Executive Summary

Chronic diseases contribute significantly to the global burden of diseases. While much effort has been made in detecting new cases with chronic conditions among populations, individuals with long-term issues face numerous challenges. A significant hurdle is the difficulty in adopting and sustaining complex behavioral changes necessary for effective disease management. A substantial proportion of patients with chronic illnesses fail to adhere to treatment plans within the first year, leading to missed doses, incorrect dosages, or treatment discontinuation. Various factors contribute to medication non-adherence, including financial constraints, low 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.

Traditionally, our health care system is organized in such a way that the patient’s role as a stakeholder in and recipient of the services is largely passive. In terms of disease management, it also places lesser emphasis on the patient’s perception of and their individual skills in disease management.

Formation of patient support groups is an innovative strategy to promote the individual’s active role 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 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 notes on effective strategies for managing conditions as well as fostering motivation among the group members to adhere to their treatment plans. 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.

The Ayushman Bharat Comprehensive Primary Health Care (AB-CPHC) program through Ayushman Arogya Mandir Operational Guidelines advocates for the formation of patient support groups facilitated by frontline workers including community health workers (CHOs), multipurpose workers (MPWs), and accredited social health activists (ASHAs). This facilitation guide aims to lay down an approach for initiating patient support groups by Ayushman Arogya Mandir (AAM) teams.

Purpose:

- The purpose of forming patient support groups (PSGs) is to provide a platform for individuals with chronic diseases to support each other, share information, and receive guidance on managing their health conditions.

- PSGs aim to improve treatment adherence, encourage healthy lifestyles, and empower patients to take control of their health.

Scope:

This guide aims to provide CHO with a step-by-step approach to facilitate PSG meetings for individuals with chronic illnesses.
Activities in the preparatory phase

- As a starting point, each AAM team should prepare a village-based list with names of individuals with specific health conditions to plan for the PSG meetings. The records maintained by the facilities or line list of individuals containing health records should be used for this purpose.

- ASHAs should be requested to reach out to the listed individuals with information on the formation of PSGs and orientation meetings on the same. This is a crucial step for mobilizing care seekers for the support group meetings.

- Collaboration with local community leaders, Jan Aarogya Samiti (JAS) and Village Health, Sanitation, and Nutrition Committee (VHSNC) members, and health authorities can be established to garner support and promote the program.

- All the patients with a particular condition for which a PSG is being formed need to be informed about the support group activity. Moving forward, a mechanism needs to be set up to orient all newly diagnosed patients with information on the PSGs.

Organizing the first meeting and orientation on PSGs

- The first meeting for each group is meant to orient patients on the concept of PSG meetings. It is important to organize the meeting at a place that is convenient for all the patients and health team members.

- Points to be focused on during the orientation:
  - Concept of PSGs
  - Expectation from health team members and patients
  - Group dynamics, buddy model, and mutual support
  - Group leadership decisions
  - Group counselling
  - Health education medicine refills
  - Health education sessions followed by discussion
  - Yoga and wellness activities such as meditation
  - Monthly routine check-ups for the condition
  - Follow-up on drug adherence and refilling
  - Teleconsultation for patients with complications (to be done separately toward the end of the meetings after the patient members not requiring teleconsultation have left).

- It is important that the PSG meeting should be conducted on a fixed day every month. The schedule for the meeting should be decided based on consensus from the participants. For instance, for non-communicable diseases (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 crucial to follow the schedule.

- The AAM team should prepare an annual calendar. A copy of this calendar should be maintained by the block and district Health offices keeping in mind the local festivals and other occasions that may possibly disrupt the meeting schedule. The meeting date can be made flexible after discussion with patients in the previous month’s meeting.

- It is important to note that seeking care from PSGs is voluntary and depends on individual willingness. Not joining such groups should never mean denial of treatment. Individuals are free to visit health facilities as per facility working schedules. However, the care-seekers not participating in PSGs should be contacted regularly to encouraged to join. This can be done by the health team and those participating in PSGs.

