

# ACCOUNTABILITY FOR HEALTH EQUITY: GALVANISING A MOVEMENT FOR UNIVERSAL HEALTH COVERAGE



# IDS Bulletin

Transforming Development Knowledge

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# IDS Bulletin

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Editors **Erica Nelson, Gerald Bloom and Alex Shankland**

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## Note

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# Foreword

Accountability mechanisms will be decisive in determining whether the needs of marginalised and vulnerable communities are met as countries, and other stakeholders, work to attain the goal of Universal Health Coverage (UHC). While equity is inherent in the definition of UHC – whereby *all* people receive the (preventive, promotive, curative, and rehabilitative) health services that they need without risk of financial hardship – there are inevitable trade-offs in policy and programming choices along the pathway towards UHC. Such decisions are highly political and they determine who benefits and who is left behind. This makes multi-stakeholder accountability mechanisms – that facilitate the cycle of monitoring, review and remedial action, and advance the principles of human rights, transparency, and participation – ever more important to ensure that UHC is *de facto* a movement for health equity.

The International Health Partnership for UHC 2030 (UHC2030) is committed to strengthening accountability for UHC, and we welcome this *IDS Bulletin* that brings to the fore concrete experiences that advance our understanding of the complex nature of accountability for health equity. This *IDS Bulletin* makes clear the importance of political economy that determines how choices are made and the longitudinal patterns of change. It acknowledges the proliferation of actors with divergent interests that influence power dynamics and can distort the social contract. And it showcases country experiences of navigating and negotiating these complex contextual realities to advance accountability for health equity. As a multi-stakeholder partnership we look to learn from this evidence in our efforts to strengthen accountability for transformational, pro-equity progress towards UHC.

The International Health Partnership for UHC 2030 (UHC2030)  
Core Team

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# Introduction: Accountability for Health Equity: Galvanising a Movement for Universal Health Coverage

Erica Nelson, Gerald Bloom and Alex Shankland

**Abstract** This issue of the *IDS Bulletin* developed out of a workshop held at IDS, 19–21 July 2017, entitled ‘Unpicking Power and Politics for Transformative Change: Towards Accountability for Health Equity’. We consider three thematic strands that emerged from the workshop. First, the nature of accountability politics ‘in time’ and the cyclical aspects of national and transnational accountability for health equity efforts. Second, the contested politics of ‘naming’ and measuring accountability, and the intersecting dimensions of marginalisation and exclusion that are missing from current debates. Third, the shifting nature of power in global health and new configurations of health actors, social contracts, and the role of technology in this new era. We conclude with a proposal for long-term approaches to the institutionalisation of accountability processes and the strategic galvanising of a broader range of partners to work towards Universal Health Coverage, as both a metric and a mechanism of achieving greater health equity.

**Keywords:** Universal Health Coverage, accountability, accountability politics, governance, health equity, health systems, institutionalisation, private sector, social accountability, global health history.

## 1 Introduction

On the fortieth anniversary of the Alma-Ata Declaration, otherwise known as the global commitment to achieve ‘Health for All by the Year 2000’, the stark reality is that substantial inequities of health persist. Tedros Adhanom, the recently appointed Director-General of the World Health Organization (WHO), has declared his intention to build a global movement to translate the revamped commitment to Universal Health Coverage (UHC) into reality by 2030 (United Nations General Assembly 2015; WHO 2018). In this new framing of primary health care, or Alma-Ata 2.0, the question of who is accountable, for what, and to whom, is wide open. From 19–21 July 2017, IDS hosted a workshop

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on 'Unpicking Power and Politics for Transformative Change: Towards Accountability for Health Equity', with the aim of generating dialogue and mutual learning among activists, researchers, policymakers, and funders working towards more equitable health systems. Whether Universal Health Coverage – however so defined – is achieved by 2030 is explicitly tied to accountability for health equity efforts to create stronger institutions, legal frameworks, social contracts, and a deeper understanding of the relationships of power that enable or constrain the realisation of this goal. The renewed push for UHC, on the eve of celebrating 40 years since Alma-Ata, is the political context and historic moment within which this issue of the *IDS Bulletin* is published.

If we take the first decades of the twentieth century as a starting point for the development of transnational efforts to combat infectious disease, poor sanitation, poor nutrition, and inadequate public health education and infrastructure, why is it that nearly 100 years later, one's chance at a healthy life remains tightly tied to place, race, gender, ethnicity, religion, education, and economic status? This is not to suggest that inequalities in health are static (or even measured in the same way over time), but rather that 'avoidable' and 'unjust' differences in health by population subgroup persist in spite of decades of efforts to minimise them.<sup>1</sup> In light of these 'avoidable' and 'unjust' differences – which range across a broad spectrum of health indicators (WHO 2017) – what new accountability relationships might be established, or which existing institutions of accountability strengthened, to ensure that basic health entitlements and rights are realised? What does 'holding power to account' mean when it comes to achieving the aims of UHC and how can local, national, and global accountability for health equity initiatives come together as a movement for change? While much has been made of the potential for greater 'public accountability' of public and private not-for-profit institutions that deliver health services (Mulgan 2003), the participants in the IDS workshop spoke of a more complex intermingling of public and private health actors, diverse political landscapes, legal grey areas, and the dangers posed to those who would challenge hierarchies of power endemic to contemporary health systems.

The term 'accountability' when used without any sense of directionality or purpose is meaningless (O'Donnell 1998; McGee and Gaventa 2011; Halloran 2016; Fox 2016). Simply calling for 'more accountability' as the means to effect health systems-level change is not enough. However, accountability processes that target the systemic and structural drivers of inequity within health systems have the potential to shape a different future (Lodenstein *et al.* 2013; Hilber *et al.* 2016; Hernández *et al.* 2017), as do those that involve citizens directly as agents of change (Cornwall and Gaventa 2000). In July 2017, the Accountability for Health Equity Programme at IDS brought together engaged intellectuals, innovating activists, and pragmatic problem-solvers in the fields of health systems strengthening and good governance to debate these issues. As a normative stance and a convening approach, 'accountability for health

equity' places relationships of power at the centre of our understanding of how health systems function – or do not – for all parts of society. It goes a step beyond the call for disciplinary bridging in health systems scholarship on accountability (Van Belle and Mayhew 2016) and stakes a claim on a different kind of co-production and co-mobilisation of knowledge. In sparking discussion, the workshop sought to catalyse new thinking that would enable interlocking networks of change agents to push the accountability for health equity agenda forward in different political spaces, and at different political levels (local, regional, national, transnational). While the precise contours of this current drive towards Universal Health Coverage have yet to be defined (Rumbold *et al.* 2017), it is clear that accountability relationships will be key to determining just outcomes of health-care priority-setting processes and the realisation of health entitlements for all people.

As a starting point for discussion and debate, we asked participants of the July workshop to set aside any preconceived notions on what accountability means in the fields in which they work, and be open to hearing about what it means to others (see note 2 for a short video by Sophie Marsden, Karine Gatellier and Sarah King that captures some of these reflections).<sup>2</sup> For example, if working on community-based social accountability interventions, we pushed for engagement with those working on accountability processes at national and transnational level, with the aim of achieving 'vertical integration' (Fox 2016). Or if working on accountability relationships within the sphere of formal political processes, we pushed for engagement with those working to improve accountability through legal frameworks, health systems management structures, or through informal challenges to hierarchies of power. We invited participants to reflect on the ways that new communications and data technologies, new forms of political organisation, new global health actors, new arrangements of public and private actors, new drugs and diseases, and new market influences have shifted the ground beneath our feet. The articles in this *IDS Bulletin* reflect the fact that while the desired outcome might be the same – *better health for all* – the proposed accountability strategies are as diverse as the contexts in which they developed.

One clear conclusion of this workshop: there is no universal language of accountability, nor is there a universalising framework capable of capturing the multiple and intersecting dimensions of power and decision-making that influence health outcomes. It is unproductive to flatten and make static the actors, institutions, legal frameworks, cultural norms, and market forces that influence the pathways that accountability travels, or to speculate on which pathway offers the most direct route to Universal Health Coverage. Crucial to moving beyond the empty rhetoric of accountability for 'improved health service delivery' or 'more resilient health systems' is a recognition that accountability processes are dynamic and should not be limited by tool-based approaches (Joshi and Houtzager 2012). Nor should our understanding of these processes be constrained by depoliticised metrics

of success or failure (Parkhurst 2016). The political and social nature of the relationships that determine who is held to account, for what, and to what end are temporally and contextually specific. They emerge and take shape according to a range of factors, only very few of which any given actor can control.

If we are to place accountability politics 'in time' (Pierson 2004), the big story at this historical juncture is that global leadership on health is up for grabs. While the language of Universal Health Coverage harkens back to Alma-Ata, the reality of our current global health landscape has substantially changed. To achieve 'better health for all' today requires innovative political strategies that acknowledge this greater diversity of actors and influences – from private philanthropic funding bodies such as the Bill & Melinda Gates Foundation, to the Chinese government's Belt and Road initiative (Gu *et al.* 2014; Husain 2017), to the limitations and possibilities for changed relationships of accountability opened up by new technologies (McGee *et al.* 2018). It also demands closer attention to the dimensions of marginalisation and exclusion that remain unresolved or misunderstood (Morgan *et al.* 2016). To tackle accountability failures requires determining the origins of the problem, and it is precisely this pinning-down of the 'who' in 'who is accountable?' that has become increasingly fraught (Bruen *et al.* 2014).

In this spirit, we have organised the *IDS Bulletin* around three principal themes that emerged from the workshop as needing deeper thinking and particular attention. First, how might our understanding of the relationships of power that mitigate health equity outcomes shift if we examine processes of change over longer time frames? Would such a shift in perspective help mobilise political will and commitment to long-term action? Second, what is at stake in the contested politics of 'naming' accountability and the epistemological battles over what types of evidence count in national-level and transnational health decision-making? Third, given the shifts in global power and new configurations of public and private health actors, what types of partnership and political action will be required to ensure functional accountability relationships, particularly where global goals such as UHC are concerned? These questions are explored both through text and, for the first time in *IDS Bulletin* history, through a selection of multimedia content online. This expansion into other forms of communication is explicitly aimed at galvanising larger numbers of people in a movement towards UHC and the linked agenda of accountability for health equity.

We conclude with a proposal for translating the globally accepted consensus on UHC into pragmatic strategies for change, stripping away any pretence that UHC is something 'technical' that can only be implemented if we have greater 'expertise'. Rather, we argue that if accountability relationships in health systems are substantially more complex, dynamic, and multi-sited than they once were (back in the days of Alma-Ata 1.0), the only way to galvanise a movement for greater health equity is through a similarly dynamic, multi-actor,

multi-level, and multi-sited approach. In short, a movement demands the coming together of perspectives, experiences, and knowledges that to this point have been largely stuck in silos. This *IDS Bulletin* is one small contribution to opening up the mutual dialogue and learning necessary to make this change.

## **2 The politics of health systems accountabilities in time**

In 2000, IDS published an issue of the *IDS Bulletin* titled ‘Accountability Through Participation: Developing Workable Partnership Models in the Health Sector’, which explored the results of a workshop convened in 1999 to share experiences on the ‘use of participatory approaches in enhancing accountability in the health sector’ (Cornwall, Lucas and Pasteur 2000: 1). The introduction noted that, per the early work of Leonard (2000) and Bloom and Standing (2001), there was increased recognition that ‘public health services in many low-income countries perform increasingly like an unregulated market’ (Cornwall *et al.* 2000: 2). Furthermore, they argued, it was clear that the ‘technical fix’ approach, so common to biomedical health interventions in the global South, had ‘singularly failed to meet the health needs of large sections of their populations.’ (*ibid.*: 11).

Within what was described at the time as a ‘rapidly changing, dynamic, complex world’, the authors promoted health system accountability at the local level, through greater community involvement in decision-making, resource allocation, and monitoring and evaluation. They warned, however, against the dangers of co-optation of accountability processes by powerful actors seeking to maintain the status quo, and of the potentially distorting effect of participatory accountability interventions if issues of marginalisation and social exclusion were ignored. Since that time, the speed of change has accelerated, the levels of complexity have increased, and the accountability challenges have become ever more glaring.

Travelling further back in time, we find within the literature supporting decentralised primary health-care services and broad-reaching sanitation, hygiene, and public health campaigns, similarly unresolved tensions between disease-specific interventions aimed at preventing epidemics and approaches to community health for meeting local needs and concerns (Packard 2016). It is telling that in meta-level historical reviews of the indicators dominant in international public health, now ‘global health’, the question of how to measure ‘equity’ – with the exception of a brief moment of attention in the run-up to Alma-Ata in 1978 – does not appear in transnational compilations of health indicators until the 2000s (Gorsky and Sirrs 2017: 370). What this history tells us is that if one drew a line connecting the creation of the International Sanitary Bureau (in 1902) (Fee and Brown 2002) to the launch of Africa CDC – Africa Centres for Disease Control and Prevention (in January 2017) (Nkengasong, Maiyegun and Moeti 2017) it would not be straight, and it would not track ever upwards towards more equitable health systems.

Yet, 40 years on from the first attempt at 'health for all', the promise of what might be achieved through global consensus remains compelling. It is clear from what we now know about accountability failures that the shapers and makers of functioning health systems are not limited to those individuals and institutions signed on to transnational global agreements. It bears emphasising that this long-standing effort to promote greater equity of health service delivery, of health education, of access to medicines, and of quality of care, is largely rooted in local and national politics, although bilateral donors and the dominant multilateral agencies have also been influential (Cornwall and Shankland 2008; George 2009; George *et al.* 2016; Lodenstein *et al.* 2013).

The temporal specificities of political change and the challenge of continuous engagement with accountability issues are threads that run the length of this *IDS Bulletin*. However, they are dealt with most explicitly in the first three articles and video content. To begin, Walter Flores and Alison Hernández describe what they call 'cycles of accountability' in their work with the Centro de Estudios para Equidad y Gobernanza en Sistemas de Salud (CEGSS) in Guatemala. Confronting inequities of power between public health service providers and members of rural indigenous communities could not be achieved through short-term, quick-fix, technical approaches. Rather, over a decade of effort, CEGSS came to understand its work as part of a longitudinal process of change in a country scarred by civil war, and in particular, the targeted violence and persecution of indigenous communities. Instead of seeking linear progress in improving the accountability of public health services, CEGSS now frames its efforts to improve indigenous health in Guatemala as a continuous returning-to and revisiting-of barriers to change. They approach strategic decision-making in line with the dynamic nature of the change they seek. The CEGSS case study challenges the notion of a straight route to the institutionalisation of accountability mechanisms for improved health service delivery.

In a photo story titled *Enabling Community Action for Maternal Health* (see Introduction to Multimedia, this *IDS Bulletin*) we hear Vaishali Zararia describe the long-term social accountability work done by a group of non-governmental organisations (NGOs) – SAHAJ, ANANDI, and KSSS – in Gujarat, India. Through a visual depiction of the material realities of this process, Zararia, Renu Khanna and Sophie Marsden's video captures both the challenges and possibilities for improved accountability relationships at the local level. Similar to the process described by Flores and Hernández, this photo story shows that the key to increased citizen and health worker engagement, and the mobilisation of local people to improve maternal health services, required dialogue at multiple levels of the health system, and an adaptive, cyclical approach to change.

In a second article that takes the 'long view', Jose Dias and Tassiana Tomé analyse the results of a recent Community Scorecard

intervention in Mozambique through the lens of political promises made by the post-independence revolutionary party Frelimo, as well as the legacy of the Portuguese colonial state. This ‘practice-based reflection’ asks whether the promise of social accountability to remedy the inadequacies of state-run health services has become distorted over time, increasingly placing the onus for improvement of health services on those who use them (versus those responsible for their delivery). In a sense, Dias’ piece sits at the other end of the spectrum from the participatory accountability approaches envisioned in the 2000 issue of the *IDS Bulletin*. Two decades on, the case of Mozambique and the transfer of roles and responsibilities for public health system functioning from state to citizen, suggests that the original meaning of ‘social accountability’ is at risk of being lost. This case study raises fundamental questions about the potentially distorting effects of tool-based accountability approaches at the point of service delivery.

In *Holding a Health System to Account: Voices from Mozambique*, produced by Denise Namburete and Erica Nelson (see Introduction to Multimedia, this *IDS Bulletin*), we hear directly from health service users and providers in the Mozambican capital city of Maputo on current accountability gaps and challenges. Filmed as part of the *Voices Desiguais/Unequal Voices* Economic and Social Research Council–Department for International Development (ESRC–DFID)-funded research project on the politics of accountability within multi-level health systems in Brazil and Mozambique, these interviews capture the frustration and injustice of health inequities as they are experienced in day-to-day life. Common problems such as unacceptably long waiting times, frequent drug stock-outs, and illicit charges for public health service delivery are described by residents of Maputo. This documentary explores what strategies are possible to ensure that these issues are comprehensively dealt with by those with the power to remedy them. In a country such as Mozambique, with a post-independence history of national health system creation and the promise made to achieve ‘health for all’, what would health management strategies and an enabling policy environment need to look like to have more meaningful accountability on health user rights and entitlements?

Jeevan Raj Sharma, Rekha Khatri and Ian Harper adopt a social history approach to understanding the dynamics of interlinked networks of actors within and beyond Nepal’s Ministry of Health in the adoption of misoprostol for postpartum haemorrhage. Through close analysis of the relationships of a constellation of state and non-state actors involved in the debate over misoprostol use, they question the accountability of bilateral donors, international non-governmental organisations (INGOs), and consultancy firms to Nepalese health service users when it comes to matters of national-level health policy. One result of the proliferation of global health actors beginning in the 1990s, as evidenced in this case study of INGO and bilateral aid agency involvement in Nepal’s health sector, is that accountability relationships become dispersed across dense and complex networks of actors.



### 3 The politics of naming accountabilities: 'accountability to whom, by whom, and for what?'

It is clear that the promise of greater accountability has the potential to both mobilise communities and advocates of health equity, as well as the potential to be subsumed into depoliticised discourses that maintain the status quo. The act of naming relationships of power, of bringing them into the light, is one step towards transforming them. It is important, then as now, to be clear about what accountability relationships people seek to change (Gaventa 2002). Part of the challenge of applying accountability approaches to improving health equity is that it demands a complex adaptive systems way of thinking, planning, and acting (Paina and Peters 2012), and this is where the meaning of accountability can become muddled. On the one hand, the relatively new field of Health Policy and Systems Research has championed interdisciplinary approaches to understand what drives and shapes health outcomes within the complex social and political worlds in which health services are delivered and health policies defined (Sheik *et al.* 2011; Gilson *et al.* 2011). On the other, the fields of good governance and accountability studies have shifted away from linear thinking on the relationship between citizen and state, and encouraged a more holistic understanding of social contracts and accountability bargains (Joshi 2014; Fox and Halloran, with Levy, Aceron and van Zyl 2016; Halloran 2016). Neither field has fully addressed the complex accountability landscape of health systems in many low- and middle-income countries, where private market actors are intertwined with government-sponsored health services at multiple levels (Leonard *et al.* 2013; Bloom *et al.* 2014).

At the IDS workshop in July there was fierce debate over what constitutes 'pro-equity accountability' in practice. As a starting point to a productive conversation, we need some shared terms and understandings. Bridging the themes of 'health systems and accountability mechanisms: the long view', and that of 'the politics of naming accountabilities', is Jonathan Fox's piece on 'The Political Construction of Accountability Keywords'. In the vein of Cornwall's challenge to unpick development 'buzzwords and fuzzwords' (2007), Fox calls for a creative reappraisal of the existing terms used in the English language to describe the multiple actions and objectives encompassed by the term 'accountability'. Fox revisits the diversity of concepts that emerged to challenge inadequate, corrupt, and/or poorly performing public services long before the word 'accountability' became codified by the World Bank (World Bank 2003). His article includes examples from Mexico, Pakistan, the Philippines, and Guatemala. He questions the tendency of some within the contemporary field of 'accountability studies' and those designing accountability interventions towards 'linguistic determinism'; that is, the inability to conceive of a richness of accountability meanings in those languages and cultures where the word has no direct translation. He suggests two possibilities for better communicating a public accountability agenda: (1) to open up the discourse to include terms and phrases already used in popular culture and 'repurpose' them; and (2) to create a new language of public accountability that has the capacity to 'go viral'.



In Linda Waldman, Sally Theobald and Rosemary Morgan's piece (this *IDS Bulletin*), they call attention to the relative absence of gender and intersectionality analyses within accountability for health equity debates. For example, within the 'Brinkerhoff Matrix', a tool used to catalogue distinct levels of power, influence, and responsiveness within a public health system, the multidimensional ways that people might negotiate and be subjected to hierarchies of gender, race, ethnicity (to name a few possibilities) are flattened out and rendered invisible (Brinkerhoff 2004). Health systems, the authors remind us, are themselves 'gendered structures', and gender itself is only 'one dimension of oppression, marginalisation, and inequality'. To truly address health inequities, they argue, we must first understand the interdependent nature of empowerment and accountability. Without empowerment of marginalised and vulnerable groups there can be no true accountability for health equity, and vice versa. What is lacking at present are new tools and indicators that would enable health systems researchers to grapple with the 'full range and complexity of gender and accountability'.

Fatima Lamishi Adamu, Zainab Abdul Moukarim, and Nasiru Sa'adu Fakai draw from their experience working on the UK aid–DFID-funded Women for Health programme in Northern Nigeria to explore gendered and spatial dimensions of social accountability. In this article, Adamu *et al.* describe a health worker crisis in five states that has resulted in dramatic inequities of maternal health quality of care and service availability. In seeking to address this front-line health worker shortage, they discuss the challenges to implementing an educational programme aimed at preparing young women from affected communities for future studies in midwifery and nursing. What they found was that gendered social norms created substantial barriers to the success of the programme, with the demands of husbands and male family members often taking precedence over the demands of training and capacity building. Adamu *et al.* point out the limitations of community-based accountability approaches that treat 'the community' in simplistic terms. They encourage those working on social accountability to be aware of, and to be prepared to challenge, relationships of power beyond the clinic–community dyad that impact on health inequities.

In a recent analysis of views on accountability among primary health-care government officials in Nigeria, George *et al.* (2016) argue that seeking to 'spark, support and steer change', rather than seeking 'social equity' might be a more effective strategy for engaging with health decision makers. If accountability interventions are designed to further burden the least powerful actors in a health system (namely, front-line community health workers) they will fail. However, if they are designed in a way that acknowledges both the complexity and multidimensionality of marginalisation and difference, *and* they are designed in a way that recognises the long-term, often cyclical nature of positive change, they have the potential to engender greater equity and meaningful relationships of accountability.

#### **4 The shifting nature of power in global health: new actors, new partnerships, and a new global consensus**

There are a number of reasons for the growing interest in ways to strengthen mechanisms for accountability in the health sector. As we have already established, the history of holding power to account within national-level health systems and at the transnational level is not in itself new. However, the particular dimensions of contemporary accountability relationships in an increasingly diffuse and complex landscape of health actors offers fresh challenges. In the last several decades, many countries have experienced rapid and sustained economic growth, which has been associated with changing patterns of inequality in income and health (Marmot 2007). At the same time, changes in technologies of communication and data-gathering have led to increased awareness of problems with access to health services within countries, as well as in comparisons of efficacy and quality between countries (though, it bears repeating, the existence of comparative transnational health indicators goes back to the early 1920s). This spread of communication and knowledge on service gaps and 'accountability failures', together with increased pressure on bilateral and multilateral donor agencies to show 'value for money', has contributed to rising expectations and pressure on governments to improve health system performance.

Alongside this increased use of certain types of metrics to establish the parameters of health 'success' or 'failure', the last three decades have been dominated by the flood of funding and transnational action targeting the HIV/AIDS 'epidemic' (such as it was originally known), and the post-Millennium Development Goals, the sector-specific, and vertically organised health responses to malaria, tuberculosis (and HIV/AIDS). More recently, global health actors and institutions have focused efforts on the perceived threat of an influenza pandemic, the spread of resistance to antibiotics, and the glaring health systems failures made evident by the Ebola epidemic in 2014–16. Each of these events and issues has contributed to an increased awareness of how health systems failures at local levels have impacts that spread beyond local spaces, and how the prioritisation of resources and funding at national and transnational level can create distortions in health system functioning that travel back down to the level of local clinics, pharmacies, and health posts.

Brazil is often touted as an exemplar of late twentieth-century universal health system creation. Currently, the Sistema Único de Saúde (or SUS) is used by close to 65 per cent of the population. In an article by Vera Schattan Coelho we learn that to meet the needs of the population in São Paulo, Brazil's largest city, the municipal government has outsourced some primary health-care services to private not-for-profit organisations. She demonstrates that this outsourcing, in combination with political competition at the municipal level, formed the backdrop to a reduction in health disparities and inequalities. This story offers hope that new models of collaboration and partnership for health service delivery, together with high levels of political engagement and a holding to account of political actors, could have real impact on reducing health disparities across all sectors of a given population.

Within the context of pluralistic health markets in India, Abhay Shukla, Abhijit More, and Shweta Marathe (this *IDS Bulletin*) explore the kinds of regulatory partnership that could provide effective stewardship and greater accountability of private sector actors. Shukla *et al.* draw attention to the lack of evidence on the quality of services provided by the non-state sector, despite the fact that they provide the majority of all health services in India. They also challenge received wisdom that health professions are self-regulating, noting that in India a wide range of medical associations (at both state and national level) have failed to protect public interest over self-interest (Peters and Muraleedharan 2008). In response to these failures of accountability, they describe how they developed an alliance of citizens and socially responsible medical professionals in Maharashtra State, in effect creating a multi-pronged movement aimed at strengthening institutional arrangements for influencing the performance of private health-care providers.

In the last article of this *IDS Bulletin*, we move from the national to the transnational and take our considerations of accountability global. Emma Michelle Taylor and James Smith consider the politicised creation of the term ‘neglected tropical diseases’ (NTDs) and its salience to current debates on global health priorities, investment, and collective responsibility. They suggest that the NTDs have the potential to function as ‘proxies of progress’, given that the 17 diseases included under this shared banner can only be eliminated through multi-sectoral action, sustained commitment to improved primary health-care services and health infrastructure, and public–private partnerships to achieve vector control and mass drug administration. If within this framing of NTDs as ‘proxy indicators’, there was a push to collect disaggregated NTD data (by sex, age, place, race, or ethnicity where possible), it would be possible to begin unpicking the dynamics that shape health inequity among the most marginalised populations, and offer a starting point for identifying accountability failures where they exist.

### **5 Conclusion: naming the moment to shape the future**

At the July workshop, Jonathan Fox reflected on a practice common among civil society activists in Latin America in the 1970s and 1980s – ‘*análisis de coyuntura*’ or ‘analysing the conjuncture’ for political analysis and action. By naming the precise political, social, and economic contours of this moment,<sup>3</sup> we can anchor future action in a recognition of all that has come before. The aim of this *IDS Bulletin* has been to provide a space for the exploration of the moment we are living; a moment in which many long-standing barriers to achieving ‘health for all’ under the current rubric of Universal Health Coverage remain solidly in place (Rumbold *et al.* 2017). At the same time, major changes to national and global power structures, alongside rapid technological and social change, open up the possibility of innovating accountability practices and processes in ways that favour greater health equity.

We do not yet have a road map for how to best join up accountability efforts at distinct levels of decision-making and influence in health

systems, nor do we fully understand how to wrestle with the accountability gaps created by new market actors (including tech actors) and changes in how we communicate. We are missing tools and indicators that would enable us to identify the influence of relationships of power, not only between levels of health systems organisation, but within them and within the communities they serve. We do not yet have a network-of-networks that joins pro-equity accountability efforts in distinct corners of the globe. We do not yet know what might be possible in terms of challenging stasis and entrenched hierarchies in global health if a true movement for Universal Health Coverage is formed.

Right now, many governments are facing increased demands to meet existing health needs and tackle health inequities. Fears about the next pandemic remain high. At the same time, the emergence of new powers and their search for global leadership roles has created a different set of possibilities for transformational change. New transnational ethical norms within health must reflect this political reality and the uneven balance of power (Bloom and MacGregor, forthcoming). Within this context of complexity and dynamic, shifting political power, a simple framework for accountability will not suffice. Instead, priority must be given to mutual learning and mutual respect between different stakeholders, different levels of health systems decision-making, different cultural norms, and understandings of health entitlements and rights.

Much of the current focus on accountability has been on monitoring the use of externally provided finance to health services (within a value-for-money framework). This can be seen as meeting the needs of an outside agency, and in support of accountability relationships that travel from top to bottom (with the least powerful actors within the system held to account, such as front-line community health workers). The discussions at the July workshop, together with the arguments put forward in this *IDS Bulletin*, are contributing to a different kind of dialogue on the political challenges to accountability. These challenges are not limited to poorly-functioning or corrupt ministries of health or quality-of-care issues in remote health posts, but rather include a much broader range of health systems actors. The new WHO Director-General has said that he hopes to stimulate a movement for Universal Health Coverage. The aim of the July workshop, this *IDS Bulletin*, and all future action connected to the Accountability for Health Equity Programme at IDS is to galvanise our networks in support of Universal Health Coverage, and through the aims of UHC, engender more functional relationships of accountability and greater health equity. It is our hope that in another 20 years' time, when the next set of *IDS Bulletin* authors reflect on what was written in 2018, they will be able to document real progress and transformational change in the health sector.

## Notes

- 1 WHO defines ‘health inequity’ as a ‘normative concept, defined as the avoidable and/or unjust differences in health between population subgroups. Statements about health inequity involve a judgement about what is deemed to be right, fair or acceptable in a society’ (2015: 5).
- 2 [www.youtube.com/watch?time\\_continue=1&v=ZFWoVvOfiBA](http://www.youtube.com/watch?time_continue=1&v=ZFWoVvOfiBA).
- 3 This methodology of ‘naming the moment’ was first developed within the popular education movement in Latin America. See, for example: [www.catalystcentre.ca/wp-content/uploads/Naming\\_the\\_Moment\\_Manual.pdf](http://www.catalystcentre.ca/wp-content/uploads/Naming_the_Moment_Manual.pdf).

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# Introduction to Multimedia

## **Unpicking Power and Politics for Transformative Change: Workshop Video**

**Sophie Marsden, Karine Gatellier and Sarah King**

In our effort to share with a broader audience the kinds of cutting-edge thinking and debates that took place during the July workshop, we asked select participants to speak on camera about their understandings of accountability, the potential for mutual learning, and priorities for future accountability for health equity work. Included in this short film are: Fatima Lamishi Adamu, Aggrey Aluso, Walter Flores, Luis Eduardo Fonseca, Asha George, Ian Harper, Elizabeth Ekirapo Kiracho, Desta Lakew, Vera Schattan Coelho, and Abhay Shukla.

## **Enabling Community Action for Maternal Health: A Photo Story**

**Vaishali Zararia, Renu Khanna and Sophie Marsden**

Here, Vaishali Zararia describes a collaborative project between three non-governmental organisations (SAHAJ, ANANDI, and KSSS) in Gujarat, India, working together to promote community action and social accountability for improved maternal health services. Through a visual depiction of the material realities of a Community Scorecard process, this photo story captures both the challenges and possibilities for improved accountability relationships at the local level. Similar to the ‘cycles of accountability’ described by Flores and Hernández in this *IDS Bulletin*, the achievements of SAHAJ, ANANDI, and KSSS were made possible through multi-stakeholder and multi-level engagement within the health system, and an adaptive, long-term approach to change.

## **Holding a Health System to Account: Voices from Mozambique (A Documentary)**

**Denise Namburete and Erica Nelson**

In this documentary we hear directly from health service users and providers in the Mozambican capital city of Maputo on accountability gaps and challenges. Filmed as part of the Vozes Desiguais/Unequal Voices Economic and Social Research Council–Department for International Development (ESRC–DFID)-funded research project on the politics of accountability within multi-level health systems in Brazil and Mozambique, these interviews capture the frustration and injustice of health inequities as they are experienced in day-to-day life. Common problems such as unacceptably long waiting times, frequent drug stock-outs, and illicit charges for public health service delivery are described by residents of Maputo. The film explores what

strategies are possible to ensure that these issues are comprehensively dealt with by those with the power to remedy them. In a country such as Mozambique, with a post-independence history of national health system creation, and the promise made to achieve 'health for all', what would health management strategies and an enabling policy environment need to look like to have more meaningful accountability on health user rights and entitlements?

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To view the above multimedia content see: [www.ids.ac.uk/publication/accountability-for-health-equity-galvanising-a-movement-for-universal-health-coverage](http://www.ids.ac.uk/publication/accountability-for-health-equity-galvanising-a-movement-for-universal-health-coverage)

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# Health Accountability for Indigenous Populations: Confronting Power through Adaptive Action Cycles\*

Walter Flores and Alison Hernández

**Abstract** Health-care providers are powerful figures in society. An informed service user may be able to identify regulatory non-compliance and abuses by these actors, but reporting them is not a mere administrative procedure. It is an act that stirs existing power relations and social hierarchies. This article argues that the essence of an accountability intervention is the process through which service users collect and analyse evidence that is then used to confront power at different governance levels. The response from authorities is assessed and strategies adjusted accordingly in adaptive cycles of accountability action. Based on ten years' experience supporting indigenous citizen-led accountability action in Guatemala, the authors describe how their approach evolved from an emphasis on technical components to a politically informed approach with interdisciplinary collaboration and explicit engagement with power. This article summarises lessons learned and their relevance for organisations working in health accountability in highly unequal settings.

**Keywords:** accountability, power relations, empowerment, indigenous populations, Guatemala, health, equity, power, marginalised populations.

## 1 Introduction

The medical doctor was loud and commanding: *'You will not be allowed to come here any more.'* Maria, a user of the local services, was banned from attending the local public health facility for showing *'no respect'* to a health official. Maria's disrespect was to ask questions about how public resources were being used in the health facility, and also asking for explanations as to why free medicines were not being provided to patients, despite being included in the national health-care delivery guidelines. Maria's questions shake up local power relations. Even her children at school felt the repercussions of their mother daring to question a government authority. The teacher called them *'the kids of the troublemaker'*.<sup>1</sup>

Maria was one of over 50 people elected by their own communities to receive training about legal frameworks, their rights, responsibilities, and entitlements, and the basics of public health policy and public budgets. The role that Maria was playing – engaging in participatory monitoring and evaluation of local health-care services – was backed by a newly adopted health law that promoted citizen participation. Maria was banned afterwards from attending health-care facilities for her attempt to implement existing laws and regulations. Although public officials knew about these laws and regulations, they ignored them. In Guatemala, cases such as Maria's are frequent among rural indigenous peoples when they engage with public services.

The remainder of this article provides an overview of the historic and social context of exclusion in which this situation occurs, and how it has been addressed by a local civil society organisation (Centro de Estudios para Equidad y Gobernanza en Sistemas de Salud, CEGSS) in alliance with grass-roots indigenous organisations. Over the last decade, CEGSS has learned and adapted its approach to civic action and accountability: from an emphasis on technical components to a politically informed and participatory approach with interdisciplinary collaboration and explicit engagement with power. This article summarises our learning and presents the stages of an adaptive cycle of accountability action that characterise our current approach to enabling indigenous citizens to demand health accountability.

## **2 Social exclusion and inequities in Guatemala**

Guatemala is one of the most unequal countries in the world. The country as a whole has one of the highest poverty rates in the region, with 54 per cent living in poverty (INE 2011). The unequal distribution of income is clearly linked to ethnicity. Among the indigenous population, poverty rates reach 73 per cent, compared to 35 per cent among the non-indigenous population (INE 2006; IWGIA 2011). Despite a decrease in the national poverty rate by 9 per cent from 2000 to 2006, indigenous poverty rose by 22 per cent during the same period (ICEFI and CESR 2009); and the most recent assessment showed that poverty rates were rising nationally (INE 2006, 2011).

Health and wellbeing are a privilege reserved for the few in Guatemalan society. Almost 50 per cent of children under five are chronically malnourished, which contributes to stunted growth, cognitive damage, and a higher risk of death due to a compromised immune system (MSPAS 2010). There are only three countries in the world with higher rates of malnutrition, and among indigenous children the rate is even higher (66 per cent) than in the most affected country (Afghanistan, 59 per cent) (ICEFI and UNICEF 2011). Death among children under five has decreased from 121 in 1987 to 45 in 2008/09 (deaths per 1,000 live births), yet the number rises to 55 among indigenous children, compared to 36 among non-indigenous children (MSPAS 2010).

Guatemala also has one of the highest rates of women dying from pregnancy- and childbirth-related causes in Latin America.

The national maternal mortality rate was calculated at 140 deaths per 100,000 live births in 2011, and indigenous women were more than twice as likely to die in childbirth as their non-indigenous counterparts (163 vs 78) (MSPAS and Segeplan 2011). However, after adjusting for underreporting, UNICEF estimated that the actual national rate is 290 (compared to the estimated national rate of 153 in 2005), indicating an even more dire situation for indigenous women (UNICEF 2009). Overall, indigenous people in Guatemala are more likely to suffer poorer health and ultimately die younger – their life expectancy is 13 years less than that of non-indigenous Guatemalans (UN 2009).

