



# Towards more inclusive urban health systems for refugee wellbeing

Lessons from Kampala,  
Uganda

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and William Monteith

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The Human Settlements Group works to reduce poverty and improve health and housing conditions in the urban centres of Africa, Asia and Latin America. It seeks to combine this with promoting good governance and more ecologically sustainable patterns of urban development and rural-urban linkages.

## About YARID

Young African Refugees for Integral Development (YARID) is an NGO based in Kampala, founded in 2007 by young Congolese refugees living in Uganda.

YARID unites urban refugees through avenues like sports, English classes, and vocational skills training in order to address social issues like ethnic conflicts, unemployment, public health, and lack of access to education. Refugees that YARID serves mainly come from the Great Lakes Region: Democratic Republic of Congo, Rwanda and Burundi.

The mission of YARID is to empower refugees, orphans and Internally Displaced Persons (IDPs) around Africa to overcome the burdens of deprivation and vulnerability to become healthy, educated, self-sustaining and contributing members of society.

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Uganda has a progressive national refugee policy that provides freedom of movement and the right to work, own land and access basic services in urban centres. However, refugees experience a number of barriers to realising these rights in practice, including hidden costs, language gaps, discrimination and institutional incapacity. This working paper examines how refugees access healthcare services in the Ugandan capital of Kampala, the barriers to access, and the impact of these barriers on refugee wellbeing. Making use of an innovative refugee-led methodology, it demonstrates the ways in which refugees themselves are extending healthcare systems in the city through the training and provision of translators and community health officers. Nevertheless, there remain significant gaps in service provision which require government and humanitarian agencies to work much more closely with refugee communities if these gaps are to be overcome.

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# Acronyms

CRRF	Comprehensive Refugee Response Framework of the UNHCR
DRC	Democratic Republic of Congo
ID	Identity document
IDP	Internally displaced person
JRS	Jesuit Refugee Service
KCCA	Kampala Capital City Authority
NGO	Non-governmental organisation
ODI	Overseas Development Institute
OPM	Office of the Prime Minister
POC	People of concern
RA	Research assistant
SDI	Sustainable Development Initiatives
UNHCR	United Nations High Commissioner for Refugees
YARID	Young African Refugees for Integral Development

# Summary

In December 2018, the United Nations Refugee Agency (United Nations High Commissioner for Refugees or UNHCR) held its annual Dialogue on Protection Challenges in Geneva on the theme of urban refugees. During a series of panel discussions and plenaries, mayors from refugee-hosting cities in Europe, the Americas, Africa and Asia were invited to present their experiences of providing a safe, welcoming environment for displaced people. The dialogue followed immediately after the official agreement of the Global Compact on Refugees. The compact is the culmination of more than 18 months of consultation and discussion aimed at setting future directions for refugee response globally (United Nations 2018). The compact emphasises a 'whole of society approach'. This involves multiple stakeholders and supporting refugee self-reliance. It was seen to fit well with the progressive approach of the mayors attending the dialogue. As was noted, they have already been taking this approach for some time. However, for UNHCR, hearing from mayors was unfamiliar. The High Commissioner for Refugees remarked that the dialogue felt like a 'first date' and asking, 'Why haven't we met before?'

Statements asserting that the majority of the world's refugees are now living in urban areas have become commonplace in discussions on the global refugee situation. Reliable statistics are not available, although the figure of 60 per cent is often quoted. This is a relatively recent shift in international policy discourse that began a decade ago with the introduction of UNHCR's long-delayed Urban Policy in 2009 – Crisp (2017) provides an explanation of the 'tortuous' progress the draft policy made through the organisation. It finally recognised that refugees should be allowed to settle

in towns and cities, and that many would prefer to do so. Judging by the words of the High Commissioner, practice has been slow to catch up with policy.

Uganda is at the centre of current debate on urban refugees. The country's Refugee Act 2006, which establishes refugees' rights to live, work and own land in urban areas, has been hailed as exemplary, and a global 'model' for humanitarian response. However, the model has been criticised in Uganda for binding assistance to the geographic location of refugees, providing relief only to those in rural camps. The model has also come under pressure from heavy refugee influxes from the Democratic Republic of Congo (DRC), Somalia and (more recently) South Sudan. Uganda currently hosts 1.2 million refugees: the highest number of refugees of any country on the African continent. Displaced populations from neighbouring South Sudan, the DRC, Somalia, Rwanda and Burundi live alongside 1.6 million internally displaced persons (IDPs) displaced as a result of the conflict between the Ugandan government and the Lord's Resistance Army in the 1990s (McKinsey 2017). The Ugandan capital Kampala's annual growth rate (3 per cent) is partly attributable to the arrival of displaced populations. UNHCR estimates there to be nearly 95,000 refugees and asylum seekers in Kampala, although this is likely to be a considerable underestimate.

As this working paper will demonstrate, research on urban refugees has also struggled to keep pace. Now, efforts are required to generate greater understanding of the role that municipal authorities can play in responding to refugee inflows, as well as the potential of refugee-led organisations to contribute to local decision-making processes.

## 1

# Research on urban displacement

*“People moving into cities due to war or persecution are, by definition, ‘displaced’, but this status does not define them. [They] are also parents, traders, students, clients, service providers, consumers and potential investors. As such, their daily lives and economic impacts on cities are shaped by policies and practices that intersect with but are not framed by protection or migration concerns.”*

Landau *et al.* (2016: 2)

Although it took until 2009 for the United Nations High Commissioner for Refugees (UNHCR) to publish its urban policy, the presence of refugees and other displaced people in urban centres has been documented for some time (Crisp 2017). Their presence was often discouraged, including by UN bodies, since urban refugees were considered to be ‘outside the purview of the international assistance and protection regime’ (Kibreab 1996: 132). Crisp (2017) notes that in the 1970s and 80s, the general perception was that urban refugees were a ‘problem’ and a disproportionately expensive population to provide for. These attitudes persist: the urban displaced are still considered ‘an expense and a security threat’ (Haysom 2013: 1). Nevertheless, at international levels a clear policy shift has taken place with UNHCR’s urban policy, finally recognising that refugees should not be prevented from settling outside of camps.

This shift appears to have been triggered, at least partially, by the response in the Middle East to the second Iraq war where hosting refugees in towns and cities was the norm. These receiving countries did not have policies of encampment, and in most cases were actively opposed to the establishment of camps, given their experiences of hosting long-term Palestinian

refugees. For their part, many of the Iraqis were originally from urban areas and had no intention of living in refugee camps (Crisp 2017). In addition, the idea that refugees could be prevented from moving from camps to urban areas (in accordance with UNHCR’s previous urban policy from 1993) was ‘proving to be fanciful’ (ibid).

