

A decorative graphic on the left side of the slide consists of several overlapping white circles of varying sizes. Inside some of these circles are white icons: a book, a speech bubble, a document with a hand cursor, a laptop, and a mouse cursor. The background is a gradient of blue and purple.

ATiA 2021

Patient-Provider Communication, Healthcare Disparities, AAC, and COVID-19

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Speaker Disclosures/Session Disclosure

Rachel Santiago is a salaried employee at Boston Children's Hospital.

Tami Altschuler is a salaried employee at NYU Langone Medical Center.

Jessica Gormley is a salaried employee at the University of Nebraska Medical Center.

Sarah Gendreau is a salaried employee at Massachusetts General Hospital.

Richard Hurtig is an unsalaried employee of The University of Iowa and Voxello, Inc. He is the Chief Scientific Officer of Voxello and the inventor of the patented noddle smart switch.

All speakers are volunteer participants of the Patient-Provider Communication Network's COVID-19 Task Force.

This presentation will mention free materials and resources created by the Patient-Provider Communication Network.

1. Identify three reasons patient-provider communication is a fundamental aspect of patient care
1. Describe three examples of low-tech strategies to enhance patient-provider communication
1. Discuss one recommendation for assessment and intervention in a patient with communication vulnerability, such as a person with COVID-19.

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Patient-Provider Communication as a Fundamental Aspect of Patient Care

Nonspeaking Patients are at risk for:

- Preventable adverse events (Bartlett et al., 2008; Hurtig, Alper, & Berkowitz, 2018)
- Serious medical events (Cohen, et al., 2009)
- Poor medication compliance (Andrulis, et al., 2002)
- Increased risk of leaving AMA (Flores, 2003)
- Increased fear, stress, and sleep disturbance (Happ, et al., 2004)
- Inability to participate in own care (Garret, et al., 2007)

Benefits of AAC:

- Augmentative and Alternative Communication (AAC) is used by individuals for whom speech is not a primary method of communication
- Patient-provider communication is paramount to patient care and patient satisfaction
- Policies in place support communication access (The Joint Commission, 2010)
- Patients who have access to an effective communication system:
 - Receive less sedation
 - Transition more quickly to lower levels of care
 - Provide increased patient satisfaction scores

Communication Vulnerable Patients:

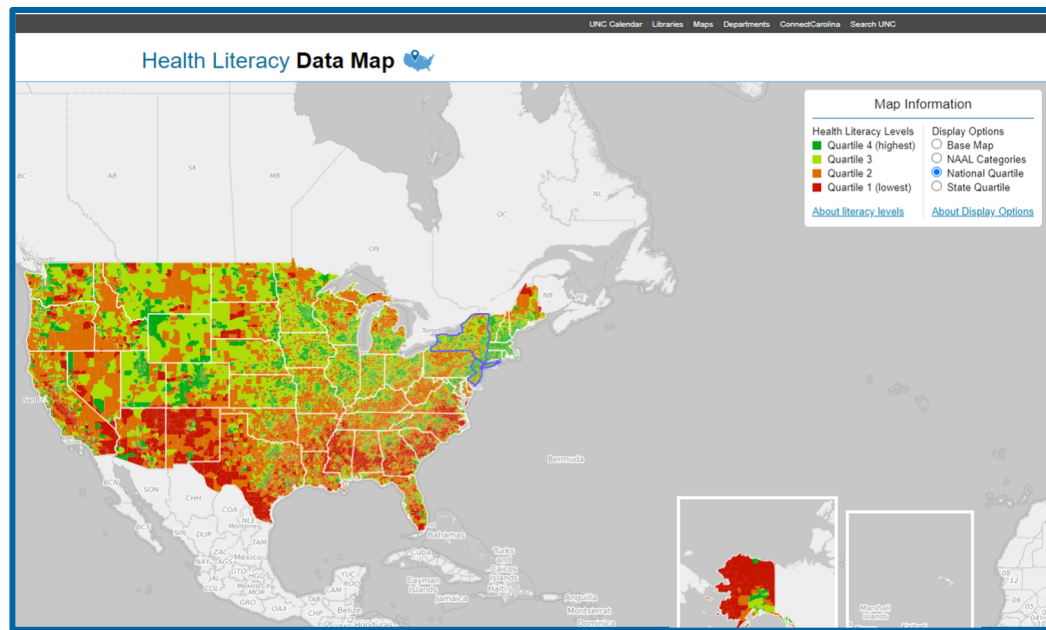
- Inability to produce intelligible speech
- Pre-existing speech/language difficulties
- Medical treatment (intubation, trach, BIPAP)
- Neurogenic deficits (aphasia, dysarthria, apraxia, TBI)
- Sensory: hearing and vision
- Limited English Proficiency
- Difficulty reading and/or writing
- Health literacy

COVID-19 Specific Barriers, Risks, and Vulnerabilities

All pre-COVID19 issues **plus:**

- Respiratory symptom sequelae
- Implications for short- & long-term speech & communication difficulties
- Personal Protective Equipment (PPE)
- Visitor restrictions
- Reduced provider time at bedside
- Reduced access to equipment
- Fewer bedside consulting teams (e.g. live interpreters, speech-language pathologists, other)

