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Abbreviations

ADC	autonomous district council
CEM	chief executive member
CHC	Community Health Centre
CRM	Common Review Mission
DHS	Directorate of Health Services
DST	digital storytelling
GHADC	Garo Hills Autonomous District Council
HIV	Human Immunodeficiency Virus
HMIS	Health Management Information System
IIPH	Indian Institute of Public Health
IIPS	International Institute for Population Sciences
IUD	Intrauterine Device
JHADC	Jaintia Hills Autonomous District Council
KHADC	Khasi Hills Autonomous District Council
MHS	Meghalaya Health Insurance Scheme
MLA	Member of the Legislative Assembly
MOHFW	Ministry of Health and Family Welfare
NFHS	National Family Health Survey
NRHM	National Rural Health Mission
NUHM	National Urban Health Mission
NGO	non-governmental organisation
PHC	Primary Health Centre
PHFI	Public Health Foundation of India
PIP	Programme Implementation Plan
RCH	Reproductive and Child Health
SRH	Sexual and Reproductive Health
SRHR	Sexual and Reproductive Health Rights
STIs	sexually transmitted infections
UHC	Urban Health Centre
UNPF	United Nations Population Fund
USHA	urban social health activist
VHSNC	Village Health, Sanitation and Nutrition Committee
WHO	World Health Organization

Executive summary

Introduction

Meghalaya is a landlocked and largely agrarian state in northeast India with an approximate population of three million. Various government surveys report that roughly half the state lives below the poverty line. Most people live in rural areas, but in recent years Meghalaya has experienced rapid population growth and urbanisation: between 2001 and 2011, Meghalaya's cities grew 20 per cent. This has put increasing pressure on urban areas. Today, one out of five people in the capital of Shillong are slum dwellers.

Meghalaya is part of India's 'tribal belt', with a predominantly indigenous population (86 per cent), of which the Khasi constitute slightly more than half. The Khasi are one of the largest matrilineal cultures in the world, with distinct political institutions that coexist alongside India's modern state system. Identities in the indigenous group are closely linked with maternal lineage: the children take the name of their mother's clan, and traditionally, the youngest daughter in a family inherits the ancestral land of her family.

Despite living in a matrilineal society, when it comes to health and education, women in Meghalaya lag behind their peers in other northeastern states. The state has some of the worst maternal health indices and the highest unmet contraceptive need in India. One of the reasons for the women's low status is the position of Khasi women in their communities – they do not participate in traditional political decision-making, which historically is a male domain. Khasi women are barred from even attending decision-making processes. There is an old saying among Khasis: '*Ynda kynih ka 'iar kynthei, la wai ka pyrthei*' or 'When the hen crows the world is coming to an end.' It is taken to mean that if women take part in politics, the world is doomed.

This paper examines how the Indian state prioritises health needs, and how and whether poor and indigenous women are able to participate in decisions about their sexual and reproductive health. The focus is on the indigenous Khasi population in Meghalaya, with its traditional systems of governance that exist in tandem with India's modern institutions. Literature and document reviews, documented participation through interviews and focus group discussions at these different levels in Shillong help explain what opportunities and barriers women have for political participation.

Lack of evidence-based urban planning

In Shillong, government health services are available and relatively easy to access. The poor benefit from insurance programmes and free or low-cost national urban and rural health programmes. Meghalaya's health indices, however, are consistently near or at the bottom of the charts compared to the rest of India, with poor programme planning and lack of funds cited as reasons. In the decade 1999–2009, there was a steady decline in health expenditure, from an 8 per cent share of total spending in 2001/02 to 3.9 per cent in 2008/09.

Another challenge is that annual targets for health indicators in Meghalaya, which the state sets, are actually developed based on indicators from national-level data that often represent much larger states, ones that differ socially, culturally and politically. Just as problematic in terms of planning is the fact that accurate and pertinent data with regard to sexual health among slum dwellers generally does not exist in Meghalaya. Overall, there is very little health research addressing the specific issues in the state.

Reasons why poor women do not seek health care

Despite the close proximity of government-run Urban Health Centres and the availability of health insurance, some women living in slums reportedly hold back from seeking health care for fear of tallying up out-of-pocket expenses. The researchers found that women often deprioritise their own health in favour of supporting the needs of others. Many internalise notions of being second-class citizens, which prevents them from asserting their rights. Despite the matrilineal family structures, some women are subordinate to spousal decision-making when it comes to reproductive health.

There is also limited awareness among women from the slums in Shillong about availability of choices and possible health conditions when it comes to sexual and reproductive health. This lack of knowledge is reinforced by a scarcity of service provision for sexual and reproductive health. In general, people in the community are uncomfortable discussing these topics. Societal norms and notions of 'good manners', together with a lack of pertinent words in the Khasi language, contribute to the silence on sexuality within the community. One hurdle is the lack of appropriate words in the local language to discuss sexual and reproductive health.

Indigenous governance institutions and their influence

Governance structures in Meghalaya are complex. Indigenous Khasi institutions exist alongside India's state government machinery in addition to the constitutionally created autonomous district councils (ADCs), specifically designed for the country's tribal areas.

At the village level, Khasi men choose their own village headman (*rangbah shnong*) and his council of executives (*rangbah dong*) to look after judicial and administrative affairs. Only men can participate. Notionally and traditionally, the local councils (*dorbars*) are accountable to *syiems*, dynastic rulers of kingdoms formed from grouping village clusters. The ADCs were created to preserve the traditional system of governance. Yet the result has been multiple, parallel power structures, which have led to confusion and even paralysis in governance in some instances. The relationships between traditional institutions and state authorities, including municipal authorities, are highly contentious, especially with regard to land.

Khasi women are barred from most traditional systems of governance

In Khasi society, women have been traditionally discouraged from participating in political matters, a sentiment echoed by participants in this study. In the Khasi governance system, Khasi women – both rich and poor – are excluded from voting and holding office, and *seng kynthei*, the traditional women's organisation in the community, has a limited role in decision-making on community matters.

Within the state governance system, the opportunities for Khasi women are relatively better, as women can vote and hold office at every level. Indian political parties typically have a women's wing, such as the Mahila Congress Committee and the women's wing of the Hill People Union. Despite the relative lack of political voice in the state, women turn out in large numbers to vote; however, only a handful of women were elected to the 60-seat legislature in 2013. The reasons cited for so few women being in politics are a lack of interest among women and an unwillingness of political parties to field women candidates.

Conclusions

Health planning in Meghalaya faces multiple challenges. The state lacks solid health-based statistics upon which public policymakers can design programmes and positive health outcomes. As a result, health planning is not based on community needs, especially from

slum areas in Meghalaya. This potentially hides health inequalities between and within communities, and obscures poor people's lack of access to health services.

The status of women is particularly troubling. They have little input into developing policy and prioritising health needs in Meghalaya. Despite the Khasi being a matrilineal and matrilocal society, women are largely excluded from local indigenous political systems and processes. In the traditional institutions in Shillong, women have no representation in the *dorbar* nor are they allowed to attend *dorbar* meetings. The tradition of public politics and administration being a man's domain is strongly embedded in the Khasi society.

As a result, women's views and perspectives are often not heard. Gender norms and inequalities are barriers to women in making decisions about their own reproductive health, which can then serve to limit their access to sexual and reproductive health services. Women reinforce their own exclusion by subordinating to a headman, who is also in many ways powerless in his relationship with the national government. The question is: when women's voices are never heard, can their sexual and reproductive health and rights be a priority?

Recommendations

- Fund and improve research at sub-national/local levels on gender, governance and health to inform policy and programme decisions.
- Facilitate and improve transparent civil participation processes that engage with men and women as recommended in the National Urban Health Mission (NUHM). Use locally meaningful labels to replace the Hindi terms that are currently used when implementing central programmes.
- Develop feedback mechanisms between state and civil society, including women's indigenous groups.
- Fund specific awareness/sensitising programmes on gender issues and gender inequalities that involve men in the health sector and other areas.
- Document women's attitudes and voices on what constitutes empowerment within the indigenous cultural and governance context.
- Develop pilot programmes to improve governance processes for direct access by women to state benefits and services through indigenous and state institutions.
- Facilitate social audits of the health system and improve human capacity of civil society groups, including indigenous groups, for undertaking social audits, and monitoring and evaluation. Develop quality assurance units and appropriate grievance redress mechanisms at health facilities.

1 Introduction

Meghalaya is a landlocked, largely agrarian state in northeast India with an approximate population of three million. Various government surveys report that roughly half the state lives below the poverty line. Most people live in rural areas but in recent years, Meghalaya has experienced rapid population growth and urbanisation. Large numbers of migrants are arriving from outside the state and many of those living in the villages are migrating to the cities for better economic and educational opportunities. This has put increasing pressure on urban areas. Today, one out of five people in the capital of Shillong live in a slum. These areas are overcrowded, with unsafe and substandard housing. They often lack electricity, water and sanitation services. They are prone to flooding and offer little protection from extreme heat or cold.

