Proceedings: Roundtable on Engaging Adolescents & Young Adults With Chronic Conditions in Patient-Centered Research for Peer Support Interventions

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Roundtable Session 1: *Clinical application of a peer coaching intervention to enhance self-management for adolescents and young adults with inflammatory bowel disease* (Pollock et al.)

[see detailed notes]

Study Summary:
This study focused on adolescents and young adults (AYAs) aged 18 to 26 with inflammatory bowel disease (IBD), including conditions like Crohn's disease and ulcerative colitis. Participants were recruited from the Duke University Health System, a large academic medical center. The intervention aimed to improve self-management and quality of life for AYAs with IBD through a mobile-based peer coaching program. The peer coaches were young adults with IBD themselves, trained in motivational interviewing techniques and supervised by mental health professionals. The study employed a randomized design, with participants receiving the peer coaching intervention or being placed in a comparison group receiving educational newsletters.

The methodology involved semi-structured interviews and call and text message data analysis to assess feasibility, acceptability, and preliminary efficacy. Outcomes were measured using electronic surveys at baseline, 3 months (end of intervention), and 6 months (follow-up), covering areas like shared decision-making, patient activation, self-efficacy, and emotional well-being.

Roundtable Discussion Summary:
We appreciated the study's employment of comprehensive and longitudinal outcome measures such as shared decision-making, patient activation, self-efficacy, and emotional well-being. This approach was recognized for providing a more holistic view of the intervention's impact, which is often missing in the peer support literature and tends to focus mainly on acceptability and feasibility.

However, confusion arose due to the study’s descriptive nature, which resembled more of a protocol paper without actual results. The lack of reported results stirred questions regarding the study’s intent and the effectiveness of the intervention, compounded by the small sample size for the randomized comparison. Roundtable members recognized a gap in the literature concerning peer support for various chronic conditions, acknowledging the study's potential as a base for comparative effectiveness research across different disease groups and intervention formats.

Despite being perceived primarily as a qualitative description, the feasibility of the model, especially in low-resource settings or during pandemics, was highlighted. The adaptability of the intervention for phone or text-based support was praised for its ability to maintain patient anonymity and overcome barriers like stigma or logistical challenges. Yet, concerns were raised about the potential limitations of a solely telephone-based connection for less engaged AYA and the challenge of applying the model across different disease groups. Roundtable members underscored the importance of adapting peer support to various cultural contexts, and respecting differences in disclosure and healthcare decision-making processes. The conversation touched on how peer support is perceived and utilized in different countries, emphasizing the need for culturally sensitive approaches.

This study further discussed the balance between more structured and organic forms of peer support. Concerns were raised about the structured nature of the intervention potentially leading to a sterile environment, where participants might feel constrained in what they can say or share, especially since the peer coach calls in this study were monitored. The heavy focus on safety was also seen as possibly intimidating, limiting genuine communication, and not fully resonating with the needs and preferences of the target demographic due to a lack of AYA involvement in the study's design.

Furthermore, our group discussed moving from medicalized outcome measures to more holistic psychosocial metrics. This highlights the challenge of utilizing evidence-based practices while recognizing peer support's non-medical benefits. Roundtable members felt this study also exemplified the need for clarity in defining and differentiating between various forms of peer support, including peer mentoring and peer coaching.

Measurement tool(s) discussed/ utilized by study:

- SDM-9 (shared decision-making questionnaire)
- PAM (patient activation measure)
- PIH (partners in health)
- GS-ES (general self-efficacy scale)
- MCH-SF (mental health continuum - short form)

Roundtable Recommendations: Future research on peer support for AYA patients with chronic health conditions should explore the balance between structured and organic forms of peer support, ensuring interventions resonate with patients' needs and preferences. Studies should also aim for a deeper engagement with patients in the design process, adapt peer support to diverse cultural contexts, and employ a broader range of psychosocial outcome measures to fully capture the intervention's impact beyond traditional medical metrics.

Roundtable Session 2: *Peer Support Needs and Preferences for Digital Peer Navigation among Adolescent and Young Adults with Cancer: A Canadian Cross-Sectional Survey* (Bender et al.) and *Initiation and changes in use of social media for peer support among young adult cancer patients and survivors* (Lazard et al.)

[see detailed notes]

Study Summaries: Bender et al. focused on understanding the peer support needs and preferences for digital peer navigation among adolescents and young adults (AYAs) with cancer. The population of this cross-sectional survey consisted of AYAs in Canada diagnosed with cancer, aged 15 to 39, who were either receiving treatment for cancer or were within 10 years of treatment completion. A total of 436 participants were surveyed, with an average age of 31.2 years and an average of 3.3 years since diagnosis. The majority of respondents were women (65%), diagnosed predominantly with breast cancer (21.7%) and Hodgkin's Lymphoma (11.2%). The survey aimed to collect descriptive summary statistics regarding the participants' need for and use of peer support, barriers to accessing peer support, interest and preferences for digital peer navigation, and peer matching characteristics. The questionnaire comprised standardized and author-developed measures and was pilot-tested with four AYAs before administration.

Lazard et al. focused on understanding how young adults with cancer initiate and adapt their use of social media for peer support and what types of connections they seek within these platforms. The population targeted for this study included young adults aged 18–39 who were either undergoing cancer treatment or were post-treatment. A total of 45 individuals participated in the research, which aimed to capture a wide range of experiences and perspectives on the use of social media for support during and after cancer treatment.

The methodology employed semi-structured interviews conducted in April and May 2020, utilizing virtual platforms to facilitate discussions. Participants were recruited through Stupid Cancer, a young adult cancer advocacy organization, which used emails and social media posts to reach potential participants. Participants provided informed consent and completed a demographic questionnaire prior to their interviews. Each interview lasted about 30 minutes, during which participants shared their experiences with online social support, including how they first learned about such resources, their motivations for seeking support online, changes in their use of social media for support over time, and the types of connections they formed. Interviews were recorded, transcribed, and manually cleaned for accuracy. Two researchers double-coded the transcripts according to an a priori codebook focusing on three broad topics: initiation of use, changes in use, and types of connections sought.

Roundtable Discussion Summary:

1. Need to define "peer support"

A key point of discussion was both studies' broad and/or unclear definitions of peer support. In the case of Lazard et al., there was a consensus that the study lacked a clear operational definition of peer support, relying on broad terms like "social support" and "online social support" without deeper exploration. Furthermore, the lack of clarity raised questions about the impact of these definitions, or lack thereof, on the research outcomes. Particularly for Bender et al., it was questioned how the lack of a clear definition of peer support may have influenced the study’s survey questions and the survey's ability to capture the multifaceted nature of peer support.

Our discussion of Bender et al. contrasted peer support with peer navigation, noting that the latter assumes a more formal role, entailing specific training to guide others in navigating healthcare-related tasks. This distinction was crucial for understanding the goals of peer support versus peer navigation, with peer support focusing more on connection and emotional validation and support, while peer navigation targets more concrete, goal-oriented assistance as patients navigate life with an ongoing medical condition.

