Human-Centered Design Research Principles & Practice







RESEARCH

A process of systematic inquiry that entails collection, analysis, and interpretation of data, in accordance with suitable methodologies set by specific professional fields and academic disciplines.

JAM

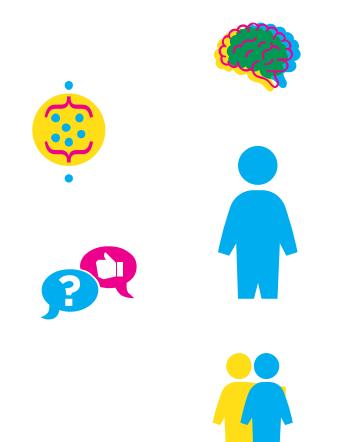
- 1. An informal, freely collaborative meeting, conference, or discussion.
- 2. Something that one particularly likes, enjoys, or does well.



Research Jam collaborates with community members, patients, care providers, and other researchers using human-centered design research & visual communication to improve health research, health services, and quality of life.



What is Human-Centered Design Research?



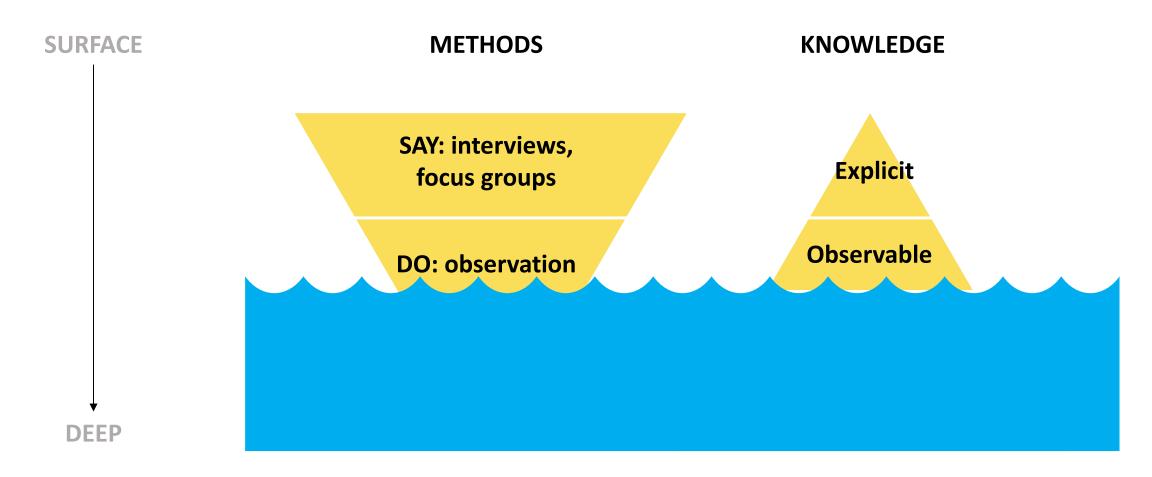




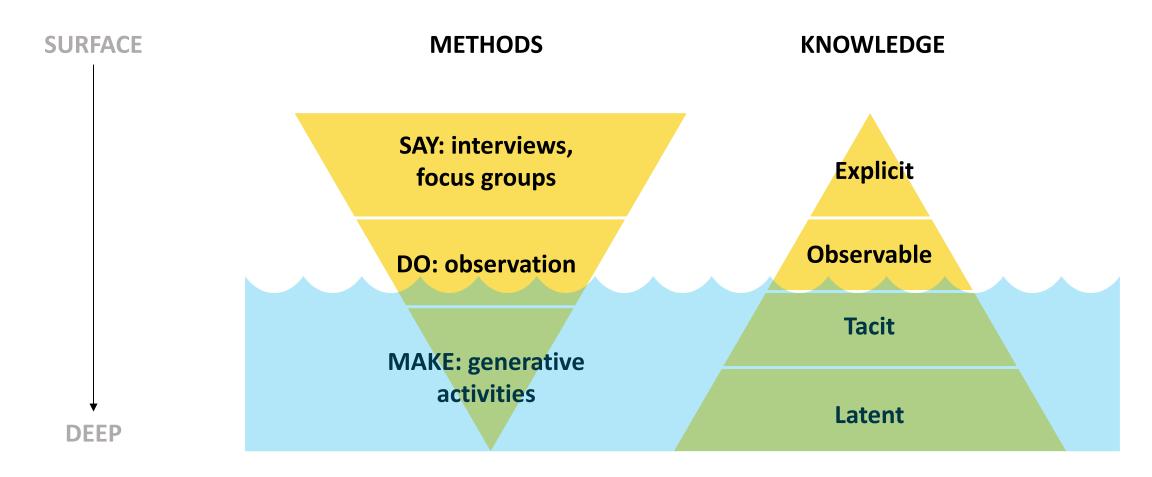
- put & keep people in the center
- develop empathy
- collaborate
- externalize ideas
- involve stakeholders
- be comfortable with ambiguity
- diverge & converge