- The group should be formed at the AAM 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:
General principles of support group formation and meetings

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

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

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

- 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 in attending the meetings regularly.

- CHOs should facilitate group meetings with support from MPWs, ANMs, and ASHAs. Ideally, every group should have their group leader and co-leader chosen by the members from among them for one year.

- 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 PSG to join the groups.

- The frequency of meetings between group pp members can be increased as per the convenience of the members. The health team's interaction with the PSG should happen once every month as per the pre-decided schedule.

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

- 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 PSG meeting attendance, compliance with treatment, healthy lifestyles, and support for each other when needed.

- Group leaders of PSGs should focused on the following key themes:
  - Treatment and medical care received and any issues to be addressed
  - Diagnostics received and issues with it
  - Drug dispensation
  - Advocacy at the local level
  - Information education and communication strategies
  - Wellness activities and health promotion activities

- Respectful group communication is the key to the successful operations of PSGs. The facilitating team should focus on participatory approaches and group communication techniques to encourage active participation among participants.

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

Health condition check-up at the PSG meeting

- All the patients attending support group meeting should undergo the necessary checks for their respective medical condition.

- This should include recording vitals, evaluation of general health condition, evaluation of complications, and an inquiry of any significant health event in the past month.

- The assigned CHO, MPW, or ANM shall also check for compliance, that is, assess whether the patient took medicines correctly and regularly during the previous month. Any gaps should be addressed both at a personal level and anonymously during the group counseling.

- The CHO shall follow the state/national protocol for refilling care accordingly.

- In case if there are any uncontrolled conditions or complications observed, the CHO need to consult a medical officer either through telemedicine or by patient referral to MO at PHC.
- Every group member should have one visit by a physician at least once every six months or based on the national or state protocol for a particular disease condition.

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

**Patient record and PSG record maintenance**

- The National Program for Prevention of Non Communicable Diseases offers आरोग्य पात्र (health card) for the NCDs, which capture most of the important information. CHOs are suggested to use these cards as patient records. Patients can bring these cards for the meetings.

- Along with health cards, a facility register needs to be maintained as well. The information from this register will be used for analyzing quantitative indicators for assessing the impact of PSGs.

- The PSG report should be filled out at the end of a group meeting and shared with the respective authorities, including MO-PHC, Block Medical Officer and district consultants.

**Resources and support**

- Organization and smooth functioning of PSGs need certain resources such as drugs and diagnostics. 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 PSG 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, some of these activities may be delegated to other staff at AAM after proper documentation and approval.

---

**Roles and responsibilities of various team members**

<table>
<thead>
<tr>
<th>Team member</th>
<th>Role and responsibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHO</td>
<td>• Overall leadership in organizing and PSG meetings</td>
</tr>
<tr>
<td></td>
<td>• Upward and downward coordination with respective stakeholders in preparing plans, ensuring resources, supply chain, and implementation</td>
</tr>
<tr>
<td></td>
<td>• Prepare plans for care-seeker awareness of specific disease conditions in the catchment area</td>
</tr>
<tr>
<td></td>
<td>• Session with care-seeker to motivate them to join the support groups</td>
</tr>
<tr>
<td></td>
<td>• Prepare activity plans for each patient support group meetings</td>
</tr>
<tr>
<td></td>
<td>• Individual health check-ups and prescribe medicines in the PSGs</td>
</tr>
<tr>
<td>ANM / MPW</td>
<td>• Support CHOs in conducting PSG meetings</td>
</tr>
<tr>
<td></td>
<td>• 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.</td>
</tr>
<tr>
<td></td>
<td>• Provide support during health checkups and medicine distribution</td>
</tr>
<tr>
<td>ASHA</td>
<td>• Generate awareness in villages and reach out to individuals with specific disease conditions</td>
</tr>
<tr>
<td></td>
<td>• Mobilize individuals to join PSGs</td>
</tr>
<tr>
<td></td>
<td>• Follow up with and support group members at the community level in case of challenges</td>
</tr>
<tr>
<td>Support group members</td>
<td>• Attend PSG meetings and support each other</td>
</tr>
<tr>
<td></td>
<td>• Encourage others with similar health conditions who have not enrolled in PSGs to join</td>
</tr>
</tbody>
</table>
### Roles and responsibilities of various team members

