The Need for Story:
A story-based co-design toolkit for supporting patient and family-centered care partnerships
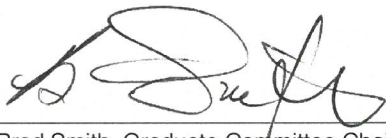
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Thesis Submitted in Partial Fulfillment of the Requirements of the Degree of Master of Design in Integrative Design

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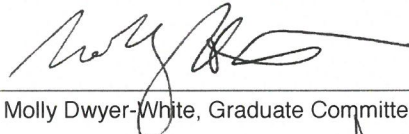Ann Arbor, Michigan

April 20, 2018

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Brad Smith, Graduate Committee Chair

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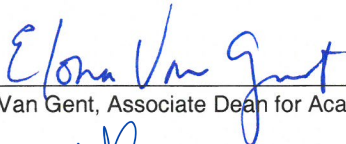Nick Tobier, Graduate Committee Member

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Molly Dwyer-White, Graduate Committee Member

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John Marshall, Director MDes Graduate Program

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Gunalan Nadarajan, Dean, Stamps School of Art and Design

Date Degree Conferred: April 26, 2018

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The Need for Story:
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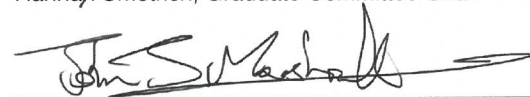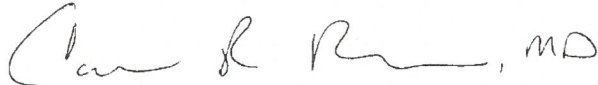
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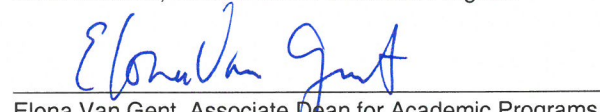John Marshall, Graduate Committee Chair
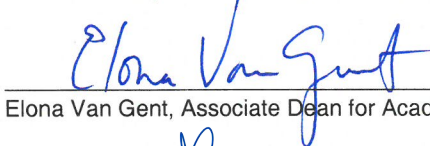
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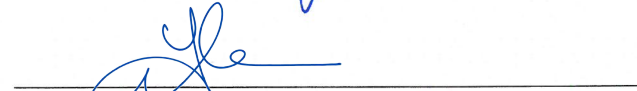Caroline R. Richardson, Graduate Committee Member

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HEALTH AND WELLBEING

THE NEED FOR STORY:
A Story-Based Co-Design Toolkit for Supporting Patient and Family-Centered Care Partnerships

Scott Dailey, Prerna Dudani,
Priyanka Raju

Candidates, MDes
University of Michigan
Spring 2018

HEALTH AND WELLBEING

THE NEED FOR STORY: A Story-Based Co-Design Toolkit for Supporting Patient and Family-Centered Care Partnerships
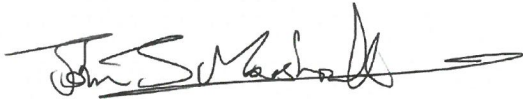
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Contents

Keywords

Story, Provotyping, Co-design, Quality Improvement,
Patient Experience, Toolkits, Integrative Design

Prelude

This is a collaborative and practice-based Master's thesis written by Scott Dailey (SD), Prerna Dudani (PD), and Priyanka Raju (PR). We are the second cohort in the Masters of Integrative Design program within the Stamps School of Art & Design at the University of Michigan. We are the first group within this program to engage in a collaborative thesis.

We come from multi-disciplinary backgrounds, have diverse work experiences, and locate ourselves within disparate geographies. Scott is from Columbus, Ohio, Prerna is from Ahmedabad, India and Fremont, California, and Priyanka is from Hyderabad, India. We are connected through interests and work experiences that transcend our disciplinary educational backgrounds of industrial design, visual communication & art studio, and architecture & regional planning, respectively. Our program is one of the very few in the United States that has a collaborative graduate program in design. The MDes in Integrative Design has a unique approach — as a cohort, we form a pro-bono integrative design firm that collaboratively works alongside real-world partners, stakeholders, and constituents in a hands-on practice-based manner — working collectively on problems that are highly complex, or wicked.

Abstract

This collaborative thesis is contextualized in the wicked realm of "quality of care." Health systems across the United States are in the process of shifting from an old paradigm focused on patient satisfaction, to a new model that aims to improve patient experience by promoting partnerships amongst patients, family caregivers, and clinical staff — this model employs patient and family-centered care practices.

The Michigan Medicine Health System in Ann Arbor, Michigan is in the midst of this transformation. The Office of Patient Experience (OPE) and their staff are working to shift the way the hospital thinks about patient experience — nudging the organization towards a more holistic understanding of patient and family-centered care practices. However, implementations of system-wide approaches to improving patient experience are challenging because of existing informal hierarchies and deeply rooted culture variances between care units. Therefore, the OPE's approach involves building buy-in and partnerships with individuals, care units, and departments across the health system using patient and family caregiver stories to build empathy. Because the organization is growing in size and capacity, they have an opportunity to build strategic and operational partnerships around patient and family-centered care. They are seeking tools that can help them scale their efforts and grow their reach.

This thesis investigates the broader question of, "How might we support the Office of Patient Experience (OPE) in building strategic and operational partnerships within the Michigan Medicine Health System around the values of patient and family-centered care?" The thesis proposes a Story-based Co-design Toolkit, a framework to amplify OPE's approach, and a process that extends the use of story to provoke collaborative problem finding and collective solution generation.

This toolkit acts as a vehicle of knowledge transfer, both as the codification of our discoveries while working to improve patient experience within Michigan Medicine, and as a means of generating insights from patients and families and translating them into making action through collaborations with clinical and non-clinical staff. It is a framework for how to design and facilitate co-design engagements grounded in provocative stories to address patient and caregiver needs. The toolkit is divided into three sections: Learning, Doing, and Teaching — reflecting the way we worked with diverse groups within the hospital, and it echoes the way the OPE currently works as a team.

