

Social Aspects of HIV

Sarah Bernays · Adam Bourne  
Susan Kippax · Peter Aggleton  
Richard Parker *Editors*

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# Remaking HIV Prevention in the 21st Century

The Promise of TasP, U=U and PrEP

 Springer

# **Social Aspects of HIV**

## **Volume 5**

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Sarah Bernays • Adam Bourne • Susan Kippax •  
Peter Aggleton • Richard Parker  
Editors

# Remaking HIV Prevention in the 21st Century

The Promise of TasP, U=U and PrEP

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# Contents

<b>1</b>	<b>Remaking HIV Prevention: The Promise of TasP, U=U and PrEP . . . . .</b>	<b>1</b>
	Sarah Bernays, Adam Bourne, Susan Kippax, Peter Aggleton, and Richard Parker	
<b>Part I Efficacy and Effectiveness: Shaping Policy and Informing Interventions</b>		
<b>2</b>	<b>‘PrEP Is a Programme’: What Does this Mean for Policy . . . . .</b>	<b>21</b>
	Hakan Seckinelgin	
<b>3</b>	<b>Making the Ideal Real: Biomedical HIV Prevention as Social Public Health . . . . .</b>	<b>35</b>
	Mark Davis	
<b>4</b>	<b>PrEP, HIV, and the Importance of Health Communication . . . . .</b>	<b>47</b>
	Josh Grimm and Joseph Schwartz	
<b>5</b>	<b>Anticipating Policy, Orienting Services, Celebrating Provision: Reflecting on Scotland’s PrEP Journey . . . . .</b>	<b>59</b>
	Ingrid Young	
<b>6</b>	<b>Fighting for PrEP: The Politics of Recognition and Redistribution to Access AIDS Medicines in Brazil . . . . .</b>	<b>73</b>
	Felipe de Carvalho Borges da Fonseca, Pedro Villardi, and Veriano Terto Jr	
<b>Part II Pleasure, Agency and Desire</b>		
<b>7</b>	<b>The Beatification of the Clinic: Biomedical Prevention ‘From Below’ . . . . .</b>	<b>91</b>
	Kane Race	

- 8 New Potentials for Old Pleasures: The Role of PrEP in Facilitating Sexual Well-being among Gay and Bisexual Men . . . . . 105**  
 Bryan A. Kutner, Adam Bourne, and Will Nutland
- 9 New Hierarchies of Desirability and Old Forms of Deviance Related to PrEP: Insights from the Canadian Experience . . . . . 117**  
 Adrian Guta, Peter A. Newman, and Ashley Lacombe-Duncan
- 10 Agency, Pleasure and Justice: A Public Health Ethics Perspective on the Use of PrEP by Gay and Other Homosexually-Active Men . . . 131**  
 Julien Brisson, Vardit Ravitsky, and Bryn Williams-Jones

### **Part III Provision Politics and New Forms of Governmentality**

- 11 The Political Life of PrEP in England: An Ethnographic Account . . . . . 145**  
 Sara Paparini
- 12 Implementation Science or ‘Show’ Trial? England’s PrEP Impact Study . . . . . 159**  
 Catherine Dodds
- 13 The Stigma Struggles of Biomedical Progress: Understanding Community Engagement with PrEP by People Who Use Drugs . . . 173**  
 Andy Guise
- 14 How the Science of HIV Treatment-as-Prevention Restructured PEPFAR’s Strategy: The Case for Scaling up ART in ‘Epidemic Control’ Countries . . . . . 187**  
 Ryan Whitacre
- 15 Getting Real on U=U: Human Rights and Gender as Critical Frameworks for Action . . . . . 201**  
 Laura Ferguson, William Jardell, and Sofia Gruskin
- 16 Falling Short of 90-90-90: How Missed Targets Govern Disease Elimination . . . . . 219**  
 Kari Lancaster and Tim Rhodes

### **Part IV Anticipating and Understanding the Consequences of Biomedicine**

- 17 Stigma and Confidentiality Indiscretions: Intersecting Obstacles to the Delivery of Pre-Exposure Prophylaxis to Adolescent Girls and Young Women in East Zimbabwe . . . . . 237**  
 Morten Skovdal, Phyllis Magoge-Mandizvidza,  
 Rufurwokuda Maswera, Melinda Moyo, Constance Nyamukapa,  
 Ranjeeta Thomas, and Simon Gregson

<b>18</b>	<b>Imagined Futures and Unintended Consequences in the Making of PrEP: An Evidence-Making Intervention Perspective . . . . .</b>	<b>249</b>
	Martin Holt	
<b>19</b>	<b>The Drive to Take an HIV Test in Rural Uganda: A Risk to Prevention for Young People? . . . . .</b>	<b>265</b>
	Sarah Bernays, Allen Asiimwe, Edward Tumwesige, and Janet Seeley	
<b>20</b>	<b>Entangled Bodies in a PrEP Demonstration Project . . . . .</b>	<b>277</b>
	Lisa Lazarus, Robert Lorway, and Sushena Reza-Paul	
<b>21</b>	<b>An Unfinished History: A Story of Ongoing Events and Mutating HIV Problems . . . . .</b>	<b>289</b>
	Marsha Rosengarten	

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# Chapter 1

## Remaking HIV Prevention: The Promise of TasP, U=U and PrEP



**Sarah Bernays, Adam Bourne, Susan Kippax, Peter Aggleton, and Richard Parker**

### 1.1 Why this Book?

HIV has always been, and continues to be, as much a social phenomenon and challenge as it is a clinical one. Controlling transmission and containing the virus relies on engaging with and adjusting the social contours of behaviours and practices. Efforts to prevent acquisition and enable ‘protection’ against HIV continue to illuminate the complexity, multiplicity and dynamism of relationships in context,

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from the micro level of person to person interaction extending up to the global stage of political economies. Despite major biomedical breakthroughs over the course of the HIV epidemic, the influence of the social has not diminished. What risks being diluted through the optimism evoked by the biomedical promise though is how immediately visible and relevant the role of the social remains in efforts to prevent, control and perhaps ‘eliminate’ HIV.