Since then, research on urban displacement has been slowly catching up with the policy shift. A series of reflections on urban displacement were captured in a special issue of *Forced Migration Review* published in 2010. Contributors noted that refugees and displaced persons are a globally understudied group that has only recently begun to appear in the literature (Pavanello and Montemurro 2010). With reference specifically to Kenya, the same group of researchers noted the ‘minimal research into the specific refugee population and their needs’ (Pavanello *et al.* 2010) who they considered to be a ‘hidden population’ about whom little is known – in stark contrast to the country’s camp-based refugees. Similarly, there is a ‘critical knowledge gap’ (Cotroneo 2017: 316) associated with urban internally displaced persons (IDPs). Little is known about their ‘demographics, basic needs and protection problems’ (Davies and Jacobsen 2010: 13).

A significant contribution to understanding of the capacities and vulnerabilities of the urban displaced was made during the 2000s by the Feinstein International Center at Tufts University, which developed a methodology for profiling the urban displaced. This has demonstrated how the delivery of a household survey ‘can not only produce IDP population estimates and patterns of distribution within the city but can also contribute to a valuable understanding of how IDPs and non-IDPs may differ with regard to some key elements, such as housing, education, employment

and their experience with forced eviction' (Montemurro and Walicki 2010: 12). Profiling takes place within a bounded geographical area, and does not require households to identify themselves as displaced (this is done through secondary analysis). This has helped to demonstrate that within neighbourhoods, 'IDPs and non-IDPs share similar demographic characteristics and experience the same stresses related to urban poverty and lack of adequate infrastructure' (Davies and Jacobsen 2010: 14).

This finding is reflected in a study of urban refugees and IDPs undertaken in eight urban centres by the Overseas Development Institute (ODI) between 2009 and 2012. Reflecting on the findings from a case study of Nairobi, the researchers conclude that 'whilst in some cases displacement has created some specific vulnerabilities and increased exposure to certain risks, it is not, in itself a direct indicator of vulnerability' (Metcalf *et al.* 2011: 33). Tufts profiling in Sudan, Colombia and Ivory Coast found 'subtle differences' between IDPs and their hosts, but 'urban IDPs were found to be poorer, at a greater disadvantage and experiencing more insecurity than their non-IDP neighbours' (Davies and Jacobsen 2010:14).

This, and other research, has identified some distinct areas in which displaced persons' vulnerabilities and risks are enhanced as a result of their status. For example, the displaced, lacking both political rights and leverage, are more at risk of abuse from corrupt police forces or militia (Davies and Jacobsen 2010; Haysom 2013). They are also likely to live in neighbourhoods where governments choose not to invest in basic services (Haysom 2013).

The displaced are also at greater risk of eviction, because they have entered into insecure arrangements or settled in particularly problematic places (Mallett 2010: 34; Grayson and Cotroneo 2018; Haysom 2013; Montemurro and Walicki 2010). Their status means they may accept higher rents and abusive behaviour from landlords (Decorte and Tempa 2010; Haysom 2013) and the quality of their shelter may 'often be of the worst type' (Pavanello *et al.* 2010: 24). Refugees often lack the right to work (Haysom 2013) and pay more for health and education services (Pavanello *et al.* 2010: 24). They also often have difficulty accessing services and paid work because their official documents were lost during their flight (Davies and Jacobsen 2010) or they lack proficiency in the local language (Monteith and Lwasa 2017). In addition, they may have lost assets and experienced trauma en route from or in their countries of origin (Davies and Jacobsen 2010; Grayson and Cotroneo 2018).

For humanitarian responders, these findings have proven to be problematic for a variety of interconnected reasons. On the one hand, humanitarians may, in response to these findings, seek to help the displaced

overcome specific barriers to livelihoods or access to services, through targeted short-term interventions. The idea here would be to create more of a level playing field for displaced people – bringing them up to the level of those around them. This causes moral difficulties for some, given that host populations are living in situations well below those to be considered of a minimum standard. Refstie *et al.*'s (2010: 33) response is an example of this:

Many of the recent methods and tools developed for identifying urban IDPs seem to focus exclusively on how to determine whether or not the IDPs are worse off than the surrounding population. In an urban setting people settle according to their income, effectively reflecting the status of people around them. IDPs therefore often end up among the very poorest in the cities. It may be worth asking the question whether being part of the urban absolute poorest population can be considered a durable solution for IDPs.

In addition, recommendations stemming from profiling activities or research on the urban displaced frequently point out that given the proximity of refugees to host communities, and endemic poverty among these populations, interventions must respond to both displaced and host communities (eg Davies and Jacobsen 2010). Interventions focusing solely on IDPs or refugees in situations of protracted displacement and wide-spread urban poverty have been criticised, not least because they may entail identifying beneficiaries by displacement status which is potentially unethical (Haysom 2013). But responding to the breadth and depth of already-existing urban poverty is regarded as beyond the scope and expertise of humanitarian actors. This leads to calls for development actors to intervene, but will require humanitarians to 'convince other actors of the relevance of urban displacement to their mandates' (Haysom 2013: 25). This is likely to be an ongoing and uphill struggle, given that many large development agencies and international donors have long been without a clear policy on their approach to urban poverty or the in-house expertise required to develop appropriate interventions at the city scale.

Adopting a place-based approach enables a holistic consideration of the overlapping needs of multiple displaced and host populations (Earle 2016; Saliba 2018). Such a perspective is critical for understanding the extent to which barriers to service provision for displaced populations are the result of systemic discrimination and/or general deficiencies that are experienced by all. By bolstering and/or extending existing systems for education, healthcare and livelihoods, place-based approaches have the potential to link short-term emergency interventions to longer-term development goals. Critically, this avoids creating parallel systems that reproduce dependency, financial waste and stigma while fanning tensions.

## 2

# From humanitarian to urban research

Most studies and accompanying tools which focus on the needs of refugees continue to have a humanitarian reader or user in mind. Recommendations are generally targeted towards external actors: non-governmental organisations (NGOs), UN practitioners or donor agencies, and occasionally the governments of host nations.<sup>1</sup> Indeed, the explicit focus of studies by ODI and the International Committee of the Red Cross (ICRC) is to identify the challenges that urban displacement generates for humanitarian action (Pavanello *et al.* 2010; Cotroneo 2017; Grayson and Cotroneo 2018). Studies of refugee or IDP livelihoods often end with lists of recommendations for interventions from external actors (eg Krause-Vilmar 2011). These studies bring a welcome focus to the nature and extent of urban displacement and the experiences of the displaced. However, largely absent from this research is any significant analysis of the role of municipalities in ensuring access to services and protection of refugees and other forcibly displaced people, and critically, the necessary conditions and catalysts for this to happen. While some of the literature does call for greater support to municipal authorities (eg Metcalfe *et al.* 2011: 34), that mayors and other municipal actors have a role at all is only slowly being acknowledged in international circles – as demonstrated by the High Commissioner's remarks noted in the introduction to this article.

