ORIGINAL REPORT

Using Electronic Dental Record Data for Research: A Data-mapping Study

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Abstract: *Anecdotal evidence suggests that, during the clinical care process, many dental practices record some data that are also collected in dental practice based research network (PBRN) studies. Since the use of existing, electronically stored data for research has multiple benefits, we investigated the overlap between research data fields used in dental PBRN studies and clinical data fields typically found in general dental records. We mapped 734 unique data elements from the Dental Information Model (DIM) to 2,487 Common Data Elements (CDE) curated by the NIDCR's PBRNs in the Cancer Data Standards Registry and Repository (caDSR). Thirty-three percent of the DIM data elements matched at least one CDE completely and 9% partially, translating to about 9% and 2%, respectively, of all data elements used in PBRN studies. The most frequently used CDEs found in the DIM included data about dental anatomy, medications, and items such as oral biopsy and caries. Our study shows that a non-trivial number of data elements in general dental records can be mapped either completely or partially to data fields in research studies. Further studies should investigate the feasibility of electronic clinical data for research purposes.*

Key Words: dental records, dental informatics, electronic health records, computerized Patient Records, clinical research, dental research.

Introduction

The National Institute of Dental and Craniofacial Research (NIDCR) is rapidly and significantly expanding practice-based research in dentistry. A key challenge for participating dental practices is integrating the research with the clinical care process (Schleyer, 2010). The capture of research data is particularly important (Gilbert *et al.*, 2011) because anecdotal evidence suggests that, during clinical care, many dental practices record at least some data that are also collected in dental PBRN studies. While different PBRN regions vary in their approaches to data collection, most research data are recorded manually on Case Report Forms (CRF). Data on CRFs are then submitted to the Data Coordinating Center (DCC), either directly or after local data entry. DCC staff then merge the data into the study database. Errors and inconsistencies are reconciled in communication between DCC and practice staff. This process is not only time-consuming and costly, but also

delays data transmission and causes possible inaccuracies (Weir *et al.*, 2003; Goldberg *et al.*, 2008; Atkinson, 2012).

The CRF for the study “CONDOR case-control study of osteonecrosis of the jaws” (CONDOR Case-Control Study of Osteonecrosis of the Jaws, 2009), shown in Fig. 1, illustrates that at least some data required for the study are already recorded in many practices’ dental records. The form (19 pages, of which 7 are data forms) solicits information on the participant’s basic demographics, dental diagnoses prior to the onset of osteonecrosis of the jaw (ONJ), dental treatment experience, and biopsies. During the ONJ study, researchers conducted a lengthy patient survey for the study because they did not know, *a priori*, if certain charts would be available and, if so, what the data quality would be. If appropriate electronic data had been available, the project may have been able to reduce the time required for acquiring data (about 40 min *per* participant [G. Gilbert, personal communication], or a total of *ca.* 500 hrs for the 191 ONJ patients and 573 controls [Barasch *et al.*, 2011]).

A detailed review of the form illustrates a non-trivial degree of overlap with data typically recorded in electronic dental records (EDR). For instance, EDRs contain most of the fields shown in the section *Patient Screening and Enrollment*

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Figure 1.

The Case Report Form for the PBRN study “CONDOR Case-Control Study of Osteonecrosis of the Jaws” includes clinical information commonly stored electronically by dentists in the United States.

A. Patient Screening and Enrollment

2. Patient Initials

3a. Date of last visit to your office / /
M M / D D / Y Y Y Y

3b. Check the box to your right if the date of the last visit is unknown. ☐

4. Patient month/year of Birth /
M Y Y Y Y Y

5. Patient Gender
F M

B. Dental Diagnoses
Prior to ONJ symptoms in ONJ subjects or since the year 2000 in controls.

Was the patient edentulous in the year 2000?
YES — Check 'N/A' box to the right and proceed to Section C. ☐ N/A
NO — Please complete the dental diagnoses details below. ☐

