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Citation

Nunn, Amy S., Lauren Brinkley-Rubinstein, Catherine E. Oldenburg, Kenneth H. Mayer, Matthew Mimiaga, Rupa Patel, and Philip A. Chan. 2017. "Defining the HIV pre-exposure prophylaxis care continuum." *AIDS (London, England)* 31 (5): 731-734. doi:10.1097/QAD.0000000000001385. <http://dx.doi.org/10.1097/QAD.0000000000001385>.

Published Version

doi:10.1097/QAD.0000000000001385

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Defining the HIV pre-exposure prophylaxis care continuum

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Pre-exposure prophylaxis (PrEP) is an effective HIV prevention strategy. There is little scientific consensus about how to measure PrEP program implementation progress. We draw on several years of experience in implementing PrEP programs and propose a PrEP continuum of care that includes: (1) identifying individuals at highest risk for contracting HIV, (2) increasing HIV risk awareness among those individuals, (3) enhancing PrEP awareness, (4) facilitating PrEP access, (5) linking to PrEP care, (6) prescribing PrEP, (7) initiating PrEP, (8) adhering to PrEP, and (9) retaining individuals in PrEP care. We also propose four distinct categories of PrEP retention in care that include being: (1) indicated for PrEP and retained in PrEP care, (2) indicated for PrEP and not retained in PrEP care, (3) no longer indicated for PrEP, and (4) lost to follow-up for PrEP care. This continuum of PrEP care creates a framework that researchers and practitioners can use to measure PrEP awareness, uptake, adherence, and retention. Understanding each point along the proposed continuum of PrEP care is critical for developing effective PrEP interventions and for measuring public health progress in PrEP program implementation.

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AIDS 2017, **31**:731–734

Keywords: HIV prevention, linkage to care, pre-exposure prophylaxis, retention in care

Pre-exposure prophylaxis (PrEP) has demonstrated efficacy in preventing HIV [1–3]. Whereas PrEP use is expanding globally, there is little consensus about how to measure progress in PrEP care other than to measure the number who initiate and adhere to PrEP and then impute reductions in HIV incidence. Standard benchmarks are

necessary in order to compare progress in PrEP programs. A ‘PrEP care continuum’ has been previously described as including the following: identifying individuals at risk, increasing their knowledge of PrEP, ensuring access to PrEP-related healthcare, and adherence to medications after PrEP initiation [4]. However, there is a need to

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Received: 1 November 2016; revised: 29 November 2016; accepted: 12 December 2016.

DOI:10.1097/QAD.0000000000001385

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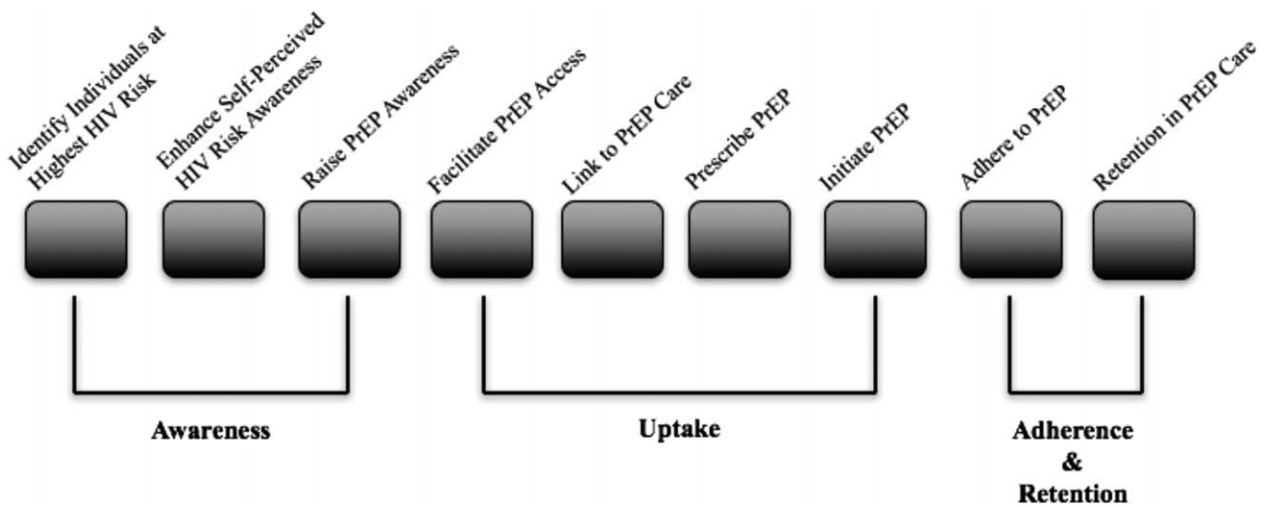


