Towards an integrated primary and secondary HIV prevention continuum for the United States: a cyclical process model

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Abstract

Introduction: Every new HIV infection is preventable and every HIV-related death is avoidable. As many jurisdictions around the world endeavour to end HIV as an epidemic, missed HIV prevention and treatment opportunities must be regarded as public health emergencies, and efforts to quickly fill gaps in service provision for all people living with and vulnerable to HIV infection must be prioritized.

Discussion: We present a novel, comprehensive, primary and secondary HIV prevention continuum model for the United States as a conceptual framework to identify key steps in reducing HIV incidence and improving health outcomes among those vulnerable to, as well as those living with, HIV infection. We further discuss potential approaches to address gaps in data required for programme planning, implementation and evaluation across the elements of the HIV prevention continuum.

Conclusions: Our model conceptualizes opportunities to monitor and quantify primary HIV prevention efforts and, importantly, illustrates the interplay between an outcomes-oriented primary HIV prevention process and the HIV care continuum to move aggressively forward in reaching ambitious reductions in HIV incidence. To optimize the utility of this outcomes-oriented HIV prevention continuum, a key gap to be addressed includes the creation and increased coordination of data relevant to HIV prevention across sectors.

Keywords: HIV; prevention; continuum; PrEP; process model; cycle; testing.

Introduction

The HIV care continuum has become a highly visual, accessible and reproducible model to improve health outcomes and minimize transmission risk among those living with the virus [1]. Viral load suppression is viewed not only as the continuum’s central outcome to minimize individual morbidity and mortality, but also as a key intervention for secondary HIV prevention, given that viral suppression reduces the risk of HIV transmission [2]. Reducing the risk of HIV acquisition among those not already infected and vulnerable to HIV exposure is equally essential.

An HIV prevention continuum, like the care continuum, is potentially valuable to identify opportunities at key steps in an HIV incidence- and health outcomes-oriented process. Such a model affords the opportunity to: 1) define best biomedical, behavioural and ancillary support practices, including those that foster integration of HIV prevention with broader primary care, wellness promotion and sexual and reproductive health services; 2) further articulate and refine the metrics of success; 3) identify gaps in provider/intervention access and utilization; 4) inform the allocation of human and financial resources; 5) establish implementation science priorities; and 6) generate and support advocacy for the highest impact HIV prevention activities.

Primary HIV prevention continua and similar heuristics have been developed by others. These include a generalized, population-based approach [3]; an infection cascade and prevention pathways model [4]; and pre-exposure prophylaxis (PrEP) and other intervention-specific cascades [5–7]. Proposed models are not without limitations, however. Most fundamentally, unlike engagement in specialized care and antiretroviral therapy after an HIV diagnosis, initiation of a particular intervention following an HIV-negative diagnosis is neither routine nor straightforward. HIV prevention needs and options are not universal or static because of individual and intrapopulation variability and temporal fluctuations in risk. Additionally, few proposed models address congruity with the HIV care continuum. A heuristic device illustrating the importance of both primary and secondary HIV prevention may prove useful in further influencing HIV incidence.

Recognizing inherent challenges, we present a novel continuum model for the United States as a conceptual framework for addressing individualized primary HIV prevention needs to achieve population-level reductions in HIV acquisition risk and to illustrate the critical link between a comprehensive primary prevention process and the care continuum to further improve health outcomes and minimize transmission risk among those who are infected with HIV. To bolster stakeholder
interest in this model, particularly among U.S. public health departments, we discuss potential approaches to address gaps in data required for programme planning, implementation, and evaluation across the elements of the primary HIV prevention continuum.

Discussion

Our model, shown in Figure 1, configures the primary HIV prevention continuum as a cycle, recognizing that the primary goal of remaining HIV negative, confirmed by repeat testing, is not a static process but rather a dynamic one, dependent on population, network and individual fluctuations in biomedical and supportive care needs over time. For example, not all HIV-negative gay, bisexual and other men who have sex with men will necessarily benefit from the HIV protection afforded by PrEP, including some men in sexually exclusive relationships and men who use condoms consistently and effectively. Even among those for whom PrEP is indicated and desired, utilization may be limited due to transient periods of risk.

