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MAPPING PATHWAYS

Community-driven
strategies for the use of
antiretrovirals as prevention

United States Workshop Report

Mapping Pathways Workshop Report

Community-driven strategies for the use of antiretrovirals as prevention

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Preface

Launched in 2011, the multi-national Mapping Pathways project provides a community-led, research-driven, multi-layered synthesis about the use of antiretroviral-based prevention strategies. Project partners included RAND, AIDS Foundation of Chicago, AIDS United, Desmond Tutu HIV Foundation, Naz India, and Bairds CMC. After two years of data collection and analysis in the United States, South Africa and India, we published a synthesis in a report titled *Mapping Pathways: Developing Evidence-Based, People-Centred Strategies for the Use of Antiretrovirals as Prevention*.

In the latter half of 2013, a subset of the Mapping Pathways team from RAND Europe and AIDS Foundation of Chicago conducted a series of three “knowledge exchange” scenario development workshops with a focus on the United States, held in San Francisco, California; Atlanta, Georgia; and Washington, DC. The aim of the workshops was to further share the findings of the report and to continue enhancing the community-driven, locally informed approach to the wider evidence base for ARV-based prevention.

This report summarizes the outputs of those three workshops. The intended audience extends beyond those who attended the workshops, to interested

policymakers, researchers, community members, advocates, activists, and other stakeholders in the HIV community. We aim to provide a report that is thought-provoking and one which will stimulate new ideas and thinking amongst local, national, and global communities engaged in HIV prevention.

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We would also like to thank the 62 people who attended the workshops in each city and gave us the generous gift of their time, their knowledge, and their enthusiasm for the topic over two days.

We would like to give credit and thanks to Jessica Plumridge for layout and design of the publication. We extend our deep appreciation to the Gilead Foundation for their unrestricted educational grant and support of the workshops in 2013.

Finally, we thank our Quality Assurance Reviewers Surajkumar Madoori, AIDS Foundation of Chicago, and Dr. Emma Pitchforth, RAND Europe, for their peer review of the report and constructive comments.

Abbreviations

ACA	Affordable Care Act
ARV	antiretroviral drug
CBOs	community based organizations
CDC	Centers for Disease Control and Prevention
FDA	Food and Drug Administration
HIV	Human Immunodeficiency Virus
HIV/AIDS	Human Immunodeficiency Virus, Acquired Immunodeficiency Syndrome
IDUs	injection drug users
MPTs	multipurpose prevention techniques
MSM	men who have sex with men
NGOs	non-governmental organisation
NHAS	National HIV/AIDS Strategy
PEP	post-exposure prophylaxis
PEPFAR	President's Emergency Plan For AIDS Relief
PEST	Political, Economic, Social, Technological
POTUS	President of the United States
PrEP	pre-exposure prophylaxis
SOPs	standard operating procedures
STI	sexually transmitted infection
TLC+	testing, linkage to care plus treatment
USCA	United States Conference on AIDS
USPSTF	United States Preventive Services Task Force

1

**AN INTRODUCTION
TO MAPPING
PATHWAYS**



Mapping Pathways – Building a community-led evidence base

We are now in the fourth decade of the global HIV pandemic, and it is clear that the array of commonly deployed HIV prevention options we have long relied on is insufficient. Millions of new HIV infections continue to occur across the globe every year. New pathways to prevention that are based on novel strategies and technologies and coupled with an enhanced assessment of their likely impact are needed to reduce HIV incidence.

Antiretroviral (ARV) drugs are opening up new options for HIV prevention, such as “treatment as prevention” (referred to here as “TLC+,” or testing, linkage to care, plus treatment), pre-exposure prophylaxis (PrEP) and post-exposure prophylaxis (PEP) – all currently available. Additionally, vaginal and rectal microbicides utilizing ARV drugs are being studied in gel and ring formulations, among others. When it comes to implementation, there are complex challenges associated with all of these strategies, related to access, behavioral and health implications, and cost. Decisions about whether and how to implement any strategy must draw on multiple data sources, in addition to the results of clinical trials. The viewpoints and knowledge of community members and stakeholders must be integrated into the evidence base.

Launched in 2011, the multi-national Mapping Pathways project provides a community-led, research-driven multi-layered synthesis about the use of ARV-based prevention strategies. After two years of data collection and analysis in the United States, South Africa and India, project partner RAND published this synthesis on 19 June, 2013 in a report titled *Mapping Pathways: Developing Evidence-Based, People-Centred Strategies for the Use of Antiretrovirals as Prevention*.

In the latter half of 2013, the Mapping Pathways team conducted a series of three US-focused “knowledge exchange” workshops, held in San Francisco, California; Atlanta, Georgia; and Washington, DC. The aim of the workshops was to further share the findings of the report and, more importantly, to continue enhancing the community-

When it comes to implementation, there are complex challenges associated with all of these strategies, related to access, behavioral and health implications, and cost.

driven, locally informed approach to the wider evidence base for ARV-based prevention. This report summarizes the outputs of those three workshops, and synthesizes the rich body of information and ideas captured within them. We do not attempt to provide any new research outside these workshops, but we hope the ideas encompassed in the following pages serve as thought-provoking “minutes” for those who attended the workshops and that the report will stimulate new ideas and thinking amongst local, national, and global audiences engaged in HIV prevention.

The Mapping Pathways Report – An adaptive approach

A resource for communities and policymakers, the Mapping Pathways report from 2013 includes evidence, voices and views about ARV-based prevention strategies from across diverse contexts, and lays out a future agenda for policymaking and further research. The findings may be used to help inform the research and analysis needed in order to enable the formulation of coherent, evidence-based decisions for HIV treatment and prevention strategies.

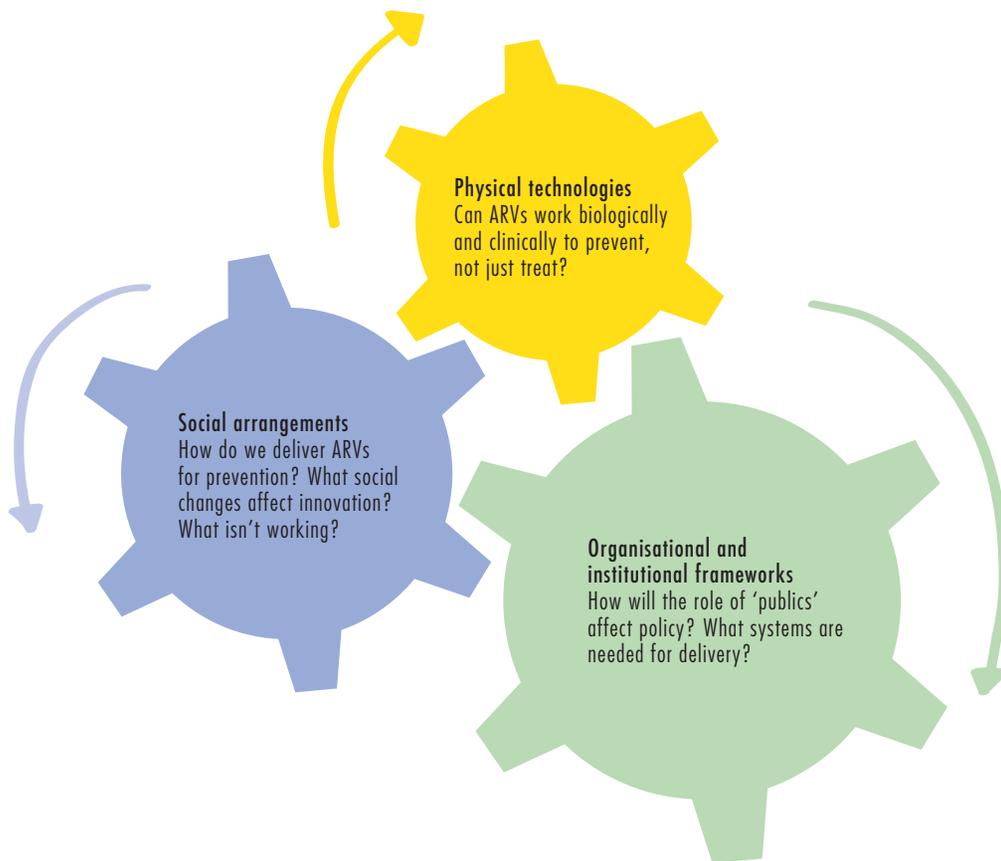


Figure 1-1
The Mapping Pathways adaptive approach

The empirical evidence base was assessed through a systematic literature review conducted at two time points in 2011 and 2012; a grassroots community-based online survey taken to understand the awareness and concerns of individuals; semi-structured interviews with stakeholders and “grasstops” community leaders carried out to identify information needs for decision making; and a Delphi-based, online ExpertLens survey conducted to understand key differences, areas of divergence, and fault-lines in the way experts interpret the evidence.

Hundreds of community respondents from the United States, South Africa, and India were engaged, including dozens of key stakeholders such as policy experts, program implementers, healthcare professionals and advocates. Participants rated the importance of various ARV-based prevention

strategies, shared their perspectives regarding barriers to implementation, and suggested the kinds of information they needed to make informed decisions about whether to implement any ARV-based strategy.

Our analysis showed that community members and stakeholders thought there were three key challenges to overcome in order to maximize the prevention potential of ARV drugs:

- Structural issues such as community-level living conditions that affect access, and other social determinants of healthcare as important as individual-level behaviors.
- More information about implementation is needed by policymakers, funders and prevention programmers in order to determine what mix of ARV-based prevention strategies, if any, are

- appropriate in various settings.
- ARV-based prevention strategies must be adapted for local contexts, as reflected in the report's foreword – “All Science is Local” – written by Archbishop Desmond Tutu.

A methodological innovation in itself, the adaptive approach used in Mapping Pathways to inform the evidence base for policy development involved experts, stakeholders, and communities engaged in reflexive and iterative exchanges of knowledge. These diverse perspectives highlight strengths and weaknesses associated with each prevention strategy. And the different perspectives of the evidence for each strategy bring into focus features that still need to be explored.

This adaptive approach builds on an analytical lens used in innovation literature (Nelson and Sampat, 2001; Chataway et al., 2010). Such a lens is appropriate because the use of ARVs for prevention, not just treatment, is in effect an innovation in a drug treatment regime. This requires us to think about the use of ARVs as prevention as something that would be implemented in the context of a dynamic innovation system. This concept was a central feature of the initial Mapping Pathways project and raised questions about the implications for biomedical innovation and prevention paradigms more broadly.

To answer these questions, (which are highlighted in the 2013 report, it is essential to distinguish between *physical technologies*, such as the protocols and clinical trials for developing safe and effective PrEP formulations, microbicides or TLC+ strategies, which prevent transmission at a biological level, and *social arrangements* (see Figure 1-1).¹ Social arrangements could include the firms that produce the drugs, the healthcare clinics that deliver the drugs, the community centers that provide education, counseling and testing, and the partnerships developed, which will be critical

¹ This concept is derived from the innovation policy literature – in particular Chataway et al. (2010) and Nelson and Sampat (2001) – which distinguishes between physical and social technologies and actual technical innovations. Here, the language has been adapted to refer to social arrangements, or partnerships.

Policy must evolve on the basis of evidence that captures the importance of contextual differences and the impact of a range of social, economic, and behavioral factors that shape outcomes.

to effective implementation. These two elements operate and interact against a wider *organizational and institutional framework*, including national and global funding structures, regulatory frameworks, healthcare systems and broader governance structures. We believe this framework is useful because it points to the idea that it is only by working together, with all three cogs turning and adapting reflexively with each other, that effective outcomes for ARV-based prevention strategies can be achieved.

Policy must evolve on the basis of evidence that captures the importance of contextual differences and the impact of a range of social, economic, and behavioral factors that shape outcomes. There is widespread agreement that this is particularly important in areas of policy where there are high degrees of uncertainty. It is with this awareness and philosophy that we approached the second phase of the Mapping Pathways project in which we aimed to more deeply understand local contexts, perspectives, and the implications for the future.

