Towards Exchanging Wearable-PGHD with EHRs: Developing a Standardized Information Model for Wearable-Based Patient Generated Health Data

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Abstract— **Wearables have become commonplace for tracking and making sense of patient lifestyle, wellbeing and health data. Most of this tracking is done by individuals outside of clinical settings, however some data from wearables may be useful in a clinical context. As such, wearables may be considered a prominent source of Patient Generated Health Data (PGHD). Studies have attempted to maximize the use of the data from wearables including integrating with Electronic Health Records (EHRs). However, usually a limited number of wearables are considered for integration and, in many cases, only one brand is investigated. In addition, we find limited studies on integration of metadata including data quality and provenance, despite such data being very relevant for clinical decision making. This paper describes a proposed design and development of a generic information model for wearable based PGHD integration with EHRs. We propose a vendor-neutral model that can work with a wider range of wearables and discuss our proposed method to employ an ontology-based approach and provide insights to future work.**

Keywords-wearables; electronic health records; interoperability; information model; FHIR; fast healthcare interoperability resources.

I. INTRODUCTION

Patient Generated Health Data (PGHD) refers to health data that a patient (or their authorized representative) records outside the clinic setting, is relevant to their wellbeing and can be used by them or clinicians for their health management. PGHD is collected using many mediums including Patient Health Records (PHRs), mobile health application (mHealth), and wearables. Wearables are a prominent source of PGHD identified in literature. Wearables can collect various granular types of data using inbuilt sensors. These devices combine sensing capabilities with algorithms to produce data in both raw and aggregated formats which can be effective for healthcare monitoring (by both the patient and clinicians) [1]. Data from sensors is used to measure various data – for example, heart rate, daily number of steps taken, distance covered, number of calories burned, number of floors climbed. From these sensors, data such as detailed heart rate history with heart rate zones, active minutes and sleep duration and quality can also be calculated and can be viewed through the associated web-based application or mobile app, and for a limited period, on the device too. For most wearables, the internal memory of the device is only able to store minute-by-minute data of the last seven days, and 30 days of daily summaries [2]. Other data can also be collected from the trackers too, such as last sync date, battery level, etc. [3]. Wearables provide an opportunity for tracking patients' health condition in their regular living settings, providing insightful data about a patient, more complete than what can be collected during infrequent clinical visits. Globally, the number of wearable devices has increased from 325 million in 2016 to 722 million in 2019, more than doubling in only three years [4]. By 2022, there will likely be more than one billion of such devices worldwide. Vendrico [5] have curated an information database of 431 wearable devices produced by 266 companies; there are potentially other bespoke ones that are unaccounted for in this estimate. The use of wearables for patient care has benefits such as: connected information, patient-oriented healthcare, and gamification [6]. For the purposes of this study, our definition of wearable did not include belt-based wearables as this has been found to be unappealing to users [7].

Due to benefits and prospects of PGHD for personalized care and population health, there is significant interest and investment in integrating PGHD with electronic health records. Jung [8] integrated PHRs with EHR using lifelogs, but suggested that wearables could help in reporting more objective data, with less burden to the patient. Similarly, Plastiras and O'Sullivan [9] developed an information-model for integrating PGHD and Observation of Daily Living (ODL) with EHR. However, they considered only one wearable in their study – a Fitbit tracker. We argue that this may not be generalizable to other wearables, as there could be more data and meta data that is unaccounted for in this approach. Also, there is less consideration for meta data on data quality such as device accuracy, which is of essence in the decision-making process of a clinician. In their study of four commercial widely used wearables, Kaewkannate and Kim [10], established that Fitbit Flex and Misfit have difficulty in detecting when a user climbs or descends stairs. Despite Fitbit leading in the consumer market of wrist-worn

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wearables [11], the Fitbit Flex model should not be relied upon for use in patient climbing or descending tasks. Reporting similar concern for other wearable-based data, Wood, Bennett, and Basch [12] state that it is not clear whether sleep data or any other data from one wearable can be interchangeable with another and whether this will result to the same meaning of the data. The aforementioned points make metadata information very important for clinical decision making, hence our interest in providing valuable metadata alongside sensor data to clinicians.

This short position paper proposes a generic framework to enable a wide range of wearable-PGHD to be interoperable with EHRs, to allow seamless exchange of clinically relevant data from patients to providers. The framework will enable a class of wearables to be integrated with EHR systems using an ontology-driven Information Model (IM) based on Fast Health Interoperability Resources (FHIR). In this paper, we provide a description of our proposed IM for transferring information in a standardized way between wearables and EHR systems. In the rest of this paper, we describe our proposed method to develop the interfacing layer between EHR and wearables as well as present insight into our proposed future work. In Section II, we describe the proposed methodology and architecture, outlining stages and steps to be carried out to design the proposed model, including the underlining technologies to be employed. Section III presents future work on the proposed design, and Section IV gives a summary and a conclusion on the position paper.