The importance of setting boundaries in peer support to prevent it from encroaching into professional realms like social work or psychology was emphasized, however, it was also noted that there seems to be an interesting amount of crossover between these areas. For example, one roundtable member explained that they identify as a patient, medical social worker, and peer support facilitator and that they have come across other support facilitators who also hold various degrees in social work, medicine, nursing, and psychology.

2. Generalizability of studies

Our group felt unsure about the generalizability of both studies, particularly regarding the applicability of cancer-specific studies to more general chronic illnesses. In the case of Bender et al., some roundtable members felt that while some findings about peer support needs and barriers could be relevant beyond cancer care, the distinct experiences of cancer patients caution against broad generalizations. Others expressed beliefs that there was likely a great deal of crossover between patient experiences, particularly for AYA patients. This was true for our discussion of Lazard et al. as well, with one roundtable member noting the potential crossover in patient experiences between those within the oncology realm and those dealing with chronic conditions, including navigating survivorship, transitioning between acute and chronic illness phases, and the decrease in resources once the illness is no longer in the acute phase. The discussion highlighted a curiosity for future research to investigate the parallels and differences in experiences, particularly for AYA patients, including how individuals perceive their illness during survivorship.

This roundtable discussion also touched on the issue of the "oncology bubble" or the siloed nature of the oncology field and its research, illuminating concerns about the limitations this segmentation may pose on broadening the scope of research to include specific interventions for adolescents and young adults (AYAs) with other serious, ongoing medical conditions. We pondered whether the isolation of oncology research stems more from societal perceptions rather than the intrinsic nature of the disease itself, suggesting that the experiences of cancer patients might not be so distinct from those with chronic illnesses.

3. Study design/needs for future research/gaps

During our discussion of Bender et al., specifically with regard for the study design, we recognized the cross-sectional survey approach for investigating peer support needs and barriers among adolescents and young adults (AYAs) with cancer. The study was commended for being guided by the Canadian Strategy for Patient-Oriented Research (SPOR) and involving AYA patients as “patient partners and collaborators on the study team.” However, roundtable members expressed a desire for future research to offer clearer peer support definitions, encompass greater diversity, and explore the digitalization of peer support. A notable gap identified was the need for research on specific matching criteria for peer support and how to connect individuals with suitable peer supporters effectively.

In our discussion of Lazard et al., we first noted the study’s population of young adult cancer patients and survivors aged 18 to 39. We considered whether further age segregation might benefit young adults while also acknowledging differences in mindset according to the stage of the patient's medical journey.

Regarding the study’s qualitative approach, we want to emphasize the importance of evaluating the quality of such studies. For example, one of our roundtable members noted that there seemed to be a lack of community engagement and the absence of member checking, which would have verified the study’s findings against participants' experiences. Another roundtable member expressed confusion over the study’s approach to the coding process, which seemed somewhat insufficient in its narrow focus on three predetermined topics. This approach seemed to overlook much of the nuanced information present in the supplemental materials, which may not have been adequately explored or highlighted in the study's findings.

The discussion identified gaps for future research, including exploring race, ethnicity, and social factors comparing the exploration of race, ethnicity, and social factors, and the comparison of video versus text-based social media interactions for peer support. Roundtable members expressed a desire for future studies to enhance the rigor of qualitative methods in research related to peer support among AYA cancer patients and to involve patients more deeply in the study design. By employing more thorough and participatory approaches, including a more in-depth definition of peer support, the inclusion of patient engagement in the research process, and strategies to ensure the research design and analysis more fully capture the nuanced experiences of those involved, future research could better capture the complexities of peer support experiences and generate findings that are more representative and actionable for the target population.

Measurement tool(s) discussed/ utilized by studies:

- Survey of Peer Support Needs and Preferences for Digital Peer Navigation among of Adolescents and Young Adults with Cancer

Roundtable Recommendations: Future research on peer support for AYA patients with chronic health conditions should prioritize clear and operational definitions of peer support to capture the multifaceted nature of peer interactions accurately. Studies should explore the generalizability of findings across different chronic conditions, investigating the parallels and potential crossover in patient experiences. Additionally, there is a need for more rigorous qualitative methodologies that include community engagement and member checking to ensure findings resonate with participants' experiences.

Roundtable Session 3: *Key Features Of Peer Support In Chronic Disease Prevention And Management* (Fisher et al.), and *Technology-Based Peer Support Interventions for Adolescents with Chronic Illness: A Systematic Review* (Berkanish et al.)

[see detailed notes]

Study Summaries: Berkanish et al. is a systematic review that aims to evaluate the effectiveness of technology-mediated peer support interventions for young individuals living with chronic illnesses. A total of 3781 articles were identified through the search process, with 32 meeting the inclusion criteria for the review: published in English, in peer-reviewed journals, with participants having a mean age within the adolescent range (11–21 years old), diagnosed with a chronic medical condition, and involved in an intervention that used technology for peer support among individuals with the same illness. The interventions primarily targeted adolescents with Type 1 Diabetes Mellitus, cancer, HIV, cystic fibrosis, and juvenile idiopathic arthritis, among other conditions. This review revealed a prevalent use of discussion forums, chat messaging, and video conferencing. While findings underscore the interventions' feasibility and acceptability, with hints at positive impacts on social support, the evidence on effects regarding isolation, quality of life, and disease self-management remains mixed, indicating a need for further research with more robust randomized controlled trials to conclusively determine these interventions' efficacy.

Fisher et al. discuss the overarching findings and insights from the Peers for Progress program, an initiative by the American Academy of Family Physicians Foundation aimed at advancing peer support as a key strategy in managing diabetes and other health conditions globally. Peers for Progress funded fourteen evaluation and demonstration projects across nine countries on six continents. These projects varied in their specific populations and methodologies but shared the common goal of assessing the effectiveness, feasibility, reach, sustainability, and adoption of peer support interventions. The populations targeted in these projects were individuals with chronic diseases, most notably diabetes, across diverse geographical and cultural contexts. The methodology of the projects funded by Peers for Progress typically involved the implementation of peer support interventions where trained peer supporters—often individuals with lived experiences of the same chronic conditions—provided support to participants. The support included assistance in daily management, social and emotional support, linkage to clinical care, and ongoing support reflecting the lifelong nature of chronic diseases. These interventions were evaluated through a mix of qualitative and quantitative research methods to assess their impact on health outcomes, behavior changes, and quality of life.

Roundtable Discussion Summary:
1. Definition and scope of peer support

There was a strong emphasis on the need for a precise definition of peer support, highlighting its variety, including mentoring (Berkanish et al.) and navigating the broad vs. specific aspects of support. One roundtable member discussed the specific challenges of comparing the efficacy of various forms of peer support, given their significant differences (e.g. online forums versus Zoom calls). Attempts to conceptualize peer support were discussed such as the SMART model, though this model does not include peers. Roundtable members questioned whether an adaptation of this could be constructed into a chronic illness model and how this could be an instrumental way to get the overall medical community to see the value of peer support. In our roundtable discussion of Fisher et al., one member pointed out that studies on peer support seem to focus on the support being provided and less so on who is providing it – studies have not focused on this distinction as far as the facilitators and this support not being provided by peers per se. Members also touched upon the key function of peer support and questioned whether or not a two-way interaction is required for peer support. Again, roundtable members acknowledged understanding peer support as an umbrella term encompassing a wide range of activities as well as the variance in structure, flexibility, training, goals (even whether or not you need a goal), measures, etc. because of the nuanced nature and sensitive nature of PS especially for young adults.