Adapted from: IDEO (Firm),. (2015). The field guide to human-centered design: Design kit.

HCD methodology



HCD methodology





Tacit

Latent

HCD methodology

Knowledge that is difficult to express. (How do you tie your shoes? How do you navigate a grocery store?)

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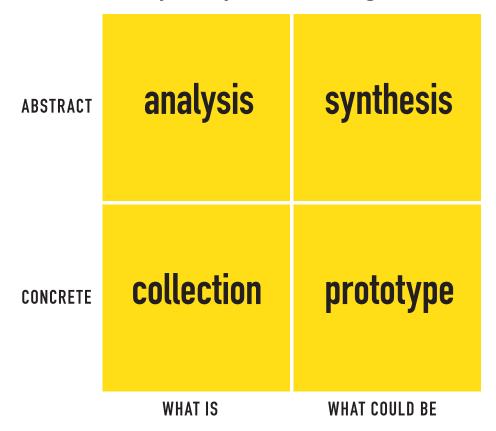
Tacit

Latent

Knowledge that you don't know you have (anytime you say, "It never occurred to me...")



Analysis/Synthesis Bridge Model

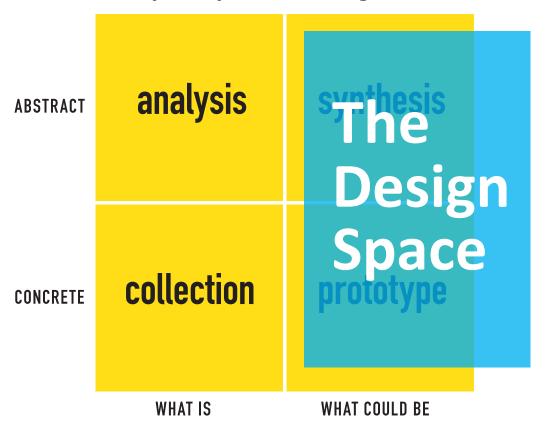


Gathering, analyzing, & synthesizing data to move from insights about what IS to ideas about what COULD BE.

Dubberly, H., et. al., "The Analysis-Synthesis Bridge Model" in Interactions, 2008



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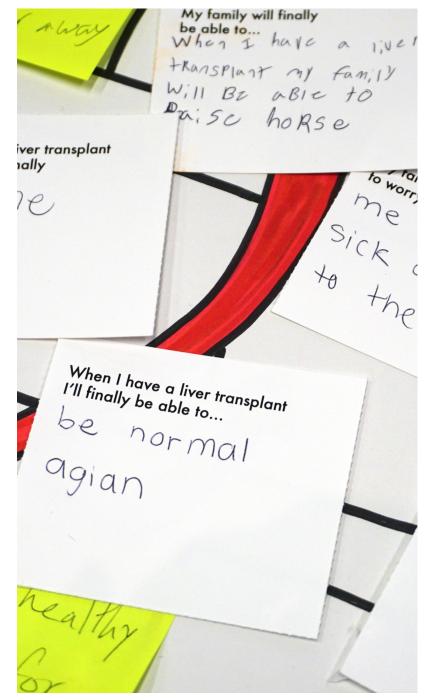
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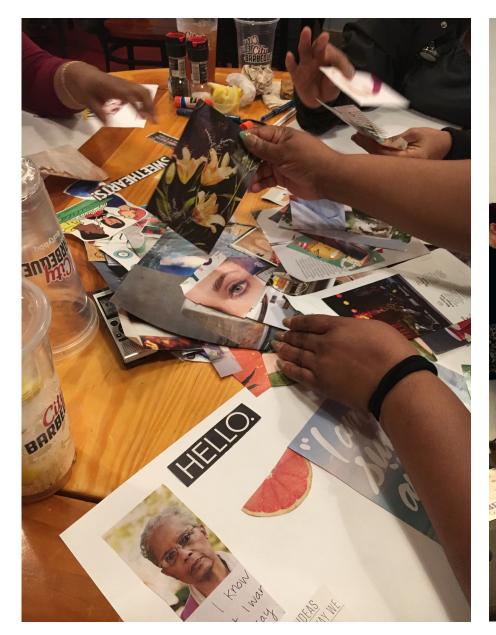
What is *a* RESEARCH















