PUBLIC AND VULNERABLE POPULATIONS' PARTICIPATION IN HEALTH-SYSTEM PRIORITY SETTING

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PRIORITY SETTING

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Lay abstract

Public participation is often considered a cornerstone of fair and legitimate priority setting. Yet, little is known about whether and how the participation of vulnerable populations is operationalized in the field of health-system priority setting. An in-depth understanding of who participates and who does not, and how participation is enabled and/or hindered is essential to ensure that policy-makers can support participation. This dissertation addresses gaps in knowledge through: 1) a literature synthesis examining the operationalization of stakeholder participation within priority-setting frameworks, with specific attention to the publics' and vulnerable populations' participation, in cases where the frameworks have been applied to health-system priority setting; 2) supportive qualitative evidence on the roles, leverages, and challenges of different stakeholders' participation in district-level health-system priority setting in Uganda; and 3) examining vulnerable women's participation within one Ugandan district, specifically outlining barriers to their participation, and solutions to address these barriers and support vulnerable women's participation in health-system priority setting. Collectively these studies can inform policymaking and development of public participation strategies that specifically target vulnerable populations for participation in health-system priority setting.

Abstract

There is a growing body of literature about public participation in health-system priority setting in different contexts and levels of governance, however, explicit focus on vulnerable populations' participation is lacking. This dissertation incorporated a mix of methodological approaches to address this gap. First, a scoping review was used to synthesize the literature on priority-setting frameworks to understand whether and how applications of the frameworks involve the public and vulnerable populations in different contexts. Second, an interpretive description study was used to examine stakeholder participation at the district level in a low-income country, Uganda. Third, a qualitative description study design was used to qualitatively assess vulnerable women's participation in health-system priority setting within a district in Uganda, from the perspectives of both vulnerable women and decision-makers. The research chapters complement and build on one another to make substantive, methodological, and theoretical contributions. Specifically, insights gained from the scoping review demonstrate that while priority-setting frameworks may require participation of all stakeholders, in practice certain stakeholder groups, namely the public and especially vulnerable populations, are not consistently integrated into priority-setting processes. The empirical research provides a rich understanding of the roles of different stakeholders in the priority-setting process and provides explanations about why vulnerable women, as a subset of the public, are not participating. This adds to the evidence base that policy-makers can access to guide future attempts to engage publics in health-system priority setting. These studies collectively contribute to a wider understanding of public's and vulnerable populations' participation in health-system priority setting in low-income contexts where health disparities are pronounced, and health resources are especially scarce. Policy-makers should aim to support vulnerable populations' participation in

health-system priority setting. Clear articulation of which vulnerable populations should participate and how they should participate can facilitate priority-setting processes. Co-developing participatory methods, frameworks, and guides with vulnerable populations can reinforce their participation and lead to mechanisms of participation that are more responsive to their needs.

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Abbreviations

A4R	Accountability for reasonableness
BOD	Burden of disease
CAO	Chief administrative officer
CEA	Cost-effectiveness analysis
CHNRI	Child Health and Nutrition Research Institute
CSO	Civil society organizations
DCE	Discrete choice experiment
DDHS	District Director of Health Services
DHMT	District Health Management Team
DHO	District Health Office
DHS	District Health System
DHT	District Health Team
HC	Health center
HiREB	Hamilton Integrated Research Ethics Board
HIV/AIDS	Human immunodeficiency virus/Acquired immune deficiency syndrome
HSSP	Health Sector Strategic Plan
HSDP	Health Sector Development Plan
HUMC	Health Unit Management Committee
JLA	James Lind Alliance
LC	Local council
LIC	Low-income country
LMIC	Low- and middle-income country
MakSPH	Makerere School of Public Health
MCDA	Multi-criteria decision analysis
MOH	Ministry of Health
NGO	Non-governmental organization
PBMA	Program budgeting and marginal analysis

PHC	Public health committee
PLWHA	People living with HIV/AIDS
PS	Priority setting
UgShs	Ugandan Shilling
VHT	Village Health Team
WHO	World Health Organization

Declaration of Academic Achievement

I, Shaghayegh Donya Razavi, declare that this thesis titled, "Public and vulnerable populations' participation in health-system priority setting" and the work presented in it are my own. I confirm that I am responsible for the conceptualization and design of the original research studies, with input from my supervisor and committee members. I conducted all analyses of qualitative data. I independently collected, analyzed, and interpreted all the data for Chapter 2 and 4. Data for Chapter 3 was collected with assistance from colleagues in Uganda. My supervisor, Dr. Lydia Kapiriri, contributed to the design of Chapter 3, interpretation of results for all research chapters, and provided revisions for every chapter. Committee members Dr. Julia Abelson and Dr. Michael Wilson provided revisions for every chapter.

Chapter 1: Introduction

This doctoral dissertation follows a sandwich thesis format. It is composed of an introductory chapter (chapter 1), three original research chapters (chapter 2-4), and a concluding chapter (chapter 5). The introductory chapter introduces the Ph.D. dissertation and includes, in the first section, a discussion of key concepts related to the main topic of interest—priority setting, stakeholder participation in health-system priority setting, vulnerability, and a snapshot of the Ugandan context. In the second section, I will briefly outline the key knowledge gaps and research objectives addressed in the thesis and introduce the three studies with an overview of the substantive, methodological, and theoretical contributions of each study.

Priority Setting in Health Systems

There are different definitions of priority setting in the health literature and at times priority setting is used interchangeably with "resource allocation" or "rationing". Williams (1988) presents a classical economics definition that priority setting means "deciding who is to get what at whose expense." (p.173)(1). Klein (2010) defines priority setting as "decisions about the allocation of resources between the competing claims of different services, different patient groups or different elements of care." (2). Youngkong, Kapiriri & Baltussen (2009) define priority setting as the "process of rank ordering interventions with the aim of informing decision-makers on the implementation of these interventions" (p. 931)(3). Martin & Singer (2003) reaffirm this definition and explain priority setting as the distribution of resources among competing programs or people (4). According to the World Health Organization (WHO), priority setting refers to using explicit criteria, about the distribution of goods and services, by policy-makers to make resource allocation decisions among competing programs or stakeholders (5). For the purposes of this dissertation, I adopt the following definition of priority setting: priority

setting is a process by which decisions about the allocation of resource are made for competing programs.

Priority setting has become an essential reality of health systems in the 21st century and an ongoing challenge for policy-makers (6,7), particularly since the growing demand for health services may threaten the sustainability of health systems worldwide (8). When resources are scarce health-system priority setting is necessary to make choices about what to fund and what not to fund, and address potential mismatches between the available resources and the demand for these resources (9). Decision-makers may struggle to set appropriate priorities, particularly due to a lack of consensus about the criteria and values that guide their decisions (10,11). Policy-makers must find ways to address the health needs of the population, while adhering to their health care budget and controlling spending. Since priority-setting processes occurs in all health systems, including all levels of governments, regional health authorities, hospitals, and at the organizational and clinical levels (12,13), flexible priority-setting mechanisms are necessary to address population needs and allocate limited funding in the most effective and efficient ways (11,14). This is especially true in low-income countries (LICs) where the context may be complex and resources are particularly scarce (12). Therefore, policy-makers may require guidance to support consideration of a range of relevant factors and consistency in decision-making. Consequently, a variety of frameworks have been developed and applied in different countries and contexts, to guide the priority-setting process. The different frameworks lay out procedures and criteria that decision-makers should apply when setting health care and health-system priorities. One criterion that is included in most priority-setting frameworks is a requirement for stakeholder participation. This is the focus of Chapter 2.

Priority Setting and Stakeholder Participation

The terms stakeholder or public involvement, participation, and engagement have been used interchangeably in some of the literature and are subject to scholarly debate. Involvement is commonly used as a blanket term referencing any contribution to the decision-making process including providing or receiving communication, consultation, participation, or engagement (15–17). Types of involvement exist on a spectrum from passive to more active involvement in decision-making (18–20). Participation involves purposeful exchange of information between stakeholders and decision-makers; this process often but not always involves some sort of dialogue (7,17–19). Engagement has been used to describe participatory processes that are more interactive and iterative in nature, emphasizing the sharing of not only of information, but also decision-making power between members of the public and governmental and other decision-makers throughout the deliberative process (18,21–23). Since the role of vulnerable populations in health-system priority setting is understudied, for the purposes of this dissertation I avoid using the terms - involvement, participation, and engagement - narrowly. Instead, I use the term stakeholder participation to broadly describe a process through which decision-makers at any level involve people who can potentially be affected by the outcomes of the decisions in the decision-making process itself (13). Furthermore, since the focus of this dissertation is public participation, specifically in priority setting, the subsequent chapters focus on participation in health-system priority setting rather than participation in health-related decision-making more generally.

In health-system priority setting, stakeholders stand to either gain or lose something based on the priorities that are set and the resource allocation decisions that are made. These stakeholders may take part in the decision-making process to shape outcomes based on their needs and interests. Stakeholder participation in priority-setting processes is considered an

essential element for enhancing the fairness and legitimacy of priority setting decisions (13,24,25). Involving multiple stakeholders in priority-setting processes is important to allow for the inclusion of a breadth of values. However, stakeholder participation in health-system decision-making and priority setting has traditionally been dominated by more powerful stakeholders such as health management officials, governmental officials, health care providers, and administrators (13). This is equally the case in LICs with one notable addition, donors (25–27), whose participation can heavily influence both the priority-setting process and the role other stakeholders play within the process (28).

Since health care services are meant to serve the needs of the population, the public is an important stakeholder group in priority-setting processes. There is substantial literature examining public participation in priority setting (7). Public participation is about including the primary users of health care in health-related decision-making (29). There is evidence that public participation has the ability to impact participants' views, the acceptability of decisions, and perceptions of fairness and legitimacy of the process (16,30,31). It has been suggested that the legitimacy and sustainability of policy decision-making is, to a degree, dependent on the extent to which it reflects public values (32). Greater participation of the public has the ability to reinforce democratic processes and hold policy-makers accountable for their decisions (33). Furthermore, public participation provides context for the research being conducted and thus, enhances its usefulness for application by decision-makers and the applicability of the recommendations made by these decision-makers (31). However, there continue to be gaps in understanding why the public is often absent from the decision-making table when health priorities are set and how the public can participate more consistently in health-system priority setting.

Conceptual frameworks or typologies that describe levels of participation in decision-making have been developed across disciplines (19,20,34–38). Two conceptual frameworks that have been applied extensively in health-related decision-making are Rowe and Frewer's (2005) "Typology of Public Engagement Mechanisms" (19) and Charles and DeMaio's (1993) conceptual framework on the "Dimensions of Lay Participation in Health" (34). While Rowe and Frewer's typology is not specific to health-related decision-making it is one of the most commonly cited frameworks in the health literature. Furthermore, the framework has been used to understand public participation in health-related priority setting (7,39). Charles and DeMaio's (1993) framework is not only focuses on levels of participation, but also contextual dimensions of participation including role perspective (user and policy) and decision-making domain (macro, treatment, and service) (34). The framework well-suited to the examination of public participation in health-system priority setting because participation is contextualized based on levels of decision-making from health services to health systems (decision-making domain), and from the perspective of the public (users) and decision-makers (policy).

Both frameworks view public involvement in terms of a hierarchical gradient and emphasize a difference between passively listening to the perspectives of members of the public and shifting decision-making power to them. Charles and DeMaio (1993) conceptualize participation with respect to the amount of control individuals have over the decision-making process, while Rowe & Frewer (2005) characterizes public involvement based on the flow of information between the decision- or policy-makers and the public. Charles and DeMaio (1993) describe a gradient of involvement from *consultation* as the least integrated form of participation, to *partnership* which involves a level of power redistributions between individuals and decision-makers to share responsibilities for health care decisions, and finally the *dominant* category,

which is about transferring full control of decision-making processes from traditional decision-makers to lay people.

Rowe and Frewer (2005) categorize engagement mechanisms based on levels of engagement in the priority-setting process ranging from least to most interactive: communication, consultation or participation. *Communication* involves the one-way transfer of information from the decision-maker to the public and examples of such a method include public hearings or internet information such as webpages. *Consultations* involve information being provided from the public to the decision-makers without any explicit deliberative process. Examples of consultations methods include opinion polls or standing citizens' advisory panels. *Participation* involves and interactive dialogue between the public and decision-makers in a potential iterative process to incorporate both opinions into the decision-making process, and examples include consensus conferences or deliberative polling.

Vulnerability

Equity and fairness are integral values that are increasingly integrated into health-related priority setting (40). Achieving equitable participation in health-system priority setting first requires an examination of the concept of vulnerability. Vulnerability is a complex construct that spans diverse disciplines and may have discipline-specific meanings. Although their meanings are nuanced, the following terms are often used interchangeably to describe special populations that have unique health needs: vulnerable, disadvantaged, marginalized, minority, underrepresented, and underserved (7,41,42). Vulnerability has been identified as the most commonly used label in health sciences research (41). In the humanitarian and public health literature, vulnerability has been defined as the degree to which individuals, organizations, or entire populations are exposed to risk and are unable to anticipate, cope with, resist, and/or

recover from the impacts of disasters, crises, or harm (40,43). In research ethics, vulnerability is understood as an inability or limited ability for research participants to fully safeguard their own interests and give informed consent, and therefore may require safeguards and protection against risks of harm or exploitation (44,45). The wider bioethics and philosophy literature highlights that lack of power, agency and autonomy makes some individuals susceptible to exploitation (46–48). While the concept of vulnerability has been the subject of scholarly critique (49), it is beyond the scope of this thesis to discuss these critiques.

For the purposes of this thesis, I adopt an understanding of vulnerability that pulls from each of these definitions. Specifically, vulnerability is when individuals possess attributes that put them at greater risk of sustaining harm. Vulnerable individuals lack power, agency, and decision-making autonomy, and may live in contexts and circumstances which exacerbate their risks of experiencing harm. Since vulnerability is characterized by both limited abilities to advocate for one's interests and lack of power and autonomy, vulnerable groups may have limited opportunity and capacity to participate in health-system priority setting. If priority-setting processes do not consider the needs of vulnerable populations, there is the potential for their interests become further marginalized, resulting in greater health inequities.

Determinants of health disparities and vulnerability include: poverty, being a member of a racial/ethnic minority, chronic physical or mental illness, lack of health insurance, old age, incarceration, immigrant status, low level of education, living in underserved areas, unemployment, widowhood, and homelessness (50,51). Globally, identified vulnerable populations include children and orphans, women and especially pregnant women, the elderly, those who are malnourished, people who are ill/immune-compromised, the poor, visible or ethnic minorities, Indigenous people, people with disabilities (7,52,53).

Furthermore, individuals and populations can experience multiple, interacting layers of vulnerability that compound their risks (49). Vulnerability exists on a spectrum and is a dynamic condition rather than a permanent fixture of a person or populations, rather vulnerability can be context-dependent (46,47). For example, in Uganda, elderly women can be perceived as both vulnerable and empowered. Elderly Ugandan women are often likely to be widows and become economically dependent on others (54), at the same time, elderly populations experience a relatively high status in Ugandan society and are well respected in the community (55).

The Ugandan Context:

Uganda is a low-income country in Eastern Africa. The country is divided into 122 districts (56). Each district is made up of counties, which are divided into sub-counties. Sub-counties are in turn divided into parishes and parishes are divided into villages. Decentralization in Uganda was initiated in the late 80s and resulted in changes of governmental structures and redistributed the concentration of power to lower levels of government (25,57–59). Decentralization through devolution involved creating and/or strengthening of local governments and a shift of authority from the central government to separate administrative and political structures at the local levels (59,60). Specifically, district officials are elected to council and have considerable powers that are distinct from national-level governance. One aim of decentralization in Uganda was to allow for local-level autonomy in decision-making. Widespread decentralization of governments and subsequent decentralization of responsibilities for social services, such as health care, means that formal decision-making power lies at the local level, this is thought to foster public participation in local decision-making (25,27,59). In fact, public participation in health-system priority setting has been mandated at sub-national levels in Uganda (25,27).

Ugandan Health System Context

The Ugandan health system operates within the country's decentralized political context. All health sector decision-making, including health-system priority setting, occurs at the sub-county, district, and national levels (61). The public sector, private sector, and donors play key roles in the health-system priority setting. The public sector consists of central government and the local district health authorities. The private sector consists of private not for profit organizations (PNFPs), private health practitioners (PHPs)/private for profit, civil society organizations, and the traditional and complementary medicine practitioners (61,62). Public and private sectors are primarily responsible for policy implementation, and service provision, whereas donors mainly provide funding. As such, all are major stakeholders in health-system priority setting.

There are three primary sources of health system financing in Uganda, which make up the country's total health expenditure (THE). Household out-of-pocket represents 35% of the total health expenditure, 45% comes from donors, and the government contributes 15%, which represents approximately 1.3% of the country's GDP (63).

Health service delivery has also been decentralized whereby each local council has a parallel health sector administrative structure, and health facility, namely health centers (HC). Health centers range from HC I-IV, with HCI providing basic health education and outreach, and preventative and promotive health services, and HC IV providing the preventive, promotive, out-patient curative, maternity, in-patient health services and laboratory services offered at the lower levels but also, more complex services including emergency surgery and blood transfusion services (64). Health centers V are the district hospitals. Further details on the health care services provided at each level are presented in Figure 1.

Figure 1. District political structures and parallel health structures under decentralization

Health Planning & Management Structures	Political Structures	Administrative Health Structures	Population Served
District Health Management Team/District Health Committee	District Council LC V	**HC V** District hospitals	500 000
County Health Management Team/County Health Committee	County LC IV	**HC IV** Mini-hospital/emergency surgery Blood transfusion capacity	200 000
Sub-county Health Committee	Sub-county LC III	**HC III** In-patient services Maternity ward Laboratory services	20 000
Parish Development Committee	Parish LC II	**HC II** Out-patient services Treatment of common diseases Antenatal care	5 000
Village Health Teams/Village Health Committee	Village LC I	**HC I/VHT** Preventive & promotive health services Health education	1 000

National-level decision-making

While the decentralization policy mandates both national and district authorities to set priorities, district level priorities are greatly influenced by national level priorities (65–67). Under decentralization, all Ministries at the national level are responsible for priority setting and policy development, monitoring and evaluating the implementation of these national policies, provision of technical advice, support supervision and training, to ensure that the local governments meet the required performance standards (68); while local governments (districts) should also set their own priorities, national priorities should be reflected in their local priorities and budgets (68). For example, within the health sector where national level health priorities have been identified in the form of a National Essential Health Care Package (65), districts are expected to follow national guidelines and reflect the national priorities included in the essential health care package when identifying and implementing their own priorities. The central

government also provides financial support to districts through block grants (for specific sectors such as health or education), and conditional grants attached to explicit programs. Conditional grants limit district flexibility in setting and implementing locally responsive priorities (69).

District-level decision-making

For the purposes of this dissertation I focused on district level priority setting rather than national level priority setting. To date, much of the literature about priority setting in LIC contexts has focused at on the national-level. While national priority setting shapes district-level priority setting, decentralization is designed to support local autonomy in all types of decision-making. Critical analyses are required to further understand participation and priority setting within districts. Responsibility for decision-making within districts lies with the administrative structure which has two components: a political division and an administrative division (70). The political division is led by the District Chairperson and includes the district council, which governs the district. The technical division is led by the Chief Administrative Officer and is composed of appointed technical people who work in the various district departments. Each department is aligned to a sector and has a sectoral committee. For example, the department of health has the health sectoral committee. (71,72). Health-system decision-making occurs at the sub-county and district levels and parallel health committees operate at each level (25,62,64). The health committees are responsible for health-system planning and budgeting, and program monitoring and evaluation (72), and are one mechanism designed to foster community participation in government decision-making (25). The District Health System (DHS) operates within the technical division of the district decision-making structures. The DHS consists of a District Health Team (DHT) which works in collaboration with the broader District Health

Management Team (DHMT), and is headed by the District Health Officer/District Director of Health Services (67).

Overarching Research Objectives and Rationale

While public participation is often invoked as a cornerstone of fair and legitimate priority setting that is responsive to population needs, less is known about whether and how it is operationalized. Even less is known about the participation of vulnerable populations, in particular, in health-system priority setting. The result has been inconsistent participation of vulnerable populations (at best) or (at worst) a complete lack of participation in health-system priority setting for vulnerable populations. The overarching aim of the thesis is to understand stakeholder participation in setting health priorities with specific attention to the public and vulnerable populations in Uganda. This was achieved through a literature synthesis and two qualitative research studies with complementary research objectives.

First, I conducted a scoping review of the literature on frameworks used to guide health-system priority setting, to understand whether and how applications of the framework involve publics and vulnerable populations not specifically in Uganda but more broadly in different contexts (Chapter 2). The priority-setting frameworks consider different factors as inputs to priority setting; one component that is required by many frameworks is public participation. While there have been studies that have assessed the operationalization of the frameworks (73,74), and synthesis of the degree to which the frameworks have impacted policy (75), to the best of my knowledge, there has not been a systematic examination of how the participation of vulnerable populations is operationalized when these frameworks are used. This has resulted in

little understanding of the degree to which frameworks operationalize public participation, including participation of vulnerable populations, in the contexts where they are applied.

To complement the scoping review of the broader literature, I examined the issue of participation in health-system priority setting empirically. I undertook an interpretive description study of stakeholder participation in health-system priority setting in three Ugandan districts (Chapter 3). There is limited literature about the roles and influence of different stakeholder groups on the participatory processes in health-system priority setting in LICs. Most of the literature that analyses stakeholders' participation in LIC priority setting is focused at the national level (65,66). In the context of decentralization in Uganda, districts play a key role as a governing body that is responsible for priority setting, planning and budgeting, and subsequent implementation of priorities (68). Decentralization created participatory structures to facilitate participation at lower levels of governance. However, the literature identified discrepancies between mandatory participation as required in the context of decentralization and actual participation for different stakeholders at the district level (25,26,67,76). This study lays out the roles, leverages, and challenges associated with the participation of different stakeholders in district priority setting. Chapter 3 also strengthens our understanding of who does not participate in priority-setting processes, namely the public.

Together, Chapter 2 and 3 provide an important foundation about stakeholder participation in priority setting and highlight that the public and specifically vulnerable groups are not consistently participating in priority setting. There continue to be gaps in understanding why the public and vulnerable populations are regularly absent from the decision-making table when health system priorities are set and how they can participate more consistently in health-system priority setting. The literature on participation of vulnerable populations in health system

priority setting is especially scarce. Efforts have been made to study the engagement of vulnerable populations in health research priority setting (42,77), in health-system priority setting in high-income countries (7,78), and for both health-system and health research priority setting low-income countries from the perspectives of decision-makers (25,79,80). However, less is known about the participation of vulnerable populations in health-system priority setting, in low-income contexts, and from the people's perspectives rather than those of decision-makers. To address this gap, I conducted a qualitative description study in one rural district in Uganda, to understand the role that vulnerable women play in health-system priority setting within the context of decentralization, from the perspectives of both decision-makers (district and sub-county levels) and vulnerable women (Chapter 4).

Substantive, methodological and theoretical contributions of the dissertation

The dissertation provides an in-depth understanding of the roles of different stakeholders, emphasizing the role of the public and vulnerable populations in health-system priority setting, using a literature synthesis and qualitative evidence. In chapter 2 the scoping review synthesizes a broad range of literature that applies priority-setting frameworks used to guide health-system priorities to different cases around the world. While the study maps the literature, it focuses on the stakeholder participation component of the frameworks, which allowed for an improved understanding of whether and how different stakeholders participate in health-system priority setting. Chapter 3 presents a detailed analysis of stakeholders' roles, leverages, and challenges with their participation in health-system priority setting in district-level priority setting in three Ugandan districts. The study highlights differential participation and influence of various groups of stakeholders, noting specifically that publics and especially vulnerable groups are not at the decision table. Chapter 4 narrows the focus from the findings of chapter 3, to examine vulnerable

women's participation through a qualitative description study of one district in Uganda. The study provides a rich qualitative analysis of why vulnerable women do not participate in health-system priority setting despite a constitutional mandate that publics, including vulnerable groups, should participate in governmental decision-making, including health-related priority setting. The focused examination of the phenomenon in the context of decentralization identifies challenges with operationalizing decentralization to facilitate public participation for vulnerable women as envisioned.

