

DECEMBER 2021

Stakeholder Engagement in the CHILD-BRIGHT Network



Part 2

**Stakeholder engagement during the COVID-19
pandemic at the CHILD-BRIGHT Network**

Survey findings

Acknowledgment

We thank all CHILD-BRIGHT Network members who completed the survey and made this report possible.

We also gratefully acknowledge the valuable input provided by CHILD-BRIGHT's Citizen Engagement Council and Knowledge Translation Committee.

Research team

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Suggested citation: Gonzalez, M., Lalonde, C., Zerbo, A., Gavin, F., Weiss, J., & Majnemer, A. (2021). Stakeholder engagement during the COVID-19 pandemic at the CHILD-BRIGHT Network. Summative report submitted to CHILD-BRIGHT's Measuring Patient Engagement Working Group. For more information: admin@child-bright.ca

The **CHILD-BRIGHT Network** is an innovative pan-Canadian network that aims to improve life outcomes for children with brain-based developmental disabilities and their families. For more information: www.child-bright.ca

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Executive summary



“Having kids home from school was fairly draining, and much of my otherwise available mental resources and time became taxed, which made it harder to participate and keep up with meetings/communications.” — Patient-partner

“All project engagement has been negatively affected. Project recruitment, analysis, diagnosis and follow-up are all 6-12 months delayed.” — Researcher

“Engaging online has become a norm which allows for more connection and ability to engage with the Network as a whole. I am grateful for [an] increased number of online opportunities.” — Trainee

“I found myself distracted and preoccupied with other matters relating to my own and my family's health and well-being. I found myself overwhelmed with the amount of work on the committees in spite of the pandemic; it seemed to slow certain parts down or accelerate others.” — Network staff/Research Assistant



Over the last year and a half, the COVID-19 pandemic has had a significant impact on every aspect of life in unprecedented ways. To better understand the impact of the pandemic on the engagement experiences of CHILD-BRIGHT Network members, we developed a brief, online survey designed for this purpose and invited all Network members to complete it. The survey was active for six weeks (May 17, 2021 to June 30, 2021). Given the patient-oriented research mandate at CHILD-BRIGHT, we worked with patient-partners during each phase of this project: developing the survey, interpreting the results, identifying recommendations and dissemination strategies, and ensuring that the report is clear and understandable.

In this report, we shed light on the impact of the pandemic on the engagement experiences of CHILD-BRIGHT Network members (patient-partners, researchers, health care practitioners, funding partners, trainees, policy makers, research assistants, and Network staff). We also highlight recommendations that can be used to facilitate engagement during public health crises and next steps our Network will take as the pandemic continues.

Summary of key findings

A total of 97 Network members completed the survey: 31% were patient-partners, 24% were researchers, and the remaining respondents were Network staff, research assistants, health care practitioners, health system administrators, trainees, funding partners, or identified as “other” (stakeholders that do not identify in the above-listed groups).

1. Different stakeholder groups experienced similar impacts

Patient-partners, researchers, and other Network members (health care practitioners, health system professionals, health administrators, network staff, research assistant, trainee, and funding partners) experienced similar impacts. These ranged from negative (e.g., lack of face-to-face interaction), positive (e.g., more engagement with the Network via online activities), to little or no impact (e.g., for some members activities were mostly virtual prior to the pandemic).

2. Network members found it challenging to engage

All stakeholder groups (patient-partners, researchers, and other Network members) found it challenging to engage with projects, committees, and the Network as a whole. Feelings of being overwhelmed, worries about health, caregiving responsibilities, and limited time and resources for research and engagement were noted as impediments to engagement.

3. Online activities facilitated engagement

Online activities (e.g., newsletters, surveys, and virtual events such as meetings or webinars) helped members stay connected and were experienced positively.

Recommendations

We shared survey findings with members of CHILD-BRIGHT’s Citizen Engagement Council and Knowledge Translation Committee who proposed strategies to facilitate engagement during public health emergencies.

Suggestions included:

- Acknowledging the needs of, and providing support to, our families (e.g., giving information on self-management and self-care, empowering our patient-partners to help others by providing advice through group support),

-
- Acknowledging the needs of, and providing support to, our researchers (e.g., regular check-ins with project team members, taking into account the impact of the pandemic on various aspects of their lives),
 - Using different approaches and strategies to facilitate stakeholder engagement (e.g., using online platforms to meet with Network members) and to continue research (e.g., providing information on what to expect during a public health crisis, and how to shift focus of research in response to a pandemic).

Conclusions and next steps

Given the negative and positive impacts experienced by Network members, it is recommended that CHILD-BRIGHT provide multiple ways for stakeholders to engage with their teams (e.g., making use of both online and face-to-face opportunities). Incorporating the feedback provided by the Knowledge Translation Committee and Citizen Engagement Council can also mitigate some of the barriers to full engagement. Since the pandemic continues to evolve, lack of action on recommendations provided can aggravate negative impacts or lead to similar negative impacts in future widespread emergencies.

1. Introduction



1.1. Background

The COVID-19 pandemic has brought about disruption to all aspects of life. At CHILD-BRIGHT, we continue to adapt as best we can to the circumstances and continue to work with our stakeholders with the goals of:

1. Improving health care systems and practices
2. Ensuring better outcomes for children living with brain-based developmental disabilities and their families
3. Contributing to the patient engagement knowledge base.



