Driving Equity in Serious Illness Care: A Convening

Executive Summary

The Serious Illness Care Program at Ariadne Labs endeavors to create scalable health system solutions that improve care for all people affected by serious illness: every patient, every time, everywhere. In June of 2021 we convened 35 interprofessional clinicians, researchers, administrators, and community advocates with national and international expertise in the delivery of serious illness care to underserved and marginalized communities. The overarching goal of this convening was to gain insights into strategies that drive sustained and equitable improvements in serious illness conversations and care, with specific attention to leadership and engagement, training and practice change, measuring results, and culture change.

This white paper highlights **convening findings** and respective **programmatic next steps** in response to the four focus areas of the convening:

- Program Messaging to Key Stakeholders
- Language on the Serious Illness Conversation Guide
- Guide Training: Challenges, Adaptations, and Innovations
- Community Engagement

Key Takeaways

Participants highlighted opportunities to emphasize equity in speaking about the Serious Illness Care Program (SICP) to patients and caregivers, clinicians, and health system and policy leaders. For patients and caregivers, participants described the importance of validating negative healthcare experiences and enabling control of care planning through serious illness conversations. For clinicians, participants noted the role of the Serious Illness Conversation Guide in building rapport with patients, and helping them more effectively meet one of their more challenging clinical responsibilities. Finally, for health system and policy leaders, participants emphasized SICP's alignment and synergy with fiscal obligations,its ability to integrate into and enrich organizational strategies and institutional missions, and to promote accountability to communities they serve.

Participants identified opportunities for the Serious Illness Conversation Guide to better meet patients and families where they are by using more accessible language. They suggested training strategies that better meet the needs of clinicians in safety net settings, through adaptations and innovations that support shorter in-person training, tailored to common experiences encountered in these settings.

Finally, they identified entities and individuals that comprise the ecosystem of care for those affected by serious illness, and considered barriers to their mutual engagement and strategies to break them down.

Insights from this convening will inform subsequent refinement of the tools, training, and systems-change approaches that are available for all health systems. In some cases, what we learned provides the seeds of processes that will require further input from interprofessional and patient stakeholders.

We appreciate the opportunity to work together toward realizing our vision that all people affected by serious illness are cared for on their own terms.

Background

Many health systems lack the know-how to systematically ensure high quality serious illness conversations to those affected by serious illness. This is also true of safety net systems, which provide care for historically underserved and marginalized populations. With the goal of addressing gaps in care for every patient, every time, everywhere, Ariadne Labs has identified the critical need of adapting program resources to better support safety net systems in implementing the Serious Illness Care Program (SICP, or the "program").

With support from an anonymous donation, Ariadne Labs hosted a convening, *Driving Equity in Serious Illness Conversations and Care*, on June 27th 2021. The convening of interprofessional clinicians, researchers, administrators, and community advocates with experience and expertise in the delivery of serious illness care to underserved and marginalized communities provided an opportunity to gain expert input on and extend findings from a similarly funded qualitative study exploring factors related to SICP implementation in safety net healthcare systems that had experience implementing the program.

Herein, we describe findings from the convening, as well as implications for future program adaptations and activities.

Defining Equity

To promote a shared space for dialogue, we asked participants to respond by text message (using Menti) to the prompt, ***What word or phrase captures what equity in serious illness care means to you?*** The resulting word cloud (Figure 1) was available as a reference during small group discussions.

Program Messaging to Key Stakeholders

Our research and experience suggests that the ways in which health system teams discuss the program with leaders, clinicians, and individuals and families affected by serious illness is a key mediator of implementation success. We asked participants to discuss health equity-focused messages to these three key stakeholder groups. Table 1 outlines types and examples of health equity-focused messages that teams should consider.

For people with serious illness and their families, participants suggested emphasis on the program's ability to validate their experiences and to prepare, inform, and empower their participation in care planning. For clinicians, participants suggested emphasis of the program's evidence-base, its facilitation of clinical responsibilities, and its role in addressing injustice; and the ability of the Serious Illness Conversation Guide to aid rapport-building and support patients' needs. Finally, for health system and policy leaders, participants suggested emphasis on the ability of the program to align and synergize with fiscal obligations, to integrate into and enrich corporate strategies and institutional missions, and to promote health system accountability.

Table 1. Health equity-focused messages by stakeholder type and category

People with Serious Illness & their Families	
Validation	*You are important to us.* *It is important to us that we understand your values, worries, and priorities.*
Empowerment	*We will strive to help you feel informed and equipped to express your wishes.*
Inclusion	*We value the diverse sources of support from which you may draw strength, including family and your community and will facilitate their inclusion in your care as you wish.*
Preparation	*We acknowledge that we cannot know the future and will help prepare you as best we can for different outcomes.*
Clinicians	
Evidence-based	*Using the serious illness conversation guide is a form of practicing evidence-based medicine.*
Rapport-building	*You can connect with patients and lend meaning and purpose to your clinical encounters in using the serious illness conversation guide.*
Facilitation	*Using the serious illness conversation guide can make your work easier; specifically providing tools to navigate challenging conversations.*
Patient Support	*You can offer your patients an additional and important layer of support in using the SICG.*
Social Justice & Addressing Mistrust	*You can play a part in decreasing structural injustices by systematically talking to all patients with serious illness with the help of the Serious Illness Conversation Guide.*
Health System & Policy Leaders	
Economic Considerations	*Improving the care of patients with serious illness is a responsible business decision (Patients with serious illness make up a large proportion of patients and represent 20-60% of spending)*
Corporate Responsibility	*Championing serious illness care is important and necessary to equitably uphold patients and families' experience*
Accountability	*Promoting quality serious illness care can help build bridges with communities who have been historically neglected and create opportunities to repair trust*

Next Steps

Diverse and shared perspectives between and within these stakeholder groups shape their engagement in program implementation and in serious illness conversations. We plan to refine, develop and test implementation materials that include these messages as a way of ensuring that health equity plays a central role in program implementation.

Language on the Serious Illness Conversation Guide

Participants identified opportunities for more accessible and inclusive language in the Serious Illness Conversation Guide (SICG or "the guide"). Changes should support patient participation and reduce pressure on patients to have socially acceptable answers or to respond with insufficient time for reflection. Participants highlighted the importance of ensuring that patients feel that their participation in conversations or receipt of prognosis is voluntary and non-coerced; suggested that the guide utilize more inclusive language (e.g. by replacing "family" with "people that are important to you"); and that the guide allows for clinicians to exploring patient responses in greater depth.

Table 2 provides examples of current language, perceived issues, and proposed adaptations. Due to time constraints, groups were unable to consider every question on the guide.