Meghalaya is part of India's northeast 'tribal belt', with a predominantly indigenous population (86 per cent), of which the Khasi constitute slightly more than half. Today, the Khasi people are one of the largest matrilineal cultures in the world. They have distinct political institutions, which coexist alongside India's modern state system. The children take the name of their mother's clan, and identities are closely linked with maternal lineage (Bareh 1997; Kyndiah 1990). Traditionally, the youngest daughter in a family inherits the ancestral land of her family, and she would be obliged to take care of her parents and unmarried siblings. The Khasis, who are largely Christian, differ from the many patrilocal and patrilineal groups in India: they do not have a caste system or a culture of expecting a dowry during marriage. Couples marry by mutual choice, often at a young age. It is not unusual for couples to elope if their parents do not agree to the match. Cohabitation is culturally and socially accepted, and prevalent, but it does not have the same legal status as marriage (*The Shillong Times* 2012b; War and Albert 2013). The Khasis have large families: the fertility rate of 3.8 is one of the highest in the country.

Despite living in a matrilineal society, when it comes to health, women in Meghalaya lag behind their peers in other northeastern states. The state has some of the worst maternal health indices in the country: home delivery without skilled birth care is 71 per cent of all births (IIPS 2010), the maternal mortality rate is 238 per 100,000 deliveries (HMIS – Meghalaya 2010–11), and 64 per cent of pregnant women are anaemic (IIPS 2009). Meghalaya has the highest unmet contraceptive needs in the country (IIPS 2007a; IIPS 2007b). According to the third National Family Health Survey (NFHS–3), 35 per cent of Meghalayan women in their child-bearing years do not have access to family planning, compared to India's average of 12.8 per cent.

Unlike other regions of India, Khasi women are largely able to make health-care decisions on their own (Singh *et al.* 2010; Chakrabarti and Chaudhuri 2007). Yet they appear no better off than other indigenous women living with health systems that don't respond adequately to their reproductive health needs (Kwagala 2013; Oosterhoff, White and Aggleton 2011). Under the Khasi's matrilineal system, property is registered in a woman's name, yet the men control the land and hold the power. Khasi women do not actually participate in the political decision-making process. Public decision-making – including the allocation of public lands – is traditionally the male domain (Mawrie 2010: 91). In keeping with the matrilineal traditions of the tribe, succession to the office of the *syiem* (chief, sometimes translated as king) is through the female line, but it is men who assume positions of power (Government of Meghalaya 2009b; Bareh 1997). An unwritten but well-known code of conduct has prevented women from attending and participating in public, political decision-making processes in the traditional governance system (Lalkima 2009: 45). There is an old saying among Khasis: '*Ynda kynih ka 'iar kynthei, la wai ka pyrthei*' or 'When the hen crows the world is coming to an end.' It is taken to mean that if women take part in politics, the world is doomed (Lalkima 2009: 45; Lyngdoh n.d.).

This paper examines how the Indian state prioritises health needs, and whether and how poor and indigenous women are able to participate in decisions about their sexual and reproductive health (SRH). In focusing on the indigenous population in Meghalaya and examining the complex web of traditional systems of governance that exist in tandem with modern state institutions, we document participation at these different levels in Shillong to understand what opportunities and barriers women have for political participation.

This case study explores the following questions:

- How are urban and state health priorities and policies developed in Meghalaya state?
- How can women and girls in urban areas engage with indigenous and state institutions with regard to SRH policies?

Box 1.1 Election and positions in the Khasi governance system

Syiem: A hereditary leader (chieftain) belonging to the *syiem* clan who looks after the *himas* (kingdoms). He is considered the first among equals in his council of *myntris*.

Myntri: A minister of the *syiem* elected from specific clans. Only a man can be a *myntri*.

Dorbar: A village council (traditional governance body) headed by the *rangbah shnong* (headman) and the executive members. This forms the basic foundation of Khasi democracy. The *dorbar* may be held every year and only the men from the community can attend. The *dorbar* gets its authority to act via a *sanad* (authorisation/document) from the *syiem* under whose jurisdiction they fall.

Rangbah shnong: The headman, locally known as the *rangbah shnong*, should be an adult Khasi man. Traditionally, only someone who has grown a moustache can contest or become a *rangbah shnong*. He is elected by the men of the community at the *dorbar* who vote by show of hands. He looks after the affairs of the community (*shnong*) along with the executive members, which include mostly the community elders.

Rangbah dong: The *rangbah dong* is an executive member of the *dorbar*. He helps the *rangbah shnong* run the administration of the community and is also answerable to him. The *rangbah dong* looks after the *dong* (blocks) in the community. He is elected by the members of the *dong*, including women.

Seng longkmie/Seng kynthei: The women's group in a community. There is no age restriction but most members are elders in the community. These groups cannot participate in the local *dorbar* but they often help the headman in the administration and welfare of the society.

Khasi Hills Autonomous District Council (KHADC): The entire state of Meghalaya is covered under the provision of the Sixth Schedule of the Constitution of India. In Meghalaya, there are three autonomous district councils (ADCs): the KHADC; the Garo Hills Autonomous District Council (GHADC); and the Jaintia Hills Autonomous District Council (JHADC). The ADCs have authority over the traditional institutions in matters related to appointment and succession of the *syiem* and headman. The chief executive member (CEM) heads the ADCs. The CEM is elected by a council of 30 members, which forms the ADC legislative body. The CEM can be either a man or a woman; however, to date there has never been a female CEM.

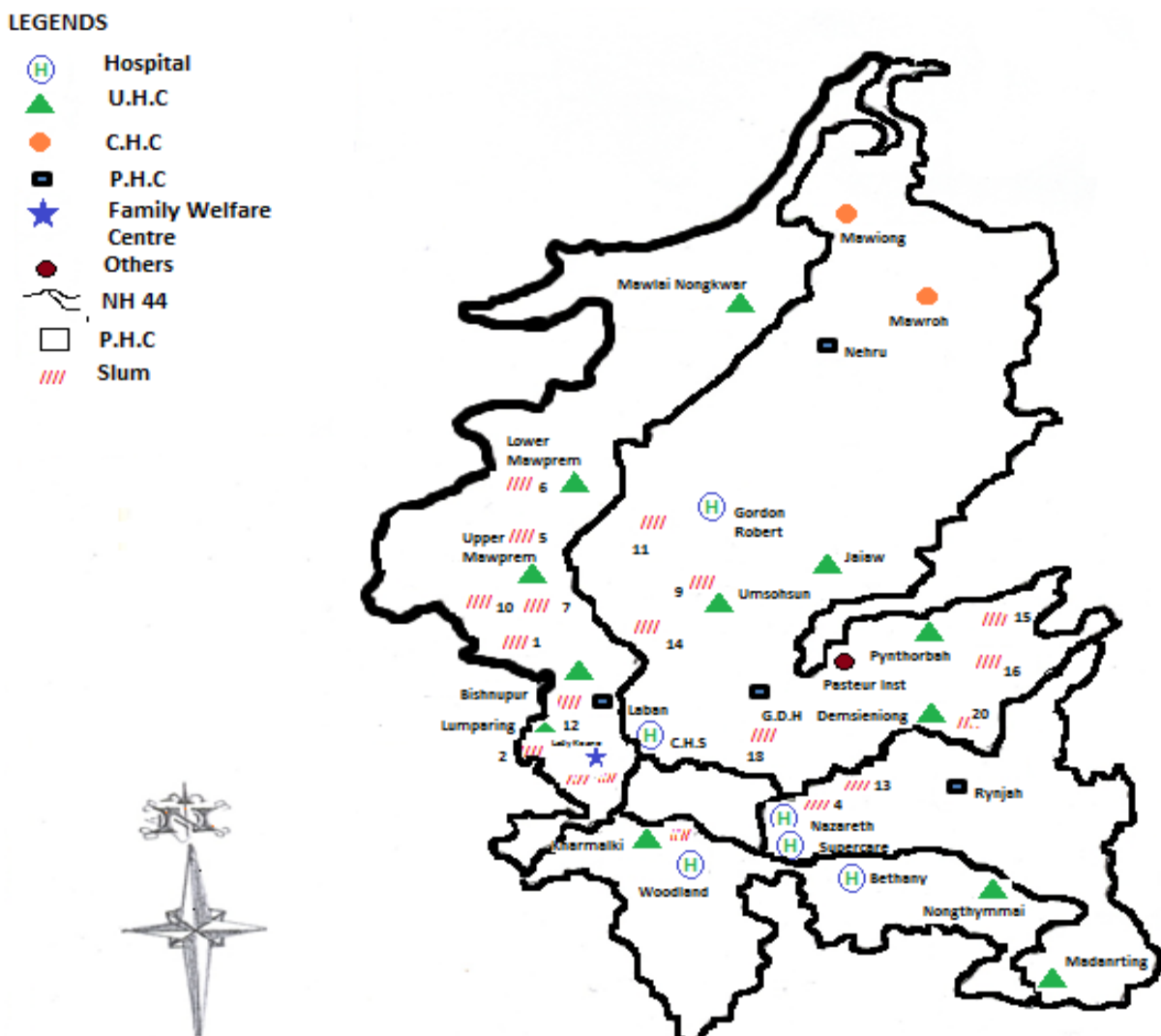
Member of the Legislative Assembly (MLA): The MLA is an elected representative of the state legislature.