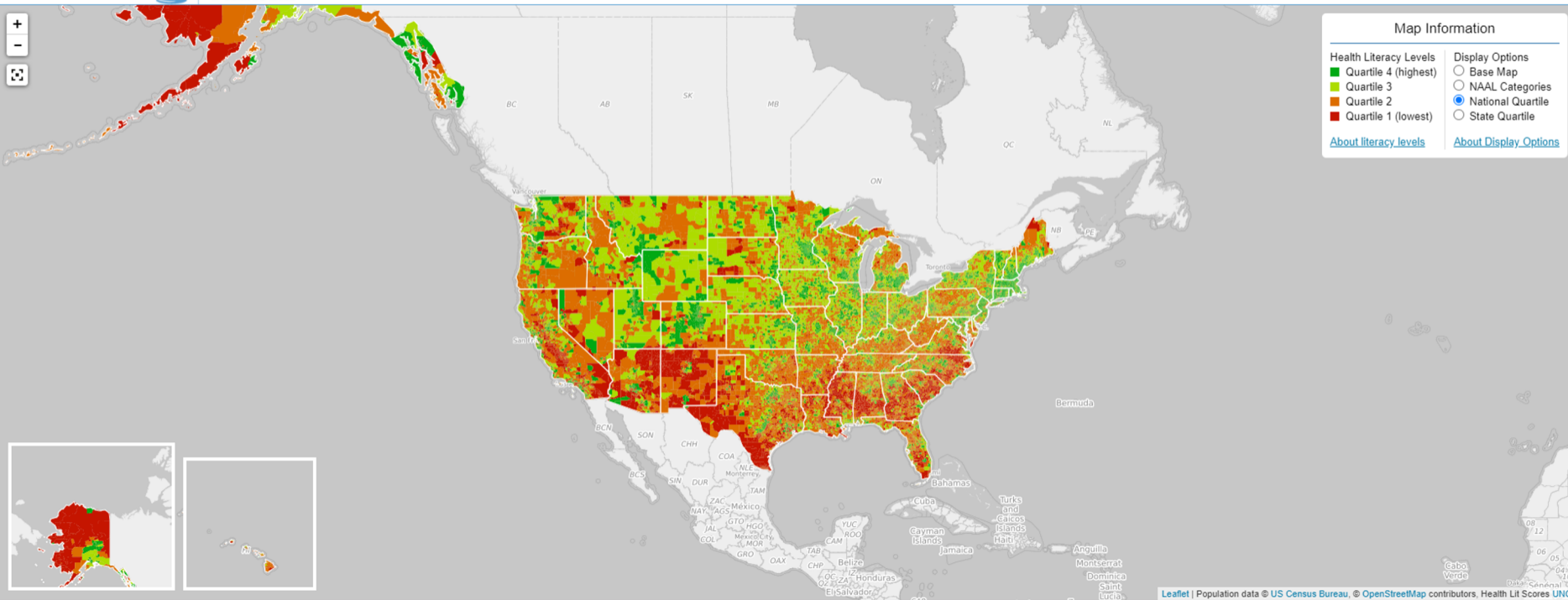
- Limited health literacy and hospital experience
 - ~36% of Americans have low health literacy
- People with communication disorders
- People with developmental disabilities
- Patients who require access to needed supports
 - Support person or caregiver
 - Equipment
 - Accessibility materials
- Patients who are Deaf/HoH
- Patients who are blind/low vision
- ...and more





