A GUIDE FOR PROMISING PRACTICES

IN ENGAGING LONG-TERM CARE COMMUNITIES IN PLANNING FOR FUTURE RESEARCH

INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE®
Transforming health care through partnerships

INTRODUCTION

Welcome to *A Guide for Promising Practices in Engaging Long-Term Care Communities in Planning for Future Research.* This resource has been developed for researchers as well as long-term care community advocates, leaders, staff, residents, and families as a step-by-step guide on promising practices in engaging residents and families in planning for Patient-Centered Outcomes Research/Comparative Effectiveness Research (PCOR/CER)*. It includes an overall description of our project and the lessons learned in successfully partnering with residents and families in research planning.

It is well recognized that residents and families are underrepresented as partners in research. We believe that improved, more focused research in long-term care will result if it originates directly from resident and family perspectives, priorities, and concerns in collaboration with researchers. Thus, this newly envisioned partnership in long-term care will answer a key question in research for residents and families alike, **"What matters most to you?"**[1]

PROJECT OVERVIEW

The impetus for this project was the devastating impact of the COVID-19 pandemic that disproportionally affected long-term care residents and revealed long-standing problems in these communities. To control the transmission of COVID-19, lockdowns were imposed in long-term care that prevented residents from seeing families and friends in person. This led to increased social isolation and loneliness, resulting in an adverse impact on mental health and well-being for residents, families, and staff.

The Institute for Patient- and Family-Centered Care (IPFCC) led this 18-month project with funding support from the Eugene Washington Patient-Centered Outcomes Research Institute (PCORI) Engagement Award program. The funding supported the creation of this guide and work leading up to its development and dissemination.

The following is an overview of the approach and activities used to elicit long-term care stakeholder involvement in planning for research related to the social isolation and loneliness experienced by residents and families during the COVID-19 pandemic.

Forming the IPFCC Project Team

IPFCC assembled a team that brought diverse perspectives and experience to this project. The Project Team included: a project lead with background in planning and building effective partnerships; a long-term care engagement consultant; an ethicist; two researchers; a family leader; and a project manager. Given this project's focus on the impact of COVID-19 on residents and families, the long-term care engagement consultant also had a background in infection prevention and control. In addition, the ethicist was a designated essential care partner for her 94-year-old mother in long-term care and is currently serving on the Heath Services Organization Technical Committee which is developing standards for long-term care in Canada.

Creating a National Advisory Committee

The Project Team formed a National Advisory Committee (NAC) with representatives from national advocacy organizations from the United States and Canada, leaders of long-term care communities and the long-term care industry, researchers, and resident and family leaders. The NAC provided guidance throughout the project on approaches, materials development, and dissemination of project findings and resources. Key to this committee was the participation of thoughtful resident and family leaders who were able to speak from their unique experience as well as leaders and researchers who brought their insights and perspectives from work in the field.

Establishing Goals and Objectives

The following goals and objectives were developed to inform all major activities of the project:

1. Develop partnerships among residents, families, and staff in long-term care, researchers, and other stakeholders for planning and conducting research.

2. Identify and prioritize root causes of social isolation and loneliness during COVID-19 with residents and families.

3. Develop topics, themes, and interventions for future research with residents and families and other long-term care stakeholders.

4. Engage long-term care stakeholders in dissemination.

Recruiting Long-term Care Communities

The Project Team developed a plan to recruit four long-term care communities that would represent some geographic and population diversity. Initial steps included surveying long-term care websites, requesting referrals from the National Advisory Committee, and seeking potential sites from IPFCC's network. Once prospective organizations were identified, conversations occurred with senior leaders and staff who had participated in research or organized supportive programs for residents and families. The project lead and the long-term care engagement consultant selected four larger communities that served diverse populations across different geographic locations. In addition, it was important that these communities had the bandwidth to continue involvement should a resurgence of COVID-19 occur within their respective communities. The following four communities were selected:

1. Garden Spot Village, a rural continuing care retirement community (CCRC), New Holland, PA

2. A.G. Rhodes Cobb, a skilled nursing and rehabilitation community, Marietta, GA

3. St. Vincent de Paul, part of ArchCare, a large, comprehensive long-term care system in New York, serving a Latino population in the Bronx

4. Brock Fahrni, a long-term care home, affiliated with Providence Health Care in Vancouver, British Columbia

Selecting and Working with Long-Term Care Support Persons

A key strategy for success was asking each of the four long-term care communities to designate a staff support person to serve as the primary point of contact. These individuals had responsibility for recruiting residents and families to participate in the project, and for supporting their involvement in each major project activity. The support persons represented a variety of disciplines including music therapy, person-centered care, recreation therapy, and operations/nursing.

Selecting and Preparing Residents and Families for Participation

Staff support persons at the long-term care communities recruited residents and families following criteria that were developed by the project lead and long-term care engagement consultant. In addition, they used project materials that included a recruitment flyer, a card with the participating long-term care communities listed and their logos displayed, a brief one-page summary, and a slide deck with an overview and introduction to research, specifically PCOR/CER.

PROJECT OVERVIEW

Eliciting Resident and Family Perspectives and Identifying Topics and Themes for Research

Residents and families were engaged in three major meetings to elicit their perspectives:

▶ **Meeting 1: Virtual, Structured, Supportive Small Group Conversations with Residents and Families.**

The purpose of these conversations was to develop a better understanding of the root causes of social isolation and loneliness, highlight the adverse impact on mental health and well-being, identify resident and family priorities, and surface potential topics for future research. From these conversations, the Project Team identified the key themes related to social isolation and loneliness, and conducted a root cause analysis that identified multiple contributing factors and four root causes. Details of this analysis can be found on pages 19 and 20.

"One resident shared with his social worker that he was invited to join a committee...about the pandemic. His social worker noted that he expressed pride in being part of the group...it gave him a sense of purpose...She saw this resident in a different light...(seeing) his strengths rather than places of need which we often focus on in skilled nursing."
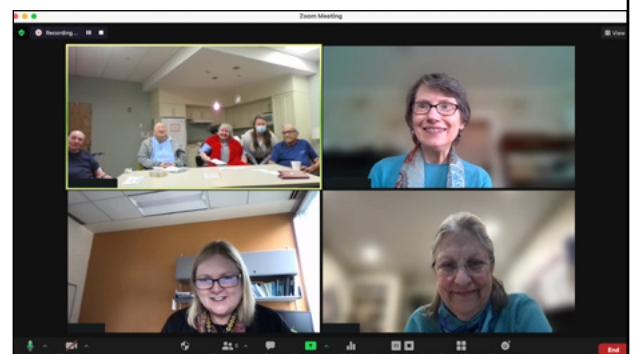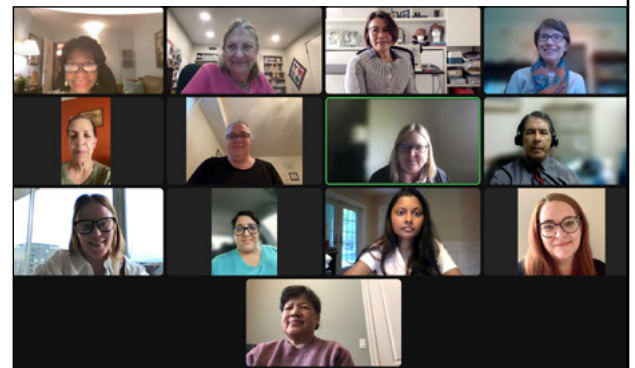
PROJECT OVERVIEW

