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## **A Resource to Guide Clinicians for Patients with Severe Mental Illness and Anosognosia: Anosognosia Mental Illness Screening and intervention Strategies (AMISS) Toolkit ©**

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A Resource to Guide Clinicians for Patients with Severe Mental Illness and Anosognosia:

*Anosognosia Mental Illness Screening and intervention Strategies (AMISS) Toolkit ©*

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### Abstract

**Background:** An alarming percentage of individuals with severe mental illness *lack insight* or awareness of their disorders, a symptom known as anosognosia. Due to the obscurity of the symptom of anosognosia, clinicians may misinterpret patients' thoughts about their diagnosis as being *in denial* rather than an extension of their disorder, a *lack of insight*. Misidentifying or inappropriately addressing this key symptom can lead to poor mental health and psychosocial outcomes. **Purpose:** The aim of this Integrative Review (IR) was to garner the best evidence to develop a Toolkit and a presentation to educate clinicians about anosognosia in mental illness, including screening tools for the symptom, and interventions for practice. **Methods:** A multi-tier IR of the literature was completed to include systematic reviews, highly graded investigations, and expert opinions. A secondary search on Google was used to find public, governmental, commercial, and academic resources. **Results:** Highly rated evidence was used to create the *Anosognosia, Mental Illness Screening & intervention Strategies (AMISS) Toolkit*<sup>®</sup>, including a Practice Algorithm<sup>®</sup>, two screening tools, two therapeutic modalities, and additional resources. The oral presentation about Anosognosia and the contents of the AMISS Toolkit significantly increased the awareness and knowledge of the clinicians in regard to screening and intervening for anosognosia in their patients with serious mental illness who *lack insight* into their disorders. With their feedback, the AMISS Toolkit was modified, and an electronic version was left as a sustainable *At-A-Glance* resource. **Conclusion:** A Toolkit (with presentation) is an ideal way to educate clinicians about a disorder and to share resources. The AMISS Toolkit can serve as a resource for clinicians who are not experts in complex mental health disorders of their patients.

Key Search Terms: *anosognosia, denial of mental health, denial, lack of insight, insight to mental illness, unawareness of mental illness, barrier in mental health, barrier to adherence in mental health, barrier to treatment in mental health*

## Introduction

An alarming percentage of individuals with severe mental illness lack insight or awareness of their disorders. Poor *insight into one's own mental illness* is a common symptom in mental illness, predictive of non-compliance, and an impediment to effective patient management (Gharahbawi, Lasser, Bossie, Zhu, & Amador, 2006). This lack of insight, when not a coping strategy, is a symptom known as *anosognosia* (American Psychiatric Association (APA), 2013). The APA's *Diagnostic and Statistical Manual of Mental Disorders-5<sup>th</sup> Edition* reports anosognosia as being the most common predictor of non-adherence to treatment, poorer psychosocial functioning, aggression, and poorer course of illness (APA, 2013, p.101). The inconspicuousness of the symptom can make it difficult for untrained clinicians to identify the symptom and to appropriately create an effective treatment plan for the affected population.

## Background

Developing a profound understanding of anosognosia can help clinicians across many clinical settings to identify points of resistance to treatment among patients, as well as to provide opportunities to introduce effective intervention geared toward improving compliance and adherence to effective treatment regimens for these patients (William et al., 2015). The misinterpretation of the patient's "denial" of illness in clinical practice is a common occurrence. The terms "denial" and "lack of insight" are often used interchangeably but may have quite different meanings depending on the clinical context (William, Olfson, & Galanter, 2015). Clinicians often assume noncompliance is a psychological process termed "denial"; a choice made by patient's exercise of their own free will. The definition of denial has been understood as a psychological defense that can, under the right circumstances, be protective and normative

(William et al., 2015). However, the dysfunction of the neural circuitry implicated in anosognosia can significantly overshadow the psychological defense of denial.

Nonvolitional impairment of “insight”, driven by dysregulation of self-appraisal, error monitoring, and of executive function, are the common responses of patients and sources of frustration experienced by clinicians when attempting to treat patients with mental illness (William et al., 2015). Patients with anosognosia are seen in clinic, given diagnosis of mental illness, and then given a treatment plan that they will never follow. Many unaware clinicians view this action as a denial of treatment, or carrying out freewill of poor judgement making, whereas, in fact, the patient may be anosognosic. This phenomenon can become an obstacle to appropriate care, which extends into the psychosocial realm of the patients’ lives (William, Olfson, & Galanter, 2015). In extreme cases of anosognosia, the disease can cause patients to create scenarios where they would place themselves or others at risk. Clinical, administrative, and legal concerns arise when anosognosia is not properly addressed in practice. The National Alliance on Mental Illness states:

“...anosognosia affects 50% of people with schizophrenia, and 40% of people with bipolar disorder. It can also accompany illnesses such as major depression with psychotic features. Treating these mental health conditions is much more complicated if lack of insight is one of the symptoms. People with anosognosia are placed at increased risk of homelessness or arrest. Learning to understand anosognosia and its risks can improve the odds of helping people with this difficult symptom.” (“National Alliance on Mental Illness,” 2019, para. 7)

The National Institute of Mental Health (NIMH) reports the financial costs associated with schizophrenia are disproportionately high relative to other chronic mental and physical

health conditions, reflecting both “direct” costs of healthcare as well as “indirect” costs of lost productivity, criminal justice involvement, social service needs, and other factors beyond healthcare (NIMH, 2018).

### **Problem Statement**

Due to the obscurity of the symptom of anosognosia in mental illness, clinicians may misinterpret patients’ thought content as being *in denial* rather than an extension of their disorder. Misidentifying and not appropriately addressing this key symptom can lead to poor psychosocial outcomes and a poor course of illness for the patients. Psychosocial dysfunction may be the only tell-tale sign, which makes the symptom more difficult to identify in a clinical setting. Lack of identification of this psychosocial dysfunction is exacerbated by the lack of awareness and knowledge about anosognosia of clinicians (RNs, NPs, SWs, CNSs, and MDs) in the healthcare community who are not equipped to screen and treat these patients.

### **Organizational Gap Analysis of Project Site**

Through discussion with staff, including the medical director of the Program of All-Inclusive Care for the Elderly (PACE) and Chief Behavioral Officer of East Boston Neighborhood Health Center (EBNHC), it was noted that not all the clinicians were familiar with anosognosia. Upon further discussion, the clinicians could identify past cases where patients might have been identified positive for the symptom and acknowledged their difficulties with these cases. There were no standing policies or procedures in place to screen or manage a patient with anosognosia at the facility at that time. All clinicians showed interest in learning more about this symptom and strategies to improve practice. This discussion pressed upon the impression that there was an opportunity for educational growth in the practice, and clinicians were receptive to learning more about the symptom.



## Review of Literature

A multi-tier integrative literature review was completed to find scholarly articles defining anosognosia, evidence-based screening tools, and evidence-based interventions, to create the AMISS Toolkit as well as a presentation for an educational intervention. A secondary search on Google was completed to find public, governmental, commercial and scholarly resources for patients, family members, and clinicians. The literature search was completed on the University of Massachusetts (UMass) online library using the Silk Library and Google Scholar. Articles from around the world that were written in English from 1993 to 2017 were included, given that the *Scale to Assess Unawareness of Mental Disorder (SUMD)* dates to a landmark study by Amador and his colleagues in 1993. The studies were evaluated for strength of research evidence using the Johns Hopkins Nursing Evidence-Based Practice (JHNEBP) Scale (Newhouse, Dearholt, Poe, Pugh, & White, 2005). A multi-tier approach was used to refine the individual search items needed to build the practice algorithm. The nursing process was the ideology used to subdivide the tiered search and in creating the practice algorithm.

### Method– Integrative Review: First Tier

The integrative literature review was completed using the online library for an in-depth assessment for anosognosia. The first medical subject headings (MeSH) terms used were *anosognosia*, *anosognosia and mental illness*, *anosognosia and schizophrenia*, *lack of insight and mental illness*, *lack of awareness and mental illness*, and *competence and mental illness*. A systematic review of literature found 36 articles. Only articles focusing solely on the topic of anosognosia in mental illness were included, resulting in seven articles meeting all the criteria. Two of the articles chosen were discussions, three were clinical trials, and two were systematic

reviews. The articles were analyzed with the JHNEBP scale to assess anosognosia as a barrier to good outcomes in mental health.

### **Results– Integrative Review: First Tier**

Lehrer and Lorenz (2014) found neurobiological and neurocognitive evidence to link the phenomenon of anosognosia to core pathophysiology of schizophrenia to explain insight deficits [Level-I grade-A]. Poor insight is a core attribute of schizophrenia, occurring in 57 to 98 percent of patients (Lehrer & Lorenz, 2014). Insight is an important outcome predictor, associated with treatment adherence, relapse frequency, symptom remission, psychosocial functioning, vocational attainment, and risk of violence toward self or others. Understanding anosognosia leads to urgency and importance of reducing psychotic relapse but this can only be achieved in most patients with consistent medication adherence which something that is often exceedingly difficult in patients lacking belief in the fact of their illness. Limited research in the field gives cause for hope that anosognosia as a symptom of schizophrenia will become a critically important therapeutic target that is amendable to treatment.

