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Who gets to sit at the table? Interrogating the failure of participatory approaches within a right to health framework

1.0 Introduction

“As we set priorities, let us keep people at the centre, particularly the most vulnerable.”

Mirai Chatterjee, Director, SEWA Social Security, Self-Employed Women's Association, India

In an ideal world, everyone would have all the health care they needed. Sadly, the world has finite resources, which means that societies must ration the health care available. Decisions on health financing always come down to which groups of people we prioritise. In practice, prioritisation is often determined by who gets to participate in the decisions on how the resources should be allocated. This has been in part due to a long-held tradition of relying on epidemiological data in making resource allocation decisions, which, in turn, has perpetuated a system of inequity.¹ Jonathan Mann, who was the head of the first UN program on AIDS, identified some of the inequities that the global public health system was reproducing. Calling for a human rights approach, he argued that:

The language of biomedicine is cumbersome and ultimately perhaps of little usefulness in exploring the impacts of violations of dignity on physical, mental, and social well-being. The definition of dignity itself is complex and thus far elusive and unsatisfying. While the Universal Declaration of Human Rights starts by placing dignity first, “all people are born equal in dignity and rights,” we do not yet have a vocabulary, or taxonomy, let alone an epidemiology of dignity violations.²

A key component of the human rights approach to health has been to encourage active participation by those affected by ill health in constructing solutions to their problems.³ This paper argues that despite increasingly diverse participation in the making of health decisions, there are still conceptual problems in determining which groups get prioritised as representatives in decision making. Drawing on previous research on how participation can enable communities to create the highest attainable standard of health,⁴ this paper demonstrates that there is still a lack of clarity when it comes to how participation ought to work in practice, particularly with regard to the engagement of new global funding institutions. Highlighting this issue is important, as these organisations now account for over 60 percent of health funding for developing

¹ Editorial, ‘Putting public health back into epidemiology,’ *The Lancet* 350 no.9073 (1997)

² J. Mann, ‘Hastings Center Report’, *Medicine and Public Health, Ethics and Human Rights* 27, no.3 (1996):6-13. A version of this paper was presented in plenary session at the III World Congress of Bioethics, San Francisco, 20 November 1996.

³ WHO, ‘The Ottawa Charter for Health Promotion, 1987’, <http://www.who.int/healthpromotion/conferences/previous/ottawa/en/> (accessed 9 November 2016).

⁴ See A. E. Yamin, ‘Suffering and powerlessness: The significance of promoting participation in rights based approaches to health’, *Health and Human Rights* 11, no.1 (2009)2-21.; S. F. Halabi, ‘Participation and the Right to Health: Lessons from Indonesia,’49-59; W. Flores, A. L. Ruano, D.P. Funchal, ‘Social Participation with a context of Political violence: implications for the promotion and exercise of the right to health in Guatemala,’ *Health and Human Rights* 11, no. 1 (2009)37-48; Susan B Rifkin, ‘Lessons from community participation in health programmes,’ *Health and Policy Planning* 1, no.3 (2009) 240-249.

countries.⁵ The question of who participates in making health decisions for development health assistance has always raised controversy due to fears that donors continue to drive decision-making at the cost of the recipient country needs.⁶ This arguably undermines country ownership of aid programmes and has a huge impact on the value of health outcomes in those countries.⁷

This paper focuses on the biggest international health funder – the Global Fund to fight AIDS, Tuberculosis and Malaria (GFATM) – and its efforts to introduce a right to health criterion in health funding decisions, particularly with regard to participation.⁸ Specifically, the paper reflects on Uganda’s experience of increasing participation of minority groups as part of its human rights obligations in the last GFATM application process in October 2014.⁹ Uganda is a particularly interesting case study, because the GFATM has invested considerable resources there to ensure adequate participation of all the key affected groups as part of a human rights approach within this new financing mechanism.¹⁰ The case study highlights three important questions the literature on participation within the right to health has not addressed. 1) Should we prioritise the participation and allocation of resources from groups of people who face intersectional discrimination (e.g. female sex workers who experience complex discrimination due to the synergistic interactions that may arise from being both female and sex workers?) 2) How do we ensure effective participation from members who are human rights experts within the very technical area of biomedicine currently used to determine health outcomes? 3) How can we measure effective participation within a human rights framework?

In responding to these questions, the paper proposes an approach to participation based on underlying vulnerabilities. The paper argues that this approach focuses not only on people who are affected by disease, such as patient groups, but also on those groups whose discrimination in society makes them more vulnerable to disease. This approach is emancipatory in that it seeks to improve the health outcomes of these latter groups in the short term while also aiming to redress underlying health inequities that have engendered their discrimination in the first place. As this paper elaborates, operationalizing such an approach would necessitate three key considerations. Firstly, we would have to account for intersectionality, to prioritise participation by members from minority groups who simultaneously face different kinds of discrimination. Secondly, it would require a socio-epidemiological approach that focuses on underlying determinants of health inequalities to ensure effective participation of minorities, as this approach simplifies the technical and focuses on the language of rights. Thirdly, it necessitates promoting first-person

⁵ Institute for Health Metrics and Evaluation (IHME). ‘*Financing Global Health, Development assistance steady on the path to new Global Goals*’, (2016): 24. <http://www.healthdata.org/policy-report/financing-global-health-2015-development-assistance-steady-path-new-global-goals> (accessed 22 November 2016)

⁶ S. Moon, O. Omole, ‘Development Assistance for Health: Critiques and Proposals for Change,’ https://www.chathamhouse.org/sites/files/chathamhouse/public/Research/Global%20Health/0413_devtassissancehealth.pdf (accessed 20 May 2016).

⁷ L Kapiriri, ‘Priority Setting in Low Income Countries: The Roles and Legitimacy of Development Assistance Partners,’ *Medicine and Public Health Ethics* 5, no. 1: 67-80

⁸ The GFATM was set up as an international financing institution in 2002, committing huge sums of money to support large-scale prevention, treatment and care of the three major diseases, AIDS, tuberculosis and malaria.

⁹ The Ugandan case study relied on fieldwork conducted in April 2015. More information is provided in the methods section.

¹⁰ S. L M Davis, ‘Measuring the Impact of Human Rights on Health in Global Health Financing,’ *Health and Human Rights* 17, no.2 (2015): 100

narratives in order to ensure that measurement approaches effectively capture whether or not participation is effective.

1.1 *The varied nature of participation*

Participation within the right to health is defined as a process through which all affected parties are included equally. The process should also be transparent, so that the participants understand all the information related to the issues being discussed to make the best possible decisions.¹¹

However, as Susan Rifkin showed in her seminal work on community participation in health, most of the common forms of participation are not truly participatory.¹² Rifkin proposed a typology of participatory approaches that covers three major types of participation. The first was referred to as a *medical approach*, where groups of people follow directions of medical professionals towards common goods, such as better health. This model relies on the provision of health services by professionals who are experts and the community participation is through the acceptance of these medical services. This approach is rarely used by global health actors, a second approach, which is deemed to be more representative, being preferred.

This second approach is a *health services approach*, which defines community participation as the mobilisation of community people to take an active part in the delivery of their health services. The problem with this approach is that the health services are still pre-determined by professionals, and the community is involved only to ensure that most people benefit from health outcomes. For instance, vaccination drives usually use this approach, as medical professionals decide on which diseases create the greatest threat to the population. The public is then engaged with health service delivery, as they try to raise awareness so that people in the community can get vaccinated to achieve the herd effect, where most people are now protected, meaning that there is less of a threat to the entire community. This model is by far the most commonly used by international health actors who are responding to the AIDS pandemic. Participation is largely symbolic and elitist, as it mainly relies on other professionals for input.

The third method is the *community development approach*, focused on the role of community organisations in dealing with underlying social economic determinants of health. This approach is truly participatory, because there is an acknowledgement that, to truly redress inequity, participants must go beyond decisions on disease responses to decisions of how to address unequal health outcomes, and this can be done only by encouraging as much participation from the community as possible. Therefore, the community is involved in deciding which health areas to prioritise, how to allocate funding to them and in responding to health threats. Using this model, it is essential for the community to take part in the discussions of a) not only AIDS as an epidemiological problem, but the underlining drivers like discrimination due to gender, sexuality and poverty that may make it worse, 2) communities are then encouraged to take part in discussions that prioritise not only responding to AIDS through access to ARVs but also thinking about other interventions that can slow the spread of AIDS. For instance, communities may focus attention on fighting discriminatory laws that perpetuate gendered health outcomes, societal norms that deal to stigma and socio-economic drivers such as a lack of food which

¹¹ H. Potts and P. Hunt, Participation and the right to the highest attainable standard of health, Project Report, (Human Rights Centre, Essex: 2008) 1-40.