THE UNIVERSITY
of NORTH CAROLINA
at CHAPEL HILL

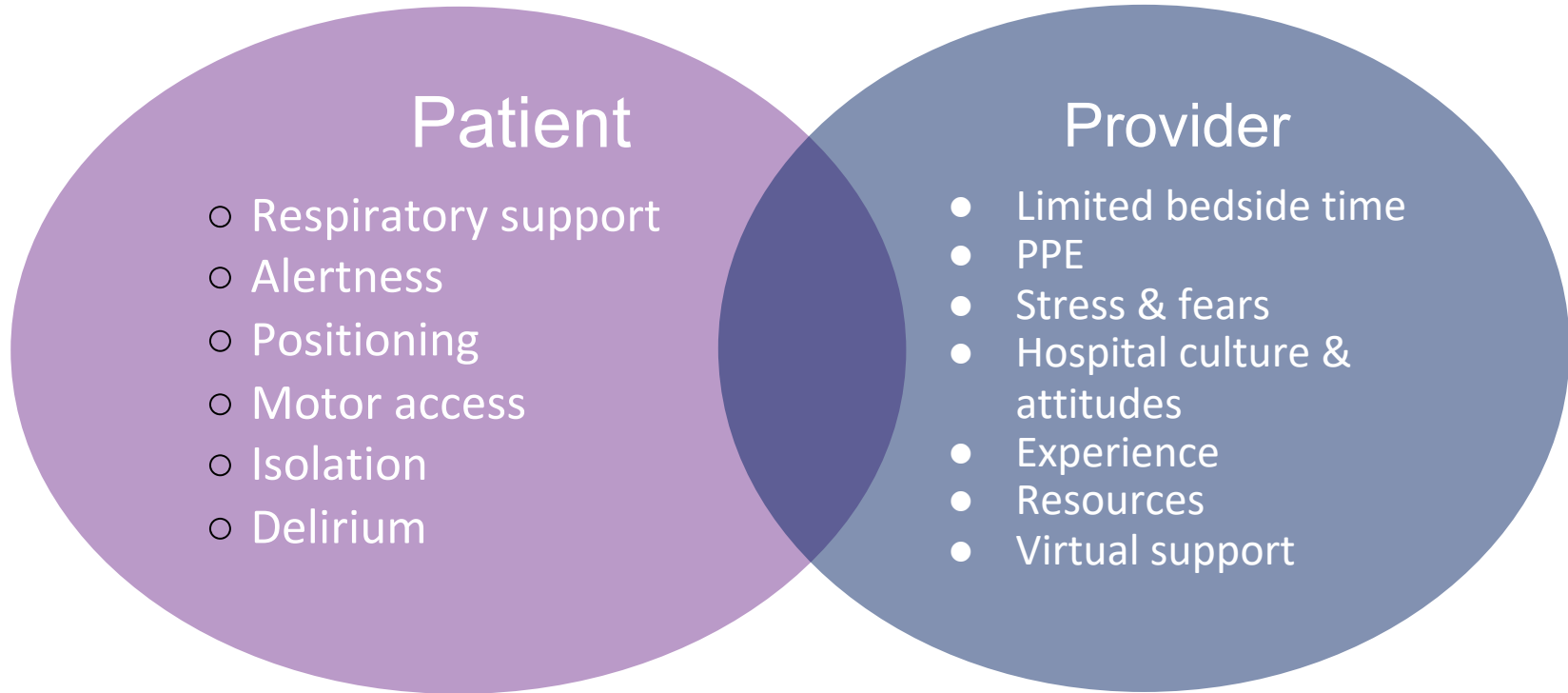
Health Literacy Data Map

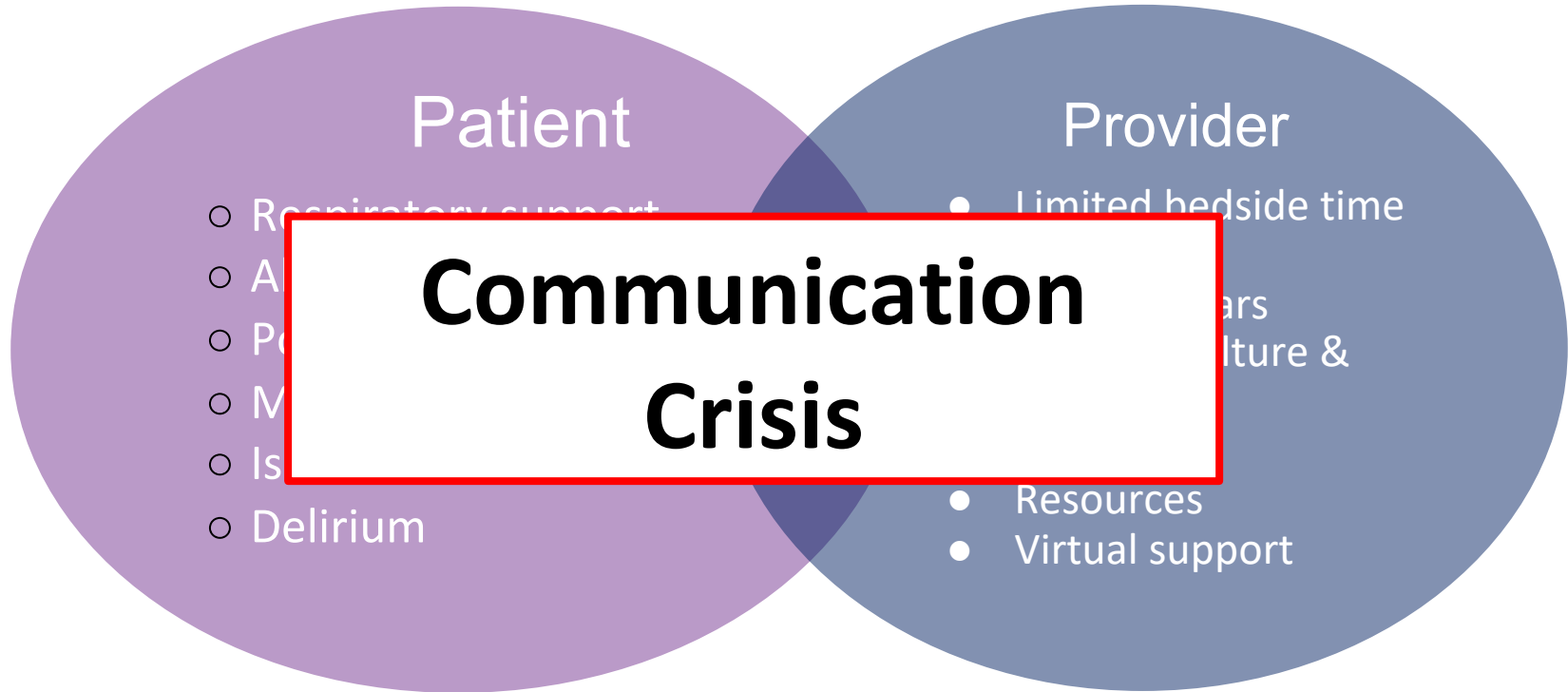


To view the map, click: <http://healthliteracymap.unc.edu/>

- Limited English proficiency + need for bidirectional communication ([ACS-LEP SURVEY 2016](#))
 - ~63.2 million people >5 y.o do not speak English in the home
 - ~25.5 million people >5 y.o speak English “less than very well”
- Affects both:
 - Patient to provider barriers
 - Provider to patient barriers
- Professional interpreters \cong half as many errors as ad hoc interpreters (Napolés et al, 2015)
- Messages must be mutually understood

MGH Data: At the height of the surge in the state of Massachusetts in April 2020, 50% of the hospital's patients had limited English proficiency compared to an average of 9% prior to COVID 19--per interpreter services data





Healthcare Providers

Educate yourself
Find out about unit & patient needs
Visit website to identify tools
Print, laminate, disseminate
Create “ready made” binders
Train staff on communication access techniques and systems
Identify patient-provider communication champions

Patients

Prepare materials that will support communication with emergency and other healthcare professionals

- Hospital Passport, emergency cards, Go Bag, etc.
- Social stories (e.g., coronavirus testing)

Know your rights
Call your local hospital:

- What are the visitation policies?
- What communication supports are available?
- What is available? What can I bring?

Advocate for your needs

Community and Educational Providers

Talk to hospital personnel
Find out about the patient experience
Assist in creating:

- Hospital Passport
- Emergency cards
- Go Bag
- Backup or low-tech communication tools
- Healthcare related page sets
- Social stories

Make sure clients can access virtual technologies

Enhancing PPC at the Bedside During the COVID-19 Pandemic

- General considerations
- Infection control concerns
- Solutions and Responses



General care considerations

- Medical acuity & communication vulnerability
 - Mechanical ventilation
 - Sedation
 - Delirium
 - Neurological and cognitive changes
 - Vocal cord dysfunction
 - etc.
- Hospital Resources
 - Capacity, equipment demand
- Access to communication and sensory aids