2 Study setting

The study was undertaken in the capital city of Shillong. The Meghalaya Slum Area (Improvement and Clearance) Act, 1973, describes a slum as the buildings in any area which 'are in any respect unfit for human habitation or are by reason of dilapidation, overcrowding, narrowness or faulty arrangement of street, lack of ventilation, height, or sanitation, or any combination of some or all of these factors are detrimental to safety or moral of the people of the area' (*The Shillong Times* 2014).

According to information obtained from the Department of Urban Affairs, there are 45 slums in different parts of Meghalaya state (see Figure 2.1). Most of these are in the capital. Shillong has a population of roughly 360,000, of whom 21.5 per cent live in slums. Nineteen of these slums have a 'notified' status and four are considered 'non-notified'.¹

Figure 2.1 City map of Shillong and its slums



Source: IIPH-Northeast (2014), adapted from sketch in NUMH State PIP 2013–14, Meghalaya.

¹ Notified slums are recognised by state governments, municipalities or local bodies. This recognition usually comes with certain rights, which can include access to water and electric power. A non-notified slum is any compact settlement with a collection of poorly built tenements, mostly of a temporary nature, crowded together, usually with inadequate sanitary and drinking water facilities in unhygienic conditions. These were included in the survey, provided at least 20 households live there (NSSO 2013).

The slum residents are rural indigenous migrants from within the state; migrants from states in mainland India, such as Bihar and Bengal; and migrants from neighbouring Bangladesh and nearby Nepal. Xenophobia is rife, due to limited economic opportunities and a fear by indigenous populations of being overwhelmed by 'outsiders'. Some groups believe that the 'growth of non-tribal population in Meghalaya is a threat to life and existence' (Choudhury and Bhattacharjee 2013: 4). Yet in reality, the percentage of non-indigenous to indigenous people in the state has been gradually dwindling since 1971 (Choudhury and Bhattacharjee 2013).

Fearing that they may become a minority in their own land, several powerful groups – notably the local Khasi Student Union – have pressed the government to implement the Inner Line Permit system.² This controversial rule, left over from the colonial era to protect British interests, would require all outsiders to have a permit to enter the state. One of the reasons for implementing the permit system would be to check the influx of illegal migrants from Bangladesh and Nepal (Mukhim 2013).

² Inner Line Permit is an official travel document issued by the Government of India to Indian citizens for travel into protected/restricted area for a limited period (MDONER 2014).

3 Methods

This qualitative case study used multiple methods for data collection.

3.1 Literature review

Information pertaining to the policies and data on urban health, gender, SRH and citizens' participation in policymaking at the state and city level were collated from the Ministry of Health and Family Welfare's (MOHFW) websites for India and Meghalaya. Due to the paucity of peer-reviewed published articles on Meghalaya, we included grey literature, such as reports that contained original and recent data. Examples include census reports, NFHSs and District-level Household Surveys (DLHSs), and the Meghalaya State Development Report. These provided some relevant background information on SRH in Meghalaya and in India at large. These reports did not provide disaggregated data on the health status and health-seeking behaviour of the urban poor.

3.2 In-depth interviews

We conducted a total of 27 in-depth interviews with participants ranging from residents of slum areas to government officials in the Department of Health. To understand issues around women's health, and urban women's participation in policy decision-making in Shillong, 17 participants (13 women and four men) were interviewed. They included women from the slums and the wider community, women leaders, female sex workers and *rangbah shnong* (Khasi male leaders). All the interviews were conducted in the local language by a team of two researchers, where one facilitated the discussion and the other took notes and observed the process. We also interviewed policy actors: government officials, members of the media, and leaders of non-governmental organisations (NGOs). Topic guides were developed and used to assist in conducting the interviews. Based on the preliminary findings and identification of information gaps, interview topic guides were refined in the field as needed. Areas that were further explored included the roles and participation of women and their ability to influence decision-making in traditional institutions. To better understand key issues, we also resorted to informal discussions with Khasi elders, men and women in the community. We had brief informal discussions (with verbal consent) with several government employees who were otherwise reluctant to sign consent forms without a specific approval letter/instructions from their supervisor.

3.3 Focus group discussions

Five focus group discussions (FGDs) were carried out, each with five to seven women. Taking into consideration participants' comfort level, FGDs were held in the women's homes, as decided by the participants. The FGDs were organised by a team of two to four researchers, and were generally conducted in the local language (Khasi). Each FGD lasted about 45–60 minutes.

All the in-depth interviews and FGDs were audio recorded. Field notes were also made by the researchers. The audio recordings were translated and transcribed by the research assistants, who were fluent in Khasi, Hindi and English.

Figure 3.1 FGD in progress



Photographer. © IIPH-Northeast, 2014.

3.4 Digital storytelling

We used personal digital storytelling (DST), a qualitative narrative story method capturing voice and imagery on iPads through various applications, to capture the lived experiences of six women from slum areas. None had ever used an iPad and were unfamiliar with the technology. They were trained in a four-day workshop to produce a personal film/digital story using iPads. The story lines were developed by the women themselves. These were transcribed and converted to story boards by participants with support from the research team. The women used the iPads to create images, to select and take photos, and art materials – pencils, crayons, coloured papers – to illustrate their stories. The women used their own voices during the audio-visual recording of their digital stories.

3.5 Participation and political system mapping

In order to understand how urban women can navigate and engage with the state and indigenous political systems on SRH, the study team brainstormed and mapped the existing social structures and institutions. In the mapping exercise, we then explored if both men and women had similar opportunities in terms of membership, voting rights, or the right to hold office in indigenous and state institutions. This exercise resulted in creating a schematic diagram (see Figure 4.2) that visualises the challenges that women face in participating in local indigenous and state government at different levels. We got feedback from Khasi women and adjusted this diagram in two focus group sessions with members of the *seng kynthei* (traditional women's organisation).

3.6 Sampling

We sampled six urban slums in Shillong, randomly chosen by drawing a straight line across the city map. Those slums that either fell on the line or in close proximity to the line were selected. The slums chosen were Pynthor bah, Nongmysong, Jhalupara, Paltan Bazar,

Madanrting and Demseiniong. A stakeholder listing was done in consultation with an NGO whose work includes interventions for female sex workers. Key informants, snowball sampling and the principle of maximum variation sampling were used to identify participants. We interviewed a total of 47 people, including NGO representatives, officials from the Department of Health, the Department of Urban Affairs, members of the media, representatives of traditional governance institutions, sex workers, and lay members of the community who resided in the slums and surrounding areas. For digital storytelling, women who participated in interviews and/or FGDs were invited to participate as long as they were familiar with using a mobile phone.

3.7 Data analysis

Data collected during interviews and FGDs were translated and transcribed by the research team, usually by the interviewer herself for the sake of consistency and quality. To enhance the quality of the data, different members of the team compared the transcripts with the audio recordings. Individual and joint analysis of the data was undertaken by members of the research team. Data analysis was initiated during data collection itself. The ongoing analysis allowed the research team to discuss, adapt and probe further into themes. Emerging themes were noted and categorised, and relevant quotes extracted.

3.8 Quality and credibility

The field data were collected by three female indigenous research assistants who had past experience in gathering qualitative data. Prior to data collection, the research assistants were briefed on the purpose of the case study and trained in the use of data collection tools.

Quality was maintained during the process of data collection through building good rapport with the respondents before the interviews, clarifying responses, and holding timely reviews and discussions among the research team. Field notes maintained by the researchers were used during debriefing sessions and for team reflections during the data collection process. We also validated the data by using different data sources and checking information with different people. Issues that needed clarification were investigated further either over the phone or in follow-up meetings. Preliminary findings were also presented to female Khasi community members during a feedback session for their comments.

3.9 Study limitations

The study had several limitations. Key concepts like health policy, policy process, community participation and SRH are difficult terms that were not easily translated into the local language and thus posed challenges and, at times, confusion. Researchers had to spend time explaining these concepts, and their explanations might have shaped people's responses. For instance, there is no exact translation for sexual reproductive health; hence, what was used was *jingpangkynthei*, which literally translates as 'diseases of women' or 'women's health issues'.

Studying slums with mixed populations in a context of xenophobia can be difficult due to cultural and political sensitivities. In addition, there are sensitivities related to the marginalised position of indigenous peoples in India. Research permission is required from the *rangbah shnong* (Khasi male headmen), who are the indigenous authorities in charge of different parts of Shillong. Clearance from New Delhi does not have much authority in this setting. The fieldwork team worked through the headmen in line with cultural protocols; however, using these leaders as gatekeepers may have affected who we gained access to and how the researchers were perceived.

This was a small sample that cannot claim to be representative of the entire urban Khasi community.

3.10 Ethics

The study received clearance from the Ethics Committee of the Public Health Foundation of India (PHFI). In addition, we obtained permission from the local council/headman before any fieldwork activities were carried out. The team also ensured that the purpose and background of the study was explained to potential participants in the local language. Prior to any interview or FGD, researchers obtained written consent from most of the participants. In some instances, for those not comfortable with signing forms, their verbal consent was obtained. Transcripts were coded and quotes anonymised during data analysis and report writing to maintain individual confidentiality.

We also obtained permission and written consent to publish the research results and reproduce the digital stories for educational, advocacy, and non-commercial purposes.

