Empowerment of Women and Girls

Constitutional Reforms and Access to HIV Services for Women in Low-resource Settings in Nairobi, Kenya

Pauline Oosterhoff and Emily Kageha Igonya

June 2015
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CONSTITUTIONAL REFORMS AND ACCESS TO HIV SERVICES FOR WOMEN IN LOW-RESOURCE SETTINGS IN NAIROBI, KENYA

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Contents

Acknowledgements 2
Abbreviations and acronyms 3
Executive summary 4

1 Introduction 9
1.1 Background 10
  1.1.1 Increasing urbanisation and urban poverty 10
  1.1.2 Gender and HIV in urban areas 10
  1.1.3 Gender and civil society in slum areas 11
  1.1.4 Civil society and the participation of PLHIV 12
1.2 Research questions 12

2 Methodology 14
2.1 Study sites 14
2.2 Methods 15
  2.2.1 Literature review 15
  2.2.2 Interviews 15

3 Findings 17
3.1 Lack of access and utilisation of government health services 17
3.2 Factors that shape health policy 18
  3.2.1 National health policy frameworks 18
  3.2.2 Institutional factors that shape county-level policy on HIV prevention and ART 19
3.3 Devolution and its impact on access and utilisation of government health services 20
  3.3.1 Slow implementation of devolution of HIV services 20
3.4 Financing and budgeting under devolution 23
3.5 Confusion over government restructuring 24
3.6 Confusion among patients 25
3.7 Participation of women and girls in making decisions on HIV services 25
  3.7.1 Lack of confidence 26
  3.7.2 Lack of knowledge 27
  3.7.3 Poverty of time 28

4 Conclusion 29
4.1 Recommendations 30

References 31

Boxes
Box 3.1 Working with county-level government: Emily Kageha Igonya’s experiences 22

Tables
Table 2.1 Distribution of the 23 key informant interviewees 15
Table 2.2 Characteristics of in-depth interview participants 16
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<thead>
<tr>
<th>Abbreviations and acronyms</th>
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<tr>
<td>AIDS</td>
<td>acquired immune deficiency syndrome</td>
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<tr>
<td>AMREF</td>
<td>African Medical Relief and Emergency Foundation</td>
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<td>ART</td>
<td>Anti-Retroviral Treatment</td>
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<td>Anti-Retroviral</td>
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<td>CBO</td>
<td>Community-Based Organisation</td>
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<td>Centers for Disease Control and Prevention</td>
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<td>CEDAW</td>
<td>Convention on the Elimination of All Forms of Discrimination against Women</td>
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<td>DFID</td>
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<td>HIV</td>
<td>human immunodeficiency virus</td>
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<td>IDS</td>
<td>Institute of Development Studies</td>
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<td>KDHS</td>
<td>Kenya Demographic Health Surveys</td>
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<td>KHADRE</td>
<td>Kenyan HIV and AIDS Disaster Response</td>
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<td>MDG</td>
<td>Millennium Development Goal</td>
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<td>MSF</td>
<td>Médecins Sans Frontières</td>
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<td>NACC</td>
<td>National AIDS Control Council</td>
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<td>NASCOP</td>
<td>National AIDS and STI Control Programme</td>
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<td>NCPD</td>
<td>National Council for Population and Development</td>
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<td>NgEC</td>
<td>National Gender and Equality Commission</td>
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<td>NGO</td>
<td>non-governmental organisation</td>
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<td>PEPFAR</td>
<td>US President's Emergency Plan for AIDS Relief</td>
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<td>PITC</td>
<td>provider-initiated testing and counselling</td>
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<td>PLHIV</td>
<td>people living with HIV</td>
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<td>PMTCT</td>
<td>prevention of mother-to-child transmission</td>
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<td>STI</td>
<td>sexually transmitted infection</td>
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<td>USAID</td>
<td>United States Agency for International Development</td>
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<td>VCT</td>
<td>voluntary counselling and testing</td>
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Executive summary

Background
After two decades of agitation for a new constitution, the violence that followed Kenya’s 2007 presidential elections finally led to a reform movement to overhaul the way the country was governed. On 4 August 2010, voters approved a new Constitution (Government of Kenya 2010) by a clear majority, reflecting a widespread desire for change. The new Constitution was designed to improve government accountability and democracy by reorganising the system of government. There are now more checks and balances, parliamentary oversight of the executive is stronger, and the Bill of Rights provides greater protection for citizens, including women and minorities.

Perhaps the most profound change brought about by the new Constitution was devolution, i.e. the transfer of power from the centre to regional authorities and to the citizens. For Kenya, this has meant statutory powers being granted to the counties. The rationale behind this devolved system of government was to promote self-governance, development, and the equitable sharing of resources. The new Constitution gives prominence to the participation of citizenry in planning and budgeting, specifically through Articles 10(2), 69(d), 174(c), 184(1)(c) and the County Government Act (sections 99 to 101) (Republic of Kenya 2013). Thus, powers once held by the legislature and the executive branch have been handed over to Kenya’s newly created 47 political and administrative counties. The county governments started up shortly after the March 2013 elections, when local representatives were elected. These new counties now oversee functions that were once the responsibility of the national government, such as education and health care. They receive a share of national revenues but are also expected to raise their own funds, i.e. from local taxes.

The devolution of health services began in 2013 with the election of governors and county principals. Devolution potentially has wide-ranging implications for Kenya’s health sector, which is already failing on several levels. In Kenya, the prevalence of the human immunodeficiency virus (HIV) slowed from between 13 per cent and 15 per cent of the general population in 1999 to 5.6 per cent in 2012. Nevertheless, this is still one of the highest rates of HIV infection in the world. Women in Kenya have been disproportionately affected by HIV.

Four years after the approval of the new Constitution, this case study examines: the difficulties that poor women and girls living in slum areas face in getting access to HIV services, including anti-retroviral treatment (ART); their perception of how devolution has affected HIV and other health-related services; and their ability to participate in political decision-making and to bring about change at the local level. Are HIV-positive women and girls in slums able to get the attention of policymakers at the county level in order to get the services they need?

The case study seeks to answer the following questions:

- What are the perceived effects of Kenya’s devolution policy on access to HIV prevention and ART services for women and girls in urban areas?
- What are the factors that shape county-level policies on HIV prevention and ART?
- Are women and girls in slums who are on ART able to get the attention of policymakers at the county levels in order to get the services they need?
- What is the role of organisations of people living with HIV (PLHIV) in the formulation of policy at county level on HIV services, including ART access?
Methods
The study was conducted in 2014 in two large slums – Kibera and Majengo – in the capital Nairobi, which is one of the 47 administrative counties under the new Constitution. It is the most populous county, with the majority of people living in one of the more than 80 slums.

Researchers conducted a literature review and collected qualitative data from key informant interviews – 53 in-depth interviews with policymakers, implementers, health staff, HIV advocates and HIV-positive women. We also used participant observations and digital storytelling, which is a qualitative narrative story method capturing voice and images on iPads through various applications, to capture the lived experiences of six women from slum areas. They can be viewed at: http://interactions.eldis.org/urbanisation-and-health/country-profiles/kenya/digital-stories.

Findings

Lack of access to and utilisation of government health services
Women and health-care workers raised concerns over a number of issues that affected their access to HIV-related services, which they would like to see changed. These issues included: (1) unavailability of HIV-related health services especially in terms of essential drug stock-outs and non-working CD4 cell-counting machines, leading to time-consuming referrals; (2) health-care workers not always respecting confidentiality; (3) lack of youth-friendly services – HIV-positive women in the study noted that a lack of youth-friendly services was a reason for young people not taking advantage of health-care services; (4) inconvenient opening hours and long waiting times in health facilities; (5) unintended negative effects of new programmes that aim to involve men but end up putting pressure on the women to produce a father and/or partner when they have none.

Factors that shape health policy
National health policy frameworks provide Kenyans with health rights including the right to the highest attainable standard of health. Despite these implicit and explicit rights, health indicators have progressively declined since 1993. Mortality rates, including child mortality rates, have risen. The HIV epidemic has contributed to this general decline in Kenyans’ health status. Policies illustrate the willingness of the government to use international and national evidence to affect change but implementation has been mixed.

The institutions that shape county-level policy on HIV prevention and ART are currently being reformed in a three-year transition period, but with the national agencies National AIDS Control Council (NACC) and National AIDS and STI Control Programme (NASCOP) still in charge of the national and county HIV interventions.

Devolution and its impact on access and utilisation of government health services
For the majority of HIV-positive women in the study, not much had changed in HIV-related services since implementation of devolution. The only really noticeable change was that the essential drugs were now frequently out of stock. Frontline health workers confirmed that procurement had suffered since devolution.

