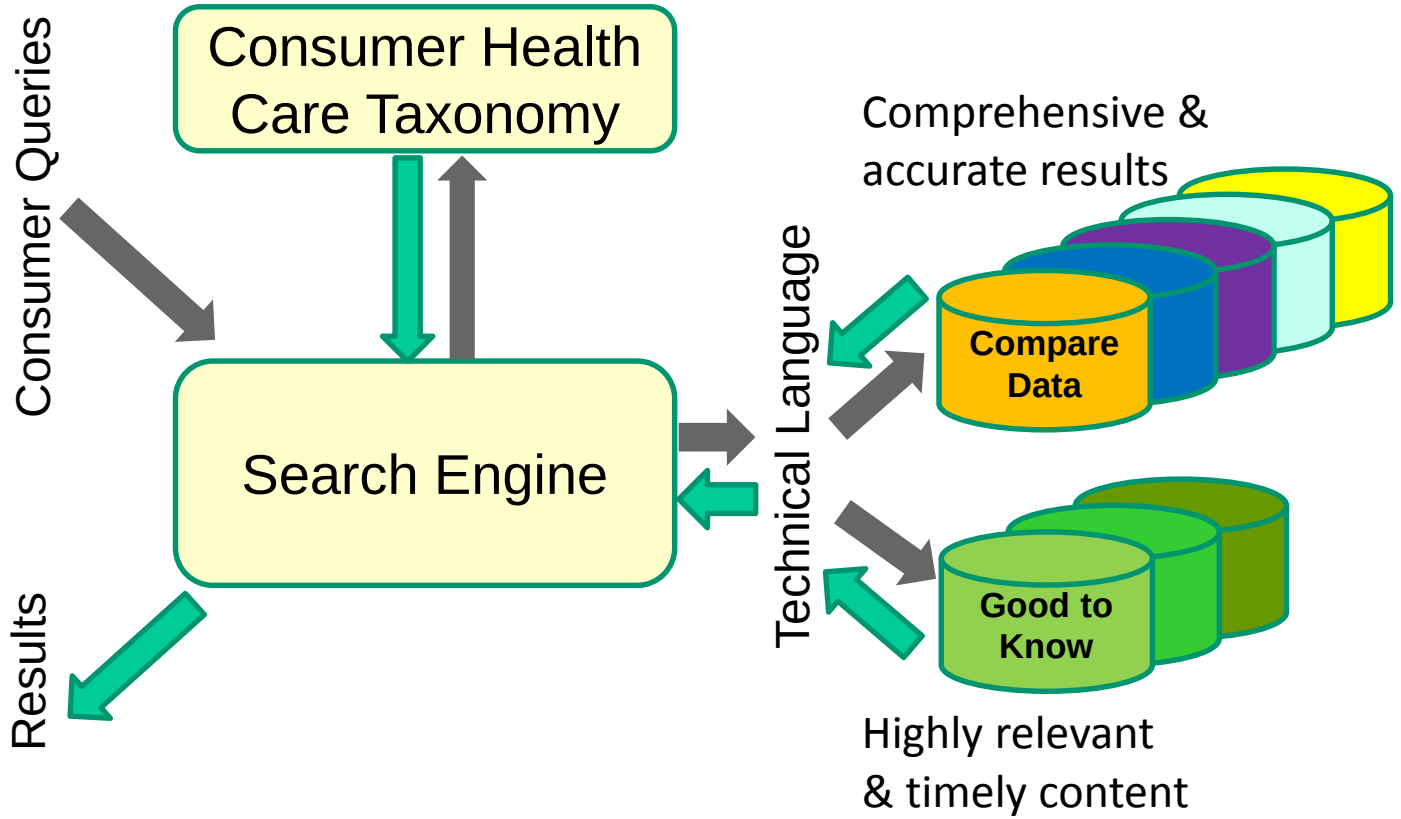
Sharon is a 52 year old with ESRD who received a kidney transplant 4 years ago. The kidney has recently begun to fail and she needs hemodialysis again 3 times a week. She also recently broke her leg and needs physical therapy 2 times a week. She works as a waitress but is currently unemployed due to her accident, and does not have insurance besides Medicaid. Sharon needs to find a dialysis center close to home since a family member will need to drive her due to her leg injury. She also needs to coordinate her dialysis (3x week) with her physical therapy (2x week).

Paula is an 85 year-old woman. She was out driving in her neighborhood when all of a sudden she lost her way and she couldn't find her way back home. This episode scared her and her family. She began to worry about her mental capacity, and wondered what kind of specialist she could see who could assess her mental acuity. Paula needs to figure out what type of specialist can help assess her mental acuity, and find a trustworthy specialist who is close to her apartment and covered by her health plan.