Methodologically, in Chapter 2, I conducted a scoping review, adopting Arksey and O'Malley's methodological framework to map the literature that applies priority-setting frameworks, focusing specifically of the stakeholder participation component of the frameworks. In Chapter 3, I apply the interpretative description methodology to a novel field of study. Interpretive description was developed to better understand clinical practices in the field of nursing (81). However, it is also well suited to the study of research questions relating to different health-care contexts and that have implications policy and practice (82). For Chapter 4, I use a qualitative description methodology, since the literature on vulnerable populations' participation in health-system priority setting in low-income contexts was lacking. What makes this approach innovative is that I examine this participation from the perspectives of multiple different stakeholders, namely vulnerable women, and district decision-makers (district and sub-county). The research methods are detailed in each chapter, and relevant tables and appendices can be found at the end of each chapter.

The dissertation provides the following theoretical contribution. In chapter 3, Elster's framework is used to examine participation and deliberative democracy based on the following dimensions: the actor and their role(s), concerns, and leverages. Upon a thorough examination of

the literature and conducting key informant interviews, challenges with stakeholders' participation emerged as an additional dimension relevant to stakeholder influence on priority setting. The perceived challenges dimension was added to the framework and applied to the key informant interviews during the analysis phase. (see Table 1 for an overview of the studies)

Overall, the findings from the three studies fill a gap in the literature about participation in health-system priority setting. This dissertation, using the case of Uganda, contributes to wider understanding of public and vulnerable populations' participation in health-system priority setting in low-income country contexts where health disparities are pronounced, and health resources are especially scarce.

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Table 1. Overview of the orginal research studies that comprise the dissertation

Dimension	Study 1 (Chapter 2)	Study 2 (Chapter 3)	Study 3 (Chapter 4)
Title	Applying priority setting frameworks: A review of public and vulnerable populations' participation in health-system priority setting	Who is in and who is out? A Qualitative analysis of stakeholder participation in priority setting for health in three districts in Uganda	Equitable public participation in health care priority setting within the context of decentralization: The Case of vulnerable women in a Ugandan district
Research Objectives	i) Examine which stakeholders have been involved in the decision-making process when priority setting frameworks are applied to different priority setting cases. ii) Understand how the public, as stakeholders, are involved in applications of the identified priority-setting frameworks. iii) Establish whether vulnerable populations participated in these priority setting exercises.	i) Examine the perspectives of district-level decision makers about stakeholders' participation in district-level priority setting; ii) Identify the stakeholders who are involved in district-level priority setting for health and the roles they play in the three districts; iii) Describe and analyse the leverages that the different stakeholders use to influence district-level priority setting; iv) Discuss the challenges associated with participation of different stakeholders.	i) Identify whether vulnerable women participate in health care priority setting within the district; ii) Understand why vulnerable women are or are not participating; iii) Establish how barriers to their participation can be addressed.
Methodology	Scoping Review	Interpretive Description	Qualitative Description
Data collection strategy	Database searches	Semi-structured interviews	Semi-structured interviews
Context of participation	Priority setting frameworks used to guide health-system priorities globally	District priority setting in three Ugandan districts	Health-system priority setting in one Ugandan district

Data sources	Scholarly literature	Transcripts from interviews with district decision makers	Transcripts from interviews with district-level decision makers, sub-county leaders, and rural women
Connections between studies	- Identifies that some of the most commonly cited priority setting frameworks do not consistently engage publics and vulnerable populations, when applied to health-system priority setting cases. This provided justification for study 2 and 3.	- Builds on the findings of study 1 to provide a deeper analysis of stakeholder participation in health system priority setting in 3 Ugandan districts. - Identifies that the public and vulnerable populations are not participating in priority setting processes. This informed the development of study 3, which provides an in-depth examination of vulnerable populations' participation, from the perspectives of people themselves.	- Complements findings from study 1 and 2 by providing a detailed understanding of vulnerable women's participation from the perspective of both decision makers and vulnerable women. - Explicitly identifies barriers to participation for vulnerable populations which were alluded to by respondents in study 2.

Chapter 2. Applying priority-setting frameworks: A scoping review of public and vulnerable populations' participation in health-system priority setting

Preface

This chapter begins the work of establishing the lack of participation among the public and vulnerable populations in health-system priority setting. Using a scoping review methodology, I examined cases where the most commonly documented priority-setting frameworks have been applied, to understand how stakeholder participation has been operationalized and whether and how publics and vulnerable groups participate in health-system priority setting. Insights gained from this study provide a foundation for further exploration of the roles of different stakeholders in health-system priority setting and how they can influence the priority-setting process.

I was responsible for conceptualizing the study and its methodological design. I conducted the data collection (literature searches) and the data analysis. The included studies were identified from a search strategy executed in February 2018. Abstract review was completed by June 2018. Data extraction occurred from July 2018 to October 2018. Data analysis, manuscript development, and revisions occurred from November 2018 through May 2019. As co-authors, all committee members (Lydia Kapiriri, Michael Wilson, and Julia Abelson) provided feedback on iterative drafts and their revisions were incorporated into the final version of this chapter.

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Applying priority-setting frameworks: A review of public and vulnerable populations' participation in health-system priority setting

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Abstract

Background: There is a growing body of literature that describes, applies, and evaluates the application of health-system priority-setting frameworks in different contexts. However, little explicit focus has been given to examining the operationalization of the stakeholder participation component of these frameworks. The literature identifies the public as a stakeholder group and recommends their participation when applying the frameworks to priority-setting cases. This paper synthesizes the current literature to examine the degree to which the public and specifically vulnerable populations have been engaged through the application of the most commonly cited priority-setting frameworks.

Methods: We conducted a scoping review to search for publications of cases where priority-setting frameworks had been applied between January 2000 and December 2017. We identified literature by searching the PubMed, EMBASE, HealthSTAR, Medline, and PsycINFO databases.

Findings: The following stakeholders are commonly involved when the frameworks have been applied to health-system priority setting: managers, administrators and coordinators, clinicians/physicians, non-physician health care providers (e.g. pharmacists, nurses), health economists, academics/researchers, experts, decision-makers, and policy-makers. Very few papers report on public participation, and even fewer identify vulnerable groups that participate.

Conclusions: While the frameworks were developed with stakeholder participation in mind, in practice not all stakeholders are participating in the priority-setting processes as envisioned. The public and especially vulnerable groups are not consistently integrated, challenging the utility of frameworks in guiding stakeholder participation in health-system priority setting. Frameworks can be more explicit about which stakeholders should participate, specifically targeting publics

and vulnerable groups, and detailing how their participation should be operationalized when applying the frameworks.

Background

Frameworks are used extensively in health policymaking to help policy-makers navigate the complexity of decision-making about health systems (1) and its various stages including problem definition and agenda setting, policy formulation and development, policy implementation, and monitoring and evaluation. Within the agenda setting stage of the policy cycle, common activities include setting health-system priorities, which may include setting priorities for achieving overall health-system goals, prioritizing diseases to target for intervention and which interventions to prioritize, determining health research priorities, and ultimately deciding how health-system resources will be allocated. Priority-setting processes, in turn, are developed according to a variety of criteria, and commonly involve the use of evidence, input from different stakeholders, and consideration of values such as equity (2–6). Given the range of approaches that could be adopted for priority setting, numerous frameworks have been developed that can provide guidance (3) to ensure that decisions are consistent, effective, and fair (2).

A variety of priority-setting frameworks have been used to guide health-system priority setting in different countries and contexts (2,7,16,17,8–15). Among the large number of priority-setting frameworks that have been developed, several have been recognized as being most frequently cited in the literature, namely accountability for reasonableness (A4R), multi-criteria decision analysis (MCDA), program budgeting and marginal analysis (PBMA), and burden of disease and cost-effectiveness analysis (BOD/CEA) (18) (Table 1). These frameworks have often been applied in different contexts and countries (both high and low- and middle-income settings), and at different levels of decision-making within health systems (e.g., national and sub-

national levels including provinces/states, regions and local/municipal). They also incorporate

multiple factors that are important to consider when setting health-system priorities with

common components including fair process, economic evaluation, burden of disease data, and

stakeholder participation.

Meaningful stakeholder participation is a particularly important component in priority-

setting processes given that it is thought to lead to legitimate and more acceptable policy

decisions that reflect the interests of those involved (19–21). Stakeholder participation is also

said to enhance fairness by increasing the opportunity for inclusion of a range of values and

principles in the prioritization process (21,22). In the literature, stakeholder participation

emphasizes the importance of specifying who is included in the decision-making process, why

they are included, how they participate in setting priorities, and the need to consider equity in

participatory processes (23–27). The conceptual literature on the four most frequently cited

frameworks (PBMA, MCDA, A4R, and BOD/CEA) explores these themes and describe the

"ideal" stakeholder participation as envisioned by the foundational papers (Table 1). Public

participation, in particular, is argued to promote accountability of decision-makers to the

population (23,28,29). Since health systems are meant to address populations' health needs, the

public is considered a key stakeholder group, and their input should be incorporated into health-

system priority setting (19). The public, as consumers of health services, arguably stand to gain

or lose the most when priorities for the health system are set. Indeed, many frameworks that

guide priority setting explicitly point to the need to engage the public when setting health

priorities (Table 1).

As a subset of the public, vulnerable populations can be strongly impacted by set health

priorities. With respect to public health and health care, vulnerability has been defined broadly

based on two dimensions: exposure, being susceptible to harm, and resilience, an inability to protect oneself from potential harm (30–32). Power imbalances among stakeholders reflect publics' and vulnerable populations' modest ability to influence the priority-setting process (33). Vulnerable groups experience pronounced health disparities (34), and their pressing needs should be reflected in health-system priority setting. Mitton et al. (2009) expand on this to highlight a potential need to develop unique or modified methods for engaging vulnerable or marginalized groups in setting health-system priorities (23). Furthermore, Yamin and Norheim (2014) argue that not only should the needs of vulnerable and marginalized groups be considered when setting health care priorities but that these decisions should be subject to public scrutiny and that they should be involved in the decision-making(35).

There is a growing body of literature that describes, applies, and evaluates the application of these priority-setting frameworks in different contexts. This literature explicitly identifies the public as a stakeholder group and recommends direct participation or representation of the general public, citizens, and/or patients when applying the frameworks to priority-setting cases (2,8,36). Beyond this, little explicit focus has been given to operationalizing stakeholder participation within these frameworks and there is a paucity of literature about the degree to which the public and specifically vulnerable populations have been engaged through the application of these frameworks.

To address this gap, our objectives are to:

1) Examine which stakeholders have been involved in the decision-making process when the most widely used frameworks for priority setting in health systems are applied to different priority-setting cases.

2) Understand how the public, as stakeholders, are involved in applications of the identified priority-setting frameworks.

3) Establish whether and how vulnerable populations participated in these priority-setting exercises.

Methods

We conducted a scoping review using Arksey and O'Malley's methodological framework, which describes five stages for conducting a scoping review: identifying the research question, identifying relevant studies, study selection, charting the data, and collating, summarizing, and reporting the results (37). Contrary to the other approaches to synthesis such as systematic reviews which typically have a narrower scope, and do not allow for thorough mapping of the literature (37), a scoping review allowed us to balance breadth (by identifying the application of the four priority-setting frameworks), and depth (by extracting specific information about stakeholder participation from the included papers).

The scoping review approach allowed us to identify peer-reviewed literature on the different priority-setting approaches. Search terms included "priority setting" or "resource allocation", and "health care", "health systems", or "health interventions", and "frameworks", "approaches", or "initiatives". Titles and abstracts for the retrieved literature were reviewed for relevance, and commonly cited priority setting frameworks were identified. Subsequently, framework-specific searches were conducted for the four most commonly cited priority-setting frameworks (PBMA, MCDA, A4R and BOD/CEA), to identify literature about applications of the and how they incorporated stakeholder participation. PBMA is an approach to setting priorities that is pragmatic in nature and based on fundamental economic principles and economic evaluation (2). MCDA is an approach meant to guide to policy makers in their priority

setting decisions by simultaneously considering many different, and at times competing, criteria including effectiveness, cost-effectiveness, burden of disease, or equity analyses (8). A4R is a procedural approach focused on fair process and used to guide priority setting decisions (38). BOD and CEA has been used to set health-system priorities, for example when defining essential health packages in LMICs (39). While there are clear distinctions in the approach that different frameworks take to health-system priority setting, each has been used to guide priority setting processes in different countries and contexts. Details on the characteristics of the identified frameworks can be found in Table 1.

Identifying relevant studies

We identified the framework specific literature by searching PubMed, EMBASE, HealthSTAR, Medline, and PsycINFO. Since most of the frameworks were developed in the late 90s, and widely applied to health-system priority setting in the 2000s the search was limited to studies published between January 2000 and December 2017. Search terms included "priority setting", "resource allocation", and "health", combined with common variations in framework nomenclature. (Details of the searches are summarized in Appendix 1.) To be included in the scoping review, articled had to: 1) be published since 2000; 2) describe health-system priority setting; 3) describe a case of the *application* of either of the four approaches; and 4) discuss the involvement of stakeholders and/or their roles in the priority-setting process.

Study selection

SDR reviewed all the abstracts retrieved from the databases for relevance. Full-text articles of abstracts identified as potentially relevant were retrieved and reviewed by SDR for final

inclusion in the scoping review. A data extraction tool was then used to extract relevant information and findings from each included article (Appendix 2).

Charting the data

SDR developed the data extraction tool based on the following themes: name of the framework, countries and level of application, priority-setting case or health issue or health program, whether stakeholders were represented, if so, who the stakeholders were (do any of the stakeholders represent vulnerable groups, and if so which ones), how stakeholders were selected, how stakeholders were involved in the priority-setting process (Appendix 2). Using the data extraction tool, SDR read through the selected manuscripts and extracted all relevant information.

Collating, summarizing, and reporting the results

SDR read through and summarized the information by framework and then by themes for each framework (number of relevant publications, level of application, and stakeholder participation), in the form of a narrative report.

<u>**Results**</u>

Our searches retrieved 824 hits. A total of 159 papers were selected for full-text review following screening of the abstracts. Of the 159 papers reviewed, a total of 96 papers were included in the study (Figure 1). Included papers were published between January 2000 and December 2017 and described applications of one of the four frameworks to a priority-setting case. The four frameworks that were included in our review (program budgeting and marginal analysis, multi-criteria decision analysis, accountability for reasonableness, and burden of disease and cost-effectiveness analysis) have been applied in both high and low- and middle-

income settings, across different contexts, countries, and administrative levels, and with varying attention to stakeholder participation in the process (Table 2). The following sections are organized according to *who* is involved in the priority-setting process, and *how* the stakeholders involved in the process. For how stakeholders are involved in priority-setting processes, we outline their roles, as well as how public participation was operationalized/incorporated with specific attention to whether vulnerable populations were reported to be involved.

Who is involved?

We found that, the papers discussed stakeholder participation in one of two ways: 1) the papers explicitly identified the stakeholders involved in the priority-setting process, specifying the type of stakeholder or stakeholder groups (n= 72), or 2) papers that did not clearly articulate who was participating in the process, referring to them more broadly as participants, stakeholders, policy-makers, key decision-makers, staff, or experts (n=24) .

Of the 72 papers that provided details about the types of stakeholders that were involved in the application of the frameworks, most were related to the application of A4R (n=33), followed by PBMA (n=20), MCDA (n=15), and last BOD/CEA (n=4). Of the 24 papers that did not clearly articulate who was participating in the process, the opposite pattern was observed where majority were with applications of BOD/CEA (n=11), followed by MCDA (n=5) and PBMA (n=5), and finally A4R (n=3).

The papers that were specific about who was involved in the priority-setting process identified the following stakeholder groups: managers, administrators and coordinators, clinicians/physicians, non-physician health care providers (e.g. pharmacists, nurses), health economists, academics/researchers, experts, decision-makers, and policy-makers (Table 3).

Stakeholder groups' labels are derived directly from the literature. While the paper did not explicitly define the stakeholder groups, some papers provide examples of the stakeholders that were participating. For example, when applying MCDA to the Universal Health Coverage Benefit Package in Thailand, Youngkong et al. (2012) identify the following stakeholders: policy-makers at the Ministry of Public Health, health professionals, academics, patients, civil society representatives including NGOs, laypeople and citizen constituencies of the Thai National Health Assembly (40). Participation of physicians, managers, and other health care providers were reported most frequently among the included studies (Table 3). Health economists were least frequently reported to participate in health-system priority setting.

Public and vulnerable populations' participation

Of the 96 included papers, only 24 discuss any aspect of public participation in priority-setting processes, of which only six report on the participation of vulnerable populations (Table 3). Of the 24 papers that report on public participation, most were applications of A4R (n=11), followed by MCDA (n=7), PBMA (n=5) and BOD/CEA (n=1). The one BOD/CEA study did not originally prioritize participation for the general public, patient groups, or vulnerable groups, but it noted since the available data was insufficient for a thorough analysis, interviews were conducted with key informants from local communities to fill the gaps in evidence (41). Across the other three frameworks, the most common form of public participation was indirect, through representation by patient representatives/groups, consumer advocates, community representatives and community-based organizations, NGOs, and civil society representatives.

Of the six papers that reported participation of vulnerable populations, most (n=4) were in applications of the A4R framework (42–45) with one example from applications of PBMA (46) and MCDA (47) (Table 3).

Vulnerable populations that were reported to be engaged in priority setting included people living with HIV, Indigenous peoples, women, youth/adolescents, farmers, and religious groups. Participation of both people living with HIV and Indigenous peoples was reported across more than one framework. People living with HIV were found to be engaged in applications of A4R (n=3) and MCDA (n=1). In the A4R cases, the framework had been used to evaluate the fairness of selecting patients for anti-retroviral treatment in Uganda (44), to set priorities for HIV/AIDS control in the West Java province of Indonesia (45), and applied when district health priorities were being set in Tanzania, Kenya, and Zambia as a part of the REACT project (43). In the MCDA case, MCDA was being used in prioritization of interventions for HIV control in Thailand (47).

Participation of Indigenous groups was reported for both A4R (n=1) and PBMA (n=1). The A4R application evaluated the processes of setting health-system priorities across seven regional health authorities in Alberta, Canada (42). Three of these seven health authorities reported holding needs assessment focus groups where participants were purposefully selected as representatives of "risk groups" including Indigenous groups, farmers, religious groups, and adolescents (42). Furthermore, Bohmer et al. (2001), applying PBMA to investment and disinvestment decisions for regional health authorities in New Zealand, identified the Maori Indigenous population as a key stakeholder group (46). They specifically engaged Maori representatives, lay community members, and consumer groups and advocates in the in their application of PBMA (46).

How are the stakeholders involved?

The retrieved literature describes the steps involved in applying each of the frameworks and/or and how the framework was applied for the specific case. Papers report on stakeholder

participation by providing general descriptions of the different steps required to develop the final list of priorities. Stakeholders were involved in health-system priority setting by: identifying a range of diseases, health interventions, and programs for prioritization; deriving methods for selecting and/or ranking proposals; developing decision criteria for prioritization; weighting the criteria; generating or collecting data and/or evidence; conducting the analyses required in each approach; and voting on or producing the final list of priorities (Table 4). Unfortunately, most applications of the frameworks do not provide details about how each stakeholder group, especially the public and vulnerable populations, is engaged in these different components of priority setting. Instead they outline more generally the ways in which stakeholders provide input into priority setting.

The only role that was common across all four frameworks was participation of stakeholders in identifying diseases, interventions, and programs for prioritization and participation took several forms. For example, applications of three of the four frameworks (PBMA, MCDA, BOD/CEA) explain that stakeholders were involved in conducting the analyses required for each approach, such as conducting or informing the conduct of cost-effectiveness analyses in BOD/CEA applications and participating in discrete choice experiments (DCEs) in MCDA. For a MCDA process, Jehu-Appiah et al. (2008) explain that when engaging in the DCE survey, all respondents were asked to choose between 16 pairs of scenarios and to score interventions based on criteria that had been determined during the group discussion as a part of the first step of the process (48). As forms of participation, two of the four frameworks describe stakeholders as participating in priority setting by developing the decision criteria for prioritization (PBMA, MCDA), generating or collecting data and evidence (A4R, BOD/CEA), and voting on and/or producing the final list of priorities (PBMA, A4R). Unique to PBMA was

the participation of stakeholders by having them included in deriving the methods for selecting and/or ranking proposals. For example, an application of PBMA in two regional health authorities in New Zealand explains that the two regional health authority stakeholder groups jointly derived the methods for choosing and ranking the investments and disinvestment proposals (46). In addition, MCDA was the only framework where the application identified having stakeholders involved in weighting the criteria used to decide on the health priorities in question. For example, in Iran where MCDA was applied to priority setting and coverage decisions about inclusion of uninsured orthopedics interventions in the healthcare transformation plans, a group of orthopedic experts and stakeholders from insurance organizations weighted the selected prioritization criteria (49). Finally, A4R was the only framework which engaged stakeholders in challenging or appealing priorities after the have been set and resource allocation decisions after they have been made. For example, in LMICs, four of the fifteen papers reporting on applications of A4R identified an explicit appeals mechanism, the existence of a suggestion box that any stakeholder could use to submit a written complaint (43,44,50,51).

Discussion

Our findings demonstrate that there is consistency between the theoretical literature (Table 1) and application of the frameworks to health-system priority-setting cases with respect to the categories of stakeholders that are represented. Across all frameworks, participating stakeholders included managers and administrators, clinicians/health care professionals, academics/researchers, and a variety of technical personnel (i.e. health economists, district medical officers, epidemiologists, statisticians). The A4R, MCDA, and PBMA frameworks all recommend or require public participation in priority setting. However, we also found discrepancies between the ideals for public participation as envisioned by the developers of the

frameworks, and actual participation since the public was often missing as a stakeholder group in applications of the four priority-setting approaches. In addition, even fewer applications of the priority-setting approaches reported on the participation of vulnerable populations.

As a result, this review points to discrepancies between what is stipulated in the frameworks and their implementation. The fact that the stipulations of the frameworks are not being followed may reflect that many of the included studies were research projects. Feasibility of comprehensive stakeholder participation that includes not only the powerful stakeholders, but also publics and vulnerable groups, can be limited in the context of a research project rather than implementation of the frameworks in actual policymaking contexts (18,23). Disconnects between the foundational papers and applications of the frameworks may also point to some practical limitations of public participation. While public participation in policy-related decision-making is believed to enhance the acceptability of decisions and increase stakeholder satisfaction with outcomes, it also comes with its own set of challenges. Traditional challenges that are well documented in the literature include that public participation can be cost prohibitive (2,23,52), it can be laborious to identify and mobilize all relevant stakeholders (2), a lack of expertise on the part of the public to meaningfully participate (21,53,54), lack of clarity in their role as participants in priority-setting processes (54), and the risk of tokenism (53,55). These challenges are common across frameworks and priority-setting cases. Ultimately, however, it is each responsible authority's (government or organization) choice as to how they choose to carry out priority setting within their jurisdiction, including if and how they use frameworks to guide the process (56). Lack of explicit criteria for selecting stakeholders, namely members of the public and vulnerable groups, and consistency in the mechanisms and methods used to engage these

populations is a weakness of these frameworks, which may explain ineffective public participation in health-system priority setting (57,58).

Within the literature there seems to be a link between the conceptual focus of a framework, and whether the public participates in cases where the framework is used. For example, A4R is focused on fairness and justice, emphasizing fair process for health-system decision-making. The conceptual A4R literature explicitly names patients and citizens as stakeholder groups that should be represented in health-system priority setting (36,59). Furthermore, A4R is the only framework that recommends considering disadvantage when selecting stakeholders to be involved in priority setting (36). In the priority setting literature, A4R is known as a guiding framework that is value-based and focused on participatory deliberative process in resource allocation and health-system priority setting. It follows that of the four frameworks examined in this review, applications of A4R report both public participation and participation of vulnerable populations more consistently than the others. Finally, it is important to note that progress has been made in attempts to enhance the procedural fairness of the other priority-setting frameworks and to integrate stakeholder participation more fully in applications of the frameworks. This is evidenced by the recent integration of PBMA with A4R (2,60,61), and MCDA with A4R (62,63), and efforts to enlist public values when determining the disability weights used in the BOD assessments (for the BOD/ CEA approach) (9,39,64).

