



HIV Continuum of
Care Collaborative

Change Package

If you had the tools to put an end to HIV and AIDS, would you use them? Are you surprised to learn that 945 people with an HIV diagnosis in BC have never accessed care, 2,156 are not coming back for care regularly, and 5,113 are not achieving treatment goals that can help them be healthy and live longer?¹

Our current systems of care are not working to optimize the health of all those in British Columbia who are living with HIV. Together, we can make improvements across the Continuum of Care and improve the lives of those we serve.

But what changes can we make that will result in improvement? This Change Package is a compilation of many ideas for change. It is designed to prompt your thinking and accelerate your team's ability to make improvements within your own context.



Using this document

This document includes ideas for improvement and change that are organized by the key domains of the cascade. They have been grouped into 3 sections:

1. Testing, diagnosis and linkage
2. Engagement in care and support
3. Treatment, adherence and suppression



Test ideas of interest in your own system using the PDSA method described in the **Preparation Resource Manual 2.0**. If we each do our part, collectively we can make a substantial difference to improve care for those with HIV!

¹ HIV Monitoring Quarterly Report for British Columbia, third quarter 2013. Indicator 5. Estimated Cascade of Care for BC. Available online at: <http://stophiv aids.ca/iv-monitoring-quarterly-reports-third-quarter-2013/>.

Aim Focus 1: Testing, Diagnosis and Linkage

a) Testing and Diagnosis

An estimated 10% of individuals in British Columbia may be unaware they are living with HIV. This leads to delayed care, increased illness burden, and even death. Individuals unaware of their infection may also unknowingly transmit the infection to others. Reducing barriers to testing helps people to become aware of their status.

Organizations may choose to offer testing to more patients, expand testing sites, or make systems to test high-risk patients more reliable. Measurement of your current testing practices



and volume compared to the testing practices and volume at the end of the Collaborative will give you a good sense of whether the changes made a difference. See the **Guide to measurement** for suggested measures.

Changes to try

1. Providers should offer HIV testing for all patients (provider-initiated)
2. HIV Testing should be offered at the client's request (client-initiated)
3. Informed consent should be obtained, but in BC written consent is not required nor recommended
4. Pre- and post-testing process should be followed as per standard guidelines
5. Consider expanded testing for high risk populations
6. Offer POC testing in high risk settings (e.g., bath houses, STI clinics)
7. Consider advocating HIV testing with social media for MSM populations
8. Provide support and empathy throughout the testing processes
9. Ensure testing is offered in culturally sensitive, non-judgmental manner
10. Arrange for follow-up assessment and treatment for HIV
 - a. Offer options that align with client preferences (Altum, 2013)
 - b. Arrange for accompaniment if desired
 - c. Arrange for interim support as needed
11. Offer voluntary partner counseling and referral services

b) Linkage to Care

Of those diagnosed with HIV in British Columbia, 945 have not linked to care. Now, we believe that some of these people tested anonymously and may be linked already. That's good! However, we do know that some of these people will not have ever had an HIV-related visit with a physician, had treatment dispensed, or had standard clinical monitoring (i.e., plasma viral load test, CD4). We also know that among those diagnosed, there are disparities in the rates of linkage to care by region and female gender, younger ages and those for whom the risk factors are unknown are at higher risk across the province.²



Improvements in linkage to care can be monitored by numbers of patients successfully linked to care. Processes at the organizational level can also be assessed. See the **Guide to Measurement** for suggested measures.

Changes to try

The approach to linkage will differ depending on whether your organization provides only testing, or rather, provides HIV care. Regardless, patients newly diagnosed with HIV benefit from additional support and having someone they can trust.

