Digital Health and Informatics Innovations for Sustainable Health Care Systems
J. Mantas et al. (Eds.)

doi:10.3233/SHTI240387

Improving Healthcare Quality with a LHS: From Patient-Generated Health Data to Evidence-Based Recommendations

Ricardo L. SANTOS[a,1] and Ricardo CRUZ-CORREIA[b]
[a] *PhD student Health Data Science, Faculdade de Medicina da Universidade do Porto, Portugal*
[b] *Associate Professor, Faculdade de Medicina da Universidade do Porto, Portugal*
ORCiD ID: Ricardo L. Santos https://orcid.org/0000-0001-6017-8255
Ricardo Cruz-Correia https://orcid.org/0000-0002-3764-5158

Abstract. One approach to enriching the Learning Health System (LHS) is leveraging vital signs and data from wearable technologies. Blood oxygen, heart rate, respiration rates, and other data collected by wearables (like sleep and exercise patterns) can be used to monitor and predict health conditions. This data is already being collected and could be used to improve healthcare in several ways. Our approach will be health data interoperability with HL7 FHIR (for data exchange between different systems), openEHR (to store researchable data separated from software but connected to ontologies, external terminologies and code sets) and maintain the semantics of data. OpenEHR is a standard that has an important role in modelling processes and clinical decisions. The six pillars of Lifestyle Medicine can be a first attempt to change how patients see their daily decisions, affecting the mid to long-term evolution of their health. Our objective is to develop the first stage of the LHS based on a co-produced personal health recording (CoPHR) built on top of a local LLM that interoperates health data through HL7 FHIR, openEHR, OHDSI and terminologies that can ingest external evidence and produces clinical and personal decision support and, when combined with many other patients, can produce or confirm evidence.

Keywords. Health data interoperability, personal health recording, openEHR, Learning Health System, clinical decision, HL7 FHIR, patient-generated health data.

1. Introduction and Objectives

This preview outlines a thesis for the Health Data Science PhD Program at the University of Porto, detailing progress in establishing a Learning Health System (LHS) to enhance healthcare quality [1]. A Learning Health System (LHS) is an innovative model aimed at continuous healthcare improvement by melding data, scientific evidence, and patient experiences. Its core principles include ongoing learning from data, making evidence-based decisions, fostering patient involvement, and maintaining a commitment to innovation [2]. The development and evaluation framework of LHS signifies a shift towards health systems that learn from every patient interaction, featuring learning communities, data conversion into knowledge, and the application of this knowledge to

---

[1] Corresponding Author: Ricardo L. Santos; E-mail: ricardolourencosantos@gmail.com.

practice, all supported by dedicated platforms. This model is designed for scalability, adaptability, and is responsive to community feedback and practical insights. [3] A key strategy to enrich the LHS involves leveraging vital signs and data from wearable technologies to boost patient engagement, support self-management, and tailor evidence-based healthcare to individual needs. Wearables offer real-time health metrics feedback, promoting active patient involvement in condition management, increasing engagement by providing health insights, and enabling personalised healthcare through a comprehensive understanding of individual health patterns and risks. Incorporating wearable data into the LHS can transform personalised medicine by monitoring and predicting health condition patterns through blood oxygen levels, heart rate, respiration rate, sleep, and exercise habits. This approach could identify at-risk individuals for early intervention, monitor chronic conditions to avoid complications and personalise treatment for greater efficacy and efficiency. Although still emerging, wearable technology in healthcare promises significant advancements in global health outcomes by enhancing data accessibility and utility. So, starting with Patient-Generated Health Data (PGHD) and integrating Evidence-Based Clinical Practice Guidelines, initially from Lifestyle Medicine (LM), the goal is both to validate or challenge these guidelines with real-world observational evidence (to accelerate the application of translational knowledge in healthcare), and to present to patients enough arguments that help them make better choices regarding health habits.

2. Methodology

2.1. LHS, PGHD and Interoperability

LHS architecture integrates improvement cycles focused on specific health issues, governance for consistency and accountability, and a socio-technical infrastructure that underpins these improvement efforts. This infrastructure encompasses digital technologies and involves human roles, policies, and processes. It provides shared services supporting various functions such as developing learning communities, performance analytics, data governance, knowledge integration, and performance enhancements. Emphasising socio-technical components aids in achieving interoperability, accelerating LHS adoption, and facilitating the integration of smaller systems into larger, cohesive networks [4]. The healthcare sector aims to integrate PGHD into research and care, enhancing treatment personalisation, prevention methods, and patient-doctor interactions beyond traditional appointments. Challenges include standardising data collection across various devices and managing the influx of information in healthcare settings. Addressing these will unlock PGHD's transformative potential for healthcare. Our strategy focuses on health data interoperability using HL7 FHIR® for system-to-system data exchange, openEHR for storing researchable data linked to ontologies and terminologies (independently of software and maintaining data semantics). Additionally, OHDSI (Observational Health Data Sciences and Informatics, derived from former OMOP) supports generating observational health evidence and includes tools for uniform data representation (Common Data Model, Standardized Vocabularies), the ETL process, and open-source analytics, paving the way for evidence-based insights from patient data [5,6].

