

Population Health Utilizing Patient Supplied Data

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Keywords

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Remote monitoring
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Security and privacy

Abstract

This project paper highlights the significant role of patient-provided data in enhancing population health management within healthcare systems. By effectively integrating patient-furnished information, healthcare providers can extend their capacity to meet the diverse health needs of populations, ultimately leading to improved overall health outcomes. The process of population health management begins with gathering crucial demographic and clinical data from sources such as electronic health records. Through data analytics and population health management strategies, providers can enhance patient outcomes, optimize care management, and address social determinants of health. Population health management focuses on understanding and addressing the health needs of entire populations, rather than just individuals. Patient data, including electronic health records, medical claims data, and public health surveillance data, are collected and analyzed to monitor population health status, identify health trends, and address health disparities within communities. By leveraging patient data to stratify populations based on health risks and needs, healthcare providers can implement targeted interventions and preventive care measures to improve population health outcomes.

Project goal:

This paper provides insights into the utilization and significance of Patient-Generated Health Data (PGHD) within the diabetes population. It delves into the methods of data collection, focusing on the types of data collected specifically for individuals affected by diabetes. Our analysis is based on the Michigan Diabetes Statistical Reports. Our project investigates the role of Patient-Generated Health Data (PGHD) and information technology (IT) in improving the management of type 2 diabetes (T2D), a condition affecting about 1 in 11 adults worldwide. Through IT interventions like mobile apps and internet-based platforms, PGHD can enhance glycemic control in T2D patients, crucial for preventing complications such as cardiovascular disease. However, barriers like privacy concerns and funding limitations exist. Effective training and integration into routine care processes are essential for successful implementation of IT and PGHD in diabetes management. PGHD, facilitated by IT, has been utilized to assist patients, alter healthcare delivery, and provide clinicians with access to valuable data. Its adoption has led to improvements in managing HbA1c levels, blood pressure, and lipids, as well as increasing the frequency of eye and

foot examinations. By summarizing the latest research findings, our project highlights the effectiveness of health information technologies (HITs) and PGHD in reducing HbA1c levels and managing T2D complications. We also identify current research limitations and suggest future directions for leveraging HITs and PGHD to improve diabetes care outcomes.

Also the aim of this project was to determine optimal approaches, areas for improvement, and potential avenues for enhancing the collection and utilization of Patient-Generated Health Data (PGHD) to potentially enhance health outcomes and lower costs by:

1. Ensuring the security of both the patient and the integrity of their health records
2. Maximizing the potential of the provider-patient relationship
3. Establishing trust among healthcare providers and researchers regarding the use of such data.

Introduction:

Patient data comprises details concerning an individual's health and medical history, encompassing personal information such as name, age, and contact details, as well as medical records, diagnoses, treatments, and test results. Healthcare providers collect and store this information to support patient care, research activities, and administrative functions. Patient data includes demographic information such as name, age, and gender, medical history, laboratory test results, diagnoses, treatments, medications, and imaging reports. Healthcare professionals utilize this data to deliver appropriate care, make informed decisions, monitor patient progress, and conduct research.

PGHD encompass various types of data, including but not limited to:

Health history

Treatment history

Biometric data

Symptoms

Lifestyle choices

Illustrative examples of PGHD comprise activities such as monitoring blood glucose levels or measuring blood pressure using home health equipment, as well as tracking exercise routines and dietary habits through mobile apps or wearable devices.

Patient Data Collection:

Whenever you visit a healthcare provider, your information is logged into their internal databases by doctors and nurses. This can result from tests and observations conducted during your appointment or from information you willingly share. Particularly, the latter offers insights into patients' behavior and lifestyles. Likewise, the proliferation of health-related applications and devices, like smartwatches, leads to the continuous recording of individual behaviors. Consequently, patient data has expanded to encompass not only basic medical details but also behavioral data. Additionally, patient data is sourced from research projects, historical records, and family medical histories.

