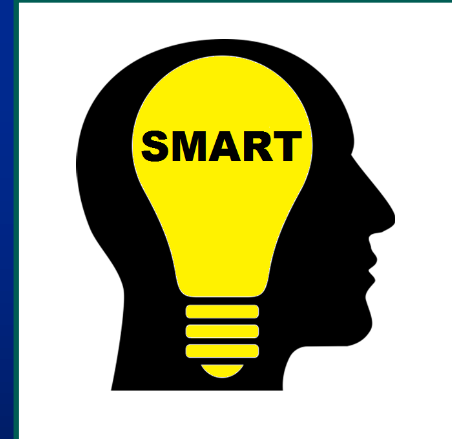


Epilepsy Self-Management for People with Epilepsy and a History of Negative Health Events (SMART): A Science-to-Service Model

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Objectives

1. Learners will be able to define epilepsy self-management as an evidence-based chronic disease management approach
2. Learners will gain familiarity with research approaches that develop, test and implement self-management interventions
3. Learners will identify approaches to build partnerships that will facilitate implementation/scale-up of evidence-based self-management approaches

Epilepsy is one of the most common neurological conditions

- Epilepsy is a chronic health condition in which individuals experience recurrent (and usually unpredictable) seizure occurrence
- 1.2% of the total US population has active epilepsy
- This translates to about 3.4 million people with epilepsy nationwide: 3 million adults and 470,000 children
- Epilepsy can have onset across the full life-span and may be acquired with events that cause brain injury (stroke, TBI)

<https://www.cdc.gov/epilepsy/about/fast-facts.htm>

Epilepsy vs Breast Cancer

United States	Number
Epilepsy total	3,000,000
New cases per year	180,000
Deaths per year	50,000

United States	Number
Breast cancer total	4,000,000
New cases per year	280,000
Deaths per year	43,000

Epilepsy Self-Management (ESM)

- Processes used to control seizures and manage the effects of epilepsy
- Current approaches generally derived from models of chronic illness self-management
- ESM can have biological effects, including reducing stress hormones, inflammation & heart rate variability

DiIorio, C. (1997). Handbook of Health Behavior research II: provider determinants. New York, Plenum Press: 213-230, Hostinar CE AJOB Neurosci. 2015 Jul 1;6(3):34-42.

ESM barriers

- Forgetting to take medication
- Sup-optimal medication efficacy
- Medication side effects
- Depressive or other mental health symptoms
- Stigma
- Lack of social supports
- Lack of access to care/medication (eg. rural residents)

Stress and mental health comorbidity in people with epilepsy

- Epilepsy in itself causes stress, exacerbated by the unpredictability of when seizures may occur
- People with epilepsy have a 2–5 times increased risk of developing any psychiatric disorder
- 1 in 3 patients with epilepsy have a lifetime psychiatric diagnosis
- Psychiatric comorbidity is a poor prognostic marker with worse response to treatment (drugs and surgery), increased morbidity, and mortality in people with epilepsy

Mula et al. Neurol Clin Pract Apr 2021, 11 (2) e112-e120



Managing Epilepsy
Well Network

MISSION

To advance the science related to epilepsy self-management by facilitating and implementing research, conducting research in collaboration with network and community stakeholders, and broadly disseminating the findings of research.



CDC Epilepsy Program

Support System Framework: Science-to-Service



Research
&
Program
Develop-
ment



Evaluation



Dissemination



Community-
Based Pilots



Evaluation



Reimburse-
ment
Cost-Studies

Patient-centered; Community-based; Stakeholder driven

Building the system

Evaluating the system

Sustaining the
system

MEW Network Self-Management Programs

Enhance and expand evidence for the efficacy of self-management with the following programs

HOBSCOTCH



Project UPLIFT



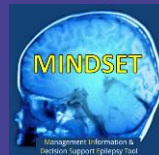
SMART



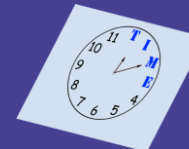
PACES



MINDSET



TIME

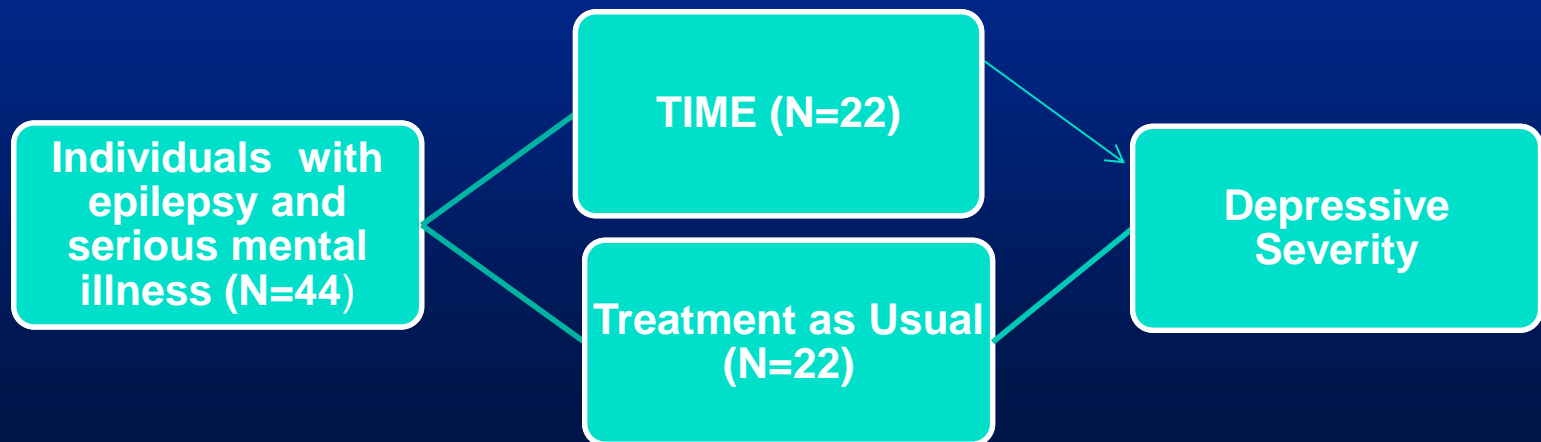


Program Development and Pilot Testing: Targeted Illness-Management for Epilepsy and Mental Illness (TIME)

