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How do local participatory governance reforms influence equitable access to health services? The role of Panchayat Raj Institutions(PRI) in Kerala, India

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How do local participatory governance reforms influence equitable access to health services? The role of Panchayat Raj Institutions(PRI) in Kerala, India

Inclusive and society-centric forms of governance are often a result of normative expectations and process of public oversight and inquiry in governance practices (Keane, 2009) and involve shifts in the focus of governance practices towards more consultative and participatory nature. Participatory governance is an institutional strategy that facilitates and promotes citizen engagement in the realm of governance. (Andersson & van Laerhoven, 2007; Nations & Development, 2000). It is a form of governance that emphasizes democratic engagement, particularly through deliberative process, with an aim to strengthen citizen participation in public policy processes by examining practices and beliefs that inhibit participation (Fischer, 2006). This form of governance seeks to give voice to participants to participate in decision-making processes and activities affecting their lives and has the potential to lead to more responsive forms of public policies with more transparent and accountable processes (Nations & Development, 2000). This is through the creation of 'intermediary spaces' that seek to readjust the boundaries between state and citizen by creating new spaces that seeks new ways of engagement and inform each other (Cornwall, 2002). Advocacy towards decentralized forms of governance calls for responsibilities and resource sharing to local governments, participation of civic societies in the development process and achieving common objectives through participatory action which include improving delivery and access of public services and deepening/consolidating of democracy; improving accountability (Blair, 2000; HELLER, 2001; Schönleitner, 2004; Speer, 2012)

A well organized and active civil society can enforce participatory governance arrangements and can keep checks on government decisions (Brinkerhoff, Brinkerhoff, & McNulty, 2007). Interest and willingness of public officials and local governments to invest in devolved decision making processes and capacity to carry out such engagements have been pointed as indispensable for successful participatory reforms (Andersson & van Laerhoven, 2007; Brinkerhoff et al., 2007). Realising such potential and benefits, these participatory reforms have been tried and taken up by governments and some developed and implemented by civil society participation to increase public participation in decision making for public services. These participatory forums have been experimented and tried in many developing countries across many public sector, vigilance committees in Bolivia and Philippines, participatory budgeting in Brazil and Peru (Schneider & Goldfrank 2002; Boulding & Wampler 2010), public hearing in India and Philippines, participatory and decision making forums for public services provisioning in Uganda and Mexico (Blair, 2000; Ackerman, 2004; Commins 2007), increasing government spending in Guatemala(Speer, 2012).

Scholars have also cautioned on use of participatory governance as a panacea and there are examples across countries where such mechanisms have not adequate to bring in change in the existing processes. A comparative study on participatory budgeting in five countries, Brazil, Ireland, Chile, Mauritius and Costa Rica by Brautigam (2004) found that participatory engagement was not enough for governments to increase pro-poor spending(Bräutigam, 2004). Similar studies from Philippines & Uganda caution that engagement is not enough to foster responsiveness in government systems (Shaktin, 2000; Francis & James).

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The Indian Context:
In Indian democratic context, the deliberative turn can be traced through the 73rd and 74th constitutional amendment with mandatory and discretionary provisions for devolution and the level of devolution varied across states. The public debate which lead to the reforms of local governance in India primarily revolved around the arguments of empowering local bodies for efficient delivery of public services, to promote equity and to eliminate deprivations related to poverty. The objective was often stated as "to revitalize the Panchayats in India" (Mathew, 1994)

The state of Kerala, India is seen as a good example in instituting devolution of power to local bodies. Active social movements and a vocal civil society were able to create a demand for local governance and sustain pressure on the state to accede to their demands (Chaudhury, 2003). According to Isaac et al (2002) the political goal was to use the planning process as an instrument for social mobilization through the people's campaign for decentralization in Kerala (Isaac & Franke, 2002).

We conducted a study in Kerala, India to study Panchayati Raj Institutions (PRIs), a form participatory governance reforms in India. PRIs are- locally elected bodies operating at village, sub-district and district levels with financial and administrative powers over social services including health services. In this paper through the case studies of pain and palliative care units and Kidney Patient Welfare Society (KPWS) we sought to understand how local participatory forums make health systems more responsive. The role of deliberation in formal spaces and informal space, i,e micro and macro spheres in facilitating the health system to be responsive to peoples need was also explored. We also share the challenges faced by local governance institutions to make health systems respond to peoples need due to administrative challenges and health being regarded as a technical subject.

In this paper, we explore the concept of micro and macro deliberation in participatory governance in health. These deliberations are created by PRIs in both formal and informal spheres, commonly referred as micro and macro deliberations. In micro deliberations we discuss the ideal and formal spaces for participation through gram sabhas, ayal sabhas and other official spaces like coordination committee meetings. Macro deliberations are described by open, unstructured deliberations in public sphere, and represented by social movements, cultural volunteerism, strong CBO-PRI associations in our study context. We further explain that how these formal and informal platforms are interconnected and provide a more integrated environment for deliberations in health.

