

HIV
THE **LONG VIEW**

**A HEALTHIER FUTURE
STARTS TODAY**

A REPORT FROM
HIV: THE LONG VIEW COALITION



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FOREWORD

FROM HIV: THE LONG VIEW COALITION

HIV: THE LONG VIEW COALITION



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AT THE CROSSROADS: THE FUTURE OF U.S. HEALTHCARE AND HIV

We are at a transformative time for U.S. healthcare, where scientific advances are happening at breakneck speed even as access to care is evolving and expanding. It is a time of tremendous opportunity, both to accelerate progress and tackle emerging challenges that can hamper future progress.

The HIV: The Long View survey commissioned for this report shows the American public is remarkably optimistic and willing to be more engaged in driving healthcare forward. More than four in 10 (43%) believe the quality of our healthcare will improve in the next 20 years and more than half (54%) are willing to donate their own healthcare data to help fuel that progress.¹

Individuals living with or at risk for HIV are front and center at this crossroad. In contrast to the early years of HIV/AIDS, advances in treatment and prevention have helped improve the lives of many, but the epidemic and the challenges of living with HIV are far from over.

These questions served as the genesis of this forward-looking report.

- What** will our healthcare environment look like in 20 years and what will it mean for HIV?
- What** will be the most vexing challenges?
- What** will be our greatest achievements?
- How** can we learn from our successes and our failures and pass our knowledge on to future generations?
- How** can we harness the tools available today to ensure better health for everyone in decades to come, particularly those living with or at risk for HIV?

Five Trends Driving Healthcare For The Next 20 Years

The findings and recommendations in this report were developed in response to five key healthcare trends, identified by an independent research organization, that are poised to transform U.S. healthcare over the next 20 years [see report methodology]. These trends are shaping where and how people deliver and receive health information and healthcare. We explored them through the lens of not only the overall healthcare landscape, but also in the context of long-term HIV prevention and care. The trending topics include:

- 1** **Access to affordable, high-quality medical care** – With the introduction of the Affordable Care Act, our nation's health system – and Americans' access to it – is undergoing major changes, many still in their infancy. The full effects will continue to play out over the next two decades, including efforts to improve value of care, not just volume of care. And through all of this, our health system is under escalating cost burdens.²
- 2** **Preventive medicine technology** – Lightning-fast advances in technology are creating new ways to connect individuals to healthcare. Beyond wearable devices and other health-tracking tools that support healthy habits and decision-making, technology has massive potential to connect patients in rural or remote locations to top specialists.
- 3** **Chronic disease and related health challenges** – The large and aging baby boomer population is bringing with it increasing rates of age-related chronic conditions, including heart and kidney disease, diabetes and obesity, among others (Figure 1).^{3,6}
- 4** **Personalized medicine** – Scientific advances, including Big Data, are now allowing better and more targeted collection and sharing of medical information. These are paving the way for more precise and individualized treatments.⁷
- 5** **Tackling and eradicating infectious diseases** – Outbreaks of new, and sometimes old, infectious diseases continue (e.g., Ebola, Zika), garnering intense media attention and stretching health resources for education, treatments and vaccine developments. At the same time, there's well-placed hope that the spread of some infectious diseases can be largely eliminated through vaccination and other types of prevention.

In examining the five key trends and the innovations supporting them, we recognize these five key trends have complex relationships, which often overlap and influence each other.

Looking Ahead: How Health Trends Will Impact HIV

The outlook for many people with HIV is shifting for the better. With early detection and proper treatment, HIV can now be a long-term, manageable chronic disease for many.⁸ But not everyone with HIV is getting tested, receiving optimal care and continuing that essential care. There continue to be infection risks and care gaps across all populations, but certain groups are particularly hard hit by HIV, including men who have sex with men (MSM), African Americans, Latinos/Hispanics, transgender women, urban poor and rural residents.

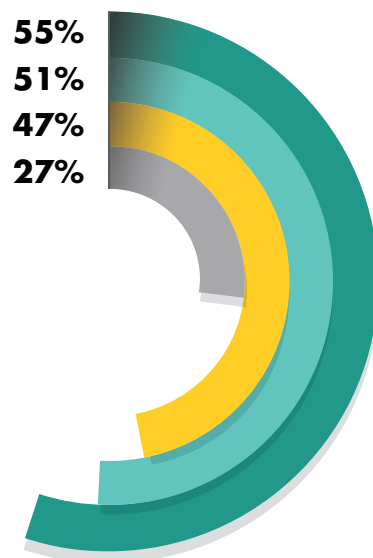
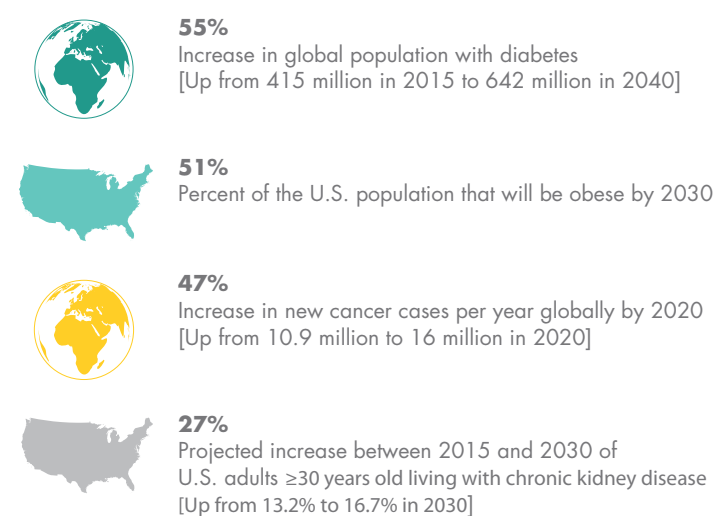
Our goal is to provide a long-term vision of better health for individuals living with or at risk for HIV, and to identify the actions required to support this vision. You will find these Calls to Action on page 28, which focus on:

- Tackling enduring challenges such as stigma
- HIV education and empowerment
- Growing our body of knowledge on HIV and its impact on long-term health
- Tailoring prevention and care to individuals and unique at-risk communities
- Greater adoption of evidence-based guidelines and interventions across healthcare providers and settings

These are lofty goals, but history has shown us that the progress borne out of the movement to fight HIV often serves as a model for other diseases and efforts to improve care across the United States. This report adds to that proud tradition.