This is problematic. ODI's research on displaced people in seven countries noted that in several cities 'the refusal of municipal or central authorities to accept the long-term presence of displaced populations has presented a major challenge to their ability to integrate into the social and economic life of the city, and has entrenched patterns of underinvestment in city infrastructure, ultimately compromising urban development itself' (Haysom 2013: 1). Findings from the ODI case studies suggest that displacement is often happening in a

national policy vacuum. But the conclusion the research teams reach is that 'having the right legislation in place may not be as important as positive acceptance of a populations' presence and the proactive provision of services to meet urban growth' (ibid 2013: 9). This leads Haysom (2013: 9), summarising the research findings from ODI's multiple studies, to conclude that, 'Important questions remain as to what incentives and strategies resolve negative attitudes to the displaced and encourage host states to enable the displaced to enter local economies and use (ideally) public services'. This is a valid statement of a gap in research and understanding, that could be very usefully applied at lower levels of the state. Indeed, most negotiations over refugee rights and entitlements have happened at national levels, and are debated in international forums. Comparably, there has been much less focus on the incentives and strategies that would encourage host towns and cities to promote an enabling and safe environment for forcibly displaced people. It should be remembered that 'Nation-states make policies that formalise the movement of people; municipalities have to manage and mediate the informal realities that do not always mirror the policies' (Keith 2014:10).

Recent work by Saliba (2018) and Landau *et al.* (2016) has started to open up alternative understandings and approaches to urban forced displacement, taking municipal authorities and urban politics as a starting point. This responds to the assessment made by Landau *et al.* (2016: 1) – specifically on the issue of refugees – that 'while a growing body of literature on refugees in urban areas outlines the challenges they face, the United Nations High Commission for Refugees and its partners in the humanitarian space have struggled to adapt their programming and interventions to recognise that urban protection is a long-term process effectively inseparable from urban politics



and development.' Landau *et al.*'s (2016) study of Johannesburg, Kampala and Nairobi begins to address the dearth of scholarship on municipal authorities' responses to displacement and refugees' (*ibid*: 2) outside the global North. This work, and that of Saliba (2018), are based on the premise that local authorities do not see themselves as humanitarian actors. 'While national governments must grapple with the legal and political differences between migration statuses such as citizen, asylum seeker or refugee, city governments are primarily concerned with the label of resident; that is, whether or not the person resides within the city's municipal boundary' (Saliba 2018: 12). In a best-case scenario, this can lead to a more pragmatic focus on responding to an enlarged local population, regardless of status, where 'city governments are willing partners looking for expertise or support to manage an arrival of new city residents while maintaining – or even strengthening – continuity and reach of public service delivery channels' (*ibid*).

For Landau *et al.* (2016), external actors would do well to tailor their approach accordingly, recognising that they are more likely to achieve goals of integration and protection for displaced people by demonstrating how their presence 'can be a political or financial asset [...] and finding creating ways of integrating people of concern [POC] into existing programs and policies or enhancing those programs in ways that can accommodate POC' (Landau *et al.* 2016: 3).

While legal protection for urban refugees is important and must be an area of focus for UNHCR and specialised humanitarian agencies, 'local governance and service delivery practices may matter more on a day-to-day basis' in fostering positive outcomes for refugees and other displaced people in urban areas (*ibid*). The trick is to build understanding of the political and institutional environment in which the displaced find themselves, and 'recognize local authorities' interests and incentives and develop strategies to align protection concerns with local political economic factors' (*ibid*: v). Moving from 'principles to politics', argue Landau *et al.* (*ibid*), is the method by which potentially future or harmful public battles over refugee rights can be avoided, 'instead naturalizing the presence of refugees in their respective communities while building solidarities with marginalised constituencies' (*ibid*: 3).

Kampala is a particularly interesting case study for the issue of urban refugees. At the time that Landau *et al.* (2016: 12) were writing, the Kampala Capital City Authority (KCCA), while it had technically been assigned a protection mandate for refugees within its boundaries, had 'little awareness of refugee rights and minimal official interest in protecting POC'. This led the authors to conclude that the KCCA was unlikely

to provide positive benefits for the forcibly displaced who were better off 'stealthily' integrating into private markets for housing and services where there was little incentive for them to be excluded. By 2018, the situation had changed considerably. The KCCA had released a Strategic Response to Displacement, Migration and Resettlement (Saliba 2018: 19). Further investigation of the specific case is required, but this change of perspective may be a reflection of the Ugandan government's engagement in the piloting of UNHCR's new Comprehensive Refugee Response Framework (CRRF). This had led to lobbying by international actors for the KCCA to consider what the roll-out of the CRRF would look like in an urban area, and had presumably raised awareness amongst the municipal authorities of the potential financial and reputational benefits that would accrue to the city through engagement in a new UN-led global initiative.

Further analysis is needed in Kampala and elsewhere on the incentives and capacities required to foster responsiveness to the needs of refugees and displaced persons. If this is to be achieved, municipal authorities will need to be moved from the sidelines of urban displacement research into to the spotlight. This focus might help to uncover the range of different pathways through which a more welcoming and safer environment for the displaced can be achieved. The findings of such research would be of considerable value to another set of actors largely absent from the literature – refugee-led organisations themselves. There is currently very little understanding of how they organise and a lack of documentation on whether or how they have brought about positive changes that impact on refugee wellbeing or protection. Haysom (2013: 12) identifies displaced groups' lack of political bargaining power and suggests that this is a major factor in their continuing marginalisation that will be hard to shift. She calls for support to help the displaced 'influence governance decisions that fundamentally affect their opportunities and access to resources in the city', although she sees a continuing need for outside actors to 'ensure their protection and raise the profile of their concerns' (*ibid*).

This is where the International Institute for Environment and Development's (IIED's) recent research on access to healthcare for urban refugees in Kampala marks a change in methodological approach, and offers new understandings of the nature and experience of urban poverty among the displaced. Critically, this work has disaggregated data by refugees' country of origin. This is relatively rare in urban refugee research, although some disaggregation on livelihoods for refugees in urban Uganda has been done by Monteith and Lwasa (2017) and Betts *et al.* (2014), and on mental health by Tippens (2017).