Implicit in the design outcomes laid out within this thesis, is the definition of our integrative design approach. Through an embodied experience working on this collaborative thesis, and reflection on each of our individual disciplinary knowledge and practices, we built an approach that: (1) sought to facilitate communication and collaboration — integrating and making explicit knowledge, perspectives, and expertise through the design of provocative prototypes and a toolkit, and (2) empowered our partners, stakeholders, and constituents with design methods and tools to construct better futures for themselves.

INTRODUCTION

This chapter introduces the background of the collaborative Masters thesis and describes the problem area. It also raises the research question and defines the thesis scope.

Quality of Care as a Wicked Problem

What are wicked problems?

The 21st century is rife with multi-causal, socio-culturally complex issues where a true-or-false rationale is disingenuous, unproductive, and even detrimental. Sanders & Stappers describe a new landscape of design where the scale of what designers are creating has grown tenfold—designers are not just designing products for users, they are also planning for the future experiences of people, communities, and cultures [Sanders & Stappers 2007]. Designing at these scales, within this century, requires designers to be comfortable working within areas defined by complexity and uncertainty.

In 1973, two social scientists, Horst Rittel and Melvin Webber, defined a class of problems they termed as "wicked problems" [Rittel & Webber 1973]. A wicked problem is not easy to describe, it has many causes, and no single solution. Its complexity arises from the fact that it lives within social contexts that are incomplete, contradictory, and ever-changing. Wicked problems are tangled in complex interdependencies that are often unique to the specific context of the problem. The intricacies of a wicked problem are understood only after its formulation and the subsequent testing of a proposed resolution.

Once a proposed resolution is tested, it can reveal consequences that further complicate the problem — uncovering systematic issues embedded deeply within the problem, similar to when the diagnosis and treatment of a cough can lead to the discovery of cancer. Moreover, just as cancer manifests differently in individual bodies, every individual has a different experience of a wicked problem because of the world-view they bring to it [Rittel & Webber 1973]. A wicked problem, like some cancers, never really goes away; it has to be continually monitored and treated. Inaction can be fatal.

Why is quality of care wicked?

Healthcare in the 21st century, specifically healthcare quality improvement, is one such wicked problem. As healthcare in the United States shifts from an old paradigm of thinking—providing volume of services for treating acute conditions — to a new paradigm, centered around providing value of care — the right care for the right patient — there is a renewed focus on the patient and family, and providing a quality patient experience to achieve better health outcomes [ACA 2013, Burwell 2015, Corrigan 2005]. However, change within any large institution happens slowly, and healthcare is no exception.

Healthcare organizations are host to highly complex experiences and knowledge systems, which makes implementing change difficult and time-consuming [Thies 2016]. Hospitals are challenging to navigate, often requiring patients and families to have prior experience of the health system to better advocate for their quality of care. The Institute of Medicine (IOM) in their report, "Crossing the Quality Chasm," documented serious deficiencies and large gaps between the care people should receive and the care they do receive [IOM 2001]. These disconnects become especially apparent when care is delivered through a fragmented system of disciplinary silos, and gaps in communication and coordination reveal themselves in the patient's experience. Few hospitals provide a high quality of care throughout the continuum of a patient's journey [Corrigan 2005]. The patient journey is not seamless, patients and their families interact with a host of individuals and systems including primary care physicians, hospitals, skilled nursing facilities, insurance companies, and other healthcare organizations throughout their care experience. While rifts in the delivery of quality of care are recognized within the field, healthcare institutions face real barriers in implementing change. These barriers stem from an individual, attitudinal level to an organizational, structural level [Epstein, Street 2007]. Healthcare delivery systems are making a prolonged shift to address these challenges within a new paradigm.

Addressing quality of care is messy. It is defined by the nature of complex interactions amongst people, practices, and materialities within a hospital that form an individual's experiences [Swinglehurst et al. 2015]. Furthermore, what quality means to each individual is rooted in the lived experiences of patients, families, clinicians, and hospital leadership and is subject to their interpretation. This leads to gaps in understandings and expectations of what it means to provide and receive a high quality of care [ibid].

Apart from barriers to a shared understanding, there is a lack of holistic measures for patient experience as understood within the new paradigm. While much progress has been made — for example, through the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS), a set of standardized surveys of patients' experiences — these measures only capture acute episodes in the patient's journey, and rarely account for the continuum of care experienced [American Medical Association 2006].

Furthermore, HCAHPS surveys focus on measuring patient satisfaction, a customer-service model for measuring quality of care, rather than focusing on a more holistic model of understanding a patient's lived experience within the system. There is a need for another form of capturing and sharing data regarding quality of care — one that is more holistic, and accounts for embedded experiential knowledge of patients, family caregivers[1] and hospital staff that dismantles assumptions, and provokes meaningful change within the system.

Our Context, Scope & Rationale

This collaborative thesis is contextualized in the wicked realm of "quality of care." More specifically this thesis is situated in our experience of partnering with the Office of Patient Experience (OPE) at the Michigan Medicine Health System, a large research hospital located in Ann Arbor,

Michigan. In the fall of 2016, Molly White, the administrative director of the OPE approached us — the first year Integrative Design graduate cohort — with an open-ended proposal: to collaborate on ways of improving patient experience and promoting patient and family-centered care within the adult wing of the hospital.

What is Patient Experience?
What makes it a challenge for Michigan Medicine?

Patient experience is defined by the range of interactions that patients have with doctors, nurses, staff, and other providers within the health system. It includes several aspects of care delivery that patients value as they seek and receive care. These may include timely appointments, access to information, and thorough communication with healthcare providers. Better patient experience is an intrinsically valuable goal for the health systems as they work towards improving quality of care. But often in complex, fragmented, and hierarchical health systems like Michigan Medicine, achieving this goal can be challenging. Hierarchies and structures exist to help the health system complete a series of clinical tasks. However, these structures, in pursuit of efficiency, can end up dehumanizing individuals and the interactions they have with each other. There are limited structural, or built-in opportunities for healthcare providers to pause and reflect on the continuum of patient and family caregiver experience. Furthermore, currently, providing quality of care within Michigan Medicine is viewed through the lens of an old model of providing high patient *satisfaction*. The "customer is always right" mentality still pervades and hinders a more holistic understanding of patient experience centered on the needs of patients and their families.

What is Patient and Family-Centered Care?

