

Stakeholder engagement in health-related decision making The Case of Prevention of Mother-to-Child HIV Transmission

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SCIENTIFIC ENVIRONMENT

The idea to pursue a PhD scrutinizing the domain of stakeholder participation in local level decision-making processes is rooted in the project with the acronym REACT (Response to Accountable Priority Setting for Trust), initiated in 2006, which had a prime focus on stakeholder participation in priority-setting processes. The project was deployed in Tanzania, Zambia and Kenya. In each country several academic and research institutions were involved. The project was implemented together with Northern partners, originating primarily from Denmark, Norway, Sweden, Belgium and Canada. Based at the National Institute for Medical Research in Tanzania, one of the institutions involved, I was actively engaged in REACT from its inception to the end. During the course of the project, a number of workshops were conducted involving investigators from each institution. My main supervisor, Professor Astrid Blystad, came from the Centre for International Health, University of Bergen, another central partner in the REACT consortium. My co-supervisors are Professor Peter Kamuzora from the University of Dar-es-salaam and Professor Ole Frithjof Norheim, University of Bergen. I met with Astrid Blystad and the rest of the team a number of times during the course of the study. Together with Professor Blystad, I developed an interest in studying how institutions and practices may carry values that influence stakeholders' engagement in decision-making processes. During the PhD proposal development, we decided to make parts of the study more focused on exploring the dynamics at work within the PMTCT programme, a programme that is located under the broad umbrella of HIV/AIDS, one of the disease domains focused on in the REACT project.

In 2009 I was encouraged to enrol at the University of Bergen with Astrid Blystad recognised as my main supervisor. The progress of the study was somewhat delayed due pregnancy complications and giving birth to premature babies during the course of the study, thus needing more time to finish the PhD.

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EXECUTIVE ABSTRACT

Background: In Tanzania, the policy of decentralisation and health sector reform advocate bottom-up approaches, and places substantial emphasis on community participation in decision-making processes. Through these reforms the Tanzanian districts have been vested with substantial authority to undertake local planning, set priorities and allocate resources fairly to promote the health of populations with varied needs. A key ingredient is the sector-wide approach, where donors support the budget of the health sector through ‘basket funding’ to enable districts to identify their own priorities. When effectively implemented this approach could facilitate smooth implementation of the decentralisation policy, and allows for a shift from vertically-focused health programmes and centrally-controlled budgets to more comprehensive and integrated health planning, and locally-controlled health budget structures at the district level. The approach is thus to ensure devolvement of decision-making powers to local levels and reduce the influence of the donors.

Objectives: The main objective of this study was to explore stakeholder engagement in decision-making and priority-setting processes in the health sector with an emphasis on district-level decision making. The first sub-study (Paper I) had a particular focus on scrutinizing the potential influence of gender, wealth, ethnicity, age, religion and education on decision-making processes. The two other sub-studies aimed to explore decision making and communication processes respectively with a particular focus on the Prevention of mother-to-child transmission of HIV programme (PMTCT) as an attempt to more concretely scrutinize decision-making processes as they unfolded within a particular health project (Papers II and III). Due to the substantial burden of HIV infection from mother to child, the WHO-initiated PMTCT programme was, from the onset, planned as a high-profile and prioritized health intervention.

Theoretical frameworks: The research broadly draws on the normative ideal of fair process as outlined in the *deliberative democratic theory* described by Gutman and Thomson (1996) and Cohen (1997). In deliberative democratic thinking a fair process is one where citizens propose, discuss and generate solutions through open deliberation among equal citizens. In a discussion of diverse levels of stakeholder engagement in decision-making processes, the study refers to *engagement theory* as developed by Rowe and Frewer (2005), outlining a broad distinction between participation, consultation and communication. To enhance the understanding of the implementation of an intervention, Rogers' *diffusion of innovations theory* is drawn upon (Rogers, 2010). The theory consists of five 'elements' to assist the assessment of the feasibility of new policy; the policy's/intervention's (1) 'relative advantage', its (2) 'compatibility', (3) 'complexity', (4) 'trialability' and (5) 'observability' (Paper III).

Methods: The study was initiated within the frame of the EU-funded project 'Response to accountable priority setting for trust' (REACT, 2006–2010) that aimed to strengthen fairness and accountability in priority setting to improve equity and access to quality healthcare at the district level in Tanzania, Kenya and Zambia. The study was carried out in the Mbarali District of Tanzania. A qualitative study design based on explorative approaches was used to generate knowledge on experience with participation in decision-making processes. A total of 23 IDIs and a single focus group discussion were carried out during Phase I (within REACT), while 35 in-depth interviews and eight focus group discussions were conducted during Phase II. The IDIs and FGDs were conducted among members of the regional and district health teams, local government officials, health care providers and community members. Informal discussion with individuals variously situated related to the topics was also of substantial value during phase I.

Study findings: We find extensive limitations in terms of broad stakeholder engagement in the decision-making processes in healthcare in the study district in Tanzania. Findings in Paper I indicate continued influence of gender, wealth and ethnicity on health care decision-making processes. Religion and age play a far less important role, while education revealed a more mixed picture. Women, poor individuals, members of minority ethnic groups/clans and less-educated individuals were found to be discriminated against in the decision-making bodies. While differentiation based on ethnic criteria was generally condemned, opinions varied among the study informants as to whether differences in terms of participation and impact based on gender and wealth should be considered as fair. Illustrations of discriminatory dynamics were more notable among at the community than at health facility- and district levels, indicating that mechanisms and structures set up to prevent discrimination of this kind in combination with higher-educational-level work against such attitudes and dynamics.

In Paper II that explored decision-making processes within the Prevention of mother-to-child transmission of HIV programme (PMTCT), a high profile global health intervention, continued challenges of ensuring inclusive and stakeholder-based decision making and communication processes were found. Despite the policy of integrating vertical programmes within broader sector-wide approaches to enhance integrated approaches and the devolving of power to the districts and lower levels, a key finding of the present study was the continued central role of the donor in setting the agenda for the PMTCT programme. The donors followed globally-defined programme priorities which, at the time of the study, emphasized PMTCT ‘coverage’. The implication of the policy was that local priorities, that is the priorities made at health facility- and district levels, the levels with direct experience with the programme, were not funded. Their priorities were to ensure the functioning of already existing PMTCT programmes. Local health

planners, on their part, did not prioritize funding to the programme, operating with the perception that the programme is donor-driven and donor-funded.

In Paper III, pertaining to communication processes within the PMTCT programme with a particular focus on the dissemination of the continuously changing infant feeding policy to HIV positive mothers, the informants demonstrated partial and incomplete knowledge about the recommendations. Challenges to the successful communication of the infant-feeding guidelines were identified as the slowness of communication, the academic and jargon-ridden English language employed in the manuals, lack of summaries, and lack of supportive supervision to make the guidelines comprehensible. The many practical challenges were amplified by a limited reading culture.

Conclusion: The study questions the manner and extent to which the ideals behind the Tanzanian health reforms and the decentralization processes are fulfilled. Rather than a culture of participation and stakeholder involvement, as advocated by the reforms, the findings of the present study add to existing evidence of a continuation of a top-down decision-making culture and a continuation of external influence, whether governmental or donor driven. A history of hierarchical power structures, including colonial and socialist top-down approaches implemented after independence in 1964, have produced a culture where lower-level staff fear open disagreement, making it difficult to meaningfully execute the authority that is granted them. This process in turn re-produces a lack of autonomy and a dependency on donors and on higher-ranking bureaucratic bodies, which seemingly locks local decision-making processes into dynamics over which they have little control.

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DEFINITION OF KEY CONCEPTS IN THE PRIORITY SETTING AND DECISION MAKING CONTEXTS

Decision making in health care: This is a complex process taking place along a continuum that moves from evidence generation to deliberation on each particular intervention and communication of the resultant decision (Goetghebeur et al., 2008:2).

Priority setting: This is a process of ranking alternatives in accordance with normative and technical rules. It is a way of allocating scarce resources and so is a form of rationing (Tragakes and Vienonen, 1998:1).

Fairness: Fair priority setting is said by Folger (1977) to have two ‘aspects’, namely distributive fairness and procedural fairness (Folger, 1977:108).

Procedural fairness: refers to the fairness of the priority-setting process, considering the allocation procedures – who gets the resources, why, how were the priorities decided, what was the degree of participation in the decision-making processes? (Folger, 1977:108). This refers in this context to the moral acceptability of a priority of decision-making processes; i.e., fair priority setting decisions are made through a process that is perceived to be morally acceptable, irrespective of outcome (Martin, 2007).

Distributive fairness: refers to ‘outcome fairness’, which is concerned with the question of the fair allocation of benefits; people with equal needs are treated equally, and those with greater or lesser needs should receive treatment that is in proportion to the magnitude of their needs (Tragakes and Vienonen, 1998:6)

Legitimacy: Decisions are seen as legitimate if all those affected by them can accept the way they are made, even if they disagree with the outcome (Daniels and Sabin, 1998).

Transparency: Decision making is often associated with *explicit* priority setting, where reasons and criteria are openly stated, and where it is clear who makes the decisions and how they do so. (Clark and Weale, 2012:7)

Planning: Making decisions about which problems should be approached and in what order of priority through consensus making among stakeholders (Cooksey and Kikula, 2005:3).

Stakeholders: These are all individuals and/or groups who potentially have an interest in the decision-making and in the prioritization process; i.e., who are potentially affected by the process, or who because of their position have or could have an active or passive influence on the decision-making and implementation process (Varvasovszky and Brugha, 2000). Examples of stakeholder's groups may include governmental agencies, private organizations, public-private partnerships, international and regional organizations, and the beneficiaries of services to be provided, such as the community and any other group with an interest in a particular prioritization process such as advocacy groups, journalists and media, lawyers, economists, experts in ethics, etc (Kapiriri et al., 2007:2).

Stakeholder engagement: This is the practice of involving various stakeholders in agenda-setting, decision-making and policy formulation activities of a certain organisation or institution (Rowe and Frewer, 2005:253).

Values: These are social in nature, shaped by social, cultural, religious or institutional features of any given society. Determining when and how decisions on priority setting are justifiable involves values relating to process (that is, how decisions are made) and to the content and reasons used (that is, what decisions are made and why) (Clark and Weale, 2012:3)

1. BACKGROUND

1.1. Stakeholder engagement in health-related decision-making processes

This thesis focuses on stakeholder engagement in health-related decision-making processes in a Tanzanian district. Stakeholder engagement ideally entails active participation, consultation or communication in the decision-making processes by the ones who may potentially be affected by a particular decision and by the ones chosen to represent them. Arnstein (1969), in a classic text, argues that the aim of stakeholder engagement is to redistribute power to enable the have-not citizens, presently excluded from the political and economic processes, to be deliberately included (Arnstein, 1969:216), which would commonly imply some degree of community participation. The concept of community participation in health was brought to the forefront of attention in the early 1970s, as it became increasingly clear that top down approaches that had characterized global health since its inception were not efficient in ensuring needed community involvement. The World Health Organisation's seventh article of the Declaration of Health for All declares the organisation's commitment to involvement by people at the grass roots: *'Primary health care requires and promotes maximum community and individual self-reliance and participation in the planning, organisation, operation and control of primary healthcare'* (WHO, 1978:4).

Active participation by a large number of stakeholders was emphasised as one of the fundamental principles in the primary healthcare (PHC) approach fully launched in the historic Alma-Ata Declaration in 1978 (Sanders et al., 2008), a strategy with the ambitious aim of achieving 'health for all by the year 2000'. The movement also grew out of a recognition that clinician-centred care and hospital-based programmes – often characterized by 'paternalistic approaches' – were inadequate, particularly in global

health (Zakus and Lysack, 1998:1). Paternalistic approaches in health care imply a passive role of patients in decisions pertaining to the treatment process. A shift towards approaches that called for increasing involvement of both the patients in the treatment processes and the communities in health-related decision making emerged during the years and decades following the Alma Ata Declaration. Thirty years after Alma Ata, WHO, at a more general level, stated that every person and all peoples are entitled to active, free and meaningful participation in, contribution to, and enjoyment of civil, economic, social, cultural and political development (WHO, 2008:7). In the coming section we will touch upon theoretical underpinnings of participatory approaches in decision-making processes and on some of the reported challenges in ensuring stakeholder engagement in decision-making and priority-setting contexts, with an emphasis on questions pertaining to levels of engagement.

1.2. Theoretical approaches to stakeholder engagement in decision making

The shift seen in global health towards community and stakeholder engagement is embedded in thinking rooted in deliberative democracy. The ideals of deliberative democracy, or decision making through discussion among free and equal citizens, has according to Elster seen a revival (Elster, 1998). Jon Elster, in his book *Deliberative Democracy* (1998), emphasises that we are talking about revival and surely not an innovation, as the idea of liberal democracy is as old as democracy itself, with its roots back to Athens and Greece in the fifth century BC (Elster, 1998:1). Gutmann and Thompson (1996) present three ‘fundamental principles’ of deliberative democracy: ‘accountability’, ‘publicity’ and ‘reciprocity’. Accountability implies holding decision makers responsible for particular decisions that are made in efforts to discourage bias and fraud. Publicity implies that reasons behind concrete decisions should be made publicly

available and accessible. The principle of reciprocity refers to procedures that are followed during discussion to ensure that the listening to and the respect for the views of others are ensured. They write: *'When citizens reason reciprocally, they seek fair terms of social co-operation for their own sake; they try to find mutually acceptable ways of resolving moral disagreements'* (Gutmann and Thompson, 1996:2).

A key notion is that through deliberation, moral disagreement – which is common and will always occur – can be resolved with reasons that are justifiable to the stakeholders (Gutmann and Thompson, 1996). Stakeholder engagement is said to increase the legitimacy of public decision making, as it ideally clarifies public values, needs and preferences through processes which allow public servants and politicians to understand how the public views a particular issue, and what emerges as most important to them. Stakeholder engagement is public decision making, moreover, has the potential to clarify what kinds of information the public needs in order to grasp an issue; how to best frame or communicate a particular an issue in order that the public can make informed decisions (Sheedy et al., 2008). In short, it is held that stakeholder engagement in public decision-making and priority-setting processes enables decision makers to make better decisions, as decision makers are to a greater extent able to understand the relevance of their decisions as well as the practical, social and ethical implications of their decisions (Sheedy et al., 2008).

Disagreement on what decisions are to be made can and will naturally arise in the process, due to differences of interests, perspectives and values of the different stakeholders, but a key aspect is the agreement on the very *process* of deliberation which will lead to decisions being made. When a particular category of people does not win the argument (i.e. they lose the argument) as a result of priority-setting decisions, it is deemed vital that, as a matter of principle, this category is able to see that both the

reasons upon which the decision is based and the process followed in reaching the decision stand out as fair (Clark and Weale, 2012:7).

Stroud et al. (2010) note that an equitable decision-making process requires that all processes and procedures are made in a transparent way, and that they are consistently employing mechanisms that foster accountability for the decisions made. In order for the public to be able to grasp the reasoning behind particular decisions or particular priority setting is dependent upon openness or *transparency* in the decision-making process. There has been a growing realization that ‘customary’ (traditional) rationing practices in many parts of the world have been implicit or hidden, and are thus inadequate in solving the immense global resource-allocation challenges (Tragakes and Vienonen, 1998). The author added that while rationing was taking place, the rules were not transparent and users of the health services were unaware of the process. However, as people developed interest in the resource-allocation process, they demanded more transparency in the priority-setting process. Fair decision- and priority-setting processes implying transparency is held out as a vital move in an effort to enhance fairness (Daniels, 2000). Transparency can imply both ‘internal’ and/or ‘external’ transparency. Internal transparency means that all members of a particular segment are knowledgeable about the issue being considered, i.e. are informed about the content of the deliberations. External transparency means that the processes, deliberations, decisions and reasoning of the decision-making body are made available to stakeholders external to the membership of the decision-making body (Martin et al., 2002b). This idea is pinpointed by Daniels (2000), who writes

... there must be no secrets where justice is involved ... people should not be expected to accept decisions that affect their wellbeing unless they are aware of the grounds for those decisions. (Daniels, 2000:1301)

Which decision is perceived to be fair will differ for a large variety of reasons, but the value of transparency remains (Clark and Weale, 2012:7).

1.3. Priority-setting approaches and stakeholder engagement

Priority setting in health care has been a challenge in many low income countries including Tanzania because the health problems are many, severe and complex and the funds available to address them are limited. Different approaches are being used to assist priority-setting decisions such as economic approach, evidence-based medicine and burden of diseases. The economic approach has been used to identify strategies that are cost-effective, hence have better health outcomes for a larger part of the population (Hutton, 2001, Denir and Zohrabyan, 2009) through application of cost effectiveness analysis (Wikler, 2003). However, the approach has been criticised as it focuses on the outcome in general terms without taking into consideration that different illness conditions may be given a different value in different settings. It has been argued that cost-effectiveness calculations may emerge as logical to the economists and governmental systems with limited resources but may be at odds with communities' priorities that, for example, may favour interventions that target severely-ill patients on the basis of their greater need for healthcare rather than relatively less-sick individuals (Lu et al., 2008:3). Lu et al (2008:3) therefore discuss the manner in which locally-defined experience and perspectives are ignored by the economic model in priority setting. Research reveals that at a general level, and when removed from economic assessment, improvements in health by patients with a severe health condition will be valued more highly than the same level of improvement in health from a less severe condition (Kapiriri and Norheim, 2004).

Evidence-based medicine (EBM) focuses on improving the safety and effectiveness of health care interventions through the integration of clinical expertise based on the available evidence (Walsh and Manyosi, 2001). The approach assists in making allocation decisions on ‘the right treatment for the right patient at the right time’ (Gibson et al., 2005a). The EBM approach has also, however, been found to have limitations in a priority-setting context due to the fact that it does not consider the social, cultural, and political contexts within which health problems are found (Kapiriri et al., 2003).

The ‘burden of disease’ approach was developed in an attempt to counteract the challenges brought about by the de-contextualized and generalized economic and EBM models. One approach to quantify disease burden for priority setting has been an estimation of so-called ‘Disability Adjusted Life Years’ (DALYs) (Murray and Lopez, 1996). Kapiriri et al. (2003), based on studies in Uganda, have criticised the ‘burden of disease’ approach by saying that, although ‘Disability Adjusted Life Years’ (DALY) attempts to take contextual dimensions into account, the value choices linked to the severity of particular illness conditions on which DALY are based are commonly made by health experts who face challenges in assessing people’s perceptions and priorities across different economic, social and cultural contexts (Kapiriri et al., 2003:21). Further, available evidence is inadequate and sometimes of poor quality. It has been pointed out that the health information systems in many low-income countries are generally weak and have incomplete, untimely and unreliable data, which means that they provide a poor foundation for priority setting and other planning processes (Lowe, 2000). Health planners hence make decisions on the basis of whatever information happens to be available. Studies conducted in Tanzania have revealed substantial health information weaknesses (Franco et al., 2003, Maluka et al., 2010).

It is important to note that the approaches of economic, evidence-based medicine and burden of disease disregarded stakeholder engagement in priority-setting processes as

they were based on principles that made stakeholders' views emerge as irrelevant. They hence ignored the inclusion of local views. Frith has written that, at one level, a society 'as a whole' will have to make decisions about the kind of health provision that it wants. He made clear that priority-setting questions pertaining to health cannot be answered by the medical sciences alone but involve important judgments of values found in particular societies (Frith, 1999: 149-50). In such contexts it seems that stakeholders' engagement in prioritisation processes, either through active participation or through consultation, is of particular importance in efforts aimed at bringing up local priorities and values.

The framework termed 'accountability for Reasonableness' has in recent years emerged as a the leading framework for priority setting in health care institutions (Daniels and Sabin, 2002). It seeks to meet the main challenges encountered by the above briefly-described approaches, but places a key emphasis on priority-setting processes that are perceived as relevant to the people in question. It is the only approach that, according to Martin and Singer (2003), is both empirically based, ethically justified, and is focused on process. The framework can arguably be employed to guide deliberations in priority-setting processes to reach agreements on *what* decisions should be made (Daniels, 2000, Martin et al., 2002a, Gibson et al., 2005a). Daniels and Sabin, central ethicists in current health-related equity debates, hold that two fundamental characteristics or values of any acceptable and successful priority-setting process are *legitimacy* and *fairness* (Daniels and Sabin, 2002), implying that the priority-setting process should be socially accepted.

Kapiriri et al. (2007), in their work from Uganda, reiterate Daniels and Sabin's arguments that ensuring legitimacy and fairness of priority-setting processes in health requires the involvement of a wide range of stakeholders in processes that elicit their *values* (Kapiriri et al., 2007). Gibson et al. (2005b:2356) similarly emphasise that it is the *values* of individuals participating in the decision-making processes that have to be taken into account to enhance procedural fairness. Daniels and Sabin (2002) made clarifications that

stakeholders' values may impact decisions through procedural processes by having access to the decisions and the rationales behind the decisions and, finally, have the authority to deliberate on the decisions that will have an impact on the final outcome. This approach favours an explicit priority setting that has been recognised as important by some countries in Europe and in the United States after the weaknesses of traditional rationing that was implicit, hence inadequate to solve resource allocation problems, had been acknowledged (Tragakes and Vienonen, 1998).

In the priority-setting context, fairness is ensured through the involvement of relevant stakeholders who can discuss and reach an agreement based on justifiable reasons – reasons that emerge as relevant in meeting people's needs and aspirations. It is thus pointed out by Clark and Weale (2012) that setting health priorities requires not only 'technical' judgments, such as the judgment of cost effectiveness of a particular intervention or the evidence base in terms of disease burden, e.g. demonstrating the high prevalence of a particular health challenge, but it also involves *value judgments* in terms of deciding what ailment should be given priority. These judgments have been said to be partly 'social'. Social value judgments may be defined as judgments made on the basis of the moral or ethical values of a particular society (Clark and Weale, 2012:3). Frith (1999) observed that the evidence on 'effectiveness' may form the basis for pursuing a particular course of action, but that value judgments are needed to decide whether to pursue the consequent course of action. He writes:

No matter how good our evidence is, it can never eradicate value judgments. Hence, the evidence will be combined with the values that the decision makers want to promote. (Frith, 1999:143)

Values in a priority-setting context may include aspects of equity (prioritising the most in need), equality (people with equal needs should be treated equally regardless of socio-economic status), solidarity (decision-making body members to work for the common

goal without bias), trust, transparency, etc. Once these value judgments have been made explicit, scientific evidence can be used to determine the best means of achieving the targeted priorities, Firth argues. Hoedemaeker's (2003:275-277) review in a similar vein establishes that, in addition to the consideration of 'evidence-based criteria' such as effectiveness, safety and cost in health-care related decision making, considerations such as *solidarity* and *just distribution* of healthcare services will have to play central roles. Identifying the particular values that guide the priority-setting processes in actual societies, however, remains an empirical issue – an issue that will be considered in a Tanzanian context in this dissertation.

1.4. Challenges to stakeholder engagement: A brief commentary

It has been strongly argued that when communities are directly involved in the identification of and the solving of their own problems, community members may become a powerful force in promoting programmes for social improvement (De Savigny et al., 2008). However, Arnstein (1969), in his classic study, asserts that community consultation offers no assurance that citizens' concerns and ideas will be taken into account. The large majority of stakeholders commonly do not participate in the final decision-making processes, and community views may simply be disregarded in later processes.

Singer (1995) has summarised some key questions regarding how participatory a decision-making process should be for the general population to be effectively represented, and asks some pertinent questions in this regard:

Within a given geographically defined community, which group should form the representative decision making body? What information will this body perceive as necessary for valid decision making? Can a participatory process that is only

consultative be sustainable, or must the decision making body be given responsibility for the allocation of resources? What types of decisions should groups of citizens make? Will different categories of citizens (lay and professional) be given the same information to reach certain decisions? (Singer, 1995:422-423)

Stakeholder involvement has similarly been discussed in terms of how to maintain the right balance between inclusivity and in terms of ensuring that the 'right' people make the decisions (Martin et al., 2003). How can such encompassing participation be a part of all stakeholders' roles and responsibilities?

Pertaining to degree of participation, Vuori (1984) has raised other central questions asking whether community participation should be a democratic or instrumental principle. The answer provided is that a democratic approach elevates community participation to a universal principle while instrumental approaches reduce community participation from a universal to a strategic or tactical consideration (Vuori, 1984). Vuori, in the process of asking what the goal of community participation in decision making should be and of what kind of power community's participation mechanism should have, also recognizes the challenge of identifying exactly what a community is.

Singer (1995), referring to Abelson and associates whose work assessed five potential decision making groups' preference on the modality of engagement in decision-making processes, reveals that randomly-selected citizens preferred mere consultative roles, whereas a majority of the elected officials, experts and members of the district health councils preferred more profound responsibilities in the decision-making processes. These findings raise a key question related to the assumption that community members are interested in and willing to participate in the decision-making process in healthcare (Singer, 1995:423) Apart from general health-care decision making, related findings have

been recorded in clinical settings, as revealed in Frosch and Kaplan's review (1999), whereas, while some patients were willing to participate in decision making, others appear to be unwilling to participate, preferring to leave such decision making to the physicians, especially when their disease conditions become severe.

Another key issue raised in Zakus and Lysack's review 'Revisiting community participation' (Zakus and Lysack, 1998) is that community participation may mean different things to government officials and to the communities. Government officials may be genuine in their desire to know community inhabitants' views pertaining to particular themes, they may also however be inclined to view somewhat pragmatically community participation as a way of legitimising public policy and to quicken its implementation, or a means to diffuse public criticism and potentially delay action. The community may, on their side, view participation as a means to communicate opinions and make an impact on decisions relevant for themselves, but also as a means to obtain power in the governmental system (Zakus and Lysack, 1998:8). The public gaining power is what is expected and desired in participation but, if the intention of government officials is to diffuse public criticism, the input may not be used in a manner of interest to the community. In such instances actual/true participation may not be encouraged, and the community may be merely informed rather than given a chance to provide reflective feedback.

A key issue that runs through the literature on participatory approaches to decision making is the concern about the lack of empowerment in marginalised populations to actively engage in decision-making processes. Those concerned with *empowerment* of the population point out that the communities or individuals whose opinions and initiatives are asked for will need to have the knowledge, the courage and the ability to be able to engage in the debate about the issues at stake. Empowerment theory is based in

Paulo Freire's ideas of Popular Education. It is based on the premise that groups of people change through a process of coming together to share experiences, in understanding social influences, and in collectively developing solutions to problems (Wallerstein and Bernstein, 1988:380). Through processes of empowerment, individuals and communities may gain the courage to express their views and grievances openly and independently. Rosato et al. write that empowerment processes aim at transforming stakeholders from passive to active participants, fostering truly shared decision-making processes (Rosato et al., 2008). Green (2000:69) is particularly concerned that the poor or otherwise-marginalized segments of a population, segments commonly divorced from the decision-making centres that may be dominated by individuals with interests diverging from their own, need to be *empowered* to participate in the decisions which affect them.

In a health-related decision-making context it is argued that empowered community members will help change the attitudes of health planners who may be content with their own expertise and ignore community priorities (Zakus and Lysack, 1998). Studies have shown that, with knowledge and increasing educational levels, people become more confident in participating in the clinical decision-making process (Frosch and Kaplan, 1999, Flynn and Smith, 2007). Studies pertaining to women's participation can also give important insights in this connection: Senarath and Gunawardena (2009), in their study from South Asia, has similarly pointed out how women's participation in decision making significantly increased with education, but also with age, number of children, area of residency (whether urban or rural) and economic status.

Empowerment approaches in global health have been criticized from several standpoints, e.g. pointing out the inherent power embedded in the roles of the persons/institutions that are to 'empower' individuals or communities, and the control over the kinds of knowledge imparted on the poorer segments of the population, potentially creating new

structures of power. While empowerment is aimed at enhancing participation and fairness in decision-making processes, ensuring that every individual participating in the decision-making process has a say, Gibson et al (2005b) caution that the effect of power differences among diverse sets of stakeholders can nonetheless undermine the overall legitimacy and fairness of decision-making processes. However, the general importance of the knowledge- and educational dimension related to the potential of speaking up, of powerfully conveying a message and of being listened to, is retained through these discussions.

Other central concerns that have been raised in discussions of how to ensure community participation in decision making are related to the cost and time dimensions. Participation, as Singer (1995) and Zakus and Lysack (1998) have pointed out, requires the cost and time factors to be carefully assessed for the full process, including information compilation and dissemination. They hold that unless all aspects of time and costs of actual participatory approaches are worked out – i.e. of actually reaching the stakeholders’ at the grass roots – only the most privileged segments of a society will commonly get a chance to participate, while low-income and less-powerful citizens are easily ignored (Zakus and Lysack, 1998:7); they will neither be reached in the communities nor elected to represent others in the decision-making bodies.

1.5. Levels of stakeholder engagement

Clearly, every individual cannot be deeply engaged in every health-related decision-making process that will potentially influence him or her. A key question that arises is thus the degree of engagement that is meaningful in order to ensure that decision-making processes generate results perceived as relevant for the ones whom they are to benefit. Singer (1995) in his writings asks questions about what level of participation one should aim at. Goetghebeur et al (2008) reveal how decision making in healthcare takes place

along a continuum that moves from evidence generation to deliberation on each particular intervention and communication of the resultant decision. Along this continuum, it is pertinent to ask at what points in time and with what rigour community members should be involved and be allowed to influence the decision-making process.

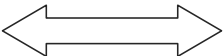
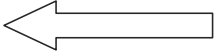
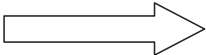
As stakeholder engagement has been employed rather vaguely, analytically speaking, the psychologists Rowe and Frewer (2005) have developed a framework, referred to as *engagement theory*, with the aim of categorising different forms or levels of engagement. Rowe and Frewer have outlined a distinction between stakeholders' active participation through physical encounters with policy or decision makers in processes of deliberation implying joint decision making; stakeholder involvement through provision of input during the decision-making process; and passive involvement through the receiving of information regarding decisions that have been made by decision makers. Based on this reasoning, they suggest that stakeholders' engagement can be broadly captured by making the following classification (2005:255); the term 'sponsors' has been used to refer to the managers, policy/decision makers.

1. **Participation:** This entails that members of the public and the 'sponsors' exchange ideas. It may involve processes where lower level stakeholders and managers have dialogues on a particular topic. The act of dialogue and joint negotiation in such processes serve to inform and transform the opinions of the members from both parties.
2. **Consultation:** This level of engagement entails that information is conveyed from members of the public to the 'sponsor' following a process initiated by the 'sponsor'; that is, lower level stakeholders are consulted by higher level managers to provide opinions or information regarding a particular phenomenon. Consultation does not imply formal dialogue or discussion between the sponsor/managers and lower level stakeholders.

3. **Communication:** This level of engagement implies that information about a certain decision is sent from the ‘sponsor’ of the initiative to the public; that is, the stakeholders are provided with information by higher level managers about a particular decision reached. This type of engagement primarily implies a one-way communication as, at this point, stakeholders have no room for providing opinions or feedback that may have impact on the decision reached.

The table below indicates the flow of the information as it relates to the three forms of involvement as detailed in engagement theory.

Table 1. Flow of information according to level of engagement (Rowe and Frewer, 2005:255)

Levels of engagement	Flow of information	Public
<i>Public participation</i>		Public representatives
<i>Public consultation</i>		Public representatives
<i>Public communication</i>		Public representatives

NB: Sponsors include managers, decision-makers or policy-makers

Rowe and Frewer recognise the substantial distinction in terms of actual engagement by the public sketched through the various approaches but, to them (2005:271), information is nonetheless perceived as a key to public engagement regardless of the model of approach employed, and whether engagement is to take place at the level of participation, consultation or communication. Of particular importance to them is ‘*maximising the relevant information from the maximum number of relevant sources and transferring this efficiently to the appropriate receivers*’ (Rowe and Frewer, 2005:263).

There are certain criteria that Rowe and Frewer hold to importantly affect the effectiveness of the ‘engagement exercise’ and, thus, have implications for how fair and efficient the exercise becomes in terms of achieving the intended objectives, whether it pertains to educating the public, achieving proper consensus in a decision-making process or eliciting stakeholders’ views and opinions. They contend that participation and consultation are meant to enhance fairness in decision making, and that it is decisive that stakeholders involved in the process feel that ‘the exercise’ has been honestly conducted with the serious intent to learn about the views of ‘an appropriate sample of the affected population’ and eventually to act on those views (Rowe and Frewer, 2005:262) (2005:262). Abelson et al.(2003:244) have pointed out that it is important to assess the particular elements of what the process consists of, such as: (1) Was ample time provided for discussion? (2) Did the participants have the opportunity to challenge the information presented? (3) Was mutual respect and concern for others emphasized throughout deliberations? Such retrospection may be extremely helpful in determining whether the decision-making process was characterized by joint reflection or dominated by certain segments of those present.

Pertaining to the communication level of the engagement theory, Rowe and Frewer (2005) indicate that information that is distributed without physical encounters commonly create reception- and understanding gaps, leading to misunderstandings and misinterpretations or distortions of the message. They argue that engagement mechanisms that employ face-to-face contact are more likely to be effective than the ones that deploy other mediums of information transfer, the latter being dependent upon how comprehensively the message is delivered (Rowe and Frewer, 2005:272). In a similar vein, Abelson (2003:240) has pointed to the many weaknesses of one-way communication approaches in health-related decision-making processes. Abelson shows

how the recognition of these weaknesses has paved way for new approaches that emphasise two-way interaction between decision makers and the public, and approaches that encourage deliberation among stakeholders, which brings us back to the more comprehensive approaches of participation laid out above.

2. JUSTIFICATION AND STUDY OBJECTIVES

2.1. Justification

There has been a substantial conceptual shift from top-down to an emphasis on bottom-up approaches within global health, approaches in which stakeholder engagement has been at the core. The idea of community participation in global health emerged in the early 1970s as it became increasingly clear that, in catering for the immense health needs of the global population, more locally-informed approaches and more involvement of local communities were decisive. Active community participation was emphasised as one of the fundamental principles in primary healthcare (PHC) fully launched in the Alma-Ata Declaration in 1978 (Sanders et al., 2008) – a strategy for achieving health for all by the year 2000. A substantial shift towards approaches calling for increased involvement of stakeholders and patients pertaining to health-related decisions took place in the decades following the Alma-Ata Declaration.

Tanzania is a country where this shift has taken place in quite manifest ways with the shift from a centrally-governed socialist state, where more or less all decision making took place centrally during the years after the state's independence in 1961, to a state that has moved strongly towards decentralization through devolution of decision making and stakeholder engagement during the past two decades. There is to date limited knowledge about how the global policy shift was manifested in actual practice in terms of concrete

decision-making processes and stakeholder engagement at lower levels of administration. The lack of knowledge is particularly evident for low-income contexts. It seems to be of substantial interest to explore the manner in which the engagement principles in health-related decision making are practised and in what ways. At a basic level, we are confronted with key human rights' principles of the right to participation – a right located at the core of deliberative democracy and reiterated in a Tanzanian context among others by the decentralisation policy. With the assumptions that stakeholder engagement is vital in ensuring the relevance and the quality of the health-related decisions and priorities, knowledge of actual stakeholder engagement in health-related decision-making processes seems to be of particular importance for low income contexts where health-related challenges remain many and complex and where resources to deal with the challenges remain extremely scarce.

This thesis is partly based on the findings from the REACT project that was implemented between 2006 and 2010 (in Tanzania, Zambia and Kenya). Referring to the distinctions made by Rowe and Frewer (2005), the papers in the present thesis can broadly be said to speak to stakeholder engagement at the level of 'participation' (Paper I), 'consultation' (Paper II) and 'communication' (Paper III). The study was not planned to collect data in a manner reflecting Rowe and Frewer's framework, but this broad framework emerged as relevant during the phase of analysis. Paper 1, which focuses on perceived engagement in health-related decision-making processes within the district level bureaucracy in Tanzania, scrutinizes the potential impact of gender, wealth, ethnicity, age, religion and education on the level of actual participation. The argument is framed within local discourses on fairness in decision-making processes.

In order to make the study on decision making in health care as concrete as possible, the project chose to focus the following exploration on a particular health-related programme

or intervention. The Prevention of mother-to-child transmission of HIV (PMTCT) programme was chosen, partly because HIV was included as one of the four health service areas explored within the REACT project to assess equity, quality and trust in the health services provided. The PMTCT is located at the intersection between the Millennium Development Goals 4 (infant mortality), 5 (maternal mortality) and 6 (infectious diseases). PMTCT was a high profile programme that had received substantial attention, and the research team perceived it to be of interest to explore the manner in which the political ideals of stakeholder engagement in decision-making processes would be carried out within such a highly-prioritized programme.

