









Improving Health Outcomes

Moving Patients Along the HIV Care Continuum and Beyond

JUNE 2017

INTERVENTION OVERVIEW & REPLICATION TIPS

"My Health Profile" Continuity of Care Record Intervention

New York-Presbyterian Hospital

This intervention document is part of a training manual, "Improving Health Outcomes: Moving Patients Along the HIV Care Continuum and Beyond" and is published by the Special Projects of National Significance (SPNS), under the HIV/AIDS Bureau (HAB) of the Health and Human Service's (HHS), Health Resources and Services Administration (HRSA).

The full manual highlights 10 interventions along the HIV Care Continuum. Individual intervention chapters as well as the full manual are available.



Diagnosing HIV



Linkage to Care







Prescription of ART & Medication Access



Beyond the Care Continuum: Addressing HCV Comorbidity and Coinfection







Retention in Care

R etention refers to the ability of a provider or care system to maintain a continuous relationship with a client.

Retention in HIV care is an independent predictor of survival.^{107,108} Mortality rates are 12 times higher for clients with missed visits versus mortality rates among clients who attended all scheduled appointments during the first year of care.¹⁰⁹

In fact,

"Patients with missed visits in the year after establishing initial outpatient HIV care had more than twice the rate of subsequent mortality, compared with patients who did not miss visits, even when controlling for baseline CD4 count and antiretroviral receipt within the first year."

Successful HIV treatment requires sustained engagement in HIV care. HIV: For many people living with HIV, the reality is quite different. Approximately one-third of HIV-infected individuals fail to sustain access to care for three consecutive years. As a result, these individuals do not have consistent access to antiretroviral therapy (ART) or other medical services.

Studies show that clients retained in care are more likely to have better overall health outcomes, including improved CD4 count, suppressed viral load, and fewer hospital admissions/emergency room visits.¹¹⁴

Many of the same strategies that are essential for linkage and re-engagement to care are also relevant for improved retention in care. These can include medical case management, patient navigation, clinic use of peers and peer support groups, flexible clinic hours, culturally responsive and culturally reflective staff,

¹⁰⁷ Mugavero MJ, Lin HY, Willig JH, et al. Missed Visits and Mortality Among Patients Establishing Initial Outpatient HIV Treatment. Clin Infect Dis. 2009;48:248–56.

¹⁰⁸ Giordano TP, Gifford AL, White AC Jr., et al. Retention in Care: A Challenge to Survival with HIV Infection. Clin Infect Dis. 2007;44:143–9.

¹⁰⁹ Mugavero MJ, Lin HY, Willig JH, et al. Missed Visits and Mortality Among Patients Establishing Initial Outpatient HIV Treatment. Clin Infect Dis. 2009;48:248–56.

¹¹⁰ Mugavero MJ, Lin HY, Willig JH, et al. Missed Visits and Mortality Among Patients Establishing Initial Outpatient HIV Treatment. Clin Infect Dis. 2009;48:248–56.

¹¹¹ Giordano TP, Gifford AL, White AC Jr., et al. Retention in Care: A Challenge to Survival with HIV Infection. Clin Infect Dis. 2007;44:143-9.

¹¹² Mugavero MJ, Lin HY, Willig JH, et al. Missed Visits and Mortality Among Patients Establishing Initial Outpatient HIV Treatment. Clin Infect Dis 2009; 48:248–56.

¹¹³ Olatosi BA, Probst JC, Stoskopf CH, Martin AB, Du us WA. Patterns of Engagement in Care by HIV-infected Adults: South Carolina, 2004–2006. AIDS 2009; 23:725–30.

¹¹⁴ Horstmann, E., J. Brown, F. Islam, J. Buck, & B. Agins. Retaining HIV- Infected Patients in Care: Where Are We? Where Do We Go from Here? Clin Infect Dis. 2010; 50: 752–761.

appointment reminders, integrated co-located care, transportation assistance, access to mental health and substance use services, and access to social support services, including stable housing.

