

# Healthcare Quarterly

Vol.25 Special Issue 2022

[www.healthcarequarterly.com](http://www.healthcarequarterly.com)

## Strengthening Pandemic Preparedness in Long-Term Care



PROMISING PRACTICE  
INTERVENTIONS

PARTNER PERSPECTIVE

LEADERSHIP PERSPECTIVE:  
**Reflecting on the Journey  
to Develop New National  
Long-Term Care Standards**







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This work is supported by the Canadian Institutes of Health Research (CIHR). At CIHR, we know that research has the power to change lives. As Canada's health research investment agency, we collaborate with partners and researchers to support the discoveries and innovations that improve our health and strengthen our healthcare system.

# Lessons from the COVID-19 Pandemic for Long-Term Care: Where Do We Go Next?

Even before the COVID-19 pandemic, I would often hear colleagues who are intimately familiar with our health and social care system remark that they would never allow themselves or those closest to them to end up in long-term care. Sadly, the conversation often progressed to an acknowledgment that more desirable alternatives to long-term care for the most part lie outside our publicly supported care system and are only accessible to those with the means. And then we had the pandemic. For too many it turned what was often dreary and uninspiring care into a modern hell – so awful that two Canadian provinces called in the military to restore care in their worst-hit homes (Howlett 2021). There can be no doubt that the challenges that we face in providing dignified, respectful care to all our seniors have been decades in the making. It would be wrong to simply blame the long-term care homes, and it would be a travesty to lay the blame on individual care providers. On the contrary, those working in long-term care have continued to do their best, against the odds. In the early stages of the pandemic, they were not given the support that they deserved, and many paid a high personal price for their service.

## Seeking Quick Action on Early Lessons from the COVID-19 Pandemic

This issue of *Healthcare Quarterly* (HQ) presents the key findings and recommendations from an ambitious, large-scale research initiative that was launched quickly in response to the experiences of the first wave of the COVID-19 pandemic in long-term care. It sought to take the early lessons from COVID-19 and move fast to reduce the harm arising from the pandemic. Healthcare Excellence Canada (HEC) and the Canadian Institutes of Health Research (CIHR) led with a rapid environmental scan to identify areas for improvement and inform future pandemic preparedness. They then recruited and funded numerous teams of distinguished researchers and practitioners to follow an implementation science approach in applying promising practices and policies much more broadly

(Strengthening Pandemic Preparedness in Long-Term Care Program Delivery Team 2022).

HEC, CIHR and the Implementation Science Teams should be applauded for their rapid response to the COVID-19 crisis in long-term care. There is no doubt that their work has identified and accelerated the adoption of practices that improved care and reduced harm in the later phases of the COVID-19 pandemic. Their work also lays valuable groundwork for responding to future pandemics. HEC, CIHR and the Implementation Science Teams focused on several key areas, including achieving much better support for the staff delivering care, increasing family presence in long-term care homes and achieving meaningful person-centred care. Their research and extensive collaboration give us an important and worthy improvement agenda for moving forward.

While the research and collaboration described in this issue of HQ focus on what can be done to make Canadian long-term care safer for future pandemics, there is also a more profound sense of concern that runs through many of the articles. Several of the authorship teams acknowledge that the tragedy that unfolded in long-term care had its roots in fundamental structural and resourcing problems that have plagued long-term care for more than a generation. The articles are written by academics and care professionals in the style that papers in this kind of journal are customarily written, but one cannot miss the underlying outrage and discouragement. One authorship team politely refers to the “ingrained systemic and structural issues” of long-term care (Glowinski et al. 2022: 26). Something has gone profoundly wrong in long-term care, and it goes back to long before the pandemic. Reports on the issues span decades, and their findings and recommendations echo across our healthcare jurisdictions (Wong et al. 2021). And while this issue of HQ sets out actions that will make long-term care safer in the near term, we as a society and our governments still have to address those systemic and structural issues. It will take more than a quick patch job.

### How Do We Define Long-Term Care?

For the benefit of *HQ* readers from outside Canada (and, perhaps, to give Canadian readers a clearer perspective), we should acknowledge what we typically mean in Canada when we talk about “long-term care.” For Canadians, “long-term care” generally refers to residential care for those unable to care for themselves. It is often synonymous with nursing home care. This stands in contrast to how the term “long-term care” is typically used in the US, UK and Europe, where it usually refers to a broader spectrum of care provided to those who require ongoing supports – including community-based and in-home services as well as residential care – and often also includes “informal services” provided by family and friends (Wikipedia 2019). Language itself can be revealing. Perhaps an appreciation of Canadians’ more restrictive use of the term might prompt us to ask whether we should adopt a broader perspective on the nature of care we offer those who are unable to care fully for themselves.

### Looking for Lessons Beyond Canada

The impetus for the Strengthening Pandemic Preparedness in Long-Term Care collaborative (Strengthening Pandemic Preparedness in Long-Term Care Program Delivery Team 2022) – which is the basis of this issue of *HQ* – was the tragically high toll of COVID-19 among long-term care residents, particularly at the outset of the pandemic. In the first wave of the COVID-19 pandemic in Canada, 81% of all deaths from COVID-19 occurred in long-term care. This compares with other Organisation for Economic Co-operation and Development (OECD) countries that on average experienced 38% of all deaths from COVID-19 occurring among those receiving equivalent care – less than half that of Canada. The next highest after Canada was Spain at 66%. Two countries were at less than 10% (CIHI 2020). These dramatically different patterns of mortality from COVID-19 raise questions. Were there opportunities we missed to substantially improve care and better protect long-term care residents? Are there lessons from other OECD countries that can help us meaningfully improve preparedness for a future pandemic? Interestingly, the HEC/CIHR-led Strengthening Pandemic Preparedness in Long-Term Care collaborative devoted almost all its attention to the Canadian context and what could be learned from long-term care settings and stakeholders in this country. There is surely an opportunity now for HEC and CIHR to support complementary work on what Canadians can learn from the other OECD jurisdictions whose long-term care residents fared so much better in the COVID-19 pandemic.

### Let Us Think about the Kind of Long-Term Care We Really Want

In addition to presenting the main takeaways from the Strengthening Pandemic Preparedness in Long-Term Care collaborative, this issue of *HQ* also includes a thoughtful commentary by Samir Sinha (Sinha 2022). Sinha recently played a leadership role in the development of the Health Standards Organization’s new long-term care standards, and much of his commentary is devoted to these standards and how they will improve the quality and safety of long-term care (Sinha 2022). Sinha also reflects candidly on the broader legacy of the COVID-19 pandemic for long-term care in Canada. On this topic, he is less optimistic, suggesting that the political will is still not there to make the “wholesale change” (Sinha 2022: 55) that is required, even after the tragic experiences of the pandemic. This begs the question of what it will take for us to make those wholesale changes to transform long-term care in Canada to the point where it is an option all of us will be prepared to embrace when our time comes.

Canadians owe it to the current and future residents of long-term care and their families to wholeheartedly adopt the lessons and recommendations from the Strengthening Pandemic Preparedness in Long-Term Care collaborative summarized in this issue of *HQ*. But let us make no mistake – much work remains. More fundamental changes are required if we are to get to a point where we are providing truly acceptable care for those who cannot live independently. Canadians must ask: What do we want long-term care to be? How do we want to be cared for when we cannot look after ourselves? Do we really want a much-regulated and often very basic institutional care – a minimally funded care of last resort, sometimes provided on an industrial scale? Or do we want an integrated range of services that includes community resources and seeks to make the most of home-based care? Do we want to learn from countries such as Denmark and the Netherlands, which offer the kind of care options most of us would seek for our loved ones and ourselves? Do we really want to simply build tens of thousands more nursing home beds – the road that the Ontario government, for example, is currently going down? Or can we learn from and expand on new models of care that have already been applied on a small scale in Canada, such as the Green House model being tested in Alberta and Quebec (Ha 2022) or the Butterfly Model for dementia care being tried in British Columbia (Morris 2018)? We have neglected these questions for far too long. Let us encourage HEC and CIHR to add them to their next research agendas.

– Neil Stuart

## About the Editor

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## Leçons de la pandémie de COVID-19 pour les soins de longue durée : où allons-nous ensuite ?

Même avant la pandémie de COVID-19, j'ai souvent entendu des collègues, qui connaissent bien le système de santé et de services sociaux, dire qu'ils ne permettraient jamais à leurs proches, ni à eux-mêmes, de se retrouver dans un établissement de soins de longue durée. Malheureusement, la conversation aboutissait souvent au constat que les choix de remplacement sont pour la plupart hors du système de santé financé par l'État et ne restent accessibles qu'à ceux qui en ont les moyens. Puis il y a eu la pandémie. Pour trop de gens, les soins qui étaient déjà trop mornes et sans intérêt sont devenus un véritable enfer – si horrible que deux provinces canadiennes ont dû faire appel à l'armée pour rétablir les soins dans les résidences les plus touchées (Howlett 2021). Il ne fait aucun doute que les défis en matière de soins dignes et respectueux pour les aînés sont présents depuis des décennies. Ce serait une erreur de simplement blâmer les établissements de soins de longue durée, et ce serait une parodie de jeter le blâme sur les prestataires de soins. Au contraire, ceux qui travaillent dans les soins de longue durée ont continué à faire de leur mieux, contre toute attente. Au début de la pandémie, ils n'ont pas reçu le soutien nécessaire et plusieurs en ont fait les frais.

### À la recherche d'une action rapide face aux premières leçons tirées de la pandémie

Ce numéro de *Healthcare Quarterly* (HQ) présente les principales conclusions et recommandations d'une initiative de recherche ambitieuse à grande échelle qui a été lancée rapidement en réaction à l'expérience de la première vague de COVID-19 dans les soins de longue durée. Cette initiative vise à tirer partie des premières leçons retenues et à agir rapidement pour réduire les dommages résultant de la pandémie. Excellence en santé Canada (ESC) et les Instituts de recherche en santé du Canada (IRSC) ont mené une analyse rapide du contexte afin de repérer les domaines à améliorer et d'éclairer la préparation à une éventuelle pandémie. Ils ont ensuite recruté et financé de nombreuses équipes de chercheurs et de praticiens distingués pour suivre une approche scientifique de la

mise en œuvre, en appliquant des pratiques et des politiques prometteuses de manière beaucoup plus large (Équipe de mise en œuvre du programme pour le renforcement de la préparation des établissements de soins de longue durée à la pandémie 2022).

On doit applaudir ESC, les IRSC et les équipes en science de la mise en œuvre pour leur réaction rapide face à la crise de COVID-19 dans les soins de longue durée. Il ne fait aucun doute que leur travail aura permis de repérer et d'accélérer l'adoption de pratiques qui ont amélioré les soins et réduit les dommages dans les phases ultérieures de la pandémie. Leur travail jette également de précieuses bases pour réagir à d'éventuelles pandémies. ESC, les IRSC et les équipes en science de la mise en œuvre se sont concentrés sur plusieurs domaines clés, notamment l'obtention d'un meilleur soutien pour le personnel qui prodigue les soins, l'augmentation de la présence des familles dans les foyers de soins de longue durée et la réalisation de soins axés sur la personne. Leurs recherches et leur collaboration donnent lieu à un important programme d'amélioration pour aller de l'avant.

La recherche et la collaboration décrites dans le présent numéro portent sur ce qui pourrait se faire pour rendre les soins de longue durée canadiens plus sûrs en cas d'éventuelles pandémies, cependant il y a aussi un sentiment plus profond d'inquiétude qui traverse de nombreux articles. Plusieurs des équipes reconnaissent que la tragédie qui s'est déroulée dans les soins de longue durée prend racines dans des problèmes fondamentaux en matière de structures et de ressources, problèmes qui caractérisent les soins de longue durée depuis plus d'une génération. Les articles sont rédigés par des universitaires et des professionnels de la santé dans le style habituel pour ce type de revues, mais on ne peut manquer de remarquer l'indignation et le découragement sous-jacents. Une des équipes fait poliment référence aux « problèmes systémiques et structurels enracinés » des soins de longue durée (Glowinski et al. 2022 : 26). Quelque chose a définitivement mal tourné dans les soins de longue durée, et cela remonte à bien avant la pandémie. Les rapports

sur les problèmes dans les soins de longue durée s'étendent sur des décennies, et leurs conclusions et recommandations font écho dans nos systèmes de santé (Wong et al. 2021). Et bien que ce numéro de *HQ* présente des actions qui rendront les soins de longue durée plus sûrs à court terme, nous en tant que société, et nos gouvernements, devons encore nous attaquer à ces problèmes systémiques et structurels. Il faudra plus qu'un travail de rapiéçage rapide.

### Comment définissons-nous les soins de longue durée?

Pour le bénéfice des lecteurs de *HQ* à l'extérieur du Canada (et, peut-être, pour donner aux lecteurs canadiens une perspective plus claire), il faut préciser ce que nous entendons généralement au Canada par « soins de longue durée ». Pour les Canadiens, ce sont généralement des soins offerts en établissement pour les personnes incapables de prendre soin d'elles-mêmes. C'est souvent synonyme de foyer de soins infirmiers. Cela contraste avec la façon dont l'expression « soins de longue durée » est généralement utilisée aux États-Unis, au Royaume-Uni et en Europe, où elle fait généralement référence à un éventail plus large de soins fournis à ceux qui ont besoin d'un soutien continu – services communautaires, services à domicile, soins en établissement – et comprend souvent aussi les « services informels » fournis par la famille et les amis (Wikipedia 2019). Le langage lui-même peut être révélateur. Au vu de l'utilisation plus restrictive de l'expression par les Canadiens, peut-être que nous pourrions nous demander s'il ne vaudrait pas mieux adopter une perspective plus large sur la nature des soins que nous offrons à ceux qui sont incapables de prendre pleinement soin d'eux-mêmes.

### À la recherche de leçons au-delà du Canada

L'étincelle qui a provoqué cette collaboration pour le renforcement de la préparation des établissements de soins de longue durée à la pandémie (Équipe de mise en œuvre du programme pour le renforcement de la préparation des établissements de soins de longue durée à la pandémie 2022) – étincelle qui est à la base de ce numéro de *HQ* – est le bilan tragiquement élevé de décès attribuables à la COVID-19 parmi les résidents en soins de longue durée, particulièrement au début de la pandémie. Lors de la première vague de la pandémie au Canada, 81 % de tous les décès dus à la COVID-19 sont survenus dans des établissements de soins de longue durée. Cela se compare à d'autres pays de l'Organisation de coopération et de développement économiques (OCDE) qui ont enregistré, en moyenne, 38 % des décès dus à la COVID-19 parmi les personnes recevant des soins équivalents, soit moins de la moitié du pourcentage au Canada. Le pays qui arrive en deuxième position après le Canada est l'Espagne, avec 66 %. Le pourcentage était moins de 10 % dans deux pays (ICIS 2020). Ces schémas de mortalité

radicalement différents soulèvent des questions. Avons-nous raté des occasions d'améliorer les soins et de mieux protéger les résidents des établissements de soins de longue durée? Y a-t-il des leçons à tirer d'autres pays de l'OCDE qui pourraient nous aider à améliorer la préparation à une éventuelle pandémie? Fait intéressant, le projet de collaboration pour le renforcement de la préparation des établissements de soins de longue durée à la pandémie dirigé par ESC et les IRSC a porté presque toute son attention sur le contexte canadien et sur ce qu'on peut apprendre des milieux de soins de longue durée et des intervenants au pays. ESC et les IRSC devraient certainement avoir maintenant l'occasion d'appuyer des travaux complémentaires sur ce qu'on peut apprendre des pays de l'OCDE où les résidents en soins de longue durée ont mieux résisté à la pandémie de COVID-19.

### Réfléchissons au type de soins de longue durée que nous voulons vraiment

En plus de présenter les principales conclusions de la collaboration pour le renforcement de la préparation des établissements de soins de longue durée à la pandémie, ce numéro de *HQ* comprend une réflexion de Samir Sinha (Sinha 2022). M. Sinha a récemment joué un rôle de premier plan, au sein de l'Organisation des normes en santé, pour l'élaboration des nouvelles normes pour les soins de longue durée. Une bonne part de son commentaire porte sur ces normes et sur la manière dont elles peuvent améliorer la qualité et la sécurité des soins de longue durée (Sinha 2022). Par ailleurs, M. Sinha porte aussi une franche réflexion sur l'héritage de la pandémie de COVID-19 pour les soins de longue durée au Canada. Sur ce sujet, il se montre moins optimiste, suggérant que la volonté politique n'est toujours pas au rendez-vous pour opérer le « changement de fond en comble » (Sinha 2022 : 55) qui s'impose, et ce, même après l'expérience tragique de la pandémie. Cela soulève la question à savoir ce qu'il faudra pour que nous apportions les changements nécessaires pour transformer les soins de longue durée au Canada, au point où ce type d'établissements serait un choix que nous serions tous prêts à accepter le moment venu. C'est par déférence pour les familles et les résidents actuels et futurs des établissements de soins de longue durée que les Canadiens se doivent d'adopter sans réserve les leçons et les recommandations résumées dans le présent numéro de *HQ* par le projet de collaboration pour le renforcement de la préparation des établissements de soins de longue durée à la pandémie. Mais ne nous y trompons pas, il reste encore beaucoup à faire. Des changements plus fondamentaux seront nécessaires si nous voulons offrir des soins vraiment acceptables à ceux qui ne sont pas autonomes. Les Canadiens doivent se demander ce qu'ils veulent comme soins de longue durée. Comment voudrions-nous être traités quand nous ne pourrions plus prendre soin de nous-mêmes? Voulons-nous vraiment des soins institutionnels très réglementés et assez souvent basiques : des soins de dernier



recours peu financés, parfois fournis à une échelle industrielle? Ou voulons-nous une gamme intégrée de services qui inclut des ressources communautaires et qui cherche à tirer le meilleur parti des soins à domicile? Voulons-nous apprendre de pays comme le Danemark et les Pays-Bas, qui offrent le type de soins que la plupart d'entre nous voudraient pour nos proches ou pour nous-mêmes? Voulons-nous vraiment construire des dizaines de milliers de lits supplémentaires dans les foyers de soins, ce qu'est en train de faire le gouvernement de l'Ontario,

par exemple? Si non, pouvons-nous appliquer de nouveaux modèles de soins comme ceux qu'on observe à petite échelle au Canada – pensons au modèle Green House testé en Alberta et au Québec (Ha 2022), ou encore au modèle Butterfly pour les soins de la démence testé en Colombie-Britannique (Morris 2018)? Nous avons trop longtemps négligé ces questions. Incitons ESC et les IRSC à les ajouter à leurs prochains programmes de recherche.

– Neil Stuart

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### À propos de l'éditeur

Neil Stuart, Ph.D., a été pendant de nombreuses années partenaire et chef de pratique pour les pratiques canadiennes de consultation en soins de santé de la firme PricewaterhouseCoopers, puis d'IBM. M. Stuart est membre du conseil d'administration

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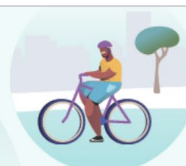
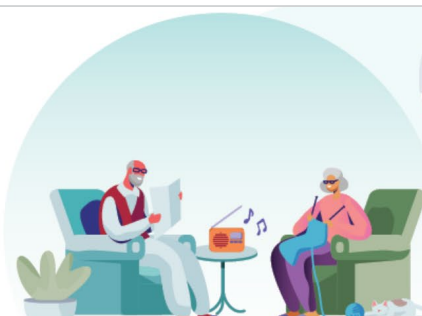
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## STRATEGIC DIRECTIONS

**Health and wellness over the trajectory of aging**

**Facing the complex health challenges of an older population**

develop and implement funding for strategic research initiatives

stimulate research capacity building by supporting trainees

play a role as a key convener and catalyst for the research community and facilitate links with stakeholders



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Achieving the Quadruple Aim (improved patient experience, improved provider experience, better population health, increased value) and health equity for all are at the centre of IHSPR's priorities.

## IHSPR Strategic Plan 2021–2026

**Accelerate** Health System Transformation through **Research** to Achieve the **Quadruple Aim** and **Health Equity for All**

- 1** Accelerate the discovery of innovations that transform health care delivery systems
- 2** Modernize the health care system with digital health solutions and data science
- 3** Integrate evidence into health services and policy decisions for improved health system performance and outcomes
- 4** Strengthen capacity for solution-oriented research and evidence-informed health care system transformation



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# In this issue *Vol.25 Special Issue 2022*

## FROM THE EDITOR

### 1 **Lessons from the COVID-19 Pandemic for Long-Term Care: Where Do We Go Next?**

*Neil Stuart*

This special issue of *Healthcare Quarterly* presents key findings and recommendations from the Implementation Science Teams – Strengthening Pandemic Preparedness in Long-Term Care rapid research program that was launched quickly in response to the experiences of the first wave of the COVID-19 pandemic in long-term care.

## INTRODUCTION

### 13 **Strengthening Pandemic Preparedness in Long-Term Care**

*Strengthening Pandemic Preparedness in Long-Term Care Program Delivery Team (including Richard H. Glazier, Joanne Goldberg, Jessica Hodge, Justin Lui, Kirstin Loates, Meghan McMahon, Jessica Nadigel, Ayah Nayfeh, Susan Rogers, Jane Rylett, Erin Thompson, Patricia Versteegh, Lindsay Yarrow and Jennifer Zelmer)*

Healthcare Excellence Canada, the Canadian Institutes of Health Research and provincial partners launched the Implementation Science Teams (ISTs) – Strengthening Pandemic Preparedness in Long-Term Care rapid research program. This article introduces the purpose of this special issue and outlines the research initiative, the ISTs' research areas of focus and the program's overall reach.

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*Amy T. Hsu, Geetha Mukerji, Anne-Marie Levy and Andrea Iaboni*

Three projects designed to enhance care delivery in the context of the pandemic are explored: addressing personhood needs during outbreaks; improving the quality of medical care by wrapping services around the medical needs of long-term care residents; and delivering personalized palliative and end-of-life care using a prediction algorithm. These projects enabled better care during the pandemic and will continue to advance person-centred care.