As part of our patient engagement measurement strategies, we launched a short survey to better understand the engagement experiences of Network members (patient-partners, researchers, health care practitioners, funding partners, trainees, policy makers, research assistants, and Network staff) during the COVID-19 pandemic.

1.2. Survey purpose

The survey was designed to gather information about how COVID-19 has impacted the engagement of CHILD-BRIGHT members in:

1. Specific projects and committees
2. The Network as a whole (e.g., activities outside of roles in a project, committee, or program such as attending CHILD-BRIGHT events or participating in Network-wide interviews and surveys).

1.3. Importance of collecting this information

The information obtained through the survey:

1. Helped us gain a better understanding of the impact of COVID-19 on members' engagement and participation in Network activities in 2020-2021
2. Provided insights as to strategies that could be used by our Network (and other research networks) to facilitate engagement during public health emergencies.

2. Methods

2.1. Survey development and dissemination

We worked collaboratively with our patient-partners during each phase of this project: survey development (survey content, language, and format), interpretation of results, identification of recommendations and dissemination strategies, and report clarity and understandability.

We kept the survey short, using five questions to collect information about survey respondents and to gauge the impact of the pandemic on engagement with the Network and with projects and committees. The online survey was designed to take five to 10 minutes to complete and was available in both English and French (see Appendix A). The McGill University Health Centre Research Ethics Board approved the use of the survey.

A total of 357 Network members who are part of research project teams or Network committees were invited to complete the survey via REDCap (a web application for building online surveys), CHILD-BRIGHT's data repository, and by email invitation sent by CHILD-BRIGHT's Citizen Engagement program coordinator. Data was collected from May 17, 2021 to June 30, 2021 from a non-random convenience sample of self-identified network members.

We kept the survey short, using five questions to collect information about survey respondents.

2.2. Data validation and analysis

A total of 113 responses (32% response rate) were received and verified for invalid responses (incompletes). We used a descriptive approach to examine responses to closed-ended questions. Content analysis techniques (e.g., open coding and category identification and refinement) were used to examine responses to open-ended questions. The data was coded by one team member, reviewed for congruence of coding by another team member, and discrepancies were resolved through discussion.

113
responses

32%
response rate

A descriptive approach
and content analysis
techniques were used to
examine responses.



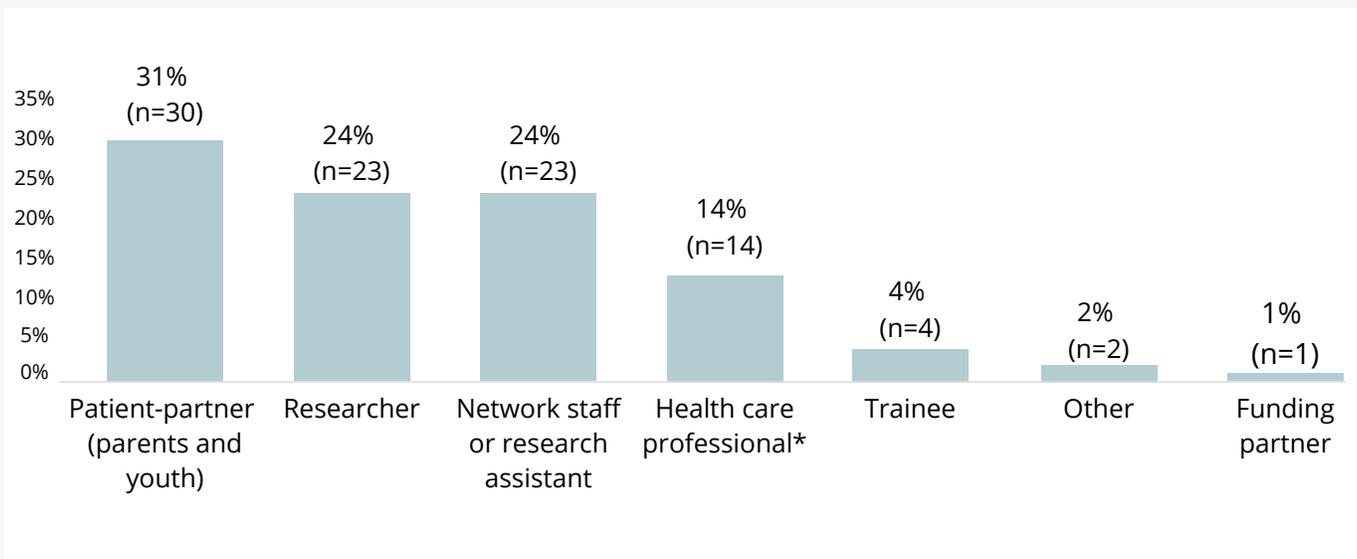
3. Main findings

Our findings are based on the 97 valid survey responses retained for analysis.

3.1. Survey respondents

Approximately 27% of those who received the survey link (n=357) completed all survey questions. Of those who responded, 31% were patient-partners, see Figure 3.1.1. To see how survey respondents compare to CHILD-BRIGHT Network members by stakeholder group, see Table 3.1.1.

Figure 3.1.1. Survey respondents' primary role within the CHILD-BRIGHT Network



*Health care practitioner/clinician, health system professional, health administrator

We asked survey respondents to indicate which projects and committees they were members of as well as their role in those projects and committees.

