E-SMART Program Evaluation (2021-2024): Impact, Outcomes, and Future Directions

Prepared for the Michigan Pediatric Epilepsy Project (MPEP)
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1. Introduction

Overview of E-SMART and Its Development

The E-SMART (Epilepsy Self-Management, Advocacy & Resilience for Teens) Program was established in 2021 by the Epilepsy Foundation of Michigan, authored by Russ Derry, Renee Roederer, and Susan Woolner, and it was funded through the Michigan Pediatric Epilepsy Project (MPEP), a five-year Health Resources and Services Administration (HRSA) grant (2019-2024). MPEP's goal was to improve health outcomes for children, teens, and families affected by epilepsy, with a focus on care coordination, transition to adult care, shared decision-making, and telemedicine. Within this framework, E-SMART was developed as a structured self-management program tailored for adolescents with epilepsy.

The Need for a Teen-Specific Self-Management Program

Epilepsy is a chronic neurological condition that affects millions of people worldwide, yet it remains one of the most misunderstood conditions, particularly among adolescents. Teenagers with epilepsy face a unique set of challenges that extend beyond the medical management of seizures. They must also navigate the complexities of social stigma, academic adjustments, and emotional well-being. Studies indicate that 30-50% of children and teens with epilepsy develop mental health conditions such as anxiety and depression.[1] [2] These conditions, if left unaddressed, can significantly impact their quality of life, educational outcomes, and future independence.

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[1] Reilly, Colin, et al. "Neurobehavioral Comorbidities in Children With Active Epilepsy: A Population-Based Study." *Pediatrics* 133, no. 6 (2014): e1586-e1593. https://doi.org/10.1542/peds.2013-3787.

[2] Caplan, Rochelle, and T. Andrew Ziegler. "Psychiatric Disorders in Childhood Epilepsy." *Epilepsy & Behavior* 4, no. 3 (2003): S39-S45. https://doi.org/10.1016/j.yebeh.2003.10.008.

Traditional healthcare settings often focus on the clinical treatment of epilepsy, primarily addressing medication management and seizure control. However, there is a critical gap in addressing the psychosocial and self-management aspects of the condition, which are just as vital for long-term well-being. Many teens with epilepsy report feeling isolated due to the stigma associated with their condition, and they may lack the resources or support to navigate social interactions confidently. Furthermore, they may struggle with adherence to treatment regimens due to a lack of understanding or motivation.

Recognizing these gaps, the Epilepsy Foundation of Michigan launched E-SMART to provide a comprehensive, holistic approach to epilepsy self-management. This program goes beyond traditional medical education by integrating self-advocacy training, emotional health support, and peer engagement to ensure that teens with epilepsy feel empowered, informed, and connected.

Program Goals and Objectives

E-SMART was designed with the following objectives in mind:

- To increase knowledge about epilepsy, seizure types, and management strategies
- To equip participants with self-advocacy skills, enabling them to communicate effectively with healthcare providers, educators, and peers
- To enhance social connectedness by creating a supportive peer environment where teens can share experiences and strategies
- To reduce anxiety and depression associated with epilepsy by providing coping mechanisms and emotional resilience training
- To encourage goal-setting and personal development, fostering long-term self-sufficiency and confidence in managing epilepsy

These goals align with MPEP’s broader objectives, which emphasize improving care coordination, easing the transition to adult healthcare, building self-advocacy, and fostering shared decision-making in relationships with medical care.

E-SMART’s Place Within National Epilepsy Care Initiatives

E-SMART is a self-management program that addresses the physical and psychosocial needs of teens with epilepsy. While many self-management programs exist for chronic conditions, few are tailored specifically for adolescents with epilepsy. The program stands out due to its:

- Virtual format, which increases accessibility for teens in rural and underserved areas
- Peer mentorship model, which integrates young adults with epilepsy as guest speakers and role models
- Holistic approach, which combines medical knowledge with self-advocacy, mental health support, and social skill-building

The virtual nature of the program also aligns with the increasing familiarity with digital learning tools, making it a scalable model for epilepsy care nationwide.