The overriding aim of the subsequent sub-studies was to scrutinise concrete priority-setting- and decision-making processes within the PMTCT programme, processes taking place within an ongoing health sector reform and within decentralisation processes (Paper II). The last sub-study explored how the policy/guidelines generated at the global level and employed by the PMTCT programme regarding infant feeding in a context of HIV were communicated to and understood by different levels of stakeholders from regional-, district-, to health facility-, and community levels (Paper III). Figure 1 attempts to show the level of stakeholder engagement with reference to the three partly overlapping study topics.

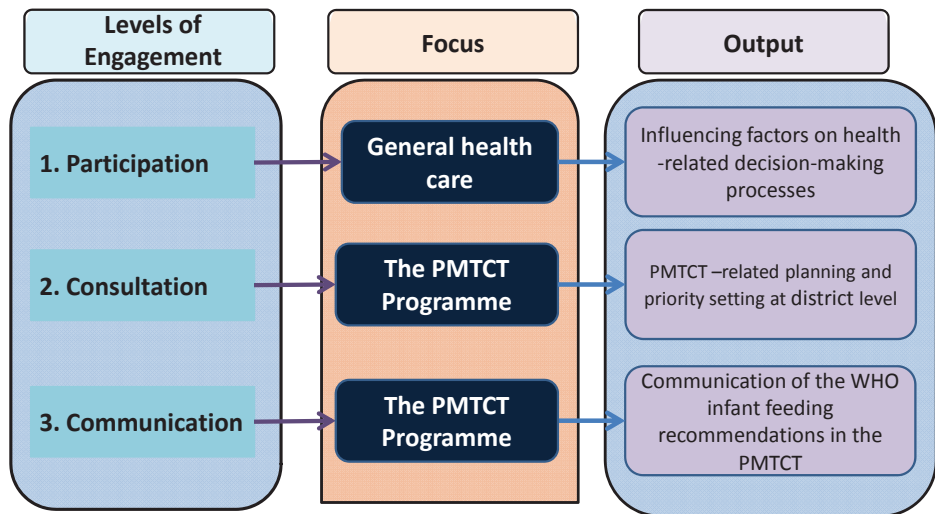


Fig. 1: Levels of engagement with reference to Rowe and Frewer (2005) related to the present project

2.2. General study objective

To generate knowledge on stakeholder experience with engagement in lower level health-related decision-making processes in a rural Tanzanian context, with the aim of feeding into global health debates on stakeholder participation in decision making in low income contexts.

2.2.1. Specific objectives (related to the three sub-studies)

1. To explore stakeholder engagement in health-related decision making at the district level in Tanzania, with a particular focus on the potential influence of gender, wealth, ethnicity and education at district and community levels.

2. To assess stakeholder involvement in priority-setting and decision-making processes through a scrutiny of the prevention of mother-to-child transmission of HIV programme (PMTCT) at district and health facility level in Tanzania.
3. To explore the ways in which changes in the infant-feeding guidelines have been communicated to and understood by the regional and district level managers of the PMTCT programme as well as by the health workers in charge of the PMTCT programme at health facility level.

3. HEALTH RELATED DECISION MAKING IN TANZANIA

I shall at this point move to the Tanzanian context and include a brief presentation of the historical political context, including information about relevant governmental structures with an emphasis on policy regulating decision-making bodies in general and health-related decision-making bodies and processes in particular. I will then say a few words about how vertical programmes are located within this structure, and briefly present the ‘Prevention of mother-to-child transmission of HIV programme’ (PMTCT).

3.1. Tanzania and its healthcare system

Tanzania is located in East Africa. It is made up of 30 regions and 169 districts. Health services are provided in a pyramidal structure starting from the *dispensary* at the lowest level via the *health centres* and the *hospitals*, with the larger *referral hospitals* at the regional or national level located at the top. Although most health services are provided by the government (64%), there is a long history of faith-based health services, and an increasing number of private health institutions and organisations operating in the country (MoHSW, 2007a).

At the district level there is a hierarchical structure pertaining to healthcare decision making, ultimately managed by the Council Health Management Team (CHMT). The role of the CHMT is to relate actively both ‘downwards’ and ‘upwards’ in the system. Diverse *committees* exist within the district, as well as at the lower levels, and their role is to develop plans for action to be submitted to the CHMT (Maluka et al., 2011, Venugopal and Yilmaz, 2010). Other important stakeholders in this system are *officials* from the local government authority, the managers of the health facilities, the health facility committees, the health boards, the non-governmental organisations (NGOs), the private health service providers, as well as the members of the community. According to the Tanzanian decentralisation policy, discussions pertaining to health-related priority setting

and decision making should start at the community- and health facility levels where different health-related committees are to be set up. Decisions made at the local levels are to be forwarded to the CHMT, and eventually to the District Full Council. However, it has been documented that in practice this flow is not always properly adhered to, as lower level committees within the district often remain inactive (Maluka et al., 2010, Maluka et al., 2011).

3.2. Governmental planning and prioritisation in Tanzania

Writing about approaches to planning at a general level in Tanzania, Cooksey and Kikula (2005:9) demonstrates how central planning was located as a core component of the post-independence policies in all sectors, a policy lasting until around 1980. He writes that this top-down planning approach allowed for the rapid, large-scale implementation of programmes, and the spending of budgets in accordance with pre-established timetables. It also gave government planners, donors and the bureaucrats a feeling of control and efficiency, as all planning decisions were centrally made with reference to a preconceived master plan. The bureaucrats and politicians involved in the planning process believed such an approach to be optimal in terms of providing solutions.

Bottom-up planning in Tanzania's health sector was gradually initiated with the introduction of primary healthcare, with its key focus on health service provision at the grassroots. The 'health for all' concept of the Alma-Ata declaration launched in 1978 became a prime global policy bearer for the movement of bringing health services closer to the world's communities (WHO., 1978), so also in Tanzania. Following this monumental declaration, the top-down approach was gradually substituted by a focus on the more inclusive and participatory processes, and on ways in which to better reach the grassroots.

The focus on reaching the grassroots and on ensuring broader participation in healthcare-related decision-making processes gained renewed attention and became more manifest in the early 1990s, when a movement and reform for improving performance of the health system was fully introduced in many countries (Mwale, 1999, Phillips, 1987). The Tanzanian government, during the course of this process, committed itself to enhancing community involvement and adopted participatory planning as a means towards empowering people to determine their own destiny of development, as reflected in the Tanzanian ‘Development Vision 2025’:

Deliberate efforts must be made to empower people and catalyse their democratic and popular participation. The strategy should entail empowering local governments and communities and promoting broad-based grassroots involvement in the mobilisation of resources, knowledge and experience with a view to stimulating initiatives at all levels of society.

(Planning Commission, 1999:17-18)

The still-ongoing ‘Local government reform’ process in Tanzania aims to ensure that citizens at the grassroots are involved in the planning and implementation of development programmes in their local areas (Fjeldstad et al., 2010). Through participatory planning and budgeting, the reforms envisage that development programmes will be of enhanced relevance to local needs and engender a sense of ownership to better facilitate implementation. According to the National Framework on Participatory Planning and Budgeting, the guide referred to as ‘Opportunities and Obstacles to Development planning’ (O&OD) is an instrument for facilitating ‘bottom-up’ participatory development. The O&OD methodology provides guiding principles for participatory planning and budgeting in local governments through descriptions of the legal framework, and the roles and responsibilities of government institutions located at different governance levels (Cooksey and Kikula, 2005).

3.3. District health planning

As stated above, Tanzania consists of 169 districts. Each district is to develop its own Comprehensive Council Health Plan (CCHP) guided by the pre-defined priority areas as outlined in the Essential Health Package (URT., 2004, URT., 2011a) The essential health package aims to improve the allocation of resources in the healthcare-delivery facilities and to enhance a population's access to essential healthcare. Lambo and Sambo (2003:S9), who have written about the history of the health sector reform in Tanzania, explain that from its inception the essential health package has been similar among the African countries, and was adopted through health sector reforms with slight variations across the region.

The council health planning guidelines state that all planned health-related activities and interventions will be selected on the basis of their effectiveness to address the overall health burden within the district (URT., 2004:13). The revised council health-planning guidelines of 2011 act as a reminder to the district planning team to integrate views and priorities of the communities and of the health facilities in the process of developing the Comprehensive Council Health Plan, in line with what is detailed in the National Essential Health and Social Welfare Package, and in the Burden of Disease and available resources (URT., 2011a:13). Through pre-planning meetings, community needs and health problems should be identified using existing tools such as 'Opportunities and Obstacles for Development' (O & OD), community dialogue and Participatory Rural Appraisal (PRA).

The district plans rely on two main sources of funding: the Health Block Grants, provided by the central government, and the Health Basket Funds, which consist of pooled donor funds. Guidelines and a formula are deployed in the allocation of both sources of funds to cater for disparities between the districts. The formula is based on the following four

parameters: the size of the population (70%), poverty rates (10%), remoteness of the district/district vehicle route (10%) and the under-five mortality rate (10%) as a proxy for burden of disease in the population (URT., 2011a:61). The allocation for each intervention in the Essential Health Package is furthermore guided by the disease burden of each district based on existing disease burden data. In the revised CCHP guidelines of 2011, the Tanzanian priority areas in health were named the National Essential Health and Social Welfare Interventions Package Priority Areas (URT., 2011a:24) (Table 2).

Table 2. List of Health related Priorities per 2011 CCHP Guidelines (URT., 2011a)

Priority area 1: Medicines, medical equipment, medical and diagnostic supplies management system	Priority area 6: Environmental Health and Sanitation
Priority area 2: Maternal, Newborn and Child Health	Priority area 7: Strengthen Social Welfare and Social Protection Services
Priority area 3: Communicable Diseases	Priority area 8: Strengthen Human Resources for Health and Social Welfare Management Capacity for improved health services delivery
Priority area 4: Non-Communicable Disease Control	
Priority area 5: Treatment and care of other common diseases of local priority within the Council	

3.3.1. Planning and decision making in vertical health programmes

Before the vertical programmes were introduced in low income contexts, all health care services both curative and preventive were provided horizontally in the existing structures in the health care systems. However, the poor performance of the general healthcare services combined with the enormous unmet needs seemed to justify the introduction of vertical programmes (Atun et al., 2008). The vertical programmes have

been defined by Atun et al. (2008:1) as the disease management or disease control programmes or interventions that are provided through delivery systems outside of the official governance structure and, thus, have separate administration and budgets. They vary regards to structure and operations, and are funded by external donors. Vertical programmes are also known collectively as ‘selective primary healthcare’, and aim to bring together the most cost-effective medical interventions. As Atun et al. have reported, vertical programmes became more pronounced after the Alma-Ata declaration, and got new boosts in the 1980s with the enormous success of WHO’s smallpox eradication programme, as well as, in 1993, the proposal of the World Development Report in investing in health for ‘essential packages of care’ (Atun et al., 2008:ii). The health services’ failure in the general healthcare attracted many multilateral organisations, bilateral international agencies and philanthropic organisations to invest in disease-specific public health programmes, creating increasing numbers of actors and new global partnerships such as the Global Fund (Atun et al., 2008). TB and Leprosy, HIV/AIDS, Trachoma, Lymphatic filariasis, and mother and child health services, the vaccination and family planning programmes were diseases or domains targeted under the auspices of such programmes in low income countries (Oliff et al., 2003, Atun et al., 2008).

Vertical programmes helped to eradicate smallpox, the number one WHO success story, and also managed to reduce the mortality and morbidity occasioned by some other vaccine-preventable diseases (Atun et al., 2008:1). However, a prime challenge with the vertical programmes was that there was a limited degree of integration of these programmes within the general health services, which led to the inefficiency in care delivery, fragmentation of the health system and the duplication of efforts. Such inherent weaknesses of the vertical programmes made integrated service delivery a preferred option (Burki, 2001). The health sector reforms and the decentralisation processes in the health sector against this background sought to facilitate local integration of the donor-

funded vertical programmes that operated in parallel with the general structure of healthcare (Mayhew, 1996, MOH., 1998, MOH., 1997), a point we will turn to now.

4. HEALTH SECTOR REFORM AND DECENTRALISATION POLICY

As has been described by Zakus and Lysack (1998), community participation requires a political and administrative system that promotes and accepts decentralisation and active local authorities in decision making and resource allocation. In support of this line of thinking, the government of Tanzania adopted the health sector reform and decentralisation policy in the 1990s as a way to promote grassroots participation in decision-making processes. The health sector reform has been defined as *'a sustained process of fundamental change in national health policy aimed at improving performance in the entire healthcare delivery system in preventive, curative, promotive and rehabilitative services, with the ultimate goal of improving the health status of the population'* (Lambo and Sambo, 2003:S2). This operational definition was employed by the participating countries in the inter-country health sector reform meeting for Sub-Saharan Africa held in Arusha, Tanzania, in 1995. It was subsequently adopted by the regional committee for Africa during its 49th session in Namibia in 1999.

Although the contextual factors for the health sector reform in Africa varied, fundamental health systems and service challenges – such as inequality in access, poor and insufficient services, uncoordinated service delivery, inadequate community participation, etc. – greatly influenced the health sector reforms in many of the countries (Lambo and Sambo, 2003). The Health Sector Reform's broad vision was to provide equity of access to cost-effective quality healthcare, particularly at the grassroots. The aim was, among others, to ensure greater collaboration between the public and the private sectors, both for-profit and non-profit sectors (Lambo and Sambo, 2003). The assumption was that the private sector would enhance the effectiveness, efficiency, accessibility and quality of the health

services, allowing the state to concentrate on health promotion and essential service provision (Tibandebage et al., 2013). The overall objective of the health policy and health sector reform in Tanzania was to encourage the health system to be more responsive to the needs of the people, with a prime focus on those most at risk. A major component of the health sector reform in Tanzania became the *decentralisation* reform, which aimed at the devolution of power to the districts, and a closer integration of the district health care services, including the vertical health programmes (Gilson et al., 1994). Decentralisation has been defined as ‘*a process of state reform composed by a set of public policies that transfer responsibilities, resources, or authority from higher to lower levels of government in the context of a specific type of state*’ (Falleti, 2005:328). The reforms in Tanzania included devolving political, administrative, financial, and personnel control from the central to lower levels, particularly the district level.

Decentralisation in the health sector gained different approaches in different African countries. In Zambia, for example, a radical intention was to establish autonomous district health boards that were vested with extensive power in areas of resource allocation, manpower recruitment and management. In Botswana, Nigeria and Tanzania the process took the form of transferring sectoral responsibilities to the elected lower-level governments officials (Lambo and Sambo, 2003:S8). The local government reform process in Tanzania aimed at ensuring that citizens at the grassroots level became involved in the planning and implementation of development programmes in their local areas. As Kessy and McCourt (2010:691) phrased it, the reforms aimed at changing the previous command relations between the central and the local governments by transferring authority and resources to the district level, including from the central government’s regional administrative structure.

Through decentralisation, the Ministry of Health and Social Welfare (MoHSW) remained with the responsibility of policy making, long-term and macro-planning, managing

medical training schools and national health programmes as well as the overall monitoring of the health sector (Lambo and Sambo, 2003, Burki, 2001). The districts, for their part, were given the authority to undertake local planning, allocate resources and to carry out the management of the district health services. The District Medical Officer (DMO) was to report to the District Executive Director (DED), a presidential appointee and secretary of the council meetings, to the Regional Medical Officer (RMO), and to the Regional Administrative Secretary (RAS) (Mubyazi et al., 2004:S168). The DMO and RMO remain in charge of the medical aspects in the district and region respectively.

There has been limited research exploring the practical implications of the large-scale reforms aimed at enhancing active engagement of lower level stakeholders in priority-setting- and decision-making processes. Two of the sub-studies making up this thesis explore stakeholder experiences with involvement from a particular WHO-initiated global health intervention, the Prevention of mother-to-child transmission of HIV (PMTCT) programme in an attempt to illustrate dynamics at work pertaining to stakeholder engagement in decision-making processes within a concrete vertical health intervention. In order to properly grasp the study focus and findings, I shall at this point briefly comment upon the programme of mother-to-child transmission, and the frequently shifting guidelines as regards to infant feeding.

5. THE PREVENTION OF MOTHER-TO-CHILD TRANSMISSION OF HIV PROGRAMME

During the course of the study the PMTCT programme emerged as an interesting case in terms of enhancing our understanding of health-related planning- and decision-making processes in Tanzania.

According to World Bank statistics, Sub-Saharan Africa continues to be the global epicentre of the disease. According to 2008 figures, about 22.5 million Africans are HIV-

positive, and AIDS is still the leading cause of premature death on the continent (World Bank, 2008). Most children living with HIV acquire the infection through mother-to-child transmission (MTCT) during pregnancy, labour and delivery or during the breastfeeding phase (De Cock et al., 2000). In 2009, an estimated 370,000 children worldwide contracted HIV during the prenatal and breastfeeding period, a number that has decreased from an estimated 500,000 in 2001 (UNAIDS, 2010:9).

Albeit not located at the very top, Tanzania is surely one of the countries seriously affected by the HIV/AIDS pandemic, with an overall prevalence of 5.7% and 5.1% in the 15-49 age group in 2007 and 2011 respectively (Tanzania Commission for AIDS et al., 2008, Tanzania Commission for AIDS et al., 2013). The most recent available survey (from 2011) shows an HIV prevalence of 6.2% among women as compared to 3.8% among men in the 15-49 age group (Tanzania Commission for AIDS et al., 2013). The National AIDS Control programme's sentinel surveillance reports of 2005 and 2008 show that the overall HIV prevalence for pregnant women attending the ANC was 8.2% and 6.9%, respectively, indicating a positive decline since then.

Prevention of mother-to-child transmission of HIV (PMTCT) is one of the central interventions outlined in the Declaration made by the United Nations General Assembly's Special Session on HIV/AIDS (UNGASS) in 2001. The Tanzanian government launched a report in 2013 on the elimination of mother-to-child transmission of HIV (2012–2015) (URT., 2013b).

Few words of background information are deemed necessary at this point: Breastfeeding has since the 1970s been a corner stone in the UN child survival strategy. However, the fear of HIV transmission through breast milk led to policy changes in the 2000 WHO guidelines for HIV-positive women. Breastfeeding was at this point substituted by replacement feeding recommended as first choice for HIV-infected women whenever it

was perceived to be ‘acceptable’, ‘feasible’, ‘affordable’, ‘sustainable’ and ‘safe’ or AFASS (WHO, 2000), as formula feeding was perceived to be the safest option with regard to HIV transmission to children. The outcomes of the policy proved to be hazardous, threatening child survival (Fawzi et al., 2002, Iliff et al., 2005).

A decade followed during which, as a response to constantly emerging biomedical evidence combined with rights-based arguments and claims, a number of different HIV and infant feeding guidelines were published by the WHO. The outcome was a highly confusing scenario for health workers and HIV mothers alike, partly due to communication challenges of the complex messages, and partly due to the fact that few women could afford the formula needed for replacement feeding. HIV-infected mothers reported that there was scarce knowledge on the hard-to-understand association between the alternative ‘exclusive breastfeeding’ policy (only breastfeeding without giving anything else to the infant) and HIV in breast milk (Leshabari et al., 2006, Kominami et al., 2007), and the nurse counsellors themselves admitted that they were confused about the prevailing guidelines as well as about the ever-changing facts about the relation between breastfeeding and HIV transmission (Fadnes et al., 2010, Moland et al., 2010, Leshabari et al., 2007).

PMTCT in Tanzania

The PMTCT programme in Tanzania was introduced in 2000. It was first introduced at a few referral hospitals before it was scaled up in 2003 to cover a number of health facilities (MOH., 2003, MoHSW, 2009). The coverage in terms of the number of health facilities providing PMTCT services increased rapidly, reaching 94% in 2010 (URT., 2013b). The rapid scale-up has aimed at bringing the services closer to the community for easy access. The implementation of the programme in Tanzania has been guided by national guidelines that, to a considerable extent, have followed the changing WHO recommendations with slight modifications. The PMTCT services provided include

routine HIV testing and counselling, antiretroviral (ARV) treatment and prophylaxis for mothers and children, safer delivery practices, counselling and support for safer infant feeding practices, and long-term follow-up care for mother, child and family. Other relevant services include paediatric care for exposed children, monitoring and evaluation and linkage of HIV-infected mothers and their families to HIV care, and treatment clinics for the continuum of care (URT., 2011b:18).

The PMTCT programme was initiated as a vertical health intervention with separate organisation and funding. According to the 2011 PMTCT guidelines of the Tanzanian Ministry of Health and Social Welfare, the PMTCT programme has at this point been fully integrated into the reproductive and child health care services from the national to the health facility levels (MoHSW, 2011). The integration initiative started in 2007, and was part of the larger effort of integrating vertical health programmes in the formal/governmental health care structure, assigning the regional level the responsibility of ensuring the inclusion of PMTCT services in the Comprehensive Council Health Plan (CCHP) produced at district level (MoHSW, 2007b:109). The districts remained with the responsibility of ensuring smooth implementation of the PMTCT services by securing the availability of equipment, supplies and trained staff. Based on the 2011 CCHP guidelines, the PMTCT services are to be covered under the second priority area of maternal, newborn and child health (see Table 1).

6. METHODS

6.1. Study site

Location and population

The study was conducted in Mbarali District, which is located in Mbeya Region in the south-western part of Tanzania (7-9⁰ S and 33-35⁰ E). According to the 2012 National Population Census, Mbarali District had a population of 300,517 people, 154,650 women and 145,867 men. The annual population growth rate is estimated at 2.7% (URT., 2013a:111). The district is predominantly rural. The main ethnic groups in the district are the Sangu and the Nyakyusa. Other large ethnic groups include the Hehe, Bena, Sukuma and Maasai. The latter four are not indigenous to this area but have settled in Mbarali in search of arable land for farming (Hehe and Bena) or for grazing of animals (the Maasai and the Sukuma). There are a considerable number of livestock keepers, particularly cattle holders, in the area. The warm climate facilitates subsistence rice farming.

Mbarali District health profile

Mbarali District is served by both public- and private health facilities. The officially registered health facilities include two hospitals, four health centres and 43 dispensaries (Fig 2). The PMTCT programme was introduced in the district in 2005. In 2008 the coverage of PMTCT services in the district was estimated at 56% (MoHSW, 2009). When the present study was conducted in 2011 the coverage of the programme had reached 86%, indicating a very rapid scale up. Table 3 presents a few central health indicators of Mbarali District as compared to the national figures.

Fig 2. Map of Africa, Tanzania and Mbarali showing the distribution of health facilities

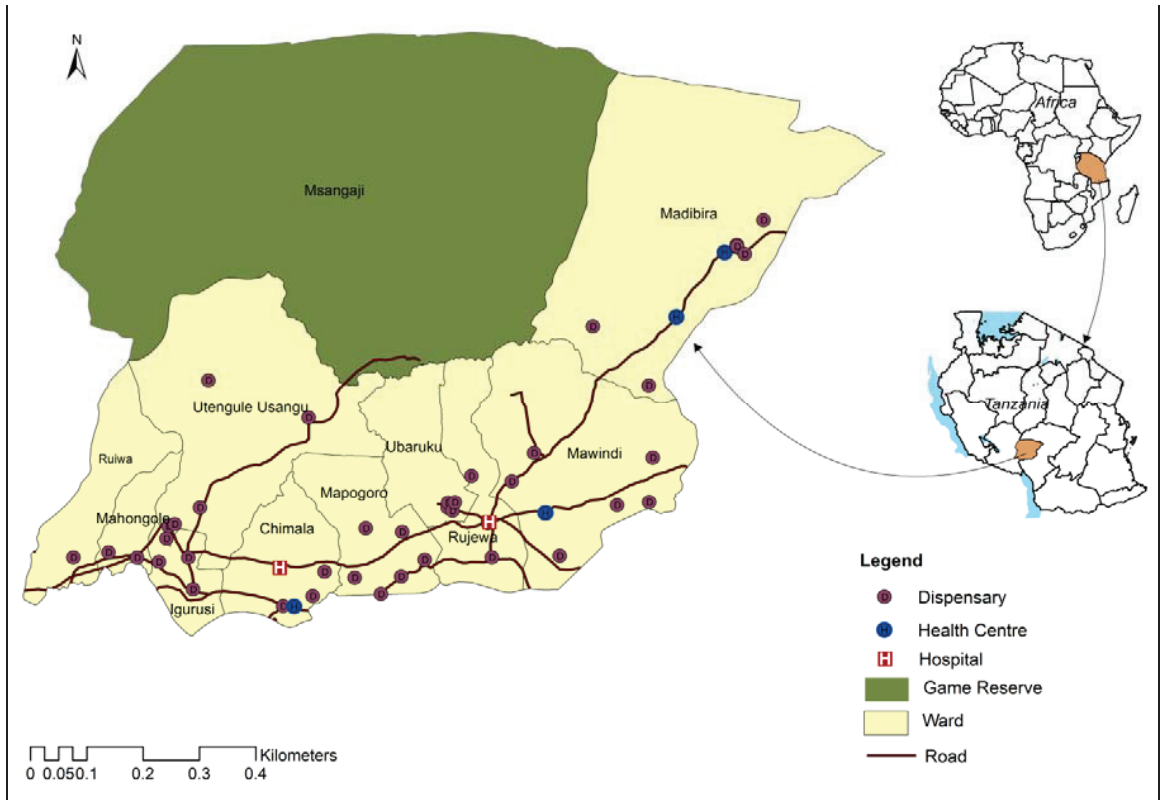


Table 3: Tanzania vs. Mbarali District Demographic and Health Indicators

Indicators	National	Mbarali district
Total population	44,928,923	300,517
Growth rate	2.7%	2.7%
Fertility rates	5.4%	4.0%
Under-five mortality rate	81/1000	102/1000

Vaccination coverage	75%	73.9%
Maternal Mortality ratio	454/100,000	247/100,000
HIV prevalence	5.1%	9%

Source: Tanzania Census report, 2012, Demographic and Health Survey, 2010 & THMIS-2012

The REACT project

– The ‘REsponse to ACcountable priority setting for Trust in health systems’ (REACT) was a five-year (2006-2011), EU-funded intervention study. REACT introduced and assessed the application and effects of an intervention of priority setting informed by the ‘Accountability for Reasonableness’ (AFR) framework, an ethically-grounded framework for priority setting. The main objectives of REACT were to describe and evaluate district-level priority setting, develop and implement improvement strategies guided by AFR, and to measure the effects of the intervention on quality, equity and trust indicators. The study covered three districts in Kenya, Tanzania and Zambia. The present study describes only a limited part of the REACT-related research that was carried out in Mbarali district in Tanzania. The potential effects of the intervention were monitored within selected disease- and programme interventions such as HIV/AIDS, emergency obstetric care, etc. The project also monitored services within human resources and health-systems management (Byskov et al., 2009). The research team was interdisciplinary and approached the field of study with qualitative and quantitative research methods and within an action research framework.

The researchers in the project represented a number of research institutions in the Global North and the Global South (see annex 1). The author of this thesis is employed at the National Institute for Medical Research, Tanzania, which was one of the REACT partner

institutions. The AFR framework for priority setting in health care operates with four so-called ‘conditions’ for fair priority setting: ‘relevance’, ‘publicity’, ‘appeal’ and ‘enforcement’. A prime aim of the framework is to enhance stakeholder involvement in priority-setting and decision-making processes in health, as well as transparency regarding the information-sharing processes. The AFR framework informed the REACT project, but has not been actively drawn upon in the present PhD project.

Mbarali District was purposely chosen as the Tanzanian study district for the REACT project – and, in extension, for the present PhD project – due to its strong rural characteristics as well as for its location in Mbeya Region, one of the regions in Tanzania that are relatively highly affected by the HIV and AIDS endemic. According to the national HIV prevalence survey of 2012, the region was estimated to have an HIV prevalence of 9%, which is substantially higher than the national average of 5.1% (Tanzania Commission for AIDS et al., 2013). REACT had a key interest in the district level, which represents the level within the decentralized system where key policy implementers are located, e.g. district health managers and health facility care providers. Mbarali was found by the REACT management to be a suitable site for the introduction and implementation of the Accountability for Reasonableness (AFR) framework and the study of the role of health managers and health care providers in health-related priority setting and decision-making processes (Byskov et al., 2009). The present PhD project was founded within the frames of REACT. Parts of the data material on which this thesis is based were collected within the frames of REACT (Phase I) leading to Paper I, while other parts were collected outside of the frames of the REACT project (Phase II) leading to Papers II and III. The data collection for the Phase II study was also carried out in Mbarali District.

6.2. Study design

The present study has a qualitative design. In-depth interviews (IDIs) were the main data collection technique, supplemented by focus group discussions (FGDs) and informal discussion. Qualitative research is referred to as ‘naturalistic’ inquiry, studying ‘real-world settings’ inductively in order to generate rich narrative descriptions. Inductive analysis taking place across diverse cases yields research findings in terms of patterns and themes related to the area focused on (Patton, 2005). In any kind of research endeavour it is important to have an understanding of the contexts within which the study participants address the problem, but this is particularly vital in qualitative research (Creswell, 2007a:40).

A qualitative approach was chosen as the most appropriate data collection method for the present study as it has the potential of gaining particularly detailed and nuanced descriptions of the views and experiences of the study informants, in this case pertaining to health care decision-making and priority-setting processes at district level in Tanzania. A key feature of qualitative research methods is the flexibility of the design; for example, it allows for a follow-up of matters that arise during the interviews or discussions, and hence allows for the adding or deletion of particular study topics. The studies that formed the basis of this thesis were implemented in the following two phases:

Phase I: A study of the factors that influence fairness in health-related decision-making processes. The study was carried out in 2006 within the frames of the REACT project.

Phase two: A study of priority setting- and decision-making processes with a particular focus on the Prevention of mother-to-child transmission of HIV (PMTCT) programme. The study was carried out in 2011.

6.2.1.PHASE I

As a member of the REACT's qualitative team, I actively participated during all the project stages; from the conception of the project design, the research 'tool' development (such as interview guides), the data collection, data analysis and interpretation, during the write-up, of diverse aspects of the material beyond the material covered by the present thesis (Byskov et al., 2009, Maluka et al., 2010, Maluka et al., 2011, Njeru et al., 2011). The most central data collection during Phase I took place during October and November, 2006.

Preparatory activities

Before the fieldwork, the qualitative group members from the three African REACT partners and from five of the European and American REACT partners convened a series of meetings to develop the study objectives and the aims of the different project domains. Standard Operating Procedures (SOPs) were developed to guide and coordinate the data-collection process between the three countries. Data-collection guides were also discussed and developed during these meetings. The interview guides were to be employed in an open and flexible manner in order to obtain as rich/detailed descriptions as possible and, not least, be open for unexpected findings. They were nonetheless designed to give structure to the interviews, in a manner described by Kvale (2007:56).

The interview- and topic guides were to collect 'baseline data' on perceptions of fairness in priority setting and decision making, and on the potential influence of gender, wealth, ethnicity, education, age and religion on decision-making processes in health care. The aim of this part of the study was to generate knowledge on the manner in which such characteristics were (potentially) made relevant in local decision-making processes. Major themes addressed in these guides included: *The manner in which and the extent to which gender, a person's ethnic affiliation, economic status, educational level, age and*

religious affiliation are made relevant in decision making processes. Central in this part of the data collection was asking for concrete examples of situations within which these characteristics emerged as relevant for the course of decision making (see the interview guide Annex II). The themes belonged to the section of the REACT data collection guides that were addressed at district-, health facility-, and community levels. Local notions of fairness in decision-making contexts and to the procedures followed during decision-making processes were also explored in these interviews.

Fieldwork was preceded by a training seminar where researchers from the three study countries met and engaged in qualitative methods training. This was conducted in Mbeya Region, Tanzania, and was facilitated by senior qualitative scholars from the REACT project. In addition to lectures, activities such as role-plays of qualitative interviews and focus group discussion were carried out by the participants. A nearby health facility and community was visited where the interview guides were tried out in a real setting to gain familiarity with the application of the guides. Discussion and feedback were a central part of the seminar, with an emphasis on the sharing of experiences within the larger group. The author of this thesis was among the seminar participants and, although I had prior qualitative research training and experience, I benefited greatly from the seminar.

At the country level, a meeting was also convened in 2006 in Morogoro, Tanzania, to enable the project investigators from the diverse Tanzanian partner institutions (National Institute for Medical Research, Institute of Development Studies and Primary Health care Institute) to familiarise themselves with the data collection guides prior to the fieldwork. The interview guides were at this point also translated from English to Kiswahili, Tanzania's national language, with substantial emphasis on retaining the original meaning of the questions raised.

After obtaining the ethical clearance, the next step implied getting to know the study area, Mbarali District. The researchers travelled to Mbarali District where the REACT country co-ordinator introduced the study team, the project, and its overall aims to the District Health Management Team. The project subsequently commenced with the collection of the project's 'baseline' information. I was part of the team collecting baseline data in Mbarali District in 2006, a study which formed the basis for Phase I of the present thesis and which led to the development of Paper 1.

Recruitment of the study participants

Purposive sampling was employed to recruit the informants. This sampling procedure is among the characteristics of qualitative approaches. It assists the researcher to recruit informants with a relevant background, who, in an informed manner, can help to shed light on the research questions (Creswell, 2007a). Participants with diverse backgrounds, knowledge and experience pertaining to the research topic were sought. Categories of informants to be recruited and from what levels, and the tentative number of informants to be included had been decided upon during the preparatory phases. The (subjective) principle of 'saturation' guided the actual process of recruiting the informants; i.e. the interview process was closed when there was a sense of repetition of the major emerging themes and when substantial richness and nuance in the data material had been reached. The REACT investigators, in close collaboration with the Mbarali District Medical Officer (DMO), discussed and agreed upon the criteria for the recruitment of the informants. Experience with participation in priority setting- or health-related decision-making processes remained an important criterion at the different levels of data collection throughout the research process. Informants were recruited at district-, health facility- and community levels. At community level, literacy and being influential in their respective localities were the main criteria. In total, 33 informants were included in the qualitative

base line study in Mbarali Tanzania, of which 23 participated in individual interviews (cf. Table 4) and 10 in a focus group discussion.

Table 4: Data collection techniques and categories of informants

Data collection technique	Level	Type of informants	Number
In-depth interviews	District	Members from the health department	7
		Members from non-health departments	4
	Health facility	Health care providers	7
	Community	Influential people	5
Focus group discussion	District	Members from the health department	10
Total			33

Most of the district-level informants were core and ‘co-opted’ members of the Council Health Management Team (CHMT). Those co-opted included the Malaria focal person, District AIDS Co-ordinator, and Reproductive and the Child Health Coordinator. Other informants at district level were central district officials (the Chairman of the District Council, District Planning Officer and District Administrative Secretary) as well as representatives of non-governmental organisations (NGOs). Health facility-based informants included health workers, particularly managers who were heads of the selected health facilities.

There were few women among the informants, despite an effort to recruit women (only two women took part in the FGD and only five of the 23 interviewed), making manifest the poor gender balance in the decision-making bodies. It was equally difficult to get

adequate numbers of women to take part in the interviews at the community level. This was explained as women not being used to making decisions outside the household and local community arena.

Data collection

In-depth interviews

In-depth interviews (IDIs) were conducted with the informants recruited from the district, health facility and community levels. IDI is one of the most commonly employed approaches in qualitative knowledge production. During IDIs individuals are to provide knowledge, views or opinions and experiences regarding the particular phenomenon under investigation (Kvale, 2007). The information that is presented by the informant is produced through the interaction between the interviewee/informant and the interviewer. Together with one of my co-supervisors (from the Institute of Development Studies of the University of Dar es Salaam and the country REACT co-ordinator for Tanzania), I carried out all the qualitative interviews in Mbarali during Phase I. Two members from the northern REACT partner institutions (Centre for International Health, University of Bergen, Norway), including my main supervisor, visited the field site during the initial stages of the data collection to discuss the progress of the fieldwork and the initial findings (these partners were conversant with Swahili).

