Peer-Support Toolkit:

Creating Spaces for Young Adults with Chronic Conditions

GenerAtion patient

About This Toolkit

At Generation Patient, we understand the profound isolation faced by those diagnosed with lifelong conditions as children and young adults. As patients ourselves, we also recognize the long-term consequences that can have on our mental and physical health and development, our life's trajectory, and our overall quality of life.

Our team has experienced firsthand how peer support can be a game-changer, helping to combat loneliness, build community, and create spaces where people truly feel validated and understood.

We developed this toolkit to help other patients and patient-led groups build and sustain inclusive, lasting peer-support spaces. Whether you're looking to start a new group or strengthen an existing one, this guide contains practical tips and insights we've gained from facilitating hundreds of peer-led spaces.

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About Generation Patient

Generation Patient is a nonprofit organization created by and for young adults with chronic conditions As young adults, we are at a pivotal life stage: navigating the transition to adulthood while simultaneously managing unpredictable health conditions and our personal, educational, professional, and psychosocial needs.

We provide peer-support programming and drive systemic change through policy work, leadership programming, and evidence generation. We amplify young adult patient voices in critical conversations where real change can occur. Through this strategy, we envision a future where young adults with chronic medical conditions can live with greater quality of life, access, dignity, and fulfillment. As an organization, we do not accept funding from private healthcare, including pharmaceutical and insurance industries.

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Introduction

Introduction

Why is peer support so crucial for young adult patients?

Young adult (YA) patients are a growing demographic, as 85% of children with chronic conditions (like Crohn's disease, lupus, rheumatoid arthritis, etc.) now survive beyond adolescence [1]. In the U.S. alone, almost 54% of young adults (ages 18-34) have at least one chronic condition, while 22% live with more than one [2]. This means that more and more patients are trying to navigate adulthood (and potentially the rest of their lives) with chronic medical conditions.

Young adulthood is often a time filled with new experiences and transitions. Patients with chronic conditions may struggle to balance medical, educational, financial, social, and emotional needs.

While support from family, a medical team, or healthy friends can make a big difference, many YA patients still experience significant feelings of stress, fear, exhaustion, and social ostracization [3].

Young adult patients may feel:

- Alone in their experiences
- 'Left behind' (socially, professionally, or academically) by others their age
- Frustrated by a lack of understanding around their disease/experiences

It can be incredibly isolating to feel like no one in your life understands what you're going through.

This is where peer support comes in! Peer support can take many different shapes, such as:

- talking one-on-one with a friend who has the same diagnosis
- joining a virtual group to talk about different challenges
- connecting with others in the chronic illness community from around the globe via social media

At Generation Patient, we define peer support as supportive connections between young adults living with chronic conditions/medical disabilities, who may be navigating similar life challenges.

Being able to talk to others with lived experience, who really get what you're going through, can help YA patients learn how to navigate the ups and downs of chronic illness. Having peers who have 'been there' themselves can have a profound impact on patients' sense of hope and connection.

There's something incredibly powerful about connecting with others who inherently understand what you're going through, and have been through similar things.

As YA patients, we know firsthand the difference peer support can make – it can truly act as a lifeline, drastically reducing feelings of isolation and enhancing overall quality of life.

Peer support can also improve disease outcomes, mental health and psychosocial well-being, resiliency, disease management, self-efficacy, and treatment adherence [4, 5, 6, 7, 8].

Despite its clear benefits [5, 9], peer support is underutilized in healthcare settings. There's a glaring lack of research promoting its inclusion in long-term care plans for YA patients with chronic conditions — a gap that, if addressed, could increase disease acceptance and reduce isolation for our community.

More on Generation Patient's Peer-Support Program

As of November of 2024, Generation Patient has facilitated over 600 virtual peer-support meetings for young adult patients.

Through our peer support program, we offer:

- General peer-support meetings (open to any YA with a chronic medical condition)
- Higher education peer-support meetings (for YA patients who are in college or graduate school)
- IBD-specific peer-support meetings (our only disease-specific group, for YA with IBD)

At Generation Patient, we think it's important to note who leads and creates these spaces: **our peer-support meetings are community-led, meaning that all our facilitators are young adults living with chronic medical disabilities**. We've noticed that some patients feel more comfortable sharing when groups are peer-led (vs. provider-led), particularly if they've experienced challenges within the healthcare system.

Some of our peer-support meetings focus on topics specific to chronic illness, while others offer informal discussions, interactive workshops, or activities to allow attendees to forge deeper connections with one another (examples of our topics can be found in **Table 1**).