Patient data attributes can be categorized into two segments:

1. Conventional medical data - This encompasses details like health history, diagnoses, current medications, vaccination records, and past or present treatments.
2. Emerging patient information - Evolving patient data now encompasses broader aspects beyond medical concerns, encompassing demographic and behavioral insights. This newer category includes details about individuals who may not be undergoing

medical treatment, such as lifestyle choices, dietary habits, and behavior patterns.

Patient data serves a dual role, meeting the requirements of both medical professionals and businesses. For healthcare providers and researchers, patient data is indispensable in diagnosing and managing medical conditions, providing essential information for tailoring treatments to individual needs and tracking patient progress. Furthermore, patient data acts as a fundamental resource for research, offering insights into diseases, treatments, and human biology, thereby driving medical progress and improving patient care. In the business realm, pharmaceutical companies utilize patient data for market research to identify gaps in healthcare solutions and develop new treatments. Marketers segment audiences based on patient data, facilitating targeted advertising campaigns to reach specific patient groups with tailored treatment options. Moreover, patient data fuels innovation in healthcare technology and informs strategies for health insurance companies, researchers, and healthcare analytics teams, all contributing to enhanced healthcare delivery and medical advancements.

Primary care experts advocate for integrating community-level data, referred to as "community vital signs," into Electronic Health Records (EHRs) to enhance patient care. Similar to biological vital signs like blood pressure and heart rate, these data serve to inform clinical decision-making, pinpoint intervention targets, and monitor population health. Bazemore et al a researcher propose incorporating community vital signs into EHRs for clinicians, alongside detailing their integration process within clinical data research networks. They expand on this by including details on appending information such as built environment, environmental exposures, and neighborhood sociodemographics to geocoded patient addresses.

Why Patient-Generated Health Data-Benefits:

The incorporation of Patient-Generated Health Data (PGHD) complements existing clinical data by bridging information gaps and offering a more holistic view of a patient's ongoing health status. Notably, PGHD differ from data collected in clinical settings and interactions with healthcare providers in two key aspects:

1. Responsibility for capturing or recording these data primarily lies with patients, rather than providers.
2. Patients have the autonomy to decide how they share or distribute these data with healthcare providers and other relevant parties.

Integrating PGHD into care delivery and research endeavors yields several benefits, including:

Enhanced insight into patients' health status between medical appointments.

Facilitation of shared decision-making regarding preventive measures and management of chronic conditions.

Potential cost savings and improvements in quality of care, care coordination, and patient safety.

The utilization and sharing of PGHD hold promise for:

Early detection of health issues or deviations from treatment plans.

Empowerment of patients to actively engage in their healthcare management.

Acceleration of research efforts by providing access to real-time patient data.

Promotion of personalized medicine approaches tailored to individual patient needs.

Drivers of PGHD

Desire to gain a more holistic and longitudinal view of patients' health.

Increased care coordination for chronic conditions.

Regulations that incent the capture and use of data from non-clinical settings.

Healthcare providers need to integrate PGHD seamlessly into clinical workflows, while technology developers must ensure user-friendly, interoperable solutions. Patients should be educated about PGHD benefits and involved in its development, fostering engagement and trust. Collaboration with payers and policymakers is essential for securing reimbursement and supportive policies. Furthermore, engaging the research community enables evidence-based use of PGHD to advance medical knowledge. Together, stakeholders can address barriers, drive adoption, and harness PGHD's potential to revolutionize healthcare delivery.

