Integrated Knowledge Management (IKM) Volume 11

Version 1 - Last Updated 3/12/2024

Table of Contents

I. Healthcare Data Management 1
1. Healthcare Data Management 3
1.1. Introduction to Healthcare Data Management 3
1.2. Mental Health Data Management 3
1.3. Population Health Management (PHM) 4
1.4. Pediatric Data Management 4
1.5. Infectious Disease Research and Management 5
1.6. Rare Disease Research and Management 6
1.7. Cross-Disciplinary Data Integration and Management 7
1.8. Future Direction for Healthcare Data Management and IKM 7
1.9. References 8

Part I. Healthcare Data Management

Table of Contents

1. Healthcare Data Management 3
    1.1. Introduction to Healthcare Data Management 3
    1.2. Mental Health Data Management 3
    1.3. Population Health Management (PHM) 4
    1.4. Pediatric Data Management 4
    1.5. Infectious Disease Research and Management 5
    1.6. Rare Disease Research and Management 6
    1.7. Cross-Disciplinary Data Integration and Management 7
    1.8. Future Direction for Healthcare Data Management and IKM 7
    1.9. References 8

1. Healthcare Data Management

1.1. Introduction to Healthcare Data Management

The healthcare data management landscape is rapidly evolving, driven by advances in technology and the increasing demand for comprehensive, interoperable healthcare systems. Data management in healthcare encompasses the practices, processes, and technologies used to collect, store, manage, and analyze health-related information. With the ultimate goal of improving patient care, healthcare data management supports clinical decision-making, research, and policy development. The integration of data from diverse sources, including electronic health records (EHRs), medical imaging, genomic data, and wearable technology, presents both opportunities and challenges to improve data quality, privacy, and security. [1]

The importance of data in clinical and research settings cannot be overstated. High-quality, accessible, and secure data is foundational to evidence-based medicine and enables healthcare providers to make informed decisions, improves patient outcomes, and enhances the efficiency of healthcare services. Moreover, in research settings, data management plays a crucial role in the discovery of new treatments and understanding health trends and disease patterns. [2]

Integrated Knowledge Management (IKM) emerges as a pivotal concept to address the complexities of healthcare data management. IKM refers to the systematic management of knowledge and information across different sources and formats to facilitate the creation, sharing, and application of knowledge within the healthcare sector. The implementation of IKM strategies can significantly enhance the interoperability of healthcare systems, ensuring that data is not only accessible and usable across different platforms and institutions but also consistent and reliable. [3]

1.2. Mental Health Data Management

Mental health data management is a critical aspect of healthcare that involves the collection, storage, analysis, and sharing of information related to mental health services and outcomes. Given the sensitive nature of mental health data, its management poses unique challenges in terms of privacy, security, and ethical considerations. Employing IKM principles can significantly enhance the effectiveness and efficiency of mental health data management, ensuring that patient information is handled with the utmost care and respect. [4]

The collection of mental health data provokes inevitable challenges, primarily due to the stigma associated with mental illness and the resultant reluctance of individuals to share personal information. Privacy concerns are paramount, as the disclosure of mental health information can have significant social and personal consequences for individuals. [5] Ensuring the confidentiality and security of mental health data is, therefore, a critical concern that requires robust data management practices. To address these challenges, healthcare organizations must implement comprehensive data management strategies that prioritize patient privacy and data security. This includes the adoption of advanced encryption methods for data transmission, secure data storage solutions, and strict access controls. Additionally, fostering a culture of trust and transparency with patients can encourage the sharing of vital health information, thereby improving the quality of mental health services. [6]

Integrating EHRs with mental-health specific modules is an example of the successful application of IKM principles in mental health data management. This application has enabled healthcare providers to access comprehensive patient profiles, facilitating personalized treatment plans and improving patient outcomes. Moreover, the use of standardized data formats and terminologies, as advocated by IKM, has improved the

interoperability of mental health data across different healthcare systems, enhancing collaborative care and research efforts. [7] With mental health data in particular, healthcare systems must carefully monitor data access and usage to navigate potential patient rights, privacy, and data access issues, including involuntary admissions, restraint and seclusion records. [8] Improvements to mental health data management and the quality of mental health data can have impacts on real world data that would then support policy makers and make more informed decisions that can be tailored to mental health data and data management approaches per type of mental health treatment settings – hospital inpatient, residential and outpatient – and levels of care. [9]