Table 1: Example Discussion Topics from our Peer-Support Groups

Topics from our Higher Education Peer Groups	Topics from our cross-disease General Peer Groups
Navigating Difficult Emotions and Decisions That Come With "Going at Your Own Pace"	Medical Trauma
Connecting with Peers, Friendships, and Relationships	Navigating Outside Perceptions of Chronic Illness
Goal Setting: The Chronically Ill Student Edition	Poetry and Creative Writing Workshops
Thinking About the Future and Life Transitions	Coping With Unpredictability and Uncertainty
Self-Advocacy in the Classroom and Beyond	Exercising and Staying Active With a Chronic Illness
Coping With FOMO During the Summer Months and Beyond	Intersecting Identities and Disclosure in a Medical Setting
Experiences Surrounding Disability Identity in College	Identifying and Mitigating Holiday Stressors
Summer "Break": Exploring Rest, Internships, and Summer Opportunities	Easy Self-Care
New Beginnings: Jumping into the School Year Back to School Prep	Accountability, Communication, and Setting Boundaries
Finding "Your People": Building Community and Seeking Psychosocial Support	Mindfulness, Techniques, and Five Senses Activity
Adjusting to Seasonal Changes	Draw and Talk Sessions
Creating Disability Culture on Campus and Beyond	Benefits of Music and DIY Instrument-Making Exercise
Navigating Exam Season	Adjusting to Life Post-Diagnosis
Travel/Settling into New Places	Virtual Painting Workshops
Anxious Relaxation: Tips for de-stressing (and managing the emotions that can come from that)	Mind-Mapping: Chronic Illness Edition
Self-Compassionate Goal Setting	Romantic Relationships and Chronic Illness

These meetings offer patients with chronic, complex, rare, or undiagnosed conditions an opportunity to connect with others who are navigating similar struggles. Attendees can share stories, exchange valuable coping strategies, and develop self-advocacy skills.

We can help one another practice articulating our experiences, and discuss how to navigate various systems and healthcare institutions as emerging adults. These activities can be helpful in building disease acceptance: **while we validate the challenges we all face because of chronic conditions, we also try to embrace disability as an aspect of identity and culture, rather than a "deficit."**

While this is how our organization structures peer-support programming, peer support groups can take many different forms, and can be tailored to meet the needs of the specific communities they serve. **While the structure, purpose, and content of these groups may vary, the core objectives often remain the same: to foster a supportive, inclusive, and engaging space for community.**

Developing a Peer- Support Space

Developing a Peer-Support Space

Getting Started: Initial Thoughts

Getting a new group off the ground can be a challenging (but rewarding!) process. **You can start by thinking through questions like:**

- **Who** is your group for? How will you get them involved?
- **What** is your purpose? Why do you want to create this space?
- **What** types of groups/activities might benefit your community?
- **When** will people most likely be able to attend? How often will you meet?
- **How** will you make the group as accessible as possible to members?
- **How** will you manage the logistics? What kind of planning is needed?

Some of these questions are important to figure out at the beginning, but other answers may evolve over time through ongoing community discussion. **A few more key considerations, before getting started:**

- **Gauge Interest:** Make sure there is interest from your community before investing time and resources into creating a group.
- **Community Check-Ins**: Consult with your community to understand their interests, availability, and needs. Make sure you're taking into account potential group member's schedules – otherwise, you may have interest but no participation!
- **Assess Capacity:** Determine how many groups you can realistically offer, what activities are feasible, and whether you can compensate facilitators.

Initial Recruitment and Outreach: Who is your group for, and how will you get them involved?

Recruitment and outreach (establishing initial connections and drawing people in) are important first steps in forming a peer support group. While the specific strategies you use may vary depending on your community's needs, **here are some tips and things to consider during this stage of planning:**

Identify Your Target Population

Clearly define the community you want to engage! Understanding the needs and preferences of the population you want to reach is key, so you can tailor your outreach effectively.

Choose the Right Communication Channels

Determine the most effective ways to reach your audience. Different groups may prefer different modes of communication, so consider the following:

- Are the individuals you're trying to reach already connected with your organization (through an email list, social media, etc.), or will you need to contact them in other ways?
- Which platforms (e.g., specific social media channels, community forums, professional networks) are most used by the people you want to reach?

Diversify Your Outreach Methods

Reflect on the outreach methods you'll use to ensure your group is visible to potential members. You can use a mix of approaches, including:

- **Word-of-Mouth:** Encourage any current members to spread the word! Personal recommendations can be incredibly powerful.

- **Online Platforms:** Use social media, online forums, a web page, email lists, or community groups. Tailor your message to fit the platform and its users.

- **Professional Networks:** Use your connections to other organizations (healthcare, community organizations, or advocacy groups) to get the word out! They may be willing to share information about your group with their community, especially if you make it easy for them (sharing suggested language, a flyer, a social media post, etc.).

Craft Engaging Materials

Make sure your advertising materials (flyers, posts, etc.) are clear and engaging – there are lots of free programs online that can help with graphic design! **Make sure your materials:**

- Articulate the purpose of your group, and what members can expect.
- Include practical details like meeting times, how to join/sign up, who can participate, and contact information for questions.
- Are visually appealing and accessible (consider readability and inclusivity).

Check out this resource with a list of accessibility tools to ensure your materials are visually accessible!

VIRTUAL PEER SUPPORT
for young adult patients

Since March 2020, we have facilitated over 450 virtual meetings for young adults with chronic and rare conditions! We host these to connect and support young adult patients around the world. We now host a total of **six virtual meetings each month** in addition to **other events**. Please note that to keep this a safe space, all meetings are exclusively for young adult patients (under 35).

OUR VIRTUAL MEETINGS
We host a variety of meetings for young adult patients including:

- General meetings for all young adults with chronic conditions
- Meetings for young adult patients with IBD
- Meetings for young adult patients pursuing higher education (including undergraduate, graduate, and professional school)

ABOUT OUR ORGANIZATION
We are **an entirely young adult, patient-led nonprofit** focused on empowering adolescents and young adults with chronic medical conditions. All of our events and online programming are focused on the unique challenges of this age group while simultaneously providing support, resources, and community.

