

**The Journey By Chris Waugh
End Well Symposium, December 7, 2017**

Start of Transcript

Hi! How are you? So we believe — I'm at Sutter Health now and with a little bit of data. Sutter Health treats three and a half million people just in Northern California. Roughly 101 Americans get their care at some point in their lives in Sutter. Raise your hand if you know the name of the hospital that you were born in. That's amazing! We have a concept that I'm gonna share with you that's around that. But a couple of other health-related statistics. There's about three and a half billion Google searches today every day. And 20% of those searches are about health. Within that — many of the searches are about mental health and so what we find there is a bit of anonymous search going on and that represents the design, the gap that's not being filled.

1 in 10 Americans **[00:01:00]** works in healthcare. What shocks me is the outsider coming into healthcare is the average health of that employee based is ____ than the people that they're serving, which is shocking! So one of our hypotheses internal at the design for Sutter centre is let's just start from within. Let's start on our own people. Let's think about care for our people. The average time between when a patient speaks and when they're interrupted... take a guess! 12 seconds. 12 seconds! So if I were starting a company right now and I pitch that company and I said, "I want a very expensive resource to meet one person at one time and expensive building that we run on a daily basis, no one would fund my startup. And so what begs is we can think about the process in a different way.

What I'm also here to share, I think there's an unnecessary **[00:02:00]** barrier to entry to this thing called design. We speak of design and we really put it up on a pedestal. But the design is to simply be human. The elements of design are empathy with each other, creativity, and then putting something out there. Just giving it a go, just trying it out. These are really the three commonalities, the main pillars of design. And to do that is to be human and to do that is to include all of us and many many more in that process.

So when we took our first project, the very first project that Sutter we did was in collaboration with Alma Mater IDEO, many of them are here today. We did the Open IDEO challenge and you heard one of those projects that came up earlier today with education and it's an amazing outcome of this platform which just said, Hey! We're all designers and end-of-life includes all of us so let's come on to this global platform and discuss that for your stories and ideas. And there were over a hundred countries **[00:03:00]** not dissimilar from what we see today and Shoshana is brilliant for bringing us all together but that over a hundred countries came to this platform, submitted stories, ideas and solutions that were not reserved — I was this specialized in palliative care — were not reserved to those that called themselves professional designers. They were anyone that had anyone with anything to share about design.

When we saw the results of this end-of-life challenge, we were sitting there looking at the winners of the challenge and if you looked at those solutions and you simply applied it to beginning of life, many of them, pretty much all of them, were also applicable to the beginning of life. So we would often open another challenge. We said how might we re-imagine the beginning of life? And now we've got the result of those challenge-questions and they can be applied to the end-of-life! And so I'd like to share with you today some of the things that we've seen but I'm **[00:04:00]** gonna start with aesthetics, where BJ brought us this morning. And between all of us, I've had a man crush on BJ since he started speaking. The guy's awesome! And if he's still here I'm gonna be so happy to be in your presence again, BJ. Thanks so much for all of us.

The constraints is what he talked about and constraints are real for all of us. We have constraints in our lives, constraints in our jobs, and this next piece was done by a very creative neighbour of ours, a company called Pixar. And they had a constraint in the form of four minutes and the constraint was we could use no human voices and we're gonna tell a whole life story from beginning to end as we set scene for this movie that we've created. So here's an example of amazing design celebrating those constraints. **[00:04:51]**

[Animated Video Presentation 00:04:52 - 00:08:16]

I weep everytime I see that and I think it summarises this day pretty nicely. What we don't know is about the rest of the poem brings, which is the beginning of his life. So the death bringing new life into his world. For me that hit home. My mother passed away — I know all of us has a death story and I'll share mine in one minute—10 years ago my mother passed away and I did something a little unusual right after the funeral.

This was in Colorado and I just rode my bike home which meant coming back here to Half Moon Bay starting November 1st **[00:09:00]** about 1900 miles and there's one particular day in Death Valley I punched my tires and the sun went down coz I got those flat tires and nobody was out there'd I was hungry and cold, and you talk about life getting simpler in what looked like something that looked lonely and cold is actually one of the best days in my entire life. And that'd be with my mother alone in Death Valley by my side.

Coming back, on December 18th, my sister had been pregnant the whole time and we were looking for to new life. On December 18th I got a call saying her full-term baby had an umbilical cord wrapped around his leg and he didn't make it. But we spent the next year making fun of pregnant women but jokingly called them sluts. It's all a joke. So my sister and I would look out and go "slut! slut! slut!" And she said — I opened **[00:10:00]** a card in March and she said "Look who's the slut now!" [Chuckles] She got pregnant again! And on December 18th, one year later, something seemed wrong... but everything was right. My nephew was born under the exact same day. Fast forward 8 years, to my wife and I getting pregnant, guess what the due date was? So if there's not enough kind of BJ Miller or soul and experience in your life and you need a wakeup call like the one we had, well suddenly December 18th means a tremendous amount.

Looking at constraint, here's another one. Healthcare has a negativity bias. We heard this earlier today. So with that negativity bias, can we introduce a more balanced point of view around things like our own mortality? And this doesn't become any more controversial, perhaps **[00:11:00]** other than our longevity conference with the talk we had earlier, we see it in genomics right now. So genomics and the way that genomics were presented to the world was swipe your cheek, we're gonna send that to the lab and you'll get it back, and you're gonna get probabilities of how you're gonna die. That was pretty much how it played out. And so that obviously scared people for right reasons and the questions around who was gonna get that information.