 - Glasses, hearing aids, cochlear implant processors, and other sensory aids (and batteries!)
 - Baseline AAC systems



Infection control concerns

- PPE
 - Shortages
 - Reduced speech intelligibility
 - Impacts ability to read lips and facial expressions
- Visitors
 - Limited or prohibited completed
 - Support personnel/family unable to be at bedside
 - Need for emotional support
- Exposure risk
 - Limited staff permitted in rooms
 - Limited staff on site
- Physical Materials
 - AAC devices



Solutions and Responses

- Interprofessional collaboration
 - Creating a culture that prioritizes communication access
 - Communication partner training
- Virtual care
 - Telehealth & video calls
 - Increased phone call follow up with families for updates
- Support personnel
 - Visitor restriction exceptions
- Enhance health literacy and access
 - Incorporate visuals
 - Easily accessible and shareable information for loved ones



Solutions and Responses (continued)

- Communication supports
 - Ensure access to baseline strategies
 - Low/no tech, ready made and single-use tools
 - Clear masks (for COVID negative patients)
 - Hearing enhancers
 - Visual aids
 - Need for bilingual tools
 - More tools were needed!



Tools and Strategies to Enhance Patient-Provider Communication

Team Members:

Tami Altschuler, Sarah Blackstone, Sarah Gendreau, Jessica Gormley, Mary Beth Happ, Richard Hurtig, Sarah Marshall, Harvey Pressman, Rachel Santiago, Stephanie Scibilia, Rachel Tobin

Goals = To create free tools that can be quickly customized to fit busy, face-paced health care settings



- Pain scales
- Yes/no
- Letter Boards
- General Needs - Adults
- General Needs - Pediatrics
- Medical Decision Making
- Serious Illness
- Create Your Own
- Instructions

<https://www.patientprovidercommunication.org/covid-19-tools/free-english-tools/>



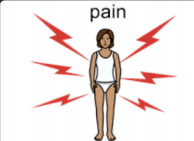
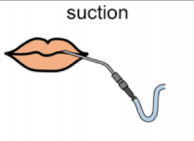

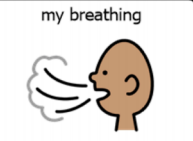
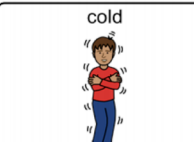










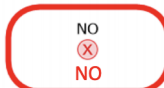
- Arabic/English
- Bulgarian/English
- Chinese/English
- French/English
- German/English
- Haitian-Creole/English
- Hebrew/English
- Italian/English
- Karen-Burmese/English
- Portuguese/English
- Russian/English
- Spanish/English
- Portuguese/English
- Tagalog/English
- Vietnamese/English