Respondents felt politicians and policymakers did not pay attention to HIV-related services and they blamed this on county governments being politicised. Members of county assemblies were seen to be advancing their interests at the expense of the constituents. NACC and NASCOP key informants reported educating county governments, especially members of county assemblies, about the need to prioritise HIV services, obtain donor
funding, and make HIV a priority. Policymakers felt that it was too early to talk about the effects of devolution on access to HIV prevention services and ART. Several blamed citizens for expecting too much from services provided by the state. County policymakers did not seem to consider ensuring access to the available services to be part of their responsibility. Instead, they saw it as a duty of their constituents to find and use the services

**Financing and budgeting under devolution**
It is not clear how HIV services will be financed under the new system of devolved government. Article 189 requires the national and county governments to have fiscal autonomy, but financial management has to be in line with the national government framework. Over 80 per cent of HIV funding in Kenya is from external donors, which is administered through NACC and NASCOP. NACC disburses funding to both local civil society and lower-level government organisations. Before devolution, the then Nairobi City Council (now the Nairobi County government) had a budget. But this year, some policymakers at the county level say they received no funding and are confused about national HIV financing. Major international non-governmental organisations (NGOs) are withdrawing and their financial support is decreasing. It is not clear where the money for HIV/AIDS will come from.

**Institutional reorganisation**
There is also confusion about who is in charge and who is responsible for programmes and services, which has delayed implementing devolution. The fate of NACC staff is unclear and this has held back planning. Patients are confused as to which changes to their health care are a result of devolution and which are not. For example, when the Médecins Sans Frontières (MSF) Kibera South clinic was handed over to the Nairobi County government, HIV clients in the study attributed the change to devolution. In fact, it was because of a choice made by MSF to hand over services, which it – as a humanitarian organisation specialising in emergencies – had provided for many years in a situation which had then ceased to be an emergency.

**Participation of women and girls in making decisions on HIV services**
PLHIV have been participating in HIV policy development since before devolution, often in a consultative role. Even though PLHIV NGOs and networks may have a membership that is mostly female, they generally do not place HIV-infected women in decision-making managerial positions. This reflects a general exclusion of women from the political arena. Under the new Constitution, public participation has a central role, and devolution is a key factor in its promotion, with citizens supposed to have access to appropriate civic education programmes. However, one year after the introduction of devolution, low overall public participation in decision-making and governance was reported. HIV-positive women had no knowledge of civic education on public participation, and they had noticed little change since the passing of the new Constitution.

Devolution, however, could be an opportunity for marginalised populations to start participating in various decentralised structures. HIV activists in Kenya have historically been successful in getting the attention of politicians. But poor women in slums face internal and external barriers to participation in the political arena, including: a lack of confidence and knowledge regarding how to engage policymakers; not knowing how the political system works, and not belonging to any networks; a lack of both income and time; and competing priorities.

PLHIV organisations in Kenya have increasingly succeeded, over the past two decades, in getting access to the national policy arena. Yet our findings suggest that policymakers at the county level are not reaching out to these groups, and nor do they see it as their job to
respond to the difficulties that people experience in getting access to health care. Rather, they feel it is the job of the women to find out where the available health-care services are. It is not a priority for policymakers to get involved in county-level politics in order to improve access to, or the quality of, services. This attitude reflects a mindset that this study found, in which policymakers take little personal responsibility for their own actions when putting devolution into practice, and are keen to blame any delays on external factors.

**Conclusion**

The new Constitution and the push for a decentralised government came in response to citizens demanding government accountability, social equity, and better access to services. Devolution of governance can be an important step towards these demands being met, bringing policymakers closer to the people they serve. We found that the HIV-positive women in this study wanted policymakers to take more interest in them and to visit the slum areas to learn about their lives. But ensuring that decentralisation brings real benefits involves major restructuring of institutions, relocating and hiring staff, and reallocation of resources, as well as the development of new systems for accountability between central and county levels in both directions. It also involves a great deal of prioritising of HIV services and citizen participation.

Women have been marginalised in the political arena as a result of gender norms and barriers. Politicians and policymakers are not easy to reach, as the researchers’ own experiences show. For HIV-positive women in slums – even if they are organised – these barriers to participation are considerably higher, not least because of practical constraints, such as a lack of time and money.

Engaging with policymakers and bureaucrats in order to obtain services has been very difficult in Kenya for decades. Although devolution represents a positive move towards citizens becoming engaged, women still have to take active steps to get the attention of policymakers. Poor women in slum areas are excluded and marginalised. They have also internalised these views and do not see themselves as political activists who can effect political change.

Since the introduction of the new Constitution and devolution, hospitals in Nairobi are being refurbished, and money is being spent on essential drugs. These changes cannot be attributed to devolution alone, though, as they reflect and build on other national health policies. Nevertheless, they show that the County is in a position to implement health policies. HIV is not a priority, however.

Citizens in slum areas have been under-served by the government for decades. Years of dysfunctional centralised governance has left them distrustful of the state. Instead, many rely on NGOs and community-based groups for social services, including ART. Now that international services are being downscaled or handed over to the State, it means they will be taken over by county-level departments. It is not clear what will happen to these services under devolution or how they will be viewed by clients, particularly women.

HIV is just one of the many health challenges that face women and girls living in slums. As women in slums have never been very active in the leadership of the PLHIV organisations that operate at national level, because of gender and class barriers, they are not familiar with effective policy engagement. They lack the confidence, knowledge and resources, including time, to be politically active.
Recommendations

- Establish initiatives to enhance the participation of poor women and girls in the political arena, and recognise the broader internal and external barriers that prevent participation.
- Acknowledge the various ways in which women do organise themselves in informal and practical needs-oriented groups, and focus on helping women to access more resources, as well as providing training on governance and organisation.
- Coach and train county-level policymakers on management, including personal and professional time-management, while implementing public accountability mechanisms, which monitor the time that transactions take.
- Provide rewards for good public management, such as awards for reducing waiting times and red tape.
1 Introduction

After more than two decades of agitation for a new constitution, the violence that followed Kenya’s 2007 presidential elections finally led to a reform movement to overhaul the way the country was governed. On 4 August 2010, voters approved a new Constitution by a clear majority, reflecting a widespread desire for change. The aim was to improve government accountability and democracy by reorganising the government. There are now more checks and balances, parliamentary oversight of the executive is stronger, and the Bill of Rights provides greater protection for citizens, including women and minorities.

Perhaps the most profound change is devolution: the transfer of power from the centre to regional authorities. In the case of Kenya, devolution has meant granting statutory powers to the counties. The rationale behind introducing a devolved system of government was to promote self-governance, development, and the equitable sharing of resources. The new Constitution gives prominence to the participation of citizenry in planning and budgeting, specifically in Articles 10(2), 69(d), 174(c) and 184(1)(c) and the County Government Act (sections 99 to 101). Thus, powers once held by the legislature and the executive branch have been handed over to Kenya’s newly created 47 political and administrative counties. The county governments started up shortly after the March 2013 elections, when local representatives were elected. These new counties now oversee functions that were once the responsibility of the national government, such as education and health care. They receive a share of national revenues but are also expected to raise their own funds, i.e. from local taxes.

The devolution of health services began in 2013 with the election of governors and county principals. Most officials in the county were not experienced in the practical aspects of devolving service delivery, designing budgets, and evidence-based health system planning and priority setting. How commodity procurement will work at the county level, including purchasing medicines for anti-retroviral treatment (ART), is unclear.

Nearly two dozen counties have experienced a loss of doctors and nurses, and there have been numerous strikes among health-care workers. Recent media reports suggest that these events are a consequence of devolution, as health-care staff feel uncertain about the future of their jobs. Devolution is occurring at a time when international donors and organisations, which have provided human immunodeficiency virus (HIV) prevention, treatment and care services in slum areas in the past, are withdrawing or reducing their services. This is due to a shift in global funding strategies, including the winding down of the US President’s Emergency Plan for AIDS Relief (PEPFAR) and the handing over of international non-governmental organisation (NGO) projects to the county-level governments.

For years, Médecins Sans Frontières (MSF) has provided HIV-related services to thousands of Kibera slum residents. In July 2014, it handed over services to the Nairobi County government. MSF’s four pre-existing clinics were merged into a single clinic, which now receives all patients in the area, contributing to stock-outs of medicines and long waiting times in an already overburdened health system. The reorganisation has been confusing to slum residents who do not understand which policies are affecting access to ART.

Devolution potentially has wide-ranging implications for Kenya’s health sector, which is already failing on several levels. Kenya is lagging behind in achieving the 2015 Millennium

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Development Goals (MDGs) 4, 5, and 6,² (Ministry of Health, Government of Kenya, Division of Vaccination and Immunisation 2011) and over 71 per cent of the urban residents in Kenya live in slum-like conditions (UN-HABITAT 2009). In these informal settlements, people live under difficult circumstances: poverty, high levels of unemployment, crime, substance abuse, and strained infrastructure. Total fertility rates remain high (4.7 per cent per woman); fewer than half of couples use modern family planning methods; maternal and infant mortality are at unacceptably high levels; and fewer than half of deliveries take place in health facilities or are attended by skilled midwives (Ministry of Medical Services and Ministry of Public Health and Sanitation 2012; WHO 2010).