Table 1-1
Summary of workshop participants and focus

City	Number of participants	Types or organizations represented	Focus (if applicable)
San Francisco	21	Community-based organizations, public health, research, policy, and advocacy	N/A
Atlanta	20	Community-based organizations, public health, research, policy, and advocacy	Women and transgender women
Washington, DC	21	Community-based organizations, public health, research, policy, and advocacy	N/A

Mapping Pathways in 2013 – Enabling knowledge exchange

While the scientific evidence base for HIV prevention strategies utilizing ARV drugs continues to grow stronger, we must not forget the importance of community members and key stakeholders, whose perspectives, experiences, and collective wisdom are as essential to progress as statistically significant trial results. The empirical evidence base for ARV-based prevention implementation is still under development. Our earlier work showed that community and stakeholder interpretations of the science, in light of policy and program implementation, vary widely.

Because all science is local, the Mapping Pathways project continued its engagement with community stakeholders in 2013 by conducting three “knowledge exchange” workshops in the United States, one each in San Francisco, California; Atlanta, Georgia; and Washington, DC.² The remit for each two-day workshop was for participants to collaboratively develop a range of future scenarios and potential strategies linked to prevention programming goals and objectives. These cities were selected based on geographic diversity as well as the diversity of experience and expertise that can be found in each setting. San Francisco has been at the

leading edge of research and early implementation of ARV-based prevention strategies, in particular PrEP and TLC+, so many of the invited individuals brought an advanced understanding of the science, and its limitations, to the conversation. In Atlanta, we introduced a specific focus on the impact of the epidemic on African American women, and invited many Atlanta women and allies playing local and national leadership roles to consider the potential outcomes associated with ARV-based prevention through a female lens. The Washington, DC workshop included a number of national leaders working in prevention research, policy, and programming, as well as individuals with a deep understanding of congressional advocacy. While the Atlanta workshop was the only one with an explicit focus from the outset, we did encourage the discussions in San Francisco to focus more around local issues, and those in Washington, DC to revolve around national issues. The ways in which this affected the nature of the outputs from each workshop are discussed in the report below. All workshops were facilitated by members of the Mapping Pathways team from RAND Europe and AIDS Foundation of Chicago.

While each city’s invited participants had their own decided “flavor”, all three workshops included a mix of approximately 20 researchers, advocates, policy experts, public health officials, and service providers (see Table 1-1 above). They were diverse in terms of age, race, gender identity, sexuality,

² Though the initial Mapping Pathways research was transnational and conducted in the United States, South Africa, and India, the workshops could only be conducted in the United States due to resource constraints and limitations.

serostatus, and years in the field, with a blend of local to national experiences and perspectives. Some of the individuals in these overlapping groups and communities have been engaged with Mapping Pathways from the project's inception. We asked participants to draw upon the evidence base for ARV-based prevention outlined in our 2013 report, and, more importantly, each other's knowledge and experience. They were asked to think more than a decade into the future – to the year 2025 – and envision an array of outcomes associated with the implementation of ARV-based prevention.

After the three workshops were completed, the Mapping Pathways team analyzed the notes, flip charts, Post-its, and ideas captured over the cumulative six days of discussions. We aggregated and synthesized the different factors, issues, drivers, and scenario components both within individual workshops and across them. We looked for common themes and ideas from all three workshops, but also sought to identify where differences emerged. With this initial analysis as a foundation, we went on to develop our own, "Mapping Pathways" scenario for the future, drawing on the participants' ideas and concepts which we present here.

2

**SNAPSHOTS OF
THE WORKSHOP
DISCUSSIONS IN
EACH CITY**



A short introduction to the Mapping Pathways scenario workshops

A scenario is a logical and consistent picture of the future that is credible and challenging to stakeholders. Scenarios are not technically predictions, but can provide insight into future trajectories and possible courses of action. The analysis of scenarios enables us to identify and prepare for the potential implications of decisions made today.

The Mapping Pathways workshops developed a collection of scenarios around the deployment and outcomes of ARV-based prevention strategies, situated in the year 2025. Building on a foundation of learning and knowledge exchange, the scenarios were informed by the rich experience and expertise of the diverse participants and stakeholders in each room. Discussions of current issues and challenges informed and inspired the consideration of future opportunities.

Each scenario workshop lasted two days and was divided into four main components (see Figure 2-1). First, each workshop began with participant introductions and a short overview of the Mapping Pathways project. Second, each set of workshop participants identified the main issues and factors they felt must be considered in order for ARV-based

prevention to be successful. These issues and factors were categorized according to a PEST framework: Political & Regulatory (P), Economic (E), Social & Cultural (S), and Technological & Scientific (T). A PEST framework (also known as “STEEP” or “PESTLE”) is a commonly used analytical tool for identifying and categorizing basic trends and information about a range of different contextual issues which will influence any future situation.³ It helps in the analysis of the future because it can ensure the process is as exhaustive as possible as it provides a useful “checklist” of the types of factors one might need to think about. It also provides a useful way to quickly brainstorm the drivers and factors important to the group within a confined timeframe, as was the case in our workshops. Thus, the PEST framework was used to help the groups identify the main external factors and drivers that could impact effectiveness of ARV-based prevention strategies. Over 150 PEST factors were collectively brainstormed in the three workshops. Small groups were then formed to prioritize the four most important factors in each PEST category. The groups were asked to respond to the questions: *Why is the factor important to effectiveness of ARV-based prevention strategies? Is it more important for some strategies than for others?*

The third part of the workshop involved creating and narrating the scenarios for 2025. Participants working in small groups were asked to develop three different scenarios, building stories that imagined the year 2025 with the following three outcomes resulting from the implementation of ARV-based prevention strategies in their local context, although participants at the Washington, DC workshop were asked to think about implementation on a national level (see Figure 2-2).

These optimistic, pessimistic, and mixed outcomes, respectively, were given to participants as a guide and to help aid in the creation of the scenarios, however participants were also free to create their own outcomes as appropriate.

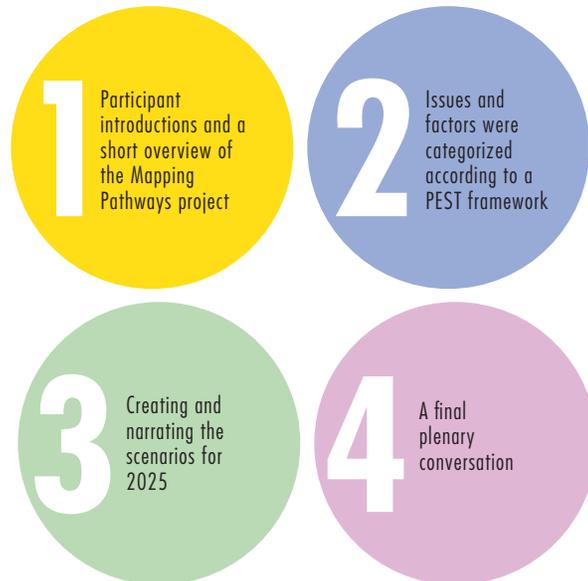


Figure 2-1
Approach to the workshops

³ See for example, Shoemaker, P. (1995). ‘Scenario Planning: A strategic tool for the future’. MIT Sloane Management Review: Winter 1995; Henry, A. (2008). Understanding Strategic Management. Oxford University Press; <http://hsctoolkit.bis.gov.uk/The-tools.html>.

By 2025 we have implemented ARV-based prevention and ...

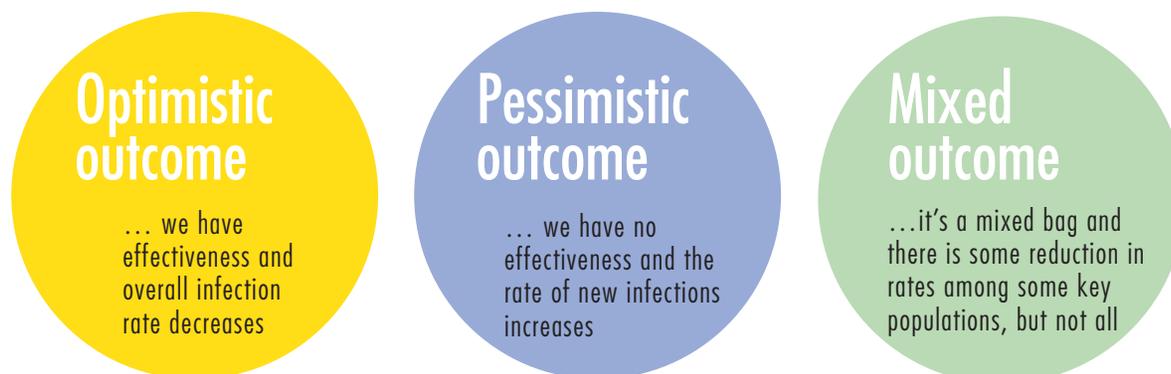


Figure 2-2
Three scenarios for 2025

Participants were asked to answer the following questions as they developed their scenarios:

- What is the mix of ARV strategies in the scenario? (PrEP, PEP, TLC+, Microbicides).
- What are the most important PEST factors to consider? How does each PEST factor play into the scenario? Do the factors intersect?
- How were the PEST factors addressed in each scenario? What is in place to make this happen?
- What is the name of your scenario?

Each group presented their scenarios and the relevant actions and actors that enabled the respective outcomes. Key themes and ideas stimulated a final plenary conversation to identify the most important information, messages, and actions needed to consider ARV-based prevention strategies in each local context.

PEST Themes

As discussed, a PEST analysis helped identify critical factors and drivers that could impact effectiveness of ARV-based prevention strategies. Factors included political and regulatory issues, economic considerations, social and cultural matters, and relevant technological and scientific developments. A discussion of the different factors identified in the workshops follows, with the more prominent themes and ideas aggregated across cities. There

were surprisingly few differences across cities in terms of the individual factors identified, though the resulting scenarios were quite different. We noted that participants found it particularly easy to come up with social and technological factors, but more challenging to name specific political and economic factors. There seemed to be a more limited amount of these, and some were viewed as particularly insurmountable, such as cost, which we will discuss.

Throughout the conversations, many ideas cut across different categories and factors. While this often led to very rich and nuanced dialogue in the workshops, it led to some difficulties in reporting, where the written word is far less dynamic. Where ideas significantly cut across categories we have noted this in the summaries. Some ideas occur multiple times, but are interpreted through different lenses.

A word about context – the Affordable Care Act

The Affordable Care Act (ACA) was passed by the US Congress and signed into law by the US President in 2010.⁴ It provides a new healthcare framework for the US, including a “Patients’ Bill of Rights” and a set of policy measures covering healthcare issues related to insurance coverage, healthcare costs and access to healthcare. Major provisions of the law are being

⁴ The full text of the Affordable Care Act can be found, as of 17 February 2014, at: <http://www.hhs.gov/healthcare/rights/law/index.html>.

enacted in 2014. As the ACA represents a distinct change in the healthcare system for the US, it was omnipresent in discussions in the three workshops. Participants in all three cities contemplated the current and future consequences of this law, ranging from the positive to the unknown to the potentially negative. They considered the impacts on people with HIV, on people at risk for HIV acquisition, and on the organizations that serve these communities, while taking note of the structures, policies, and procedures that would likely change.

Across all of the PEST factor categories, participants named issues that will shape and be shaped by the ACA and must be considered when

mapping pathways for ARV-based prevention, for example the cost of ARV drugs, access to health insurance coverage, and the role healthcare providers may play in this new context. Because of this presence across all the discussions, we have not highlighted the ACA explicitly as a stand-alone factor in the analyses, but rather one that shaped and affected the majority of other issues. Therefore, the PEST analyses below reflect, among other things, the prominence of healthcare reform, and reveals opportunities and challenges to access, understanding, management, and delivery of ARV-based prevention strategies.

As the ACA represents a distinct change in the healthcare system for the US, it was omnipresent in discussions in the three workshops.

Participants felt that more concerted political advocacy is needed, including the articulation of the connections between ARV-based prevention and the ACA.

to healthcare services, HIV-related and otherwise. It was noted that these types of restrictions are frequently felt most strongly by the very populations in which HIV is a significant problem.

