Appendix: Content Summaries of Best Papers for the Health Information Management Section of the 2021 IMIA Yearbook

Powell KR, Deroche CB, Alexander GL Health data sharing in US nursing homes: a mixed methods study

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Efforts to achieve nationwide interoperability in the US have been ongoing for several years in part due to federal legislation and regulation. Some providers, such as long term and post-acute care providers did not receive incentive payments for implementing electronic health records. The authors studied nursing homes' capability for data sharing and nursing home leaders' perceptions of data sharing with other health care facilities and with residents and family members. The authors explore longstanding challenges to improve data access by patients and their caregivers as well as provider-to-provider data sharing and exchange across sites of care. This was an exploratory mixed methods study. The authors performed a secondary analysis of data from a national survey of 815 nursing home administrators in the United States and used a survey developed to measure nursing home information technology (IT) adoption. The authors used descriptive statistics and logistic regression models to examine the relationship between health data sharing capabilities and nursing home characteristics such as location, bed size, and type of ownership. Additionally, between November 2018 and December 2019, researchers conducted qualitative interviews with nursing home administrators. Interviews included questions about processes for sharing data with residents and family members and perceptions of data sharing with other clinical partners (e.g., hospitals and other entities). Perceived barriers to data sharing included privacy and security concerns, transparency and control, fear of lawsuits, and organizational factors which slowed the uptake of technology.

These organizational factors included an overregulated and punitive environment, perceptions about lack of interest among residents and providers, available and accessible resources, and other constraints (including financial, workflow, and technical issues), such as lack of patient portal availability through the health IT vendor. Perceived benefits of data sharing included improved communication and care planning and being able to anticipate future demand. The authors found that nursing homes varied greatly in their technological capabilities and perceptions about what and with whom they could share information. The COVID-19 pandemic highlighted the need for data collection and reporting about quality-of-care in nursing homes, testing and immunization of patients and staff. The pandemic also demonstrated the need for health information technology and electronic health records to help address infection prevention, and mitigation. Powell and colleagues include recommendations for additional research and public policies to address health IT gaps and challenges. Addressing these gaps and shortcomings will improve the secure exchange of information during public health emergencies, as well as on a more routine basis.

Cappetta K, Lago L, Potter J, Phillipson L

Under-coding of dementia and other conditions indicates scope for improved patient management: A longitudinal retrospective study of dementia patients in Australia

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The importance of the quality, accuracy, and consistency of clinical coding of medical information in hospitals is important for various use cases including payment, resource allocation, surveillance, epidemiological research, prevention, treatment, and to inform policy. This paper by Cappetta and colleagues was a longitudinal study of coding quality of dementia after the initial diagnosis to examine the implications for patient management and quality of care when dementia was not coded ("under coding") given a prior confirmed diagnosis of dementia. The researchers sought to inform future intervention studies to improve

identification and management of dementia in hospitals. The population-based retrospective cohort study was conducted in a regional local health district of New South Wales, Australia with five hospitals. This study described rates of dementia coding over the 5 years (the study period was from 1 July 2006 to 30 June 2015 with a 5-year lookback period from 1 July 2001) after an initially coded admission for dementia. The study also identified unintended consequences related to lack of clinical coding (such as the potential under-management of dementia) and identified patient subgroups at risk of having inaccurate or incompletely coded diagnoses. The diagnoses were recorded using the International Classification of Diseases. Australian modification (ICD-10-AM Ninth Edition). The researchers found that dementia was coded in 63.9% of admissions in the 12 months following the index admission for dementia and that the coding of dementia decreased to 53.7% after 5 years. They also reported that patients were 20% more likely to have dementia actively managed when it co-occurred with delirium. The paper highlights the relationship of data accuracy and clinical documentation completeness. Coding accuracy relies on robust clinical documentation and the absence of documentation (and related coding) raises questions about gaps in care delivery, patient management, quality of care and patient safety. The authors offer recommendations to address under-coding of chronic conditions and improve identification and management of dementia through dementia-specific care, enhanced clinical protocols, and other interventions.

Sheriffdeen A, Millar JL, Martin C, Evans M, Tikellis G, Evans SM

(Dis)concordance of comorbidity data and cancer status across administrative datasets, medical charts, and self-reports

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As Sherffdeen and colleagues note, risk-adjustment for co-morbidities often requires data from sources that were originally designed for other purposes; therefore it is important to understand the underlying foundational principles and definitions of the datasets and the reliability of different data sources. In Australia, prostate cancer represents the second leading cause of cancer-related mortality in males. The Prostate Cancer Outcome Registry-Victoria (PCOR-Vic) was developed in 2009 as a clinical quality registry, to measure and report on quality of care, using benchmarking of performance at a clinician and hospital level. The researchers used a retrospective cohort study design to study the completeness and accuracy of co-morbidity documentation as reflected in different data sources. The authors studied the level of concordance for same-patient comorbidity data extracted from administrative data sets (coded from ICD-10 AM), from the medical record, and data self-reported by men with prostate cancer who had undergone a radical prostatectomy between January 2017 and April 2018 at one of six convenient hospitals. The authors analyzed diseases based on the conditions included within the Charlson Comorbidity Index and compared comorbidities across the three data sources. Concordance was

calculated using percentage agreement and the kappa statistic. The paper reports on the level of statistical concordance between the medical chart and administrative datasets; the medical chart and patient self-report data; and administrative data and patient self-report data. The researchers also included a summary of the concordance of comorbidity data across the three data sources. The study notes that agreement between comorbidity data collected by the Victorian Admitted Episodic Dataset, medical charts, and self-reports by men who have undergone a radical prostatectomy varied across the analyzed comorbidities. The authors identified discrepancies between (coded) administrative data sets and the medical charts and noted the need to further explore the impacts of coding guidelines and practices. They also found discrepancies between patient self-reported data and the other datasets which might highlight a need for better patient education or improved communication between patients and providers. Comorbidity data are important for accurate monitoring of

risks and understanding the accuracy of data sources is critical to data use. The findings about the data quality of various sources are highly relevant to the HIM domain and functions. HIM is concerned with the reliability of coded data and the completeness and accuracy of the documentation to support coding. There are unintended consequences of incomplete and inaccurate data sources including documentation and coding. Recognizing that data completeness, accuracy, definitions, and formats may vary by sources is also relevant to the COVID-19 pandemic since multiple data sources (such as medical records, laboratory test results, case reports, immunization registries, patients, and caregivers) across sites of care are critical for public health surveillance, care delivery, disease management and analytics. Recognizing and reconciling discrepancies in data reporting, data and interoperability standards, and definitions is also essential to information sharing and exchange between health care and public health use cases.