

Adult Epilepsy Self-Management Measurement Instrument (AESMMI-65)

The Adult Epilepsy Self-Management Measurement Instrument (AESMMI) is a 65-item scale that assesses frequency of use of epilepsy self-management practices. The scale was developed by a team of experts convened by the Managing Epilepsy Well Network, using a multi-phased approach, including: 1) a review of the literature on epilepsy self-management and self-management scales; 2) an item generation phase leading to a 113-item instrument; 3) an expert review by a panel of epilepsy researchers and clinicians; 4) a field-testing of the 113-item instrument with adults with epilepsy; 4) reliability and factor analyses of the collected survey data resulting in a 65-item instrument.

10 exploratory domains for epilepsy self-management guided the initial development of the 113-item instrument: treatment, symptom, seizure, lifestyle, wellness, safety, information, communication, social support and stigma management. Items were rated on a 5-point Likert scale ranging from 1 to 5 (i.e., none to all of the time, never to always, not at all to completely true), including a “Not Applicable” option. Total scores are found by reverse-coding 9 negatively worded items and by summing the scores to all 113 individual items. Higher scores for the AESMMI-113 and AESMMI-65 suggest more frequent use of self-management strategies (Escoffery et al. 2015a).

The research team field-tested the 113-item instrument among adults with epilepsy, which were recruited from multiple clinical sites and on-line. The team then conducted reliability and factor analyses using the valid surveys (n=422). Following analyses, the number of items for the instrument was reduced from 113 to 65. The Cronbach’s alpha for the resulting 65-item instrument is 0.935 (Escoffery et al., 2015b). The factor analysis grouped the 65 items under 11 discrete factors: 1) healthcare communication, 2) treatment management, 3) coping, 4) social support, 5) seizure tracking, 6) wellness, 7) seizure response, 8) safety, 9) medication adherence, 10) stress management, and 11) proactivity (Escoffery et al., 2015b). Results from the analyses show that the AESMMI-65 has acceptable internal consistency and construct validity. Participants who reported better health status or quality of life were likely to engage more frequently in epilepsy self-management behaviors ($r = .228$, $p < 0.000$ and $r = .314$, $p < 0.000$, respectively). Conversely for discriminant validity, the AESMMI was negatively associated with depression ($r = -.323$, $p = .000$), seizure severity ($r = -.109$, $p = .027$) and seizure problems ($r = -.134$, $p = .006$).

Descriptive Statistics for the Final Factors for the AESMMI-65

Domain	No. of Items	Cronbach’s alpha
Healthcare Communication	14	.904
Treatment Management	11	.877
Coping	10	.868
Social Support	7	.800
Seizure Tracking	3	.868
Wellness	3	.750
Seizure Response	3	.659

Safety	4	.627
Medication Adherence	4	.563
Stress Management	3	.618
Proactivity	3	.517
Total	65	.935

Both versions of the AESMMI are presented here. The AESMMI-65 follows immediately below. The AESMMI-113 is appended to this document.

References

Escoffery, C., Bamps, Y., Thompson, N., LaFrance Jr., W.C., Stoll, S., Shegog, R., Buelow, J., Shafer, P., McGee, R., & Hatfield, K. (2015a). Development of an Epilepsy Self-management Instrument for Adults with Epilepsy. *Epilepsy & Behavior, 50*, 172-183.

Escoffery, C., Bamps, Y., Thompson, N., LaFrance Jr., W.C., Stoll, S., Shegog, R., Buelow, J., Shafer, P., McGee, R., & Hatfield, K. (2015b). Factor Analyses of an Adult Epilepsy Self-Management Measurement Instrument (AESMMI). *Epilepsy & Behavior, 50*, 184-189.

Adult Epilepsy Self-Management Measurement Instrument (65 items)

AESMMI-65

Anchors:

None of the time	A few times	Some of the time	Most of the time	All the time	Not Applicable
Never	Rarely	Sometimes	Often	Always	Not Applicable
Not at all true	Rarely true	Sometimes true	Mostly true	Completely true	Not Applicable
1	2	3	4	5	MISSING DATA

Items in **bold face** are negatively phrased and need to be reverse-coded.

SCALE SCORING: Items are rated on a scale of 1 to 5 (except for those negatively phrased items, where the scale is from 5 to 1). “Not Applicable” choices should be treated as missing values. Higher scores indicate more frequent use of self-management practices.