Before the data collection started, appointments were made with the informants. During the initial phase of the interview encounters with the informants the informed consent form was read out loud; the project objectives were discussed before the informants were asked to sign the consent form. None of the individuals asked to participate declined. It was requested that the interviews be recorded. Three informants did not wish to have their interviews audio-recorded, in these cases rapid note-taking sought to capture the central content. Those who did not consent to being recorded were all women. One of

these women was very open and articulate, but said she would feel unsafe in providing the information if it was recorded. The others who did not wish to have their interviews audio-taped seemed to refuse out of shyness. The interviewer made efforts to make the interview environment friendly and relaxed by starting with typical Tanzanian small talk. During the interviews at the district level the discussion by and large emerged as smooth and relaxed. All the informants recruited were actively engaged in priority-setting and decision-making processes, and had ample experience to draw upon and to share. They eagerly engaged in and explained the intricacies of decision-making processes and the many challenges encountered. The community informants were less vocal than the other categories of informants, most likely due to the fact that they were less consulted to voicing their health-related concerns during the decision-making processes at district level. However, the community informants expressed that they were happy to be included in the study. For them, this implied a rare opportunity to voice their opinions and concerns about the dynamics at work in decision-making processes.

The researcher made an effort to establish a good environment for the various discussions. She followed prevailing dress codes at the various levels, acted in a polite and humble manner, and showed interest and respect for the opinions and information that was provided. Whereas the interviews with district and health facility informants were conducted in their respective office premises, the interviews with the community informants were conducted in their homes. In all venues, a quiet room/place was asked for to allow for undisturbed discussions and audio recordings. By and large quiet venues were provided. During all the interviews the researcher was cautious to let the informants reflect at length – whenever the informant managed to do so – over the topics raised. Each evening, researchers reviewed the IDIs' content and unexpected challenges to further improve or deepen the upcoming interviews.

The focus group discussions

After all the individual interviews were completed, one fairly large focus group discussion (FGD) was convened with 10 members of the Council Health Management Team (CHMT). Both core and co-opted members of the CHMT took part. The aim was to ‘confirm’, complement, nuance and challenge the knowledge gained during the IDIs by discussing central patterns in the findings, unclear findings, apparent contradictions, etc. The FGD was arranged during the last week of the fieldwork. The FGD had both male and female participants, albeit fewer women than men, as stated above. The discussion was facilitated by the REACT country co-ordinator while I took notes and ensured the smooth recording of the discussion. The facilitator explained the objective of the study before each member briefly introduced themselves. We were cautious about names and asked the participants to keep the information provided within the group.

The topic guide provided the same general questions as had been discussed during the IDIs but probing was done on the specific areas that emerged in the interviews, for example about gender discrimination that featured in all interviews, groups of people perceived to be wealthy, the role of older people and the power of councillors vs. their lower level of education, etc. In addition, a lengthy discussion was held on the topic of *‘What is fairness and what characterises fairness in priority setting and decision-making processes at district level?’* These notions were in turn linked to the potential influence of gender, wealth, ethnicity, education, religion and age in district-level decision making. The discussion was recorded with consent from the participants.

Informal discussions

Informal discussions took place after the formal interviews, commonly after the audio recorder had been switched off, as well as during informal encounters during the fieldwork period. The discussions commonly centred on various dimensions of the

bureaucratic procedures in the decision-making processes. Substantial knowledge was gained during these informal talks, including more information on topics that emerged as difficult during the more formal interview context. The informal talks also provided information of a more general kind, including a number of illustrations and examples which deepened the understanding of the information that emerged during the interviews. Detailed handwritten field notes covering the content of such informal talks were made on a daily basis during the fieldwork period.

6.2.1.1. Data transcription and analysis

The recordings from the interviews and FGDs were transcribed verbatim into Swahili by an experienced social scientist recruited from the University of Dar es Salaam. The transcriptions were later translated from Swahili to English. During the first round, the transcription was very poor, and the material in practice remained almost useless. The interviews thus had to be re-transcribed; this time discussion revolved around retaining the culturally-embedded expressions and meanings. The process was carefully monitored by the author of the thesis who is conversant in both languages.

Since the prime part of the analysis actually takes place in the field, the research team discussed the findings after each interview during the fieldwork in order to discover new issues and questions that were brought up. Thereafter, a very different phase of analysis took place after the closing of the fieldwork and the transcriptions had been completed. During this phase familiarisation with the data was a first step. Both key researchers carefully read all the transcripts and all the field-notes, and listened to all the recordings in order to gain comprehension of the full material and the main themes emerging when all the data had been reviewed. It was deemed important to get an understanding of the core topics in the material through such a thorough scrutinising process before embarking on the detailed coding process in order not to lose sight of the main findings, as called for in qualitative analysis (Kondracki and Wellman, 2002).

During the next step, a time-consuming round of manual coding of the entire data set was carried out in a search for information on local perceptions on fairness in decision-making processes as well as those related to the potential influence of gender, ethnicity, wealth, age, religion, and education on decision making – themes that had been located at the core of the interviews. The detailed coding process entailed the review of each sentence and paragraph of text, creating codes that condensed the meaning of the section. Words or concepts were chosen that were closely related to the content of the piece of text it referred to, commonly using a part of a statement. The codes were noted down in the margins of the transcripts such as ‘fairness implies following rules and regulations’, ‘women have less capacity than men’, ‘women cannot make strong points’, ‘rich people are intelligent’, ‘old people have been passed by time’, etc. The numerous codes were subsequently grouped into the categories that were pre-defined in the data collection guide (such as gender, wealth, ethnicity, education, etc).

6.2 .2. PHASE II

The second study phase took place in the same district and with an emphasis on the PMTCT project, but was located outside the frames of the REACT project. This part of the project implied a major data collection phase from January to April 2011.

Preparatory activities

In preparation, interview guides were developed and discussed with the main supervisor. Different guides were developed for different levels of informants (regional, district, health facility and community), but the main themes to be explored remained the same (cf. Annex III). The guides had two main sections: (i) planning and priority setting and (ii) information communication pertaining to the PMTCT programme. In the first section, the interviews and focus group discussions aimed to generate a broad understanding of the experiences with priority setting, planning and decision-making processes within the

PMTCT interventions in Mbeya Region, with a specific focus on Mbarali district. Since the decentralisation policy is implemented in all Tanzanian districts, an assessment of the manner in which local priorities were brought on board during the planning phases of the programme was of particular interest. Central themes in this part of the interviews included: *mechanisms of setting priorities related to PMTCT in the planning process at district level; types of planning existed, budget allocation for PMTCT activities; the sources of funds for the planned PMTCT activities; potential experience with consultation during the prioritisation process; potential challenges encountered in the setting of priorities within the PMTCT programme* (refer to Annex III). In the second section, the guides aimed at assessing stakeholders' understanding of the various changes or modifications that had taken place in terms of shifts of global infant feeding recommendations, and their experience with the communication of the continuously changing content of the guidelines. Central topics addressed in the interview guide were: *awareness about the major changes in the infant feeding options for the HIV-infected mothers; information provided to the stakeholders about the major shifts in recommendation; reflections on the changes and on challenges experienced in the communication of the modifications in the infant feeding guidelines* (refer Annex III).

The original interview guide did not focus specifically on the content of the diverse infant feeding guidelines but, rather, assessed the understanding of the challenges and opportunities in implementing the PMTCT guidelines, the involvement in the development of the guidelines and how different recommendations were communicated to different stakeholders. The substantial interest the informants revealed for the content of the continuously changing infant feeding guidelines, and the processes linked to the challenges of the communication of these modifications, however, implied an incorporation of these topics, including the development of additional questions relating to these issues, in the interview guide (Annex III).

Two research assistants were recruited for this part of the study. The research assistants were assigned different tasks: one assisted in managing the digital recording and carried out note taking on observations during the interviews and discussions; the other was responsible for data transcription while still in the field. Both assistants had a bachelor degree in Social Science from the University of Dar es Salaam, and had substantial experience with qualitative data collection and transcription. A three-day workshop was held for the research assistants at the National Institute for Medical Research (NIMR) headquarters in early January 2011 to inform about the study, discuss the objectives of the study, the different categories of informants targeted for the interviews and the discussions, the data collection methods, and the research ethic dimensions of the study. We also jointly reviewed the English version of the data collection tools, tools that were later translated to Swahili. The team members travelled together to the study site (Mbarali District) where we met the District Medical Officer (DMO). The principal researcher introduced the team members and the objectives of the study. The relationship between the REACT project (Phase I) and the sub-project focusing on decision making and communication within the PMTCT programme (Phase II) was also carefully described during this visit.

Recruitment of study participants

During Phase II, study participants were recruited at regional-, district-, health facility- and community levels (Table 4). It was of prime interest to assess how the responses evolved and compared from one level of informants to the next.

At the district level, the District Medical Officer (DMO) invited the District AIDS Control Co-ordinator (DACC) into the discussion about the coming study. The participants to be recruited to the study included individuals within the health care system with experience in managing the PMTCT programme or in working practically with the PMTC programme. At the regional level, the DMO assisted with the recruitment of three

informants leading the HIV/AIDS, RCH and PMTCT sections in Mbeya region, while at the district level nine informants were recruited, the majority being the core and co-opted CHMT members; others were from the Tanzania Commission for AIDS focal person and a representative from a Non-Governmental Organisation. The majority of the recruited individuals were also interviewed during the first phase of REACT project.

The District AIDS Co-ordinator assisted in the recruitment of the health facility informants managing the PMTCT services. Rural-urban considerations were made in this part of the recruitment process. For example, of the ten PMTCT in-charges/leaders recruited at health facility level, five were from rural and five from urban health facilities. At the hospital facilities, 22 health care providers were recruited from different departments such as the pharmacy-, laboratory-, maternity- and reproductive and child health departments for focus group discussions. All these latter participants played either direct or indirect roles in the PMTCT programme. Among them, 10 individuals were from a faith-based hospital and 12 from the government hospital in the district.

At the community level, the researcher was accompanied by the DACC to all the selected health facilities. The researcher explained the purpose of the study to those in charge of the PMTCT services and the categories of informants that we were particularly interested in talking to. The PMTCT in-charges thereafter facilitated the recruitment of the community informants from within the facility catchment areas. The individuals enrolled in the study at community level were HIV-infected mothers enrolled in the PMTCT programme (5 were pregnant and 8 were breastfeeding), pregnant mothers of unknown sero status (20), traditional birth attendants (TBAs) (3 rural, 4 urban) and community leaders (18) (Table 5). Community leaders facilitated identification of the TBAs in their respective areas.

Table 5: Data collection techniques and categories of informants

Data method	collection	Types and number of informants	Total no. of informants/groups
In-depth interviews		Health facility (PMTCT in-charges) (10) HIV-infected mothers (13) District managers (9) Regional managers (3)	35
Focus discussions	Group	Two groups of health facility workers with 10 and 12 participants respectively Community leaders; two groups (10 and 8 participants) Pregnant mothers; two groups (10 participants each) Traditional birth attendants; two groups, (participants; 3 rural and 4 urban)	8 groups

Data collection

In-depth interviews and focus group discussions were employed in the collection of the data, as outlined in Table 5. The information, broadly separated under two separate sections, was collected at the same time and thus incorporated in the same interview- and topic guides for each level of informants. Although the topic guides were similar, the questions were raised in slightly different ways with fewer questions so as to allow the group participants to discuss among themselves. The author of this thesis carried out all the interviews and moderated all FGDs during Phase II.

In-depth interviews (IDIs)

Experiences from the interviews carried out during Phase I, were drawn upon during the Phase II of the study. At an overarching level, the same procedure was followed. Proper self introduction was carried out before the start of each interview; the investigator explained the objective of the study and read the informed consent form out loud. Also during Phase II, all the individuals asked to take part in the study had consented because they were first approached by the respective in-charges of the areas as explained in the recruitment section. Consent was sought to record the interviews and everyone consented. During the interviews, the informants at district and health facility levels were by and large active and articulate when discussing prioritisation and information-sharing processes related to PMTCT; they were knowledgeable and had many thoughts and opinions about the topic. The district level informants were naturally far more aware of or informed about the prioritisation processes pertaining to the PMTCT programme than the health facility informants since they were the ones who solicited the priorities from the different departments before going to the district planning sessions. Health workers employed at faith-based facilities were less informed about the prioritisation processes than their governmental counterparts, as they remained somewhat on the outside and were rarely directly involved in district level decision-making processes.

During the course of the interview new topics emerged. For example, during the interview with the managers, information emerged about a separate PMTCT plan that was prepared at the regional level – information with substantial impact on the dynamics of the decision-making process. This necessitated probing about the role of the plan, how it was prepared, who was involved in its preparation, what priority areas were covered by the plan, the sponsors of the plan, etc. Likewise, regarding the challenges in implementing the PMTCT guidelines, the informants cited examples reflecting the infant feeding recommendations in a manner that made it important to add further questions and carry out further probing in the respective areas.

The interviews with regional- and district-level managers and with health facility workers were conducted in their respective offices, including offices at the health facilities. To avoid interference with their work, most interviews were conducted in the late afternoon and some in the evening hours. The researcher provided soft drinks during the discussions.

Despite the fact that the information collected from community level does not directly emerge in Papers II or III, this category of informants has importantly informed the study in terms of a general understanding of the topic in question. The interviews were conducted in the homes of the study participants as well as at the health facilities. The community women revealed substantial trust in care providers employed at the health facilities, hence no one declined after being approached by the PMTCT in-charges in their respective areas. Whether in the homes or at the health facilities, a quiet place was sought to avoid disturbance and to make sure that no one could listen in on the discussion. The mothers did not want to be seen by other people while taking part in interviews, hence a private room was particularly sought for these talks. At the start of the interviews the mothers responded to the questions in a very low tone, they appeared shy, and fearful that the prying ears could get to know the details of their responses. However, as the interviews progressed, most of the mothers emerged as outspoken and appeared to freely express themselves. They did not seem to find the questions about prioritisation and decision-making processes and information sharing to be sensitive. A digital recorder was used to record the conversation after obtaining consent from the participants. However, six informants (three at community level and three at health facility level) were not recorded due to technical problems. During these interviews the research assistant wrote rapid handwritten notes. The notes were carefully reviewed and refined in detail by the main researcher and the research assistant immediately after the interviews had taken place. The interviews lasted between one and two hours each. Not

surprisingly maybe, the informants at community level were more informed and had more opinions about the changing infant feeding policy than about the degree of participation in prioritisation- and decision-making processes, the central focus of the present study.

Focus group discussions (FGDs)

A total of eight FGDs were conducted: two with health care providers, two with community leaders, two with pregnant mothers of unknown HIV status and two with traditional birth attendants. Six groups had from 8 to 12 participants while two had from 3 to 4 participants. The primary aim of the FGDs was to raise questions based on the knowledge gained in the IDIs in order to further broaden the understanding – in terms of seeking confirmation of key findings, nuanced or potential contradiction of views. Before the discussions started, the moderator and the note-taker as well as the participants introduced themselves. Each participant was given a number to ease the discussion and coding process, and to ensure anonymity. The participants were kindly asked to allow recording of the discussion and the participants in all the groups consented. All FGDs were moderated by the author of the thesis with an assistant handling the recording and note taking. Short topic guides were used during the focus group discussions (see Annex III). The moderator introduced the topics in question and encouraged the informants to reflect broadly on the topics among themselves. It was attempted to give every participant an opportunity to contribute, and to reduce the chance that particular individuals dominated the discussion. A brief description of the FGD's that generated knowledge drawn upon in the articles is provided below.

The FGDs with the health care providers were held in hospital settings. It was found appropriate to conduct these two FGDs within the hospital premises. The groups were composed of both male and female health care providers. By and large the participants

willingly presented their experiences regarding prioritisation and decision-making processes, and the communication of HIV-related infant feeding recommendations. The participants at the public hospital were noted to be far more active and vocal than those who participated at the faith-based facility, leading to the polite encouragement of a more active role by the moderator while probing and asking for examples and experiences. A similar scenario featured in the IDIs as presented above. The major topics that emerged during the discussion were largely in line with the knowledge gained during the IDIs.

The two FGDs with community leaders were conducted in their respective offices. The majority of the participants in this category were males. Most of the participants from the urban setting were more articulate and more aware of the prioritisation- and decision-making processes than their counterparts from the rural setting. This seemed to be partly related to the fact that they had been consulted by the DMO to submit their health-related priority areas, which had provided them with some contact with the district priority-setting processes. It was also of interest that the leaders from urban setting were largely aware of the various infant feeding recommendations and therefore examples of the debate centred around them. FGDs with pregnant mothers and traditional birth attendants (TBAs) were also carried out. Information gained was to some extent useful, but is not included in the articles because participants were less informed of the prioritisation and decision-making processes. They discussed in depth the infant feeding recommendations and the implementation challenges. They will therefore not be discussed further.

All the focus group discussions lasted between one and two hours and all were audio recorded. Figure 3 provides an overview over the different components of Phases I and II

of the study.

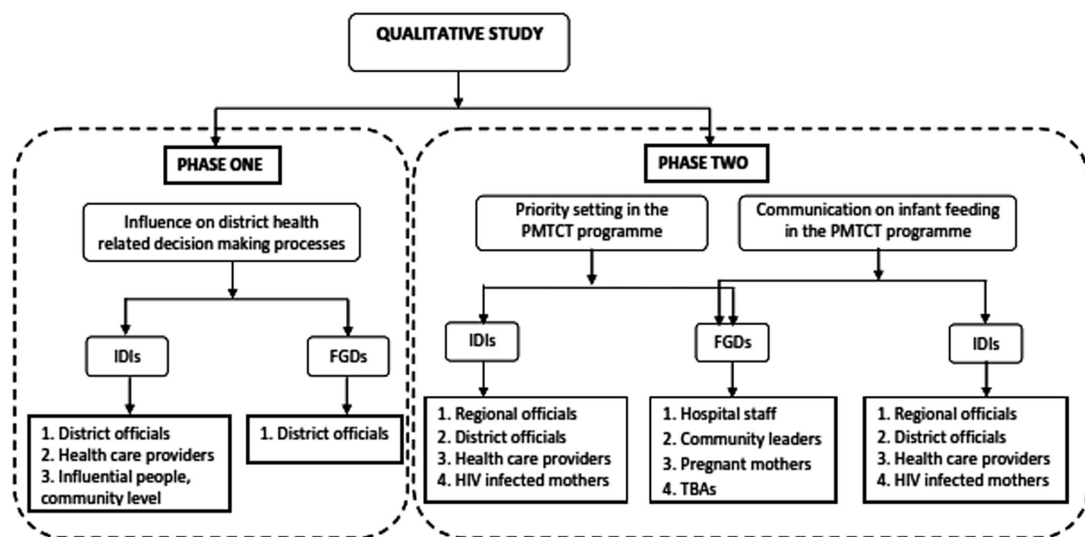


Fig 3. Graphic presentation of data collection techniques and categories of informants in phase I and II of the study

The audio-taped interviews and focus group discussions were transcribed verbatim into ‘a written discourse’, as suggested by Kvale (2007) and Malterud (2001). This time-consuming task was carried out by a competent social scientist, learning the hard way after the difficult experience from Phase I. As the transcriber joined me in the field, the transcription exercise started during the fieldwork, which made close follow-up of the process possible.

6.2.2.1. Data analysis

As with the information gained during Phase I, the data analysis and interpretation for both IDIs and FGDs started during the fieldwork period. After the interviews and discussions, important conversations took place between the research assistant and the researcher about emerging themes, any lack of clarity, apparent contradictions, etc. These reflections were carried along to the next interview/FGD, occasionally leading to new questions and follow-ups. Thus continuous analysis and interpretation of the data took place from the very beginning of the first interview, and continued throughout the fieldwork. This is in line with what is spelled out as a key principle in qualitative analysis (Giorgi, 1985).

As for the Phase I interviews, a second phase of interpretation and analysis was carried out during the post data-collection period. At this point content analysis was more explicitly drawn upon than during Phase I. The researcher carefully read all the transcripts and the handwritten notes, and listened to all the recordings in order to get a sense of the whole material (Tesch, 1990). As defined by Hsieh and Shannon (2005), content analysis implies the interpretation of the content of textual data through the systematic classification process of coding and the identification of patterns and themes (Hsieh and Shannon, 2005:1278). After the completion of the reading of all the transcripts and notes, and having listened to the recordings in attempts to get a sense of the full data set, the researcher immersed herself in the coding process. The time-consuming detailed coding process was carried out manually during two separate processes, following up on the major themes for Papers II and III respectively:

Step I: Stakeholders' participation in planning and priority setting in the context of a decentralized health care system: the case of prevention of mother-to-child transmission of HIV programme in Tanzania

Step II: Challenges of disseminating clinical practice guidelines in a weak health system: the case of HIV and infant feeding recommendations in Tanzania.

In both steps of the analysis, the codes marked in the margins of the paper pages were derived from the data, and commonly implied the writing down of concrete and central expressions that the informants had used. The quotations helped to bring the voice of the participants into the text, as suggested by Creswell (2007a:182). The long lists of codes were shared and discussed with the main supervisor. Thereafter, the codes were sorted into categories. During Step I, analysis some of the key categories that emerged were: *plans that accommodate PMTCT activity; donors' influence, the influence of the Ministry of Health, non-inclusion of local priorities, limited knowledge of the planning process, communication gap*. These were later grouped into major themes such as: *experience with priority setting related to PMTCT; challenges of including PMTCT activities in the district health plan; challenges pertaining to the inclusion of PMTCT activities in the regional plan; challenges of the district health planning team; etc.*

In the Step II analysis, brief quotes or summaries of the content were noted in the margins of the transcripts. The following categories were formed after the coding process: *confusion regarding infant feeding recommendation; rationale behind the diverse infant feeding recommendations; language barriers; lack of a reading culture; lack of graspable updates; lack of interdepartmental collaboration*. These categories were later grouped and located within the major themes pre-determined by the data collection guides: *knowledge on the infant feeding recommendations and communication challenges*. Recurring issues or patterns, as well as nuances, ambiguities or contradictions within the emerging categories, were systematically sought during each phase of analysis; for example, the ambiguity regarding consultation in the prioritization process. While the

higher level managers said they had consulted lower staff, the lower staff refuted this, and each level complained that the next level had contributed to the non-inclusion of the local priorities. While facility workers directed their complaints to the CHMT, the CHMT on their part directed their complaints to the regional secretariat, and regional secretariat directed the complaints to donors and ministry of health for directing them to include new activities in the plan that were not initially planned for. The figure below summarises the analysis process.

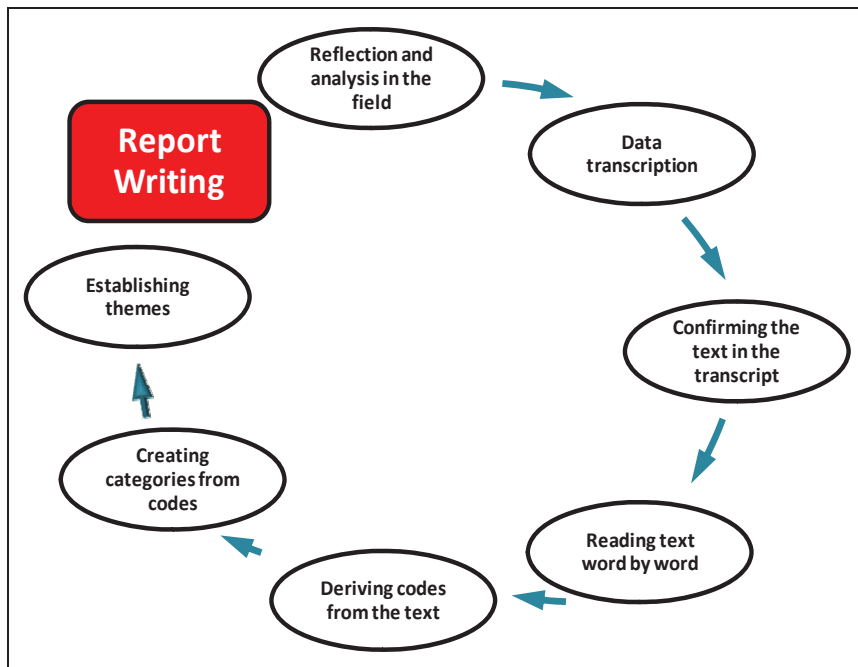


Fig 4: *Data analysis flow*

6.3. Ethics

The study received ethical approval from the Medical Research Co-ordinating Committee of the National Institute for Medical Research (NIMR), Tanzania (Phase I, NIMR/HQ/R.8a/Vol. 1X/ 416 (Annex IV), and for Phase II NIMR/HQ/R.8a/Vol. IX/1094) (Annex V). During both Phase I and Phase II of the study, permission was also obtained from the Mbeya regional and Mbarali district authorities. Within the frames of the REACT project, standard operating procedures (SOPs) were developed on the data use. Due to the complexity of the project, a scientific committee responsible for the overall data management was established to avoid overlaps and conflicts pertaining to the usage of the data. Publishing health-related data from Tanzania requires permission from the Director General of NIMR. Permission was granted for Papers I, II and III.

Informed consent

The consent form, written in Swahili, included information about the objectives of the study, expected benefits of the study, as well as issues of confidentiality, anonymity and the right of the participants to withdraw from the study at any time they so wished without any consequences, in line with general research ethics conduct (Creswell, 2007a:123). The researcher read the consent form out loud to all informants, thus allowing the informants to get to know the aim of the project and their rights in connection with participation in the study (Annexes VI & VII). Written- and verbal informed consent was sought in Phases I and II respectively. Informants were further fully assured that participation in the study was voluntary and that it would have no implications whatsoever if they did not wish to take part or if they wished to reply to merely parts of the questions. The informants were assured that no name would appear in any of the resulting documents and, hence, they would remain anonymous. In connection with the HIV-positive informants, particular care was taken to ensure that their participation remained hidden and, because of the continued stigma linked to the diagnosis, no one could listen in on the discussion.

7. BRIEF SUMMARY OF THE FINDINGS

This chapter provides a very brief summary of the main study findings. The findings presented under the heading Phase I correspond with the themes in Paper I, whereas the findings presented under Phase II correspond with Papers II and II. The presentation briefly mentions findings that were not incorporated in the papers.

7.1.PHASE I

Paper 1: Challenges to fair decision-making processes in the context of the healthcare services

Paper I describes the decision-making structures in the Tanzania bureaucracy, explores the potential influence of stakeholders' gender, wealth, ethnicity, education, religion and age on contributions in health-related decision-making processes.

Local concepts of fairness in decision-making processes

The decision-making processes at district level in Tanzania follow a relatively clear structure. At the top is the District Full Council, the final decision-making body at district level. The District Full Council approves decisions that have been raised by representatives of the diverse administrative committees located from the community to the district level within the decentralized health care system. This process was designed to facilitate grassroots participation and fairness (*haki* in Swahili) in decision-making processes.

Thoughts regarding the content of the concept of 'fairness' or '*haki*' in the decision-making processes were located at the core of the discussions. At the district- and health-facility levels, fair decision-making processes were strongly linked to processes that follow established or agreed rules. Informants would, moreover, emphasise how a

process deemed fair would ensure the involvement of relevant stakeholders, and were reluctant to accept a disproportionately large share of attention to be given to particular categories of individuals. Every stakeholder should ideally be given an equal opportunity to contribute to and to be heard in decision-making processes that are relevant to them. The informants at district and health facility levels also talked strongly in favour of a majority vote as a prime principle to ensure *haki*.

A general concern was raised, particularly by the health facility informants, that although the decentralized system is designed to ensure community-driven approaches, the system does not operate properly when the committees that are to ensure feedback are not functioning. The committees located at the health facilities were commonly found to be inactive, hence starkly limiting their potential roles in communicating facility experience and needs to the district level. This was noted to be true of the committees located at the community level as well, particularly in the geographical periphery. The implication was that health care needs were commonly discussed by the CHMT (Council Health Management Team) without feedback from communities and health facilities that had not managed to communicate their input. District level informants, on their side, acknowledged that they were not able to properly involve the community- and health facility committee members in district decision-making processes, not least during the planning phases. This was partly related to time constraints in the budget sessions, and partly due to a culture of limited grassroots involvement. Space restraints prevented the above findings being reported fully in Paper I.

The potential influence on health-related decision-making processes of gender, economic status, ethnicity, education, religion and age was scrutinized at the district, health facility and community levels. The interviews followed a pattern that largely generated ‘politically correct’ replies during the early phases of the interviews, before more nuanced, ambiguous and at times, apparently contradictory information emerged.

Pertaining to the issue of *gender*, informants at the district level would instantly communicate that they were aware of the requirements of the present guidelines in terms of inclusion of certain numbers of women in every district level decision-making body. The majority of informants would also hold that the guidelines pertaining to the recruitment of particular numbers of women were properly followed. They moreover argued that women were today located at the core of the decision-making processes. On further scrutiny, however, a majority of the informants seemed to backtrack and explain that women were in fact still under-represented in many decision-making bodies. In their explanations it also emerged that there was a high level of distrust of women's contributions. Thus, even when actively involved, women's views were not necessarily taken into consideration in the same manner as input from their male counterparts. This challenge was strongly confirmed by the female informants at district level who narrated that their input was commonly either ignored or not taken seriously.

Several of the informants, indeed, explained that oppression and harassment of women was also part of the political decision-making processes at district level. Diverse reasons were mentioned for the common lack of equal influence for female representatives in decision-making processes. It was reported that many women had yet to gain sufficient confidence in making up their mind, and in presenting 'strong points'. As women commonly had limited public exposure, they often appeared shy in decision-making contexts, informants argued. The situation was also explained in terms of women's lack of adequate skills and generally lower levels of training and education than their male counterparts. Lack of interest in certain district positions was also mentioned as part of gender-based hindrances. Remnants of what may at a very broad level be referred to as 'patriarchal attitudes' emerged among informants at every level; some male informants would question the intellectual capacity of women, and insisted that some skills or activities were rather masculine in nature and hence unsuited for the female cadre.

Attitudes questioning women's relevance/suitability in decision-making contexts were far more pronounced at community level than at higher administrative levels.

At the district and health facility levels, a person's *affluence or economic status* was said to have very limited influence on the people's actual impact on decision-making processes. It was strongly argued that what mattered was the power of the arguments of an individual, and not their wealth. At the community level, a majority of the informants did however assert that, since time immemorial, the wealthy have exerted undue influence in decision-making processes, both directly and indirectly. Moreover, at this level, there were strong perceptions that wealthy individuals were more intelligent than the poor. They were talked of as 'better fed', thus enhancing their capacity to engage in wiser and more complex thinking. Among community members these notions were embraced as not only logical but also made it fair to include wealthy individuals in decision-making contexts to a larger extent than the poor.

Pertaining to the potential influence of *ethnicity*, district and health facility informants instantly referred to the enormous emphasis former President J Nyerere had placed on reducing ethnic and kinship influence since the time of independence. There was strong awareness of the dangers of tribalism. The formal requirements were also explained to be strong in terms of regulations that also guide the ethnic composition of decision-making bodies. This has led to a mix of ethnic groups within the governmental system which precludes the dominance of certain ethnic categories in decision making. At the community level, however, ethnic or clan-based influence was apparent; for example, the informants reported that the largest clan, particularly wealthier individuals of a certain major clan, exploited and even oppressed members of other clans. Hence there seem to be remaining traits of discrimination based on ethnic or clan affiliation on lower levels.

The impact of formal education pertaining to decision-making processes was also assessed. It was, on the one hand, expressed to be both natural and right for individuals

with higher educational levels to have more influence in decision-making processes than individuals with lower levels of education, as these were individuals who had worked hard to gain particular competence or expertise within their fields. On the other hand, the occasional undue influence of a particular category of largely-uneducated individuals, namely the councillors, was addressed by many of the informants. The councillors are elected to represent the ward level and, hence, represent the grassroots level in the district. These individuals are commonly awarded extensive power to approve or disapprove district level decisions, also on issues which they may not be well equipped to make informed decisions about, informants explained. Opinions varied sharply on whether or not the substantial influence of the councillors should be considered as fair. The potential impact of *age* and *religion* on decision-making processes were also investigated in this part of the study. Regardless of the administrative level of scrutiny, the informants argued that it was only in the past that age was an important factor in decision making; its importance had waned in the current generation. All the categories of informants expressed that a person's religious affiliation had minimal influence on decision-making processes in Mbarali district.

7.2. PHASE II

Paper 2: Stakeholders' participation in planning and priority-setting in the context of a decentralised health care system

This part of the study sought to assess potential experience of lower-level stakeholders in the priority setting- and decision-making processes of the PMTCT programme. The findings revealed that PMTCT activities in principle could be accommodated within the comprehensive council health plan (CCHP) as well as within the regional PMTCT plans. However a large number of challenges were voiced by informants about the inclusion of lower-level priorities within both plans.

Substantial confusion was reported at diverse levels with regard to who was consulted in the priority-setting processes. The regional managers asserted that they sought input from the district level when developing the regional plan, but the district informants challenged this notion. The priorities established from the different health departments and from health facility level were, in a similar vein, reportedly discussed by the CHMT, information often refuted by the PMTCT leaders at the local health facilities. Except for the informants at the district hospital, the informants from other health facilities unanimously upheld that they had never been asked to bring forth their priorities related to the PMTCT programme. Communication gaps were also found between the people in charge of the PMTCT activities and the representatives in charge of the priority and planning sessions.

The HIV-infected mothers, expectant mothers and traditional birth attendants were altogether unaware of the prioritisation process, and explained that they had not been consulted regarding their views on the priorities or challenges they faced in the PMTCT programme. Some of the community leaders said that they had been asked by the District Medical Officer (DMO) (in 2009 and 2010) to submit their lists of health priorities and had been assured that they would be considered, but explained that none of their input had been accommodated in the final plans. Health facility workers on their part expressed that, although they did involve community leaders in the priority-setting processes, they often received little input from them, as most of the leaders felt incompetent in such contexts, and simply responded *'Yes, just as you have said'* when asked for their opinions. Within the study on the PMTCT, a discrepancy between administrative ideals of inclusion of lower level views and what actually happened were thus often found to be at odds.

Informants reported that, although the district in principle had two main sources of

funding (the basket funding and the block grants), health-related planning would largely rely on basket funding with stringent guidelines, which regulated the allocation of the funds. The Comprehensive Council Health Plan (CCHP) was said to be consistently reviewed by the regional secretariat to ensure conformity with national planning guidelines before it was approved by the district's Full Council. During this process, the list of priorities made at the district level was said to be subjected to substantial alterations. In the context of the PMTCT programme, most of the proposed activities were weeded out as the programme was recognized as donor-funded, creating associations of abundant funding. In a context of a more-than-tight district budget, the donor-funded domains were thus removed from the activities they funded.

A key challenge was that the regional managers did not dare to speak up when the donors' priorities were at odds with local priorities. The regional team appeared, rather, to be intent on reflecting the donors' priorities, which at the point of the research emphasised 'coverage' of the PMTCT programme – thus a broad roll-out and not the follow-up of the existing programmes. In consequence, local PMTCT priorities were conspicuously absent from the final regional plan. In the context of donor funding, the PMTCT programme was thus not able to stick to the priorities made by the district and the health facilities that were running the PMTCT programme on the ground. The perception of the PMTCT as a 'vertical programme', and hence as donor-funded, seemed to generate substantial challenges regarding the inclusion of locally-prioritised project activities in the present district. A number of other factors were found to further complicate the picture. It was, for example, reported that there was limited practical knowledge among the district planning team members about how to plan using the allocated ceiling and the means of defending prioritisation of activities that were perceived to be costly.

Paper 3: Challenges of disseminating clinical practice guidelines in a weak health system: The case of HIV and infant feeding recommendations in Tanzania

This sub-study aimed to explore the ways in which knowledge in terms of global health guidelines developed at the global level feed into local health policy and practice. In our study this implied specifically the exploration of how such global knowledge on infant feeding for HIV infected mothers is communicated to lower level stakeholders in the health care system. In the process, it was scrutinized how the major PMTCT policies conceived at the global level were understood at local level and, in turn, were related to by actors from regional to community levels. For the lack of space, the community level material was not included in Paper III

A majority of the informants at the regional, district and health facility levels were aware of the major policy shifts on infant feeding that had taken place within the frames of the PMTCT programme since its introduction in 2000. However, a large number of quite serious misunderstandings or misconceptions were encountered from the regional level and down to the district-, health facility- and community levels, with substantial implications for the health services. Whereas the WHO 2000 guidelines recommended exclusive replacement feeding as the first option and exclusive breastfeeding as the second option for HIV-infected mothers, informants, including those placed as high as the regional level, said the guidelines solely promoted replacement feeding, and thus had not grasped that exclusive breastfeeding was already an option at this point. The HIV-infected women were, therefore, commonly presented with no infant feeding choice beyond formula feeding, a practice creating severe challenges as a large majority of the women were extremely poor and could not afford infant formula products for their babies. The informants found this misinterpreted WHO recommendation highly unfair and unpalatable as it placed an undue burden on already marginalized women.