▶ **Meeting 2: Two 90-minute Facilitated Virtual Stakeholder Meetings— One Each with Two of the Participating Long-Term Care Communities.**
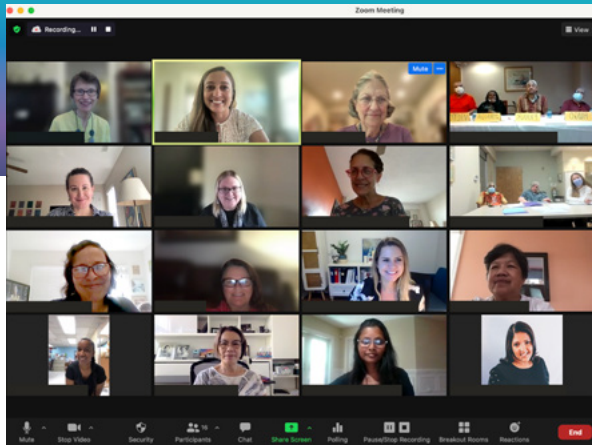
During the meeting, residents, families, staff, and leaders from long-term care communities discussed and prioritized topics and themes for future research informed by the key themes of social isolation and lonelinenss and four root causes.

▶ **Meeting 3: Final International Stakeholder Summit and Dissemination of Resources.**

As the final virtual meeting, an International Stakeholder Summit was planned to serve as the launch for dissemination. The agenda included the sharing of project findings, resources, and plans for future collaboration in research. Prior to the meeting, the Project Team identified funders, and additional researchers, residents, families, and long-term care leaders and staff to participate in the Summit.

Lessons Learned from Engaging Residents and Families in Long-Term Care Communities in Planning for Research

This project identified strategies that may be helpful to others in partnering with residents and families in research. They range from how to get started by forming a project team to planning for meeting evaluations. In addition, approaches are described that ensure meaningful participation by residents and families in virtual meetings. The following are promising practices for advocates and researchers.

Creating a Project Team and Advisory Committee

Assemble a team with diverse perspectives, expertise, and experience with group facilitation, planning, and working collaboratively with residents, families, and staff across disciplines.

Ensure that the voices and perspectives of residents and families are central to all project activities, (e.g., on the Project Team, the Advisory Committee, and in key meetings). If further expertise is needed on the Project Team to facilitate direct collaboration with residents and families, seek guidance from individuals or organizations with this experience from the community or nationally and internationally.

Depending on the scope of the project, consider having either a local/regional advisory committee (drawing on community or state/provincial-wide expertise). or one with national expertise and perspectives. In either case, include resident and family leaders as essential members who will help guide the project and provide important insights from their unique perspective. For assistance in identifying resident and family leaders as research partners, the following organizations are examples of those that might be consulted: The Green House Project and Pioneer Network, Healthcare Excellence Canada, Ontario Association of Residents' Councils, National Continuing Care Residents Association, Caregivers for Compromise, and the Institute for Patient- and Family-Centered Care.

Establishing Goals and Objectives

Create and share clearly stated goals and objectives at the beginning of your project.

Goals and objectives should inform each phase of a project, guide key decisions, and ensure that there is a shared understanding among all members of the Project Team and Advisory Committee.

Recruiting a Long-Care Community or Communities

Use the scope of your project to guide how many long-term care communities to involve while selecting those that represent diverse resident and family populations.

If involving more than one community, ensure that the budget allows for virtual meetings or, if in-person, there is transportation within local communities and travel and lodging across geographic regions. Also, compensation should be offered to residents and families in appreciation of their time and effort.

Selecting and Working with Long-Term Care Support Persons

Consider identifying a support person to be the key contact with residents, families, and staff at long-term care communities.

The support person's role in recruiting and supporting residents and families proved to be invaluable in working with the long-term care communities in this multi-site project. It is helpful to have someone clearly designated in this role so that staff and leaders can refer potential resident and family partners to them. Similarly, residents and families will know whom to reach out to with questions. Of note, many people who have served in roles facilitating collaboration with residents and families have found it rewarding.

Selecting and Working with Long-Term Care Support Persons continued

To help identify individuals with relevant skills and qualities, the following criteria were shared with leaders of the long-term care communities:

- Experience in working directly with residents and families within the long-term care community.

- Experience with the long-term care community's isolation and family/visitor presence restrictions due to the COVID-19 pandemic.

- Understanding of the culture of the long-term care community.

- Ability to see strengths in all people and in all situations to build on these strengths.

- Organizational and time-management skills.

- Ability to listen and communicate effectively.

- Experience or familiarity with Zoom Meetings or connections with a staff person who has this experience.

- Demonstrated interest in furthering knowledge about the value of resident and family voices in organizational improvement activities and their potential as research partners.

- Flexibility to accommodate last minute changes in plans and willingness to think creatively.

- Sense of humor.

Partnering with residents in any type of improvement activity may be a new experience for support person(s). A benefit of participation may be that it provides a professional growth opportunity. It is important to recognize that staffing shortages may present challenges for long-term care communities in identifying a staff member to assume this role. This situation may require leadership to intervene and provide support where necessary.

For projects with multiple sites, consider the following:

- Identify a designated support person at each long-term care community to be on point for recruitment, resident and family support, and overall coordination at their site.

- Hold regular virtual meetings between the project staff and the support persons.

- Use these meetings to provide a forum for exchanging ideas, troubleshooting problems, and promoting learning from one another.

Selecting and Working with Long-Term Care Support Persons continued

In this project, weekly one-hour meetings were held for two months to orient and prepare staff support persons on how to recruit and support residents and families for their participation in the Small Group Conversations. Later in the project, meetings were held less frequently when they prepared residents and families for the Stakeholder Meetings.

With effective facilitation, the support persons can become a cohesive team and can proactively identify issues and strategies that improve on the initial plans for collaboration with residents and families. Through this process, the support persons may also discover new strengths in residents and families and their potential for working as partners in research and other improvement activities.

"I benefitted a lot from meeting with our team working on recruiting strategies, bouncing ideas off each other and continuing to support one another."

Encourage flexibility among support persons and all team members in working with residents and families to accommodate last minute changes in their needs or plans. A willingness to think creatively will benefit the project. Residents and families may need special accommodation to participate meaningfully (e.g., hearing loss, visual impairment, health care appointments, or other issues) and these may change over the course of the project.

The Project Team should also be prepared for situations when there is turnover of long-term care leaders and/or staff. When this happens, the project may lose some continuity and support. Both time and preparation are needed in bringing new leaders and/or staff on board. Additional communication about the project and its important goals and benefits to the organization may be necessary.

Long-term care leaders balance multiple responsibilities and, thus, may need to step back from their engagement in the project. To this end, it's critical to identify someone else to fill this role, but may be challenging given the ongoing staffing shortages confronting long-term care communities. Stressing the benefits and the potential value of the project to the long-term care community may be helpful in recruiting leadership involvement.