<table>
<thead>
<tr>
<th>S. No.</th>
<th>Session</th>
<th>Activity</th>
<th>Duration</th>
</tr>
</thead>
</table>
| 1      | Welcome and introduction | 1. Welcome and greet all participants  
2. Icebreaker for the meeting  
3. Start with a prayer or meditation or any culturally relevant activity as an icebreaker | 10 mins  |
| 2      | Group formation and expectations | 1. Explain the concept of PSGs—initially to be done by the AAM team and later on preferably by a PSG member. Repeat in every meeting for the benefit of any new members or caregivers.  
2. Discuss expectations of participants and group members  
3. Emphasize the importance of group dynamics and supporting each other | 10 mins  |
| 3      | Health education         | 1. Health education session to be provided on various topics with focus on hypertension and diabetes (Refer to Annexures 1 and 2)  
2. Other topics as per the demand of the group members can also be incorporated in the session | 20 mins  |
| 4      | Group counselling        | 1. Answer the questions asked or problems raised by group members  
2. The CHO should encourage members to actively participate | 15 mins  |
| 5      | Buddy model and peer     | 1. Implement the buddy model system, where each member selects a buddy for mutual support  
2. Encourage buddies to help ensure attendance, medication adherence, and a healthy lifestyle beyond meeting duration  
3. Encourage buddies to provide updates on their assigned members’ progress  
4. Discuss any challenges and provide mutual support  
5. Encourage group members to actively engage and support each other | 10 mins  |
| 6      | Group Activities         | 1. Engage in wellness activities such as yoga and meditation  
2. Asanas and pranayama beneficial for chronic conditions should be taught and practiced  
3. Encourage members to share their personal experiences and difficulties | 10 mins  |
| 7      | Routine health check-up and follow up | 1. Conduct health check-ups for all members, including blood pressure and bloodsugar monitoring  
2. Evaluate the general health condition of participants  
3. Inquire about any significant health events in the past month  
4. Distribute prescribed medications to the group members  
5. Ensure all members have an adequate supply for the upcoming month  
6. Assess medication adherence and address any gaps | 30 mins  |
| 8      | Complications monitoring and referral | 1. It is important to monitor uncontrolled conditions and related complications  
2. Refer to a higher facility for management of complications  
3. Discuss a follow-up plan with the patient |         |
| 9      | Next Meeting Schedule    | 1. Date of every month should be fixed. Discuss change in date and time for the next meeting if any  
2. Remind members about the voluntary nature of participation  
3. Encourage members to bring more members; patients and caregivers to participate if the group size is small | 5 mins   |
| 10     | Closing remarks          | 1. Summarize key takeaways from the meeting  
2. Encourage members to provide feedback and suggestions | 5 mins   |
| 11     | Teleconsultation         | Conduct teleconsultation calls if any member needs additional support |         |
| 12     | Record keeping and reporting | 1. Ensure the completion of PSG report (minutes of meeting) for this meeting  
2. Update NCD records, both manual and online | 5 mins   |
Suggestive list of topics for the session on health education