<sup>1</sup> See for example Haysom (2013); Pavanello *et al.* (2010).

## 3

# Institutional responses to refugee integration in urban Uganda

On 20 March 2019, Wilson Sanya, the mayor of Koboko municipality in northwest Uganda embarked on a 10-hour overland journey to the capital of Kampala to share his experiences of managing protracted displacement with an audience of researchers and policymakers. Northwest Uganda has one of the highest ratios of refugees to host population anywhere in the world (Komakech *et al.* 2019).

Mr Sanya spoke of the opportunities and challenges of managing a municipality in which 35 per cent of the residents have been displaced by conflicts in South Sudan and the DRC, and have moved to Koboko following periods spent in nearby refugee camps. On the one hand, he noted that with numbers increasing on a daily basis, there is a heightened strain on already-stressed service delivery systems that has not been accounted for within Uganda's municipal budgeting process. However, on the other hand, he spoke of the innovative ways in which his administration has sought to meet the needs of displaced and host populations through inclusive urban programming, including, for example, an education programme where Ugandan residents teach Lugbara to non-native speakers and act as translators in local health clinics. There is also a cultural programme through which Ugandan, Congolese and South Sudanese residents share dance practices and compete in a 'Miss Koboko' competition. And there is a female entrepreneurship programme through which Ugandan residents are given incentives to invest in Congolese and South Sudanese businesses.

Uganda's Refugees Act 2006, which established refugees' rights to live, work and own land in urban areas, has been hailed as exemplary and a global model for humanitarian response. However, recent research has shown that rights to move, work and access basic services are often unmet in urban areas owing to a lack of institutional capacity and coordination (Monteith and Lwasa 2017). On arrival in towns and cities, refugees in Kampala are required to register with the police and the Office of the Prime Minister (OPM), where they are given an identification card and directed towards InterAid (UNHCR's implementing partner in urban Uganda) for emergency support. However, most refugees are ineligible for assistance in urban areas and thus slip between the cracks of municipal and humanitarian assistance. Mr Sanya's testimony speaks to the both the gaps in the institutional response to protracted displacement in urban Uganda, and the influential role played by sympathetic city leaders and administrations in responding to such gaps.

In addition to mayors and municipal authorities, community groups, faith-based organisations and refugee associations also play a critical role in bridging the divide between policy and implementation in Ugandan towns and cities. This research set out to examine the ways in which refugees access healthcare services in the Ugandan capital of Kampala, the barriers to access, and the organisations and initiatives working to overcome these barriers.

## 4

# Methodology

The British Academy's Cities and Infrastructure Programme funded IIED and the Young African Refugees for Integral Development (YARID) to undertake research that has informed this working paper. Taking a unique approach, Congolese, South Sudanese, Somali and Burundian refugees were trained to gather qualitative data on how refugees access basic services including healthcare, water and sanitation, and reflect on the results. The approach engaged the refugee communities during the research design, data collection, analysis and dissemination phases. It gave them insights into the trajectories and experiences of other communities in the city and strengthened links between all the communities involved. As a result, leaders from each refugee community have tried and tested skills in research and participatory methods that can be developed and applied beyond the life of the project.

A combination of focus group discussions and semi-structured interviews were used to elicit the perspectives and experiences of refugees, community leaders and healthcare providers across the city. Particular focus was given to the four largest refugee groups in Kampala: the Congolese, Burundians, Somalis and South Sudanese.

There are at least two significant challenges of doing health research with marginalised populations in dense urban areas. Firstly, it is very difficult to identify and access research participants from the selected groups and secondly, it is difficult to create a space in which participants feel they can speak openly about health issues.

In response to these challenges, we designed a refugee-led methodology which placed refugees from the selected communities at the centre of the research process:

- Drawing upon YARID's existing contacts, two research assistants (RAs) were employed from each of the four refugee communities.
- The RAs were provided with extensive methodological training facilitated by researchers at IIED and YARID.
- The RAs participated in the design of the research instruments, including the selection, phrasing and translation of key questions for the interview and focus-group exercises.
- The RAs facilitated these exercises in their respective communities, selecting interview and focus group participants to ensure as diverse a pool of participants as possible.

The project generated a total of 15 focus group discussions, 22 household interviews and 6 key stakeholder interviews. We analysed the translated transcriptions using thematic coding. The most significant themes (eg language, cost of access and discrimination) structure the analysis below. We also held a multistakeholder workshop to discuss initial findings (eg refugees' key health challenges, barriers to care) and identify promising practices to be investigated. Finally, we organised an international workshop to share recommendations and to discuss how the research could best have an impact across the humanitarian, urban development, and public health communities.

## 5

## Findings

## 5.1 Arriving in Kampala: identification and orientation

*“We leave our country with stress and sometimes we are desperate when we reach here, we find that no hope, there is no food, no shelter... In most cases you do not know where the health facilities are located.”*

Female participant, Burundi

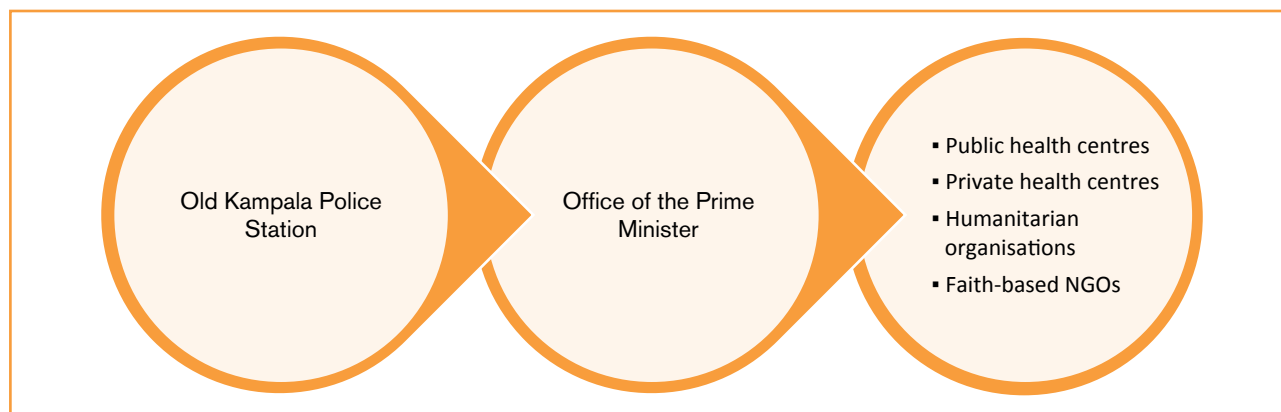
Stella Hakizimana fled Burundi towards the end of the civil war in 2004, crossing the border into Uganda while eight months pregnant. She initially registered at Nakivale refugee camp but felt unsafe on account of the presence of people thought to be working for Burundian state security services. She therefore took the difficult decision to travel onwards to Kampala in the ninth month of her pregnancy. On arrival in Kampala, Stella spoke neither English nor Luganda (the local language in Kampala). She recalled her first interactions in the city as being ‘very stressful and challenging’. After several hours in Kampala, she found a police officer who

directed her to Mulago hospital, where she was given a bed in preparation for the delivery of her child. The medical staff at Mulago gave her instructions that she was unable to understand. Nevertheless, Stella gave birth to a healthy baby boy the following day.