The guideline revisions made between 2003 and 2007 that made exclusive breastfeeding the first infant feeding option were thus, in this context, perceived as a transformation from an '*authoritative*' to a more '*friendly*' approach. As it was for the regional district and health facility informants, community informants such as HIV-infected mothers and community leaders had a positive attitude towards exclusive breastfeeding as breastfeeding was the only realistic option, as well as having an observable positive impact on HIV-free babies born of HIV-infected mothers.

A lack of understanding of the scientific reasoning behind the many and quite dramatic policy changes pertaining to the infant feeding recommendations also featured prominently during the interviews. Most of the informants at regional, district and health facility levels were unable to provide even a rudimentary scientific reason behind the changes made in the HIV and infant feeding recommendations. For example, informants at all levels were unaware of the reasoning behind the policy of abrupt cessation of breastfeeding in 2003. The informants were similarly unaware of the reasoning behind the 2011 changes in banning the previously permitted animal milk used as a replacement feeding option, based on the 2007 guidelines. The regional informants explained that they were only informed superficially and vaguely of these changes by the national managers and were given no clarification.

The sub-study also aimed at exploring the potential strengths and limitations in how the content of the diverse policy shifts had been communicated. The PMTCT managers at the regional and district levels reported that they found it difficult to present messages to the care providers in the face of the frequent changes occurring in the infant feeding guidelines. They were afraid of being seen as confused and clueless, as they had to provide starkly different and partly contradictory messages within short periods of time. Examples of dramatic shifts pointed out included the policy that HIV-infected mothers should ideally avoid breastfeeding (2000 guideline) vs. the policy that mothers should

breastfeed (2003 guidelines); the policy of abrupt breastfeeding cessation (2003 guidelines) vs. gradual cessation and extended breastfeeding (2011 guidelines) and the policy encouraging mothers to use animal milk as a replacement product (2007 guidelines) vs. the banning of the use of animal milk (2011 guidelines). The abrupt and conceptually incongruent shifts were perceived to be both dramatic and difficult to relate to, for both the health personnel and the mothers. Not least, such policy transformations were difficult to communicate to the various stakeholders, particularly to stakeholders located at the grassroots level.

A large number of more practically oriented challenges were said to add to these difficulties. The regional informants argued that a lack of a reading culture among the health care providers challenged the communication of the guideline's content. The district and health facility informants, on their part, complained about the difficult language and academic jargon employed in the guidelines, which made them shy away from them. Other related challenges included a lack of summaries presenting key recommendations in a readily understandable vernacular. These challenges in the written material were said to be combined with a continuous lack of supportive supervision given to the care providers, compounded by the inadequate number of trained staff. The district informants indeed reported that they had been largely unable to provide refresher courses, and to provide meaningful supportive supervision, partly due to the fact that they themselves did not feel competent; their own expertise was perceived to be too shallow and inadequate for competent teaching. The enormous challenges encountered in terms of communicating the continuously shifting content of the HIV and infant feeding guidelines indeed seem to underscore the earlier documented scenario, which has pointed to how the PMTCT programme, through its lack of consistency and local relevance, has too often added to the confusion and bewilderment of the healthcare providers and to the suffering of the HIV-infected mothers.

8. GENERAL DISCUSSIONS

8.1. Discussion of the study findings

Deliberative democratic theory launched collective problem-solving through discussion as the most critical element of deliberation through which individuals with potentially different backgrounds, and with potentially diverging interests, engage in processes that imply listening, understanding, persuading, and ultimately reaching more reasoned, informed and public-spirited decisions than would have been the case without this process (Gutmann and Thompson, 1996). A key feature in these debates has been the focus on ‘procedural fairness’, a point which highlights the significance of bringing relevant stakeholders into decision-making processes. Deliberative democratic theory provides the theoretical fundament for this PhD. It has been argued that a key requirement for deliberative democratic approaches, and what are considered to be a fair decision-making processes, to take hold is a political climate that supports community participation (Zakus and Lysack, 1998). Not surprisingly, the concept of *fairness* is, as we have seen, located at the core in deliberative democratic theory.

Stakeholder engagement: the ‘why’, ‘who’ ‘what’ and ‘how’ questions

Zakus and Lysack (1998:3) write that it is not immediately easy to understand what community participation actually implies, and there may be substantial difference in the understanding of the meaning of community participation. The reason for the challenge is partly related to the perceived complexity of facilitating community participation processes and the differences in perception about what community participation actually entails in different contexts. Abelson et al. (2003:249) write that a key to fruitful participation is to think about *why* one wants to consult stakeholders, *whom* one should

engage in the process, *what* the engagement should entail and *how* people should be engaged.

As to the *why* question, an overarching aim of engagement in health-related decision-making and priority-setting process is arguably to enhance fairness in decision making, both procedural fairness (i.e. the procedures involved in arriving at a fair decisions) and distributive fairness (i.e. how resources are eventually distributed to the population in need) (Daniels and Sabin, 1998). This notion also emerged as a key ingredient in the Tanzanian concept of '*haki*'. Ensuring a fair and inclusive priority-setting process is to lead to enhanced relevance of the priorities being made and, ultimately, to the quality of the services offered. As we have seen in the present document, the substantial attempts by the Tanzanian government to ensure a shift from top-down to bottom-up approaches in priority-setting and decision-making processes through health reforms and a decentralisation policy were rooted in the realisation that the grass roots had to be included in decision making in attempts to enhance fairness, relevance, a sense of local ownership and, thus, enhanced quality of governmental services.

Moving to the question of *whom*, Abelson et al. ask key questions regarding representativeness: Who has the right to speak for the community? Who are legitimate community representatives? How can one ensure proper representation of community views? Zakus and Lysack have pointed out similar challenges in determining who is a legitimate community representative. They, moreover, ask central questions related to who may be willing to allocate the required time and effort for the benefit of the community. Zakus and Lysack argue that, because of resource constraints, time constraints and fear of limited professional knowledge, very few community members are actually in a position to represent their community. Abelson et al. (2003) have cautioned that the public may dislike participating in time-consuming processes, particularly if there

are no assurances that their involvement will make a difference. Thus, in actual practice, decisions are for a number of reasons preventing a level of local participation often achieved by the dominant majority – i.e. by those already in power – with limited meaningful input from the population targeted by a particular service (Zakus and Lysack, 1998:6).

Participants in Boivin et al.'s (2010:2) study emphasise the importance of recruiting stakeholders early enough in the decision-making process to facilitate influence. However, the key question of '*what*' stakeholder engagement actually implies is whether the stakeholders come to represent the ideas of their fellow community members, the ones they are to represent, or merely bring their own personal views. Rowe and Frewer (2005:271) state that the main aim of stakeholder engagement is to obtain relevant information from relevant individuals or institutions and transfer it to the relevant recipients – a series of requirements that are not necessarily ensured by securing that stakeholders are represented in the decision-making process.

Saltman (1994) also brings up the point that, for a sustainable participatory process to take place, citizens and other stakeholders need to be 'empowered' to be able to take part in a manner that facilitates actual influence on, for example, budget and/or resource-allocation decisions. To address the challenge of community members not being sufficiently secured, informed or empowered, Tanzania has emphasized the importance of arranging pre-planning meetings at community level which assesses and identified needs and health problems, in the process employing tools such as 'Opportunities and Obstacles for Development' (O &OD), and Participatory Rural Appraisal (PRA) (URT., 2011a).

The question of *how* is the key question on how community should be engaged in a meaningful way in decision-making processes to produce what, for the majority of them, will be perceived as a desired outcome. Rowe and Frewer (2005) have, as we have seen, been concerned with clarifying the content of the stakeholder engagement concept, and have made attempts at providing a conceptual basis for the discussion. They argue that the term ‘participation’ or ‘engagement’ has been used too loosely or too broadly, leaving too much room for interpretation (Rowe and Frewer, 2005). They thus proposed a distinction between diverse levels of engagement – from passive involvement in pre-determined activities to full control in health-related decision-making activities. They suggest a distinction between engagement through active *participation*, engagement through *consultation* and engagement through information *communication* as discussed in the introduction section.

In Tanzania, the district level has, as we have seen, been identified as a central lower level administrative level which has been given the mandate to involve the community and other relevant stakeholders in decision-making processes. In a country with a strong history of donor presence since independence, the decentralisation policy that has emphasised the integration of donor-funded vertical programmes into the horizontal services has been important in a process aiming at increased power to coordinate services vested at district level. The aim has been the development of an approach that aligns priority areas and resource allocation found within the vertical programmes with the priority areas and resources found within the horizontal services, hence ensuring that the national policy agenda remains the driving force.

The study findings have revealed that the political bodies of structures and the policies aiming at local participation were largely in place within the study district. Health committees at district-, health facility- and community levels with a prescribed numbers

and types of members were, at least in principle, established, with the aim of ensuring discussion of health-related issues that were to be brought to the Council Health Management Team (CHMT) for discussion, and finally for deliberation by the Full District Council Meeting. This is a system that is today, with relatively limited variation, found in large parts of the world. (Abelson (2001). These councils are expected to play major roles in bringing in community views into decision-making processes through the use of membership in council committees. A structure is by and large established, although the study findings revealed that the lower level committees within the study district were unfortunately largely inactive.

The study findings revealed that today the district prepares its own plans, and that the release of both the 'basket funds' and the 'block grants' remitted to the district are based on these district plans (URT - joint Ministry of Health and Presidents office Regional administration and local government, 2004). A study carried out by Makundi et al (2002) has demonstrated that such remittance of basket funding to the districts has facilitated a strengthening of the health system by bringing the funds closer to the people. A number of processes have worked in the same direction. The National Institute of Medical Research (NIMR), having the responsibility of setting national health research priorities for the period 2013–2018, has, for example, made an unprecedented effort to involve categories of individuals from diverse governmental sectors as well as from marginalised and vulnerable groups in the priority-setting exercises (NIMR, 2013).

With reference to Rowe and Frewer, we have seen how Paper I indicates substantial barriers linked to gender, age, religion, wealth, ethnicity and education in terms of actual *participation* in decision-making processes. Paper II suggests the processes of *consultation* pertaining to the PMTCT programme were severely limited and uncertain, and that the limited local input rarely had an impact on the actual outcomes in terms of being accommodated in the final health plans. Paper III indicates *communication*

processes that were both limited and confusing, causing uncertainty and delays in updated information for the healthcare providers. Thus the findings of the present study at an aggregated level unfortunately add credence to earlier indications of a continued top-down culture, including continued and substantial external influence in Tanzania, whether donor- or government-driven. Similar findings have been found in other studies (Johansson et al., 2011:223, Maluka et al., 2010:756)

The substantial challenges of participation encountered among the informants in the present study seem to be fundamentally at odds with the fairness principles that are spelled out by deliberative democratic theorists, and, in extension, with the visions of the decentralisation policies and health reforms. Indeed, the study raises questions related to the manner in which the ideals behind decentralisation are fulfilled within the study district. Let us for a moment reflect on the mechanisms behind the study findings indicating continued top-down dynamics in decision-making processes at district level. It seems meaningful to link the challenges of actual stakeholder engagement described in the three papers with a set of cultural and structural barriers which intersect and overlap in diverse ways.

The question of culture

The study findings suggest that, even though a substantial effort has been made to establish policies and structures that are to enhance local participation and power, inclusive participatory processes are hampered in a number of ways. It is difficult to make sense of the scenarios described in the present study without dealing with ‘the question of culture’. Tylor, in a classic definition from 1871, defined culture as ‘[t]hat complex whole which includes knowledge, belief, art, morals, law, custom and any other capabilities and habits acquired by man as a member of society’ (Tylor, 1871:1).

In the present study context one cannot, at an overarching level, understand the political historical context without pointing to a top-down decision-making culture. From German and British colonial law and through the years of Tanzanian socialism developed by Julius Nyerere a heavy top-down political culture has been the rule. Hence a top-down approach was the template that the independent government of Tanzania also employed in its efforts to ensure enhanced health and education to its people. The orders had to come from the top – whether from foreign colonialists or from a leader with visions for a fair and independent nation – with little involvement from the people (Cooksey and Kikula, 2005). Hence, it was within a historical context of more than 100 years of strong centrally-administered rule that the shifts towards grass-roots involvement in priority setting and decision making were introduced.

The lack of a culture of inclusiveness in decision-making processes emerged in diverse ways in the present study. Paper II reveals the intricate ways in which stakeholder engagement and inclusion of their priority areas were ignored or avoided in the priority-setting and decision-making processes surrounding the PMTCT programme. In this case, the strong donor voice emerged and articulated with national priorities in health. At times, diverse stakeholders were actually consulted and given voice in a close-to-prescribed manner, only to be refuted at a higher level later in the priority-making process. Such scenarios have to be understood, at least partly, in the context of the long history of top-down decision making where individuals and institutions at the bottom of the ladder have rarely been asked for advice and input. The culture of challenging the power or the authority has not been encouraged in Tanzania; rather, the lower levels became accustomed to systems dependent upon respect and obedience of higher-level authorities, with little chance for criticism.

A top-down culture also emerged in Paper III in terms of the *communication* of the content of the PMTCT guidelines providing prescription about approaches to infant feeding among HIV infected mothers. The guidelines developed by the WHO that were adopted in Tanzania have been heavily criticized for their top-down approach and their lack of empathy with the context for which they were designed, leading to substantial confusion among health workers and added suffering for HIV-infected mothers (Moland et al., 2010, Blystad and Moland, 2009). After more than a decade of implementation at the time of the present study, there was reason to believe that this high-profile global health intervention had ensured an inclusive approach that would secure feedback mechanisms facilitating a well-functioning programme. What was found was that, far away from proper local feedback mechanisms, the programme struggled with communicating their key messages and the content of the WHO's infant feeding recommendations was not properly distributed and understood by the implementers at district and health facility level. The guidelines were characterized by difficult academic and jargon-ridden English, and were commonly dumped at lower-level offices with few or no attempts at making them understandable through summaries in Swahili.

The present study indicates that, despite policy and structures to facilitate stakeholder engagement being largely in place, a top-down culture is still alive and well in the Tanzanian administrative system. Mubyazi et al. (2004) and Maluka et al. (2011) describe how there is a persistence of top-down thinking during planning and prioritisation. They have demonstrated how district health plans are largely directed by national and international priorities rather than by local priorities. In the present study, both the international donor of the PMTCT programme and the Ministry of Health utilised their power to influence and even coerce district- and regional-level decisions; the regional secretariat employed its power to review the district plan cancelling the PMTCT prioritised activities; at district level, the Council Health Management Team in

turn would again readily ignore priorities made at facility levels. The result was that, despite political intentions made manifest through health reforms and decentralisation policy, the content of the district health plans would be largely dictated by national and international priorities rather than by local experiences and priorities.

A study by Johansson et al (2011) established that there was so little interaction across health-system levels in Tanzania the facility staff at lower levels believed that they had no impact on priority-setting exercises whatsoever. Byskov et al, similarly found that approaches in health-related priority setting in Tanzania are not participatory in practice (Byskov et al., 2009). Mboera et al. and Mlozi et al. argue that community views are rarely taken into consideration in health decision-making contexts in Tanzania (Mboera et al., 2007, Mlozi et al., 2006). Mubyazi, furthermore, found little community participation in priority-setting, and primarily linked it to poor communication and distrust between the elected community leaders and professionals (Mubyazi et al., 2007). The apparent cultural dimension surfaced in the present study beyond the top-down decision-making tradition. The study of decision-making practices at district level described in Paper I revealed not only a lack of inclusion of certain categories of individuals but also indications of a systematic discrimination of certain categories of individuals. Gender, ethnicity, wealth and education were all factors that were found to some extent determine an individual's chance of being listened to and given actual influence in decision-making processes.

From the time he entered office, Nyerere made the fight against tribalism and ethnic discrimination a prime focus due to the apparent dangers of tribalism in a nation with more than one hundred and thirty distinct ethnic groups. The present study did find remnants of ethnic or clan based bias in Mbarali. However, to a greater extent, ethnic affiliations had no influence in the district decision-makings processes. The study

however found strong indications of gender-based discrimination. In recent years there has been strong political will to ensure proper political representation of women in the bureaucratic and political structures. For example, the policy states that women should be represented on every decision-making body in Tanzania and make up a minimum of one-third of all members. Since 1995 there has been a steady increase of women candidates in the Parliament of Tanzania (Yoon, 2010, Meena, 2003) and, in the 2010 political elections, there was a particularly strong emphasis on gender representation with the aim of reducing existing gender-based power differences. Despite all these efforts there is little reason to believe that a study like this would not encounter gender-based discrimination, as prevailing patriarchal attitudes and cultures are well documented and described from Tanzania and beyond (see for example Senarath and Gunawardena (2009), Shayo(1999), and Okoko and Yamuah (2006). However, the extent to which gender-based discrimination seemed to systematically influence decision-making processes at district level in Mbarali was nonetheless noteworthy. Study findings revealed that men were often given far more say than women. The same was the case with wealthy individuals. The gender- and wealth-based discrimination was in fact partly defended, particularly by community-level informants who would question women's and poor people's ability to properly reason and contribute in decision-making contexts. The indications of a continuation of a culture of biases in terms of ethnicity, gender and socio-economic status obviously emerge as highly challenging in a context where fair and inclusive approaches in decision making are aimed at. Indeed it challenges the very basis for fairness and legitimacy in decision-making and priority-setting processes. It is important to note that these findings were more strongly evident at community than at higher administrative levels, indicating that education and socialization into a culture that emphasizes inclusion in a non-biased manner does have an impact, albeit not to the extent that such biases are alleviated.

The question of structure

Zakus and Lysack write in their excellent work from 1998 that proper community engagement allows people to participate in activities that impact upon their health, but emphasise that community participation becomes possible only when people recognise their rights to participate in their own health affairs; when there is awareness and expectations of participation among the poor; when there is loss of confidence in top-down policies made by professionals and health experts; and when there is a fundamental recognition of inadequate performance of the health system in terms of meeting the health-related needs of the population (Zakus and Lysack, 1998:2).

Deliberative theory discourages authoritarian approaches, and advocates mechanisms that reduce the influence of asymmetric power relations in decision-making processes. The findings of this thesis have indicated that both policies and lower-level structures such as community-based committees, health facility-based committees and district-level health committees have been established as a part of the health reform to lay grounds for inclusionary processes. However it was found that a number of the committees were inactive and were thus not able to serve their purpose. Other sub-studies have also revealed that health committees at Tanzanian district level are not engaged with by the district officials. As a result, committee members remain unaware of how they should participate in health-related decision-making processes; they were unaware of their roles in the health care decision-making processes and thus remained inactive (Byskov et al., 2009, Maluka et al., 2011, Mubyazi et al., 2007).

In a context of structural barriers to participation, we need at this point to comment on the donors' continued central position as encountered within the present study. The decentralisation policy stipulates, as described above, the integration of vertical programmes into the horizontal services to facilitate an integration of planning and priority setting as well as state control over donor-funded activities. The present study

however indicates that, at least as far as the PMTCT programme is concerned and at least within this particular Tanzanian district, this vision is far from being implemented in actual practice. The reason for the continuation of the strong power of the donors is most likely partly *cultural*, as discussed above, in the sense of not questioning power structures. In a donor context, this point may be exemplified by the regional managers' fear of speaking up against the priorities of the donors, even in cases where they were sharply at odds with local priorities. The challenge at hand is, however, clearly a structural challenge in the sense that substantial power is vested in the donors through their position of funding of programmes. The donors would insist on inclusion of their priorities for the PMTCT programme, with the consequence that locally-established priorities were left out. Although the intentions was surely good – in this case in the sense of strong attempts to ensure the implementation of the global policy aim of 'PMTCT coverage' – this aim collided with local priorities that sought to ensure that the already-available PMTCT programmes operated properly and were able to assist the HIV-positive mothers seeking to prevent infecting their infants.

Experience has further shown that PMTCT guidelines developed by the WHO are adopted at country level with only minor modifications, hence piling up the workload and tension among local care providers and HIV-positive mothers (MoHSW, 2007b, MoHSW, 2011). Through their roles as funders of the PMTCT programme in the present study, donors were shown to negatively influence the potential for stakeholder engagement, and were primarily attentive to the WHO policy and less so to the local input and priorities. The study findings indicate strong remnants of a structure where the donors, with their control of the funds, remain in powerful and privileged positions in implementing their own agenda.

Beyond such macro political dynamics, which is not the main emphasis of the thesis, central structural barriers to stakeholder engagement in decision-making processes are also found locally – a key issue being the question of knowledge or awareness. *Knowledge* is a vital component in ensuring that proper stakeholder engagement thrives. In the present study, the actual or perceived knowledge gap between decision makers and the community was found to hinder proper and meaningful engagement mechanisms in diverse ways. Although the Tanzanian planning guidelines demand the involvement of stakeholders during the planning and prioritisation exercises, district officials would explain that this remained problematic in practice as the health managers did not know when and how to involve them. It was noted that district officials had little knowledge of how to solicit community priorities and harmonise them with health facility and district priorities, a point that reveals the intimate connection between cultural and structural barriers.

It also emerged that district officials believed that including the views of community dwellers with limited knowledge on the issue in question may not yield a meaningful or desired outcome, hence it may not be worth the effort to try to explore community views. Community dwellers themselves would, moreover, commonly feel that they had too little knowledge of particular topics to contribute to many decision-making or priority-setting processes in meaningful ways, and would thus be happy to leave decision making to others. This point emerged strongly during Phase II of our study when many of the community informants stated that they were confident with decisions made by the care providers, and would only listen to priorities identified by them, as they believed that care providers were more knowledgeable. As shown in Paper II, pregnant women willingly and happily allowed priority setting to be carried out by health care professionals without their input, and when community leaders were invited by care providers to get involved and provide their view in priority-setting exercises, they would merely support the priorities identified by the care providers adding no input from their own experience,

perceiving it as of less value. Similar findings in terms of the challenge of inclusionary processes due to a perceived lack of knowledge have been reported from many other contexts; in Indonesia, for example, some villagers reported being sceptical about community participation because of their limited professional knowledge (Zakus and Lysack, 1998)

The very feeling of being inferior in terms of knowledge implies that although at times attempts at including the views and experiences of community members are made, they may not have much actual influence due to perceived or actual differences in the level of knowledge of a particular issue, and are not able to contribute, thus ending up consolidating the power of the professionals and undermining the ideal of achieving broad-based local involvement (Zakus and Lysack, 1998:8). Studies have documented that when the public/community and experts (clinicians) are involved in healthcare decision making, the public tends to be 'polite' out of respect for the professionals and the belief that the elites are superior and more knowledgeable (Frosch and Kaplan, 1999, Charles et al., 1997).

The institution of the councillor in Tanzania is located at the core of the vision of ensuring grassroots influence as these are individuals elected by the local community to represent them and their views in the district council. In priority-setting and decision-making contexts, it is important that, before making a final decision through a vote in the council, the councillors have vital information at their disposal, such as community sentiments and views on the topic at hand as well as central knowledge coming from other stakeholders (including from documents). In an effort to ensure informed decision making, the Prime Minister's and local government offices in Tanzania conducted capacity-building workshops focusing on the how to fulfil the role of councillor and its responsibilities (Venugopal and Yilmaz, 2010). It is important that people who are to

represent others are knowledgeable, sensitive and, open to the fact that they are representing others. Although the Councillors were to represent community views, a number of challenges were raised, as presented in Paper I. Councillors with a lower level of education, for example, were often not able to make informed decisions, and there were numerous cases where councillors would be pressured or bribed by stronger stakeholders, hence undermining the views of the community.

The challenge of knowledge emerged in many ways; serious factual knowledge gaps were also encountered at higher levels, as presented in Paper III. Both at district and at regional levels, a lack of knowledge of the main content of earlier and prevailing HIV- and infant-feeding guidelines was found among key individuals in the field. The knowledge gaps must be understood partly with reference to continued poor communication strategies. Despite the continuous shifts in infant-feeding policy, a vital field of knowledge in terms of infant survival, there were limited efforts to ensure that the constantly changing knowledge and policies were disseminated through seminars, written documents with readily comprehensible content (published in the right language), etc. Rather, bulky documents in English with challenging academic jargon were failing the crucial players. Serious gaps in the dissemination of knowledge supported by the evidence and the reasoning behind it led to dependence on ‘expert’ opinion, as pointed out by Grol (2001) and Van de Perre et al (2013:11) or, alternatively, uncertainty and misinterpretation of policy. Lack of knowledge, moreover, causes managers to lose confidence in disseminating the content of policy to the lower administrative levels.

Problems of dissemination of PMTCT-related information have been reported from other parts of Africa as well, and health workers in diverse contexts are reported to have limited capacity to carry out proper infant-feeding counselling through lack of supportive supervision and inadequate knowledge and skills (Chopra et al., 2009, Fadnes et al.,

2010). Related frustration and challenges have been revealed in other programmes in Tanzania, such as in the programme against Sexually Transmitted Infections, where poor communication channels and contradictory directives from higher level authorities were experienced (Oliff et al., 2003). Rowe and Frewer have emphasised that engagement mechanisms will only function in a system where there is a clear structure ensuring smooth flows of information and lack of a proper communication structure will hamper the realisation of a meaningful engagement process and its outcomes (Rowe and Frewer, 2005). The significance of proper information diffusion to reach the targeted groups and the employment of adequate communication channels is highlighted by theories such as Diffusion of Innovation Theory (Rogers, 2010) and Engagement Theory (Rowe and Frewer, 2005).

Along the entire continuum, a sense of being uninformed is seen to create uncertainty and to prevent engagement; what has been referred to as a lack of empowerment. The concept of empowerment has been central in this context as the courage to speak up and to participate in deliberation is dependent upon empowered citizens. Through empowerment, as pointed out by Paulo Friere, groups of people share experiences, understand social influences, and collectively develop solutions to problems (Wallerstein and Bernstein, 1988:380). Knowledge can hardly be overemphasized in a context where the aim is to empower people to participate in the decisions that affect them. Reservations have been raised about the empowerment movement as empowerment processes may also imply that the powerful are those who define the agenda and, in the process, oppress the less powerful in the name of empowerment (Zakus and Lysack, 1998).

8.2. Discussion of methods

8.2.1. Reflexivity

In no research endeavours can the researchers' interpretations be separated from their own background, their prior understanding and context. However, the researcher's role implies that they have to make substantial attempts to reduce subjectivity, and continuously reflect over the numerous potential biases of which a study commonly consists. This is, not least, important in qualitative research where the researcher uses him/herself as the instrument. Reflexivity implies 'turning back upon itself' (Macbeth, 2001:36), such as the researcher self-disclosing their position from the conception of the study to the final interpretation of the findings. Reflection over own roles and positions within the research process is a vital part of any research endeavour. According to Malterud (2001:484), preconceptions are important to consider as part of the reflexive process. Preconceptions include previous personal and professional experiences; pre-study beliefs about what is being investigated; motivation and qualifications for the exploration of the field; and perspectives and theoretical foundations related to the researcher's education and research interests. The researcher's professional background and previous work experiences will have a bearing on all stages of the research undertaking: from the conception of the idea, the method selection, the data collection, and the continuous interpretation of the material collected (Malterud, 2001). According to Patton (2005), critical reflection and self-knowledge, implying consideration of personal characteristics that can influence the observation, the questions asked and the understanding of the research field, are imperative in enhancing the quality of the study. Malterud (2001) asserts that, if reflexivity is thoroughly maintained, personal issues can be valuable sources for relevant and specific research.

In the present research project, for example, it is vital to reflect on how such characteristics as being a woman, a person with higher education, and coming from a

national institution with prior experience within the area of research clearly influenced the data-collection process. The research process implied the exploration of the experience of a largely male-dominated bureaucratic category of informants, of community dwellers with limited education and of HIV-positive women – a highly vulnerable category of informants. The potential biases and factors that may have influenced such complex encounters are numerous, but I shall briefly try to dwell on the seemingly more overt potentials for bias.

Being a female researcher clearly implied an advantage in the interviews with the HIV-positive women, and potentially also in the interviews with other female informants. The fact that I was a woman and a mother meant that it was taken for granted that I would share a certain basis of embodied knowledge with my informants, leading the female informants at district level to be more open about the types of discrimination they faced in meetings and decision-making contexts. In encounters with male informants, however, it is likely that the fact that I was a woman made it (even more) difficult to talk about potential gender biases found at district level. This is indicated by the fact that they commonly started out with statements establishing that the decision-making processes were following the prescribed rules and were not subject to bias or discrimination. With time, and potentially because of substantial research experience, the course of the interview process revealed a far more complex picture where at least parts of a more nuanced decision-making scenario emerged. It is still likely that my gender impacted on the interview process over the degree of openness among many male informants.

My educational level and the fact that I came from a national institution may also have had a problematic impact on the participation in the study. All the informants who were approached needed to consent to participating in the study and, while one would expect that not every person approached would like to participate, everyone consented, perhaps partly because the researcher came from a national level institution: potential participants

might be hesitant to decline from participating due to fear of possible implications. This is highly a problematic topic with relevance for a lot of research taking place in a part of the world where knowledge and education levels differ sharply and where there is a highly hierarchical structure. In an attempt to reduce the chance of other types of bias taking place during the recruitment process, a set of criteria for the informants was developed in collaboration with the District Medical Officer.

A few of the informants refused to have their interviews recorded, which indicated some degree of agency on parts of the informants, but the great majority accepted and it is not unlikely that this category was hiding a number of individuals who would have liked to refuse recording but who did not dare to voice their wish or concern, again because my educational status or possibly, and even more importantly, due to my links to the National Institute for Medical Research.

By and large I believe that my previous research experience implied strength in the study. Working with the National Institute for Medical Research (NIMR) proved to be an added advantage; I was accustomed to an institution that undertakes research in a wide range of areas from biomedical to social and cultural determinants of health, of the health system as well as policy analysis. This background had given me knowledge of the administrative structure in the country's health sector, of existing health programmes as well as knowledge about a range of potential health system challenges. It enabled me to identify categories of informants relevant to the study, although some shortcomings were certainly encountered (to be discussed below). It is clear that prior knowledge may cause the researcher to be open primarily to similar findings and thus less open to a different scenario of results. I do however think that my research experience led me to be open to potentially-emerging findings in a manner that would not have been the case with less experience. I think, for example, that my previous research experience enabled me to capture many of the sensitive topics that emerged during the Phase I of the study – such

as sexual harassment, corruption, nepotism, as well as problematic bureaucratic procedures related to the roles of the councillors – in a way that would otherwise have been difficult.

The Phase I interviews were certainly experienced as a resource during the Phase II of the data collection, although one cannot rule out that prior research may have blocked my openness to potentially new arenas of knowledge. Being a native Swahili speaker was an advantage, as the large majority of Tanzanians can speak Swahili, although there were a number of local languages used which I could not speak. The national language, Kiswahil, facilitated a smooth running of the interviews and eased the process of transcription, translation and analysis of the texts. Lacking local roots in the Mbarali area – I am from Kilimanjaro in northern Tanzania – I may have missed certain local nuances and culturally-specific aspects of the field explored. The study also has other shortcoming that need to be addressed.

Despite being conversant with the health system structure in Tanzania, I (as researcher) did not take the role of the national level seriously enough. My focus was on the fact that, today, the implementers of health interventions are located at the regional, district and health-facility levels and I underestimated the importance of the national level. As a result, I missed out on some important information, including national-level reflection, around the process of dealing with the WHO-developed infant feeding recommendations for HIV-infected mothers implemented in the PMTCT programme. Such information could have made me more conscious of the ways in which the WHO-developed recommendations articulated with those operating at the lower levels of implementation, or the existing knowledge and practice in the health care system found at lower levels. Furthermore, interviewing national level informants would have enabled me to have more knowledge of the procedures in the development of nationally-adjusted guidelines, the thinking surrounding the language and vernacular employed in the communication of the

challenging PMTCT messages, planned training components within PMTCT, programme monitoring mechanism, etc. Such knowledge would have eased the process of assessing the dynamics at work locally.

The recruitment of community informants such as the pregnant women, the HIV-infected mothers and the traditional birth attendants also needs to be addressed. While our assumption was that the experiences from the lowest level of decision makers, the community dwellers, would add important information about community engagement in district level decision-making processes as perceived by the decentralisation policy, it turned out that most of the community informants recruited had never been involved in decision-making processes in terms of actively being engaged in providing their views to processes of decision making at district level. This meant that a number of interviews at community level by and large yielded very little information beyond establishing that they were not involved and thus had very limited experience of decision making at district level beyond what they may learn from occasional visits by district teams and through discussion with their elected councillor. I could most likely have stopped the interview process at community level at a somewhat earlier stage since a number of these interview yielded relatively meagre information.

8.2.2. Trustworthiness

Trustworthiness in a research context is also referred to as internal validity, meaning the assessment of the accuracy of the findings as described by the participants and in turn by the researcher (Creswell, 2007a:206-207). Trustworthiness is also said to establish how confident one can be about the research findings, based on descriptions of the research design, the informants, the research context, etc (Lincoln and Guba, 1985, Guion et al., 2011), and to what extent the study corresponds with the study objectives. In the present study, ensuring trustworthiness was attempted in several ways. First of all, I participated in all the interviews and FGDs in an attempt to ensure the appropriateness or

relevance of the material collected in relation to the intended research objectives. During Phase I of the study, the interviews were facilitated through alternating the researcher and note taker/assistant role with the Tanzanian co-supervisor of the study, as described in the methods section. During Phase II of the study, I moderated all the interviews and FGDs myself, and was assisted by a note-taker/assistant. The data collection took place in settings where people live and work and thus have experience of the problem under study (Creswell, 2007a). It is as important in qualitative research to carry out observations, conversations or interviews as close to the actual setting as possible. (Malterud, 2001:483). A clear limitation was that the researcher was not able to take part in any meetings at district level and, hence, was not able to observe decision-making processes in actual practice. This is potentially a serious limitation as talking about or reflecting on dynamics at work, including challenging aspects of decision-making processes, is not the same as being present in the very context where decisions are made. Observational data would however have required long-term ethnographic study which was not feasible in the present context.

Krefting (1991:216) argues for the importance of the principle of neutrality in enhancing trustworthiness, which can only be achieved by ensuring that findings, to as great an extent as possible, reflect the motivations and perspectives of the informants. In the present study, digital recorders were used to make sure that the informants' own words were captured properly. Although transcription was not carried out by the principle researcher, the researcher reviewed all the transcripts carefully, and listened to the audio recordings to cross-check for correctness of the texts. However, the transcriptions in the first phase of the study were poorly done, necessitating the use of more resources for re-transcription. The weakness was discovered through my commitment and competence as a researcher in listening to the audio tapes and comparing them to what was transcribed. Furthermore, the principle researcher coded the raw data to ensure the authenticity of the

coding scheme, and all emerging codes and categories were carefully discussed with the main supervisor to be sure that main patterns and themes were based on the data in an agreed manner. Creating a written manuscript based on selected quotes and cases emerging from extensive and complex qualitative material clearly entails a lot of interpretation and judgement on part of the researchers, and can thus never represent a reality as perceived or experienced by the informants. It entails a construction and a representation of what is perceived of what the study informants have expressed in connection with certain themes discussed and understood by the researcher. During each step during the research process, the principal researcher discussed the emerging findings with the supervisor and with other co-researchers in attempts to gain an enhanced understanding of the data, and to enhance the soundness of the interpretation of the material.

The researchers should have thorough knowledge of the study materials during the analysis process, and thus be as familiar as possible about the content of the data and its meanings (Malterud, 2001). I tried to link the emerging findings to the study objectives, although I was also open to new, emerging issues not thought about during the process of preparing for the fieldwork.