¹² Rifkin, (note 3) 241.

would reduce the efficacy of interventions such as ARVs, 3) All interventions such as education and health service delivery are designed with the help of community representatives.

A community development approach, which is more inclusive, can serve four major functions in attaining the right to health.¹³ First, it can attempt to address the democratic deficit within structures of domestic¹⁴ and global health governance that were previously mainly focused on medical interventions, as opposed to community outcomes. At the domestic level, a more participatory process can counter government power by giving a voice to more vulnerable members of society. Secondly, a more participatory process, especially one with broad civil society engagement, could offer a comparative advantage over the government in delivering services, in view of its outreach and presence within the target communities. Thirdly, it offers a revalidation of the public interest within healthcare systems.¹⁵ Fourthly, a participatory process can enable communities to seek mechanisms of redress if their health outcomes are not met.¹⁶ This may be through judicial review processes if international funders violate fundamental elements of due process, but, in some instances, redress may also be sought through compelling the government to take advantage of international funding, as happened with the Treatment Action Campaign (TAC) case, in which an active civil society group brought a case against the government on behalf of HIV-positive mothers in South Africa.¹⁷ The TAC campaign has been lauded for enabling many poor people who were living with HIV/AIDS to challenge political marginalization. Through these cases, the organisation became a social movement which used courts to challenge the legal status quo but also consequently used civil disobedience to achieve its objectives.¹⁸ Robins and Lieres describe:

...the Treatment Action Campaign, [as] an AIDS activists group that is facilitating innovative participation. It is promoting these activities in multiple sites, ranging from intermediary institutions that serve as an interface between the state and the poor, to more transient, non-institutional forms of participation in spaces created by the marginalised themselves.¹⁹

However, there are dangers in conflating civil society involvement with effective participation, as we will see further in this article. Civil society involvement may not always be effective, especially if top-down pressures seek to impose certain kinds of civil society. For example, the GFATM has been criticised for favouring certain kinds of civil engagement to the detriment of others that may be better suited in some community settings.

2.0 Methods

¹³ S. R Sekalala, 'Normative Considerations underlying Global Health Financing: Lessons for the Framework Convention on Global Health,' *Global Health Governance* 9, no. 1 (2015):24 – 39

¹⁴ *Id.* 24

¹⁵ This is particularly important in areas of the world where health systems are being privatised.

¹⁶ Sekalala (note 13) 31.

¹⁷ *Ministry of Health v Treatment Action Campaign (TAC)* (2002) 5 SA 72 (CC) The court ruled that the government had a duty to provide nevirapine to all expectant mothers. In this case, the court took into account the fact that the government had acted unreasonably because they had not set up an implementation plan that included all the relevant sections of society.

¹⁸ A. Cornwall, 'Making Spaces, Changing places: Situating Participation in Development,' *IDS Working Paper 173* Institute for Development Studies Brighton. (2002) 20.

¹⁹ S. Robins, B.V, Lieres, 'Remaking citizenship, unthinking marginalisation: The Treatment Action Campaign in Post- Apartheid South Africa,' *Canadian Journal of African Studies*, ' 38 (3) (2004) 576.

This paper relies on an extensive review of international human rights literature, research articles on participation within health, the proposed funding model of the GFATM and grey literature pertaining to the GFATM's human rights record.²⁰ To complement this deskwork, the paper uses an illustrative case of Uganda's experience during the last grant application process in October 2014.²¹ The author conducted nine in-depth interviews with key informants from the Ministry of Health, civil society organisations and representatives of people within the key affected populations. These were chosen through a snowballing method in order to ensure that a diverse range of representatives were contacted. To triangulate these interviews, the author also sent out questionnaires to all members of the Country Coordinating Mechanism, resulting in responses from 14 members.

3.0 Locating a human right to participate within an institutional context

Currently, all the major international treaties recognise the essential role of participation in the realisation of fundamental human rights²². Article 4 of the Alma Ata on Primary Health Care states that 'people have the right and duty to participate individually and collectively in the planning and implementation of their health care.'²³ The Alma Ata's emphasis on community participation shifted the focus from health care delivery and decision making that relied solely on medical professionals. Through the Primary Health Care model, ordinary people in communities were in theory supposed to be given the power to make decisions about health and health services to provide the type of health care that was most appropriate to their circumstances.²⁴

The United Nations Committee on Economic Social and Cultural Rights, in General Comment No 14 of 2000, puts participation at the core of health decision making at the community, national and international levels.²⁵ Under General Comment No 14, various vulnerable groups, such as women, children, disabled people and indigenous people, must be consulted as a condition of respecting, protecting and fulfilling the right to health. Paragraph 43(f), in particular, directs states to use participatory methods to adopt and implement a national public health strategy and implement a plan of action to achieve it.²⁶ Paragraph 54 of General Comment No

²⁰ In particular, the paper relies on another study that looks at participation on a selection of countries that implemented the new funding model early by the Independent Observer of the Global Fund AIDSPAN. A. Kageni et al, 'Representation and Participation of Key Populations on Country Coordinating Mechanisms (CCM) in six countries in Southern Africa.' January 2015.

²¹ For more on using case studies in an order to illustrate conceptual analysis see, N. Siggelkow, 'Persuasion with case studies,' *Academy of Management Journal* 50, no.1: 20-24

²² International Conference on Primary Health Care, Alma-Ata, USSR, 6-12 September 1978; The United Nations Committee on Economic Social and Cultural Rights, in General Comment No 14 of 2000; Principle 7 of the Maastricht Guidelines; United Nations General Assembly, 'The Interim Report of the Special Rapporteur on the Right of Everyone to the Highest Attainable Standard of Physical and Mental Health' (ibid 23)

²³ World Health Organization, http://www.who.int/hpr/NPH/docs/declaration_almaata.pdf (accessed on 23 November 2016)

²⁴ Id.

²⁵ Committee on Economic, Social and Cultural Rights, General Comment No 14, The Right to the Highest Attainable Standard of Health (Article 12) UN Doc. No. E/C.12/2000/4 (2000), [http://www.unhcr.ch/tbs/doc.nsf/\(symbol\)/E.C.12.2000.4.En](http://www.unhcr.ch/tbs/doc.nsf/(symbol)/E.C.12.2000.4.En).

²⁶ Id.

14 also clarifies that the purpose of social participation is to achieve equality of opportunity through the proposal, design and implementation of public policies from various social sectors.²⁷

Principle 7 of the Maastricht Guidelines creates an obligation for States to ensure that everyone has the ability to participate in decisions that affect their human rights. States are therefore urged to consult widely with various stakeholders – including parliaments and civil society – in order to design and implement policies and measures that are relevant to a broad cross-section of the population.²⁸

Despite the rise of institutional actors dealing in global health, there has been a lack of clarity on the issue of whether international funders are subject to the same obligations as States in ensuring that there is adequate participation. In 2012, the Special Rapporteur on the right to health released a report which sought to clarify the issue: *The Interim Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Standard of Physical and Mental Health*.²⁹ This report presents an account of the duties imposed on domestic and international funders to ensure that their financial assistance enables developing countries to achieve the right to health through global health initiatives.³⁰ It calls for participation of civil society and affected populations within community health governance structures in order to ensure responsiveness and sustainability. Better participatory procedures recognise that, at their core, health programmes belong to the communities and not to donors. Therefore, communities ought to be at the centre of creating responses to their health needs. In many instances, many of the people in these communities have lacked the capacity to participate in their health governance.

As an international funding agency, the GFATM does not have human rights obligations which are structured around the state. However, General Comment No 14 directs non-state actors capable of providing economic and technical assistance to cooperate effectively with States to realise their legal obligations for the right to health of their citizens. Given that the GFATM has decided to integrate the right to health within its programmes, the onus is on donor countries who contribute to it to ensure that the organisation fulfils the fundamental spirit of this right regarding participation.³¹

The Special Rapporteur's report acknowledges that rights can only be exercised through mutual recognition. This mutuality presupposes the need to understand the requirements of the most vulnerable in society; i.e. paying attention to health as it is experienced by communities. Different

²⁷ *Id.*

²⁸ L.O. Gostin and E. Friedman, 'Towards a Framework Convention, A Transformative Agenda for Global Health Justice,' *Yale Journal of Health Policy, Law and Ethics* 13, no.1 (2013): 59, 71-2

²⁹ United Nations General Assembly, "The Interim Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health," A/67/302 (2012),

³⁰ Although General Comment No. 14 and the Maastricht Guidelines deal with health financing, the current report presents the most detailed analysis of the issue. Previous Special Rapporteur's, such as Paul Hunt, had dealt with financing only incrementally through the access to medicines issue.

