Managing Vulnerability and Uncertainty: Developing design competencies within an American healthcare non-profit

ALEXANDER Rhea; JONES Sarah and MYSORE Vinay Kumar*

The New School, USA
* mysov916@newschool.edu
doi: 10.33114/adim.2019.c04.139

This case study explores building design competencies and a design-driven organizational culture within an American healthcare non-profit. With a staff are primarily from the healthcare space, as well as some in banking and sales, we look at how the staff has adapted to working within a design-driven organization. By applying iterative design methods and embracing innovation and uncertainty we observe how the organization’s founder has helped guide team members through a process of discomfort and vulnerability within an experimentally-driven and human-centered organization. Using interviews with employees and the founder at various points in new employee onboarding processes we chart a transformational arc over six months. The learnings to share include both the universal and the particular: what are the core competencies to develop in all organizational members, and what are the specific and different ways competencies can take form. From building explicitly shared languages to facilitated sensemaking this case study offers an opportunity to share new and developing practices for embedding design-driven innovation and management practices in new fields and contexts.

Context & Problem/Opportunity Area

Parkinson & Movement Disorder Alliance, PMDalliance, offers opportunities for people impacted by Parkinson’s and other movement disorders to learn, live more fully and connect to a support community by including the often neglected spouse or loved one that is the primary caregiver, support group leaders and adult children. Through an inclusive, human-centered design approach, they fill a gap in the American healthcare system, by addressing the needs of caregivers providing critical opportunities for connection, support, and community. Their business model is a non-profit service and network. Facilitating workshops and meetups for the groups they serve, PMDAlliance offers not only an opportunity to connect with others in similar situations but an opportunity to learn management tools and coping mechanisms to help them better manage their responsibilities and quality of life. They also offer emotional support opportunities for self-care for caregivers an often neglected group that suffer alongside the afflicted. PMDAlliance’s staff is distributed, with team members operating from different parts of the country who travel to other parts of the U.S. to help support PMDAlliance activation hubs.

Design-driven practices are critical to PMDalliance’s success. By regularly attending to the needs of their constituents, PMDAlliance continues to innovate and prototype new approaches. In the words of their founder, Sarah Jones: “Our prototypes are our programs.” PMDAlliance relies on this model to ensure that they consistently can deliver value to members, nimbly and with low overhead. Team members need to be adaptive, quick-footed, emotionally available to hear unmet needs, and able to operate within uncertainty and ambiguity as they continually test, learn, assess the impact and try again to improve.
This process is all within the context of highly rigid and structured medical and healthcare systems. With a staff all trained outside the design field, including healthcare backgrounds, team members come in with high comfort for rules, and familiarity with approaches grounded in didactic, non-user centered methods, typically framed in the language of ‘best practices. While often viewed as a design opportunity, many interventions are limited to realms of physical space and equipment, and not addressing underlying cultural norms at play (Bown et al, 2010). While strategic design could be seen as a point of high leverage, to date its impact has been somewhat limited (Taylor et al, 2011).

The three authors connected through Parsons ELab, a design-driven academic incubator at The New School. The founder of PMDAlliance, a contributing author, was a 2016 Fellow, and the remaining two authors at Parsons ELab, including its founder, have been advisors and mentors to her work since then. The authors are drawn to collaborate in this case study because of its application in extending of design into new fields. They find the approach of PMDAlliance, and its focus on the underlying mental models and emotional competencies necessary for design innovation to be novel and generalizable to other similar organizations.

This case study explores the ways by which PMDAlliance, through their hiring and onboarding process, help facilitate the development of designerly competencies, comfort within the design process, and embed design-driven innovation throughout their organization.

Narrative

PMDAlliance views their goal as having new team members able to facilitate a conference within 4-6 months of joining. This goal is seen as the culmination of an onboarding process steeped in a designerly approach that begins with the pre-hiring phase. (see figure 1, PMDAlliances Roadmap for Onboarding)

![The 6 Month Onboarding & Design Training Roadmap](image)

*Figure 1: PMDAlliances Roadmap for Onboarding and Design Training. Source: PMDAlliance*

Potential employees for PMDAlliance are screened and interviewed, but also are assessed on their ability to complete a values and position based exercise in the second round and an interactive project brief in the third round. These tests are not just about competency, but more for the ways, they can assess potential employees’ openness to risk-taking, capacity to engage in vulnerable work and empathically engage with PMDAlliance members. An example might be a project brief around a new artifact to help support a member, but also simulated communications with members. These soft skill assessments are PMDAlliance’s way of understanding if there is good culture fit, and also if there is potential to develop, within these non-designers, the designerly competencies needed to be a self-starting innovator within PMDAlliance’s distributed network model.

Once hired, a critical artifact given out in the onboarding process is their ecosystem map. Developing a systems-level understanding of the interdependencies within the lives of those impacted by Parkinson’s and
other muscular disorders, their caregivers, support networks and touchpoints throughout the health and medical system. This map is used as an anchor for staff and members. This phase is the initial ‘knowledge transfer’ phase of the on-boarding process. Formally, it takes place over a 2-week process, with once per day lessons and introductions to the variety of tools and operational practices of the organization (see figure 2, PMDAlliance Support Ecosystem Map).

![MOVEMENT DISORDER CARE & SUPPORT ECOSYSTEM](image)

**Figure 2: PMDAlliance Movement Disorder Care and Support Ecosystem. Source: PMDAlliance**

One design-driven skill at the core of the PMDAlliance process is empathy. Empathy not only is a critical person-to-person service skill that builds trust for the organization, but also a foundational skill for other competencies, including design research and also for building comfort with vulnerability and uncertainty as members constantly prototype and test new models of service delivery.