Patient Family-Centered Care (PFCC) is an approach to the planning, delivery, and evaluation of healthcare that is grounded in partnerships among healthcare providers, patients, and families. It redefines human

relationships in healthcare by emphasizing collaboration among all stakeholders. This perspective is based on the recognition that PFCC leads to better health outcomes, improved patient and family experience of care, better clinician, and staff satisfaction, and better allocation of resources. PFCC also emphasizes that patients and families are essential allies on quality — not only in direct care interactions, but also in quality improvement, safety initiatives, education of healthcare providers, research, facility design, and policy development.

How does OPE work towards improving patient experience?

Staff within the Office of Patient Experience (OPE) are change agents within the Michigan Medicine Health System. They view their work through the new paradigm of healthcare, which considers patient experience through the lens of patient and family-centered care. They are working to shift the way Michigan Medicine thinks about patient experience, nudging the organization towards a more holistic understanding of PFCC practices by building partnerships through the use of story. See a visualization of their approach in Figure 1, below.
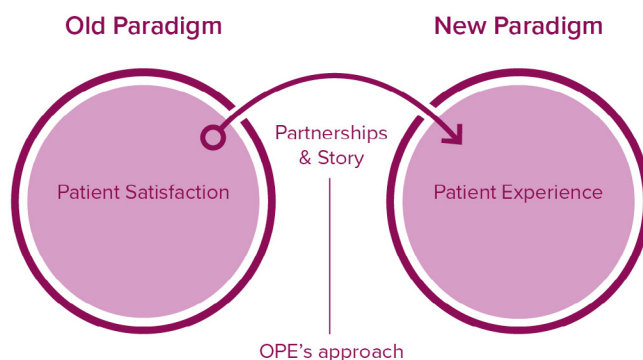

Figure 1. OPE's approach of building partnerships and using story to shift Michigan Medicine from an old paradigm of understanding quality of care as providing patient satisfaction, to a new paradigm that looks more holistically at patient experience as patient and family-centered care.

The OPE has a bold vision: to empower everyone at Michigan Medicine with a voice in improving patient experience. They aim to build partnerships within the hospital that facilitate three objectives: (1) Learning about the barriers to PFCC (2) Implementing PFCC initiatives and (3) Teaching the value of PFCC. They advocate for the improvement of patient experience by building buy-in and partnerships around patient and family-centered care with individuals, units, and departments across the health system. However, they face barriers to achieving this vision. Each patient care unit[2] at Michigan Medicine differs significantly in its culture, patient population, practices, and degree of investment in the ideals of patient and family-centered care. Not everyone in the hospital shares the same vision or believes in the value of partnering with patients and families in the same way. Also, prescriptive, system-wide approaches to improving patient experience are challenging because of the multiple competing cultures and practices between units. This fragmentation has led the OPE to approach partnership at an individual level, first building buy-in and collaborative relationships with clinical staff at a unit-level before embarking on system-wide approaches. To advance this effort, the OPE has leveraged patient and family experiences in the form of personal stories as catalysts. Stories are defined as real world, first-person accounts of a lived experience; they could be fragments of an individual's experience lacking a narrative arc, or a plot line — this definition aligns with the Oxford English Dictionary's definition of story as an account of past events in someone's life, or a particular person's representation of the facts of a matter [Oxford English Dictionary]. They use story to help teams reflect and empathize with the needs of patient and families. These stories are shared in the form of anecdotal narratives by the OPE staff as they engage with teams during committee meetings, visioning sessions, or other advisory roles.

What is the opportunity?

While these efforts have been effective in particular contexts, this targeted approach has been difficult to scale to date despite the opportunities to effect greater impact within the system. See Figure 2, below, for a visualization of the opportunity within which this collaborative thesis is contextualized and situated.

OPE's approach is evolving organically and is still being codified within its team. One employee described the situation as, "A lot of that information lives in people's heads, which we're finding out is really challenging." As the organization is expanding, from a staff of five to an expected staff of nineteen, they are looking for ways to codify and share their approach with new hires, and more broadly, within the hospital. Furthermore, they desire to become more strategic in their approach and operationalize their processes; moving from reactively addressing barriers to patient and family-centered care within familiar units, to proactively engaging and building partnerships with all units so that patient experience can be improved throughout the health system. There is also an opportunity to extend the role of story — to use design tools and provide a structure for moving the use of story from its current state of building empathy and reflection to a future state

Reactive → Strategic and Operational

Story to build empathy and reflection → Story to provoke collaborative making

MDes Collaborative Thesis

Figure 2. Visualization of the opportunity space where this collaborative thesis is situated and contextualized.

where it can be used to provoke collaborative problem-finding and the subsequent making of solutions. To realize this opportunity, however, the OPE needs support. The administrative director of the Office of Patient Experience Molly White states that "We have specific engagement processes, but we don't have consistent tools." This is where we, SD, PD, and PR, found an opportunity to support the organization's work. Our collaborative thesis is situated within this context and during this moment in the organization's history.

Research Questions & Objectives

The broad research question we investigate within this thesis is:

"How might we support the Office of Patient Experience (OPE) in building strategic and operational partnerships within the Michigan Medicine Health System around the values of patient and family-centered care?"

Our main objectives for this research are as follows:

Objective One   Develop an understanding of the current barriers and opportunities to patient and family-centered care within Michigan Medicine.

Objective Two   Support the Office of Patient Experience with design methods that codify the use of stories as a tool for provocation, reflection, and collaborative making.

Our Approach & Interventions

How did we address the research question?