³¹ A. Grover et al, 'Strengthening the Global Fund's Commitment to Human Rights,' Available from <https://www.opensocietyfoundations.org/sites/default/files/global-fund-human-rights-20110901.pdf> last accessed 22 November 2016. In this article, the former Special Rapporteur also inferred human rights obligations for the GFATM from the duty to protect and made analogies to the obligations that businesses now have under the Ruggie principles in order to assert that the GFATM had a positive obligation in order to ensure that its activities ensured a positive realisation of the right to health.

stakeholders within these communities need to play their part in framing what the right to health means for them. This transformative approach ensures that groups that are normally excluded from the political structures of global political economy are given a voice in the decision-making process. However, as the case study of GFATM funding will illustrate, even with this guidance there have still been problems in conceptualising what participation means for international funders who try to promote the right to health within their programmes.

4.0 The GFATM and participation: Progress and Challenges

Global Health underwent a resurgence with the formation of numerous institutions dedicated to solving global health problems at the beginning of the 21st century.³² Many of these new institutions had participation embedded in their governance structures. Moving away from the traditional model of vetoes and stringent voting procedures that excluded many developing countries from participating effectively in health outcomes that affected them, new institutions encouraged greater participation by including a mixture of developed and developing countries on their decision-making boards and using consensus to ensure more equitable participation.³³ They also provided for civil society representation in decision making at the international level, and, in some instances, such as UNAIDS and the GFATM, included representatives of people living with diseases.³⁴ The GFATM was revolutionary in going even further by seeing participation at the domestic level as crucial to making health financing decisions.

To ensure domestic participation, countries applying for GFATM programmes submit proposals, which are reviewed by a panel of independent experts and considered for approval by the board. The application must be through the Country Coordination Mechanism (CCM), which usually includes a wide range of stakeholders.³⁵ The CCM is supposed to ensure local ownership by designing health initiatives that seem most suited to local needs.³⁶

However, by 2008 it was clear that although the system was meant to be broadly representative this was not happening in practice. A survey of eight CCMs showed that there was not a single representative of people living with malaria and tuberculosis, despite that being one of the core areas of the GFATM's work.³⁷ A 2010 survey of all the GFATM grants revealed that on the CCMs only eight percent of representatives came from people living with HIV/AIDS, and other

³² L. Gostin, *'Global Health Law'*, (Harvard University Press 2015), 129.

³³ These organisations included organisations such as GFATM, The Joint Programme to fight AIDS, (UNAIDS), UNITAID and The Global Alliance on Vaccines and Immunisations (GAVI). For instance, the GFATM is governed by a board of 18 representatives which includes representatives from nine regions (most which are from the developing world), six donor countries, and a representative from an NGO in the developed world and another one from the developing world, 2 private foundations, 2 representatives of people living with the disease, and 4 non-voting members representing the WHO, World Bank, UNAIDS and a Swiss representative.

³⁴ T. Hale and D. Held, *'Handbook of Transnational Governance, Institutions and Innovations'* (Polity Press, 2011), 161-166.

³⁵ CCMs typically include representatives of health professionals, NGOs and the private sector, as well as government representatives of development International organisations.

³⁶ GFATM, 'What We Do' <<http://www.theglobalfund.org/>> (accessed 27 June 2015).

³⁷ Global Fund, *CCM Sector Composition for QTR 2, 2010* Accessed at <http://www.theglobalfund.org/documents/ccm/CCMgraphs/CCM%2010%20Sector%20Composition%20Global%20and%20Regional.pdf>.

Key Affected Populations (KAPs) comprised only one percent of representatives on the CCMs.³⁸ There were also allegations that the GFATM prioritised certain civil society groups over others which may have been more vulnerable.³⁹ This process was exacerbated by the fact that selection processes to the CCM designed to engender broader participation were often not transparent or democratic in many countries.⁴⁰

Moreover, there was an acknowledgment that many marginalised groups lost out in GFATM funding because they came from criminalised groups and were unable to participate in the CCM⁴¹. For instance, because homosexuality is outlawed across 38 Sub-Saharan countries, it is almost impossible for gay people to self-identify and put themselves forward as participants who could represent the interests of those constituencies.

GFATM grants also illustrate the tension between the predominant medical approach and the rights approach, resulting in a lack of participation from minority groups from KAPs. For instance, the United Nations Development Programme (UNDP) reported that, in countries which demonstrated generalised epidemics,⁴² there was a lack of focus on minority groups, such as men having sex with men, prisoners, sex workers and transgender people.⁴³ UNAIDS defines a generalised epidemic as one which affects 1–5 percent of couples who are sexually active. This rate is sufficient for the sexual networking needed to drive the epidemic, so in a generalized epidemic with more than 5% adult prevalence, no sexually active person is “low risk”. However, even under this scenario, the most at-risk groups, such as sex workers, are at a higher risk of catching AIDS. However, many public health interventions which privilege a medical approach have used epidemiological data to focus on responses that are geared towards the whole population at the expense of minority groups.

The head of the GFATM, Michel Kazatchkine, acknowledged that, ‘The lack of support for programs that protect and promote human rights is one of the failures in the response to AIDS’.⁴⁴ As a result, in 2014 the GFATM restructured its funding mechanism to include key human rights stakeholders at the domestic level in order to ensure better human rights outcomes in funded projects as well as create a more accountable form of funding for health outcomes.⁴⁵

³⁸ The Global Fund, ‘Country coordinating mechanism governance and civil society participation,’ (The Global Fund, 2008)

³⁹ A. Kapilashrami and B. McPake, ‘Transforming governance or reinforcing hierarchies and competition: Examining the public and hidden transcripts of the Global Fund and HIV in India,’ *Health Policy and Planning* 28, no.6 (2012) 4-6.

⁴⁰ International Council of AIDS Service Organisations, International Treatment Preparedness Coalition, Global Fund Country Coordinating Mechanisms: A prescription for change in a Time of Promise... and Peril’

⁴¹ International Council of AIDS Service Organizations (ICASO); international treatment preparedness coalition (ITPC) Treatment Monitoring & Advocacy Project, CCM Advocacy Report, Global Fund Country Coordinating Mechanisms: A Prescription for Change in a Time of Promise ... and Peril’ (ICASO, 2012): 5

⁴² http://hivpreventiontoolkit.unaids.org/support_pages/faq_diff_epi_scenarios.aspx

⁴³ UNDP, GFATM ‘Analysis of Key Human Rights Programmes in Global Fund HIV- supported programmes’, <http://www.undp.org/content/dam/aplaws/publication/en/publications/hiv-aids/analysis-of-key-human-rights-programmes-in-global-fund-supported-hiv-programmes/Analysis%20of%20Key%20HRTS%20Programmes%20in%20GF-Supported%20HIV%20Programmes.pdf> (accessed 20 May 2016).

⁴⁴ The Global Fund, Funding Model, <http://www.theglobalfund.org/en/fundingmodel>, (accessed November 22nd 2016).

⁴⁵ This was part of a much wider restructuring process which introduced a new model that was supposed to streamline the process of health financing in order to make it more flexible and ensure that there was better

The GFATM referred to these groups as Key Affected Populations (KAPs), and their participation was to be a central component of this new funding regime.⁴⁶ Mark Dybul, the Secretariat's executive director of the GFATM, stated that:

We are committed to ensuring that Global Fund money is used for programmes that focus on human rights in the fight against the three diseases. We believe that the rights of sexual minorities should be respected, as key populations hold the key to the effective fight against the pandemic.⁴⁷

As part of the new procedure for applying for funding, each country is given a fixed allocation of resources. The CCMs, which should have a wider number of participants from KAPs, are then tasked with engaging in a 'country dialogue process', taking into consideration the epidemiological data, national health strategic plans and the past performance of health programmes, to draft a concept note and budget, which they then submit to the GFATM for consideration. The Technical Review Panel, which is an independent team of experts that reviews the process, may then recommend that the country make changes to areas of prioritisation in order to consider the needs of the KAPs.

The GFATM has hired evaluators to ensure that members of KAPs can meaningfully participate in the design, implementation and monitoring of GFATM-funded programmes.⁴⁸ The Board has also made US\$ 15 million available to give technical support to countries in order to help them address amongst other things greater representation when making concept notes.⁴⁹ The GFATM also stipulated that participation must be increased at the implementation and service delivery level by increasing the participation of civil society and community groups as primary and sub recipients and in monitoring and evaluating GFATM-funded programmes.

However, despite these measures, the GFATM has still faced problems in ensuring greater participation among CCMs at the country level, and even when they had effective participation this did not always translate to a prioritisation of programmes that focused on the specific human rights needs of people from KAPs. The Technical Review Panel noted that

many concept notes lack meaningful and effective interventions to address human rights barriers. Some concept notes lack prevention and advocacy activities focused on key populations despite evidence of concentrated epidemics among key populations. Others fail to present epidemiological data for key populations... In a number of concept notes, the TRP noted that human rights issues were articulated in the background section, but that applicants did not follow through with activities designed to address some of the specific issues raised... [suggesting] that in some cases, human rights issues were not

alignment with country budgeting processes, <http://www.theglobalfund.org/en/fundingmodel/> (accessed on 23 November 2016).

