

Co-Designing Video Welcome Tours with Children in Paediatric Healthcare

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Master of Design in Inclusive Design.

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Abstract

Best practices in sharing information with children is scarce in a healthcare environment, and there is limited literature that involves children as co-designers of their own information. To demystify the hospital space for child clients and their families, a co-design project was conducted and designed with two research questions: (1) How can paediatric hospitals produce meaningful information designed by children, for children? (2) What are some best practices for co-designing with children with disabilities in healthcare settings? This study's aim was to produce a video tour of Holland Bloorview Kids Rehabilitation Hospital that is co-designed by children in the disability community, for children in the disability community. The ability to assess the co-design process reflexively helped to identify practices that can inform and guide similar paediatric co-design in the future. The need for projects that are co-created and accessible online have risen. Co-created healthcare projects that centre the voices of the young disability community are feasible, applicable, and impactful, and this population should not be overlooked or unrecognized. Through this study, a template and resources are provided for healthcare systems to easily implement their own unique co-design sessions with young participants.

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Dedication

This research is dedicated to Scott, Lenny and Yuen Ngo – who always found a way.

This project is dedicated to the past, current and future clients of Holland Bloorview, who have always had something to tell us.

In particular, I recognize the passion, care, humour and advocacy of the ten participants who worked so hard to create this video welcome tour for other children. I regrettably cannot share your real names, but you know who you are:

Expert Cat
Funtendo Guy
Ginger Thunder
Luna
Malachi
Moe Szyslak
Onomatopoeia
Pugicorn
Sparkle Kitty
Stinky Cheese

Sincerely yours (and I know we're overtime),
Miss Glitter Shorts & Captain Underpants

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Introduction

In paediatric health care settings, the waiting periods for initial appointments and follow-up clinical visits are often emotionally challenging and a source of stress (Moh et al., 2012). For children's mental health services, 90% of parents report that the biggest gap in care is long waiting times and the lack of information about the transition into care (Children's Mental Health Ontario, 2019). While parents and caregivers typically manage their children's appointments and clinical information, and often serve as their proxies for decision-making, the application of a family-centred care model is receiving increased attention. A family-centred model of care involves sharing information and decisions between parents, health care practitioners, and the clients themselves, and it is increasingly viewed as a favourable way to support the emerging capacity of the paediatric patient (Coughlin, 2018). This model also helps to acknowledge and embrace the agency and critical perspectives of child/youth clients in health care.

Families take many forms and compositions, and are not only comprised of the traditional nuclear structure. The diversity of families seen in paediatric hospitals can be reflected by the involvement of the family-centred care framework, in which families can define themselves and can partner with healthcare staff. Giving accurate resources in accessible formats to clients and their families "is an important aspect of empowering clients with information that can guide their decision making and their own self management of conditions" (Frampton et al., 2008). In a recent report about the impact of giving information to families in advance of their paediatric health care visits, it was noted that parents and caregivers felt they were more supported, better connected, and knew what to expect from their child's first appointment (Penner et al, 2019; Marofi et. al, 2018). In a paediatric rehabilitation setting, Ballantyne et al. (2019) note that during hospital transitions for families, there are three key themes: "Wanting to know what to expect, feeling supported in their transition, and getting there emotionally and physically." Tourigny et al. (2011) note that giving information in advance through a virtual tour aids the well-being of the entire family.

Research problem

While numerous researchers have noted the value of providing child clients and their families with useful orientation information in advance of their visits, and there is growing acknowledgement of the value of children's input, there is a surprising gap in the research: there remains a notable need to investigate how paediatric hospitals can use digital formats to engage clients' perspectives and to disseminate information to them prior to their initial appointments. Moreover, given our COVID-19 pandemic circumstances, it would be timely and useful to develop pandemic-time digital welcome tours about how COVID-19 pandemic protocols affect visits so that they are aware of them and know what to expect prior to their visit.

Literature review

A scoping review was conducted between November 2019 and February 2020 as an initial stage of this study. The review considered peer-reviewed articles, grey literature, and media. The intent of this review was to understand what research exists (and what it has found) about involving children as co-designers of first-point-of-contact resources (i.e., resources that support clients and their families as they prepare for their first visit, such as information pamphlets, posters, or videos). In total, 18 documents presenting research about involving children as co-designers of hospital resources were identified for review. (See Appendix A for reviewed materials).

Children can be valuable partners in research (Verjans, 2018), but disabled children are less commonly involved in research than their non-disabled peers, indicating a gap in research (Bailey, et al., 2014; Flynn et al., 2019). Grootens-Weigers et al. (2017) and Comstock (2020) note that children's autonomy in healthcare settings help with their ongoing development for decision-making capacity. While there are nuances when it comes to co-creation with children such as involving them at every step, choosing the right people to lead co-creation sessions, and location of study (Whitehouse et al., 2013; Liedtka et al., 2018; Comstock et al., 2019) the capacity and potential of learning new information can be enhanced through co-creation (Stensæth, 2013; Bevelander 2019).

In research involving children with disabilities in the design of healthcare technology, "the need to involve end users within the design of healthcare technology was highlighted, with particular attention to the need for greater levels of participation from children with disabilities within all healthcare research." (Allsop et al., 2010). This view was echoed in a co-creation study for a therapeutic robot that children should be directly involved in the next iteration (Huijnen, 2017). Therefore, co-design with children for information-sharing with new patients in the disability community will likely provide insight on how to support the whole family effectively, at first point of contact.

Studies (Grootens-Weigers et al., 2017; Ciaglia, 2017; The Canadian Institute for Health Information, 2012) show that the communication of health information is one of the ways in which support the mental health and confidence of patients and families, and can be made health literate to people and children with varying levels of understanding. Research suggests that more investigation is needed around providing information to children before their first appointments. However, there is a growing number of studies that indicate using digital technologies or gamification may be a meaningful way of sharing information with young people. (Johnson et al. 2016; Boydell et al., 2014).

The reviewed studies primarily focused on children as co-designers, technology design for child-related information in health, or the importance of children's autonomy within their healthcare. Very few studies have considered all three of these topics together (Whitehouse et al., 2013). This review also identified a need to involve children in healthcare design and decision-making when it comes to their own health, as well as a best practices gap (Flynn et al., 2019; Bailey et al., 2015; Allsop et al., 2009). Further,

hospital tours and wayfinding products have been found to be effective for reducing anxiety and worry (Penner et al., 2019; Marofi et al., 2018; Boydell et al., 2014).

This study aims to address an under-researched area in academia that involves co-design with children using technology. The aims of this project lent itself to a children's healthcare environment due to the level of engagement with families in paediatric care, and existing family-centred care models in paediatric hospitals. Children are often not thought of as 'experts' next to clinicians and parents, but have critical (and often overlooked) insight as to how hospitals can improve, and can provide their own experiences to guide this work.

Research questions

This study has engaged the following problem statement: *"In healthcare, best practices in sharing information with children is scarce, and there is limited literature that involves children as co-designers of their own information."*

To engage this problem statement with a view to demystify the hospital space for child clients and their families, a co-design project was conducted and designed with two research questions in mind:

1. How can paediatric hospitals produce meaningful information designed by children, for children?
2. What are some best practices for co-designing with children with disabilities in healthcare settings?

This study has two key objectives:

1. To produce a video tour of Holland Bloorview Kids Rehabilitation Hospital that is co-designed by children with disabilities, and for new child clients and their families.
2. To assess the co-design process reflexively in order to identify some best practices that can help to inform and guide similar co-design projects in the future.

Methodology

Informed by co-design and participatory research methodologies, this study will use focus groups with children 7 to 18 years of age at a paediatric hospital to achieve study objectives. Co-design is described below by Trischler et al. (2019):

"Co-design is closely connected with the tradition of participatory design, and the argument that those affected by a design should have a say in its design process (Ehn, 2008; Holmlid, 2009). Co-design uses a collaborative team approach that allows non-designers to become equal members of the design team (Sanders et al., 2008). During the process, design tools, e.g. games, visualizations, and probes, are used to engage all the participants and to facilitate a 'joint inquiry and

imagination' whereby 'problem and solution coevolve' (Steen, 2013). In so doing, participants who are not normally involved in design activities can directly contribute their knowledge and fresh perspectives to exploring problems and possible solutions."

Within this study, the 'collective-making' (Langley et al., 2018) of a hospital tour was important to this methodology as the goal of the project includes creating shared knowledge for multiple stakeholder groups.

"Within a co-design model, we offer a specific approach to share, mobilise and activate knowledge, that we have termed 'collective making'... We describe how collective making creates the right 'conditions' for knowledge to be mobilised particularly addressing issues relating to stakeholder relationships, helps to discover, share and blend different forms of knowledge from different stakeholders, and puts this blended knowledge to practical use allowing stakeholders to learn about the practical implications of knowledge use and to collectively create actionable products."

The subsection that follows provides an overview of the research process.

Co-Design Focus Groups

Focus groups were used to support the co-creation of a video tour led by children to increase their representation in media and to help other children feel more at ease when entering the hospital for the first time. Co-leading research allows children to be 'experts' in their own lived experiences, which challenges the norm of a caregiver or medical professional being the 'expert' in the healthcare space. Children on the Children's Advisory Committee at Holland Bloorview Kids Rehabilitation Hospital have indicated that they would like to co-create such a video tour. Engaging children in a participatory co-design process to produce a video tour is an effective way to recognize children's agency and valuable input, and the viewing of the video tour will also help first-time hospital clients feel welcome. Ten participants (5 who are between 7-12 years old, and 5 who are between 13-18 years old) who are clients at Holland Bloorview Kids Rehabilitation Hospital were recruited for this study. For recruitment materials, please see Appendices D, E and F. These children participated in co-creation focus group sessions that were organized remotely and conducted online (on Zoom for Healthcare). The participants were able to communicate their ideas clearly using verbal or alternative communication methods, in English, online. These alternative communication methods include: typing using their computer or another electronic device, drawing and writing, using nonverbal body cues (such as pointing, nodding or shaking their head) or by choosing their answer when given options. They were capable of providing independent consent to participate in co-design or assent with their substitute decision maker's consent (see Appendices G and H). They were not required to come to the hospital, as onsite staff would be able to showcase spaces in the building that are needed for

feedback. Participants were recruited from the Children's Advisory and Family Advisory and Committees, where most children were already involved in feedback and projects to make significant changes at the hospital. Participants were also recruited via Holland Bloorview social media postings. The video tour is available to new clients and their families to 'visit' the hospital online so that they can explore the hospital at home and know what to expect upon arrival. This tour may also serve as a tool for bridging wait times by providing with information and resources during what may be an isolating period in families' lives.