Dental Diagnoses	Possible entries	2000	2001	2002	2003	2004	2005	2006	2007
Number of maxillary teeth present	0-16								
Number of mandibular teeth present	0-16								
Periodontal Disease (Circle the appropriate response)	I/II/III/IV NA	I II III IV NA	I II III IV NA	I II III IV NA	I II III IV NA	I II III IV NA	I II III IV NA	I II III IV NA	I II III IV NA
Caries (two or more per year) (Circle the appropriate response)	Yes/No NA	YES NO NA	YES NO NA	YES NO NA	YES NO NA	YES NO NA	YES NO NA	YES NO NA	YES NO NA
Endodontic Problems (Circle the appropriate response)	Yes/No NA Tooth#	YES NO NA	YES NO NA	YES NO NA	YES NO NA	YES NO NA	YES NO NA	YES NO NA	YES NO NA
Gingival Bleeding (Circle the appropriate response)	Yes/No NA	YES NO NA	YES NO NA	YES NO NA	YES NO NA	YES NO NA	YES NO NA	YES NO NA	YES NO NA

D. Periodontal Treatments

Has the patient had any periodontal treatment since the year 2000?
NO — Check 'N/A' box to the right and proceed to Section E. ☐ N/A
YES — Please complete the details of periodontal treatment given either prior to onset of ONJ or as indicated in the years below. ☐

Treatment	Code	2000	2001	2002	2003	2004	2005	2006	2007
Periodontal maintenance (check under each year, if performed)	4910	YES NO NA	YES NO NA	YES NO NA	YES NO NA	YES NO NA	YES NO NA	YES NO NA	YES NO NA
Scaling and Root Planing (circle the quadrant/s)	4341	UL UR LL LR	UL UR LL LR	UL UR LL LR	UL UR LL LR	UL UR LL LR	UL UR LL LR	UL UR LL LR	UL UR LL LR
Other non-surgical periodontal procedures	Local Antibiotics (4381) (tooth #) Other Procedures (List codes and oral medications)								
Surgical periodontal procedures (For each quadrant enter dates and codes)	Upper Left Date Code								

of Fig. 1, such as patient initials, date of last visit to the office, month/year of birth, and gender. The same is true for the number of present teeth in the section *Dental Diagnoses* and for the procedures in the section *Periodontal Treatments*. Data fields for *Periodontal Disease*, *Caries*, *Endodontic Problems*, and *Gingival Bleeding* (see section *Dental Diagnoses*) are available in most EDR systems (Schleyer *et al.*, 2007). Our studies have shown significant growth in the amount of clinical information that dentists in the US store on computers (Schleyer *et al.*, 2006, 2012), making these data potentially available for research.

As of March 2013, almost none of the approximately 47 PBRN studies conducted to date has used electronic patient data. Experience in medicine has shown that doing so can have multiple benefits, including increased efficiency (Sung *et al.*, 2003; Kahn *et al.*, 2007), reduced costs (Kohane, 2011), avoidance of selection biases, conduct of longitudinal studies, detection of rare events, and early discovery of drug side-effects (Brownstein *et al.*, 2007; Wilke *et al.*, 2007; Seyfried *et al.*, 2009). For dental PBRN studies, the most attractive aspects of EDR data at this time may include mitigating the data entry burden for office staff, conducting studies faster, reducing costs, and decreasing errors. A key question is which data elements in EDRs *could* potentially be used in research studies. To answer this question, we determined which research data elements (1) can be found in a comprehensive content taxonomy for general dentistry and (2) have been used most frequently in dental PBRN studies. The results of this study will provide initial guidance on which types of practice-based studies are most feasible based on the data currently available in EDRs.

Materials & Methods

We used 2 data repositories for our study: (1) the Cancer Data Standard Registry and Repository (caDSR), developed by the National Cancer Institute (National Cancer Institute, caDSR, 2012); and (2) the Dental

Figure 2.

The CDE Tooth Sensitivity Hot Assessment Scale shown in the CDE Browser.

CDE Browser

Back Help

Data Element Data Element Concept Value Domain Classifications Usage Data Element Derivation Admin Info

Data Element Details

Public ID:	2509345
Version:	1.0
Long Name:	Tooth Sensitivity Hot Assessment Scale
Short Name:	PT_HOT_SEN_T_ASS_SCA
Preferred Question Text:	When I eat hot food or drink hot liquids, I feel
Definition:	the patient's assessment of his/her tooth's sensitivity or ability to respond to physical stimuli of heat, increased heat energy, or to register small physical amounts or differences in heat content of food or liquids.
Value Domain:	Tooth Sensitivity Scale
Data Element Concept:	Tooth Sensitivity Hot Assessment
Context:	NIDCR
Workflow Status:	RELEASED
Origin:	PEARL CRF:Practitioners Engaged in Applied Research and Learning Network Case Report Form
Registration Status:	Qualified
Direct Link:	https://cdebrowser.nci.nih.gov/CDEBrowser/search?elementDetails=9&FirstTimer=0&PageId=ElementDetailsGroup&publicId=2509345&version=1.0

