Leaps of Faith for Healthy Hearts

Experiments in participatory process design for patient-powered research

As I mentioned [in my recent blog post](#) introducing our work with [The Health eHeart Alliance](#), there's a new movement afoot in the world of health care. It's not talked about too much yet in the media — it's not about fancy drug trials or big business. It's about patients, and to me it's one of the more exciting and potentially transformative movements in the history of health care in the US.

This movement is about shifting power within the healthcare system, and putting more of it in the hands of the patients. Some call it "patient-centered research", "patient-powered research", or "community-based participatory research". All share an orientation of including patients in the process of researching improvements to their own medical outcomes. And all are rooted in the belief that improving patient care requires treating patients as human beings rather than objects of medical interventions, and valuing their input as experts of their own experience.

Last year, [The Patient-Centered Outcomes Research Institute (PCORI)](#) — as part of the Patient Protection and Affordable Care Act — put out a grant to fund 18 patient powered research networks around the country. One of those 18 grant recipients was the UCSF Health eHeart study team, led by [Dr. Mark Pletcher](#). He had a vision of creating a patient-researcher alliance linked with UCSF's ground-breaking [Health eHeart study](#) — the largest longitudinal heart disease data collection effort ever undertaken. Of the 18 grants awarded, the Health eHeart Alliance is the only patient-powered research network

(PPRN) linked with a large existing study. And it is also the only one that hired process designers to help.

And because of our innovative and deeply co-created work this past year and the success of our opening [design summit](#) this last month, the Health eHeart Alliance is quickly becoming one of the forefront models for patient-powered research in the US. This is thanks to PCORI's generous funding, to the unusually high-performing team at UCSF, to the collaborative design approach of my colleague Rebecca Petzel (herself a Groupaya alum), and to a passionate core of volunteers. Together this past year our core group has co-created a new community, vision, mission, culture, approach, and core values for patient-powered and patient-centered medical research.

"You cannot do things to people, only with them." — Kurt Lewin.

This was the foundational principle behind Rebecca's proposal for this project. From the onset, the intention was to use a radically inclusive co-design process for the formation of the patient-powered research alliance. And when awarded this rather daunting piece of work, luckily for me, Rebecca chose to walk her collaboration talk and not work alone on this project. We began our engagement by taking the time with each other to set our own ground rules, culture, and practices for how the two of us wanted to work together.

We also worked with our client team at UCSF team to do some goal setting work for the 18 month grant period. It became clear early on that the #1 goal of this project (in addition to meeting grant milestones) was to create strong relationships in our founding alliance community. We began monthly 2 hour virtual meetings (in Adobe Connect) with our steering committee of 16 patient and research representatives last March. In these calls we have been doing the work of building relationships and designing our collective future as an alliance. Every month's call has been followed with

synthesis work by myself and Rebecca team, a design conversation with the core UCSF team and a few patient representatives, and discovering together what the right topic is for our next call.

It's a complex design challenge — how to build and scale a research alliance from scratch. We had some fun head-scratching design meetings early on where we laid out a roadmap for our 18 month process and achieving our grant goals. But what's fun and so unusual about the participatory design approach is that the roadmap is just that — a loose guide to remind us of our goals and grant deliverables. *It is not a project plan.* The timelines are loose and flexible, and we've revised it a few times already. Ultimately much of the real design work is done in our monthly steering committee meetings. **Our job as process designers is to constantly adjust the 'plan' to keep up with the emerging wisdom of the group.**

Just shy of half-way through this 18 month process, we made it through the trust-building and visioning phase of the project and into some of the meatier work. A few months ago we launched our Alliance at our first in person summit, and tested or our research co-design process. Now we are refining our process and working through the tricky details of governance; how to expand our network and the work we are doing together while maintaining our core values around collaboration, inclusion, transparency, and trust.

Reflections from the Field

As we pause and reflect halfway through this project before we begin a new stage of our work together, I also pause and reflect on what I've learned as a practitioner. Here are some cliff-notes on my personal take-aways from this project so far:

1. Implementing the "Slow down to move fast" principle isn't always easy! As process consultants, our entire line of work

is about establishing relationships, shared vision, and processes for clear communication. We trust the value of slowing down to do this work in the early stages of projects because we have seen the value time and time again. But for many professionals, the more familiar model is one where work is all about output. Our group includes a diverse mix of professionals with various levels of experience with collaborative design. For some, the importance of early foundational 'storming and norming' work is clear. Yet others were eager to get 'to work' (our grant deliverables) right away, and we often have to navigate tension around practices like [check-ins](#) and the more divergent and creative design conversations.