The continuing evolution of the healthcare system in the context of the ACA cut across all discussions, but was particularly prominent in the political factor for two reasons. First, the potential opportunities it provided for integration of HIV prevention services in healthcare could lead to improved access and uptake. Participants noted there were many opportunities provided by the ACA to create a more holistic healthcare system with better health outcomes. However, there was also a concern that policies which restrict access to healthcare in relation to differing state regulations at both intra- and inter-state levels could have negative effects in future. These kinds of structural barriers to improving access to ARV prevention strategies were discussed in all three cities.

General attitudes towards HIV and the stigmatization (and criminalization) faced by people living with HIV underpinned “P” conversations as well. It was noted that PrEP users, PrEP advocates, and PrEP providers/prescribers could be labeled and judged in negative ways. Additionally, people felt that PrEP users might face scorn for their supposedly

“reckless” sexual behaviors, and PrEP advocates and providers may be criticized for somehow promoting or encouraging “risky” behavior.

Participants underlined the need for inclusive political and policy coordination in relating to education and capacity building activities in particular. They thought this should occur at state, community, and grassroots levels to bring in impacted groups from the outset. To this end, opportunities were identified for CBOs in helping to improve awareness and subsequently increase uptake. This could be done through utilizing social media to deliver information (see also discussions about the “S” and “T” factors). However, the political difficulties were seen to lie in identifying who would pay for education and awareness activities (see “E” factors) and how to get and maintain community buy-in.

A number of additional points emerged from discussions in the individual workshops:

- *Legislative change:* Some participants noted that improving legislation and regulations, such as removing the prohibition on gay men and other MSM giving blood, could reduce HIV stigmatization.
- *HIV exceptionalism:* In considering the difficulties in overcoming stigmatization, participants identified issues related to HIV exceptionalism, which has resulted in HIV having a distinct infrastructure from other areas of public health, including funding streams, policies, and healthcare procedures. This exceptionalism has allowed for resources, expertise, and other advances which have benefitted the HIV community and has had positive spillover effects into other groups as well. ARV-based prevention may entail integration of HIV testing, prevention and treatment procedures into general health policies and some felt that this could be a danger. For example, some groups highlighted the danger of certain providers using patient behavior and adherence metrics to make treatment and prevention decisions. However, opinion was divided as some felt that HIV exceptionalism could be a barrier to future progress as it may also undermine more holistic healthcare efforts

and could exacerbate the stigma faced by people living with and at risk of HIV.

- *Prevention guidelines:* Some participants highlighted that there was a need to improve and clarify the guidelines given to healthcare providers, and the HIV workforce for different kinds of ARV-based prevention strategies.
- *Restrictions to prescription provision:* Participants also discussed regulatory issues surrounding prescriptions to minors, including parental consent. Access to ARV-based prevention options for a range of communities was discussed, and in particular for victims of sexual assault (specifically with regard to PEP) and commercial sex workers. These were seen to raise complications in terms of “eligibility criteria”.
- *Access to policymakers:* The communities hardest

hit by HIV tend to suffer political and social disempowerment, and access to members of Congress and other centers of power and influence are limited.

- *Need for strategic partnerships:* Apart from the need for multi-level coordination mentioned above, some groups underlined the need to target other political and advocacy efforts for strategic constituency building, for example continuing to work with Medicaid and health insurance expansion efforts. Additionally, HIV treatment and prevention, exemplified by the use of ARV drugs for both, have blurred their former boundaries. Participants noted the need to combine advocacy forces across these domains, and to do the same with PrEP, microbicide, vaccine, and cure research communities as well.

E: Economic Factors



Figure 2-4
“Wordle” for economic factors

The core ideas which emerged from the economic factors are summarized in the “wordle” figure above (Figure 2-4). As is apparent from the figure, factors related to cost, resources, and the ongoing fiscal challenges dominated the discussion. It was recognized across all three workshops that the infrastructure needed to deliver ARV-based prevention would need significant investment. Cost consideration is at both the system level (for example, health agencies and clinics) as well as at the individual level. How will these costs change over time? Who will pay at different points?

Given the difficult recovery from the recession and the negative impacts of fiscal policy such as

sequestration, participants in all cities were deeply concerned about the long-term prognosis for the economy. They expressed anxiety over diminished resources for basic, clinical, behavioral, and implementation research on new HIV prevention technologies and fewer funds for CBOs delivering prevention and care services. It was thought that funding for prevention might be particularly disadvantaged due to the perceived propensity of policy makers and funders to focus on the short-term, whereas prevention requires long-term investments.

Another prominent economic factor identified in all cities was related to the costs of HIV prevention for individuals. It was noted, for example, that

Given the difficult recovery from the recession and the negative impacts of fiscal policy such as sequestration, participants in all cities were deeply concerned about the long-term prognosis for the economy.

insurance plans, including private plans and Medicaid, may not always cover services related to HIV prevention and could result in additional costs to individuals. A number of other barriers related to individual insurance coverage were also identified, including the influence individual insurers will have on uptake strategies, and access to prevention services for uninsured versus insured individuals. For women, it was thought that limitations on family planning may have a knock-on effect on HIV prevention and testing services.

In addition to these common themes across all three cities, a number of additional points emerged from discussions in the individual workshops:

- *Overcoming structural and cultural barriers:* Participants felt that the high cost of overcoming cultural barriers and correcting socioeconomic disparities between affected groups had a negative impact on access to prevention. In this sense, investment would be required to help change social attitudes.
- *Delivery systems:* There are of course many costs associated with actually delivering healthcare and the wider system in which it is provided. However, participants noted that the cost of monitoring healthcare delivery must be taken into account as this kind of data would be important to making delivery more effective in the future.
- *Intellectual property:* Patent restrictions can affect access and affordability of ARVs, as well as the availability of generics which can help to reduce costs. All of this will affect costs of ARV-based prevention in the future.
- *Reimbursement and incentives:* Participants felt that the economic incentive was missing for providers to engage people in prevention decisions.
- *Research and data gaps:* Participants felt that more effective streamlining and reallocation of costs could be achieved through increased investment in research beyond technology and biomedicine. For example, research which investigated the social, economic, and cultural determinants of access to HIV prevention and were considered key by some participants.
- *Private sector engagement:* Groups identified the potential for cost-sharing opportunities with the private sector, which could include partnerships to involve businesses in HIV and AIDS awareness, prevention, education, and mobilization.
- *New opportunities for community-based organizations to access resources:* In the context of funding challenges faced by most community-based organizations (CBOs) and the impending transformation of the Ryan White CARE Act, the ACA offers opportunities for organization to consider adopting fee-for-service payment models.

Organizational changes in CBOs are widely anticipated to occur out of economic necessity.

could be faced with decisions to redirect efforts so as to meet new government priorities (potentially at the cost of the communities they serve), merge with other organizations, or close their doors. Some participants stated that each of these avenues could result in a loss of population specific expertise and capacity to reach these communities, in addition to having a destabilizing effect on things like health education.

Distrust and mistrust of healthcare and research systems were named as significant barriers to reaching communities most impacted by HIV. Participants expressed that those smaller agencies with established trust within a community serve as a critical entry point to healthcare services. However, such agencies frequently have little capacity to operate in a medically-focused environment and it is possible that many such agencies will not survive. Loss of such agencies, participants noted, will lead to an inability to reach communities with HIV prevention in a culturally responsive way. Also of concern to workshop participants was the impact that agency mergers and new government policies would have on marginalized populations' ability to access culturally responsive services.

Participants in each city, but particularly in Atlanta where the workshop focus was explicitly on women, honed in on the challenges and opportunities that exist for women with regard to ARV-based prevention. Reproductive health providers see the majority of women on an annual basis. However, the vast majority of providers are not talking with the women they serve about HIV prevention, nor are they offering services such as HIV testing to

them. Such providers could serve as an effective and efficient access point for education and access to ARV-based prevention. Additionally, many women of reproductive age use hormonal contraceptive methods (the pill, Depoprovera, NuvaRing) that utilize delivery methods similar to those that exist or are in development for ARV prevention (PrEP, microbicide rings, long-term injectables).

In addition to these common themes across the cities, a number of additional points emerged from discussions in the individual workshops:

- *Addressing information gaps:* Participants suggested engaging and supporting community stakeholders and institutions in education efforts as well as making information about ARVs accessible for low-literacy audiences.
- *Shifting the prevention paradigm:* Providers need to reconceptualize risk, protection, and “safer sex” with a definition of HIV prevention that doesn't defer to “condoms only” but embraces new strategies, including those based on the use of ARV drugs.
- *Sexual health and pleasure:* Participants felt that discussions around sexual health are about wellness, and not simply the absence of disease. Linked to this was the idea that pleasure is important and should not be ignored in discussion of sexual health and wellness.
- *PrEP and sex workers:* Sex workers are often paid more if they don't use condoms. In these situations, PrEP offers a means of HIV protection that needs no negotiation with clients. That said, participants expressed the worry that sex workers who consistently use condoms could be coerced into using PrEP instead, increasing their risk for other STDs.
- *Personal empowerment:* Some participants commented that ARVs could help individuals take a more active role in their own health and HIV prevention, and that providers could help people at risk of HIV see ARV-based prevention as a tool of empowerment.
- *Holistic care:* Participants noted opportunity afforded by the ACA to integrate care, treatment, and prevention services into a more holistic system of care could help reduce HIV stigma.

T: Technological and Scientific Factors

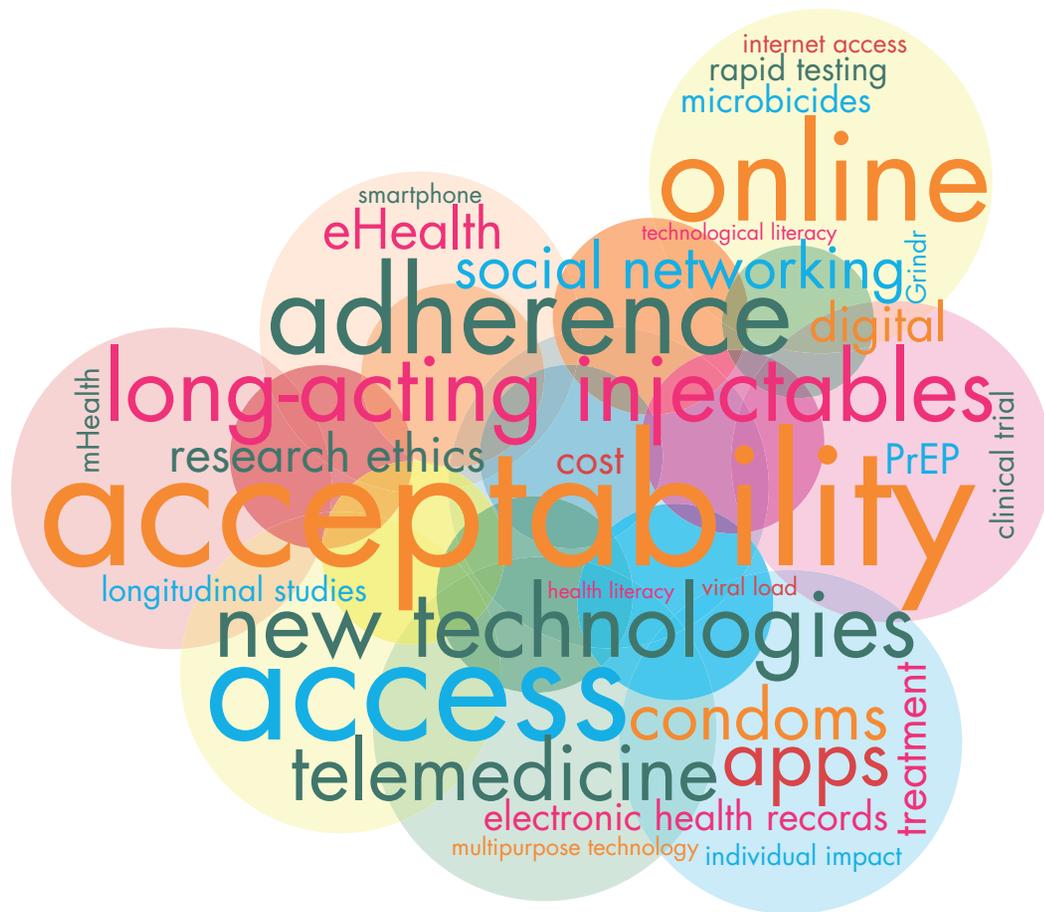


Figure 2-6
“Wordle” for technological and scientific factors

The workshop groups addressed the question of external technological and scientific factors in diverse ways that nonetheless shared common threads. Each group identified ways in which technological and scientific factors could both act as barriers to progress on ARV prevention as well as provide opportunities. What is most interesting is that even though individual new information and health technologies, such as online media, “apps”, and long-acting injectables stand out, the word at the center is “acceptability”. This was clearly a core issue for the majority of workshop participants – an HIV prevention technology may be safe and it may be

effective, but if it is not acceptable (and accessible) to the individuals for whom it is targeted, it is worthless.