Two articles were expert opinions, Level-V Grade-A research, both authors showed great understanding and expertise in the subject but had no scientific underpinnings or references in their articles. Williams (2015) writes an expert opinion paper that implores that insight can be assessed by shared decision making and motivational interviewing. Williams and team continue on to explain that these techniques may clarify the patient's decision making and can help in addressing specific barriers that can likely increase treatment adherence. A critical appraisal by Reddy (2016) offers clinicians a way forward by integrating various phenomenological, neurobiological, and socio-cultural findings in patient assessment. Reddy and team state that the

phrase “lack of insight” is too narrow to encompass the ethical, clinical, and medicolegal aspects, and encourage clinicians to understand the complexity of the concept of lack of insight.

A randomized control trial (RCT) by Amador and team (1994) found decreased insight to be strongly correlated with poorer course of illness, impoverished psychosocial functioning, and noncompliance with treatment [Level-I grade-A]. A Level-1 Grade-A systematic review by Lincoln, Lullmann, and Rief (2007) found that poor insight is connected to poor treatment adherence. Lincoln and colleagues also found that high insight in schizophrenia was associated with depression and hopelessness but found no evidence suggesting that high insight would lead to adherence during treatment (Lincoln, Lullmann, & Rief, 2007). Lincoln and colleagues (2007) recommended further research in this area. A systematic review by Velligan and team (2017) compiled seven articles on anosognosia and found that there is a strong correlation between poor insight and competence [Level-I Grade-A]. Of those articles analyzed, 55.6% identify insight as the reason for non-adherence to antipsychotic medication (Velligan, Sajatovic, Hatch, Kramata, & Docherty, 2017).

### **Method- Integrative Review: Second Tier**

The second-tier integrative literature review was completed using the UMass online library for an assessment tool for patients with anosognosia. The first MeSH terms used were *Scale to Assess Unawareness in Mental Disorder (SUMD)*, *SUMD*, *SUMD and short version*, *SUMD and long version*, *insight questionnaire*, *SUMD and systematic review*, populating 14 articles. Nine of them were excluded for non-relevance, four were RCT on SUMD, and the other a systematic review on SUMD. Two articles were RCT for Beck Cognitive Insight Scale (BCIS).

**Results- Integrative Results: Second Tier**

Four articles were research studies and one was a systematic review, all Level-I Grade-A research per JHNEBP. In 1993, Amador and team, created the multidimensional SUMD, which samples discrete and global aspects of insight across a variety of manifestation of illness with 74 items (Michel et al., 2013; Amador et al., 1993). The length of the screening tool made it impractical for practice due to its length although it had good reliability and validity. In 2013, Michel et al. developed an abbreviated version of the SUMD which appeared to also have reliability and validity according to the research article (Michel et al., 2013). A systematic review of all studies from 1993 to 2013 that used all forms of the SUMD, by Dumas et al. (2013), found that abbreviated SUMD may compromise the psychometric proprieties of the scale and lead to erroneous conclusions. Dumas' systematic review recommended the need to standardize the use of SUMD.

**Method- Integrative review: Third Tier**

From the first search, it was happenstance to come across a secondary assessment tool for insight entitled Self Appraisal of Illness Questionnaire (SAIQ) which was shorter and self-administered. A second-tier integrative literature review was completed using the UMass online library to assess its reliability and validity. The first MeSH terms used were *SAIQ and insight and reliability and validity*. All articles were from 2014 to 2019, in English, and from all over the world. Only full articles were included, reducing the results to 4 articles. Duplicates were excluded and only RCTs were included. The studies were evaluated for strength of research evidence using the JHNEBP Scale. Three articles were analyzed.

**Results– Integrative review: Third Tier**

A Level-I Grade-A study by Kriscinda and team found that subscales in SAIQ are valid when compared with researcher-rated insight scales and neuropsychological tests (Kriscinda, Fastenau, Lysaker, & Bond, 2000). Results indicate that the Need for Treatment and Presence/Outcome subscales are significantly correlated with both researcher-rated insight scales and with neuropsychological tests of executive functioning. Their research concluded that the Need for Treatment and Presence/Outcome subscales may be used in combination as a brief screening instrument for clients with schizophrenia receiving outpatient psychiatric treatment who may be at risk for treatment non-compliance due to a lack of insight into illness (Kriscinda et al., 2000). Kao (2010) indicated that the three subscales of the SAIQ and its total score were significantly associated with both the research-rated insight scale and psychopathology and mood state. Kao's culture-specific study shows that the Taiwanese version of the SAIQ is a simple and reliable scale for use (Kao & Lui, 2010). Jovanovski and team argue that the scale does have validity, but the order of use is important. The scale is self-administered and must be administered prior to a clinician administered scale or it will diminish its validity (Jovanovski, Zakzanis, Atia, Cambell, & Young, 2007).

**Method– Integrative review: Fourth Tier**

The Fourth-tier integrative literature review was completed using the UMass online library for interventions and evidence-based treatments for patients with mental illness and anosognosia. The first MeSH terms used were *motivational interview and insight and mental illness*, and *cognitive behavioral therapy and anosognosia*. The first search populated 17 articles, of which 3 were chosen and the rest were excluded due to non-relevance, duplicates, or the language not being English. The second search led to 92 articles. The search was limited to the

first 3 pages, 2 RCT articles and one systematic review were chosen, and the rest were excluded due to non-relevance, duplicates or the language not being English. The studies were evaluated for strength of research evidence using the JHNEBP scale.

### **Results– Integrative review: Fourth Tier**

Three Level-I Grade-A RCT articles were analyzed for motivational interviewing and insight. Ertem & Duman (2019) examined the effects of motivational interview (MI) on treatment adherence and insight of the patients diagnosed with schizophrenia at a hospital in Turkey and found both the psychiatric patients and the health institutions can benefit from increased levels of treatment adherence and insight by the adoption of the MI methods starting with a patient's first registration to a psychiatric outpatient clinic. An RCT by Chien and colleagues (2016) found statistical significance that a adherence therapy/motivational interviewing group reported significantly greater improvements in symptom severity (0.003), insight into illness/treatment (0.001), functioning (0.005), duration of re-hospitalizations (0.005), and medication adherence (0.005) over 18 months of follow-up, when compared with usual care alone. MI-based adherence therapy can be an effective approach to treatment for people with early stages of schizophrenia who poorly adhere to medication regimen (Chien, Mui, Gray, & Cheung, 2016). Dikec and Kutlu (2016) found adherence therapy/MI is effective in improving adherence to treatment but not in increasing insight and internalized stigma in patients with schizophrenia (Dikec & Kutlu, 2016).

Two Level-I Grade-A RCT articles on cognitive-behavioral therapy (CBT) were analyzed. Guo and team (2017) found that of 220 patients with schizophrenia from four districts of Beijing who were randomly assigned to either brief CBT plus treatment as usual (TAU) or TAU alone, at 6- and 12-month follow-ups by raters masked to group, found that patients who

received brief CBT showed greater improvement in overall symptoms, general psychopathology, insight and social functioning. In total, 37.3% of those in the brief CBT plus TAU group experienced a clinically significant response, compared with only 19.1% of those in the TAU alone group ( $p = 0.003$ ) (Guo et al., 2017). An RCT by Malik (2009) found that brief CBT had beneficial effects on relapse and rehospitalization when delivered by mental-health nurse to community-based patients with schizophrenia and the benefits were maintained at 24-month follow-up (Malik, Kingdon, Pelton, Mehta, & Turkington, 2009). Occupational recovery is not improved by brief CBT (Malik et al., 2009).

A systematic review by Newton-Howes and Woods (2013) analyzed nine RCTs on the topic and finds that theoretically based CBT therapies, although proving effective, may not outperform more accessible and simpler forms of therapy for patients with schizophrenia in reducing psychopathology (Newton-Howes & Wood, 2013).

#### **Method- Integrative review: Fifth Tier**

The Fifth-tier integrative literature review was completed using the UMass online library for interventions and evidence-based treatments for patients with mental illness and anosognosia. The first MeSH terms used were *PACT and schizophrenia* and yielded 12 articles, 10 of which were excluded for non-relevance, one was an RCT, and the last one a systematic review of the Program for Assertive Community Treatment (PACT). Lastly, *power of attorney and legal insanity* yielded 4 articles, 3 of which were excluded due to non-relevance to the subject. The studies were evaluated for strength of research evidence using the JHNEBP scale.

#### **Results– Integrative review: Fifth Tier**

Luo et al.'s (2018) Level-I grade-A research share an RCT of assertive community treatment in mainland China. They reported statistically significant differences between the

assertive community treatment group and the control group with less admissions, less relapses, and shorter duration of relapses, and increased employment in the assertive community treatment group. The systematic review by Firn and team showed much evidence in favor of PACT from studies conducted in the United States [Level-I Grade-A](Firn, 2018); these results were however not replicated in Europe. RCTs in the United Kingdom and the Netherlands failed to show a reduction in bed use. A likely explanation for this difference is the increasingly marginal gap between the quality of care and treatment in the control and intervention groups (Firn, Alonso-Vincente, & Hubbling, 2018).