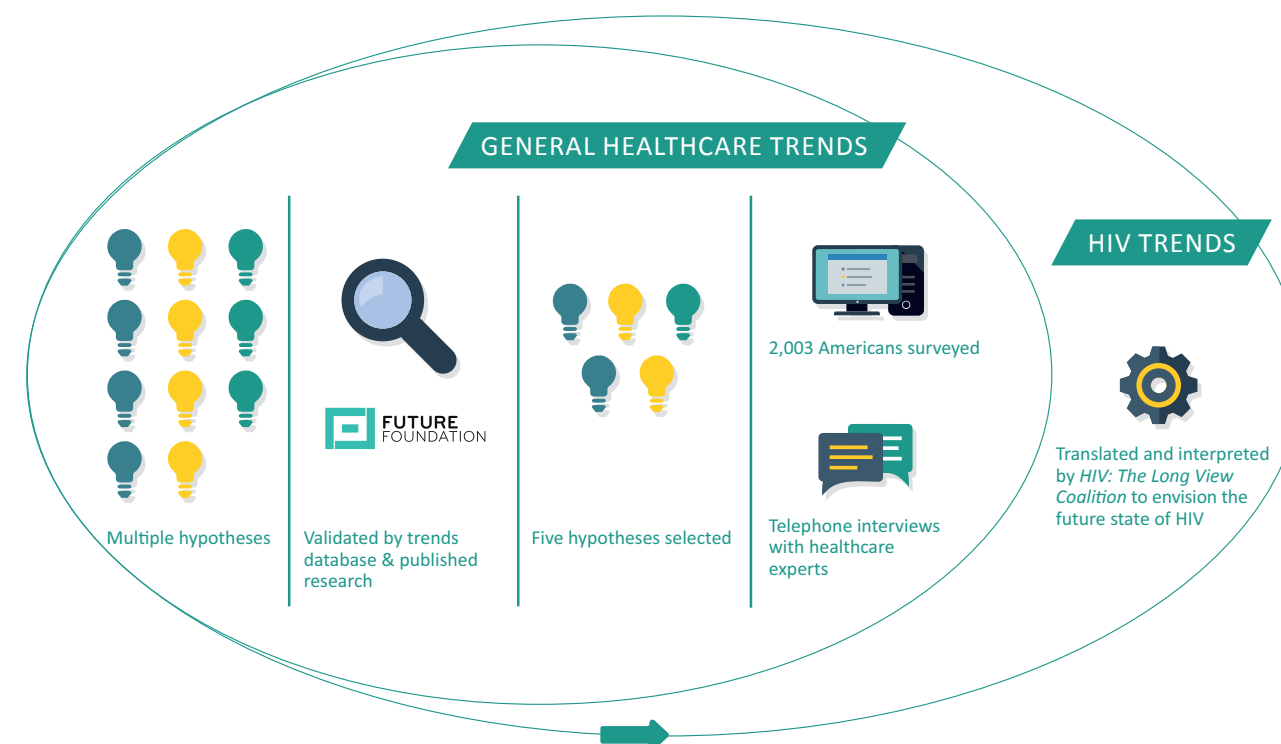
Figure 1

CHRONIC CONDITIONS ARE ON THE RISE³⁻⁶



REPORT METHODOLOGY

This report applies an exclusive and in-depth research methodology, including many qualitative and quantitative inputs, to provide a forecast of the future of U.S. healthcare. The data and predictions described are based on a comprehensive analysis of U.S. healthcare trends over the next 20 years conducted by The Future Foundation, an independent global consumer trends and insight firm. These findings have been examined and discussed by a multidisciplinary group of HIV experts to look at the implications for individuals living with or at risk of HIV.



The Future Foundation began its analysis with 11 hypotheses, which were explored through extensive review of published literature and nVision, the Future Foundation's proprietary database of consumer trends, insights and data. Five nuanced and validated hypotheses were further authenticated through a consumer survey of 2,003 U.S. adults aged 18 years and older and through one-on-one interviews with experts in an array of fields that intersect U.S. healthcare. The HIV: The Long View Coalition gratefully acknowledges their input:

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HIV: THE LONG VIEW COALITION & PARTNERS

HIV: The Long View Coalition Members

AMERICAN ACADEMY OF HIV MEDICINE (AAHIVM)

AAHIVM is the nation's largest community of HIV care providers, including physicians, HIV-specializing pharmacists, nurse practitioners, physician assistants and medical students. AAHIVM supports the HIV provider and promotes accessible, quality care for all Americans living with HIV. Its membership of HIV practitioners and credentialed providers gives direct care to the majority of HIV patients in the United States.

Theresa Mack, MD, MPH, is a member of the New Jersey/New York chapter of AAHIVM and an internist affiliated with Mount Sinai Doctors Faculty Practice who provides HIV care.

Amber McCracken is AAHIVM's Director of Communications and Marketing.

GAY MEN'S HEALTH CRISIS (GMHC)

GMHC is the world's first provider of HIV/AIDS prevention, care and advocacy; it is based in New York City.

Kelsey Louie, MSW, MBA, is GMHC's Chief Executive Officer.

HEALTHYWOMEN

HealthyWomen educates, informs and empowers women to make smart health choices for themselves and their families.

Beth Battaglino, RN, is President and Chief Executive Officer of HealthyWomen.

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NATIONAL BLACK LEADERSHIP COMMISSION ON AIDS (NBLCA)

NBLCA educates, mobilizes and empowers black leaders to meet the challenge of fighting HIV/AIDS and other health disparities in their local communities.

C. Virginia Fields, MSW, is NBLCA's President and Chief Executive Officer.

Margaret Reneau, EdD, is NBLCA's Director of Programs.

NATIONAL COUNCIL ON AGING (NCOA)

NCOA is a respected national leader and trusted partner to help people aged 60+ meet the challenges of aging. Its mission is to improve the lives of millions of older adults, especially those who are struggling.

Kathleen Zuke, MPH, is a Program Associate for NCOA's National Chronic Disease Self-Management Education (CDSME) Resource Center, which supports the expansion and sustainability of CDSME and other evidence-based health promotion programs.

HIV: The Long View Partners

FUTURE FOUNDATION

The Future Foundation is an independent global consumer trends and insight firm that works to transform strategy, marketing, research, service, innovation, analysis and training. The Future Foundation uses proprietary tools and global research to highlight the real truth behind the changes happening and not simply trends for trends' sake.

GILEAD SCIENCES

Gilead Sciences, Inc. is a research-based biopharmaceutical company that discovers, develops and commercializes innovative medicines in areas of unmet medical need. Gilead Sciences strives to transform and simplify care for people with life-threatening illnesses around the world.



THE FUTURE OF HEALTH IN AMERICA

RESULTS OF THE FUTURE FOUNDATION RESEARCH

Based on extensive research into consumer attitudes about healthcare and projected health trends from sources including the U.S. Centers for Disease Control and Prevention, the U.S. Census Bureau, Oxford Economics, the Pew Internet and American Life Project, Kaiser Family Foundation and others, as well as extensive proprietary research, the Future Foundation identified five health hypotheses likely to drive change in healthcare attitudes and behaviors, and shape the future healthcare landscape.

20 Years From Now, American Consumers Believe That:

1. Nearly all Americans will have [access to affordable, high-quality medical care](#).
2. [Personalized medicine](#) will become more common and real-time patient data will be regularly and immediately analyzed.
3. [Preventive medicine technology](#) to help the public avoid chronic conditions will be a mainstay of healthcare.
4. Having multiple health challenges related to [chronic diseases](#) and aging will remain a significant challenge.
5. Advances in research have the potential to eradicate some of the most challenging [infectious diseases](#) in the United States, but the need to discover new treatments and cures will remain urgent.

TREND #1: FEWER UNINSURED AMERICANS MAY NOT MEAN BETTER ACCESS FOR ALL

Support for equal access to medical care is high among the American public, yet they are guardedly optimistic that the quality of medical care will continue to improve (Figure 2).¹ Confidence is highest among young adults (age 18-34), where more than half are optimistic about continued progress.¹ While more Americans are covered by health insurance today than ever before, experts and the public recognize that the healthcare system will face many challenges in the next 20 years.⁹

TREND AT A GLANCE

The move toward broadening access to healthcare will continue, but disparities in quality and consistency of access will persist.

- There is social and political will in large sectors of the U.S. population for healthcare to be extended to all U.S. citizens.
- The role of non-physicians (nurse practitioners, physician assistants) in healthcare is becoming more important, and has the potential to reduce some healthcare costs.
- Online resources as well as self-health technologies can democratize healthcare for those who may not be able to afford full checkups.

