

# Tailoring Your Knowledge Translation Strategies for Your Intended Users

KTDRR's 2023 Virtual KT Conference

November 6, 8, and 9

Center on  
**KNOWLEDGE TRANSLATION FOR  
DISABILITY & REHABILITATION RESEARCH**

Working With Community Partners and Ensuring  
Meaningful Results

# **Lessons Learned from a Two-Year Pan-Canadian Academic-Community Partnership Project**

Ana Paula Salazar, PhD

Center on  
**KNOWLEDGE TRANSLATION FOR  
DISABILITY & REHABILITATION RESEARCH**

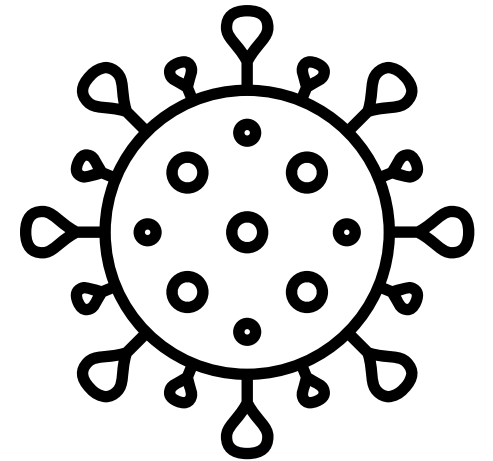
# Overview

- Community-based participatory research
- Brain injury pandemic preparedness (BIPP) project
  - Outcomes of the project
  - Challenges and successes
  - Lessons learned

# Community-Based Participatory Research

- Uses a **collaborative approach**.
- **Involves community and academic partners equally** in the research process.
- Has research topics that are **relevant to the community**.
- **Combines knowledge with action** and achieves social change to improve health outcomes and **eliminate health disparities**.
- Brings a **diversity of experiences and perspectives** that are needed to create evidence and **develop appropriate approaches** when **addressing the needs and well-being of vulnerable populations**.

# How did the BIPP project start, and what is it about?





**Carolina Bottari, PhD**  
Principal Investigator  
Associate Professor  
Université de Montréal



**Lisa Engel, PhD**  
Co-Principal Investigator  
Assistant Professor  
University of Manitoba



**Michelle McDonald**  
Co-Principal Investigator  
Executive Director  
Brain Injury Canada



**Ashley Brosda**  
Executive Director  
Brain Care Centre



**Monique Gignac, PhD**  
Full Professor  
University of Toronto



**Cassandra Stockley**  
Coordinator of Programs  
NL Brain Injury Association



**Gladys Hrabi**  
Executive Director  
MB Brain Injury Association



**Glenda James**  
Executive Director  
SK Brain Injury Association



**Carolyn Lemsy, PhD**  
Clinical Director  
CHIRS of Toronto



**Emily Nalder, PhD**  
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**Shlomit Rotenberg, PhD**  
Assistant Professor  
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**Julia Schmidt, PhD**  
Assistant Professor  
University of BC