Methods

The study was conducted in Malappurum district of Kerala and the study team visited 4 municipalities, 3 block Panchayats and 3 Grama Panchayats. District level, block level, and Grama Panchayat level PRIs, KPWS offices and Palliative care centers were also visited. The data was collected between January and March 2016 in two phases.

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We used the case study of Pain and Palliative Care units and Kidney Patient Welfare Societies. The reason for choosing these tracers were that the Pain and palliative care units emerged from civil society initiatives and the Panchayats took it to scale whereas the KPWS was initiated by the District Panchayat and hence would give the study two different spectrums regarding the role of Panchayats in equitable health services delivery.

Pain and Palliative Care units (PPC)**:** Pain and Palliative care (PPC) emerged as a response to the caring needs of the population which was ageing. The pain and palliative initiative seeks to alleviate the pain of the chronically ill patients. The need for home based care for the terminally ill patients is catered through the pain and palliative initiative. In Kerala, the PRIs have taken the pain and palliative care to scale (Santha, S 2011).

Kidney Patients Welfare Society (KPWS): A separate society was formed in 2007 as Kidney Patients Welfare Society (KPWS) under the aegis of the District Panchayat with president of Panchayat as chairperson of the society. The objective was to establish dialysis units for End stage renal disease patients in the public facilities at Block and District levels. Medicines support is also provided to kidney patients as well as for the transplanted patients.

Qualitative research methods like in-depth interviews and focus group discussions were used for the study. Since the objective was to explicate pathways, purposeful sampling method was employed and study participants were selected according to the maximum variability principles (Silverman, 2000). We conducted 24 in-depth interviews with key-informants, health system actors, elected representatives and community volunteers at pain and palliative care and dialysis units. The key informants were selected based on their knowledge, having long standing engagement and rich experience of engaging with Kerala's LPG reforms. The other in-depth interviews with elected, health system representatives and volunteers focused on knowing their experience of implementing various health and panchayat programmes and working with both the departments. We conducted these interviews at block, district and municipality level to capture the functioning at all levels.

We further conducted 6 Focus Group Discussions (FGDs) to elicit community experiences, of LPG mechanisms and access to health services. These were conducted with women self-help group, youths, fishermen, tribal community and community volunteers. The process of data collection was guided by an interview guide and main domains to enquiry were on understanding context, inclusiveness & equity, participation, localness, responsiveness and accountability.

We followed the principle of framework method for qualitative data analysis and applied policy research (Ritchie & Spencer, 1994). We first started with listing of *a priori* codes and then created free listing of emergent codes. Further to this we applied the codes to the interview transcripts. This was followed by an in-depth discussion within the research team for classification of larger domains and themes under it. A refined set of themes and sub-themes were used to code the data. The data was coded using Atlas.Ti.

Ethics, consent and permissions

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The researchers ensured that data collection did not disrupt the day-to-day functioning of the functionaries. Confidentiality of information was maintained; anonymity of sources was also maintained throughout the study. Coding of respondents was done on the same day as data collection, before the data was entered. Ethical approval for the study was obtained from the Public Health Foundation of India's Institutional Ethics Committee. Besides, the study findings will be shared with the key state officials and the final report will also be shared. An attempt will be made for wider dissemination of the findings.

Findings

The importance of deliberation in participatory governance is its core value in encouraging engaged debates and discussion to facilitate rational, public oriented outcomes (Hendricks 2006). Deliberative practice is made up of the micro and macro spheres; The micro sphere is focuses on formal political forums, consisting of legislatives, parliamentary and town hall meetings, and associated procedural and structured conditions to encourage discussions and debates. The macro sphere focuses on ongoing discussions and debates in the public sphere. and is associated with unstructured, informal ways in with discussions and conversations shape deliberations. In our study, through the exploration of PPC and KPWS we found that formal spaces for deliberation are grama sabhas (village councils), special sabhas and ayal sabhas and a central space for to promote coordination between panchayats and other departments called coordination committee. Unstructured deliberations in public sphere, and represented by social movements, cultural volunteerism, strong CBO-PRI associations in our study context.

We then explain how an integrated deliberation between micro and macro spheres is created to sustain the participatory governance. The deliberation view put forward by integrated deliberative systems (Hendricks 2006), views these public spaces as 'discursive space', wherein both formal and informal spaces bring together mixed mode of deliberation. More fundamentally Hendrick explains, *"'mixed' venues encourage the cross fertilisation of ideas across different kinds of actors, connecting broader public discourse to the conversations and decisions of the political elite".* (Hendriks, 2006)

Micro deliberations- the formal forums

Gram sahbas, special sabhas and ayal sabhas

Our study findings suggest that PRIs have worked to create local, participatory, inclusive and equitable deliberative forums that promote citizen participation in health and promote bottom up accountability. One of the distinguishing feature was to reach out to people of all sections and places by creating statutory platforms of Gramsabha (Village assemblies), special gramasabhas. These special platforms were created to invite participation from women, differently abled people, old age people, fisher folks and tribal communities. The purpose for these meetings was suggested as to be able to provide a platform to raise their voices, as in mainstream forum their opinions might get overlooked.

