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Developing evidence-based, people-centred strategies for the use of antiretrovirals as prevention

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Summary

While the HIV pandemic peaked in the late 1990s, there are still more than 2 million new infections globally every year – the bulk of which occur in sub-Saharan Africa. Approximately 34 million people on the planet are living with HIV, and nearly 2 million people die from the disease each year. Although therapeutic approaches can extend and improve the quality of people's lives, the human and socio-economic cost of ongoing treatment for millions is widely viewed as unsustainable, particularly in the world's poorest countries. We must move beyond treating HIV/AIDS as a chronic condition and improve our ability to stop new infections.

But current prevention strategies need help. The provision of male and female condoms is necessary, and voluntary counselling and testing programmes, sterile syringe exchange, and behavioural counselling remain critical. Increased screening and treatment of sexually transmitted diseases, as well as voluntary male medical circumcision must also be part of a broad array of prevention practices. However, to date all of these strategies have proven to be inadequate to the task of fighting HIV. New pathways to prevention, based on enhanced assessment and analysis of likely impact, are needed to address new infections effectively, as 2 million new HIV infections every year are 2 million too many.

Although some antiretroviral (ARV)-based prevention strategies have recently shown efficacy in clinical trials, real-world, successful programmatic implementation is complex and still relatively uncharted. Significant challenges include cost, access to and appropriate use of ARV drugs, behaviour change, potential behavioural disinhibition, and possible drug resistance. Furthermore, the

implementation of each prevention strategy differs across cultural and geographic regions.

Mapping Pathways is the first integrated, research-driven, and community-led study to provide a multi-layered synthesis for ARV-based prevention strategies in a single evidence base. The project's aim is to provide a resource for communities and policymakers with evidence, voices and views about ARV-based prevention strategies from across diverse global contexts, and synthesise this in a manner which lays out a future agenda for policy-making and further research. The findings can be used to help inform the research and analysis that communities and policymakers will need in order to help formulate coherent, evidence-based decisions for HIV/AIDS treatment and prevention strategies in the fourth decade of the HIV pandemic.

The Mapping Pathways project had the following objectives:

- to review the social, economic and clinical impacts of the following ARV-based prevention strategies: TLC+ (testing, linkage to care plus treatment), microbicides, pre-exposure prophylaxis (PrEP), and post-exposure prophylaxis (PEP) in the contexts of South Africa, India and the US
- to translate the perspectives and current state of knowledge of stakeholders at the 'grasstops' and community members at the 'grassroots' into an analysis of what their views mean for future research and decisionmaking
- to explore the views of experts on the state of the evidence base, and determine where they believed further evidence was needed and why

- to synthesise the information, views and interpretations of the evidence base from these multiple perspectives in a manner which would allow us to establish what further research and analysis was needed, and why.

Ours is not an exhaustive study into the nature of the policy contexts, HIV epidemics, treatment options, prevention strategies, healthcare systems, and other relevant areas within which each scientist, community advocate, person living with HIV, policymaker and healthcare worker we engaged with might have found themselves. The findings that emerged from the study, and which we present in this monograph, are a grounded, community-led interpretation of what people in diverse settings think ARV-based prevention could mean for their particular situations, and what questions it raises for them. Participation and engagement is at the heart of our study, and stakeholder input across the community, research, policy and governmental spheres is a core focus. The views and opinions of these groups are as important a part of the evidence base as the peer-reviewed, scientific studies about the efficacy of the prevention strategies themselves. Effective policy answers, and the pathways to them, need to be developed by engaging such a diverse range of voices.

We used four complementary methodologies to provide a scientific snapshot of the published literature and to highlight the complex and sometimes contradictory perspectives of community members and stakeholders from India, South Africa and the US who in 2011 were grappling with a rapidly evolving scientific landscape in real time.

These are the four methodologies we used to assess the empirical evidence base:

- a systematic literature review
- a grassroots, community-based online survey to understand the awareness and concerns of individuals
- semi-structured interviews with stakeholders and grassroots community leaders to identify information needs for decisionmaking
- a Delphi-based, online ExpertLens survey to understand key differences, areas of divergence

and fault-lines in the way experts interpret the evidence.

The adaptive approach used in *Mapping Pathways* to inform the evidence base for policy development is a methodological innovation in itself, with experts, stakeholders and communities engaged in reflexive and iterative exchanges of knowledge.