Reference Documents

Document Name	Document Type	Document Text	Context	URL
CRF Text	Preferred Question Text	When I eat hot food or drink hot liquids, I feel	NIDCR	
CRF Text2	Alternate Question Text	If yes, On a scale of 1-10 where 0 is no pain and 10 is worst pain, how intense is the pain?	NIDCR	

Information Model V. 1.0 (DIM) (Acharya *et al.*, 2009a), developed by the University of Pittsburgh's Center for Dental Informatics.

The caDSR is a directory of all 2,487 research data elements, called Common Data Elements (CDE), used in the NIDCR's 47 PBRN studies conducted to date. The purpose of this project is to standardize data collection and reporting for clinical trials by providing terminology for questions and values on CRFs (Tobias *et al.*, 2006). The NIDCR used CDEs for its PBRN studies to identify discrete, defined items for data collection, promote consistent data collection in the field, eliminate unneeded or redundant data collection, and facilitate data-sharing. All NIDCR PBRN study data elements can be viewed at <http://cdebrowser.nci.nih.gov/> (click NIDCR in the *caDSR Contexts* tree). Fig. 2 illustrates the information about each CDE we used to map data elements. Specifically, we used the following tabs: Data Element ("Document Text" or "Preferred Question Text" of a CDE, *e.g.*, "When I have hot food or drink, I feel..."), Data Element

Concept (concept terms and codes used to construct the question, such as *Tooth, Sensitivity, Hot,* and *Assessment*), Value Domain (valid values for answering the question), and Usage (protocol number[s] of studies using the CDE).

The DIM (Acharya *et al.*, 2009b) is a comprehensive content taxonomy for patient records in general dentistry developed from 14 patient record formats and 76 de-identified patient records of nine US dentists. It was validated through a Delphi study involving dental practitioners, researchers, and educators (Acharya *et al.*, 2013). The DIM contains 986 data elements, of which 734 are unique.

Fig. 3 shows the workflow of mapping the 734 data elements in the DIM to the 2,487 CDEs. The directionality of mapping was "DIM data elements" to "CDEs" for 2 reasons. First, mapping the smaller body of DIM data elements to the larger body of CDEs reduced the workload. Second, the CDE Browser offers sophisticated search mechanisms that facilitated the mapping process. The process included 2 steps:

(1) Preliminary Mapping

An experienced caDSR Expert (SA), who created over 3,573 CDEs in the caDSR and worked on the NIDCR PBRN project for the entire duration of the contract, completed the initial mapping using the CDE Browser (<http://cdebrowser.nci.nih.gov/>) and CDE Curation Tool (<http://cdecurate.nci.nih.gov/>). To identify potential matches, she searched for all or part of the name of each DIM data element, such as "*tobacco*". For each potential match, she compared the DIM data element with the detailed information about each CDE described above. She then determined (1) whether one or more CDEs were a match, and, if so, (2) how closely the elements matched (*Complete match* or *Partial match*).

(2) Final Mapping

The DIM Expert (AA), the main developer of the DIM and a dentist with extensive dental informatics training, then validated each mapping by comparing each DIM data element with the

Figure 3.

Workflow of the mapping process between DIM data elements and caDSR CDEs (errors due to rounding).

information about matching CDEs. If a mapping was not accurate, he coded the correct mapping and documented the reason for the change. To guard against false-negative mapping decisions by the caDSR Expert, we randomly sampled 20 (5%) DIM data elements classified as *No Match* during the preliminary mapping and checked them against the CDE during final mapping.

At the end of the 2 mapping phases, we summarized the mapping results descriptively.

CDEs that were mapped as *Complete* or *Partial match* to a DIM data element were further analyzed for their frequency of use in PBRN studies. This frequency was determined by counting the number of CRFs that used the CDE as one of the data elements on the Usage Tab for each CDE. However, this method only approximated how often a CDE was used, for 2 reasons. First, some CDEs occurred multiple times on a CRF, which is not reflected on the Usage Tab. Second, some CDEs were not associated with electronic forms in the caDSR, underrepresenting their usage.

