

Electronic Health Record Repositories: Benefits and Challenges of Data Standardization in Rehabilitation

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References

1. Friedman, C. P., Rubin, J. C., & Sullivan, K. J. (2017). Toward an information infrastructure for global health improvement. *Yearbook of medical informatics*, 26(01), 16-23.
2. Evans, R. S. (2016). Electronic health records: then, now, and in the future. *Yearbook of Medical Informatics*, 25(S 01), S48-S61.
3. Shawn N. Murphy, Henry C. Chueh, Christopher D. Herrick, Chapter 13 - Information Technology, Editor(s): David Robertson, Gordon H. Williams, *Clinical and Translational Science (Second Edition)*, Academic Press, 2017, Pages 227-242.
4. Timbie, J. W., Rudin, R. S., Towe, V., Chen, E. K., Hunter, L. E., Case, S. R., ... & Ridgely, M. S. (2015). National patient-centered clinical research network (PCORnet) phase I. Santa Monica, CA: RAND.
5. Gamal, A., Barakat, S., & Rezk, A. (2021). Standardized electronic health record data modeling and persistence: A comparative review. *Journal of biomedical informatics*, 114, 103670.
6. Hart et al., (2017). *Manual for Rehabilitation Treatment Specification*, v 6.2.
7. Koscielniak, N. J., Tucker, C. A., Grogan-Kaylor, A., Friedman, C. P., Richesson, R., Tucker, J. S., & Piatt, G. A. (2022). Evaluating completeness of discrete data on physical functioning for children with cerebral palsy in a pediatric rehabilitation learning health system. *Physical therapy*, 102(1), p234-244.
8. Koscielniak, N., Jenkins, D., Hassani, S., Buckon, C., Tucker, J. S., Sienko, S., & Tucker, C. A. (2022). The SHOnet learning health system: Infrastructure for continuous learning in pediatric rehabilitation. *Learning Health Systems*, e10305.
9. Cerebral palsy research network <https://cprn.org/>
10. VA Health Services Research & Development cyberseminars <https://www.hsrd.research.va.gov/cyberseminars/>

11. Data Resources

- a. VA Informatics and Computing Infrastructure (VINCI) <https://www.research.va.gov/programs/vinci/default.cfm>
- b. DaVINCI Data Training <https://www.research.va.gov/programs/vinci/davinci-data-training.cfm>
- c. ACT Network. The ACT Network is a real-time platform allowing researchers to explore and validate feasibility for clinical studies across the NCATS Clinical and Translational Science Award (CTSA) consortium, from their desktops <https://www.actnetwork.us/National>
- d. Food and Drug Administration (FDA) Sentinel Initiative <https://www.sentinelinitiative.org/about>
- e. TriNetX platform <https://trinetx.com/>

- f. PCORnet Front Door The Front Door is an access point for potential investigators, patient groups, healthcare organizations, clinicians and clinician groups, government, industry scientists, sponsors, and all stakeholders seeking to leverage PCORnet infrastructure and collaborate on patient-centered research <https://pcornet.org/front-door/>
- g. Cerebral palsy research network <https://cprn.org/research/cprn-registry-elements/>

12. Common data models

- a. Informatics for Integrating Biology and the Bedside Star Schema(i2b2). i2b2 is an open-source clinical data warehousing and analytics research platform used at over 250 locations worldwide <https://community.i2b2.org/wiki>
- b. Food and Drug Administration (FDA) Sentinel Initiative <https://www.sentinelinitiative.org/about> PCORnet CCommon Data Model (CDM) Specification, Version 6.0 <https://pcornet.org/wp-content/uploads/2022/01/PCORnet-Common-Data-Model-v60-2020-10-221.pdf>
- c. The PCORnet Common data model <https://pcornet.org/news/pcornet-common-data-model/>
- d. Observational Medical Outcomes Partnership (OMOP) The Observational Medical Outcomes Partnership (OMOP) Common Data Model (CDM) is an open community data standard, designed to standardize the structure and content of observational data and to enable efficient analyses that can produce reliable evidence <https://www.ohdsi.org/data-standardization/> /<https://www.ohdsi.org/data-standardization/>
- e. Common Data Model Harmonization Tools for mapping several CDM to each other project <https://www.healthit.gov/topic/scientific-initiatives/pcor/common-data-model-harmonization-cdm>