Evaluation of Printable Sepsis Patient Education Material for Usability and Actionability

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## Abstract

Sepsis is common, costly, and is a leading cause of death worldwide. During the past decade, quality improvement efforts in sepsis management have led to increased survival. Many sepsis survivors experience sequelae that contribute to unplanned hospital readmission associated with poor outcomes. Despite ongoing efforts to improve sepsis patient care, methods for reducing sepsis readmissions is limited. Additionally, public and patient knowledge regarding sepsis is lacking. Improving sepsis patient outcomes requires early diagnosis and treatment. Increasing patient and caregiver knowledge of sepsis and when to seek medical care is essential, particularly for patients at risk for readmission. No current standards exist regarding effective methods or tools to provide sepsis patient/caregiver discharge education. An evaluation of an available sepsis education tool using a validated measure to assess printable patient education material for understandability and actionability was conducted. An electronic survey was completed by nine national sepsis content experts, with a 90% response rate. Mean usability and actionability scores were above 80% with fair to moderate agreement across 24 survey items. Areas for improvement include providing a summary, modification of images and simplifying language. Results from this project may be useful for future sepsis patient education material.

**Problem Identification**

Sepsis is a serious infection complicated by acute organ failure affecting more than 750,000 patients in the United States annually and is one of the leading causes of death worldwide (Angus et al., 2001).  In 2013, costs associated with sepsis exceeded $23 billion dollars, marking sepsis as the most expensive hospital condition (Torio & Moore, 2016).  Quality improvement efforts in sepsis care have led to decreased mortality (Levy et al., 2014).  Yet, sepsis survivors are frequently readmitted to the hospital (Goodwin, Rice, Simpson, & Ford, 2015).  One in twenty sepsis survivors are readmitted within 20 days and one in five is readmitted within 30 days (Donnelly, Hohmann, & Wang, 2015).  In forty-five percent of septic shock survivors, the primary cause for readmission is due to a new, unresolved or recurrent infection (Ortego et al., 2015).

Poor outcomes are associated with sepsis readmissions (Chang, Tseng, & Shaprio, 2015).  Comparing readmissions after non-sepsis hospitalizations to readmissions after the initial (index) sepsis admission revealed that sepsis readmissions were more likely to require intensive care unit (ICU) services, were less likely to be discharged home and more likely to result in death or hospice care (Jones et al., 2015).  Targeting interventions to decrease unplanned readmissions and improve outcomes is needed.

Decreasing readmissions is a national health care priority (CMS, 2014).   Since the introduction of the healthcare readmissions reduction program (HRRP), heart failure readmissions have decreased.  Standardized patient education focused on self-care management along with follow-up telephone calls was effective in reducing readmissions and improving outcomes in the heart failure population (Baptiste, Mark, Groff-Paris & Taylor, 2013).  Utilizing a similar standardized approach to educate sepsis patients may improve patient and caregiver

understanding of sepsis signs and symptoms and inform patients when to seek medical care. Educating patients and caregivers may also lead to a reduction in sepsis readmissions and improve outcomes.  A review of the literature resulted in a lack of information related to sepsis patient discharge education lacking.

## Literature Search Strategy

A computerized literature review search included identification of experimental and academic references that discussed or studied patient and caregiver sepsis knowledge, discharge education practice, discharge tools and patient outcomes focused on patient and caregiver knowledge retention and teach back in an acute hospital setting. The literature search consisted of several databases including PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Cochrane Library and the British Medical Journal of Quality.  A Virginia Henderson library search consisted of a review for current and previous research studies, presentations and dissertations for additional references.

Search terms included sepsis, patient education, patient knowledge, discharge education, discharge tools, patient and caregiver education, health education, health literacy, sepsis prevention, signs and symptoms, and teach-back communication.  To eliminate irrelevant material, the search limits included only adults, English language, and publications within the previous 10 years.  Due to the limited number of publications in this newly evolving field of a study, the search was extended beyond the current 5 year literature review to obtain applicable historical literature. The search strategy included a series of steps to search the individual terms and explore them individually. The second step included an advanced search stringing terms together including a Boolean operator AND to link primary and MeSH terms to interventions followed by outcomes to further narrow the literature content toward the focused question.

A series of terminology reviews were completed allowing for a comprehensive search of the literature.  MeSH terms for sepsis included sepsis, severe sepsis, septic shock and septicemia.  MeSH terms for patient education included patient handout and education of patients.  MeSH terms for prevention included prevention, secondary prevention, relapse prevention, early therapy, and therapy early.  MeSH terms for patient discharge included, discharge patient, patient discharges, discharge planning, and planning discharge. MeSH terms for caregiver include carer, care givers, spouse caregivers, family caregivers, and family caregiver.

Search results did not reveal any literature specific to sepsis patient or caregiver education tools, sepsis discharge education or sepsis discharge education strategies to prevent readmissions.  The literature search identified two references that evaluated patient knowledge of the risk of sepsis post-splenectomy. White et al. (1991) reported a low level of patient knowledge and subsequently developed a pamphlet for patient education.  Another study found that 50% of splenectomy patients had knowledge of their infection risk and the role of vaccinations to reduce the risk, yet deficiencies in knowledge prompted development of a protocol and improvement in patient education (Wilkes, Wills, & Smith, 2008).

Sepsis literature has evolved over the past 15 years. However, much of the research literature has been fixed on new drug or device therapy, resuscitation and treatment strategies and quality improvement initiatives.  As the landscape of sepsis management changes with associated improved survival, a new body of literature is emerging regarding sepsis survivors and readmissions. Yet, research literature in sepsis prevention and discharge education yielded zero publications in this search.

**Significance**

Campaigns to increase public awareness of acute myocardial infarction (MI) and stroke occurred in the 1980s and 1990s to encourage the public to seek early treatment using slogans such as "time is muscle" and the stroke symptoms Face-Arm-Speech-Time (FAST) (Herlitz et al., 1992; Wolters, Paul, Li, & Rothwell, 2015).  These awareness activities have been effective in promoting early presentation to the hospital. Similar public awareness recognition educational campaigns may contribute to improved knowledge and early treatment for sepsis.

**Sepsis Awareness**

A survey conducted in France, Germany, United Kingdom, Italy, Spain and the United States revealed that 88% of respondents had never heard of the term sepsis, representing poor public awareness (Rubulotta et al., 2009).  Researchers in Sweden carried out an online survey of adults evaluating awareness of stroke, chronic obstructive pulmonary disease (COPD), leukemia and sepsis reporting that only 21% of respondents had heard of sepsis, whereas the other diseases achieved 86% awareness or greater (Mellhammar, Christensson, & Linder, 2015).  In 2016, the Centers for Disease Control and Prevention (CDC) launched a campaign to urge sepsis awareness. The promotion integrated basic information along with patient education tools, videos and fact sheets on sepsis awareness (CDC, 2016a).  The CDC included information on improving survival through sepsis prevention and early recognition encouraging healthcare facilities to collaborate to improve care processes (CDC, 2016a).

**Internet Sepsis Education**

In an era of global internet connection, patients and families search websites for health education information. A prospective study evaluated internet use among surrogates of sepsis patients and found that 55% of the surrogates searched the internet for sepsis (Nguyen et al., 2017).  Numerous sepsis websites captured essential content and definitions but in many cases

the reading level was at a 10th grade level or higher (Oermann & McInerney, 2007). To ensure understandability, agencies providing patient education should confirm that the material is suitable for people with varying levels of health literacy.

