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Department of Political Studies

Representation Dilemmas in Civil Society Organisations in Global Health Donor Resource Prioritisation Decisions: The Case of PEPFAR in South Africa

A Research Report
Submitted in partial fulfilment
Of the requirements
For the Degree of Masters in Political Studies

By:

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Supervisor: Professor Daryl Glaser

Declaration

I declare that this research report, *"Representation Dilemmas in Civil Society Organisations in Global Health Donor Resource Prioritisation Decisions: The Case of PEPFAR in South Africa,"* is my own work submitted to the Faculty of Humanities, University of the Witwatersrand, Johannesburg, in fulfilment of the requirements for the degree of Masters of Political Studies. It has not been submitted before for any other degree or examination in any form.

Signature…….

Date……

Student Name: AMANDA BANDA 397774

Dedication

To my late mother, Miriam Sautso Chawo

Acknowledgements

Profound gratitude to the Lord God Almighty for mental strength despite the challenges of balancing life, demanding work schedules out of the country and studying. I would further like to extend my special thanks to my family and friends for the moral support, words of encouragement when the physical and mental strength energy was low. My supervisor, Professor Daryl Glaser, thank you so much for your patience, understanding and giving me more time to finish my research report. You could have given up, but you didn't. I owe the participants of the in-depth interviews a lot of gratitude for making time and allowing me into their space and for speaking freely without reserve on the issue. I am truly indebted to; this study would not have been complete without you.

The author declares no conflict of interest.

ACRONYMS AND ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
CBO	Community Based Organisation
CSO	Civil Society Organisation
COP	Country Operational Plan (PEPFAR)
GFTAM	Global Fund to Fight AIDS, TB and Malaria
GHI	Global Health Institutions
HIV	Human Immunodeficiency Syndrome
KFF	Kaiser Family Foundation
LGBTI	Lesbian, Gay, Bisexual, Transgender and Intersex
NAPWA	National Association of People Living with AIDS
NSP	National Strategic Plan on HIV, TB and STIs
PEPFAR	Presidents' Emergency Plan for AIDS Relief
PLHIV	People Living with HIV
PrEP	HIV Pre-exposure prophylaxis
PWN	Positive Women's Network
SANAC	South African National AIDS Council
SANAC CSF	South African National AIDS Council Civil Society Forum
SANERELA	South African Network of Religious Leaders Living with AIDS
SAPWA	South African Positive Women's Ambassadors
TAC	Treatment Action Campaign
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
USG	United States Government
WHO	World Health Organisation

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Human Research Ethics Approval

ABSTRACT

Juxtaposing citizen and civil society representation in a democracy, some scholars assert that civil society organisations assume representation in their public interest advocacy work on behalf of marginalized populations. They argue that civil society organisations lack formal members or constituents to authorise and hold them accountable as representatives.

I conducted a study to understand the representation dilemmas in civil society organisations in global health donor resources prioritisation decisions looking at the case of United States President's Emergency Plan for AIDS Relief (PEPFAR) in South Africa between 2016 and 2018. Specifically, I assessed, what and who gives civil society authority to speak on the citizens' behalf, how they are held accountable by the people they represent and how internally democratic civil society organisations are.

A mixed method of questionnaire and in-depth interviews was used. In some cases, I observed some meetings and engagement processes between PEPFAR and civil society organisations. Using a purposive sampling method, a total of ten participants were interviewed. One was working for PEPFAR and nine participants were staff who 'represent' people living with HIV in their participation in the PEPFAR's resource prioritisation processes. Thematic content analysis was used to analyse and interpret the interviews. Democratic theory, particularly examining the concept of representation, was the theoretical framework used to guide the discourse and interpretation of the research study.

The study suggests that there was both authorised, delegated as well as assumed representation in the PEPFAR resource prioritisation. There is either formal independent electoral systems in place to elect and appoint representatives or membership based structures. The study found deep polarisation of civil society organisations. On one camp is a group with formal electoral systems group engaging in an 'invited' space through the SANAC Civil Society Forum. On the other is a camp with membership based structures participating in an 'invented' space. I argue while there are deep internal democratic flaws and gaps, there was no evidence of the impact of this polarisation on the legitimacy of the representation work done by both camps. In both camps, accountability and responsiveness mechanisms exist but are very weak.

The study found participation remains very elite with those in Director role engaging with PEPFAR every week. Two out of the eight representatives were in contact at least once every two to three months, another two were in contact once every six months with the remaining four in contact once every twelve months only for the consultation processes.

I argue that representatives' participation in the process is only for compliance of the requirements of the process. There was no little evidence of issues raised by the representatives translate into changes to the initial proposed prioritisation of resources, design of programmes, and monitoring of implementation.

CHAPTER 1: INTRODUCTION

1.0 Introduction.

Established in 2003 by President George W. Bush, the United States funded President's Emergency Plan for AIDS Relief (PEPFAR) is the largest funder of the HIV response in the highest HIV-burdened populations and geographic locations globally. By the end of 2017, PEPFAR had provided more than US$70 billion for HIV funding globally, with a total of US$ 6.56 billion alone in 2017 making it the largest financial commitment by any country in the world to address a single disease (Kaiser Family Foundation, 2017:1).

In 2017, it is estimated that over 7.2 million people are living with HIV, with approximately 4.3 million people (55.7%) currently receiving antiretroviral therapy in South Africa. (PEPFAR SDS, 2018:6). PEPFAR currently provides about one-quarter of all HIV funding in South Africa (Kavanagh, 2018:2). The total planned expenditure on HIV in South Africa for 2018 is a total of US$ 1,888,072.275 billion, with government covering 71%, PEPFAR 26% and the Global Fund about 3% (PEPFAR SDS, 2018:17). Over the past years, PEPFAR has focused its resources geographically to the 27 highest burden districts in the country that account for about 82% of the total people living with HIV in the country, aligning well to South Africa's own National Strategic Plan for HIV, TB and STIs. (PEPFAR SDS, 2018:21)

Civil society is widely recognised to constitute a central and defining pillar of the global AIDS response (World Health Organisation, 2006:202). In development circles, (Miraftab, 2004:2) notes that development organisations are increasingly paying attention to community participation and grassroots activism at community level in planning development programmes. Allowing the affected communities to have a say in the decision and programme that directly impact them improves the donor and programme implementers understanding and quality of implementation of the said programmes (Cornwall and Coelho, 2007:4). As such, consultations with civil society and affected communities in the planning of use of resources is one of PEPFAR's priorities to ensure accountability and effective, high impact prevention and treatment services for affected communities (PEPFAR 2018: 68).

Consultation with the affected communities in the expenditure of large amounts of funding matters. Buse and Harmer (2007) argue that the failure of Global Health Institutions (GHIs) to include appropriate and representative stakeholders, leads to misalignment with country and

community health priorities, as well as poor buy-in from target communities. Ooms et al. (2008) give an excellent analysis of current GHI coordination with country health system priorities and suggest that the current GHI paradigms create islands of health resource sufficiency that are neither sustainable nor strengthen the country's health response.

According to Cornwall and Coelho (2007:8), inclusion of affected communities in decision making processes of programmes aimed to help them implies representation, and so they question the basis on which these representatives claim legitimacy to speak on behalf of others. This research assessed representation by civil society organisations in global health institutions' decisions and resource prioritisation processes in terms of what and who give civil society authority to speak on the citizens' behalf when they engage with GHI and how are they held accountable?

With a particular focus on the case of civil society organisations in South Africa, the research analysed the internal democratic dynamics within and among civil society organisations participating in national-level PEPFAR's resource prioritisation processes. The research analysed how affected communities are consulted and the basis on which civil society organisations represent the issues of the affected communities in the process, as well as the implications this has for PEPFAR's investment priorities in its HIV response in South Africa.

The research report has been organised in the following way, in the introduction chapter, the report gives a contextual background and essential information about the research topic. The introduction also argues for the rationale and justification of the research. In addition, the introduction chapter highlights the gaps in existing literature, clear specific research questions and expected impact and implications of the findings.

Following the introduction, the second chapter of this study presents an overview of the theoretical framework, analyses existing literature and frames the issue within the existing academic literature.

The third chapter outlines in detail how the research was conducted, providing an overview of the study population, how the study population was sampled, how data was collected and analysed, and outlining ethical considerations.

The fourth chapter of the research presents the findings and analysis of the questionnaire and in-depth interviews. The fifth and last chapter draws conclusions and presents a summary of the findings, makes recommendation for further research and outlines limitations of the study as encountered.

1.1 Contextual Background

This section gives an in-depth understanding of PEPFAR's resource prioritisation process and of its importance, and outlines implications for the people living with HIV in South Africa. In addition, the section clarifies how PEPFAR engages with and selects civil society in this process and why the selected civil society organisations and members are considered to be representative of the affected communities.

1.1.1 The PEPFAR Country Operational Plan (COP) and Civil Society Engagement

PEPFAR (2018:11) itself defines and describes the Country Operational Plan (COP) process and documents as

> U.S. government annual investments linked to specific results in the global fight against HIV/AIDS to ensure every U.S. dollar is maximally focused and traceable for impact. The [Country Operational Plan] process is the basis for approval of annual U.S. government bilateral HIV/AIDS funding in most partner countries.

In November 2012, the Obama Administration released the *PEPFAR Blueprint: Creating An AIDS Free Generation* (PEPFAR, 2012). This blueprint outlined how PEPFAR would work, including increasing the involvement of communities living with and affected by HIV in planning and implementation both at US government level and partner country level. Working with civil society organisations has always been one of the core principles of PEPFAR. Yet, it is only in 2013 that PEPFAR, amid criticism of lack of transparency and real engagement with the affected communities in prioritisation process of the expenditure of its resources announced plans to establish a mechanism for civil society engagement in country-level planning and priority setting through the development of yearly Country Operational Plans or COPs.

In June, 2013, PEPFAR headquarters in Washington sent an unclassified memorandum to all its country directors, outlining a process of engagement with civil society organisations in partner countries (PEPFAR, 2013). In the memorandum, PEPFAR country teams were

instructed to hold consultative meetings early in the planning process with representatives of communities of people living with HIV (PLHIV).

In these meetings, PEPFAR teams would propose goals and priorities of PEPFAR for the upcoming year. Written comments and feedback from communities of people living with HIV would be solicited. The PEPFAR country teams were to subsequently report to PEPFAR headquarters how CSOs were involved in the process and how their input was considered and taken into account. The PEPFAR country teams would provide written feedback to CSOs on how their input was included and be given reasons where their input was not taken into consideration. Since then, PEPFAR annually provides a COP guidance document that includes among other things how civil society should participate and engage in the decisions around prioritisation of United States government (USG) HIV annual funding for its partner countries.

The COP annual process normally lasts between four to five months. The key formal milestones for engagement with civil society organisations include the release of the final COP guidance and tools. The draft guidance note is disseminated to all local and global civil society organisations to give their inputs. In addition to this, civil society organisations are invited to strategic planning retreats where PEPFAR teams and its agencies present their vision for the country for the particular year and outlines available resources. This retreat takes place at country level and engages Ministries of Health, UNAIDS, the Global Fund to Fight AIDS, TB and Malaria (GFTATM), the World Health Organisation (WHO) and other key donor agencies.

Civil society organisations representatives are then invited to regional planning meetings and reviews where plans are further defined and elaborated and about 80 to 90% of the decisions are made pending further consultations and more engagement and feedback back at country level. The last milestone of the process is the COP approval meetings also attended by civil society organisation representatives.

In South Africa, PEPFAR attempts to consult with as many civil society organisations and representatives of people living with HIV as possible. Consultations take place using the SANAC Civil Society Forum and outside of these structures. According to one of the civil society representatives interviewed, “the process has evolved from no engagement to random meetings leading to proper consultations and structured engagement in 2017 and 2018. For example, the representative notes that in December 2017, PEPFAR invited a number of

randomly selected people openly living with HIV identified through various networks of people living with HIV to a meeting to consult on what the priorities should be (REP8).

In January 2018, PEPFAR in South Africa held an additional meeting with key representatives from the SANAC Civil Society Forum (SANAC CSF). Previously, PEPFAR nominated representatives of the wider community of civil society in these decisional meetings without any criteria. However, the research study found from this year, about five representatives were further selected by the Forum to represent civil society and people living with HIV in the regional consultations and approval meetings where decisions are made and finalised. Additional meeting between the five representatives and PEPFAR were held in February to prepare for the regional consultations meetings (REP7).

The SANAC Civil Society Forum is the formal structure for engagement with civil society on the HIV response in South Africa. However, there exist other civil society organisations and networks of people living with HIV who question the representative legitimacy of SANAC Civil Society Forum. These organisation claim they do not 'recognise' and validate this SANAC structure. Regardless of approval of SANAC, they engage with PEPFAR outside of the SANAC structures.

As such, how these civil society and community based organisations (CBOs) are governed among themselves and work to engage with any HIV policy and decisions processes is important to understand. Of particular importance is understanding how they represent the needs and issues of the affected communities in global resource prioritisation and decision making in South Africa.

The next part of the research report gives an overview of the formalised structure and mandate of SANAC Civil Society Forum and the gaps and dilemmas of representation within this structure.

1.1.2 Civil Society Governance through SANAC and Representation Dilemmas

This section provides an overview of the structure of SANAC and the Civil Society Forum. Understanding the representation of affected communities in PEPFAR COP helps us to understand the level of representation more generally within PEPFAR, as well as challenges involved in civil society representing people living with HIV. Understanding this section also help to unpack the contentions and claims around legitimacy to represent the issues of communities by either those civil society organisations participating in the process through the Civil Society Forum and those participating outside of it.

