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The human right to health, inclusion and essential health care packages in low income countries: “health for all” in Malawi

Jean Grugel, Sarah C. Masefield and Alan Msosa

Abstract

Purpose – Health in low-income countries has become associated with the provision of minimum guaranteed public health services through Essential Health Packages (EHPs). How far do EHPs deliver the human right to health for all? This study addresses this question through qualitative research into access to health care for vulnerable communities, using Malawi as a case study. This study shows that there are significant accountability gaps and perceptions of weak service provision in Malawi's EHP in relation to some particularly marginalised (and stigmatised) groups that limit the right to health and the promise of “health for all”.

Design/methodology/approach – This study extends the body of qualitative work on EHPs in general and on Malawi in particular by exploring the perceptions of key stakeholders in relation to inclusivity and the delivery of health policies to particularly vulnerable groups. To do so, this study adopted an approach based on interpretive epistemologies (Scott, 2014). This study conducted largely unstructured interviews with a range of health stakeholders, speaking to stakeholders individually, rather than through focus groups due to the potentially sensitive nature of the topic.

Findings – The findings of this study are as follows: limited inclusion of civil society actors and local communities; local communities and local policymakers feel frustration with the gap between the promises of consultation in the EHP and the reality, and the difficulties of not having effective channels of communication; and exclusionary health practices for particularly vulnerable groups.

Research limitations/implications – There are limitations based on the qualitative methodology, and in terms of the particularly vulnerable groups – the authors studied two such groups (people with disabilities and those who identify as LGBTQ) but a wider survey of vulnerable groups is needed to extend and confirm the findings.

Practical implications – Greater attention to the health rights of vulnerable groups would improve access and services, even in the context of resource restrictions. This study suggests that a deeper engagement with human rights-based approaches would pay dividends in terms of increasing access to health in Malawi, even within the constraints of the EHP process. Furthermore, without this, there is the risk that discrimination and exclusion will become more embedded in health policies, rather than progressively minimised.

Social implications – Without addressing these issues, there is the risk that discrimination and exclusion will become more embedded in health policies, rather than progressively minimised.

Originality/value – This paper makes an important contribution to the growing literatures on EHP in sub-Saharan Africa and Malawi in particular and to the importance of listening to stakeholder perceptions. It provides original data on stakeholder perspectives of the challenges associated with universalising health care in resource-constrained countries. To the best of the authors' knowledge, it is one of the first papers to focus on the rights of disabled and LGBTQ people in relation to EHPs.

Keywords Malawi, Health for all, Human rights, The human right to health, Accountability, Vulnerability, Inclusion, Civil society, Sexual orientation, Disability

Paper type Research paper

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Introduction

Health is an essential condition for equitable, sustainable and human rights-based development. The Sustainable Development Goals (SDGs), the basis for global

development policies 2015–2030, include the promotion of policies to ensure healthy lives for all (SDG 3). Yet the critical task of delivering everyday health services for the most vulnerable still remains a major health and development challenge, especially in low-income countries.

The delivery of everyday health care in low-income settings has become associated with the provision of a basket of affordable and minimum guaranteed public health services, often referred to as Essential Health Packages (EHPs). [Mueller *et al.* \(2011\)](#) describe EHPs as provisions that “direct resources to interventions that aim to address the local burden of disease and be cost effective”. Another way of understanding everyday health care is through the lens of human rights. As [Mason Meier *et al.* \(2018, p. 85\)](#) note, “a rights-based approach transforms the power dynamic that underlies public health. Rather than passive recipients of governmental benevolence, individuals are recognized as rights-holders, with human rights imposing corresponding obligations on governmental duty-bearers”. Can the human right to health approach serve as a support for EHPs and help to enable better and more inclusive minimum health services? This question resonates particularly in settings where health systems are weak and deficient in resources and where vulnerable groups have traditionally found their health needs ignored.

Our research makes two key contributions to this important debate, using Malawi as a case study. First, it explores perceptions of limited inclusion in EHPs by a range of stakeholders and service users. Secondly, it identifies accountability gaps and perceptions of service provision omissions on the part of some particularly marginalised (and stigmatised) groups, namely, persons with disability and sexual minorities. It therefore contributes to the expanding literature on EHPs and health provision in Malawi, and low-income settings more widely, by taking a qualitative approach to focus on the perspectives of stakeholders, communities and marginal groups, in contrast to the mainstream body of research on EHPs that has tended to be “technocratic [and] top-down” ([Abihiro *et al.*, 2014](#)).

Background

The right to health forms part of the backbone of the SDGs and it is set out in articles 25(1) of the Universal Declaration of Human Rights and 12(1) of the International Covenant on Economic, Social and Cultural Rights. [London \(2008, p. 65\)](#) suggests that taking a human rights approach to health care would promote the agency of those vulnerable to rights violations and establish greater accountability for health expenditure. [Farmer \(1999, p. 1487\)](#) asserts that “public health and access to medical care are social and economic rights; they are every bit as critical as civil rights”. A rights-based approach to health policy has the potential to address not only health violations rooted in social and economic inequalities but also the discrimination that some particularly vulnerable groups experience in relation to health policies and implementation ([Bowleg, 2012](#)). However, delivering an expansive programme of health for all based on the human right to health is expensive and demands a fine-grained understanding of what policies are needed for different groups. For these reasons, rights frameworks can sometimes be seen as idealistic or impractical, in contrast to utilitarian public health frameworks, or data-driven interventions intended to produce the best outcome for the majority of the population from the resources available at the time.

