Building a Platform for Meaningful Patient Partnership to Accelerate "Bench-to-Bedside" Translation of Promising New Therapies

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P = Patient partner.

Appendix 1.

TABLE A1.
GRIPP2–Short form

Selection and topic	Item
Aim	We partnered with four individuals with lived experience of blood cancer to co-develop documents and services (i.e., informed consent documents, peer support panels, policy briefs) to support participants of an early phase trial.
Method	The CLIC-01 trial is the first academic investigator-led Canadian clinical trial assessing the safety and feasibility of a novel immunotherapy in treating hematologic malignancies (CAR-T cell therapy). We scheduled bi-monthly team meetings with patient partners to discuss areas of the CLIC-01 trial where trial participants may require further support.
Results	Our patient partners identified the informed consent process as an area requiring further attention. Hence, patient partners co-developed a visual informed consent document and a one-page non-technical summary of the formal informed consent document to facilitate participants' understanding of trial procedures. Additionally, patient partners informed the planning of an online peer support panel to provide emotional support for trial participants. Finally, patient partners contributed to the policy brief development by conceptualizing three ways that funding agencies can encourage applicants to engage patients in the development and conduct of early-phase clinical trials.
Discussion	Patient partners highlighted important trial components that could be improved, which would not have been identified without their input, ultimately informing the development of documents and services to support the participants of an early-phase clinical trial. For example, patient partners highlighted the important role played by caregivers when receiving treatments and participating in a clinical trial. As a result, we incorporated the caregiver's perspective when developing supporting documents for the informed consent process by including information about visit length to allow caregivers to prepare accordingly.
Reflections	Overall, early-phase clinical trials offer a unique opportunity to incorporate the patient perspective early in the "translational" pipeline of therapy development. Patient partners provided invaluable expertise and perspective when developing clinical trial documents. While this project highlights the impacts of patient engagement, some limitations should be noted. For example, it is important to maintain consistent communication with all team members in order to provide updates on the progress of the project. This is a shortcoming of our engagement activities that we hope to address in future initiatives.

Source: Staniszewska et al. 2017.