The current ‘biomedical’ response to the HIV epidemic has been framed as a shift from an understanding of prevention as dependent on changes in social norms and practices and political responses to one predominately associated with pill-taking and injectables by individuals. This biomedical turn within HIV prevention has been interpreted by some, falsely we believe, as indicative of the failure of the earlier social programmes and associated behavioural interventions. Furthermore, such a framing serves only to create or maintain a false separation, as biomedical responses always depend on social processes in order to be put into practice (Hankins and de Zaluondo 2010). Treatment as Prevention (TasP), through consistently adhering to anti-retroviral treatment (ART), or negotiating Pre-Exposure Prophylaxis (PrEP) use, rely on behavioural responses as much as interventions explicitly referred to in behavioural terms, such as condom use or serosorting. The effectiveness of biomedical methods is shaped by, and indeed dependent upon, social processes, which are indivisible from their prescribing, delivery and consumption contexts.

Since the early days of the HIV epidemic, social scientists have understood that behavioural responses are essentially social. The same is true in relation to the responses of people to the HIV-related biomedical programmes and interventions we see around us now. These have, in many respects, been brought into being by global advocacy and social movements. They have been made accessible (in some contexts) by activism, by politics and by sustained civil society engagement. They have been made acceptable (to some) by community organising, peer-based communication and other creative ways of facilitating awareness, interest and uptake. It is also social and cultural forces that have restricted access for some, and that have denied the possibilities afforded by the biomedical to some groups, particularly those most stigmatised or criminalised. The success or failure of prevention interventions in achieving an end to the epidemic, and in ensuring health equity, will rest heavily on the ability, willingness or determination of societies and cultures to drive change. This was integral to the emphasis of combination prevention, which reflected a concerted effort, especially in resource-stretched settings, to ensure that the learning about the value of structural interventions and attending to the intersection of social practices across a range of distinct but complementary prevention options was not lost in the rush to embrace biomedical prevention (UNAIDS 2009; Hankins and de Zaluondo 2010; Kurth et al. 2011). Despite this approach losing political favour in some places, such as Brazil, in recent years (Montenegro et al. 2020), there remains much to be learned from how biomedical approaches can be incorporated into existing approaches and programmes, rather than framed as substituting them (Brown et al. 2015; Cáceres et al. 2015; Mahase 2020; O’Reilly et al. 2020; Tolley et al. 2020).

Much of the optimism generated through the expectation that biomedical prevention will accelerate progress towards HIV elimination, and in doing so will redress the ‘failings’ of earlier behavioural interventions, has been derived from efficacy data generated under controlled trial conditions. Producing similar levels of effectiveness within the messy contexts of everyday life has proved more challenging (Cohen et al. 2011; Kippax 2003). This illustrates not only the entanglement between biomedical interventions and behaviours, but also the interconnected social, economic and political spheres which constitute the conditions in which HIV prevention must operate. How these interventions have come to be framed, shaped and experienced through this nexus of social conditions and across various contexts is the focus of this book.

In this edited collection, we consider the effects of the increasing forms of biomedical prevention through developments such as Treatment as Prevention (TasP), Undetectable equals Untransmittable (U=U) and Pre-Exposure Prophylaxis (PrEP) on continually reframing policy, practice and research. Although these approaches are commonly described under the collective banner of biomedical prevention, it is constructive to delineate how they differ in form and effect. PrEP is a medication taken in the form of a pill or injection to prevent acquiring HIV. TasP exists both as a treatment policy and as a powerful slogan to inspire engagement in this treatment policy because it also prevents transmission: U=U. Although intangible, the value of TasP and U=U as slogans reflects the ongoing powerful influence of community advocacy in shaping the aspirational course of global HIV policy in the pursuit of the ‘elimination’ of AIDS. The subsequent appeal of these slogans rests in part in their capacity to produce powerful possibilities about how HIV risk can be managed and controlled. Although predicated on universal opportunity, the extent to which they are feasible under current conditions across communities is much more fractured.

For many people and communities, these developments have increased hope for the future, even if the attainment of this promise has been unevenly experienced so far. These new forms of prevention raise a number of political, social, cultural and ethical issues that thus far have received insufficient attention. As with all behaviours or practices, there is a need to acknowledge the central role of these concerns in influencing the delivery, consumption and effects of biomedical prevention, which in turn is influencing the success or failure of current HIV prevention efforts.

Thus, while accepting that TasP, U=U and PrEP hold great promise, this book takes a broad social science stance and examines the social and political impacts of the recent and ongoing move to biomedical prevention and the variable attention paid to combined prevention. This is vital to illuminate the influence of the social on the effects, mechanisms and outcomes of interventions, which are now predominantly framed as being biomedical. We argue that a social lens, one that illuminates affected communities’ active and creative appropriation of biomedical information and technologies, including those whose participation may be indirectly impeded, is essential to distinguish more or less effective developments in prevention. Attending to what becomes visible through this lens is necessary to ensure that we are responding to the opportunities to maximise the success of biomedical and other

‘new’ technologies and are able to adapt programmes to meet the varying needs of all those at risk of acquiring HIV. We intend that the analyses of a range of political, economic and cultural concerns, which coalesce to create the ‘social’, across the chapters of this book should offer a clear call for biomedical and social scientists to ensure together that the realities of everyday life are understood as central to the success of all forms of HIV prevention and to avoid the pitfalls of unintended and unwanted outcomes.

