



Processes and outcomes of developing a continuity of care document for use as a personal health record by people living with HIV/AIDS in New York City

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ABSTRACT

Purpose: To describe the processes and outcomes of developing and implementing a Continuity of Care Document (CCD), *My Health Profile*, as a personal health record for persons living with HIV (PLWH) in an HIV/AIDS Special Needs Plan in New York City.

Methods: Multiple qualitative and quantitative data sources were used to describe the processes and outcomes of implementing *My Health Profile* including focus groups, Audio Computer Assisted Self Interview (ACASI) surveys, administrative databases, chart abstraction, usage logs, and project management records. Qualitative data were thematically analyzed. Quantitative data analytic methods included descriptive and multivariate statistics. Data were triangulated and synthesized using the Reach, Efficacy/Effectiveness, Adoption, Implementation, Maintenance (RE-AIM) Framework.

Results: **Reach** – SNP members are predominantly African American or Hispanic/Latino and about one-third are female. A larger proportion of African Americans and smaller proportions of Hispanics/Latinos and Whites were trained to use *My Health Profile*. **Efficacy/Effectiveness** – CCDs were produced for 8249 unique members and updated on a monthly basis, 509 members were trained to use *My Health Profile*. Total number of member logins for 112 active users was 1808 and the longest duration of use was 1008 days. There were no significant differences between users and non-users of *My Health Profile* in clinical outcomes, perceptions of the quality of medical care, or health service utilization. **Adoption** – *My Health Profile* was well-matched to organizational mission, values, and priorities related to coordination of care for a high-risk population of PLWH. **Implementation** – Pre-implementation focus group participants identified potential barriers to use of *My Health Profile* including functional and computer literacy, privacy and confidentiality concerns, potential reluctance to use technology, and cognitive challenges. Key strategies for addressing barriers included a dedicated bilingual coach for recruitment, training, and

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support; basic computer and *My Health Profile training*; transparent audit trail revealing clinician and case manager access of *My Health Profile*, time-limited passwords for sharing *My Health Profile* with others at the point of need, and emergency access mechanism. **Maintenance** – *My Health Profile* was integrated into routine operational activities and its sustainability is facilitated by its foundation on standards for Health Information Exchange (HIE). Although potential barriers exist to the use of personal health records (PHRs) such as *My Health Profile*, PLWH with complex medical needs, low socioeconomic status, and limited computer experience will use such tools when a sufficient level of user support is provided and privacy and confidentiality concerns are addressed.

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1. Introduction

By the end of 2011 the Centers for Disease Control and Prevention (CDC) estimated that 1.2 million individuals in the U.S. were infected and living with HIV [1]. As in other developed countries, the advent of modern antiretroviral therapy (ART) has resulted in the potential for people living with HIV (PLWH) to alter an almost uniformly progressive and fatal condition when untreated into a chronic medical illness that for many can be well managed and lead to near normal life expectancy [2,3]. Unfortunately, nearly 40% of PLWH are either unengaged in care or poorly engaged in care at any specific point in time [4,5], thereby compromising the ability to benefit from ART and other beneficial medical and care coordination efforts.

New York City is home to the oldest and largest HIV epidemic in the U.S. The current public health response comprises federal, state, and municipal programs each designed to address specific needs of PLWH, including access to care and medications, supportive services, care coordination, and public health surveillance. By 2003, in response to an evolving healthcare environment, the New York State Department of Health AIDS Institute had pioneered the development of HIV Special Needs Plans (SNPs) as a chronic HIV-specific Medicaid managed care plan [6]. SNPs were envisioned as a vehicle to provide complex care coordination and medical services to a population with rates of chemical dependency, mental health disorders, and other complex co-morbidities (Hepatitis C, tobacco use) many fold higher among PLWH than the general population [7,8] and rates of care engagement below that necessary to obtain acceptable health outcomes.

Health Information Technology (HIT) has helped foster improved outcomes in clinical care, care coordination, and public health reporting and may hold promise as a means to improve overall care engagement. Initial HIT advancements have largely focused upon providing tools to clinicians, ancillary staff, and institutions to better manage laboratory reporting, clinical documentation, and medication administration [9–11]. More recently, the potential benefits of utilizing HIT to empower consumers, such as PLWH, to more vigorously participate in healthcare decisions and management have gathered momentum and are now widely seen as critical components of high quality healthcare delivery systems. Indeed, an important HIT objective of Healthy People 2020 focuses upon increasing the proportion of persons who use electronic personal health management tools, specifically the proportion of individuals who use the internet to keep track

of personal health information, such as care received, test results, or upcoming medical appointments [12].

Continuity of Care Records (CCRs) [13] and the subsequent Continuity of Care Document (CCD) [14,15] standard have been widely cited as promising HIT tools designed to promote clinical care coordination across often segregated care sites and provider types through health information exchange (HIE). The initial CCR standard was developed by multiple stakeholders, including ASTM International, the Healthcare Information and Management Systems Society (HIMSS), the Massachusetts Medical Society, the American Academy of Family Physicians, and the American Academy of Pediatrics, as a highly structured, flexible, potentially interoperable health summary standard that was intended to be a ‘snapshot’ of core demographic, clinical, and care team information that could be used and updated during clinical encounters that may occur in the absence of a patient’s full medical record. The CCD standard is the outgrowth of a harmonization effort between ASTM International and Health Level Seven International (HL7) and specifies an implementation of CCR domains according to the semantics of HL7’s XML-based clinical document architecture (CDA) standard to produce a CCD. Ideally, a CCR or CCD could be used by patients to bridge gaps in medical records that exist in disparate sites of care due to the lack of any shared electronic health record (EHR), thereby ensuring that at least an important subset of critical clinical information exists at all points of care. The CCR and CCD standards specify a few required elements (e.g., patient identifying information, payers) and clinically important optional elements (e.g., practitioners, medications, laboratory results, family history). More broadly, CCR/CCD contents can be viewed as a limited form of a Personal Health Record (PHR), although by definition a ‘concise’ form rather than a ‘full’ PHR and without total control of information access by the patient.

The development and deployment of electronic personal health management tools remain in their infancy and a number of high profile examples, such as Microsoft’s *Health Vault* and Google’s *My Health Record*, have recently been scaled back or are under internal review. However, meaningful use objectives for EHRs [16] include providing patients, upon request, with an electronic copy of their health information, an objective that can be facilitated through the development of a PHR based upon CCR/CCD standards. Thus, it is likely that adoption and use of PHRs, particularly those based upon CCR/CCD standards, is likely to expand as organizations and providers attempt to meet meaningful use standards and consumers seek access to their medical records across the care spectrum.

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