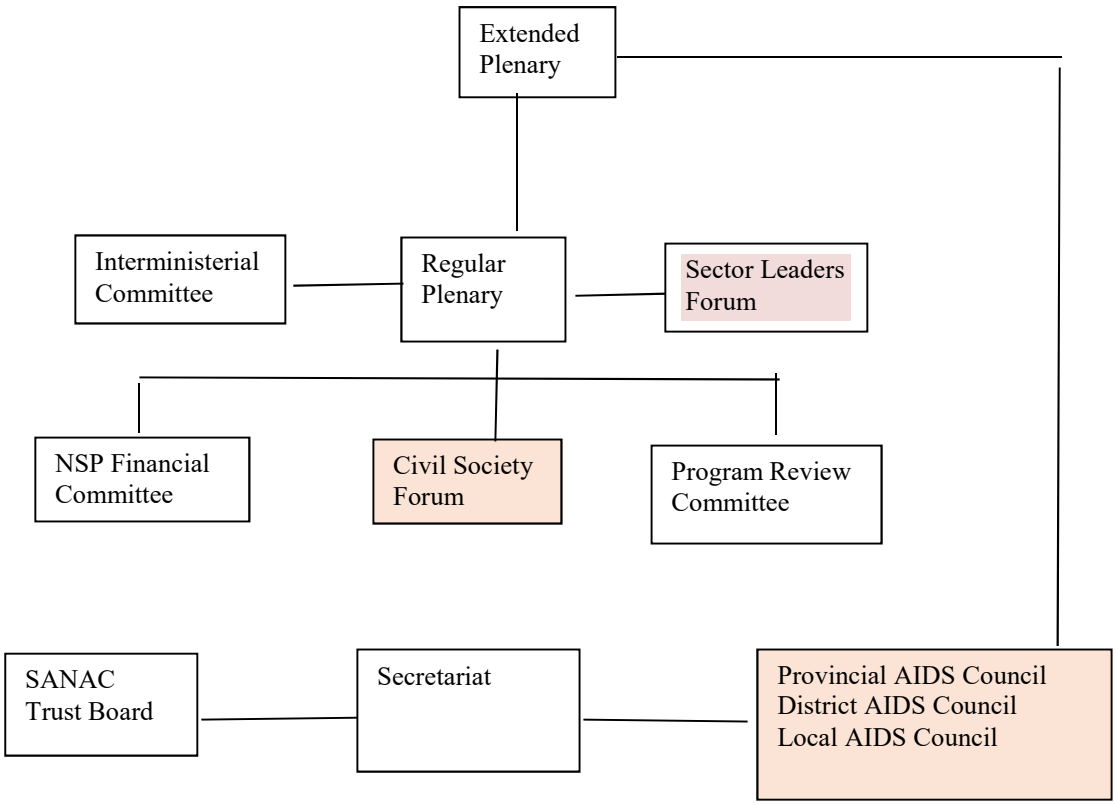
South Africa has an extensively organised and vibrant civil society, as seen in the high numbers of voluntary registered Non-Profit Organisations (which the Department of Social Development associates with CSOs): there were 136 453 by the end of March 2015. This number followed an average growth of 86% from 65 633 registered NPOs in 2009/10. Of the total 11 966 NPOs were categorised as working in health (8.8%), 3 090 in law, advocacy and politics (2.3%), 16 703 in religion (12.2%) and 54 392 in social services (39.9%) (SANAC, 2017: 19).

Established in 2000, SANAC is a national multi-sectoral advisory body and legal institution. It is convened by the Deputy President of the government of South Africa, with a Deputy Chairperson elected through the Civil Society Forum. It is mandated to coordinate and advise the South African government on how to respond to HIV, TB and sexually transmitted infections (STIs). (SANAC, 2017:46).

Figure 1 below gives a good overview of the SANAC structure. To be part of the Civil Society Forum, the local AIDS Council elects representatives to the District AIDS Council. In turn, the District AIDS Council elects representatives to the Provincial AIDS Council who in turn elects representatives to become sector leaders of the National AIDS Council SANAC. Sector leaders do not represent their particular organisations when elected into this space but rather the entire sector. From the research gathered, each of the eighteen sectors has about three representatives except the people living with HIV sector which has five representatives. The exception has been made to have more representatives because they are the most affected sector by HIV.

Representatives from the sector leaders' forum are then elected and voted to serve in various forums within the SANAC structures including the Civil Society Forum. In the figure below, important for this research report is the Sector Leaders Forum, the local, district and provincial AIDS Councils and the Civil Society Forum.

Figure 1: South African National AIDS Council structure. Source: SANAC 2017:46



The Civil Society Forum has an elected chairperson and two deputy chairpersons. The chairperson automatically becomes the Deputy Chairperson of SANAC and a Board Member. It comprises of eighteen constituent sectors organised demographic population groups (men, women, children, youth, labour, people living with HIV, traditional leaders, LGBTI [lesbian, gay, bisexual, transgender and intersex] and disabled persons); specialist occupations and interests (sex work, research, health professional, traditional health practitioners, sports and entertainment, law and human rights), organisational types (non-governmental organisations) and institutionalised sectors (higher education, faith-based organisations) (SANAC, 2017:46-47).

Each of these eighteen sectors is led by an elected leader. As the study findings later suggests, there is a very complex and bureaucratic grassroots or bottom up election that happens through the local, district and provincial AIDS Councils that appointing leaders to become sector leaders in SANAC. The sector leaders in turn elect representatives to the SANAC Civil Society Forum.

One of the participants explained,

> Before you are a member of the Civil Society Forum, you must have been an active member within your sector, so it's a democratic principle. Secondly, a sector must have elected you to be one of the leaders. Sectors have national office bearers to represent the sector and are deployed to the national [SANAC] Civil Society Forum through elections. The Civil Society Forum has terms of reference as guiding principles of the national Civil Society Forum, how we operate, how we engage, how we coordinate ourselves and we reach resolutions, how we vote and so forth, and these terms of reference are adopted and approved by the national civil society forum. The term of the CSF are aligned to the National Strategic Plan (NSP) for a maximum of ten years, so there are guiding principles and governance principles that have been adopted. (REP6)

When asked for further clarification of how these elections are administered and by which body, the participant mentioned that in the past, the elections were internally administered. However, the Forum has in the past years engaged the Independent Electoral Commission of South Africa to administer the elections and voting at all levels within the SANAC structure.

According to SANAC, sectors are each made up of over 6000 community networks and related organisations involved in the response to HIV, TB and STIs. Across all sectors, these organisations include service focused non-governmental organisations, grassroots and community based service organisations, social justice activist and advocacy organisations, faith-based organisations, as well as research and academic organisations (SANAC, 2017:15).

One of the key sectors in the HIV response in terms of representation of affected communities is the People Living with HIV sector, which cuts across civil society. People living with HIV are represented in all sectors and key decision and governance-making bodies as constituted by the National Association of People Living with HIV and AIDS (NAPWA), Treatment Action Campaign (TAC), Positive Women's Network (PWN) and the South African Network

of Religious Leaders Living with or Personally Affected by HIV or AIDS (SANERELA+) (SANAC, 2017:70).

The structures of the SANAC Civil Society Forum are positioned to be the entry point of all engagement by government and donors including PEPFAR and other actors with civil society on HIV, TB and STIs in South Africa. Yet, as this research finds, there is deep polarisation among civil society organisations. Not all civil society organisations recognise or validate this structure and some question its legitimacy in representing the real issues affecting people living with HIV in donor policy processes.

Kavanagh (2014) argues for the inclusion of all independent civil society organisations representing people living HIV in the processes. "Despite the presence of a strong, well-capacitated civil society sector representing PLHIV, LGBTI people, sex workers, faith communities and academics, no substantial effort has been undertaken to enable their expertise to inform PEPFAR's strategy," argues Kavanagh (2014: 26). He suggests that "consideration should also be given to including independent civil society representing people living with HIV." (Kavanagh, 2014:31). Ensuring that the 'right' civil society organisations participate in the resource prioritisation process is key for both PEPFAR and civil society organisations themselves.

Another issue with civil society representation within PEPFAR structures is that there is a lack of representation of CSOs based outside of the capital cities, according to Zapfel and Gibbs (2015:34). The main criticism of the regional reviews is that "too few organisations were able to be involved at that level and the review was, therefore, not representative of all populations' needs." (Zapfel and Gibbs, 2015:34). Providing resources for travel and/or holding consultations in priority geographic regions were suggested as a way to improve engagement by these groups.

In South Africa's 2016 PEPFAR Consultation process with affected communities on the prioritisation of resources, there was clear criticism of PEPFAR's prior exclusion of civil society organisations in the resource prioritisation processes. While PEPFAR has tried to address this criticism by opening up the process to civil society organisations, ironically, PEPFAR question internal civil society democratic and representation processes.

Before this research study, it was not clear to what extent SANAC's civil society sector consulted other communities outside of the core representatives of the forum. What was evident however were the alleged accusations by the Treatment Action Campaign (TAC) and Section 27, two key leading civil society groups in the HIV response in South Africa, that they were not consulted and represented in the process and they in turn have been engaging since 2016 separately and directly with PEPFAR outside of the SANAC structures, injecting their own separate input and comments into the consultation process. From my observations, it seems that while TAC and Section 27 are official members of the civil society forums, they boycott the Civil Society Forum.

TAC and Section 27 claimed SANAC Civil Society Forum has no legitimacy but is a mere government arm and not independent enough and therefore cannot be trusted. According to them; "SANAC is not the final word on AIDS until it can claim to be inclusive as most of the relevant CSOs are outside of the structures of the Civil Society Forum and SANAC does not try to reach them" (PEPFAR CSO Meeting Notes 2016).

In subsequent three-day regional review meetings in 2016 of the COP for South Africa, SANAC was absent during the first day and came only late into the discussions on the second day and represented by a Sector leader from the Sports and Culture of the SANAC Civil Society Forum. Neither TAC nor Section 27 were presented or invited to the meetings. However, they organised a separate meeting on 21 May 2016, which I attended with the PEPFAR Country Coordinator and his core team to raise concerns on lack of engagement and involvement and disappointment that they, as key civil society organisations, were not 'represented' in the process.

On one hand, the Civil Society Forum of SANAC claimed to be the legitimate representatives in any consultative and engagement process of the PEPFAR COP. On the other hand, TAC and Section 27 and other organisations claimed they were not consulted and did not consider SANAC to be the legitimate representatives of people living with HIV.

While not particularly referring to the PEPFAR resource prioritisation process, the deepened crisis of representation among civil society organisations working in the HIV sector is South Africa is de facto acknowledged and evident in Mark Heywood, Director of Section 27's note in *The Spotlight* (July 2016), a magazine produced jointly by TAC and Section 27 to track the

implementation of the National Strategic Plan for HIV and other issues related to the HIV response in the country.

Heywood juxtaposes activism and what he terms “slacktivism”. In summary, he suggests that activism is connected to the impoverished and marginalised communities such as the people still at most risk of HIV and AIDS, it amplifies the voices of the communities and it is accountable. On the other hand, slacktivism, he argues, likes proximity to political power. It seeks public stages and photo opportunities, mainly so it can advance its own self or organizational interests. It likes to create organisations with rights-sounding names, it talks about “our people”, and likes to claim to be the sole representative of people living with HIV. But it is neither transparent nor accountable to any community or constituency (Heywood, 2016).

In a separate newspaper interview, one of the notable activists cautions that civil society should never become service providers for governments or the United Nations. “How can leaders acknowledge privilege and its problems when they live in that privilege? How can they set the agenda for the poor?” she asks. She continues to argue that “the biggest problem in South Africa is civil society selling out our actions. They are amongst us. We have the wrong leaders in civil society groups like SANAC, the South African National Aids Council [who pander to government]” (IOL, 2016).

Ironically, TAC and Section 27 are represented in the SANAC CSO Forum and leading the sector of people living with HIV with Section 27 leading the law and human rights sectors within SANAC. In one of the internal meeting notes, TAC claims that they were removed from the communication groups by one of the CSF deputy chairs, claiming that TAC was not representing the people living with HIV, a decision that was challenged by TAC leading to them being reinstated in the forum and its communication channels (TAC Internal Meeting Notes on SANAC, NSP, 2017:2).

Internally within SANAC’s Civil Society Forum, it was reported that sectors were not submitting reports to the Civil Society Forum coordinating body and there was no improvement on this. According to TAC, there is no clear and realistic plan to address this matter and sectors claim that they are not funded by SANAC hence they are not obliged to submit reports and that there is no support received from SANAC nor the Civil Society Forum. TAC (2017: 6). TAC

further asserts that “there is no accountability and mandate to participate in this forum, to some extent it feels like a waste of time” (TAC Internal Meeting Notes on SANAC, NSP, and 2017:6).

For the PEPFAR South Africa country team, the core question was to try to understand how to accurately identify the essence of needs felt by the communities, so that they can directly respond to these. How best can PEPFAR in its consultation have a wide representative relationship with civil society? It is important to understand how representation takes place within civil society space. How are the real affected communities consulted for their say and priorities before this is collectively fed back into the COP process? Who are SANAC, TAC and Section 27 representing if they are not the same communities? How does PEPFAR in its engagement include all relevant communities while also ensuring they capture the real essence of the needs of the affected communities?

In other countries in the region, through interacting with some civil society organisations at regional meetings, I inferred that there are similar challenges of civil society representation and internal accountability with PEPFAR teams.

1.2 Justification

The lack of clarity and research around the research question is the strongest justification for this research.

While the study of social movements and civil society organisations is well established in political science, there is a considerable gap in applying the political science discipline to HIV, especially in sub-Saharan Africa (Boon and Batsell 2001, Omms Gorick 2016, Gomez 2016 and Paxton 2012).

As stated by Boone and Batsell (2001:4,26), “nearly two decades into a pandemic that poses one of the greatest threats to public health and development in sub-Saharan Africa, political science can no longer afford to ignore the political implications of AIDS in Africa. A rich array of research agendas linking AIDS and politics is worthy of systematic attention.”

Paxton (2012:2) acknowledges the existence of research in global and comparative health policy, impact on international development and foreign policy or relations, social movements and activism, security and governance, but strongly asserts that political scientists are uninterested in HIV. He argues that there is still much we do not know about the interrelationship of the disease with the politics of developed and developing countries. Paxton (2012:11) asserts that political scientists are uniquely equipped to examine ideas, interests, institutions, power and decisions in relation to the syndrome. He argues that plenty of potential research remains to be done on the politics of the response to HIV and in examining the disease as an example of a political phenomenon (Paxton 2012:11). Ooms (2016:1) doubts that "the academic arm of global health can 'survive' in any meaningful way without addressing the role of norms, politics and power in global health head on."

According to Gomez (2016), while political scientists have accumulated research and studies of health policy-making in developed countries, the application of political science theory and method to the study of global or international health is a relatively new area of scholarly research and even more so in developing countries. He argues that there are gaps in the political science community in explaining and understanding international and domestic health politics and policy. This proposed research seeks to contribute to the closing of this gap.

The research findings could provide value in contributing to understanding how international global health institutions perceive and value the role of communities in informing major strategies to the response to HIV. It potentially will inform the efforts of the global health institutions to create better space for participation and engagement with civil society organisations. In addition, it will assist organisations working to build capacity of civil society engagement in the PEPFAR COP process, helping to establish how best to build their capacity to effectively participate and bring about change. For civil society organisations, understanding how they engage and represent the grassroots and represent issues on behalf of the affected populations will further improve their capacity and has the potential to improve their legitimacy.