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These sort of special sabhas should be convened just before the Gramasabha because those special category people when they are in the Grama sabha meeting, together only they can be assertive. Otherwise in main stream, these voices will be isolated. You won't be able to hear them. If you are given a space separately then you have the identity and they will discuss it. Only the differently abled people sitting together, only the aged vayojanam people, women are sitting together. Children are sitting together, they can open-up their thoughts. They will have more confidence in raising their voice. So it can be recorded. (KI_03_16022016_PS)

More recently, these village assemblies have been moved to a collective of 50-100 families, called as Ayalsabha to include more participation in these forums. The aim of these decentralized and dispersed form of participatory forums have been to identify the local issues and concern and bring them to the gram sabha. These compact *Ayalsabhas* prepare 'community plans' and take it to the Gramsabhas for discussion and making it a part of the Panchayat plan. An official from an autonomous Government Institute explained the process to us, as below.

At the ward level there would be a community plan and this community plan is prepared from the suggestions given at Ayal sabhas. So before the formal gram sabha meeting, meeting of ayal sabha or mini gram will be there. It has now been formed, it has been through a GO (Government order) it has been set up. These Ayal sabhas have been set up as per GO. Still suggestion from Ayal sabha is taken in community plan for gram sabha. So it will get formally approved by the ward sabha and it is as per the community plan, panchayat plans are there. So lot of stages are there, you can see ayal sabhas, then ward sabha also gram sabha then community plan, then action plan from gram sabha to be taken to finalize the community plan at ward level and seva gram office, the office of gram sabha. (KI-02)

These councils have been created potentially to tackle the issue of middle class and upper-class people abstaining from Gramasabhas. When we explored the participation in these special sabhas with a special(tribal) group in a focus group discussion, they also agreed that these special forum gives them a chance to express their concerns and raise their voice for their needs. Though they also expressed that process of integration of their issues into the main plan was unclear and they expressed to be informed of how decisions are taken at a high level on their issues

Change is slow indeed, but not absent after all.
How did these changes come about?
Thanks to the ooru-koottams (special gram sabhas) and the Kudumbashree (self-help groups), there have been changes. We pin the rest on hope.
Are there deliberations between you and people who are easily bought into opposing the projects?
Yes, of course, especially in ooru-koottams. Kuttichal Grama Panchayat has the distinction of holding ooru-koottams and thoroughly discussing such issues than any other Grama Panchayat in Kerala. While ooru-koottams elsewhere finish the

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proceedings with reading the minutes of the preceding meeting and sanctioning the projects–all within an hour or so, we do, in fact, take our discussions seriously. We take suggestions from the ooru-koottams to the Panchayat, rest not assured. …………(later) Moreover, people here have started raising questions when things do not happen as expected. (GP_FGD_TG_07_19022016)

These forums have created the necessary platform for participation enabling people with varied need to participate and express their concerns. Participants agreed on definite need for creation of such forums to provide a space for participation, though a general expectation was to develop a more transparent feedback to report back on how decisions at higher level are taken for their choices. Though on a broad level, the same group informed that they do feel supported by the panchayat and cited the following example,

An example would be the support given to us by the Panchayat when officials of the Forest Department filed a suit against us when we tried to pave the road by ourselves. This was before the Government took up the project. Having realized the importance of a road in educational improvement and health system access, we used to come together in free will once in a week to build this road, with our kids, and cooking by the road.
So, the Panchayat intervened in settling a case filed by the Forest Department?
Yes (GP_FGD_TG_07_19022016)

In another group discussion with two women's group, it was expressed that PRIs are approachable and they do not feel hesitant to reach out to PRI office to get something done or request for a service. Though they also shared that this was not same for other government institutions or health care facilities. The below mentioned quote expresses the hesitancy to reach out to other institutes, beyond PRIs

Once, my sister-in-law had to get an operation. The doctor was very rude to her. We tolerated it. People told us that it's because we didn't give bribe.
Did you complain to anybody?
No we didn't. Also, once my son was down with fever and I took him to the hospital the doctor gave him an injection and he became Blue in colour. When I told him that he said it is ok, but my son's condition worsened overnight and we took him to a private hospital. The doctor there treated him and he was better. My son was under treatment for 3 months at Calicut.
Do you know that the hospitals come under the panchayat?
No we didn't. But if that's so, Next time onwards we will go to the panchayat directly if something of the sort happens.
Do you feel empowered to approach the panchayat now?
Yes. (From women group FGD)

Have you ever raised a specific issue and got it rectified?

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I have approach the panchayat then there was a problem in getting a gas connection and got it rectified.

How did you do that? Did you go directly to the panchayat?