Health information technology has also proven valuable in supporting retention efforts, by tracking client care receipt, improving communication across multidisciplinary providers caring for the same client, and for prompting follow up. In their SPNS Electronic Networks of Care initiative grant, New York-Presbyterian (NYP) Hospital was able to illustrate that providing clients access to their medical continuity of care records could increase client autonomy, improve client involvement and interest in their care services, and increase overall retention, even among those clients with very low health literacy.

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INTERVENTIONS AT-A-GLANCE INTERVENTION SUMMARY TABLE



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Social Networks Testing

Wisconsin Department of Health Services

INTERVENTION OVERVIEW & REPLICATION TIPS

Assess, Test, Link: Achieve Success (ATLAS) Program

Care Alliance Health Center (OH)

Enhancing Linkages to Care for Women Leaving Jail

University of Illinois at Chicago

Video Conferencing Intervention

Louisiana Department of Health and Hospitals

Active Referral Intervention

Virginia Department of Health

Louisiana Public Health Information Exchange (LaPHIE)

Louisiana State University, Health Science Center and Louisiana Department of Health Hospitals, Office of Public Health



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Care Coordination Intervention

Virginia Department of Health



Beyond the Care Continuum: Addressing HCV Comorbidity and Coinfection

INTERVENTION OVERVIEW & REPLICATION TIPS

Hepatitis Treatment Expansion Initiative

University of California, San Francisco, San Francisco General Hospital HIV Clinic

Hepatitis Treatment Expansion Initiative

Washington University School of Medicine (MO)

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"My Health Profile" Continuity of Care Record Intervention



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New York-Presbyterian Hospital

The table below provides a general overview of the My Health Profile intervention so readers can assess the necessary steps required for replication. My Health Profile is a patient portal leveraged across a regional health network containing critical health information to improve continuity of care.

Intervention at-a-Glance	
Step 1	Identify What Information the Continuity of Care Record (CCR) will Highlight Work with staff to identify what information is critical to be displayed in the CCR's "snapshot."
Step 2	Engage an Information Technology (IT) Partner Contract with an IT vendor to host the CCR and work with the intervention team to ensure CCR components meet IT standards, and offer interoperability, and multidirectional information-sharing.
Step 3	Identify How Information Will be "Tethered" Evaluate how existing health network and electronic medical record data will be pulled and pre-populated into the CCR.
Step 4	Conduct Focus Groups with Key Stakeholders Engage physicians, case managers, and clients to assess interest in the CCR, address concerns, and solicit input.
Step 5	Provide Coaching and Training Offer CCR and computer (as well as Internet browsing) training to users, particularly clients.
Step 6	Conduct Evaluation Although more robust evaluation like that of a SPNS grant isn't necessary for all organizations, those implementing a CCR will want to establish periodic reviews to ensure the system is working correctly and to assess whether engagement is meeting organizational standards. If not, adjustments may be necessary.

Source: New York-Presbyterian Hospital. New York-Presbyterian/SelectHealth CCR Demonstration Project. Final Report. August 2012.

Diagnosing HIV Linkage to Care



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Resource Assessment Checklist

conduct this work. If organizations do not have these components in place, they are encouraged to develop their capacity so that they can successfully conduct the "My Health Profile" Continuity of Care Record intervention. Questions to consider include: Has your organization surveyed or does it plan to survey the municipality your organization resides in to assess any larger regional or statewide health networks or initiatives in place or planned for the near future? Are the proposed participating medical sites able to share electronic health records? Is your organization able to ensure bi-directional flow between participating medical provider sites and the continuity of care record (CCR)? Has your organization identified or is it able to identify an open-source, non-proprietary software system that can be integrated into the existing health information network and electronic medical system software? If not, is your organization willing to find one or engage a knowledgeable IT consultant to help find one? Does your organization provide direct HIV primary care services or have a very strong and active partnership with an organization that does? ☐ Is your organization able and willing to engage people living with HIV in the development process of your CCR? Has your organization assessed or do you have plans to assess what critical information should be displayed in the CCR "snapshot" of information? ☐ Is your organization able to ensure security of patient health information and, ideally, create an "audit trail" within the CCR to show who has accessed the record? If not, is your organization able to create the necessary security components and audit features to do this work? ☐ Is your organization cognizant of patient health literacy issues and will it be taking that into consideration in the design of the CCR?

