White Paper

ESTABLISHMENT OF THE OHDSI CENTER AT THE ROUX INSTITUTE AT NORTHEASTERN UNIVERSITY

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Abstract

In the 5 years of its existence, OHDSI has been remarkably successful, building a community of researchers and developing a rigorous standardized approach to observational research. This has yielded science with high impact research and helped to establish the integrity and value of observational evidence in general. OHDSI has achieved all this as a largely self-organizing community with few resources devoted to its supporting institutional structures.

The community's success and rapid growth now pose challenges, however, and these will require new capacities to meet. The innovations and evidence generated so far have brilliantly demonstrated what is possible. But some aspects of the demonstrated modes of research do not scale easily, and others will require a rapid increase in OHDSI-specific institutional assets and individual skills if they are to be implemented more broadly. To meet these challenges, we are proposing to create a new OHDSI Center within the Roux Institute at Northeastern University. The Center will serve as an administrative and legal hub of OHDSI and will develop formal programs for education and training and research.

This paper lays out the principles that this new institution will follow in engaging with the OHDSI Coordinating Center and in advancing the structural capacities of the overall OHDSI initiative so it can fulfill its promise in meeting the worlds' healtcare evidence needs.

Background

OHDSI is a global, multi-sector, open science community that collaborates on key topics related to effective use of electronic health data to generate reliable evidence for healthcare practice. These topics include:

- Epidemiologic and data science research infrastructure
- Methodologic research resulting in tools and best practices for using them
- Health research resulting in reliable evidence, using this infrastructure, tools and best practices
- Activities to promote participation and collaboration in the community and help individuals and institutions develop relevant competencies

OHDSI is the largest observational health research community in the world both in its geographic scope and in the number of patient records in its members' datasets. It has the most mature set of standardized analytic tools born of an established approach to empirically developing and supporting best practices. These cover a wide range of research use cases from descriptive statistics for basic epidemiology and healthcare utilization, drug safety and comparative effectiveness, health economics to healthcare quality. The communitiy's activities have resulted in more than 400 publications and a large-scale research result repository that is freely available on the public internet.

OHDSI has a central Coordinating Center at Columbia University. It coordinates network studies, maintains the OHDSI web presence (including a very active discussion forum), organizes the OHDSI GitHub repository, and manages centralized medical vocabulary services. It has also established a series of symposia, workshops, and studyathons. These activities have been crticially important enablers of the entire grassroots movement responsible for an impressive production of know-how, tools, methods, and evidence.

In countries outside the US, regional chapters of OHDSI are now established following OHDSI's core Open Source, Open Science, and open participation principles. These chapters have benefited from leveraging the centrally-funded formal and informal structures.

We believe the global OHDSI community has a large opportunity to continue drive growth, maturity and reputation for research excellence. The path to that growth in our opinion lies in the preservation of its grassroots and Open Source culture, combined with the introduction of an improved structure to some of its foundational activities combined with better defined rules of engagement with members and external partners. We are considering the following components:

- Define tiers of OHDSI Network membership in terms of obligations and benefits
- Develop formal training coursework leading to accredited certificates or degrees
- Mark, define, and protect our brands, in particular "OHDSI" and "OMOP"
    - Enforce Open-Source licensing and Open Science approach
    - Improve transparency mechanism and documentation
    - Credential appropriate use through certification programs
- Manage scope, priorities and quality of OHDSI's capacity-building work:
    - Support development and maintenance of OHDSI tools and software applications
    - Incorporate IP from external institutions (private or public)
- Scale up community building
    - Create fundraising and distribution mechanisms
    - Introduce service to external institutions (private or public)

These will help OHDSI to make progress on a number of elements requiring focus:

1. Overcome technical debt and improve coordination between tool development, evolution of the CDM and increased transparency, particularly of vocabulary management,
2. Overcome collaboration debt and decrease the burden involved in implementing and using OHDSI resources through better documentation, guidance, and training,
3. Develop the network through maturity model enabling standard queries and analytical package execution against high-quality certified data assets.
4. Increase research production capacity for generating scientific insights.

We believe an administrative home for OHDSI that complements the Coordinating Center at Columbia will catalyze addressing these issues. We are proposing to place this Center at the Northeastern University, primarily through its Roux Institute in Portland, Maine. It seeks to make significant contributions to research and learning in the same areas OHDSI focuses on.. The OHDSI THE CENTER at the Roux seeks to become an important asset to the OHDSI community, contributing to the research agenda and providing educational offerings that advance the community globally.

Proposal

We propose to create the OHDSI Center for Learning, Investigation, and Partnerships at the Roux Institute. The Center will have the following aims:

1. Pursue a research and learning agenda related to OHDSI's core objectives. Develop training material for online and direct presence learning
2. Create a legal entity for OHDSI and as an administrative hub to support management of funding and contracts
3. Create a support infrastructure for collaborators, facilitating technical and organizational readiness and the conduct of studies
4. Support Maine Health Data to become an OHDSI network partner
5. Build collaboration with external partners such as IQVIA, Tufts MC etc. through formal data use and research agreements

At the same time, we do not wish to disrupt the highly productive, open, collaborative and lean operation of OHDSI. Therefore, the guiding principles for the Center would be:

- Preserve the radically open and grassroots character of OHDSI that fosters contribution from all quarters while promoting improved attribution of credit to contributors
- Continue support for all community projects and contributions while promoting a more effective and more centralized work prioritization process
- Formalize the modes for community representation in decision making

In order to preserve the open nature and strengthen the role of the community, we intend to adapt approaches that have proven successful in other open source communities such as the Apache Foundation.

Staffing

To get started, we propose to hire an Executive Director, OHDSI Center for Research, Learning,and Partnerships. Appointed as a Senior Research Scientist at the Roux Institute, the Executive Director will be an existing member of the OHDSI community who is fully committed to its culture and mission. The Executive Director will be a leader with a vision for what the OHDSI Center at Roux should look like in order to accomplish the mission. The Executive Director will be charged with development, implementation, and oversight of:

Governance
- Development of governance for the OHDSI Center at Roux
- Development of an administrative plan and establishment of a legal entity that will enable the goals outlined above.
- Oversight of contracts, finances
- Develop interactions with the Coordinating Center at Columbia University
- Develop "Member Services" that are designed to engage the OHDSI community at all levels of involvement
- Develop and implement a sustainability plan built on licensing of of marketable applications, angel investor partnerships, etc.

Education Mission

- Development of educational training opportunities to apply data science to meet clinical needs

Research Mission
- Support of research programs that advance data science focused on health care data analysis
- Enhanced organization, documentation, and cataloging of OHDSI community assets to make it all more searchable, reliable, and productive
- Development of OHDSI institutional readiness: observable indicators that a data-holding institution has what it takes to use the OHDSI resources effectively.