Survey respondents came primarily from the READYorNot™ (18%) and BRIGHT Coaching (15%) project teams. One-third (33%) of respondents were patient-partners or staff.

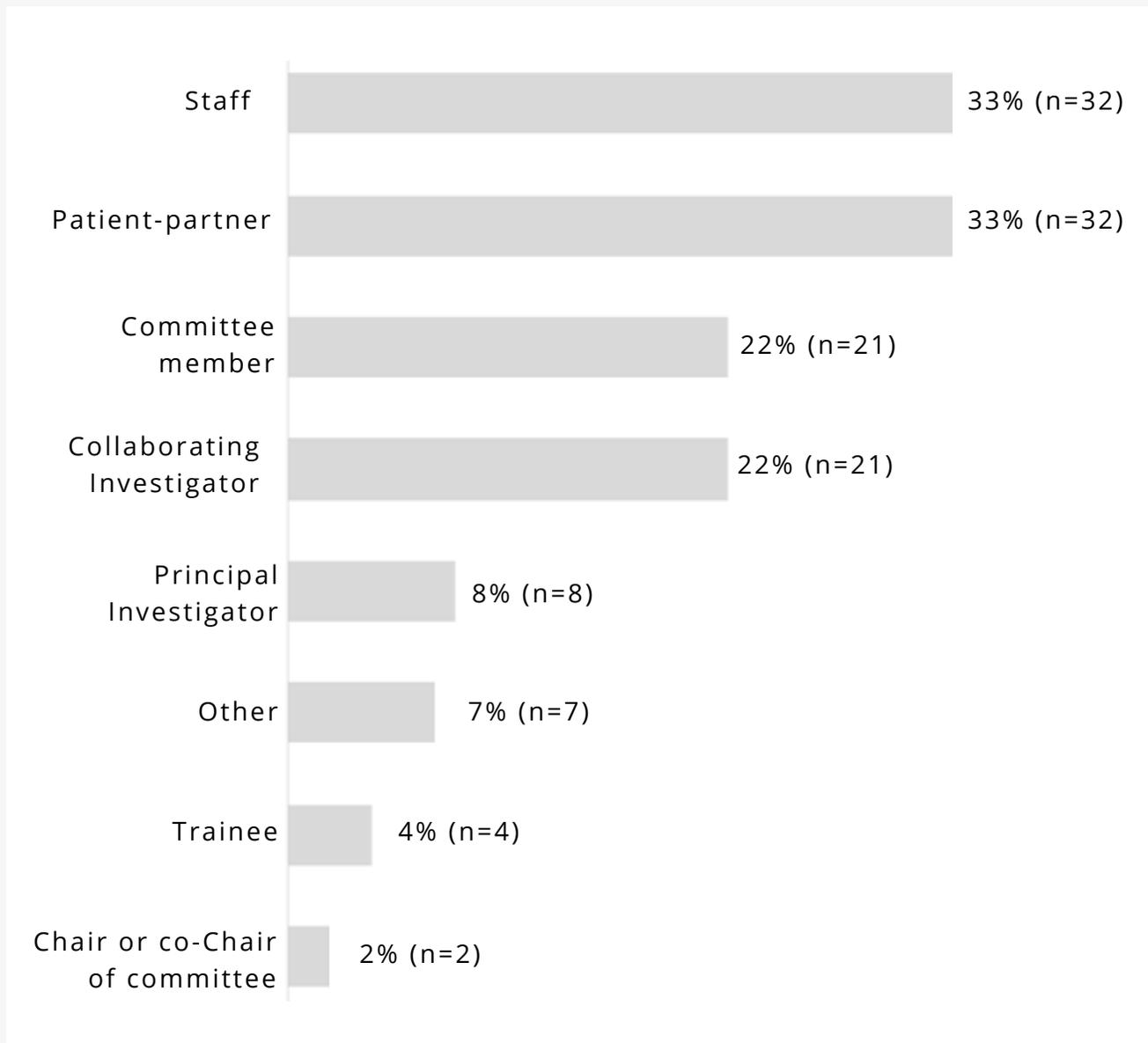
Table 3.1.1. Survey respondents and CHILD-BRIGHT Network members by stakeholder group

| Stakeholder group | COVID-19 survey respondents May-June 2021 (n=97) | | CHILD-BRIGHT Network stakeholders (N=394) ¹ | |
|---|--|----|---|----------------|
| | n | % | n | % ² |
| Patient-partner (parents and youth) | 30 | 31 | 72 | 18 |
| Researcher | 23 | 24 | 143 | 36 |
| Network staff or research assistant | 23 | 24 | 78 | 20 |
| Health care practitioner/clinician, health system professional or administrator | 14 | 14 | 109 | 28 |
| Trainee | 4 | 4 | 35 | 9 |
| Funding partner | 2 | 2 | 2 | 0.5 |
| Other | 1 | 1 | 25 | 6 |

Notes:

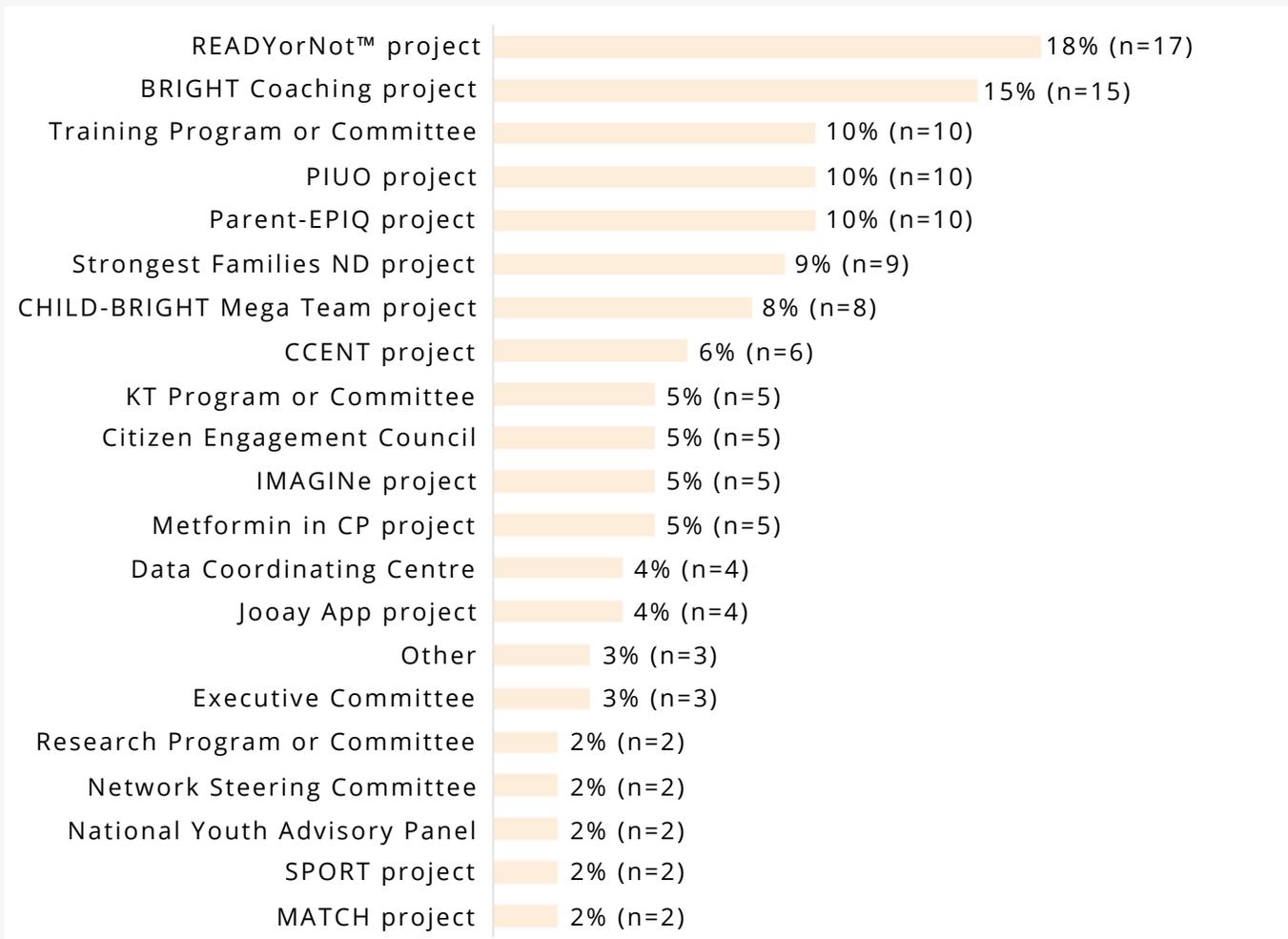
1. CHILD-BRIGHT Network stakeholders as of March 31, 2021. Only 357 members received the survey as other members opted out of receiving surveys.
2. Percentages do not add up to 100% as respondents could select all that apply.

Figure 3.1.2. Survey respondents' role(s) on the CHILD-BRIGHT Network's project(s) or committee(s)



Note: Percentages do not add up to 100% as respondents could select all that applied.

Figure 3.1.3. Respondent affiliation to CHILD-BRIGHT research projects, committees, and programs



Notes: Percentages do not add up to 100% as respondents could select all that applied.

READYorNot™ Brain-Based Disabilities Project: Moving Ahead with Transition of Care from Adolescence to Adulthood. **BRIGHT Coaching:** A Developmental Coach System to Empower Families of Preschoolers with Developmental Delays. **PIUO:** Optimizing the Management of Pain and Irritability in Children with Severe Neurological Impairment. **Parent-EPIQ:** Parent-Centred Evidence-Based Care for Premature Graduates. **Strongest Families ND:** Strongest Families Neurodevelopmental Program. **CHILD-BRIGHT Mega Team:** Treatments to Improve Emotional and Behavioural Self-Regulation. **CCENT:** Coached, Coordinated, Enhanced Neonatal Transition. **KT Program or Committee:** Knowledge Translation Program or Committee. **IMAGINe:** Diagnosis Using Integrated Metabolomics And Genomics In Neurodevelopment. **Metformin in CP:** Enhancing Brain Repair with Metformin. **Jooay App:** Promoting Participation in Leisure. **Other:** categories not listed. **SPORT:** Stimulation for Perinatal Stroke Optimizing Recovery Trajectory. **MATCH:** MATernal hyperoxygenation in Congenital Heart Disease.