We engaged in ethnographic research through a **discovery** phase where we sought to understand patient and family caregiver experience within Michigan Medicine, and uncover barriers to patient and family-centered care. As we reached the seams of what could be learned through ethnographic research, we designed and iterated through provotypes[3] aimed at **provoking reflection** and collaborative problem-solving with our partners, stakeholders, and constituents. Through a set of **co-design** tools and workshops, we built partnerships with patients, caregivers, and nursing staff that was explicitly aimed at improving the patient and family caregiver experience within the hospital. The workshops were grounded in stories. These stories were gathered during the **evaluation** phase of our process, and they were also generated during the co-design workshops. We have, over the course of this year-and-a-half-long project, designed *with and for* our partners, stakeholders, and constituents: patients, caregivers, clinicians, hospital staff, administrators, and the Office of Patient Experience within the Michigan Medicine Health System. This process is the embodiment of our — SD, PD, and PR's — integrative practice. See Figure 3, below, for a visualization of our integrative design process.
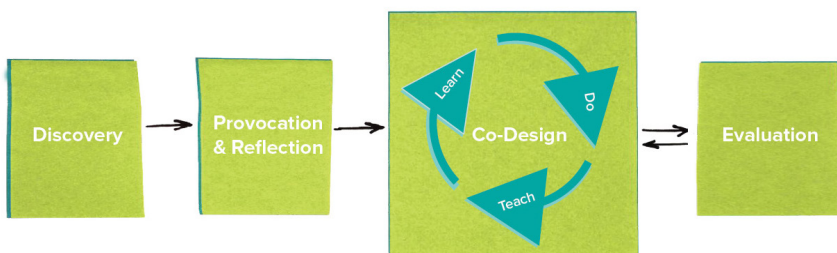

Figure 3. SD, PD, PR's Integrative Design process.

Through these iterative loops of discovery, provocation & reflection, and co-design, we integrated our practice with OPE's process of **Learn**, **Do**, and **Teach**. OPE's approach is building partnerships that allows them to: learn about patient and caregiver issues, do collaborative generation of PFCC initiatives, and teach the value of PFCC, and the skills required to provide improved quality of care. See Figure 4, below, for a visualization of their process.

We brought together our insights and design process into a *Story-based Co-design Toolkit*, a framework to amplify OPE's approach. This toolkit acts as a vehicle of knowledge transfer, both as the codification of our discoveries while working to improve patient experience within Michigan Medicine, and as a means of generating insights from patients and families and translating them into making action through collaborations with clinical and non-clinical staff. It is a framework for how to design and use co-design engagements grounded in provocative stories to address patient and caregiver needs. The toolkit is divided into three sections: Learning, Doing, and Teaching — these reflect the way we've worked with diverse groups within the hospital, and it echoes the way the OPE currently works as a team. With this toolkit, we aim to make ours and the OPE's tacit knowledge[4] explicit and scale the organization's approach to leveraging codified design methods.

Learn

Do

Teach

Learn about patient and caregiver issues

Work with partners to collaboratively generate PFCC initiatives

Teach the value of PFCC within the hospital

Figure 4. OPE's process of Learn, Do, Teach to implementing PFCC within Michigan Medicine.

Notes for Introduction

1 Family caregiver, or caregiver, within this thesis is any friend or family member who assumes the role of caregiving for their patient.

2 Patient care unit, or a unit, are those areas of the hospital which provide specialized patient care. They usually are in the inpatient setting.

3 Provotypes, or provocative prototypes, are defined as "ethnographically rooted technically working and robust artefacts that deliberately challenge common stakeholder conceptions" [Boer et al. 2013].

4 Tacit knowledge is knowledge that is deeply rooted in an individual's actions and experiences that manifests as subjective insights, intuitions, and hunches; this makes it hard to formalize, and difficult to communicate and share with others [Polyani 1966].

CONTEXTUAL
REVIEW

This chapter is structured to clarify the current dominant paradigms and barriers in patient and family-centered care. It goes on to discuss the role of reflection and the use of story as a way of transferring knowledge. Lastly, this review locates and critically assesses existing design approaches and tools that support the transfer of knowledge to build partnerships.

Patient and Family-Centered Care: Emergence and Barriers

Emergence of Patient Family-Centered Care as an approach to improve quality of care

Patient and Family Centered Care (PFCC) is an approach to the planning, delivery, and evaluation of healthcare grounded in partnerships among healthcare providers, patients, and families. It redefines human relationships in healthcare by emphasizing collaboration among all stakeholders [Johnson, Abraham, Shelton 2009]. This perspective is based on the recognition that patients and families are essential allies on quality — not only in direct care interactions, but also in quality improvement, safety initiatives, education of healthcare providers, research, facility design, and policy development. PFCC leads to better health outcomes, improved patient and family experience of care, better clinician, and staff satisfaction, and wiser allocation of resources. Further, it also acknowledges that families are essential members of the care team and have a huge impact on patients' health outcomes [Barry 2012]. In a fragmented system, where patients interact with several healthcare providers over the course of their treatment, family caregivers are often the only people who experience the entire trajectory of their family member's illness [Davidson, Judy, et al. 2007]. Family caregivers become near experts and often serve to bridge the gap in communication between healthcare providers and patients. They accomplish this by providing context to care teams, and continuity of support to their patient [Epstein, Street 2007].

PFCC, globally, has roots dating back to post–World War II changes in healthcare [Rawson, Moretz 2016]. As changes in maternity care and child care for chronic diseases included more family participation, the trajectory of healthcare at an organizational and policy level was set for increased collaboration. Leaders such as Harvey Picker, Institute of Patient and Family-Centered Care (IPFCC), the Commonwealth

Fund, and Institute for Healthcare Improvement further refined the concept of PFCC [Shelton, Stepanek 1994]. A revival of interest in PFCC is, in part, due to the increasing burden of chronic conditions and the recent linking of hospital reimbursement to the patient experience [Schoen et al. 2009].

A shift of policy, stimulated by the Affordable Care Act [ACA 2010] and the Centers of Medicare and Medicaid Services Quality Strategy [CMS 2013], has brought a focus on the need to deliver care that provides quality patient experience within healthcare systems. The ACA linked hospital reimbursements to patient experience, shifting priority from the volume of services provided to the value of care provided. This values-based model created a paradigm shift in the healthcare system. The new paradigm suggests that improved patient-centered care and satisfaction will lead to better health outcomes. Hospitals are now paying more attention to the experiential aspects of patient care which lead to higher satisfaction. For patients, this means more control and agency to communicate needs and preferences [Swinglehurst et al. 2014]. It also means better communication with hospital personnel, attention to pain levels, explanations about medications, discharge instructions, etc. For hospitals, a values-based model incentivized providing a high value of care for patients, and penalized poor quality of experience; it meant that to receive payments and contain costs, hospitals needed to improve the experience patients and families were having within their organization [Burwell 2015]. Research has established empirical evidence making a case for a patient and family-centered approach that helps health systems shift their practice from the old paradigm focused on a physician-centric and customer-service based approach on a fee-for-service model to a new paradigm that places the patient and their families at the center and reorients the mission of healthcare.

