The role of artificial intelligence for the application of integrating electronic health records and patient-generated data in clinical decision support

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Abstract

This narrative review aims to identify and understand the role of artificial intelligence in the application of integrated electronic health records (EHRs) and patient-generated health data (PGHD) in clinical decision support. We focused on integrated data that combined PGHD and EHR data, and we investigated the role of artificial intelligence (AI) in the application. We used the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines to search articles in six databases: PubMed, Embase, Web of Science, Scopus, ACM Digital Library, and IEEE Computer Society Digital Library. In addition, we also synthesized seminal sources, including other systematic reviews, reports, and white papers, to inform the context, history, and development of this field. Twenty-six publications met the review criteria after screening. The EHR-integrated PGHD introduces benefits to health care, including empowering patients and families to engage via shared decision-making, improving the patient-provider relationship, and reducing the time and cost of clinical visits. AI's roles include cleaning and management of heterogeneous datasets, assisting in identifying dynamic patterns to improve clinical care processes, and providing more sophisticated algorithms to better predict outcomes and propose precise recommendations based on the integrated data. Challenges mainly stem from the large volume of integrated data, data standards, data exchange and interoperability, security and privacy, interpretation, and meaningful use. The use of PGHD in health care is at a promising stage but needs further work for widespread adoption and seamless integration into health care systems. AI-driven, EHR-integrated PGHD systems can greatly improve clinicians' abilities to diagnose patients' health issues, classify risks at the patient level by drawing on the power of integrated data, and provide much-needed support to clinics and hospitals. With EHR-integrated PGHD, AI can help transform health care by improving diagnosis, treatment, and the delivery of clinical care, thus improving clinical decision support.

Introduction

The recent widespread routine use of smartphones, wearable sensors, and the Internet of Things (IoT) technologies have emerged as promising data sources for health care research.¹ These technologies are driving more targeted patient engagement thanks to the massive development of digital capacities. Personal health information has also spiked with the broad availability of low-cost devices designed to monitor and inform healthy lifestyles.²

Patient-generated health data

Patient-generated health data (PGHD), defined by the Office of the National Coordinator for Health Information Technology (ONC), includes health symptoms, medical history, biometric information, treatment history, lifestyle data, and other information.³ PGHD is created, gathered, and recorded either by patients or their designees (i.e., care partners or those who assist them) to help address a health concern.⁴ By reviewing and discussing PGHD with patients remotely, clinicians can address clinical issues efficiently outside of clinical settings. PGHD allows health issues to be closely monitored without inconvenient traffic, insurance copayments, or lost days at work. It also provides actionable information for disease risk assessment and identification of issues that require urgent attention. In addition, PGHD can improve provider-patient communication and relationships by promoting mutual understanding, follow-up and feedback, and thought sharing.⁵ Various opportunities regarding PGHD are envisioned in the context of big data and artificial intelligence (AI) in health care. The ONC has initiated several activities to advance knowledge of the PGHD and identify policies and promising practices to support this field.

Artificial intelligence

AI aims to mimic human cognitive functions in the analysis, presentation, and comprehension of complex health data and bring a revolutionary paradigm innovation to health care. This innovation is powered by the increased availability of health data (structured and unstructured) and rapid progress of analytical techniques. AI has unique abilities to collect and gather data, process it, and give a well-defined output to the end-user. AI can use sophisticated algorithms to learn features from a large volume of health-related data, and then use the obtained insights to assist clinical practice. Embedding AI technologies into health care can help to reduce diagnostic and therapeutic errors that are inevitable in human practice, thus improving health care quality and patient safety. AI can also extract useful information from a large patient population data, including PGHD and EHR, to assist in making

real-time inferences for health outcome prediction and health risk alerts. AI technologies have been successfully applied to clinical practices such as diagnosis processes,⁶ treatment protocol development,⁷ personalized medicine,⁸ drug development,⁹ and patient monitoring and care.¹⁰ Various specialties in health care have shown an increase in research related to AI.¹¹ Currently, many countries, including the United States, are investing billions of dollars to support the development of AI in health care.¹².