2.2. GDPR and Evidence-Based Clinical Practice Guidelines (CPGs)

Implementing a low-code Electronic Health Record (EHR) system with open-source elements within the openEHR framework is practical despite the lack of open-source tools for frontend development like form generation [7]. OpenEHR aligns with many General Data Protection Regulation (GDPR) mandates on data integrity, confidentiality, and access, supporting data protection by design. Yet, it does not cover all GDPR aspects, such as processing limitations and consent management. Still, openEHR-based systems can aid GDPR compliance, enhancing privacy and data security in healthcare IT [8]. OpenEHR is pivotal in modelling healthcare processes and decision-making, with its Task Planning and Decision Language specifications bolstering workflow and clinical decisions. The evolution of openEHR's support for clinical guidelines via the Guideline Definition Language (GDL) and its advanced version, GDL2, has improved clinical decision-making. The Decision Language (DL) specification further refines guideline management, enabling structured clinical rules and guidelines through Decision Logic Modules (DLM), designed for easy use by healthcare professionals to support varied decision-making processes. This simplification and broad applicability highlight DL's role in enhancing clinical decision support systems [9,10]. HL7 FHIR and openEHR are complementary standards in healthcare IT. Evidence-Based Medicine on FHIR (EBM-on-FHIR) and Clinical Practice Guidelines on FHIR (CPG-on-FHIR) are initiatives leveraging FHIR to digitally represent clinical guideline recommendations, processing data from evidence generation to guidelines formulation. This approach facilitates the use of structured data in developing actionable, evidence-based clinical protocols, indicating a convergence of standards to improve healthcare delivery and decision-making [11].

2.2.1 Co-produced Personal Health Recording - CoPHR and Local LLM

Co-produced personal health recordings (CoPHR) represent a collaborative approach in health data science that emphasises shared responsibility between patients and healthcare providers, patient empowerment through control and contribution of their data (including from wearables, apps, or self-reported symptoms), and the integration of data from diverse sources via open platforms. This approach aims to enhance patient engagement by involving them in their health management, creating a more comprehensive health profile by merging various data, and improving communication and collaboration through shared access to health records. Challenges such as data privacy, security, standardisation, and the need for technical infrastructure are acknowledged, with openEHR providing solutions through standardisation and infrastructure support. The CoPHR model focuses on overcoming the limitations of traditional personal health records by fostering interoperability and avoiding data silos through an open platform that enables seamless integration of different applications and data sources. It leverages an openEHR-based standardised data structure and a user-friendly API to facilitate application development, ensuring medico-legal validity, data provenance, and detailed audit trails within a governance framework that protects all stakeholders. By treating patients as active partners and prioritising the coPHR as the central data repository, this model aims to transform personal health data management, leading to more personalised and efficient healthcare [12]. Local Large Language Models (LLM) can be a practical approach to combine data from different sources (PGHD, EBM, CPG) and where we can develop a model that combines external health data and evidence and/or guidelines that can produce new evidence based on personal, specific and at appropriate time. This information can also help patients take control of their own choices, having the health professionals as co-pilots instead of main deciders. The integration of chain-of-thought prompting in large language models (LLMs) and the development of machine learning–enabled clinical information systems (ML-CISs) using Fast Healthcare Interoperability Resources (FHIR) standards represent significant advancements in healthcare technology. Chain-of-thought prompting enhances decision-making in specialised fields by making AI processes more transparent and aligned with human reasoning, thus improving diagnostics, treatment planning, and patient outcomes through a structured, ethical approach. This method emphasises breaking down complex problems into smaller, manageable steps for clearer AI reasoning, aiming to close the gap between AI capabilities and human cognitive processes. There lies the importance of interoperability, data management, and the utilisation of advanced computing strategies like cloud systems and Bayesian networks. Both areas underline the need for scalable, secure, and ethically grounded frameworks to enhance real-time clinical applications. This suggests a future where AI significantly contributes to personalised and efficient healthcare delivery [13,14]. A general view of information way can be stated in Figure 1.

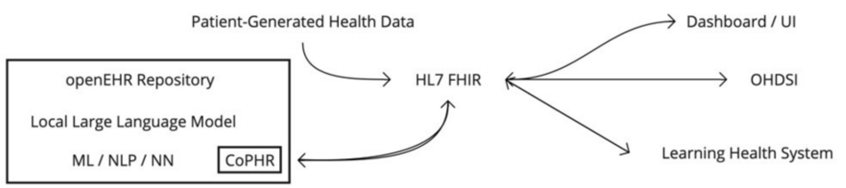

Figure 1. General view of Information paths.