**Bonnie Swaine, PhD**  
Full Professor  
Université de Montréal



**Marjolaine Tapin**  
Executive Director  
Connexion TCC- QC



**Ruth Wilcock**  
Executive Director  
ON Brain Injury Association



**Sareh Zarshenas, PhD**  
Scientific Research  
Associate  
University of Toronto



**Ana Paula Salazar, PhD**  
Postdoctoral Researcher  
Université de Montréal



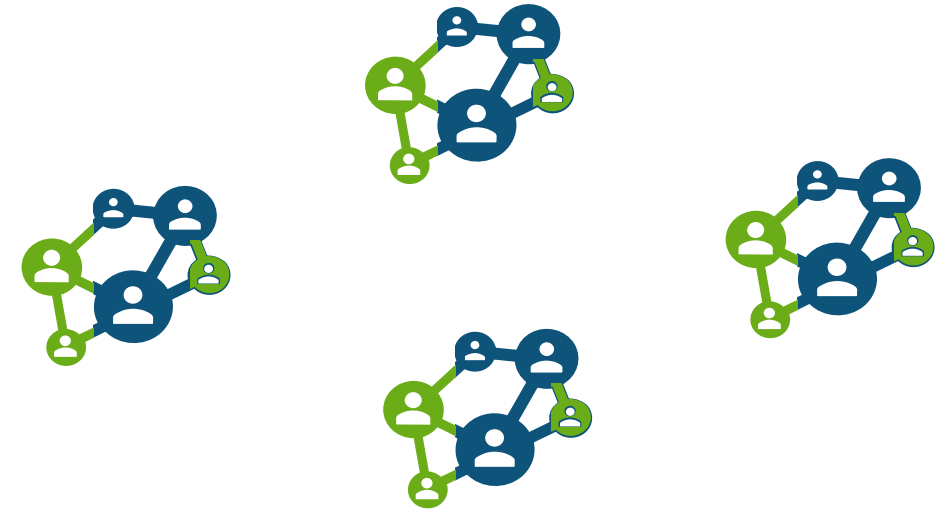
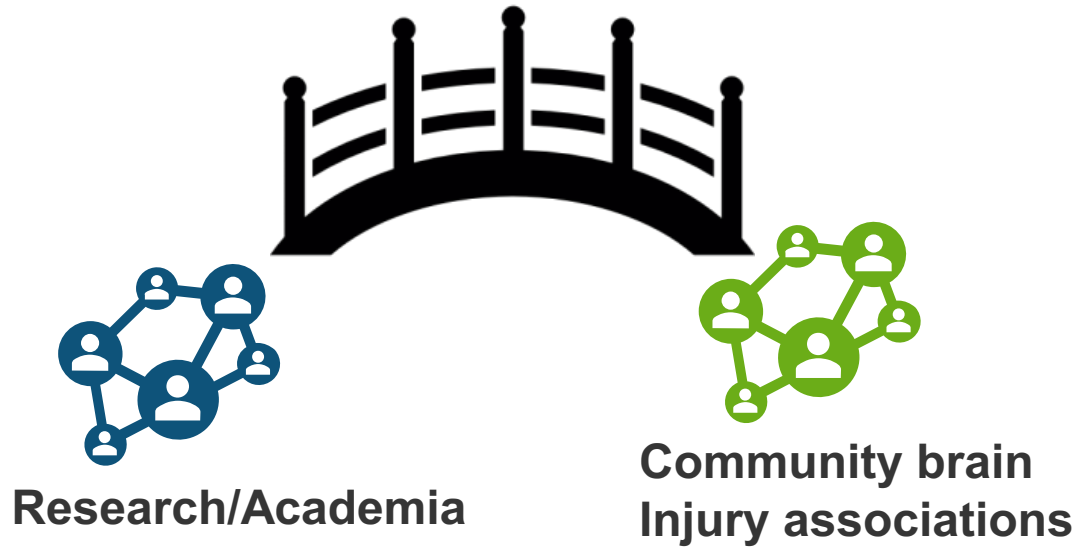
**Sophie Lecours, PhD**  
Research Assistant  
IURDPM

## BIPP TEAM

# Brain Injury Pandemic Preparedness Project



# BIPP Project – Key Steps



- 1) Identifying & prioritizing (issues, gaps)
- 2) Research question and design/funding plans
- 3) Project management/development

- 4) Data Collection
- 5) Data Analysis & Interpretation of Findings
- 6) Dissemination & Sharing



# Brain Injury Pandemic Preparedness (BIPP) project: Optimizing Community Strategies

- Purpose/Aim:
  - To optimize community brain injury response in the context of COVID-19 and future public health crises.
- Objectives:
  - To explore the effects of the COVID-19 pandemic on brain injury association services.
  - To increase networking among associations.
  - To develop resources for future health crises.