Our findings also have important implications for policy and practice. Frameworks are thought to be pragmatic in nature, acting as tools to guide action (65). Numerous frameworks have been developed to guide health-system priority setting, some of which were the focus of this study. In some cases, these frameworks have even been adopted for routine use in

policymaking and health-system priority setting (18). However, while other priority setting criteria such as conducting cost-effectiveness analyses or calculating burden of disease measures, are always adhered to, the recommendation to integrate the public is often not followed. Since the literature argues that public participation is a key component of equitable priority setting, processes to support it should be made more explicit. For example, laying out clear guidelines as to who should be involved and how they should be involved, including vulnerable populations. Other areas of health-related priority setting appear to have more well-defined guidelines for public participation in the process. For example, in health research the Child Health and Nutrition Research Initiative (CHNRI) and the James Lind Alliance (JLA) are two examples of priority setting approaches that have explicit mechanisms for public, patient, and community participation integrated into the different stages of the process (66–68). Boivin, Lehoux, Burgers, and Grol (2014) lay out key elements of public participation in priority setting for health care improvement and policy (53). In the field of health technology assessment (HTA), substantial efforts have been made to develop frameworks to operationalize public and patient participation in the prioritization process (69,70). Modifying the existing health-system priority-setting frameworks, in similar ways to those identified above, could make them more effective with respect to participation of all stakeholders.

Strengths and limitations

The main strength of this review is that it fills a gap in the literature about stakeholder participation and public participation in health-system priority setting. More specifically, it examines the degree to which priority-setting frameworks have operationalized public participation and illuminates the lack of public and vulnerable populations' participation.

Nevertheless, the findings should be interpreted cautiously since there are potential limitations. First, the review was not exhaustive, the search and study selection were conducted by a single reviewer, and there are priority-setting frameworks that were not examined. However, since the frameworks examined are among the most commonly published and applied, the information is useful. Second, we compare economic and explicit criteria-based frameworks (PBMA, MCDA, BOD/CEA), with a deliberative framework (A4R). While the findings may have been predictable (i.e. a likelihood to have stakeholder participation in A4R), the study provides valuable insight since in addition to assessing *whether* stakeholders are engaged, we also examined *how* the frameworks operationalize different stakeholders' participation. Arguably, the latter is relevant to all the frameworks. Third, there are limits to the included literature. Specifically, stakeholders may have been integrated into priority-setting processes, but this may not have been reported. While commenting on stakeholder participation was not an identified aim of the papers, the fact that it is not discussed at length is significant. One possible explanation is that this lack of discussion demonstrates that stakeholder participation is not often top of mind when reporting on priority setting. This may provide evidence that the roles of some stakeholders are undervalued. Lastly, we focused on peer-reviewed literature rather than integrating study protocols, grey literature, and other unpublished literature, or conducting interviews with those applying the frameworks. We can only report on what was documented. For example, the literature on A4R showed that most applications of the framework are retrospective evaluations of priority-setting processes. Consequently, discerning the role that different stakeholders play with respect to the application of the framework is challenging through synthesis methods. While this is a limitation of our review, it also points to the need for concerted efforts to be made for systematically

evaluating stakeholder participation as a key criterion in all priority-setting exercises and to explicitly report on it in academic literature.

Conclusion

Our review found that while the frameworks were developed with stakeholder participation in mind, in practice all stakeholders are not participating in the priority-setting processes as envisioned. The public and especially vulnerable groups are not being consistently integrated into priority-setting processes, challenging the utility of frameworks in guiding stakeholder participation in health-system priority setting. When frameworks specifically name stakeholder groups that should be involved, implementers of the frameworks are more likely to include these stakeholders in the decision-making. Furthermore, stakeholders are more likely to participate when their roles are well defined in the framework and integrated into the prioritization process. When frameworks do not specify who should participate and how they should participate in the different stages of the priority-setting process, implementers are likely to be unaware of whether and how they should engage different stakeholders. Particularly, powerful stakeholders and implementers may not involve vulnerable populations or consider their values when identifying health-system priorities. Failure to do this may result in further marginalization of the vulnerable populations and broadening of the existing health inequities.

At a conceptual level, frameworks can be more explicit about who should participate and how stakeholder participation should be operationalized when applying the frameworks to actual priority-setting cases. A clearer vision for integrating participation of different stakeholders (public and vulnerable group participation in particular), at each stage of the priority-setting process can facilitate application of the frameworks. Since priority-setting frameworks are applied across the globe, in a variety of contexts, we recognize the need to balance flexibility

(ability to apply the frameworks in a variety of contexts), with specificity (being clear about included criteria and how the frameworks should be used). At the practical level, we call for further study on how to operationalize participation when implementing the priority-setting frameworks. Furthermore, we suggest that lessons can be learned about how to effectively operationalize stakeholder participation from frameworks and approaches that have been developed for priority setting in other areas.

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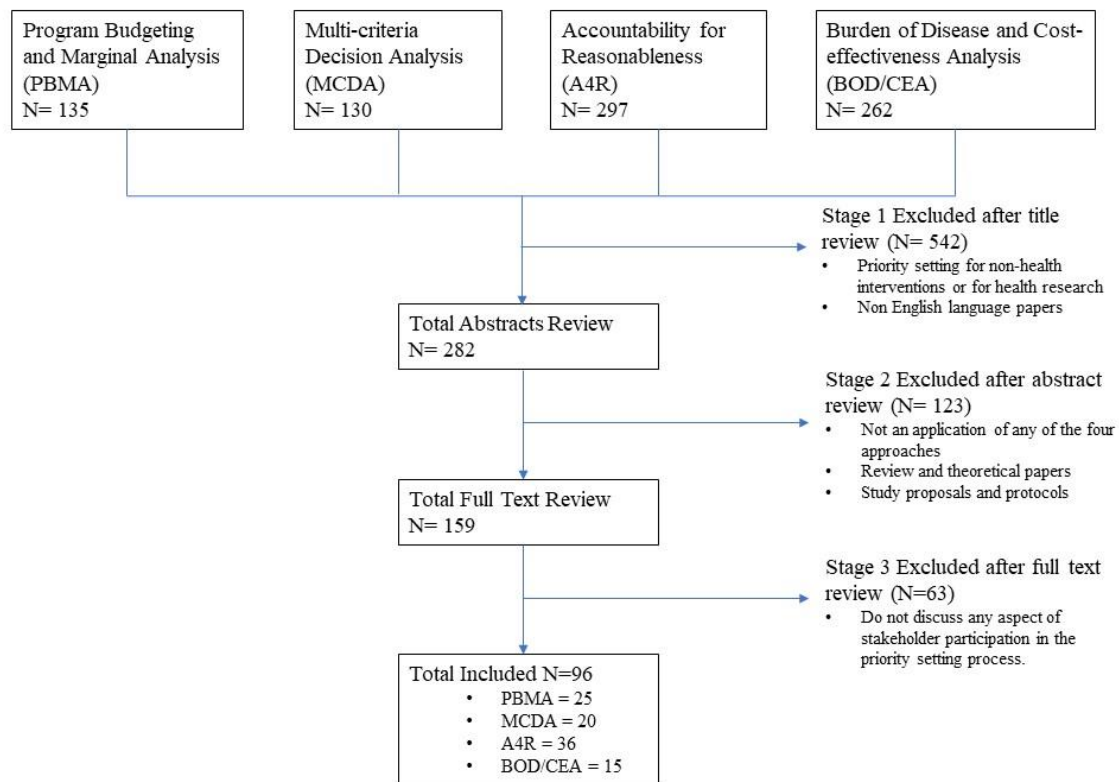**Figure 1. Flowchart of Search Strategy.**

Table 1. Summary of the "ideal" stakeholder participation as envisioned by the foundational papers that describe each framework.

Priority setting framework	PBMA[1]	MCDA[2]	A4R[3]	BOD/CEA[4,5]
Intended purpose	Develop a final list of health interventions/programs for investment or disinvestment.	Guide complex priority setting and decision-making and set priorities.	Set health priorities based on principles of ethics and fairness.	Develop a package of most cost-effective services that should be provided to reduce disease burden and target them for prioritized resource allocation
Key features	Applies two fundamental economic principles. Opportunity cost: investing resources in one area, necessarily forfeits benefits in another area, an automatic trade-off. Marginal analysis: potential benefits gained	Considers multiple streams of information to establish preferences between options by using an explicit set of objectives and criteria.	Applies 4 main conditions required to meet the fairness principle: publicity, relevance, revisions/appeals, and enforcement.	Applies burden of disease (BOD) with cost-effectiveness analysis (CEA) to arrive at final list of priorities.

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	with the last unit of production of two or more given programs.			
Who should be involved?	• Citizens • Clinicians • Administrators • Financial personnel • Managers • Board of Directors of the health organization	• Community representative • Clinicians & other health personnel • Finance & information staff • Decision makers & policy makers	• Citizens/patients • Clinicians • Technical experts • Decision makers	• Citizens/patients • Health professionals • Health system planners & managers • Academics & researchers • Donors • Politicians & policy makers
Is there a role for the public? Who is explicitly identified by the framework?	Yes, public consultation and lay membership on advisory panel	Yes, specifically community representatives	Yes, patients and citizens	Not explicitly identified
Is participation of vulnerable groups required?	No	No	Should consider disadvantage when selecting members of the public to participate in priority setting	No
How should stakeholders be identified ie. are criteria used in stakeholder selection?	No	No	"fair-minded" – people who seek reasonable grounds for cooperation	No

			when engaging in priority setting[6]	
What role should stakeholders play?	• Identifying areas of service growth • Defining decision-making criteria • Putting forward a list of priority areas • Rating options against the criteria	• Defining relevant criteria for priority setting • Measuring performance and scoring alternatives • Weighting criteria • Making recommendations for priorities • Highlighting pragmatic concerns	• Making allocation decisions publicly accessible • Determining reasonable explanations for allocation decisions • Challenging, appealing, or revising allocation decisions • Regulating the priority setting process	• Identifying priority areas/diseases and interventions • Informing and/or carrying out the analysis

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http://www.ncbi.nlm.nih.gov/pubmed/11090498%0Ahttp://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC1119050

Table 2. Overview of the common frameworks' applications with respect to characteristics of the literature.

Characteristic of the literature	Total (n=96)	Framework			
		Program budgeting & marginal analysis (PBMA) (n=25)	Multi-criteria decision analysis (MCDA) (n=20)	Accountability for reasonableness (A4R) (n=36)	Burden of disease & cost-effectiveness analysis (BOD/CEA) (n=15)
Areas of application of priority-setting cases					
Region of application ie. high- (HIC) or low- and middle-income country (LMIC)	HIC (62) LMIC (45)	HIC (25) LMIC (0)	HIC (7) LMIC (19)	HIC (25) LMIC (15)	HIC (4) LMIC (11)
Countries where framework was applied	Australia (5) Canada (36) Chile (2) The Netherlands (1) New Zealand (2) Norway (3) UK (including England, Wales, Scotland) (8) US (1) Singapore (1) Sweden (3) Brazil (2) Bulgaria (1) Burkina Faso (1) Colombia (1)	Australia (2) Canada (19) New Zealand (1) UK (4)	Canada (2) Chile (1) Norway (2) UK (2) Brazil (2) Bulgaria (1) Burkina Faso (1) Colombia (1) Cote d'Ivoire (1) Cuba (1) Ghana (1) Iran (1) Nepal (2) Palestine (1) South Africa (1)	Australia (2) Canada (15) The Netherlands (1) New Zealand (1) Norway (1) UK (2) Sweden (3) Indonesia (1) Kenya (3) South Africa (1) Tanzania (5) Uganda (3) Zambia (2)	Australia (1) Chile (1) US (1) Singapore (1) Malawi (1) Mexico (1) Niger (1) Nigeria (2) Peru (1) Sri Lanka (1) Tanzania (1) Uganda (2) Zimbabwe (1)

	Cote d'Ivoire (1) Cuba (1) Ghana (1) Indonesia (1) Iran (1) Kenya (3) Malawi (1) Mexico (1) Niger (1) Nigeria (2) Nepal (2) Palestine (1) Peru (1) Sri Lanka (1) South Africa (2) Syria (1) Tanzania (6) Thailand (2) Tunisia (1) Turkey (1) Uganda (6) Zambia (2) Zimbabwe (1)		Syria (1) Thailand (2) Tunisia (1) Turkey (1) Uganda (1)		
Administrative level(s) where framework was applied	Global (3) National (36) Provincial (3) Regional (22) District (9) Municipal (2) Hospital (22)	National (1) Regional (18) Hospital (6)	Global (2) National (15) Provincial (1) Regional (1) Municipal (1)	National (9) Provincial (2) Regional (3) District (9) Municipal (1) Hospital (16)	Global (1) National (11) District (3)

* The total N and the numbers identified in the columns for areas of application for each framework may not add up since some papers discuss applications of the frameworks in both regions, different countries, and at multiple levels.

Table 3. Number of papers per framework reporting on participation of different stakeholders when applied to priority-setting cases.

Stakeholder group	Total (n=96)	Framework			
		Program budgeting & marginal analysis (PBMA) (n=25)	Multi-criteria decision analysis (MCDA) (n=20)	Accountability for reasonableness (A4R) (n=36)	Burden of disease & cost-effectiveness analysis (BOD/CEA) (n=15)
Participation of non-public stakeholders					
Clinicians/physicians	57 (59%)	18 (19%)	10 (10%)	25 (26%)	4 (4.2%)
Other health care providers	33 (34%)	5 (5.2%)	9 (9.4%)	18 (19%)	1 (1.0%)
Administrators/coordinators	17 (18%)	5 (5.2%)	5 (5.2%)	7 (7.3%)	0 (0%)
Managers (i.e. health, hospital, departmental, clinical, program, or senior managers)	49 (51%)	18 (19%)	8 (8.3%)	20 (21%)	3 (3.1%)
Academics/Researchers	26 (27%)	9 (9.4%)	9 (9.4%)	7 (7.3%)	1 (1.0%)
Health economists	10 (10%)	7 (7.3%)	3 (3.1%)	0 (0%)	0 (0%)
Expert (i.e. clinical, content, local, or technical)	20 (21%)	1 (1.0%)	5 (5.2%)	5 (5.2%)	9 (9.4%)
Decision-maker (e.g. executive directors, local/regional health authority representatives, Boards of Health/Directors members)	27 (28%)	3 (3.1%)	3 (3.1%)	16 (17%)	5 (5.2%)
Policy-maker (e.g. Ministry of Health officials, members of Directorates of Health)	20 (21%)	0 (0%)	7 (7.3%)	9 (9.4%)	4 (4.2%)
Participation of the public					
Papers reporting public participation	**24 (25%)**	**5 (5.2%)**	**7 (7.3%)**	**11 (11%)**	**1 (1.0%)**
Citizens/the public/community members	6 (6.3%)	1 (1.0%)	3 (3.1%)	1 (1.0%)	1 (1.0%)

Community representatives	9 (9.4%)	4 (4.2%)	0 (0%)	5 (5.2%)	0 (0%)
Patients	12 (1.3%)	2 (2.1%)	3 (3.1%)	7 (7.3%)	0 (0%)
Patient representatives/groups	8 (8.3%)	1 (1.0%)	4 (4.2%)	2 (2.1%)	1 (1.0%)
Civil society representative or community-based organizations	5 (5.2%)	0 (0%)	1 (1.0%)	4 (4.2%)	0 (0%)
NGOs	7 (7.3%)	0 (0%)	1 (1.0%)	6 (6.3%)	0 (0%)
Participation of vulnerable populations					
Papers reporting participation of vulnerable populations	**6 (0.063%)**	**1 (0.010%)**	**1 (1.0%)**	**4 (4.2%)**	**0 (0%)**
Adolescents and youth	2 (2.1%)	0 (0%)	0 (0%)	2 (2.1%)	0 (0%)
Farmers	1 (1.0%)	0 (0%)	0 (0%)	1 (1.0%)	0 (0%)
Indigenous populations	1 (1.0%)	1 (1.0%)	0 (0%)	1 (1.0%)	0 (0%)
People living with HIV	4 (4.2%)	0 (0%)	1 (1.0%)	3 (3.1%)	0 (0%)
Religious groups	1 (1.0%)	0 (0%)	0 (0%)	1 (1.0%)	0 (0%)
Women	1 (1.0%)	0 (0%)	0 (0%)	1 (1.0%)	0 (0%)

* The total N and the numbers for each stakeholder group may not add up since most papers discuss the role of multiple stakeholders in the applications of the frameworks.

Table 4. The different roles played by stakeholders and the number of papers that identify these roles for each framework.

Types of roles that stakeholders can play*	Program Budgeting and Marginal Analysis (PBMA) (n=25)	Multi-criteria Decision Analysis (MCDA) (n=20)	Accountability for Reasonableness (A4R) (n=36)	Burden of Disease and Cost-effectiveness Analysis (BOD/CEA) (n=15)
Identifying a range of diseases, health interventions, and programs for prioritization	8	6	14	4
Deriving methods for selecting and/or ranking proposals	6	0	0	0
Developing decision criteria for prioritization	9	14	0	0
Weighting criteria	2	15	0	0
Generating or collecting data/evidence	14	0	18	5
Conducting the analyses	14	19	0	8
Voting on and/or producing the final list of priorities	14	0	21	0
Challenging or appealing priorities and allocation decisions after the fact	0	0	18	0

* These are the roles that "stakeholders" are typically reported to play for each framework. While not all stakeholder groups would be playing the same roles, the application papers are rarely specific about the role of the different stakeholder groups

Appendix 1. Search with search terms and hits per framework.

Database	Stage 1 Initial search and hits	Stage 2 Total Abstract Review	Stage 3 Total Full Text Review (duplicate removed)	Stage 4 Total included
Program budgeting and marginal analysis **Search terms:** "health" AND ("priority setting" OR "resource allocation") AND ("PBMA" OR "program budgeting and marginal analysis" OR "programme budgeting and marginal analysis")				
PubMed	76	31	35	25
Ovid	59	29		
Multi-criteria decision analysis **Search terms:** "health" AND ("priority setting" OR "resource allocation") AND ("multi-criteria decision analysis" OR "MCDA" OR "multicriteria decision analysis" OR "multi criteria decision analysis")				
PubMed	68	29	31	20
Ovid	62	26		
Accountability for reasonableness **Search terms:** "health" AND ("priority setting" OR "resource allocation") AND ("Accountability for reasonableness" OR "A4R" OR "AFR")				
PubMed	198	57	55	36
Ovid	99	63		
Burden of disease and Cost-effectiveness analysis **Search terms:** "health" AND ("priority setting" OR "resource allocation") AND ("burden of disease" OR "BOD" OR "BoD" OR "DALY" OR "disability adjusted life year" OR disability-adjusted life year") AND ("cost effectiveness analysis" OR "cost-effectiveness analysis" OR "cost effectiveness" OR "cost-effectiveness" OR "CEA")				
PubMed	149	21	38	15
Ovid	113	47		

Appendix 2. Data Extraction Tool.

Country	Level of application (ie. national, regional, provincial, district)	Priority setting case, health issue, or health program	Stakeholders represented	Were criteria that were used for selection of stakeholders? If so, what were they?	How were stakeholder involved	Do the stakeholders involved represent any vulnerable groups? If so, which ones?	Reference

Chapter 3. Who is in and who is out? A qualitative analysis of stakeholder participation in priority setting for health in three districts in Uganda

Preface

This article has been published in *Health Policy and Planning* and is available at https://doi.org/10.1093/heapol/czz049. This chapter moves away from the broad examination of the global literature and priority setting frameworks, to empirical research. This study provides a deeper analysis of stakeholder participation in health-system priority setting processes in a low-income country, Uganda. This study uses an interpretive description methodology and an analytic framework to examine the roles, leverages, and challenges of different stakeholders' participation in district-level priority setting in three Ugandan districts. Findings from this study identified that, from the perspectives of district decision-makers, the public and vulnerable populations do not participate in district priority setting across multiple districts in Uganda.

This study was conducted as a part of a larger research program focused on health care priority setting in Uganda. Partners from Uganda, Dr. David Okumu and Brendan Kwesiga, assisted with the data collection. The study was conducted from 2014–2016 in three districts of Uganda. My supervisor, Lydia Kapiriri, and I conceptualized the study presented herein. I was responsible for data analysis and drafting the manuscript. As co-authors, all thesis committee members (Lydia Kapiriri, Julia Abelson, and Michael Wilson) provided feedback on several drafts, which were incorporated into the manuscript.

Table 1. Overview of the orginal research studies that comprise the dissertation

Dimension	Study 1 (Chapter 2)	Study 2 (Chapter 3)	Study 3 (Chapter 4)
Title	Applying priority setting frameworks: A review of public and vulnerable populations' participation in health-system priority setting	Who is in and who is out? A Qualitative analysis of stakeholder participation in priority setting for health in three districts in Uganda	Equitable public participation in health care priority setting within the context of decentralization: The Case of vulnerable women in a Ugandan district
Research Objectives	i) Examine which stakeholders have been involved in the decision-making process when priority setting frameworks are applied to different priority setting cases. ii) Understand how the public, as stakeholders, are involved in applications of the identified priority-setting frameworks. iii) Establish whether vulnerable populations participated in these priority setting exercises.	i) Examine the perspectives of district-level decision makers about stakeholders' participation in district-level priority setting; ii) Identify the stakeholders who are involved in district-level priority setting for health and the roles they play in the three districts; iii) Describe and analyse the leverages that the different stakeholders use to influence district-level priority setting; iv) Discuss the challenges associated with participation of different stakeholders.	i) Identify whether vulnerable women participate in health care priority setting within the district; ii) Understand why vulnerable women are or are not participating; iii) Establish how barriers to their participation can be addressed.
Methodology	Scoping Review	Interpretive Description	Qualitative Description
Data collection strategy	Database searches	Semi-structured interviews	Semi-structured interviews
Context of participation	Priority setting frameworks used to guide health-system priorities globally	District priority setting in three Ugandan districts	Health-system priority setting in one Ugandan district

Data sources	Scholarly literature	Transcripts from interviews with district decision makers	Transcripts from interviews with district-level decision makers, sub-county leaders, and rural women
Connections between studies	- Identifies that some of the most commonly cited priority setting frameworks do not consistently engage publics and vulnerable populations, when applied to health-system priority setting cases. This provided justification for study 2 and 3.	- Builds on the findings of study 1 to provide a deeper analysis of stakeholder participation in health system priority setting in 3 Ugandan districts. - Identifies that the public and vulnerable populations are not participating in priority setting processes. This informed the development of study 3, which provides an in-depth examination of vulnerable populations' participation, from the perspectives of people themselves.	- Complements findings from study 1 and 2 by providing a detailed understanding of vulnerable women's participation from the perspective of both decision makers and vulnerable women. - Explicitly identifies barriers to participation for vulnerable populations which were alluded to by respondents in study 2.

Who is in and who is out? A qualitative analysis of stakeholder participation in priority setting for health in three districts in Uganda

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Abstract

Stakeholder participation is relevant in strengthening priority setting processes for health worldwide, since it allows for inclusion of alternative perspectives and values that can enhance the fairness, legitimacy, and acceptability of decisions. Low-income countries (LICs) operating within decentralized systems recognize the role played by sub-national administrative levels (such as districts) in health care priority setting. In Uganda, decentralization is a vehicle for facilitating stakeholder participation. Our objective was to examine district-level decision makers' perspectives on the participation of different stakeholders, including challenges related to their participation. We further sought to understand the leverages that allow these stakeholders to influence priority setting processes. We used an interpretive description methodology involving qualitative interviews. A total of 27 district-level decision makers from three districts in Uganda were interviewed. Respondents identified the following stakeholder groups: politicians, technical experts, donors, non-governmental organizations (NGO)/civil society organizations (CSO), cultural and traditional leaders, and the public. Politicians, technical experts, and donors are the principal contributors to district-level priority setting and the public is largely excluded. The main leverages for politicians were control over the district budget and support of their electorate. Expertise was a cross-cutting leverage for technical experts, donors, and NGO/CSOs, while financial and technical resources were leverages for donors and NGO/CSOs. Cultural and traditional leaders' leverages were cultural knowledge and influence over their followers. The public's leverage was indirect and exerted through electoral power. Respondents made no mention of participation for vulnerable groups. The public, particularly vulnerable groups, are left out of the priority setting process for health at the district. Conflicting priorities, interests, and values are the main challenges facing stakeholders engaged in district-

level priority setting. Our findings have important implications for understanding how different stakeholder groups shape the prioritization process and whether representation can be an effective mechanism for participation in health-system priority setting.