SUCTION  شفط	WHAT'S MY STATUS?  ما هو وضعي؟	CALL MY FAMILY  إتصل بعائلتي	LIGHTS ON/OFF  تشغيل / إطفاء الأضواء
TROUBLE BREATHING  صعوبة في التنفس	PAIN  ألم	MEDICINE  دواء	HOT COLD  حار / بارد
BATHROOM  الحمام (المرحاض)	REPOSITION  تغيير موضع	MOUTH CARE  العناية بالفم	LETTER BOARD  لوحة الرسائل
MAYBE- يمكن		DON'T KNOW- لا أعرف	LATER- في وقت لاحق

<https://www.patientprovidercommunication.org/covid-19-free-bilingual-tools.htm>

WHAT IS MY PROGNOSIS? ¿CUÁL ES MI PROGNÓSTICO?	WHAT ARE MY OPTIONS? ¿CUÁLES SON MIS OPCIONES?	WILL I GET BETTER? ¿VOY A MEJORAR?	AM I GOING TO DIE? ¿VOY A MORIR?
WHAT WILL HAPPEN NEXT? ¿QUÉ PASARÁ DESPUÉS?	WILL I HAVE PAIN? ¿TENDRÉ DOLOR?	I WANT TO DISCUSS MY DECISIONS QUIERO DISCUTIR MIS DECISIONES	I WANT MY FAMILY TO DECIDE QUIERO QUE MI FAMILIA DECIDA
WHEN WILL I COME OFF THE VENTILATOR? ¿CUÁNDO SALDRÉ DEL RESPIRADOR?	WHAT HAPPENS IF I AM TAKEN OFF THE VENTILATOR? ¿QUÉ PASARÁ SI ME QUITAN EL RESPIRADOR?	I AM NOT READY TO MAKE A DECISION NO ESTOY LISTO(A) PARA TOMAR UNA DECISIÓN	I HAVE ANOTHER QUESTION TENGO OTRA PREGUNTA
MAYBE - TAL VEZ		DON'T KNOW - NO SE	LATER - MÁS TARDE

Spanish Medical Decision Making – 12 target

 <p>pain</p> <p>DOLOR</p>	 <p>suction</p> <p>SUCCIÓN</p>	 <p>fix pillow</p> <p>ARREGLAR LA ALMOHADA</p>	 <p>my breathing</p> <p>MI RESPIRACIÓN</p>
 <p>cold</p> <p>FRÍO</p>	 <p>hot</p> <p>CALIENTE</p>	 <p>adjust bed</p> <p>AJUSTAR LA CAMA</p>	 <p>When tube out?</p> <p>¿CUÁNDO RETIRAR EL TUBO?</p>
 <p>bathroom</p> <p>BAÑO (INODORO)</p>	 <p>toys</p> <p>JUGUETES</p>	 <p>entertainment</p> <p>ENTRETENIMIENTO</p>	 <p>family</p> <p>FAMILIA</p>
 <p>YES</p> <p>SÍ</p>	 <p>I DON'T KNOW ?</p> <p>NO LO SÉ</p>	 <p>SOMETHING ELSE</p> <p>ALGO MÁS</p>	 <p>NO</p> <p>NO</p>

Spanish Pediatric General Needs – Line drawings – 12 targets

Time-saver to assist with the personalization of communication supports



If it's hard for patient to point, please use "partner-assisted scanning" This is how:

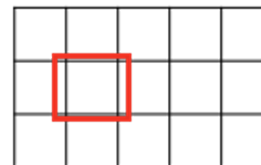
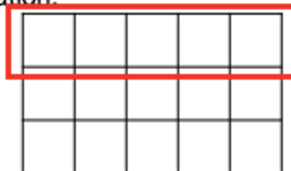
Ask patient to focus on the communication board and find the message they want to communicate.
Establish patient's "yes" (i.e. nodding, blinking, thumbs up, etc.)

- Instructions posted on the back side of each board to help with partner training

1. **Proceed row by row. Point to each row and ask if the desired message is in that row**
(e.g. point to 1st row and ask, "Is it in this row?" followed by 2nd row, and so on)
2. **Patient will select a row using the established YES response. Verify the choice out loud.**
3. **Point to each message within the selected row ("Is it suction?" "Trouble breathing," etc.).**
4. **Patient will signal that you are pointing to the desired message using established YES response.**
5. **Confirm the selection & repeat.**

Additional Considerations:

- Hold this tool ~12 inches (~30 cm) from the patient's face.
- Ensure good lighting, head positioning, and vision.
- Speak **loudly** and **clearly** using **simple language**.
- Wearing masks and other PPE may make it difficult to understand speech. Consider using communication tools when speaking to the patient as well.
- If the patient can't use this tool effectively now, that does not mean the patient won't be able to use it later today, tomorrow, or this week. Continue to provide opportunities to support communication.