One article was found for the legal representation in a Level-V Grade-A research. The UK passed the Mental Capacity Act in 2005, providing a variety of legal mechanisms for people to plan for periods of incapacity for decisions relating to personal care, medical treatment, and financial matters (Bartlett, Mudigonda, Chopra, Morris, & Jones, 2016). “For many persons with disabilities, the ability to plan is an important form of support, whereby they can state their will and preferences which should be followed at a time when they may not be in a position to communicate their wishes to others. All persons with disabilities have the right to engage in advance planning and should be given the opportunity to do so on an equal basis with others. States parties can provide various forms of advance planning mechanisms to accommodate various preferences, but all the options should be non-discriminatory. Support should be provided to a person, where desired, to complete an advance planning process” (United Nations Committee on the Right of Persons with Disabilities, 2013, para 17). Ruissen (2012) terms incompetence as not being able to meet the legal requirement for informed consent.



### **Method– Google Search**

A Google search was done with the search term *anosognosia* leading to 303,000 web results. Only websites that had reliable information and credible sources were included in the Toolkit. Websites included were evaluated for the following information: provider and purpose, funding, information quality, privacy, and design. Inclusion criteria was being in the first 10 pages of the search and having been published within the past 5 years.

### **Results– Google Search**

The TEDx (<https://www.youtube.com/watch?v=NXxytf6kfPM>) by Xavier Amador on the topic of anosognosia will be included in the Toolkit. TED/TEDx is a nonprofit company devoted to spreading ideas, usually in the form of short, powerful talks (18 minutes or less). TED employs curators as well as fact-checkers and topic-specific advisors. Before a speaker is invited to the TED stage, they strive to ensure that their work has been publicly accepted as credible and that their talk accurately reflects current knowledge in their respective fields. TED and TEDx are platforms for showcasing and explaining genuine advances in science that are backed by research. The TEDx talk by Dr. Amador was chosen for illustration of the symptom of anosognosia who a leading psychotherapist on the topic is.

The article by Rachel Aviv in the New Yorker, *Denying a Diagnosis*, will also be displayed via hyperlink in the Toolkit (<https://www.newyorker.com/magazine/2011/05/30/god-knows-where-i-am>). *The New Yorker* works on advertisements and subscriptions from customer, but is renowned for its in-depth reporting, political and cultural commentary, fiction, poetry, and humor. *The New Yorker* stands apart for its commitment to truth and accuracy. The article was chosen mainly to paint an illustrative picture to the symptom of anosognosia and not for scientific underpinnings. The article serves as a case study for clinicians.

The webpage PDF for mental health advance directives will be included in the Toolkit. The webpage is run by Substance Abuse and Mental Health Services Administration (SAMHSA), which is a government funded agency ([https://www.samhsa.gov/sites/default/files/a\\_practical\\_guide\\_to\\_psychiatric\\_advance\\_directive\\_s.pdf](https://www.samhsa.gov/sites/default/files/a_practical_guide_to_psychiatric_advance_directive_s.pdf)). The link to the website leads to a PDF that states the purpose of the document clearly on the first page. The purpose of the document is clearly stated in the title: “A Practical Guide to Psychiatric Advance Directives”.

WebMD’s website on anosognosia (<https://www.webmd.com/schizophrenia/what-is-anosognosia#1>) will be included in the toolbox. The website’s objective is to inform the public on topics of disease and health, which includes the topic of anosognosia. The webpage is sponsored by advertisement that is disclosed along with the advertisement policy. The WebMD content staff blends award-winning expertise in medicine, journalism, health communication, and content creation, to bring the best health information possible. MedicineNet.com Medical Editorial Board members are frequent contributors to WebMD. The information on this page is timely, credible, and reputable, and will serve as a good point of reference for education for clinicians to share with patients and families.

The National Alliance on Mental Illness (NAMI) website (<https://www.nami.org/learn-more/mental-health-conditions/related-conditions/anosognosia>) will be included in the Toolkit. The website’s objective is to inform the public on topics regarding public health of anosognosia and other mental health disorder. The webpage is a registered 501(c)(3) non-profit organization (EIN: 43-1201653), and it is listed on their webpage how they obtain the finances through clearly listed donations and grants. There were no prompts for personal information to be given. The design of the website seems official yet welcoming. It is in English and at a 6<sup>th</sup> grade level.

The Treatment Advocacy Center will also be included in the Toolkit (<https://www.treatmentadvocacycenter.org/key-issues/anosognosia>). The webpage is a national nonprofit organization dedicated to eliminating barriers to the timely and effective treatment of severe mental illness. The website is funded by a host of individual donors, foundations, and grants. The Treatment Advocacy Center does not accept funding from companies or entities involved in the sale, marketing, or distribution of pharmaceutical products. The website did not ask for personal information. The design was professional, and the wording was at a 12<sup>th</sup> grade level.

The web link for the LEAP Foundation (<https://lfrp.org>) was also included in the Toolkit. The LEAP Foundation clearly states in their mission statement that they are a foundation for Research to Practice and are a non-profit (c)(3) dedicated to serving family caregiver of person with serious mental illness (SMI) and addiction, mental healthcare professionals, criminal justice professionals, and others involved in the care, recovery, and safety of persons suffering from these disorders. The Foundation's primary mission is to educate about the unmet needs of persons with mental illness and addiction who have anosognosia. The website offers educational courses – online and in-person – which would be beneficial for clinicians and families. The LEAP Foundation provides science-based education and training and other support to organizations and individuals wishing to learn about these disorders, anosognosia, and the LEAP program. Training and certifying LEAP trainers is among their top priorities. The website did not ask for personal information. The design was professional, and the wording was at a 12<sup>th</sup> grade level.

The BECK Institute cognitive behavioral therapy webpage was included in the Toolkit as well (<https://beckinstitute.org/workshop/ct-r-for-schizophrenia-and-serious-mental-health->

[conditions/](#)). Although the BECK Institute does not disclose whether it is for-profit or non-profit, the Beck Institute for Cognitive Behavior Therapy has scientific underpinnings and validity. The institute was founded in 1994 by Dr. Aaron Beck and his daughter, Dr. Judith Beck, both psychotherapists providing training in CBT to health and mental health professionals worldwide. The website did not ask for personal information. The design was professional, and the wording was a 12<sup>th</sup> grade level.

### **Evidence-Based Practice (EBP): Verification of Chosen Option**

An Integrative Review (IR), development of the *Anosognosia, Mental Illness Screening & intervention Strategies (AMISS) Toolkit<sup>®</sup>*, and Power Point presentation (PPT) of the Toolkit was the EBP intervention chosen for this DNP capstone project. Imbedded within the AMISS Toolkit, is the definition of anosognosia, EBP screening tools, links to evidence-based courses, links to educational resources, and a guide for practice (Appendix A) that was created by the DNP student. The Toolkit is an educational intervention aimed to expand the repertoire and clinical resources of clinicians and is intended to support them in clinical practice to better navigate the complexities of a patient with mental illness and the anosognosia. The EBP screening assessment tools in the kit were cataloged and are available in the Appendix of the Toolkit with copyright permission from the authors. Live links within the document were enabled for clinicians to access all resources within the Toolkit via the internet.

### **Theoretical Framework / Evidence-Based Practice Model**

The Dick and Carey Model is an instructional systems design (ISD) model taking a systems approach and based on the computer assisted instruction research of Walter Dick of Florida State University and Lou and James Carey of the University of South Florida. The Dick and Carey Model was chosen for this project because of the numerous complexities between the individual

components of the instructor, learners, materials, instructional activities, delivery system, and learning and performance environments, as well as how these components intersect and interact with each other in trying to achieve the desired instructional effect (Pappas, 2015; Dick, Carey & Carey, 1996). All these vital components are addressed in Dick and Carey's (1996) Model within a 9-step approach to Instructional Design.

The first step was to identify the goals and objectives as outlined by Dick and Carey. The learner must be aware of what they will be able to do once they review the AMISS Toolkit and presentation, and of the skills they will develop and the knowledge they will acquire after the educational intervention. The Toolkit included real-world applications so the clinicians are aware of how the AMISS Toolkit will benefit them outside the virtual learning space.

The second step of Dick and Carey's Model is to complete an instructional analysis. This is done to determine where the learner's baseline knowledge stands. Once that was understood, it was used to develop a plan to fill the learning gap. This was done through informal assessments and interviews that focus on the clinician's current skill sets and knowledge base.

The third step was to determine entry behaviors and learner characteristics. This step was already known as the demographics for the Toolkit were aimed at clinicians from PACE. The site for this capstone project was in the organization of East Boston Neighborhood Health Center (EBNHC), with the members of the Neighborhood PACE program. EBNHC is a community health center that provides services such as primary care, obstetric, pediatric care, urgent care, and mental health services. The population that received the educational intervention was the EBNHC clinicians who volunteered their time to attend the educational session. The clinicians were from an interdisciplinary team, which included social workers, nurses, medicine, and

administrative staff. These clinicians are all individual with college degrees and baseline to expert knowledge on medical conditions.