Political Uncertainty And Cost Concerns Could Impede Access

Some politicians are seeking to repeal aspects of the Affordable Care Act, and the impact of the 2016 elections is uncertain. With or without health insurance, almost nine in 10 Americans say healthcare is too expensive.¹ Dr. Rani Whitfield agrees: "Having insurance is not the only barrier; patients also need the finances to pay for the services that are needed or desired." Patients are bearing increasing financial responsibility for their healthcare in the form of higher deductibles and co-pays.

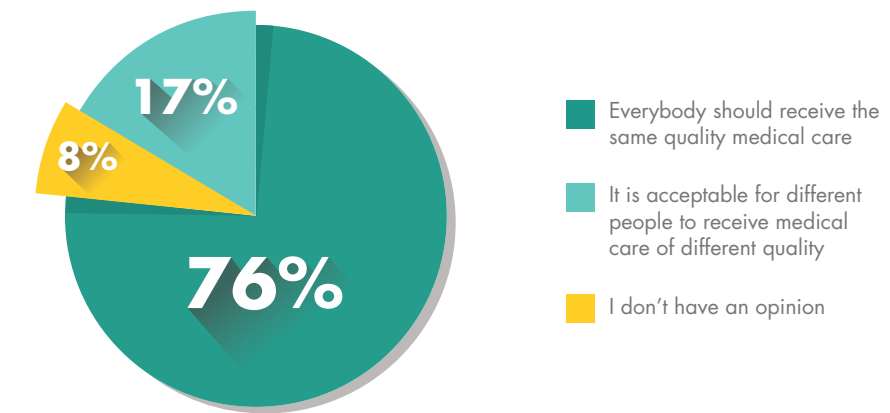
"Even the Affordable Care Act, which was the broadest, most impactful policy since the New Deal, deliberately left some people out – the undocumented population – and it also allowed some people to opt out of coverage, which... from a policy perspective, makes sense, but that means there are some people that are going to remain uninsured."

– Nadereh Pourat, PhD

One way to reduce costs associated with healthcare may be to increase the role of healthcare providers beyond doctors (e.g., nurse practitioners, physician assistants) in primary care. From 1995 to 2009, the number of nurse practitioners in primary care more than doubled in the United States.¹⁰ Newer technologies, which are discussed later in this report, may also help to bring better healthcare to more Americans while controlling costs. It is interesting to note, though, that nearly three in 10 Americans believe patients should pay the same amount for virtual ("telemedicine") healthcare as they do for in-person healthcare.¹¹

Figure 2

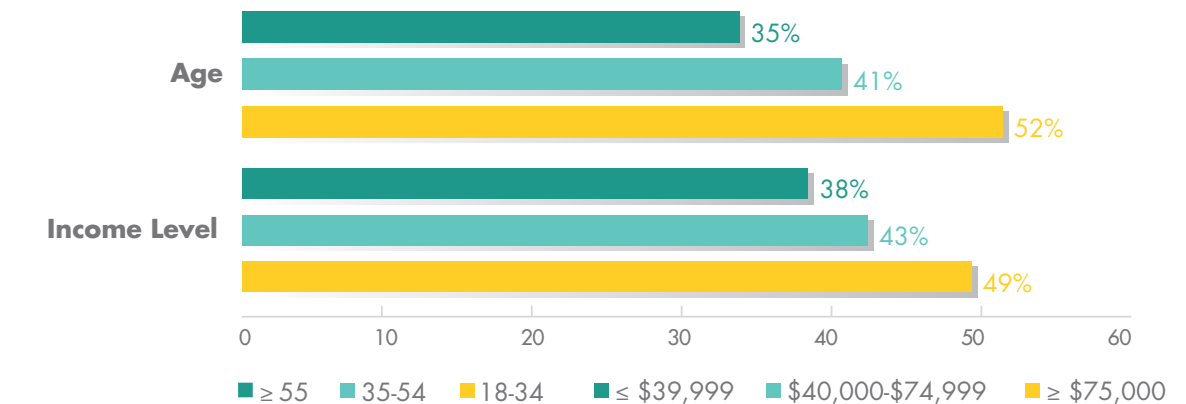
THE AMERICAN PUBLIC SUPPORTS EQUAL HEALTHCARE FOR ALL



Figures are rounded to nearest whole number

HEALTHCARE OPTIMISM INCREASES WITH YOUTH AND INCOME

Percent who agree the quality of healthcare services in the United States will improve



Source: Long View Future Foundation Survey

Ensuring access for everyone will continue to be a challenge, but even more so for those at lower income levels. Those with lower income levels have lower expectations that quality of healthcare will improve for them: 38 percent in the lowest income category of \$39,999 or less compared to 49 percent for those with an income of \$75,000 or more (Figure 2).¹ But those at lower income levels are the people the healthcare system needs to reach most. "The greatest changes usually occur in those areas which are lowest income," says Dr. Arnold Monto. "We need to ensure low-income people have access to good care and prevention services."

HIV Implication: The Affordable Care Act removes some cost barriers to healthcare access and ensures that no one will be denied insurance because of a pre-existing health condition, including HIV/AIDS. However, people living with HIV and at risk for HIV still face other barriers, including stigma and discrimination.



TREND #2: NEW PREVENTIVE MEDICINE TECHNOLOGY WILL IMPROVE HEALTH AND HEALTHCARE

Preventive medicine technologies such as health screenings, health-tracking apps and virtual house calls (also known as telemedicine) are becoming more common, and Americans appear receptive to them. One-third (36%) say they would use health-tracking or wearable devices and over one in three (38%) would use virtual house calls.¹

TREND AT A GLANCE

More consumers will try to reduce the personal cost of illness by using new technologies.

- Technology will create new pathways for access to care.
- Efforts to decrease spending on public programs and economic uncertainty will result in a trend toward more self-reliance.
- Self-motivation tools and incentive programs will accelerate healthy behavior.
- As technologies become more intuitive, time and literacy burdens will be overcome.

“Bricks and mortar in the form of clinics and hospitals is not the end-all-be-all of providing healthcare. You don’t have to have a hospital or doctor’s office to see a patient if the technology is available. It may be harder for those who need it most to access telemedicine – like people living in rural areas of the country, particularly here in the South – but that’s something that needs to be strongly considered.”

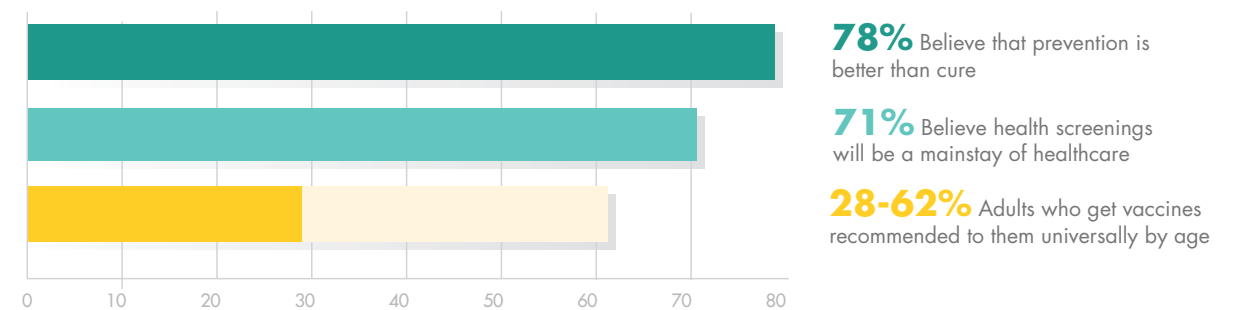
– Rani Whitfield, MD

The Winning Formula: Patient Engagement Plus New Technology

According to survey data, the majority of the U.S. public believes prevention is better than cure (78%) and that health screenings will be a mainstay of healthcare (71%) in the next 20 years.¹ Despite this, as many as seven in 10 adults do not receive recommended vaccines, one of the easiest and cheapest preventive methods available to them today (Figure 3).^{1,2} Moving consumers to act on their beliefs is not easy, according to Thomas Getzen, PhD. “The prevention that everybody wants is something like fluoride in the water or a smallpox vaccine, but the most valuable preventions are often tough stuff like changing behavior,” he says, “That’s much more difficult and it requires that people take a very active role.”