Report Purpose and Structure

This report provides a comprehensive evaluation of the E-SMART program from its inception in 2021 to its most recent sessions in 2024. The purpose of this evaluation is to:

1. Assess program effectiveness using both qualitative and quantitative data, including participant feedback, pre- and post-program surveys, and facilitator insights
2. Identify key strengths and areas for improvement, ensuring that E-SMART continues to meet the needs of teens with epilepsy
3. Provide recommendations for future expansion and sustainability, including potential partnerships, funding opportunities, and enhancements to program delivery

The report is structured as follows:

- Section 2 outlines the vision and core learning components of E-SMART
- Section 3 details the program's design, implementation, and structure
- Section 4 discusses the methodology used to assess program outcomes
- Section 5 presents key findings from participant evaluations, including mental health impacts, self-advocacy improvements, and social connection outcomes
- Section 6 explores challenges faced, strategies implemented, and recommendations for future iterations of E-SMART
- Section 7 provides a final conclusion, summarizing the program's significance and long-term impact on epilepsy self-management for teens

2. Program Vision and Goals

The Development of E-SMART's Core Learning Framework

E-SMART's foundation is rooted in evidence-based principles of self-management education, peer support, and mental health intervention. The program was built to address multiple dimensions of epilepsy care, including basic seizure control and medication adherence, and social, psychological, and advocacy-related aspects of managing the condition as a teenager.

Recognizing that epilepsy affects more than just physical health, the program was designed to be interactive, empowering, and community-oriented. Each session focuses on a different core competency, ensuring that participants gain a well-rounded understanding of how to navigate epilepsy in their daily lives.

Core Learning Components

E-SMART is structured around six sessions, ensuring a well-rounded approach to self-management:

1. **Understanding Your Epilepsy** – Covers seizure types, medication adherence, and communication with healthcare providers
2. **Epilepsy Self-Management** – Addresses lifestyle factors such as sleep hygiene, stress reduction, and seizure tracking
3. **Self-Advocacy** – Equips participants with skills to advocate for themselves in medical, academic, and social settings
4. **Resilience-Building** – Focuses on emotional coping strategies and mental health awareness
5. **Building a Social Circle** – Helps teens navigate friendships, social stigma, and disclosure of their diagnosis
6. **Planning for the Future** – Prepares participants for transitions related to education, employment, and independent living

Each session integrates guest speakers from the Young Adults Call and Connect, a support group offered by the Epilepsy Foundation of Michigan, featuring young adults with epilepsy who share their experiences to foster mentorship and learning.

The next section will detail how E-SMART is structured and implemented.

3. Program Design and Implementation

Structuring E-SMART for Effective Learning

E-SMART is designed as a six-week virtual program that provides adolescents with epilepsy a structured yet flexible framework for learning, engagement, and self-advocacy. The program follows a consistent weekly structure, ensuring that each session builds upon the previous one while reinforcing core concepts through interactive learning. Participants engage in a combination of facilitator-led discussions, guest speaker presentations, goal-setting exercises, and peer-supported learning.

The sessions are structured as follows:

Each session begins with a review of the ground rules for communication and participation, ensuring that the group maintains a respectful and supportive environment. This is followed by an icebreaker activity designed to help participants bond, build connections, and feel comfortable engaging with one another. These icebreakers vary each week but are intentionally selected to foster a sense of camaraderie and ease participants into discussion.

After these initial activities, facilitators introduce the week's core learning component through a concise, interactive presentation. These presentations are designed to be engaging and accessible, incorporating visual aids, personal anecdotes, and discussion prompts to encourage active participation. Following this, facilitators lead a guided discussion, where participants share personal experiences, challenges, and insights related to the session topic. This peer-sharing model helps normalize epilepsy-related experiences and reduces feelings of isolation.

Each week also includes a guest speaker from the Young Adults Call and Connect program, a young adult living with epilepsy who shares their lived experience related to the session's theme. These guest speakers provide a real-world perspective, allowing teens to relate their learning to actual experiences, reinforcing the sense that they are not alone in their journey. The session concludes with a goal-setting exercise, where participants identify personal goals related to the topic of the week. These goals are revisited in subsequent sessions, allowing for continuity, reflection, and accountability in self-management practices.

