

# Centers for Disease Control and Prevention (CDC) Epilepsy Program

**Evaluation Report** 

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# **Executive Summary**

Epilepsy impacts over 3 million people in the United States<sup>1</sup> and is a complex disease to manage for people with epilepsy (PWE) and health care providers. In response to this important public health problem, the Centers for Disease Control and Prevention (CDC) Epilepsy Program created two Notices of Funding Opportunity (NOFO).

The first NOFO (DP-21-2101), entitled "Improving Epilepsy Education, Systems of Care, and Health Outcomes through National and Community Partnerships," funded five recipients and began on September 30, 2021. This funding opportunity aimed to improve the health and quality of life of people with epilepsy by educating health professionals, improving the delivery and coordination of community services, informing media to increase awareness and reduce stigma, and expanding educational opportunities for people with epilepsy and their families.

The second NOFO (DP-23-0007), entitled "Building Capacity for Implementing Evidence-Based Epilepsy Self-Management Supports in Health Care Settings," funded four recipients and began on September 30, 2023. This NOFO is designed to build healthcare system capacity to deliver evidence-based self-management supports and improve the health and quality of life of people with epilepsy. An interesting element of this funding opportunity is one recipient is funded to provide critical training and technical assistance in health care system change strategies to the other three recipients.

This report summarizes and highlights evaluation findings gathered from DP-21-2101and DP-23-0007 Annual Performance Reports (APRs) submitted to CDC by recipients. The evaluation findings provided critical insights into recipient performance through February 29, 2024, and the overall impact of these funding sources to improve the health and quality of life for people with epilepsy.

#### From September 30, 2021 - February 29, 2024, CDC Epilepsy DP-21-2101 recipients:

- **referred 25,774 people<sup>2</sup> with epilepsy** to epilepsy-focused or other community-based services, self-management programs, and/or health care providers, including:
  - **39,149 informational referrals** to epilepsy-focused or other community-based services;
  - 4,320 informational referrals to self-management programs; and
  - **6,944 informational referrals** health care providers.
- reported **650,991,873 total media impressions** acquired through broad media channels, such as broadcast TV or radio, for the "Change Our Epilepsy Story" anti-stigma campaign, including:
  - 597,284,525 media impressions<sup>3</sup> prioritizing Hispanics in Phoenix through FirstLine Media;
  - **31,489,433 media impressions** prioritizing Black/African Americans in Philadelphia, Tampa and Chicago through FirstLine Media;

<sup>&</sup>lt;sup>1</sup> MM, Kobau R. National and state estimates of the numbers of adults and children with active epilepsy - United States, 2015. MMWR Morb Mortal Wkly Rep. 2017;66:821-4 of 49 825.

<sup>&</sup>lt;sup>2</sup> EF, AES, and EAWCP reported totals that represent the number of *referrals* to services, not deduplicated *people* with epilepsy referred to services. These capacity-related data are extremely relevant to exhibit the effort required to make successful referrals for people with epilepsy; therefore, these data are reported in Tables 1-3 with relevant footnotes. Some data were also unreported leading to discrepancies in the findings. <sup>3</sup> EF reported piloting digital media tactics in the Phoenix market, such as geo-fencing tactics that deliver location-based marketing and

advertising when a device enters or exits a pre-defined geographical boundary. EF attributed these media tactics to the larger totals of media impressions reported in this market.

- **16,469,673 media impressions** prioritizing Black/African Americans in Philadelphia, Chicago, NY and LA through CBS Media Ventures;
- **2,407,380 media impressions** prioritizing Hispanics in Phoenix and Tampa through Univision Media; and
- **3,340,862 media impressions** prioritizing Black/African Americans in Philadelphia, Tampa and Chicago through iHeartMedia.
- reported **10,522,427 website pageviews** where they disseminated educational content.
- disseminated educational content through **social media platforms** reporting:
  - 6,436,590 media impressions;
  - 123,879 views, clicks, or engagement with ads or posts;
  - 58,656 people reached via various platforms; and
  - **94,310 followers.**
- disseminated educational content through newsletters and other informational publications reporting:
  - **1,251,446 newsletters, informational emails, publications, and flyers** distributed to partners; and
  - 12,530 newsletter views or clicks on informational content in emails.
- reported **11 health systems** that are reporting, monitoring, and tracking epilepsy clinical data (e.g., seizure frequency, depression screening) to improve outcomes for people with uncontrolled seizures.
- enhanced their involvement with stakeholders to achieve project goals and activities;
- expanded training and education for law enforcement, school staff, and health care providers, improving epilepsy awareness through outreach campaigns and marketing; and
- improved referral processes by promoting self-management programs and tools via diverse communication channels, including social media and newsletters, leading to an increase in referrals.

"We've made substantial progress in educating relevant professionals about epilepsy and seizure first aid over this reporting period. Growth in the number of school nurses and school personnel being trained through the Epilepsy Learning Portal continues to be strong." -Epilepsy Foundation

"American Epilepsy Society (AES) aimed to deliver education content to 200-500 learners per grant year and have to date achieved 570 course completions across all activities. AES also aimed to provide 6-11 hours continuing education credits to providers and was able to offer a total of 36.5 hours to providers during this reporting period. " - American Epilepsy Society

#### CDC Epilepsy DP-23-0007 Evaluation Findings from September 30, 2023 - February 29, 2024:

- **Two of the three recipients** are working in **at least 2 health care settings** implementing epilepsy self-management supports.
- Recipients **implemented innovative patient referral strategies** (e.g., electronic health record screening tools and referral prompts; provider decision-support tools) to test for effectiveness.
- **Over two hundred patients** with epilepsy were referred to self-management supports; these totals are impressive given that this was completed in the first five months of the funding opportunity.

- All three recipients increased the number of people with epilepsy referred to a self-management supports from the start of the funding opportunity.
- Component 2 recipient, Epilepsy Alliance America, has **contracted with the Veritas Management Group (VMG)** who is the lead for the Epilepsy Learning Collaborative.
- Component 2 recipient implemented listening sessions and a needs assessment with each component 1 recipient to inform the learning collaborative structure.
- Recipients established strong relationships and communication with stakeholders, developed comprehensive training curriculum and implementing self-management supports, while creating robust data collection systems, including working with hospitals and their electronic health system software.

"We are implementing epilepsy self-management supports in two distinct health care settings: 18 epilepsy centers and 6 primary care practices." - Dartmouth Hitchcock

"Electronic Heath Record (EHR) screening tools have been completed at University of Iowa and University of Cincinnati, which will screen for people with epilepsy who have had seizures in the last 6 months, have barriers to medication adherence, are in the age range of 18 to 24 years, or have moderate depression or anxiety, which will result in a best practice alert for providers in the epilepsy clinic, recommending referral for SMART intervention. " - University Of Iowa

The CDC Epilepsy Program has successfully funded nine recipients across two funding opportunities, contributing to the education of health professionals; enhancing self-management supports and community services; raising awareness through media; and expanding educational opportunities for people with epilepsy and their families. The CDC Epilepsy Program evaluation underscores the substantial progress made by the recipients in supporting people with epilepsy and emphasizes the importance of ongoing evaluation and quality improvement practices to continue to address epilepsy.