Yes. I met the Panchayat president. Even otherwise if we go directly and meet somebody they will direct us to the person who can help us. Normally the complaints are received at the front office and then taken care of. (GP_FGD_KS_01_19012016)

These experiences of reaching out to PRIs for help or their concern, highlight the approachable and available nature of PRIs. This also suggests that these bodies are locally connected and people at certain level have trust in them to be able to listen to them and take some action. Through these wide varied councils and special councils, PRIs try to reach out to people and create a local space for people to express their needs and respond to them. This can be best summarized through this expression a group discussion in special (tribal) population. We also raised the question on a situation, where panchayats are absent and participants explained the following to us

What if there still was no panchayats and the State Government was the body of governance?

In that case, you will not have even visited us. Panchayats provide immediacy to common man's needs. We have ooru-koottams only because we have Panchayats, and ooru-koottams have helped us know what initiatives are underway. For any matter, be it regarding Kudumbashree or incentives, one has to go to the Panchayat Office. If Panchayats were not there, we would have been like any other state. (GP_FGD_TG_07_19022016)

The counter factual question extended to different groups about how things would have been different, if PRIs were not there, fetched near uniform answers. All were of the opinion that none of the initiatives, collective livelihood related actions, activities of self help groups (micro-credit groups), and local participation for developmental activities would have taken place in the absence of PRIs.

These local participatory platforms have led to prioritization of peoples need. Elected representatives from the study spoke of them as a step towards identifying local needs and discussing them with bureaucrats, members of palliative care network, ward members and community. When we asked the participants what are the usual discussion in these sabhas and special sabhas, they expressed that they are linked with development of village, may range from health, education, physical infrastructure like roads and bridges.

What are the concerns of these meetings?

There would be discussions regarding common concerns like those pertaining to development–roads, bridges, education etc. although individual issues are also raised as a minor agenda.

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Do you have a platform where you can appraise the doctor for his involvement in the health domain of the settlement?
Oh, yes. The doctor is so accessible that he participates at our ooru-koottams, and everyone has his phone no. He attends to patients even at odd hours in the night and helps in whichever ways he can, without any discrimination. When called in for emergencies, he makes sure that he has dialled 108 and arranged for the ambulance service before rushing to the spot.(GP_FGD_TG_07_19022016)

The participants also expressed that these sabhas also have participation from medical officer from respective primary health centre. Hence these sabhas are also platform to raise any concern with the health department. Though the above group was pleased with the experience of working with the medical professional, but we also came across cases where people expressed that health department need to listen to peoples need. One of the community volunteer in pain and palliative care unit mentioned that they also face the challenge of arranging home visits, as desired and required in palliative care units.

The thing is that most of the doctors find it is as an indecent activity to go visit houses and give care. Also there's no palliative care specialist in the service. Since palliative care is a social setup, only the socially well connected doctors will be interested" MC_IDI_CV_05_18012016.

The community members shared that issues specific to medical doctors is challenging to address, but other programmes for health promotion and prevention are addressed by the panchayat more easily.

There are so many activities happening in the health sector. Mosquito eradication and related works are actively happening. Chlorination of wells and palliative care activities are also happening with the initiative of the panchayat.
What was the reason behind starting mosquito eradication programme?
*It happens during summer as a joint venture between the panchayat and kudumbasree (self-help group). we all actively take part in it. (*GP_FGD_KS_01_19012016)

The participatory forums are also seen as accountability forums as under stipulated rule of Panchayati Raj Act, the panchayats have to read out the expenditure statement in the gramasabha (village assembly). The panchayat also needs to put forth a proper budgetary document in the gramasabhas for the gramasabha's consideration. The gramasabha needs to endorse the income and expenditure statement. Participants in the Gramasabha could raise questions, objections, ask for clarifications and justifications and then it gets finalized. A official from an independent institute, explained the process to us when we explored on accountability through panchayats

Coming to this accountability issue, what are the ways in which panchayats are accountable for any of the services? One is of course the panchayat audit is there. To

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the people how are they accountable?

Accountability means, gram sabha there is a stipulated rule that they should read out the expenditure statement and everything, put the budget and also the expenditure and there will be social audit, something like that. That much you cannot say it is fully evolved, social audit. There is provision in gram sabha meeting, left for discussion on expenditure part. How much you have spent on the road construction of road, bridges, how much medicine has been purchased, regarding development of health centres and sub centres. So questions will be there and that will be addressed by the chair. (KI_02_16022016_PS)

We also explored this issue on how panchayats maintain their accountability towards people with community volunteer in pain and palliative care unit. It was explained to us that process are in place to promote transparency within the system through submission of detailed report to panchayats in timely manner. These are used as back up during the discussions in sabhas, if any questions pertaining to the process are asked

How does the panchayat report to the people?