Fig. 1. The PrEP care continuum. PrEP, pre-exposure prophylaxis.

revisit and expand the framework to assess progress in PrEP implementation. Therefore, we draw on more than 4 years of PrEP implementation experience [5–10] and propose a PrEP care continuum that assesses the multiple steps related to PrEP uptake, adherence, and retention in care.

Because PrEP is intended to reduce HIV acquisition rather than treat disease, PrEP-related outcomes differ from the HIV treatment continuum [11]. We propose that the PrEP care continuum should include the following steps:

- (1) Identifying individuals at highest risk for contracting HIV
- (2) Increasing HIV risk awareness among those individuals
- (3) Enhancing PrEP awareness
- (4) Facilitating PrEP access
- (5) Linking to PrEP care
- (6) Prescribing PrEP
- (7) Initiating PrEP
- (8) Adhering to PrEP
- (9) Retaining individuals in PrEP care (see Fig. 1).

The first three steps in the PrEP care continuum focus on PrEP awareness. Steps 4 to 7 are related to PrEP uptake, and steps 8 and 9 focus on adherence and retention in PrEP care. Our experiences implementing PrEP suggest that each of these steps present opportunities for patients to continue using PrEP or disengage in care [5–10], and are important points of intervention.

The first outcome on the PrEP care continuum is identifying populations most at risk of HIV contraction, and, therefore, suitable for PrEP, who also understand their own risk for HIV (step 2). Debate about how many Americans are suitable candidates for PrEP continues; however, the Centers for Disease Control and Prevention

estimate that 25% of all MSM in the United States may benefit from PrEP [12]. In the United States, MSM are most impacted by HIV, and misperception of risk has impeded PrEP uptake among this group [13,14]. Even among those who realize they are at risk for HIV, knowledge about PrEP remains limited [15]; the third step in the Continuum is therefore PrEP awareness. A recent study in the Deep South found that among those accessing PrEP services, only 18% were MSM, even though this group represented close to 50% of incident HIV cases [16]. Addressing these awareness challenges will increase PrEP uptake.

The fourth step in the PrEP care continuum is facilitating access to PrEP care. In the United States, this involves scheduling an appointment with a medical provider who prescribes PrEP and usually requires having health insurance that covers the cost of clinical care and medications. Lack of insurance coverage may present significant barriers to engaging in PrEP care, as medications and provider fees can create financial barriers to PrEP uptake [6]. Although industry-sponsored medication assistance programs may help offset costs of PrEP, other fees related to provider time and laboratory monitoring may still not be covered [6]. Moreover, many regions of the United States do not yet have dedicated PrEP providers [17].

During the initial PrEP appointment, patients are educated about PrEP and an assessment is performed to determine whether PrEP is indicated. Among patients who have access to PrEP care services, not all patients present for and link to initial PrEP appointments (the fifth step), highlighting another opportunity to intervene. The sixth step is prescribing PrEP medications to those who meet clinical criteria. At this step, there may be opportunities to measure disengagement from care when patients do not fill their PrEP prescriptions. After PrEP