Background

In setting priorities for health systems, it is critical that the people who stand to gain or lose from the decisions that are made (stakeholders) are involved in the prioritization process (1,2). Priority setting for health systems involves making decisions about how resources are allocated between different and, at times, competing health programs and interventions (3). Meaningful stakeholder participation in priority setting processes is thought to lead to legitimate and more acceptable policy decisions that reflect the interests of those involved (4–6). In the health sector, stakeholder participation is also thought to foster shared learning about the need to set limits on what can and cannot be funded (7). This paper contributes to the priority setting literature by exploring the role and influence of different types of stakeholders in sub-national level (district) health-system priority setting in low-income countries (LICs).

Wide stakeholder involvement is thought to facilitate representation of, and increase the potential for including a range of relevant values and principles the prioritization process (8). In turn, this involvement is believed to enhance fair priority setting (6), acceptability, and applicability of the decisions (4,9,10). In particular, there is a critical need to involve and consider the public as a special stakeholder group whose values should be reflected in the prioritization process, since the public stands to either benefit or lose the most from the priority setting decisions (4,9).

In LICs, the participation of a broad range of stakeholders (including the "powerful", experts, and health users) is particularly relevant for strengthening district-level democratic processes, because involving stakeholders allows for the inclusion of alternative perspectives and values. Including all stakeholders also contributes to ensuring that the priority setting process is fair, legitimate, and acceptable (4–6).

Decentralization: A tool facilitating stakeholder participation in LICs

In recent years, the role of decentralization in facilitating stakeholder participation in LICs has become more prominent (11). Decentralization, in its various forms (e.g., devolution, deconcentration, delegation, and privatisation), involves a shift of power within the formal institutional structures (12–14). Widespread decentralization of governments and subsequent decentralization of responsibilities for social services such as health care have led to the promotion of public participation to enhance transparency and inclusiveness (15). In fact, as a result of implementing the decentralized framework, public participation in health-sector priority setting has been mandated at sub-national levels in many LICs, including Uganda, Tanzania, Kenya, Indonesia, India, Philippines, among others (1,5,15). For example, decentralization across all sectors in Uganda involved devolution, whereby decision-making powers were redistributed from the central government to lower levels of government, namely districts. (5,12,14,16). Decentralization is thought to have resulted in local-level autonomy in decision making, policy implementation, and the allocation of resources received from the national level. Decentralization of responsibilities for social services, including health care, is believed to have enhanced transparency and inclusiveness, and to have fostered stakeholder (particularly public) participation in decision making and priority setting for the health sector (5,15).

Challenges with stakeholder participation

While stakeholder participation in policy-related decision making is believed to enhance the legitimacy, acceptability, and stakeholder satisfaction with the outcomes, it also has challenges. First, sustained inclusion and participation of a wide range of stakeholders can be time consuming and cost prohibitive (6,17). Second, meaningful participation may be inhibited by limited expertise of some of the stakeholders—especially the public (18–20). Third, different

stakeholders may have different values and needs that require balancing (20–22). However, balancing these values may be challenging since the most powerful and influential stakeholders often push their values using the resources they have through their political and/or financial influence. This challenge of balancing different stakeholder values is especially relevant in LICs. In low-income settings, the role of donors as the funding agencies, and their subsequent influence on priority setting in LICs is particularly strong (1,23–26). This is especially the case at the province or district levels where the influence of donors and other political stakeholders may overshadow that of "lower-ranked" stakeholders (23).

Knowledge gaps

Despite the growing body of literature on priority setting in LIC health systems, several key gaps remain: in-depth examination of different stakeholders' specific roles; and discussion of the power and points of leverages that allow stakeholders to shape priority setting. The priority setting literature often identifies similar sets of stakeholders who are routinely engaged in prioritization processes, among them politicians, government officials, technical experts and health professionals, health administrators and health managers, and patients and the public (1,5,15). Similarly, the meager literature on stakeholder participation in priority setting in LICs identifies the main stakeholders as health management officials, governmental officials, health care providers, administrators, and donors (1,5,15). While some of the literature briefly mentions the roles of stakeholders (5,6,9,27,28), they are not often discussed in depth. Rather than expanding on the participation of each type of stakeholder, their participation as a group is typically contrasted with other groups that are involved in priority setting processes.

Moreover, while existing literature discussed district-level priority setting and identified relevant stakeholders, the stakeholders' power and influence (i.e., leverages), how these factors

shape prioritization processes and outcomes, and the related challenges, are rarely discussed. To date, most of the literature that analyses stakeholders' participation in priority setting for LICs has focused on the national level. The critical role that districts play in the overall prioritization and implementation of health interventions necessitates that a similar critical analysis be conducted to assess the contributions, influences, and challenges attributed to the participation of the various stakeholders in district-level priority setting.

Our study addresses these critical knowledge gaps by identifying and exploring the specific roles of stakeholders in priority setting and their leverage within these processes in three Ugandan districts. Specifically, we (i) examine the perspectives of district-level decision makers about the participation of different stakeholders in district-level priority setting; (ii) identify the stakeholders who are involved in district-level priority setting for health and the roles they play in the three districts; (iii) describe and analyse the leverages that the different stakeholders use to influence district-level priority setting; and (iv) discuss the challenges associated with the participation of the different stakeholders and make recommendations to alleviate these challenges.

Methods and materials

Study Approach

This study used an interpretive description methodology involving qualitative interviews to examine the perspectives of district-level decision makers about the participation of different stakeholders in district-level priority setting and the challenges related to their participation. Interpretive description is a research methodology that originates in clinical research settings. It borrows from phenomenology, grounded theory, and ethnography to become more responsive to

practical, experience-based research questions, and it can be applied in contemporary health-care contexts with implications for applications and practice (29). The methodology is a theoretically driven approach that allows for the use of organizing frameworks to analyse data and explore the phenomenon of interest (30). The researcher uses both inductive reasoning and deductive techniques to answer research questions. The aim is not to discover a new theory, as is done in grounded theory, but to allow for themes and patterns to emerge, and also to identify variations in themes as a way of generating a coherent, conceptual understanding of application-based research questions or phenomena (29). Interpretive description is well-suited to understanding the phenomenon of stakeholder participation in health-systems priority setting and the implications of this participation for future policy making.

Study Context

Study Settings: The study was conducted from 2014–2016 in three districts of Uganda. Uganda provides a relevant case to study stakeholder participation given its historical commitment to stakeholder participation within its political system. Decentralization in Uganda resulted in the devolution of both political and technical sectors to subnational levels. To facilitate this division of political power, the country is divided into districts, which are then divided into counties. Counties are divided into sub-counties, which are then divided into parishes and parishes are divided into villages. Within this context, Uganda has mandated representative participation, including a mandate that one third of the representatives at all administrative levels (parliament, district, sub-county, parish, and village councils) are women (31).

Existing structures for stakeholder participation in district-level priority setting

There are two formal participation structures within the districts: a technical division and a political division (32). The political division which governs the district, includes the district council which is elected, and is led by the District Chairperson (see Table 1). The technical division is led by the Chief Administrative Officer and is composed of appointed technical individuals who work in the various district departments. Each department is aligned to a sector and has a sectoral committee. For example, the department of health has the health sectoral committee. The District Health System (DHS) operates within the technical division of the district decision-making structures. The DHS consists of a District Health Team (DHT), which works in collaboration with the extended District Health Management Team (DHMT) and is headed by the District Director of Health Services (33–35). Donors and non-government organizations/civil society organizations are also technical stakeholders, and they play a role in priority setting in many districts (1,5,15,24–26,33).

We recognize that district priority setting happens in the broader context of national health care priority setting in Uganda (36). National priorities may not always align with those of the districts (33,36). Therefore, decision-making space may be limited for stakeholders within local governments since the priorities set at the national level can have trickle-down effects at sub national level which limit the districts' ability to set priorities with input from local stakeholders and according to local needs (5,36,37).

Study sites: The three districts were selected to represent different regions in the country (District A, from the Eastern region; District B, from the Northern region; and District C, from the Central region), as well as the year the district was formed, ranging from old (56 years), intermediate (44 years), and new (13 years) (Table 2).

Study population, sampling, and data collection:

Purposive sampling was used to identify prospective interviewees. Initial respondents were members of the District Executive Committee, specifically the secretaries for health, who are identified as the designated decision makers for health at the district level (Table 1). The District Executive Committee was selected due to its members' specialized knowledge with regards to how priority setting and decision making occur within districts. The index respondent in each district was the District Director of Health Services, who then identified the additional respondents they deemed knowledgeable. In each district we contacted all 7 members of the district health team. In District A, the DHT members identified additional respondents, namely, members of the extended DHMT and District Executive Committee, who they thought were key to decision making within their district.

Interviews were conducted by two trained Ugandan research assistants using a pilot-tested semi-structured interview guide. The interview guide included questions about the health priorities in the region and details of the prioritization process (e.g., who is involved and the roles they play, factors that influence the process, whether the decisions are publicized, whether the priorities are implemented, and the priority setting challenges). All interviews were conducted in English, audio recorded (with permission from the respondents), and transcribed verbatim.

Data analysis:

Analytical Framework

Elster's (1994) framework was applied iteratively to analyse the study data. The framework categorizes stakeholders (actors) involved in priority setting according to the level of

decision making at which they participate. It further provides four dimensions related to stakeholder participation (see Table 3). Stakeholders, as participants in the priority setting, have roles (functions that they play in the process). Furthermore, stakeholders have concerns that are shaped by their interest in the prioritization process and its outcomes. Different stakeholders embody characteristics that empower and enable them to influence the prioritization process and its outcomes.

This study examines stakeholder participation based on the stakeholder roles and leverages in Elster's framework. Elster's *concerns* dimension was excluded, since this information was not emphasized in our interviews and also because we found some overlap in respondents' perspectives about concerns and roles, and about concerns and leverages. However, since participation of different stakeholders also presents challenges (1,5,23,26,27,38), we added a new dimension—challenges—to the original Elster framework prior to the analysis. The added *challenges* dimension explains the problems or difficulties stemming from the participation of stakeholders in priority setting as perceived by the other respondents.

Coding

Interview data were entered into NVIVO-10. A member of the research team read through the initial transcripts to identify texts, which were given code labels. At an abstract level, related codes were grouped together under overarching categories. Related categories were grouped together into broader themes, which contributed to our understanding of priority setting within the districts. The identified themes included: description of the priority setting processes, criteria used in determining priorities, use of evidence, legitimacy, challenges to the implementation of priorities, and stakeholder engagement. For the purposes of this study we expanded on the stakeholder engagement theme. Based on the study objectives, we focused on

understanding district-level decision makers' perspectives about stakeholder participation in priority setting. Detailed analysis involved applying Elster's framework to the data to specify the different dimensions of stakeholder participation as outlined by the district-level decision makers. The broad theme of stakeholder participation was further broken down into sub-themes in accordance with the analytical framework. These included: stakeholders, and the roles, leverages, and challenges related to their participation.

Ethics

The study was reviewed by the McMaster University REB as well as the Makerere School of Public Health IRB. All respondents signed a written consent form before participating in the interview.

Results

We interviewed a total of 27 respondents from three districts (District A–15, District B–5; District C–7). Most of our respondents were members of the District Health Team (e.g., District Director(s) of Health Services, Assistant District Health Officers (ADHO), Chief Administrative Officer(s) (CAO), Health Committee Chairperson(s), district planners, secretaries for health, and public health nurses); depending on the district, respondents also included a small number of individuals from other departments (e.g., labor office, biostatistics, engineering, population, health management, and information technology systems). With a minimum of 5 out of 7 representatives of the DHT, we had a fair representation of both technical and non-technical decision makers.

Respondents identified the following stakeholders as being engaged in priority setting processes: politicians, technical experts, donors, NGO/CSOs, cultural and traditional leaders, and the general public (see Table 4).

For each category of stakeholder, we apply the modified version of Elster's analytic framework to present the roles, leverages, and challenges related to their participation as reported by respondents.

Stakeholder Roles

Table 5 presents the reported roles played by the different stakeholders in district-level priority setting supported by illustrative quotes. The roles included politicians as decision makers, technical experts as evidence producers and synthesizers, donors as funders of priorities, NGO/CSOs as implementing partners, cultural and traditional leaders as cultural knowledge experts, and the public as the primary beneficiaries of health services. While we delineate the roles of the different stakeholders, the interviews revealed overlapping roles between stakeholders. For example, providing evidence and expertise are roles that technical experts, donors, and (to a lesser extent) NGO/CSOs share, while local government, donors, and NGO/CSOs were identified as playing a role in funding and implementing priorities.

This overlapping of the roles of the different stakeholders may lead to conflicts. When roles are clearly defined there is the potential to reduce conflict between the stakeholders. As explained by one of the technical key informants, explicit specification of roles (e.g., technical experts as consultants and politicians as decision makers) enhances the priority setting processes. When stakeholders are aware of their role and other stakeholders' roles in the process, disagreements can be reduced and resolution of emerging disagreements between stakeholders

with differing perspectives can be facilitated. For example, a politician from District B stated the following:

> "In our committees, I must say that we have very good relationships… because it depends on the leadership… we as [Health] committee members have to know our role. We also have to understand where the role of the technical people starts and ends. So, when you're aware of that you don't have any conflicts between your committee members. We always (consider) both technical and political (perspectives) and sometimes we disagree. But disagreement, well that is to bring the way forward, then we agreed and say, 'Yes this is the priority area that we should work on…" (Politician, District B)

Some stakeholders were perceived by respondents as more influential than others. Specifically, politicians were viewed as the final decision makers and, therefore, were perceived to have significant authority in setting district-level priorities.

Stakeholder leverage in the prioritization process

As defined in Table 3, leverage refers to the stakeholders' ability to influence decision-making processes, either directly or indirectly. Directly, stakeholders participating in the prioritization process can use their leverage to shape the decisions and priorities that are establish/hed. Indirectly, stakeholders influence the decisions by exerting pressure on those who *directly* participate in the decision-making process.

We found that stakeholders such as politicians, technical experts, and donors directly influence decisions, while the public and cultural and traditional leaders do so indirectly. While politicians were identified as the ultimate decision makers with responsibility for budgeting and

resource allocation decisions (see Table 5), they can also be influenced by other stakeholders. The public influences politicians, since they elect the politicians to represent their community needs and interests. The public can therefore apply leverage through elections, whereby if they are dissatisfied, they do not re-elect the responsible politician. Thus, the public can pressure politicians to make decisions that are aligned with their needs and goals. Another example of how stakeholders use their leverage indirectly is the case of cultural and traditional leaders and the community. Cultural and traditional leaders are often well-known and respected individuals who hold significant clout with their communities. Their role as leaders allows them to shape public opinion, perspectives, and perceptions about health priorities, and they influence community participation and support for government programming. Consequently, cultural and traditional leaders can leverage their unique community and cultural knowledge and guide the priority setting process (Table 6).

Furthermore, we found differences in the perceived ability that stakeholders have for leveraging their influence in priority setting processes. These are demonstrated in Figure 1, whereby the thickness of the lines represents the perceived strength of the stakeholders' influence. For example, politicians' influence is demonstrated by the thickest line since they were perceived to be the ultimate decision makers. As demonstrated by one respondent, "Priority setting is done by the politicians" (Politician, District B). Furthermore, while the public may have a weak direct influence on the priority setting process (represented by the thin arrow in Figure 1) because they may not have a seat at the decision-making table, their indirect influence is stronger through the pressure they can exert on politicians through their electoral power (represented by the dashed arrow). By contrast, NGO/CSOs and donors have a direct seat on

technical planning committees and are involved in the decision making and therefore have a direct influence on priority setting at the district level.

Reported challenges related to the participation of different stakeholders

The most commonly reported challenge for participation of different stakeholders was poor alignment of or conflicting priorities between the stakeholders, most notably between the district officers and donors and NGO/CSOs (see Table 7). According to the respondents, donor funding is often conditional, based on, and aligned with the priorities of the donor organization, and donor priorities may or may not align with the priorities of the district. Therefore, while local governments are not obliged to set priorities in accordance with donor priorities, donors tend to fund programs that reflect their own interests. Hence, in a context where government funding is inadequate, the districts' ability to use the donor's support for the priority programs (as identified by the district) is limited.

Additional challenges were associated with stakeholders' conflicting interests and/or values with respect to the health priorities that are set. For example, respondents discussed the differences between technical experts and cultural and traditional leaders (as illustrated by the quote in Table 7). The extent to which the stakeholders with conflicting interests may affect the prioritization process depends on the nature and strength of their leverage (See Figure 1). Notably, respondents did not identify any challenges related to the participation of district technical experts in priority setting.

Which stakeholders are missing?

All respondents emphasized the need to involve the public (as users of the services and health programs) in priority setting processes. They identified the various ways the public can be

and have been involved the prioritization process, but they also criticized the limited role

currently played by the public.

Respondents talked about the existing avenues for public participation, including public

meetings such as village council meetings, budget conferences and meetings (open forums that

are announced on the radios and advertised), and through communicating with village health

teams (VHTs), as illustrated in the quotes below:

> "Always in planning we involved the beneficiaries of our service delivery. We always
>
> either informally or formally meet them in public galleries; we always conduct
>
> participatory planning where the political leaders in each and every department sit
>
> together..." (Politician, District B)

> "…Leaders and lay people who can come to the budget conference, an open discussion
>
> which is announced on the radio: the budget conference is on such and such a date and in
>
> such and such a place those who can; attend. Everybody's free to come and attend."
>
> (Technical expert, District C)

There was also a sense that the public tends to participate more at the lower levels of

decision making:

> "I think at parish level in the sub-county they attend. The local people may not but the
>
> opinion leaders and other important people in the community attend." (Technical person,
>
> District C)

> "For us we want them to plan, we give them the information through the structures that
>
> we have, because if you're asking their [the public] participation, they get involved. We

have the village health teams at that level. In the review meetings, they [Village Health Teams] let us know why things have not happened that way. So those are the big voices." (Technical person, District B)

Another way that the public contributes to decision making is through their elected officials (politicians), community leaders, cultural and traditional leaders, and advocacy organizations:

"We have the community leaders … they raise issues to the departments or to the committees about their priorities in a certain area. Then action is taken according to where they (the priorities) are raised. And what we do, we normally put as a priority area … we as a committee identify… but also we need to get responses from the lower local government community and the community themselves who are also involved in that." (Politician, District B)

Despite these existing structures and avenues for public participation, most of the respondents across all three districts decried the limited participation of the public in district-level priority setting. For example, a respondent commenting on public participation at the budget conferences said, "(they are) very few, they (the public) don't normally attend" (Technical expert, District C).

Discussion

We found that politicians, technical experts, and donors are the principal contributors to district-level priority setting, and the public is largely excluded. Politicians participate primarily through direct mechanisms including budget control and responsibility for resource allocation, while technical experts are viewed as authority figures whose priority recommendations are supported by evidence and expertise, and, in this way, able to exert influence over decision making.

Respondents also strongly emphasized the role of donors and NGO/CSOs in setting health care priorities. These stakeholders are directly involved in the priority setting process: they have a seat at the decision-making table and can influence priorities courtesy of the resources they provide in this low-income setting, as well as by using their specialized set of skills in producing evidence and providing expertise. Cultural and traditional leaders are involved to a lesser extent. They can directly influence priority setting and exert an indirect effect on the public in shaping public opinion. Finally, while the public was reported to influence priority setting through exertion of their electoral power, our findings demonstrate that they often do not attend budgeting, planning, and priority setting meetings that occur within the district.

Our findings about the stakeholders that dominate priority setting in the Ugandan districts are reinforced by the broader literature on the stakeholder participation in health-system decision making. Politicians are often the stakeholder group most involved in priority setting for health care (6). The participation of district politicians in priority setting decisions at the district level is legitimized by their role as the primary stakeholders responsible for representing the interests of people and communities within the district. However, some literature has questioned the degree to which politicians represent the public's interests as opposed to the politicians' own political interests (5,20,39,40). Politicians may have their own motives and political agendas and therefore may not always act as honest brokers of the public's health care priorities (33). This calls into question the legitimacy of politicians as representatives of the public and suggests that they may have compromised abilities when it comes to making fair decisions when setting priorities for health. Our findings further reinforce the literature that asserts that, as evidence producers and knowledge synthesizers, technical experts are essential to guiding the prioritization process (41). Finally, as reflected in our results and in the literature, especially in

low-income settings, donors are able provide the necessary resources to compensate for local governments' lack of resources; these resources can be used to fund priorities and priority programs once they have been confirmed (15,23,26). Furthermore, our respondents claimed that donors and NGO/CSOs had similar roles and leverages over district decision-making. This may be reflective of the nature of partnership relationships in development assistance (42). Donor-NGO partnerships are often characterized by the flow of resources (namely money) with donors controlling the funds that NGOs/CSOs seek to finance their programming with (42). This relationship may explain our respondents' perceptions of donors and NGO/CSOs throughout the health care priority setting process, and most notably the view that donors have a seat at the decision-making table and have a strong influence in priority setting processes.

Our findings also strengthen the evidence that the general public is missing from priority setting processes where health and health system priorities are being set. More specifically, the public is not *directly* participating in the priority setting process. Our respondents appeared to attribute lack of public participation to individual factors such as lack of expertise or lack of time. This is reflected in the literature which attributes this lack of public participation to the public's perceived lack of knowledge and objectivity, the leadership's challenges with commitment and lack of time, and an inability to achieve representation (4–6,38). However, there are structural factors that impede public participation. While these factors were not explicitly mentioned by our respondents, structural barriers identified in the literature that hinder public participation in health care decision-making include poverty, gender, lack of decision-making power (5,15,43). While some of the literature mentions limited direct public participation and difficulties with achieving representation, there is additional literature that discusses participation through representatives. The literature that supports public participation through

representation argues that it may be practically impossible to bring everyone to the decision-making table (19,44). Others have questioned the capacity of the public to meaningfully participate and engage in decision-making processes (44,45). Our findings contribute to the global literature by providing additional insight into public participation through indirect pathways such as political representation. This may support the politicians' domination of district-level decision making (discussed above).

The case of Uganda contrasts with some of the wider literature because there does appear to be commitment from leadership to include the public in decision making, and there are also structures aimed at achieving representation. Specifically, the Ugandan constitution mandates public (with specific emphasis on vulnerable populations including women, the elderly, people with disabilities, and youths) participation in governmental decision making, and the subsequent decentralization provided participatory structures to facilitate public participation (31,34,46). However, our respondents reported very little, if any, public participation. This is surprising given the existing opportunities, but is consistent with the other literature that identifies limited public participation in priority setting and health sector decision making in both high- and low-income settings (4–6,9,38). In Uganda, this lack of participation has been attributed to a lack of both individual and community empowerment, poverty, a lack of interest, and a lack of mobilisation, as well as a failure to effectively implement policies mandating public participation in health-sector planning and priority setting (5,47).

Challenges with stakeholder participation

The two main challenges with stakeholder participation that emerged in our study—conflicting priorities and/or interests, and conflicting values—are consistent with the literature. For example, as some of the literature identifies, politicians may forgo technical evidence if it

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does not align with their interests (39). This is demonstrated in findings from our study, as our respondents identified the potential for competing interests between political priorities and evidence-informed priorities as a challenge with respect to the participation of politicians in district-level priority setting. Furthermore, there is literature that specifies challenges with the participation of donors and their ability to skew decisions to reflect their own priorities at the expense of local priorities (1,23–26). This was exemplified in this study where respondents discussed the impact of the conditions that donors attach to their funding. Since donors and NGO/CSOs often provide funds that the government lacks to support program implementation, local governments are, to an extent, dependent on these stakeholders. Ugandans may lack a degree of agency, while simultaneously holding their own forms of leverage to influence district decision-making, Anderson and Patterson (2017) term this dependent agency(48), which makes balancing these competing interests a major challenge for district health care priority setting.

The findings also identified challenges stemming from competing values, such as balancing evidence from technical experts with religious doctrines and traditional beliefs. These findings are consistent with the literature, which acknowledges that priority setting in the health sector is a value-laden process that involves balancing stakeholders' different criteria and values (49). When different stakeholders hold different values or weights for the criteria (17,22,50), it is important that the values of all stakeholder groups are presented, and that these values are all carefully and systematically considered when making priority setting decisions. The inclusion of all views can be achieved through stakeholders' direct participation (either in the prioritization and decision-making processes, or through the enlisting of their values), or through representation—as long as the representatives present stakeholders' values (19,39,45).