We categorize people such as expired patients, patients who require more support, female patients, patients with autism, patients with high and low depression levels and submit reports for each category of patient. The report also contains information about the participation in the meetings also. These reports are supplemented by the comments of the volunteers and what they learnt from the visits such as facilities the patients lack and what kind of support should be provided to them. (P31: GP_IDI_CV_04_18012016_PS)

The other possible source for disagreement could have been the process of beneficiary selection but PRIs have worked on processes and made the selection process for beneficiary selection more transparent. This was repeatedly probed during the study. In an interaction with the community women, the women took it as a natural, with no remorse, that the below poverty line people are getting preference as beneficiaries. There are clear cut criteria laid out for selection of the beneficiaries. The community volunteers had this to say:

We convince everyone about the selection. Also, people who receive assistance, who were given before and then discontinued, who never received any assistance, all can approach us again in the future if the need arises. They can also approach the district panchayat for the same. We will go through the screening process from the beginning again in that case (MC_IDI_CV_01_18012016).

The system also had not received any complaints from people about the choice of beneficiaries. The logic suggested was everyone is going through the same struggle and hence are in a position to understand. On the part of the panchayat as they want to respond to people's needs they keep expanding the ambit of the scheme to provide more people the service. They keep developing proposals to expand the programs. At the same time, the

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panchayats provide for a grievance redress mechanism but the study did not come across any instance of this facility having been utilized.

Co-ordination committees- convergence space

During our study we were briefed on efforts to enhance coordination between PRIs and other departments at different levels to promote better coordination. At higher level a coordination committee has been constituted, this was referred by respondent as 'mini-cabinet'. The purpose of this high level meeting is to promote better harmonisation between panchayats and other social welfare departments including health, through mutual discussion. The meeting is strategically held before the cabinet meeting, giving the members of coordination committee to propose new projects and get Government orders issued as required from the cabinet.

> *Some of the issues we are taking to coordination committee to get it discussed and then government orders will be issued. So every week, cabinet meeting starts at 9'oclock in the morning, so our minister will come 8 o'clock in the morning. Only to discuss the issues related to panchayat, decision will be taken then and there and GO will be issued within no time. Otherwise to get a government order issued, it takes weeks and months sometime. The next week itself the GO will come. So in such discussions lot of health issues will be discussed (KI_02_16022016_PS.)*

> *Coordination committee is a mechanism that you cannot see anywhere else other than in Kerala. Three ministers, Panchayat ministers, Urban ministers, Rural development minister, and concerned department officers, government secretaries, director of KILA, director of IKM, Kudumbasree all these officials, they are sitting together every Wednesday to sort out issues.*
> ***Physically?***
> *Yes. Every Wednesday 8 O' clock, early morning…..(later) They have been given the mandate of making decisions even sending the proposals to the ministries. So it is called the mini cabinet.*
> *(KI_03_16022016_PS)*

These meetings were seen a potential stage for quick resolution of differences between different departments through a dialogue and finally having an agreement. These agreements are translated into action through Government orders, which usually takes months to get issued but here are issued instantaneously within a week, promoting a quicker action.

Apart from coordination at central level, district level coordination mechanisms were also frequently discussed. Coordination between CBOs and health department help them to coordinate their services for palliative care programme, enabling them to prevent duplication of efforts leading to more coverage and also help pooling support from various agencies

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during emergencies. Coordination starts from the primary health centre, where meetings are held to discuss home visits and discuss patient outcomes and challenges. These meetings are attended by a panchayat member, ASHA worker (community health worker) and other volunteers.

Macro deliberations- informal spheres

Historical background- KSSP and participatory planning

The PRI reforms in Kerala were preceded by the people's campaign run by Kerala Shastra Sahitya Parishad (KSSP) a science movement which had involved itself in popularizing science and scientific temper. The people's campaign, simply called the campaign, itself was preceded by many movements – Library, cultural and political movements. Kerala State Planning Board- the implementing agency for decentralization-designed the campaign in such a way that there was active role for local citizen in shaping local development plans and budgeting. Rather than giving people the role to choose between various plans and policies, they were given direct role in the preparation of these plans, going through a prioritization process.

> *Our literacy programme nobody believed that is possible. About 20-25000 people came forward as teachers in a district as organisers, all over Kerala it became two and half thousand- three lakh people. ………………Such a mobilization it can be done for literacy then it can be done for development also. But development is a much larger cake, not that easy and longer one, not one year campaign and every organisation has to prepare for it. Development is not showbiz? Its actual hard action which requires knowledge so we started panchayat level resource mapping or participatory resource mapping. So we did major socio economic survey again 100 people participated in it and analysis of the survey, the best thing was it was not done by computer. It was done by 100 people sitting together for one week, drawing columns. They made 50-60 tables they make, once they made those by hands they knew what it is (*P17: KI_01_21012016_PS)

> *The mechanism provides ample space for the organizations to get involved. The sort of suppression are not visible ones. The framework provides ample space for almost all type of stakeholders to get involved. That is the advantage. Especially, the people's plan campaign. Decentralization through a strategy called people's plan. Where people have much stake. So it was kind of a new thing. So, in a way it influenced everyone to get involved. Before that planning was an affair of a technocrat or bureaucrat (KI_03_16022016_PS)*

State Planning Board (SPB) not only provided oversight of functions, templates for planning, technical assistance, and administrative capacity, but it also conducted a massive training programme for Key Resource Persons in Grama Sabhas which included 100,000 people. The role of civil society organizations was also very critical in the implementation of the campaign, notably KSSP-Kerala Sastra Sahitya Parishad- the people's science movement. SPB relied