# Background

Epilepsy impacts over 3 million people in the United States<sup>4</sup> and is a complex disease to manage for people with epilepsy (PWE) and health care providers. People with epilepsy are more likely to have more than four chronic conditions<sup>5</sup> and many children with epilepsy live at or close to the poverty level<sup>6</sup>. People with epilepsy are not only impacted by the physical management of the disease but the social determinants of health impacted by the complexity of their disease. This includes lack of transportation and social resources<sup>7</sup>. In response to this important public health problem, the Centers for Disease Control and Prevention (CDC) Epilepsy Program created two Notices of Funding Opportunity (NOFO).

The first NOFO (DP-21-2101), entitled "Improving Epilepsy Education, Systems of Care, and Health Outcomes through National and Community Partnerships," funded five recipients and began on September 30, 2021. This funding opportunity aimed to improve the health and quality of life of people with epilepsy by educating health professionals, improving the delivery and coordination of community services, informing media to increase awareness and reduce stigma, and expanding educational opportunities for people with epilepsy and their families. The introduction of this NOFO signified a substantial change in the strategy of the CDC Epilepsy Program. It aims to utilize a component-based approach in non-research funding to support multiple recipients who are involved in program activities that align with their distinct organizational missions and capacities. This departure from the previous practice of funding a single organization engaged in multiple activities reflects a notable shift in the program's approach.

The second NOFO (DP-23-0007), entitled "Building Capacity for Implementing Evidence-Based Epilepsy Self-Management Supports in Health Care Settings," funded four recipients and began on September 30, 2023. This NOFO is designed to build healthcare system capacity to deliver evidence-based self-management supports and improve the health and quality of life of people with epilepsy. An interesting element of this funding opportunity is one recipient (Component 2) is funded to provide critical training and technical assistance in health care system change strategies to the other three recipients.

## Purpose

In 2021, the CDC Epilepsy Program contracted with Chickasaw Health Consulting, LLC (CHC) to provide evaluation services and create infrastructure to evaluate the impact of their non-research funding opportunities. CHC was tasked with several evaluation activities to support the CDC Epilepsy Program and its recipients in evaluation planning and implementation that align with the goals and outcomes of each NOFO. This report describes the progress on these evaluation activities, summarizes recipients' evaluation and performance measure data reported to CDC to highlight key findings and themes across recipients, and provides considerations for the CDC Epilepsy Program to implement that could inform quality improvements and strengthen the potential impact of their funding opportunities.

<sup>&</sup>lt;sup>4</sup> MM, Kobau R. National and state estimates of the numbers of adults and children with active epilepsy - United States, 2015. MMWR Morb Mortal Wkly Rep. 2017;66:821-4 of 49 825.

<sup>&</sup>lt;sup>5</sup> Kadima NT, Kobau R, Zack MM, Helmers S. Comorbidity in Adults with Epilepsy - United States, 2010. MMWR Morb Mortal Wkly Rep. 2013;62(43):849-853.

<sup>&</sup>lt;sup>6</sup> Cui W, Kobau R, Zack MM, Helmers S. Marshalyn Yeargin-Allsopp M. Seizures in children and adolescents aged 6-17 years - United States, 2010-2014. MMWR Morb Mortal Wkly Rep. 2015;64(43):1209-1214.

<sup>&</sup>lt;sup>7</sup> Helmers SL, Kobau R, Sajatovic M, et al. Self-management in epilepsy: Why and how you should incorporate self-management in your practice. Epilepsy Behav. 2016.

# **Evaluation Goals**

The CDC Epilepsy Program NOFOs summarize 5-year evaluation goals through short- to long-term outcomes listed in each NOFO logic model. Both NOFOs fund recipients at different levels who implement strategies and activities that lead to shared long-term outcomes. CHC worked with all nine recipients and provided evaluation services that ensure all recommended evaluation planning and implementation activities align with these NOFO outcomes (see below).

## DP-21-2101 Recipients

There are two types of DP-21-2101 recipients, Component A and Component B (see below). The Component A recipient is required to address six strategies and activities listed in the NOFO logic model at a higher funding amount. Component B recipients are required to address up to two strategies listed in the logic model that align with their organizational missions and capacities at a lower funding amount.

Component A	Component B		
• Epilepsy Foundation	<ul> <li>American Epilepsy Society</li> <li>Epilepsy Association of Western and Central Pennsylvania</li> <li>Epilepsy Foundation New England</li> <li>National Association of School Nurses</li> </ul>		

#### Short-term and Intermediate Outcomes

#### Component A (1 recipient):

- Increased referrals to community-based services, self-management programs, and/or health care providers.
- Increased awareness of epilepsy, seizure first aid, SUDEP prevention, and epilepsy stigma among the general public.
- Increased reporting, monitoring, and tracking of epilepsy clinical data by health systems to improve identification, management, and treatment of patients with uncontrolled seizures.

#### **Component B (4 recipients<sup>8</sup>):**

- Increased knowledge about epilepsy, seizure first aid, and epilepsy stigma among relevant professionals.
- Increased knowledge among health care providers regarding effective diagnosis, treatment, and management of epilepsy.
- Increased reporting, monitoring, and tracking of clinical data by health systems to improve identification, management, and treatment of patients with uncontrolled seizures.
- Increased referrals to community-based services, self-management programs, and/or health care providers.

#### Long-term Outcomes

- Improved social participation among people with epilepsy (PWE).
- Reduced public stigma of epilepsy.
- Reduced social isolation among PWE.
- Improved health and quality of life among PWE.

<sup>&</sup>lt;sup>8</sup>Component B recipients are only responsible for outcomes relevant to the strategies they have selected.

#### DP-23-0007 Recipients

There are two types of recipients, Component 1 and Component 2 (see below). Component 1 recipients build capacity to implement evidence-based self-management supports and programs within health care settings. The Component 2 recipient provides expert technical assistance and training on health care system change strategies to Component 1 recipients.

Component 1	Component 2
<ul> <li>Dartmouth Hitchcock Clinic</li> <li>Emory University</li> <li>University of Iowa</li> </ul>	• Epilepsy Alliance America (working with Veritas Management Group)

#### Short-term and Intermediate Outcomes

#### **Component 1 (3 recipients):**

- Increased patient referrals for evidence-based epilepsy self-management supports.
- Improved completion of evidence-base self-management supports among patients with epilepsy.
- Improved self-management behaviors among patients in with epilepsy.

#### **Component 2 (1 recipient):**

- Increased recipient knowledge of quality improvement strategies or tools to guide program implementation.
- Increased use of quality improvement strategies or tools among Component 1 recipients to guide effective program implementation.

#### Long-term Outcomes

- Improvements in health and quality of life among people with epilepsy.
- Decreased in health care utilization.
- Increased number of health care settings effectively implementing self-management supports.
- Increased referral of epilepsy patients for epilepsy self-management supports.

## Progress on Evaluation Activities

CHC supported the development of recipient evaluation and performance measurement plans to demonstrate how each recipient will fulfill the requirements described in each NOFO. CHC provided ongoing technical assistance during the planning and implementation phases of each recipient's evaluation plan. CHC developed an evaluation and performance measurement plan review guide, which included documentation that each recipient met NOFO and CDC Epilepsy Program requirements, such as inclusion of key performance measures developed by CDC and outlined in the NOFO. Most recipients provided high-quality evaluation and performance measurement plans aligned with *CDC's Framework for Program Evaluation*, the CDC Epilepsy Program NOFO, and met industry standards for evaluation quality and best practices. Recipients met all the NOFO and CDC Epilepsy Program requirements after review by CHC and revision. Recipients have begun implementing their evaluation plans and reporting on the progress and impact of their NOFO activities. CHC will provide ongoing technical assistance on evaluation implementation and reporting throughout the period of performance.