Advocates of human rights approaches acknowledge that human rights of any sort, including those to health, are not easy to translate into deliverable policies ([Hunt, 2016](#)). Doing so is especially challenging in conditions of resource constraints. This is one reason why [Alston \(2005, p. 755\)](#) notes that discourses of human rights and “realistic” development targets, including in health, have frequently been “ships passing in the night”, rather than allies. Even “work on the social determinants of health has rarely acknowledged the potential contributions of a human rights approach” ([Chapman, 2010, p. 17](#)). Yet, without also endorsing a concept of the right to health, public health provision, and EHPs in

particular, may be rendered less effective because they do not tackle the injustices that give rise to health inequalities. If EHPs are simply layered onto social systems “based on privilege and oppression” (Bowleg, 2012, p. 1267) they risk being less inclusive than intended. For this reason, the World Health Organisation (WHO) advocates the adoption of both the right to health, which is acknowledged in its 1946 constitution, and targeted interventions based on the reality of resource constraints (WHO, 2017).

The practical challenges of providing equitable health systems when budgets are restricted was recognised in 1993 in the World Development Report *Investing in Health*, which set out the need for low- and middle-income countries to identify minimum, state-guaranteed health services. EHPs have since become the main vehicle for governments in low- and middle-income countries to decide on the most effective forms of health service provision and planning provision, in the context of resource constraints, inadequate funding and a political economic context of growing marketization of health provision. Diverse models of EHPs had been adopted in at least 64 low- and middle-income countries by 2012, containing an “essential package” of core services guaranteed for all, based on a “realistic” assessment of what public resources will stretch to and the services it makes most sense for the state to “buy” (Ochalek *et al.*, 2018, p. 1).

The WHO recommends that EHPs should not be merely “technical” exercises. Instead, they should be open to input from stakeholders and civil society in relation to their “purpose and design” and adapt to changing circumstances (WHO, 2008). Human rights organisations have called for this to mean the introduction of better monitoring of health policies, more inclusive policies and greater public accountability of the EHP process to nudge EHPs along their intended goal of supporting more effective inclusive and rights-based interventions (London, 2003; Chapman *et al.*, 2018).

Methods

We have chosen to focus on the EHP in Malawi because, as the country with the lowest income per capita in the world (Mzale, 2015), it exemplifies the challenges faced by low-income countries including inadequate health funding, weak health systems, an acute burden of disease and structural inequalities that leaves the majority of its (mainly rural) population unable to afford private health care (IMF, 2017; World Bank, 2018). At US\$39.2, Malawi’s per capita spending on health is significantly lower than the sub-Saharan Africa average of US\$98 (Chansa *et al.*, 2018). It has a high rate of AIDS/HIV and tuberculosis infections, the highest maternal mortality rate in Africa (WHO, 2018) very high rates of cervical cancer (Msyamboza *et al.*, 2012) and a rising rate of non-communicable diseases (with 33% of adults aged 25–64 suffering from hypertension, for example) (Gowshall and Taylor-Robinson, 2018).

There is now considerable research on Malawi’s EHP (WHO, 2008; Chansa *et al.*, 2018; Carlson *et al.*, 2015; Maseko *et al.*, 2015). Researchers such as Abihiro *et al.* (2014) have noted this mainly quantitative research needs to be complemented by qualitative studies to better understand the experiences of communities, the range of local needs and coverage gaps. Walsh *et al.* (2019, p. 1572) used qualitative methods to explore disagreements between actors over the EHP package that “raised questions regarding [...] the inclusivity of health policy processes”. We build on this research and, additionally, address the need for studies on how far the health needs of particularly vulnerable groups are addressed, or perceived to be addressed, through EHPs.

Our study thus extends the body of qualitative work on EHPs by exploring the perceptions of key stakeholders in relation to inclusivity and the delivery of health policies to particularly vulnerable groups. To do so, we adopted an approach based on interpretive epistemologies (Scott, 2014). We conducted largely unstructured interviews with a range of health stakeholders, speaking to stakeholders individually, rather than through focus groups

due to the potentially sensitive nature of the topic, especially when some stakeholders we interviewed work closely with the government. This also allowed us to be certain that when stakeholders identified concerns, they were expressing their own opinions and not being led by the reflections of others.

We used a purposive sampling strategy to reach health stakeholders working in decision-making or regulatory roles in the government-funded health system or who have advocated for change in the health sector at the government level. They were identified via a mapping exercise and invited to interview. Using their local and specialist knowledge from conducting health research in low-income countries and in Malawi, the authors (specifically, A.M.) and Thanzi la Onse project partners in the College of Medicine at the University of Malawi identified government and non-government institutions providing health services or performing health-care governance activities located in Malawi. This was supplemented by electronic searches of health sector websites and registries (such as the register of the Council of Non-Governmental Organisations and delegate lists from health conferences and workshops) and searching health-related newspaper articles in *The Nation* and *The Times*. Key individuals ($n = 22$) within these institutions and located in Lilongwe and Blantyre were identified. These urban locations were selected for logistical reasons and due to limited resources.