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heavily on the stock of practical knowledge and ideas drawn from KSSP's 25 years long local planning experiments. KSSP supplied many field coordinators and an overwhelming majority of officials in the State Planning Board. During implementation of the campaign KSSP and other NGOs were instrumental in organizing neighborhood groups which increased the participation of women in the campaign

> *Before the people's campaign, planning was considered a technical activity only to be undertaken by technocrat or a bureaucrat but after the campaign took up the issue of participatory planning it was a new thing and people thought that they have much at stake (KI_01)*

So by the time the PRI Act came, the blueprint was ready, the methodology was known and the Act helped it to be taken to scale. As far as the campaign's contribution towards empowering citizens is concerned, Heller notes that, the magnitude and social composition of participation, quality of participation, and process dimension of participation made the campaign achieve extents to which participatory inputs made their way through institutions and materialized into actual outputs (Heller, 2005).

> *Earlier the village accountant used to wield enormous power and held on to the data and did not want to let go of it. But participatory planning is about people taking power (KI_01_21012016_PS).*

In an evaluative study conducted on the impact of decentralization in Kerala, Harilal, et al. conclude that the campaign created participatory governance structures where none existed before. Firstly, there was a substantial fiscal decentralization through the transfer of 35-40% of all development expenditure directly to bodies of local governance. Secondly, significant levels of authoritative decision making powers devolution have been brought by the legislative architecture of the campaign. The whole pain and palliative care initiative came into existence in the larger context of community participation advocated through the campaign.

Socio-cultural practices

The relation between literacy campaign, people's planning campaign and creation of socially aware population was commonly mentioned. It was further described as a way of creating culture of volunteerism in the populations. The emergence of initiatives like pain and palliative care network and KPWS were traced to the spirit of volunteerism and willingness to contribute towards ones' community. On a broader sphere the presence of socially aware population, commonly referred as 'social capital' was linked to success of decentralization in the state, promoting an active engagement in the process.

> *Because Kerala is having social capital. Social capital in Kerala comparatively in a better position than other states.*

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Why so?

May be it's influenced by people's movements. Literacy and education are also in a better position. We have a success story of literacy movement, land reforms. Lot of examples are there. All these have influenced. The major factor that influences all sort of such reforms is the high social capital. The success of decentralization is also very much influenced by social capital. Decentralization we have introduced, we proceeded quality plus campaign the involvement of people. Civic society is very important. (KI_03_16022016_PS)

How did that contribute?

All these may have had a role in creating an enabling environment as I mentioned. It is also the historical process of decentralization in Kerala. So many other factors such as better literacy, political involvement, the culture of community participation, better media coverage, social movements, etc. all have played role. (KI_07_01032016_JV_PS)

We also came across unique cultural practices, promoting participation of community in healthcare. Muslim communities have culturally had the practice of *Zakat* – a tradition where each earning member has to set aside a portion of his/her income for societal purposes. This role of Zakat culture in facilitating local fund raising and fund mobilization campaigns focusing on religious institutions, and religious celebrations is prominent. Since the inception of the palliative care networks, the funds are generated through micro-funding mechanism and this has been the major form of community participation in these activities. The local fund raising also gives the community a right to actively engage with panchayat programs and vice-versa. The other major form of participation which is volunteerism, have seen a dip lately. Another form of participation has been that of organizations which provide food kits for patients during festive seasons.

Integration of formal and informal spheres

Participation & need identification through formal and informal forums

Kerala's history of literacy campaign and people's planning campaign success still remains as the backbone social capital for initiatives like palliative care network and KPWS in Malappuram district. The initiatives could manage and survive many challenges of fund restrictions due to culture of participation and volunteerism. The trend of local agenda setting for initiatives and especially for Palliative care network and KPWS was very marked. Decision to start a Kidney Patients Welfare Society was finalized after a meeting with kidney patients and Malappuram district panchayat representatives, and Pain and Palliative Care initiative Malappuram volunteers.

Pain and Palliative care (PPC) emerged as a response to the caring needs of the population which was ageing. The PPC initiative seeks to alleviate the pain of the chronically ill patients. The need for home based care for the terminally ill patients is catered through the pain and

palliative initiative, and PRIs have taken the PPC initiative to scale. In early 1993, first pain and palliative initiative was started at Calicut Medical college, which was later adopted as civil society initiative in Malappuram. The programme was sustained by small donations from patients and provision of medicine was through a low key medicine distribution center, run to help needy patients on expensive medicines through donations as religious activity. This palliative care network attracted social support and volunteers to keep it moving, and with the increase in the number of volunteers coming into the fold, a Neighbourhood network in Palliative care (NNPC) was formed in 2005. A community volunteer described us how an important need in the population was identified through civil society organisantions and community volunteers, which was gradually scaled up to the whole state by PRIs.