For more information, please visit:
generationpatient.org/virtual-meetings

Structuring your Peer Support Group

Your group's format should reflect its goals and the needs of participants. Here are a few examples of common peer group structures:

- **Activity-Based Groups:** Casual gatherings centered around shared interests, such as art, games, or book discussions.

- **Topic-Based Discussions:** Sessions guided by a specific theme, such as coping strategies, self-advocacy, or navigating healthcare.

- **Advocacy Groups:** Members work on shared goals/projects, such as policy change, mutual aid, or creating community resources.

- **Hybrid Models:** Many peer groups blend social interaction, discussion, and structured activities for variety and engagement.

We use a 'hybrid model' for our peer groups, incorporating a mix of casual gatherings, topic-based discussions, and activities. We've found that offering a variety of group formats helps our community foster different types of relationships, address their different needs, provide support and validation, and share resources and knowledge with one another.

Broadening the Scope Beyond Illness

Peer support doesn't always have to be exclusively disease-oriented! Sometimes it's just nice to be around others who inherently understand the difficulties of being a young person with a chronic condition, even when it isn't explicitly being discussed. Focusing on other aspects of life can provide a holistic approach to support. For example, groups can center things like life skills, professional development, hobbies, or cultural discussions!

This approach can help improve disease acceptance while also promoting a multifaceted sense of self.

Consider the diverse ways people connect, share, and grow. Aligning the structure and content of your group with an overarching goal helps ensure that the support offered is meaningful and empowering. Effective peer support resonates with participants' needs and aspirations, and fosters an environment of mutual respect, understanding, and growth.

Some group styles/activities we use (and why!):

- **Casual chats** allow group members to get to know one another and share things that may/may not have to do with chronic illness – meaning that we learn about each other as whole people.

- **Specific discussion topics** allow participants to share their experiences with others who 'get it,' as well as coping strategies and helpful resources. Example topics include disability identity, navigating invisible illness, or body image.

- **Games** provide space to relax, have fun, and take our minds off of everything else. Also a great way to strengthen connections between members of the group!

- **Art activities** allow for creative space to express ourselves and share with one another in a different way. Examples include poetry and creative writing workshops or our "Draw & Talk" sessions.

How to Find Facilitators

Finding people who can facilitate peer support spaces can be challenging. You may want to start by looking within your community for individuals with experience in peer support or relevant fields, such as community health, facilitation, or professional degrees (e.g., MSWs, MFTs). This approach can be helpful for smaller organizations that may not have the capacity to provide extensive training initially.

Lived experience can be just as valuable as professional training, and anyone who is passionate about connecting with others can become a great facilitator. As your group grows, you may find community members who are natural facilitators, or others who have interest in growing that skill!

We look for individuals who:
- Validate and affirm others' experiences
- Reflect on what others have shared and add their own experiences to connect stories
- Are careful not to push unsolicited advice and are mindful when offering solutions (especially anything that could be misinterpreted as medical advice)
- Show interest in connecting others and are invested in the community
- Are passionate about many different topics and activities

If your organization has the resources, consider offering training opportunities for community members interested in facilitation. This can engage consistent group members who want to take on more responsibility.

If official or in-depth training isn't feasible, it's important to create general guidelines or expectations, to ensure facilitators understand their role and know how to handle potential issues.

Accessibility and Inclusivity

Chronic conditions and other disabilities can create a wide range of accessibility needs. While there are some basic "best practices" you can use as a starting place (see Access Living's "Planning an Accessible Virtual Event" or Autistic Self Advocacy Network's "Guide to Accessible Event Planning"), you can't predict every access need that may arise.

We recommend having a clear and direct way for potential/current group members to ask about and request accommodations. While you shouldn't rely on community members to educate, it's important to have opportunities for open dialogue about ways to increase accessibility!

Key things to consider:

- **Ask for Input:** Engage with your community to understand their specific needs. Be open to feedback and provide easy ways for members to reach out.

- **Recognize Limitations:** Acknowledge any access needs you can't meet due to resource constraints. Some solutions are low-cost, like enabling closed captioning on Zoom, while others, like hiring a sign language interpreter, may require more funding.

Benefits of virtual meetings:

All our peer-support meetings are held virtually via Zoom to prioritize accessibility. Virtual meetings offer several advantages:

- **Eliminates Geographical Barriers:** Members can join from anywhere, making it easier for those in remote areas or without transportation.

- **Flexibility:** Participants can join from any location, whether bed, couch, or hospital, and choose how they wish to engage based on symptoms/energy levels (e.g., camera off or using the chat).

- **Safety and Convenience**: For those with compromised immune systems or mobility issues, virtual meetings provide a space to connect without worrying about exposure to infections or navigating physical barriers.

Establishing Group Guidelines:

Setting clear group guidelines helps create a comfortable and accountable environment. **Here are some steps and examples:**

Define the Group's Purpose: Communicate the group's focus and goals. For example, our Higher Education group's purpose is: "psychosocial support, camaraderie, and solidarity with fellow young adults navigating higher education while living with chronic medical conditions. We aim to foster community and provide real-world tools to navigate challenges."

Establish Guidelines: Outline some norms to ensure group members know what to expect in the space! Here are abbreviated versions of some of our group norms:

- We don't give medical advice - we talk about advocacy skills, navigating life with chronic illness, and share resources.