⁴⁶ The GFATM defines Key Affected Populations (KAPS) as those groups that experience a high epidemiological impact from AIDS, malaria and tuberculosis combined with reduced access to services for whatever reasons and a group that may be criminalised or otherwise marginalised thereby hindering access to key services or basic rights.

⁴⁷ K. Kinyanjui, Human rights, women and children, and sexual minorities dominate discussion at African AIDS meeting', http://www.aidspace.org/gfo_article/human-rights-women-and-children-and-sexual-minorities-dominate-discussion-african-aids-m (accessed 17 May 2016).

⁴⁸ Davis (note 70) p 110.

⁴⁹ Id.

adequately discussed in the process of the concept note development and that key populations were not adequately represented.⁵⁰

While some of these are particular problems with the GFATM as an institution, it is arguable that many of the problems are derived from the particular normative problems that are inherent within a human rights approach to participate in health financing decisions, as we will see when we examine the case study.

Ugandan Case Study

Uganda is an interesting case study because the country is considered one of the success stories in its use of resources from the GFATM in the fight against AIDS, malaria and tuberculosis.⁵¹ Despite this, Uganda has struggled with ensuring adequate participation from all stakeholders during the grant application process. In 2005, many sub-recipients felt that they did not have adequate representation in the CCM, and the government addressed this by expanding the membership. At its height, the body had 65 members, but this made it too unwieldy, so that it was very difficult for the CCM to make effective decisions.⁵² Many members of civil society organisations felt that they were largely left out of decision-making processes, which were tightly controlled by the government, and this led to a lack of effective accountability procedures, leading to widespread corruption and the suspension of all three GF grants in 2006.⁵³

The Ugandan case is also interesting due to the increasingly repressive system in which many minority organisations currently operate. In 2014, Uganda passed anti-homosexuality and anti-pornography legislation. The anti-homosexuality law went beyond the existing prohibitions under the Penal Code and not only outlawed homosexual acts but also compelled citizens to report suspected homosexual activity to the police, triggering increased levels of prejudice, violence and discrimination against the gay community. The anti-pornography law effectively imposed a dress code on women and led to an increase in the number of attacks on women.⁵⁴ The effects of these laws have been felt in the fight against HIV/AIDS, and in April 2015, after the closure of a civil society research organisation suspected of having links with gay people, the GFATM released a statement expressing its concern over the criminalisation of civil society groups. This criminalisation is in addition to already criminalised behaviour of groups such as sex workers and injecting drug users, who are very susceptible to contracting AIDS. Criminalisation makes participation almost impossible, as individuals would have to self-identify with potentially criminal behaviour.

These two problems are not restricted to Uganda. Although this research focuses on Uganda, empirical evidence shows that there is a widespread problem of civil society groups finding it very hard to engage as full partners in the decision-making process that enables countries to

⁵⁰ GFATM, 'Report of the TRP on the Concept Notes Submitted in the Third and Fourth Windows of the Funding Model,' Available at <http://www.theglobalfund.org/en/trp/reports/> (accessed 20 May 2016).

⁵¹ WHO, UNAIDS, 'Country Success Stories', <http://www.who.int/3by5/3by5countryfacts.pdf> (accessed 20 May 2016).

⁵² Interview with the current head of the Ugandan CCM Professor Prof Vinand Nantulya on file with the author.

⁵³ R. G. Biesma, 'The effects of global health initiatives on country health systems: a review of the evidence from HIV/AIDS control,' *Health and Policy Planning* 24, no.9 (2009) 239-252, **244**,

⁵⁴ <http://www.monitor.co.ug/OpEd/Commentary/Anti-Pornography-Act-a-setback/-/689364/2249082/-/aywph5/-/index.html>

apply for GFATM grants.⁵⁵ For instance, over 70 countries outlaw homosexual behaviour, and, in the past two years, Nigeria and Russia have joined Uganda in introducing repressive laws which ban homosexual acts, both in private and in public.⁵⁶

In a bid to ensure authentic participation, and as part of the new funding procedure, the GFATM tried to be proactive in countries that it deemed suffered disproportionately from access to credible representation in the country dialogue process. As Sara Davis, the former human rights officer of the GFATM notes,

...this country dialogue approach did seem to create space for ground-breaking and meaningful engagement (for instance in Cambodia, South Sudan, Uganda and Vietnam). In a few countries, a safe space was created - even by flying community representatives to other countries - to enable their consultation.⁵⁷

My fieldwork in Uganda in the wake of the country dialogue process indicated that although there was much broader representation at the country level due to the new guidelines, there were still several limitations. The paper uses this case in order provide us with an insight into some of the broader issues of needing varied stakeholders to agree on often complex technical health matters while still retaining fundamental human rights values.⁵⁸ The discussion will analyse this by looking at the underlying assumptions that are embedded in participatory mechanisms that are charged with trying to ensure better right to health outcomes with regard to allocation of financial resources.

4.1 *Dangers of over-simplification: Single narratives from multiple representatives*

The current model of participation advanced by the GFATM's CCM seems to follow Rifkin's health services approach, but the reality is that in most places it is still being driven very much by a medical approach. Both the medical approach and the health services approach 'blatantly or tacitly suggest that health professionals should decide how the programme should progress.'⁵⁹ This creates problems for engendering participation as a tool for putting human rights on the agenda, as human rights participants and health professionals may have different agendas, and different human rights groups may also have different priorities for resource allocation.

For instance, women's interests are not homogeneous. A representative for women may, for instance, not have the same interests as a female representative of sex workers or a women's youth representative. Many HIV/AIDS epidemics take place largely among women who

⁵⁵ International Council of AIDS Service Organisations (ICASO), International Treatment Preparedness Coalition (ITPC), 'Global Fund Country Coordinating Mechanisms: A prescription for Change in a time of Promise ... and Peril' (ICASO, 2012)

⁵⁶ International HIV/AIDS Alliance, Challenging criminalisation of LGBT people: Recommendations for governments, multilaterals, companies and NGOS, http://www.aidsalliance.org/assets/000/001/746/ccriminalisationv2_original.pdf?1437394342, (accessed on 22nd November 2016)

⁵⁷ Davis (note 7): 103

⁵⁸ See Davis supra also A. Kageni et al, 'Representation and Participation of Key Affected Population on Country Coordinating Mechanisms (CCMs) in Six Countries in Southern Africa AIDSPAN publications January 2015. ICASO, 'Country Coordinating Mechanism: Key Affected Populations and People living with the Diseases Engagement Initiative Pilot Evaluation Report Summary 2015.'

⁵⁹ Id at 241.

contract AIDS in marriages, and so sex workers and young women may be perceived as part of the problem.

4.2 The limitations of increasing participation amongst repressed groups

Any approach that tries to increase the participation of human rights groups has to contend with the fact that ‘rights do not exist in a vacuum but are embedded in social relations: these very social relations may either enable or constrain the exercise of agency.’⁶⁰ This is manifested in two repressive ways – criminalisation, and often stigmatisation – both of which serve to exclude members of these groups from accessing key services. As a result, half of all new HIV infections worldwide are currently from people who come from KAPs.⁶¹ Excluding people from these groups has also meant that many are driven underground and away from the reach of health information and services.⁶²

Some CCMs, such as the one in Uganda, have been vocal in rejecting the criminalisation of minorities. For instance, the head of the Uganda AIDS Commission, who is also the head of the CCM in Uganda, opposed the criminalisation of minority groups, arguing that Uganda has adopted a medical approach which does not discriminate at the point of treatment; for instance, no one is asked to disclose their sexual orientation as a pre-requisite for ARV treatment.⁶³

It is particularly striking that the head of the CCM in Uganda refers to a medical approach based on non-discrimination. However, non-discrimination does not necessarily lead to a human rights approach because it does not sufficiently challenge the exclusion of groups that are culturally discriminated against. This narrow medical focus is illustrated by the interventions that the CCM applied for in the last grant application process with the most expensive expenditure being allocated to treatment.⁶⁴

This repressive social environment has a significant impact on participation as a means of addressing resource allocation. Within the Ugandan context, no one on the CCM self-identified as being gay, transgender, a sex worker, or a drug user, which was understandable given that they are criminal offences. In some instances, some representatives who did not directly identify but purported to represent these groups felt that, even without self-identifying, they were highly stigmatised.⁶⁵ This lack of self-identification of criminalised groups has been borne out in other

⁶⁰ F Cleaver, The social embeddedness of agency and decision making,’ in Hickey and Mohan (eds) *Participation: From tyranny to transformation? Exploring new approaches to participation in development* (Zed Books London 2004.)