2. Research gaps, methodological concerns, and the role of technology

In our roundtable discussion of Berkanish et al., roundtable members appreciated the review's role in identifying research gaps, including the absence of randomized control trials, efficacy studies, economic evaluations, and the involvement of young adults in co-designing peer support interventions, aligning with the roundtable's objectives to pinpoint areas needing attention in peer support research. Concern was echoed about the absence of randomized trials and the fact that the interventions reviewed showed positive or neutral effects, but not adverse ones, on aspects like care decision-making and feeling supported. Given the majority of data in this review came from type 1 diabetes studies, the potential for for condition-specific trials was suggested. Roundtable members also discussed the impact of technology's evolution on peer support, suggesting the need for research comparing different technological modes of peer support to understand generational differences in digital communication preferences and their effectiveness. During our discussion of Fisher et al., members reflected on the challenges of peer support in a medical system focused on measurable outcomes and advocating for the recognition of the value of emotional outcomes. One roundtable member raised the important question of identifying "meaningful measures of connection" within peer support, acknowledging evidence that mindfulness can reduce pain. They suggested that the group could develop a logic model to map out how peer support impacts its recipients, potentially clarifying the mechanisms through which support fosters beneficial outcomes.

3. Geographic and cultural differences

Roundtable members highlighted the importance of understanding how different demographics and personal preferences influence the choice and effectiveness of peer support technologies (Berkanish et al.). In our discussion of Fisher et al., members appreciated the importance of culture emphasized in this study. One member noted the importance of having multiple facilitators encompassing a variety of intersecting identities.

Measurement tool(s) discussed/ utilized by studies:
- SMART model (discussion of conceptualizing peer support – doesn't actually include peers

Roundtable Recommendations:
- Developing a more nuanced definition of PS that includes the facilitator's role.
- Balancing structure and flexibility in PS programs to accommodate diverse needs.
- Tailoring training for PS facilitators based on the intervention's goals.
- Advocating for the inclusion of emotional and connection-based outcomes in PS evaluation.
- Emphasizing the importance of cultural sensitivity and diversity among facilitators to reflect varied participant identities.

Roundtable Session 4: *The roles of quality of life and family and peer support in feelings about transition to adult care in adolescents with gastroenterology, renal, and rheumatology diseases* (Zimmerman et al.) and *Volunteer-Based Social Support Structures and Program Exposure Outcomes in an Adolescent Young Adult Palliative Care Peer Support Program* (Walker et al.)

[see detailed notes]

Study Summaries: Zimmerman et al. explored the impact of health-related quality of life (HRQOL) and the support from family and peers on adolescents' perceptions and feelings regarding their transition to adult healthcare. The study sampled 135 adolescents, aged 17 to 23, who were outpatient attendees at a major children's hospital in the southwestern United States. These participants had various chronic conditions, including Crohn's disease, ulcerative colitis, lupus, juvenile idiopathic arthritis, dermatomyositis, and those undergoing kidney transplants or managing hypertension and chronic kidney disease. Participants completed four questionnaires that assessed their current health-related quality of life (HRQOL), perceived support from peers and family, and their feelings about transitioning to adult care. The HRQOL was measured using the CDC's HRQOL-4 module, while family and peer support were assessed through the Loneliness Scale for Children and Adolescents - Parent Component and the Social and Emotional Loneliness Scale for Adults - Short Form, respectively. Feelings about the healthcare transition were measured using the Feelings about Transition Scale.

Walker et al. focused on the adolescent and young adult (AYA) patients aged 13 to 25 who were part of the Streetlight palliative care peer support program at UF Health Shands Hospital, a program designed to provide social support through volunteer visits, hospital-based events, and an online virtual health community for AYAs with chronic and life-limiting illnesses. The study utilized retrospective record review and social network analysis, involving 69 AYA patients who participated in the program, to analyze the social networks formed with volunteers and understand the impact of these interactions.

Data collected included patient characteristics, hospital admissions, length of stays, and detailed records of volunteer visitations. Using this data, egocentric social network analyses were performed for each patient to calculate various network outcomes, such as network size, volunteer repeat visits, network density, and network diversity based on volunteer interactions. This approach allowed researchers to quantitatively assess the structures and dynamics of social support networks between patients and volunteers, aiming to identify how patient-specific factors, such as disease group and length of hospital stay, influenced the formation and characteristics of these networks.

Roundtable Discussion Summary:

1. Definition and effectiveness of peer support:

In our discussion of Walker et al., roundtable members were curious about the criteria used to define a “peer” within the support program this study analyzed. Although the volunteers and patients were of similar ages, the volunteers did not share the experience of living with chronic health conditions, prompting further discussion as to what characteristics need to be matched in order for one to be considered a peer. Roundtable members discussed the power dynamics between patients and volunteers and expressed a desire to have been given more details on the training volunteers received. Questions were raised about the extent of involvement of young adult patients in developing the program and its overall effectiveness, with roundtable members suggesting that methods such as triangulation and member-checking could have been particularly useful in providing a clearer picture of the program’s benefits.

In our discussion of Zimmerman et al., the definition of peer support and its effectiveness were analyzed as well, with a strong focus on the diversity of patient needs. One roundtable member stated that while peer support can be broadly defined, it is essential to recognize and address the nuances within that definition. Furthermore, it is important to understand how cultural, familial, and individual factors shape the needs and effectiveness of peer support initiatives. One of our roundtable members expressed a desire for deeper insights into family structures (such as whether the adolescents came from single-parent households or had additional family support like grandparents) and mental health comorbidities which could impact the type of support they receive and their overall well-being. Roundtable members unanimously agreed that adaptive approaches to defining and delivering peer support, tailored specifically to meet the unique needs and circumstances of diverse patient populations, are needed.

2. Outcomes and measurements of peer support (Zimmerman et al.)

Our roundtable group also discussed the importance of understanding what measurement tools and outcomes are being looked at in peer support research. In particular, we discussed the benefits and limitations to using measures such as Health-Related Quality of Life (HRQOL).

Benefits: HRQOL is a more comprehensive measure than something like “disease outcomes;” it acknowledges that while peer support may not cure chronic conditions, it can significantly enhance patients’ quality of life. Zimmerman et al. highlighted *modifiable* psychosocial factors within the context of HRQOL, which is helpful from our perspective as a patient-centered organization (knowing what factors we *could and/or should* work to improve, vs. knowing there’s a problem but not being able to meaningfully change it).

On the other hand, there are also limitations to existing HRQOL measures, particularly if used as the sole measure in peer support research. This measure asks about overall physical/mental health and limitations but does not ask about satisfaction with other aspects of life. From a patient perspective, *health-related* QOL may be vastly different from *overall* QOL - without gathering information regarding a patient’s *overall* satisfaction with other factors (social life, career/academics, family relationships, their ability to engage in activities they enjoy, etc.), research may be assuming overall lower happiness or not identifying specific areas for improvement of support. We emphasized the need for tools that more accurately reflect the multidimensional aspects of well-being, and capture the real-life complexities of patients’ experiences.