# BIPP Project – 2 Years

## Online survey

- 45 participants
- 29 questions

## Co-creation

- 31 participants
- 2 focus groups
- 2 town halls

# Outcomes

**Creating Useful &  
Impactful Resources**

Strengthening Networks

Lessons Learned

# Knowledge Mobilization Documents

**SURVEY STUDY**

## BRAIN INJURY PANDEMIC PREPAREDNESS

A pan-Canadian community-partnership research project documenting community brain injury associations' experiences during the COVID-19 pandemic

**METHODS**

- Online survey (January 2022, English-French).
- 45 brain injury associations' key representatives from across Canada responded to 31 open- and closed-ended questions about the impacts of the COVID-19 pandemic.
- Topics included: association sustainability, meeting clients' needs, and public health and safety.

Location of participating brain injury associations

**RESULTS**

**ASSOCIATION SUSTAINABILITY**

- 76% reported reductions in financial resources.
- 67% received pandemic-related funding but still struggled.
- 31% received sufficient funds to address additional COVID-19 related expenses.

**MEETING THE NEEDS OF CLIENTS**

- 62% reported increased demand for programs and services.
- 91% offered remote services.
- 93% innovated or created new programs/services to keep all programming available.

**PUBLIC HEALTH & SAFETY**

- 91% reported difficulties for their clients in understanding and/or following public health guidelines.
- 93% provided services and information to demystify COVID-19 symptoms and vaccines and to explain new protocols for in-person programs.

**CONCLUSION**

The COVID-19 pandemic challenged brain injury associations across Canada to remain sustainable and meet the needs of their clients while complying with public health measures.

The vital work performed by brain injury associations through a global crisis should be acknowledged and supported by policy makers and health researchers.

**Brain Injury Pandemic Preparedness Project - bipp.project@gmail.com**

Co-Primary Investigators: C. Battari (PhD, UdeMontreal), L. Engel (PhD, UofManitoba), M. McDonald (Brain Injury Canada)  
 Creators: AP Salazar (PhD, UdeMontreal), S. Lecours (PhD, IURDPM)

Funded by the Canadian Institutes of Health and Research (CIHR)  
 CIHR Ethics approval - #2022-1424; Document available in December 2022

**SURVEY STUDY**

## BRAIN INJURY PANDEMIC PREPAREDNESS

A pan-Canadian community-partnership research project documenting community brain injury associations' experiences during the COVID-19 pandemic

**SURVEY STUDY**

## BRAIN INJURY PANDEMIC PREPAREDNESS

A pan-Canadian community-partnership research project documenting community brain injury associations' experiences during the COVID-19 pandemic

**BACKGROUND**

Community brain injury associations are essential to the health and well-being of thousands of Canadians living with the effects of a chronic brain injury. However, these associations are largely underfunded and under-recognized in the brain injury care continuum. Since the onset of the COVID-19 pandemic, these associations have experienced significant challenges in ensuring services/programs continuity for the people they serve.

**METHODS**

- Online survey (January 2022, English-French).
- 45 brain injury associations' key representatives across Canada responded to 31 multiple choice and open-ended questions about the impacts of the COVID-19 pandemic.
- Topics included: association sustainability, meeting clients' needs, and public health and safety.

**KEY FINDINGS**

ASSOCIATION SUSTAINABILITY	MEETING CLIENTS' NEEDS	PUBLIC HEALTH & SAFETY
The COVID-19 pandemic created a challenging environment for brain injury associations as it disrupted the provision of services/programs and affected their financial sustainability.	According to associations, brain injury survivors experienced diverse psychosocial challenges during the pandemic, especially social isolation, loneliness, and anxiety, as well as online access challenges.	Given that COVID-19 related information and public health guidelines were constantly evolving, clients experienced difficulties understanding and following sanitary measures.
<ul style="list-style-type: none"> <li>→ 67% of associations received pandemic-related aids from the Canadian government, but still struggled with sustainability.</li> <li>→ 76% of associations lost funding or financial resources during the pandemic.</li> <li>→ 31% of associations received sufficient funds to address additional COVID-19 related expenses.</li> </ul>	<ul style="list-style-type: none"> <li>→ 62% of associations reported an increase in demand for programs and services.</li> <li>→ 93% of associations innovated or created new programs and services to keep all programming available.</li> <li>→ 91% of associations offered remote services. The challenges of the digital divide were mainly addressed by providing clients with devices and technology training.</li> </ul>	<ul style="list-style-type: none"> <li>→ 91% of brain injury associations reported difficulties for clients in understanding and/or following public health guidelines.</li> <li>→ 93% of associations provided their clients with tailored information (plain language and accessible format) to improve their understanding and compliance with public health measures.</li> </ul>