Once the needs of the clinicians were understood, step four was used to transform their needs and goals to clear-cut goals, objectives, and outcomes. The goals, objectives, and expected outcomes also included the specific conditions in which the task or skill should have been achieved.

Step five included developing a survey that involved finding the ideal assessment type for the intended audience. Dick, Carey & Carey (1996) recommend multiple-choice questions or interactive scenarios. For the presentation and Toolkit, 3-item questionnaire using a 5-point Likert scale, were created to meet step five of this process. A question-and-answer (Q&A) session also provided some informal and qualitative feedback post-educational intervention.

Step six included the development of the instructional strategy. The nursing process was the basis ideology for the IR, multi-tiered search, and development of the toolkit and algorithm.

Step seven of the process was choosing learning materials and online activities. This was the lengthiest portion of the project which included the multi-tier IR finding the learning materials, tools, and online exercises that serve the learning goals and objectives. This step also involved the content creation of the practice algorithm and hyperlink embedded AMISS Toolkit as instructional aids. To facilitate a fully future online learning experience, a one-time live presentation was recorded to be able to reach a wider audience in the future.

Step eight included the carryout of a formative evaluation, which took place even before unveiling the AMISS Toolkit to the public. It involved a focus group for the release of beta versions that help to iron out any issues prior to formal deployment. The rough draft was sent out

to peer student reviewers for feedback, which helped to identify weak areas in the AMISS Toolkit and allowed time to fix them and ensure that every element was as effective as possible.

The last step was to carry out summative evaluation to assess whether the presentation of the AMISS Toolkit course achieves the desired outcome. This was determined through learner pre- and post-assessments, at the beginning and the end of the lesson.

Applying the Dick and Carey Model as the corner stone of this DNP Capstone helped to overcome the challenge of meeting the learner's needs. Once the initial data from the formal session was gathered, it was used to improve upon the educational material, while keeping in mind that educational intervention should be adaptable and evolve with the needs of the learners. If something is not working effectively, then per the recommendations of Dick and Carey's Model, one should not be hesitant to make changes when necessary to achieve the goals one has set out to achieve.

### **Ethical Considerations/Protection of Human Subjects**

The UMass Amherst Internal Review Board (IRB) approval was obtained prior to initiating the DNP project. This was a quality-improvement project and the participants were healthcare providers in primary care. Approval for the educational session was obtained from the site administrators, which included the center manager, medical director, and chief medical officer. There was no patient contact or review of medical records in this project. Possible ethical considerations included respecting the thoughts and sensitivities of the learners regarding past experiences with this topic. Ethical consideration when using the Toolkit in practice concerned crossing basic human rights of people with disabilities by using legal aids to influence their treatment course. Such impairment in insight raises important ethical issues regarding how these individuals should be viewed with regards to autonomy, free will, self-determination and the

extent to which coercion (such as involuntary hospitalization or forced medication) is justifiable (Marley, 2007). Marley (2007) explores the ethical considerations of such interventions and explains that under some circumstances, certain levels of coercion may be justified based on an ethics of care approach when individuals with schizophrenia have substantially impaired insight into the presence and nature of their illness. Benevolent coercion which would only be temporary while the patient is unable to recognize their own disorder due to anosognosia would be promptly returned once participant reestablished capacity.

The AMISS Toolkit is meant to be an educational intervention to allow clinicians to have the most information during a clinical scenario and make the best decisions for their patients given their circumstances. Furthermore, this Toolkit would not encourage traditional routes of coercion. Instead it would encourage use of screening, MI, cognitive behavioral intervention, and proper placement of systemic support to be able to achieve health in the individual.

**Goals, Objectives, and Expected Outcomes**

The goals, objective and expected outcomes were chosen to align with the Dick and Carey ISD. The table below has the comprehensive markers the DNP student set out to meet.

**Table 1.**

*DNP Project Goals, Objectives, and Expected Outcomes*

<b>Goals</b>	<b>Objective</b>	<b>Expected Outcome</b>
1. Complete an IR of the literature	1. Perform a comprehensive search of the literature through multiple databases using MeSH. 2. Select high-quality studies that meet inclusion criteria. 3. Review and analyze selected articles for anosognosia that can introduce the symptom, along with screening tools and interventions to primary care clinicians.	1. Complete an IR of the literature that finds evidence-based screening tools and interventions for anosognosia that can be implemented in the primary care.



<p>2. Create an evidence-based, AMISS Toolkit and presentation for primary care clinicians.</p>	<ol style="list-style-type: none"> <li>1. Create AMISS Toolkit with findings from IR.</li> <li>2. Include evidence-based screening tools and interventions found in IR.</li> <li>3. Create an easy-to-follow algorithm to illustrate use of the Toolkit.</li> <li>4. Create links to appropriate educational materials on anosognosia and mental illness for patients and families.</li> <li>5. Include recommendations of evidence-based courses that clinicians can pursue to improve skills in treating this population.</li> </ol>	<p>1. AMISS Toolkit and presentation will meet all objectives.</p>
<p>3. Deliver a high quality, professional presentation to educate providers on the use of the AMISS Toolkit.</p>	<ol style="list-style-type: none"> <li>1. The presentation will be limited to 1 hour and 15 minutes to ensure maximal participation.</li> <li>2. This timeframe includes completion of the pre-presentation survey, formal presentation, Q&amp;A session, and post-presentation evaluation.</li> <li>3. Educate providers on poor outcomes when patients are not screened for anosognosia.</li> <li>4. Demonstrate use of the Toolkit including algorithm, evidence-based screening tools, interventions and patient/family/clinician educational websites and links.</li> <li>5. Use pre-presentation surveys to assess knowledge had.</li> <li>6. Use post-presentation evaluations to assess knowledge gained.</li> </ol>	<ol style="list-style-type: none"> <li>1. Increase provider’s knowledge about anosognosia by 60%.</li> <li>2. Providers will find the Toolkit educational and practical to use.</li> <li>3. Providers will be confident in their ability to use the Toolkit and provide education to patients and their caregivers.</li> </ol>

### Implementation

#### Preamble

The IR was an extensive, exhaustive process and a significant portion of this DNP project, that was completed months prior to IRB submission. The contents of the IR were the primary preliminary component of this DNP project that yielded the best evidence that was used to create the AMISS Toolkit (<https://people.umass.edu/jbardina/AMISS.pdf>) and the PowerPoint ([https://people.umass.edu/jbardina/FINAL\\_AMISS\\_POWERPOINT\\_JB.pptx](https://people.umass.edu/jbardina/FINAL_AMISS_POWERPOINT_JB.pptx)) presentation (see also Appendix F). The preliminary outlines of the Toolkit and PPT were created and included

with the IR in proposal to the UMass IRB for approval. Once approval was obtained, the DNP student launched with the development of the actual AMISS Toolkit and the PPT Presentation.

A summary of the requirements for the DNP project and topic were presented to the Medical Director of the Neighborhood PACE and Chief Medical Officer of EBNHC in September 2019. The relevance and applicability of this project was emphasized to the Center Director to ensure support. Besides advocating for the educational value of the Toolkit and presentation, the DNP student also suggested that implementation might help boost enrollment into the PACE program. Both the educational value of the Toolkit and the potential for implementing a quality-improvement initiative helped to facilitate verbal approval for the Toolkit presentation. The most significant barrier encountered was deciding on a date for the presentation that did not conflict with the mandatory interdisciplinary team meetings for staff on all weekdays except Monday and use of the presentation area with patients during regular lunch hours. The weather also acted as a barrier as during the fall/winter months the health center closed during severe weather, which would greatly reduce staff presence in the clinic; the presentation had to be changed once due to unforeseen weather events.

## **Methods**

### ***Pre-Toolkit Preparation***

Qualitative interviews were coordinated in person, email or via Zoom by the DNP student and the Neighborhood PACE/EBNHC clinicians in Fall 2018. The qualitative data included unstructured, informal, open-ended, qualitative interviews with six clinicians. The interviews lasted 10 to 30 minutes, depending on the level of interest of the individual clinician. Information gathered helped the DNP student decide what content was critical to include in the AMISS Toolkit. Some clinicians were familiar with the symptoms, others were not, all reported not having a

screening tool for the symptom in practice, and all were receptive to more education or information. The DNP student used qualitative approaches to guide the interviews.

An IR was conducted to find a scholarly consensus about the concept of anosognosia. The DNP student also gathered information during the IR for both EBP screening tools and EBP clinical interventions for anosognosia in mental illness. The DNP student continued to find additional supportive resources that clinicians might need to navigate a case comprehensively, including advance directive, involved ethics, involved laws, history, educational resources, and public and private agency that might be of assistance to them or their patients. This information was rigorously checked for academic validity against the JHNEBP scale.