We conducted 22 face-to-face interviews in a private space in the participants' place of work, the preferred location of all participants. Everyone approached for interview consented to participate. The sample consisted of representatives from the following organisation types: international non-government organisations (NGOs) ($n = 3$); faith-based NGOs ($n = 2$); civil society organisations (CSOs) ($n = 9$); local government and government-funded organisations ($n = 6$); and governance bodies ($n = 2$). In the research, we explored the perceptions of a range of civil society actors engaged directly with citizens, community groups and civil rights movements/projects, as well as rural and urban, government and central and district level representatives as, due to decentralisation, the Blantyre and Lilongwe District Health Offices are not part of central government or the referral health system.

In the interviews, open questions were asked to capture each person/organisation's experience and perception of the functioning of the health system, health-care decision-making in Malawi and the experiences of vulnerable groups in terms of access to services and provision for their health needs. Guiding questions were set by A.M. and J.G. and reviewed by the relevant ethics committees. Given the diverse stakeholders, the detail of questions varied in each interview. Ethical approval for the study was received from both the University of York (6 July 2018) and from the College of Medicine in the University of Malawi (16 October 2018). Interviews were conducted by A.M. in a combination of English and Chichewa between December 2018 and February 2019. The interviews lasted between 45 min and 1.5 h.

Each interviewee was informed as to the purpose of the research and given an information sheet before giving signed consent to participate in the interview study. Six consented to audio recording via dictaphone. The remainder ($n = 16$; 72.3%) consented to field notes with the possibility of citing direct quotations but not audio or video recording as they wanted to speak freely and without concern for government (or employer/colleague) reprisal. Guidelines for making field notes and their integration with study data were followed (Phillippi and Lauderdale, 2018). The verbatim transcribed recordings and field notes (with direct quotations) for the non-recorded interviews comprise the transcripts used in the analysis. Due to the potentially politically sensitive nature of the content, every effort has been made to anonymise the individual participants in the reporting of this research. Attribution is made by type of organisation and participant number only.

Interviews were complemented by a focus group discussion involving government officials and civil society leaders. We included local government (district and city level) representatives in the focus group discussion as, due to decentralisation, the Blantyre and Lilongwe District Health Offices are not part of central government or the referral health system, and therefore, like other non-government stakeholders, they see their role as encompassing advocacy for the health needs of their populations to be included in national health policies and implementation. Similarly, the National HIV/AIDs Commission was included as they are (largely) independent of the government and cooperate with NGOs, CSOs and health-care providers at the local level and advocate for the needs of communities who, are not always visible at the government level. All focus group discussions were also anonymised as most of the participants asked to speak without being named.

This paper is the final output in a series using this rich qualitative data to explore perceptions of stakeholder engagement in different elements of health care decision-making in Malawi (Masefield *et al.*, 2020, 2021). In this paper, we focus in particular issues of accountability and inclusion in EHP decision-making and on the perceptions of civil society groups from disabled advocacy groups and LGBTI representatives who seek to engage with the EHP. These groups were selected because of the very considerable social and cultural barriers in accessing health services due to issues of stigma and shame. They serve, therefore, as a good test of how far the EHP is inclusive of marginal and stigmatised communities.

Results

Limited inclusion and lack of accountability to stakeholders over the Essential Health Package

The EHP in Malawi was one of several adopted across East and Southern Africa in the early 2000s. In line with other EHPs, Malawi's package seeks to direct resources towards addressing the local burden of disease through the lens of cost effectiveness. Its focus was on tackling infectious diseases such as tuberculosis and HIV/AIDS, maternal and infant mortality, common injuries and nutritional deficiencies (Mueller *et al.*, 2011). The current EHP, which runs to 2022, was updated in 2011 to cover 11 categories, namely, reproductive, maternal, neonatal and child health; vaccine and preventable diseases; malaria; integrated management of childhood diseases; community health; neglected tropical diseases; HIV and AIDS; nutrition; tuberculosis; non-communicable diseases; and oral health (Government of Malawi, 2017). Preselected interventions are guaranteed, at least in principle, free of charge in all public and government sub-contracted health facilities (Government of Malawi, 2017). To deliver these services, the EHP coincided with significant increases in Malawi's health budget. With support from key donors, health expenditure increased from US\$168m in 2002 to US\$632m in 2012 (Ochalek *et al.*, 2018).

Analyses of Malawi's EHP have often been critical. Budgets do not meet demand, there are failures of implementation, staff training is inadequate, working conditions are poor and there is a lack of clarity over which tier or facility of the health system is responsible for delivery of particular services (Mueller *et al.*, 2011). Local health centres regularly run out of essential medicines. "Stock-outs", as they are known, are common (Oxfam, 2010). Wild and Cammack (2013, p. 1) note that "on average 75% of facilities are thought to have experienced significant drugs stock-outs in recent years". This leaves patients effectively having to pay, if they can, to source basic medicines. There are also wider issues with funding that mean that many basic services are not provided. Funding challenges intensified after 2013, when a corruption scandal known as "cashgate" led to donors moving away from supporting government health services in favour of directly running services of their own. In short, the EHP has tended to promise significantly more than could be delivered given the budget, while the Ministry of Health itself acknowledges: "the cost continues to outstrip resources" (Ochalek *et al.*, 2018). This translates on the ground into a

situation whereby “the new EHP cannot provide services to the entire population in need” (Interview with a District Health Officer, Malawi, December 2018).