Four years after voters called for a new constitution, this case study examines the difficulties that poor women and girls living in slum areas still face in getting access to HIV and related services, including ART; their perception of how devolution has affected this situation; and their ability to participate in political decision-making and to bring about change at the local level. Are HIV-positive women and girls in slums able to get the attention of policymakers at the county level in order to get the services they need?

1.1 Background

1.1.1 Increasing urbanisation and urban poverty
Kenya has experienced economic growth for more than a decade, with GDP increasing steadily during the past three years.³ However, this has been accompanied by growing inequality, violence and unrest.

The country has urbanised rapidly during this period of economic neoliberalism. Today, the majority of Nairobi residents live in informal settlements or slums. These settlements are politically, economically and ethnically diverse within and between each other. Some, such as Kibera, the largest slum in East Africa, have existed for decades. While cities offer many benefits, rapid urbanisation also poses certain risk factors for migrant populations (WHO 2010). Slum growth reflects a lack of employment opportunities in rural areas – many people migrate to urban areas in the hope of getting jobs, only to end up unemployed or in low-paying jobs (Gulis et al. 2004). Slums turn into permanent rather than transient places. Emina et al. (2011) analysed demographic and health data between 2003 and 2009 for residents in the Korogocho and Viwandani slums in Nairobi. In Korogocho, 57 per cent of women and 63 per cent of men had lived there for more than ten years, while in Viwandani, the figures were 25 per cent and 36 per cent, respectively. Slum residents maintain contact with rural areas through kinship and economic ties, blurring the boundary between the city and rural areas. Access to state resources and social sector services, including health services, is generally poor. Slum residents are trapped in their present situation and lack the power and opportunity to make significant contributions to community development (United Nations Population Division 1998).

1.1.2 Gender and HIV in urban areas
In Kenya, the prevalence of HIV slowed from between 13 per cent and 15 per cent of the general population in 1999 (Joint UNAIDS Programme 2005; Kenya Central Bureau of Statistics 2008) to 5.6 per cent in 2012 (National AIDS and STI Coordinating Programme [NASCOP] 2013). This is still one of the highest rates of HIV in the world. Urban HIV prevalence has remained higher than that in rural areas. Nairobi County reports the highest urban HIV prevalence, consistently over 9 per cent (Republic of Kenya, KNBS and ICF²)

² MDG 4: reduce under-five mortality rate by two-thirds between 1990 and 2015; MDG 5: reduce the maternal mortality rate by three-quarters between 1990 and 2015; MDG 6: combat HIV/AIDS, malaria and other diseases.
³ Annual GDP growth rates were 8.4 per cent in 2010, 6.1 per cent in 2011, 4.5 per cent in 2012 and 5.7 per cent in 2013. http://data.worldbank.org/indicator/NY.GDP.MKTP.KD.ZG (accessed 24 August 2014).
Women in Kenya have been disproportionately affected by HIV (Republic of Kenya, KNBS and ICF Macro 2010; Republic of Kenya, CBS, MOH and ORC Macro 2004; Republic of Kenya, NCPD, CBS and Macro International Inc 1999; NASCOP 2009, 2013). Given the high prevalence of HIV in urban areas, women, particularly in Nairobi, are more likely to be infected than men. Socioeconomic and cultural factors account for this, for example: the early age at which many girls have sexual intercourse with older male partners; transactional sex due to poverty; school drop-out rates higher for girls than for boys; women’s and girls’ limited knowledge of sexual health matters; and difficulties negotiating condom usage. Prevention efforts for unmarried women and girls have been hindered by unrealistic national and international policies that condemn premarital sex, such as the American approach known as ‘Abstinence, Be Faithful, Use Condoms’, or ‘ABC’, which emphasises abstinence (Santelli et al. 2006; Boonstra 2007; Dietrich 2007).

High numbers of sexually transmitted infections (STIs) and unplanned pregnancies are reported among girls in poor urban areas. A study by Donatien Beguy and colleagues (2013) of poor adolescents in Korogocho and Viwandani slums in Nairobi reveals sexual debuts before the age of 15, infrequent use of condoms and other contraceptives, a disconnection between adolescents’ sexual and reproductive health attitudes and their behaviour, and a high burden of unwanted and mis-timed pregnancies. According to the study, many adolescents do not have access to reproductive health services.

HIV intensifies poverty, while poverty puts women at risk of HIV infection. HIV has a profound impact on everyday activities (Poku 2001; United Nations Development Programme [UNDP] 2006). In spite of improved health and longer lives, thanks to ART, people living with HIV are faced with myriad challenges. They need to visit care centres, manage complex HIV treatments, treat opportunistic infections and side effects, undergo medical tests, and maintain a balanced diet (NASCOP 2008). All these needs require money and time, and people living with HIV may not be as productive as their HIV-negative counterparts (Marsland 2012). Additionally, most adult breadwinners in low-resource settings rely on small businesses and casual work, but these activities become very difficult for PLHIV, as illness restricts them physically, socially and economically.

1.1.3 Gender and civil society in slum areas
Slum dwellers in Nairobi have had a difficult time engaging with state authorities in order to improve their situation, and the government has not been responsive to their plight (Mitullah 2003). Historically, women in Kenya have not participated in the public arena. Gender inequality and poverty have limited their involvement with development issues, particularly with regard to the formulation of policy. There have been strenuous efforts to empower women since the UN’s Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), which Kenya ratified on 9 March 1984, but a strong affirmative action policy has still not been adopted.

The 2010 Constitution of Kenya enshrines provisions for affirmative action, in particular the two-thirds gender principle, which aims to increase the number of women in public office and in development roles. Specifically, Article 10(2) lists national governance values, including equity, social justice, equality, inclusiveness, non-discrimination, and protection of marginalised groups. The National Gender and Equality Commission (NGEC) Act of 2011 mandated gender equity in health (Government of Kenya 2011). However, following the 2013 elections in Kenya, implementation of the two-thirds principle fell short of expectations, as few women were elected or appointed to office.
1.1.4 Civil society and the participation of PLHIV

The Kenyan government had an ambivalent response to the AIDS crisis in the 1980s and 1990s. Even when the epidemiological impact became obvious, international development organisations did not fund HIV interventions, owing to fears of massive corruption, a dictatorial government, and a lack of political will. Instead, funding was directed to civil society organisations (Prince 2012). The declaration of HIV as a national disaster in 1999 opened the door to large-scale donor funding of HIV initiatives. The government quickly set up the National AIDS Control Council (NACC) to lead the multi-sectoral approach that brought together the government, development partners and civil society organisations in the fight against the epidemic.

HIV was articulated as a development issue in the Kenya National AIDS Strategic Plan (KNASP) 2000–2005 (NACC 2000). HIV prevention and the mitigation of its socioeconomic effects became central to HIV interventions (World Bank 2000). Kenya’s strategic plan was developed at about the time when there were international calls for people with AIDS to be enabled to become more involved in efforts to halt the HIV epidemic. This created opportunities for people, including those with HIV/AIDS, to participate in HIV interventions at all levels. Development partners focused on building a strong civil society to counter dictatorial and corrupt state governance, and to help Kenya make headway in its fight against HIV. An inclusivity strategy under the broader theme of social change became a key focus of KNASP 2005/06–2009/10, which implemented the Total War Against AIDS (TOWA) project (NACC 2005).

To bypass government and the massive corruption that was linked to government circles, donor funding was instead given to civil society organisations. This led to the growth of a local economy of NGOs (Prince 2012), principally through the four-year Kenyan HIV and AIDS Disaster Response (KHADRE) project, which allocated US$30m to community-based organisations (CBOs) and private research initiatives (World Bank 2000). Most of these funds went to community-based activities, NGOs formed by PLHIV, and PLHIV support groups, mainly in Nairobi. PLHIV were involved in creating awareness and educating communities, establishing home-based care services, fighting stigma and discrimination, and pressing for economic empowerment. Networks of PLHIV organisations and support groups were formed to advocate for the rights of PLHIV, especially around stigma, discrimination, and sustainability of treatment and funding.

Women have played key roles in CBOs, especially in terms of implementing activities at the grass-roots level. Representatives of PLHIV, including those from ‘key populations’, have been successful in working at the national level and are, for example, consulted about policies by NACC and NASCOP. Slum residents have largely been excluded from these national-level consultations. The question now is what roles these representatives of PLHIV will play in the decentralised counties, and whether devolution could create new spaces for the participation of slum residents.