These stark inequalities in income and health are the result of historical, social, and political processes that stem from European colonisation, decades of military dictatorships, the exclusion of poor and indigenous populations from development, and a 36-year-long internal war. The armed conflict from 1960 to 1996 was one of the most vicious and violent in the American continent. Guatemala's Historical Clarification Commission (CEH in Spanish) estimated that 200,000 people were executed or 'disappeared', and the number of orphans as a result of the armed conflict approached 150,000. The massacres and destruction of villages gave rise to the forced displacement of more than 1.5 million people. Although the political violence affected more than one third of the population, the largest burden of violence fell on the indigenous population – more than 80 per cent of all crimes verified by the CEH were on indigenous citizens. In addition to the violence, political instability and high levels of political repression characterised this period: in the years between 1955 and 1985, the government abolished all workers' unions and political organisations because they were perceived as dangerous. After several years of negotiations, peace was finally declared on 29 December 1996. According to the Peace Accords signed by the state and the guerrilla leaders, peace could only be achieved through the equitable social and economic development of the entire population. The Peace Accords specified the state's commitment to expand the tax base and progressively increase social investment in the most vulnerable sectors of society.

Despite modest increases in tax revenues and social spending since the 1990s, Guatemala is distinguished as the country with the lowest levels of tax collection and social spending in the world, relative to the size of its economy (World Bank 2014). Taken together, insufficient tax revenue and low social spending represents a major impediment to redressing inequities and attending to the urgent needs of the population.

### **3 Power: concepts and attributes<sup>2</sup>**

At its core, this situation of social exclusion and the accountability failures it engenders reflect inequities in power. The first two entries in the *Oxford English Dictionary* define power as: (a) The ability or capacity to do something or act in a particular way, and (b) The capacity or ability to direct or influence the behaviour of others or the course of events (OED 2018). While these two definitions are sufficient to

understand what power is about, theoretical definitions of power are more complex, shedding light on different dimensions and sources, and there is no single concept that captures its full meaning. In our accountability work, we have found that instead of navigating the dense theoretical literature on power in detail, it is more useful to identify and understand power attributes and how they can help to explain social structures and interactions. The next paragraphs summarise some of the theories and attributes that have been influential in our understanding of power and its relevance in accountability work.

Power has the ability to produce changes in society, as much of these changes can be the result of conflict between individuals or, on the contrary, of consensus (Haugaard 2002). Many social processes and relations are determined by how some actors are able to manage social structures such as religion, education, formal and informal rules, the economic system, and even social class (Clegg, Courpasson and Phillips 2006). These different structures grant power resources to some actors, and create an environment that is more prone to staying the same and perpetuating the status quo than to promoting change. This is because powerful actors can use these social structures to mould relational processes and exchanges according to their needs and interests, without necessarily considering the position of less powerful populations. This describes the historical situation of Guatemala in which an economic elite with an ancestry of European colonisers have successfully created social, economic, and political structures that control and exclude indigenous populations who constitute about half of the total population in Guatemala.

Another theory of power poses that it is the result of building consensus among individuals: power is the result of the human capacity to act and work together. This means that power does not belong to one individual but to many, and that by creating more consensuses and including more people in a social process, the process itself becomes more powerful (Arendt 1970). Understanding power as consensus building is important to understand the relevance of agreeing on collective action, particularly in social movements. Consensus building is also important when service users and front-line health-care workers – particularly those allocated in deprived rural areas – are able to recognise each other's situations of exclusion within the broader health system and public services. Through this consensus, providers and users do not confront and fight each other but work together to demand changes higher up in the system.

Power can also be understood as 'latent' and expressed as 'influence' in decision-making. From this perspective, there are no powerless individuals, but only people who are yet to become conscious about, and activate, their hidden power in order to exercise influence (Morriss 2002). This perspective of power as a 'latent' force is useful in explaining social changes in several South American countries during the last decade, such as the *piqueteros* movement in Argentina

(Benclowicz 2006), workers' unions and peasants in Bolivia (Regalsky 2006), and indigenous movements in Ecuador (Pachano 2005). All are examples of how traditionally, socially excluded groups became 'conscious' through organising and political action, and activated their collective power to generate a shift resulting in a change of governments and social policies.

For our work in Guatemala, the three theories and attributes of power described above have been crucial to understand how power is expressed, not only at the macro or structural level (socioeconomic system) but also at the micro level, such as the relationship between a provider and a user of public services. The case of Maria described at the beginning of this article, when the medical doctor accused her of 'disrespect' and banned her from a public facility, despite lacking the authority to do so, shows how power can be abused at the micro level of a social relationship. At the same time, power can be built and expanded through dialogue and consensus between service users and front-line health-care workers when both actors recognise how the system is negatively affecting them, and, therefore, the need to work together to achieve systemic changes.

In our accountability work, while we always remind ourselves that our goal is to establish relations of dialogue and consensus, we must also be prepared to handle conflict. When working with grass-roots organisations, it does not help if we see them as powerless people, nor if they perceive themselves as powerless. For all of us, our work in accountability is driven by the consideration of ourselves as holders of power in latency, which needs to be activated through collective consciousness-raising and action. This view is very similar to the approach and practice of popular (Freirian) education and participatory action research, which have provided the core guiding values and principles of our work for the past decade.

#### **4 Promoting accountability in rural indigenous municipalities**

The CEGSS team began its first project in 2006, with the idea of promoting participatory planning and monitoring in local health services in six rural indigenous municipalities. From that initial experience, CEGSS expanded its work to cover a larger number of municipalities, reaching 35 by 2014, which represents about 10 per cent of the total number of municipalities in Guatemala, and about 22 per cent of the municipalities with a majority indigenous population.

When we started our work, we had a technical and linear view of accountability. There was a new law mandating citizen participation in the monitoring and evaluation of public services, and our project focused on providing training to both service providers and the communities that use those services. Once trained, both groups of actors would engage in participatory planning, monitoring, and evaluation. In our first project, the intervention seemed straightforward. Nonetheless, the results we obtained included many cases like that

of Maria, described at the beginning of this article. We did not take into account that a law ordering the participation of communities in the planning of public services was not sufficient to change the social hierarchy, racism, and discrimination embedded in the social relations between professionals, health officials (all of them non-indigenous), and the rural indigenous communities that use public services.

When our first project did not go as expected, we carried out in-depth interviews with community leaders who had had similar experiences to that of Maria. We wanted to understand what went wrong and to offer an apology to them. Although we were expecting that they would rightly hold us responsible for putting them in a vulnerable situation before health officials, this was not the case. Each of the community leaders we interviewed wanted to continue learning about their entitlements, how public services should work, and how to identify when services are not working well. All of the leaders interviewed were also aware that advancing in their desire to participate in the planning and evaluation of their local services would be difficult, and that they would receive more negative responses from authorities. They asked us to continue supporting them not only with training, but also with our support and solidarity.

The interviews with those community leaders were a breakthrough. They were basically telling us that although information and knowledge are important, they needed support to challenge the social hierarchy and unequal power relations in their municipalities. We at CEGSS reflected about this reality and decided to continue working in those municipalities. We refined our view of the driving force of our work, shifting from a central focus on the information, knowledge, and tools for participatory planning to explicit engagement with how power and power relations influenced access to public services in rural indigenous communities. For the next few years, CEGSS' work became embedded in ongoing analysis of how conflict and violence shaped existing power relations in those communities, including the distrust between communities, public officials, and service providers (Flores, Ruano and Funchal 2009). We also studied how existing public spaces for participation exemplified asymmetries of power between officials and rural indigenous communities (Flores and Gómez 2010). Through this specific study, we concluded that existing 'invited' public spaces were not responsive to communities' demands and that there was a need to pursue strategies to create new 'claimed' spaces.<sup>3</sup>

In line with our shifting focus towards understanding how power and power relations were expressed in these rural indigenous communities, we were also gradually diversifying the team within CEGSS. From an initial team of solely public health experts, we evolved into an interdisciplinary team that includes lawyers, political scientists, anthropologists, social workers, and journalists. Also, about 50 per cent of our team is of indigenous ethnicity. Collaboration with the grass-roots organisations that are at the forefront of accountability work



in rural municipalities has played a critical role in the development of strategies, actions, and tools to redress power asymmetries in these contexts. As such, the knowledge generated and learning acquired are a product of collective action between CEGSS and grass-roots organisations on the front lines of local accountability struggles.

In 2013, our collaboration with communities evolved to working with citizen leaders mobilised in the role of Community Defenders for the Right to Health (from now on referred to as ‘defenders’ in this article). There are currently over 120 defenders (about 60 per cent male and 40 per cent female) elected by their own communities to (a) defend them from abuses by officials and providers of health services, (b) act on their behalf to dialogue and engage with officials to improve the responsiveness of local services, and (c) to inform and educate communities about their rights, entitlements, and obligations. The defenders are all volunteers who receive ongoing training and support to develop and implement their knowledge of human rights, legal frameworks, evidence-gathering techniques, public policy and services, advocacy, negotiation and conflict resolution, and the basics of public budgets.

In the past couple of years, CEGSS’ work has also focused on the integration of the defenders from different indigenous municipalities across the country in the Network of Community Defenders for the Right to Health (REDC-SALUD as per its name in Spanish). This network serves as a platform for the municipal-level grass-roots networks to link up at a national level and develop consensus regarding their common struggles and interests. This consensus provides a base for identifying collective goals regarding the problems they will seek to influence. The network elects a group of ‘regional coordinators’ who are in close and constant communication with CEGSS staff and who also coordinate collective actions such as campaigns, and represent the network at meetings with provincial- and national-level authorities. The details of our approach and the work of the defenders are described in Section 5.

### **5 Adaptive cycles of accountability action**

Our work towards accountability is approached as an action–reflection–action process in which service users collect and analyse evidence that is then used to confront and engage with power at different governance levels. The response from officials is assessed (e.g. commitment to resolve problems, denial of problems, hostility towards community leaders) and strategies are adjusted accordingly. The strategies may involve the implementation of a plan when there is willingness and collaboration by officials, or a confrontational approach when an official is in denial or hostile towards communities. We follow up on the implementation of agreed action plans and verify the resolution of problems and complaints that were put forward by service users. Once resolution is confirmed, we plan a new cycle. Figure 1 presents the six stages in the cyclical action–reflection–action process, and the remainder of this section describes each of the stages in detail.

Figure 1 Stages in the adaptive cycle of accountability action



Source Authors' own.

### 5.1 Evidence gathering

In our approach, evidence is not understood as an academic construct according to the hierarchy of scientific evidence, but as information gathered collectively with communities which contributes to opening channels of engagement with officials. Defenders receive verbal complaints from service users about problems at health-care facilities, such as not receiving the required medicines, opening hours not being respected, the ambulance service not being available, or a service provider that is disrespectful or abusive towards patients. The defender obtains as much detail as possible about the complaint and then classifies it based on a catalogue of 23 different types of complaint.<sup>4</sup> Once classified, the defender sends a coded SMS message to an electronic platform that converts the SMS message into an individual complaint that is geo-referenced on a digital map.<sup>5</sup>

Depending on the type of complaint, the defender may also take photographs or video recordings of infrastructure, shelves inside health facilities showing stock-outs of medicines and medical supplies, or verbal testimonies from service users about their complaints. By analysing the complaints received, the defender identifies whether a recurrent problem is emerging: several patients not receiving the required medicines, reports of abuse and disrespect by the same health-care worker, the local ambulance not transporting patients, etc. In coordination with CEGSS advisors, the recurrent problem

is identified, and all evidence related to this problem (individual complaints in the electronic platform and any audiovisual evidence) is compiled in a report to be presented to public officials.

A different process of evidence gathering occurs when a defender receives a complaint about a case that needs urgent action (based on medical grounds stated by a provider, or a blatant violation to the right to health care). For instance, a patient referred by doctors to a higher resolution facility due to his/her condition who is not transferred because the ambulance driver is demanding an illegal payment, or cases in which a patient is refused care because he/she does not speak Spanish. In these cases, the defender gathers as many facts as possible and then communicates immediately by phone with the official in charge of the facility where the problem occurred. If there is no response from the official, the defender communicates with CEGSS advisors, who contact or advise defenders on contacting higher level officials at provincial and national level.

### **5.2 Preparing the space for engagement with authorities**

Once the report on recurrent complaints is ready, the defenders, together with CEGSS advisors, analyse what would be an adequate space of engagement for the type of complaints that will be brought to public officials for their resolution. In Guatemala, there are several institutionalised spaces for engagement at different governance levels (local, regional, and national). However, many of those 'invited' spaces (e.g. municipal council meetings, local health committee meetings) are not effective in the resolution of community demands, due to *de facto* barriers restricting access or voice. Defenders have been more successful in 'claiming'<sup>6</sup> spaces of engagement with officials at local and regional level (e.g. monthly or quarterly meetings between defenders and officials specifically set up to review and plan actions to resolve complaints by service users, officials providing their phone number to defenders to establish direct communication, etc.). However, some problems such as infrastructure deficits require engaging in other spaces where resource allocation decisions are addressed (e.g. municipal development council). Also, if the complaint directly involves officials at the local or regional level (e.g. engaged in illegal charges or abuse towards patients), then the complaint must be brought to a higher level of government to avoid conflict of interest by the corresponding official. To aid the identification of an adequate strategy and space for engagement, CEGSS developed a decision tree that is used by defenders and CEGSS advisors.

### **5.3 Presenting evidence and demands to officials**

When defenders present the evidence and concrete demands for a resolution, officials usually react in any of the following ways:<sup>7</sup>

- (a) acknowledge the problem and commit to an action plan to resolve it;
- (b) show politeness but unwillingness to commit to a resolution;
- (c) deny that the problem presented exists and refuse further engagement;
- (d) show open hostility towards defenders that may include implicit or explicit threats. The engagement may involve one or several face-to-face

meetings. Once defenders feel the engagement stage is over (e.g. because there is an agreed action plan; the authority continues being polite but no commitment to an action plan; or hostility does not warrant additional meetings), defenders consult with CEGSS advisors to analyse the next steps and adjustments to the strategy that may be required.

#### **5.4 Adjusting the strategy**

The adjustment to the strategy depends on several factors such as the type of complaint (e.g. illegal charges and corruption are more serious than medicine stock-outs), the level of collaboration and communication at higher governance levels at a given time (which fluctuates between low and high and is influenced by external political factors), and the strength of the community grass-roots network and their mobilisation capacities. Some examples of adjustments to the strategy follow. For an authority that collaborates and commits to resolution, the defenders organise their schedule to participate in the implementation of the agreed action plan. When the authorities refuse to commit to a resolution, the strategy will involve requesting the mediation of the Ombudsman office and engaging with officials at a higher level of government. If the higher level of government is also non-responsive, the defenders will request the involvement of parliamentarians who represent the geographical district where the complaint occurred, or who are members of the Human Rights and Indigenous Population Commissions within Parliament.

In those cases where the authorities deny the problem and refuse to engage, the defenders call for press conferences in which the evidence is presented, and naming and shaming occurs if deemed as needed. The defenders will also seek alliances with other civil society organisations and may decide to mobilise their communities in a civic protest outside the official's office. A situation of hostility and threats requires immediate legal assistance. CEGSS deploys its legal advisors and at the same time requests the engagement of the Ombudsman. It supports the defenders to present a formal complaint at the local court of justice or the nearest public prosecutor's office. Defenders are also networked with other civil society organisations that specialise in the legal defence of Human Rights Defenders. The latter type of cases that involve threats by an official are not common. However, CEGSS keeps specific protocols in place to act whenever such cases occur.

#### **5.5 Follow-up actions**

This stage involves implementing actions after adjusting the strategy. Actions may include municipal-level activities to inform communities about the resolution process or preparing a civic mobilisation. Travelling to the regional and national capital cities to meet up with Ministry of Health officials, parliamentarians, the Ombudsman, and other actors is also a common activity at this stage.

#### **5.6 Verifying resolution of demands and planning a new cycle**

During the follow-up actions, an official may inform defenders that the problem has been resolved. Defenders then visit the site where

the complaint originated to verify such information and to gather a means of verification that could be: a photograph or video of repaired infrastructure, medicine shelves fully stocked, an official letter informing that an abusive and disrespectful health-care provider has been removed from post, or the testimony of service users that emergency transport was allocated without out-of-pocket payment. The verification is sent to the electronic platform (which is administered by CEGSS staff) and the status of the original SMS complaint is changed to 'resolved'. The cycles that are still ongoing are assessed and planning for a new cycle may commence.

It is important to note that at any given moment, the Network of Community Defenders and CEGSS are engaged in several simultaneous and parallel cycles of accountability action. For instance, a cycle related to continuous stock-outs of medicine in several municipalities in a specific geographical region runs in parallel to another cycle tackling illegal charges for emergency transport in a particular municipality. Also, some problems may require different strategies with more actions at local level with health and municipal officials, versus actions engaging with higher levels of government. Whether action occurs at local or regional or national level also implies different time periods. Usually, engagement at the national level with parliament and the Ombudsman takes several months, whereas actions at the local level can be carried out over shorter periods.

### **6 Changes in rural health-care facilities as a result of adaptive accountability action**

Adaptive cycles of accountability action have led to a range of changes in rural health-care facilities. As a result of defenders' monitoring and advocacy, local officials in many municipalities have taken responsive action to address some of the pressing problems affecting service delivery (Flores 2016). Municipal officials have mobilised funds to improve emergency transport, by paying for fuel and maintenance for the district ambulance, hiring drivers, and coordinating vehicles. Some mayors have designated funds for a municipal pharmacy, enabling service users to obtain free medicines when they are not available in the health facilities. Projects to repair and improve infrastructure and purchase equipment have been implemented with municipal and provincial funds. Engagement with local and provincial health officials to present problems reported by service users of mistreatment and discrimination has led to improved quality of care through corrective action, including transfers and firing, and changes in provider attitudes (Hernández *et al.* forthcoming, 2018). These examples of responsive action represent important achievements in contexts of extreme inequalities and marginalisation.

### **7 Contribution to citizen empowerment in accountability ecosystems**

We consider these to be short-term changes that address problems infringing on the right to health, but that would likely not be sustained by the next local authority if they are not accompanied by the changes in active citizenry that adaptive accountability action cycles also

engender. The role of accountability cycles in activating marginalised indigenous citizens' power to collectively identify and act upon rights violations has been observed in their enhanced participation in local decision-making spaces, both in the health system and municipal governance (Hernández *et al.* forthcoming, 2018). Iterative efforts to mobilise the community in demands for accountability further build power through virtuous cycles in which the realisation of previous actions builds recognition and self-efficacy, contributing to an enabling environment for further action. Defenders are increasingly engaging with authorities beyond the local level to voice their problems and demands with provincial and national officials with greater capacity to address the systemic root causes. Even while they continue to face strong power asymmetries and lack of political will in these spaces, this participation represents a significant gain in light of their historic socio-political exclusion. These incremental advances demonstrate the internal changes and political capabilities developed through adaptive accountability cycles that provide the grounds for activating latent power, and generating greater collective power to influence the decisions and policies that affect citizens' lives.

### **8 Conclusions and lessons learned**

Systematic exclusion and discrimination against indigenous communities in Guatemala results in very unequal relationships. When marginalised populations confront embedded power structures to demand their rights, overcoming the socio-political forces that perpetuate the status quo is a major challenge. Through our experience over the past decade, CEGSS has learned that even when we aim for dialogue and constructive engagement, sometimes conflict is unavoidable in these situations. Organisations pursuing accountability in unequal contexts should be aware of this.

The need to navigate between constructive engagement and adversarial strategies to pursue health accountability for marginalised populations has recently been observed and documented in other unequal settings in Africa, Asia, and Eastern Europe (Joshi 2017). The technical teams that support citizens and public officials should look beyond expertise in monitoring tools to include legal and anthropological advisors, and develop strategies and protocols to handle conflict and cases of serious abuse of power uncovered by accountability action. In practice, this means applying strategies and expertise from both legal empowerment and social accountability fields (Joshi 2017; Feinglass, Gomes and Maru 2016).

In the case of Maria, support from the Ombudsman, her own community, and the wider network of community defenders enabled her to continue monitoring health services, and in time she developed a collaborative relationship with health officials once they better understood her role. It should also be noted that many providers and health officials that defenders have engaged with perceive their work as a support, bringing attention and, in some cases, solutions to the deficits that they face in delivering rural health-care services (Hernández and Sebastián 2017).

From our initial technical approach to accountability through supporting implementation of a legal mandate for participatory monitoring and planning of health services, CEGSS' support has evolved to focus on adaptive cycles of accountability action. Through close engagement with the indigenous citizens, communities, and grass-roots organisations on the front lines, we have observed that it is not the information generated by monitoring that influences accountability, but the process through which citizens gain and confront power. With a central focus on activating citizens' latent power and their power as a group, reading the response in the political context and adjusting strategies accordingly guides adaptive cycles of gathering evidence and advocating with public officials.

In addition, throughout the years, CEGSS as a team have expanded their expertise to support the engagement of defenders at different governance levels (municipal, provincial, and national). This kind of engagement reflects the recent call for vertical integration of accountability actions (Fox, Aceron and Montero 2016) to achieve systemic and sustainable change. We at CEGSS feel that together with the network of defenders, we have only partially achieved such integration, so our current work plan and strategies are aiming to advance in that direction.

### Notes

- \* The authors are grateful for the valuable comments on a draft of this article by two anonymous reviewers and Alex Shankland. Thanks also to all the team members that have been part of the Centro de Estudios para Equidad y Gobernanza en Sistemas de Salud (CEGSS) during its existence. Also, thanks to all community leaders who are members of the health defenders' network.
- 1 The information in this paragraph is a reconstruction of an in-depth interview carried out by CEGSS in 2010 with a community leader after she experienced hostility from health authorities. Maria's real name has been changed to preserve her anonymity.
- 2 This section is partially based on Flores (2016).
- 3 Invited and claimed spaces for social participation are key concepts in the power cube framework. An 'invited' space is an institutionalised setting in which people are consulted or invited to give opinions. The invitation to participate may be a one-off event or a continuous attendance such as a health committee at local level. A 'claimed' space is a setting which excluded groups create for themselves in which to address their own concerns, including planning social actions to engage and influence public officials or any other actor. For more information, see Veneklasen and Miller (2007); Gaventa (2006).
- 4 The list of 23 different types of complaint are organised around seven category groups: (1) lack of medicines and medical supplies; (2) corruption and illegal charges; (3) denial of rights to health-care service users; (4) users' lack of satisfaction with services provided; (5) providers not following rules and regulations; (6) obstructing access to information by providers; and (7) any other type of complaint. This list was compiled after 18 months of consultations about the most

common problems and barriers that rural indigenous communities experience when seeking health-care services. The consultations were carried out in ten different communities and in four different indigenous languages. CEGSS, together with community leaders, agreed a final list of the most common complaints, which was later validated with the same ten communities. The technical team at CEGSS converted the final list into a text that would reflect the existing legal framework in the country.

5 See the electronic platform at: <http://vigilanciaysalud.com/plataforma>.

6 As it is understood by the power cube framework.

7 These four different reactions from officials were summarised by CEGSS staff after reflecting about the experience of both defenders and CEGSS field staff while engaging with the authorities.

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# Inverted State and Citizens' Roles in the Mozambican Health Sector

Jose Dias and Tassiana Tomé

**Abstract** This article aims to understand the inversion of roles between the state and citizens, by exploring its historical roots and current implications for processes of social accountability in Mozambique, particularly in the health sector. This is a practice-based reflection grounded in the evidence collected through the implementation of Community Scorecards in the health sector in 13 districts of Mozambique. The evidence has revealed a transfer of responsibilities from local governance institutions and service providers to the communities; diluting the frontiers between the state and citizens' duties and rights, resulting in the inversion of roles. This inversion results in the minimisation of the state's performance of its duties and accountability in the health sector to respond to local communities' needs, allegedly due to the lack of financial resources. It also leads to the overburdening of local communities, who assume the responsibility of meeting their own demands, risking participation fatigue.

**Keywords:** social accountability, health sector, rights demand, participation, community scorecard.

## 1 Background

In general, social accountability presupposes the existence of clearly defined relationships and roles, which enable the process of accountability from the state to its citizens. However, in the case of Mozambique there are some ambiguities regarding the mandate and competencies of the state. This results from changes in its role after independence amongst other political, economic, and cultural factors, which undermine the very essence and operationalisation of the concept of social accountability.

An analysis of the evidence collected through the implementation of Community Scorecards in the basic health sector in 13 districts of Mozambique has shown a transfer of responsibilities and tasks from local governance institutions and service providers to communities, and has revealed an inversion of the state and citizens' duties and rights.

This article is a practice-based reflection that seeks to explore the causes and implications of the transfer or inversion of the roles between the

state and citizens, subverting the purpose of social accountability. On the one hand, it results in the minimisation of the state's performance of its duties and accountability in the health sector to respond to the local communities' needs and rights, allegedly due to lack of financial resources. On the other hand, it results in the overburden of local communities, who assume the responsibility of meeting their own demands, which they place on the health service providers at the local level, risking participation fatigue.

The remainder of this article is structured as follows. Section 2 focuses on a theoretical analysis of the inversion of the roles of state and citizen, and discusses citizen participation in the context of (neo) liberal democracy. Section 3 presents a historical perspective on the construction of the Mozambican post-independence state and its implications in the conceptualisation of citizenship. Section 4 discusses specifically community participation in the health sector in Mozambique, and analyses some of the normative instruments that regulate the participation. Section 5 offers a critical assessment of the Community Scorecard. Section 6 concludes with some elements for future reflections.

## **2 Inversion of the state and citizen roles within neoliberal democracy – a critical analysis**

Social accountability is fundamental in ensuring a democratic and transparent governance able to respond to citizens' needs. The process of social accountability entails the capacity of citizens to monitor the performance of political representatives and service providers, in order to have their rights secured. It also involves a government and public servants capable of providing and responding to citizens' demands in order to realise their rights (Commins and Ebel 2010).

Within this approach, citizens are understood as 'direct beneficiaries' but also as 'monitors' of public services and government performance, which uses public funds to respond through their programmes and services to citizens' needs and proposals. In this context, the participation of the citizen emerges as central to a democratic governance, which is reflected in the growing creation of public spaces for civil society involvement in the discussion and decision-making related to public issues. These formal public spaces theoretically propose the sharing of power between citizens and public authorities as a means for deepening and broadening democracy. However, as discussed by Gaventa, participation in such public spaces 'has failed to deal with the hard politics of party building and mobilisation of demands (Houtzager 2003), thus enabling weaker forms of participation to be easily captured and co-opted by a neoliberal agenda' (2006: 17).

However, some experiences reveal that frequently spaces open to the participation of citizens and different sectors of civil society in the evaluation of public services and formulation of public policies end up being spaces used for the transfer of functions and responsibilities from the state to civil society. This transfer of tasks is related to the

implementation and execution of the established plans of the local government, in such a way that civil society and citizens begin to provide services or perform responsibilities previously considered as duties of the state (Dagnino 2008).

Such transfer of responsibilities and inversion of the roles of the state and citizens was identified in the experience of social accountability at the local level in the health sector. It was facilitated by district platforms of community-based organisations that are partners of the Centre for Learning and Capacity Building for Civil Society (CESC), Maputo, Mozambique.

A byproduct of this process of local social accountability in the health sector, which also involves planning and joint action between public providers and citizens, has been the growing responsibility of local communities to contribute to the construction and improvement of health infrastructures. As a result, the social functions of the state were reduced with regard to this aspect.

In a recent study, Kleibl, Ilal and Munck (2014) question how Mozambicans conceptualise 'civil society'. One of the interviewees, a worker at a local non-governmental organisation (NGO), stressed that 'it is very important to have clear lines between the state, the market and civil society' (*ibid.*: 14). At the same time, he stated that civil society organisations (CSOs) should complement the state's work in cases where it is weak and unable to fulfil its role. In this light, it is possible to note that while there is a need for clear boundaries, there is a sense amongst different CSO actors that civil society has a moral responsibility or obligation to complement or fill the gaps of the state.

According to Dagnino (2008), this transfer of social responsibilities and the 'exploitation' of citizens' participation in ways that lead to the handing over of accountability from public institutions and services to its citizens, is the result of what she calls 'perverse confluence'. It is the confluence between two distinct political and cultural movements of democratisation, which use the same references and lexicon but with different underlying understandings, such as 'citizenship' and 'participation', and make use of similar operational mechanisms such as joint participatory planning.

On the one hand, there is the political and cultural project of neoliberal democratisation. It is based on a minimalist state with fewer social responsibilities and a smaller role in realising citizens' rights, as it relies on facilitating the privatisation of different public services. This project is also based on an active but neutral and technocratic civil society, which also assumes the role of a public servant (Tar 2009; Shivji 2011).

On the other hand, there is a political project of democratisation emerging from endogenous social movements and initiatives seeking an effective sharing of power between state and civil society. Such co-sharing of power involves deepening the capacity for citizens' greater deliberation in public spaces, and the construction of citizenship as

the exercise of redefining and expansion of rights. This is not only in the formal politico-judicial sense, but also in the sense of a more egalitarian sociability between state agents and citizens in the resolution of structural issues, and in the designing of the development agenda and its underlying political and economic paradigms.

Both projects require an 'active and engaged' civil society and 'participatory citizenship', but there are fundamental distinctions in the aims and meanings of this common terminology (Dagnino 2008).

For instance, the exercise of social accountability, civic engagement, and power-sharing at the local level is marked by joint planning and resolution of local problems, bringing together the state and citizens. However, in the neoliberal context of a minimalist state, this exercise tends to involve rather immediate, individualistic, and 'managerial' resolutions of local problems that end up becoming the responsibility of the most vulnerable and low-income citizens, who already have a restricted access to quality services. For Dagnino (2008), this mere technical management of the precariousness of social services and poverty results in depoliticised micro-interventions, which do not take into account deeper structural power asymmetries, such as class relations, and also remove from the arena of participation notions of justice and social equality as struggles towards correcting such power imbalances.

In this sense, the democratising political potential of this exercise of participatory monitoring and joint planning is reduced, since a greater balance and reciprocity of power between state and citizens is not achieved (Commins and Ebel 2010). Citizens' efforts to demand the realisation of their rights is replaced by efforts to fill the gaps in public services. Most of the time, these efforts in resolving local problems are realised in ways that are disconnected from the macroeconomic and structural causes underlying the deficiencies of the public services and state's performance. This situation can potentially generate fatigue amongst citizens, who get a sense of having their participation 'exploited' to carry out already established agendas, and can exempt public agents from their role of serving and guaranteeing the materialisation of community rights. The disconnect between local effort and more central and structural resolution of the problems faced by citizens reveals the need for decentralisation policies that allow greater accountability to local authorities, and greater local autonomy shared equally by the state and the citizen.

It is also relevant to propose an analysis of class and power to better grasp how participation and citizenship have been performed. This illustrates precisely how the most economically disadvantaged groups are the ones most overburdened, and the ones who undertake the tasks the local services and government are unable to realise. With regard to power analysis, Osaghae (2003) discusses the existence of two publics or social groups in the context of citizenship in Africa: a civic public that participates in local formal spaces such as consultative councils, and a

primordial public residing within the context of family and community life and solidarity networks. Such analyses are important to understand the different hierarchies and inequities that shape the ways civic participation is happening within the public space.

As argued by Dagnino (2008), it is necessary to understand citizenship as the search for greater equality, not only in relation to the state, but at the very heart of society, and thus it is equally fundamental to understand the hierarchies within the public space as well as within civil society.

In this light, it is vital that the premises of collaboration and complementarity between state and citizen also privilege a space for contestation and antagonism. It is in this space that citizens can become shapers and makers. They can continuously propose redefinitions of the roles of the state and civil society in order to respond to the visions and proposals of new approaches towards a more egalitarian and just public responsibility and accountability (Cornwall and Gaventa 2000). This resonates with Gaventa's argument that 'democracy-building is an ongoing process of struggle and contestation rather than the adoption of a standard institutional design' (2006: 3).

In this sense, in order to guarantee the democratic potential of social accountability frameworks within local services, it is necessary to re-politicise the processes of citizen participation. In other words, it is necessary to consider citizens not only as beneficiaries of public services with already defined rights, but as formulators of these same rights, and agents in the definition of governance models and new social contracts (Dagnino 2008).

Similarly, Kleibl *et al.* (2015) put forward the idea that to overcome this 'crisis' in civic engagement, in Mozambique, it is crucial to go beyond purely technical processes of citizen participation, and to take into account the historical and current imbalances of local political and economic powers. In this sense, Section 3 presents a historical analysis of the processes of construction and redefinition of the state in Mozambique, including the historical roots of inverted accountability and its implications for citizen participation.

### **3 Building the post-independence state – to what extent has this context been building an active citizenship?**

During the colonial period, Mozambique's economic structure was characterised by two main functions: (i) to maximise the extraction of resources, through production methods based in the exploitation of massive labour work; and (ii) mobilising foreign economic resources. Regarding the exploitation of labour work, in particular, the colonial state used slavery methods, including forced labour, forced crop cultivation, high taxes, and low wages, in order to ensure the raising of revenues for the state (Maloa 2016).

The rationale used by the colonial state was to consolidate the profit into fewer hands and promote conditions that favoured capital accumulation

by Portugal and the Portuguese over all others. In such an environment, citizenship was a condition granted by the colonial state to certain populations, namely, the Europeans and the converted naturals – the 'assimilados'. On the other hand, the colonial state, through the regulation of indigenous labour, and discriminating against African tradition, assumed that its competence lay in taking responsibility for safeguarding the life of the indigenous people, who for 'civilisational' reasons were not in a position to take responsibility for themselves (Macamo 2014).

After gaining independence in 1975, the political relationship between the state and its citizens did not change significantly (Macamo 2014; Paredes 2014). In fact, the attempt to create citizens that were aligned with the state-party opened up space for the reconceptualisation of colonial practices in a new post-colonial socialist branding. One of the typical experiences that illustrates this is the so-called '*Operação Produção*', which was used in the policy of building the 'new' Mozambican citizen. In existence since the early 1980s, this was an organisation of a popular re-education project in big rural farming fields, mainly located in the north of the country. These farms served as true laboratories for the political reconversion of any individuals who expressed political dissent. These individuals cultivated the farms, built their homes, and by the end of the day would participate in the Marxist–Leninism political courses (Paredes 2014).

On the other hand, based in the territorial control of the liberated zones, the liberating party controlled agricultural production, creating an economy based on the trade of goods produced by farmers such as peanuts, maize, and cashew, and goods provided by the military which the farmers could not cultivate such as salt, sugar, and clothes. Despite the early incentives the farmers had for trading, they later became convinced that the terms of trade were unfair, and they also became aware that the liberating party was primarily serving its own interests (Bragança *et al.* 1983).

In practice, the post-colonial state had the prerogative to direct the dynamics of the political, economic, and social spheres, and eliminated any form of social pluralism (Lalá and Ostheimer 2003). Such logic contributed to the conversion of the liberating party into a hegemonic political institution, in relation to civil society and to the institutional spheres in which the society was founded: namely, the market, the state, and the family (Francisco 2011).

The current phase began in 1990, having as the key feature the approval of the new democratic and multiparty Constitution that grants new rights and freedoms, including the right to information, freedom of expression, and freedom of association. In general, this phase seeks to consolidate the democratic model and the liberal economy, building on, amongst other aspects, the gradual decentralisation and deconcentration of the state administration and the promotion of citizen participation (CIRES 2001).



In the early 1990s, this environment enabled the creation of religious and professional organisations that sought to contribute to emergency and relief actions during the civil war, contributing to the provision of medicines and the building of basic social infrastructures, particularly in the health and education sectors. Later on, with the approval of the new Law of Associations, the country witnessed the development of interventions related to civic education, human rights, elections, accountability, and participation in a plural society (Lalá and Ostheimer 2003).

The quest for the promotion of citizen participation in governance, in particular, has also been witnessed in the progressive formulation of a set of general and sectoral public administration legislation aimed at creating a vibrant citizenship. It is within this framework that one can find general instruments, such as the law and the basic decree of organisation and functioning of the public administration (Law 7/2012 and Decree 30/2001), the law of local state bodies (Law 8/2003), as well as the Charter of the patient's rights and duties, in the health sector, which provide a set of mechanisms that guide the individual or collective participation of citizens for influencing public decision makers on issues that affect them.

Despite these normative efforts made for deepening democracy, there are key factors posing challenges for achieving the outcomes of citizen participation and engagement. For instance, although access to information is a precondition for citizen participation in service provision and local governance, there is insufficient culture of accountability in most public institutions, especially at local level. In such an environment, the provision of information about services for the citizen is not prioritised.

Power relations are the other key factor hindering the achievement of the outcomes of participation. At the local level, power relations are very unfavourable towards citizens, particularly vulnerable groups such as poor women, the elderly, and children, and social structures are dominated by the local elite, mostly related to the governing political party (CEP 2013).

The other barriers to the exercise of citizenship have to do with inequalities of gender and wealth, poverty, illiteracy, and lack of access to the formal structures of the state. Even with the opening of new spaces of interaction between the government and the citizens, such as development observatories and consultative councils, such spaces need clear arrangements for citizens' recommendations to be taken into account in government policymaking (AfriMAP and OSISA 2009; Forquilha and Orre 2011).

#### **4 Functional issues in the health sector: who does what, when?**

Apart from little openness, and weak political inclusion, the state is affected by the lack of clarity in the separation of roles between the public sector and the citizen. In our view, the notion that the

provision of services is not an exclusive role of the state, but a shared responsibility, which is also reflected in health sector policies, is the root of this ambiguity.