Phase I : 1-10 Months



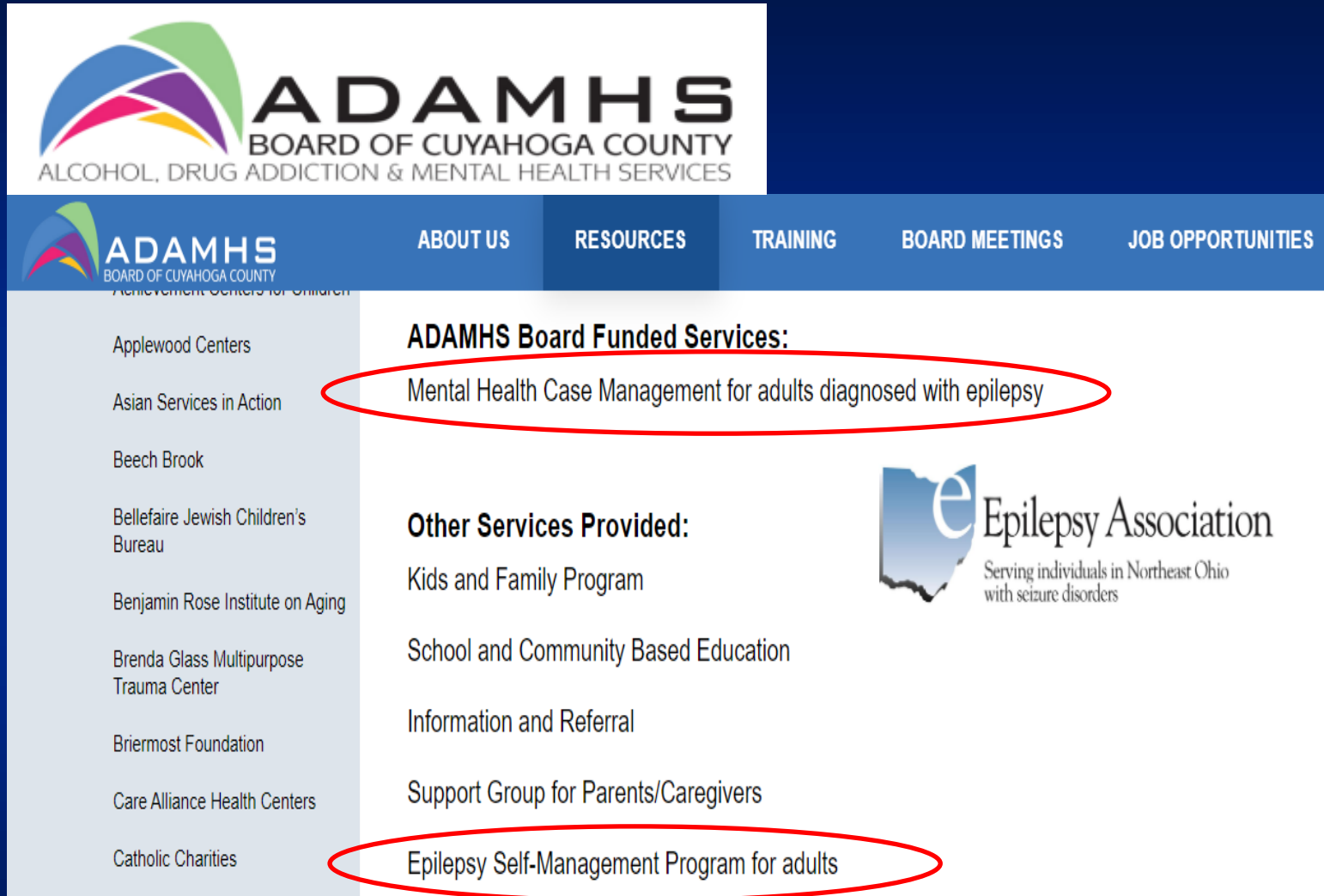
Phase II : 11-36 Months



TIME Results

- 44 individuals enrolled, mean age 48.25 (SD=11.82), 25 (56.8%) African-Americans.
- The majority (N=31, 70.5%) were unemployed, and most (N=41, 95.5%) had annual income <U.S. \$25,000.
- There was a significant effect for MADRS ($p=0.036$; effect size of 0.70), with lower MADRS at 16 weeks in TIME, while TAU MADRS did not change.

TIME Implementation: Community TIME (C-TIME)



ADAMHS
BOARD OF CUYAHOGA COUNTY
ALCOHOL, DRUG ADDICTION & MENTAL HEALTH SERVICES

ADAMHS
BOARD OF CUYAHOGA COUNTY
Achievement Centers for Children

ABOUT US **RESOURCES** **TRAINING** **BOARD MEETINGS** **JOB OPPORTUNITIES**

Applewood Centers

Asian Services in Action

Beech Brook

Bellefaire Jewish Children's Bureau

Benjamin Rose Institute on Aging

Brenda Glass Multipurpose Trauma Center

Briermost Foundation

Care Alliance Health Centers

Catholic Charities

ADAMHS Board Funded Services:

Mental Health Case Management for adults diagnosed with epilepsy

Other Services Provided:


Kids and Family Program

School and Community Based Education

Information and Referral

Support Group for Parents/Caregivers

Epilepsy Self-Management Program for adults

 **Epilepsy Association**
Serving individuals in Northeast Ohio
with seizure disorders

Sajatovic M, et al.. Epilepsy Behav. 2018;89:175-180.