Barriers to patient and family-centered care

Improved quality of care depends on three factors: (1) an informed and involved patient and family; (2) receptive and responsive health providers; and (3) a well-coordinated and well-integrated health-care environment that supports the efforts of patients, families, and clinicians [Epstein, Street 2007]. Over the past decade, even though many health systems have embraced the value of a PFCC approach in achieving improved quality of care, the integration of this approach in policies, programs, and practices poses many barriers [Conway, Jim, et al. 2006]. Among them are the following:

Attitudinal barriers   Healthcare providers' attitudes are represented by three main points of view: (1) belief that they have always practiced PFCC and thus do not require any change; (2) uncertainty about what would be the best way to make the transformation happen; (3) not wanting any change to the status quo [O'Malley, P. J, Brown & Krug 2008]. These attitudes suggest a varying degree of buy-in to the need for a patient and family-centered approach. The reasons for these disparities in perspectives include the lack of educational programs and systemic implementation strategies [Betancourt, Joseph, et al. 2005]. Due to the fragmented and hierarchical nature of healthcare, providers tend to become task-oriented in their relationships. There is a need to reconnect staff with the value of patient and family-centered care [Steiger, Balog 2010]. Patient and family attitudes also have a great impact on the implementation of patient and family-centered care [Davidson, Judy, et al. 2007]. They are the most important drivers of change within health systems. When patients and families have an increased sense of agency and control, they can meaningfully engage and collaborate with their care teams on quality of care [Carman, Kristin, et al. 2013]. Tools to support patients in embracing this expanded decision-making role are becoming more widely available [Stacey, Dawn, Rajiv Samant, and Carol Bennett 2008], although further work is needed to help patients become aware of these opportunities.

Educational Barriers   Evidence demonstrates that patient-centered communication has a positive impact on outcomes, including patient satisfaction, adherence to treatment, and management of chronic disease [Epstein, Street 2007]. Communication, both verbal and non-verbal, plays a pivotal role in the caring process, and when improperly instituted causes barriers in the provision of care [Betcher 2010]. However, doctors and nurses are trained to communicate differently. Nurses are more descriptive in communicating clinical situations, whereas physicians learn to be very concise [Leonard, Graham, Bonacum 2004]. The lack of effective communication skills on the part of healthcare providers and administrators as well as of patients and families creates barriers to implementation of patient and family-centered care. Changes in practices related to communication and coordination of care require that staff acquire new skill sets such as fostering healing relationships, exchanging information, responding to patients' emotions, managing uncertainty, making informed decisions, and enabling patient self-management [Cleary, McNeil 1988].

Communication skills should be taught systematically, including practicing and receiving constructive feedback. Once they have completed medical school, most providers get little professional feedback or mentorship about their interactions with patients or families [Levinson, Lesser, Epstein 2010]. This means that health systems must be willing to provide teams with the time and support, not only to engage in education and training programs but also to engage in a learning practice that enables exploration and reflection.

Organizational Barriers   Studies indicate that the successful implementation of patient and family-centered care requires that patients, families, healthcare practitioners, and hospital leaders have the opportunity to collaborate in policy development, implementation, evaluation, healthcare facility design, and in the delivery of care [Epping-Jordan et al. 2004]. Collaboration and coordination across these boundaries are essential to minimizing gaps in quality of care

[Corrigan, Janet M, Adams, Eds 2003]. An organizational shift towards a PFCC focus takes a lot of time and effort, given that culture change does not happen quickly [Sutcliff, Lewton, and Rosenthal 2004]. Introducing and sustaining culture change involves power shifts [Wicks 2008]. However, hierarchical, professional, and disciplinary boundaries mark the formal structure and division of work in highly specialized and knowledge-intensive systems such as health systems. Apart from barriers to collaboration, another barrier to system-wide implementation of patient and family-centered care is the lack of consensus over measures of patient experience. There has been much progress — for example, through the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS), a public-private initiative that has developed standardized surveys of patients' experiences with ambulatory and facility-level care [American Medical Association 2006]. However, there is still a need to inform health policy through more definitive measures of patient experience. Studies point to the need for another form of capturing data that bring insights into the meaning of quality beyond just quantification using surveys.

Building Reflective Communities

Knowledge exchange for change making in healthcare

Adopting a patient and family-centered care approach means working in partnerships centered around co-construction of knowledge, development of shared meanings, and the application of a shared approach in addressing issues of central concern [Conway, Jim, et al. 2006]. These partnerships are essential to building bridges amongst clinicians, patients, families, community programs, and policymakers at all levels, to achieve better quality outcomes [Johnson, Abraham and Shelton 2009].

The objective of knowledge exchange in health systems spans from organizational learning, to collaborative problem solving, and capacity building [Abidi 2007]. These objectives necessitate making knowledge explicit and facilitating its flow throughout care teams, or what may be referred to as "communities of practice" [Wenger 1998], i.e., groups of individuals who share a common practice [ibid]. Traditionally, health systems have relied on communities of practice which are disciplinary. The use of clinical disciplines and their associated divisions of labor proved to be an efficient approach in the old paradigm, where health systems focused on a provider-centric model. However, with the increasing complexity of healthcare and a shifting paradigm towards a patient and family-centered care model, there is a need for reimagining these communities. Complex problems require more knowledge than any one person possesses, and the knowledge relevant to a problem is distributed amongst stakeholders [Fischer 2001]. Bringing different perspectives and conflicting points of view together to create a shared understanding leads to new, and often surprising insights and artifacts [ibid]. There is a need for transformative communities that leverage the collective creativity of these distributed groups of people and knowledge systems.

Health systems, similar to social systems [Luhmann 1995], are characterized by their "dynamic conservatism," that is, they have a strong tendency to resist change. However, several internal and external factors continually threaten their "stable state" [Schön 1973]. Any disruption causes systems to move from one state to another, in pursuit of stability. This means that organizations need to embrace a continuous process of transformation. They need to understand and manage these transformations to restore a stable state. Health systems must, in other words, become adept at learning and reacting, in response to changing situations and requirements. There is a need for establishing 'learning systems' that enable knowledge exchange: where people are continually learning from diverse perspectives; where people are collec-

tively reflecting on their practice; and where people continually expand their capacity to create change [Senge 1991].