- We use "I statements" rather than generalizing experiences.

- We don't share other participant's details outside of the group.

- We are respectful of each other's accessibility needs.

- We join in whatever way is most accessible: camera on or off, use the chat, etc.

- We make sure everyone (who wants to) has a chance to share.

Check out Generation Patient's full Group Guidelines here.

Facilitating a Peer-Support Group

What Works for Us? What Have We Learned?

Here, we'll discuss some practices we've found helpful when facilitating our peer support spaces. We break our peer groups into three main 'sections' when planning: *introductions, activities or discussion, and wrap-ups*. For each section, we'll discuss its purpose, share suggestions for planning and considerations for facilitating, and provide some specific examples from our groups.

Introductions & Icebreakers

Introductions and icebreakers are important ways of building trust and a sense of community.

We usually offer 3 introduction/icebreaker questions, and invite group members to choose any (or all) questions that they are comfortable answering. We also share our group guidelines at the beginning of each group (verbally or in the chat), to make sure everyone is on the same page.

Example introduction/icebreaker questions:

- **Name/pronouns**

- **A general check-in question, to gauge how folks are doing in the moment:** *"If your mood was an emoji today, what would it be?"*

- **A question related to the group's topic:** *for a college-focused group "Where do you go to school, and what are you studying?"*

- **A fun/silly question to build comfort with each other:** *"What's your favorite warm beverage/comfort food/activity to do when it's cold out?"*

- **A reflective question:** *"What are 1-2 things you did this week that felt nourishing to you/brought you some joy?"*

- **A question about accessibility:** *"Any access needs you'd like to share/ anything you need to join us in this space today?"*

Building Trust

In support spaces, you want attendees feel as comfortable and safe as possible when sharing their stories and experiences. There are many ways to build trust and community – here are a few of our recommendations:

→ **Self-disclosure**: We've noticed that when peer facilitators share some of their personal experiences up front, it can help make participants more comfortable and willing to share their stories in return.

→ **Accessibility:** Encouraging participation in any way that feels accessible (using the chat, raise hand feature, cameras off, just observing, etc.) can help people feel safe and supported.

→ **Comfort:** Participants may also appreciate invitations to use fidget toys, doodle, bring a craft project to work on, etc. to help them feel more comfortable in the space.

→ **Ease them in:** Sometimes, peer-support conversations can be heavy (which is okay!) – it can be nice to start with lighter intro questions (so group members feel connected on a basic level) before diving into more serious topics.

Main Discussion & Activities

Activities or discussions usually make up the bulk of a peer group - this is where participants will share experiences, get to know each other, and build community. For our peer support meetings, we offer a mix of discussion topics and activities (*see the "Developing a Peer-Support Space" section for more information*). Below are some things our facilitators consider when choosing a topic/discussion questions for our meetings.

Tips for choosing discussion topics:

- **Connect your topics to the overall goals of your group.**
  - *Ex: our Higher Education group has discussions like "navigating exam season with chronic illness" or "self-advocacy in the classroom."*

- **Make note of common or recurring themes/questions that come up during discussions to use for future meetings.**
  - *Ex: our Higher Education group often has recurring/seasonal themes around "exam season" or "summer break."*

- **Think about common challenges or experiences that your community navigates.**
  - *Ex: many young adults find it difficult to explain symptoms to peers, or struggle with body image.*

- **Ask your community what topics are important, relevant, and exciting to them!**

Co-creating spaces (for, with, and by young adult patients) can include:

- opportunities for group members to suggest topics/activities
- hearing real-time input from the group and adapting activities to suit current mood/energy levels
- discussing as a group how to best meet different access needs or address conflicts
- including community members in decisions that impact the group, and providing opportunities for feedback!!
- and much more!!

Turning a Topic into a Discussion:

Once you've decided on a topic, it helps to brainstorm a few (3-6) questions to guide the discussion and add structure. Even if you don't get to all of your questions, it's nice to have on hand to keep the conversation flowing. **A few suggestions for creating thoughtful discussion questions:**

- Use open-ended questions (rather than yes/no) to help invite participants to share in more detail.

- Include questions that encourage group members to share a range of experiences – it's nice to provide space for folks to share challenges (if they're comfortable doing so), and also strengths/moments of pride! To help strike this balance, we like to invite people to *share a challenge they've dealt with,* and then *share something that's helped them navigate that challenge.*

Facilitation Tips: Encouraging Discussion

Some facilitators find the RASA Framework helpful for keeping group conversations flowing. RASA stands for Recieve, Appreciate, Summarize, and Ask:

- **Receive**: Listen to understand what participants are saying, and show you're actively listening.
- **Appreciate**: Affirm what it is someone says, either verbally or nonverbally.
- **Summarize**: Repeat your understanding of what they've said (and allow space for corrections).
- **Ask**: Open-ended questions (rather than yes/no).

You can learn more about the RASA framework [here](#).

Encouraging discussion (especially when group members don't know one another) can sometimes be tricky. Ideally in a peer space, you want all group members to feel comfortable and confident sharing, if they'd like to do so.