1.3 Research Questions

The overall question that this proposed research aimed to answer was: what and who gives civil society authority to speak on the behalf of citizens when they engage with GHI's resource prioritisation agenda? How are they held accountable? How internally democratic are civil society organisations participating at national level PEPFAR's resource prioritisation processes in their engagement with the communities they represent?

My starting assumption was that the representation system operative in civil society is assumed; it is elite-based, only involving the savvy networks at the national level interested in pushing their own agenda, lacking authorisation, accountability and responsiveness and therefore not democratic.

1.4 Specific Questions:

1.4.1 How do civil society organisations engage and consult among themselves and with the affected people living with HIV before engaging with the PEPFAR COP?

1.4.2 What are the participation spaces that civil society has created within their organisations for communities to engage with when they participate in the prioritisation of PEPFAR resources, and what are the communities' perceptions of this participation space?

1.4.3 Outside of the created spaces for engagement with civil society, how have civil society organisations applied pressure to amplify their demands regarding PEPFAR service delivery and priorities?

1.4.4 What is the perception of PEPFAR and the civil society's participation and representation in the PEPFAR processes?

1.5 Conclusion

This chapter introduced the research report, highlighting the objective of the study and the specific research questions. The chapter gave a background as well as insights as to why the research is particularly important and as such justifying the study.

The next chapter will position the research question in existing theoretical frameworks as well as highlighting existing literature that attempts to explain the research within a scholarly framework.

CHAPTER 2: THEORETICAL FRAMEWORK AND LITERATURE REVIEW

2.1 Introduction

This chapter discusses the theoretical framework guiding interpretation of the research namely democratic theory. A detailed review and analysis of existing literature and research on the concepts of participation, civil society and representation is done. In the review of the concept of participation, focus is given to the intersection between participation and representation. Overall, a review and analysis of existing literature on the research question will be presented while positioning the research question within that literature. Key arguments on civil society representation are presented followed by a conclusion.

2.2 Theoretical Framework and Literature Review

There does not exist much literature on political representation of civil society organisations particularly in the global south.

On the concepts of democracy and representation in general, the review and analysis largely draws from the works of Dahl (1989) and Beetham (1993), Pitkin (1967), Weale (2007) and Pitkin (1967).

The review and analysis on civil society organisations in general is informed by the historical work on Locke, Paine, Hegel, Mills and Tocqueville and most recently Keane (1988).

Participation concept as used and analysed in this research largely draws from the works and analysis of Miraftab (2004), Cornwall and Coelho (2007), Arnstein (1969), Wainwright (2002) and Botes Van Rensburg's work on South Africa (2000).

Houtzager and Lavalle (2009, 2010) have extensively written on civil society and political representation and as such the analysis on the key arguments for civil society and political representation is largely drawn from their work as well as Buccus and Hicks (2011) who write particularly on South Africa and Della Porta (2009).

2.2.1 Democracy:

According to Dahl (1989:29), democracy is simply rule by the people. Beetham's (1993:55) understanding of democracy further elaborates this classic definition, underlining the two central principles of equality and popular control.

PEPFAR, although not a state in itself, exercises the government-like function of authoritatively allocating resources. It ultimately represents and executes the work of the US government, a sovereign state, but also wants its decision making to be representative of the concerns and interests of HIV-affected populations and the HIV-related civil society sectors in recipient countries. The issue is not whether PEPFAR is a democracy (it is not and does not claim to be) but whether it is representative, responsive and accountable and open to engagement with affected populations. Nor are the CSOs elected representatives. The question is whether they nevertheless represent their constituencies effectively through non-voting processes of representation and whether they encourage effective participation by their constituency.

2.2.2 Representation:

According to Weale (2007:133), the notion of representation simply means that one thing stands for another, or in this case, one person stands for a community or group of people. He notes that "representatives undertake those tasks that citizens lack time or opportunity to undertake."

Pitkin (1967) identifies authorisation, accountability, substantive representation, descriptive and symbolic representation and responsiveness as critical elements for representation. He draws the distinction between authorisation, accountability and descriptive representation as is quoted in Weale (2007). He argues, "authorised as a representative is to be able to carry commitments on behalf of others; to be accountable is to be liable to explain your actions, substantive representation is to be able to act in the interests of others." (Weale, 2007:133).

Beetham (1993:62) adds that through this process of authorisation and accountability in representation, there is an inherent inequality, as a few representatives are entitled to be part of the decision-making process and the vast majority are excluded. According to this argument,

representation involves a justifiable surrender of control or autonomy over decisions to others so that any control is exercised indirectly.

Dahl (1989) traces the origins of representation to medieval institutions of monarchical aristocratic governments where in monarchs summoned assemblies to deal with important state issues. Those summoned were meant to represent various estates of medieval European society. It was impossible for the people to meet as a legislative body and therefore they were called upon to choose persons to represent them (Dahl, 1989:29).

Critics of representation trace the concept and roots of representation in democracy to the concept of guardianship whose proponents include Plato, Confucius and Lenin. The idea of guardianship believes that ordinary people are not able to understand and defend their own interests and those of society at large. Instead some people are competent to rule and rulership should be entrusted to a minority of persons who are specially qualified to govern, reason and make decisions based on their superior knowledge and virtues. Although this highly elitist view of representation is accepted by some modern elite theorists of democracy, it is rejected by Dahl, Beetham and others. Beetham (1993:63) does not agree that the "vast majority of people are inherently incapable of making principled decisions and choices in matters of policy or legislation, and therefore at best they must select others to do it for them." However, he supports the idea of representation in that it can make democracy possible in circumstances where it otherwise might not be and provide a framework for popular participation (Beetham 1993:65).

Using these definitions of representations, the study's initial assumption was that civil society cannot claim representation as they are not authorised or elected and there can possibly be no accountability or responsiveness structures. As such, this initial assumption disagreed with Weale (2007:133) who argues that it is possible to represent someone without authorisation or accountability to them.

The weaknesses and limitations of these definitions and discourse on representations is that they only relate to state and legislature and other representative forms of government. As such, one cannot apply these definitions in the same sense to civil society. This is because generally, civil society is a civic space that is not necessarily accountable to anyone, is not elected, does

not have structures for representation and governance and is often perceived to already represent the will of the people.

2.2.3 Participation

Miraftab (2004:1) introduces the concepts of 'invited' and 'invented' spaces for citizenship that transition very well the discussion from representation to participation. She moves the concept from the traditional understanding limited to its relation which government to another space outside of government political structures such as development spaces in which this research study is positioned. She defines 'invited' spaces as "ones occupied by the grassroots and their allied non-governmental organisations, that are legitimised by donors and government interventions."

In the case of the scope of this research, one could argue that the engagement of PEPFAR with civil society organisations through the SANAC civil society forum fits this description as earlier highlighted in the first chapter, it is recognised as the formal structure and mechanism for government and donor engagement with civil society organisations in the response to the HIV epidemic in South Africa.

Miraftab (2004:1) describes another spaces she terms "invented" spaces, which she argues are "those spaces also occupied by grassroots and claimed by their collective action, but directly confronting the authorities and the status quo in the hope of larger societal change and resistance to the dominant power relations" (Miraftab 2004:4).

This definition of 'invented' fits TAC and Section 27 as this research found that since 2016 PEPFAR COP process, they engaged with PEPFAR separately outside of the invited spaces. In 2018, they wrote what they called a 'Peoples COP' outlining key issues and demands from the people living with HIV that PEPFAR ought to prioritise with resources for their financial year 2018. With this document, they organised separate consultation meetings with PEPFAR prior to the Regional Meetings. In addition, they organised an event with the Ambassador of PEPFAR from Washington just prior to the regional meetings SANAC Civil Society Forum representatives were not invited to this event and neither did TAC and Section 27 participate jointly in any of SANAC Civil Society Forums meetings with PEPFAR.

SANAC Civil Society Forum votes and appoints representatives for this regional meetings, in this case five representatives. However, TAC and Section 27 pushed their own invitation into these meetings. Observing one of the meetings, I noted clear perplexity on the part of PEPFAR as there was strong verbal exchanges among the TAC and Section 27 participants with those appointed by SANAC. Each camp challenged the others legitimacy to represent the issues of people living with HIV in the PEPFAR resource prioritisation process. At the same time both camps called on PEPFAR to consider as a priority their issues presented. PEPFAR responded by giving both camps time and space to share their issues, concerns and engage in the process.

Cornwall & Coelho (2007:8) explore the question of community participation in decisions that directly impact them. They argue that first communities need to see themselves as citizens not beneficiaries or clients. This unfortunately as the research finds is not yet the case. PEPFAR sees the representatives of civil society and people living with HIV as beneficiaries. Participation does not only mean involvement in the sense of listening to the affected communities concerns but rather commitment from the programme implementers to ensuring an active engagement in implementation and monitoring of policies (Cornwall & Coelho, 2007:9).

A number of factors may intimidate communities from effective participation. These include lack of the technical knowledge and capacity to speak the same language of the programme implementers in technical jargon. It is the role of the programme implementers to provide support with mediation, training and coaching to enhance the communities' abilities to engage in the programme decisions. (Cornwall & Coelho, 2007:13).

As I observed during the PEPFAR processes, other international civil society organisations were present to assist local and community based organisations and civil society organisations to engage. There was greater success in getting a commitment from PEPFAR to act on suggestions raised by the civil society organisations than where local communities or civil society organisations worked alone. For example, one representative notes;

> they want to hold people by the hands and keep saying there is no sufficient capacity in organizations on the ground, but we know the issues, we are just speaking a different language but talking of the same thing, to them we can't speak their language, we can't speak properly. (REP3)

Intersecting with representation, Cornwall and Coelho (2007) raise the difficult question of who civil society represent when they speak on citizens' behalf and the tension on the sources of legitimacy of authorisation where civil society claim to speak on citizens behalf. Inclusion is a key element in ensuring that those traditionally under represented and the left behind and outside are included. This is required if the representation is to be real rather than simply mediation (Cornwall and Coelho 2007:15).

Arnstein (1969:2) presents a ladder analogy of citizen participation. The highest rungs in her ladder are occupied by an empowered citizenry that is able to bring about significant social changes, change the status quo, affect the outcomes of decisions and processes and share the benefits of the society in which they live. Her key argument is that for participation to be meaningful, it needs to bring about power redistribution to the affected and involve them in the monitoring and implementation of programmes that directly impact them. A further application of this ladder of participation will be done in the findings of the research study in trying to explain the perceptions of participation of civil society organisation in the PEPFAR case in South Africa.

Arnstein (1969:2) highlights eight types of participation and 'non-participation', namely manipulation, therapy, informing, consultation, placation, partnership, delegated power and citizen control. 'Manipulation' and 'therapy', according to Arnstein's (1969:4) analysis, are effectively forms of non-participation. On this step of the ladder, citizens are simply engaged or included merely to rubberstamp decisions and positions, with the real aim to educate the participants (Arnstein 1969:4). This theory of 'manipulation' and 'therapy' can be used to describe the nature of past engagements and consultations with civil society organisations in the PEPFAR COP resource prioritisation process.

According to Arnstein's (1969:6) argument, the 'consultation' and 'informing' rungs of the ladder are usually played out in the forms of public hearings, perception surveys and other public forums where citizen's views are actually listened to and heard, but hardly taken on board in the decision-making of the powerful. This results in the very few changes to the status quo. In this research study, a lot of the interviewee's alluded to seeing few changes in the status quo and perceived the process by PEPFAR as a rubber stamping mechanism where they are listened to but not taken into account translating to real changes.

The ‘informing’ rung of the ladder in Arnstein’s (1969:7) opinion is followed by ‘placation’, where she claims the marginalised and powerless play advisory roles and are recognised and given advisory seats in key committees and decision-making processes, but still the powerholders retain the right to decide. While the have-nots are placed in such positions, they have little technical capacity to put across and negotiate their priorities, as well as mobilise their communities for support.

The next level up is that of ‘partnership’. This enables the have-nots to negotiate and engage in trade-offs with power holders. In the two top levels of ‘delegated power’ and ‘citizen control’, citizens make the majority of the decisions (Arnstein, 1969:3). It is the ideal rung of citizen engagement as the affected communities are able to make the decisions that impact their lives. As illustrated in the findings of this research, PEPFAR and people living with HIV are far from the partnership level.

Arnstein’s (1969) analysis may be seen as over-simplified, where often in reality, as the findings of this research show, participation is a more complex process than a simple step process and categorisation of participation and representation or lack thereof. It is difficult to categorise the ‘rung’ of the ladder in which civil society engagement in the PEPFAR process falls but certainly as the findings chapter will show, it has only moved from the manipulation and therapy rungs to consultation phases and is definitely far from reaching the partnership rung.

Adding a voice on participation in addition to Arnstein, Wainwright (2002) documents a number of case studies focusing on activism and diverse movements of citizens who have taken responsibility for democracy themselves. Amid failing systems, poor service delivery, corruption and privatisation and lack of political will from politicians, through a combination of political parties, community movements and active trade unions, Wainwright (2002) overall portrays how local citizens begin to establish new forms of democracy aimed at transforming the aspects of the state susceptible to public pressure and making it more accountable.

In Porto Alegre, Brazil, Wainwright (2002) documents how the Brazilian Workers party born out of popular struggle against dictatorship engaged in direct forms of participation to bring the state under democratic control and exert bargaining power in dealing with the market. Municipal financing processes were opened up by government for public participation. The

public was invited to participate in decisions on investments, by sharing the decision-making power, with citizens deciding on priorities including managing financial difficulties. Transparent processes were held through annual assemblies, budget councilors and community coordinators were elected regular meetings and people's plenaries held throughout the year. The case highlights that solutions are found from those who suffer the inefficiencies of the government systems and that power can be shared with the public (Wainwright, 2002:31).

While Wainwright's research focuses more on local participatory actions, her conclusions are similar to that of Arnstein and resonate with the findings of this research that successful participation depends on state in this case the PEPFAR's willingness to share power and state resources, as well as commitment and transparency. She notes that community social actions and movements and resistance will have little lasting resonance if it cannot harness the powers and resources of the state in order to secure a fairer redistribution of resources, both worldwide and locally (Wainwright, 2002:36).

Botes and Van Rensburg (2000) bring a different dimension to Arnstein's arguments though this time located in the context of the development agenda and in South Africa have written on community participation highlighting what they call the nine plagues and offering what they call twelve commandments as solutions. It is interesting to relate their arguments to the findings on this research which are also located in the same context and paradigm of donor programme engagement with communities as opposed to the Arnstein's analogy based on citizen participation in the United States.

First of all, they argue that the fact that the majority of development programme are initiated by outsiders and not the communities themselves is problematic (Botes and Van Rensburg, 2000:42). They further push against the 'development experts' idea of them knowing what is best for the communities and the assumptions that the communities do not know how to resolve their problems, in the process undervaluing the capacities and knowledge of the local communities.

