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Co-Design with Pediatric Patients

A guide to help you include children's voices in the design of immersive technologies

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About This Handbook

Purpose of the Handbook

This handbook is your guide to being a design partner with pediatric patients. It will help you learn how to capture children's ideas and thoughts, how to support children as they create and design, and how to analyze and use their feedback to develop meaningful solutions!

What You'll Find in This Handbook

- **Training Materials** — Information about co-design as a practice and how to be a design partner
- **Analysis Methods** — Ways to transform your data from children into useable applications
- **Possible Problems and Roadblocks** — Examples of problems you may run into and what you can try to solve them
- **Safety Information** — Information about keeping children safe, physically and emotionally

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01 Co-Design

1.1 Overview

Co-design with children is a research process that involves empowering children and incorporating their thoughts and ideas in the process of design [4]. Co-design with children originated in the field of Child-Computer Interaction, and has expanded to many other fields.

The purpose of co-design is to generate thoughtful solutions for children that truly meet their needs. Despite usually lacking knowledge in specific technical fields (e.g. software engineering, game design), children have unique perspectives and ideas. Solutions created by a team of children and respectful, open adults have been shown to be highly successful [4].

1.2 User Research

User research is the process of learning about and understanding users - the people who you are designing for [9] (in this case, children). There are many user research techniques, including interviews, focus groups, and co-design!

Why is it important to conduct user research?

Designers and developers (DD) have a wealth of technical knowledge, but most of the time, they are designing for groups of people with different identities than their own. Even if the DD have experienced similar situations, the users have unique experiences, thoughts, and opinions. User research focuses on including those unique perspectives into the design process [9].

What can happen when developers and designers put their own opinions and ideas ahead of user needs?

If the opinions and thoughts of the DD are placed ahead of the user needs, the product may not be helpful or useful to the people they are designing for [9]. In the worst case scenario, the product could be offensive or even harmful [11].
For example, let's say there's a group of middle-class Americans designing a VR application for low-income families in a small village in India. The Americans have decades of experience developing applications and some of them are from India. They decide that it would be exciting to design a scene of an Indian village based on other solutions that have worked in the past. They design with the thoughts and ideas of the developers from India at the forefront of all design decisions. After they develop the solution, they bring it to the families. Some of the families have an awful experience, because their cultural processes are portrayed in a stereotypical fashion, and there are cues in the application that make it seem like they are being pitied by the DD. They do not appreciate the product, and tell the DD they no longer want to use it. The DD did not intend to make anything harmful, but they did not involve their users in the design process until after they already created something.
Not all products and games directly relate to identity, race, or other deep topics. However, we are all human, and may have unconscious biases. Adults do not truly remember what it is like to be a child. Also, every child has different hospitalization and life experiences. DD cannot create solutions that please everyone, but they can consider that their users have knowledge and experience that they lack. When developing therapeutic and healing applications for pediatric patients, user research can help you create inclusive and meaningful solutions.

When is user research conducted?

User research attempts to include users during **all** stages of development: initial research, idea generation, prototyping, etc. Involving users throughout the process can help developers:

- **Create Relevant and Sensitive Products** — Products can meet the user needs and solve problems for the children.
- **Reduce Bias and Assumptions** — User research involves putting your thoughts and opinions aside to open your mind to other's perspectives.
- **Give Users a Great Experience** — Making a product easy to use can greatly improve the experience that children have.

1.3 Why co-design?

Children are a minority in an adult world. Adults often assume they have better ideas than children because they know what is best for them more than the children themselves [4]. As a result, children are often left out of the design process, despite the fact that the solutions are for them [4]. This often leads to adult-created solutions which don't always work for children or are designed based on assumptions.

Pediatric patients face unique challenges which can hinder their growth and development [8]. They often have a lack of control over and understanding of what adults do to their bodies which can contribute to medical trauma [8].

Children are not just tiny adults, they are unique human beings with their own thoughts, feelings, and ideas. Co-design gives children a chance to:

Problem Solve	Children can develop their own ideas and solutions to problems they are facing.
Form Healthy Relationships with Adults	A team of children and adult design partners can help children develop aspirations and feel smart and capable.
Enhance Communication	Children may have difficulty verbalizing their ideas. Co-design can help them express themselves using other forms of communication.

02

Child Development (Neurotypical) & Design Considerations

2.1 Ages 4 - 6 (Little Kids)

Little kids love to explore and learn about the world around them. They have constant questions and want to know about everything. Little kids enjoy problem-solving, and their ideas are often based on what they see and feel in the moment [2].

Children at this age have difficulty distinguishing real and make-believe [2]. They may believe in magic and fantasy, and their ideas often reflect this. As an adult design partner designing with little kids, it is important to not dismiss make-believe ideas, no matter how fantastical or impossible they may seem. Using make-believe as inspiration can eventually lead to very creative realistic solutions!

Little kids enjoy playing with other children their age, and often start developing preferences in who they want to spend time with. However, they may still be learning how to share and take turns [2]. When working with a group of little kids, ensure that all children are given space and materials to express their thoughts and ideas.

Young children usually do not fully understand their illness or medical circumstances. When designing things related to medical topics, it is best to avoid technical terms and details. Children may have an easier time understanding when adults use metaphors, play-acting, and drawing.

If you are having difficulty communicating an abstract or difficult topic with little kids, try leveraging play or art. Play is an amazing tool, especially for children around this age [2]. Little kids may have difficulty verbalizing their ideas, as their vocabulary is still developing [2]. However, they usually are capable of using toys and play materials to act things out.

2.2 Ages 7 - 10 (Big Kids)

Big kids are starting to explore relationships with people other than their family, like teachers, friends, and mentors [2]. As they try new things, they begin to develop preferences, strengths, and weaknesses [2].

Children at this age are more capable of understanding abstract concepts, such as time. They are eager to fit in and please others, as they are trying to learn who they are and what they enjoy [2]. As an adult design partner designing with big kids, it is important to avoid imposing your opinions onto childrens' ideas, especially if those opinions are negative. Children may want to please you or create things that you approve of. However, the purpose of co-design is not to use children to validate your ideas, but to allow them to create their own and express their true thoughts and opinions.