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*Britney J. Glowinski, Shirin Vellani, Mona Aboumrad, Idrissa Beogo, Thea Frank, Farinaz Havaei, Sharon Kaasalainen, Bonnie Lashewicz, Anne-Marie Levy, Katherine S. McGilton, Josephine McMurray and Joanie Sims-Gould*

The COVID-19 pandemic rattled Canada's long-term care (LTC) sector by exacerbating the ingrained systemic and structural issues, resulting in tragic consequences for the residents, family members and LTC staff. A group of diverse and renowned researchers from across Canada set out to implement innovative evidence-informed solutions in various LTC homes. Their findings call for immediate action from policy makers and LTC decision makers.

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*Sheena Campbell, Mary Boutette and Jennifer Plant*

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## PROMISING PRACTICE INTERVENTIONS

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*Natasha L. Gallant, Marie-Soleil Hardy, Idrissa Beogo, James Conklin, Denise Connelly, Sharon Kaasalainen, Janice Keefe, Annie Robitaille, Marie-Lee Yous, Chaimaa Fanaki and Courtney Cameron*

Long-term care (LTC) visitor restrictions during the COVID-19 pandemic contributed to adverse health outcomes among residents (and family caregivers) due to a lack of family presence. Eight Implementation Science Teams explore interventions, including technological and virtual innovations, increased funding to the sector and partnerships with family caregivers as effective methods to promote family presence within LTC.

## PARTNER PERSPECTIVE

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*Samir K. Sinha*

Samir K. Sinha – Implementation Science Team lead and chair of the Health Standards Organization's National Long-Term Care (LTC) Services Standard Technical Committee – sheds light on the development of the LTC national standards and what they hope to achieve for improved quality of care and quality of life across the sector.

## CONCLUSION

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*Erin Thompson, Meghan McMahon, Kirstin Loates, Lindsay Yarrow, Jane Rylett, Richard H. Glazier and Jennifer Zelmer on behalf of the Strengthening Pandemic Preparedness in Long-Term Care Program Delivery Team*

Healthcare Excellence Canada and the Canadian Institutes of Health Research reflect on lessons learned from the articles of the special issue and summarize key takeaways for next steps in evidence-informed long-term care pandemic preparedness in Canada. The implications of their cross-organizational partnership for achieving collective impact now and in the future are discussed.





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## DU RÉDACTEUR EN CHEF

### 4 Leçons de la pandémie de COVID-19 pour les soins de longue durée : où allons-nous ensuite ?

Neil Stuart

Ce numéro spécial de *Healthcare Quarterly* présente les principales conclusions et recommandations du programme de recherche rapide « Équipes en science de la mise en œuvre : Renforcer la préparation des établissements de soins de longue durée à la pandémie », qui a été lancé rapidement en réaction à l'expérience de la première vague de la pandémie de COVID-19 dans les soins de longue durée.

## INTRODUCTION

### 13 Renforcer la préparation des établissements de soins de longue durée à la pandémie

*Équipe de mise en œuvre du programme pour le renforcement de la préparation des établissements de soins de longue durée à la pandémie (comprenant Richard H. Glazier, Joanne Goldberg, Jessica Hodge, Justin Lui, Kirstin Loates, Meghan McMahon, Jessica Nadigel, Ayah Nayfeh, Susan Rogers, Jane Rylett, Erin Thompson, Patricia Versteegh, Lindsay Yarrow et Jennifer Zelmer)*

Excellence en santé Canada, les Instituts de recherche en santé du Canada et des partenaires provinciaux ont lancé le programme de recherche rapide « Équipes en science de la mise en œuvre : Renforcer la préparation des établissements de soins de longue durée à la pandémie ». Cet article présente l'objectif du présent numéro spécial et décrit l'initiative de recherche, les domaines de recherche des ESMO ainsi que la portée globale du programme.

## INTERVENTIONS PRATIQUES PROMETTEUSES

### 19 Préparation à la pandémie et au-delà : des soins axés sur la personne pour les personnes âgées dans les établissements de soins de longue durée pendant la pandémie de COVID-19

Amy T. Hsu, Geetha Mukerji, Anne-Marie Levy et Andrea Iaboni

Trois projets visant à améliorer la prestation des soins dans le contexte de la pandémie sont explorés : les besoins de la personne pendant les épidémies, l'amélioration de la qualité des soins médicaux en concentrant les services sur les besoins des résidents des établissements de soins de longue durée, et la prestation de soins palliatifs et de fin de vie personnalisés à l'aide d'un algorithme de prédiction. Ces projets ont permis de meilleurs soins pendant la pandémie et continueront de faire progresser les soins axés sur la personne.

### 26 Effondrement du secteur canadien des soins de longue durée à cause de la COVID-19 : des innovations pour soutenir la main-d'œuvre

Britney J. Glowinski, Shirin Vellani, Mona Aboumradi, Idrissa Beogo, Thea Frank, Farinaz Havaei, Sharon Kaasalainen, Bonnie Lashewicz, Anne-Marie Levy, Katherine S. McGilton, Josephine McMurray et Joanie Sims-Gould

La pandémie de COVID-19 a secoué le secteur canadien des soins de longue durée (SLD) en exacerbant les problèmes systémiques et structurels enracinés, ce qui a eu des conséquences tragiques pour les résidents, les familles et le personnel des SLD. Un groupe de chercheurs diversifiés et renommés, provenant de tout le Canada, a entrepris de mettre en œuvre des solutions novatrices fondées sur les données probantes dans divers établissements de SLD. Leurs conclusions demandent une action immédiate de la part des décideurs politiques et des décideurs des SLD.

## POINT DE VUE DES PARTENAIRES

### 33 Leçons tirées des partenaires des foyers de soins de longue durée pendant la pandémie de COVID-19

Sheena Campbell, Mary Boutette et Jennifer Plant

Une réaction rapide à une pandémie qui évolue rapidement est essentielle pour assurer la sécurité des résidents des établissements de soins de longue durée (SLD) ainsi que celle des prestataires de soins qui y travaillent. Les organismes Perley Health et peopleCare Communities font état de considérations clés pour améliorer la qualité des soins et la qualité de vie des résidents des SLD maintenant et à l'avenir.

## INTERVENTIONS PRATIQUES PROMETTEUSES

### 40 Améliorer la présence de la famille dans les établissements de soins de longue durée pendant la pandémie de COVID-19

*Natasha L. Gallant, Marie-Soleil Hardy, Idrissa Beogo, James Conklin, Denise Connelly, Sharon Kaasalainen, Janice Keefe, Annie Robitaille, Marie-Lee Yous, Chaimaa Fanaki et Courtney Cameron*

Les restrictions imposées aux visiteurs des établissements de soins de longue durée (SLD) pendant la pandémie de COVID-19 ont eu des effets néfastes sur la santé des résidents (et des proches aidants) en raison d'un manque de présence familiale. Huit équipes en science de la mise en œuvre se penchent sur certaines interventions, notamment les innovations technologiques et virtuelles, l'augmentation du financement du secteur et les partenariats avec les proches aidants, qui sont des méthodes efficaces pour favoriser la présence des familles au sein des SLD.

## POINT DE VUE DES PARTENAIRES

### 47 L'expérience de partenaires de soins essentiels pendant la pandémie de COVID-19

*Pauline Johnston, Margaret Keatings et Allan Monk*

Trois partenaires de soins essentiels (PSE) partagent leur expérience personnelle dans la prise en charge d'un être cher en soins de longue durée (SLD) avant et pendant la pandémie. Les partenariats avec les établissements de SLD, les résidents, les familles et les PSE sont définis comme une voie unificatrice pour le renforcement de la préparation à une éventuelle pandémie et pour garantir que les résidents actuels et futurs reçoivent des soins sûrs et de haute qualité.

## POINT DE VUE DU LEADERSHIP

### 54 Réflexion sur le cheminement vers l'élaboration de nouvelles normes nationales pour les soins de longue durée

*Samir K. Sinha*

Samir K. Sinha – directeur de l'équipe en science de la mise en œuvre et président du comité technique de la norme sur les soins de longue durée de l'Organisation des normes en santé – fait la lumière sur l'élaboration des normes nationales dans les soins de longue durée et présente ce qu'on attend d'elles pour l'amélioration des soins et de la qualité de vie dans le secteur.

## CONCLUSION

### 60 Ce que nous avons entendu : prochaines étapes pour la préparation des soins de longue durée en cas de pandémie au Canada

*Erin Thompson, Meghan McMahon, Kirstin Loates, Lindsay Yarrow, Jane Rylett, Richard H. Glazier et Jennifer Zelmer au nom de l'équipe de mise en œuvre du programme pour le renforcement de la préparation des établissements de soins de longue durée à la pandémie*

Excellence en santé Canada et les Instituts de recherche en santé du Canada se penchent sur les leçons tirées des articles du présent numéro spécial et résument les principaux points à retenir pour les prochaines étapes d'une préparation aux pandémies fondée sur les données probantes dans les soins de longue durée au Canada. Ils abordent aussi les répercussions de leur partenariat interorganisationnel, lequel vise l'obtention d'un impact collectif maintenant et à l'avenir.



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For deliveries to our studio:

54 Berkeley St., Suite 305, Toronto, Ontario M5A 2W4, Canada.

## Subscriptions

Individual subscription rates for one year are [C] \$109 for online only and [C] \$155 for print + online.

Institutional subscription rates are [C] \$380 for online only and [C] \$589 for print + online.

For subscriptions contact Barbara Marshall at 416-864-9667, ext. 100 or by e-mail at bmarshall@longwoods.com.

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To discuss supplements or other publishing issues contact Rebecca Hart at 416-864-9667, ext. 114 or by e-mail at rhart@longwoods.com.

*Healthcare Quarterly* is published four times per year by Longwoods Publishing Corp., 260 Adelaide St. East, No. 8, Toronto, ON M5A 1N1, Canada. Information contained in this publication has been compiled from sources believed to be reliable. While every effort has been made to ensure accuracy and completeness, these are not guaranteed. The views and opinions expressed are those of the individual contributors

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Circulation Department, Longwoods Publishing Corporation, 260 Adelaide Street East, No. 8, Toronto, Ontario M5A 1N1, Canada.

*Healthcare Quarterly* was founded in 1997 by Editor Peggy Leatt (1940–2019) and Publisher Anton Hart (1946–2022).

ISSN No. 1710-2774  
eISSN No. 1929-6347  
Publications Mail Agreement  
No. 40069375  
© December 2022



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# Strengthening Pandemic Preparedness in Long-Term Care

## Renforcer la préparation des établissements de soins de longue durée à la pandémie

Strengthening Pandemic Preparedness in Long-Term Care Program Delivery Team (including\* Richard H. Glazier, Joanne Goldberg, Jessica Hodge, Justin Lui, Kirstin Loates, Meghan McMahon, Jessica Nadigel, Ayah Nayfeh, Susan Rogers, Jane Rylett, Erin Thompson, Patricia Versteegh, Lindsay Yarrow and Jennifer Zelmer)

### Key Takeaways

- The COVID-19 pandemic has had profound impacts on residents, families, essential care partners and staff in long-term care (LTC), requiring a rapid system response to identify practical solutions for mitigating the effects of COVID-19 outbreaks and to inform future pandemic preparedness.
- Rapid research response programs, such as the Strengthening Pandemic Preparedness in Long-Term Care program, demonstrate the value of marrying quality improvement initiatives with implementation science expertise to find new and innovative ways of working together to better support the needs of residents, families, essential care partners and staff for greater system learning and impact.
- The sharing of key takeaways, implications and lessons learned from individual research projects can inspire spread and scale, and encourage reflection on the next steps for pandemic preparedness across the LTC sector.

### Abstract

In response to the COVID-19 pandemic, Healthcare Excellence Canada, the Canadian Institutes of Health Research and several provincial partners launched the Implementation Science Teams – Strengthening Pandemic Preparedness in Long-Term Care rapid research program. The program provided funding and a range of supports to the Implementation Science Teams (ISTs) that implemented and evaluated at least one of six promising practice interventions/policy options within Canadian long-term care and retirement homes. This article provides context in terms of introducing the purpose of this special issue and outlining the research initiative, the ISTs' research areas of focus and the program's overall reach.

### Résumé

En réaction à la pandémie de COVID-19, Excellence en santé Canada, les Instituts de recherche en santé du Canada et plusieurs partenaires provinciaux ont lancé le programme de recherche rapide « Équipes en science de la mise en œuvre : Renforcer la préparation des établissements de soins de longue durée à la pandémie ». Ce programme offre du financement et une gamme de services aux équipes en science de la mise en œuvre (ESMO) qui ont implanté et évalué au moins une de six pratiques ou politiques dans les établissements de soins de longue durée et les résidences pour personnes âgées au Canada. En guise de contexte, cet article présente l'objectif du présent numéro spécial et décrit l'initiative de recherche, les domaines de recherche des ESMO et la portée globale du programme.

\* In alphabetical order.

## Background and Impetus

The COVID-19 pandemic has had a profound impact on those who live and work in long-term care (LTC) and their family members. LTC residents accounted for more than 80% of Canada's COVID-19 deaths during the first wave, (CIHI 2020; Estabrooks et al. 2020) and harm in LTC quickly became one of the biggest patient safety issues across the country.

LTC homes faced many challenges during this time, including high rates of workforce infection, severe staffing shortages, lack of personal protective equipment and testing capacity and significant psychological and moral distress among staff (McGilton et al. 2020). Some residents faced unsafe and harmful living conditions, abuse and neglect, visitation restrictions, loneliness and psychological distress and significantly increased risk of death. Family members were often restricted access and could not provide care and comfort, including in times when their loved ones were dying during a COVID-19 outbreak (Stall et al. 2020). LTC homes have had to respond rapidly and seek practical solutions to support people and save lives.

At Healthcare Excellence Canada (HEC) and the Canadian Institutes of Health Research (CIHR), we partnered to find ways to strengthen pandemic response across the sector through the development and implementation of a rapid research response initiative that sought to improve LTC and retirement homes' pandemic preparedness and mitigate the effects of future outbreaks. Through this partnership, which was expanded to include provincial partners, cross-organizational resources were leveraged to support the rapid implementation and evaluation of interventions within LTC and retirement homes designed to support residents, families, essential care partners and staff during the COVID-19 pandemic.

The rapid research response initiative, called Strengthening Pandemic Preparedness in Long-Term Care (HEC 2022a), comprised 22 Implementation Science Teams (ISTs) (HEC 2022b) (see Figure 1). These ISTs involved:

- partnerships between researchers; LTC and retirement homes; and residents, family members and essential care partners with lived experience;
- co-design approaches to addressing the challenges; and
- implementation of scientific methods and rapid learning and improvement approaches (described below) to bring evidence to bear on improving pandemic preparedness and response.

Collectively, these ISTs partnered with 91 LTC and retirement homes across 10 provinces, caring for more than 14,000 residents. The ISTs focused on six promising practice intervention areas (discussed in the section "Overview of the Strengthening Pandemic Preparedness in Long-Term Care Initiative").

The advancement of learning health systems (LHSs) (Institute of Medicine of the National Academies 2007) or the continuous use of new knowledge and data to inform system improvement were important lenses that HEC and CIHR applied to the development of this program. We hoped that the IST projects would reinforce the benefits of continuous learning and improvement at the LTC home level and also inform LTC policy more broadly via lessons learned across teams. The ISTs worked to advance LHSs within their promising practice areas by studying what works for whom, under what circumstances and why. Generating a greater understanding of how evidence-informed practice can be implemented effectively was not only presumed to yield better care in the home but also lend itself to promoting future spread and scale that would allow for reach and impact across the system.

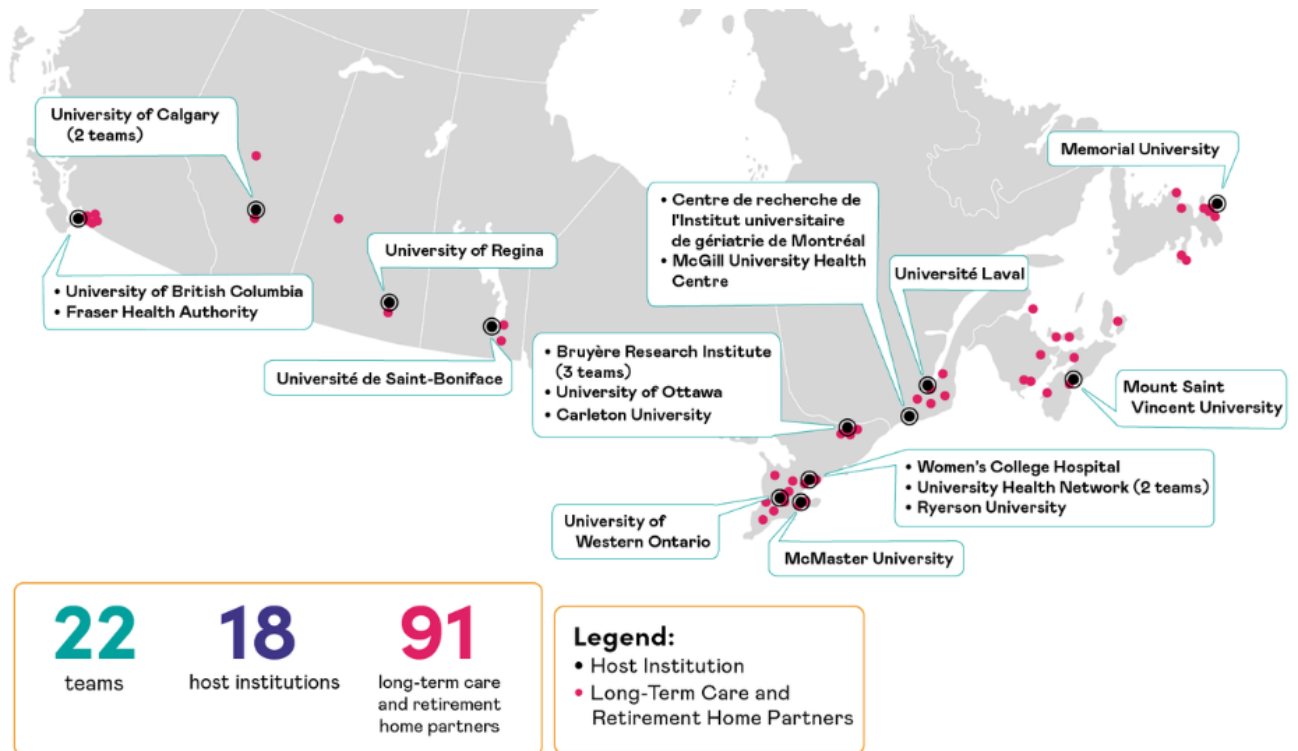
**Ultimately, research** – specifically research guided by those with lived and living experience – can help to improve health system performance and the health and well-being of people, communities and populations.

## Purpose of This Special Issue

There is an important role for research evidence in health-care policy and the provision of care. Research is a powerful tool for developing and testing new innovative solutions, for understanding which interventions are effective and why, for informing changes and improvements that make interventions more effective and for supporting the spread and scale of successful interventions. The power of research can be reinforced by partnerships with people who can benefit from the findings as their lived experiences can guide the design and implementation of individual projects for greater applicability and relevance. Ultimately, research – specifically research guided by those with lived and living experience – can help to improve health system performance and the health and well-being of people, communities and populations. However, the power and potential of research are underutilized if the results are not shared with those charged with the complex task of designing and delivering health programs and services.

Therefore, through this special issue, we aim to share key takeaways and implications of the ISTs' work with the *Healthcare Quarterly* readership. Given the rapid nature of this program, our hope is that findings will quickly reach LTC stakeholders across Canada, inspire the spread and scale of individual projects and key lessons learned and/or encourage reflection on the next steps for what is needed in the sector with

**FIGURE 1.**  
**The Implementation Science Teams – Strengthening Pandemic Preparedness in Long-Term Care initiative**



Source: HEC 2022b

the ultimate goal of strengthening future pandemic preparedness and response efforts. Where applicable, the papers in this issue provide citations to additional resources that may be of interest to our audience.

The IST Strengthening Pandemic Preparedness in Long-Term Care initiative is one piece of the puzzle in addressing current challenges faced by the LTC sector. While situated in Canada, the issues confronted by LTC and retirement homes, the evidence-informed solutions implemented and the lessons learned may be of interest and relevance to all countries and health systems that witnessed a range of pandemic-related impacts in LTC.

### Overview of the Strengthening Pandemic Preparedness in Long-Term Care Initiative

Strengthening Pandemic Preparedness in Long-Term Care is built on and aligned with a rapid environmental scan and a

pan-Canadian quality improvement initiative (HEC 2022b), both led by HEC, to help support LTC and retirement homes to respond to the quickly evolving and adapting pandemic context.

The rapid environmental scan (HEC 2020a) was conducted at the outset of the pandemic and included key informant interviews with essential care partners, care providers and health system leaders across the country. It identified six promising practices and policy options to better prepare LTC and retirement homes for future outbreaks, including the following:

- *Prevention:* Implementing strong infection prevention and control protocols to prevent and mitigate outbreaks.
- *Preparation:* Ensuring that protocols are in place to respond to COVID-19 outbreaks.



- *People in the workforce:* Supporting staff to provide the best quality of care to residents.
- *Pandemic response and surge capacity:* Ensuring that appropriate measures are in place to provide surge capacity and reduce virus spread in the case of an outbreak.
- *Plan for COVID-19 and non-COVID-19 care:* Ensuring that residents have access to person-centred, integrated care to meet their unique health needs.
- *Presence of family and essential care partners:* Ensuring that homes recognize and support family and other caregivers as essential partners in care, policy and practice, including during outbreaks.