They assert that in most cases participation only begins way after the programme have already been designed and decisions have been made, and questions strongly the motives behind a dressed-up participation that only seeks to validate and legitimise the decisions already made (Botes and Van Rensburg, 2000:42). In the research interviews, there was common reference

to them and us, with us being the communities who know the issues but who feel they are not respected or listened to. For example, one responded strongly asserted:

> Previously on the COP, they [PEPFAR]wouldn't even come to the Civil Society Forum, ….relations have improved but they are not as meaningful as we want them to be so now we now say we want to deepen this thing, … people should not come with their priorities and say no this is what we want to see happen yari ya! So yeah, that's really where we are moving toward to, there must be meaningful engagement between PEPFAR and civil society in South Africa. (REP7)

Secondly, for Botes and Van Rensburg (2000) representation of civil society of communities which they call self- selecting representation perpetuates the already existing challenges that NGOs that are not well rooted in communities since they are not democratically elected, their representation does not reflect the issues and the needs of the communities as they are self-appointed and may already be co-opted into the agenda of the programme implementers. For them this is a problem because "the needs and issues at stake are determined by the people who do not experience poverty in society." (Botes and Van Rensburg, 2000:46)

2.2.4 Civil Society Organisations

It is important to understand the concept of civil society and its foundations in modern democratic theory. While much of the literature available speaks to civil society in relation to state, as a tool for checks and balances and watchdog of the state, this research rather dwells on the internal dynamics of democracy within civil society itself.

Keane (1988:35) and others show how civil society was originally envisaged as the form of organised society that emerges when people in the state of nature decide to form a state. Their view of the rights of citizens was informed by whether they thought life in the state of nature was good or bad. If it was good, the role of the state was to preserve natural freedoms, now adding further conveniences. If it was bad, the state needed to be more authoritarian. Later, civil society emerged as an intermediary layer of associations between citizens and the state or as an autonomous space outside the state. Locke (1681), Paine (1776)

For Hegel in Pelczynski (1984) civil society associations helped to unify an atomised society, for Mill (1861) and Tocqueville (1873) they played an educative role, for still others civil

society served as a check and balance on the state. More recently social justice activists have conceived of it as a space of popular movement mobilisation. They see it as an organised space of struggle against governments and states and have shifted the focus to take on the social justice concerns of rights, justice and equality where government fails to deliver and holds governments to account. Lately, there has been wide space for the involvement of civil society engagement in policy making and decision making.

In their most recent definition, PEPFAR (2018:69) expands their definition of civil society to specifically also include,

> international nongovernmental organisations in addition to local organisations, traditional health practitioners, community elders and leaders, networks/coalitions; religious and faith-based groups; professional associations; activist and advocacy groups, including those representing key and priority populations; organisations representing PLHIV; human rights groups; women's rights groups; youth organisations; access to justice and rule of law groups; groups representing other populations highly affected by the epidemic, such as persons with disabilities and woman and girls; PEPFAR programme beneficiaries or end users; community associations; and champions of data-driven decision-making.

2.3 Key Arguments on Civil Society and Representation

Houtzager and Lavalle (2010:3) raise similar questions as Cornwall and Coelho as well as the research questions of this report that is, "on what basis can civil society actors such as neighborhood associations, urban movements, or advocacy non-governmental organisations (NGOs) claim to represent a "constituency"? What gives these civil society representatives the authority to engage in public decision making, and how and by whom, are they held accountable for their decisions?

In response to the criticism on the lack of authorisation and accountability of civil society organisations, they argue that civil society representatives are no less accountable and responsive than the traditionally accepted representatives of citizen participation, a claim that this proposed research will further try to test. Houtzager and Lavalle (2010:4)

In their study, Houtzager and Lavalle (2010:1), they argue that civil society organisations assume representation in their public interest advocacy or lobby on behalf of specific marginalised social groups, as most of the civil society organisations they studied lacked formal

members or constituents and did not select their leaders through elections and there was lack of mechanisms for the constituents to authorise and hold accountable their representatives. In particular, while they acknowledge some form of authorisation might exist, they question the democratic legitimacy of this is contested and institutionalisation especially in the absence of law limited. Houtzager and Lavalle (2010:4)

However, they also note that representation in civil society is distinct to the traditional representation and thus must be explored on its own terms (Houtzager and Lavalle 2010:3). I argue that they contradict themselves when at the same time they assert that, " in the absence of widely accepted and institutionalised mechanisms for authorising civil society representation, our focus is on representative's subjective commitment to the people they represent, rather than on institutional mechanism of authorisation." In other words, commitment to the represented is more important and this is more prevalent in the civil society organisations than the traditional forms of representation. Houtzager and Lavalle (2010:3).

They agree there is no satisfactory criteria to assess whether civil society organisations are effective representatives or not. Houtzager and Lavalle (2010:3). In this case, only authorisation applies as a strong argument, for which this research found there was both authorisation and assumed representation. If we are to allow for the distinctiveness of the representation in civil society, I agree with Houtzager and Lavalle that it has to be explored in its own terms.

In this report, I demonstrate that there was both authorisation and delegation through voting and elections as well as assumed representation and such a situation Houtzager and Lavalle do not address despite their acknowledging that some evidence of forms of authorisation exists. Given that they also agree that the traditional representation is no less accountable than that of civil society, is it safe to argue indeed that while they are not comparable, representation in civil society should be allowed to take a life of its own. Houtzager and Lavalle (2010:4). The weakness that I identified in the study of Houtzager and Lavalle is that it is an either or situation. Applying their arguments to the findings of their study makes sense but unfortunately some of it does not apply and can be questionable to this particular research study as will be shown in the following section when their six notions of representation are applied and compared to this research study.

Houtzager and Lavalle's study (2010) identifies and discusses six notions of assumed representation; electoral, membership, identity, proximity, mediation and service.

First, the electoral notion they argue, "offers a formal procedural argument for establishing its legitimacy- the procedure is the selection of organisation leaders through elections." In their study they found four percent of civil society organisations in Sao Paulo acknowledged that, "the existence of electoral mechanisms for selecting leaders is evidence of the actor's representativeness" (Houtzager and Lavalle 2010:19). This research study surprisingly found that six of the nine representatives of civil society organisations were formally elected in elections run by the Independent Electoral Commission of South Africa as described in the earlier chapter on SANAC Civil Society Forum.

This research study also found one was a volunteer and two were working with membership based organisations in which they also formally elected in their roles within the organisation. This surprising large number of formally elected representatives is not anticipated or discussed in Houtzager and Lavalles study, particularly the presence of an independent external election commission. I agree with their argument on election as a mechanism for authorization. However, I question their either or approach which cannot be applied to this study. This study found both authorised and assumed representation by their definitions but not one or the other.

The second notion of representation that Houtzager and Lavalle discusses is membership. This notion they argue is, "based on the argument that the creation of the organisation, by its members, simultaneously establishes the interests to be represented." In their study, seven percent of the civil society organisations make this claim and it is interesting that none of them were community based organisations but that coordinators of interest groups. Houtzager and Lavalle (2010:19). In this study only two of the nine representatives made this claim and these were community based organisations. So again, while I agree to their membership arguments, the conclusions of their study and arguments cannot be generalised as again they do not match with the findings of this study.

Thirdly, they discuss the notion of identity that argues that the,

> resemblance or substantive attributes of the representatives and the represented is the basis of the identity notion of representation. Civil organisations which make this argument suggest the substantive likeness of the leadership and the represented ensures

> that the interests of the latter are known by the former and will be faithfully represented because of their shared interests. Houtzager and Lavalle (2010:19).

In this research study, identity was strongly alluded to. While the research study did not require the participants to disclose their HIV status or gender identity, the participants spoke of constituents that they represented who were living with HIV, women or LGBTI. I agree with Houtzager and Lavalle who argue this identity notion eliminates the accountability mechanism as it removes the differences between the representatives and the represented. In the study of Houtzager and Lavalle, only five percent made this claim Houtzager and Lavalle (2010:19). In this study almost all the nine civil society organisations made this claim and one can argue is a strong basis of authorisation on its own in the sense of the representatives having the lived experiences of the issues of which they saw themselves speaking on behalf of other people like themselves. In this sense, Houtzager and Lavalle's study falls short and cannot be compared to this research study.

The fourth notion that Houtzager and Lavalle discusses is that of proximity. They note, "actors point to their solidarity with the represented, as signaled by their physical closeness to and horizontally of relations with the represented public." Houtzager and Lavalle (2010:20). To a large extent, I agree with their argument that proximity can be favourable to accountability between the representatives and the representatives. In their study, Houtzager and Lavalle found only 20% made the proximity argument. Houtzager and Lavalle (2010:21). In this research study, only two out of the nine representatives made the proximity claim and is the basis as highlighted in the introduction of the contentions of the legitimacy of representation between TAC, Section 27 and the rest of the civil society organisations represented through the SANAC Civil Society Forum. This study found that the "Peoples COP" document summarising the needs and the issues of the people living with HIV to be taken into account by PEPFAR has stronger influence. It is referred to in the final PEPFAR Strategic document as useful and impactful and most of the issues raised in this document translated into real changes in terms of shifts of resources to priorities identified in the document.

The fifth notion that Houtzager and Lavalle (2010:21) discusses is that of mediation largely made by advocacy groups and civil society organisations. They argue the notion is the least authorised and lacks accountability mechanisms as the representative make claims on behalf of the represented purely based on their capacity to do so. In particular, the ability to provide

access to the decision makers by the affected communities who would otherwise have no access is what gives the mediator legitimacy. “It does not focus on the actors’ relationship with the represented but on its locus of representation Houtzager and Lavalle (2010:21). Again I am skeptical of applying this analysis to this particular research study as the characteristics of the organisations of the research participants are both advocacy groups at the same time they are also networks of people living with HIV that closely relate to the identity argument that the mediation argument. The characteristics of the participants’ organisations are further defined in the findings chapter.

The last notion presented by Houtzager and Lavalle is that of service, which speaks to the legitimacy of representativeness based on the commitment to the interests of the represented through provision of services Houtzager and Lavalle (2010:21). While they do not provide figures of how many of their study participants shared this notion, this research study found that all the nine representatives had a strong component of service delivery.

Moving from Houtzager and Lavalle’s arguments for civil society representation, some scholars are more skeptical. Writing on civil society and participatory policy making in South Africa, Buccus and Hicks (2011:113) identified some of the gaps and research opportunities on the issues of participation and representation in South Africa. They strongly question the notion of civil society organisations speaking up on behalf of citizens and see representation as a merely being ‘dressed up’ as participation. They note that, “policy making is primarily reduced to participation by the elite, organised civil society in the form of predominantly non-governmental organisations and business and other interest groups with access to resources.” (Buccus and Hicks, 2011: 101). These civil society organisations often bypass, or fail to connect with the much broader grassroots sector of community based organisations which they often purport to represent (Buccus and Hicks, 2011: 101).

Buccus and Hicks (2011:113) argue that, “organised CSOs often dominate the policy processes where there is space for civil society to engage, and community based organisations (CBOs) often characterised by a lack of resources fail to influence these processes and it is worse for women’s and children’s groups as the process tends to be dominated by men.”

Della Porta (2009:3) is not convinced about democratic practices within civil society. In a combination of studies on democracy in social movements, she argues that there is some level of lack of recognition or will to practice those same democratic values in their internal organisation.

2.4 Conclusion

The literature reviewed agrees with my initial research statement that the representation system operative in civil society is assumed, it is elite as it only involve the savvy networks at the national level interested in pushing their own agenda, lacking authorisation, accountability, responsiveness and therefore are not democratic.

The focus of the literature review was on the concept of representation. In addition, the literature on participation was also reviewed in details in particular; Arnstein's, Cornwall's and Coelho and Botes' and Van Rensburg's works on participation and the interface with representation.

Overall, the research study and analysis while agrees with the overall definitions and the arguments that civil society representation cannot be compared to the traditional forms of representation, I disagree with Houtzager and Lavalle's (2010) assumed six notions of civil society representation assertions. I found them simplistic and not generalizable to this particular study due to the differences in the characteristics of the participants' studies. The most notable weakness of their study is that it is either you are authorised and accountable or you are not. This research study found a lot of grey areas which was difficult to compare to and apply to their study.

CHAPTER 3: METHODOLOGY

3.1 Introduction

This chapter provides an overview of the methodology used in conducting the research. The research study was conducted using mixed methods. It employed a questionnaire and used structured in-depth interviews, as well as observations to collect data. Thematic analysis was used analyse and interpret the findings from the interviews. The study setting was South Africa and all interviews were conducted between November 2017 and February 2018. However, observation of some of the meetings has been on-going since February 2016.

3.2 Study Population

The main study population of this research were key representatives of the civil society organisations and community groups working in the HIV response in South Africa that engage in the PEPFAR resource prioritisation process. The research identified at least ten assumed representatives of these civil society organisations that 'represent' communities of people living with HIV either in advocacy or service delivery and interact or work closely with PEPFAR at the national or community level directly or indirectly.

Organisations selected all had head offices based in Johannesburg or Pretoria and came from organisations that are part of the SANAC Civil Society Forum as well as those outside of the SANAC Civil Society Forum engaging with PEPFAR. For example, the National Association of People living with HIV (NAPWA), Show Me Your Number, South Africa Positive Women Ambassadors (SAPWA), Positive Women's Network (PWN), SANAC Civil Society Forum Chairperson (also working for Access Chapter 2), Treatment Action Campaign (TAC), Section 27, South African Network of Religious Leaders Living with HIV (SANERELA), LGBTI Centre Helpline and PEPFAR Country Office personnel. All participants gave their signed consent and were willing to be recorded except the PEPFAR personnel who opted to be off record due to the sensitive nature of the research.

In-depth interviews were only conducted with ten participants only because it is an acceptable sample size number to reach saturation within qualitative research literature. The concept of saturation, refers to "the point when new data produce little or new information". This is "the

well accepted standard by which sample sizes for qualitative enquiry are determined." (Guest et al. 2006; Guest and McQueen 2008 in Emily Namey, 2017). According to this argument, the first five to six in-depth interviews produce the majority of new data and approximately 80% to 92% of concepts are identified within the first ten interviews, as outlined in Table 2 below (Guest et al et al, 2016 in Emily Namey (2017)

This is illustrated in a systematic inductive thematic analysis of 60 in-depth interviews among female sex workers in West Africa conducted by Guest et al. (2006), as shown in Table 1 below. Of the 114 themes identified in the entire dataset, 80 (70%) turned up in the first six interviews, and 100 themes (92%) were identified within the first 12 interviews. Additionally, those 100 themes comprised 97% of the most common highest prevalence themes, indicating that the big ones were evidently early on. As such the choice of ten participants is acceptable and justified. I reached saturation at around the sixth interview, it was the same information repeated by different participants.