1. Provide strengths-based case management support at diagnosis (Gardner, 2005; Li 2008; IAPAC)
 - a. Identify socially marginalized populations and provide targeted support to reduce discrimination, stigma, and barriers to HIV care linkage
 - b. Provide intensive youth-focused case management for adolescents and young adults to improve entry into and retention in care (adapted IAPAC)
2. Create standardized and varied options for linkage to care that respect patient preferences
 - a. Ready access: every door is the right door
 - b. Use evidence-based engagement skills in all programs that link to care
3. Monitor successful entry into care for all individuals diagnosed with HIV (IAPAC)
 - a. Create and manage information systems to track important care processes in linkage to care (Barr, 2003)

² With data from the HIV Quarterly Monitoring Report for British Columbia, Third Quarter 2013. Available at: http://stophivaids.ca/WP/wp-content/uploads/2013/10/monitoring_reports/third_quarter_2013/BC-Monitoring-Report-2013Q3-FINAL-Dec-6.pdf

- b. Emphasize building of trust and relationships
4. Support completion of initial HIV medical care visit
 - a. Consider intensive outreach for individuals not engaged in medical care within 6 months of diagnosis (Mugavero, 2009)
 - b. Facilitate access and initial appointments for HIV care by standardizing processes and providing clearly defined options for care
 - c. Consider using peer or paraprofessional care navigators
 - d. Offer accompaniment as desired
 - e. Assess and eliminate policy barriers (Barr et al., 2003)
 - i. Expand hours to include evenings and or Saturday hours
 5. Scan community data sources to identify and connect services to people that are currently unknown to you
 - a. Partner with community public health nurses and local Medical Health Officers
 - b. Review regional data on how many people are diagnosed with HIV in your region but not yet linked to care
 - c. Connect with community AIDS services organizations

Aim Focus 2: Engagement in Care and Support

a) Engagement in Care and Support

Even when linked to care, a significant number of patients (over 14%!) do not engage in ongoing care for a variety of reasons. Patients are especially vulnerable during that period just following diagnosis and benefit from the support of a trusting relationship.

For patients who engage in care initially, retention in care is not guaranteed. System issues such as inconvenient access, a bad patient experience, lack of cultural sensitivity, and lack of systematic follow-up can contribute. Patient-centric issues such as addictions, mental health issues, and social determinants of health may also interfere with ongoing engagement.



Engagement in care can be monitored by tracking visit frequency, participation in clinical monitoring, uptake of ART, and as well as immunization and screening status. See the **Guide to Measurement** for suggested measures.

Changes to try

Make a great first impression! Success in early engagement in HIV care has a significant impact on future health outcomes.

- 1) Make the first medical visit a good one
 - a) Look for and eliminated policy barriers that may deter engagement (Barr et al., 2003)
 - b) Use patient navigators and peer support during initial visit
 - c) Allow sufficient time for the initial visit
 - d) Host a new patient orientation “Meet and Greet” to welcome new patients and help them understand available services
 - e) Establish a patient advisory board and/or gather feedback from each patient’s first visit



“Rather than coming in with an area you’d like to focus on, have the patient help determine what is the most important is the first step for their care”

- 2) Use evidence-based engagement skills that emphasize compassion, empathy, and respect
 - a) Use techniques such as teach back or ask-tell-ask to deliver information respectfully

- 3) Look for and eliminated systems or policy barriers that make engagement difficult (Barr et al., 2003)
- 4) Regularly assess patient experience and act on the data
- 5) Provide patient-centric care
 - a) Maintain ready access to support and information, including after hours (e.g., handouts, self-care apps, key website resources, etc.)
 - b) Reduce fragmentation by coordinating multiple services and appointments (e.g., pair physician and pharmacy appointments for patient convenience)
 - c) Promote easy access to care (e.g., walk-in welcome, evenings available, Saturday hours)



“When I go to do bloodwork and go back for results, I keep my doctor and pharmacy appointment at pretty much the same time to avoid numerous trips. Sounds simple, but you’d be amazed how many people don’t do this, or have the option.”