Role of reflection in establishing a learning system

Reflection has been advocated as a way of facilitating learning through the exchange of experience-based knowledge [Schön 1983]. Reflection is crucial for learning as it leads to a better understanding of an individual's practice and can guide future behavior [Jarvinen, Poikela 2001] [Moon 1999]. Reflecting on past experiences is an effective mechanism for individual and collaborative learning [Dewey 1933] [Argyris, Schön 1978]. Through a process of critical reflective thinking, an individual can direct their attention to various aspects they experience within their practice. This, in turn, enables them to improve their practice, by using the knowledge they gain from experience.

Reflection also helps make tacit knowledge more explicit and available, both for examination and modification [Dewey 1933]. Healthcare organizations are characterized by a mostly tacit knowledge base [Lam 2000]. Tacit knowledge is highly personal and hard to formalize, making it difficult to communicate and share with others. It consists of subjective insights, intuitions, and hunches; it is deeply rooted in an individual's actions and experience as well as in the ideals, values, or emotions they embrace [Polanyi 1966]. Patients and family caregivers become experts in the experiential aspects of living with disease and navigating health systems [Coulter 2001]. They acquire tacit knowledge over extensive periods of time, not only about symptoms, but also pragmatic insights into living with chronic diseases and the realities of the care delivery process [Carr 2001]. Their knowledge is tacit, uncodified, and difficult to diffuse. There is a need for processes that allow healthcare providers to halt from their overwhelming pace of task-oriented action and engage in reflection on patient and family experiences [Daudelin 2000].

Stories: A way of codifying tacit experience-based knowledge

Tacit knowledge is the hardest to capture and share, as it cannot be formally communicated and is often embedded in routines and standardized operations [Augier 1999] [Scarbrough et al. 1999]. Health systems have an existing system for exchanging explicit knowledge, but there are relatively few current methods and tools to help deal with the tacit dimension of knowledge. One mechanism suggested for the transfer of tacit knowledge is storytelling [Thomas 2001] [Reamy 2002] [Denning 2012]. Stories are a powerful and omnipresent part of human existence. Humans, throughout history, have used stories to educate, persuade, and even better understand their context [Steiner 2005].

Stories have also been identified as a way of bridging gaps between information and knowledge [Reamy 2002]. An essential characteristic of stories is that they convey not only information, but they also carry meaning and knowledge [Bruner 2002]. Through the use of context, information can be seamlessly incorporated into a story. The amount of knowledge that a story is capable of activating in the mind of the listener is far greater than the relatively small amount of information that is explicitly coded into the story. Research shows that not only do people recall knowledge more effectively from a story but that a story also helps people process knowledge more logically [ibid]. Because it is easier for humans to remember knowledge rather than strings of unrelated bits of information, stories can act as a medium to codify knowledge and facilitate learning.

Stories are also an entry point to understanding a different perspective of the world, which is an important component of creating shared understanding and a sense of community [Morgan, Dennehy 1997]. These stories give an opportunity to learn from another person's experience and shape, strengthen or challenge individual opinions and values. By invoking reflection, they allow for imagination and envisioning of alter-

native futures [Gidley 1998]. Within healthcare, stories are a useful tool for engaging people in efforts to improve quality of care. Telling the story of a patient or staff experience can effectively illustrate challenges in a care pathway. Sharing the story of a patient, or a frontline worker, with a larger team can quickly and effectively bring a situation to life and focus discussions around quality improvement and patient experience. Statistics and data have an important place in monitoring and understanding services and facilitating improvement, but a story can have the power to motivate and change minds [Kalitzkus, Matthiessen 2009].

The content of stories can be represented in the form of text, audio, or visuals. Stories in text form allow many interpretations and a greater degree of empathy — giving the time and space for readers to draw from their own experiences and reflect on their practice. In the case of an auditory relay, stories leverage the human sensitivity to changes in loudness, pitch, position, etc. Similarly, humans are tuned to pay attention to visual transitions in social and emotional situations. Stories in these forms act as transmitters of tacit knowledge allowing the reader or listener to simulate a multidimensional experience for themselves, one that is rich in emotional and social context [Thomas 2001].

There has been considerable exploration into the use of patient and caregiver stories by healthcare organizations. With the evolution of "modern" technology-enabled medical practice, stories have been increasingly neglected in favor of evidence-based facts and figures. This evolution has given rise to many forces that restrict healthcare professionals' ability to reflect on their clinical experiences and relationships. But in recent years, stories about patient illnesses and the interwoven story of the quality of care that they experience within the health system is gaining momentum, leading to the creation of an entire field called Narrative Medicine [Greenhalgh 1999]. Narrative Medicine was born out of an effort to re-humanize medicine; to recognize, absorb, interpret, and be moved by stories of illness. The human capacity to

understand the meaning and significance of stories is being recognized as critical for effective healthcare practice. Narrative Medicine has been employed in treatment, medical training, and quality improvement work [Charon, Wyer 2008].

Increasing recognition has been given to the importance of patient and family caregivers' stories. Their voice has played a key part in the redesign of healthcare processes around patient and family-centered care over the past decade, or more. Patients and families are included in stakeholder events, discovery interviews, surveys, mapping healthcare processes and even in the design of new hospitals alongside healthcare professionals. However, these efforts have not necessarily focused on the patient's experience beyond asking what was good and what was not. Understanding experience entails a more in-depth inquiry into how well people understand a service, how they feel about it while they are using it, how well it serves their purpose, and how well it fits into the context in which they are using it [Bate, Robert 2006]. Limited opportunities exist for patients, families, and healthcare professionals to pause, come together and reflect on these questions to co-construct knowledge and understand ways of acting on this knowledge.

Co-Design as an Approach

Co-design as an approach to provoke action
Healthcare quality improvement, in the twenty-first century, especially improving patient and family caregiver experience can be seen as a wicked problem. The context of care is complex, inherently unpredictable, and populated by individuals with unique needs.

There is a need for adopting approaches and processes that are rooted in the lived experiences of patients, their families, and healthcare providers. Design practice has seen a similar need for a paradigm shift.