Tips for Bedside Communication & Materials Preparation



COVID-19 patients may have difficulty understanding you when you are speaking through the protective masks. Here are some tips to remember and use:

- Get the patient's attention by touching their shoulder or arm and locking eyes.
- Speak loudly, slowly and distinctly.
- Establish a clear YES-NO signal (ex: head nod/shake; thumb up/closed fist; eyeblink/eye shut; look up/eyes shut)
- Post a sign so all providers know the YES-NO signal
- Speak in simple phrases – like a television announcer. Repeat important words.

[Supporting Communication with Patients who have COVID-19](#)

[FREE English Tools](#)

[FREE Bilingual Tools](#)

[Case Examples](#)

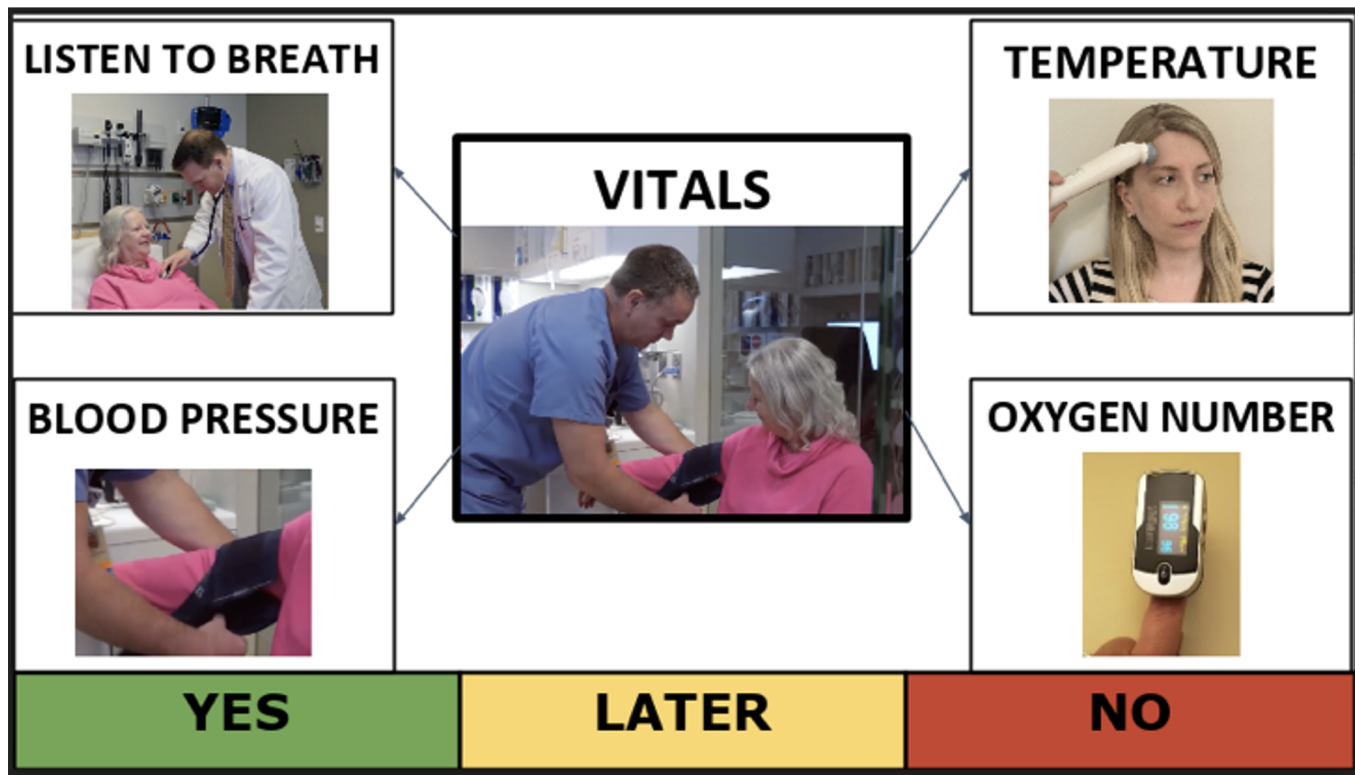
[Tips for Bedside Communication & Materials Preparation](#)

[Additional Resources](#)

[The PPC Taskforce](#)



Comprehension Supports for Patients



WHAT DO YOU WANT TO DISCUSS?

MAIN PAGE 1

MEDICAL DECISION MAKING <small>p. 3</small>		MEDICAL STATUS QUESTIONS <small>p. 15</small>		
EMOTIONS <small>p. 17</small>		RELIGION / SPIRITUALITY <small>p. 19</small>		
YES	I DON'T KNOW/ UNDERSTAND	LATER	LETTER BOARD/ OTHER	NO

MY DECISIONS <small>p. 5</small>	BREATHING TUBES & MACHINES <small>p. 7</small>	CPR / RESUSCITATION <small>p. 9</small>	DIALYSIS <small>p. 11</small>	FEEDING TUBES <small>p. 13</small>
HEALTH CARE PROXY	COMFORT CARE	ALLOW NATURAL DEATH	FUNERAL PLANS	ORGAN DONATION
YES	I DON'T KNOW/ UNDERSTAND	LATER	LETTER BOARD/ OTHER	NO