Detailed Breakdown of E-SMART's Structure

Week 1: Understanding Your Epilepsy

The first session lays the foundation for participants by ensuring they have a clear understanding of epilepsy and how it affects them individually. Facilitators introduce the different types of seizures, explaining how they present and what distinguishes them. They also cover the importance of tracking seizure activity, helping teens recognize potential triggers that may influence seizure frequency. In addition, participants learn about medication adherence, including how to manage side effects and maintain consistency in their treatment. This session also equips teens with strategies for effective communication with healthcare providers, teachers, and peers, ensuring they feel confident discussing their condition in different settings. A guest speaker typically shares their personal experience with receiving an epilepsy diagnosis and navigating their treatment journey. Participants are encouraged to reflect on their own experiences and write down questions they may have for their doctors or caregivers, fostering a proactive approach to epilepsy management.

Week 2: Epilepsy Self-Management

Self-management is a crucial skill for teens with epilepsy, and this session emphasizes practical strategies to help them navigate daily life. Facilitators introduce the importance of developing routines for medication adherence and explore the role that sleep, nutrition, and exercise play in overall epilepsy management. Participants learn to identify early seizure warning signs and create personalized strategies to respond to them effectively. Preparation also a focus, with facilitators guiding participants through the process of building a seizure action plan and understanding seizure first aid. This session integrates interactive activities such as using seizure tracking apps and developing personalized self-care routines. By the end of the session, participants have concrete strategies to apply in their daily lives, helping them take ownership of their condition with confidence.

Week 3: Self-Advocacy and Communication

This session focuses on building participants' ability to advocate for themselves in various settings, from healthcare appointments to school and social environments. Facilitators provide guidance on how to communicate effectively with doctors, educators, family members, and employers, ensuring that teens can articulate their needs and rights. The session introduces disability laws such as Section 504 and IDEA, helping participants understand the accommodations available to them in academic settings. Role-playing exercises allow participants to practice self-advocacy skills, such as requesting school accommodations or explaining epilepsy to peers in a way that feels comfortable and empowering. This session helps reduce anxiety around disclosure while fostering confidence in communicating about epilepsy in everyday interactions.

Week 4: Resilience-Building and Emotional Well-Being

The emotional impact of epilepsy is often overlooked, yet it is a critical component of a teen's overall well-being. This session addresses how epilepsy can affect self-esteem, anxiety, and mental health, and provides participants with tools to navigate these challenges. Facilitators introduce cognitive behavioral strategies (CBT) that help teens reframe negative thoughts about their condition. Mindfulness and stress reduction techniques are also introduced, providing practical exercises that participants can incorporate into their daily routines. Teens also learn how to identify sources of emotional support and when to seek professional help. A young adult guest speaker shares their experience with overcoming the stigma of epilepsy and the mental health struggles that often accompany it, reinforcing the importance of self-acceptance and resilience.

Week 5: Building a Social Circle and Support Network

Many teens with epilepsy experience social isolation due to misconceptions and stigma surrounding the condition. This session explores strategies for fostering meaningful social connections while living with epilepsy. Participants learn how to navigate friendships, including how to share their diagnosis in a way that feels comfortable and empowering. They also explore ways to recognize supportive relationships versus those that may be unhelpful or unsupportive. The session introduces the benefits of connecting with epilepsy-focused peer groups, support organizations, and online communities that provide safe spaces for engagement. One particularly impactful moment in the 2024 cohort occurred when three participants realized they had each experienced a significant family loss in the same year. Their shared grief allowed for a deep moment of peer-led support and emotional validation, demonstrating the power of community-building within the program.

Week 6: Planning for the Future

The final session prepares participants to transition into adulthood with a clear plan for managing epilepsy in the long term. Teens explore topics related to transitioning from pediatric to adult healthcare, navigating higher education and employment while managing epilepsy, and understanding their legal rights in workplace settings. Facilitators help participants create long-term epilepsy advocacy plans and strategies for maintaining self-care practices as they enter adulthood. A young adult guest speaker — often a college student or early-career professional living with epilepsy—shares their personal experiences in navigating school, work, and independent living, providing real-world examples of resilience and success. This final session serves as both a reflection on the participants' growth throughout the program and an opportunity to set forward-thinking goals for continued self-management.

Program Flexibility and Adaptability

While E-SMART follows a structured curriculum, it remains adaptable to meet participants' needs. Facilitators assess participant engagement and adjust session content dynamically, ensuring that discussions remain relevant and personalized. This flexibility has allowed for thematic expansions in conversations, such as incorporating additional content on mental health, family relationships, and intersectional experiences with epilepsy.

Additionally, E-SMART's virtual format ensures statewide accessibility, allowing teens from urban and rural communities alike to participate without transportation barriers.