1.2 Research questions

One year after the implementation of devolution in 2013, we are looking at its effects on access to HIV services among women in low-resource settings. We want to know in particular how change happens at the local level and how women and girls can be part of it.

The case study seeks to answer the following questions:

- What are the perceived effects of Kenya’s devolution policy on access to HIV prevention and ART services for women and girls in urban areas?
- What are the factors that shape county-level policies on HIV prevention and ART?

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4 ‘Civil society’ includes community-based organisations, NGOs, UN agencies, and faith-based organisations.
• Are women and girls in slums who are on ART able to get the attention of policymakers at the county levels to get the services they need?
• What is the role of organisations of PLHIV in the formulation of policy at county level on HIV services, including ART access?
2 Methodology

2.1 Study sites
The study was conducted in two large slums in Nairobi – Kibera and Majengo. Nairobi is Kenya’s capital city and commercial centre, and is one of the 47 administrative counties under the new Constitution. It is the most populous county, with over 80 slums.

Kibera is Kenya’s largest slum and is located in the Nairobi suburb of Lang’ata. It consists of 13 villages: Raila, Mugumoini, Laini Saba, Sara Ngombe, Gatwekera, Mashimoni, Shilanga, Lindi, Kichingio, Kambi Muru, Soweto West-Kianda, Soweto East and Kisumu Ndogo.

Unemployment is as high as 50 per cent in Kibera. Small businesses and casual employment are the main sources of income. Casual employment opportunities are available in the nearby industrial area and the neighbouring affluent residential areas. Recreational amenities are limited to football, watching movies and playing lottery games. There is a significant population of sex workers (Pamoja Trust 2009).

Kibera is generally characterised by poor infrastructure, high poverty levels, in- and out-migration, and limited public services, including health facilities, schools and water supply. Most of Kibera’s residents live in squalid conditions due to poor sanitation and a lack of basic amenities. The quality and size of the housing varies, but most structures are one-room, made of mud walls, with iron-sheet roofs and earthen floors. Each room accommodates between five and ten people. Monthly rental charges for each structure range between KSh350 and KSh1,000 (US$4 and US$12). There are several water points within Kibera, which charge KSh5 per 20 litres of water. Most houses have no electricity, and for those that do, it is available only between 6pm and 6am.

There is only one public health facility in Kibera’s slums: the Kibera Health Centre. Four other public health facilities serving the Kibera division are located in neighbouring middle-income areas: Lang’ata and Mbagathi hospitals, and Woodley and Dagoretti City Council Health Centres. Kenyatta National Hospital is three kilometres to the north of Kibera. There are a number of small private clinics, chemists, and shops selling over-the-counter drugs, as well as traditional healers and numerous Pentecostal religious groups offering treatment based on prayer.

The high prevalence of HIV, high morbidity and mortality rates, and extreme poverty, put Kibera on the national and international map for HIV intervention. There are six international NGOs and civil society organisations providing HIV services in Kibera: the Centers for Disease Control and Prevention (CDC), the African Medical Relief and Emergency Foundation (AMREF), Médecins Sans Frontières (MSF), Sirikwa, Lea Toto, and Carolina for Kibera. At the time of the study, MSF had established three additional clinics in different parts of Kibera.

Majengo sits next to the famous Gikomba market. In Kenya, the market is known for female sex workers, who have attracted international HIV researchers (Bandewar, Kimani and Lavery 2010). Researchers tried to develop a HIV vaccine based on the immunological protection mechanisms found in the commercial sex workers in Majengo, who remained negative despite extended exposure to HIV-positive men.

With a large population, Majengo is divided into four smaller settlements: Sofia, Mashimoni, Gatanga and Digo. Most house structures have mud walls and earthen floors, and monthly rent ranges between KSh250 and KSh300 (US$3 and US$3.50). The availability of basic amenities varies with the cost of the house even though the county government provides
water to the community at no charge. Majengo also has a number of health facilities: three public clinics and a number of facilities run by private and faith-based groups.

Similar to those living in other slums in Kenya, Majengo residents experience high rates of unemployment, poverty and crime. Recreational amenities are limited. Prostitution, including child prostitution, involving girls aged 12–17 years, is blamed on high poverty, the loss of parents to HIV/AIDS, parental neglect of children, abandonment by partners, and higher payment for sex work compared with the alternatives (Bandewar et al. 2010; Pamoja Trust 2009).

2.2 Methods
This case study is based on a literature review and on qualitative data collected from key informant interviews, in-depth interviews, and digital storytelling, a qualitative narrative story method capturing voice and images on iPads through various applications, to capture the lived experiences of six women from slum areas.

2.2.1 Literature review
Electronic searches of relevant government ministries and department websites included the National AIDS and STI Control Programme (NASCOP), the National AIDS Control Council (NACC), the Ministry of Health, Nairobi City Council, Kenya’s National Bureau of Statistics, and the World Health Organization (WHO). Information collected included HIV policies, plans and guidelines, health surveys, health indicators, strategic plans, and health policies, bills and strategic plans.

2.2.2 Interviews
Key informant interviews

Table 2.1 Distribution of the 23 key informant interviewees

<table>
<thead>
<tr>
<th>Policymakers</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>National AIDS Control Council</td>
<td>3</td>
</tr>
<tr>
<td>NASCOP</td>
<td>1</td>
</tr>
<tr>
<td>Nairobi County policymakers</td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Advocates</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>PLHIV representatives</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Implementers</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>National AIDS Control Council</td>
<td>1</td>
</tr>
<tr>
<td>NASCOP</td>
<td>3</td>
</tr>
<tr>
<td>Nairobi County government</td>
<td>4</td>
</tr>
<tr>
<td>Health-care workers</td>
<td>4</td>
</tr>
</tbody>
</table>

Because the county was only recently formed, policymakers were new to their positions. The accounts staff and HIV workplace staff were inherited from the former Nairobi City Council.

In-depth interviews
Table 2.2 provides a breakdown of the 30 in-depth interview respondents in this study. All respondents were HIV-positive women accessing HIV services. Most were aged 35 years or younger and the majority (84 per cent) were single mothers. The participants were selected with the help of community-based organisations and health facility staff working in slum areas. The women selected for the study had to be HIV-positive and a user of HIV services. Health-care staff asked every fifth client over 25 years of age they saw in a single day to
participate in the study. Because of a low turnout of adolescents and young adults, staff reached out to all girls and women under the age of 25 seen at the clinic that day.

Table 2.2  Characteristics of in-depth interview participants

<table>
<thead>
<tr>
<th>Age category</th>
<th>(n=30)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 25</td>
<td>3</td>
</tr>
<tr>
<td>26–30</td>
<td>11</td>
</tr>
<tr>
<td>31–35</td>
<td>5</td>
</tr>
<tr>
<td>36–40</td>
<td>6</td>
</tr>
<tr>
<td>41–45</td>
<td>4</td>
</tr>
<tr>
<td>46–50</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Marital status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single, never married</td>
</tr>
<tr>
<td>Single, divorced</td>
</tr>
<tr>
<td>Single, widowed</td>
</tr>
<tr>
<td>Married or cohabiting</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Residence</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Kibera</td>
<td>16</td>
</tr>
<tr>
<td>Majengo</td>
<td>14</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>HIV testing by type</th>
</tr>
</thead>
<tbody>
<tr>
<td>PMTCT</td>
</tr>
<tr>
<td>PITC</td>
</tr>
<tr>
<td>VCT</td>
</tr>
<tr>
<td>Door-to-door/mobile</td>
</tr>
</tbody>
</table>

Digital storytelling
Digital storytelling is a process where participants are given the means to tell their own stories, unfiltered by researchers or programme managers. In this study, six HIV-positive women were given iPads and trained on how to use them. They were shown how to combine images, sounds and narration using digital technology, and asked to tell about one aspect of their life. The results were two-minute narratives about living as HIV-positive women in Nairobi’s slums. These short films have been shared with civil society groups and local government officials so they can better understand these women’s experiences. They can be viewed at: http://interactions.eldis.org/urbanisation-and-health/country-profiles/kenya/digital-stories.

Participant observation
The Kenyan researcher used participant observation as a way to understand the challenges women have in contacting high-level policymakers. For example, when she attempted to get an appointment to secure permission from the Nairobi County government to conduct research in health facilities, she was met with stonewalling and bureaucratic red tape. Obviously, the Kenyan researcher is in a better position to get an appointment as compared with a slum dweller, yet her difficulty in reaching local leaders helped to show why less-connected women would lack confidence attempting to do so, and what it means when women say that trying to reach a representative or a policymaker is very hard.
3 Findings

3.1 Lack of access and utilisation of government health services

Women and health-care workers raised concerns over a number of issues that affected their access to HIV-related services, which they would like to see changed.