## 1.2 Situating Biomedical Prevention

### 1.2.1 *Treatment as Prevention (TasP) and Undetectable=Untransmittable*

The term Treatment as Prevention (TasP) refers to the range of biomedical prevention methods and programmes that use antiretroviral treatment (ART) to decrease the risk of HIV transmission. There is increasingly clear evidence that when people adhere consistently to ART, on a treatment regimen to which they are not resistant, the HIV viral load in their blood or other bodily fluids (semen, vaginal fluid and rectal fluid) can be reduced to such a low level that blood tests cannot detect it (Cohen et al. 2011; Rodger et al. 2019). This is described as viral suppression or an ‘undetectable’ viral load. In such circumstances, not only is a person’s health not affected by HIV but also, they cannot transmit HIV to others. This advance has given rise to the ‘undetectable equals untransmittable’ (U=U) campaign to enhance awareness that if a person has an undetectable viral load and takes their ART medications as prescribed, they will not transmit HIV to their sexual partners (Eisinger et al. 2019).

The concept of expanded access to ART to curb the epidemic through a ‘treat-all’ strategy was initially proposed by UNAIDS and then formally recognised by the World Health Organization (WHO) in 2015, which recommended that all those diagnosed with HIV should be started on ART immediately, regardless of HIV viral load. It is anticipated that this approach will decrease community viral load (the average viral load across a certain group) and thereby reduce the rate of new infections. This underpins the WHO’s 95-95-95 strategy (95% of people living with HIV knowing their HIV status; 95% of people who know their HIV status on treatment; and 95% of people on treatment with suppressed viral loads) and is an essential component of the modelling studies that have predicted that TasP could lead to HIV transmission being dramatically reduced if not eliminated. Despite consensus to work towards these goals, the powerful rhetoric encapsulated within these slogans can serve to overstate the progress being made on the ground, given the existing limitations in treatment access and coverage, rendering the gaps between aspirational policy and reality less visible. We argue that in spite of these positive developments, the approaches and models that provide the foundation for current

global AIDS policies and programmes face major challenges when rolled out in the real world: a world characterised by limited resources, variable political will, continued HIV-related stigma and discrimination, and social and economic inequality.

### ***1.2.2 Pre-Exposure Prophylaxis***

Pre-exposure prophylaxis (PrEP) is a course of anti-retroviral treatment taken by HIV-negative people to protect them against HIV infection. Truvada, which was first approved in the USA for use as PrEP in 2012 and has since been approved in dozens of countries, is a single pill combining two anti-retroviral treatments, tenofovir and emtricitabine. In some settings, generic alternatives have also been approved for use as PrEP (Mameletzis et al. 2018; Hodges-Mameletzis et al. 2019). Injectables and other long-acting options have also been developed and may serve to further increase the appeal and scalability of PrEP coverage globally. A number of large, high profile clinical trials have shown the efficacy of PrEP in preventing HIV, if taken correctly. It is evident that under controlled conditions, the harms associated with particular sexual practices and with illicit injection drug use have been dramatically reduced by the presence of PrEP. Mathematical modelling studies have predicted that among populations of gay, bisexual and other men who have sex with men; a large and early effect on HIV incidence can be achieved if PrEP is implemented with high coverage of those at risk. This has changed the face of HIV prevention, especially for gay and other men who have sex with men in the high-income countries of the world.

Ongoing research continues to investigate levels of knowledge about and attitudes towards PrEP, to measure levels of uptake and adherence, and, more generally, to evaluate the impact of PrEP on a number of different populations over time, that is, to investigate effectiveness. As alternative formulations become available, such long-acting injectables, the appeal, scalability and impact of PrEP for a wider range of populations groups, in particular heterosexual men and women, is likely to change too (Mahase 2020; Tolley et al. 2020). Addressing contested questions such as for whom PrEP is for and how to ensure greater equity in its availability and accessibility, as well as exploring its varied appeal and ability to meet the needs (and risks) of potential users, particularly women and those in resource-constrained settings, have been shown to be much more complicated.

## **1.3 HIV Prevention for all?**

Learning from HIV prevention spans almost four decades and has consistently shown that there is no one approach that will work for everyone all of the time. Indeed, prior to the advent of biomedical approaches, combination prevention—involving a range of safer sex and safer drug use options—was often advocated as

the strategy to adopt, in recognition of people's and communities different (and often changing) circumstances and needs.

Importantly, the opportunities afforded by biomedical interventions do not negate the need for a continued emphasis on combination approach, which are tailored to population groups, attentive to social marginalisation and adapted to be delivered at scale. There is no intrinsic tension in this approach. However, there is a risk that in the pursuit of biomedical interventions there may be a neglect of the pertinence of social structures and contexts in shaping effectiveness as interventions are rolled out at scale. In so doing, the narrative which blames the intended user for not adequately engaging with the intervention may gain traction, reproducing or creating new forms of inequity, detracting attention from how biomedical methods need to be adjusted to improve equity and to better meet the prevention needs of individuals and groups.

