

MISSION ALLIANCE HANDBOOK

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MEET OUR MISSION ALLIANCE TEAM



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INTRODUCTION

The Patient Centered Outcomes Research Institute (PCORI) funded the Mission Alliance Engagement Project in November 2021. Our Mission Alliance team completed the PCORI Research Fundamentals training modules (<https://www.pcori.org/engagement/research-fundamentals>) and the Veteran-specific Operation Patient Centered Outcomes Research (PCOR) modules (<https://www.operationpcor.com>) then engaged Veterans with PTSD and stakeholders during virtual meetings to discuss the impact of COVID-19 on social isolation, loneliness, mental health, and well-being. From this dialogue, we captured Veteran and stakeholder opinions on emerging PTSD-related PCOR/Comparative Effectiveness Research (CER) needs and developed a prioritized research agenda related to COVID-19. This handbook is a culmination of our work and includes the templates, prioritized research agenda, evaluation tools, best practices for conducting virtual focus groups, and PTSD-related community resources developed and utilized during the Mission Alliance project. Our hope is that others will make use of these tools by adapting them to other populations and traumatic events.



FIELD NOTE TEMPLATES

The Mission Alliance Team created questions related to the topics of social isolation, loneliness, mental health, and well-being for veterans with PTSD. The veteran lead in conjunction with the academic researcher used the questions in the field note templates to guide the virtual meetings.

Demographics Obtained & Information Read Prior to Meetings

- Total number of veterans attendees
- Total number of stakeholder attendees
- Types of stakeholders present (e.g. family, service providers, policymakers)
 - Number of Vietnam Veterans?
 - Number of Korean War Veterans?
 - Number of Gulf War Veterans?
 - Number of Post 9/11 Veterans?

READ PRIOR TO QUESTIONS SO PARTICIPANTS UNDERSTAND PCOR/CER:

Mission Alliance is a community engagement project to help us understand Veterans' experiences and address questions and meaningful study outcomes that are important to them and other healthcare stakeholders. Another name for this type of research is patient centered outcomes research or PCOR. Veterans' experiences will also help us develop comparative effectiveness research or CER questions which compare the effectiveness of two or more interventions or approaches to health care. With this in mind, we developed questions for this meeting with a focus on Veterans and social isolation during the pandemic and its effects on PTSD symptoms.



Social Isolation Field Note Template

Question #1: Tell us how social isolation during the pandemic has impacted the ability to work, attend school, complete household tasks, or maintain social activities or relationships.

Question #2: Tell us how social isolation during the pandemic has affected health and access to health care.

Question #3: People might look for support from many different sources, including different kinds of providers, helpers, or healers. Discuss the kind of help, advice, or healing that has been beneficial for Veterans during the pandemic.

Question #4: Describe the types of communication used during the pandemic (e.g., phone, computer, social media interactions, in person).

Question #5: What have been the major concerns of Veterans with PTSD symptoms during the pandemic?



Loneliness Field Note Template

Question #1: Tell us how the pandemic impacted veterans' ability to seek and maintain connection with others.

Question #2: Describe key ways in which Veterans felt supported during the pandemic.

Question #3: Discuss how the pandemic may have affected Veterans with PTSD who were coping with loneliness? a) Describe coping strategies to prevent loneliness, such as sponsors, battle buddies, or service animals. b) Were any of these coping strategies related to military training?

Question #4: Discuss how symptoms of PTSD are related to loneliness. a) How does loneliness impact the treatment or healthcare for Veterans with PTSD? b) How does loneliness impact overall health care for Veterans with PTSD?

Question #5: Discuss how the pandemic may have influenced Veterans or their friends/family recognizing and identifying loneliness in Veterans.

Mental Health

Field Note Template

Question #1: How has the pandemic impacted your overall mental health? a) How has it changed your overall mental health concerns, e.g., pre-existing PTSD concerns, new mental health issues, and access to mental health care? b) What coping methods have you used in your daily life to manage your mental health?

Question #2: Veterans with PTSD have unique experiences compared to civilians. What risks do Veterans with PTSD have that may have affected overall mental health during the pandemic? a) Veterans with PTSD often experience anger, frustration, and the adrenaline rush that accompanies it. In what situations, if any, did you find yourself getting frustrated with people and/or triggered during the pandemic?