Early recognition and treatment are key to improving sepsis outcomes. Educating the public, patients and caregivers on sepsis signs and symptoms is essential to inform individuals when to seek medical care. The fundamental purpose of public/patient education is to facilitate prompt provider contact allowing for early sepsis diagnosis and treatment with antibiotics and fluids if appropriate.

**Hospital Readmissions and Discharge Processes**

Hospital readmissions are costly and carry poor consequences for patients and potential financial consequences for hospitals where they are treated (Fingar & Washington, 2015). Approximately 500,000 readmissions totaling $7 billion in hospital costs occurred in 2013 for several high-volume diagnoses that included acute myocardial infarction (AMI), congestive heart failure (CHF), COPD and pneumonia (Fingar & Washington, 2015). Data comparing sepsis readmissions to other conditions including AMI, CHF, COPD and pneumonia concluded that unplanned readmission after a sepsis hospitalization, had a longer length of stay and the highest mean cost when compared to the other high-volume diagnoses (Mayr et al., 2017).

In a retrospective study evaluating 5,206 patient admissions over a one year period, 1.6% were readmitted within 30 days with the same condition (Cakir & Gammon, 2010). The top two readmission diagnoses were pneumonia and sepsis (Cakir & Gammon, 2010). Although the readmission rate in this study was low, the authors concluded that weaknesses in discharge processes including patient education and family involvement in discharge planning were contributing factors (Cakir & Gammon, 2010). Not all factors associated with readmissions are

preventable.  However, providers may reduce the risk with improved discharge education instructions. Instructions should be tailored to patients and families, using visual enhancements with animation or handouts, at an appropriate literacy level (Polster, 2015).

Interventions to improve sepsis discharge education may contribute to increased patient and caregiver understanding of sepsis symptoms, including actions to take should signs or symptoms develop.  Increasing the level of understanding can potentially contribute to a reduction in hospital readmissions and better outcomes.  Currently no standards exist regarding effective methods or tools to provide valuable sepsis patient/caregiver discharge education. Thus, institutions and providers currently deliver routine or "usual" discharge education which may include printable information, educational pamphlets, verbal instructions and/or written instructions.  The combination of lack of public awareness, risk of poor outcomes and no standard methods to educate patients and caregivers about sepsis sets the stage for needed improvement.

## Problem Identification

Despite the high incidence of sepsis, and its associated high cost and mortality, public knowledge and patient educational resources are lacking.  Early recognition and treatment are essential to improve patient outcomes, yet patient delays in seeking treatment due to lack of knowledge regarding the symptoms of sepsis may contribute to poor outcomes (Rubulotta et al., 2009).

**Practicum experience**

**Staff.** During the practicum experience, the doctoral student engaged in conversation with staff regarding the discharge process for sepsis patients.  Patients may have spent days or weeks in the critical care area before transfer to a general medical floor.  However, the general

medical floor is often the unit preparing most patients for discharge. The nursing staff described challenges with patient education due to little warning of impending discharge and limited time to provide education before discharge. Nurses indicated that the amount of time that they had to spend with patients was restricted due to high patient volume on the unit and the need to address acute patient care needs. Most nurses stated that they spent approximately 5 minutes on discharge education using the documents, within the electronic record, prepared by the hospitalist. Hardcopy discharge instructions were printed on white paper with black text. To ensure that this phenomenon was not unique to the practicum site, the doctoral student contacted a few nurse colleagues outside the practicum site. No facility contacted had a unique discharge education program in place for sepsis patients.

Physicians varied on the time spent with patients at discharge, ranging from 10-40 minutes per patient. Some did not discuss sepsis at discharge, stating that "they only had sepsis in the ICU; they do not have it now". Others indicated that they focus on medications and follow-up appointments. No specific sepsis patient instructional materials, printed, video or web-based were provided.

**Patients.** During the practicum experience, the doctoral student sought to develop an understanding patients' knowledge of sepsis and offered sepsis patient education using printed material and discussion. A needs assessment was completed through informal conversations with approximately 40 patients. Patients transferred to the general medical unit from the ICU who had been diagnosed with sepsis were asked if they had heard of *sepsis*. None were familiar with this diagnosis. Conversely, most patients were able to describe signs and symptoms of other common acute critical illnesses such as heart attack and stroke and understood the urgency of seeking medical care for those acute illnesses.

To develop an understanding of what patients preferred in regards to discharge education, the doctoral student printed a sepsis education page from the nursing resource center at the site and the CDC *Sepsis Fact Sheet* (CDC, 2016b).  The doctoral student allowed the patient to choose which one they preferred and asked them to elaborate on their choice.  All patients selected the *Sepsis Fact Sheet* over the standard white with black text discharge instructions, due to the appeal of pictures, color and sections with small bits of information on the *Sepsis Fact Sheet*.

Discharge education using graphics and small chunks of information can be helpful to patients and caregivers to remember information easily.  The National Institute of Health (NIH) outlines a process for developing print material termed *Clear & Simple* for people with limited-literacy skills (NIH, 2016).  The NIH process includes content/style that presents *how-to* information, layout and organization of text and white space, use of illustrations to support the text with cues that point to important information, and readability (NIH, 2016).  The CDC *Sepsis Fact Sheet* appears to be in alignment with the NIH principles. The proposed project will potentially provide valuable information regarding the usability and actionability of the tool.

When the doctoral student asked if the patient preferred to review the document alone or that the doctoral student discuss the material at the bedside, all patients but one preferred that the doctoral student sit and review the printed material.  All engaged in discussion.  Most patients were unaware that they had sepsis during their hospital stay and focused attention on their underlying chronic condition as the reason for hospitalization.

Patient education material should consider cognitive factors, health literacy and potential disabilities that could affect usefulness.  Resources for patients with disabilities were not explored during my practicum experience. However, the CDC *Sepsis Fact Sheet* may be copied

and provided in black and white for those patients with color deficiency. Appendix A - Figure 2

provides an example of a black and white version of the CDC *Sepsis Fact Sheet*.

**Project Purpose**

The purpose of this project was to evaluate the understandability and actionability of the

CDC *Sepsis Fact Sheet* using the Patient Education Materials Assessment Tool (PEMAT-P) for

printable material.   Understandability is defined as patient educational material that is

understandable by individuals from various backgrounds and health literacy to process and

explain important messages (Shoemaker et al., 2014).  Actionability is the ability of the

individual to identify what action they can take based on the information provided in the

educational material (Shoemaker et al., 2014).  The important messages in the *Sepsis Fact Sheet*

include understanding what sepsis is including signs and symptoms and when to take action in

seeking medical care.

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**Methods/Implementation**

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**Components**

This project was designed to evaluate a printable sepsis patient education tool using a

systematic method to evaluate the understandability and actionability of patient education

material.  The printable material for evaluation is the CDC Sepsis Fact Sheet (Appendix A,

Figure 1).  The evaluation tool is the Agency for Healthcare Research and Quality (AHRQ)

PEMAT-P (Shoemaker, Wolf, & Brach, 2013).  The PEMAT-P was used to measure

understandability and actionability content for up to 24 items.

Project activities included inviting ten sepsis content experts to participate in the project.

An independent expert panel with content expertise should be able to determine the instrument

content appropriateness, accuracy and representativeness within the domain specified (Berk,

1990).  The number of recommended panel experts differs from 2-20 but should be

representative of various aspects of the instrument content (Grant & Davis, 1997).  Ten potential

participants were targeted to include physicians and nurses representing roles in quality, critical

care, and hospital medicine. Participants practice in small and large hospital systems and/or state

organized sepsis improvement programs.  Invited experts should represent different geographic

locations to help identify improper or slang terms within the instrument (Grant & Davis, 1997).