Selecting and Preparing Residents and Families for Participation

Consider how to include multiple levels of care, as appropriate, including skilled nursing, memory care, assisted living, and independent living when recruiting residents and families from continuing care retirement communities, and develop relevant recruitment materials and strategies.

Consider the average length of stay for residents and how long your project will be from inception to completion. For example, one long-term care community noted that the average length of stay was only 18 months.

The level of care areas selected will depend on the goals and objectives of your project. Residents, in this project, needed to have the cognitive ability to communicate effectively in a group setting and, in a facilitated conversation, express ideas that potentially can inform research. In other projects, the focus may be on learning from residents with dementia and other cognitive impairments. In these situations, plan for the support necessary to involve these residents effectively.

To have broader representation of the long-term care community, choose family members who are not related to the residents selected for participation. In some situations, it might be beneficial to recruit a resident and family member dyad to elicit information on their shared experience.

Selecting and Preparing Residents and Families for Participation continued

If it is determined that families of residents will participate, recognize that some residents have family that is not accessible, or they may not wish to involve their family in the project. Residents could be asked to identify others outside of the long-term care community who serve in significant supportive roles in their lives to participate.

In recruiting residents and families for research planning and improvement activities, consider the following qualities and skills:

- Have lived experience in the long-term care community relevant to the proposed project.

- Share their perspectives based on personal experience within the long-term care community including interactions they may have had with other residents, family members and staff.

- Reflect the diversity of the long-term care community.

- See beyond their own personal experience.

- Show an interest in more than one agenda item or issue.

- Respect diversity and differing opinions.

- Listen well and be receptive to other points of view.

- Display an interest in improving quality of life for residents.

Look for residents and families who have partnered with long-term care leaders and staff in initiatives related to quality improvement, safety, promotion of quality of life, facility design, and even pandemic planning as they can provide valuable knowledge and have the confidence to serve as research partners. Some long-term care communities may not have experience with these partnerships, but they may have experience with resident and family councils.

"People really do have a story to share if you offer a listening ear…even if a story isn't formulated in a way that this is our path for research, having them tell their story can lead to a direction for change…"

Selecting and Preparing Residents and Families for Participation continued

In working with the staff support persons, provide them with resources containing useful information to recruit residents and families for participation. This includes plain language about the purpose of the project, what is entailed in participating, and the importance of resident and family perspectives. Recruitment materials need to offer succinct, practical strategies for recruitment, including how to support residents and families in recognizing that their insights and experience add value to research. When developing a recruitment brochure, consider the need for translation as well as common terminology used in long-term care communities. For example, one community referred to residents as "elders" and staff as "employee care partners." These resources could then be used in whatever ways are most helpful. Ensure that the language and terms used are understandable to the residents and families.

Elders & Families Needed!

HOW CAN YOU HELP?

Share your thoughts and feelings in a small group conversation about your personal experiences with the many changes made during the COVID-19 pandemic. These changes, made to keep everyone safe and prevent the spread of infection, have been a challenge for everyone.

YOUR EXPERIENCE MATTERS

This is an important opportunity for you to reflect on your experiences and make recommendations for improvement to ensure that future changes and research will benefit elders and families as well as employee care partners. A small thank you payment will be provided in appreciation for your time and thoughtfulness.

INTERESTED?

Please contact

_____

at _____
for more information if interested in contributing to this important project!

INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE®

The Institute for Patient- and Family-Centered Care (IPFCC), a non-profit organization, is leading this work with support from the Patient-Centered Outcomes Research Institute (PCORI) in order to encourage residents and families to partner with researchers in the future.

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NECESITAMOS
Ancianos y Miembros de la Familia

COMO PUEDEN AYUDAR?

Comparte tus pensamientos en una conversacion de grupo pequeños sobre su experiencias personales con los muchos cambios realizado durante la pandemia del COVID-19. Estos cambios, hechos para mantener a todos seguros y prevenir la propagacion de infeccion, han sido un desafio para todos.

TU EXPERIENCIA SE VALORA

Esta es una oportunidad importante para que reflexione sobre sus experiencias y hacer recomendaciones para mejorar y asegurar que futuros cambios e investigaciones beneficien a los Residentes, las Familias asi como el Personal. Se proporcionara un pequeño pago de agradecimiento por su tiempo y consideracion al final de este proyecto.

INTERESADOS?

Por favor contactar

_____

al _____
para mas informacion y si deseas contribuir para este proyecto importante.

INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE®

El "Institute for Patient- and Family-Centered Care" (IPFCC), es una organizacion sin fines de lucro y esta liderando este proyecto con el apoyo del "Patient-Centered Outcomes Research Institute (PCORI)" para alentar a los residentes y las familias a asociarse con investigadores en el futuro.

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Selecting and Preparing Residents and Families for Participation continued

Additional materials may include:

- A card with the long-term care communities listed (if more than one in a project) and logos displayed to help residents and families see that they will be part of a larger project—important for their community, but one that reaches far beyond. (See page 5)

- A brief one-page summary of the project. **(Click here for a sample).**

- A set of slides divided into short sections. The first could be used to explain the project and another section could introduce the importance of residents and families to early research planning. **(Click here for a sample).** Consider sharing slides in stages to provide flexibility for varying attention spans and not to overwhelm residents and families with too much information in a single session. This approach may also address staff time constraints. In the project, one support person shared the slides in a meeting with residents and CNAs. This proved to be beneficial because the nursing assistants had a close relationship with residents and could help reinforce what was learned.
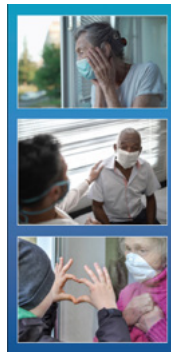
Partnering with Residents and Families to Learn about the Impact of the COVID-19 Pandemic

A First Step for Future Research

Residents & Families Needed!

Project Overview

April/May 2022 Virtual Small Group Conversations

September 2022 Virtual Stakeholder Meetings

March/April 2023 Virtual International Stakeholder Summit

Three Sessions Over the Next Year

Selecting and Preparing Residents and Families for Participation continued

Consider the following strategies in recruiting residents and family members to participate in the project:

- Post the brochure in key public areas such as dining and activity rooms.

- Place a notice on the long-term care community's website.

- Send a notice via email to the target population.

- Attend staff and/or management meetings and share slides and recruitment brochure.

- Ask staff and clinicians for their recommendations.

- Attend Resident and Family Council Meetings.

- Write an announcement for an internal employee newsletter.

- Write a letter to families about the project.

- Review letters from families that have constructive ideas for improvement for the long-term care community.

Create a letter of agreement that specifies responsibilities, an honorarium, and timing of payment for resident and family participation. You may want to include a photo release form as well.

Throughout the recruitment process and beyond, help the long-term care communities develop their understanding of the value of the resident and family voice in research and how to partner with them effectively.
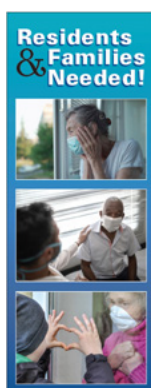
You Can Make a Difference!
Thank you for your
participation and ideas!