The main issue here is the lack of clarity in the delimitation of the criteria from where the role of the state and the citizen begins and ends. This is confirmed in different health sector policies, of national and international origin, where it is possible to find diversified and even disjointed concepts regarding the role to be played by the citizen participating in the solution of health problems:

- In one of its seven guiding principles, the Health Sector Strategic Plan (2014–19) reveals the intention of the health sector to establish a partnership with civil society and NGOs to promote advocacy and service provision (MISAU 2013). The underlying notion of this policy is the sectoral partnership expected with the intermediary institutions and not with the citizen.
- As a community health agent (CHA), the citizen plays the role of service provider, increasing the coverage of basic health services for the community. This concept is reflected in the community involvement strategy, which defines CHAs as 'all individuals, chosen in the community, who are trained by the health sector, or NGOs and religious institutions, to carry out promotional, preventive and/or curative activities at the level of communities. Within the CHAs group are the elementary polyvalent agents (APE), traditional midwives and activists' (MISAU 2014: 1). If we accept that the elementary APEs assume the role of a service provider, then we should also accept the inherent double accountability relations in which they are involved: they are subordinated to health institutions in performing their function; for example, regarding the request of medicines and accountability for their use. But they are also accountable to local communities regarding their performance.
- The citizen appears as co-manager and decision maker of the health facility, as a member of the co-management committee, and a community agent when integrated into the health committee. The former committee is a multidisciplinary body made up of workers, health managers, and community members working together to plan, execute, and monitor activities, including analysis and decision-making on all aspects of the health facility (MISAU 2012a). The latter committee is a socio-community structure composed of members chosen or elected by the community for 'its representation' at all times and to make decisions on health (MISAU 2012b: 9).

However, by virtue of its inherent functions, in practice, by possessing key information and knowledge, the health workers and managers integrated into the co-management committee have greater decision-making power than other members. Regarding the health committee, although it is established that it should not be subordinated to health

institutions, it is expected that political parties will participate in this committee, risking the co-optation of the opinion of other actors, and minimising the freedom of expression of the citizens integrated therein.

- The Charter of the Rights and Duties of the patient can be considered an instrument of empowerment that seeks to instil the sense of self-agency of the citizen as a health service user. The Charter can be defined as a guiding instrument that establishes the standards to be demanded and respected by the citizen and health personnel, respectively, in the provision of services (MISAU 2011). However, despite its aim of empowering the citizen, the lack of knowledge and experience of exercising the rights foreseen by the user and the provision of rights locally is not feasible, because of the lack of resources which restrain the degree of its implementation.

Overall, it is noted that in addition to the lack of conceptual harmonisation of the role of the citizen in the health sector policies listed above, the mechanisms of participation therein established are affected by operational dynamism that impedes the performance of a substantial citizenship. This results in the demand for accountability from citizens to the service providers and political leaders.

There is a compelling empirical example that shows one of the effects of lack of conceptual harmonisation on paper in everyday practice. During the monitoring visits conducted by CESC in Montepuez District in 2016, members of the co-management committee expressed that because of the role they played as co-managers and decision makers of the health facilities, they felt it would be impossible to individually demand the implementation of the Charter of the Rights and Duties of the patient when accessing these health facilities as users. The point being made here is that they did not feel like community members and expected this role to be played by others – referring to those whom they mobilised. This case shows clearly that these members abdicated from some of their rights, particularly regarding active citizenship, in order to assume other rights.

### **5 The Community Scorecard: an opportunity for the exercise of an active citizenship?**

The Community Scorecard can be defined as a participatory tool that (i) is conducted at micro/local level and uses the community as the unit of analysis; (ii) generates information through focus group interactions and enables maximum participation of the local community; (iii) provides immediate feedback to service providers and emphasises immediate response and joint decision-making; and (iv) allows for mutual dialogue between users and providers, and can be followed by joint monitoring (CARE Malawi 2013).

Like other social accountability tools, the Community Scorecard has a high potential to promote the exercise of active citizenship. In this vein, Malena, Forster and Singh (2004) argue that social accountability mechanisms are top down, and contrary to the elections which are blunt, accountability mechanisms allow citizens to express their preferences

**Table 1 Cases of government, joint, and community responsibilities in infrastructure construction in the health sector**

District	Year	No. of cases	Responsible		
			Government	Joint	Community
Alto Molócué	2014	2	2	-	-
Ancuabe	2014	1	-	1	-
Ancuabe	2015	1	-	1	-
Chibuto	2014	2	1	-	1
Cuamba	2015	4	3	-	1
Gujjá	2014	2	2	-	-
Maganja da Costa	2014	1	1	-	-
Malema	2015	4	3	-	1
Mandimba	2015	7	4	-	3
Mandlhakazi	2014	3	1	-	2
Mandlhakazi	2015	17	9	-	8
Milange	2014	2	2	-	-
Montepuez	2014	1	-	1	-
Montepuez	2015	11	11	-	-
Ngauma	2015	1	1	1	-
Quissanga	2014	2	2	-	-
Quissanga	2015	3	1	-	2
<b>Total (%)</b>		<b>64</b>	<b>42</b>	<b>4</b>	<b>22</b>

Source Extracted by the authors based on CESC (2015, 2016) reports.

on specific issues, participate in the decision-making process, and hold public officials accountable for particular decisions and behaviour.

However, the experience of implementation of the Community Scorecard by CESC partners shows that there are a considerable number of cases where, after scoring in relation to their satisfaction regarding health service delivery, community members assume the responsibility for providing resources, building infrastructure, and/or providing services during the building of infrastructure, in partnership, or even replacing the government.

Table 1, extracted from CESC partners' Community Scorecard reports from 2014 and 2015, shows that out of a total of 64 infrastructure construction cases, such as nursing homes, medical staff residences, and opening of hospital landfills, the government assumed full responsibility for the performance of this function in only 66 per cent of cases.

In the remaining 34 per cent of cases, the local government counted on community labour, with the community assuming full responsibility in building such infrastructure. The community also shared responsibility with the local government in building such health infrastructure in 6 per cent of cases.

There are also situations of change of responsibility between the government and communities over time in at least two districts. While in 2014 the community assumed more responsibility in the building of infrastructure in Mandlhakazi District, in 2015 this picture changed as the government took responsibility for more cases than the local community. Similarly, in 2014 in Quissanga District, the government assumed more responsibility than the community, a situation that changed in 2015 when the community took over more cases than the government.

It is worth noting that in 2015 Mandlhakazi District appears with a high number of cases of community involvement in the process of building infrastructure, tending to be almost in balance with the government's responsibilities in this regard.

The key lesson to be drawn from the data in Table 1 is that the nature of contradictory accountability in current relations established between state and citizen can significantly influence the way in which social accountability is implemented.

In other words, and in light of the discussion in Section 4, we can argue that although it constitutes an opportunity for the exercise of freedom of expression and accountability, the representations, resulting from the past experience of playing passive citizenship roles, and the lack of experience of exercising a substantial permanent citizenship, can subvert the sense of accountability that one intends to construct within the social accountability approach.

It is worth noting that although the type of infrastructure built by communities does not necessarily follow the technical standard established for public infrastructure, and even though the efforts and costs mobilised in the infrastructure built by the state differs from that of communities, community infrastructure is locally accepted and used by medical staff, because it closes the gap of lack of conventional infrastructure, in an environment of scarcity of resources.

In practice, this kind of scenario has often resulted in the overburden of local communities, who assume the responsibility of meeting their own demands, reproducing historical patterns of unequal labour demands, and risking a sense of participation fatigue.

## **6 Concluding remarks**

Knowledge of prior relationships and construction of roles of the state and the citizen is a key element for CSOs promoting the social accountability approach. Knowledge is necessary in order to define the entry points to promote the transformation of roles and values in order

to establish vertical relationships between the parties. Otherwise, they risk not achieving the desired results.

The Community Scorecard tool operates in a complex context, of existence of mechanisms of citizen participation promoted by the state that instils inverted accountability relations. Thus, there is a need for a holistic effort to reconceptualise the role played by citizens and public institutions, as a requirement for creating an enabling environment in which a sense of accountability can flourish. However, given the historical background that we have discussed, it must be acknowledged that this may only be achievable in the long run.

The studies that may bring further data to deepen the discussion raised here would include the following subjects:

- Citizens' belief in public institutions and their capacity to solve their priority demands;
- Perception of the community regarding participation mechanisms, including those promoted by the state and civil society; and
- Knowledge of rights and duties of citizenship and the willingness for long-term civic and political engagement.

The central issue, regarding the transfer of responsibilities from the state to the citizen, is how to alter the maintenance of asymmetrical power relations between these agents, and the non-resolution of structural questions relating to social inequality. These asymmetrical power relations are camouflaged in the processes of social accountability through planning and joint resolution mechanisms, in which participation is vulnerable to instrumentalisation, thus reducing the democratic possibility of greater transparency and the co-sharing of decision-making power.

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# Accountability and Generating Evidence for Global Health: Misoprostol in Nepal\*

Jeevan Raj Sharma, Rekha Khatri and Ian Harper

**Abstract** Postpartum haemorrhage (PPH) is a major cause of maternal morbidity and mortality in Nepal. Compounded by the remote terrain, endemic poverty, and a lack of access to health facilities, the use of misoprostol has advantages over the standard use of oxytocin for PPH management. Drawing on our qualitative study of a pilot intervention managed by the Nepal Family Health Programme, we map the institutional relationships involved in the design, implementation, and practices for bringing misoprostol into national policy. In the intense and competitive global and national policy arena, sustained lobbying and getting the ‘right people’ on board were as powerful drivers as the quality of the intervention itself. The case study takes us to the heart of the debate around the politics of generation of evidence for interventions in global health programmes, and ultimately the question of accountability for health policy and practice.

**Keywords:** maternal health, accountability, evidence, health policy, Nepal, misoprostol, development.

## 1 Introduction

Postpartum haemorrhage (PPH) is a major cause of maternal morbidity and mortality in Nepal and in the global South. It is estimated that about a quarter of maternal deaths are caused by PPH (Rushwan 2011; Say *et al.* 2014). Misoprostol is a drug that causes the uterus to contract and thus stop PPH (Allen and O’Brien 2009). In May 2011, the World Health Organization (WHO) 18th Expert Committee on the Selection and Use of Essential Medicines approved the inclusion of misoprostol for the prevention of PPH in settings where injectable uterotonics,<sup>1</sup> mainly oxytocin, are not available or feasible (Chu, Brhlikova and Pollock 2012). In this article we explore, in the context of Nepal, a programmatic intervention set up to demonstrate the feasibility of misoprostol distribution by female community health volunteers (FCHVs) run prior to WHO approval. As a part of the Biomedical and Health Experimentation in South Asia (BHESA) research project conducted in Nepal, India, and Sri Lanka between

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2010 and 2013, we investigated a pilot intervention carried out under a bilateral programme of the United States Agency for International Development (USAID) and the Government of Nepal that took place in Nepal's Banke District between 2005 and 2007. At the time of our field research, this had already been incorporated into national policy.

We began by researching the individuals, organisations, and institutional arrangements that were responsible for bringing the idea of misoprostol to Nepal, managing this pilot intervention and lobbying for its scaling up into national policy. This included mapping the role of organisations and individuals and their key relationships and networks in this process. We looked through the webpages of all the organisations involved in the bilateral programme managing the pilot intervention, and collated their publications including reports, technical briefs, and two academic articles that were published in 2006 and 2010 in the *International Journal of Gynecology & Obstetrics*. We carried out interviews with staff members and consultants involved in this initiative, and government staff who were directly involved in the pilot and its scaling up into policy. We also conducted ethnographic fieldwork in Banke District where the pilot intervention took place, and interviewed staff at the District Health Office, health workers in sub-health posts, as well as FCHVs who were involved.

Our aim was to chart the considerable work done by the individuals and organisations, and understand their relationships and networks during the process of getting misoprostol into national policy. We reveal how in the intense and competitive policy arena, sustained lobbying and getting the 'right people' on board were as powerful drivers as the quality of the intervention itself. Underlying the intervention were strong ideological drivers and the vested interests of USAID, WHO, and international research organisations, and complex national and international organisational politics.

Central to these relationships and their configurations is the question of accountability. In our view, there are two ways to think about accountability in the context of this empirical research. First, the global health landscape and associated accountability structures is increasingly complex, with the entanglement of public and private actors (Horton 2014; Bruen *et al.* 2014). The involvement of chains of private actors that mediate the relationship between global health policies and local populations raises critical questions on overlapping and competing mandates (Sharma *et al.* 2017) as well as risks involved with diluting responsibility across a broadening set of actors (Bruen *et al.* 2014). Who should be accountable for global health programmes that involve a large number of actors with varying degrees of power and influence? How should the relationships of accountabilities be worked out amongst different actors, including funding agencies, host governments and their ministries, the implementing agencies (be that primary health-care providers from government and/or non-governmental organisations (NGOs)), and the recipient populations?

Second, accountability concerns within global health programmes are being informed by new norms such as value for money and measurable results as a way to address accountability (Fan and Uretsky 2017). There is increased economic and political pressure to demonstrate the impact of projects and programmes in terms of demonstrating that the disbursement of resources is tied to measurable results (Horton 2014; Valters and Whitty 2017). This has given rise to new institutional forms including monitoring and evaluation and the critical importance of generating evidence within programmes. Not only are programmes increasingly organised as a set of measurable results, with costs directly linked to the achievement of those measurable results, they are also increasingly organised around ‘pilot’ interventions. Essentially, these shifting norms shape the very idea of health and how health programmes should be designed and implemented. In this sense, the ideas associated with accountability are shaping the way we define the problem, prioritise the interventions, and measure their outcomes.

Thus, this case study takes us to the heart of the debate around the politics of generation of evidence for interventions in global health programmes, and ultimately the question of accountability for health policy and practice. It is an example of but one programmatic intervention being undertaken in Nepal, reflecting the increasing complexity of constellations of organisations involved in the provision of health services. A final caveat is methodological. We do not make normative claims or suggestions for change to accountability mechanisms, or ascribe normative judgements (be these ideological, ethical, or political). Our approach is ethnographic, and we provide this case study as a way to think where we place the primacy of responsibility: either at the level of the state, or with bilaterals that fund, or with NGOs in this context.

## 2 Background

PPH is defined as loss of greater than 500ml of blood following within 24 hours of vaginal delivery (WHO 2009). Given widespread poverty, anaemia, unequal gender relations, remote terrain, and limited access to health facilities resulting in high numbers of home deliveries without skilled birth attendants (SBAs), PPH is a major cause of maternal death in Nepal and much of the developing world (Rushwan 2011; Say *et al.* 2014; Suvedi *et al.* 2009).

Endorsed by WHO, oxytocin is the preferred option for the management of postnatal care but it needs to be administered by injection by a health professional, and requires a cold chain for storage (Chu *et al.* 2012). Thus, whilst effective, this limits its use practically (Prata, Bell and Weidert 2013). Despite considerable efforts to increase institutional delivery in Nepal, including new innovations such as maternity incentive programmes,<sup>2</sup> the institutional delivery rate stood at 35 per cent in 2011 (MOHP, New ERA and ICF International 2012).

Misoprostol was developed by SEARLE (now Pfizer) in 1973. The US Food and Drug Administration (FDA) first registered it in 1988 for

the treatment of gastric ulcers (Millard, Brhlikova and Pollock 2015). It was also found to cause the uterus to contract, which is why it is considered as an option to stop PPH, and was increasingly used 'off-label' for different purposes (*ibid.*). More importantly, unlike oxytocin, it can be taken orally, sublingually, or vaginally, and does not require a cold chain for its storage, and thus it is considered by some to be a suitable option in the absence of skilled medical professionals. For these reasons, it is thought to be a suitable solution for the management of PPH in low-income settings (*ibid.*). In the last two decades, there have been a large number of pilot interventions in low-income countries such as Nepal that assess misoprostol's efficacy and the feasibility of distribution by community health volunteers (*ibid.*).

Jhpiego conducted the first study on community-based distribution of misoprostol in Indonesia (Sanghvi *et al.* 2004). The purpose of this study was 'to demonstrate the safety, acceptability, feasibility, and program effectiveness (SAFE) of community-based distribution and use of oral misoprostol to reduce PPH in areas where a large proportion of births are not attended by skilled providers' (Sanghvi *et al.* 2004: viii). As we were told by a senior official at Jhpiego, they wanted to take 'misoprostol treatment outside of the formal system'. It showed dramatic impact. Although interestingly this was never published, the results were widely disseminated at a meeting in 2004, and were widely cited, and – we were informed – therefore 'didn't really need publication'.<sup>3</sup>

As is apparent from cautionary statements put out by WHO, their resistance to the use of misoprostol was mainly threefold: first, against the ideas of self-administering; second, concern with the as-of-yet unreported side effects of the drug (for example, uterine rupture if taken too early). One of the publications advocating WHO's cautionary approach quoted Sir Iain Chalmers: 'Because professionals sometimes do more harm than good when they intervene in the lives of other people, their policies and practices should be informed by rigorous, transparent, up-to-date evaluations.'<sup>4</sup> And third, as reiterated in the interviews we conducted, that it would detract from the use of SBAs. The subsequent approval of misoprostol by WHO in May 2011 has increased promotion for community-based distribution in low-income countries, although the scientific evidence has been contested.<sup>5</sup>

Called '*matrisurakchya chakki*' in Nepali (literally translated as 'safety tablet for mothers'), the push for its widespread use was directly stimulated by targets for Millennium Development Goal 5, and is embedded in the rise of metrics and measurement in global health programmes (Adams 2016). This discourse is driven by 'magic bullet' solutions to complex global health challenges. In addition, scholars have commented on the role of networks of organisations and individuals with substantial financial and political backing from major foundations, in influencing WHO's decision to include misoprostol in its Essential Medicines List (Millard *et al.* 2015), and the role of civil society organisations in Uganda (Atukunda *et al.* 2015). In this article, we offer an ethnography

of how misoprostol made it into Nepal's national health policy as a part of a pilot intervention despite resistance from WHO. We offer an analysis of how sustained lobbying and getting the right people on board were critical in this process.

### 3 Evidence generation in the health sector in Nepal

Elsewhere we have charted the history of scientific research in the health sector in Nepal and its close ties to development aid (Sharma, Khatri and Harper 2016). Much of this research activity in the health sector is sponsored by bilateral aid agencies such as USAID and/or carried out by development institutions, often in collaboration with universities and research institutions. Not only have the discourses on evidence become central in proposing solutions to health challenges, health programme interventions are increasingly designed to generate evidence. With organisations like the Global Fund, for example, demanding that the resources are now dispersed based on performance linked to indicators, this increasingly drives how organisations design their programmes.<sup>6</sup> Thus, the accountability and results agenda in global development and health debates have directly shaped these forms of interventions (Adams 2016; Valters and Whitty 2017).

This form of generation of evidence around programmatic interventions has been sustained by assemblages of local and international organisations and universities, and supported and funded by aid institutions. These assemblages and institutional forms involving donors and their advisors (bilaterals; international non-governmental organisations (INGOs)), government policymakers, programme managers working for governments, INGOs, and NGOs, and researchers are not only critical in the generation of evidence but also provide much-needed networks of support for the successful up-scaling of pilot projects (Sharma *et al.* 2016; Harper 2014). In Nepal, several NGOs and a few private research firms specialising in health systems research have emerged that mainly work on short-term sub-contractual agreements with the government, bilateral, multilateral, and private philanthropic organisations.<sup>7</sup>

Given the small number of these institutions, reflecting the limited research capacity in-country, they are often oversubscribed by the sponsors. The short-term nature of the contracts mean that they are constantly busy in simultaneously handling multiple projects while moving to the next one (*ibid.*). These evidence generation activities are dispersed and hidden under various programmatic interventions and it is almost impossible to map all the ongoing activities (Sharma *et al.* 2016). There is no clear definition as to what is regarded as health research activity and thus what needs approval from the Nepal Health Research Council (NHRC) and what does not. The misoprostol pilot intervention that this article reflects on did secure NHRC approval.

Given this background, Section 4 examines the specific institutional arrangements around the introduction of misoprostol.

#### 4 Institutional arrangements

In Nepal, the network to introduce misoprostol into the government's national programme coalesced around the Nepal Family Health Program (NFHP). It has broad aims, particularly to support the Government of Nepal's goals of decreasing fertility and under-five mortality, through providing basic family planning, and maternal and child health services.

This has involved the following partners, for phase 1 (2002–07): John Snow Inc. (JSI); EngenderHealth; Johns Hopkins University/Center for Communication Program (JHU/CCP); Jhpiego; CARE; Save the Children Federation/US (SCF/US); the Nepal Fertility Care Center (NFCC); the Nepali Technical Assistance Group (NTAG); Management Support Services (MASS); and the Adventist Development and Relief Agency (ADRA).<sup>8</sup> And for phase 2 (2007–12): JSI Research and Training Institute (RTI), and its partners – Save the Children; EngenderHealth; Jhpiego; World Education; NTAG; NFCC; MASS; the Nepal Red Cross Society; the United Mission to Nepal; the BBC World Service Trust; the Digital Broadcast Initiative Equal Access Nepal; and the Family Planning Association of Nepal.<sup>9</sup>

This ostensibly bilateral programme funded by USAID had its own office, separate from the Ministry of Health. Its well-furnished offices and staffing conditions by far exceeded the budget of government departments. One senior member in NFHP described it as 'a consortium of different parties' – not registered as a different organisation, and staff are paid by different partners.<sup>10</sup> Thus NFHP was not an NGO, government department, or a unit of USAID; it was essentially a consortium of several key organisations that brought together different expertise on technical knowledge on maternal health, logistics, and communications. It had significant leverage in health systems development in Nepal.

Accountability fell to both USAID and the Government of Nepal. NFHP management had to report to USAID. As a bilateral programme, NFHP had the authority of the Government of Nepal, although it sat outside of the government structure. Although the activities of NFHP were carried out through the government structure and with the engagement of government staff, these staff did not have leading roles in shaping the programme. In other words, the government was accountable for the programme, although NFHP project staff largely carried out its activities. NFHP had a budget of about US\$25m. It had hired a number of highly experienced expatriates as well as Nepali professionals with deep knowledge of the health system and service provision in Nepal. Many of the employees were former employees of the government, or had been employees in phased-out USAID-funded projects with the required skills and relationships for navigating the health system. At the time of our fieldwork, the team leader of NFHP was hired under EngenderHealth, a New York-based organisation. Some of the key organisations have headquarters in the US (Jhpiego in Baltimore, JSI in Boston, SCF/US in Connecticut with project offices in Nepal, Venture Strategies in California). The others are based in Nepal.

**Table 1 Key organisations in the NFHP consortium**

Organisation	Main objectives	Role in NFHP
Jhpiego <sup>11</sup>	Promotes practical, low-cost innovations to improve the health of women and their families	Technical support and training
EngenderHealth <sup>12</sup>	Develops private sector involvement, particularly around sexual and reproductive health, and promotes social franchise	'Nepalising' the training materials
John Snow Inc. (JSI) <sup>13</sup>	Improves the health of underserved people and communities	Management of logistics
Johns Hopkins University/Center for Communication Program (JHU/CCP) <sup>14</sup>	Mobilises health communications to save lives and transform public health system	Development of communications strategy and materials
CARE Nepal <sup>15</sup>	Empowerment of poor, vulnerable, and socially excluded people to fulfil their basic needs and achieve social justice	Support in the formal handover of health facilities to local communities in 17 districts
Save the Children (SCF/US) <sup>16</sup>	Improves the lives of children worldwide	Support in the formal handover of health facilities to local communities in 17 districts
Nepal Fertility Care Center (NFCC) <sup>17</sup>	Provides standardised reproductive health services across Nepal as well as supporting the government by training direct and indirect government and NGO health personnel	Technical support on family planning and reproductive health services
Adventist Development and Relief Agency – Nepal (ADRA) <sup>18</sup>	Creates just and positive change through empowering partnerships and responsible action	Implementation of the programme in selected districts
Valley Research Group (VaRG) <sup>19</sup>	Conducts applied socioeconomic research including action research, and offers training and consultancy services	Carries out operational study with a baseline and endline survey
Management Support Services (MASS) <sup>20</sup>	Delivers innovative and customised management services which include logistics planning, supply chain management, HR management, organisation development, and research studies	Financial and organisational management
Nepali Technical Assistance Group (NTAG) <sup>21</sup>	Enhances technical and management capabilities of health personnel working in various health programmes	Technical support on the delivery of community-based approaches to the programme
Venture Strategies for Health and Development (VSHD) <sup>22</sup>	Stabilise global population by securing women's freedom to choose their family size	Lobbying for misoprostol to be registered as an essential medicine <sup>23,24</sup>

Sources See endnotes 11–24.

Table 1 details the key organisations, their objectives, and roles in the NFHP consortium.

**Table 2 Misoprostol in Nepal: key developments**

1973	SEARLE (later incorporated into Pfizer) develops misoprostol
1988	FDA registers it for off-label use
2001	NFHP (2001–06) starts in Nepal
2003	NFHP submits published evidence on misoprostol to FHD
2000–03	Jhpiego carries out first pilot of community distribution of misoprostol in Indonesia, which gets published in 2004
2004	Jhpiego organises PPH Bangkok meeting – attended by director of FHD from Nepal
2004	NESOG Scientific Meeting
2005	Department of Drug Administration (DDA) approval of drug for pilot
2005	NHRC approval for pilot study
2005	TAG (technical advisory group) meeting makes recommendation to National Safe Motherhood and Neonatal Sub-Committee
2005	Baseline study in Banke, training and pilot intervention starts
2006	Paper from baseline published in <i>International Journal of Gynecology &amp; Obstetrics</i>
2007	Endline/follow-up survey in Banke
2007	A follow-up to NFHP, NFHP II (2007–12) starts in Nepal
2008	Misoprostol included in national Essential Drug List (EDL)
2008	Approved for national programme
2012	WHO approves the inclusion of misoprostol for the prevention of PPH in settings where parenteral uterotonics are not available or feasible

Source Chu *et al.* (2012); Hobday *et al.* (2017); and interviews in Nepal (see endnotes 25–45).

This constellation of organisations indicates that there is a complex relationship between them, their roles and responsibilities (frequently in the guise of ‘technical support’), and the state. Calls for proposals to implement programmes are now increasingly issued by USAID, and others such as the Department for International Development (DFID) (UK aid), and consortia such as these apply.

Having outlined the main organisational arrangements of NFHP, we now turn to the work involved in bringing misoprostol’s programmatic presence into Nepal and stabilising it.

### **5 Misoprostol enters Nepal**

Under NFHP, there was considerable work undertaken to bring misoprostol to Nepal (see Table 2 for a chronology of the key dates in this process). Initially, the Ministry of Health was reluctant to start the



misoprostol pilot.<sup>25</sup> It took more than a year for NFHP to convince the government. In 2003–04, NFHP staff presented the concept of using misoprostol in various forums in Nepal. Its lobbying included giving presentations at the Nepal Society of Obstetricians and Gynaecologists (NESOG) and to other critical stakeholders on maternal health in Nepal.<sup>26</sup>

In 2004, Jhpiego organised a conference in Bangkok to disseminate the results of its study on community-based distribution of misoprostol in Indonesia,<sup>27</sup> to which it had invited teams from 18–20 countries.<sup>28</sup> NFHP took a strong team from Nepal led by the director of the Family Health Division (FHD) who committed that Nepal would pilot the misoprostol study.<sup>29</sup>

Following on from this, a senior staff member from Jhpiego shared the idea of using misoprostol in the National Safe Motherhood and Neonatal Sub-Committee meeting in September 2004.<sup>30</sup> Likewise, NFHP facilitated the visit of an expert on misoprostol from Indonesia, who shared the Indonesian experience in the sub-committee meeting.<sup>31</sup> Presentations by these authorities at the FHD were an important part of the lobbying. NFHP worked with the Ministry of Health to ask for the opinion of NESOG and the Maternity Hospital regarding the use of misoprostol.<sup>32</sup> A major constraint in bringing misoprostol to Nepal was that the drug was not licensed in Nepal at that time, plus there were fears that it could be used for abortion.<sup>33</sup> Resistance was an issue from the perspective of the programme director. There was widespread speculation that misoprostol use could also deskill SBAs.<sup>34</sup> Overcoming such resistance was also about having the right political weight behind the programme. Therefore, lobbying and networks of alliances of NFHP was critical. Hence, as one senior Nepali researcher argued, getting research into policy is about leadership:

*I think it's the leadership. It depends on the leader how he thinks for the country. Our Director-General, Dr X is one of the best in public health and among those who understands what is needed for our country. In the beginning, he initiated... There were programmes like chlorhexidine and other programmes and we all voted for [this programme] and he also felt strongly [about] it. So, when the leader says it, it's not difficult.<sup>35</sup>*

When NFHP started this work, there was no legal provision for medical abortion in Nepal<sup>36</sup> and therefore the use of the drug was a sensitive issue. But there was a provision that the drug could be imported with specific instructions under the recommendation by NESOG. NFHP applied to the Department of Drug Administration (DDA) and also to the NHRC for ethical clearance. NFHP held a few meetings with the director of DDA, after which Cipla started dealing with the DDA.<sup>37</sup> It did not take much time at the NHRC to get the clearance because the pilot intervention was seen to be the 'FHD's work'.<sup>38</sup>

## 6 Banke pilot intervention

Banke District in the western Terai region of Nepal was chosen for the pilot intervention. This district was regularly used for pilot interventions and trials, and so already had experience and an operational research infrastructure in place.<sup>39</sup>

The research study was designed to test the feasibility of community-based delivery of misoprostol by existing public sector community health volunteers, with self-administration of three 200mcg tablets by women delivering at home (Rajbhandari *et al.* 2010).

This PPH-related work was one of a broader set of activities, intended to improve maternal and neonatal outcomes, implemented by the district public health system with support from the Nepal Family Health Program (NFHP) funded by the United States Agency for International Development (USAID) (Rajbhandari *et al.* 2010: 283).

In this sense, NFHP already had an infrastructure and relationships set up for this pilot intervention.

From USAID's perspective, it was important that the pilot intervention included distribution of misoprostol through FCHVs, a community-based unpaid cadre that it has been supporting over the years. As part of its focus on services for and by women, extending services beyond the health facilities and promoting maternal and child health, USAID has continued to provide technical and financial support for the FCHV programme's expansion (Justice *et al.* 2016).

Health posts in Banke were painted with the message to use misoprostol. A senior official said: 'We had to picturise shivering (a potential side effect) for the flip chart. This was very challenging. Transferring technical knowledge was very difficult and it was a turning point for me.'<sup>40</sup>

Logistics was a major component of this work and JSI managed all the logistics as they had been managing it for the family planning programme. NFHP had set up a monitoring and evaluation system, and it used highly experienced staff who had served at a well-known research organisation – New ERA – for a long time. International consultants were hired to help with monitoring and evaluation work.<sup>41</sup> The regional office of NFHP was fully dedicated to implementing the project in Banke, and provided oversight for misoprostol distribution and other community-based maternal–neonatal work.<sup>42</sup> The District Public Health Office (DPHO) team in Banke was fully involved in supporting the implementation of the project and provided management oversight.

The USAID budget could not be used for buying the misoprostol tablets and therefore Plan International Nepal paid for the medicines.<sup>43</sup> When the tablets came from Cipla, there were four 200mcg tablets in one packet. NFHP repackaged them to contain three tablets in one packet as the required dose was 600mcg, and also relabelled the packet as '*Matri Surakscha Chakki*'.

Government staff trained FCHVs for seven days, of which three days were focused on misoprostol. In addition, as a part of the pilot intervention, household surveys (which included 30 clusters of 30 households each) were conducted at baseline and at endline. A Nepali private research organisation, Valley Research Group, was subcontracted to conduct the survey. Baseline fieldwork was done in May–June 2005, about six months prior to the implementation of the programme, and the endline survey was done in June–July 2007.

The study found that out of 840 post-intervention survey respondents, 73.2 per cent received misoprostol. The standardised proportion of vaginal deliveries protected by the uterotonic rose from 11.6 per cent to 74.2 per cent (Rajbhandari *et al.* 2010). The study concluded that community-based distribution of misoprostol for PPH prevention can be successfully implemented under government health services in a low-resource, geographically challenging setting, resulting in much increased population-level protection against PPH (Rajbhandari *et al.* 2010).

### **7 From evidence to policy**

The findings from the Banke intervention were published in the *International Journal of Gynecology & Obstetrics* in 2006 and 2010 (Rajbhandari *et al.* 2006; Rajbhandari *et al.* 2010). However, as we show above, the decision that misoprostol and its community-based distribution was the right policy direction had already been made by a committed group of individuals and institutions prior to the publication of results. The key players – the FHD, NESOG, and the DDA – had all been involved from the beginning. The process was incremental. Not only was the pilot intervention implemented through the government system in Banke, but there was considerable work to engage decision makers in government offices through frequent working group meetings. The health minister had come to Banke to launch the programme. The Director-General was very supportive from the outset, and is one of the co-authors of the article, indicative of the support levered for the intervention.

As we have seen, the role of NFHP was central to this process. NFHP had created the necessary social and political networks to scale up the pilot into a national programme. After the successful result from the pilot, the programme was implemented in additional districts where further partner organisations could monitor and the government had begun to take responsibility to implement and monitor without external support.<sup>44</sup> In March 2010, there was a presentation on misoprostol at another conference in Bangkok. The government then committed to a national-level programme for misoprostol. An action plan was announced and the findings of the study were further discussed in the National Safe Motherhood and Neonatal Sub-Committee meeting, supported by the technical advisory group (TAG). The final ratified decision to make it a national programme was taken by the Ministry of Health.

## 8 Discussion

As shown above, the technical brief and the journal articles demonstrate that the narrative framing was set up to push debate within the health sector in Nepal. The intervention also fell firmly within the existing drive of USAID-funded programmes: that not only was it possible to run such a programme through the FCHVs, but they actively asked for more of this kind of work; that the programme reaches the disadvantaged segments of the community (hence hitting the right social inclusion discourses, pushed in particular by the World Bank); that this intervention is only *complementary* to the push (mainly by DFID) to attempt to increase the institutional delivery of babies, and where the drug sanctioned is the injectable oxytocin, thus attempting to allay these fears; and that the pilot intervention had demonstrated that it is possible to mobilise the resources and will of a range of partners so that rapid expansion could occur.

At stake here, we argue, was an ideological disagreement between WHO and Jhpiego, and its acolytes: WHO promoted the use of SBAs for delivery and were not on board with the use of misoprostol. We were informed by a senior member of NFHP that WHO also mentioned that if misoprostol has to be distributed, it must be through the health workers, not the community-based volunteers. The research participants felt that the difficulty was also because the Nepal government strongly adheres to WHO recommendations, and therefore it took quite some time to convince the authorities to pilot this study, which was an exercise solely intended for policy uptake.<sup>45</sup>

While Millard *et al.* (2015) have pointed to the increasing role of networks in getting misoprostol onto the WHO Essential Medicines List, what they miss in our opinion is the underlying ideological struggle that misoprostol was able to lever: the relationship between the power of medical authorities and women; that is, ultimately, a question of who has control. We were informed that the first presentations of the SAFE study were to NESOG in Nepal and other professional societies, such as the Nepal Paediatric Society, for this very reason. It was the obstetricians and doctors that were particularly against this use of misoprostol on the grounds that the mode of delivery is crucial, and institutional support is a necessity, should anything go wrong, for identifying the side effects, etc. It is, however, this very lack of institutional support through much of rural Nepal that the pro-misoprostol lobby were using in arguing for its use. As one interviewee stated in lobbying the use of FCHVs, 'Every question was answered'. Thus it was able to show that here was a country 'reaching an MDG with less than 30 per cent skilled birth attendants, and it is community driven!'

Our conclusion from this work is that whether a study becomes policy or not ultimately depends on how well the researchers take part in the policymaking discourse. Researchers can work on their own and disseminate their findings, but successful scaling up depends on the strength and relevance of the political and policy networks of the

research group. Hence, we might argue, as Mosse (2004) has done more broadly for development interventions, that the outcome of policy or research is not as important as the generation of increasingly dense networks to sustain these relations and the flow of resources.

To conclude, the research delved into the interstices of development and health, but also the arena of where programmatic interventions and research intersect. We felt that we could make visible some interpretive dimensions on accountability that might have otherwise escaped us. This ethnography poses questions as to where to situate responsibility and accountability in the context of overlapping and competing mandates between different public and private, and national and international organisations, and the degree of programmatic evidence needed. Our work shows how accountability is dissipated across the organisations, each of which has a different role to play in the consortium, but is accountable financially to USAID, or their board which lies beyond the Nepalese state. In addition, the use of pilot projects such as the one we have described, and the increasingly evidence-based drive (to persuade at the level of national policy and for sceptics in powerful positions) makes it possible to lay broader claims for the model. If accountability is about laying claims to success and failure, then the programmatic pilot intervention mediates this task.

### Notes

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- 1 Uterotonics lessen blood loss during childbirth and are very important in the prevention and treatment of PPH.
- 2 These are financial incentive schemes aimed at assisting women and their families with regard to childbearing.
- 3 Interview with a senior official at Jhpiego, Kathmandu, 12 August 2011.
- 4 [http://apps.who.int/iris/bitstream/10665/70328/1/WHO\\_RHR\\_10.11\\_eng.pdf](http://apps.who.int/iris/bitstream/10665/70328/1/WHO_RHR_10.11_eng.pdf).
- 5 For more on this evidential debate, see Chu *et al.* (2012).
- 6 See, for example: [www.theglobalfund.org/media/5198/me\\_monitoring\\_andevaluation\\_brochure\\_en.pdf?u=63648896434000000](http://www.theglobalfund.org/media/5198/me_monitoring_andevaluation_brochure_en.pdf?u=63648896434000000).