In recognition of this, we pay particular attention to the political and economic motivations behind the roll-out of recent innovations in HIV prevention. Policymaking with regards to TasP, U=U and PrEP varies significantly internationally and highlights not only continued inequities between the global North and global South, but also in-country divisions between those who are economically and socially marginalised, and those who are not.

The active embrace of TasP, and its ensuing success in reducing new infection, has been concentrated in resource-rich countries, primarily in the global North. It is within such contexts that not only are good quality second and third-line treatment regimens with low level side effects available, but also civil society organising and activism has, to date, been most effectively focused towards the needs of ethnically and economically dominant groups. While numerous high-income countries have observed declines in HIV incidence associated with TasP among white, middle class, native-born gay and bisexual men, such success has not often been achieved among those from minority ethnic backgrounds, Indigenous communities or among migrants. In the context of low- and middle-income countries, primarily in the global South, where supply chain management may be weaker (especially in the absence of donor support), older treatment regimens with significant side effects (and related challenges for the levels of adherence necessary to avoid viral resistance) are often the only options that are available. This has created a tier of relatively affordable but 'second class' accessible treatments in many resource-constrained settings. Despite improving rates of global treatment coverage, which is celebrated within annual reports, the limited effectiveness and tolerability of available ART regimens impede the chances of the success of TasP and widespread viral suppression. In addition, across contexts the communication of the U=U message has not always been coherent and/or straightforward, being influenced by and framed by political and social complexities and tensions. The heterogeneity in progress, including the time that it will take to attain the global targets (if ever), are commonly obscured within the buoyancy of these slogans and global reports. We aim to draw attention to the uneven topography by attending to the variation across contexts in achieving viral suppression and thus realising the promise of TasP and U=U.

Similar inequities exist with regard to PrEP. Whereas most of the research related to use by gay, bisexual and other men who have sex with men has occurred in North

America, Europe and Australia, with the notable exceptions of intense research activity on PrEP in Peru (Perez-Brumer 2019), most of the sex worker related research has taken place in Africa (Eakle et al. 2018; Busza et al. 2020), where there is also an emerging focus on transgender women (Poteat et al. 2020). Furthermore, access to PrEP for use in public health prevention programmes continues to be disproportionately available principally in high-income economies and for certain population groups. The uneven effect of PrEP, even within countries which have demonstrated successes (Laborde et al. 2019), indicates that its positive impact currently remains more posited than proven (Rosengarten and Murphy 2019) and reflects the power invested in promises to leverage funding and to guide global HIV policy. Promising ‘the end of AIDS’ in resource rich countries thus goes hand in hand with the politics of outsourcing clinical trials for biomedical prevention methods to low- and middle-income countries (as well as those in unsympathetic political regimes), while in many middle- and low-income countries access to PrEP is all but impossible and/or limited to those enrolled in ‘demonstration’ trials (Patton and Kim 2012; Kenworthy et al. 2018).

The positive impact of PrEP has not yet been broadly realised in many low-income settings. Although there are some notable exceptions to this trend in Latin America (Galea et al. 2018; Luz et al. 2019), again we must be cautious to avoid assuming that positive outcomes are uniform across different populations and subgroups (Torres-Cruz and Suárez-Díaz 2020). Retention in PrEP trials and demonstration projects by key populations in numerous countries in Sub Saharan Africa (e.g. Kenya) has been very low (Wahome et al. 2020). Similarly, adherence to PrEP in South Africa, Uganda and other contexts has not met expectations (Mayer et al. 2019; Kinuthia et al. 2020; Pillay et al. 2020), which suggests there is much still to understand about the cultural context within which this new intervention is perceived, understood and actioned. Decades of research relating to HIV testing and treatments has taught us the value of local wisdom in facilitating uptake and adherence and this remains true for newer forms of biomedicine (Cowan et al. 2016). It has always been, and will continue to be, inappropriate and ineffective to transfer interventions conceived and developed in one context into another without examining and attending to the diverse, nuanced and creative situated reality (Syversten 2019; Well and Ledin 2019).

These disparities are compounded by inequalities in the ways in which science operates globally. While scientific decision-making and authority, as well as most major funding is concentrated in the hands of scientists from the global North, the implementation of trials has taken place primarily in the global South, sub-contracted to local institutions and more junior co-investigators. Such inequities reflect the power of Big Pharma and existing trade regulations, which, when combined with how science gets done, places low- and middle-income countries at a significant disadvantage. Existing intellectual property rights and commercial trade regulations create significant barriers to access for new biomedical approaches in low- and middle-income countries, and pharmaceutical companies in the global North have consistently fought against the approval of generic versions of PrEP in countries across the global South.

The move to biomedical prevention reflects a shift from the community to the clinic, which has been associated with the individualising and privatisation of prevention. The physician's office and clinic offer very different contexts from the settings in which most of the early successful epidemic responses took place. As a result of social solidarity and collective action among gay, bisexual and other men who have sex with men, injection drug users and sex workers, social norms were developed over time, which protected community members from HIV transmission. HIV prevention, whether it involved condom use, serosorting, the education of clients by sex workers, or the use of sterile needles and syringes was intimately tied to the sexual or injection act and depended on communication between social actors. The development and strength of social and community norms, which are themselves so central to the take up of new technologies, depend on such conversation and talk. HIV prevention remains a deeply social practice and, in order for biomedical prevention to be effective, it too must be understood as a social practice and interventions be developed through participatory dialogue.