Children at this age are usually aware that they are sick or injured to some degree, but may not understand the technical details of their illness or medical circumstances. When designing things related to medical topics, allow children to ask you questions and learn about their bodies [1]. Try not to hide details from them unless it's truly necessary.

Big kids enjoy working with other children their age, but they are easily influenced by them [2]. When working with a group of big kids, be aware of existing friendships (or enemies) before grouping children together. This will often lead to less conflict and more cooperation.

2.3 Ages 11- 14 (Pre-teens)

Pre-teens are maturing physically and are starting to desire more independence. They are more capable of understanding body language, and question everything, including the authority of adults [2].

Children at this age are beginning to think abstractly about the future, their actions, and responsibility. They are exploring their identities, and often feel uncertain about themselves [2]. As an adult design partner designing with pre-teens, it is important to stay honest and real. Treat them like equals, and avoid talking to them as if they are little kids. You can disclose the reasoning behind your collaboration, and ensure that they know that you care about their thoughts and opinions.

At this age, children are usually fully aware that they are sick or injured and may understand the technical details of their illness or medical circumstances [1]. When designing things related to medical topics, children may express anger or not want to share private details about their bodies. Never force children to discuss things that they don't want to discuss.

Just like big kids, pre-teens enjoy working with other children their age, but they are easily influenced by them [2]. When working with a pre-teens, be aware of existing friendships (or enemies) before grouping children together. This will lead to less conflict and more cooperation.

2.4 Ages 15 - 20 (Teens)

Adolescence is emotionally and physically challenging. Mood swings are common, and it can be difficult for teens to regulate their emotions [2]. Adding the factor of hospitalization can only exacerbate this.

Teens are starting to thinking less about their own lives and more about how the world works. They're developing a sense of right and wrong, but still struggle with their identities [2]. As an adult design partner designing with teens, it is important to stay honest & real and respect their knowledge. Treat them like equals, and avoid talking to them as if they are little kids. They may have experience in design or software. Validate this experience. You can disclose the reasoning behind your collaboration, and ensure that they know that you care about their thoughts and opinions.

At this age, teens are typically fully aware that they are sick or injured and understand the technical details of their illness or medical circumstances [1]. When designing things related to medical topics, they may express anger or not want to share private details about their bodies. Conflict with family and possibly caretakers is normal, as teens are usually trying to develop their independence. Never force teens to discuss things that they don't want to discuss.

Teens often excel at working with other teens [2]. They enjoy experimentation in other aspects of life, and may develop out - of - the - box solutions [2]. Again, be aware of existing friendships (or enemies) before grouping children together.

03 Co-Design Methods

3.1 Likes, Dislikes, Design Ideas

Description

Likes, Dislikes, Design Ideas is a design technique that involves capturing children's likes, dislikes, and design ideas about a specific program or object [14].

When to Use

Use this design technique when you have a specific application or prototype that is already made and you want children's feedback on it.

Materials Needed

Sticky Notes

Writing Utensils

How it Works

Adults will first describe the application to the child(ren) in broad terms. Don't discuss specific details, just introduce the purpose of the application and some main parts of it. After this, separate children in to groups (if with a group) with each group having 1 or 2 adult partners and 1 - 2 children. Once children are in groups, introduce the application to them. As they play with it, encourage them to think out loud and tell you what they like and dislike in the application and brainstorm ideas or additions for the application. As they say things, write each individual thought on a separate sticky note. You can label them as "Like", "Dislike", or "Design Idea." It can be helpful to use different colors to differentiate different children.

Tips

- You can outline the general way the game is supposed to work and specific parts of application you want kids to test. If they are not using the application correctly or are confused, don't correct them unless it is relevant to what you are testing. Take note of what they find confusing or what they need help with. This will help you improve the application later on.
- If children aren't speaking, or are having trouble understanding what they are supposed to do, try asking them some questions or giving them a few examples ("What about adding a tree here?" or "Do you like the colors? If not, how can they be improved?").
- You don't need to capture what the children say word for word. Just make sure you understand what they mean. Do not make assumptions. If you are unsure, just ask.

3.2 Bags of Stuff

Description

Bags of Stuff is a design technique that allows children use physical materials to brainstorm new ideas, which can be related to a specific theme or topic [14].

When to Use

Use this design technique when you want to create a new application or a new interaction in an existing application and want ideas from children.

Materials Needed


Paper


Tissue Paper


Cardboard

Glue


Scissors


Pom Poms


Pipe Cleaners


Beads


Wood

Markers


Clay


Other Craft Materials

How it Works

Adults will first discuss the topic or theme so children have a focus area. You can introduce any possible limitations, but try to keep them at a minimum. The less you limit, the more creative the solutions. After this, separate children in to groups (if with a group) with each group having 1 or 2 adult partners and 2 - 4 children. Once children are in groups, give them a bag of materials and let them create. You can help if the children want you to, or you may just observe. It depends on the preferences of the children in your group. Make sure to record your session (audio).

Tips

- Do not think about limitations or technical feasibility. Allow the children to brainstorm freely. You can always adjust their ideas later on if they are not possible.
- If children are stuck, try asking them some questions (“What do you think of when you hear the word ‘x’?” or “This is an interesting material. What could we use this for?”).
- If it helps you, take notes on what the children are creating and saying so that when you go and look back at their creations, you remember what they are.
- Let children go off-topic (to a point). Sometimes their ideas may not seem relevant but creating solutions later on is easier when you have a large pool of ideas.

3.3 Layered Elaboration

Description

Layered Elaboration is a design technique that allows children to build upon and adjust each others' ideas [14].

When to Use

Use this design technique when you want detailed ideas with various different parts that may or may not be accepted by all children.

Materials Needed

Markers

Transparent Film Paper

How it Works

Adults will write questions or draw categories on the transparent paper. These questions will relate to what you want the children to create. For example, if you want children to create "good" ideas, "medium" ideas, and "bad" ideas, you can draw a category for each of those. After this, separate children in to groups (if with a group) with each group having 1 or 2 adult partners and 1 - 2 children. Once children are in groups, allow them to draw on the paper with markers. As an adult partner, you can help the kids brainstorm or come up with ideas. After some time, place another transparent paper on top of the first one, and pass it on to another child or group. The child will be able to see the first child's drawing, and then can draw on the new paper to add to the idea without ruining the drawing on the original paper. Continue this process until all of the children have drawn on every stack. Make sure to record your session (audio).