In interviews, stakeholders linked the funding challenges to limited inclusion of civil society and lack of accountability for health spending. The limitations in terms of inclusion in Malawi’s EHP have been acknowledged (Todd *et al.*, 2016). Many civil society actors we spoke to were extremely critical of health consultation processes for this reason. One interviewee from the district level noted:

Maybe we were only consulted 20% and by the time we were consulted, the process was already at an advanced stage and there was little room to make changes on the issues and content [...]. Ministry of Health consultation are more of a window dressing to show the nation that they have consulted with different stakeholders before adopting a national document, but there isn’t much room for external stakeholders (outside the ministry) to influence the process. (Interview with a District Health Officer Southern region of Malawi, December 2018)

Local communities and local policymakers felt intense frustration with the gap between the promises of consultation in the EHP and the reality, and the difficulties of not having effective channels through which to communicate their needs. One told us:

[...] the EHP is [...] all about politics, but little to do with bringing change to better the lives of the poor Malawian. Whatever the case, what Malawi is promising in the policy and strategy in terms of the EHP, it cannot sustain due to domestic funding constraints. (Interview with a Member of Parliament and Member of Health Governance Committee, Malawi, December 2018)

Stakeholders perceived that their complaints about the budget, services, the availability of drugs and services and the implementation of agreed programmes went unheard.

Moreover, many service providers shared their view that policies were not sufficiently inclusive. District health officers, whose job is to align centrally set budget with district- and community-level health needs, complained in interviews they were often left with no choice but to ignore important health needs, with budget cuts that directly affected essential service provision almost the norm:

Revising budgets downwards is not my favourite moment because it is the time everyone is under huge pressure. We just close our eyes and slash, maybe 20% cuts across the board. (Interview with a District Health Officer in the Central Region, Malawi, January 2019)

Another district health officer claimed that:

There are drug shortages in the district health facilities [...] when there are drug shortages in the hospitals or health centres, the cost is pushed to the patients. The patients have to find money and buy medicines which they have been prescribed. (Interview with a District Health Officer in the Central Region of Malawi, January 2019)

According to Anders and Chirwa (2018), some of these problems reflect the “under-utilization and misuse of resources”, in Malawi’s health sector, with up to a third of the drug budget misappropriated. Stakeholders perceived misspending to be partly the result of the fact that government as indifferent to their efforts to hold government to account for budgets and spending. One said:

Malawi has organisations advocating for health rights e.g. Malawi Human Rights Commission, Centre for Human Rights and Rehabilitation, Centre for Development of People, Women in Law Association, and Malawi Law Society. Malawi Human Rights Commission has done some studies on access to health, but their recommendations have not been implemented by government. The recommendations have not been treated with the urgency and importance which they deserve. (Interview with a District Health Officer in the Central Region of Malawi, January 2019)

Concerns were also voiced that the EHP only determined expenditure for health centres dependent on public funds: donors and international organisations in Malawi allocated their

budgets according to their own priorities, leading to a focus on some aspects of health provision at the expense of other areas:

Most of them [donors] do not follow the essential health package and district plans [...] the external stakeholders, especially the international organisations, do not follow the national plans (e.g. the National Health Policy, health strategic plan, or any other policy). They do not follow the requirements of the Essential Health Package. This because they have their own resources and have control over how it is spent. (Interview with a District Health Officer in the Southern Region, Malawi, December 2018)

Limited inclusion: health services for particularly vulnerable groups

Group-based disadvantage is a significant, under-researched health challenge, especially in low- and middle-income countries (Groce *et al.*, 2011). Prejudice and bias contribute to poverty, stigma and marginalisation that intensify health problems and can make health care systems unwelcoming and unresponsive to group-based needs. Yet if “health for all” EHPs are to be successful, it is critical to address the health needs of the most vulnerable groups who experience group-based disadvantage. To explore how far Malawi’s EHP is successful in reaching particularly disadvantaged groups and responding adequately to their health needs, we examined the perceptions of civil society representatives and activists from two particularly vulnerable groups in Malawi, namely people with disabilities and those who identify as LBTQI. To summarise the findings, both groups viewed the EHP as doing little or nothing to address their health needs. Interviewees interpreted these failings to be a result of the fact that budgets are not set aside for their needs, the weight of stigma and the absence of a joined-up strategy to address the structural disadvantages that underpin the poor health experienced by both communities.