Project participants were representative of different U.S. regions.

Experts reviewed the step-by-step project instructions, PEMAT-P guide, and *Sepsis Fact

Sheet.*  The final participant activity was to complete scoring of the *Sepsis Fact Sheet* content for

usability and actionability using the PEMAT-P score system.  Participants used the Survey

Monkey hyperlink provided within the email invitation to participate to complete the scoring.

## Project Setting

The setting for the project was an academic medical center in the northeast United States.

The doctoral student used an email to invite expert participants (5 nurses and 5 physicians) to

take part in the project. Appendix B represents the email inviting sepsis experts to participate in

the project. The email included instructions for project participation.

## Project Resources

Resources for the project included the CDC *Sepsis Fact Sheet*, PEMAT-P and User's

Guide.  The PEMAT is a tool to assess the understandability and actionability of print and

audiovisual education material.  This project evaluated the CDC *Sepsis Fact Sheet* printable

material.

The project was implemented after receiving a letter of determination (LOD) approval

from the Cooper University Hospital Internal Review Board (IRB) and Drexel University IRB.

Investigators conducting research that has been determined to **not** involve human subjects may qualify for protocol approval by Letter of Determination (LOD). Both IRBs determined that the survey research was seeking the subjects' opinion and no personal information was being collected.

Participants were contacted by phone and email to provide a brief introduction and background for the project, purpose, why they were considered for project participation, project procedures and timeline for completion.

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**Stakeholders**

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Key stakeholders for this project include local, national and international agencies interested in providing usable and actionable educational material for sepsis patients and caregivers. Local stakeholders include hospital administration and clinical staff (physicians and nurses) that provide patient education during the hospital stay and at discharge. National stakeholders include sepsis performance improvement programs moving toward patient empowerment through education to help reduce readmissions.

The *Sepsis Fact Sheet* is provided on the CDC website. The CDC is an international agency with worldwide influence. During the project development, I contacted staff at the CDC to determine if the *Sepsis Fact Sheet* had undergone a validation process. The staff member indicated that the *Sepsis Fact Sheet* had not been validated and that the CDC was planning a new patient education campaign with development of new materials. The new materials are expected to go through a qualitative evaluation process.

This project will provide the CDC with valuable information regarding the *Sepsis Fact Sheet* understandability and actionability. Additional benefit may include potential areas for improvement that may be useful for development of new patient education material.

## Project Participant Criterion

Participants were selected based on clinical and quality improvement expertise in sepsis care. Invited participants contributed to advancement in sepsis management, led sepsis performance improvement program(s) and/or contributed to the body of peer-reviewed sepsis literature. Invited participants included both physician and nurse leaders practicing in the United States.

Expertise in sepsis management was evaluated. Sepsis proficiency was determined using criterion of sepsis expertise in a leadership role. Participants met one or more criteria including serving in a leadership role in the Surviving Sepsis Campaign (SSC), as a member of the sepsis guidelines committee, faculty for a SSC performance improvement program, or led statewide sepsis performance improvement collaboratives.

## Sources of information

The printable patient education material, CDC *Sepsis Fact Sheet*, was assessed for understandability and actionability. The assessment tool selected for this project was the PEMAT prepared by the AHRQ (Shoemaker et al., 2013). The PEMAT was intended only for printable or audiovisual materials. The assessment tool for printable material was used for this project. The tool was designed to be used by professionals including healthcare providers charged with providing high-quality materials to patients and consumers (Shoemaker et al., 2013). The purpose of the tool is to aid in selecting patient educational material that is easy to understand and easy to act on (Shoemaker et al., 2013).

The PEMAT was developed by experts in health literacy, content creation, patient education and communication. PEMAT underwent reliability testing and revisions. Consumer testing with readability assessments to determine construct validity to measure whether the

PEMAT was truly measuring understandability and actionability was completed.  The PEMAT demonstrated strong internal consistency, reliability and evidence of construct validity (Shoemaker, Wolf, & Brach, 2014).

The PEMAT was used to assess if the *Sepsis Fact Sheet* is understandable by diverse backgrounds with varying levels of health literacy to process and explain basic messages.  The basic messages include defining sepsis, describing the signs and symptoms and what to do if sepsis is suspected.  The assessment for understandability contains 19 items within six topic areas.  The breakdown of topic areas and items include 1).  Content-two items 2).  Word choice and style-three items 3).  Use of numbers-two items 4).  Organization-four items 5).  Layout and design- one item and 6).  Use of visual aids-five items.  The actionability content includes 7 items. Each of the items are assessed by a response rating of disagree, agree or not applicable (Appendix C).

## Contribution of Expertise

Over the past 13 years, I have been a nurse leader in local, statewide and national quality improvement (QI) collaboratives directed to improve sepsis patient care and outcomes.  I functioned as faculty for the International SSC Phase III and IV QI programs and currently serve as co-director for the New Jersey and Maryland statewide sepsis collaboratives.  In association with two members of the SSC Phase III team, I co-developed, tested and implemented the SSC database for sepsis management that was used by more than 200 hospitals worldwide.

Accomplishments in Phase III allowed me to develop the course curriculum for 60 hospitals participating in the SSC Phase IV performance improvement program.  Phase IV focused on the importance of nurses in early sepsis identification through use of a nurse driven sepsis screening tool for every patient on every shift, in general medical and surgical patients

(Schorr et al., 2016).  Prior sepsis QI experience set a good foundation for this current project and future programs to improve sepsis patient/caregiver education.

## Timeline

A project timeline was based on one week blocks (Appendix E).  The first step was to submit the project for chair and co-chair review and approval, followed by protocol submission to the Cooper University Hospital Internal Review Board (IRB) followed by the Drexel University IRB for protocol review.  After the protocol was reviewed by both IRBs, the doctoral student extended an invitation to the participants by email to provide a brief review of the project purpose, procedures and timeline for completion.

At the project start date, an email was sent to the invited participants with step by step instructions, *Sepsis Fact Sheet*, PEMAT guide and hyperlink to complete the Survey Monkey PEMAT-P assessment.  Submission of the PEMAT-P assessment constituted consent to participation. One week after the invitation, an email was sent thanking those that submitted the survey and prompt those who have not submitted the assessment indicating that one week remains for survey completion.  The survey closed after two weeks from the initial invitation date.  A follow-up email was sent to the participants thanking them for their participation and informing them that the survey was closed.

## Evaluation

Data collection included an evaluation of the *Sepsis Fact Sheet* using of the PEMAT-P by means of Survey Monkey (Appendix D).  The link to the survey was provided to the participants with the invitation to participate.  A free text box was included at the end of the survey to allow participants to provide feedback that may be useful when reporting results back to the CDC staff.

Survey data were blinded.  Even though Survey Monkey has the capability to identify internet protocol (IP) addresses, this functionality was not accessed or utilized for this project. Data were stored on a password protected USB flash drive.

## Data Analysis

A descriptive analysis was completed where the maximum (max), minimum (min), mean and standard deviation (SD) is reported for the overall PEMAT-P score and the usability and actionability scores separately.  A question with a N/A response was dropped and was not included in the analysis. An evaluation of the percentage of participants whose usability and actionability scores were above 80% is reported.  The PEMAT-P guide instructed the participants to choose agree if the item is met 80% - 100% of the time.  This guidance helps minimize the limitations in scoring.  Items where discrepancies were common were reviewed and described.  Interrater reliability was completed using the Fleiss Kappa statistic.