Triangulation of data from different sources can also ensure trustworthiness. Triangulation is used by qualitative researchers to check and establish validity in the studies by analysing research questions from multiple perspectives (Patton, 2005, Guion et al., 2011). Using different sources of information strengthens the process of confirming the emerging data as related to a particular topic under study (Lincoln and Guba, 1985, Creswell, 2007a). Triangulation in this study unfolded in two ways: through methods and source triangulation. Information was obtained from individual interviews, from focus groups and from informal conversations during both study phases, and was triangulated

in the analysis process in order to enhance confidence in the emerging data. When findings gathered through different research techniques are compiled and compared, it is likely that the data becomes more reliable and valid. For example, the information gained during informal conversations in Phase I was also reviewed and compared with information generated from the IDIs and the FGDS, and the various sources informed each other, questioned each other and confirmed each other in a process that was experienced as enhancing the understanding of the material. This by and large produced a clear pattern in the sense that it revealed the challenges of stakeholder engagement. There were very few exceptions contradicting this general pattern of response. During Phase I, there were, for example, similar responses emerging on the influence of gender, wealth, education, ethnicity, age and religion across the IDIs, the FGDS and the informal talks, although the information emerged in different ways. The informal discussions featured more detailed information of the oppression that women experienced, indicating that interviews and formal discussion regarding this topic were not able to capture the more sensitive aspects in the same way as informal talk, everyday communication.

The study also contained source triangulation. The inclusion of informants from different levels of the health care system was an attempt to gain a broader picture of the dynamics at work in decision-making processes. By and large this was perceived as meaningful, allowing the researcher to learn, for example, how systems of blame worked across the different levels: the health facility staff directed their complaints to the Council Health Management Team (CHMT) for the failure to accommodate their priorities in the CCHP, the CHMT directed their complaints to the regional secretariat for dropping their prioritized activities when reviewing the CCHP, and the regional informants directed their complaints to the Ministry of Health for directing them to include activities in the CCHP that were not initially planned for, as well as to the donors for operating the

budget with predefined activities. The study emerged as more dynamic and was able to become further nuanced through the source triangulation.

8.2.3. Transferability

Transferability refers to the degree to which the findings can be applied to or may be relevant to other contexts and settings (Malterud, 2001). The term ‘transferability’ is found to fit qualitative studies better than ‘generalisability’. A study’s findings are said to be transferable when they seem to be relevant for contexts beyond the study situation. An important aspect to assess is the degree of similarity or fit between the two contexts (Lincoln and Guba, 1985). Creswell (2007b) argues for the importance of thick descriptions of the study findings if they are to be assessed in terms of transferability. In the present study it seems reasonable to believe that quite a few of the findings may be transferable to other Tanzanian settings: a similar administrative set up of the health services; similar health and decentralisation reforms; similar roles of councillors; broad cultural similarities despite the complex ethnic composition in the country; donor funding of the PMTCT programme across the country; etc. It is thus likely that study findings such as the continued influence of gender, wealth and ethnicity are found beyond the study district, and that it is particularly manifest at community level.

However, it is clearly possible that findings in Mbarali district will not be quite the same elsewhere in Tanzania because of differences among the particular staff employed; local dynamics at work in particular offices; available health facilities; etc. However, by and large it is likely that the main study findings would have emerged if the study was replicated in a different Tanzanian setting. It is indeed also likely that many of the findings would be found outside of Tanzania due to many broad similarities in terms of

weaknesses in the administrative structure, cultural traits etc. although such assessment would demand more consideration of processes and context to be meaningful.

9. CONCLUSION AND POLICY IMPLICATIONS

The present dissertation has at a very general level draw upon and discussed the study findings based on the principle of fairness of participation as outlined in the deliberative democratic theory. In deliberative democratic thinking a fair process is based on reasoning through deliberation among equal citizens, and in processes where citizens propose, discuss and generate solutions through what is deemed a fair process. A fundamental argument made by deliberative theorists is that the reduction of influence of all asymmetric power relations and authoritarian approaches in decision-making processes are decisive for a just society, where decisions are made collectively and thus become a public good. It is established that when priority setting- and decision-making processes are grounded in the local context, the priorities and decisions made are more likely to be perceived as relevant by the stakeholders – a vital aspect in a health systems context. The health system- and decentralisation reforms that were carried out in Tanzania set up a structure that were to facilitate priority setting- and decision-making processes that were located closer to the people who are to receive the services, and thus to enhance grassroots participation and the relevance and quality of decision making made, and in extension the services provided. The present project set out to explore the ways in which decision-making processes at district level did indeed reflect the ideals of deliberate democratic thinking in terms of the health reforms and decentralisation policies implemented in the country.

The present study findings indicate a series of shortcomings pertaining to participation in priority setting- and decision-making processes, and the continuation of a top-down decision-making structure in the study district. A complex web of cultural and structural

barriers seems to account for the challenges encountered. A continuation of biases based on gender-, ethnic/clan- affiliation and wealth, and a tradition of non-participation in governmental decision-making processes and of not opposing policy presented from higher ranks emerged as central culturally-embedded barriers detailed by the informants. These barriers were coupled with the indications of the continuation of a hierarchical structure, where the Ministry of Health and the regional level in combination with a strong donor community continue to have a strong impact on district planning and decision-making processes, including the allocation of funds. The study thus found a series of prevailing cultural and structural barriers to bottom-up oriented approaches in the present study district. In the discussion of the diverse challenges detected, the study refers to *engagement theory* as developed by Rowe and Frewer (2005), which outlines a broad but useful distinction between ‘participation’, ‘consultation’ and ‘communication’, a distinction broadly reflected at the level of concern within the three sub-studies (Papers I, II and III respectively).

The study also indicates a substantial lack of knowledge and reflection surrounding the ways in which more inclusive and grassroots-oriented decision-making processes are supposed to function; who is to participate, in what ways and at what levels are key questions that seem to remain largely unanswered. There seemed to be both partly a lack of acceptance and a lack of knowledge about of the principles on which the administrative system is built within the study district. The important councillor system based on the election of individuals to represent the communities in the district council is, for example, set up to ensure communication between the community and the district. However, it was argued that while the councillor institution in itself was vital, the councillors were commonly not able to follow the complex planning processes at district level that often demanded extensive and at times expert knowledge about particular topics to be discussed. They were thus often not able to play importantly into these

processes and discussions and were not feeding the district council with the views and priorities of the communities they represented.

To the extent that these study findings are valid beyond the study district, which there is reason to believe is the case (see section above), intensive advocacy related to fairness principles and to people's rights to participation in decision-making processes should be strongly emphasised in Tanzania in the years to come. The study findings indicate an urgent need to assure a fundamental re-emphasis on the principle of participation and on fair decision-making processes on which their system is built. At a very general level, there seems to be a need for the distribution of information, training and education to empower the population and thus encourage processes where individuals engage fully in informed decision making. There also seems to be an urgent need to assess and revive the strategies and aims spelled out in the health reforms and in the decentralisation policy at all levels in the health care system to assess how they can become more responsive to grassroots needs and priorities. This clearly includes a strengthening of the councillor institution, enhanced functioning of the committee system which is to ensure active information and feedback mechanisms to the district council, as well as enhanced fairness based on gender, wealth and ethnicity and thus ensure inclusive and non-biased planning processes at district level. A particular focus, moreover, needs be placed on the problematic continuation of the influence and perpetuation of the influence and top-down approaches employed by the donors and the Ministry of Health to ensure that the planning and prioritisation processes follow established procedures and guidelines, with the overall aim of improving health service delivery in a manner perceived as relevant and fair to the populace, including at grassroots level.

The findings of the present research endeavour are based on a limited number of informants located within just one Tanzanian district, which obviously poses severe

restriction in terms of the possibility of indicating a generalization of the results. There nonetheless seems to be reason to believe that the key findings may have relevance beyond the study district, as policy, administrative structures, multi-ethnic environments and donor presence are found in all parts of Tanzania, and it is likely that many of the dynamics at work found in the present study area will be found also in other Tanzanian districts. It is indeed possible that some of the findings are of some relevance for other settings in new democracies where there has been less focus on community voice and involvement than in Tanzania.

10. REFERENCES

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RESEARCH

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Challenges to fair decision-making processes in the context of health care services: a qualitative assessment from Tanzania

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Abstract

Background: Fair processes in decision making need the involvement of stakeholders who can discuss issues and reach an agreement based on reasons that are justifiable and appropriate in meeting people's needs. In Tanzania, the policy of decentralization and the health sector reform place an emphasis on community participation in making decisions in health care. However, aspects that can influence an individual's opportunity to be listened to and to contribute to discussion have been researched to a very limited extent in low-income settings. The objective of this study was to explore challenges to fair decision-making processes in health care services with a special focus on the potential influence of gender, wealth, ethnicity and education. We draw on the principle of fairness as outlined in the deliberative democratic theory.

Methods: The study was carried out in the Mbarali District of Tanzania. A qualitative study design was used. In-depth interviews and focus group discussion were conducted among members of the district health team, local government officials, health care providers and community members. Informal discussion on the topics was also of substantial value.

Results: The study findings indicate a substantial influence of gender, wealth, ethnicity and education on health care decision-making processes. Men, wealthy individuals, members of strong ethnic groups and highly educated individuals had greater influence. Opinions varied among the study informants as to whether such differences should be considered fair. The differences in levels of influence emerged most clearly at the community level, and were largely perceived as legitimate.

Conclusions: Existing challenges related to individuals' influence of decision making processes in health care need to be addressed if greater participation is desired. There is a need for increased advocacy and a strengthening of responsive practices with an emphasis on the right of all individuals to participate in decision-making processes. This simultaneously implies an emphasis on assuring the distribution of information, training and education so that individuals can participate fully in informed decision making.

Keywords: Fairness, Decision-making processes, Health care services, Health systems

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Background

This paper focuses on decision making processes in health care with a particular emphasis on the potential influence of gender, wealth, ethnicity and education. Decision-making in health care is a complex process that ideally means identifying and choosing between alternatives on the basis of the values and preferences of the stakeholders in question. Fair process grounded in liberal democratic theory implies the involvement of stakeholders who discuss and reach an agreement based on reasons that are justifiable and appropriate in meeting people's needs [1]. Stakeholders in health care include managers, care providers, patients, and the leaders and members of communities. The active participation of stakeholders in decision-making processes is one of the fundamental principles in primary health care (PHC) in the Alma-Ata Declaration [2]. It implies the delegation of power and the inclusion of all segments of the population to ensure that everyone gets an opportunity to participate effectively in decision making related to issues that affect their lives.

Active participation is achieved through a joint process of sharing ideas which enables individuals to influence decisions in a 'representational' manner [3]. The basic assumption is that shared decision making helps to improve the quality of the decision-making process, and, in the context of health, improves health outcomes [4]. This line of thinking is grounded in liberal democratic theory and decentralisation policy which argues for the importance of involving stakeholders in decision making processes. Immense challenges remain as to how to ensure stakeholder participation and how to decide at what points they should be actively involved.

The reasoning behind active participation in health care-related decision making moves beyond the equity aspect. Stakeholder involvement has been deemed vital in the sense that it enhances the likelihood that local needs are addressed hence increasing efficiency and responsiveness in health service delivery. A fundamental equity principle is that everyone affected by a particular decision is involved in the process with their ideas being listened to and taken into consideration. This approach is perceived to enhance the chance that individuals can access the basic needs necessary to protect and maintain good health [5]. It has been demonstrated that people prefer to implement ideas that they, themselves, find important [6] rather than those imposed by others [5]. Because of different values and interests among the stakeholders, deliberative democratic thinking puts an emphasis on deliberation and joint reflection [1]. Joint reflection is achieved through consensus building or through voting. However, a majority vote does not necessarily guarantee that the decisions made are the most appropriate ones. For a well functioning health system, empowerment of stakeholders [7,8] through awareness

raising is important so they can be fully involved and can vote on the aspects they think are important to them. This will ultimately enhance fairness in decisions being made.

Deliberative democratic theory calls for collective decisions that are arrived at by stakeholders when they come together. Through deliberations, moral disagreement can be resolved with reasons that are justifiable by stakeholders who can think and act fairly despite the presence of different interests [1]. Deliberative democracy has been defined by Cohen as an association whose affairs are governed by the public deliberation of its members [9]. Gutmann and Thompson have suggested three 'fundamental principles' as keys in deliberative democracy theory; publicity, accountability and reciprocity [1]. Publicity in this context means that reasons behind decisions should be publicly available and accessible. Accountability implies that decision makers are held responsible for particular decisions in ways that discourage biases and fraud, and Reciprocity implies that procedures are followed during discussions to ensure that everyone maintains respect for and listens to each other's ideas and views. With an emphasis on these principles, deliberation can be achieved despite disagreement among the group members. Gutmann and Thompson argue; "when citizens reason reciprocally, they seek fair terms of social cooperation for their own sake; they try to find mutually acceptable ways of resolving moral disagreements" Pg.2[1]. To allow this to happen, it is vital to create, an environment that allows participation to take place.

Under the decentralisation policy and health sector reforms initiated in the 1990s in Tanzania, decision-making processes in health care services were devolved to the local authorities at district level [10,11]. Substantial emphasis was placed on community participation and on securing health care decisions that emerge from the grassroots level. A key policy element has been to ensure that the community is actively involved in identifying and prioritising between the problem areas they experience. This approach is to enhance the fairness and legitimacy of the decisions being made and links with what is advocated in deliberative democratic theory. However, studies from Tanzania indicate that, despite the well formulated policy intentions of the decentralisation and the health sector reforms, community views are rarely taken into consideration in district-level decision-making processes [12–14]. Top-down and authoritarian approaches prevail in that managers make decisions based on their own assumptions, knowledge and priorities.

Even when stakeholders are involved, the extent to which the 'reciprocity' principle works is unclear. The aspects that can affect the ability and opportunity for individuals or segments of the population to make a contribution to and be listened to during decision-making processes in health care have not been assessed sufficiently

in low income settings. The objective of this study was to explore the challenges to achieving fairness in decision-making processes with special focus on the potential influence of gender, wealth, ethnicity and education.

The Tanzanian health care system

Tanzania is located in East Africa, and is made up of 26 regions and 129 districts. The health care system is structured from the community to the national level, and each level plays a defined role. Health services are provided in a pyramidal structure starting from the dispensary as the lowest level via the health centres and the hospitals, with the larger referral hospitals at regional or national level at the top. Although most health services are provided by the government (64%), there is a long history of faith-based health services as well as an increasing number of private health institutions and organizations [15]. There is a private public partnership in the delivery of health services.

There is also a hierarchical structure in health care decision making at district level. The Council Health Management Team (CHMT) has the mandate to prepare the council health plan and to make health care decisions that are submitted to the district Full Council for discussion and approval. The role of the CHMT is to relate actively both 'downwards' and 'upwards' in the system. Diverse committees exist within the district, as well as at lower levels, and their role is to develop plans to be submitted to the CHMT [16,17]. Apart from the CHMT members, other important stakeholders in this system include the local government authority, the managers of health facilities, health facility committees, health boards, non-governmental organizations, private health service providers, and members of the community. According to the principles of the Tanzanian decentralisation policy, the discussion about health related priority setting and decision making is to start from the community and health facility levels where different committees exist. Decisions made at the local levels are later to be forwarded to the CHMT and eventually to the Full Council. The aim is to ensure that the decision making process is informed by the people in the district. It has, however, been documented that in actual practice this flow is not adhered to, as many of the committees within the district remain inactive [18].

Our study was carried out in the Mbarali District. The district is located in the south western part of Tanzania. The study is part of a larger EU funded project entitled, 'Response to accountable priority setting for trust' (REACT) which had its base in the same district between 2006 and 2011 [19]. REACT assessed approaches to improving fairness in priority setting within the health sector drawing upon the framework, 'Accountability for Reasonableness (AFR)'. Our study does not actively draw upon the AFR framework, which is directly linked to the

dynamics of priority setting processes, but uses the findings obtained within the REACT project that reflect general decision making processes in health care. As explained above, the paper draws upon a theoretical approach based within deliberate democratic thinking to frame the study and make sense of the findings.

Methods

Study site

In the 2002 National Population Census, the Mbarali District had a population of 234,101 (114,738 males and 119,363 females) with an estimated annual growth rate of 3%. The district has strong rural characteristics. The main ethnic groups are Sangu, Hehe, Bena, Sukuma, Maasai and Nyakyusa, with Sangu and Nyakyusa being the most numerous. A majority of the inhabitants depend on subsistence rice farming and livestock keeping as the main economic activities. The district is served by public and private health facilities including two hospitals, two health centres and 43 dispensaries. Figures from 2002 indicate that 46% and 5.2% of the adult population had primary and secondary education respectively [20].

Study design

The study applied a qualitative design with in-depth interviews as the main data collection technique. A qualitative method was chosen in an attempt to gain a detailed and nuanced description of the experiences with health care decision making. This method allowed for the follow up of topics arising during the course of the interviews. In addition to the interviews, one focus group discussion was carried out with members of the Council Health Management Team (CHMT) in order to discuss the findings emerging from the interviews.

Recruitment of the informants

A purposive sampling technique was employed to recruit the informants. The investigators, in collaboration with the Mbarali District Medical Officer (DMO), discussed and agreed upon the criteria for the selection of the informants. Participation in the decision making process was used as a main criteria in the recruitment process. A total of 33 informants were included in the study: 23 in the interviews and 10 in the focus group. In the interviews, 11 informants were recruited at district level, seven at health-facility level and five at community level. The focus group discussion comprised 10 members at district level. The district-level informants were key members of the CHMT and co-opted members such as the malaria focal person, the district AIDS coordinator, and the reproductive and child health coordinator. Other targeted informants included district officials and representatives of non-governmental organisations (NGOs). Facility-based informants included health workers, among them the managers' (head of the health

facilities). In order to gain an indication of how perceptions of the factors influencing decision making in health care at district and facility levels compared with views at the community level, a few knowledgeable individuals were recruited. At this level, literacy and being influential in their respective localities were the additional criteria.

Data collection

Interview guides were developed for each subcategory of informants. The guides were aimed to measure the gaps in the Accountability For Reasonableness conditions which the REACT project aimed at. They were also designed in an open manner in an attempt to generate data related to the potential influence of gender, wealth, ethnicity and education on decision making in health care. Questions related to the representation of women or members of particular groups, to their particular roles, examples of their participation/nonparticipation were included in the guide. The focus group guide covered the same topics. The guides were developed by REACT's qualitative team, and were later refined and translated into Kiswahili. Five of the authors of this paper speak Swahili, and all interviews and the focus group discussion were carried out in Swahili, which is the lingua franca of Tanzania. Although interview and topic guides were used during the interviews, the researchers encouraged the informants to reflect broadly on the topic and were sensitive to themes that arose in the course of the interviews and discussions. With consent from the study participants, digital recorders were used to record the interviews and the discussion. For those who did not wish to be recorded (five out of 23 in-depth interviews), detailed handwritten notes were taken by a research assistant. The notes were carefully reviewed and refined in detail immediately after the interviews took place. The interviews and the focus group discussion lasted between one and two hours each. Informal discussions with informants at district, health facility and community levels took place during the data collection period. These conversations contributed to deepening the understanding of the findings emerging from the interviews, and created grounds for further probing in particular areas. Handwritten field notes were made on a daily basis.

Data analysis

The recorded interviews and focus group discussions were transcribed verbatim, and were later translated from Kiswahili to English with an emphasis on retaining culturally embedded expressions. After translation had been completed, the first author carefully read all the transcripts and notes and listened to all the recordings to get to know the full material well. Thereafter, a process of detailed coding was carried out manually drawing upon the pre-defined major categories of

gender, wealth, ethnicity and education as a general guide. This enabled us to identify the specific pieces of text that expressed the informants' experiences and perceptions related to the influence of gender, wealth, ethnicity and education on of decision-making processes in health care. Brief quotes or summaries of the content were noted in the margins of the transcripts. Recurring issues or patterns as well as nuances, ambiguities or contradictions within the emerging topics were systematically searched for. Information obtained from the interviews and the focus groups were triangulated in the analysis process to enhance the confidence of the data. The information gained during the informal conversations was also reviewed again at this point to increase the understanding of the material, but no direct quotes are drawn from the field notes in the results section. At each step the investigators discussed the emerging findings to enhance the soundness of the interpretation, with the first and last author being most active in the process.

Ethics

The study received ethical approval from the Medical Research Coordinating Committee of the National Institute for Medical Research, Tanzania (NIMR/HQ/R.8a/Vol. 1X/416). Permission to conduct the study was further obtained from Mbeya regional and Mbarali district authorities. Permission to use the data was also obtained from the REACT scientific committee. The objective of the study was clearly expressed to informants before written informed consent was sought. The principles of voluntariness, rights of withdrawal, confidentiality and anonymity were strictly adhered to throughout the study.

Results

Owing to the targeting of district officials and health workers, the informants were more educated than the average population. Only five out of the 23 informants in the interviews and two in the focus group were women. This gender bias was related to the fact that the levels from which our informants were recruited were dominated by men. The age range of the informants was 39–70 years: 40–54 at district level, 39–55 at health-facility level and 43–70 at community level. As explained above, informants at all levels were asked to reflect broadly on their knowledge and experience regarding the potential influence or lack of influence of the dimensions of gender, ethnicity, wealth and education on health related decision making processes.

Gender

Informants were asked about the level of women's representation in and contribution to decision-making bodies, the extent to which their views were taken into consideration, how women's participation was perceived and potential barriers to their participation and influence.

The initial response of the study informants at all levels referred to the clear political agenda of Tanzania, and emphasised the importance placed on gender considerations in decision-making bodies. It was reported that at governmental level it is spelt out clearly how many men and women are to be part of various committees. Decision-making bodies followed these guidelines so women were well represented. Women were said to be appointed to central positions, and informants said that women's views were listened to and taken into consideration in the same way as those of men. They explained that what matters in decision-making processes is the strength of the arguments made and not the gender of the person raising the concern. The following statement was common throughout the interviews:

"Nowadays the gender issue is considered. Women are given leadership positions. In this district, the District Commissioner and Education and Agriculture Officers are women. We have a woman in the Council Health Management Team, and she is involved in everything at the office. If she is not present a meeting is postponed. Women are given opportunities to contribute and are listened to like men." (District informant, male)

It was maintained by most of the informants that the more women gain confidence and influence, the more fairness will be achieved.

In the course of the interviews a far more nuanced picture of women's actual involvement in decision making processes emerged. For example, informants explained that actual voice given to a woman depended on the section or committee in which she works. Women were said to have particular influence in the district meetings where decisions about maternity issues are discussed. Therefore the opinions of women were particularly listened to and valued in these sub-meetings and sub-committees. At the community level, women were also reported to be given substantial influence in the Village Health Committees, as they are the main implementers of health-related issues at a family level. It emerged that beyond the women-dominated spheres of maternal health, women's attendance in and contribution to health related discussions were far from obvious. The discrepancy between the ideals of equality in terms of representation in diverse committees and the actual practice was also questioned during the interviews. One informant put it this way:

"If you think carefully about our district you will find that women make up the majority (of the population), but they are the minority in the decision-making bodies. In the district council, we have three women out of the total of 11 councillors. Now, when voting,

even if they (the female representatives) have an important issue to bring up, when counting the votes they lose. I will say that women aren't sufficiently represented, and I think this is not solely this district's problem but a problem found in the entire country." (District informant, male)

Informants held that the fewer of females in the decision making bodies, the smaller the chance for their views to be taken on board because, they would be outvoted.

Many male informants claimed that low levels of education were a challenge for women's involvement in the decision making bodies. The necessary expertise among women was often lacking. Informants said that, even when vacancies were advertised, women would not apply for the positions because they lacked formal skills, and they could not be forced to apply. This challenge was related to a lack of adequate skills, interest and ability. This scenario was said to make it difficult to implement the official guidelines of equal representation of men and women in decision-making bodies at the district level.

In the course of the interviews, differences emerged between male and female informants regarding women's influence. Male informants emphasised women's participation more strongly while female informants brought up numerous complaints related to women's actual roles in decision-making bodies from the community to the district level. Female informants argued that women's views were not sufficiently listened to.

"An opinion can be rejected just because it comes from a female member. . . A woman can argue for the importance of providing training related to health service provision in the planning meetings, but the issue may not be considered, as other suggestions like constructing buildings (suggested by men) are given priority." (District informant, female)

Women were said to end up crying sometimes because of frustrations resulting from being undermined by men as revealed in the following quote;

"My opinions are taken into account because of my confidence and standing. But sometimes women are even crying in the planning meeting as their views are not taken into consideration" (District informant, female)

It was held that, even for the educated women, it was difficult to get their views through simply because they came from women. At the community level, the challenges of women's involvement in decision making

emerged as particularly serious with more direct reference to the female gender *per se*. One female community informant explained:

“In the meetings, even when there are knowledgeable women present, we are not listened to when we present our views. We are always asked, “Who are you?”

Throughout the interviews at all levels it was maintained that women had not gained sufficient confidence in formulating and presenting ‘strong points’ (*hoja za msingi*). It was held that little public exposure and shyness made them lag behind. Apart from reservations regarding women’s skills and competence, a scepticism regarding the appropriateness of women’s involvement in decision-making bodies emerged, particularly at community level. A lack of trust in women’s abilities to carry out proper assessment and decision making emerged among some of the informants. They were very direct in expressing their views about women’s incompetence as one said:

“There are very few things which women can do because of their nature. There are things which we just force them to do, although we know that they really can’t do them. For example women cannot supervise the construction of the dispensary, so why should we listen to their opinions?” (Community informant, male)

It was concluded by the majority of the informants that the actual influence of women varies starkly from one decision-making body to another and from one level of authority to another, with the community level facing the greatest challenges in terms of ensuring the inclusion of women’s views.

Wealth

The potential impact of economic status on decision-making processes in health care services was also explored. At the district and health facility levels, a very limited influence of wealth was recorded from the informant’s statements. Informants stated that in areas where guidelines were properly followed, the influence of well-to-do people was minimal. One informant concluded:

“We are not influenced by an individual’s economic status. If you are well-off, it is relevant to you and your family but not for the hospital management team. What matters here is how strong a person’s arguments are.” (Health facility informant, male)

Informants also argued that at the community level the wealth of a person had little impact, particularly if

it was combined with low education. One informant stated:

“... People are after constructive ideas and only that. What is more, rich people are few in our village. Others may have many cattle, but they don’t have a substantial influence owing to their poor education.” (Community informant, male)

A different picture of the influence of wealth emerged as we moved closer to the community. Informants acknowledged that as far back as people could recall the wealth of a person has influenced decision-making processes. A continued impact of rich people emerged because of their ability to offer assistance in various matters. Rich individuals used their power to influence decisions in more direct ways, as this quote illustrates:

“There are individuals here known as “Burushi”. These people are a mixture of Arabs and Africans, and are financially well-off. They have plenty of money. In the meetings, if they want a certain decision to be made, even if it is of no benefit to the community, it is commonly accepted. Decision makers have no choice as the “Burushi” make substantial contributions to health-related issues.” (District informant, male)

A more common phenomenon touched upon by almost all the informants was the ability of rich people to influence decision-making processes more directly through bribery. Bribery brings wealth to the heart of decision making, and gives affluent individuals more power. The asset implied by the well-to-do was linked with male gender.

It emerged in the interviews that when a wealthy person speaks he is listened to more than others, not only because he is in a better position because of his resources, but because of perceptions that wealthier people are more ‘intelligent’ than the poor. One informant put it in the following way:

“I must be frank; a poor person’s influence on the decision-making process is minimal because of his status. He might have good ideas, but because he is poor, he has no influence... It is the opinions of the rich person that to a large extent are implemented. I know myself that when you have a good life you also have a good ability to think, but if you are poor your thinking capacity becomes limited as you are thinking about very small things. While you are thinking about stiff porridge (*ugali*) others are thinking of cars. Therefore, to convince people becomes really hard because you’re thinking: “How am I going to get my

lunch today?" while your friend is thinking of cars and machines." (Community informant, male)

The manner in which a degree of legitimacy was given to such scenarios emerged in several of the interviews and informal talks at community level. Moreover, the influence of wealth emerged as more pronounced when it was coupled with high education of an individual.

Ethnicity

As with the other points raised, the immediate response from the district and health facility informants regarding the potential influence of ethnic affiliation was that ethnicity had a very limited influence in Tanzania. This instant reply was situated within the discourse of the late Tanzanian President Julius Nyerere, who used his entire career to advocate against differentiation based on ethnic criteria. The fact that members of the district decision-making bodies and facility committees would always belong to different ethnic groups was also brought up as a factor that worked against tribalism. It was maintained that individuals in such positions were obliged to follow governmental rules and regulations, which makes it very difficult to promote decisions that favour particular ethnic groups. Emphasis was again placed on an individual's knowledge and skills relating to a particular topic. One informant stated:

"... Although you may find that a majority of the health staff in a certain unit/department originates from the same ethnic group, when it comes to decision making in health care services, the person's capabilities or skills are considered to a greater extent than their ethnic affiliation." (District informant, male)

Regarding gender and wealth, a more complex picture did emerge in the course of the interviews. For example, informants expressed that a leader at any level will listen far more attentively to the opinions from individuals who originate from his/her own ethnic group. District and health facility informants provided numerous examples of how ethnic affiliation was made relevant concerning issues such as staff transfers, payment of allowances, promotions and training opportunities. The following quote illustrates:

"... Here there is a department that is dominated by a certain ethnic group. When it comes to decision making, you may reach an agreement in relation to a particular health issue, but later you find that the decision has been changed without any official reason. If you ask yourself who changed the decision, you will realise that it is the head of the department, who originates from the same ethnic group as the person who ends up being favoured. He commonly favours

his "colleagues" (from the same ethnic group) and that is not a secret here." (District informant, female)

Informants expressed the view that, in the community, certain ethnic groups have a strong tendency to dominate or influence others. The largest ethnic group in the community was said to use their numerical advantage to exploit or oppress others. This was even more apparent as this group was also wealthy. Large and strong clans within particular ethnic groups could also have undue influence as reflected in the following quote:

"... There is a certain clan in this community with a very strong influence in decision-making meetings. Even the local government leaders are afraid of them. It is a very big clan that affects the government of this village. This is also a rich clan that doesn't follow government regulations." (Community informant, female)

Education

Informants perceived educational level as a very important factor in decision-making processes. Educated individuals and professionals were strongly depended upon by their leaders when making decisions. The importance of education was emphasised strongly to an extent where local knowledge was devalued. One informant said:

"... An educated person first of all is a professional and the advice he gives has scope. Opinions and decisions given by non-educated individuals are doubtful" (Community informant, male)

Two different concerns regarding the representation of groups with low education emerged: one related to a lack of influence and the other related to too much influence in the decision making processes. It was argued that if individuals with lower level of formal education were better represented, common people's problems would be more readily identified and addressed. One informant had this to say:

"We, health facility managers are not involved in the District Health Committee meetings. As a result we don't receive most of the things we are in need of. Let them invite us to these meetings even once a year, even if it will be at our own expense. They are afraid to call us because they fear being asked questions specifically related to the expenditures." (Health facility informant, male)

It was argued that a real challenge was linked to the fact that when the formal educational level of an individual is low, a person tends to lack the necessary confidence to take an active part in discussions, and will not

be able to present his/her argument clearly. This view supported the argument provided by some informants that the attendance and representation of less educated individuals often does not lead to the desired results in terms of a true grass-roots engagement and does not impact on the decision-making processes.

There was a strong focus among the district level informants on the substantial influence of individuals with very low levels of education in the decision making processes. They referred specifically to the Full Council where the majority of the members are made up by the Councillors who represent communities. The informants from district level raised serious concerns that these councillors are given substantial power to engage in district-level decision making but often lack the education and expertise related to the issues they discuss and eventually vote on. It was held that as councillors, they are often not in a position to be well enough informed and to judge the issue at stake from different positions. According to the informants, the result are uninformed decisions;

"Most of the Councillors have little knowledge to conceptualise what is being discussed. Usually they attend the meeting just to listen, and when it reaches the time for voting they just agree and sign in order to pass the resolution. From my experience I can say that some of these members do not understand what is being discussed. Most of the health issues are not understood by non-medical personnel. A resolution may be passed with the understanding that the council has reached consensus, but in reality it might be a decision proposed and enforced by a single member of the council as the other voters simply have agreed but may not have understood the issue being discussed." (District informant, male)

The informants reported that the impact of grass-roots representation in actual practice was limited as the representatives were unable to grasp many of the issues at stake, and would vote in ways that would not favour community opinion. However, many informants would also argue that there are community members who, despite a lack of formal education, have an excellent ability to provide constructive ideas by drawing upon their varied competence and experience. Thus, a complexity of views were raised regarding the challenges of ensuring informed grass-roots engagement and grass-roots impact at a time when formal education and specialised knowledge is increasingly demanded.

Discussion

This study indicates extensive limitations in terms of fair participation in the decision-making processes in health

care in the study district in Tanzania. The influence of gender, wealth, ethnicity and education presents substantial challenges. At a general level, the tendency was clearly one of placing more trust and power in men, in wealthy and formally educated individuals as well as in individuals from powerful ethnic groups. The influence was more pronounced at the community level than at the district and facility levels. At the district level, the influence, particularly of wealth and ethnicity, was deemed to be minimal. This was attributed to the fact that members of decision making bodies would come from different ethnic origins and would have different economic status. For example in the Full Council meetings, these factors were said to hardly play a role as the members are obliged to adhere to government rules and regulations that strictly stipulate the procedures to be followed and it is not easy to deviate from them.

At the onset of the discussion, it is interesting to note the way the interviewees started their responses by addressing the importance of the principles of fairness in terms of gender, ethnicity, wealth and education, and the lack of discrimination on the basis of such characteristics. This immediate response was seen to become more nuanced and ambiguous in the course of the discussions. It is important to comment upon this seemingly 'politically correct' response with a brief reference to Tanzanian history.

In Tanzania, the former president Mwalimu J. K. Nyerere's political agenda from independence focused on fighting against a class society based on poverty, disease and ignorance, which he saw as the main enemies of development. He worked on the basis of socialist ideals and the village became the core of his policy through the 'ujamaa na kujitegemea' (socialism and self reliance). A prime legacy of Nyerere was to unite all ethnic groups in the country through a joint language 'Kiswahili' [21]. Through this agenda, the battle against tribalism in Tanzania was fought through slogans such as 'united we stand, divided we fall' ('umoja ni nguvu, utengano ni udhaifu'). This made Tanzania a showcase for maintaining peace and unity in a multi-ethnic setting [22]. Nyerere based his policy on social justice principles where each individual was to have the right to be respected and be listened to regardless of social status [23]. Despite his good intention, he did not spell out clearly the manner in which the grass-roots' level was to be heard in the face of a strong and authoritarian state.

The immediate response of the informants regarding gender, wealth, ethnicity and education must also be understood in light of the later health sector reform and the decentralisation policy in Tanzania which strongly advocate bottom-up approaches in decision making [24]. Emphasis is placed on community or grass root involvement where every individual is to participate equally in discussing their problem areas and suggesting solutions.

The recognition and emphasis of the village or the community as the focus of or basis for development has remained central for close to 50 years in Tanzania. In recent years, active engagement of people in debate has been encouraged [24,25]. This has increased recognition of the importance of poor and marginalized segments of society having a right to air their grievances. The fundamental assumption is that when diverse stakeholders from grassroots are involved, decision making improves as it takes place closer to where the problems are located. Communities are called upon to take an active part in and to challenge decisions that affect their health. These visions have been a central part of Tanzania's independent history, and it is within this contextual backdrop that the immediate response from the informants must be understood. However, the implementation of ideas of decentralization policy has largely remained theory [14]. The initial responses are also in line with the deliberative democratic thinking that in a fair process, there should be reasoning among equal citizens and shared commitment to the resolution. To achieve this, in the deliberation, stakeholders should decide on the agenda, discuss the issue, propose solutions and support those solutions with reasons [9]. Each stakeholder is to have equal voice in the decision making since the distribution of power and resources is not supposed to shape their chances of contributing or playing an authoritative role in the deliberations.

Beyond the initial response, our study findings indicate that gender, ethnicity, wealth and education do, in practice, pose substantial challenges in making fair decisions. This study cannot, in any substantial manner, quantify or explain the discrepancy between the levels of ideals and values on the one hand and the level of practice on the other. But we can indicate a few aspects of the challenges that emerged in our study findings, and ways in which some of these seem to not only appear at the level of discriminatory practice, but also at the level of ideas and ideals in a way that may impose serious constraints on principles of fairness.

Our findings indicate that, despite the strong focus on gender balance in decision-making bodies, substantial challenges remain. There is still a lack of women with the necessary formal competence or skills to occupy certain positions. Beyond this, women were said to be listened to less seriously during discussions than their male counter parts. Informants expressed the view that, in meetings where educated and active women were involved, it was often difficult for them to be heard beyond the field of maternal and child health. At the community level, the findings were even more serious as the fundamental ability of women to make a meaningful contribution to the discussions was questioned by several of the male informants, revealing a true distrust

between the genders. This lack of ability was not merely linked to a lack of experience in voicing their views or to a lack of formal education or training, but was related to their nature as women. These findings reflect strong traces of patriarchal ideology as have been found also in a number of other studies [26–28].

