Guidance Document for Implementing Patient Support Groups

(As Part of Comprehensive Primary Health Care Roll-out under Ayushman Arogya Mandirs)
Guidance Document for Implementing Patient Support Groups
Foreword

In the public health domain, the Ayushman Bharat Health and Wellness Centres initiative shines brightly as a symbol of optimism and profound change. The comprehensive primary healthcare program seeks to bring quality medical care closer to the communities across India. I am immensely happy to share that Maharashtra has progressed very well in establishing the AB-HWCs as per the targets. The AB-HWCs are providing care on 13 package of services in Maharashtra and all the service packages recommending long term care suggest the strategy of establishment of Patient Support Groups, an innovative and holistic approach to healthcare delivery. This Toolkit for Implementing Patient Support Groups is a significant step forward in empowering both patients and AB-HWC teams with the tools and knowledge needed to foster a more patient-centric healthcare system.

The journey towards accessible and equitable healthcare requires not only state-of-the-art infrastructure but also a compassionate and community-driven approach. Patient Support Groups are instrumental in this regard, facilitating peer-to-peer support, information sharing, and a sense of belonging among patients. This toolkit, meticulously designed and curated, is a valuable resource that will enable healthcare professionals, community leaders, and patients themselves to establish and nurture these groups effectively. By fostering a collaborative environment, we are not only treating diseases but also addressing the emotional and psychological aspects of healing, a cornerstone of comprehensive healthcare.

Let us remember that the success of Ayushman Bharat Scheme and our vision lies not only in the hands of policymakers and healthcare providers but also in the active participation and engagement of our communities. It is my hope that this resource will serve as a catalyst for change in sparking an approach towards patient-centered care that not only addresses immediate health needs but also creates lasting bonds of support and empathy.

I appreciate the efforts taken by my department in bringing up this toolkit and wish the entire health team all the very best for implementing this approach. Together, we can build a healthier and more resilient Maharashtra!

Best wishes,

Prof. Dr. Tanaji Sawant
Health Minister,
Public Health and Family Welfare
Maharashtra
I am deeply honoured to introduce this Guidance Document for Implementing Patient Support Groups' as an essential resource in our pursuit of comprehensive primary healthcare through the Ayushman Arogya Mandirs in Maharashtra. This guidance document represents a significant step in our mission to provide accessible and empathetic healthcare services to all individuals needing longer term care, regardless of their circumstances.

Ayushman Arogya Mandirs in India as well as in Maharashtra, have become the cornerstone of healthcare delivery, reaching the most remote and underserved communities. However, true health services extend beyond clinical interventions; encompassing the community engagement for holistic well-being. Patient support groups, as a key intervention of the Ayushman Arogya Mandirs, will help promote this holistic approach by offering a sense of community, understanding, and empowerment to patients.

This guidance document offers a structured and practical guide for the establishment and management of patient support groups within the healthcare ecosystem. It will address the unique cultural and regional nuances of our geography, ensuring that these groups are not just functional but deeply rooted in the communities they serve. It emphasizes the importance of collaboration between healthcare providers, patients and their families.

Patient support groups have the power to transform lives, fostering resilience and hope in the face of health challenges. This guidance document is a testament to our dedication to improving health of the community.

I commend the tireless efforts of the respective divisions in the department of health and PATH team who were involved in developing this invaluable resource, and I encourage healthcare professionals, administrators, and community leaders to use it as a compass in their mission to provide comprehensive and compassionate care in Maharashtra and in the country. Together, let us build a healthier, more vibrant, and more connected Maharashtra under the Ayushman Bharat Comprehensive Primary Health Care Initiative.
Foreword

In the ever-evolving landscape of healthcare, the Comprehensive Primary Healthcare (CPHC) initiative under Ayushman Bharat has emerged as a beacon of hope, illuminating the path towards a healthier and more equitable India. At the base of this transformative journey are the Ayushman Arogya Mandirs, which have been established with the vision of providing comprehensive healthcare services to every citizen.

Recognizing that health encompasses not just the absence of illness but the overall well-being of individuals, this Guidance Document for Implementing Patient Support Groups' represents a pivotal milestone in the realization of this vision. It is prepared from the healthcare landscape of Maharashtra, a state that embodies the rich cultural tapestry and diverse healthcare needs of our nation.