- **Unavailability of HIV-related health services.** There were reports of essential drug stock-outs, non-working CD4 cell-counting machines, and a lack of tubal ligation services for family planning, and of cervical cancer screenings. This resulted in referrals to clinics that were too far away, or to facilities that the women would not attend due to fears of compromised confidentiality.

  There are challenges here as well. Like the CD4 machine is always broken down these days and we are referred to Mbagathi or Mathari or Rhodes, or if you can afford you pay for private health facilities. Mbagathi is very far from where I live. Going to other health facilities is very complicated because it is new, you meet there new people. I am used to one clinic and I would like it to remain that way. Since I was given referral for CD4 test, I have not gone for it. I do not have the money to pay for it in private hospital, and I find it inconveniencing to go to other public health facility because I fear long queues and also I am not familiar with the environment.

  (HIV-positive woman, Majengo resident)

- **Concern that health-care workers did not always respect confidentiality.** Some women in the study, particularly from Majengo, reported travelling long distances to access services in order to avoid meeting anyone they might know. Concern for confidentiality was one of the reasons why most women from Majengo preferred seeking services from the Casino clinic. The clinic is a standalone facility strategically located on a less busy street in Nairobi’s central business district, far away from residential areas.

- **Lack of youth-friendly services.** HIV-positive women in the study noted that a lack of youth-friendly services was a reason why young people did not take advantage of health-care services.

  You find the youth do not access HIV services including prophylaxis, HIV care, even testing. They attribute this to Kenya’s health-care workers’ attitudes. We do not have youth-friendly services here to encourage the youth to come for services. Maybe that is one thing we should look into… Also, you know in Kibera, we have young mothers. So when they come here to the clinic for various reasons the young can meet their mothers and fathers here. They do not feel free to go to a family planning clinic. Youth-friendly services are lacking in our facilities.

  (Facility health manager, Kibera)

- **Opening and waiting times were cited as challenges in health facilities.** It was reported that public health facilities opened late and closed early, resulting in the hurried delivery of services. The NGO health services opened early; however, the merging of MSF clinics resulted in overcrowding, leading to long waiting times. In a setting where users depend on casual jobs and small businesses, delays in opening hours and longer waiting times disrupted casual job opportunities and other errands.
I have to work or sell fish. Selling fish involves going to the market, and the market closes early. I have to cook lunch for children. So, when we come here we should be seen first, and the doctors can chat after they have seen us.

(HIV-positive woman, Kibera resident)

I had a client who went to a health facility and was not attended on time. She was very upset and left. Now she did not have ARVs for a week. Clients do not want to stay long in the health facilities because they have other things to do. Some clinics that offer free HIV services and also offer other services for free have high numbers… They are crowded.

(PLHIV group leader, Kibera)

- **Well-intentioned programmes sometimes created additional burdens.** For example, the ‘PMTCT option B+’ offered HIV-positive women lifelong ART regardless of their CD4 count. But to qualify, women had to be accompanied to the clinic by their male partners. This was a difficulty for single women. A support group leader noted that women should have been consulted by policymakers, as the women were under pressure to produce a father and/or partner even when they did not have one.

From our interviews, we found that HIV-positive poor women are suspicious of government services. At the same time, they understood the challenges in delivering HIV prevention and care programmes. The health-care staff agreed with most of their assessments. Neither the staff nor the HIV-positive women knew who should or could help solve the problems raised.

### 3.2 Factors that shape health policy

#### 3.2.1 National health policy frameworks

Kenya’s Constitution, Article 43(1)(a), states that all Kenyans have the right to the highest attainable standard of health. Article 21(2) provides for the State to take legislative action or make policy changes, including the setting of standards to achieve this. The Health Care Bill of 2012 (Government of Kenya, Ministry of Health Service and Ministry of Public Health and Sanitation 2012) confirmed the constitutional right to health care.

Despite these implicit and explicit rights, health indicators have progressively declined since 1993. Mortality rates, including child mortality rates, have risen. The HIV epidemic contributed to this general decline of health status. After an initial reluctance to intervene, the national government issued its first HIV/AIDS official policy statement – Sessional paper No.4 (Government of Kenya 1997) – in 1997. This provided a policy framework and directed HIV interventions, AIDS prevention efforts, and care for the next 15 years and beyond. Specifically with regard to women, it pointed out the need for socioeconomic empowerment as well as empowerment to access information. While the framework recognised the risk to youth and young adults, its recommendations were limited to AIDS educational programmes and protection of youth against anti-social behaviour that puts them at risk, rather than involving PLHIV and civil society groups.

Once HIV/AIDS was declared a national disaster, the government became more proactive. The National AIDS Control Council (NACC) was formed under the Ministry of Special Programmes\(^5\) to spearhead the HIV response in Kenya. The NACC was mandated to provide a policy and strategic framework for mobilising and coordinating resources and HIV intervention activities founded on a multi-sectoral strategy. PLHIV and civil society groups were still mainly seen as policy targets and implementers rather than experts who could also be consulted in policy formulation.

\(^5\) The Ministry of Special Programmes was one of the ministries disbanded by the current government.
The first Kenya National AIDS Strategic Plan (KNASP) was based in part on a World Bank report (World Bank 2000). The HIV policy development process used a consultative approach involving various stakeholders that included development partners, government agencies, civil society organisations, and people living with HIV. According to a national policymaker, people living with HIV had already formed organisations, and were involved as stakeholders in HIV programming, including the development of the national strategic plans.

KNASP I aimed to prevent HIV infections, mitigate the socioeconomic impacts of HIV, increase care, and strengthen institutional capacity. KNASP 1999/2000–2003/04 did little to mitigate the socioeconomic effects of HIV/AIDS. Instead, HIV stigma increased in communities (NACC 2005). Gender issues and feminisation of HIV transmission were evident. KNASP II 2005/06–2008/09 was developed to respond to issues identified in the first strategic plan. KNASP II delivered the government’s HIV response under the United Nations’ ‘Three Ones’ initiative. This landmark agreement encouraged the creation of a single national HIV/AIDS coordinating authority, a single HIV/AIDS action framework to coordinate the work of partners, and a single monitoring and evaluation system.

Following revelations arising from the Kenya HIV Prevention Response and Modes of Transmission Analysis about a concentrated epidemic (NACC 2009a), a third Kenya National AIDS Strategic Plan (KNASP III 2009/10–2012/13) focused attention on key populations: men who have sex with men, sex workers, and injecting drug-users.

Other HIV-related policies and laws include the HIV and AIDS Prevention and Control Act; Act No. 14 of 2006; and the male circumcision policy (NACC 2009b). NASCOP has been a leader in developing HIV guidelines based on policies and strategic plans. These policies illustrate the willingness of the government to use international and national evidence to affect change, even if they have not been implemented perfectly.

3.2.2 Institutional factors that shape county-level policy on HIV prevention and ART

The NACC is in charge of implementing Kenya’s HIV policies; however, this does not exclude the county governments from participating in developing national policies and strategic plans. As a key stakeholder in HIV interventions, county governments are represented in the development of HIV policies by NASCOP. For seamless delivery of services in the three-year transition period, NACC and NASCOP are still in charge of the national and county HIV interventions.

NASCOP seconded staff to the county governments. Seconded staff are invited to represent the counties in the development of national policies and strategic plans. They participate in the national HIV technical working groups and in various committees, which allows them to lobby for what ought to be included in the strategic national plans. These seconded staff, who were mere implementers of national strategic plans in the last Constitution, are now recognised by national-level policymakers in the devolution in policy development:

Before, NACC never included us in development of plans, but this year we were invited to be part of the key populations’ technical working groups, which include other stakeholders working on these issues.

(County-level policymaker)

These seconded staff do not yet have any relations with civil society groups at the county level. Civil society groups have historically been crucial in lobbying for better access to HIV prevention and treatment services. Has there been any change in access to HIV services in the Nairobi slums since devolution?
3.3 Devolution and its impact on access and utilisation of government health services

For the majority of HIV-positive women in the study, there had been no changes in HIV-related services since the implementation of devolution, other than stock-outs:

_In my opinion, I haven’t seen any changes in services with devolution. Everything is just the same. The services are not bad and neither have they improved._

(HIV-positive woman, Majengo resident)

_Every time you come to a clinic you must get a prescription for some drugs. There is no day you get all drugs – one or two must be missing._

(PLHIV group leader, Kibera)

Frontline health workers do find that procurement has suffered since devolution:

_I don't see that the county is doing [anything] apart from disorganising us. Before devolution, already the health care was devolved; we have structures from the national to the community level. And with HIV, we were getting supplies from KEMSA [Kenya’s medical supplies agency]. You know we had worked on the process that bureaucracies that used to delay delivery of drugs were removed, so I could order drugs direct from KEMSA. Now with devolution we have gone back to bureaucracies, we are back to long procedures when ordering for drugs. So devolution has taken us back to where we came from. We have ended up with delays on procurement for drugs to arrive at the clinics. The county government is doing nothing, we only see them changing staff. We do integrated services and when staff is changed we are disorganised._

(Health-care facility manager, Kibera)

According to a facility manager, the complexity of delivering HIV services, particularly ART, makes it difficult to assess the effects of devolution on HIV prevention and ART services. This is because HIV services are largely offered by international NGOs, such as the African Medical Relief and Emergency Foundation (AMREF Health Africa), the United States Agency for International Development (USAID)/the US President’s Emergency Plan for AIDS Relief (PEPFAR), the University of Maryland, and Pathfinder. However, international organisations work with national authorities and institutes, and these are being changed as a result of devolution.