Eliciting Perspectives of Residents and Families and Other Relevant Stakeholders through Virtual Meetings

Plan the details for effective participation, anticipating technology challenges and the unique needs of residents, families, and, when included, staff and leaders.

Planning for Facilitation for Effective Virtual Meetings:

- Develop two detailed protocols or facilitator guides (one for residents and one for families) for facilitating the conversations. These step-by-step playbooks should include a welcome and introduction, timeline, and questions designed to elicit feedback from participants.

  - Plan for the use of interpreter(s) if needed.

  - Consider sharing some of the questions from the protocols with residents and families in advance of the meetings to increase their level of comfort with the topic and think about their responses.

- Assign a Project Team member to take detailed notes, record the session, and transcribe the recording via Otter.ai or other transcription software.

- Create a checklist of tasks to be completed by a support person or other team member before the session begins.

- Convene a Project Team debriefing right after each meeting and modify the facilitator guide accordingly.

Checklist to Complete before Small Group Conversations

Name of Long-Term Care Community: Date:

Task	Yes	Comments
FOR RESIDENT MEETING		
Secure meeting space		
Notify nursing well before date of conversation to ensure that medications, bathroom visits, last minute doctor or therapy visits, etc. are coordinated in a timely manner to avoid any undue delays		
Several days before the conversation: Check access to Zoom in this room and test sound for where residents will be sitting (if possible). Is a microphone or the use of an extra laptop needed? Is an AV tech needed? Is a spider phone or conference microphone needed for a teleconference if WIFI is unstable?		
Share information sheet with the general questions with residents several days before the scheduled conversation		
Consider informing residents in advance of the conversation about support available following the gathering		
Reminder to residents of date and time and to arrive 15 minutes early		
Second reminder on day of conversation		
Arrange for help to escort residents who need assistance to come to meeting (but not stay for the meeting)		
Create tent cards with first name of participants (or name they prefer)		
Provide a box of tissues on the table		
Provide glasses of water		
Check access to Zoom and sound before assembling (30 minutes before the start time)		
Have pad of paper and pen available in case you want to take any brief notes, but your role is to be available if any resident needs extra support.		
FOR FAMILY CALLS/MEETINGS		
Secure meeting space if not a Zoom call		
Send Zoom link to families participating from home		
Notify nursing well before date of conversation to ensure that medications, bathroom visits, last minute doctor or therapy visits, etc. are coordinated in a timely manner to avoid any undue delays		
If in a meeting room, **several days before the conversation:** Check access to Zoom in this room and test sound for where family members will be sitting (if possible). Is a microphone or the use of an extra laptop needed? Is an AV tech needed? Is a spider phone or conference microphone needed for a teleconference if WIFI is unstable?		
Share information sheet with the general questions with families several days before the scheduled conversation		
Consider informing family members in advance of the conversation about support available following the gathering		
Reminder to families of date and time and to arrive 15 minutes early		
Second reminder on day of conversation		
If in person, create tent cards with first name of participants (or name they prefer)		
If in person, provide a box of tissues on the table		
If in person, provide glasses of water		
Check access to Zoom and sound before assembling (30 minutes before the start time)		
Have pad of paper and pen available in case you want to take any brief notes, but your role is to be available if any family member need extra support.		

Eliciting Perspectives of Residents and Families and Other Relevant Stakeholders through Virtual Meetings continued

Supporting Resident and Family Participation:

- Begin to assemble residents well in advance of session and "expect the unexpected!" This may include unanticipated family members visiting, delayed therapies, or change in health status.

- Check seating arrangement around conference table to ensure all residents can be seen by the facilitator(s). This can be done shortly before the session begins.

- Set a tone in all virtual meetings of respect, warmth, and inclusivity. Welcome participants individually as they join and create an informal conversational atmosphere.

- Ensure residents and families can hear what others are saying and are able to visualize other participants on the screen.

- Use large tent cards that visibly display the residents and family members' names.

- Provide adequate time for responses.

- Consider including a five-minute stretch break in the middle of the conversation. An hour-long session may be too long for some residents.

Managing the Technology for Virtual Meetings:

- Have a backup plan in case of equipment failure, e.g., extra laptop or an available cell phone.

- Ensure residents can see the screen. In many instances this was a laptop. A television may also serve this purpose, or even a large sceen in a conference room, if available.

- With virtual technology, welcome residents to participate who may be away from the long-term care community during the call. In this project, one resident was visiting her son in another state and the support person was able to coordinate arrangements with the resident's son.

- Create a backup plan for residents and families unable to participate at the last minute. Consider individual interviews via phone call or Zoom.
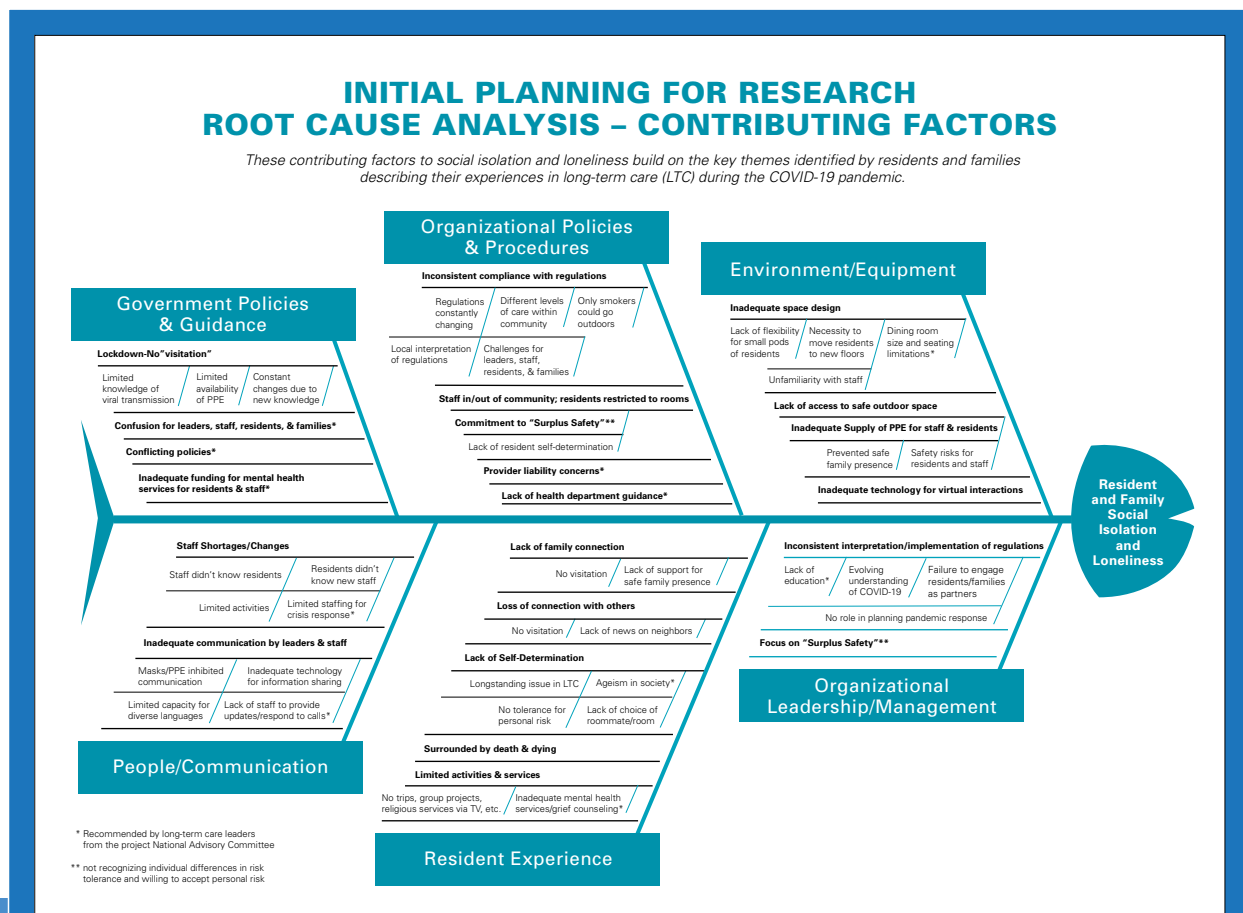
Identifying and Prioritizing Research Topics and Themes through Interdisciplinary Stakeholder Meetings