**CONCLUSION**

Community brain injury associations across Canada adapted their programs and services in a considerable way to respond to the increasing psychosocial and safety needs of their clients during the COVID-19 pandemic. The crisis, however, added further challenges to their financial sustainability.

To ensure community brain injury associations' survival, it is essential to recognize and better support their indispensable work on the brain injury continuum.

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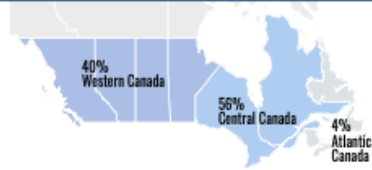
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# Knowledge Mobilization Documents (cont'd)

## BRAIN INJURY PANDEMIC PREPAREDNESS

A pan-Canadian community-partnership research project documenting community brain injury associations' experiences during the COVID-19 pandemic

Representatives from 31 Canadian brain injury community associations participated in successive online focus groups to share their associations' challenges and adaptations during the first and second year of the pandemic.



Location of participating associations

## Association Sustainability during the COVID-19 pandemic

Year 1

Year 2

Year 3 and beyond

- Lack of financial resources and new COVID-related expenses
- Disruption in services
- Staff mental health challenges - difficulties with remote work

- Financial aid stopping and virtual fatigue for fundraising
- Increased administrative burden
- Hybrid services: additional logistics and workload

### Important Steps to Future Readiness

- Building long-term sustainable funding
- Creating a new business partnership model
- Networking among brain injury associations
- Recognizing brain injury associations as essential services providers
- Taking care of staff well-being
- Having a national brain injury strategy

### Crisis Intervention

- Applying for COVID-related grants and adapting fundraisings
- Pivoting services to online
- Starting to deliver essential services
- Supporting staff well-being

### Strategic Planning

- Reducing expenses - sharing spaces
- Increasing partnerships
- Expanding brain injury associations' mission to include essential services delivery
- Continuing to support staff

"If you need a mental health day, you take a mental health day. If you need a mental health afternoon, you take one if that's what you need to do to be able to do your job." -- Participant 1--

"September 2021 was when we switched back and [started] doing a lot of in person again. So, there was a lot of planning happening through the summer in terms of logistics, managing the schedule, getting volunteers back, and trained..." -- Participant 17 --

"...I think that every person who works in brain injury across the country agrees that we should have a brain injury strategy." -- Participant 3 --

2020

2021

2022 ...



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Location of participating associations

## Public Health Safety during the COVID-19 pandemic

Year 1

Year 2

Year 3 and beyond

- Challenges in understanding and following public health guidelines - Complex guidelines
- Lack of disability-inclusive communications
- Confusion about brain injury associations being essential or not (lack of recognition)

- Inconsistency and constant changes in guidelines
- Confusing and misinformation about vaccines
- Vaccination hesitancy
- Clients experiencing anxiety, fear, confusion, and/or paranoia around vaccination

### Important Steps to Future Readiness

- Disability-inclusive preparedness
- Better public health resources to support the work of community associations;
- Accessible and accurate public health information
- Recognition of brain injury associations as essential service providers within the continuum of care

### Crisis Intervention

- Disseminating trustworthy information about COVID
- Simplifying information (adapting guidelines to plain language)
- Providing clients with reminders

### Strategic Planning

- Providing education about vaccination
- Addressing misinformation about vaccines & helping clients with the vaccination process
- Offering hybrid services to include everyone

"It was so confusing, the information that we were receiving from the government. We're on, we're off, we're moving ahead, we're stepping back, so that really confused a lot of our clients." --Participant 10--

"...I would just provide [clients] with reminders. I would remind them that you have to wear a mask, there's going to be social distancing [...] It was really hard for them because they just kept forgetting." --Participant 7--

"...I guess every organization should be essential for their clients [...] no matter what." --Participant 6--

2020

2021

2022 ...