Conducting a co-design study with children with disabilities requires a flexible research process. There were five co-design sessions in total, where it was planned that five clients ages 7-12 will meet for two sessions, and five clients ages 13-18 will meet for two sessions. For the final co-design session, all 10 participants met to review and approve what was already co-designed. All co-design sessions were planned to be shorter (e.g., 45-60 minutes maximum) than typical sessions for adults to account for the children's attention spans and comfort as they participate through online interactions. Facilitators used plain language, offer breaks between tasks, and obtained feedback in different, engaging ways (e.g., verbal or movement-based responses, artistic responses, responses via video chat functions, or voting). Some examples of feedback activities include creating a slideshow presentation to record responses, voting through Zoom (using the reaction function), creating surveys for gathering responses, and a three-point rating scale using thumbs up, middle, or down. Facilitators were Daniel Scott (Holland Bloorview Playroom Administrator) and Melissa Ngo (Holland Bloorview Family Support Specialist). Daniel is a Registered Early Childhood Educator and Melissa has a background in co-design with clients and families. Both have TCPS2 and RCR certifications prior to conducting co-design group sessions. Idea generation for feedback activities were designed between the researcher and staff who regularly interact with the Children's Advisory Committee, with attention to the needs of child participants. The co-design participants were also engaged by determining which activities they feel most comfortable using to provide their opinions on the project. Their opinions were asked at the first co-design session about how they liked to provide feedback. This is where verbal discussion, the slideshow presentation and surveys were suggested by participants. (To see an example of a survey, please see Figure 1 on page 18.) Other options also given included drawing and using reaction functions on Zoom, which participants were amenable to trying, but not as enthusiastic about. This was done to help ensure that child participants feel comfortable to provide feedback and to ensure that their input is present from the very beginning of co-design.

Co-design materials and activities were meant to be appealing and fun to ensure ongoing engagement throughout the co-design process. Since participants were directing the co-design itself, they not only were more invested in these sessions but also had a sense of co-ownership over the process, proving this to be an effective engagement strategy. The facilitators' knowledge and familiarity with children and co-design also contributed to active participation as they were able to adjust as needed. For example, facilitators often would rephrase questions, give examples, or make references that children were able to recognize. The final product was reviewed with the

co-design participants for them to approve before sharing outside the group. During these sessions on Zoom, photos and videos were not collected to ensure confidentiality of the participants. However, examples of the activities are shown in the Presentation of Findings section below.

Reflexivity

To support co-design sessions' aims, the facilitating researcher has incorporated reflexivity practices to question their biases, how their positionalities relate to the research and participants, whose voices are being heard and not heard, if engagement techniques are working as intended, and more. This reflexivity practice involves the facilitating researcher undergoing 'kitchen table' reflexivity (Kohl & McCutcheon, 2015) following each co-design session by having a discussion with another research team member (e.g., Sium, Wyndham-West, or Ross). These discussions considered how the co-design session unfolded, its positives and negatives, a reflection on how the researcher' and their positionalities relate to the research and participants, and potential changes that could be made in future sessions. For example, staff co-design facilitators completed debriefs after each session, and compared field notes with discussion on how each session could have improved, or if there are different strategies for the next co-design session. Dr. Timothy Ross provided input with the staff facilitators afterward, adding additional perspectives and suggestions. Often, different activities were suggested, and reminders between staff facilitators that each session could look completely different was helpful. This practice would eventually help with identifying challenges and best practices for co-designing with children in a health care context.

Videography

A videographer, Carmela Ferro was involved in this project. Carmela has produced documentaries and video projects with children previously, and fully understands video accessibility standards. This videographer has provided a quote for services, which has been incorporated into the study budget (see Appendix C). The videographer was given the option to join the virtual co-design sessions, depending on the children's input and desires, and opted to join in on the final co-design session. Children who were involved in co-design sessions were very interested in presenting the video tour, as expressed in co-design sessions. Any child/youth participating in video production in the hospital (e.g., by narrating) completes a Holland Bloorview communications and video consent form.

Risks and Confidentiality

For the purposes of co-design, participants were asked to disclose their name, age, and method of communication. As they provide input, co-design participants may have recalled when they entered a hospital for the first time, or recalled certain periods of

anxiety, fear or worry upon entering a healthcare space. They were assured that confidentiality will be maintained throughout the research, they could leave the study at any time, and they could speak with a Family Support Specialist or staff about their experiences afterward if need be.

Data was collected and stored confidentially on the hospital's secure server, and any physical or paper materials were locked and stored in an office within Holland Bloorview Kids Rehabilitation Hospital. A master list of co-design participant identifiers was kept on the hospital's secure server. Since participants were recruited through established groups or networks for hospital clients and families, access to the medical health record was not necessary.

Presentation of findings

Recruitment and onboarding process

Co-design participants were confirmed to be existing Holland Bloorview clients, meaning that they have been to an appointment at the hospital within the last two years.

After discussing with each participant and their substitute decision makers, groups were formed based on age, with one exception of a client who felt more comfortable in a younger age group.

Group 1, which was meant to have a 7-12 age group, consisted of:

- three children with developmental disabilities
- three children with physical disabilities
- three females (self-identified and/or parent-identified)
- three males (self-identified and/or parent-identified)
- ages 9-13

Group 2, which was meant to have a 13-18 age group, consisted of:

- two children with physical disabilities
- two children with developmental disabilities
- one female (self-identified and/or parent-identified)
- three males (self-identified and/or parent-identified)
- ages 13-18

During the recruitment process, many participants (from both the above groups) expressed that they wanted to provide their own email addresses in addition to their parent's, caregiver's or substitute decision maker's email addresses. This allowed for

more direct communication with young participants, increased the amount of autonomy, and contributed to the feelings of true involvement with this study.

Families also preferred having the consent phone call on Zoom rather than on the phone, noting that this would be more engaging for their child during the consent process. This allowed participants to not only engage with the staff, but perhaps deepened their understanding of consent and assent as there were both able to see and hear the staff member they were speaking with. Assent forms that were written in plain language were more helpful to use during these calls, and appropriate to use when discussing the project with the young participants. Overall, the usage of plain language was beneficial throughout the study. For the consent form and assent form in plain language, see Appendices G and H.

Before co-design began, emails were sent that prepared participants with the questions that they were going to be asked in co-design sessions (see in Appendix F), along with the date and time of the session, and Zoom link. These questions can also be found in the 'Building the foundation of a co-design process' section below. These sessions took place over the span of three weeks, with the following age groups:

Table 1: Co-design schedule

Co-Design Session 1A	Ages 9-13	June 29, 2021
Co-Design Session 1B	Ages 9-13	July 6, 2021
Co-Design Session 2A	Ages 13-18	July 12, 2021
Co-Design Session 2B	Ages 13-18	July 14, 2021
Co-Design Session 3	All participants	July 19, 2021

These dates were decided upon due to the availability of the participants. The full project timeline can be found in Appendix B.

Building the foundation of a co-design process

At the beginning of each co-design session, participants were reminded first and foremost about privacy, ability to leave the study, and taking breaks when the session commenced. When everyone understood these reminders, the session started with ice breakers which helped the participants find common ground in some cases, and help them to feel comfortable and acquainted with sharing their ideas on Zoom. Participants were then led through the Focus Group Guide that was developed by staff facilitators prior to co-design (found in Appendix I).

Below are some questions that were used in the Focus Group Guide. For full Focus Group Guide, please see Appendix I.

Warm up/rapport building:

1. Can you each introduce yourself with your code name, and tell us about one activity or hobby that you like to do in your spare time?

2. Can you tell us in a sentence or two about why you wanted to help create a video welcome tour for other kids at our hospital?

The co-design questions included:

1. How long should the tour be?
 - a. For younger participants, this question may include options such as “5 minutes, 10 minutes, or 15 minutes”
2. If the tour is a video, should it be one single video that kids can watch all at once, or should it be a set of short videos where you can choose your own adventure?
3. What feelings do you feel now when you walk into Holland Bloorview?
4. What feelings do you want other kids to have when they walk into Holland Bloorview for the very first time?
5. How many places should we visit on the tour, keeping in mind that we have set a time limit?
 - a. For younger participants, this question may include reminders that we set out a time limit for the tour, and asking them ‘how many places do you think we can visit in ____ minutes?’
6. Which places or areas should we visit on the tour?
7. What are your favourite things about the areas that will be on the tour?
8. What should we say in the video script about each area?
 - a. For younger participants, this may include asking ‘how would you introduce this area to a friend?’
9. Where and how should kids and their families find the tour?
 - a. For younger participants, this may include providing options such as Youtube, website, or social media.
10. Review questionnaire that will be given to survey participants
11. What did you think of this experience overall?

Participants were asked in their very first co-design sessions how they prefer to give feedback during co-design sessions, with the promise that staff would integrate activities into the three sessions that they would participate in. Below is how the question was phrased to the participants. The options were also typed out in the Zoom chat so that participants could see the options.

“These are some ways in which you can give your opinion on questions that we’ll ask you later in the co-design sessions. Can you tell us which ones you like the best? What ways would you like to give your opinion?”

- Option 1: Voting through Zoom
- Option 2: Open discussion by verbally talking or typing in the text box
- Option 3: Draw out your thoughts on a piece of paper and explain it over Zoom
- Option 4: Rank or think of your top three answers and tell us
- Option 5: A ‘take home’ project where you come back with thoughts for the next co-design session
- Option 6: Are there other ways you’d like to give your opinion?