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Some groups will have participants that are more vocal, or more quiet. While silence can feel awkward in the moment, it can help provide space for reflection or for someone to gather the courage to speak. **Facilitators can find opportunities to draw quieter folks into the conversation (without "cold-calling" on participants), while gently guiding more vocal participants to make space for others.**

Potential phrases to use:

- *"I'm hearing a common theme of _ _ _ _ coming up! Is that something that resonates with anyone else?"*
- *"That sounds really challenging, it seems like _ _ _ is something many of us can relate to."*

Inviting participants to share their struggles as well as their coping strategies or victories can turn individual stories into collective wisdom, making peer support spaces a richer source of comfort, strength, and shared resilience.

Potential phrases to use:

- *"Would anyone like to share something that's helped them navigate _ _ _?"*

Lastly, gratitude is a powerful tool. **Thanking participants for sharing their experiences, especially the challenging ones,** helps build a supportive and caring environment.

Potential phrases to use:
- *"Thank you for sharing that."*
- *"I appreciate the courage it must have taken you to share that."*

Concluding/Wrap-up

Taking a few minutes at the end to "check-out" allows participants to reflect on the discussion/activity. This is a good time to invite group members to share any takeaways, assess how the topic landed, or check in about topics to address in future meetings.

Especially after discussing heavy topics, it can be nice to end on a lighter note: invite participants to share something they can do to check in on themselves later, name a self-care activity they are looking forward to, and/or share some resources that have been helpful for them.

Example check-out questions:
- *"Share something that resonated with you during today's discussion, or a "takeaway" you got from group today."*
- *"Share something nice/relaxing you have planned for yourself this week."*

Meeting Structure Example (from our Higher Education Groups)

Discussion Topic: Compassionate Goal Setting

- **Welcome everyone to the space!**
- **Share group guidelines & any access reminders**
- **Introductions**
  - name/pronouns
  - Where do you go to school/what is your major?
  - What was your favorite thing you did for winter break?
  - Any access needs you'd like to share/anything you need to join us in this space today?

- **Briefly explain/contextualize the discussion topic**
  - Compassionate Goal Setting means:
    - not holding ourselves to able-bodied standards
    - setting reachable goals (not setting ourselves up to feel bad)
    - being gentle/kind to ourselves
    - and remembering that even small goals are important!

- **Discussion questions/prompts** *(leave time in between for folks to think, facilitators can share examples if participants need a minute!)*
  - Thinking back on the last year:
    - Can you think of something you were proud of or something that went well?
    - Is there anything you'd like to continue working towards? Any small goals/shifts that feel do-able?
  - For any of these small goals/shifts:
    - Is there something specific related to this goal that someone could help you with? Who might that be?
  - Are there any other intentions that you'd like to bring with you into this year? (good experiences, feelings, etc.)

- **Check out Question**
  - Did anything in particular resonate with you during our group today?

  - Do you want to share something nice/relaxing you have planned for this week?

Cultivating Engagement:

Participation and Retention

While recruitment involves building interest in your group, to keep a peer-support group going you also need to foster participation and retention. Community members have to want to join the group, *and* continue to show up!

> **Two main questions to keep in mind:**

- How do we initially connect with new group members, and help them feel welcome?

- How do we keep group members engaged long-term?

Participation: Getting People Invested and Involved

How you initially connect with group members may vary depending on your group's structure, but in general, **fostering a sense of comfort and camaraderie from the get-go is important**! There are many ways to do this throughout each group (*see the "Facilitating a Peer-Support Group" section*), but a few things you can do from the get-go that help encourage new members to participate are:

- **Clear expectations** – provide some information to folks who sign up, so they know what to expect when they join for the first time!

- **Warm welcomes** – make new members feel like a valued part of the group from the beginning. Invite them to contribute however they feel comfortable (even if that's just listening in), and thank them for joining.

- **Light-hearted icebreakers** – incorporating fun get-to-know-you activities at the beginning of each group can help strengthen connection and comfort.

Retention: Keeping People Involved Long-term

Creating a supportive environment and offering engaging opportunities can help encourage group member retention. Here are some other strategies that may be useful in building ongoing engagement for groups that are peer-support (or advocacy/project) focused:

- **Quality Over Quantity:** While it's great to offer lots of different opportunities, it's also important to prioritize *quality* over *quantity* – make sure the topics/activities feel meaningful and beneficial to the community, before offering more!

- **Routine Communication:** Foster a sense of community through regular updates or sharing stories. Consistent communication keeps members informed, involved, and connected to the group's mission and each other.

- **Connection to Passion Projects:** Encourage members to engage with projects that match their interests (and feel feasible). Regular surveys or check-ins can help gauge their interests and connect them with relevant projects.

- **Different Opportunities for Involvement:** Offer various ways for people to contribute ideas, such as surveys, synchronous meetings, or asynchronous reviews. This ensures that members can get involved in ways that fit their preferences and schedule.

- **Inclusive Dynamics:** Pay attention to group dynamics during meetings. Are certain people speaking more (or less), or getting talked over? Making sure all group members feel heard, valued, and respected can have a big impact.

Other Considerations:

Maintaining group engagement over time can require commitment and intentionality. This might look like setting aside time to reach out to community members, eliciting feedback from group members, or budgeting for dedicated staff to coordinate the groups.

One thing to keep in mind - especially for groups that center individuals with chronic illnesses or other disabilities - is that people's support needs and capacity ebb and flow, *and that's okay!* Group members might need more/less support at certain times, may have fluctuating energy, or might decide the group isn't the best fit for them. **Don't take these things personally!**

That said, if an ongoing member stops attending, gently checking in may be useful for a couple reasons. First, it shows you care, and reinforces their value as a community member. Second, it can help you identify if there is an issue within the group that should be addressed. Asking for feedback helps ensure your group is serving the needs of your community effectively.