The establishment of patient support groups within the framework of Ayushman Arogya Mandirs is a testament to our commitment to holistic healthcare. These groups offer individuals facing long term health challenges an opportunity to connect, share experiences, and draw strength from a community that understands their unique journey. This guidance document serves as a comprehensive guide for healthcare providers, administrators, and community leaders, offering invaluable insights into creating and nurturing patient support groups in their own geography.

My sincere appreciation goes to Directorate Health Services Mumbai office, Joint Director-Technical and their team, Deputy Director Pune Circle and PATH officials, who have contributed in preparing this document.

As we embark on this journey, let us remember that the strength of healthcare lies not just in medical expertise but in the compassion, empathy, and support we offer our fellow citizens. By implementing patient support groups, we are not only addressing physical ailments but also uplifting the human spirit. Together, let us strive for a healthier and more connected Maharashtra through the Ayushman Arogya Mandirs initiative.

Shri. Dheeraj Kumar
Commissioner (Health Services) &
Mission Director (NHM)
Mumbai
The fight against ever-increasing burden of chronic diseases in the country calls for moving beyond individual well-being to encompass the broader objective of fostering community engagement and constructing a more responsive and decentralized healthcare system.

To bridge the gap in effective post-diagnosis management of chronic diseases, PATH in collaboration with Public Health Department, Government of Maharashtra and District Administration, Satara proposed a unique strategy—forming patient support groups facilitated by frontline workers. This aligns with the concept of health promotion and behavior change communication to encourage people living with chronic conditions to adopt healthier lifestyles. Patient support group provide a platform for individuals with similar health conditions to come together, share their experiences, and offer each other support and guidance.

As part of the district approach to strengthening primary healthcare, learnings from Jan Swasthya Sahyog, Chhattisgarh in successfully implementing patient support groups for chronic illnesses were observed by a group of CHOs, district and state program managers. Currently, district administration Satara is implementing the patient support groups under the Ayushman Arogya Mandirs for diabetes and hypertension.

This is the opportune time to adopt patient centric approaches to bolster patient compliance, reduce stigma and improve patient knowledge about their illnesses. Patient support groups envisages to instill a culture of patient participation and decision making in seeking long term treatment for chronic illnesses. This initiative will bring a sharper focus on treatment adherence.

By involving communities and providing them with education and support, the Ayushman Bharat Program aims not only to fill the gap in chronic disease care but also to create an empathetic and decentralized healthcare system that understands and addresses each patient's unique needs and challenges.

This holistic approach holds promise in improving the lives of individuals living with chronic conditions as well as galvanize the efforts of state and district health departments in combatting the burden of non-communicable diseases and strengthen primary healthcare.

Neeraj Jain
Country Director – India
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<th>Abbreviation</th>
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<tbody>
<tr>
<td>AAM</td>
<td>Ayushman Arogya Mandir</td>
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<tr>
<td>AB-CPHC</td>
<td>Ayushman Bharat-Comprehensive Primary Health Care</td>
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<tr>
<td>ANM</td>
<td>Auxiliary Nurse Midwife</td>
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<tr>
<td>ASHA</td>
<td>Accredited Social Health Activist</td>
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<tr>
<td>BMO</td>
<td>Block Medical Officer</td>
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<tr>
<td>CHO</td>
<td>Community Health Officer</td>
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<tr>
<td>CPHC</td>
<td>Comprehensive Primary Health Care</td>
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<tr>
<td>DALYs</td>
<td>Disability-Adjusted Life Years</td>
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<tr>
<td>DHO</td>
<td>District Health Officer</td>
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<tr>
<td>MO-PHC</td>
<td>Medical Officer - Primary Health Centre</td>
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<tr>
<td>MPW</td>
<td>Multi-Purpose Worker</td>
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<tr>
<td>NCD</td>
<td>Non-Communicable Diseases</td>
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<tr>
<td>PSG</td>
<td>Patient/Peer Support Group</td>
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<tr>
<td>RMNCHA</td>
<td>Reproductive, Maternal, Newborn, Child, and Adolescent Health</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
<tr>
<td>YLD</td>
<td>Years Lived with Disability</td>
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<tr>
<td>YLL</td>
<td>Years of Life Lost</td>
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Introduction

Chronic illnesses comprise various types of illnesses that require long-term care, including communicable and non-communicable illnesses, chronic respiratory illnesses, genetic illnesses such as sickle cell disease, geriatric health issues, and others. Globally, chronic illnesses have emerged as a significant public health concern over the past few decades.