The two groups identified different co-design activity preferences, which allowed the staff facilitators to weave in these activities during the sessions:

Group 1

- Surveys
- Verbal and chat discussion
- Ranking
- Powerpoint slideshow

Group 2

- Verbal and chat discussion
- Ranking
- Live voting

This helped the sessions to be centred on the opinions of the participants and provided leadership by them for co-creating the flow of sessions. It helped with relationship-building between the staff facilitators and participants, in showing that the staff were listening and learning from the participants on how their co-design process should be created in the first place.

Participants then were asked to set the parameters of the welcome tour before starting the decision-making process. They voted on the length of time of the tour, where other clients and families can find or access it, and if it should be one video or a set of many videos. After much discussion about the advantages and disadvantages of each, participants agreed that the hospital video tour should be:

- Approximately 15-20 minutes
- Found on the hospital's Youtube account, the hospital website (www.hollandbloorview.ca), and the hospital's social media
- 6 separate videos, highlighting each floor (from basement to fifth floor), and act as a 'choose-your-own-adventure' where clients can pick which floors they want to visit in the order of their choosing.

These discussions included calling on each participant to ask if they'd like to answer, with different participants responding in different ways. This included verbally or typing their answer in the chat function of Zoom. Staff facilitators also implemented using the 'share screen' function of Zoom to show a Powerpoint slideshow where one staff facilitator recorded participant answers. This responded to the feedback that Group 1 provided, but this was beneficial strategy for both groups as they could visually see their responses and others' responses recorded live. This was consistently utilized throughout all five co-design sessions.

Participant responses and consensus building

Through co-design sessions, participants answered questions about their feelings when coming to the hospital. This revealed emotions and thoughts related to entering the hospital after many visits, compared with feelings they may anticipate other children to be feeling when they enter the hospital for the first time.

The first question was, "How do you feel when you go to Holland Bloorview (currently)?" Below are some examples of responses to this question.

"I feel like home when I go to this amazing hospital."

"I feel very comfortable now because over the years I've been there I've gotten to know everyone I just feel like I'm in good hands I know the hospital, I trust it, I feel so comfortable walking into Holland Bloorview.... that's what I want everyone else to feel I want them to feel like they know the hospital."

"If it's necessary for them to be there, I want them to be happy there."

"It's a whole village with a school, playground and dentist which is pretty awesome. You actually build a connection."

"I feel very happy and comfortable when I go into Holland Bloorview because I've already been there for so long, I know all the people and I trust them, I could navigate the entire hospital blindfolded."

"I feel excited when I go into Holland Bloorview, it has video game systems."

"You meet a lot of new friends, I met a lot of new friends when I went into the playroom."

"When you go back in, you're saying hi to old friends, and they do a good job of knowing everyone."

"When I go to Holland Bloorview I am really excited to achieve new skills and goals."

"I feel amazing and relaxed, and all that stuff, that's all I can say... Happy. Never sad never scared and never mad."

"I feel like I know where everything is and it's easy to navigate, and I feel comfortable."

The next question was, "How do you want people to feel when it's their very first visit?" Below are some examples of the responses to this question.

"I want people to feel really excited, really happy to go to the hospital after they see what we have created."

"Happy, not scared or nervous anymore."

"I want them to feel comfortable like they know the place...obviously they're not going to know the place – but I don't want them to feel they're walking into a random hospital, and I don't want it to be all scary. I want them to get to know the place for what it is, get to know the place and the people - and to not be scared."

"I want them to feel happy and excited to go there and not be scared. I know that at Holland Bloorview, it is really fun!"

"I want them to feel amazed but not too nervous!"

"I want people to have positive feelings, feel welcomed and so on and so forth."

"I want them to feel welcome and comfortable to be there. Happy also."

"Happy, positive, I want them to think that they are in a good place and all that stuff."

Participants were asked for the most important spaces to them in the hospital. Through a brainstorming session, participants presented ideas and voted on the hospital spaces that they would like to feature on the tour. The first group (aged 7-12) brainstormed individually at home since they had taken the co-design session time to discuss more in depth, and the second group brainstormed during the co-design session as they were quicker with discussions. Identified were 25 spaces for visiting, with consensus from all 10 participants in the final co-design session:

- | | |
|--|---|
| 1. Front of Holland Bloorview Kids Rehabilitation Hospital | 14. Dentist |
| 2. Front lobby | 15. 3 rd floor units: BIRT, SODR, CCC |
| 3. Pool and change rooms area | 16. Inpatient hospital room |
| 4. Gym | 17. Inpatient kitchen and dining area |
| 5. MRI machine | 18. Snoezelen room |
| 6. School | 19. 4 th floor front desk and waiting area |
| 7. Spiral Garden | 20. Prosthetics and orthotics area |
| 8. Ronald McDonald Playroom | 21. Bloorview Research Institute and lokomat |
| 9. Family Resource Centre and Health Sciences Library | 22. Communication and writing aids area |
| 10. Cafeteria | 23. Foundation |
| 11. Elevator | 24. Accommodations |
| 12. 2 nd floor waiting area | 25. View from the fifth floor |
| 13. Outpatient therapy room | |

The survey created by staff facilitators for the first group's (aged 7-12) brainstorm is below.

Figure 1: Brainstorming survey for tour locations

Tour Spots at Holland Bloorview

Please list the spaces at the hospital that you think should be on the welcome tour! We will review all of our answers together, at our next co-design session. List as many as you would like. Keep in mind that we decided our tour should be 15 minutes long. Thank you for your ideas in advance!

Are there spots/rooms/areas on the first floor that you think should be on the tour? If so, list them here.

Long answer text

Are there spots/rooms/areas on the second floor that you think should be on the tour? If so, list them here.

Long answer text

Are there spots/rooms/areas on the third floor that you think should be on the tour? If so, list them here.

Long answer text

As homework for the participants in their second co-design sessions, they were asked to come up with a few sentences describing each of the places in the above list, given two prompts. This provided the skeleton for a script that would be reviewed in the final co-design session:

"This is _____. Kids might come here when _____.
At the _____, you will find _____.

Participants came up with a number of responses that were then voted on in the final co-design session to determine which parts should become part of the hospital tour script. This can be seen in the figures below, where popular responses were highlighted.

Figure 2: Example 1 of PowerPoint slide during discussions for scripting

This is the pool and change room area. Kids can come to the pool when...

- They go swimming
- They are doing school, swimming lessons and therapy
- Swimming
- they have swimming lessons or aquatic therapy.
- you can go swimming in here
- for swimming lessons or therapy
- they have swimming lessons
- they have swimming lessons, or when there is Free Swim.
- They have swim therapy or if they are signing up for lessons. Or if they go to school here.

Figure 3: Example 2 of PowerPoint slide during discussions for scripting

At the pool and change room area, you will find...

- * One long pool and another enclosed hot tub
- Changing rooms, showers, and bathrooms
- The change rooms have nice big adjustable tables and one of them is for families. The pool has a big ramp to get in. There is also a small snoozlen pool that is really warm.
- you can get changed here
- shower and bathroom
- Ramp on the pool to exit the pool
- A big pool in the middle of the room. Outside of the room, you will find the pool staff room. This is where the swim teachers and pool staff watch the kids and adults while they swim and make sure that they are safe. On the other side of the pool, you'll find the locker area where kids and sometimes adults can get dressed into their swim suits and swimwear before coming into the pool to swim.
- Washrooms, accessible changerooms, water transfer chairs, a lot of toys and a lift to help get in the pool. You would also find lifeguards.
- ** change to: "Universal changeroom"

This portion took longer than expected as there was much discussion. As a result, there was also homework for the final co-design session. However, this led to a rich script that many participants have contributed to and accurately describe each area of the hospital.

As an example, the final script for the pool and change room area of the hospital reads as such:

“This is the pool and change room area. Kids can come to the pool when they have swimming lessons, swim therapy or if they are going to school here. At the pool and change room area, you will find that the pool has a big ramp to get in. There is also a small Snoezelen Pool that is really warm. Around the pool, you will find the pool staff room. This is where the swim teachers and life guards watch the kids and adults while they swim and make sure that they are safe. You’ll also find that the change rooms have nice, big adjustable tables and one of them is for families. There are washrooms, water transfer chairs, a lot of toys and a lift to help get in the pool. Our changerooms and pool are accessible.”

Throughout the sessions, participants also expressed why they wanted to help co-design this welcome tour in the first place. Below are examples of their responses:

“When I came to the 3rd floor [inpatient floor] of the hospital for the first time, it was hard to find information. I want to fix that.”

“They have no information. I’d be able to bridge that gap.”

“Kids should know about Holland Bloorview. There are a lot of rooms and spaces that are really cool.”

“I wanted to do this so I can give them tips in the playroom when they’re playing video games.”

“People don’t know what to do when they come here.”

Overall, while there were times that the participants wanted to talk longer and discuss more (some sessions ran overtime by 45 minutes), and there was a need for additional take-home work, consensus-building during co-design was significant to the final product and to create a team environment. After each co-design session, participants were asked for their thoughts on the session. 100% of participants agreed that they had a positive experience in every co-design session and 100% of the participants agreed that they felt they were heard.

Table 2: Survey responses for co-design sessions 1A, 1B, 2A, 2B, 3

Question	Response Options	Result
How did you feel about today’s session?	Bad, Okay, Good	100% - Good
Do you think you got to say everything you wanted to say?	Yes, No	100% - Yes

Do you have anything else you want to tell us that we have not asked you about?	Yes, No (if Yes, what what is)?	100% - No
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Participants were also asked two open-ended questions about co-design sessions:

1. What is your favourite part about today's session? (open-ended)
2. Was there anything you didn't like about today's session? If so, what was it? (open-ended)

Participants consistently noted that they liked talking to everyone about their opinions, they liked talking about the spaces at the hospital and liked voting on their favourite options. Some of their responses included:

"This was so fun. I liked talking to everyone!"

"I liked when we talked about the spaces that I knew about!"

"Voting on my favourite things."

"I am so excited to see this tour!"

"I learned about other spaces."