PGHD in diabetes management:

Diabetes, affecting about 1 in 11 adults globally, primarily in the form of type 2 diabetes (T2D), poses significant health challenges. Successful management of T2D relies heavily on glycemic control to prevent complications such as cardiovascular disease, kidney disease, blindness, neuropathy, and limb amputation, as well as reducing related mortality. However, achieving and maintaining optimal glycemic control requires continuous monitoring and treatment, which can be both costly and challenging. To address these challenges, innovative self-care strategies are

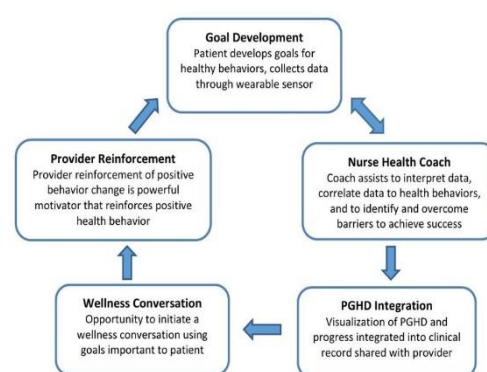


Figure 1 PGHD in public health management essential. One such strategy is the utilization of Patient-Generated Health Data (PGHD). Advances in health information technologies (HITs) have enabled the integration of PGHD into healthcare delivery systems, supporting effective and affordable patient education and care. "Digital health" encompasses the integration of healthcare and technology, utilizing connected devices, software, and apps to gather and utilize data, along with new care models to improve chronic disease outcomes. This field has seen remarkable growth, with investments exceeding \$4.5 billion in 2015, doubling from \$1.8 billion in 2013, and projected to exceed \$6 billion by 2017. Integrating PGHD into digital health initiatives is vital for improving diabetes management outcomes.

PGHD sources in diabetes management:

Wearable Devices: These include trackers and smartwatches equipped to monitor biometrics like blood glucose levels and physical activity, providing real-time data on a diabetic patient's health status.

Continuous glucose monitoring (CGM) systems provide real-time and predictive glycemic data, improving upon traditional blood glucose monitoring (BGM). CGM helps detect trends, asymptomatic events, and glycemic variability, leading to reduced hypoglycemia and improved A1C. It's particularly beneficial for patients with inconsistent glycemic control, those involved in managing their condition, or those at risk of hypoglycemia.

Mobile Health Apps: Applications designed for diabetes management offer features such as symptom tracking, medication reminders, and dietary monitoring, helping patients monitor and manage their condition more effectively.

Home Health Monitoring Devices: Devices like glucometers and blood pressure monitors enable diabetic patients to regularly check their vital signs from home, promoting proactive monitoring and early detection of fluctuations.

EHR: Healthcare professionals managing diabetes understand the critical role of data in the treatment process. Electronic Health Records (EHRs) play a

pivotal role in this regard by providing comprehensive diabetes flow sheets. These flow sheets enable clinicians to monitor a wide range of data, including vital signs, laboratory test results, and real-time changes from continuous glucose monitors. Compared to traditional paper-based records, EHRs offer enhanced functionality, making them essential tools for physicians. They have become an integral component of diabetes management due to their ability to capture and organize diverse data efficiently.

Online Portals and Personal Health Records (PHRs): These platforms allow patients to access and input medical information such as blood sugar readings, medication history, and doctor's appointments, facilitating better communication with healthcare providers and comprehensive management of diabetes.

Social Media and Online Health Communities: Platforms for sharing experiences and insights among diabetes patients provide valuable support networks, enabling individuals to exchange tips, advice, and encouragement.

Patient-Reported Outcome Measures (PROMs): Surveys and assessments capture subjective health data such as quality of life, treatment satisfaction, and emotional well-being, offering insights into the holistic impact of diabetes on patients' lives.

Telehealth and Remote Monitoring Platforms: Telemedicine offers remote monitoring of vital signs and glucose levels, ensuring timely access to healthcare services, delivering patient education and self-management resources, managing medications including dosage adjustments and prescription refills, and enhancing communication between patients and healthcare providers. and provide education and support, enhancing accessibility and continuity of care.

Patient-Generated Health Data (PGHD) has significant implications for diabetes

1. Continuous Monitoring and Management:

PGHD from wearable devices, mobile health apps, and home health monitoring devices enable diabetic patients to continuously monitor key health metrics such as blood glucose levels, physical activity, and vital signs. This continuous monitoring allows patients and healthcare providers to track trends and fluctuations in real-time, facilitating timely interventions to manage blood sugar levels and prevent complications.