Disability-adjusted life years (DALYs) are a metric used to quantify the burden of disease by combining years of life lost (YLL) due to premature mortality and years lived with disability (YLD). Chronic illnesses contribute significantly to the global burden of disease and DALYs. This impact is also observed in the Indian context. In recent decades, a significant epidemiological transformation has been witnessed in terms of both DALYs and fatalities attributed to chronic diseases. According to a recent study, non-communicable diseases (NCDs) have had a substantial impact, with DALYs increasing from 30.5% to 55.4% and deaths rising from 37.9% to 61.8% between 1990 and 2016. The World Health Organization (WHO) estimates that NCDs alone are responsible for around 71% of all global deaths, translating to a substantial DALY burden. Addressing such a high burden due to chronic illnesses requires a multi-faceted approach that includes public health campaigns, health care system strengthening, and individual behavior change to promote healthier lifestyles.

Efforts to combat the rising DALYs due to chronic illnesses in India include implementing national health programs, promoting healthier lifestyles, and strengthening health care infrastructure with an emphasis on primary care. These initiatives aim to reduce the burden of chronic illnesses by increasing awareness, early diagnosis, and access to affordable treatment.

While these efforts have helped detect new cases of chronic conditions among the population, individuals with long-term conditions face numerous challenges. A significant hurdle is the difficulty in adopting and sustaining complex behavioral changes necessary for effective disease management. Studies show that a substantial proportion, about 50% to 60%, of patients with chronic illnesses fail to adhere to treatment plans within the first year, leading to missed doses, incorrect dosages, or treatment discontinuation. This non-adherence results in a considerable loss of lives and incurs significant health care costs. Traditionally, our health systems have focused on facility-based disease care and management. Various factors contribute to medication non-adherence, including financial constraints, literacy levels, lack of awareness, and inadequate family or community support. To improve compliance with the treatment of chronic diseases, a comprehensive approach that places patients at the center of disease treatment and management is necessary.


Program model/patient support groups

Traditionally, our health care system is organized in a way that the care-seeker's role as a stakeholder in the services received by them is largely passive. Disease management places lesser emphasis on aspects such as the care-seeker's perception of disease management and the skills required of care-seekers at the individual level for disease management. While the new national programs suggest various ways of community engagement, those are yet to be fully active.

Patient support groups are one innovative strategy to promote individual's active engagement in managing their health condition. Literature shows the positive impact of patient support on self-management, attributing it to increased knowledge and a sense of social connectedness. From an individual perspective, such support groups potentially harness the unique strengths of their members, creating a collective support system rather than each person independently grappling with their challenges. Moreover, these groups offer a platform for members to exchange effective strategies for managing conditions and fostering motivation among the group members to adhere to their treatment plans, as well as act as a safe niche to share with their peers the emotional upheaval such as sadness and hopelessness, which individually every patient gets due to illness. The approach is proven to be effective in driving positive behavior change. Patient support is also recognized as a feasible, cost-effective, and adaptable intervention for improving chronic care and health outcomes in low-resource settings.

Recognizing the value of community engagement, the Ayushman Bharat-Comprehensive Primary Health Care (AB-CPHC), through Ayushman Arogya Mandir Operational Guidelines, advocates for the formation of patient support groups facilitated by frontline workers, including community health officers (CHOs), multi-purpose workers (MPWs), and accredited social health activists (ASHAs). These groups are tailored to specific disease conditions and aim to improve treatment compliance and engage not only care-seekers but also their family members. Active community engagement through patient support groups is considered pivotal in achieving successful long-term management of chronic illnesses.

Examples of operational patient support groups

There are several initiatives in India that demonstrate creating patient/peer support groups for various use cases. Listed below are a few examples, while there could be other examples that the group may not have come across:

1. Jan Swasthya Sahyog (JSS), a voluntary, non-profit organization, has worked on establishing and running patient support groups for various chronic illnesses, including diabetes, hypertension, epilepsy, sickle cell disease, etc., in Bilaspur, Chhattisgarh's

Jain Y. Communitisation of healthcare: peer support groups for chronic disease care in rural India. BMJ. 2018;360:k85.
doi: 10.1136/bmj.k85.
tribal and rural areas. Initiated in 2015/16, the patient support groups demonstrate good results in caring for patients with chronic illnesses.

