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POINT OF VIEW

The open data revolution: Enhancing healthcare in intensive care units

La revolución de los datos abiertos: mejorando la atención médica en unidades de cuidados intensivos

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In the contemporary information-driven landscape, data has attained profound value, prompting a global paradigm shift towards data openness and democratization. Within the realm of health research, open access data (OAD) encompasses publicly available datasets fostering collaborative access for researchers. These datasets empower scientific progress, enhance transparency of algorithms, and encourage result reproducibility. To ensure responsible and secure data access, a regulatory and ethical framework is imperative, engaging various stakeholders in a governance process. This governance model establishes stringent policies safeguarding privacy and data integrity while promoting transparency and accountability. It necessitates users' commitment to responsible research conduct, data usage constraints, prohibition of patient re-identification attempts, and the sharing of associated code in public repositories. OAD, sometimes defined interchangeably as FAIR data, adheres to principles articulated by the European Union in the FAIR framework.[1] These principles, encapsulated in the acronym FAIR (Findable, Accessible, Interoperable, and Reusable), were outlined in a March 2016 Scientific Data paper by a consortium of scientists and organizations. FAIR principles prioritize machine-actionability, enhancing computational systems to find, access, interoperate, and reuse data with minimal human intervention. As data creation grows, FAIR becomes crucial for accessibility and usability. In the OAD context, data accessibility divides into restricted availability for designated users or within organizational boundaries and open accessibility for the global research community, contingent on ethical and

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institutional prerequisites. This OAD ethos fosters interdisciplinary collaboration, creating impactful health solutions while preserving data integrity and privacy.

The role of Open AI technologies in healthcare

Using Open AI (OAI) technologies in healthcare seamlessly aligns with the OAD concept. Open healthcare datasets, as a crucial component of this concept, enable the training of adaptable AI models within secure environments. This not only enhances prediction accuracy but also fosters transparency in algorithms, collaboration, and equitable healthcare provision. The OAD concept promotes the open exchange of information, and in the context of healthcare, it ensures that the benefits of AI-driven improvements in diagnosis, personalized treatment, and clinical predictions are accessible to all while safeguarding the confidentiality of sensitive medical data.

Global initiatives in open access data for healthcare

Committing to OAD principles, exemplified by the concept, establishes a critical foundation for advancing healthcare through transparent information exchange. This philosophy finds resonance in the transformative landscape shaped by open health data initiatives. Notable international examples include Medical Information Mart for Intensive Care (MIMIC-IV),[2] OpenEHR,[3] Health Data Research UK (HDR UK),[4] and the Cancer Genome Atlas (TCGA).[5] MIMIC-III is a vast repository of de-identified critical care records from Beth Israel Deaconess Medical Center, facilitating the development of healthcare machine learning algorithms. If we put the focus on Europe, the European Health Data Space (EHDS)[6] serves as a crucial initiative within the European Union, designed to enable secure cross-border sharing of health data, enhance healthcare quality, promote medical research and innovation, facilitate cross-border healthcare services, and empower patients with greater control over their health information. Its impact on open data in the health context promises to be substantial, as it fosters collaboration, research, and innovation while ensuring data privacy and security, ultimately advancing healthcare outcomes across Europe.

Advancements in healthcare through open access data in Spain

Open health data globally fosters collaboration, research, and innovation while ensuring data privacy. Spain's initiatives notably embody this commitment, shaping substantial advancements in healthcare outcomes. Spain's National Health System is creating a data platform and services, aligning with Digital Europe Programme and European Health Data Space goals to build a cohesive European data space for AI assimilation. Notably, this initiative transcends primary utility, deliberately incorporating secondary use with the explicit aim of enhancing and fortifying open data initiatives.[7] Across Spanish regions, strategic directives from Public Foundations for Health Innovation and Research actively promote biomedical big data research. Focused on areas like medical imaging and clinical data, the overarching goal is to advance personalized medicine, enhancing patient care and sustaining the public healthcare system economically. At the same time, there are several private experiences from databases such as SANITAS, HM Hospitals group and the University Hospital Clínic of Barcelona, supporting the OAD and the development of machine learning algorithms in healthcare.[8] These initiatives are in consonant with the worldwide imperative to expedite research concentrating on COVID-19, driven by the European Society of Intensive Care Medicine (ESICM) Data Sharing Initiative and the Swiss Federal Institute of Technology (ETH) Zürich.