Tips

- Let children know that they can cross things out and add as much as they want to other's ideas. Ensure that they understand they are not actually drawing on other people's ideas because the papers can be separated at any time.

3.4 Storyboarding/Comicboarding

Description

Storyboarding is a design technique where children draw out a comic or story about how an application or object will be used [14].

When to Use

Use this design technique if you're in the process of designing something but are not sure how and where it will be used.

Materials Needed

Paper

Writing Utensils

How it Works

Adults will draw out an empty comic strip (boxes). After this, separate children in to groups (if with a group) with each group having 1 or 2 adult partners and 1 - 2 children. Once children are in groups, allow them to draw out a comic about someone using your design/prototype/application. Make sure to record your session (audio).

Tips

- The way that you intend your idea to be used may not be the same as the way the children would use the idea. Take note of how children believe your idea would be used, and do not correct them or tell them their process is wrong. It will help you improve your design later on.

3.5 Big Paper

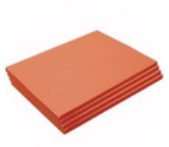
Description

Big Paper is a design technique where children explore their ideas on a huge piece of paper [14].

When to Use

Use this design technique if children are having difficulty working together or agreeing on ideas.

Materials Needed



Giant Paper

Writing Utensils

How it Works

Separate children in to groups (if with a group) with each group having 1 or 2 adult partners and 2 - 4 children. Once children are in groups, allow them to draw out their ideas on separate parts of the big paper. You can draw out ideas as well. Sometimes, the kids may start working together after seeing each other's work. Make sure to record your session (audio).

Tips

- The children may not want to work together, and that's okay. The purpose of the big paper is to encourage collaboration but don't force it if the children don't want to.

3.6 Mixing Ideas

Description

Mixing Ideas is a design technique that allows children to combine each others' ideas [14].

When to Use

Use this technique when you want one final detailed and well-thought-out idea from multiple children.

Materials Needed

Paper

Writing Utensils

How it Works

Adults will first discuss the topic or theme so children have a focus area. You can introduce any possible limitations, but try to keep them at a minimum. After this, separate children in to groups (if with a group) with each group having 1 or 2 adult partners and 1 - 2 children. Once children are in groups, allow them to brainstorm on the paper. As an adult partner, you can help the kids brainstorm or come up with ideas. After some time, combine the groups so that you have half the number you started with (so if you started with 6 groups, combine them to end up with 3). In the new bigger groups, have the children attempt to combine their ideas into one central idea. After some time, combine the groups again. Continue this process until you have one giant group with all of the children. You should end up with one idea that has multiple parts. Make sure to record your session (audio).

Tips

- It may be difficult for children to combine their ideas, especially if they are very different. As an adult partner, try to facilitate compromises and make sure that each child has at least one thing that they have contributed to the final idea.

3.7 KidReporter

Description

KidReporter is a design technique where children document design sessions using video cameras [14].

When to Use

Use this design technique when you have a specific application or prototype that is already made and you want children's feedback on it/want to see how children use it.

Materials Needed

Phones or Tablets

How it Works

Adults will first describe the application to the child(ren) in broad terms. After this, separate children in to groups (if with a group) with each group having 1 or 2 adult partners and 1 - 2 children. Give one or two children the job of being the reporters and have them record different groups. Once children are in groups, introduce the application to them. As they play with it, encourage them to think out loud.

Tips

- If you're with a group of kids, it is likely they will all want to be the reporters. You can switch off between kids during the session so everyone gets a chance to record videos.

3.8 Big Props

Description

Big Props is a design technique where children explore their ideas through acting out scenarios and movements with large props [11].

When to Use

Use this design technique if you are designing something dynamic and moving (that cannot be easily represented with typical stagnant prototypes) and you have a group of children.

Materials Needed

Household Objects

How it Works

Separate children in to groups (if with a group) with each group having 1 or 2 adult partners and 2 - 4 children. Give each group a random set of household objects (they can be anything). Have each group come up with a scenario to act out a motion-based technology. As an adult partner, you can help the kids brainstorm and be a part of their scenario. Have each group act out their scenario to the other groups. Make sure to record your session (video and audio).

Tips

- Ensure you have enough open space for children to accurately represent what they are trying to show.

04

Being an Adult Design Partner

4.1 Empathy and Encouragement

One of the most negatively impactful things that hospitalized children experience is lack of control [5]. Various adults control their care, their schedules, their meals, and more. As an adult co-designer, part of your job is to give children some of that control back.

Listen: don't assume. Every child's hospitalization experience is different. Even if you have experienced something similar, you should not assume that you know how children feel or you know what they need. Avoid phrases like "I know what you're going through" or "I know what you need." To design, you and the children need to be at the same level of respect [3]. That means that you respect the childrens' unique experiences and truly want their input, even if you have more technical knowledge and experience.

Allow the children to express whatever they may be feeling [8]. They may feel upset or anxious, and that's okay. Avoid phrases like "Don't feel bad" or "Don't worry, be happy" or "You'll feel better soon", especially if you do not know the details of their medical circumstances. If they are not in the mood to design, don't force them.

It can be tempting to sympathize rather than empathize. Even if you are used to working with sick or injured children, you may feel sorry for them. Of course, it's okay to feel that way, but a lot of the time these children just want to be treated like any other child [1]. Talk to them as you would talk to any other child [1].

4.2 Prompting and Questioning

Sometimes, providing guiding questions as children are creating can help them develop their ideas. For example:
"What is that? How does it work?"
"What about 'x'? Would that be a good addition to your idea?"
"That's really neat. Can you tell me more about it?"
"Do you think kids would like this? How would it make them feel?"
The questions will vary depending on what your topic of focus is. The purpose of questioning is to encourage kids to think more deeply about their ideas.