3.3.1 Slow implementation of devolution of HIV services

Respondents felt politicians and policymakers did not pay any attention to HIV-related services and blamed this on county governments being politicised. Members of county assemblies were seen to be advancing their interests at the expense of the constituents. ‘See what is happening with the members of the county assembly?’ said one key informant. ‘Now they are busy making demands to benefit themselves and do not care about HIV/AIDS. They only think about their salaries and comfort.’

The majority of study participants who use HIV services from various service providers, PLHIV group leaders, and health-care providers recommended that policymakers come to the slums to see their problems and noted that devolution had had no effect, to date, on HIV-related services.

NACC and NASCOP key informants reported educating county governments, especially members of county assemblies, about the need to prioritise HIV services, obtain donor funding, and make HIV a priority:
You know politicians' priorities are different. There are those promises they made to the electorate which they feel will be the indicators for re-election. So they put their priorities to the promises they made. If HIV was not an issue promised to address during campaigns, then it is not a priority for them. So we are sensitising them on the HIV/AIDS issue to make sure it is one of the priorities. We are sensitising them, especially the members of the county assembly, to take on HIV as a priority issue that requires funding.

(County-level policymaker)

The majority of policymakers felt that it was too early to talk about the effects of devolution on access to HIV prevention services and ART. Several blamed citizens for expecting services from the state or the elections for the slow implementation and for suggesting that bureaucrats serve the political party in power:

**The problem with you Kenyans, something begins and you want results immediately. You do not give the implementers time. We just started devolution last year, structures are being put in place, we have just been hired, and we have barely begun work and you are demanding outcomes. Come on, give us a break. I have been here for three months. The governor is still settling. Everyone seems to be waiting for miracles.**

(County-level policymaker)

I do not think devolution has had much effect on HIV services and prevalence yet. We cannot speak about that until transition period is over. Right now it is complex, and to measure impact it is early because we had new Constitution in 2010, but it started to be implemented by the new government, which was elected in 2013 March. They put much time on setting structures, and setting up the county government. Meanwhile, HIV services were not disrupted by devolution because of NASCOP and NACC.

(National-level policymaker)

County policymakers did not seem to consider access to the available services part of their responsibility. Instead, they saw it as a duty of their constituents to find and use the services:

**We offer free FP [family planning] services, but if the services you are looking for are not there, then get them where they are found.**

(County Chief Health Officer)

When asked about factors that inhibit sex workers' access to HIV treatment (specifically those who dropped ARVs in favour of herbal medicines because of problems in getting access to services) one policymaker observed:

**HIV care services are available, and people can access them. I get disturbed that in Kenya we keep begging people to take medicine. There is medicine available, but then the sick want to be begged to take medicines! Public health demands that you do take medicines. You are taking medicines for your own good, your life, it is your moral obligation to take medicines and take responsibility to protect other people.**

(County-level policymaker)

The issues of concern raised by women and health-care workers need to be addressed by county governments. The existing opportunities for participation in civil society and PLHIV groups at the national level, which have partly been enabled by long-term international support, have not yet been translated to the county level.

Leading PLHIV groups such as the Kenya Network of Women with AIDS (KENWA) in Kariobangi and Korogocho; Women Fighting AIDS in Kenya (WOFAK) in Kayole and Korogocho; and the Kibera Community Self-help Programme (KICOSHEP) are national NGOs with headquarters in upmarket areas in Nairobi. Over the years, they have managed
to gain access to national-level policymakers and are invited by the Ministry of Health to provide input to policies. Their activities are spread across Kenya, but their advocacy structure is linked to the national level and thus the top-down approach. Given the importance of such groups in Kenya’s history of access to HIV prevention services and AIDS medicines, this is a point of concern. County-level government staff are not very accessible, as illustrated by the experiences of this report’s Kenyan researcher (see Box 3.1).

Box 3.1 Working with county-level government: Emily Kageha Igonya’s experiences

Before devolution, one could spend weeks visiting offices, registering and waiting in line to reach the right person. Devolution should bring policymakers closer to the people. One hoped this would make it easier to get things done, but this frustrating situation has not yet changed.

To start the research, for example, I had to get an authorisation letter from the Nairobi County government. I went to the office of County Chief Health Officer. The secretary allowed me to put in the application, basically my proposal, and asked me to come back two days later. I went back, I found another secretary who checked through a pile of research documents that had been authorised, but mine was not among them. I was told to check after two days, which I did. I found the secretary again who I saw on my first visit. She apologised and told me she had not realised that HIV research was no longer authorised by her department. Instead I should go to the research department at the County AIDS/STI Coordinating office, located a few blocks from Nairobi County offices.

I could not interview county staff before I had the go-ahead from the County Chief Health Officer. The County Chief Health Officer was also one of the key informants I had to interview. On my first attempt I arrived at 8.30am. I found five other people waiting to see him. I was asked to record my name and the organisation I am representing in a book. A group of four smartly dressed men arrived, bypassed the queue, and went straight to his office. It was one hour before they came out together with the Chief Health Officer and rushed away. Meanwhile, other people had joined the queue. We were informed that the Chief Health Officer was going to an urgent meeting, and that we would not be able to see him that day. The secretary asked us to see him the following day. The following day at 8.00am I arrived, recorded my name at the secretary’s office, and joined the queue. A few minutes later, the Chief Health Officer left the office, saying he was going to a meeting with the governor. He did not know how long it would take. We were asked to come back at 14:00. I was there, recorded my name and joined the queue. I did not get to see the Chief Health Officer. On the third day, I was informed that he would not be in the office for the next three days. After three days I was back in this office at 8.00am. On this day I found no queue, and I was very happy that I was going to be seen. I recorded my name as usual. On this day, there were three ‘urgent’ meetings – one after the other – in the Chief Health Officer’s office. At 1.00pm the Chief Health Officer came out and informed those in the queue he would not be able to see us, we should come back tomorrow. Tomorrow came, I was there at 8.00am. As usual, recorded my name and joined the queue. I was the sixth in the queue. This day, he tried to see everyone in the queue but was disrupted by two meetings in between. My turn came. Finally I met with the Chief Health Officer. After introducing myself and the study, and mentioning interviewing him, he told me to come and see him at 7.00am the following day when he would have time, and there would be no interruptions. I was there the following day. He did not turn up, but I waited. When he finally arrived at 9.00am, he said he had other meetings and that I should come the following day. Again, the following day, I was there at 6.30. I found a queue. The secretary had not arrived, therefore the usual recording in the book did not take place. However, each person took their position. The Chief of Health Services arrive at 7:30am, accompanied by three well-dressed men in suits. At 10.00am those men were still in the office. I took a break to have some breakfast, but made sure the secretary to Chief of Health Services was informed. Thirty minutes later I returned. The women who were ahead of me in the queue told me they had not seen the Chief Health Officer, who had rushed out for an urgent meeting. I decided to see the County Clinical Officer for an interview. She told me she could only have the interview after it has been okayed by the Chief Health Officer. It was 20 days after my first attempt to see the Chief Health Officer that I finally managed to see him. And when I got to see him, he told me I had only five minutes. After meeting with him he referred me to the County Chief Finance Officer, who referred me to the County Accountant, who referred me to County Health Accountant, who referred me to HIV/AIDS workplace officer, plus other referrals.
Some of the people to whom I was referred were available immediately, while for others I had to spend time talking and explaining what I needed, again and again.

My own experience shows that it is totally unsurprising that women say they are unable to reach policymakers, and that there is little point in even trying. As the researcher, I am well-educated, with resources and institutional backing to conduct this study. I am paid to track down my study informants, who included policymakers. If this is what happened to me, imagine what it is like for women in low-resource settings such as Kibera or Majengo, who have to take a bus to Nairobi Central district. It costs 100 shillings for the round trip, and one to two hours’ travel time, as well as many hours, days, weeks or months of chasing after policymakers, despite their more pressing competing priorities.