3-Tiered Health Promotion Approach (HPA) Model for Individuals with Epilepsy ^{1,2}

Universal HPAs:

- ALL patients
- Minimally intensive
- Easily disseminated (example, WebEase , Standard education)

Selected HPAs :

- target those at risk for poorly controlled epilepsy , comorbid depression or cognitive impairment
- Identification often based on demographic or clinical variables
- Individually or group tailored (example, SMART, HOBSCOTCH, UPLIFT)

Indicated HPAs: target those known to be at very high risk (more serious depression or SMI). Highly tailored and of greater intensity (example, TIME)

¹Zerhouni Bull Acad Natl Med. 2007

² Adapted from Velligan, Sajatovic, Riley et. al. 2010

ESM for People with Epilepsy and a History of Negative Health Events (SMART)

- 8 group-format sessions delivered in a web-based format using posters/graphics and emphasizing interactive discussion. Telephone call-in available for those with limited internet access or familiarity.
- Group-sessions completed over approximately 8 weeks
- Detailed curriculum and semi-scripted instructions for delivery
- Groups are co-lead by a nurse/health professional and a peer educator (person with epilepsy trained in SMART)

Importance of Peer Educators

- People with epilepsy who serve as guides to support participants
- Have personal experience and willing to share their experiences including how they struggled with behavior change and what they learned.
- Peer Educators are not “perfect models” of health.
- Peer Educators help people realize that they are not alone, that learning health self-management takes time and that investing in the self has VERY high return on investment!!
- We often learn more from our mistakes than our successes!

SMART Curriculum

Session 1	Orientation and introductions; Emphasize ground rules; Establishment of a therapeutic relationship; Facts and myths about epilepsy and general epilepsy management principles
Session 2	Relationship of epilepsy and stress; Stigma and “double stigma”; Strategies to cope with stigma; Introduction to personal goal-setting
Session 3	Treatments for epilepsy; Complications of epilepsy; Minimizing epilepsy complications; The importance of daily routine and good sleep habits
Session 4	Problem-solving skills and the IDEA approach (Identify the problem, Define possible solutions, Evaluate the solutions, Act on the best solution); Talking with your health care providers; Role play of communication with care providers
Session 5	Nutrition for best physical and emotional health; Substance abuse and its effects on epilepsy; Specific stress-management approaches
Session 6	Effects of exercise and being outdoors on physical and emotional health; Medication routines; Prioritizing medication side effects and discussing it with your clinician
Session 7	Social supports and using your available supports; Advocacy groups for epilepsy; A personal care plan to take care of the mind and the body
Session 8	Normalizing your life in spite of having a chronic but unpredictable condition; Self-management as a life-style; Acknowledgement of group progress; Setting the stage for Ongoing Illness Management and Recovery (Step 2)

SMART 1.0 Efficacy RCT Outcomes

Decrease in Negative Health Events (NHE)

	SMART	Waitlist	P-value
% ↓ total NHE counts	82.4%	59.6%	0.02
Change total NHEs	-10.16	-1.93	0.04

		Baseline	10 Weeks	24 Weeks	
Variable		Mean (SD)	Mean (SD)	Mean (SD)	p
PHQ-9	SMART	10.03 (6.6)	7.85 (6.2)	7.27 (6.6)	0.03
	WL	11.45 (7.8)	11.93 (7.4)	10.82 (7.0)	
MADRS	SMART	16.52 (10.7)	11.94 (10.6)	10.92 (11.5)	0.01
	WL	19.72 (12.1)	20.66 (11.5)	18.38 (11.5)	
QOLIE-10	SMART	3.00 (0.9)	2.52 (0.9)	2.46 (1.0)	0.01
	WL	2.99 (0.9)	2.99 (0.8)	2.97 (0.9)	

SMART 2.0: An effectiveness RCT

- ❖ 18-month randomized controlled trial (RCT) of SMART **vs.** 6-month wait-list controls (WL).
- ❖ Enrolled from 2 sites (Iowa, Ohio)
- ❖ Prioritize under-served & rural settings
- ❖ 8 group-format, 60-90 minute sessions (Up to 10 participants) co-delivered by a Nurse Educator-Peer Educator dyad.
 - Sessions delivered using internet with posters/graphics and emphasizing interactive discussion.
 - Telephone call-in available for those with limited internet access or familiarity.
 - Group-sessions completed over about 8 weeks.
 - Detailed curriculum and semi-scripted instructions for delivery
 - Monthly phone follow up by nurse for 3 months

Recruitment and program optimized for rural and vulnerable populations (Engaging Stakeholders)

- Focus groups with rural healthcare providers, people with epilepsy, and family members
- Suggestions to increase participation
 - Involve community providers (PCPs, rural hospitals, social workers, pharmacists, drug rehab centers, public health centers)
 - Provide information at community centers (churches, public libraries, and senior centers)
 - Target locations where men congregate (VFA, Lion's club, Barber shops)
 - Epilepsy Foundation/Association events