Study Strengths & Limitations

The primary strength of this paper is that it builds on previous work on stakeholder participation and offers an in-depth analysis of different categories of stakeholders based on their roles, leverages, and challenges with their participation in priority setting processes for health. Furthermore, the findings of the paper provide insight into power relations among stakeholders who may or may not have a seat at the decision-making table.

The original intent of the study was to examine the perspectives of district-level decision makers about priority setting within their districts. Therefore, study respondents were targeted for their unique knowledge of district priority setting as members of the District Health Team and extended DHMT; however, this limited our respondents to politicians and technical experts. This sampling strategy may have biased the findings (e.g., none of our respondents identified challenges related to the participation of technical experts). However, the people sampled are responsible for setting priorities at the district level. A different group of respondents may not have had detailed understanding of district-level prioritization and stakeholder participation.

While respondents were asked about stakeholder involvement, it was not explored in further detail. Specifically, Elster's framework was not used to design the study, therefore we lacked information on the detailed leverages and types of influences. A strength of our use of an inductive approach to data analysis is that although the information about leverages and influences emerged from the data, it was not specifically asked of the respondents.

<u>Conclusion</u>

Our research illuminates differential participation and influence over the decision-making process for health care priorities in Uganda. There are numerous policies in place in Uganda meant to facilitate stakeholder participation in governmental decision making. Stakeholders'

different types of leverage affect their ability to influence the priority setting process. Imbalances of power, resources, and expertise between the identified stakeholders affect the extent to which they can influence priority setting. Stakeholders appearing to have weak direct influence, may in fact have strong leverages that indirectly influence those directly engaged in priority setting, thus enhancing the ability of the former group of stakeholders to shape priority setting. Stakeholders' leverages may also have implications for legitimacy. We assert that the current participatory structures seem to give more power and legitimacy to politicians—as representatives of the public—rather than to the public itself. It is evident that decentralization in Uganda has led to the development of devolved structures from the national level all the way down to the village level, with mechanisms for relaying information up through these pathways of communication. This invites the question: is representation an effective mechanism for participation? By exploring the degree to which politicians represent the interests of the public in a decentralized setting enhances our understanding of the mechanisms can be used to access public perspectives about health priorities and to effectively represent these priorities at the district level. Even at the lower levels where the public should participate, the public is reported to not be directly participating. As discussed above, there are certain barriers to participation for members of the public. We recommend enhanced mechanisms for participation at lower levels to facilitate politicians' ability to gain input from communities, while strengthening channels of communication between the local and district levels so that participation through representation can prove effective. Future studies should focus on the examination of the public as a key stakeholder group and on understanding participation from the perspective of groups missing from the prioritization process to discern how these groups can more thoroughly participate within the district.

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Table 1. Decision-making structure in Ugandan districts

Committee/Council	Members	Role
Local Council V (District Council)	- District Executive Committee - Sectoral committees (finance and planning, health and environment, production, marketing and industry, works and urban planning, education and sports) - Speaker - Deputy Speaker - District Councillors	- The planning authority for the district. - May devolve various functions to lower levels of government. - Responsible for preparing a comprehensive and integrated development plan incorporating plans of lower level local governments for submission to the National Planning Authority.
District Executive Committee	- District Chairperson - Vice Chairperson 3-5 Secretaries (one per sectoral committee, including health)	Monitors the implementation of council programs and coordination of NGO activities, and initiates and formulates polices to be put before the district council for approval.
District Technical Planning Committee	- Chief administrative officer - Assistant chief administrative officer - Department heads for the district - Districts department heads - Technical persons recruited by the CAO (including the DHMT)	Coordinates and integrates all the sectoral plans of lower-level local governments for presentation to the district council.
Local Council IV (County council)	- Chairperson - Vice Chairperson - All district councillors representing constituencies in the county	Monitors implementation of programs with the county.
Local Council III (Sub-county council)	- Sub-county Chairperson - Sub-county Vice Chairperson - Sub-county Secretaries	Delivers services and local economic development within the sub-county.

	• One councillor representing each parish including two youth councillors and two councillors with disabilities	• Monitors implementation of programs and delivery of services within the county, and resolve problems or disputes referred to it by relevant sub-county, parish or village councils.
Local Council II (Parish Council)	• Chairperson • Vice chairperson • General secretary • Secretary of information, education and mobilisation • Secretary of security • Secretary of finance • Secretary of production & environmental protection • Chairperson of the organisation for persons with disabilities • Chairperson of the youth council • Chairperson of the women councils	• Monitors service delivery at the parish level.
Local Council I (Village Council)	• Chairperson • Vice Chairperson • One councillor representing each parish including two youth councillors and two councillors with disabilities • General secretary • Secretary for information, education and mobilisation • Secretary for security • Secretary for finance • Secretary of production & environmental protection	• Village Health Teams (VHTs) link health facilities to the communities and are the first health contact for people living in all villages in Uganda. Emphasis is on primary health care, and VHTs facilitate health promotion, service delivery, and community participation within the village that they serve (72).

	- Chairperson of the organisation for persons with disabilities - Chairperson of the youth council - Chairperson of the women councils - Village Health Teams - All citizens of the village aged 18+	

Table 2. District demographics table

District	Region	Year formed	Administrative structure	Estimated population size
A	Eastern	1962	17 sub-counties 88 parishes 926 villages	517,082
B	Northern	1974	13 sub-counties 89 parishes 751 villages	408,043
C	Central	2005	14 sub-counties 1 town council	328,964

Table 3. Elster framework definitions

Dimension	Definition
Actor	A participant in the priority setting (PS) process.
Role*	The function that is played by an actor in the PS process.
Perceived Concerns	A matter of interest or importance to the identified stakeholder as perceived by the study respondents.
Leverage*	Influence or power that is used to achieve a desired result.
Perceived Challenges*↓	Problems or difficulties stemming from the participation of stakeholders in PS as perceived by the study respondents.

* Dimension included in our analysis.

↓ Added dimension.

Table 4. Description of stakeholder categories

Stakeholder	Description
Politicians	• Members of the district executive committee, and district councillors who are elected by the community to represent their interests • Involved in decision making at the village, sub-county, district, and national levels
Technical experts	• Appointed personnel with expertise in the different district departments • Comprise the district technical planning committees and the district executive committee
Donors	• Agencies that provide financial aid to partner countries and/or organizations to respond to humanitarian or social justice concerns • Including development assistance partners, bilateral and multilateral organizations, foundations, and charities
Non-governmental organizations (NGOs)/ Civil society organizations (CSOs)*	• Organizations that support the implementation of government programs and initiatives • Often work in partnership with donors, governments, and local communities
Cultural & traditional leaders	• The kings of the different cultural tribes, and religious leaders in Uganda, such as pastors, priests, imams, and rabbis
Public	• Beneficiaries of health services

* The respondents did not make a distinction between NGOs and civil society organizations, discussing both types of organizations under the "NGO" label.

Table 5. Stakeholders' roles in district-level decision-making

Stakeholder	Role	Illustrative quotes
Politicians	Involved in decision-making process	"…the executive plays a very big role… they [politicians] make the final decision but if their decision is not lawful then we [technical experts] come in and put it right. But if it is lawful, they have got the final decision that is the way the whole thing is structured." (Technical expert, District C)
	Representing view of the public at the decision-making table	"We normally, for us politicians mobilize people especially the counsellors to gather views from the people they represent. Then also to come into that meeting where we collect the priorities for. And too because for us we move district-wide we go on analysing the different priorities given by the people." (Politician, District C)
District technical experts	Provide expert evidence to inform decision-making process	"The district technical planning committee involves all the heads of departments, the district head of education, head of engineering, head of production, head of community all those are there, stakeholders, who plan the presentation of this report which we call the district planning committee and the district planning and the district plan." (Technical expert, District C)
	Guide the decision-making process	"Then the technical people they are here to guide us that the actual funding we have is enough or it's not enough. Then too they go into details of finding out. For example, if it requires staffing we look at the issue of staffing by the HR officer. So, to guide as to whether the project we are deciding or we are taking on will be… will be able to be fitting in within the available resources we have." (Politician, District C)
Donors	Funding priorities once they have been set	"The participation of the donors in those conferences, and in other relevant meetings have been able to convince the donors that I think where government has a problem [with funding], they can come in." (Technical expert, District B)
	Providing technical advice/facilitating	"…during the Budget Conference, all those issues come up and the partners pick from our plan that this is… considered important by the district, but they [the district] have no funds.

	the collection of evidence	So, I think we have an opportunity here. You know our partners are opportunists. They get opportunity where we have the gaps. So, they should bridge that gap." (Technical person, District B) "They play a very big role. At times, we have them as technical advisors." (Technical expert, District C)
NGO/CSOs	Support the implementation of programs and initiatives	"After planning, we call in actors who come and we are given such implementing partners mandate to work within our system…who readily accepted to work within our system… [they] come and work within the structure of the local government, looking at the health plan, the departmental plan, and financing site plans... That's why, even their staff that they have recruited, they are being placed within our system and then their salary coming as from the district payroll. Yes. Embedded in the district payroll. So that means you find out [District B] is local standing as a local government but partners are also now inside, so it makes us easy to drive the things forward." (Politician, District B) "We also use the services of advocacy implementing partners. I cited [Organization X] for them to do purely advocacy. They conduct their own surveys, they come organize a sitting and then they share with us their findings, and then jointly we come up with recommendations. And through that we are able to identify that through these at least we need to step up our effort." (Politician, District B)
Cultural & traditional leaders	Involved in decision-making process to provide cultural knowledge	"On a number of occasions, we have also brought on board cultural traditional leaders and really, just leaders. For example, a number of times traditional leaders and then the religious leaders are always brought on board when planning for HIV struggle because we realize there are some church doctrines that try to conflict with the health practitioners' strategies in terms of maybe HIV struggle. When a health practitioner says condoms should be distributed and used, a religious leader will preach something different." (Politician, District B)

	Health education and assisting with implementation	"Many of them coming now say okay, as religious leaders we feel health packages, information packages to be delivered through our congregations we should be given the ones we are able to do, we shall do it." (Politician, District B)
Public/ community	Beneficiaries of health services	"Always in planning we involved the beneficiaries of our service delivery. We always either informally or formally meet them in public galleries; we always conduct participatory planning where the political leaders in each and every department sit together..." (Politician, District B) "For us we want them to plan, we give them the information through the structure that we have, because if you're asking their [the public] participation, they get involved. We have the village health teams at that level. In the review meetings, they [VHTs] let us know why things have not happened that way. So those are the big voices." (Technical person, District B)

Table 6. Stakeholders' leverage(s) in district level decision-making

Stakeholder	Leverage	Illustrative quote(s)
Politicians	Control over the district budget Support of their electorate	"So, priority setting is done by the politicians. Then the technical people they are here to guide us that the actual funding we have is enough or it's not enough." (Politician, District C) "…politicians mobilize people, especially the counsellors, to gather views from the people they represent." (Politician, District C)
District technical experts	Expertise Ability and resources to access, synthesize and communicate evidence	"But before all of this we know that the decisions of the executive… that is the politicians are informed by findings of the technical people... the technocrats." (Technical expert, District C) "…So, the technical planning committee everybody gets informed of the resources available and how to apportion it… so the technical planning committee also help us on insight of where we cannot see alone as a sector… so I think those are other areas that help us resource allocation and apportion." (Technical expert, District B)
Donors	Resources Expertise and evidence	"At times, we have them as technical advisors. Then at times as they come in with their support [financial and other resources] they also give conditions that we must fulfill. So, it might be a condition, it might be out of sheer giving of technical expertise. So, they definitely play a big role especially in those areas where they've got a lot of interest, they play a very big role." (Technical expert, District C)
NGO/CSOs	Resources Expertise and evidence	"… during the Budget Conference all those issues come up and the partners [NGO/CSOs] pick from our plan that this is important, considered important by the district, but they [the District] have no funds. So I think we have an opportunity here. You know those, our partners are opportunists. They get opportunity where we have the gaps. So they should bridge that gap." (Technical expert, District B) "…there is also Parliament meetings at that level, their sector group, they call it technical working groups of the Ministry. And the technical working groups always incorporate

		the partners [NGO/CSOs]—just like we are incorporating partners at this level…" (Technical expert, District B)
Cultural & traditional leaders	Cultural knowledge Ability to influence their followers	"The cultural institutions can influence failure or success of any health programme, because they influence attitudes, they have norms." (Technical expert, District A)
Public/ community	Electoral power	"We normally, for us politicians mobilize people, especially the counsellors, to gather views from the people they represent. Then also to come into that meeting where we collect the priorities for." (Politician, District C)

Table 7. Challenges related to stakeholders' participation in district level decision-making

Stakeholder	Perceived challenges	Illustrative quote(s)
Politicians	Potential for competing interests between political priorities and those generate from data and evidence	"[s]o, the politicians also now come in… and if you don't have a good backing of your priorities, then they have their own political priorities." (Technical expert, District B)
District technical experts	None identified	N/A
Donors	Donor priorities may influence or overpower local priorities	"Yea donor money is conditioned. You can't use money from donors for something else." (Technical expert, District C)
	Potential misalignment between organizational priorities and local priorities	"…the donors because of their input, because if they put in money and they say well this money should go A B C D, there's no way that we're going to say we're going to take this money for roads." (Technical expert, District C)
NGO/CSOs	Organizational priorities may influence or overpower local priorities	"Then at times as they [NGOs] come in with their support they also give conditions that we must fulfill." (Technical expert, District C)
Cultural & traditional leaders	Balancing evidence from technical expert with religious	"We realize there are some church doctrines that try to conflict with the health practitioners' strategies in terms of maybe HIV struggle. When a health practitioner says condoms should be distributed and used, a religious leader will preach something different." (Politician, District B)

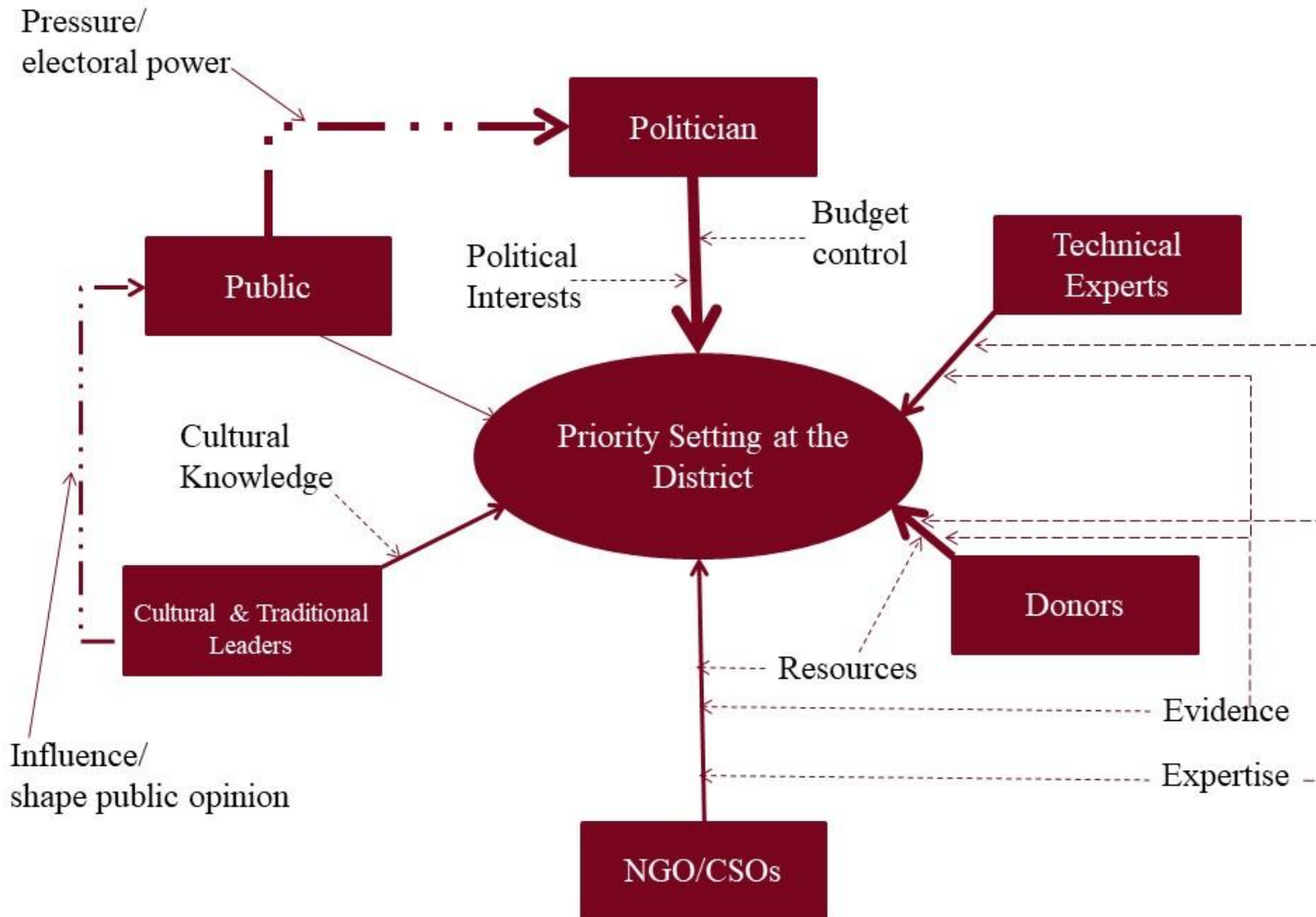|	doctrines and traditional beliefs	
Public/ community	Lack of awareness about how priorities are determined	"They are not aware. We try to use the centre, actually the office of the Prime Minister tries to create awareness… You are given so much money, what did you do for the community?" (Technical expert, District A)

Figure 1. Stakeholders' influence on priority setting at the district.

Chapter 4. Equitable public participation in health-system priority setting within the context of decentralization: The Case of vulnerable women in a Ugandan district

Preface

This chapter provides a detailed examination of vulnerable women's participation in district priority setting in Uganda, from the perspective of both decision-makers (district health management team members and sub-county leaders) and vulnerable women. Using a qualitative description study design, this study explored the role that vulnerable women play in health-system priority setting within the context of decentralization in a district in Uganda. The study explicitly identifies barriers to participation for vulnerable women and highlights practical and innovative solutions to address the barriers as recommended by both groups of respondents. Since decision-makers' perspectives have been explored in the past, a special focus is placed on conveying vulnerable women's views on their own participation in priority setting within the district.

I was responsible for conceptualizing the study, with input from my supervisor, Lydia Kapiriri, and its methodological design, with input from all committee members: Lydia Kapiriri, Julia Abelson, and Michael Wilson. The study was conducted in Tororo district, Uganda. Data collection occurred in May and June of 2017. I was responsible for data analysis and drafting the manuscript. As co-authors, all thesis committee members provided feedback on several drafts, which were incorporated into the manuscript.

Table 1. Overview of the orginal research studies that comprise the dissertation

Dimension	Study 1 (Chapter 2)	Study 2 (Chapter 3)	Study 3 (Chapter 4)
Title	Applying priority setting frameworks: A review of public and vulnerable populations' participation in health-system priority setting	Who is in and who is out? A Qualitative analysis of stakeholder participation in priority setting for health in three districts in Uganda	Equitable public participation in health care priority setting within the context of decentralization: The Case of vulnerable women in a Ugandan district
Research Objectives	i) Examine which stakeholders have been involved in the decision-making process when priority setting frameworks are applied to different priority setting cases. ii) Understand how the public, as stakeholders, are involved in applications of the identified priority-setting frameworks. iii) Establish whether vulnerable populations participated in these priority setting exercises.	i) Examine the perspectives of district-level decision makers about stakeholders' participation in district-level priority setting; ii) Identify the stakeholders who are involved in district-level priority setting for health and the roles they play in the three districts; iii) Describe and analyse the leverages that the different stakeholders use to influence district-level priority setting; iv) Discuss the challenges associated with participation of different stakeholders.	i) Identify whether vulnerable women participate in health care priority setting within the district; ii) Understand why vulnerable women are or are not participating; iii) Establish how barriers to their participation can be addressed.
Methodology	Scoping Review	Interpretive Description	Qualitative Description
Data collection strategy	Database searches	Semi-structured interviews	Semi-structured interviews
Context of participation	Priority setting frameworks used to guide health-system priorities globally	District priority setting in three Ugandan districts	Health-system priority setting in one Ugandan district

Data sources	Scholarly literature	Transcripts from interviews with district decision makers	Transcripts from interviews with district-level decision makers, sub-county leaders, and rural women
Connections between studies	- Identifies that some of the most commonly cited priority setting frameworks do not consistently engage publics and vulnerable populations, when applied to health-system priority setting cases. This provided justification for study 2 and 3.	- Builds on the findings of study 1 to provide a deeper analysis of stakeholder participation in health system priority setting in 3 Ugandan districts. - Identifies that the public and vulnerable populations are not participating in priority setting processes. This informed the development of study 3, which provides an in-depth examination of vulnerable populations' participation, from the perspectives of people themselves.	- Complements findings from study 1 and 2 by providing a detailed understanding of vulnerable women's participation from the perspective of both decision makers and vulnerable women. - Explicitly identifies barriers to participation for vulnerable populations which were alluded to by respondents in study 2.

Equitable public participation in health-system priority setting within the context of decentralization: The Case of vulnerable women in a Ugandan district

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Abstract

Background: Decentralization of responsibilities for health care in Uganda have led to the promotion of public participation. Participatory structures have been developed to facilitate public participation in health-system priority setting at sub-national levels. However, the degree to which decentralization has contributed to improving the participation of vulnerable populations, specifically vulnerable women, has not been explored in-depth. Our objectives are to understand, from the perspective of both district decision-makers and vulnerable women, whether and how vulnerable women living in rural Uganda are involved in health-system priority setting, identify any barriers to vulnerable women's participation, and to establish how the barriers to vulnerable women's participation can be addressed.

Methods: The study used a qualitative description study design involving interviews with district decision-makers, sub-county leaders, and vulnerable women living in rural Tororo District, Uganda. Data collection occurred from May to June 2017. We used an editing analysis style to examine the data.

Results: Our results show that while vulnerable women believe in the value of their contribution and want to participate in health-system priority setting, they are not consistently participating at different levels of decision-making. A variety of barriers prevent vulnerable women from participating. We grouped these barriers into six categories: financial (transportation and lack of incentives), biomedical (illness/disability and menstruation), knowledge-based (lack of knowledge and/or information about participation), motivational (perceived disinterest, lack of feedback, and competing needs), socio-cultural (lack of decision-making power), and structural (hunger and poverty) barriers. Both vulnerable women and

decision-makers share practical and innovative recommendations to facilitate women's participation.

Conclusion: Vulnerable women are underrepresented in health-system priority setting. While there are significant barriers to participation, decentralization in Uganda is designed to address many of these barriers. Existing participatory structures can be modified to facilitate meaningful participation of vulnerable populations. The integration of women's creative and feasible ideas to enhance their participation in health-system decision-making should be prioritized over the implementation of top-down strategies.

Background

Decentralization was used as an instrument to reconfigure the formal institutional structures in many countries around the world during the 1980s and 90s (1,2). Decentralization takes different forms, namely devolution, deconcentration, delegation and privatization (3,4). Each of these different forms of decentralization has had implications for health reforms regarding the nature of the accountability relationships between local decision-makers and central government or local constituents (2,3). In Uganda, decentralization was characterized by the devolution of authority to the local government level (3,5). There was a shift of hierarchical authority and responsibility across sectors from the central government to separate administrative and political structures at the local levels (primarily the districts) (1,4). This redistribution of power and decision-making has been promoted as a mechanism through which public participation can be improved (5,6). While decentralization has improved public participation in decision-making (1,7–9), the degree to which it has contributed to improving the participation of vulnerable populations in decision-making has not been well explored. Our paper seeks to address this gap.

The Ugandan Constitution 1995 and the Local Government Act 1997 devolved decision-making through the development of political structures called local councils at the district, sub-county, parishes, and village levels (10) (Figure 1). The local councils are responsible for their own elections, they often raise their own funds, and have independent authority to make budgeting decisions (1). Since the local councils are composed of representatives elected by local constituents, local governments and politicians should be accountable to their electorate (2). According to the Constitution, local authorities should be autonomous and able to make local decisions. Article 38 of the Constitution explicitly mandates public participation in governmental

affairs, government policies, and the local decision-making processes (1,10,11). The constitutional mandate for participation is quite broad referring to active participation of all citizens in governmental decision-making either individually or through representatives and civic organizations, without further elaboration about how this participation should be operationalized (10,11).