4.3 Avoiding Influence

It is important to avoid influencing children. You can share your opinions, but stay open-minded and don't worry about technical feasibility. Avoid phrases like "that's a bad idea" or "that's not possible" or "we've tried something like that before and it didn't work." Part of bringing in children's perspectives is opening your mind to things that adults could never think of. Let them explore their ideas, and gently guide them if you are straying into "impossible" territory (like "hatching a dragon egg"). Redirection is not necessarily a bad thing. If children are developing truly impossible or unrelated ideas, it is okay to remind them of the focus. Tell them that their ideas are great, but that you are trying to solve "x" and ask them if you and them could talk more about "y." If you are going to do this, though, try to avoid completely shutting them down (unless they are being violent, offensive, etc.). Use phrases like "Hmm, we're trying to create something about 'x', could we talk more about that?" or "This would be so cool if it was real! But do you think we could try designing something about 'y'?"

05 General Co-Design Sessions

5.1 Snack Time / Warm-Up

When starting a co-design session it helps to start with snack time or circle time and a warm up [3]. During this time, adults and children sit together at the same level and discuss random topics. This process is intended to reduce the power imbalance between adults and children.

1. Start by introducing yourself and telling the children/child why you are there. Allow them to ask you any questions they may have.
2. Tell the children that this is a safe space. That means that what they share with you there stays there (except for medical information important to their care). For younger children, you can use examples (i.e., If you told me your leg was hurting here, and then I went and told all my friends, that wouldn't make you feel good right?). Refer to Chapter 7 for more information.
3. If you are allowed to eat approved food with the child, you can do that. Be aware of health restrictions like food allergies or pre-operative care. Never give a child food without permission from their caregivers or doctors. Otherwise, start by talking about anything the child wants to talk about for 5 - 10 minutes.
4. Introduce a warm-up question that relates to the topic you are designing. If you are with a group of kids, go around a circle and have them say their name, age, and answer. Some children may feel shy or nervous to talk in front of others. You can tell the children that they are allowed to "pass" if they don't want to answer. Make sure to record this conversation. You will need it later on in your analysis.

This may look a little different if you are only working with one child.

5.2 Review and Reflection

Next you will host the session with one or more of the co-design techniques mentioned in Chapter 3. At the end of the session, gather the children together and go over what everyone came up with. You can allow each group of children to present what they created, or present for them if they do not want to present. Make sure to record this discussion, as you will use it later on in your analysis. If you are discussing medical topics, ensure that the children in your group feel comfortable with you sharing their ideas with other children before presenting. If you are working with only one child, you can still do a general overview and make sure you accurately captured their ideas and thoughts.

06 Possible Roadblocks

6.1 Disagreements Between Children

When working with groups of children, you will often experience disagreements between them. These disagreements may be surface level or deep. Try these techniques if you see some conflict.

- **Compromise** — If the children are disagreeing on a specific design idea, try to allow them to come to a compromise. If they do not seem to be getting anywhere, you can intervene and offer suggestions that include all of their ideas.
- **Redirect** — If the children are disagreeing about something unrelated to the co-design, try to shift their focus back to their work.
- **Separate** — If children truly cannot work together without fighting, try separating them into different groups and giving them separate materials.
- **Discuss or Refer** — Sometimes children get into disagreements because something else is bothering them. They may be in pain, scared, or tired. If it is unclear why a child or children are fighting, you can try to ask them about how they are feeling or refer them to their parents, social worker, or child life specialist.

6.2 Sibling Disagreements

It is possible that you will be working with siblings. Some siblings have difficult relationships, and may argue a lot. Try these techniques if you see some conflict.

- **Remind** — If a child is teasing their sibling or being rude, remind them that this is a safe space where everyone is kind to one another.
- **Separate** — Try to separate siblings into different groups in the beginning unless they say they want to work together.
- **Discuss or Refer** — Sometimes siblings get into disagreements because something else is bothering them. They may be in pain, scared, or tired. If it is unclear why a child or children are fighting, you can try to ask them about how they are feeling or refer them to their parents, social worker, or child life specialist.

6.3 Lack of Participation

Some children may be easily distracted or not want to participate. That is okay. You can try validating their feelings and asking them what is going on. For example:

- Hey you seem kind of distracted today. Is everything okay?
- Do you want to stop for today? If you do it's okay, I can come back another time!
- Would you like to try "x"? (insert an activity)

If children truly do not want to participate, leave them be. You can try coming back at another time.

6.4 Lack of Ideas

We all run into blocks where we can't come up with ideas. If children are having trouble coming up with ideas, you can try:

- Having a dance or music party
- Discussing something else for a while and then coming back
- Moving to another location (only if the child can move and you notify healthcare providers where you are going)
- Recharging (eating or drinking, again only if the child is allowed)

6.5 Shy Children

Some children are naturally shy, and others may be quiet or shy or scared due to their hospitalization. You can try:

- Complimenting them (like their outfit or objects they own)
- Asking them about themselves (like their favorite movie)
- Sharing something about yourself first and then asking them something

If children truly do not want to talk, leave them be. You can try coming back at another time.

6.6 Pain or Medical Emergencies

When working with pediatric patients, you may witness children in pain. If a child seems to be in deep pain and is having trouble focusing, offer to come back at another time. If they seem worried about stopping, assure them that it is okay and they are not letting you down.

If there is a medical emergency (i.e., the child is not breathing) follow the instructions of the hospital you are in for what to do when specific things happen. For example, you may need to press a Code Blue button or call a nurse (depending on the situation).

6.7 Tricky Topics

You may be designing applications that relate to medical illnesses, bodily functions, or mental health. These can be difficult topics to discuss, especially if the children you are working with don't know you very well. Creating a safe space can help children feel more at ease when discussing topics like these (read more in Chapter 7). Ensure that the children know you are not there to judge them and they are welcome to share anything they would like.

If you are trying to discuss abstract or layered topics (like racism or equality) and the children are having trouble understanding, try using art or play.

6.8 Challenging Behaviors

Some children may have challenging behaviors while you are with them. They may be doing this to get your attention, or that might be their way of expressing how they are feeling.

- **Express Your Feelings** — If a child is being rude to you, you can tell them that that makes you feel sad or bad. If they continue to be rude, you can excuse yourself from the session and come back at another time.
- **Redirect** — If a child is doing something inappropriate or talking about something inappropriate, you can try to redirect them. Mention something else, or ask them a question.
- **Discuss or Refer** — You can try asking the child if something is bothering them and if they would like to talk. If they don't want to, you can try referring them to their parents, social worker, or child life specialist.