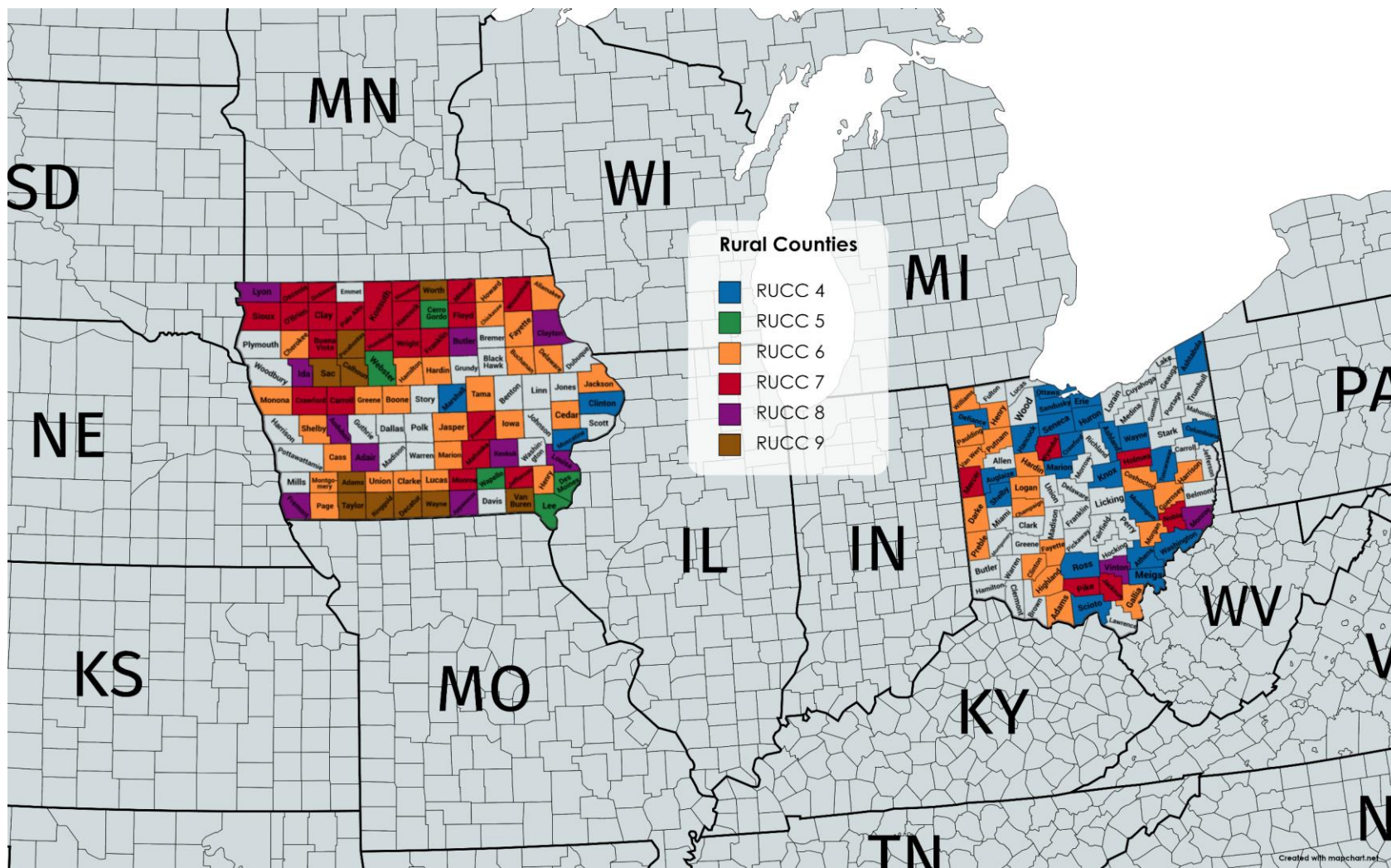
Blixen et al. Epilepsy and Behavior. 2021 118

Perceptions of the SMART epilepsy self-management program for a rural population (N = 34).