- Understanding hypertension (causes, symptoms, risk factors)
- Understanding Diabetes (causes, symptoms, risk factors)
- Effects of high blood sugars on our body
- How do various medicines work in combating diabetes and hypertension
- Side effects of medicines
- Red flag signs in diabetes and hypertension
- Importance an annual check-up
- Comorbidities and complications in diabetes and hypertension
- Importance of nutrition in adults and the elderly (healthy cooking demonstrations)
- Importance of physical activity and maintaining healthy body weight
- Eye care and early warning signs of complications in diabetic patients
- Importance of a healthy heart
- Footcare in diabetes
- Mental health in the elderly
- Stress management
- Quitting tobacco (health risks associated with tobacco, cessation strategies, tobacco and mental health)
- Salt reduction
- Overview of chronic conditions and early warning signs for CKD, NAFLD, COPD, asthma
- Home-based care for the elderly and palliative care (especially for caregivers)
- Preventive and control measures for vector-borne diseases in the community WASH (community-level practices)
- Introduction to relevant government schemes

Roles and responsibilities of various team members

<table>
<thead>
<tr>
<th>S.No.</th>
<th>Date</th>
<th>Name of the support group member</th>
<th>Health condition</th>
<th>Systolic BP</th>
<th>Diastolic BP</th>
<th>FBS</th>
<th>PPBS</th>
<th>RBS</th>
<th>HBA1C</th>
<th>Compliance of medicine in the previous month</th>
<th>Condition controlled status</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td>DM</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Regular</td>
<td>Controlled</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>HTN</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Irregular</td>
<td>Uncontrolled</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>S.No.</th>
<th>Any abnormality observed in the previous month</th>
<th>If yes, what abnormalities</th>
<th>Any major health event in the previous month</th>
<th>Referral required</th>
<th>Referral reason</th>
<th>Referred facility (e-Sanjeevani, MO-PHC, Other)</th>
<th>Medicines prescribed</th>
<th>Number of days for which medicines is prescribed</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: Annual health calendar can also be followed for health promotion activities.
Annexures

Annexure 1: Diabetes treatment protocol:
Public Health Department, Government of Maharashtra.

MAHARASHTRA DIABETES PROTOCOL

Step 1: Measure BSL(R) of ALL ADULTS
- IF BSL(R) ≥ 140 mg/dl

Step 2: Check BSL (F) & BSL (PP) × Adherence counseling

Step 3: PRESCRIBE DEPENDING ON BSL
- IF BSL (F) = 126-180 mg/dl & BSL (PP) = 200 mg/dl
  Start Metformin 500 mg OD

- IF BSL (F) = 126-180 mg/dl & BSL (PP) ≥ 200 mg/dl
  Start Metformin 500 mg BD

Step 4: Review after 1 month
- IF Target BSL not achieved
  INTENSIFY Metformin 500 mg BD

Step 5: Review after 1 month
- IF Target BSL not achieved
  INTENSIFY Metformin 500 mg TDS

Step 6: Review after 1 month
- IF Target BSL not achieved
  ADD Glimeperide 1 mg OD

Step 7: Review after 1 month
- IF Target BSL not achieved
  INTENSIFY Glimeperide 1 mg BD

Step 8: Review after 1 month
- IF Skill Target BSL not achieved
  CHECK that patient has been taking drugs regularly & correctly.
  IF so, REFER patient to specialist

WANT, TREAT & REFER
- Hypoglycemic Symptoms:
  - Watch for Sweating, Confusion, Palpitation, giddiness, tremors, incoherent talk, and unconsciousness
  - Stop O.A. and treat with 10% Dextrose IV or Sugar / sweet orally if patient is conscious.
  - Refer immediately after first line of treatment.

- Diabetic Retinopathy:
  - Examine Retina / Fundus every year if no eye symptoms
  - Eye symptoms: spots or dark strings in vision, blurred vision, fluctuating vision, impaired color vision, dark or empty areas in vision, vision loss
  - Refer immediately

- Diabetic Neuropathy:
  - Examine feet for sensation and circulation also for ulcers, dryness, sores, infection, injuries.
  - Refer for neuropathy caustics, gangrene immediately.
  - Treat infection with antibiotics, Refer if not cured.