Item	Factor	Anchors
1 I talk to my health care provider if my seizure medicine affects my emotions or the way I act (feeling depressed, anxious, irritable or edgy)	Healthcare Communication	none of time -all the time
2 I tell my healthcare provider if I have problems with my sleep.	Healthcare Communication	none of time -all the time
3 I tell my health care provider when I think I am having side-effects from my seizure medicine.	Healthcare Communication	none of time -all the time
4 I talk to my health care provider if my seizure medicine causes physical problems (for example, changes in weight, upset stomach, feeling shaky, off-balance, or tired)	Healthcare Communication	none of time -all the time
5 I talk to my health care provider if my seizure medicine affects my memory, my attention and my ability to think.	Healthcare Communication	none of time -all the time

Item	Factor	Anchors
6 I talk with my healthcare provider about the long-term effects of my epilepsy treatment.	Healthcare Communication	none of time -all the time
7 I talk to my health care provider about my emotions.	Healthcare Communication	none of time -all the time
8 I talk about how I take my seizure medicine with my health care provider.	Healthcare Communication	none of time -all the time
9 I keep track of the side-effects of my seizure medicine.	Healthcare Communication	none of time -all the time
10 I talk with my healthcare provider about my sleep habits.	Healthcare Communication	none of time -all the time
11 I set treatment goals with my healthcare provider on how to manage my epilepsy/seizures.	Healthcare Communication	none of time -all the time
12 I stay informed about what treatments I need or are available to me.	Healthcare Communication	none of time -all the time
13 I talk to my health care team if I am too tired or sleepy during the day.	Healthcare Communication	none of time -all the time
14 I call my health care provider if I am having more or different seizures than usual.	Healthcare Communication	none of time -all the time
15 I put off having my seizure medicine refilled.	Treatment	none of time -all the time
16 When my seizure medicine is running out, I spread out the time between doses.	Treatment	none of time -all the time
17 I plan ahead so that I do not run out of my seizure medicine.	Treatment	none of time -all the time
18 When my seizure medicine is running out, I take less medicine each day.	Treatment	none of time -all the time
19 I skip doses of seizure medicine without checking with my healthcare provider.	Treatment	none of time -all the time
20 Before my seizure medicine runs out, I get it refilled.	Treatment	none of time -all the time
21 When my seizure medicine is running out, I stop taking it.	Treatment	none of time -all the time

Item	Factor	Anchors
22 I forget to take doses of my seizure medicine.	Treatment	none of time -all the time
23 I have blood tests or other tests done when ordered by my healthcare provider.	Treatment	none of time -all the time
24 I take my seizure medicine as prescribed even on holidays, birthdays, vacations and other special occasions.	Treatment	none of time -all the time
25 I keep healthcare provider or clinic appointments.	Treatment	none of time -all the time
26 I do things that I enjoy with my family and friends despite my epilepsy/seizures	Coping	none of time -all the time
27 I continue my hobbies or recreation despite my epilepsy/seizures.	Coping	none of time -all the time
28 I do things that I enjoy to help manage stress.	Coping	none of time -all the time
29 I have ways to change my negative thinking.	Coping	none of time -all the time
30 I have healthy ways to solve problems related to my epilepsy/seizures	Coping	none of time -all the time
31 I set long-term goals for my life.	Coping	none of time -all the time
32 I have healthy ways to cope when I am feeling sad or down.	Coping	none of time -all the time
33 I have ways of dealing with physical pain or discomfort so that it does not interfere with the things that I want to do.	Coping	none of time -all the time
34 I have ways to make sure that my fatigue does not interfere with the things that I want to do.	Coping	none of time -all the time
35 I have ways to manage my worries or fear about having another seizure.	Coping	none of time -all the time
36 I get family and friends to help me with the things I need (such as household chores, shopping, cooking, or transportation).	Social Support	none of time -all the time
37 I seek emotional support from family and friends.	Social Support	none of time -all the time

Item	Factor	Anchors
38 I get the help I need with problems at home, work, school, or other community settings.	Social Support	none of time -all the time
39 I have ways to get help if I have a seizure.	Social Support	none of time -all the time
40 I talk with someone about my epilepsy/seizures when I need to.	Social Support	none of time -all the time
41 I talk to my family or my friends about their worries about my epilepsy/seizures.	Social Support	none of time -all the time
42 I tell people who need to know that I have seizures	Social Support	none of time -all the time
43 I keep track of when my seizures occur.	Seizure Tracking	none of time -all the time
44 I keep track of how often I have seizures.	Seizure Tracking	none of time -all the time
45 I keep a record of the types of seizures I have.	Seizure Tracking	none of time -all the time
46 I do things to maintain a healthy weight.	Wellness	none of time -all the time
47 I eat a healthy diet almost every day.	Wellness	never-always
48 I exercise at least half an hour most days of the week.	Wellness	Never-always
49 I teach my family and friends what to do during a seizure.	Seizure Response	none of time -all the time
50 I teach others not to put something in my mouth when I have a seizure.	Seizure Response	none of time -all the time
51 I have seizure drills with my family and friends so that they know what to do when I have a seizure.	Seizure Response	not at all true-completely true
52 I use safety precautions when I cook.	Safety	none of time -all the time
53 I use safety precautions if I take a shower.	Safety	none of time -all the time
54 I climb on high stools, chairs, or ladders when I need to reach something.	Safety	none of time -all the time