# Methods

## Data Collection

Annually, the CDC Epilepsy Program collects Annual Performance Reports (APRs) from recipients that include key reporting elements, such as performance measure data, evaluation methods and outcomes, and programmatic successes/challenges, to understand and evaluate progress on NOFO strategies and activities. Data were reported through 1) the CHC-developed standardized evaluation reporting template and 2) the performance measure and evaluation data to highlight key findings and themes across recipients. The CDC Epilepsy Program's required performance measures can be found below for each funding opportunity.

#### DP-21-2101 Performance Measures

Corresponding to the NOFO strategies that each recipient selected,

- five (5) recipients reported on this performance measure:
  - Number of people with epilepsy referred to epilepsy-focused or other community-based services, self-management programs, and/or health care providers;
- four (4) recipients reported on this performance measure:
- Traffic to educational content promoted by awareness and educational campaigns; and
- two (2) recipients reported on this performance measure:
  - Number of health systems reporting, monitoring, and tracking epilepsy clinical data (e.g., seizure frequency, depression screening) to improve outcomes for people with uncontrolled seizures.

All DP-21-2101 recipients reported the performance measures for three time periods to assess changes over time in key outcomes for the five-year cooperative agreement:

- 1) previous reporting periods, from September 30, 2021 March 30, 2023;
- 2) current reporting period, from March 31, 2023 February 29, 2024; and
- 3) cumulatively, from September 30, 2021 February 29, 2024.



#### DP-23-0007 Performance Measures

Corresponding to the NOFO strategies that each recipient selected,

- three (3) recipients reported on these performance measures:
  - Number of health care settings implementing epilepsy self-management supports<sup>9</sup>;
  - Number of health care settings referring epilepsy patients to epilepsy self-management supports;
  - Number of patients with epilepsy referred for self-management supports;
  - Number of patients with epilepsy who completed self-management support interventions in total;
  - Number of epilepsy patients with improvements in health outcomes (e.g., reduction in psychological distress, reduction in seizure frequency, improved attention) in total; and
  - Number of epilepsy patients with improvements in overall quality of life.
- one (1) recipient reported on this performance measure:
  - Number of health care system change strategies disseminated with Component 1 recipients.

All DP-23-0007 recipients reported the performance measures for the current reporting period from September 30, 2023 - February 29, 2024, with plans to report these data annually to assess changes over the period of performance.

#### Analysis

CHC reviewed each recipient's quantitative performance measure data for the respective reporting periods by NOFO and performed data quality checks prior to analysis. If CHC found any discrepancies, the recipient was notified and asked to clarify any questions on the performance measure data they

reported. Once data quality checks were complete, CHC aggregated performance measure data across recipients per NOFO and generated descriptive statistics, such as total frequencies and the statistical range across recipients for each reporting period.



Additionally, CHC conducted a thematic analysis of all recipients' qualitative evaluation collected through the APRs, such as evaluation results, challenges, and successes. This process allows themes to emerge from the recipients' complex and diverse projects. CHC utilized inductive coding after close



reading and analysis of all qualitative data. CHC identified themes that were consistent across all recipients within each specific funding opportunity.

#### Limitations

The results presented below include several limitations. Currently, the DP-21-2101 funding opportunity funds five recipients in total with four Component B recipients only focusing on two specific strategies, as required in the NOFO. The DP-23-0007 funding opportunity funds four recipients in total with three Component 1 recipients implementing the health care change strategies. Given these sample sizes, the number of recipients providing data for each performance measure is low, which made it unhelpful to calculate certain descriptive statistics (e.g., means, medians) for certain performance measures.

Additionally, many DP-21-2101 recipients experienced challenges collecting and reporting performance measure data on the "number of *people* with epilepsy referred", reporting instead data on the "number of

<sup>&</sup>lt;sup>9</sup>The NOFO requires at least 2 health care settings.

*referrals*". CDC and CHC have provided ongoing education and technical assistance on appropriate units of measurement for each performance measure and discussion of optimal strategies to collect these data in coordination with media or communication partners. However, we have observed that counting the "number of *people* with epilepsy referred" continues to present a challenge to recipients. Each summary table includes relevant footnotes to clarify any data quality issues that were unable to be resolved by the recipients after data quality checks were completed.

Lastly, CHC only analyzed the evaluation data that recipients submitted through their APRs to assess recipient progress and overall NOFO impact. No additional quantitative or qualitative data was collected by CHC outside of what recipients reported to the CDC through their APRs.

## Results

DP-21-2101: Improving Epilepsy Education, Systems of Care, and Health Outcomes through National and Community Partnerships

#### **Current Reporting Period: Key Findings**

#### From March 31, 2023 - February 29, 2024, CDC Epilepsy DP-21-2101 recipients:

- **referred 16,823 people<sup>10</sup> with epilepsy** to epilepsy-focused or other community-based services, self-management programs, and/or health care providers, including:
  - **23,042 informational referrals** to epilepsy-focused or other community-based services;
  - 2,495 informational referrals to self-management programs; and
  - **4,579 informational referrals** health care providers.
- reported **633,199,105 total media impressions** acquired through broad media channels, such as broadcast TV or radio, for the "Change Our Epilepsy Story" anti-stigma campaign, including:
  - 592,907,291 media impressions<sup>11</sup> prioritizing Hispanics in Phoenix through FirstLine Media;
  - **31,489,433 media impressions** prioritizing Black/African Americans in Philadelphia, Tampa and Chicago through FirstLine Media;
  - **6,062,381 media impressions** prioritizing Black/African Americans in Philadelphia, Chicago, NY and LA through CBS Media Ventures;
  - **1,382,000 media impressions** prioritizing Hispanics in Phoenix and Tampa through Univision Media; and
  - **1,358,000 media impressions** prioritizing Black/African Americans in Philadelphia, Tampa and Chicago through iHeartMedia.
- reported **5,898,514 website pageviews** where they disseminated educational content.
- disseminated educational content through **social media platforms** reporting:
  - 2,042,130 media impressions;
  - 87,635 views, clicks, or engagement with ads or posts;
  - 49,658 people reached via various platforms; and

<sup>&</sup>lt;sup>10</sup> EF, AES, and EAWCP reported totals that represent the number of *referrals* to services, not deduplicated *people* with epilepsy referred to services. These capacity-related data are extremely relevant to exhibit the effort required to make successful referrals for people with epilepsy; therefore, these data are reported in Tables 1-3 with relevant footnotes. Some data were also unreported leading to discrepancies in the findings. <sup>11</sup> EF reported piloting digital media tactics in the Phoenix market, such as geo-fencing tactics that deliver location-based marketing and advertising when a device enters or exits a pre-defined geographical boundary. EF attributed these media tactics to the larger totals of media impressions reported in this market.

- **40,307 followers.**
- disseminated educational content through newsletters and other informational publications reporting:
  - **559,383 newsletters, informational emails, publications, and flyers** distributed to partners; and
  - **8,073 newsletter views or clicks** on informational content in emails.
- reported **10 health systems** that are reporting, monitoring, and tracking epilepsy clinical data (e.g., seizure frequency, depression screening) to improve outcomes for people with uncontrolled seizures.