Measurement tool(s) discussed/ utilized by studies:

- CDC's Health-Related Quality of Life (HRQOL) Module
- Loneliness Scale for Children and Adolescents - Parent Component
- Social and Emotional Loneliness Scale for Adults - Short Form
- Feelings about the Transition Scale

Roundtable Recommendations: Roundtable members noted limitations in existing health-related quality-of-life measures, arguing that they often fail to capture the real-life complexities of patients' experiences. This discussion highlighted the need for tools that more accurately reflect the multidimensional aspects of well-being. There was a keen interest in how these findings could help tailor peer support programs to better meet the psychosocial needs of young adult patients and how more nuanced and precise measurement tools could guide the development of peer support initiatives that are truly responsive to the varied and specific needs of these patients.

Roundtable Session 5: *iPeer2Peer program: a pilot feasibility study in adolescents with chronic pain* (Kohut et al.) and "*It just made me feel better": qualitative examination of the implementation of a novel virtual psychosocial support program for adolescents with cancer* (Kilfoy et al.)

[see detailed notes]

Study Summaries: Kohut et al. examines the impact of a tailored peer mentorship program aimed at enhancing the self-management of chronic pain in adolescents. This study employs a pilot randomized controlled trial involving a series of 10 Skype video calls over an 8-week period, facilitated by trained peer mentors aged 18-25 years who themselves had successfully managed chronic pain. These peer mentors were selected based on criteria such as maturity, emotional stability, and communication skills, as nominated by their healthcare providers.

The peer mentors underwent comprehensive training, which included 20 hours of in-home self-directed learning and in-person sessions. The training covered a variety of topics necessary for effective mentorship, including informational, emotional, and appraisal support. The study revealed significant improvements in participants' coping efforts and self-management skills.

Kilfoy et al. present a qualitative examination of the implementation of the novel virtual psychosocial support program, Teens4Teens, aimed at adolescents with cancer. The study discusses the program's necessity, its operational feasibility, and its acceptability as viewed by participating adolescents, guest speakers, and program moderators, along with their perspectives on the program's impact.

The study was conducted through semi-structured interviews with all available participants, moderators, and guest speakers who participated in the Teens4Teens program. Thematic analysis was used to process the data from these interviews, identifying key themes related to the entry paths into the program, implementation capacity, positive impacts, and areas for improvement in the Teens4Teens program. Insights gathered emphasized the importance of tailored psychosocial support for adolescents with cancer, highlighting how such programs can enhance participant engagement and address specific psychological needs.

Roundtable Discussion Summary:

1. Defining "young adults" and "adolescents"

This roundtable discussion focused on several critical issues related to defining "young adults" and "adolescents" in peer support programs and research. A major point of contemplation was the broad age ranges often used in studies, such as 12 to 18 years, which do not adequately reflect the significant developmental differences within these groups. Participants emphasized that younger adolescents (e.g., 12-14 years old) are in a vastly different developmental stage compared to older adolescents (e.g., 16-18 years old). This lack of specificity can complicate both research outcomes and the implementation of support programs.

2. Recruitment challenges and defining important outcomes for peer support

Recruitment challenges were also discussed, specifically, researchers often need to broaden age ranges to achieve adequate sample sizes, particularly in rare population groups, which can further dilute the relevance of findings. Roundtable members highlighted that while this approach is common, it is not sufficiently addressed in the literature.

Roundtable members also explored the need to define important outcomes for peer support. It was noted that outcomes might vary significantly with age, and there was a consensus on the need to identify critical outcomes relevant to different age brackets to ensure that peer support programs are both effective and meaningful. Tailoring interventions to specific age groups was deemed essential, focusing on developmental milestones rather than broad age ranges. For example, peer support for a 13-year-old in middle school would differ significantly from that for a 19-year-old entering college.

3. Rarity of qualitative studies with direct AYA patient input and ethical concerns around recruitment and privacy

A significant part of the discussion centered on the rarity of pediatric qualitative studies, which often lack direct input from children and adolescents. These studies tend to rely on retrospective accounts from adult patients or input from parents and caregivers, which may not accurately reflect the current experiences of younger populations. Roundtable members emphasized the need for clearer guidelines in conducting intervention studies to understand better and standardize methodologies used in research involving younger populations. Ethical concerns around recruitment and privacy were also discussed. Recruiting adolescents for studies can be challenging due to stricter IRB protocols and the need for parental consent, which is not as stringent in adult studies. Privacy issues further complicate adolescent recruitment, as researchers cannot always discuss sensitive topics with parents present.

Roundtable Recommendations:
Future directions proposed by the roundtable included a more standardized definition of young adults, potentially involving regulatory agencies, societies, or international bodies.

Roundtable Session 6: *Development of the Functional Social Network Index for Adolescent and Young Adult Cancer Survivors* (Huang et al.)

[see detailed notes]

Study Summary:
Huang et al. addresses the lack of research on social network status in adolescent and young adult (AYA) cancer survivors. The authors developed and validated the Functional Social Network Index (FSNI) specifically for AYA survivors, comparing its performance with traditional

social network indices like density and betweenness centrality. The study recruited 102 AYA cancer survivors and 102 noncancer controls, matched for age, sex, and race. Participants reported relationships with up to 25 close friends and/or relatives. The FSNI was developed using reported marital status, contact frequency with friends/relatives, and available resources for emotional and tangible support, physical activity, and weight management advice. Linear regression analyzed the associations between the FSNI, cancer diagnoses, treatments, and coping skills.

Roundtable Discussion Summary:

1. Age separation: Distinguishing between adolescent and young adult patients 18+

As discussed in our previous roundtable session, young adult patients are often grouped with adolescents, leading to a scarcity of research focused specifically on those aged 18 and older. This roundtable discussion centered on the study by Huang et al., one of the few studies that focused on young adult patients aged 18 to 30. Participants appreciated this age range, noting that it more accurately represents the young adult patient population and emphasized the importance of refining age brackets to better tailor support resources for different life stages.
It was also noted that the type of cancer can significantly impact access to resources and social support networks. Further discussion highlighted the frequency of individuals' interactions with their support networks and how conditions with more available resources might influence satisfaction with the support received.

2. Outcomes measured and patient involvement

The FSNI (Family Support Network Index) tool was identified as particularly suitable for the targeted age group, as opposed to traditional indices like the Berkman-Syme Social Network Index (BSSNI). Roundtable members discussed the potential for the development of a similar tool that could be developed to help identify young adult patients in need of peer support and the best type of support based on the individual patient. Roundtable members acknowledged that this study extended beyond peer support, examining access to and interaction with various support resources. Key metrics considered included marital status, contact frequency with friends and relatives, and available health support resources.

A significant point raised was the extent of young adult patient involvement in the development of the study and outcomes measured, questioning the relevance of categories like weight management for young adults and the absence of fertility considerations, which are crucial for this demographic.

3. Future roundtable discussions and revisiting recurring questions

Roundtable members also revisited recurring questions from previous discussions, such as how to measure the success of peer support, defining appropriate outcomes, and identifying gaps in current measurement tools. A major theme was the need to clearly define peer support to ensure the research is applicable and useful. It was decided that our next meeting would focus on establishing a clear definition of peer support and differentiating between peer support programs and adjacent support activities. We aim to narrow down and define key components of peer support for young adult patients to enhance the clarity and applicability of our research.