Another major challenge for mental health data management and IKM is keeping up with and integrating emerging technology. Today, more than 10,000 mental or behavioral health apps are publicly available on the iOS App Store with roughly 69% of them focusing on providing therapy, collecting self-assessment information, and monitoring symptoms. [10] The recently updated guidance on cellphones, health information, and the Health Insurance Portability and Accountability Act (HIPAA) by the U.S. Department of Health and Human Services (HHS) dictates that HIPAA Privacy Act does not apply to most health apps as these apps are not “covered entities” under the law. Currently, only official healthcare system patient portals that exchange messages with providers and store test results are protected by HIPAA. [11] As technology continues to improve and be implemented across the healthcare ecosystem, it is critical that data management efforts work to ensure that self-reported, at home, and other non-traditional methods of data collection meet required privacy, storage, and transmission standards.

1.3. Population Health Management (PHM)

Population health management (PHM) is an approach aimed at improving the health outcomes of a specifically defined group. PHM relies heavily on the aggregation, analysis, and application of health data to drive decision-making and resource allocation. The integration of IKM principles into PHM can significantly enhance the ability to analyze complex datasets, identify health trends, and implement effective interventions. [12]

Population health data encompasses a wide range of information, including healthcare utilization, outcomes, and social determinants of health. This data is crucial for identifying health disparities, managing chronic diseases, and improving community health. Effective PHM requires a robust data management system that can handle the volume and variety of data continually generated by healthcare systems and patient interactions. [13]

Advanced analytics, including predictive modeling and machine learning, are key to extracting actionable insights from population health data. These techniques allow healthcare providers and policymakers to predict health outcomes, optimize resource allocation, and tailor interventions to specific populations. Implementing IKM principles ensures that real-world data from disparate sources is standardized and interoperable, facilitating comprehensive analyses and informed decision-making. [14]

The application of IKM in PHM has the potential to transform healthcare delivery. Healthcare organizations can improve the accuracy of health assessments, enhance the effectiveness of interventions, and ultimately, achieve better health outcomes at lower costs by employing IKM to ensure data interoperability and leverage advanced analytics. Moreover, IKM supports continuous improvements to data quality and the adoption of PHM best practices. [15]

1.4. Pediatric Data Management

Pediatric data management focuses on the unique healthcare needs and challenges associated with collecting, storing, and utilizing health information for children. This area requires special attention due to the distinct physiological, developmental, and psychological characteristics of pediatric populations. The application of IKM principles can significantly improve the management and use of pediatric health data,

ensuring that healthcare providers can deliver age-appropriate care that supports the healthy development of children. [16]

Pediatric health data encompasses a broad spectrum of information, from birth records and immunizations to growth charts and developmental milestones. Managing this data effectively requires systems that can adapt to the rapid changes in health status and needs that characterize childhood and adolescence. Additionally, pediatric data management must address consent and privacy issues, particularly as they relate to the rights of minors and the involvement of parents or guardians. [17]

Consent and ethical considerations are paramount in pediatric data management. Healthcare providers must navigate the complex legal and ethical landscape surrounding the collection and use of health data from minors, ensuring compliance with regulations that protect children's privacy while simultaneously facilitating necessary medical care. IKM can support this process by providing frameworks for managing consent documentation and ensuring that data use policies are clearly communicated and followed. [18]

An area of particular interest for pediatric data management is school, a core site of care for children aged five through 17 years old. Less than half of the US children have an assigned healthcare provider, but over 95% of children aged five through 17 years old go to school. [19] Evidence-based research suggests that healthy students earn better grades and have better attendance, stressing the opportunity for healthcare organizations, health partners, or schools themselves to use school as an opportunity to provide health screenings or address gaps in students' care. Approximately 17% of public schools in the US offered telehealth services to students in the 2021-2022 school year, and this trend is projected to go up. IKM can support advancements in pediatric data management by coordinating care between clinics, schools, and other health systems involved in the delivery of care. [19]