A similar line of reasoning emerged from the findings related to wealth and influence. People with higher income were reported to be listened to more than the poor. This finding emerged as far more apparent at lower levels, and not least at the community level. Informants at the community level argued that the rich would be in a better position not only because of their financial resources, but because poor individuals were perceived to have lower thinking capacity; the more affluent were perceived to be more intelligent than the poorer. The influence of wealth has been reported in another study where members of decision making bodies were chosen because of their fundraising ability [29]. This implies that poor people's views will be heard to less extent, although they may be the ones who may experience a problem more acutely and may be most affected by the potential decisions. This tendency to allow the wealthy to have more influence has been pointed out as reason for caution also in other studies [30] if fairness is to be achieved. Despite the enormous historical focus on the dangers of tribalism, ethnicity did also emerge as challenge in our study. The majority ethnic group in the community was said to be more likely to be respected and listened to than other groups, not least if its power in terms of numbers was coupled with wealth. A bias was noted also in the district departments when a majority of the staff belonged to a particular ethnic group. Our findings indicate that advantage or disadvantage based on ethnic criteria in decision-making contexts needs to be watched carefully also in present day Tanzania.

The influence of education was, not surprisingly, pronounced. People with formal education were said to have substantial influence owing to their increased knowledge and competence, while individuals with little education had less influence. Other studies have found that educated individuals were thought to have more confidence [31] and thus feel more comfortable in engaging in complex discussion. In our study, the elected councillors who approve district decisions were considered by some informants to lack the necessary education and understanding to vote in an informed way in many of the questions addressed. These councillors have authoritative power, yet at times lack the necessary knowledge in approving decisions in health care. This point has been raised also in other studies [29,32–34]. With this in mind, the approaches to ensuring proper community representation need to be thought out, and the necessary knowledge and information need to be imparted to councillors so that they can make informed decisions for better health outcomes.

The study findings indicate that deliberative democratic thinking that advocates fairness and legitimacy in decision-making processes [1,9] continues to be undermined, and that it is not yet adequately practiced or conceptualised in our study district. The objective of participation in decision making is to make sure that decisions reached are informed by the people. For this principle to function, as the reciprocity principle of deliberative democratic theory states, each stakeholder needs to have an equal chance to contribute and being heard regardless of inherent power differences. Our findings bring a serious dilemma. How can one possibly take on board ideas from all stakeholders in an effort to enhance the democratic process and, at the same time be able to address the needs in an adequate and informed way as perceived by stakeholders themselves? Our study indicates that the basis for fair and legitimate decision making is far from being reached, and that the challenges need serious and renewed efforts. Despite this, enhancing fairness and legitimacy through the inclusion of people beyond powerful individuals is deemed vital, as shown by Kapiriri and Martin [35].

When informants question women's or poor people's innate ability to take part in informed decision making constructively, and consider it fair that other individuals legitimately act or decide on their behalf, we are not talking merely of discrimination, but of challenges to human rights-based fairness principles in a more fundamental way.

Prevailing biases affect people's self esteem and sense of worth, which in turn affect their ability to be open, creative and vocal. On such grounds Gibson et al. propose adding 'empowerment' to the fairness conditions as proposed by the ethical framework Accountability for Reasonableness [36]. This line of thinking, emphasizes appropriate training and orientation to enable stakeholders to contribute substantially [14,33,37–39]. Empowerment has been defined as the process and outcome whereby those without power gain information, skills, and confidence and thus control over decisions pertaining to their own lives [40]. Empowerment processes can take place at the individual, organizational or community levels. Green argues; "The poor, divorced from centres of decision making dominated by elites with different interests, must be empowered to participate in the decisions which affect them" [7]. In a decision-making context, stakeholders should be obliged to respect the opinions of each other. This is the fundamental argument of deliberative theorists who advocate for mechanisms that reduce the influence of all asymmetric power relations and authoritarian approaches in decision-making processes. Deliberative democracy advocates for a just society where decisions are made collectively and become a public good [9]. Rawls clarifies that power in decision making has to

be located independently of the economic and social position of individuals [41]. More consultative and participatory approaches are called for in an attempt to secure the participation of broader segments of the population [1,6]. The struggle to find ways to include the views of women, the poor, individuals from every ethnic segment and from both educated and non-educated parts of the population has to remain in focus in the years ahead.

Strengths and limitations of the study

The findings of this study are based on a limited number of informants located at different levels within the district. There is nonetheless reason to believe that the findings have relevance beyond the study district as policies, bureaucratic structures and multi-ethnic environments are found in all parts of Tanzania. It is indeed likely that the findings may have relevance for many other settings in newly developing democracies where there has been less focus on community voice and involvement than in Tanzania.

Conclusion

The findings from this study have revealed that fairness principles in health care decision making processes are greatly undermined in the present study district in Tanzania. Women, poor individuals, members of minority ethnic groups and less educated individuals were found to be discriminated against in decision-making bodies. The findings were more pronounced at community than at health facility and district levels. The findings revealed that such biases were related to perceptions of women, the less educated and poor individuals as less knowledgeable and having a lower thinking capacity. These notions imply fundamental challenges to the implementation of democratic and justice theories as spelled out by deliberative democratic thinking. We argue that such notions pose a very real threat in health care decision making as they may systematically undermine the views and experiences of particular segments of the population. There seems to be a prevailing lack of knowledge and also a lack of acceptance of the principles on which the political system is built, including the fundamental right of everyone to be heard. Intensive advocacy related to fairness principles and to people's rights to participation in decision making processes should be strongly emphasised in the years to come. The clear distinctions between the findings at community levels and at district levels indicate that ensuring equal opportunities in terms of access to education and information will, in the long run, lead to a situation where stakeholders at every level are given a chance to participate in a fair way and make legitimate decisions in health care since they will be knowledgeable on the issues at stake. Only in this way can the true community voice be secured regardless of gender, wealth, ethnic origin and educational level.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

EHS participated in the development of the tools, collected and refined the data, carried out the analysis and drafted the manuscript. AB was central in the process of developing the guides, made a follow-up visit to the field site during data collection, took part in the analysis process and revised the draft manuscripts. PK participated in the development of the tools, took part in the data collection process and reviewed the manuscript. OFN, LEGM and SM reviewed the manuscript several times. JB conceived the idea of the project, developed the methodology and reviewed the manuscript. All authors read and approved the final manuscript.

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RESEARCH ARTICLE

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Stakeholders' participation in planning and priority setting in the context of a decentralised health care system: the case of prevention of mother to child transmission of HIV programme in Tanzania

Elizabeth H Shayo^{1,2*}, Leonard EG Mboera² and Astrid Blystad¹

Abstract

Background: In Tanzania, decentralisation processes and reforms in the health sector aimed at improving planning and accountability in the sector. As a result, districts were given authority to undertake local planning and set priorities as well as allocate resources fairly to promote the health of a population with varied needs. Nevertheless, priority setting in the health care service has remained a challenge. The study assessed the priority setting processes in the planning of the prevention of mother to child transmission of HIV (PMTCT) programme at the district level in Tanzania.

Methods: This qualitative study was conducted in Mbarali district, south-western Tanzania. The study applied in-depth interviews and focus group discussions in the data collection. Informants included members of the Council Health Management Team, regional PMTCT managers and health facility providers.

Results: Two plans were reported where PMTCT activities could be accommodated; the Comprehensive Council Health Plan and the Regional PMTCT Plan that was donor funded. As donors had their own globally defined priorities, it proved difficult for district and regional managers to accommodate locally defined PMTCT priorities in these plans. As a result few of these were funded. Guidelines and main priority areas of the Ministry of Health and Social Welfare (MoHSW) also impacted on the ability of the districts and regions to act, undermining the effectiveness of the decentralisation policy in the health sector.

Conclusion: The challenges in the priority setting processes revealed within the PMTCT initiative indicate substantial weaknesses in implementing the Tanzania decentralisation policy. There is an urgent need to revive the strategies and aims of the decentralisation policy at all levels of the health care system with a view to improving health service delivery.

Keywords: Planning, Priority setting, PMTCT, Decentralisation, Donor influence, Tanzania

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Background

The introduction of primary health care implied a focus on enhancing health service provision at the grassroots. In fact, the 'health for all' concept of the 1978 Alma-Ata declaration became a prime policy bearer for the movement of bringing health services closer to the communities [1]. A grassroots and participatory focus, rather than a top-down approach, has since then gained recognition as a fundamental principle in attempts to ensure stakeholders involvement and fair priority setting in health care. The focus on ensuring broader participation in health care decision-making processes gained renewed attention and became more manifest in the early 1990s when many countries started implementing reforms as a strategy geared towards improving the performance of their health systems [2,3].

One of the major components of the health sector reforms in Tanzania was decentralisation through devolution and integration of the district health care services [4]. This reform included devolving political, administrative, financial, and personnel control from the central to the lower levels. In Tanzania, sectoral reforms were implemented in three phases between 1999 and 2001 involving all sectors. Each phase comprised a third of all local authorities [5]. Within the district health care system, the Council Health Management Team (CHMT) was formed, and was later followed by the District Health Boards (DHBs). By devolving decision-making to local authorities, decentralisation aimed at improving planning and accountability and ensuring that priority setting and decision-making processes were located close to the beneficiaries in the health sector [6,7]. Under this structuring process, the Ministry of Health and Social Welfare (MoHSW) remained with the responsibility of overall policy making, long-term and macro-planning, as well as of overall monitoring of the health sector. The districts, on their part, were given the authority to undertake local planning, allocate resources and manage district health services. The districts were also given the authority to supervise, monitor and evaluate the district's programmes and interventions. With decentralisation, each district was moreover scheduled to develop its own Comprehensive Council Health Plan (CCHP) using block grants from the central government and basket funding (pooled donor funds). In this regard the CCHP has to be developed within the overall frames as outlined in the Essential Health Package produced by the MoHSW [8]. The distribution of funds to the districts is dependent on the CCHP guidelines and is furthermore based on the criteria of population size and special needs as developed and categorised at the national level [9]. The main expected benefits of decentralisation were local participation in the planning of the services, increased responsiveness to locally-experienced

problems, and ultimately increased efficiency and quality. A few studies have been carried out to assess the status and the functioning of the decentralisation reform in Tanzania. These studies reveal that decentralisation has generally facilitated the establishment of health bodies and committees from national to community levels, a structure through which community priorities are to be brought up and later forwarded to the higher authorities. Studies by Maluka and Mubyaz found that well-defined structures aimed at ensuring grassroots participation have been established [10,11]. Some studies have also demonstrated the success of such structures in terms of community participation. These studies have, for example, demonstrated that communities identified and articulated their own problems, and through the available administrative structures found resources for implementing what they perceived to be relevant projects. Concrete success stories in the health system have been noted in the immunisation, malaria control and maternal and child health service provision. Active community participation has been described to contribute to such success, a success enhanced by increased empowerment in the population [12-14]. Other studies have shown how Tanzanian districts are preparing their own plans and how the 'basket funds' and 'block grants' are remitted to the district level based on these plans [8]. Basket funding in Tanzania remitted to the districts has facilitated the renovation of health facilities, the purchase of essential equipment and drugs to supplement inadequate kits. It has also been noted to increase opportunities for in-service-training of the existing staff, and facilitated the improvement of utilities such as water and electricity supply at many health facilities [15]. However other studies have documented substantial challenges within the decentralised health system. Although in principle health committees existed from the grass root level, in practice, some of the committees were largely inactive [11,16]. Moreover, the problem has been compounded by the failure to include effectively community priorities in the district health plan [10]. These latter findings are problematic as decentralisation was expected to bring about more public deliberation on major, unsolved public policy problems, with people engaging in debates on how to utilise limited resources fairly to promote the health of a population with substantial and varied needs [17,18]. Generally, previous studies in Tanzania have demonstrated that this has not been the case in actuality [16,19].

While only few studies have been carried out on priority setting and planning processes within general health care in Tanzania [16], we wished however to scrutinise a more narrow-based initiative with the aim of giving a close look at the concrete priority setting and decision-making processes in the country's health sector in the face of ongoing decentralisation processes. To date little is known about

the present experiences in the decentralised planning processes pertaining to the programmes such as the prevention of mother to child transmission of HIV (PMTCT) programme. The objective of the present study was to assess the processes of priority setting in the planning process through a scrutinisation of the PMTCT programme implemented at district level in Tanzania in a decentralised health care system. More concretely the study explored the extent to which the needs and challenges identified and brought forward by key stakeholders at the regional, district and health facility levels pertaining to the PMTCT programme were incorporated into the health plans.

A brief note on the PMTCT programme

The PMTCT programme was introduced in Tanzania in 2000. By 2007 its coverage was 32% [20]. In December 2009 the coverage had reached 78% (i.e. 3,626 of the 4,647 health facilities in the country were providing PMTCT services) [21]. PMTCT service provision has, as such at a very rapid pace become available in the majority of the country's health facilities that offer Reproductive and Child Health (RCH) services. Priorities relating to the programme are to be covered by both the Communicable Disease Control (the second priority area of the Essential Health Package) under which HIV/AIDS-related activities fall, and under the RCH programme (the first priority area of the Essential Health Package) [8]. In 2007, the regional level was assigned under the PMTCT guidelines produced by the Ministry of Health with the responsibility of ensuring that the PMTCT services were included in the Comprehensive Council Health Plan produced at the district level [22]. The districts on their part remained with the tasks of implementing the PMTCT services by ensuring the availability of equipment, supplies and trained staff. The programme initially operated as a vertical programme, implying that funding was received directly from the donors by the implementers. However, with decentralisation all vertical programmes were to be subsumed within the larger health systems structure and were to operate horizontally. The 'Prevention of Mother to Child Transmission of HIV' (PMTCT) programme was in principle in 2011 fully integrated into the reproductive and child health care services from national to health facility levels [23]. While PMTCT coverage has been a success story in general, it does not imply improved quality of care. The PMTCT programme has struggled with challenges of adherence and uptake, among others due to the demanding requirements of the changes of the guidelines [24-26] attributed by socio-cultural and economic inappropriateness. To date little or nothing is known about the experiences with priority setting processes within the PMTCT programme being executed in the country.

Methods

Study setting

The study was conducted in 2011 in Mbarali district which is located in south-western Tanzania. Mbarali was chosen because it was the location of the study setting for the EU funded umbrella project for the present study, the Response for Accountable Priority Setting for Trust in Health System (REACT) [27]. The present sub-study, therefore, was loosely linked to the umbrella project. HIV was one of the major health domains studied under the auspices of REACT. The project was located in Mbeya partly due to the relatively high HIV prevalence in the region: 9% as compared to the national estimates of 5.1% in the country as a whole [28]. According to the 2002 National Population Census, Mbarali district had a population of 234,101 (114,738 male and 119,363 female) with an estimated annual growth rate of 3%. The main economic activities of the district are rice-farming and livestock-keeping. The district is served by both public and private health facilities. It has two hospitals, one health centre, and 43 dispensaries. The coverage of the health facilities providing PMTCT services in Mbarali at the time of the present study was 86% (32/37 health facilities). Since much has been documented on HIV/AIDS in general, the PMTCT programme seemed to provide a particularly interesting case in a priority setting context due to the substantial focus that has been given to the programme during the last decade.

Study design and recruitment of informants

The present study employed a qualitative study design using in-depth interviews (IDIs) and focus group discussions (FGDs) in the data collection. Purposive sampling was employed to recruit informants at the regional, district and health facility levels. All individuals being enrolled in the project had experience in either the management or the administrative aspects of the PMTCT programme. The main categories of informants included: 1) members of the regional team (three individuals: coordinators for HIV/AIDS, Reproductive and Child Health and for PMTCT; 2) members of the district management team (eight individuals including the District Medical Officer, District AIDS Coordinator, District Reproductive and Child Health Coordinator, District Nursing Officer, District pharmacist, District laboratory technologist, District home based care coordinator and the Tanzania Commission for AIDS focal person (TACAIDS); and 3) the PMTCT in-charges at the health facilities who were also managing the RCH services (10 individuals, five rural and five urban). The 22 participants in the two FGDs were recruited from two hospitals providing PMTCT services (one faith-based and one government hospital with 10 and 12 participants respectively) (Table 1). The FGDs were deemed appropriate because the hospital settings had

Table 1 Data collection and number of informants

Data collection method	Number of IDIs/FGDs	Total	No. of informants
In-depth interviews	Health facility PMTCT in-charges	10	21
	District managers	8	
	Regional managers	3	
	Total	21	
Focus Group discussions	Health facility workers involved in PMTCT	2	22
	Total number of informants		43

many health workers performing PMTCT-related tasks both directly and indirectly (for example, the pharmacy, the laboratory, the maternity and reproductive child health clinic). The FGDs gave them an opportunity to participate in joint discussions to share their experiences of the implementation of the programme. The district HIV/AIDS focal person assisted in identifying the PMTCT in-charges from the selected health facilities while the District Medical Officer assisted in the identification of the informants at the regional and district levels. The selection criterion that the DMO used was 'performing the PMTCT roles.' Additional criteria factoring the rural-urban divide and the distance were applied to recruit PMTCT in-charges from different health facilities.

Data collection

Individual in-depth interviews (IDIs) were carried out with the informants recruited at regional, district and health facility levels. The IDIs were supplemented by FGDs conducted with health care providers at the hospital level. All the informants had experience with the PMTCT services either as health workers or as administrators of the programme. The interviews and discussions were aimed at generating a broad-based understanding of the experiences with priority setting processes related to the PMTCT services. Since decentralisation is implemented at district level, an assessment of the manner in which local priorities were brought on board during the district planning process leading up to the CCHP was particularly focused. The district health plans are prepared annually and include all prioritised health-related activities of that respective year with financial allocations.

A research guide with similar themes was developed for each category of informants. Central questions in the guides included: *How are priorities related to PMTCT made at the district level? What criteria or procedures guide the priority setting processes? In what part of the budget are PMTCT activities accommodated? Have you ever been asked to provide inputs or submit your priority areas regarding PMTCT to the CHMT? What are the sources of funds for the planned PMTCT activities? What are the potential challenges you encounter in setting*

priorities related to the PMTCT? The first author of this paper collected the data assisted by a competent social scientist. The last author provided guidance during the data collection process. The questions were addressed in an open manner, and the informants were allowed to speak at length without being subjected to interruptions. The interviews allowed for further probing to gain more information and insights on emerging issues relevant to the problem. All IDIs and FGDs were recorded with a digital recorder after obtaining consent from the informants. Three interviews were not voice-recorded due to technical problems. These interviews were recorded through rapid note taking. The FGDs had a mix of female and male participants as the discussion of the study topic was not perceived to be particularly sensitive to the gender composition of the groups. In fact, the informants did not find the topic particularly challenging to talk about; they seemed engaged in the topic and were highly articulate during both the interviews and the discussions. All interviews were carried out in Swahili, the national language and lingua franca for East and Central Africa.

Data analysis

All the interviews and FGDs were transcribed verbatim by a competent transcriber. Preliminary analysis started right in the field. A more detailed analysis was carried out after the completion of the data collection period. Conventional content analysis [29] was employed in the analysis of the material. In our case the analysis process the following steps: the first author read all the transcripts and listened to the audios carefully to confirm the correctness of the transcriptions. This helped to achieve immersion and obtain a sense of the whole in the material [29]. The last author also reviewed a large number of the transcripts, and the content of the interviews was discussed in some detail between the two authors to ensure that the subsequent data analysis was in line with the research objective. The second stage entailed reading the transcripts slowly, highlighting the parts of the text pertaining to particular aspects of the present study. Relevant 'codes' briefly summing up the content, were created throughout the entire data set, implying the manual insertion of the 'codes' in the margins of the transcript pages. All the codes were sorted, listed and clustered into larger categories / themes addressing the key research questions as contained in the data collection guides as well as new themes emerging from the interviews. Quotes were employed that reflected the informants own words in a narrative report. Matrices were created by cutting and pasting related statements or dialogues into categories, making it possible to track patterns as well as nuances and ambiguities within the material. During the final phase, a systematic comparison of the content generated from both the IDIs and FGDs was

carried out as well as between different levels of the informants. We believe such comparison of the data strengthened the reliability of the study findings and its trustworthiness, thus making the knowledge generated transferable to other similar settings. The study undertaken adhered to the guidelines on qualitative research as required by the *BMC Health Services Research Journal*.

Ethical considerations

The study obtained ethical approval from the Medical Research Coordinating Committee of the National Institute for Medical Research of Tanzania (NIMR/HQ/R.8a/Vol. IX/1094). Permission to conduct the study was also obtained from regional and the district authorities. Also permission to publish the data was sought from the Director General of the National Institute for Medical Research, Tanzania. Before the interviews were initiated, oral informed consent was received from informants at all levels after the objectives of the study had been well explained to them. Privacy and confidentiality were strictly emphasized and maintained throughout the study. Informants were also assured of their right to withdraw from the discussion at any time they would wish.

Results

Experiences with planning and priority setting in PMTCT programme-related activities

The informants reported two plans in which locally-prioritised PMTCT activities could be accommodated: the Comprehensive Council Health Plan (CCHP) and the Regional Health Plan. Whereas the council health management team was responsible for preparation of the CCHP, the regional health management team was responsible to prepare the regional health plan. Within the decentralised model, the regional secretariats were tasked with reviewing the District Council Comprehensive Health Plans (CCHP) before they were further reviewed and approved by the District Full Council. The Regional Medical Officer, on his/her part was responsible for the approval of the regional plan before it was submitted to the funding agents who are mainly external partners. The prime planning and priority setting processes related to the PMTCT programme were, according to the regional and district informants, carried out at the regional level since international donors were the main funders of the programme and their offices were established at the regional level.

Challenges of including PMTCT activities in district health plans

Despite the decentralised management of the PMTCT programme, the informants at the district, regional and health facility levels shared their frustration, as they explained that their PMTCT-related priorities were rarely taken into account in the final plans meant for

actual implementation. The main challenge, they pointed out, was the central roles of the donor and of the MoHSW in the prioritisation processes, on the one hand, and the inherent weaknesses in the proceedings of the District Health Team on the other. We shall look at these findings in some detail below, starting with the district informants' experience, the level located at the heart of Tanzania's decentralisation policy.

Donor influence over the district health plans

The involvement of the region in the review of the prioritised activities in the CCHP was perceived by all the district informants as a serious barrier to the accommodation of their own prioritised PMTCT-related activities. District informants raised concerns that activities that were included in the Council Comprehensive Health Plan would not necessarily guarantee that they would be honoured by the regional secretariat. It was established that this was commonly the case with PMTCT related activities. A district informant explained the reason behind this: *"Our idea was to train more persons from the health facilities providing PMTCT services so that when one staff is not around service provision doesn't stop. We also planned to provide refresher training in accordance with changes in the guidelines to enable each health facility to provide anti-retroviral combination therapy to the mothers. But the Regional Secretariat cancelled the activities because the PMTCT programme is a priority of the donors (i.e. They were left to them). Last year (2010), we did not have any activity in the Comprehensive Council Health Plan related to PMTCT"* (IDI- district informant).

The challenges that continue being reported in the PMTCT programme from the local levels have prompted district managers to push consistently for the establishment of follow-up mechanisms aimed at improving the quality of the PMTCT services in the many facilities that did offer them. However, the proposed activities were not accommodated in the plan: *"The reported priorities are to improve the quality of the services provided at the health facilities that have already received PMTCT training by making sure that services are provided in accordance with the guidelines. This implies preparing a budget for purchasing HIV diagnostic kits in case facilities run out of stock, and having a budget item to support the transportation of specimen from health facilities to the zonal laboratory and returning the results on time. Now, because the managers at the regional level are the ones making decisions on HIV in general and on PMTCT in particular in collaboration with the donors, you find that the plan is not approved"* (IDI-district informant). The informants explained that the donors' primary aim was to increase coverage in terms of the number of health facilities providing PMTCT services and trained health care providers to expand their care and treatment services: *"What donors*

focus on is the coverage of the PMTCT service in terms of number of facilities providing services and trained staff. When we were invited to the region to defend our plan (CCHP) we were told that health care providers at 32 of the 37 health facilities in Mbarali district have already been trained. The remaining five facilities are now included in the donor budget. Consequently our prioritised activities were cancelled" (IDI-district informant). The district informants also complained that whatever activity they proposed with a view to enhance the PMTCT programme would be cancelled by the regional secretariat as the aims and the priorities had already been made by the donors. The district informants thus reported that they experienced loss of influence over the planning process that they were otherwise supposed to own.

Ministry of Health's influence over the district health plans

District informants expressed a lack of autonomy when reviewing the PMTCT priorities in the district health plans. This experience was not only related to the substantial influence of the donors, but also to the directives coming from the national level. The district informants explained that they received guidelines from the MoHSW relating to the inclusion of nationally-prioritised health interventions. In particular they said that the need to adhere to the demands laid out in the Essential Health Package while attempting to set local priorities proved tricky: "The challenge in the planning for PMTCT activities is that the district planning team is always faced with a challenge on how to address the requirements of diverse guidelines while simultaneously adhering to the Essential Health Package. There are several groups to consider in each priority area. Taking into consideration our capacity in terms of funds and staff, they found it increasingly difficult to prioritise (some of the locally-relevant issues)" (IDI-district informant).

In fact, the Regional Secretariat was often in an ad hoc manner, instructed by the MoHSW to include activities in the CCHP that were neither prioritised nor planned for locally. An informant at regional level had this to say: "In the 2010 financial year we were instructed by the Ministry of Health to include 'Kangaroo Mother Care' activities' (i.e. procedures for saving the lives of neonates) during the review of the Comprehensive Council Health Plans. This necessitated the cancellation of other prioritised activities at the district level because the budget ceiling had already been exhausted" Additionally, informants at the regional level found the restrictions imposed upon them by both the donors and the national authorities as limiting their abilities to manoeuvre independently. In a similar vein, informants at the district level reported that restrictions placed upon them by the regional and donor levels as well as by the nationally established priority areas (including the budget ceilings) limited their potential for independent

priority setting and consequent allocation of funds. In practice, such imposition blocked all PMTCT activities prioritised by the district, they explained.

Challenges pertaining to the inclusion of local PMTCT priorities in the regional plans

Regional informants emphasised that PMTCT activities are usually planned at the programme level which is located at the regional level. This was linked to the fact that international donors had moved their project administration from the national to regional levels in an effort to 'decentralise' their activities and to work more closely with the regional teams. Although the donors had been instructed by the MoHSW to respond to the regional and district plans and priorities, the informants lamented that the donors did not follow these instructions, and the regional administration was not in a position to halt the donors' continued follow up of their own globally defined priority areas. Despite being aware of their obligation to ensure the development of the regional PMTCT plans, the regional team found it increasingly difficult to intervene as they remained mindful to reflect the donors' priorities: "Donors have their own priority areas and they do stick to them. For example, Walter Reed is concentrating on care and treatment alone. It is difficult to include our local priorities," (IDI- regional informant). Regional managers were moreover given strict budget ceilings by the donors, ceilings that hindered them from expanding or modifying the scope of the activities during the planning phase. The regional managers for example expressed their dissatisfaction with the lack of preventive effort in the plans executed. One regional informant said that they were so alarmed by this anomaly that they asked donors directly: "If you are focusing on care and treatment alone while individuals are continuing to get infected with HIV, we are doing nothing" (IDI-regional informant).

In a few cases, the informants explained that the donors would allow regional managers to include their own priorities in the plan after they had received substantial complaints: "This financial year (2010–2011) donors brought a ceiling of 10 million Tanzania shillings and they wanted us to train health workers on male involvement in PMTCT. We said "no"- we have no problem with the health workers as they have already been trained on PMTCT. We don't need to invest again in the health workers at this point. Let's invest in community sensitisation so that we can talk to community leaders about the importance of the PMTCT programme; how to prevent HIV from infecting the children, etc" (IDI-regional informant). The donors were said to have eventually warmed to this suggestion, paving way for planning of several community meetings with the same 10 million Tanzania shillings budget ceiling. The regional managers clarified that since the PMTCT

programme is managed at the regional level, the districts do not receive funds to carry out these activities. Instead, it is the regions that handle funds for implementing PMTCT-related activities: *"If it is training, the district is told to bring the participants (to the regional level); if it is supplies we at the regional level purchase everything and send the same to them* (IDI-regional informant). Regional informants expressed that when district priorities are not met they do encourage the districts to use the money collected from 'cost-sharing' (collected from user-fees and Community Health Funds) to implement the priority areas presented by the health facilities.

Administrative confusion

Confusion emerged among district informants regarding who was actually involved in the processes of setting priorities related to PMTCT. Although the regional managers claimed that they had sought inputs from the district in the PMTCT planning processes, this was strongly refuted by the district informants. Key individuals managing the PMTCT programme at the district level explained that they had never been asked for their opinions or priorities when the regional plan was being developed, nor did they receive a copy of the approved plan. In practice they explained that they were merely 'receiving instructions', primarily in terms of PMTCT coverage: *"The regional staff may visit the district and ask 'how many health facilities are not providing PMTCT services'. You respond – 'five facilities'. You are then asked, 'Give us their names'. Once you provide the names that becomes the end of the business"* (IDI-district informant). The district perceived the regional level to act according to the donors' wishes and demands without involving relevant stakeholders at the lower levels, hence overlooking the overriding interests at the grassroots level.

Challenges of the district health plan team

Experiences from the health facility informants over the planning processes

The findings from the interviews indicated moreover that there were challenges beyond the donor/regional/national vs. district dynamics that had implications for local priority setting processes in relation to the PMTCT programme. Key stakeholders at the health facility level found that, although they were the ones with hands-on experience with the programme, their experiences and views were not taken into account by the district planning team, and they rarely surfaced in local discussions, plans or in budgets relating to the PMTCT programme. Health facility staff participating in the FGDs revealed substantial frustrations about this situation. One participant recounted how the PMTCT focal person at the hospital level had prepared a detailed list of prioritised PMTCT activities after being asked to do so. The list

was then submitted to the district HIV/AIDS coordinator, but she said: *"I have noticed that during the planning sessions we are always asked to bring in our priorities. We as hospital staff therefore said, 'Let's prioritise training so that each staff who works under the Reproductive and Child Health Department becomes aware of PMTCT and how to take care of an infected mother"* (FGD-participant, health facility). As was often the norm, their main priority area, in this case, the training of staff was not accommodated in the eventual plan.

Other informants from health facilities similarly emphasized the lack of inclusion of their priorities and explained the feelings of frustrations among staff due to that development: *"When someone from a PMTCT programme requests the inclusion of a certain activity in the plan, it is because s/he [and in Swahili is a gender neutral prefix] knows its importance. The problem with the planning team is that some members don't know the importance of the activities, so they don't prioritise them. For instance, in the current plan, when the district planning team came back from the planning meeting, the facility staff asked-'If we had identified our priorities and sent them to the planning team, and later we saw that none of our priorities was taken on board... Would it then make sense to involve us?' If managers ignore our activities, then what is our role in the planning?"* (IDI-health facility informant). Health facility informants also questioned the rationale of involving normal staff in identifying their priorities and submitting them to the higher level when at the end these suggestions are never considered in the plans. They insisted that the planning team included only activities that they themselves believed were important without even providing proper justifications.

Seeking inputs from facility staff during planning processes at the district level

None of the PMTCT in-charges, except at the hospital level, had been asked to bring in their priorities related to PMTCT. The health personnel did not even know the source of funds that were used to implement the PMTCT activities and found themselves far removed from the priority setting and decision-making bodies. The uncertainty about the funding and priority setting situation strongly emerged in the FGDs, particularly at the Faith-based hospital. The group participants expressed that they were not aware of what was going on regarding general priority setting even though they were aware that, as a faith-based facility they should get a certain allocation from the district budget: *"May be we are not asked to bring our priorities because we are located at a mission hospital so we are just waiting to be informed by the district on what to do"* (FGD-health facility). The FGD participants at the district hospital on the other hand, were somewhat more aware of the priority setting processes. Nevertheless, none

of the staff who participated in the FGDs or IDIs was aware of the regional health plan which specifically targets the PMTCT programme. A majority of the PMTCT facility in-charges would readily present their own thoughts about the challenges and their priorities related to PMTCT, but they insisted that they were not asked by the district to present them. Among the many critical areas brought up during our discussions included the need for funds for: refresher training on how to fill in the PMTCT forms and on how to carry out basic PMTCT-related tasks; follow-ups of mothers who drop out of the PMTCT programme, the purchase of waste bins for keeping of highly infectious materials; the purchase of sufficient HIV test kits; renovation of the counselling room to enhance privacy; continuous community education; and strengthening of male involvement.

Health facility informants explained that the priorities especially at the maternity section where safe delivery is encouraged and expected as per PMTCT guidelines, were rarely considered. When a few PMTCT-related items were included, they were regularly purchased in an insufficient amounts. As a result several health facility workers reported about the use of personal funds to purchase important items such as dishes and waste bins. Generally, as the participant explained, there was a discrepancy between what they wanted and what was actually implemented.

Knowledge and communication gaps

A planning session is held annually at district level in Tanzania. At this meeting, prioritisations and allocation of resources take place on health-related activities, leading to the production of the CCHP. Despite the fact that the district members attending this planning session were educated at the diploma level and above, substantial weaknesses were revealed in terms of a lack of knowledge on how to properly plan employing the allocated ceilings. Challenges of communication between the diverse sections within the district and between diverse administrative levels also surfaced. The communication gap that was found between the people in charge of the PMTCT activities and the representatives of the relevant department during the planning sessions surfaced in many of the interviews. A regional level informant explained: *"In the district health plan, it becomes difficult to accommodate activities related to PMTCT because the PMTCT coordinator does not participate in the planning; rather he/she is represented. There may be a communication gap between them. Since the district health plan accommodates a lot of activities you find that each member is struggling for the inclusion of his/her activities"* (IDI-regional informant). The implication of this statement was again that very few PMTCT activities were taken on board due to budgetary constraints. The challenging organisational structure of the PMTCT programme further complicated the process

of including priorities found meaningful at the local level: *"The programme coordinator, for example, does not include PMTCT activities such as budgeting for diagnostic kits, medicines, delivery kits and delivery bed in the plan. If you ask her, she would tell you 'Wait for the pharmacy budgeting', and she will only budget for training. As a result, when it reaches the time for pharmacy budgeting I budget for general supplies and drugs"* (IDI-district informant). Generally, what emerged was a confusing structural landscape, which compounded the already existing challenges of incorporating local priorities.

Discussion

We started out this paper by presenting Tanzania's commitment to promote decentralised health care, a system in which decision-making and priority setting processes have been devolved to the district level to ensure local level prioritisation, control and accountability [9]. Whereas the decentralisation policy advocates for local planning processes that start at the grass-roots level and move up through the system, this ideal was hardly reflected in the findings of our study related to the PMTCT programme. Neither the district nor regional health plans were seen to incorporate the views and priorities of the categories of people most closely and strategically placed within the PMTCT programme. In spite of the existing structures and the clearly spelled out ideals of decentralisation, we found that in the case of the PMTCT programme the system remained heavily reliant on external funders who tend to guard their own globally generated priority agendas in a manner that disregards local experiences and priorities. Also the district's dependency on basket funding with minimal internal revenues accruing from within the district has amplified the burden of non-inclusion of local priorities in the annual health plans.

In response to the changes, the donors who support the PMTCT interventions have made attempts at moving closer to the people by relocating their operational base from the national to the regional level. In other words they have shifted their arenas from the international, to the national and more recently to the regional levels. Although presently they work with the regional managers of the programme, the regional administrative level in Tanzania is still far removed from local communities and health facilities. According to the governmental structure the role of the region is to translate policy guidelines from the national level, advise and supervise districts, and review the district health plans to ensure conformity with the national guidelines before they are approved by the District Full Council [8]. In this regard, the donor devolvement to the 'local' level appears to have failed to ease and facilitate the inclusion of the priorities identified by the districts in the PMTCT-related activities, when this level is at the heart of the grassroots-based priority setting and decision-

making in the Tanzania's decentralised system. The donors operating in the PMTCT field, according to this study seem to be fairly rigidly sticking to their own globally-defined set of priority areas with little or no willingness to include the district's experienced demands. The dynamics at work related to priority setting in PMTCT thus seem to operate in a fashion that remain far-removed from the staff at the health facilities, the district administrators and, apparently, even from the programme managers at the regional level.