Within the health sector, decentralization has involved the devolution of the responsibilities for planning, budgeting, and implementation of the health policies from the national level to District Local Governments (10–12). Decentralization of responsibilities for health care has led to the promotion of public participation to enhance transparency and inclusiveness (13). As with the country's broad mandate for public participation, public participation in health-system priority setting has been mandated at sub-national levels in Uganda (5,13). According to the Ministry of Health reports and policy documents, the public can participate in priority setting either directly e.g. in community-based activities (e.g. in public health campaigns) or by attending village council meetings (8,12), or indirectly through publicly elected representatives (8,12). Health-system decision-making occurs at the sub-county and district levels. Each local council has parallel health committees (5,9,14). The health committees are responsible for health-system planning and budgeting, and program monitoring and evaluation (12), and are one mechanism designed to foster community participation in government decision-making (5). Health unit management committees (HUMCs) were developed, in part, to facilitate community participation in decision-making about health services and their delivery (8,15). At the village level, village health teams (VHTs) were developed to improve community ownership and responsibility for implementation of health promotion and prevention campaigns and overall community health education, and act as a link between the

community and health facilities and encourage active participation in the management of their local health services (9,12). However, guidance around explicit standards for effective participation and operationalization of participation remain unclear. In fact the most recent Health Sector Development Plan 2015/16-2019-2020 and the Uganda One Health Strategic Plan 2010-2022 do not explicitly discuss public participation in health-related decision-making nor its operationalization (16,17).

One function of the devolved political structures, specifically the districts, is to set health system priorities. Priority setting is a process through which decisions about resource allocation are made for competing programs (18). Public participation in the health sector emphasizes the involvement of members of the public in decisions about health services and health policy at different levels of decision-making and is a key component of ensuring equitable health-system priority setting that considers the unique needs of different groups (19,20). While members of the public may not have technical health care expertise, they are able to provide insight into their values and contexts, which are important inputs to the priority-setting processes (19–21). Public participation is a critical part of the process because: public perspectives provide context and local expertise, which can strengthen decision-making and enhance the applicability of the decisions and recommendations made by decision-makers (19,22–26). Furthermore, it is thought to promote accountability among decision-makers (21,27,28); it enhances acceptability of decisions and can ease processes of adoption and implementation (19,26); and it focuses on engaging the primary consumers of health services, the public (29). One subset of the public that appears not to be participating in health-system priority setting are vulnerable groups (30).

Vulnerability is a complex construct that is often used interchangeably with concepts such as "marginalized" or "disadvantaged". We adopt a combination of the World Health

Organization (WHO) and the Uganda Human Development Report 2015 understanding of vulnerability. The WHO explains that vulnerability is the degree to which individuals, organizations, or entire populations are unable to to anticipate, cope with, resist, and/or recover from the impacts of disasters, crises, or harm (31). The Uganda Human Development Report 2015 echoes this understanding and explains that vulnerability is composed of two dimensions: exposure and resilience. Exposure relates to the susceptibility to risk, and resilience is reflected in the choices that are available and ability to deal with the exposure to harm (32). Addressing the health concerns and priorities of vulnerable groups is essential to health equity, since their needs may be different and more severe or urgent than those of the general public. For example, vulnerable populations often experience a disproportionate burden of disease (33,34). Exclusion of vulnerable groups from health-system decision-making can mean that their voices are not heard and their perspectives and health needs are not integrated into health-system priorities. When priority-setting processes do not consider the needs of vulnerable populations, their interests can become further marginalized resulting in greater health disparities (33).

The literature on participation of vulnerable populations specifically in priority setting for health system and health care is scarce. Efforts have been made to study the engagement of minority, disadvantaged, and underserved populations in health research priority setting (35–37). This work demonstrates that the health research priorities of these populations may be different than those of decision-makers and other powerful stakeholders, and that their participation has the potential to make the research agenda more equitable and responsive to their values and needs (35,38). Mitton, Smith, Peacock, Evoy, & Abelson's (2009) review of public participation in health care priority setting reported that there is some evidence that efforts have been made to engage disadvantaged, marginalized, or vulnerable groups, namely the poor, children, visible or

ethnic minorities, Indigenous persons, persons with disabilities, seniors, women, people with

mental health concerns, illiterate or persons of low education, the homeless, and single parents

(27). However, much of this research has been conducted in high-income countries. In the low-

income country context, Kapiriri (2018) and Bhaumik, Rana, Karimkhan et al. (2015) examine

stakeholder involvement, paying specific attention to public participation and marginalized

groups, in health research priority setting in Zambia and Nepal respectively (36,39). McCollum

et al. (2018) explore power dynamics and participation in health-system priority setting

following devolution in Kenya (40). However, these studies focus on the perspectives of

decision-makers rather than those of vulnerable populations. Others have studied the feasibility

of methods to operationalize public participation in high income countries (41), and low-income

countries with varying levels of success, such as in Tanzania (42). This literature reflects

limitations of public participation, identifies vulnerable populations, and highlights the relevance

of their involvement (42,43) but falls short of examining barriers to participation for vulnerable

groups. Our study seeks to addresses these gaps.

The Ugandan government explicitly recognizes the historical exclusion of vulnerable

populations and has developed policies to enhance their participation in health system decision-

making. The following populations are identified as vulnerable within Ugandan policy

documents: women, widows, orphans, children, adolescents, the elderly, people with disabilities,

displaced persons, and people living in chronic poverty (12,44,45). They also recognize that

vulnerability can vary based on: gender, age, ethnicity, occupation, and social status (46).

Article 32 of the Constitution recommends affirmative action for traditionally marginalized

groups, such as women (11). This aligns with the overarching equity focus of Uganda's National

Health Policy (45).

Women are considered a vulnerable group in Uganda, due to asymmetry of power in the household, in the workforce, and society at large, and their subsequent lack of participation in decision-making (47). Uganda's National Gender Policy compels all government policies and programs to work towards elimination of gender inequalities (48). The policy should guide all levels of planning, resource allocation, and implementation of development programs with a gender perspective. One policy strategy is to ensure that women's participation in decision-making and governance is prioritized (48). In line with this strategy, the Local Governments Act 1997 mandates one-third representation of women across all levels of decentralized local governments including districts, sub-counties, parishes, and village councils (10). Therefore, we would expect that women are being sought out to participate in health-related decision-making, including priority setting.

However, community participation and empowerment has been limited thus far (9,14). The Ugandan Constitution, Local Government Act, Health Sector Strategic and Development Plans, and the National Health Policy highlight aims to enhance partnership with the community (10–12,44,45). Since we are interested in the experience of vulnerable populations with participation in health-system priority setting and there is an explicit governmental mandate to include women in these processes, we have chosen to focus on the women living in a rural district of Uganda.

Study Objectives

This study explored the role that vulnerable women play in health-system priority setting within the context of decentralization in a district in Uganda. Specifically, we aimed to: (i) examine self-reported and decision-maker reported vulnerable women's participation in health-system priority setting within the district; (ii) identify the barriers to vulnerable women's

participation; and (iii) establish how the barriers to vulnerable women's participation might be addressed.

Methodology

Study design: We used a qualitative description design (49,50). The qualitative description methodology is used when research aims for an in-depth understanding of phenomena but focused on description of the phenomenon rather than interpretation (49,50). The approach is especially useful when the researcher hopes to understand phenomena of interest from the lens of those experiencing it (51).Qualitative description supports the use of techniques from the other dominant qualitative methodologies, while combining both deductive and inductive analytic techniques. This approach is malleable to answering health policy-related questions, including those related to health-system priority setting (51,52).

Qualitative description provided the opportunity to explore the phenomenon of participation of vulnerable women in health-system priority setting, within the specific context of a rural district in Uganda, using different data sources. The study set out to answer the questions of whether vulnerable women are participating, how they are participating, and why they may (not) be participating in health-system priority setting. We did not manipulate the behavior of study participants but aimed to elicit their perspectives about the role they play in health system priority setting.

This study also aims to gain insight as to how vulnerable women believe they can be better engaged in priority setting. Consequently, a flexible and pragmatic approach that allows for the voices of vulnerable women to be heard, like qualitative description, is vital to comprehensively address our study objectives (51).

Study setting: The study was conducted in a rural district in Uganda. Uganda is a decentralized LIC, which has mandated and developed participatory structures at each level of government (11). Within Uganda, rural dwelling and gender are both identified as important dimensions of vulnerability. The study district, Tororo is a rural district in Eastern Uganda. The district has one of the highest poverty levels in the country (53). Tororo district is made up of 17 sub-counties. There are two major ethnic groups in Tororo, the Jopadhola and the Iteso. Four sub-counties were sampled. We selected one Jopadhola dominant sub-county, one Iteso dominant sub-county, and two mixed ethnicity sub-counties. The sub-counties were geographically dispersed to represent the western, central, and eastern regions of the district.

Study population: We interviewed both: vulnerable women living in rural communities in Tororo and Tororo district decision-makers.

Vulnerable women were included since we were interested in understanding their perception of the degree to which they participated in health-system priority setting. They were the best respondents for this objective. Furthermore, and consistent with the literature on equitable participation, it is important that people who are most affected by the research phenomenon are interviewed, even if they are vulnerable or marginalised (37,54,55). The women were sampled to reflect the relevant dimensions of vulnerability in Uganda namely; women who are poor, those that lack education, single or widowed women, and women who may be unable to make their own decisions.

However, we also interviewed district decision makers to gain varying perspectives on the vulnerable women's participation. We recruited the members of the district health management teams (DHMTs). The DHMT is responsible for health planning, organizing, monitoring & evaluation of services across the district (44).

Sampling strategy: We used snowball sampling to sample across three age groups-adolescent/young adult (10-24 years), adult (25-55 years), and elderly (55+ years of age). In each of the selected sub-counties, we identified our first index respondent was randomly selected (the first woman we met who met our criteria and was willing to participate in the study) The index respondent was then asked to refer us to any additional women within their sub-county, who met the age criterion. Once we achieved saturation of the research themes (i.e. desire to participation, whether and how they participate, barriers to participation, and recommendations to enhance participation), we tallied the vulnerabilities that were represented (ethnicity, level of educational attainment, marital status, and income/type of employment) within the interviews in order to identify vulnerabilities that may be lacking in the sample. Further sampling focused on achieving saturation along all the predetermined and emerging dimensions of vulnerability.

For the decision-makers, a purposeful approach to sampling was used whereby all members of the DHMT were interviewed. At the sub-county level, technical leaders for each of the study sub-counties were interviewed.

Data collection: In-depth interviews were conducted using pilot-tested, semi-structured interview guide developed based on themes from the literature on participation in priority setting and Ugandan policy documents. Interviews with the rural women were conducted by SDR with the help of a translator, who translated the questions that were asked in English, to the women's respective local languages. The translator also translated the women's responses back to English for the interviewer. Samples of questions asked of the women included: "How are decisions about healthcare made in your community?"; "In what ways are you involved in decision making processes about the health system in the district? At the village level?"; "What do you believe you can contribute to the decision-making process about how resources for health are allocated

within district?"; "How do you believe the district can improve the participation of women in decision making about resource allocation in the health system?" (see Appendix 1 for the full interview guide).

Interviews with the decision-makers (district and sub-county levels) were conducted in English by SDR. District decision-makers were asked the following questions: "Tell me about participation within the district?"; "Who are considered vulnerable women in Tororo District from the perspective of the district?"; "How do these vulnerable women participate in priority setting decisions at the local level?"; "How should these women be involved in making decisions about the distribution of resources?" (see Appendix 2 for the full interview guide).

Ethics: Ethics approval was obtained from the Hamilton Integrated Research Ethics Board (HiREB), Canada (Protocol number 2808), and the Makerere University School of Public Health (MakSPH) Institutional Review Board, Uganda. All interviews were audio-recorded, with permission from the participants. All respondents provided either written or thumbprint consent prior to participating in the interview.

Data analysis: All interviews were transcribed by Ugandan transcriptionists with expertise in either of the local languages (Ateso or Japadhola) and English. Interviews with the DHMT and sub-county leaders were transcribed verbatim, in English. Interviews with the women were back translated and transcribed verbatim from the local language to English. QSR NVivo12 qualitative data analysis software was used to code interview transcripts. We used an editing analysis style, which supports an inductive approach to data analysis and grounding of emerging concepts in the data (56,57). We conducted line-by-line reading of the interview transcripts and used an open, inductive stance to microcode five interviews from each respondent group (vulnerable women and district decision-makers). Similar ideas were grouped together and given

a concept label, from either the literature or the data (58). We used the generated concept labels

to code the rest of the interviews (58–60). We pursued emerging concepts for theoretical

variation to the point of saturation. Categories were then grouped into related themes, which we

report on below.

Results

We interviewed 57 respondents including 12 decision-makers at the district level (three

women, ten men), 10 decision-makers at the sub-county level (two women, eight men), and 35

vulnerable women living in rural villages in Tororo District of whom 11 were adolescents (10-24

years), 12 were adults (25-55 years), and 12 were elderly women (55+ years of age). All twelve

members of the DHMT were interviewed. Sub-county leaders interviewed included sub-county

chiefs, community development officers, secretaries for health, and health inspectors. Of the 35

women, we had relatively even distribution across ethnic groups with 17 Iteso women, 12

Jopadhola women, five Japadhola-speaking Iteso women, and one Mugisu woman (married to an

Iteso) interviewed (Table 1). We report the different perspectives using the following labels

"rural woman" for the vulnerable women, "DHMT member" for the district level decision-

makers, and "sub-county leader" for the sub-county decision-makers. Four themes relating

vulnerable women's participation were identified: whether vulnerable women want to participate

in health-system priority setting, whether vulnerable women do participate, barriers to their

participation, and recommendations to enhance participation for vulnerable women in health-

system priority setting. The following section is organized according to these themes.

Do vulnerable women want to participate?

When asked about their desire to participate and whether the women believed they had contributions to make to health-system priority setting, all vulnerable women interviewed expressed a desire to be engaged in decision-making processes of priority setting and planning for the health-system in the district. They believed in the value of their contribution and they believed they have a unique understanding of their communities and specialized knowledge of community needs. For example, one respondent pointed to the role of elder women in their village as experts about the needs of their community:

> "If you approach them, you can get more ideas from those elders also, they will advise you how to go with people, that is if you have not understood how to organize the community. Those elders know how, they have lived there for long, so they are better off of any other person who is growing up…" (Rural woman, 50, Iteso)

Do vulnerable women participate?

Responses to the question of whether vulnerable women participated in health-system priority setting yielded consistent responses from both the vulnerable women and the decision-makers. The vulnerable women respondents explicitly stated that vulnerable populations including children and youth, the elderly, people with disabilities, and the very poor do not participate in health-system priority setting within Tororo district. For example, a 55-year-old Iteso woman explained, "I think children are not involved… we have some very, very old women, very, very old men who are really vulnerable and you find that they are really not healthy, they are sick."

Our respondents provided further nuance to this observation, specifying that in each identified group, women do not participate (Table 2). The perspectives of district decision-

makers were consistent with the rural women that vulnerable populations, namely vulnerable women, generally do not participate.

Perceptions of vulnerable women's participation varied depending on the administrative level where participation was to occur rather than the category of respondent (women or decision-makers). At the community level, district decision-makers and vulnerable women agreed that women and powerful men (i.e. local leaders), participate more often (Table 2). The vulnerable women reported participating more actively than men in both formal and informal meetings, including local council and community meetings. While, the women identified that both women and men participate, they explained that women attend more than men when informal community meetings are held. A 64-year-old Japadhola woman reported that "If a [*village*] meeting is called according to how I see, women are usually more." The women respondents also explained that older people participate more than youth at the community level. One 16-year-old Iteso woman stated that "the old people participate more the youths are very few."

Beyond the community, vulnerable women and district decision-makers also agreed that not only do men participate more, but also men are more consistently part of the decision-making structures, such as the district council, that ultimately make resource-allocation decisions. The rural women further explained that their village leaders participate more at the higher administrative levels rather than lay members of the community. One 60-year-old Iteso woman identified that those who participate beyond the community at the higher administrative levels are "the health workers and the chairman LC [*local council*] 1…we have our parish chiefs and we have LC II chairmen, then sub county chairman or sub county chief…we have the health assistant… and the in charge the health unity."

District and sub-county level decision-makers identified that vulnerable groups were either underrepresented or not engaged in priority setting for the health-system within the district. One member of the DHMT specifically identified that women do not participate in budget conferences, "Who is not there... Most times the woman in the village, does not get that opportunity." They explained that while, at each administrative level, there were representatives for women, youths, the elderly, and the disabled who participate in budgeting meetings, the wider public was generally missing at meetings like budget conferences.

"Nearly every group except children are involved in decision making but indirectly... Through their elected leaders because in the district council the ultimate decision-makers in the district is the district council will have a representation of the youth, but we only have two youth representing the young people in the council of about forty people, then we have two elderly persons representing the elders in the council. We have two people representing the PWDs [people with disabilities] ... we have special interest groups, women have their specific representatives." (DHMT member)

"There are those who know about it [*budget conference*] are the ones who will come to present their ideas, so some people miss out and then there are people who don't care, they don t even know what this is all about. Even when we make an announcement, some people don't have radios to get to hear about it or they don't bother, they think it is not for them... such people don't get involved" (DHMT member)

Barriers to participation

While there was a desire among the rural women to participate, respondents emphasized the role of different barriers that hinder their participation. Respondents identified twelve key

barriers specifically preventing participation for women, which we grouped into six overarching categories: financial (transportation and lack of incentives to participate), biomedical (illness/disability and experiencing menstruation), knowledge-based (lack of knowledge, specifically with respect to general education, literacy, and English language skills, and lack of information about rights and opportunities to participate), motivational (perceived disinterest, lack of feedback, competing needs and time commitments), socio-cultural (lack of decision-making power for women), and structural (hunger and poverty).

As illustrated in Table 3, all barriers were identified by both district decision-makers (either DMHT members and/or sub-county leaders) and rural women, except for menstruation and lack of decision-making power. Menstruation was identified only by adolescent women in the villages. Lack of decision-making power for women was uniquely identified by sub-county leaders. The barrier most commonly identified by our women respondents was a lack of information about their right to participate and opportunities to participate in health-system planning and budgeting meetings. One Iteso woman, aged 24, clarified her desire to participate but lack of opportunity: "If I am not called for the meeting, because me I am interested in meetings but what can prevent me from going is when I am not given… if I have not got the information, I don't go." When the women *did* hear about these meetings, lack of education was a barrier that was top of mind for them. This deterred them from attending meetings because either they felt they did not have the English language skills to participate or they felt their contributions would not be as meaningful as those with higher levels of education (Table 2). Specifically, many women were troubled by their inability to communicate in English. One 49-year old Japadhola women remarked, "There are questions they ask in English and if you are not educated and you cannot communicate." Another concern reported by both decision-makers and

the vulnerable women was a lack of feedback from decision-makers and decision-making structures to communities and a lack of follow through on promises that had been made. Women were frustrated by the resources they perceived to be concentrated at the district or distributed elsewhere, but they did not benefit from them in their villages. One 30-year old Iteso women explained, "They usually bring things there at the district there, but sometimes those things don't reach here in the village... that's what makes people say that ahh what I am going to get." Additional illustrative quotes for each of the aforementioned barriers can be found in Table 3.

District decision-makers reiterated many of the barriers identified by the rural women when discussing participation at budget conferences.

"The budget conference is one of the initial stages where we present what we did in the previous year and what we intend to do in the coming year. Normally it takes place around September, October. The budget conference is attended by various stakeholders of the district, religious leaders, cultural leaders, other implementing partners, NGOs, CBOs, Faith based organizations, we have the civil society, the, the press, the business community, everybody. Who is not there... Is the person who cannot read and write or speak English because it is conducted in English..." (DHMT member)

"We are supposed to call the public for a budget conference... we send the announcements we call… we tell the councillors you inform everybody who is interested to come for the budget conference, so the budget conference is ideally an open conference, open to anybody who wants to contribute in sharing about how resources should be allocated actually financial resources. It's an open thing but the problem is are people aware about the budget conference? How many people get information about it? First off, information does not reach, many, two you find that some of them think that

even if they come, their views may not be listened to, who am I, that's the question, even me the poor woman in the village if I go there to the district level, who will recognize me. That's another big problem, they have somehow given up, who will listen to us ... I think it's some kind of inferiority complex. Then thirdly I think this meeting is held at district level headquarters, how do you expect somebody to travel from [*one of the furthest sub-counties from the district headquarters*]." (DHMT member)

Furthermore, often there is not simply a single barrier that prevents women from participating, but multiple interacting barriers. For example, one adolescent mother explains:

"sometimes when it finds that my baby is sick like last time when I was supposed to go to a meeting, it found that that baby was sick, I had no transport, so it was difficult for me to go from here to the meeting place on foot with the baby" (Rural woman, 16, Iteso)

We found that many of the identified barriers are inter-related. For example, while our rural women respondents strongly emphasized lack of transportation, hunger, and lack of incentives to attend meetings as direct barriers to participation, these are also symptoms of poverty. While this demonstrates the complexity of including vulnerable women in participatory processes for health-system priority setting, planning, and budgeting, it also provides for the opportunity to develop holistic solutions that address multiple barriers.

Recommendations from the field

Two types of recommendations were made by our respondents (1) specific recommendations about ways to address the barriers that prevent participation (Table 4), and (2) general strategies to enhance participation for vulnerable women across the district.

The vulnerable women respondent's recommendations to address hunger, transport, and lack of incentives, primarily involved compensation for the time spent and resources required to travel to and participate in planning and budgeting meetings. Women in rural Uganda have a plethora of responsibilities. The need to support and feed their families creates competing needs and time commitments that hinder their ability to participate. For example, women must work in their fields to maintain their livelihoods, rather than take time away from cultivating their land to participate in planning meetings. One Iteso woman, age 57, explained, "Women from the village cannot go to the sub county, because there are competing time needs like; digging, cooking, and like for me who is a widow I have a lot of responsibility." While the recommendation from the field to address this barrier was to host meetings at times that more appropriately fit women's schedule, this and many of the other barriers and accompanying recommendations reflect the poverty that exists in rural Uganda.

Our respondents reported two general strategies that can facilitate public participation which included: (i) improving channels of communication from the local level up to the district, and (ii) developing and implementing economic and social empowerment initiatives. The vulnerable women noted that even when they participate, decision-makers do not set priorities according to what they have asked for and resources are allocated elsewhere. This can discourage them from participating in the future. One woman noted:

> "because there is a way things happen, if they come to the sub-county or if they begin from the district level, before they it reaches to the sub-county like you have heard about the problem we had in [county]… we have a difference here which it has been disturbing us so from the beginning of the year up to now. People are not very much happy on what is

happening in our county…when they bring things, resources for the sub-counties they end up going the other side [another county]." (Rural woman, 50, Iteso)

The vulnerable women expressed that this lack of follow through on the part of decision-makers to allocate resources as requested by the community may result from problems with the channels of communication that relay information from the village to the district, and vice-versa. The following quotes reveal that while the local council system is established to convey information from local communities to district decision-makers, our respondents believe that these structures are not working as they should be.

> "It doesn't happen unless the District sends people to the villages then they mobilize and hold a meeting then they gather information from the villagers and any decisions made… through the sub-county, parish and then village, they [should] follow the channels of communication [but] They don't follow." (Rural woman, 50, Japadhola)

> "I think, you know the district is too large for me to say maybe they come down to meet the local women, it might be very, very difficult that is why they are using the other system of LC [*local council*]…then they will not know that where do we find such and such a person with good ideas like that… there is communication barrier." (Rural woman, 55, Iteso)

This demonstrates that the vulnerable women are aware of the local council system, have a general understanding of how the decentralized system functions, and how their participation and input should be channeled through the administrative structures to inform health-system priority setting and resource allocation decisions. They believe that these channels should be strengthened to work as envisioned and to facilitate their participation.