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Location of participating associations

## Meeting the needs of clients during the COVID-19 pandemic

Year 1

Year 2

Year 3 and beyond

- Isolation & loneliness
- Fear & anxiety related to COVID-19
- Basic needs insecurities
- Digital divide

- Increased isolation & suicidal ideation
- Specific fear about vaccination
- Difficulty maintaining healthy habits
- Persistent digital divide

### Crisis Intervention

- Reaching out to members
- Offering more individualized services
- Providing remote services
- Meeting in person for urgent needs only
- Providing food assistance
- Helping members to use technology

### Strategic Planning

- Offering new support services targeted to sub-groups (e.g., young men, women, seniors in long-term care, etc.)
- Creating new social, recreational, and educational activities (hybrid mode)
- Opening in-person meetings to all members
- Focusing on healthy lifestyle habits
- Continuing to help members use technology

### Important Steps to Future Readiness

- Reinforcing preparedness strategies specifically tailored to the unique needs and challenges faced by individuals with brain injury
- Creating a solid foundation for online services to facilitate member access to online resources

"We had staff ordering groceries and having it delivered to our members... We had staff picking up and dropping off documents to doctors and lawyers' offices, really taking the time to identify what the priority was and making sure those basic needs were met first..." --Participant 1--

"We were finding that some of our younger clients that are more severely brain injured who lived in long-term care were probably the most isolated and so we did start a group that was targeted for those sorts of younger, severe guys that were living in long-term care." --Participant 17--

"...basic internet should be a basic need." --Participant 1--

2020

2021

2022 ...



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# Knowledge Mobilization Documents (cont'd)

CONNEXION MAGAZINE - 1<sup>er</sup> numéro

## PAROLES D'EXPERTES STRATÉGIES COMMUNAUTAIRES EN TEMPS DE PANDÉMIE

Un projet pancanadien pour soutenir les personnes vivant avec un traumatisme crâniocérébral et leurs proches aidants.

**Sophie Lecours**

Assistante de recherche (IURDPM)

**Ana Paula Da Silva Salazar**

Stagiaire postdoctorale (École de réadaptation de l'UdeM)

**Lisa Engel**

Professeure adjointe (Université du Manitoba)

**Marjolaine Tapin**

Directrice générale (Connexion TCC/QC)

**Michelle McDonald**

Directrice générale (Lésion cérébrale Canada)

**Carolina Bottari**

Professeure agrégée (UdeM)

Cela fait déjà deux ans que la pandémie de la COVID-19 a bouleversé nos vies. Nous sommes nombreux à vouloir la mettre derrière nous, voire l'effacer de notre mémoire! L'Organisation mondiale de la santé nous met toutefois en garde de la faire: pour rendre le monde de demain plus sûr, il ne faut pas oublier l'ampleur des conséquences de cette crise sanitaire.

Les associations communautaires de personnes vivant avec un traumatisme crâniocérébral (TCC) ont été des témoins de première ligne des répercussions de la pandémie sur les personnes desservies et elles ont développé diverses stratégies pour leur venir en aide. Pour ne rien oublier, plusieurs d'entre elles collaborent à un projet de recherche permettant de tirer des leçons de la pandémie.

### IMPACTS DE LA PANDÉMIE SUR LES PERSONNES VIVANT AVEC UN TCC

La COVID-19 a frappé inégalement les populations, notamment celles qui nécessitent régulièrement des soins ou du soutien et celles pour qui les mesures sanitaires ont entraîné des défis supplémentaires. Par exemple, plusieurs ont vécu des coupures de services et d'autres ont éprouvé des difficultés à comprendre certaines directives comme la distanciation sociale.