07 Safety and Privacy

7.1 Emotionally Safe Spaces

A “safe space” is a place where everyone is free to exist and discuss their feelings without fear of judgement, ridicule, physical danger, or persecution [5]. Hospitalization is emotionally taxing on children. It is important that adult design partners prioritize children’s emotional safety and allow children to express themselves freely [5]. Creating a safe space involves:

- Introducing yourself and building rapport with the children.
- Explaining the concept of privacy before the sessions begin. Tell children that you cannot share anything you say with others unless it is separated from their name and they give direct permission for you to share it (read more in the next section about privacy).
- Introducing respect. Ask the children what they think that means. You can give them some examples if they are unsure. Ensure that children know that they should respect you and that you will respect them.
- Allowing children to express their feelings without judgement. Ensure the children know that it is okay to feel upset or sad, and you are not there to judge them.
- Reminding the children that this is voluntary and they can stop at any time. Children need to know that they do not have to participate if they do not want to.
- Listening. You are there to learn from the children, not control them or tell them what to do.
- Try to hold your design sessions in a place that feels safe for the child(ren). This is most likely a space where procedures are NOT performed [5].

7.2 Medical Information and Privacy

Note: This will differ between each hospital. The following is general information, but use your best judgment for your situation.

If you are not allowed to discuss specific medical information with the children, be sure to avoid asking them personal questions related to their circumstances.

Sometimes children may tell you details or information about their health. That's okay, just be sure to not share that information outside of the session unless you are cleared to do so.

Respecting the childrens' privacy is important, even from their parents or guardians. If the children share something with you that they do not want to tell their parent or guardian, try to respect these wishes. This will contribute to making the space feel safe for children. However, you may be obligated to report to their doctor if they mention anything related to:

- Current physical pain
- Self-harm or suicidal thoughts
- Abuse or neglect

7.3 Avoiding Contamination

Note: This will differ between each hospital. The following is general information, but use your best judgment for your situation.

When you are working with groups of children in a medical setting, there are some considerations to be aware of.

- Be aware of the protections that the children in your care need. For example, ensure that all children are wearing the proper protective equipment if applicable (i.e., masks).
- Be aware if children need to be separated by a specific amount of space.
- Wipe down all shared spaces and furniture with hospital - grade wipes before and after using them.
- Wear the proper protective equipment when visiting children in their rooms.
- Do not reuse materials unless you can properly wipe them down with hospital-grade wipes. Things like paper, crayons, clay, etc. must be disposed of after use to prevent the spread of illnesses.

08 Analysis

8.1 Preparation and Using Childrens' Prototypes & Ideas

So you have all of this data from children. What do you do with it? Since most of the data you will get from children is qualitative, there are a few analysis methods that can help.

If you used the techniques "Bags of Stuff" or "Mixing Ideas," or "Storyboarding," "Big Paper," "Layered Elaboration," "KidReporter," or "Big Props," you will have audio recordings of the children. First, transcribe this audio. Then, separate out individual quotes/thoughts. If you are going to use affinity diagramming (explained in next section), write each quote on a separate sticky note. If you can tell which children are speaking, you can label the sticky notes with identifiers (like "User1"). If you used the technique "Likes, Dislikes, Design Ideas," you will already have sticky notes.

If you used the techniques "Bags of Stuff" or "Mixing Ideas," or "Storyboarding," "Big Paper," or "Layered Elaboration," you will have one or more prototypes or designs from the children. The prototype(s) can serve as inspiration for your ideas. If you have multiple prototypes/ideas, you may not choose to use every one, but you can take bits and pieces from each one. For example, maybe you are developing an application to teach children about chores, and through your design session they have created a prototype for a magic mirror, a talking chore robot, and a stuffed animal that soaks up dust. You do not need to include all of these in your final prototype. You can try to combine these ideas (i.e., a stuffed robot who shows you dust in its mirror eyes), take bits and pieces of them (i.e., magic + robot + stuffed animal), or focus on the actual concept(s) that the children are expressing (i.e. chores are done by external beings that clean things like magic).

8.2 Iterative Categorization

Description

Iterative categorization or coding is the process of "identifying key issues or themes (codes) and then attaching segments of text (either original text or summarized notes) to those codes" [10].

How it Works

This technique is best when done with a group of people. First, go through all of your data and identify significant phrases and themes. Then, generate a "codebook" (a list of "codes" or themes) and label each piece of data with a code [10]. After each quote/idea has a code, categorize the codes into groups [10]. For example, if one code is "adding new controls" and another is "less confusing menus," you could group those together under the new theme "user experience." After some time, look at the codes you created and see if you need to adjust anything. Doing this with a group will help you think about different patterns that you may have not seen before. This analysis process is iterative, which means you are consistently going back and adjusting [10]. You will end up groups that summarize your overall findings.

Improving/Creating Your Product

For actually editing your product, the codes can give you a sense of the main issues with your product. However, the prototypes (depending on which technique you did) may be more directly helpful.

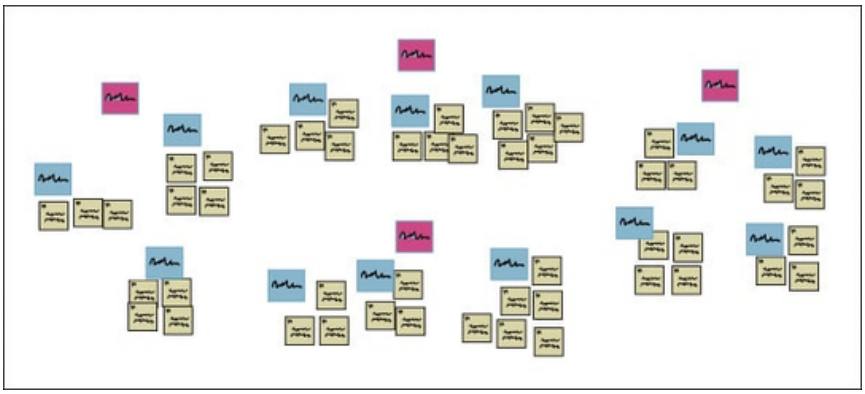
8.3 Affinity Diagramming

Description

Affinity diagramming is a technique that is used to categorize qualitative findings into clusters and themes.