The rights of disabled people and the essential health packages

To provide effective health provision for disabled people, providers need to challenge stigma as well as providing services (Hellum Braathen *et al.*, 2015). In Malawi, disability is still sometimes understood as a consequence of bad luck and even witchcraft. These prejudices generate shame and have sometimes led to or justified violence against disabled people. Even medical professionals sometimes view disability as an illness, and frequently promote a medicalised model of disability, that differentiates disabled people *en masse* from those without disabilities (Hellum Braathen *et al.*, 2015, p. 1388). The quotidian health needs of albinos, for example, sunscreen for protection from sunburn and skin cancer referred to above, and treatment for visual impairment (which is associated with albinism) frequently go unmet especially in rural communities (Interview with a representative of the Movement of Persons with Albinism, Malawi, January 2019).

In addition to stigma and prejudice, the absence of up-to-date and comprehensive data stands in the way of delivering effective health policies for Malawi’s disabled communities. Disabled people are frequently “statistically invisible” (UNDESA, 2020, p. 39) so the starting point for any effective health services that address the rights of disabled people is to understand the scale and nature of how disability manifests (Grugel and Ruggirozzi, 2018). The Malawian state has been duty-bound to gather this data since the 2012 Disability Act, as part of its commitment to providing persons with disabilities with appropriate health care services, including prevention, early identification, intervention and other services designed to minimise and prevent occurrence of additional or greater disability.

Both gathering data on disability and countering stigma effectively require the involvement of relevant stakeholders. Our interviews revealed that disability stakeholders currently do not feel their voices are sufficiently heard in health policymaking. One reported:

Disability issues are considered as an after-thought. Sometimes [disability organisations] are asked to give input as an afterthought, and some issues are taken aboard while some are not. But the key health issues [...] are: affordability of health services (disabled people should be able to afford to reach and access health services), availability of health services, and accessibility of health facilities. (Interview with representative of a disability organisation, Malawi, December 2018)

Another noted that limited engagement only happened after donors encouraged the government to organise consultations:

On Malawi Growth and Development Strategies (which was donor funded), initially [disability organisations] were not included in consultations but eventually they were sneaked in after some stakeholders needed to see persons with disabilities at the table. (Interview with representative of a disability organisation, Malawi, December 2018)

One area of particular concern that emerged in interviews was the gap between EHP provision and services and the health needs of Malawi's sizeable albino population, comprising approximately 134,636 people or 0.8% of the population. People with albinism in Malawi are subject to social exclusion and even violence, including ritualistic attacks, violence and murder. Women with albinism can be particularly vulnerable to rape and sexual abuse ([Amnesty International, 2016](#)). One civil society representative told us:

[...] because of stigma and superstition, [people with albinism] are not taken to the hospital [with skin cancers] as a clinical issue, rather they are taken to traditional practitioners thinking that they have been bewitched. Yet we know it's just the sun or sun damage. Traditionally, locally they feel like they have been bewitched. It turns out to be skin cancer but by the time they go to the hospital its terminal. (Interview with the Country Director of an NGO for people with albinism. Malawi, January 2019)

The scale of violence in recent years has resulted in government declaring the protection of rights of persons with albinism a priority ([African Union, 2021](#)). The government was criticised by a commission for failing to investigate ritual killings of albino people headed by retired Supreme Court judge Robert Chinangwa in 2019 (The Guardian, Nigeria, 8 March 2019). But interviewees did not perceive that this growing political recognition is, as yet, informing health policymaking.

The essential health packages and the rights of LGBTQI people

The delivery, even the recognition, of the health needs of people who engage in "same-sex intimacies" has proven extremely challenging in Malawi where "the local narrative remains dominated by the view that homosexuality is alien [...] and an import from the West [...]. Most Malawians believed that there was a historical period, not so long ago, when homosexuality did not exist in Malawian societies" ([Msosa, 2018](#), p. 65). Homosexuality is treated as a form of mental illness and laws remain in place from the colonial era that penalise sexual difference ([Msosa, 2018](#)). This context makes it difficult to assert the health rights of LGBTQI people and for the EHP to deliver AIDS/HIV treatment (which is included in it) to homosexual men, whose health needs incite little sympathy within the wider Malawian community. In interviews, NGO representatives complained that "LGBTI persons would not normally be welcome" in the health system (Interview with the Executive Director of an LGBT civil society organisation Malawi, December 2018).

Malawi's first national HIV Policy, set out in 2003, recognised that men who engage in same-sex relations are highly vulnerable to HIV infection and therefore needed to be included in the HIV and AIDS response. A 2010 nationwide HIV prevalence study found that men who have sex with men had an HIV prevalence that was twice the national average ([Beyrer et al., 2010](#)). The EHP identifies AIDS is a priority for health funding and sexual minorities fall under *Category 7* of the EHP (HIV/AIDS) which includes access to HIV testing services and

HIV treatment for all ages. Yet health services are not effectively delivered to homosexual men for a range of reasons. In the first place, the anti-gay laws that remain in operation and social attitudes, stigma and discrimination, including in public health facilities, go unchallenged and mean that many people in need of treatment do not come forward for it (Cox, 2014; Baral *et al.*, 2009; Fay *et al.*, 2011). As a result, HIV/AIDS treatments for men who have sex with men tend to be met in donor facilities such as the Bill and Melinda Gates Foundation and the AIDS Vaccine Advocacy Coalition (Interview with a paralegal of a human rights NGO Malawi, December 2018).