Common themes regarding barriers to progress as well as opportunities for advancement were identified. While the areas of focus varied, all groups underscored the need for more research and data that is accessible to all. Moreover, any future research should be driven by community needs and be inclusive in terms of representation. For example, some noted the need for more transgender representation in research as well as behavioral research into adherence across diverse populations.

Similarly, belief in the potential for online

An HIV prevention technology may be safe and it may be effective, but if it is not acceptable (and accessible) to the individuals for whom it is targeted, it is worthless.

and mobile technologies to improve information-sharing, communication and delivery was common across all groups. Technological innovation in terms of medicines, new prevention technologies, improved HIV and viral load testing, and care provision was seen as an area for growth that could have a real impact on uptake, adherence, and outcomes. The scope offered by technology for more personal ownership of healthcare and empowerment with regard to care management also emerged as an interesting theme.

Finally, the opportunity for improved education of communities and providers around technology, science and ultimately, health and prevention came through as a key consideration for future progress on ARV prevention.

In addition to these common themes across all three cities, a number of additional points emerged from discussions in the individual workshops:

- *Specific research gaps:* Participants highlighted the lack of research on the use of incentives and associated ethical issues as well as the need for increased research investment in the use of nanotechnology to track pills. Additional

research gaps included the need for better metrics on prevention, for longitudinal studies on current uptake and behavior and for better data on long-term safety and toxicity as well as the need to address gaps in our understanding of viral suppression and in post-study or — clinical trial impact assessments for individual and communities. For a broader, more accurate information base, they identified a need to combine community and empirical data and to find better ways to track information online.

- *Online technologies and platforms for dissemination:* Online tools such as mobile apps were seen to offer opportunities for sharing HIV-related information, providing real-time electronic health records and complementing advances in healthcare itself (for example, telemedicine). eHealth and mHealth could have positive implications for drug delivery and improved uptake. The group also saw promise in the linking of social websites and healthcare providers to allow for easier access to provider expertise and/or care management. Groups did underscore the downside of increased reliance on online technologies, such as risks to privacy, and that many of our most vulnerable communities do not have regular access to these tools and could be neglected if we only focus on electronic engagement.
- *Literacy:* Participants focused concerns surrounding technological literacy and health literacy for progress with ARV prevention.
- *Improved communication:* They also underlined the importance of demystifying science in order to translate research effectively and of facilitating communication between researchers, providers, and the community.
- *Personal health ownership:* The potential for more individual ownership of healthcare was highlighted with the idea of online access to personal medical data, mobile apps for self-testing and risk assessment and an emphasis on the sharing of personal stories.

Scenario Themes – What does 2025 look like after implementation of ARV-based prevention?

The following tables provide brief snapshots of the three future scenarios developed by small groups in each of the city workshops. Small groups were asked to create titles for their scenarios and discuss the key features and PEST factors they forecasted for each outcome. Each participant was asked to share their perspectives and expertise, as well as their hopes and concerns, to inform scenario development. The resulting scenarios and notes include insights into the groups’ thinking as they contemplated what might happen with the implementation of ARV-based prevention, and the potential results we are faced with in the year 2025. Due to the nature of the work and limited time, some scenarios contain more details than others. We recommend reading this section to ascertain the scenarios’ “lessons learned” and to gain a sense of the different ideas

each group presented. The aspects that result in optimistic, pessimistic, and mixed outcomes are illustrative, and can provide guidance into current planning activities at city, state, and national levels. The opinions and reflections represented are those of the workshop participants, and do not necessarily reflect those of the Mapping Pathways project.

As a reminder, the scenarios were each developed according to the following three outcomes:

By the year 2025, we have implemented ARV-based prevention and...

1. ... we have effectiveness and overall infection rate decreases (*Optimistic*)
2. ... we have no effectiveness and the rate of new infections increases (*Pessimistic*)
3. ... it’s a mixed bag and there is some reduction in rates among some key populations, but not all. (*Mixed*)

Table 2-1
Future scenario – San Francisco

	Outcome: We have effectiveness, infection rate decreases	Outcome: No effectiveness, infection rate stays same	Outcome: It’s a mixed bag...
Group 1	<p><i>Title: HIP+</i></p> <p>The CDC prioritizes ARV-based prevention. Routinized testing is rolled out across different communities. Why this occurs:</p> <ul style="list-style-type: none"> • Pharmaceutical and insurance companies invest portion of profits into ARV-based prevention. • This investment covers advocacy, communications, positive messaging, etc and would help to promote uptake and effectiveness. 	<p><i>Title: Same S– Different Day</i></p> <p>Even though TLC+, PEP, and PrEP are implemented uptake is incomplete. Why this occurs:</p> <ul style="list-style-type: none"> • HIV providers lose funding and agency in the current economic climate due to lack of political will. • Biomedical and behavioral research remains siloed which limits our ability to encourage uptake. • Advocacy for HIV prevention is fractured and ineffective. • Due to the lack of funding and tightened economic climate, community organizations shut down and/or make HIV less of a priority. • There is no progress in the reduction of HIV stigma. 	<p><i>Title: Privileged Prevention</i></p> <p>Well-resourced, educated, and savvy people have access to ARV-based prevention, leading to a situation of privileged prevention. Why this occurs:</p> <ul style="list-style-type: none"> • Privileged people may feel more comfortable disclosing status. • Marginalized communities experience greater stigma, less support and feel less able to disclose their status and risk behaviors. • Lack of resources and coordinated plan to help marginalized communities/populations exacerbates health disparities.
Group 2	<p><i>Title: Best</i></p> <p>All types of ARV-based prevention strategies are researched, made available, and scalable. Access to healthcare is good and political will has helped to make the resources and investments for the science and implementation available. In addition, our approach to healthcare is more holistic, which</p>	<p><i>Title: Worst</i></p> <p>There is still a daily ARV pill – for both treatment and for prevention. Due to a lack of investment in research, there is no cure on the horizon, no microbicides, and no vaccine. The outlook for reducing infection rates has not improved, Why this occurs:</p>	<p><i>Title: Middle of the Road</i></p> <p>There is a mixed level of successful implementation of ARV-based prevention strategies due to not enough investment and motivation around implementation. However, we haven’t seen a rise in infection rates due to the availability of current biomedical prevention</p>

	Outcome: We have effectiveness, infection rate decreases	Outcome: No effectiveness, infection rate stays same	Outcome: It's a mixed bag...
Group 2 cont.	<p>helps to make sure people receive care when they need it. However, this does mean we have to protect against a loss of political will due to less HIV exceptionalism in the system. Treatments are longer-acting and there is increased tolerability. Why this occurs:</p> <ul style="list-style-type: none"> • Formalization of TLC+. • Availability of sterilizing and curative vaccines. • Sex-positive and behavior-focused comprehensive sex education. Engagement with non-traditional stakeholders, like police and churches. • Focus on holistic health for all. • System of chronic disease management. • Training programs to improve the cultural competency of primary care physicians. • De-emphasis on HIV exceptionalism. • However, the biggest barrier is finding people who are flying “under the radar” and knowing how to help those who can’t be on treatment or can’t take ARVs as prevention. 	<ul style="list-style-type: none"> • PrEP and other prevention strategies weren’t effective for a variety of reasons including a lack of investment in implementation science and a lack of community buy-in. • Communities were not engaged in science and research, and were skeptical and distrusting of it. • Misuse of PrEP and PEP as prevention strategies, leading to resistance and in some cases seroconversion. • Safer sex behaviors shift to higher risk behaviors because of complacency and a failure to bridge the gap between HIV and STI prevention. • Health disparities increase due to ineffective community outreach. 	<p>strategies, including TLC+. Why this occurs:</p> <ul style="list-style-type: none"> • Research continues, particularly around a cure and vaccine research, and there has been an expansion of our prevention toolbox. • More effective integration of low-technology and high-technology interventions. • Reaching IDUs, white gay men, other MSM, and people with insurance. • Difficulty reaching IDUs in urban settings, other gay men/MSM, and women of color. • Limiting factors which inhibit progress on ARV-based prevention strategies include mixed race relations and class; primary care providers not knowing enough about ARVs or discouraging their use; limited awareness, utilization, and uptake; and a mixed roll-out of the ACA.
Group 3	<p><i>Title: Different World</i></p> <p>We live in a completely different world. Resources, money, and political will are strong. We have fully implemented ACA, expanded Medicaid, maintained the benefits of the Ryan White Care Act, and all undocumented people have unfettered access to care. This universality of care reduces HIV stigma. Why this occurs:</p> <ul style="list-style-type: none"> • Increase in expertise and capacity for health services delivery, including the expansion of peer advocates and special training programs to help people navigate into health plans. • Community based organizations (CBOs) brought into the delivery of TLC+. • Establishment of contracts between health departments and CBOs. California is also able to implement a medical home model through this system. • CDC funds PEP PrEP, and testing (including epidemiological-based funding). • PEP and PrEP are easily accessible and not solely based on risk. • USPSTF HIV testing guidelines are followed and fully funded. • Breakthrough in vaccine research, due to the political will and monetary commitments, which further boosts enthusiasm and kept funding sustainable. • Measures are put in place to prevent erosion of HIV prevention resources in successive administrations. 	<p><i>Title: Wagging the Dog</i></p> <p>There are too many policy siloes and not enough integration across federal agencies to help manage care, due to too much focus on a medical model of care and not enough on social determinants of health. In this scenario, the Ryan-White Care Act was not reauthorized, or was shrunk due to the ACA. Why this occurs:</p> <ul style="list-style-type: none"> • ACA is not fully implemented; undocumented immigrants do not have a safety net. • AIDS Service Organizations and CBOs close. • Funding for new biomedical and implementation is limited No new technologies or long-acting technologies. • People are not retained in care. • Providers lack necessary HIV expertise. No unified strategy among PEP or PrEP emerges and no clear funding for PEP or PrEP. • Surge in so-called “disco dosing” and black market sales of Truvada. • Coercion to use treatment as prevention, particularly among gay men and other MSM. 	<p><i>Title: Paradise Lost</i></p> <p>In this scenario we have let the different world, the “paradise” of reduced infection rates, slip from our grasp. PrEP is rejected by communities because they don’t understand it works, or it doesn’t work for the community. Why this occurs:</p> <ul style="list-style-type: none"> • Demand for PrEP doesn’t increase; uptake is limited. • Social drivers are not addressed. • Funding is successively watered down or misdirected because funders don’t allow time for retention and adherence programs to evolve. • A reduction in new technologies, a lack of money for behavioral science research and a limited understanding of how to achieve effective implementation. • Ryan White funds are reduced and redirected from helping people be retained in care to helping to support the implementation of the ACA. • ACA implementation is slow and rocky. • ACA cost-sharing is too high. • Co-pays are huge percentage of cost. • ACA doesn’t pay enough attention to structural barriers. • Medicaid is not expanded.