One example of the dynamic and divergent social practices, which emerge from engaging with biomedical prevention, is pill-taking. If pill-taking can be done privately, then this can have distinct advantages for those who wish to avoid the stigma associated with being known as gay or a person who injects drugs or a sex worker, as it reduces the likelihood of talk and communication between community members, but this absence of talk may undermine needed communication. Furthermore, the experience of PrEP use itself may produce stigma and discrimination. On the one hand, PrEP has been associated with promiscuity and pleasure and those using PrEP in the gay community have been subject to 'slut-shaming' discourse, while, on the other hand, gay, bisexual and other men who have sex with men choosing not to use PrEP may find themselves subject to social censure and questions about 'good gay' citizenship.

Stigma may also be produced among young women. For example, the advocacy in some southern African countries to place all young women on PrEP because they are 'vulnerable' to infection, is likely to position (once again) women as 'vessels of disease' responsible for HIV transmission. For some, such interventions may have a liberating influence: for others, without due attention to how meanings are produced and intersect with existing disadvantage, the unintended effects of biomedical prevention may further solidify inequity.

## 1.4 Blind Spots

While the emphasis on biomedical prevention can detract from and blur the visibility of social influences that moderate their effectiveness, it is also vital to illuminate the blind spots that exist within this book. The chapters follow the trajectory of the development of biomedical HIV prevention within HIV policy, tracking the implementation of interventions within and beyond trials into programmes. As such, this is a collection of insights and reflections which maps the social effects of what *is* being

implemented rather than what is not. Being predominately empirically informed, in each chapter the authors broadly focus their analytical attention on the presence of biomedical interventions, rather than its absence. The resulting limitations in coverage both reflects and reproduces the centripetal force which guides empirical research attention and funding. In pursuit of the operation of biomedical prevention, the chapters reveal the hierarchy of concerns which are driven by profit margins and systemic opportunities in which some population groups are prioritised over others.

Within this collection there is only limited attention to people who use drugs or transgender people. This does, however, reflect the fact that, comparatively speaking, far less research has been conducted with and for these populations, which itself reflects a lack of political attention or will (and thus funding) to engage with populations that are doubly disadvantaged, highly stigmatised and whose experiences and needs have often been placed on the periphery of the HIV response. Although the chapters deliberately highlight who or what may be explicitly or indirectly left out of existing scientific and programmatic classifications and mechanisms, our focus on all population groups is partial at best, and broadly incomplete.

A pertinent example of this are the debates which coalesce around PrEP, which have predominately considered gay, bisexual and other men who have sex with men. There is much to be learnt from the groups that continue to be framed as absent from the discussion, as well as the reasons why they are indirectly excluded. The blind spots around how biomedical prevention can engage with the needs of specific and marginalised population groups, such as trans women or trans men, as well as extensive, but also at times invisible, populations such as women living in poverty and men and women in migration, demand more empirical and analytical attention.

Having outlined the purpose of this book, as well as identifying its limitations, we turn next to explaining how the book is structured and the chapters organised thematically.

## **1.5 Efficacy and Effectiveness: Shaping Policy and Informing Interventions**

As we navigate an era of new HIV biomedical technologies, social scientists across the world have sought to examine how the promise such interventions offer within tightly controlled trial settings can be—or has been—realised in real world settings.

Chapters in this first part—which focuses largely on the opportunities and difficulties associated with PrEP—pose important questions about how biomedical science is understood and acknowledged in policy, programming and health promotion, as well as how effectiveness is advanced through social action. By so doing, this part raises important questions about the growing emphasis on biomedical interventions in an epidemic that is intensely social in character, including the need to acknowledge the interwoven relationships between the biomedical, social and political.

In the first chapter, Hakan Seckinelgin invites readers to consider the idea of PrEP as a programme rather than just a pill. By reconsidering what exactly PrEP trials have demonstrated in terms of efficacy and what efficacy might mean for policy in non-trial contexts, the chapter raises critical questions about the relationship between biomedical interventions and the contexts in which they are applied. Related ideas are explored in Mark Davis' chapter which follows. This interrogates how dominant assumptions about biomedical HIV prevention view social factors as largely secondary to effectiveness, either as barriers to the rollout and uptake of interventions or as conduits for the same processes. Such an approach marginalises the reflexivity of those who are the subjects of HIV prevention, ignoring the unanticipated effects this may have on social and sexual lives. The chapter encourages a rethinking of biomedical HIV prevention as an assemblage of biomedical, social and political forces and effects, each of which is necessary for the approach to be effective. The next chapter, by Josh Grimm and Joseph Schwartz, focuses on PrEP, HIV and health communication. Engaging with the idea that messages and messaging matters, it argues that communication in general and mass media, interpersonal communication and app-based communication, in particular, are valuable tools to increase awareness and adoption of biomedical HIV prevention such as PrEP. When employed strategically, mass media can encourage discussion—helping build relationships and support the adoption of PrEP. Dating and hookup apps such as Grindr and Scruff provide additional ways of reaching gay, bisexual and other men who have sex with men providing hyper-local information about PrEP, HIV and sexual health resources.