Sustainability

Creating a Lasting Peer-Support Space

What Does Sustainability Mean for Peer Support?

Centering sustainable practices is important to ensure peer-support programs are **reliable** and have **long-term impact**.

For a peer-support program, "sustainability" might mean:

- Your organization has the capacity to consistently host groups
- Your pool of facilitators is relatively consistent (low turnover/ high retention)
- Your groups don't rely on one person to keep going

Here, we'll share some tips for building sustainable sources of peer support.

What can organizations do to support facilitators & prevent burnout?

➡ Build a Strong Team:

Assembling a group of facilitators can be tricky, especially in the beginning. However, over time, reducing your dependence on just a few individuals to lead your peer support meetings is important to prevent facilitator burnout.

➡ Opportunities for Communication/Feedback:

It's important for facilitators to have space to share feedback, discuss challenges, and celebrate successes! Implementing suggestions from facilitators shows they are valued members of the team – and since facilitators directly interact with group members, they have essential insight into group dynamics or common issues that may arise.

Provide Support/Backup:

Encouraging facilitators to co-lead groups can be a great built-in support system and allow for more flexibility. This is often a more accessible practice for facilitators managing chronic health conditions, and reduces the need to multitask during a group – one facilitator can lead the discussion, while the other monitors the chat or troubleshoots issues that arise.

Fair Compensation:

Facilitating peer support groups can take time, effort, and energy. Compensating community members for their work is an important practice to promote equity within these roles – considering the financial strain that can accompany chronic illness, this can help draw facilitators with a wider range of lived experiences. Currently, we compensate our facilitators $50 per meeting.

Clear Roles/Expectations:

Make sure facilitators have a clear understanding of what their role does or doesn't involve. This is important for logistical tasks (pre-group planning, sending out reminders, setting up the meeting link, etc.), as well as the scope of their role during a group (what advice they can/cannot provide to group members).

Quality over quantity:

Prioritize the quality of your groups over the quantity – consider your organization's and facilitators' capacity when scheduling!
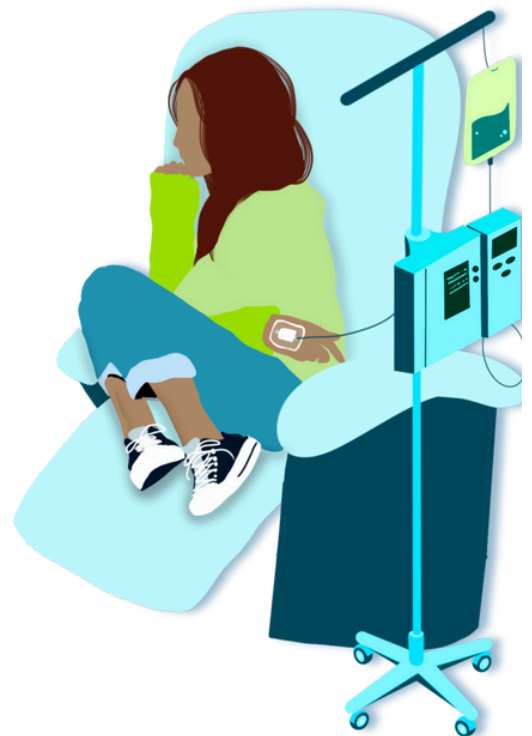
Other Considerations: Facilitator Boundaries

Depending on your facilitator and organizational capacity, you may want to consider if any formal boundaries are necessary to communicate to group participants. **When facilitators are a part of the community they serve, there may be some gray areas in terms of what is "appropriate contact" outside of the group**.

If this seems to be the case, here are some things you may want to discuss with your facilitators:

- Are they comfortable with participants reaching out to them, or adding them as friends on social media/other platforms?

- If they share personal contact information with group members, are there things they don't want to discuss outside of the group?

- If group members contact them outside of the group, is it clear that this is a "peer" relationship, rather than professional advice?

- If they are not comfortable being contacted outside of the group, how is this boundary shared with community members?

- If they feel boundaries are being crossed, how can your org help support everyone involved?

Special Considerations:

Considerations for Adapting Peer Support Globally

Introduction

The Generation Patient model of peer support spaces is a flexible, inclusive and accessible way to create a peer support community or service. It allows for members of the community to participate when they want, from a space where they feel most comfortable, using web-based technologies that are widely available and accessible. However, chronic illnesses are rising across the globe, especially in regions where access to technology and the internet might be limited and can also be expensive. Additionally, the needs and priorities of communities in these regions can be quite different from the needs and concerns of communities in regions with greater treatment options and better access to care.

While the Generation Patient model of peer support encourages community members to interact and engage outside of a healthcare setting, those in low-resource regions with increasing burden of chronic illnesses may find it difficult to build such a space without the inclusion and assistance of health practitioners and health workers. The presence of healthcare professionals can deter many from sharing freely, especially when they have had negative experiences with healthcare institutions and personnel. However, those of us who lead communities in low-resource regions have observed that the presence of healthcare personnel increases trust amongst patients and encourages them to share, participate, and engage. As the standard of care develops and the concerns of community members shift towards the non-medical aspects of living with a chronic condition, the peer support space may better benefit patients by adopting an approach similar to Generation Patient.