Since the early 1970s, there have been calls to consider new ways of designing that move away from a traditional approach of 'user as subject,' which excludes critical stakeholders from the creative process, to a more inclusive approach of 'user as partner,' which leverages the collective creativity of key stakeholders [Sanders & Stappers 2008]. This participatory approach, which finds its roots in Scandinavian design practice, focuses on the role of design as an activator of change, shifting from design driven by individual perceptions, to one that draws from a broader social conscience.

Within this landscape of human-centered design, in the area of partici-patory design, the notions of co-creation and co-design have been growing. Because of its democratic and open design process, we have found that our project and practice align closely with the co-design approach. Sanders and Stappers define co-design as "collective creativity as it is applied across the whole span of a design process" [Sanders & Stappers 2007]. Another useful definition is provided by Kleinsmann and Valkenburg, who describe co-design as "the process in which actors from different disciplines share their knowledge about both the design process and design content to create shared under-standing" [Kleinsmann, Valkenburg 2008]. The term co-design over the past decade has grown to include a myriad of approaches such as social design [Papanek 1985], participatory design [Bødker et al. 1987] [Ehn 1988], meta-design [Fischer et al. 2004], and co-creation [Fuad-Luke 2009].

Co-design embodies the following principles: (1) Participative: people involved in the development of a design have the right to raise their voices and intervene in the design process [Carroll 2007]; (2) Inclusive: it aims to question the traditional hierarchies of power and provide inclusiveness [Broadbent 2003]; (3) Context-based: it encourages an interdisciplinary and multi-actor framework that collectively draws at-tention to the context of research [Fuad-Luke 2009]; (4) Inquiry-based: facilitates joint inquiry that promotes communication and cooperation,
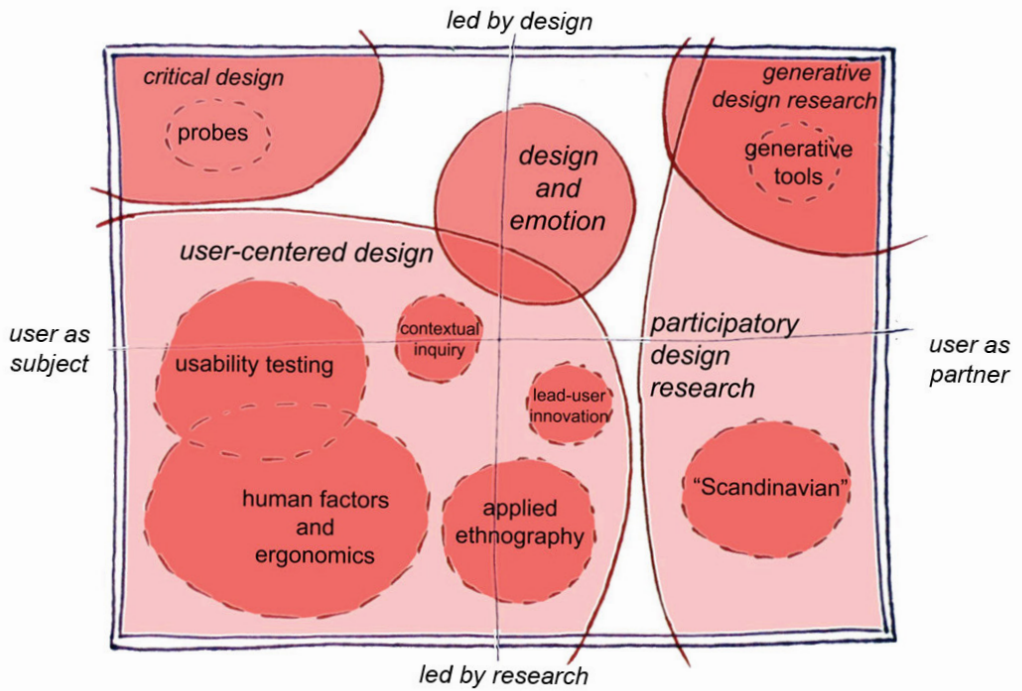
Figure 5. An overview of the current state of the human-centered design landscape [Sanders 2006].

and organizes positive change [Dewey 1934], and (5) Imaginative: it requires imagination as a way of creating "empathic projections" to understand others, and to escape current patterns and imagine alternative futures.

Co-design is rooted in democracy and intentionality [Fuad-Luke 2009]. It can be initiated and led by professional designers, but can also be practiced and facilitated by businesses, organizations or communities. However, service intensive organizations like healthcare, have been slow in adopting co-design as a way for sharing knowledge and creating a space for reflection, because this approach fundamentally threatens the existing stable state, it is antithetical to consumerism and is considered a theoretical effort with little operational relevance [Sanders & Stappers, 2008].

Barriers to implementing a co-design approach and the need for relevant design methods

When aiming at embedding co-design in organizations, building design capability, and contextual co-design practices are more sustainable than short-term solution-based approaches [Bailey, 2012].

However, as illustrated in Figure 6, next page, there are several barriers and enablers that hinder or support co-design practices in service-based organizations.