Measurement tool(s) discussed/ utilized by studies:
- Functional Social Network Index (FSNI)
- Berkman-Syme Social Network Index (BSSNI)

Roundtable Recommendations:
The roundtable emphasized the need for a more nuanced definition of peer support that includes the facilitator's role and the balance between structure and flexibility in peer support programs to accommodate diverse needs. They recommended tailoring training for peer support facilitators based on the intervention's goals and advocating for the inclusion of emotional and connection-based outcomes in peer support evaluation. Additionally, they highlighted the importance of cultural sensitivity and diversity among facilitators to reflect varied participant identities. The group also discussed the necessity of clearly defining factors in peer support studies, such as who leads the group, participant demographics, and the role of the community in creating/co-creating topics and activities. Finally, they suggested creating tools similar to the FSNI to identify who needs peer support and what type of support is needed, ensuring the research is applicable and yields useful data.

Roundtable Session 7: Coming up with a working definition of peer support for young adult patients

[see detailed notes]

Roundtable Discussion Summary:

1. Key components of peer support

This roundtable discussion began with the goal of developing a working definition of peer support for young adult patients, emphasizing several key factors essential factors. The first component of peer support members outlined was the shared experience of illness and living with a chronic health condition as a young adult. Facilitator identity was also acknowledged as playing a crucial role. Several members agreed that facilitators who are peers or community members serve to enhance the effectiveness of peer support spaces. Life stage and the distinction between early young adults (teens/early 20s) and older young adults (late 20s/30s) was highlighted, recognizing their unique challenges and support needs. Roundtable members also discussed the importance of flexibility in programs, adapting to different needs and contexts (e.g., online vs. in-person), was also discussed as essential for effective peer support.

2. True support vs. peer support adjacent

The roundtable delineated between what patients might see as “true peer support” versus adjacent concepts. Roundtable members acknowledged that isolation is often a significant issue for young adult patients. One roundtable member discussed the results from a recent evaluation of Generation Patients peer-support meetings, citing the free-text data that was taken from surveys that seemed to indicate that, for patients, true peer support is focused on connection and that friendship and meeting those social needs that these patients aren’t able to meet in more conventional ways because there of illness-related barriers. Several members spoke from their own experience, stating that true peer support seems to provide connection, validation of experiences, and opportunities to both give and receive emotional support from other young adult patients. Members also noted that these spaces are typically led and organized by patients themselves. In contrast, adjacent to peer support might include mentorship programs, informational sessions, lectures, or webinars, which are often not created by patients and are provider-led rather than patient-led.

3. Developing a framework for researchers to better understand peer support

The roundtable decided to shift away from defining peer support, and instead focus on developing a checklist or inclusion criteria to help researchers understand and evaluate peer support for young adult patients. This includes considering who leads the program, whether it is patient-led or professionally facilitated, and the extent of patient involvement in creating and facilitating the support spaces. Members also discussed the structure and content of programs as well as functionality aspects such as how participant feedback is incorporated, the balance between emotional and practical support, and meeting the needs for connection and information are also important considerations. Emphasis was also placed on using existing frameworks, such as concept analysis, to develop a robust understanding of peer support.

Roundtable members also examined potential reporting guidelines, suggesting researchers should explicitly state the level of patient involvement, acknowledge whether the support was peer-led or professionally facilitated, and provide details on the training and background of facilitators. Members also felt researchers should clearly define their interpretation of peer support to ensure a common understanding and facilitate effective comparison and evaluation of peer support programs.

Studies discussed:

- Dennis, C. (2003). Peer support within a health care context: a concept analysis. *International Journal of Nursing Studies*, 40(3), 321–332. https://doi.org/10.1016/s0020-7489(02)00092-5
- National Association of Peer Supporters. (2019). *National practice guidelines for peer specialists and supervisors*. Washington, DC: N.A.P.S. Retrieved from https://www.peersupportworks.org/wp-content/uploads/2021/07/National-Practice-Guidelines-for-Peer-Specialists-and-Supervisors-1.pdf

Roundtable Recommendations:

The next roundtable discussion will focus on developing a reporting guideline or checklist to assist researchers in understanding what should be included in research/studies about peer support of young adult patients. Roundtable members will also work to incorporate the applicable recommendations from this roundtable session into their proposed framework including:

Program creation and leadership

- Identify who leads the program (patient-led or professionally facilitated)
- Assess the extent of patient involvement in creating and facilitating support spaces

Program Structure and Content

- Ensure programs facilitate discussion, validation, and connection
- Balance emotional and practical support
- Incorporate participant feedback

Reporting Guidelines

- Researchers should state the level of patient involvement.
- Specify whether the support was peer-led or professionally facilitated.
- Provide details on facilitators' training and background.
- Clearly define their interpretation of peer support for consistency and effective comparison.

Roundtable Session 8: Developing a Checklist/Guidance for Patient-Centered Research on Peer Support

[see detailed notes]

Roundtable members decided to draft a checklist to guide patient-centered research on peer support for young adult patients. Their goal was to help researchers understand key considerations before conducting peer support studies.

Along with insights from previous discussions, Dennis (2003) is being utilized as a basis for the first section of this checklist, and the group was asked to review it and provide input.

Roundtable Discussion Summary: Roundtable members discussed the first section of our checklist, which stipulates that researchers should provide a clear definition of peer support within the context of their research and key considerations when coming up with this definition.

Draft: Checklist/Guidance for Patient-Centered Research on Peer Support

Section One: Definition of Peer Support

Researchers should provide a definition of peer support as it relates to their research.

1. **Shared Experience as a Minimum Requirement:** Shared experience of chronic illness should be a mandatory component of your definition, with shared identity becoming relevant depending on the specific research or population being studied. Shared identity can vary based on what researchers are looking at.

- Example: Those who have the lived experience of chronic illness experience as a young adult **and** also the shared identity as trans or non-binary.

2. **Core Components of Peer Support Interventions:** Emotional, informational, and appraisal support were discussed as core components, but it was agreed by roundtable members that Generation Patient team members would evaluate these facets more in-depth to ensure they resonate with their experience and consider what components feel most true to their work.

3. **Method of Peer Support:** It was agreed that Researchers should clarify the method of peer support and make note of why they chose a particular modality.

4. **Distinguishing True Peer Support from Other Forms of Support**

- **Lay Helpers:** The group discussed the importance of differentiating between natural helpers (friends, coworkers) who do not share the lived experience of chronic illness.
- **Caregivers/Carepartners:** Roundtable members stressed the importance of clearly distinguishing between peer supporters and caregivers or care partners. Caregivers provide immense support but still do not share the same lived experience as the patients themselves (this is not to discount the experiences of care partners, but to differentiate).

5. **Special Consideration: Paraprofessionals -** Paraprofessionals are individuals with lived experience of chronic illness who have received additional education or training and sometimes occupy complex roles within peer support frameworks. This is the case for many of Generation Patient's peer support facilitators, all of whom have lived experiences with young adult patients but are also social workers, therapists, medical students, nurses, or residents. The discussion highlighted the importance of understanding and carefully navigating the dynamics that paraprofessionals introduce to peer support interventions, particularly for young adult patients.

