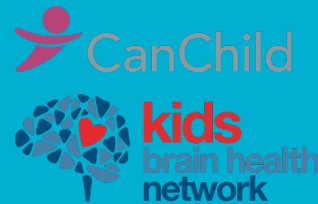


Guidelines for researchers

to complete research
with family/patient partners

including the SECRET to success

Liz Boyer, Pamela Libralesso, Sara Pot



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Gillette Children's roots



Jessie Haskins with her **lived experience**

Dr. Gillette with his **medical expertise**

Together designed an idea
that became a reality...

not just about treatment but about ways
to support children and families living
their **best lives**



Family/patient partners in research

When we weave **lived experience** and **clinical research expertise**,

we learn

from family/patients' unique knowledge gained from living with and managing their condition

we uncover

gaps in knowledge about patient priorities

we develop

relevant, sustainable patient outcomes & broader knowledge translation

better ways for patients and families to live their best lives.

Guidelines for your first project



The SECRET to a successful, authentic partnership

Shared leadership

Equity

Communication

Respect

Empowerment

Trust & **T**ransparency

IDENTIFY



2+ family/patient partners

- representative of the research population, ideally with unique viewpoints
- recruitment methods: case-by-case (pre-est. relationships), directories, or third-party match <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-017-0067-x>

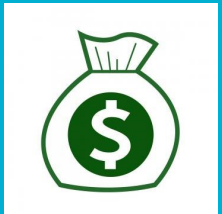
Platforms on which to meet, communicate & file share

- allow for flexibility using remote, asynchronous access
- e.g., Slack, Zoom, Microsoft Teams, Facebook, Google Drive
- anticipate barriers & have plans to address (e.g., unexpected family illness)



Compensation

- determine institution's capacity for compensation
- create a line item on research budget
- https://sporevidencealliance.ca/wp-content/uploads/2019/08/SPOR-EA_Patient-Partner-Appreciation-Policy-and-Procedure.pdf
- <https://www.pcori.org/sites/default/files/PCORI-Compensation-Framework-for-Engaged-Research-Partners.pdf>



BUILD



Relationships beyond the research context

- create short biographies (max 3 sentences), including professional and personal information, avoiding laundry list of intimidating accolades and awards
- first 15-30 mins of each meeting is friendly, informal conversation



Understanding of what it means to be a researcher or family/patient partner

- share presentations on research basics and family/patient values & perspectives
- <https://www.canchild.ca/en/research-in-practice/current-studies/family-engagement-in-research-course/student-projects>



Training support for different project roles

- webinar, checklist, relevant reading material
- incorporate feedback to modify training support for maximum effectiveness

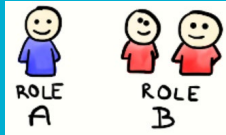
ESTABLISH



Insperty

What form of compensation is preferred

- if possible, ask each individual what form compensation should be provided (e.g., hourly, honorarium, check, gift card, services, none)
- establish a fair amount by talking with family/patient partners at first meeting
- consider their expenses separately from compensation



Crisp

Roles & expectations together at the start (including time investment)

- ask when, how, and why patients would like to be engaged
- write these down for future reference
- consider formalizing a team agreement between parties
- re-evaluate team agreement regularly as the project evolves
- <https://www.kcrutrecht.nl/wp-content/uploads/2019/04/Involvement-Matrix.pdf>

CONDUCT



Regular communication

- throughout study, including all stages & levels of involvement



Study *with* family/patient partners

- co-design the research question, plan methods/study design, recruit & retain participants, collect data, data analysis, interpret results, disseminate



Partnership evaluations

- at study conclusion to reflect on successes and address challenges
- e.g., <https://ppe.mcmaster.ca/our-products/public-patient-engagement-evaluation-tool>

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