A unique feature of the proposed model is a depiction of the link between the primary HIV prevention continuum and the HIV care continuum and the critical interplay of both in maximizing health outcomes and minimizing ongoing spread of the virus. For example, an HIV-negative individual who seroconverts while engaged in a prevention programme featuring regular HIV testing may quickly be linked to and engaged in HIV care and, thereby, benefit from early anti-retroviral therapy, including reduction in further onward HIV transmission.

HIV testing and retesting

HIV testing is the entry point in the HIV prevention cycle, as it generally provides a critical point of contact with the healthcare and service delivery systems for individuals who are HIV negative but are vulnerable to the infection, as well as being a gateway to treatment for people diagnosed with HIV infection. The cycle is repeated for as long as an individual remains at risk for HIV acquisition. In effect, 100% of people at risk for HIV infection who test seronegative at the beginning and end of one cycle should re-enter the cycle and be retested at least annually [8–10], coupled with regular HIV prevention risk and needs assessments to determine linkage and intervention needs.

Risk and needs assessment

As part of a comprehensive prevention strategy, following a negative HIV test, people vulnerable to HIV infection should receive risk and needs assessments. These can best ensure linkage to medical and other service providers capable of providing or coordinating evidence-based interventions and social services appropriate for that individual. The cyclical framework of our model, with HIV retesting as a central indicator, allows for repeated risk and needs assessments to meet an individual’s changing HIV prevention requirements.

For those testing for HIV in acute care (e.g. emergency departments) or non-healthcare settings (e.g. community-based organizations (CBOs)), minimum assessments may include knowledge of and eligibility for a range of risk-reduction strategies, including PrEP, in accordance with U.S. Centers for Disease Control and Prevention (CDC) recommendations, and healthcare provider and insurance status navigation needs [11]. For vulnerable individuals testing for HIV in healthcare settings, or having been referred for HIV prevention services by an acute care or non-healthcare testing site, possible assessments include the following: screenings for sexually transmitted infections, mental health disorders, substance abuse, intimate partner violence and trauma; adequacy of health insurance to cover necessary prevention services; and other primary or specialty care needs [12,13].

The development of simple risk and needs assessment instruments, including online self-assessment and navigation tools, to help maximize linkage to and engagement in HIV care.

![Diagram of HIV prevention processes](image)

Figure 1. Comprehensive HIV prevention processes. Conceptual framework illustrating the interplay between processes to halt both the acquisition and transmission of HIV. The primary HIV prevention cycle, left, begins with HIV testing. Risk and needs assessments, linkage to services, engagement in risk-reduction prevention interventions and HIV testing are repeated for as long as an individual remains at risk for HIV acquisition.
prevention services while minimizing the added burden to providers and systems should be an implementation priority.

**Linkage to prevention services**
For individuals tested for HIV and having undergone comprehensive risk and needs assessments in primary care settings, linkage may include referrals to specialized medical, mental health and substance abuse services and CBO-provided psychosocial and ancillary services (e.g. housing, employment, nutritional and social support) [12,13]. For individuals tested for HIV and having undergone basic risk assessments in acute and non-healthcare settings, linkage to culturally sensitive medical and other service providers with knowledge and experience providing or coordinating various primary HIV prevention interventions is essential [11]. These may include providers in primary care settings; reproductive, sexual, transgender or other community health programmes (including PrEP clinics); and intervention programmes at CBOs. In all cases, assistance with health insurance and other benefits, including linkage to health insurance navigators, case management and intervention-specific programmes (e.g. PrEP medication and co-pay assistance programmes), must be prioritized to ensure adequate coverage for medical care and other services identified as necessary during risk and needs assessments.

**Engagement, retention and adherence**
The final element in the primary prevention cycle addresses uptake of, engagement in and adherence to optimal, high quality HIV prevention and risk-reduction interventions. These include PrEP; post-exposure prophylaxis (PEP); syringe exchange programmes (SEPs) and substance abuse treatment; mental health services; housing assistance; sexual health services; and behavioural change interventions. To help optimize engagement in HIV prevention programmes and related systems of care, the use of culturally competent case managers, patient navigators and/or other client-centred services should be considered [14–18].