- 6) Use information systems to better understand retention and respond proactively
 - a) Use registry functionality to monitor retention (adapted IAPAC, Barr et al. 2003)
 - b) Standardize procedures for follow-up of missed appointments
 - c) Standardize outreach to patients not seen in 180 days or at provider discretion
 - d) Provide high acuity and at risk patients with case management services
- 7) Support patients between visits
 - a) Ensure all patients know who to contact with questions and after hours
 - b) Link patients with reliable sources of information
 - c) Link patients with appropriate community organizations
 - d) Encourage self-management goal setting and follow-up



“We have many ASOs across the province that offer a plethora of services to improve the lives of PHAs, having ready, available resources to link patients to. This not only will give them the help they need but also is more likely to keep them engaged, at least in some type of care.”

- 8) Emphasize trusting relationships and respect for patient priorities in care provision
 - a) Pacing – respect where people are and what they can do
 - b) Engage the patient in determining what goals and most important first steps

- c) Provide cultural safety
 - d) Ensure confidentiality; extra care may be needed in rural communities
 - e) Utilize patient engagement strategies including shared decision making (Altum, 2013)
 - f) Ask 'how are you doing?' before reviewing clinical data
- 9) Use reminders to promote appointment attendance
- a) Text message for adult and youth patients to remind of upcoming appointments
 - b) Personal phone call reminders
 - c) Use consistent and positive messaging to reinforce kept appointments
 - d) Incorporate patient preferences into reminder strategy
- 10) Support patients who struggle with engagement in care
- a) Consider nurse or counselor-based care in under-resourced settings (adapted IAPAC)
 - b) Work with community organizations that can support shared goals
 - i) Link to enhanced outreach efforts that involve more in depth community approach
 - ii) Identify barriers to retention and engage client in creation of strategies to overcome
 - iii) Offer bus passes or taxi vouchers
 - iv) Liaise with Patient navigator program
 - c) Address mental health, addiction and social determinants of health if these are barriers to continuous engagement in care (adapted IAPAC)
 - d) Use pediatric and adolescent-focused therapeutic support interventions using problem solving approaches and that address psychosocial context (adapted IAPAC)
- 11) Provide multidisciplinary education and counseling intervention approaches (adapted IAPAC)
- a) Provide linkages to community as appropriate
 - i) Create formal partnerships with discharge planners to improve linkage to follow-up
 - ii) Create formal agreements with Department of Corrections to facilitate follow-up care
 - iii) Meet with incarcerated patients to advocate for ongoing care and facilitate the transition to clinic-based care

- b) Ensure access to high quality information about evidence-based HIV care
- 12) Ensure each patient has a most responsible provider to organize and coordinate care
- a) Map out organizations/care providers with whom you frequently share care
 - b) Define who does what and when including care elements and after hours contact
 - c) Create standard procedures for scheduling care, sharing information, and sharing care
- 13) Create standardized policies/procedures to manage common care transitions
- a) List/map frequent care transitions for your patients (e.g., hospital to home, hospital to skilled nursing, corrections to home, home health to routine ambulatory care, etc.)
 - b) Monitor transitions for reliability and safety (resources and tools available:
<http://www.ntocc.org/>; <http://www.caretransitions.org/>;
<http://www.bu.edu/fammed/projectred/>;
<http://www.ihl.org/offerings/Initiatives/PastStrategicInitiatives/STAAR/Pages/default.aspx>
 - c) Ensure mutual accountability of each party involved in a transition (NQF adaptation)
- 14) One patient, one care plan: All care organized in a single plan, shared with everyone
- a) Create, document, execute and update a plan of care with every patient (adapted NQF National Voluntary Consensus Standards for Care Coordination)
 - b) Include patient preferences in the care plan (Altum, 2013)
 - c) Provide support for self-management (Adapted NQF)

Aim Focus 3: Treatment, Adherence and Suppression

Does it surprise you that 2,733 people living with HIV are not on the very treatment that can improve their health, save their lives, and help them protect their partners?

ART is recommended for almost everyone, with very few exceptions (exceptions include >1% of the HIV-positive population that are able to control their infection without ART and individuals that decline treatment). Often health system issues and patient-centric issues create barriers to treatment access and uptake.