Finally, communities with a high degree of linguistic and cultural diversity may find it difficult to create a space that is comfortable for all members and conducive to participation from everyone. While web-based technologies are becoming better at translation, the accuracy of such technologies is not good enough for many of the languages that are not spoken in developed parts of the globe.

Chronic illness communities in countries like India often face this roadblock when creating communities that consist of members living in different parts of the country, speaking different languages, and living culturally varied lives. Effective communication requires participants to be proficient in a common language, but that may not always be the case.

In summary, creating a peer support space or service based on the Generation Patient Model can be quite challenging in resource-constrained regions and/or regions with sparsely located community members with a high degree of linguistic and cultural diversity. We enlist some measures that can be taken to create effective support spaces within the limitations prevalent in a region and community.

Navigating Technological Barriers

The peer support meetings held by Generation Patient are facilitated over video-conferencing platforms like Zoom and Google Meet. These platforms have become widely available and used across the globe for various activities, post the pandemic. They are not very expensive and offer security and accessibility features like closed captioning and live transcription as well. These platforms are well suited to the needs of communities of persons with chronic conditions. **However, these platforms require two things – a high-speed internet connection and a portable device capable of running video-conferencing applications.**

We may think that both of those things are ubiquitous in today's day and age. However, high-speed internet and portable devices like smartphones, tablets, and laptops, are not equally affordable and accessible across the globe. Even when available, the awareness and familiarity with video-conferencing platforms may not be uniform across all the members of the community.

When the availability and cost of high-speed internet is an impediment, utilizing audio-only modes of video-conferencing applications or conducting meetings over audio-only communication platforms may be an acceptable compromise. However, facilitators need to come up with activities that can enable effective engagement of community members over audio. Additionally, uniformity of language and consolidation of theme or context before every meeting needs to be taken care of. The Generation Patient model employs an overarching theme with three main questions for each peer support meeting. A similar approach could be used in audio-only meetings. The limitation of an audio-only space could sometimes be a blessing in disguise. Keeping cameras off or utilizing an audio-only medium could encourage the community members to share and engage without hesitation or discomfort.

Another alternative would be to eliminate the dependence on technology entirely and conduct in-person meetings. In-person meetings, if done the "right way", can be very beneficial to community members. However, in-person meetings require several careful considerations and decisions, which can impact the overall usefulness and impact of the meetings on community members. Aspects of in-person meetings have been discussed after this section.

In-person meetings or audio-only platforms conserve the synchronous nature of communication that is a feature of Generation Patient peer support meetings. However, this need not always be the case. Asynchronous communication or near-synchronous communication over platforms like Facebook Groups, WhatsApp, and Telegram are popular amongst online communities and have existed since the days of chat-based internet forums. Such platforms allow community members to engage in conversations with great flexibility. However, the text-based nature of such communities often prevents community members from expressing and discussing complicated aspects of their experience with one another. An additional challenge is the moderation of such communities.

The effectiveness of such alternate models of peer support spaces can be debated, but in view of the limitations and challenges in resource-constrained settings, such alternatives can enable community members to connect with each other and support each other, which ultimately reduces feelings of isolation and can help community members cope with the psychosocial impact of chronic illnesses.

In-Person Peer Support

In-person peer support spaces require a lot of energy and effort and are more burdensome logistically compared to virtual peer support spaces. **However, in many circumstances, these can be the most rational and effective choice for an impactful peer support program.**

People living with chronic conditions in resource-constrained geographies often find themselves at the end of an overburdened healthcare system as the under-resourced healthcare system struggles to manage the increasing burden of chronic conditions. Such systems have two particular features - a dismal appointment duration, which may range from a few seconds to a few minutes, and a waiting time that is typically at least a few hours. These few hours which people spend idly in the waiting rooms of outpatient departments can be used to engage them in an in-person peer support program hosted in the hospital or clinic premises itself. The fact is that there is a great amount of stigma surrounding chronic conditions as well, and most people living with these conditions are not open about it when they exit the doctor's office. The doctor's office may be the only place where they feel safe talking about their experiences with the condition and engaging with their peers. If the presence of healthcare personnel is seen as a detriment to a safe and open space for patients, the peer support spaces hosted inside a clinic or a hospital may not include any healthcare personnel. However, in our discussions with advocates from these regions, community members often find the inclusion of a doctor or nurse comforting. One reason for this might be that the most pressing concerns of people living with chronic conditions in low-resource settings are primarily medical.

The facilitators of these meetings have greater freedom to conduct a variety of activities, but language can be a barrier, if the community members come from linguistically varied geographies and cultures, which is a common phenomenon in diverse geographies with few treatment centers for chronic conditions. However, community members can facilitate translation as well as volunteer to increase the accessibility of the meetings. Finally, in-person peer support programs may also be hosted outside of a healthcare institution, but it would be even more burdensome economically and logistically. Informal peer support programs may be conducted in this manner. In-person peer support programs, especially those which utilize the hospital or clinic premises can typically accommodate a greater number of members as compared to virtual spaces. Hence, crowd control and moderation is a concern. Additionally, breaks may be required during sessions to prevent disengagement. These breaks can be filled with simple physical activities for community members. More on facilitation can be found in the next section.