Organizations should walk through a Resource Assessment (or Readiness) Checklist to assess their ability to

Source: New York-Presbyterian Hospital. New York-Presbyterian/SelectHealth CCR Demonstration Project. Final Report. August 2012.

Setting the Stage: Grantee Intervention Background

As Dr. Peter Gordon at New York-Presbyterian (NYP) Hospital explains, "Our healthcare system is in many ways hopelessly fragmented with silos of information existing at multiple sites and, in the end, the cost of not having this information flow freely is too great to society and too great at an individual level."

NYP proposed developing a "continuity of care record" (CCR) to bridge this information divide with the goal of facilitating timely, high-quality, and user-centered care that could be easily accessible, comprehensive, and improve clinical outcomes and quality of life.

With funding through the Special Projects of National Significance (SPNS) **Electronic Networks of Care initiative**, NYP was able to develop and test this CCR intervention. At the time this intervention was first proposed and funded, bundling aspects of individual care was a novel idea, but today this concept has moved fairly center-stage as health information technologies have grown more sophisticated and users have become increasingly more comfortable with technology as part of the clinical equation.

Description of Intervention Model



CHALLENGE ACCEPTED

THE CHALLENGE: Silos of information exist across providers and healthcare facilities that can complicate care delivery and create duplications and inefficiencies.

Intervention Model:

Continuity of Care Record Across a Regional Health Information Network

The My Health Profile CCR intervention "tethers to [an] electronic network system, thereby pre-populating important demographic, care coordination, laboratory, medication, and other critical information." Unlike a comprehensive electronic medical record, a CCR isn't exhaustive. Instead, via secure Internet connection, it provides a "snapshot in time" of a client's critical information and allows clients—in addition to providers and case managers—to access this information.

The idea of sharing a snapshot of health information with clients, particularly low-health-literacy, high-need, and sometimes-transient people living with HIV (PLWH), represents an innovative and forward-thinking approach. Because a CCR pulls from existing electronic health records, it ensures information is accurate, timely, and does not require inputting of data into the system; as such, it avoids some of the pitfalls that other forward-facing "patient portals" have encountered in the past.

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¹¹⁵ Gordon, P and RDE Systems. My Health Profile. 2013. Available at: http://ecompas.me.

¹¹⁶ New York-Presbyterian Hospital. New York-Presbyterian/SelectHealth CCR Demonstration Project. Final Report. August 2012. p.1

To establish this intervention there are four primary phases:

- IT development. The first phase consists of activities such as contracting with an IT vendor to host the CCR, making enhancements to the existing IT network, conducting staff recruitment and training, and developing promotional material about the intervention.
- 2. Evaluation and data assessment. The second phase includes assembling local evaluation methodology and ensuring that technology can readily pull necessary data.
- 3. *User testing*. This third phase includes gathering pre-disposing and enabling factors related to the adoption and use of the CCR. This includes conducting focus groups with core users, both providers and clients.
- 4. Evaluation. The fourth phase includes postimplementation surveys every 6 months to both
 CCR adopters and non-adopters to facilitate
 intervention review. For cross-site evaluation,
 audio computer-assisted self-interviewing
 (ACASI) software is immensely useful. In
 addition, an annual comprehensive data
 abstraction of important demographic, clinical,
 and care coordination data took place.

HITECH & Meaningful Use

The Health Information Technology for Economic and Clinical Health (HITECH) Act promotes the adoption and meaningful use of health information technology. *Meaningful use* is using certified electronic health record technology to

- improve quality, safety, efficiency, and reduce health disparities;
- engage and empower patients;
- improve care delivery, transparency, and efficiency;
- maintain privacy and security of patient health information; and, ultimately,
- lead to improved public and patient health outcomes.