Building on some of these ideas the final two chapters in this part, focusing on two different contexts—Scotland and Brazil respectively—shift the focus to examine the effects of PrEP and related forms of biomedical HIV prevention on the everyday experiences of those who use them, as well as for the communities of which they are a part. Ingrid Young's chapter signals how the arrival of PrEP in Scotland came with expectation and celebration. As the first country in the UK to offer PrEP through the national health service, Scotland was heralded as a leader in HIV prevention. The chapter asks how anticipation of PrEP and its focus on specific risk practices affected not only awareness, access and use, but also wider narratives about prevention, inequality and 'progress'. The chapter signals how PrEP roll-out contributes to an orientation towards certain (gendered) PrEP users and PrEP use. It considers how the anticipation of PrEP as a biotechnology for particular risk practices, bodies and communities shaped promissory HIV prevention futures and determined what success and 'celebration' could be like. The struggle for PrEP access figures strongly in Felipe de Carvalho Borges da Fonseca, Pedro Villardi and Veriano Terto Jr's chapter that follows. This chapter addresses, through a historical perspective, the role of organised civil society in the struggle for access to HIV medicines in Brazil. Through concepts of recognition and redistribution, the text shows how recognition of the rights of people living with HIV and the participation of the AIDS social movement in policymaking were decisive in the establishment and sustainability of universal access to HIV treatment in Brazil. Over the course of the past decade, activism around new HIV prevention methods such as PrEP has

shown that expanded access to these technologies depends on the fight against both moral and market barriers. The future is far from certain, as recent setbacks to democracy both in Brazil and elsewhere mean less recognition of civil rights and threats to universal access to medicines and HIV prevention tools.

## 1.6 Pleasure, Agency and Desire

Part II of this book moves beyond effects, efficacy and effectiveness to consider questions of agency, pleasure and desire. PrEP, TasP and the opportunities provided by U=U afford HIV affected populations the opportunity to have sex without condoms—with both regular and other partners—in ways that reduce or eliminate the chances of acquiring or transmitting HIV. After more than 30 years of ‘use a condom every time’ messaging, this represents a fundamental change in how people understand and operationalise constructions of sexual safety in negotiation or combination with forms of sexual pleasure. The new biomedical and technological affordances have been acknowledged and embraced by actors in some settings who have sought to promote PrEP. However, while they may facilitate new forms of sexual satisfaction, they also intensify opportunities for the policing of groups and their practices (both internally within communities and externally by others), especially when considered in isolation from the assemblages that shape or foster desire. In other contexts, notions of pleasure have been ignored and reproduced the denial of sexual agency and the right to pleasure that has permeated much of the HIV epidemic response to date.

These and other issues are examined in Kane Race’s chapter on biomedical prevention ‘from below’. With the introduction of biomedical prevention, gay community-based agencies have sought to optimise biomedical prevention by establishing non-judgemental, anonymous community-based clinics offering rapid HIV and STI testing in shopfronts, mobile clinics and gay neighbourhoods. To maximise accessibility these services have framed sex as a valid form of pleasure and experimentation rather than an object of moral correction. While these modes of implementing biomedical prevention represent a case of intensified biomedicalisation, they are continuous with a history of collective experimentation with bodies, pleasures and care practices that has long distinguished gay community responses to HIV. Bryan A. Kutner, Adam Bourne and Will Nutland’s chapter develops similar ideas to show how by decoupling fear about HIV from the sex lives of gay, bisexual and other men who have sex with men, PrEP presents an opportunity to broaden programmes and interventions beyond HIV prevention to embrace sexual wellbeing more generally. Case studies from organisations and advocacy groups that have worked to acknowledge and promote pleasure are explored together with the cultural and structural forces that seek to deny pleasure as a healthy feature of the sex lives of gay, bisexual and other men who have sex with men in many parts of the world.

The following chapter by Adrian Guta, Peter A. Newman and Ashley Lacombe-Duncan shifts the focus slightly to consider new hierarchies of desirability in the context of PrEP availability. Through a new materialist-informed reading of qualitative data collected from PrEP users and non-users in Toronto, Canada and health promotion campaigns, they explore how PrEP-mediated desirability is produced and deployed within a neoliberal context. For some gay, bisexual and other men who have sex with men, PrEP is experienced as empowering and offers anxiety-free condomless sexual exploration. For others, PrEP remains aspirational, and a condition of their desirability. Between, there is considerable ambiguity, flexibility and movement. Their analysis considers emerging hierarchies of desirability within an assemblage of bodies, relations, affects, pills, evidence, technologies, discourses and material conditions, which expands theorising about PrEP beyond it being a repressive biomedical prevention technology. Developing issues of empowerment further, Julien Brisson, Vardit Ravitsky and Bryn Williams-Jones's chapter on agency, pleasure and justice offers a public health ethics perspective on the use of PrEP by gay and other homosexually active men. It argues that such men should be understood as agentic in their use of PrEP as opposed to being the passive victims of biomedicalisation. Applying a reproductive justice framework, the chapter argues that the worldwide inaccessibility of PrEP constitutes a more serious ethical issue than the medicalisation of gay men's sexuality.

## 1.7 Provision Politics and New Forms of Governmentality

Like all actions in response to HIV, TasP, PrEP and U=U are intensely political. Structurally, they have raised significant questions regarding access, the division of resources and the role of targets in shaping epidemic responses, which have produced new or altered forms of governmentality for the individual and for heavily affected communities. As has been evident at so many points in the history of the HIV epidemic, community activism has once again been central to ensuring access and facilitating uptake, often coming into conflict with political forces that have sought to pit one community or population against another in the struggle for attention and resources. The four chapters included in this part, in their different ways engage with the politics at work here and the forms of governmentality they imply.