In addition to the above recommendations for virtual Small Group Conversations, consider the following:
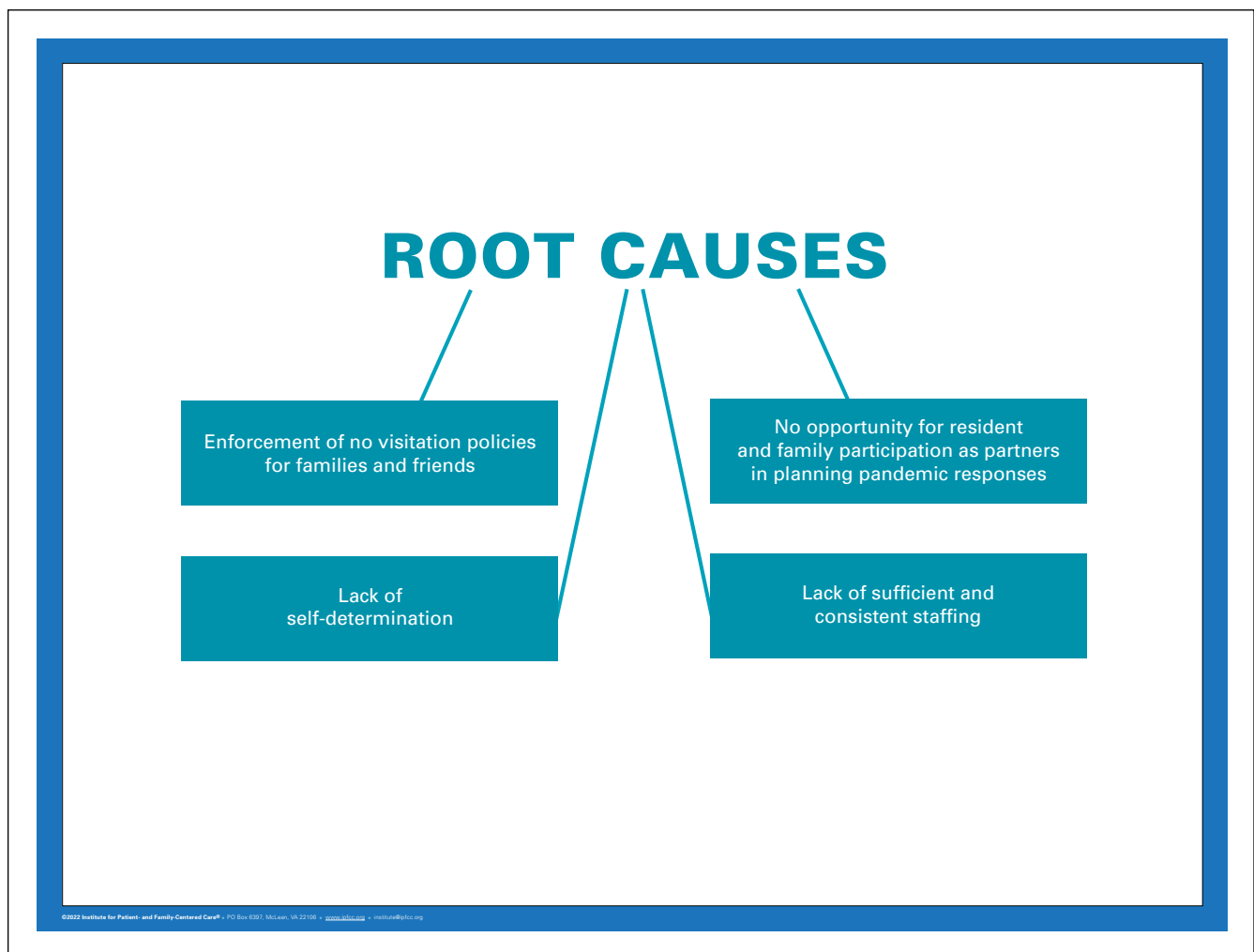
Planning for Facilitation

- Create a list of invitees and reach out to residents, families, staff, and leaders.

- Summarize and identify key themes from information gathered in initial meetings with residents and families and disseminate findings to participants in the Small Group Conversations, long-term care community leaders, and Advisory Committee members for their review.

  – A root cause analysis is one approach to identify core issues that may inform the development of research topics and themes. A fishbone diagram may be used to facilitate this process.

INITIAL PLANNING FOR RESEARCH
ROOT CAUSE ANALYSIS – CONTRIBUTING FACTORS

These contributing factors to social isolation and loneliness build on the key themes identified by residents and families describing their experiences in long-term care (LTC) during the COVID-19 pandemic.

Organizational Policies & Procedures

Inconsistent compliance with regulations

| Regulations constantly changing | Different levels of care within community | Only smokers could go outdoors |

Local interpretation of regulations | Challenges for leaders, staff, residents, & families

Environment/Equipment

Inadequate space design

Lack of flexibility for small pods of residents | Necessity to move residents to new floors | Dining room size and seating limitations*

Unfamiliarity with staff

Lack of access to safe outdoor space

Inadequate Supply of PPE for staff & residents

Prevented safe family presence | Safety risks for residents and staff

Inadequate technology for virtual interactions

Government Policies & Guidance

Lockdown-No"visitation"

Limited knowledge of viral transmission | Limited availability of PPE | Constant changes due to new knowledge

Confusion for leaders, staff, residents, & families*

Conflicting policies*

Inadequate funding for mental health services for residents & staff*

Staff in/out of community; residents restricted to rooms

Commitment to "Surplus Safety"**

Lack of resident self-determination

Provider liability concerns*

Lack of health department guidance*

Resident and Family Social Isolation and Loneliness

Staff Shortages/Changes

Staff didn't know residents | Residents didn't know new staff

Limited activities | Limited staffing for crisis response*

Inadequate communication by leaders & staff

Masks/PPE inhibited communication | Inadequate technology for information sharing