Lesbian women may have even less access to HIV/AIDS health support because of stigma and the threat of gender-based violence that they experience (Interview with the Executive Director of an LGBT civil society organisation, Malawi, December 2018). For non-binary and inter-sex people, meanwhile, inclusion in the health system is even more problematic. In interviews, civil society stakeholders claimed hospital officials lacked knowledge of the health issues inter-sex people experience. They added:

One issue that is of concern [...] is the 'corrective' surgery of intersex babies upon birth or early childhood (Interview with the Director of LGBTI civil society organisation (Malawi, December 2018). And for transgender people, there is no provision for 'effective gender-affirming health services for transgender persons (for example...), including provision of hormones' and inadequate information about the process and options of access to treatment including information about the option of referrals abroad'. (Interview with spokesperson of LGBTI civil society organisation, Malawi, December 2018)

Conclusion

In the context of limited resources for health, setting out priority areas for funding and services that are available to all, independent of income, in the way Malawi's EHP does, is, clearly, an important step in the right direction. But it is also important that those priority areas are agreed in consultation with society and are inclusive of the rights and needs of particularly vulnerable groups. Our research shows that there are major lacunae in terms of the consultation and inclusion process associated with Malawi's EHP and many stakeholders felt that their voices were not sufficiently heard. We also show that some particularly vulnerable groups who experience group-based disadvantage perceived their health needs to go systematically unmet under the current EHP. Stakeholders we interviewed identified serious limitations in terms of access to health for people with disabilities and LGBTI people. Stigma and prejudice, as well as the limitations of EHP policies, prevented both communities from accessing health services and receiving life-saving health treatments. Stakeholders felt that that Malawi's EHP did not deliver minimum health services for both of these communities, despite an endorsement of human rights approaches to health on the part of the government and a discursive commitment to inclusion in health policy.

It is understandable that policymakers everywhere are generally wary of putting themselves under pressure to widen the scope of already-stretched services and frequently seek to keep the input of some civil society groups to what they understand as a "manageable" level as a result. Nevertheless, this approach tends to reduce opportunities for policy makers to benefit from expert advice from groups that are knowledgeable about health needs on the ground, as well as leaving vulnerable groups feeling that their health needs do not count. It can lead to missed opportunities to mobilise joint efforts by government and civil society organisations to challenge the stigma that contributes to poor health outcomes for vulnerable communities. Instead, sustained dialogue between public health officials and representatives of vulnerable groups, many of whom deploy human rights claims in their advocacy for better services, might better enable governments to address "the pathologies of power" (Farmer, 1999) that lead to poor public health outcomes. Closer attention to the voices of civil society actors and other stakeholders would also be in line with the recommendation of UNDESA (2020) which calls on governments urgently to address

discrimination and inequalities across the policy spectrum, including health. Our research shows, in Malawi, that these organised stakeholders stand ready to contribute to improving inclusion and access to health of the most vulnerable as part of the EHP process.