3.2. Impact of the pandemic on engagement with projects and committees

Survey respondents reported how the pandemic impacted their engagement with projects and committees. Impact reported is listed by stakeholder group.

| Patient-partner (parent and youth) | |
|---|--|
| Impact reported | Selected responses from patient-partners |
| Multiple challenges to engagement (e.g., caregiving responsibilities, feeling overwhelmed, and internet, school or health problems) | <p>“Having kids home from school was fairly draining, and much of my otherwise available mental resources and time became taxed, which made it harder to participate and keep up with meetings/communications.”</p> <p>“The respite stopped due to [the] pandemic and [I] could not participate in any virtual meetings as my area was interrupted with high volume of usage from other users in my service area.”</p> <p>“Feeling overwhelmed and constantly interrupted”</p> |
| Greater ability to engage thanks to transition to virtual environment | <p>“It has been great, as someone joining meetings out of province alone on teleconference, to be able to do meetings where I don't feel left out because everyone is online.”</p> |
| Disruption to face-to-face interaction and participant recruitment | <p>“Some items have been halted a bit because of COVID restrictions like recruitment for studies and conference planning, [and] in person engagement.”</p> |
| Little or no impact | <p>“It hasn't had any significant effect.”</p> <p>“There has been little [effect] on the engagement of patients and families.”</p> |

Researcher

Impact reported

Selected responses from researchers

Negative effect on all aspects of project (recruitment, attrition, loss of patient-partners as in they could no longer participate on the project, implementation, data collection and analysis, follow-up, progress delays, changes to patient care provision)

"All project engagement has been negatively affected: Project recruitment, analysis, diagnosis and follow-up have all been delayed by six to 12 months."

Limited contact with patients/families and added stress (for staff, participants, and family/youth advisors)

"[The pandemic] limited our ability to meet, which put stress on participants."

Little effect

"As collaboration for this national study was already done remotely, it did not have much of an impact on my engagement."

Increased demands on researchers and reduced availability/energy of health care workers to contribute

"I was able to continue my engagement although there were more competing demands to my time."

"COVID measures took priority over other projects and health care workers did not have the energy to participate in QI [Quality Improvement] projects."

Other*

Impact reported

Selected responses from others*

Little or no impact

"I haven't really felt any [effects]. We still do our team meetings virtually (which we were doing previously) and when I reach out to any members of the team for clarification [or] discussion etc they are readily available."
— Health care practitioner/Clinician

"Impact has been minimal, as pre-pandemic work [and] meetings [were] largely conducted remotely." — Network staff/Research Assistant

Challenges to engagement (worries about health, caregiving responsibilities, difficulty concentrating, feeling overwhelmed, limited time for research and engagement)

"I found myself distracted and preoccupied with other matters relating to my own and my family's health and well-being — I found myself overwhelmed with the amount of work on the committees in spite of the pandemic — it seemed to slow certain parts down or accelerate others." — Network staff/Research Assistant

"Working from home while having to care for [my] child has been challenging." — Network staff/Research Assistant

"Decreased time allotted to research and QI [Quality Improvement] initiatives due to refocusing work on urgent pandemic-related issues/policies." — Health care practitioner/Clinician

Greater ability to engage thanks to transition to virtual environment

"Having the opportunity to engage via Zoom/electronically has been [a] really great [way] to connect during the pandemic, especially since I am joining from out of province." — Trainee

Other* (continued)

| Impact reported | Selected responses from others* |
|--|--|
| Limited face-to-face interactions | "At times we have not been allowed on the unit to visit families. This has taken away the personal touch and the daily check-in with families." — Health care practitioner/Clinician |
| Difficulty providing direct patient care and recruiting patients | "Every aspect of patient care has been made more complicated by the pandemic. Direct work with patients and families was impacted by hospital restrictions limiting in-person clinic visits." — Health care practitioner/Clinician "There are fewer numbers of baseline recruitments and hence less clinical assessments." — Network staff/Research Assistant |

*Notes: *Other* encompasses the following categories: health care practitioner/clinician, health system professional, health administrator, Network staff, research assistant, trainee, and funding partner. A *trainee* refers to someone in an undergraduate, master's, PhD, or post-doctoral program.

3.3. Impact of the pandemic on engagement with the Network as a whole

Survey respondents were also asked how the pandemic affected their engagement with the Network as a whole. Impacts reported are presented with illustrative quotations by stakeholder group.