2. Personalized Care Plans:

PGHD provides valuable insights into each patient's unique health status, behaviors, and responses to treatment. Healthcare providers can use this data to develop personalized care plans tailored to the individual needs and preferences of diabetic

patients, optimizing treatment strategies and improving adherence.

3. Improved Patient Engagement and Adherence:

Mobile health apps equipped with PGHD features like medication reminders, symptom tracking, and dietary monitoring empower diabetic patients to actively participate in their own care. By engaging patients in self-management tasks and providing personalized feedback, PGHD promotes adherence to treatment plans and adoption of healthier lifestyle behaviors.

4. Enhanced Communication and Collaboration: Online portals and personal health records (PHRs) allow for seamless communication and information sharing between patients and healthcare providers. Diabetic patients can easily share their PGHD with their care team, facilitating collaborative decision-making and ensuring continuity of care.

5. Peer Support and Community Engagement: Social media and online health communities provide diabetic patients with valuable peer support networks and opportunities to share experiences. Engaging with peers facing similar challenges can help patients feel supported, motivated, and better equipped to manage their condition effectively.

6. Data-Driven Insights for Population Health: Aggregated and anonymized PGHD can be analyzed to identify trends and patterns in diabetes management at the population level. Public health authorities can use this data to design targeted interventions, implement preventive measures, and allocate resources more effectively to address diabetes prevalence and its associated risk factors within communities.

7. Remote Monitoring and Telehealth Services: Telehealth and remote monitoring platforms enable remote consultations and monitoring of diabetic patients, particularly those in rural or underserved areas. This improves access to healthcare services, allowing diabetic patients to receive timely care and support regardless of geographical constraints.

Research Insights from Michigan diabetes statistical report:

The prevalence estimates for risk factors in Michigan between 2017 and 2021 can provide insights into the health trends and challenges faced by the population during that period. Common risk factors for various health conditions, including obesity, no leisure physical time (sedentary lifestyle), alcohol consumption, cigarette smoking, hypertension awareness, no routine checkups, age (risk increases with age), metabolic syndromes,