The Neighbourhood Network in Palliative Care concept is to bring all the agencies to the patient's bedside to provide them with decent care and decent death. In order to ensure this people should be strengthened. The caregiver should be strengthened, the family should be strengthened, the neighbors should be strengthened, and the community should be strengthened. The awareness and knowledge to provide care for a bedridden patient should be generated and this is what CBO is doing right now. In a way, this is what should be done at the government level also. So the district panchayat took this responsibility in 2007. The NNPC experiment was a success. People were supporting the initiative. So they decided to expand it to all the panchayats. The plan was to start it in 25 panchayats initially. A newspaper ad was given, inviting 25 interested panchayats. Around 33 panchayat presidents responded to the advertisement and wrote letters to the district panchayat showing their interest. So it was started in these 33 grama panchayats.
(MC_IDI_CV_02_18012016_PS)

Finally, in 2008, the government started the Pariraksha program, the PPC program, throughout the state helping it to be implemented at a state wide scale. It was necessary to bring in the government mechanism to the initiative as stated by the respondents for sustainability and scale. Another key respondent also agreed the key role of Community based organization and further uptake of the issue of PPC by PRI has led to greater acceptance and expansion. It was also shared that now the programmes is harmonized with other national programmes under National Health mission (NHM) and community health workers under the programme also a play a role. On a broad level it was seen as a result of decentralization efforts created through panchayats to reach people.

Earlier while talking about the positive sides of decentralization I forgot to mention that it has contributed a lot in making palliative care activities populist one. Palliative care activities came into existence in the context of community participation in Healthcare. Decentralization have contributed to this. even if the palliative care activities started as a different initiative all together it expanded through Panchayat Raj institutions. Panchayat Raj system and to and extends NGOs contributed. National health Mission (NHM) and Asha program has a palliative component now. There is a state palliative care coordinator also (KI_07_01032016_JV_PS)

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Everyone talks about palliative care in Kerala. But what actually prepared the ground for it was decentralization in Kerala. I think this is most important. Kerala health system is very good in preventive care. That was one of the early achievements.
(KI_08_01032016_JV)

Though the programme has not stopped evolving, community volunteers play a key role in assessing peoples need and adapting the programme accordingly. Pain and Palliative care network Malappuram which started as a care giving program to cancer patients later expanded to accommodate more patients with different diseases and disabilities. This expansion happened when the volunteers encountered such patients during their home care visits. The volunteers pointed out that there are more people who need assistance and care in the locality and made it a point that they cannot be ignored. This feedback from the field led to the expansion of the program. The expansion was not a one-time process but is still in progress.

The case of KPWS is also a case of interaction of formal and informal deliberative spheres. Started by Malappuram district panchayat, it looked to address the need of increasing number of patients suffering from kidney related diseases and associated financial burden. The district panchayat decided to give more focus on the issue as there was no government scheme or programme to address kidney disease patients, and the medicines were also not available through the public health system. Hence it was decided by the District Panchayat to start this activity. A separate society was formed in 2007 as KPWS under the aegis of the District Panchayat with president of Panchayat as chairperson of the society. The objective was to establish dialysis units for End stage renal disease patients in the public facilities at Block and District levels. Medicines support is also provided to kidney patients as well as for the transplanted patients

It was interesting to note that KPWS is registered as a society, hence it efficiently utilizes support from the government system, benefiting from the associated legitimacy but at the same time as a society resorts to crowd funding. It accesses crowd funding spaces like educational institutions and religious institutions which otherwise a governmental/non-governmental organization could not have.

KPWS as an initiative, is uniquely placed as it receives support of the panchayats as the district panchayat president is the ex-officio chairperson of the society. This goodwill of the panchayats has been used by the KPWS and this has also helped in obtaining the trust of the general population. The KPWS office has also got shifted to inside of the district panchayat office and hence the differentiation between the panchayat and KPWS is not there anymore. Also the accounts of KPWS are submitted at the district panchayat board meeting. *"We won't get public support also without the backing of such a governing body"* (KPWS member). In fact, one community volunteer of a PPC unit had this to say:

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> *There are certain areas to which the palliative care network cannot enter - For example, in schools and government offices. But KPWS developed as a sector where both community and the government are equally involved (MC_IDI_CV_01_18012016).*

Though it was also clarified that fund raising activities have been consciously being kept at local level and not towards seeking large donations to ensure accountability. Multitude sources of funding has also necessitated creation of multiple reports, hence each accounts are managed separately. Panchayats also provide Rs. 2000 support to kidney patients for their medicines thorough KPWS. Panchayats also prepare their utilization certificate for the funds allocated, which are shared before the board of the panchayat.

KPWS further moved forward and devised mechanism for beneficiary identification as technical criteria alone will not address inequality issues. KPWS have developed a system using palliative care network volunteers, ASHA workers, ward members, Kudumbashree members, and social activists. A survey was conducted to develop a list of beneficiary along with their support needed and financial condition. For each new application, there is a volunteer visit at home to access the situation. The name of the beneficiaries are announced in respective gram sabhas and special sabhas. They are also displayed at panchayat office to avoid and conflict. KPWS till date have no conflict in beneficiary selection due to its transparent process. The governing body of KPWS also consists of community volunteers, elected representatives, and social activists. Some of the members in the governing body were patients of kidney diseases themselves.

