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Co-creating community engagement and involvement strategies: understanding challenges and needs of people living with multiple long-term conditions and stakeholders' perspectives in India and Nepal

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ABSTRACT

Living with multiple long-term conditions (MLTCs) presents significant healthcare and patient-level challenges, which are further compounded by fragmented and poorly coordinated healthcare systems, leading to difficulties in access, dissatisfaction with quality of services, non-engagement with treatment protocols and poor outcomes. Overcoming these barriers requires a strong and equitable primary healthcare system that prioritises people-centred care and fosters meaningful community engagement. We aimed to understand how individuals with MLTCs navigate healthcare systems and co-create strategies to support community engagement.

10 community conversations (n=90 respondents) were held in New Delhi, Jodhpur, Visakhapatnam (India), Duwakot and Bhaktapur (Nepal) between October–November 2021. These structured discussions explored experiences, beliefs, needs and perceptions of people living with MLTCs, caregivers and healthcare providers. Participants included adults aged 30–75 years, with an equal distribution of men and women. Respondents living with MLTCs reported conditions such as diabetes, hypertension, cardiovascular disease, chronic respiratory diseases and mental health conditions. Using a six-step inductive thematic analysis, we examined access, availability, affordability of healthcare services, continuity of care, expectations of health system interventions—electronic decision support system, assisted telemedicine, patient-facing services and community engagement and involvement (CEI).

Six key themes emerged: (1) definition of community; (2) disease labelling, identity, social stigma, discrimination and coping mechanisms among people living with MLTCs; (3) access, availability and affordability of medications and healthcare services and associated challenges in receiving care; (4) role of local leaders, decision makers and healthcare professionals; (5) uptake, acceptability and building capacity on use of digital interventions such as telemedicine for healthcare service delivery; (6) community engagement methods, including the need for creation of

SUMMARY BOX

- ⇒ Multimorbidity (MLTCs), defined as having two or more chronic conditions, is rapidly increasing in LMICs like India and Nepal, yet health systems remain fragmented and primarily focused on single diseases.
- ⇒ Meaningful community engagement and involvement has gained global recognition as an approach for bridging systemic healthcare gaps and improving health outcomes by involving PLWMLTCs, caregivers and other key stakeholders in co-creating programmes, research and service delivery; however, there remains limited empirical evidence on the impact of meaningfully engaging PLWMLTCs and the role of CEI in LMIC settings, especially in South Asia.
- ⇒ This study offers novel cross-country insights from India and Nepal, showing how PLWMLTCs and their caregivers navigate fragmented healthcare systems, facing barriers such as poor access, high costs, stigma and impersonal care, while identifying key enablers like strengthened primary care, telemedicine, empathic communication, community champions and co-created CEI strategies to support more equitable, person-centered care.
- ⇒ Primary healthcare in LMICs is likely to shift toward a more inclusive, equitable and community-led model by integrating PLWMLTCs, caregivers and community members in care design and delivery, supported by digital health solutions, community champions and lived experience networks, enhancing access, trust, continuity of care, self-management and system responsiveness.

community champions and innovative approaches to improve healthcare service delivery.
The findings highlight significant barriers to accessing care yet also demonstrate the community's readiness to embrace digital tools, especially when guided and supported by trusted local leaders. These insights have key implications for health policy and programme design. Meaningfully engaging people with lived experiences as community champions can improve trust, screening, early diagnosis and self-management, while also bridging gaps between communities and health systems. Digital health interventions such as telemedicine should be embedded within primary care systems through culturally resonant and locally tailored approaches that build digital literacy and foster acceptance. Co-created CEI strategies can help design more equitable, people-centred and scalable health interventions.

INTRODUCTION

Multiple long-term conditions (MLTCs or multimorbidity), defined as the presence of two or more chronic conditions (physical or mental) within an individual, are a growing public health concern.[1] In low- and middle-income countries (LMICs), like India and Nepal, the burden of MLTCs is rising rapidly, though research remains limited. A recent systematic review reported the pooled prevalence of MLTCs in Nepal as 25.1% (95% CI: 17.0% to 34.1%).[2] In India, the National Family Health Survey-5 (2019–2021) reported a prevalence of 1.6% for multimorbidity.[3] These figures highlight the variability and uncertainty in population estimates across studies and settings.

Globally, socioeconomically disadvantaged communities often experience the onset of MLTCs a decade earlier, leading to premature death, diminished function and quality of life and increased healthcare utilisation.[4] People living with MLTCs (PLWMLTCs) have complex needs and face concerns due to factors such as poor health, advancing age, susceptibility to infections, cognitive impairment, inadequate health literacy, polypharmacy, the affordability of medications, complex treatment protocols and difficulties with adherence and self-management regimens. The intricate needs of these individuals necessitate clear communication and people-centred care as well as self-management for effective disease control.[5 6] Despite the high prevalence, research on MLTCs is limited, and current guidelines mostly address single conditions. In addition, the financial burden is substantial, due to frequent primary and secondary care consultations and unplanned hospital admissions. The combination of mental and physical conditions further complicates care and increases costs, especially in deprived areas.[7]

In the absence of people-centred care, combined with a fragmented approach and inadequate coordination of care, those with MLTCs are compelled to consult multiple healthcare professionals in primary and secondary care settings, leading to dissatisfaction and occasional confusion regarding the care they receive, consequently leading to poor disease management and poor health outcomes. Even when treatment is appropriate, the improper use of medication, poor medication adherence and polypharmacy heightens the risk of complications, especially among marginalised, hard-to-reach populations.[8] This issue is notably widespread in LMICs like India and Nepal, where there is insufficient access to screening and management of chronic conditions,[9] limited data regarding effectiveness of health services[9] and limited qualified and trained personnel to manage multiple complex health needs, especially at the primary healthcare level.[10]

Recent research emphasises the importance of community engagement and involvement (CEI) in enhancing the management and outcomes of chronic diseases.[11] The WHO, in its report *'Nothing for Us Without Us'*, has highlighted the critical role of involving communities, particularly people living with non-communicable diseases (NCDs)/MLTCs to improve health outcomes.[12] CEI emphasises integrating perspectives of people with lived experience into health system responses by fostering collaboration and empowering stakeholders to address challenges collectively.[13] This approach enables individuals and communities to actively participate in health decisions, tackle local issues and identify sustainable solutions.[14] The *WHO Framework for Meaningful Engagement of People Living with Non-communicable Diseases, and Mental Health and Neurological Conditions*[15] and *Global Charter on Meaningful Involvement of People Living with NCDs*[16] by the NCD Alliance, recognises the need to bring people with lived experiences on decision-making tables. National Institute for Health and Care Research's (NIHR) vision for CEI is that global health research should involve collaboration with the communities affected by the outcomes. The goal is to give marginalised individuals a meaningful voice in research funding, design, delivery and dissemination.[17] In addition, involving communities in LMICs is believed to enhance the reach, quality and impact of the research.[18]

In light of multiple MLTC-related challenges, there is increasing global recognition that clinical and system-level responses alone are insufficient. CEI has emerged as a critical approach to bridge the gap between health systems and PLWMLTCs. Substantial empirical evidence supports that meaningful CEI and emerging partnerships are mutually beneficial, enhance community health and reduce the burden on health systems.[19 20] Additionally, achieving equity in healthcare services access, availability and affordability requires community participation and meaningful involvement to ensure people-led and people-centred care outcomes are considered.[21] PLWMLTCs have unique, first-hand insights and expertise of the contextual challenges related to prevention, diagnosis, treatment, care and palliation.[22] According to the WHO, 'community involvement', preferred over 'participation', points to the idea of partnership and shared responsibility with and beyond health services.[23] Principally, the active role of community stakeholders is necessary to ensure fair, equal and equitable representation of the communities they serve.[24] Despite the growing burden, there remains limited empirical evidence on the impact of meaningfully engaging PLWMLTCs and the role of CEI in LMIC settings, especially in South Asia.

METHODS

Study design and setting

This qualitative exploratory study focuses on presenting insights obtained from 10 community conversations (CCs) conducted in four locations—Delhi, Jodhpur and Visakhapatnam in India and Duwakot and Bhaktapur districts in Nepal—during October–November 2021. A CC is a participatory approach that facilitates dialogue and collaboration within a community to address issues and develop solutions. These small, informal group discussions offer a safe and supportive environment, especially for PLWMLTCs to share their perceptions and important grassroots experiences that are uniquely valuable to inform the direction of implementation strategies.[16 25] The CCs aimed to provide inputs to identify facilitators and barriers for addressing MLTCs at individual, family, community and health system level.

Funded by the NIHR, the Global Health Research Centre on MLTCs, led by the Public Health Foundation of India, New Delhi, and the University of Leicester, UK, with collaborators, Health Related Information Dissemination Amongst Youth (HRIDAY), New Delhi, All India Institute of Medical Sciences Jodhpur and Kathmandu Medical College, Nepal, focuses on a co-designed, people-centred, technology-driven intervention for managing MLTCs (defined as ≥2 chronic conditions in an individual)[1 26] in India and Nepal. The intervention incorporates electronic decision support systems while emphasising CEI, capacity building and knowledge exchange. As per the NIHR Global Health Research Centre application guidelines, applicants invited to Stage 2 were required to demonstrate meaningful engagement with local communities and relevant stakeholders, to ensure the proposed research priorities, questions and approaches are contextually appropriate and aligned with local needs.[27] The pre-application CCs shaped the Centre's research and intervention through feedback and iterative discussions, aligning with NIHR's guidance on community-driven research. Two PLWMLTCs contributed to the lay summary of the application and were invited to join key committees, including the programme steering committee, CEI committee, monitoring, evaluation and learning committee and operations committee.

Participants and inclusion criteria

The CCs included participants from two groups: PLWMLTCs and caregivers of PLWMLTCs (group 1) and Frontline health workers (FHWs), including accredited social health activists, auxiliary nurse midwives and community health officers (group 2). Participants were eligible if they were aged 18 years or above, resided in one of the study locations and had direct experience with or responsibility of managing MLTCs, either as individuals, caregivers or health providers.

Sampling procedure

Participants were recruited using purposive sampling through existing community contacts and ongoing health programmes by local centre partners. This approach aimed to ensure representation from key stakeholder groups relevant to managing MLTCs while acknowledging potential bias in recruitment.

Community-based organisations such as HRIDAY and the Healthy India Alliance (HIA)/India NCD Alliance have been prioritising meaningful engagement of people with lived experience in all NCD prevention and control research and programmes in India, since 2017. The National Level CC in Delhi was facilitated through an established network of HIA. This work has amplified the voices of people with lived experience in NCD policy and programme planning, informing national health policies and programmes. Notably, the *India Advocacy Agenda of People Living with NCDs*,[28] which was co-developed through a consultative process garnering inputs from people with lived experience across the country through CCs, has been included in the revised operational guidelines of the *National Programme for Prevention and Control of Non-Communicable Diseases* 2023–2030, emphasising meaningful engagement of people with lived experience.[29] This experience helped in including meaningful engagement of PLWMLTCs in strengthening our centre application under the requirement of CEI.

Data collection

The conversations focused on providing solutions to codevelop a comprehensive intervention for tackling MLTCs. The CC guide was developed in English and then translated into Telugu, Marwari and Hindi before administration and back-translated to ensure accuracy. The CC locations were selected based on identified sites under the proposed Centre and existing relationships and ongoing community activities, with study partners in Jodhpur (n=3), Visakhapatnam (n=4) and Nepal (n=2) and a virtual National session in Delhi (n=1) covering a total of 90 respondents. Each session was facilitated by two trained qualitative researchers who were fluent in the local language and culturally aligned with the participants. Facilitators had prior experience in qualitative health research, enhancing rapport and trust within the group discussions. The facilitators were trained to use the CC guide by the HRIDAY team to ensure PLWMLTCs felt safe in sharing their perceptions and experiences. The CCs were conducted in local languages (Hindi, Marwari, Telugu) and were guided by a semistructured discussion guide developed by a multidisciplinary team of qualitative experts at HRIDAY. These CC guides have been used by HRIDAY and HIA for their earlier work[28] and were adopted for the current study on MLTCs. The CC guide covered key domains such as access and availability of healthcare services, affordability of care, continuity of care, experiences with the health system, expectations from the health system intervention, community and family-level support. In addition to audio recordings, field notes were taken to capture contextual nuances, group dynamics and non-verbal cues.

Data analysis and transparency

The authors employed a six-step inductive thematic analysis approach to construct meaning and interpret experiences and perceptions of the participants recruited for this exploratory work.[30] In step 1, all CC recordings were heard while simultaneously reading the transcripts and field notes to understand the overall meaning of the responses provided by the participants. In step 2, each transcript was read line by line to make sense of the data and drive initial coding. The initial codes were organised in MS Office Word to assign coding schemes inductively. Then, focused coding was applied to reduce the volume of the raw information and to identify significant patterns for categorising and assigning themes and subthemes. Codes were identified and categorised into subthemes and themes to compare and identify similarities and differences across themes. In steps 3 and 4, subthemes (basic themes) and organising themes were constructed. In steps 5 and 6, the researchers interpreted the themes and developed a written report of the themes generated.[30]

Two researchers were involved in the coding process. To ensure intercoder reliability, transcripts were independently coded by them, followed by consensus meetings to resolve discrepancies and refine the thematic framework. Data were manually organised and analysed using MS Office Word and Excel. All final themes were discussed and agreed on collaboratively.

Findings

The CCs identified and focused on the following themes: (1) definition of community; (2) disease labelling, identity, social stigma, discrimination and coping mechanisms among PLWMLTCs; (3) access, availability and affordability of medications and healthcare services and associated challenges in receiving care; (4) role of local leaders, decision makers and healthcare professionals; (5) uptake, acceptability and building capacity on use of digital interventions such as telemedicine for healthcare service delivery; (6) community engagement methods, the need for creating community champions and innovative approaches to improve healthcare service delivery. Table 1 summarises key challenges and proposed solutions identified from the CCs.

Definition of community

The CCs helped gain deeper insights into identifying '*who*' was being left behind in meaningful community engagement. These conversations expanded the definition of '*community*' to encompass a wider range of key stakeholders, including caregivers, FHWs, local and religious leaders, traditional healers, civil society organisations, self-help groups (SHGs) and policymakers. Notably, one specific recommendation included exploring the role of traditional healers as an important stakeholder in mobilising communities for health seeking.

Disease labelling, identity, social stigma, discrimination and coping mechanisms among PLWMLTCs

PLWMLTCs described a profound transformation in their identity and lifestyle following diagnosis. This labelling by themselves and others led to a sense of isolation and lack of empathy from healthcare providers. Furthermore, caregivers were also not exempt from this issue. They experienced mental stress tied to disease labelling of the person they cared for. Some of the PLWMLTCs identified themselves as patients and had accepted their identities as patients with the disease. Furthermore, PLWMLTCs shared that community members often labelled them as '*someone with the disease*' by continually advising them on maintaining a healthy lifestyle, which left them feeling disheartened about their food and lifestyle choices. *'People suggest to us on what to eat and what not to eat everywhere we go. Inside our mind, we are very confident that we are not ill, and when people say this, we feel bad. However, ignoring whatever people say and remaining self-assured is what we try.' - PLWMLTC, female, Nepal.*

This, in turn, led to psychological stress, as noted by one respondent, compounding the challenges of managing multiple NCDs. *"We feel like it is better to die rather than being on the bed" - PLWMLTC, male, Visakhapatnam, India.*

Amidst these challenges, PLWMLTCs emphasised the importance of personal attributes like motivation, self-love and positivity as key factors to manage their conditions. Positive habits and mental well-being play significant roles, as one participant stressed, *"Our walking habit has a 50% role; medicines are just 20%, and the rest depends on our mental health, confidence and determination" - PLWMLTC, male, Visakhapatnam, India.*

Recovered individuals played a pivotal role in encouraging others to seek treatment, sharing their experiences and promoting the benefits of proper medical care. People living with MLTCs suggested that involving celebrities or role models to share personal stories, along with promoting awareness in schools, communities and workplaces, could help reduce stigma and discrimination by showing that these conditions can affect anyone.

Access, availability and affordability of medications and healthcare services and associated challenges in receiving care

Representing diverse conditions, PLWMLTCs shared how these conditions significantly impacted their daily lives and influenced their healthcare-seeking behaviours. While most of the PLWMLTCs opted for private healthcare services, a few with limited resources resorted to public healthcare and the primary reason for this choice lay in the perceived disparity in service quality. Dissatisfaction with the public healthcare system was attributed to a lack of provision of detailed information and proper communication between the healthcare professionals

Table 1 Key challenges and proposed solutions identified from the community conversations

Theme	Key challenges	Proposed solutions
Barriers to access	► Distant or overburdened tertiary care facilities ► Inadequate PHC-level diagnostics and medication supplies	► Use of telemedicine and community outreach interventions ► Strengthen PHCs with essential NCD/MLTC services and medicines
Affordability of care	► High out-of-pocket expenditure due to repeated referrals, visiting different specialists and indirect expenses	► Awareness of government schemes for free/low-cost diagnostics and medicines at PHCs ► Streamline referrals and use of telemedicine and community outreach activities to minimise travel-related costs
Stigma and disease labelling	► Stigmatising attitudes from healthcare providers and community members	► Sensitisation training for healthcare providers ► Peer-led storytelling and lived experience support networks to normalise discussion on chronic disease treatment and management experiences
Lack of empathic care	► Healthcare providers dismiss patient concerns and conduct impersonal and rushed consultations	► Train healthcare providers in empathy, listening and non-verbal cues
Fragmented care and disease-centric approach	► Over-specialisation leading to fragmented care	► Adopt holistic, integrated, co-created person-centred health systems
Digital divide	► Low digital literacy ► Limited access to smartphones and connectivity issues in rural/tribal areas	► Train people with lived experiences and community members in using digital models/interventions ► Co-create CEI models with digital and in-person support (through community/lived experience network) for continuity
Narrow definition of 'Community'	► Definition of community did not include traditional healers, faith leaders, local leaders, SHG and civil society representatives	► Broaden community definition to include all stakeholders for maximum uptake of interventions and impact
Lack of community ownership	► Top-down approach leading to community fatigue and tokenistic involvement	► Train community champions to co-lead interventions and be a part of decision-making processes ► Institutionalise community champions in health policy frameworks and programmes
Limited follow-up and continuity	► No structured follow-up after diagnosis or hospital discharge	► Create community/lived experience networks for community-level tracking and digital intervention for follow-up and continuity

CEI, community engagement and involvement; MLTCs, Multiple long-term conditions; NCD, non-communicable disease; SHGs, self-help groups.

and PLWMLTCs. One person with lived experience quoted, *"They just ask us the problem and prescribe medicines. They don't tell us for what the medicines are" - PLWMLTC, female, Visakhapatnam, India.*

PLWMLTCs reported checking blood pressure at pharmacy regularly, preferring local doctors and nearby hospitals. One major reported challenge was the unavailability of prescribed medicines in remote areas. CC participants stressed the urgent need for good quality and affordable services at the primary healthcare level.

Other barriers included most of the PLWMLTCs having limited health literacy which led them to rely on quack doctors/traditional healers for disease and lifestyle management. One participant reported, *"Someone tells something, we hear something else from another person, and we start following that. I knew a lady, she also had breast cancer* *like me, she kept visiting different Babas (quack doctors) for the treatment"- PLWMLTC, female, Jodhpur, India.*

Several challenges were reported by PLWMLTCs while seeking healthcare services such as high out-of-pocket expenditure, travel expenses leading to treatment discontinuation, dissatisfaction with government hospitals, limited awareness and extended waiting time. Financial strain was evident, with a significant portion of earnings spent on medicines. PLWMLTCs faced other issues related to healthcare system accessibility and out-of-pocket expenditures, quoting costs ranging from Rupees 1000 to Rupees 5500 (US$12–67) per month for check-ups.

Further, PLWMLTCs highlighted that they spent on average half/whole day when they visit public healthcare facility. *"On average, we spend 1–2 hours at the healthcare facility, but when it's crowded, it can stretch to 3–4 hours. A hospital visit takes up the entire day, factoring in travel and waiting time. Even after arriving, it takes at least half an hour to 1 hour before we can see a healthcare provider."- PLWMLTCs, male, Nepal.*

Additionally, PLWMLTCs highlighted that primary healthcare centres face significant challenges, such as understaffing, making it difficult for individuals to consult doctors. Furthermore, inadequate supplies, including essential medicines and limited laboratory testing facilities, hindered effective diagnosis and treatment. *"Accessing healthcare services at public healthcare centres is difficult and time-consuming for patients as doctors keep on referring from one healthcare centre to another or a hospital" - PLWMLTC, female, Jodhpur, India.*

Role of local leaders, decision makers and healthcare professionals

PLWMLTCs, caregivers and FHWs suggested involving local leaders including village heads in rural areas, volunteers and doctors in the co-developing of the CEI strategy. Their active involvement was seen as essential for advocating improved resource availability at the PHC level, ensuring community needs are met effectively. *"The leaders and government officials should work more actively and invest in the health of public" - PLWMLTC, male, Nepal.*

PLWMLTCs further highlighted the role of healthcare professionals, pointing to a perceived lack of empathy from both the health system and the community. One *PLWMLTC (female)* from Visakhapatnam, India shared, *"Doctors don't look at us with much respect. They just ask us about the problem and prescribe medicines, and it is also the same in private hospitals."* This sentiment underscored the need for more compassionate, informative interactions to foster trust and respect between people with lived experience and healthcare providers.

Uptake, acceptability and building capacity on use of digital interventions such as telemedicine for healthcare service delivery

The transformation of healthcare through digital platforms was reported as pivotal in tracking patient progress, preventing referral disruptions and facilitating navigation through healthcare systems. The significance of building technological capacity for accessing healthcare services and fostering digital literacy among stakeholders was emphasised, with input from PLWMLTCs shaping technology dissemination. Community readiness for digital healthcare was underscored to overcome challenges such as long travel time to seek healthcare especially in remote areas. Telephone consultations gained traction during COVID-19, notably in Kathmandu, Nepal, reducing waiting time and visits for disease management and follow-up. *"The need to maintain social distancing has caused difficulty in going to the community, but it is necessary and can be done through digital tools like telemedicine, mass media, radio, TV etc." - FHW, female, Kathmandu, Nepal.*

Telemedicine emerged as a useful tool across all four sites, complementing in-hospital services despite initial preferences for the latter. Recognised for its potential in early diagnosis, its success was linked to trusted doctor-patient relationships and quality consultations, particularly when facilitated by tertiary hospitals. *"Telemedicine could help increase access to health services in remote and tribal areas. It would be easier if we [PLWMLTCs] could make follow-up appointments over the phone or the internet"- PLWMLTC, male, Kathmandu, Nepal.*

Challenges associated with existing digital interventions were identified, including issues with patient acceptability, awareness, digital literacy, rapport building and the necessity for experienced healthcare providers. One of the FHWs reported, "*The number of health workers that are given the training is very low, like one or two in a health centre, while the requirement is very high."- FHW, female, Kathmandu, Nepal.*

Language barriers, connectivity issues and perceptions of telemedicine as merely for appointment booking were additional obstacles. Despite challenges, PLWMLTCs and caregivers saw the value of telemedicine for regular check-ups and follow-ups. Assisted telemedicine for symptom tracking and medication provision was also suggested.

Community engagement methods, the need for creating community champions and innovative approaches to improve healthcare service delivery

Community engagement stood out as a central theme in both sets of narratives (perceptions of PLWMLTCs, caregivers and FHWs) with various methods such as *nukkad nataks* (role plays), use of social media and lived experience videos/microdocumentaries being recognised for their effectiveness in fostering a sense of community, exchanging ideas and providing support. Additionally, PLWMLTCs and caregivers expressed a desire to actively participate in decision-making related to their health and leverage their lived experiences to assist others in their communities, particularly those newly diagnosed with MLTCs, by serving as community champions. These suggestions reinforced our approach. Health workers emphasised their role in motivating others to seek timely treatment and fostering a supportive community environment.

Suggested engagement methods included door-to-door service delivery, extended health camps, one-on-one and group discussions (eg, women SHG meetings), bulk messaging and community networks. Recovered individuals expressed willingness to voluntarily build networks to support and inspire others. One participant summarised the urgency of this collective effort: *“Time is precious, and while some of us are already halfway through life, many are just beginning their battle with diseases. We must urgently share our message and voice our opinions to higher authorities for the sake and future of these new patients” - PLWMLTC, male, Visakhapatnam, India.*

Both PLWMLTCs and FHWs advocated involving local leaders to build trust and ensure community support for new healthcare initiatives. PLWMLTCs expressed interest in forming peer support groups for mutual encouragement and experience sharing but sought guidance on initiating such programmes. Civil society organisations were identified as critical to addressing healthcare challenges, engaging communities and keeping MLTCs prominent in policy discussions. One participant from Delhi emphasised, “*There is a need for sensitisation about health promotion measures to prevent and/or control chronic conditions. It is important that NGOs lead this drive to sensitise the public about the nature of NCDs. They should undertake awareness campaigns to spread the importance of family support for a person living with chronic conditions” - PLWMLTC, female, Delhi.*

DISCUSSION

Through CCs, the need to expand the community definition beyond PLWMLTCs, caregivers, FHWs, to include traditional healers, policymakers, local leaders, NGOs and SHGs emerged as a critical finding. In addition, the creation of community champions came out as an essential need and a viable approach corroborating with the proposed mechanisms in the application. This finding underscored the importance of meaningfully engaging PLWMLTCs and caregivers to bridge the gap between the health system and the community. These empowered people can play a vital role in improving healthcare access, early diagnosis and better management of their conditions. Krist *et al* in their study emphasised that involving patients and caregivers effectively in the care process is crucial for enhancing health outcomes, improving satisfaction with the care experience, reducing costs and even benefiting the clinician experience.[31]

The need for imbibing CEI principles by the researchers, relevant stakeholders and the health system emerged as an important finding. Effective community engagement emerged as a central theme, with innovative methods such as women SHG meetings, role plays, social media for health promotion and lived experience videos fostering community support. These methods align with evidence emphasising community-based interventions and peer support in managing chronic diseases.[32] The findings also highlighted the importance of personal attributes such as motivation, self-love and positivity in managing health and disease conditions. Participants emphasised that mental well-being and lifestyle choices played crucial roles alongside medical treatment for management of MLTCs.

Participants reported a preference for private healthcare services due to perceived disparities in service quality between private and public healthcare providers. Dissatisfaction with public healthcare was primarily attributed to poor communication between the doctor and the patient and the lack of provision of detailed information. Evidence from an earlier study suggested that individuals with high rates of diabetes and hypertension reported better relationships with primary care providers, based on the time spent on consultation, effective communication and the trust between the individual and the provider.[33]

PLWMLTCs and caregivers lacked understanding on self-management approaches and were heavily dependent on the healthcare system for management, focusing primarily on lifestyle adjustments at the individual level. The transformative potential of digital interventions, particularly telemedicine, was noted, especially in remote areas with limited access to physical healthcare facilities. While challenges such as digital literacy, patient acceptability and language barriers exist, telemedicine has the potential to improve early diagnosis and continuity of care.[34–37]

Participants emphasised the importance of door-to-door service delivery, extended health camps and the involvement of local leaders to enhance healthcare accessibility. The findings also underlined the need to engage people with lived experiences and caregivers meaningfully, from research design to dissemination, empowering them as community champions and codeveloping strategies, which aligned with the proposed strategies in the application. Civil society organisations were seen as pivotal in sustaining healthcare interventions and reducing stigma and discrimination.[38–40]

Recommendations

Redefining community and stakeholder involvement

Policymakers

- Formally recognise and include PLWMLTCs, community champions and civil society actors in community engagement research, policies and healthcare planning.
- Ensure inclusive representation of PLWMLTCs and caregivers in advisory panels and health system governance structures.

Healthcare professionals

- Engage with traditional healers, SHG representatives for streamlining patient referrals and follow-up mechanisms.

- Collaborate with community gatekeepers to better understand socio-cultural beliefs and healthcare needs.

Community actors

- Map local influencers like religious leaders, SHG representatives and traditional healers to co-lead health awareness efforts.
- Advocate for the inclusion of PLWMLTCs in decision-making processes.

Address disease labelling and stigma

Policymakers

- Co-design public awareness campaigns that normalise conversations around NCDs and MLTCs with people living with MLTCs and caregivers.
- Integrate and institutionalise trained people with lived experiences as peer educators and community champions to act as a bridge between the health system and the community.

Healthcare professionals

- Undergo sensitisation training to ensure respectful, empathic and ethical communication with patients in health systems.
- Recognise and support the emotional and mental well-being of both PLWMLTCs and caregivers.

Community actors

- Share lived experience stories through community events, schools and media to reduce stigma and normalise discussion on chronic disease treatment and management experiences.
- Establish peer-support lived experience networks for motivation, experience-sharing and for better health outcomes.

Improve access, affordability and availability of healthcare services

Policymakers

- Ensure availability of essential medicines and diagnostic services at the PHC level, especially in remote areas.
- Strengthen infrastructure to reduce referral loops and waiting times.
- Adopt a holistic, integrated, co-created person-centred health system approach.

Healthcare professionals

- Improve patient-provider communication by explaining diagnoses, long-term management and prescriptions clearly.
- Provide regular community-based follow-ups and undergo training in the use of digital interventions such as telemedicine to reduce patient travel and dropout rates.

Community actors

- Disseminate evidence-based and correct health information especially on existing government schemes using trusted channels such as through SHGs, volunteers and community networks.
- Establish peer-support lived experience networks to support new patients in navigating the health system, disease care and self-care management.

Scale and improve digital health interventions

Policymakers

- Invest in infrastructure for telemedicine and ensure digital tools are accessible in rural and tribal areas.

Healthcare professionals

- Undergo training to deliver effective teleconsultations and maintain continuity of care digitally.
- Use telemedicine for symptom tracking and routine follow-ups.

Community actors

- Promote awareness of digital tools through community network meetings, SHG sessions and local media.
- Assist PLWMLTCs in navigating digital services through community champions, youth volunteers, among others for continuity.

Meaningfully engage community champions and strengthen CEI approaches

Policymakers

- Operationalise CEI in national/state health activities aligned to the Federal Government guidelines on NCDs.
- Involve people with lived experiences in decision-making processes and institutionalise community champions in health policy frameworks and programmes.

Healthcare professionals

- Co-develop health messages and community mobilisation materials with community champions.
- Participate in community mobilisation activities alongside lived experience champions.

Community actors

- Identify, train and support PLWMLTCs and caregivers as community champions.
- Lead peer support networks and community awareness initiatives using locally relevant formats.

CONCLUSION

These findings highlight the critical importance of co-designed, contextually tailored interventions to ensure equitable healthcare access for PLWMLTCs and their communities. Meaningfully engaging people with lived experiences as community champions can improve trust, diagnosis and self-management, while also bridging gaps between communities and health systems. Digital health interventions such as telemedicine should be embedded within primary care systems through culturally resonant and locally tailored approaches that build digital literacy and foster acceptance. Co-created CEI strategies can help design more equitable, people-centred and scalable health interventions.

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Ethics approval This study involves human participants but was not approved and community conversations (CCs) described in the manuscript were conducted to gather insights from the community members and informing the funding application for the NIHR Global Health Research Centre for Multiple Long-Term Conditions (GHRC for MLTCs). These CCs were not undertaken as part of a funded research study, but rather as preparatory work to ensure meaningful involvement of community voices from the earliest stages of proposal development. As such, ethical clearance from a formal Institutional Ethics Committee was not sought. However, we maintained strict adherence to ethical principles throughout the process. Informed written consent was obtained from all participants, and a detailed participant information sheet describing the purpose of the discussions and the nature of the funding application was shared and explained prior to participation. Confidentiality, voluntary participation and the right to withdraw at any time were emphasised. Participants gave informed consent to participate in the study before taking part.

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