- 7 The most active local research institutions include New ERA, the Valley Research Group, the Center for Research on Environment Health and Population Activities, the Health Research and Social Development Forum, and the Nepal Public Health Foundation. New ERA, for example, was established by three Peace Corps Volunteers in 1971, and was the first research firm established to work in Nepal.
- 8 [www.jsi.com/JSIIInternet/IntHealth/project/display.cfm?ctid=na&cid=na&tid=40&id=147](http://www.jsi.com/JSIIInternet/IntHealth/project/display.cfm?ctid=na&cid=na&tid=40&id=147).
- 9 [http://nfhp.jsi.com/Docs/nfhp\\_flyer.pdf](http://nfhp.jsi.com/Docs/nfhp_flyer.pdf).
- 10 Interview with a senior NFHP staff, Kathmandu, 26 August 2011.
- 11 [www.jhpiego.org/who-we-are/our-history/](http://www.jhpiego.org/who-we-are/our-history/).
- 12 [www.engenderhealth.org/our-countries/asia-near-east/nepal.php](http://www.engenderhealth.org/our-countries/asia-near-east/nepal.php).
- 13 [www.jsi.com/JSIIInternet/](http://www.jsi.com/JSIIInternet/).
- 14 <https://ccp.jhu.edu>.
- 15 [www.carenepal.org/](http://www.carenepal.org/).
- 16 [www.savethechildren.org/](http://www.savethechildren.org/).
- 17 [www.nfcc.org.np/](http://www.nfcc.org.np/).
- 18 [www.adranepal.org/](http://www.adranepal.org/).
- 19 For details, see VaRG (2008).
- 20 <http://mass.com.np/>.
- 21 [www.ntag.org.np/](http://www.ntag.org.np/).
- 22 <http://venturestrategies.org/>. This organisation is a key 'node' in the international network involved in lobbying WHO to have the drug registered for PPH on the WHO Essential Medicines List (Millard *et al.* 2015).
- 23 [www.venturestrategies.org/programs/womens-options/](http://www.venturestrategies.org/programs/womens-options/).
- 24 We received the following information from a VSHD representative via email about their lobbying activities in Nepal: 'In Nepal, my organization, VSHD, was investigating the status of the registration of misoprostol for PPH. We verified that it had been registered by the drug company Cipla (Bombay) via Yetichem for PPH very recently, perhaps in July. Two registrations, also by Cipla, of misoprostol for abortion preceded the PPH registration. Access to misoprostol is quite restricted, however'.
- 25 Interview A, NFHP staff, Kathmandu, 26 August 2011.
- 26 Interview B, NFHP staff, Kathmandu, 26 August 2011.
- 27 Interview A, NFHP staff, Kathmandu, 26 August; Interview, NFHP staff, Kathmandu, 12 August 2011.
- 28 Interview, NFHP staff, Kathmandu, 12 August 2011.
- 29 Interview A, NFHP staff, Kathmandu, 26 August 2011; Interview, NFHP staff, Kathmandu, 12 August 2011.
- 30 Interview B, NFHP staff, Kathmandu, 26 August 2011.
- 31 Interview B, NFHP staff, Kathmandu, 26 August 2011.
- 32 Interview B, NFHP staff, Kathmandu, 26 August 2011.
- 33 Interview A, NFHP staff, Kathmandu, 26 August 2011.
- 34 Interview A, NFHP staff, Kathmandu, 22 March 2011.
- 35 Interview A, NFHP staff, Kathmandu, 29 December 2011.
- 36 Abortion was made legal in Nepal in 2002.
- 37 Interview A, NFHP staff, Kathmandu, 26 August 2011.

- 38 Interview A, NFHP staff, Kathmandu, 26 August 2011.  
 39 See, for example, Khanal *et al.* (2013); VaRG (2005).  
 40 Interview A, NFHP staff, Kathmandu, 26 August 2011.  
 41 Interview, NFHP staff, Kathmandu, 12 August 2011.  
 42 Interview, NFHP staff, Kathmandu, 16 November 2011.  
 43 Interview A, NFHP staff, Kathmandu, 26 August 2011.  
 44 Interview, NFHP staff, Kathmandu, 12 August 2011.  
 45 Interview A, NFHP staff, Kathmandu, 26 August 2011; Interview, NFHP staff, Kathmandu, 12 August 2011.

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# The Political Construction of Accountability Keywords\*

Jonathan Fox<sup>1</sup>

**Abstract** Terminology in the accountability field is ambiguous, encompassing both top-down, technocratic control initiatives and bottom-up efforts to challenge the abuse of power and promote equity. The main proposition is that communicating accountability strategies should rely on conceptual and cross-cultural translation rather than awkward attempts at direct linguistic translation. To illustrate how accountability keywords are both politically constructed and contested, this article briefly reflects on the origins, circulation, and transformation of six relevant terms: transparency, the right to know, whistle-blower, advocacy, openwashing, and social accountability – including reflections from accountability advocates from Pakistan, Guatemala, and the Philippines. The conclusion calls for a two-track approach to communicate public accountability strategies, which involves (1) searching within popular cultures to find existing terms or phrases that can be repurposed, and (2) inventing new discourses that communicate ideas about public accountability that resonate with culturally grounded common-sense understandings.

**Keywords:** accountability, transparency, right to know, whistle-blower, advocacy, openwashing, *contraloría social*, *incidencia*.

## 1 Introduction

The issue of terminology is not ‘merely academic’. Key terms in the field of accountability practice are both politically constructed – and contested. Accountability keywords have different meanings, to different actors, in different contexts – and in different languages. The resulting ambiguity can either constrain or enable diverse strategies for promoting public accountability. Discourse analysis has long emphasised the power over naming the issues that are considered to be problems and its association with control over how agendas are set for addressing them.<sup>2</sup> This article addresses these agenda-setting issues by bringing together discussion of the political origins and implications of six relevant terms in the accountability field with examples of their translation and circulation in diverse contexts, including Mexico, the United States, the Philippines, Guatemala, Pakistan, and India.

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One of the key issues is whether accountability refers to an externally imposed tool of top-down control – or to bottom-up initiatives to address impunity and the abuse of power. Put another way: is accountability discourse inherently technocratic and foreign, associated with financial reporting, induced bureaucratisation, and neoliberal governance, alienated from most cultures and locally grounded pro-people social and civic actors (e.g. Martinez and Cooper 2017)? Or is the notion of accountability a fundamentally trans-ideological idea, so malleable that it can be appropriated by a diverse array of actors, basically contested and up for grabs?<sup>3</sup>

This political debate is complicated by terminology, insofar as the cross-cultural translation, importation and circulation of the word 'accountability' can get mixed up with analysis of the actually-existing ways in which diverse actors understand and discuss the various *ideas* behind it. This is not exclusively a North–South issue. Indeed, the first problem is with the discourse *in English*: accountability clearly refers to the exercise of power, but its *directionality* remains profoundly ambiguous. Who is supposed to be accountable to whom, and who decides?<sup>4</sup>

## **2 Disentangle upward vs downward accountability**

The first issue that needs to be clarified when discussing accountability in health systems is the distinction between *upward* vs *downward* accountability (Fox 2016). Development studies applies this distinction to the relationship between international non-governmental organisations (INGOs) and their local counterparts (e.g. Kilby 2006), while political science frames 'vertical accountability' in terms of states responding to their citizens (O'Donnell 1998). In the context of health equity and accountability, *upward* accountability involves service providers reporting to their managers, who in turn report to policymakers, who may in turn report to international donors. In contrast, *downward* accountability refers to health service providers being responsible to their national and local publics. This raises the question: when the arrow is supposed to go both ways, what happens when these pressures push in opposite directions?<sup>5</sup>

This question of the *directionality* of accountability relationships is especially relevant in the field of global health, where an upward notion of accountability often predominates because of its association with donor compliance in terms of financial inputs and output metrics.<sup>6</sup> This approach pulls accountability upwards and inwards, towards funders, rather than downwards and outwards, towards the public. For example, while donor reporting requirements for public health delivery systems have led to the creation of elaborate monitoring systems, the resulting institutional performance data are rarely proactively disclosed to the public. There is a major missed opportunity if the data are not made available to enable citizen action to help to both identify and address bottlenecks, plus donor-driven data agendas may not measure actual access or quality of care (e.g. Boydell, Fox and Shaw 2017).

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**Box 1 The language of accountability in Pakistan**

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Almost all the words referring to accountability one way or the other – for example, responsiveness, transparency, participation, inclusion, accountability, rule of law – are used as they are (as English words), despite the fact that there are stronger Urdu corresponding words that can spell out an even stronger meaning that also relates to local context. For example, the Urdu word for ‘responsiveness’ is *‘jawabdahi’*, which means that one is not only expected to respond in a timely manner, but is also accountable for doing/not doing so. Similarly, the term ‘rule of law’ is understood as *‘qanoon ki hukmarani’*, which explicitly distinguishes between rule of law and rule of lawmaker/implementer (which is often the case). ‘Transparency’ means *‘shafaf’* or *‘shafafat’* – meaning transparency in entirety and not in parts, which happens when a government, in the name of transparency, just displays its decisions on the internet/websites once they are made, and does not open up about how the respective policy issues were identified.

In 2010, a few civil society organisations (CSOs) started using the term ‘social accountability’, and it has taken seven years to introduce and infuse a relatively more neutral, bottom-up meaning of accountability in the society. People in media who want to speak about accountability usually refer to the broader term of ‘good governance’.

To promote improvements in health service delivery, state actors have been promoting upward accountability measures, while CSOs (and their international allies) are promoting downward accountability initiatives. For example, the government appointed district monitoring officers (mostly retired army officials) to monitor and report on the presence of doctors in the village-level public health facilities. The government also used electronic attendance machines (which are easily dodged both by the doctors and the monitoring officers, so the government has been only adding to monitoring layers). Lately, the government opted for direct citizens’ feedback in Punjab through mobile phone messages – called the *citizen feedback model* – again an English language terminology. Had the programme used the local term *‘Awami Jawabdehi ka Nizam’*, the directionality of the accountability would have been clearer by referring to the accountability of the health service providers to citizens.

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The upward vs downward distinction is also especially relevant in the global health field because of the influential United Nations metrics intended to incentivise national improvements. This approach prioritises framing accountability in terms of annual national performance averages, which are relevant both to inform donor resource allocation priorities, and the implicit prospect of international naming and shaming when outcome metrics fall short. Yet national averages are rarely tools that national and local civic groups or social constituencies can use to address specific health service issues – they need metrics that disclose health service performance indicators in their community, district, city, or province, in as close to real time as possible. In other words, the implicit theory of change behind relying on metrics based on national averages for measuring accountability relies more on upward than downward accountability.<sup>8</sup> To address the ambiguity caused by the directionality dilemma, those concerned with bolstering and communicating the democratic dimensions of accountability may want to add an adjective, as in: *public* accountability.<sup>9</sup>

The different ways in which diverse actors frame accountability poses a challenge: how can our languages communicate accountability's democratic potential more effectively to diverse publics? For those operating in global English language arenas, the first step is to resist the risk of 'linguistic determinism', which can easily slide into the problematic assumptions associated with cultural determinism. In other words, some Anglophones assume that if a direct translation of an English language term is not readily available in another language, then the concept itself must therefore be unfamiliar to that culture (Stephenson 2017). For example, those engaged in accountability work in Latin America will recall frequent comments that a direct translation for the term is lacking in Spanish and Portuguese.<sup>10</sup> This approach has two major problems. First, it assumes that alternative terms that clearly convey the *idea* of accountability do not exist (see evidence in Box 1 and Figure 1). Second, when direct translations do not exist, the 'linguistic determinist' view curiously assumes that new terms could not quickly emerge and circulate where the ideas behind them resonate (Stephenson 2017).

The basic proposition in this article is that accountability strategies face the challenge of communicating to publics more effectively by using engaging, accessible terms that are grounded in national and popular cultures. This involves either repurposing existing terms to harness them to accountability initiatives, or inventing new terms that have the potential to resonate and go viral. To make this point, here follow six examples of the political construction of keywords related to accountability, as well as three related boxes with relevant propositions from multilingual accountability strategists in the global South.

### **3 Six illustrations of the political construction of accountability keywords**

#### **3.1 Transparency**

This term's scope is constrained by its implied focus on access to information that is already in the hands of the state. This is a problem, especially in health, because much important information is not actually

collected by the state. For example, governments rarely document the degree to which medicines are actually available to the entire population, patterns of disrespect and abuse, or measure the toxicity of numerous chemical substances in everyday use in homes, factories, and fields, such as pesticides.

In Latin America, the term ‘transparency’ is now commonly used by diverse actors across the political spectrum, though perhaps widely seen as fairly technocratic. The term ‘open government’ appears to resonate more in the region, though it still refers primarily to information that the state chooses to collect. Yet popular culture is filled with long-standing expressions that resonate widely, such as the call for ‘*cuentas claras*’ (a clear accounting) or ‘*quien paga manda*’ (s/he who ‘pays the piper, calls the tune’).

Consider an example of an effort to reframe the term ‘*transparencia*’ to make it resonate more with popular discourse. Twenty years ago, before the term took off, CSO colleagues in Mexico deliberately tweaked it to make it more amenable to grass-roots organising. They chose a little-used but still legitimate alternative spelling of the Spanish word for transparency – *trasparencia* – which omits the first ‘n’ present in the more commonly used spelling, *transparencia*.<sup>11</sup> One reason was that organisers were concerned that the more commonly used term sounded too close to a popular, grass-roots expression for fraud: *transa*. A second reason was that it allowed the organisers to unpack the words into two parts – ‘*tras las apariencias*’ – which meant they could talk about the need to go ‘behind appearances’, an idea that could engage grass-roots movements for fairer governance (their logo even separated the word into two parts – *Tras – parencia*). A third reason was that the main independent Mexican internet provider at the time, La Neta, could not handle that many characters – but ‘*trasparencia*’ just fit...<sup>12</sup>

### 3.2 Right to know

In contrast, the concept of the ‘right to know’ is broader than transparency, since it includes a broader notion of the types of information citizens actually need to address accountability failures. For example, the literal translation into Spanish is widely used and understood: ‘*derecho a saber*’, and gets more than 11 million Google hits (in quote marks). In India, the national right to information campaign launched the slogan ‘right to know, right to live’ in 1996 (*‘Jaan-ne ka Adhikar, Jeene ka Adhikar’*). This call was inspired by grass-roots organisers in the Mazdoor Kisan Shakti Sangathan (MKSS) movement, who strategically linked their social justice and anti-corruption struggles with demands for the right to information about government anti-poverty programmes (Pande 2014).<sup>13</sup>

The term had also been widely used by environmental health campaigners in the US, and reached a milestone when the Congress passed the 1986 Emergency and Community Right-to-Know Act. The law responded to a convergence of a grass-roots anti-toxics movement and the 1984 Bhopal disaster in India (a horrific industrial disaster involving an American company). The law mandated

industrial corporations to report their volumes of toxic emissions to the government. Public interest group Environmental Defense then invested in a pioneering online platform to make those data user-friendly and readily accessible at the level of postal codes.<sup>14</sup> The theory of change behind this effort was that if citizens had access to this granular data, they would be motivated to contribute to public oversight of the dangers located in their own backyard, while being empowered by the identification of the specific company behind the threat – a paradigm case of ‘targeted transparency’ (Fung, Graham and Weil 2007). While the 1986 law did not raise the legal standards for toxic exposure, it provided tools to promote the enforcement of existing laws. The volume of reported emissions of listed toxics dropped dramatically during the first decade of the law’s implementation.

### 3.3 Whistle-blower

One example of an accountability keyword that is difficult to translate into other languages is ‘whistle-blower’. In Spanish, translations have a negative implication – *informante, denunciante* – i.e. squealer, informer. This legacy is deep in many societies that either recall or still experience authoritarian regimes that widely deployed informers.

Yet at the same time, whistle-blower is also an example of a term whose contemporary meaning – even in English – was politically constructed. The term used to refer only to sports referees or to the police on the beat (because they blew whistles in response to wrongdoing).<sup>15</sup> In 1969, the pro-war press used the term to try to stigmatise Ron Ridenhour, the US soldier who blew the whistle on the infamous My Lai massacre of Vietnamese civilians.<sup>16</sup> By the early 1970s, the growing consumer rights movement gave the term ‘whistle-blower’ its current political content (Nader, Petkas and Blackwell 1972). The term now recognises the commitment to public service by those from inside powerful institutions who take the risks inherent in revealing abuse and corruption – either internally or publicly. Another, perhaps more translatable option could be ‘truth-teller’ – a term that has recently become widely politically contested in the US.<sup>17</sup>

### 3.4 Advocacy

The current meaning of this accountability keyword was politically constructed about a half century ago.<sup>18</sup> The origins of the word ‘advocacy’ are narrowly legal, referring to lawyers’ defence of their clients. That meaning later extended to the role of other service providers, such as social workers, who were tasked with defending the interests of individual clients. In the US, however, the movements for peace, racial, and gender justice of the 1960s and 1970s broadened the use of the term to encompass the defence of interests of broader groups of the excluded.

Public interest advocacy’s challenge to the systemic production of social exclusion means that in the context of contemporary social accountability discourse (see Section 3.6), development agencies that claim to support citizen voice consider advocacy to be adversarial and therefore in tension

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## Box 2 Inventing accessible accountability concepts in the Philippines: the ‘*bibingka* strategy’

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The ‘*bibingka* strategy’ is one of the popular frameworks used by civil society groups in the Philippines to pursue reforms and promote accountability. This strategy proposes that reforms are likely to occur if: (1) there is sustained citizens’ pressure from below, and (2) sufficient action is taken by state reformers from above. Pressure from below is generated by CSOs clamouring for substantive policy changes or better policy implementation. Action from above, on the other hand, comes from state officials who seek to enhance service delivery or curb government inefficiency.

The term ‘*bibingka* strategy’ was coined by Filipino scholar Saturnino Borras in his study of agrarian reform implementation in the Philippines (1999). It comes from the word ‘*bibingka*’ – a type of Filipino rice cake where live charcoal is placed simultaneously on top and below the dough during the baking process.

The ‘*bibingka* strategy’ draws from Fox’s concept of sandwich strategy, which combines pressure from above and below to counteract anti-accountability forces (1992). It is obviously not a direct translation, but using the term ‘*bibingka* strategy’ has the advantage of enabling ordinary Filipinos to immediately grasp the meaning of the concept. While sandwich coalition can be easily understood, the phrase sounds too foreign and distant for local ears. But the response is almost automatic when Filipinos hear the term ‘*bibingka* strategy’, creating a mental image of ‘*apoy sa taas at apoy sa baba*’ (fire on top and fire below).

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with their preferred ‘constructive engagement’ approach. Yet the term had different implications during its original politicisation phase in the US. In the late 1960s, an influential cadre of liberal policy professionals promoted community participation in national anti-poverty programmes under the banner of ‘advocacy planning’. Yet this professional-led approach to advocacy was not necessarily grounded in relationships of accountability with those whose interests were ostensibly being defended. Critics at the time argued that advocacy planners’ focus on participation via official ‘proper channels’ – what are now called ‘invited spaces’ – was in tension with then-widespread mass protest, which they considered to be the principal lever for pro-poor policy influence (Piven 1975).

The potential for ‘elite’ insider advocates to promote sustainable power shifts depends significantly on whether they coordinate with or

actively enable mobilised social constituencies. In other words, insider public interest advocacy initiatives and mass protest can potentially be mutually reinforcing, as in the Mexican case of 'sandwich strategy' efforts to coordinate openings from above with mobilisation from below (Fox 1992). Borrás (1999) then reframed the term 'sandwich strategy', culturally adapting it to the Philippine context, where it subsequently took off and became embedded in both national CSO and policy reformer discourse (see Box 2).

'Advocacy' turns out to be another one of those words that lacks a precise translation into Spanish (not unlike 'accountability'). The literal translation of advocacy into Spanish is '*abogacía*' which refers only to the practice of law, in contrast to the broader notion of intervention with authorities on behalf of third parties. The Spanish term '*gestoría*' could be an option, but it has the disadvantage of appearing to be restricted to seeking limited material concessions. '*Defensoría*' clearly refers to advocacy in response to specific cases of abuse, but whether it also encompasses broader public interest causes is an open question – the Colombian government's People's Defender office is a notable case (*Defensor del Pueblo*).

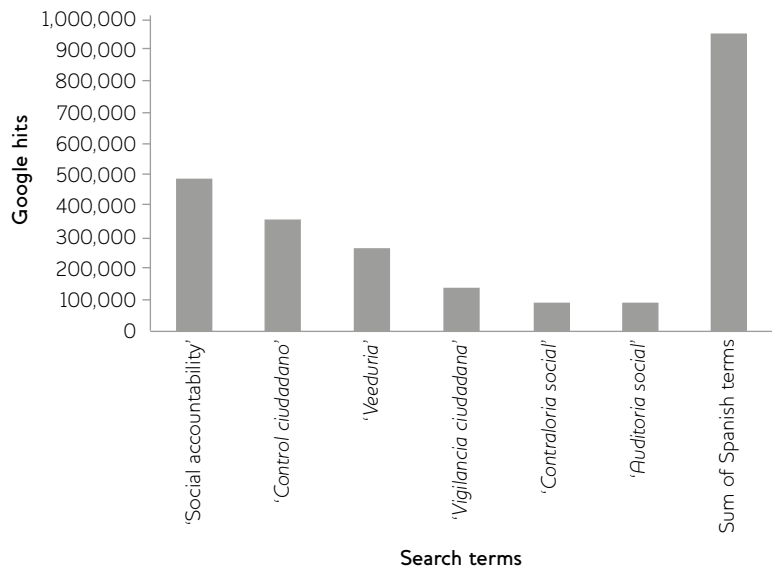
Guatemala's grass-roots, indigenous Community Defenders of health rights have also broadened the usage of the term – including using a gender-inclusive term in Spanish: *defensor(a)*.<sup>19</sup> '*Promoción*' could also work, since it can refer broadly to grass-roots organising, but that may or may not involve policy advocacy. Some use the term '*cabildeo*', to refer specifically to lobbying national policy elites, which is only one of several possible tactics for influencing public policy (not to mention the term's strong connotations of 'influence peddling').

The Spanish term of choice for advocacy in Latin America is now '*incidencia*', meaning 'to have influence on'. This term was invented through cross-border dialogue in mid-1990s partnerships between human rights and public interest groups in the US and Central America, in the context of shift in CSO focus in the region as 'from protest to proposal'.<sup>20</sup>

### 3.5 Openwashing

A more recent example of a politically constructed term is: 'openwashing' (sometimes referred to as 'window-dressing'). This refers to the actions of powerful institutions that appear to promote transparency but actually hide the persistent abuse of power and impunity – an intuitive response after more than a decade of widespread transparency initiatives have often fallen short of producing expected accountability gains. For example, when Guatemala joined the Open Government Partnership, the Vice President was in charge of the government's follow-up – but she later ended up in prison for corruption, which suggests that she had much to hide. The term is a variation on the classic term 'white-washing', which refers to efforts to gloss over or cover up misdeeds. An earlier variation was invented in 1989, when the Greenpeace anti-toxics campaign invented the term 'green-washing'



**Figure 1 Comparing usage of social accountability terms in English and Spanish**

Source Google searches were conducted on 12 October 2017 and 19 October 2017. All search terms were in quotes. The search language was Spanish for Spanish terms, and English for 'social accountability'. The Google hits for all of the Spanish terms are summed, for comparison with the English equivalent, 'social accountability'. Since multiple terms are used in Spanish, the equivalent approach in English would be to add search terms like 'citizen oversight' (121,000 hits) and 'social audits' (112,000). The Spanish total would still be higher – plus, most usage of the term 'social audit' appears not to refer to social accountability as used here (additional search conducted on 1 January 2018). Thanks to Chris Wilson for this suggestion. Notably, inclusion of the usage of another Spanish term for social accountability, 'control social' would add more than 3 million additional hits, but it is not included here because it is sometimes used to refer to concepts other than social accountability (see Box 3). Thanks to Julia Fischer-Mackey for research assistance.

to describe corporations that claimed to have good environmental credentials whilst their core business continued to be environmentally harmful.<sup>21</sup> Yet defining openwashing with precision poses a challenge: it could refer both to weak transparency initiatives that coexist with persistent accountability failures, and to more deliberate attempts to cover up abuse and impunity. Yet only the second sense of the term includes openwashing's implicit emphasis on the *intent* to deceive.<sup>22</sup>

### 3.6 Social accountability

In its origins more than a decade ago, the term 'social accountability' created a new political space by allowing mainstream development agencies such as the World Bank and larger INGOs to value and invest in the promotion of citizen voice, albeit usually bounded to local 'invited spaces'.<sup>23</sup> When one tracks its diffusion, 485,000 Google hits turn up – though this total also includes usage of the term 'social accountability' with a different meaning, to refer to corporate social responsibility.

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**Box 3 Different understandings of 'control social' in Latin America**

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The Spanish language term '*control social*' has been widely used in South America to mean 'social oversight' both by governments and in civil society. In Bolivia, Brazil, Ecuador, and Colombia the term appears often in national laws and policy regulations. Historically, the idea is linked to processes of democratisation, elected governments of the centre-left, and the view that public sector oversight should be in the hands of the citizenry. Diverse social and civic organisations use the term widely, including in many training manuals available online. More recently in South America, younger activists – perhaps with more exposure to global discourse – use the term '*rendición de cuentas*' (a more direct translation of 'accountability') more than '*control social*' – perhaps to differentiate themselves from governmental uses of the term to refer to the official channels for citizen oversight. In Central America, in contrast, the term '*control social*' was understood very differently, and did not gain the same degree of acceptance. In Guatemala and El Salvador, for example, the words are associated with governmental manipulation and repression – closer to the literal translation into English: 'social control'.

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In spite of the widespread reference to the lack of a direct translation of accountability in non-English languages, when one adds the adjective 'social' it turns out that there are several different Spanish terms for social accountability. Widely used terms for social (or citizen) oversight of the public sector include: '*contraloría social*', '*control ciudadano*', '*veeduría*', '*auditoría social*' and '*control social*', with usage varying by sub-region and over time within Latin America (see Box 3).

The use of these terms in Spanish took off more than a decade before Anglophone development agencies began using the term 'social accountability', driven both by governments and public interest groups. For example, the term '*contraloría social*' was first widely deployed by the Mexican government in the early 1990s to refer to official channels for citizen oversight (Hevia de la Jara 2009). Remarkably, if one adds up the Google hits for these various synonyms, one ends up with what may be a counterintuitive finding: they are significantly *more* widely used than their English language term 'social accountability' – which itself includes an overstated number of hits because of its other meanings, such as corporate responsibility (see Figure 1).

#### 4 Conclusions

Stepping back to the original dilemma about how to communicate strategies for public accountability more effectively with terms that resonate more widely across cultures and languages, this article's reflections suggest a two-track approach:

- 1 Search within popular cultures to re-appropriate existing terms or phrases, possibly even from the private sphere, that can make sense in the public sphere.
- 2 Unleash our creativity to invent new discourses that both communicate ideas about public accountability, and have the potential to go viral because they crystallise and resonate with common-sense understandings.

In conclusion, the emerging field of transparency, participation, and accountability needs to do a better job of communicating the key steps on the path to accountability-building. This involves conceptual and cross-cultural translation, rather than awkward attempts at direct linguistic translation.

#### Notes

\* This article expands on Fox (2017). Thanks to participants in the July 2017 IDS conference on accountability for health equity for the discussions that informed this think piece. Thanks also to feedback on earlier versions from Joy Aceron, Chris Wilson and two reviewers.

- 1 Jonathan Fox is Professor of Development Studies at the School of International Service at American University in Washington DC, where he directs the new Accountability Research Center ([www.accountabilityresearch.org](http://www.accountabilityresearch.org); @AcctResearchCtr), an action-research incubator. @jonathanfox707.
- 2 See Cornwall and Eade's landmark collection on the construction and contestation of development discourse (2010), originally published in 2007 as a thematic issue of *Development in Practice*, including this author's attempt to disentangle transparency from accountability (Fox 2007a). On accountability as a keyword, see Dubnick (2014). The seminal discussion of definitions is by Schedler (1999), who stressed the twin dimensions of 'answerability' and sanctions. See also McGee and Kroesschell (2013), among others. Pettit and Wheeler's earlier discussion of the discourse of rights-based development is relevant to accountability discourse today: they emphasised that the possible tension between its strategic value or risks of co-optation would depend on how the discourse was 'understood and challenged, in context' (2005: 3).
- 3 For one recent example of the malleability and contestation of accountability-related terms, consider the trajectory of the term 'fake news' in the US. The term was actively deployed during the 2016 US election campaign by opponents of right-wing disinformation, but those efforts were thwarted by the effective co-optation of the term by the proponents of disinformation themselves, who continue

- to use it to refer to the mainstream news media's investigative reporting.
- 4 For a discussion from the point of view of international relations, see Grant and Keohane (2005). Accountability is also conceptually associated with the idea of responsibility – a much more widely-used term (Abadzi 2017).
  - 5 In health systems, some potentially pro-accountability actors find themselves in contradictory locations. For example, are community health workers supposed to represent citizens to the state, or are they supposed to represent the state to citizens? The first role involves projecting citizen voice upwards, towards authorities, to improve performance and address abuse, while the second role involves focusing on authorities holding patients accountable for adherence to prescribed behaviours. For the results of a researcher–practitioner discussion of this dilemma, see Schaaf *et al.* (2018).
  - 6 See, for example, the recent CIVICUS critique of INGO-driven 'accounts-ability' by Sriskandarajah (2017).
  - 7 For additional discussion of usage of accountability terms in Pakistan, see Fancy and Razzaq (2017).
  - 8 For an effort to address this upward tilt in the contexts of the Sustainable Development Goals (SDGs), see <http://participatesdgs.org/prg/>. For a recent analysis of SDGs and accountability that stresses diverse monitoring and accountability strategies from governments to their peoples, see UNESCO GEM (2017).
  - 9 The question of who the relevant publics for accountability are is also politically constructed, ranging from media elites to urban middle classes to socially excluded populations. Everyday discourse would suggest focusing on public accountability to citizens, but that frame would exclude many immigrants and displaced people.
  - 10 For a detailed discussion of translation issues involving accountability in the case of Portuguese, see Gomes de Pinho and Silva Sacramento (2009). The term '*responsabilização social*' is also used in Mozambique.
  - 11 For more on *Trasparencia*, which spent a decade engaging in grass-roots organising, CSO coalition-building, and advocacy to encourage informed citizen action involving World Bank-funded rural development projects, see Fox (2007b).
  - 12 For another example of politically invented Mexican accountability discourse, consider the phrase first proposed by the Zapatista movement in Chiapas in 1994, '*mandar obedeciendo*' (to lead by obeying), which draws on indigenous community governance traditions to refer to grass-roots leadership that remains accountable to movements of the excluded. See [https://es.wikisource.org/wiki/Discurso\\_del\\_Subcomandante\\_Marcos\\_%22Mandar\\_obedeciendo%22](https://es.wikisource.org/wiki/Discurso_del_Subcomandante_Marcos_%22Mandar_obedeciendo%22).
  - 13 Suchi Pande reports that the original phrase was '*hum janenge, hum jiyenge*' in a Hindi newspaper editorial, which literally translates into 'we will know, we will live' (email communication, 29 December 2017). See also Khaitan (2009) and Roy and Dey (2015).
  - 14 See <http://scorecard.goodguide.com/>.

- 15 In late eighteenth-century Mexico City, a similar term was used to refer to night watchmen: *guardas de pito* – ‘whistle guards’ (Puck 2017).
- 16 [www.phrases.org.uk/meanings/whistle-blower.html](http://www.phrases.org.uk/meanings/whistle-blower.html).
- 17 Recalling the exposé of the My Lai massacre, the Ridenhour Awards now publicly honour the courage of truth-tellers each year: [www.ridenhour.org/](http://www.ridenhour.org/).
- 18 This paragraph draws from Fox (2001).
- 19 See the work of the Center for the Study of Equity and Governance in Health Systems (CEGSS), <http://cegss.org.gt/>.
- 20 Email communications, former Washington Office on Latin America Directors George Vickers (4 October 2017) and Joy Olson (2 October 2017). See for example: Mckinley (2002).
- 21 Email communication, Kay Treakle (22 August 2017).
- 22 For further analysis of the challenges involved in defining the term, see Brockmyer and Fox (forthcoming, 2018).
- 23 Key early formulations were broader (e.g. Malena, Forster and Singh 2004). The World Bank’s more bounded 2004 *World Development Report* approach was much more influential, but it did not explicitly use the term.

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# Key Considerations for Accountability and Gender in Health Systems in Low- and Middle-Income Countries\*

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**Abstract** This article poses questions, challenges, and dilemmas for health system researchers striving to better understand how gender shapes accountability mechanisms, by critically examining the relationship between accountability and gender in health systems. It raises three key considerations, namely that: (1) power and inequities are centre stage: power relations are critical to both gender and accountability, and accountability mechanisms can transform health systems to be more gender-equitable; (2) intersectionality analyses are necessary: gender is only one dimension of marginalisation and intersects with other social stratifiers to create different experiences of vulnerability; we need to take account of how these stratifiers collectively shape accountability; and (3) empowerment processes that address gender inequities are a prerequisite for bringing about accountability. We suggest that holistic approaches to understanding health systems inequities and accountability mechanisms are needed to transform gendered power inequities, impact on the gendered dimensions of ill health, and enhance health system functioning.

**Keywords:** accountability, gender, health systems, power, empowerment.

## 1 Introduction

Accountability and gender are both critical dimensions of health systems.<sup>4</sup> There is a long, rich, and detailed analysis of the role of gender in health systems which, since it emerged in the 1970s, has examined the visibility and legitimisation of women's health issues, the significance of gender as a social determinant of health, and the promotion of policies and other interventions to address gender-related challenges and inequities (see, for example, Alvarez-Dardet and Vives-Cases 2012). Gender is conceptualised as the 'socially constructed roles, behaviours, activities and attributes that a given society considers appropriate for men and women' and people of other genders (WHO 2016), and has

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been shown to create differential health systems' needs, experiences, and outcomes (Morgan *et al.* 2016; Theobald *et al.* 2017). In contrast, the emphasis on the concept of accountability within the health system is relatively new (Brinkerhoff 2003; Cleary, Molyneux and Gilson 2013). Consequently, there has been little work which brings together these two bodies of work from a health systems strengthening perspective; and this is an important gap that needs addressing.

Within health systems, accountability 'refers to the processes by which those with power in the health sector engage with, and are answerable to, those who make demands on it, and enforce disciplinary action on those in the health sector who do not perform effectively' (Murthy 2008: 1). The advantages of an accountability agenda include ensuring that health system resources are appropriately used, that positions are allocated to trained and skilled personnel, and that health systems continuously strive for enhanced performance and learning (Brinkerhoff 2004). The focus is primarily on governments' provision of health services. Accountability mechanisms operate at multiple levels and provide tools for holding governments and health sectors accountable to international agreements and instruments (Murthy 2008), yet tend not to engage with informal markets, private sector interests, and the new possibilities opened up by mobile technology and digital health.

The importance of both gender and accountability in health systems is undisputed as a way of improving health outcomes and as a moral imperative. What is less well understood is how gender and accountability interact, what mutual benefits and tensions exist, and what opportunities there are for developing gender-transformative accountability processes that address and transform unequal gender norms, roles, and relations at all levels. This article explores these related areas, and the tensions within/between them, in relation to power and inequity, intersectionality, and empowerment. More specifically, it explores three key considerations regarding the relationship between gender and accountability, namely that: (1) power relations are critical to both gender and accountability and, while gender is a pervasive driver of inequity in health systems, accountability mechanisms can address and transform health systems to be more gender-equitable; (2) gender is only one dimension of marginalisation and intersects with other social stratifiers, such as race, class, education, etc. to create different experiences of vulnerability; and it is necessary to take account of how these stratifiers collectively shape accountability; and (3) while accountability mechanisms can be used to create systems of empowerment, empowerment is a prerequisite for bringing about accountability. We review each of these considerations in turn.

## **2 Power and inequity**

*Power relations are critical to both gender inequities and accountability mechanisms and, while gender is a pervasive driver of inequity in health systems, accountability mechanisms can be used to address and transform health systems to be more gender-equitable.*

The health system is a multifaceted and disparate entity, within which there are many and diverse aspects where both gender and accountability come together; for example, in the ways in which power relations between actors are experienced, both within and beyond the health system (Bloom *et al.* 2008; Dworkin, Ghandi and Passano 2017).

Nonetheless, debates that deal specifically with health system accountability often still fail to address gendered power relations (Brinkerhoff 2003, 2004; Murthy 2008; Waldman, Reed and Hrynick 2017), and work on gender and health systems seldom discusses accountability issues (Murthy 2010), with the exception of some scholars (see George 2003; George, Iyer and Sen 2005; Murthy and Klugman 2004).

Accountability relationships operate at many different levels in relation to the health system. Brinkerhoff and Bossert (2008) identify three different sets of accountability actors and relationships. One set concerns those actors who are relatively high up the health system – policymakers, senior government bureaucrats, and politicians who operate within, and in relation to, the health system. The second set of actors are those who are more distant from the central health system hierarchy, overseeing health-care facilities and outreach workers. The third set of actors refers to patients, users, communities, and citizens. The relationships between these three sets of actors are characterised by power relations, status, and influence, with the first two sets of actors tending to have considerably more power, status, and health knowledge than the third (Brinkerhoff and Bossert 2008).