### ***Toolkit Development***

The results of the IR were used to create the Anosognosia, Mental Illness Screening & Intervention Strategies (AMISS) Toolkit<sup>®</sup> (<https://people.umass.edu/jbardina/AMISS.pdf>). The goal of the Toolkit was to educate clinicians on how to recognize anosognosia in practice, screen with validated tools, and intervene using evidence-based strategies usable in the primary-care setting. Therefore, Toolkit contents were organized in sequential order using nursing process of assessment, diagnosis, outcome, implementation, and evaluation, to create a more realistic flow of practice. The results of the IR support a comprehensive guide that primary care providers can use to provide comprehensive care for those with mental illness and anosognosia. Three main interventions are covered: 1) recognition of symptom in practice, 2) implementation of two validated screening tools, and 3) MI and cognitive behavioral continuing education to address the specific population. The electronic Toolkit is modeled like a webpage and includes a table of contents at the beginning of the document with hyperlinks to navigate all sections of the Toolkit. A comprehensive but easy-to-follow recommended practice algorithm is included to

illustrate how to effectively utilize the tools within the Toolkit in practice. Like the table of contents, the algorithm contains hyperlinks to various sections within the Toolkit. Most pages of the Toolkit also have hyperlinks that can be used to return to the table of contents. The DNP student also included information on MI training and cognitive behavioral courses, mental health resources, webpages such as the NAMI and the Treatment Advocacy Center, and useful PDF from SAMHA on Health Care Proxy documents to include in the Toolkit.

### ***PowerPoint Presentation and Speech Development***

After developing the AMISS Toolkit, an educational PPT presentation and speech was created from the information gathered from the IR and the contents of the Toolkit. Executing a captivating and convincing oral presentation during the educational intervention was essential to the success of the project because the presentation was professionally recorded for future dissemination. The one-hour presentation was designed to outline a case study that was included in the Toolkit to deliver a more realistic presentation of how anosognosia presents in practice and the barriers created due to the symptoms. The presentation included a summary of the IR findings on anosognosia and the importance of the primary care setting to addressing the symptom to reduce disparities in mental health. A hyperlink to the actual electronic Toolkit was also included so the DNP student could display and navigate the document during the presentation.

### ***Formal Presentation***

Permission from the organization and medical director was secured and a room was booked by the medical director for the official first presentation. The presentation was communicated to all available Neighborhood PACE and EBNHC staff members by the medical director on December 9, 2019. Lunch was provided to encourage participation. The presentation

included a pre-presentation survey and a post-presentation evaluation and allowed time for a Q&A session at the end. Copies of the unedited Toolkit were provided by the medical director in the initial email invitation and the DNP student distributed paper copies during the presentation.

#### ***Data Collection Procedure Formal Presentation***

The DNP student was responsible for all data collection and analysis. Quantitative and qualitative data were collected. There were two surveys created for quantitative data collection. Qualitative data was collected using a Q&A and informal discussions after presentation with participants.

The quantitative data was collected using three anonymous, one-sided surveys that included the *Awareness/Knowledge Survey*<sup>®</sup> (Appendix E) for use pre-and post-presentation and the *Perceived Efficacy of the Toolkit*<sup>®</sup> survey. The first two surveys were an identical pre and post 3-item questionnaire using a 5-point Likert scale, that assessed the participants' knowledge level of anosognosia as a symptom, their self-efficacy in screening it in practice, and implementing a thorough care plan. The *Awareness/Knowledge Survey*<sup>®</sup> was aimed at capturing knowledge gain. The second survey was created to assess participants' *Perceived Efficacy of the Toolkit*. The second survey contained 3-item questionnaire using a 5-point Likert scale, and inquired if they thought the Toolkit addressed barriers to adherence, was easy to use, and their likelihood to recommend it to a colleague.

Qualitative data was collected using a Q&A and informal discussions after the presentation with participants, the verbal session was recorded on professional video for later review by the DNP student. The student was equipped with a professional microphone for her speech and provided a microphone for participants to ask questions. The video was then

reviewed after postproduction from the film agency and the Q&A session and informal discussions were analyzed and documented on a word document.

### ***Toolkit Adjustment Based on Formal Presentation Feedback***

The AMISS Toolkit was condensed to essential information only needed for *At-A-Glance* review during practice. The additional hyperlinks leading to supporting academic resources, along with information to create an anosognosia champion in practice, link to the PPT, access to the surveys and Likert scales, and brief history on mental illness and its complications were excluded from the actual Toolkit. This information seemed to be overwhelming and too distracting to the first audience during the brief initial presentation and was omitted based on the Dick and Carey ISD. While not part of the ISD model, Dick, Carey and Carey (1996) note that after training, there should be a summative assessment to evaluate “the absolute and/or relative value or worth of the instruction” and then revise instruction based on the data collected in step 8. The omitted information was later turned into a separate AMISS Toolkit Resource Packet (<https://people.umass.edu/jbardina/AMISS.pdf>) and was also shared with the site.

### ***Informal Presentation***

A second informal presentation was completed on February 13, 2020, to Neighborhood PACE clinicians who could not attend the first formal presentation. The informal presentation had 8 participants and was conducted during lunch hour to all who wanted to attend. The modified AMISS Toolkit was only presented in its digital format on a computer screen with a copy provided via email to all attendees that included Toolkit and Resource Packet. A brief 15-minute overview of six items on the Toolkit and the Practice Algorithm were discussed. To make best use of the time and to try not to overwhelm the group with too much information, no case study was used, and none of the live links were demonstrated during this presentation. The initial

recorded PPT presentation was emailed to clinicians for viewing at their own convenience, post presentation, but was not discussed. The second presentation only included post-presentation Q&A session at the end.

### ***Informal Presentation Data Collection***

Only qualitative data was gathered during this review session with a Q&A session post presentation. Only one comment was recorded post presentation and it was recorded by the DNP student on a word document.

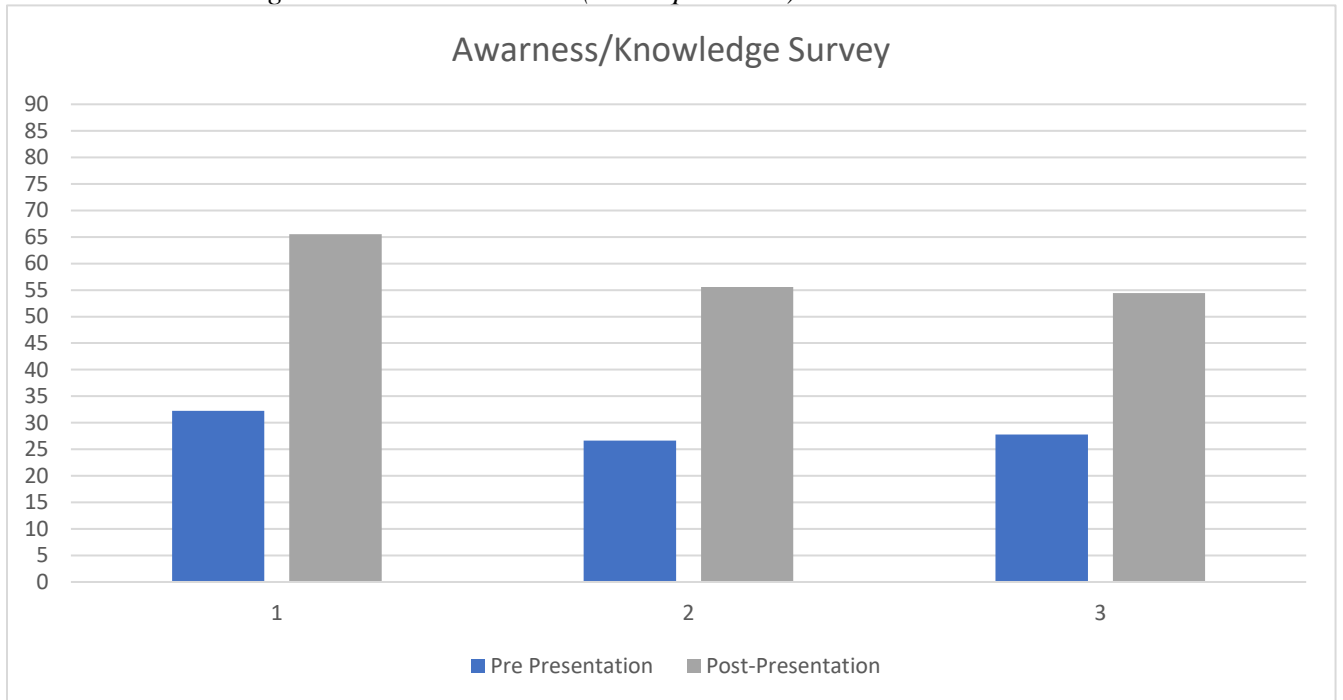
### ***Information Dissemination***

Finally, the Anosognosia, Mental Illness Screening & intervention Strategies (AMISS) Toolkit<sup>®</sup> At-A-Glance( <https://people.umass.edu/jbardina/AMISS.pdf>) was distributed via email by the Medical Director of PACE to all Staff across facilities. The posting of the AMISS Toolkit and presentation was uploaded to the web (Appendix F) for sustainable access was completed.