How it Works

This technique is best when done with a group of people. First, organize small groups of sticky notes into multiple categories. You do not need to label the categories yet, just “look for sticky notes that reference similar ideas, issues, or functionality” [7]. Everyone may not agree on what sticky notes go in which groups. That is okay. It is good to involve different perspectives as it will help you think outside of the box. Once you have multiple groups, sort those groups into larger themes. Continue this until you have one or two giant overarching themes. It will look something like this:



The yellow sticky notes were sorted into groups under blue themes. Then the blue groups were sorted under pink themes.

https://sixsigmastudyguide.com/affinity-diagram/

Improving/Creating Your Product

For actually editing your product, the individual sticky notes may be more helpful than the themes you grouped them into. However, the themes can help you think about what children are expressing about your application. Maybe the controls are too hard. Maybe there needs to be more colors or decoration. Think about what the majority of children mentioned when going back to your product.

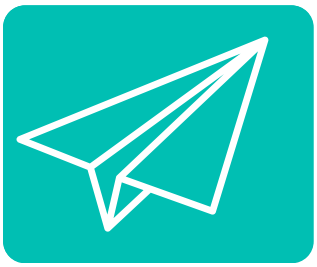
Tips

- It is okay if some sticky notes don’t seem to belong anywhere. You can have a sticky note “graveyard” for notes that are so distinctly different from everything else. Try not to eliminate too many though, as those are valuable pieces of data.
- It will be hard to agree on categories sometimes. Try your best to be open to other researchers’ thoughts and opinions [7].
- You may need to do this over multiple sessions. This process can be time-consuming and exhausting [7].

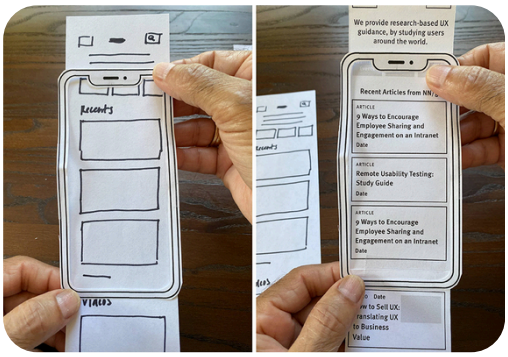
09

User Testing

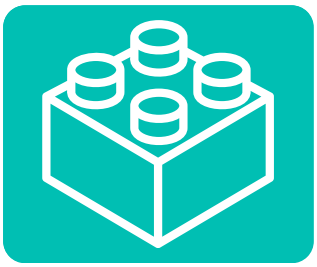
9.1 Paper Prototyping



After conducting design sessions with children and doing some analysis, you will probably create a prototype of your product. Sometimes, it helps to create a paper prototype so you do not waste your time and resources on something that may not be a good solution. A paper prototype is a low-fidelity version of a regular prototype. It is often made out of paper (hence the name) and shows the general actions and movements that would occur on a technology. You can construct pieces out of paper representing characters, buttons, etc. Here is an example for a phone app:



To test your paper prototype, take the prototype to a child (or children) and have them act out how they would use your application. You can guide them with questions (i.e., “How would you add a new profile?”) and allow them to pretend to press buttons, scroll, etc. If you record this conversation, you can do another analysis and continue to improve your product.



9.2 Prototyping

Doing testing with a normal prototype can help you see what is good about your current project and what can be improved.

1. Introduce the project to the children if they are not familiar with it.
2. You can generally describe how it is supposed to be used but do not go into detail. This will allow you to observe where the children get stuck.
3. Observe the children while they are using your prototype. Note any difficulties they have (with the software material itself or the controls).

This will be kind of similar to some of the co-design techniques introduced in Chapter 3. User-centered design is all about iteration - constantly going back and asking your users what they think as you design the product. Remember, a prototype is not a finished product. Be open to the suggestions that children give you.

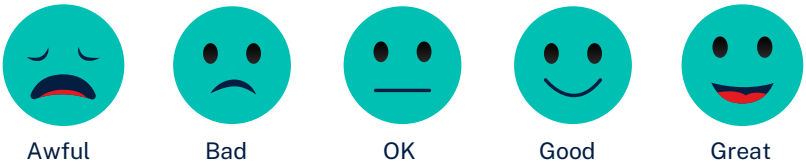
9.3 Evaluation Methods

Typical survey methods don't always work well for children, especially younger ones who may be pre-literate. After your analysis and prototyping, you may want a quick evaluation of the childrens' enjoyment of your product. Here are some methods you can leverage.

Smileyometer

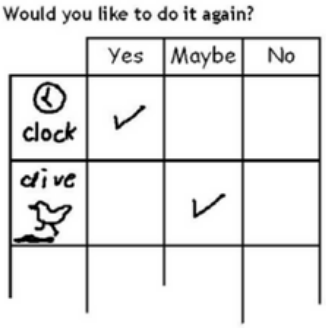
The smileyometer is the kid-friendly version of a Likert scale [12]. Generate statements or questions about your product (i.e. "how hard was it to learn how to play?") and then have a set of faces for each one that children can circle. Here is an example:

Q1. My experience playing the game was:



Again-Again Table

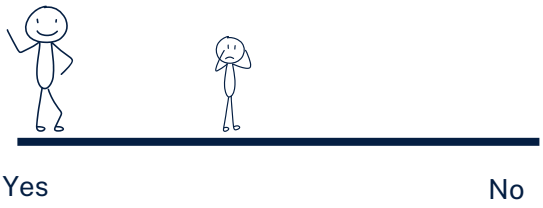
The again-again table is a way to capture children's engagement with a product [12]. Generate tables that list activities included in your product (i.e. "climbing a wall") and then have a set of choices (i.e., "Yes, Maybe, or No"). Here is an example:



[12]