Consumer Health Care Taxonomy: Purpose





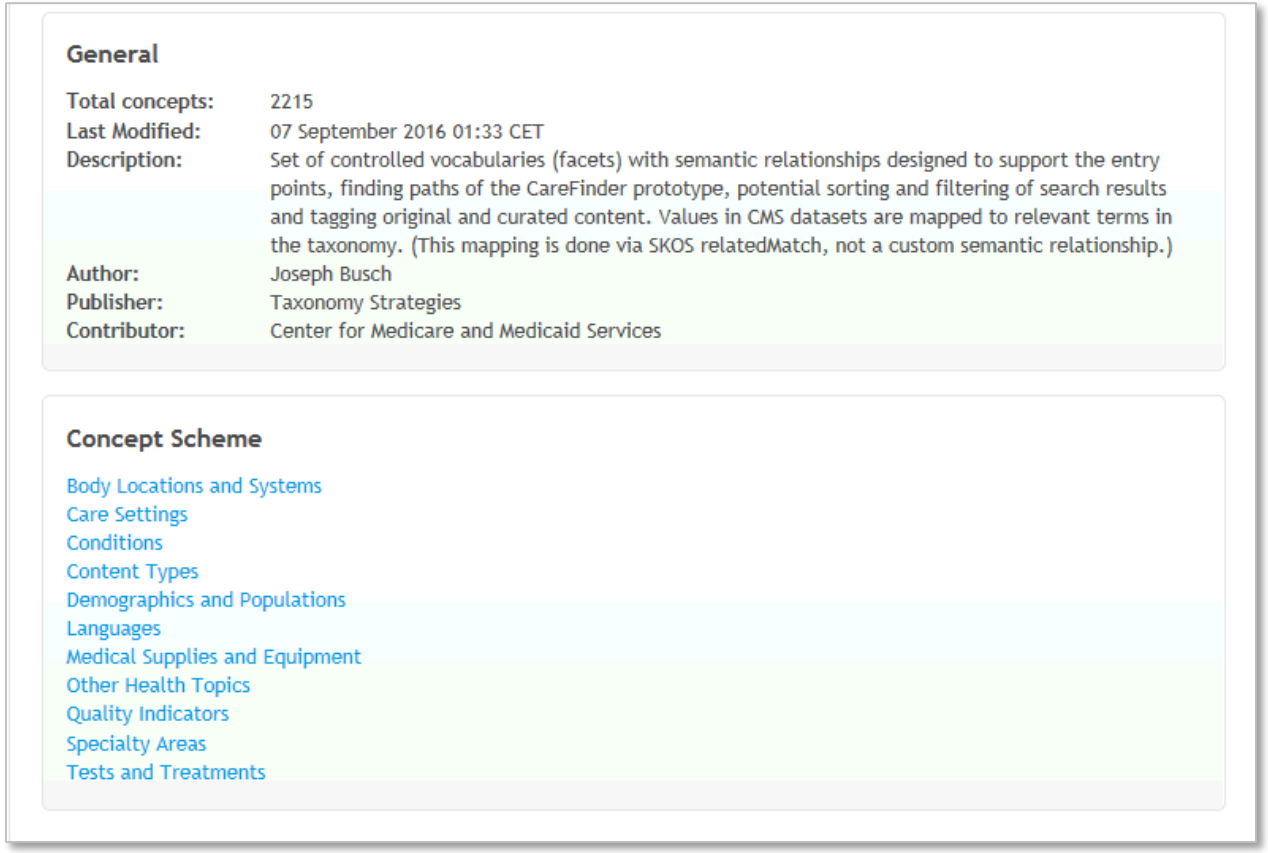


Needs to function as middleware that translates consumer queries into the language necessary for retrieval of data from Medicare.gov datasets and Good to Know (GTK) content.

Consumer Health Care Taxonomy: Functional requirements

- Provide enough information for any user, tool, or program to find and use content in any Medicare.gov dataset or GTK content.
- Define what vocabularies are needed to support consumer health care decision making.
- Identify authoritative vocabulary sources for each taxonomy facet.
- Provide vocabularies for each taxonomy facet that are sufficiently defined to be used to build a functional application (i.e., a CareFinder-like application).
- Be readily extensible to support new application requirements.
- Be flexible enough to accommodate additions of missing categories and changes to existing categories as needed.
- Define relationships between the vocabularies useful for searching Medicare.gov datasets and GTK content.

Consumer Health Care Taxonomy: Concept scheme



General

Total concepts:	2215
Last Modified:	07 September 2016 01:33 CET
Description:	Set of controlled vocabularies (facets) with semantic relationships designed to support the entry points, finding paths of the CareFinder prototype, potential sorting and filtering of search results and tagging original and curated content. Values in CMS datasets are mapped to relevant terms in the taxonomy. (This mapping is done via SKOS relatedMatch, not a custom semantic relationship.)
Author:	Joseph Busch
Publisher:	Taxonomy Strategies
Contributor:	Center for Medicare and Medicaid Services

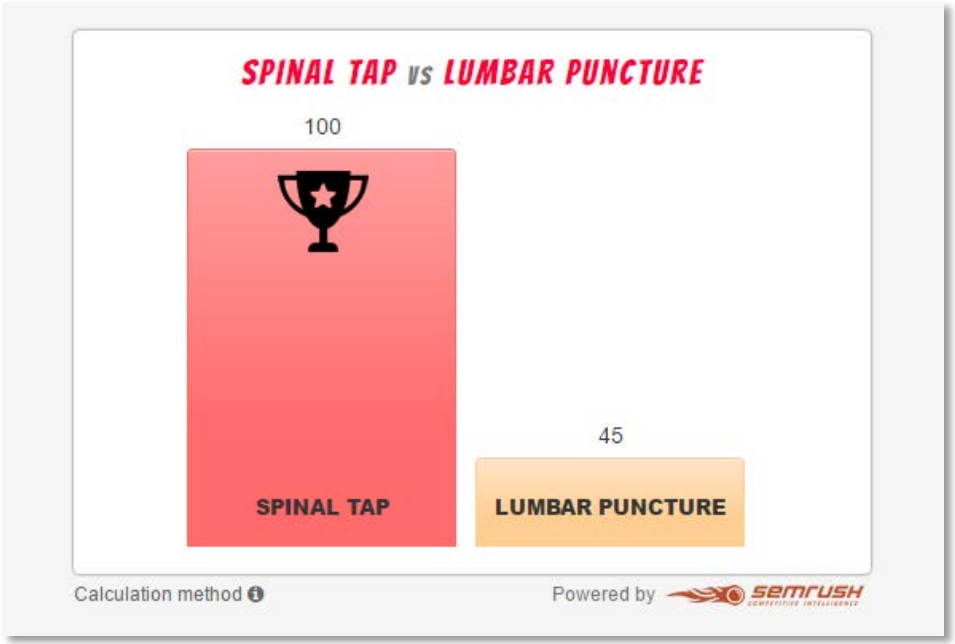
Concept Scheme

Body Locations and Systems
Care Settings
Conditions
Content Types
Demographics and Populations
Languages
Medical Supplies and Equipment
Other Health Topics
Quality Indicators
Specialty Areas
Tests and Treatments

Eleven facets in the Consumer Health Care Taxonomy displayed in the PoolParty Linked Data frontend.