Figure 3^{1,12}

CONSUMERS’ ACTIONS DO NOT MATCH BELIEFS



Getting consumers to use new technology may be slowed by concerns about its cost and accuracy, as well as the security of their health information. Anywhere from two to four in 10 people express these concerns about new and emerging technology such as health screenings, virtual house calls, health-tracking apps and wearable devices.¹

A SAMPLER OF NEW TECHNOLOGY AND THE QUEST FOR MORE



A wearable device for the elderly identifies early signs of bigger health problems. It can also send notifications to relatives and care staff to alert them when patient patterns change.



Telemedicine improves patients' health by allowing them to consult with medical professionals. The U.S. government views this as a cost-effective alternative to traditional in-person care and allows it to be paid for by Medicaid programs.



A mobile health app translates steps, sleep, weight and blood sugar data from various tracking devices into simple, actionable insights to help people with chronic conditions achieve their health goals.



A global competition is looking for ways to build a device that will empower individuals to know their vital signs and accurately diagnose 12 health conditions.

HIV Implication: New technologies that connect people to healthcare professionals, services and resources could help those at risk of HIV get good prevention advice. These technologies can also help link HIV-positive people to care, which may help prevent the spread of HIV to others.



TREND #3: OUR AGING POPULATION WILL HAVE MORE CHRONIC DISEASES

The Milken Institute reports that there will be a 42 percent increase in seven chronic diseases in the United States by 2023.¹³ These are diseases that worry most of us – cancer, diabetes, hypertension, stroke, heart disease, lung disorders and mental health conditions – and that can often be prevented. Unhealthy risk factors – obesity, tobacco use, poor nutrition and physical inactivity – underlie many of these conditions. We can and should modify our eating, smoking and exercise habits to improve our future health. But even in those who take the very best care of themselves, aging brings increased risk of chronic diseases and other health complications.

TREND AT A GLANCE

An increasing societal emphasis on health, as well as availability of better health screenings, will help more people take proactive steps to prevent chronic conditions.

- Because our population is aging, the incidence of comorbidities will increase despite more screening and preventive measures.¹³
- Data indicate that the U.S. obesity rate may have plateaued between 1999 and 2010, but now it is on the rise again.¹⁴⁻¹⁶
- Calorie intake among both adults and children has decreased in recent years as public health campaigns promote healthy eating and as social stigma and the financial cost of overeating rise.^{17,18}
- Employers and insurers are incorporating consumer healthfulness into their business plans.¹⁹

“ A lot of people believe obesity is like smoking. You might smoke up to the age of 30 and then quit and be fine, but with obesity this is not true. Sure, you can lose weight and get back to a healthy weight, but your body will make major metabolic adjustments to biologically drive your weight back to the obese level. This drive back to the higher weight does not appear to go away with time. But it’s important to note that even just maintaining a five to 10 percent weight loss is enough to help many of the chronic health problems of obesity. ”

– Ken Fujioka, MD

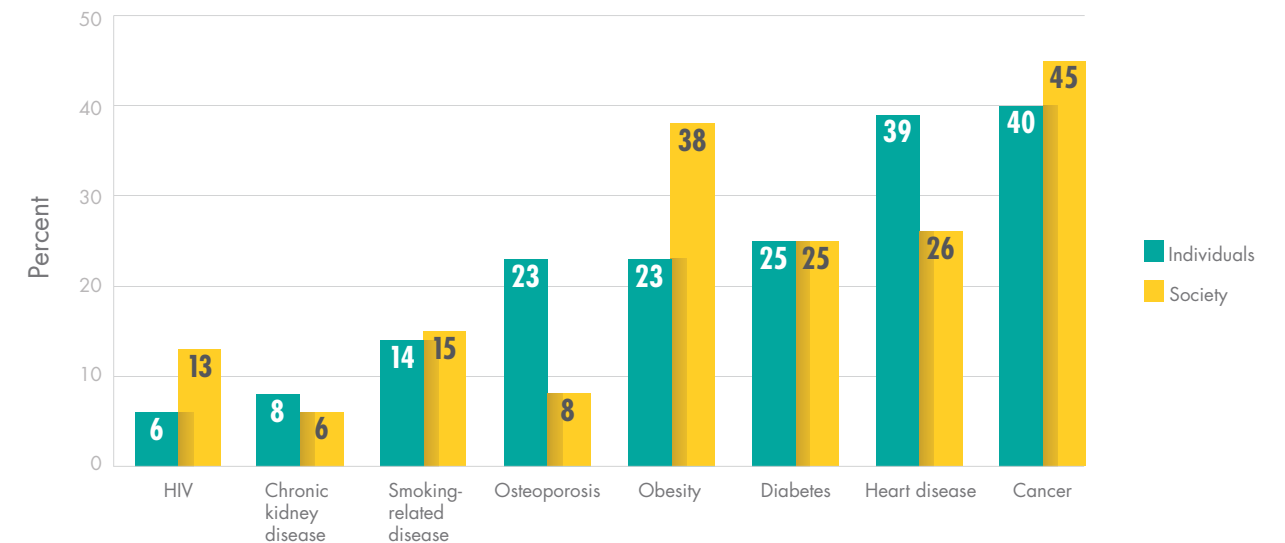
Individuals Must Share In The Responsibility To Reduce Chronic Conditions

The public is well aware of the challenge of chronic conditions, with 32 to 55 percent saying either they or someone they know has cancer, heart disease, diabetes, smoking-related disease, osteoporosis or is obese.¹ Large proportions of the public say these chronic conditions will continue to be a problem for both individuals and our society in 20 years (Figure 4).¹ There is a growing movement toward empowering individuals and communities to take action for healthy living. In fact, nearly seven in 10 (68%) people believe we need to take more personal responsibility for living healthfully.¹

Dr. Alan Taege agrees, but says doctors need to share in this responsibility. “We need to help patients maintain better health earlier in their lives. The decisions they make when they’re young will have an impact on their future health and the amount of healthcare resources we spend later on.”

Figure 4

NATIONAL SURVEY: WHICH CONDITIONS WILL HAVE A MAJOR IMPACT ON INDIVIDUALS AND SOCIETY 20 YEARS IN THE FUTURE?



Source: Long View Future Foundation Survey

Research suggests that public health campaigns that promote healthy eating may be helping to reduce calorie intake and more employers are incorporating consumer healthfulness into their business plans.^{17,19} Finances may also play a role, both positive – the cost of overeating is rising – and negative – more than one in 10 American families worry about being able to afford nutritious meals.¹⁸

HIV Implication: People with HIV age five to 14 years faster than people without HIV, which may translate into earlier onset of some chronic conditions for them compared with those who are HIV-negative.^{20,21}

TREND #4: TECHNOLOGY WILL HELP MAKE PERSONALIZED MEDICINE MORE COMMON

Real-time data collection and sharing already penetrate our daily activities. Information about consumer buying and online habits are continually collected and used to market products and services: search about a possible vacation spot and find ads for hotels in your Facebook feed just minutes later, along with online ads for the perfect suitcase for packing. The same technology makes it possible to analyze millions of patient records to find common patterns and genetic traits that can be used to help choose the best medical options for an individual who matches them. This technology is already being used today, with the potential for wide-scale implementation in the next 20 years.