4. Methodology

Evaluation Framework

The evaluation of E-SMART is based on a multi-method approach that integrates both quantitative and qualitative data to assess the program's impact on participants. The assessment framework consists of three key elements: pre- and post-program surveys, attendance and engagement tracking, and qualitative participant feedback. By utilizing this mixed-method approach, the evaluation captures both measurable improvements in self-management and advocacy skills as well as personal narratives that illustrate the program's impact on participants' lives.

Quantitative Data Collection

To assess changes in participants' mental health, self-management skills, and overall confidence in navigating epilepsy, E-SMART employs validated survey instruments such as the Patient Health Questionnaire-2 (PHQ-2) and the Generalized Anxiety Disorder-7 (GAD-7). These assessments are administered at two key points in the program: the pre-program assessment, conducted before the initiation of the program, establishing baseline understanding of participant's mental health and self-efficacy levels, and the post-program assessment, administered at the conclusion of the six-week curriculum to measure changes in depression and anxiety symptoms.

The PHQ-2 is a brief depression screening tool that evaluates the frequency of depressive symptoms over the past two weeks, while the GAD-7 assesses the severity of anxiety symptoms and provides insight into the participants' emotional well-being. Changes in these scores between the pre- and post-program assessments help evaluate whether E-SMART contributes to reductions in depression and anxiety symptoms among participants. In addition to these mental health metrics, participants complete a self-efficacy survey, which measures changes in their confidence levels regarding medication adherence, communicating with healthcare providers, and engaging in self-advocacy. The data collected from these instruments is analyzed to determine overall program effectiveness and to identify specific areas for future improvement.

Participant Retention and Attendance Tracking

Since E-SMART is a voluntary program, tracking participant retention and attendance is essential for evaluating engagement and the program's ability to sustain participation. Attendance is recorded for each session, with a completion benchmark set at attending at least four out of the six sessions. Participants who meet this benchmark are eligible to receive the $50 Amazon gift card incentive, reinforcing the importance of consistent engagement. Trends in attendance are analyzed to identify dropout patterns and potential barriers to participation. Some of the common challenges observed in past cohorts include scheduling conflicts, school-related commitments, and technological issues such as lack of reliable internet access. By examining these trends, the program can refine its outreach strategies and consider modifications to ensure greater accessibility for future participants.

Qualitative Data Collection and Analysis

Beyond numerical assessments, qualitative feedback is a crucial component of the evaluation process. Participants are encouraged to share their personal experiences, reflections, and feedback through open-ended questions in post-program surveys. Additionally, facilitators document notable moments of peer connection, instances of personal growth, and participant challenges throughout the program cycle. One example comes from the 2024 cohort, where a participant who has challenges with delayed speech processing was able to engage fully in discussions with his peers, demonstrating increased confidence and participation. His mother later shared in a follow-up email, *"After today's session, he seemed much more upbeat. I think the sessions have been having an impact on him!"* Such testimonials provide invaluable insight into the program's emotional and psychological impact that numerical data alone cannot capture.

Themes that emerge from qualitative responses are categorized to identify key patterns. These themes often include increased confidence in managing epilepsy and advocating for personal needs, decreased feelings of isolation, greater awareness of epilepsy self-care strategies, and a desire for continued peer engagement beyond the six-week program duration. By analyzing these themes, facilitators can tailor future iterations of E-SMART to better meet the needs of participants and address specific areas for growth.

Data Analysis and Interpretation

The combination of quantitative and qualitative analysis allows for a well-rounded assessment of E-SMART's effectiveness. Data from PHQ-2 and GAD-7 assessments is analyzed to identify changes in depression and anxiety symptoms among participants, with results compared between pre- and post-program surveys. Additionally, participants' self-reported reflections on their experiences in E-SMART provide qualitative insights into how they perceive their own growth and confidence in managing epilepsy. To ensure the credibility and reliability of findings, only participants who completed both pre- and post-program surveys are included in the primary analysis, ensuring that data reflects full program participation. Additionally, facilitators' observations help provide additional context to survey responses, highlighting trends in participant engagement and emotional well-being.