Consumer Health Care Taxonomy: Entry terms (skos:prefLabel)

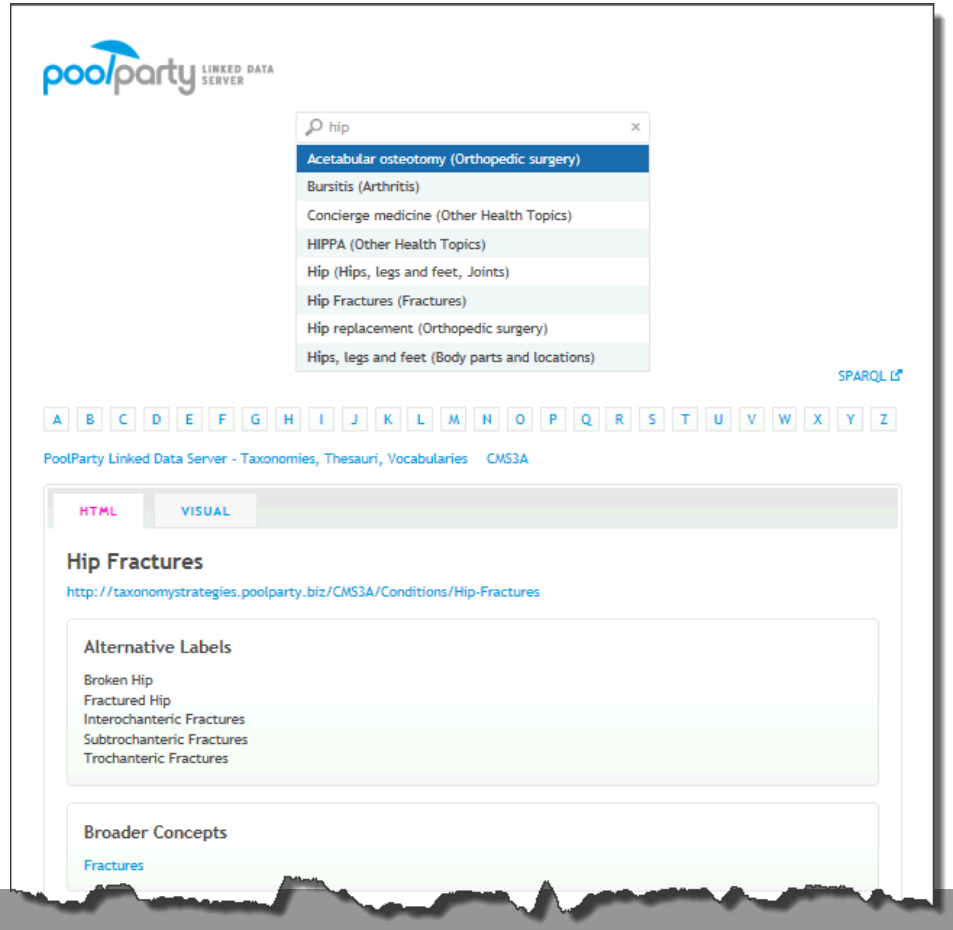
- Entry terms have been identified by analyzing search logs for similar sites, related and curated content, popular news sources, and user research including uses cases.
- We capture both the technical version of a term and the consumer-friendly or colloquial version(s) of a term.
- Sometimes the best entry term is the technical version, and sometimes it is the consumer-friendly version.



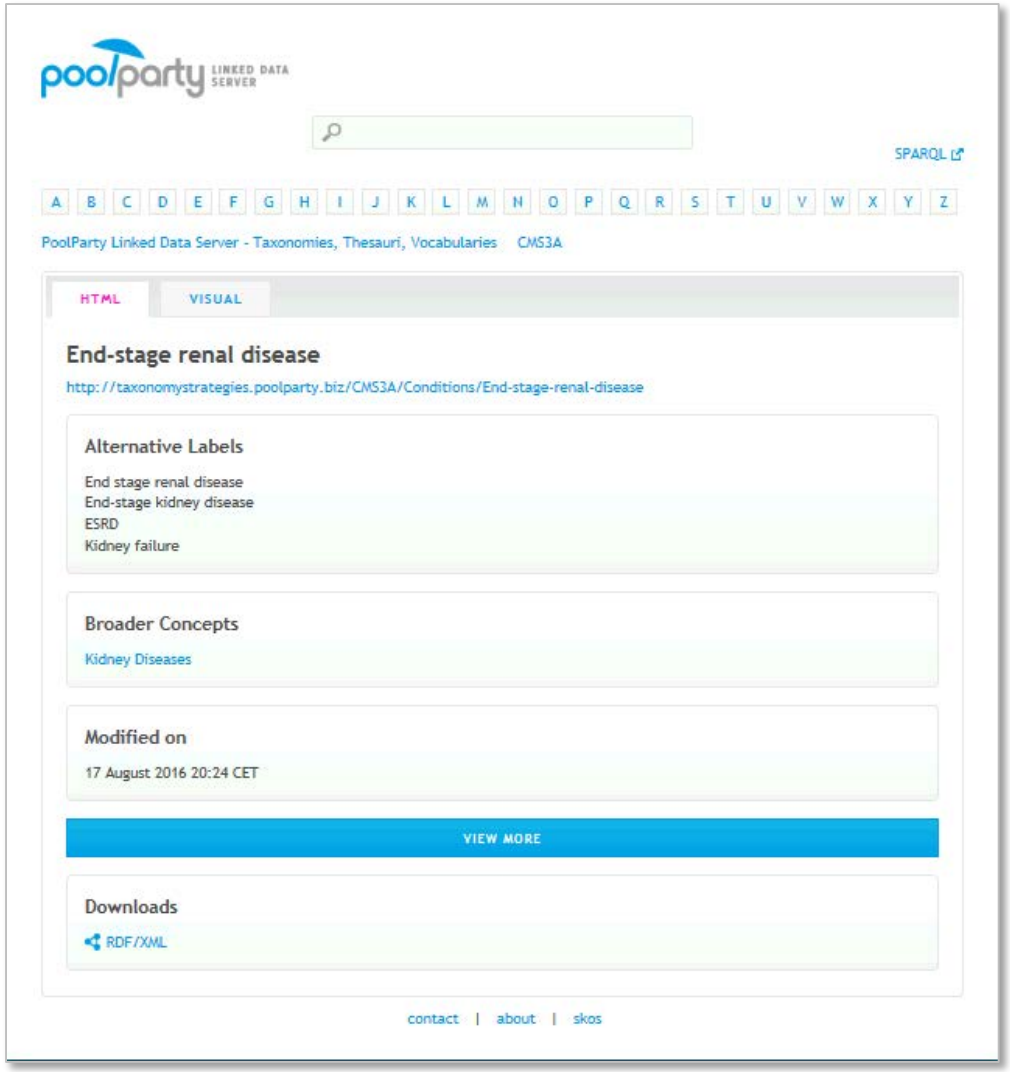
Results of Spinal tap v. Lumbar puncture in Google Fight.