2. The Department of Public Health, Tamil Nadu, initiated a pilot on the formation of patient support groups for NCDs in all the universal health coverage blocks across the state. The pilot was initiated in 2020 and is expected to yield good results in improving compliance with care.

3. Health administrations in the districts of Uttar Pradesh (District Filaria Patient Support Groups) have become a core part of raising awareness about MDA, removing the stigma around the disease, and promoting healthy habits among patients. In Uttar Pradesh, such groups are operating in Kanpur, Lucknow, Deoria, and Ballia. One of the main objectives of these groups is to enable the patients-survivors to connect with each other and promote patient-survivor involvement in strengthening the elimination program.

4. The Public Health Department in Maharashtra has been working on demonstrating the operationalization of patient support groups in selected facilities of the Satara district, Maharashtra, from September 2023.

This implementation guidebook has been prepared based on learnings from these different examples of operationalizing patient/peer support groups. This document will be a ready reckoner for operationalizing, running, managing, and evaluating patient support groups in any geography and by any institute/health department.

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Integrating patient support groups into Ayushman Arogya Mandir (AAM) represents a significant step forward in enhancing the quality of health care services and promoting holistic well-being within communities. This endeavor requires careful planning, coordination, and a commitment to community engagement.

The team involved in this activity should include the district comprehensive primary health care consultant, district non-communicable disease consultant, block medical officer (BMO), medical officer - primary health center (MO-PHC), CHO's, auxiliary nurse midwife (ANM)/MPWs, and ASHAs. Under the guidance of the district health officer (DHO) in charge of primary health care, this team will coordinate for formation, facilitation, and monitoring of patient support groups in their geography.

Based on the focused health condition, a line list needs to be prepared for already diagnosed people for the health condition. The support group meetings can be organized in the villages to the extent possible. CHO's can be the convener/facilitator for the patient support group meetings. However, based on several groups, some of the activities in the group meetings shall be delegated to other team members, such as MPW.

The following steps outline a comprehensive approach to successfully integrate patient support groups into Ayushman Arogya Mandirs, thereby contributing to improved health care outcomes and strengthening community bonds.

The program can be initiated phase-wise, i.e., the preparatory, implementation, and output and sustainability phases.

Preparatory phase

1. Selection and training of personnel

- Prepare a pool of master trainers to conduct training on patient support groups at the Ayushman Arogya Mandir level. While all the team members, including the district CPHC consultant, district NCD consultant, BHO, MO-PHC, CHO's, ANM/MPWs, and ASHAs, need to be aware and trained on patient support groups' operationalization, particular emphasis is required on the frontline team.

- Ensure all staff members, especially the ANM/MPW and ASHAs, are adequately trained in the concept, objectives, and operational dynamics of patient support groups. Training will support them with the necessary skills to effectively engage with individuals with specific health conditions.

- District CPHC consultant should conduct a review and orientation or capacity-building session at least once a year. The list of master trainers shall be maintained by the program manager at the state level and the CPHC consultant at the district level.
• District-level master trainers, in coordination with a respective district-level consultant, may conduct the following activities for the respective district:
  • Schedule district-level training to inform the structure of the patient support group and the roles and responsibilities of CHO, ASHA, and ANM.
  • Conduct training on the operationalization of patient support groups and maintain a list of CHO's, ANM, and ASHA trained to conduct patient support groups at Ayushman Arogya Mandirs.
  • The respective district consultant should prepare a plan for the following:
    • Training of master trainers
    • Training of staff mentioned above by the master trainers
    • Refresher training of facility staff, once a year

2. Undertaking disease burden mapping and awareness generation on the activity

• Ideally, patient support group activity should start from the health facilities at the time of diagnosis of a chronic condition. The diagnosing MO, CHO shall share the information on patient support groups with patients and encourage them to join the patient support group. However, there may already be diagnosed patients who may not be aware of the patient support groups. To reach such patients, awareness activities can be done.