Stella’s story is illustrative of many refugees’ first interactions with the healthcare infrastructure in Kampala, often characterised by confusion, frustration and helplessness. Stella’s status as a heavily pregnant woman rendered her particularly vulnerable on arrival. However, the obvious and immediate nature of her health needs facilitated faster access to health services than that available to refugees with chronic and/or mental health conditions requiring of further explanation (see below).

Legally, refugees are required to register first with the police and then the Office of the Prime Minister in Kampala to obtain the refugee identification card required to access public services. However, this procedure was not always clear – or possible – for refugees with immediate health needs such as Stella. Furthermore, several participants reported that they were instructed by the OPM to go back and register

Figure 1. The process of accessing health services for new refugees in Kampala



at a refugee camp first, in contravention of Uganda's Refugee Act. It was not uncommon for refugees to spend days navigating this system and still be none the wiser on the question of how to access health services in the city. As a Burundian refugee explained: 'After getting an ID [identity document], you are left nowhere – you don't know where JRS [Jesuit Refugee Service] is, or what kind of services they offer'.

Our research revealed the existence of four different types of organisation involved in health service provision for refugees in Kampala:

- Public health centres (provided by the Kampala City Council Authority),
- Private health centres,
- Humanitarian organisations (including UNHCR's implementing partner in Kampala, InterAid), and
- Faith-based NGOs (including the Jesuit Refugee Service).

While the first two providers are accessible (at least in theory) to refugee and host populations, the latter two are exclusively for refugees. Insofar as 'free healthcare' exists in Kampala, it requires refugees to first present at KCCA health centres to obtain a diagnosis and (where necessary) a prescription, and then to present at InterAid or a faith-based organisation such as JRS to request financial and in-kind support to access appropriate courses of medicine and treatment. However, in the absence of clear instructions on arrival, refugees often approach these organisations in the wrong order – for example, by presenting at InterAid prior to a KCCA health centre – causing considerable anxiety. As a Burundian participant reflected, 'New arrivals need people to guide them on where to access refugee IDs and hospitals'. The absence of such support appears to chime with previous studies that found 'little awareness of refugee rights and minimal official interest in protecting POC' within the KCCA (Landau *et al.* 2016: 12).

Established refugee communities have responded to these gaps by creating their own forms of guidance and support. For example, Somali mosques and Congolese churches in Kampala double as citizen advice bureaus, providing newly arrived refugees with essential information on health services in the city in a language that is understandable. As a Somali participant explained:

*"The first thing [we do] for a newcomer is to receive him and to introduce him to the offices we talked about earlier [InterAid and OPM]. He can register at the police and from there we can direct him to YARID for English classes then to InterAid to open a file [for support]. If you are sick you should know the KCCA health*

*centres like that you can feel at home... When a new person arrives in the Somali community, the community is well organised to receive him and to direct him."*

Somali community leaders are stationed at the central bus station and Old Kampala Police Station to identify new arrivals and guide them through this process. Such is their success that Burundian and South Sudanese refugees emphasised the need for a similar support system that is able to orient new arrivals from their own communities in the city and translate complex institutional procedures. However, such systems require organisation and volunteers who are prepared to give up their time to support new arrivals without compensation. There is therefore scope for municipal government to support initiatives designed to orientate and integrate refugees from the first moments of their arrival in the city. These could include, for example, employing translators and/or community liaisons in and around key points in the city (Old Kampala Police Station; Office of the Prime Minister) and translating signs and procedures into appropriate languages.

## 5.2 Language barriers

Language continues to constitute a significant barrier at several key points to refugee access to health services in Kampala long after their arrival in the city. In the absence of familiarity with English or Luganda, refugees were less likely to be able to arrange an appointment with a doctor at a KCCA health centre and more likely to receive a false or incomplete diagnosis on the occasions where they were seen. As several participants explained:

*"You cannot see the doctor because of the poor communication: your Kiswahili, my French, his Kinyarwanda, your Lingala... You leave the hospital without seeing the doctor and without medicine. You cannot talk to the doctor because you don't know his language."*  
Male refugee, DRC

*"[The] doctors speak English and Luganda which we don't know. You can try to explain your problems but they prescribe you the wrong medicine due to the language barrier".*  
Female refugee, Burundi

As one Burundian participant explained, even for those able to locate an appropriate health facility, language is still a barrier. 'If you are in line [queue], the Ugandans pass in front of you because you don't understand the information the staff are giving'. As a result of this distance, refugees were less likely to seek medical treatment, and more likely to be withdrawn and subdued when they did. For those able to arrange a consultation, miscommunication often led to a patient

waiting in the wrong area of the hospital and/or missing their appointment when it was called ('We find there is a lack of consultation with refugees from doctors and nurses'). And those able to arrange and attend an appointment often found it difficult to communicate their symptoms and/or understand the prognosis. As a result, participants reported numerous cases of misdiagnosis, and of being prescribed painkillers irrelevant of their particular condition. A South Sudanese participant reported that his son had been proscribed antimalarials when he was suffering from typhoid, leading to the further degradation of his health.

Rather than just accepting this situation, refugee communities have responded by training their own translators and health extension workers. For example, Stella, who arrived in Kampala from Burundi while pregnant (see above) responded to her situation by learning English and Luganda and studying for a degree in public health. She now volunteers as a health extension worker in the Burundian community, travelling to medical centres with patients to reassure them and translate their symptoms to medical professionals. However, she is not always available as the role is unpaid and her time has to balance with other forms of paid work.

