Overview of the Serious Illness Care Program’s COVID-19 Response Toolkit

Ariadne Labs | April 2020
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Today’s objectives

At the end of this webinar, participants will be able to:

1. Describe the rationale and components of the SICP COVID-19 Response Toolkit
2. Engage in conversations with patients and/or families using COVID-19 conversation guides for outpatient or inpatient care
3. Know where and how to access additional resources and updates
Context for creating COVID-19 Toolkit
This is an extraordinary time with unprecedented challenges
We developed COVID-19 communication tools and implementation resources to help...

- **Patients and families** feel informed, prepared, & cared-for
- **Clinicians** feel prepared and supported to engage in conversations and decision-making with patients and families
- **Implementers and leaders** have access to adaptable, scalable tools and resources to implement and disseminate within their organization
Overview of Serious Illness Care Program’s COVID-19 Response Toolkit

Available on the Ariadne Labs website

https://www.ariadnelabs.org/coronavirus/clinical-resources/covid-conversations/
The Serious Illness Care Program’s COVID-19 Response Toolkit

**Outpatient Care**
- Outpatient conversation guide
- Context 1-pager
- Video Demonstration
- Telehealth Tips
- Care Planning Tool
- Recommendation Aid

**Inpatient Care**
- Inpatient conversation guide
- Context 1-pager
- Video Demonstration
- Conversation Guide for Crisis Standards of Care

**Patient Resources**
- Patient guide
- Outreach email/letter to patients

Complete | Finalizing | Developing
COVID-19 Response Toolkit

- COVID-19 Conversation Guide for Outpatient Care
  - Case Studies & Toolkit for the Outpatient Guide
- COVID-19 Conversation Guide for Inpatient Care & Toolkit
- Patient Resources
- Additional Tools
COVID-19 Response Toolkit

- COVID-19 Conversation Guide for Outpatient Care
  - Case Studies & Toolkit for the Outpatient Guide
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- Patient Resources
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Design Principles

- **Person-centered** - Focuses on what matters most to patients
- **Simple** - One page with relatable language
- **Usable** - Accompanied by implementation resources
- **Refined** - Rapid iteration based on feedback and experience
### Process for Design

#### Adaptation
- Assembled a team (n=6)
- Adapted SICG v1.0
- Guiding principles and values

#### Rapid Feedback and Iteration
- Face validity from external reviewers (n=8)
- Feedback from simulations with patient actor (n=4)
- Feedback from user experience in clinical encounters (n=6)
The COVID High-Risk Conversation Guide for Outpatient Care...

- **Equips** clinicians for proactive outreach
- **Emphasizes** prevention and preparation
- **Focuses** on what matters most and surrogate decision making
Simulated Telehealth Demonstration of COVID-19 Conversation Guide

Outpatient Care
This is a difficult and scary time with the coronavirus. I’m hoping we can talk about what’s important to you so we can provide you with the best care possible. Is that ok?
Assess

What do you understand about how the coronavirus could affect your health?

What are you currently doing to protect yourself from getting the virus?

May I share with you my understanding of how the coronavirus could affect your health?
Tensions of Sharing Info

- **How much information to share**
- Conveying **uncertainty**
- Titrating to the patient’s anxiety
Most people who get the coronavirus get better on their own. However, people who are older or have other health problems like yours can get very sick and may not survive. The treatments that we use to try to help people live, like breathing machines, may not work. If they do work, recovery from the illness is uncertain.

[Pause, respond to emotion]
We really hope that you don’t get the virus, but it is important to prepare in case you do.

Given your [medical condition]/age, I’d like to think together about what would be important to you if you became very sick and couldn’t speak for yourself.
Explore

What would be **most important** for your healthcare providers or loved ones to know if you became very sick?

With all that’s going on, what are you most **worried** about?

What **abilities** are so important to you that you can’t imagine living without them?
If we think they may not help or may cause suffering, some people make decisions to avoid treatments like breathing machines or CPR if they get very sick. If that happened to you, have you thought about medical treatments that you may or may not want?