Patient-partner (parent and youth)

| Impact reported | Selected responses from patient-partners |
|--|---|
| Challenges to engagement (limited time/resources, having children at home, hard to feel as engaged via Zoom) | “My time and mental resources are more limited so keeping up with meetings and communication with the Network and [in] general has been a challenge.” |
| Increase in involvement and engagement through online activities (meetings, webinars, and newsletter) | “I have become more involved with the Network! COVID has opened up a lot of doors to meet new individuals and to get involved in different ways.” |
| Disruptions in face-to-face interactions | “[We have not had] face-to-face engagement, which is always much more positive and fruitful for everyone.” |
| Little or no impact | <p>“My participation in other Network activities was usually by completing online surveys so it hasn't been affected by COVID.”</p> <p>“[I have experienced] very little change as most of engagement is virtual anyway.”</p> |

Researcher

| Impact reported | Selected responses from researchers |
|---|--|
| Decrease in engagement (due to limited time/resources, and feeling overwhelmed) | "The demands brought on by the pandemic have decreased my engagement because something had to give." |
| Transition to online engagement in a virtual environment (meetings, newsletters, and surveys) | "We participated in a Network symposium to present our work to others in the Network (Nov. 2020). We read the newsletters and complete surveys as requested." |
| Limited in-person interaction and Network activities (clinical/research activities, reports to community) | "Opportunities to meet in person at the annual meetings/conference is an unfortunate loss. This was a great way to continue personal connections." "Competing demands [on] everyone's time [created] delays on the work of the Network as a whole (e.g., report to community)." |
| Little or no impact | "From our perspective, Network activities have been affected to only a minor degree." "It was being done remotely prior to pandemic so it did not impact my engagement." |

Other*

| Impact reported | Selected responses from others |
|--|---|
| No impact | “My engagement was not affected.” — Network staff/Research Assistant |
| Increased engagement through online activities (meetings, newsletters, virtual events) | “Engaging online has become a norm which allows for more connection and ability to engage with the Network as a whole. I am grateful for increased number of online opportunities.” — Trainee |
| Challenges related to virtual engagement (screen fatigue, limited time) | “I find that I have been opening CHILD-BRIGHT correspondence more than ever to stay connected but I do find it challenging to engage with the virtual activities (webinars, conferences...) as I am experiencing a bit of screen fatigue.” — Network staff/Research Assistant |
| Limited face-to-face interaction/events | “The pandemic has limited face-to-face interactions and events.” — Network staff/Research Assistant |
| Less engaged, connected, or motivated | “The pandemic affected my engagement with the Network: I found myself less excited about attending virtual events or reading certain news items as I am on the computer or looking at screens 24/7. I found myself to be less connected to other people in the Network.” — Network staff/Research Assistant |

*Notes: *Other* encompasses the following categories: health care practitioner/clinician, health system professional, health administrator, Network staff, research assistant, trainee, and funding partner. A *trainee* refers to someone in an undergraduate, master’s, PhD, or post-doctoral program.

4. Recommendations



4.1. Recommendations for facilitating engagement during public health emergencies

CHILD-BRIGHT's Knowledge Translation (KT) Committee and Citizen Engagement Council (CEC) were asked to bring their perspectives to bear on the project background and survey findings. They then formulated a series of recommendations for facilitating engagement during a public health emergency.

Members were asked to:

- Reflect on the findings of the survey
- Identify strategies that could be used to facilitate engagement during public health emergencies
- Provide suggestions for disseminating findings. Comments were reviewed by two research team members and recommendations are listed below.

Suggestions for the dissemination of the findings included:

- Sharing with other disability groups (e.g., cerebral palsy)
- A webinar presentation of the findings
- Creating and sharing an easy to read one-page summary (e.g., infographic) highlighting key findings with a link to this report for those wishing to obtain additional information.



Recommendations for the CHILD-BRIGHT Network

Technology

Use technology (e.g., Zoom, Miro/virtual blackboard, Google Drive) to facilitate engagement.

Citizen engagement

Have the Citizen Engagement Council act as a “go-to” group for discussions with other parents/patient-partners on topics such as mask-wearing.

Patient-partners’ support group

Add space for a patient-partners’ support group on the CHILD-BRIGHT Facebook page. This could be run by a patient-partner and would allow patient-partners to discuss/share information, engage with other patient-partners, and support each other.

Lay language

Provide information in lay language about:

- Self-management
- Self-care
- How to prioritize commitments and tasks
- Zoom and screen fatigue and how to mitigate its effects
- Public health guidelines and recommendations by the federal government.

Recommendations for researchers

Adapt

Adapt recruitment and engagement based on public health measures.

Provide guidance

Provide guidance to project leads regarding approach noted above to foster an accommodating environment.



Check in

Check in with project team members, recognize impact of pandemic on competing demands, and increase awareness of challenges.

Share

Share with other researchers an outline of:

- What to expect during a public health crisis (e.g., disruption to recruitment)
- Ways to shift focus of research in response to a pandemic
- Strategies to use to keep research going (e.g., advocate for funds to maintain personnel, ask for a no-cost extension).



Facilitate engagement by:

- Using technology,
- Adding space for a patient-partners' support group, and
- Providing information in lay language.

5. Conclusions

5.1. Take-home message

The COVID-19 pandemic has affected the engagement of Network members. Interestingly, different stakeholders (patient-partners, researchers and others) experienced similar impacts. Some of these impacts were negative; members missed the community-building and networking of the annual conference and found it challenging to engage due to increased responsibilities, for example. Members also reported positive impacts, especially when it came to increasing their engagement with the Network through online activities. Others still found the pandemic has had little or no impact on their engagement, as with members and teams whose activities were already mostly virtual prior to the pandemic.

Different stakeholders (patient-partners, researchers and others) experienced similar impacts.