In the absence of a community health volunteer or translator, established members of the Congolese community encourage fellow refugees to ask to be treated the same way as deaf patients, 'Because the deaf have the right to be treated'. Such advice demonstrates the lack of awareness within public health facilities in Kampala of the situation of refugees relative to other populations, and of the absence of any systematic response to the language barriers that present a significant obstacle to their treatment. The comparison with the deaf community is interesting here insofar as it shows the possibilities that can exist for inclusive health systems where the needs of particular communities are identified and taken seriously. At a minimum, such a system would require public health facilities to invest in community health volunteers and translators, and to provide sensitisation training to existing staff, including both medical professionals and administrators.

### 5.3 The myth of 'free healthcare'

*"Everything here in Uganda, everything here, it's money. There's nothing for free. Whatever is free, you will still have to pay something... [Pause] If you delay you will die... The government will say it is free but the person who is handling the free things will not give them to you for free."*

Female participant, South Sudan

*"For us refugees we don't have money so we are sentenced to death."*

Male participant, DRC

Part of the rationale for suspending systematic humanitarian assistance to urban refugees rests on the idea that displaced populations are able to access public services in towns and cities free of charge. Indeed, at the final project workshop, a delegate from the Office of the Prime Minister emphasised that registration and health services in Kampala are free at the point of access to refugees. However, our research findings revealed a number of hidden costs associated with accessing healthcare services including those of transport, informal payments and medicine. Consequently, the idea of 'free' access was emphatically contested in testimonies such as those above.

Perhaps the first hidden cost of access to health services in Kampala is that associated with travelling to a government health centre. There are four official KCCA health centres in the city, which refugees are encouraged to use. However, these are often located several miles away from the areas where refugee populations are concentrated such as Nsambya, Kisenyi and Namuwongo. As a female Congolese resident of Nsambya explained, 'The distance is too long – sometimes you don't have money to pay transport when you are sick'. For refugees in Kampala, accessing health services in the city required a minimum of 2,000 Ugandan shillings (US\$0.53) to cover the costs of transport – a significant amount considering the difficulties of finding work on arrival (Monteith and Lwasa 2017).

Upon arrival at public health centres, refugees were often met with a second hidden cost:

*"I went to Mulago Hospital to see a specialist [but] they tell you to pay 50,000 shillings without a receipt. There are some instances where you have to give money to a cleaner in order to reach a doctor... If you do not have money, they cannot treat you."*

Female participant with a chronic illness, Burundi

This figure of 50,000 Ugandan shillings (US\$13) appeared frequently in the interview and focus group transcripts: 'When you are admitted, they will ask you to pay 50,000 Ugandan shillings.' 'We were told by the medical attendants to pay a sum of 50,000.' 'They ask for transport for doctors... 50,000 without receipt.' However, these payments were rationalised by centre staff in different ways. For example, as the cost of arranging an appointment, for the doctor's transport, or the cost of the examination gloves and equipment. No receipts were issued.

It is important to contextualise such payments – or forms of petty corruption – in the broader context of a public health system in Kampala which is chronically underfunded, and in which staff earn low wages and are often paid late. Nevertheless, the predominance of hidden payments and informal transactions placed refugees at a particular disadvantage. They often lacked the language skills and cultural competency required to navigate such requests, to reject them where appropriate, or to demand their right to a free medical consultation. Such payments therefore served as a significant barrier to access, and one which was interpreted as a ‘death sentence’ for elderly and disabled patients with chronic illnesses. In the words of a Burundian parent, such costs forced refugees to become ‘the doctor of your own child’ by diagnosing and medicating them yourself.

The final hidden cost articulated by refugees in Kampala was that associated with the procurement of medicines. In cases where refugees were able to arrange consultations, they were often given prescriptions for specific medicines. The majority of medicines are not provided free of charge in government hospitals. As a result, patients in Kampala are required to visit pharmacies and pay for prescriptions that range from 5,000 Ugandan shillings (eg for basic painkillers) to more than 100,000 Ugandan shillings (eg for a series of insulin injections) – costs that most refugees are unable to meet. As a result, refugees are instructed to visit InterAid, which has the remit to provide medicines to displaced populations in cases where they have prescriptions that they cannot afford. Our participants described this process in detail:

*“I have had complications with pressure since last year. I was told to take a tablet every day to regulate it. My medicine was finished and I have nothing to do. I went to hospital where they prescribed for me some drugs, I went to InterAid they told me to go to JRS. I went to JRS and I got nothing. I went back to InterAid... They told me to go to a pharmacy and get a voucher so that they can get money from UNHCR but up to now I have never received the medicine.”*

Male participant, DRC

*“When you go to InterAid you don’t find any medicine there, you go to UNHCR there is no medicine, you go to hospital as well there is no medicine.”*

Female participant, DRC

In seeking free access to essential medicine, refugees were pinballed between different municipal, humanitarian and faith-based organisations across

the city – in similar fashion to the point of their arrival in Kampala – and often ended up empty handed. Testimonies such as those given here convey a sense of institutional and jurisdictional confusion in the provision of essential medicines to refugees in the city. Furthermore, they demonstrate the frequent delays and lack of medical stocks that frustrated the attempts of participants to access medicines (‘no one receives medicine’), often with fatal consequences. Health workers reported that government and humanitarian health centres generally stock a small range of drugs for generic conditions, including painkillers, antibiotics and antiretroviral (ARV) drugs. Anything else has to be ordered in, taking up to four weeks to arrive. As a consequence, there is a severe shortage of medicines for the treatment of chronic diseases. A Somali participant described the implications of such shortages on her life in Kampala:

*“I am diabetic and always get treatment and injections from the doctors. But it’s expensive and I really can’t buy it and if I missed one day, I get a lot of problems. Whenever I go to InterAid and JRS, they say come back after weeks. After that they call me to take some tablets which are not enough for me especially when my condition gets worse.”*

The interview and focus group discussion transcripts provide a catalogue of examples of the ways in which out-of-stock drugs and delays are having a catastrophic impact on the lives of refugees in Kampala. There is evidence that refugee-led savings groups and welfare organisations are playing an important role in raising money to treat serious conditions in well-established communities, such as those of the Somalis and Congolese. However, other groups were not so fortunate. As a Burundian participant argued, ‘Refugees are dying due to the lack of enough drugs and care’.

## 5.4 The health implications of poor housing and basic services

The study also considered some of the specific social determinants of health and physical hazards facing displaced populations living in low-income and unplanned urban settlements. Unplanned urbanisation drives the growth of informal settlements in East African cities such as Kampala. These settlements provide affordable homes to low-income households and refugees with limited resources. But they also pose unique infrastructural, environmental and social challenges to refugees which can exacerbate health hazards and risks. Informal settlements that have urbanised without formal basic service infrastructure including water and sanitation make the local population

more vulnerable to malaria and water-borne diseases. These health risks and vulnerabilities are intensified by the limited resources and support networks that often characterise refugee households, particularly for those who have only recently arrived.