⁶¹UNAIDS, ‘The GAP Report,’ http://www.unaids.org/sites/default/files/media_asset/UNAIDS_Gap_report_en.pdf available May 2016. (accessed on November 22nd 2016)

⁶² The Lancet Series, ‘HIV: science and stigma’, *The Lancet* 384, no. 9939 (2014): 207

⁶³ Interview with head of CCM on file. Also see Press Release by the GFATM, available at http://www.globalfundccm.org/uganda%20HSS%20Concept%20Note%202014%20-%20Funding%20Request%20Split%20by%20PR.pdf/?page_id=2last (accessed 20 May 2016).

⁶⁴ The Global Fund, ‘TB and HIV Concept Note’, (The Global Fund, 2014).

⁶⁵ Interview with respondent 4.

research on KAPs in other countries.⁶⁶ There are dangers that if members of these groups cannot effectively participate, their views will not be heard.⁶⁷

While the GFATM has tried to create spaces for these groups by flying representatives abroad in order to consult fully, one of the interviewees felt that the consultation period had been useful in raising awareness about the human rights issues of the LGBT population⁶⁸ in Uganda, there are still broader questions about whether this amounts to meaningful participation.

The GFATM has also introduced alternative funding and targeted schemes in order to encourage participation of human rights groups, such as funding for regional groupings, which has tended to focus primarily on issues affecting KAPs. For instance, in 2016, 15 Regional concept notes were submitted to the GFATM, and these dealt with a diverse range of interventions, such as harm reduction for people who inject drugs, and the removal of legal barriers and supportive services for people with disabilities, and community system strengthening.⁶⁹ However, although the regional mechanism involves civil society groups working together to apply for a grant, they must still get CCM endorsement at the national level in order to ensure coordination between the national and regional levels. In reality, it means that if there is resistance at the national level for prioritising these excluded groups they will not be successful, and one of the applicants involved in the process described it as the ‘most challenging part of the process.’⁷⁰

4.3 The role of power in participation

The goal of a rights-based approach to participation is to subvert the subordination and marginalisation that prevents certain groups from realising their rights.⁷¹ In order to do so successfully, participatory groups can either expand the number of participants or reassign participation from one group to another in order to ensure that groups that have been traditionally excluded can now have a say. Each option can present its own challenges.

As we saw in the background to the case study above, expansion of participatory groups may not necessarily work. The head of the CCM in Uganda felt very strongly that trying to go back to a massive CCM did not in itself engender greater participation from members of KAPs.⁷² In the past, many members of these groups had also been nominated as reserve candidates in a form of ‘symbolic participation’, which did little to help the members from excluded groups in making decisions on funding. Reserve candidates, for instance, had previously argued that they had not

⁶⁶ In an AIDSpan study of 6 Sub Saharan countries, only two members self-identified as gay and none identified themselves as sex workers, transgender, or IDUs although several people intimated that they spoke for these groups.

⁶⁷ Flores, Ruano and Funchal, (note 3)

⁶⁸ LGBT stands for lesbian, gay, bisexual, and transgender

⁶⁹ These are some of the initiatives that were approved for Sub Saharan Africa. For more information see C. Baran, ‘Update on the second wave of regional concept notes,’ (Global Fund Observer, 2016).

⁷⁰ Quote from Bangyuan Wang who was involved in the India HIV/AIDS Alliance proposal. Id. ‘

⁷¹ Yamin (note 3)

⁷² Interview with GFATM member (record on file with author)

had access to the minutes of meetings and were not invited for major meetings during which decisions were made.⁷³

Increasing community participation can have political repercussions that may be unpopular, as it often involves including groups who challenge more established groups for the right to participate in health-making decisions.⁷⁴ The result would ideally lead to reassigning resources to previously excluded groups. While this may improve their health outcomes, it may cause resentment from other actors who previously benefited from power asymmetries. The Ugandan case study clearly illustrated the limitations of this approach. Despite more equitable representation during the last grant application process, many of those involved in the process felt that there was difficulty in finding consensus on which human rights issues should be prioritised. Some representatives, especially those from the KAP, felt that they were side-lined by other groups, who were focused on maintaining the status quo, due to cultural or religious prejudices.

4.4 Performance-based funding: Limiting effective participation?

The GFATM, like many international organisations, is focused on greater accountability, which promotes evidence-based funding. In its strategic document that deals with monitoring and evaluating, it states that, ‘Impact, outcome and coverage data are important in making funding decisions that ensure grants are contributing to national program goals and are grounded in evidence-based interventions.’⁷⁵ Ideally, this strategy would enable civil society to develop a culture of reporting that creates much stronger civil society interventions and also ensures that resources are distributed where they are needed most.

Evidence-driven requirements favour certain kinds of civil society, which may not necessarily be grassroots-based groups who work closely with affected populations. Because of these new criteria, many of the groups that represent vulnerable people would be excluded, because there was no evidence of their impact. For instance, criminalised groups who struggle to register may not have evidence trails. One of the respondents interviewed talked about the problems encountered in trying to get evidence about people who use illegal drugs in most East African countries, as it is not only criminalised but there are also strong social taboos against it.

Some of the respondents from KAPs felt that the GFATM’s focus on evidence-based mechanisms favoured certain kinds of NGOs which are already highly organised and professional and can therefore take advantage of existing systems to collate data. Other respondents also expressed concern that groups for which data were readily available may have multiple representatives, which makes it hard for them to choose a unifying actor who can represent them.

There is also a danger that in resource-poor settings, where minorities’ human rights cannot be expressed, let alone researched, it may not be easy to find the requisite evidence. Applications

⁷³ ICASO, ITPC, ‘Global Fund Country Coordinating Mechanisms: A prescription for change in a time of promise and ... Peril’ (ICASO, 2012).

⁷⁴ Rifkin, pg 243.

⁷⁵ The Global Fund, ‘The Global Fund’s approach to monitoring and evaluation’, <http://www.theglobalfund.org/en/me/framework/>, (accessed on November 22nd 2016).

must be supported by country strategic planning documents, but such areas may not have been captured in the documents.⁷⁶

The elections for the Ugandan representatives for KAP illustrate the complexities of this process. In February 2015, several KAPs in Uganda decried an election that had taken place and accused members of the country CCM of trying to block members from social minorities. Vinand Nantulya, who chairs the CCM, is on the record as noting that the election process had contained irregularities and had not been transparent, which led to the election of a brother and sister both from the same organisation, Most At Risk Populations (MARPS) Network.⁷⁷ The same two people were re-elected subsequently, and one of the members of the CCM noted to the author in an interview that this was due to the fact that they needed to elect people who could navigate the Geneva bureaucracy in order to represent them.⁷⁸ This example illustrates the complexities of selecting representatives, which presupposes that competing groups can all express their voices on a level playing field.⁷⁹

4.5 Epidemiological and human rights approaches to public health

Under the new funding guidelines, the GFATM wants to see what it calls ‘smart programming that creates the strongest impact’, which refers to programmes that reach the most affected populations. While at the heart of any prioritisation debate there are always considerations of equity, it is difficult to quantify the most-affected populations without resorting to epidemiology, which is the study of how often diseases occur in different groups of people and why. *The Lancet* has rebuked the discipline of epidemiology for focusing too intently on causal mechanisms, as opposed to underlying determinants of health which fit better with a human rights approach.⁸⁰ We can see this trend when we look at the Ugandan submissions on KAPs. In the concept note, all countries have to give a country context that defines the nature of their epidemics for AIDS, malaria and tuberculosis. Under that section, the concept note defines the Most-at-Risk-Group populations to include fishing communities, sex workers and their partners, men who have sex with men, uniformed services and truckers. However, the subsequent breakdown expends the majority of time describing epidemiological trends of fishing communities, truckers, prison services and urban populations, and it is evident that the bulk of the data relies on causal trends.⁸¹

While some respondents thought that human rights were being written into the grant application, others felt that the language of human rights does not lend itself to the technical language which the GFATM adopted for its grants. Some of the respondents interviewed in the Ugandan case study argued that the grant templates were often too technical and relied on too

⁷⁶ Respondent No 3. However, the GFATM has put together a long term strategic goal of creating research projects in order to identify areas that may not have adequate data.

⁷⁷ A. Russell, ‘Key affected populations in Uganda continue to struggle to ensure their legitimate direct representation in Uganda’s Global Fund Country Coordinating Mechanism’ Health Gap Global Access Project

⁷⁸ Interview with author. Notes on file.