Clinical decision support

Clinical decision support (CDS) systems provide health care workers with essential knowledge, intelligently manage electronic health data, present critical information at appropriate times, produce clinical advice, and thus enhance health care. CDS encompasses a variety of tools to enhance decision making in the clinical workflow¹³, including clinical guidelines, documentation templates, computerized alerts and reminders to clinicians and patients, patient reports and summaries, diagnostic support, and contextually relevant reference information. The Institute of Medicine (IOM) also promotes the use of CDS systems to advance the quality of patient care.¹⁴ CDS has contributed to health care by minimizing medical errors (e.g., medication prescription errors, adverse drug events, and administration errors), providing tools to measure clinician performance and patient outcomes,¹⁵ and simplifying the workflow by integrating real-time PGHD into EHR.

Integrating PGHD into EHRs further expands the capacity to monitor patients' health status without requiring office visits or hospitalizations. The combination of PGHD and EHR enables health care providers to have a more comprehensive view of the patients. Although there is increasing attention on the application of AI using either EHR or PGHD (**Figure 1a** and **1b**), little is known about its application to integrated EHR and PGHD data (**Figure 1c**). It would be valuable to (1) investigate and understand the current state of the integration of PGHD and EHR with a focus on AI application in clinical care, and (2) identify potential roles of AI in the efficient translation of EHR-integrated PGHD into meaningful health care applications.



Figure 1. Artificial intelligence applications on EHR, PGHD, and EHR-integrated patient generated health data. AI= artificial intelligence, EHR= electronic health records, PGHD= patient-generated health data.

This narrative review aims to identify and understand the role of AI in the application of EHR-integrated PGHD in health care, including clinical decision support, health care quality, and patient safety (**Figure 2**). We will focus on applications of AI that use integrated data and identify the opportunities, successful experiences, challenges, strategies, and implications.



Figure 2. The framework of artificial intelligence application of electronic health record (EHR)–integrated patientgenerated health data (PGHD) system on clinical decision support, health care quality, and patient safety. This narrative review aims to identify and understand the role of AI in the application of EHR-integrated PGHD in clinical decision support. We will focus on applications of AI that use integrated data and identify the opportunities, successful experiences, challenges, strategies, and implications.

METHODS

We designed and reported this systematic review according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA).¹⁶ In addition, we also synthesized seminal sources, including other systematic reviews, reports, and white papers, to inform the context, history, and development of this field.

Search strategy

We searched six databases: PubMed, Embase, Web of Science, Scopus, ACM Digital Library, and IEEE Computer Society Digital Library. We used common data capturing modalities, such as wearable sensors, wearable devices, mobile health, m-health, patient-reported outcomes, and artificial intelligence. Years ranged from 2000 to 2022. Given the recent advancement in health information technology that is relevant to this intersection topic, we restricted the study time period to the last two decades. We searched all keywords and synonyms related to patient-generated health data and clinical decision support. Supplemental Table 1 outlines our search strategy for each database. We were broadly inclusive of digital or paper and focused on studies using human participants that were written in English and available in full text (but not constrained to free article access). We augmented this search with six papers known to us but not identified by keyword search.

Inclusion criteria

Given the focus of this review on EHR-integrated patient-generated health data for health care applications (unlike the use of PGHD for the sole purpose of collecting data for a research protocol or without the involvement of clinicians), inclusion was based on two main criteria: (1) The article must have been peer-reviewed and represent empirical work (data, whether qualitative or quantitative, collected as part of the study and reported in the article); (2) We included a few review papers, vision statements, and similar pieces that provide context information for some terminologies and this review. We mainly focus on two PGHD capture systems and platforms: patient-reported outcomes (PROs) and mobile health. PROs are defined by the US Food and Drug Administration (FDA) as "reports of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else."¹⁷ PROs can be categorized as disease-related symptoms, side effects of treatment, or quality of life.¹⁸

Exclusion criteria

We excluded papers that only discussed PGHD issues and case reports that focused on the architecture of particular systems or apps. Articles in which the data were simulated or fabricated for test purposes were also excluded. We solely included PGHD that has been integrated into EHR or health systems. The data in the studies should have been used for clinical decision support. **Figure 3** provides a PRISMA flow diagram of the screening process.



Figure 3. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram of the review process.

Results

Integration of PGHD into EHR

EHR data include health information of clinical checkups, medical procedures, and drug prescriptions, and is focused on individual patients. In a traditional health care environment, providers typically make decisions based on the data they collect in clinical care settings. These data create a snapshot of the patient's health at single points in time rather than continuous measurements outside of clinical settings.⁴ Clinicians can only draw upon EHR data to develop personalized diagnosis and treatment plans. EHR can be combined with other high-value datasets, such as administrative and claims data, genomic data, and other personal health information to develop rich longitudinal profiles of individual patients and populations.¹⁹ Analytic opportunities regarding PGHD are envisioned in the context of big data and AI in medicine. AI applications are more effective when they can integrate large amounts of data, such as PGHD and EHR, both of which present diverse facets of health. PGHD has been envisioned to supplement EHR data, with a rich picture of a person's environmental context, behavioral patterns, and lifestyle information. Filing in the clinical visit's gaps using PGHD has the potential to inform better clinical decision making, with patients' active engagement in the process (Figure 4).