	Outcome: We have effectiveness, infection rate decreases	Outcome: No effectiveness, infection rate stays same	Outcome: It's a mixed bag...
Group 4	<p><i>Title: Rainbows, but not Unicorns</i></p> <p>Investments in a cost-savings analysis help to make the case for where resources should be dedicated to save money later. This helps to create political will and shows clearly where we can achieve viral suppression in a sustainable way. Why this occurs:</p> <ul style="list-style-type: none"> • Implementation started with TLC+ because it is “easiest” out of the interventions and had already begun to show success in reducing community viral loads. • Lessons learnt on how to build infrastructure to implement PEP and PrEP. • The CBO network became critical to achieve viral suppression to support retention and adherence. • Strong CBO network helps to ensure PEP and PrEP are delivered to marginalized populations. • CBOs communicate with one another and with advocates, help to get people into healthcare marketplaces. • Cost savings identified are reinvested into the system through a dedicated funding stream, enabling a sustainable funding source. • Ongoing surveillance and epidemiological research continues so that we shift to targeting, micro epidemics. 	<p><i>Title: No Name — Too Sad to Name</i></p> <p>This scenario saw some small gains being made in improving healthcare access through the ACA, but these were offset by diverted funds that defunded other programs leading to a failure to create demand for ARV-based prevention strategies. Why this occurs:</p> <ul style="list-style-type: none"> • xCDC is underfunded and this trickles down to departments of health and other organizations (eg CBOs) throughout the country. • Lack of political will. • Linkage and care does not increase. • Transition in government leads to an inability to make changes and adaptations necessary. • No new ARV-based prevention strategies. • Some reduction in viral load suppression through TLC+. • Though PrEP is implemented, educating people, rolling it out, or marketing is ineffective due to lack of any effective implementation research. • PEP awareness and access stays stagnant and remains relatively unknown as a strategy. 	<p><i>Title: A Brighter Tomorrow*</i></p> <p>This was seen as the more realistic scenario for this group, where there is an increase in early detection due to better testing programs and access to care for some populations, but not all. Some disparities persist, and some are exacerbated. Why this occurs:</p> <ul style="list-style-type: none"> • Importance of CBOs is highlighted and they are appropriately funded, eg “wrap-around” services in the TLC+ model. • Sex education includes PrEP. • Reproductive health is used as a service delivery model to build bridges with Title X clinics. • There have been some advances in the science and we might have some long-acting treatments. • TLC+, PrEP, and PEP do well resulting in increased viral suppression. • MPTs just enter the market. • Potential to scale up PEP resulting from advancement of a PEP research agenda. • Injectable PrEP and other forms of delivering PrEP enter the market, including intermittent PrEP, a ring, and seasonal use. • New iteration of the National HIV AIDS Strategy which focuses on finding people earlier, addressing co-occurring infections, and improving the uptake of routine screening guidelines. • Leveraging of revised NHAS helps to increase political will and keep the focus on domestic improvement in prevention. <p>* Please note that this group took a more optimistic view of the mixed outcome scenario than other groups.</p>

Table 2-2
Future scenario – Washington DC

	Outcome: We have effectiveness, infection rate decreases	Outcome: No effectiveness, infection rate stays same	Outcome: It's a mixed bag...
Group 1	<p><i>Title: Prevention driven health system</i></p> <p>A system is created that is not disease specific and the ACA moves forward by removing silos and integrating activities across the healthcare system. Prevention is considered a very strong piece of healthcare. Why this occurs</p> <ul style="list-style-type: none"> • Strong implementation of the health home model. 	<p><i>Title: PrEP clinic silo</i></p> <p>We have a system that fails to scale-up ARV-based prevention services and there is a loss of faith in the system. It is subject to negative politics, disengaged communities and further stigmatization. Why this occurs:</p> <ul style="list-style-type: none"> • Unable to convince people they're entitled to healthcare, which undermines the ACA. 	<p><i>Title: Steady state</i></p> <p>2025 is no different from 2013 and few advances have been made. Though the ACA continues to gain traction, coverage does not equal access and health does not equal healthcare. Prevention activities remain siloed. Why this occurs:</p> <ul style="list-style-type: none"> • Markets for new drugs have been delayed. • Microbicides and other ARV technologies fail

	Outcome: We have effectiveness, infection rate decreases	Outcome: No effectiveness, infection rate stays same	Outcome: It's a mixed bag...
Group 1 cont.	<ul style="list-style-type: none"> Restoration of public health fund. Ability to make the cost-effectiveness argument to conservatives (eg 2008 election). Better congress is elected in 2016 and 2020, driven by a strong messaging of "hope" for the future in their election campaigns. Increase in supportive voting population due to immigration. Research breakthrough is made on microbicides. Fewer and long acting ARVs on the horizon. 	<ul style="list-style-type: none"> Failure to scale up TLC+. PrEP causes further stigmatization of HIV Immigration reform or the lack thereof becomes more conservative, which impacts HIV services. Community pushed aside. Sequestration continues. Destruction of National HIV/AIDS Strategy, which can't survive a Republican administration. 	<p>due to issues related to scientific research and issues related to access.</p> <ul style="list-style-type: none"> Access failures exacerbates health disparities. More conservative governments are elected. National HIV/AIDS strategy is at risk under a conservative government.
Group 2	<p><i>Title: Rodeo Drive Boutique</i></p> <p>This is inspired by the model in San Francisco of tailored and specialized care for different groups and populations. Clinics and CBOs work together to deliver. Why this occurs:</p> <ul style="list-style-type: none"> Presence of stronger political will to address most at risk populations. Organizations mobilize communities to maintain political will, resulting in more expansive mix of options. New social actors are leading (eg DREAMERS, etc) broad-based community mobilization efforts. Political and economic investments made in systems to support and help black gay men and other MSM, sex workers, and others. 	<p><i>Title: Thrift Shop</i></p> <p>The scenario is inspired by the situation in the South where there is a fragmented healthcare system and limited funding. There is an incomplete impact of ARV-based prevention. Why this occurs:</p> <ul style="list-style-type: none"> Sequestration continues and efforts to erode ACA are entrenched, resulting in a dismal future financial picture. Conservatism increases. Incomplete adaption of healthcare and fragmented system, accompanied by dis-investments. The already racialized epidemic becomes more so; stigma and disparities increase. Collapse of civic sense around Ryan White, etc. Clinics and CBOs lack incentive to collaborate and consequently work on their own and struggle. 	<p><i>Title: Department Store</i></p> <p>The scenario is based on the Massachusetts model. There is a national expansion of healthcare coverage and access, focus on care coordination, chronic disease management, and HIV is integrated into rest of system. It's a "department store", though, because if you have the credit card it's great, but it doesn't work for marginalized populations. Why this occurs:</p> <ul style="list-style-type: none"> Community based care system and infrastructure is now part of larger healthcare system; more bureaucratic healthcare model. ARVs scaled up through TLC, but lose community mobilization for rolling out other interventions like PEP and PrEP. Space for other interventions diminishes as the healthcare system "borg" absorbs CBOs.
Group 3	<p><i>Title: Optimistic</i></p> <p>The scenario assumes that the ACA exists, but isn't sufficient. It adopts a PEPFAR-like approach for the US where every state would present a plan which would reflect their epidemic. This enables a "big picture" understanding of state epidemics and streamlines funding to strategic partners (like CBOs) and key populations. The proliferation of direct service models focus on creating broad services with real flexibility. Why this occurs:</p> <ul style="list-style-type: none"> New technologies help meet clear goals. \$1 billion annually, directed through lens of national HIV strategy with clear accountability measures. Funding is provided from Minority AIDS Initiative, Ryan White parts C and F, CDC funds, and local surveillance efforts. States required to say who they are strategically partnering with to address key populations' needs. Recognition that disease is generally is influenced by host of societal factors. Sexual health education, youth education 	<p><i>Title: Pessimistic</i></p> <p>*Note – group chose not to develop a pessimistic scenario.</p>	<p><i>Title: Mixed</i></p> <p>In this scenario ACA is implemented and the core focus is around increasing treatment coverage (treatment as prevention is the priority). However, we find that we are not achieving results in the South or around key populations. This leads to a concerted effort to learn why these populations are not doing well. Why this occurs:</p> <ul style="list-style-type: none"> Integration of community mobilization efforts to reach key populations. Responses are tailored to address key population issues, including development of special initiatives for failing populations and integration of medical and community initiatives. Create tailored directional grants. Educate people to see a doctor when they think they have a cold/flu to catch those with acute infections. PEP does not make a population level difference – but could have emergency PEP packs at community levels at school clinics, CBOs.

	Outcome: We have effectiveness, infection rate decreases	Outcome: No effectiveness, infection rate stays same	Outcome: It's a mixed bag...
Group 3 cont.	<p>is provided and is responsive to community needs.</p> <ul style="list-style-type: none"> • Recognition that many of these communities will not have the private support needed. • CBOs protected only if performing and recognize what makes them successful/unsuccessful. • Have appropriate messaging to at-risk communities that says “you are worth a billion dollar investment”. 		<ul style="list-style-type: none"> • Strategies around PrEP change rapidly and innovations will be swift moving. • PrEP becomes easier to use. • Microbicides part of PrEP conversations, but there is still a question around whether the two are interchangeable.
Group 4	<p><i>Title: The Cure Solution</i></p> <p>This scenario is driven by the science, which has led us to a cure. The promise of the discovery of a cure triggers euphoria and the social expectations will drive political response and strong political will. Why this occurs:</p> <ul style="list-style-type: none"> • Science has delivered, but operational program science is needed to help with delivery. • Sufficient programmatic capacity to implement a cure-based approach. • Cure enables savings on treatment. • Longer-acting treatments are available for those who are HIV-positive, eg requiring shots every few months and ongoing care and follow-up. • PEP and PrEP still play role during the 20 years getting us to cure. • Improvement in care delivery systems • Major player, like Gates, helps with distribution. • Cure may also trigger risk disinhibition. • Celebrities involved to help message cure to public. 	<p><i>Title: The Band-Aid Approach</i></p> <p>This is more of a mixed-bag approach where things get incrementally better, but there wasn't a wider integration across the system. Some clinics will be open and there was improvement in the health literacy system, but investments weren't great. Young leaders understand the issues better than the older generation and try to change social norms, but do not always succeed. There are some older leaders in place who could help, but it's not always clear they are willing to act.</p>	<p><i>Title: The Longevity Solution</i></p> <p>In this scenario we see the addition of drugs to the public water supply (akin to fluoride). The drugs would include ARVs, but other drugs would address diabetes, heart disease, and obesity. We would have done enough research to know that toxicity was not an issue, or we were able to address it through some other technology. The scenario is based on the realization that the discussions we have about PEST and other factors can paralyze us. We need to just act. Why this occurs:</p> <ul style="list-style-type: none"> • Costs saved by not having these chronic illnesses. • Addresses and eliminates large disparities of access and health — help avoid healthcare reaching crisis point. • Creates a new medical formulation with statins, ARVs, anti-diabetes which would also complement treatment for these illnesses.
Group 5	<p><i>Title: We found out how to get to Sesame Street</i></p> <p>In this scenario CBOs, providers, and other key stakeholders came together at USCA to create a super PAC which mobilized and created a strong political force that could not be stopped and introduced new policy. Why this occurs:</p> <ul style="list-style-type: none"> • Individualized populations create a political force. • Secure celebrity to create support re-branding HIV. • Re-branding campaign unites fight against chronic diseases. • Enables more conversations and HIV disclosure. • Life management app to manage appointments, fitness, play dates, and all. • Innovations on social media with responsive apps which help people to manage their lifestyle. 	<p><i>Title: We're F--- No Condom, No Lube.</i></p> <p>There is no access to treatment because the ACA was repealed. Why this occurs:</p> <ul style="list-style-type: none"> • Repeal of the ACA. • No ARV dissemination; people can't access treatment. • Resource allocation and investments are insufficient. • Long-acting interventions and microbicides not developed. • Stigmatization and discrimination remains as a result of inaction. 	