II. PROPOSED METHODOLOGY AND ARCHITECTURE

Plastiras, and O'Sullivan [9] and Plastiras, O'Sullivan, and Weller [13] describe steps for designing and developing an ontology-driven information model for EHR integration. This includes, but may not be limited to, analysis of common functionality and data to determine information to be exchanged, review of standards, and developing a middleware for document exchange. Similar to [9], our research proposes the use of an ontology-driven IM to address issues of semantic and syntactic interoperability between wearable-based PGHD and EHR systems. Figure 1 below depicts our proposed architecture for wearable-based PGHD-EHR integration based on FHIR standard. The following section describes the proposed architecture and future steps and thoughts around our proposal for developing ontology-driven IM, to be derived directly from common wearable-based PGHD and functions.

As previously mentioned, most wearables have a separate persistent long-term data staging, visualization and storage platform, due to their limited memory and battery size. So, in addition to owning a wearable device, most users have an accompanying mobile application that they use alongside the wearable, to enable them to visualize and store data. In addition, they can sync and have access to their data online. With this structure, wearable data can be accessed, manipulated and shared only through the web or mobile application. In our architecture, we have embodied this, but in addition, we depict data sharing capabilities that can be explored for integration (Figure 1, Stage 1 - 3). Wearable-based PGHD can be shared with an EHR system using standard clinical document exchange format such as Clinical Care Document (CCD), Clinical Care Record (CCR), and XML [14]. However, because FHIR is the most recent standard from Health Level 7 (HL7)[15] that overcomes the shortcomings of the previously mentioned document exchange standards, we intend to employ FHIR as the messaging standard in our proposed design. FHIR has been previously employed to exchange some wearable based data with an EHR application [14], [16]. However, most of the studies have relied on the use of data from one specific brand or device, which may not make it generalizable.

In our design, we propose that whenever wearable-based PGHD is to be shared with clinicians (providers), it will go via a middleware interface that will transform the data into FHIR-ready data, a procedure we refer to as FHIRification (Figure 1, Stage 4). At this layer, data will also be mapped to standard and custom ontologies present at that interface, which can fit to the terminology component of FHIR. The FHIRification involves transforming data to fit into existing FHIR Resources and Extensions. The transformation engine should also generate a FHIR relevant Conformance and Capability Statement that documents the required server implementation of the FHIR resources. Thereafter, data is made available to the EHR for use (Figure 1, Stage 5). Similar to the approach in many studies [14], we propose that demographic data related to patients are transformed into the Patient resource, data related to actual sensor data is fitted into the Encounter resource, and data related to the device are transformed into the Device resource of FHIR. Derived data from patient's medical history can also be considered under Condition resource. In addition, we intend to explore the use of Provenance resource in integration [17], to help document data provenance. We also posit that a PGHD profile will be desirable to provide a container for all PGHD resources, for ease of reference, use and management.

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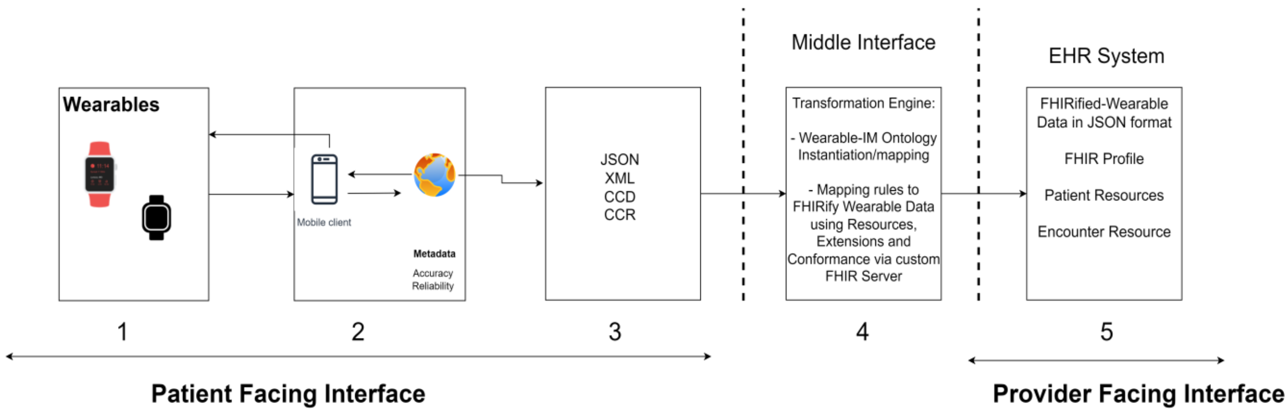