"I can't wait to film... please let me sign my name up to be a host. I would really like to host this tour."

The only feedback that participants had on the sessions that they didn't enjoy, were that they ran overtime. However, many also asked if they could say "one more thing" or if they could discuss the next area after being reminded that the sessions ran past 1 hour long. Many also wanted to be reminded of when the next co-design session would take place so that they could attend.

Participants expressed that they wanted to be a part of presenting the tour and help move the tour into production as well. Many of them either expressed interest in being behind the camera, or hosting certain areas of the hospital on the tour. They were excited to talk about how they could be featured in it and when they could come in to help film. This required an addendum with the Research Ethics Board, plus additional partnership with the Communications and Public Engagement team of Holland Bloorview.

Staff facilitator reflections

Staff facilitators practiced flexibility in co-design throughout the entire process. Accounting for the speed of discussions for two different groups, the different types of activities dictated by both groups, the length of activity or moving the activities forward, having different co-design tools at hand, managing time and constant iteration of the co-design process were all part of the facilitator's duty. Below is an example of a

presentation prepared by the staff facilitators to discuss video tour spots in the final co-design session.

Figure 4: Example 1 of PowerPoint presentation for participants



Figure 5: Example 2 of PowerPoint presentation for participants

1ST FLOOR	
GROUP 1 (AGES 7-12)	GROUP 2 (AGES 13-18)
SCHOOL	SCHOOL
SPIRAL GARDEN	SPIRAL GARDEN
PLAYROOM	PLAYROOM
LIBRARY	ELEVATORS (BOTH SIDES)
CAFETERIA (including Tim Hortons and food area)	FRONT ENTRANCE

Staff also demonstrated reflexivity when creating the co-design process, as acknowledging that the lens and assumptions that they came with could and would constantly be challenged by the participants. As the process was being built through consensus by the participants, staff were there not to be the 'experts' in healthcare nor co-design, but as facilitators to ensure that everyone's opinions were included and decision-making was fair and concise.

The code names of every participant and staff facilitator proved to be more humorous and engaging than staff had thought. Participants enjoyed choosing their own names, that could be anything they wanted, and this brought liveliness to each session. They specifically enjoyed that staff also had amusing names as well. Participants did extremely well at using everyone's code names even if they knew each other from other experiences at the hospital. Additionally, asking questions about why each participant wanted to join co-design sessions was meaningful not only to staff, but to children as well. They were able to build consensus right from the beginning, and understood that each person wanted to be there for a similar reason. The participants enjoyed hearing about others' experiences and adhered to using each other's code names during the session even if they had known each other previously. The staff leads (both co-design facilitators and note taker) also shared about themselves, and chose code names which was engaging for the participants as well.

The usage of smaller groups (divided by age) that then amalgamated into one larger co-design review session at the end was beneficial for the process. Each group had unique perspectives and knowledge to bring, and engaging in small groups online allowed participants time and space to provide their opinions. It allowed for a wider range of children to provide feedback, but also enough space, and a comfortable space, for each participant to share their opinions. Additionally, having a minimum of two staff members to conduct sessions was helpful for moving activities forward and collecting information and data throughout the session.

It needs to be acknowledged that the younger age group wanted to do more surveys during the co-design sessions. Staff facilitators designed a few surveys through Zoom for their second co-design session, however many of the participants were confused by it and didn't quite know how to use it. By pivoting to voting live with hands, reactions or the chat function through Zoom, the activity was able to move forward. However, staff discussed the possibility that the younger age group has seen their caregivers, parents, siblings or school mates use surveys online, especially during the pandemic. It is possible that they wanted to reflect what has been modeled to them in other instances or situations throughout the pandemic. As this caused staff to spend more time on a specific activity, facilitators were reminded that each co-design session could look very different from the next, and that the preparedness of back-up feedback activities was key.

From these findings, best practices for co-design with children in healthcare were identified and explained below.

Best Practices for Co-Design with Children in Healthcare

1. **Use plain language.** When describing the project to possible participants and their caregivers (or substitute decision makers), it is important to speak directly to the participants (alongside their caregivers). In this study, creating both a consent form for signing, and an assent form in plain language were helpful for explaining the project. Children understood the research study process that includes privacy, risks and benefits.
2. **Recruit for a diverse set of children.** Each participant's unique lenses made for rich conversation, appropriate decision-making, and more relevant material for the resource that was created. Children were recruited with intention for diversity in type of disability (developmental, physical, acquired), gender, age, communication style, and race. Children do not need to be verbal to participate.
3. **Involve participants in every step of the creation process.** It is important to include participants at every step in the process and to clarify and validate their opinions. In this project, children were involved in the idea pitch stage, the consent and assent process, the co-design process itself (in choosing how they wanted to provide their opinions), the concept creation, script creation and production of the video tour.
4. **Implement unique identifiers and the reason for joining.** Asking each participant to provide some information about themselves at the beginning of each session (e.g. a 'code name' and why they wanted to join co-design sessions) were not only beneficial for privacy and creating common ground, but had a positive impact on their engagement level before co-design even began. This allows participants to be uniquely positioned while understanding that everyone is there for very similar reasons.
5. **Use a familiar video calling platform if possible (if co-design is online).** Children from this hospital were familiar and knowledgeable about how to use Zoom and troubleshoot if there were internet issues, and/or if they wanted to use the chat or react function. During the pandemic, school had been conducted largely through Zoom.
6. **Group by similar age ranges, making appropriate exceptions.** With a wide age population (0-18), it was helpful to split up the groups first by age, then to reconvene at the end with all participants to review content. This ensured that participants were comfortable with each other and were able to see themselves reflected in the group. Accounting for developmental age is an additional consideration that may be beneficial.
7. **Implement small groups for fair engagement.** In this research project, five participants per co-design meeting (which was approximately 45 minutes to an hour) was manageable for two staff and allowed for engagement of every

participant. Staff were able to ensure each person could provide opinions for every question. In the last co-design session, all ten participants were able to review and quickly provide an opinion for consensus.

8. **Participants with varying experiences contribute to a rich co-design.** Holland Bloorview is fortunate enough to have a Children's Advisory Committee with a number of diverse children who are very comfortable and aware of the feedback and co-design process, in addition to being ambassadors of the hospital. Children were recruited from this advisory committee for this project, in addition to children who were not a part of this committee. Valuable contributions were made by children who were new to giving their feedback, and could share their lens as someone involved strictly in clinical services. All were incredible contributors to this project.
9. **Build in extra time.** The extra time that was needed was put toward: a quick ice breaker at the beginning (asking everyone what hobby they liked, or what they did on the weekend); extra discussion on specific questions; or additional conversation at the end. Having an additional co-design session would also be helpful if staff are not willing to assign 'homework' between sessions.
10. **Prepare your sessions beforehand with a multitude of questions and opinion-gathering tools to use.** This allowed staff facilitators to be agile if participants preferred to answer questions or provide an opinion in various ways. It also ensured that participants were co-designing the meeting itself, which made it more engaging. Some of the tools that staff facilitators prepared were: online surveys, quizzes, slideshows, drawing tools, reactions, chat functions, and raise hand functions. Each co-design session will look different from the last.
11. **Have at least two staff facilitators (who are both familiar with online tools, if co-design is done online).** It was beneficial when one staff facilitator was able to facilitate the activity and manage group discussion while the other set up the activity and/or created the activity with the online tools. In this study, we had a third facilitator who specifically took notes. Staff facilitators also benefitted from reflexive discussion after each co-design session.
12. **Compensate and/or recognize your participants.** These participants have put in several hours and thought into their feedback and should be recognized in some way throughout the process.

Discussion and limitations of the study

It is first and foremost recognized that this research is conducted from a privileged lens, hospital and environment. Not all hospitals, healthcare facilities, clients and families or geographical areas will have the means to purchase or obtain technological equipment or videography services, have access to internet, or have staff or participants that

understand the intricacies of using virtual services and tools. In other healthcare settings where this is not readily available, there will need to be more research and intentionality to evaluate and perhaps increase access, before a project like this could be undertaken. Future research could potentially focus on the accessibility of healthcare co-design with children using technological equipment in particular areas or regions. Or, future research could focus on healthcare co-design with children in person. In these cases, researchers may need to host sessions (when it is safe to do so), and rely on more traditional tools and activities for feedback that could include markers and paper, sticky notes, stickers, and paper surveys. It also should include other considerations for accessibility, such as participants' safe travel to a meeting place. These materials and considerations would require a different budget than this project. Please see Appendix C for this study's budget.

Participants in this study were able to communicate in English. Although some preferred and used different methods of communicating in co-design sessions (e.g. through typing or using the chat function of Zoom), all were also able to express their ideas verbally. Exploration is needed in both including and investigating co-design with participants who use a variety of different languages, have limited vision or vision loss, or use alternative methods of communication (other than verbal skills or typing).

Although subtitles have been added to the final video tour, these subtitles are also in English. Additional work is needed for the video tour to provide a script in different languages and/or to obtain translation.

All participants were enthusiastic to participate and felt comfortable participating even if they hadn't had experience in co-design previously, did not consider themselves to be 'outspoken', or didn't know any other participants of the co-design session. As this project didn't have any participants who were averse to participating, this data does not include how to anticipate issues with participation and/or when a participant refuses to join in on conversation and discussion.

Study participants also felt largely positive about their hospital experiences, and noted that they felt a sense of comfort and ease when being at the hospital. It is worth noting that there were not negative experiences discussed by the co-design participants except feeling some anxiety about getting vaccinations or needles.

Lastly, although this research was initially planned to include in-person co-design sessions at the idea generation phase, the COVID-19 pandemic caused the research team to turn to virtual co-design. Although there are still applicable best practices for both in person and virtual co-design included in this study, there may be other considerations and best practices that could have been explored if sessions had been conducted in person. For example, other family feedback practices in healthcare include providing funding for parking and/or travel to and from the meeting site, providing a meal if conducting meetings during mealtimes, and providing childcare for siblings during feedback sessions. Meeting places need to meet accessibility standards (doorway widths, automatic door entry, elevators, and accessible washrooms for

example), and consideration for other accessibility needs should be taken into consideration (such as the availability of a sign language interpreter, instead of utilizing live captioning through Zoom). Children may also benefit from being able to be in each other's presence and/or moving around the room for breaks, or to complete co-design activities.