- **Implications for Research and Practice:** When studying peer support involving paraprofessionals, it's crucial to clearly define their roles and consider how their dual identities might influence study outcomes, such as participants' comfort levels and perceptions of support.
- **Situational Role Shifts & Bracketing Identities in Peer Support:** The roundtable discussion explored situations where paraprofessionals might have to navigate their dual identities as both a peer and a professional. The concept of "bracketing" identities was discussed as a way for paraprofessionals to consciously separate their professional identity from their peer identity when providing peer support.
    - **Situation 1:** An individual (with both lived experience as a young adult with a chronic illness who is also a medical social worker) facilitating a peer support space in a non-hospital setting.

    - **Situation 2:** Individuals with lived experience who are hired to be a social worker/physician/nurse. That is their role and what ultimately comes first in this situation, with their lived experience coming second to role expectations.
- **Transparency & Power Dynamics:** It is important to acknowledge that the introduction of professional training can alter the power dynamics within peer support settings. Roundtable members agreed that individuals with professional training might still act as peers, depending on the context. However, power dynamics must be carefully managed, and transparency about professional roles is critical to maintaining peer dynamics, managing expectations, and maintaining trust.

Read more under “Section One: Defining and Understanding Peer Support in Research” and “Section Two: Peer- vs. Professional-led Support” in our Guidance Document for Patient-Centered Peer-Support Research.

Studies discussed:

- Dennis, C. (2003). Peer support within a health care context: a concept analysis. *International Journal of Nursing Studies*, 40(3), 321–332. https://doi.org/10.1016/s0020-7489(02)00092-5

Roundtable Recommendations:

To summarize, in the first section of our checklist, our roundtable recommends that researchers define peer support with a focus on the shared experience of chronic illness as the minimum requirement for this definition. Additional layers, such as shared identity or community, should be considered based on the specific population being studied. Core components of peer support interventions—emotional, informational, and appraisal support—were identified, with a consensus to further evaluate how these elements align with the lived experiences of the Generation Patient team. Our roundtable also encourages researchers to clearly articulate the method of peer support chosen and the rationale behind it. Researchers should also distinguish true peer support, rooted in shared lived experience, from other forms of support, such as those provided by healthy friends and caregivers. Special consideration should be given to paraprofessionals—individuals with shared lived experience who also have additional education, training, or professional identities (e.g., social workers, nurses, healthcare providers, therapists). It is important to carefully navigate the dynamics that paraprofessionals bring to peer support interventions and consider the implications of these dynamics within research.

Roundtable Session 9: Developing a Checklist/Guidance for Patient-Centered Research on Peer Support Cont.

This discussion was a continuation of the previous roundtable session. Roundtable members continued their work to draft a checklist to guide patient-centered research on peer support for young adult patients, with the goal being to help researchers understand key considerations before conducting peer support studies. This conversation focused on Program creation and leadership, outcomes and patient involvement throughout each phase of research.

[see detailed notes]

Roundtable Discussion Summary:

Draft: Checklist/Guidance for Patient-Centered Research on Peer Support

Section Two: Program Creation and Leadership

A. Defining Leadership Roles: *Why should researchers consider patient-led and professionally facilitated peer-support programs when designing their studies? What impact might this distinction have on study outcomes?*

Patient-Led vs. Professionally Facilitated Programs

The group first examined the **core differences** between patient-led and professionally facilitated programs. Patient-led programs were highlighted as spaces where participants connect more deeply through shared experiences, fostering a greater sense of community, understanding, and emotional safety.

- **Example**: One roundtable member noted that in patient-led settings, individuals feel more empowered to share personal stories, and the dynamic is often more informal and empathetic.

In contrast, **professionally facilitated programs** tend to be more structured, often led by healthcare professionals or paraprofessionals. While these programs provide more stability and access to resources, they may not foster the same level of emotional connection as patient-led groups.

- A member shared an example from India, where programs labeled as "peer support" were more akin to educational sessions dominated by doctors, with minimal interaction between patients, underscoring the need for clear definitions in research.

The Impact on Outcomes

It was agreed that the leadership structure significantly influences the results of peer support programs. Patient-led programs tend to result in higher emotional satisfaction and a stronger sense of connection among participants, while professionally facilitated programs might deliver more standardized outcomes, such as improved access to information and healthcare resources.

- One participant pointed out that **these two types of programs are not interchangeable** and offer distinct benefits and challenges. This distinction is essential for researchers to recognize as they design studies that measure the effectiveness of peer support interventions.

Roundtable members underscored the importance of defining what is and is not considered peer support. For example, while professionally facilitated programs that primarily focus on education can be beneficial, they may not qualify as true peer support.

- One roundtable member noted that in some countries, such as India, hospitals often label informational sessions as “support groups” when, in reality, they function more like lectures with minimal peer interaction. This confusion highlights the need for clear definitions in research.
- Another participant added that peer support involves shared experience and mutual exchange, whereas professionally facilitated programs might lean more towards education or therapeutic intervention. **The group agreed that researchers need to differentiate between these models to avoid conflating different forms of support.**

Guiding Researchers

The group noted that a key responsibility for researchers is to compare these different leadership structures to understand what makes peer-led support distinct. This comparative approach will help delineate the specific outcomes and benefits of peer support versus other interventions like education or mentorship. It was suggested that the checklist should guide researchers to make comparisons between patient-led and professionally facilitated programs, helping them identify what truly makes peer support effective and unique.

B. Patient Involvement in Study Design: *To what extent should chronically ill patients be involved in designing peer-support interventions? How can researchers ensure that this involvement is both meaningful and ethically sound?*

Challenges of Involving Young Adults in Study Design

Several members noted the ongoing challenge of young adults being perceived as needing extra hand-holding or, conversely, being grouped with older adults without considering the unique nuances of their age group. Young adults often feel stuck in between, not fully recognized as adults but no longer considered children. The conversation emphasized that this demographic, while often capable of self-advocacy, still faces challenges in being taken seriously within the research process. Furthermore, the group acknowledged that young adults are either not trusted to lead or are viewed as not yet fully developed in their decision-making abilities. This creates a barrier to meaningful participation in study design.

Successes in Patient-Led Research

One roundtable member shared a success story where young adults were deeply involved in the design, dissemination, and writing phases of research conducted in collaboration with Generation Patient and Boston Children's Hospital. One of the young adult participants described her involvement as an empowering and confidence-building experience that extended into other areas of her life, including her education.

Another member added that this experience seems to have a significant impact on the young adult participants' confidence and engagement in their community. This, in turn, has a positive impact on the quality and relevance of the research, as the young adults' input shapes the study to better reflect the needs and preferences of the population it aims to serve.

Ethical and Meaningful Engagement

Creating Bi-Directional Learning: The group discussed the need for bi-directional learning, meaning that patient involvement should not be limited to providing input but should also include educating patients about the research process itself.

- Described this as a critical aspect of meaningful engagement, where patients not only contribute but also understand the significance of their role in shaping the research outcomes.
- **Example:** Having patients help refine study questions to ensure they are relevant and understandable for the target population.