4 Results

4.1 Health policy and evidence-based urban health planning

In 2013, the National Urban Health Mission (NUHM) was launched with the aim 'to improve the health status of the urban population in general, but particularly of the poor and other disadvantaged sections, by facilitating equitable access to quality health care through a revamped public health system, partnerships, community-based mechanism with the active involvement of the urban local bodies' (NUHM 2013: 29). These goals are to be achieved by strengthening the existing health-care system, and by working with various government efforts in slum areas, such as those to improve access to sanitation, clean water and education. The NUHM framework for implementation provides for both institutional mechanisms as well as partnerships with community and local bodies for a more proactive involvement in planning, implementation and monitoring of health activities.

Under the NUHM there are 19 Urban Health Centres (UHCs) in Meghalaya that cater to the needs of the urban poor in terms of basic health-care services. The UHCs are located in Shillong (13), Jowai (2), Nongstoin (1) and Tura (3). The UHCs are functional but require additional manpower, equipment, and medicines to make them fully operational (CRM-7 2013). Urban Reproductive and Child Health (RCH) service delivery indicators like antenatal and postnatal check-ups show poor performance.

So while there are policies to improve urban health, and ample political goodwill, there are still gaps in care and much more needs to be done on the ground.

4.1.1 Meghalaya state-specific policy and planning

Under India's federal structure, health is the purview of the state (Article 246, List II, Constitution of India). States have the power and responsibility to develop their own health policy. But Meghalaya has not yet published one. Although a draft was formulated, it has not been finalised or made public. In its absence, the health policy and programme guidelines issued by the central government are used in shaping state programmes.

One of the reasons cited for poor health outcomes in Meghalaya is the low and declining levels of public spending on health. The state drafts a health budget and contributes a proportion of its finances towards health programmes. Yet in the decade 1999–2009, there was a steady decline in the share of expenditure on health and family welfare, from an 8 per cent share of total spending in 2001-02 to 3.9 per cent in 2008-09 (see Table 4.1).

The bulk of national programmes, such as the National Rural Health Mission (NRHM), are funded by the central government, where the Centre (central government) provides 90 per cent and states contribute 10 per cent of the fund (Chaturvedi 2011). In the absence of a declared state health policy, national guidelines and policies are implemented in the state by default.

Most of the SRH-related services are implemented through India's RCH and HIV/AIDS control programmes. Though these are independent components, there is a convergence of these programmes. For example, all pregnant mothers reporting for antenatal care must undergo HIV screening.

Table 4.1 Expenditure on health and family welfare in Meghalaya

Year	State total: Expenditure in lakhs (1 lakh=100,000 rupees)	State expenditure on health and family welfare	Share of expenditure on health and family welfare (% of total)
1999–2000	85,864.37	6,368.00	7.4
2000–01	1,03,697.08	7,050.59	6.8
2001–02	1,02,447.99	8,206.93	8.0
2002–03	1,09,579.18	8,186.40	7.5
2003–04	1,82,084.77	8,256.43	4.5
2004–05	2,07,234.21	9,194.87	4.4
2005–06	2,00,709.28	9,602.81	4.8
2006–07	2,32,010.25	9,910.97	4.3
2007–08	3,44,846.82	12,742.89	3.7
2008–09	3,97,322.38	15,484.94	3.9

Source: Government of Meghalaya (2009b: 40).

On paper, national programmes recommend a bottom-up planning process of health schemes (MOHFW 2005). However, this bottom-up planning process, where the Centre tries to incorporate state-based plans, which are collated by districts, works only to a limited extent. The process is reportedly quite lengthy as the collation of information at different levels is both time consuming and fraught with challenges, especially when there are delays along the chain in submitting reports.

But see when we do the PIP [programme implementation plan], we do the planning [from district level], we have to prioritise our needs, but then approval is with the state. The state collects from all the districts and makes the state PIP. It is then sent to Centre, so it's not up to us.
(Senior Medical Officer, woman)

Projections are made based on the number of pregnant women or women of reproductive age. One government official's interpretation of tailoring national guidelines to the state's needs is that this is at times limited to ordering the right number of items from the central government.

We have to ask the Centre according to our needs and what we require. For example, maternal care: according to the population or survey, we know the number of pregnant mothers. So the Centre will provide money for iron, folic acid, for immunisations, for institutional birth corresponding to our requirements.
(Senior Technocrat, government official, woman)

The amount that the state projects in its PIP is often not fully approved by the Centre. In such instances, one of the challenges reportedly faced within the health department is the lack of a mechanism to efficiently allocate resources at the block and district levels, taking into consideration the initial plans and the final (lower) allocation.

During interviews, NGOs and community members observed that the centrally sponsored schemes are developed based on indicators from national-level data that often represent much larger states. It was pointed out that states such as Uttar Pradesh, Bihar and Rajasthan are different socially, culturally and politically, thus strategies based on their experiences may not be appropriate for Meghalaya. One example that was provided is the emphasis on hospital-based deliveries and the overlooking of locally available and experienced traditional birth attendants.

For instance, if we are to make a health policy to address the infant mortality rate or maternal mortality rate, institutional delivery is not the best option [in Meghalaya]. As many women do not have the time or money to travel and spend two or three days in the hospital before labour. They have totally ignored the role of traditional birth attendants and traditional healers. It is the same old cut-and-paste policy. The national programme is important but there is no innovation anywhere.
(Executive Director – NGO, woman)

The lack of participation and engagement with the community in an ongoing manner was indicated as a reason for the failure, or poor effectiveness, of many well-intended programmes.

It has been top down. It has been talked down to people and programmes never came from the ground. And it was never participatory you know. You had those Government of India programmes on reproductive health, so you just brought it here, and you just imposed it on people. And you are giving out condoms and you are telling people to do IUD and all of that without first explaining to them, without having these participatory sessions. Because I think the problem with the government is that, it takes shortcuts and it is target driven where you have to complete the target.
(Activist and media representative, woman)

Those outside the health system were unsure if Meghalaya's officials engaged sufficiently with the Centre to develop more appropriate health intervention strategies. Bureaucrats having to handle multiple portfolios and the associated time constraints were cited as another potential reason for the lack of sufficient engagement.

I'm not sure it is done. Because in order to change any component of that policy you have to go to Delhi; you have to debate it out with people [at the national level]. You have to convince them that what you are giving us was conceived by looking at a few parameters in some of the big states, which don't suit the smaller states or the hill states [...] A bureaucrat doesn't specialise in any single issue or in any single sector. He is looking at health, he is looking at something else, and something else, and therefore his concentration is on diverse [portfolios] you know... They are not informed enough to be able to be engaged with the planning commission in Delhi.
(Activist and media representative, woman)

Thus, despite the rhetoric of bottom-up planning and involvement of the community, planning is fairly centre dependent. To some activists the current planning is seen as inappropriate for Meghalaya, as the northeastern states are seen to differ from many of the larger Indian states. State plans are often based on population data, especially numbers of women of reproductive age in the community. This may not reflect the actual needs of SRH services within different age groups.

4.1.2 Evidence-based health systems planning

Accurate and pertinent data with regard to sexual health among slum dwellers generally does not exist in Meghalaya. The main source of health data is the Health Management Information System (HMIS), yet its statistics are not disaggregated for slums. The NFHSs gather information on urban dwellers but not on SRH. This is a challenge for policymakers.

We have 13 urban health centres [UHCs] in Shillong, so based on the HMIS reports from them we make the planning and all. We do not have any segregated data of slums or urban poor. But we have the aggregated information including the slums that lie within the jurisdiction of that UHC.
(Senior Medical Officer, woman)

NGOs working in health expressed scepticism on the quality and relevance of the HMIS system as the main source of data for monthly plans and target setting for the government.

But how reliable are these HMIS reports? When most of the health centres do not function properly, my question is how are they able to generate data which shows good performance? It is not projected genuinely. Despite the drawback in the quality of data, these HMIS data are also not easily accessible to civil society, and the government maintains them as though they are their private property.
(Executive Director – NGO, woman)

Overall, there is very little health research addressing local issues in the state. There is a paucity of epidemiological data, as well as information about sociocultural, political and economic factors. There is limited data on health-seeking behaviours in the state. From health records it is almost impossible to distinguish between the health-seeking behaviour of a slum dweller from those in other locations or of a different social class. The geographic boundaries of the slum areas are rather fluid, especially in terms of residents' perception of what a slum is. Also, in many parts of the city, relatively economically well-off (middle-class) residents live adjacent to slums and use nearby health services. This highlights some of the challenges in detecting whether there are differences in health-seeking behaviours and the health status between the middle class, the urban poor and slum residents.

4.2 Health seeking and perceptions of quality of facilities

Government health services are available and relatively easy to access. In many instances, the urban poor access health services, including sexual and reproductive health (SRH) services, from government-managed public health centres. Those interviewed noted that health centres and tertiary hospitals were located near slum areas. The services provided were cost effective when compared to services in the private sector.

We are happy because the dispensary is nearer you see; moreover, we don't have to pay much. Visiting a private doctor, the expenses are more.
(Lay member of the community, woman)

But it was reported that visits to (free or low-cost) government-managed health centres can result in out-of-pocket expenses, when patients must purchase prescription drugs and have laboratory tests performed at private labs.