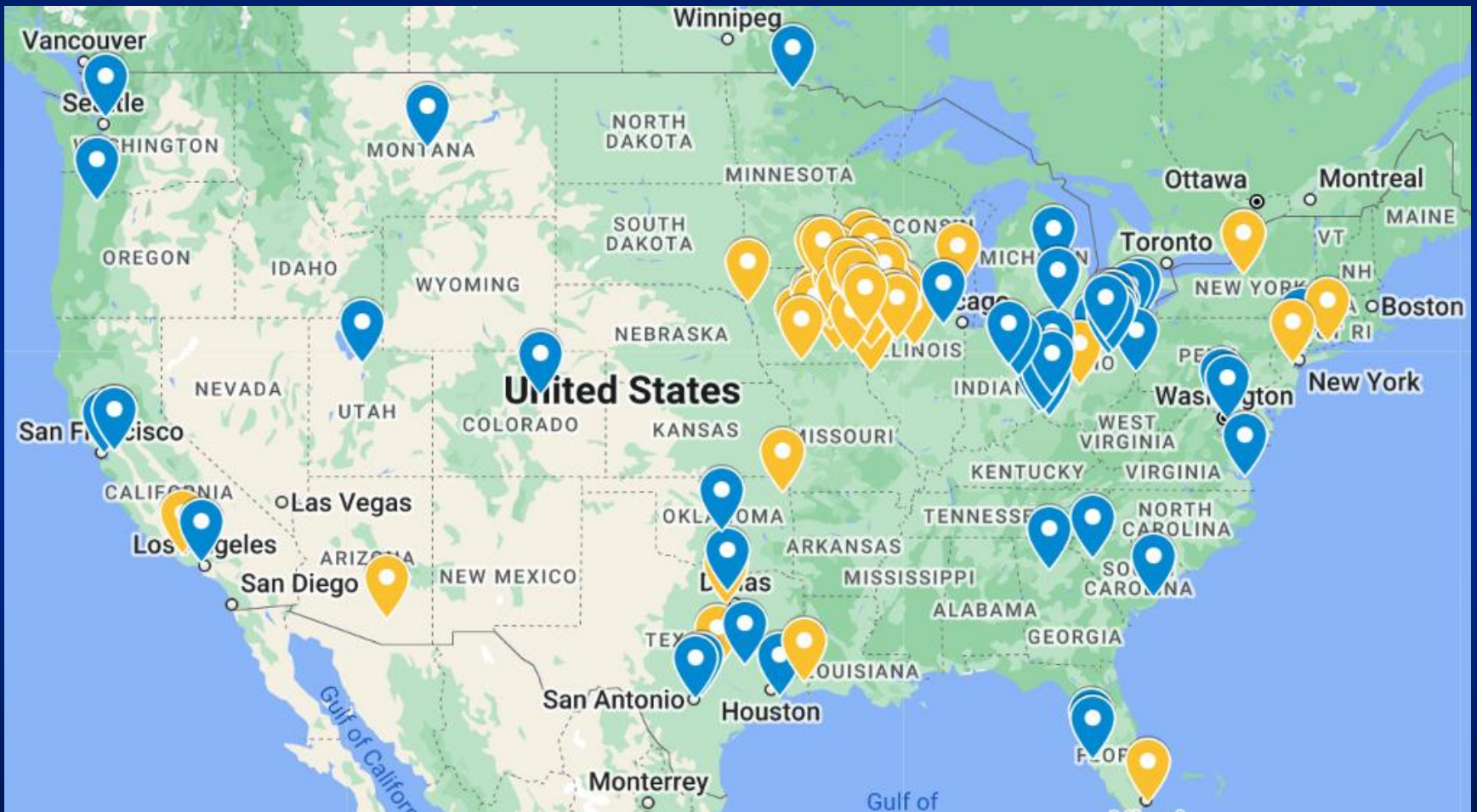
Themes	Categories
Strengths of the Program	Fills a gap in epilepsy care Comprehensive curriculum Use of peer educators Zoom format decreases isolation Group format provides interaction with others
Challenges to Implementation	Access to internet Access to cell phones
Suggestions for Improvement	Provide support to help access zoom meetings Curriculum issues Involve caregivers in meetings
Suggestion to Facilitate Patient Participation	Enhance recruitment strategies Enhance engagement and retention strategies

SMART 2.0 RCT Inclusion Criteria

- Have received a previous diagnosis of epilepsy
- Be adults \geq age 18,
- Have experienced at least 1 Negative Health the previous 6 months.
 - Seizures
 - Hospitalization
 - ED visit
 - Self-harm attempt
- Be able to speak and understand English
- Be able to provide written, informed consent to study participation or have a legally authorized representative
- Peer Educators \geq 3 lifetime NHEs



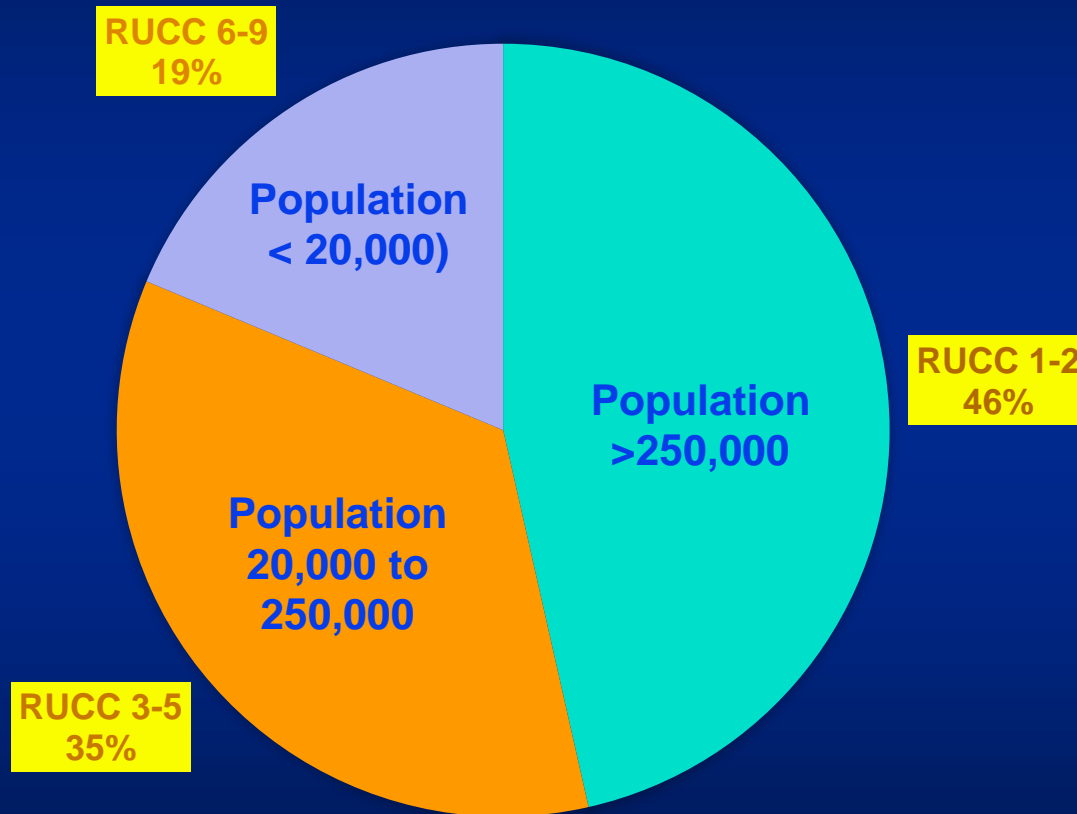
SMART 2.0 national enrollment (N=160)