En tant que personnes qui avez subi un TCC, peut-être avez-vous aussi été davantage touchés par la pandémie? Si oui, vous n'étiez pas seuls. En effet, bon nombre de personnes présentant un TCC ont trouvé plus difficile de faire face à la pandémie en raison de leurs atteintes cérébrales. Les problèmes de santé mentale et d'isolement social étaient perçus comme les défis majeurs.

#### Un financement à la hauteur des objectifs

L'équipe peut se féliciter de l'octroi d'un financement pour deux projets distincts, l'un financé par l'Université de Montréal et l'autre par les Instituts de recherche en santé du Canada. Une première pour le secteur des associations communautaires de personnes vivant avec un TCC!



### ORIGINE D'UN PROJET COLLABORATIF PANCANADIEN



**Lisa Engel**

Professeure adjointe (Université du Manitoba)

**Carolina Bottari**

Professeure agrégée (UdeM)

**Michelle McDonald**

Directrice générale (Lésion cérébrale Canada)

Bien au fait de cette dure réalité, Carolina Bottari, Lisa Engel et Michelle McDonald ont voulu venir en aide aux personnes vivant avec un TCC et à leurs proches aidants. Elles ont ainsi jeté les bases d'un vaste projet pour:

Documenter les défis rencontrés par les associations canadiennes et les adaptations de services réalisées afin de minimiser les impacts de la pandémie sur les personnes desservies;

Créer des liens entre les associations par le partage et l'entraide;

Développer un outil de référence pour garantir leur préparation face à la pandémie de la COVID-19 et au-delà.

Rappelons qu'au Canada, environ 70 associations communautaires jouent un rôle central dans l'éducation, la défense des droits et le bien-être de dizaines de milliers de personnes ayant subi un TCC ou autres lésions cérébrales acquises et de leurs proches aidants.

### GRANDE MOBILISATION DES ASSOCIATIONS COMMUNAUTAIRES

D'abord, il ressort du sondage qu'une majorité d'associations (62%; 28/45) a fait face à une demande de services accrue. Ensuite, les résultats signalent que les personnes desservies ont été confrontées à des réalités difficiles durant la pandémie (voir fig.1).

Devant ce constat, les associations se sont vite adaptées pour maintenir leurs services et répondre aux nouveaux besoins. Voici des exemples d'adaptation rapportés lors des groupes de discussion:

• LE PREMIER RÉFLEXE DE BEAUCOUP D'ASSOCIATIONS A ÉTÉ D'APPELER LES PERSONNES DESSERVIES POUR IDENTIFIER LEURS BESOINS EN CONTEXTE DE CRISE.

#### Tournées d'appels

«[...] nous avons divisé notre liste d'environ 300 membres dans la province et nous avons appelé tous nos membres pour savoir s'ils avaient accès à Internet? comment les contacter? de quoi avaient-ils besoin? [...]»

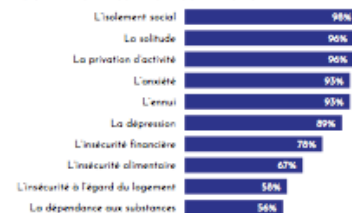
• EN SUITE, LES ASSOCIATIONS ONT RÉORGANISÉ LEURS SERVICES RÉGULIÈREMENT À DISTANCE:

- Activités en ligne: conférences, soutien individuel et de groupe;
- Appels téléphoniques: information, référence, appels d'amitié;
- Rencontres extérieures/intérieures dans le respect des mesures sanitaires.

#### Soutien en ligne

«[nous] avons commencé à organiser des groupes de soutien par Zoom qui perdurent encore aujourd'hui. Cela a vraiment été un grand succès, cela a permis aux personnes qui se trouvaient dans de plus petites communautés de se joindre à nous [...]»

FIG. 1 POURCENTAGE D'ASSOCIATIONS AYANT PERÇU LES RÉALITÉS SUIVANTES CHEZ LES PERSONNES DESSERVIES DURANT LA PANDÉMIE



#### Sources des données

Sondage réalisé en ligne en janvier 2022 auprès de 45 associations communautaires canadiennes.