#### **Cumulative: Key Findings**

#### From September 30, 2021 - February 29, 2024, CDC Epilepsy DP-21-2101 recipients:

- **referred 25,774 people**<sup>12</sup> **with epilepsy** to epilepsy-focused or other community-based services, self-management programs, and/or health care providers, including:
  - **39,149 informational referrals** to epilepsy-focused or other community-based services;
  - **4,320 informational referrals** to self-management programs; and
  - **6,944 informational referrals** health care providers.
- reported **650,991,873 total media impressions** acquired through broad media channels, such as broadcast TV or radio, for the "Change Our Epilepsy Story" anti-stigma campaign, including:
  - 597,284,525 media impressions<sup>13</sup> prioritizing Hispanics in Phoenix through FirstLine Media;
  - **31,489,433 media impressions** prioritizing Black/African Americans in Philadelphia, Tampa and Chicago through FirstLine Media;
  - **16,469,673 media impressions** prioritizing Black/African Americans in Philadelphia, Chicago, NY and LA through CBS Media Ventures;
  - **3,340,862 media impressions** prioritizing Black/African Americans in Philadelphia, Tampa and Chicago through iHeartMedia; and
  - **2,407,380 media impressions** prioritizing Hispanics in Phoenix and Tampa through Univision Media.
- reported **10,522,427 website pageviews** where they disseminated educational content.
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  - **58,656 people reached** via various platforms; and
  - **94,310 followers.**
- disseminated educational content through newsletters and other informational publications reporting:
  - **1,251,446 newsletters, informational emails, publications, and flyers** distributed to partners; and

<sup>&</sup>lt;sup>12</sup> EF, AES, and EAWCP reported totals that represent the number of *referrals* to services, not deduplicated *people* with epilepsy referred to services. These capacity-related data are extremely relevant to exhibit the effort required to make successful referrals for people with epilepsy; therefore, these data are reported in Tables 1-3 with relevant footnotes. Some data were also unreported leading to discrepancies in the findings. <sup>13</sup> EF reported piloting digital media tactics in the Phoenix market, such as geo-fencing tactics that deliver location-based marketing and advertising when a device enters or exits a pre-defined geographical boundary. EF attributed these media tactics to the larger totals of media impressions reported in this market.

- 12,530 newsletter views or clicks on informational content in emails.
- reported **11 health systems** that are reporting, monitoring, and tracking epilepsy clinical data (e.g., seizure frequency, depression screening) to improve outcomes for people with uncontrolled seizures.
- enhanced their involvement with stakeholders to achieve project goals and activities;
- expanded training and education for law enforcement, school staff, and health care providers, improving epilepsy awareness through outreach campaigns and marketing; and
- improved referral processes by promoting self-management programs and tools via diverse communication channels, including social media and newsletters, leading to an increase in referrals.

# Performance Measure Summary

#### **Current Reporting Period: People with Epilepsy Referred to Services**

Table 1. Aggregated number of people\* with epilepsy referred to epilepsy-focused or other communitybased services, self-management programs, and/or health care providers across recipients (n=5) overall and by referral type for the **current reporting period from March 31, 2023 - February 29, 2024** 

Aggregated Total/Subcategory	Total Frequency (across recipients)	Mean (across recipients)	Lowest Frequency (within recipients)	Highest Frequency (within recipients)
Total number of PWE referred to services	16,823	3,365	11	13,234
Epilepsy-focused or other community-based services	23,042	4,608	9	11,513
Self-management programs	2,495	499	1	1,911
Health care providers	4,579	916	0	2,530

\*EF, AES, and EAWCP reported totals that represent the number of *referrals* to services, not deduplicated *people* with epilepsy referred to services. These capacity-related data are extremely relevant to exhibit the effort required to make successful referrals for people with epilepsy; therefore, these data are reported in Tables 1-3 with relevant footnotes.

#### **Cumulative Totals: People with Epilepsy Referred to Services**

Table 2. Aggregated number of people\* with epilepsy referred to epilepsy-focused or other communitybased services, self-management programs, and/or health care providers across recipients (n=5) overall and by referral type **cumulatively from September 30, 2021 - February 29, 2024** 

Aggregated Total/Subcategory	Total Frequency (across recipients)	Mean (across recipients)	Lowest Frequency (within recipients)	Highest Frequency (within recipients)
Total number of PWE referred to services	25,774	5,155	14	20,003
Epilepsy-focused or other community-based services	39,149	7,830	11	21,947
Self-management programs	4,320	864	3	3,482
Health care providers	6,944	1,389	0	4,066

\*EF, AES, and EAWCP reported totals that represent the number of *referrals* to services, not deduplicated *people* with epilepsy referred to services. These capacity-related data are extremely relevant to exhibit the effort required to make successful referrals for people with epilepsy; therefore, these data are reported in Tables 1-3 with relevant footnotes.

Figure 1. Aggregated number of people\* with epilepsy referred to epilepsy-focused or other communitybased services, self-management programs, and/or health care providers across recipients for the **previous reporting periods** (September 30, 2021 - March 30, 2023), current reporting period (March 31, 2023 - February 29, 2024), and cumulatively (September 30, 2021 - February 29, 2024)



\*EF, AES, and EAWCP reported totals that represent the number of *referrals* to services, not deduplicated *people* with epilepsy referred to services. These capacity-related data are extremely relevant to exhibit the effort required to make successful referrals for people with epilepsy; therefore, these data are reported in Tables 1-3 with relevant footnotes.

#### People with Epilepsy Referred to Services by Recipient

Table 3. Number of people\* with epilepsy referred to epilepsy-focused or other community-based services, self-management programs, and/or health care providers by recipient and referral type for the current reporting period (March 31, 2023 - February 29, 2024), previous reporting periods (September 30, 2021 - March 30, 2023), and cumulatively (September 30, 2021 - February 29, 2024)

Recipient Total/Subcategory	Current Reporting Period Frequency	Previous Reporting Periods Frequency	Cumulative Frequency
Epilepsy Foundation <sup>†</sup>	13,234	6,769	20,003
Epilepsy-focused or other community- based services <sup>†</sup>	11,513	3,726	15,239
Self-management programs <sup>†</sup>	83	236	319
Health care providers <sup>†</sup>	558	779	1,337
American Epilepsy Society <sup>§</sup>	N/A	N/A	N/A
Epilepsy-focused or other community- based services <sup>§</sup>	829	0	829
Self-management programs <sup>§</sup>	498	0	498
Health care providers <sup>§</sup>	669	0	669
Epilepsy Association of Western and Central Pennsylvania	2,611	2,012	4,623
Epilepsy-focused or other community- based services <sup>¶</sup>	9,724	12,223	21,947
Self-management programs <sup>¶</sup>	1,911	1,571	3,482

Health care providers <sup>¶</sup>	2,530	1,536	4,066
Epilepsy Foundation of New England	967	167	1,134
Epilepsy-focused or other community- based services	967	159	1,123
Self-management programs	1	17	18
Health care providers	822	50	872
National Association of School Nurses	11	3	14
Epilepsy-focused or other community- based services	9	2	11
Self-management programs	2	1	3
Health care providers	0	0	0

\*EF, AES, and EAWCP reported totals that represent the number of *referrals* to services, not deduplicated *people* with epilepsy referred to services. These capacity-related data are extremely relevant to exhibit the effort required to make successful referrals for people with epilepsy; therefore, these data are reported in Tables 1-3 with relevant footnotes.

† EF reported totals that are not unique *people* with epilepsy as many can be repeat contacts using EF's services multiple times; these data represent the total number of *referrals* provided for each contact.