1.5. Infectious Disease Research and Management

Infectious disease management and research are pivotal in the global healthcare landscape, especially in the wake of recent pandemics. Effective management requires the collection, analysis, and transfer of vast amounts of data to track disease spread, identify outbreaks, and inform public health responses in real time. IKM principles can enhance infectious disease management by ensuring high-quality, standardized, and interoperable real-world data that can be used by organizations to outline actionable management plans. [20]

Infectious disease data management and research track the spread of infectious diseases, enabling health authorities to identify outbreaks quickly and implement containment measures. Real-time data collection and analysis are essential for monitoring disease patterns, responding to outbreaks, and predicting future health patterns. IKM facilitates the integration of data from multiple sources, including healthcare facilities, laboratories, public health departments, and non-traditional data collection methods like at home testing, to ensure a comprehensive view of the disease landscape across the US and around the world. [21]

The integration of research and clinical data is vital for developing effective treatments and vaccines for infectious diseases. IKM principles support the standardization of data formats and terminologies, making it easier for researchers to aggregate and analyze data from diverse studies. IKM accelerates the translation of research findings into clinical practice, improving patient outcomes and public health responses around the world. [22]

One notable example of a data-driven approach to infectious disease management is the global response to the COVID-19 pandemic. Health organizations worldwide utilized IKM principles to standardize data reporting, enabling the effective tracking of cases, vaccination rates, and emerging variants. This coordinated effort facilitated rapid research, informed public health policies, and guided the allocation of resources to areas most in need. [23] Another example of how IKM principles can support improved infectious disease

management is the work by the Infectious Diseases Data Observatory (IDDO). IDDO is a scientifically independent, multi-disciplinary coalition that has been trying to identify and collate de-identified individual patient data (IPD) in a format-agnostic way. IKM could facilitate and support their efforts to track surveillance data in an established system for a wide range of infectious diseases, such as: [24]

- COVID-19
- Malaria
- Visceral leishmaniasis
- Medicine quality
- Antimicrobial resistance
- Chagas disease
- Ebola
- Schistosomiasis
- Soil-transmitted helminthiasis
- Lymphatic filariasis
- HIV
- Trachoma
- Mycetoma
- NOMA
- Melioidosis
- Scrub typhus

1.6. Rare Disease Research and Management

Rare disease research and management present unique challenges due to the low prevalence of each condition, making data collection and analysis particularly difficult. The scarcity of data, combined with its often fragmented nature, hinders the development of effective treatments and care strategies. The application of IKM principles facilitates the aggregation, standardization, and sharing of rare disease data across health systems that may not normally have access. [25]

Data plays a crucial role in the identification and research of rare diseases. Comprehensive data collection and analysis are essential for understanding the genetic and environmental factors associated with rare diseases, developing diagnostic tools, and identifying potential treatments. IKM can enhance the quality and accessibility of rare disease data, enabling researchers and clinicians to uncover patterns and connections that would otherwise remain obscured. [26] IKM principles advocate for the use of standardized data formats and terminologies to facilitate data sharing and collaboration among researchers worldwide. This approach not only improves the efficiency of data collection but also increases the chances of breakthroughs in understanding and treating rare diseases. [27]

IKM plays a pivotal role in advancing rare disease research and improving patient care. IKM enables the integration of research findings into clinical practice more rapidly by supporting interoperable and easily

accessible data from various sources. This integration is vital for developing effective treatment protocols and care strategies for rare diseases, ultimately improving patient outcomes and quality of life. [28] In addition, IKM can support efforts to improve rare disease management and research with the goal of obtaining more complete datasets, as shown in the work of the *Task Force on Clinical Research Networks for Rare Diseases* by the International Rare Diseases Research Consortium (IRDRC). The IRDRC designed the task force with the objective of analyzing the quality of data to be obtained via the growing global network, removing communication and technical barriers in managing and sharing rare disease data globally. [29] The National Institutes of Health (NIH) reports more than 7,000 rare diseases. Lurie Children's Hospital of Chicago states that one in 10 Americans has a rare disease. About half of these Americans are children. [30]