⁷⁹ Yamin (note 3)

⁸⁰ Lancet Editorial. Putting public health back into epidemiology. *Lancet* 350 (1997):229; Shy CM. The failure of academic epidemiology: witness for the prosecution. *Am J Epidemiol* (1997), 145: 479–84. N. Pearce . Traditional epidemiology, modern epidemiology, and public health. *Am J Public Health* 86 (1996): 678–83. R. Beaglehole R. Bonita *Public health at the crossroads: achievements and prospects*. Cambridge University Press NewYork, (1997): 120. M. Susser E., Susser. ‘Choosing a future for epidemiology, II: from black box to Chinese boxes and eco-epidemiology.’ *Am J Public Health* 86 (1996) :674–77.

⁸¹ There are two exceptions sex workers and women. All the other vulnerable groups are dealt with under legal barriers to access.

much empirical data for evidence, which excluded smaller rights groups, who wanted to include experiential experiences in the grant. Even the members who were not from minority KAP groups worried that the lack of input from these groups, would impact on their chances of successfully accessing GFATM resources.

4.6 Limitations of complaints mechanism

Participation is critical to realising the right to health, the GFATM does not reflect this in its complaints procedure, which was introduced in April 2015. This procedure enables individuals to confidentially report any claims of human rights abuses to the Office of the Inspector General.⁸² The new complaints mechanism, which has been hailed as ‘one of the boldest commitments to human rights accountability,’⁸³ seems to concern itself with a restricted list of human rights abuses. While the Technical Board, which looks at the grant, must ensure that there are views from KAPs, there doesn’t seem to be any standard for analysing the equity of participation. The process seems to be focused on a transparent and documented selection process which totally ignores the realities of power in choosing participants within most developing country settings.

5.0 The concept of vulnerability in participation as part of the right to health: Lessons from the GFATM

If you cannot get a broad cross-section of people from minority groups who experience discrimination to participate in the decision-making process, there is a danger that the agreed health outcomes may perpetuate injustices. Therefore, this section of the paper explores whether thinking about vulnerability can be helpful in trying to think about how we ought to conceive of participation as part of a right to health. Vulnerability can be defined in numerous ways. Human rights experts have defined it the recognition that some sections of the society are disadvantaged and need some sort of reparation from the entire society.⁸⁴ Health experts describe vulnerable populations as, ‘a group at increased risk for poor physical, psychological, and social health outcomes and inadequate health care.’⁸⁵

Vulnerability can result in human beings becoming more susceptible to suffering pain or loss of dignity.⁸⁶ In the AIDS case, we see this loss of dignity through stigmatisation and a lack of prioritisation of some groups who will disproportionately be affected, as well as through more direct suffering from the disease itself. Vulnerability in this sense is shaped by many factors, including political and social marginalization and a lack of socioeconomic and societal resources. Due to the diversity of conditions that underlie vulnerability, there is a tension between the individual who is suffering and the group. ‘Agency vulnerability’ refers to an individual’s ability

⁸² GFATM, ‘Global Fund introduces Human Rights Complaints Procedure,’ Available from <http://www.theglobalfund.org/en/news/2015-04-27-Global-Fund-Launches-Human-Rights-Complaints-Procedure/> (accessed 20 May 2016).

⁸³ Davis, (note 10) 99

⁸⁴ A H E Morawa, ‘Vulnerability as a concept in International Human Rights Law,’ *Journal of International Relations and Development* 10, (2003): 139-55.

⁸⁵ J.H. Flaskerud and B.J. Winslow, “Conceptualizing Vulnerable Populations Health-Related Research,” *Nursing Research* 47, no. 2 (1998): 69–78. S. A. Hurst, *Vulnerability in Research and Health Care: Describing the Elephant in the Room*. *Bioethics* Volume 22 no 4 (2008)195

⁸⁶ B. S Turner, ‘Vulnerability and Human Rights,’ *Essays on Human Rights* Pennsylvania State University Press, Pennsylvania, (2006) 25- 29.

to reflect critically on different options and choose deliberately between them.⁸⁷ Since every excluded individual cannot personally make these decisions, effective participation from these groups becomes instrumental, i.e. groups engage in participation for the sake of it.⁸⁸ Goulet argues that, to be effective, participation must be non-elitist.⁸⁹

A vulnerability approach would enable us to prioritize the claims of those most affected. The right to health under General Comment No 14 requires vulnerable people to be involved in the determination of the right. Committees which decide on human rights violations, and Special Rapporteurs, have also used their positions to protect the rights of vulnerable people.⁹⁰ For instance, the Special Rapporteur on the right to health argues that the most vulnerable people in society must play a part in determining what the right to health means to them.⁹¹

One of the main ways of redressing this vulnerability is to focus on the underlying resource issues that underpin vulnerabilities. Fineman notes that the experience of vulnerability 'is greatly influenced by the quality of and quantity of resources we possess or command.'⁹² Baxi argues that globalisation also makes these vulnerabilities more acute because it fails to constrain global markets, which exist amidst states that no longer serve redistributive functions.⁹³ This makes institutional responses, such as that of the GFATM, to these redistributive questions particularly compelling, as it has the potential to emancipate vulnerable groups who have traditionally been excluded in resource allocation.

The European Court of Human Rights (ECHR) provides useful lessons regarding how we can do this in practice. The ECHR has adopted this concept of vulnerability in order to protect vulnerable groups in society who have suffered discrimination in the past.⁹⁴ Some of the categories, such as gender and sexual orientation, which have been captured by many of the KAPs, have been accepted by European jurists as vulnerable groups which suffer from social exclusion.⁹⁵ The ECHR has laid out three tests for the concept of vulnerability that can enable us to make sense of how vulnerability would work in order to flesh out a fairer participatory process under the right to health. Firstly, the Court considers vulnerable groups as relational, because it views their vulnerability as a direct consequence of being shaped by social, historical and institutional forces. Second, the Court deals with 'particular vulnerabilities', as opposed to just vulnerable groups, which presupposes some form of hierarchy amongst groups that may be vulnerable. Third, the

⁸⁷ D. Crocker, *Ethics of Global Development* Cambridge University Press, Cambridge (2008) 219- 220.

⁸⁸ S. J. Kosko, 'Agency vulnerability, participation and the self determination of indigenous peoples.' *Journal of Global Ethics* 9:(3) 293- 310.

⁸⁹ D Goulet, 'Participation in Development: New Avenues,' *World Development* 17 (2) 165-178

⁹⁰ A. R. Chapman, B. Carbonetti, 'Human Rights Protections for Vulnerable and Disadvantaged Groups: The Contributions of the UN Committee on Economic Social and Cultural Rights,' 33 *Human Rights Quarterly*, 682 (2011)

⁹¹ United Nations General Assembly, "The Interim Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health," A/67/302 (2012), <http://daccess-ddsny.un.org/doc/UNDOC/GEN/N12/461/01/PDF/N1246101.pdf?OpenElement>.

⁹² M.A. Fineman, 'The vulnerable subject: Anchoring inequality in the human condition,' 20 *Yale J L & Feminism* 20, no.1, (2008-2009): 10.

⁹³ U. Baxi, *The Future of Human Rights* (Oxford University Press, New Dheli 2002) 248

⁹⁴ L. Peroni, A. Trimmer, 'Vulnerable groups: The promise of an emerging concept in European Human Rights Convention Law,' *International Journal of Constitutional Law* 11, no.4 (2013): 1056-1085.

⁹⁵ A.S Sajó, 'Victimhood and Vulnerability as sources of injustice,' eds D. Kochenov, G. de Búrca, Andrew Williams, 'Europe's Justice Deficit,' (Hart Publishers, 2015), 334-347.

ECHR has focused on the harm that occurs or would continue to occur as a result of this vulnerability.

At the beginning of the AIDS pandemic, Mann and Tarantola used vulnerability as a basis from which to argue a case for human rights interventions.⁹⁶ Rights, in this case, are useful because they can help to cushion human beings from the excesses of uncertainty and ameliorate the misrecognition where institutionalised patterns of cultural value construct some actors as excluded due to certain perceptions of inferiority.⁹⁷

At the 2006 High Level Meeting on AIDS, the Member States and civil society members reiterated the commitment underlining the need for ‘full and active participation of vulnerable groups ... and to eliminate all forms of discrimination against them while respecting their privacy and confidentiality’.⁹⁸

In using vulnerability as an approach, the focus ought to be on ensuring that the human rights outcome engenders equity for those groups which were traditionally excluded. Thus, the aim of this approach ought to be emancipatory in nature, in order to ensure that a human rights framework actually addresses historic inequalities caused by what Fraser terms ‘maldistribution’, which results when, ‘some actors lack the necessary resources to interact with others as peers.’⁹⁹

The GFATM has emphasised vulnerability as being central to the idea of KAPs, as is evident in the discourse on increased representation of these groups as part of the CCM, which makes decisions on resourcing of AIDS, malaria and tuberculosis at the national level. However, as the discussion above illustrated, there are still numerous problems with implementing this in practice.¹⁰⁰ This section argues that international financing organisations need to lay down clearer guidelines that affect not only participation but also the criteria that must be followed in allocating resources, as this is the fundamental issue at the heart of effective participation.

