Nurses and the outcomes of nursing care are underrepresented in large clinical trials and national clinical research networks in the United States. Researchers struggle to share and compare data within and across clinical sites. Despite widespread use of electronic health records (EHRs), we are plagued by a lack of standardized data, interoperability, and willingness or ability to share data for research. Today, there are large research networks maintained by the National Institutes of Health, Agency for Healthcare Research and Quality, Veterans Health Administration, Food and Drug Administration (FDA), and, increasingly, by health systems. These emerging repositories show promise in identifying system-level performance that could lead to better overall clinical and operational outcomes in the future.

Some national networks use a distributed data model, as opposed to one centralized data warehouse. A distributed data network is a set of data warehouses with no central repository. The data can be shared and compared for research, by use of common data definitions and structures. Each organization maintains its own data security, privacy, and proprietary information. The National Patient-Centered Clinical Research Network (2019) has developed a system of distributed data networks (PCORnet®) to harness the power of data from EHRs while taking advantage of partnerships between patients, clinicians, and health systems (Kim, Mahajan, Miller, & Selby, 2017). The Observational Medical Outcomes Partnership (OMOP) is another data-sharing model developed by the FDA in a public-private partnership to bring out the value of health data through large-scale analytics (Observational Health Data Sciences and Informatics, 2019).

Within these data networks, providers of care are linked to the patient through provider billing data. Determining the nursing unit where care was provided, or which nurse provided the care, can be difficult as there is no consistent structure or definition for the location or non-billing provider. A group of nurses and data scientists at the Universities of Kansas and Colorado are working on a structure for the PCORnet and other distributed data networks to make the location of care and nurse characteristics visible to researchers.

How Can We Measure the Value of Nursing?

With an emphasis on the Quadruple Aim and value-based health care, there is a growing if not urgent need to better understand and measure how nurses add value to patient care. Welton and Harper (2016) proposed the Nursing Value Data Model (NVDM) framework to use big data (clinical, administrative, and operational data sets) to model and explore innovative methodologies that improve ways of leveraging data and conduct clinical research. Like medication, the patient’s need for care can be precisely measured to ensure the “right dose” of nursing for optimal outcomes. Traditional outcome metrics have been measured at the unit level in terms of length of

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**National Clinical Research Networks: Where Is the Nurse?**

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stay, adverse events, mortality and satisfaction (American Nurses Association, 2015). Secondary use of data in the electronic systems used in health care provides new options for understanding the patient need for care (Harper, 2012). Today, the volume of nurse-generated data not only allows the examination of short-term changes in individual patient outcomes, but also that which is attributable to nursing care (Garcia, 2017). Alignment of nursing data with a nursing taxonomy facilitates precise measurement of outcomes and acuity representing the holistic care needs of the individual patient (Garcia & Lovett, 2018). These automated measures provide decision support for level of care, staffing, and nurse-patient assignment (Welton, 2017). This has great potential to improve the patient’s experience by identifying the interventions most likely to improve patient outcomes, specifically around pain reduction and alleviation.

While nurse value modeling efforts have undergone some advancement, it has occurred in isolation, and is not aligned with the nationally deployed infrastructure. Thus, it remains unlikely to be supportable at scale across institutions. Currently, data infrastructure and modelling efforts allowing detailed examination of care delivery and care team environments are bifurcated. Widely adopted data models and deployed infrastructure such as PCORnet and OMOP have minimal consideration for clinical data sensitive to nursing practice.

Proposing a New Data Structure in PCORnet

The NVDM (Welton & Harper, 2016) includes a structure for information about the location of care and the nurse or other team members providing care. A review of the literature and consideration of use cases led to a list of data that would support research on the value of nurses and nursing. Table 1 includes a list of data elements from the model.

The NVDM uses definitions from existing, commonly used data standards. Much of the NVDM data regarding the nurse can be found in Human Resource Information Systems and payroll systems, but may also be found in a Learning Management System or collected by individual nursing directors.

We propose that PCORnet and other distributed data networks be augmented with additional data structures and definitions to support research on the impact of nurses, nursing, and the location of care on patient outcomes.

An Example

Understanding data about location of care can be problematic. Naming conventions vary widely; nursing units may be named for the type of population (pediatrics), the location (5 East), or a donor (Gordon wing). Lacking standardization, there is no way to share or compare data for multi-site research. Such data are absent in PCORnet and OMOP. The best solution would be to adopt widely accepted definitions of nursing units, such as the National Database of Nursing Quality Indicators (NDNQI).
The NDNQI developed a set of codes to precisely describe the many different populations cared for in nursing units. For example, the code 02.04.01.01 indicates an Adult Burn Critical Care Unit, while code 02.04.01.03 indicates an Adult Coronary Critical Care Unit (University of Minnesota Center for Nursing Informatics, 2015).

The NDNQI codes have been adopted into the Nursing Management Minimum Data Set and coded into the Logical Observation Identifiers Names and Codes or LOINC (Pruinelli, Delaney, Garcia, Caspers & Westra, 2016). Integration of the NDNQI coding into the PCORnet would enable nurses across the country to compare data from like units.

Summary

The ability to link each nurse to each patient provides a new capability to investigate not only nursing care in general, but the contribution of each nurse providing care to each patient. Linking nurses to patients using identifying keys could open new lines of research. For example, the individual nursing costs for each patient could be calculated based on individual wage and hours of care provided. Other researchable questions of interest to nursing leaders include:

- What are the costs and outcomes of nursing care with varied skills and skill levels?
- How are nursing assignments allocated based on nursing experience?
- Do delays in administering critical medications such as anticoagulants or antibiotics lead to poor clinical outcomes?

Creating an ability to identify nurses as well as other healthcare providers in existing data repositories such as PCORnet add an additional dimension of care focused on multiple providers that can inform both clinical care as well as policymaking and reimbursement for health care. These are crucial additions that need further development and consensus to build capacity for future shared data warehouse strategies. $