BREATHING TUBES & MACHINES 7

WHAT IS A VENTILATOR?	WHAT ARE MY OPTIONS?	COULD I GO HOME WITH IT?	WILL I BE ABLE TO SPEAK?	
WHAT IS A BREATHING TUBE?	OK WITH A <u>CHRONIC</u> BREATHING TUBE	OK WITH A <u>TEMPORARY</u> BREATHING TUBE	I DON'T WANT A BREATHING TUBE AT ALL	
YES	I DON'T KNOW/ UNDERSTAND	LATER	LETTER BOARD/ OTHER	NO

MEDICAL STATUS QUESTIONS 15

WHAT IS HAPPENING TO ME?	WILL I GET BETTER?	AM I GOING TO DIE?	HAVE WE DONE ALL WE CAN?	
WHAT ARE MY OPTIONS?	WILL I BE AWAKE?	WILL IT HURT?	I WANT TO TALK WITH MY FAMILY	
YES	I DON'T KNOW/ UNDERSTAND	LATER	LETTER BOARD/ OTHER	NO

<https://www.patientprovidercommunication.org/download/library/covid-19-free-tools/serious-illness-conversation-communication-boards-141.pdf>

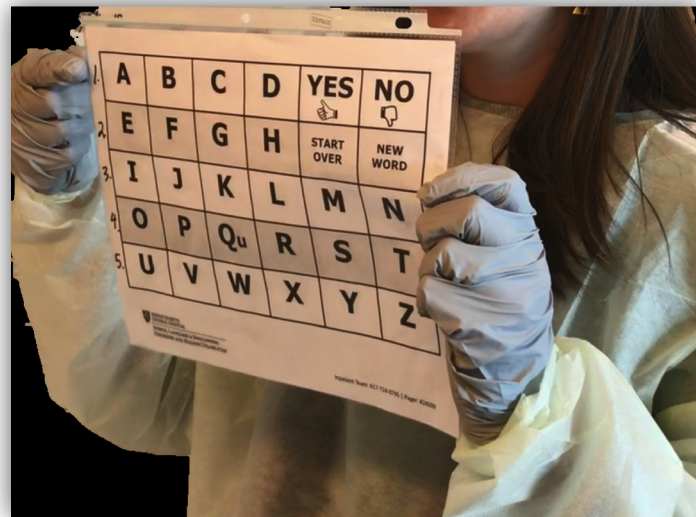
Patient Stories: Communication Vulnerability and COVID-19

Young adult woman with hx of obesity, depression/anxiety, and asthma, who presented with COVID-19 respiratory failure.

- Treated with hydroxychloroquine and tocilizumab (c/f cytokine storm), paralytics, intermittent proning (periods of 48 hours)
- 21-day intubation, trach/PEG on day 21
- Total of 5 weeks ventilation
- Critical illness myopathy, tongue mucosal injury, facial cellulitis, pneumonia

SLP consulted for swallow evaluation, but also...

- Communication vulnerable!
 - Aphonic due to open trach
 - Profound deconditioning
 - Resolving delirium
- Identified communication methods
 - Primary: Mouthing at phrase level. Mouths single words letter-by-letter if there's breakdown
 - Back up: Partner-assisted-scanning/spelling
 - List of common, ranked yes/no questions
 - Pain scale
 - Working on functional gestures (shoulder shrug, pointing) and writing



Young adult male with a h/o TBI and spastic quadriplegia was admitted with COVID-19.

- Tracheostomy at baseline and able to speak yet now required ventilator support and suddenly non-verbal
- Before his hospitalization, he used a tablet which he accessed via direct selection with an adapted stylus, however the stylus was lost during transport
- He typed out messages on the Notes app yet physical access was challenging and providers needed to be in closer proximity to read the messages which increased virus exposure