These power relations and differential access to knowledge and information have, as Brinkerhoff (2003) recognises, implications for accountability. Expanding on these different levels of interaction between health system actors, Cleary and colleagues (2013) argue that accountability is also influenced by available resources, by the actors' perceptions and attitudes, and by the values, beliefs, and culture embedded within the health system. These factors result in imbalances of power and different accountability consequences at different moments in time and in different places. For example, in some cases, national priorities and health officials' preferences may override local processes and choices, while in others, a lack of trust between local users and health-care personnel may inhibit local people from challenging health-care personnel. In other cases, power relations, culture, values, and beliefs are further complicated by the blurred boundary between communities and health systems, as some community members also hold formal or informal health provision roles (see, for example, Mafuta *et al.* 2015).

Both Brinkerhoff (2003) and Cleary *et al.* (2013) recognise the importance of power relations for accountability, yet do not link the experience and impact of these to gender roles, relations, and inequities. The interactions between power and gender in health systems cannot, however, be overlooked. Gendered power relations exist at all three

of these health system levels and inform who is able to engage (e.g. by influencing access to resources and norms around engagement), what the terms of engagement might be (e.g. what forms of engagement are acceptable for whom), how much ability different actors have to negotiate accountability (e.g. who has the power to hold another actor accountable), and who can meaningfully implement change (e.g. who has the power to implement changes in support of accountability practices). Accountability in health systems is complex, multifaceted, and 'encompasses a vast array of potential power relationships' (Cornwall, Lucas and Pasteur 2000: 3). These gendered power relations bias health system research and negatively impact health systems (Sen, Östlin and George 2007). The lack of consideration of gender inequities within health system accountability research, for example, is a gender bias in and of itself, resulting from a lack of recognition or understanding of its relative importance. As within all research, if something is not included, analysed, and/or measured, it is not addressed. Without understanding and analysis of the role of gender power relations and how it might affect research content, processes, and outcomes, research findings and subsequent interventions will be negatively skewed (Morgan *et al.* 2016).

In contrast to work on accountability, literature on gender and health systems critically analyses how gender roles and relations shape the experiences and room for manoeuvre of women as users, as community members, as low-level employees of the health system and, occasionally, as senior leaders (Percival *et al.* 2014; Dhatt *et al.* 2017; Morgan *et al.* 2016; Theobald *et al.* 2017), although this is not always linked to discussions on accountability. This research and literature calls attention to three characteristics of health systems: firstly, that the health system is itself a 'gendered structure', in which important policy actors are mainly male; secondly, that men do not tend to prioritise women's health issues; and thirdly, that women actors, in the levels of interaction identified by Brinkerhoff and Bossert above, experience issues and challenges – often ignored by the health system – which their male counterparts do not (Hulton *et al.* 2014; Pendleton *et al.* 2015), and largely feminised cadres often have less power and influence. Even when women policy actors do achieve levels of seniority, they still tend to have less power than their male colleagues and to be allocated less prestigious, 'softer', feminine ministries (environment, women, family, education, and even health) as opposed to the masculine, prestigious areas of finance and defence – where decisions about funding are ultimately made (Paxton and Hughes 2017; Dhatt *et al.* 2017).

In their review of global public–private partnerships which had an emphasis on accountability, Hawkes, Buse and Kapilashrami (2017) revealed how gender inequity is poorly attended to despite widespread recognition of the significance of gender in relation to health status, exposure to health determinants and health behaviours, leadership within the health system, and responses to illness. Instead, public–private health partnerships favoured men on their governing bodies, neglected

to report sex-disaggregated data for the projects, and failed to focus on ailments which had the highest burden of disease for both men and women (Hawkes *et al.* 2017). This failure was linked to a complex interplay of factors including protecting private partners' financial interests and the failure to use gender analysis to explore the structural and complex power relations that shape health determinants.

Thus, while approaches to health system accountability have recognised power relations between different sets of actors and levels within the health system, they have yet to acknowledge the pervasiveness of gender power inequities across these levels. As a result, while on the one hand researchers working on gender within health systems are not doing enough to explore and link accountability to power relations, on the other hand, research into health system accountability overlooks the significance of gender in relation to power relations. This results in missed opportunities for accountability mechanisms and processes to actively transform health systems to be more gender-equitable. This includes ensuring that accountability processes themselves – such as governing bodies and community advisory groups – are gender-equitable (i.e. reasonable representation of different men and women), assessing whether services are equitably provided and distributed, and analysing whether the needs of all service users are met, including the most vulnerable and marginalised within different contexts.

### **3 Intersectionality**

*Gender is only one dimension of marginalisation and intersects with other social stratifiers, such as race, class, education, etc., to create different experiences of vulnerability; and it is necessary to take account of how these stratifiers collectively shape accountability.*

Gender is only one dimension of oppression, marginalisation, and inequality. Intersectionality analysis is being increasingly embraced within the gender and health system literature. Intersectionality, as described by Springer, Hankivsky and Bates, is:

an approach that explores simultaneous intersections between aspects of social difference and identity (e.g. as related to meanings of race/ethnicity, Indigeneity, gender, class, sexuality, geography, age, disability/ability, migration status, religion) and forms of systemic oppression (e.g. racism, classism, sexism, ableism, homophobia) (2012: 1661).

Intersectionality originated as a result of Kimberlé Williams Crenshaw's critical observation that women in the USA could experience both legal and racial discrimination in simultaneously multiplicative, or 'reciprocally constructing' ways (Collins 2015: 2). Intersectionality theory points out, for example, that 'gender intersects with economic inequality, racial or ethnic hierarchy, caste domination, differences based on sexual orientation, and a number of other social markers' (Sen and Östlin 2008: 2). Focusing only on one social stratifier, such

as economic inequalities, across households 'can seriously distort our understanding of how inequality works, and who actually bears much of its burdens' (*ibid.*).

Literature on accountability within the health system often focuses on generic categories of users and inadequately examines the differences that impact on users' experience of health system delivery. In so doing, users are homogenised and certain categories elevated to the norm (male, urban, educated, heterosexual users). Alternatively, in an attempt to include 'vulnerable and marginalised groups' in accountability mechanisms, such as community scorecards, token representatives from such groups – such as poor female, disabled male, young female, old male – are often included to represent an entire group of 'marginalised' people. These processes are often not appropriately critically analysed; for example, there is little consideration of how gendered power relations may affect the ability of different groups to participate and share their experiences and challenges. Analysis of community scorecards (CSCs) as a mechanism to enhance accountability within Afghanistan's health system, for example, focuses on disaggregating participation according to the binary categories of male and female and on community requests for female doctors (Edward *et al.* 2015), but fails to examine gendered power relations either in relation to accountability or in relation to health, access to health services, and health outcomes.

At the same time, certain sections of a population can also be stigmatised by health system staff, affecting their ability to engage in accountability measures; poor women, for example, may be labelled uneducated or illiterate, blamed for their failure to practise healthy behaviours and, as a consequence, not be able to productively contribute to accountability processes (George 2003). Moreover, women users may struggle to communicate with health service providers because of their lack of voice and asymmetric power relations (George 2003; George *et al.* 2005; Murthy and Klugman 2004; Mafuta *et al.* 2015). Women's increased reliance on the health system as a result of their reproductive roles may also negatively influence their willingness to hold service providers accountable when they experience poor services or discrimination, especially when accountability mechanisms do not effectively or sensitively include or empower women, and in particular women with limited voice, such as migrant women or women with disabilities.

Social accountability emphasises 'the extent and capability of citizens to hold politicians, policy makers and providers accountable and make them responsive to their needs' (Mafuta *et al.* 2015: 1). The most effective strategies for doing this, Fox argues, are 'mutually empowering coalitions of pro-accountability actors in both state and society' (2015: 347). He stresses the importance of having state actors who are able to listen and respond to citizen voice, and of having citizens engaging and demanding accountability. Yet, as suggested above, not all citizens are in the same position or equally able to do this: gendered power relations limit voice and decision-making space. The inability

of some citizens to effectively participate, or the lack of inclusion of certain citizens, means that their unique needs and experiences may not be addressed in quality of care interventions or service provision improvements which result from accountability processes. For example, young women may not feel able to speak up if certain men (e.g. senior men to them, male family members or male partners, or men who occupy a supervisory position) are in the room, or a disabled woman's unique experience of discrimination may be disregarded for the sake of consensus. Implementers therefore need to ensure that power dynamics are effectively managed within accountability processes. Effective participation of marginalised and vulnerable categories within health system accountability processes may require additional activities and resources, including separate data collection exercises. CARE (2013) has produced some helpful guidance on including marginalised groups within CSC processes which may be applied to health system accountability. In its overview of gender inclusion and accountability, LMG (2014) recommends more gender disaggregation and the inclusion of women; it suggests that participation (and the corresponding politics) be articulated in ways that resonate with particular excluded peoples, and that partnerships and alliances be built which make politics more accessible to them.

While we know that gender is only one dimension of marginalisation, and interacts with other dimensions in complex and multifaceted ways, we do not yet have the tools to look at the intersections within health systems and in particular within accountability processes. More work is needed in terms of how we operationalise the complexity of power relations within the health system, and how this relates to the wider sociocultural environment to go beyond simply acknowledging that marginalisation exists. In addition, we need to know more about how privilege and disadvantage adhere at all levels and affect all actors within the health system, not just at the community or service delivery level.

#### **4 Empowerment**

*While accountability mechanisms can be used to create systems of empowerment, empowerment is a prerequisite for bringing about accountability.*

The term 'empowerment' encompasses both liberal and liberating components, focusing on both the ways in which individual women achieve greater self-actualisation and autonomy and on the collective consciousness required to transform gender structures (Cornwall and Sardenberg 2014; Sen and Östlin 2008). While both these components require attention to power dynamics, there is also an inherent tension between empowerment as an individual action that stems from within, and empowerment as collective conscientisation. The concept of relational empowerment, introduced by VanderPlaats, offers a lens for understanding empowerment for some through the actions of others. She argues that:

At the very heart of the concept of relational empowerment is the principle that one never can be just an empowerer or a person in

need of empowerment... The ability to be empowering or to support someone else's capacity to be empowering grows out of the mutual recognition that all of us can contribute to the construction of knowledge and social change but that, in the process, all of us have a lot to learn. In a truly empowering process, everybody changes (VanderPlaat 1999: 777).

Engaging with the concept of empowerment thus always involves paying attention to power relations (Cornwall and Sardenberg 2014) and how they play out at multiple levels.

In her review of using accountability to improve reproductive health care, George recognises that incapacity and inferiority in relation to officialdom is a form of disempowerment. She thus stresses the importance of participation and argues that accountability measures that 'encourage the active participation of marginalised groups can support the assertiveness and empowerment of those who are socially excluded' (George 2003: 165).

Inclusion in accountability processes can nurture citizenship and foster a sense of agency and entitlement among those who are involved. According to George (2003), increased and better representation of marginalised groups – and the information, dialogue, and negotiation that accompanies this – can not only change how marginalised people see themselves, but also how service providers perceive these groups.<sup>5</sup> In northern Ethiopia, for example, social accountability committees used community scorecards to monitor health service delivery; while also promoting women's increased participation, and offering training and support to facilitate their engagement in accountability initiatives (LMG 2014). Such empowerment therefore has the potential to contribute to better health and improved health systems by improving interactions between health providers and different types of clients, and through ensuring that all types of clients are agents and advocates in their own health care.

At the same time, however, empowerment can also be a prerequisite for bringing about accountability. For example, as stated above, certain sections of a population can be stigmatised and, by so doing, their ability to engage in accountability measures can be undermined. These subtle barriers to accountability are seldom recognised, even when accountability measures are sensitive towards social hierarchy and exclusion and foster both meaningful participation and empowerment (George 2003). Barasa and colleagues (2016) examine two Kenyan examples where community members occupied positions on the hospital management committees, which had oversight responsibilities for the hospitals. In both instances, these committees were seen as passive, disempowered bodies that merely approved hospital decisions. Several factors contributed to this, including: the power relations between hospital staff; hospital managers' convictions that community members were ill-equipped (illiterate, uneducated, unable to understand



budgets, and too narrowly focused on personal experiences) to play a useful role; and as a result, this affected managers' power to minimise community engagement; managers' failure to interrogate whom from the community participated; and the consequent potential for elite community representatives to benefit from the information shared in committee meetings (Barasa *et al.* 2016).

The outcome was that community members were 'minimally involved' in the priority setting and resource allocation processes undertaken by the hospitals. Barasa and colleagues (2016: 11) conclude that 'there is still the need to put in place measures that ensure that these actors are empowered to participate' and to confirm that accountability processes do not inadvertently work to disempower those involved. Gender can also shape this. Recent work on governance and devolution in Kenya has also highlighted how gender power relations intersecting with health system hierarchies limit women's ability to actively participate in accountability mechanisms at both the county and community level (McCullum 2017).

This chicken-and-egg situation suggests that, while we know that there is a relationship between accountability and agency, we still do not know enough about how it flows. Does accountability lead to empowerment or empowerment lead to accountability? Moreover, how do gender and power relations shape these trajectories and intersect with other drivers of inequality? Clearly, more information is needed about how accountability and agency are co-constructed and related.

### **5 A way forward**

In order to create lasting change which protects the health of all people, including those defined as poor, marginalised, and vulnerable, and recognises the gender-specific health needs of both men and women, we need to advance both theory and practice in relation to both gender and accountability. In particular, this article identifies three areas where this is critical: *power relations*, *intersectionality*, and *empowerment*. The importance of power relations and inequities is recognised in debates on gender and in accountability perspectives, yet not enough is being done to explore how to bring these together, and pursue an agenda of change that promises win-win situations which benefit both. In terms of intersectionality, gendered approaches to health systems have drawn attention to the importance of multiple social stratifiers and how these intersect to shape different people's vulnerability and health system needs. This sophisticated theorisation shows how social stratifiers can collectively and uniquely inform people's health needs, behaviours, and responses to accountability debates, and enhance understandings of how best to promote and use accountability mechanisms to meet the needs of different groups. And finally, empowerment, like power relations and intersectionality, is implicated in both gender and accountability, but there is little understanding of the ways in which these dynamics are co-produced, the synergies between them, and how they can best be realised and promoted.

What is clear from this overview, however, is that researchers of health systems have neither the tools nor the indicators to conceptualise the full range and complexity of gender and accountability. Further work is required to ensure that all citizens, including those most marginalised, are engaged in the monitoring of health system provisions and to support health systems' managers and practitioners to recognise gender-related needs. Focusing on gender and accountability may mean that, even if accountability initiatives do not always achieve expected health-related outcomes (increased life expectancy, transparency of arrangements, improved health), they may produce other valued results. These include greater knowledge and understanding of health system functioning (including of power and gender dynamics), constraints, or political process alongside individual or community empowerment and may, in so doing, make health systems more equitable for men and women, people of other genders, marginalised populations, and for diverse communities.

### Notes

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- 4 Although often conceived of as the provision of health services, Gorsky and Sirrs define health systems as 'a holistic understanding of organized medicine, incorporating not only services but also labour force, financing, regulatory framework, patients, treatments, and health outcomes' (2017: 362). Bloom, Standing and Lloyd expand on this understanding, drawing attention to the ways in which health systems operate in low- and middle-income countries, their pluralistic nature formed through highly marketised systems, and the presence of knowledge asymmetries. They argue that health systems should be recognised as 'knowledge economies which produce and mediate access to health knowledge embedded in people, services and commodities and which can potentially be organised in different ways. These ways encompass context-dependent factors, such as types of governance and relative strengths of states, and other factors such as changes in technologies and health needs' (2008: 2077). Other critical analyses of health systems emphasise the need for analysis to go beyond health, and to include more sociological analyses of corruption, human development, the construction of metrics, and policy (Gorsky and Sirrs 2017).

- 5 George (2003) recognises the potential for accountability initiatives that promote collective consequences and foster participation, assertiveness, and empowerment amongst communities to produce negative results, as critical assessments of health system and service providers do not always address power relations. She proposes that other actors within the health system, such as non-governmental organisations, be involved to counteract negative consequences and challenge vested interests.

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# Gendered Dimensions of Accountability to Address Health Workforce Shortages in Northern Nigeria

Fatima Lamishi Adamu, Zainab Abdul Moukarim and Nasiru Sa'adu Fakai

**Abstract** Northern Nigeria has some of the worst health indices in sub-Saharan Africa. Poor health outcomes are the result of multiple factors, including the lack of front-line health workers in rural and hard-to-reach areas. In 2012, funded by UK aid and DFID, the Women for Health programme was created to address the issue of gendered barriers of access to health education programmes and the subsequent dearth of nurses and midwives. It emerged that a different kind of 'accountability' was required to achieve improved maternal health outcomes: holding to account powerful actors within the community for their role in creating barriers of access to education for women and girls, as well as barriers to the retention of female health workers. This article, drawn directly from programme activities in Jigawa, Kano, Katsina, Yobe, and Zamfara states, documents strategies to shift gender norms that limit women's professional choices and their access to quality maternal health services.

**Keywords:** social accountability, maternal health, human resources for health, Northern Nigeria, health education, gender dynamics, health inequity, social determinants of health.

## 1 Introduction

The northern region of Nigeria has some of the worst health indices in sub-Saharan Africa (NPC and ICF International 2014; WHO 2017). In one recent review of progress across a range of health interventions in all states between 2000 and 2013, indicators show a clear stagnation and decline of health system functioning in the northwest and northeast regions when compared with other regions of the country (Wollum *et al.* 2015). These poor health outcomes are the result of multiple factors, one of which is the shortage of front-line health workers, particularly in rural and hard-to-reach areas of the region. While skilled health workers are crucial to the functioning of any health system, the

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northern region of Nigeria has suffered limited financial investment and the requisite political will to ensure sufficient health worker coverage.

In light of this challenge, Women for Health (W4H), a UK aid–DFID-funded programme established in 2012, worked with communities in five states in Northern Nigeria to enable young women to access (and maintain access to) the necessary education and training to become front-line health workers. After identifying factors associated with the dearth of front-line workers, and in particular those responsible for maternal health care, W4H created community support mechanisms to both identify and support the entry of promising young women into the professional health workforce. This support carried through from identification to graduation to ensure retention, ownership, and sustainability in producing a new generation of health workers to serve the population needs of the northwestern and northeastern regions of Nigeria.

Through engaging and empowering communities to address this gap in health workforce coverage at the local level, it became clear that a different kind of 'accountability' was required: in this case, a holding to account of powerful (largely male) actors within the community, and a challenge of existing gender norms that created barriers to the training and retention of female health workers. The aim of this article is to document community efforts towards mobilising young women to become health workers, and how the process challenges the existing gender norms that limit women's marriage options. The content of this article is drawn from the experience of W4H, established in 2012 to support five northern states of Jigawa, Kano, Katsina, Yobe, and Zamfara to increase training of female health workers, with the aim of improving health worker coverage at primary health-care facilities in rural and hard-to-reach areas of the northwestern and northeastern regions.

## **2 Inequity as the root of the 'human resources for health' (HRH) crisis in Nigeria**

Current understandings of health worker shortages and their impact on health were brought to global attention in the 2006 World Health Report, *Working Together for Health* (WHO 2006). The report defined the HRH crisis as the critical shortage of front-line health workers. It identified 57 countries, mostly in Africa, where the national ministry of health failed to ensure the minimal threshold of health workforce density (defined as 2.3 health service providers per 1,000 individuals).

In some respects, Nigeria is doing better than many neighbouring countries with a total of 0.39 doctors and 1.24 nurses per 1,000 people as compared to the sub-Saharan African average of 0.15 doctors and 0.72 nurses per 1,000 (*ibid.*). However, when this data is disaggregated by state and region, the stark inequity of health worker distribution is revealed. The crisis of HRH in Nigeria is a 'northern' problem. The northern regions (broken down into northwest, northeast, and north central) have fewer health workers and fewer health training institutions (HTIs) than other regions, in spite of having the greater total population



and higher levels of ill health. For example, in 2012 there were 27 accredited medical training schools in the whole country, the majority of which (78 per cent) were based in the southern region (Federal Ministry of Health Nigeria 2016).

To meet the minimum World Health Organization (WHO)-recommended HRH threshold for nurses and midwives by 2030, Keller *et al.* (2013) concluded that key states in Northern Nigeria would have to substantially increase enrolment in health training programmes. This increase would be by a factor of 20.6 for Jigawa, 19.4x for Kano, 26.5x for Katsina, 14.7x for Yobe, and 17.6x for Zamfara states. ‘Without these massive investments’, they argued, ‘millions of Nigerians will not have access to basic health services’ (*ibid.*: 4). Another characteristic of the HRH crisis in Nigeria, beyond regional disparities, is the unequal distribution of health workers across rural areas and primary health-care (PHC) facilities. In Katsina State, for example, 90 per cent of the midwives employed by the Katsina State government work in Katsina City (Katsina State HRH policy 2012). Furthermore, there is the problematic concentration of health workers (including doctors, nurses, and midwives) in the tertiary levels of care (Federal Republic of Nigeria 2007: 19).

### **3 Addressing interconnected challenges to health workforce shortages: Women for Health’s holistic approach**

In a technical proposal, Health Partners International (2012) identified four interconnected challenges to account for the shortage of health workers in rural Northern Nigeria: first, a failure to attract and train sufficient numbers of female health workers; second, a failure to deploy female health workers to rural health facilities and retain them in rural posts; third, a failure to address a multitude of governance inadequacies that perpetuate inequity; and fourth, a failure to address women’s subordinate position in society and the socio-sexual norms of female modesty, respectability, and honour. W4H structured its programme of work in Northern Nigeria to address each of these issues in a holistic way.

#### **3.1 Attracting and training a sufficient female health workforce in Northern Nigeria**

One of the key priorities of families is to protect the moral integrity of their daughters by marrying them off early (Perlman *et al.* 2017). The average age at first marriage is 15.3 years in the north, with the lowest being in Zamfara State at 14.4 years (NCP and ICF International 2014), and the percentage of women aged 15–19 that began child-bearing was 32.1 per cent and 35.7 per cent in the northeast and northwest respectively. In addition, cultural perceptions of girls as childminders, ‘marriage material’, and a burden to the family influences their educational attainment in contemporary society (Mercy 2017). This means that many young women miss out on the educational opportunities that could facilitate progress into a career of their choice (Perlman *et al.* 2017). The anticipation of early marriage also reduces educational or training aspirations. For unmarried women who do get as far as enrolling in training courses, the primacy of marriage

leads many to withdraw before completing their training. Indeed, it is not uncommon for training courses to be treated as a 'waiting room for marriage' – a means of hiding the fact that a husband has not yet been secured; or a place to keep young unmarried women busy until a husband is found. In her doctoral research, Adamu (2000) reported several such views of mothers. Within this context, pursuing a health career is therefore a daunting task.

### **3.2 Training and retaining female health workers in rural posts and primary health-care facilities: the impact of socio-sexual norms**

Within the context of the W4H programme, one key factor in the health worker shortage crisis has been the inadequate provision of public health education that meets the needs of female students. This can mean, on the one hand, biased admissions practices in health worker training programmes that give preference to male students, and to students from urban areas. It can also mean a lack of consideration of the specific needs of female students, and female staff. At the start of the W4H programme, it was clear that there was little to no gender sensitivity or gender mainstreaming of health education institutions, and therefore no consideration of what actions and institutional reforms would be required to enable women to study and teach without compromising on their family responsibilities (per existing gender norms). Nor did these institutions make provision for the particular safety and safeguarding needs of female students and staff (SurrIDGE, Moukarim and Fakai 2016).

Once trained, there is the issue of retention, particularly within PHC facilities and rural health posts. In the predominantly Muslim northwestern and northeastern regions of Nigeria, religious and cultural norms contribute to both the difficulty in attracting and retaining female health workers who originate from other regions of the country, and to attracting and retaining women of the Muslim faith for whom living apart from their husbands is not an option. Under Islamic family law, a husband is expected to have rights and control over his wife's mobility (Adamu 2008; Imam 1993). Consequently, a 'good' wife accepts deployment away from her husband's place of residence with his permission only.

In a qualitative study of health workforce deployment in Katsina, Zamfara, and Jigawa states, 60.2 per cent of female health workers (n=24) reported their willingness to accept a rural posting; however, only 25 per cent of their husbands would permit them (Adamu 2013: 3).<sup>1</sup> One midwife said: 'No matter the incentive my husband will not permit me' and 'No incentive will compensate for my children's education.' (*ibid.*). In the same study, another sociocultural factor identified is the concern women have that their absence from the marital home will result in their husband taking another wife, or a loss of influence in a polygamous family because of long absences, or of being accused of abandoning a husband and children by in-laws. As noted in the technical proposal (Health Partners International 2012), a refusal to move into a rural posting is often justified on religious grounds, but the reality may

be attributed to women's limited negotiating power and the inability to balance the demands of a health career and family obligations. In this study, one husband reflected the wider view of male household heads that having women away from the home is problematic because, 'she is the only one taking care of the children and the house'. The proposal concluded that 'in the absence of support from their husbands, families or the wider community, there is too much to lose in accepting or staying in a rural post' (Health Partners International 2012: 2).

The need to support communities to produce their own health workers is imperative, considering the fact that 39 per cent and 26 per cent of women in the northwest and northeast regions respectively, stated that they had serious problems accessing care due to a lack of female providers (NPC and ICF Macro 2009). This is particularly important where social norms prohibit women from receiving care from male health workers, a common situation in rural areas of Northern Nigeria. In a W4H study, one community leader in Katsina was quoted as saying,

*I visited a health facility in this community where a male health worker was attending to a woman after delivery. There was a lot of intimacy in the process which is not acceptable in our culture and in our religion. That was when I decided my wife will never give birth in these facilities.* (Surridge 2017)

This remark aligns with the statistical data on births in the northwest and northeast regions, where the overwhelming majority of women report at-home births, and the indices of maternal and child mortality are ten times higher than in the southwestern region of the country (NPC and ICF 2009). In short, as stated in a Save the Children report:

if the North West region was a country, it would have a population of nearly 40 million and its rate of skilled birth attendance would be the second lowest in the world. The northeast region would have over 20 million in population and the fourth lowest birth attendance in the world (Keller *et al.* 2013: 7).

These stark geographic inequities extend beyond the circumstances of birth and the survival of mothers and infants. In the most recent Nigeria Demographic Health Survey, it is clear that women in the northeast and northwest regions report substantially lower percentages of access to antenatal care, and accessing care in general due to a lack of female providers. Further indications of inequity become apparent once the inter-regional data is taken into account. The states selected for participation in the W4H programme have, as is shown in Table 1, some of the worst maternal health indicators in the country.

#### **4 The Foundation Year Programme: the intervention**

Against this background, W4H, as funded by UK aid—DFID, created the Foundation Year Programme (FYP) in 2012. The FYP was designed to help young women from rural areas raise their level of educational achievement to meet the standards required to enter schools of nursing, midwifery, and health technology, taking into account both academic

Table 1 Health indices in Women for Health intervention sites

Indices	Jigawa	Kano	Katsina	Yobe	Zamfara
Maternal mortality rate/100,000	950	1,025	590	1,549	1,025
Delivery by health professional (%)	76	5.1	5.1	3.1	22.3
Facility base delivery (%)	6.7	6.7	23.6	7.5	5

Source NPC and ICF International (2014).

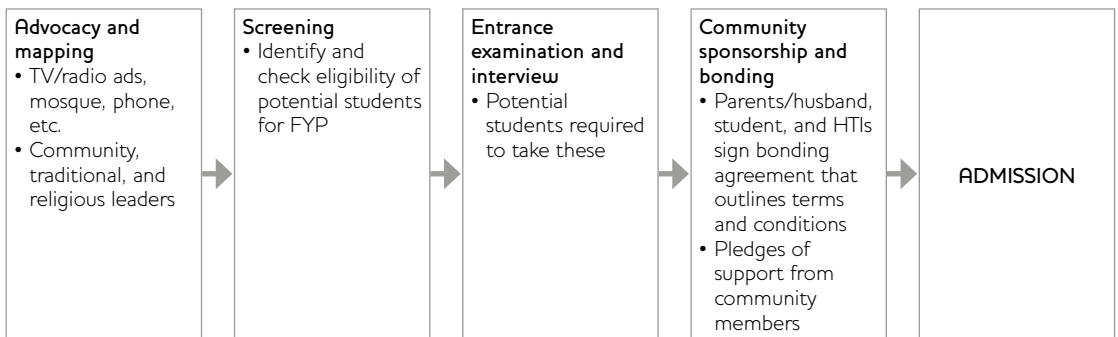
challenges, gendered social norms, geographic, and cultural barriers that have hindered the creation of a female health workforce sufficient to serve the northern region. The FYP is a bridge programme intended for girls from rural communities who have studied science at senior secondary school level, but who do not have the required five credits for entry into nursing, midwifery, or community health extension worker (CHEW) training courses, or alternatively, have the credits but not the capacity to pass the required entrance exams. The FYP is designed to support the girls to gain the required credits and also to build the knowledge, skills, and attributes that will enable them to be successful as students and in their future profession as a nurse or midwife.

The FYP has two strands: a bridging strand and a preparatory strand. The bridging strand enables students to study science subjects as well as English and Maths for which they need a credit. The six months' preparatory strand is for students who already have all the required credits for entry into an HTI but who would benefit from additional support to prepare them for the entrance examination and to develop the knowledge, skills, and attitudes they will need to be successful and confident learners. By December 2016, 478 rural young women, married and unmarried, were enrolled and in training to become nurses, midwives, and CHEWs, with the expectation that 110 will be graduating as health workers in 2017. The FYP is also expecting an additional 190 graduates of the programme in 2018.

#### 4.1 The Foundation Year Programme selection process

The selection criteria for the FYP starts with selecting a PHC facility or hospital that lacks either a female health worker, or lacks a health worker that is consistently local. Once selected, there are a range of community engagement strategies employed by W4H; for example, making an advocacy visit to the Emir, religious leaders, and imams responsible for the towns and villages around the health facilities. Once the collaboration of an Emir is achieved, the next step is to call together district heads and village heads to the Emir's palace where the FYP working group (interagency government team) introduces the programme and explains the criteria for gaining admission. Other methods of sensitisation involve working with religious leaders in mosques after prayers, communication campaigns via mobile phone, and other mediums to generate awareness of the programme, and to recruit eligible young women from the hospital or health facility

Figure 1 The Foundation Year Programme selection process



Source Authors' own.

catchment areas. The result of these efforts has been a substantial turnout of young rural women interested in joining the programme.

The selection criteria for FYP participation began with requisite documentation of educational credentials, an identification letter from their village or local government leader, and a statement of interest. Community and religious leaders interviewed potential candidates, and those who met all the requisite criteria were then asked to sit an entrance qualification exam. An oral interview was held immediately after the examination for those successful in the written exams. Collated examination results (written and oral) were forwarded to the Health Training Institution hosting the FYP who would use the predetermined cut-off grades to produce the final list. An additional consideration was to ensure a representative proportion of students from every selected local government area (LGA), based on LGA populations. All students that reached the cut-off grade were accommodated. The selection process is presented in Figure 1.

It is important to reiterate that supporting young women from rural areas to gain admission to HTIs is only a first step to addressing the health worker shortages in northeast and northwest Nigeria. It is also crucial to create a supporting and enabling environment for the education of girls and young women at the community and school level. This can only be achieved through significant changes to both the community-level and institutional cultures, including student welfare mechanisms, guidelines on the professional conduct of staff, and ensuring the safety and security of the learning environment.

#### 4.2 Community action

Any strategy aimed at promoting gender and health equity in Northern Nigeria must first address potential areas of cultural and religious conflict in the minds of husbands, families, and the wider community. Failure to do so will result in doing more harm to women than good. The FYP's guiding ethos in negotiating these gender dynamics was one of 'do no harm', taking great care to create an enabling environment

for the training, recruitment, and retention of female health workers without alienating potential male allies.

One way the FYP operated in respect of existing cultural norms, was to make clear to participating communities that solving their localised health worker crisis – given the limits on married women's freedom of movement – was to support the creation of a local female health workforce. If communities continued their reliance on female health workers from urban or distant areas, they would run the risk of losing the health worker if her husband demanded her to return, or denied her permission to travel. In this sense, the community is ultimately accountable for the production of a reliable workforce capable of meeting the needs of local women. Through this process of raising awareness, it became possible to make the financial and social costs associated with the health training a social and communal responsibility (note: where a candidate was not able to secure the needed financial support, the programme provided funding through its grants and incentives scheme).

Within this context of a social contract, the FYP working group would meet with individual FYP programme candidates, together with her parents or husband and with other key community gatekeepers. The objective of these initial meetings with candidates and their extended social and familial networks was to create awareness – at the community level – of FYP expectations of family, extended family, and broader community support of the programme participants. This involved signing collective bond forms and consent forms, not just for the young female participants, but also for her family members and community leaders. This commitment includes financial and logistical support, as well as emotional and social support to the FYP participants, from the beginning of their educational programme through to their placement at a health post, clinic, or hospital.

Recent data on the FYP shows that 57 per cent of participants report receiving financial support from their communities, over 90 per cent report receiving advice and prayers, 23 per cent were visited in school by their communities, and 46 per cent have received phone calls (W4H 2017). In order to ensure the successful transition of FYP students into HTIs, and subsequently into full-time employment, a bonding agreement has been devised in consultation between stakeholders. The bonding agreement sets out the responsibilities of each partner as follows: (1) State Ministry of Health (SMoH) to accept all FYP students who pass the entrance examination into nursing, midwifery, or CHEW training at an HTI upon completion of the FYP; (2) SMoH and Ministry of Local Government to offer a full-time, pensionable appointment to the student upon completion of training; and (3) student to commit to returning to work within her community/LGA upon completion of training.

Across 912 communities and 1,617 married and unmarried young women and mothers, this bond-pledging has largely been successful.

**Box 1 A case of community sponsorship**

Fatima Lami is from the Iggi community in Jigawa. It has a population of 26,700 and is made up of 14 community wards. It has a PHC facility but does not have a health worker. The nearest referral facility for women is in Birnin Kudu about 45km from Iggi or Dutse (40km). The community had set up a small committee to collect the pledges made by community members every quarter. The committee treasurer Malam Umar is responsible for documenting the pledges from both family members and community pledges, collecting them when due and making sure that these pledges are redeemed by the FYP students. These are documented in a notebook for each student. Pledges redeemed for Fatima include two plates of Garri,<sup>2</sup> 12 bars of bathing soap, cream, 18 bars of washing soap, seven packets of detergent, NGN600 [about US\$1.67], one packet of cabin biscuits, six packets of detergent, 12 notebooks, and visits to her in the school by the community.

*My interest is in my daughter's education. A lot of suitors have come to ask for her hand in marriage and I have told them that she has to finish school first. She currently has a suitor who is also a graduate of NCE [National Certificate of Education]. I have made my stand, she will marry after school.<sup>3</sup> (Fatima's father)*

Source: Community dialogue meeting, Jigawa State, W4H.

However, in the first and second cohorts of the FYP, there were several reported cases of husbands negating on their pledge to permit their wives to attend training as health workers. Despite the FYP's efforts to achieve 'no harm' to the young, there were still substantial barriers to success. Negative pressure to drop out did not just fall on women, but also on their male partners. Some of those husbands who permitted their wives to enrol in the FYP were then called names such as *dankwali ya jawo hula* (scarf drags hat)<sup>4</sup> or *mijin ungwazoma* (husband of birth attendant), and were labelled 'yes ma' husbands. This social pressure resulted in some husbands withdrawing their wives from training. There were also cases of FYP participants' husbands going polygamous or seeking divorce as a consequence of the wife's training and absence. While increased dialogue at the community level, in particular with religious and community leaders, has helped mitigate some of these challenges, they still remain. As members of the FYP working group, religious and 'traditional' leaders have played an integral role mediating and resolving these interrelationship and marital struggles. They also helped the programme to identify key messages from religious texts that emphasised the importance of women working to save lives, and to formulate the messages to reach rural communities.

Some of the backlash by FYP participants' husbands in the first two years of programme implementation helped push W4H to engage more proactively with religious and 'traditional' leaders. Four years of health worker training can be a transformative experience for rural young women, and this requires additional social, emotional, and psychological support to prepare them for their new realities. The capacity of these young women was built so that they could become local champions across the cohorts of the programme. In an assessment conducted among three cohorts to identify the level of empowerment, and how much the young women are serving as role models, the reports show that 53 per cent of 313 participants in 2015 reported feeling empowered in terms of their confidence level, their ability to negotiate for themselves, make decisions, advocate for other young girls, and in serving as role models in their communities. The figures rose to 89 per cent of 321 participants in 2016, and 82 per cent of 333 participants in 2017 (Surrridge, Moukarim and Fakai 2016, 2017). One graduate explained:

*I was inspired into this profession because of difficulties my people are facing over the years when it comes to child delivery... Since I joined the programme I have become a local champion with many young girls looking up to me as their role model. They always see me as their saviour, meeting me at home, morning and night, for advices and services. (FYP midwife graduate in Kunchi)<sup>5</sup>*

Despite the aforementioned challenges, the FYP is beginning to positively influence gender norms at the community level, and to build new relationships of accountability that help to ensure the training, recruitment, and retention of female health workers. Perlman *et al.* (2017) and Adamu (2004, 2008) have previously documented the priority that many parents in the northwest and northeast regions of Nigeria place on daughters' marriage prospects versus education. Under the current circumstances, many parents have sided and supported their daughters to sacrifice their marriages for training to become health workers. A community leader in one of the communities noted that:

*I am encouraged by this initiative (FYP), especially as it relates to the issue of girl-child education. We do not take girl-child education seriously, perhaps that explains why we are facing a lot of difficulties. We don't have women to attend to our wives on our health facilities and in schools no teachers. (Ngbokai 2017: 29)*

The effect of the FYP goes beyond the community to affect the running of HTIs.