§ AES reported *referrals* to epilepsy-focused or other community-based services, self-management programs, and health care providers for people with epilepsy; they <u>did not</u> report a total of unique *people* with epilepsy referred to services.

| EAWCP reported referrals to epilepsy-focused or other community-based services, self-management programs, and health care providers for people with epilepsy; they <u>did</u> report a total of unique people with epilepsy referred to services.

#### Anti-stigma Campaign "Change Our Epilepsy Story" Traffic to Educational Content

Table 4. Aggregated performance measures (n=1\*) reporting "Change Our Epilepsy Story" anti-stigma campaign traffic to educational content through broad media channels (e.g., broadcast TV, radio) for the current reporting period (March 31, 2023 - February 29, 2024), previous reporting periods (September 30, 2021 - March 30, 2023), and cumulatively (September 30, 2021 - February 29, 2024)

Performance Measure	Current Reporting Period Frequency	Previous Reporting Periods Frequency	Cumulative Frequency
Total number of anti-stigma campaign media impressions through broad media channels	633,199,105	17,792,768	649,966,493
CBS Media Impressions – Prioritizing Black/African Americans in Philadelphia, Chicago, NY and LA	6,062,381	10,407,292	16,469,673
iHeartMedia Impressions - Prioritizing Black/African Americans in Tampa and Chicago	1,358,000	1,982,862	3,340,862
Univision Media Impressions – Prioritizing Hispanics in Phoenix and Tampa	1,382,000	1,025,380	2,407,380
FirstLine Media Impressions - Targeting Black/African Americans in Philadelphia, Tampa and Chicago	31,489,433	0	31,489,433
FirstLine Media Impressions - Targeting Hispanics in Phoenix <sup>†</sup>	592,907,291	4,377,234	597,284,525

\*The Epilepsy Foundation is the single recipient funded to implement a media campaign using broad media channels.

† EF reported piloting digital media tactics in the Phoenix market, such as geo-fencing tactics that deliver location-based marketing and advertising when a device enters or exits a pre-defined geographical boundary. EF attributed these media tactics to the larger totals of media impressions reported in this market.

Figure 2. Aggregated number of "Change Our Epilepsy Story" anti-stigma campaign media impressions through broad media channels (e.g., broadcast TV, radio) for the **previous reporting periods** (September 30, 2021 - March 30, 2023), current reporting period (March 31, 2023 - February 29, 2024), and cumulatively (September 30, 2021 - February 29, 2024)



#### Traffic to Educational Content: Websites, Social Media, and Newsletters

Table 5. Aggregated performance measures reporting traffic to educational content promoted by awareness and educational campaigns by media channel for the **current reporting period** (March 31, 2023 - February 29, 2024), previous reporting periods (September 30, 2021 - March 30, 2023), and cumulatively (September 30, 2021 - February 29, 2024)

Media Channel/Performance Measure and number of recipients reporting data	Current Reporting Period Frequency	Previous Reporting Periods Frequency	Cumulative Frequency	
Websites				
Total website pageviews (n=4)	5,898,514	4,623,913	10,522,427	
Social Media				
Total number of social media impressions (n=1)	2,042,130	4,394,460	6,436,590	
Total number of social media views, clicks, or other engagement with a post or ad $(n=3)$	87,635	36,244	123,879	
Total number of people reached via social media (n=2)	49,658	8,998	58,656	
Total number of followers across various social media platforms (n=1)	40,307	54,003	94,310	
Newsletters or Informational Publications				
Total number of newsletter views or email clicks (n=2)	8,073	4,457	12,530	
Total number of newsletters, informational emails, publications, and flyers distributed (n=2)	559,383	739,022	1,251,446	

#### Health systems reporting, monitoring, and tracking epilepsy clinical data

Table 6. Aggregated performance measures reporting the number of health systems reporting, monitoring, and tracking epilepsy clinical data (e.g., seizure frequency, depression screening) to improve outcomes for people with uncontrolled seizures across recipients (n=2) for the **current reporting period (March 31, 2023 - February 29, 2024), previous reporting period (September 30, 2021 - March 30, 2023), and cumulatively (September 30, 2021 - February 29, 2024)** 

Aggregated Total/Subcategory and number of recipients reporting data	Current Reporting Period <u>Targets*</u>	Current Reporting Period <u>Frequency</u>	Previous Reporting Period <u>Frequency</u>	Cumulative <u>Frequency</u>
Total number of health systems (n=2)	16	10	10	11
Submitting data on seizure frequency (n=1)	14	9	10	10
Submitting data on barriers to medication adherence screening (n=1)	14	8	6	8
Submitting data on demographics (n=1)	14	9	10	10
Submitting data on depression screening (n=1)	14	7	5	7

\*As part of their evaluation and performance measurement plans, recipients are required to develop performance measure targets.

# Qualitative Data Thematic Summary

CHC utilized inductive coding to identify key themes in the qualitative information submitted through recipients' Annual Performance Report (APR). CHC identified themes that were consistent across all Component A and B recipients (n=5).

#### Partnership Capacity and Stakeholder Engagement

- Recipients increased their involvement and consistency of interactions with internal and external stakeholders to achieve project goals, implement activities, and meet needs.
- Recipients collaborated with stakeholders and their partners to develop targeted educational content and training opportunities.

"Another success is building on National Association of School Nurses' (NASN) previous relationship with the Advisory Board to expand collaboration for the CSSSE project. This expanded collaboration includes sharing of expertise, resources, idea generating for the project and sharing of experts in epilepsy care for NASN professional development. The Advisory Board and Navigators supported the development of the resource hub webpage on the NASN website." -National Association of School Nurses

#### **Social Determinants of Health**

- Recipients increased their focus on social determinants of health and expanded efforts to address these needs in rural areas.
- One recipient funded ten organizations to address social determinants of health in rural communities and expand their capacity to address needs in areas with limited access to epilepsy care and social services. Of these ten organizations, seven integrated rural disparities into their health, education, outreach, and epilepsy awareness initiatives, while one focused on addressing digital inequities.

• Recipients demonstrated webinar participants' increased knowledge on equitable care, mental health, and cultural competence; participants reported high satisfaction with the educational content. Specifically, the recipients identified the need for additional learning modules and trainings focused on social determinants of health.

#### **Increased Dissemination Efforts and Broadened Outreach**

"Continuing Education/Continuing Medical Education (CE/CME) evaluations for the on-demand and interactive modules also show positive uptake and knowledge change. For example, professionals completing the CE/CME evaluation of the epilepsy self-management interactive module increased confidence in identifying self-management program for patients and referring them to participate in a program." -American Epilepsy Society

- One recipient published the updated *School Nursing Evidence-Based Clinical Practice Guideline: Students with Seizures and Epilepsy*, along with an accompanying toolkit. The recipient distributed these resources through a newsletter to a listserv of over 50,000 subscribers, which resulted in 1,803 engagements based on the reported click rate.
- Recipients extended their reach to epilepsy specialist providers, non-epilepsy specialist providers, and medical organizations.
- One recipient developed a comprehensive Care Management model centered on the one-on-one relationship between a Community Health Worker (CHW) and an individual with epilepsy. Over 70 CHWs were trained in this model, which implements screening for mental health and social determinants of health as well as providing necessary support and connections to social services.
- Recipients expanded trainings and education to law enforcement, non-nurse school staff, school personnel, and health care providers with progress in educating professionals about epilepsy utilizing comprehensive outreach campaigns and marketing materials.