Table 2. Sample of existing conversation guide language, perceived issues, and proposed adaptations

Current language	Perceived issue	Proposed adaptation
I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want -- is this okay?	This language may not give patients an opportunity to provide truly informed permission	*Is this a conversation we could have now? Or the next time we meet? We can also include people who are close to you in this conversation. It is also okay if you don't want to have the conversation at all.*
What is your understanding now of where you are with your illness?	Can sound insulting, like a quiz or test of patients' knowledge	*What have your doctors told you? What are you hearing about your illness?*
How much information about what is likely to be ahead with your illness would you like from me?	Language can trigger fears that you are withholding information	Using probes to steer the conversation: • *Tell me more.* • *Tell me what you'd like to know.*
What abilities are so critical to your life that you can't imagine living without them?	"Critical" is subjective and a high-literacy word	Use examples of abilities or say: *What in this world gives you joy?*
How much does your family know about your priorities and wishes?	People may have complex or absent relationships with "family" in ways that make this word potentially polarizing	*How much do the people closest to you know about your priorities and wishes?*

Next steps

Ariadne Labs will integrate findings from the convening into a human-centered design[1] process to create an updated version of the Serious Illness Conversation Guide with the goal of making the language more accessible and inclusive.

[1] Marijke Melles, Armagan Albayrak, Richard Goossens, Innovating health care: key characteristics of human-centered design, *International Journal for Quality in Health Care*, Volume 33, Issue Supplement_1, January 2021, Pages 37–44, https://doi.org/10.1093/intqhc/mzaa127

Guide Training: Challenges, Adaptations & Innovations

Participants identified opportunities for Guide Training to better support inclusion of diverse interprofessional team members, and to better represent training cases that may be more familiar to clinicians working safety net systems. While, as one participant highlighted - "Teaching people to have this conversation is hard, even before adding an equity layer." - discussion centered around overcoming challenges due to common safety net resource constraints and on serving patient populations with diverse or complex social and socioeconomic circumstances. Table 3 highlights perceived challenges and adaptations or innovations proposed by participants.

Table 3. Perceived training challenges and proposed adaptations or innovations

Challenges	Adaptations & Innovations
Remote and hybrid work undermine in-person training	***Innovations*** ● Use videos for didactic portions of training ● Employ video platforms for skills practice
Training time constraints	***Adaptations*** ● Reduce training to 2 hours ● Use "built in" time to conduct training
Clinicians face challenges related to having conversations with patients from different backgrounds (e.g.limited English proficiency or low health literacy)	***Adaptations*** ● Include more representative patient cases in training materials ● Include real patients and physicians in training videos ● Ensure realistic representation of challenging experiences in training materials ***Innovations*** ● Utilize chaplains or social workers as "patients" to diversify role play ● Develop modules focused on equity in as a program component ● Include family member(s) in modelings videos or practice
Interprofessional training, talking about prognosis & license limitations.	***Adaptations*** ● Create a version of the guide without prognosis related language for use by non-prescriber members of interprofessional team ● Focus on uncertainty and function as a prognosis ● Add question to guide: What do I need to know about you to provide you with the best ca*re possible?* ***Innovations*** ● Demonstrate hand off from provider to nurse, social work, etc. in training materials

Next steps

Having already transitioned to a virtual training approach, the Ariadne Labs team plans to draw from the other suggested adaptations and innovations to refine the program curriculum and supporting materials. The current training curriculum supports virtual training through the use of three didactic (asynchronous) videos followed by a 2.5 hour synchronous skills practice. We plan to update didactic materials to ensure diverse patient and interprofessional representation and to explicitly address health equity. Additionally, we plan to incorporate more representative cases in the skills practice, and to develop supplementary videos to demonstrate the conversation with interprofessional clinicians and diverse patient scenarios, including those that include caregivers.

Community Engagement

People affected by serious illness require and benefit from an ecosystem of caring that includes but is not exclusive to health systems. Improving the links between entities in this ecosystem may center people from underserved and marginalized communities in ways that enhance equity in serious illness care. Participants identified key stakeholders in this ecosystem (Figure 2), challenges related to their mutual engagement, and strategies to enhance engagement. This pursuit of tighter integration across the caring ecosystem is done with the aspiration to recenter voices at the margins, champion holistic approaches to care, improve care coordination, and reinforce processes that prioritize people over organizations.

Figure 2. Stakeholder ecosystem for people affected by serious illness

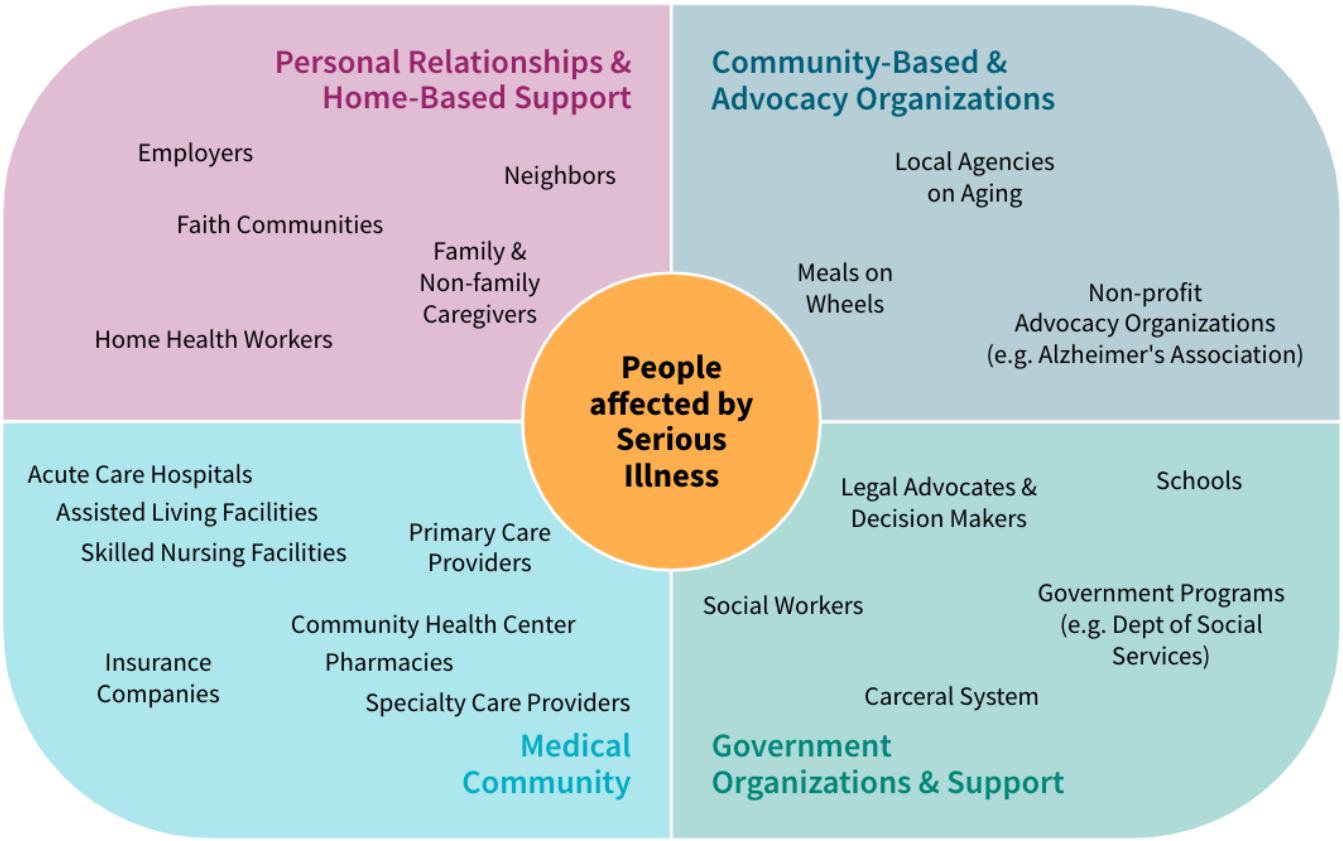

Table 4. Barriers to health system engagement with community partners

Domain	Examples
Health system-centric model	• Primary, specialist, and acute care are seen as dominant forces • Failures in measurement, financing, and accountability fail to incentivize (or disincentivize) engagement with community partners
Silos between community groups and healthcare	• Stakeholders are unfamiliar with each others activities and resources • Stakeholders may not feel welcome in each other's spaces (e.g. faith community may not feel welcome in medical community if a person with serious illness identifies their faith leader as someone important to attend a serious illness conversation)
Patient & family level barriers	• Lack of insurance • Language differences and english health literacy • Cultural barriers and other individual factors