Table 1: Summary of Saturation Finding from Empirical Studies adapted from Guest et al. 2016 in Emily Namey (2017)

Study authors	**Saturation definition**	**Findings**
Individual interviews		
Morgan and colleagues (2002)	Not identified	• Five to six interviews for most concepts • In all four sets of interviews, approximately 80-92% of concepts identified within 10 interviews (extrapolated from reported data)
Guest et al. 2006	The proportion of identified themes at a given point in analysis divided by the total number of themes identified in that analysis	• six interviews to reach 70% saturation • 12 interviews to reach 92% saturation
France et al. (2010) (gated)	The point, after conducting ten interviews, when three additional interviews yield no new themes	• Most themes in both studies identified within five to six interviews • Saturation reached within 17 interviews in one study, and not reached within 14 interviews in a second study

Coenen et al. (2012) (gated)	The point at which linking concepts from two consecutive focus groups or individual interviews reveals no additional second-level categories	• Inductive approach: 13 interviews to reach saturation • Deductive approach: eight interviews to reach saturation
Hagaman and Wutich (2016) (gated)	The number of interviews required to identify the most common themes in a total of three interviews	• Less than 16 interviews at site level • 20-40 interviews to identify cross-cultural meta-themes
Namey et al. (2016)	The proportion of identified themes at a given point in analysis divided by the total number of themes identified in that analysis	At the median: • eight interviews to reach 80% saturation (range 5-11) • 16 interviews to reach 90% saturation (range 11-26)

3.3 Sampling

According to Guest (2015) the credibility and usefulness of research and evaluation findings are inextricably connected to how participants are selected through sampling.

Purposive sampling, sometimes also called purposeful sampling, is a process of selecting interviewees who are intended to generate the appropriate data for the research objectives. "The logic and power of purposeful sampling lies in selecting in formation-rich cases for study in depth. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the research, thus the term purposeful sampling," notes Patton (1990:169).

Since the study population was not statistically large, I used the purposive sampling method, with research participants not randomly selected, aiming for maximum variation by identifying a broad spectrum of organisational representatives sharing similar characteristics which met the objectives of the research. As such, the sample unit were civil society organisations representatives that engage with the PEPFAR resource prioritisation process.

According to Patton (1990:172) the maximum variation strategy for purposeful sampling aims to capture and describe the key themes or outcomes that cut across the variation of participants and programmes. He cautions that for small samples there may be a great deal of heterogeneity, which may be a problem, because individual cases are so different from one another. However,

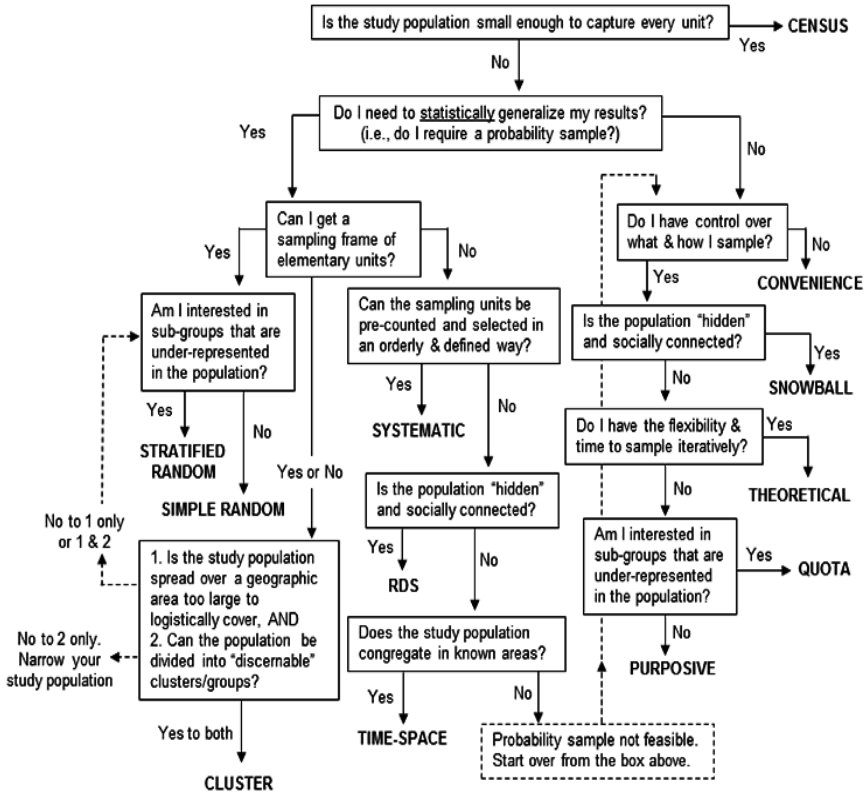
this apparent weakness can be transformed into a strength, by following the logic that common patterns that emerge from great variation are of particular interest and value to the research findings, as they capture "the core experience and central, shared aspects or impacts of a programme." (Patton, 1990:172)

As such, for this research, I purposively sampled directors and/or persons responsible for advocacy (policy entrepreneurs) from civil society organisations or networks of people living with HIV that have policy dialogue functions and regular contact with policy makers, such as PEPFAR, and who generally already have representative functions on behalf of their organisations in key meetings or consultations. In other words, the individuals generally are entrusted as representatives of their organisations to key meetings and functions and do speak 'legitimately' on behalf of their organisations were part of the study population.

Primarily characteristics such as gender, nationality, race and other such characteristics were not used in sampling, as it was difficult to predict these in the correct target participants and focusing on these may have limited getting suitable participants for the study. Rather, selection was based on the characteristics and objectives of the study. For example, some key inclusion criteria characteristics included being representatives of civil society organisations or community based organisations, those representing organisations working with people living with HIV with components of both advocacy and service delivery in their work, representatives that engage with PEPFAR on a regular basis and had claims to represent communities of people living with HIV in their engagements.

The figure below from Guest (2015) summarises the process as described, which I followed to arrive at the purposive sampling technique.

Figure 2: Sampling Decision Tree (Guest, 2015)



Once the study sample participants had been selected, the ease of gaining access and conducting the interview varied among participants. Entry to the core assumed representatives was facilitated by one of the leaders of the SANAC Civil Society Forum at one of the initial PEPFAR consultation meetings with civil society organisations, which I attended to observe and establish rapport with potential participants of the research study. In some cases, I did some cold-calling to reach participants. As Green and Thorogood (2004:95) note, the most difficult interviews are those where one has to cold-call the participants. In my case, they were suspicious of the motives of the study given existing tensions among civil society organisation but soon became more responsive.

3.4 Data collection

Data was collected and analysed from both primary and secondary sources. I developed and personally administered a questionnaire as well as a structured in-depth interview tool with the primary sources. An in-depth interview tool "schedules the kind of data produced quite tightly flowing a specific set of questions in a specified order for each interview to generate comparable answers from each respondent," according to Green and Thorogood (2004:80).

The interview is the most widely used method in qualitative research. Green and Thorogood (2004:80) describe the interview as "a conversation that is directed, more or less, towards the researchers' particular needs for data." With consent of the participants, in a setting based on the interviewees' choice and comfort, the interviews were recorded and transcribed and analysed by thematic content. Secondary sources consulted were newspapers, reports of the various organisations involved in this research, journal articles and books on the subject matter, as well as previous research.

While in-depth interviews are seen only to provide access to what people say and not their actions, interview data can be valid so long as the interview is treated as a contextual account (Green and Thorogood, 2004:87). As such, in the analysis of the in-depth interviews, I looked beyond what the interview participants stated and analysed the issues in the context of South Africa and the environment within which civil society work. To improve the validity and the reliability of the data analysed, the interviews were recorded so that they could be transcribed for better use and reference (Green and Thorogood, 2004:100). All the interviewees agreed to be recorded except one who preferred to speak off the record.

It is important to note that the language used for data collection was English as I am not South African and do not share the same common first language. However, this did not in any way affect the understanding and results of the interviews as all interviewees were fluent in English. Another important aspect to be taken into consideration is that although not a South African national, I have lived and worked in South Africa for the past five years.

To ensure that the questions in the interviews are clear and easy to understand, the researcher tested the interview questions with at least two individuals from organisations that were not formally part of the study. This was also to measure the amount of time the interview takes and correct any potential and possible problems that could impact the quality of the interviews.

I also observed a number of interactions and participated in meetings and engagements between PEPFAR and civil society organisations. According to Green and Thorogood (2004:94), "if the aim is to gather the less official accounts of, for instance, how policy is made or implemented, methods other than in-depth interviewing may be needed, such as observations of meetings."

Qualitative and quantitative methods were used to triangulate the study findings, since the research population is small. The qualitative method specifically ensures that all views and different perspectives are taken into account and analysed, as well as giving an in-depth understanding of the relationship between the variables and answering the whys of the research question. However, to better collect data on the nature of the organisations and persons interviewed, a short questionnaire, which accompanied the interview, to capture characteristics and other aspects of the sample was administered to complement the qualitative information collected for a comprehensive analysis and understanding of the proposed research topic.

3.5 Ethical Considerations

For ethical consideration purposes, I distributed and obtained a written informed consent from the interviewees and organisations to give permission for interview responses, reports and other information to be used for the purposes of this study. In addition, I declared no conflict of personal interests that could cause some bias towards the results, other than academic pursuits, resulting from this study. I clearly explained to the respondents the confidentiality of the interviews or questionnaires and that results would be anonymous and that the identity or source of views would not be attributed to any names of the participants. I used the REP (for representation) code to attribute quotes to participants in the analysis.

However, due to the nature of the work of the participants, it is possible that they could be identified through the analysis of this study. To minimise these risks, unless with the permission of the participants, the names and organisations, or suggestions of locations and mention of specific consultations and meetings were not attributed to in the analysis and written account of the research results. Copies of the ethics approval, as well as information sheets about the study, were provided to all participants to read before the interview to keep in order to revisit after the interviews.

3.6 Data Analysis

The primary data collected through interviews and a short questionnaire were analysed through a thematic analysis to focus on key and emerging themes and responses that form the basis of analysis of the study. The use of content analysis enhances the reliability and validity of research since it can easily be replicated by other researchers from the raw data (Burnham 2008:259).

Keeping in mind the research questions, three main coding categories were developed, namely: What and who gives civil society authority to speak on the citizens' behalf when they engage with GHI's resource prioritisation agenda? How are they held accountable? How internally democratic are civil society organisations participating in PEPFAR's resource prioritisation processes? This was done with the aim of identifying popular themes and issues as well as to help organise, structure and present the results of the analysis of the in-depth interviews.

Following the categorisation of the research questions, the main codes for analysis were civil society's perceptions of representation, accountability and responsiveness and lastly, participation and engagement. Under each of these categories, further sub-coding was developed to identify the popular themes. For example, under perceptions of representation, further sub-codes such as constituents, delegation or authorisation and recognition were further developed. In addition, under internal democracy, accountability mechanisms, accountability structures and responsiveness were further developed. Lastly, under participation, additional sub-codes such as consultations, engagement with the masses, resources, influence and advocacy were used. Race was one of the most common and popular themes that emerged, while not falling under the three main themes.

3.7 Conclusion

Without yet discussing findings and results, this chapter started with an overview of the study population, outlining how they were sampled and selected, as well as describing the semi-structured questionnaire and in-depth interviews used for data collection. The section reviewed ethical considerations including how consent to participate in the studies was obtained and concluded with an overview of how the data was analysed and interpreted which leads to the next chapter, which discusses the findings of the research.

In brief, a mixed method was used employing a short questionnaire and in-depth structured interviews. In some cases, I observed some meetings and engagement processes between PEPFAR and civil society organisations. Using a purposive sampling method, ten participants who 'represent' people living with HIV in participating in the PEPFAR's resource prioritisation processes were identified. Thematic content analysis was used to analyse the results and findings.

CHAPTER 4: FINDINGS AND RESULTS

4.1 Introduction

This chapter will outline the findings related to the overall research question which is: what and who gives civil society authority to speak on citizens' behalf when they engage with GHI's resource prioritisation agenda? How are they held accountable? How internally democratic are civil society organisations participating at national level PEPFAR's resource prioritisation processes in their engagement with the communities they stand for and represent?

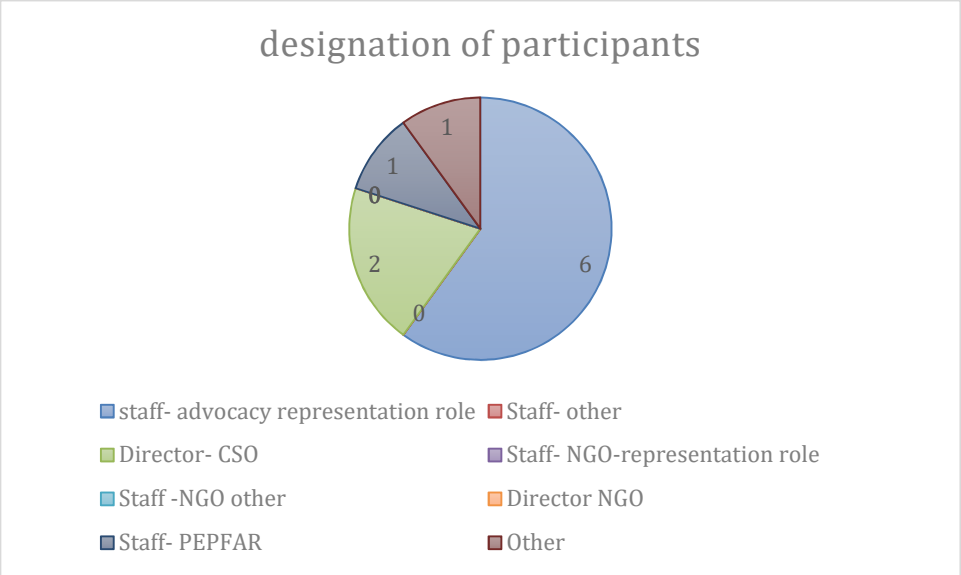
The results are divided into the three main themes around which the in-depth questions were structured, as well as those that emerged during the research interviews. The three main themes each entail further sub-themes, as defined in the previous chapter. The three main themes based on the categorization of the research questions are perceptions of representation by civil society organisations with further sub-themes of delegation, authorisation and recognition; internal democracy including accountability mechanisms and structures as well as responsiveness; and lastly, perceptions of participation and engagement.