The PMTCT services in Tanzania have recently been fully integrated into routine RCH services [23], according to the 2011 PMTCT guidelines. It does however seem to remain extremely difficult to locate and coordinate where, when and in what ways the PMTCT activities should be integrated in the planning process within an extremely complex reproductive health package. The findings moreover add substance to the experience that the integration of the PMTCT services into the RCH services has revealed little success in terms of integrated planning, since health planners operate with the (very real) perception that the PMTCT programme is donor-driven and donor-funded. The implication is that the programme is left to others and consequently receives little attention within the complex priority setting processes that surrounds the production of the annual CCHP. An important assessment study of the performance of the health sector reforms and of decentralisation revealed a similar scenario: programmes dealing with diseases that were perceived to be located under 'vertical programmes' and thus under donor funding received far less attention during processes of prioritisation as they were perceived to be already catered for, the implications being that local priorities were often not incorporated [15]. In the present study, little knowledge on how to plan properly using the ceiling allocated in a diverse set of priorities, communication gaps between representatives attending the planning sessions and PMTCT in-charges, and lack of interdepartmental collaboration have added to this difficulty and has made it challenging to carry out a meaningful prioritisation process in the PMTCT programme. It has previously been documented that challenges of conflicting personal interests coupled with poor interpretation and implementation of the guidelines are other aspects that may undermine the priority setting processes and overall performances of the district health planning teams [15].

Although the districts have been given the autonomy to prepare and implement their health plans, the Ministry of Health retains a central role in developing policies to be implemented at the local levels in the decentralised health care system [5]. In practice, however, the MoHSW in this particular case seems to continue producing policy guidelines that are perceived as 'must' or 'orders' by the lower

levels of administration. Although the basket funds are re-mitted to the districts, the planning teams are also in this case given guidelines to follow in their allocations implying: 5-10% (community initiatives), 15-20% (health centre), 10-15% (voluntary agency hospital), 25-35% (council hospital), and 15-20% (office of the DMO) [8]. Thus the guidelines that may be helpful in guiding the process end up limiting the planning team's capacity to plan as they would wish since the above distribution has to take precedence over all other additional items. Sometimes the ministry officials would ask for the inclusion of activities in the district health plans that are not of local priority. Members of the secretariat at the regional level, who review the CCHP for conformity with the national guidelines, would thus in this case e.g. cancel PMTCT-related activities that were initially planned for in order to accommodate national demands. These national demands are again often generated by global policy and funding bodies such as the UN system and become demands that nations find hard to refrain from. Daniels, the scholar behind the Accountability for Reasonableness Framework for priority setting, has argued that to improve fairness, the planning teams need to work like 'a football team' where all players work together for the common goal [30]. Under this notion, activities perceived to be of important will receive attention in the prioritisation process regardless of whether they are from the vertical programme or not, or from lower level staff or not. In fact improved priority setting decisions improve the quality of service provision; they improve stakeholders' satisfaction, and reduce complaints, thus enhancing trust and proper allocation of resources. The REACT project from which this sub-project emerged has reported positive results pertaining to stakeholder involvement in processes of priority setting, as documented by Maluka for example [31]. However, more studies are deemed necessary to assess reasonably the status of priority setting processes within diverse health related programmes in this and other districts in order to draw broader conclusions.

The scenario that has emerged in the present study is challenging as it seems to question the legitimacy of the priority setting processes pertaining to the PMTCT programme as exercised in the country. Moreover, it asks questions on the manner in which the ideals behind decentralisation are fulfilled. The findings of the present study add to existing evidence of a continuation of top-down and external influence, whether donor or governmental documented in other studies [16,32]. Johansson [32] has, for example, in his study on Tanzania revealed how priorities are set by international and national managers pertaining to the project related to the eligibility criteria for receiving antiretroviral drugs, a scenario which implies that lower level actors from where implementation takes place had no room to contribute. Other studies have

focused on the challenges in priority setting processes at the district level [11,16,27]; indicating that health facility and community views are rarely taken into consideration, that no clear procedures are followed and that there are no clearly spelled out roles for the different committees at the district and health facility levels, rendering the health committees redundant and inactive. Weak health information systems, moreover, hinder the availability of credible and reliable evidence required by the District Health Plan team at the time of setting priorities [10,33], a situation which in turn makes it difficult to make meaningful prioritisation. The involvement of lower levels in the planning process should be aimed at ensuring that resources are targeted to those in need. On this point, the Council on Health Research for Development (COHRED) asserts, 'The ones who own the problem are the ones who can provide the solutions', and they need to actively participate in setting priorities [34].

In principle, one must be also careful when indicating that the study findings are relevant beyond the field we have focused on. However, we do wish to suggest that the findings of the present study together with similar findings from other studies [11,16] indicate that the decentralisation policy seem to work to reinforce the established power structures rather than integrating priorities of lower levels stakeholders which was aimed at with the reform. It is also important to keep in mind that colonial legacies and customary power structures lead lower level staff to fear open disagreement, making it difficult for them to meaningfully execute the authority granted to them. This tendency creates a new form of dependency on the donors/ foreign experts and other higher ranking individuals, creating scenarios where local officers remain locked in a system over which they have little control.

In this particular case, the continued donor-dependence has contributed to the continuity of a top-down approach where PMTCT managers feel that they have little option but to adhere to the donor's priorities, hence they experience a loss of autonomy. In the past few years the PMTCT related priority areas of the donors have been to improve access in terms of coverage of services [35]. This has been a worthy contribution with tangible results in a vast numbers of African countries. The PMTCT services are today available in most health facilities with RCH services in Tanzania [21], and at least a single member of staff has been trained in each facility providing the services. These measures however, do not ensure the quality of the programme which continues to experience severe challenges [26,36]. Moreover, the health systems challenges continue to hamper its successes and raise concerns over the quality of the services on offer. Similar findings were reported by Johansson from another rural district in Tanzania [32].

On the whole, effective implementation of sector-wide approaches where donors support the budget of the health sector through basket funding emerges as a useful way to enable districts to identify their own priorities [37]. These approaches, when effectively implemented, can facilitate the smooth implementation of the decentralisation policy as it can allow for a shift from vertically-focused health programmes and centrally-controlled budgets to more comprehensive health planning and locally-controlled health budget structures at the district level. Such approaches, moreover, are aimed at reducing external power influences [38]. In this study these aims do not seem to be fulfilled in the case of the PMTCT programme. The claim that funds were inadequate could result from a lack of readiness to allocate the budget items to the programmes perceived to be donor-driven or could stem from a lack of experience and capacity to prepare or implement the plan. A study by Semali [12] revealed that there might be opposition to the transfer of authority by district stakeholders by giving less priority to vertical programmes activities even when they are integrated into the horizontal services. Despite these challenges, it is important to note that improving the implementation of the decentralisation policy entails eliciting values and criteria for priority setting from lower level stakeholders in the health care system. In this effort, special attention should be paid to the methods to be used in bringing up local priorities. Only a continuous concern with the dynamics at work in the health systems will allow for continued pressures to be kept on local authorities in a manner likely to facilitate increasingly fair and inclusive priority setting processes whether in PMTCT or other health programmes. When priority setting processes are grounded in the local context, it is more likely that the decisions reached will be perceived as relevant by the stakeholders, and that decisions will ultimately be experienced as improving the quality of health services on offer, which should be the main outcome of a fair priority setting process in a decentralised health care system.

Study strengths and limitations

This study is based on a single rural district. As such it is hardly possible to generalise its findings to the rest of the Tanzanian districts. Nevertheless, the emphasis placed on donor funding of the PMTCT programmes and the integration of the activities in the CCHP is a national policy. Thus, it is likely that dilemmas of priority setting related to the continued central role of the donors and of MoHSW, and the challenges linked to the weaknesses inherent in the district planning team that were found in this study as hampering the effective implementation of the decentralisation policy can be of some relevance also in other districts in the country.

Conclusion

The priority setting processes related to the prevention of the mother to child transmission of HIV programme demonstrate substantial weaknesses, weaknesses that challenge the principles of Tanzania's decentralisation policy where principles of bringing local priorities up-front are located at the core. The findings of this study indicate that the strong donor influence coupled with the MoHSW's high profile role in the country's priority setting facilitate the continuity of the top-down approaches that were supposed to have been eliminated through the promotion of the participatory, grassroots-based bottom-up approaches. There is an urgent need to streamline the present strategies and aims of the decentralisation policy at all levels of the health care system to ensure that they are responsive to actual grassroots needs. Particular focus should be placed on the problematic continuation of undue influence and perpetuation of the top down approaches by donors and the Ministry of Health to ensure that the planning and prioritisation processes follow laid-down procedures and guidelines with the overall aim of improving health service delivery in a manner that is perceived as relevant and fair to the populace, particularly at the grassroots level.

Abbreviations

CCHP: Comprehensive Council Health Plan; CHMT: Council Health Management Team; DHBs: District Health Boards; FGDs: Focus Group Discussions; IDIs: In-depth interviews; MoHSW: Ministry of Health and Social Welfare; PMTCT: Prevention of Mother to Child Transmission of HIV; RCH: Reproductive and Child Health.

Competing interest

The authors declare that they have no competing interests.

Authors' contributions

EHS conceived the idea of the project in collaboration with AB, collected the data, analysed and drafted the manuscript. AB took part in the analysis of the data. AB and LEGM reviewed and provided substantial inputs to several drafts of the article. All the authors have read and approved the final manuscript.

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Challenges of disseminating clinical practice guidelines in a weak health system: the case of HIV and infant feeding recommendations in Tanzania

Elizabeth H Shayo^{1,2*}, Bodil Bø Vågå^{1,3}, Karen Marie Moland¹, Peter Kamuzora⁴ and Astrid Blystad¹

Abstract

Background: Clinical guidelines aim to improve patient outcomes by providing recommendations on appropriate healthcare for specific clinical conditions. Scientific evidence produced over time leads to change in clinical guidelines, and a serious challenge may emerge in the process of communicating the changes to healthcare practitioners and getting new practices adopted. There is very little information on the major barriers to implementing clinical guidelines in low-income settings. Looking at how continual updates to clinical guidelines within a particular health intervention are communicated may shed light on the processes at work. The aim of this paper is to explore how the content of a series of diverging infant feeding guidelines have been communicated to managers in the Prevention of Mother to Child Transmission of HIV Programme (PMTCT) with the aim of generating knowledge about both barriers and facilitating factors in the dissemination of new and updated knowledge in clinical guidelines in the context of weak healthcare systems.

Methods: A total of 22 in-depth interviews and two focus group discussions were conducted in 2011. All informants were linked to the PMTCT programme in Tanzania. The informants included managers at regional and district levels and health workers at health facility level.

Results: The informants demonstrated partial and incomplete knowledge about the recommendations. There was lack of scientific reasoning behind various infant feeding recommendations. The greatest challenges to the successful communication of the infant feeding guidelines were related to slowness of communication, inaccessible jargon-ridden English language in the manuals, lack of summaries, lack of supportive supervision to make the guidelines comprehensible, and the absence of a reading culture.

Conclusion: The study encountered substantial gaps in knowledge about the diverse HIV and infant feeding policies. These gaps were partly related to the challenges of communicating the clinical guidelines. There is a need for caution in assuming that important changes in guidelines for clinical practice can easily be translated to and implemented in local programme settings, not least in the context of weak healthcare systems.

Keywords: Clinical guidelines, Communication challenges, Healthcare system, The PMTCT programme, Tanzania

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Background

The drive towards 'evidence-based practice' has increased the demand for standard procedures in health-care provision globally. Global and national clinical guidelines are being developed and revised at an increasing speed as new evidence emerges. In many clinical areas knowledge is short-lived, and new evidence calls for the frequent revision and updating of clinical guidelines. HIV and infant feeding has been a particularly dynamic and demanding area of research, and, between 1992 and 2013, new evidence has regularly been incorporated into global and national guidelines leading to a fast pace of change. In this paper, we discuss the challenges related to the dissemination of frequently changing guidelines in weak healthcare systems. Specifically, we explore infant feeding guidelines and their dissemination and adoption in the Prevention of Mother-to-Child Transmission of HIV (PMTCT) Programme in Tanzania as a case study.

The aim of clinical guidelines is to improve the quality of care and health outcomes for patients by translating new research findings into practice [1,2]. The guidelines are to assist practitioners and patients in making appropriate healthcare decisions for specific circumstances [3]. They should be based on the 'best evidence' available and should be implemented with clinical expertise combined with fundamental consideration of patients' preferences.

Research continually produces new findings that may contribute to more effective and efficient healthcare. However, this new knowledge cannot change patient outcomes unless health services and health workers adopt the findings in practice [4]. Translating evidence into practice, i.e. the implementation of new policy and knowledge, is an active process involving individuals, teams and organizations [5]. Such processes can be challenging since they involve changes in knowledge, attitudes and behaviour. In this context, identifying barriers is an important step in the process of knowledge translation [6]. Although governments, professional associations and healthcare organisations commonly play an active part in the development and dissemination of clinical guidelines [7], there is often a substantial gap between procedures detailed in guidelines and actual healthcare practice [8]. In their review, Grol and Grimshaw [8] pointed out the different levels in the healthcare systems where challenges may occur; at the level of the patient, the healthcare professional, the healthcare team, the healthcare organisation, and within the wider environment. In the implementation of evidence/knowledge in healthcare it is important to understand the obstacles in order to develop effective channels of communication/information and, in turn, improve health interventions.

A number of concrete barriers have been identified which hinder the smooth adoption of clinical guidelines. These include lack of awareness of the existence of the guidelines among care providers, a lack of agreement between providers and experts about the scientific evidence behind the changes, and a lack of ability to adopt new medical practices into daily routines [9-11]. In a systematic review that involved studies outside Africa, almost all studies revealed that the quality of care did not attain the standard set in national guidelines or those set by the researchers themselves [12]. Jackson and Feder [3] write that characteristics of good guidelines include their ability to present evidence and recommendations in a concise, accessible manner and in a format which facilitates quick retrieval and assimilation of information. Guidelines should present relevant and valid evidence for the clinicians to relate to. They should be relevant to patients and they should be presented in a format that is flexible enough to be applicable to specific patients or circumstances.

Our findings will draw upon Jackson and Feder's findings, and will be discussed in-depth by drawing upon the 'diffusion of innovations theory' developed by Rogers [13], a theory which enhances the understanding of the dissemination of policy. At a very general level, Rogers underscores the fundamental importance of considering the potential 'benefits and costs' of health 'innovations' before implementing them. The theory suggests five elements which should be carefully considered during the phase of assessing the feasibility of new health policy, namely the innovation's (1) 'relative advantage', its (2) 'compatibility', (3) 'complexity', (4) 'trialability' and (5) 'observability' (see Table 1). Roger's five elements will guide our discussion of the study findings.

Infant feeding guidelines in the PMTCT programme provide us with an interesting case for looking at the process of introducing globally defined guidelines (in this

Table 1 Five elements to be considered in the diffusion of innovation theory

Elements	Details
Relative advantage	The degree to which an innovation is perceived as better than the idea it supersedes.
Compatibility	The degree to which an innovation is perceived as being compatible with existing values, past experiences, and the needs of potential adopters.
Complexity:	The degree to which an innovation is perceived as difficult to understand and use. A clinical procedure is more likely to be adopted if it is simple and well defined.
Trialability	The degree to which the innovation may be piloted to explore the implementation of the procedure, its acceptability to patients, and the potential outcomes.
Observability	The degree to which the results of the innovation are visible to others.

case produced by WHO) into constrained health systems. This case illuminates the particular challenges of frequent and radical changes pertaining to health policy implementation in the global south.

Global infant feeding guidelines in PMTCT programmes

Acting upon the evidence that HIV can be transmitted through breastfeeding [14,15], the World Health Organization (WHO) developed a series of global infant feeding guidelines on how an HIV positive mother should feed her infant. The guidelines targeted policy-makers, health workers and HIV-infected mothers. Over time, these series of guidelines involved major changes in the infant feeding recommendations for women living with HIV.

WHO issued new infant feeding guidelines in 1992, 1997–98, 2000–01, 2003, 2006, 2009, 2010, 2012, and 2013. The major changes and the rationale underlying the changes can be summarized as follows:

- 1992: Breastfeeding was strongly encouraged for both HIV-infected and non-infected women with the rationale that the risk of malnutrition and death in infants from not breastfeeding outweighed the risk of HIV infection from breastfeeding [15].
- 1997: Choice of infant feeding method by mothers was encouraged after they had been counselled about the risk of breastfeeding and the risks of not breastfeeding. The rationale was based on new evidence about the risk of HIV transmission through breastfeeding, coupled with a stronger emphasis on patients' rights to participate in healthcare decision-making [16].
- 2000–01: Exclusive replacement feeding (formula feeding) was recommended as the first option for HIV-infected mothers if found to be 'acceptable', 'feasible', 'affordable', 'sustainable' and 'safe' (AFASS) in the particular context [17] owing to fear of exposure to HIV in mothers' milk. In cases where formula/replacement feeding was not considered to be AFASS, exclusive breastfeeding with rapid cessation at six months was recommended in order to reduce the risk of mixed feeding
- 2003: Exclusive breastfeeding for the first six months of life was recommended as the first infant feeding choice for HIV-infected mothers due to the improved HIV free survival with exclusive breastfeeding [17,18] including the recommendation of abrupt cessation of breastfeeding after six months to prevent mixed feeding patterns.
- 2006: An extended period of breastfeeding was allowed for. The rationale behind the change was an increasing number of studies that documented improved HIV-free survival with exclusive

breastfeeding [18–22], combined with evidence of increased death and malnutrition in formula-fed infants.

- 2010: Twelve months of breastfeeding was recommended (six months exclusive breastfeeding and the introduction of complementary feeds thereafter) [23]. This change was based on evidence showing the efficacy of antiretroviral drugs (ARVs) in preventing postnatal transmission during breastfeeding [24].

Most countries have largely adopted the HIV and infant feeding guidelines developed by the WHO with only minor modifications. Tanzania is an important case in point. Table 2 briefly summarises the main WHO policy shifts, and Tanzania's response to them.

The PMTCT programme in Tanzania

The PMTCT programme was introduced in Tanzania in 2000, starting with referral hospitals as pilot areas, followed by a rapid nation-wide scale-up from 2003 and onwards. The programme relies largely on donor support. The implementation of the programme has been guided by national guidelines that to a considerable extent have followed the changing WHO recommendations (as indicated in Table 2) [25–27]. The PMTCT services provided in Tanzania have aimed to include routine HIV testing and counselling, antiretroviral (ARV) treatment and prophylaxis for mothers and children, safer delivery practices, counselling and support for safer infant feeding practices, and long-term follow-up care for mother, child and family. The programme is implemented within health facilities that provide reproductive and child health (RCH) services including hospitals, health centres and dispensaries, both public and private. The policy has been to train at least one member of staff on PMTCT and its subsequent changes in every health facility providing PMTCT services.

In 2013 Tanzanian authorities reported, without any reference to quality or structure, that 96% of the RCH facilities had integrated the PMTCT programme, albeit with variations in implementation rates across the country [28]. During the decade of PMTCT programme implementation, Tanzania has seen a positive trend towards the reduction of HIV infection among pregnant women from 6.9% in 2008 to 3% in 2012 [29]. Despite the reduction in HIV prevalence, the country has experienced substantial challenges related to preventing postnatal transmission, particularly related to breastfeeding. A number of studies have documented implementation challenges, especially of the 2001 guidelines, which, with their recommendation of early and abrupt weaning, were most radically different from customary feeding patterns of prolonged breastfeeding with early initiation of

Table 2 Summary of infant feeding changes of the global infant feeding guidelines for HIV infected mothers

YEAR	World Health Organization	Tanzania
1992	• Breastfeeding	• Adopted
1997	• Right to choose either to breastfeed or use replacement milk	• Adopted
2000/2001	• Replacement feeding first option when AFASS criteria are met	• Adopted
2003	• Exclusive breastfeeding for the first 6 months first option; abrupt cessation at 6 months • No mixed feeding; alternatively replacement feeding using formula or animal milk; heating of mother's milk	• Adapted in 2003: Animal milk was encouraged for replacement fed children • Heating of mothers' milk not recommended
2006	• Exclusive breastfeeding for the first 6 months first option; extend breastfeeding if replacement feeding is not AFASS • No mixed feeding for the first 6 months of age; alternatively replacement feeding using formula or animal milk; heating of mother's milk; wet nursing	• Adapted in 2007, heating of mother's milk and wet nursing not recommended.
2010	• Breastfeeding for 12 months: i.e. exclusively for the first six months then introduce complementary foods thereafter • ARVs are administered during the breastfeeding period; Express and heat mothers' milk if ARVs not available; Gradual weaning • Decision regarding feeding option is left to the country • Animal milk strictly prohibited	• Adapted in 2011

supplements [30,31]. Other than the studies mentioned, there is a dearth of information about the dissemination process during this period of rapidly and radically changing policies and clinical guidelines on HIV and infant feeding. Our study aimed to explore the ways in which changes in the infant feeding guidelines have been communicated to and understood by the regional and district level managers of the PMTCT programme as well as the health workers in charge of the PMTCT programme at the health facilities.

Methods

The study setting

The study was conducted in Mbarali District in Mbeya Region in 2011. According to the 2012 National Population Census, Mbarali has a population of 300,517 people (males =145,867, females = 154,650) [32] with a growth rate of 2.7%. The district is predominantly rural, and is populated largely by rice cultivating farmers from Sangu, Hehe, Bena and Nyakyusa ethnic groups and livestock keepers from Sukuma and Maasai ethnic groups. The district is served by both public and private health facilities: two hospitals (one public and one private), four health centres and 43 dispensaries. The coverage of the PMTCT programme services, introduced in the district in 2005, was 56% in 2008 [33], but was, during the study period, scaled up to 86%, i.e. to 32 of the 37 health facilities providing Reproductive and Child (RCH) health services (2011, personal communication by the first author).

Mbarali was chosen as a study site because the infant feeding sub-project was part of a larger EU- funded health systems research project, REACT - "Response to

accountable priority setting for trust in health systems". REACT assessed the application of the ethically based priority setting framework 'accountability for reasonableness' (AFR) [34]. HIV/AIDS was one of the focus areas of the project. The Mbeya region has a HIV prevalence of 9%, well above the national estimates of 5.1% [29]. The PMTCT programme seemed to provide a particularly interesting point of departure because of the many and substantial policy changes within infant feeding that had characterized this high-profile global health intervention.

Study design

Because the project aimed at generating knowledge about the dissemination and communication of information about clinical guidelines within the health system, a qualitative design with an exploratory approach was deemed appropriate. A triangulation design was chosen, combining individual in-depth interviews (IDIs) and focus group discussions (FGDs). The focus groups were used in an attempt to probe deeper into the findings in the IDIs and to enhance the validity of the findings.

Recruitment of informants

We aimed to interview individuals who were centrally located within the running of the PMTCT programme. All study participants had experience from different levels of administration of or more concrete management of the PMTCT programme. Regional, district and health facility levels were targeted as these are the administrative levels with most direct contact with the PMTCT programme. The main categories of informants included: 1) members

of the regional management team (three individuals); 2) members of the district management health team, both permanent and co-opted members (nine individuals); and 3) PMTCT in-charges at health facilities (10 individuals, five in rural and five in semi-urban settings). In addition, two FGD focus group discussions were carried out with health workers at the health-facility level (public and faith-based hospitals) with 12 and 10 participants respectively (Table 3). The aim of the FGDs was to discuss the findings from the IDIs to increase the knowledge gained from the health workers who have the day to day contact with the women targeted by the policies. All the regional informants and six from the district level had followed the PMTCT programme since its introduction in their respective areas. However, at the health facilities variations existed depending on the period when the programme was introduced, since the scaling-up started with hospitals, then health centers followed, and lastly the dispensaries with RHC services. Three district officials and two health workers had experience of less than two years. All informants could recall some of the changes that had taken place in the infant feeding guidelines, and a majority of them received some training on PMTCT management.

The District HIV/AIDS focal person helped to identify and select the health facilities and potential care providers we could approach for participation in the study. The District Medical Officer facilitated the identification of potential district and regional informants. We recruited informants at health facility level from both rural and urban areas. The exact number of informants was not pre-determined; recruitment continued until there was a general sense that major themes/findings were repeated, indicating a general level of data saturation. The topic did not emerge as particularly sensitive, and the recruited informants were highly engaged in the study topic. No one who was approached declined to take part in the study.

Data collection

An interview guide was developed for the IDI's (with some variation pertaining to level), and a broader topic

Table 3 Data collection methods and number of informants

Data collection method	Informants	No. of IDIs/FGDs	No. of participants
In-depth interviews (IDIs)	Health facility PMTCT in-charges	10	10
	District managers	9	9
	Regional managers	3	3
Focus Group discussions (FGDs)	Health workers from faith-based institution	1	10
	Health workers from government institution	1	12
Total participants			44

guide was developed for the FGDs. The guides focused on the following main themes: (1) *awareness about the changes and content of the various infant feeding policies for women living with HIV*, (2) *knowledge about the reasons behind the various policy changes* (3) *information provided to relevant stakeholders about the HIV and infant feeding policy at various points in time* and (4) *reflections on the way the HIV and infant feeding policies and guidelines were communicated*.

While it is difficult to avoid bias in qualitative studies, an effort was made to reduce it. The interviews were conducted in venues within the office premises of the interviewees but in a separate room in attempts to enhance the freedom of expression, confidentiality, privacy and noise reduction. The study participants in both the IDIs and the FGDs eagerly engaged in the discussion about the information received about the PMTCT guidelines, and the large majority had lots of experience and opinions to share. Each IDI and FGD lasted between one and two hours. Emphasis was placed on letting the participants discuss without interruption, allowing for emerging responses and probing. In the FGD an effort was made to ensure that no single participant dominated the discussion. At the closing of each theme the moderator (the first author) made attempts to sum up the main points brought up, asking for the participants' feedback.

To enhance validity and further reduce potential bias of the informants' responses, all interviews/discussions except three IDIs were tape recorded with the permission of the informants.

Data analysis

In qualitative research, the data analysis starts in the field, implying continuous interpretive processes. The IDIs and FGDs were transcribed verbatim by a competent social scientist with previous experience of transcription. The first author carefully read all the transcripts and listened to the audio-tapes to confirm what was written and to gain a sense of the main emerging themes. The second stage involved close re-reading of each transcript, developing codes by summarizing the content of each sentence or sequence of text seeking to capture the key idea in each section. To as large an extent as possible the informants' own expressions were employed as codes. The last author of this paper also read a number of the transcripts, and the codes developed were carefully discussed between the first and the last author to enhance coherence. During the next stage, the codes were sorted into larger categories, and were finally linked to the main themes brought up in the interview guides such as 'awareness of the changes in the infant feeding guidelines', 'the reasons behind the changes'; and 'communication challenges'. The data analysis was carried out manually. Detailed matrices containing the key findings were created, making it possible to

detect evolving responses and similarities and differences among and between the different levels of informants. Triangulation in data collection aims to increase the understanding of complex phenomena using different sources [35]. In this study triangulation of data from the IDIs and FGDs was carried out in a manner where information gained in the IDIs was dwelled upon in the FGDs in attempts at refining, nuancing and validating the findings.

Ethical considerations

The study obtained ethical clearance from the Medical Research Co-ordinating Committee (MRCC) of the National Institute for Medical Research in Tanzania (NIMR/HQ/R.8a/Vol. IX/1094). Permission to conduct the study was also received from the regional and district authorities in Mbeya and Mbarali. Oral informed consent was sought from informants at all levels after the aims of the study had been explained. Informants were assured of the voluntary nature of participation, and of their right to withdraw from the discussion at any time without consequences. The principles of privacy and confidentiality were strictly maintained throughout the study.

Results

Misconceptions and lack of knowledge about the PMTCT guidelines

The findings section emphasizes the prime study findings; namely the many challenges experienced in receiving sufficient information about the continuously changing HIV and infant feeding guidelines. The regional informants were aware of the entire period of HIV and infant feeding guidelines, including the relatively recent 2010 guidelines, so the interviews with this category covered the entire period the PMTCT programme had operated in Tanzania. With the district and health facility informants, the period from 2005 was discussed as this was when the PMTCT programme was introduced in Mbarali. Before presenting the challenges of communication experienced, we will briefly discuss the understanding of the infant feeding policies that we encountered among the study participants.

Despite there being an understanding of the major policy changes in the PMTCT infant feeding recommendations during the past decade, we found serious gaps of knowledge at every administrative level included in the study. Knowledge gaps, for example, included the serious misunderstanding that the 2000 WHO guidelines promoted replacement feeding only, i.e., the informants were not aware that the policy at this time presented an option of breastfeeding if replacement feeding was not considered to be feasible. This misunderstanding was found as high as at the regional level. The changes that were introduced in the 2003–2007 policy were thus perceived as a

move from an *'authoritative'* (providing no choice) to a more *'friendly'* approach providing HIV-infected mothers with alternatives – alternatives that had, in reality, been in the PMTCT guidelines all along.

A fundamental lack of awareness of the scientific explanations behind the many policies was a theme that ran throughout the material. For example, the scientific basis behind abrupt vs. gradual weaning, or behind the recommendations of first allowing for and later removing the possibility of using animal milk as replacement product. Serious misunderstandings were moreover encountered: *"Research evidence has revealed that abrupt cessation or early cessation increases the risks of HIV transmission to the babies"* (IDI-regional informant).

Vital policy changes were not widely known among the informants. For example, few informants knew that the 2007 Tanzania guidelines opened up for HIV-infected mothers to continue breastfeeding after six months, and to introduce complementary foods until they could wean their infants safely. When asked about the most recent recommendations, most of the informants answered six months of exclusive breastfeeding with abrupt cessation, a policy that had long since been replaced in Tanzania. Importantly however, all the study participants expressed a strong belief in exclusive breastfeeding being linked to the observation of HIV free babies born by HIV infected mothers.

Top down communication challenges

Informants were asked about the ways in which changes on infant feeding guidelines had been or were presently communicated. At the regional level, stakeholders were informed by national managers through workshops and meetings, whereas at the district and health facility levels healthcare providers were informed by regional managers through training. Training sessions had, for example, been provided on testing and counselling, on how to administer ARVs as well as on how to advise mothers on best feeding practices, how to prepare replacement milk and on how to ensure early infant diagnosis. In both IDIs and FGDs at health facility level, this training was said to be characterized with a top-down approach, and care providers did not feel they were given sufficient opportunity to question or comment upon the recommendations.

The challenges encountered in communicating the continual modifications were increased by confusion over how to deliver messages that in themselves were difficult to grasp.

Communicating a complex public health message: ". . . there is a likelihood that they will forget"

The enormous challenge of trying to communicate a public health message that was perceived to be not feasible in the local context ran through the discussion. The

district and health facility informants particularly emphasised the difficulties in delivering the message about formula feeding to the HIV-infected mothers. Most of the mothers were from rural areas with limited education and very low incomes. Thus, the care providers in both FGDs and IDIs explained that it was difficult for these mothers to meet the standards required for replacement feeding:

"The information about the preparation of replacement feeding is difficult for mothers to understand... This might be taken by policy-makers as a challenge, and alternative ways should be sought rather than (merely promoting) issues of heating mother's milk" (IDI-district informant).

After the substantial difficulties faced in delivering the messages on replacement feeding, regional informants found the 2011 recommendations that allowed for an extended breastfeeding period reassuring:

"We cannot teach care providers to tell mothers to rely on replacement milk. It is difficult because the criteria required for replacement feeding are difficult for rural women to understand; there is a likelihood that they will forget when they are required to adhere to all of them" (IDI-regional informant).

Communicating a constantly changing message: ". . . that is where the confusion started"

The frequent changes in the infant feeding guidelines were said to confuse the PMTCT managers. It was perceived to be challenging to deliver new messages in a comprehensible and trustworthy manner to lower level care providers, who in turn would have to present the information to the HIV-infected mothers. All managers at regional level complained about this issue.

"In 2000, we were entrusted with advising HIV-infected mothers not to breastfeed as the risks of transmitting infection were high. Later on we received training, and that is where the confusion started, because we were asked to advise HIV-infected mothers to breastfeed rather than rely on supplementary milk" (IDI-regional informant).

A regional informant was also frustrated about the changes, fearing for his reputation:

"At one time you tell them 'don't allow mothers to breastfeed', another time you come and insist strongly 'you should advise mothers to breastfeed'. Care providers might consider you confused" (IDI-regional informant).

Another regional informant revealed similar frustration regarding the changing messages, this time relating to the acceptance of vs the banning of animal milk:

"These changes have brought about confusion, because in previous training we taught health workers that animal milk is recommended as it is affordable by the majority of the women, in contrast to formula milk. Now the new guidelines have banned the use of animal milk, and we are supposed to train healthcare providers. . . We don't know how we are going to make it clear" (IDI-regional informant).

Lacking reasons behind the health message: ". . . I haven't heard of any reasons behind that"

The tendency of not providing reasons or sufficient explanation for policy changes within the PMTCT programme was reported to be common in the communication surrounding the guidelines. The study informants expressed that being provided with the reasons behind the various policy shifts would have facilitated important clarifications during the training, and would have eased the education of the mothers:

"Different guidelines are produced based on the research evidence. But we managers have never seen a person from the Ministry of Health telling us that the guidelines have changed because of 1, 2, 3, etc" (IDI-regional informant).

Another explained:

"We have been told that animal milk is no longer recommended. I haven't heard of any reasons behind that. . . We were just told that 'from now on children below six months of age should not feed on animal milk. It was just a single sentence on the slide in the power point presentation" (IDI-regional informant).

Lack of explanation of the reasons for changes was found to contribute to superficial and confusing health messages:

"For example there are messages like. . . 'You (speaking to a mother) just squeeze your breast milk, put it in a pan, and then heat it and all viruses will die'. Messages like this one will definitely confuse the mothers" (IDI-district informant).

Such statements were seen to be far too shallow to allow for a proper comprehension of the particular behavioural change called for (although such message was not recommended in the Tanzanian guidelines).

A limited number of health workers in each health facility, usually only one of higher rank, was trained on the many and constantly changing guidelines. As a result, the lower cadres found it difficult to understand the rationale behind the changes as they were only briefly oriented onsite, causing mistakes of various kinds:

"You know very few staff received training. . . For example there was an HIV infected woman who was to give birth when I was out of the office; I instructed the nurse assistant on duty to provide the medicines to the mother and the child. She didn't do so because she didn't understand why the mother should also get medicines" (IDI, health facility informant).

Guidelines clouded by English academic jargon: ". . . they are more for academia"

Informants who had been exposed to one or more of the versions of the PMTCT guidelines found the language difficult to comprehend.

"If you open the PMTCT guidelines [researcher saw it on the table], their page numbers and the way they are written... there is no way our care providers will understand them. These guidelines need a person who has gone to school up to an advanced level." (IDI-district informant).

District managers found it difficult to translate or simplify the guidelines as the English language is not used in daily communication in Tanzania:

"It is extremely difficult to translate the guidelines from English into Kiswahili to meet healthcare providers' needs at the health facility level" (IDI district informant).

Another district officer explained:

"Most of our facility staff has a lower level of education, so if you give them guidelines in an English version they just put them on the table without reading them. Unless we managers provide thorough supportive supervision to clarify some of the issues outlined in the guidelines facility, staff will not understand them" (IDI-district informant).

Whereas the regional informants interviewed did not have a problem with the language used in the guidelines, informants at the district and health facility levels found the use of English language in the development of the PMTCT guidelines prohibitive for their understanding. Indeed, the majority of the health personnel at the health

facilities, the first line implementers of the guidelines, expressed that they simply did not understand the content. District informants thus found it difficult to provide refresher training to health workers employing the guides:

"Training facility staff requires that the trainers understand the guidelines thoroughly so that care providers can receive the messages correctly and consistently, (and that is not the case)" (IDI-district informant).

The care providers complained about the lack of abridged guideline versions. Posters with easy steps to take when HIV infected mothers turn up for delivery were said to be available at the hospital's maternity section only. With no summaries to help them understand the core issues, many care providers felt that they were not in a position to pass on knowledge properly about the content of the changing PMTCT guidelines. In fact, informants at the district and facility levels had difficulty understanding how many of the changes presented in the guidelines reflected the realities in Tanzanian communities; *"The guidelines are more theoretically based; they are more for academia, and don't reflect the realities in our communities"* (IDI-facility informant). Moreover, some informants suggested that the PMTCT guidelines might reflect the interests of the donors supporting their ARV provision.