1.7. Cross-Disciplinary Data Integration and Management

Cross-disciplinary data integration and management are essential for addressing complex health issues that span multiple areas of expertise. Integrating data from various disciplines, such as genomics, epidemiology, and social sciences can lead to a more comprehensive understanding of health and disease. The IKM principals can facilitate this integration, ensuring that data is not only interoperable but also meaningful across different research and clinical contexts. [31]

The integration of data across disciplines is crucial for developing a holistic approach to patient care and public health. It allows for the consideration of a wide range of factors affecting health, from genetic predispositions to environmental and social determinants. IKM supports this integration by standardizing data formats and terminologies, enabling seamless data exchange and analysis across diverse fields. [32] Implementing IKM to support cross-disciplinary efforts will involve adopting common data standards, utilizing interoperable platforms, and fostering collaboration among stakeholders from different disciplines. These strategies ensure that data is not only accessible but also usable for all parties involved, facilitating multidisciplinary research and care initiatives. [33]

Numerous examples of integrated data management have led to improved patient outcomes. For instance, combining clinical data with social and environmental information has enabled healthcare providers to offer more personalized care plans that address the broader context of patients' lives. Similarly, integrating epidemiological data with genomic research has accelerated the identification of disease markers and the development of targeted therapies. These successes underscore the value of IKM in enhancing the effectiveness of health interventions across disciplines. [34]

1.8. Future Direction for Healthcare Data Management and IKM

As healthcare continues to evolve, the future of data management and IKM looks toward leveraging emerging technologies and methodologies to further enhance the quality, accessibility, and interoperability of health data. These advancements promise to transform healthcare delivery, research, and policy-making, driving improvements in patient outcomes and healthcare efficiency. [35]

As the healthcare sector prepares for these advancements, it faces challenges such as ensuring data privacy and security, managing the ethical implications of AI and big data, and addressing disparities in access to technology. However, these challenges also present opportunities to redefine healthcare practices, improve patient engagement, and foster a more data-driven and patient-centric healthcare ecosystem. Embracing IKM principles will be crucial in navigating these changes, ensuring that data management practices continue to evolve in alignment with technological advancements and healthcare needs. [36]

1.9. References

1. Office of the National Coordinator for Health Information Technology. Health IT Playbook [Internet]. USA; 2023 [cited 2023 Feb 20] Available from: https://www.healthit.gov/playbook/

2. Kwok CS, Muntean EA, Mallen CD, Borovac JA. Data Collection Theory in Healthcare Research: The Minimum Dataset in Quantitative Studies. [Internet] Clinical Practice; 2022 [cited 2023 Feb 20] Available from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9680355/

3. Somasundaram P. How is knowledge management used in healthcare? [Internet] Document360; 2022 [cited 2023 Feb 19]. Available from https://document360.com/blog/knowledge-management-in-healthcare/

4. World Health Organization. Mental Health: Strengthening Our Response. [Internet] WHO; 2023 [cited 2024 Feb 23] Available from: https://www.who.int/news-room/fact-sheets/detail/mental-health-strengthening-our-response

5. Stronge I. The complex challenges in sharing mental health data. [Internet] National Elf Service. 2022. [cited 2024 Feb 23] Available from: https://www.nationalelfservice.net/commissioning/technology/sharing-mental-health-data/

6. Lustgarten SD, Garrison YL, Sinnard MT, Flynn AW. Digital privacy in mental healthcare: current issues and recommendations for technology use. [Internet]. Current Opinion in Psychology; 2020 [cited 2024 Feb 27]. Available from https://pubmed.ncbi.nlm.nih.gov/32361651/