Table 2-3
Future scenario – Atlanta⁵

	Outcome: We have effectiveness, infection rate decreases	Outcome: No effectiveness, infection rate stays same	Outcome: It's a mixed bag...
Group 1	<p><i>Title: Can We Have a Second Sexual Revolution?</i></p> <p>Hillary Clinton is elected as POTUS as a voice of women's rights. Global leaders are engaged via a UN-level conference, developing and expanding the base of advocates with a focus on community-level integration and grassroots engagement health reform. Why this occurs:</p> <ul style="list-style-type: none"> • Stigma against sex workers and HIV-positive people is eliminated through education and an elevated understanding of the issues. • Providers are educated and better informed, capable of building relationships with and serving women, supported by grassroots faith leaders. • A Robin Hood tax on banks frees up funding to be invested in preventative strategies, supplemented by contributions of individual donors. • Cost analysis is driven by the community to identify ways in which prevention for women makes economic sense and engages political leaders, manufacturers of products and drugs and funders. • Young people are involved in the communication of real stories about HIV and prevention and electronic platforms are used to share knowledge. • Real HIV-positive women are depicted. • A framework is developed to translate science to the community-level and health workers are (certified) trained to contribute. • Sustained innovative and outcome-driven research on MPTs and delivery systems helps to establish timelines for progress and implementation. • Community-driven, low-dosing options are articulated that women will use and find appealing. This community-driven research motivates and mobilizes. 	<p>* Group did not develop a pessimistic scenario due to lack of time.</p>	<p>* Group did not develop a mixed scenario due to lack of time.</p>
Group 2	<p><i>Title: Chicks Rule</i></p> <p>In this scenario high-profile female leaders provide the main driver for increasing awareness of HIV prevention, which is a multi-platform and multi-method, but always centered around women's needs. Why this occurs:</p>	<p><i>Title: Status Quo</i></p> <p>The status quo of 2013 is maintained.</p>	<p><i>Title: Haves and Have Nots</i></p> <p>Prevention initiatives are not tailored to at-risk communities and scope of CBO involvement is limited. Funding is limited and so is prioritized to treatment, not prevention strategies. Progress in reducing infection rates is only seen in more</p>

⁵ The Atlanta workshop had a specific focus on women's issues in relation to ARV-based prevention.

	Outcome: We have effectiveness, infection rate decreases	Outcome: No effectiveness, infection rate stays same	Outcome: It's a mixed bag...
Group 2 cont.	<ul style="list-style-type: none"> Multi-platform/multi-method communication takes place with the support of male-associated organizations (eg NFL, NBA) and high profile men that buy in to HIV prevention among women. A cadre of credentialed educators provide culturally and linguistically appropriate training about ARV prevention and treatment. Capacity-building is supported by funding from existing foundations and a new foundation created by the private sector (manufacturers of women's products such as RED), allowing the expansion of CBOs, the promotion of a population of women informed about interventions, and training and support for providers. Funding is allocated to disseminate information and produce a female population informed about all intervention options. Access for all is supported by financial incentives to providers for routine and risk screenings, "Ladies Board First" mobile vans providing full range of education and clinical ARV services and nationwide, state-specific Project ECHO (Extension for Community Healthcare Outcomes). Promotion of HIV prevention by First Ladies at the national and state levels (starting with Michelle Obama) helps to increase political will. Mandatory pre-marital HIV screening is resumed, potentially with an expanded opt-out mechanism. 		<p>privileged populations/communities. Why this occurs:</p> <ul style="list-style-type: none"> Communication of the HIV prevention message is mass media, not tailored to at-risk communities and is with the involvement of only a few male-oriented organizations. An increased cadre of educators (without credentials) is active, but mostly focuses on treatment options. No funding for CBOs in many key communities; funding is often unsustainable and piecemeal. Funding is only directed at treatment options, not prevention. Effectiveness is limited by requirement for funders to match state funding streams (as with Medicaid). Access is constrained by stigma attached to "Ladies Board First" vans, the failure of financial incentives to providers and the limitation of Project ECHO to urban areas. The First Ladies did not support prevention for women, choosing to focus on other priorities. No preventative HIV screening takes place.
Group 3	<p><i>Title: The Queen</i></p> <p>In 2018 HIV prevalence is up by one quarter among women, triggering massive panic and releasing funding to make Truvada available over the counter. This leads to a huge uptake and decrease in infection rates. Why this occurs:</p> <ul style="list-style-type: none"> Extensive media coverage results in elimination of HIV stigma Women are empowered; many move into powerful decision making positions. Women have options available to them and can choose according to their own lifestyle. By 2025, we have rolled out a vaccine against HIV. 	<p><i>Title: The Peasant</i></p> <p>In 2017–2018, PrEP is rolled out, but against all current indications is endangering HIV-negative women. This causes people to lose trust in it and insurance companies to stop paying. Without money available, PrEP fails completely. Why this occurs:</p> <ul style="list-style-type: none"> Advocacy and research drop off. Less testing is carried out and there is no push for insurance coverage. Crisis in support for biomedical prevention. TLC+ remains important, but receives limited funding and can only be accessed in hospitals. Lessons need to be learned from Zidovudine (AZT). 	<p><i>Title: The Princess</i></p> <p>Women are now well educated about HIV prevention and treatment, but not all can gain access. The infection rate among white women is down due to their advantageous access to money and resources, but uninsured or under-insured women, particularly those of color, have no access. Why this occurs:</p> <ul style="list-style-type: none"> Information is disseminated through social media, grassroots advocacy and some political leaders. The Affordable Care Act is not fully implemented. Some women are empowered, but are not engaging with or listening to un-empowered women, creating instability and sustaining inequity.

	Outcome: We have effectiveness, infection rate decreases	Outcome: No effectiveness, infection rate stays same	Outcome: It's a mixed bag...
Group 4	<p><i>Title: Optimistic</i></p> <p>Wealthy philanthropists and private sector funding bodies are prioritizing HIV and funding is being specifically allocated to ARV prevention options. The stigma of HIV is eliminated thanks to its greater integration into pop culture (through a popular figurehead/icon) and decriminalization in US territories. Funding is increased for the development of infrastructure and the language of messages is adapted to communities.</p>	<p><i>Title: Pessimistic</i></p> <p>Funding for the Affordable Care Act is withdrawn. The use of ARV prevention options is criminalized and no leadership emerges on a national level to support it.</p>	<p><i>Title: Mixed</i></p> <p>ARV prevention options are used, but only by privileged members of society ("upper class"). [This group ran out of time to fully develop this scenario.]</p>

Common themes across the scenarios did emerge

Optimistic Scenarios

Each of the workshop groups across the cities developed rather different optimistic scenarios. For instance, some were strongly influenced by scientific advances and others by paradigm shifts in the advocacy landscape. However, each emphasized the critical importance of mobilizing communities to build and maintain political will to secure the necessary resources that will enable effectiveness. Another common theme among the cities was identifying combination funding strategies to support the interventions, care, and community mobilization strategies. Participants underscored the diversification of funding through heavy involvement of the private sector in order to achieve effectiveness. Enhanced education efforts are also mentioned in each of the cities as an important element in any future scenario with an optimistic outcome. A holistic approach to the delivery of health services was viewed as critical to success. Integrating activities and local, state, and federal polices provides essential support for intervention effectiveness.

Pessimistic Scenarios

Within the pessimistic scenarios, where infection rates stay the same after ARV-based prevention strategies have been implemented, a downward spiral was predicted in many of the workshop groups.

A common catalyst for this phenomenon was a decreased political will to support ARV preventions and resistance to changing the prevention paradigm's status quo. Participants highlighted the circular relationship between stigma, community disengagement, and political inaction. The lack of advocacy, coupled with continued sequestration and severe fiscal constraints led reductions in funding for CBOs, advocacy groups, and further research. Oppositional politics could also lead to the collapse of the ACA and result in a lack of interest at both the national and local level to advocate for ARV-based prevention strategies. In the long term, this climate would have an impact on the progress of technological development, with investigational agents and formulations such as new drugs, long-acting injectables, and microbicides no longer moving into the research and development pipeline. It may also further increase disparities in care provision, due to increased stigmatization of marginalized sectors of society.

Mixed Scenarios

Central in the scenarios with mixed outcomes was the idea of fragmentation in the interventions implemented. For example, participants suggested that the ACA could be implemented but not in a holistic manner. Additionally, it was felt that CBOs and advocacy groups may not have the ability to reach out to every community, especially those populations that are deeply affected. This fragmentation can obstruct access, which would be further exacerbated by insufficient personal

and organizational resources and communication campaigns that are not targeted correctly. Most participants felt that with constrained resources, the focus would most likely to be on expanding treatment, rather than other ARV-based strategies that could be provided to HIV-negative individuals. Because of this, across the workshops, scenarios with mixed outcomes consistently forecasted problems with PrEP effectiveness, acceptability, and accessibility where a concerted and well-resourced implementation effort was not in place.

Cross-cutting themes and points of discussion across all workshops

Regardless of whether the outcome of the scenario was optimistic, mixed, or pessimistic, or the focus of the PEST discussion was centered on one factor or another, there were several themes that rose to the surface in the discussions over the course of the three city workshops. The impact of the Affordable Care Act (ACA) came out strongly in all the workshops. While participants felt it offered major opportunities for expanding access to healthcare, it was also recognized that it could offer just as many challenges. For example, it could offer the opportunity for a much more holistic approach to healthcare for individuals where primary care and specialist care are much better integrated for the individual. It could provide opportunities to link together general health with sexual and reproductive health, allowing for discussions about multi-purpose prevention technologies to come to the fore. However, a challenge participants identified was the greater role primary care physicians might play in treating people living with HIV or at risk for HIV and the potential lack of HIV-specific expertise to affect care in negative ways. The interplay between these challenges and opportunities was widely recognized as an evolving story, being played out in real time and requiring all actors invested in the provision of HIV prevention and care to be actively involved in each chapter.

As workshop participants contemplated the notion of a more holistic response to healthcare, spurred on by the ACA and related policy changes, they pointed out a need for a more holistic approach

Each emphasized the critical importance of mobilizing communities to build and maintain political will to secure the necessary resources that will enable effectiveness.

to prevention itself. Especially as we consider the ways in which ARV drugs can be used by both HIV-positive and HIV-negative people to halt new infection, prevention and treatment should not be seen as mutually exclusive. The TLC+ “cascade”, which identifies people who are positive and links them into care and treatment, should be expanded to articulate and measure the identification of HIV-negative people at risk to link them into appropriate care and services so they maintain their serostatus. So, the TLC+ would be for all people. The ACA could play a crucial role here, offering new pathways to healthcare access for many key populations who previously had none. This will require a greater focus on frequent testing as the gateway to all prevention, and will likely mean that advances in testing will need to be accelerated. The greatest excitement across the workshops in relation to biomedical advances were around the prospect of technologies in early stages of development, including: long-acting injectables for both PrEP and treatment; rapid HIV testing technologies and viral load testing which are accurate, sensitive, quick, and able to be done by the individual; and new adherence technologies which use radio-frequency identification to enable real-time monitoring of how pills are being ingested and absorbed into the bloodstream. Such technology

was seen as an opportunity for greater personal ownership of one's health that would enable greater empowerment, accessibility, as well as management.

Alongside the enthusiasm for the science was an even more strongly expressed awareness that social research had to sit alongside, and be integrated with, the biomedical research into new prevention technologies. Advocacy in support of socio-behavioral research, implementation science, longitudinal monitoring, cost analyses, and modeling research was thought to be lacking and existing resources were not enough. A number of participants warned of the danger of just providing pills to communities, without considering the behavioral and social components of their uptake. This was a strong message of the original Mapping Pathways research as well – that all science is local and research into how to achieve effectiveness at a community level, coupled with ongoing, substantive community engagement, was just as important as research about efficacy.⁶ Related to this was a recurring discussion about the role communities could play in the future, in particular community-based organizations. Participants consistently articulated the ongoing need for community-based services and community-driven strategies and research. It was thought that just as the ACA would provide opportunities and challenges for delivering healthcare, it could also provide many opportunities and challenges for CBOs. There is an open question, which some groups in the workshops attempted to address (see in particular the Washington, DC examples), around the ways in which we can keep CBOs viable and ensure they provide needed, gap-filling services alongside the medically-oriented providers and clinics.

Technology of all sorts animated the workshop participants. All observed that the growing interplay with, and reliance on, digital technologies would and could, affect access, uptake, and adherence. Social media has the potential to greatly affect how new

Alongside the enthusiasm for the science was an even more strongly expressed awareness that social research had to sit alongside, and be integrated with, the biomedical research into new prevention technologies.

health information is disseminated, but also risks marginalizing people who have low technological literacy, or do not have access to “e”, “m” or app-based technology outlets.⁷ A related concern expressed by participants was that issues around stigma and criminalization had the potential to be exacerbated with new ARV-based prevention technologies, as people could be stigmatized for using these new strategies, or coerced into taking them.