Empathy begins with personal storytelling and modeling from within the entire organization. Staff share and show their own vulnerability, and engage in open and honest discussions about where they are in their own lives during their quarterly meetups, zoom video meetings and even their day-to-day communications over Voxer. They share videos and readings, from Brené Brown and her writing on vulnerability and openness to enneagrams as models of behavioural motivations to help build confidence, comfort, and attentiveness to their own emotional states in preparation for, and as part of the work, they do with others. Crucially this is modeled from the beginning of employees interactions with PMDAlliance, so by the end of this 2-week on-boarding process, they are immersed and enmeshed in a culture that values and prioritizes emotional attunement and intelligence.

From here, curriculums become more personalized and individualized based on the needs and capacities of each member of the team.

One element that all team members will engage in is design research. Typically taking the form of fly-on-the-wall observations and design ethnography, new members are instructed to undertake their own process of discovery. This research is a facilitated learning experience. After observation of a support group, PMDAlliance will debrief with the new team member, discussing observations and understanding key takeaways. This process of facilitated research allows for new members to slowly build a more embodied sense of what PMDAlliances’ work truly entails, and allows the team to understand and see where their new hire is struggling and thriving. This reflection also begins a practice of deep listening, as they guide new hires into understanding the underlying pain points being expressed by participants and helps build intuition and skill to identify and start creating design hypotheses around the needs of PMDAlliance’s constituents.

If a particular challenge is emerging, Sarah and the team may use other design research methods to help new members. One example was a new hire struggling with the lack of clear directives and operating procedures for each conference and event. PMDAlliance needs to be nimble and reactive to the needs of its constituents, but this member, a former healthcare (Director of Surgical Services) professional, continued to express deep
discomfort with this approach. Using analogous research to surgery department operations, wherein the best-laid plans of the morning are scuttled within minutes, their team member had an ‘aha!’ moment. The use of analogous research, this time in a context more familiar to the team member, facilitated discovery and development of competency and capacity within the new hire and helped bring them along this journey of becoming a more design-driven practitioner in PMDalliance’s work.

The second element that needs to be developed, and draws from the combination of vulnerability and empathy work started on day one, with the facilitated design research and discovery process, is a capacity to prototype. Prototyping involves being able to identify unmet needs, combining the observation skills of design research with the emotional attunement to meet their constituents. It also involves a belief in one’s own skills and a comfort with discomfort and uncertainty as not all prototypes can succeed. In a caregiving environment and context, there is much discomfort with possibly failing, and prototyping necessitates both an emotional and practical element of facilitation.

For PMDAlliance, testing is an existential necessity. It is continuously in an experimental state, iterating endlessly, and also evaluating the efficacy of its work. Prototyping is how they build and develop programs. There are no scripts or similar organizations for the kind of work PMDalliance does, and that means that they must continuously be in dialogue and engagement with participants in order to serve their community best.

By building these successive competencies, PMDAlliance arrives at their target goal, which is a hosting or facilitation of an event by a new hire within 4-6 months. For employees to do so, requires many operational and organizational competencies. They must be able to manage the event logistics, and deliver on critical parts of the PMDAlliance experience. They will need to appropriately document, track and report on the event using the variety of platforms that PMDAlliance uses in their operations.

However, it also demands numerous designerly competencies. They must be attentive, aware, and attuned to their own emotional needs and the needs of those around them. As care partners and support group leaders share their personal stories and seek support within this community, the new team member must be able to meet them emphatically and empathetically at their level. They need to pair that capacity with a design research lens allowing them to identify opportunities for alternative methods. They need a caring vision in order to see where PMDAlliance could be offering more, and how exactly it helps. These then must also be combined with a capacity and familiarity with a prototyping process and iterative mindset. They must be able to adjust quickly, find new ways of testing new possibilities, and embrace the uncertainty and risk involved in that process. They must be able to test nimbly and learn quickly, and embody the kind of agile approach that PMDAlliance uses as the foundation of its value proposition.

Key Learnings

PMDAlliance’s experience of developing design-competencies maps the second arc of capacity building and transformation in the onboarding of new employees. They show how a facilitated design-education process can help build critical competencies and an organizational competitive advantage for, in this case, a distributed not-for-profit.

Within a healthcare system that struggles with innovation, PMDAlliance’s approach is exciting and promising. Their success in building high-level design competencies and a design-driven innovation mindset within their team highlights an opportunity for other healthcare organizations. As the call for a more human-centered approach to healthcare continues to be heard, they offer a practical study on how to address the underlying human and cultural problem in the implementation of design innovation.

A key learning for the authors are the many subtle ways that these competencies are developed. As opposed to a singular process, the journey of each employee is distinct, with its own educational inflection points. It is notable that as opposed to experiencing a series of design workshops or design sprints, these competencies were developed through a more collaborative and coached model of education.

The authors observe that an approach grounded in a design research and empathy development process could allow for a more bottoms-up approach to developing design capacity within organizations. By creating mechanisms and opportunities for staff to safely practice design as a form of learning and doing, teams have the space for growing a design approach that is reflective of, and responsive to, the needs of the team and organization.
In many sectors, and particularly in healthcare, calls for innovation are often heard and left unaddressed. This case study begins to look at ways to approach the underlying mental models within the practice of healthcare and suggests ways by which design processes can themselves help transition an organization to become more design-driven in its practices. A process that builds comfort with uncertainty and vulnerability and that creates space for prototyping and testing, can help build a muscle and capacity for design innovation. Such approaches must be contextualized for the specific work being done by the organization, by the individual and by the competencies and capacities of all participants involved. That said, the authors believe that the core principles that are exposed through this case study offer avenues for other organizations to find similar success in bridging design innovation and management in challenging and novel sectors of the new economy.

References