Building on the report's recommendations, HEC launched the LTC+: Acting on Pandemic Learning Together quality improvement program (now known as Reimagining LTC) in July 2020 (HEC 2020b) to support LTC and retirement homes with the implementation of these promising practice areas and to help mitigate the impact of subsequent waves. More than 1,500 homes caring for over 180,000 residents came together to share experiences and best practices. HEC also provided coaching, virtual learning opportunities and seed funding to support and strengthen implementation.

Throughout the pandemic, rapid research has been essential for understanding the impact of COVID-19 and informing the health system's response. The success of rapid research depends in part on ensuring that the infrastructure is in place to mobilize the best available evidence, rapidly evaluate the effects of policies and interventions in different settings and contexts and inform real-time learning and improvement. With that in mind, the Strengthening Pandemic Preparedness in Long-Term Care rapid research program was designed as a key complement to the LTC+: Acting on Pandemic Learning Together initiative.

Canadian LTC and retirement homes are characterized by considerable heterogeneity across regions and facilities in how care is funded, organized, managed, delivered and evaluated for quality and safety (CIHI 2021). Implementation science – defined as the scientific study of the methods and strategies used to implement evidence-informed interventions within routine healthcare in clinical, organizational or policy contexts – can be a pragmatic research option when such heterogeneity exists (BioMed Central 2020). Implementation science learns from real-world experience and generates insight on how best to adapt an intervention for successful implementation in different regions, conditions, populations and/or contexts. Essentially, implementation science seeks to answer this question using rigorous and pragmatic scientific methods:

What works for whom, under which circumstances, and why does it succeed or fail?

In September 2020, HEC and CIHR launched the rapid pan-Canadian call for proposals seeking ISTs in LTC (ResearchNet 2020). The goal of this initiative was to strengthen the pandemic response through the implementation of promising practice and policy interventions in different LTC/retirement home settings across Canada and generate evidence on which interventions and approaches are most effective, in which contexts and why.

IST applications were required to do the following:

1. comprise expertise in LTC and implementation science,
2. focus on the implementation of one or more of the six promising practice areas,
3. involve multiple LTC and/or retirement homes in at least two different jurisdictions (i.e., two different municipalities, cities, health regions or provinces/territories),
4. involve a decision maker from each LTC/retirement home with which they were partnering and
5. involve at least one resident/family member/essential care partner with lived experience in care for themselves or their family in a Canadian LTC/retirement home.

Proposals were evaluated in October 2020 by a pan-Canadian peer review panel of researchers, LTC leaders and residents/essential care partners. They were assessed for their research approach, the quality of their team (including the partnerships between the researchers and the LTC/retirement homes) and the potential for the research to make an impact. Successful teams were notified in November 2020 and granted \$150,000 for one year to support their work.

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**It is critical** that organizations find new and innovative ways of working together to better support the needs of residents, families, essential care partners and staff.

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Additionally, one of the ISTs received supplemental funds to lead a cross-team project to advance a common set of indicators and inform a collective understanding of the enablers of and barriers to implementation success and intervention impact. This project, called the Common Measurement Framework Project, generated a common set of indicators for measurement and reporting by all teams that captured the facility characteristics (e.g., ownership type, size, chain status, urban vs. rural locale), staffing characteristics (e.g., staffing level, skill mix),

resident characteristics (e.g., resident case mix, demographic characteristics), intervention characteristics and policy context of each partnering LTC/retirement home (Hardy et al. 2022). The Common Measurement Framework Project was launched at a time when momentum was building to develop Canada's first-ever national LTC standards and provided a timely opportunity to rapidly enhance the evidence base for LTC pandemic preparedness and meaningful indicators for measurement.

## Conclusion

It is critical that organizations find new and innovative ways of working together to better support the needs of residents, families, essential care partners and staff. The program partnership between HEC, CIHR and provincial partners demonstrates the value of marrying quality improvement initiatives with implementation science expertise for greater system learning and impact.

## Acknowledgment

The Implementation Science Teams – Strengthening Pandemic Preparedness in Long-Term Care initiative was made possible through the partnership of Healthcare Excellence Canada; Canadian Institutes of Health Research (CIHR), including CIHR's Institutes of Aging, Circulatory and Respiratory Health, Gender and Health, Health Services and Policy Research, Infection and Immunity, Musculoskeletal Health and Arthritis and Population and Public Health; and the following partner organizations: the Centre for Aging + Brain Health Innovation, Michael Smith Health Research BC, the New Brunswick Health Research Foundation and the Saskatchewan Health Research Foundation.

The partners express thanks and appreciation to the researchers, long-term care and retirement homes, decision makers, residents, family members and essential care partners who participated in the Implementation Science Teams throughout the pandemic and who shared their findings and lessons learned in this special issue.

## Disclaimer

This work is supported by Healthcare Excellence Canada (HEC). HEC works with partners to spread innovation,

The commentaries featured in this special issue include voices of essential care partners and those of the participating LTC homes as essential program partners. Ultimately, healthcare is delivered with people and by people, and we cannot forget the “why” behind this important work. The commentaries also include syntheses framed around promising practice areas to distil key outcomes and findings. To situate this work within the broader LTC context and ongoing efforts to improve quality of care and quality of life in LTC, a commentary from Samir Sinha (2022) that sheds light on the parallel development of LTC national standards is provided. Finally, HEC and CIHR highlight the next steps for evidence-informed LTC pandemic preparedness in Canada.

We hope that you find this useful and informative. We encourage you to reach out to us for more information regarding any of these initiatives or promising practices. **HQ**

build capability and catalyze policy change so that everyone in Canada has safe and high-quality healthcare. The views expressed herein are those of the authors and do not necessarily represent the views of HEC.

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# Pandemic Preparedness and Beyond: Person-Centred Care for Older Adults Living in Long-Term Care during the COVID-19 Pandemic

## Préparation à la pandémie et au-delà : des soins axés sur la personne pour les personnes âgées dans les établissements de soins de longue durée pendant la pandémie de COVID-19

Amy T. Hsu, Geetha Mukerji, Anne-Marie Levy and Andrea Iaboni

### Key Takeaways

- Transformative changes and innovative integrative care models that aim to build capacity within long-term care are required to address the ongoing and complex care needs of residents who receive care in this setting.
- The pandemic has offered an opportunity to create innovative approaches to how person-centred care can be provided in an under-resourced healthcare setting. The partnership with research teams has accelerated the development of context- and environment-specific tools and resources for LTC.
- Solutions designed to support person-centred care must be flexible and adaptable to the environment. Allowing LTC providers to articulate the needs and goals of their own homes has been essential for motivating change.

### Abstract

**The increasing complexity of residents' needs, emphasis on social distancing and limited access to high-quality support presented challenges to patient-centred care during the pandemic. Yet the pandemic created an opportunity to explore novel approaches to achieving person-centred care within long-term care (LTC). We share three projects designed to enhance care delivery in the context of the pandemic:**

**to address personhood needs during outbreaks, to improve the quality of medical care and to deliver personalized palliative and end-of-life care using a prediction algorithm. These projects enabled better care during the pandemic and will continue to advance person-centred care beyond the pandemic.**

## Résumé

La complexité croissante des besoins des résidents, l'accent mis sur la distanciation sociale et l'accès limité à un soutien de haute qualité ont posé des défis en matière de soins axés sur le patient pendant la pandémie. Pourtant, la pandémie a créé une occasion d'explorer de nouvelles approches pour obtenir ce type de soins dans le cadre des soins de longue durée (SLD). Nous faisons état de trois projets conçus pour améliorer la prestation des soins dans le contexte de la

pandémie : répondre aux besoins de la personne pendant les épidémies, améliorer la qualité des soins médicaux et offrir des soins palliatifs et de fin de vie personnalisés à l'aide d'un algorithme de prédiction. Ces projets ont donné lieu à de meilleurs soins pendant la pandémie et continueront de faire progresser les soins axés sur la personne au-delà de la pandémie.

## The Context and Challenges of Person-Centred Long-Term Care

Even before the pandemic, long-term care (LTC) homes struggled to meet the complex care needs of their residents. Across the sector, homes were under-resourced, with low staff-to-resident ratios and inadequate access to high-quality medical services and support. Many residents, given their advanced age, have limited life expectancy, experience severe physical and cognitive deficits and can benefit from a palliative approach to care. Yet discussions about prognosis, advance care planning and palliative care are not always prioritized. These gaps left LTC homes woefully unprepared for the pandemic in March 2020, with catastrophic results, including unnecessary suffering and death. We need to learn from these failures to be prepared for the future and support the transformation of this sector.

For this transformation to take place, there needs to be a common value underlying our efforts. Person-centred care is ubiquitous in discussions of quality of care within LTC homes. However, the understanding and application of this principle in real-world settings vary enormously (Godfrey et al. 2018). At its core, person-centred care is care that is respectful of an individual's personhood, values them as social beings and understands their psychosocial needs (Hanley 2017). It prioritizes approaches to care that ensure that residents' needs for attachment, inclusion, identity, occupation and comfort are met (Flicker 1999; Hanley 2017). Beyond theory, person-centred care is, in fact, a highly practical and evidence-based approach to improving care (Kim and Park 2017). It is an approach to care that is of importance throughout a resident's care journey – from the day-to-day nursing care and personal support they receive in the LTC home, to the care that they receive in the home or in the hospital, to their end-of-life care.

Achieving person-centred care within LTC has been challenging, with time constraints, lack of staffing, cost, educational gaps, poor teamwork and lack of management support as the usual culprits (Griffiths et al. 2019; Kloos et al. 2020; Kong et al. 2021; McArthur et al. 2021). During the pandemic, the frequently changing care practices and public health measures

were additional obstacles to achieving person-centred care. We witnessed how these measures negatively impacted attachment bonds and meaningful occupation in LTC. Visitors were barred, recreational activities for residents were curtailed and high staff turnover resulted in a loss of knowledge about who the residents were and the life they lived. We lost sight of the need to provide holistic and comfort care, even as residents approached end of life, with restrictions resulting in many family members being unable to say their final goodbyes or hold the hands of a loved one before they died.

**At its core,** person-centred care is care that is respectful of an individual's personhood, values them as social beings and understands their psychosocial needs.

Despite these challenges, the COVID-19 pandemic has provided the opportunity to create innovative approaches to how we provide person-centred care in an under-resourced healthcare setting. In this article, we share insights and stories on promising practices related to the planning of COVID-19 and non-COVID-19 care. Specifically, we focus on the theme and examples of person-centred integrated care to meet the unique and complex needs of frail residents in Canada's LTC homes. These insights have come from three projects funded through the Implementation Science Teams – Strengthening Pandemic Preparedness in Long-Term Care Program (HEC 2022), which examined the implementation of tools and interventions designed to improve the quality of care in LTC homes during the pandemic:

- The first project is the Dementia Isolation Toolkit (DIT) ([www.dementiaisolationtoolkit.com](http://www.dementiaisolationtoolkit.com)) that includes a person-centred isolation care planning tool designed to bring personhood needs to the forefront during an outbreak.
- The second project is a collaborative program that aims to provide rapid access to a suite of virtual and in-person clinical and diagnostic services for all LTC home residents.

- The third project is a personalized mortality risk communication tool, called Risk Evaluation for Support: Predictions for Elder-life in the Community Tool in Long-Term Care (RESPECT–LTC), which supports discussions about goals of care as the resident declines in health and the early identification of palliative care needs.

We synthesized the main themes across the three studies into evidence-informed strategies for delivering high-quality, person-centred care in LTC settings during the pandemic and beyond.

## Promising Practices and Policies for Person-Centred Care

### Dementia Isolation Toolkit

The DIT was designed and developed with people working in LTC homes to support the delivery of person-centred care during infectious disease outbreaks. At the foundation of the DIT is the idea that while many infection-control interventions (such as quarantine/isolation) conflict with the principles of person-centred care, it is still possible to deliver these interventions in a way that is compassionate and respects the personhood of the resident. The most popular tool is a Person-Centred Isolation Care Plan worksheet (Iaboni et al. 2020), which is a supplement to a resident's care plan, addressing the fact that usual care is disrupted by an outbreak and that an individual's needs may be different under outbreak conditions or when isolated in their room. Some learnings from this project are outlined here under the themes of motivating change, flexibility of process and innovating in partnership.

### Motivating change

Allowing the local team to articulate the needs and goals of their own home was essential for motivating change. The uptake of COVID-19 vaccines was high among residents of LTC homes in Ontario by March 2021, and COVID-19 cases and outbreaks had become rare. With wishful thinking that the pandemic was behind us, motivation was low: the focus had shifted to staffing challenges in the wake of vaccine mandates and to re-opening the homes to visitors and essential care partners. By working with the local implementation teams to identify gaps and opportunities, the implementation goals shifted to proactive planning for isolation care, preparedness for future waves and the need to integrate more person-centred information into the process for new admissions.

### Flexibility of process

Each home required an individualized and flexible approach to implementation. When faced with a choice between using

the DIT exactly as designed or integrating it sustainably within existing processes, the implementation team chose the latter option. This required a good understanding of the local work processes and a recognition of their strengths and limitations. An example is the homes' varying approaches to care planning: the extent to which these care plans were living, accessible documents used to guide care versus a document that was inaccessible to front-line staff providing care. One adaptation was to reduce the care planning tool to a one-page document as the implementation teams were wary of the original two-page version and the administrative burden it may impose on staff. At two of the implementation sites, they tried to avoid redundancies in the process by replacing the "Personhood" and "Isolation" sections of the paper-based tool with existing electronic care plan documents and developing processes for collecting more personhood information about residents.

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**The largest challenge** is ensuring that these process changes translate into genuine practice and culture changes so that we are outbreak-ready at all times.

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### Innovating in partnership

The largest challenge is ensuring that these process changes translate into genuine practice and culture changes so that we are outbreak-ready at all times. It became clear that the biggest strides in the project were facilitated by the enthusiasm and energy of champion staff members. The individuals who had a large impact were those who saw the value of the intervention and the parallels between the principles guiding the toolkit and the homes' culture-change journey, and those who knew the home well enough to identify the gaps and opportunities to advance the DIT and its principles. To leverage this important enabler, we innovated using the huddle model developed in the patient safety field to bring together the team for a 10-minute stand-up meeting facilitated by a colleague who would introduce and apply the Person-Centred Isolation Care Plan tool to a single resident known to the staff. While we are still evaluating and refining these DIT huddles, they have advantages: they create a non-judgmental, safe space for staff to reflect on and communicate about care and for facilitators to model a person-centred frame.

### A novel model for integrated COVID-19 and non-COVID-19 care

Preventing avoidable emergency department transfers of LTC home residents has been an important focus for quality improvement efforts even before the pandemic (Andrea 2013). Prior research suggests that nearly 50% of LTC home transfers to acute

care facilities are considered potentially avoidable (Gruneir et al. 2010), and one approach to reducing such transfers is to provide access to high-quality medical and diagnostic services within the homes (Razak et al. 2020). Meeting the medical care needs within the LTC setting (i.e., providing care in place) has intrinsic value as it reduces the need for unnecessary and, often burdensome, transfers. It is also person-centred in its alignment with residents' goals of care and their preferences. As frailty increases, most residents and their substitute decision makers report preferring comfort-focused rather than aggressive care (Mitchell et al. 2017). In addition, it minimizes risks of delirium, care discontinuity and functional decline associated with transfer to acute care settings (Creditor 1993; Walsh et al. 2012).

### **Developing the capacity to provide high-quality specialized person-centred care through partnerships**

In the first wave of the COVID-19 pandemic, we developed and rapidly implemented a multi-institutional specialized integrated virtual care model that provides LTC homes in the Greater Toronto Area (GTA) with rapid access to specialists and diagnostic services (Wong et al. 2022). Our program, GTA-LTC+ (<https://ltcplus.ca/about-ltc/>), focused on preventing avoidable hospital transfers and wrapping high-quality healthcare services around LTC homes, reflecting the perceived priority at the time of the pandemic. While the need for more coordinated access to specialist care and rapid access to diagnostic imaging and services existed pre-pandemic, the urgency of the pandemic accelerated the implementation of this integrated care program.

Early results of the GTA-LTC+ program's implementation have been published (Wong et al. 2022). Briefly, from April 2020 to June 2021, the GTA-LTC+ program provided 381 general internal medicine (GIM) consultations and 65 nurse navigator calls. The perceived emergency department avoidance rate by GIM consultants and nurse navigators was approximately 46%, where the consults had sufficiently addressed care needs to potentially avoid the need for acute care transfer. All 36 primary care physicians who consulted the GTA-LTC+ program reported satisfaction with the advice provided. Robust evaluation is under way and will assess the impact of the GTA-LTC+ program and inform strategies for improving, scaling and sustaining this model for enhancing care for residents in LTC homes. The GTA-LTC+ program can enable timely access to high-quality care and ensure that residents receive more person-centred specialized care in this setting, which is useful in pandemic and non-pandemic contexts.

### **Earlier identification of palliative care needs using RESPECT**

Without reliable prognostic information (e.g., an estimate of the survival of residents based on their present health and frailty status), clinicians in LTC may find it difficult to identify which residents are the most frail and at the highest risk of death from both COVID-19 and non-COVID-19 causes.

RESPECT is a mortality-risk communication tool originally developed for application in the home and community settings (Hsu et al. 2021). It accurately predicts an older adult's six-month mortality risk, reports their life expectancy and can inform care providers, residents and their families when the resident may be approaching end of life by estimating their survival in days, weeks and months – a metric that has been shown to be patient-oriented and meaningful for care planning (Kirk et al. 2004; Parker et al. 2007). It was designed to inform health and social service providers' decision making regarding initiating palliative and/or end-of-life care. RESPECT is one of the tools recommended by the Ontario Palliative Care Network for the early identification of palliative care needs in the homecare setting and is publicly accessible from ProjectBigLife.ca.

At the onset of the pandemic, the high mortality rate within LTC homes expedited the need to assess, review and document frail residents' goals and values as their health declined. By recognizing the value in providing personalized risk estimates during goals-of-care discussions, our research team rapidly adapted the community-based version of RESPECT for use in LTC.

RESPECT-LTC was developed and validated in over 2.5 million health assessments performed in Ontario's LTC homes between 2010 and 2017. The algorithm stratifies patients into 37 distinct risk groups to support the operationalization of frailty; each risk group represents an actionable time frame – ranging from 28 days to more than eight years – to empower providers to determine if and when the resident will benefit from a palliative care approach, which may be initiated as early as 18 months prior to death, or whether and when the resident will need end-of-life care.

The implementation of RESPECT-LTC involved a needs assessment, appraisal of technological readiness and motivation for a palliative approach to care within the LTC homes.

### **Appraisal of technological readiness**

Most LTC homes do not have access to technology support or an in-house information technology (IT) team. To enable the tool's implementation, the research team provided technical support, from a web developer and an implementation



coordinator; they helped with installation and troubleshooting and further modified our web-based RESPECT–LTC application to support seamless integration with the electronic medical record systems that the homes were using.

#### **Motivation and readiness for a palliative approach to care**

While the partner LTC homes were highly motivated to implement a palliative approach to care, most did not have access to all the resources or tools to enable them to achieve this culture change. To support behavioural change across the decision-making and care hierarchy within the LTC homes, the research team provided training on:

- how to use RESPECT–LTC and how prognostic information from RESPECT–LTC can facilitate discussions regarding goals of care to physicians on staff, as well as nursing and other front-line unit workers;
- how to conduct serious illness conversations with residents and care partners; and
- how to action or use or clinical pathways that precipitate the identification of a resident's morality risk and palliative care needs.

Each of these learning modules was co-developed with representatives from partner LTC homes as homes and staff within each home varied greatly in skills and competencies as well as in their comfort in communicating about palliative care and the end of life. The implementation and training also had to be flexible to accommodate the sporadic outbreaks that affected the availability of staff to participate in training.

The evaluation is still ongoing. But early findings indicate that the education provided (especially the training on conducting serious illness conversations) significantly improved physicians' and nurses' confidence and comfort in discussing goals, values and wishes with residents and care partners to support a more person-centred approach to care toward the end of life.

#### **A Call for Dynamic and Multi-Dimensional Approaches to Person-Centred Care**

Achieving person-centred care within LTC has been a challenging but not an insurmountable task. However, there is no one-size-fits-all solution, and allowing the LTC providers to articulate the needs and goals within their homes was essential for motivating change. Findings from the three implementation projects featured here suggest that person-centred care in under-resourced settings is not only achievable in a

pandemic context, but the tools developed over the course of the pandemic can be leveraged to support more person-centred care in this environment in the future.

Prior to the pandemic, the lack of person-centred care may be attributable to low staffing levels, time constraints, cost, educational gaps, poor teamwork and a lack of management support. While not all of these barriers have been removed, the partnership with research teams accelerated the development of context- and environment-specific tools and resources for LTC. We must also recognize that each LTC home needs to find its own motivations for bringing about change in practice and may have to overcome unique challenges in their implementation of a new tool, technology or program. Accordingly, solutions that are designed to support person-centred care must be flexible and adaptable to the environment – be it a lack of technological and IT support, staffing shortages and time constraints or the culture within the home. This includes, as shown by all three projects, adapting existing evidence-based tools at no or very low costs to the LTC providers, as well as the provision of education to fill existing knowledge and practice gaps.

While many of these tools and programs have shown promising advancement toward greater internal capacity within LTC to provide more person-centred care, they can still benefit from being part of a network of service providers that includes hospitals, home care and other community-based organizations. As most LTC homes receive limited access to specialist and diagnostic services that could aid their decision making and capacity to treat in place, the provision of coordinated support and forming a network of providers are crucial for reducing unnecessary transfers to hospitals while improving access to timely assessment and diagnosis. Similarly, while the provision of training in serious illness conversations has boosted providers' confidence in leading these discussions, many admitted that they could benefit from access to palliative care expertise that may exist outside the LTC home. With the education, as well as the partnership with other providers within the same geography, we were able to augment the LTC homes' internal capacity for providing person-centred dementia, medical and palliative care.