To ensure that patients in our care have attractive treatment options, we must understand for whom we are accountable and then evaluate the percentage of those taking ART. Start by



developing a measurement system to understand which clients are on treatment. The few clients that are not on treatment should have a plan or rationale for not being on treatment. See the **Guide to Measurement** for suggested measures.

Changes to try

The gap between who is on ART and who would benefit is complicated to close and requires evaluation of systems issues; issues relating to the care team as well as patient issues. Examples of system issues are poor access, lack of systematic monitoring of care delivery, or the inability to provide all needed care due to inventory or other barriers such as overscheduling. Commonly encountered health team issues include lack of awareness of current evidence-based guidelines, conscious or unconscious biases about important care, lack of support staff to support comprehensive care, and lack of appropriate communication skills to fully educate patients about the importance of ART. Patients may refuse care or have difficulty following through with recommended care for a variety of reasons.

1. Monitor ART status for all HIV patients in your care.
2. Ensure the care team is trained on current evidence-based guidelines that advocate ART for all patients with HIV with rare exceptions (refer to HIV primary care guidelines: <http://cfenet.ubc.ca/therapeutic-guidelines/primary-care>)
 - a. Decision support tools for the practice
 - b. Ongoing educational support for care teams
 - c. Make HIV consult expertise available by referral or telehealth
3. Optimize ART regimens for ease of use and to decrease side effects
 - a. Among regimens of similar efficacy and tolerability, once-daily regimen are recommended for treatment naïve patients beginning ART (IAPAC)

- b. Switching treatment-experienced patients receiving complex or poorly tolerated regimens to once-daily dosing is recommended, given regimens with equivalent efficacy (IAPAC)
 - c. Among regimens of equal efficacy and safety, fixed-dose combinations are recommended to decrease pill burden (IAPAC)
 - d. Develop protocols and standardization of key care guidelines
4. Support patients with information about ARTs in a respectful way
- a. Individual one-on-one ART education is recommended (IAPAC)
 - b. Group education and group counseling that is effective for your patient population is recommended (adapted IAPAC)
 - c. Multidisciplinary education and counseling intervention approaches are recommended (IAPAC)
 - d. Offering peer support may be considered (IAPAC)
 - e. Use shared decision making as appropriate
 - f. Use patient-centric methods of giving information (e.g., Ask-Tell-Ask, Teach Back)

b) Adherence

Ideally, every patient would have the support they need to follow an evidence-based care plan that reflects their preferences and values. But since patients ultimately decide what they will do, we need to partner with them to provide culturally sensitive self-management support that will enhance adherence to the care plan including taking ARTs as recommended.

Our current systems are not working for 2,345 people who are not adhering to treatments that can improve their health, save their lives, and help them protect their partners.



To improve adherence, we must understand which of our clients experience challenges and barriers to adherence. See the **Guide to Measurement** for suggested measures.

Changes to try

Care for HIV is complex and adhering to the care plan can be daunting even under the best of circumstances. These changes include both those relating to creating the care plan with patients as well as additional supports needed for subsets of patients to change behaviors that impact care or to improve the reliability of them being able to follow their care plan.

1. Simplify ART regimens as appropriate to improve adherence
 - a. Among regimens of similar efficacy and tolerability, once-daily regimen are recommended for treatment naïve patients beginning ART (IAPAC)
 - b. Switching treatment-experienced patients receiving complex or poorly tolerated regimens to once-daily dosing is recommended, given regimens with equivalent efficacy (IAPAC)
 - c. Among regimens of equal efficacy and safety, fixed-dose combinations are recommended to decrease pill burden (IAPAC)
2. Provide appropriate education about the importance of adherence
 - a. Provide education and counseling using specific adherence-related tools (IAPAC)
 - b. Individual one-on one ART education is recommended (IAPAC)
 - c. Providing one-on-one adherence support to patients through one or more adherence counseling approaches is recommended (IAPAC)
 - d. Group education and group counseling that is effective for your patient population is recommended (adapted IAPAC)
 - e. Target PMTCT treatment including HIV testing and serostatus awareness to improve adherence to ART for PMTCT
3. Engage patients in options relating to ART
 - a. Respect for patient preferences
 - b. Shared decision making for treatment options
4. Monitor self-reported adherence [over the few days to one week] routinely (adapted IAPAC)
 - a. Use pharmacy refill data to monitor adherence when medication refills are not automatic (adapted IAPAC)
 - b. Assays of drug concentrations in biological samples, pill counts, routine DAART or EDMs are NOT recommended