Figure 4. Patients' journeys between clinical visits and other settings.

Integrating PGHD into EHR adds value by expanding the scope of biomedical, public health, and population health research that can be conducted, which would not have been feasible by relying on EHR data alone. EHR-integrated PGHD can capture the patient's voices and perspectives, amplify real-life situations, and strengthen the patient-provider relationship, thus improving clinical decision support, health care quality, and patient safety.

Clinical decision support

The EHR-integrated PGHD can empower patients to manage their health and collaborate with clinicians via shared decision-making. Clinicians can gain a better understanding of the patient's health over time and reduce unnecessary visits or hospital admissions, and patients can undergo targeted interventions in the preoperative setting to mitigate the massive burden on the health care system postoperatively, all of which could contribute to better patient satisfaction and save medical resources.²⁰ PRO, as one example of PGHD, is particularly important when patients need to make a decision from multiple treatment plans that demonstrate similar benefits regarding survival. PRO data can inform decision-making in this situation by providing insight into quality of life, such as the ability to maintain one's roles and responsibilities during treatment and the ability to engage in physical activity, which can also have significant financial benefits.²¹ In addition, PROs may be less vulnerable than traditional clinical assessments to "white coat syndrome", in which patients are less likely to report symptoms during an interview.²² **Table 1** demonstrates the roles of AI in the application of integrated EHRs and PGHD in clinical decision support.

| Domains | Definition | Roles and functions of AI-assisted EHR- integrated PGHD system | Examples |
|---|--|--|---|
| Administrative function/ automation | Diagnostic code selection, automated documentation and note auto-fill. | Facilitate the scheduled review and approaches for acquiring and implementing new clinical knowledge. Simplify the data entry and documentation workflow. | Epic Systems Corporation (Verona, WI) is a common EHR that has a library of PROs and allows patients to add their own. Via a patient portal, users can trigger PROs at particular set time points or in response to a particular clinical event. ²³ |
| Clinical management | Adherence to clinical guidelines, follow-up and | • Help clinicians and care teams gain a more holistic view of their patients' health and | Researchers have trained algorithms to analyze images of retinas taken using a smartphone-based device and |

| Table [*] | I. Roles AI | in the an | plication o | of the i | ntegrated | EHRs and I | PGHD i | n clinical | decision | support |
|--------------------|-------------|------------|-------------|----------|-----------|------------|--------|------------|----------|---------|
| ranc. | I. RUIUS AI | . m uie ap | pheauon o | n uic i | megrateu | Lins and I | | n chincai | uccision | support |