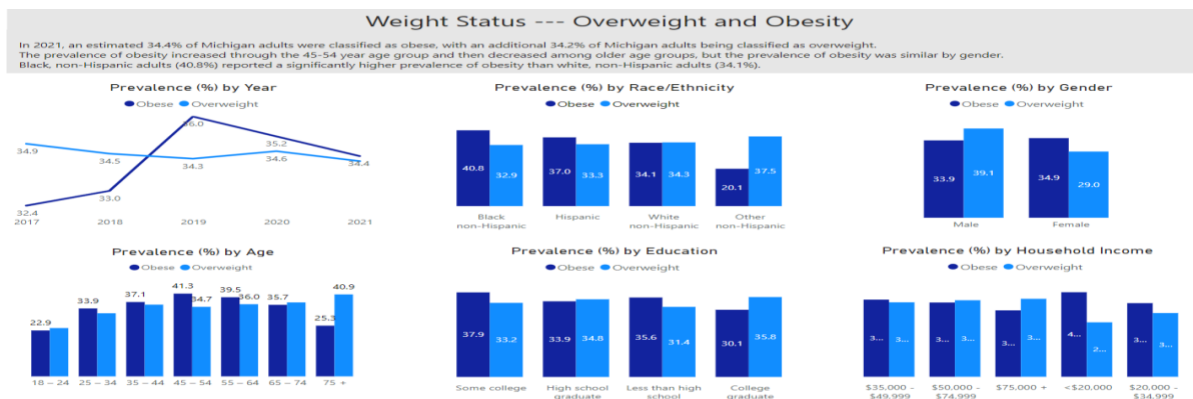


Figure 3 Obesity Prevalence in Michigan

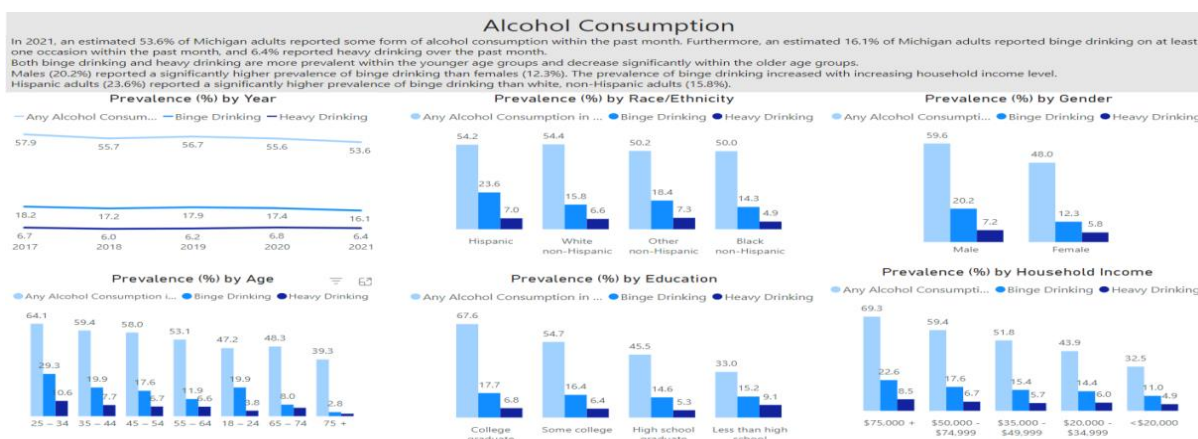


Figure 2 Alcohol consumption prevalence in Michigan

ethnicity/certain ethnic groups, such as African Americans, Hispanic/Latino. PGHD plays a crucial role in population health management. Without it, we wouldn't have access to essential data from patients. All the data points concerning risk factors and determinants are derived from PGHD.

The Michigan Department of Health and Human Services' Diabetes Prevention and Control Program (DPCP) has developed a comprehensive five-year plan in collaboration with various stakeholders to enhance diabetes care across the state. This plan focuses on three key priority areas: state leadership, diabetes prevention, and diabetes management. Under state leadership, the DPCP aims to strengthen partnerships, engage leaders, foster innovation, and provide support and education for diabetes professionals. In the realm of diabetes prevention, efforts will be made to lower barriers to participation in prevention programs, improve policy and coverage for prediabetes interventions, and establish systems for early detection and referral. In terms of diabetes management, the plan seeks to enhance medical coverage for diabetes education and support, leverage technology, incentivize healthcare providers, and improve overall care for individuals living with diabetes. A significant emphasis of the plan is on health equity, with a focus on addressing disparities by directing resources to communities with the greatest needs.

Opportunities:

1. Empowering Patients: Consumer technologies enable patients to manage their health better through capturing, using, and sharing PGHD.
2. Enhancing Clinical Insights: PGHD offers a holistic view of a patient's health, aiding in treatment adherence and timely interventions, thus improving outcomes and patient-provider relationships.
3. Expanding Research Opportunities: PGHD provides researchers with a larger pool of participants and data, while remote data collection reduces costs and improves efficiency.

Challenges:

Leveraging Patient-Generated Health Data (PGHD) offers potential benefits, yet several obstacles must be addressed:

1. **Patient Engagement:** Understanding the advantages of capturing and sharing PGHD with healthcare providers and researchers may elude some patients. Challenges such as limited access to PGHD technologies, varying health and tech literacy levels, and apprehensions about data privacy and security may deter involvement.

2. **Infrastructure and Workflow Constraints:** Many healthcare systems, practices, and research institutions lack the requisite technical infrastructure, workflows, workforce capacity, and training to accommodate PGHD integration. Methodological and technological limitations, coupled with the sheer data volume, impede the extraction of actionable insights.

