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Toward Vocabulary Control for Chief Complaint

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Abstract

The chief complaint (CC) is the data element that documents the patient's reason for visiting the emergency department (ED). The need for a CC vocabulary has been acknowledged at national meetings and in multiple publications, but to our knowledge no groups have specifically focused on the requirements and development plans for a CC vocabulary. The national consensus meeting "Towards Vocabulary Control for Chief Complaint" was convened to identify the potential uses for ED CC and to develop the framework for CC vocabulary control. The 10-point consensus recommendations for action were 1) begin to develop a controlled vocabulary for CC, 2) obtain funding, 3) establish an infrastructure, 4) work with standards organizations, 5) address CC vocabulary characteristics for all user communities, 6) create a collection of CC for research, 7) identify the best candidate vocabulary for ED CCs, 8) conduct vocabulary validation studies, 9) establish beta test sites, and 10) plan publicity and marketing for the vocabulary.

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The chief complaint (CC) is the data element that documents the patient's reason for visiting the emergency department (ED). In spite of the potential clinical, administrative, and public health significance of CC, there is no standard vocabulary for this data element. The need for a CC vocabulary has been acknowledged at the national and international levels, including at the *Academic Emergency Medicine* 2004 Consensus Conference "Informatics and Technology in Emergency Care,"[1] the Frontlines of Medicine Project,[2] Data Elements for Emergency Department Systems (DEEDS),[3] the National Center for Health Statistics,[4] the National Syndromic Surveillance conferences,[5] the Canadian Association of Emergency Physicians,[6] and the Victorian Emergency Minimum Dataset Overview.[7,8] ED CC data are increasingly used to facilitate symptom-driven surveillance for early detection of bioterrorism and other disease outbreaks of interest to public health.[9–12] The syndromic surveillance conferences focused on public health surveillance, including some systems that incorporate CC. However, no groups have specifically focused on discussing requirements and development plans for a CC vocabulary.

In 2006, a group of 40 stakeholders, including emergency medicine clinicians, researchers, administrators, vendors of ED information systems, and

health care information services professionals, met for a national consensus meeting ''Towards Vocabulary Control for Chief Complaint'' (October 2006, Baltimore, MD) to identify the multiple potential uses for ED CC data and to develop the framework for CC vocabulary control. Institutional review board approval was not needed for this meeting. This white paper summarizes the conference deliberations and the recommendations for developing standardized terminology for ED CC.

DEFINITION

Symposium's Working Definition of Chief Complaint
The patient's reason for seeking care or attention in the emergency department, captured by a clinician at initial presentation.

"Chief Complaint" is DEEDS v1.0 data element 4.06.[3] DEEDS is a list of 156 standardized data elements that are generally accepted parts of an ED record. It was developed to improve the accuracy and completeness of ED data, to allow data sharing between different electronic systems, and thus to make ED data accessible for a wide variety of uses.[13] Without a standard vocabulary for recording and reporting CCs, successful use of CCs requires extensive cleaning and normalization to improve its quality.[14] CC data for the more than 115 million annual visits to U.S. EDs[15] are difficult or impossible to aggregate due to variation in the way that CCs are documented.

USES FOR A CC VOCABULARY

Chief complaint data are useful for clinical care and ED operations, education, surveillance, and research. Because CC data are not standardized, there is unmet potential for these uses.

Clinical Care and ED Operations
The primary use of CC data must be to support clinical care and ED operations. The CC is the first data element collected by a clinician during the process of clinical care. It affects decision-making at triage, prioritizes patients for treatment, organizes patient flow in the ED, and helps focus medical evaluation. Other clinical applications of a CC vocabulary include incorporating the data elements into electronic health record systems, initiating and monitoring compliance with clinical guidelines, linking clinical information to bibliographic resources, facilitating decision support systems and quality improvement activities, and implementing complaint-specific history and physical examination prompts.[1,2,9,16-18]

Since CC focuses the medical evaluation, standardized CC terminology can impact coding and billing.[18] Analysis of the ED CC could improve the understanding of health policy-makers about the real reasons patients seek emergency care.