Methodological Limitations

While E-SMART's evaluation framework is robust, it is important to acknowledge certain limitations. One limitation is the reliance on self-reported data, which may be influenced by personal perception or response bias. Another challenge is the small sample size, as E-SMART targets a specific demographic, making it difficult to generalize findings beyond the immediate participant population. Additionally, there is limited longitudinal data, as the current evaluation measures impact only at the end of the six-week period. Future iterations of E-SMART may benefit from conducting follow-up surveys six months to a year after participation to assess long-term retention of self-management skills and emotional well-being.

Summary of Methodological Approach

The methodology employed in this evaluation provides a comprehensive assessment of E-SMART's impact, combining validated mental health assessments, attendance tracking, and rich qualitative insights. While certain methodological constraints exist, the findings provide strong evidence of the program's effectiveness in enhancing self-management, reducing feelings of isolation, and improving mental health outcomes for teens with epilepsy. The next section will present the key results and findings from the collected data, offering a detailed look at how participants benefited from E-SMART across multiple years.

5. Results & Key Findings

Overview of Participant Outcomes

The evaluation of E-SMART over the past four years demonstrates significant positive outcomes in the areas of mental health improvement, self-management confidence, and social connectedness. Data collected from pre- and post-program assessments, qualitative feedback, and facilitator observations indicate that participants not only acquire practical epilepsy self-management skills but also experience emotional and psychological growth.

A comparison of pre- and post-program survey data reveals a consistent trend of improvement in self-reported mental health and epilepsy self-management skills across all program years. The majority of participants report reduced anxiety and depression symptoms, greater confidence in managing their epilepsy, and stronger connections with peers who understand their experiences.

Mental Health Impact: PHQ-2 and GAD-7 Outcomes

The results from the Patient Health Questionnaire-2 (PHQ-2) and the Generalized Anxiety Disorder-7 (GAD-7) assessments provide quantitative evidence of E-SMART's impact on participant mental health.

Analysis of the pre- and post-program PHQ-2 scores reveals that a significant portion of participants demonstrated a reduction in depressive symptoms. Many teens entered the program reporting feelings of frustration, isolation, and sadness related to their epilepsy diagnosis. By the program's conclusion, their responses indicated increased emotional resilience and a more positive outlook. Across all cohorts, the mean PHQ-2 scores decreased by 43%, reflecting an improvement in self-reported well-being and emotional support.

Similarly, the GAD-7 results indicate that E-SMART participants experienced notable reductions in anxiety symptoms. Before starting the program, many teens reported high levels of worry regarding seizure unpredictability, social stigma, and academic concerns. The post-program assessments show a 29% reduction in GAD-7 scores, demonstrating a measurable decrease in anxiety levels. Many participants attributed this improvement to learning effective coping strategies, gaining self-advocacy skills, and developing supportive peer relationships within the program.

Self-Management and Advocacy Skills

Beyond mental health improvements, the data also shows that E-SMART is highly effective in equipping teens with practical epilepsy self-management skills and advocacy strategies. Participants report increased confidence in recognizing seizure triggers and implementing preventative strategies, adhering to medication schedules and managing side effects, and communicating with healthcare providers and educators about epilepsy needs.

Post-program evaluation surveys show a consistent increase in participant confidence levels, with 85-90% of participants across all cohorts indicating that they feel more prepared to manage their condition independently. Many teens express that before E-SMART, they felt hesitant or unprepared to talk about their epilepsy, while post-program responses indicate that they now feel empowered to explain their condition to peers and request accommodations when necessary.

Social Connectedness and Peer Support

One of the most impactful aspects of E-SMART is the sense of belonging and support that participants develop throughout the six-week program. Many teens with epilepsy report that they had never met another person their age with the condition before joining E-SMART. By the end of the program, nearly all participants express that the experience helped them form meaningful peer connections and feel less alone.

Qualitative feedback highlights the profound emotional support that teens provide one another. In multiple program years, participants shared personal struggles unrelated to epilepsy—such as the loss of a loved one or difficulties in school—and found comfort in the shared experiences of their peers. One participant reflected, *“I feel like I have brothers and sisters now,”* while another stated, *“I found all of the experiences I had with the group amazing and love the people and group as if they were family.”*

The presence of young adult guest speakers also plays a crucial role in fostering a positive sense of future possibilities. Many participants express that seeing older peers successfully navigating college, careers, and independent living with epilepsy reassures them about their own futures.

Preparation for Long-Term Empowerment

Participant reflections in post-program evaluations indicate that E-SMART provides lasting skills and confidence that will continue to benefit them well beyond the program's conclusion. Many teens expressed that they now feel better prepared to manage their epilepsy, advocate for themselves, and approach social situations with greater confidence.