Focusing on intensive care data in Spain offers a unique opportunity. Establishing an open, collaborative repository for the intensive care medical community could unlock vast medical knowledge. Given the current circumstances, the primary aim is clear: engage regions in collaboration with national scientific associations to construct a collaborative OAD repository. The repository would accelerate state-of-the-art digital solutions, cultivating insights for critically ill patients in Spain. Its goal would be to refine diagnostic accuracy and customize treatment protocols for ICU patients, streamlining operational processes. In response to urgent imperatives, cutting-edge technologies like Big Data and Artificial Intelligence have enabled predictive models, anticipating medical responses. These technologies also would allow performance comparisons with other open databases, fostering a dynamic community centered around ICU data in various regions of Spain, advancing the overall understanding and treatment of critically ill patients.

Ethics and data governance

Conclusively, integrating OAI technologies with open data principles, advanced technologies, and ethical governance in ICUs signifies a transformative initiative with broad healthcare implications. This holistic approach not only revolutionizes patient care but positions intensive care as a leader in shaping a healthier future. By embracing the potential of Big Data, Artificial Intelligence, and Open AI within a framework of responsible data management, we are poised to expedite medical insights, refine treatments, and ultimately enhance outcomes for critically ill patients. This OAD-driven transformation underscores our commitment to medical excellence and ethical considerations, calling for collective engagement to propel the field of intensive care into a new era of innovation and patient-centered care. Furthermore, these principles serve to foster a sense of community, leading to more efficient collaboration, which in turn helps eliminate biases and promotes more equitable healthcare delivery.

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Conflict of interests

The authors declare that they have no conflict of interest.

References

1. Jacobsen A, de Miranda Azevedo R, Juty N, Batista D, Coles S, Cornet R, et al. FAIR principles: interpretations and implementation considerations. Data Intell. 2020;2(1–2):10–29, http://dx.doi.org/10.1162/dint_r_00024.
2. Johnson AEW, Bulgarelli L, Shen L, Gayles A, Shammout A, Horng S, et al. MIMIC-IV, a freely accessible electronic health record dataset. Sci Data. 2023;10(1):1, http://dx.doi.org/10.1038/s41597-022-01899-x.
3. Cunha J, Duarte R, Guimarães T, Santos MF. OpenEHR and Business Intelligence in healthcare: an overview. Procedia Comput Sci. 2023;220:874–9, http://dx.doi.org/10.1016/j.procs.2023.03.118.
4. Home. HDR UK. Accessed November 17, 2023. https://www.hdruk.ac.uk/.
5. Wang Z, Jensen MA, Zenklusen JC. A practical guide to the cancer genome atlas (TCGA). In: Mathé E, Davis S, editors. Statistical genomics: methods and protocols. Springer; 2016. p. 111–41, http://dx.doi.org/10.1007/978-1-4939-3578-9_6. Methods in Molecular Biology.
6. Aarestrup FM, Albeyatti A, Armitage WJ, Auffray C, Augello L, Balling R, et al. Towards a European health research and innovation cloud (HRIC). Genome Med. 2020;12(1):18, http://dx.doi.org/10.1186/s13073-020-0713-z.
7. Ministerio de Sanidad - Professionals - Digital Health. Accessed November 17, 2023. https://www.sanidad.gob.es/en/areas/saludDigital/home.htm.
8. de Kok JWTM, de la Hoz MÁA, de Jong Y, Brokke V, Elbers PWG, Thoral P, et al. A guide to sharing open healthcare data under the General Data Protection Regulation. Sci Data. 2023;10(1):404, http://dx.doi.org/10.1038/s41597-023-02256-2.