So as a propagation and experiences was done with Genentech at IDEO for the tech conference so these TED participants have swabbed their cheek; send it to the lab overnight; got the genetic sequence back. And it turns out, many of you ate asparagus today for lunch. Genetically some of your urine will smell later today because of that asparagus and for some of you, it won't. That's the genetic barrier. Some of you have this sprinter's gene. If you don't have some jogging shoes and you got the sprinter's gene, you should get some **[00:12:00]** and your sensitivity to caffeine is really different so what happened was participants would come back and they put on these headphones. This was the design. We knew that there were imprinted variations in our genomics. As there are variations of notes in music. So people would put on

the headphones and ... if I could play here, just a second. You should hear a genetic song. Probably it's not gonna play and that's okay. I won't make you sit through that thing again I promise.

[Background Music Starts Playing 00:12:35] So this is a participant putting on headphones and listening to a song that's uniquely his based on his unique genetic markers as he flips through an iPad and sees probabilities but also exciting information about his body and the body that he has — and why it's beautiful! Why it's remarkable and not just the percentages of likelihood of ways that he's gonna die [00:13:00].

We look at this in time horizon. Here's another prior IDEO, a piece of work that was done by a different team and they were just playing out around with time so they said, "Well, time is money!" So all of us think a lot about money and time and what can we afford, so this was simply an outlet. You type in your salary and when you scanned items, it say "That's gonna cost you about a week of your time." Is that worth it? Is that car worth five years of your time? And reframing the decisions, that area of behaviour in economics is a big deal. It's design and economics that are very interesting. And we do these hacks in our lives all the time. Something like an app is just manifesting that.

So in new life, we look at the new life experience and you see in just the design talks today, you see a lot of journey mapping and simply what journey mapping is doing is saying what are the various touchpoint that somebody goes through and healthcare has a really important one to help the clinical [00:14:00] encounter, but if you look at the whole variety of touchpoints, it's looking at appointment, driving out appointment, parking lot appointment. If you look at the average maternity journey there's 14 appointments before labor.

So I'm gonna cut to the chase here and listen to where to talk to moms and they said, "The drop-off is this big problem for me and it was the moment that healthcare was celebrating. They call it discharge!" So healthcare says, you're discharged! Parents says, "WTF I have all my questions! Like this is...it just started!" And so we honed in on this as an opportunity's base and we look at people's emotional journey and we also noticed that that dad or partner or most people show up at the hospital with somebody; a loved one, even if it's a single mother. We noticed that the partner of the other ones all babied up. They're so anxious and they have nothing to do to relieve that [00:15:00] anxiety so we've simply been taking as a prototype the partner aside and saying, "Capture this moment." Trust me. Because the mothers were asking when we were interviewing them. They said, "Can I record this conversation? I wanna capture this experience. Coz my baby loves the story of the day that they were born." And so we thought we're uniquely in that position. Why don't we capture it? Some say, "Dad, what's the weather like? Partner, what's the weather like? What's it smell like? What's it sound like? What were you thinking? What was she thinking? But we didn't tell mom. We don't tell mom any of this is happening. And we start playing around with time.

So 30 days later, something like this shows up on the doorstep. [Chuckles] Here's one we got. The team made it for me and it's honestly the best gift I ever received. And this is the story, told in animated form, step-by-step the day that the baby was born [00:16:00]. And a fit prototype for us. The test was if people cry, it's working. [Crowd Laughing] So far everybody cries!

But a prototype is why else could you put in the word when you know something could go wrong? So we put in the world what is interesting. The first week we had eight language requests. Eight. We had one couple that made us very nervous. They said the baby's going up for adoption. And I was like oh, no. This is gonna backfire and they said "The book and the card is the only thing that would go forward with the baby and we'll leave it up to the adoptive parents if they ever wanna get a cartoon and it says 'gone along with that adopted baby.'"

So let's get back to end-of-life. If you can think about this book, think about the book for every death. I would love this book for the death of my mother. For the death of my grandmother. Should remember them in a special way.

The Open **[00:17:00]** IDEO winner was called *Vykarious* and all of us have end-of-life things that we didn't get to as much as we try to fill every moment there are some things on that bucket list where someone we didn't talk to or a place we wanted to see, and the concept here is about waking up the living through death. And what happens here is Vibhu, who created this concept, she's a student, she's certainly not a professional in end-of-life care and we think that's amazing! She created the concept *Vykarious* and the way that it works is people's end-of-life wishes can be published and those that are willing family members, young people, anyone, can take that wish and vicariously live it on the patient's behalf, communicating back to that patient as they're going through the end-of-life experience. This is what it smells like, feels like, tastes like, to be in the Grand Canyon as the sun went down. That's **[00:18:00]** the last thing you want to do and then doing it on your behalf. So *Vykarious* is in development right now. It's been funded and we're looking forward to prototyping this with Vibhu.

Thank you very much. My email address is chris@sutter.org Love to stay in touch! I'm with all of you and I appreciate Shoshana and the team for inviting us here today.

[Crowd Clapping]

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