Education
Medical and nursing students need training to translate a patient's words into a clinically coherent CC. Other than triage educational programs, mentoring and "on-the-job training" are the only current modalities for such training. Curricula for nursing and medical students should be developed based on clinical need, which can be identified through CC analysis.[19]

Surveillance
Chief complaint is a major tool for providing timely and reliable data for a variety of surveillance applications, including infectious disease outbreaks, bioterrorism, emerging infectious diseases, seasonal disease outbreaks, toxic exposures, radiation exposure, prevalence of chronic diseases, adverse effects of drugs or procedures, injuries, and deaths. Because surveillance is most useful when applied to large populations, CC standards must be exceptionally rigorous and validated across EDs, while still allowing for some local freedoms and modifications. A controlled CC vocabulary must be accepted by standards organizations and adopted by the majority of vendor systems so that it can be widely used. The increasing use of ED CC data for syndromic surveillance provides compelling evidence of the value of these data for public health purposes and a clear indication that a controlled vocabulary would facilitate communication of CC data between information systems.[2,3,5,10-12,20-23]

Research
A standardized vocabulary for CC would allow the aggregation of CC for investigations into the presentations of disease. CC analysis can identify patients eligible for clinical studies. Prospective screening can be used before patients are approached. Retrospective screening can be used to identify the true denominator for studies and to identify potentially eligible patients missed by screening. A generalizable system for CC would allow clinical comparisons of population groups in different geographic regions and institutions, would facilitate analysis of geographic or institutional variations in processes of care for symptom clusters, and could impact national and regional benchmarking.[18,24]

CONSENSUS POINTS REGARDING THE CONSTRUCTION OF CC TERMINOLOGY

Goals for the ED CC vocabulary were conceptualized by symposium participants as follows. The vocabulary should:

1. Be a collection of controlled concepts. Controlled vocabulary terms are unambiguous words or phrases that can only represent a single concept. For example, "attack" cannot be used to refer both to "heart attack" or "assault." A controlled vocabulary does not allow variant spellings, synonyms, or popular terms or jargon.

2. Have face validity: be reliable, reproducible, generalizable, practical, sharable, and clinically relevant.

3. Fit well into the clinical work flow.

4. Be scalable, extensible, and interoperable. *Scalable* means that the vocabulary system could be applied to large or small data sets and can accommodate expansion. For example, it will function well when a health care system adds multiple EDs to its network.

Extensible means that new CCs, concepts, or terms can easily be added to the vocabulary with minimal disruption of its organization. For example, specific terms like chemical or ocular burns can be added as needed. *Interoperable* means that the design of a CC vocabulary system would be compatible with other health care information systems, not just the ED information system.

5. Be sufficiently granular but be organized so that users can select more or less granular terms depending on their needs.

6. Be easily adoptable to user groups from several perspectives: usability, affordability, and compliance with regulatory requirements.

7. Add minimally, if at all, to data entry requirements.

8. Be based on established vocabulary principles.[25] This means, among other things, that relationships between terms establish the hierarchy of the vocabulary so that narrower terms come under broader terms. For example, ocular burns and chemical burns would come under the broader term "burn."

The creation of a set of controlled concepts is complicated by many factors, including the extensive scope of coverage of a CC vocabulary; the CC's relationship to other fields in the ED and hospital record; needs for expressivity and completeness of the vocabulary; identifying the best way of providing a standardized vocabulary, such as a controlled term list or thesaurus; and determining whether to adapt an existing vocabulary or create a new one.

Once the key elements of a controlled vocabulary are identified, development and maintenance will still require long-term commitment. Development and maintenance include means of validating, evaluating, and maintaining a resulting vocabulary; the role of stakeholder organizations in design and development; the road to adoption as a standard; and application of lessons learned in other vocabulary research.

SYMPOSIUM RECOMMENDATIONS

Symposium participants developed ten recommendations to encompass the scope of tasks from development to implementation and maintenance.

Recommendation 1: Begin Work on Developing a Controlled Vocabulary for CCs

It was the consensus of the participants that work should be initiated to develop a controlled vocabulary for ED CCs, and the remaining recommendations describe the work plan in detail.

Recommendation 2: Obtain Stable Source(s) of Funding and Other Support for Immediate and Long-term Activities

Developing and maintaining a standard CC vocabulary for ED use will require a concerted effort by subject matter experts and stakeholders, along with adequate funding. Funding is needed to support developmental research, initial vocabulary authoring, subsequent corrections and updates, publishing and disseminating the vocabulary, and training in its use. The level of investment in a CC vocabulary should be commensurate with its considerable importance for direct patient care, health care worker training, public health surveillance, and health services research.

Recommendation 3: Establish Infrastructure and Organization for Immediate and Long-term Actions

A prime locus of responsibility must be identified to support development and maintenance tasks for a CC vocabulary. The conceptual and operational tasks cut across disciplines and will pose a variety of challenges, from solving initial research and development problems, to production and dissemination of a first version and then subsequent versions. Above all else, the organizational home for a CC vocabulary must have the personnel and resources needed to lead and manage a long-term, multipartner project.