References

- Abihiro, G.A., Mbera, G.B. and De Allegri, M. (2014), "Gaps in universal health coverage in Malawi: a qualitative study in rural communities", *BMC Health Services Research*, Vol. 14 No. 1, doi: [10.1186/1472-6963-14-234](https://doi.org/10.1186/1472-6963-14-234).
- African Union (2021), "Report: regional action plan on ending attacks and human rights violations against persons with albinism in Africa (2017-2021)", available at: www.ohchr.org/Documents/Issues/Albinism/RAP_Report_01-07_21_EN.pdf
- Alston, P. (2005), "Ships passing in the night: the current state of the human rights and development debate seen through the lens of the millennium development goals", *Human Rights Quarterly*, Vol. 27 No. 3, pp. 755-829.
- Amnesty International (2016), "We are not animals to be hunted or sold" violence and discrimination against people with albinism in Malawi", available at: www.amnesty.org.uk/files/we_are_not_animals_-_malawi_report_-_final_formated.pdf
- Anders, G. and Chirwa, C.W. (2018), "The importance of practical norms in government health and education services in Malawi", available at: <https://ace.globalintegrity.org/wp-content/uploads/2019/09/Practical-norms-Malawi.pdf>
- Baral, S., Trapence, G., Motimedi, F., Umar, E., Ipinge, S., Dausab, F. and Beyrer, C. (2009), "HIV prevalence, risks for HIV infection, and human rights among men who have sex with men (MSM) in Malawi, Namibia, and Botswana", *PLoS ONE*, Vol. 4 No. 3, doi: [10.1371/journal.pone.0004997](https://doi.org/10.1371/journal.pone.0004997).
- Beyrer, C., Trapence, G., Motimedi, F., Umar, E., Ipinge, S., Deausab, F. and Baral, S. (2010), "Bisexual concurrency, bisexual partnerships, and HIV among Southern African men who have sex with men", *Sexually Transmitted Infections*, Vol. 86 No. 4, pp. 323-327, doi: [10.1136/sti.2009.040162](https://doi.org/10.1136/sti.2009.040162).
- Bowleg, L. (2012), "The problem with the phrase women and minorities: intersectionality – an important theoretical framework for public health", *American Journal of Public Health*, Vol. 102 No. 7, pp. 1267-1273.
- Carlson, C., Chirwa, C.W., Hall, N. and Cammack, D. (2015), "Study of health sector efficiency in Malawi", available at: www.academia.edu/23732303/Study_of_Health_Sector_Efficiency_in_Malawi
- Chansa, C.T., Mwase, T.C., Matsebula, P., Kandoole, P., Revill, J.B., Makumba, M. and Lindelow, (2018), "Fresh money for health? The (false?) promise of "innovative financing" for health in Malawi", *Health Systems & Reform*, Vol. 4 No. 4, pp. 324-335.
- Chapman, A.R. (2010), "The social determinants of health, health equity, and human rights", *Health and Human Rights Journal*, Vol. 12 No. 2, pp. 17-30.
- Chapman, A.R., Forman, L., Lamprea, E. and Khanna, K. (2018), "Identifying the components of a core health services package from a human rights perspective to inform progress toward universal health coverage", *Human Rights Quarterly*, Vol. 40 No. 2, pp. 342-368.
- Cox, N. (2014), "Human rights, sexual orientation and gender identity in the commonwealth: struggles for decriminalisation and change", *The Round Table*, Vol. 103 No. 1, pp. 128-130.
- Farmer, P. (1999), "Pathologies of power: rethinking health and human rights", *American Journal of Public Health*, Vol. 89 No. 10, pp. 1486-1496.
- Fay, H., Baral, S.D., Trapence, G., Motimedi, F., Umar, E., Ipinge, S., Dausab, F., Wirtz, A. and Beyrer, C. (2011), "Stigma, health care access, and HIV knowledge among men who have sex with men in Malawi, Namibia, and Botswana", *AIDS and Behavior*, Vol. 15 No. 6, pp. 1088-1097.
- Government of Malawi (2017), "Health sector strategic plan II (2017-2022)", available at: www.healthdatacollaborative.org/fileadmin/uploads/hdc/Documents/Country_documents/HSSP_II_Final_HQ_complete_file.pdf
- Gowshall, M. and Taylor-Robinson, D. S (2018), "The increasing prevalence of non-communicable diseases in low-middle income countries: the view from Malawi", *International Journal of General Medicine*, Vol. 11, pp. 255-326.

- Groce, N., Kembhavi, G., Wirz, S., Lang, R., Trani, F.J. and Kett, M. (2011), *Poverty and Disability– a Critical Review of the Literature in Low and Middle-Income Countries*, UCL. London. available at: <https://bit.ly/3dCITQ5>
- Grugel, J. and Ruggirozzi, P. (2018), "New directions in welfare: rights-based social policies in post-neoliberal Latin America", *Third World Quarterly*, Vol. 39 No. 3, pp. 527-543.
- Hellum Braathen, S., Munthali, A. and Grut, L. (2015), "Explanatory models for disability: perspectives of health providers working in Malawi", *Disability & Society*, Vol. 30 No. 9, pp. 1382-1396.
- Hunt, P. (2016), "Interpreting the international right to health in a human Rights-Based approach to health", *Health and Human Rights Journal*, Vol. 18 No. 2, pp. 109-130.
- International Monetary Fund (2017), "Malawi: economic development document", available at: www.imf.org/en/Publications/CR/Issues/2017/07/05/Malawi-Economic-Development-Documents-45037
- London, L. (2003), *Can Human Rights Serve as a Tool for Equity?*, University of Cape Town. Cape Town available at: <http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.462.552&rep=rep1&type=pdf> (accessed 11 May 2020).
- London, L. (2008), "What is a human rights based approach to health and does it matter?", *Health and Human Rights Journal*, Vol. 10 No. 1, pp. 65-80, available at: www.hhrjournal.org/2013/09/what-is-a-human-rights-based-approach-to-health-and-does-it-matter/
- Masefield, S., Msosa, A. and Grugel, J. (2020), "Challenges to effective governance in a low income healthcare system: a qualitative study of stakeholder perceptions in Malawi", *BMC Health Services Research*, Vol. 20 No. 1, p. 1142, doi: [10.1186/s12913-020-06002-x](https://doi.org/10.1186/s12913-020-06002-x).
- Masefield, S., Msosa, A., Chinuwo, F.K. and Grugel, J. (2021), "Stakeholder engagement in the health policy process in a low income country: a qualitative study of stakeholder perceptions of the challenges to effective inclusion in Malawi", *BMC Health Services Research*, Vol. 21 No. 1, doi: [10.1186/s12913-021-07016-9](https://doi.org/10.1186/s12913-021-07016-9).
- Maseko, C.F., Chirwa, L.M. and Muula, S.A. (2015), "Health systems challenges in cervical cancer prevention program in Malawi", *Global Health Action*, Vol. 8 No. 1, pp. 262-282.
- Mason Meier, B., Evans, D.P., Kavanagh, Keralis, M.J. and Armas-Cardona, G. (2018), "Human rights in public health: deepening engagement at a critical time", *Health Human Rights*, Vol. 20 No. 2, pp. 85-91, available at: www.ncbi.nlm.nih.gov/pmc/articles/PMC6293343/
- Msosa, A. (2018), "Human rights and same-sex intimacies in Malawi", PhD thesis, University of Essex, available at: <http://repository.essex.ac.uk/id/eprint/21553>
- Msyamboza, K.P., Dzamalala, C., Mdokwe, C., Kamiza, S., Lemerani, M., Dzwowela, T. and Kathyola, D. (2012), "Burden of cancer in Malawi; common types, incidence and trends: national population-based cancer registry", *BMC Research Notes*, Vol. 5 No. 1.
- Mueller, H.D., Lungu, D., Acharya, A. and Palmer, N. (2011), "Constraints to implementing the essential health package in Malawi", *PLoS One*, Vol. 6 No. 6, p. e20741, doi: [10.1371/journal.pone.0020741](https://doi.org/10.1371/journal.pone.0020741).
- Mzale, D. (2015), "Malawi has world's lowest income per person – report", available at: www.mwnation.com/malawi-has-worlds-lowest-income-per-person-report/
- Ochalek, J., Revill, P., Manthulu, G., McGuire, F., Nkhoma, D., Rollinger, A., Sculpher, M. and Claxton, K. (2018), "Supporting the development of a health benefits package in Malawi", *BMJ Global Health*, Vol. 3 No. 2, doi: [10.1136/bmjgh-2017-000607](https://doi.org/10.1136/bmjgh-2017-000607).
- Oxfam (2010), "Missing medicines in Malawi", available at: <https://oxfamlibrary.openrepository.com/bitstream/handle/10546/226732/pi-local-governance-malawi-25052012-en.pdf?sequence=1&isAllowed=y> (accessed 11th May).
- Phillippi, J. and Lauderdale, J. (2018), "A guide to field notes for qualitative research: context and conversation", *Qualitative Health Research*, Vol. 28 No. 3, pp. 381-388.
- Scott, J. (2014), *A Dictionary of Sociology*, 4th Edition. Oxford University Press, Oxford.
- Todd, G., Mamdani, M. and Loewenson, R. and Ifakara Health Institute (2016), "Literature review: essential health benefits in East and Southern Africa", available at: <https://core.ac.uk/download/pdf/77102183.pdf>
- United Nations Department of Economic and Social Affairs (2020), "Inequality in a rapidly changing world", available at: www.un.org/development/desa/dspd/wp-content/uploads/sites/22/2020/02/World-Social-Report2020-FullReport.pdf