Developers of the PEMAT-P recommend assessment of readability for print material in combination with the PEMAT-P (Shoemaker, Wolf, & Brach, 2014).  A number of readability assessment tools are available in word processing programs. *Microsoft Word* readability statistics were completed using the Flesch Reading Ease and the Flesch-Kincaid Grade Level. The Flesch Reading Ease scores range from 0 - 100 and a high score means easier to read.  A score of 70-80 would indicate Flesch-Kincaid Grade Level of seventh grade (McGee, 2010).

## Results

Nine of the ten invited participants (90%) responded to the survey.  Results are located in Appendix F and include the mean scores as understandability 80.74, actionability 90.74 and overall score (understandability and actionability combined) 83.33 (Table F1).  An evaluation of the percentage of participants whose usability, actionability and overall scores were above 80%

resulted in 6 of the 9 participants (75%) reporting that the *Sepsis Fact Sheet* met the PEMAT-P

criteria 80-100% of the time. An assessment of interrater reliability found that there was

moderate agreement for actionability and fair agreement among the participants for

understandability and the overall content (Table F2).

Each of the PEMAT-P items were appraised to determine if a discrepancy was present

among participants.  An item with a percent agree that was less and 70% was reviewed. The

understandability section had several items with an agreement below 70% including items 1, 2,

3, 11, and 17 (Table F3).  Items 1 and 2 were content related and three of the nine participants

selected disagree. One of the participants did not answer item 2 which reduced the percent agree

to 62%.  Item number 3 refers to the use of common, everyday language and three of the

participants disagreed that the tool met the criteria 80-100% of the time. A majority of the

participants selected disagree for question 11, "*The material provides a summary"*. Two of the

nine participants selected agree for item 17, "*The material uses simple tables with short and

clear row and column headings"*, whereas seven of the participants selected not applicable.

Table F4 displays the actionability items. Items with agreement of 70% or less include

21, 22, and 23.   Six of the nine (66.67%) participants indicated that the tool provided a tangible

tool whenever it could help the user take action. Items 22 and 23 had a low number of

participants that selected agree, with most selecting not applicable (N/A). These two items

reflected some disagreement among the participants and challenges with the question

interpretation as it applied to the *Sepsis Fact Sheet*. Several participants provided feedback

regarding these two questions.  Additional participant comments and feedback entered into the

survey free text field may be found in Appendix G.

An assessment of readability was completed by converting the *Sepsis Fact Sheet* into a *Microsoft Word* document.  The option for readability statistics was activated.  Upon review of the spelling and grammar, readability was assessed.  The *Sepsis Fact Sheet*  in the current form has a Flesch Reading Ease score of 49.9 and a Flesch-Kincaid Grade level of 9.5 (Appendix H).

## Outcomes

Results provide an appraisal of a currently available sepsis patient education tool that has been evaluated by esteemed leaders in sepsis quality improvement and research.  Survey participant response rate was excellent. Mean usability, actionability and overall scores were above 80% which would indicate that the tool provides useful patient information.  Six of nine participants scored the tool above 80% in all three PEMAT-P sections.  Interrater reliability provided fair to moderate agreement across all of the survey items. Areas of improvement include providing a summary, removing distracting images and some modification of the language.  Readability may be improved by lowering the grade level.  Steps to improve the readability include only using words with one or two syllables, decreasing the number of words per sentence and the number of sentences per paragraph.

Results from this project indicate that the tool is viewed as effective educational material to provide patients and caregivers to increase knowledge of sepsis (understandability). Additionally, the actionability score was associated with a high score providing the patient and caregiver with signs and symptoms of sepsis and guidance on when to contact medical assistance (actionability). The *Sepsis Fact Sheet* received lower scores for several items, indicating that there are areas for improvement. The information obtained from this project may be useful to the CDC, for future sepsis awareness campaign patient education tools.

## Plans for Information Dissemination

The information obtained from this project will be shared with the CDC communication staff by email/telephone. The project will be prepared as an abstract presentation at a future national nursing organizational meeting. The final manuscript will be submitted to a peer reviewed journal.

Results will be shared locally with nurses and physicians at Cooper University Hospital. Lessons learned from this project guided development of a Sepsis Patient and Caregiver brochure, developed along with staff from the New Jersey Hospital Association (NJHA). A similar evaluation of the NJHA brochure using the PEMAT-P will be completed during a future Sepsis Learning Activity. Prospective plans include development of a study protocol using a sepsis tool that has been evaluated for usability, actionability and readability, along with the teach-back technique to evaluate patient/caregiver understanding of sepsis at hospital discharge, recall at 7-days and secondary outcome of readmission to an acute care facility.

## Strengths and Limitations

Strengths of the study include the validity of the PEMAT-P for evaluating patient education material. Scoring allowed participants to select N/A for items that were considered not present in the CDC tool. A majority of the questions were dichotomous with options of agree or disagree. Additionally, the *Sepsis Fact Sheet* was developed by a highly regarded international agency. Use of a hyperlink to the PEMAT-P survey with radio button selection contributes to ease of assessment completion. The participants in this project represent national and international leaders in the field of sepsis. Response rate was 9 of 10 (90%) representing a good sample size for this study. Results from this project may guide future sepsis patient education tools.

Limitations of the project included the brief time period for project participation. Although the scoring system used in the PEMAT-P is primarily dichotomous forcing the participant to choose from only two categories, agree or disagree, a few questions did not apply to the *Sepsis Fact Sheet*. The choice of N/A generated challenges for the participants in how to best answer a few items.  Interrater reliability was fair to moderate, suggesting varied interpretation of either the question or the CDC *Sepsis Fact Sheet*.

## Summary

Although sepsis is common, costly, has high readmission rates with associated poor outcomes, public and patient awareness of sepsis is deficient.  The *Sepsis Fact Sheet* would benefit from minor modifications to improve individual usability, actionability and readability. Modification to the Sepsis Fact Sheet may offer a valuable discharge education tool to improve patient/caregiver knowledge of sepsis signs and symptoms and when to seek medical care.  The information obtained from this project may be useful to the CDC to guide revisions in new sepsis educational tools.  Dissemination of these results may provide valuable information to individual hospital sites and agencies considering development of sepsis patient education material.

**References**

Angus, D.C., Linde-Zwirble, W.T., Lidicker J., Clermont, G., Carcillo J, & Pinsky, M.R. (2001)

      Epidemiology of severe sepsis in the United States: analysis of incidence, outcome, and

      associated costs of care. *Critical Care Medicine, 29*(7), 1303-1310.

Baptiste, D. L., Mark, H., Groff-Paris, L., & Taylor, L. A. (2013). A nurse-guided patient-

      centered heart failure education program. *Journal of Nursing Education and Practice*,

      *4*(3), 49.

Berk, R. A. (1990). Importance of expert judgement in content-related validity evidence.

      *Western Journal of Nursing Research, 12*(5), 659-671.

Cakir, B., & Gammon, G. (2010). Evaluating readmission rates: how can we improve? *Southern*

      *Medical Journal*, *103*(11), 1079-1083.

Centers for Medicare & Medicaid Services. (2014, August 4*). CMS to improve quality of care*

      *during inpatient stays. Sepsis Measure*. Retrieved from

      https://www.cms.gov/newsroom/mediareleasedatabase/fact-sheets/2014-fact-sheets-

      items/2014-08-04-2.html

Centers for Disease Control and Prevention. (2016a, September 16). *Sepsis.* Retrieved from

      https://www.cdc.gov/sepsis/index.html

Centers for Disease Control and Prevention. (2016b, September 16). *Basic information and*

      *patient resources. Sepsis Fact Sheet*. Retrieved from

      https://www.cdc.gov/sepsis/pdfs/sepsis-fact-sheet.pdf

Chang, D. W., Tseng, C. H., & Shapiro, M. F. (2015). Rehospitalizations following sepsis:

      common and costly. *Critical Care Medicine*, *43*(10), 2085-2093.