Practical consideration: Post-coordination vs. pre-coordination

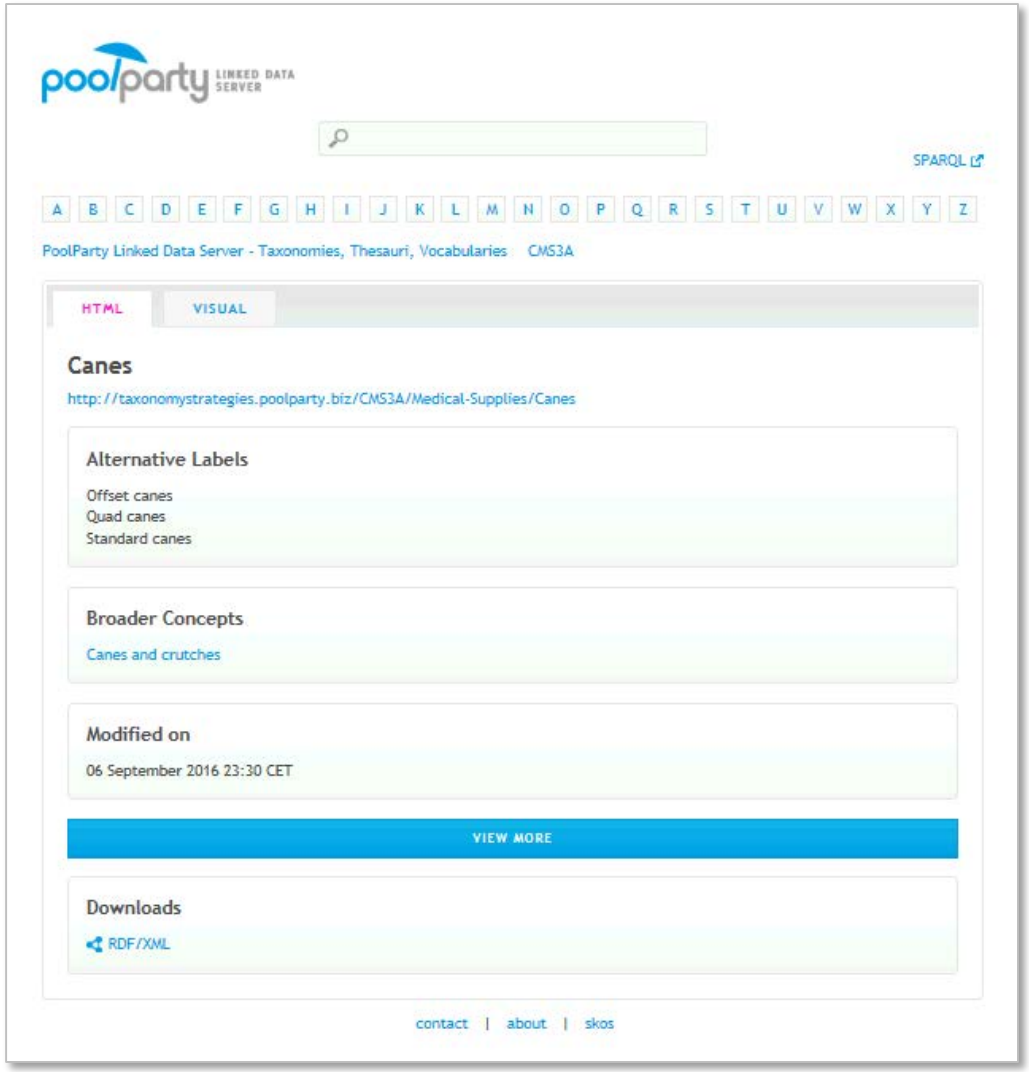
- As middleware assisting consumers by reflecting their language, many multiple word concepts need to be kept together (that is, pre-coordinated) in this taxonomy.
- For example, “Hip fracture” is included in the Taxonomy as a pre-coordinated phrase in the Conditions facet.



Synonyms and Quasi-synonyms (skos:altLabel)

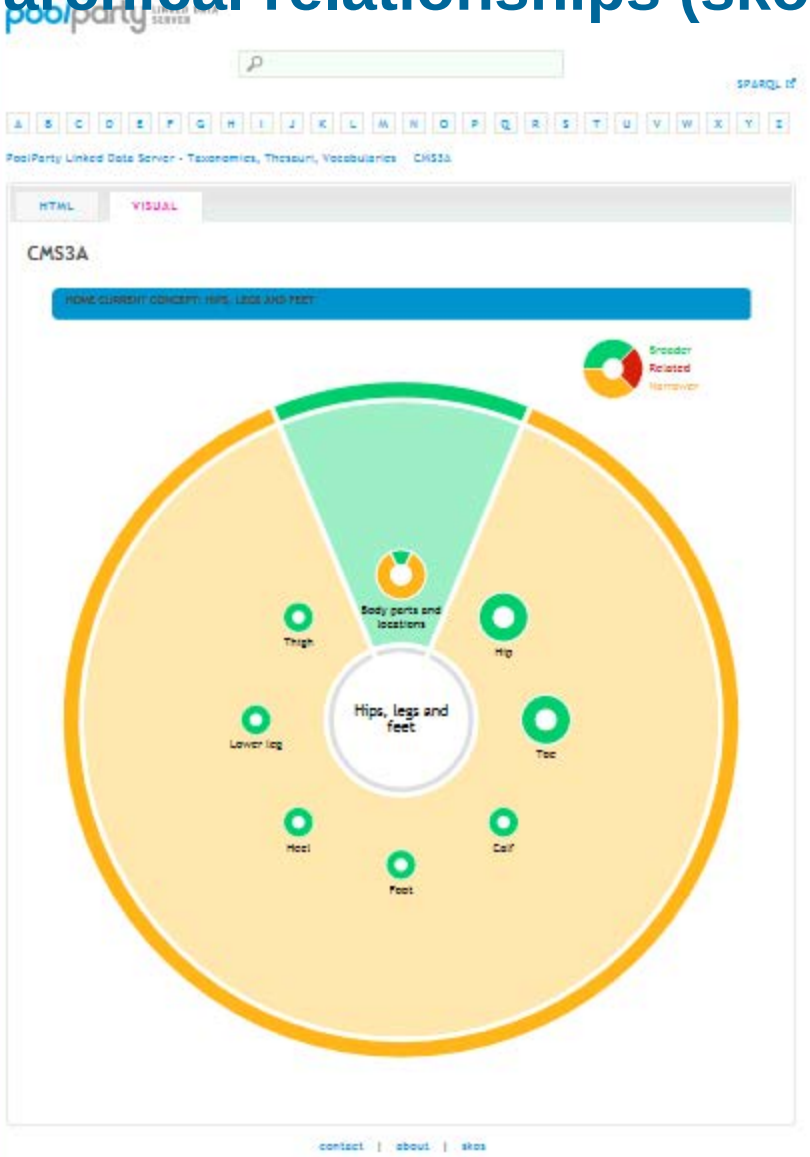


Variants of “End-stage renal disease”.