One of the constant areas of discussion in every workshop was the question of money – at the individual level and organizational level. Questions such as the following dominated the discussions:

*Who would pay for expensive ARV-based prevention?
Will advances in research reduce, or increase, costs*

⁶ Morgan Jones, M, et al. 2013. *Mapping Pathways: Developing evidence-based, people-centred strategies for the use of antiretrovirals as prevention*. RAND Europe: Cambridge, UK. RR-326-MERCK. Available at http://www.rand.org/pubs/research_reports/RR326.html.

⁷ “E” refers to *electronic* technology, such as computers. “M” refers to *mobile* technology, such as cellular phones, tablets or other mobile devices. “Apps” are mobile applications designed to run on mobile devices.

to individuals? How would the current economic climate play out in the future for individuals and organizations? What will the role of CBOs be in the future? How do we make funding dedicated to healthcare, and in particular to meeting the needs of HIV-positive and HIV-negative people sustainable?

These recurring concerns about resource also came up in our 2013 report and were expressed repeatedly across stakeholders engaged in that study. Diversified funding streams will be needed in the future, and many of the optimistic scenarios included ideas about how to engage a wide range of funders. There was recognition that there are critical

tensions between resources which would be needed for provision of healthcare and prevention strategies, resources for improving access, resources for the mobilization of different communities, and resources needed for further research. Cutting across this was also the role of political will. There was seen to be a circular relationship between political will, capacity-building, momentum, and resources. The resolution of these tensions will be central in making sure that those who need access to prevention tools and technologies are able to receive them, particularly when we are dealing with wider social factors like poverty, social injustice, and structural barriers.

3

**AN INTEGRATED
PATHWAY FOR
THE FUTURE**



The Mapping Pathways Scenario revolves around systems of integration

The rapidly changing nature of the evidence base poses challenges for how policymakers, clinicians, advocates, community members, and people living with HIV synthesize and integrate their understanding of the evidence base for different treatment and prevention options. The contextual importance of decision making, as was discussed in the workshops, will be important, and this is where the Mapping Pathways project and an adaptive approach to facilitating an understanding of the evidence base can help.

In each of the workshops we asked participants to come up with three scenarios for the implementation of ARV-based prevention strategies in 2025. As we saw in the summaries, the ideas presented across the three workshops were fascinating. We now try to draw these together, building on our experience in the Mapping Pathways project to date, and present our future scenario. First, though, a few caveats.

It is not our intention to present this as a definitive assessment of the future, which is not possible in any regard. What was most striking from the workshops was the breadth and depth of insights that emerged across each city. While there were features in common, each city's conversations reflected the composition of the participants and their specific take on local issues, priorities, and possibilities. For example, the local grassroots voice was strong in Atlanta, whereas in Washington, DC there was a wider discussion of how to address the system from a national policy perspective. Participants in San Francisco were able to reflect more on the real challenges which are occurring there because ARV-based prevention efforts are already being rolled out. Each discussion was local but also included national threads, and taken together areas for joint learning emerged.

We are also conscious of not wanting to diminish the interesting points of discussion at the expense of the common. While there were common themes across all cities in the PEST analysis and the scenarios, there were also interesting points which we have attempted to highlight. These should not

be lost in the conversation going forward. Finally, though we asked stakeholders in the workshops to discuss scenarios according to three different sets of outcomes, here we present only one scenario with no particular outcome, but rather as one possible pathway to implementation informed by the work from all participants in the three cities.

Context

The first step was to identify the context and the different certainties and uncertainties which would play a role in the future. These are summarized in the table opposite.

We then considered which PEST factors and drivers, out of all the ones identified in the three workshops, would play a key role in the future. Building on those which played a key role in each of the participants' scenarios, we identified the following:

- funding for research and implementation
- evolution of the healthcare system in the context of ACA
- the role of healthcare providers in the context of ACA
- uncertainty over the role of community-based organizations
- the need for greater capacity-building/education
- digital technologies and the role of social media
- advances in biomedical technologies
- political will to change the status quo
- community buy-in to advance ARV-based prevention
- grassroots knowledge of and demand for ARV-based prevention.

In looking across these factors, though, it is not just important to think about them according to their political, economic, social or technological nature, but also through the lens of the adaptive framework we outlined at the beginning. Through this lens, the potential impact of each driver becomes dependent upon the ways in which the factors interact. In other words, they cannot be viewed in isolation, and none will be successful without the others.

Thus, just as we began the Mapping Pathways project with an idea about the way that different technologies, social arrangements, and organizations

Table 3-1
Contextual elements of the scenarios

What is known (certainties)	What is unknown (uncertainties)
ACA will change the healthcare and access landscape.	How and whether providers will cover ARV-based prevention.
Adherence and implementation is critical to effectiveness of ARV-based prevention.	Whether CBOs will be able to survive in the current economic climate and how the ACA will change their role.
Social injustices and inequities will continue to require advocacy to mitigate them.	How will community and provider support for ARV-based prevention be maintained?
New agents and formulations, such as microbicides in gel or ring form, and long-acting injectables, are arguably the next wave of biomedical prevention.	How biomedical prevention strategies will evolve further (eg multipurpose prevention technologies, vaccine, cure).
Funding will be squeezed for many years due to the economic crisis.	How ARV-based prevention research and access will be funded. Will there be investment in behavioral research?
Disparities do exist in healthcare provision and any scenario will have to address these in some way.	Will political winds shift?

need to interact and adapt to each other, we revisit this idea now. Each driver identified above could be placed into one of these three categories, and each comes to be dependent on the other for success. In particular, we see that much of our attention is drawn away from the new technologies of the future, to the social tools which might help us with implementation. It is the integration of the social and organizational, together with the technologies, which will be crucial. Our scenario, then, is one which embraces this integrated and adaptive approach.

Our scenario: Adaptive pathways of integration

Informed by our efforts across the entire Mapping Pathways project, we believe that a much more integrated approach to all aspects of HIV prevention will be the pathway to implementation in the year 2025. The main driver of this future scenario is one of integration across political, economic, social, educational, and technological factors, and integration across the broader scientific, healthcare, and delivery systems. This means that we integrate both treatment and prevention strategies, including how we develop them, how we fund them, and how we deliver them, into one holistic approach. This

approach does not distinguish between prevention for HIV-positive and HIV-negative individuals, but recognises that prevention, care, and appropriate treatment is for everyone. Of course integration is an easy word to use, but is a formidable challenge to apply in a meaningful way. But integration must happen, and it must happen at multiple levels and with multiple actors and stakeholders playing a role. Here we provide some examples of where integration is particularly needed and what that might look

We believe that a much more integrated approach to all aspects of HIV prevention will be the pathway to implementation in the year 2025.

like in relation to, for example, scientific research and healthcare delivery. Of course these ideas are preliminary and need further discussion and development.

We will start with the science. In an integrated future, advances in technologies to help prevent HIV are tied to the social contexts in which they will be implemented. Research siloes are a thing of the past, because in an era of tightened funding across the entire system, we cannot afford to develop new technologies for which we have little understanding of how they will be accepted and implemented. In order to achieve this there was strong advocacy for maintaining and expanding resources for research. Because some up-front investments had been made in detailed cost-benefit and modeling research, a strong case could be made which helped to make the political argument.

Alongside these biomedical technologies, new digital technologies that harness the power of social media will be used. These may help younger generations connect, share information, and become engaged, and can also help to drive messaging from the grassroots up. They can also provide a way of harnessing a whole new set of data about implementation. E-health, m-health and apps designed to monitor medical data and activity could allow for the use of real-time information to emerge about adherence and effectiveness and allow for more accurate HIV testing, and possibly viral load testing, done at home.

All of this means that in the future, delivery is considered as new technologies are being developed, leading to a more effective and efficient use of resources. In addition, and following current scientific development trajectories, long-acting injectables will likely be a key method through which ARVs are delivered for both treatment and prevention purposes. This will lead a shift in the way we organize and manage prevention, care, and treatment. However, this shift in both the use of new technologies and disease management has implications for the healthcare system.

In the future, healthcare systems are integrated because of the changes both driven and harnessed by healthcare reform in the US. We have the healthcare system that has abolished most siloes in care delivery

In an integrated future, advances in technologies to help prevent HIV are tied to the social contexts in which they will be implemented.

and, as a result, has less of a single disease focus. This has meant a move away from HIV exceptionalism, though this has its risks as well as rewards. The risk is the loss of HIV expertise, and that HIV advocacy loses its focus, the reward is that there is a much more holistic approach to care which can extend beyond HIV prevention and treatment for communities as well as individuals. Healthy individuals and communities are those with access to services that support their mental, emotional, physical, spiritual, and sexual lives. As was mentioned in several of the workshop groups, this “universality of care” could mean that the enduring barrier of HIV stigma is diminished.

The change in healthcare systems also raises questions about delivery. Integration across new delivery platforms means we should think differently about how to deliver prevention strategies, not just research and fund them. Community-based organizations have a leading role to play. CBOs could help in generating political will, mobilizing communities, driving research agendas, identifying implementation needs, and delivering integrated care to communities and populations in need. When it comes to the delivery of the integrated prevention system, we need to ensure that we do not lose expertise in HIV specialist care and that primary care physicians who may handle more HIV cases (and may be prescribing ARV drugs to

We must capitalize on the HIV community's established track record of developing innovative programs and systems to provide holistic care that meets the varied needs of individuals.

HIV-negative individuals) are adequately trained. In addition, if CBOs are to become more integrated into delivery systems, then we must ensure they have what they need to succeed.

We must capitalize on the HIV community's established track record of developing innovative programs and systems to provide holistic care that meets the varied needs of individuals. This experience and expertise could be brought to the fore in the new policy and program environment created by the ACA. HIV advocates can help to create a political environment that enables the design and implementation of programs to meet the specialized needs of people living with HIV, and those at risk. The HIV sector has long recognized that health outcomes are contingent on more than just the absence or presence of HIV and STDs, or even on health-related factors in general, and therefore must be addressed in a holistic manner.⁸ For this reason, additional support systems that avail

people living with HIV with housing, mental health, substance use, adherence support, retention in care, transportation, food, and other services are currently a part of the Ryan White Program serving people living with HIV. In the future, CBOs can offer great value and expertise to new, larger systems that are emerging as a result of the ACA, while ensuring that the complex needs of marginalized populations are met. Ryan White can continue to play an important role in filling gaps in services and helping to deliver wrap-around care for HIV-positive people, and thought should be given to how we systematically address gaps for HIV-negative individuals in key populations.

Healthcare providers also have a strong role to play in contributing to ongoing research and monitoring which help to improve effectiveness and implementation. CBOs will need to work with them to ensure they are educated and have the tools to feed back in a positive way to the populations they are serving. As was raised by many workshop groups, there are certification and education programs which ensure that we have consistent and high-quality training and education within communities. This builds capacity at local levels, raises awareness, and is a mechanism for expanding the employment opportunities for people living with HIV.

Lest we paint too rosy a picture of this future scenario, it is imperative to mind the risks such a future could hold. A more integrated system could result in a loss of HIV exceptionalism, which could reduce the quality of HIV prevention, care and treatment services and hinder efforts to advocate and argue for additional resources. Equally, a more integrated approach to research means that we could lose some degree of "science exceptionalism", and drive needed resources away from important threads of biomedical research. If biomedical research makes a big breakthrough, such as partially effective vaccine, there may still be concerns about risk disinhibition and acceptability. Again, well-planned and integrated social research will be needed.

In any future, resources will be constrained. It is not only a risk to avoid this inconvenient truth, it is also a risk to not be aware of how we handle that and consider the tools which might be used to help

⁸ See for example: Gillespie, S., Kadiyala, S., and Greener, R. (2007) 'Is poverty or wealth driving HIV transmission'. *AIDS*, 21: p.S5–S16; Prince, M., et al. (2007). 'No health without mental health'. *The Lancet*, 370(9590): 859–877.

secure funding in new and innovative ways. New, diverse, and dedicated funding streams need to be explored. Finally, there will always be a risk that a lack of political resolve will derail any effort.