Before proceeding to the analysis of the results, a brief overview analysis of the description and characteristics of the representatives interviewed and their organisations is presented below.

4.2 Description of the Role of the Interviewees in Civil Society Organisations

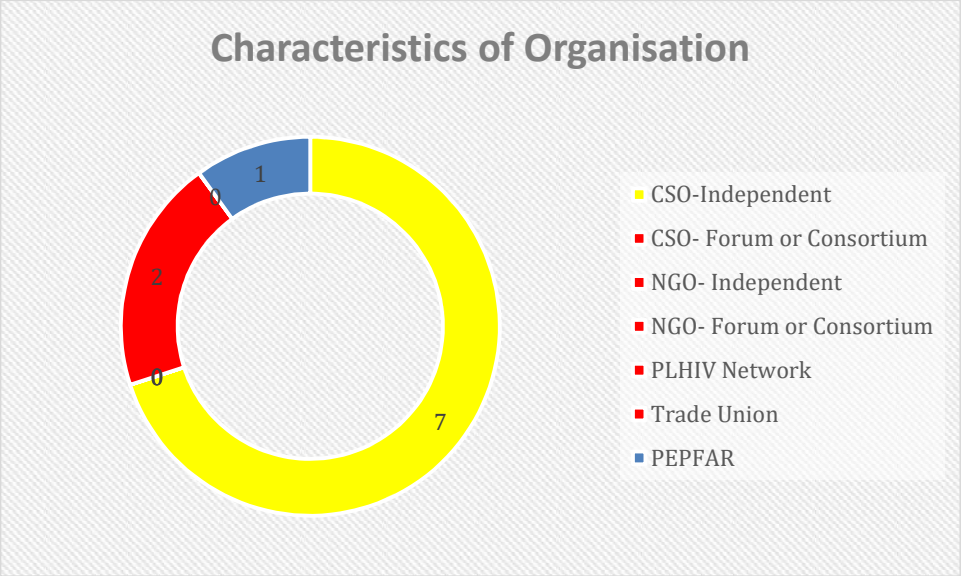
Eight of the nine civil society participants identified themselves as staff working with a civil society organisation in a capacity whose role engages and represents the issues of people living with HIV in policy processes. Two of these nine were working in a Director capacity of their organisations. One of the nine civil society representatives identified themselves as 'other'. When asked to explain, they said they were not a paid staff of any civil society organisation, but rather unpaid volunteers for a civil society organisation, also serving in a representation role and capacity.

Figure 3: Designation of Interviewees in Civil Society Organisations



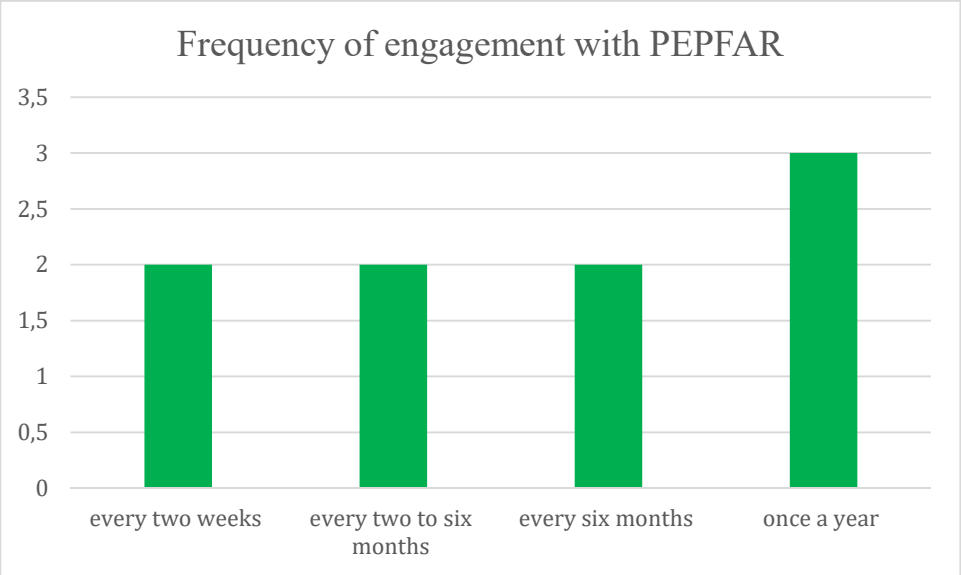
The majority of the research participants (seven out of ten) identified themselves as working for independent (as opposed to a consortium of) civil society organisations, with two out of ten working for networks of people living with HIV, and one for PEPFAR as illustrated in Figure 4 below.

Figure 4: Characteristics of Organisations



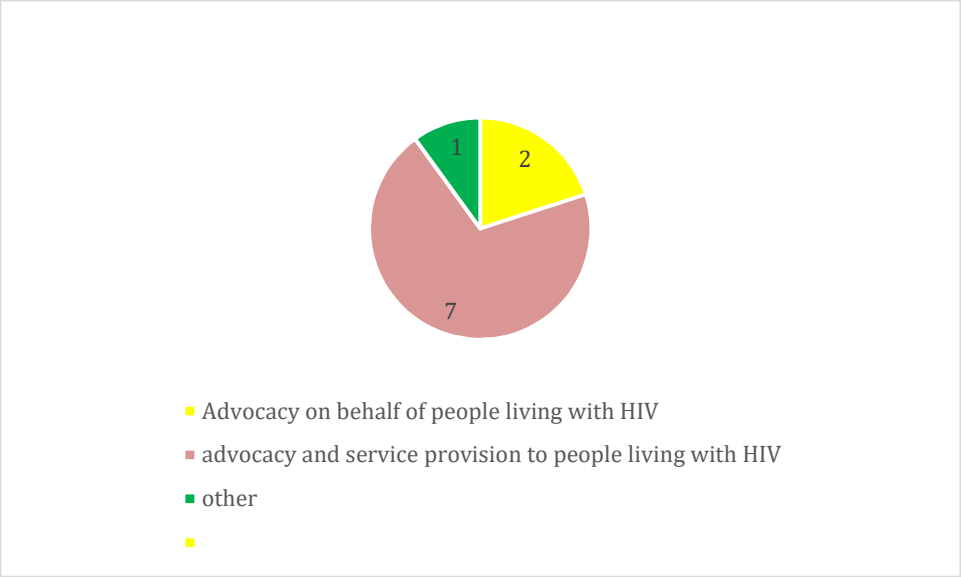
Three out of nine of the participants reported engaging with PEPFAR once a year, two out of the nine participants reported that they engage with PEPFAR every six months or at least twice a year, with another two reporting engagement at least once every two to three months and the remaining two engaged every two weeks as outlined in Figure 5 below. Those designated in Director role in Figure 3 above reported engagement with PEPFAR at least every two weeks.

Figure 5: Frequency of Engagement with PEPFAR



As shown in the pie below, seven of the participants worked in organisations that did both advocacy and service delivery, while about two were advocacy only organisations with one identified as other (working for PEPFAR)

Figure 6: Main Areas of Work/Focus Areas



4.3 Perceptions of Representation by Civil Society Organisations

The research found that the concept of representation was well understood and articulated by the participants in their own words. Weale (2007:133) argues that a representative is someone authorised to act for others, but he also agrees that someone can act on behalf of others' interests without being authorised or accountable to that person. All of these notions come out quite clearly in the understanding and perceptions of representation by the participants. The key words that were frequently used or that emerged in their own definitions as quoted below include 'voices', 'views', 'positions' and issues of the people being represented, in this case the people living with HIV.

Participants articulated their understanding as direct representatives of the affected communities. In one participant's words, they see representation as, "you're being basically the voice of the people you say you are representing, and you're just the vessel passing the message from the broader group of people to, in this case, to the COP meeting." (REP4)

Another participant noted that (REP2),

> you don't talk your own views, you share your own views as leaders and get the inputs or the views of the people you are leading. It could be that your views are not the priority of the people you are leading that is why it's important for us before we go to those meetings, we don't go to those meetings and represent our own views, we must go to those meetings and represent the views of those we are leading in this case, people

> living with HIV and our communities. So whatever we say, whatever we influence, whatever we lobby it's around the position and agenda of people living with HIV.

One of the interviewee's (REP6) defined representation that resonates with Weale's (2007) general definition, particularly with the understanding that one can act in the interest of another without being authorised or represented as follows:

> When we say we are representing people living with HIV, it means we are informed by the people living with HIV and you know we have major, major, organizations 'cause we got a lot of people living with HIV in the country because people living with HIV are organising in this case. For example, [mentions organisation] works directly with people living with HIV and knows the experience, tracks the experience and monitors engagements and livelihoods and that's what I mean by informed.

The participant elaborated that they may speak about an issue as a representative of PLHIV, even though they do not work on the specific issue that they are speaking about (REP6), as articulated below:

> If you have issues like drug stock out, I personally don't work on those issues or implement drug stock out programme and interventions, a particular organisation does that. So if my speech during the council meeting speaks to that, I have been informed by the work of my constituency and in this case, it will be people living with HIV. So this is why I am saying this issue of representations, it's not only having the PLHIV on the space but another person representing the issues in a process and structural manner by other people representing the issues.

The research analysis found that some of the participants alluded to directly representing organisation's views, as opposed to directly representing the views of the people living with HIV. Representatives delegated by the SANAC Civil Society Forum, expressed wider attachment and used the word 'sector' more than the 'people living with HIV'. For example, one participant argued that the concept of representation was about expressing their organisation's views or that of the sector collectively. "I come from [mentions sector], but through the [mentions sector], we form part a collective of the civil society so that representation, the basic unit is organizational and then bringing other voices to speak as a collective to speak on issues that we agree on" (REP5).

Another civil society representative (REP 2) asserted that,

> It's the voices of the sector that we are representing through consultations because you can't go to any platform, I will make an example as we are also serving in a multi-sectoral forum of sectors responding to HIV and STIs, for us as leadership of people living with HIV, like my organisation is also taking part there. That is my understanding of representing.

4.4 Delegation, Authorisation and Recognition

Asked if they think they do representation in their work on behalf of others, participants unanimously responded with a yes, citing that in the PEPFAR resource prioritisation plan for South Africa, all the views and inputs they presented and shared in the process and consultations represented those of the people living with HIV.

Almost all the participants strongly felt that these constituents know of their representation roles, by the fact that they were elected by those constituents into these roles. The election process is described in the introduction section on SANAC structures, the process starts at the local to the district and provincial AIDS Councils and finally to the national AIDS. However, of the nine civil society participants interviewed, about six were elected through this mechanism identified in SANAC while one representative was a volunteer and the other two were voted for and appointed by their membership organisations. To particularly engage in the PEPFAR processes, some of the research participants spoke of being appointed and delegated by the Civil Society Forum where they have already been voted for and elected by their sectors and through the local, district and provincial AIDS Councils.

Most of the participants felt that their constituents are aware of their roles and accept and validate them. All participants highlighted that they do consult with their sectors and constituents on what issues they have to raise before engaging in the PEPFAR resource prioritisation processes.

"I talk a lot about people living with HIV," said one of the participants who further highlighted that she was appointed and nominated by the PLHIV sector [meaning a group of elected representatives for people living with HIV] in SANAC Civil Society Forum.

> "I was voted into the representative role and capacity. They know I was appointed or nominated by the PLHIV Sector, [mentions name of previous representative] was representing PLHIV Sector on SANAC and then I was alternative when she was not there I was there, but now because [mentions confidential information], the sector said

> I had to replace [mentions person's name] on that position, so they voted, then my name comes up. The PLHIV Sector with all other Sectors of SANAC voted" (REP1).

For clarification, the sector is elected and voted for through the local, national and provincial AIDS Councils and are thereby mandated in the governance mechanism of SANAC to vote and nominate members to further represent the sector in particular issues and discussions.

Asked to give an example of how the consultation and interaction with the constituency's works internally with people living with HIV before such decisional meetings, one participants (REP4) stated,

> one of the issues is the condom issue, the female condom, that's one thing that young women are asking for the availability of it, the female condom, they were also asking me today on our WhatsApp group, talking of male condoms that the new ones are too small for their partners but I don't know how I am going to address that one and raise it up, and also PrEP, even myself I want it and they want it too.

However, not all are voted into the representative role, as the research analysis finds. There was some recognition among the participants of the internal gaps and weaknesses in how they carry out their work. Not all of them have a sector or a constituency of communities voting for them or delegating them into the official roles. As highlighted elsewhere previously, six of the nine representatives were elected and voted for while the other two assume representation by being appointed by their membership based organisations to represent their views with one also assuming representation as a volunteer.

One participant (REP4) firmly argued that she does not have to be voted or elected but assumes the notions of identity and mediation representation as discussed by Houtzager and Lavalle (2010):

> I do it because it's part of my voluntary work, but you must also understand that everyone, the young girls that we work with, it could have been any of us and so it depends on which position are you in at that time, are you able to represent all of us because it doesn't matter, other people represent me somewhere else if opportunity arises where you are at that time and space to take forward our views then that's okay.

In addition, another participant (REP5) defended the lack of delegation by arguing for the proximity notion of representation discussed by Houtzager and Lavalle (2010) that,

> [mentions name of organization] is a membership based organisation, which have a firsthand experience of issues and also always interacting with the communities almost on a daily basis, we know things through our members

> and our structures, the machine is always fed up, right up until the leadership of the organisation, then therefore we are very much informed based on the internal structures of the organisations, these are branch members chair persons forums, community dialogues, attending the nurses centers, sitting in the clinic committees, the local district and provincial and district AIDS Councils including SANAC .

Another representative (REP2) responded that although elected and voted to the SANAC Civil Society Forum, he is skeptical of the election and delegation arguments on representation. The participants further alludes to the fact that it does not matter whether you are elected or not, as long as the issues of the communities face are represented. In essence it is not a representation of the people but of the issues. He rather supports the argument made by Lavalle and Houtzager (2010:4) on the subjective commitment to the people they represent being more important than being elected or voted for as well as the mediation notion of representation. He notes and argued as does Houtzager and Lavalle that mediation is the weakest in terms of authorisation and delegation.

> Let me be honest with you, we have a challenge here in South Africa, neh. What I have said in responding to your questions, this is what we are supposed to do but we are not responding in the way we are supposed to do, reason because we lack coordination of this sector. At national level, we have about five organisations that are representing the PLHIV Sector [mentions the names of the sectors]. We are at the national level, our role is to engage with the provinces where we have leaders, before we go to the national meetings we must engage and get our mandate from our provinces [meaning community based organisations and networks of people living with HIV working at community and provincial levels] but it doesn't happen in most cases because we lack resources to convene teleconferences or go to the provinces to engage them. (REP2)

The research findings reveal some weak structures of accountability and responsiveness exist in the sense of lack of strong structural mechanism and spaces from which the represented constituents can hold accountable the representatives at the national level through the SANAC Civil Society Forum. Even within the organisations outside of the SANAC Civil Society Forum, some structures exist, though weak and not systematic.