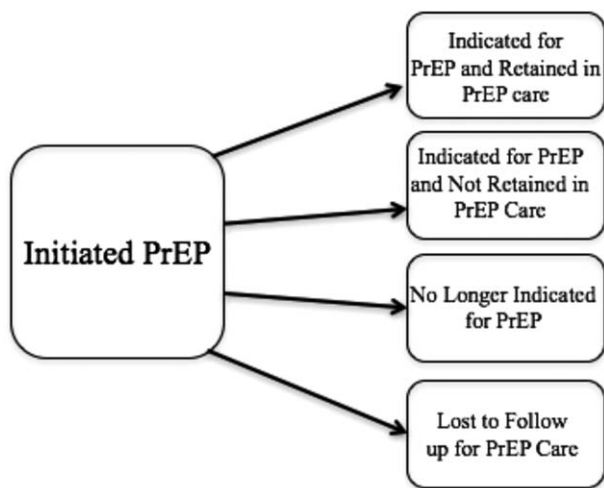


Fig. 2. The PrEP retention continuum. PrEP, pre-exposure prophylaxis.

has been dispensed, patients can initiate PrEP, which is the seventh step in the PrEP care continuum.

The eighth step is adherence, which includes consistently taking PrEP. Previous studies have shown that PrEP adherence is critical to efficacy [1] and can significantly reduce the risk of HIV acquisition among those who adhere [18–20]. The final step of the PrEP Continuum is retention in PrEP care. Retention in PrEP care poses a significant barrier to successful implementation of PrEP programs; some studies suggest that patients who are retained in PrEP care adhere to their medications [6,18]. However, greater efforts are needed to evaluate and clarify what is meant by retention in PrEP care. Defining who is successfully retained in care presents challenges. In contrast with the HIV care continuum, in which individuals take HIV medications over their lifetime, discontinuation of PrEP does not necessarily mean that an individual is lost to care or at increased risk for HIV. The term ‘prevention effective adherence’ has been used to acknowledge HIV acquisition risk may change over time in accordance with relationship changes or decreased engagement in risky behaviors [21,22].

‘Retention in care’ has been broadly used to describe whether patients are maintained in PrEP care; however, we posit that measuring retention is a complex phenomenon. Building on the ‘prevention effective adherence’ concept, we propose four distinct categories to characterize and measure retention in PrEP care: indicated for PrEP and retained in PrEP care; indicated for PrEP and not retained in PrEP care; no longer indicated for PrEP; and lost to follow-up for PrEP care (see Fig. 2). Our experiences implementing PrEP programs suggest that individuals change their behaviors and sexual partnerships over time [5,6]. Some individuals may not need PrEP and are not lost to follow-up; rather,

they no longer meet clinical criteria for taking PrEP. Capturing each of these retention-related outcomes is important for measuring progression through the PrEP continuum, both for individual patients, and also for population health metrics.

Understanding how and why patients take up, adhere, and are retained or disengage from PrEP care is critical for developing effective PrEP interventions. This proposed PrEP care continuum has some limitations; for example, in developing countries where PrEP is not yet commercially available or provided in public health systems, patients may never even have opportunities to advance through the PrEP Care Continuum. Nevertheless, this preliminary effort to define benchmarks for evaluating the impacts of PrEP programs can be useful for prioritizing interventions to enhance measures to benchmark PrEP-related progress.

Acknowledgements

Author contributions: A.S.N. lead writing and editing the article; L.B.-R. contributed to writing and editing of the article; M.M. edited the article and provided conceptual oversight; K.M. edited the article and provided conceptual oversight; and P.A.C. contributed to writing and editing.

P.A.C. received funding from National Institute of Allergy and Infectious Diseases: K23AI096923. P.A.C. and A.S.N. received funding from National Institute of Mental Health: R34MH109371, and the National Institute of Allergy and Infectious Diseases: P30AI042853. A.S.N. is supported by National Institute of Alcohol Abuse and Addiction: K01AA020228. L.B.-R. and A.S.N.’s efforts are supported by National Institute of Drug Abuse Brown Initiative in HIV and AIDS Clinical Research for Minority Communities: R25MH083620. L.B.-R.’s efforts are supported by National Institute of Drug Abuse UCLA HIV/AIDS, Substance Abuse and Trauma Training Program (HA-STTP): R25DA035692; the HIV and Other Infectious Consequences of Substance Abuse: T32DA013911; and the Lifespan/Brown Criminal Justice Research Program on HIV and Substance Use: R25DA037190.

Conflicts of interest

There are no conflicts of interest.

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