## **Results**

### **Descriptive Statistics Results**

Descriptive statistics were used to analyze the two sets of data from the surveys, which assessed the clinicians increase in Knowledge/Awareness<sup>®</sup> and Perceived Efficacy<sup>®</sup> of the AMISS Toolkit. Responses from the surveys, which were gathered from 18 mixed group clinicians the day of formal presentation by the DNP student were entered as values into the table format in Excel. Those values were used for averages and evaluating percentages of increase in knowledge. Two bar graphs (Figure 1. and 2.) were created to visually display the results of the Awareness/Knowledge survey<sup>®</sup> and the Perceived Efficacy of AMISS<sup>®</sup> Toolkit.

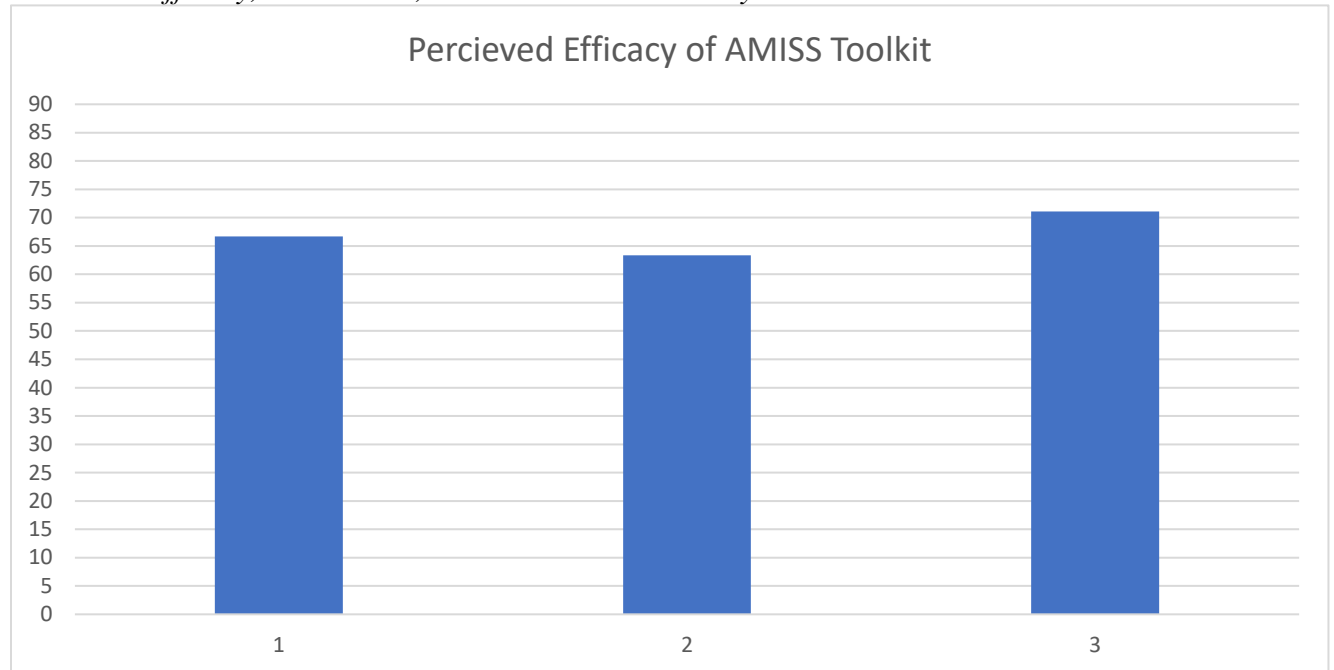
**Figure 1.***Awareness/Knowledge Pre and Post Results (three questions)*

Note. Y-Axis represents total possible score for individual question. The X-Axis represents Questions 1-3 of the survey. In this project with 18 participants on 5-point Likert the total maximum score would have been 90 point.

A minority of the staff members (36%) had knowledge of anosognosia prior to the intervention. Awareness/Knowledge of anosognosia grew to 72% post intervention. Only 29% of the staff knew how to screen for anosognosia prior to the intervention and 31% knew what interventions to use for the symptom, which grew to 61% and 60%, respectively.

Results of Perceived Efficacy Likert questionnaires demonstrated that 73% percent of clinicians found that the AMISS Toolkit addressed the barriers to adherence in patients with severe mental illness. Initial qualitative results show that clinicals found 70% found the AMISS Toolkit easy to use and 78% of the respondents would recommend the AMISS Toolkit to their colleagues.



**Figure 2.***Perceived Efficacy, First Phase, Post Presentation Survey*

Note. Y-Axis represents total possible score for individual question. The X- Axis represents Questions 1-3 of the survey. In this project with 18 participants on 5-point Likert the total maximum score would have been 90 point.

### Qualitative Results

After the formal presentation, a Q&A session was held where most of the respondents were prescribing clinicians (NPs, CNS, MDs) who were seeking further clarification on the topic. Questions that arose surrounded “how to diagnose anosognosia” or “if MRI was needed for identification, since there were neurological underpinnings”; clarification was provided that anosognosia was not a diagnosis but rather a symptom of severe mental illness. Another question that needed clarification by providers was whether the “screening tools could be used on anosognosia in other diagnoses such Alzheimer’s”; clarifications were made that the evidence-based screening tools were only tested on patients with mental health disorders and not yet proven effective on other conditions. One physician seemed concerned with the ethics behind the Motivational Interviewing (MI) treatments proposed. He voiced that it may be misleading or

ineffective therapy. Clarifications were made that MI is a technique to use in practice and in no way intended to bring harm to patients and it has been rigorously examined in studies showing it is in fact an effective strategy for this population. The prescribers expressed that they wanted the information in a condensed format that would be readily available and streamlined for practice, more condensed than the AMISS Toolkit as it was presented.

After the first formal presentation and the Q&A session, social workers approached the DNP student on a one-on-one session, seeming to have a better understanding of the symptom, and offered additional resources for the DNP student to consider adding to the Toolkit. Social workers seemed interested in the mental health advance directives and asked for guidance on how to facilitate this in practice if not currently an instituted practice in their state.

Finally, after the first formal presentation, an administrative worker appreciated the presentation's contents and discussed an anecdotal life experience. The administrative worker recognized the symptom in a family member and the struggles that it caused. No further questions or comments were elicited.

The second informal presentation was given to a cohort of registered nurses. After the presentation, a Q&A session was held. The only questions nurses elicited were specific case studies in current practice to further understand the presentation of patients with such a symptom. No further questions or comments were brought forward.

### **Discussion**

The descriptive statistics were the best measure in indicating the project goals had been met successfully. Analysis of the *pre* and *post* data shows that implementation of the DNP project met all three goals, objectives, and expected outcomes identified for the project (see Goals, Objectives, and Expected Outcomes, Table 1). The analysis of the Perceived Efficacy

Likert scales demonstrated that the AMISS Toolkit was an overall successful resource. The Toolkit and presentation were an effective method guiding achievement of the goals project. These three goals and the actual outcomes are discussed below.

### **Goal 1. Complete an Integrative Review of the Literature**

A lengthy multi-tiered IR of the literature was completed, and the information was scrutinized against JHNEBP. The DNP student found many academic, public and private resources to include in educational intervention on anosognosia. The IR was targeted for the clinician in the primary-care setting wanting to expand their assessment and interventional repertoire on mental illness.

### **Goal 2. Create an Evidence-Based Toolkit on Anosognosia for Primary Care Providers**

From the IR findings, with screening tools and intervention strategies the Toolkit was successfully created. The Toolkit includes education for providers about the symptom of anosognosia, two evidence-based screening tools, and evidence-based strategies to engage patients in practice. The SUMD and SAIQ, two validated assessment tools are included in the Toolkit. Additionally, the DNP student created an anosognosia algorithm to guide clinicians through practice with patients with this symptom. After modifications to the Toolkit, the post-presentation evaluations revealed that staff members found the Toolkit easy to use.

### **Goal 3. Deliver a High Quality, Professional Presentation to Educate Providers on Anosognosia Mental Illness Screening and Strategies Toolkit**

Presentation of the Toolkit with a summary of the DNP project and IR findings was given to geriatric members of PACE and met all objectives. Participants included mixed clinician group in primary care. The presentation was limited to 1 hour to ensure maximal participation and included a pre-presentation survey and a post-presentation evaluation. After some revisions,

the post-presentation evaluations showed that staff members found the presentation timely, educational, and professional. They found the presentation and Toolkit informative and believed the presentation enhanced their understanding and knowledge on anosognosia in severe mental illness. A Q&A session after the presentation addressed any unclear information and allowed for more discussion on how the clinic could improve its process in providing more education during wellness visits.