Source: HealthIT.gov. Meaningful Use Definition & Objectives. n.d. Available at: www.healthit.gov/providers-professionals/meaningful-use-definition-objectives

Major components of the My Health Profile CCR include the following:

- *Easily accessible*. My Health Profile is mobile-, tablet-, laptop-, and desktop-friendly. Because this password-protected information lives online, clients can access it wherever they are.
- Easy-to-use dashboard. The client dashboard is dynamic. It includes
 - ⇒ a multifunctional tool with the ability to graph clinical information;
 - ⇒ FAQs and an information button with definitions of key words and medications;
 - ⇒ list of current medications; and
 - ⇒ to-do lists, including upcoming appointments.
- Improved communication. Clients can email their provider within the CCR. Similarly, providers can
 view where else clients are accessing care, including any additionally prescribed medications and lab
 work—thereby reducing risk of errors, duplications, and drug-drug interactions.
- Audit trail. The CCR keeps track of everyone who has seen the record, which helps address client
 worries about confidentiality.
- Selected sharing. Clients can offer access to their CCR to an individual of their choosing on a limited basis, which helps offer coherence and engagement in care (e.g., when traveling or getting a new provider up to speed or to show a benefits counselor proof of HIV status to quality for services or if in the ER and wanting to make providers aware of HIV status and existing medications).
- Supports the "blue button initiative." The CCR information can be downloaded and printed at the user's choosing.
- *Supports low-health literacy clients*. The platform was developed with health literacy in mind and tested among target users.

Clients feel empowered with the information they are given. They became more engaged in their care, less timid to ask questions about their HIV or other healthcare issues, and find that proof of HIV status vis-à-vis My Health Profile limited the amount of time necessary to enroll in social support services. One client recalls previously having to call their case manager, request information be mailed to them, deliver it to the housing coordinator, and then wait for the information to be processed. With My Health Profile, the same client was able to ask the housing coordinator if they had Internet access and almost instantaneously bring up their CCR and provide the necessary documentation right on the spot.



Staffing Requirements & Considerations

Based on the NYP work, here are the types of staff necessary to replicate this intervention.

Project coordinator: This individual oversees the project design and continued maintenance. They identify key data points for presentation in the CCR, assess existing regional or other available electronic health networks, and provide support to coaches and intervention evaluator.

Staffing

Project evaluator: The project evaluator works with the intervention team to create an evaluation methodology. This individual manages any cross-site evaluation efforts as well as assessment of pre-disposing enabling factors related to adoption and use of the CCR as well as post-implementation surveys and data abstraction.

IT vendor/contractor: Oversees build of multi-directional data system. Ensures information is pulling from care site electronic health systems and pre-populating into the CCR in real-time. Builds and tests CCR to meet industry standards.

Coach: The coach provides training to CCR users, particularly clients. These trainings cover basic computer skills, safe Internet browsing practices, discussions of where the CCR can be accessed, the role of the CCR, and how to log in and use the CCR.

Additional staff, such as clinicians, nurses, and case managers participate in focus group activities and use the CCR as part of clinic operations.

Staff **Characteristics**

- Experience with, and understanding of, surveillance data and qualityassurance strategies.
- Knowledge of the existing electronic medical record system and integration of health information technology systems, to facilitate bi-directional communication.
- Interest in working with and improving health outcomes for people living with HIV.

Sources: New York-Presbyterian Hospital. New York-Presbyterian/SelectHealth CCR Demonstration Project. Final Report. August 2012.

Replication Tips for Intervention Procedures and Client Engagement

This section provides tips for readers interested in replicating the intervention and, where applicable, includes grantee examples for further context.

Identifying Technology Needs and Developing IT Support

In doing this work, it is critical to adopt interoperable national health information network standards. Organizations will likely need to enlist an IT contractor to help implement the CCR into current standards and the current electronic health record while keeping in mind that health information technology (HIT) is a fast-evolving field and nimbleness of design is of equal importance.

To limit expenditures and possible challenges down the line, NYP purposefully chose to avoid proprietary/commercial software or any design that could interfere with how their electronic health record system was constructed.