What comes next?

What is most striking is that this future is not driven by the science, it is driven by communities and the needs of implementation. While science will determine some of our future trajectories, it will not be the whole story and cannot be the sole driver. But what does all of this mean for what we need to do now? While not an exhaustive list, the actions below did clearly emerge from the workshops as things which participants thought could be done now.

- Develop cost-benefit and modeling analysis driven by communities/outcomes and with a focus on what to do now to save money later.
- Identify new funding mechanisms to support ARV education and capacity building.
- Communicate and educate about different ARV-based prevention strategies, including those currently available as well as the pipeline of new agents and formulations.
- Engage actively in healthcare reform, taking advantage of opportunities and meeting challenges as they occur.
- Advocate for more and better-integrated implementation and socio-behavioral research to take place alongside biomedical research.
- Engage with key actors and enabling organizations, including CBOs, health insurance providers, medical institutions, celebrities, pharmaceutical companies, politicians, advocates, youth, media and people who are both living with HIV and who are HIV-negative.
- Identify key champions who can help to mobilize communities and maintain political will.

The analytical lens used throughout the Mapping Pathways project looks beyond the clinical trial data to the importance of human agency and local context in delivering effective HIV prevention strategies. The original report and the workshops summarized here gathers information and perspectives and unpacks the iterative nature of the relationships to help the

What is most striking is that this future is not driven by the science, it is driven by communities and the needs of implementation.

wheels of progress and new ideas turn smoothly, be effective, and reflect local needs. While the evidence base is rapidly moving forward in terms of physical technologies, the direction social arrangements and organizational structures are taking, or should take, are less clear and just as dynamic.

The workshops emphasized that it is critical to understand locally contingent factors when considering how and why different strategies may or may not be effective in different communities. Each workshop group came up with a unique set of ideas which reflected their local concerns and needs. There are multiple pathways that communities and policymakers may take to arrive at their own answers. We know that scientific endeavor improves the lives of people living with HIV and provides us with new tools to fight it. However, new scientific findings are only one avenue for successful ideas and breakthroughs. The understanding and utility of the scientific evidence base, coupled with the perspectives and views of communities and stakeholders, are local. Pathways are locally developed. All science is local, and ARV-based prevention strategies need to be successful at local levels before they can have a global impact.

Appendix A – City-by-city summary

The following are the outcomes of the brainstorm sessions that occurred in each city. It is a complete list of the majority of the factors, simply listed by city and PEST “letter”. These factors have not been analyzed for content and there are some issues that may cross over letters and which we addressed in

the analysis. The presentation here is simply meant to capture the full group summary of the initial brainstorm that went on in each workshop. Please note that Political, Regulatory and Economic factors are combined in this presentation because they were discussed together in Atlanta and Washington, DC.

PEST factors

Political, Regulatory and Economic Factors

SAN FRANCISCO

Inclusive access

- Cost of correcting disparities and cultural barriers
- Legal restrictions on access
- State regulations (intra/inter-state differences)
- Parental permission/consent

Attitudes – stigma and resistance

- HIV exceptionalism
- Politics involved in training - resistance needs to be addressed
- Name calling to those on PrEP – people feel need for anonymity
- Criminalization: how will this change definition of intent to infect? (sex workers)

System and provision costs

- Cost may not be the issue in the US
- Economics of delivery systems – Patent/generics, Monitoring, Injectables
- Black market considerations

Insurance coverage – costs for patients

- Companies negotiating higher co-pays
 - Will insurance continue to pay? Medicaid?
- Restrictions from insurers and pharmaceutical companies
 - Bureaucratic barriers
 - People need to test regularly
- Individual insurers will influence uptake strategies – no national policy
- Provider reimbursement
- Uninsured/insured access

- Co-pays
- Reimbursement
- Will young gay men and other MSM have access?
- On campuses: university attitudes towards insuring
- Immigration bill considerations

Funding

- Resources for prevention vs care
- Economic resources for new research
- Slow development
- Investing beyond technology
- Resources for training/outreach/language translation
- Economic argument of doing non-biomedical research
- Resources for deep community engagement

Systems of provision

- People being put on PrEP without being informed
- Implications of HIV partner services
 - Using surveillance data to reach people
 - Impact on research agenda

Legislative change

- Helms Amendment — goes away?
- Access to healthcare is seen as a human and civil right (Obamacare expansion)
- Hate crime legislation: can it diffuse stigma?
- Prohibition of gay men and other MSM giving blood goes away — impacts on stigma and affords legal rights

Scope for strategic approach to costs

- Shift to conversation with payers (not government)
- Pricing caps
- Cost effectiveness assumptions
 - Drug costs
 - No nuanced social data

Healthcare system integration of services: system infrastructure

- Economics of integration of services

Evolution of healthcare system

- Disease-based vs patient-based healthcare
- Capacity
 - Role of private companies (eg Walgreens) needs consideration

WASHINGTON DC

Inclusive access

- Do affected groups have access to congress/decision makers?
- Access problems in rural areas

Attitudes — stigma and resistance

- Areas of increased conservatism are precisely the same as increased infection

System and provision costs

- Small CBOs/NGOs going out of business and impact on education & uptake
- Should PrEP be priced the same as treatment?

Insurance coverage – costs for patients

- Possible future payment problems – covered under Essential Health Benefits (EHB)?
- Limitations on Medicaid cover for family planning and testing
- Lack of cover for prevention

Funding

- ARV prevention demand on health systems
- Hard to invest in something with long-term results – prevention is disadvantaged
- Resource allocation directly affected by political barriers – sidestepping issue due to label as treatment

Private sector

- Food and Drug Administration (FDA) has tied hands of Pharma to not promote ARV prevention

No “one size fits all” – take into account developing country contexts**Legislative change**

- Less abusive of laws due to enhanced awareness and knowledge by 2025
- Progress at state level on expungement
- Patent reform – getting new generics quicker

Capacity-building

- Future of ACA – invest in mobilising advocates, incentivize (including utilization)

Education

- Promotion of PAPs - must educate case workers, etc.
- Will CBOs help educate to increase uptake?
- Treatment guidelines – getting to the final stage – may be fluid (can still learn)

Scope for strategic approach to costs

Streamline and reallocate costs more effectively through increased modeling on health literacy

ATLANTA**Inclusive access**

- Getting more community clinics at local levels and in neighborhoods
- Eligibility criteria – restriction of prescription provision related to:
 - Providers themselves
 - Age of individual and parental consent (treatments vs prevention for minors)
 - Questions about responsibilities relating to mandated reporting of statutory rape in cases where minors are having consensual sex with adults
 - Sexual assault (specifically with regard to PEP)
- Commercial sex workers can experience barriers to prevention services due to their work

Attitudes – stigma and resistance

- “Closet” PrEP providers – stigma
- Using adherence decisions and patient behavior to make treatment and prevention decisions?

System and provision costs

- Cost to whom? Both system-level (health agencies, clinics) and personal
- Cost over time: what kind of cost and who pays at different points?
- Tight fiscal climate: agency closures and shifting resources

Insurance coverage – costs for patients

- Insurance

- What happens when it is a new compound (eg microbiocides)?
 - People do not care or want to enroll
 - Who pays?
 - “Closet” PrEP providers — floodgates with ACA, etc
- Systems of provision**
- Who are the HIV responders? Not family clinics, women’s centers, etc.
 - Treatment guidelines: Where is the entry point for prescriptions (data from Gilead poster)? And what incentivizes them?
- Legislative change**
- Policy around sexual reproductive health — how will these conversations play out?
 - Integrating prevention into basic healthcare laws
 - Guidelines / Standard Operating Procedure (Emory example)
- Capacity-building**
- Achieving a partnership with state and federal leadership — who leads? How do we develop the infrastructure?
 - Capacity building needed at state, community, and grassroots levels
 - Strategic constituency building, eg shore up Medicaid expansion and leverage other advocacy / R&D efforts, eg vaccine community
 - Engaging women in the decision making process from the beginning in at ground level
- Education**
- Education and awareness: who pays and how do we get the community to buy in?
 - Delivery of message about the strategies
 - Harnessing patient narratives
 - Which tools — social media?
 - Engagement only through research efforts is problematic
 - Need political and policy coordination, particularly on education
 - Between federal / state / local levels
 - Pharma / CBOs
- Scope for strategic approach to costs**
- Important to understand the attribution and contribution of system costs
 - Cost-sharing opportunities with private sector?
 - Economic incentive to engage people in prevention decisions is missing
 - Create the economic arguments for garnering political support — cost effectiveness as a political strategy
 - **Healthcare system integration:** how will conversations around sexual reproductive health policy play out?

Social and Cultural Factors

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- Low healthcare literacy. Information needs to be basic and accessible.
- Stigma from slut shames, providers, community
- Absorption of smaller agencies by larger ones, resulting in potential loss of services
- Distrust of science, drugs, health systems
- Changes to social support offered—more emphasis on bio-medical and less on psycho-social support. Redirection of resources alienating providers and agencies
- PrEP use could be coercive by pimps on sex workers
- Help people understand personal agency and empowerment
- Need to change how we talk about risk

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- ACA will cause CBOs to face new challenges resulting in having to choose between satisfying government regulations vs. the needs of marginalized populations
- Closures of community health clinics and CBOs that will result in losing population specific expertise
- Limited education/health literacy among young people
- Stigma against HIV status, sexual behavior, orientation, activity, lack of viral suppression, pleasure
- Racial, gender, economic, educational & geographic injustices
- OB/GYNs won't/don't talk to women about HIV
- Integration of care, treatment, and prevention could help reduce stigma
- ACA provides opportunity to create more holistic healthcare system with better health outcomes
- CBOs could access new resources via fees for service
- Invest to change social norms

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- Stigma of HIV-positive status, sexual behavior, drug use, etc
- Mistrust/distrust of healthcare and research systems due to experienced/perceived discrimination
- Low-literacy
- Limited view among providers that prevention only equals condom use
- Women's experience using birth control
- Women access regular healthcare though OB/GYN. Need to make sure reproductive health providers must ask/talk about HIV
- Engage/support community stakeholders and institutions in education around these issues

Technological and Scientific Factors**SAN FRANCISCO****Need for more research/data on certain areas**

- Incentive research
- Ethics research
- Monitoring data
- Nanotechnology

Cost of research/new technologies**Acceptability of technologies****Access to most at risk****Too biomedical focused**

- Need more focus on behavior

Treatment focus

- Should drug be the only solution?

Use of online technologies

- Phone apps for distributing HIV information
- Advances in healthcare must be considered (eg telemedicine)
- Real time electronic health records

Development of new technologies

- Vaccines, long-acting, injectable PrEP, microbicides
- Condoms
- Adherence technologies
- New rapid testing
- Role of pharmacists

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Need for more research/data on certain areas

- Metrics for providing prevention
- Behavioral research into adherence for different populations
- Longitudinal studies about uptake/behaviors/etc
- Transgender equality in research

Clinical trial access

Technologies of social networking have risks

Varying capacity levels for technological development

Use of online technologies

- eHealth/mHealth – implications for delivery – provide better coordination
- Social networking and real technology - linkage of social websites with healthcare providers (e.g. Grindr)
- Telemedicine to improve uptake

Development of new technologies

- Better male and female condoms (dissolving)

Role of policy/public health depts. to bring people into care managing

Improve uptake of health education

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Need for more research/data on certain areas

- Better understanding of viral suppression
- Post-study/trial/project access to intervention – individual/community impact
- Combine empirical and community data
- Better ways to find and track information online
- Digital information maps: geographic snapshots of uptake and knowledge

Access to technologies

- Internet access

Use of online technologies

- Digital information: apps and a cross-device platform
- Viral load and HIV testing via mobile devices (smartphone and tablet access)

Development of new technologies

- Long-term injectables

- Multipurpose Prevention Technologies (MPTs)
- Therapeutic/preventative vaccine

Improve uptake of health education

- Communications between community and:
 - scientific research
 - providers (education and support)
- Technological literacy and health literacy
- Research questions must driven by community – bi-directional conversation and the community sets the agenda

Inclusiveness and representation in terms of validity to populations