Finally, an often-overlooked aspect of the implementation of new tools, technology and programs in low-resource settings is ongoing and robust monitoring and evaluation to inform scale and spread. For example, in a systematic review on the effectiveness of person-centred care for dementia patients, the authors only identified 17 interventional studies within LTC (Kim and Park 2017). As part of these implementation projects, the research teams brought content and methodological

expertise to these partnerships to support the evaluation of the interventions that can inform scale and spread, as well as the sustainability of these tools or programs. This exemplifies the importance of such partnerships; however, as researchers we have learned to appreciate the context, needs and resource constraints that LTC providers face before engaging them in research projects.

## Summary and Conclusion

Transformative changes and innovative integrative care models that aim to build capacity within LTC are required to address the ongoing and complex care needs of residents who receive care in this setting. Using frameworks and methods from the field of implementation science, we examined barriers to and facilitators of the systematic uptake of evidence-based practices into routine care to support person-centred care in LTC. Learnings from the three projects highlighted in this article demonstrated that there is a need for flexibility when introducing and adapting promising solutions to the varied

needs and environments within this sector. To be successful, new interventions should be supplemented (at least initially) with external support and education and ideally with training material that is co-designed with LTC providers. Researchers can bring valuable knowledge and expertise to these partnerships; however, thoughtful planning and consideration for the constraints that LTC providers face will ensure that their engagement in the research project adds value rather than increasing the workload of an already overextended sector.

Our experience through the pandemic highlighted the existing needs and gaps within the LTC sector. At the same time, it has created an opportunity for the accelerated implementation and evaluation of innovations to support more person-centred care to meet the needs of a highly frail and vulnerable population. Our learning from the failures of the past will not only prepare us for a possible future pandemic but also support the transformation of this sector beyond this current one. **HQ**

## Declaration

### RESPECT-LTC

This project was funded in part by Health Canada through the Health Care Policy and Strategies Program. The views expressed herein do not necessarily represent the views of Health Canada.

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# The Canadian Long-Term Care Sector Collapse from COVID-19: Innovations to Support People in the Workforce

## Effondrement du secteur canadien des soins de longue durée à cause de la COVID-19 : des innovations pour soutenir la main-d'œuvre

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### Key Takeaways

- On top of the long-standing lack of resources, including the ever-existing staff shortages, long-term care (LTC) workers experienced an unprecedented increase in their workload during the pandemic without justifiable compensation – including a lack of sufficient time off and absence of communication to promote work–life balance.
- All categories of LTC staff experienced immense moral distress, burnout and compassion fatigue due to high rates of COVID-19 cases and deaths of residents and staff, policy changes and staff turnover. A preventative approach where staffing is optimized and supports are readily available is necessary to prepare the LTC sector for another health crisis.
- Decades of research have shown that strong evidence is not sufficient to change LTC policies and practices. A rejuvenation of the LTC sector urgently requires adequate staffing with access to competitive benefits, compensation and mental health supports to allow workers to effectively care for residents and effectively implement changes to improve LTC in Canada.

### Abstract

**The COVID-19 pandemic rattled Canada's long-term care (LTC) sector by exacerbating the ingrained systemic and structural issues, resulting in tragic consequences for the residents, family members and LTC staff. At the core of LTC's challenges is chronic under-staffing, leading to lower quality of care for residents and higher degrees of moral distress among staff.**

**A rejuvenation of the LTC sector to support its workforce is overdue. A group of diverse and renowned researchers from across Canada set out to implement innovative evidence-informed solutions in various LTC homes. Their findings call for immediate action from policy makers and LTC decision makers.**

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## Résumé

La pandémie de COVID-19 a secoué le secteur canadien des soins de longue durée (SLD) en exacerbant les problèmes systémiques et structurels enracinés, ce qui a eu des conséquences tragiques pour les résidents, les familles et le personnel des SLD. Au cœur des défis propres aux SLD se trouve le manque chronique de personnel, ce qui entraîne une moindre qualité des soins et des degrés plus élevés de détresse morale parmi le personnel. Un rajeunissement du

secteur des SLD en soutien de la main-d'œuvre se fait toujours attendre. Un groupe de chercheurs diversifiés et renommés, provenant de tout le Canada, a entrepris de mettre en œuvre des solutions novatrices fondées sur les données probantes dans divers établissements de SLD. Leurs conclusions demandent une action immédiate de la part des décideurs politiques et des décideurs des SLD.

## Introduction

The long-term care (LTC) sector provides around-the-clock services and care to people whose health needs prevent them from living independently. This care and service is provided by a workforce whose historic marginalization has been highlighted by researchers dating back to the 1970s (Linn et al. 1977), yet little has changed in Canada over the last half century (Badone 2021; Estabrooks et al. 2020). The COVID-19 pandemic illuminated historic under-investment in LTC. The LTC sector is inadequately resourced to care for an aging population that has increasingly complex needs due to high levels of frailty and multiple health conditions, including dementia. An integrated palliative approach with chronic disease management is needed as many residents die within two years of admission (Ayalon et al. 2020; Vossius et al. 2018).

The LTC workforce is characterized by limited overall staffing levels and too many residents for workers to care for adequately. The resulting workloads leave little time to complete essential care, coupled with scant support from experts and specialty clinicians, low pay and poor access to mental health resources. Accordingly, the LTC workforce is at a high risk for burnout, occupational stress, physical injury and job precarity (Hunter et al. 2020). Pervasive under-recognition and undervaluing of care work helps create less than desirable working conditions that go unaddressed by policy makers and decision makers (McGilton et al. 2020). The devaluation of the LTC workforce's hard work is compounded by the composition of the workforce being predominantly racialized immigrant women, whose needs and value to society are systemically overlooked (Gahwi and Walton-Roberts 2022). Moreover, negative systemic ageist stereotypes have contributed to policies, suboptimal budgets and resource allocation and institutional practices that resulted in Canada's inevitable COVID-19-related death rate of 81% in LTC, compared to the global average of 38% (Badone 2021).

We must not wait for another public health crisis to address the glaring needs of LTC; the workforce has been overburdened and the sector needs immediate intervention. This paper is a collaborative effort by research teams across Canada

and calls on policy and decision makers to stop studying and start implementing often-repeated, evidence-informed recommendations that address the marginalization of LTC workers and, subsequently, the marginalization of those under their care.

## Context

The COVID-19 pandemic has had a profound impact on the health of older adults, particularly those living in congregate care settings, with over 80% of COVID-19 deaths occurring in LTC homes across Canada (Hunter et al. 2020). Patients diagnosed with COVID-19 were treated differently because of their age with regard to decisions on receiving the limited supply of life-sustaining treatments and equipment, such as ventilators (Montero-Odasso et al. 2020). As such, LTC homes were discouraged from transferring residents to hospitals at the onset of the pandemic, while a large number of older patients from acute care were discharged to LTC and other settings to create more space for the younger COVID-19 patients (Sibbald 2020). At the same time, LTC staffing and medical resources were limited, leading to suboptimal care for in-house residents (Stall et al. 2020). Also, the increase in patients transferred from acute care led to an increase in outbreaks in LTC and burdened the staff because of the care required by additional residents. Furthermore, because of public health restrictions aimed at preventing the spread of the COVID-19 virus, several categories of staff were deemed non-essential to LTC, thus compromising the delivery of day-to-day recreational, rehabilitative, primary, acute, episodic and palliative care to residents (Vellani et al. 2022).

LTC was consistently underrepresented by government officials and policy makers in public addresses about Canada's healthcare system during the pandemic, leaving individual LTC organizations and workplace leaders struggling to interpret new policies and regulations. The resulting gaps in care and inconsistencies across LTC sites had devastating consequences. Inconsistent standards of care not only put residents at risk but also created morally distressing choices for LTC staff

to either follow directives or provide the quality of care that they knew they should (Stall et al. 2020). Moreover, years of governments deprioritizing the sector rendered LTC workers more vulnerable to being infected with COVID-19 (Armstrong et al. 2020) and the associated moral distress.

**The devaluation of** the LTC workforce's hard work is compounded by the composition of the workforce being predominantly racialized immigrant women ...

### The Strengthening Pandemic Preparedness in Long-Term Care Project

In November 2020, the Implementation Science Teams (ISTs) – Strengthening Pandemic Preparedness in LTC initiative was launched by Healthcare Excellence Canada (HEC 2022) in partnership with Canadian Institutes of Health Research, New Brunswick Health Research Foundation, Saskatchewan Health Research Foundation, Centre for Aging + Brain Health Innovation and Michael Smith Health Research BC. The goal was to generate evidence and determine promising practices and policies that are effective in optimizing the safety of residents, families and other essential care partners, as well as staff, during and beyond the COVID-19 pandemic in LTC facilities

across Canada. Six ISTs identified challenges experienced by LTC workers, some unique to the COVID-19 pandemic and some extending beyond pandemic conditions. The teams came together to share their findings and inform policy and decision makers in LTC on the accomplishments and challenges of the pandemic on the LTC workforce. As part of their projects, each team developed an evidence-based innovation to implement in LTC (Table 1). The findings are promising; however, implementation is challenging and requires immediate attention by policy makers, administrators and decision makers. We linked findings from each of the six projects to construct key themes that represent the relationships among the findings (Popay et al. 2006).

### We Need More Long-Term Care Workers and to Fully Value Them

Amid the unprecedented pandemic conditions, LTC workers adapted to rapidly changing policies and working conditions as best as they could with limited supports. While the pandemic has highlighted many areas of need, the most urgent has been staffing. The LTC workforce has been stretched thin, and often understaffed workers interviewed by ISTs emphasized the severe consequences of inadequate staffing, which included longer working hours and irregular schedules. Time needed to care for each isolated resident multiplied while workers missed

**TABLE 1.**  
**Summary of Implementation Science Teams and projects**

Teams	Goal of project	Innovation
Katherine McGilton, KITE-UHN	To improve staff resiliency and mental health while reducing moral distress in the LTC workforce	Developed a toolkit to empower nurse practitioners to facilitate team huddles to share relevant information and conduct regular check-ins with staff
Bonnie Lashewicz, University of Calgary	To better support LTC staff in managing moral distress	Developed an application to enable LTC organizations to support workers in managing moral distress
Andrea Iaboni, KITE-UHN; McMurray, Wilfrid Laurier University; Grigoravich, Brock University	To improve moral resilience among staff and support the compassionate and effective isolation of residents and address moral distress in LTC workforce	Created DIT to help staff balance decisions related to infection prevention and control measures with principles of person-centred care (DIT n.d.)
Sharon Kaasalainen, McMaster University	To provide easily accessible educational resources to build staff confidence to take a palliative approach to care	Developed a virtual palliative toolkit (SPA-LTC 2020) to supply staff with educational modules and information on integrating a palliative approach to care
Joanie Sims-Gould and Farinaz Havaei, University of British Columbia	To describe the process and impact of the implementation of the single-site employment order in LTC on residents and staff To generate a roadmap to effectively implement future policies in LTC	Used the Consolidated Framework for Implementation Research (CFIR 2022), which outlines a five-step process by which researchers can translate findings into realistic outcomes, to describe the implementation and impact of the single-site employment order
Idrissa Beogo, University of Ottawa	To create a community of practices among residents to reduce isolation and loneliness during and after the COVID-19 pandemic	Focused on the importance of linguistic minorities – namely, the presence of relatives as key partners in providing care and reducing social isolation and loneliness

DIT = Dementia Isolation Toolkit; KITE = Knowledge, Innovation, Talent, Everywhere; LTC = long-term care; UHN = University Health Network.

shifts due to a COVID-19 infection or fear of contracting it. LTC staff worked extra shifts and longer hours to avoid feelings of guilt stemming from leaving residents isolated and without care, resulting in consecutive weeks and even months without a single day off. Consequently, the quality of resident care declined as staff burnout climbed. Immense workloads carried during pandemic conditions did not match the compensation staff received from governing bodies and LTC organizations. Yet LTC workers continued to show up and adapt to dynamic working conditions.

When asked what their organization and supervisors could have done better, workers highlighted the importance of leaders recognizing the increased workload and offering greater compensation, including offering sufficient time off and providing a communication-based environment that promotes work–life balance. Workers shared that having LTC leaders more available on the floor to support front-line staff and answer questions would have increased worker comfort. LTC leaders also shared that they were strained as they tried to regularly communicate with families while keeping up-to-date on the latest policies and procedures to implement in their facility, leaving little time to fulfil their regular duties. Some managers had to transition roles when their facility experienced a COVID-19 outbreak and assist with resident care to compensate for exceptional staff shortages. Conversely, some novice workers were thrown into leadership roles at the onset of the pandemic and struggled to adapt to the intense workloads. Consequently, an unprecedented number of workers are now leaving the LTC sector, either because of extended stress leave or to transition to work in other healthcare sectors with less distressing work environments. In all, LTC workers essentially pleaded for more resources to alleviate their workloads.

### **Moral Distress in Long-Term Care Staff Was a Prominent Finding across All Projects**

Disproportionately high rates of COVID-19 cases and deaths in LTC homes among residents and staff combined with acute or chronic insufficient staffing, high rates of staff turnover and ever-changing policy mandates served to drive staff burnout, compassion fatigue and moral distress. Workers expressed feelings of guilt as they enforced visitor restrictions in accordance with COVID-19 protocols. Workers vividly described the emotional distress of watching residents' mental and physical health decline despite workers' persistent efforts to provide adequate care. Workers also felt guilty for neglecting their personal responsibilities and relationships as a result of spending so much of their time at work. Young members of the LTC workforce (under 30 years) experienced an extraordinary emotional burden due to being new in the field with less ability to cope amid ever-changing rules imposed by the pandemic, leading to greater moral distress. While staff often

felt unsupported by their management teams, who were not present to answer their questions and support resident care, managers themselves were exceptionally exhausted working unreasonable hours in their office responding to concerns from families and listening to staff concerns. Managers were unprepared for their increased workload and desperately needed mental health supports to mitigate burnout. Workers felt they had limited abilities to affect change or easily access information related to resident care without the help and approval of their managers. The COVID-19 pandemic deepened longstanding divides between different categories of staff and affected communication and task performance.

### **Pandemic-Imposed Policies Led to a Decrease in Person-Centred Care**

To ensure the health and safety of staff, residents and their families, the Public Health Agency of Canada mandated several rapid redesign and resource redeployment practices, such as strict visitation policies, COVID-19 screening, use of personal protective equipment and the single-site employment order. Emerging pandemic evidence shows that despite important contributions to limit the spread of infection, these policies were complex and had many unintended consequences for LTC homes, the residents and caregivers (Chen et al. 2020; Havaei et al. 2022). Furthermore, depending on the funding structure and accountability (i.e., municipal run, for profit or not for profit), there were differences in how these directives were interpreted and executed.

Given the increasingly high level of frailty and complexity of LTC residents, what we need is a workforce that is prepared to care for them in a competent and dignified manner with opportunities to uplift their own capacity, grow professionally and feel valued and supported by their institutions. The principles of person-centred care were all but abandoned as pandemic-related directives contributed to the LTC sector taking a task-oriented approach to care that overlooked resident needs and had staff focus on risk aversion instead. LTC homes also had few opportunities to train staff to care for residents with dementia who have complex and dynamic care needs, integrate a palliative approach to care that transitions into end-of-life care and effectively deal with multiple losses within a short period. All combined, this led to compromised resident care; grief among residents, staff and families that was more fully felt than in the wider society; and an exhausted workforce (Kaasalainen et al. 2021; Maben and Bridges 2020).

### **Chronic Staffing Crisis Is a Barrier to Implementing Change**

During implementation activities, each IST faced barriers related to staff availability to take part in the projects.

Iaboni's and Kaasalainen's respective teams provided LTC staff with easily accessible virtual educational resources to build confidence and competence but found that staff lacked the time and energy to meaningfully engage with the resources provided.

McGilton's and Lashewicz's respective teams dedicated their projects to improving the mental health and resiliency of staff experiencing high moral distress. The teams reported that LTC workers had excessive workloads, leaving no time to incorporate huddles on the floor. There was little willingness to commit their free time to using an app that focused on their mental health because of limited days off work, which the largely feminized workforce has to dedicate to housework and trying to spend time with friends and family. These ISTs adapted by shortening the script for staff members facilitating the huddles and reconceptualizing the app to require less time and effort from staff. Staff submitted a short checklist that put the onus on employers to aggregate results and provide corresponding supports, to which staff and employers were more receptive.

Sims-Gould's team reviewed the impacts of the single-site employment order and found the implementation of this order challenging, given limited human and material resources, including less competitive employee compensation. Likewise, the single-site employment order itself exacerbated staffing inadequacies, resulted in an increased use of staff overtime and overburdened staff and compounded burnout. Researchers found that policy implementation effectiveness could be improved through (1) clear and timely communication within and between organizations, (2) effective leadership, (3) more human and non-human resources to support policy implementation, (4) use of standardized data systems to track employment information of LTC staff and (5) increasing staffing levels to address the loss of staff caused as a result of the policy implementation.

Finally, Beogo's team aimed to develop a user-friendly digital platform for connecting residents with family members that could be used without the additional support of LTC workers, who spent a large portion of their workdays facilitating video and phone visits with resident family members. The implementation of the virtual platform resulted in more time for LTC workers to dedicate to other care-related tasks while still reducing the social isolation and loneliness experienced by residents.

### A Call to Action

LTC staff experience high levels of moral distress, yet they typically wait until their mental health has deteriorated to alarming levels before seeking help. At the same time, there is a lack of readily accessible mental health resources for staff and management, especially to help them manage their own grief and bereavement from enduring many resident deaths

during the COVID-19 pandemic. This raises concerns about the future of the LTC workforce that has been working under threadbare conditions. A preventative approach would be valuable and is urgently needed, where staffing is optimized, staff is supported by their supervisors and internal and external resources are readily available. Current mental health supports are underutilized, and decision makers need to reallocate resources to invest in solutions that workers will engage with and benefit from. Then workers may be able to provide person-centred care that is tailored to residents' comprehensive needs.

Each IST received positive feedback on their innovation from advisory groups, LTC partner sites and LTC workers interviewed, and we found promising data that staff were receptive to using the innovations. While all ISTs want to continue and expand their innovations, we feel that help from policy and decision makers is urgently needed to intervene on the chronic staffing issue that prevents other changes from being successful. Furthermore, we need continued efforts to strategize how best to implement innovations, given that strong evidence is not sufficient to change practice. In most implementation science models, facilitators are key to assessing and responding to the characteristics of the innovation and the recipients within the settings. LTC leaders must support workers in facilitating the implementation of new innovations and addressing barriers as they emerge.

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**... what we need** is a workforce that is prepared to care for them in a competent and dignified manner with opportunities to uplift their own capacity, grow professionally and feel valued and supported by their institutions.

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### Moving Forward

One after another, researchers and subject matter experts over the past 50 years have called on decision makers to address the malignant cocktail of deficiencies plaguing the LTC sector in Canada in the domains of standards of care, funding, infrastructure, workforce and staffing, and the need for person-centred care. The frailest and most medically complex individuals enter LTC homes, yet their care providers are insufficient and lack the skills, time and equipment to care for them. The chronic staffing crisis is crippling the LTC sector as overworked, underpaid and burned out staff struggle to provide basic care to residents. Innovative practices that might better educate and prepare workers or provide tools to mitigate moral distress experienced at work are abandoned in the face of these stressors.



It is critical that LTC homes re-evaluate and reallocate Employee Assistance Program funds so that LTC workers can easily and equitably access and benefit from supportive services. We also need to institute policies and measures that help retain the existing workforce and attract highly qualified and passionate workers to this challenging yet fulfilling environment, including through competitive remuneration (regardless of ownership of the LTC home), continuing education and professional development opportunities. Policies implemented during emergency situations must be guided by person-centred care that incorporates residents' values, wishes and preferences. The essential role of families, informal care partners and volunteers in care provision needs to be explicitly acknowledged as

crucial to residents' overall well-being throughout their stay in LTC.

Researchers, professionals and LTC staff have been calling for change for half a century, and it took a global pandemic to magnify the evidence to prove that the current system is broken. The quality of the LTC sector reflects the quality of care provided to residents, and it starts with a well-resourced workforce. It is time to adequately staff the LTC sector and provide appropriate benefits, compensation and mental health supports to the workforce to allow workers to effectively care for residents and reshape Canada's LTC system into a sustainable and high-quality healthcare field. **HQ**

### Disclaimer

This work is supported by Healthcare Excellence Canada (HEC). HEC works with partners to spread innovation, build capability and catalyze policy change so that everyone in Canada has safe and high-quality healthcare. The views expressed herein are those of the authors and do not necessarily represent the views of HEC.

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This work is supported by the Canadian Institutes of Health Research (CIHR). At CIHR, we know that research has the power to change lives. As Canada's health research investment agency, we collaborate with partners and researchers to support the discoveries and innovations that improve our health and strengthen our healthcare system.

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# Lessons from Long-Term Care Home Partners during the COVID-19 Pandemic

## Leçons tirées des partenaires des foyers de soins de longue durée pendant la pandémie de COVID-19

Sheena Campbell, Mary Boutette and Jennifer Plant

### Key Takeaways

- Adequate pandemic preparation allowed Perley Health and peopleCare Communities to rapidly adapt to the changing pandemic environment. Strong leadership facilitated quick responses to potential outbreaks, reinforced communication channels and advocated for personal protective equipment and testing supplies.
- Partnership between researchers and long-term care (LTC) homes provides an opportunity to work through organizational-level challenges and ensure that interventions are designed to fit within current workflow processes and systems.
- Although the Strengthening Pandemic Preparedness in Long-Term Care research program built research capacity within the LTC sector, longer-term and sustained solutions will require new policies reflecting what has been learned through this initiative to enhance quality of care and quality of life for those living in LTC.