The qualitative data the DNP student gathered, aligned with the evidence found in the IR, and was also confirmed in this project. Clinicians are truly at ground zero in terms of how to identify and care for patients who exhibit anosognosia in severe mental illness. With an average knowledge gain of 29.6% on pre post questions, the results mirror what was found in the literature, that there is low understanding of anosognosia among clinicians in current practice and an educational toolkit can indeed help fill the knowledge gap. From the Formal Q&A session, the DNP student inferred that the clinicians likely felt bombarded by the magnitude of educational material about anosognosia via the AMISS Toolkit, which had to be delivered in a short one-hour time period at the end of their demanding clinic day. From their responses, the DNP student found that they were much more naïve to the symptom of anosognosia than originally considered, and perhaps distracted by their workday residues. It also became quite clear that they needed the concept and materials to be further simplified or the information much more readily accessible for practice (instead of theory). Mainly, the prescribing clinicians that led the Q&A sessions had generally more practice-related questions and other disciplines were not as interactive after the session for reasons currently unknown. Each discipline of clinician seemed to have their own special set of needs and questions and should probably warrant separation of individual cohorts of clinicians in future dissemination of information. The

capstone project did have the limitation of being too anonymous on the surveys. Discipline inquiry on the surveys could have helped with the re-visitation of the Dick and Carey Model edits and refinements. Knowing which discipline gained the most or least from the educational intervention would have been useful to tailor educational sessions that were best suited to meet the learning needs of each individual discipline. In the future, suggested cohort can be divided by discipline such as nursing, medicine, or social work and their individual learning gaps understood prior to providing them a more comprehensive educational session geared toward their profession and clinical role.

### **Conclusion**

Although not the only barrier to non-adherence in mental illness, anosognosia is one of the leading causes for poor health outcomes in those who do have it. Anosognosia in mental illness is a significant worldwide problem found across all communities and social strata. The symptom continues to be investigated, but research on screening and treatment strategies within office practices is widely missing. The symptom of anosognosia is multifactorial in how it affects patients in their ability to obtain proper care. Patients who cannot recognize a disorder within themselves cannot willingly engage with healthcare clinicians, let alone take their prescribed medications. Patients with active symptoms often suffer from social dysfunction and these deficits in inappropriate social interaction limit the person's ability to secure for themselves basic resources, often making it hard to lead a normal life and earn a living. When both the clinician and the patient do not recognize the symptom of anosognosia, patient and family are alienated from healthcare. This is the result of a health system not designed to work with such a healthcare issue that requires taking a comprehensive and global assessment of the patient to create a care plan with enough structure to be able to overcome the barrier of anosognosia.

Currently, there are no formal recommendations or guidelines to assess the symptom of anosognosia in primary care practice and, with 50% of schizophrenic and 40% of bipolar patients without insight, a large portion of patients with this diagnosis can be potentially undertreated if their only sources of mental health care come from primary care or integrated behavioral health primary care centers such as the Neighborhood PACE. Furthermore, this Toolkit would not encourage traditional routes of coercion. Instead it would encourage use of screening, MI, cognitive behavioral intervention, and proper placement of systemic support to be able to achieve optimal health in the individual. The Toolkit is meant the first steps to bring dignity and assistance to those who have been amiss from healthcare and mental healthcare due to lack of infrastructure and policy with respect to their disorders.

The AMISS Toolkit was found to be an exceptional front line *At-A-Glance* comprehensive resource that can be used by clinicians to help eliminate gaps in mental health practice. This DNP student used Dick and Carey's framework to bring forth the changes needed at the EBNHC to break the anosognosia-caused barriers for those patients with mental illness and anosognosia who are seen in the practice. This Capstone project had very positive findings. Clinicians attitudes and beliefs about the AMISS Toolkit agreed with the principles of this project.

This Toolkit serves as a foundational resource to be expanded and enhanced through post-doctoral work by, adding more interventions to the algorithm to address additional health risks and to custom tailor to specific disciplines for targeted teaching. The Toolkit can be further refined during post-doctoral work with the recommended tools being used for actual practice. Currently, the research in the area of anosognosia continues to be limited and the next steps would be to implement the Toolkit and evaluate its usefulness in practice. Finally, collecting

actual data on whether implementation of the Toolkit and its EBP tools improves mental health outcomes in the mentally ill is worth further support of clinical use of the AMISS Toolkit. This DNP student is available for further collaborative efforts in deploying the AMISS Toolkit in practice.

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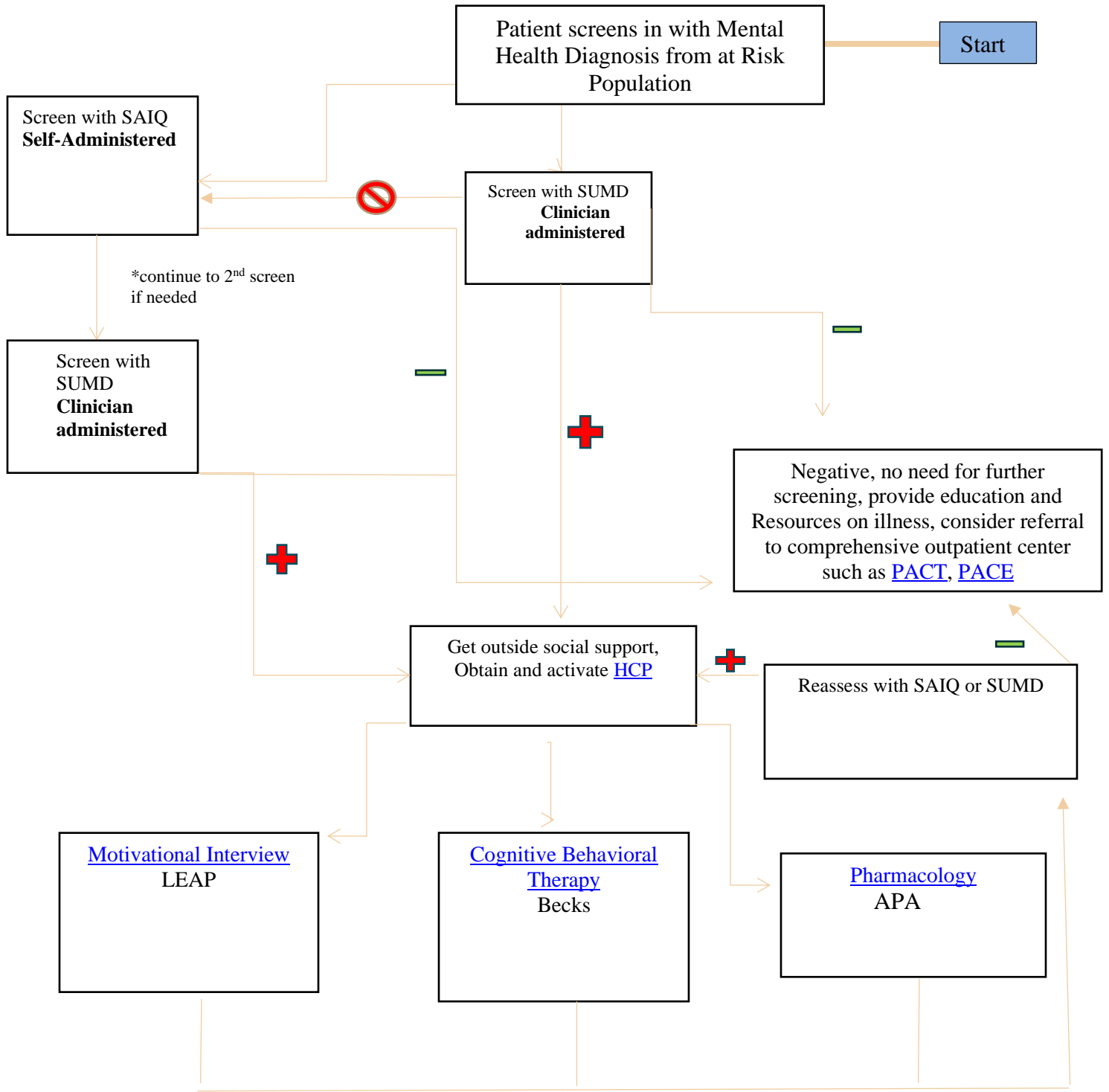
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Appendix A

AMISS Practice Algorithm<sup>©</sup>



**Appendix B (SAIQ)**

The following resource was not fully presented during the presentation; it was only introduced to clinicians. Should they wish to use it in practice the copyright and copy of the scale are included in the AMISS Toolkit. Below is the permission of reproduction from Elsevier.

Self-Appraisal of Illness Questionnaire

PsycTESTS Citation: Marks, K. A., Fastenau, P. S., Lysaker, P. H., & Bond, G. R. (2000). Self-Appraisal of Illness Questionnaire [Database record]. Retrieved from PsycTESTS. doi: <https://dx.doi.org/10.1037/t15494-000>

Instrument Type: Inventory/Questionnaire

Test Format: Participants are asked to respond to the statements and questions using Likert scales, which vary according to the statement or question content. Higher scores indicate greater denial of the presence and symptoms of illness, an increased belief that the illness will subside, greater denial of need for treatment, and less worry.