How much do your loved ones know about your priorities and wishes?
Tensions in the Recommendation

- **Specificity** of the recommendation
- **Variety** of possible next steps depending on numerous factors (e.g. patients’ current illness, prior discussions, readiness, needs, social and cultural context)
This can be hard to talk about. At the same time, this conversation can help us ensure that what matters most to you guides your care if you get sick.

I’ve heard you say ____. I think it’s important to share this information with your loved ones so they can speak for you if you can’t. I recommend that we complete a healthcare proxy so we know who you trust to make decisions if you can’t.
[If additional recommendations] I also recommend ______________.

This is an uncertain time for all of us. **We will do everything we can** to help you and your family through this.
COVID-19 Response Toolkit

- COVID-19 Conversation Guide for Outpatient Care
  - Case Studies & Toolkit for the Outpatient Guide
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- Additional Tools
79 yo woman with asthma, diabetes, hypertension, and well-controlled schizophrenia (full decision-making capacity)

Her daughter lives close by

5 days of fever, intermittent wheezing: Coronavirus PCR positive.
Febrile, wheezing improves with albuterol, able to speak without difficulty.

What she tells you: She would like to stay home if possible but is open to hospitalization if needed to help her feel better. Would prefer to have DNR/DNI order but wants her PCPs guidance about whether or not hospitalization would be helpful.

Recommendation: Increase home services, document DNR/DNI
Case Studies: Palliative Care Telehealth Visit

66 yo man: type I diabetes, stage IV lung cancer, progressing
Lives with wife and daughter
Does not have symptoms of Covid-19
Portuguese-speaking

What he tells you: “If I get sick, just make me comfortable. I don’t want to suffer.”
What his wife says: “Do everything you can to save him.”

Recommendation: Hospitalization if needed. If he got sicker, would recommend intensive comfort measures.
86 yr old woman with advanced dementia, frail and prone to falls, requires 24 hr care
Lives in assisted living
Son is her healthcare proxy
Exposed to the coronavirus (by a direct caregiver)

What you learn: Patient had prior MOLST w/ DNR/DNI but OK to send to hospital. After the conversation, no hospitalization under any circumstances.

Recommendation: Referred her to hospice (that accepts patients with Covid), updated MOLST to include DNH, confirmed with assisted living that they could care for her.
Case Studies: Palliative Care Telehealth Visit

42 yr old man lives with wife and 2 teenage sons
Advanced sarcoma, on 3rd line chemotherapy, responding to treatment

What you learn: Patient did not want to discuss: ‘Let’s not think about that right now.’ Numerous questions about coronavirus in general. Very anxious and ‘anything besides living is not ok.’ Paused the conversation and responded to his questions

## Implementation Resources

### COVID-19 Telehealth Communication Tips

**Opening a COVID-19 Outpatient Conversation with a Patient**

Patients may or may not want family members involved with the patient to invite those they want to be involved and/or desired.

**Techniques for responding to emotion: verbal and non-verbal**

- **Normalizing and validating positive and negative emotion understood**. For example: "It makes perfect sense that it feels so good that you’ve been able to laugh with your family during this time.

- **Silence**: Pausing with silence after sharing hard news allows during silence, continue to look into the camera and use heal to break the silence by re-initiating eye contact or talking again with a gesture of empathy.

- **Reflection and curiosity**: Allowing patients the space to explore relationship and connection. Statements like "I hear what you’re thinking" enable patients to share their concerns.

### COVID-19 Recommendation Aid

A resource for making recommendations.

This aid provides a framework to the health professional who has underlying health conditions in the context of COVID-19, should they contract it. It includes decisions about ventilation or resuscitation, patient's needs, values, and priorities.

“Thank you for sharing that with me. Would you like to plan moving forward. Would that be helpful?

“I’ve heard you say that ____ is important to you. How are you thinking about your illness and this current situation?”