### **5 Community and health training institutions linkages<sup>6</sup>**

The involvement of educators *and* communities in the recruitment, selection, and support of FYP participants has contributed to the development of stronger collaborative ties and meaningful accountability relationships between health education institutions and the populations they serve. This section explores the nature and effect



of these strengthened relationships. Prior to the implementation of the FYP, there was limited communication and weak relationships between communities and HTIs. Although the HTIs would sometimes advertise educational opportunities on the radio/TV, they were not seen as institutions relevant to the community.

With the creation of the FYP and the first cohorts of successful participants, the relationship between HTIs and the communities involved began to change. The FYP students themselves become a crucial link or lever in an evolving accountability relationship between the health education sector, health services, and health users. To begin with, FYP students keep their home communities up to date on their experience and their progress. Family members relay their daughters' experiences in the health education sector to other community members. When back home from their studies, the FYP cohort representatives serve as role models and encourage other young women to follow their footsteps into health training. Current and former students frequently give advice to others on the practicalities and requirements of applying for the programme, which helps to spread the message of the FYP.

In addition to the linkages created via the students themselves, the HTIs involved in the programme also reach out to parents, male partners, and community leaders, inviting them to meet with school heads and educators. This initial visit gives parents, partners, and community leaders an opportunity to see where the female student will live and to understand the set-up. Beyond the initial visit, contact is maintained throughout between the participating HTIs and district heads, representatives of community organisations, tutors, and the FYP coordinator. This contact contributes to the enabling environment for the existing FYP cohort, as well as furthering the recruitment of future cohorts.

The result of this ongoing dialogue between participating HTIs and targeted communities of the FYP, is an increased awareness of the benefits of sending more girls and young women into health education (to meet community-level health worker shortages), and of working together to ensure the educational success of each cohort. Over the course of the programme, W4H has documented not only an increase in the number of applications for the FYP, but also for nursing and midwifery training more broadly. There has also been a shift in attitudes among community members towards HTIs which, in the past, were seen as 'out of reach'. The HTIs are no longer seen as serving only those girls partnered to, or the daughters of, the richest 'big men'. In fact, some participating institutions have changed their admissions policies to allocate specific spots to young women from rural areas.

The FYP has helped engender a new-found sense of pride in participating students and their families, both for their educational achievements, and for the fact that these students would be mixing with young women perceived as being of higher social and economic status. This sense of pride and purpose is contributing to shifting

attitudes of parents and communities, and galvanising them in support of girls' education. As one community leader remarked,<sup>7</sup> 'I am ready and willing to take the lead as a champion for girl-child education and specifically for their entrance into health training institutions'. In regions where early marriage is a common practice, and a common factor in the truncated education of young women, this shift in attitudes is no small feat. The possibility that health education for young women creates is both a change in social and gendered norms, as well as the practical outcome of having more female health workers available to serve women's health needs in rural and otherwise neglected areas of the northeast and northwest regions of the country. The FYP has given communities a strong argument in favour of educating girls, and through the example set by FYP graduates, has opened up new professional aspirations. One FYP student training in nursing remarked,<sup>8</sup> 'I have become a role model. My friends too have developed an interest, praying that they will have a similar opportunity later in life.'

## 6 Conclusion

As outlined in the previous sections, social, cultural, and religious perceptions limit the ability of women, particularly those from rural areas, to train and work as health workers in Northern Nigeria. The ultimate aim of W4H, namely the sustainable deployment of female health workers to rural areas, can only be achieved if these social, cultural, and religious perceptions are taken into consideration, and a supportive environment for female health workers is created. An additional factor critical to the success of the FYP, and to ensure the programme's contribution to a more equitable distribution of health workers, is the assurance that each student will return to work in a rural area upon completion of her studies. Hence all partners, including the student, her husband and family, her community, and LGA (who are responsible for employing students after graduation) must have a common understanding of this commitment, and their respective obligations, from the outset.

While it would be artificial and probably impossible to entirely separate those links that involve W4H and those that do not, it does seem that wider links, often led by community members are now being established. Through dialogue and community engagement, the FYP initiative has helped raise awareness about HTIs and has helped to create pathways for young women to develop careers in the health sector. A new form of social accountability has been engendered by the programme. Male leaders, partners, husbands, fathers, and other powerful actors within the communities involved now understand the real health impact of keeping young girls and women from educational opportunities and health worker training. To create a sustainable health workforce, these communities now understand that they have to be part of the solution, in this case through contributing to a supporting and enabling environment for the recruitment, training, and retention of young women as nurses, midwives, and front-line health service providers. The accountability relationships in the FYP travel in multiple directions – young women are accountable to their communities for their studies and for their successful

deployment, communities are accountable (and in particular adult men) for encouraging and supporting girls' educational attainment, and health training institutions are accountable for creating environments that are supportive and nurturing. Women for Health's Foundation Year Programme exemplifies what is possible when relationships of mutual accountability are established and sustained, on the basis of a shared goal of improving health outcomes and health equity.

### Notes

- 1 For further project information see: [www.gov.uk/dfid-research-outputs/project-closure-report-partnership-for-reviving-routine-immunisation-in-northern-nigeria-maternal-newborn-and-child-health-initiative-prinn-mnch](http://www.gov.uk/dfid-research-outputs/project-closure-report-partnership-for-reviving-routine-immunisation-in-northern-nigeria-maternal-newborn-and-child-health-initiative-prinn-mnch).
- 2 Garri is processed cassava flakes, often taken with water and sugar.
- 3 Interview, March 2016, Iggi Town.
- 4 Meaning that the husband would follow his wife wherever she goes (scarves are worn by women and hats are worn by men).
- 5 Interview, November 2017.
- 6 A substantial part of Section 5 has been paraphrased from Mitchell (2015).
- 7 Interview, November 2017.
- 8 Interview, November 2017.

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# Reducing Health Inequalities in Brazil's Universal Health-Care System: Accountability Politics in São Paulo<sup>\*†</sup>

Vera Schattan Coelho

**Abstract** Brazil relies on the Sistema Único de Saúde (SUS), a public health-care system used by nearly 65 per cent of the population. This article analyses the role played by accountability mechanisms in expanding access to primary health care in the municipality of São Paulo, Brazil's largest city. Two accountability mechanisms are described and discussed: political competition and outsourcing. The article shows that from 2001 to 2016 the supply of primary care grew and the disparities in access to public health services decreased across the city areas with both the best and worst indices of income, education, and health. These distributive results are striking given how difficult it is to reverse inequalities, as attested by the findings of a number of studies in different parts of the world which indicate that the richest populations tend to persistently benefit more than the poorest from public spending on health.

**Keywords:** Brazilian public health system (Sistema Único de Saúde), primary care, policy process, health inequities reduction, political accountability, managerial accountability, Universal Health Care.

## 1 Introduction

In Brazil, the issue of inequalities in the distribution of health services and in health status among different population groups has figured in public debate since the late 1970s, and has received considerable attention from the Ministry of Health since the early years of implementation of Brazil's universal national health-care system, the Sistema Único de Saúde (SUS).<sup>1</sup> The SUS was enacted by the 1988 Constitution, which restored democracy in the country after a period of military dictatorship. The health-care system offers all Brazilians free access to appointments, tests, hospitalisation, and a wide range of medicines, in addition to vaccination campaigns, and prevention and health surveillance actions.

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The SUS defines national policies, which are implemented in a decentralised manner by states and municipalities and are financed by the three spheres of government: federal, state, and municipal.<sup>2</sup> The implementation of primary care is a municipal responsibility, which means that political accountability for primary care is located principally at the municipal level.

This article profiles the distribution of primary health care provided by the SUS from 2001 to 2016 among the 31 sub-municipal boroughs that make up the municipality of São Paulo. The municipality has 12 million inhabitants, with 6.6 million of them exclusively using the SUS.<sup>3</sup> In 2001, distribution of public health services in the city was heavily concentrated in the central areas, which also had the best socioeconomic indicators (Coelho and Silva 2007). This situation changed over the years that followed, spanning four municipal administrations whose mandates were exercised by mayors from political parties with very different political orientations; chronologically, the left-wing Workers' Party (PT), the centrist Brazilian Social Democracy Party (PSDB), the right-wing Democrats (DEM), and then the PT again. Despite this left–centre–right oscillation, during this period, service distribution consistently tended towards greater equity. There was also a consistent trend towards increased use of outsourcing to deliver primary care services, despite the parties' very different ideological positions on outsourcing.

These results are not negligible and can hardly be explained solely by the arrival of new federal programmes and funding in the municipality:<sup>4</sup> had these programmes simply been implemented, and new funding used, according to the same logic reflected in the distribution of existing health facilities, this would have easily led to the inequalities already present being maintained, or even worsened. Therefore, with a view to explaining the results, this study examined the role of political and managerial accountability mechanisms present in the municipality of São Paulo in the period 2001–16.

This article's two main contributions to the literature are that it: (1) profiles the distribution of SUS services within the municipality of São Paulo over a 16-year period spanning four complete administrations, and analyses that profile in terms of its distributive impact; and (2) discusses this impact in light of the presence of the accountability mechanisms in place in the city during the period: electoral competition, as a tool for political accountability, and outsourcing, as a tool for managerial accountability.

The remainder of this article is organised into four sections. Section 2 presents the debate concerning the role that accountability may play in tackling health inequalities. Section 3 describes the main primary care policies implemented between 2001 and 2016 by the various political parties in office in the São Paulo municipal government. Section 4 describes the changes that happened in the distribution of primary

health facilities and services in the 31 boroughs during the period, and Section 5 discusses the role of accountability mechanisms in establishing the policies that helped to address health inequalities.

## **2 Conceptual and methodological approach**

The findings of a number of studies in different parts of the world indicate that the richest populations tend to persistently benefit more from public spending on health than the poorest populations (World Bank 2004; Huber *et al.* 2006; Liu, Hotchkiss and Bose 2007; WHO and UN-HABITAT 2010). More recently, a growing body of literature on accountability, aligned with its definition in terms of answerability and sanctions, argues that accountability approaches may help to break this vicious cycle (Brinkerhoff 2004; Fox 2015).

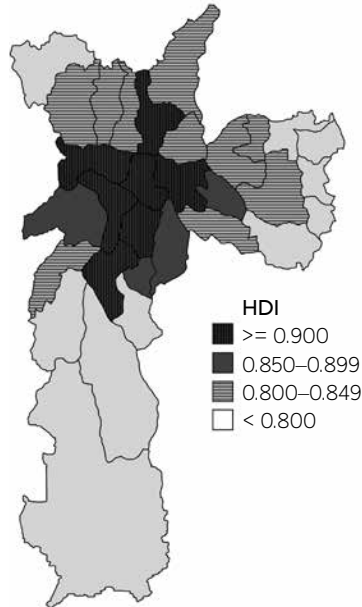
Brinkerhoff (2004), in particular, distinguishes three types of accountability related to health systems that may play a role in effectively informing policy and programmes: financial, performance, and political/democratic. According to Brinkerhoff, in the realm of financial accountability, provider payment systems can be important mechanisms for enforcing increased financial accountability and cost control among participating private providers, while performance accountability refers to demonstrating and accounting for performance in light of agreed upon targets.

Political/democratic accountability, in turn, has to do with ensuring that government delivers on electoral promises, lives up to public trust, and responds to ongoing and emerging societal needs and concerns, with the political process and elections being the main avenues for this type of accountability.

In this article, we explore the relationship between changes to the distribution profile of health services offered by the SUS in the municipality of São Paulo and two types of accountability – electoral and managerial – which relate to the three spheres indicated by Brinkerhoff.

In the Brazilian debate, these topics have been discussed in parallel. Political scientists analyse the importance of decentralisation in making politicians and public policies more responsive to citizens, as well as association between party orientation – right, centre, and left – and preferences for more redistribution, or more state or market (Arretche and Marquez 2002; Viana, Fausto and Lima 2003; Ouverney and Fleury 2017). Specialists in public management have explored the capacity of different contractual arrangements to promote greater efficiency in public services (Barradas and Mendes 2007; Ibañez and Vecina Neto 2007; La Forgia and Couttolenc 2008; Sano and Abrucio 2008; Médici 2011; Greve and Coelho 2017),<sup>5</sup> while authors connected to public health have made efforts to demonstrate the connections between advances in primary care and improvement, whether in health indicators or in reducing inequalities (Hone *et al.* 2017; Macinko *et al.* 2007; Landmann-Szwarcwald and Macinko 2016).

Figure 1 Human Development Indices by borough, municipality of São Paulo, 2013



Source Author's own, based on data from the São Paulo Municipal Department of Urban Development.

This article tries to bring these debates closer, to shed light on the connections between the mechanisms of answerability and sanctions in the political and managerial spheres and their relationship with changes to the distributive profile of the supply of public health services. To explore these connections we have systematised: (1) the primary health-care policies implemented by each of the four municipal administrations of São Paulo in the period 2001–16; (2) the types of contracts adopted in these administrations to implement the policies; and (3) the distribution of health facilities and services in all the municipal boroughs during the period.

The policies implemented by each municipal administration were analysed systematically through a qualitative study which included participant observation at health facilities and 28 interviews in which São Paulo Municipal Health Secretariat managers, health service providers, and politicians responded to closed and semi-open questions. Official documents and academic and press articles were also collected.

Analysis of the distribution of health facilities and services was carried out by ordering the 31 boroughs by their Human Development Indices (HDIs), which are calculated by the municipality using the United Nations Development Programme (UNDP) methodology and census data on income, education, and health. Higher HDI indicates better socioeconomic conditions (see Figure 1).

For each borough, the percentage of the total population that exclusively uses SUS services is calculated by the São Paulo Municipal



Health Department of Epidemiology and Information.<sup>6</sup> Peripheral areas of the city present the highest percentages of SUS users, as those who exclusively use the SUS tend to be poor. Quantitative data on service provision were obtained from the SUS Department of Information Technology (DATASUS).<sup>7</sup> From there, two indicators related to primary care supply were calculated for the population of each borough that exclusively used the SUS: (1) provision of primary care appointments per year, and (2) percentage of live births with provision of seven or more antenatal appointments. To facilitate description, the boroughs were grouped into quartiles according to their HDI scores; lower quartiles include boroughs with lower HDIs.

The supposition explored in this study is that in a context of strong electoral competition and modest access to public health services in poor and densely populated areas, the promise of improving services for the poor represents an attractive programme that could garner votes for parties with different ideological orientations. The institutional conditions found in the city – financial and managerial capacity located inside the Municipal Health Secretariat to contract private, not-for-profit social health organisations (*organizações sociais de saúde* – OSSs) and the presence of these organisations already delivering primary care – explain ‘how’ this programme could be achieved. In short, the presence of claims for answerability and the possibility of sanctions at both the political and managerial levels played a crucial role in facilitating the expansion of public primary health services in the poor peripheries of São Paulo.

It should be noted that our analysis of the role of accountability mechanisms in generating policies with distributive impact in favour of areas with worse socioeconomic indicators was constructed from a single case. This limits the study’s claim to validity. In that light, we offer one plausible explanation of relations among distributive gains and political and managerial accountability mechanisms; causal relations among these events remain an open question. After all, variables omitted from our analysis may be more strongly associated with these distributive gains than those examined here. The possibility of replicating this type of study in other large cities certainly offers scope for advancing, beyond what was possible in this study, our knowledge of the role of accountability mechanisms in reducing inequalities in the distribution of public health services.

### **3 Politics and policies**

#### **3.1 Baseline**

From 1988, through the SUS, municipalities were given greater responsibilities in the area of health policy. In São Paulo it was up to Eduardo Jorge, the Health Secretary in the Luiza Erundina (Workers’ Party – PT) administration (1989–92), to begin implementing the system in the city. Jorge was a historical leader of the health reform movement that had led the creation of the SUS. His work was marked by investments being directed towards providing services in peripheral areas of the city.

Health districts and regions were created, a situation that guaranteed relative autonomy for expenditure since districts were budgetary units (Junqueira 2002; Pinto, Tanaka and Spedo 2009; Coelho, Szabzon and Dias 2014). From 1989 to 1992, 50 rounds of civil service exams were made available, nearly doubling the number of Municipal Health Secretariat civil servants. After Erundina's term was up, the staff at the Secretariat included 42,000 civil servants, which reflected this administration's preference for expanding services through direct contracting of health professionals (Junqueira 2002). This expansion followed the traditional management model used in public administration, where there are several bureaucratic controls, but no sanctions if performance targets are not achieved.

The election of Paulo Maluf (1993–96), of the right-wing Social Democratic Party (PDS), represented an about-turn in this trajectory and a clear setback for the SUS in the city. The mayor-elect decided to interrupt implementation of the system and create his own Health Care Plan (*Plano de Atendimento à Saúde – PAS*) focused on contracting medical cooperatives to provide care services. This programme, the object of great controversy and many grievances, was maintained by his successor, Celso Pitta (1997–2000) of the right-wing Brazilian Progressive Party (PPB) (Junqueira 2002; Coelho *et al.* 2014). Paulo Maluf and Celso Pitta drastically cut the number of Municipal Health Secretariat civil servants: in 2000, there were just 29,000 direct civil servants – a little over half as many as during the previous administration – because the PAS contracted medical cooperatives to provide services (Junqueira 2002).

A parallel action began in 1995, when the Ministry of Health and the State Health Department – both controlled by Brazilian Social Democracy Party (PSDB) administrations – together with David Capistrano, a leader of the health reform movement and former PT mayor of Santos city, began to support implementation of a pilot Family Health Program (FHP) in the peripheral areas of São Paulo. The programme was given the name *Qualis* (Qualidade Integral em Saúde) and was implemented with the participation of non-governmental organisations (NGOs) that already had experience of providing health services.<sup>8</sup> By late 1999, *Qualis* comprised approximately 140 family health teams, providing care for about 400,000 residents in the city's peripheral areas (Capistrano Filho 1999).

In short, between 1989 and 1999, as political control of the São Paulo municipal government changed between left and right, the public health policies implemented in the city also changed. These changes help to illuminate the close relationship, to which we are calling attention, between political competition and the concepts and guidelines that have been structuring municipal health policy.

In the 2000 election, all of the candidates with the exception of Paulo Maluf were in favour of terminating the PAS and moving forward with the SUS. Marta Suplicy (PT) was already the front runner in the early

weeks of the electoral calendar, remaining in this position and winning in a run-off election against Paulo Maluf, with 58.51 per cent of the vote. With this, in 2001, the PT took back control of the city. At the time, the PT and PSDB were both in opposition to the PDS and PPB. However, after 2000, the PDS and PPB lost ground and were eventually replaced by another right-wing group, the Democrats (DEM), while the PT and PSDB began to fiercely dispute municipal elections – with the PSDB eventually allying itself with the DEM party. Below are the main policies pursued by each of the four municipal administrations between 2001 and 2016.

### 3.2 Policies pursued, 2001–04

In 2001, Suplicy took over as mayor and Eduardo Jorge was again appointed as Municipal Health Secretary. At that time, while the SUS user population was concentrated in the periphery, the supply of public health facilities and services was still predominantly allocated to the more central, older areas of the city. That is, SUS user populations living in areas that enjoyed better socioeconomic indicators were favoured by better service supply than those living in peripheral areas (Coelho and Silva 2007).

Eduardo Jorge's arrival at the Municipal Health Secretariat brought a series of important changes to this situation. He resumed the SUS project that started during the Erundina administration, beginning with the creation of 41 health districts, which were later incorporated into the city's 31 borough administrations.<sup>9</sup> At the same time as this structure was being set up, Jorge invested in expanding the FHP, at the heart of national policy on primary care. Family health teams comprised of a medical general practitioner, nurses, and community health workers delivered a wide range of comprehensive and preventive health-care services to defined local populations (approximately 3,400 individuals).

When Jorge took over the Municipal Health Secretariat, there were some 180 teams and his plan was to increase their number tenfold, to the order of 1,700 teams by 2004. However, the Fiscal Responsibility Act, enacted in May 2000, posed a serious obstacle to this plan. According to the rules of the Act, municipal expenditure on active and inactive personnel cannot exceed 60 per cent of its net current income, and the municipality had already practically reached this limit. Faced with this constraint, Jorge chose to implement '*convênios*' (service agreements) with private OSSs, several of which already provided primary care services in the municipality. Under these agreements, a government agency disbursed funds to an OSS that had committed to perform the activities contained in the work plan and, later, would account for the use of these resources. This solution resulted in an increased supply of services without qualifying as direct hiring.

By 2002, when Eduardo Jorge left the Municipal Health Secretariat,<sup>10</sup> the number of teams had more than doubled. This expansion was made possible by *convênios* signed with 12 OSSs that had a tradition of social assistance and health service provision.

By the end of Marta Suplicy's administration, in 2004, the number of primary health care centres (PHCCs) had grown by 70 per cent. The criterion used for distributing these facilities was 'one for every 20,000 users, with no facility being more than 30 minutes away by foot from the user's residence.'<sup>11</sup> In placing these centres, priority was given to areas where health facilities were scarcest and where health, education, and income indicators were worst. These measures helped, as will be seen in Section 4, to trigger a process that was to change the profile of health service distribution in the city of São Paulo.

The 2004 elections were polarised between Marta Suplicy of the PT and José Serra of the PSDB, former health minister for Brazilian President Fernando Henrique Cardoso. Health was a prominent topic in electoral debates, with José Serra winning the elections with 54.86 per cent of run-off election votes.

### 3.3 Policies pursued, 2005–08

In 2005, José Serra took over as mayor. He held the position from 2005 to 2006, when he ran for governor, leaving his deputy, Gilberto Kassab (from the DEM party – now allied with the PSDB) in his place.

Investment in the FHP continued and an important innovation was introduced: outpatient care facilities (*assistência médica ambulatorial* – AMAs). These facilities were intended to meet demand for low-complexity urgent and emergency care cases, which the public system was unable to cope with, and which was acknowledged to be a chronic problem that ended up encouraging these types of patients to turn to accident and emergency facilities in the hospital system.

Starting in 2005, the service agreements with OSSs for staffing the FHP indirectly via labour contracting were replaced with management contracts; a management tool largely used by the PSDB when it was at the helm of the federal and state governments. In these contracts pre-certified OSSs were chosen, based on public call processes, to manage public facilities and provide services that were pre-defined by health authorities, receiving government funding granted on the basis of results-based oversight.

This type of contract established a more demanding process than the *convênios* that had been used up to that point. These stricter demands applied to the health authority, which now had to plan what would be demanded from units, price the contracted services, and monitor the performance of these services on a quarterly basis; they also applied to the provider, who now had to deliver the previously agreed-upon results. These contracts also began to be used at AMAs. In 2007, 39 PHCCs and four AMAs were being managed under contracts of this kind.

Januário Montone took over the Municipal Health Secretariat in November 2007, and was tasked by Kassab with extending the OSS-administered management contract model. That task was to be facilitated by new regulations that the government had just managed

to enact through the Municipal Council, relaxing the OSS selection procedures and easing the requirements social health organisations had to meet in order to participate in the arrangement. This legislation was passed amidst heated debates between groups in favour of and against contracting OSSs.

These shifts in direction meant that between 2005 and 2008, important changes were made to the profile of the municipal public health system. From 2008 onwards, the city saw AMAs proliferate and the numbers of urgent and emergency appointments grow in all regions.

The 2008 elections were competed between the PT, PSDB, and DEM. Candidates from these three parties promised to expand the primary care network and FHP teams. Marta Suplicy moreover proposed strengthening the Municipal Health Council, while Geraldo Alckmin and Gilberto Kassab promised to add more OSS contracts. The dispute was heated between the three candidates in the first round of voting, with Kassab (DEM) taking 33.6 per cent of the vote, Suplicy (PT) 32.7 per cent, and Alckmin (PSDB) 22.48 per cent. Kassab won the run-off election with just over 60 per cent of the vote.

### 3.4 Policies pursued, 2009–12

From 2009 to 2012, Kassab and Montone continued as mayor and head of the Municipal Health Secretariat respectively throughout the entire administration. During Montone's mandate, outsourcing processes intensified and OSSs started to be engaged under contract to manage both health facilities and micro-regions. In his own words,

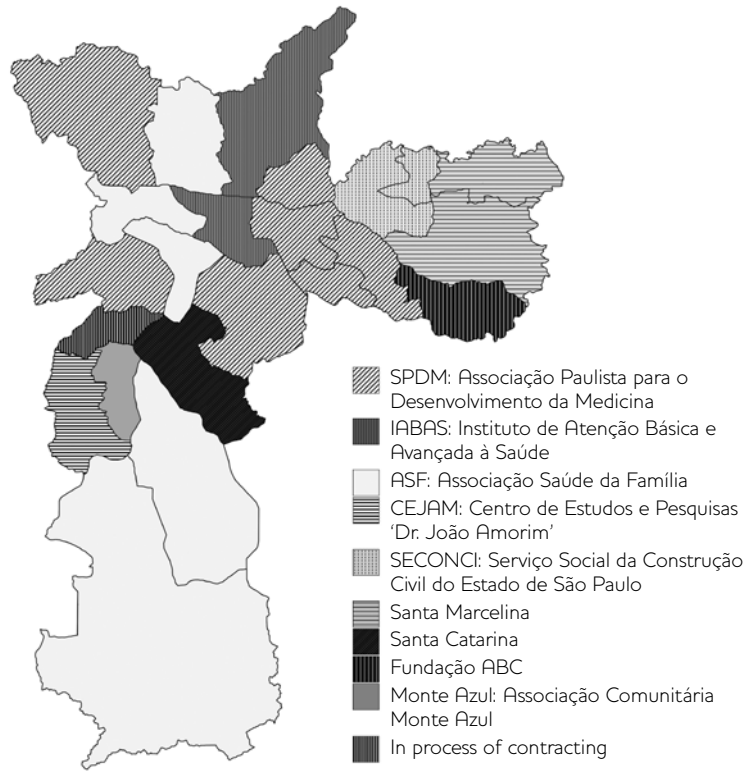
*I know of no other municipality in Brazil that has invested as much in partnering with non-profit enterprise as São Paulo. This was due not only to the city's enormous size, but also to the ongoing endeavour to develop this model, which had been started at the state level in 2001 and adopted by the capital in 2005.<sup>12</sup>*

Disputing the 2012 election were Fernando Haddad of the PT, ex-President Luiz Inácio Lula da Silva's former Minister of Education; José Serra (PSDB), once again running in the municipal election; and Celso Russomanno (Brazilian Republican Party), a reporter and host of popular TV programmes. While Serra was the ruling-party candidate, forced to defend and propose continuing Kassab's legacy, Haddad used party propaganda to criticise the PSDB candidate's health policy and OSS contracts, proposing that rounds of civil service exams be held to reinforce health civil servant staff, in addition to effectively decentralising management of the health system and strengthening mechanisms of control and social participation. Celso Russomanno did not present any health proposals. Haddad defeated Serra in run-off voting with 55.6 per cent of the vote.

### 3.5 Policies pursued, 2013–16

In 2013, Fernando Haddad (PT) took over as mayor and in 2015, Alexandre Padilha, the Health Secretary and a former Minister of Health in the national PT-led government of Dilma Rouseff,

Figure 2 OSSs responsible for territorial health-care system management in the municipality of São Paulo, 2017



Source Adapted from Municipal Health Secretariat/CEInfo, [www.prefeitura.sp.gov.br/cidade/secretarias/saude/aceso\\_a\\_informacao/index.php?p=178347](http://www.prefeitura.sp.gov.br/cidade/secretarias/saude/aceso_a_informacao/index.php?p=178347).

expedited migration of OSS contracts to a new management model aimed at promoting quality and guaranteeing better management accountability. With this, the four types of OSS contracts used up to that point – micro-region, municipal hospital management, boroughs, and emergency care contracts – began to be replaced with integrated health-care system contracts. At the time, a public call for bids was held for OSSs to apply to manage the 22 territorial systems that were then instituted. These contracts had a five-year term, with the work plan renewed every 12 months. At the same time, this innovation contradicted one of Haddad’s campaign promises to reduce the presence of OSSs in the city, and recovered the PT’s traditional stance on territorialisation, aimed at promoting intersectorality<sup>13</sup> based on a territorial focus. Figure 2 shows the OSSs responsible for these 22 territorial systems.

An expansion of the supply of emergency care units (*unidades de pronto atendimento* – UPAs) was also planned. The UPAs are somewhat more complex units than the AMAs and were launched in 2003, under a PT administration, as part of the National Urgent and Emergency Policy.

**Table 1** Number of public health facilities, municipality of São Paulo, 2000–16

Public health facilities	Mayor																
	Suplicy				Serra/Kassab				Kassab				Haddad				
	2000*	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016
Hospitals	51	50	53	51	51	52	53	53	55	53	55	55	54	54	49	54	54
PHCCs	135	225	237	236	382	392	407	407	416	434	438	439	442	443	454	449	451
AMAs <sup>14</sup>	0	0	0	0	0	10	33	55	116	130	131	133	139	134	133	53	42
UPAs	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	1	1

Note \* Entries start in 2000 to show the pre-existing figures.

Source Author's own, based on data from the Municipal Health Secretariat.

The election of 2016 was once again polarised between the PT and PSDB, with João Doria (PSDB) promising to increase basic health coverage in the city from 61 per cent to 70 per cent and to reduce waiting times for examinations and other more complex procedures. Doria was elected in the first round of voting with 53.29 per cent of the vote.

The distributive impacts of the policies described above are explored in Section 4.

#### **4 Changes in distribution of facilities and services**

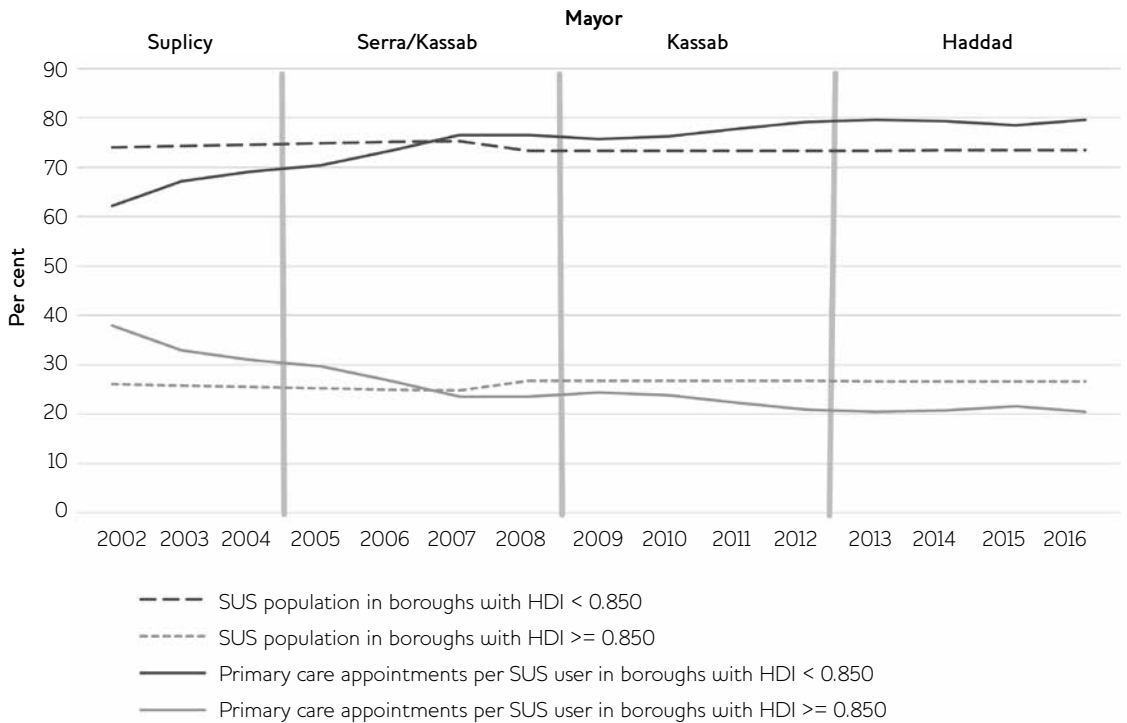
As mentioned in Sections 1 and 3, in 2001 there was a strong distributive bias in favour of central areas of the city, which also enjoyed the best socioeconomic and epidemiological indicators. In this section, evidence is sought on what impact the policies applied by the municipality between 2001 and 2016 had on that profile. To do this, we chose indicators that describe the distribution of health facilities and primary care services over the period: (1) provision of primary care appointments per year, and (2) percentage of live births with provision of seven or more antenatal appointments.

##### **4.1 Facilities**

Table 1 shows that health facilities, particularly the number of primary health care centres (PHCCs), expanded significantly during the period.

The Marta Suplicy administration saw substantial growth in PHCCs. These were FHP centres offering primary care through priority programmes and scheduled appointments. Under Serra and Kassab, growth was in the number of AMAs, which offered urgent and emergency care and low-complexity tests and treatment. Haddad introduced the UPAs. Expansion of the PHCCs was initially made feasible through service agreements, and later, starting in 2008, through management contracts with OSSs.

Figure 3 Percentage of primary care appointments offered to SUS population, grouped by borough HDI, municipality of São Paulo, 2002–16



Source Author's own, based on data from the Municipal Health Secretariat.

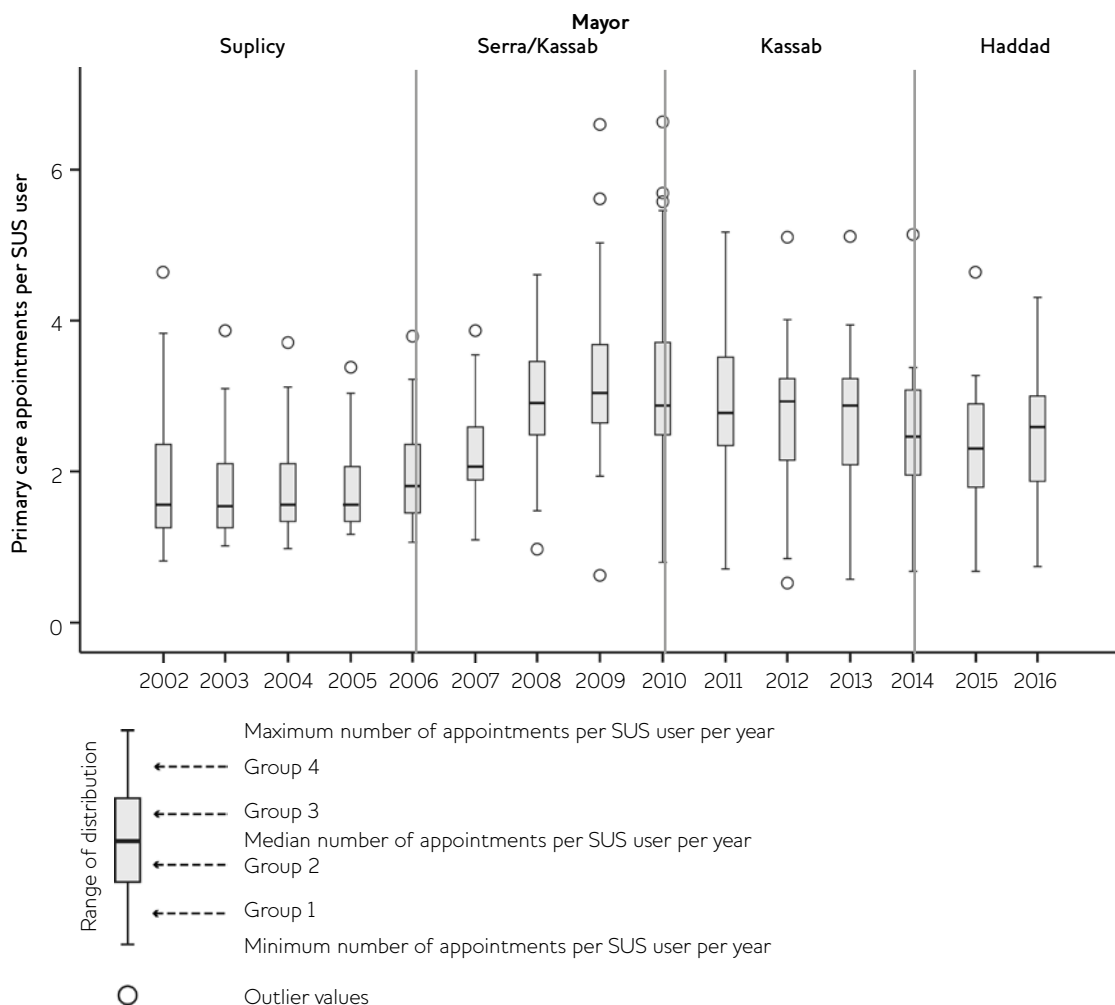
#### 4.2 Service supply

Figure 3 shows the percentage of primary care appointments offered to the population who exclusively used the SUS, grouped by the HDI of the borough they lived in. It can be seen that the percentage of SUS users living in boroughs with the worst indicators remained constant during the period, while the percentage of primary care offered to the SUS users in these low-HDI boroughs grew significantly.