### Abstract

Rapid response to a quickly evolving pandemic was critical to keep residents and those who provide care in long-term care (LTC) safe. Two Ontario-based LTC homes, Perley Health and peopleCare Communities, share key aspects of their pandemic response that left both homes well positioned to partner in the Strengthening Pandemic Preparedness in Long-Term Care rapid response research program (HEC 2022a). To share lessons learned and generate evidence around practical solutions to mitigate future outbreaks, Perley Health and peopleCare Communities identify key considerations to enhance quality of care and quality of life for LTC residents now and in the future.

### Résumé

Une réaction rapide à une pandémie qui évolue rapidement est essentielle pour assurer la sécurité des résidents des établissements de soins de longue durée (SLD) ainsi que celle des prestataires de soins qui y travaillent. Deux établissements ontariens de SLD, Perley Health et peopleCare Communities, partagent des aspects clés dans leur réaction à la pandémie, ce qui leur a permis de s'associer au programme de recherche rapide Renforcer la préparation des établissements de soins de longue durée à la pandémie (ESC 2022a). Afin de partager les leçons apprises et de générer des données sur les solutions pratiques pour atténuer l'effet d'éventuelles épidémies, les organismes Perley Health et peopleCare Communities font état de considérations clés pour améliorer la qualité des soins et la qualité de vie des résidents des SLD maintenant et à l'avenir.

## Introduction

During the first wave of the COVID-19 pandemic in 2020, the impacts of the virus were significant in hospitals and long-term care (LTC) communities. As leaders within LTC homes caring for residents with complex health needs, who are more vulnerable to severe illness, we were determined to take quick and decisive action to keep our residents and homes safe, to keep everyone informed and to support quality of life during this challenging time.

At our LTC homes, Perley Health in Ottawa, ON, and peopleCare Communities, headquartered in Waterloo, ON, previous work in pandemic preparation allowed us to respond quickly to the ever-evolving challenges brought about by COVID-19. Yet as the pandemic continued to unfold, we quickly recognized that the LTC sector was in dire need of practical solutions to mitigate the impacts of future outbreaks and to keep residents, families, caregivers and staff safe from COVID-19. We felt that our LTC homes were well positioned to partner in the Implementation Science Teams – Strengthening Pandemic Preparedness in Long-Term Care rapid response research program (HEC 2022a) and we joined a broader community of over 90 LTC homes committed to the implementation and evaluation of policies and practices to strengthen pandemic preparedness.

This program brought evidence and research capacity to LTC homes. It helped us understand how to focus our resources and what strategies to implement now as well as in the future. As members of the research team, our voices were not only heard, but we were also equal partners at the table and helped contextualize the research within the reality of LTC. Our partnership with the implementation sciences teams (ISTs) contributed to success within each individual team and to the program more broadly. In this article, our two LTC homes share our responses to the pandemic, the lessons learned from it and common issues that emerged. We also discuss implications of the IST research within each of our LTC homes and share suggestions as to how we can move forward together for a stronger LTC system.

It is important for us to acknowledge that the following reflects our experiences and perspectives, and we recognize that across Canada, individual LTC homes' involvement with the pandemic and with the research program varies.

## Background

### Perley Health

Perley Health is a unique and innovative community that empowers seniors and veterans to live life to the fullest. Home to more than 600 seniors and veterans in LTC care and in independent apartments, Perley Health provides a growing

number of clinical, therapeutic and recreational services to residents, tenants and people from across the region. One of the largest and most progressive LTC homes in Ontario, Perley Health is also a centre for research, education and clinical innovation. The Perley Health Centre of Excellence in Frailty-Informed Care conducts and shares the practical research needed to improve care.

### peopleCare Communities

As a third-generation family-owned and operated organization, peopleCare Communities' compassionate and skilled team is dedicated to supporting individualized lifestyles in a welcoming community that enhances the quality of life for all the people involved. We believe that no matter where you live, it is the presence of family that makes a home feel like home. With an ingrained appreciation for our families and their many contributions in our homes, families are true caregiving partners with our teams and engaging with them is always top of mind.

## Pandemic Preparation

With a well-established Infection Prevention and Control (IPAC) team, Perley Health was on high alert in preparation for the COVID-19 pandemic, although we could have never anticipated the magnitude and its extraordinary impact on our community and home. Preparations began in advance of the pandemic and included a strong leadership team, a committed workforce and a supportive board of directors. Regular communication with regional partners also helped with information-sharing and collective problem-solving. An established business continuity plan allowed quick redeployment when needed with “just-in-time” training and support. However, we knew more would be needed to help our LTC home navigate the uncertainty of the pandemic.

Early in the pandemic, Perley Health reviewed literature related to leadership in times of crisis. Five principles emerged that guided our work: demonstrate compassion, be agile, distribute authority, be transparent and prioritize psychological health and safety. With the official declaration of the COVID-19 pandemic on March 11, 2020, daily command team meetings were initiated. Members of the management team were brought together to share information (such as changing health measures), solve problems in real time and be proactive about solutions and “what-if” scenarios (e.g., the purchasing of a decontamination machine for personal protective equipment [PPE]). These meetings also gave us an opportunity to review the five principles guiding our work with both our leadership team and work teams.



Operationally, significant measures were taken to mitigate risk. Another team member was added to the IPAC team to support employee health. Responsibilities for this role included answering staff questions, performing contact tracing, vaccine administration/tracking and organizing testing clinics, among others. The IPAC team expanded their coverage to seven days per week to help manage the increased workload. Perley Health initiated surveillance COVID-19 testing for all residents and staff leading to the establishment of a process for mass testing in the home. An isolation unit was earmarked for COVID-19-positive resident cases and cohorting began for both residents and staff. The isolation unit proved to be effective with the Therapeutic Recreation and Creative Arts staff, Psychogeriatric and Behavioral Support staff and a dedicated team of personal support workers, nurses and physicians supporting person-centred care.

Perley Health leveraged technology for temperature checks and screening using a customized application. Eventually our screening process went electronic (a mobile application) and was routinely tailored to our changing needs. For those without devices or who preferred not to use them, we always had the option of verbal screening and devices on-site to accommodate them. Overall, technology has streamlined our approach to screening and reduced the time it would take to screen people compared to only using verbal and paper-based approaches.

Upon reflection, it is easy to document a list of key actions taken to prepare and respond to the pandemic but these new practices and the overall response took an incredible amount of dedication from staff across the organization.

### **People in the Workforce**

Perley Health prioritizes a “people first” approach in its organizational strategy. The strategy commits to honouring health-care workers by prioritizing their well-being and professional growth and investing in recruiting, developing and retaining people dedicated to enriching the lives of older adults. This priority is supported by a robust health human resources strategy and workplan focused on the employee experience, talent acquisition and enabling human resources infrastructure.

During the pandemic, Perley Health introduced a Psychological Health and Safety program with key initiatives and supports targeting employees’ mental, physical and social fitness. Training staff in the areas of resilience, end-of-life care with COVID-19 and practice changes related to COVID-19 were priorities and required a champion model with an “all-hands-on-deck” approach. This meant that all staff, regardless of the nature of work, were expected to be present on site and ready to help where needed.

Despite these efforts, Perley Health, like other homes, was severely impacted by staffing shortages (this is an ongoing challenge in LTC and exacerbated by the pandemic, even today). By July 2020, we had lost over 100 staff members due to either restrictions (i.e., staff were only able to work in one LTC or retirement home) or personal reasons (i.e., childcare, health concerns, etc.). We also lost more than 400 volunteers who were no longer allowed on site.

Decisions had to be made regarding resident care and services, ensuring that essential care needs were met. Where possible, routines and workflows were streamlined (e.g., medication administration), and in some cases tasks were deferred (e.g., conducting annual care conferences). A business continuity plan was developed early on to plan for a variety of redeployment scenarios. To offset the impact, staff were redeployed between departments to ensure that direct care needs and staffing ratios were met. Staff were also redeployed to other units where they may not know the residents, which impacted continuity of care.

Staffing shortages also meant that staff had less time to spend with residents on other activities that contribute to quality of life, such as friendly conversations. There were fewer opportunities for residents to socialize with each other due to cohorting requirements and reduced group recreation activities. During the first phase of the pandemic, residents were unable to spend time in person with family members, friends and volunteers due to sector-wide visitor restrictions within LTC. Therapeutic Recreation and Creative Arts staff spent a significant portion of their time supporting one-one virtual visiting. While this was essential work, it did not replace the value of family presence and further eroded the team’s ability to offer small group programs.

### **Family Presence**

At peopleCare Communities, we have worked hard to support an uninterrupted presence for designated family caregivers in our LTC and retirement homes during the pandemic. Given the circumstances, our teams were challenged to think differently and our conversations changed to why we absolutely should support family presence during outbreaks. It took time and focus, but we worked together to alter our practices to make family presence possible.

Starting with digital engagement, our teams leveraged apps to support thousands of online visits. Next came creating safe, accessible and meaningful outdoor visits. We were determined to do even more.

Along with keeping families informed and engaged, when government LTC directives changed and residents were able to designate “essential” caregivers, peopleCare was ready with communication, training, PPE and unique resources, such as a caregiver pledge and “I am a Caregiver” ID badges.

This was due in part to relationships with groups such as the Ontario Caregiver Organization, which partnered with people-Care as an early adopter of their practical resources aimed at supporting family caregivers in healthcare settings.

Perley Health was able to lean on existing communications infrastructure to engage with family caregivers, also known as essential care partners (ECPs). Regular communication was sent to families through multiple channels (emails, an automated phone messaging system, websites, posters, etc.) to update them on the constantly changing public health measures. Senior management held monthly virtual COVID-19 focused townhalls with the Family and Friends Council; a dedicated family helpline was established and emails were regularly monitored to support our connection with families and ECPs.

At different times during the pandemic, it was difficult to manage competing priorities but we knew communication and engagement with family members and ECPs was crucial. To be creative, supportive and flexible in our approach we made on-site testing and vaccination available to families, supported virtual visits, facilitated outdoor visits, enabled flexibility for family members to rotate ECP status, provided free parking and made meal kits for purchase available in our cafeteria.

We learned that timely, regular and transparent communication about the current situation explaining the “why” behind measures and not being afraid to share bad news helped maintain our credibility and establish trust. We admitted to not knowing the answer, acknowledged it when we were struggling and were open about what we were doing to resolve the issue.

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### Uniting Long-Term Care Homes and Research for Rapid Implementation

Perley Health partnered with two different ISTs focused on independent research projects. The first was with Annie Robitaille, whose research focused on the essential nature of family/volunteer caregiving in LTC (HEC 2022b). Our work with Robitaille involved interviewing family members and their loved ones living in LTC. We collaboratively designed the research project to ensure Perley Health had the opportunity to participate in the interviews, knowing that our presence would strengthen the relationship our home had with the ECP community.

Some of these interviews occurred on a weekly basis and we observed how family members began to look forward to these meetings. We recall one discussion with Robitaille, who shared her experience facilitating interviews as having therapeutic value for the residents and their loved ones. This work built a different type of research capacity at Perley Health. There was a collective understanding that this research project was contributing more toward solutions that everyone wants for LTC and less toward theoretical research. This also generated energy and enthusiasm to continue with future research and implementation.

The second project, led by Amy Hsu, was the implementation and evaluation of the Risk Evaluation for Support: Predictions for Elder-life in the Community Tool in Long-Term Care (RESPECT-LTC) (HEC 2022b). It is intended to support ongoing efforts to embed palliative approaches to care within existing processes and culture in LTC homes. With Hsu’s team, our focus was on the implementation of the RESPECT-LTC tool into our existing workflows. One of the challenges within LTC is taking tools generated in academia and other non-LTC settings and translating them into practice. One of the benefits of implementing this tool in a research context was the ability to provide real-time feedback and troubleshoot what was working and what could be improved. We need tools that are simple and easily embedded into workflows to be successful and part of that process is having dedicated time to evaluate the tools and modify them along the way. Through this project, we were able to work through organization-level challenges and ensure integration of the tool within current workflow processes and systems.

At peopleCare, the organization partnered with the IST led by James Conklin to investigate how to further enable ECPs’ safe access to their loved ones’ LTC home (HEC 2022b). This research project drew on existing approaches and tools supported by the Change Foundation, Ontario Caregiver Organization, Ontario Centres for Learning, Research and Innovation in Long-Term Care (Ontario CLRI) and Healthcare Excellence Canada to initiate designated care partner programs in LTC homes. We learned a great deal through the implementation of our Family Caregiver program, including the following:

- Supporting family caregivers in LTC requires a culture shift. Staff who acknowledge the importance of family caregivers in care and quality of life may also feel unsure of the benefits of formalizing the role and apprehensive about certain care roles and tasks. It is essential that staff buy into the program and the many advantages that come from having families as care partners.

- The role families want to play depends on the nature of the relationship with their loved one. Some are comfortable providing physical care, while others are happier to engage in conversation and high-touch activities. It is also important to encourage residents and families to visit when it suits them, rather than allow visitation based on the home's routines and schedules.
- It is important to engage families in the program's purpose, and then provide targeted training that focuses on how to make every visit more meaningful. When asked for ideas on improvement, staff proposed regular "huddles" with the family caregiver and the care team at the start of each visit to offer updates on the resident's health conditions, mood and behaviours.

There are now over 1,150 designated family caregivers at peopleCare. In any given week, we are supporting hundreds of these care partners to safely spend precious time with their loved ones in the home. We recognize the incredible contributions they make as members of the care team. Currently, ongoing work has shifted toward evaluation. To do this, we are working with Ontario CLRI to evaluate our Family Caregiver program with the goal to identify what is working well and where enhancements could better support residents and integrate families into the community of the home.

### Looking Toward the Future

Looking to the future, Perley Health believes it is important that the health system learn from what did not go well in LTC while leveraging the successes. As a centre that is committed to research and learning, we believe that evidence needs to be shared broadly to influence policy so that more LTC homes can benefit. Some of the key lessons are discussed below.

#### Leadership

Perley Health had a flexible leadership structure and leadership capacity in place before the pandemic; this allowed team members to fill emerging roles and take on tasks that were outside of their normal portfolio.

#### Relationships

Our strong relationship with families was critical to our success. This relationship is grounded in principles of person-centred care and includes good lines of communication focusing on openness and transparency. Our SeeMe program – which focuses on a shared understanding of quality of life and ensuring person-centered care – was established several years before the pandemic. This put us in a better position to understand residents' and families' needs and wishes during times of uncertainty. Importantly, this helped ensure quality of life stayed at the forefront of our decision making.

### Culture of innovation, learning research and quality improvement

Perley Health is an organization committed to problem solving, trying new things and building programs and infrastructure to address our needs and challenges. This has encouraged us to build relationships with conventional and unconventional partners, including academia, the private industry and government relations networks, which we were able to leverage during the pandemic to find solutions. Examples include the following:

- When faced with a looming shortage of PPE, we were able to source supplies from China, procure a novel decontamination machine and participate in a national advisory committee to understand and spread the research supporting the decontamination technology.
- Our relationship with academic institutions allowed us to continue with safe student placements, which helped us partially alleviate staffing pressures.
- We found ways to safely bring back volunteers earlier than most homes because we had the infrastructure to do so. Through our structured volunteer program, Perley Health was able to find innovative ways to train, vaccinate and screen volunteers and find appropriate roles for them to fill. This also helped address the quality-of-life issue for residents as we know what an important role volunteers play in the lives of our residents.

### Risk management framework

Perley Health had an existing risk management and ethical decision-making framework that helped us analyze and respond to risk. This structure was already integrated into our existing processes and made it easier to assess pandemic-related risks. As a result, we were comfortable trying new things aligned with our risk tolerance and applied this framework as challenges surfaced – for example, in re-integrating volunteers. Our daily command meetings included a standing agenda item on quality of life; this ensured that it was top of mind when weighing risks and benefits.

We also want to be part of the solution and leverage our experiences to enhance care and quality of life for residents living in LTC now and in the future. Perley Health is committed to the following goals:

- a continued focus on people first – as learned from researcher Pat Armstrong et al. (2020) that "the conditions of work are the conditions of care (p. 7);"
- acknowledging the impact of social isolation on the well-being of residents. Knowledge from research in Perley Health's Centre of Excellence in Frailty-Informed Care will

be leveraged. This includes finding ways to foster meaning in life for each person and working with researchers to develop, evaluate and share best practices in person-centered care and social connection in LTC. There must be a balance of risk and quality of life as LTC is the resident's home; and

- improving relationships among those in the system and influencing policy. There is tremendous expertise in LTC and the time to listen is now.

At peopleCare, the pandemic has shown that despite any misgivings or challenges, it is possible to successfully and safely engage families to support resident care and well-being in all situations. Along with the opportunity to continue building meaning and value into our overall program and resources, we now have a pool of informed and engaged family caregivers who could be tapped, for example, to strengthen and bolster our family councils.

We also intend to build on the success of our enhanced Family Caregiver program as peopleCare explores emotion-based models of care, which is about caring for each resident as an individual. By knowing their history, wishes, likes and dislikes, we can use the information to enhance experiences, engage with them and accomplish care together in a way that is meaningful to each resident. Families have a unique insight into their loved ones. They are at the heart of knowing who that person is and who they were in their past lives.

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**Evidence and research** are important components as we think of the future of LTC.

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### Disclaimer

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### Moving Forward

Throughout the pandemic, there has been a spotlight on the LTC sector and while in many ways this has been uncomfortable and difficult, we have an opportunity to think about how we can do things differently. While the pandemic magnified existing vulnerabilities, these challenges did not develop in weeks or months and will not all be solved in the short term. We will need long-term and sustainable solutions to long-standing vulnerabilities to reform our LTC system. Evidence and research are important components as we think of the future of LTC. With the rapidly growing number of people over 85 years of age, we need to find better ways of caring for older adults living with frailty.

The people who live and work in LTC already intimately understand impacts of social isolation on frailty, physical health, quality of life and life expectancy. We know this but we need to be enabled by policies that support flexibility in our approaches to care to ensure that all care is person centred. We are lacking people who work and live in LTC and who are engaged in identifying and solving problems in LTC. While the IST initiative has strengthened partnerships among researchers, LTC homes, residents and their loved ones and built research capacity across the sector, policy to influence longer-term reform must reflect what we learn from this initiative.

LTC homes need to work in partnership to make system-level changes. There is a wealth of expertise in LTC to be leveraged when it comes to decision making, and we deserve a seat at the table. The people living in LTC are in the last stage of life and it is essential that we support the whole journey, which requires optimizing quality of life and active end-of-life care. **HQ**

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This work is supported by the Canadian Institutes of Health Research (CIHR). At CIHR, we know that research has the power to change lives. As Canada's health research investment agency, we collaborate with partners and researchers to support the discoveries and innovations that improve our health and strengthen our healthcare system.



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# Improving Family Presence in Long-Term Care during the COVID-19 Pandemic

## Améliorer la présence de la famille dans les établissements de soins de longue durée pendant la pandémie de COVID-19

Natasha L. Gallant, Marie-Soleil Hardy, Idrissa Beogo, James Conklin, Denise Connelly, Sharon Kaasalainen, Janice Keefe, Annie Robitaille, Marie-Lee Yous, Chaimaa Fanaki and Courtney Cameron

### Key Takeaways

- Partnerships between long-term care (LTC) homes and family caregivers should allow for active engagement in policy development and implementation of programs that improve residents' quality of life.
- Technological and virtual innovations are promising avenues for promoting stronger family presence within LTC homes.
- Public health policies coupled with under-resourcing in the LTC sector impacts family visitation due to a lack of staffing and infrastructure.

### Abstract

Family caregivers play a vital role in supporting the physical and mental health of long-term care (LTC) residents. Due to LTC visitor restrictions during the COVID-19 pandemic, residents (as well as family caregivers) showed significant adverse health outcomes due to a lack of family presence. To respond to these outcomes, eight implementation science teams led research projects in conjunction with Canadian LTC homes to promote the implementation of interventions to improve family presence. Overall, technological and virtual innovations, increased funding to the sector and partnerships with family caregivers were deemed effective methods to promote stronger family presence within LTC.

### Résumé

Les proches aidants jouent un rôle essentiel pour la santé physique et mentale des résidents des établissements de soins de longue durée (SLD). En raison des restrictions imposées aux visiteurs pendant la pandémie de COVID-19, les résidents (ainsi que les proches aidants) ont vécu d'importants effets néfastes sur la santé en raison d'un manque de présence familiale. En réaction à ces résultats, huit équipes en science de la mise en œuvre ont mené des projets de recherche en collaboration avec des établissements de SLD canadiens dans le but de promouvoir la mise en œuvre d'interventions qui visent à favoriser la présence familiale. Dans l'ensemble, les innovations technologiques et virtuelles, l'augmentation du financement du secteur et les partenariats avec les proches aidants sont considérés comme des méthodes efficaces pour favoriser une présence familiale plus soutenue au sein des SLD.

## Importance of Family Presence

### Impact of the COVID-19 pandemic on the presence of family in long-term care

Across Canadian provinces and territories, long-term care (LTC) homes saw an unprecedented number of COVID-19 infections and deaths. During the first wave of the COVID-19 pandemic, for example, almost 80% of COVID-19 deaths across the country were among LTC residents (CIHI 2020). Compared to Canada, the average number of COVID-19 deaths in LTC homes across all other countries belonging to the Organisation for Economic Co-operation and Development was only 42% (CIHI 2020). To prevent the spread of COVID-19 within LTC homes, Canadian authorities put in place several public health measures, including restrictive visitation policies (Stall et al. 2020).

Although well-intentioned, restrictive visitation policies within Canadian LTC homes led to increased feelings of loneliness and social isolation among residents, which themselves are risk factors for the development of depression, cognitive impairment, physical frailty, recurrent stroke, obesity, elevated blood pressure and mortality (Cacioppo et al. 2015; Choi et al. 2015; McArthur et al. 2021; Read et al. 2020; Simard and Volicer 2020). Moreover, these policies resulted in increased worry among family caregivers as they were unable to engage with residents, monitor their well-being or provide comfort to them (Mitchell et al. 2022). Even before the pandemic, family presence was known to improve residents' quality of life and reduce mortality (Verloo et al. 2018). According to the most recent survey on family caregiving in Canada, 7.8 million Canadians over the age of 15 years provided care to relatives with a long-term health condition, a disability or problems associated with aging (Statistics Canada 2020).