LIFESTYLE MANAGEMENT ADVICE FOR ALL PATIENTS
- Avoid fasting and advice to skip medication if fasting.
- Avoid sugar, sweets and added sugar.
- Stop all tobacco use, avoid second hand tobacco smoke.
- Avoid alcohol intake.
- Increase physical activity equivalent of brisk walk 150 minutes per week.
- IF overweight, lose weight.
- Eat healthy diet, avoid fried food.
- Eat ≥ 5 servings of vegetables per day.
- Avoid fruits like Banana, Mango, Grapes, Chilcon, Fig (Asparagus) and Staphal (Castard Apple).
- Use healthy oils (e.g. Groundnut, Sunflower).
Annexure 2: Hypertension management protocol: Public Health Department, Government of Maharashtra.

Hypertension Protocol

Measure blood pressure of **all adults** over 18 years

High BP: **SBP ≥ 140** or **DBP ≥ 90 mmHg**

Check for compliance at each visit before titration of dose or addition of drugs

**Step 1**
If BP is high*
Prescribe Amlodipine 5 mg + adherence counseling

**Step 2**
After 30 days measure BP again. If still high:
Add Telmisartan™ 40mg

**Step 3**
After 30 days measure BP again. If still high:
Increase Telmisartan to 80mg

**Step 4**
After 30 days measure BP again. If still high:
Increase Amlodipine to 10mg

**Step 5**
After 30 days measure BP again. If still high:
Add Chlorthalidone 6.25mg

**Step 6**
After 30 days measure BP again. If still high:
Increase Chlorthalidone to 12.5mg

* If BP is high:
**Women who are or could become pregnant**
- **DO NOT** give Telmisartan or Chlorthalidone.
- **ACE inhibitors**, angiotensin receptor blockers (ARBs), thiazide diuretics, and statins should not be given to pregnant women or to women of childbearing age not on highly effective contraception.
- Calcium channel blocker (CCB) can be used. If not controlled with initialisation dose, refer to specialist.

**Diabetic patients**
- Treat diabetes according to protocol.
- Aim for BP target of <140/90.

**Heart attack in last 3 years**
- Add beta blocker to Amlodipine at initial treatment.

**Heart attack or stroke ever**
- Begin low-dose aspirin (75 mg) and statins.

**Chronic kidney disease**
- **ACE inhibitor** or **ARB** preferred if close clinical and biochemical monitoring possible after specialist opinion.

- **If SBP 140-159 and/or DBP 90-99**, start on lifestyle management for one month prior to initiation of medications.
- **If SBP ≥ 160 and/or DBP ≥ 110** start treatment and refer to specialist immediately.

**Recommended Investigations at initiation of therapy:**
- CBC, blood sugar, serum creatinine, electrolytes (optional). If S creatinine >1.5 mg, refer to specialist.
- If Telmisartan not available: replace withenalpril 5 mg (initiation dose) and 10 mg (intensification dose).

**Lifestyle advice for all patients**
- Eat less than 1 tsp of salt per day. Avoid papads, chips, chutneys, dips, pickles, etc.
- Exercise regularly. 2.5 hours per week.
- Avoid alcohol and tobacco.
- Limit intake of fried foods.
- Avoid foods with high amounts of saturated fats (e.g., cheese, ice cream, fatty meat).
- Avoid processed foods containing trans fats.
- Avoid added sugar.
- Eat 5 servings of fruits and vegetables per day.
- Use healthy oils: polynaturated and monounaturated oils.
- Reduce fat intake by changing how you cook; remove the fatty part of meat, use vegetable oil, boil, steam or bake rather than fry. Limit use of oil for frying.

India Hypertension Management Initiative:
Maharahtra 1.08.0-16
PATH is a global nonprofit dedicated to achieving health equity. With more than 40 years of experience forging multisector partnerships, and with expertise in science, economics, technology, advocacy, and dozens of other specialties, PATH develops and scales up innovative solutions to the world’s most pressing health challenges.
path.org