Now if we go to the doctor, they say: go for blood tests, urine tests. If I listen to the amount [price] of the blood test, I am done. I do not have enough money and they say, go and do blood test. I cannot afford.
(FGD No 2 – Demseiniong, lay member of the community, woman)

In recent years, the government introduced the Meghalaya Health Insurance Scheme (MHIS) that covers a family of five for a fixed amount of health expenses. But the programme, according to those interviewed, does not cover all costs.

There are those illnesses that are included and there are those that are excluded in this insurance. If the illness is covered in this scheme, the amount spent, say some thousands a year, will be given back by the government. Okay, some get this money and some do not.
(Lay member of the community, woman)

Moralistic attitudes and rude behaviour of staff caused some women to hesitate seeking help from government-run facilities especially for sexually transmitted infections (STIs).

When I sent people for STIs to civil hospital [government], people are not so comfortable... The behaviour of the people at the ticket counter also is not so good: they don't open in time, have to wait so long, people are frustrated. The doctors are fine but the other people, they don't know how to speak. They should be very polite to the people – the suffering people, but they are rude.
(Lay member of the community, woman)

Although the urban poor turned to public sector facilities, at times they report having to seek care at private hospitals due to the long waiting times that would force them to miss work.

There are many hospitals around Shillong but poor families mostly go to the dispensary [UHC] here. But sometimes they don't have time to wait there all day... They have to think [about time lost] for they work too.
(Lay member of the community, woman)

4.3 Social determinants, poverty and health

Despite the close proximity of UHCs and the availability of health insurance, some women living in slums reportedly hold back from seeking health care for fear of out-of-pocket expenses. Going to the doctor could involve spending money that they would otherwise use to buy food or spend on their children's education. Women often subordinate their own health to the needs of others.

The only thing we fear are the medical bills. We know in advance that a certain sickness is going to cost us that much in this or that hospital. Other than that there is no fear. If we can afford, yes, we would be happy to get our treatment at the hospitals.
(Lay member of the community, woman)

In addition to not always seeking health care, poor women reported not getting enough to eat. But a lack of education/nutritional awareness also contributes to poor dietary practices.

Food was a problem for us and we cannot afford nutritious food. We ate only twice a day, and only rice and some vegetables.
(DST participant, woman)

Another thing is that the poor people in our locality, many of them are anaemic. Maybe many times they do not know what to eat or overeat other things that they are not supposed to. Also the poor do not have too many choices as to the varieties of food to eat – food that contains sufficient nutrition. They only consume the food that they can afford to buy. Unless the poverty line can be raised, there will always be many poor and sick people.
(Lay member of the community, woman)

During the making of the digital stories, the six women provided detailed narratives of their life stories. Issues, both economic and social, that affected their lives and influenced their decisions about health became evident in these narratives. Two of the six women reported that they lived in women-headed households because of an illness-related death. Three women had experienced the death of a child.

In the digital stories, alcohol and its effects on the family appeared as a cross-cutting theme. Although the women did not specifically highlight alcohol as an issue, the research team was struck by how excessive consumption of alcohol by a family member (usually a spouse or parent) had negatively affected four of the six women's lives at some point in time.

He starts drinking at night. When he is drunk he looks for fights, accuses me of having an affair. When I was pregnant with my first child he told me he had an affair with another woman. So I decided to leave him, I was 20 years old. I could not think properly, I felt ashamed to be a single mother. I felt scared... I thought I would go crazy with worry.

(DST participant, woman)

Women internalise notions of being second-class citizens, which prevents them from asserting their rights.

Some women will come with problems for not conceiving a baby... They don't know where to go and what to do. Maybe it is not because of the woman. It may be the husband. But they will never say it's the man who may have the problem. They will blame the women for not conceiving.

(Lay member of the community, woman)

Although studies reported that Khasi women are able to make health-care decisions on their own (Singh *et al.* 2010; Chakrabarti and Chaudhuri 2007) we encountered several women who reported being subordinate to spousal decisions on seeking health care.

No I haven't taken any medicines because when I told my husband that I need to take medicines regarding these [STI] problems, he doesn't allow me to. He always questions me if I ask him for money for medicines.

(FGD No 5, Demseiniong, lay member of the community, woman)

In sum, poverty restricts women's decision-making when it comes to their own health and in using services that enable them to live a healthy life. While poverty influenced their health-seeking behaviour, a death in the family invariably pushed these women further into poverty. Excess alcohol consumption had a deleterious effect on the lives of several urban women interviewed. Despite the matrilineal family structures some women are subordinate to spousal decision-making when it comes to health.

4.4 Narrow view of sexual and reproductive health (SRH)

Sexual and reproductive health rights (SRHR) are understood as the rights of all people, irrespective of age, gender, and socioeconomic status to make informed choices regarding their own sexuality and reproduction, provided others' rights are respected (UNPFA 2008). It includes the right to access information and services to support these choices and promote SRH. In Shillong, there is seemingly a narrow understanding of SRH issues, which is often restricted to contraception and pregnancy. Women's rights and sexual rights are related. Women have a right to pleasurable and safe sexual experiences, free of coercion, discrimination and violence.³ Domestic violence in various forms – including forced sex and forced pregnancy – was an important theme in the digital stories. Women recalled their own lack of awareness and the need for information about SRH.

I had a baby in my stomach. I did not even know that I was pregnant. There was an aunty in the neighbourhood she said, 'You are pregnant.' I said, 'No, I am not; my stomach is also same, I just had food, so it's big.'

(Lay member of the community, woman)

³ The World Health Organization (WHO) defines sexual health as 'a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled.'

I only want information about how to delay pregnancy, because I have never tried it before so I don't know anything about it. What should I do? I already have three children.

(Lay member of the community, woman)

In general, people in the community are uncomfortable discussing sexual health. Societal norms and notions of what 'good manners' are contributes to the silence on sexuality within the community.

It'll be tough to speak about that [sexual matters] with people. They will say that women do not have manners or are shameless.

(FGD No 5 –Demseiniong, lay member of the community, woman)

It is very difficult to talk about that with other people openly.

(FGD No 2 – Demseiniong, lay member of the community, woman)

One limitation is the lack of appropriate words in the local language to discuss SRH. This was one of the challenges faced by the research team during fieldwork. Women often used general phrases that literally translated as women's problems or women's diseases.

It is very difficult we don't have such words to explain what sexual reproductive health means.

(Lay member of the community, woman)

In most of the interviews, women reported that they prefer to receive information about SRH services from their peers. Women, especially, rely on the experiences of peers for decision-making on choice of provider or general health-seeking behaviour.

If they tell us about their problems, if we know, we will tell them, 'Oh! I am facing the same problem, I go to this doctor for treatment and now I am cured.' So we would only suggest where to seek help but we will never force them.

(FGD No 1 – Jhalupara, lay member of the community, woman)

We talk only among ourselves with friends whom we can trust.

(FGD No 2 – Demseiniong, lay member of the community, woman)

Some policymakers and survey findings have indicated the Khasi people have a cultural preference for large families (CRM-7 2013) and thus limited interest in family planning. Our interviews found that women did want more information on contraception and the spacing of children. In the view of one social activist, reflected in the quote below, men too would be interested if they were addressed appropriately:

The men will not come [if the focus is on women] whereas to my mind if you are looking at reproductive health you ought to look at men and women. Otherwise it's never going to happen. Because at the end of the day, if you talk only to the woman and expect that the woman will convince the man, the man will not be convinced and they will say what nonsense and all. And I have seen this happening in West Khasi Hills where I have done a few programmes. We've called both men and women and the men became so enlightened, they feel that as if a veil is being lifted about something that they never thought of before and they said that if somebody would have told us 10–20 years ago, we might not have so many children. We would have known how to space and all that.

(Activist and media representative, woman)

Men and women worry about the contraceptive technologies offered by the state because there is a shortage of trained staff, and facilities are often closed. There was some hesitation

about relying on hormonal contraceptives, such as the Pill, and on technologies, such as IUDs and tubectomies that require regular follow-ups by trained medical staff. To suggest that the Khasi people have a lot of children only because of religious and cultural beliefs is a view based on very limited information (Oosterhoff, Dkhar and Albert 2014).

Overall, there is limited knowledge among women from the slums in Shillong about health conditions and choices when it comes to SRH. This lack of knowledge was also reinforced by a lack of service provision for SRH. For example, there are very limited services to terminate pregnancies in the state.

The lack of awareness of SRH-related issues and the need for raising awareness was also highlighted.

Counselling of people should be there, to teach what health is. Through this, only people will come to know and participate. Awareness should be there. Like there are women who have STIs and they drink alcohol; they want to die fast. They don't know it's curable, why?

(Lay member of the community, woman)

In sum, there is a general silence in society about sexuality. Women find it difficult to discuss SRH issues due to negative cultural mores on the 'inappropriateness' of discussing sex and sexuality. There is a narrow understanding of SRH issues that is often restricted to contraception and pregnancy.

4.5 Civil society participation in policy

Few civil society organisations and NGOs engage with the state on policy. Most are implementing programmes that provide services.

In order to formulate a policy or to adapt central guidelines for the state, community people have to be consulted. It will be a long process. We've been waiting since 2009 [for the Meghalaya Health Policy draft]. We are in a democratic country so start practising democracy at least from one policy. But even when the health policy becomes a reality that still will not have voices of the people.