3.4 Financing and budgeting under devolution
How HIV services will be financed in the devolved government is not clear. Article 189 requires the national and county governments to have fiscal autonomy, but financial management has to be in line with the national government framework. County governments should receive 45 per cent of the national budget, which has to be supplemented by local taxes and grants. Each county was going to have to produce its own programme-based budget for the 2014/15 fiscal year.

Over 80 per cent of HIV funding in Kenya is from external donors, the government and civil society organisations. NACC then disburses pooled funding to its own structures (mainstream national government ministries and departments known as AIDS Control Units), the constituency AIDS Control Units, through the respective members of parliament, and local civil society and lower-level government organisations. The lack of clear plans for HIV funding under the new government system has caused some implementers to worry about their budgets. Some have received money from NASCOP for activities, but at the time of writing this report – August 2014 – the county had not given any funds to the County AIDS/STI Coordinating Programme as had been expected by the County AIDS/STI Coordinator:

I have done strategic plans, work plans, and budgets, and presented to the county government, but I have not received any money [from the county government]. NASCOP, on the other hand, gives us very minimal money for activities. All I see is that the county government is busy with renovations and refurbishing infrastructure and no money for HIV/AIDS, yet HIV/AIDS is a problem to this county. I need money for supervision and trainings. So I have to look for well-wishers to fund HIV/AIDS activities at the county level.
(County-level policymaker)

Before devolution the city council had a budget. But this year, the officer in charge says she received no funding and is confused about national HIV financing:

When we were under Nairobi City Council this programme used to get 17 million Kenya shillings (US$197,674). Of these, each of the former city council departments received one million Kenya shillings per year. This year, 2014, there is an omission; there are no funds set aside for HIV activities. We have made proposals but we have not received any funds. We made a work plan and a budget but it is yet to be approved. We presented the work plan and the budget to the County Medical Officer… then he has to discuss with the Minister of Health, who then will present it to the Treasurer, who will present it to the county assembly, who make the final decision.
(County-level policymaker)

In the financial year 2014/15, the Nairobi County government allocated 37 per cent of the funds it received from the national government to health care. The county did not allocate
any health money specifically to HIV programmes, despite the disease’s high prevalence, and clear signs that major international NGOs are withdrawing and their financial support is decreasing. It is not clear where the money for HIV/AIDS is going to come from.

3.5 Confusion over government restructuring

Devolution required restructuring staff positions and reorganising government ministries and departments. But there has been a significant delay in setting up county structures (Commission for the Implementation of the Constitution 2014). The upheaval resulted in confusion over who was in charge and who was responsible for programmes and services, and has delayed implementation of devolution:

There is no government structure that changes and gets results in one year. See what is happening in all counties: health services collapsed in one year, we have health workers going on strikes, resigning, but we have managed to survive. You know there was confusion over who should take over the health staff. Many were resistant to be under county governments, and some county governments wanted them to apply afresh.

(Minister for Health, Nairobi County)

There was also confusion over the fate of NACC staff. In the previous governments, the NACC was under the Ministry of Special Programmes in the Office of the President. NASCOP was in the Ministry of Health (Ministry of Medical Services and Ministry of Public Health and Sanitation). The fate of the NACC was uncertain. Was it going to be an independent government agency or be merged with NASCOP under the Ministry of Health? This confusion, according to staff, somewhat limited NACC’s ability to adjust to devolution. As a result, they did not work with counties to make HIV a priority area and nor did they discuss the need for local authorities to solicit donor funds.

NASCOP staff seconded to county governments were also confused about who they worked for – NASCOP or the county government. According to county health principals, NASCOP was running the show:

Yes, you know we have the national programme, and now we have counties. So for us, we get so confused whether we are under the national programme or we are servicing the counties. Like here I am employed by NASCOP, and the Lang’ata sub-county Medical Officer is an employee of Nairobi County. So you see the confusion. Actually, I should be working under the sub-county Medical Officer. But I am now answerable to NASCOP, whereas before devolution we were all under the Ministry of Health, and in the hierarchy, I would be under sub-county MOH.

Also, there is confusion with the boundaries of NACC and NASCOP. NACC is responsible for national HIV policies, and NASCOP is responsible for the technical side, including guidelines and service delivery, but you find NACC overstepping their boundaries.

You know, with devolution, the county governments were to absorb the national staffs they found working in those counties, but it has been a very contentious issue. So the national government gives our salaries to the national treasury to pay us… The county AIDS/STI coordinators [CASCO] that fall under the county’s Director of Public Health, in the division of epidemic disease control, now implement what NASCOP used to do before devolution, and are answerable to NASCOP even though we work at the county.

(Nairobi County AIDS/STI coordinator).

6 Currently, NACC is a semi-autonomous government agency under the Ministry of Health.
Even as NASCOP defended its service delivery role – ensuring that drugs are available, providing test kits, and training health-care staff – what that role involved was not clear at the health-care facility level. Health-care providers are trained by other partners and the availability of drugs is ensured by international NGOs. NASCOP’s key informant reported that NASCOP’s engagement at the county level was limited:

> Everything is in transition. When HIV/AIDS is fully devolved, the counties should be able to offer all HIV services, and NASCOP should play a role in development of policy, guidelines, collecting data, building capacity, and ensuring commodities are available because the provision of ARVs and test kits remains the responsibility of the national government. Ideally, NASCOP should provide technical capacity to county governments and health facilities.

(Key informant, NASCOP)

While NASCOP provided services in the county, a key informant reported that under the devolution arrangement, NASCOP has to seek the permission of county government officials. It is the prerogative of the county governments to allow them to work there.

### 3.6 Confusion among patients

Clients were not always able to distinguish which changes to their health care were a result of devolution and which were not. For example, when MSF’s Kibera South clinic was handed over to the Nairobi County government, HIV clients in the study attributed the change to devolution. In fact, it was because of a choice made by MSF to hand over services, which they – as a humanitarian organisation specialising in emergencies – had provided for many years in a situation that had then ceased to be an emergency.

The current strikes and health challenges in counties have raised confusion and fears among some clients despite reports that strikes did not affect the provision of and access to services. The women who were interviewed were concerned about whether counties could bar people from other counties from accessing health services:

> I hope with devolution there will be no limitations on where one can pick up ARVs as long as you have your clinic card. Because when I travel and I run out of drugs, I go to any HIV clinic, and I show my HIV clinic card. I am always being given [drugs] but I am just afraid like now in the counties, we have so much politics around health provisions, and it may reach a point when they may decide counties can only provide health services to people in their counties, and not those from outside.

(HIV-positive woman, Majengo resident)

Just as many health-care employees are confused about devolution, those seeking health care are also confused. It seems that during the first year of Kenya’s devolution effort, many things were unclear. The transition period was characterised by some successes, as well as a number of teething problems, such as low public participation at meetings and in committees, politicisation of the Constitution, politicians’ focus on salaries and allowances, a delay in establishing required government structures, striking workers, and the lack of clear and appropriate national policies.

### 3.7 Participation of women and girls in making decisions on HIV services

PLHIV have been participating in HIV policy development since before devolution – often in a consultative role. Even though PLHIV NGOs and networks may have mostly female members, they generally do not place HIV-infected women in decision-making managerial positions. This reflects a general exclusion of women from the political arena.
Although adult (18 years and older) men and women can vote, citizen participation and state accountability to citizens are underdeveloped. In the new Constitution, public participation is crucial, and devolution is a key element in this. Article 10(2) states that public participation is a national value and a principle of governance, as well as patriotism, national unity, sharing and devolution of power, and democracy. Article 174(c) gives powers of self-governance to the people and enhances the participation of the people in the exercise of the powers of the state and in making decisions affecting them. The Constitution and the County Government Act 2012, provide for legislation to facilitate citizens’ participation in public governance. Counties are required to put in place appropriate civic education programmes and establish a civic education unit.

However, a year after devolution, low overall public participation in decision-making and governance has been reported (Commission for Implementation of the Constitution 2014). This is supported by findings of this study. HIV-positive women had no knowledge of civic education on public participation. They observed little change since the new Constitution had come into effect. ‘Here in Kenya, policies are made by leaders, and not beneficiaries’, said one health-care staff member, ‘Leaders make policies that favour them’. One NACC officer complained that the top-down approach, where subcommittees meet with other subcommittees, excludes members of community groups. As HIV-positive women are often members of PLHIV interest groups rather than leaders, this top-down approach can silence poor women and girls living in slums. A handful of representatives, mainly organisations’ directors, are selected to represent women’s views, which ends up preventing women from participating in policy development:

*Here in Kibera we are never involved in policy development. Policies are made at NACC head offices… NGOs like Women Fighting against AIDS in Kenya [WOFAK] and Kenya Women Network with AIDS [KENWA] represent people infected with HIV, including women and girls. These organisations are represented by the directors, so they purport to speak on behalf of women. We have the Kibera Post Test Club [KIPOTEC], a network of support groups in Kenya, but I do not think they play any role in policy development. The problem with NACC is they make policies without involving people in the groups; they think people are in similar conditions in Kenya. There are many dynamics; people in slums are different from middle class or people from the village. In the slums, women and girls live in difficult circumstances. (Men’s PLHIV group leader, Kibera)*

PLHIV are a heterogeneous category, and the boundaries of PLHIV as a group – in either geographical or conceptual terms – are not always clear. The term ‘PLHIV’ masks socioeconomic and gender differences between PLHIV. If ‘participation’ is promoted without active attempts to transform existing power structures, such as gender and class-based inequities, participation can be captured by local elites, including male PLHIV elites who may be HIV-positive, but not poor and living in slums.