Therefore, participation and resource allocation decisions should be structured to take into account the needs of vulnerable populations as part of achieving a fundamental right to health. With this in mind, the paper next turns to address several questions that illustrate fundamental flaws in the current system of participation within the right to health. Firstly, there is a question of intersectionality of vulnerability. Secondly, given that some people fall within multiple groupings that may suffer from various forms of discrimination, what criteria do we use to prioritise the needs of the most vulnerable groupings? Thirdly, if there is a danger that democratic processes may perpetuate the advantages of a privileged group of people, how do we counter this equitably? Finally, how do we evaluate the quality of participation?

5.1 Intersectional Vulnerability

⁹⁶ D. Tarantola, *AIDS in the world II: global dimensions, social roots, and responses. The Global AIDS Policy Coalition*, edited by J. M. Mann and D. Tarantola. (New York, Oxford University Press, 1996), 463-76.

⁹⁷ N. Fraser, ‘Rethinking Recognition’ *New Left Review* 3, (2000): 116

⁹⁸ [Paragraph 64 of 2001 Declaration of Commitment on HIV/AIDS and Paragraphs 20 and 29 of the 2006 Political Declaration on HIV/AIDS].

⁹⁹ Fraser (note 96) 107-113

¹⁰⁰ A Kageni et al, (note 20)

The way in which society treats some people can often exacerbate their already vulnerable status.¹⁰¹ One manifestation of this is the exclusion of some people from determining their health outcomes. This vulnerability can be derived from several factors: from exclusion from law through making certain behaviours like prostitution or homosexuality illegal. Societal/structural exclusions can create discrimination due to gender, culture, poverty race, age or beliefs, all of which make it difficult for people in these groups to access health care and education.

Having AIDS can enhance these vulnerabilities in many ways. For instance, biologically, women are more vulnerable to contracting HIV due to ‘vaginal microbiology and physiology’, which puts them at a higher risk of contracting sexually transmitted diseases.¹⁰² There are also laws in many developing countries that make them particularly vulnerable to discrimination by creating obstacles, such as parental or spousal support, which many women must navigate before they can obtain HIV treatment, prevention care and support services.¹⁰³ Women are also constrained by cultural and societal values, and, even in marriage, many are unable to bargain effectively for safe sex, leaving them particularly vulnerable to contracting AIDS.¹⁰⁴ These issues are compounded by structural problems, as women are more likely to be out of full time education and therefore unable to access sex education, they are more like to be victims of intimate partner violence, which increases the risk of transmission through vaginal tearing, and when they contract the disease they are more likely to be saddled with caring responsibilities. Moreover, the traditional nature of this caregiving means that women’s roles as caregivers are so ingrained within communities that they are mostly unsupported, unrecognised and above all unremunerated.¹⁰⁵

Vulnerability is embedded in interconnectedness, so people are often faced with multiple vulnerabilities that become intersectional. Some groups of people suffer from exclusion on more than one basis; for instance, young girls engaged in sex work may fall within three distinct vulnerable groups: they are women, children and sex workers. Their social position, and the discrimination that they face on this basis, can be characterized as intersectional.¹⁰⁶ Initially meant to capture complex experiences of black women, the term intersectionality has since been expanded to include other experiences of inequality that arise from the interactions between a range of personal and group characteristics on the basis of which discrimination occurs.¹⁰⁷

Our earlier example of the woman and the young girl illustrates problems with the current KAPs approach. At the moment, the GFATM seems to assume that a woman who is still part of a wider vulnerable group faces the same burden as a young girl, because the system makes three erroneous assumptions. Firstly, that either the representative of KAPs will be able to participate and agree to a prioritisation of resources that can target and address the different needs of the woman and the girl. Secondly, as we have seen above, it is highly unlikely that the girl is going to

¹⁰¹ Mann (note 2)

¹⁰² T.C. Quinn, Julie Overbaugh, ‘HIV/AIDS in women: An expanding epidemic,’ *Science* 308 (5728) pp 1582-1583.

¹⁰³ UNAIDS, AIDS Global Progress Report 2014.

¹⁰⁴ Carolyn Baylies, ‘HIV/AIDS and Older Women in Zambia: Concern for Self Worry Over Daughters Towers of Strength’ (2002) *Third World Quarterly* 23(2) 351-75.

¹⁰⁵Id at 16.

¹⁰⁶ Intersectionality refers to the study of overlapping or *intersecting* social identities and related systems of oppression, domination, or discrimination. K. Crenshaw, ‘Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine’, *Feminist Theory, and Antiracist Politics*, *University of Chicago Legal Forum* (1989) 14: 538–54.

¹⁰⁷ K. Davis, ‘Intersectionality as a buzzword, A sociology of science perspective on what makes a feminist theory successful,’ *Feminist Theory* 9, no.1 : 67-85

be allowed to represent the entire group of women in financing decisions, because of the repressive legal and social environment that excludes her as a credible participant. Trying to enable her to participate will entail a direct challenge to the exclusion that prevented vulnerable people like her from having power over decisions and processes that have a direct impact on their health in the first place.¹⁰⁸ Thirdly, if there was an option that enabled her to have her distinct representatives for each of the three vulnerable groups that she falls under, there is a danger that this approach would further fragment representative groups and lead to infighting, due to the homogenous interests of each group, which would lead to none of the groups achieving their priorities, and possibly losing out to more organised, privileged groups.¹⁰⁹

The vulnerability approach proposed here would consider questions of intersectionality by prioritising groups who face multiple incidences of vulnerability, and ensuring that the allocation of resources increases to redress systemic injustices. This approach would therefore introduce quotas for groups based on an intersectional approach that is backed by socio-epidemiology evidence.

This prioritisation in the resource allocation process would be helpful, because it would force CCMs to think beyond the more 'elite' vulnerable groups, such as private sector representatives, who usually participate, and consider representatives from groups that face multiple vulnerabilities. They would have more to contribute in writing more successful concept notes in order to make a case to the international community about the need for resources.

5.2 Integrating socio-epidemiology and the right to health

Socio-epidemiology links vulnerability to disease.¹¹⁰ Using this approach, scientists move away from a disease-focused approach, which narrowly looks at the cause and treatment of disease within particular populations. The socio-epidemiological approach is compatible with a human rights framework, and shifts public health attention from biological and behavioural determinants to power relations that are underlying health outcomes.

Human rights have the power to bridge social epidemiology and social action.¹¹¹ Relying on a social epidemiological approach allows the inclusion of traditionally excluded groups in decision making processes, but does not create agency unless there are actions that improve the material conditions of the population.¹¹² Thus, a socio-epidemiology approach focuses on how countries deal with discriminatory laws that exclude groups from decision making, social and cultural sensitivities, economic inequalities that may exclude younger participants, such as the youth or rural uneducated members of the population, from being able to participate in decision making. Recently, the GFATM changed its guidance in order to push all countries to rely on socio-epidemiological data when including KAPs as a CCM requirement. However, this must go much

¹⁰⁸ Yamin, (note 3)

¹⁰⁹ See the experiences of representatives of victims groups. G Dawson, 'Making Peace with the Past?: Memories, Trauma and the Irish Troubles', (Manchester: Manchester University Press, 2007).

¹¹⁰ J Cassel, 'The contribution of the social environment to host resistance,' *Am J Epidemiology*(1976): 104, 107-123

¹¹¹ S. Venkatapuram, R. Bell, M. Marmot, 'The right to sutures: Social Epidemiology, Human Rights and Social Justice,' *Health and Human Rights Journal* 12, no.2 (2010)

¹¹² Flores, Ruano and Funchal,(note 3)

further to address questions of power in making decisions and become an integral part of allocating resources.

This paper argues that given the underlying problems of a participation approach, this approach should also be used to make a case for funding decisions as well, as this will push participants to engage with the systemic injustices that underlie health inequalities, which lead to some groups becoming more vulnerable than others, and replace the technical bio-medical language with human rights language.

