Abstract
A number of developments have made possible and shaped the necessity for a national effort to collect data to monitor and manage the national response to HIV/AIDS: the 2010 National HIV/AIDS Strategy (NHAS), medical advances in the treatment and care of people living with HIV/AIDS (PLWHA), and the evolution of the demography of HIV/AIDS. Since the release of the NHAS in 2010, several federal policy initiatives have significantly affected the environment in which health care organizations, community-based organizations (CBOs), and state and local health departments tasked with identifying and providing care for PLWHA are operating. The Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009 and the Patient Protection and Affordable Care Act (ACA) of 2010 contained provisions mandating and encouraging the use of Electronic Medical Records (EMRs) that altered both the data infrastructure to support the identification and care of PLWHA and the ways in which care is paid for. The provisions of both legislative acts are currently creating a fair amount of uncertainty among grantees of the federal programs that support the identification and treatment of PLWHA. This translates into both rapid and often uncontrolled change in the collection and management of the data that undergirds federal reporting requirements. Equally challenging are the institutional partnerships that will come about as the ACA transforms both Medicaid eligibility and the role of private insurers in caring for PLWHA. In this presentation, I will discuss an evaluation conducted in 2013 by staff from NORC at the University of Chicago and ICPSR at the University of Michigan under contract to the Office of HIV/AIDS and Infectious Disease Policy to understand the current status of the measurement of key HIV/AIDS surveillance and tracking measures and the characteristics of the data infrastructure that supports data collection on these measures.