Item	Factor	Anchors
55 I take steps to stay safe when I have a seizure.	Safety	none of time -all the time
56 I take my seizure medicine the same way every day.	Medication Adherence	none of time -all the time
57 I take my seizure medicine at about the same time each day.	Medication Adherence	none of time -all the time
58 I take my seizure medicine the way my healthcare provider prescribes it.	Medication Adherence	none of time -all the time
59 I plan my seizure medicine schedule around things that I do every day.	Medication Adherence	none of time -all the time
60 I do things such as relaxation or breathing exercises to keep myself from having seizures or to stop them.	Stress Management	none of time -all the time
61 I use/I have used non-medical techniques in addition to my treatment to keep myself from having seizures.	Stress Management	none of time -all the time
62 I use some techniques (such as relaxation, guided imagery, and self-hypnosis) to manage stress.	Stress Management	none of time -all the time
63 I check with my doctor, nurse or pharmacist before taking other medicines.	Proactivity	none of time -all the time
64 I bring an up-to-date list of all my medicine to healthcare provider's appointments.	Proactivity	none of time -all the time
65 I avoid situations or things that might cause seizures.	Proactivity	none of time -all the time

APPENDIX

Adult Epilepsy Self-Management Measurement Instrument (113 items)

AESMMI-113

Anchor types:

None of the time	A few times	Some of the time	Most of the time	All the time	Not Applicable
Never	Rarely	Sometimes	Often	Always	Not Applicable
Not at all true	Rarely true	Sometimes true	Mostly true	Completely true	Not Applicable
1	2	3	4	5	MISSING DATA

Items in **bold face** are negatively phrased and need to be reverse-coded

SCALE SCORING: Items are rated on a scale of 1 to 5 (except for those negatively phrased items, where the scale is from 5 to 1). “Not Applicable” choices should be treated as missing values. Higher scores represent indicate frequent use of self-management practices.

Item	A Priori Domain	Anchor Type
1 I do the different tasks needed to manage my epilepsy/seizures.	Treatment/medication	none of time -all the time
2 I have healthy ways to solve problems related to my epilepsy/seizures	Treatment/medication	none of time -all the time
3 I work with my healthcare team on plans to manage my epilepsy/seizures.	Treatment/medication	none of time -all the time
4 I have ways to remember things that I have to do.	Treatment/medication	none of time -all the time
5 I keep healthcare provider or clinic appointments.	Treatment/medication	none of time -all the time
6 I have blood tests or other tests done when ordered by my healthcare provider.	Treatment/medication	none of time -all the time

Item	A Priori Domain	Anchor Type
7 I set treatment goals with my healthcare provider on how to manage my epilepsy/seizures.	Treatment/medication	none of time -all the time
8 I talk about my epilepsy treatment (such as medicine, diet, device or surgery) with my health care provider.	Treatment/medication	none of time -all the time
9 I take my seizure medicine the way my healthcare provider prescribes it.	Treatment/medication	none of time -all the time
10 I have a way to remind myself to take my seizure medicine.	Treatment/medication	none of time -all the time
11 I keep track of the side-effects of my seizure medicine.	Treatment/medication	none of time -all the time
12 When my seizure medicine is running out, I take less medicine each day.	Treatment/medication	none of time -all the time
13 When my seizure medicine is running out, I spread out the time between doses.	Treatment/medication	none of time -all the time
14 Before my seizure medicine runs out, I get it refilled.	Treatment/medication	none of time -all the time
15 When my seizure medicine is running out, I stop taking it.	Treatment/medication	none of time -all the time
16 When my medicine is running out, I take more of another seizure medicine.	Treatment/medication	none of time -all the time
17 I take my seizure medicine at about the same time each day.	Treatment/medication	none of time -all the time
18 I forget to take doses of my seizure medicine.	Treatment/medication	none of time -all the time
19 I skip doses of seizure medicine without checking with my healthcare provider.	Treatment/medication	none of time -all the time
20 I bring my seizure medicine with me when I go away from home.	Treatment/medication	none of time -all the time
21 I plan ahead so that I do not run out of my seizure medicine.	Treatment/medication	none of time -all the time
22 I put off having my seizure medicine refilled.	Treatment/medication	none of time -all the time
23 I check with my doctor, nurse or pharmacist before taking other medicines.	Treatment/medication	none of time -all the time
24 I take my seizure medicine the same way every day.	Treatment/medication	none of time -all the time
25 I take my seizure medicine as prescribed even on holidays, birthdays, vacations and other special occasions.	Treatment/medication	none of time -all the time
26 I do what my healthcare provider instructs me to do when I miss a dose of my seizure medicine.	Treatment/medication	none of time -all the time
27 I keep track of how often I have seizures.	Seizure	none of time -all the time
28 I keep track of when my seizures occur.	Seizure	none of time -all the time
29 I keep a record of the types of seizures I have.	Seizure	none of time -all the time