Several participants shared that they gained the language and self-assurance needed to explain their epilepsy to others, whether among peers, in school settings, or during medical appointments. One participant reflected, *"Before E-SMART, I didn't know how to talk about my epilepsy. Now I feel like I can explain it to anyone, and I'm not scared of what they'll think."* Others emphasized the practical impact of the program, highlighting how it equipped them to seek the support they need. Another participant shared, *"The program gave me the confidence to ask my teacher for accommodations, and now I don't have to struggle alone."*

Beyond self-advocacy, many participants also expressed that E-SMART fostered a sense of belonging and connection, reinforcing the importance of peer support in epilepsy management. The relationships built during the program helped teens feel less isolated and more empowered to navigate challenges with the knowledge that they are not alone.

These reflections demonstrate that E-SMART is more than just a six-week program—it is a foundation for long-term empowerment, equipping teens with skills, confidence, and connections that will continue to support them in their journey with epilepsy.

Key Findings Summary

The key findings from four years of E-SMART evaluation demonstrate that the program is highly effective in achieving its goals of improving mental health, increasing self-management skills, and fostering peer support among teens with epilepsy. Quantitative data from PHQ-2 and GAD-7 assessments consistently show reductions in anxiety and depression symptoms, while self-efficacy surveys indicate increased confidence in managing epilepsy. Qualitative feedback further underscores the program's success in helping teens develop meaningful social connections and feel a greater sense of empowerment.

The next section will discuss the challenges encountered in program implementation and explore strategies for future improvements and expansions.

6. Challenges & Barriers

Attendance and Engagement Consistency

One of the primary challenges faced in the implementation of E-SMART has been ensuring consistent attendance and participant engagement throughout the six-week program. While initial registration numbers tend to be strong, attendance can fluctuate due to external commitments, extracurricular activities, and personal circumstances. Some participants, particularly those managing multiple health conditions, face difficulties in maintaining regular attendance, which can impact their ability to fully benefit from the program.

To address this challenge, E-SMART implemented a $50 Amazon gift card incentive, awarded to participants who attended at least four of the six sessions. This incentive has been effective in encouraging attendance, and when explicitly mentioned in weekly reminder emails and verbal session introductions, it creates a shared goal among participants to complete the program together. This collective motivation fosters a sense of accountability and commitment.

Scam Attempts on Registration Platforms

A unique challenge encountered in 2022 and 2023 was the appearance of fraudulent registrations submitted by individuals seeking to exploit the Amazon gift card incentive. When the incentive was publicly advertised on social media and the Foundation's website, there was a surge in applications from non-legitimate participants attempting to register with false information. This added an unexpected administrative burden, requiring facilitators to carefully screen applications and verify participant eligibility before the program began.

To mitigate this issue, the program adjusted its promotional strategy, ensuring that the incentive was communicated directly to eligible audiences rather than being openly posted on public-facing platforms. This refinement in outreach helped to reduce fraudulent applications while maintaining accessibility for genuine participants.

Technology and Accessibility Considerations

E-SMART's fully virtual format has allowed teens from across the state to participate without the geographic and transportation barriers that often limit access to in-person programs. For those who enrolled, technology access did not present a significant challenge, and participants were generally able to engage in sessions without difficulty. However, because the program is conducted online, it is difficult to assess whether lack of internet access or digital devices may have precluded some individuals from registering in the first place.

While no major technical issues were reported among participants, digital access disparities remain a broader concern. Teens in rural or low-income communities may have limited connectivity or access to reliable devices, which could prevent them from taking part in the program. Additionally, some teens with cognitive or developmental disabilities may require extra support to navigate virtual learning environments.

To ensure that E-SMART remains accessible to as many teens as possible, facilitators provide clear technical guidance throughout the program to help participants engage fully. While alternative participation options (such as joining via phone) were available, further exploration of technology access gaps among potential participants could help identify whether additional outreach or resource support is needed.

Parental Involvement and Support Structure

While E-SMART is designed specifically for teens, the role of parental support in reinforcing program principles cannot be overlooked. Some parents have actively engaged in the process, helping their teens apply lessons from E-SMART into daily life. Facilitators believe more could be done, however, to include parents in the program.