PRIs seem to identify the felt needs better, but it is also providing space for participation and inputs from CBOs, volunteers, activists. Such a platform, and a beneficiary identification mechanism overseen by all the above mentioned actors leads to a fairer situation, overcoming political pressure and nepotism. Panchayat Raj Institutions have interacted with various civil society organizations, community organizations and religious institutions and in effect turned them into structures of participation, especially in local health initiatives and programs. A symbiotic relationship between formal and non-formal structures of community participation is observed in the area under study where the PRIs are supported by non-formal agencies in the forms of community volunteers, beneficiary identification, felt need identification, and even trainings. Formal Institutions extend support in the form of funds, medicines, services from the health department, and also in assuring the society about the legitimacy of such initiatives. Both the tracer initiatives benefited from community mobilization, and a sense of ownership that PRIs provided.

The government could also achieve the objectives of local resource mobilization, and increased community participation in development activities indirectly through these emergent platforms for participation. These agencies could better exploit different cultural, religious, and regional characteristics of the community for the cause than the formal institutions of local governance, and even bypass their restrictions and limitations. Through a transparent mechanism of functioning overseen by the community, such initiatives have overcome political as well as other pressures for favoritism.

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Discussion

Participatory governance in practice is a complex process subject to various influences, our cases of KPWS and PPC illustrate that citizens can participate though this process needs to be facilitated, promoted and nurtured. On one hand the formal spheres of deliberation through gram-sabhas, tackles the problem the problem of scale by reaching to populations through micro sabhas and special sabhas, and identifying their needs. The coordination committee serves platform for convergent space between panchayats and social welfare departments, promoting better coordination through discussions and if required requesting special orders. On the other hand, the macro sphere of deliberation is situated within Kerala's rich history of evolution of LPG reforms. The progressive social movements involved people in participatory planning and budgeting, building essentials skills and a larger social capital to participate in the such participatory processes. Another key feature in macro sphere is social and cultural practices of volunteerism and donations.

These governance reforms are sustained by mixed spheres, where micro and macro constantly interact with each other. The need for both KPWS and PPC was recognized by community volunteers and civil society and sustained through local fundraising and volunteer initiatives but later taken up by panchayats and institutionalized. Though the interaction with civil society and input from volunteer still continues to refine and advance the initiatives. Here in practice we found that micro spheres are well surrounded and impacted by their macro discursive context. Mixed sphere combining both formal and informal encourages, 'cross-fertilisation' and innovation, like in case of KPWS with restriction of government fund on certain items, resourced to more informal ways of raising funds as donations to fulfill the need of the patients. It also led to devise innovative ways of identifying beneficiaries for the programme through the help of community volunteers and avoiding any conflict. Hendricks has also suggested the benefit of mixed spaces as they encourage cross-fertilisation, connecting ideas across different actors hence a medium to connect public discussion to conversations and resolutions of political elite.

Fung and Wright (2001, 2003), argue that while discussing participatory governance, closer examination need to be paid to political contexts, social and cultural realities to supplement the structure and design. They explain that beyond institutional rules, right and policies, the meaning in these social spaces lies in understanding these sociocultural practices in which these social actors operate. These processes deepen the ability of citizen to participate, engage and shape the relevant programme and policies according to their own need. Though they also suggest that procedural features of participation are commendable and necessary but need to adapt and contributions towards effectiveness and sustainability needs to be measured (Fung and Wright 2001; 2003). On our case it is best demonstrated through mixed discursive spheres, where some structured, some non-structured forms co-exist and overlap. They are crucial forms as they encourage diverse form of participation through diverse spheres and promotes exchange of ideas and scope for innovation.

Through interaction of these mixed spheres local participatory governance structures in Kerala were able to initiate many innovations, initiatives and projects to respond to local people's health needs. They were also able to circumvent, through creative ways, some of

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the restrictions imposed by the present form and level of devolution. However, despite this there have been instances when the local bodies faced challenging situation specifically in health context. Health sector was not completely devolved to the local bodies. The idea was that health being a technical subject, it would be best left to the health department to take action on them. So administratively health personnel are accountable to their line department while functionally they were devolved to the LPGs. Hence PRIs have limited control over functionaries/personnel of Public Health Institutions. PRIs have no role in the appointment, transfer, or promotion of these employees. This situation has resulted in "dual responsibilities and controls system". In many instances personal relationship building among health and PRI personnel have led to better coordination, though conflicts are not uncommon.

Participatory governance while not a panacea for addressing issues of health inequity, but when supported by carefully created and managed institutional mechanisms can address and the issues of marginalised sections and promote equity. The big challenge is to restructure governance system to make it appropriate for decentralization and participation without losing its core essence of being accountable and transparent.

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