**Wellbeing (consider the following)**

<table>
<thead>
<tr>
<th>Share facts about COVID-19 and how to prevent infection.</th>
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</thead>
</table>

**Assure the patient that you will**

- Revisit the conversation with them.
- Involve members of the patient’s support system as they desire.

### COVID-19 Care Planning Resources

#### Site-Specific Resources & Services

Identify a health professional who can help complete this worksheet to document the resources and services available to patients and their loved ones at your site. This document can be used as a reference by all clinicians having conversations about COVID-19. Please indicate what services are available by telehealth when relevant. Since this situation is changing quickly, date each entry and update regularly.

<table>
<thead>
<tr>
<th>MENTAL &amp; BEHAVIORAL HEALTH</th>
<th>HOME SERVICES (MEDICAL CARE, FOOD DELIVERY, PHARMACY DELIVERY)</th>
</tr>
</thead>
<tbody>
<tr>
<td>For example: psychiatrists, psychologists, social workers</td>
<td>For example: Specific agencies’ contact info</td>
</tr>
<tr>
<td>Type resource here</td>
<td>Type resource here</td>
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</tbody>
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<tr>
<th>PATIENT/FAMILY SUPPORT</th>
<th>PALLIATIVE CARE</th>
</tr>
</thead>
<tbody>
<tr>
<td>For example: social work, patient advocate, community health workers, social services)</td>
<td>For example: Inpatient, outpatient, and home-based resources</td>
</tr>
<tr>
<td>Type resource here</td>
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</tr>
</tbody>
</table>
COVID-19 Response Toolkit

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## Process for Design

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- Rapid Feedback and Iteration
  - Face validity from external reviewers (n=10)
  - Feedback from simulations with patient actor (n=4)
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The COVID-19 High-Risk Conversation Guide for Inpatient Care...

- **Equips** clinicians to have conversations in the hospital with patients with confirmed or suspected Covid-19
- **Emphasizes** patients’ values, priorities, and care preferences
- **Informs** decision-making about life-sustaining treatments
- **NOT** a guide for Crisis Standards

This is a difficult and scary time with the coronavirus. I’m hoping we can talk about the upcoming hours and days and what’s important to you so we can provide you with the best care. Is that okay? Is there anyone that you would want to join us by phone or video?

What about your health are you most worried about right now? Thank you for sharing that with me.

Can I share some information with you about how this illness might affect you?

Many people will recover from this infection. We will do everything we can to help you recover. As you’ve probably heard, some people get so sick that they do not survive. (Pause)

[If Normal Risk] Because there is some uncertainty about how this illness affects people, we are asking everyone to share what would be important if they became very sick and couldn’t speak for themselves.

[If High Risk] Because of [high-risk condition], if you get really sick, I worry that the treatments that we can use to try to help people get better, like breathing machines or CPR, are not likely to work or get you back to the quality of life you had before. (Pause) This must be hard to hear.

What is most important for your loved ones and medical team to know if you were to get very sick? What abilities are so important to your life that you can’t imagine living without them?

Some people are willing to go through a lot, including being on machines for many weeks, even if there is only a small chance that this could help them survive. Others avoid these treatments to focus primarily on comfort, especially if the medical team thought the treatments wouldn’t work or would leave someone unable to do things that are important to them. How do you think about this?

If you couldn’t speak for yourself, who do you trust to make medical decisions for you?

How much do they know about what is important to you?

This can be hard to talk about. I really appreciate your sharing this information with me.

I heard you say that ___ is really important to you. Given what you told me, and what we know about your current health, I would recommend that we... [CHOOSE A or B]

A. use intensive care if necessary, including CPR or breathing machines. If something changes to make us worry that these treatments are not likely to work, we will tell you or your [named decision maker]. Is that okay?

B. provide only treatments that we think will be helpful. This means that we would not do CPR or breathing machines but will provide all other available treatments to help you recover and be comfortable. Is that okay?