The Genomic Data Commons, an initiative of the National Cancer Institute, facilitates data sharing among cancer researchers to promote advances in personalized medicine for many types of the disease.²²

Personalized medicine replaces a 'one-size-fits-all' approach with one that is tailored to individual patients.

TREND AT A GLANCE

Personalized medicine will become routine, though at a cost.

- Diagnosis, treatment and lifestyle interventions will be increasingly personalized to individual patient genetics, family history and other factors.
- Technologies are making it easier for healthcare professionals to track patient health information and provide personalized care.
- Big Data will revolutionize healthcare, with large-scale data and data processors set to become a core part of healthcare quality improvement and decision making.

Widespread Data Sharing Is Essential To Better Care For All

The American public seems to understand that personalized medicine is beneficial for them and that sharing medical data is important. More than half agree that personalized medicine will increase accuracy of testing, improve treatment effectiveness and help identify certain disease risk factors.¹ While 54 percent would be comfortable anonymously sharing their health data, many still have concerns (Figure 5).¹

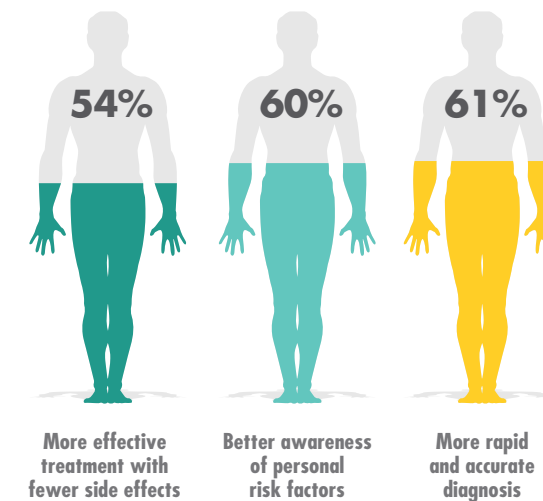
"You can't have personalized medicine without large-scale data sharing," says Thomas Getzen, PhD, so increasing consumers' comfort about sharing their data will be essential. But even as technology experts are scrambling to find the capacity to store and process the enormous amount of data being collected, Dr. Getzen says "There is a giant fight over data access currently in the United States. HIPAA* makes it hard to exchange data, and is making some kinds of research very difficult to do."

*Health Insurance Portability and Accountability Act of 1996, which requires that personal medical records be kept confidential.

Figure 5

CONSUMERS ARE AWARE OF THE BENEFITS OF PERSONALIZED MEDICINE...

Percent who say that personalized medicine leads to...



Source: Long View Future Foundation Survey

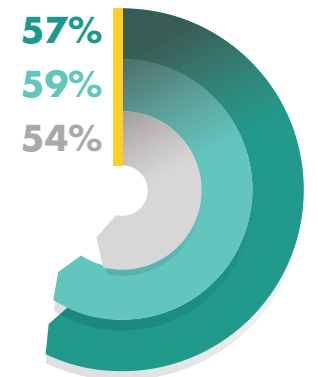
...AND ARE (SOMEWHAT) WILLING TO SHARE THEIR DATA TO GET THERE

More than 6 in 10 (64%) believe technology will allow all stages of medical treatment to be tailored to individual and precise needs

57% say making personal health data more accessible will lead to better health for all

59% wish their health data could be shared by their healthcare providers more easily

54% will share their data (if it can't be traced back to them)



HIV Implication: Because of stigma attached to an HIV diagnosis, it may be challenging to get people with HIV to share personal data, which will limit the opportunity for all individuals with HIV to benefit from advances in personalized medicine.

"One way to predict what health issues a patient may face is by knowing their family medical history. But the accuracy of that information may not always be reliable; sometimes in certain communities, especially the African-American community, there's a fear of sharing or discussing family medical history with the physician."

– Rani Whitfield, MD

"Collecting personal information and then using it to make faster decisions about the best care for individuals – that is personalized medicine and it is absolutely happening already. This will be especially impactful in chronic conditions like diabetes, which drives a significant portion of global healthcare costs."

– Rick Altinger

TREND #5: INFECTIOUS DISEASES WILL BE AN ONGOING THREAT

In the last decade alone, the United States and the world have dealt with many infectious diseases including Zika, Ebola, MERS (Middle East Respiratory Syndrome), pandemic flu and more. While experts expect outbreaks like these to continue, a measurable segment of the public (45%) is optimistic about our ability to vaccinate against and perhaps even eliminate (36%) many infectious diseases in the next 20 years (Figure 6).¹

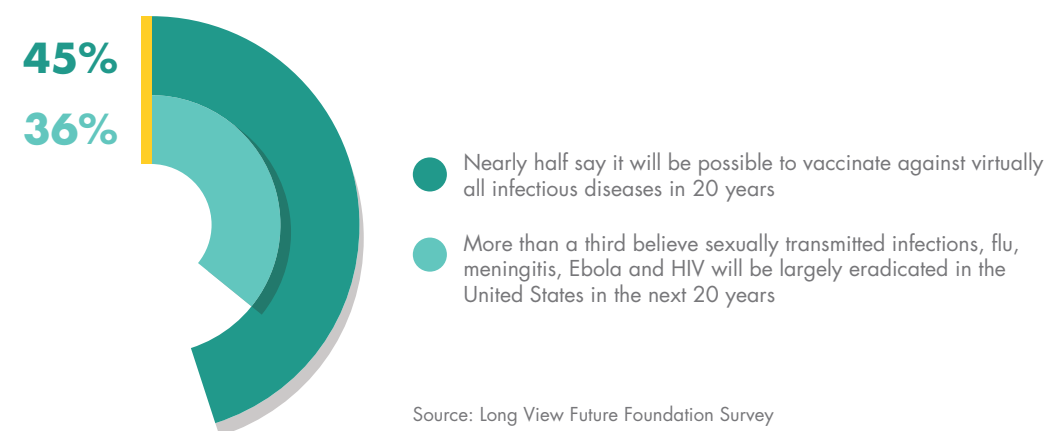
In less than two years from the start of the Ebola outbreak in Africa, one study enrolled over 8,000 participants to test the safety and efficacy of a potential vaccine.²³

TREND AT A GLANCE

- Infectious disease will continue to be a global burden.
- Confidence in science and medical progress may encourage greater risk-taking in the short term as consumers believe the health system can heal them later.
- Greater movement of populations and increasingly diverse societies will present new challenges for controlling infectious diseases.
- Overuse of antibiotics will drive more antibiotic resistance, adding a new layer of challenges in the fight against infectious diseases.

Figure 6

CONSUMER OPTIMISM: FIGHTING INFECTIOUS DISEASE



Views On Infectious Disease Present Some Striking Contrasts

While consumers are optimistic about our ability to fight currently known infectious diseases, 84 percent predict that new infectious diseases will inevitably replace them.¹ While greater access to health information should improve consumer knowledge about behaviors that can stop the spread of infectious diseases (e.g., good hygiene, better protection for healthcare workers, practicing safer sex), infectious diseases still spread with ease. For example, despite access to information about the dangers of risky sexual behavior, U.S. cases of sexually transmitted infections are on the rise.²⁴

Stark contrasts between fears and actions endure: two-thirds of U.S. adults worry about having effective antibiotics available in the future, but about 30 percent of all antibiotics prescribed in the United States may be inappropriate.^{1,25} For example, in one study, almost two in 10 adults sought and took antibiotics inappropriately for a sore throat.²⁶ "Antibiotic overuse is one cause of antibiotic resistance," according to Dr. Alan Taege. "If patients don't leave the doctor's office with a prescription for an antibiotic for their cold, they think they have been deceived and cheated. Cutting down on these needless antibiotic prescriptions is important."