Demographic Characteristics of SMART 2 Participants (N =160)

Sociodemographic Characteristics	Mean (SD) or N (%)
Age (n= 160)	39.4 (12.2), range 19 to 77
Gender	
Male	52 (32.5%)
Female	107 (66.9%)
Marital Status	
Married/cohabitating	84 (52.5%)
Not married	76 (47.5%)
Education Level	
More than high school	124 (77.5%)
High school or less	36 (22.5%)
Employment Status	
Employed	69 (43.1%)
Unemployed	91 (56.9%)
Income (n= 159)	
>\$25,000	95 (59.8%)
<\$25,000	64 (40.3%)
Insurance (n=159)	
Private	73 (45.6%)
Public	87 (54.4%)

Rural Urban Continuum (RUCC) Scores for SMART 2 Participants



Seizure frequency differs by rural/urban status

Interim analysis of first 94 patients in SMART 2.0

Variable	RUCC 1-2 (Pop: >250,000)	RUCC 3-5 (Pop: 20,000-250,000)	RUCC 6-9 (Pop: <20,000)	P
N (%)	32 (34.0%)	41 (43.6%)	21 (22.35)	
Age – Mean, SD	38.7 (9.9)	37.7 (14.4)	39.9 (9.1)	0.39
Gender- N (%)				
Female	21 (65.6%)	27 (65.9%)	62 (66.7%)	1
Male	11 (34.4%)	14 (34.2%)	32 (33.3%)	
Race – N (%)				
African-American	2 (6.3%)	4 (9.8%)	0 (0%)	0.30
White	26 (81.3%)	35 (85.4%)	20 (95.2%)	
Asian	1 (3.1%)	0 (0%)	0 (0%)	
30-day seizure frequency – median, IQR; mean, SD	2 [0, 5.5]; 3.8 (4.7)	0 [0, 4]; 5.2 (16.1)	3 [2, 15]; 8.1 (9.5)	Overall: 0.0028 1 vs 2, p=0.06 1 vs 3, p=0.039 2 vs 3, p=0.0011 1+2 vs 3, p=0.0026
6-month seizure frequency – median, IQR; mean, SD	6 [2.5, 21.5]; 14.4 (18.3)	4 [1, 12]; 10.6 (15.2)	12 [8, 50]; 40.1 (53.9)	Overall: 0.0016 1 vs 2, p=0.22 1 vs 3, p=0.009 2 vs 3, p=0.0003 1+2 vs 3, p=0.0005

Implications for Clinical Practice

- Evidence-based ESM can:
 - -reduce stress/depression & epilepsy complications
 - -improve quality of life
- Partnering with community & clinical stakeholders can facilitate practical models of care
- ESM should be more widely recommended by epilepsy care providers

Clinician-facing Service Gaps

- In spite of the robust body of evidence supporting ESM, it is not currently a standard of care
- ESM is not typically integrated into epilepsy care workflows
- Reimbursement can be challenging and inconsistent

Patient- facing Service Gaps

- Patients and families may not be aware of evidence-based ESMs
- Access to ESMs remains limited
- Problems with digital access is still a problem for some people with epilepsy
- ESM curricula for children/adolescents still lacking/in development

“Systems” Service Gaps

- ESMs need to be implemented differentially when implemented by clinical programs (i.e. epilepsy centers) vs. community agencies (i.e. epilepsy support social service agencies)
- Training ESM providers takes time and effort
- Establishing fidelity to ESMs is important—fidelity “drift” can be a problem

SOME SILVER LININGS FROM COVID:

- Healthy systems routinely use remote care delivery
- Social media can be used to do good/get the word out about our interventions
- Many people with epilepsy now familiar with telehealth and many (but not all) have digital access
- Payers may be more amenable to paying for remotely-delivered services



THE ROAD AHEAD:

Parity with diabetes care may provide a useful model for how to help make ESM a standard of care

Diabetes Education is a standardized, widely available complement to medical management of diabetes mellitus and usually in conjunction with medications or other biological therapies



Diabetes Self-Management Education (DSMS)

- **DSMS teaches people how to manage and stay healthy with diabetes.**
- **Led by a Certified Diabetes Care and Education Specialist (CDCES), also known as a diabetes educator.**
- **Diabetes educators help meet personal diabetes and health goals**
- **A standard of care for many types of diabetes (Type 1, 2, gestational)**

Diabetes Self-Management Education (DSMS)

- Individual or group format classes anywhere from 30 min-2.5 hours in duration
- Covered by most insurance plans including Medicaid
- In many cases health systems will offer financial assistance for uninsured or under-insured individuals

Ongoing work in SMART scale-up

- SMART 3.0: CDC-funded, 5-year project to embed SMART implementation across 3 epilepsy-focused social services agencies (Epilepsy Alliance of Ohio, Epilepsy Association Northeast Ohio, Epilepsy Association Western and Central Pennsylvania)
- SMART-RM: Investigator-initiated prospective pilot (PIs Sajatovic, Londono, McVoy) funded by Pharma to link SMART with FDA-approved nasally-inhaled seizure rescue medication
- DoD funded project (PI Kwan) to adapt and preliminarily test SMART among adults with brain tumor
- EXPAND: CDC-funded project to embed SMART into clinical care settings (PIs Ghearing & Privitera)

A case study in science-to-service application of epilepsy self-management. Epilepsy & Behavior : yebeh.2024.109945.