2.3. Lifestyle Medicine and the 2019 Nobel Prize

The six pillars of LM (food, sleep, exercises, social engagement, stress management and avoiding risk substances) can be a first attempt to change how patients see their daily decisions affecting their health improvement's mid to long-term evolution [15]. This can be an extremely powerful tool to be combined with PGHD in a CoPHR to give specific and tailored evidence of the importance of health and habit-related choices. One example of the relation between habits, vital signs and diseases is the 2019 Nobel Prize in Physiology or Medicine awarded to William Kaelin, Jr., Sir Peter Ratcliffe, and Gregg Semenza for their discoveries on cellular responses to oxygen availability [16]. They identified key mechanisms, including the role of the Hypoxia Inducible Factor (HIF-1) and the von Hippel-Lindau tumour suppressor gene (VHL), in adjusting gene expression to oxygen changes, affecting cell metabolism, tissue assembly, and physiological responses like increased heart rate and ventilation. This understanding links oxygen levels directly to gene expression through HIF-1, enabling cells to adapt to low oxygen conditions (hypoxia) by avoiding HIF-1 degradation, thus activating genes for hypoxia response. This mechanism has implications for various diseases, as HIF-1 levels are elevated in many cancers and cardiovascular disorders. The research underscores the critical role of oxygen in cellular energy conversion and disease development, tracing back to Louis Pasteur's 1858 insights. So, our project aims to create an information system within an LHS framework to, for example, detect hypoxia, analyse its pathophysiological links to diseases, and monitor vital signs for early warning, enhancing understanding and prevention of related conditions.

3. Conclusions

Our objective is to develop the first stage of the LHS based on a CoPHR built on top of a local LLM that interoperates health data through HL7 FHIR, openEHR, OHDSI and terminologies that can ingest external evidence and produces clinical and personal decision support and when combined with many other patients, can produce or confirm evidence. Information will be presented to the patient and the healthcare professional in a dashboard to help present data in a friendly user interface (UI). Patient literacy, patient empowerment, self-management, patient-centred care, and family and community engagement will be central to the UI development of the front end. Still to be addressed in future publications: the Extraction Transform Load (ETL) process, data collection, data analysis, interpretation, integration, visualisation, reporting, sharing and data reuse. Also, more details on the local LLM, Natural Language Processing (NLP), Machine Learning (ML), and Neural Networks (NN) will be included in this project shortly.

References

[1] Santos RL, Cruz-Correia RJ. Improving Healthcare Quality with an LHS. In: Studies in Health Technology and Informatics, Volume 302: Caring is Sharing - Exploiting the Value in Data for Health and Innovation, Pages: 145 - 146, 2023, DOI 10.3233/SHTI230088.
[2] Institute of Medicine. 2007. The Learning Healthcare System: Workshop Summary. Washington, DC: The National Academies Press. https://doi.org/10.17226/11903.
[3] Foley T, Vale L. A framework for understanding, designing, developing and evaluating learning health systems. Learn Health Sys. 2023; 7(1):e10315. doi:10.1002/lrh2.10315
[4] Friedman CP, et al. Socio-technical infrastructure for a learning health system. Learn Health Sys. 2024; 8(1):e10405. doi:10.1002/lrh2.10405
[5] Vaidyam A, et al. Enabling Research and Clinical Use of Patient-Generated Health Data (the mindLAMP Platform): Digital Phenotyping Study JMIR Mhealth Uhealth 2022;10(1):e30557
[6] The Book of OHDSI, Observational Health Data Sciences and Informatics. Accessed March, 2024.
[7] Frade S, et al. OpenEHR Implementation Guide: Towards Standard Low-Code Healthcare Systems, In: Studies in Health Technology and Informatics, 290, 52-55, IOS Press, 2021.
[8] Sousa M, et al. OpenEHR Based Systems and the General Data Protection Regulation (GDPR). In: Studies in Health Technology and Informatics, Volume 247: Building Continents of Knowledge in Oceans of Data: The Future of Co-Created eHealth, 91 - 95, DOI: 10.3233/978-1-61499-852-5-91.
[9] Silva B, et al. OpenEHR logic module: a tool for creating decision rules, Procedia Computer Science, Volume 231, 2024, Pages 427-432, ISSN 1877-0509, https://doi.org/10.1016/j.procs.2023.12.229.
[10] Beale T. Decision Language specification. 2021. url: https://specifications.openehr.org/releases/PROC/Release-1.6.0/decision-language.html.
[11] Lichtner G., et al. Representation of evidence-based clinical practice guideline recommendations on FHIR. Journal of Biomedical Informatics 139 (2023) https://doi.org/10.1016/j.jbi.2023.104305
[12] Apperta Foundation -A Blueprint for a Co-produced Personal Health Record (co-PHR) Ecosystem. https://apperta.org/coPHR/, Acessed 2024, March.
[13] Miao J, et al. Chain of Thought Utilization in Large Language Models and Application in Nephrology. Medicina 2024, 60, 148. https://doi.org/ 10.3390/medicina60010148
[14] Balch JA, et al. Machine Learning–Enabled Clinical Information Systems Using Fast Healthcare Interoperability Resources Data Standards: Scoping Review. JMIR Med Inform 2023;11:e48297
[15] Clayton JS, Bonnet J. Foundations of lifestyle medicine Board review manual, 4th edition, 2023, Published by the American College of Lifestyle Medicine, ISBN: 979-8-218-17015-8
[16] The Nobel Prize in Physiology or Medicine 2019, https://www.nobelprize.org/prizes/medicine/2019/advanced- information/ , accessed 2023-05-28