This idea that relationship-building does not count as work is rampant in American work culture — I personally still struggle with breaking this belief pattern myself, despite what I do for a living. Yet it is especially counter-productive for informal networks and alliances where most participants are volunteering their time because they care. Taking the time to get to know each other and connect around that shared care and vision is absolutely essential to this kind of work. Relationships are literally the foundations on which any long-term collaborative project are built, and without their strength these kinds of projects are all too susceptible to crumbling when challenges arise.

The learning for us as consultants is to field all this feedback and filter it so that we are adjusting our process to meet client needs while staying true to our role — as the ones whose job it is to make everyone stop and reflect over and over on our shared vision, values, and relationships. It's a great reminder that **clients may not always like what we're doing in the moment, and sometimes that's okay.** They often experience a shift and see the value of this approach in time, as the below testimonial highlights.

"I wasn't really clear on what Groupaya's role was when we

*started, but after a few months it became very clear —
Rebecca and Brooking are doing the most to ensure that the
patients are heard; much more than the standard 'we are
doctors, sit at the table and listen,' approach that I am,
unfortunately, accustomed to in physician-patient groups.
Leaders in the patient-centered research movement would do
well to bring in Groupaya to moderate all their meetings!"*

2. Planning looks different for participatory events. This
reality tends to make the design team a bit nervous if we
associate clear plans with being prepared. Many of us have
achieved great success with this approach — and it makes a lot
of sense for a lot of kinds of work. So, unsurprisingly, we
had some emotional ups and downs in planning for our summit as
our group navigated the discomfort of an ever-evolving agenda.
This is a great sign that the team *cares* about succeeding, and
so is a great problem to have.

There is a core tension that one gets used to living with when
you do this kind of work — in order to make room for genuine
emergence of collective intelligence and co-creation amongst
participants, you have to let go of control and planning in
the old ways of project management. For our all-star clients
who are used to being 'on top of things' and having a very
clear and detailed action plan, this is *uncomfortable*. Yet
**with participatory processes, getting comfortable with
ambiguity is a key survival skill.** Part of our job is to help
them hang with this discomfort, to keep reminding them of the
reason for it, to address real logistical concerns, and to ask
for their faith in our approach.

This is a big ask! With the Health eHeart Alliance, the event
crew hung in there so well with this anxiety-inducing
approach, and really did offer us their trust. And thankfully
the event was a success. The notable practitioner learning
point for me here is similar to my first point above: there's
a skill in hearing client fears and feedback, and filtering

for what to adjust, where to just ask for trust, and to trust ourselves as well. Rebecca modeled this skill beautifully in our design process for the summit, always holding the goals and vision at the forefront and trusting her own instincts to the end. It can also be helpful as a consultant in this role to remind your clients in these scary moments that they chose you for this project because they believed in this approach to meeting your shared goals. In this case: that we discover a new way of conducting research that includes patients' wisdom.

3. How do you integrate new members into a co-created culture?
All that goal setting, visioning and trust building work that we did at the beginning of our project was painfully slow for some, but it has begun to prove its value these last few months as our group now cruises through meaty research design work together with a high level of trust and shared understanding. But we've since encountered a new challenge: integrating people who have joined the group after all the foundational culture-building work. We went from a core of 16 to a group of 75 overnight after the success of our launch event. There's a natural mis-match in level of shared understanding between those who have been in the process from the beginning and those who joined later — after the co-creation of values, ground rules, and visioning.

One key thing we've done to help so far was effectively design the summit itself to be an introduction and immersion in our culture and values, so all who attended got a real first-hand taste of this different way of working. But what about integrating new members into our co-created culture as the alliance grows? Do we always begin with a live event? Would website text and a video suffice? A webinar? A buddy system to help new people feel integrated? Maybe you have some ideas you want to share in the comments below. As we grow our Alliance, this question of integration becomes all the more important — *How do we keep the participatory approach and culture alive as the alliance grows?*

In closing I'll just say that it is a real pleasure to be involved in such a unique project — for health care as well as for participatory process design. I couldn't have a better colleague for this work than [Rebecca](), and our Alliance team is poised for real leadership in this new field. But of course, it's a process, so I can't tell you yet what that will look like.