We can revisit this at any time. We will do everything we can to help you and your family through this.
“This is a difficult and scary time with the coronavirus. I’m hoping we can talk about the upcoming hours and days and what’s important to you so we can provide you with the best care. Is that okay?”

“Is there anyone that you would want to join us by phone or video?”

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What is most important for your loved ones and medical team to know if you were to get very sick?

What abilities are so important to your life that you can’t imagine living without them?

Some people are willing to go through a lot, including being on machines for many weeks, even if there is only a small chance that this could help them survive. Others avoid these treatments to focus primarily on comfort, especially if the medical team thought the treatments wouldn’t work or would leave someone unable to do things that are important to them. How do you think about this?

If you couldn’t speak for yourself, who do you trust to make medical decisions for you?

How much do they know about what is important to you?

This can be hard to talk about. I really appreciate your sharing this information with me. I heard you say that __ is really important to you. Given what you told me, and what we know about your current health, I would recommend that we... (CHOOSE A or B)

A. use intensive care if necessary, including CPR or breathing machines. If something changes to make us worry that these treatments are not likely to work, we will tell you or your [named decision maker]. Is that okay?

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We can revisit this at any time. We will do everything we can to help you and your family through this.
What about your health are you **most worried about** right now?

Thank you for sharing that with me.

Can I share some information with you about how this illness might affect you?
Tensions of Sharing Information

- **Uncertainty** and how quickly people get sick (need to normalize)
- Different **levels of risk**
- Communication with surrogate, interpreters, PPE, virtual tech

This is a difficult and scary time with the coronavirus. I’m hoping we can talk about the upcoming hours and days and what’s important to you so we can provide you with the best care. Is that okay? Is there anyone that you would want to join us by phone or video?

What about your health are you most worried about right now?

Thank you for sharing that with me. Can I share some information with you about how this illness might affect you?

Many people will recover from this infection. We will do everything we can to help you recover. As you’ve probably heard, some people get so sick that they do not survive. (Pause)

If you have any uncertainty about how this illness affects people, we are asking everyone to share what would be important if they became very sick and couldn’t speak for themselves.

If you’re high risk because of [high-risk conditions], if you get really sick, I worry that the treatments that we can use to try to help people get better, like breathing machines or CPR, are not likely to work or get you back to the quality of life you had before. (Pause) This must be hard to hear.

What is most important for your loved ones and medical team to know if you were to get very sick?

What abilities are so important to your life that you can’t imagine living without them?

Some people are willing to go through a lot, including being on machines for many weeks, even if there is only a small chance that this could help them survive. Others avoid these treatments to focus primarily on comfort, especially if the medical team thought the treatments wouldn’t work or would leave someone unable to do things that are important to them. How do you think about this?

If you couldn’t speak for yourself, who do you trust to make medical decisions for you?

How much do they know about what is important to you?

This can be hard to talk about. I really appreciate your sharing this information with me. I heard you say that __________ is really important to you. Given what you told me, and what we know about your current health, I would recommend that we... (choose A or B)

A. use intensive care if necessary, including CPR or breathing machines. If something changes to make us worry that these treatments are not likely to work, we will talk to you or your [named decision maker]. Is that okay?

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Many people will recover from this infection. We will do everything we can to help you recover. As you’ve probably heard, some people get so sick that they do not survive. [Pause]

- [High Risk] Because of [high risk condition], if you get really sick, I worry that the treatments that we can use to try to help people get better, like breathing machines or CPR, are not likely to work or get you back to the quality of life you had before. [PAUSE] “This must be hard to hear.”
Explore

“What is most important for your loved ones and medical team to know if you were to get very sick?”

“What abilities are so important to your life that you can’t imagine living without them?”

