EDITORIAL



# **Presidential Elections and HIV-Related National Policies and Programs**

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Abstract The November 2016 general election and subsequent voting of the Electoral College resulted in the selection of Donald Trump as President of the United States. The incoming Administration ran a campaign that indicated a desire for substantial change in health policy, including the repeal of the Affordable Care Act (ACA). President Trump has said very little directly about HIV programs and policies, but some campaign positions (such as the repeal of the ACA) would clearly and substantially impact the lives of persons living with HIV. In this editorial, we highlight important HIV-related goals to which we must recommit ourselves, and we underscore several key points about evidence-based advocacy that are important to revisit at any time (but most especially when there is a change in Administration).

**Resumen** La elección nacional de Noviembre de 2016 y el voto subsecuente del Colegio Electoral resultaron en la selección de Donald Trump como Presidente de los Estados Unidos. La nueva Administración hizo campaña que indicaba el deseo para un cambio considerable en la política de la salud, incluyendo la revocación de la Ley del Cuidado de Salud Asequible (ACA). El Presidente Trump ha dicho muy poco directamente con respecto a sus políticas y programas para el VIH, pero algunas posiciones de la campaña (como la revocación de la ACA) tendrían un

impacto claro y sustancial en las vidas de las personas que viven con el VIH. En este editorial, destacamos metas importantes relacionadas al VIH a las que debemos reafirmarnos, y subrayamos varios puntos claves sobre el apoyo basado en evidencia que son importantes a revisar en cualquier momento (pero especialmente cuando ha sucedido un cambio de Administración).

Keywords HIV  $\cdot$  AIDS  $\cdot$  Policy analysis  $\cdot$  Translational research  $\cdot$  Communication

# Introduction

The general election of November 2016, and the subsequent voting of the Electoral College, has resulted in the selection of Donald J. Trump as President of the United States. The incoming Administration ran a campaign that indicated a desire for major change in health policy, including the repeal of the Affordable Care Act (ACA) [1]. Newly-elected President Trump has said very little directly about HIV programs and policies, however, some campaign positions (such as the repeal of the ACA) would clearly and substantially impact the lives of persons living with HIV and communities disproportionately impacted by HIV.

In this editorial, we do not attempt to divine what will be the detailed HIV-related policies of the incoming Administration; rather, we highlight important HIV-related goals to which we must recommit ourselves and underscore several key points about evidence-based advocacy that are important to revisit at any time (but especially when there is a change in Administration).

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# **Recommitment to Key National HIV/AIDS Goals**

With the new Presidency, it is timely to ask ourselves which core principles of HIV programming and policy must be highlighted and to which we must firmly recommit. We assert that the principles and goals listed immediately below have a strong evidentiary basis to them and are considered by many to be touchstones of central importance and guidance for persons working on HIV policies and programs. (While the points noted below focus on the HIV epidemic in the US, we strongly emphasize the ongoing importance of US support for international efforts to prevent and treat HIV infection, as well.)

- 1. Continue to embrace the National HIV/AIDS Strategy as an evidence-based plan for minimizing the impact of HIV on the health of Americans [2]. This will require that we maintain and even expand and extend the 2020 goals of the National HIV/AIDS Strategy (NHAS) [2–4].
- 2. Address the severe health inequities among persons living with, and impacted by, the HIV epidemic [2].
- 3. Promote universal access to HIV treatment and comprehensive wellness services (including stable housing) for persons living with HIV, and promote access to HIV prevention and wellness services for persons at risk of becoming infected with HIV [2].
- 4. Invest in HIV-related services at the level necessary to achieve (at least) the goals of the NHAS (wherein doing so would appear to be not only impactful for public health but also potentially cost-saving or cost-effective) [3, 4].
- 5. Utilize systems thinking approaches to coordinate and integrate health, social and wellness services for persons living with HIV within and across all levels of government, and between governmental and civil society partners [5].
- 6. Routinely perform unbiased evaluations of progress toward the NHAS goals, and make mid-course corrections whenever necessary [6].
- 7. Recommit the field to the Denver Principles established in 1983 which lay out a basic set of rights for persons living with HIV (and which focus especially on the reduction and avoidance of HIV-related stigma) and affirm the importance of involving persons living with HIV in decision making about the policies and practices that affect their lives [7].

We do not elaborate further on these seven major touchstones because we believe that they are very widely and well accepted among persons working on HIV policies and programs in the US.

# Recommitment to Core Principles of Evidence-Based Advocacy

Leadership changes present an opportune time to re-examine not only what evidence-based HIV-related goals we are attempting to achieve but also to scrutinize what communication and advocacy methods are best used to ensure that current and emerging empirical evidence is effectively translated into HIV-related programs and policies. Here we discuss some key points about evidencebased advocacy.

First, it is critically important to stress that the NHAS must *not* be viewed through a partisan lens. Instead, we must emphasize that the NHAS "game plan" represents the findings and thoughts of a wide variety of experts (through its evidence base and subsequent recommendations) and communities affected by HIV. Developing successful programs and policies to address HIV in the US can and should be a public health priority that transcends partisan politics. We dare not abandon the NHAS because it was released under the previous Administration, noting, instead, that multiple communities and involved stakeholders have been advocating decades for this evidencebased national roadmap.