The 2 data resources used in this study were entirely devoid of patient informa-

tion. The DIM is an abstract model of patient data elements typically found in general dental records, and the caDSR is a collection of fields on (empty) CRFs. No human subject data of any kind were used in this study. Therefore, regulations for human subjects research and protected health information were not applicable, and institutional review board approval was not required.

Results

During preliminary mapping, 280 of 734 (38%) of the DIM data elements matched CDEs completely and 59 of 734 (8%) partially (see Fig. 3). During validation, the DIM Expert rated 39 (14%) *Complete matches* and 15 (25%) *Partial matches* as inaccurate. Of the inaccurate *Complete matches*, 23 were converted to *No Match* and 16 to *Partial match*. Of the inaccurate *Partial matches*, 12 were converted to *No Match* and 3 to *Complete match*. Two (10%) of the 20 randomly selected DIM data elements rated as *No Match* by the caDSR Expert were inaccurate, with one each converting to *Complete match* and *Partial match*.

The validation changed these results to 245/734 (33%) and 61/734 (8%), respectively. Looking at the pool of 2,487 CDEs, 230 unique CDEs (9%) matched a DIM data element completely and 57 unique CDEs (2%) partially.

The Table shows the CDEs used in 5 or more of the 47 PBRN studies and their matching DIM data elements. General anatomic terms, such as *Quadrant* and *Tooth number*, matched completely, as did data elements related to medications. Various dates related to clinical findings also matched, as well as highly specific data elements such as oral biopsy, bruxism, and periradicular pathology. (A list of the 100 most frequently used CDEs matching DIM data elements can be found in the Appendix.)

Discussion

An increasing body of evidence (Sung *et al.*, 2003; Brownstein *et al.*, 2007; Kahn *et al.*, 2007; Wilke *et al.*, 2007; Seyfried *et al.*, 2009; Kohane, 2011) indicates that data from EDRs for research can have multiple benefits. This study determined which data elements used in

Table.

CDEs Used in 5 or More PBRN Studies and Their Matching DIM Data Elements

CDE	CDE Definition	CDE Usage Frequency	DIM DE	Mapping
Has the patient had any biopsies?	'Yes/no/unknown/not available', whether there was removal of tissue specimens or fluid from cavity lying at the upper end of the alimentary canal, bounded on the outside by the lips and inside by the oropharynx and containing, in humans, the tongue, gums, and teeth, performed to establish a diagnosis.	18	Biopsy of oral tissue	Complete
Agent dose	The dose of the agent given to the patient.	15	Anesthetic amount Drug dosage Pre-medication drug dosage	Complete Complete Complete
Tooth number	The values and value meanings for tooth designation.	15	Tooth number	Complete
Tooth quadrant	The location or position of a tooth, a hard bone-like structure in the jaws of vertebrates, primarily used for eating, by quarters of the mouth, the cavity lying at the upper end of the alimentary canal, bounded on the outside by the lips and inside by the oropharynx and containing, in humans, the tongue, gums, and teeth.	15	Quadrant	Complete
Agent name	A text name for an Agent. An agent is a distinct substance or ingredient or compound/product/mixture thereof, contained in drugs, biologics, foods, and devices that acts to produce a specific effect (commonly health related). This can include radiopharmaceutical, nutritional, complementary and alternative medicine (CAM), molecular components of devices (<i>i.e.</i> , silicon in implants), and nano-technologic agents but does not include whole devices (implants) or procedures (<i>i.e.</i> , surgeries). Individual agents included in a treatment regimen or therapy are included in this definition; however, whole regimen names or other broad classifications of therapies are not.	12	Alert agent Drug name Over-the-counter medication name Prescribed medication name Pre-medication drug name	Complete Complete Complete Complete Complete
Has the patient had any new caries in the last 24 months?	A person who receives medical attention, care, or treatment, or who is registered with a medical professional or institution with the purpose of receiving medical care when necessary. The decay of a tooth in which it becomes softened, discolored, and/or porous. An area of abnormal tissue change. An account of all medical events and problems a person has experienced. A term that is used to indicate a question with permissible values of yes/no/unknown.	12	Caries	Partial
Date of assessment	The date on which the assessment of the patient/participant was performed.	11	Progress notes date Problem date	Complete Complete
Signature	The signed legal name of the person who documented information on the case report form.	11	Signature	Complete
Has the patient noticed his/her sleep bruxism?	The yes/no indicator related to sleep involuntary clenching or grinding the teeth as reported coming directly from patients or subjects through interviews or self-completed questionnaires or other data capture tools such as diaries about their life, health condition(s), and treatment.	5	Bruxism	Complete
Is peri-cemental disease present?	The yes/no indicator related to the disease or disorder in the area around or surrounding a root, especially the root of a tooth.	5	Periradicular pathology	Complete

the NIDCR's dental PBRN effort (1) can be found in a comprehensive content taxonomy for general dentistry and (2) have been used most frequently in dental PBRN studies. Our results indicate that approximately 33% of the data elements in general dental records matched research data elements completely and 9% partially, translating to about 9% and 2%, respectively, of all data elements used in PBRN studies.