Question #3: Describe your own ideas and solutions to self-care during the pandemic. a) What outside resources, e.g., VAs/non-profits, have influenced your mental health? b) How did you find out about accessing these resources for mental health care?

Question #4: When you think about self-care, overall mental health care, wellbeing, non-profits, VA, hospitals, doctors, mindset, personal support, and overall treatment, how supportive or unsupportive is it in your “home life”? a) Describe some of the changes that you, your family, or those around you made to influence the dynamics of your home that either supported or undermined your mental health.

Question #5: Apart from PTSD, what do you see as the most relevant, challenging, and prominent mental health concerns for Veterans since 2020? a) Discuss ways health care providers or programs could address these challenges. b) Have you been involved in or are you aware of any initiatives to address mental health concerns? If so, how did you find out about them or become involved?

Question #6: Describe any change in your sense of personal resilience during the pandemic.

Well-being Field Note Template

Question #1: What does well-being mean to you? a) What biological, physical, mental, and emotional health outcomes related to PTSD symptoms are important to maintain your well-being?

Question #2: Discuss encouragement or pressures from society that Veterans (you) felt during the pandemic. a) How did these encouragements or pressures affect Veterans' (your) well-being individually and within the community?

Question #3: Discuss how the pandemic may have affected Veterans physically and mentally with the balance of life, family, friends, work, and mindfulness. a) What PTSD coping skills helped or prevented you from finding that balance in your life during the pandemic?

Question #4: Describe some goals, skills, hobbies, or activities in your daily life that you had before the pandemic and how you achieved them some other way or gave up on them during the pandemic? a) Were these goals, skills, hobbies, or activities ways to improve your well-being, and what were the challenges in pursuing them? b) Which of these goals, skills, hobbies, or activities are possible to engage with others while doing?*

Question #5: Tell us about the types of barriers you face when accessing resources or activities aimed at improving your well-being, e.g., time, costs, location, etc.

Question #6: Discuss how the public health responses and recommendations made during the pandemic may have influenced the way you relate with friends, family, colleagues, and/or society.

RESEARCH AGENDA

Veterans who attended the Mission Alliance regional focus group meetings described their struggles related to **social isolation** and **loneliness** during the COVID-19 pandemic such as disappointment at the missed opportunities to support other veterans with PTSD. Veterans' social circles became smaller making it more difficult for those who already had few social connections. Many Veterans worked from home which either improved or worsened family relationships and made finding work-life balance troublesome. They were, however, able to reconnect with old friends from the military and cultivate those relationships.

Many Veterans with PTSD experienced intensified symptoms during the COVID-19 pandemic. Instead of seeking care, some Veterans self-medicated with alcohol or drugs which negatively impacted their families. Other Veterans with PTSD found encouragement in virtual support groups led by fellow Veterans. They suffered together while alone and isolated in their home. Many veterans felt that the virtual environment was practical and better than nothing allowing them to look out for each other and adapt and overcome their feelings of loneliness.

Veterans lost confidence in health care systems. They were confused about public health messages, especially those about COVID-19 vaccines. Veterans needed support and trusted resources to manage their worsened PTSD symptoms such as telehealth services, virtual support groups (professional and peer to peer), access to mental health professionals who specialize in treating PTSD, and the freedom to choose their preferred pharmacological or non-pharmacological treatments. By bolstering the health care workforce, we can strive to meet the high demand for these services and ensure that veterans with PTSD gain the necessary tools to enhance and maintain their **mental health** and **well-being**.

Researchers and clinicians must continue to involve Veterans and stakeholders in community-based engagement, dissemination, and implementation projects to improve health care options that are meaningful to Veterans with PTSD. To this end, the Mission Alliance team developed and prioritized a Veteran-driven PTSD-related PCOR/CER agenda related to COVID-19 which is outlined in the following pages.