The average number of primary care appointments per SUS user per year grew significantly in the 31 boroughs during the period, increasing from 1.8 in 2002 to 2.6 in 2016. Figure 4 visualises the distribution of primary care appointments during the period based on boxplot. It shows the 31 boroughs ordered by number of appointments per SUS user per year, from lowest to highest, and split into four equal groups – Group 1 includes the boroughs offering the lowest 25 per cent of appointments, Groups 2 and 3 the middle 50 per cent, and Group 4 the highest 25 per cent. These groups are represented along the range of distribution for each year in the period, with the median number of appointments shown by the black line in the grey box. It shows that in 2002, the median was below two primary care appointments, an amount corresponding to the parameter recommended by the Ministry of Health; while in 2016, over 50 per cent of boroughs offered appointments in excess of this parameter.<sup>15</sup>



Figure 4 Primary care appointments per SUS user per year in boroughs of the municipality of São Paulo, 2002–16



Source Author's own, based on data from the Municipal Health Secretariat.

Table 2 shows that, for the population of the municipality as a whole, the percentage of live births with provision of seven or more antenatal appointments increased by 24.1 per cent between 2001 and 2012. In this period, the boroughs in the first and second quartiles posted increases greater than the municipal mean. These increases in excess of the mean occurred during Marta Suplicy's administration and also, to a lesser degree, during the Serra/Kassab administration. As a result of that trend, by 2016, the situation had changed, with the values of the three lower quartiles converging strongly.

Overall, considering the profile of service distribution in 2001 among the boroughs ordered in quartiles by HDI, the fourth quartile can always be seen as better placed, followed by the third, second, and first quartiles. By 2016, the situation had changed, with the values of

**Table 2 Percentage of live births with provision of seven or more antenatal appointments, by quartile,\* municipality of São Paulo, 2001–16**

Municipality/ Quartile	Mayor								Variation (%)
	Suplicy		Serra/Kassab		Kassab		Haddad		
	2001 (%)	2004 (%)	2005 (%)	2008 (%)	2009 (%)	2012 (%)	2013 (%)	2016 (%)	2001–2016
Municipality	60.0	65.4	69.8	73.3	74.0	74.5	75.8	77.9	29.8
1st Quartile	51.5	58.7	65.5	69.9	71.5	71.0	72.2	75.3	46.3
2nd Quartile	58.0	63.7	67.0	70.5	71.3	74.0	75.2	77.6	33.7
3rd Quartile	61.9	67.5	72.0	74.3	73.7	73.6	75.1	77.0	24.3
4th Quartile	73.8	77.9	80.0	81.8	82.4	81.8	83.8	84.8	14.9

Notes Dates refer to the beginning and end of each mandate.

\* Quartiles represent boroughs grouped by HDI, as described in Section 2; lower quartiles include boroughs with low HDIs.

Source Author's own, based on data from the Municipal Health Secretariat.

the three lower quartiles converging. These results show that public health services expanded considerably during the period to areas of the municipality where socioeconomic conditions were worse.

### 5 Discussion and final remarks

This article contains an analysis of the primary care policies implemented in the municipality of São Paulo from 2001 to 2016. As can be seen above, the physical infrastructure of the SUS, particularly PHCCs and AMAs, expanded considerably over the period, as did the volume of primary care provided to the city's residents. The inequalities in access to those services were also found to have diminished, with rates of service delivery converging among the three quartiles of boroughs grouped by lower municipal HDIs. These results, as pointed out earlier, are not trivial and deserve attention as they represent a rather unusual pattern.

The supposition explored in this study is that these results were made possible by strong electoral competition and modest access to public health services in poor and densely populated areas. In this context, the promise of improving services for the poor represents an attractive programme that could garner votes for parties with different ideological orientations.

The institutional conditions found in the city – financial and managerial capacity located inside the Municipal Health Secretariat, and the presence of OSSs already delivering primary care – explain 'how' this programme could be achieved. In short, the presence of claims for answerability (from the poor to politicians and from public officials to OSSs) and the possibility of sanctions (losing elections and contracts) at both the political and managerial levels played a crucial role in facilitating the expansion of public primary health services in the poor

peripheries of São Paulo. The closeness of the contest waged between the PT and the PSDB/DEM alliance for the municipal government is clear from the electoral results: none of the successful candidates took more than 61 per cent of votes in the four run-off ballots. Added to this is São Paulo's importance in Brazilian national politics and the value the parties ascribe to their electoral performance in the city. There is also the politicians' aspiration to leave their mark on the history of public health in the country's leading economic and cultural hub.

Eduardo Jorge, Marta Suplicy's Health Secretary, strongly supported the FHP, investing in primary health care and betting on the possible electoral returns that might accrue from a programme implemented quickly and that would reach a considerable portion of the population, particularly in the city's underserved areas. In order to carry that plan forward and in the face of the limits on direct hiring imposed by the Fiscal Responsibility Act, he invested in expanding installed capacity and signing agreements with 12 OSSs, several of which had already operated in the city's primary care programmes.

The Serra and Kassab administrations continued to invest in the FHP, but the Serra/Kassab flagship was the AMAs, which concentrated on urgent and emergency care, with a view to both electoral gains from decongesting and rationalising the service network and an SUS that was more closely aligned with the model of care applied by the private sector. The underlying alignment of interests supporting this project rested on strengthening service supply via OSSs.

The Haddad administration maintained investment in the FHP and also, contrary to electoral campaign promises, the alliance with OSSs. However, it sought to redefine the management model, focusing it more on the concept of integrated management of the territory, which sounded more like a PT-type platform.

To better understand how managerial accountability worked, it should be considered that outsourcing made it easier to both hire new staff when health units were opened or expanded and to lay off staff when performance was not satisfactory, or even to hire staff in the case of high turnover. This mechanism made an important contribution to guaranteeing that there were health professionals, and especially physicians, in the periphery and hard-to-access areas of the city. The fact that health-care providers linked to these partnerships had more incentive to accurately deliver, as their contracts were dependent on achieving pre-defined goals, was also a significant factor. Finally, the Municipal Health Secretariat invested in establishing management capacity in relation to contracts.

In 2001, the Municipal Health Secretariat expanded the FHP, initially using service agreements (*convênios*), a looser form of contract and a type of accountability mechanism focused on accountability for money. In 2005, at the start of the Serra administration, these agreements began

to be replaced by performance contracts with OSSs, which introduced a new logic into the relationship between public managers and providers, based on the possibility of these organisations managing equipment and providing public services. At that point, contracts focused on service outputs and indicators. Finally, in 2015, the various types of management contracts in effect were replaced by those where a single OSS would manage the contracts for a health region. The rationale was to shift from a service-centred evaluation to accountability for health outcomes in a given territory. In parallel, investments were made in establishing management capacity in relation to these contracts, with the creation of a Technical Center for Contracting Health Services to plan, define, and assess OSS contracts and performance in the regions.

These movements to expand service supply by offering continuing care, urgent care, and emergency care to poor peripheral areas of the city were aligned with the programmes of left-wing and centrist parties, which since the 1980s had called attention to the need to expand the offer of public health-care services to those areas. In the 2000s, at a moment where it was important for the PT, PSDB, and DEM to ensure the votes of the poor, this flagship appeared as a political priority. Nevertheless, political priority alone does not explain the distributive changes described in this article. It was the combination of the political environment with the existence of experienced OSSs in the city, as well as financial and managerial capacity in the Municipal Health Secretariat that worked together to promote the changes described. Demands for answerability – from the poor to politicians and from public officials to OSSs – and the existence of sanctions – the possibility of losing elections and contracts – were core to explaining how the changes described in the distributive profile were made possible.

In short, if the presence of political accountability mechanisms contributed to making the health equity agenda attractive to municipal politicians, it was the ability of these same politicians along with the Municipal Health Secretariat to mobilise OSSs – several of which were already present in the city and had know-how in relation to implementing primary care programmes – and hold them accountable under service delivery contracts that made it feasible to expand the supply of services to areas on the periphery of the city. Ultimately, these accountability mechanisms make it possible to understand why and how the new policies were adopted and were able to contribute to the distributive changes examined in this article.

### Notes

- \* This article presents the results of the Equity and Contracting of Services in the SUS project, supported by the São Paulo Research Foundation (FAPESP) – FAPESP 2013/07616-7, and the Accountability Politics of Reducing Health Inequities: Learning from Brazil and Mozambique project, supported by the Department for International Development (DFID) and the Economic and Social Research Council (ESRC). The projects are coordinated by the

Citizenship, Health and Development team at the Brazilian Center for Analysis and Planning (CEBRAP), the Center for Metropolitan Studies (CEM), Brazil and the Institute of Development Studies (IDS), UK. The opinions, hypotheses and conclusions or recommendations expressed herein are the responsibility of the author and do not necessarily reflect the visions of FAPESP, DFID, or ESRC.

- † This article was presented at the Unpicking Power and Politics for Transformative Change: Towards Accountability for Health Equity workshop at IDS in July 2017. I am thankful for the valuable comments I received at that workshop from the participants in the Accountability Responses to the Spread of Health Markets panel, and to the external and internal reviewers of this *IDS Bulletin*.
- 1 In 2010, CEBRAP's Citizenship, Health and Development team joined CEM's project Inequality Trajectories in Brazil, which revisited 50 years of official data produced by the national census. The project team agreed to use the notion of inequalities instead of inequities, as it avoids the normative content of the concept of equity, which is highly disputed in political debates in Brazil. The team use the term 'health inequalities' to refer to the differences, in descriptive terms, in levels of health among population groups identified on the basis of socioeconomic, gender, race, colour, and ethnic characteristics.
  - 2 By law the federal government and the municipalities are obliged to spend 15 per cent of their revenues on health promotion and service delivery, while states are obliged to spend 12 per cent of their revenue.
  - 3 Information on the number of SUS users is estimated using data on the number of people with private health insurance. An SUS user does not have access to private health insurance. Information on private health insurance is available from the Agência Nacional de Saúde Suplementar (National Agency of Supplementary Health).
  - 4 For the period 2001–16, changes to how official expenditure was registered hindered construction of historical series showing total amounts spent by the three spheres of government on health in the municipality of São Paulo. Nevertheless, we know that between 1995 and 2010, health-care spending in Brazil rose from 6.7 per cent to 8.9 per cent of gross domestic product (GDP), with the public sector portion of that total rising from 43 per cent to 47 per cent. In addition, the amount spent on primary care grew from 10 per cent of total public sector spending in 1995, to around 18 per cent in 2011 (Mendes and Marques 2014). Consolidated data on São Paulo for the period 2013–15 show stability in expenditure, even with a fiscal crisis occurring, and primary care received 13 per cent of total expenditure, which is a significant amount when it is noted that São Paulo holds the highest concentration of services for high-complexity care in Brazil (Xavier 2017).
  - 5 In informal conversations, it is usual to hear that the services provided by private not-for-profit social health organisations (*organizações sociais de saúde* – OSSs) in São Paulo are more expensive than direct administration services. The little work that has tested this relationship suggests that greater expenditure is accompanied by gains in

- efficiency, which would be reflected in lower costs per unit offered (Barradas and Mendes 2007; Medici 2011). These observations are interesting since they are in opposition to the international debate, which associates the use of outsourcing with constraining costs.
- 6 The SUS population is calculated from the population who exclusively use the SUS, which means those without private health insurance. For the Municipality of São Paulo, see: [www.prefeitura.sp.gov.br/cidade/secretarias/upload/saude/arquivos/boletimeletronico/n01popsus.pdf](http://www.prefeitura.sp.gov.br/cidade/secretarias/upload/saude/arquivos/boletimeletronico/n01popsus.pdf).
  - 7 The information is provided by the Ministry of Health and the São Paulo Municipal Health Secretariat.
  - 8 *Qualis* was implemented in the East Zone by Casa de Saúde Santa Marcelina, in the North and Southeast Zones by Fundação Zerbini, and in the South Zone by Universidade Santo Amaro and Congregação Santa Catarina (Coelho *et al.* 2014).
  - 9 According to the 2010 census, these boroughs had populations ranging from 139,441 to 594,930.
  - 10 Gonzalo Vecina took over as Health Secretary when Jorge left.
  - 11 Interview with Gonzalo Vecina, 16 November 2011.
  - 12 <http://saudeweb.com.br/22516/gestao-com-oss-e-ppp-e-modelo-de-sucesso-diz-januario-montone/>.
  - 13 Intersectorality is an approach that is meant to bring together different policy areas such as health, sanitation, education, urban policies, environment and so forth. The idea is to break the strong vertical hierarchy present in these policies (where decisions in each policy area are made independently) and promote more horizontal connections between them.
  - 14 AMAs here include Ambulatório Médico de Especialidades (AMEs – outpatient facilities designed to handle medium-complexity cases in various specialities). In 2012, there were 16 AMEs in the city.
  - 15 The Friedman Test shows that the distribution of primary care appointments per SUS user in the boroughs in 2002 was different to the distribution in 2012.

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# Making Private Health Care Accountable: Mobilising Civil Society and Ethical Doctors in India\*

Abhay Shukla, Abhijit More and Shweta Marathe

**Abstract** Though the private sector dominates health care in India, it lacks social accountability and effective regulation. Hence, health activists and health-care professionals have adopted a three-pronged approach of mobilising civil society for patients' rights, networking with ethical doctors towards social responsiveness, and advocating with government for accountable regulation. Health movement strategies adopted mainly in Maharashtra State include organising a regional public hearing in collaboration with the National Human Rights Commission; developing 'Citizen–Doctor Forums'; mobilising citizens around patients' rights through a 'people's poll'; and campaigning for people-oriented regulatory legislation. A national network of doctors is also being developed to promote ethical health care. Key lessons include: identifying patient rights as popular idiom for citizens' mobilisation, relevance of ethical voices within the medical profession to complement social accountability of private health care, potential of moving beyond citizen–doctor adversarial positions to promote accountable health-care options, and placing participatory social regulation on the agenda.

**Keywords:** private health care, social accountability, medical ethics, patients' rights, medical malpractice, dissenting diagnosis, health movement, ethical doctors, Citizen–Doctor Forum, social regulation.

## 1 Introduction

The vision of Universal Health Care (UHC) involving public as well as private health-care providers is gaining traction in countries across the globe. However, the quality of care currently delivered by private health-care providers in low- and middle-income countries (LMICs) remains an issue of concern; two recent *Lancet* global health series have dealt with this issue in detail. The series on *Right Care* has emphasised the paradoxical coexistence of failure to deliver needed health-care services (underuse), alongside delivery of unnecessary health-care

services (overuse), with one of the drivers being market-based systems of health care linked with fee-for-service-type incentive systems for providers (Saini *et al.* 2017a, 2017b). The *Lancet* series *Universal Health Coverage: Markets, Profit, and the Public Good* notes that effective regulation of the private medical sector in LMICs is rare, and governments in most such countries lack capacity to provide effective regulation, contributing to serious concerns about the failure of this sector to deliver the expected social benefit (Morgan, Ensor and Waters 2016; Montagu and Goodman 2016; Horton and Clark 2016).

Within this global context, the private health-care sector in India has grown rapidly since the 1990s, largely linked with inadequate allocation of resources for public health services, and a policy environment viewing health care as a 'business opportunity' while promoting India as a favourable destination for investment in health care (Hooda 2015). Although the private sector dominates the health sector in India with the overwhelming majority of patients accessing it – 80 per cent of outpatient care and 60 per cent of inpatient care (Government of India 2015) – today it is very weakly regulated from the perspective of users' concerns. Although certain frameworks exist for social accountability of public health services in India (Government of India 2005), accountability of the private medical sector is yet to be institutionalised, with frequent complaints of patients' rights being denied.

Here we encounter a paradox, due to the gap between systematically gathered scientific evidence, and widespread, though scattered and often undocumented, social experience. Existing large-scale quantitative surveys related to the health sector in India are focused on public health services and only peripherally deal with private providers, and there is a dearth of systematic studies on the private medical sector. However, individual anecdotes on medical malpractices in this sector are extremely widespread. In this situation, a few exceptional studies such as the book *Dissenting Diagnosis* (Gadre and Shukla 2016), based on testimonies from 78 doctors across India, stand out due to striking testimonies regarding malpractices in the private medical sector provided by 'whistle-blower' doctors.<sup>1</sup> By documenting systematically the decline of ethical practices in the medical profession, and the challenges faced by those doctors committed to a 'rational' practice, this book brought to light the current extent of medical malpractice in India's private health-care sector.

The publication of *Dissenting Diagnosis* and subsequent public responses exemplify how groups of health-care professionals and civil society activists have catalysed social action to demand greater accountability from private medical providers in India. Key issues highlighted in this process include price gauging, over-priced diagnostics, collusion between doctors and diagnostic facilities, extremely high costs of private medical education, and serious concerns regarding quality of care. Innovative social action in Maharashtra State, where this story is based, required the involvement of three major groups of stakeholders: civil

society organisations, government, and the medical profession. In the following sections, the efforts made by a range of civil society networks and actors for promoting accountability and regulation of the private sector are outlined. These efforts involved a three-pronged strategy of mobilising civil society organisations, networking with ethical, rational doctors, and advocating with the state for regulation of the private medical sector. This article presents the lessons learned through this process and the challenges faced, and offers broader perspectives that have emerged.

## **2 SATHI and the health movement: a three-pronged approach**

SATHI (Support for Advocacy and Training to Health Initiatives), a health sector civil society organisation based in Western India, has been contributing to strategies of the health movement for social accountability and responsiveness of private medical providers for the last decade. This strategy has been based on a combination of three complementary approaches: enabling civil society organisations and activists to demand protection of patients' rights in the private medical sector; creating a voice in favour of rational health sector regulation within the medical profession; and engaging with the state government to promote and shape regulation of the private medical sector, with emphasis on social accountability and participation.

Here we need to recognise the unique 'expert' status of the medical profession (perhaps regarded as more exclusive than any other profession), based on monopolies of knowledge (Foucault 1973). Traditionally, key aspects of regulation of medical care have been entrusted to bodies such as medical councils, with the strong expectation that the profession would self-regulate in accordance with the guidance of these councils (Davies 2007). The information asymmetry and associated power relationships between patients and health-care providers are well known, which has implications for the role of social contracts in shaping regulatory processes, particularly in LMIC contexts (Bloom, Standing and Lloyd 2008).

A recent parliamentary committee report in India on the Medical Council of India concluded that 'self-regulation alone may not work because medical associations have fiercely protected their turf, and bodies consisting primarily of members from the same profession are unlikely to promote and protect public interest over their self-interest' (Parliament of India 2016: 18). Given this context, not only to influence formulation of regulation towards social responsiveness, but also to ensure effective implementation of such regulation, sections of doctors who take a public stand in favour of ethics and social accountability in the profession have a critical role to play. This is the justification for SATHI's diversified strategy, which includes developing a network of such 'ethical doctors'<sup>2</sup> to neutralise the dominant 'anti-regulation' stance of mainstream medical associations, which reflects widespread scepticism regarding regulation amongst ordinary medical practitioners. It seems difficult to ensure regulation of the private medical sector

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**Box 1 Key actors in campaign and advocacy processes****Support for Advocacy and Training to Health Initiatives**

**(SATHI)**<sup>3</sup> is a Maharashtra-based civil society organisation working in the health sector since 1998, which has been a pioneer in the area of promoting community and social action for health rights in India. Through its consistent promotion of participatory action and advocacy together with policy research, SATHI has been able to give some prominence to the issue of patients' rights and regulation of the private medical sector within Maharashtra State, and also at national level.

**Jan Arogya Abhiyan (JAA)**, the Maharashtra State chapter of the People's Health Movement – India,<sup>4</sup> is a diverse network of civil society organisations, health activists, doctors, and public health professionals. This coalition has been mobilising people and advocating with decision makers for the promotion of patients' rights in private hospitals and related regulation, for over a decade.

**Alliance of Doctors for Ethical Healthcare (ADEH)**<sup>5</sup> is a pan-Indian network of doctors who are committed to promoting ethical and rational health care, and who are critical of widespread medical malpractices linked with the unregulated nature of the private health sector in India.

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without the bringing together of various strands of participatory action. These include social mobilisation for patient rights, and a stand being taken by a section of medical professionals in favour of ethical practice and appropriate regulation. Box 1 briefly describes three key actors – SATHI, Jan Arogya Abhiyan (JAA, or the People's Health Movement (PHM) – Maharashtra), and the Alliance of Doctors for Ethical Healthcare (ADEH) – which have played key roles in the campaigns and advocacy processes.

**3 Initiatives to mobilise citizens and facilitate participatory dialogue towards responsive health care**

Maharashtra is the second largest state in India, with a dynamic economy and a highly commercialised, predominantly private health-care sector. Given the lack of regulation of this large and powerful sector, JAA has tried to broaden the technical issue of medical regulation (traditionally an exclusive domain of health-care experts, doctors, and health officials) to include the larger public issue of social accountability. This has been achieved by developing popular discourse around patients' rights.

In India, the regulation of health-care professionals such as doctors (from modern medicine as well as systems such as Ayurveda and homeopathy), dentists, nurses, pharmacists, etc. is carried out through statutory self-regulatory bodies. At the national level, these include

institutions such as the Medical Council of India, the Central Council for Indian Medicine (CCIM), the Dental Council of India, the Indian Nursing Council (INC), and the Pharmacy Council of India (PCI). There are corresponding professional councils in every state. Such councils are highly prone to ‘expert capture’; for example, the national- and state-level medical councils consist primarily of representatives of doctors and health officials, and these councils are widely known for bias towards protecting medical professionals. They are not known for their responsiveness to patient complaints.

In this context, JAA has adopted the following strategies to promote social accountability of the private medical sector (Phadke *et al.* 2013): (1) bringing hitherto unexposed malpractices of private hospitals into the public domain, by documenting and publicising such malpractices and organising campaigns for patients’ rights. One example of this is the documentation of cases of violations of patients’ rights as part of the National Human Rights Commission (NHRC) hearing, described later in this section; (2) challenging the monopoly of medical professionals over regulation, while asserting the role of patients as important stakeholders, during dialogue with decision makers and the medical association; (3) mobilising citizens to demand participatory regulatory systems including grievance redressal mechanisms, as an alternative to bureaucratic command and control type of regulatory systems;<sup>6</sup> and finally, (4) promoting dialogue and the alliance of active citizens with sections of rational, socially responsive doctors (for example, through the practice of Citizen–Doctor Forums). The JAA’s work has prioritised doctors, amongst other possible allies within the medical professions, as they are the most vocal, organised, and politically influential section of health-care professionals in India. These strategies have been developed to engage doctors, as powerful health systems actors, to achieve health policy change.

Certain key actions by JAA in recent years, which exemplify the above-mentioned strategies, are described here as examples.

### **3.1 Public hearing organised by the People’s Health Movement in collaboration with the National Human Rights Commission of India**

There is growing consensus at international level that all patients have some fundamental rights and that ‘patient rights are human rights’. Obligations to the patient by physicians, health-care providers, and the state have taken the shape of Patients’ Rights Charters in various contexts. Patients’ rights are violated to a substantial extent in a country like India, where the public health-care system is deficient owing to inadequate resources, compounded by the highly commercialised and dominant private health-care sector which lacks effective regulatory frameworks and legally binding provisions for patients’ rights. Patients are often denied free, quality health care in the public health system and are forced to seek costly and often irrational care<sup>7</sup> from private providers. As a result, in India, nearly 50 million people are pushed into poverty every year due to catastrophic expenditure on health care

(WHO and World Bank 2017). In this setting, basic patients' rights such as the right to emergency care, the right to information, the right to informed consent, and the right to a second opinion are frequently violated.

Given this context, the People's Health Movement – India, of which JAA is an active state constituent, approached the NHRC in 2015, to review the human rights violations of patients in both the public and private health-care sectors. As a result, the NHRC and People's Health Movement – India collaboratively organised a Western region public hearing on the Right to Health Care in January 2016 to make an assessment of human rights violations in public health facilities, private hospitals, and public–private partnership (PPP) health-care arrangements, while drawing attention towards key systemic and policy issues and proposing recommendations for the protection of health rights (NHRC 2015). During the public hearing, testimonies concerning the serious denial of the right to health care were heard by a panel consisting of the Commission members and health experts, in the presence of various state health officials who had to offer appropriate explanations. Consequently, the NHRC issued a set of recommendations to ensure corrective actions (NHRC 2016).

During the hearing, the NHRC did not hear cases related to private hospitals, citing its lack of legal jurisdiction over the private medical sector; however, the Commission took serious note of the failure of the medical councils, lack of regulatory framework for private hospitals, and the absence of a grievance redressal mechanism for patients (*ibid.*). The NHRC recommended that state governments should either set up a new regulatory body for private hospitals or amend the Medical Council Act to empower medical councils to regulate private hospitals (Medical Dialogues 2016). The public hearing generated significant media attention (*The Times of India* 2016), while galvanising the health movement on the theme of patients' rights in the private sector. Subsequently, the NHRC has initiated the development of a Patients' Rights Charter, to be applicable to all public and private hospitals. What is clear from this case is the potential of mobilising human rights commissions to engage in the issue of patients' rights, particularly in those LMICs where national human rights commissions are both functional and active.

### **3.2 Fostering dialogue through 'Citizen–Doctor Forums'**

Health activists view the current violation of patients' rights in private hospitals as being grounded in systemic distortions linked with the overall commercialisation of health care, and not just the individual profit-motive of private providers. Hence, while developing processes for people-oriented reform of the health sector, it is considered necessary to move beyond adversarial 'patients vs doctors'-type positions, and to develop collaborative dialogue with those sections amenable to reform. SATHI team members, together with other civil society activists, have initiated Citizen–Doctor Forums in the metropolitan cities of

Mumbai and Pune in Maharashtra, by bringing together active citizens and doctors supportive of rational, ethical health care. The Mumbai Citizen–Doctor Forum has been providing technical and social support to patients who have suffered from serious medical malpractices,<sup>8</sup> and has expressed public critique of the mishandling of patients’ grievances by the Maharashtra Medical Council (MMC), while demanding major reforms within this body. The Pune Citizen–Doctor Forum (PCDF) has created a database of patient-friendly doctors from Pune City based on certain criteria, with the aim of offering lists of such doctors to patients in need. This is accompanied by the development of a web-based platform which can be used by patients to suggest names and provide feedback on doctors whom they have found to be patient-friendly.<sup>9</sup> The PCDF also periodically organises discussions between citizens and doctors on key policy issues related to health care.

### **3.3 The ‘Patients’ Voice, Citizens’ Initiative’ campaign**

The ‘Patients’ Voice, Citizens’ Initiative’ campaign (Voice of Patients 2017) was launched by JAA in mid-2017, and is centred around a civil society-based public poll in the Pune district of Maharashtra. Citizens were approached to cast their vote on three questions, focused on expected action by the state government related to the regulation of private hospitals; steps to improve the quality of care in public hospitals; and the enactment of legislation to protect patients’ rights. Activists reached out to more than 21,000 people at nearly 100 different locations, who agreed to cast their vote. A wide social spectrum was covered in the voting process, ranging from unorganised sector workers to government employees, doctors, nurses, and middle-class professionals. Over 99 per cent of the voters expressed their support for the protection of patients’ rights, the regulation and standardisation of private hospitals, along with improved quality of care in public hospitals (Sandilya 2017). The campaign received widespread publicity in the media, and the results were shared with members of the Legislative Assembly, the health minister and the chief minister of the state. JAA activists used the results of this poll for legislative advocacy during the State Assembly session in December 2017, and to convince a large number of elected representatives with regard to the widespread popular support for regulation of private hospitals, and the need for state legislation to ensure such regulation.

This campaign was another unique example of public outreach, which generated widespread popular awareness while documenting dissatisfaction amongst ordinary people regarding private and public health-care services. The idiom ‘people’s poll’ found strong resonance amongst health activists, students, and active citizens who volunteered to conduct the polling process, while the simple act of voting generated awareness amongst the thousands of people who participated. This campaign also sensitised political representatives, who usually consider health care as a non-issue in a country such as India.



#### **4 Advocacy with the state for accountable, people-oriented regulation of the private medical sector**

Advocacy for improved accountability of the private medical sector to both patients and citizens is a complex process, with no clear fulcrum for rights-based activism. This is distinct from public health system accountability actors, where there can be a basis for demanding entitlements within legal and policy frameworks at the national level (Phadke *et al.* 2013). Compared to the somewhat technical approach to regulating private medical providers, the demand to protect patients' rights in private hospitals has broad, popular appeal. Given this context, JAA organised a 'Patients' Rights Convention' in Pune City in July 2009 where citizens and civil society groups presented cases of patients' rights violations in private hospitals. Representatives of the Indian Medical Association (IMA) and the Hospital Owners' Association were invited to respond (Express News Service 2009). When representatives of doctors and hospitals were exposed to organised public opinion under the gaze of the media, they publicly agreed to respect patients' rights. Taking this lead forward, JAA conducted several rounds of discussion with the IMA resulting in the formulation of the consensus 'Joint Charter of Patients' Rights and Responsibilities' (see Box 2), which was released in a joint press conference (*The Times of India* 2010). Although in the absence of a broader regulatory policy and legal framework, this Charter could not be implemented widely (Phadke *et al.* 2013), it became an important reference document for future advocacy, helping to reduce the resistance of the medical associations to accepting patients' rights in principle.

In 2010, the Parliament of India passed the Clinical Establishment Act (CEA) to regulate clinical establishments in both the public and private sector (*Gazette of India* 2010) with certain positive features such as the publication of Standard Treatment Guidelines, mandatory display of rates for services, and the standardisation of rates. In addition, this act created the multi-stakeholder Clinical Establishment Council to agree to both rules and generalised standards in the sector. However, the CEA of 2010 was not sufficiently comprehensive. For example, it did not mention the Charter of Patients' Rights, nor did it offer a grievance redressal mechanism. Furthermore, it created an over-centralisation of standard-setting procedures (Phadke 2010). Given this context, JAA demanded that the state government of Maharashtra should enact its own state-specific CEA by incorporating positive features of the national act, while adding key provisions to protect patients' rights, including grievance redressal mechanisms, and removing certain impractical provisions which would be unfair to doctors. To press for this demand, JAA organised mass demonstrations during Legislative Assembly sessions in 2012 and 2013 (*The Times of India* 2012), supplemented by advocacy with political representatives and submission of a parallel draft bill to the Maharashtra government. These efforts led the Health Minister of Maharashtra to form a multi-stakeholder drafting committee to prepare a 'Maharashtra Clinical Establishment Bill'<sup>10</sup> (*The Times of India* 2013).



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**Box 2 Key provisions in the ‘Joint Charter of Patients’ Rights and Responsibilities’**
**Patients’ rights**

- 1 Right to emergency medical care
- 2 Right to information and medical records
- 3 Right to informed consent
- 4 Right to confidentiality
- 5 Right to second opinion
- 6 Rights to respect human dignity and privacy
- 7 Right to non-discrimination
- 8 Right to choose alternative treatment if options are available
- 9 Right to make suggestions/complaints and seek redressal of grievances
- 10 Compliance with statutory guidelines for biomedical research and clinical trials involving patients
- 11 Compliance with provision of free beds in charitable trust hospitals for poor patients.

**Patients’ responsibilities**

- 1 Provide health-related information
- 2 Cooperate with doctors during examination, treatment
- 3 Follow all medical instructions
- 4 Pay hospital’s agreed fees on time
- 5 Respect dignity of doctors and other hospital staff
- 6 Never resort to violence against health-care providers.

Source: Samiti (2015).

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JAA adopted a two-pronged approach of working within the committee, while also promoting wider social mobilisation for appropriate regulatory provisions (*Maharashtra Times* 2014). This ensured that key provisions were incorporated in the draft bill including the Charter of Patients’ Rights, rate transparency, a district-level multi-stakeholder appellate body with representation to civil society groups, and a grievance redressal mechanism. Provisions for rate standardisation were

met with stiff resistance from representatives of medical associations in the drafting committee and were not included in the final draft. However, the much-negotiated bill has now been put into cold storage by the state government after a change of political regimes at both national and state levels following the 2014 elections. This has forced JAA to adopt new strategies for social mobilisation in this uphill struggle, some of which have been discussed in Section 3.

### **5 Networking doctors to promote ethical health care**

When *Dissenting Diagnosis* was published (Gadre and Shukla 2016), it was well received by certain sections of doctors and formed the backdrop to the creation of the Alliance of Doctors for Ethical Healthcare (ADEH). A small but significant group of physicians were attracted to the objectives of the ADEH, since it provided a much-needed platform to raise their concerns. These doctors, mostly practising in the private sector, realised that there are many scattered 'voices of conscience' amongst doctors within the sea of commercialisation, which can come together and support each other. Hundreds of doctors from various parts of India have joined ADEH as an emerging national network of doctors committed to promoting ethical and rational health care. Many of them are facing their own survival struggles, since they refuse to join the commercial bandwagon which is based on unethical practices such as kickbacks for patient referral. Senior practising doctors from various states (such as Punjab, Kerala, Maharashtra, West Bengal, Delhi) have signed onto a declaration of the ADEH network, and have begun to take a public stand on key policy issues concerning both the practice of medicine and the conduct of medical professionals.

Some noteworthy interventions by ADEH include initiating public demand for reform and the restructuring of the Medical Council of India; providing technical inputs to the National Pharmaceutical Pricing Authority (NPPA) of India towards fixing the ceiling price of coronary stents and other medical devices; and submitting a range of suggestions to the central government regarding the draft 'National Medical Commission' bill. ADEH is emerging as a distinctive network of doctors articulating an alternative voice from within the medical profession, while working for major reforms in the health-care sector. The ADEH is providing a new platform for medical professionals who choose not to support the conventional lobbying adopted by colleagues associated with doctor-centric mainstream medical associations. By networking with small but socially significant sections of doctors who seek health system reforms, ADEH can complement wider civil society social mobilisation around accountability and the responsiveness of the private medical sector in India today.

### **6 Discussion**

Regulation of the private medical sector has generally been viewed from the lens of state-led policy. We argue that this top-down perspective needs to be strongly complemented by a bottom-up view of care delivered by the private sector, based on the experiences of

patients and citizens concerned with the accountability of care, as well as the concerns of doctors struggling to reconcile ethical medicine with the realities of highly commercialised and market-driven health care. To effectively regulate the private medical sector to ensure its responsiveness to social concerns, state regulation is essential, but needs to be complemented by participatory action.

Participatory initiatives over the last decade in Maharashtra State yield significant lessons about how such processes might be promoted at a national level in a country such as India, which has a large, dominant, heterogeneous, and poorly regulated private medical sector. These experiences can also enrich conceptual health system frameworks, through emerging approaches to accountability in regulatory bodies and the role of participatory, social regulation. Key insights and potential approaches emerging from this experience are outlined in the following discussion.

### **6.1 Patients' rights as a popular idiom for mobilisation around the regulation of the private medical sector**

*The demand for the protection of patients' rights could be an important fulcrum for social mobilisation around regulation of the private medical sector.* Raising demand for including provisions to protect patients' rights in any regulatory framework concerning the private medical sector can help orient regulatory reform around patient-centred accountability (Phadke *et al.* 2013). Here, the trans-class, multi-sectional nature of demand for patients' rights is a significant strength. Unlike issues related to land, livelihoods, and basic social services which are largely limited to lower-income sections of the population, the demand for patients' rights is of a cross-cutting nature, which can attract support from sections of the middle class who have significant voice and political leverage.

### **6.2 The need for multiple platforms to work with diverse constituencies related to the private medical sector**

Social actors working towards greater accountability and responsiveness of the private medical sector need distinctive organisational forms for engaging with diverse constituencies. JAA works with civil society organisations and citizens, the ADEH works with sections of doctors, while Citizen–Doctor Forums combine both types of members. The SATHI team works centrally with all three groups in collaboration with many other members and organisations. This helps maintain a common thread of accountability and ethics, while developing each platform in concordance with the perspectives and priorities of concerned constituents.

### **6.3 Moving from adversarial positions to social concern-based dialogue: Citizen–Doctor Forums**

The experience of Citizen–Doctor Forums exemplifies the relevance of ensuring regular, constructive dialogue between members of the general public and the medical profession. It may be noted that these two constituencies have traditionally often held adversarial positions on private sector regulation. A key lesson is that this sector cannot be reformed by

the sole efforts of organised citizens or the medical profession; rather, each group needs to engage in greater dialogue with the other to overcome misconceptions, while helping to equalise the traditional power imbalance between lay people and the medical profession. Alliances can be developed around common issues such as accountability of state regulatory frameworks, and the adverse consequences of extreme commercialisation of health care, especially linked with corporate and large for-profit private hospitals. A further medium-term objective of such forums could be preparing the ground for moving towards a system of UHC which would ensure justice for both patients and ethical doctors, by de-commercialising the health-care system overall.

#### **6.4 The development of voices for ethics within the medical profession as a complement to social accountability**

Advocacy related to regulation of the private medical sector is somewhat unique. Unlike many other issues involving the binary opposition of stakeholders (typically civil society organisations/affected social groups vs the government), in this case there are three major categories of stakeholders. Along with citizens and the state, the private medical profession is another powerful, autonomous stakeholder which decisively influences health sector policy. Hence, any major change is bound to be a complex, triangular process. Since primary resistance to regulation of the private medical sector comes not from the state but from the medical profession, without moderating this resistance, while ensuring elements of participation in the regulatory process, it may not be possible to develop effective regulation. Hence, along with citizen mobilisation, there is an ongoing need to work with the medical profession, towards developing voices for social responsiveness. These voices would include doctors concerned about the negative impacts of gross commercialisation. The involvement of physician advocates can both reshape regulation, by ensuring that the critical concerns of doctors are taken on board, and also helps overcome resistance to regulation from mainstream medical associations.

