



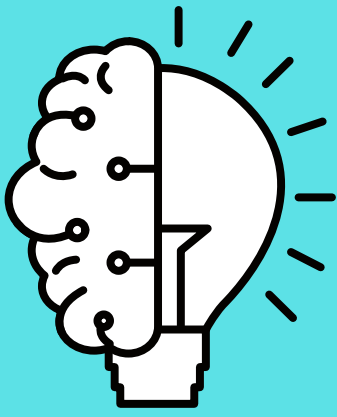
# REFLECTIVE QUESTIONS

## Safety

- Has the research team put in place resources and support for families involved in the research?
- Does the research partnership include a consent process?
- Does the research team provide compensation for the family partners?
- Have roles and expectations been established at start?
- Has visibility and easy access to the research team been developed by securing a dedicated space?

## Equity

- Is there an entity within the research team identifying partner families?
- Does it include a diversity of voices and permit peer-to-peer mentorship?
- Does the research schedule include regular face-to-face meetings?



# REFLECTIVE QUESTIONS

## Trust

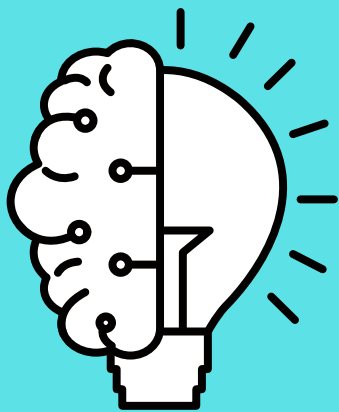
- Does the research program ensure that no decisions are made without the patient and family advisory board and the director of research?

## Respect

- Have the research team established processes for the partnership to share their perspectives through various communication platforms?

## Mutuality

- Do the research partners share their knowledge?
- Does the partnership draw on the expertise of each partner in a cyclical iterative process at all stages of the research process?



# REFLECTIVE QUESTIONS

## Transparency

- Have roles and expectations been established at start?
- Has it been discussed why each member of the partnership was involved and how the research would assist in developing interventions in clinical and non-clinical settings?

## Beneficence

- Did the research partners acknowledge unspoken assumptions and expectations when engaging in the research program?
- Has a feedback loop been established throughout the research process to assess whether all partners are benefiting from the research?

# References

- Alberta SPOR Support Unit Patient Engagement Platform, 2020.
- Canadian Institutes of Health Research. (2020). Ethics guidance for developing partnerships with patients and researchers. [https://epe.lac-bac.gc.ca/100/201/301/weekly\\_acquisitions\\_list-ef/2020/20-28/publications.gc.ca/collections/collection\\_2020/irsc-cihr/MR4-86-2020-eng.pdf](https://epe.lac-bac.gc.ca/100/201/301/weekly_acquisitions_list-ef/2020/20-28/publications.gc.ca/collections/collection_2020/irsc-cihr/MR4-86-2020-eng.pdf)
- Lukes, S. (2005). *Power: a radical view* (2nd ed.). Palgrave Macmillan. 200 p.
- O'Neill, B., Aversa, V., Rouleau, K., Lazare, K., Sullivan, F., & Persaud, N. (2018). Identifying top 10 primary care research priorities from international stakeholders using a modified Delphi method. *PLOS ONE*, 13(10), e0206096. <https://doi.org/10.1371/journal.pone.0206096>
- Rivers, B. M., Hernandez, N. D., Rivers, D., Cooper, D. L., Enis, S. J., Belizaire, C., & Matthews, R. (2019). Utilizing Community-based Participatory Research Principles in a Safety-Net Hospital to Develop a Research Partnership. *Journal of Health Care for the Poor and Underserved*, 30(4S), 27-35. <https://doi.org/10.1353/hpu.2019.0112>



This resource was created as part of the McMaster University, CanChild, and Kids Brain Health Network Family Engagement in Research Certificate of Completion Program. Copyright © 2021. Berna Elias, Catrine Demers, Delphine Gaudin-Drouelle, & Maude Champagne. All Rights Reserved