• Each Ayushman Arogya Mandir team shall prepare a village-wise list of individuals with specific health conditions to plan for the patient support group meetings. The facility registers or line list of individuals with various conditions shall be used for this.

• The ASHAs shall be instructed to reach out to the listed individuals with information on the formation of patient support groups and orientation meetings on the same. This is a crucial step for mobilizing care seekers for the support group meetings.

3. Preparation of annual calendar/monthly planner

• Each patient support group meeting should be conducted on a fixed day every month. The schedule for the meeting should be decided based on consensus with the support group participants. For instance, for NCDs such as diabetes and hypertension, it can be planned on the first Saturday of every month, which is designated for NCD screening under Ayushman Mela.

• Once decided, it is essential to follow the schedule.

• Accordingly, ASHA and ANM/MPW should continue mobilizing identified individuals with specific illnesses to concerned Ayushman Arogya Mandirs.

• The Ayushman Arogya Mandir team should prepare annual calendar information and a copy of it to be maintained by the block and district health offices, keeping in
mind the local festivals and other occasions that may possibly become a hindrance to conducting meetings in those months. The meeting date can be made flexible after discussion with patients in the previous month's meeting.

4. Stakeholder engagement

- Collaboration with local community leaders, medical professionals, and health authorities can be established to garner support and promote the program.

Implementation phase

1. Care-seeker orientation and mobilization

- An initial orientation of care-seekers on various aspects and benefits of the support groups should be conducted by the MPWs in their villages, along with a plan for the first support group meeting (date/time/location).
- Patients referred from higher facilities or by the CHO shall be enrolled and listed in the patient support group based on their willingness.

2. Meetings of the patient support groups

- The patient support group activity aims to improve treatment outcomes of all chronic illnesses. In the initial stages of operationalization, the focus should be on common chronic illnesses in the community. Once the groups are established for one condition, move on to other disease areas.
- After the frontline health workers have ensured reaching out to all the individuals with a specific condition and their orientation on the patient support group processes, organize the first meeting.
- It is important to note that seeking care from patient support groups is voluntary and depends on individual willingness. Not joining patient support groups, in any way, should not mean denial of treatment. Individuals are free to visit health facilities as per facility working schedules. However, the care-seekers not participating in patient support groups should be reached out regularly to encourage them to join the groups. This can be done by the health team and the individuals participating in patient support groups.
- The group should be formed at the Ayushman Arogya Mandir level or the village level based on the number of individuals diagnosed with a specific condition, convenience of people, availability of space at the village level, etc.
- These meetings shall include the following:
  - Educational sessions followed by discussions
  - Yoga and wellness activities such as meditation, aerobics, sports
  - Monthly check-ups
• Follow-up on drug adherence and refilling
• Teleconsultation for patients with complications (to be done separately toward the end of the meeting after sending back patient members who do not need the teleconsultation)
• Detailed information on basic principles and activities in the patient support groups are mentioned separately.

Resources and support

Organizing and smooth functioning of patient support groups need certain resources such as drugs and diagnostics and financial resources. It is extremely important to plan for these resources before the team meeting.

Medicines: The CHO should estimate the drug requirement for at least one month's supply based on the disease condition and number of patient support group members. Availability of drugs needs to be ensured before the support group meeting through regularized supply chain mechanisms. Support from MO-PHC, consultant CPHC, NCD, and pharmacy officers at various stages will be crucial.

Diagnostics: Similar to drugs, diagnostic requirement estimation should be done and availability ensured.

Human resource: The responsibility of conducting and facilitating the meeting will be vested with the CHO. The CHO is responsible for ensuring drug availability, screening equipment, and conducting Yoga activities. However, considering the engagement, some of these activities may also be delegated to other staff at Ayushman Arogya Mandir after proper documentation and approval.

Financial resources: Organizing support groups will involve providing healthy snacks to the group members. A support of Rs 250–400 for the snacks should be planned for each support group meeting. Additionally, provision should be made for an incentive of Rs 250 per patient support group meeting with the CHO leading to the patient support groups. These financial resources should be budgeted under the program implementation plan.

Output and expansion phase

Ongoing record keeping and evaluation

Implement a regular reporting mechanism for Ayushman Arogya Mandirs to provide regular updates to the district regarding patient support group activities, challenges, and achievements. A suggested monitoring format is mentioned separately.