EXPAND STRATEGIES



- Expansion of SMART program with demonstrated efficacy in producing short and long-term outcomes for PWE.
- Use of a widely-available EHR (Epic) to identify and refer PWE
 - Help to prioritize PWE who may have specific need for self-management support.
 - Can be implemented in many clinical settings
- A service delivery model using dyads of peer educators and nurse educators to virtually deliver interventions and provide follow-up.
- A partnership with CWRU for the provision of technical support, training, and evaluation.
- A stakeholder advisory panel (SAP) taking advantage of existing partnerships with rural healthcare and epilepsy care stakeholders

EXPAND priorities



The SMART program may be especially beneficial for people with epilepsy who:

- Had a recent seizure
- Have self-reported barriers to medication adherence
- Have depression or anxiety symptoms
- Are young adults transitioning from the pediatric to the adult clinical setting
- Live in rural regions

EXPAND uses the electronic health record to allow healthcare providers to easily refer patients to SMART



Patient completes surveys in MyChart or on a tablet in the waiting room



Best Practice Alert (BPA) appears in chart when the provider sees the patient

2



Provider talks with patient to see if SMART is appropriate

Provider clicks on BPA to refer patient to SMART



4

Referral goes to coordinator who schedules SMART group

5



SMART delivered virtually by Nurse and Peer educators



6

Collaboration with Epic Community Connect Program



- Help implement the BPA in settings where people with epilepsy receive care, such as emergency departments and primary care clinics.
- After patients referred through the BPA, EXPAND program staff will enroll and schedule patient.
- Interested nurses and patients may be able to be trained as SMART educators in the future.
- Other resources:
 - Recruitment materials
 - Education on epilepsy self management support for staff
 - Other Epilepsy EHR screening tools for medication adherence, quality of life, and seizure frequency.

Enhancing Research Collaborative Productivity: MEW Network Integrated Database (MEW-DB)

Pooled data from ~1,700 unique individuals from 19 studies (2012-2024).

Selected publications:

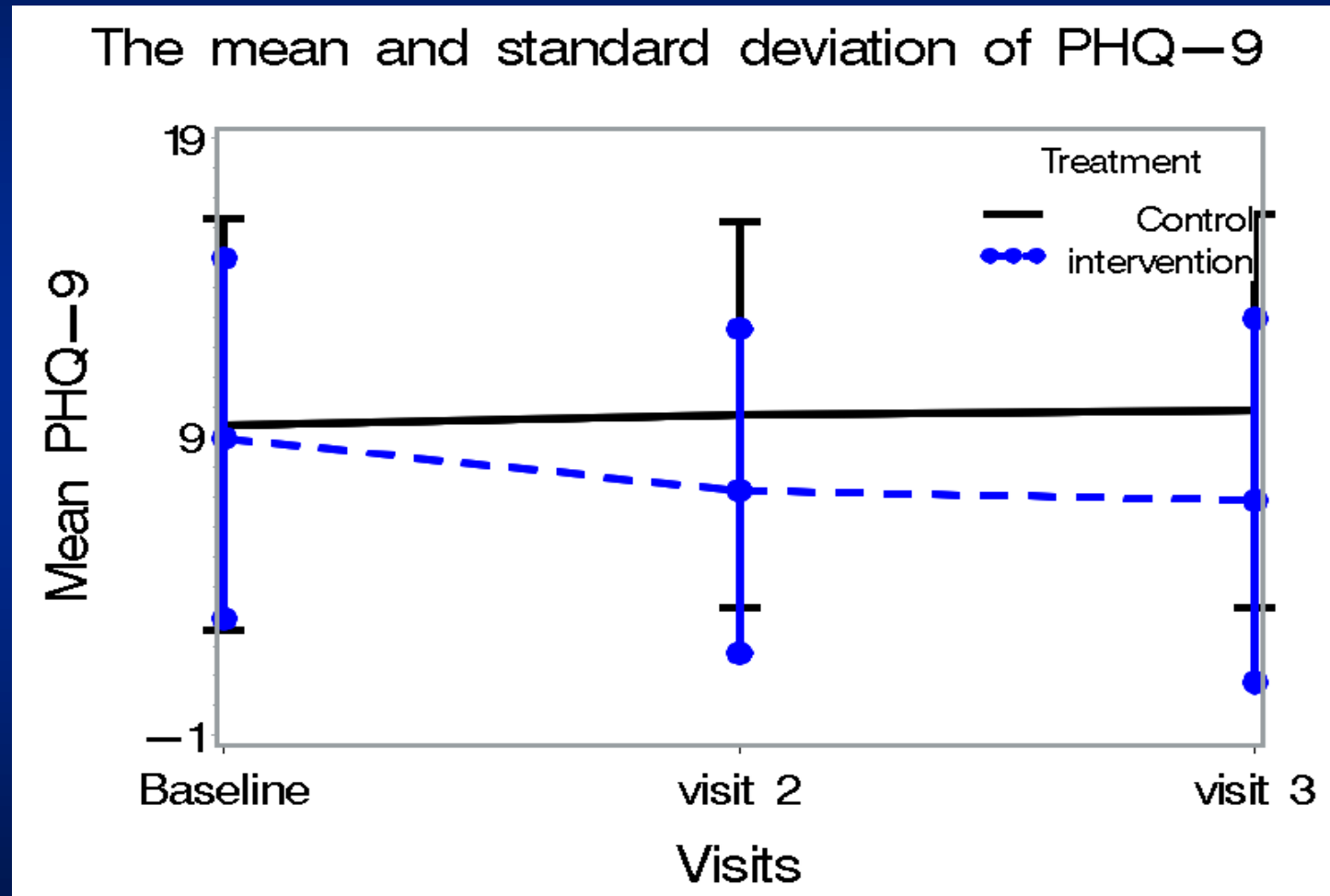
The Managing Epilepsy Well (MEW) Network Database: Lessons Learned in Refining and Implementing an Integrated Data Tool in Service of a National US Research Collaborative. *Epilepsy & Behavior*. 2021 Feb 1;115:107650

Depression and suicidality among Hispanics with epilepsy: Findings from the Managing Epilepsy Well (MEW) Network integrated database. *Epilepsy Behav*. 2021 Dec;125:108388.