A missing 'reading culture': ". . . but have they opened the manuals and read them?"

Aggravating the challenge of manuals that were not readily accessible was a reported lack of a culture of reading, even among district and health facility staff. This was a point identified by regional informants as another major limitation in a communication context:

"Some care providers think that to implement anything there must be training. For example the manual has explained the use of combination ARVs since 2007, but the health facility providers are still prescribing a single dose. If you ask them they respond... oh ... I haven't received training ... but have they opened the manuals and read them?" (IDI-regional informant).

The implication of this lack of using the manuals was a lack of understanding and the spread of rumours or hearsay like: *"mothers' milk should be warmed for some minutes to kill the virus instead of feeding the baby directly from the breasts"* (IDI, district informant). This kind of statement was commonly heard, despite the fact that the Tanzanian guidelines do not recommend the pre-heating of mothers' milk.

Lacking administrative procedures: "Here are your books"

The lack of sufficient knowledge was partly linked to a perceived lack of supportive supervision from the district level. Most of the informants at district and health facility levels also reported the lack of a clear administrative structure that would facilitate a smooth flow of communication of information. This led to poor distribution of PMTCT related information to the lower levels:

"You can receive a phone call from the region; if you go there they tell you 'here are your books', and if you open them you find that they are guidelines. In the district, I also circulate them to the health facilities without any discussion, because even those who bring them simply just dump them" (IDI-district informant).

At the district level, the informants reported poor links between the departments that play direct and indirect roles in the PMTCT programme, making it difficult to enforce the implementation.

Missing clinical PMTCT guidelines: "We implementers have never seen it"

Some versions of the PMTCT guidelines were found to be available at the district offices and at a few health facilities, but many informants complained of not having received a copy of the updated recommendations;

"The national staff may change the guidelines but we implementers never get them. You see? Recently we were told that there is a preventive package outlined in the national strategic plan of 2009. We implementers have never seen it. But there [at national and regional level]. . . they have it" (IDI-district informant).

This problem was also reported by the health facility staff: *"There is a problem in the distribution of the guidelines. Some of them are not available at our health facilities"* (IDI-health facility informant). The same complaints emerged in the group discussion with health workers at faith-based health facility who described receiving little attention from the district in terms of getting copies of the continuously changing guidelines, giving them no chance of retrieving updated information.

Discussion

In the discussion of the study findings, we will draw upon Rogers well-established 'diffusion of innovation theory' [13] as it seems particularly suited to highlighting key challenges that emerged in the study. Use of FGDs and IDIs have helped to elicit views from different informants related to the communication of infant feeding guidelines, the views that can be well linked with Rogers

theory. Sanson-Fisher [36] argues that Rogers' 'diffusion model' is particularly useful in providing insights into why some practices change as a response to particular health interventions while others do not. We shall attempt to assess the PMTCT guidelines as revealed in our findings in terms of (1) 'relative advantage', (2) 'compatibility', (3) 'complexity', (4) 'trialability', and (5) 'observability', to recall the theory's five elements. First, we will briefly consider the meaningfulness of each of these aspects in the context of our research findings.

Relative advantage

'Relative advantage' turns our attention to the degree to which 'an innovation is perceived as better than the idea it supersedes' ([13] p. 212), and as such indicates the benefits and costs resulting from the adoption of the innovation. This point emerges as immediately relevant when assessing the serious confusions and misunderstandings documented in this and other studies pertaining to the implementation of the many changing WHO infant feeding recommendations [37]. The proposed changes were, as we have seen above, not always perceived as better than the practice they were to replace. The recommendation that an HIV-infected mother should not breastfeed her baby if replacement feeding was 'acceptable, feasible, affordable, sustainable and safe' (AFASS), was clearly perceived as a problematic given that many mothers in low income contexts cannot afford infant formula [38,39]. The information that HIV-infected mothers - for whom replacement feeding was 'not AFASS' - should exclusively breastfeed, knowing that there is HIV in breast milk, was similarly perceived as a problematic and frightening idea.

This indicates that there was doubtful side to each infant feeding recommendation.

It is important to recall that this particular PMTCT policy (2000-01) was introduced in a context of devastating experiences of AIDS-related death in large parts of sub-Saharan Africa, and was combined with increasing awareness that HIV-infected mothers in rich parts of the world were counselled not to breastfeed in order to avoid HIV-transmission to their infants. In a context where the horrors of mass AIDS-related death in infants was feared, it was the message of replacement feeding as the only option that was preached. The confusion regarding the policy of early and abrupt cessation of breastfeeding, and the later policy preaching against giving infants animal milk produced similar confusion.

Although the response on the increased risk of HIV infection due to abrupt cessation was interpreted as misunderstanding, the later study that was published 2013 has revealed a similar scenario whereby HIV concentration increased in breast milk after breastfeeding cessation than when breastfeeding was continued [40],

revealing the validity of the quote provided in the Results section. The confusion can again be explained by the fact that the recommendations could hardly be perceived as having a 'relative advantage' compared with those they were to replace. Relative advantage is seen by Rogers as a prime indicator of success.

Compatibility

The second element in Rogers' theory – 'compatibility' – emerges in our material as closely related to 'relative advantage', and refers to the degree to which an innovation is seen as compatible with the existing values, past experiences, and needs of the target population ([13] p. 224). This relates to the fundamental recognition that decision-makers have to consider the relevance and appropriateness of an intervention for any local setting. Let us briefly recall a few examples from the study to discuss the relevance of this point. Although regional managers perceived earlier on that avoidance of breastfeeding was the only solution in preventing HIV infections in infants, there was a very quick realization that dependence on infant formula was incompatible with the lives of the HIV-infected mothers, for a complex mix of economic, social and cultural reasons. In short, formula milk was too expensive. In addition, the PMTCT programme was confronted with the normative position of breastfeeding, and its deep-seated connection to motherhood within which the practice is embedded [31,39,41,42].

Beyond the lack of congruence between the various policy recommendations and the local cultural and economic context, the study findings suggest a lack of compatibility between the policy changes' massive demands for communication and the realities on the ground. The frequent and radical changes proposed in the guidelines had to reach and be understood not only by key individuals in the PMTCT chain, but also by a vast network of stakeholders within and beyond the health system. The study findings reveal that the means and structures needed to facilitate such complex communication of information were not in place.

At one level the challenge was related to the lack of sufficient training. The workshops that were organized to educate PMTCT managers and care providers were characterized by top-down teaching; care providers were given little opportunity to question and comment upon the feasibility of the interventions. Rogers' theory emphasizes that one-way communication - from 'experts' to stakeholders – is problematic because it leads to information being transferred from the 'source' to the receiver without discussion ([13] p. xvi).

In other studies conducted in Africa, health workers have similarly reported limited capacity to carry out proper infant feeding counselling due to lack of supportive supervision and inadequate knowledge and skills

[43,44]. Without a general understanding of the rationale behind the continual changes, health managers and healthcare providers felt uncertain and found it difficult to implement the new policies. The demands for continuous updating and training implied in the PMTCT programme were simply not matched with the resources and structures encountered on the ground. The lack of compatibility between the many proposed changes in infant feeding and locally established values and practices, as well as the inability of existing structures to ensure dissemination of the information created a most challenging backdrop for the introduction of new recommendations.

Complexity

Rogers' 'complexity' concept refers to 'the degree to which an innovation is perceived as difficult to understand and use' ([13] p. 242). He suggests that clinical procedures are 'more likely to be adopted if they are simple and well defined.' With reference to our material; the scientific knowledge underpinning the many and diverse PMTCT policies has simply not been easy to understand. It is, for example, challenging to explain that 'there is HIV in your breast milk which can infect your infant, but if you *only* breastfeed the likelihood of transmission is very low'. It was also highly challenging for the health workers to relate to the demanding assessment implied by the AFASS criteria. The many and radical policy shifts seriously complicated the process of presenting key concepts in a straightforward manner.

The sense of complexity in the intervention has been increased by the lack of simple information and instruction materials. The study informants referred to the large and complex PMTCT manuals written in language that was not easily comprehensible to people without higher education. The manuals were written in English rather than in Swahili, the *lingua franca* of Tanzania, and the language barrier was naturally seen to add to the knowledge gap. Proper translation of the recommendations was therefore not secured. Neither did the informants find any guides or pamphlets that communicated key policy information including the evidence or reasons behind the policy changes. These findings are contrary to what Jackson and Feder recommend as vital, namely that the evidence and recommendations should be presented in a concise, accessible manner and in a format that makes it possible for the implementers to understand and enforce them [3]. Jackson and Feder's ideas are in line with what Rogers advocates under the 'complexity' element. Our finding that there is a lack of a "reading culture" among health workers emphasises the importance of simple and clear information. Bowen [45] in his study from Canada points out how the language barrier contributes to low participation of stakeholders in various interventions, increases the risk of misdiagnosis,

poor patient understanding of the recommendations, low patient satisfaction, and low quality of care with implications for poor health outcomes. Brinkher and Crosby (2002) argue that the development of a strong rapport requires the use of a language that makes the proposed recommendation understandable and appealing to potential supporters [46]. Others have likewise suggested that a main requirement of a successful implementation process is producing guidelines in a user-friendly format [3,47].

Rogers' diffusion of innovation theory stipulates that complexity in communicating new policy may arise from the complexity of the innovation itself or from its modality of delivery. Findings from our study indicate that, in the PMTCT programme, both the policy itself and the delivery mode have been challenging, and have matched poorly with the realities on the ground. This has led to confusion and frustration among health managers, care providers and HIV infected mothers alike.

Trialability

Trialability refers to the degree to which the proposed innovation is tested to assess how it works in the specific conditions ([13] p. 243). Trialability thus aims at exploring the feasibility of the implementation of the procedure, its acceptability to patients, and the potential outcomes prior to its intervention. The frequent policy changes in the WHO's infant feeding recommendations in the PMTCT programme point to a lack of sufficient evidence relating to the outcomes of the intervention. Before the PMTCT programme was scaled up in Tanzania, it was piloted in a few referral hospitals, but the last decade has clearly proven that the pilot was not sufficient to avoid massive confusion and frustration during the implementation of the programme. The review by Van de Perre et al. [10] argues that, in the case of the PMTCT programme, the WHO produced global recommendations which lacked the necessary scientific basis in terms of clinical trials, and was largely based upon 'expert' opinion.

Observability

Rogers writes that the observability of positive outcomes of an innovation is positively related to its rate of adoption ([13] p. 244). The question of observation of positive or productive outcomes of the many infant feeding recommendations was not discussed in a direct manner with the study participants. However, the observable negative outcomes of the policy of replacement feeding as first choice have been reported by Moland and Blystad [39], and shows that hardships produced by the PMTCT policy led to continuous attempts at modification. Informants, in our study, would mention the trust they had developed in recent years towards the recommendation of exclusive breastfeeding, pointing at the observable outcomes of HIV free babies who were born and breastfed

by HIV infected mothers. This immensely important observation has been vital in a PMTCT context. The success of the recent emphasis on extended breastfeeding and complementary feeding has, in a powerful manner, demonstrated the significance of the Rogers' other points: the breastfeeding policy was seen to have a relative advantage over earlier recommendations; it was compatible with local culture; it did not imply a complex message; and it has been tried out as a successful strategy for infant feeding; for thousands of years.

Study limitations and strengths

This study has several limitations. The sample size is limited as it was carried out merely within one district in Tanzania and it did not include the national level which could have informed the study of PMTCT policy dissemination and communication in important ways. The beneficiaries (the women) were not included in this study because the aim was to focus to health workers and managers who were to communicate the messages of the frequent changes of the guidelines to the lower levels. Despite these limitations, we believe that the study findings may be of interest and relevance for other Tanzanian districts dealing with the communication of PMTCT related policy. We suggest that the findings may potentially be of interest to the study of communication of health related policy or guidelines at a more general level, particularly within weak health systems.

Conclusion

The study has revealed substantial challenges in the implementation of changing global HIV and infant feeding guidelines among healthcare managers at regional, district and health-facility level. The challenges were related to the incompatibility of the infant feeding recommendations with the local socio-economic context but also to factors beyond that. Structural barriers generated severe challenges to the dissemination of information within the programme. Current HIV and infant feeding guidelines have turned in a direction that is more compatible with local perceptions and practices, and it is more feasible for the health system and the HIV-infected mothers to relate to them. This generates hopes that lessons have been learnt in terms of the multiple challenges that are likely to arise in when new and updated clinical guidelines are introduced at ever-increasing speed within weak health systems.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

EHS conceived the idea of the project in collaboration with AB, and collected and analysed the material and developed the manuscript. AB, KM, BBV, PK reviewed and contributed substantial inputs to the manuscripts. All approved the final version of this manuscript.

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APPENDICES

I. Research institutions participated in the REACT project

- | | |
|---|---|
| 1. DBL-Centre for Health Research and Development, Denmark. Co-ordinating institution | 7. Primary Health Care Institute (PHCI), Tanzania |
| 2. Centre for International Health (CIH), University of Bergen, Norway | 8. Research Centre for Public Health Research (CPHR), Kenya |
| 3. Prince Leopold Institute of Tropical Medicine (ITM), Belgium | 9. Institute of Anthropology, Gender and African Studies (IAGAS), Kenya |
| 4. Umeå International School of Public Health (UISPH), Sweden | 10. Department of Community Medicine (DCM), Zambia |
| 5. Institute of Development Studies (IDS), University of Dar es Salaam, Tanzania | 11. Institute of Economic and Social Research (INESOR), Zambia |
| 6* National Institute of Medical Research (NIMR), Tanzania | 12. Joint Centre of Bioethics, University of Toronto, Canada |
-

II. STUDY PHASE ONE: DATA COLLECTION TOOLS

REACT WORK PACKAGE FIVE

In-depth interviews

Introduction

- Information about the project, the purpose of the interview
- Explain what the information will be used for
- Information on the ethical principles that guide the research
- Ask for permission to tape-record the interview

Interviewee information

- Age, marital status, number of children, ethnic group, clan, occupation, educational level, place of residence (rural/urban)
- Role/status of the informant in decision making processes, i.e. what office, elected or appointed position does the informant hold
- What terms do you employ to describe the concepts '*quality*', '*equity*', '*access*', '*trust*' and '*fairness*' ?
- Are these concepts relevant in a decision making context at health district level?
- What do you value as most important in decision making processes? (with reference to the concepts introduced in the two bullet points above)

The decision making process

- This question implies a general and broad mapping of the decision making process (with more concrete questions following below). Re: the mapping of the decision making process it is important:
 - to ask for the procedures followed in a regularly scheduled meeting (channels regarding information about the meeting, the sequencing of diverse activity, welcome, minutes, agenda, hearing of members' views / participation, decision making, decision regarding new meetings, closing of meeting)
 - to observe concrete meetings (if possible)
- How are decisions made in the decision making bodies in which you participate ?
 - By vote, by reaching consensus, force, the most central leaders decide, other? (ask for examples of how a good decision / a poor decision is made)
 - Whose views are most important in the discussion / deliberation (elected members, appointed members, ex officio members, others, + cf. points detailed below) ?
 - Potential external influence on the decision making process (elders, religious leaders, rich individuals, churches, institutions at other levels, others)?

Characteristics / statuses with potential influence on decision making / priority setting at district/health facility/community level

- Gender and leadership / decision making:
 - What is the level of women's representation in decision making?
 - To what extent are women's views taken into consideration?
 - Examples of committees / institutions where women are particularly visible / influential
 - Examples of activities / situations where women are not visible / influential in decision making processes ?
 - Has gender been emphasized more in decision making processes in recent years ?
- Economic status and leadership / decision making:
 - How does economic status (income from business, large number of cattle ++) affect influence on decision making processes ?
 - Examples of activities / situations where wealthy individuals are particularly visible / influential, alternatively are not visible / influential in decision making processes?
 - Examples of activities / situations where economically weak or poor people are particularly visible / influential, alternatively are not visible / influential in decision making processes ?
 - Is individual leaders' economic status becoming more / less important in terms of actual influence?
- Formal educational level and leadership / decision making:
 - How does educational level affect decision making?
 - Examples of activities / situations where people with high education are particularly visible / influential, alternatively are not influential in decision making processes?
 - Examples of activities / situations where people with low education are particularly visible / influential, alternatively are not visible / influential in decision making processes?
 - Is individual leaders' educational level becoming more / less important in terms of individuals' leaders' influence?
- Age and leadership / decision making:
 - How does age affect decision making and influence?
 - Examples of activities / situations where people with old age are particularly visible / influential, alternatively are not visible / influential in decision making processes?
 - Examples of activities / situations where young individuals are particularly visible / influential alternatively are not visible / influential in decision making processes?
 - Is individual leaders' age level becoming more / less important in terms of influence?
- Ethnicity and leadership / decision making:
 - How does ethnicity affect decision making / influence?
 - Examples of activities / situations where people with certain ethnic affiliation are particularly visible / influential, alternatively are particularly invisible / non-influential in decision making processes?
 - Is individual leaders' ethnic affiliation important in terms of influence?
 - Is any ethnic group marginalized in decision making?

- Any change in recent years regarding the importance of ethnicity in decision making processes?
- Religious affiliation and leadership / decision making:
 - How does religious affiliation affect decision making / influence?
 - Examples of religious groupings that are particularly visible / influential, alternatively are not visible / influential in decision making processes?
 - Are individuals in religious leadership positions particularly influential in decision making processes; alternatively are any individuals in religious leadership positions particularly invisible in decision making processes?
 - Potential conflict lines between the diverse religious groups in the area in terms of leadership positions / decision making?
 - Any marked change in terms of religious influence over decision making processes?

Closing remarks

- Ask for potential additional areas of relevance not touched upon in the interview that could be added
- Thank the informant for his/her participation!

FGD GUIDE with district officials

Introduction of the investigators and the project objectives

Seek consent for the district officials to participate in the FGD

Seek consent for tape recording

Self introduction of the participants including their positions, age, education and the duration they have stayed in the district with the respective positions

Fairness

- What is your understanding of fairness?
- Kindly describe the relevance of fairness in setting priorities and in health related decision making in general

The decision making process

- What are the procedures followed in a health related decision making process in the district? Who is involved and how
- How are decisions made in the decision making bodies in which you participate?
 - Probe: By vote, by reaching consensus, force, the most central leaders decide, other? (ask for examples of how a good decision / a poor decision is made)
- Whose views are most important in the discussion / deliberation (elected members, appointed members, ex officio members, others, + cf. points detailed below)?

- Potential external influence on the decision making process (elders, religious leaders, rich individuals, organizations, churches, institutions at other levels, others)?

Characteristics / statuses with potential influence on decision making / priority setting at district/health facility/community level

- Gender and leadership / decision making:
 - What is the influence of gender in the decision making processes. Probe if males and females have equal chance to participate and to be listened to
- Economic status and leadership / decision making:
 - How does economic status of an individual influence on decision making processes? Probe for examples focusing on reach and poor individuals
- Formal educational level and leadership / decision making:
 - How does educational level affect decision making? Probe for examples focusing those with low and high level of education
- Age and leadership / decision making:
 - How does age affect decision making and influence?
- Ethnicity and leadership / decision making:
 - How does ethnicity affect decision making / influence? Probe for examples focusing on majority and minority ethnic groups
- Religious affiliation and leadership / decision making:
 - How does religious affiliation affect decision making / influence? Probe for examples

Closing remarks: Thank the participants for their participation

III. STUDY PHASE TWO: DATA COLLECTION TOOLS

IN-DEPTH INTERVIEWS WITH REGIONAL INFORMANTS

General information

1. I would like to get the information about your age, sex, marital status, ethnic group, occupation, educational level, place of residence (rural/urban)
2. What are your responsibilities at regional level as far as PMTCT services are concerned?

Now I would like to discuss about priority setting on PMTCT services

3. Currently what are the priority PMTCT services at national/regional level?
 - Who is specifically responsible to identify priority related to the PMTCT activities? (Remind on the annual health planning).
 - How are priorities related to PMTCT set at the district level in the planning process? Where are the identified PMTCT priority activities accommodated?
 - Were you involved in setting such priorities? (Probe when, where, how and specifically for what?).
 - a. What input did they seek from you?
 - b. Why did they decide to involve you?
 - c. Which information did they request you to bring with? (probe where she/he gets such information)
 - d. What were the criteria used to arrive to those priorities
 - e. How did you arrive to those priorities? (probe for voting, consensus, etc)
 - f. What is the source of funds for the prioritized activities
4. Who has the final say in identifying priorities related to PMTCT services and HIV preventions in general? Why
5. What challenges do you encounter in setting priorities related to the PMTCT?
6. We know that district is the main implementer of the PMTCT interventions as they are closer to the people. At this level, how do you involve the lower levels and other stakeholders in the identification of priorities related to the PMTCT services are concerned? (Probe how, how often and why)
7. After decisions on PMTCT priorities are made, are you informed if you are involved in the priority setting process till the end? (Probe how and how often)
8. Do you have a room to appeal in case you are not satisfied with the decisions? Explain with example

Now I would like to discuss about decision making in the PMTCT programme and involvement of stakeholders in the information sharing

9. When was the PMTCT services introduced in this region (probe: about the progress from the time it was introduced to date, including challenges and success stories)
 - How are they implemented (probe whether they integral part of ANC services in the districts or not)

10. Before decisions were made to introduce the PMTCT programme in this region/in the country, were you involved to provide opinions to on how should it look like, type of services and the best way to implement it? Please explain
11. What are the guidelines/ policy that guide implementation of PMTCT services?
 - Probe: where did they come from and whether he/she was involved to provide some opinions? How easy or difficult to implement them with examples
 - How does the PMTCT related decision making at different levels of the health care system adhere to these policies? (Make reference to the infant feeding guidelines)
 - You at the regional level what did you do before introducing the PMTCT programme in the districts?
12. In PMTCT programme, there have been multiple changes in the guideline. Are you informed in whatever change and how? Please describe the changes that has taken place since the inception of the PMTCT programme in this region (probe on the infant feeding guidelines)
 - Are the reasons behind those decisions accessible? Are they reasonable?
 - How are different stakeholders informed of the frequent changes, what can you comment on the comprehensiveness of the messages regarding changes? (Are they adequately described? Are they well understood? Are the reasons behind changes explained)
13. What are the challenges experienced in the communication of the modifications of guidelines not the least the infant feeding guidelines?

INDEPTH INTERVIEW GUIDE FOR DISTRICT AND HEALTH FACILITY INFORMANTS

General information

1. I would like to get the information about your age, sex, marital status, ethnic group, occupation, educational level, place of residence (rural/urban)
2. What is the situation of HIV/AIDS in this district? Explain (probe about the trend from the time when the first case was reported)

Now I would like to discuss about priority setting on PMTCT services

3. Can you describe different types of PMTCT services that are advocated national wise?
4. Currently what are the priority PMTCT services in this district? (probe for the reasons).

5. Where those priorities are accommodated ready for funding?
6. How are priorities related to PMTCT set at the district level in the planning process? What guides the priority setting processes? In what part of the budget are PMTCT activities accommodated?
 - Who is specifically responsible to identify those priorities?
 - Have you ever been asked to provide inputs or submit your priority areas regarding PMTCT to the CHMT and later to the district planning team? (Probe when, where, how and specifically for what?).
 - What input did they seek from you?
 - Why did they decide to involve you?
 - Which information did they request you to bring with? (probe where she/he gets such information)
 - How did you arrive to those priorities? (probe for voting, consensus, etc).
 - What is the source of funds for the prioritized activities
 - What are the sources of funds for the planned PMTCT activities?
7. Who have the final say in identifying priorities related to HIV preventions? Why
8. After decisions on PMTCT priorities are made, do you get informed if you are involved in the priority setting process till the end? (Probe how and how often)
9. Are the reasons behind those priority decisions accessible? Are they reasonable? Please explain
10. What challenges do you encounter in setting priorities related to the PMTCT?
11. Do you/other stakeholders have a room to appeal in case you are not satisfied with the priority decision made? (Probe how and why and examples and any kind of revision made based on the complaint/input from you and others)
12. At the district/facility level, do you involve community and other district stakeholders to identify their own priorities as far as PMTCT services are concerned? (Probe how, how often and why)

Now I would like to discuss about decision making and information communication pertaining to the PMTCT services

13. When was the PMTCT services introduced in the district/health facility? (probe: about the progress from the time it was introduced to date, including challenges and success stories)
14. How are they implemented in this district/health facility (probe whether they integral part of ANC services or not)
15. Before decisions were made to introduce the PMTCT programme in this district, were you involved to provide opinions on how should it look like, type of services and the best way to implement it?
16. What are the guidelines/ policy that guide implementation of PMTCT services?
 - Probe: where did they come from and whether he/she was involved to provide some opinions? How easy or difficult to implement them with examples

17. How does the PMTCT related decision making at district level adhere to these guidelines? (reference to the infant feeding guidelines)
18. In the PMTCT programme, there have been multiple changes in the guideline. Are you informed of whatever change is made and how? (probe on infant feeding guidelines)
19. What are the major changes in the PMTCT guidelines? (probe specific on the infant feeding options for the HIV-infected mothers)
20. How are different stakeholders informed about the frequent changes, what can you comment on the comprehensiveness of the messages regarding changes? (are they adequately described? Are they well understood? Are the reasons behind changes explained)
21. What are the challenges experienced in the communication of the modifications of guidelines? (probe on the infant feeding guidelines)
22. What can you comment on the experience of involving community on PMTCT and other HIV interventions (probe for problems/challenges, success stories, failures etc)

FGD GUIDE WITH HEALTH FACILITY WORKERS

Introduction

Introduction of the investigators and study objectives; self introduction of the participants and seeking consent for their participation (refer to the consent form). In addition seeking consent to be tape recorded

Now I would like to discuss a bit about priority setting on HIV prevention interventions

1. Currently what are the priority PMTCT interventions in this district? (probe how did they get to know those priorities)
2. How are priorities related to PMTCT set at the district level in the planning process? What guides the priority setting processes? In what part of the budget are PMTCT activities accommodated?
 - i. Who is specifically responsible to identify those priorities? Probe whether they have ever been involved and how
 - ii. What are the criteria used to set PMTCT priorities?
 - iii. Who has the final say in passing priorities related to PMTCT services? Why (probe for internal influence/external influence)
 - iv. After decision on PMTCT service priorities are made, how are you getting informed?
 - v. Are the reasons behind those decisions accessible? Are they reasonable /relevant to the people? Please explain

You are the important stakeholders in the PMTCT as some of you are playing direct roles and others indirect. Now let us discuss about decision making and information communication pertaining to the PMTCT services

3. Before decisions were made to introduce the PMTCT programme in this district and particularly to this health facility, were you involved to provide opinions on how should it look like, type of services and the best way to implement it?
4. What are the guidelines/ policy that guide implementation of PMTCT services?
 - i. Probe: How easy or difficult to implement them with examples specifically on the infant feeding guidelines
5. How does the PMTCT related decision making at district level adhere to these guidelines? (reference to the infant feeding guidelines)
6. In the PMTCT programme, there have been multiple changes in the guideline. Can you comment on the way you have been informed of the changes and how?(probe on infant feeding guidelines)
7. What are the major changes in the PMTCT guidelines? (probe specific on the infant feeding options for the HIV-infected mothers)
8. How are different stakeholders informed about the frequent changes, what can you comment on the comprehensiveness of the messages regarding changes? (are they adequately described? Are they well understood? Are the reasons behind changes explained)
9. What are the challenges experienced in the communication of the modifications of guidelines? (probe on the infant feeding guidelines)

Now I would like to discuss how you involve other stakeholders

10. At this facility, how do you involve community to identify their own priorities as far as PMTCT services are concerned? (Probe how and how often and why)
 - i. How did you inform the community when PMTCT services were introduced in this facility? In case of new changes do you also inform them? (probe for mechanisms used e.g meetings, health education, leaders etc)
11. What do you think should be done to improve trust on PMTCT services and later improve uptake and roll-out of PMTCT services?

FGD GUIDE FOR COMMUNITY LEADERS

Introduction

Introduce study objectives; self introduction and seeking consent for their participation (refer to the consent form). In addition seeking consent to be tape recorded

May you kindly introduce yourself by mentioning your name, your age, education, and residency, your position in the village government and number of years you have worked with the village government?

Before starting our discussion regarding priority setting and decision making pertaining to the PMTCT, what is the situation of HIV/AIDS in your area? Explain (probe about the trend from the time).

I would like to discuss about priority setting on PMTCT interventions

1. Please, may you describe different type of priority PMTCT services in this district? (probe how did you know about those priorities,
2. Do you have an idea of who is responsible to identify PMTCT related priorities? You as leaders, have you ever been involved in setting such priorities? (Probe when, where, how and specifically for what?). if yes:
 - How did you arrive to those priorities? (probe for voting, consensus, etc)
 - What are the criteria used to set priorities?
 - Who has the final say in passing priorities related to PMTCT intervention? Why (probe for internal influence/external influence).
3. You as leaders, do you have a room to appeal in case you are not satisfied with the decision made? (Probe how and why). How about other community members?
4. After decision are being made about PMTCT priorities, are you informed of the deliberations if not involved up to the end? (Probe how)
 - Are the reasons behind those PMTCT decisions accessible? Are they reasonable /relevant to your people?

Now I would like to discuss on how the information pertaining to the introduction of the PMTCT programme and its implementation was communicated to different stakeholders.

5. In Tanzania, PMTCT services have been introduced in different districts and health facilities. Now, in this districts before the PMTCT programme was introduced, you as leaders were you involved to provide opinions on how to implement it? Please explain (reference to the infant feeding guidelines). How was the community informed about the PMTCT programme?
6. What are the challenges in communicating about the PMTCT programme recommendations? (probe for examples in the infant feeding guidelines).
7. What can you comment on the experience of involving community on PMTCT and other HIV interventions (probe for problems/challenges, success stories, failures etc).

Thank you for your participation.

NB: Guides for HIV infected mothers, pregnant women of unknown sero status and traditional birth attendants are not included because the data obtained were not used in the published papers.

IV. ETHICAL CLEARANCE CERIFICATE, STUDY PHASE I



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03rd March 2006

Dr Peter Kamuzora
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**CLEARANCE CERTIFICATE FOR CONDUCTING
MEDICAL RESEARCH IN TANZANIA**

This is to certify that the research entitled: Strengthening fairness and accountability in priority setting for improving equity and access to quality health care at district level, in Tanzania, Kenya and Zambia. (*Kamuzora P et al*) whose Principal Investigator is Peter Kamuzora, has been granted ethics clearance to be conducted in Tanzania.

The Principal Investigator of the study must ensure that the following conditions are fulfilled:

1. Progress report is made available to the Ministry of Health and the National Institute for Medical Research, Regional and District Medical Officers after every six months.
2. Permission to publish the results is obtained from National Institute for Medical Research.
3. Copies of final publications are made available to the Ministry of Health and the National Institute for Medical Research.
4. Any researcher, who contravenes or fails to comply with these conditions, shall be guilty of an offence and shall be liable on conviction to a fine.

Name: Dr Andrew Y Kitua

Signature

CHAIRMAN
MEDICAL RESEARCH
COORDINATING COMMITTEE

Name: Dr Gabriel L Upunda

Signature

CHIEF MEDICAL OFFICER
MINISTRY OF HEALTH

V. ETHICAL CLEARANCE CERTIFICATE, STUDY PHASE II

THE UNITED REPUBLIC OF
TANZANIA



National Institute for Medical Research
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Ministry of Health and Social Welfare
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Dar es Salaam
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10th December 2010

Elizabeth Shayo
NIMR Headquarters
P O Box 9653,
DAR ES SALAAM

**CLEARANCE CERTIFICATE FOR CONDUCTING
MEDICAL RESEARCH IN TANZANIA**

This is to certify that the research entitled: The Challenges of Health Related Priority Setting in Low Income Context: The Case of HIV Prevention of Mother to Child Transmission Strategies in Tanzania (Shayo E *et al*), has been granted ethics clearance to be conducted in Tanzania.

The Principal Investigator of the study must ensure that the following conditions are fulfilled:

1. Progress report is submitted to the Ministry of Health and the National Institute for Medical Research, Regional and District Medical Officers after every six months.
2. Permission to publish the results is obtained from National Institute for Medical Research.
3. Copies of final publications are made available to the Ministry of Health & Social Welfare and the National Institute for Medical Research.
4. Any researcher, who contravenes or fails to comply with these conditions, shall be guilty of an offence and shall be liable on conviction to a fine. NIMR Act No. 23 of 1979, PART III Section 10(2).
5. Approval is for one year: 10th December 2010 to 09th December 2011.

Name: Dr Mwelecele N Malecela

Signature

**ACTING CHAIRPERSON
MEDICAL RESEARCH
COORDINATING COMMITTEE**

Name: Dr Deo M Mtasiwa

Signature

**CHIEF MEDICAL OFFICER
MINISTRY OF HEALTH, SOCIAL
WELFARE**

CC: RMO
DMO

VI. Consent to participate in research

STUDY PHASE ONE

PROJECT TITLE: Strengthening fairness and accountability in health systems priority setting for improving equity and access to quality health care at district level in Tanzania, Kenya and Zambia.

PURPOSE OF THE STUDY

The purpose of the study is to improve priority setting in the district health system. This study is being conducted by *(Name of institution and country)*

CONFIDENTIALITY

Please note that no names will be used in the report or made public for any reason. If information from your interview is used in publications or reports, we will not refer to your identity in any way. All data will be kept strictly confidential.

Confidentiality will be maintained by using codes for identification of the persons interviewed and the interview transcripts. Only research team members will have access to the list of codes and the original data.

PARTICIPATION AND WITHDRAWAL

Your participation in this study is voluntary. You can choose whether to participate in this study or not. Please note that if you volunteer to be in this study, you may still withdraw at any time without consequences of any kind.

PROCEDURES

If you volunteer to participate in this study, we would invite you for an interview. This could take a maximum of one and half hours and will deal with questions related to what you know about the management practices in the health service. Please feel free to ask

questions or make comments at any time during the interview. This interview will be taped and/or notes will be taken.

POTENTIAL DISCOMFORTS

The interview will be carried out preferably during normal working hours and will involve two researchers. In order not to disturb the work of the unit or department you are working in, we request that you arrange for an appropriate time for the interview.

POTENTIAL BENEFITS

Your contribution will help us to better understand and interpret issues that will go a long way in improving quality, equity, accessibility and affordability of health care at district level. There will be no benefit for your participation in the study apart from the direct benefit to the community.

CONTACT PERSONS

If you have any questions or concerns about the study, please feel free to contact any of the following:

Name of Coordinator: PETER KAMUZORA

Contact Address: University of Dar-es-salaam, Institute of Development Studies, P. O. Box....., Phone number..... Email address.....

SIGNATURE / THUMB PRINT OF THE INFORMANT / PARTICIPANT

I understand the information provided above. Any questions or concerns I had have been answered to my satisfaction, and I willingly agree to participate in this study.

Name of Informant/Participant

Signature/Thumbprint of Informant/Participant

Date

SIGNATURE OF THE RESEARCHER

In my judgment the informant/participant is willing and has consented to participate in this study.

Name of Researcher

Signature of Researcher

Date

VII. Consent Form

STUDY PHASE TWO

The following statement will be read to all individuals asked to participate in the study.

Introduction and objective of the study

My name is, and I am working with National Institute for Medical Research and a PhD candidate at the Centre for International health, University of Bergen. I am with my fellow researcher.....We are interested in understanding how priority setting and decision making process in relation to Prevention of mother to child transmission of HIV (PMTCT) takes place in this district. We are not intending to talk to all people in this area, but have selected several (from different levels within the district) to represent views of all residents in this area. You are one of those selected to give your views in this kind of research.

The responses we will get from you and several others will be analyzed to get the general picture on how priority setting and decision making process takes place in relation to PMTCT services which will enable us to identify strength and areas for improvement. This interview will take approximately one to two hours to complete. Please feel free to participate in our study.

Confidentiality and anonymity: We are assuring you that the information you will provide will be treated as confidential and no names will be mentioned. However, you have the right to choose to participate in this study or not. You are free to terminate the discussion at any point during the interview.

Do you wish to participate? Yes No

Signature of the interviewee/ thumbprint.....

Signature of the researcher

Date

For further information please contact the principle investigator

ELIZABETH H SHAYO, NATIONAL INSTITUTE FOR MEDICAL RESEARCH,
P.O.BOX 9653, DAR-ES-SALAAM, PHONE NUMBER +255 22 2121400 OR +255
754 262924.