Periodically assess patient support groups' effectiveness and adjust strategies based on feedback and results. In the initial period, quarterly feedback should be collected from participants, CHO, MO, and other stakeholders to streamline the operationalization. In the later phases, half-yearly feedback should be collected to evaluate the effectiveness of support
groups. Necessary modifications should be made to improve the impact of support groups in consensus with the BMO, MO-PHC, and Ayushman Arogya Mandir teams.

**Awareness and outreach:** ASHA and ANM/MPW to conduct awareness campaigns and community outreach work to attract new participants and raise awareness about the support groups.
Basic principles and activities involved in organizing support group meetings

1. The number of members in each group should be a maximum of 25 and a mixture of both genders. If more than 25, the group should be split into two.

2. Group members should attend meetings regularly. In the case of difficulty for care-seekers to attend the meeting, their caregiver may represent the member at the meeting.

3. The caregivers from the family should be encouraged to join the meeting, though they are not the members. This is aimed to foster better support for the patients by the caregivers in their families.

4. Attending group meetings intermittently should be discouraged. If any group member is attending the meeting intermittently, the facilitating team (health workers) and other group members should discuss the challenges with such group members and support the member to attend the meetings regularly.

5. The CHO should facilitate group meetings with support from MPW/ANM/ASHA.

6. Ideally, every group should have their group leader and co-leader chosen by the members from among them for one year.

7. The group leader and co-leader should be present during their group meetings to coordinate and support the facilitator. Additionally, the group leader and other group members should also try to encourage individuals with similar illnesses and those not enrolled in the patient support group to join the groups.

8. The group meeting among the members can be of more frequency as per the convenience of the members for supporting each other. The health team interaction with the patient support group should happen once a month without fail as per the pre-decided schedule.

9. All group members should be respectful toward each other and receive the sharing by others with regard and concern.

10. To support each other, a buddy model can be followed, where the group members will select a buddy. Through this model, the CHO will try to establish a support system within the group members for positive behaviors to ensure patient support group meeting attendance, compliance with treatment, healthy lifestyles, and support for each other when needed.

11. Patient support groups need to be focused by facilitators or group leaders on the following key themes/motives:

   a. Treatment and medical care received and any issues
   b. Diagnostic care received and issues with it
   c. Drug dispensation
d. Advocacy at the local level  
e. Information education and communication strategies  
f. Wellness activities and health promotion activities

12. Communication: Respectful group communication is the key to the successful operations of patient support groups. The facilitating team should focus on participatory approaches and group communication techniques to encourage active participation, encouraging participants to actively engage and continue with the group.

13. Group activities: Culturally appropriate group activities can bring unity among the group. Locally relevant activities should be promoted as an icebreaker.

14. Every group member should have one visit by a physician at least once every six months or based on the national/state protocol for a particular disease condition.

15. The drug distribution should be done at the end of the monthly session after checking for disease control by CHO.

16. The Ayushman Arogya Mandir team is suggested to define the objectives of every meeting and undertake activities accordingly.

17. The group report should be filled out at the end of a group meeting and shared with the respective authorities, including MO-PHC, BMO, and district consultants.
# Roles and responsibilities of various team members

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<tr>
<th>Team member</th>
<th>Role and responsibility</th>
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| **District CPHC consultant and NCD consultant** | • Coordinate the overall activity at the district level.  
• Prepare and implement district-level plans.  
• Prepare a list of master trainers, ensuring the Training of Trainers.  
• Ensure cascading training in the field at regular intervals.  
• Ensure smooth supply chains for drugs and diagnostics.  
• Allocate program implementation plan for financial support.  
• Prepare an activity plan for the patient support group meetings.  
• Prepare and share guidance material at regular intervals. |
| **BMO**                           | • Provide inputs in the block-level planning.  
• Guide and monitor the patient support group’s overall activity at the block level.  
• Support in troubleshooting in the case of any query/liaisoning requirements with the district. |
| **MO-PHC**                        | Support and guidance in terms of the following:  
• Clinical review and management of patients attending patient support groups at regular intervals (half-yearly).  
• Referral of newly diagnosed patients to respective patient support groups.  
• Monitor the program in their work areas.  
• Visit and participate in the patient support groups (at least once/twice a year for each group). |
| **CHO**                           | • Overall leadership in organizing and patient support group meetings.  
• Upward and downward coordination with respective to stakeholders in preparing plans, ensuring resources, supply chain, and implementation.  
• Prepare plans for care-seeker awareness of specific disease conditions in the catchment area.  
• Session with care-seeker to motivate them to join the support groups.  
• Prepare activity plans for each patient support group meeting.  
• Individual health check-ups and prescribed medicines in the patient support groups. |
| **ANM/MPW**                       | • Support CHO’s in conducting patient support group meetings.  
• Take the lead in encouraging new individuals with similar health conditions to join the groups, wellness activities, IEC, and other related activities in the meeting. |
| **ASHA** | • Generate awareness in villages and reach out to individuals with specific disease conditions.  
  • Mobilize the individuals to join patient support groups. |
| --- | --- |
| **Members from support groups** | • Attend patient support groups and support each other.  
  • Encourage other individuals with similar health conditions not enrolled in patient support groups. |
## Monitoring and evaluation