The fact that about 40% of the data elements in general dental patient records are potentially re-usable for research is encouraging. A large percentage of the data that dental practices gather on a day-to-day basis can potentially be used to improve patient care and generate new knowledge. The fact that only 11% of research data elements used in PBRN studies match data in dental records, either completely or partially, should be interpreted carefully, for several reasons. First, not all of the studies conducted in dental PBRNs to date have focused on dental patients. Second, CDEs are pre-coordinated, while DIM data elements are atomic. A CDE combines all concepts included in a research data field, such as *Tooth*, *Sensitivity*, *Hot*, and *Assessment* in the example above, while DIM data elements are single concepts that cannot be subdivided further, such as *Tooth*. Several DIM data elements could have been combined to match a CDE, but resource constraints prevented us from performing this analysis. Third, a simple match between a dental record data element and a CDE says fairly little about its practical effects. For instance, a single matching data element, like a CDT code field, may facilitate the analysis of hundreds of records for a single patient (as illustrated for the ONJ CRF in the Introduction), yielding potentially huge efficiencies for a particular study.

EDR data have multiple limitations compared with the data collected in well-controlled clinical trials. First, data in EDRs, as those in EHRs (Stewart *et al.*, 2009; Terry *et al.*, 2010), are collected for clinical, not research, purposes. Resulting biases can range from threats to the representativeness of the population and clinician-related biases to missing data

and poor characterization of outcomes (Olsen *et al.*, 2007). Second, EDRs do not always store data in structured form, allow users to store the same or similar information in multiple places, and validate data inconsistently. Third, like EHR data (Hogan and Wagner, 1997; Faulconer and de Lusignan, 2004), EDR data often vary in their accuracy and are difficult to extract systematically. Last, clinical data rarely capture the information that is necessary to address a study's specific aim(s) adequately (Maupomé *et al.*, 2006).

This study has several strengths. First, both data resources we used are unique in health care. The DIM is currently the most comprehensive content taxonomy for general dental records in existence. Similarly, the caDSR is a complete repository of all research data elements used in dental PBRN studies to date. Second, the mapping was completed by 2 individuals with the most in-depth of expertise available about each data resource. In the process, the caDSR expert made recommendations based on existing CDEs, and the clinical and data experts decided whether the proposed data element(s) fit their particular use case. Data validation by our DIM expert showed that misclassifications by the CDE expert were mainly due to semantic differences, such as the exact clinical meaning or the level of granularity between the respective data elements. For example, the caDSR Expert rated "Family history of bleeding disorder" (DIM) and "Does the patient have active bleeding or pathologic conditions that carry high risk of bleeding such as known bleeding disorder, coagulopathy, or tumor involving major vessels?" (CDE) as a *Partial match*. However, this was *No Match*, because in the DIM, the history of bleeding disorder referred to the family, not the patient. Another example is "Root canal therapy" (DIM) and "Since the year 2000, did you have a root canal treatment?" (CDE). This rating changed from *No Match* to *Partial match* because the DIM data element indicates whether the patient had an RCT, but not when.

Three limitations of this project were that: (1) we compared only data fields and their definitions, not actual data

content; (2) the CDEs were much more rigorously and comprehensively defined than the DIM data elements; and (3) we did not exhaustively validate all items that were rated *No Match* by the caDSR Expert, because of time and resource constraints.

We believe that the results of our study, as well as anecdotal evidence collected in the PBRN effort, make a strong case for further investigating the utility of using EDR data for research. In future work, we will begin to use data from EDRs for clinical research studies on a variety of topics. Discovering the limitations of EDR data for research based on empirical studies can and should lead to insights into how to improve data collection in clinical practice. Thus, research using EDR data may become a valuable complement to traditional clinical research studies.

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