Practical implications and future iterations

The co-designed hospital video tour will be shared with new families who will be entering the hospital for the first time through the hospital's Outpatient Orientation program. It will also be put on the Holland Bloorview website in the resources section for families so that future clients and families can access it at any time.

This tour acts as a choose-your-own-adventure for different floors of the hospital. There are six floors that will each receive their own video, plus an intro and exit video (with a total of 8 videos to watch). Viewers can choose which floor they want to visit after each video ends. This video will be featured on the Holland Bloorview website at www.hollandbloorview.ca and also on Holland Bloorview's Youtube channel at www.youtube.com/user/PRBloorview, as per the participants' suggestions.

There will be an additional survey given to new viewers of the tour to evaluate whether or not this tour was helpful, effective and relevant for them. These findings will also be important to determine the validity of co-design by children, for children, in paediatric healthcare.

Standardizing compensation and recognition for the work that young co-designers do is significant both to the fields of inclusive design, healthcare and the designers themselves (Russell et al., 2000; Grant et al., 2004; Grady, 2005). This allows both: these fields to recognize the emotional and practical work that was achieved through engaging diverse populations and sends the message to young patients that their voice and feedback is not only respected, but powerful. Genuine and meaningful co-design may contribute to the increase of trust and care between healthcare systems and the disability community. It is noted with heaviness, that there needs to be reparations and active change by healthcare systems for past and present harm and violence, discrimination, exploitation, loss of autonomy, and eugenics that have contributed to the mistrust and injustices that the disability community faces regularly (Braveman et al., 2011; Krahn et al., 2015). It is with hope that this project encourages healthcare staff and systems to hold their patients' ideas, feedback, and voices to high esteem and to help shift existing and long-standing power imbalances.

The research team anticipates peer-reviewed publications about this study's co-design methods, and an additional findings paper that reports the survey results. Content will also be prepared to present these findings at healthcare conferences and symposiums. The intent is to produce publications and opportunities that will help to advance and normalize the practice of co-design in paediatric healthcare settings.

Conclusions

Co-design research with children in healthcare was long overdue, given the body of research on involving children in their own healthcare, the importance of co-creation with end-users, and the effectiveness of technology in healthcare settings. Continued efforts made toward co-design with children may lead to better outcomes in family mental health, client self-advocacy, and a smoother healthcare journey in transitional periods. This project meant to challenge the idea that children were not valuable co-designers of their own information. It is the hope that this study will support healthcare systems in co-designing with young clients and patients more often, instead of viewing the process as unattainable. Participants were knowledgeable, enthusiastic, passionate about the work, and eager to share. They have created a resource that was not only important to them but understood the effect it would have on new clients of the hospital. Healthcare projects that are co-created and centre the voices of the young disability community are feasible, applicable, and impactful.

The need for more engaging digital learning materials has been enhanced by the current pandemic. It also speaks to the strategic directions in which healthcare may change in the future, with additional services and supports being maintained or added virtually. Although not new, stark inequities in healthcare have been illuminated by the pandemic, both locally and globally. Virtual resources may create better access to services, alleviate concerns before entering the hospital or attending an appointment, counter in-person staff unavailability, or bridge the gap while on a waitlist. Evaluating the effectiveness of the co-created resource will be explored in the future through surveying new clients.

Children's feedback in healthcare should not be overlooked or unrecognized, and is especially critical in paediatrics as they learn to advocate for their own healthcare. Typically in paediatrics, healthcare staff's (learned) instinct is to veer toward parents and caregivers first for expertise and information on their child, however this needs to be questioned. There has been incredible value in involving children in the disability community as experts in their own health, bodies and care. It will not only ensure that hospital services are appropriate and client-centred, but will also set children up for success and obtain the skills they would need in adulthood. A welcome and much-needed change to paediatric research, initiatives and projects involves pivoting the lens of expertise to centre the young disability community, in order to create healthcare that is equitable and accessible.

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Appendix A: Scoping Review

Table 3: Studies on the impact of children as co-designers in healthcare research for first-point of-contact resources

Study	Sample	Study Design	Key Findings	Comments
ACADEMIC JOURNAL Allsop, M. J., Holt, R. J., Levesley, M. C., & Bhakta, B. (2009).	n/a	This literature review aims to identify research methodology that involves children with disabilities in the design of healthcare technology.	The need to involve children within healthcare technology design was highlighted, pointing to the need for greater levels of participation from children with disabilities within all healthcare research.	Verifies that there is a lack of children with disabilities involved in co-creation in healthcare technology.
ACADEMIC JOURNAL Bailey, S., Boddy, K., Briscoe, S., & Morris, C. (2014).	n/a	This review collated recommendations for involving disabled children as partners in research; however, few well-reported examples were identified. Systematic review where twenty-two papers were included.	The importance of developing effective communication methods when involving disabled children and young people in research was a common theme among papers identified by the review, particularly for those with non-verbal communication	Verifies gap in research on co-design in healthcare with children who identify as disabled and also any best practices.
ACADEMIC JOURNAL Bevelander, K. E., Laset, E., Zeinstra, G., Molleman, G., & Kwakernaak, L.	n/a	The local health authority of the city Nijmegen in the Netherlands started a program in collaboration with the local hospital, university, city council, restaurants, primary schools and children's	During the co-creation lessons at schools, children became more aware of unhealthy food.	Focused on healthy eating, does not go into detail about the co-creation process or demographic information, does not target children who identify as disabled, nor does it provide best practices for

Study	Sample	Study Design	Key Findings	Comments
(2019, November 13).		council to promote healthy kids' meals.		accessibility.
ACADEMIC JOURNAL Boydell, K. M., Hodgins, M., Pignatiello, A., Teshima, J., Edwards, H., & Willis, D. (2014, May).	n/a	A scoping review on the use of technology to deliver mental health services to children and youth in order to identify the breadth of peer-reviewed literature, summarize findings and identify gaps.	The use of technologies will play a major role in the future delivery of mental health programs aimed at providing prevention, assessment, diagnosis, counseling and treatment programs.	Demonstrates the effectiveness of designing health-related programs with technology, does not identify many co-creation research studies.
GREY LITERATURE Comstock, J., & Mobi Health News. (2019, November 27).	n/a	n/a	Best practices on co-design need to include patients early, often, and in all five phases of the co-creation process. Five phases identified as co-ideation (the initial brainstorming of the product), co-design, co-evaluation (exploring the different possible ideas), co-test, and co-launch (involving patients in the marketing process).	Does not target children who identify as disabled, nor does it provide best practices for accessibility or paediatric healthcare in specifics, as this is a consumer business website.

Study	Sample	Study Design	Key Findings	Comments
ACADEMIC JOURNAL Coughlin, K. W. (2018, April 12).	n/a	Position statement from the Canadian Paediatric Society, and summarizes legal age decision-making capacity, role of sole decision makers, and recommendations for moving forward.	The participation of children and adolescents in health care decision-making should increase in proportion to their developing capacity.	A position statement on children's decision-making and the collaboration between health care providers, caregivers and the patient themselves.
ACADEMIC JOURNAL Flynn, R., Walton, S., & Scott, S. D. (2019).	n/a	Scoping review of various strategies that have been used to engage patients and families in pediatric health research.	Findings show that there is a gap in guidelines and strategies for child involvement. Developing such evidence can provide more rigorous guidance to child health researchers who want to engage patients in their research.	Verifies gap in strategies on co-design in healthcare with children, and the need for evidence-based research.
ACADEMIC JOURNAL Grootens-Wiegers, P., Hein, I. M., Broek, J. M. V. D., & Vries, M. C. D. (2017).	A population of pediatric patients between 6 and 18 years of age was studied	Aim was to contribute to insights on the complexity of children in medical decision-making. Decision-making capacity standards were measured with the MacArthur Competence Assessment Tool (MacCAT).	Children should be increasingly involved in decision-making when it comes to their health, and information needs to be adapted to the child's level of communication and understanding. At the age of 12, children may have the capacity to be decision-making competent, given favorable environmental factors, however, may need	No other demographic information was shared, mostly used existing research to compile conclusions.

Study	Sample	Study Design	Key Findings	Comments
			support of facilitating environmental factors.	
<p>ACADEMIC JOURNAL</p> <p>Huijnen, C., Lexis, M., Jansens, R., & de Witte, L. (2017, October).</p>	<p>Participants (n=22) were service providers for people with Autism Spectrum Disorder (ASD), people with ASD, their partners, or parents of children with ASD in the Netherlands</p>	<p>The aim of the co-creation sessions was to create new therapy robot interventions for children with ASD, incorporating the identified requirements of the focus groups, in a multidisciplinary group of participants.</p>	<p>A total number of 10 new mediated interventions were created during the co-creation sessions. The aim was to increase chances for clinical relevance and uptake and overcome typical barriers for robot mediated interventions to reach clinical applicability, but they have not researched the effectiveness of the interventions.</p>	<p>A Netherlands-based study, with a lack of description on the effectiveness of a therapeutic robot. Although co-creation was done with adults, creating (regular) evaluations is suggested, both with the children to learn more about their experiences as well as with professionals using the tool.</p>

Study	Sample	Study Design	Key Findings	Comments
ACADEMIC JOURNAL Johnson, D., Deterding, S., Kuhn, K.-A., Staneva, A., Stoyanov, S., & Hides, L. (2016).	n/a	Assessment of the amount and quality of empirical support for gamification applied to health and well-being. Identified seven potential advantages of gamification from existing research and conducted a systematic literature review.	19 papers report empirical evidence on the effect of gamification on health and well-being. Evidence supports that gamification can have a positive impact in health and wellbeing, particularly for health behaviours.	This was a systematic review that supports gamification in healthcare but does not talk about co-creation processes.
ACADEMIC JOURNAL Jordan, Z., Tremblay, C., Lipstein, E., Jordan, I., & Boland, L. (2020, February 11).	n/a	Qualitative collection of viewpoints from physician, parent and youth in healthcare on shared decision making (SDM). Pragmatic recommendations were given for using SDM in paediatric clinical practice.	The simple act of inviting the child and family members to participate in decisions making and collaborating to determine the best course of action promotes patient comfort, feeling valued, and fosters trust in the patient, parent and paediatrician relationship	Does not share any demographic information and shows three specific narratives only. Focuses more on shared decision making, which can be related to co-creation but does not define it necessarily.
MEDIA SOURCE Liedtka, J., MacLaren, E., & Harvard Business Review. (2018, November 7).	n/a	Children's hospital in the US used a 7-step co-creation process in a pilot program where families were engaged in their own well-being, had a greater sense of control in their lives, and took greater control in their	Development of a metric of family wellbeing, based on five key dimensions: family members' sense of control over healthcare, understanding of their wellness goals, their sense of self, the quality of their access to information and knowledge,	American, and sample size or demographic information not disclosed, as this is a media article.