| | treatment reminders. | understand how contributing factors may influence health outcomes and quality of life. Improve the interactions between clinicians and patients by aligning with patients' health needs and goals, ultimately increasing patient engagement and adherence to care plans and improving care delivery. Provide more holistic views of a patient's health and quality of life over time, which increases visibility into a patient's adherence to a treatment plan or study protocol and enables timely intervention before a costly care episode. | diagnose this disease with over 90% accuracy. ²⁴ |
|--------------------------------|--|---|--|
| Diagnostics support | Providing diagnostic suggestions based on patient data and automating output from test results. | Increase trust by providing direction for patients to update their knowledge in case they were not aware of the recommendation. Provide equitable opportunities for patients with limited mental and communication capabilities to record and share information about their health with their caregivers. Provide tailored support, advocating on behalf of the patient, and engaging in discussions about care coordination and the patient's care plan. | AI can deploy technologies like image recognition, NLP, and deep learning to quickly detect life-threatening conditions and assess risks for diseases like brain cancer ²⁵ or heart disease. ²⁶ |
| Patient decision support | Decision support administered directly to patients through PGHD system. | Empower patients and caregivers to manage their health by collaborating with clinicians via shared decision-making that considers patients' preferences. Enable patients to participate in the data collection process, observe how their health may fluctuate over time, and understand how certain actions and behaviors may influence their health outcomes. | Using advanced machine learning, AI has also been leveraged to analyze EHR- integrated PGHD with a diverse array of datasets and identify potential biomarkers that indicate the onset of deterioration ranging from a concussion to coma. ²⁷ |
| Cost containment | Reducing test and order duplication, suggesting cheaper medication or treatment options, automating tedious steps to reduce provider workload. | Gain a better understanding of the patient's health by receiving and analyzing PGHD between clinical encounters. Periodic review of data can reduce unnecessary clinician's office for routine, inperson visits, and travel costs. Ensure that patients remain in good health by dynamically monitoring the integrated data and avoid costly escalations in care, such as emergency room visits. Monitor patient data between clinical visits to intervene timely to prevent hospital visits or other costly care encounters. | Through NLP and other pattern recognition tools, machines can rapidly process EHR-integrated PGHD and automatically transcribe clinical notes. Automation can free up time and reduce costs by eliminating manual data entry. |
| Workflow improvement | Improving and expediting an existing clinical workflow with better retrieval and presentation of the integrated data. | Facilitate the establishment of the workflow and "chain of command" that help to reduce organizational and clinician liability concerns by assigning accountability and responsibility through clearly defined procedures. The electronic processes reduce the amount of effort required by providers and reduce the potential human errors. | AI algorithms draw upon EHR- integrated PGHD to better identify patterns and assist clinicians in making diagnoses and developing treatment plans. AI can also help doctors diagnose diabetic retinopathy, one of the world's leading causes of blindness, by using image recognition ²⁴ |

AI plays a vital role in the utility of integrated data and in creating prediction models of outcomes including complications, readmissions, and mortality risk. Advanced statistical algorithms and modeling, including descriptive modeling (to dissect patterns and relationships in the observed data), predictive analytics (to predict future events based on existing data), and statistical hypothesis testing (to assess causal inference), can enable a comprehensive

and rigorous analysis of the integrated heterogeneous data sets. We acknowledge that AI's goal is not to replace physicians' clinical judgment but to help them rapidly prioritize patients' symptoms and assess a range of diagnostic possibilities.

Challenges

While leveraging AI in the application of the integrated EHRs and PGHD promises to benefit patients and clinicians, challenges must be overcome to realize that potential. The large volume of data requires stakeholders to determine and invest in data storage and technical architecture to support the analysis, which can be used to serve clinical use and workflow redesign.²⁸ In addition, to review the PGHD, health care providers may have to allocate time from the actual patient visit that is not remunerated separately.²⁹

Given the variations in accuracy, usability, and validity, some PGHD may not yet be fit for clinical use where data quality is paramount.³⁰ For instance, the quality of the data collected by a home-monitoring device may be insufficient compared to a registered medical device, which is an instrument intended for medical use in the diagnosis of disease and regulated by the FDA.³¹ This situation calls for the integration of EHR that can resolve the discrepancies.

Undeveloped interoperability standards are one of the challenges of PGHD. Each system develops its own technical infrastructure for PGHD integration.³² Without standards that fully address PGHD use cases and consensus on which interoperability standards to use, variations in data representation and coding limit the exchange, normalization, and completeness of the integrated data. This hinders the system's ability to draw valuable insights. The lack of standardized terminology and format for PGHD limits the secondary uses of the data in research studies and clinical trials.

Ensuring the security and privacy of PGHD is also a challenge. EHR-integrated PGHD may be at risk for security breaches that could affect data integrity and expose the data to access for malicious purposes because they are not subject to the same security regulatory framework as HIPAA-regulated entities.³³ Concerns include insecure points of data collection and movement that potentially expose the device or the clinician's information system to pollutants. In addition, there is growing potential for risks related to unauthorized access, including cyber threats.

Recommendations

Using AI to clean and filter the PGHD before integration is helpful to reduce the volume of the data streams. To prevent the duplication of records when integrating PGHD with EHR, clinicians and researchers can employ AI-assisted patient matching techniques. Current procedures that use statistical algorithms to match data in local EHR systems with PGHD have shown increased levels of reliability. Technologies like the application programming interfaces (APIs) are portable packages of code that make it possible to add AI functionality to existing software packages and products.³⁴ They can add capabilities for image recognition to home security systems, calling out patterns and insights of interest in PGHD. APIs could also facilitate data accuracy, privacy, and security by their authentication function. ONC is leading a PCOR Trust Fund project on Patient Matching, Aggregating, and Linking that aims to use APIs to enable linking of patient data, including PGHD, to other clinical and claims data.³⁵ AI tools are capable of cleaning integrated data and simplifying the process of ensuring data are complete and prepared for analysis. These electronic processes reduce the volume of data and amount of effort required to clean and manage the integrated system and reduce the potential for human errors.