Item	A Priori Domain	Anchor Type
30 I recognize situations that might cause seizures.	Seizure	none of time -all the time
31 I avoid situations or things that might cause seizures.	Seizure	none of time -all the time
32 I use/I have used non-medical techniques in addition to my treatment to keep myself from having seizures.	Seizure	none of time -all the time
33 I do things such as relaxation or breathing exercises to keep myself from having seizures or to stop them.	Seizure	none of time -all the time
34 I call my health care provider if I am having more or different seizures than usual.	Seizure	none of time -all the time
35 I tell my health care provider when I think I am having side-effects from my seizure medicine.	Symptom	none of time -all the time
36 I tell my health care provider when I think I am having side-effects from my seizure treatment (such a VNS device or diet).	Symptom	none of time -all the time
37 I talk to my health care team if I am too tired or sleepy during the day.	Symptom	none of time -all the time
38 I talk to my health care provider if my seizure medicine causes physical problems (for example, changes in weight, upset stomach, feeling shaky, off-balance, or tired)	Symptom	none of time -all the time
39 I talk to my health care provider if my seizure medicine affects my emotions or the way I act (feeling depressed, anxious, irritable or edgy)	Symptom	none of time -all the time
40 I talk to my health care provider if my seizure medicine affects my memory, my attention and my ability to think.	Symptom	none of time -all the time
41 I tell my healthcare provider if I have problems with my sleep.	Symptom	none of time -all the time
42 I stay informed about what treatments I need or are available to me.	Information	none of time -all the time
43 I keep up-to-date on information to help me manage my epilepsy/seizures.	Information	none of time -all the time
44 I use the correct name(s) for my seizure type(s).	Information	none of time -all the time
45 I can describe accurately my seizures.	Information	none of time -all the time
46 I talk with my health care provider about how alcohol affects my seizure control.	Information	none of time -all the time
47 I talk with my health care provider about how smoking affects my seizure control.	Information	none of time -all the time
48 I talk with my health care provider about how illicit or recreational drug use affects my seizure control.	Information	none of time -all the time

Item	A Priori Domain	Anchor Type
49 I can name my seizure medicine.	Information	none of time -all the time
50 I bring an up-to-date list of all my medicine to healthcare provider's appointments.	Information	none of time -all the time
51 I take steps to stay safe when I have a seizure.	Safety	none of time -all the time
52 I go swimming alone.	Safety	none of time -all the time
53 I wear or carry information stating that I have epilepsy or seizures.	Safety	none of time -all the time
54 I take showers instead of baths.	Safety	none of time -all the time
55 I wear head protection (such as a helmet) when I play sports such as riding a bike, skating or skiing.	Safety	none of time -all the time
56 I carry a cell phone with me to call someone if I need help.	Safety	none of time -all the time
57 I keep the water temperature in my home low enough so that it would not burn me if I have a seizure in the shower.	Safety	none of time -all the time
58 I don't keep open flames or lighted material (such as candles, space heaters, cigarettes) when I am alone.	Safety	none of time -all the time
59 I use an iron with automatic shut off.	Safety	none of time -all the time
60 I climb on high stools, chairs, or ladders when I need to reach something.	Safety	none of time -all the time
61 I lie down or sit down when I know that I am going to have a seizure.	Safety	none of time -all the time
62 I keep the bathroom door unlocked at home when I am using it.	Safety	none of time -all the time
63 I keep a lid over my cup when I drink a hot liquid.	Safety	none of time -all the time
64 I use power tools such as electric saws, hedge trimmers, or knives, with an automatic shut off.	Safety	none of time -all the time
65 I use safety precautions if I take a shower.	Safety	none of time -all the time
66 I avoid having glass furniture in my home.	Safety	not at all true-completely true
67 I use safety precautions when I cook.	Safety	none of time -all the time
68 I have carpet or rugs with thick padding on the floor where I live.	Safety	not at all true-completely true
69 I have padding on the sharp edges of the furniture in my home	Safety	not at all true-completely true