Limited capacity for diverse languages | Lack of staff to provide updates/respond to calls*

Lack of family connection

No visitation | Lack of support for safe family presence

Loss of connection with others

No visitation | Lack of news on neighbors

Lack of Self-Determination

Longstanding issue in LTC | Ageism in society*

No tolerance for personal risk | Lack of choice of roommate/room

Surrounded by death & dying

Limited activities & services

No trips, group projects, religious services via TV, etc. | Inadequate mental health services/grief counseling*

Inconsistent interpretation/implementation of regulations

Lack of education* | Evolving understanding of COVID-19 | Failure to engage residents/families as partners

No role in planning pandemic response

Focus on "Surplus Safety"**

Organizational Leadership/Management

People/Communication

Resident Experience

* Recommended by long-term care leaders from the project National Advisory Committee

** not recognizing individual differences in risk tolerance and willing to accept personal risk

Identifying and Prioritizing Research Topics and Themes through Interdisciplinary Stakeholder Meetings continued
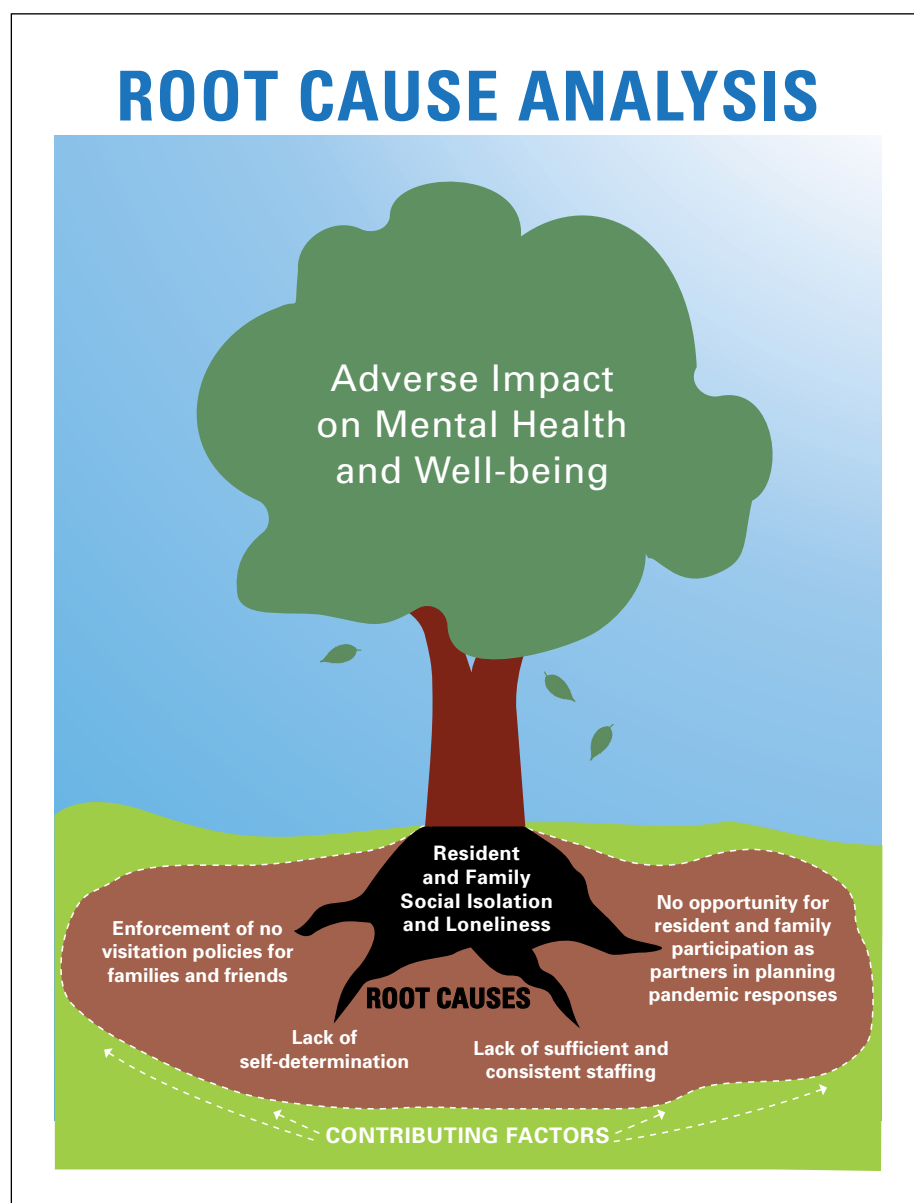
- In preparing material for these virtual meetings:
  - Consider visual acuity of residents, in particular (e.g., the root cause analysis/ fishbone diagram and summary of root causes were printed on poster size paper in a large font, 24 point).

ROOT CAUSES

Enforcement of no visitation policies for families and friends

No opportunity for resident and family participation as partners in planning pandemic responses

Lack of self-determination

Lack of sufficient and consistent staffing

Identifying and Prioritizing Research Topics and Themes through Interdisciplinary Stakeholder Meetings continued

– In addition, a large graphic describing the process may be used,
(e.g., a tree diagram illustrating the root cause analysis process).

ROOT CAUSE ANALYSIS

Adverse Impact
on Mental Health
and Well-being

Resident
and Family
Social Isolation
and Loneliness

No opportunity for
resident and family
participation as
partners in planning
pandemic responses

Enforcement of no
visitation policies for
families and friends

ROOT CAUSES

Lack of
self-determination

Lack of sufficient and
consistent staffing

CONTRIBUTING FACTORS

• Develop a detailed facilitator guide for these virtual stakeholder meetings that includes strategies for prioritizing research topics and themes.

Identifying and Prioritizing Research Topics and Themes through Interdisciplinary Stakeholder Meetings continued

Planning for Active Participation

- Send materials in advance of the meeting to provide adequate time for support persons to discuss with residents and families and for staff to review. Request that all meeting participants begin to think of potential topics and themes for research.

  – Consider the use of brief videos (narrated slide decks) to prepare all stakeholders to participate meaningfully in identifying and prioritizing research topics and themes. **(Click here for a sample).**
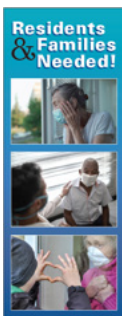
Introduction to Research and Your Potential Roles as Research Partners

- The current project you are participating in is called an "**engagement project**."
- It is the first step in planning for research by gathering insights, perspectives, and priorities of residents and families.

- In this project, you are helping to identify topics, themes, and approaches that matter most to residents and families. This is an important initial step in planning for research.
- This information will inform development of research questions in the future.
- An ultimate goal is that residents and family members will develop an interest in partnering with researchers in the future.

- Recognize that leaders and staff will have limited time to prepare for participation and provide them with materials in succinct formats.

- Plan for at least one 90-minute meeting. Because more time may be necessary, it might be advisable to have two shorter meetings if budget permits.

- Consider offering initial suggestions for research topics and themes evolving from the resident and family key themes identified in Small Group Conversations.

  – Review initial list with stakeholders and elicit feedback and additional recommendations.