Donnelly, J. P., Hohmann, S. F., & Wang, H. E. (2015).  Unplanned readmissions after

    hospitalization for severe sepsis at academic medical center-affiliated hospitals.  *Critical*

    *Care Medicine*, *43*(9), 1916.

Fingar, K., & Washington, R. (2015).  Trends in hospital readmissions for four high-volume

    conditions, 2009–2013.  *HCUP AHRQ Statistical Brief*, (196), 1-17.

Goodwin, A. J., Rice, D. A., Simpson, K. N., & Ford, D. W. (2015).  Frequency, cost and risk

    factors of readmissions among severe sepsis survivors.  *Critical Care Medicine*, *43*(4),

    738.

Grant, J. S. & Davis L. L. (1997).  Focus on quantitative methods: Selection and use of content

    experts for instrument development.  *Research in Nursing and Health*, *20*, 269-274.

Herlitz, J., Blohm, M., Hartford, M., Karlson, B. W., Luepker, R., Holmberg, S., ... &

    Wennerblom, B. (1992).  Follow-up of a 1-year media campaign on delay times and

    ambulance use in suspected acute myocardial infarction.  *European Heart Journal*, *13*(2),

    171-177.

Jones, T. K., Fuchs, B. D., Small, D. S., Halpern, S. D., Hanish, A., Umscheid, C. A., ... &

    Mikkelsen, M. E. (2015).  Post–acute care use and hospital readmission after

    sepsis.  *Annals of the American Thoracic Society*, *12*(6), 904-913.

Levy, M. M., Rhodes, A., Phillips, G. S., Townsend, S. R., Schorr, C. A., Beale, R., ... &

    Dellinger, R. P. (2014).  Surviving Sepsis Campaign: Association between performance

    metrics and outcomes in a 7.5-year study.  *Intensive Care Medicine*, *40*(11), 1623-1633.

Mayr, F. B., Talisa, V. B., Balakumar, V., Chang, C. C. H., Fine, M., & Yende, S. (2017).

    Proportion and cost of unplanned 30-day readmissions after sepsis compared with other

    medical conditions.  *Journal of the American Medical Association*, *317*(5), 530-531.

McGee, J. (2010). *CMS Toolkit for making written material clear and effective. Section 4:*

*Special topics for writing and design. Using readability formulas: A cautionary note.*

Retrieved from https://www.cms.gov/Outreach-and-

Education/Outreach/WrittenMaterialsToolkit/Downloads/ToolkitPart07.pdf.

Mellhammar, L., Christensson, B., & Linder, A. (2015). Public awareness of sepsis is low in

Sweden. *Open Forum Infectious Diseases*, 2(4), ofv161.

National Institutes of Health (2016, July 29). *Clear Communication: What is clear & simple?*

Retrieved from https://www.nih.gov/institutes-nih/nih-office-director/office-

communications-public-liaison/clear-communication/clear-simple

Nguyen, Y. L., Porcher, R., Argaud, L., Piquilloud, L., Guitton, C., Tamion, F., ... & Mira, J. P.

(2017). "RéaNet", the Internet utilization among surrogates of critically ill patients with

sepsis. *PloS one*, *12*(3), e0174292.

Oermann, M. H., & McInerney, S. M. (2007). An evaluation of sepsis web sites for patient and

family education. *Plastic Surgical Nursing: Official Journal of the American Society of

Plastic and Reconstructive Surgical Nurses, 27*(4), 192.

Ortego, A., Gaieski, D. F., Fuchs, B. D., Jones, T., Halpern, S. D., Small, D. S., ... & Mikkelsen,

M. E. (2015). Hospital-based acute care use in survivors of septic shock. *Critical Care

Medicine*, *43*(4), 729.

Polster, D. (2015). Preventing readmissions with discharge education. *Nursing Management*,

*46*(10), 30-37.

Rubulotta, F. M., Ramsay, G., Parker, M. M., Dellinger, R. P., Levy, M. M., Poeze, M., &

Surviving Sepsis Campaign Steering Committee. (2009). An international survey: public

awareness and perception of sepsis. *Critical Care Medicine*, *37*(1), 167-170.

Schorr, C., Odden, A., Evans, L., Escobar, G. J., Gandhi, S., Townsend, S., & Levy, M. (2016).

    Implementation of a multicenter performance improvement program for early detection

    and treatment of severe sepsis in general medical–surgical wards. *Journal of Hospital*

    *Medicine*, *11*(S1) 32-39.

Shoemaker, S.J., Wolf, M.S. & Brach, C. (2013, November). The patient education materials

    assessment (PEMAT) and user's guide. Agency for Healthcare Research and Quality

    (AHRQ) Publication No. 14-0002-EF.  Retrieved from

    https://www.ahrq.gov/professionals/prevention-chronic-care/improve/self-

    mgmt/pemat/index.html

Shoemaker, S. J., Wolf, M. S., & Brach, C. (2014). Development of the Patient Education

    Materials Assessment Tool (PEMAT): A new measure of understandability and

    actionability for print and audiovisual patient information. *Patient Education and*

    *Counseling*, *96*(3), 395-403.

Torio, C. & Moore, B. (2016). *National Inpatient Hospital Costs: The Most Expensive*

    *Conditions by Payer, 2013*. Retrieved from https://www.hcup-

    us.ahrq.gov/reports/statbriefs/sb204-Most-Expensive-Hospital-Conditions.jsp

White, K. S., Covington, D., Churchill, P., Maxwell, J. G., Norman, K. S., & Clancy, T. V.

    (1991). Patient awareness of health precautions after splenectomy. *American Journal of*

    *Infection Control*, *19*(1), 36-41.

Wilkes, A., Wills, V., & Smith, S. (2008). Patient knowledge of the risks of post-splenectomy

    sepsis. *ANZ Journal of Surgery*, *78*(10), 867-870.

Wolters, F. J., Paul, N. L., Li, L., & Rothwell, P. M. (2015). Sustained impact of UK FAST test

public education on response to stroke: A population based time series

study. *International Journal of Stroke*, *10*(7), 1108-1114.

## Appendix A

*Figure A1 Sepsis Fact Sheet (Original color version)*

## SEPSIS FACT SHEET

### How is sepsis diagnosed?

Doctors diagnose sepsis using a number of physical findings like fever, increased heart rate, and increased breathing rate. They also do lab tests that check for signs of infection.

Many of the symptoms of sepsis, such as fever and difficulty breathing, are the same as in other conditions, making sepsis hard to diagnose in its early stages.

### How is sepsis treated?

People with sepsis are usually treated in the hospital.  Doctors try to treat the infection, keep the vital organs working, and prevent a drop in blood pressure.

Doctors treat sepsis with therapy, such as appropriate use of antibiotics, as soon as possible. Many patients receive oxygen and intravenous (IV) fluids to maintain normal blood oxygen levels and blood pressure.

Other types of treatment, such as assisting breathing with a machine or kidney dialysis, may be necessary. Sometimes surgery is required to remove tissue damaged by the infection.

### Are there any long-term effects of sepsis?

Many people who have sepsis recover completely and their lives return to normal. But some people may experience permanent organ damage. For example, in someone who already has kidney problems, sepsis can lead to kidney failure that requires lifelong dialysis.

### How can I prevent sepsis?

1 **GET VACCINATED** against the flu, pneumonia, and any other infections that could lead to sepsis. Talk to your doctor for more information.