Walsh, C.M., Mwase, T. and De Allegri, M. (2019), "How actors, processes, context and evidence influenced the development of Malawi's health sector strategic plan II", *Int J Health Plann Manag*, Vol. 35 No. 6, pp. 1571-92.

Wild, L. and Cammack, D. (2013), "The supply and distribution of essential medicines in Malawi", available at: www.odi.org/sites/odi.org.uk/files/odi-assets/publications-opinion-files/8176.pdf

World Bank (2018), "Piecing together the poverty puzzle", available at: <https://openknowledge.worldbank.org/bitstream/handle/10986/30418/211330ov.pdf>

World Health Organisation (WHO) (2008), "DRAFT technical brief no. 2 - essential health packages: what are they for? What do they change?", available at: www.who.int/healthsystems/topics/delivery/technical_brief_ehp.pdf

World Health Organisation (WHO) (2017), "Human rights and health", available at: www.who.int/news-room/fact-sheets/detail/human-rights-and-health

World Health Organisation (WHO) (2018), "Country cooperation strategy – Malawi", available at: https://apps.who.int/iris/bitstream/handle/10665/136935/ccsbrief_mwi_en.pdf;jsessionid=9DF84FCF2F0E4526FEBF8B2C5DA7ED06?sequence=1

Futher reading

African Commission on Human and Peoples' Rights (2003), "Purohit and moore v. The Gambia", available at: www.escri-net.org/caselaw/2006/purohit-and-moore-v-gambia-cited-communication-no-2412001-sixteenth-activity-report

Anderson, E.L. (2018), "African health diplomacy: obscuring power and leveraging dependency through shadow diplomacy", *International Relations*, Vol. 32 No. 2, pp. 194-217, doi: [10.1177/0047117817751595](https://doi.org/10.1177/0047117817751595).

Chirwa, D.M. (2005), "A full loaf is better than half: the constitutional protection of economic, social and cultural rights in Malawi", *Journal of African Law*, Vol. 49 No. 2, pp. 207-241.

Chirwa, D.M. (2011), *Human Rights under the Malawian Constitution*, Juta, Malawi.

Government of Malawi, National Statistical Office (2018), "Malawi population and housing census report", available at: www.nsomalawi.mw/index.php?option=com_content&view=article&id=3D226:2018-malawi-population-and-housing-census&catid=E2%80%89%3D%E2%80%89:reports%26Itemid%E2%80%89%3D%E2%80%896

UN Economic and Social Council (2000), "General comment no. 14: the right to the highest attainable standard of health (art. 12 of the covenant)", UN Committee on Economic, Social and Cultural Rights (CESCR) 2,7, 19.

United Nations (2006), "Convention on the rights of persons with disabilities and optional protocol", available at: www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

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