- Facilitate prioritization exercises using the list of research topics and themes.

  – Consider using sticky notes for participants to record responses. Websites such as Mentimeter, Google Jamboard, or Poll Everywhere may also be used for voting.

Sharing Project Findings among Stakeholders and Launching Broad Dissemination in a Virtual International Stakeholder Summit

- Prepare final project materials for dissemination at the Summit and beyond.

- Develop a list of invitees, including researchers, funders, policy makers, representatives of government agencies, residents and families, long-term care community leaders and staff, and other industry/advocacy leaders.

  - Include relevant project participants, residents, families, leaders and staff as well as the Advisory Committee.

- Plan an agenda that includes residents and families as presenters, reinforcing their meaningful participation in the project and their roles as research partners.

  - Prepare residents and families who are presenters for their roles as well as other residents and families who are participants in the meeting.

- Identify the key strategies for broad dissemination. Some examples of these include:

  - Newsletters and websites of national and regional long-term care advocacy organizations.

  - Webinars.

  - Targeted outreach to research communities and foundations.

IPFCC's website section on Long-Term Care Partnerships: https://ipfcc.org/long-term-care-partnerships

Evaluating Meetings

Use a variety of ways to learn about the effectiveness of meetings and gather information for improvement, especially as it relates to the meaningful participation of residents and families.

- Include evaluation as part of the agenda for all meetings.

- Consider sending brief questionnaires via email or using Survey Monkey following each meeting. A Project Team member may need to interview residents unable to participate in on-line surveys. Examples of questions to consider using are:

  - Prior to the meeting, you were sent information including (describe). I found these materials helpful in preparing me to be an active participant in the meeting.

    * Participants were asked to specify their level of agreement or disagreement on a 5-point scale: 1) Strongly Agree, 2) Agree, 3) Neither Agree or Disagree, 4) Disagree, and 5) Strongly Disagree.

  - My opinions were listened to and valued.

    * Participants were asked to specify their level of agreement or disagreement on a 5-point scale: 1) Strongly Agree, 2) Agree, 3) Neither Agree or Disagree, 4) Disagree, and 5) Strongly Disagree.

  - Please share any ideas you have about how we could have made your experience more meaningful or satisfying.

- Consider polling the group with one or two questions before the meeting ends. This addresses the issue that residents or families might not be able to access a follow-up survey.

"The information gathered in this project is so important. It gave people the opportunity to finally, finally express themselves..."

Evaluating Support Persons' Perceptions of Recruiting Residents and Families and Supporting Them in Small Group Conversations

Seek information from support persons about their experience in recruiting and preparing residents and families in early research planning.

1. What was hardest for you in a) recruiting residents, and b) recruiting families?

2. What might you do differently in the future in a) recruiting residents for a project, and b) recruiting families for a project?

3. What was hardest for you in coordinating the a) resident Small Group Conversations, and b) family Small Group Conversation?

4. What might you do differently in the future if coordinating a) a resident Small Group Conversation, and b) a family Small Group Conversation?

5. Is there anything the Project Team could have done to be more helpful or improve your experience when a) recruiting residents and families, and b) coordinating the Small Group Conversations?

6. What are you hearing, if anything, from residents and families following the Small Group Conversations?

7. Anything else you wish to share?

Thank you!

Conclusion

The COVID-19 pandemic highlighted the need for research in long-term care to ensure safety, quality of life, and well-being of residents, families, and staff. Currently there is limited involvement of residents and families in organizational planning and improvement. This guide describes processes to support the essential role of residents and families in long-term care communities in planning for future research.

We are grateful to the residents, families, long-term care leaders and staff, the support person team, and our National Advisory Committee for their thoughtful participation throughout this project.

ORGANIZATIONAL RESOURCES

Institute for Patient- and Family-Centered Care (IPFCC) Website
Long-Term Care Partnerships: https://ipfcc.org/long-term-care-partnerships
Research Partnerships: https://ipfcc.org/research-partnerships.

PCORI Resources

Research Fundamentals: Preparing You to Successfully Contribute to Research
www.pcori.org/engagement/research-fundamentals

Building Effective Multi-Stakeholder Research Teams
www.pcori.org/events/2020/building-effective-multi-stakeholder-research-teams

AARP Policy Institute. Long-Term Services and Supports and Family Caregiving, *AARP Nursing Home COVID-19 Dashboard*. www.aarp.org/ppi/issues/caregiving/info-2020/nursing-home-covid-dashboard.html

Altarum. https://altarum.org/populations/eldercare

Americans for Financial Reform Education Fund (AFREF). *The Deadly Combination of Private Equity and Nursing Homes During a Pandemic — New Jersey Case Study of Coronavirus at Private Equity Nursing Homes,* August 2020. https://ourfinancialsecurity.org/2020/08/report-3-private-equity-nursing-homes-coronavirus/

American Institute of Architects (AIA). *Strategies for Safer Senior Living Communities,* May 2020. https://www.aia.org/resources/6307024-strategies-for-safer-senior-living-communi

Canadian Centre for Caregiving Excellence (CCCE). *An Approach to a Better Caregiving Landscape in Canada,* November, 2022. https://canadiancaregiving.org/wp-content/uploads/2022/11/CCCE_Giving-Care.pdf

Caregivers for Compromise. A coalition of leaders across the U.S. working to establish legislation that eliminates the isolation of residents in long term care facilities like that experienced in response to COVID-19. https://caregivers4compromise.com

Center for Advance Design Research and Evaluation (CADRE). *Resilient Access to Social Connection for Lower-Income Older Adults: Tapping the Potential of the Built Environment.* www.cadreresearch.org/resilient-social-connection

Resources

Centers for Disease Control. www.cdc.gov/longtermcare/index.html

CJE Senior Life. *Bureau of Sages* – Research Advisory Board comprised of long-term care community members and stay-at-home elders. www.cje.net/bureauofsages

Facilities Guideline Institute (FGI). *Guidance for Designing Health and Residential Care Facilities that Respond and Adapt to Emergency Conditions,* March 2021. https://fgiguidelines.org/resource/guidance-for-designing-health-and-residential-care-facilities-that-respond-and-adapt-to-emergency-conditions/

FrameWorks. *How to Share the NASEM Report, The National Imperative to Improve Nursing Home Quality, with Public Audiences,* April 2022. www.frameworksinstitute.org/wp-content/uploads/2022/04/Nursing-Homes-Framing-Guidance_2022.pdf.

Healthcare Excellence Canada (HEC). LTC+ Resources and Promising Practices for Those Living and Working in Long-Term Care. www.healthcareexcellence.ca/en/what-we-do/all-programs/ltc-acting-on-pandemic-learning-together/ltc-resources-and-promising-practices-for-those-living-and-working-in-long-term-care/

- *Practices of Interest to Support In-Person Family Presence and Communication with Families.* www.healthcareexcellence.ca/media/jamgqx4q/20211015_supportfamilypresenceandcommunication_en.pdf.