2 **PREVENT INFECTIONS** that can lead to sepsis by:

- **Cleaning** scrapes and wounds

- Practicing good **hygiene** (e.g., hand washing)

3 **LEARN THE SIGNS AND SYMPTOMS** of sepsis. If sepsis is suspected, seek medical attention immediately.

### Where can I get more information?

- Centers for Disease Control and Prevention (CDC)—CDC works 24/7 protecting America's health, safety and security. Whether diseases start at home or abroad, are curable or preventable, chronic or acute, stem from human error or deliberate attack, CDC is committed to responding to America's most pressing health challenges. cdc.gov/sepsis cdc.gov/cancer/preventinfections

- The Rory Staunton Foundation for Sepsis Prevention— Supports education and outreach efforts aimed at rapid diagnosis and treatment of sepsis, particularly in children. rorystauntonfoundationforsepsis.org

- Sepsis Alliance®—Created to raise sepsis awareness among both the general public and healthcare professionals. Sepsis Alliance offers information on a variety of sepsis-related topics. Visit sepsis.org/library to view the complete series of titles. sepsis.org

THE RORY STAUNTON FOUNDATION
FOR SEPSIS PREVENTION

SEPSIS ALLIANCE
Suspect Sepsis. Save Lives.

*This fact sheet was developed in collaboration with CDC, Sepsis Alliance® and the Rory Staunton Foundation for Sepsis Prevention.*

*Figure A2 Sepsis Fact Sheet (Example only for patients with color deficiency)*



# SEPSIS FACT SHEET

### A POTENTIALLY DEADLY OUTCOME FROM AN INFECTION

**What is sepsis?**

Sepsis is a complication caused by the body's overwhelming and life-threatening response to an infection, which can lead to tissue damage, organ failure, and death.

**When can you get sepsis?**

Sepsis can occur to anyone, at any time, from any type of infection, and can affect any part of the body. It can occur even after a minor infection.

**What causes sepsis?**

Infections can lead to sepsis. An infection occurs when germs enter a person's body and multiply, causing illness and organ and tissue damage. Certain infections and germs lead to sepsis most often. Sepsis is often associated with infections of the lungs (e.g., pneumonia), urinary tract (e.g., kidney), skin, and gut. *Staphylococcus aureus* (staph), *Escherichia coli* (*E. coli*), and some types of *Streptococcus* (strep) are common germs that can cause sepsis.

**Are certain people with an infection more likely to get sepsis?**

Anyone can develop sepsis from an infection, especially when not treated properly. However, sepsis occurs most often in people aged 65 years or older or less than 1 year, have weakened immune systems, or have chronic medical conditions (e.g., diabetes).

A CDC evaluation found more than 90% of adults and 70% of children who developed sepsis had a health condition that may have put them at risk.

Ask your doctor about your risk for getting sepsis. If you suspect sepsis, ask your doctor, "Could it be sepsis?

**What are the symptoms of sepsis?**

There is no single sign or symptom of sepsis. It is, rather, a combination of symptoms. Since sepsis is the result of an infection, symptoms can include infection signs (diarrhea, vomiting, sore throat, etc.), as well as **ANY** of the **SYMPTOMS** below:

**What should I do if I think I have an infection or sepsis?**

- Call your doctor or go to the emergency room immediately if you have any signs or symptoms of an infection or sepsis. This is a medical emergency.

- It's important that you say, **"I AM CONCERNED ABOUT SEPSIS."**

- If you are continuing to feel worse or not getting better in the days after surgery, ask your doctor about sepsis. Sepsis is a common complication of people hospitalized for other reasons.
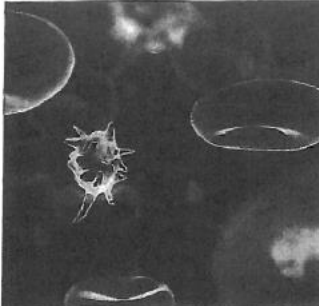
Shivering, fever, or very cold

Extreme pain or discomfort

Clammy, or sweaty skin

Confusion or disorientation

Short of breath

High heart rate

Centers for Disease Control and Prevention
National Center for Emerging and Zoonotic Infectious Diseases

CDC

CS257671C

## SEPSIS FACT SHEET

### How is sepsis diagnosed?

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Doctors treat sepsis with therapy, such as appropriate use of antibiotics, as soon as possible. Many patients receive oxygen and intravenous (IV) fluids to maintain normal blood oxygen levels and blood pressure.

Other types of treatment, such as assisting breathing with a machine or kidney dialysis, may be necessary. Sometimes surgery is required to remove tissue damaged by the infection.

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- The Rory Staunton Foundation for Sepsis Prevention— Supports education and outreach efforts aimed at rapid diagnosis and treatment of sepsis, particularly in children. rorystauntonfoundationforsepsis.org

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**Appendix B**

Invitation to Participate Email

Dear Colleague,

You have been identified as a sepsis content expert and are being invited to participate in a Doctoral of Nursing Practice (DNP) project to evaluate a sepsis patient education tool. Although sepsis is common, costly, has high readmission rates with associated poor outcomes, public and patient awareness of sepsis is deficient. Currently, no standard discharge education methods exist for sepsis survivors and caregivers. A printable sepsis patient education tool may be useful to increase awareness and improve outcomes.

The purpose of this project is to appraise the Centers for Disease Control and Prevention (CDC) *Sepsis Fact Sheet* capacity to explain important messages (usability) and action(s) to take based on the messages (actionability). The Agency for Healthcare Research and Quality (AHRQ) Patient Education Materials Assessment Tool (PEMAT-P) for printable material will be used to score the understandability and actionability of the *Sepsis Fact Sheet* instrument.

Participating in the project is voluntary. Your involvement will require approximately 1-1 ½ hours to review the material and to complete the survey. No identifiable information will be collected about you for this project. You can choose not to participate. Completion of the survey will constitute consent for participation. The survey hyperlink for this project will be available for two weeks starting ___/___/___ and ending ___/___/____.

**If you are agreeable to participate, please complete the steps below.** The PEMAT-P guide and the *Sepsis Fact Sheet* are attached for your reference. The Survey Monkey hyperlink is available to you following steps 1-5 below.

> **Note:** The guide to Patient Education Materials Assessment Tool for Printable Materials (PEMAT-P) includes a total of seven steps. You do not need to complete steps 6 & 7. Steps 6 & 7 are scoring calculations and will be completed after survey submission.

Steps 1-5 are outlined below.

 **Step 1: Read through the PEMAT and User's Guide.** Before using the PEMAT, read through the entire User's Guide and instrument to familiarize yourself with all the items.

**Step 2: Read or view patient education material.** Read through or view the patient education material (*Sepsis Fact Sheet*) that you are rating in its entirety.

**Step 3: Decide which PEMAT to use.** The PEMAT-P for printable materials has been selected for this project.

**Step 4: Go through each PEMAT item one by one.** All items will have the answer options "Disagree" or "Agree." Some—but not all—items will also have a "Not Applicable" answer option. Go one by one through each of the items, 24 for printable materials and indicate if you agree or disagree that the material meets a specific criterion. Or, when appropriate, select the "Not Applicable" option.

You may refer to the material (*Sepsis Fact Sheet*) at any time while you complete the form. You don't have to rely on your memory. **Consider each item from a patient perspective**. For example, for "Item 1: The material makes its purpose completely evident," ask yourself, "If I were a patient unfamiliar with the subject, would I readily know what the purpose of the material was?"