Prioritized Social Isolation Research Agenda

1. What are some preventative measures that healthcare providers and Veterans with PTSD can use to mitigate the effects of social isolation?
2. Which forms of communication best facilitate/optimize social connectedness among veterans with PTSD?
3. Which platforms and formats foster higher engagement among veterans with PTSD? Additionally, which are linked to improved well-being and mitigates social isolation?
4. How do telehealth and in-person services differ in regard to access to care and in consideration of geographic location?
5. What are the potential benefits and harms of using online platforms vs. in-person meetings to reduce social isolation among veterans with PTSD?
6. What are transferable military-related skills that help foster social connectedness between veterans with PTSD and the civilian sector?
7. What beneficial vs. harmful factors (e.g., perceived sense of control) moderate levels of social isolation within Veterans with PTSD vs. civilians with PTSD?
8. What are the benefits and harms of clinician-led versus peer-to-peer support regarding social isolation for veteran with PTSD?
9. What veteran-informed communication languaging improves attendance and engagement at social events among veterans with PTSD?
10. Are there differences in healthcare outcomes, including social isolation, for Veterans with PTSD who receive care via telehealth vs. in-person appointments?
11. What workplace policies and COVID-related regulations are linked to improved quality of life and mitigate social isolation among veterans with PTSD? (e.g., Whole health initiative)

Prioritized Loneliness Research Agenda

1. Which forms of communication are more conducive to mitigate loneliness for older adult veterans with PTSD who face barriers to utilizing technology?
2. What are the benefits and harms of clinician-led versus peer-to-peer support regarding loneliness for veteran with PTSD?
3. What frequency and types of engagement by support systems improve loneliness and quality of life for Veterans with PTSD?
4. What is the effectiveness of civilian patient navigators compared to VA/DoD veteran patient navigators for veterans with PTSD who experience loneliness?
5. How do interpersonal relationships and loneliness relate to substance use and mental health outcomes in veterans with PTSD?
6. What are effective and efficient methods for primary health care providers to screen for loneliness in veterans with PTSD?
7. What interpersonal responses impact loneliness and mental health outcomes for Veterans with PTSD?
8. What type of vocational and recreational activities affect loneliness in veterans with PTSD?

Prioritized Mental Health Research Agenda

1. What complementary and integrative health interventions improve mental health for Veterans with PTSD?
2. What complementary and integrative health interventions in conjunction with provider-driven evidenced-based treatments affect mental health among veterans with PTSD?
3. What coping strategies mediate the relationship between perceived social support and improved mental health among Veterans with PTSD during transitions?
4. What platforms and formats connect veterans with PTSD, across different geographic locations, to credible resources that impact mental health?
5. What behavioral self-assessment tools/training enhance self-awareness and acceptance of varying viewpoints to impact mental health in veterans with PTSD?
6. What routines (e.g., buddy checks), structures (e.g., community engagement), and/or internal factors (e.g., mindfulness, optimism, self-control) improve mental health for Veterans with PTSD?
7. What mechanisms (e.g., care giver, child care, internet and costs) or means of transportation are most effective to facilitate access to and attendance to mental health care appointments?

Prioritized Well-being Research Agenda

1. How do health systems, work places and community organizations design spaces that enable veterans from various points in their transitional period to enhance social engagement and sense of well-being?
2. How do you support and enhance training for veterans who are in leadership positions to enhance well-being in veterans with PTSD?
3. What factors facilitated or hindered coping skills during the COVID-19 pandemic to maintain well-being for veterans with PTSD symptoms?
4. What factors related to sense of autonomy impacted well-being among veterans during the COVID-19 pandemic?
5. How does individual compared to dyadic psychotherapies affect well-being among Veterans with PTSD?
6. What vocational factors relate to sense of purpose to impact well-being for veterans with PTSD?
7. What Veteran-delivered complementary and integrative interventions compared to provider-delivered interventions impact well-being in veterans with PTSD?



EVALUATION TOOLS

To improve the Mission Alliance Engagement project, the team developed three evaluation tools. We utilized Google Forms for two of the tools and the Zoom post-meeting survey for the third tool. The Stakeholder Comment Ebox was the first evaluation tool created to provide a safe space for Mission Alliance stakeholders to contribute comments or suggestions for program improvement. The second tool was the Regional Meeting Evaluation that was sent to veteran and key community stakeholder participants who attended the regional virtual meetings. The purpose of this tool was to gather information about the regional meetings and adapt the meetings accordingly. The Post-Convening Evaluation was the last tool developed during the project to capture the effectiveness of the virtual platform used for the convening and the success of the presentations to convey the importance of community engagement in Patient-Centered Outcomes Research.