While nearly eight in 10 (77%) U.S. adults say tackling infectious diseases should be one of the main objectives of U.S. healthcare over the next 20 years, three in 10 think it's parents, not medical experts, who should be able to decide whether to vaccinate their child.^{1,27}

// The whole world has to deal with infectious diseases because bacteria and viruses spread rapidly and they don't care about political borders, they don't care about ethnic distinctions. //

– Miriam Barlow, PhD

// We are on the verge of seeing vaccines pop up for dengue and Ebola. But we have a long way to go for an HIV vaccine because it's such a tricky virus. //

– Alan Taege, MD

HIV Implication: Medical experts say HIV is unlikely to be eradicated in the next 20 years, but its impact can be reduced greatly. Increasing access to and education about proven HIV prevention methods for individuals who are not infected can help them maintain their negative status.

Better access to testing and connecting those who test positive with early and ongoing treatment and self-management education can improve future health and reduce the risk of transmitting the virus to others.

The growing risk of antibiotic resistance will be especially dangerous for people with HIV because of their already compromised immune systems.



HIV IN AMERICA:

DECADES OF PROGRESS, BUT A LONG WAY TO GO

For many people with HIV, early detection and proper treatment have made the infection a long-term, manageable chronic disease.⁸ While this is a testament to remarkable progress against the virus, a new challenge has emerged: an aging and growing HIV population. Today approximately a quarter of people living with HIV in the United States are over age 55 and in the current decade alone, officials expect a 38 percent increase in the number of Americans living with HIV.^{28,29} The advances in care and improved life expectancy since the beginning of the HIV epidemic are major achievements, yet they are also leading to greater complacency about HIV among those at risk of infection, particularly young people.³⁰ In fact, today those age 13 to 24 account for more than 20 percent of new HIV diagnoses.³¹ Similarly concerning, more than four in 10 young adults between age 18 and 24 are living with HIV and do not know it.³¹



“ Young people tell me that HIV isn’t that big a deal to them anymore. ”

– Margaret Reneau, EdD
National Black Leadership
Commission on AIDS

FAST FACTS: HIV IN HIGHLY IMPACTED POPULATIONS

While anyone who has sex without a barrier or shares needles is at risk for contracting HIV, the HIV: The Long View Coalition recognizes the importance of allocating additional attention and resources to populations highly impacted by HIV.

African Americans are the most affected of all races and ethnicities.

African Americans account for **40% OF PEOPLE LIVING WITH HIV** in the United States

and more than 40% of new diagnoses every year.³²



TWO IN 10 PEOPLE



living with HIV in the United States are **Hispanic or Latino**. The rate of new infection is **3X** higher in Hispanic/Latino men and **4X** higher in Hispanic/Latino women than in their non-Hispanic/Latino counterparts.³³



Transgender women are among those at **HIGHEST RISK FOR HIV INFECTION**



with African-American transgender women at even higher risk than their white and Hispanic counterparts.³⁴ Some of the reasons for this increased risk are a high rate of sex work and multiple sex partners, as well as violence, stigma and discrimination aimed at the transgender population. Other factors include drug and alcohol abuse, mental health disorders, homelessness and negative healthcare encounters, among others.³⁴ Data on transgender women are not uniformly collected nationwide, therefore health experts rely on data collected by local health departments and other scientists to provide a picture of the impact of HIV in this community.

Men who have sex with men (MSM) account for

60%

of the 1.2 million people living with HIV in the United States and for two-thirds of the new HIV cases each year.³⁵ MSM in the South are disproportionately affected by HIV compared to MSM in other parts of the country.³⁶

If current trends continue in the United States

50%

BLACK GAY AND BISEXUAL MEN

25%

LATINO GAY AND BISEXUAL MEN

will be diagnosed with HIV in their lifetime.³⁷

Poverty and the risk of HIV are linked for people living in **urban areas** of the United States.³⁹



The chance of having HIV increases as income decreases among the urban poor, regardless of their race or ethnicity. The overall rate of HIV in U.S. urban poor areas is similar to the rate in low-income countries that have generalized HIV epidemics, such as Haiti and Guyana.⁴⁰

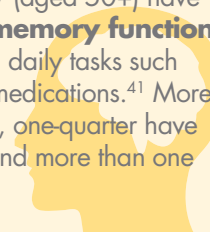
Risks Among Women and Young Americans

20% 20% of new diagnoses are in **women**, and nearly 90% of cases in women are due to heterosexual sex.³⁸

>20% More than two in 10 new infections are in **young people** age 13 to 24 years.³¹

>40% More than four in 10 young adults age 18 to 24 years living with HIV **do not know they have it**.³¹

Nearly half of **older people** with HIV (aged 50+) have **changes in their mental and memory functions** and may report difficulty completing daily tasks such as housework and managing their medications.⁴¹ More than one-third have some vision loss, one-quarter have suffered a fall in the previous year and more than one in 10 are hearing impaired.





THE FUTURE OF HIV IN AMERICA:

A LOOK FORWARD

The HIV: The Long View Coalition met in New York City to discuss the five core healthcare trends identified by the Future Foundation, explore what they will mean for the future of individuals living with or at risk for HIV, and devise action steps to improve HIV prevention and care 20 years from today. This group developed recommendations to help individuals and communities take full advantage of health advances and mitigate health challenges through the choices they and their healthcare providers make today.

The founding members of HIV: The Long View Coalition represent HIV-focused organizations and organizations that advocate for the communities likely to be impacted by HIV in the future. Together, their decades of experience inform this section of the HIV: The Long View Report.

Public health officials expect a 38 percent jump in the number of Americans living with HIV over the current decade alone.²⁹

HEALTHCARE ACCESS AND AFFORDABILITY: KEYS TO HIV CARE AND PREVENTION

The rate of uninsured Americans is at an all-time low.⁹ Having health insurance and access to regular preventive care is especially important to the long-term health of people with HIV and those at risk of infection. But even if the cost barriers are removed, these communities face additional barriers – stigma and discrimination – when they seek counsel about prevention options, testing and care.⁴²

Access is also particularly challenging for people living in rural areas because they have fewer HIV specialists near them.⁴³ This may be a particular problem in the South, which accounts for nearly seven in 10 rural HIV cases. Access to HIV prevention education, treatment and care is also a concern for economically disadvantaged Americans living in urban areas, who are hit especially hard by HIV.³⁹

“Overcoming all access barriers is so important because testing and early treatment with antiretroviral therapy is important not only for the individuals with HIV but for control of the HIV epidemic itself.”

*– Theresa Mack, MD, MPH,
HIV/AIDS physician in New York
City’s Harlem neighborhood;
American Academy
of HIV Medicine Member*

“Access to care is one important issue – the care you receive once you get access is the next one. Doctors usually don’t ask women about their sexual health. If there is a discussion about sexually transmitted infections and HIV, it’s the woman who usually initiates these conversations. Healthcare providers have to make these conversations a part of every woman’s annual checkup. After all, women account for one in five new HIV infections in this country.”