7. Golay P, Bonsack C, Silva B, Pauli G, de Boer E, Morandi S. Patterns of Service Use in Intensive Case Management: A Six Year Longitudinal Study. [Internet] Administration and Policy in Mental Health and Mental Health Services Research. 2022 May; [cited 2024 Feb 28] Available from: https://link.springer.com/article/10.1007/s10488-022-01198-y

8. Tracy N. Types of Mental Health Facilities. [Internet] HealthyPlace; October 2019 [cited 2024 Feb 28]. Available from: https://www.healthyplace.com/other-info/mental-illness-overview/types-of-mental-health-facilities

9. Insel T. Digital mental health care: five lessons from Act 1 and a preview of Acts 2-5. [Internet] Nature; January 2023 [cited 2024 Mar 5]. Available from: https://www.nature.com/articles/s41746-023-00760-8

10. Iqbal M. App Download Data. [Internet] Business of Apps; January 2024 [cited 2024 Mar 7]. Available from: https://www.businessofapps.com/data/app-statistics/#:~:text=Today%2C%20there%20are%20over%20four,of%20sub%2Dgenres%20and%20niches

11. American Psychiatric Association. Thousands of Mental Health Apps Available: Supporting Evidence Not So Plentiful. [Internet] Patients and Families; July 2019 [cited 2024 Mar 8]. Available from: https://www.psychiatry.org/news-room/apa-blogs/mental-health-apps-evidence-not-so-plentiful#:~:text=There%20are%20more%20than%2010%2C000,%E2%80%9D%20(1)%20Several%20recent%20studies

12. Tewari S. How to Navigate Mental Health Apps That May Share Your Data. [Internet]. American Civil Liberties Union (ACLU); Sept 2022 [cited 2024 Mar 7]. Available from: https://www.aclu.org/news/privacy-technology/how-to-navigate-mental-health-apps-that-may-share-your-data

13. Hujala T. Laihonen H. Knowledge management in a regional integrated health and social care system. [Internet] Journal of Integrated Care; December 2023 [cited 2024 Feb 27]. Available from: https://www.emerald.com/insight/content/doi/10.1108/JICA-06-2022-0032/full/html

14. Agency for Healthcare Research and Quality. Data Management in Health Care. [Internet] Data Analytics; 2023 [cited 2024 Feb 26] Available from: https://www.ahrq.gov/data/resources/index.html

15. Lee K. What is population health management (PHM)? | Definition from TechTarget. [Internet] Health IT; June 2017 [cited 2024 Feb 24]. Available from: https://www.techtarget.com/searchhealthit/definition/Population-health-management-PHM

16. McIsaac JLD, Penney TL, Storey KE, et al. Integrated knowledge translation in population health intervention research: a case study of implementation and outcomes from a school-based project. [Internet] Health Research Policy and Systems; August 2018 [cited 2024 Feb 26]. Available from: https://health-policy-systems.biomedcentral.com/articles/10.1186/s12961-018-0351-8

17. Anziolotti A. What Is a Medical Record? [Internet] Nemours KidsHealth; January 2021 [cited 2024 Feb 25]. Available from: https://www.aap.org/en/patient-care/pediatric-health-records/

18. U.S. Department of Health & Human Services. Understanding HIPAA Privacy For Individuals. [Internet] Health Information Privacy; June 2017 [cited 2024 Feb 26]. Available from: https://www.hhs.gov/hipaa/for-individuals/index.html

19. Healthcare Information and Management Systems Society. Interoperability in Healthcare; 2023 [cited 2024 Feb 18]. Available from: https://www.himss.org/resources/interoperability-healthcare

20. Obregon R, Slighton E, Krasniansky A. Next gen innovation: Opportunities in pediatric digital health. [Internet] Rock Health; November 2023 [cited 2024 Mar 6] Available from: https://rockhealth.com/insights/next-gen-innovation-opportunities-in-pediatric-digital-health/

21. Centers for Disease Control and Prevention. Data and Statistics on Infectious Disease. [Internet] 2023 [cited 2024 Feb 24]. Available from: https://www.cdc.gov/datastatistics/index.html