Groupes de discussion menés sur Zoom avec 7 directrices générales d'associations communautaires canadiennes entre octobre 2021 et janvier 2022.

• AVEC LA CRÉATIVITÉ DE LEURS ÉQUIPES, LES ASSOCIATIONS ONT INNOVÉ POUR RÉPONDRE AUX NOUVEAUX BESOINS:

- Diversification des moyens de communication: envois massifs de textos, téléconférences, réseaux sociaux, infolettres, appels;
- Accès aux technologies: formations, manuels d'utilisation;
- Systèmes de livraison et visites de balcon.

#### Programme de livraison à domicile

«[...] nous avons organisé notre personnel et nos bénévoles pour effectuer une livraison hebdomadaire à toutes les personnes desservies qui le souhaitent et nous avons commencé à créer de petits colis de soins à déposer; la première chose que nous avons déposée était des masques [confectionnés] par l'un de nos membres [...]»

• ENFIN, LES ASSOCIATIONS ONT VULGARISÉ LES DIRECTIVES DE SANTÉ PUBLIQUE. RAPPELONS QUE L'INFORMATION VENAIT DE PLUSIEURS SOURCES, QU'ELLE ÉTAIT CHANGEANTE ET PARFOIS CONTRADICTOIRE! EN S'APPUYANT SUR LEUR EXPERTISE EN ÉDUCATION POPULAIRE, LES ASSOCIATIONS ONT RÉUSSI À DIFFUSER DE L'INFORMATION SIMPLIFIÉE ET ADAPTÉE:

- Bulletins COVID en langage et format accessible;
- Rappels fréquents des consignes en vigueur;
- Sensibilisation à la vaccination.

### VERS DES STRATÉGIES COMMUNAUTAIRES OPTIMISÉES

À l'heure actuelle, le travail des associations communautaires de personnes présentant un TCC et leurs proches aidants est peu reconnu. Nos données montrent qu'il est absolument indispensable en temps de crise, alors que les personnes desservies font face à des défis supplémentaires. Saluons les initiatives remarquables des associations en réponse à la pandémie, avec toujours pour objectif premier de maintenir le lien avec les personnes desservies.

Presque à mi-chemin du projet, les associations vont bientôt collaborer au développement d'un outil de référence pour garantir leur préparation face aux futures crises de santé publique. Elles en ressortiront plus fortes et plus unies. À suivre!

Un grand merci à toutes les associations qui ont généreusement collaboré à ce projet.

# Scientific Papers

Accepted  
Original Research

**Impact of the COVID-19 pandemic on brain injury community associations across Canada: A cross-sectional survey study**

ON TIME

Ana Paula Salazar, Carolina Bottari, Sophie Lecours, Michelle McDonald, Monique A.M. Gignac, Bonnie Swaine, Julia Schmidt, Carolyn Lemsky, Ashley Brosda and Lisa Engel

**Handling Editor:**

Maximilian Pangratus de Courten



Frontiers in Public Health  
Public Health Policy

## INQUIRY

**Understanding the early impacts of the COVID-19 pandemic  
on brain injury associations across Canada: a qualitative  
study**

Ana Paula Salazar, Sophie Lecours, Lisa Engel, Monique A.M. Gignac, Shlomit Rotenberg,  
Sareh Zarshenas, Michelle McDonald, Carolina Bottari

# Outcomes

Creating Useful &  
Impactful Resources

Strengthening  
Networks

Lessons Learned





# CANADIAN BRAIN INJURY ASSOCIATION NETWORK

[www.cbian.ca](http://www.cbian.ca)



**About the BIPP  
Project**




**Tools and  
resources**



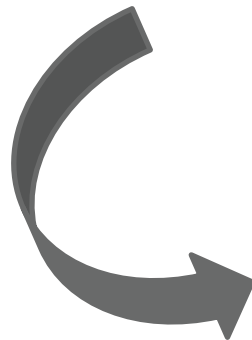
**Events Calendar**



**Networking with  
BIAs (Forum)**



**Find BIAs across  
Canada**



**Meeting the Needs of  
Clients**

Resources to help clients during a  
public health crisis.