Academic institutions, professional organizations, or government agencies are prime candidates for an organizational home. Each has advantages and disadvantages. For example, an academic organization may be relatively well positioned to undertake research and development tasks needed for vocabulary authoring and maintenance, but is perhaps less well suited than a professional group or government agency to foster wide adoption and use of a standard vocabulary. The public health value of CC data coupled with movement by the U.S. Department of Health and Human Services (DHS) toward health data standards and interoperable information systems suggest that the locus of responsibility could reside within the department or one of its agencies.

To complete the tasks at hand, a public–private partnership could be formed to assure that triage nurses and emergency physicians are supported as active participants in vocabulary development,[26,27] while providing research support to answer key questions about vocabulary structure and content coverage. However, regardless of where a CC vocabulary resides organizationally, developing and maintaining it will almost certainly require the expertise and work effort of numerous individuals from a variety of organizations.

Volunteer contributions should be sought, but they are unlikely to be sufficient to accomplish all near- and long-term tasks. More sustained effort and stable financial support will be needed to assure the infrastructure and the capacity are available to produce a high-caliber, field-tested vocabulary at the outset and to provide updates and enhancements over time.

Recommendation 4: Work with Standards Organizations, Including Health Level Seven (HL7) and DEEDS

From its inception, a CC vocabulary project will require careful planning and execution to assure that user requirements and subject matter expertise are gathered and focused in a well-coordinated way. Interaction with standards development organizations, professional groups, government agencies, and individual experts will likely be needed from the outset. This is necessary to ensure semantic interoperability for data exchanges between health care information systems and between health care and public health. It is

important to team with Health Level Seven (HL7) work groups, especially the HL7 Emergency Care Special Interest Group (HL7 EC SIG)[28] and the HL7 Vocabulary Technical Committee (TC).[29] HL7 is a consensus group that develops and promotes standards that enable different health care electronic applications or systems to exchange data.[30] The CC vocabulary should not duplicate or collide with other work efforts or products and should have all the vocabulary attributes that are necessary and sufficient for use in conjunction with HL7 data standards.

Recommendation 5: Address Required CC Vocabulary Characteristics Needed by All User Communities

This recommendation is met by collecting and analyzing existing CC lists. Historically, CC lists in EDs were difficult to maintain because they grew without any plan or control. This led to local variations that were idiosyncratic, unique to the local implementation, and not sharable. They were not scalable to support large integrated delivery networks and hospital systems.

CC data are currently collected in most, if not all, EDs in the United States, but there is no standardized approach to recording the information. EDs currently document the CC in free text form or using a variety of locally developed or vendor-supplied terminologies. These terminologies vary greatly in granularity, in semantic organization, and in their use of synonyms and lexical variants. Few of the locally developed CC terminology systems have been described in the literature and none are widely used in the United States.[31–33]

The National Hospital Ambulatory Medical Care Survey (NHAMCS)[15] retrospectively analyzes emergency visits at a number of survey hospitals and categorizes the final diagnoses using "A Reason for Visit Classification"[34] codes. The Frontlines of Emergency Medicine Workgroup defined a set of CC categories for bioterrorism that are based on the International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM).[35]

Travers and Haas[36] analyzed a very large set of ED CCs and were able to categorize more than 99% of these using 1,136 concepts from the Unified Medical Language System (UMLS). The Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT) was found to include concepts for 79% of all ED CC entries, although some common CCs were not found in SNOMED CT (e.g., wound check, medical clearance).[36] Collecting and analyzing existing published and unpublished lists will describe current practices and help ensure complete coverage by providing content for vocabulary development and supporting mapping between existing lists and final vocabulary.

In addition to the above-mentioned sources, CC lists will be gathered by contacting known developers of CC lists including vendors of Emergency Department Information Systems (EDIS). Information about each list will be collected, including where it is used, who uses it, where it came from, how it is used, and who "owns" it. Each list will need to be analyzed for the extent of concept coverage, organization, gaps in coverage, and terminology source. Analysis of the lists will reveal

"high-priority" concepts that occur in multiple lists and must be included in the CC vocabulary, as well as less frequent concepts that can also be considered for inclusion. Based on this information, a content map and/or crosswalk will be developed.