Figure 1. Proposed Wearable-based PGHD-EHR integration

With emerging diseases and in preparation for another pandemic, more wearables with new capabilities are churned out, leading to newer forms of datasets and features and data that are bespoke. Data such as temperature sensing (relating to women's health), ECG (for atrial fibrillation monitoring) and skin temperature etc, are evolving and need to be considered. Hence, our approach is to make this consideration of this diversity in data from these wearables to enable wider adoption and use of the framework.

III. FUTURE WORK

Information Model development is carried out in stages which include identification, and evaluation of available data and functionality, determining candidate data to be exchanged, leveraging existing EHR standards required for candidate data syntactic integration, and the design of an ontology for semantic integration [9]. Hence, more work is expected to fully develop the system and demonstrate the effectiveness. However, here we outline steps to be undertaken towards our proposed ontology-driven IM, and how we will leverage other state of art like the use of FHIR standards.

A. Analysis of common wearable functionality and features

We propose to review the features and functionality of wearables based on the work of Kaekwannate and Kim [10] who identify common data and functions of four popular wearable devices. In their studies, they outline features of JawboneUp24, Fitbit Flex, Withings Pulse, Misfit Shine wearables [10]. However, in addition to this, more wearables will be identified from [5] to be included for comparison and evaluation. Wearables like Apple Watch and Xaiomi are included in the list of wearables to be compared for the purpose of common data and functions identification. While generalizable categories of data such as Activity Tracking Data (Distance, Calories, Floors climbed, Intensity), Sleep Data (Duration, Stage, Score), Stress Data and other known health data from wearables will be prioritized, we will also consider bespoke data. A scoring system will be employed to assign a utility score to each wearable based on a select criterion, to help us identify generalizable data, but also bespoke data and data with the most value.

B. EHR Data Exchange standards and interoperability

Recent work by Microsoft [18] focused on achieving interoperability by developing a platform to share historical patient data from Fitbit into FHIR server. We will learn from this work but extend it to embrace other data and functions that may come from other wearables, and data that could enhance Fitbit's overall value within a PGHD-EHR ecosystem, such as accuracy and reliability metadata. In our proposed architecture, we intend to pay attention to data quality using metadata and provenance, to improve clinicians' confidence in PGHD. Data accuracy, reliability validity, and completeness are foremost data quality issues that have hindered PGHD integration [19], [20]. In our proposed system, data exchanged between wearables and EHRs must conform to relevant structure and syntactic rules. The syntactic rules will closely align with FHIR standards, and in that case, information can be transformed to and transferred as a JSON document. However, it will also be transformable to legacy standards such as XML.

C. Design of Wearable-based PGHD Ontology

We intend to employ open source software Protégé for developing a wearable-based PGHD ontology, and OWL to instantiate the ontology at the middle interface [13]. Using an ontology-based approach, semantic interoperability issues can be avoided. The usage of different terms by wearables and EHRs to define the same concept can prevent data sharing with EHRs. Data such "Oxygen Saturation Measurement" in one wearable can be represented as "SpO2" in another wearable, hence a standardize ontology that will fit appropriately to the Terminology component of FHIR becomes desirable. The ontology will define relationship, constraints, and concepts about the data from the wearables. Similarly, standard coding schemas will be employed too. For instance, the SNOMED CT code for

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SpO2 is “431314004”. By assigning this code to Oxygen Saturation Measurement, the meaning of these two data could be interpreted as same.

IV. CONCLUSION

Wearables are digital health products or devices that are being used to collect, store and process health data, also known as PGHD, towards providing holistic digital health information that can be used for patient monitoring or to encourage or enact behavior change. Data collected by wearables are used across a broad set of health domains and towards population health, becoming a key contributor to digital health initiatives. They are often combined with mobile and web applications to process and manage data. In this paper, we present preliminary work in designing an ontology-based IM for wearable-based PGHD for integration with EHR. The proposed IM is proposed to be derived from common features and functionality of a wide range of consumer-grade wearables and will employ the FHIR standard for interoperability with EHR. We outline steps required to develop this fully in the future and discussed how this can be implemented.

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REFERENCES

[1] A. Godfrey, V. Hetherington, H. Shum, P. Bonato, N. Lovell, and S. Stuart, “From A to Z: Wearable technology explained,” *Maturitas*, vol. 113, pp. 40–47, 2018.