Second, and perhaps quite obviously, we believe that it is important that evidence-based advocacy happens in public health. At a speech given at the Johns Hopkins Bloomberg School of Public Health on October 4, 2012, Dr. William Foege (former Director of the US Centers for Disease Control and Prevention) was asked if researchers should advocate, to which he responded in the affirmative. The questioner followed up by asking how far should researchers go in their advocacy, to which Dr. Foege powerfully and concisely replied, "the line is the truth." These few words convey a wealth of meaning in that they assert that investigators have an obligation to engage in, support, and promote efforts that help to ensure that their empirical work is translated into policies and programs (otherwise the scientific investment is wasted), but that there is a firm boundary for researchers at the limits of the evidence. Adherence to this boundary is what builds credibility (and thereby impact) for researchers over the long run.

Third, while data (such as data about the effectiveness of sterile syringe programs as a necessary HIV prevention program component [8]) do not change because there is a new incoming Administration, the communication strategies about those data may need to evolve to ensure effective communication to policy makers and program managers. Decision makers, even those committed to the use of scientific evidence in policy making, may well be confronted by fiscal, legal, and other social considerations that are also involved in their choice processes [9]. The more that researchers can communicate their findings in a way that also includes relevant information in such domains, the more likely the uptake of that information. For example, the inclusion of cost, cost-effectiveness, needed investment levels, and resource optimization information to go along with empirical findings may well help in answering key questions held by policy makers [10]. As another example, information about the cost-effectiveness of PrEP services and the level of investment required to provide such services to all persons who need them in a given community may serve to inform implementation decisions about this type of service. The converse is clearly true; if policy makers have questions about the economic aspects of a program but no such information is available, the odds of the uptake of that evidence-based program are likely to be minimized. Further, it is often helpful for decision makers to understand the public health and economic consequence of inaction. In the field of public health-and this is certainly true for HIV-doing nothing can be both costly and harmful.

Fourth, we believe it is always important to identify the most accurate, unbiased, and timely method for evaluating progress toward a key public health goal. Optimally, this involves assessment and feedback from multiple perspectives, both inside and outside of government (and this is certainly true as it relates to the goals of the NHAS). For example, the DC Appleseed Center for Law and Justice has for years issued periodic report cards on the progress of HIV-related efforts in the Washington DC area [11]. The Department of Health in Washington DC also evaluated its own programs, but the DC Appleseed report gave a critical and timely "outside" look as well. Another example is the work of the Institute of Medicine (now the National Academy of Medicine) which often is asked to review and comment on the evidence of the effectiveness of various major health programs (such as PEPFAR) [12]. Thirdly, the Presidential Advisory Council on HIV/AIDS (PACHA) was charged under the previous Administration with giving ongoing feedback as to the progress being made (or not) toward specific NHAS goals; [13] this was in addition to the Administration's own selfevaluations [14].

Fifth, we assert that it is critical that researchers not selfcensor their work in the face of real or perceived challenges to scientific study in certain arenas. Data suggest that researchers have sometimes allowed a sense of concern about funding priorities to lead to a self-censoring of scientific questions [15]. We would argue that both censoring and self-censoring lead to unfortunate impacts on research agendas, gaps in critically needed scientific knowledge, and negative impacts on the communication about these lines of scientific inquiry.

Sixth, we believe it is important for researchers to help train their mentees and students in taking a long view of scientific inquiry. For example, former US Representative Henry Waxman participated in a panel (November 30, 2016) at Johns Hopkins Bloomberg School of Public Health during which he gave remarks about the interplay between the US Congress and the Executive Branch of government, as well as his observations about voters' evolving opinions and behaviors over time. Similar to the point we made above about remarks by Dr. Bill Foege in 2012 at Johns Hopkins, Rep. Waxman noted the importance of evidence-based advocacy in public health. Such intergenerational conversations can be critically important for students to hear of these historical lessons, but also for older researchers and practitioners to see current events through the lens of a new generation. We believe that such conversations are part of our collective pedagogical duty in public health.

## Conclusions

We recognize that HIV infection and disease progression (like many other chronic diseases) occur within a broader context of social, economic, and political conditions (often called the "social determinants of health", or "SDOH") which affect persons living with HIV and those at risk of acquiring HIV [16]. A change of administration and the subsequent, resultant policy changes that occur may well be considered a social determinant of health, and perhaps it is helpful to view the recent election through the SDOH lens.

The NHAS unveiled by President Obama in 2010 and updated in 2015 helped to coalesce the HIV efforts in the US and served to build a collective vision of a nation where incident HIV infections would become a rarity, and where HIV-associated health impacts and disparities would be substantially reduced. Some locales have taken this a step further, developing plans to "end AIDS" in their jurisdiction over the coming years, and some authors have offered suggestions about necessary national HIV-related goals by 2025. Where we need to head seems clear; the question is whether the elections of 2016 will keep us on that pathway, or slow or even divert the journey. We do not yet know, but signs such as focus on the repeal of the Affordable Care Act (and possible scaling back of Medicaid funding) are troubling for everyone and acutely so for persons living with HIV; such actions could lead to lack of coverage for needed services, disruption in care systems, and place a strain on the ever-important safety net services provided under the Ryan White Care Act (especially its AIDS Drug Assistance Program provisions). [17, 18] Many segments of society have a role to play to ensure that we stay true in our tracking to the "northstar" of the NHAS; we assert that researchers' roles include that of evidence-based advocacy and we must recommit to these efforts. To do any less is to let down the people and communities most heavily and disproportionately impacted by HIV, and to dishonor the memory of so many loved ones who lost their lives to HIV.

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#### **Compliance with Ethical Standards**

**Conflict of interest** The authors declare they have no conflicts of interest. While we do not consider these to be conflicts, in the spirit of transparency we disclose that Dr. Holtgrave is a former member of the Presidential Advisory Council on HIV/AIDS, and Dr. Valdiserri was formerly employed in the Office of the Assistant Secretary for Health, US Department of Health and Human Services.

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