This not only improves the study design but also enhances recruitment and retention by making the research more accessible and patient-centered.

Clarifying Expectations and Time Investment: An important point was raised about the time and capacity needed for meaningful patient involvement. It’s crucial to explain the research process to participants, especially those who have never been involved in research before, as this helps set expectations and ensure their contributions are fully integrated into the study.

The group acknowledged that involving patients in study design requires additional time and resources, but it is necessary to ensure that their involvement is genuine and not merely tokenistic.

Overcoming Power Imbalances: Researchers need to create environments where patients feel empowered to participate. There is often a mistrust between young adult patients and researchers, as patients may feel that their input will not be valued or that they are being used as a token. Addressing these power imbalances is crucial for creating authentic collaboration. The group agreed that ethical considerations in patient involvement should go beyond informed consent. Researchers must ensure that patients are aware of how their input will be used and how it will influence the study’s direction. Engaging patients in the consent process itself, and making sure the study materials are accessible, are key to improving retention and ensuring ethical standards are met.

Strategies for Researchers

Translating Research Language: Roundtable members stressed the importance of translating complex research language into terms that patients can easily understand. It was suggested that researchers should ask patients to rephrase study aims and goals in their own words to ensure clarity and mutual understanding. This process helps create research that is more aligned with patient needs and ensures that patients are fully informed participants in the study.

Building Trust Through Patient Leadership: Roundtable members felt that young adult patients should not only be involved in study design but should also lead peer-support groups, where possible. This promotes a sense of ownership and agency in the research process, which can be particularly impactful for young adults who may feel undervalued in healthcare settings.

C. Challenges of Patient-Led Programs: *What are the potential methodological challenges in studying patient-led peer-support programs, and how can these be addressed in the research design?*

Fidelity and Standardization: Maintaining Fidelity in Patient-Led Programs

Maintaining Fidelity in Patient-Led Programs: One of the main challenges in patient-led peer support programs is maintaining **fidelity**, which refers to the consistent application of the intervention across multiple sites or contexts. In research, ensuring that an intervention is applied uniformly is critical for accurate measurement and comparison of outcomes. However, in patient-led programs, there is often greater flexibility and personalization, making it difficult to enforce strict protocols.

One roundtable member explained that peer support often lacks the rigid structure of other medical interventions, which complicates measuring the "dose-response" relationship (i.e., how much intervention is needed to achieve a specific outcome). It was suggested that the less structured, more organic nature of peer-led programs can make researchers uncomfortable, as it challenges the traditional models of standardized intervention and measurable outcomes.

Need for Flexibility in Program Design: The highly individualized nature of patient-led programs makes it difficult to apply standardized measures. Peer support, by its very nature, varies based on the needs and dynamics of the participants, which can make the intervention feel too "fluid" to fit within traditional research models. This lack of rigidity, while a challenge for researchers, is also a key strength of peer support, as it allows for more responsive and tailored interventions.

Perception of Peer Support as Ancillary Care

Peer Support Viewed as Supplementary Rather Than Core Intervention: Rountable members raised the issue of how peer support is perceived in clinical settings and noted that many clinicians and researchers view peer support as an **ancillary service**—an optional, supportive resource rather than a primary intervention.

This perception affects how peer support programs are integrated into research studies, where they are often added as an extra component rather than the main focus. It was suggested that this perception could be one reason why peer support is not prioritized in clinical research, even though it has the potential to be a powerful standalone intervention.

Barriers to Adoption as a Primary Intervention: Part of the reason for the reluctance to treat peer support as a primary intervention is the lack of an established, evidence-based toolkit that can be uniformly applied across multiple clinical settings. Without a clear, consistent framework, peer support programs are often excluded from rigorous clinical evaluation. This presents a barrier to peer support being recognized as an official, measurable intervention.

Methodological Challenges and Addressing Them in Research Design

Challenges with Metrics and Measurement:Participants agreed that a major challenge in studying peer-support interventions, especially patient-led programs, lies in defining the appropriate metrics. Understanding the mechanisms of change within peer support is critical, as these are often harder to measure compared to more traditional clinical interventions. The group acknowledged that peer support interventions are dynamic and interpersonal, making it difficult to establish concrete, standardized measures of success. Unfortunately, researchers often face discomfort in dealing with less tangible outcomes, particularly when fidelity is hard to standardize across different contexts.

Dissemination Issues: One member also raised concerns about how to disseminate patient-led peer support programs effectively while ensuring that essential elements remain intact across different sites.

Balancing Structure with Flexibility: There is a need for research designs that balance the flexibility inherent in patient-led programs with the structure necessary for scientific rigor. Roundtable members suggested researchers may need to rethink their approach to measuring outcomes in peer support programs, as the traditional models may not be suitable for such interventions.

- For example, psychosocial support, which is a core component of peer-led programs, is inherently difficult to measure using conventional quantitative methods. One member proposed that a more mixed-methods approach, combining both quantitative and qualitative data, could provide a fuller picture of the impact of peer support.

Collaborative Design to Improve Fidelity: The group proposed researchers co-create peer support programs with the community, allowing for a more collaborative and negotiated process. By involving patients and peer leaders in the design phase, researchers can better monitor fidelity while still preserving the core values and flexibility of peer support. This would allow for some level of standardization without losing the individualization that makes patient-led programs effective.

Shifting the Paradigm: Moving Away from Clinical Outcomes

The group concluded that there may be a need to **shift the research paradigm** when studying patient-led interventions. A suggestion was made to focus more on **intermediate outcomes** rather than strictly clinical ones (ex. psychosocial benefits or improvements in patients' sense of community and support)

Rather than trying to fit peer support into the same mold as traditional clinical interventions, researchers should develop new frameworks that embrace the unique characteristics of peer support—such as its flexibility, patient-driven nature, and focus on psychosocial outcomes. This may involve developing new tools and metrics that can capture the more subjective and relational aspects of peer support.

Recommending new measures that are not necessarily clinical but still meaningful to the patient experience could provide researchers with a more comprehensive way to evaluate peer support.

Roundtable Recommendations:

- **Develop Flexible but Structured Protocols**
- **Conduct Comparative Studies:** Comparative studies should be conducted to explore the outcomes of different leadership models in peer support (patient-led vs. provider-led). This will help researchers understand the specific impacts of patient-led versus professionally facilitated programs.
- **Adopt Mixed-Methods Evaluation:** Use a combination of quantitative and qualitative measures to capture the full impact of peer support programs. This includes measuring psychosocial benefits and emotional connections, which may not be captured by traditional clinical metrics.
- **Shift the Perception of Peer Support:** Researchers and healthcare providers should reframe peer support as a primary intervention rather than supplementary care.
- **Develop New Evaluation Frameworks:** Researchers should move beyond traditional clinical outcomes and develop new tools to capture the relational and subjective aspects of peer support, such as community engagement and emotional well-being.

Read more under “Section Four: Methodological Challenges & Considerations” and “Section Five: Ethical and Practical Considerations” in our Guidance Document for Patient-Centered Peer-Support Research.