Most stakeholder groups experienced some barriers to engagement as they faced having to balance work, leisure, care, home-schooling their children, and their own feelings of turmoil. Increased opportunities afforded by the Network for online activities (e.g., meetings, webinars, newsletters) helped members stay connected. Researchers, many of whom are full-time clinicians or academics, experienced disruption in all aspects of project engagement and difficulty continuing Network activities (e.g., reports to community). This was in part due to challenges in overcoming obstacles to conducting their research studies and to increasing demands on their time in clinical settings and at universities.

There are lessons to be learned from our members' engagement experiences to date: online activities (e.g., Zoom meetings, webinars, newsletters, emails) can facilitate engagement and are well-received.

Recommendations provided by Network members range from supporting the needs of the families we work with (e.g., providing information on self-care, allowing for the Citizen Engagement Council to be a "go-to" group for advice), supporting the needs of CHILD-BRIGHT researchers (e.g., checking in with project team members, recognizing the pandemic's impact on competing demands), to strategies that can be used to facilitate both engagement of Network members (e.g., using online platforms) and the work of researchers (e.g., providing information on what to expect during a public health crisis and strategies that can be used to keep research going).

The insights obtained through this work will be useful for CHILD-BRIGHT and other research networks in facilitating engagement not only during future public health crises but as we continue to adapt to the evolving pandemic.

5.2. Next steps

The findings of this survey represent a snapshot of Network members' experience from May to June 2021. Current and long-term impact of the pandemic on Network engagement requires ongoing assessment. Given the wide variability of experiences including both positive and negative impacts, the importance of providing blended formats (e.g., both online and face-to-face opportunities) of stakeholder engagement and incorporating some of the recommendations provided by the Citizen Engagement Council and Knowledge Translation Committee as mitigating strategies should be prioritized by the Network, as appropriate.

Appendix

Appendix A: Consent statement and survey

Dear CHILD-BRIGHT Network Member,
We hope that you and your loved ones are safe and well. At CHILD-BRIGHT, we continue to adapt as best we can to the circumstances brought about by the pandemic, while also continuing to gather important information and insights from our members about their experiences with patient engagement in research. That is why we are inviting you to tell us how COVID-19 has impacted your engagement in Network activities since March 2020. This is part of a study: Stakeholder Engagement in the CHILD-BRIGHT Network. The survey consists of 5 questions and should take about 5 to 10 minutes to complete.

Please note your participation is completely voluntary. You may choose not to respond or to answer only the questions you feel comfortable answering. The survey system will not record your e-mail address or IP (Internet protocol) address.

There are no costs or anticipated risks (for example, physical, psychological, and/or emotional) associated with completing the survey. The survey has a 'Save and Return Later' feature which allows you to save your progress and complete it any time in the future until the survey period closes (June 30, 2021). You will be given an auto-generated return code to return to where you left off. Please note that when you click on "submit" at the end of the survey, you will not be able to withdraw or make any changes to your responses as we cannot link them back to you. Your participation is very important to us. Your feedback will help us determine how COVID-19 affected your engagement in participating in Network activities in 2020-21. The information and insights from the survey will also be used in our reporting (for example, Report to Community, CIHR). If you have any questions or comments about this survey, please do not hesitate to contact CHILD-BRIGHT's Knowledge Translation Program Coordinator at kt@child-bright.ca. This survey has been approved by the McGill University Health Centre Research Ethics Board.

Cher/Chère membre du Réseau BRILLEnfant,
Nous espérons que vous et vos proches vous portez bien et êtes en bonne santé. Au Réseau BRILLEnfant, nous continuons à nous adapter du mieux que nous pouvons aux circonstances provoquées par la pandémie, tout en continuant à recueillir des informations et des idées auprès de nos membres sur leurs expériences en matière d'engagement des patients dans la recherche. C'est pourquoi nous vous invitons à nous dire comment la COVID-19 a affecté votre engagement dans les activités du réseau depuis mars 2020. Ceci est fait dans le cadre de l'étude: L'engagement des parties prenantes du Réseau BRILLEnfant. Ce sondage comprend 5 questions et prendra environ 5 à 10 minutes à remplir.

Veillez noter que votre participation est entièrement volontaire. Vous pouvez choisir de ne pas répondre aux questions, ou de ne répondre qu'aux questions auxquelles vous vous sentez à l'aise de répondre. Le système de sondage en ligne n'enregistra pas votre adresse de courriel ni votre adresse IP (adresse de protocole Internet).

Il n'y a ni coûts ni de risques anticipés (par exemple, physiques, psychologiques et / ou émotionnels) associés à votre participation au sondage. Le sondage dispose d'une fonction « Enregistrer et retourner plus tard » qui vous permet d'enregistrer votre progression et de compléter le sondage à votre guise jusqu'au dernier jour du sondage (30 juin 2021). Vous recevrez un code de retour généré automatiquement pour revenir là où vous vous étiez arrêté. Veuillez noter que lorsque vous cliquez sur « Soumettre » à la fin du sondage, vous ne pourrez pas retirer vos réponses car nous ne pouvons pas les connecter à vous. Votre participation est très importante. Vos commentaires nous aideront à déterminer comment la COVID-19 a affecté votre engagement dans les activités du réseau en 2020-21. Les informations et les idées provenant du sondage seront également utilisées dans nos rapports (par exemple, le Rapport à la communauté, IRSC). Si vous avez des questions ou des commentaires au sujet du sondage, n'hésitez pas à communiquer avec notre coordonnatrice du programme de transfert des connaissances du Réseau BRILLEnfant par courriel: kt@child-bright.ca. Ce sondage a été approuvé par le Comité d'éthique de la recherche du Centre universitaire de santé McGill.