Table 5. Strategies to enhance engagement between health systems and community partners

Stakeholders	Recommended Actions
Clinicians	• Be mindful about who is participating in conversations and intentional about reaching those who have not • Ask patients who is important to them and include them in conversations and planning
Clinical sites	• Forge relationships with other service providers who work within the community • Make an effort to assess and address patients' social determinants of health as a part of their health care visits • Employ care navigators to facilitate decision making and transitions
Health systems	• Offer Serious Illness Conversation Guide training within the healthcare system as well as the community setting • Measure continuity of care and peoples experiences • Engage communities to determine how resources are allocated • Improve access by taking services into the community, e.g. mobile health care

Next steps

Community Engagement is a new area of exploration for the Serious Illness Care Program. We believe wider community engagement has potential to contribute to better serious illness care, especially for people with serious illness from underserved and marginalized communities. Learnings from this session will inform future proposals that will center person, family, and community engagement into the Serious Illness Care Program design, implementation, and evaluation. Additionally, we will integrate recommendations about Community Engagement into our health system support model for current and future health system partnerships.

Acknowledgements

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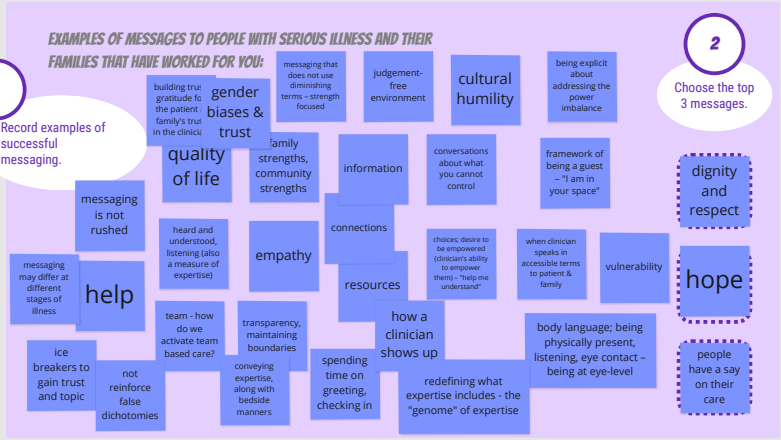
We extend our deep gratitude to our participants for their valuable time and insights and to the patients whose experiences informed their expertise and for whom we pursue this work.

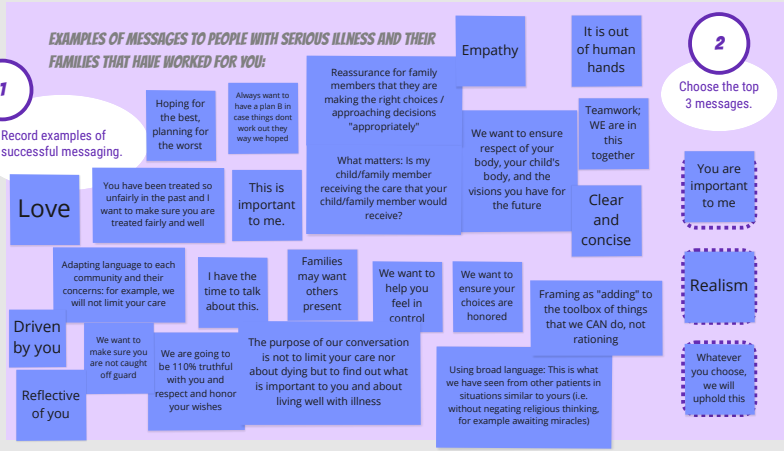
Contributions

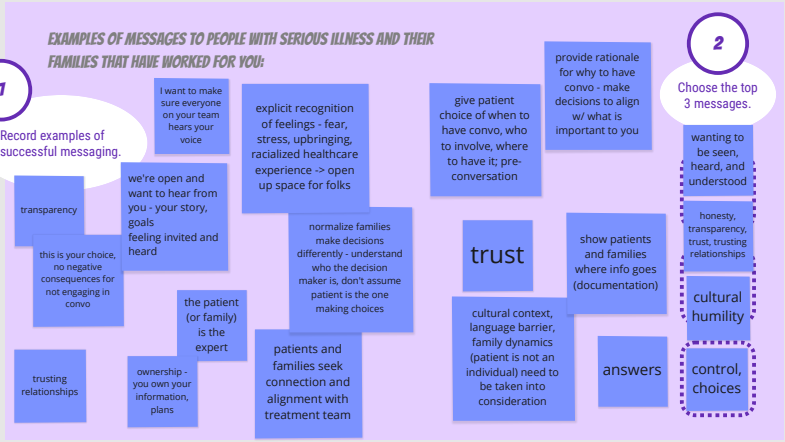
Meeting Logistics | Sharelle Davis, Nora Downey, Rebecca Robert
Facilitation | Evan Benjamin, Emily Benotti, Stacey Downey, Ashley Eng, Erik Fromme, Carolina Jaramillo, Kurt Lowery, Suzanne Mitchell, Namita Seth Mohta, Joanna Paladino, Jennifer Rodine, Justin Sanders, Buki Sihlongonyane, Ayush Thacker
Report Drafting & Review | Nora Downey, Grace Galvin, Carolina Jaramillo, Namita Mohta, Justin Sanders

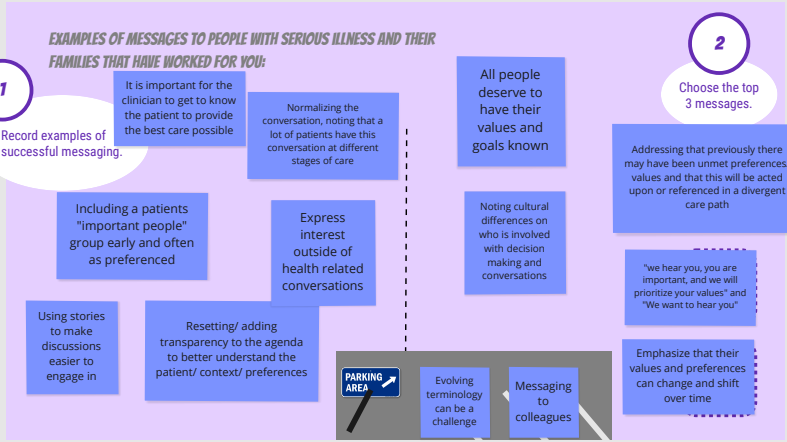
A detailed convening agenda is available upon request.