Study	Sample	Study Design	Key Findings	Comments
		health management.	and quality of the community support system.	
ACADEMIC JOURNAL Marofi, M., Mokhtari-Dinani, M., & Ghazavi, Z. (2018).	Study conducted on attendees of a hospital tour. The study was performed with 84 children in Iran (n=84).	The self-report image anxiety scale and State-Trait Anxiety Inventory (STAI) were used for the assessment of anxiety among children and their mothers, respectively.	Hospital visiting tours are effective in decreasing the anxiety of children who were candidates for surgery and their mothers.	Noted that it would be more effective to categorize tours based on age. Explanations would have been provided based on the age range, the children would have been more similar, and had mutual understanding.
GREY LITERATURE Penner, M., Ngo, M., & Peters, C. (2019).	Caregivers (n= 22) interested in information about children's hospital prior to attending their first healthcare appointment	Using the Measure of Processes of Care (MPOC), asked families to rate perceptions before and after attending a workshop that provided information prior to their first hospital appointment. Co-creation was utilized in development of the workshop.	Families felt more prepared, less worried, and more comfortable to ask questions after receiving information from an Outpatient Orientation workshop before their first appointment.	Small sample size, measured only in two clinics over a 6-month period.

Study	Sample	Study Design	Key Findings	Comments
ACADEMIC JOURNAL Stensæth, K. (2013, August 7).	Participants are six children (n=6), 7 to 15 years (developmental ages range from 6 months to 7 years) in Norway	Using co-creation with children on various 'musicking' objects, and researcher observation, analysis was done to see what impacts the co-creation process had on participants.	Co-creation with music has a positive impact on health and prevents poor health outcomes. It also showed to strengthen agency, mastery and creation of embodied, sensory and empowering interactions with both objects and other people.	Norwegian, took place in a school setting, small sample size, but demographics of children participants are closest to the intended demographic for this project.
ACADEMIC JOURNAL Tourigny, J., Clendinneng, D., Chartrand, J., & Gaboury, I. (2011).	English-speaking parents and their children who were having a day surgery; 82% of children and parents (N = 138) agreed to participate.	Study at a Canadian university-affiliated paediatric hospital. Children and their parents were provided with a preoperative questionnaire and the same questionnaire on the day of the operation to measure their feelings before and after viewing a virtual tour.	With money constraints and staff shortage, a Web-based, pre-surgery preparation could be the best way to prepare children and families and to decrease the parent and child's anxiety related to the process of a child surgery.	Absence of randomization and control group, emotional distress visual analog scale could have captured distress unrelated to surgery, and researchers had no control on how and the amount of time spent viewing the Virtual Tour on the hospital website.
GREY LITERATURE Verjans, J., & U-Sentric. (2018, February 16).	n/a	n/a	Five best practices for co-creation with children.	Does not target children who identify as disabled, nor provides best practices for accessibility or paediatric healthcare.

Study	Sample	Study Design	Key Findings	Comments
ACADEMIC JOURNAL Whitehouse, S. R., Balka, E., McLellan, S., Penn, D., Issenman, R., Paone, M., ... Deevska, M. (2013, October 18).	80 adolescents, 12-18 years, and 38 medical staff-residents, pediatricians, and surgeons in Canada (n=80).	This project sought to address limitations in administration of youth health questionnaires by moving data collection to an online platform. Brainstorming, focus groups, loopback and discussion groups were utilized to co-create with youth.	Co-creative design methodology with stakeholders was effective for informing design and development processes to leverage effective eHealth opportunities.	Future studies would benefit from engaging all health care providers involved in the patient's care, variations in response between study sites may reflect differences in how the application was introduced, time in waiting area, or other variables.

Appendix B: Timeline

Table 4: Project Timelines

Task #	Work Breakdown Structure	Start	End	Person Involved
1	<i>Establish formal partnership agreement between Holland Bloorview and OCADU</i>	<i>Feb 2020</i>	<i>Nov 2020</i>	<i>OCADU Graduate Student, HB Student Services, BRI Research Institute, OCADU Graduate Directors</i>
2	<i>Search for Principal Investigator at Bloorview Research Institute</i>	<i>May 2020</i>	<i>Jun 2020</i>	<i>OCADU Graduate Student, HB Principal Investigator</i>
3	<i>HB PI to find reviewer for Science Review; review to be conducted</i>	<i>Sep 2020</i>	<i>Oct 2020</i>	<i>HB Principal Investigator</i>
4	<i>Research Ethics Board submission (OCAD and HB)</i>	<i>Dec 2020</i>	<i>May 2020</i>	<i>HB Principal Investigator and OCADU Graduate Student</i>
5	<i>Research and apply for funding sources</i>	<i>Jul 2020</i>	<i>Mar 2021</i>	<i>OCADU Graduate Student</i>
6	<i>Recruitment of co-design participants</i>	<i>June 2021</i>	<i>June 2021</i>	<i>OCADU Graduate Student</i>
7	<i>5 Co-design sessions</i>	<i>June 2021</i>	<i>July 2021</i>	<i>OCADU Graduate Student & Co-design Participants</i>
8	<i>Filming</i>	<i>Aug 2021</i>	<i>Aug 2021</i>	<i>Videographer</i>
9	<i>Review with participants and last edits</i>	<i>Aug 2021</i>	<i>Aug 2021</i>	<i>OCADU Graduate Student, Videographer & Co-design Participants</i>
10	<i>Finalization of research project</i>	<i>Aug 2021</i>	<i>Aug 2021</i>	<i>OCADU Graduate Student</i>

Figure 6: Project Schedule

Task #	2020											2021								
	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	
1																				
2																				
3																				
4																				
5																				
6																				
7																				
8																				
9																				
10																				

Appendix C: Budget

The budget presented in Figure 6.1 includes honorariums for co-design participants and test participants, co-design supplies, and filming by a videographer who has provided an approximate quote.

Table 6: Budget

Category	Item	Number and cost of each	Total
Honorariums for co-design participants	Gift cards	\$20 per session x 3 sessions x 10 participants	\$600
Honorariums for test participants	Gift cards	\$15 x 10 participants	\$150
Co-design supplies	Zoom for Health account	\$0	\$0
Co-design supplies	iPads x 5	\$429 +tax x 5	\$2,423.85
Co-design supplies	Otterbox case for iPads	\$60 x 5	\$300
Filming	Full day to film the tours	\$900 +tax	\$1017
Filming	Rentals (e.g. microphone)	\$150 +tax	\$169.50
Filming	Editing, with inclusion of timed closed captions and full written transcript	\$550 +tax	\$621.50
TOTAL			\$4581.85

As the researcher is also employed at Holland Bloorview Kids Rehabilitation Hospital, some costs related to co-design supplies (like a paid professional Zoom account) may be either borrowed from other departments that may have these supplies already, or can be covered through the Client and Family Integrated Care department that supports client and family-led initiatives.

Appendix D: Recruitment script for website

Holland Bloorview 'Participate in Research' webpage information (CMS Template)

Co-Design Participants

- **Summary:** We are inviting Holland Bloorview clients aged 7-18 to participate online in the co-design of a video welcome tour of the hospital. We want to find the best way to co-design with children in a hospital environment by creating a tour for new clients of Holland Bloorview.
- **Call to action:** Are you a client of Holland Bloorview aged 7-18 and interested in co-designing a welcome tour for new families of the hospital? We want your input and help to craft a video welcome tour of Holland Bloorview!
- **Who can participate:** Holland Bloorview clients aged 7-18, who would like to co-design a hospital welcome tour online are eligible to participate. They must be willing to participate in three 45-60 minute online co-design sessions. They must have internet access and a family email address.
- **Funding Agency:** N/A
- **What's Involved:** Participants will attend three online co-design sessions over a one-month period where we will do activities like brainstorming, voting, ranking, drawing and creating a script for the tour.
 - o Participants will receive a small token of appreciation, a \$20 gift card per co-design session, to thank them for their time.
- **Deadline:** Date TBD
- **Interested in Participating?:** If you are interested in participating in this study or have additional questions, please contact Melissa Ngo at mngo@hollandbloorview.ca and she will get back to you shortly. Contacting us does not obligate you or your child to participate in the study.
 - o The wording for the Interested in Participating section has been developed with parents, please use this wording and fill in contact info.

Appendix E: Recruitment letter template for co-design participants

[DD/MM/YYYY]

Dear [name(s) of parent(s)],

I hope that this letter finds you as well as could be expected under the circumstances. I hope that you, your families and networks are safe and healthy during the pandemic.

As you know, at Holland Bloorview we are always looking for ways to partner and co-design with clients and families, even during a pandemic. With that in mind, I'm writing to you today to let you know about a research project that your child may be interested in. This study, led by Dr. Timothy Ross, is being conducted by a team of researchers at the Bloorview Research Institute and OCAD University. They are interested in the process and effectiveness of co-creating a video welcome tour of the hospital that is designed by kids, for kids.