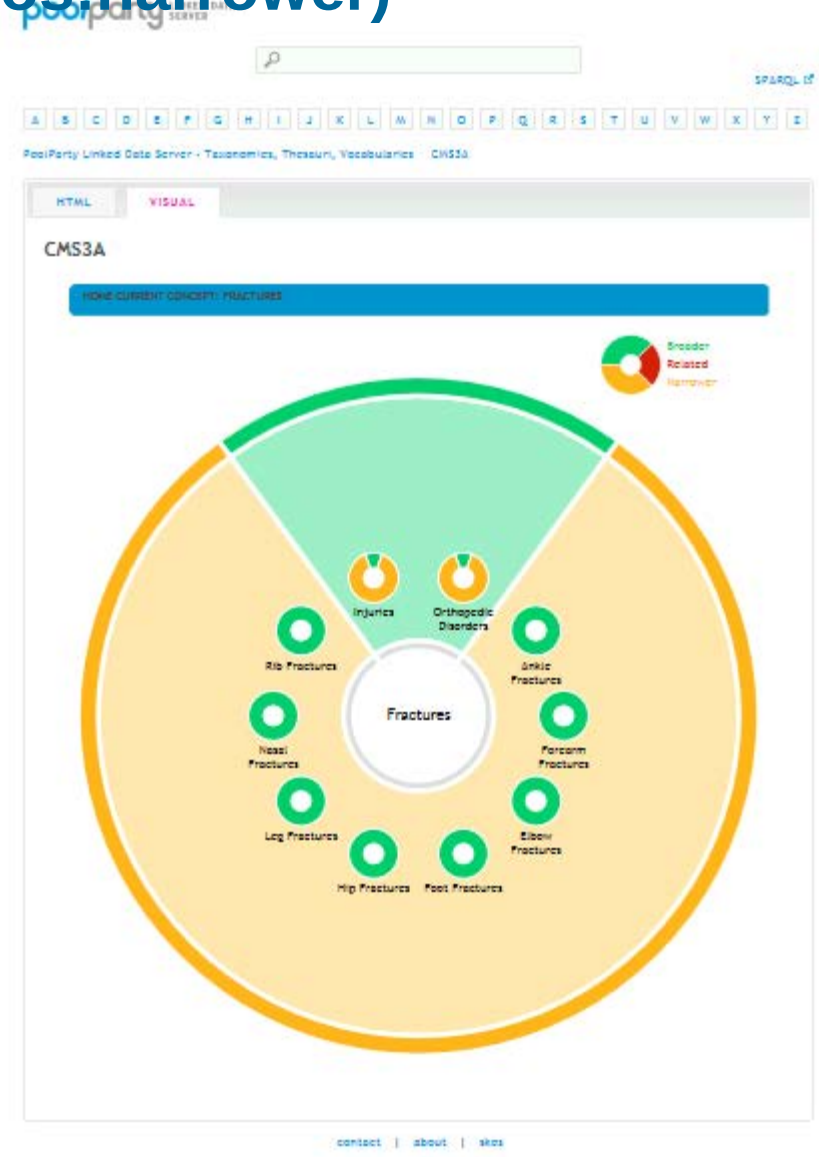


Quasi-synonyms of “Canes”.

Hierarchical relationships (skos:broader, skos:narrower)



Part of “Hips, legs and feet”.



Type of “Fracture”.

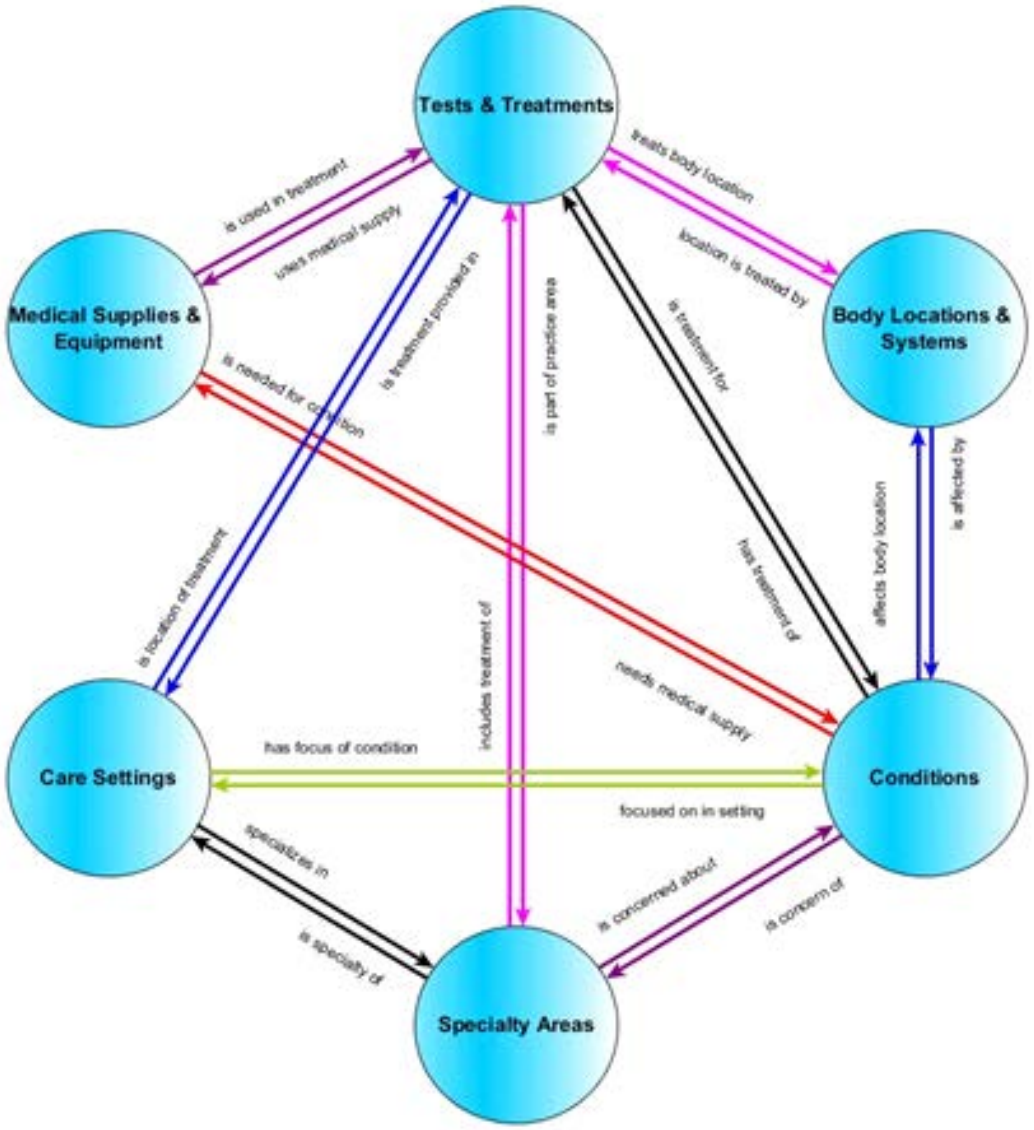
Relationships to entry terms in other facets are a custom schema

Semantic Relation			Inverse Semantic Relation		
Facet Class		**Facet Class**	**Facet Class**		**Facet Class**
Body Locations and Systems	**is affected by**	**Conditions**	**Conditions**	**affects body location**	**Body Locations and Systems**
Kidneys	*is affected by*	*End-stage renal disease*	*End-stage renal disease*	*affects body location*	*Kidneys*
Conditions	**has treatment of**	**Tests & Treatments**	**Tests & Treatments**	**is treatment for**	**Conditions**
End-stage renal disease	*has treatment of*	*Dialysis*	*Dialysis*	*is treatment for*	*End-stage renal disease*
Conditions	**is concern of**	**Specialty areas**	**Specialty areas**	**is concerned about**	**Conditions**
End-stage renal disease	*is concern of*	*Nephrology*	*Nephrology*	*is concerned about*	*End-stage renal disease*
Conditions	**needs medical supply**	**Medical Equipment & Supplies**	**Medical Equipment & Supplies**	**is needed for condition**	**Conditions**
End-stage renal disease	*needs medical supply*	*Dialysis Equip. & Supplies*	*Dialysis Equip. & Supplies*	*is needed for condition*	*End-stage renal disease*
Care Setting	**is location for treatment**	**Tests & Treatments**	**Tests & Treatments**	**is treatment provided in**	**Care Setting**
Dialysis Facilities	*Is location for treatment*	*Dialysis*	*Dialysis*	*Is treatment provided in*	*Dialysis Facilities*

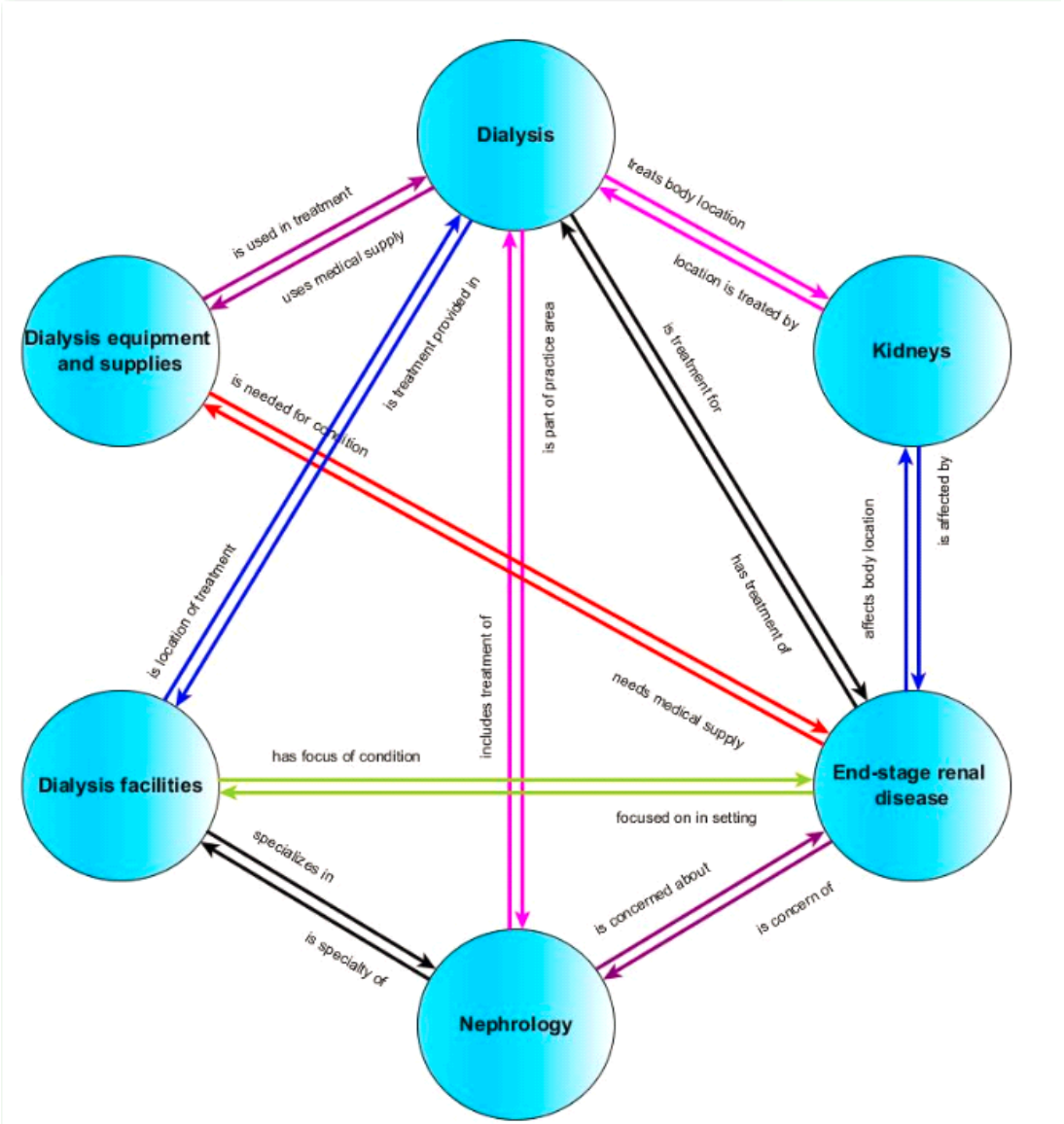
Relationships to entry terms in other facets are a custom schema (2)