"We've made substantial progress in educating relevant professionals about epilepsy and seizure first aid over this reporting period. Growth in the number of school nurses and school personnel being trained through the Epilepsy Learning Portal continues to be strong. We released an updated instructor-led training course for Law Enforcement Officials and delivered it at several national conferences." -Epilepsy Foundation

#### **Increased Referrals and Support for People with Epilepsy**

- Recipients improved referral processes through education on self-management programs and promotion of self-management tools utilizing diverse communication channels, including social media and newsletters.
- Recipients recognized that facilitated referrals through direct, warm-hand offs are an effective practice to support people with epilepsy, especially when working through community partners and organizations that can link to helpful resources.

"Utilizing diverse communication channels such as support groups, messaging through CareMessage, newsletters, and social media platforms, Epilepsy Alliance-Florida (EAFLA) successfully reached and engaged individuals with epilepsy to spread awareness about self-management programs. Through the CareMessage platform, EAFLA reached 1500 individuals, introducing them to the programs and encouraging them to reach out to their case managers for additional information." - American Epilepsy Society [AES partnered with the Epilepsy Alliance-Florida]

#### Challenges

• Recipients faced various challenges specific to their individual projects with one major challenge identified across all recipients: data collection and evaluation. For example, although interest among people with epilepsy for self-management programs continues to grow, there has been no corresponding increase in the number of participants willing to complete the surveys throughout the duration of the program.

## DP-23-0007: Building Capacity for Implementing Evidence-Based Epilepsy Self-Management Supports in Health Care Settings Performance Measure Summary

#### **Current Reporting Period: Key Findings**

Evaluation Findings from September 30, 2023 - February 29, 2024:

- **Two of the three recipients** are working in **at least 2 health care settings** implementing epilepsy self-management supports.
- One recipient is working with **18 epilepsy centers across the US** and **6 primary care practices in one state. All 6 primary care practices** are referring patients through electronic health (EHR) record integrated referral options and a best practice alert (BPA) is in place to support provider education and referral decision making.
- **One recipient** is working with an epilepsy clinic in a public safety-net hospital and a tertiary care epilepsy center.
- Recipients have implemented **innovative patient referral strategies** (e.g., electronic health record screening tools and referral prompts; provider decision-support tools) to test for effectiveness.
- **Over two hundred patients** with epilepsy were referred to self-management supports; these totals were completed in the first five months of the funding opportunity.
- All three recipients have increased the number of people with epilepsy referred to a selfmanagement supports from the start of the funding opportunity.
- The Component 2 recipient, Epilepsy Alliance America, **contracted with the Veritas Management Group (VMG)** who is the lead for the Epilepsy Learning Collaborative.
- The Component 2 recipient implemented listening sessions and a needs assessment with each Component 1 recipient to inform the learning collaborative structure.

# Performance Measure Summary

Table 7. Aggregated performance measures for Component 1 recipients for the current reporting period from September 30, 2023 - February 29, 2024

Aggregated Total/Subcategory and number of recipients reporting data (n=3)	Total Frequency (across recipients)	Lowest Frequency (within recipients)	Highest Frequency (within recipients)
Number of health care settings implementing epilepsy self-management supports.	4	0	2
Number of health care settings referring epilepsy patients to epilepsy self-management supports.	4	0	2
Number of patients with epilepsy referred for self- management supports.	202	34	134
Number of patients with epilepsy who completed self-management support interventions in total.	28	0	25
Number of epilepsy patients with improvements in health outcomes (e.g., reduction in psychological distress, reduction in seizure frequency, improved attention) in total.	0	0	0
Number of epilepsy patients with improvements in overall quality of life.	0	0	0

Table 8. Aggregated performance measure data for Component 2 (n=1) recipient for the current reporting period from September 30, 2023 - February 29, 2024

Aggregated total	Total Frequency
Number of health care system change strategies disseminated with Component 1 recipients	0

# Qualitative Data Thematic Summary

CHC utilized inductive coding to identify key themes in the qualitative information submitted through recipients' Annual Performance Report (APR). CHC identified themes that were consistent across all Component 1 recipients (n=3).

#### **Stakeholder Engagement**

- Recipients established strong relationships and communication with stakeholders, highlighting increased stakeholder engagement.
- Recipients described high levels of engagement from stakeholders, such as site champions institutional leaders, which will ensure smooth project implementation and sustainability.

"It is important to note that relationship building extended beyond site Champions as concerted efforts have involved outreach to departmental chairs and epilepsy section chiefs when and where appropriate. This layering of communication has been of benefit to our early success with clinical teams." - Dartmouth Hitchcock

#### **Training and Professional Development**

- Recipients developed a comprehensive training curriculum and materials.
- Recipients emphasized the need to train clinicians, nurse educators, peer educators and other epilepsy support staff. In addition, one recipient highlighted their efforts to integrate neuropsychology and psychology related to epilepsy in their trainings.

#### **Data Collection and Evaluation**

• Recipients highlighted the creation of robust data collection systems, utilizing REDCap and electronic health system software, survey instruments (e.g., baseline, pre- and post-surveys), and other systematic feedback mechanisms as part of their evaluation and performance measurement plans.

"Electronic Heath Record (EHR) screening tools have been completed at University of Iowa and University of Cincinnati, which will screen for people with epilepsy who have had seizures in the last 6 months, have barriers to medication adherence, are in the age range of 18 to 24 years, or have moderate depression or anxiety, which will result in a best practice alert for providers in the epilepsy clinic, recommending referral for SMART intervention." - University Of Iowa

#### Challenges

• Recipients encountered challenges, such as technology delays, product development delays, and other challenges related to working with complex hospital and university systems. In addition, the coordination of large teams across multiple sites presented logistical difficulties for the recipients.

## Program Improvement Considerations

- CDC may consider continuing monthly technical assistance calls with recipients to discuss their challenges and provide insightful solutions. Recipients highlighted that these calls were extremely helpful in guiding their programmatic decisions thus far through the cooperative agreement.
- CDC may consider offering a targeted evaluation technical assistance call prior to the APR deadline to talk through important topics, such as reviewing the evaluation reporting template; discussing self-identified performance measure targets; clarifying the required performance measure units of measurement (e.g., measuring people vs. referrals); discussing metrics to measure traffic to educational content for various media channels; and offering review of evaluation reporting template prior to APR submission.
- CDC may consider continuing to require that recipients dedicate funds for evaluation support across the remainder of the cooperative agreement, either through subcontractors or internal FTE. This support will ensure that evaluation is embedded in all phases of work plan implementation, evaluation plans are updated based on adjustments in work plan activities, and that evaluation activities are implemented on schedule based on recipient needs.

"Our CDC Program Officers have acted to provide valuable technical assistance and resource linkages to influence project growth and refinement. Their support in 2023-24 made invaluable contributions to helping the project make a deeper impact at two project sites rather than a more superficial impact at numerous sites." –Epilepsy Foundation New England

# Appendix

**Recipient Performance Snapshots** 

DP-21-2101: Improving Epilepsy Education, Systems of Care, and Health Outcomes through National and Community Partnerships

*Epilepsy Foundation (EF)* Annual Award: \$3,500,000

Strategy 1: Support a nationwide consumer epilepsy information and referral system.

- As of February 29, 2024, the Epilepsy Foundation Helpline has answered over 5,000 inquires.
- There has been a **15% increase** in contact volume to the helpline from federal fiscal year 2022 to 2023, reaching 15,313 contacts and sharing 53,000 educational materials for the 2023 federal fiscal year, with the **most requests for medical information**. Despite growth trends, the overall penetration of the helpline does remain small. Facilitated referrals have increased dramatically through thoughtful, warm-hand offs from client to a key partner.
- EF reported **13,234 referrals** to epilepsy-focused or other community-based services, selfmanagement programs, and/or health care providers in the current reporting period.