Restrictive visitor policies put in place during the COVID-19 pandemic highlighted the essential role of family presence within LTC homes, and several policy and practice recommendations have emerged that challenge us to rethink the ways in which family caregivers are part of care planning (Gaugler and Mitchell 2022). As a group of researchers, we have worked in partnership with family caregivers and LTC homes to identify how to improve family presence during the COVID-19 pandemic and beyond. In this article, we discuss the purpose of our work and the recommendations that stem from these findings.

### Purpose of This Work

The Implementation Science Teams (ISTs) (Table 1) partnered with LTC homes across several provinces – including homes in Saskatchewan, Manitoba, Ontario, Quebec, New Brunswick, Nova Scotia and Prince Edward Island – to support the

successful implementation and sustainability of promising practices and interventions to maintain family presence within LTC homes. Within these homes, the total number of participants across ISTs included over 100 residents, 250 family and other informal caregivers and 150 staff members. Interventions varied greatly across the teams, but they were primarily focused on strengthening connections between residents and family caregivers through policy analysis, digital interventions and adaptations of established programs and resources.

### Policy analysis

A couple of teams took a policy analysis approach to their intervention. Janice Keefe and Annie Robitaille each looked at the current policies in their respective jurisdictions and conducted interviews with key stakeholders – including family caregivers, LTC staff members and government policy makers. Following this policy analysis, both teams provided recommendations on current LTC policies so that visitation policies could be more inclusive and recognize the important role of family caregivers.

### Digital interventions

Marie-Soleil Hardy and Idrissa Beogo each led a team of researchers and knowledge users to equip LTC staff members with the necessary technological tools to preserve communication between residents and family caregivers during the COVID-19 pandemic. Both teams used digital platforms (e.g., Zoom) to interview residents, family caregivers and LTC staff members on their thoughts on these technological tools before and after they were implemented. Sharon Kaasalainen and her team focused on providing opportunities for reflective debriefing using digital platforms, as well as access to a virtual course to roll out the Strengthening a Palliative Approach in Long-Term Care toolkit (SPA-LTC 2020). Natasha Gallant's team also created a virtual course, but this virtual course was focused on infection prevention and control procedures for family caregivers so that they can protect LTC residents from COVID-19 or other infections.

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### Adaptations of established programs and resources

A few teams adapted established programs and resources to better fit the context of the COVID-19 pandemic. James Conklin's team, under his leadership, implemented the

**TABLE 1.**  
**Implementation Science Teams improving family presence in long-term care homes**

Team lead	Study design	Participants (N)	Location (N)	Intervention
Natasha Gallant	Mixed-method (checklists, interviews, surveys)	Residents (11) Family (6) Staff (9)	SK (1) ON (1) NB (1)	A virtual course on infection prevention and control procedures for family caregivers and inclusive satisfaction surveys for residents and family caregivers
Marie-Soleil Hardy	Mixed-method (checklists, interviews, surveys)	Residents (27) Family (27) Staff (16)	QC (4)	Virtual meetings between residents and their family caregivers using tablets
Idrissa Beogo	Mixed-method (interviews, surveys)	Residents (45) Family (11) Staff (25)	MB (2) QC (2) NB (2)	A digital platform to strengthen the connection between residents and their family caregivers
James Conklin	Mixed-method (interviews, surveys)	Residents (39) Family (117) Staff (78)	ON (3)	An adapted version of the Caregiver ID Program that includes supportive tools and creating a learning collaborative
Denise Connelly	Mixed-method (focus groups, interviews, surveys)	Residents (12) Family (6) Research partners (4) Staff (9) PIECES mentors (3)	ON (2)	Virtual delivery of the PIECES intervention along with virtual team huddles
Sharon Kaasalainen	Mixed-method (interviews, surveys)	Residents (2) Family (5)	ON (2)	Palliative care pamphlets and booklets for family caregivers, as well as a virtual course and reflective debriefing for staff
Janice Keefe	Mixed-method (document review, interviews, surveys)	Family (57) Staff (54) Key informants (10)	NS (4) PEI (2)	Policy analysis of family visitation programs from the point of view of various stakeholders
Annie Robitaille	Qualitative (interviews)	Residents (ongoing) Family (59) Staff (ongoing) Volunteers (9)	ON (7) NS (1)	Interviews with stakeholders to discuss new ideas or changes to existing policies and practices

MB = Manitoba; NB = New Brunswick; NS = Nova Scotia; ON = Ontario; PEI = Prince Edward island; PIECES = Physical, Intellectual, Emotional health, Capabilities for quality of life, Environment, Social; QC = Quebec; SK = Saskatchewan.

supportive tools and collaborative aspects of the Caregiver ID Program (Sault Area Hospital 2022) created by The Change Foundation (<https://changefoundation.ca/>) and The Ontario Caregiver Organization (OCO n.d.). In collaboration with three Ontario-based LTC homes, Conklin's team adapted the Caregiver ID Program to fit the individual needs of each LTC home. To do so, Conklin and his colleagues used developmental evaluation. Developmental evaluation is a highly participatory process that involves the program's team members in all the design and decision processes.

One of the other teams – led by Denise Connelly – used the Physical, Intellectual, Emotional health, Capabilities for quality of life, Environment, Social (PIECES) model (Pieces Canada n.d.) to implement better supports for residents, family caregivers and LTC staff members during the COVID-19 pandemic. Similar to Conklin's adaptation of the Caregiver ID Program, Connelly adapted the PIECES model to include virtual team huddles. Although not a traditional part of the PIECES model, the virtual team huddles were aimed at providing an opportunity for the interdisciplinary health



professional care teams to come together to discuss the care of residents. Virtual team huddles allowed care teams to problem-solve ways of addressing the residents' behavioural expressions and engaging family caregivers within the context of restrictive visitation policies.

### What Was Learned?

ISTs conducted varied research in LTC homes to improve family presence but a few common observations emerged. We asked each team to reflect on their experiences to improve family presence in LTC during the COVID-19 pandemic. We outline some of these reflections below.

#### Digital innovations show promise for promoting stronger family presence in long-term care homes

One promising avenue for the involvement of caregivers was the introduction of digital innovations. These innovations can provide a way of maintaining communication between residents and their caregivers while also enabling caregivers to remain informed and advocate for their loved ones even if they are not physically present in the home. For example, Beogo and Hardy noted the importance of digital platforms, mainly through videoconferencing software, in preserving communication. Beogo explained how digital platforms could help keep residents connected to their family caregivers:

Digital applications have become a promising avenue to reduce social isolation and loneliness by providing a way to maintain communication between LTC residents and their families and will certainly remain in the post-COVID-19 pandemic world.

Meanwhile Hardy explored how the use of tablets in LTC homes would help residents, especially cognitively impaired older adults, connect with their caregivers:

Videoconferencing can be complementary to face-to-face visits in LTC homes in an effort to provide residents with cognitive stimulation. In this way, electronic tablets offered residents and their family caregivers an opportunity to increase and maintain communication regardless of visitation restrictions that were in place and other challenges, such as geographical distance.

The introduction of this innovation in LTC homes has created more opportunities to increase social connections by simply increasing the frequency of contact for caregivers who already had face-to-face visits or by providing the opportunity

to potential caregivers living far away from the residents' home to have more visits with their loved ones. As Hardy explained:

When we started this project, caregivers who were living in different cities and provinces were delighted and excited to be able to check on their relative[s] whom they hadn't seen for a long time. Others appreciated the availability of this option to talk to residents when they didn't have enough time to travel to the LTC homes.

The potential to use technology to enable family presence is substantial and a learning that can be taken forward to improve care beyond our COVID-19 pandemic response.

#### Interventions need to be designed with equity and inclusion at front of mind

While digital innovations are a promising avenue for LTC homes, we still need to address barriers for residents and their caregivers so that they can equitably access and meaningfully engage with these innovations. For example, throughout the COVID-19 pandemic, gaps have been identified in the linguistic obligations (i.e., bilingualism) of public institutions and governments in various jurisdictions in Canada (Chouinard and Normand 2020). Beogo noted that some residents and family caregivers required further support to engage with digital innovations:

For better inclusivity and accessibility to health services, older adults in LTC homes and, especially, in the context of linguistic minority, deserve special attention in health crises such as the COVID-19 pandemic.

As a numerical minority, few LTC homes across Canada are devoted to Francophones in anglophone settings and vice versa. Older adults in linguistic-minority LTC homes often live far away from their families, so improving interactive virtual conversations with the help of technology is of utmost importance.

Similarly, Hardy highlighted the necessity of equity-based and person-centred approaches to adapt interventions for vulnerable populations – such as residents with cognitive impairments – to counter the negative outcomes of social isolation this population usually suffers from:

It is important to prioritize the emotional well-being and quality of life of residents and implement more equitable standards to family caregiver presence as they play an essential role on the care and quality of life of residents.

Gallant and her team also spent some time working with LTC knowledge users to outline several recommendations for equitable and inclusive intervention development and implementation within LTC settings (Finnegan et al. 2022).

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**The potential** to use technology to enable family presence is ... a learning that can be taken forward to improve care beyond our COVID-19 pandemic response.

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#### **A lack of staffing and physical infrastructure adversely impacts family visitation policies**

While individual barriers are important to address, the greatest barriers to accessible and inclusive family visitation policies are a lack of staffing and physical infrastructure within an underfunded LTC sector. For example, Hardy explained the importance of having the resources to support digital innovations: “LTC homes need to be equipped with the necessary resources – mainly staffing and technological resources – to preserve communication between residents and their family caregivers.” Kaasalainen, who led the implementation of the palliative care toolkit for residents and their family caregivers, echoed this need for resources:

The COVID-19 pandemic highlighted the lack of available resources in LTC homes – including staff and money – that negatively impacts the care of LTC residents and impedes the implementation of a palliative care toolkit.

Through Kaasalainen’s work, it became evident that LTC staff were pulled in multiple directions, impeding staff members’ ability to focus on developing and implementing policies that promoted the inclusion of family caregivers. Relationships between family caregivers and LTC staff members suffer when staff members struggle to meet government priorities in a health emergency, such as the COVID-19 pandemic.

#### **Including and partnering with family caregivers leads to better outcomes for residents**

Encouraging partnerships between LTC homes and residents’ family and other informal caregivers can improve resident outcomes. As Connelly noted, for example, “implementing a new process for care planning requires partnerships between researchers and stakeholders in LTC.” In fact, for the PIECES program, involving key LTC stakeholders, researchers and PIECES program experts during all stages of the project – from

conception to implementation – was the most important ingredient for success. Connelly went on to explain the benefits of such partnerships:

These partnerships ensure that the priorities, needs and experiences of residents, families and staff members are used to inform care planning processes that reflect the realities of LTC during COVID-19 and beyond.

Partnerships between stakeholders and researchers in LTC work by ensuring that LTC homes continue to have access to evidence-based solutions. With the effect of the COVID-19 pandemic on the LTC sector engrained in everyone’s minds, Conklin explained:

There is growing recognition that the care provided by family members is essential, and conditions are favourable to strengthening the natural partnership that exists between family and frontline care providers to bolster the wellbeing and health of residents.

These findings suggest that LTC staff appreciate and value the role of family caregivers, that family caregivers appreciate LTC staff members’ good intentions and that both parties find the existing situation regarding family presence in LTC to be unacceptable.

Family caregivers can also be engaged in policy development and implementation to ensure that new and ongoing policies – especially, visitation policies – enrich and add meaning to residents’ lives. As noted by Keefe, “family caregivers need to be engaged throughout policy development and implementation to ensure [that] they can play a meaningful and vital role in their relatives’ lives.” Keefe also explained that a bottom-up approach allowed for flexibility in the development and implementation of these visitation policies to facilitate better accessibility and inclusivity within LTC homes.

#### **Recommendations**

Based on our collective learnings, we have outlined recommendations to improve family presence within the LTC sector in Canada:

- Create opportunities and partnership programs to promote family caregivers’ and residents’ roles in decision making within LTC homes.
- Tailor inclusive and patient-centred approaches so that they are adapted to the different characteristics of LTC homes, including the specific characteristics of residents and their family caregivers.

- Support the use of digital innovations and improve digital literacy for residents, family caregivers and LTC staff members by providing training opportunities and the resources needed to use these innovations.
- Build capacity among LTC staff to implement interventions prioritizing family presence and person-centred care approaches during a health emergency.
- Integrate research efforts and program evaluations within the LTC sector so that policy makers and decision makers can be provided with evidence-based information.

## Conclusion

The evidence that we have collectively gathered has revealed the importance of the presence of family on the well-being

and quality of life of LTC residents. This is especially true in the context of the pandemic, but it is also essential beyond it. We recommend that researchers, LTC managers and policy makers collaborate and create partnerships with family caregivers that facilitate the successful development and implementation of evidence-based strategies to support family presence in LTC homes. Within these partnerships, LTC residents and family caregivers need to be centred in the work. Whether interventions focus on the use of technological innovations, educational materials or feedback mechanisms, the voices of residents and their family caregivers must be considered and reflected in the interventions and policies that are developed and implemented. **HQ**

## Disclaimer

This work is supported by Healthcare Excellence Canada (HEC). HEC works with partners to spread innovation, build capability and catalyze policy change so that everyone in Canada has safe and high-quality healthcare. The views expressed herein are those of the authors and do not necessarily represent the views of HEC.

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This work is supported by the Canadian Institutes of Health Research (CIHR). At CIHR, we know that research has the power to change lives. As Canada’s health research investment agency, we collaborate with partners and researchers to support the discoveries and innovations that improve our health and strengthen our healthcare system.

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# Experiences of Essential Care Partners during the COVID-19 Pandemic

## L'expérience de partenaires de soins essentiels pendant la pandémie de COVID-19

Pauline Johnston, Margaret Keatings and Allan Monk

### Key Takeaways

- Family presence in long-term care (LTC) is invaluable and the designation of essential care partners (ECPs) is one way to ensure that family caregivers will always have access to provide care to loved ones who live in LTC.
- Research in LTC is more impactful when residents, families and ECPs are fully engaged as partners. They have unique perspectives that can help researchers and LTC homes identify areas for improvement and support the design, implementation and evaluation of policies and practices in LTC.
- Meaningful family presence can be achieved when the LTC system demonstrates commitment and adaptability to the unique needs of each resident, family member and ECP.

### Abstract

Visitor restrictions in long-term care (LTC) have had many consequences for residents, their families and care providers. The value of family presence in LTC was obscured during the COVID-19 pandemic until the designation of essential care partners (ECPs) was introduced to support the re-entry of family caregivers into LTC. Three ECPs share their personal experiences of caring for a loved one in LTC before and during the pandemic. Partnerships with LTC homes, residents, families and ECPs are identified as a unifying way forward to bolster future pandemic preparedness and ensure that current and future residents receive safe and high-quality care.

### Résumé

Les restrictions concernant les visiteurs dans les établissements de soins de longue durée (SLD) ont eu de nombreuses conséquences pour les résidents, leurs familles et les prestataires de soins. L'importance de la présence de la famille dans les SLD a été occultée pendant la pandémie de COVID-19 jusqu'à ce que la notion de partenaires de soins essentiels (PSE) soit introduite pour appuyer le retour des proches aidants dans les SLD. Trois PSE ont partagé leur expérience de prise en charge d'un être cher en SLD avant et pendant la pandémie. Les partenariats avec les établissements de SLD, les résidents, les familles et les PSE sont définis comme une voie unificatrice pour le renforcement de la préparation à une éventuelle pandémie et pour garantir que les résidents actuels et futurs reçoivent des soins sûrs et de haute qualité.

## Introduction

The pandemic renewed the discussion around the importance of family engagement and the benefits it brings to the care and well-being of loved ones in long-term care (LTC). When the presence of families and caregivers was restricted, there were many consequences and, in some cases, harms, that impacted the safety, experiences and outcomes of residents in LTC, their families and their providers. While we were sometimes called *visitors* early in the pandemic, this language later shifted to *essential care partners* (ECPs) (HEC 2022a).

While this designation is new, the roles and responsibilities of an ECP are not. ECPs provide physical, psychological and emotional support as deemed important by the person receiving care. This care can include support in decision making, care coordination and continuity of care. ECPs are identified by the person receiving care (or the substitute decision maker) and can include family members, close friends or other caregivers. The designation of an ECP may also include paid caregivers at the discretion of the person receiving care (or the substitute decision maker).

In some jurisdictions, language such as *essential visitor* was adopted to describe us among others who were able to re-enter LTC during the pandemic (Government of Ontario 2022). However, the designation of ECP is intended to be broadly applicable across care settings and jurisdictions.

Before or during the COVID-19 pandemic, we have each found ourselves in the ECP role to a loved one in an LTC home. We were connected by researchers engaged in the Implementation Science Teams – Strengthening Pandemic Preparedness in Long-Term Care research program (HEC 2022b). While we have had varying levels of engagement in these research projects, we will share our journey through the pandemic, our perspectives on the research and our involvement with an Implementation Science Team.

We believe that by sharing our personal experiences as ECPs and by contributing to the research program, we can foster a greater understanding of the ways that the pandemic affected residents and their ECPs. We hope that this will support the LTC system in strengthening its response to future pandemics and in improving the care delivered within LTC homes.

## Who We Are

### Allan Monk

My wife was a resident in an LTC home during the pandemic. There were very few problems in the home where she lived. It was organized, prepared to respond and flexible. Except during a six-week lockdown, I was with my wife daily and know the incredible impact that staff can have on the care provided to both residents and their families. After my wife passed, I

learned that Bonnie Lashewicz and her team were conducting research on supporting mental health and preventing moral injury among LTC workers in the LTC home where my wife lived (HEC 2022c).

### Pauline Johnston

I provided care to my father and uncle, who were in the same LTC home. My father entered the LTC home in 2018, so this environment was new to me and at the time, I did not realize how a pandemic could affect the sector. It was important for me to be involved in the research because I wanted families to never be denied access to their loved ones again the way we were when LTC homes implemented no-visitor policies early in the pandemic. I became involved in a research project led by James Conklin on reintegrating ECPs in LTC homes through a designated care partner program (HEC 2022c). It was important to me that caregivers be given the designation of an ECP and be viewed as an integral part of the care team to support our loved ones in LTC in a safe way.

### Margaret Keatings

Prior to the pandemic, my sister or I were a daily presence with our father, who lived in an LTC home for almost eight years until he died at the age of 100 years. I was able to observe the challenges facing LTC both as a healthcare professional and as a daughter. During this time, I developed strong relationships with the staff and other residents and family members. Early in the pandemic, as restrictions to access were introduced, I anticipated the impact on vulnerable residents who were denied the presence of even one designated essential family member. After the death of my father, I remained engaged in opportunities to improve the care of older adults and was invited to join – as a family member with lived experience – the implementation science team that Katherine McGilton was leading. This project focused on a nurse practitioner-led implementation of health workforce recommendations in LTC homes during the pandemic (HEC 2022c). As a family member and a former healthcare professional, I understand the value of integrating families and patients into the interdisciplinary care team.

## Our experiences and perspectives

It is important for us to note that this article reflects our experiences and perspectives, and we recognize that across Canada, each person's involvement with the pandemic, with individual LTC homes and with the research program is unique. In addition, we would like to clarify that the use of the term *family* is to be understood as a person whom the resident defines as a family member, which does not necessarily mean biological

family and in many instances can refer to friends or chosen family members. We hope that our words provide perspectives and observations from which we can move forward and learn together.

### Being an Essential Care Partner during the COVID-19 Pandemic

As ECPs, we never doubted the value of family engagement, but the COVID-19 policies implemented in care facilities early on during the pandemic seemed to disregard it. As members of the care team, we represent an important voice that can advocate for those who are, in some cases, vulnerable and require our help in communicating their needs. We also act as a connection point between residents and staff as we have a unique relationship with the residents; they are our loved ones. We know their histories, their likes and dislikes and the little things that will make a difference in their day.

For Pauline and Allan, we agreed that being locked out and restricted from visiting our loved ones took a toll emotionally and was difficult. Media coverage of LTC homes in crisis only added to our worry and concern for loved ones. As we saw how powerless we were to influence the fast-moving policy directives during the pandemic in a system as complex as LTC, we felt helpless. We also noticed how quiet life was without being able to pay our usual visits to our family members.

Although it was necessary for LTCs to limit the number of ECPs, the decision was very difficult for families. It meant that grandchildren did not see their grandparents and, as families, we needed to make difficult choices as to who could see our loved ones and who could not.

When we were allowed back into these homes, we became even closer with staff than we were before. During the second wave, one of Margaret's family members moved into the same home as her father and noted that she was grateful that this was during a time when more access was permitted. We noticed firsthand the additional stress and challenges for staff during the pandemic as they had to constantly don and doff personal protective equipment (PPE) and sanitize to try and stop the virus from taking hold and spreading. This led us to worry about all the other residents, especially the more vulnerable and more at-risk ones. It is impossible to spend the hours that we have spent in LTC homes and not become connected to other residents and their families.

### Changing Roles, Rules and Processes

One of the constants of the pandemic was change. Change in staffing, change in policies and change in routines were just some of what we experienced. At times, the staff seemed as unsure of these changes and new rules as we were. For Pauline and Allan, there was a need to adapt and find new ways

to assure themselves that the needs of their loved ones were being met.

Communication was critical. Yet it both helped and hindered the process of adapting to these many changes. The pandemic dramatically altered the traditional ways in which we communicated with staff and they communicated with us. In many cases, the COVID-19 restrictions meant that we could not visit the LTC homes in person to see our loved ones. The natural communication points as we walked down the hall to visit our family members were all removed, replaced with long waits for testing procedures before being allowed to enter. In addition, the restrictions on access meant that as ECPs, we could neither serve as connectors between our loved ones and the staff nor between our loved ones and our extended families and others who could not be present.