Semantic Relation			Inverse Semantic Relation		
Facet Class		**Facet Class**	**Facet Class**		**Facet Class**
Care Settings	**specializes in**	**Specialty Areas**	**Specialty Areas**	**is specialty of**	**Care Settings**
Dialysis Facilities	*specializes in*	*Dialysis Services*	*Dialysis Services*	*is specialty of*	*Dialysis Facilities*
Medical Supplies & Equipment	**is used in treatment**	**Tests & Treatments**	**Tests & Treatments**	**uses medical supply**	**Medical Supplies & Equipment**
Dialysis Equipment & Supplies	*is used in treatment*	*Dialysis*	*Dialysis*	*uses medical supply*	*Dialysis Equipment & Supplies*
Specialty Areas	**includes treatment of**	**Tests & Treatments**	**Tests & Treatments**	**is part of practice area**	**Specialty Areas**
Nephrology	*includes treatment of*	*Dialysis*	*Dialysis*	*is part of practice area*	*Nephrology*
Care Settings	**has focus of condition**	**Conditions**	**Conditions**	**is focused on in setting**	**Care Settings**
Dialysis Facilities	*has focus of condition*	*End-stage renal disease*	*End-stage renal disease*	*is focused on in setting*	*Dialysis Facilities*
Body Locations & Systems	**location is treated by**	**Tests & Treatments**	**Tests & Treatments**	**treats body location**	**Body Locations & Systems**
Kidneys	*location is treated by*	*Dialysis*	*Dialysis*	*treats body location*	*Kidneys*