[2] M. Schellevis, B. Jacobs, C. Meijer, and J. de Ruiter, “Getting access to your own Fitbit data,” *Radboud University*, 2016.

[3] G. Crenshaw, “FitBit API,” *The ABCs of Fitbit APIs*, Jul. 11, 2022. https://pages.fitbit.com/2021_11-WebinarVideo-TheABCsofFitbitAPIs_21-VideoReplay.html?aliId=eyJpIjoiUlhncUlZUHU0SWVpMWR6MiIsInQiOiJ2TVd0VEhGS05cL0JBRzc4Zk80d0oyQT09In0%253D (accessed Jul. 11, 2022).

[4] F. Larichhia, “Global Connected Devices Worldwide 2022,” *Global Connected Devices Worldwide 2022*, 02 2022. https://www.statista.com/statistics/487291/global-connected-wearable-devices/ (accessed Jun. 07, 2022).

[5] Vendrico, “The Wearables Database,” *Wearable Device Database*, Jul. 08, 2022. https://vandrico.com/wearables.html (accessed Jul. 08, 2022).

[6] S. R. Islam, D. Kwak, M. H. Kabir, M. Hossain, and K.-S. Kwak, “The internet of things for health care: a comprehensive survey,” *IEEE access*, vol. 3, pp. 678–708, 015.

[7] I. Bendich, “Changes in prospectively collected longitudinal patient-generated health data are associated with short-term patient-reported outcomes after total joint arthroplasty: a pilot study,” *Arthroplasty Today*, vol. 5, no. 1, pp. 61–63, 2019, doi: 10.1016/j.artd.2019.01.005.

[8] S. Y. Jung, “Development of comprehensive personal health records integrating patient-generated health data directly from samsung s-health and apple health apps: Retrospective cross-sectional observational study,” *JMIR mHealth and uHealth*, vol. 7, no. 5, 2019, doi: 10.2196/12691.

[9] P. Plastiras and D. O’Sullivan, “Exchanging personal health data with electronic health records: A standardized information model for patient generated health data and observations of daily living,” *International journal of medical informatics*, vol. 120, pp. 116–125, 2018.

[10] K. Kaewkannate and S. Kim, “A comparison of wearable fitness devices,” *BMC public health*, vol. 16, no. 1, pp. 1–16, 2016.

[11] A. Ng, R. Kornfield, S. M. Schueller, A. K. Zalta, M. Brennan, and M. Reddy, “Provider perspectives on integrating sensor-captured patient-generated data in mental health care,” *Proceedings of the ACM on human-computer interaction*, vol. 3, no. CSCW, pp. 1–25, 2019.

[12] W. A. Wood, A. V. Bennett, and E. Basch, “Emerging uses of patient generated health data in clinical research,” *Molecular oncology*, vol. 9, no. 5, pp. 1018–1024, 2015.

[13] P. Plastiras, D. O’Sullivan, and P. Weller, “An ontology-driven information model for interoperability of personal and electronic health records,” 2014.

[14] R. K. Saripalle, “Fast Health Interoperability Resources (FHIR): current status in the healthcare system,” *International Journal of E-Health and Medical Communications (IJEHMC)*, vol. 10, no. 1, pp. 76–93, 2019.

[15] D. Bender and K. Sartipi, “HL7 FHIR: An Agile and RESTful approach to healthcare information exchange,” presented at the Proceedings of the 26th IEEE international symposium on computer-based medical systems, 2013, pp. 326–331.

[16] J. Ruminski, A. Bujnowski, T. Kocejko, A. Andrushevich, M. Biallas, and R. Kistler, “The data exchange between smart glasses and healthcare information systems using the HL7 FHIR standard,” presented at the 2016 9th International Conference on Human System Interactions (HSI), 2016, pp. 525–531.

[17] J. Moehrke, A. Rosenthal, and A. Chapman, “Extending the FHIR standard to handle provenance,” *The MITRE Corporation*, 2016.

[18] Microsoft, “FitBit on FHIR.” Accessed: Jul. 06, 2022. [Online]. Available: https://github.com/microsoft/FitbitOnFHIR

[19] J. Codella, C. Partovian, H.-Y. Chang, and C.-H. Chen, “Data quality challenges for person-generated health and wellness data,” *IBM Journal of Research and Development*, vol. 62, no. 1, pp. 3–1, 2018.

[20] R. Abdolkhani, “Patient-generated health data management and quality challenges in remote patient monitoring,” *JAMIA Open*, vol. 2, no. 4, pp. 471–478, 2019, doi: 10.1093/jamiaopen/ooz036.