*“Malaria, typhoid, diarrhoea and infections. You know people in living in the slums sometimes don’t have access to safe water. Others don’t have clean toilets or toilets are shared by the entire population, etc. We receive so many cases here of viral and bacterial infections and these are related mostly to the living conditions.”*

Kampala City Council Authority nurse

Adapting to life in an informal settlement in a new city and country takes time. Although displaced households might understand how to reduce the risks that they are exposed to, they might not have the resources to do so. Poor basic service provision, and limited access to resources to mitigate risks or navigate access to improved basic services puts refugee households at a health disadvantage from the outset. A South Sudanese health worker explained,

*“The issue of clean water, you know some of the people – if you don’t have enough money to buy charcoal to boil that water [...] some people, when cooking they put it on that small fire [...] This thing will not boil, it will just warm because the charcoal is so small. So, you cannot buy the charcoal for the boiling water because it is expensive. You just put the pot on and it can become warm, just warm. Just to clear your conscience and you just take it.”*

Overcrowded living conditions are commonplace. It is not unusual to find 10–15 people sharing a poorly ventilated house, where diseases and illness are easily transmitted. However, without adequate access to resources or support networks, the households interviewed had little option but to stay in overcrowded living conditions. As one Burundian refugee explained,

*“When it comes to shelter, it is worse. We rent houses from the slums because that it is the money we can afford and we are many in the house, which is not good. If someone has a flu, all of us we fall sick since we do not have enough ventilation.”*

In cities such as Kampala, the state cannot guarantee equitable access to affordable basic services such as sanitation. Some of the most vulnerable households (including refugees) are forced to make decisions that

amplify the health hazards they face. One Burundian refugee explained how he is often unable to buy sufficient water to meet the basic needs of everyone in the household, which means that refugees have to compromise on drinking water or being able to sustain basic levels of hygiene, both of which have significant implications for their health. Another Burundian refugee who suffers with chronic diseases told us,

*“We are looking for house which costs less whereby you can’t afford a toilet of a rich man... Another thing, water bill is too expensive. It is too dirty whereby you can expose yourself to diseases once you drink it before boiling it, such as typhoid.”*

Refugees reported that the cheapest housing options were often in the least desirable parts of a settlement with the most inadequate infrastructure or access to infrastructure. The health risks linked to poor sanitation infrastructure, where wastewater and sewage is not safely disposed of, requires a collective response. Even if a household can invest in improving sanitation at the household level, a neighbour’s poorly lined or overflowing pit latrine will continue to pose a health hazard in the neighbourhood (McGranahan 2015).

*“The income you are having makes you to live in cheaper places. In the cheaper places you can see, when you are leaving your house, you see the sewage open. There is a hole where everyone who comes puts their things and sometimes it smells bad and when the smell reaches to your house you can get sickness from there. Sometimes you have... and people say “You have infections”. Some are saying that you are having, what? How do we call it? “Infection and diarrhoea.” All because of the environment you are living in.”*

Participant in the focus group for refugees with disabilities

Although the impacts of poverty on health are well understood, a renewed focus on slum health recently highlighted the specific physical and environmental hazards facing host and displaced populations living in such settlements (see Ezeh *et al.* 2017). However, refugees face particular challenges if they have recently arrived and do not have resources or social networks to draw on. Refugees who have only recently arrived do not own their homes and, as renters, are not well-connected in the city. They are not in a position to influence landlords, or collectively organise, or even to lobby local government for improved services. Worse still, some refugees stated that they are often blamed



for poorly managed and dirty toilets, and were forced to clean the toilets every day.

## 5.5 Discrimination and vulnerability

Focus group discussions and interviews with key informants highlighted the vulnerabilities facing specific groups of refugees, in particular women, children and the elderly. Our research demonstrates that the most vulnerable refugees are susceptible to similar diseases, poor nutrition, sexually transmitted diseases (STDs) as other low-income urban residents. But given the barriers to healthcare we described earlier, these vulnerabilities are often exacerbated. One KCCA nurse stated that about 80 per cent of the refugees that she tended to were female. Meanwhile, one health worker provided more detail on the challenges facing the most vulnerable groups.

*"If we talk about vulnerability, we always have children – they have malaria, flu, malnutrition. We see malnutrition in children less than five years, where we always refer them to Mwanamugimu [nutrition unit] in Mulago hospital. Especially for elderly, they always have issues of arthritis and back pain. Also, for pregnant women, they always have issues of antenatal kits. They don't have the delivery kits."*

Burundian health extension worker

Our findings reveal the secondary burden of vulnerability facing many refugees. Vulnerabilities linked to age, existing disabilities or chronic illness can exacerbate the physical and psychological traumas that refugees experience before or during displacement. Overstretched and poorly resourced health services face the double challenge of responding to their specific, complex and intersecting needs and vulnerabilities.

*"We are vulnerable twice: first as refugees, secondly as elderly [...] Even if you have a family or children like abroad – we have refugees here who have children abroad and family abroad. Once you become an elder person, they start giving you very little [...] compared to their siblings who are strong. So, parents become a burden [...] because they are not earning any money. So, we are vulnerable twice as refugees and as elder persons."*

Interview with Congolese elder

Our research revealed some of the reasons why certain groups become more vulnerable than others. Congolese elders explained how female refugees work to feed their families, forgoing their own food for their children and partner. Giving birth without adequate support or access to healthcare often makes women refugees more vulnerable. The poorest and most marginalised individuals are also increasingly vulnerable to further health risks and exploitation as they seek resources, services and even healthcare. A Burundian refugee explained how the poorest, most disconnected youths and women undertake intermittent sex work when necessary, increasing their risk of unplanned pregnancies and sexually transmitted diseases.

In cities like Kampala, where there is pressure on basic services and healthcare resources, discrimination towards weaker groups who are perceived to be less deserving is more common. As a Congolese elder recounted,

*"One day at hospital there was a person who said: 'If an elderly person is sick, let him die to give chance to others'. He said it in public. I heard that and I said, 'An elder person is someone who is worthless, he deserves to die and no one cares about him'."*

## 5.6 The role of social networks and refugee-led organisations

### 5.6.1 Social networks

Although refugee groups are exposed to the same infrastructural deficits and environmental hazards as others living in low-income areas, newly arrived refugees in particular do not have the social networks that can help them navigate better access or support during times of protracted poverty, hardship and/or ill health. As a Burundian refugee who participated in the chronic disease focus group explained, 'Ugandans have their properties and have friends and relatives here. Even if they have problems, they get rescue easily from neighbours. But as refugees, none can care for us'.