**Obtaining essential data**
In contrast to the relatively straightforward data elements used to assess outcomes along the HIV care continuum, the metrics required to populate a primary HIV prevention continuum involving different systems of service delivery, interventions and outcome measures are incredibly complex and often without adequate or complete population-based data sources. Here we discuss two potential approaches to address the gaps in data required for programmatic planning, implementation and evaluation across the elements of the prevention cycle.

**Primary HIV prevention continuum metrics**
One strategy involves coordinating existing HIV prevention-related data. For example, the U.S. CDC, utilizing data from the National Health and Nutrition Examination Survey, the National Survey on Drug Use and Health and the National Survey of Family Growth, has estimated the number of U.S. adults with indications for PrEP based on behavioural risk factors for HIV and the 2014 U.S. Public Health Service’s PrEP clinical practice guideline to be 1,232,000 (95% confidence interval: 661,000 to 1,803,000) [19,20]. This effort to organize and analyze data across national surveys produced a valuable estimate of the number of US adults at elevated HIV risk, which could be used immediately as a lower-bound threshold for the prevention cycle’s primary denominator, as well as to evaluate PrEP coverage and advocate for scale-up.

A similar large-scale effort to identify and validate data sources for mid-cycle elements of the HIV prevention continuum, such as rates of health insurance coverage, linkage to service providers and utilization of evidence-based interventions, has not yet been undertaken. One potential data source for this work might be the National HIV Prevention Program Monitoring and Evaluation (NHM&E) system, which collects current and prior HIV testing data, referrals to specific HIV prevention activities and “intervention completion” each time a client enrols in or completes an intervention after HIV testing at a CDC directly funded CBO [21]. Available publications, presentations and reports from NHM&E data focus primarily on HIV testing results [22–24]. Collating and publishing data on referrals and completion of HIV prevention services, as well as indication for HIV testing, would be an important contribution – albeit a labour-intensive one – to informing HIV prevention service coverage and building local or national HIV prevention continua. Other potential data sources to inform elements of the HIV prevention cycle are listed in Table 1.

**Identifying “missed opportunities” and primary HIV prevention continuum gaps**
A second approach includes leveraging extant, robust HIV surveillance data among individuals who tested positive for the virus. Since the early days of the U.S. epidemic, such data pertaining to transmission risk among individuals testing positive for HIV have been used to inform HIV prevention planning and funding.

Each new infection continues to represent a missed opportunity for primary HIV prevention. In the setting of expanded prevention options available to those vulnerable to HIV infection, there is a need for renewed and strategic use of HIV surveillance data on new diagnoses to systematically understand prevention gaps and missed prevention opportunities, with rapid translation to “reverse engineer” primary HIV prevention continuum element priorities. Other areas of public health, including efforts to prevent maternal mortality, have employed similar approaches and have benefited from studying “near misses” in order to inform population-level best practices and implementation strategies [25–27].

Current CDC data systems allow for the collection of information to make some inferences about an individual’s attributable risk factor(s) for HIV acquisition and to track linkages to appropriate services after receiving a positive diagnosis. However, not enough surveillance data are gathered following diagnosis to learn about missed HIV prevention opportunities inherent in every new HIV infection. Treating each new infection as a sentinel health event is necessary to understand exactly where gaps in the primary HIV prevention continuum are occurring, especially as PrEP and PEP implementation is ramping up in many jurisdictions. Examples of probable gaps include the following: lack of knowledge...
regarding the symptoms of, and high transmission risk during, acute HIV infection; lack of awareness or availability of PrEP, PEP, SEP or other interventions; poor retention in or adherence to prevention services; and structural barriers to affordable health insurance, adequate medical care, safe housing or other supportive services. A fundamental assumption in the reverse engineering approach is that people vulnerable to HIV infection will have similar characteristics and risk factors to those who were recently diagnosed, such that extrapolation of data between populations is valid. Local programmes targeted at increasing early or immediate treatment following HIV testing, such as the University of California, San Francisco’s RAPID programme [28], are well poised to collect data on recently diagnosed individuals and inform data for local HIV prevention gaps.