What did not clearly emerge is what levels of delegation, authorisation, recognition as well as accountability occur at grassroots level, as the current structure, as the study found, is biased to only engage the elite urban based civil society organisations. Buccus and Hicks (2011: 103-

113) argue representation is merely dressed up as participation, done by the elites with little connection to the grassroots and communities

4.5 Internal Democracy: Accountability within CSOs, Mechanisms, Structures and Responsiveness

This section reports on the findings of the research on internal democracy in response to the research question how civil society organisations are held accountable and how internally democratic they are in engaging in the PEPFAR processes. Some of the questions that this section further explored included: how do civil society organisation engage and consult among themselves and with the affected people living with HIV, before engaging with the PEPFAR COP? What are the participation spaces that civil society has created within the institutions for communities and sectors to engage in the prioritisation of its resources, and what are the communities' perceptions of this participation space? And lastly, outside of the created spaces for engagement with civil society, how are/have civil society organisations applied pressure to amplify their demands regarding PEPFAR service delivery and priorities?

4.5.1 Accountability: Internal Structures and Mechanisms

Most of the representatives interviewed claimed that engagement (consulting the communities on the issues to raise in the policy engagement process) and feeding back to the communities is working well. However, the research analysis found that there exist weak accountability mechanisms and structures primarily with respect to how civil society are held accountable by the communities they represent. It was beyond the scope of the research to assess how the communities that the participants claim to represent themselves interpret and view the representation roles.

Civil society has structures and mechanisms to engage and interact with their communities but often lack resources and support to do so. Community dialogues, reports from the field, the daily presence of members on the ground, meetings, local and provincial AIDS Councils, branch structures and activities in the communities themselves, are some of the ways used to engage with grassroots organisations as well as people living with HIV. For example, one respondent (REP8) noted that,

> One of the participants notes that, [mentions name of organization] is a membership based organisation, which has a first-hand experience of issues and also always interacting with the communities almost on a daily basis. So we

> know things through our members and through our structures and that information is always fed up right to the leadership of the organisation then therefore, we are very much informed based on our internal systems, our structured internal systems of the organisation. These internal systems are the branch members, chairpersons' forum, through the community dialogues, attending the health centres, meetings with the teams, sitting in the clinic committees, the local district and provincial AIDS Councils including the national AIDS Council which is SANAC, so these are all our source of information and the basis on which we participate in the process.

One participant (REP1) reported that:

> Our members membership are the ones on the ground, they take that information and challenges and bring them to the office or write a report so end of the months we consolidate the reports and we see the challenges and we see how we are going to address….. every month we need to record successful stories, challenges and we need evidence… even take photos sometimes for the reports…

Another respondent (REP4):

> Basically, we use a WhatsApp group, basically we plan our lives and work, generally we are just going to discuss on a topic and get in depth about it. You know, you have to stay in the know on the current situation of what's going on around us you know because PrEP [HIV pre Exposure prophylaxis, a new drug available taken daily or at regular intervals to prevention HIV infection] is new, I have not always not known about it. Someone comes with a topic or whatever and we actually discuss it and if you have questions you actually post them.

Another participant (REP4) noted,

> With the Board, they do have structured meetings so they plan also of the direction its going and with us smaller people that actually do the work, we do have meetings but they are not often. I'm not going to lie, like I feel like it's a bit like technology is the way forward basically but I do have like sit ins you know like right now when I was coming here I did have sit ins with the girls and we actually discussed some of the issues they think that should be brought forward, so yeah and I still presented the case on the WhatsApp group for the people that weren't there.

I was able to get a rough picture of how the civil society representatives collected issues from the grassroots communities and fed them into the process, but it was not quite clear how they are held accountable by those communities, and how they engage and respond to the communities. The weakness also lies in the fact that civil society is diverse and heterogeneous

and if they do not fall under SANAC or the other structures of TAC or Section 27 and others. It is then safe to argue that there is a lack of inclusivity in the sense that it is not clear how then they are engaged and consulted

Here a participant attempts to describe how civil society is held accountable.

> Feedback from the national level representatives filters back to the communities through some structures as the AIDS Councils at the local, district, and ward and provincially, we disseminate the information to them so that they can take the information until the branch level. In some districts, they have got war rooms. War rooms is where we talk about the issues of that communities, all stakeholders, all organisations come together at that meeting so that, if there is issues of gender-based violence, we know the police are there, if there issues of health, we know the nurses are there, so it's a combination of a national and government stakeholders but they didn't launch in all provinces…" (REP1)

Yet on further probing and interrogation, some of the participants agree to the weaknesses internally. One participant described a formal electoral process:

> We work with an independent electoral body to run the elections [meaning elections of sector leaders nominated from the local, district and provincial AIDS Councils and Civil Society Forum representatives by SANAC], the last two elections was run internally in 2012 and later in 2017 the Forum felt the need to appoint an independent body to run the elections, and ICE was appointed. All Sector leaders are appointed in this manner (REP6).

Another respondent (REP4) noted weaknesses in the internal civil society consultations processes with their constituents,

> I feel like with the interactions, yeah I feel like if it was more structured, I am just thinking now how we would make it better, maybe like if there's a need for more face-to-face conversations, but the one challenge we normally have is not everyone is going to pitch up, so even if we do organise and there is this issue of venue, like I said there's no funding where are we actually meet up, like I said the last we met was at the beach, we were there for a specific cause to do some work. I'm just giving an example, there could be more improvements.

Another acknowledges that;

> The process [meaning internal consultation processes within civil society organisations] is not adequate, at the moment we are talking of internal processes, which is the national way of doing things, the process should be broader than that because [mentions name of the organisation] is just a drop in

> the ocean compared to the communities that are out there, due to shortages of resources we would have conducted community based consultations on the process itself but that is not happening (REP8).

In addition, referring to the interactions in one of the PEPFAR civil society meetings, one representatives notes,

> There was a horrible scene, where there is like power struggles and evident for everyone to see. I feel a bit uncomfortable. I feel like we are very old mature for that behavior. Also there is a lot of talks about who is supposed to be here and who is not supposed to be here as civil society and we are not looking at is that person or whatever raising the right kind of issues because at the end of the day it's about we are representing not about us so it's about is the person doing the job while they are here, so that's not being looked at. There is just a lot of fights basically and I am uncomfortable with it (REP3).

Finally, one participant argued,

> the civil society organisations are sector leaders, they need to take responsibility, yes, to make sure that the grassroots, organisations have this information [meaning information the representatives also receive from PEPFAR in their consultation meetings] in the right way and be assisted. We are not doing this well enough, the home-based carers are alone and not linked to the AIDS councils, not enough resources to link them to all the home-based carers and the AIDS Councils. I don't think we are doing justice. I think we need to do something. We need to make sure that civil society have enough resources that they have enough resources to go around because it will be easier. (REP1)

There is little literature available that analyses the rifts and divides of civil society. However, one publication by SANAC (2017:120-121) acknowledges the gaps and challenges, where it is noted that:

> One of the things that has happened in the last five or six years is that civil society itself has changed. The broader civil society of the country is not the same as that of 2012, precisely because of new social and economic currents. But these new movements are not part of SANAC. In fact, they are not even consulted by SANAC. For example, the trade union movement has split. New social movements have emerged. Look at the university students for example. ….So if civil society is erupting outside of SANAC, if there is a ferment of new ideas and organisations, the question is how does SANAC insert itself into that space?

The last two section have looked at the understanding of civil society organisations of the term representation as well as interrogated the internal accountability and responsiveness

mechanisms within civil society organisations. The next section presents the findings on the perceptions of civil society organisations on participation and representation.

4.5.2 Perception of the civil society's participation and representation

From PEPFAR's perspective, one respondent opting for anonymity said,

> It is not the intention of PEPFAR to divide CSOs, but want to know, can CSOs have a process of electing representatives into the process, is there something PEPFAR can do to support communication and engagement within CSOs so that both PEPFAR and CSOs can support and benefit from the process? Interest is to understand better the structures and processes for engagement to work with everyone and ensure the broadest scope of input [in a] difficult political environment, but have learnt how best to include community processes in the work of PEPFAR, to understand the internal processes so PEPFAR doesn't stumble in the work of engagement. How do we make things better in the end for the end-user [of services which is the patient [meaning people living with HIV]?

Most of the organisations interviewed felt that PEPFAR was doing well in consultations. They felt that there is an open-door policy and access to PEPFAR outside of the COP structures. However, the questionnaire reveals otherwise. The questionnaire shows that only 12% of the participants interacted every two weeks with PEPFAR at all given times. 25% interacted with PEPFAR every two to three months with another 25% only interacting every six months. The remaining 38% interacted with PEPFAR at least once a year only around the COP processes. The majority of the respondents felt that the communication and engagement was largely initiated by the civil society organisations although PEPFAR also reached out to them when they needed something.

Most of the representatives alluded to improved engagement with PEPFAR over time. For example REP8:

> Since COP 17, it is the first time that civil society have been extensively consulted, in the previous COPs civil society were overlooked, we were in the house but not necessarily recognised, our inputs were not taken into account and it was more a government and PPEFAR, only in COP 17 we saw civil society gaining voice in the space. So COP 18 is a different issue because we started the process in the provinces, that was happening for the first time but however we still feel that if the process can be driven through district to district and then provinces, it will give you a very deep understanding and analysis so that you better understanding the policies and the pitfalls (REP8).

Another put it thus:

> They are probably listening, the issues of Test and Treat [a WHO recommendation to immediately start people on treatment when tested HIV positive with their consent of course at least with seven days] and linkage to care, the issue of adherence clubs, they thumb suck that if they have adherence clubs, it's a gold standard but we seconded that we also need support groups and the issue of community health care workers. (REP 8)

Noting the improvements, one representative hoped for more:

> PEPFAR now is different from PEPFAR then, when [mentions name] what he did was to create, even if he doesn't agree with what we say he has subjected himself to the engagement, he has basically humbled himself to understand that there is a process. Previously on the COP, they wouldn't even come to the Civil Society Forum…. relations have improved but they are not as meaningful as we want them to be so now we now say we want to deepen this thing, … people should not come with their priorities and say no this is what we want to see happen yari ya! So yeah, that's really where we are moving toward to, there must be meaningful engagement between PEPFAR and civil society in South Africa. (REP7)

Some of the participants clearly noted that the process could be better. One representative argued:

> The consultations needs to be grassroots driven, a bottom up approach, ….the process is not there, the process is only focusing on the national which in a way there's is a lot of diluting of issues, you do not find the wholeness of issues … It's the bottom up approach that needs to be applied, not the helicopter view of things, the need analysis will be coming from below not at the national level because that is where they miss a lot of true information. PEPFAR needs to make available resources for such consultations to take place (REP8).

In terms of Arnstein's (1969) analysis of levels of civil society organisations, PEPFAR is far from the partnership rung of the ladder. That more needs to be done to get to that rung is implicit in the following plea from a civil society participant:

> We will be happy and then if PEPFAR can make sure that within the country everything that they are doing they also communicate with the SANAC civil society structures so that we can know that in district so and so these are the interventions that the partners of PEPFAR are doing then we are able to monitor the work that they are doing, it could be that there's something wrong that they are doing so we need to support each other, we need to respect each other, we need to keep constant communication among each other….. they must respect the autonomy of the small organisations but not impose their work (REP 2).

One could get the impression from REP3 that PEPFAR is still stuck on the manipulation stage.

> It feels restricted... it feels like we are being brushed aside by PEPFAR, tape is put on our mouths. They want to hold people by the hands and keep saying there is no sufficient capacity in organisation on the ground ….it sounds like they are listening but not really listening. Some issues, they keep repeating that they will do what we have said no to, it means we haven't been heard. For example, sexual gender-based violence is a big issue in South Africa, culturally you cannot give an HIV-positive woman a self-test to take to her husband, and you are asking for more of the violence we are trying to prevent (REP3).

In addition, REP 3 argued that they are not convinced PEPFAR is listening and that the process is made worse by the fact that PEPFAR contracts other agencies to implement their work which civil society have no access to so even if PEPFAR supposedly listens ultimately it's the implementing partners that will need to do the changes on the ground:

> When the implementing partners are not performing, it is difficult to talk to PEPFAR. They don't seem to be interested or willing to change, if you're not happy with the services and doors are closed, there's nothing we can discuss with the implementing partners, only in these meetings we feel heard.

Another representative (REP5) stated: "We don't want to be wheelbarrowed into a room, to make inputs on the COP when what is just been done is to tick a box that we have consulted and engaged with civil society but the things we say don't really matter so why waste our time?"

For the process to be really seen as meaningful from the civil society perspective, resource availability was identified as key to enable to engagement and participation, in effect echoing both Wanwright (2002) and Arnstein (1969).

Asked what meaningful engagement entails, one representative (REP5) argued:

> making resources available, we don't have a problem with PEPFAR funding these big guys, but we are saying make 1% of your total spent for civil society because that 1% coming from PEPFAR will enable us to increase our capacity to monitor what you're funding people to do because now people are getting lots of money but when we get to the ground, there is no impact and yet you give us reports to say there is work that needs to be done. We have seen that a lot of the PEPFAR partners are US based organisations that have set up base in South Africa so they are not South African organisations, they are not funding South African organisations but they are funding American organisations who then create some exploitative practices that ultimately undermines and kills

> civil society. Their money must not be a source of trouble, it must help to propel us forward, if it's a source of trouble but we don't need it, if the money is a problem then we are better off without it.

4.6 Race

Race was not considered as a characteristics or issue for consideration in the research. However, from the analysis of the in-depth interviews, there was frequent reference to race. Civil society feel undermined and not taken seriously by PEPFAR and alluded to their race being the reasons why they do not access resources.

Responding to the perceptions of the engagement process with PEPFAR and the issue of making resources available to civil society to ensure a meaningful engagement process, one participant argued (REP7):

> they do engage, but when it comes to addressing the gaps and challenges, we see the same privileged organisations implementing the programmes. AIDS is black, when we meet PEPFAR we tell them resources are allocated on racial grounds, but PEPFAR plays hide and seek with community grants. It's not only about money, it's investment in capacity building needed to be able to manage resources and implement.