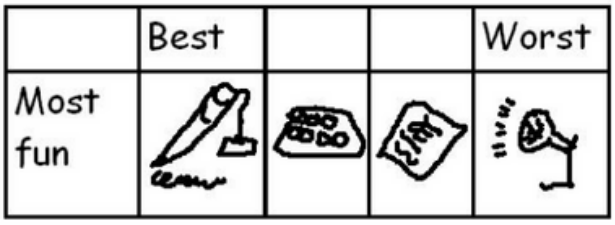
Line Judging

Line judging is an evaluation method where children move across a physical line to show their answer to a question [14]. Line judging differs from the Smileyometer in that the children can see each other's responses. Set up a piece of tape on the ground. Label one side "YES" or "AGREE" and the other side "NO" or "DISAGREE." Then, come up with questions or statements about your product, and have the children move anywhere on the line to answer. Take a picture to capture the childrens' locations. If you want more details as to why the children moved where they did, it helps to go through each child and ask them. Here is an example:



Fun Sorter

The Fun Sorter allows children to rank activities or items against each other [12]. Give the children a list of activities that exist in your application, and then have them draw or write in a ranking table. Here is an example:



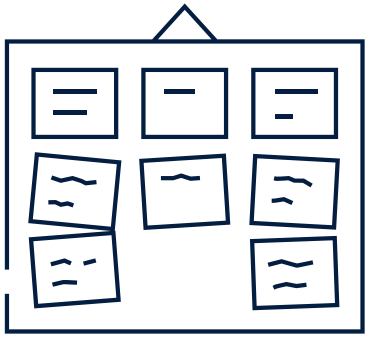
[12]

This or That

This or that is a simple method that allows children to choose between two things [13]. You can use cards and pictures, and ask children questions related to your product (that can be answered by pointing). For example: “Which game do you like better?” or “Which of these ideas is the most boring?” This method won’t give you deep insight, but it may be easier to use with very young children.

Card Sorting

Card Sorting is a method that can help you understand childrens’ mental models [6]. You can use this method when trying to design a menu or information architecture or if you are simply trying to understand how children connect a specific set of items. Give the children a set of cards (preferably with pictures and words) and ask them to sort them into categories. Once they sort them, you can ask them to explain what each category is and why they put the cards where they did.



Notes

- The results you will get from these methods are surface-level. Use co-design techniques to dive deeper into childrens’ thoughts.
- For methods like the Smileyometer and Line Judging, children are likely to respond in extremes, especially younger children [12]. For example, if a child has a difficult time with a controller, they may rate their experience as “Awful” as opposed to “OK”. If a lot of children are responding in extremes, ask the children why they put a specific answer. This will help you determine if their experiences were truly that bad or good.

10 Other Considerations

10.1 Children With Physical Disabilities

While working with pediatric patients, you will most likely encounter children with (short or long term) physical disabilities. This may include (and is not limited to):

- Lack of control of the upper extremities or inability to move one arm (i.e., due to an I.V.)
- Inability to walk, stand up, or get out of bed
- Inability to speak or vocalize
- Sensory disabilities (i.e., blindness, deafness)
- Epilepsy/Seizures
- Spina Bifida
- Amputations

Be cognizant of this when running design sessions. For example, if you have planned an activity that involves drawing, but you have a few children who cannot move their arms, consider adjusting the activity or adding in additional support (like a person who can draw for the children). If you're using technology, it should be accessible and useable for everyone.

10.2 Children With Intellectual or Developmental Disabilities

You may also work with children with intellectual or developmental disabilities. This may include (and is not limited to):

- Learning disabilities like Dyslexia or Dyscalculia
- Autism Spectrum Disorder
- Down syndrome or Williams syndrome
- Cerebral Palsy
- Fetal Alcohol Spectrum Disorders

Be cognizant of this when running design sessions. For example, if you have planned an activity that involves working in groups, but you have a few children on the Autism spectrum who prefer to work alone, consider adjusting the activity to better fit the needs of the children you are working with. Children with learning disabilities may require you to be more patient with your instructions and guidance.

10.3 Children With Visible Injuries

In a hospital setting, you may work with children who have visible injuries or sympotms of illnesses. This may include (and is not limited to):

- Exposed wounds (i.e., burns, cuts, bruises, swelling, rashes, marks)
- Exposed or covered organs (i.e. intestines)
- Broken bones/fractures
- Bandages
- Vomiting
- Coughing/Sneezing
- Trouble breathing

Be cognizant of this when working with children. Children may not want to draw attention to their injuries, and may attempt to hide them. Do not ask the children about their injuries unless they bring it up or you are cleared to do so. The focus of a child's hospitalization is their health and/or injuries; Your presence as a design partner can give them a sense of normalcy. Try to keep your facial expressions neutral if a child is showing you their injury.

10.4 Children With Mental Health Disorders

You may also work with children with mental health disorders. This may include (and is not limited to):

- Anxiety
- Depression
- Bipolar Disorder
- Suicidal Thoughts/Self-Harming Tendencies
- Eating Disorders
- PTSD (Post-Traumatic Stress Disorder)
- Oppositional Defiant Disorder

Be cognizant of this when working with children. Be patient, and try not to judge. Children may have difficulty regulating their emotions or may be easily upset. Depending on the rules in your hospital, you may be notified or aware of self-harming tendencies in children before you work with them. If you are working in a safe room, consider what materials you are allowed to bring in.

11 Permission and Recruitment

11.1 Child Consent

When applying for IRB approval, you will most likely need a child consent form. Young children aren't allowed to give consent without permission from a caregiver. However, they can give **asset**. In other words, they can verbally say yes or no.

11.2 Parent Consent

Parent/guardian consent is essential and will be required by all IRBs. The consent form should lay out all possible activities that you would be doing with the children, and the possible risks.

11.3 Giving Children Credit

When conducting co-design research with children, it is important to give children fair compensation for their participation. Depending on your funding, you may be able to offer monetary compensation. Otherwise, consider giving children toys or activities.

When publishing a product, be sure to give written credit to the children who helped you. You should not use their names, but can refer to them as “patients from ‘x’ hospital.”

11.4 Recruiting Children

Not all children may want to participate in co-design sessions, especially those who are in a lot of pain or cannot move. Be considerate when deciding what children you want to include. For example, if you’re designing an application about disability, including children with disabilities is a good way to ensure you are accurately capturing their experience(s). When looking for children to recruit, child life specialists will usually be aware of which children may be a good fit. **Always** get verbal consent from parents/guardians and minors before doing anything.