Item	A Priori Domain	Anchor Type
70 I make sure that my space heater is secure when I use it.	Safety	none of time -all the time
71 I have seizure drills with my family and friends so that they know what to do when I have a seizure.	Safety	not at all true-completely true
72 I talk about how I take my seizure medicine with my health care provider.	Communication	none of time -all the time
73 I talk to my health care provider about my emotions.	Communication	none of time -all the time
74 I talk with my healthcare provider about the long-term effects of my epilepsy treatment.	Communication	none of time -all the time
75 I talk with my healthcare provider about my sleep habits.	Communication	none of time -all the time
76 I have ways to get help if I have a seizure.	Communication	none of time -all the time
77 I teach others not to put something in my mouth when I have a seizure.	Communication	none of time -all the time
78 I teach my family and friends what to do during a seizure.	Communication	none of time -all the time
79 I set long-term goals for my life.	Lifestyle	none of time -all the time
80 I arrange for transportation to get to my appointments.	Lifestyle	none of time -all the time
81 I plan my seizure medicine schedule around things that I do every day.	Lifestyle	none of time -all the time
82 I can take my seizure medicine when I am away from home.	Lifestyle	none of time -all the time
83 I do things that I enjoy to help manage stress.	Lifestyle	none of time -all the time
84 I keep from being discouraged when nothing I do seems to make a difference.	Lifestyle	none of time -all the time
85 I do things that I enjoy with my family and friends despite my epilepsy/seizures	Lifestyle	none of time -all the time
86 I use some techniques (such as relaxation, guided imagery, and self-hypnosis) to manage stress.	Lifestyle	none of time -all the time
87 I have healthy ways to cope when I am feeling sad or down.	Lifestyle	none of time -all the time
88 I have ways to manage my worries or fear about having another seizure.	Lifestyle	none of time -all the time
89 I have ways to make sure that my fatigue does not interfere with the things that I want to do.	Lifestyle	none of time -all the time

Item	A Priori Domain	Anchor Type
90 I have ways of dealing with physical pain or discomfort so that it does not interfere with the things that I want to do.	Lifestyle	none of time -all the time
91 I avoid eating foods that interfere with my medicines.	Lifestyle	none of time -all the time
92 I continue my hobbies or recreation despite my epilepsy/seizures.	Lifestyle	none of time -all the time
93 I have ways to change my negative thinking.	Lifestyle	none of time -all the time
94 I seek emotional support from family and friends.	Social Support	none of time -all the time
95 I talk to my family or my friends about their worries about my epilepsy/seizures.	Social Support	none of time -all the time
96 I talk with other people (in person, on-line) who have epilepsy/seizures.	Social Support	none of time -all the time
97 I seek support from other people with epilepsy (for example on-line or in support groups) when needed.	Social Support	none of time -all the time
98 I get family and friends to help me with the things I need (such as household chores, shopping, cooking, or transportation).	Social Support	none of time -all the time
99 I get the help I need with problems at home, work, school, or other community settings.	Social Support	none of time -all the time
100 I have ways to take my seizure medicine on schedule even around people who do not know that I have seizures.	Stigma	none of time -all the time
101 I tell people who need to know that I have seizures	Stigma	none of time -all the time
102 I talk with someone about my epilepsy/seizures when I need to.	Stigma	none of time -all the time
103 I have ways to deal with other people's reactions if I have a seizure in public.	Stigma	none of time -all the time
104 I make sure I get enough sleep.	Wellness	none of time -all the time
105 I go to bed and wake up at about the same time every day.	Wellness	never-always
106 I eat a healthy diet almost every day.	Wellness	never-always
107 I do things to maintain a healthy weight.	Wellness	none of time -all the time
108 I exercise at least half an hour most days of the week.	Wellness	never-always
109 I skip meals.	Wellness	none of time -all the time
110 I drink more alcohol than I should.	Wellness	none of time -all the time

Item	A Priori Domain	Anchor Type
111 I follow my healthcare provider's recommendations about drinking alcohol.	Wellness	none of time -all the time
112 I follow my healthcare provider's recommendations about smoking.	Wellness	none of time -all the time
113 I follow my healthcare provider's recommendations about illicit or recreational drug use.	Wellness	none of time -all the time