Another participant (REP7) added:

> I will be honest, in the apartheid era, we had problems with the health system, the country is still divided into blacks and whites in this case, white civil society organisations with resources, offices, money they can call PEPFAR and put their agenda and black civil society organisations without resources who have to wait for PEPFAR to call them and it's difficult for PEPFAR to attend to all the groups, but it investing in the same privileged civil society organisations, leaving those lacking capacity. We are getting donations, we can't stop AIDS with donations, it is not a matter of jealousy, we must work together, and the rich organisations must adopt the small organisations and work with them. But what PEPFAR does is request others to attend to the black issues, those ones will get money and come and divide us with their money and we become their volunteers. We want PEPFAR to come to this building of poor black civil society organisations and say we hear you, we are going to build your capacity, exchange skills with the white civil society organisations.

4.7 Conclusion

Seven out of the nine participants interviewed were working for independent civil society organisation with two working for a network of people living with HIV and one staff of PEPFAR. Seven out of the nine were organisations engaged both in service delivery and advocacy. The study found there was little engagement outside of the PEPFAR prioritisation processes with only two of the participants engaging with PEPFAR every two weeks and another two, once every two to three months.

The study suggests that civil society engagement in the PEPFAR resource prioritisation was both assumed, and authorised and delegated as presented and argued in the earlier chapters by their constituents of people living with HIV. The engagement remains very elite with those in Director role engaging more often, while the majority did not interact with PEPFAR at all outside of the resource prioritisation process.

In addition, civil society representatives argued that their input has to a large extent not been taken on board by PEPFAR. The people living with HIV are not yet seen as partners in the engagement process, but rather as the group that needs to be present during the resource prioritization process for compliance reasons. Within civil society organisations, the study reveals little or no internal accountability, especially at provincial and district levels. There is also deep polarisation of civil society between the camps in their engagement in the process of those under the structures of SANAC and those outside of the SANAC structures.

CHAPTER 5: CONCLUSION

5.1 Introduction

The chapter draws overall conclusions from the research findings and considers their implications and impact on policy and practice, while identifying gaps for further research. This chapter also gives an overview of the limitations of the study and where applicable, how these noted limitations were addressed.

5.2 Limitations of the Study

The research consists of in-depth interviewing the key main individuals/organisations that have a central role in engaging with PEPFAR's resource prioritisation processes. The individuals may have biased perceptions of themselves and their organisation and this may affect the findings of the study (Lilleker, 2001: 1). In other words, issues of power manipulations may distort the reality.

> Interviews do provide insights into events about which we know little: the activities that take place out of the public or media gaze, behind closed doors. We can learn more about the inner workings of the political process, the machinations between influential actors and how a sequence of events was viewed and responded to within the political machine, though one has to be aware that some details may be exaggerations or even falsehoods (Lilleker, 2003:2).

Particularly this study found major existing tensions among key civil society organisations interviewed regarding the others' legitimacy to engage with PEPFAR in the processes.

The possibility of an interviewee giving only information that the interviewer wanted to hear could not be ruled out. However, these limitations were carefully considered when developing the data collection tools and also when conducting the actual interviews. Additional secondary sources were used in the analysis to validate the interview results.

Given the existing tensions among civil society organisations, institutional allegiance cannot be ruled out which may affect the data. However, I addressed this in the analysis by ensuring the results are strongly placed within the framework of the existing literature as well as

observing a number of meetings and engagements between PEPFAR and civil society organisations to gain a firsthand understanding of the processes.

I was objective despite an initial skepticism about the representation claims made by civil society organisations expressed in the research statement and examined the evidence with an open mind.

The research only covers civil society engagement with PEPFAR in South Africa and therefore the findings cannot be generalised to other donor institutions in South Africa or other countries or sectors outside of the health sector as the contexts and processes certainly differ.

In-depths interviews were limited to representatives at national level. They were not conducted at the lower structures at provincial levels to verify the claims of the national representatives.

5.3 Conclusion and Summary of Findings

The lack of space for interaction and ability to influence and engage further with PEPFAR outside of the Country Operational Plan resource prioritisation process is quite worrying and suggests to lack of meaningful engagement as defined by Arnstein (1969) and Wainwright (2002).

The study began with an initial assumption that representation in civil society organisation is assumed, lacking authorisation, accountability and responsiveness and therefore not democratic. However, a review of the SANAC Civil Society Forum indicated that there is elections and delegation done and hence authorisation takes place. Five of the nine civil society participants interviewed participants were delegated to engage in this process by this structure.

The study argues that representation was part assumed because the three of the remaining four claimed representation based on their appointed and voted role to engage in the process from the membership based organisations as well as identity. One representative of the four assumed representation on the basis of mediation as well as identity.

I therefore conclude that civil society engagement in the PEPFAR resource prioritisation was both assumed, and mostly authorised and delegated by their constituents of people living with

HIV. While I agree with Houtzager and Lavalle's arguments that representation in civil society cannot and should not be compared with the traditional representation, I argue that Houtzager and Lavalle's six notions of civil society representation are weak and not applicable to wider contexts. In the chapter reviewing literature I compared each of the six notions to this study and found them largely to be weak.

Houtzager and Lavalle seem to have a black and white position of either authorized or assumed with little acknowledgement that there is some form of authorisation going on. This study clearly shows the grey areas that were not considered before and thereby presenting a new challenges to the complex debates of representation in civil society organisations. I acknowledge that the SANAC Civil Society Forums structure is quite unique especially with its independently run elections that is not found in many coordination civil society organisations that Houtzager and Lavalle speaks to.

On participation, the research agrees with the literature reviewed and confirmed engagement remains very elite with those in Director roles engaging more often, while the majority not interacting with PEPFAR at all outside of the resource prioritisation process. The people living with HIV are not yet seen as partners in the engagement process, more as a 'tick box', as a lot of issues with the exception of partially the 'Peoples COP' input are still not taken onboard by PEPFAR. Internally within civil society organisations, the study reveals little or no accountability especially at provincial and district levels.

There is deep polarisation of civil society between the camps in their engagement in the process, specifically between those under the structures of SANAC and those outside of the SANAC structures (or at least those who are not fully included).

5.4 Recommendations for Further Research

The study is limited to the context of South Africa and one institution PEPFAR only and therefore cannot be generalised to other countries and sectors other than health's engagement of civil society, although valid lessons can be applied to all. It would be interesting to conduct further research in other countries, sectors and institutions to see if the same findings can be found before generalising the results of this study and widen the scope of the period of the study for consistent findings.

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7.0 Annexes

7.1 *Annexure 1: Information for participants*

1. Introduction

I would like to invite you to take part in a research study. Before you decide, it is important that you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Do not hesitate to ask if anything is not clear or if you would like more information.

2. What is the study's purpose?

This is an academic study towards completing a Master's Degree in Political Studies. The overall question that this proposed research seeks to answer is; how people living with HIV's interests are represented by various civil society organizations especially in influencing donor policy and funding decisions. How are they held accountable? How internally democratic are civil society organizations participating at national level PEPFAR's resource prioritization processes in their engagement with the communities they stand for and represent the issues of the affected communities in this process.

3. Why have I been chosen?

The study focuses on organisation's representatives sharing similar characteristics as frequent and regular policy interactions with PEPFAR. You have been chosen if for example, you represent your organisation and or people living with HIV in key meetings or consultations with donors especially PEPFAR.

4. Do I have to take part?

Involvement in the study is entirely voluntary. If you do decide to take part, I will ask you to sign a consent form to show that you have agreed to participate. You can change your mind and decide not to be involved at any time, including during the interview, without giving reasons and with no consequences.

5. What do I have to do if I take part?

I would like you to be available for one interview of around 45 minutes to an hour maximum. The tools used for data collection is a brief questionnaire and an open ended interview questions

i.e. discussing your thoughts and seeking detailed information. Basically you will be asked to tick boxes or choose between different options for the answer in the questionnaire and then share your experiences and thoughts during the interview on certain issues that relate to the objective of this study. There will be no need to seek for extra information before this interview.

6. Will I be recorded, and how will the recorded media be used?

Yes. I will ask your permission as part of the consent form to make an audio recording of the interview. This provides a more accurate record of the discussion than relying on written notes, which makes it easier to use the information you provide as it is hard to take notes quickly enough. The recording will only be used for this study not to be accessed by other people. If you do not wish to be recorded, the interview can be done just taking notes by hand but this will compromise the accuracy of the research results.

7. What are the possible disadvantages and risks of taking part?

There are no risks for taking part in the study. The main disadvantage will be the use of your time.

8. What are the possible benefits of taking part?

There are no personal benefits for taking part in this study

9. Will my taking part in this study be kept confidential?

The recording, notes and transcripts from the interviews will not be shared beyond the use of the research purposes.

Some of the information and perspectives you provide may be used in publications on the study, but your name will not be used in any of these reports. Quotes from the interview may be also used in reports on the study, to illustrate issues and support the findings, but again, your name will not be used in relation to these quotes.

We can decide together whether or not to use your name, the name of your CSO or Organisation in study reports. If you prefer, none of these will be mentioned to make it easy to speak openly. However, please note that while all necessary measures will be taken to ensure your anonymity as noted, confidentiality regarding your participation cannot be completely assured merely because of the positions you hold in your organization. For example, while your name or

identity will not be used, it is possible for someone reading the analysis and results of the research to speculate and attribute them to you or your organization.

10. What will happen to the results of the research study?

The full report of the study will be analysed and written up as a research report towards a Masters in Political Studies. The data may also be used for academic articles based on sections of this thesis. Draft copies of these publications will be shared with individual participants on request, and feedback will be welcomed. However, final decisions on their content will be my responsibility.

11. How big is the study and who is organising and funding it?

The study is quite small. It is not more than ten participants. It is organised and self-funded with academic support from one Supervisor from the Department of Political Studies at the University of Witwatersrand, South Africa

12. Contact for further information

For further information, please contact:

Researcher: Amanda Chawo Banda: Email: mandi.banda@gmail.com. Telephone: 0027 714141475

Supervisor: Daryl Glaser. Email Daryl.Glaser@wits.ac.za Tel: 0117174362

Thank you for taking the time to read through this information.

7.2 *Annexure 2: Consent Form*

CONSENT TO PARTICIPATE IN THE INTERVIEW

Name/ Organisation: *[enter name/ organisation]*

I have been given adequate information about the research study and its intended purposes, and I understand that it is up to me whether or not to be interviewed.

I understand that there will be no consequences of any kind through my responding to this questionnaire; in particular, that I can chose to respond as anonymous.

I understand that I can ask the person interviewing me to stop the interview at any time.

I understand that the information that I give will be treated in the strictest confidence and that my name will not be used when the interviews are analyzed.

I understand that the data collected will used solely for academic purposes and will only be published on this ground.

I understand that the interview will be audio recorded and I have no problem with that and give my permission for the recording as long as it strictly is used for the purposes of the research only.

Yes, I give my permission to participate in the interview ☐

Yes, I give my permission for the audio recording of the interview ☐

_____ _____

Interviewee's signature Date

_____

Interviewer's name (please print)

_____ _____

Interviewer's signature Date

7.3 *Annexure3 : Structured Questionnaire*

BACKGROUND QUESTIONS ABOUT THE ORGANISATIONS AND OTHER RESPONDENTS

1.Desgnation of Interviewee	Staff- CSO- Advocacy or representation role	1
	Staff CSO- Other	2
	Director CSO	3
	Staff NGO- Advocacy or representation role- local NGO	4
	Staff NGO- other	5
	Director- NGO	6
	Staff- PEPFAR	7
	Other	8
If other, explain:		
2 .Type of organisation and characteristics	CSO - independent	1
	CSO- Consortium or Forum of different CSOs	2
	NGO- Independent	3
	NGO- Consortium of different NGOs	4
	PLHIV Network	5
	Trade Union	6
	PEPFAR	7
If other: describe category:		
3. How frequent did you engage with PEPFAR regarding the Country Operational Plan	Never	1
	Every day	2
	Every week	3
	Every 2 weeks	4
	Every Month	5
	Every 2to 3month	6
	Every month	7
	At least once a year/ or whenever necessary	8
	Other	9
	If other, explain	
4. Describe the main area of focus of your	Never	1
	Provide services to people living with HIV	2
	Advocacy on behalf of people living with HIV	3

work/sector - (key aims of orgs	Both Advocacy and service provision to people living with HIV		4
	Trade Union		5
	Other		6
	If other, explain		

7.4 *Annexure 4: OPEN ENDED IN-DEPTH INTERVIEWS*

a. Who do CSOs represent? Assessment of the understanding and perception of representation concept among CSOs

1. In your participation and involvement in PEPFAR's Country Operational Plans, What do you understand by the word representation?

2. Do you think you do representation in your work with PEFAR on behalf of others? If yes answer 3, 4, 5 and 6. If no answer 7, 8 and 9

3. Who do your input and participation represent in the PEPFAR processes?

4. Were you officially appointed as a representative by the communities you represent or you do it because it is part of your policy work job/ part of your profile?

5. Do you think the sector or communities you represent know you represent them, recognize you as one? Depending on the response, do you think this has advantages and disadvantages?

6. Do you have examples of what the said people you mentioned in 3 said about your work in representing their issues or your organizations representation of their issues?

7. How did you indirectly participate in the PEPFAR prioritization process?

8. Do you feel that your voices, issues were raised and taken on board?

9. Do you recognize the individuals that were in close meetings and engagements with PEPFAR in the process as your representatives? If yes, why? If no, why not?

b. Internal Democracy with CSOs. Assessment of how Civil Society Organization represent other affected communities

1. How do you ensure you bring valid issues from your organisation and the communities you work with and includes ALL voices to the PEPFAR meetings and consultations and how are these issues prioritised?

2. Are there any formalised structures or ways of doing this?

3. How do you bring feedback to your organisation and communities from your consultations and participation in the PEPFAR Prioritisation Process?

4. Are these platforms/spaces or mechanisms that you mentioned above organised by your organisation or PEPFAR?

5. Can you give examples of your experiences and some challenges you face with 1, 2, 3, and 4 above?

6. Outside of the created spaces for consultations and feedback with communities, how do you or your organisation apply pressure to amplify their demands regarding PEPFAR resource prioritisation?

c. Perceptions of representations by PEPFAR and Implication on Resource Prioritization

1. To what extend do you think CSOs have been successful in influencing the outcomes of the PEPFAR COP in South Africa?
2. Can you explain your answer for the first question above?
3. How were you able to measure this?
4. Generally do you think CSOs actually represent the needs and challenges of the people in the process?
5. What is the reason to your response to the question above?
6. What are your recommendations on what civil society organization should do to ensure that all voices are consulted and widely represented in the PEPFAR prioritization process?

General Comments/Observations:

Do you have any general comments/opinions about CSO engagement with the PEPFAR resource prioritizsation process that were not discussed here or are outside the scope of this study?