Despite the rapidly changing context, staff worked hard to maintain strong communication with family and friends. Often this meant that staff had to work collaboratively to find creative ways to keep the lines of communication open when we were not able to visit our loved ones in person. We received e-mail updates – sometimes daily, monthly newsletters with photos of residents and phone calls and bulletins as required. The phone calls, both from the home to us and from us to the home, worked well and gave us comfort. Some homes had dedicated staff to help handle the technology involved in virtual online chats. One home even held a monthly live update on YouTube. On the other hand, we were also acutely aware that these increased communication efforts meant increased time staff spent away from directly caring for residents.

The LTC home where Allan's wife was cared for held regular memorials to honour residents who had died. During the COVID-19 pandemic, this home adapted these regular memorials to Zoom, bringing together residents, families and staff to grieve their losses together. While this adaptation was not perfect (e.g., not everyone had the technology required), it created a virtual space to remember the residents who had passed and for residents, families and staff to support one another.

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**One of the** constants of the pandemic was change. Change in staffing, change in policies ...

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When communication went well, it was because it was timely, gave us clear information about our loved ones and informed us of what the home was doing to provide care in the new environment. Our experience was that strong communication was reassuring and helped us feel connected to our loved ones, even when it was not possible to visit them. In many cases

during the lockdown, we observed that staff were considerate, kind and polite in how they communicated with us. Friendly but firmly, they emphasized the importance of keeping our loved ones safe.

There were times, however, when communication was less than ideal and failed to meet our needs. Inconsistent messaging regarding changing rules was just one example. A lack of communication around the total care plan was another. Other times, there were delays in receiving updates about our family members or challenges with technology that made it difficult to get in touch. In addition, not all homes had access to technology that could enable one-on-one video calls. When the lines of communication broke down, we had no way to know how our loved ones felt, what kind of care they were receiving or whether they were safe. All we could do was wait for the phone to ring, the e-mail to arrive or for technology to bring us together again.

### **The New Reality: Infection Prevention and Control Measures and Restrictions**

Another change that the families had to adjust to was the increased emphasis on infection prevention and control (IPAC). Keeping our loved ones living in LTC safe was always a priority, but the pandemic brought an unprecedented need to be vigilant. IPAC became even more important in LTC homes. For some families, the concept of IPAC was very familiar, while for others it was completely new and another adjustment. Regardless of familiarity with IPAC, at times it was overwhelming to hear evolving IPAC guidance from so many different sources as we continually learned more about the virus and how to keep ourselves and our loved ones safe from it.

Another challenge was that sometimes what was being enforced did not match the science behind IPAC measures. In addition, in some cases, the IPAC guidelines were inconsistent from home to home. For instance, while some homes allowed the same ECP to be designated for two individuals, in many homes this was not the case, and an individual could only be given the designation of an ECP by a single resident.

Despite the sometimes-confusing guidance, we are grateful for the IPAC training some LTC homes put in place through videos, pamphlets and individual guidance or conversations. The opportunity to feel in control of our ability to keep our family safe while being able to provide the care they needed was critical, and this information supported that need. LTC staff took the time to show us how to follow proper IPAC procedures, such as donning and doffing PPE, and we were provided with the PPE we needed. In homes where there were private rooms, this helped considerably and is an opportunity for future improvement.

### **Workforce Challenges and Opportunities**

Having a family member in LTC means expanding the circle of individuals who support the loved one and their family. The staff who surround residents have a substantial impact on not only the residents but their families as well. From dietary aides, housekeeping staff, maintenance staff, care aides, nurses and others, all staff play a critical role in the quality of life of each and every resident in the home. During the COVID-19 pandemic, we saw how resources were mobilized from across and outside the organization, including virtual visits facilitated by staff and recreation therapists redeployed to support residents virtually.

We also saw the tremendous stress that staff were under and the incredible resilience they showed in caring for both our loved ones and their own families during these extraordinary times. We also witnessed their moral distress when they had to implement policies that they knew were causing harm to residents, especially when that meant restricting families from seeing loved ones.

Allan shared his lockdown experience and how the relationship he had with the staff meant that he trusted them to provide excellent care to his wife even when he was not present. This lessened the burden of the pandemic for him as he knew that she was well cared for even in his absence. This situation speaks powerfully to the importance of having the individuals with the required skills and competencies to provide safe, compassionate and high-quality care within LTC homes.

We have heard much about staffing levels, and we agree that more care staff in homes is critical; however, it is equally important to have staff with the right mix of skills and characteristics to care for older adults with complex health needs. It is essential that staff engage in person-centred care and are guided by their knowledge of individual residents' needs and wants, regardless of whether we as ECPs are there to advocate for them. Staff with strong training and a warm demeanour are essential to ensuring good care. We should be seeking staff who demonstrate kindness, gentleness and compassion and have the capacity to be in the moment with the resident, rather than simply completing the scheduled tasks.

How do we do this? LTC homes could integrate these qualities and characteristics into their hiring practices to create a conscious hiring strategy. Schools and universities could also review their curricula to ensure that these values and principles are embedded in their teaching, especially for those showing an interest in gerontology. Pre-existing staff could be offered training or mentoring on how to develop and show compassion and kindness to residents on a regular basis. We also need to ensure that staff are compensated adequately and appropriately for the unique skills that they bring to this work.



## Working Together for a Better Long-Term Care System

Before or during the pandemic, we have each worked with the respective LTC homes caring for our loved ones with a goal to ensure they received the best possible care. As family members, many of us have a long commitment to improving care in LTC even after our loved one(s) have died. Part of this commitment is sharing our expertise to ensure that current and future residents are able to receive safe and high-quality care. Two of us were heavily engaged in the research process, with the goal to create greater system improvement across the LTC system for staff, families, residents and communities. We discuss our experiences and thoughts in the following sections.

### Margaret Keating

I was engaged with a small core group that tracked the research while it happened. There were weekly meetings to plan, review methods and discuss strategy. I worked with the team to design research to address some of the issues that I had observed during my father's time in LTC. These included the need for stronger leadership (e.g., closer monitoring and supporting having nurse practitioners in each home), improved coordination and planning of residents' care and creating a healthy work environment, including emotional support for staff who experience the diminishing quality of life and the death of residents on a regular basis – challenges that can lead to moral distress. I was involved with preparing the proposal, developing the intervention and planning. Often, this work included meeting with residents, family members and the LTC home management teams to review strategy and plans together. This engagement, especially with leadership within the LTC homes, was important because it helped address these issues.

Residents, family members and ECPs must be involved in research on the care of older adults living in LTC. We can help identify the real issues in LTC because our lived experiences are non-negotiable. Through my work with McGilton, I believe that the research goals aligned with my lived experiences, and it was rewarding to see that my lived experience could make a difference in how the research project was designed. Residents, family members and ECPs have unique insights, and see LTC through a lens that is invaluable to research endeavours, and their voices should be heard.

### Pauline Johnston

I participated in the research, and I sat on an advisory board that reviewed it. I appreciated this opportunity because the researchers were thorough and determined to get information from the source (that being our lived experiences). It was also interesting to be part of the advisory board. Some of the things that we learned through data review were shocking, but being

on the advisory board helped me, as a former ECP, to see how we all view what happens in LTC homes from different vantage points – as nursing staff, designated care partners and all the team members in between.

My involvement in the research let me see that there was a desire to learn across LTC homes, from management to the residents and their family members. I have a renewed sense of hope that there is a way forward. My hope for the future is that we can shift our thinking away from compliance within LTC and focus on implementing what we have learned from this pandemic to ensure that care is person centred and that we have resources in place to support staff who experience moral distress now and beyond the pandemic.

There is power in involving family members in end-of-life care, which adds layers of dignity, flexibility and compassion to make an LTC home feel like a home. In the home where my father and uncle lived, we had a very positive experience and felt like we were part of the care team. Yet the people in LTC – the residents, their families and the staff – are ever changing. And with this change, the needs of residents and their families change, and staff are continuously learning to ensure that the care they provide is individualized. My hat's off to the staff who are continuously learning to provide the best, person-centred care. Our LTC system must reflect the same priorities.

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**There is power** in involving family members in end-of-life care, which adds layers of dignity, flexibility and compassion to make an LTC home feel like a home.

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### Allan Monk

For Allan Monk, who was not as heavily involved with a research team, an important focus going forward is ensuring that lockdowns do not happen again. Residents should always have access to their essential care person. It is up to the people who make decisions about LTC regulations to re-evaluate every aspect of preparation for a pandemic. Next time, we should be prepared with a full medicine chest of information to protect residents living in LTC.

## Recovery, Resilience and Re-Engagement

The research that occurred through the Implementation Science Team projects targeted many of the areas that we, ourselves, had identified as needing improvement. Achieving meaningful family presence in LTC requires commitment and adaptability across the LTC system to create space and time to recognize, understand and respond to the unique needs of each resident, their families and ECPs. Engaging residents and families in research can contribute to it being more robust,

meaningful and impactful – we have each experienced this in unique ways. We know that the investment in improving LTCs is critical and has the potential to make meaningful changes for residents, families, ECPs, staff and communities.

Although our experiences are unique, our goal is the same. We must all find ways to walk the talk on person-centred care to ensure that every resident in LTC receives safe and high-quality care based on their individual needs. The quality of each person's life matters – especially at the end of life – and we hope that from this work all of those who deliver care to older adults in LTC can learn and improve for the future. It is important to us that we never lose sight that the journey to recovery must be walked together, with residents, families, staff and homes included.

### Future Pandemic Preparedness: Practices and Policies for Safe and High-Quality Care

We have summarized five key takeaways for future pandemic preparedness in LTCs based on our personal experiences as ECPs.

1. Across the LTC sector, policies that support residents to identify and designate ECPs must be adopted. Residents, family members and caregivers must have a voice in the development of these policies.
2. All LTC homes need to be equipped with communication technology tools to help residents stay connected to their loved ones; this includes finding solutions for family members who may not have access to these tools. LTC homes should also consider how to support residents and their family members who may not know how to use these tools.
3. Staff working in LTC homes need to have the skills and characteristics to care for older adults with complex health needs. This includes providing training and education to everyone on the care team.
4. There needs to be adequate staffing within LTC homes. This includes both staffing numbers and the appropriate category of staff based on resident needs. We need to ensure that staff are given the time to learn about the individualized needs and wishes of each resident, so that safe, high-quality and person-centred care is provided.
5. Residents, family members and essential caregivers must be given the opportunity to participate in the development of practices and policies that will impact them.

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### About the Authors

**Pauline Johnston** is a retired elementary school teacher from the Bluewater District School Board. She and her husband, Tim, live on their farm. Their two daughters are currently away, studying at a university.

**Margaret Keatings** is a retired nurse leader. Though her career involved acute adult and pediatric care, her recent volunteer work is focused on older adults, end-of-life care and the care of vulnerable populations in the community. She can be reached by e-mail at [margaretkeatings@gmail.com](mailto:margaretkeatings@gmail.com).

**Allan Monk, OC** (Officer of the Order of Canada) is a retired advocate for the disabled community and residents in care centres. He has run a charity of volunteer inventors creating assistive devices for the disabled community for 10 years and has been visiting and assisting staff in care centres for the past 19 years.

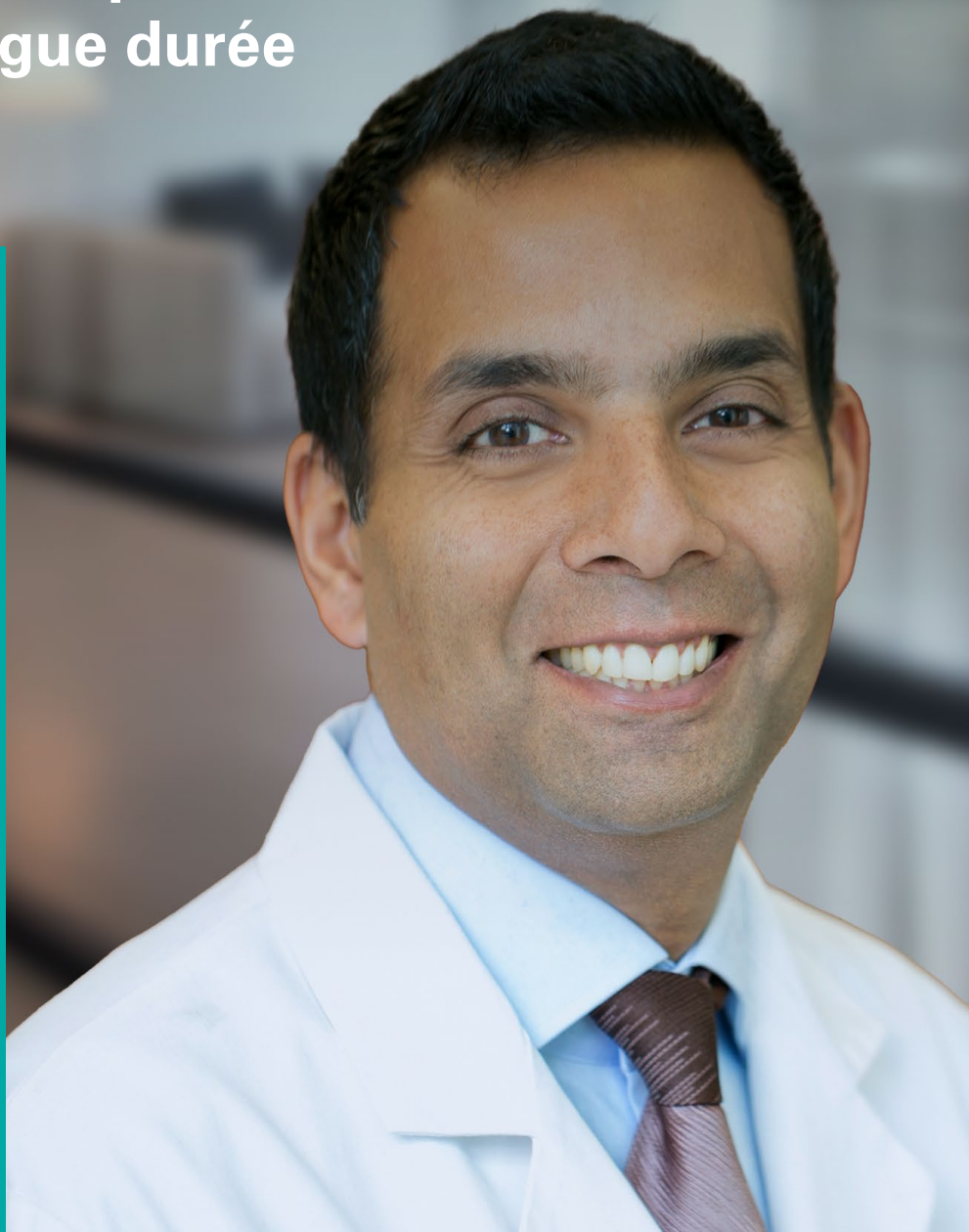
# Reflecting on the Journey to Develop New National Long-Term Care Standards

## Réflexion sur le cheminement vers l'élaboration de nouvelles normes nationales pour les soins de longue durée

Samir K. Sinha

### Key Takeaways

- The Health Standards Organization (HSO) and Canadian Standards Association Group (CSA Group) are leading the creation of two new standards that aim to provide evidence-informed guidance on how individual (long-term care) LTC homes – in partnership with federal, provincial and territorial governments – can deliver safe, reliable and high-quality LTC services.
- The HSO standard clearly articulates the importance of providing resident-centred care that consciously adopts the perspectives and preferences of residents, emphasizing a shift across the LTC sector that puts the residents' needs first.
- Ongoing research that engages residents, family members, essential care partners, LTC homes and staff is essential to help us better understand what is happening in homes, what needs to be done moving forward and how to deliver the best possible care across varying settings and contexts.



**Abstract**

**Samir K. Sinha – Implementation Science Team lead and chair of the Health Standards Organization's National Long-Term Care Services Standard Technical Committee – sheds light on the development of the long-term care national standards. Sinha also discusses what the standards hope to achieve for improved quality of care and quality of life across the sector.**

**Résumé**

**Samir K. Sinha – directeur de l'équipe en science de la mise en œuvre et président du Comité technique de la norme sur les soins de longue durée de l'Organisation des normes en santé – fait la lumière sur l'élaboration des normes nationales dans les soins de longue durée et présente ce qu'on attend d'elles pour l'amélioration des soins et de la qualité de vie dans le secteur.**

**Introduction**

As both the lead of an Implementation Science Team (through the Strengthening Pandemic Preparedness in Long-Term Care research program [HEC 2022]) and chair of Health Standards Organization's (HSO's) National Long-Term Care Services Standard Technical Committee (HSO National Long-Term Care Services Standard n.d.) that is tasked with co-designing new standards for care and services provided by Canada's long-term care (LTC) homes, Samir Sinha was invited to share his insights and perspectives on LTC in Canada through this featured Q&A session. Sinha discusses how the pandemic has impacted LTC, what the development of national standards hopes to achieve for quality of life and quality of care and the role of research and evidence-informed decision making to move the sector forward.

**The pandemic has had such a devastating impact on residents, family members/ caregivers and staff in LTC. What have we learned from the pandemic and what is going to be its legacy for how we offer LTC in the future?**

Sadly, this pandemic has yet to end, even though I think many would like to think it's over and are desperate to get back to things as they once were. As I answer this, Canada has officially entered its seventh wave of COVID-19 infections, and once again we see cases and, sadly, deaths on the rise across Canada's LTC settings. The good news is that this latest wave is not as devastating as the first two; we have really seen the miraculous impact that vaccinations and strong infection prevention and control (IPAC) measures can have.

I think the first two waves helped all Canadians truly realize how poorly supported our LTC systems are. Never enshrined in the creation of our beloved medicare system in the '60s or our *Canada Health Act* (1985) in the '80s, LTC has long remained the poor cousin of other parts of our public healthcare system. It is part of the reason why nurses, allied health professionals and personal support workers in publicly funded LTC homes make far less than the same professionals working in our publicly funded hospitals. It is no wonder that the majority of Canada's LTC homes were struggling to recruit and retain staff even before the pandemic hit. The slightly more than 200,000

residents of these homes are mostly frail older persons, often living with dementia, which makes their care needs complex and requires a staffing skill mix that provides quality of care and quality of life. As well, it is hard for these individuals to advocate for their own care needs. We largely ignored and did not truly appreciate the critical role that devoted families and friends of LTC residents have played as essential care partners – until we locked them out. The fact that many residents in provinces like Ontario lived in older, more cramped buildings and with two, three or four to a room only further contributed to the rapid spread of COVID-19 in these settings. Finally, we also came to realize the negative impact that not prioritizing these settings early and adequately can have as demonstrated when Canada earned the dubious distinction of leading the world with 80% of its first-wave deaths recorded in LTC homes – twice the international Organisation for Economic Co-operation and Development (OECD) average (CIHI 2020).

The mounting tragedies witnessed in Canada's LTC settings triggered new and necessary reviews (CIHI 2021; Estabrooks et al. 2020; NIA 2021; Stall et al. 2021), research (Brown et al. 2021; Sepulveda et al. 2020; Stall et al. 2020) and enquiries (Marrocco et al. 2021) that led in some cases to new measures, funding and commitments to improve the overall system. However, I honestly think that the wholesale change that many have been long advocating for continues to elude us. I think what has frightened some politicians away from making the necessary changes to fix a long-neglected system will require more money and more fundamental changes than there is political will to see through. Nevertheless, Canadians are now more enlightened about the state of our LTC systems than they have ever been. Canada's LTC homes have more advocates and researchers helping to better understand and action evidence-informed changes to how we deliver LTC services, and we have a growing aging population that will continue to demand improvements in this area of care for years to come.

**How would you characterize the problem the new LTC standards are seeking to fix?**

I think that most Canadians were likely not aware that Canada had LTC standards prior to the pandemic. The existing HSO Standard (HSO 2020) was first developed over a decade ago



to help enable the voluntary accreditation of the majority of Canada's LTC homes against one national standard, the way all Canadian hospitals are accredited, which has been helpful. National standards have the ability to become so much more: form the basis of legislation, policy and governance while also helping individual homes engage in continuous quality improvement efforts.

In 2020, the Standards Council of Canada (SCC), a federal Crown corporation, selected HSO and the Canadian Standards Association Group (CSA Group) to oversee the development of new complementary National LTC Standards that address the way care is delivered in a home and also how homes are built and operated. This has created an enormous opportunity to create new national standards that reflect where Canada needs to move toward in the provision of LTC (Box 1). Overall, the broad engagement by HSO and CSA Group to gather expert input will lead to the creation of two new standards that aim to provide evidence-informed guidance on how individual LTC homes, in partnership with federal, provincial and territorial governments, can deliver safe, reliable and high-quality LTC services (HSO National Long-Term Care Services Standard 2021).

**We largely ignored** and did not truly appreciate the critical role that devoted families and friends of LTC residents have played as essential care partners – until we locked them out.

#### **What were the biggest challenges in developing the standards? What is the role of evidence (in the development, implementation and evaluation of the standards)?**

One of the biggest challenges in developing the new standards has been ensuring that as many Canadians as possible were given an opportunity to participate in their creation. More than 20,000 Canadians participated in the creation of both the HSO and CSA Group National LTC Standards, which speaks to both the interest and willingness of Canadians to contribute to improving Canada's LTC systems. We have been particularly proud of how many residents, front-line workers, families and essential care partners have provided their input to ensure that the new standards truly reflected their lived experiences of both receiving and providing LTC services.