COVID-19 Conversation Guide for Inpatient Care

- This is a difficult and scary time with the coronavirus. I'm hoping we can talk about the upcoming hours and days and what's important to you so we can provide you with the best care. Is that okay? Is there anyone that you would want to join us by phone or video?
- What about your health are you most worried about right now?
- Thank you for sharing that with me.
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- What is most important for your loved one and medical team to know if you were to get very sick?
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- Some people are willing to go through a lot, including being on machines for many weeks, even if there is only a small chance that this could help them survive. Others avoid these treatments to focus primarily on comfort, especially if the medical team thought the treatments wouldn't work or would leave someone unable to do things that are important to them. How do you think about this?
- If you couldn’t speak for yourself, who do you trust to make medical decisions for you?
- How much do they know about what is important to you?

This can be hard to talk about. I really appreciate your sharing this information with me. I heard you say that _____ is really important to you. Given what you told me, and what we know about your current health, I would recommend that we... [CHOOSE A or B]

A. use intensive care if necessary, including CPR or breathing machines. If something changes to make us worry that these treatments are not likely to work, we will tell you or your [trusted decision maker]. Is that okay?
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“Some people are willing to go through a lot, including being on machines for many weeks, even if there is only a small chance that this could help them survive. Others avoid these treatments to focus primarily on comfort, especially if the medical team thought the treatments wouldn’t work or would leave someone unable to do things that are important to them. How do you think about this?”
“If you couldn’t speak for yourself, who do you trust to make medical decisions for you?

“How much do they know about what is important to you?”
Tensions of the Recommendation

- **Mismatch** between patient preferences and medical situation
- **Uncertain** preferences—not clear which direction to go in
- **Worries about crisis standards**

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**COVID-19 Conversation Guide for Inpatient Care**

- This is a difficult and scary time with the coronavirus. I'm hoping we can talk about the upcoming hours and days and what's important to you so we can provide you with the best care. Is that okay? Is there anyone that you would want to join us by phone or video?

- What about your health are you most worried about right now?
- Thank you for sharing that with me.
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- Many people will recover from this infection. We will do everything we can to help you recover. As you've probably heard, some people get so sick that they do not survive. (Pause)

- (If Normal Risk) Because there is some uncertainty about how this illness affects people, we are asking everyone to share what would be important if they became very sick and couldn't speak for themselves.

- (If High Risk) Because of [high-risk conditions], if you get really sick, I worry that the treatments that we can use to help people get better, like breathing machines or CPR, are not likely to work or get you back to the quality of life you had before. (Pause) This must be hard to hear.

- What is most important for your loved ones and medical team to know if you were to get very sick?
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- If you couldn't speak for yourself, who do you trust to make medical decisions for you?
- How much do they know about what is important to you?

- This can be hard to talk about. I really appreciate your sharing this information with me.
  - I heard you say that ___ is really important to you. Given what you told me, and what we know about your current health, I would recommend that we... [CHOOSE A or B]
    - A. use intensive care if necessary, including CPR or breathing machines. If something changes to make us worry that these treatments are not likely to work, we will talk to you or your [trusted decision maker]. Is that okay?
    - B. provide only treatments that we think will be helpful. This means that we would not do CPR or breathing machines but will provide all other available treatments to help you recover and be comfortable. Is that okay?

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“This can be hard to talk about. I really appreciate your sharing this information with me.”

“I heard you say that ___ is really important to you. Given what you told me, and what we know about your current health, I would recommend that we…[CHOOSE A or B]
A. “use intensive care if necessary, including CPR or breathing machines. If something changes to make us worry that these treatments are not likely to work, we will tell you or your [trusted decision-maker]. Is that okay?”

B. “provide only treatments that we think will be helpful. This means that we would not do CPR or breathing machines but will provide all other available treatments to help you recover and be comfortable. Is that okay?”

