Yale University Open Data Access (YODA) Project
Public Comment Response to Public Access to the Results of VA-Funded Research

The Yale University Open Data Access (YODA) Project at the Yale-New Haven Hospital Center for Outcomes Research and Evaluation (CORE) supports and applauds the draft VA Policy on Public Access to the Results of VA-Funded Research, expanding public access to the results of federally-funded research. This draft policy document demonstrates a sound understanding of the need for expanding and ensuring public access, of the competing risks involved, and of the importance of innovative partnerships. The requirement for data management plans for all VA investigators conducting VA-funded research is necessary and commendable. The steps laid out by the VA for the planning of future expansion of datasets available for unrestricted public access are detailed, feasible, and provide a practical model for other organizations. The VA's actions to make data available from research funded by the VA to the public has great potential to generate new scientific understandings and maximize the re-use and value of the data collected with VA financial support.

The YODA Project strongly supports the fundamental need to protect patient privacy and understands the current restrictions on use of data outside the VA and/or beyond the study for which the data were collected. However, the YODA Project suggests that this policy would be stronger if the scope was expanded to apply retrospectively to previously initiated research. Planning for future expansion of availability of datasets should consider proposed steps for how to include data from retrospective studies. In addition, moving forward, informed consent agreements should explicitly include data sharing as a possible future use of a research participant's data.

In addition, the YODA Project also suggests that this policy be made highly visible in the research and healthcare policy communities. This is an important step forward in promoting the responsible and comprehensive dissemination of results of federally-funded research, and should be sufficiently publicized in order to provide a model for other organizations to follow suit. Through rigorous data access policies set forth by the VA, we can increase the availability and use of federally-funded research data to generate new knowledge that will benefit society.