#### **6.5 The problematic record of regulation of the private medical sector in India, with potential for corruption**

Studies point to the inadequacy of the existing regulatory architecture concerning the private medical sector in India and other LMICs (Sheikh, Saligram and Hort 2013; Bloom, Henson and Peters 2014; Tangcharoensathien *et al.* 2008). Regulatory gaps are underpinned by ambivalence in the roles of regulatory organisations, ineffective coordination between regulatory groups, and extensive contestation of regulatory policies by private stakeholders (Sheikh *et al.* 2013). Other studies have indicated that pursuing traditional approaches to enforce rules through administrative and bureaucratic controls may be inadequate, because they fail to deal with the political economy and the social realities of health care (Bloom *et al.* 2008; Mackintosh and Tibandebage 2002), emphasising the need for innovative approaches to regulation. Further, during discussions with sections of doctors and hospital owners regarding regulation of their sector, one of the strongest

objections was concerning the corruption that often accompanied traditional regulatory frameworks in India. State actors entrusted with the regulation of private hospitals might use minor administrative lapses as a pretext for rent-seeking, with the original rationale of regulation being lost. Even ethically practising doctors who were opposed to giving bribes complained of such coercion based on the denial of key sanctions, if the expected 'gratification' was not provided. While this may be an exaggerated view of the seamy side of regulation, it emphasises the need to ensure social accountability of the regulators themselves.

### **7 Emerging concepts of participatory social regulation**

Continued contestation of regulation by private actors, and the danger of capture of the regulatory process by powerful elements within and outside the state form the backdrop for re-imagining regulation from a citizen-centric perspective. The current weak regulation of the private medical sector in many LMICs is often linked with minimal political will to regulate this sector, since the private health-care industry often has significant financial and political clout. Weak political will may also be linked to a lack of organised popular demand for accountability of the private medical sector, despite widespread yet diffuse discontent about malpractices. Overall weak accountability of the state for enforcing regulations is an additional barrier to effective regulation.

Hence, unless regulation is buttressed by a social accountability framework and participatory processes, in LMICs like India there is a danger of regulatory capture or ineffective regulation, which would defeat its social objectives. Given the powerful influence exerted by the organised medical sector on health policy, there is a need to ensure such participatory action not only amongst citizens, but also amongst socially responsive sections of doctors, to jointly provide inputs for developing and informing the regulatory framework. Building effective public regulatory frameworks must be complemented by the promotion of a social climate of accountability and patients' rights, while strengthening an ethos of ethical, rational care within the medical profession. The state and its policies do not function in a vacuum, but are deeply embedded in social structures and relationships. Hence, it is highly desirable that *health sector transformations linked with state regulation and civil society action be interlinked and mutually reinforcing*.

Regulation of the private medical sector has often been looked upon as a bureaucratic function of the state, divorced from issues of patients' rights and accountability of private hospitals to health-care users. However, if we proceed from an understanding that regulation is a form of social accountability, then regulators need to become accountable to health-care users in particular, and citizens in a broader sense. (It may be noted that practically all citizens would be health-care users, or carers for patients at various points in their life.) Hence, patients' and citizens' concerns must be strongly reflected in a regulatory framework, otherwise regulatory bodies might be captured by elites, or may become an additional channel for corruption. In this context, social regulation

envisages that regulatory design should emerge from participatory processes, while its implementation and oversight is provided by multi-stakeholder bodies. Such social regulation would have three inter-related components: state regulatory bodies, multi-stakeholder oversight and monitoring committees, and technical committees consisting of diverse medical professionals. State regulation would be based on legal frameworks, executive authorities, grievance redressal mechanisms, and inspectors. Multi-stakeholder accountability and oversight bodies including civil society and patients' groups, as well as representatives from the medical profession would monitor the regulatory and grievance redressal processes. The technical elements of self-regulation such as standard treatment protocols would be developed by medical professionals drawn from the public, private, and non-profit sections of health-care providers. This participatory model of social regulation envisions action-oriented approaches to reinvent and democratise regulation, with greater patient and citizen involvement in monitoring of enforcement from a rights-based perspective.

If the stalled processes of regulation of the private medical sector in India are to be accelerated and given a direction which would enable regulatory processes to achieve their core social objectives, then social regulation may be the much-needed dynamo required for the long-overdue transformation of this sector.

### Notes

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- 1 We use the term 'whistle-blower' here to describe those clinicians within the medical profession who are privy to information about the unethical practices of fellow clinicians and in private hospitals, and who take the risk of making these unethical practices public.
- 2 We use the term 'ethical doctor' to describe a doctor who takes a public stand that is critical of widespread malpractices in the medical profession, and who publicly commits to abide by the Code of Medical Ethics as formulated by the Medical Council of India. They are often recognised by their peers for their avoidance of prevalent professional malpractices.
- 3 [www.sathicehat.org](http://www.sathicehat.org).
- 4 [www.phmindia.org](http://www.phmindia.org).
- 5 [www.ethicaldoctors.org](http://www.ethicaldoctors.org).
- 6 Nursing Home Acts in various Indian states are examples of traditional regulatory laws, which are outdated, ineffective in achieving regulatory objectives, linked with rent-seeking by inspectors, and which promote corruption.

- 7 Irrational care is a deviation from scientific Standard Treatment Guidelines developed by the medical professionals' associations/bodies. Such deviations are generally indulged in for improper material gain.
- 8 Shreya Nimonkar is one such victim of alleged medical negligence. She was advised to have a hysterectomy by her doctor despite this not being medically indicated, and during the procedure both her ureters got badly damaged, leading to lifelong suffering. Shreya is fighting to get justice through the Maharashtra Medical Council, and she is one of the leading organisers of the Citizen–Doctor Forum, Mumbai.
- 9 [www.medimitra.org](http://www.medimitra.org)
- 10 [www.ayurvedinstitute.com/Director/CEA\\_Maharashtra\\_2014\\_final\\_4th\\_june\\_1\\_pm\\_Taori..pdf](http://www.ayurvedinstitute.com/Director/CEA_Maharashtra_2014_final_4th_june_1_pm_Taori..pdf)

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# Neglected Tropical Diseases and Equity in the Post-2015 Health Agenda\*

Emma Michelle Taylor and James Smith

**Abstract** The Millennium Development Goals' focus on just three infectious diseases (HIV/AIDS, malaria, and belatedly, tuberculosis) configured the global health funding landscape for 15 years. neglected tropical diseases (NTDs), a group of 17 or so diseases that disproportionately afflict the world's 'bottom billion', are a symbol of global health inequities, in terms of prioritisation, research attention, and treatment. This article traces efforts to include NTDs in the Sustainable Development Goal (SDG) agenda and, having achieved that goal, lobby for an influential position in the post-2015 aid agenda. The SDGs herald a shift to a more expansive approach and there is a risk that NTDs will once again be left behind, lost in a panoply of new goals and targets. There is, however, an opportunity for NTDs to lever their 'neglect' and be recast as a tool of accountability, acting as both a target for and proxy indicator of health equity for the SDGs.

**Keywords:** NTDs, SDGs, MDGs, global health, evidence, indicators, health policy.

## 1 Introduction

'To fulfil our vision of promoting sustainable development, we must go beyond the MDGs. They did not focus enough on reaching the very poorest and most excluded people...'

*A New Global Partnership: Eradicate Poverty and Transform Economies through Sustainable Development. The Report of the High-Level Panel of Eminent Persons on the Post-2015 Development Agenda, High-Level Panel of Eminent Persons on the Post-2015 Development Agenda 2013, page i*

'The NTD agenda... is fundamentally aligned with the SDG commitment to leave no one behind'

*Integrating Neglected Tropical Diseases into Global Health and Development: Fourth WHO Report on Neglected Tropical Diseases, World Health Organization, 2017, page 66*

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**Box 1 Neglected tropical diseases**

Neglected tropical diseases (NTDs) are a group of parasitic and bacterial infections which are usually endemic in low-income populations in Africa, Asia, and the Americas. They affect over 1 billion people and are a significant disease burden. Populations living in poverty, without adequate sanitation, and in close proximity to vectors and livestock are amongst the most vulnerable. Some NTDs have known preventative measures or medical treatments – there may be a problem of access. These include: schistosomiasis; soil transmitted helminthiasis; lymphatic filariasis; onchocerciasis; trachoma. Some require new tools – drugs, diagnostics, and control measures. These include: leishmaniasis; Chagas' disease; human African trypanosomiasis (HAT).

Source: WHO (2010).

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Equity and inclusion are threads running through the Sustainable Development Goals (SDGs). The goals are conceptualised as both a pathway to equity and as targets that cannot be sustainably achieved without being built on an equitable base. The jump from eight Millennium Development Goals (MDGs) to 17 SDGs underpinned by a range of sub-goals, and the devolution of the delivery of goals down to nation states is welcome, and is partly a byproduct of more accountable notions of development. While the SDGs present a fuller and more grounded concept of development and how it might be achieved, they present significant challenges: firstly, for how one counts, and accounts for, 'progress'; and secondly, for who is responsible for progress. This is perhaps especially true for global health, where the institutional landscape is particularly complex: the MDGs cast a long shadow, increasing funding for certain diseases and often-vertical programmes; state and non-state actors have proliferated; and demands for transparency and accountability have driven calls for better evidence, policy, and practice.

Global development goals – whether they be millennium or sustainable – are fundamental to questions of accountability and equity for global health. The transition from the MDGs in 2000 to the SDGs in 2015 was a febrile time for health advocacy as intense lobbying sought to create new goals to reflect new priorities and aspirations (Buse and Hawkes 2015). In this article, we use the case of neglected tropical diseases (NTDs) to reflect on the relationships between equity, accountability, and priority in global health. The NTDs, a group of 17 or so diseases that, it is argued, especially within the NTD community, disproportionately afflict the world's 'bottom billion' (Collier 2007), are a symbol of health inequities, in terms of prioritisation, research attention, and treatment (see Box 1; also Hotez *et al.* 2014). This article tracks the course of ostensibly successful lobbying for these diseases to

receive special attention in the post-2015 agenda (*cf.* Smith and Taylor 2013, 2016). The SDGs herald a shift to a more expansive approach to development, but there is a risk that the NTDs could fail to gain traction in the new agenda, lost in a panoply of goals and targets. There is also, conversely, an opportunity for the NTDs to lever their earlier ‘neglect’ and be recast as tools of accountability – to act as both a primary target for, and a proxy indicator of, health equity in the framework. In this article, we highlight the politics that have struggled to place the NTDs centre stage, partly by recasting them as indicators of equity in the post-2015 agenda, as a means to reflect on what the shift to SDGs may mean for accountability.

## 2 Why the MDGs?

Prior to the time-bound goals and related targets established by the *Millennium Declaration* in 2000 (United Nations 2000), a striking feature of development diplomacy in the twentieth century was the tendency of governments to rehash the same vague commitments time and again, without recourse. A key example of what William Easterly has labelled the ‘historical amnesia’ (2002: 49) of the development industry was the pledge that governments would provide 0.7 per cent of their gross national product as official development assistance (ODA). Originally set as a target in 1970, it took 45 years for the UK to honour the UN aid commitment. When it did, it became the first G7 country to do so. There are countless other examples of unmet development pledges – the point being that for much of development’s history, there was no consequence for aid donors who chose to promise one thing, then do another.

The MDGs, then, marked a sea change in how development was approached. Galvanised by the seeming simplicity of tackling ‘development’ via eight narrowly focused, time-bound goals (as tracked through 18 targets and 48 technical indicators), the international community showed commitment to delivering on the MDGs in a manner not witnessed before. Data collection methods were devised, and data systems built to provide the evidence needed to track progress against the goals. To support the goals, new resources were leveraged, and dedicated aid-disbursement initiatives such as the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) were established to increase the likelihood that goals would be met on time. In 2005, the Paris Declaration on Aid Effectiveness set out five principles that helped to further align and harmonise aid to focus on results and accountability (OECD 2005). A sea change in the delivery of development was emerging, theoretically at least. It is significant that the adoption of the MDGs came at the end of a decade in which the purpose and usefulness of official development aid had come under increased scrutiny. A changing political climate in the 1990s, coupled with the poor results of decades of work and billions of dollars aimed at improving social and economic conditions in poor countries, led to a questioning of the effectiveness of aid and development practices (Riddell 2007). In response, there was a renewed appetite to make aid work for development.

The MDGs gave a new prominence to the health issues affecting poor populations. However, their focus was narrow and derived from top-down deliberation rather than broader participatory approaches. Consequently, the narrowness of the MDGs left gaps in coverage, and failed to realise potential synergies between the discrete foci of the goals (education, health, poverty, and gender) (Waage *et al.* 2010). MDG 6, in particular – *combat HIV/AIDS, malaria and other diseases* – effectively sidelined many of the communicable and non-communicable diseases that perpetuate the cycle of poverty in developing countries (including the NTDs). Conversely, singling out HIV/AIDS and malaria within MDG 6 raised the profile of these diseases, stimulating a reconfiguration and refocusing of ODA for health. Global health initiatives such as the GFATM and the President's Emergency Plan for AIDS Relief (PEPFAR) ushered in an era of vertical aid on an unprecedented scale, diverting resources away from existing health programmes (Shiffman 2008). In a funding climate of narrowing focus, advocacy groups were left to argue that it was *their* disease being referred to in the ambiguous wording: 'other diseases'.<sup>1</sup>

### 3 Establishing the NTDs – fighting for a voice

The 17 NTDs identified by the World Health Organization (WHO) in 2010 represented some of the MDGs' 'other diseases'. Their neglected tag stems from the disparity between the attention and funding they receive (0.6 per cent of ODA for health), and their large impact in terms of Disability-Adjusted Life Years (DALYs) (Liese and Shubert 2009; Murray *et al.* 2012). The NTDs are repeatedly identified as drivers of poverty (Durrheim *et al.* 2004), undermining efforts to meet a host of development goals and targets through an erosion of people's ability to live, thrive, and work (Hotez *et al.* 2006; Global Network 2013). In the context of the MDGs, the narrow focus of the goals, the health goal in particular, tended to drive a siloed approach to interventions. The consequent lack of emphasis on the interrelationships between the goals limited concerted efforts to focus on the NTDs.

The omission of NTDs from the MDGs led to a group of concerned stakeholders working hard to place NTDs firmly on the international agenda. The emergence of a global alliance of stakeholders – ranging across the gamut of global health actors – mobilised to raise the profile of NTDs (Smith and Taylor 2013). Progress was swift: in 2003, the Drugs for Neglected Diseases *initiative* (DNDi) and the Foundation for Innovative Diagnostics (FIND) were established. In 2010, WHO released its *First Report on the NTDs*, pinning down the disparate 17 diseases we now know by the shorthand 'NTDs' (WHO 2010).<sup>2</sup> Progress was such that the then WHO Secretary-General, Dr Margaret Chan, somewhat ironically described the story of the NTDs in the twenty-first century as one of 'rags to riches' (Chan 2012), given the great efforts expended to intrinsically link tackling the NTDs to pulling the 'bottom billion' out of poverty (Hotez *et al.* 2009).

#### 4 The NTDs and the SDGs – leaving no one behind

On 1 January 2016, the SDGs came into force. The particulars of the goals were finalised at the UN summit in September 2015, with the NTDs gaining a special mention in SDG 3.3: ‘By 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases’ (United Nations General Assembly 2015: 16). The decade-long effort of the NTD lobby had been successful, they had ‘won’.

While it was important to be name-checked, and have one’s seat at the global goal table, it was apparent that the SDGs were to be quite different from the MDGs. A recurrent critique of the MDGs was that they were restricted in focus and conceived of by committee. This cannot be levelled at the SDGs, which were the result of an extensive three-year consultation, involving multiple perspectives from government, civil society, expert groups, the private sector, and individuals. Instead of eight goals, there are now 17 accompanied by 169 targets. Has the High-Level Panel which originally drafted the framework document been ignored? ‘The international community will need to ensure that a single, sustainable framework agenda is not overloaded with too many priorities. A product of compromise rather than decisions...’ (HLP 2013: 14).

The post-2015 vision – enacted through the SDGs – is to create a single universal agenda in which the social, economic, and environmental dimensions of sustainability are integrated, underpinned by the tenet ‘leave no one behind’ (HLP 2013: 7). This tenet presents an opportunity for the NTDs.

#### 5 Framing the NTDs as cross-cutting

The success of a name-check in SDG 3.3 was tempered by extensive references to other health concerns, as detailed in the overarching Goal 3: *Ensure healthy lives and promote wellbeing for all at all ages*. Goal 3 is accompanied by nine targets and four means of implementation, and covers everything from maternal health to non-communicable diseases and traffic accidents. There is a risk of the NTDs disappearing amongst a panoply of other targets.

For those concerned with tackling NTDs, there is also a pressing financial need for NTDs to gain greater prominence and policy traction if they are to be effectively addressed. Current funding commitments for the NTDs (from various sources including ODA, philanthropic giving, and national budgets) for the period 2015–20 have been projected at less than US\$200 million a year;<sup>3</sup> yet WHO has suggested that the total investment needed to support the NTD Roadmap for the 2015–20 period is US\$18 billion (WHO 2015a: 24). This is a problematic disparity, yet one that could feasibly be lessened by the NTDs’ impact being emphasised across the SDG framework. As editor of *The Lancet*, Richard Horton, has suggested: ‘Unless high-level political recognition is given to NTDs by their inclusion in new development goals, the financing to meet WHO’s targets is unlikely to materialise’ (*ibid.*: 758).

The NTD lobby has, unsurprisingly given its genealogy, been proactive in formulating a case that the NTDs should be anchored across the broader SDG agenda, whether that be rhetorically (the argument that the NTDs are both outcomes and drivers of poverty has already been rehearsed (Durrheim *et al.* 2004)), by partnering directly with other agendas such as water and sanitation for health (WHO 2015b), or by proxy, by suggesting the NTDs should be used as tracer indicators for other SDG targets (Smith and Taylor 2016).

The recently retired director of the WHO Department of Control of Neglected Tropical Diseases, Dirk Engels, has argued that it is necessary to use the NTDs as 'tracers' (or proxy indicators) for a number of other SDG targets, such as Universal Health Coverage (SDG 3.8) and access to safe water (SDG 6.1) to monitor equity in the post-2015 agenda, 'precisely because NTD endemic populations are the least likely to have access to these services at present' (Engels 2016: 224). In this manner, the burden of NTDs is suggested as 'a proxy for inequitable access to the systems – especially health systems – through which people improve their health and wealth' (WHO 2015a: 12), and Universal Health Coverage (UHC) depicted as 'one of the most powerful social equalizers among all policy options' (Margaret Chan, cited in WHO 2015a: x).

In WHO's fourth Report on NTDs – *Integrating Neglected Tropical Diseases into Global Health and Development* – the case is made that 'tackling NTDs significantly improves the prospects of attaining all of the SDGs, from reducing poverty and malnutrition to improving water and sanitation, gender equality and education' (WHO 2017: 66). Specifically, it has been argued by the NTD lobby that NTDs directly impact on six of the 17 SDGs.<sup>4</sup> Although even outside those goals, 'more subtle' alignments and potential synergies are hinted across the broader framework (WHO 2017: 68; also see Bangert *et al.* 2017 for a fuller discussion on all the ways the NTDs are argued to impact on the SDG framework).

The underpinning importance of the NTDs for the attainment of a wider range of SDGs is repeatedly stressed by adherents. Moreover, a value-for-money argument is supported by creating the logic that investment in the NTDs could maximise returns across a broad range of SDG goals and targets – a point Dirk Engels has been quick to stress:

I do not share the opinion that the main outcome for the inclusion of the NTDs within the Sustainable Development Goals would be more money for the NTDs. Inclusion of NTD indicators and tracers will, on the contrary, help to maximise returns on investments in a broad portfolio of Sustainable Development Goal targets (2016: 224).

WHO's most recent report on the NTDs suggests NTD interventions could act as 'tracers of equity' in relation to six goals and eight targets (WHO 2017). Effectively, NTDs are being framed as both *a target for, and an indicator of* equity in the new SDG framework.



## 6 Lobbying for primary and proxy indicators

Increasing demands for accountability for health present both a challenge and an opportunity for the NTD lobby (Smith and Taylor 2016). If accountability drives increasing demands for targets and evidence to measure progress against those targets, it is vital for NTDs to secure indicators if they are to access resources and marshal activity. The indicator that most concerns the NTD community seeks to measure the ‘number of people requiring interventions against neglected tropical diseases’ (IAEG-SDG 2015: 9). In theory, these data could be collected from a number of existing sources (for example, accounting for donated medicines for preventative chemotherapy or results from active screening for disease) to inform an overarching indicator. There is, in fact, no precedent for collecting these kinds of data systematically or universally, and WHO admits to several data gaps in the current NTD reporting systems (2017).

Thanks in part to their inclusion in the MDGs, the ‘big three’ diseases already boast indicators with proven data collection methodologies. The NTDs are not so well endowed, with the groups addressing the 17 diseases tending to affect the people who live outside the formal health-care systems now being tasked with tracking interventions. To address the data gaps, WHO has suggested that a comprehensive information management system will need to be developed. This would be a mammoth task but one that helps underline the SDG’s equity focus:

The NTD indicator [for SDG target 3.3] counts, and thus renders visible for the first time the more than one billion people estimated to require treatment and care for NTDs... this indicator will drive efforts and in some cases build from the beginning, systems that will greatly improve the lives of neglected populations (WHO 2017: 108).

The NTD indicator can help focus attention on neglected populations; a need for data can prompt the development of systems to count and assess activity and impact. NTD proxy or tracer indicators can do more than that, helping to build health systems. For this reason, arguments are being made in favour of an NTDs tracer being adopted as an indicator for SDG 3.8 on UHC.<sup>5</sup>

UHC has been defined as ensuring that all people have access to needed promotive, preventative, curative, and rehabilitative health services, of sufficient quality to be effective, while also ensuring that people do not suffer financial hardship when paying for these services (WHO 2015c). UHC needs to be understood within country contexts, the reality and ambition of health-care service coverage being limited by funding, capacity, and often political will. Regardless of income, virtually every country strives to provide greater health-care service coverage, hence ‘the UHC endeavour is generally referred to as a journey rather than a destination, as a dynamic, continuing process rather than a permanent solution or state that can be achieved’ (WHO 2017: 87).

Of all the SDG targets that the WHO department for NTDs has determined could benefit from NTD tracers, UHC is the one it has attached the most importance to. It argues that this is because 'UHC is the only target that binds all of the targets of the health goal, as well as addressing linkages with health-related targets in the other goals' (WHO 2017: 85). In short, UHC, much like the NTDs themselves is viewed as cutting across the SDG agenda, and pivotal to the success of several goals. This effectively allows NTDs to not only directly piggyback on certain goals but also potentially interact with other goals indirectly via UHC, should it indeed become a proxy indicator.

Due to the complex nature of UHC – which presents a shifting target, and one that will not look the same in every context – it is acknowledged that measuring progress towards SDG 3.8 will prove very challenging. There cannot therefore be one indicator, but many – all effectively proxies/ tracers – that will serve to track people's ability to access a basic package of health-related interventions and services. Moreover, the precise composition of this package will differ by country to reflect the context-specific health priorities at play. Despite this, and in order to help assess regional and global progress towards the UHC target, WHO has determined that it would be helpful to identify a set of tracer indicators that could then be combined to form a monitoring index. To date, 16 tracer indicators (things like child immunisation and HIV treatment) have been adopted and grouped under the four categories of: reproductive, maternal, newborn, and child health; infectious diseases; non-communicable diseases; service capacity and access; and health security. So far, no NTD interventions have been included in the UHC coverage index. Nevertheless, WHO has developed an 'NTD coverage index' based on the coverage of preventative chemotherapy for five of the NTDs, and continues to campaign for its adoption. In short, the campaigning around the NTDs' meaningful inclusion in the SDG framework continues, with WHO arguing that 'it is clear that monitoring NTD coverage could still make a significant contribution to tracking the coverage of essential health services' (WHO 2017: 117).

### **7 Discussion: not forgetting what is left behind**

The changing relationship between the NTDs and Global Goals highlights the dynamics of the relationship between accountability and global health, which help us problematise and reframe current notions of accountability. Bruen *et al.* (2014: 12) argue that 'accountability is a frequently invoked though arguably less questioned concept in global health operation'. Accountability is rather more complex than one actor holding another to account; rather, it is a dynamic process that shapes and is shaped by relationships between increasingly diverse sets of actors, and framed by priorities, data, and evidence.

The reference to NTDs within a Global Goal and the realities of the transition from MDGs to SDGs highlights dimensions of accountability that warrant further analysis if we are to develop more transparent, participatory, and equitable methods of delivering a transformational global health agenda.

The MDGs were criticised as being top-down, too narrowly focused, and too disconnected from each other. The emergence of the SDGs are themselves a recognition of this, specifically recognising the interactions between goals (one of the proposed selling points of the NTDs) and greatly broadening our conceptions of health and development, as well as developing a broader sense of who is responsible for delivering on them (Buse and Hawkes 2015). The SDGs are also a reflection of broader shifts in development thinking, towards holistic, integrated, intersectoral, indivisible goals for which the responsibility of delivering is collective. Equity is conceived of as both an overarching aspiration and a prerequisite for delivering the goals. The potential place of the NTDs within an SDG-inflected world presents important implications for accountability with regard to global health.

Firstly, the NTDs highlight practical challenges for accountability: how are priorities set and how is progress measured? There is an emphasis on countries to set their own targets that reflect their national circumstances. The concentration of NTDs in less-developed countries, which typically have less capacity to deliver the sorts of systematic interventions necessary to, for example, deliver active disease screening or mass drug administration, presents a challenge, and suggests that tough decisions around priorities and programmes have to be made. This may be viewed as an opportunity for NTDs, given their connections to other goals and targets and potential to act as proxies of progress, thus cementing investment and focus. At this stage, however, it is unclear whether increased efforts aimed at controlling NTDs may supplement or complement broader efforts to map, measure, and tackle global health concerns, or whether NTDs may become again lost in a panoply of priorities in resource-constrained settings.

Secondly, the cross-cutting nature of the SDGs and NTDs in particular suggests complications around the who of accountability. Cross-cutting approaches to NTD control, often but not always embedded in national contexts, require broader sets of actors, including the private sector in, for example vector control, or local communities with regard to mass drug administration. There are of course many examples of intersectional approaches to dealing with health and development issues, but the broadening of the ambitions of the SDG agenda suggest both a broadening of responsibility to deliver against that agenda and attendant issues around which countries, agencies, and actors will be held to account.

There is a risk that accountable practices, so important to the thinking behind the concept of Global Goals and central to the delivery of the SDGs, will become lost or unimplementable amongst the white noise of multiple goals and targets. Accountability may suffer from the technical perspective of difficulties in measuring progress across complex topographies of goals, targets, and nations; from the conceptual perspective of truly understanding how interventions interact between goals and targets; and from the ethical perspective of whom can legitimately be held to account when so many are involved in delivery.

The NTDs underline some of the problems of accountability in the emerging SDG era. A more complex, nuanced, and ambitious global health and development agenda requires new ways of doing things. There are technical and conceptual challenges, which may be partially addressed by new technologies and data sets that can map progress and shed light on the relationships and trade-offs between economic, social, and environmental development. There are issues of ethics and equity, who is responsible for what, and how priorities are arrived at. This may be more difficult to address, and involves us reflecting on just who is responsible for delivering development. Plural pronouns are powerful, but are they organisationally useful?

The NTDs themselves, until recently hidden in the netherworld of global health, can act as a mirror to accountability. For many years unprioritised, recently recognised, with ambitious elimination plans not yet realised (or accounted for). Their attraction is partly that they are multipurpose, they are a global target and may be adopted as a useful proxy indicator. This attractiveness highlights some of the immense difficulty of realising accountability in the new era of complex, multiple, connected goals and associated indicators. We should not forget that NTDs are diseases of poverty: controlling and treating them will improve lives and livelihoods and help progress towards equity, and as the SDGs assert, this is a concern for all of us.

### Notes

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- 1 It is noteworthy that tuberculosis was able to transcend 'other diseases' through its close association with HIV/AIDS, as witnessed in the focus of the GFATM. It showed that lobbying and making associations could shape discourses and influence priorities around global health.
- 2 Note that in 2017, the list of NTDs has been enlarged to include chromoblastomycosis and other deep mycoses, scabies and other ectoparasites, and snakebite envenoming.
- 3 Not including in-kind donations of drugs.
- 4 Goal 1: End poverty in all its forms everywhere; Goal 2: End hunger, achieve food security and improved nutrition and promote sustainable agriculture; Goal 3: Ensure healthy lives and promote wellbeing for all at all ages; Goal 4: Ensure inclusive and equitable quality education and promote lifelong opportunities for all; Goal 6: Ensure availability and sustainable management of water and sanitation for all; Goal 11: Make cities and human settlements inclusive, safe, resilient and sustainable (WHO 2017: 68).
- 5 While indicator 3.8 is the most important, WHO is also making a similar case for NTD 'tracers of equity' to help monitor six SDGs and eight targets (WHO 2017: 119).

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## Glossary

- ADEH** Alliance of Doctors for Ethical Healthcare [India]
- ADRA** Adventist Development and Relief Agency [USA]
- AfriMAP** Africa Governance Monitoring and Advocacy Project [South Africa]
- AMA** *assistência médica ambulatorial* [outpatient care facility, Brazil]
- ANANDI** Area Networking and Development Initiatives [India]
- APE** polyvalent agent [*agent polyvalent de l'environnement*]
- BHESA** Biomedical and Health Experimentation in South Asia
- CARE** Cooperative for Assistance and Relief Everywhere [Switzerland]
- CBO** community-based organisation
- CCIM** Central Council for Indian Medicine
- CEA** Clinical Establishment Act [India]
- CEBRAP** Centro Brasileiro de Análise e Planejamento [Brazilian Centre of Analysis and Planning]
- CEGSS** Centro de Estudios para Equidad y Gobernanza en Sistemas de Salud [Center for the Study of Equity and Governance in Health Systems, Guatemala]
- CEH** La Comisión para el Esclarecimiento Histórico [Commission for Historical Clarification, Guatemala]
- CEM/USP** Centro de Estudos da Metrópole/Universidade de São Paulo [Centre for Metropolitan Studies/University of São Paulo, Brazil]
- CEP** Citizen Engagement Programme [Mozambique]
- CESC** Centre for Learning and Capacity Building for Civil Society [Mozambique]
- CESR** Center for Economic and Social Rights [USA]
- CGD** Center for Global Development [USA]
- CHA** community health agent
- CHEW** community health extension worker
- CIAT** Inter-American Center of Tax Administrations [Panama]
- CIRESP** Comissão Interministerial da Reforma do Sector Público [Interministerial Commission for Public Sector Reform, Mozambique]
- convênios** service agreements [Brazil]
- COPASAH** Community of Practitioners on Accountability and Social Action in Health [India]
- CSC** Community Scorecard
- CSO** civil society organisation
- DALY** Disability-Adjusted Life Year
- DATASUS** Sistema Único de Saúde Department of Information Technology [Brazil]
- DDA** Department of Drug Administration [Nepal]
- DEM** Democrats [Brazil]
- DFID** Department for International Development [UK]
- DNDi** Drugs for Neglected Diseases *initiative*
- DPHO** District Public Health Office [Nepal]



**DSAI** Development Studies Association Ireland  
**ECLAC** Economic Commission for Latin America and the Caribbean [Chile]  
**EDL** Essential Drug List  
**ERC** European Research Council  
**ESRC** Economic and Social Research Council [UK]  
**FAPESP** São Paulo Research Foundation [Brazil]  
**FCHV** female community health volunteer  
**FDA** Food and Drug Administration [USA]  
**FHD** Family Health Division [Nepal]  
**FHP** Family Health Program (also known as Qualis) [São Paulo, Brazil]  
**FIND** Foundation for Innovative Diagnostics  
**FYP** Foundation Year Programme [Nigeria]  
**GFATM** Global Fund to Fight AIDS, Tuberculosis and Malaria  
**HAT** human African trypanosomiasis  
**HDI** Human Development Index  
**HRH** Human Resource(s) for Health  
**IAEG** Inter-Agency and Expert Group  
**ICDS** Integrated Child Development Services [India]  
**ICEFI** Instituto Centroamericano de Estudios Fiscales [Central American Institute of Fiscal Studies, Guatemala]  
**ICT** information and communications technology  
**IDB** Inter-American Development Bank [USA]  
**IESE** Instituto de Estudos Sociais e Económicos [Institute of Social and Economic Studies, Mozambique]  
**IMA** Indian Medical Association  
**INC** Indian Nursing Council  
**INE** Instituto Nacional de Estadística [Spanish Statistical Office, Guatemala]  
**INGO** international non-governmental organisation  
**INZI** Investigating Networks of Zoonosis Innovation  
**IUGIA** International Work Group for Indigenous Affairs [Denmark]  
**JAA** Jan Arogya Abhiyan [India]  
**JHU/CCP** Johns Hopkins University/Center for Communication Programs [USA]  
**JSI** John Snow Inc. [USA]  
**KM** knowledge management  
**KSSS** Kaira Social Service Society [India]  
**LGA** local government area  
**LMG** Leadership, Management & Governance  
**LMICs** low- and middle-income countries  
**MASS** Management Support Services [USA]  
**MDG** Millennium Development Goal  
**MINEDUC** Ministerio de Educación [Ministry of Education, Guatemala]  
**MISAU** Ministério de Saúde [Ministry of Health, Mozambique]  
**MKSS** Mazdoor Kisan Shakti Sangathan [Organisation for the Power of Labourers and Farmers, India]  
**MMC** Maharashtra Medical Council [India]  
**MOHP** Ministry of Health and Population [Nepal]



**MSPAS** Ministerio de Salud Pública y Asistencia Social [Ministry of Public Health and Social Assistance, Guatemala]  
**NCE** Nigeria Certificate in Education  
**NCSD** Núcleo de Saúde, Cidadania e Desenvolvimento [Citizenship, Health and Development Team, CEBRAP, Brazil]  
**NDHS** Nigeria Demographic and Health Survey  
**NESOG** Nepal Society of Obstetricians and Gynaecologists  
**NFCC** Nepal Fertility Care Center  
**NFHP** Nepal Family Health Program  
**NGN** Nigerian Naira  
**NGO** non-governmental organisation  
**NHRC** National Human Rights Commission [India]  
**NHRC** Nepal Health Research Council  
**NPC** National Population Commission [Nigeria]  
**NPPA** National Pharmaceutical Pricing Authority [India]  
**NTAG** Nepali Technical Assistance Group  
**NTD** neglected tropical disease  
**ODA** official development assistance  
**OECD** Organisation for Economic Co-operation and Development [France]  
**OSISA** Open Society Initiative for Southern Africa [South Africa]  
**OSS** *organização social de saúde* [social health organisation, Brazil]  
**OVC** orphans and vulnerable children  
**PAS** Plano de Atendimento à Saúde [Health Care Plan, São Paulo, Brazil]  
**PCDF** Pune Citizen–Doctors Forum [India]  
**PCI** Pharmacy Council of India  
**PDS** Social Democratic Party [Brazil]  
**PEPFAR** President’s Emergency Plan for AIDS Relief  
**PHC** primary health care  
**PHCC** primary health care centre  
**PHFI** Public Health Foundation of India  
**PHM** People’s Health Movement [India]  
**PPB** Brazilian Progressive Party [Brazil]  
**PPH** postpartum haemorrhage  
**PPP** public–private partnership  
**PRRINN-MNCH** Partnership for Reviving Routine Immunization in Northern Nigeria; Maternal Newborn and Child Health Initiative  
**PSDB** Brazilian Social Democracy Party [Brazil]  
**PT** Workers’ Party [Brazil]  
**Qualis** Qualidade Integral em Saúde [Family Health Program, São Paulo, Brazil]  
**REDC-SALUD** La Red de Defensores Comunitarios por el Derecho a la Salud [Network of Community Defenders for the Right to Health, Guatemala]  
**RESYST** Resilient and Responsive Health Systems [South Africa]  
**RinGs** Research in Gender and Ethics [UK]  
**RTI** Research and Training Institute [USA]  
**SAFE** safety, acceptability, feasibility, and programme effectiveness  
**SATHI** Support for Advocacy and Training to Health Initiatives [India]

**SBA** skilled birth attendant  
**SC/US** Save the Children/US  
**SDG** Sustainable Development Goal  
**SMoH** State Ministry of Health [Nigeria]  
**SMS** Short Message Service  
**SUS** Sistema Único de Saúde [Health Care System, Brazil]  
**TAG** technical advisory group  
**UHC** Universal Health Coverage/Care  
**UNDP** United Nations Development Programme [USA]  
**UNESCO** United Nations Educational, Scientific and Cultural Organization [France]  
**UN-HABITAT** United Nations Human Settlements Programme  
**UPA** *unidade de pronto atendimento* [emergency care unit, Brazil]  
**USAID** United States Agency for International Development  
**VaRG** Valley Research Group Private Limited [Nepal]  
**VSHD** Venture Strategies for Health and Development [USA]  
**W4H** Women for Health [Nigeria]  
**WHO** World Health Organization [Switzerland]

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‘The articles in this *IDS Bulletin* reflect the fact that while the desired outcome might be the same – *better health for all* – accountability strategies are as diverse as the contexts in which they have developed.’