Source: Marks, Kriscinda A., Fastenau, Philip S., Lysaker, Paul H., & Bond, Gary R. (2000). Self-Appraisal of Illness Questionnaire (SAIQ): Relationship to researcher-rated insight and neuropsychological function in schizophrenia. *Schizophrenia Research*, Vol 45(3), 203-211. doi: [https://dx.doi.org/10.1016/S0920-9964\(99\)00208-X](https://dx.doi.org/10.1016/S0920-9964(99)00208-X), © 2000 by Elsevier. Reproduced by Permission of Elsevier.

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Describe why numbered way they are—clustered .... Variable internal consistency and reliability –convergent or divergent --

**SAIQ**  
**Need for Treatment**

Questions	Not at all/Bad	Some/I Don't Know	Good/Yes
#1 When someone first recommended the present treatment, how did you feel about this person's recommendation for treatment?	1	2	3

#10 Do you believe your current treatment to be necessary?	1	2	3
#11 If you had not received treatment, how do you think you would be doing right now?	1	2	3
#12 I can gain a lot from being in treatment.	1	2	3
#15 I think my condition requires psychiatric treatment.	1	2	3
#16 I have symptoms of mental illness.	1	2	3
Total			

**Source:** Kriscinda, Fastenau, Lysaker, & Bond, 2000 © 2000 by Elsevier. Reproduced by Permission of Elsevier

## SAIQ

### Worry

Questions	Not at all/Bad	Some/ I Don't Know	Good/Yes
#2 In general, how much do you tend to worry?	1	2	3
#3 How much do you worry about your condition?	1	2	3
#6 How much do you worry about being unable to work because of your condition?	1	2	3
#4 How much do you worry about getting into trouble because of your condition?	1	2	3
#5 How much do you worry about losing friends because of your condition?	1	2	3
#7 How much do you worry about not recovering?	1	2	3
#14 How much do your thoughts and feelings interfere with getting things done ?	1	2	3
Total			

**Source:** Kriscinda, Fastenau, Lysaker, & Bond, 2000 © 2000 by Elsevier. Reproduced by Permission of Elsevier

## SAIQ

### Presence/Outcome of Illness



Questions	Not at all/Bad	Some/I Don't Know	Good/Yes
#8 I think my condition will go away by itself.	1	2	3
#9 There's no doubt in my mind that I'll be better someday.	1	2	3
#13 If I were to discontinue treatment today I would do fine.	1	2	3
#5 How much do you worry about losing friends because of your condition?	1	2	3
#17 How ill do you think you are?	1	2	3
Total			

Source: Kriscinda, Fastenau, Lysaker, & Bond, 2000 © 2000 by Elsevier. Reproduced by Permission of Elsevier.

**Appendix C Copy right permission SUMD**

Dear Dr. Xavier Amador,

I understand that you are the copyright holder of the assessment scale titled “Scale to Assess Unawareness in Mental Disorder (SUMD)”.

I am a doctoral student at the University of Massachusetts – Amherst I would like to use your scale to create a toolkit to help clinicians identify anosognosia in practice. The above-mentioned scale would be placed in a toolkit for mental health practice and presented to providers at East Boston Neighborhood Health Center. The scale will also be published on Scholar Works as part of my completed project. Proper acknowledgement to you will be included with the reproduction of the scale at all steps of the process.

If you agree to provide me with permission, please sign this permission letter and return one copy to us by email (a scanned version is fine) or regular mail.

I appreciate your consideration of our permissions request.

Sincerely,

Jessica Bardina  
31 Anderson St Apt 2  
Boston MA 02114

By signing below, I warranty that I have the right to grant the permission requested herein, and that I hereby provide you with that permission.

Signature:

Date:

Email Response Reply 4/14/19 12:31am CC Jason Savage(jason@leapfoundation.center) and Dr. Xavier Amador(xa1@coulumbia.edu): You have permission to use SUMD for the purpose you have described. I ask that you send me a copy of your final product. If you do not provide a copy you will be in breach of the permission granted herein. Acceptable?

**Appendix D SUMD**

**SUMD**

Symptom Checklist: Circle either c for current or p for past, next to the item number to denote which symptom time and time period are to be rated.

ITEM/SYMPTOM	CURRENT	PAST
4. Hallucinations	C	P
5. Delusion(s)	C	P
6. Thought disorder	C	P
7. Inappropriate affect	C	P
8. Unusual dress or appearance	C	P
9. Stereotypic or ritualistic behavior	C	P
10. Poor social judgement	C	P
11. Poor control of aggression impulses	C	P
12. Poor control of sexual impulses	C	P
13. Alogia	C	P
14. Flat or blunt affect	C	P
15. Avolition-Apathy	C	P
16. Anhedonia-Asociality	C	P
17. Poor attention	C	P
18. Confusion-Disorientation	C	P
19. Unusual eye contact	C	P
20. Poor social relationships	C	P

**Source:** Xavier Amador ©

1. Awareness of Mental Disorder	C	P
In the most general terms, does the subject believe that s/he has a mental disorder, psychiatric problem, emotional difficulty, etc?		
	0	0

Cannot be assessed Aware: Subject clearly believes s/he has a mental disorder	1	1
	2	2
Somewhat: Is unsure about whether s/he has a mental disorder, But can entertain the idea that s/he might	3	3
	4	4
Unawareness: Believes that medications have not lessened the Intensity or frequency of his/her symptoms	5	5

2. Awareness of the Achieved Effects of Medication. What is the subject's belief regarding the effect of medication? Does the subject believe that medication have lessened the intensity or frequency of his/her symptoms (i.e. if applicable)?	C	P
Cannot be assessed Aware: Subject clearly believes s/he has a meds have lessened The intensity or frequency of his/her symptoms	0	0
	1	1
	2	2
Somewhat: Is unsure about whether s/he has a medication, Have lessened the intensity or frequency of symptoms	3	3
	4	4
Unawareness: Believes that medications have not lessened the Intensity or frequency of his/her symptoms	5	5

3. Awareness of the Social Consequences of mental disorder. What is the subject's belief regarding the reason s/he has been admitted to the hospital, involuntary hospitalized, arrest, evicted, fired, injured, etc.?	C	P
Cannot be assessed or item is not relevant	0	0
Aware: Subject clearly believes social consequences are related to having A mental disorder	1	1

	2	2
Somewhat: Is unsure about whether relevant social consequences Are related to having a mental disorder	3	3
	4	4
Unawareness: Believes that the relevant social consequences have Nothing to do with having a mental disorder	5	5

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**Appendix E**  
**Guide for Clinicians with patient with severe mental illness and anosognosia**

December 9, 2019

University of Massachusetts – Amherst

College of Nursing

**Pre-Presentation Awareness/Knowledge Survey<sup>©</sup>**

For the Following questions please circle only one answer per question on a scale of 1: No knowledge 2: Below Average 3: Average 4: Higher than average 5. Expert			
1. What is your knowledge level of the symptom anosognosia in mental illness?	1 2	3 4	5
2. What is your level of self-efficacy in screening for anosognosia in serious mental illness such as schizophrenia or bipolar disorders?	1 2	3 4	5
3. What is your level of self-efficacy in implementing a thorough care plan for patients presenting with the symptom of anosognosia in a serious mental illness?	1 2	3 4	5
Total			

**Source:** Jessica Bardina University of Massachusetts Amherst College of Nursing ©

**Guide for Clinicians with patient with severe mental illness and Anosognosia**

December 9, 2019

University of Massachusetts – Amherst

Post-Presentation Awareness/Knowledge Survey®

For the Following questions please circle only one answer per question on a scale of 1: No knowledge 2: Below Average 3: Average 4: Higher than average 5. Expert			
4. What is your knowledge level of the symptom anosognosia in mental illness?	1 2	3 4	5
5. What is your level of self-efficacy in screening for anosognosia in serious mental illness such as schizophrenia or bipolar disorders?	1 2	3 4	5
6. What is your level of self-efficacy in implementing a thorough care plan for patients presenting with the symptom of anosognosia in a serious mental illness?	1 2	3 4	5
Total			

**Source:** Jessica Bardina University of Massachusetts Amherst College of Nursing ©

**Guide for Clinicians with patient with severe mental illness and anosognosia**

December 9, 2019

University of Massachusetts – Amherst

College of Nursing

Perceived Efficacy of AMISS Toolkit®

For the Following questions please circle one answer on a scale of 1: No knowledge 2: Below Average 3: Average 4: Higher than average 5. Expert			
1. The toolkit is addressing a barrier to adherence for patient with severe mental illness	1 2	3 4	5
2. The toolkit is easy to use	1 2	3 4	5
3. I would recommend this toolkit to a colleague	1 2	3 4	5
Total			

**Source:** Jessica Bardina University of Massachusetts Amherst College of Nursing ©



## **Appendix F**

PowerPoint presentation and AMISS Toolkit

Power Point Presentation:

[https://people.umass.edu/jbardina/FINAL\\_AMISS\\_POWERPOINT\\_JB.pptx](https://people.umass.edu/jbardina/FINAL_AMISS_POWERPOINT_JB.pptx)

AMISS Toolkit:

<https://people.umass.edu/jbardina/AMISS.pdf>