- *LTC+ – Mental Health and Resiliency Resources for Healthcare Providers, Staff and Leaders*. www.healthcareexcellence.ca/en/what-we-do/all-programs/ltc-acting-on-pandemic-learning-together/ltc-mental-health-and-resiliency-resources-for-healthcare-providers-staff-and-leaders/

- *Promising Practices for Supporting Long-Term Care Provider Resilience*. https://www.healthcareexcellence.ca/media/amycqp4n/20211004_promisingpracticesforsupportingltcproviderresilience.pdf

- *Safely Re-entering Long-Term Care Homes During COVID-19: A Resource for Essential Care Partners*. https://www.healthcareexcellence.ca/en/what-we-do/all-programs/ltc-acting-on-pandemic-learning-together/safely-re-entering-long-term-care-homes-during-covid-19/

- *Essential Together Tool: Identifying Strengths and Improvements to Reintegrate Essential Care Partners.* www.healthcareexcellence.ca/media/eudefits/20211222_essentialtogethertool_en.pdf

Resources

Innovation in Aging. *Does Living in a Higher Proportion Minority Facility Improve Quality of Life for Racial/Ethnic Minority Residents in Nursing Homes?* June 2020. https://academic.oup.com/innovateage/article/4/3/igaa014/5851608

Institute for Healthcare Improvement (IHI). *COVID-19 Resources: Care of Older Adults.* www. ihi.org/Topics/COVID-19/Pages/COVID-19-Care-of-Older-Adults.aspx

- *Might the COVID-19 Pandemic Lead to Better Practices in Long Term Care.* https://www.ihi.org/about/news/Pages/Might-the-COVID-19-Pandemic-Lead-to-Better-Practices-in-Long-Term-Care.aspx

- *COVID-19 Rapid Response Network for Nursing Homes.* https://www.ihi.org/Engage/Initiatives/COVID-19-Rapid-Response-Network-for-Nursing-Homes/Pages/default.aspx

- *Leveraging National Nursing Home Huddles for Rapid COVID-19 Response.* https://www.mdpi.com/2308-3417/6/2/62

National Academies of Sciences, Engineering, and Medicine (NASEM). *The National Imperative to Improve Nursing Home Quality: Honoring Our Commitment to Residents, Families, and Staff,* 2022. https://nap.nationalacademies.org/catalog/26526/the-national-imperative-to-improve-nursing-home-quality-honoring-our

Ontario Association of Residents' Councils (OARC). *Communicating with Residents During Outbreaks: OARC Tips and Template.* www.ontarc.com/tools/20210719ComTipsTemplate.pdf

- *Residents' Council: Considerations and Strategies for Long-Term Care Homes During Outbreaks*: https://www.ontarc.com/education-support/tools.html#outbreaks

Ontario Centres for Learning, Research and Innovation in Long-Term Care (CLRI). Resources: https://clri-ltc.ca/resource/essential-care-partner/

- *Essential Care Partners Are Essential: Infographic Resource.* https://clri-ltc.ca/files/2022/10/Infographic-Report_V5_Final_FINAL-s-2.pdf

- *Program Implementation Guide.* https://clri-ltc.ca/files/2022/10/Essential_Care_Partner_Implementation_Guide_V5_Final_FINAL-s-1.pdf

Resources

Pioneer Network. https://www.pioneernetwork.net/

- *Honoring Preferences When the Choice Involves a Risk: A Process for Shared Decision Making and Care Planning,* August 2018. www.pioneernetwork.net/wp-content/uploads/2021/02/Honoring-preferences-when-the-choice-involves-risk.pdf

Planetree. Guidelines on Family Presence During a Pandemic. https://planetree.org/wp-content/uploads/2020/08/Published-Guidelines-on-Family-Presence-During-a-Pandemic-Final-8.13.20v5.pdf.

- *Family Presence Policy Decision-Making Toolkit.* https://planetree.org/wp-content/uploads/2021/05/Family-Presence-Policy-Decision-Making-Toolkit.pdf

The Green House® Project. https://thegreenhouseproject.org

- *Elevate Eldercare Podcast.* "Rethinking "Surplus Safety" in Long-Term Care," October 26, 2022.

JOURNAL ARTICLES AND BOOKS

Healthcare Quarterly. "Lessons from Long-Term Care Home Partners during the COVID-19 Pandemic." *December 2022.* https://www.longwoods.com/content/26981/lessons-from-long-term-care-home-partners-during-the-covid-19-pandemic

International Journal of Health Policy and Management (IJHPM). "Structural and Managerial Risk Factors for COVID-19 Occurrence in French Nursing Homes." February, 2022. www.ijhpm.com/article_4207.html

JAMA Internal Medicine. "Association Between Nursing Home Crowding and COVID-19 Infection and Mortality in Ontario, Canada." February, 2021. https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/2772335

Journal of Alzheimer's Disease. "Dementia-Friendly 'Design': Impact on COVID-19 Death Rates in Long-Term Care Facilities Around the World." 2021 www.j-alz.com/content/dementia-friendly-design-impact-covid-19-death-rates-long-term-care-facilities-around-world

Resources

Journal of the American Medical Directors Association (JAMDA)

- "Allowing Visitors Back in the Nursing Home During the COVID-19 Crisis: A Dutch National Study Into First Experiences and Impact on Well-Being*." June 2020. www.jamda.com/article/S1525-8610(20)30526-0/fulltext

- "Caring for a Relative With Dementia in Long-Term Care During COVID-19." December 2021. www.jamda.com/article/S1525-8610(21)01013-6/fulltext

- *Dementia.* "Family members' reasoning in relation to pleasant environments in nursing homes." January 2023. https://journals.sagepub.com/doi/epub/10.1177/14713012221142474

- "Essential Family Caregivers in Long-Term Care During the COVID-19 Pandemic." May 2021. www.jamda.com/article/S1525-8610(20)30430-8/fulltext

- "Nontraditional Small House Nursing Homes Have Fewer COVID-19 Cases and Deaths." March 2021. www.jamda.com/article/S1525-8610(21)00120-1/fulltext

- "Nursing Home Design and COVID-19: Balancing Infection Control, Quality of Life, and Resilience." November 2020. www.jamda.com/article/S1525-8610(20)30788-X/fulltext

- "Nursing Home Design and COVID-19: Implications for Guidelines and Regulation.*" January 2021. https://www.jamda.com/article/S1525-8610(21)00120-1/fulltext

- "Predicting Mortality Risk in Older Hospitalized Persons With COVID-19: A Comparison of the COVID-19 Mortality Risk Score with Frailty and Disability.*" July 2021. www.jamda.com/article/S1525-8610(21)00512-0/fulltext

- *"*Reimagining Long-Term Care." February 2022. www.jamda.com/issue/S1525-8610(21)X0011-4

- "The Adverse Events of the COVID-19 Pandemic on Nursing Home Resident Well-Being" *May* 2021. www.jamda.com/article/S1525-8610(21)00306-6/pdf

- "The Inevitability of Reimaging Long-Term Care." February 2022. www.jamda.com/article/S1525-8610(21)01106-3/pdf

Neglected No More: The Urgent Need to Improve the Lives of Canada's Elders in the Wake of the Pandemic. André Picard, Random House Canada, 2021. www.penguinrandomhouse.ca/books/669793/neglected-no-more-by-andre-picard/9780735282247