Secondly, improved economic and/or social empowerment was a recommendation made by both groups of respondents- district health team members and sub-county leaders, and the rural women. Many respondents addressed that while numerous barriers prevented women from participating in health planning, the overarching barrier was poverty. As a structural barrier, poverty was perceived as the root of many of the barriers addressed above. They explained that when the country is experiencing periods of drought and famine, populations are hungry and experience illnesses, citizens lack adequate shelter and housing, parents cannot afford to send their children to school, people do not have money for transportation, and women lack decision-making power in the home, participation in health-system decision-making are not top of mind.

> "like this time of famine, you find that someone did not eat him, or she has no energy… Another one can be sickness where one is admitted and cannot attend the meeting some did not go to school, so they are not able to know." (Rural woman, 49, Japadhola)

> "Because my parents, we were many, so the father decided to educate the other ones and say by that time a girl child [young female child] you need not to go school, so your work is to get married." (Rural woman, 38, Iteso).

When asked to consider the barriers they identified and strategies to improve participation for vulnerable women, respondents suggested that women need to become empowered through social assistance and skills development programs (Table 4). This in turn, would develop women's capacity and motivation to engage in participatory processes for health-system planning. A 50-year-old Iteso woman explained:

> "Vulnerable women in the community, if they are given… loans I saw them participating very well... as their getting those loans, monitor them not to give them pressure, make

terms on how they should operate in that income or make them get groups like poultry keeping, craft work, the bakery, decorate functions, here in the village actually those kinds of things don't exist" (Rural woman, 50, Iteso)

There was consistency between the vulnerable women and decision-makers in identifying economic empowerment and social assistance programs as ways to improve participation (Table 4). Furthermore, a DHMT member explained that existing microfinancing programs provide an opportunity to engage the program participants in health-system priority setting.

"they are not reaching them, if the cultural institutions, religious institutions, the CDOs [*community development officers*], the CSOs [*civil society organizations*], this is where they should have been going to the different groups because the groups are there, if you're going to use a livelihood program of fifteen young men and women, if they are having their meeting, why don't you go and talk to them."

Discussion

Both vulnerable women and district decision-makers reported that women living in rural Uganda were not consistently participating in health-system priority setting within the district. Powerful stakeholders, specifically those in political and technical leadership positions, participate in district priority setting. We learned that while vulnerable women were eager to participate, there are numerous barriers that prevent them from participating (Table 3). Our respondents had innovative ideas about how to best address these barriers to enhance participation for women within the district (Table 4).

The evidence supports our findings that the public, vulnerable groups, and women in particular, are missing from the decision-making table (5,19,27,61). Across the different

categories of respondents, there was agreement that active participation in decision-making, at all administrative levels, continues to be dominated by locally elected political leaders, like government councillors. This lack of participation is echoed by Bolsewicz Alderman, Hipgrave, and Jimenez-Soto (2013) who reviewed public engagement in health priority setting LMICs (13). The rural women provided unique insights by identifying that women seem to be participating more at the community/village level. However, decision-making occurs at the sub-county and district levels, where women's participation is lacking.

The identified barriers are not unique to Tororo district, Uganda, but have been reported in other districts and low-income countries. For example, lack of decision-making power and general female disempowerment have been reported in Mukono district, Uganda. Lack of information and time constraints have been reported in Kenya (62) and Tanzania (63). In this study, a prominent barrier seemed to be poverty. The classification of barriers into six categories (financial, biomedical, motivational, socio-cultural, knowledge-based, and structural) support the understanding that barriers to participation are inter-related. Poverty appears to have strongly impacted vulnerable women's participation in health-system priority setting. People living in poverty often feel that they lack a voice in the decision-making and feel that input does not affect policy-makers' decisions (5,64). This sentiment was echoed by our respondents. Poverty, as experienced by women living in rural Uganda, was intertwined with additional barriers. This presented further practical constraints to participation. The desire for financial compensation and other incentives to participate such as providing food or transportation fees, are symptoms of poverty and recognizable barriers to participation in low-income settings (5,13,64). While it is necessary to address poverty at a structural level, completely alleviating poverty is not currently a feasible solution to improve vulnerable women's participation in Uganda. However, incentives

for participation may not be necessary if the public feels that their views are heard and valued, and that when they do participate, their voices affect change. The inter-related nature of barriers to participation suggests that the solutions presented by our respondents can potentially address multiple barriers to facilitate vulnerable women's participation.

The Ugandan government has previously stated its commitment to women's participation (10,11,48). Yet, post decentralization, the structures meant to enhance participation in health-system care planning and priority setting do not seem to be functioning as intended. The local council system was intended as a channel of communication to enable bottom-up planning, from the village, through the parish and sub-county, to the district. Previous work has highlighted the role of health unit management committees (HUMC) and public health committees (PHC) as vehicles to facilitate public participation (5,9). However, these structures were not identified by the women as avenues they used to participate. This is consistent with literature that explains that the existing structures have not operationalized public participation (5), and participation of vulnerable groups' (8). Nevertheless, we found that women gather informally at the village level to voice their concerns. Therefore, perceived laziness and disinterest about participation may result from other barriers such as: competing time commitments; lack of feedback and dialogue between district decisions-makers and the vulnerable women; and lack of information about where, when, and how they can participate. These barriers may make women feel that their contributions are not actively sought out nor valued by decision-makers (8), and that their time is better spent working to support their families. This appears to have fostered apathy among vulnerable women in Uganda towards participation. However, lack of participation for this population may not be a function of a failure in decentralization. We actively sought out especially vulnerable, remote, and disenfranchised women, which may have been difficult for

local leadership to access considering the district's limited resources (65). Instead our study offers insight into opportunities for decision-makers to use existing decentralized structures to encourage vulnerable groups' participation in health-system priority setting and planning.

For priority setting and planning to be truly bottom-up, all publics should be able to access the participatory structures. When engaging vulnerable populations for health-system care decision-making, transparency and accountability are necessary to maintain community interest in the participatory process (5,13,66). We often blame decision-makers when priorities are not set with community input or according to community needs. However, decision-space for district leaders to set health-system priorities may be limited (5,67), restricting their ability to be responsive to community needs. Consistent dialogue with communities provides opportunities to explain and justify the decisions in ways that are acceptable, and this is especially important when resource allocation does not align with public input. Feedback about programming is essential to maintain a trusting relationship with communities (5,13,64). Community dialogues or barazas, as they are called in Uganda, should involve representatives from the district, sub-county, parish, and villages levels of governance, who are well informed and able to communicate information and engage in a two-way dialogue with the public. While there is limited decision-space for decision-makers at the district level, creating an understanding between local leadership and communities may help overcome the limited decision-space by enhancing their ability to act and mobilize in concert.

Strengths and Limitations

The primary strength of this paper is that it offers an in-depth analysis of vulnerable women's participation in health-system priority setting from multiple perspectives, namely the perspectives of vulnerable women and decision-makers (district and sub-county level).

Furthermore, the findings of the study highlight recommendations from participants about how to improve vulnerable women's participation and provide insights into how the decentralized framework can be used to facilitate this participation. While the study fills an important gap in the literature about the lack of vulnerable populations' participation in health-system priority setting and planning in rural Uganda, there are limitations to our findings.

Firstly, we found that the language for some questions directed at the rural women were overly technical. Some respondents had difficulties understanding the questions and began to provide inappropriate responses. This limitation was mitigated through regular debriefing meetings with the translator and working collaboratively to modify the way questions were asked to elicit suitable responses.

Secondly, most of the rural women did not speak or understand English. Therefore, interviews were conducted with the support of a translator. There was potential for the meaning of the questions and the women's responses to be changed through the translation process. However, the translator was briefed about the goals of the research and trained to translate the participants' responses verbatim. We were able to lessen the effects of inaccurate translation by having the transcriptionist provide English versions of the transcripts of the women's responses, the translator's questions and responses, and the researcher's questions. The researcher then specifically coded the women's responses based on the English language transcripts that were transcribed verbatim.

Finally, we did not interview HUMC members. While these committees are recognized as important participatory structures, the committees focus on the health unit, and planning and priority setting for health services rather than health systems. Therefore, these committees were beyond the scope of the study.

Conclusion

Our study adds to the limited literature on engagement of vulnerable populations in health-system priority setting. Existing participatory structures in Uganda are meant to enable public participation in governmental decision-making, from the village up to the district level. However, vulnerable women are not actively participating at all levels. Women's participation is localized to village meetings, most often informal meetings and discussions among friends and neighbors rather than the local council meetings. They rarely participate directly at higher administrative levels. This is problematic because policy-making and resource allocation decisions are most often made at the sub-county or district. While there are opportunities for participation at the sub-county, such as budget conferences, direct participation for vulnerable women at the district may be impractical. Since participation at the district is meant to occur through representation facilitated by decentralization and mandated by the Ugandan Constitution and the Local Governments Act, future studies could explore whether representation is an effective mechanism for participation.

A variety of barriers prevent women from participating. Both vulnerable women and district decision-makers shared practical and innovative recommendations to facilitate women's participation. One powerful suggestion was the idea to educate motivated women from the village about participation and train them as local leaders to promote participation in their communities. This could create an environment of empowerment within the community where the women can act as peer leaders and educators in the community, fostering relationship with women and other vulnerable populations and encouraging their participation in health-system planning and priority-setting processes.

Decision-makers can change their approach to community engagement by understanding why women do not participate and recognize the root causes of these barriers. Two-way channels of communication and mechanism for feedback between communities and decision-makers is essential to women's motivation to participate. Strengthening community dialogues allows for mutual learning between these parties. Existing participatory structures need to be modified for meaningful participation of vulnerable populations. The integration of women's creative and feasible ideas to enhance their participation in health-system decision-making should be prioritized over the implementation of top-down strategies.

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Decision space for health workforce management in decentralized settings: A case study in Uganda. Health Policy Plan. 2017;32:iii59–66.

Figure 1. District political structures and parallel health structures under decentralization

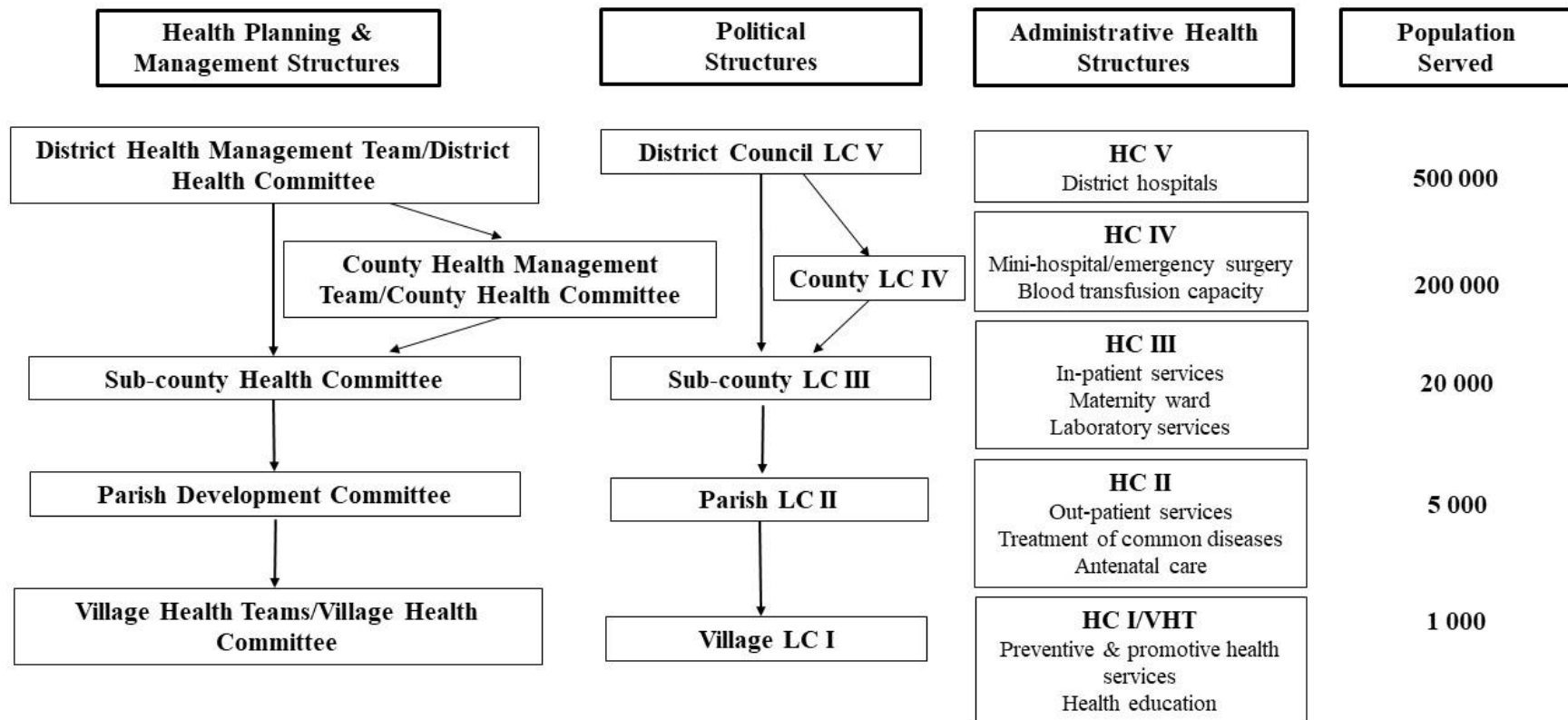| Health Planning & Management Structures	Political Structures	Administrative Health Structures	Population Served
District Health Management Team/District Health Committee	District Council LC V	**HC V** District hospitals	500 000
County Health Management Team/County Health Committee	County LC IV	**HC IV** Mini-hospital/emergency surgery Blood transfusion capacity	200 000
Sub-county Health Committee	Sub-county LC III	**HC III** In-patient services Maternity ward Laboratory services	20 000
Parish Development Committee	Parish LC II	**HC II** Out-patient services Treatment of common diseases Antenatal care	5 000
Village Health Teams/Village Health Committee	Village LC I	**HC I/VHT** Preventive & promotive health services Health education	1 000

Table 1. Demographic information for the rural women interviewed (N=35)

Demographic characteristics/ Vulnerabilities of interest	Adolescent/ Young Adult 10-24 years (N=11)	Adult 25-54 years (N=12)	Elderly 55+ years (N=12)
Ethnicity			
Jopadhola	3	5	4
Iteso	6	5	6
Japadhola-speaking Iteso	2	2	1
Other	0	0	1
Education			
None	0	1	5
Primary	8	7	6
Secondary	3	3	1
Post-Secondary	0	1	0
Marital Status			
Single (i.e. never married)	6	0	0
Married	3	9	4
Divorced	2	1	0
Widowed	0	2	8
Employment			
Not working (including subsistence farming)	9	5	8
Petty Business (e.g. farming for sale, handcrafts, hair stylist)	2	7	4

Table 2. Perceptions of participation for vulnerable populations, as identified by our respondents

Type of respondent	Rural women	District decision makers
Who participates?		
Community level (ie. village)	- Adult women - Adult men	- Women - Local leadership
Beyond the community (ie. parish, sub-county, district)	- Village Health Team members - Local leadership e.g. LC1 chairman councillors	- Village Health Team members - Local councillors - The district representatives of women, youth, elderly, disabled, people living with HIV/AIDs - Sub-county leaders (political and technical) - District leadership (political and technical) - Civil society organizations (CSOs) and non-governmental organizations (NGOs)
Who does not participate?		
Community level (ie. village)	- Children and youth (adolescent girls) - The very poor (poor women) - The elderly (elderly women) - Those who are in ill health or living with disabilities	Vulnerable populations (children and youth specifically young and adolescent girls, the poor, the elderly, people with disabilities, people living with HIV/AIDS, women)
Beyond the community (ie. parish, sub-county, district)	- Women - Children and youth (adolescent girls) - The very poor (poor women) - The elderly (elderly women) - Those who are in ill health or living with disabilities	- The public - Vulnerable populations (children and youth specifically young and adolescent girls, the poor, the elderly, people with disabilities, people living with HIV/AIDS, women)

Table 3. Barriers to participation for vulnerable women in health sector priority setting

Category of barrier	Barriers to participation	Identified by	Illustrative example(s)
Financial	Transport (distance/cost)	• DHMT • Rural women	"I don't reach to the higher-level meetings, I haven't gone, I hear that there are meetings concerning budget, I don't always attend because it is difficult for me to reach there, it is far." (Rural woman, 59, Iteso)
	Lack of incentives/ compensation for time	• Sub-county leaders • Rural women	"They should be given something for motivation and if other sees this they will be encouraged to attend the meetings." (Rural woman, 80, Japadhola) "Why I don't go for meetings, there is something like allowances there, you come back without allowances, maybe you go there you feel like you just come back with words" (Rural woman, 39, Iteso)
Biomedical and/or health	Illness/Disability	• DHMT • Sub-county leaders • Rural women	"I was willing to continue [*participating*] but I have a problem with my leg I cannot walk easily." (Rural woman, 80, Japadhola) "Another one [*barrier*] can be sickness where one is admitted and cannot attend the meeting." (Rural woman, 49, Japadhola)
	Menstruation	• Rural women	"Sometimes when I am in my menstruation period starts I stay at home… actually absence of pads… I miss I don't go." (Rural woman, 16, Japadhola)
Knowledge-based	Lack of education (knowledge/literacy)	• DHMT • Sub-county leaders • Rural women	"So even if you go there you find people who come who ended in P.7[seven years of schooling], S.4 [eleven] years of schooling, S.2 [nine years of schooling] and for you who have never gone to any level are mixed with you, so you can understand anything." (Rural woman, 57, Iteso)

			"Is the person who cannot read and write or speak English because it is conducted in English, most times the woman in the village, does not get that opportunity." (DHMT member)
	Lack of information about participation (rights/opportunities)	• DHMT • Sub-county leaders • Rural women	" prevents people from going for meetings is because they are not informed, so they cannot know that a meeting is going to take place, but if they were informed, they would go…I may have the interest of attending the meeting but I may not know the date the meeting is scheduled to take place because I am not informed." (Rural woman, 52, Japadhola)
Motivational	Perceived laziness/disinterest	• Sub-county leaders • Rural women	"People in the village are lazy" (Rural woman, 16, Iteso) "People who are drunk are married to drunkard-ness, they are married to alcohol, they don't want to listen to the chairman or to the people who come telling them things like that, they want only their drinking" (Rural woman, 59, Iteso)
	Competing needs/time commitments	• DHMT • Sub-county leaders • Rural women	"Women from the village cannot go to the sub-county, because there are competing time needs like; digging, cooking, and like for me who is a widow I have a lot of responsibility." (Rural woman, 57, Iteso) "I have never attended because I cannot keep on absenting myself from school because the meetings are on school days." (Rural woman, 18, Japadhola)
	Lack of feedback/follow through	• Sub-county leaders • Rural women	"Things are supposed to be there but they don't reach to people at their homes, sometimes you hear that they have given out things from there, medicines, but here people don't get sometimes… the only thing I am going to say, I want them to help us, the time they come like this, they should not go

			back without coming back. You just come once and never come back, you should always be coming." (Rural woman, 30, Iteso) "Personally, my idea is that whatever has been discussed should not remain here, it should be put in practice." (Rural woman, 18, Japadhola)
Socio-cultural	Lack of decision-making power	• Sub-county leaders	"In some of these communities you may find women may be too interested in being involved but the nature of their cores they can't come in or their husbands do not allow them to come in for the meetings so it's more of the power relation bit in a home where the man says I am going to attend the meeting, you don't need to go, I can still bring you feed back in relation to that meeting." (Sub-county leader)
Structural	Hunger	• DHMT • Sub-county leaders • Rural women	"You see, when somebody… you come like trying to ask them questions and if someone slept hungry will not be able to talk to you." (Rural woman, 50, Iteso)
	Poverty	• DHMT • Sub-county leaders • Rural women	"those people, the very poor, when you tell them to come, they come, yeah, they [*may*] attend meetings but after the meetings there is a problem… they want something [money]" (Rural woman, 60, Iteso)

Table 4. Recommendations to address barriers and enhance participation for vulnerable women in health care prioritization and planning processes

Category of barrier	Barriers to participation	Recommendations from the Field	Illustrative example
Financial	Transport (distance/cost)	Hold meetings at the health centers (HCs) within the community	"If the health center is near it will reduce our distance and costs of traveling." (Rural woman, 49, Japadhola) "Use the opportunity of these facilities, they come every other day, we use this opportunity, five to ten minutes and listen to them." (DHMT member)
	Lack of incentives	Provide incentives including transport, allowance, food	"they should make movement for people easy, then they mobilize people for the meetings when they have provided that transport. Like they get a way of coming to take people to and bring them back or if not if people go there, they get a way of giving people even if it were UGX1000/- only so that people can use for transport people will accept." (Rural woman, 59, Iteso)
Biomedical and/or health	Illness/Disability	Provide transportation	"[*send*] a boda boda to pick me" (Rural woman, 60, Japadhola)
	Menstruation	Provide adolescent women with female hygiene products	"Absence of pads… when I have pads [*I go*]… if I am sure it is going to come I pad myself and go and attend." (Rural woman, 16, Japadhola)
Knowledge-based	Lack of knowledge (education/literacy)	Hold meetings in local language and/or provide interpreter services	"There are questions they ask in English and if you are not educated and you cannot communicate." (Rural woman, 49, Japadhola) "But if it is being done in the native language you will find everybody is interested. But if you speak English it's like you are speaking Arabic. People switch off." (DHMT member)

	Lack of information about participation (rights/opportunities)	Identify an enthusiastic, capable woman from the community sensitize & educated about participation. She would return to collaborate with the community.	"There are right now who are educated that the district should know, like those leaders in the village they know educated women. Such educated women should be taken to the district then they will also come back and spread the information to others. So as to empower them." (Rural woman, 57, Iteso)
Motivational	Competing needs/time commitments	Host meetings at times when target populations can attend	"For example, if you organise a meeting in the morning hour…at the time when the women are expected to be in the garden, you will not achieve what you have planned. But when you plan it like for example if it is during dry season, and people are not working much in the garden, people will turn up in big numbers to participate" (Sub-county leader)
	Perceived laziness/disinterest	The women already gather informally, add a formal representative to meetings	"They should bring… meetings to the villages because there are those women who don't attend but when they hear that the district level person who has, come to meet the people, they will come… if those higher level people come, and these people hear that, maybe the chairman LC V or the district woman councillor, or the woman MP are around, the will come." (Rural woman, 60, Iteso)
	Lack of feedback/follow through	Strengthen community dialogues/barazas to enhance two-way communication between rural women and local governments	"Personally, my idea is that whatever has been discussed should not remain here it should be put in practice." (Rural woman, 18, Japadhola) "What do they have to say about our services? We are the ones always giving them, it is the one way to get feedback from them and I look at it also as a good platform to listen from these vulnerable people, not a mother to just come and listen from you and walk away, they leave when they have something burning, so if we give them that platform, it will also be good." (DHMT member)

Socio-cultural	Lack of decision-making power	Develop and support females within the local governance structures	"Okay so the beginning point is let's empower the women who are in decision-making within the local governance structure…they can take lead in seeing to it that they can define a vulnerable woman. They spearhead the whole process as per creating a difference in the livelihood of this woman sometimes when a woman is speaking to a fellow woman she will be able to speak out compared when she is speaking to a man. He may not ably understand how she feels and what it takes for her to get out of a particular situation" (Sub-county leader) "In some of these communities you may find women may be too interested in being involved but the nature of their cores they can't come in or their husbands do not allow them to come in for the meetings so it's more of the power relation bit in a home where the man says I am going to attend the meeting, you don't need to go, I can still bring you feed back in relation to that meeting." (Sub-county leader)
Structural	Hunger	Organizers provide some type of snack or lunch	"I mean things, right now the hunger is smoking hot, they should give food." (Rural woman, 70, Iteso)
	Poverty	Social assistance and development programs to target poverty and daily living expenses ie. school fees, adequate housing, skills training	"I think that the only way that can be done is motivation if they can be motivated or maybe put a learning center at a certain place like in parishes where they can go, they say if you don't know how to write, we don't know how to do what, we need all of to come here. When they go there maybe somebody to train them on crafts to train them on hat maybe the tailoring machine so that can help them to do what, can help integrate them, then they also begin participating" (Sub-county leader)

Appendix 1: Semi-Structured Interview Guide (Rural Women)

Participation of Vulnerable Women in Priority Setting Processes in a Rural District of Uganda

Background

I would like to thank you for agreeing to participate in this interview. I would also like to remind you that if there are any questions that make you uncomfortable and you would prefer not to answer, you are free to decline answering. You are also free to stop the interview and withdraw from the study at anytime. If you choose to do so, all you have to do is let me know that you no longer wish to continue. If you have any questions at any point throughout the interview, please do not hesitate to ask for clarification.