I voluntarily consent to participate in this survey / J'accepte volontairement de participer à ce sondage

- Yes / Oui
- No / Non

1. Which stakeholder group do you PRIMARILY belong to, in your role within CHILD-BRIGHT? / À quel groupe de parties prenantes appartenez-vous PRINCIPALEMENT dans votre rôle au sein de CHILD-BRIGHT?

- Patient-partner (Parent) / Patient partenaire (Parent)
- Patient-partner (Youth) / Patient partenaire (Jeunesse)
- Healthcare practitioner/clinician, health system professional or health administrator (including hospitals, hospital networks and health authorities) / Praticien / clinicien de la santé, professionnel du système de santé ou administrateur de la santé (y compris les hôpitaux, les réseaux hospitaliers et les autorités sanitaires)
- Researcher / Chercheur
- Funding partner / Partenaire de financement
- Trainee (undergraduate, master's, PhD, post-doctoral fellow, other) / Stagiaire (premier cycle, maîtrise, doctorat, post-doctorant, autre)
- Policy-maker (municipal, provincial, federal government) / Décideur politique (municipal, provincial, gouvernement fédéral)
- Network staff or research assistant / Personnel du Réseau ou assistant(e) de recherche
- Other (please specify) / Autre (veuillez préciser)

2. Which project(s), committee(s), or program(s) you are part of? (Check all that apply) / De quel(s) projet(s), comité(s) ou programme(s) faites-vous partie? (Cochez toutes les réponses qui s'appliquent)

- MATernal hyperoxygenation in Congenital Heart Disease (MATCH)
- Parent-Centred Evidence-Based Care for Premature Graduates (Parent-EPIQ)
- Enhancing Brain Repair with Metformin (Metformin in CP)
- Stimulation for Perinatal Stroke Optimizing Recovery Trajectory (SPORT)
- Diagnosis Using Integrated Metabolomics And Genomics In Neurodevelopment (IMAGINE)

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- Prenatal Opioid Exposure and Neonatal Abstinence Syndrome: A Research Project with Indigenous Peoples in Ontario First Nations
 - Optimizing the Management of Pain and Irritability in Children with Severe Neurological Impairment (PIUO)
 - Strongest Families Neurodevelopmental Program (Strongest Families ND)
 - Jooay App: Promoting Participation in Leisure
 - CHILD-BRIGHT Mega Team: Treatments to Improve Emotional and Behavioural Self-Regulation
 - Coached, Coordinated, Enhanced Neonatal Transition (CCENT)
 - BRIGHT Coaching: A Developmental Coach System to Empower Families of Preschoolers with Developmental Delays
 - 'READYorNot' Moving Ahead with Transition of Care from Adolescence to Adulthood
 - Data Coordinating Center
 - Data Safety Monitoring Board (DSMB)
 - Executive Committee
 - Citizens Engagement Council
 - International Scientific Advisory Committee (I-SAC)
 - National Youth Advisory Panel
 - Network Steering Committee
 - Health Economics
 - Knowledge Translation (KT) Program or Committee
 - Research Program or Committee
 - Training Program or Committee
 - Other (please specify) / Autre (veuillez préciser)

Other (please specify which project(s), committee(s), or program(s) you are a member of) / Autre (veuillez préciser le(s) projet(s), comité(s) ou programme(s) dont vous êtes membre)

3. What role(s) do you have on the project(s), committee(s), or program(s) you are part of? (Check all that apply) / Quel(s) rôle(s) avez-vous dans le(s) projet(s), comité(s) ou programme(s) dont vous faites partie? (Cochez toutes les réponses qui s'appliquent)

- Patient-Partner / Patient partenaire
- Principal Investigator / Chercheur principal
- Collaborating Investigator / Chercheur collaborateur

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- Staff / Le personnel
 - Trainee / Stagiaire
 - Chair or co-Chair of committee / Président(e) ou coprésident(e) d'un comité
 - Committee member / Membre de comité
 - Other (please specify) / Autre (veuillez préciser)

4. How has the pandemic affected your engagement with the particular project(s), committee(s), or program(s) you are part of? / Comment la pandémie a-t-elle affecté votre engagement dans le(s) projet(s), comité(s) ou programme(s) dont vous faites partie?

5. How has the pandemic affected your engagement with the Network as a whole (i.e., outside of the activities related to your role on a project, program, or committee, e.g., engaging in network-led activities such as reading the Connections newsletter, attending our events (CHILD-BRIGHT policy forum, webinars, virtual symposium, etc.), and participating in network-wide interviews and surveys)? / Comment la pandémie a-t-elle affecté votre engagement dans le Réseau dans son ensemble (c'est-à-dire en dehors des activités liées à votre rôle dans un projet, un programme ou un comité, par exemple, votre participation à des activités proposées par le réseau comme la lecture du bulletin Connections, assister à nos événements (forum politique Réseau BRILLEnfant, webinaires, symposium virtuel, etc.) et votre participation à des entrevues et sondages à l'échelle du réseau)?

Thank you for your participation! / Merci pour votre participation!

CHILD-BRIGHT Network / Réseau BRILLEnfant

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