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## Big Data in Health Care: An Urgent Mandate to CHANGE Nursing EHRs!

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### Introduction

The United States spends more per person on health care than any other nation in the world—without obvious evidence of better outcomes. Thus it is no surprise that many are determined to reduce the cost of care and demonstrate its effectiveness. The McKinsey Global Institute (2011) estimates that over the next 10 years, there is an opportunity to capture more than \$300 billion annually in new value to health care through “Big Data” initiatives with the right infrastructure investments, analytical abilities, and economic incentives. “Big data” typically refers to a large complex data set that yields substantially more information when analyzed as a fully integrated data set as compared to the outputs achieved with smaller sets of the same data that are not integrated. The movement toward use of larger integrated datasets in health care follows other industries that have realized multiple cost savings and improvements in business processes, customer services, and forecasting. Specifically, health care stakeholders expect the availability of high quality “big data” gathered in Electronic Health Records (EHRs) to bring value through enabling (McKinsey Global Institute, 2011):

1. comparative effectiveness research that can reduce the over and under treatment of patients by the identification and dissemination of best practices
2. research and development efforts focused on predictive modeling and improvements in the efficiencies and analysis of clinical trial data
3. personalized medicine in which suggestions for life style practices and the prevention and early detection of diseases are generated from a person's health care history and genetic profile
4. new business models such as on-line platforms for like communities of patients, administrators, clinicians that can be gleaned from the aggregation and synthesis of clinical and claims data
5. rational payment pricing strategies that are based on fraud detection, application of health economics principles, and outcome research.

What may shock most of our readers, is the fact that little to none of the data nurses currently enter into EHRs can be used in the “big data” analysis. Unfortunately, all of that time spent checking pick-lists and entering narrative descriptions of one's nursing care has essentially yielded nursing data that is NOT analyzable. As Stagers (2013) pointed out in her recent testimony to the Office of the National Coordinator, this is due to the fact that nursing and other clinical the data are not standardized and thus NOT interoperable.

Interoperable data contains data elements that are defined, measured, and retrievable in the exact same format. Instead, EHRs across organizations have been assembled and tailored to meet the unique needs of each organization. This tailoring, even within organizations that use the same basic EHRs, severely compromises the ability to compare data collected within one organization to data collected across organizations a necessity for creating “big data” conducive to research. This is particularly problematic for nursing departments in health care organizations which have over and over built out EHR starter modules, such as care planning, only to learn; 1) that the data generated have limited use due to poor interoperability, and 2) that the modules built to address their unique needs are also not financially sustainable. As such, without substantial change, nursing will remain absent from the revolutionary and very important “big data” initiatives in health care.

### Levers needed to generate “Big Nursing Data”

As is noted in the McKinsey (2011) report the most basic first step necessary to create analyzable “big data” systems is to digitize and structure the data so that it is interoperable (e.g., collected, represented, measured, and stored in the same way across EHRs and organizations). For nursing this means, that use of tailored approaches to developing key nursing data is no longer defensible and must be IMMEDIATELY STOPPPED!! Instead nursing leaders at all levels in our professional associations and health care organizations must demand and participate in promoting the use of EHR systems that “genuinely” produce interoperable nursing data. In line with this, nursing leaders MUST also demand that vendors clearly demonstrate that interoperable nursing data is generated and can be merged and analyzed with the same interoperable nursing data from other organizations and EHRs. In my experience over the years in the field of nursing EHR research, vendors tell customers that they can build systems together with their customers that will create interoperable nursing data but repeatedly fail to do so. It is impossible to produce interoperable data across organizations by setting EHR data goals customer by customer.

Further, if nurses are to practice to the full extent of their training, a recommendation of the IOM's Future of Nursing Report (2010), it is essential to have the means to demonstrate the impact of nursing care on patient outcomes linked to the nurse provider type. Generating high quality interoperable big nursing data is not only the first step to participating in big health care data analysis but also MUST be fully controlled by nursing. Nursing is the DOMAIN of the nursing profession and thus abdicating responsibility for building appropriate information technology (IT) systems, as has been a common practice to date, will continue to fuel the creation of data that are not useful and EHRs that are not optimal for nurses.

At a recent conference of multiple nursing stakeholders at the University of Minnesota a broad action plan was developed to support nursing's ability to take the 1<sup>st</sup> step in building interoperable nursing data for big data health care research (Shlaefer, 2013). The most important recommendations of the action plan are to:

1. urgently adopt standardized nursing terminologies (SNTs) at the point of care (ANA recognized) and NIDSEC database standards

2. promote institutional and public policies that supports the use, refinement, and expansion of IT standards that enable the documentation and exchange of key nursing data across systems including empowering nurse informaticians to advocate for the integration of SNTs into EHRs.
3. create and implement a campaign for rapidly educating nursing students, nurses, faculty, nurse executives, nursing informaticians, and the inter-professional care disciplines on key aspects of nursing informatics;

While I agree with the Minnesota recommendations, the work ahead need not be as onerous as it may appear. As a researcher who has led multiple teams whose primary focus has been the development of interoperable nursing data systems for nearly 2 decades, I am pleased to report that nursing has done its homework and is fully prepared to quickly meet the big data challenge. Although the various nursing data systems in EHRs today still do not produce interoperable data, research efforts, in our public research institutions over the years have created the knowledge needed to implement valid data systems that produce key interoperable nursing data. Scientists, an example being my multi-disciplinary team of colleagues at the University of Illinois Chicago, College of Nursing, have conducted extensive research that has resulted in the creation a fully tested standards based electronic method for collecting interoperable nursing data under real time conditions. As a result, the knowledge needed to produce interoperable nursing data (in contrast with the other health professions) already exists due to the collective vision, determination, and actions of dedicated scientific teams. Such knowledge is ready for prime time use in the rapid deployment interoperable nursing data systems that comply with the fully tested standards. So too other teams have targeted the development, testing, and refinement of educational materials on the implementation and use of nursing terminologies and EHRs.

In conclusion, the secret to our success in rapidly deploying interoperable nursing data systems is directly tied to our willingness as a profession to build on versus recreate from scratch knowledge already generated through substantive research. How might you disseminate this message to your fellow colleagues? Stay tuned and be prepared to advocate further for the “big nursing data” initiatives in the weeks and months ahead.

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