Roundtable Session 10: Measurement Challenges in Peer Support Research and Logic Model Development

[see detailed notes]

Roundtable Discussion Summary:

Measurement and Fidelity in Patient-Led Peer-Support Programs

Roundtable members discussed the challenges of ensuring fidelity in patient-led research programs, particularly in measuring effectiveness. One member highlighted the difficulty in determining the "active ingredient" that made a difference when comparing multiple locations, emphasizing the need for a better understanding of what makes a program effective. Members collectively agreed that while some structure is necessary, flexibility is also crucial. They also discussed the importance of defining appropriate metrics for peer support interventions, acknowledging that traditional measures of fidelity may not be applicable in this context.

Key Points:

- **Program Fidelity Concerns**:
    - The structured nature typically seen in literature contrasts with the inherently flexible nature of peer support, which varies based on factors like group dynamics, facilitator style, and discussion topics.
    - There's a challenge in maintaining fidelity while allowing the necessary flexibility that peer support inherently requires.
- **Structural Recommendations**:
    - Ground structures should be introduced, such as consistent opening statements or core components that define each session.
    - Flexibility should be preserved to maintain the authenticity of peer interactions.
- **Methodological Approach**:
    - A shift towards qualitative analysis of peer support meetings is suggested to better understand and measure fidelity.
    - The use of specific metrics like the UCLA Loneliness Scale is recommended to quantify aspects that peer support aims to alleviate.
- **Research Structure Advice**:
    - Researchers are warned against overly structuring interventions to the point where it may hinder the genuineness of peer support.
    - Encouragement to think differently about peer support compared to more rigid interventions.

Read more under "Section Four: Methodological Challenges & Considerations" in our Guidance Document for Patient-Centered Peer-Support Research.

Logic Model Development

The topic of logic models was introduced and their potential to guide the evaluation and outcomes of peer support in a distinct manner compared to other interventions.

- Participants recognized the need to think differently about evaluating peer support, underscoring the initial creation of a logic model specifically for Generation Patient's program evaluations.
- Emphasized the value of providing a logic model to researchers to help them conceptualize peer support differently, recognizing its unique elements compared to more traditional health interventions.

You can view the full logic model here: Logic Model for Generation Patient's Peer Support Groups

Guiding questions to populate logic model:

1. What is the problem we're trying to solve?
Isolation, loneliness, lack of shared experience, feeling alone, invalidation, mental/emotional/social well-being challenges, hopelessness; Simply wanting to have someone to talk to who has shared or lived experience/not feel alone! Seeking out tools/ strategies for coping

2. Inputs: What resources are needed to implement the activities?

- Grants/ Funding to support programming
- Peer support coordinator position - (staff) to provide group coordination, overall strategy, facilitator outreach, etc.
- Peer Facilitators (individuals with lived experience, interest in leading groups, and experience facilitating discussions
- Other resources for peer group logistics: group guidelines, group planning template, accessibility coordination, attendance tracker
- Other resources for facilitator logistics: onboarding procedures, facilitator training/guide
- Community outreach: social media campaigns for participant recruitment/retention, up-to-date website page, flyers, email listserv for communications, community relationships (people who spread the word)

3. Outputs:

A. **What specific activities will you undertake?**
    - Three types of peer-support groups, which consist of topic-based discussions, art activities, games, poetry workshops, etc.
        - General peer-support meetings for all young adults with chronic and rare medical conditions
        - Higher education peer-support meetings for young adult patients who are current or prospective students in either undergraduate or graduate school undergraduate or graduate
        - Peer support for young adults with IBD (our only disease-specific group)

  - Sharing/Creating Community
  - Resources based on peer group discussions

B. **Whom are you trying to reach through your activities?**
  - Young adult patients (18 to 35) living with chronic medical conditions such as Crohn's disease, lupus, Lyme disease, rheumatoid arthritis, and more.

4. Outcomes: What changes do you expect to see in the short-term, intermediate, and long-term?

Short-Term to Intermediate (< 1 year to 2 years)

- Less isolation and loneliness
- Connection, social support, community relationships
- Validation self-ouse ficacy and
- Gaining language to talk about health conditions, general increased confidence in communication
- Tools and resources to help participants navigate life with a chronic medical condition
- Improved disease acceptance, sense of self, confidence
- Improved mental well-being

Intermediate to Long-Term (2 years+)

- Friendships and connections that extend beyond the meetings
- Increased interest and involvement in community and community advocacy
- Professional development
- Mentorship
- Improved social health
- Greater access to social and professional opportunities

5. Impact: What do you want to see as a result of your actions?

Young adult patients have what they need to move beyond survival and ***thrive*** while living with chronic medical conditions.

Measurement tool(s) discussed/ utilized by studies:

- UCLA Loneliness Scale
- Measuring What Matters: Creating a Logic Model By the Center for Community Health and Evaluation

Next Steps:

- Refine the logic model based on this discussion to explore additional ways to adapt the model to better capture the essence of peer support.

- Roundtable members encouraged to continue providing input and to think about how the logic model could be used not just within their own contexts but as a tool for the broader community of peer support researchers and practitioners.

Roundtable Session 11: Revising Guidance Document and Checklist
[see detailed notes]

Roundtable Session 12: Revising Guidance Document and Checklist Cont.
[see detailed notes]

Roundtable Session 13: Future Research Priorities
[see detailed notes]

For this discussion, roundtable members focused on clarifying priorities in future peer-support research, particularly for young adult patients. Roundtable members who also represent members of the young adult patient community were asked to come to this meeting with answers to the following questions:

- Which specific research questions (relating to peer support) should be prioritized?
- What is most important/useful to patients regarding peer support research?

Read more under "Section Six: Opportunities for Future Research" in our Guidance Document for Patient-Centered Peer-Support Research.

Appendix A: Logic Model for Generation Patient's Peer Support Groups

The following logic model illustrates the conceptual framework guiding Generation Patient's peer support groups. It is designed to help researchers conceptualize peer support differently, recognizing its unique elements compared to other health interventions.

Logic Model Overview:

- Inputs: The necessary resources to implement the peer support activities.
- Outputs: The specific activities undertaken and the target participants.
- Outcomes: The short-term, intermediate, and long-term changes anticipated from the peer support groups.
- Impact: The ultimate goal of enabling young adult patients to move beyond survival and thrive while living with chronic medical conditions.

You can view the full logic model here: Logic Model for Generation Patient's Peer Support Groups

Appendix B: Guidance Document for Patient-Centered Peer-Support

Our Guidance Document for Patient-Centered Peer-Support Research provides comprehensive recommendations for conducting research on cross-disease peer support for young adult patients. This guidance document outlines important considerations for developing and executing studies about peer support, including definitions of true peer support, methodological challenges, ethical considerations, and strategic directions for future research.

You access the full document here: Guidance Document for Patient-Centered Peer-Support Research.

Appendix C: Companion Checklist to the Guidance Document for Patient-Centered Peer-Support Research

This checklist functions as a practical tool for researchers to reference throughout the research process, distilling essential insights, best practices, and recommendations from our comprehensive Guidance Document on Patient-Centered Peer-Support Research for Young Adult Patients.

You access the full checklist here: Companion Checklist to the Guidance Document for Patient-Centered Peer-Support Research.