– Vera Sizensky, HealthyWomen

As More People Have Access To Healthcare In The Future, The HIV: The Long View Coalition Believes HIV Will Be Impacted In The Following Ways:

- More widespread HIV testing will improve health outcomes and lead to better prevention and control of the HIV epidemic.
- People living with HIV will have better access to specialized HIV care.
- The HIV healthcare provider workforce will expand beyond specialists to accommodate the growing number of people living with HIV.
- The aging population of people with HIV will need more care for non HIV-related chronic conditions, such as high blood pressure, brittle or weak bones, obesity, kidney and liver disease and certain forms of cancer, among others. The combined effects of aging, the natural progression of HIV and long-term HIV treatment on the development and exacerbation of chronic conditions is relatively unknown. Each of these conditions may require medication; taking multiple medications increases the risk of side effects and drug interactions.

Recommendations

- Medical professionals providing primary care must be trained so they have the skills and sensitivity needed to provide HIV care and counsel about all methods of prevention, treatment (including the importance of self-management) and care.
- New care models must focus on patient engagement and fully integrated care for people with HIV of all ages (i.e., care that addresses all aspects of the person’s health, not just HIV).
- Stigma must be reduced to improve access to prevention and HIV testing, and also to improve access and retention in care.
- The healthcare system will need to adopt different, more tailored HIV testing models that increase testing rates and create a streamlined linkage to care system, especially for groups that are at high HIV risk.

NEW PREVENTIVE MEDICINE TECHNOLOGY: A PATHWAY TO BETTER HIV PREVENTION AND CARE

Preventive medicine technology is becoming more common. Expanding access to new technologies can create new pathways for better prevention of chronic conditions that are common in everyone, including those living with HIV, as they age.

“ Nowhere is democratization of new technologies more important than HIV medicine. We must work toward equal access to technology so everyone can benefit. Women, for example, often put their own health last – caring for children, husbands and parents first. Access to new technology can help women connect with a healthcare professional more easily. ”

– Tom Conti, HealthyWomen



PEP (post-exposure prophylaxis) involves taking anti-HIV medications as soon as possible (within three days) after you may have been exposed to HIV to reduce the chance of becoming HIV positive.⁴⁴

PrEP (pre-exposure prophylaxis) is when people at very high risk for HIV take HIV medicines daily to lower their chances of getting infected. While PrEP can significantly reduce the risk of HIV infection if taken daily, it is much less effective if it is not taken consistently. It is recommended that PrEP be combined with condoms and other prevention methods as part of an overall risk reduction strategy.⁴⁵

The HIV: The Long View Coalition Believes New Preventive Medicine Technology Will:

- Increase access to and quality of care for individuals living with or at risk for HIV.
- Help people with HIV manage the virus itself and other chronic conditions.
- Decrease the rate of new HIV infections.

Recommendations

- Leverage new technology to provide more opportunities for dialogue between patients and healthcare professionals about prevention, testing and treatment, including the importance of self-management.
- Encourage use of new technology to help reduce new infections by encouraging better use of proven prevention tools (e.g., condoms, PrEP, PEP, viral suppression in people with HIV, engaging in less risky sex, not sharing needles) and to help manage other chronic conditions.
- Work to improve access to technology among vulnerable groups, which may help alleviate current and future health inequalities.
- Overcome consumer fears about new technologies, including those about information privacy and security.

PEOPLE WITH HIV ARE LIVING LONGER, GETTING MORE AGE-RELATED CONDITIONS

Research shows that about half of all U.S. adults have a chronic health condition and one quarter has at least two chronic health conditions.⁴⁶ Chronic diseases are more common as we age, so now that people with HIV are living longer, they will face more of these often debilitating conditions.⁴⁷ With over 85 percent of U.S. healthcare costs associated with chronic diseases, the message is clear – it is much better to prevent chronic conditions than to treat them – and this is especially true for people with HIV.⁴⁸

“ I tell everyone with HIV to think about their long-term health. Diet, exercise, not smoking, getting enough rest and taking medications as recommended – these choices will have a big impact on your health later in life. This is very important for black and Hispanic people because even without HIV they are already at higher risk for some chronic diseases, like diabetes. ”

– Margaret Reneau, EdD, National Black Leadership Commission on AIDS

“ To have the best chance of feeling good as you age, you need to start making healthy decisions much earlier. This is especially true if you have HIV. ”

– Kathleen Zuke, MPH, National Council on Aging

Now That Antiretroviral Therapy Is Leading To Long-term Survival For People With HIV, The HIV: The Long View Coalition Believes...

- The number of older people with HIV will grow, and we will spend more resources on prevention and management of their chronic conditions.
- Quality of life will become a much more important measure of health.

Recommendations

- The healthcare system, policy makers and patients must work toward an integrated care model for people with HIV, one in which healthcare professionals treat the whole person, not just his or her HIV viral load. Integration with HIV community groups and services can also play an important role.
- Primary care providers will need training to become proficient in HIV prevention counseling, as well as HIV testing and treatment. Additionally, more providers will need to be trained as HIV specialists.
- Research is needed to understand the relationship between HIV, inflammation, aging and the risk of chronic conditions.
- Quality of life measures for individuals living with or at risk for HIV must be developed, tested and validated before they can be deployed.
- People with HIV need more information about their increased risk of chronic conditions (such as high blood pressure, brittle or weak bones, obesity, kidney and liver disease and certain forms of cancer) and methods to manage them. They should also be aware that the long-term effects of aging on these chronic conditions in people with HIV is relatively unknown.
- Improve information sharing among healthcare providers and develop and maintain care and treatment guidance around clinical issues related to persons aging with HIV.
- Improve education for those age 55+ on the risk of contracting HIV.

UNIQUE CHALLENGES MAY DELAY BENEFITS OF PERSONALIZED MEDICINE FOR PEOPLE WITH HIV

Personalized medicine is already delivering results for people with cystic fibrosis, cancer and other conditions.^{49,50} Developing personalized approaches to medical care requires large-scale data collection from similarly affected people.⁵¹ Getting people with HIV into care and then getting them to share data is an obstacle that must be overcome if people living with or at risk for HIV are to benefit from advances in personalized medicine in the next 20 years.

The HIV: The Long View Coalition Envisions That Personalized Medicine Will...

- Have a large impact on HIV treatment selection and management and the prevention of chronic conditions in people with HIV.
- Be supported by health information technology that allows for real-time, secure data sharing and analysis to make medical decision making faster, more precise and in alignment with treatment guidelines.

Recommendations

- More research is needed to apply personalized medicine to people with HIV.
- Large-scale sharing of data from HIV studies, between disciplines and by HIV patients is essential to the success of personalized medicine.
- People seeking HIV testing or prevention counseling, as well as those living with HIV, will need assurance that their information is secure and that sharing it will not impact them negatively.

“ We need people with HIV to come see us and to share their information for their own benefit and the benefit of others. If we have any hope of this happening, we need to remove all the stigma and judgment in the healthcare system and in our society that holds people back from coming in and talking honestly to people like me. ”

*– Theresa Mack, MD, MPH,
HIV/AIDS physician
in New York City’s
Harlem neighborhood;
American Academy of HIV
Medicine Member*

“ Not many years ago a genetic test was introduced that predicted whether an HIV patient would have a negative reaction to an antiviral medication. That was the first time we could run a test and tell an individual patient if the treatment would be safe for him. We will see much more personalized medicine in the future. ”

– Alan Taege, MD

IMPORTANCE OF IMMEDIATELY CONNECTING PEOPLE WHO TEST POSITIVE TO CARE

Some individuals with HIV will seek care regularly because they understand it will help them stay healthy. Others may delay treatment because they believe they can be “cured” or at least made well in the future when they begin to have symptoms of the disease.