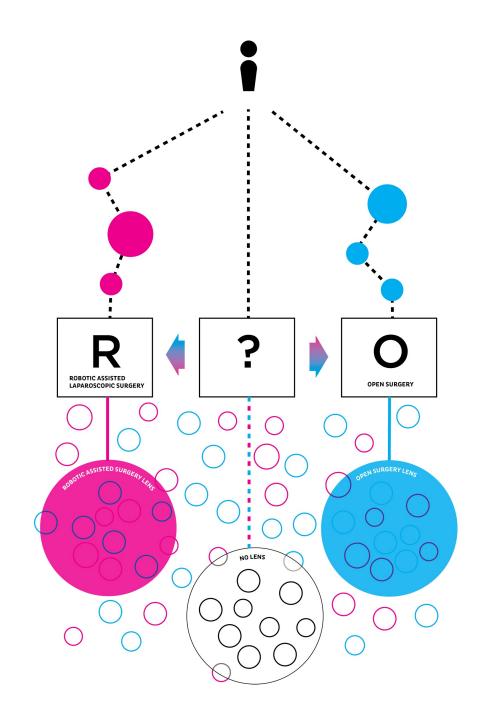


How might we make an RCT acceptable to parents of children

with UPJ obstruction.

Barrier:

Asking parents to let which surgery performed on their child be determined by the flip of a coin...And then not told which surgery they received for 48 hours after.



Case Study

in:	the PEC works with:	to address:	by:	
Session 1	parents of "RALP" recipients parents of "OP" recipients	measurement & acceptability	Using "rapid idea generation" to discover QOL factors affected by this surgery Using "experience mapping" to discover influential factors in choosing RALP or OP	
Session 2	13-17 yr old "RALP" recipients 13-17 yr old "OP" recipients	measurement	Using "remote elicitation" & "on-line discussion" to discover QOL factors affected by this surgery	
DELIVER PATIENT-GENERATED QOL MEASUREMENTS				
Session 3	parents of 2-8 yr old children with no Hx of surgery	acceptability	Using "role play" & "interpretation" to discover barriers to randomized testing and generate solutions	
DEVELOPMENT OF RECRUITMENT STRATEGY				
Session 4	parents of 2-8 yr old children with no Hx of surgery	acceptability	performing user testing of the recruitment strategy	
REFINEMENT OF RECRUITMENT STRATEGY				
Field Testing	parents of children with UPJ diagnosis	acceptability	performing field testing of the recruitment strategy	
DELIVER RECRUITMENT STRATEGY FOR PILOT STUDY				
Session 5	Study participants 3 months post study	validation	performing field testing of the recruitment strategy	
DELIVER REVISED STRATEGY FOR FURTHER USE /				

measurement & acceptability

parents of "RALP" "0P" parents of ' recipients



QUESTION ON THE BOARD:



MEASUREMENT

collect notecards

ON THE NOTECARD PROVIDED PLEASE AN-SWER: Why did you choose surgery? Was it a choice?

WHY?

This "bookends" the session by getting the participants to think about their reasons for choosing one surgery over another before hearing about the experiences of others.

SHARED EXPERIENCE MAP PART **TWO**



MEASUREMENT

ON THE STICKY NOTES PROVIDED

Please write how you felt at this moment at this location? Where would you have been had you not been here? etc. Drill down, more questions. Lots of post-its.



WHY?

By further exploring the moments along the experience map, we uncover barriers and opportunities to decision-making and how they may change based on context. This process also makes it easier to answer "how did you feel?" questions by "how did these things happening at this time make you feel?"