Stakeholder Comment Ebox



Our goal is to be in full partnership with Veterans and key community stakeholders to develop a Veteran-driven PTSD-related Patient Centered Outcomes Research agenda including mental health and well-being topics and Comparative Effectiveness Research questions related to COVID-19. We need your help with comments and suggestions on how we can improve this work. Your opinion matters!

1. Comment and/or Suggestion
2. Would you like to leave your name or contact information?

Regional Meeting Evaluation

Thank you so much for attending your Regional Mission Alliance Meeting and for taking the time to leave feedback about your experience. This survey should take less than 5 minutes.

1. Which regional meeting did you attend?

- a. West
- b. Midwest
- c. Northeast
- d. South

2. Which of the following most accurately describes you? (Choose as many as you like)

- a. Female
- b. Male
- c. Non-binary
- d. Transgender
- e. Intersex
- f. I prefer not to answer

3. The Mission Alliance Team created a trusting environment for people to engage in an open and honest discussion.

- a. Strongly disagree
- b. Disagree
- c. Somewhat disagree
- d. Neither agree nor disagree
- e. Somewhat agree
- f. Agree
- g. Strongly disagree

4. My participation in the Mission Alliance meeting was valued and respected.

- a. Strongly disagree
- b. Disagree
- c. Somewhat disagree
- d. Neither agree nor disagree
- e. Somewhat agree
- f. Agree
- g. Strongly disagree

Regional Meeting Evaluation

5. I feel my experience can help shape future research questions.

- a. Strongly disagree
- b. Disagree
- c. Somewhat disagree
- d. Neither agree nor disagree
- e. Somewhat agree
- f. Agree
- g. Strongly disagree

6. I feel it is important to be involved in the development of research questions and discussion of treatment outcomes that are meaningful to me.

- a. Strongly disagree
- b. Disagree
- c. Somewhat disagree
- d. Neither agree nor disagree
- e. Somewhat agree
- f. Agree
- g. Strongly disagree

7. I was adequately compensated for my time.

- a. Strongly disagree
- b. Disagree
- c. Somewhat disagree
- d. Neither agree nor disagree
- e. Somewhat agree
- f. Agree
- g. Strongly disagree

8. Is there anything else you would like to share with us about the meeting or about PTSD-related research topics and themes associated with social isolation, loneliness, mental health or well-being?

Post-Convening Evaluation

1. For purposes of this evaluation, with which group do you identify the most?

- a. Veteran
- b. Health Care Provider
- c. Researcher
- d. Community Stakeholder

2. The remote conference was easy to follow.

- a. Strongly agree
- b. Agree
- c. Disagree
- d. Strongly disagree

3. Technological assistance was adequately provided.

- a. Strongly agree
- b. Agree
- c. Disagree
- d. Strongly disagree
- e. Not Applicable (N/A)

4. There were no difficulties when registering for the Mission Alliance National Convening.

- a. Strongly agree
- b. Agree
- c. Disagree
- d. Strongly disagree

5. The information presented clarified the benefits of Patient-Centered Outcomes Research for Veterans and other populations.

- a. Strongly agree
- b. Agree
- c. Disagree
- d. Strongly disagree

Post-Convening Evaluation

6. The information presented clarified the importance of Veterans' role in research related to PTSD.

- a. Strongly agree
- b. Agree
- c. Disagree
- d. Strongly disagree

7. As a result of attending the event, you better understand Patient-Centered Outcomes Research and its purpose.

- a. Strongly agree
- b. Agree
- c. Disagree
- d. Strongly disagree

8. As a result of attending the event, you are interested in learning more about patient-centered outcomes research.

- a. Strongly agree
- b. Agree
- c. Disagree
- d. Strongly disagree

9. Would you like to be contacted for future opportunities to engage or participate in Veteran-centered research by our team?

- a. Yes
- b. No

10. If interested, please provide your preferred method of communication to be contacted for upcoming events, e.g. veteran1@gmail.com or 444-333-2222.



Best Practices Conducting Virtual Focus Groups

Guidelines and Lessons Learned
2021-2023

Role of the facilitator

The facilitator's role is to manage interactions between group members and engage all participants. Facilitators set the tone in order for each participant to share, feel heard, and feel positive about their contributions to the session. The facilitator's ability to inquire and draw upon the experiences of the participants affects the data received.



