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## Review

# Reusing electronic patient data for dental clinical research: A review of current status

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## ABSTRACT

**Objectives:** The reuse of electronic patient data collected during clinical care has received increased attention as a way to increase our evidence base. The purpose of this paper was to review studies reusing electronic patient data for dental research.

**Data sources:** 1527 citations obtained by searching MEDLINE and Embase databases, hand-searching six dental and informatics journals, and snowball sampling.

**Study selection:** We included studies reusing electronic patient data for research on dental and craniofacial topics, alone or in combination with medical conditions, medications and outcomes. Studies using administrative or research databases and systematic reviews were excluded. Three reviewers extracted data independently and performed analysis jointly

**Results:** The 60 studies reviewed covered epidemiological (32 studies), outcomes (16), health services research (10) and other (2) topics; were primarily retrospective (58 studies); varied significantly in sample size (9–153,619 patients) and follow-up period (1–12 years); often drew on other data sources in addition to electronic ones (25); but rarely tapped electronic dental record (EDR) data in private practices (3). Type of research was not associated with data sources used, but research topics/questions were. The most commonly reported advantages of reusing electronic data were being able to study large samples and saving time, while data quality and the inability to capture study-specific data were identified as major limitations.

**Conclusions:** Dental research reusing electronic patient data is nascent but accelerating. Future EDR design should focus on enhancing data quality, begin to integrate research data collection and implement interoperability with electronic medical records to facilitate oral-systemic investigations.

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Abbreviations: EHR, electronic health records; EDR, electronic dental records; NDPBRN, National Dental Practice-based Research Network; NIDCR, National Institute of Dental and Craniofacial Research; PBRN, practice-based research network; EMR, electronic medical records; ONJ, osteonecrosis of the jaw; VA, Veterans Affairs; OSA, obstructive sleep apnea; AO, atypical odontalgia; CHD, coronary heart disease; DMF, decayed missing and filled teeth; HMO, health maintenance organization.

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*Clinical significance:* Measuring and improving the quality of dental care requires that we begin to reuse electronic patient data collected in practice for clinical research. Practice data can potentially serve as a useful complement to data collected in traditional research studies

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## 1. Introduction

Traditional clinical research is considered to increasingly fall short of the needs of clinicians, patients and funding agencies for many reasons.<sup>1,2</sup> They include the high cost of clinical trials, slow results, difficult enrollment, often poor generalizability, and challenges in discovering clinical outcomes and side effects in a nuanced and clinically meaningful manner.<sup>1,3,4</sup>

In consequence, the reuse of electronic data collected during clinical care has received increased attention as a method for increasing our evidence base.<sup>3–7</sup> Reusing data from electronic health records (EHR) is complementary to or synergistic with more traditional research approaches,<sup>3,8</sup> and has a number of potential advantages. EHRs can support many types of research, ranging from epidemiology and outcomes of chronic diseases to pharmacovigilance, adverse drug events and comparative effectiveness.<sup>7</sup> Using EHR data for research can help increase efficiency,<sup>1,4</sup> lower research costs,<sup>9</sup> allow the study of patient rather than research participant populations, avoid certain selection biases, implement longitudinal studies, detect rare events, and discover drug side effects earlier than possible with traditional methods.<sup>10–12</sup>

Reuse of electronic dental record (EDR) data has become increasingly attractive in the context of the National Dental Practice-based Research Network (NDPRN) initiative by the National Institute of Dental and Craniofacial Research (NIDCR). The experience during the practice-based research network (PBRN)'s initial funding period has shown that there are more relevant research questions than can be practically addressed using the typical PBRN study approach; that some important long-term research questions do not fit very well into the timeframe of a PBRN study; and that costs and practice workflow issues limit the “throughput” of the PBRN system. Given the fact that approximately 75% of DPBRN practitioners use a computer to manage clinical information and 15% are paperless,<sup>13</sup> secondary analysis of EDR data is increasingly compelling.

Fig. 1 illustrates the workflow of a continuous cycle of improvement based on the analysis of electronic patient data in the context of a Learning Health Care System.<sup>3</sup> Initially, patient data generated during the clinical encounter are captured electronically, ideally in standardized form. A data extraction, validation and analysis process produces answers to clinical questions. Once disseminated, those answers can help change clinical practice, resulting in improved care outcomes.

Clearly, data from EHRs have multiple limitations compared to the data collected in well-designed and – executed clinical trials. First, EHR data are collected for clinical, not research purposes.<sup>6,14</sup> Resulting biases can range from threats

to the representativeness of the population and clinician-related biases to missing data and poor characterization of outcomes.<sup>3</sup> Second, data in EHRs tend not to be very standardized for multiple reasons.<sup>6,15</sup> Many medical systems still favour free text over structured data entry<sup>16</sup>; allow users to store the same or similar information in multiple places; and validate data inconsistently. Last, EHR data exhibit variable levels of accuracy<sup>17,18</sup> and typically provide poor support for systematic data extraction.<sup>6</sup>

Despite these limitations, EHRs are increasingly seen as a potential source of data for research. This is evidenced in three large-scale initiatives in medicine using electronic medical records (EMR): the Distributed Ambulatory Research in Therapeutics Network (DARTNet) Institute,<sup>19</sup> the electronic Primary Care Research Network (ePCRN) Consortium,<sup>20</sup> and the Deliver Primary Health Care Information (DELPHI) project in Canada.<sup>14</sup> In dentistry, the Consortium for Oral Health Research and Informatics (COHRI)<sup>21</sup> has created a data warehouse for research from patient records at several dental schools (see Appendix A).

As this review shows, there are three compelling reasons to develop our capabilities for reuse of EDR data collected during patient care. First, reuse of EHR data for research has added significantly to our capacity to generate knowledge from routine clinical care. Second, EDR data are a potentially valuable data source for clinical, comparative effectiveness, epidemiology and other research, especially given NIDCR's recent emphasis on practice-based research. Last, electronic data are increasingly available from private practices due to the rapid adoption of computers. We therefore performed a review of the current status of reuse of electronic patient data for dental research, guided by the following questions: what types of research projects have used EDR/EMR data and what were the characteristics of these studies? What research questions did they examine? How did study characteristics relate to data sources, either EMR, EDR or both? What study variables were extracted from EDR and EMR systems? What advantages did reusing EDR/EMR data convey to these studies? What barriers/limitations were reported?

## 2. Materials and methods

### 2.1. Data sources and search strategy

A list of MeSH terms, Emtree (Embase) thesaurus terms and general keywords was developed to search the MEDLINE and Embase databases. A biomedical librarian (RA) tested multiple combinations of terms to optimize the search (see Appendix B). Searches were limited to English, French, German, Finnish, Norwegian and Swedish language articles between January 1992 and January 2013. The database search

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