Recognizing this, the Epilepsy Foundation of Michigan has explored ways to increase parental engagement without shifting the focus away from the teens themselves. One proposed solution is the development of an E-SMART Parent Guide, which would provide an overview of weekly session topics, discussion prompts, and resources for supporting teens at home. Additionally, parents of E-SMART participants have been invited to attend the Foundation's Parents Call and Connect support group, though participation in this group has remained limited.

Summary of Challenges and Barriers

While E-SMART has successfully reached and engaged teens with epilepsy, several challenges have emerged in its implementation, including attendance variability, technological access barriers, scam attempts, and limited parental involvement. However, proactive adaptations—such as attendance incentives, strategic outreach adjustments, and technical support initiatives—have helped mitigate these issues. Moving forward, continued refinements in participant outreach, engagement strategies, and parental support resources can further strengthen the program's impact and sustainability.

The next section will explore recommendations for future expansions and improvements, ensuring E-SMART continues evolving to meet the needs of teens with epilepsy.

7. Future Expansion & Recommendations

Enhancing Parent and Caregiver Involvement

While E-SMART is designed as a teen-centered program, enhancing parent and caregiver involvement has the potential to reinforce the lessons and self-management strategies introduced in the program. A key recommendation is the creation of an E-SMART Parent Guide, which would provide structured guidance on the topics covered each week. This guide could include conversation starters, reinforcement activities, and practical tips for parents to help their teens apply program lessons at home. Additionally, increasing promotion of the Parents Call and Connect support group could provide an avenue for caregivers to receive peer support while learning about effective ways to assist their teens.

Long-Term Participant Engagement and Alumni Networks

Currently, participants engage in E-SMART for six weeks, after which they return to their personal routines. Establishing a structured alumni network could provide long-term benefits, allowing teens to continue accessing peer support and reinforcing self-management skills. This could include periodic check-in sessions and opportunities for past participants to mentor new enrollees. Developing an E-SMART Graduate Group would ensure that participants do not feel disconnected after completing the program.

Exploring Copyright Protections for Program Materials

Given the unique structure and success of E-SMART, the Epilepsy Foundation of Michigan has explored ways to protect its intellectual property. While trademarking the program name has proven difficult due to common use of “E-” and “SMART” in educational contexts, pursuing a copyright for the E-SMART Leader Guide remains a viable option. This would allow for structured dissemination while maintaining program integrity. The possibility of licensing E-SMART to other epilepsy organizations could further its reach and impact.

Building Partnerships with Schools and Healthcare Providers

Further integration of E-SMART into healthcare settings and educational institutions could expand its reach. Strengthening partnerships with pediatric epilepsy centers, school nurses, and guidance counselors can ensure that more teens are referred to the program. Creating school-based epilepsy education modules could also allow for hybrid models, where students participate in elements of E-SMART within their academic settings.

Refining E-SMART for Its Long-Term Future

E-SMART has demonstrated significant impact in improving self-management, mental health, and social connectedness for teens with epilepsy. Future expansions should focus on deepening engagement beyond the six-week program, increasing accessibility, strengthening partnerships, and protecting program materials. By continuing to refine and expand E-SMART, the Epilepsy Foundation of Michigan can ensure that this program remains a vital resource for teens navigating epilepsy.

8. Conclusion

Over the past four years, E-SMART has demonstrated its effectiveness as a comprehensive self-management program for teens with epilepsy. Through structured learning, peer support, and self-advocacy development, participants have gained critical skills and confidence in managing their condition while fostering lasting connections with others who share their experiences. The program’s measurable impact—evidenced by improvements in mental health, increased self-efficacy, and enhanced social connectedness—reinforces the need for continued investment in epilepsy education and support initiatives for adolescents.

While E-SMART has successfully reached many teens, this evaluation also highlights areas for further growth, including expanding outreach, enhancing accessibility, and deepening participant engagement beyond the initial six-week program. Addressing these opportunities will ensure that more young people affected by epilepsy can access the tools, community, and resources necessary to navigate their condition with confidence.

As the Epilepsy Foundation of Michigan looks to the future, the lessons learned from E-SMART provide a strong foundation for continued innovation. By refining program strategies, strengthening partnerships, and exploring avenues for broader implementation, E-SMART can continue to evolve as a transformative resource for teens with epilepsy, equipping them for long-term success in self-management, advocacy, and personal empowerment.