User verification solutions, such as biometric authentication and multi-step identity verification, could increase data accuracy and validity. Graphical processing units (GPU) provide outstanding computing power for iterative processing,³⁶ which enables the integration of PGHD and EHR, health information exchange (HIE), and higher speed calculation. Big data companies enable the use of predictive analytics such as NLP and ML on structured or unstructured data, coupled with GPUs, to help doctors and hospitals make their data more usable.³⁷ Data brokers, gateways, and aggregators could assess and manage data lineage and accuracy.³⁸ Research has also shown that the accuracy of AI applications and models could be developed with greater accuracy if the algorithms were to be shared publicly.³⁹

The emerging data exchange standard, Fast Healthcare Interoperability Resources (FHIR), and APIs provide opportunities to flexibly create software that securely pulls discrete data from the EHR into third-party software.⁴⁰ FHIR could be used to improve the presentation and visualization of the integrated data. FHIR's latest extensions, SMART Markers and SMART-on-FHIR, are also approaches developed to streamline and simplify data integration.⁴⁰ The interface needs to have digital flexibility so that data exchange is convenient and versatile.⁴¹ Leveraging standards-based data exchange through interoperability could potentially solve both the interoperability challenges as well as ease PGHD integration.⁴² making it an achievable goal for more health care systems.⁴³

Discussion

PGHD provides the potential for a holistic perspective of people's health conditions by presenting rich information about their lives. PGHD captured by digital health and informatics tools, such as wearable devices, portable pointof-care devices, smartphone apps, PROs through online questionnaires, and connected IoTs, can allow patients to become more engaged in the process of health care. The AI-driven application of the EHR-integrated PGHD has the potential to close health care gaps and support personalized medicine, including empowering patients and families to engage via shared decision-making, improving patient-provider relationships, and reducing the time and costs of clinical visits. Challenges mainly stem from the large volume of integrated data, data standards, data exchange and interoperability, security and privacy, interpretation, and meaningful use. In addition, the use of PGHD must be implemented in a way that prevents the exacerbation of health disparities. Pernicious disparities, such as gender or race differences in health conditions related to social inequality within health data, have negative impacts on AI model performance and results.⁴⁴ Developers of such software should draw heavily from research in the fields of user-focused design and human-computer interaction to create intuitive data visualizations that focus on important clinical information and allow health care providers to identify patterns that provide clinically meaningful insights. The use of PGHD in health care is at a promising stage and inevitable but needs further work for widespread adoption and seamless integration into health care systems. AI has the capacity to optimize PGHD integration into EHRs considering resources, standards for data exchange, security and privacy, and clinical workflows. With the EHR-integrated PGHD, AI can help transform health care by improving diagnosis, treatment, and the delivery of clinical care. AI-based computing systems can greatly improve clinicians' abilities to diagnose their patients' health issues, classify risks at a patient level by drawing on the power of the integrated data, and provide much-needed support to clinics and hospitals in under-resourced areas.⁴⁵ AI can also expand the operational capacity of EHRintegrated PGHD systems, and identify potentially and streamline manual tasks in the health care system to boost productivity.46

EHR-integrated PGHD allows for transformation from historically aggregated, population-based data to individual, longitudinal data, where more advanced methodologies need to be applied to identify an individual's patterns, changes, and outliers.⁴⁷ AI provides advanced methodologies for interpreting EHR-integrated PGHD, including predictive analytics (which uses various techniques to predict future events based on existing large data sets), machine learning (which uses computer systems to complete tasks relying on inferences over time), and deep learning (which focuses on learning data representations), and other complex analyses. The appearance of PGHD makes patients, caregivers, and families become part of the integrated health care system.⁴⁸

Conclusion

The use of PGHD in health care is at a promising stage but needs further work for widespread adoption and seamless integration into health care systems. AI-driven, EHR-integrated PGHD systems can greatly improve the capacity to deal with the large volume of data, control data quality, enable data exchange with better interoperability, ensure security and privacy, make understandable interpretations, and generate more meaningful use. With EHR-integrated PGHD, AI can help transform health care by improving clinical decision support. Further efforts are needed to understand how EHR-integrated PGHD systems can better support health care with the assistance of AI.

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