5. Offer additional adherence support depending on need
 - a. Offer reminder devices and interactive communication technologies as adherence tools (adapted IAPAC)
 - b. Multidisciplinary education and counseling intervention approaches are recommended (IAPAC) (e.g., multidisciplinary case conferences)
 - c. Offering peer support may be considered (IAPAC)
 - d. Interventions providing case management services and resources to address food insecurity, housing and transportation needs are recommended
 - e. Consider integration of medication management services into pharmacy settings
 - f. Offer buprenorphine or methadone to opioid-dependent patients
 - g. Maximally Assisted Therapy / Daily Observed Therapy (MAT/DOT) is recommended for individuals with substance abuse disorders
 - h. Integration of MAT/DOT into methadone maintenance treatment for opioid-dependent patients is recommended
 - i. Screening, management, and treatment for depression and other mental illnesses in combination with adherence counseling are recommended.
 - j. MAT/DOT is recommended during incarceration and may be considered upon release to the community
 - k. Case management is recommended to mitigate multiple adherence barriers in the homeless
 - l. Pillbox organizers are recommended for persons who are homeless
 - m. MAT/DOT improves short-term treatment outcomes and may be considered in pediatric and adolescent patients
 - n. There is growing evidence related to the role of contingency management (incentives) to improve adherence

c) Suppression

Ideally, patients who are receiving regular care will have been offered appropriate ART with resultant suppression of viral load. Whether at the provincial or organizational level, our goal is that every person receiving ongoing care for HIV has an undetectable viral load. Current data indicates that 5,113 HIV-positive people in BC, around 50%, are not achieving this goal.

At the organizational level, teams can monitor the last plasma viral load (pVL) for each patient.



Patients should be monitored with these tests at least every 6 months and values should be less than 200 copies/ml (threshold determined by the current sensitivity test). See the **Guide to measurement** for suggested measures.

Changes to try

Poor engagement, lack of or limited psychosocial supports, unrecognized adherence issues, drug interaction (complementary, herbal as well as pharmaceutical preparations), taking medications incorrectly or inadequate dosing as well as evolving drug resistance may play a role in patients who are not suppressed despite regular care. For this section, we will also focus on those patients in our care who are NOT suppressed so that they achieve viral load suppression.

For those NOT suppressed:

- 1) Re-evaluate adherence in non-judgmental manner; refer the prior section on adherence if an adherence issue is discovered
- 2) Evaluate clinical rationale for inadequate suppression: viral resistance studies, reassessment of all medications looking for adequate dosing, potential drug interactions
 - a) Consider a pharmaceutical evaluation for demonstration of how meds taken, appropriateness of regimen and to search for interactions
 - b) Standardize protocols for evaluation of resistance and ART regimen changes
- 3) Support clinicians to make clinical decisions in challenging situations
 - a) Telehealth linkages for advice to make changes in complex regimen
 - b) Pharmacy support services available
 - c) Consultation with HIV experts

For those currently suppressed:

- 4) Continued monitoring of engagement in care and key biomarkers
- 5) Anticipate challenges and proactively provide support
- 6) Bolster support networks to provide ongoing whole-person needs of individuals
- 7) Regularly assess patient experience and act on the data

References & Resources

- Altum S, Koloroutis M. Using Engagement Techniques to Partner With Patients, Improve Care. *Case in Point*. 2013; 11(7). Available online: http://www.chcm.com/wp-content/uploads/2013/06/CaseInPoint_reprint_0713_PatientEngagement_Altum_Koloroutis.pdf
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