3. **Workload and Workflow Interruptions:** Absent clear guidelines and best practices for integrating PGHD into clinical and research workflows, healthcare professionals fear increased workload and disruptions. Scarce conclusive evidence regarding the health and cost benefits of PGHD usage further complicates funding and implementation efforts.

Data and Device Challenges: High rates of device abandonment for consumer health technologies pose obstacles to data capture, utilization, and sharing. Ensuring PGHD accuracy, managing security risks, and standardizing data from diverse devices are additional hurdles. Concerns about liability arise if inaccurate PGHD influences clinical decisions or if clinicians choose not to review or act on received PGHD.

Collaboration among stakeholders is vital to boost the adoption of Patient-Generated Health Data (PGHD).

Healthcare providers need to integrate PGHD seamlessly into clinical workflows, while technology developers must ensure user-friendly, interoperable solutions. Patients should be educated about PGHD benefits and involved in its development, fostering engagement and trust. Collaboration with payers and policymakers is essential for securing reimbursement and supportive policies. Furthermore, engaging the research community enables evidence-based use of PGHD to advance medical knowledge. Together, stakeholders can address barriers, drive adoption, and harness PGHD's potential to revolutionize healthcare delivery. PGHD plays a crucial role in population health management. Without it, we wouldn't have access to essential data from patients. All the data points concerning risk factors and determinants are derived from PGHD.

Patient-Generated Health Data (PGHD) is an evolving field with continuous advancements. One notable development is the integration of PGHD into artificial intelligence (AI) and machine learning (ML) algorithms. These technologies analyze large volumes of patient data to generate insights and predictions, aiding in diagnosis, treatment planning, and personalized care. Additionally, there's a growing trend towards interoperability of PGHD, allowing different healthcare systems and devices to seamlessly exchange data. This interoperability enhances care coordination and provides a more comprehensive view of patient health. Moreover, PGHD is increasingly being used in remote patient monitoring programs, enabling healthcare providers



Figure 4 Adoption of PGHD

to monitor patients' health status outside of traditional clinical settings in real-time. This facilitates early intervention and improves patient outcomes, particularly for chronic conditions like diabetes and hypertension.

How Healthcare Companies Should navigate PGHD:

Healthcare companies can innovate with PGHD, engaging patients and improving efficiency. Traditional players risk obsolescence without embracing PGHD. They must invest in solutions encouraging physician adoption of PGHD, leading to better patient outcomes and reduced healthcare burden. PGHD offers insights and market opportunities for healthcare, biopharma, and med-tech firms. New digital health companies are emerging to leverage these data assets. Investing in PGHD unlocks actionable insights and infonomics. It enables understanding of patient health over time and reduces office visits and readmissions. PGHD is a key driver for industry transformation. Healthcare providers must adapt to PGHD to stay competitive and relevant. Embracing PGHD fosters better patient care and improves healthcare efficiency.

Current State:

In today's healthcare, clinicians rely on data from clinical settings, offering only snapshots of patient health. Real-time data outside clinics is rare, limiting holistic patient understanding. Patient-Generated Health Data (PGHD) from digital tools like apps and wearables can enhance engagement. The popularity of these tools stems from smartphone convenience, passive data collection, and real-time feedback. For instance, wearable fitness trackers help users track activity and sedentary time, promoting healthier behaviors.

Strategies for implementation

Successful integration of patient-provided data into public health management relies on strong information governance frameworks, cross-sector collaboration in healthcare, and the development of data analytics capabilities. Engaging patients in the data collection process and addressing ethical considerations, such as privacy and consent, are essential strategies for ensuring successful implementation.

Security and privacy

Security and privacy concerns surrounding Patient-Generated Health Data (PGHD) pose challenges for patients, clinicians, and researchers alike. Currently, there is an uneven application of security and privacy protections for PGHD, lacking a consistent legal and regulatory framework. Unlike HIPAA-regulated entities, PGHD is not subject to the same security standards, leaving it vulnerable to security breaches that could compromise data integrity and expose it to malicious access. Vulnerabilities such as insecure data collection points and data movement increase the risk of exposure to pollutants like malware. With the rising threat of unauthorized access and cyber threats, the potential for security breaches is significant. Addressing these concerns requires ongoing security risk assessments and management to mitigate risks and enhance resilience against security breaches.