22. World Health Organization. Global Health Observatory (GHO) Data. [Internet] WHO; 2023 [cited 2024 Feb 24]. Available from: https://www.who.int/data/gho

23. National Institutes of Health. NIH Data Sharing Repositories. [Internet] NIH; 2023 [cited 2024 Feb 22]. Available from: https://www.nlm.nih.gov/NIHbmic/nih_data_sharing_repositories.html

24. Johns Hopkins University & Medicine. Ongoing Johns Hopkins COVID-19 Resources [Internet] Coronavirus Resource Center; March 2023 [cited 2024 Feb 23]. Available from: https://coronavirus.jhu.edu/

25. Infectious Diseases Data Observatory. Research Themes [Internet] IDDO; 2024 [cited 2024 March 1] Available from: https://www.iddo.org/research-themes

26. Griggs RC, Batshaw M, Dunkle M, et al. Clinical research for rare disease: opportunities, challenges, and solutions. [Internet] Molecular Genetics and Metabolism; January2009 [cited 2024 Feb 27]; Available from: https://www.sciencedirect.com/science/article/abs/pii/S1096719208002539

27. Liu J, Barrett JS, Leonardi ET, et al. Natural History and Real#World Data in Rare Diseases: Applications, Limitations, and Future Perspectives. [Internet] Journal of Clinical Pharmacology; December 2022 [cited 2024 Mar 13]. Available from: https://pubmed.ncbi.nlm.nih.gov/36461748/

28. Orphanet. Knowledge of rare diseases and orphan drugs [Internet] Orphanet Access Our Services; February 2024 [cited 2024 Feb 22]. Available from: https://www.orpha.net/

29. Subbiah VThe next generation of evidence-based medicine [Internet] Nature Medicine; February 2024 [cited 2024 Mar 7]. Available from: https://www.nature.com/articles/s41591-022-02160-z

30. Nabbout R, Zanello G, Baker D, Balck L, Branbilla I, Buske O, Conklin L, Davies E. Julkowska D, Kim Y, Klopstock T, Nakamura H, Nielsen K, Pariser A, Pastor J, Scarpa M, Smith M, Taruscio D, Groft S. [Internet] Orphanet Journal of Rare Diseases; May 2023 [cited 2024 Feb 29]. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10169162/

31. Ann & Robert H. Lurie Children's Hospital of Chicago. Lurie Children's Hospital First in Illinois to Be Designated as a Rare Disease Center of Excellence by National Organization for Rare Disorders (NORD). [Internet] News Release; May 2023 [cited 2024 Feb 29]. Available from: https://www.luriechildrens.org/en/news-stories/lurie-childrens-hospital-first-in-illinois-to-be-designated-as-a-rare-disease-center-of-excellence-by-national-organization-for-rare-disorders-nord/

32. Interdisciplinary Standards for Systematic Data Integration. [Internet] Guidelines for Data Integration Across Disciplines; 2023 [cited 2024 Feb 23]. Available from: https://www.issdi.org/guidelines-for-data-integration

33. Green BN, Johnson CD. Interprofessional collaboration in research, education, and clinical practice: working together for a better future. [Internet] Journal of Chiropractic Education; March 2015 [cited 2024 Feb 23]. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4360764/

34. Zaugg I. Top 10 Strategies for Successful Data Science Teamwork. [Internet] The Data Science Institute at Columbia University; March 2021 [cited 2024 Feb 23]. Available from: https://datascience.columbia.edu/news/2021/top-ten-advice-for-successful-data-science-teamwork/

35. Caizon B. 24 Real Life Examples of Big Data In Healthcare Analytics. [Internet] Business Intelligence; June 2013 [cited 2024 Feb 23]. Available from: https://www.datapine.com/blog/big-data-examples-in-healthcare/

36. Ginburg PB, Loera-Brust A, Brandt C, Durak A. The opportunities and challenges of data analytics in health care. [Internet] Brookings; November 2018 [cited 2024 Feb 23]. Available from: https://www.brookings.edu/articles/the-opportunities-and-challenges-of-data-analytics-in-health-care/