Patient Story 2 - Intervention

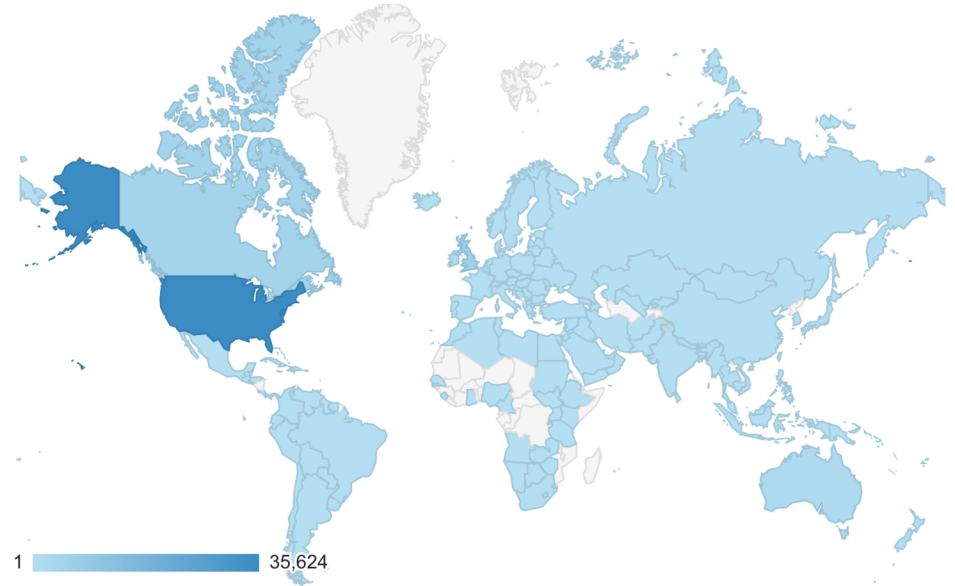
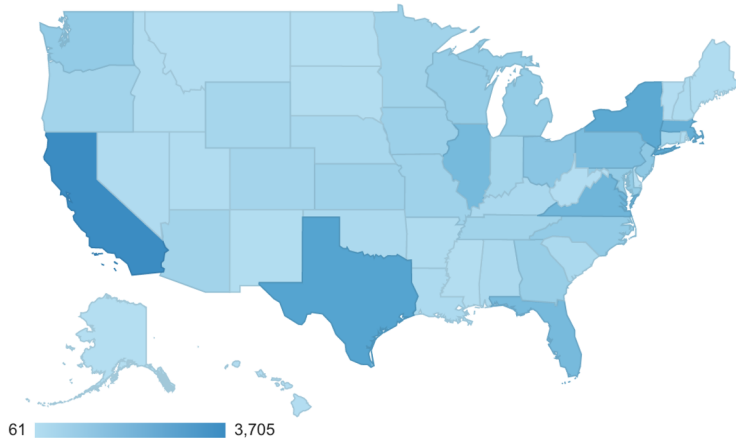
- Patient was seen for AAC evaluation at the bedside and with family connected via FaceTime
- SLP downloaded a text to speech app (Verbally) to his personal iPad and he was able to use this independently via direct selection with adapted stylus provided by SLP
- Voice output enabled him to communicate with nurses using the call bell and with providers who stood at his doorway - this decreased burden of care on staff with limited time to be at his bedside for every communication exchange
- With voice output via text to speech app, he was able to self-advocate, navigate medical decision making, request referrals (e.g. social work), and interact with his family virtually



*"When can I go home?"
Verbally app on personal iPad with
adapted stylus*

From March 21, 2020 - January 23, 2021

- 55,017 users visited the website
- 175,127 page views
- 169 countries
- 27,103 downloads



- 37 participants
- Majority of respondents were SLPs (n = 36)
- Majority of respondents practiced in the USA (n = 26)
- 17 of respondents experienced a surge in COVID patients in their region at the time of the survey completion
- More than half used the bilingual tools
- 81% had used the PPC tools with patients at time of survey. Of those, 50% used them with more than 10 patients.
- Materials were used: in acute care (51%), when patients were intubated (24%), in the setting of cognitive and/or language impairment (72%), post-acute setting (7%), following tracheostomy (51%), outside of acute care (44%), other (7%)

Challenges encountered when using the tools and suggestions from participants:

“We had surge of cases amongst foreign workers who are non English speaking and came from different countries (Bangladesh, India, China, Myanmar, Thailand). In the end we translated the resources and changed the photos to make it relevant to the community here and made different charts for this purpose.”

“I was able to print the tools and provided a copy for each ICU room in our hospital. The problem is that when patients were intubated, they were so sedated they were not alert enough to use the tools. Unfortunately at our large hospital, a very small percentage of patients were able to successfully wean off the ventilator.”

“importance of video-call-instructions and information to support the contact between primary caregiver and (non-speaking) patients during lock down and visitor-restrictions in hospitals even I work with AAC in the hospital I do not see the Covid-patients. These are separate units in the hospital.”

“Your materials are perfect for training, for addressing communication challenges with people who are not familiar with I/DD. I also provide them to all the SLPs who are acute care and ICU providers, as well as anyone who will listen to me about the huge value of these materials. Thank you so much!”

1. We want to hear from YOU!!!
 - a. You can still take the survey:
https://redcap.tch.harvard.edu/redcap_edc/surveys/index.php?s=KCXFYC3FYX
2. What materials should we create next?
3. Projects are in the works:
 - a. Video materials to demonstrate communication techniques
 - b. Social stories for getting the COVID-19 vaccine
 - c. Communication materials
 - d. “Front lines stories” and “patient stories”
 - e. More “Open Access” articles to ensure that updated research and available to a larger audience

- Although workflow has changed, communication remains a medical priority
- Pandemic practice highlights the need for flexibility
- Communication partner training and handoff is needed for carryover of supports and strategies
- Virtual connections offer a platform for social connectedness and communication opportunities
- Emergency preparedness is not always possible, however emergency response is

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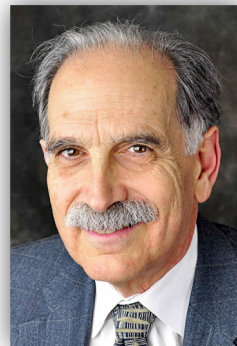
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