Ethical Considerations:

Respecting the affected person's autonomy and making sure knowledgeable consent is paramount while gathering and using patient-supplied information. Safeguarding an affected person's privacy and information security calls for adherence to strict ethical guidelines and regulations. Transparency and duty in facts usage are essential for building consideration with sufferers and stakeholders.

Patient Consent:

Patient consent is crucial in PGHD for several reasons. Firstly, it upholds autonomy and individual rights. Patients have the right to control their health data and make informed decisions about its use. Consent fosters trust between patients and providers,

ensuring open communication and engagement with healthcare services. It also helps organizations comply with privacy regulations and demonstrates a commitment to transparency and accountability. Ultimately, respecting patient consent leads to better-tailored care and improved health outcomes.

Future Directions

In the future, emerging technologies like AI and ML will optimize the use of patient-provided data (PGHD) in population health management. AI and ML can swiftly analyze vast datasets, providing deeper insights and enabling tailored interventions. Addressing disparities through data-driven approaches and collaboration with diverse stakeholders will be crucial for improving population health outcomes. Overall, the future of PGHD holds promise for enhancing health outcomes and promoting equity across communities.

MARKET SIGNALS SHOW THAT THE TIME TO TAKE ACTION IS NOW

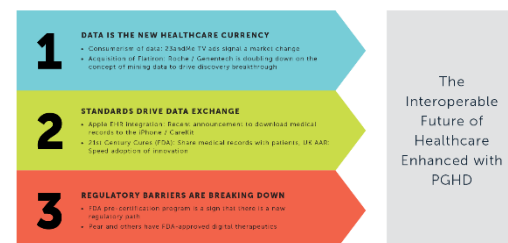


Figure 5 Future of healthcare with PGHD(17)

Limitations

Our study has limitations. Firstly, our literature search might have missed relevant studies due to our choice of outlets and keywords. Using alternative terms like "Patient-Reported Outcomes" could yield more relevant articles. Future research should consider terms like "Patient-Reported Health Outcomes." Additionally, our coding process simplified the results, potentially missing some insights. We focused on three main literature streams: PGHD collection, integration into clinical workflows, and patient-clinician interaction through PGHD. While this allowed for more detailed findings in these areas, other insights may have been overlooked. Lastly, the research gaps and challenges we identified may be influenced by the perspectives of the included authors, leaving room for further open issues to be discovered in future work.

Conclusion:

This project emphasizes the crucial role of Patient-Generated Health Data (PGHD) in advancing population health management within healthcare systems. By effectively integrating PGHD, healthcare providers can expand their ability to address various health needs, leading to improved overall health outcomes. This process begins with collecting essential demographic and clinical data, which, when combined with data analytics and population health management strategies, can optimize care, tackle health disparities, and enhance outcomes. Integrating PGHD allows for a more comprehensive understanding of patient health beyond clinical settings, promoting personalized care, early detection, and preventive measures. However, challenges like patient engagement, infrastructure constraints, and security concerns must be addressed for successful implementation. Collaboration among stakeholders is crucial to drive adoption, overcome barriers, and fully realize the potential of PGHD to revolutionize healthcare delivery and promote equity across communities. As emerging technologies such as Artificial Intelligence (AI) and Machine Learning (ML) continue to evolve, the future of PGHD holds promise for further improving health outcomes and advancing population health management practices. Adopting PGHD is a significant undertaking, and companies can pursue various paths to achieve it. The future vision entails a healthcare ecosystem where partners share PGHD electronically to enhance care delivery and research. Collaboration among stakeholders is paramount to realize increased use and sharing of PGHD in a learning health system.

Acknowledgments:

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