A research team member will follow up on your interest in the study if we don't hear from you in the next 10 days. If you do not want to participate, you may contact Melissa Ngo at 416-425-6220 ext. 6348 or mngo@hollandbloorview.ca to request no further contact. Your child is under no obligation to participate in this study. Choosing not to participate will have no impact on the ongoing services, programs or support that your family may receive at Holland Bloorview.

Please see the poster attached and feel free to contact Melissa Ngo at mngo@hollandbloorview.ca with any questions. Thanks for your time!

Sincerely,

[Name of staff name]

Appendix F: Telephone screening for recruitment call to families

Sample Telephone Screening Script for Recruitment Call to Families

Hello. May I please speak with _____? My name is Melissa Ngo. I am a research student from the Bloorview Research Institute at Holland Bloorview Kids Rehabilitation Hospital.

Recently, _____ (name of staff) in the _____ (name of program) at Holland Bloorview spoke to you about a research project we are doing and told me that you had agreed to be contacted to hear more. Are you still interested in hearing about this project? May I speak with you about it now?

or

You should have received a letter about a study our research team is doing. Do you recall seeing the letter about the study in the mail/from a Holland Bloorview staff? Is this a good time to talk? ***If the parent did not read the letter, book a time to call back in 2 days or send another letter and book a time 1 week later. If sending another letter, confirm the mailing address.***

If Yes: May I speak with you and [child's name] about it now?

If NOT A GOOD TIME: Would there be a better time for me to call?

If NO: That's fine. I will not contact you again. Thank you for your time.

If YES: Great! Let me tell you more about this study. Before I explain a little more about the study, please invite [child's name] to be on this call on speakerphone so they can also learn about the study. Please interrupt me at any time if you have a question. For this study, we are inviting Holland Bloorview clients aged 7-18 to help us with a research study about how hospital staff and kids can make helpful information for other kids. This is called co-design: where we design things together. We want to find the best way to co-design with children in a hospital environment, because kids are experts on their own healthcare experiences. We will do this by making a hospital tour together for other children who are coming to the hospital for the first time. In three meetings, a group of hospital staff and kids will do activities and talk about what a hospital tour should look like, and how it can be shared.

As part of this research study, [child's name] would be involved in three meetings where we will design together. The meetings will happen online, in a group with other kids and staff that [child's name] might know. At the meetings, we will have activities that might involve brainstorming, giving an opinion, voting on ideas, ranking ideas, creating tour scripts, or testing

a tour. The meetings will be around 45 minutes to an hour. We will give you instructions and information before each meeting so that [child's name] knows what to expect.

We would like to invite [child's name] to take part. Do you or [child's name] have any questions about the study before you decide?

Is [child's name] interested in participating in the study?

If NO: That's fine. Thank you for speaking with me today and thank you for your time.

If UNSURE: Would you like more time to read and think about this study with your child? May I call you back in a few days to answer any questions you may have and see whether you and your child would be interested in taking part in the study?

If YES: Great! Could I please ask you a few questions to make sure your family would be eligible for this study? This should only take a few minutes.

- Does [child's name] receive services at Holland Bloorview?
- Is [child's name] between 7-18 years old?
- Does [child's name] communicate in English?
- Is [child's name] able to navigate a computer or tablet? We will be using these for the purposes of the co-design activities. (If you do not have a computer or tablet, the research team can provide one).
- Is [child's name] able to participate in a co-design session online for 45 minutes at a time?
- Does your family have access to internet and either an email belonging to [child's name] or a parent that you can provide to us?
- Is [child's name] able to provide independent consent to participate or assent to participate with a substitute decision maker (such as a parent or guardian?)

If INELIGIBLE: I'm sorry, [child's name] is not eligible to participate in our study as we need consent from him/her. Thank you for your time and interest, and have a great day.

If ELIGIBLE: Great. [Child's name] is eligible to participate in this study. We would like to invite [child's name] to take part in this study. Could we please email you the information and access to the e-consent form? This form will provide you with more information about the study before we speak again. If you do not have time to review the form, we can review it the next time that we speak. Due to the pandemic, we will send this information over email. Afterward, we will also contact you through email to give you the dates and Zoom links for our co-design sessions. Can you provide your email address?

Record email in database

Would you like us to email you the day before to remind you of the co-design sessions we schedule? **If yes, make note of the day to email.**

I also wanted to tell you about the research consent process we will follow for this study. I can review the information about the study with you and your child right now or at another time. I will ask [child's name] questions to see whether he/she understands what he/she will be asked to do. If he/she seems to understand what the study involves and appreciates how it applies to him/her, I will ask him/her whether he/she wants to take part and sign the consent form (if he/she can). I will ask you to sign a statement supporting your child's decision. If [child's name] does not seem to understand what the study involves, then I will try different ways to help him/her understand what we will ask him/her to do.

Did you have any questions about how I will ask your child to take part in the study?

If family would like to review consent: Review consent form

If family would like to receive a follow up phone call: What time would be best for me to call back to review the forms?

I will send you the information and consent form for this study for you to review before we talk again. I will send the forms today and will call [date and time].

Could I please confirm your email address? ***Read the email address that is on file and make corrections where necessary. Provide any additional instructions for returning the consent form to the study team.*** Do you have any questions before we end the call?

If you think of any other questions or would like to speak to me about this, please call me at 416-425-6220 extension 6348 or email me at mngo@hollandbloorview.ca.

Thank you for taking the time to speak with me.

END CALL

Appendix G: Consent Form

Information and Consent Form to Participate in a Research Study Co-Design Participants

Study Title: Co-Designing and Sharing Virtual Tours with Children in Paediatric Healthcare

Principal Investigator:

Dr. Timothy Ross
Scientist, Bloorview Research Institute
Holland Bloorview Kids Rehabilitation Hospital
tross@hollandbloorview.ca

Co-Investigator *Primary Contact for Information*:

Melissa Ngo
MDes student, Inclusive Design
OCAD University
mngo@hollandbloorview.ca

Dear *Participant*,

My name is Melissa, and I am a student completing a Master of Design in Inclusive Design at OCAD University. I am being co-supervised by Dr. Timothy Ross from the Bloorview Research Institute and Dr. Michelle Wyndham-West from OCAD University. For the purposes of this project, I will be a student doing research instead of a staff at the hospital.

What is the study about?

The purpose of this study is to document the best practices of co-design with children in a hospital environment, as they are experts in their own healthcare. We will do this by co-designing a hospital tour for other children who are attending an appointment for the first time. Through three co-design sessions, our group would like to facilitate activities and discussion on what a hospital tour should look like and how it should be shared. We are reaching out to you because we are interested in your background as a client or previous client of a paediatric hospital. The findings of this research will be used to create a hospital tour that future clients can access, and to identify best practices for applying co-design in paediatric healthcare settings that could support further co-design initiatives in paediatric healthcare spaces.

Why do you want to talk to me?

As an individual with experience navigating a hospital space, you are invited to participate in a research study about how paediatric hospitals can measure and provide meaningful information designed by children, for children.

How will I be involved?

As part of this research, you would be involved in our co-design sessions. The sessions will be conducted online. Co-design sessions will involve prepared activities, such as brainstorming, giving your opinion, voting on ideas, ranking ideas, creating scripts, and test-running a tour. Each session will be approximately 45 minutes to an hour. We will also come up with questions you'd like to ask to other kids who will see the tour for the first time, in a survey. Basic information, instructions, and an introduction will be provided to you before the co-design sessions.

Do I have to do this?

Participation in this study is voluntary. If you wish, you may choose not to answer any questions or participate in any component of the study. Further, you may decide to withdraw from this study at any time, or to request withdrawal of your data (prior to data analysis).

What are the risks and benefits?

Possible benefits of participation include the involvement in co-creating more accessible and user-friendly ways to share information with future clients, which may be meaningful. There is also the potential for empowerment of children's voices in healthcare and the enhancement, continuation or building of self-advocacy skills. The solution can lead to less frustration and stress for families who may feel worried or anxious about coming to the hospital for the first time. There also may be risks associated with participation. These include sharing personal stories in which the outcomes or experience itself was negative, and can cause the co-design participant to re-live a stressful or upsetting experience.

Will anyone know what I say or do?

All information you provide will be considered confidential and grouped with responses from other participants. However, with your consent (see last page), some of the photographic data may be used as we share findings in a final report, journal articles, and/or conference presentations. Your name will not be included in any of these.

All of the materials from our meetings will be stored in locked cabinets and/or will be protected by a password that only researchers have. We will keep all materials from our meetings for seven years, all paper materials will be shredded and all materials on computers will be erased.

Access to this data will be restricted to the Principal Investigator and Student Researcher. Other researchers will only be granted access to the data if this access receives necessary research ethics approval. If we decide to continue the research after this period, we will contact you again for your permission. We will do so, only if you give us permission to contact you in the future.

How will my privacy be protected?

The following people may come to the hospital to look at your personal health information to check that the information collected for the study is correct and to make sure the study followed the required laws and guidelines: People from the Holland

Bloorview Research Ethics Board and/or other Holland Bloorview Staff who oversee the conduct of research at Holland Bloorview.

Compensation

As a thank you for your participation in the study, you will receive a \$20 gift card for each session that you participate in. You can receive a summary letter at the end of the study to learn about the study findings.

What if I have questions?

If you have any questions or concerns regarding this study, please contact Melissa Ngo at mngo@hollandbloorview.ca. If you leave a message, she will return your call within 48 hours.

If you have any questions about your rights as a research participant or have concerns about this study, contact the Research Ethics Office at 416- 425-6220 ext. 3221 or researchethicsboard@hollandbloorview.ca.