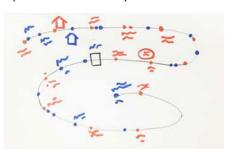
SHARED EXPERIENCE MAP PART ONE



MEASUREMENT

On a (minimum 3' x 4') large sheet of paper, create a path that begins with UPJ diagnosis and ends

Points along the path will be divided into the OPEN experience and the RALP experience



WHY?

By examining the peripheral experiences leading up to and extending beyond the surgery, we uncover moments that exist within the experience of surgery that may not have previously been considered to impact the family's quality of life.

ADVICE FROM THE FUTURE:



ACCEPTABILITY

Consider the things you had to think about when you recieved the UPJ Dx. If you could go back in time and tell yourself something to make your decision easier what would it be?

round table discussion

What if you were given a third choice to be randomized? How would you feel about that then, versus now.

round table discussion

WHY?

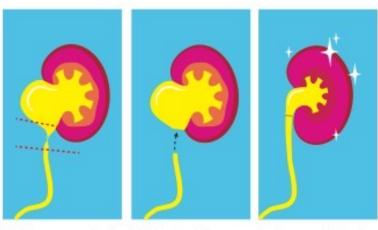
Asking people what advice they would give themselves can reveal the language that is most acceptable to that person.

This also completes the bookend question on the



Deliverable 1:

We can fix it.



We'll use an anesthetic so your child will be asleep the whole time, detach the ureter from the kidney and remove the narrowed part. We'll reatta ureter using a temporary is removed to the harrowed part.

We'll reattach the ureter using stitches & a temporary stent that is removed after the site heals...

leaving your child with a patched up ureter and a perfectly operating kidney.

There are two approaches to the procedure: Open Pyeloplasty & Robotic Assisted Pyeloplasty. Let's take a look at the medical outcomes for each:

	open	robot
0	a few hours in surgery and 1 to 2 days recovery	a few hours in surgery and 1 to 2 days recovery
	one 3-4 centimeter incision on the side	x3 three 1 centimeter incisions on the belly
4	1 to 2 weeks rest before resuming normal activity.	1 to 2 weeks rest before resuming normal activity.
3	greater than 95% success rate	greater than 95% success rate

Other than incisions, the two approaches are medically the same. So which one is best for YOUR child?

The short answer is, we don't know. Usually a surgeon recommends the approach he/she specializes in, which is fine, but it means you're getting the approach most appropriate for your surgeon, not necessarily the one most appropriate for your child.



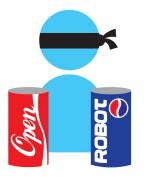
So how do we find out?...



We need to do a study

We don't want your expectation of pain and recovery time to influence your perception of pain and recovery time.

Deliverable 1:



It's the same idea as a blind taste test. It's easier to compare things fairly when you don't know which is which.

Both approaches have the same (very high) success rate, so no matter what, your child is getting great care.

How does the study work?



People in the study would get one of two highly skilled surgeons, picked randomly, to perform the operation; one specializing in Robotic Assisted Pyeloplasty, the other in Open Pyeloplasty.



You would get to meet and talk to both surgeons beforehand, and both surgeons will be there during the procedure so you won't have a bias that could influence your perception of your child's recovery.



We'll even bandage up both sites so for the first 24 hours you won't know where the incision is. Before you leave the hospital we'll check the incision site and the mystery will be over.

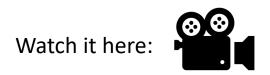


We'll look at the results from the 2 approaches in an unbiased way and learn if they might have aspects that are better for certain cases, or maybe they're exactly the same and we should phase one out.

Case Study

Deliverable 2:







How might we make an RCT acceptable to parents of children with UPJ obstruction.

Insights:

The bias of the initial surgeon was the largest factor in the parent's choice of surgery. By mitigating that bias, parents were receptive to the idea.

The word "surgery" is strong. There can't be 2 "right" surgeries for the same condition. But there CAN be two approaches to the "right" surgery.



How might we make an RCT acceptable to parents of children with UPJ obstruction.



Insights:

This was a small trial of 10 participants.

Using the recruitment tools Research Jam developed, it took 11 attempts to recruit all 10 participants. The bias of the initial surgeon was the largest factor in the parent's choice of surgery. By mitigating that bias, parents were receptive to the idea.

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UNEXPECTED INSIGHT:
asking a child to remove a
stint at home can be a
traumatizing event.
Preparing parents for this
and giving them options
mitigates this stress.

Questions?