This way of thinking is dangerous, according to Kelsey Louie, Chief Executive Officer of GMHC in New York City, the world’s first provider of HIV/AIDS prevention, care and advocacy. “People with HIV need to understand that even though medication can keep their viral loads low, their immune systems are made weaker by having HIV. The longer you remain untreated, the more damage that’s done.”

In The Next 20 Years, The HIV: The Long View Coalition Envisions...

- HIV eradication will remain the ultimate goal.
- The spread of HIV will be significantly slowed through expanded HIV prevention efforts, combined with early testing, education, treatment and treatment adherence leading to viral suppression.
- Viral suppression in more people with HIV will lead to more people living longer with HIV than ever before.
- Maintaining the strongest immune system possible will be important for people with HIV to provide as much protection as possible against other circulating infectious diseases.

Recommendations

- Significant investment and resources are needed to support policies and HIV interventions aimed at prevention and viral suppression.
- Highly impacted communities (MSM, African American, Hispanic/Latino, transgender) need to be engaged to formulate prevention and treatment engagement strategies for their members.
- Early HIV treatment and self-management is an essential part of maintaining the strongest immune system possible, but people with HIV need to understand that infection will always lead to some damage to the immune system and other aspects of health.

“ Some people living with HIV opt out of treatment because they incorrectly assume they don’t need medication while they feel well. But what they often don’t know is that when they are in care, their viral load is more likely to be suppressed making them much less likely to transmit HIV to others. Healthcare providers need to stress this for the good of the patient and their partner. ”

*– Amber McCracken,
American Academy
of HIV Medicine*





HIV: THE LONG VIEW COALITION

CALLS TO ACTION

The **HIV: The Long View Coalition** encourages everyone living with or at risk for HIV to make informed decisions today to prepare themselves for a healthier life in the coming 20 years. The Coalition also calls on every healthcare provider, their professional societies, patient advocates, policymakers and other stakeholder groups engaged in health improvement to encourage proactive choices by those living with or at risk for HIV around healthy living, prevention and optimal care today for the benefit of them and of communities in the Long View.

Consistent with the goals of the National HIV/AIDS Strategy, the below **Calls to Action** aim to reduce new HIV infections, increase access to care and improve health outcomes for people living with or at risk for HIV, reduce HIV-related health disparities and inequities and achieve a more coordinated national response to the HIV epidemic.⁵²



1. Eradicate stigma related to sexual behavior, sexual health and HIV status so that everyone who needs HIV care and counseling about prevention will be comfortable seeking it.

Why this matters: Stigma, fear of judgment and discrimination prevent individuals living with or at risk for HIV from seeking appropriate medical care, speaking openly with their healthcare team or even getting tested. It is essential that they can access the healthcare system for current health needs to give them the best chance for a healthier future. Reducing stigma will also help patients feel more secure in sharing their personal data, which is vital to developing personalized medicine options for everyone living with HIV.



2. End the “one size fits all” approach to HIV prevention, treatment and education by tailoring HIV-related efforts to specific at-risk populations whenever possible.

Why this matters: The population living with HIV is diverse. Highly impacted populations like African Americans, Hispanics/Latinos, MSM and transgender women each have unique educational needs and factors that will motivate them to action. But even as information is tailored to specific audiences, including those of younger and older ages, it should be harmonized in its underlying messages, such as:

- Everyone who has sex is at risk when it is without a condom
- Regular testing and early and continuous antiretroviral treatment are essential for individual health and epidemic control
- The best chance of long-term health for people living with HIV includes making active decisions and engaging in self-management practices, such as healthy lifestyle behaviors, to protect themselves against chronic diseases of aging and mental health issues that are common in people living with HIV



3. Push for 100 percent adoption of evidence-based guidelines in every U.S. healthcare practice to ensure access to preventive counseling and care, regular HIV testing, and immediate connection and retention in care for those who test positive.

Why this matters: Early HIV testing and antiretroviral treatment are the cornerstone of good patient care and essential to controlling the HIV epidemic. But HIV patients require more – their fully integrated care includes counseling and self-management education to prevent or delay the onset of age-related conditions that disproportionately affect people with HIV even more so than those who are HIV-negative. HIV specialists and non-specialists, who will be called on to provide more HIV care in the coming years, need to be educated and prepared to deliver the best care possible.



4. Develop pathways to collect more HIV patient data to enhance the body of knowledge about HIV, inform treatment algorithms and ensure people with HIV have every opportunity to benefit from advances in personalized medicine.

Why this matters: The general public is uncomfortable sharing their health information; we can expect this to be an even bigger issue for people with HIV due to the long history of stigma attached to an HIV diagnosis and even seeking HIV prevention counseling. Establishing pathways to collect more HIV data from patients is not just about technical capacity to collect and integrate electronic health data; it will rely on our ability to remove stigma and ensure that data are not used in any punitive way against people with HIV.



5. Educate and empower every person living with or at risk for HIV to take charge of their prevention and care now to prevent or delay the onset of chronic conditions in the future.

Why this matters: Better access to healthcare prevention and treatment, including counseling and self-management education, provides consumers with an opportunity to take a more active role in their healthcare. Changing media, including social media, are facilitating delivery of more focused messages to the diverse groups that make up the HIV community. This combination of heightened communication with healthcare professionals, whether in-person or virtual, and increased uptake of communications messages provides an opportunity to educate and empower more people living with HIV or at risk to make more informed decisions for their long-term health now.



RESOURCES

[AIDS.gov](#) expands the visibility of timely and relevant federal HIV policies, programs and resources; increases use of new media tools by government, minority and other partners to extend the reach of HIV programs to communities at greatest risk and increases knowledge about HIV and access to HIV services for people most at risk of or living with HIV.

[AIDSinfo](#) is a service of the U.S. Department of Health and Human Services, offering access to the latest, federally approved HIV/AIDS medical practice guidelines, HIV treatment and prevention clinical trials and other research information for health care providers, researchers, people affected by HIV/AIDS, and the general public.

[AIDSvu](#) provides an interactive online map illustrating the prevalence of HIV in the United States. The national, state and local map views allow users to visually explore the HIV epidemic alongside critical resources such as HIV testing center locations, HIV treatment center locations and NIH-funded HIV prevention and vaccine trials sites.

[Centers for Disease Control and Prevention](#) provides comprehensive information about HIV in the United States including the latest data on new infections and the number of American living with HIV, risk behaviors and prevention, HIV testing, guidelines and recommendations, and program resources for organizations working to prevent HIV.

[The National HIV/AIDS Strategy](#) is a five-year plan that details principles, priorities, and actions to guide our collective national response to the HIV epidemic. The 2020 update reflects accomplishments and scientific developments since 2010 and charts a course for collective action across the Federal government and all sectors of society to move us towards the Strategy's vision.

[World Health Organization](#) tracks and reports data on the global AIDS epidemic, provides population-specific information (e.g., MSM, transgender, sex workers, etc.) and makes recommendations to help stem the impact of HIV across the world.

More Information On HIV From The Individual Coalition Members

[American Academy of HIV Medicine](#): www.aahivm.org and www.hiv-age.org

[Gay Men's Health Crisis](#): www.gmhc.org

[HealthyWomen](#): Living With HIV: What Women Need to Know, as told by Maria Davis [www.healthywomen.org/content/article/living-hiv-what-women-need-know-told-maria-davis]

[National Black Leadership Commission on AIDS](#): www.nblca.org

[National Council on Aging](#): Fact sheet on the Chronic Disease Self-Management Program, an evidence-based program for managing chronic conditions like HIV. [https://www.ncoa.org/wp-content/uploads/Chronic-Disease-Fact-Sheet_Final-Sept-2015.pdf]



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