Some Somali refugees received some financial help from family overseas, but generally refugees explained how they had limited social capital in the city. They are less trusted than Ugandans, and often thought to be responsible for issues such as poor sanitation conditions. In this context, they are more vulnerable to more expensive basic services and sudden eviction, particularly if they rely on informal landlords and basic services.

*"If refugees delay to pay rent, he is chased out and hasn't where to go. [Landlords] then increase the rent but the citizen doesn't care because neighbour could host him. About electricity, refugees are paying 20,000 shillings per month while Ugandans are paying 10,000 shillings."*

Burundian refugee and participant in chronic illness focus group discussion

### 5.6.2 Refugee-led organisations

During our research, the practical and strategic benefits of refugee-led organisations became increasingly apparent. Refugees have organised diverse groups around a range of themes. These include savings groups (given the challenges that refugees face in obtaining a bank account), faith groups and even networks of small businesses. These organisations offer practical support for refugees who are finding their way in the city, to improve their living conditions and livelihoods. Support provided ranges from how to access the formal services that are available to refugees in the city (such as the translation described earlier) as well as more informal support and welfare. As one Somali refugee explained,

*"I don't receive any support from anywhere, either [from] NGOs like InterAid, OPM or UNHCR. The only support I get is from the Somali community and our mosque."*

The support offered by local refugee-led organisations ranges from informal fundraising for recently bereaved families to cover funeral costs, to a women-led group established in the South Sudanese refugee community known as *Akon Buoi*, which provides welfare to members during times of particular hardship.

The depth and reach of these organisations often reflect the amount of time that refugees from a given context have been in the city, and the size of the community. Over time and with a growing presence in the city, refugee networks and informal institutions evolve to provide mutual support and assistance such as interpretation services, help in understanding refugees' basic rights, accessing medical care, housing and basic services, and help finding work. Given that

refugees tend to be scattered across the city, smaller groups of refugees with weaker social networks such as recently arrived South Sudanese refugees can have a more challenging time than established groups like the Congolese, who have a long history and extensive networks across the city.

Another issue is that little attention has been paid to the implications of having refugees from opposing sides of the same conflict arrive in the same city at the same time, for example Burundians. The funding from the British Academy's Cities and Infrastructure which was used to support our research was the first opportunity that Congolese, South Sudanese, Somali and Burundian refugees have worked together and shared reflection on how refugees access basic services including healthcare, water and sanitation in the city. There is an increasing appetite for more collaboration and interaction, as refugees recognise the potential and agency in networks that can reflect on the lived experiences and collective needs of displaced populations in the city.

The Kampala project has led to new opportunities for YARID to engage in practical research on the needs of refugees in the city. As a next step, YARID and the refugee researchers are undertaking additional research with the World Bank on how refugees access basic services in Kampala. Based on the success of this project, and the longstanding work of similar initiatives, YARID are now exploring how data collection can support their practical and strategic objectives in the city. Gathering data on access to services enables communities to understand the realities of service provision in the city, monitor the effectiveness of interventions designed to support refugees, and thus prioritise their specific needs in relation to city-level authorities and international agencies. This is pertinent to wider debates around how and to what extent refugees are able to access existing basic services. The refugees who were interviewed expressed the wish to be inconspicuous in the city and said they would prefer not to receive 'different' services to host populations. Challenges remain in terms of how to build a system that serves all, including the most marginalised. This will require new kinds of cooperation between agencies, service providers and city authorities, with meaningful participation from low-income groups and refugees.

## 6

# Conclusions and future research agendas

Despite Uganda's progressive refugee policies, many refugees continue to face obstacles in accessing health services in Kampala. Furthermore, newly arrived refugees often end up in informal settlements, and there are specific social determinants of health and physical hazards that disproportionately affect them. And while refugees are as susceptible to similar diseases and poor nutrition as other low-income urban residents, the barriers to healthcare described here often exacerbate vulnerabilities linked to age and gender.

State responses to these barriers suggest that the basic needs and experiences of refugees in urban areas are poorly understood. Moreover, the lack of institutional clarity around the different roles and responsibilities of national, municipal and humanitarian organisations tends to impede the effectiveness of the responses and services available. Despite challenges linked to registration and inadequate resources, some municipal authorities have been more responsive to the needs of refugees than national government, as demonstrated by the mayor of Koboko. Refugee-led and faith-based organisations are working hard to fill the gaps in service provision, often taking up formal and informal roles as health workers, translators and welfare providers. They also facilitate access to and navigation of policies and associated services, and, as demonstrated in this paper, are starting to gather data on the specific needs of refugees to highlight the specific needs of refugees in cities. These networks continue to be a vital resource for refugees who are looking to secure housing, access services and build livelihoods in the city. More could be done to integrate intersecting formal and informal

initiatives into broader planning processes at national and municipal levels. This could include employing health extension workers and refugee translators, thus bringing them under the remit of the KCCA or the Ministry of Health.

To improve access to healthcare housing and basic services, national governments need to recognise that municipal authorities require improved resources and decision-making powers. Meanwhile, humanitarian responses to refugees need to be harmonised with urban planning process. In Uganda, this might involve the promotion of area-based approaches and OPM and UNHCR facilitating the registration of refugee status and access to healthcare in towns and cities. It could also involve the development of a much-discussed urban refugee policy, that recognises the roles of municipal authorities with improved coordination amongst local actors including local grassroots organisations.

The audience for research on urban refugees should not be purely aimed at improving humanitarian programming, or feeding into national-level policy forums. Moving away from a humanitarian mindset and focusing on displaced people's organisations and their relationships with service providers and municipal authorities would help to reconceptualise urban refugees, IDPs and vulnerable migrants as local citizens. From this perspective, the idea of the right to the city for the urban displaced (Saliba and Beluer 2017) could provide a useful framing for local responses to the needs of urban refugees and IDPs.

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Uganda has a progressive national refugee policy that provides freedom of movement and the right to work, own land and access basic services in urban centres. However, refugees experience a number of barriers to realising these rights in practice, including hidden costs, language gaps, discrimination and institutional incapacity. This working paper examines how refugees access healthcare services in the Ugandan capital of Kampala, the barriers to access, and the impact of these barriers on refugee wellbeing. Making use of an innovative refugee-led methodology, it demonstrates the ways in which refugees themselves are extending healthcare systems in the city through the training and provision of translators and community health officers. Nevertheless, there remain significant gaps in service provision which require government and humanitarian agencies to work much more closely with refugee communities if these gaps are to be overcome.

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