Let us start with an example. If food is limited and all members of your family fall ill, who would you choose to give the food to first, and who would you decide to get medical attention for first? In health care, decisions need to be made in a similar way. Options are ordered, and people need to make decisions about what is most important, and what cannot be done due to lack of resources. The purpose of this study is to explore and understand involvement of women like you in making decision about how resources should be distributed in your health system. I'd like to learn about your perspectives in order to understand how you can meaningfully participate and provide input into these types of decisions.

Are you comfortable to proceed?

Background Demographics

In order to provide some context, I will ask you to tell me a bit about yourself.

[Probes]

- How old are you?
- Which ethnic group do you identify with?
- Are you married? Do you have children? If so, how many?
- Tell me about your education?
- Tell me about your work/occupation? [Your spouse's work?]

General: Community level decision making

- Do you know how decisions about healthcare are made in your community? Tell me about this process.
- Who is involved in these processes? How are they involved?
- Who is not is not involved? Can you tell me about the reasons that you believe they are not involved?
  - o [Probes] vulnerabilities including age, gender, socioeconomic status
  - o What are some of the barriers that you think prevent their involvement?
    - ▪ [Probe] financial, physical factors, etc.

General: Participation

- In what ways are you involved in decision making processes about the health system in the district? At the village level?
- [Probes]
    - Structures for participation
        - Can you tell me about participation at the Budget Conference?
        - I am aware that budget conference occur both at the district and the sub-county level, can you tell me a bit more about at what level you would participate and how?
        - Are there other structures that you participate in? Ie. Involvement with Village Health Teams (VHTs)
    - How are you made aware of these opportunities?
        - Ie. Radio announcements? Others?

- To what extent are you satisfied with your level of involvement in decision making about where resources are allocated in your health care system?
    - What are the barriers to your involvement? How would you rank these barriers based on their importance to you?
    - What can be done to improve your level of satisfaction with your involvement?

- What factors are important to you and do you think should be considered when making decisions about resource allocation within the health system?
    - Provide example(s)

Participation: What could your contribution be?

- What do you believe you can contribute to the decision-making process about how resources for health are allocated within district?
- What do you feel would be the benefit of including your perspectives or perspectives of people like you in decision-making?

Participation: How?

- How do you think that your perspectives about where resources should be allocated, and your health needs can be better communicated to decision makers?
- What if it is not possible personally attend meetings like budget conferences where resource allocation decisions are made, how can your interests and needs be represented?
- How do you believe the district can improve the participation of women in decision making about resource allocation in the health system?
    - [Probe] Based on your identification that …. Are not participating, how do you believe the district can improve participation for them?

Is there anything further that you wish to add?

Thank you for your participation.

Appendix 2: Semi-Structured Interview Guide (District decision-makers)

Participation of Vulnerable Women in Priority Setting Processes in a Rural District of Uganda

Background

I would like to thank you for your willingness to participate in this interview. If there are any questions that make you uncomfortable and you would prefer not to answer, you are free to decline answering. You are also free to stop the interview and withdraw from the study at anytime. If you choose to do so all you have to do is let me know that you no longer wish to continue. If you have any questions at any point throughout the interview, please do not hesitate to ask for clarification.

The purpose of this study is to explore and understand participation of vulnerable women in priority setting processes in Uganda. Priority setting is a process through which choices are made about how to distribute resources. Any health care system requires priorities to be identified and from the list of possible priorities, decisions need to be made about how resources are distributed between competing health programs, services, and drugs delivered with health systems. The resource allocation process involves making choices about where resources are allocated based on ordering items in terms of importance with justifications for those choices. I am hoping to learn about your perspectives in order to understand how vulnerable women can meaningfully participate and provide input into decision making about resource allocation decisions.

Are you comfortable to proceed?

Background Demographics

In order to provide some context, will you tell me about yourself and your role in the DHMT?

[Probes]

- What are some of your major responsibilities as [Participant's Title]?
- How long have you served as a member of the DHMT?
- Can you tell be about your education prior to working at the DHMT?

General: Decision Making

- How are resource allocation decisions made at the district level?
  - [Probe]
    - Role: the executive, district council, standing committees
- From your perspective, how does the district define vulnerability?
- Who is considered vulnerable from the perspective of the district? Why?
- How are decision makers informed about the health needs of vulnerable groups?

General: Participation

- Can you tell me about participation within the district?
  - [Probes]:

- Who participates directly in decision making for resource allocation in health care?
- What are some of the barriers to participation?
- Who represents those who do not participate directly?
- Can you tell me about their role in the budget conferences?

- Can you tell me more about the groups that are represented in resource allocation processes for health systems decision making?
  - [Probes] (age groups, genders, income levels, etc.)

- How are the interests of vulnerable groups represented in the district for resource allocation decisions?
  - [Probes]:
    - If I'm a person living in the village how does the district gain my input when making health-related resource allocation decisions?
    - Who represents these interests?
    - What do you believe are some of the barriers to the participation of vulnerable women in decision making at the village level? At the district?

Now that we've talked about women who are vulnerable, we will concentrate on this group.

Participation: Vulnerable women

- Who are considered vulnerable women in the context of Tororo District from the perspective of the district?
- How are their interests represented at the district level? By whom, are their interests represented at the district level?
- How are vulnerable women or those who represent them identified for the purposes of engaging them in priority setting for health care?
  - What are the strengths of this approach? What are the weaknesses?
- How do these vulnerable women participate in resources allocation decisions at the local level?

Participation: How?

- How should these women be involved in making decisions about the distribution of resources?
- What are some of the challenges with engaging vulnerable women in resource allocation decisions?
- How can the district facilitate the participation of these women considering [the barriers identified by the participants above]?

Is there anything further that you wish to add?

Thank you for your participation. Please feel free to contact me if necessary.

Chapter 5. Conclusions

The three original research studies presented in chapters 2-4 of this thesis contribute to an increased understanding of the public's and vulnerable populations' participation in health-system priority setting. Chapter 2 maps the literature on different stakeholders' participation in health-system priority setting, using applications of commonly cited priority-setting frameworks. Chapters 3 and 4 focus on a low-income country and examine participation in district priority setting in Uganda. Compared to other academic scholarship in the area of priority setting and participation, my dissertation presents a unique perspective because not only does it examine public participation but focuses on the participation of vulnerable populations in a low-income country. Furthermore, Chapter 4 examines participation in the context of decentralization, which is a governance structure that is meant to facilitate public participation in all governmental decision-making. Chapter 4 offers key insights about whether the implementation of decentralization has facilitated participation for a specific vulnerable group, namely vulnerable women in rural Uganda. This chapter begins by summarizing the main findings of each of the studies presented in chapters 2-4. The chapter then focuses on the contributions of the studies, presents the overall strengths and limitations of the thesis, policy implications, and areas for future research.

Key Findings

The dissertation incorporates a mix of methodological approaches to develop an understanding of the roles of the public and vulnerable populations in health-system priority setting. Chapter 2 concentrates on the priority setting literature, using a scoping review to map the literature that applies priority-setting frameworks to real-world cases, and focuses on the participation of stakeholders, the public and vulnerable populations. Specifically, the chapter

examined the ideals for stakeholder participation as stipulated in the frameworks versus who participated and how they participated in priority-setting processes where the frameworks were applied. The following stakeholders were found to more commonly participate when the frameworks have been applied to health-system priority setting: clinicians/physicians, other health care providers, administrators/coordinators, managers, academics/researchers, health economists, various types of experts, decision-makers, and policy-makers. The literature recommends participation of the public (1–4), and highlights the need to incorporate vulnerable populations perspectives in priority setting (2,5). Central to this study was the finding that while three of the four frameworks identify public participation as a required component of priority setting, very few papers reported on participation of the public. Furthermore, the frameworks did not explicitly identify whether and which vulnerable populations should participate in the process. It follows that even few papers reported on vulnerable populations' participation in health-system priority setting.

Chapter 3 moves away from a broader examination of the literature and the priority-setting frameworks to empirical research. An interpretive description study was conducted to address gaps in understanding about the roles of different stakeholders in health-system priority setting and focused on district-level priority setting in a low-income country, from the perspective of decision-makers. There is support for stakeholder participation in priority setting for health systems (6–8), however most of the literature has omitted in-depth analysis of stakeholders' roles, the leverages that the different stakeholders use to influence the process, and the challenges associated with their participation in district-level prioritization processes. I found that politicians, technical experts, and donors are the principal contributors to district-level priority setting in Uganda, and the public is largely excluded from the process. Decentralization

in Uganda is meant to facilitate stakeholder participation in governmental decision-making, however, it seems to be giving more power and legitimacy to politicians—as representatives of the public—rather than to the public itself. These findings reinforce some literature that has questioned the degree to which politicians represent the public's interests as opposed to the politicians' own political interests (4,9–11). However, stakeholders have different leverages that augment their ability to influence the priority-setting process, which include: budget control and decision-making authority, political interests, resources, evidence, expertise, cultural knowledge, electoral power, ability to shape or influence public opinion. Stakeholders who have a weak direct influence may in fact have strong leverages by influencing stakeholders that are directly engaged in priority setting. For example, since the public does not always have a seat at the decision-making table, they may have weak direct influence on the priority-setting process. However, they have indirect influence on shaping politicians' policies by exerting pressure at the ballot box. Conflicting priorities, interests and values between stakeholders were among the most commonly identified challenges. Consideration of these challenges is relevant to policymaking when selecting stakeholders for participation in priority-setting processes and ensuring broad representation of perspectives in decision-making.

Similar to Chapter 3, Chapter 4 empirically explores health-system priority setting within a district setting. It provides an in-depth examination of vulnerable women's participation, from the perspectives of the women themselves as well as the perspectives of decision-makers. The study qualitatively explores whether vulnerable women participate in health-system priority setting, barriers to their participation, and how they believe the barriers to their participation could be overcome. Although decentralization across sectors in Uganda was designed to support participation in governmental decision-making for all citizens, vulnerable women continue to

experience barriers to participation in health-system priority setting. Both vulnerable women and decision-makers at two levels of decision-making (sub-county and district) reported that while women participate more actively in village meetings, they are not directly participating in health-system priority setting beyond the community (parish, sub-county, and district). This is important since decision-making occurs at the sub-county and district levels, where the women's participation is lacking. There was often consensus between the perspectives of vulnerable women and decision-makers about the barriers that prevent their participation. For example, the lack of information about the right and opportunities to participate was identified as a barrier by each group of respondents. Both groups of respondents came up with creative suggestions for ways to overcoming these barriers and enhance participation for the vulnerable women. One recommendation that was echoed by both vulnerable women and decision-makers was to strengthen community dialogues, also called barazas in Uganda, to enhance two-way communication between rural women and local governments. Evidently, while one of the goals of decentralization was to facilitate community participation, existing participatory structures need to be modified to ensure that vulnerable populations can meaningfully participate in health system priority setting.

Study Contributions

Taken together, the three original research studies presented in chapters 2-4 of this dissertation address gaps in knowledge by developing an understanding of broader stakeholders, and specifically the public and vulnerable populations' participation in health-system priority setting through: 1) a synthesis mapping the literature on public and vulnerable populations' participation in health-system priority setting when priority-setting framework are used to guide real-world priority setting; 2) an examination of the roles, leverages, and challenges with

participation of different stakeholders in district-level priority setting in a low-income country; and 3) understanding the barriers to vulnerable women's participation in health-system priority setting and recommendations from respondents about how to address the barriers. The dissertation makes substantive, methodological, and theoretical contributions, which are discussed below.

Substantive Contributions

To date, there has been limited scholarship on the participation of vulnerable populations in health-system priority setting, especially at sub-national levels in low-income countries. Each study supports the discourse that the public and vulnerable populations are not participating. The dissertation provides a rich understanding of the roles of different stakeholders in the priority-setting process (chapter 3). Chapter 3 demonstrates that different types of leverage can influence the priority-setting process, and that pathways of influence can be direct or indirect. Especially when considering the role of the public, indirect influence through electoral power and pressure is highlighted in this study. Furthermore, the dissertation provides explanations about why vulnerable women, as a subset of the public, are not participating, thereby adding to the evidence base (chapter 4). Chapter 4 identifies twelve inter-related barriers that specifically prevent vulnerable women living in rural Uganda from participation in health-system priority setting. The study further groups these barriers into six overarching categories: financial, biomedical, motivational, knowledge-based, socio-cultural, and structural barriers. This analysis of the barriers to participation along with recommendations from the vulnerable women and the decision-makers, support development of solutions to overcome these barriers and enhance participation. Finally, the dissertation challenges commonly accepted norms of participation in priority setting. While chapter 2 questions how effectively the stakeholder participation

component of priority-setting frameworks is operationalized, chapter 4 identifies barriers to implementing vulnerable women's participation and challenges decentralization as a mechanism to facilitate participation.

Methodological Contributions

The methodologies selected in this thesis aim to achieve an in-depth understanding of the publics' and specifically vulnerable populations' participation in health-system priority setting. First, a scoping review was used to provide a focused examination of participation when priority-setting frameworks have been applied, rather than map the entire literature on stakeholder participation in health-system priority setting. Instead of coding the articles in their entirety and examining each dimension of the framework, I focused on the specific dimension of stakeholder participation. Furthermore, this dissertation is methodologically unique in its application of interpretative description to the study of priority setting and participation in health systems. While interpretive description is a research methodology that originates in clinical research settings (12), I apply the methodology in chapter 3 to the policy-focused phenomenon of priority setting and participation. Interpretive description blends techniques from different methodologies like phenomenology, grounded theory, and ethnography to fit complex, experience-based research questions (12), therefore, the methodology is well-suited to the study of application and policy-based research questions and phenomenon, including stakeholder participation in health-system priority setting.

Theoretical Contributions

This dissertation advances the understanding of different stakeholders' participation in health-system priority setting. Although numerous frameworks have been used to understand stakeholder participation, most of these e.g. Charles and DeMaio's "Dimensions of Lay

Participation in Health" and Rowe and Frewer's "Typology of Public Engagement Mechanisms" (discussed in the introduction of this dissertation); have largely focused on understanding the nature of stakeholder participation in health-system decision-making. I decided to use a modified version of Elster's approach because of its analytical strength. Elster's approach enabled me to understand the nature of stakeholder participation as well as stakeholder influence and leverage over the priority setting process. Based on the literature and iterative data analysis I modified Elster's analytic framework to add the dimension of *challenges* with different stakeholders' participation in priority setting. The added challenges dimension explains the problems and/or difficulties stemming from the participation of stakeholders in priority setting as perceived by the other respondents.

Strengths and Limitations

Taken together these three studies have three main strengths. Firstly, compared to the literature in the field, this work is among few that focuses on the participation of vulnerable populations in health-system priority setting. To date, much of the research on participation in priority setting has focused on either powerful stakeholders or the public more generally. As a whole, the dissertation explores the participation of vulnerable populations and identifies their lack of participation (chapters 2 and 3), and the nature of and barriers to their participation (chapter 4). Specifically, Chapter 4 presents an in-depth analysis of vulnerable women's participation from their own perspectives and their recommendations about how to address barriers to their participation in health-system priority setting.

Secondly, the empirical studies that constitute this thesis have robust sample sizes. Relatively small sample sizes are the accepted norm in qualitative research since the aim of this type of research is to explore and/or understand phenomenon in depth. It is commonly agreed

that sample sizes of between 7-15 key informant interviews are sufficient to achieve theoretical

saturation of themes around the phenomenon of interest (13–16). Saturation is considered the

point at which no further new information about the themes emerges from the data or key

informant interviews (13,16–18). While saturation in both studies (Chapter 3 and 4) may have

been achieved with fewer participants, Chapter 3 aimed to balance perspectives from both

technical and political members of the District Executive Committees in each district. Chapter 4

incorporates equity considerations into the selected methodology and aims for an equitable

approach to sampling. Given the many dimensions of vulnerability the sampling strategy not

only targeted saturation, but variations on all included dimensions of vulnerability (ie. ethnicity,

education, marital status, and employment).

The third strength of this dissertation is the inductive approach taken to data analysis. The

strength of using of an inductive approach to data analysis is that insightful information

expressed by our respondents (without being prompted), was captured in the open coding and

subsequent categories that were developed. This inductive approach allowed for rich analyses

around the themes of interests. For example, in Chapter 3 information about the ways in which

different stakeholders can influence decision-makers and their ability shape district priority

setting, developed from open conversation with respondents and the inductive approach to data

analysis and interview coding.

There are also three main limitations. The first limitation relates to the literature included

in the scoping review. The aim of the first study was to examine participation in contexts where

priority-setting frameworks have been used to guide the process and set priorities. While the

studies included in this research synthesis may have incorporated stakeholder participation into

the process, the published articles may not have reported on it at all or lacked adequate detail to

enable meaningful analysis. This may reflect the study's use of published, peer-reviewed literature rather than integrating study protocols, grey literature, and other unpublished literature, or conducting interviews with those applying the frameworks. In many cases, priority-setting exercises may not be published.

A second limitation relates to the recruitment of key informants for the interpretive description study in chapter 3. The key informants were identified due to their knowledge of district priority setting. This limited our respondents to only two of the six groups of stakeholders that were reported on in the study; politicians and technical experts. This may be viewed as a biased sample. However, politicians and technical experts are responsible for setting priorities at the district level. A different group of respondents may not have had as detailed an understanding of district-level priority setting and stakeholder participation. To mitigate the potential bias, the study in chapter 4 explicitly targeted vulnerable populations.

The third limitation relates to conducting key informant interviews in a language other than English in chapter 4. Using translators in interviews introduces the potential for distortion of meaning through the translation process (19). This can threaten the trustworthiness and credibility of the study findings (20). To mitigate these affects the translator was trained and instructed to translate the participant's responses verbatim. Furthermore, the effects of inaccurate translation were lessened by having the transcriptionist provide English versions of the transcripts of the women's responses, the translator's questions and responses, and the researcher's questions.

Implications for policy and practice

The studies that comprise this dissertation present three specific implications for policy and practice. First, the ways that participation should be operationalized are not always explicitly laid out. Since the literature argues that public participation is a key component of equitable priority setting, processes to support it should be more clearly defined. The dissertation demonstrates that both frameworks (chapter 2) that are used to guide health-system priority setting and structures of governance (namely decentralization in chapter 4) fall short of clearly defining how participation should be implemented. This challenges the usefulness of these frameworks and structures to implement participation of the public and vulnerable populations as an integral component of health-system priority setting. While the studies acknowledge the need for priority-setting processes to be flexible and responsive to context, traditional challenges of public participation can be overcome by: explicitly stating that vulnerable populations should participate; identifying which vulnerable populations should participate; explaining how they should be identified and selected for participation; and outlining how and in what capacity they should participate in the process.

The second implication for policy and practice relates to the roles that different stakeholders can play in health-system priority setting. Chapter 3 demonstrates that different groups of stakeholders may play similar roles, possess similar types of leverages, and create similar challenges when it comes to their participation in health-system priority setting. When policy-makers engage different stakeholders in health-related decision-making, including priority setting, role clarity and specificity around the scope of participation is necessary (21). Clear articulation of who should participate and how they should participate in the process can support a successful priority-setting process.

Third, policy- and decision-makers should consider co-creating and co-developing solutions to barriers to participation for certain populations. In particular, the study in chapter 4 showed that vulnerable populations have practical and innovative ideas about ways to facilitate and enhance their own participation. Moreover, their recommendations are contextually relevant, potentially feasible, and drawn from their unique understanding of and expertise about their context. Policy-makers may also consider co-development of participatory methods, frameworks, and guides. Policy-makers should not only partner with the broader community, but specifically engage vulnerable populations for their contextual expertise, including barriers to and facilitators of their participation.

Taken together the dissertation also has wider key implications. Firstly, the strategies proposed herein by the vulnerable women and decision-makers in chapter 4, can be considered by different of decision- and policy-makers to support vulnerable populations to participate in a variety of health-system decision-making processes. At the local level in Uganda, district level decision-makers can use the findings from chapter 4 to support their appeal to national governments and donors for increased flexibility and autonomy over local resource allocation, especially as it relates to resources to support the participation of vulnerable groups in health-system decision-making. Although focused on Uganda, the study findings and strategies maybe relevant to other low-income countries, especially those operating within the decentralized context.

Secondly, the three studies demonstrate that while desirable, public's and vulnerable populations' participation in health-system priority setting is lacking. Public participation if not done well, can be detrimental and exacerbate inequities, especially for populations that are already vulnerable. There is cost to participation, this is more so for vulnerable populations who

face numerous barriers. When such populations are not empowered to meaningfully participate in decision-making, and their input is not used, then the cost of their participation is futile. Furthermore, it may lead to the vulnerable populations losing interest in and failing to participate in priority setting, which reinforces the existing inequities in participation. Failure to participate may also lead to inequities in the priority setting decisions, whereby vulnerable populations' needs may not be considered if they are missing from the decision-making table.

Finally, I assert that the key findings from this dissertation are transferable across different types of health-system decision-making and different contexts, in both HICs and LMICs (22). Health-system decisions such as funding and financing, governance, health care delivery, implementation, and health research all involve stakeholders. In such decisions, which involve the participation of various stakeholders, it is critical that the publics and especially vulnerable populations are involved. Detailed stakeholder analyses can provide insights into the roles, leverages, and challenges and support improved understanding of participation in a variety of health-system decision-making processes. Furthermore, the findings could be applicable in other contexts, including other LICs and HICs. In LICs, the role of donors' in shaping decision-making is especially prominent (7,23). The leverages that donors can use to influence decision-making would be of interest to policy-makers in LICs. Additionally, vulnerable populations exist in both LICs and HICs and the barriers to participation for these groups have been reported in both contexts (4,24–27). This suggests that there are opportunities to develop solutions to address these barriers that can be effective in different contexts and countries.

While vulnerable populations' participation is currently lacking, their participation considered a key component of successful health-system priority setting and their desire to participate is strong. Supporting the participation of vulnerable populations in ways that are fair

and equitable, meaningful for participants, and useful for policy-makers requires feasible, pragmatic solutions like those suggested by the vulnerable women and decision-makers in Uganda.

Future Research

By filling conceptual gaps through highlighting vulnerable populations' lack of participation in health-system priority setting, deepening the understanding of the roles of vulnerable women and identifying barriers to their participation in health-system priority setting in low-income country contexts, three primary areas for future research have emerged from this thesis. First, there is a need to examine how to operationalize the participation of the public and vulnerable populations in health-system priority setting. Future study in this area could focus on the development of or modification of existing tools or frameworks that inform public participation in health-system decision-making, such as the public and patient involvement framework developed in Ontario, Canada to guide participation in HTA (28) or the James Lind Alliance approach to patient participation in health research priority setting (29). The resulting approach should place emphasis on vulnerable populations' participation and be tailored to priority setting and low-income countries. Although there is intrinsic value for public participation in health-system priority setting (26,30,31), the pragmatic value of how to engage the most vulnerable groups is a consideration that is presently missing (26). There is a gap with respect to both creative and meaningful ways to include vulnerable populations' participation in priority setting given the barriers they face, especially in low-income countries. Vulnerable populations should be included in the process when developing methods for participation in all health-related priority setting.

Secondly, specifically with respect to priority-setting frameworks, other areas of health-related priority setting appear to have more well-defined guidelines for public participation. This dissertation calls for further study on how existing priority-setting frameworks can be modified so that those using the frameworks to guide priority-setting processes have a clear roadmap for how to operationalize participation in their priority-setting exercises. Chapter 2 suggests that lessons can be learned about how to effectively operationalize public and vulnerable populations' participation from approaches that have been developed for priority setting in other areas.

A third area for future research involves a deeper examination of representation as a mechanism for channeling vulnerable populations' health priority preferences to decision-makers and ensuring their consideration when health-system priorities are determined. This literature describes and recommends representation of the public as a mechanism for participation (4,32,33), especially when direct participation may be impractical (10). In this dissertation we focus on Uganda in part because of the context of decentralization, which is meant to facilitate community participation through representation. However, Uganda is not the only country that elicits public input for governmental decision-making through representatives (24,34–36). Future studies could explore whether representation is an effective and/or sufficient mechanism for publics' and vulnerable populations' participation.

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