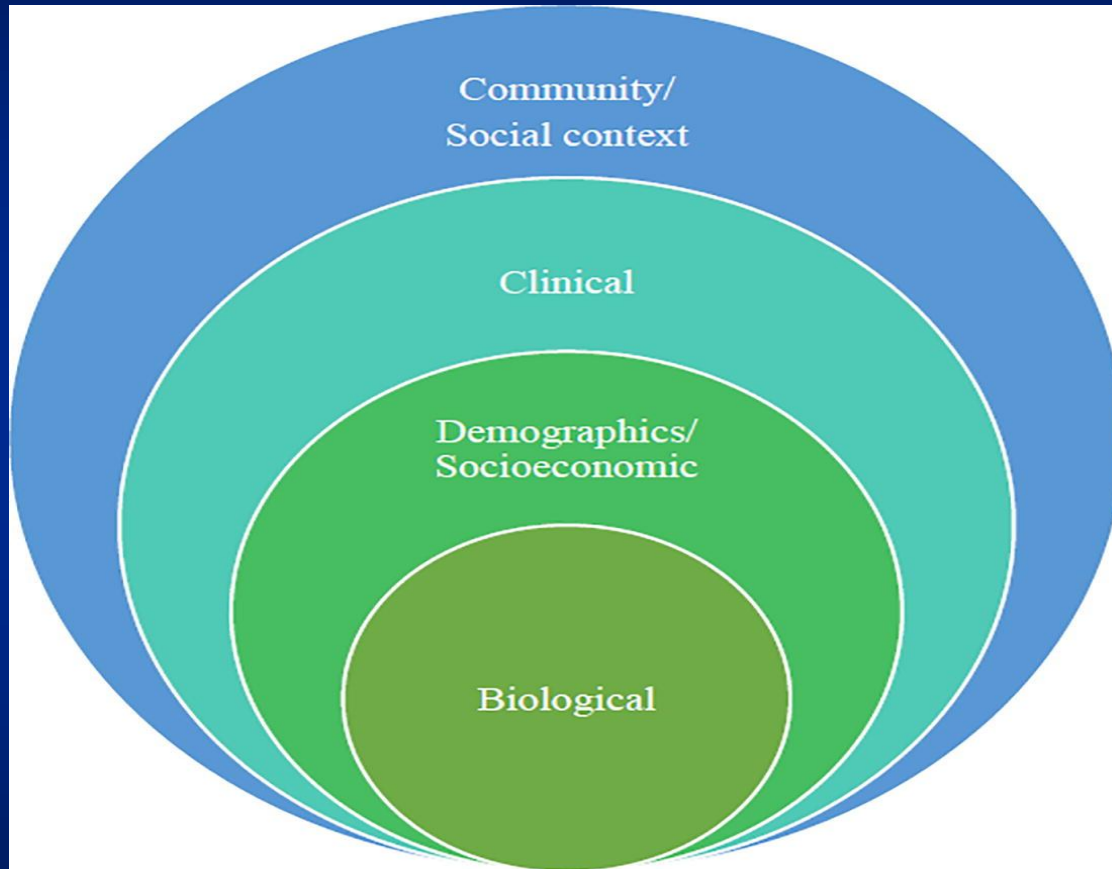
Supervised machine learning to predict reduced depression severity in people with epilepsy through epilepsy self-management intervention. *Epilepsy Behav*. 2022 Feb;127:108548.

Premature discontinuation among individuals with epilepsy participating in epilepsy self-management research interventions. *Epilepsy Res*. 2022 Nov;187:107034.

Depression Severity Over Time in 5 pooled MEW Network Epilepsy Self-Management RCTs (N=472)



Socio-ecological levels of MEW DB variables.



Sajatovic et al. Epilepsy Behav. 2021 Feb;115:107650.

The Road Ahead

- SMART –U: NINDS-funded RCT to test an adapted version of SMART in the Ugandan health care setting
- SMART- AYA: NIH R21 proposal to adapt and preliminarily test SMART in adolescents and young adults (AYA)
- Cultural and linguistic adaptations in global health settings

The teamwork makes the dream work!



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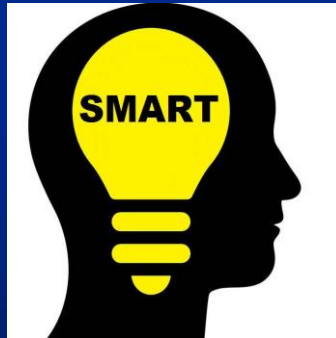
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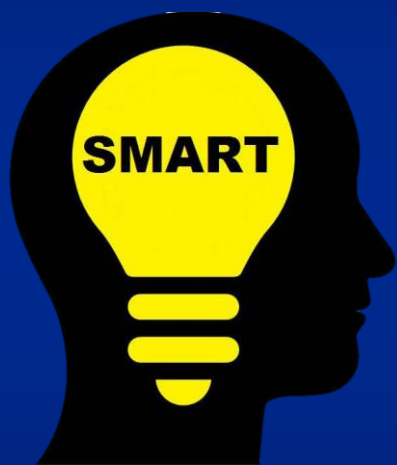


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Questions??



"I learned a couple ways to help that I hadn't even considered or known about, and since implementing them into my life the number of "bad seizure days" I've had has gone down, which is really important to me." ~past SMART participant