Semantic relationships diagram

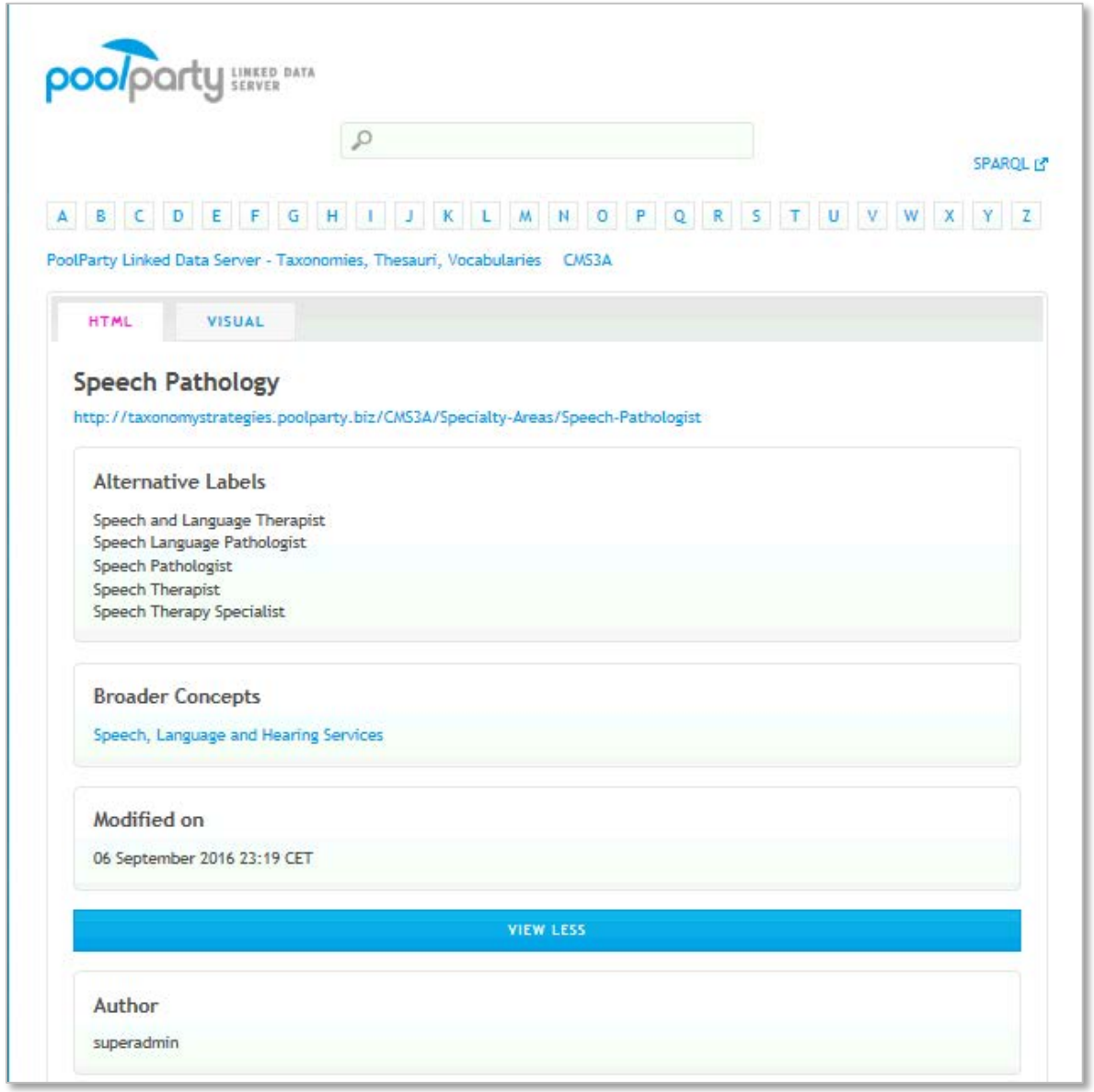


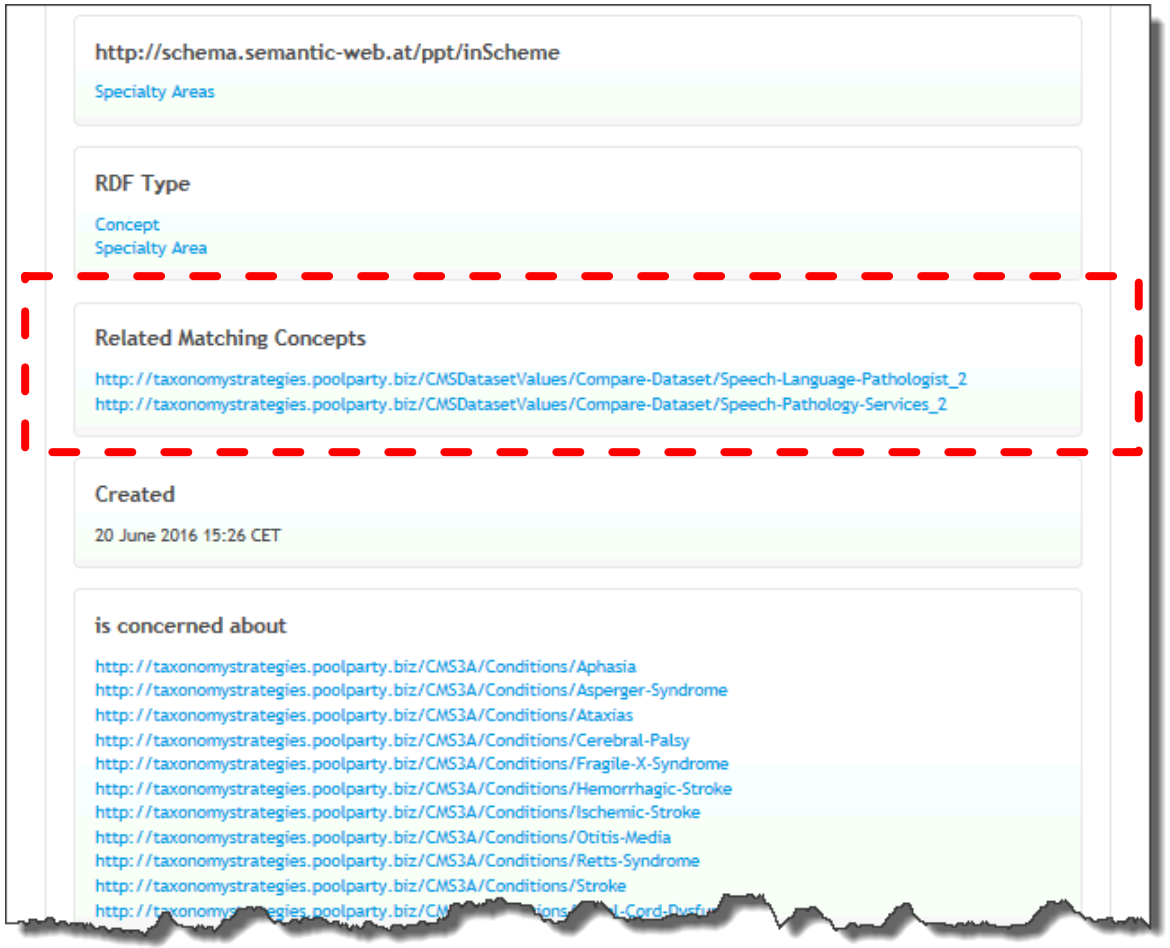
All relationships



ESRD relationships

Mapping to Medicare.gov dataset values (skos:relatedMatch)





Example of mapping a Specialty Area to Medicare.gov data set. (Initial mappings are narrow in scope).

Project observations

- Consumer healthcare related decision-making behavior is different from clinicians.
  - Focus on the problem to be solved: Translate consumer queries into the language necessary for retrieval of data from Medicare.gov datasets and Good to Know web content.
  - Exhaustivity is not a requirement.
- While there are many healthcare-related technical KOS available, consumer-friendly terminology is generally not available from authoritative sources.
  - A lot of work is required to compile a useful KOS from many sources.
  - Documentation of editorial guidelines supports this activity and helps to make it scalable.

Project observations (2)

- A small set of extensible taxonomies and custom semantic relationships are sufficient to develop the domain model.
  - A concise set of subject predicate object relationships, e.g., **Condition** *is_concern_of* **Specialty Area**.
  - SKOS is not intended for encoding more complex ontologies beyond thesaurus relationships (hierarchy, equivalent and generic associative), so a custom schema was developed for specific associative relationships.
- A strategy to setup separate concept schemes for the Consumer Health Care Taxonomy and the Medicare.gov datasets controlled vocabularies provided flexibility and extensibility.
  - SKOS relatedMatch was used to map across the concept schemes.
- KOS management tools are immature in their capacity to accurately and efficiently batch import and export KOS, interim taxonomies and semantic relationships.

Resources: Background research

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- Pew Research Center. “Health Fact Sheet.” (December 16, 2013). http://www.pewinternet.org/fact-sheets/health-fact-sheet/. Last checked October 3, 2016.
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- M. Schlesinger, R. Grob, D. Shaller, S. C. Martino, A. M. Parker, M. L. Finucane, J. L. Cerully, L. Rybowski “Taking Patients’ Narratives about Clinicians from Anecdote to Science.” 373 New England Journal of Medicine (August 13, 2015) pp. 675-679. http://www.nejm.org/doi/full/10.1056/NEJMsb1502361. Last checked: September 7, 20016.

Resources: Background research (2)

- K. M. Doing-Harris, Q. Zeng-Treitler. “Computer-Assisted Update of a Consumer Health Vocabulary through Mining of Social Network Data.” 13(2) J Med Internet Res (2011) p. e37. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3221384/. Last checked: September 7, 20016. http://www.PatientsLikeMe.com/ is a free website where people can share their health data to track their progress.
- Pew Research Center. “Tracking for Health.” (January 28, 2013). http://www.pewinternet.org/2013/01/28/tracking-for-health/. Last checked October 3, 2016.

Resources: Center for Medicare and Medicaid Services (CMS) websites

- Hospital Compare. http://www.medicare.gov/hospitalcompare/.
- Nursing Home Compare. http://www.medicare.gov/nursinghomecompare/.
- Physician Compare. http://www.medicare.gov/physiciancompare/.
- Home Health Compare. http://www.medicare.gov/homehealthcompare/.
- Dialysis Facility Compare. http://www.medicare.gov/dialysisfacilitycompare/.
- Supplier Directory. http://www.medicare.gov/supplierdirectory/.
- Data.Medicare.gov. https://data.medicare.gov/.

Resources: Symptom checkers

- Mayo Clinic Symptom Checker. http://www.mayoclinic.org/symptom-checker/select-symptom/itt-20009075.
- Cleveland Clinic Symptom Checker. http://my.clevelandclinic.org/health/mysymptomchecker.aspx.
- HealthDirect Symptom Checker. https://www.healthdirect.gov.au/symptom-checker.

Questions?

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