Sara Paparini's chapter on the political life of PrEP in England offers an ethnographic account of these developments. It took six years from the first release of the results of the PROUD PREP trial for NHS England to begin to provide PrEP as a routine service to people considered at high risk of acquiring HIV. These years have been marked by significant controversy, activism, a court case and heated media debate. The chapter tells the story of the emergence of PrEP in England through the accounts of key stakeholders showing how new HIV prevention technologies intensifying the relationship between pharmaceutical private interest and public health have a political life animated by moral, legal and material antagonisms.

Such antagonisms leverage clinical evidence and activist alliances to extend the history of HIV politics into new realms. In a complementary account to that offered above, Catherine Dodds traces the policy events that gave rise to the Impact trial in England, which followed several years after PROUD and provided a means of accessing PrEP for some gay and bisexual men while ostensibly examining real-world integration within relevant health systems. Interviews with key stakeholders demonstrate that rather than achieving its aims as a practical implementation trial that might have enabled and shared learning on the best ways to roll out PrEP, the Impact trial was designed as a ‘show trial’ to help manage a policy and financial impasse. But because the trial’s power dynamics were rooted in traditional hierarchies concerning the production of evidence, this undermined its potential as anything other than a stop-gap measure. Ultimately, rather than enabling the identification of lessons for those planning England’s future PrEP services, the trial’s legacy will largely be about the divisions and inequalities that it exacerbated.

Community responses to PrEP diverge. For some communities PrEP has offered a ‘revolution’ in HIV prevention; for others—including people who use drugs—PrEP access and use is complicated by on-going struggles for health and rights. Andy Guise’s chapter explores diverging responses of revolution and struggle to PrEP with a particular focus on people who use drugs. Building on an analysis of community engagement in the early HIV epidemic response as well as recent stigma scholarship, the chapter explains how PrEP is bound up in long-running processes of resistance to stigma. The character of these ‘stigma struggles’ shapes the potential for PrEP to be experienced as either revolution or struggle, while the norms of biomedical science exacerbate and complicate these struggles, through their symbolic power to erase history from analysis. The chapter concludes by reflecting on how an analysis of stigma struggles and their role in biomedical progress can inform relevant and tailored HIV prevention strategies.

The following two chapters progress the widening of focus that has occurred throughout this volume. In his chapter, Ryan Whitacre considers how the advent of TasP restructured the strategy adopted by the US President’s Emergency Plan for AIDS Relief (PEPFAR). It demonstrates how TasP, conceptualised as an ‘evidence-based’ solution for effectively treating and preventing HIV, came progressively to inform the organisation’s use of metrics for evaluating performance, and decisions for allocating funds to specific programmes and countries. Whereas under previous efforts to ‘lead the global response’ to the epidemic, PEPFAR supported a wide variety of programme areas, including strengthening health systems, following the advent of TasP, PEPFAR came to prioritise treatment programmes over and above all others. Emphasising the clinical logic of TasP, PEPFAR justified spending on a limited number of programmes in a small set of countries that could produce what it defined as the right kinds of outcomes. This ultimately laid the groundwork for the retreat of US foreign aid.

In their chapter entitled ‘Getting Real on U=U: Human rights and gender as critical frameworks for action’, Laura Ferguson, William Jardell and Sofia Gruskin push this analysis further by pointing to the selective way in which international non-governmental organisations and UN system bodies selectively engaged with the

opportunities and constraints which Undetectable equals Untransmittable (U=U) offered, subsequent to the roll-out of TasP by PEPFAR and other agencies. Reminding us of the importance of gender and human rights to any understanding of justice and equality in HIV prevention, their analysis highlights the challenges posed by the complex institutional landscape and the sometimes inconsistent policies and contested politics of the different agencies and systems that have grown rapidly as a result of the global scale-up of the HIV response, signalling the key role of international non-governmental organisations and civil society movements in seeking to monitor and advocate for more effective policies internationally.

In the chapter which brings to close this third part of the book, Kari Lancaster and Tim Rhodes consider how all too often global health targets are not met. Writing in the context of the COVID-19 pandemic, and as the anticipated future of 2020 imagined in the UNAIDS targets becomes the past, their chapter considers how missed targets such as these come to govern disease elimination. Drawing on studies of numbering practices in science and technology studies, their chapter explores how global health targets continue to govern even when they fail to be achieved. Enumerating prevention (and other health) targets—and progress towards them—does its work through progression and not completion, constructing disease elimination as but a vague predicate. Success or failure in HIV prevention (by biomedical means or otherwise) thereby has a latitude which makes ongoing governance and imagined futures possible. Within the context of HIV, 90-90-90 targets afford the possibility of virtual elimination—even as they fall short. Taking this reality seriously requires us to think differently about the timescapes of disease elimination and what the outcome of global targets such as these might be.

## **1.8 Anticipating and Understanding the Consequences of Biomedicine**

Like all actions that take place in the social world, the introduction of PrEP, TasP and U=U has not been without its consequences. Some of these may be intended, embraced or celebrated as evidence of efficacy or impact, others perhaps not. This final part of the book focuses on a range of anticipated and unanticipated issues, including those related to broader health benefits and dis-benefits; human rights and social justice; intended and unanticipated community and political responses; the status and engagement (or otherwise) of particular populations such as sex workers and young people; and other issues. In doing so, authors of the chapters connect the current phase of an increasingly biomedicalised response to the epidemic with challenges pervasive throughout its history, particularly in respect of gender equity, HIV stigma and discrimination.