**Step 5: Rate the material on each item as you go.** After you determine the rating you would give the material on a specific item, enter the number (or N/A) that corresponds with your answer in the "Rating" column of the PEMAT. Do not score an item as "Not Applicable" unless there is a "Not Applicable" option. Score the material on each item as follows:

| | |
|---|---|
| If Disagree | Enter 0 |
| If Agree | Enter 1 |
| If Not Applicable | Enter N/A |

*Additional Guidance for Rating the Material on Each Item (Step 5)*
- Rate an item "Agree" when a characteristic occurs throughout a material, that is, nearly all of the time (80% to 100%). Your guiding principle is that if there are obvious examples or times when a characteristic could have been met or could have been better met, then the item should be rated "Disagree." The User's Guide provides additional guidance for rating each item.
- Do not skip any items. If there is no "Not Applicable" option, you must score the item 0 (Disagree) or 1 (Agree).
- Do not use any knowledge you have about the subject before you read or view the patient education material. Base your ratings ONLY on what is in the material that you are rating.
- Do not let your rating of one item influence your rating of other items. Be careful to rate each item separately and distinctly from how you rated other items.

Please use the hyperlink below to complete the survey. A text box is available at the end of the survey should you have additional feedback.

https://www.surveymonkey.com/r/PEMATSurvey

Thank you for your participation. Your time and expertise are sincerely appreciated.

Best,

Christa Schorr RN, MSN

Drexel Doctoral Student

**Appendix C**

PEMAT Scoring Tool

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*Read the PEMAT User's Guide (available at: http://www.ahrq.gov/professionals/prevention-chronic-care/improve/self-mgmt/pemat/) before rating materials.*

**UNDERSTANDABILITY**

| Item # | Item | Response Options | Rating |
|--------|------|------------------|--------|
| **Topic: Content** | | | |
| 1 | The material makes its purpose completely evident. | Disagree=0, Agree=1 | |
| 2 | The material does not include information or content that distracts from its purpose. | Disagree=0, Agree=1 | |
| **Topic: Word Choice & Style** | | | |
| 3 | The material uses common, everyday language. | Disagree=0, Agree=1 | |
| 4 | Medical terms are used only to familiarize audience with the terms. When used, medical terms are defined. | Disagree=0, Agree=1 | |
| 5 | The material uses the active voice. | Disagree=0, Agree=1 | |
| **Topic: Use of Numbers** | | | |
| 6 | Numbers appearing in the material are clear and easy to understand. | Disagree=0, Agree=1, No numbers=N/A | |
| 7 | The material does not expect the user to perform calculations. | Disagree=0, Agree=1 | |
| **Topic: Organization** | | | |
| 8 | The material breaks or "chunks" information into short sections. | Disagree=0, Agree=1, Very short material*=N/A | |
| 9 | The material's sections have informative headers. | Disagree=0, Agree=1, Very short material*=N/A | |
| 10 | The material presents information in a logical sequence. | Disagree=0, Agree=1 | |
| 11 | The material provides a summary. | Disagree=0, Agree=1, Very short material*=N/A | |
| **Topic: Layout & Design** | | | |
| 12 | The material uses visual cues (e.g., arrows, boxes, bullets, bold, larger font, highlighting) to draw attention to key points. | Disagree=0, Agree=1 Video=N/A | |

---

* A very short print material is defined as a material with two or fewer paragraphs and no more than 1 page in length.

Patient Education Materials Assessment Tool for Printable Materials (PEMAT-P)                    3

| Item # | Item | Response Options | Rating |
|---|---|---|---|
| **Topic: Use of Visual Aids** | | | |
| 15 | The material uses visual aids whenever they could make content more easily understood (e.g., illustration of healthy portion size). | Disagree=0, Agree=1 | |
| 16 | The material's visual aids reinforce rather than distract from the content. | Disagree=0, Agree=1, No visual aids=N/A | |
| 17 | The material's visual aids have clear titles or captions. | Disagree=0, Agree=1, No visual aids=N/A | |
| 18 | The material uses illustrations and photographs that are clear and uncluttered. | Disagree=0, Agree=1, No visual aids=N/A | |
| 19 | The material uses simple tables with short and clear row and column headings. | Disagree=0, Agree=1, No tables=N/A | |

*Total Points:* _____

*Total Possible Points:* _____

**Understandability Score (%):** _____
*(Total Points / Total Possible Points) × 100*

## ACTIONABILITY

| Item # | Item | Response Options | Rating |
|---|---|---|---|
| 20 | The material clearly identifies at least one action the user can take. | Disagree=0, Agree=1 | |
| 21 | The material addresses the user directly when describing actions. | Disagree=0, Agree=1 | |
| 22 | The material breaks down any action into manageable, explicit steps. | Disagree=0, Agree=1 | |
| 23 | The material provides a tangible tool (e.g., menu planners, checklists) whenever it could help the user take action. | Disagree=0, Agree=1 | |
| 24 | The material provides simple instructions or examples of how to perform calculations. | Disagree=0, Agree=1, No calculations=NA | |
| 25 | The material explains how to use the charts, graphs, tables, or diagrams to take actions. | Disagree=0, Agree=1, No charts, graphs, tables, or diagrams=N/A | |
| 26 | The material uses visual aids whenever they could make it easier to act on the instructions. | Disagree=0, Agree=1 | |

*Total Points:* _____

*Total Possible Points:* _____

**Actionability Score (%):** _____
*(Total Points / Total Possible Points) × 100*

Appendix D

*Sepsis Fact Sheet* Assessment-PEMAT-P Survey Monkey Version

**Sepsis Fact Sheet Assessment**

*UNDERSTANDABILITY - Content*

| | Agree | Disagree | N/A |
|---|---|---|---|
| The material makes its purpose completely evident. | ☐ | ☐ | ☐ |
| The material does not include information or content that distracts from its purpose. | ☐ | ☐ | ☐ |

*UNDERSTANDABILITY - Word Choice & Style*

| | Agree | Disagree | N/A |
|---|---|---|---|
| The material uses common, everyday language. | ☐ | ☐ | ☐ |
| Medical terms are used only to familiarize audience with the terms. When used, medical terms are defined. | ☐ | ☐ | ☐ |
| The material uses the active voice. | ☐ | ☐ | ☐ |

*UNDERSTANDABILITY - Use of Numbers*

| | Agree | Disagree | N/A |
|---|---|---|---|
| Numbers appearing in the material are clear and easy to understand. | ☐ | ☐ | ☐ |
| The material does not expect the user to perform calculations. | ☐ | ☐ | ☐ |

*UNDERSTANDABILITY - Organization*

| | Agree | Disagree | N/A |
|---|---|---|---|
| The material breaks or "chunks" information into short sections. | ☐ | ☐ | ☐ |
| The material's sections have informative headers. | ☐ | ☐ | ☐ |
| The material presents information in a logical sequence. | ☐ | ☐ | ☐ |
| The material provides a summary. | ☐ | ☐ | ☐ |

*UNDERSTANDABILITY - Layout & Design*

| | Agree | Disagree | N/A |
|---|---|---|---|
| The material uses visual cues (e.g., arrows, boxes, bullets, bold, larger font, highlighting) to draw attention to key points. | ☐ | ☐ | ☐ |

*UNDERSTANDABILITY - Use of Visual Aids*

| | Agree | Disagree | N/A |
|---|---|---|---|
| The material uses visual aids whenever they could make content more easily understood (e.g., illustration of healthy portion). | ☐ | ☐ | ☐ |
| The material's visual aids reinforce rather than distract from the content. | ☐ | ☐ | ☐ |
| The material's visual aids have clear titles or captions. | ☐ | ☐ | ☐ |
| The material uses illustrations and photographs that are clear and uncluttered. | ☐ | ☐ | ☐ |
| The material uses simple tables with short and clear row and column headings. | ☐ | ☐ | ☐ |