"Recognizing that many people with epilepsy may benefit from facilitated referrals (referrals in which the Helpline provides a direct, warm-hand off of a client to a referral partner), we have introduced that capability and increased the number of facilitated referrals by nearly 400%. "- Epilepsy Foundation Helpline

Strategy 2: Conduct public awareness and public education activities related to epilepsy, seizure first aid, SUDEP prevention, and epilepsy stigma.

- The anti-stigma campaign message "Change Our Epilepsy Story" was very effective in both Philadelphia and Phoenix. The campaign expanded to four additional cities using multiple media channels, resulting in increased website engagement and Helpline contacts.
- Evaluation results highlight increased traffic to the campaign page and calls to the 24/7 Helpline from the markets where spots aired.
- The campaign drove traffic to both English and Spanish landing pages and an increase on the campaign page "Share Your Story" and featured stories.
- EF completed 17 total seizure first aid certification trainings with 5 trainings delivered in Spanish.

"The Foundation has devoted significant time and resources to this objective over the reporting period. The number of people certified in Seizure First Aid has grown dramatically since the start of this 5-year Cooperative Agreement, largely due to the accessibility of the on-demand learning system, the Epilepsy Learning Portal." -Epilepsy Foundation Strategy 3: Educate health care providers and relevant professionals about epilepsy, seizure first aid, and epilepsy stigma.

- Progress has been made in educating professionals about epilepsy and seizure first aid. Seizure training numbers by profession include:
  - Over 180,000 non-nurse school staff
  - Over 10,000 school nurse staff
- An instructor-led training course for Law Enforcement Officials has been released and delivered at several national conferences training **15 law enforcement officers and 23 instructors.**
- **106 participants completed the 9 sessions** of "The (Not so Rare) Epilepsies ECHO" pilot program with evaluations indicating increases in their knowledge.

"We've made substantial progress in educating relevant professionals about epilepsy and seizure first aid over this reporting period. Growth in the number of school nurses and school personnel being trained through the Epilepsy Learning Portal continues to be strong." -Epilepsy Foundation

Strategy 4: Expand access to, delivery of, and participation in evidence-based epilepsy self-management (ESM) programs.

- EF partnered with the Self-Management Resource Center to implement a new facilitator program of the Chronic Disease Self-Management Program (CDSMP) adapted for epilepsy in collaboration with 7 local chapters. EF trained 8 facilitators and initiated workshops in English, with plans to deliver the workshops in Spanish in the future. However, EF encountered challenges with recruitment and low retention.
- EF collaborated with the Barrow Neurological Institute to implement a quality improvement initiative to assess effective implementation and use of an evidence-based epilepsy self-management decision support tool (MINDSET). However, current progress is slow as implementation has required more effort than originally planned. In contrast with other sites that have implemented MINDSET, providers are reluctant to use the screening tool for self-management due to extended patient times.

"We have continued a pilot project to implement the MINDSET program in the epilepsy center setting at Barrow Neurological Institute. This project has been slow to implement because of time delays due to institutional approvals and agreements but is now recruiting participants." -Epilepsy Foundation

Strategy 5: Improve epilepsy care and management through health systems interventions.

- Nine epilepsy centers have successfully reported a standardized outcome measure set for seizure control in their patients to the Epilepsy Learning Healthcare System<sup>14</sup>.
- Data demonstrates that adherence to medication is a major challenge and breakthrough seizures are often due to non-adherence. In response to this finding, eight of the epilepsy centers are

<sup>&</sup>lt;sup>14</sup> CDC provides some support to the ELHS; however, EF is primarily using funding from other sources to support the ELHS.

reporting on standardized screening for barriers to medication adherence and providing resources and referrals to overcome these barriers.

"Challenges in being adherent to medication are the top reason for breakthrough seizures in people who can otherwise control seizures with available treatments. We have adapted the Barriers to Adherence Tool for epilepsy and implemented this screening tool in Epilepsy Health Care System (ELHS) centers." -Epilepsy Foundation

Strategy 6: Develop partnerships with multi-sector agencies to address the social needs of people with epilepsy and link to underutilized community resources.

- **Ten grants were awarded** to organizations throughout the country which include Epilepsy Foundation affiliates, community-based organizations, faith-based organizations, and national multi-sector partners. The grantees and their projects focus on connecting more people with epilepsy to social services in rural areas and community health worker support services.
- Grantees report a total of **174 people with epilepsy were referred** directly to social services.
- A notable project includes the first ever Wyoming Epilepsy Symposium.

"During this reporting period, we have expanded the Foundation network's capacity to address the needs of those living in rural areas with limited access to epilepsy care (Y2) and through partnerships related to public safety and criminal justice." -Epilepsy Foundation

## American Epilepsy Society (AES)

Annual Award: \$300,000



AES increased engagement and reach across various modalities and platforms, including over 10,000 website views across the various pages that AES promotes.

- AES reported increased engagement and reach that resulted in broader audiences for AES education and training opportunities. Notably, AES observed an increase in registrations and participation among non-AES-members.
- The Epilepsy Alliance of Florida (EAFLA) Partnership referred **over 800 people** with epilepsy to epilepsy focused or other community-based services. The EAFLA partnership was successful, including increased referrals, the establishment of a memorandum of understanding, enhanced staff education on epilepsy management, and the expansion of the coaching network.

"Epilepsy Alliance-Florida (EAFLA) made significant strides in spreading the word and expanding their coaching network, with five newly trained HOBSCOTCH and two PACES coaches from their own pool of staff members. This will allow EAFLA to do away with the current waitlist and serve more individuals interested in these programs."- American Epilepsy Society

- The AES team held 5 webinars and developed 6 on demand courses and 2 learning modules focusing on content for both primary care providers and specialists. Evaluations of the learning opportunities indicate high levels of satisfaction and knowledge gained among participants, specifically the professionals completing the Continuing Education and/or Continuing Medical Education.
- The AES team developed and presented **12 Management Epilepsy Well Network (MEW)** poster sessions and delivered **5 presentations** at the 2023 Annual Meeting.
- A major challenge experienced by AES is the lack of completion of individuals trained to deliver self-management programs. Despite the expanded reach and increased registration capacity, only 18 participants completed a training, primarily HOBSCOTCH.

"American Epilepsy Society (AES) made significant gains in raising awareness of selfmanagement resources and training through social media and paid internet advertising. AES newsletters on self-management webinars and module availability maintain a high open rate of approximately 33%." – American Epilepsy Society

*Epilepsy Association of Western and Central Pennsylvania (EAWCP)* Annual Award: \$300,000



EAWCP trained over 70 nurse and peer educators have in SMART and over 4,000 people with epilepsy referred to epilepsy focused self-management programs or community-based services.

- EAWCP reported a substantial increase in overall referrals to community services, **exceeding 25,000**, specifically benefitting people with epilepsy, with **over 2,000 people with epilepsy** referred over the reporting period. This success highlights the effectives of EAWCP to foster multi-sector partnerships in increasing referrals and connecting people with epilepsy to community resources.
- EAWCP reported **111 SMART program participants**, **8 of which are based in a rural community, and 22 are between the ages of 18-24**, representing difficult-to-reach populations. Notably, this figure represents a **36% increase** in participants compared to the previous reporting period.
- EAWCP reported increased online engagement across their three websites, including over **300,000 page views** and **40,000 social media users** over the past year.
- The EAWCP data team captured cumulative outcomes on quality of life, seizure frequency, and depression/anxiety utilizing validated screening tools such as the QOLIE-10 and PHQ-9.