Devolution, however, could be an opportunity for marginalised populations to start participating in different decentralised structures. HIV activists in Kenya have historically been successful in getting the ear of politicians. But poor women in slums face internal and external barriers to participation in the political arena, including a lack of confidence and knowledge. These are discussed in more detail below.

3.7.1 Lack of confidence

According to the HIV-positive women we interviewed, including those who are skilled in group organising, they felt that other people should represent them or were better qualified to do so. They were quick to note that women were not necessarily advocates for women’s issues:
Have you not seen how the county woman representative has been fighting with other leaders, not for the women but her own personal issues with the Senator! The other women politicians are quiet; they do not talk about women’s issues other than their salaries. They need cars; they need allowances; yet as women they should represent women by presenting issues affecting women in the county. Also, accessing such women is very difficult. You only access them when they want your vote, and they make promises but wait till they are elected. They do not come to you. (HIV-positive woman, Kibera resident)

Women do participate in health discussions at health-care facilities, and during outreach efforts at community forums. However, women in the study wanted their issues and concerns presented to policymakers. They hoped this would be done by policymakers coming to them – not by them going to policymakers – or through health-care providers and researchers presenting their issues to policymakers.

Women also exclude themselves and maintain passive roles when they are unsatisfied with services. They may complain among themselves in groups but do not go beyond the support group:

Interviewer: How do you think women can participate in policymaking?
Respondent: (Laughs) How? Women do not have access to policymakers. How can they participate? Even through support groups it is very difficult. They will really need training and encouragement. You know women fear if they talk and they know they will be denied services, so you better keep quiet. That is how it goes here. If you do not like the services, you go somewhere else. (HIV-positive woman, Kibera resident)

Women shy away from participation in support groups and policy development because of the reasons mentioned above. But when motivated and encouraged, women become more confident to take steps towards participating in support groups and policy engagement:

Like when I started this group, sex workers did not want to join, they shied away. Some said they were too busy for the group, but then with time our numbers grew. (PLHIV group leader, Majengo)

Joining a local HIV support group is a sign that women accept their HIV-positive status and are ready to share this with their peers, who can be a source of emotional support. But such groups can also provide practical support, and is a condition for becoming a HIV activist. However, few women are ready to move beyond the boundaries of these groups. Engaging with policymakers will raise their profile and make them more identifiable as HIV activists – thus making themselves more vulnerable to threats – and that is not an easy transition.

3.7.2 Lack of knowledge
The majority of women felt they lacked the capacity to participate because they had little education and were from low-income households. Women said they did not know how to participate in policy development, and that they had not grasped the notion of devolution:

We need to understand how devolution works, how we can participate, and how to prevent politicians from making by-laws that are anti-sex work. Now that we have a representative at a national Kenyan coordinating mechanism, we would like to see how NACC is going to involve us in county interventions and activities. I think not much has been done yet. Devolution just began this year, so we are waiting for another year to see how it goes. (PLHIV group leader)
To get women interested in policy development, and to increase their participation in it, there is a need to encourage and educate women and girls:

*Girls shy away. They are not empowered. You know, for me to know more about advocacy, I have been taken for trainings. Initially I was never bothered. I did not know I should participate. I am sure if you asked me three years ago I would tell you I do not want to participate because I am too busy or I do not see the need. But I have come to learn. Women and girls have to be empowered through seminars.*

(PLHIV group leader, Majengo)

*By taking women and girls to workshops and seminars they are sensitised about policies. When they are informed about policies for women they can stand up for their rights.*

(HIV-positive woman, Kibera resident)

3.7.3 Poverty of time

Major challenges to engaging women in policy development are their lack of time, and competing priorities. A return on the investment of their time is not immediate or tangible, and among low-income women, immediate economic survival takes precedence over health. As noted above, actually getting to meet with policymakers is just one of many difficulties encountered. Policymakers, and those who should be representing women’s issues, are inaccessible. Women do not have the time, confidence, knowledge, or energy to track them down and engage them.

Women’s groups do exist, even in low-income communities, where state services are absent. In fact, sometimes these conditions are the reason why they were set up. These groups mostly focus on practical needs and priorities that can save time and money, such as accessing micro-credit and employment opportunities.

If public participation is at the centre of devolution, and the Constitution gives prominence to it, why is there still such a low level of public participation? How can women learn about devolution? How can they articulate their issues in the absence of any civic education?
4 Conclusion

The new Constitution and the push for a decentralised government were in response to citizens demanding government accountability, social equity, and better access to services. Devolution of governance can be an important step towards fulfilling these desires, bringing policymakers closer to the people they serve. We found that the HIV-positive women in this study wanted policymakers to take more interest in them and come to the slum areas to learn about their lives. But realising the benefits of decentralisation involves major restructuring of institutions, shifts of staff, and reallocation of resources, as well as the development of new systems for upwards and downwards accountability between central and county levels. It also involves a great deal of prioritising of HIV services and citizen participation.

Women have been marginalised in the political arena owing to gender norms and barriers. Politicians and policymakers are not easy to reach, as the researcher’s own experiences show. For HIV-positive women in slums – even if they are organised – these barriers to participation are considerably higher, not least because of practical restraints, such as a lack of time and money.

Engaging with policymakers and bureaucrats to get services has been very challenging for decades in Kenya. While devolution is a positive step towards engaging citizens, women need to take active steps themselves to get the attention of policymakers. Poor women in slum areas are excluded and marginalised. They have also internalised these views and do not see themselves as political activists who can affect political change.

Since the introduction of the new Constitution and the start of devolution, hospitals in Nairobi are being renovated, and money is being spent on essential drugs. This cannot be attributed to devolution alone, as it reflects and builds on other national health policies. But it shows that counties can implement health policies. Although at the time of conducting this study the notion that decentralised political environments could provide greater political space for HIV/AIDS response could be contested by our findings, on 2 December 2014, the Daily Nation published stories on World AIDS Day that highlighted some of the measures that counties with a high prevalence of HIV/AIDS were taking to combat HIV. It was reported that the Governor of Homabay County (25.7 per cent HIV prevalence) said his county had hired a consultant to offer advice on an effective anti-HIV campaign strategy, and that the county would adopt a multi-sectoral approach to combat the disease. His counterpart in Migori County said his county had launched an initiative aimed at reducing new infections. The neighbouring Kisumu County governor called on the national government to channel more funds to the region to fight HIV.

Citizens in slum areas have been underserved by the government for decades. Years of dysfunctional centralised governance has left them distrustful of the state. Instead, many rely on NGOs and community-based groups for social services, and for ART. Now that services run by international NGOs are being downscaled or handed over to the state, it means they will be taken over by county-level departments. It is not clear what will happen to these services under devolution or how they will be viewed by clients, particularly women.

PLHIV organisations in Kenya have increasingly managed, over the past two decades, to get access to the national policy arena. Yet our findings suggest that policymakers at the county level are not reaching out to these groups, and nor do they see it as their job to get services to the people. Rather, they feel it is the job of the women to find out where the available health-care services are. It is not their priority to get involved in politics to improve access to or the quality of services. This attitude reflects a mindset this study found in which
policymakers take little personal responsibility for their own actions in realising devolution, and are keen to find external excuses for delays.

HIV is just one of the many health challenges facing women and girls living in slums. As women in slums have never been very active in the leadership of the PLHIV organisations that operate at the national level, owing to gender and class barriers, they are not familiar with effective policy engagement. They lack the confidence, knowledge, and resources, including time, to be politically active.

4.1 Recommendations

- Establish initiatives to enhance the participation of poor women and girls in the political arena, recognising the broader internal and external barriers that prevent participation.
- Acknowledge the various ways in which women do organise themselves in informal and practical needs-oriented groups, and focus on helping women to access more resources, in addition to providing training on governance and organisation.
- Coach and train county-level policymakers on management, including personal and professional time-management, while implementing public accountability mechanisms, which track the time that transactions take.
- Provide rewards for good public management, such as awards for reducing waiting times and red tape.
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