*ACTIONABILITY*

| | Agree | Disagree | N/A |
|---|---|---|---|
| The material clearly identifies at least one action the user can take. | ☐ | ☐ | ☐ |
| The material addresses the user directly when describing actions. | ☐ | ☐ | ☐ |
| The material breaks down any action into manageable, explicit steps. | ☐ | ☐ | ☐ |
| The material provides a tangible tool (e.g., menu planners, checklists) whenever it could help the user take action. | ☐ | ☐ | ☐ |
| The material provides simple instructions or examples of how to perform calculations. | ☐ | ☐ | ☐ |
| The material explains how to use the charts, graphs, tables, or diagrams to take actions. | ☐ | ☐ | ☐ |
| The material uses visual aids whenever they could make it easier to act on the instructions. | ☐ | ☐ | ☐ |

**Any Additional Feedback?**

[                    ]

[ Done ]

Appendix E

Project Timeline

*Project Timeline*

| Activity | Week of 6/12/17 | 6/19/2017 | 6/26/2017 | 7/3/2017 | 7/10/2017 | 7/24/2017 | 7/31/2017 | 8/7/2017 | 8/14/2017 | 8/21/2017 | 8/29/2017 |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Prepare for project defense | | | | | | | | | | | |
| Submit proposal to Cooper IRB/await approval | | | | | | | | | | | |
| Send email invitation to participants | | | | | | | | | | | |
| Email prompt | | | | | | | | | | | |
| Email assessment closure | | | | | | | | | | | |
| Data analysis | | | | | | | | | | | |
| Preparation for project defense manuscript | | | | | | | | | | | |

Appendix F

Statistical Results

Table F1

*PEMAT-P Descriptive Analysis*

| PEMAT-P Section | Score |
| --- | --- |
| Understandability Score, Mean (SD) | 80.74 (+/-13.41) |
| Actionability Score, Mean (SD) | 90.74 (+/-14.10) |
| Overall Score, Mean (SD) | 83.33 (+/-12.16) |

PEMAT-P=Patient Education Materials Assessment Tool for printable material; N/A not included in this analysis

Table F2

*Interrater Reliability*

|  | Kappa | Agreement |
|---|---|---|
| Understandability* | 0.210 (95% CI = 0.147, 0.273) | Fair |
| Actionability* | 0.430 (95% CI = 0.328, 0.552) | Moderate |
| Overall* | 0.290 (95% CI = 0.239,0.341) | Fair |

*Note.* Fleiss Kappa statistic *P Value <0.001

Table F3

*Understandability Items*

| # | Understandability items N=9 | Agree | Disagree | N/A | Percent Agree |
|---|---|---|---|---|---|
| | Topic: Content | | | | |
| 1 | The material makes its purpose completely evident. (n) | 6 | 3 | 0 | 66.67% |
| 2* | The material does not include information or content that distracts from its purpose. (n) | 5 | 3 | 0 | 62.50% |
| | Topic: Word Choice & Style | | | | |
| 3 | The material uses common, everyday language. (n) | 6 | 3 | 0 | 66.67% |
| 4 | Medical terms are used only to familiarize audience with the terms. When used, medical terms are defined. (n) | 7 | 2 | 0 | 77.78% |
| 5 | The material uses the active voice. (n) | 7 | 1 | 1 | 77.78% |
| | Topic: Use of Numbers | | | | |
| 6 | Numbers appearing in the material are clear and easy to understand. (n) | 8 | 0 | 1 | 88.89% |
| 7 | The material does not expect the user to perform calculations. (n) | 7 | 1 | 1 | 77.78% |
| | Topic: Organization | | | | |
| 8 | The material breaks or "chunks" information into short sections. (n) | 9 | 0 | 0 | 100% |
| 9 | The material's sections have informative headers. (n) | 9 | 0 | 0 | 100% |
| 10 | The material presents information in a logical sequence. (n) | 8 | 1 | 0 | 88.89% |
| 11 | The material provides a summary. (n) | 2 | 7 | 0 | 22.22% |
| | Topic: Layout & Design | | | | |
| 12 | The material uses visual cues (e.g., arrows, boxes, bullets, bold, larger font, highlighting) to draw attention to key points. (n) | 8 | 1 | 0 | 88.89% |
| | Topic: Use of Visual Aids | | | | |
| 13 | The material uses visual aids whenever they could make content more easily understood (e.g., illustration of healthy portion size). (n) | 8 | 1 | 0 | 88.89% |
| 14 | The material's visual aids reinforce rather than distract from the | 8 | 1 | 0 | 88.89% |

| | | | | | |
|---|---|---|---|---|---|
| | content. (n) | | | | |
| 15 | The material's visual aids have clear titles or captions. (n) | 8 | 1 | 0 | 88.89% |
| 16 | The material uses illustrations and photographs that are clear and uncluttered. (n) | 7 | 2 | 0 | 77.78% |

*Note.* *One participant did not answer the question

Table F4

*Actionability Items*

| # | ACTIONABILITY Items N=9 | Agree | Disagree | N/A | Percent Agree |
|---|---|---|---|---|---|
| 18 | The material clearly identifies at least one action the user can take. (n) | 9 | 0 | 0 | 100% |
| 19 | The material addresses the user directly when describing actions. (n) | 9 | 0 | 0 | 100% |
| 20 | The material breaks down any action into manageable, explicit steps. (n) | 9 | 0 | 0 | 100% |
| 21 | The material provides a tangible tool (e.g., menu planners, checklists) whenever it could help the user take action. (n) | 6 | 1 | 2 | 66.67% |
| 22 | The material provides simple instructions or examples of how to perform calculations. (n) | 1 | 0 | 8 | 11.11% |
| 23 | The material explains how to use the charts, graphs, tables, or diagrams to take actions. (n) | 3 | 1 | 5 | 33.33% |
| 24 | The material uses visual aids whenever they could make it easier to act on the instructions. (n) | 7 | 2 | 0 | 77.78% |

Appendix G

Expert Comments and Additional Feedback

- *Too much information being provided on one sheet; overwhelming*
- *Great job! There are still some words not typical for common vernacular such as "gut" to mean digestive tract.*
- *I would not lump infection and sepsis together with instructions that 'this is a medical emergency'. Stratify response based on severity or number of symptoms, for example.*
- *This tool is excellent! It is clear, provides a lot of good practical information and will be an asset to healthcare providers teaching patients about sepsis. I also see this as a great handout in doctors offices and clinics. I am looking forward to having access to it.*
- *Instead of "SEPSIS FACT SHEET, A POTENTIALLY DEADLY OUTCOME FROM AN INFECTION" as a title maybe something like "I think I have sepsis, what do I do"*
- *No explanations for meaning of pictures on left top and left bottom, just interesting looking colored clutter.*
- *Didn't know whether to click agree or N/A for the calculations question. No calculations are required so none are done.*
- *Actionability - visual aids could have been used more, especially for actions.*

Appendix H

Assessment of Readability

| Readability Statistics | |
| --- | --- |
| Counts | |
| Words | 775 |
| Characters | 4083 |
| Paragraphs | 42 |
| Sentences | 53 |
| Averages | |
| Sentences per Paragraph | 1.8 |
| Words per Sentence | 13.0 |
| Characters per Word | 4.9 |
| Readability | |
| Passive Sentences | 7% |
| Flesch Reading Ease | 49.9 |
| Flesch-Kinkaid Grade Level | 9.5 |