In establishing the CCR, developers need to be clear on how the electronic network system is integrated and what information is being pulled in to populate the CCR profile. For example, is there currently a regional health information network (RHIO) where your organization is located? If so, what organizations are connected to the RHIO (e.g., hospitals and medical clinics, pharmacy database, claims database) where information could be pulled from and displayed? Equally important to *what's* being displayed is *how* it is being displayed.

Implementers should also review "standard Internet access." Don't assume a challenge for clients is Internet access. Survey users and potential users. They may be quite savvy in knowing where community resources exist, including where they can access computers for free (e.g., libraries, CBOs). Consider creating a list of computer access points, such as libraries and coffee shops, open to the general public. Provide this list during all CCR trainings.

Providing Trainings

Recruit and train staff and "coaches." Provide targeted "coaching" so that prospective users receive training not only in the CCR application but also in safe Web browsing techniques and basic computer literacy. As NYP describes,

"An important 'first principle' when contemplating population level health information technology interventions [is] to ensure that adequate resources are targeted for human capital that can be deployed to educate, coach, and support potential adopters and users of a specific HIT application."

¹¹⁷ New York-Presbyterian Hospital. New York-Presbyterian/SelectHealth CCR Demonstration Project. Final Report. August 2012. p.7-8.

Enlisting the Target Audience

It is important to identify providers within the regional health network, including primary care providers, subspecialists, case management agencies, skilled nursing facilities, and participating hospitals. Then, conduct focus groups with these key personnel. For example, NYP held five focus groups to solicit input, concerns, and desired uses and displays. They found that the addition of an "audit trail" (more specifically, a screen that allowed clients to see who has accessed their record) allayed client concerns over potentially compromised privacy and confidentiality.

When the CCR prototype is developed, have clients, care coordinators, and clinicians review and evaluate it. Keep in mind that not every "bell and whistle" needs to be included—sometimes a more stripped-down version is easier to use and actually increases functionality among users.

The My Health Profile intervention demonstrates that clients with HIV—including those with low health literacy—will adopt and use a CCR as a personal health record at comparable rates to those of more affluent and more educated populations. The intervention is also able to show that, through access to a CCR, clients

- develop increased understanding of their HIV disease and medications;
- develop greater autonomy;
- have improved retention in care;
- demonstrate a relatively high level of trust in providers; and
- are largely supportive of efforts to share protected and sensitive health information via electronic information networks when security and privacy concerns are adequately addressed.¹²⁰

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By providing a more comprehensive view of client engagement in the healthcare system, the intervention improves provider-to-provider and provider-to-client communication and reduces duplicative services. The My Health Profile intervention model also informs clinical and care coordination information needs of case managers too. ^{121,122} Given that case managers represent a critical group in client care yet are often overlooked when clinical information-sharing policies are discussed or implemented, this is an important quality of the intervention. Altogether, these lead to improved quality and coordination of care as well as decreased costs, enabling providers to focus on more pressing client issues. Clients are more engaged in care and subsequently better retained in care.

¹¹⁸ New York-Presbyterian Hospital. New York-Presbyterian/SelectHealth CCR Demonstration Project. Final Report. August 2012.

¹¹⁹ Gordon P. My Health Profile. New York State Patient Portal Challenge. NY eHealth Collaborative (NYeC) Public Forum. 2013.

¹²⁰ New York-Presbyterian Hospital. New York-Presbyterian/SelectHealth CCR Demonstration Project. Final Report. August 2012.

¹²¹ New York-Presbyterian Hospital. New York-Presbyterian/SelectHealth CCR Demonstration Project. Final Report. August 2012.

¹²² Camhi E. New York State Department of Health AIDS Institute. "Health Information Technology: Consumer Engagement and Education." Quality of Care Consumer Advisory Committee Meeting, June 8, 2011.

Securing Buy-in

To secure buy-in, clearly outline project plans and processes. Invest time and research into IT standards and ensure the proposed intervention fits within existing health information system and electronic medical records. Provide information about the CCR intervention through meetings with stakeholders across the regional health network, as well as focus groups with target users, assess their perceptions on ease of use and usefulness, and make modifications along the way.