(Programme Manager – NGO, woman)

NGOs in Shillong seemingly serve as either beneficiaries or implementing agencies of government projects. Though they also lobby the government, they are limited to securing services and benefits within the existing policies and programme.

We look if the CHC⁴ or the PHC⁵ is functioning properly or not, and we also assess the needs of the people. We look at different existing policies and programmes and the components in it. We advocate if those components do not reach the people.

(Programme Manager – NGO, woman)

One activist and media representative argued that civilians in Meghalaya in general did not engage much with policymaking. One reason for disengagement was a lack in capacity of most civil society groups to engage meaningfully at different levels.⁶ The lack of an evolved and informed civil society that engages with government meaningfully in policy development was highlighted.

⁴ Community Health Centre.

⁵ Primary Health Centre.

⁶ There are, however, some interest/pressure groups, such as those that work on the Inner Line Permit that do manage to get access to the media and to political leaders.

You see, the civil society here has never engaged itself with policymaking... So we don't really have an evolved civil society that is enlightened enough to engage with government. Because in order to engage with government you need to have a set of shadow policies of your own to present to the government.

(Activist and media representative, woman)

Community engagement in health programmes could conceivably take place through the Village Health, Sanitation and Nutrition Committees (VHSNCs). A recent assessment of the state health system by a national team, however, observed that there is low engagement of VHSNCs in the state, and poor involvement of members of local governance institutions with the health system (CRM-7 Meghalaya 2013). They also observed that monitoring mechanisms are poor and that often immunisation schemes get priority over other health services.

When we asked about the relevance of various programmes under the NUHM in Meghalaya, a key informant and social activist flagged the need to put terms into the local language in order to improve the grasp of the relevant issues:

I asked somebody why do you have these funny Indian words... why not have a Khasi word appropriate for that? Then I can own it. If I don't understand that stupid word then how can I own it? Why would I collaborate? Why would I participate? I don't care, it's all a government of India thing. In some places people have understood the meaning of ASHA,⁷ they've used their services, but this USHA⁸ is completely new to the people.

(Activist and media representative, woman)

In general, community monitoring, social audits and grievance redressal systems are absent or rudimentary in the state. At the community level, it is not yet clear what the new urban public health system is, who the partners are, and what the community mechanisms are through which people can speak about health care. The result is disengagement and a lack of interest in the formal governmental processes of urban health policy formulation even when there are opportunities for greater participation. The community also requires capacity strengthening for meaningful engagement with the government.

4.6 Participation in an indigenous context and relationship with the state

4.6.1 Traditional governance institutions and their relevance

Governance structures in Meghalaya are complex, with both indigenous Khasi governance institutions, national state and government machinery, and constitutionally created autonomous district councils (ADC). These diverse institutions and structures exist independently yet wield power in parallel.

Urban Shillong consists of villages that have been absorbed by the city. The governance structures of these villages are still operational. At the village level, in terms of administration and justice, the Khasis have their own *dorbar* (traditional governance institutions). Khasi men choose their own *rangbah shnong* (village headman) and his *rangbah dong* (council of executives) to look after judicial and administrative affairs (Mawrie 2010: 88–91). Only men can be members.

⁷ Locally accredited social health activists.

⁸ Urban social health activists, frontline health workers for urban areas.

Figure 4.1 Notification by *dorbar shnong*, village council



Photographer: © Oosterhoff, 2014.

Notionally and traditionally, the *dorbars* are accountable to *syiems*, dynastic rulers of kingdoms formed from grouping village clusters (Bareh 1997). The *syiems* and their councils of *myntiris*, perform both executive and judicial functions.

The Sixth Schedule of the Indian Constitution provides for a special administrative setup allowing partial self-governance of tribal areas in some northeastern states (NIPFP 2013: 1). It established ADCs, which have elaborate legislative, administrative and judicial powers on paper. In Meghalaya, there are three ADCs that have official authority over traditional institutions, although in practice their authority is fairly limited. The councils are endowed with power over traditional institutions in matters related to appointments and the succession of chiefs and headmen during emergencies (NIPFP 2013). The creation of the ADCs, supposedly to preserve the traditional system of governance, has in fact thus introduced a non-traditional apex administrative institution that has – on paper – executive powers over the *hima* (kingdom) and the *dorbar shnong* (locality level). At the same time, the state government has overriding and overlapping powers with respect to the ADCs and this creates an anomalous governance system (Chatopadhyay 2013).

Within the state government there are also some misgivings about the relevance of the ADCs, especially considering its record of achievements (Government of Meghalaya 2009a: 9). The Meghalaya People's Human Rights Council (MPHRC 2012) has criticised such an arrangement as ineffective and unproductive in the absence of adequate mechanisms for coordination between the district council, the state government, and traditional institutions. As a consequence, the MPHRC has argued that 'the councils have neither been able to do anything of standard in the interest of hill masses nor to involve the poor indigenous peoples in development activities either as beneficiaries or as decision-makers on any significant scale' (MPHRC 2012: 4).

There are too many parallel institutions, they are all working at cross purposes and the government is happy to allow this to happen because you can blame this and there are many people to blame... The district councils have no important matters to look after, frankly speaking, and they don't have the mechanism to deliver.
(Activist and media representative, woman)

Thus there are multiple and parallel power structures, which lead to confusion and even paralysis in governance in some instances. The relationships between traditional institutions and the state authorities, including municipal authorities, are highly contentious, especially

with regard to land. A Supreme Court ruling upheld an appeal of the traditional authorities that establishes the authority of the indigenous authorities, the *syiem* of Myllem in the municipal areas (*The Shillong Times* 2012a). Although the hierarchical relationships between the municipal and the indigenous authorities can be subject to diverse interpretations, for effective implementation of programmes, the state should involve local indigenous authorities, as governance at a local level is controlled by the traditional indigenous authorities.

4.6.2 Women's participation in the indigenous context

We explored women's participation in relation to the Khasi traditional governance and the state institutions further to understand the dynamics. Figure 4.2 was developed during the course of the study to visualise the various channels through which women could participate in decision-making. We focused on exploring the ability of women and men to vote and hold offices within traditional and modern institutions.

In Khasi society, women were traditionally not encouraged to participate in political matters. These sentiments were echoed by participants in this study:

Women are barred from holding office: they can't be rangbah shnong, they can't be the executive members, they can only be in the periphery – you know to sort of help the men to carry on their work.

(Activist and media representative, woman)

In the traditional Khasi governance system, Khasi women – rich and poor – are excluded from voting and holding office. The *seng kynthei* (traditional women's organisation) has a limited role in decision-making in community matters. The roles that women play in the community are mostly welfare-related activities, such as helping with funeral services and village cleaning tasks, and assisting in enforcing rules and regulations made by *rangbah shnong*. 'We are only looking at whether there should be no alcohol in the village,' said one member of *seng kynthei*. Larger decisions, she said, were left to the men.

Well, I would say that the seng kynthei or seng samla are the branches of the community shnong but finally if it comes into the decision-making we [dorbar] are the ones to take the decision not them.

(Headman)

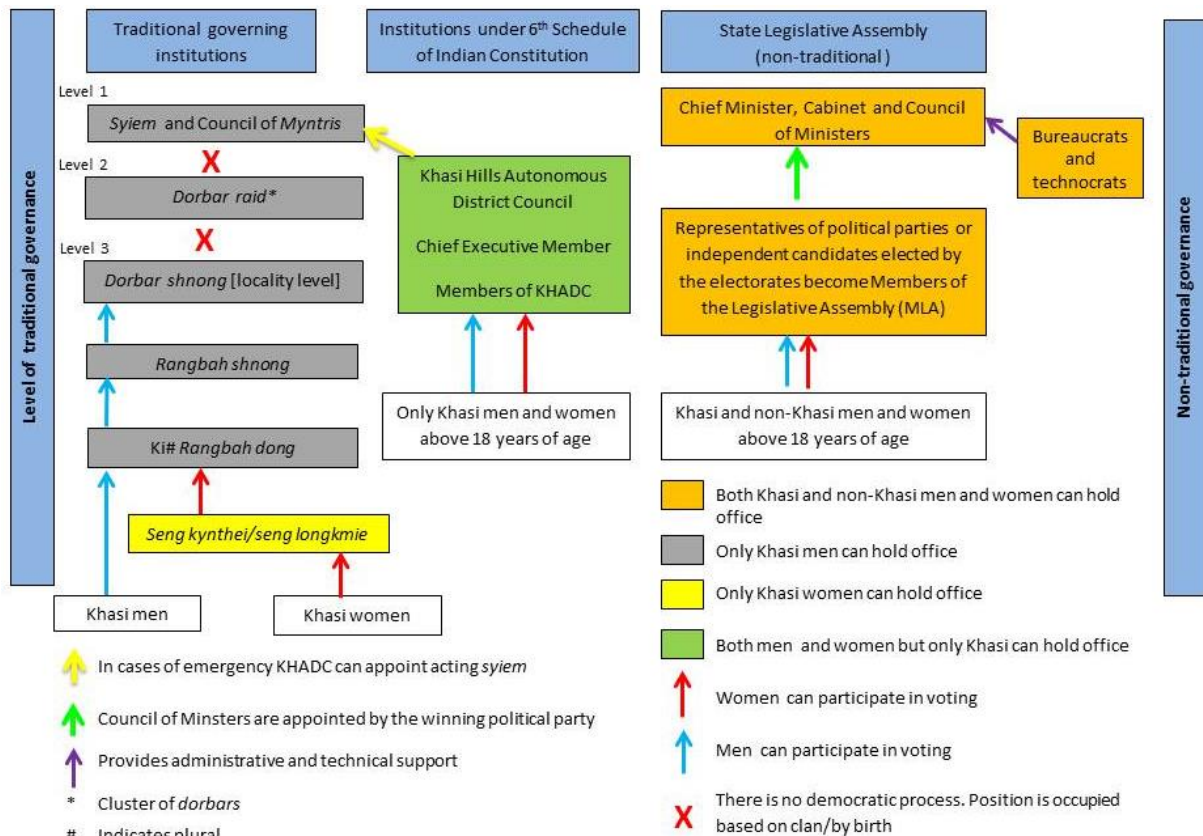
In recent years, there is reportedly one locality, Laitumkhrah, where some progress has been made in allowing women to be part of the *dorbar*, but again it is a rather limited kind of participation as the quote below from the headman reveals:

Traditionally, dorbars don't even allow the women to vote; they are not allowed to hold office in the executive committee. In a locality [like Laitumkhrah] you may have one or two women who are members of the executive committee, but they are not allowed to hold the post of secretary or rangbah shnong [headman].

Within the state governance system the opportunities for Khasi women are relatively better, as women can vote and hold office at all levels. Political parties typically have a women's wing, such as the Mahila Congress Committee and the women's wing of the Hill People Union. These groups give some political and administrative representation to women (Joshi 2004). During elections, they actively participate in political campaigns. And despite the relative lack of a political voice in the state, women turn out in large numbers to vote. In the 2013 state election, four women were elected to the 60-seat legislature. Three of them hold ministerial portfolios – in the Home Department, the Department of Urban Affairs and the Department of Social Welfare (Liberty Institute 2013a). In the 2013 assembly election, of the 345 candidates who ran for office, 25 were women and eight of these women ran as

independent candidates, not representing any political party (Liberty Institute 2013b). The reasons cited for so few women in politics are a lack of interest among women and an unwillingness of political parties to field women candidates.

Figure 4.2 Opportunities and barriers for participation of men and women in traditional and constitutional political institutions



Source: Authors' own.

5 Discussion and conclusions

Research and collection of data at different levels is crucial for improving health systems (Ranson, Law and Bennett 2010; Remme *et al.* 2010; WHO 2007; WHO 2009). Estimation of disease burden based on sound epidemiological investigations can help shape public policy regarding health (NCMH 2005). Such evidence can also inform and enable policymakers and health professionals to judiciously target and prioritise disease and decide on where and when they will launch interventions (WHO 2014a). This is generally lacking in Meghalaya. Currently, there is no comprehensive data available on disease burden and health trends in the state. Nor is there much local research on the social and cultural factors that affect health. Similarly, the absence of good-quality empirical data can affect programme design and, consequently, outcomes (NCMH 2005). Most of the policies and programmes in the state of Meghalaya are Centre-driven to achieve national goals. It is unclear what proportion of the national priorities reflects local ones. Although it could be argued that poor health indices necessitate focusing on national health goals, it could also be argued that availability of locally relevant contextual data would enhance local goal setting and policy formulation, and also help in implementing programmes effectively (for example, family planning).

Meghalaya is not unique in terms of this lack of health-based statistics. Many cities lack city-specific epidemiological data, have inadequate information on the urban poor, and/or are unaware of the use of existing health facilities. The result is that health planning is not based on community needs (NUHM 2013: 27). When data is available in survey form, there is a lack of disaggregated data. This potentially hides health inequalities between and within communities, and obscures poor people's lack of access to health services. Being unable to determine which women are dying from what interferes with designing strategies to reach the most vulnerable populations (Khanna 2013; Hazarika 2010).

Though government and policymakers are beginning to recognise the importance of community participation in decision-making, often public policies are made without adequate input from outside sources and without adequate debate on the issues (Agrawal and Somanathan 2005). In Meghalaya, there is limited opportunity for public participation and a lack of transparency in the decision-making process. Poor understanding of the policy process and a lack of capacity may also be factors hindering the proactive participation of public and civil society in the process. There are few, if any, structural and procedural mechanisms for community participation when it comes to developing policy and prioritising health needs in Meghalaya. Although the NUHM envisages active community participation and provides guidelines for establishing community processes, these are rudimentary at present and fraught with challenges. The community-based selection of the ASHA worker is an important tenet of the NUHM but in Meghalaya often it is the headman who controls this selection (CRM-7 Meghalaya 2013).

In Meghalaya, despite the Khasi society being matrilineal and matrilineal, women are largely excluded from local indigenous political systems and processes. In the traditional institutions in Shillong, the *dorbar* (local council) women cannot hold office nor are they allowed to attend *dorbar* meetings (Lalkima 2009: 45). The *seng kynthe*, (traditional women's organisation) has a limited role and capacity in decision-making in community matters. The tradition of public politics and administration being a man's domain is strongly embedded in Khasi society. First, women cannot hold the highest post of governance. Second, their membership is limited to women's organisations. Third, they are deprived of voting rights within traditional institutions. As a result, women's views and perspectives are often not heard. The question is: when women's voices are never heard, can their SRH and rights be a priority?

SRHR are understood as the rights of all people, irrespective of age, gender and socioeconomic status to make informed choices regarding their own sexuality and reproduction (UNFPA 2008). Our findings suggest a narrow understanding of SRH issues

among both the urban poor and policymakers in Shillong that is restricted to family planning. The dominant discourse among both groups pays no attention to women's sexual and reproductive rights, including the right to pleasure. Instead, SRH is related to a narrow view of family planning with a focus on specific contraceptive technologies and a narrow view of maternal health focusing on hospital-based deliveries.

There also exists a culture of silence with respect to SRH among Khasi women. Despite cultural mores that are more liberal than in other parts of the country, for example with regard to co-habitation and choice of marriage partner, women acknowledged that it is not easy to discuss matters pertaining to sexual health. These views have been corroborated by young indigenous Khasi students (War and Albert 2013).

Gender norms and inequalities are barriers to women in making decisions about their own health, which can then serve to limit their access to health services. Women reinforce their own exclusion by subordinating to a headman, who is also in many ways powerless in relationship with the government. Given their limited political power, the ability of women to participate in public decision-making when it comes to SRH is minimal. Although women do participate to some extent in state governance bodies, their own experiences, needs and preferences are largely invisible to policymakers. Many women have internalised a sense of inferiority that prevents them from actively participating and voicing their ideas.

Economic and social conditions are factors that influence differences in health status and health inequality. Poverty is a contributory factor to illness, as the poor typically lack proper shelter, clean water and sanitation, and they have limited access to nutritious food (WHO 2014b). The general issues related to water, sanitation and shelter hold true for urban slums in Shillong too. As purchasing power shrinks, so too does the ability to afford nutritional food. Malnutrition and illness mean that more money will be spent on health care (Black *et al.* 2008). Out-of-pocket expenditure for health can be so high that they can push households into poverty (WHO 2005). Our findings also suggest that poverty, illness, and out-of-pocket expenses are part of a vicious cycle that deters women from accessing health services.

6 Recommendations

- Fund and improve research at sub-national/local levels on gender, governance and health to inform policy and programme decisions.
- Facilitate and improve transparent civil participation processes that engage with men and women as recommended in the NUHM. Use locally meaningful labels to replace the Hindi terms that are currently used when implementing central programmes.
- Develop feedback mechanisms between state and civil society, including women's indigenous groups.
- Fund specific awareness/sensitising programmes on gender issues and gender inequalities that involve men in the health sector and other areas.
- Document women's attitudes and voices on what constitutes empowerment within the indigenous cultural and governance context.
- Develop pilot programmes to improve governance processes for direct access by women to state benefits and services through indigenous and state institutions.
- Facilitate social audits of the health system and improve human capacity of civil society groups, including indigenous groups, for undertaking social audits, and monitoring and evaluation. Develop quality assurance units and appropriate grievance redress mechanisms at health facilities.

