



The Role of Data in Our Health Records

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LEARNING OBJECTIVES STATEMENT

After reading this paper, readers should be able to:

- Define data informatics
- Communicate the role data informatics plays within health records to patients

INTRODUCTION

When patients arrive at medical appointments and fill out the required medical history and current symptoms forms, they provide physicians with medical data. The information patients provide and release to this medical provider can then, in turn, be used in a myriad of various ways. This article will describe:

How patients' medical information is used in the healthcare system, and

What patients can do to be an integral part of how their medical information is used.

Medical Data of Patients

The information from patients is not just left on their records; it is now available for data analysis and potential informatics. Scholars define data informatics as "the interdisciplinary study of the design, development, adoption and application of IT-based innovations in healthcare services delivery, management and planning" (US National Library of Medicine). The American Medical Informatics Association defines data informatics as "using the data, information, and knowledge to both improve the delivery of healthcare services and improve patient outcomes." Data analytics and informatics serve different purposes in healthcare and patient engagement (Clack et al.21-22). Still, both are necessary for data communication and collection in health services (Clack et al.21-22).

Breast Cancer and Patient Data

Medical forms and the information contained within them can contribute to advancements in medical care. One example of this can be seen in action by examining breast cancer prevention and the role of data informatics in chemoprevention. In one study by Nichols et al., the research team decided to assess the application of integrated health care data to distinguish and describe breast cancer chemoprevention usage. This study used electronic medical records to review the medical indication, patient risk assessment and patient adherence to breast cancer chemoprevention. In addition, the scholars “sampled cancer-free women age 35 to 69 years who used tamoxifen, raloxifene, exemestane, anastrozole, or letrozole from 2005 to 2013” within in the Kaiser Permanente Northern California healthcare system (Nichols et al. 1).

It is vital to ensure the accuracy of the information within medical health records when the potential of utilizing medical records becomes this impactful. For example, in Nichols et al.’s study on chemoprevention, let’s, for a moment, think about the role data accuracy played in the clinical outcome. This study used data from patients’ medical records to review and determine the medical indication for chemoprevention utilizing key factors. If the information in the medical records were inaccurate, the ultimate analysis and decision on chemoprevention would have been decided upon under false pretenses. According to Prosperie et al.’s research, “Technological advancements permit the collection and merging of large heterogeneous datasets from different sources, from genome sequences to social media posts or from electronic health records to wearables. Additionally, complex algorithms supported by high-performance computing allow one to transform these large datasets into knowledge. However, despite such progress, many barriers still exist against achieving precision medicine and precision public health interventions for the benefit of the individual and the population.” (Prosperie et al. 1).

What does this mean regarding patient data? Health information from patients is significant and influential when used to tell a story or create an argument. When researchers are collecting data, they must use it correctly. Prosperie et al. (12) stated that there is a call for precision and holding researchers accountable for their actions, whether it is in a lab or automatically run software that computes results. More importantly, “Precision medicine demands interdisciplinary expertise that understands and bridges multiple disciplines and domains up to a point where the fulcrum of the research is located on the bridges themselves. This defines transdisciplinary, knowledge discovery going beyond disciplines, which demands new research and development paradigms,” which requires research to be done collaboratively (Prosperie et al. 12).

The Role of Patients in the Medical Community

How can patients leverage large amounts of data in the medical community? One method would be to utilize a patient-centered functionality like an interactive preventative health record (IPHR). According to Krist et al. (312), “An IPHR links patients to their clinician’s record, explains information in lay language, displays tailored recommendations and educational resources, and generates reminders.” The purpose of IPHR is crucial for building trust and ensuring transparency among patients and medical providers. The patient-centered component of an IPHR is designed to appoint patients in their own care. The IPHR takes the clinical data and utilizes it to remind patients of critical steps in their care (Krist et al. 313). Also, some IPHRs allow patients to customize questions for the clinical team before one’s next appointment, which can allow the patient and medical providers to prepare and be proactive.

Krist et al. (318) found, “Increasingly, patient-centered information systems are recommended as an essential tool to improve the delivery of care and health. The functionality of many systems is lacking, however, and there is insufficient evidence to show that they can support their intended use. This study shows that the IPHR and similar systems can improve important patient outcomes, such as the delivery of evidence-based preventive care. To have a broad impact on public health, attention is needed to ensure that future personal health records can deliver higher levels of functionality, similar to the IPHR, and that a greater proportion of patients and clinicians actively use the systems.” Utilizing an IPHR or another patient-centered method allows patients to actively participate in their care, document, and inform of data inaccuracies. If interested in doing this, patients should speak with their primary care physicians and inquire how they can take on a more active role in how their data is collected and used.

The data shows that having the patient directly involved increased the care plan compliance and, in turn, resulted in outcome improvements.

CONCLUSION

So, the next time patients fill out countless papers or sign a medical information release, they must remember: 1) they have a wealth of information, and 2) shape the future of healthcare when they turn in that information to be processed as data. Patients can inquire what patient-centered platforms are available in their doctor’s offices. Data is powerful on its own, but when utilized with consent and accuracy, the healthcare system can transform into an equitable institution. The next logical step in this arena would be to use patient-centered platforms to mitigate health disparities. By sharing and engaging with medical data informatics, patients potentially reduce health disparities. Medical information, processed into data, from under-represented groups can be analyzed with the intention that their data is used to bridge the gap in representation.

Sources

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Patient Perspective for Paper 5

The Role Data Informatics Plays Within Health Records

Interviewer: Virginia Leach

Patient Expert: Dr. Neosho Ponder, Ph.D.

In addition to the Inclusion Pledge Paper Series, breast cancer warriors have been asked to describe their experience with each topic. Patient advocacy-based organizations should want to increase the literature of breast cancer research and create space for patients to share their experiences, inspire others, and build a community of love and support.

Interviewer: Has the usage of patient portals and online medical records been helpful in your breast cancer diagnosis? If so, in what ways?

Neosho: Yes. I have been able to keep track of my labs, treatment, and meds. It also allows me to correspond with my doctors without being put on hold for hours or waiting days for a callback.

Interviewer: Do you think there is an issue with online health platforms that hold onto your data? If so, what problems raise concern for you?

Neosho: Not immediately. They could make patient information vulnerable to cyber-attacks versus paper files kept in the doctor's office.

Interviewer: For the most part, have you had positive or negative experiences navigating online health platforms?

Neosho: Positive.

Interviewer: Can you describe different scenarios where you have been happy to use the platform and others where it has been a challenge?

Neosho: Patient portals have been helpful to me when I need to know my treatment and pharmaceutical history. I also have found it easier to build rapport with the different doctors and their staff. If a patient is not familiar with online portals, it could present issues with receiving treatment information.

Interviewer: Is there anything you would like to share with the Tigerlily Foundation readers and warriors regarding the quality of life of breast cancer survivors?

Neosho: While every breast cancer survivor's approach to 'life after' can differ significantly, the quality of life of a breast cancer survivor can be a beautiful story of resilience and empowerment. Survivors have a superpower that allows them to see solutions and outcomes to health issues through a different lens. The question is, HOW WILL YOU USE YOUR SUPERPOWER? There is no right or wrong answer, but I pray that no one will let this superpower we earned go to waste.

Interviewer: What else do you think is important to share on this topic?

Neosho: There needs to be training on how to navigate patient portals. Patients with disabilities, older patients, and those who may not have access to technology are most at risk for inequity.