The other biggest challenge has been having the necessary bandwidth to adequately review all of the feedback and available evidence to support the creation of more comprehensive and truly evidence-informed standards. As we are keen for the new standards to enable evidence-informed implementation

#### **Box 1. New national long-term care standards**

Health Standards Organization (HSO) and Canadian Standards Association Group (CSA Group) are working collaboratively on developing two new national standards for long-term care (LTC) in Canada:

- *HSO's National Long-Term Care Services Standard*: To address the delivery of safe, reliable and high-quality LTC services.
- *CSA Group's National Long-Term Care Home Operations and Infection Prevention and Control Standard*: To address the design, operation and infection prevention and control practices in LTC homes.

and evaluation, we are spending a great deal of time ensuring that they are made very accessible so that every home can participate in evaluating their own performance and areas for improvement using existing data that are already routinely collected in the provision of LTC. So, in short, the role of evidence has and will be essential in every aspect of the development, implementation and evaluation of these standards.

#### **The draft standard that you recently released talked about *resident-centred care*. What does this mean, and what is it going to take to realize it?**

The draft HSO standard for LTC defines resident-centred care as an approach to care that consciously adopts the perspectives of residents as participants in, and beneficiaries of, trusted health and social services systems. Resident-centred care further ensures that an individual's preferences for care are used to guide decision making and is based on the philosophy of person-centred care.

I was really pleased that this became a key takeaway for many from the release of the draft HSO standard. This represented a real reorientation of focus across LTC systems, where we sometimes forget that it is the residents' needs (and not necessarily staff's, the organizations' that provide LTC or the government's) that should come first. There was no debate among our technical committee members around this, and the decision to create such a strong focus was greatly aided by the fact that our committee includes LTC residents, who were able to guide us on how to structure this work in a way that was enabling to all necessary stakeholders involved in providing safe, high-quality LTC.

Through the development of the new HSO standard, I think we have found a good way to clearly articulate the importance of providing resident-centred care. We make it clear that LTC homes are a place where people both live and work, and by creating the right conditions of work, we can create and truly

enable resident-centred care. Nevertheless, it will require jurisdictions to appropriately fund and enable this care by encouraging a culture of continuous quality improvement.

**We have been** particularly proud of how many residents, front-line workers, families and essential care partners have provided their input to ensure that the new standards truly reflected their lived experiences ...

**There is a view that we simply have the wrong model for delivery of LTC, with too much emphasis on large-scale residential care facilities. What are your thoughts on this? Do the standards in any way address this?**

The HSO standard aims to address the delivery of safe, reliable and high-quality LTC services in a home, no matter the size. The complementary CSA Group standard will address the design and operation of LTC homes.

There is growing evidence that smaller, well-staffed home-like settings that offer residents single-room accommodations, such as the Green House LTC model (The Green House Project n.d.), can deliver better resident, staff and system outcomes, especially during the COVID-19 pandemic (Zimmerman et al. 2021). This is a model that is getting a greater level of attention in the development of new LTC homes in both Quebec and Alberta. While some jurisdictions, such as Ontario, are encouraging the building of much larger homes, you can still implement a Green House LTC model with single-room accommodations and other home-like features in larger, traditional settings as well. The challenge is that some places focus solely on the *hardware*, forgetting that this small home-like model of care does not work unless homes are adequately staffed to provide truly resident-centred care. While the HSO standard will speak to the right *software* that is needed to power safe and high-quality LTC, the CSA Group standard will further address the *hardware* that needs to be properly considered in the design and operation of LTC homes.

**What do you expect to be the impact of the new LTC standards?**

I took on the role of chairing the development of the new HSO standard partly because, in my view, we had the right confluence of factors that could allow for this new standard (along with the new complementary CSA Group standard) to have demonstrable impact in the provision of resident-centred LTC across Canada. The federal government's expressed support for the standard development work, including oversight of the SCC

and funding from Health Canada, have allowed us to truly engage a record number of people in its creation. The further commitment of \$3 billion in the 2021 federal budget to support implementation of national LTC standards will assist provincial and territorial governments to further advance their ability to deliver safe, reliable and high-quality LTC. Developing the new HSO standard in partnership with national groups, such as the Canadian Institute for Health Information and Healthcare Excellence Canada (HEC); key federal, provincial and territorial government partners; and several other key stakeholder organizations, has fostered a highly collaborative process (with the specific input of over 20,000 Canadians). This incredibly high level of engagement will ensure that the new HSO standard truly reflects and enables the achievement of what matters most to those living, working and interested in the provision of LTC services.

At the end of the day, our hope is that once the HSO standard is implemented across the country (along with appropriate funding and support for the provision of LTC), residents, their families and staff can all speak to the high quality of care that they routinely experience and/or are proud to deliver.

**Why are research and improvement initiatives such as the ones featured in this special issue important?**

Research and improvement initiatives are a critical way to help us better understand what is required to provide safe, reliable and high-quality LTC. The incredible research that has been enabled over the past few years – with new dedicated funding via the Canadian Institutes of Health Research in partnership with HEC through its LTC Implementation Science Teams initiatives (HEC 2022) – has allowed us to better understand (in an evidence-based way) things that we had little insight into before the pandemic. Research, especially research that engages residents, family members, essential care partners, LTC homes and staff as partners at the table, helps us better understand what is actually happening, why it is happening and what likely needs to be done to make sure that the right things happen moving forward. Improvement work – including quality improvement and implementation science – is essential, as providing LTC is not easy and requires an understanding of how to deliver the best possible care across varying settings and contexts. What is clear is that LTC is an area of the health-care research landscape that has historically not easily attracted funding and, thus, the necessary attention of researchers prior to the pandemic. Subsequent funding and infrastructure (e.g., the LTC Implementation Science Teams program) have helped to demonstrate that LTC is an area ripe for much more scholarly and improvement work.

We have an obligation to improve quality of care and quality of life for those living and working in our LTC homes. I look forward to working with others across the country to advance

the provision of LTC in Canada, enabled by the new evidence-informed National LTC Standards.

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# What We Have Heard: Next Steps for Long-Term Care Pandemic Preparedness in Canada

## Ce que nous avons entendu : prochaines étapes pour la préparation des soins de longue durée en cas de pandémie au Canada

Erin Thompson, Meghan McMahon, Kirstin Loates, Lindsay Yarrow, Jane Rylett, Richard H. Glazier and Jennifer Zelmer  
on behalf of the Strengthening Pandemic Preparedness in Long-Term Care Program Delivery Team\*

### Key Takeaways

- The long-term care (LTC) sector has experienced long-standing challenges, which were exacerbated by the COVID-19 pandemic. Despite these circumstances, LTC homes and the people who work, live or provide care in these settings continue to persevere using existing resources and push to prioritize high-quality care and quality of life.
- Implementation Science Teams noted that strengthening the LTC sector will require investment in staffing and infrastructure; design and implementation of national standards that support resident-focused quality of care and quality of life; long-term and sustained investment in data and research that support continued building of an LTC learning health system in Canada; and successful implementation, spread and scale of promising, evidence-informed policies and interventions.
- Opportunities for future investment include aligning research with real-time operational needs by embedding research capacity within LTC homes and investing in LTC research initiatives and capacity in the science of implementation and spread and scale.

### Abstract

In this concluding article, Healthcare Excellence Canada and the Canadian Institutes of Health Research reflect upon and respond to the lessons learned from the contributing articles in the special issue and summarize key takeaways for the next steps in evidence-informed pandemic preparedness in long-term care in Canada. The implications of their cross-organizational partnership for achieving collective impact now and in the future are also discussed.

### Résumé

Dans cet article de conclusion, Excellence en santé Canada et les Instituts de recherche en santé du Canada se penchent sur les leçons tirées des articles du présent numéro spécial et résument les principaux points à retenir pour les prochaines étapes d'une préparation aux pandémies fondée sur les données probantes dans les soins de longue durée au Canada. On y aborde également les répercussions de ce partenariat interorganisationnel qui vise l'obtention d'un impact collectif maintenant et à l'avenir.

\*In alphabetical order: Including Joanne Goldberg, Jessica Hodge, Justin Lui, Jessica Nadigel, Ayah Nayfeh, Susan Rogers and Patricia Versteegh.



## Background

The Strengthening Pandemic Preparedness in Long-Term Care initiative (HEC 2022a) was launched as a rapid research response to the COVID-19 pandemic by Healthcare Excellence Canada (HEC) and the Canadian Institutes of Health Research (CIHR) in partnership with the Centre for Aging + Brain Health Innovation, Michael Smith Health Research BC, the Saskatchewan Health Research Foundation and the New Brunswick Health Research Foundation. The initiative aimed to mobilize the research community, partner it with long-term care (LTC) homes and support the implementation and evaluation of evidence-informed interventions designed to support pandemic response and recovery in LTC and, ultimately, keep LTC staff, residents and caregivers safe from COVID-19.

In total, 22 Implementation Science Teams (ISTs) were funded and partnered with 91 LTC and retirement homes across 10 provinces, caring for more than 14,000 residents. The ISTs focused on six promising practice intervention areas (Box 1). Key ingredients of the ISTs were partnerships and engagement among researchers, residents, essential care partners (ECPs), staff and knowledge users with decision-making authority within LTC homes, targeted funding and contribution to a Common Measurement Framework (CMF) project (Hardy et al. 2022). The CMF results, to be published in the future, aim to inform a collective understanding of the enablers of and barriers to implementation success across homes.

### Box 1. Six key promising practice and policy areas

- *Prevention:* Implementing strong infection prevention and control protocols to prevent and mitigate outbreaks.
- *Preparation:* Ensuring that protocols are in place to respond to COVID-19 outbreaks.
- *People in the workforce:* Supporting staff to provide the best quality of care to residents.
- *Pandemic response and surge capacity:* Ensuring that appropriate measures are in place to provide surge capacity and reduce virus spread in the case of an outbreak.
- *Plan for COVID-19 and non-COVID-19 care:* Ensuring that residents have access to person-centred, integrated care to meet their unique health needs.
- *Presence of family and essential care partners:* Ensuring that homes recognize and support family caregivers as essential partners in care, policy and practice, including during outbreaks.

Overall, this special issue shares key evidence and implications stemming from the work of the ISTs in the areas of family presence, people in the workforce and planning for COVID-19 and non-COVID-19 care. The special issue also

includes papers featuring the voices of ECPs and partnering LTC homes, as well as a paper by Samir Sinha, who led one of the ISTs and is leading the development of the new national LTC standards (Sinha 2022). In this final response paper, we reflect on their contributions and the next steps for LTC research and transformation in Canada.

## What We Heard

### COVID-19 and non-COVID-19 care

True person-centred care is the gold standard, whether in a pandemic context or not. Three ISTs outlined their work in advancing person-centred care in LTC, including the implementation of a Dementia Isolation Toolkit, preventing avoidable emergency department transfers of LTC home residents via an integrated virtual care model and a tool to assess palliative care needs (Hsu et al. 2022).

The authors emphasized that solutions designed to support person-centred care in LTC must be flexible and adaptable to the environment (Hsu et al. 2022). While historic challenges faced across the sector are acknowledged – including low staffing levels, time constraints, cost barriers, educational gaps and lack of teamwork and management support – partnership with research teams was identified as a notable strategy to accelerate the development and implementation of interventions that address person-centred COVID-19 and non-COVID-19 care.

### People in the workforce

Supporting the healthcare workforce has been a critical challenge since the onset of the COVID-19 pandemic, with extraordinary demands and staffing issues leading to the potential for long-lasting consequences (Tardif et al. 2022).

Six ISTs came together to share key findings and takeaways regarding projects related to the LTC workforce (Glowinski et al. 2022). The authors reiterated prominent issues faced by overburdened LTC staff, including low wages, burnout, moral distress, lack of access to mental health services and job precarity – all compounded by the fact that a high proportion of the LTC workforce includes many racialized immigrant women facing or at risk for conditions of vulnerability stemming from the social and structural determinants of health.

Very real and severe consequences of understaffing were urgently noted in Glowinski et al.'s (2022) paper, resulting in staff burnout and decrease in the quality of care. In addition, the implementation of policies designed to prevent further spread of disease, such as single-site employment, brought unintended consequences and exacerbated staffing burdens. Importantly, excessive workloads and lack of time were barriers to staff engaging in the research projects.

The authors emphasized the need for appropriate resourcing to alleviate workload and stress, strengthen the sector and ensure that improvement interventions such as those studied by the ISTs can be successful and sustainable.

### Long-term care home partners

Two Ontario-based LTC homes (peopleCare and Perley Health) that participated in the IST initiative also shared their perspectives and reflections on engagement with the research teams (Campbell et al. 2022). Both were well positioned to participate in this initiative, given the successes achieved in their early pandemic response. The goal of their participation was to not only build capacity within their own homes but also generate evidence by implementing and evaluating practical solutions that could be shared across the LTC sector to mitigate future outbreaks and strengthen pandemic preparedness, overall. According to Perley Health, “There was a collective understanding that this research project was contributing more toward solutions that everyone wants for LTC ... generat[ing] energy and enthusiasm to continue with future research and implementation” (Campbell et al. 2022: 36).

Other key themes identified by the LTC homes include the importance of ECPs in LTC (as core and important members of the resident’s care team); prioritization of person-centred care; preparation as a key for success; the criticality of communication (with both families and staff) in a pandemic context and utilizing new and creative approaches to address communication gaps; designing interventions to fit within existing workflows; leveraging research to understand what works; and spreading and scaling learnings to other homes and contexts.

The commitment that exists within these LTC homes and many others across the country to partner with residents, families, ECPs and researchers further bolsters the opportunities that exist to improve the LTC care system, together. Overall, we heard that research is fundamental to the future of LTC and we are encouraged by this sentiment – reinforcing continued and strong connections between academia and care delivery.

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**... equity and inclusion** must be a central consideration so that all residents are able to access and meaningfully engage with innovations brought forward.

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### Family presence

Family presence was a prominent issue during the pandemic, particularly when visitor restrictions were enacted. Eight ISTs that focused on the promising practice involving the presence of family and essential care partners came together to identify

key evidence, common themes and lessons learned across their projects (Gallant et al. 2022).

The teams concluded that the establishment of strong partnerships with family caregivers and residents, inclusive and patient-centred approaches to care, digital innovations and continued integration of research and evaluation within the LTC sector to promote evidence-informed decision making are key strategies for improving family presence and, ultimately, resident outcomes.

Importantly, we heard that equity and inclusion must be a central consideration so that all residents are able to access and meaningfully engage with innovations brought forward. We also heard that the greatest barriers to accessible and inclusive family visitation policies are a lack of staffing and physical infrastructure, speaking to the need for appropriate resourcing in the LTC sector.

### Essential care partners

The literature supports the involvement of ECPs as key to quality of care and quality of life (HEC 2020). Notably, the past two years have invigorated and re-enforced the critical role they play in LTC. We heard from three ECPs about their experiences broadly in LTC throughout the pandemic, as well as in engaging with ISTs (Johnston et al. 2022). As shared by Johnston et al. (2022): “There is power in involving family members in end-of-life care, which adds layers of dignity, flexibility and compassion to make an LTC home feel like a home” (p. 51).

The ECPs highlighted the toll that the continuously changing COVID-19 context and LTC visitor restrictions had on them, their loved ones and the staff. Barriers and facilitators to ECP involvement were also emphasized, including adaptive and flexible thinking by LTC homes that allowed for continued communication channels when family members were not able to visit. Yet, inconsistent messaging and technology challenges (or lack of access to technology altogether) created difficulty.

Praise for the LTC workforce was ample, with the ECPs emphasizing their resilience throughout this trying time. In addition, the ECPs stressed the need for more staff who are adequately prepared and equipped with the skill set and characteristics required to meet complex care needs with a person-centred approach.

By integrating care partners into research teams, their experiences, knowledge and expertise were incorporated into the research program, thereby creating “more robust, meaningful and impactful” work (Johnston et al. 2022: 51–52). As one ECP wrote, involvement in the research process provided the opportunity to address real issues that they were familiar with through their lived experience (Johnston et al.

2022). The ECPs concluded by stating that “[a]lthough our experiences are unique, our goal is the same. We must all find ways to walk the talk on person-centred care to ensure that every resident in LTC receives safe and high-quality care based on their individual needs” (Johnston et al. 2022: 52).

We see the cruciality of ECP involvement as a strong and key takeaway of the broader Strengthening Pandemic Preparedness in Long-Term Care initiative. Furthermore, as the system looks to improve the quality of care and quality of life in LTC, meaningful engagement and partnership with residents and their ECPs must be a priority.

### **Improving the quality of care and quality of life in long-term care: Development of Canadian national standards**

Samir Sinha, lead researcher for an IST and chair of the Health Standards Organization’s National Long-Term Care Service Standards Technical Committee, reflected on the importance of the new national standards and their potential for impact (Sinha 2022). According to Sinha, the standards have the potential to indicate the direction in which Canada needs to move in order to provide high-quality, safe and resident-centred care, where the residents come first in all facets of care planning and delivery in LTC homes, regardless of their size, location or organizational structure.

Moreover, the standards have the potential to make a transformative impact by forming the basis of legislation, policy, governance and quality improvement efforts. He emphasized that there is a critical role for research in the implementation and evaluation of the standards, noting that “[r]esearch and improvement initiatives are a critical way to help us better understand what is required to provide safe, reliable and high-quality LTC” (Sinha 2022: 57).

Overall, more than 20,000 Canadians were engaged in the process to create the new standards, reflecting the committee’s underlying and fundamental commitment to transform toward resident-centred LTC.

### **Next Steps for Evidence-Informed Long-Term Care Pandemic Preparedness in Canada**

Overall, five key themes emerged from the ISTs and the evidence presented in this special issue.

- *Person-centred care* (also referred to as patient- or resident-centred care across papers) is a must in all contexts and settings and should be foundational to future work in the sector.
- *ECPs* are critical. They must be meaningfully engaged as care partners and have a seat at the table. They have invaluable knowledge and insight that must be considered and

reflected in intervention development and implementation.

- *Clear, consistent and reciprocal communication* must be maintained between residents, family members and other ECPs and staff during a pandemic and leveraging technology can help in doing so.
- *Supporting people who work in LTC* is essential and requires urgent attention, including strengthening competencies and capacities to meet resident needs and ensuring appropriate supports, working conditions and staffing levels.
- *Research* – in partnership with LTC homes, residents and ECPs – is an important lever to support the implementation of evidence-informed interventions and, ultimately, better care, quality of life and health outcomes.

The LTC sector faced long-standing challenges prior to the COVID-19 pandemic, and the challenges that the sector continues to face are profound. LTC was disproportionately vulnerable to the pandemic and disproportionately in need of focused attention and resources to respond, recover and renew. Despite their challenges, the research and the experiences that have been shared with us through this work highlight the incredible resilience of the people who work, live at or provide care in these settings and their commitment to pushing forward to a future where high-quality care and quality of life are prioritized.

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**... the research** and the experiences that have been shared with us through this work highlight the incredible resilience of the people who work, live at or provide care in these settings ...

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The Strengthening Pandemic Preparedness in Long-Term Care initiative was made stronger with collective partnerships and the union of quality improvement with implementation science. This initiative generated momentum across the sector to think about sustainable solutions for LTC system transformation. To address long-standing challenges and renew a sector that cares for some of our most vulnerable, the ISTs note that much more will be needed – including investment in staffing and infrastructure; design and implementation of national standards that support resident-focused quality of care and quality of life; long-term and sustained investment in data and research that supports the continued building of an LTC learning health system in Canada; and successful spread, scale and implementation of promising, evidence-informed policies and interventions. This initiative also generated momentum to think about the power and promise of research-based

investment in LTC. The ISTs involved co-design approaches, partnerships between researchers and LTC homes, essential caregivers and the expertise of implementation science. Opportunities for future investment in LTC include embedding research capacity directly within LTC homes (aligning research with the real-time operational needs of the health system), capacity development in the science of implementation (what works, for whom and in what contexts?) and spread and scale.

### Partnering for Collective Impact

We would be remiss if we did not highlight the pan-Canadian partnership that supported the Strengthening Pandemic Preparedness in Long-Term Care initiative as we see this as a model to learn from and replicate in the future (HEC 2022b). Altogether, HEC, CIHR, four additional funding partners and 91 LTC and retirement homes across Canada partnered in this research program to support the rapid implementation and evaluation of interventions that aimed to keep residents, families, caregivers and staff safe from COVID-19 – an investment of \$3.4 million that will undoubtedly see long-lasting returns.

The most notable outcomes of this innovative partnership model include:

- leveraging cross-organizational work and resources to rapidly respond to the LTC sector's needs;
- building LTC system capacity to rapidly improve care during and beyond the COVID-19 pandemic;

- creating a structure to achieve shared research, knowledge translation, implementation and sustainability objectives; and
- strengthening a community with a shared commitment to and expertise in LTC improvement.

The partnership also resulted in new opportunities that may not have occurred otherwise. It built relationships among researchers and LTC homes, created learning and networking opportunities and allowed for the rapid mobilization of knowledge and resources to a sector where this was previously lacking. Even more broadly, the partnership successfully demonstrated the value of marrying quality improvement initiatives with implementation science expertise for greater system impact.

Along this journey, we felt honoured and humbled to hear from staff, residents, families and ECPs about their experiences both before and during the COVID-19 pandemic. We have heard experiences across the continuum of care from those who experienced substantial and irrevocable harm, as well as those who have found new ways to partner, collaborate and innovate. Across Canada, the pandemic has affected each one of us differently. The profound impact it had on LTC residents, families, ECPs and staff cannot be understated, and we are grateful that in the midst of one of the largest global crises, these individuals engaged so thoughtfully in the work of improving LTC systems. We were inspired by the scale of engagement, impact and passion that we saw across those participating.

We hope that this initiative can be a source of learning and inspiration for the future, wherein organizational partnerships are established as an effective way to improve the quality, safety and outcomes of care with evidence.

### Disclaimer

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This work is supported by the Canadian Institutes of Health Research (CIHR). At CIHR, we know that research has the power to change lives. As Canada's health research investment agency, we collaborate with partners and researchers to support the discoveries and innovations that improve our health and strengthen our healthcare system.

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This issue of *Healthcare Quarterly* was made possible through the support of:

