

LEARNING TOGETHER:

THE USE OF SIMULATION TO ENHANCE AND ENABLE AUTHENTIC AND MEANINGFUL RESEARCH PARTNERSHIPS

Multidisciplinary team

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Dear Instructors,

There is a growing body of evidence that involving patients/clients and their families in applied clinical research as research partners can enhance the relevance, quality and increase impact and utility of research findings.^{1,2} Literature suggests that patients/clients should be involved in all aspects of the research process, from idea conceptualization, research design, and dissemination to realize the full benefit of the patient perspective and expertise³. Although evidence to support the benefits of partnering with patients/clients and their families throughout the research process is emerging, recent research has identified that these individuals often lack the understanding and skills to engage in meaningful partnerships.^{3,4} This has been found to be especially true among youth with disabilities and their family members.⁵

Holland Bloorview Kids Rehabilitation Hospital (HBKRH) is Canada's largest children's rehabilitation hospital located in Toronto, Ontario. As a world-class teaching hospital fully affiliated with the University of Toronto, we train future health-care specialists in the field of childhood disability. The Bloorview Research Institute at HBKRH is dedicated to conducting applied, clinically relevant and family-centred research to support the most meaningful and healthy lives for children, youth and families living with disability. We have been actively pursuing structures and strategies to support client and family-centred research since 2013. In 2014, we developed a framework for engaging clients and families in all aspects of the research process from idea conceptualization through to dissemination of research results.^{6,7} Through funding from CHILD-BRIGHT, our team used a simulation based, co learning approach to design and develop a suite of four simulations and this accompanying facilitation resource for research teams and clients/families to learn how to support each other through some of the most complex and challenging situations associated with patient engagement in research.

Note to users: As Holland Bloorview is a pediatric facility, and parents and caregivers are intimately involved and invested in their child's care and the research we conduct; we partner actively with family members as well as children and youth. Therefore, here in, the term patient partner will be replaced with family / youth partner. That being said, these simulations can be applied to research partnerships with patients, clients, families and caregivers.

We hope that by using the simulation-based educational program, you will be able to support clients, patients, families and all members of the research community to authentically and meaningfully partner with one another in the research process.

All the best,

Holland Bloorview and the Bloorview Research Institute

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Simulation Description

#	Name of Simulation	Characters	Family Engagement Guiding Principles*
1	Finding a family partner	Researcher: Dr. Sarah Smith Youth Engagement Specialist: Ben	Co-Develop: Stakeholders work together from the beginning to identify problems and gaps, set priorities and implement solutions Transparency: Goals and expectations for all team members should be clearly identified and communicated Support: Adequate support and flexibility are provided to all members of the team to ensure that they can contribute fully
2	Partnering to set research objectives	Researcher: Dr. Nadine Jones Family Partners: 3 parents of children with disabilities, named as Knowledge Users on the grant.	Transparency: Goals and expectations for all team members should be clearly identified and communicated Co-Develop: Stakeholders work together from the beginning to identify problems and gaps, set priorities and implement solutions Inclusiveness: Family engagement in research integrates diversity of family perspectives Mutual Respect: Acknowledge and value each other's expertise and experiential knowledge
3	Reviewing results	Youth Partner Seika Principal Investigator: Dr. Sarah Smith	Mutual Respect: Acknowledge and value each other's expertise and experiential knowledge

			<p>Transparency: Goals and expectations for all team members should be clearly identified and communicated</p> <p>Support: Adequate support and flexibility are provided to all members of the team to ensure that they can contribute fully</p> <p>Inclusiveness: Family engagement in research integrates a diversity of family perspectives</p>
4	Navigating concerns around knowledge translation (dissemination of results)	<p>Family Partner: Mary</p> <p>Research Student: Kim</p> <p>Kim's Supervisor: Dr. Vilanpour</p>	<p>Transparency: Goals and expectations for all team members should be clearly identified and communicated</p> <p>Co-Develop: Stakeholders work together from the beginning to identify problems and gaps, set priorities and implement solutions</p> <p>Inclusiveness: Family engagement in research integrates a diversity of family perspectives</p> <p>Mutual Respect: Acknowledge and value each other's expertise and experiential knowledge</p> <p>Support: Adequate support and flexibility are provided to all members of the team to ensure that they can contribute fully</p>

**Holland Bloorview has developed five guiding principles for family engagement. These principles were informed by SPOR, PCORI and INVOVE and co-created with clients, families, staff and researchers at Holland Bloorview. The principles can be accessed at brirequests@hollandbloorview.ca.*

Recommended Structure for Video Based Discussion

Each video addresses a point in time in the research process (i.e., setting research objectives). Multiple issues and learning opportunities arise within each video. To promote rich discussion and deep learning, it is our suggestion that each video be shown independently in a one-hour training session. The entire series can be shown through four weekly/monthly workshops. The videos should be shown in the order that they appear in the Simulation description table (page 5), which follows the stages of the research process. If more than one video is to be shown in a single workshop, please ensure that a minimum of 45 minutes is allocated for each video and subsequent discussion. It is also recommended that facilitators familiarize themselves with the guiding principles of Client and Family Engagement (see table on page 3).

Setting up and running the simulations

The following steps will help you maximize the learning potential of the simulations.

Step 1: Setting up the simulation with the learners (the “Pre-Brief”)

The “Pre-brief” is defined as “an information or orientation session held prior to the start of a simulation activity in which instructions or preparatory information is given to the participants. The purpose of the pre-briefing is to set the stage for a scenario, and assist participants in achieving scenario objectives”. – Society for Simulation in Healthcare.

Tasks for the Pre-Brief include;

- Introduce the reason for the simulation
- Provide an overview of what will happen during and after the simulation (the debrief)
- Provide learners with an opportunity to ask any questions about the simulation process

Step 2: Running the simulation with the learners

- Run the video and instruct the learners not to take notes but just to watch.
- Run the video a second time and instruct the learners to note take anything that happens or anything that anyone says in the simulation that learner has an emotional reaction to.
- Following the 2nd showing of the video, allow the learners a couple of minutes to jot down their thoughts and reflections and/or expand on their reactions that they listed in the step above.

Step 3: Debrief the simulation with the learners

Many debriefing models exist in simulation so it really is about choosing the model that works well for you. If you have not had prior training in simulation debriefing, you may want to start with the Delta, Plus model which centres around two questions;

“What went well in the simulation?”

“What could be improved?”

In general, the debrief should be at least 3 times as long as the simulation (5 minute simulation = 15 minute debrief) and should cover the main messages contained in this guide. You may also want to review the learning objectives for each simulation prior to the pre-brief.

Simulation 1: Finding a Family Partner



Lesson Plan for Simulation 1:

Finding a Family Partner

Why did we choose this situation?

All situations were created out of real-life challenges that youth, family members, researchers, research staff and trainees shared throughout the simulation build process.

In the current applied clinical research environment, many grant applications require representation from key stakeholders including families and youth. It is critical that time and effort go into matching the family/youth partner to the project. Details are needed to identify a family/youth partner who has the appropriate skills, knowledge, interest, and availability for a particular project. The family/youth partner role should be co-created by the research team and family/youth partner. Project expectations should be negotiated and clearly defined with all partners prior to finalizing the partnership. Short timelines, insufficient preparation, or lack of knowledge about stakeholder roles may lead to poorly defined requests for engagement which may be difficult to respond to and lead to inauthentic engagement and tokenism.

Characters

Dr. Sarah Smith – Researcher

Ben – Youth Engagement Specialist

Background (for the instructor)

The learning objectives for this simulation are as follows:

- 1- Understand the value of building rapport and trust through time management for grant submissions and other academic deadlines to promote authentic engagement.
- 2- Co-create expectations of the role of a family/youth partners on the research team considering details such as point of involvement, level of involvement, and activities
- 3- Understand the importance of identifying the right partner, at the right time, for the right project.- Customize partnership opportunities to the specific research project and move *beyond* the generic request for an individual who fulfills certain criteria to a request that results in authentic partnership
- 4- Consider who is asked to partner and how to reach under-represented groups.
- 5- Generate a list of considerations that may impact the youth/family partnership in the project (e.g. school, family demands, timing, parking, honorariums, travel, accessible space, communication)

Scenario information (for the group)

Prof. Sarah Smith, researcher, is submitting a grant proposal for funding. One of the requirements for the grant application is youth or family engagement. Sarah has requested an urgent meeting with Ben, Youth Engagement Specialist (responsible for partnering youth leaders with research teams), to identify a youth partner who would be interested in partnering with her on her research project. The grant application is due next week.

NOTE: Although some organizations have dedicated staff to support family/youth partnership matches, we recognize that not all do. This scenario can also be applied to researchers connecting directly with families or youth to request partnership.

Video-based Discussion

Discussion point	Questions to Ask	Main Messages
Intro question: How did you feel watching the simulation?		
1	<ul style="list-style-type: none"> Describe the interaction between Ben and Prof. Smith Is the researcher's intent authentic? 	<ul style="list-style-type: none"> Authentic partnerships require thoughtful preparation. There is a risk of tokenism if this is not taken into account.
2	<ul style="list-style-type: none"> How might that encounter have been different? How could it have been improved? What information should be provided to family/youth partners before they consider a partnership opportunity? 	<ul style="list-style-type: none"> The importance of preparation and "setting the stage" before seeking a family/youth partner.
3	<ul style="list-style-type: none"> What is at risk when the role of the family/youth partner is not thought out in advance of the request? How will this request be received by potential family/youth partners? How can family/youth partners advocate for themselves when 	<ul style="list-style-type: none"> The advantage of tailored vs. generic requests for family/youth partners.

	asked to partner on a research grant?	
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Simulation 2: Partnering to Set Research Objectives



Lesson Plan for Simulation 2:

Partnering to Set Research Objectives

Why did we choose this situation?

All situations were created out of real-life challenges that youth, family members, researchers, research staff and trainees shared throughout the simulation build process

This situation was chosen because family/youth partners may have different desired outcomes for a project than others on the research team. The desired outcomes youth/families bring to the project may be driven by personal or collective concerns, hopes, or lived experiences. Depending on the stage in the research process, project outcomes maybe predefined according to the research proposal and funding opportunity and thus may not be aligned with the lived experience of the family/youth partner. Time and skill are required by all research team members to negotiate project goals and deliverables that are mutually agreeable and relevant.

Characters

Dr. Nadine Jones, researcher, has just received a large grant to study the effects of physical activity on children with disability.

Background (for the instructor)

The learning objectives for this simulation are as follows:

- 1- Construct strategies to negotiate and include different perspectives and priorities when deciding on research objectives.
- 2- Co-create partnership objectives and team member roles at the outset of a project.
- 3- Implement questions and strategies to ensure research staff and family/youth partners obtain the required information about their roles before, during and after engaging in a research partnership to ensure meaningful and authentic contributions.
- 4- Analyze the challenging distinction between research participant and research partner.

Patient information (for the group)

Dr. Nadine Jones, researcher, has just received a large grant to study the effects of physical activity on children with disabilities. Dr. Jones is meeting with three family partners (listed as Knowledge Users* on the grant) to solicit their feedback on the research objectives for this research. They are meeting for the first time in Dr. Jones' office.

*We acknowledge that family members play many different roles during the partnership process. This simulation can be generalized to any role a family member might play on a study team including, but not limited to, co- investigator, advisor, partner or knowledge user.

Video-based Discussion

Discussion Point	Questions to Ask	Main Messages
Intro question: How did you feel watching the simulation?		
1	<ul style="list-style-type: none"> • How do you think Prof. Jones and the three family partners felt throughout the encounter? • What made you feel that way? 	<ul style="list-style-type: none"> • Demeanor of the researcher can impact the relationship with the family/youth partner. • Paying attention to verbal and non-verbal cues (ie., tone, body language, etc)is also critical.
2	<ul style="list-style-type: none"> • Focus on the video – Pay attention to the communication. • What characterizes the communication between Dr. Jones and the family leaders? • What are all the individuals in the simulation thinking, feeling or wanting? 	<ul style="list-style-type: none"> • It is critical to obtain clarity around the role of the family – participant vs. partner. • Navigating the tension when there may be different priorities between the researcher and the family partner is crucial.
3	<ul style="list-style-type: none"> • How could this exchange have gone differently? • Why is it important to create a positive family experience, especially for children and youth with special needs and their families? • If you were leading this conversation with family partners, what might you do 	<ul style="list-style-type: none"> • It is critical to articulate the hopes and expectations of all members of the research team including clients and families

	<p>differently? What difference do you think that would make?</p> <ul style="list-style-type: none">• How might you as a researcher or family partner, have set this up differently to ensure expectations and roles were clearly articulated?• What are the potential impacts on a research project if family partners and researchers do not agree about the goals and desired outcomes?	
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Simulation 3: Reviewing Results



Lesson Plan for Simulation 3:

Reviewing Results

Why did we choose this situation?

All situations were created out of real-life challenges that youth, family members, researchers, research staff and trainees shared throughout the simulation build process. Choosing who will participate on a research team and why are important considerations that are tied to the role they may play on the team. Choosing a family/youth partner is no exception. Family/youth partners bring their whole self to the research team, including their lived experience, education and training. If particular elements of their expertise are ignored or unwelcome, the partnership may feel inauthentic and the family/youth partner may feel undervalued. This situation was chosen to highlight that although it may be difficult to navigate disagreement, or differing opinions within the research team, everyone's opinion and contributions should be acknowledged and respected.

Characters

Seika - now 21 years old, was previously diagnosed at age 14 with a brain tumour and associated acquired brain injury (ABI). She underwent surgery to remove the tumour along with chemotherapy treatment. Following hospital discharge several months after surgery, Seika received outpatient physiotherapy at Holland Bloorview where the focus included muscle strengthening, flexibility, endurance, and tasks of daily living. Seika and her family also had a home-based exercise program, to support one of Seika's goals to return to the sporting activities that she enjoyed. Seika has greatly improved and, experiences balance and coordination challenges when fatigued. Seika was motivated by her experience in rehabilitation to pursue graduate studies in a Physical Therapy program.

Dr. Sarah Smith - Researcher

Background (for the instructor)

The learning objectives for this simulation are as follows:

1. Identify strategies to maintain meaningful and authentic partnerships throughout the research process.
 - a. Discuss roles and expectations of partner contributions upfront and throughout the partnership process.
 - b. Invite family partners to represent the totality of their lived experience
 - c. Use plain language and define difficult or unfamiliar terminology.
 - d. Ensure the family/youth partner is involved throughout the process and not just brought in as a consultant at the end.
2. Understand and demonstrate the value of lived experience.

- a. Define lived experience.
 - b. Develop an awareness of the multiple identities and experiences a family/youth partner brings to a research project (having an acquired brain injury, participating in physiotherapy, being a physiotherapy student).
 - c. Demonstrate respect, appreciation and empathy for the family partner's lived experience.
3. Identify strategies for avoiding and managing scope creep, when an individual's role or the project outcomes move beyond the original expectation.

Scenario information (for the group)

Seika, a former client treated for an acquired brain injury, and Dr. Sarah Smith, principal investigator, are collaborating on a research project that examines the efficacy of at home physiotherapy. Data has been collected and an initial analysis has been conducted by a member of the research team. Dr. Smith has asked to meet with Seika to get her thoughts on the data analysis. The two are meeting in Dr. Smith's office.

Video-based Discussion

Discussion Point	Questions to Ask	Main Messages
Intro question: How did you feel watching the simulation?		
1	<ul style="list-style-type: none"> • Describe the interaction between Seika and Dr. Smith. • What were the issues with this interaction? • Were there things that were done right? • How do you think Seika feels? 	<ul style="list-style-type: none"> • Seika's ideas are not welcomed (watch verbal and non-verbal cues). • The importance to establishing roles within partnerships. • Researcher is using language and a manner that is not overly friendly to the youth partner.
2	<ul style="list-style-type: none"> • How can you address opinions or concerns raised by family/youth partners if /when they go beyond the project scope or their role? • What does lived experience mean? How do you honour all of the expertise family/youth partners bring to the research team? 	<ul style="list-style-type: none"> • The research is not honouring how the youth's lived experience (youth with ABI + grad student experience) shapes Seika's interpretation of the analysis.

	<ul style="list-style-type: none"> • What does the researcher's response indicate to Seika? How might this impact future engagement opportunities for both the researcher and the family/youth partner? 	<ul style="list-style-type: none"> • Capitalize and learn from different opinions (opportunity to think outside the box, to include fresh perspectives for current or subsequent studies). • The researcher appears to dismiss her enthusiasm and parts of her lived experience.
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Simulation 4: Navigating Concerns about Knowledge Translation

(Dissemination of Results)



Lesson Plan for Simulation 4:

Navigating Concerns about Knowledge Translation (Dissemination of Results)

Why did we choose this situation?

All situations were created out of real-life challenges that youth, family members, researchers, research staff and trainees shared throughout the simulation build process. Expectations around how, when and where research findings are shared may differ between family/youth partners and other members of the research team. This situation was chosen because family partners may be eager to share and implement research findings with their peers and community, while researchers are often required to share findings through publications and formal presentations. The method of sharing information, the audience, and the timing should be discussed, acknowledged and agreed upon by all team members. Information sharing should also be a continued conversation, as we know things can change.

Characters

Mary - family partner – **Mary** has a son named **Sam** who is in the first grade. Sam is greatly improving with the help of this study; Sam's family and teachers are noticing his improvements.

Kim - PhD student

Dr. Vilanpour - Kim's supervisor

Background (for the instructor)

The learning objectives for this simulation are as follows:

- 1- Construct appropriate knowledge translation (dissemination of results) activities and products to ensure the priorities of everyone on the team are adequately addressed, while ensuring the integrity of the research process is upheld.
- 2- Develop strategies to successfully navigate co-authorship discussions with family/youth partners.
- 3- Have key discussions (goal of the study; expectations; limitations) at the beginning of the partnership to reduce confusion and disappointment.

Scenario information (for the group)

Mary, family partner, has been working with Kim, PhD student, on Phase One of Kim's PhD research for two years. Phase One is a pilot study examining the feasibility of a group based early literacy program for children with disabilities. The pilot study is complete and results are ready for publication. Dr. Vilanpour (Kim's supervisor), Kim and Mary meet in Dr. Vilanpour's office to discuss next steps for publication and knowledge translation.

Video-based Discussion

Discussion Point	Questions to Ask	Main Messages
Intro Question: How did you feel watching the simulation?		
1	<ul style="list-style-type: none"> • Describe the interaction between Mary, Kim and Dr. Vilanpour. • How might Mary feel about her value as a research team member after this interaction? 	<ul style="list-style-type: none"> • Holding and respecting the family partner's and trainee's emotional response (e.g., excitement and disappointment). • The importance of the publication to the trainee. • Misunderstandings around basic research terminology.
2	<ul style="list-style-type: none"> • How might that encounter been different – how could it have been improved? 	<ul style="list-style-type: none"> • Information sharing about research publication was needed.
3	<ul style="list-style-type: none"> • What specific recommendations would you have for Dr. Vilanpour? • As a supervisor/family/youth partner, what advice might you give a trainee after this encounter? • Compare the priorities of Kim, Mary, and Dr. Vilanpour with respect to next steps. • How should knowledge translation activities and products be developed to ensure the priorities of all research team members are addressed? 	

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