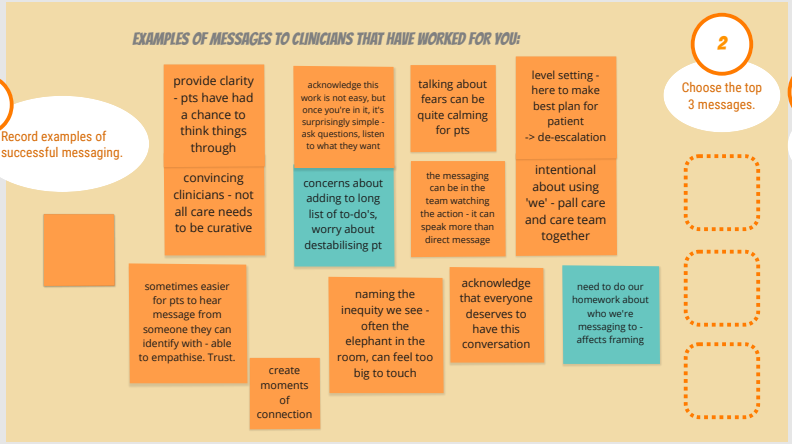
Appendix: Miro Board Images

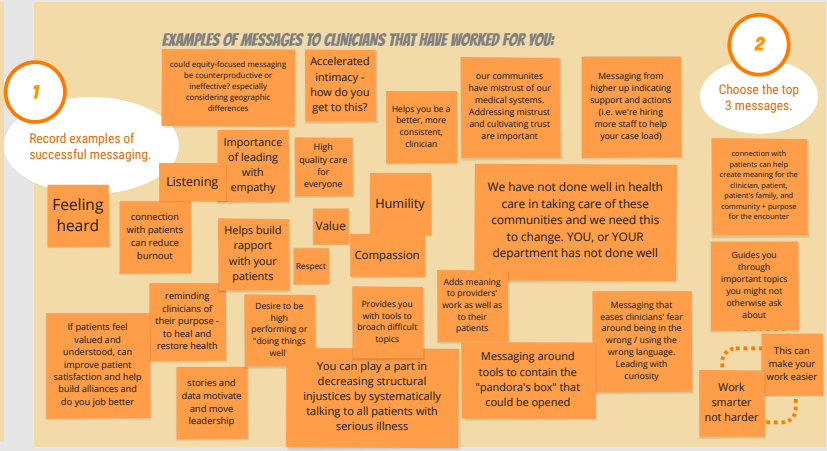

EXAMPLES OF MESSAGES TO PEOPLE WITH SERIOUS ILLNESS AND THEIR FAMILIES THAT HAVE WORKED FOR YOU:
1
Record examples of successful messaging.
2
Choose the top 3 messages.
gender biases & trust
cultural humility
quality of life
family strengths, community strengths
information
conversations about what you cannot control
framework of being a guest – "I am in your space"
messaging is not rushed
connections
empathy
resources
how a clinician shows up
choices; desire to be empowered (clinician's ability to empower them) – "help me understand"
when clinician speaks in accessible terms to patient & family
vulnerability
help
team - how do we activate team based care?
transparency, maintaining boundaries
ice breakers to gain trust and topic
not reinforce false dichotomies
conveying expertise, along with bedside manners
spending time on greeting, checking in
redefining what expertise includes - the "genome" of expertise
body language; being physically present, listening, eye contact – being at eye-level
dignity and respect
hope
people have a say on their care

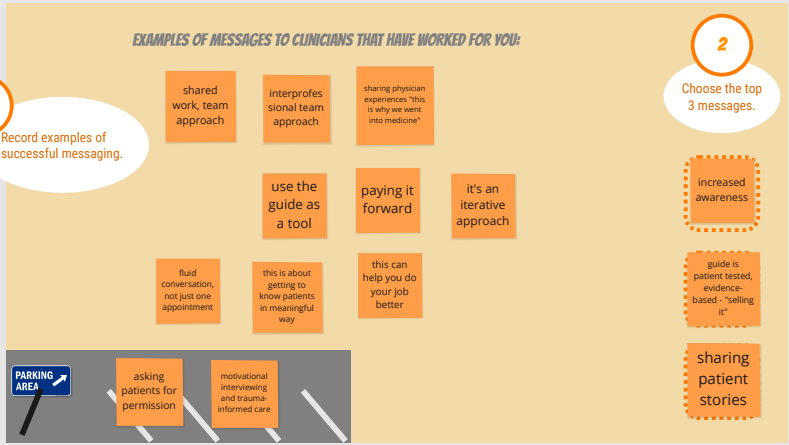

EXAMPLES OF MESSAGES TO PEOPLE WITH SERIOUS ILLNESS AND THEIR FAMILIES THAT HAVE WORKED FOR YOU:
1
Record examples of successful messaging.
2
Choose the top 3 messages.
Empathy
It is out of human hands
Hoping for the best, planning for the worst
Reassurance for family members that they are making the right choices / approaching decisions "appropriately"
Teamwork; WE are in this together
We want to ensure respect of your body, your child's body, and the visions you have for the future
Love
You have been treated so unfairly in the past and I want to make sure you are treated fairly and well
This is important to me.
What matters: Is my child/family member receiving the care that your child/family member would receive?
Clear and concise
You are important to me
Adapting language to each community and their concerns: for example, we will not limit your care
I have the time to talk about this.
Families may want others present
We want to help you feel in control
We want to ensure your choices are honored
Framing as "adding" to the toolbox of things that we CAN do, not rationing
Realism
Driven by you
We want to make sure you are not caught off guard
We are going to be 110% truthful with you and respect and honor your wishes
The purpose of our conversation is not to limit your care nor about dying but to find out what is important to you and about living well with illness
Using broad language: This is what we have seen from other patients in situations similar to yours (i.e. without negating religious thinking, for example awaiting miracles)
Reflective of you
Whatever you choose, we will uphold this

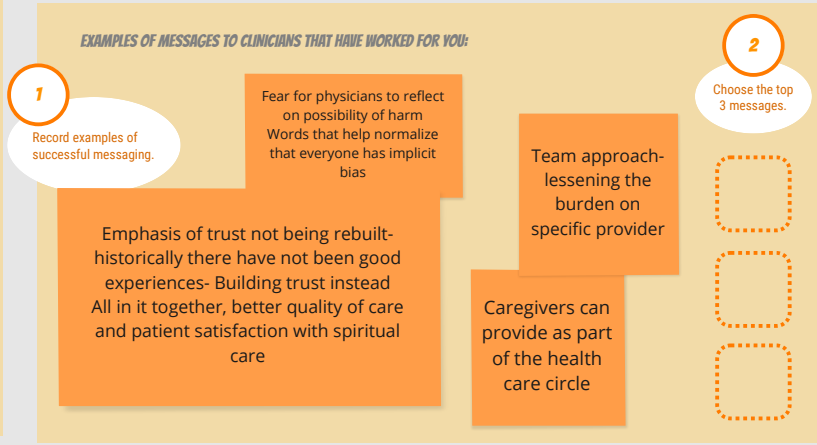

EXAMPLES OF MESSAGES TO PEOPLE WITH SERIOUS ILLNESS AND THEIR FAMILIES THAT HAVE WORKED FOR YOU:
1
Record examples of successful messaging.
2
Choose the top 3 messages.
I want to make sure everyone on your team hears your voice
explicit recognition of feelings - fear, stress, upbringing, racialized healthcare experience -> open up space for folks
give patient choice of when to have convo, who to involve, where to have it; pre-conversation
provide rationale for why to have convo - make decisions to align w/ what is important to you
wanting to be seen, heard, and understood
transparency
we're open and want to hear from you - your story, goals feeling invited and heard
honesty, transparency, trust, trusting relationships
this is your choice, no negative consequences for not engaging in convo
normalize families make decisions differently - understand who the decision maker is, don't assume patient is the one making choices
trust
show patients and families where info goes (documentation)
cultural humility
the patient (or family) is the expert
cultural context, language barrier, family dynamics (patient is not an individual) need to be taken into consideration
answers
control, choices
trusting relationships
ownership - you own your information, plans
patients and families seek connection and alignment with treatment team

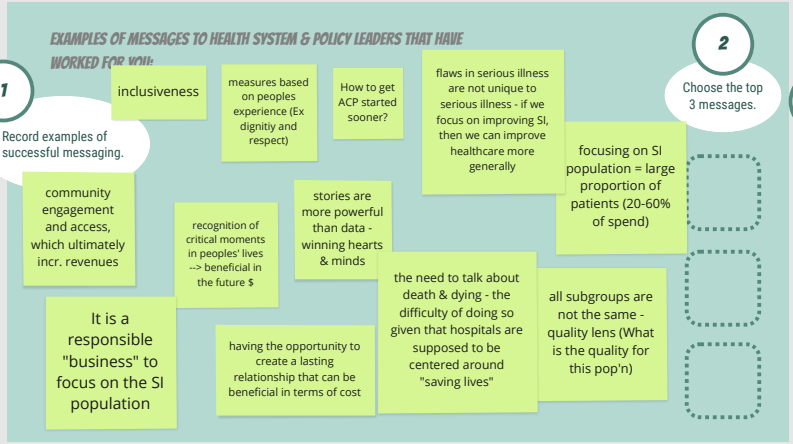

EXAMPLES OF MESSAGES TO PEOPLE WITH SERIOUS ILLNESS AND THEIR FAMILIES THAT HAVE WORKED FOR YOU:
1
Record examples of successful messaging.
2
Choose the top 3 messages.
It is important for the clinician to get to know the patient to provide the best care possible
Normalizing the conversation, noting that a lot of patients have this conversation at different stages of care
All people deserve to have their values and goals known
Addressing that previously there may have been unmet preferences/ values and that this will be acted upon or referenced in a divergent care path
Including a patients "important people" group early and often as preferenced
Express interest outside of health related conversations
Noting cultural differences on who is involved with decision making and conversations
"we hear you, you are important, and we will prioritize your values" and "We want to hear you"
Using stories to make discussions easier to engage in
Resetting/ adding transparency to the agenda to better understand the patient/ context/ preferences
Emphasize that their values and preferences can change and shift over time
PARKING AREA
Evolving terminology can be a challenge
Messaging to colleagues

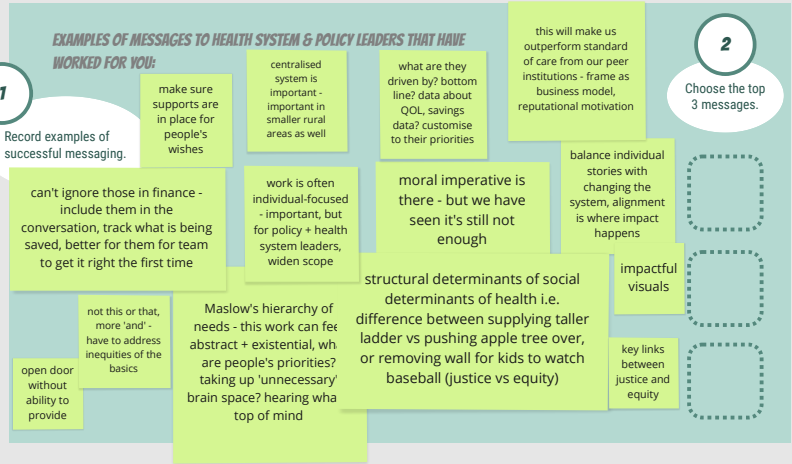

EXAMPLES OF MESSAGES TO CLINICIANS THAT HAVE WORKED FOR YOU:
1
Record examples of successful messaging.
2
Choose the top 3 messages.
provide clarity - pts have had a chance to think things through
acknowledge this work is not easy, but once you're in it, it's surprisingly simple - ask questions, listen to what they want
talking about fears can be quite calming for pts
level setting - here to make best plan for patient -> de-escalation
convincing clinicians - not all care needs to be curative
concerns about adding to long list of to-do's, worry about destabilising pt
the messaging can be in the team watching the action - it can speak more than direct message
intentional about using 'we' - pall care and care team together
sometimes easier for pts to hear message from someone they can identify with - able to empathise. Trust.
naming the inequity we see - often the elephant in the room, can feel too big to touch
acknowledge that everyone deserves to have this conversation
need to do our homework about who we're messaging to - affects framing
create moments of connection

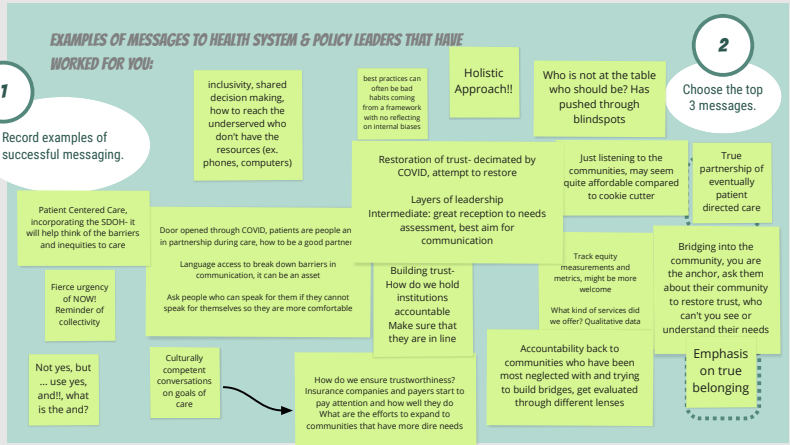

EXAMPLES OF MESSAGES TO CLINICIANS THAT HAVE WORKED FOR YOU:
1
Record examples of successful messaging.
2
Choose the top 3 messages.
could equity-focused messaging be counterproductive or ineffective? especially considering geographic differences
Accelerated intimacy - how do you get to this?
Helps you be a better, more consistent, clinician
our communites have mistrust of our medical systems. Addressing mistrust and cultivating trust are important
Messaging from higher up indicating support and actions (i.e. we're hiring more staff to help your case load)
connection with patients can help create meaning for the clinician, patient, patient's family, and community + purpose for the encounter
Importance of leading with empathy
High quality care for everyone
Listening
Feeling heard
connection with patients can reduce burnout
Helps build rapport with your patients
Value
Humility
Compassion
Respect
We have not done well in health care in taking care of these communities and we need this to change. YOU, or YOUR department has not done well
Guides you through important topics you might not otherwise ask about
Adds meaning to providers' work as well as to their patients
Messaging that eases clinicians' fear around being in the wrong / using the wrong language. Leading with curiosity
If patients feel valued and understood, can improve patient satisfaction and help build alliances and do you job better
reminding clinicians of their purpose - to heal and restore health
Desire to be high performing or "doing things well'
Provides you with tools to broach difficult topics
This can make your work easier
stories and data motivate and move leadership
You can play a part in decreasing structural injustices by systematically talking to all patients with serious illness
Messaging around tools to contain the "pandora's box" that could be opened
Work smarter not harder

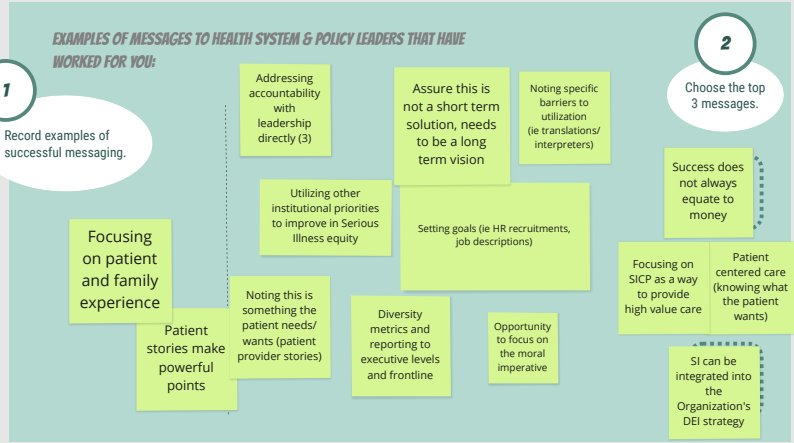

EXAMPLES OF MESSAGES TO CLINICIANS THAT HAVE WORKED FOR YOU:
1
Record examples of successful messaging.
2
Choose the top 3 messages.
shared work, team approach
interprofes sional team approach
sharing physician experiences "this is why we went into medicine"
use the guide as a tool
paying it forward
it's an iterative approach
fluid conversation, not just one appointment
this is about getting to know patients in meaningful way
this can help you do your job better
increased awareness
guide is patient tested, evidence-based - "selling it"
sharing patient stories
PARKING AREA
asking patients for permission
motivational interviewing and trauma-informed care


EXAMPLES OF MESSAGES TO CLINICIANS THAT HAVE WORKED FOR YOU:
1
Record examples of successful messaging.
2
Choose the top 3 messages.
Fear for physicians to reflect on possibility of harm
Words that help normalize that everyone has implicit bias
Team approach- lessening the burden on specific provider
Emphasis of trust not being rebuilt- historically there have not been good experiences- Building trust instead
All in it together, better quality of care and patient satisfaction with spiritual care
Caregivers can provide as part of the health care circle


EXAMPLES OF MESSAGES TO HEALTH SYSTEM & POLICY LEADERS THAT HAVE WORKED FOR YOU:
1
Record examples of successful messaging.
2
Choose the top 3 messages.
inclusiveness
measures based on peoples experience (Ex dignitiy and respect)
How to get ACP started sooner?
flaws in serious illness are not unique to serious illness - if we focus on improving SI, then we can improve healthcare more generally
focusing on SI population = large proportion of patients (20-60% of spend)
community engagement and access, which ultimately incr. revenues
recognition of critical moments in peoples' lives --> beneficial in the future $
stories are more powerful than data - winning hearts & minds
the need to talk about death & dying - the difficulty of doing so given that hospitals are supposed to be centered around "saving lives"
all subgroups are not the same - quality lens (What is the quality for this pop'n)
It is a responsible "business" to focus on the SI population
having the opportunity to create a lasting relationship that can be beneficial in terms of cost


EXAMPLES OF MESSAGES TO HEALTH SYSTEM & POLICY LEADERS THAT HAVE WORKED FOR YOU:
1
Record examples of successful messaging.
2
Choose the top 3 messages.
this will make us outperform standard of care from our peer institutions - frame as business model, reputational motivation
make sure supports are in place for people's wishes
centralised system is important - important in smaller rural areas as well
what are they driven by? bottom line? data about QOL, savings data? customise to their priorities
balance individual stories with changing the system, alignment is where impact happens
can't ignore those in finance - include them in the conversation, track what is being saved, better for them for team to get it right the first time
work is often individual-focused - important, but for policy + health system leaders, widen scope
moral imperative is there - but we have seen it's still not enough
impactful visuals
not this or that, more 'and' - have to address inequities of the basics
Maslow's hierarchy of needs - this work can fee abstract + existential, wh are people's priorities? taking up 'unnecessary' brain space? hearing wha top of mind
structural determinants of social determinants of health i.e. difference between supplying taller ladder vs pushing apple tree over, or removing wall for kids to watch baseball (justice vs equity)
key links between justice and equity
open door without ability to provide


EXAMPLES OF MESSAGES TO HEALTH SYSTEM & POLICY LEADERS THAT HAVE WORKED FOR YOU:
1
Record examples of successful messaging.
2
Choose the top 3 messages.
inclusivity, shared decision making, how to reach the underserved who don't have the resources (ex. phones, computers)
best practices can often be bad habits coming from a framework with no reflecting on internal biases
Holistic Approach!!
Who is not at the table who should be? Has pushed through blindspots
Restoration of trust- decimated by COVID, attempt to restore
Layers of leadership
Intermediate: great reception to needs assessment, best aim for communication
Just listening to the communities, may seem quite affordable compared to cookie cutter
True partnership of eventually patient directed care
Patient Centered Care, incorporating the SDOH- it will help think of the barriers and inequities to care
Door opened through COVID, patients are people an in partnership during care, how to be a good partner
Language access to break down barriers in communication, it can be an asset
Ask people who can speak for them if they cannot speak for themselves so they are more comfortable
Building trust-
How do we hold institutions accountable
Make sure that they are in line
Track equity measurements and metrics, might be more welcome
What kind of services did we offer? Qualitative data
Bridging into the community, you are the anchor, ask them about their community to restore trust, who can't you see or understand their needs
Fierce urgency of NOW!
Reminder of collectivity
Not yes, but ... use yes, and!!, what is the and?
Culturally competent conversations on goals of care
How do we ensure trustworthiness? Insurance companies and payers start to pay attention and how well they do
What are the efforts to expand to communities that have more dire needs
Accountability back to communities who have been most neglected with and trying to build bridges, get evaluated through different lenses
Emphasis on true belonging


EXAMPLES OF MESSAGES TO HEALTH SYSTEM & POLICY LEADERS THAT HAVE WORKED FOR YOU:
1
Record examples of successful messaging.
2
Choose the top 3 messages.
Addressing accountability with leadership directly (3)
Assure this is not a short term solution, needs to be a long term vision
Noting specific barriers to utilization (ie translations/ interpreters)
Success does not always equate to money
Utilizing other institutional priorities to improve in Serious Illness equity
Setting goals (ie HR recruitments, job descriptions)
Focusing on patient and family experience
Noting this is something the patient needs/ wants (patient provider stories)
Diversity metrics and reporting to executive levels and frontline
Opportunity to focus on the moral imperative
Focusing on SICP as a way to provide high value care
Patient centered care (knowing what the patient wants)
Patient stories make powerful points
SI can be integrated into the Organization's DEI strategy

CONSIDER THE LANGUAGE ON THE SERIOUS ILLNESS CONVERSATION GUIDE

THOUGHTS ABOUT CURRENT LANGUAGE

Step 1: Read line below and decide where it belongs on the board below
Step 2. Add blue stickies with thoughts about its current language
Step 3. Add green stickies with rewording suggestions

REWORDING SUGGESTIONS

FINE, KEEP AS IS

NEEDS SIGNIFICANT

SET UP

"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — is this okay?"

Line 1

It is important that we provide quality SIC to patients, and yet too little too late.

A choice is not a choice if it is not an option

Many community members dont want to talk about options as they are just trying to get access to care

Everyone "wants" to live - struggled with this word

Youre not really asking for permission, just confirmation. very hard to say no

Good - sentiment. Less helpful: Language does not match what I would say. I like the permission statement

Patient is assumed to be sole driver of their care when they may have SDM model

ASSESS

"What is your understanding now of where you are with your illness?"

Can sound very insulting, like a quiz or test of patients knowledge

What are doctors telling you? What are you hearing?

You meet a lot of people, what have they been telling you?

ASSESS

"How much information about what is likely to be ahead with your illness would you like from me?"

Line 3

Most people want info and they want it all especially when they havent been receiving it

Sentiment is appropriate but clunky language

For marginalized patients, this can trigger fears that you are withholding information

Threats to trust building

Assessing readiness

Exploring reasons for and against exploring prognostication

Not clear how patients would respond if they didnt want everything

You dont know what you dont know. Difficult to quantify

Academic language, not very usable with every population

Using probes like tell me more, tell me what you'd like to know to steer the conversation

SHARE

"I want to share with you my understanding of where things are with your illness."

Line 4

Worries about there not being a permission statement; feels like the patient doesnt have a choice

doesnt account for responding to body language other signs that we need to slow down

Needs to allow for more room for patient's uncertainty

Would it be okay if we talked more about what may lie ahead?

I want to share what the other doctors have been sharing with me

other questions could include: what are you worried about? how will you know when you are ready? what do you think would help you become ready?

SHARE

"I want to share with you my understanding of where things are with your illness."

Line 4

outpatient vs inpatient settings - context matters

"team" vs "my"

SET UP

"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — is this okay?"

Line 1

"want" - tough word, not always realistic, expectation setting - what's possible?

making sure the people the pt makes decisions with are present

long run on sentence - often needs to be made simpler. creating pauses

can't be false question - respect 'no'

ASSESS

"How much information about what is likely to be ahead with your illness would you like from me?"

Line 3

often not sure of what we know

find language to see where pt is

SHARE

"and" vs "but"

"It can be difficult to predict what will happen with your illness. I hope you will continue to live well for a long time but I'm worried that you could get sick quickly, and I think it is important to prepare for that possibility."

Line 5

frame for pt

ASSESS

"What is your understanding now of where you are with your illness?"

Line 2

"health" replace "illness"

"where you are now" can feel uneasy

"understand" can feel loaded - don't want to feel like they failed a test

"what have you heard from your ___?" e.g. cardiologist, oncologist

sometimes try not to say "goals"

sometimes gaining more time is not the goal - "tradeoffs", emphasise quality

can be a good question with examples shared

"ability" can feel charged with someone living with a disability

"what in this world gives you joy?"

feels like a leading question - anything other than fighting can connote failure

inclusivity of family language

SHARE

"I wish we were not in this situation, but I am worried that time may be as short as __ (express as a range, e.g. days to weeks, weeks to months, months to a year)."