Overcoming Implementation Challenges

To address low client computer skills, enlist "coaches" who are responsible for training clients to use the CCR and on basic computer skills. This can lead to increased autonomy in client care. For example, at NYP, clients have gone from not knowing how to open up a browser to feeling confident to research their HIV, side effects, and medications, and feel empowered to bring up questions to their providers. For many clients, the myriad medical appointments they attend are, in fact, "siloed." Seeing a snapshot of all of their critical health information in one place gives them a better understanding of how it all fits together.

NYP initially hypothesized that clinicians, followed by case managers, would be the most likely to adopt the CCR, while clients would be least likely/hardest to adopt the CCR. What NYP found was, in fact, the opposite. Clients proved most likely to adopt, followed by case managers. Clinicians adopted the system but required some education to curtail the assumption that the system created more work for them on a daily basis. ¹²³ As such, organizations should be proactive in educating all stakeholders who would come into contact with the CCR and address any misperceptions early on.

NYP experienced some system restructuring. In an effort to avoid the possibility of an interruption of the NYP electronic information network upon which the CCR relied to obtain its data, the NYP intervention team met with a regional health information exchange organization to assess the possibility of tethering the CCR to this evolving exchange. This was possible *only* because the CCR application is built to IT standards that are intended to facilitate interoperability in the fast-changing world of HIT. This underscores a critical lesson that HIT applications need to fit within both current HIT standards and keep in mind the evolving nature of the field so that they, too, can evolve as technology or circumstance demand.¹²⁴

Promoting Sustainability

With e-scripts and the influence of meaningful use criteria requiring that organizations begin to extend personal health profiles, coupled with the increasing number of medical facilities and institutions that have electronic health record systems, the environment is ripe for My Health Profile-style functionality and replication of similar models.

¹²³ New York-Presbyterian Hospital. New York-Presbyterian/SelectHealth CCR Demonstration Project. Final Report. August 2012.

¹²⁴ New York-Presbyterian Hospital. New York-Presbyterian/SelectHealth CCR Demonstration Project. Final Report. August 2012.

The My Health Profile CCR demonstrates that personal health records integrated with health information exchanges are an ideal mechanism to ensure that essential and actionable information is available at the *right time* and the *right place* for clinical care and decision-making and for data quality management. ¹²⁵ As of the publication of this manual, the My Health Profile intervention is influencing the design and efforts across the state of New York to connect individuals to their medical records.

Conclusion

As the My Health Profile intervention team explains:

"People living with HIV, and other safety-net populations, uniquely benefit from direct access to their personal health information as associated barriers regarding access to care, housing instability, and an often revolving door of health care providers, fragment their health care delivery system." 126

If organizations are willing to take into consideration client health literacy and ease-of-use in the CCR design, provide coaching to users (particularly older clients), and have an existing electronic health network with which to tap into and tether the CCR, this work is certainly feasible to improve care coordination and client retention in HIV primary care.

Other Available Resources

- Electronic Networks of Care Initiative
- My Health Profile
- Gordon P, Camhi E, Hesse R, et al. 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
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- Schnall R, Smith AB, Sikka M, et al. Employing the FITT Framework to Explore HIV Case Managers'
 Perceptions of Two Electronic Clinical Data (ECD) Summary Systems. International Journal of Med
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 Influencing the Use of a Continuity of Care Document in Special Needs PLWH. J Health Care Poor
 Underserved. 2012. 23(4):1457–76.

¹²⁵ Camhi E, Thomas J, Gordon P. Promoting Consumer Access to the EMR to Improve Quality of Care and Data Reporting. Health Resources and Services Administration, HIV/AIDS Bureau All-Grantee Meeting. Conference Presentation. November 28, 2012.

¹²⁶ Camhi E, Thomas J, Gordon P. Promoting Consumer Access to the EMR to Improve Quality of Care and Data Reporting. Health Resources and Services Administration, HIV/AIDS Bureau All-Grantee Meeting. Conference Presentation. November 28, 2012.