Publication of results

Results of this study may be shared in classroom presentations, student expositions, a final report, journal articles, conference presentations, as well as the websites of Holland Bloorview and OCADU. In sharing results, the data will be presented without using your name. Any photographs of you will not be presented without your permission. Information about publications or knowledge translation materials will be shared with you if you wish, and a summary of the study will be sent to all participants. *Thank you for your consideration.*

By signing this form I confirm that:

- This study has been explained to me. I have read the attached study information letter and understand what this study is about
- All my questions have been answered
- I understand the risks and benefits of participating in this study
- I understand that I do not need to participate and that I can leave the study at any time
- I am free now, or in the future, to ask questions about the study
- I understand that any identifying details about myself will not be shared
- I agree to participate in this study

I wish to receive feedback about this study (e.g. news about presentations of our results.):

Yes: ____ No: ____

I agree to let whole or parts of photos from the study to be used for presentation of the research results:

Yes: ____ No: ____

Name of Participant

Date of Participant Consent

Name of Parent or Legal
Guardian

Date of Parent or Legal Guardian
Consent

Name of person obtaining
consent

Signature of person obtaining
consent

Date

Appendix H: Assent Form

Information and Assent Form to Participate in a Research Study Co-Design Participants

Study Title: Co-Designing and Sharing Virtual Tours with Children in Paediatric Healthcare

Principal Investigator:

Dr. Timothy Ross
Scientist, Bloorview Research Institute
Holland Bloorview Kids Rehabilitation Hospital
tross@hollandbloorview.ca

Co-Investigator *Primary Contact for Information*:

Melissa Ngo
MDes Student, Inclusive Design
OCAD University
mngo@hollandbloorview.ca

Dear Participant,

My name is Melissa, and I am a student in Inclusive Design at OCAD University. I am being co-supervised by Dr. Timothy Ross from the Bloorview Research Institute and Dr. Michelle Wyndham-West from OCAD University. You might know me from the Family Resource Centre at Holland Bloorview, but I am working on a project for school which I would like to tell you about. For this project, I will be a student doing research instead of a staff at the hospital.

We are inviting you to help us with a research study. It will be about how hospital staff and kids can make helpful information for other kids. This is called co-design: where we design things together.

What is the study about?

We want to find the best way to co-design with children in a hospital, because you are an expert on your own healthcare! We will do this by making a hospital tour together for other children who are coming to the hospital for the first time. In three meetings, a group of two hospital staff and kids will do activities and talk about what a hospital tour should look like, and how it can be shared.

Why do you want to talk to me?

We wanted to talk to you because you have lots of experience at the hospital. Through this project, we will create a hospital tour that future clients can look at, and we will record what worked best during our meetings by writing down information and taking pictures. We are reaching out to you because you have lots of experience at the hospital. Through this project, you can tell us how we should create a video welcome tour for kids who will come to this hospital in the future. We will also think about what

works and doesn't work in the co-design sessions so that we can make co-design sessions better at Holland Bloorview and other kids' hospitals in the future.

How will I be involved?

As part of this research study, you would come to three meetings where we will design together. The meetings will happen online, in a small group with other kids and staff that you might know. At the meetings, we will have activities that might be about: brainstorming, giving your opinion, voting on ideas, ranking ideas, creating scripts, or testing a tour. The meetings will be around 45 minutes to an hour. We will also come up with questions you'd like to ask to other kids who will see the tour for the first time, in a survey. We will give you instructions and information before each meeting so that you know what to expect.

Do I have to do this?

You can always choose if you want to be in the co-design or not. If you wish, you can choose not to answer any questions. You can decide to leave the study at any time, or to ask us to take out your opinions from the study.

What are the risks and benefits?

When you are finding more ways to share information with other kids, this might mean something to you and you might feel good about it. Also, sometimes it is hard to see or find children's opinions in healthcare, but this study might help to show more of these opinions. You may also feel good about sharing your opinions and experiences to help make healthcare more welcoming. You might also want to continue or improve on your 'self-advocacy'. This means speaking up for yourself. The tour that we make together might help families feel less worried about coming to the hospital for the first time. There also may be times where participating is hard. You might share a personal story that was sad or bad to you, and it might be very hard to tell that story. But, hospital staff are here to support you if that happens, and you can always stop or take a break.

Will anyone know what I say or do?

All of the information you share will be private, which means it will only be shared with the researchers on this team. What you say in our meetings will be grouped with answers from other participants. With your permission (see last page), we might take some photos, and your opinions may be used in a report to share what we learn. We won't use your name in these.

All of the materials from our meetings will be stored in locked cabinets and/or will be protected by a password that only researchers have. We will keep all materials from our meetings for seven years. After seven years, all paper materials will be shredded and all materials on computers will be erased.

Only the Principal Investigator and Student Researcher will be able to see this information. Other researchers will only be able to see the information if they get permission from our Research Ethics Office. If we decide to continue the research later,

we will contact you again for your permission. We will do so, only if you give us permission to contact you in the future.

How will you keep my information private?

People may come to the hospital to check that the information collected for the study is correct and to make sure the study followed the rules. These might be people from the Holland Bloorview Research Ethics Board and/or other Holland Bloorview Staff who make sure research is done well at Holland Bloorview.

Compensation

As a thank you for your participation in the study, you will receive a gift card for \$20 per session that you participate in (\$60 in total for participating in all three co-design sessions). You can receive a letter at the end of the study to learn about the study findings.

What if I have questions?

If you have any questions regarding this study, please contact Melissa Ngo at mngo@hollandbloorview.ca. If you leave a message, she will return your call within 48 hours.

If you have any questions about being a research participant or have concerns about this study, contact the Research Ethics Office at 416- 425-6220 ext. 3221 or researchethicsboard@hollandbloorview.ca.

Sharing the results

The results of this study and the tour may be shown in classroom presentations, a final report, and through Holland Bloorview's website and the OCAD University website. In any presentation, the results will be shown without your name. Photos of you will not be shown without your permission. Information about what we found will be shared with you, if you want.

Thank you for your consideration.

By signing this form I confirm that:

- This study has been explained to me. I have read the attached study information letter and understand what this study is about
- All my questions have been answered
- I understand the risks and benefits of participating in this study
- I understand that I do not need to participate and that I can leave the study at any time
- I am free now, or in the future, to ask questions about the study
- I understand that any identifying details about myself will not be shared
- I agree to participate in this study

I wish to receive feedback about this study (for example, news about presentations of our results.):

Yes: ____ No: ____

I agree to let photos from the study to be used to present research results:

Yes: ____ No: ____

_____ Name of Participant	_____ Date of Participant Assent	
_____ Name of Parent or Legal Guardian	_____ Date of Parent or Legal Guardian Consent	
_____ Name of person obtaining consent	_____ Signature of person obtaining consent	_____ Date

Appendix I: Focus Group Guide for Co-Design Participants

Note: *Focus group guide questions will be refined based on the feedback from co-design sessions with participants.*

In preparation for co-design sessions, each participant will be asked for:

- Their age, after signing the consent form
- Their email address or their parents' email address for sending the Zoom link and information on what to expect during the co-design
- A chosen code name that will appear as their name in Zoom
- All information will be de-identified and stored in the secure server at Holland Bloorview

Overall goal: Determine collaborative and relevant ways for children to give feedback to co-create a video welcome tour.

1. How can paediatric hospitals produce meaningful information designed by children, for children?
2. What are some best practices for co-designing with children with disabilities in healthcare settings?

Review purpose of study, focus group format, and consent processes.

We want to remind you all that we will be video-recording our co-design sessions so that we don't miss anything you say.

We also want to remind you there are no right or wrong answers because everyone has different ideas.

We ask you to be respectful of everyone and to not talk about what you've discussed outside of the focus group. We can't control what happens outside of the focus group. You don't have to answer any of your questions and if anyone must leave for a moment, that is fine. You can rejoin when you are ready (it could be that children may mute their mic/camera when they step away and/or note it in the chat).

You can stop at any time you want, or request that we do not record your information for the research, but you have to request that by the end of the three co-design sessions.

We prefer that your video is turned on while you are in the co-design session, but if you have to turn it off, that is okay.

We will take a short break in the middle.

Before we begin, are there any questions?

Warm up/rapport building:

3. Can you each introduce yourself with your code name, and tell us about one activity or hobby that you like to do in your spare time?
4. Can you tell us in a sentence or two about why you wanted to help create a video welcome tour for other kids at our hospital?

Explain possible activities for co-design below and ask if kids like these options. These are some ways in which you can give your opinion on questions that we'll ask you later in the co-design sessions. Can you tell us which ones you like the best?

What ways would you like to give your opinion?

- Option 1: Voting through Zoom
- Option 2: Open discussion by verbally talking or typing in the text box
- Option 3: Draw out your thoughts on a piece of paper and explain it over Zoom
- Option 4: Rank or think of your top three answers and tell us
- Option 5: A 'take home' project where you come back with thoughts for the next co-design session
- Option 6: Are there other ways you'd like to give your opinion?

Review the questions below related to tour-building for both age groups. Order of questions in co-design sessions will be determined based on what the participants prefer.

1. How long should the tour be?
 - a. For younger participants, this question may include options such as "5 minutes, 10 minutes, or 15 minutes"
2. If the tour is a video, should it be one single video that kids can watch all at once, or should it be a set of short videos where you can choose your own adventure?
3. What feelings do you feel now when you walk into Holland Bloorview?
4. What feelings do you want other kids to have when they walk into Holland Bloorview for the very first time?
5. How many places should we visit on the tour, keeping in mind that we have set a time limit?
 - a. For younger participants, this question may include reminders that we set out a time limit for the tour, and asking them 'how many places do you think we can visit in ____ minutes?'
6. Which places or areas should we visit on the tour?
7. What are your favourite things about the areas that will be on the tour?
8. What should we say in the video script about each area?
 - a. For younger participants, this may include asking 'how would you introduce this area to a friend?'
9. Where and how should kids and their families find the tour?
 - a. For younger participants, this may include providing options such as Youtube, website, or social media.
10. Review questionnaire that will be given to survey participants
11. What did you think of this experience overall?

Announce that we will take a washroom break in the middle.

Questions for participants at the end of each co-design session:

- How did you feel about today's session? (using a 3-point rating scale)
- Do you think you got to say everything you wanted to say? (yes or no)
 - If no, what did you want to say?

- What is your favourite part about today's session? (open-ended)
- Was there anything you didn't like about today's session? If so, what was it? (open-ended)
- Do you have anything else you want to tell us that we have not asked you about? (open-ended)