Findings from across the four elements of the Mapping Pathways project indicate broad, divergent and incomplete evidence related to the viability of implementing ARV-based prevention strategies. Though the diverse perspectives highlight strengths and weaknesses associated with each strategy, our aim was not to make a definitive determination about which, if any, of the ARV-based strategies is stronger than any other. Rather, we highlight how the different perspectives and snapshots of the evidence for each strategy bring into focus features which still need to be explored.

The literature review pointed to the dominant role of clinical trials in shaping current policy and the need for further research into the contexts and conditions which will shape the real-world 'trials' that now need to take place as communities consider how these strategies may or may not be implemented. The literature shows there is a strong focus on *efficacy*, but more limited evidence on *effectiveness*. This is crucial, as a theme emerging from all four strategies was that behaviour and adherence will play a central role in the relative successes, and potential failures, of any ARV-based prevention strategy. It is intertwined with efficacy, alongside other parameters which determine effectiveness, such as cost, access, drug resistance, side effects and the wider socio-political context.

The grassroots perspective highlighted that people need more information in order to better understand and make individually appropriate decisions for their communities. There was general support for using ARVs as a prevention strategy, and in particular TLC+ and PrEP, but the types of concerns people expressed about what would happen if these strategies were implemented varied by country. This calls attention to the very real fears the front-line communities have about the effects of these strategies on their communities.

Mirroring this, but coming from the grass-tops, the findings from the stakeholder interviews showed the very divergent ways leaders in different countries viewed the scientific evidence base. It was striking that within each country the same sets of scientific data were interpreted, framed and perceived in different ways depending on the local context. Stakeholders in decisionmaking positions seemed highly reluctant to make determinations on the basis of one clinical trial or study. Finally, the ExpertLens exercise highlighted that fault-lines in the evidence base exist, revealing where experts disagreed on the strength of the science in different areas and the implications of that disagreement for decisionmaking.

In India, stakeholders from the grass-tops and the grassroots offered the most scepticism throughout and the most hesitancy about the idea that efficacy in a clinical trial means effectiveness on the ground. They often highlighted the different sets of cultural barriers to consider in India, ranging from cultural stigmas against HIV, to the complexity of healthcare treatment and testing facilities. In South Africa, stakeholders were worried about trade-offs and resource decisions that would need to be made. There were also concerns that existing prevention strategies and approaches to treatment might be side-lined in favour of this new science. Stakeholders from the US seemed more willing than other groups to accept scientific data at face value. They were consistently the most positive about each of the ARV-based prevention strategies and raised the fewest concerns about the nature of the science.

Across all countries, stakeholders cared about issues such as costs, resources, efficacy, effectiveness, adherence and resistance, but differed in the weight or priority they gave to a particular concern. Efforts to find pathways for the adoption of evidence-based practices in a given country have to take into account not only the strength of the scientific evidence, but also how that evidence and the study methodology

are perceived as being applicable to the particular circumstances in that country.

The findings of this study point to a need for innovation not only in our approach to different prevention strategies for HIV/AIDS, but equally in our approach to policymaking. The opportunities highlighted in the pages of this monograph suggest we can develop much more tightly integrated understandings of both the scientific data about efficacy, which tells us whether recent innovations in the use of ARV drugs work or not, and the 'social', multi-disciplinary data about effectiveness. The right sets of social arrangements and organisational frameworks need to be in place in order for any scientific innovation to be useful, appropriate and adaptable.

The series of Mapping Pathways 'snapshots', culled from a highly dynamic and emerging evidence base, will not provide answers, but they highlight the importance of locally contingent factors in understanding how and why different strategies may or may not be effective in different communities. They help to illuminate the multiple pathways communities and policymakers must take to arrive at their own answers.

Scientific endeavour improves the lives of people living with HIV and provides us with new tools to fight it. However, science is interpreted differently by diverse communities; understood in varied ways for multiple reasons; and utilised for diverse means and ends. Context is critically important and the new scientific findings are only one part of successful ideas, innovations and breakthroughs.

As Archbishop Desmond Tutu says in his foreword, 'all science is local'. 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. ARV-based prevention strategies need to be successful at local levels before they can have a global impact.