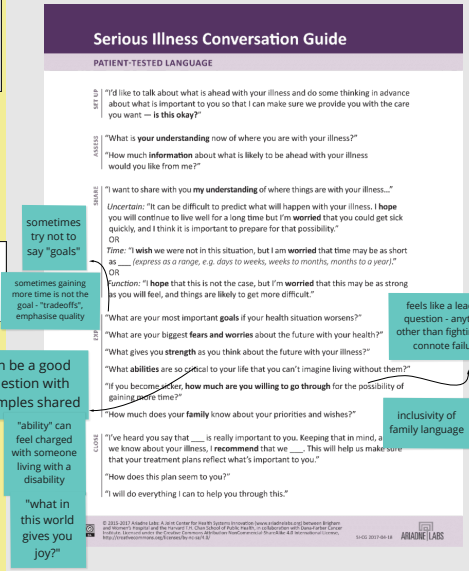
Line 6

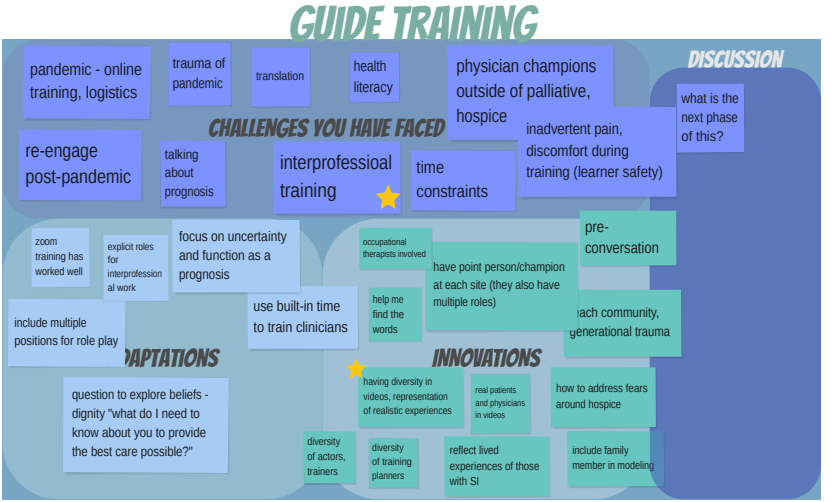
adding a pause

SHARE

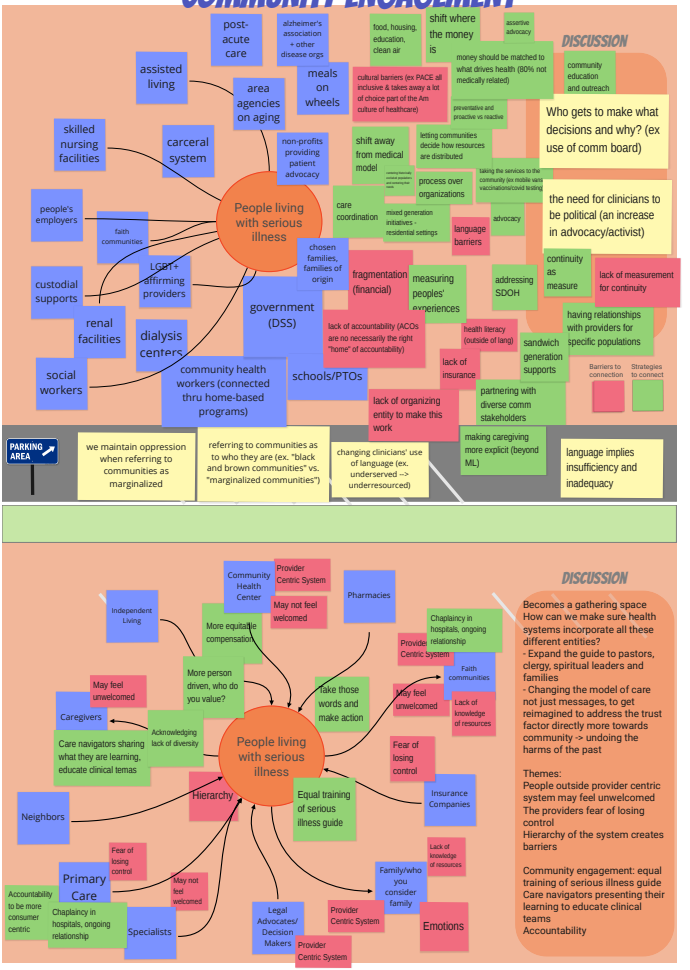
"I hope that this is not the case, but I'm worried that this may be as strong as you will feel, and things are likely to get more difficult."

Line 7




GUIDE TRAINING
DISCUSSION
what is the next phase of this?
CHALLENGES YOU HAVE FACED
pandemic - online training, logistics
trauma of pandemic
translation
health literacy
physician champions outside of palliative, hospice
inadvertent pain, discomfort during training (learner safety)
re-engage post-pandemic
talking about prognosis
interprofessioal training
time constraints
zoom training has worked well
explicit roles for interprofession al work
focus on uncertainty and function as a prognosis
occupational therapists involved
have point person/champion at each site (they also have multiple roles)
pre-conversation
include multiple positions for role play
use built-in time to train clinicians
help me find the words
ach community, generational trauma
APTATIONS
INNOVATIONS
question to explore beliefs - dignity "what do I need to know about you to provide the best care possible?"
having diversity in videos, representation of realistic experiences
real patients and physicians in videos
how to address fears around hospice
diversity of actors, trainers
diversity of training planners
reflect lived experiences of those with SI
include family member in modeling


Too long (3hrs)
Training does not equal use
Guide does not allow for enough improvisation with people that have different context
Guide does not provide enough guidance on how to respond to different context
Knowing what to do with information gathered from conversation
Equipping providers to have conversations with patients from different backgrounds
DISCUSSION
Too long (3hrs)
Some trainees have many more questions at the end and want more practice (not currently part of program)
CHALLENGES YOU HAVE FACED
Lack of diversity in standardized patient examples
Getting initial buy in
Some licensing limitations change how people can interact with guide
Some trainees have many more questions at the end and want more practice (not currently part of program)
Pushback on nudges for potential patient conversations
Teaching how to have this conversation is hard, even before adding a equity layer
Equipping providers to have conversations with patients from different backgrounds
Teaching how to have this conversation is hard, even before adding a equity layer
Updated prognosis section in guide relevant to license (social work, dietician etc) (2)
Shortened training to 2 hours
Reached out to a more diverse SP training group (chaplains, social workers to role play patients)
Hand off demo from clinician to social work
Modules for pre-watching didactics
Hybrid model (1.5 hour online, 1.5 hour in person role play)
Social work version of the guide without prognosis related questions
Pre-recorded didactic components
Updated prognosis section in guide relevant to license (social work, dietician etc) (2)
Developed new challenges for standardized patient examples
ADAP
INNOVATIONS
Metric sharing competition to improve guide use
Nudging trainees with lists of potential patients (Onc) (improved documentation rate especially in marginalized communities)
Live discussion focusing on equity
More focus on emotion while preparing for this conversation
Developed new challenges for standardized patient examples
One hour live skills practice session
Reached out to a more diverse SP training group (chaplains, social workers to role play patients)
Live discussion focusing on equity


COMMUNITY ENGAGEMENT
DISCUSSION
People living with serious illness
post-acute care
alzheimer's association + other disease orgs
food, housing, education, clean air
shift where the money is
assertive advocacy
money should be matched to what drives health (80% not medically related)
community education and outreach
assisted living
area agencies on aging
meals on wheels
cultural barriers (ex PACE all inclusive & takes away a lot of choice part of the Am culture of healthcare)
preventative and proactive vs reactive
Who gets to make what decisions and why? (ex use of comm board)
skilled nursing facilities
carceral system
non-profits providing patient advocacy
shift away from medical model
letting communities decide how resources are distributed
process over organizations
taking the services to the community (ex mobile van vaccinations/covid testing)
the need for clinicians to be political (an increase in advocacy/activist)
people's employers
faith communities
care coordination
mixed generation initiatives - residential settings
language barriers
advocacy
chosen families, families of origin
continuity as measure
lack of measurement for continuity
custodial supports
LGBT+ affirming providers
fragmentation (financial)
measuring peoples' experiences
addressing SDOH
having relationships with providers for specific populations
renal facilities
dialysis centers
government (DSS)
lack of accountability (ACOs are no necessarily the right "home" of accountability)
health literacy (outside of lang)
sandwich generation supports
social workers
community health workers (connected thru home-based programs)
schools/PTOs
lack of insurance
Barriers to connection
Strategies to connect
lack of organizing entity to make this work
partnering with diverse comm stakeholders
PARKING AREA
we maintain oppression when referring to communities as marginalized
referring to communities as to who they are (ex. "black and brown communities" vs. "marginalized communities")
changing clinicians' use of language (ex. underserved --> underresourced)
making caregiving more explicit (beyond MIL)
language implies insufficiency and inadequacy
DISCUSSION
Becomes a gathering space
How can we make sure health systems incorporate all these different entities?
- Expand the guide to pastors, clergy, spiritual leaders and families
- Changing the model of care not just messages, to get reimagined to address the trust factor directly more towards community -> undoing the harms of the past
Themes:
People outside provider centric system may feel unwelcomed
The providers fear of losing control
Hierarchy of the system creates barriers
Community engagement: equal training of serious illness guide
Care navigators presenting their learning to educate clinical teams
Accountability
People living with serious illness
Community Health Center
Provider Centric System
May not feel welcomed
Pharmacies
Independent Living
More equitable compensation
Chaplaincy in hospitals, ongoing relationship
Provider Centric system
Faith communities
More person driven, who do you value?
Take those words and make action
May feel unwelcomed
Lack of knowledge of resources
May feel unwelcomed
Caregivers
Acknowledging lack of diversity
Care navigators sharing what they are learning, educate clinical temas
Fear of losing control
Hierarchy
Equal training of serious illness guide
Insurance Companies
Neighbors
Lack of knowledge of resources
Family/who you consider family
Fear of losing control
Primary Care
May not feel welcomed
Accountability to be more consumer centric
Chaplaincy in hospitals, ongoing relationship
Specialists
Legal Advocates/ Decision Makers
Provider Centric System
Emotions
Provider Centric System