"In conclusion, while generalizability is limited due to sample size and individuals variability, findings suggest a trend for improved quality of life in people with epilepsy. [In reference to the improvement in health and wellbeing of patients utilizing validated screening tools ] "-Epilepsy Association of Western and Central Pennsylvania

*Epilepsy Foundation of New England (ENFE)* Annual Award: \$300,000

Increase in the number of referrals to both HOBSCOTCH and PACES selfmanagement programs. Trained more than 70 community health workers in the care management model across the two sites.

- EFNE reported successful and focused **implementation at two sites** that led to a streamlined referral process, including **two signed memorandums of understanding**. In addition, the EFNE developed an informative process map for the referral process.
- EFNE reported **over 1,000 people with epilepsy referred** to an epilepsy self-management program or community-based service from the beginning of funding. The three highest types of referrals are for epilepsy support groups, other epilepsy focused social supports, and social supports in general.
- During this reporting period, **100% of individuals with epilepsy** (**n=967**) were provided with at least one referral representing an increase from previous reporting period.
- EFNE reported that **100% of the participating implementation sites are staffed with the program's target number of supervisors and community health workers**, highlighting both sustainability and progress.
- Despite the initial failure with Activate Care to support tracking referrals and care, EFNE successfully identified a technology solution with the overhaul of the Salesforce Care Management and Resource/Referral system and a new system is near completion.

"In this project year, we refined the project to focus on two host sites, developed clarity with regard to our process map for our Referral Process, improved electronic Referral processes, and articulated how hospitals are increasing the collection of patient clinical data."-Epilepsy Foundation New England

#### National Association of School Nurses (NASN)

Annual Award: \$300,000

• NASN reported the successful completion of a needs assessment from Epilepsy School Nurse Navigators and school nurses (n=68) to identify knowledge gaps for students with epilepsy. The findings highlight the need for more education on school policy development and change, identification and support for students with epilepsy and mental health challenges and addressing health disparities.



Over 200 school nurses have been trained in a variety of seizure training for school nurses across the 3 pilot states, Indiana, South Carolina and West Virginia.

- Publication of updated school nurse clinical practice guidelines for students with epilepsy.
- NASN reported increased awareness of existing epilepsy resources by Epilepsy School Nurse Navigators demonstrating an expanded reach and knowledge gained.

- Data from the annual Navigators Needs Assessment Survey (n=3) revealed critical insights into gaps in knowledge and confidence among navigators and school nurses. Notably, only 22% of school nurses report extensive confidence in connecting students with epilepsy and their families to community-based services or resources. Similarly, only 33% of Navigators rate their knowledge and confidence in providing referrals to meet students' needs as extensive. These findings underscore the necessity for targeted training and educational content to enhance support provided to students with epilepsy and their families.
- The Advisory Board remains actively engaged, supporting the project with **11 active members** and holding **four meetings per year**, featuring diverse membership. An advisory group survey (n=9) reported progress in providing oversight and project expertise on product development to include reviewing, editing, and providing content.

"A focus of the school nurse survey was to identify topic areas for future professional development activities. The topic areas with the largest increase in percentage points included 'seizure first aid', 'emergency medication administration for seizures', 'screening for student safety', and 'seizure action plans or ECPs'. Each of these increased by at least 10 percentage points between Year 1 and Year 2. "-National Association of School Nurses

### DP-23-0007: Building Capacity for Implementing Evidence-Based Epilepsy Self-Management Supports in Health Care Settings Performance Measure Summary

#### Dartmouth-Hitchcock

Annual Award: \$450,000

- Implemented self-management supports in 18 epilepsy centers and 6 primary care centers.
- During this reporting period, **134 patients were referred** to HOBSCOTCH across both the epilepsy centers and primary care practices.
- Implemented baseline surveys early in the funding period which has allowed clinicians to identify key social determinants of health that impact epilepsy care, as well as the level of patient engagement in self-management behaviors.
  - 51% of providers report lack of support for comorbid mental health issues most negatively impact epilepsy care.
  - 78% of clinicians reported that some or few patients currently engage in self-management behaviors.
- Successful integration of neuropsychology and psychology trainees in the HOBSCOTCH program.

"As of February 29,2024, 82 epilepsy center providers completed a baseline survey. They were asked to select which social determinants of health (SDOH) most negatively impacted their patients' epilepsy care -51% of providers surveyed report that a lack of support for comorbid mental health issues most negatively impacts epilepsy care, 43% report that a lack of transportation most negatively impacts care, and 29% indicated low income, 29% indicated patient health literacy, and 24% indicated rural residence as most negatively impacting care. " -Dartmouth Hitchcock

#### Emory University

Annual Award: \$450,000

- Successfully finalized pre- and post-test patient surveys for UPLIFT and HOBSCOTCH programs and developed a comprehensive evaluation system in REDCap.
- During this reporting period, Emory University referred **34 patients with epilepsy** to a selfmanagement program.
- Identified and started training facilitators and staff for UPLIFT and HOBSCOTCH programs.
- Effective and productive collaboration meetings have been initiated, fostering strong relationships with Emory neurology faculty and external partners.

"We have been finalizing our evaluation and process evaluation measures over the past 4 months. Program participants will complete a survey that asks about key outcomes before and after they complete the selfmanagement programs. We will conduct yearly surveys and interviews with delivery staff to understand implementation delivery at both Emory clinics." –Emory University

#### University of Iowa

Annual Award: \$450,000

- Establishment of a **9-member stakeholder advisory panel** has been successful, featuring comprehensive representation from the epilepsy care sectors in both Iowa and Ohio.
- Formation of a core team with expertise in Epic electronic health record (EHR) tools, focusing on implementation at the University of Iowa and University of Cincinnati. These efforts have led to the development of a best practice alert for providers and a recommendation for the SMART Program.
- **Thirty-four patients referred** to be participants in EXPAND from the two health care settings at the University of Iowa and University of Cincinnati.

"Electronic Heath Record (EHR) screening tools have been completed at University of Iowa and University of Cincinnati, which will screen for people with epilepsy who have had seizures in the last 6 months, have barriers to medication adherence, are in the age range of 18 to 24 years, or have moderate depression or anxiety, which will result in a best practice alert for providers in the epilepsy clinic, recommending referral for SMART intervention." - University Of Iowa

#### Epilepsy Alliance America

Annual Award: \$150,000

- To provide support and expertise in health care system change Epilepsy Alliance America has **contracted with the Veritas Management Group (VMG)**; they will be the lead for the Epilepsy Learning Collaborative.
- The Learning Collaborative is in its developmental stage. To facilitate its establishment and identify potential health care change strategies and priority areas, VMG conducted focus groups, utilized questionnaires, and gathered information from each Component 1 recipient. Common themes identified through the needs assessment included provider education, best practice alerts, patient education, and facilitated referral systems.

• A portal to house health care system change strategies, tools, and other resources, in addition to monthly updates provided to each Component 1 recipient has been established for storage and dissemination.

"Veritas Management Group incorporated background material review and questionnaire results into a focus group protocol. Focus group inquiry with each of the three Component 1 partners comprised a targeted needs assessment to elicit training priorities and quality improvement strategies to inform Learning Collaborative development." - Epilepsy Alliance America