**Public Health Safety**

Resources to keep staff and  
clients safe during a public health  
crisis.



**Sustainability of  
Association**

Resources to help sustain the  
association during a public health  
crisis.

# Outcomes

Creating Useful &  
Impactful Resources

Strengthening Networks

**Lessons Learned**

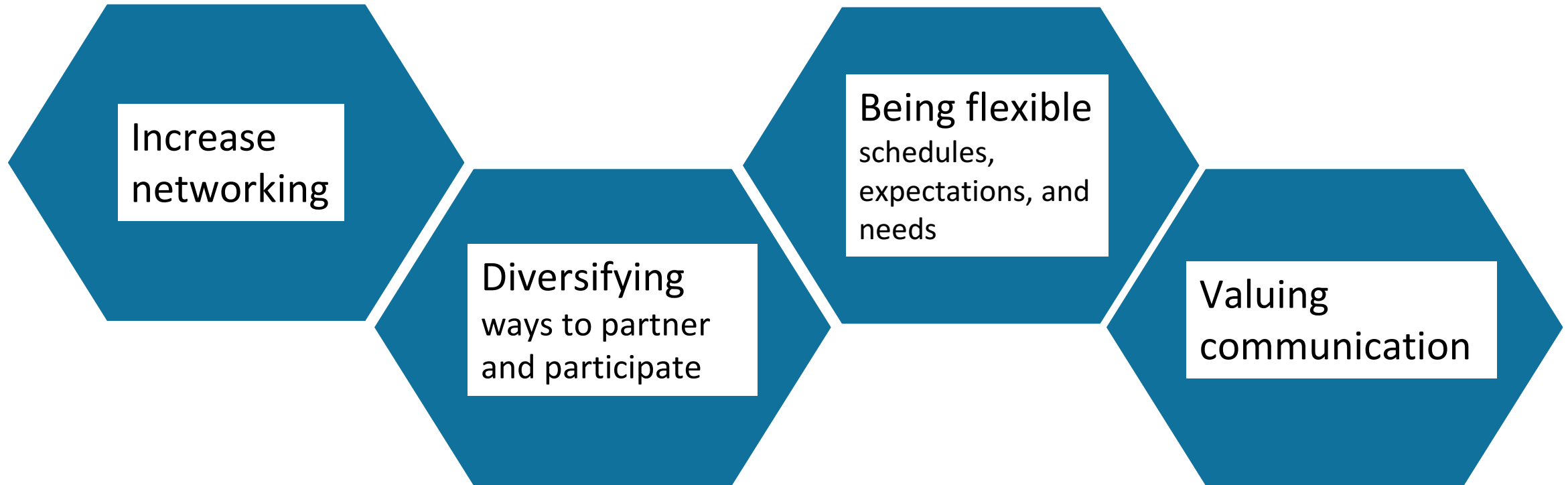
# Challenges and Successes

- Bilingual
- Online – PanCanadian

- COVID-19
- Research ethics delays
- Lay language
- Schedules

- Full engagement of researchers and community partners
- Frequent meetings with core team and full team
- Small committees
- Learn from each other
- Results – empowered BIAs

# Lessons Learned



“This project has brought BIAs together and served as a catalyst to move toward networking and resource sharing. Building a stronger network means a stronger voice, empowerment of associations and recognition of their work.”

*Michelle McDonald – Executive director*



**Michelle McDonald**  
Co-Principal Investigator  
Executive Director  
Brain Injury Canada

“... This project was very interesting. It filled me with energy to think that there’s more of a chance that [the research] will have an impact... That it’s more tangible than other research work that I do sometimes.”

*Shlomit Rotenberg – Associate professor*



**Shlomit Rotenberg, PhD**  
Assistant Professor  
University of Toronto

# Thank you!

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**Q&A**

 [www.ktdrr.org](http://www.ktdrr.org)

 [ktdrr@air.org](mailto:ktdrr@air.org)

 800.266.1832

Center on  
**KNOWLEDGE TRANSLATION FOR  
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