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<th>Type</th>
<th>Data point/indicator</th>
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| **Inputs** | • Number of trainings conducted.  
  • Number of staff trained on patient support groups segregated by cadres: DHO, district consultants, BMO/THO, MO-PHC, CHO.  
  • Number of ASHA/ANM/MPWs sensitized on patient support groups.  
  • Number of Ayushman Arogya Mandirs with drugs and diagnostics available for patient support groups.  
  • Number of total patients with particular chronic conditions in the area. |
| **Process** | • Number of patients sensitized about patient support groups.  
  • Number of patients willingly participating and enrolled under patient support groups.  
  • Number of patient support groups operational in the district.  
  • Number of patient support group meetings conducted. |
| **Output** | • Proportion of total individuals with a particular chronic condition participating in the respective patient support groups.  
  • Proportion of patient support group meetings conducted regularly without any gap.  
  • Number and proportion of individuals participating in the patient support groups regularly.  
  • Number and proportion of individuals with controlled health indicators. |
| **Outcome** | • Number of non-accidental emergency events recorded in individuals participating in patient support groups. |

A suggested data recording structure is annexed in this document. It will be useful to analyze the above-mentioned indicators. It will be best to share these indicators with the respective authorities at regular intervals, ideally every month.
The patient support group training program anticipated several valuable outcomes that would contribute to the participants' professional growth and the enhancement of community health care practices:

- **Patient-centric care:** Transformation of individuals from passive recipients of health care to empowered individuals who actively participate in their treatment, leading to better self-management and improved overall well-being.

- **Holistic well-being:** Covering aspects of an individual's well-being, including physical, emotional, social, and mental health, through patient support groups can lead to a more balanced and improved quality of life.

- **Lifestyle modification:** With the support and education offered by the groups, individuals are expected to adopt healthier lifestyle habits, such as improved nutrition, regular physical activity, and stress reduction, contributing to better long-term health outcomes.

**Enhanced medication adherence:** Comprehensive care involves addressing factors affecting medication adherence, leading to increased compliance with treatment regimens and improved disease control.

**Community engagement:** The engagement of patient support groups in community health initiatives can contribute to better public health outcomes. By promoting disease prevention, early detection, and effective management, these groups play a vital role in improving the community's overall health.

**Improved patient-provider communication:** Patient support groups can improve patient-provider communication by empowering care-seekers to express their concerns, ask questions, and actively engage in their health care decisions.

**Advocacy and policy impact:** Engaged patient support groups can advocate for better health care policies, increased funding for chronic disease management, and improved access to health care services, benefiting the broader community.
Potential application of the patient/peer support group strategy beyond chronic diseases

The current document discusses the patient/peer support group strategy primarily within the context of chronic disease care. However, it is widely acknowledged that peer support can be of significant value in promoting healthy behavior across various health conditions, whether related to diseases or non-disease factors.

This guidance document will serve as a flexible template for structuring peer support group interventions for such diverse conditions. Below, we have outlined some of the potential scenarios:

<table>
<thead>
<tr>
<th>Program</th>
<th>Particular activity</th>
<th>Aim</th>
<th>Potential convener/facilitator</th>
</tr>
</thead>
<tbody>
<tr>
<td>RMNCHA</td>
<td>Antenatal care and post-natal care</td>
<td>To promote necessary care seeing, healthy behavior approaches during pregnancy, post-natal care, newborn care, feeding for the newborn and infant, etc.</td>
<td>ANM</td>
</tr>
<tr>
<td></td>
<td>Early childhood development</td>
<td>To ensure full immunization, monitor developmental milestones, and guide early childhood nutrition and development among children aged 2 years.</td>
<td>ANM</td>
</tr>
<tr>
<td></td>
<td>Adolescent reproductive &amp; sexual health</td>
<td>To promote adolescent health issues and awareness of reproductive and sexual health.</td>
<td>ANM</td>
</tr>
<tr>
<td>Tuberculosis/leprosy</td>
<td>Treatment compliance of patients with tuberculosis</td>
<td>To ensure treatment compliance and improve the success rate of individuals affected by tuberculosis and leprosy.</td>
<td>STS/MPW</td>
</tr>
<tr>
<td>Nutrition</td>
<td>Nutritional monitoring and suggestions</td>
<td>To reduce undernutrition among children aged between 3 and 6 years.</td>
<td>Anganwadi Worker</td>
</tr>
<tr>
<td>Mental health</td>
<td>Treatment compliance of individuals needing psychiatric therapy</td>
<td>To ensure treatment compliance.</td>
<td>CHO</td>
</tr>
<tr>
<td>De-addiction</td>
<td>Sustaining de-addiction efforts and positive behaviors</td>
<td>To ensure the continuation of de-addiction therapy and control over addictive consumption.</td>
<td>CHO/MPW</td>
</tr>
</tbody>
</table>

The current document discusses the patient/peer support group strategy primarily within the context of chronic disease care. However, it is widely acknowledged that peer support can be of significant value in promoting healthy behavior across various health conditions, whether related to diseases or non-disease factors.

This guidance document will serve as a flexible template for structuring peer support group interventions for such diverse conditions. Below, we have outlined some of the potential scenarios:
| Cancers | Improving treatment compliance, linking patients with support schemes, and providing social support to patients diagnosed with various cancers | To promote necessary care seeking, guiding patients on various treatment modalities, linking patients with support schemes, and ensuring social support. | Social workers available at district/block level, either in public health facilities or NGOs |
# Annexure

## Suggestive record keeping format for diabetes and hypertension group at group / facility level

<table>
<thead>
<tr>
<th>Sr No</th>
<th>1</th>
<th>2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Name of the support group member</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health Condition</td>
<td>DM</td>
<td>HTN</td>
</tr>
<tr>
<td>Systolic BP</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diastolic BP</td>
<td></td>
<td></td>
</tr>
<tr>
<td>FBS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PPBS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>RBS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HBA1C</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Compliance of medicine in previous month</td>
<td>Regular</td>
<td>Irregular</td>
</tr>
<tr>
<td>Condition controlled status</td>
<td>Controlled</td>
<td>Uncontrolled</td>
</tr>
<tr>
<td>Any abnormality observed in the previous month</td>
<td></td>
<td></td>
</tr>
<tr>
<td>If Yes, what abnormalities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any major health event in the previous month</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Referral required</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Referral reason</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Referred facility (e.- Sanjeevan, MO-PHC, Other)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicines prescribed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of days for which medicines prescribed</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

## Suggestive monitoring format for patient support groups at block / district level

<table>
<thead>
<tr>
<th>Sr No</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name of village</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Name of HWC</td>
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<td></td>
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<tr>
<td>PHC</td>
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<td></td>
<td></td>
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<tr>
<td>Block</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Name of CHO</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group operationalized</td>
<td>Yes</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Health condition</td>
<td>Diabetes</td>
<td>Hypertension</td>
<td></td>
</tr>
<tr>
<td>Total patients diagnosed with the condition in area</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of patients sensitized on PSG</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of members registered in the group</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicines available for condition</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diagnostics available for condition</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Sep-23</td>
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<td>Oct-23</td>
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<td>Nov-23</td>
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<td>Dec-23</td>
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<tr>
<td>Jan-24</td>
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<td>Feb-24</td>
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<tr>
<td>Mar-24</td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>
Address:
15th Floor, Dr. Gopal Das Bhawan,
28, Barakhamba Road,
New Delhi - 110001