Morten Skovdal, Phyllis Magoje-Mandizvidza, Rufurwokuda Maswera, Melinda Moyo, Constance Nyamukapa, Ranjeeta Thomas and Simon Gregson commence this work with a chapter focusing on obstacles to the delivery of

Pre-Exposure Prophylaxis to adolescent girls and young women in east Zimbabwe. Despite efforts to scale-up biomedical HIV prevention such as PrEP, many countries and regions are off-track in reaching HIV prevention targets. Uptake of, and adherence to, PrEP amongst adolescent girls and young women in sub-Saharan Africa is particularly challenging. Drawing on qualitative individual interviews and focus group discussions with thirty participants in east Zimbabwe, as well as interviews with healthcare providers, this chapter looks at the root causes of this challenge. Stigma and the worry that privacy and confidentiality cannot be maintained in health clinics and by local healthcare providers, presents a major barrier to young women's uptake of PrEP. Action is needed to tackle the socio-cultural norms and practices that interact to make engagement with PrEP an (im)-possible and (un)desirable thing to do for many adolescent girls and young women.

The next chapter by Martin Holt considers the way in which pre-exposure prophylaxis (PrEP) was imagined before it was widely used, the evidence generated as it has been trialled and implemented, and how knowledge-making practices have been incorporated into the making of PrEP as an HIV prevention strategy. The analysis attends to the ways in which unintended consequences (such as difficulties with adherence, high rates of discontinuation, reduced condom use and sexually transmitted infections) have been conceptualised and responded to as PrEP has been trialled and implemented. A tension is identified between considering PrEP as a discrete and stable intervention that can traverse contexts unchanged, and as an emergent process or assemblage that is enmeshed within local conditions and enacted in practice. Responses to unintended consequences suggest that it is not possible to separate PrEP from existing practices like condom use, or longstanding arguments about appropriate forms of sexual conduct and responsibility. To make PrEP work effectively, we should recognise the dense networks of relations on which it relies, and the positive and disruptive effects it can simultaneously provoke.

A key component of current global HIV prevention efforts is widespread HIV testing. This strategy in part reflects the focus on the broader global targets to eliminate AIDS by achieving high rates of viral suppression. Sarah Bernays, Allen Asimwe, Edward Tumwesige and Janet Seeley's chapter examines young people's engagement with HIV prevention options in South-West Uganda. A qualitative approach is used to examine how young people aged 16–24 years old navigate risks and opportunities within their daily lives. These risks include HIV, but also economic precarity. Within a context in which using HIV prevention methods, such as condoms or abstinence, is severely compromised by contextual realities, some young people report relying on irregular HIV testing as their primary method of prevention. One unintended consequence of the 'push' for HIV testing may be that it overrides other behavioural prevention strategies. Findings illustrate the impact such biomedical interventions may have if implemented in isolation from the structural drivers of vulnerability and the social context of young people's lives.

This theme of unintended consequences is extended in Lisa Lazarus, Robert Lorway and Sushena Reza-Paul's ethnographic study of a PrEP demonstration project in South India among female sex workers. The authors analyse a set of narratives in which participants claim PrEP as a 'cure all' for a range of physical

ailments. What becomes clear is how participation in the demonstration project has intensified a relationship with their bodies, leading women to reflect on and track various changes pertaining to bodily wellness. 'The body' thereby becomes a highly reactive site that entangles global HIV science, sex workers' engagements with health promotion, and regimes of self-care. Engaging with these local biologies holds important insights for the design and implementation of future biomedical interventions.

Marsha Rosengarten's chapter ends our book by pointing to an unfinished history of constantly changing HIV problems. It takes as its focus the thinking that has come to prevail with regard to women and HIV and, by so doing, working backwards through the genealogy of the development of PrEP. Without disputing the affordances of PrEP, in either pill or long-term form, it is suggested that WHO/UNAIDS 90-90-90 goals and optimism for a future end to the epidemic are founded on a misplaced conception of what is at stake. Drawing on process philosophy and 'event-thinking', it argues that if biomedicine is to be responsive to the what is most relevant to those affected by HIV, a more open conception of what is assumed by international health authorities as the 'dynamics of the epidemic' may be warranted. This is especially pertinent to the situation of women in heavily affected communities whose reluctance to participate in the community trials of PrEP documented in the chapter should be understood as a profoundly ethical stance raising questions about for whom, and in what ways, biomedical advance proves beneficial. What is at stake here is that through their discourse, international agencies and national authorities, as well as most in biomedicine and public health, have positioned and continue to position women as both vulnerable and yet responsible for the heterosexual transmission of sexually transmissible infection.

Throughout this book, authors attempt to draw attention to the social dimension to what is often construed as 'biomedical' HIV prevention. We invited them to do so because ultimately biomedicine is as much a social enterprise as it is a biological and medical undertaking. The programmes and interventions developed, the priorities they respond to, and the aims and ambitions of scientists and clinicians are as much cultural enterprises as they are scientific ones. They are driven by the passions and interests of individuals and communities—of scientists as well as advocates, activists and people living with HIV—which in turn reflect broader (and sometimes narrower) social priorities and concerns. To deny this, or to pretend otherwise, is not only blinkered but dishonest. Too often, initiatives such as TasP, PrEP and U=U have been promoted as 'good things' simply because they represent what is thought to be the latest advance in HIV prevention. To do this, however, is to present them shorn of their genealogy, significance and placement alongside other elements of the social assemblage that comprises HIV prevention today. Our call here is for an opening up of discourse and dialogue about these 'goods' in the hope that this may lead to a more critical appreciation of their strengths and limitations for some people, in some contexts, some of the time. We hope you feel inspired to contribute to this work.

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