“We can revisit this at any time. We will do everything we can to help you and your family through this.”
Conversation Guide Tips

- Read the guide aloud before using it with a patient or surrogate
- Stick to the language on the Guide - “I’m going to use this Guide, just to make sure I don’t miss anything”
- When working with surrogates, consider using video where possible rather than phone
- When working with interpreters, have a discussion with interpreter before-hand to review questions and discuss potential challenges
- Use silence and acknowledge emotions when they arise
- Never struggle alone: Debrief with a colleague for support and self-care
COVID-19 Response Toolkit

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Patient Resources

- Jointly developed with The Conversation Project
- Being Prepared in the Time of COVID-19
- Email letter to patients (forthcoming)

Being Prepared in the Time of COVID-19
Three Things You Can Do Now

This is a challenging time. There are many things that are out of our control. But there are some things we can do to help us be prepared—both for ourselves and the people we care about. Here are three important things each of us can do, right now, to be prepared.

1. Pick your person to be your health care decision maker

Choose a health care decision maker (often known as a proxy, agent, or health care power of attorney) — a person who will make medical decisions for you if you become too sick to make them for yourself.

- Here’s a simple guide to help you choose a health care decision maker.

Have a talk with your health care decision maker to make sure they know what matters most to you.

- Make a plan to talk with your decision maker as soon as possible.
- Phone calls or video chats are good if you don’t live with that person.

Fill out an official form naming your health care decision maker.
Give one copy of the filled-in form to your decision maker and one copy to your health care team.

- Get a free health care decision maker form here or download a form for free from your state attorney general website.
- In a time of social distancing, you may not be able to create an official legal document. That’s okay! Writing it down is still better than nothing!

YOU SHOULD KNOW

- First and foremost, do everything you can to stay personally safe and protect others!
- Follow the CDC’s recommendations for social distancing. Stay home. Clean your hands often. Avoid close contact. Cover coughs and sneezes.
- Most people who get COVID-19 get a mild or moderate illness and don’t need to go to the hospital.
- Those who do get a severe case of COVID-19 are mostly people who are older or have other medical problems.
- Some people, especially those who are young and healthy, will get better with routine hospital care. But many, especially those who are older and sicker, are not likely to survive even with a ventilator (breathing machine).
- Those who survive may be left with
COVID-19 Response Toolkit

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- Additional Tools
What’s Next?

Additional tools in development
- COVID-19 Conversation Guide for crisis standards
- Email letter for outreach to patients

Quality improvement methods
- Brief survey for feedback on the COVID-19 conversation guides to refine the tools based on diverse experiences
- Case studies of implementation with health systems
- Development of new implementation tools
Additional Resources

Serious Illness Care Program COVID-19 Response Toolkit
https://www.ariadnelabs.org/coronavirus/clinical-resources/covid-conversations/

The Conversation Project IHI/Serious Illness Care Program Patient Guide

VitalTalk COVID-ready Communication Skills
https://www.vitaltalk.org/guides/covid-19-communication-skills/

Center to Advance Palliative Care COVID-19 Response Resources
https://www.capc.org/toolkits/covid-19-response-resources/

CDC Fact Sheet and ACP Decisions Video for information about coronavirus
https://acpdecisions.wistia.com/medias/rgbuphegzi
Join our Community of Practice

- Continue the conversation and share resources on the Serious Illness Care Program Community of Practice
  https://portal.ariadnelabs.org

- Become a Serious Illness Care Program Ambassador
  - Applications can be found on the Community of Practice
  - Applications due by June 1, 2020
THANK YOU!
<table>
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<th>Ariadne Labs Team</th>
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<tr>
<td>Evan Benjamin, MD, MD, FACP</td>
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<td>Rachelle Bernacki, MD, MS</td>
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<td>Nora Downey</td>
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<td>Erik Fromme, MD, MCR</td>
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<td>Sue Gullo, RN, MS</td>
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<td>Kendra Kim</td>
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<td>Emily Lincoln</td>
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<td>Francine Maloney, MPH</td>
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<td>Suzanne Mitchell, MD</td>
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<td>Buki Sihlongonyane</td>
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<td>Kaeng Takahashi</td>
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<td>Liz Wilson, MBA</td>
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