Conclusions

Our proposed model provides a standardized roadmap for moving aggressively forward in reaching national HIV incidence and care targets by: 1) conceptualizing primary HIV prevention as a repeating, comprehensive and outcomes-oriented process that is applicable to vulnerable populations comprised of individuals with fluctuating risks and intervention needs; and 2) illustrating the value of HIV retesting as both a metric to continuously gauge the effectiveness of the primary HIV prevention cycle and an opportunity to stream-

line successful linkage, engagement and viral load suppression through the HIV care continuum. A limitation of our model is the absence of the complete data required to test the proposed primary HIV prevention continuum steps, which will be necessary indicators of success. An obstacle to model validation is the lack of a robust and coordinated HIV prevention monitoring system, which is sorely needed to help guide the implementation of key modalities of HIV prevention, such as PrEP and PEP. Our hope is that, in suggesting a way forward, we can catalyze an effort to address these limitations, which have stymied the promulgation of a meaningful primary HIV prevention continuum to date.

Given the current state of data collection infrastructure in the United States, efforts to vitalize HIV prevention will need to focus on increasing coordination between existing systems, including those not specifically focused on HIV, to prioritize the reporting of data for people vulnerable to HIV infection. The need for these data, however, must be weighed against efforts to decrease federal data collection and reporting burdens among health departments and CBOs as well as the need for increased resources required to more fully support these surveillance activities. Creating new primary prevention-focused variables in existing data collection tools, as well as conducting more analyses of current variables, will inform regional, state and national public health evaluation of prevention service coverage, identify gaps and facilitate
advocacy for scale-up of highly effective prevention services in the United States.

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Competing interests
The authors have no competing interests to declare.

Authors' contributions
TH and JS conceptualized the paper, which was drafted and edited by TH, JS and JA. DN and RHR provided significant edits to the paper. All working group members reviewed and approved the original manuscript and agreed to be acknowledged, with several working group members providing edits to the paper.

Acknowledgements
The authors thank the members of the Treatment Action Group and Foundation for AIDS Research HIV Prevention Continuum Working Group, which conceptualized this model during a July 2015 convening in Washington, DC, all of whom have agreed to be acknowledged as follows: K. Rivet Amico, PhD, Research Associate Professor of Health Behavior and Health Education, University of Michigan School of Public Health, Judith D. Auerbach, PhD, Professor, School of Medicine, University of California, San Francisco. Jeffrey Crowley, MPH, Program Director, National HIV/AIDS Initiative, O'Neill Institute for National and Global Health Law, Georgetown University Law Center. Dazon Dixon Diallo, MPH, DHL, Founder and CEO, SisterLove, Inc. Jonathan Fuchs, MD, MPH, Director, Center for Learning and Innovation in Public Health Community Health and Safety Branch, HIV Epidemiology Section, San Francisco Department of Public Health, Associate Clinical Professor of Medicine, University of California, San Francisco. Christopher Gordon, PhD, Branch Chief, Division of AIDS Research, National Institute of Mental Health. David Holgrave, PhD, Professor and Chair, Department of Health, Behavior and Society, Johns Hopkins Bloomberg School of Public Health. Tim Horn, MS, HIV Project Director, Treatment Action Group. Jeremiah Johnson, MPH, HIV Prevention Research and Policy Coordinator, Treatment Action Group. Jennifer Kates, PhD, Vice President, Director of Global Health and HIV Policy, Henry J. Kaiser Family Foundation. Kali Lindsey, former Deputy Director, amfAR, the Foundation for AIDS Research, Public Policy Office. Terrance Moore, Deputy Executive Director, National Alliance of State and Territorial AIDS Directors. Jim Pickett, Director of Prevention Advocacy and Gay Men's Health, AIDS Foundation of Chicago. David Purcell, JD, PhD, Deputy Director for Behavioral and Social Science, Division of HIV/AIDS Prevention, Centers for Disease Control and Prevention. Robert H. Remien, PhD, Director, Professor and Research Scientist, HIV Center for Clinical and Behavioral Studies, New York State Psychiatric Institute, Columbia University. Jennifer Sherwood, MSPH, Policy Associate, amfAR, the Foundation for AIDS Research, Public Policy Office. Melanie Thompson, MD, Principal Investigator, AIDS Research Consortium of Atlanta. Richard I. Wolitski, PhD, Acting Director, Office of HIV/AIDS and Infectious Disease Policy, Office of the Assistant Secretary of Health, Department of Health and Human Services. The authors also thank Lei Chou of Treatment Action Group for his contributions to the model design.

Funding
This work was supported by the MAC AIDS Fund, the Ford Foundation and Gilead Sciences.

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