In-person meetings may also be combined with virtual meetings that happen less frequently. This would facilitate a gradual shift of the support space from a medical environment to a more neutral environment. While we need to do what's best for communities in the short term, some efforts must be made to raise awareness about what's best for community members in the long term. While facilitators can co-create this space with community members, it is beneficial to introduce alternate forms of interaction and educate the community about potential conflicts of interest which arise out of healthcare personnel being included in a space that's meant to empower patients to share freely. This could also be a way to keep the community engaged in between the in-person meetings, which may not happen very frequently or community members may not be able to participate very frequently.
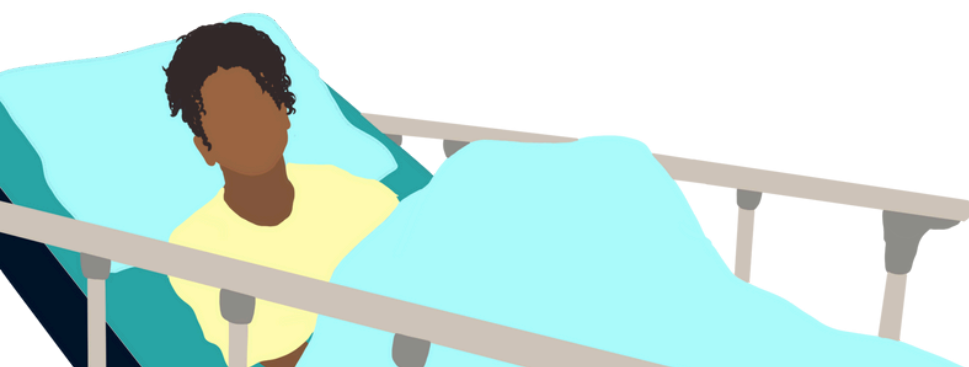
Conclusion & Case Studies

The ultimate choice of a peer-support space depends on the available resources and the willingness of community members to engage in the space. The peer support space should be easy to facilitate and moderate. At the same time, it must be easy to participate in as well. Healthcare personnel may be included when deemed beneficial to the overall community. However, the inclusion of healthcare personnel may not be suitable in meetings where sensitive issues centered around the patient experience have been scheduled for discussion. Finally, we believe that any peer support model must be community-centric.

Case Study 1: Enable Vaani

70% of persons with disabilities in India live in rural India, where mobile connectivity is present but not everyone may have access to data. Enable Vaani, from Enable India, is an asynchronous voice based social network for persons with disabilities in India that utilizes the Interactive Voice Response System (IVRS).

Enable Vaani enables persons with disabilities to create and share content with each other. It is a knowledge sharing and an experience sharing platform, where any participant can share issues, feelings, solutions, employment opportunities, etc. There is no cost incurred on behalf of the participant. There are separate phone numbers for various languages which help participants connect with other persons with disabilities speaking the same language.

Enable India is scaling this solution through strategic partnerships with local partners in rural geographies. Enable India provides their disability expertise and the technology platform, training and relevant support. Local partners create and curate the content and develop strategic relationships with local stakeholders.

Enable Vaani has been accessed by over 28,000 unique callers, from 16 different states in India. 98% of the content is user-generated. Enable Vaani won the Zero Project award in 2018 and was presented in the Workability Asia conference in 2017, with the presentation titled "Using Technology to Reach the Unreached in Rural Parts of India."

More info : https://www.enableindia.org/EnableVaani/

Case Study 2: Peer Support via Telegram in Ethiopia

Telegram Messenger, commonly known as Telegram is a cloud-based, cross-platform, instant messaging service, similar to WhatsApp Messenger (commonly known as WhatsApp). Telegram allows users to form large groups composed of up to 200,000 members. WhatsApp is the most popular messaging app with approximately 2 billion monthly active users. However many features of Telegram, such as greater privacy and generous file sharing quotas, have increased its popularity evident by over 50 million monthly downloads and 900 million monthly active users. In Ethiopia, Telegram is more popular than WhatsApp for instant messaging.

A Telegram support group founded by Dr Fasika Teferra has over 500 members who are either persons living with chronic illnesses or their caregivers. A minority of the members are doctors and other healthcare personnel who volunteer their time and expertise to aid patients.

The members interact in an asynchronous fashion, posting questions, messages and replying to each other. Along with Dr Fasika, Yeabsira Taye, a medical student, and Mahder Ayalew, a nurse, volunteer as group moderators and content translators to provide educational content (sourced from various resources and often in English) in Amharic to overcome the language barrier problem. Members often reach out to each other privately for discussion on shared experiences and sensitive issues. The group has a dedicated phone number for members who require support in a discreet manner.

The group is also used to conduct live discussions with healthcare experts and group members via group audio calls. The same are recorded and shared via a social media news outlet with a combined following of 1.5 million across several platforms, thereby increasing the reach of the group beyond its members and raising awareness about chronic illnesses in Ethiopia as well. Lack of sufficient internet bandwidth, patient comfort and privacy issues are reasons to avoid video interactions. There is interest in in-person meetings, however, geographical and financial barriers exist.

The group grows mostly by word-of-mouth, when persons with chronic illnesses meet each other in clinics and hospitals. However, YouTube and television media have been used as well to spread word about the group.

Telegram Group Link : https://t.me/ibdethdiscussion
Telegram Channel Link : https://t.me/ibdeth

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Other resources linked in this toolkit:

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