5.3 Measuring Participation

Global health institutions need to try to think of ways in which they can effectively gain information from the most excluded segments of communities.¹¹³ Currently, there are a wide range of tools from the GFATM, UNAIDS and at the national level to do this. However, many of these rely on quantitative indicators or binary yes/no responses to explain whether states are complying with international financing organizations' requirements to ensure greater participation. As Engle and others have noted, quantitative indicators have limitations in measuring human rights performance, as they are unable to reveal the full complexity of human rights performance.^{114,115} For instance, as we have seen in the discussion above, a numerical indicator would be able to tell us the number of participants from KAPs, but wouldn't necessarily tell us much about the quality of participation. In order to measure the effectiveness of participation more effectively, quantitative indicators can be supplemented with 'structural' and 'process' indicators, which deal with efforts that states have taken to transform their commitments in the protection of human rights. These indicators have been used successfully by the CESCR which accepts structural indicators that give narrative information about countries' progress in the realisation of some rights, such as the right to social security, because of a realisation that quantitative indicators may not fully capture the situation in those countries.¹¹⁶ Several methodologies have been developed for process indicators, such as 'Most significant change', which is based on a storytelling approach, which explores key questions, such as "What changes occurred because of whose actions?" and asks when, why and why is it important?¹¹⁷ This approach has proved successful in Latin America in examining wider questions regarding

¹¹³ S. Gruskin, N. Daniels, 'Process is the point: Justice and human rights: Priority setting and fair deliberative process,' *American Journal of Public Health* 98, no. 9 (2008): 1573-77.

¹¹⁴ S. M. Engle, 'Measuring the World: Indicators, Human Rights, and Global Governance,' *Current Anthropology* 52, no. 3 (2011) R. L. Barsh, 'Measuring Human Rights: Problems of Methodology and purpose,' *Human Rights Quarterly* 15 (1) (1993) A. J. Rosga, M.t L Satterthwaite, 'The trust in indicators: Measuring human rights,' *Berkeley Journal of International Law*, 27 :2 (2009) 299. A. Janette R. and M. L. Satterthwaite, 'Measuring human rights: UN Indicators in critical perspective,' in K.Davis, A. Fisher B. Kingsbury, and S Engle Merry (eds), *Governance by Indicators: Global Power through Quantification and Rankings* (Oxford University Press, Oxford, 2013) R J Goldstein, 'The Limitations of using quantitative data in studying human rights abuses,' in T. B Jabine, and R. P. Claude (eds) *Human Rights and Statistics: Getting the Record Straight* (University Press of Pennsylvania, Philadelphia 1992) pg 40. OHCHR, 'Human Rights Indicators: A Guide to Measurement and Implementation', UN Doc. HR/PUB/12/5 (2012), S. Gruskin, Using indicators to determine the contribution of human rights to public health efforts,' *Bulletin of the World Health Organisation*, 87 (9) 3.

¹¹⁵ Gruskin,(note 113) 3.R J Goldstein, (note 113)' pg 40. OHCHR, (note 113)

¹¹⁶ J. Harrison, S. Sekalala, 'Addressing the compliance gap? UN initiatives to benchmark the human rights performance of states and corporations,' *Review of International Studies* 41, no. 5 (2015): 933.

¹¹⁷ F. Polet et al, 'Empowerment for the Right to Health: The use of the 'Most Significant Change' methodology in monitoring,' *Health and Human Rights* 17, no. 2 (2015)

whether new participatory processes are enabling the redistribution of health resources for marginalised groups.¹¹⁸

The language of measurement is important. While human rights language is a potent tool, this paper argues that providing first-person narratives would supplement this in order to capture the varied needs of participants. Narratives have traditionally been used to capture human rights violations. Victims of abuse, including sexual abuse, genocide, torture, slavery and forced displacement, have all used powerful personal narratives to communicate the suffering that underlies human rights violations.¹¹⁹ There have been some experimental attempts to capture the narratives of people who have been stigmatised due to the AIDS pandemic.¹²⁰

Therefore, the use of first-person narratives within indicators would give a voice to the authentic feelings of participants who had formerly been excluded in taking part in participatory processes in decision making. This chimes with an intersectional approach that recognises the lived experiences of those groups who may have formerly been excluded.

Therefore, this paper proposes that, in addition to quantitative indicators (such as number of people from KAPs on CCM bodies), international funding programmes should consider using structural and process indicators. Countries would respond to these indicators using narratives that give further detail about the process and reflect on how successful the process was in engaging with members from KAPs. *These reflections could include first person narratives that aim to capture how different groups perceive the process of participation.* The reporting mechanism would therefore start off with a reflection on how the CCM identified vulnerable groups. The structural indicators would consider an assessment of legal and societal norms that hinder the participation of some groups. The societal norms are particularly important, because they may be more critical than law in creating vulnerability amongst some groups. The proposed indicators would then ask CCMs to reflect on the process of writing the grant.

This paper suggests using mixed methods to measure participation (see below). This would be through: one quantitative outcome indicator, and qualitative indicators (two of which would be structural and six process). These indicators would use narratives to include further detail on how CCMs raised awareness about the existence of vulnerable groups, how representatives were chosen and a reflection of the contribution that these groups made to the grant application process (see below). These indicators would be bolstered by the involvement of civil society to provide independent validation of government reporting processes.

Proposed Outcome Indicator

1. Percentage of KAPs as part of the CCM

Proposed Structural Indicators

¹¹⁸ Id.

¹¹⁹ K. Schaffer, S. Smith, *Human Rights and Narrative Lives: The ethics of Recognition* Palgrave Macmillan (2004) pp 1- 13.

¹²⁰ S. Schwartz, R. Nowak, I. Orazulike, et al., "The immediate effect of the Same-Sex Marriage Prohibition Act on stigma, discrimination, and engagement on HIV prevention and treatment services in men who have sex with men in Nigeria: Analysis of prospective data from the TRUST cohort," *Lancet HIV* 2/7 (2015), pp. e299–e306; Available at [http://www.thelancet.com/journals/lanhiv/article/PIIS2352-3018\(15\)00078-8/abstract](http://www.thelancet.com/journals/lanhiv/article/PIIS2352-3018(15)00078-8/abstract); S. M. Peitzmeier, A. Grosso, A. Bowes, et al., "Associations of stigma with negative health outcomes for people living with HIV in the Gambia: Implications for key populations," *Journal of Acquired Immune Deficiency Syndrome* 68/Suppl 2 (2015), pp. S146–S153

1. Assessment of laws that may present challenges to full and effective participation of vulnerable groups.¹²¹
2. Assessment of culture, customs and societal norms that may prevent effective participation of members of vulnerable groups.
3. Taking 1 and 2 into consideration, how the CCM identifies and encourages vulnerable groups, taking into account intersectional characteristics that increase some groups' vulnerabilities to HIV/AIDS, malaria and tuberculosis.

Proposed Process Indicators

1. A description of how the CCM engaged with vulnerable groups to choose representatives to participate in the grant application process.
2. A description of the steps that the CCM took to ensure that representatives from these groups could fully understand and engage with the epidemiological priorities of the country.
3. How decisions were made in the CCM to take into account the needs of different vulnerable groups with particular prioritisation of intersectional vulnerabilities and evidence of interventions to address these in the application.
4. A reflection from members of KAPs on how they engaged with the application process and whether they felt that members took their views seriously. *These would be in the form of first-person narratives.*
5. A reflection from the head of the CCM about how they encouraged members from KAPs to contribute fully to the grant application process.
6. How will the GFATM programs raise awareness about different vulnerabilities, change attitudes, behaviours and practices?

All these indicators would be supplemented by engaging a diverse range of civil society who are invited to write shadow reports that challenge not only the quantitative data but also the government's record of the structural and process indicators.

6.0 Conclusion

This paper has looked at how the GFATM has embedded participation at both the international and national levels as part of a process of incorporating human rights within its programmes. However, as the paper has noted, the process has not been without problems. In response, the paper offered some practical areas of focus for the GFATM, such as 1) simplifying its grant proposal process to enable human rights practitioners to contribute and requiring less evidence from participants at the ground level. The paper also proposed a series of quantitative and qualitative indicators which would help the GFATM to establish the broadest possible representation of KAPs that considers intersectionality, how domestic governments are dealing with structural problems that impede representation and first-person narratives from KAPS representatives that illustrate how they contributed to the grant application process.

However, the paper's major focus was on the systemic failures of participation that may be inherent in the vague conceptualisation of a right to health. To address this, the paper developed

¹²¹ This is already an indicator in the Global Fund's efforts to remove legal barriers. However, this approach would strengthen this indicator because it is not aimed at removing legal barriers but rather at thinking about ways of ensuring participation despite the existence of these legal barriers.

a paradigm of vulnerability to ensure that problems such as multiple discriminations, underlying determinants of health and effective measurement of participation could be better dealt with in the participatory process.

Because critical consciousness is needed before human rights can be really empowering, it is also worth asking about the dangers of co-opting domestic actors into global injustices.¹²² Efforts to increase participation at the local level may be effective, but, ultimately, they need to do more than allocate resources – they may need to ask the hardest questions of all. Are new international organisations that deal with funding merely creating complacency at the national level to stem disagreement by local actors on a wide range of global inequity issues, where the real agenda for trade, economic and development policy occurs?

¹²² Yamin, (note 3) 2.