Limit bias



- Avoid asking leading questions, and prevent "groupthink"
- Be careful to not add too much personal information on a topic
- Remain nonjudgmental, impartial, and neutral through verbal and nonverbal objectivity

Use various approaches to questions



- Explain that different formats will be used (e.g., open-ended, round robin)
- Emphasize that there are no right or wrong answers
- Probe for details by drawing out differences and/or encouraging a diverse range of meanings

Keep the discussion on track



- Deal tactfully with outspoken members
- Move conversation forward when it is drifting or has reached a minor conclusion
- Monitor time closely

Before the session



Correspond in advance

Confirm participation and personal goals for attending the group. Participants are more likely to show up for a virtual meeting if they have a vested interest.



Send a test link

Request that participants try the link in advance on their device and at the location that they will use for the meeting to make sure that technology is compatible and there are no issues. Troubleshoot with participant in advance if there are any issues.



Reminders

Resend the actual link one hour prior to the session. Inform participants that their immediate surroundings will be visible on camera, so they may want to adjust their background appropriately. Ask the participants to sign in 5–10 minutes prior to the session.



Double checking

In the minutes prior to the session, allow participants to ask questions and ensure that cameras, mics, and other technology features are all working properly.

Other considerations:

Pseudonyms

Incentives

Not-for-profit studies

Beginning the Group



01

Welcome each person individually

02

Welcome the entire group

03

Obtain informed consent

04

Express gratitude to the group for attending

05

Express gratitude for the group's input and feedback

06

Introductions and explanation of all roles

07

Explain focus group and structure

08

Provide purpose and background information

Before asking questions



Explain the online features

Chat function, muting, showing of hands, etc.

Technological issues

Provide procedures on what to do if participant's internet connection is lost or if they have technological issues.



Set the ground rules & explain session purpose

Give an overview of the session. Explain what will be done with the information from the session and any other logistical information. Inquire if anyone has questions prior to asking the first question.

Logistics

Considerations are different than those of in-person groups.

Logistics	Virtual Platform
Recruitment	More participants due to higher attrition
Size	4-6 (Possibly 6-8)
Length	60-90 minutes

- Confidentiality agreements can be obtained via a secure link, email, and/or verbally depending upon IRB determination.
- Types of questions
 - Opening/Introductory question
 - Key questions: 2-5
 - Conclusion question
 - Any other comments?

Advantages of Virtual Focus Groups



Less travel logistics



Not affected by location



Reaches a broader audience

Virtual conversation challenges

Considerations to name and address, as they might be disruptions to the natural flow of conversation.



Cameras turned off

- Set norms of cameras on (or off) for the meeting



Visual cues (e.g., eye contact)

- Acknowledgement of participant responses without having visual cues typically offered in person



Technological and software issues

- Facilitators should be familiar with common technological challenges and be able to assist participants as necessary.
 - Access
 - Connectivity/Bandwidth
 - Video freezing
 - Sound quality
 - Connecting to internet
 - Battery life
 - Power failure
 - Outdated hardware
 - Unfamiliarity with use

Virtual participant considerations

- Techniques to encourage discussion:
 - Inquiring: Could you expand on that? Could you tell us more? Is there anything else? Could you please describe what you mean?
 - Echoing: Does anyone see it differently? Has anyone had a different experience? Are there other points of views?
 - Reflective listening: I think I am hearing... is that correct? It sounds like... is that correct?



Participant considerations

- Digital literacy
- Withdrawal
- Time and setting
- Difference in dynamics
- Distractions (personal, external)
- Privacy issues (e.g., non-participant listening to session off screen)
- Online conference fatigue
- Unexpected commitments inhibiting attendance
- Time zones (e.g., international)
- Multitasking during meetings

Participant characteristics

- The "expert"
 - Emphasize that everyone is an expert and has important thoughts to share
- Dominant talkers
 - Shift attention and say "thank you, [name]"
 - "We have a limited amount of time, and I want to be able to hear from everyone."
 - "Are there others who wish to comment on the question?"
 - "That's one point of view. Does anyone have another?"
- Rambling respondents
 - Repeat question to get back on track
 - At a pause, interrupt and move the discussion
 - Divert back to topic (e.g., "You raised a good point; however, the main purpose is...")
 - "I am cognizant of the time..."
- Shy participants / Reflective thinkers
 - Acknowledge them by name
 - "[Name], I don't want to leave you out of the conversation. What do you think?"



COMMUNITY RESOURCES

988 Suicide & Crisis Lifeline

<https://988lifeline.org/>

The Lifeline provides 24/7, free & confidential support for people in distress, prevention/crisis resources, and best practices for US professionals.

Canines Providing Assistance to Wounded Warriors (C-P.A.W.W.)

<https://nursing.fau.edu/outreach/c-paww/>

C-P.A.W.W.'s mission is to advance interdisciplinary research, education and evidence-based practice for wounded warriors and veterans through the development of restorative interventions, to support health initiatives by building community partnerships, and to emphasize system planning, innovative public policymaking, and thorough care development protocols.

Give an Hour

<https://giveanhour.org/military/>

Give an Hour's Military Program provides no-cost counseling through a network of volunteer mental health professionals and empower community through collaborative programs, peer support and educational opportunities that benefit clients and providers.

Grey Team

<https://www.greyteam.org/>

The Grey Team in Boca Raton, Florida provides comprehensive health and wellness programs with one-on-one personal training, infrared detoxification, low-level laser therapy, electromagnetic therapy, acupuncture for pain relief, 3D body scanning, community safe-spaces, and much more.

Military OneSource

<https://www.militaryonesource.mil/>

Military OneSource offers individualized consultations, coaching and non-medical counseling for many aspects of military life.



COMMUNITY RESOURCES

National Alliance on Mental Illness (NAMI)

<https://www.nami.org/Your-Journey/Veterans-Active-Duty>

NAMI provides advocacy, education, support and public awareness so that all individuals and families affected by mental illness can build better lives.

Objective Zero Foundation

<https://www.objectivezero.org/>

The Objective Zero Foundation connects the military community to mental health and wellness resources and to a network of peer and civilian supporters to prevent suicide through the Objective Zero App.

Outward Bound

<https://www.outwardbound.org/expeditions/-outward-bound-for-veterans/>

Outward Bound for Veterans helps returning service members and recent veterans readjust to life at home through powerful wilderness courses that draw on the healing benefit of teamwork and challenge through use of the natural world.

Project Healing Waters Fly Fishing, Inc.

<https://projecthealingwaters.org/>

Project Healing Waters is dedicated to the physical and emotional rehabilitation of disabled active military service personnel and disabled veterans through fly fishing and associated activities including education and outings.

PTSD Foundation of America

<https://ptsdusa.org/>

The PTSD Foundation of America focuses specifically on combat trauma because they believe that Veterans dealing with combat specific trauma deserve a safe environment to share their experienced trauma with other combat Veterans. The PTSD Foundation of America also believes that PTSD in combat Veterans contributes to the 20+ a day suicide rate.



COMMUNITY RESOURCES

South Texas Research Organizational Network Guiding Studies on Trauma and Resilience (STRONG STAR) - <https://www.strongstar.org/>

STRONG STAR Network Providers: <https://strongstartraining.org/network/>

STRONG STAR is focused on reducing the suffering of our nation's wounded warriors and first responders and helping them prevent the development of chronic psychological health problems.

The Headstrong Project

<https://theheadstrongproject.org/>

The Headstrong Project is a non-profit mental health organization providing confidential, barrier-free, and stigma-free PTSD treatment to our veterans, service members, and family connected to their care.

The Mission Continues

<https://www.missioncontinues.org/>

The Mission Continues connects veterans with under-resourced communities. Their programs deploy veteran volunteers to the community to improve educational resources, tackle food insecurity, foster neighborhood identity, and more.

Wounded Warrior Project

<https://www.woundedwarriorproject.org/programs/wwp-resource-center>

The Wounded Warrior Project empowers wounded warriors. Their Project Resource Center serves as a connection point for veterans by listening, identifying next steps, and connecting them with Wounded Warrior Project programs and resources.

US Department of Veterans Affairs; National Center for PTSD

<https://www.ptsd.va.gov/>

The National Center for PTSD is the world's leading research and educational center of excellence on PTSD and traumatic stress.

Veterans Crisis Line

Call 1-800-273-8255 and Press 1

Text to 838255 or chat online at VeteransCrisisLine.net/Chat.

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