12 Involving Families

12.1 Caregivers

Getting Ideas or Gaining Insight

Caregivers such as parents and guardians are often a huge part of a child's hospitalization experience. They can provide emotional support, stand up for their child, and make medical decisions for them on their behalf. It's important to consider that caregivers have unique insight on their childrens' lives and preferences. When designing, consider including ideas from caregivers as well as children.

The most straightforward way to getting ideas and thoughts from caregivers in this setting is to do a short interview. Do this separately from the child, so the caregivers can give their honest opinions. You can ask questions like:

- What types of activities does you child enjoy?
- Do you think immersive experiences could help your child? Why or why not?
- What types of experiences does your child enjoy? Do they like action games? Do they like puzzles?
- What types of things would you want an application to teach your child? Information about their medical diagnosis? Coping skills?

Children's Design Sessions

It is not recommended to have caregivers present while doing design sessions with children, as caregivers may influence what children say and do. However, in a hospital setting, caregivers may feel more comfortable being close to their child. If you are conducting co-design sessions in the child's room, the caregiver can stay in the room, but ask the caregiver to listen to music, watch TV, or direct their attention elsewhere. This will ensure that the child feels free to speak their mind. This is especially important when working with pre-teens and teens [2].

Tips

- Remember to be patient and understanding when working with caregivers. Having a child in the hospital is very stressful and strenuous, and caregivers may be experiencing burnout, financial issues, and more. If they are not interested in immersive experiences for their child, do not force them to be involved.

12.2 Siblings

Getting Ideas or Gaining Insight

Siblings staying at the hospital may want to participate in design sessions as well. That is okay! It is easy for siblings of pediatric patients to feel pushed aside when their siblings are hospitalized. Co-design sessions can be helpful for them as well.

Children's Design Sessions

Consider holding separate co-design sessions for children who are not hospitalized. You may want to separate the data you get from these children, as it will likely differ from the data you get from hospitalized children. It is okay to combine this data, but ensure that you specify this if you are presenting your findings.

Tips

- Siblings of pediatric patients may be feeling frustrated, powerless, left out, or ignored [5]. They may also be afraid of losing their sibling and want to help. Be patient, and remind them that they are helping their siblings by giving you ideas and thoughts for immersive applications. If a child is having a very hard time, refer them to their family (or child life specialist).

13 Closing

Closing

This handbook is intended to help you learn how to include the voices of pediatric patients into the design of immersive applications. It is based on research in child development, human-computer interaction, child-computer interaction, child life, and psychology. If you want to learn more, please refer to the references on the next page.

We encourage you to revisit this document whenever you have questions about co-design with children. If you need further clarification, do not hesitate to reach out to Invincikids.

Together, we can create inclusive, sensitive, and healing products that truly meet the needs of pediatric patients. Thank you for your contributions!

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References

[1] Bell, J., & Condren, M. (2016). Communication Strategies for Empowering and Protecting Children. The Journal of Pediatric Pharmacology and Therapeutics : JPPT, 21(2), 176–184. https://doi.org/10.5863/1551-6776-21.2.176

[2] Castella, K. (2019). *Designing for kids: Creating for playing, learning, and growing*. Routledge, Taylor & Francis Group.

[3] Druin, A. (1999). Cooperative inquiry: Developing new technologies for children with children. Proceedings of the SIGCHI Conference on Human Factors in Computing Systems the CHI Is the Limit - CHI '99, 592–599. https://doi.org/10.1145/302979.303166

[4] Druin, A. (2002). The role of children in the design of new technology. Behaviour & Information Technology, 21(1), 1–25. https://doi.org/10.1080/01449290210147484

[5] Gordan, J., Ahrens, A., Barnett, S. Barnhart, D., Barrentine, C., Clark, H., Cross, J.N., Davis, J., Gottwein, L., James, C., Kellett, M., Koenig, S., Luongo, J., Millar, T., Ortiz, B., Romito, B., Rosburg, N., Wagner, K., & Woods, T. (2021). Emotional Safety in Pediatrics. Association of Child Life Professionals. https://emotional-safety.org/wp-content/uploads/2025/03/Emotional-Safety-Paper_2025.pdf

[6] Hourcade, J. P. (2022). Child-Computer Interaction.

[7] Kraus A., & Pernice K. (2024). Affinity Diagramming: Collaboratively Sort UX Findings & Design Ideas. Nielsen Norman Group. https://www.nngroup.com/articles/affinity-diagram/

[8] Lerwick, J. L. (2016). Minimizing pediatric healthcare-induced anxiety and trauma. World Journal of Clinical Pediatrics, 5(2), 143–150. https://doi.org/10.5409/wjcp.v5.i2.143

[9] Mortensen, D. H. (2025). User Research: What It Is and Why You Should Do It. The Interaction Design Foundation. https://www.interaction-design.org/literature/article/user-research-what-it-is-and-why-you-should-do-it

[10] Neale, J. (2016). Iterative categorization (IC): A systematic technique for analysing qualitative data. Addiction (Abingdon, England), 111(6), 1096–1106. https://doi.org/10.1111/add.13314

[11] Neely, E. L. (2017). No player is ideal: Why video game designers cannot ethically ignore players' real-world identities. SIGCAS Comput. Soc., 47(3), 98–111. https://doi.org/10.1145/3144592.3144602

[12] Read, J. C., & MacFarlane, S. (2006). Using the fun toolkit and other survey methods to gather opinions in child computer interaction. Proceedings of the 2006 Conference on Interaction Design and Children, 81–88. https://doi.org/10.1145/1139073.1139096

[13] Sim, G., & Horton, M. (2012). Investigating children's opinions of games: Fun Toolkit vs. This or That. Proceedings of the 11th International Conference on Interaction Design and Children, 70–77. https://doi.org/10.1145/2307096.2307105

[14] Walsh, G., Foss, E., Yip, J., & Druin, A. (2013). FACIT PD: A framework for analysis and creation of intergenerational techniques for participatory design. Proceedings of the SIGCHI Conference on Human Factors in Computing Systems, 2893–2902. https://doi.org/10.1145/2470654.2481400