Crosswalks need to be created between existing lists and any other candidate vocabularies. A crosswalk defines links between terms from different vocabularies that represent the same or similar concepts. Links may represent exact synonymy, broader or narrower terms, or other types of relationships useful for analysis. The crosswalk analysis will help shape the scope of the controlled vocabulary by identifying the terms and concepts included in all, some, or one of the lists or vocabularies.

Additional investigations will be needed to inform other design dimensions. The utility of existing lists for secondary uses such as surveillance should also be investigated.

Another branch of investigation should explore the related information that is associated with CC. Information that is closely related to CC, but not specifically CC, is important for triage and clinical uses of CC and, indeed, is often recorded in the CC data field. Such information includes the patient's own words describing the reason for seeking care, words recorded by a clinician, words from a controlled vocabulary list, secondary CCs, patient self-reported diagnoses, mechanism of injury, comorbidities, previous visits to the ED or other health care venue, and a variety of temporal information.

Recommendation 6: Create Collection of CC Data for Use by Vocabulary Researchers

A publicly available collection of CCs could support further vocabulary research efforts involving CCs. To be most useful, the collection should represent the diverse institutions and geographic locations that generate CCs. The CCs in the collection could be categorized by 1) the nature of the institution that generated the complaint (e.g., academic vs. rural ED), 2) the job title of the person who entered the CC (e.g., triage nurse, data entry clerk), and 3) the data type the CC represents (e.g., free-text or coded). Once collected, natural language processing techniques could automatically process and characterize the CCs to address questions such as: 1) what are the most frequently appearing CC concepts? 2) How many lexical variations are used to describe the same concept? 3) What proportion of CCs describe more than one presenting problem? 4) What proportion of CCs have modifiers such as negation, uncertainty, sidedness, severity, etc.?

A potential source of CC data for vocabulary research has been made available by the National Center for Health Statistics. ED data from the 2005 NHAMCS of EDs is publicly available and includes verbatim CCs for more than 35,000 ED visits.[4]

Recommendation 7: Identify the Best Candidate Vocabulary for Adaptation to ED CCs

The consensus group considers the SNOMED to be a candidate vocabulary in light of the requirements laid out thus far. SNOMED has been developed by the

College of American pathologists over the past 40 years. Ownership has recently been transferred to the International Health Terminology Standards Development Organization (IHTSDO [SNOMED SDO]; http://www.ihtsdo.org/). The most recent iteration is a comprehensive health care domain terminology set containing more than 300,000 active concepts in a hierarchical organization with formal definitions. The hierarchy contains 17 categories; there are 770,000 descriptions and 900,000 defining relationships. SNOMED was licensed for use in the United States by the National Library of Medicine; Great Britain has a similar license. There are also Spanish- and German-language versions of SNOMED.

SNOMED-CT has emerged as the preferred vocabulary standard for most applications. It is not a perfect tool for CCs in emergency medicine, but it is expected to evolve in the future. SNOMED coverage of various discrete terminology domains such as reason for visit and problem lists generates about an 80% match for emergency care terms.[36] The SNOMED editorial process and regular release schedule provides a mechanism for updating the hierarchy and adding terms.

Systems that both allow recording of the original text-based complaint and also require clinicians to categorize the complaints using a predefined standardized scheme may be a useful approach for meeting the need to capture information as close as possible to the patients' own words while also consistently capturing codified complaints. Utilization of a defined subset of SNOMED-CT terms, augmented by additional terms that are needed for EM, but not yet incorporated into SNOMED-CT, may be a means for accomplishing consistent categorization using a controlled vocabulary across the emergency health care industry.

Recommendation 8: Conduct Validation Studies of the Proposed Vocabulary

All users of the new CC vocabulary must be confident of its quality. To that end, its validity must be clearly tested and demonstrated. Internal and external validation studies should be conducted to ensure that the vocabulary adheres to good vocabulary principles[25] and accurately represents concepts needed for triage. In addition, the vocabulary should be evaluated for usability by stakeholders, especially for triage and clinical uses. In this context, usability includes expressiveness, clarity, ease of use (particularly for frequently used CCs), and adaptability for a variety of system interface styles (pick list, pre- or postcoordination, or background translation from free-text).

Recommendation 9: Establish Beta Test Sites for the New Vocabulary

Beta testing of the new vocabulary should be done in a realistic setting. Issues of usability, expressivity, and even ease of learning cannot be fully explored in off-site studies. To that end, we propose the establishment of beta test sites: EDs, health networks or other places of care, and vendors of hospital information technology (IT) systems. Such sites would need to have the means

to set up test environments, by swapping the new vocabulary for what is currently used, and to provide resources for the project. We recognize that this is a challenging request for any organization to provide, but such test sites would provide great benefits for both the initial development and the deployment of the vocabulary and for subsequent modifications and updates.