Annex 1 List of respondents (in-depth interviews with community members)

Respondent code	Place of residence	Sex	Age	Date of interview	Marital status	Education	Position in the community	No of children	Slum inhabitant
R-001	Nongmynsong	F	46	09-08-2014	Single	Class VI	Female sex worker	5	Yes
R-002	Paltan Bazar	F	30	09-09-2014	Married	Class X	<i>Anganwadi</i> ⁹ worker	1	Yes
R-003	Jhalupara	F	39	09-09-2014	Married	Class X	<i>Anganwadi</i> worker	2	Yes
R-004	Pynthor bah	M	43	09-11-2014	Married	PhD	Headman	NA	Yes
R-005	Pynthor bah	F	63	09-11-2014	Married	Class VI	President, <i>Seng kynthei</i>	2	Yes
R-006	Pynthor bah	F	18	09-11-2014	Married	Class II	Community resident	2	Yes
R-007	Nongmynsong	F	43	09-11-2014	Married	Graduate	Community resident	3	Yes
R-008	Nongmynsong	F	40	09-12-2014	Married	Class X	Community resident	0	Yes
R-009	Madanrting	F	41	16-09-2014	Married	Class X	Community resident	4	Yes
R-010	Madanrting	F	54	16-09-2014	Married	Class IX	Community resident	6	Yes
R-011	Madanrting	F	58	16-09-2014	Married	Graduate	Community resident	3	No
R-012	Madanrting	M	40	18-09-2014	Married	Masters	Headman	NA	No
R-013	Madanrting	F	28	19-09-2014	Married	Graduate	Ex-ASHA facilitator	2	Yes
R-014	Pynthor bah	F	23	20-09-2014	Married	Class II	<i>Dorbar</i> clerk	2	Yes
R-015	Pynthor bah	F	28	20-09-2014	Married	Class I	<i>Dorbar</i> clerk	3	Yes
R-016	Laitumkhrah	M	65	14-10-2014	Married	NA	Headman	NA	No
R-017	Laitumkhrah	M	62	14-10-2014	Married	Masters	Headman	NA	No

⁹ *Anganwadi* workers are frontline health workers from the Integrated Child Development Services under the Ministry of Women and Child Development.

Annex 2 List of respondents (in-depth interviews with policymakers)

	Respondent code	Sex	Institution	Position	Date of interview
1	PM-001*	F	State Government	Senior Medical Officer	15 September 2014
2	PM-005*	M	State Government	Senior Bureaucrat (urban affairs)	16 October 2014
3	PM-006	M	State Government	Senior Bureaucrat (Health Dept)	16 October 2014
4	PM-007*	F	State Government	Senior Technocrat (Health Dept)	13 October 2014
5	PM-008*	F	State Government	District programme official (NRHM)	15 September 2014
6	PM-009#	F	State Government	State programme official (NUHM)	5 September 2014
7	PM-010#	F	State Government	District programme official (NUHM)	15 September 2014
8	PM-011#	F	State Government	Researcher (urban affairs)	16 October 2014
9	PM-012*	M	State Government	Consultants	27 November 2014
10	PM-013*	M	State Government	State programme official	26 November 2014
11	PM-002	F	NGO	Programme Manager	17 September 2014
12	PM-003	F	NGO	Executive Director	17 September 2014
13	PM-004	F	Media	Activist and Editor	25 September 2014

* Verbal consent.

Informal discussion with verbal consent.

Annex 3 List of respondents (FGDs)

FGD (1) Place: Jhalupara Date: 10 September 2014					
No	Participant's ID	Age	Sex	Occupation	Member of <i>seng kynthei</i>
1	Respondent 1	56	F	Housewife	No
2	Respondent 2	35	F	Housewife	No
3	Respondent 3	39	F	Urban link worker	No
4	Respondent 4	30	F	Housewife	No
5	Respondent 5	32	F	Housewife	No
6	Respondent 6	60	F	Domestic worker	No
FGD (2) and FGD (5) Place: Demseiniong Dates: 15 September 2014 and 11 October 2014					
No	Participant's ID	Age	Sex	Occupation	Member of <i>seng kynthei</i>
7	Respondent 1	41	F	Daily wage labourer	Member
8	Respondent 2	38	F	Daily wage labourer	Member
9	Respondent 3	42	F	Daily wage labourer	Member
10	Respondent 4	30	F	Daily wage labourer	Member
11	Respondent 5	27	F	Daily wage labourer	No
12	Respondent 6	37	F	Daily wage labourer	Member
FGD (3) Place: Madanrting Date: 22 September 2014					
No	Participant's ID	Age	Sex	Occupation	Member of <i>seng kynthei</i>
13	Respondent 1	67	F	Retired govt. servant	President of a ward
14	Respondent 2	28	F	Ex-ASHA facilitator	Member
15	Respondent 3	54	F	Housewife	Secretary
16	Respondent 4	41	F	Housewife	Member
17	Respondent 5	58	F	<i>Anganwadi</i> worker	Member
18	Respondent 6	40	F	Housewife	Member
19	Respondent 7	36	F	Ex-ASHA	Member
20	Respondent 8	60	F	School teacher	President of a ward
FGD (4) Place: Nongmynsong Date: 10 October 2014					
No	Participant's ID	Age	Sex	Occupation	Member of <i>seng kynthei</i>
21	Respondent 1	45	F	Female sex workers	No
22	Respondent 2	40	F	Female sex workers	No
23	Respondent 3	26	F	Female sex workers	No
24	Respondent 4	23	F	Female sex workers	No
25	Respondent 5	18	F	Female sex workers	No

Annex 4 DST participants

No	Participant's code	Marital status	Sex	Age	Residence	Occupation	Participation in other methods
1	DST 1	Married	F	39	Jhalupara	<i>Anganwadi</i> worker	FGD & In-depth interview
2	DST 2	Married	F	28	Madanrting	Ex-ASHA facilitator	FGD & In-depth interview
3	DST 3	Married	F	23	Pynthor bah	Laywoman	In-depth interview
4	DST 4	Widow	F	41	Demseiniong	Laywoman	FGD
5	DST 5	Widow	F	38	Demseiniong	Link worker	FGD
6	DST 6	Married	F	58	Madanrting	<i>Anganwadi</i> worker	FGD

Annex 5 Topic guide (for men and women)

Participation in city and state policy development and public decision-making on SRH

1. What NGOs or (religious) organisations do you know that are working in your area? What is their type of work? How do you know these organisations? Have you ever been in touch? How? What was your experience?
2. Are you aware of any NGOs or any organisations (like ethnic or church-based organisations) in your area that work on health? And what is their type of work? How do you know these organisations? Have you ever been in touch? How? What was your experience?
3. Who, in your opinion, decides about the health facilities in your area? How do they do that?
4. In your opinion, how could women and girls in urban areas participate in helping government/non-government design suitable SRH programmes?
5. What are the differences between the ability of women and men to participate? Why do these differences exist? Can you think of other social characteristics that enable or prevent men and women to participate in policy development and decisions (i.e. class, ethnicity, age)?
6. Can you think of examples of people from your community who managed to get the attention of policymakers? How did they do that?

Slum

What is a slum? Who lives in slums? What are the advantages of living in a slum? What are the disadvantages?

Sexual and reproductive health (SRH) services (government and private – ask about self and the community)

7. Where do you/people in the community mostly access SRH services (government, private facility, or pharmacy)? What services? Why?

Probes (on factors that hinder you/your family/community from accessing SRH services)

- a. Family/other members
- b. Work pressure
- c. No knowledge/awareness
- d. Financial constraints/costs involved, i.e. transport, medicine, informal fees
- e. Do not need such services
- f. Hospital related: staff attitude, distance, not satisfactory, quality
- g. Taboo or too self-conscious

Participation of patients in health system accountability

8. When you are not happy with a health service, what do you do? What would you like to do?
9. Are there patient organisations or interest/pressure groups that can hold health services accountable? Example: *Mahila Arogya Samitee* (MAS).¹⁰

¹⁰ A community-based federated group of 20–100 households responsible for health and hygiene behaviour change promotion and facilitating community risk pooling mechanisms in their coverage area.

Annex 6 Topic guide for policymakers/those who can influence policy

Use of health system data on SRH in poor urban areas, and urban and state health priorities setting at the state level

- What do you think should be the main SRH priorities? What different types of data sources are used in the state to develop health plans? And to what extent are these data also used for decision-making in slum areas? What data are collected for health planning, including from slum areas, with respect to sexual and reproductive health? (*monitoring/emerging epidemics/formulating plans/HR management/resource allocation*)
- The data available on SRH is mostly from the NFHS, DHS, and the census report. But we do not have data that reflects the situation in the slums. How then are the needs of slums prioritised?
- Please share your experience of any debates about the policy/programme before it was implemented in the state. How can you adapt central-level policies to the state contexts?
- The National Urban Health Mission (NUHM) has been a Centre-sponsored programme since 2013. How in your opinion can it address the health needs of poor urban people? How can *Mahila Arogya Samitee* (MAS)/USHA¹¹ play a central role in voicing the needs of the poor urban community?
- Meghalaya has a Slum Act. What are the criteria used to categorise an area as a slum? What were the reasons for the recent controversy related to Mawlai being mentioned as a slum? What responses do we get from people?

Ability of women and girls in (poor) urban areas to participate in city and state policy development and public decision-making on SRH

- Which stakeholders are influential in decision-making with respect to slum issues?
 - Politician/bureaucrat/civil society/international donor/central government?
- What are the differences between the ability of women and men to participate? Why do these differences exist? Can you think of other social characteristics that enable or prevent men and women to participate in policy development and decisions (i.e. class, ethnicity, age)?
- What are the characteristics of individuals and organisations that are successful in speaking with policymakers? What stops people from reaching out to you? What advice do you have for women and girls in slum areas to work effectively with you?
- What do you do to engage with civil society groups in policy/health programme planning? What are your experiences (positive and not-so-positive) with civil society, especially with respect to SRH?

¹¹ Urban social health activist – leader of MAS.

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