Encouraging hospitals, organizations, and individuals to participate as beta test sites and in the validation studies is one way of informing stakeholders of the new CC vocabulary, gaining buy-in, and learning more about the necessary adoption process for various sites. In addition, both the validation process and the good results from validation studies will increase confidence in the quality of the vocabulary.

Recommendation 10: Plan Publicity, Marketing, Cooperation, and Adoption of the Controlled CC Vocabulary

Participants in the CC symposium are already convinced of the need for a CC vocabulary and have agreed upon the general development plan. Success in the adoption of the CC vocabulary depends on working with stakeholders, including triage nurses, emergency physicians, registration clerks, hospital administration and IT departments, vendors, professional organizations, and state and federal agencies. All stages in the design, development, evaluation, and validation process laid out in this white paper are opportunities for building these relationships, drawing on stakeholders' expertise, and thus fostering acceptance of the vocabulary.

Each participant group can start to enlist others, working through their home institutions and organizations by organizing conference panels and focus groups and other opportunities to publicize our efforts. Stakeholder organizations should be asked to endorse CC development. Effort should be made to put the CC definition into the standards stream as soon as possible, including HL7 and DEEDS, to ensure coherence with existing standards.

In addition to providing opportunities for stakeholders to participate in vocabulary development and evaluation, it is also important to show how the CC vocabulary will benefit individual users, departments, institutions, and the general public. Use cases for each of the various groups can help demonstrate improvements in such areas as patient care, workflow, record-keeping, coding, and billing. If this is the carrot, we should also keep in mind the stick. Acceptance of the new CC vocabulary into standards organizations and vendor's information systems would move its use from the voluntary into the required sphere.

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Appendix A

Other members of the Chief Complaint Symposium Group:

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REFLECTIONS

What Are You Doing Here, Doc?

We met in my first months of residency at Bellevue. We saw each other intermittently, sometimes not for months, sometimes three times a day. We would go through our usual routine; he would come in intoxicated when it got dark, when emergency medical services brought people in out of the cold. He would get his glucose checked, thiamine injection, and a quick once-over for trauma and then he would sleep. The only variable was his occasional set of labs or computed tomography (CT) scan of his head. In the morning, the social worker would bring clothes, the nurses would give him a sandwich, and I would discharge him at 6 AM rounds in anticipation of sign-out. He was ''one of the nice ones,'' which for me meant that he would leave after his second sandwich and that I only rarely had to call security to escort him out. Our relationship continued for 4 years and he became one of my regulars. I am sure he had been many other residents' regulars before me. I always wondered where patients like this went when they were not in my emergency department (ED); a few years later, I found out.

During my fourth year I began moonlighting at a smaller hospital in the city. It was close by, but it seemed like worlds away. I was by myself with no residents. I was the attending and people wanted me to make decisions. It was a surprise the first time I saw this patient I knew. I recognized his name on the triage list and I went to the waiting room to see if it was him. When I called his name, I was greeted with a friendly ''What are you doing here, Doc?'' I thought back to the medical school advisor who told me emergency medicine had no continuity of care.

After graduation, I took a job at a teaching hospital, near my resident moonlighting job. Several months after I started, the same patient came into that hospital. He was disheveled, and his mentation was altered from what I knew to be his baseline. It was a busy weekend overnight shift, and he did not have a scratch on him. Had I not seen him so many times before, I might have just left him alone until morning rounds.

The CT scan showed a large subdural hematoma necessitating an emergent trip to the operating room. The neurosurgeons said to me, ''we can't find any next of kin to sign the consent. Your residents told us you know him.'' I said, ''I've seen him more times than anyone else here if that's what you mean, and I know him well enough to say you're probably not going to be able to find anyone to sign.'' He went to the operating room with my signature endorsing consent.

I worried about him for days. It made me think about the interesting relationships emergency physicians have. From the visiting tourist who sprains his or her ankle and never comes back, to the alcoholic that comes three times a day, these personal interactions only occur inside of the ED. These ''regular'' relationships are difficult to sort out. Anger may be a typical reaction to the patients we see over and over; however, we get to know them and secretly or not so secretly we worry about them.

To this day, I am not sure what my computer engineer husband thinks when my ''regulars'' say hello to me from the curb in the street. This patient reminded me that the easiest populations to overlook can actually be the most susceptible, and they need our attention and advocacy the most. The patient did well and was discharged the following week. I am sure I will see him again.

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