Though the figure [Pirinen, 2016], gives an overview of the critical barriers faced in undertaking a co-design approach and provides a robust list of enablers mapped to these barriers, we have found that drawing from such a linear causal relationship without contextualizing them specifically to stakeholder needs is detrimental to a co-design practice. For example, building trust through collaborative making may not always mitigate misconceptions and prejudices. Given the wicked nature of healthcare quality improvement, it is important to work across disciplinary boundaries and divergent realms of perspectives,
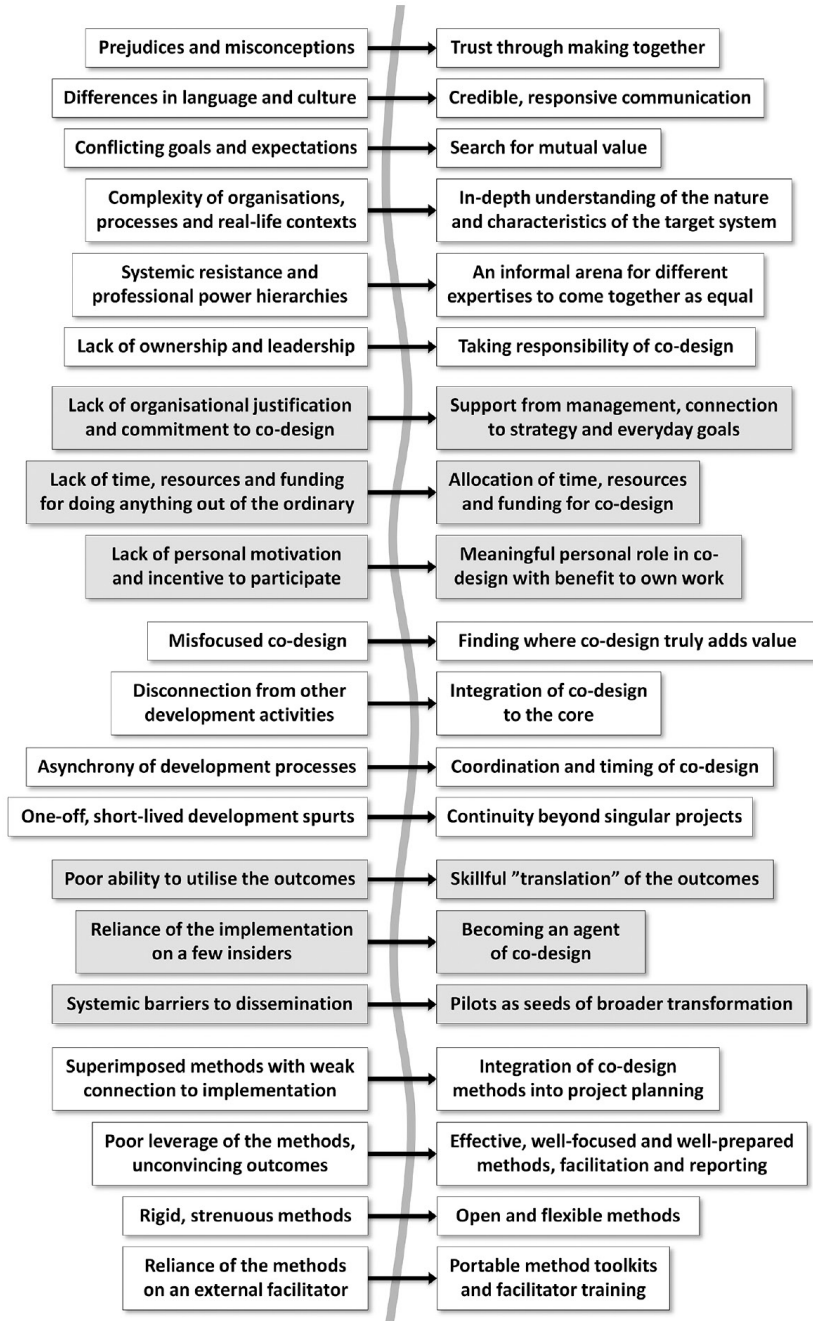
Prejudices and misconceptions	Trust through making together
Differences in language and culture	Credible, responsive communication
Conflicting goals and expectations	Search for mutual value
Complexity of organisations, processes and real-life contexts	In-depth understanding of the nature and characteristics of the target system
Systemic resistance and professional power hierarchies	An informal arena for different expertises to come together as equal
Lack of ownership and leadership	Taking responsibility of co-design
Lack of organisational justification and commitment to co-design	Support from management, connection to strategy and everyday goals
Lack of time, resources and funding for doing anything out of the ordinary	Allocation of time, resources and funding for co-design
Lack of personal motivation and incentive to participate	Meaningful personal role in co-design with benefit to own work
Misfocused co-design	Finding where co-design truly adds value
Disconnection from other development activities	Integration of co-design to the core
Asynchrony of development processes	Coordination and timing of co-design
One-off, short-lived development spurts	Continuity beyond singular projects
Poor ability to utilise the outcomes	Skillful "translation" of the outcomes
Reliance of the implementation on a few insiders	Becoming an agent of co-design
Systemic barriers to dissemination	Pilots as seeds of broader transformation
Superimposed methods with weak connection to implementation	Integration of co-design methods into project planning
Poor leverage of the methods, unconvincing outcomes	Effective, well-focused and well-prepared methods, facilitation and reporting
Rigid, strenuous methods	Open and flexible methods
Reliance of the methods on an external facilitator	Portable method toolkits and facilitator training

Figure 6. Barriers and Enablers of Co-design [Pirinen, 2016].

to co-construct relevant knowledge and develop ways of acting on this knowledge [Carlile 2002] [O'Flynn 2014]. Building and embedding new practices within a system requires methods and tools that enable individuals to negotiate the boundaries of diverse fields to create new joint fields of practice [Levina & Vaast, 2005]. In this regard, Carlile [Carlile 2002] and O'Flynn [O'Flynn 2014] stress the role of 'boundary objects' [Star, Griesemer 1989], to align interests, transfer knowledge and learning across boundaries.

Boundary objects are plastic enough to be perceived and used differently by different actors, yet commonly understandable across learning systems [Star, Griesemer 1989]. Design methods play a crucial role in the creation of these boundary objects. The representations of knowledge generated by employing design methods in the various phases of a co-design process act as useful boundary objects (personas, scenarios, concepts, process maps, etc.) [Jones 1992]. In contrast to system-centric implementation strategies employed by healthcare organizations, co-design is supported by design methods and tools that facilitate exploration and redefinition of needs, sharing of knowledge, negotiation of conflict, and generation of new interventions through rapid prototyping [Ehn 1988]. But, design methods are challenging to implement, since there are not many established tools, techniques or shared language for consistent knowledge transfer. While conceptual models and frameworks can be leveraged for knowledge transfer, there is a need for stronger contextual grounding of these tools and techniques. In popular discourse, design methods tend to be interchangeably referred to as design processes, which further complicates implementation. While they are two sides of the same coin, they are different. A design process contains a series of actions, events, or mechanisms, which in turn, include methods [Jones 1992].

Existing design thinking discourse and the need for a contextualized design process

Co-design can be understood as a process of "collaborative design thinking"— a process of joint inquiry and imagination in which diverse people jointly explore and define a problem and jointly develop and evaluate solutions [Steen 2013]. It is a process in which participants can express and share their experiences, to discuss and negotiate their roles and interests, and to jointly bring about positive change [Vaaja-kallio, Lee, Kronqvist, & Mattelmäki 2013]. Herbert Simon, in his seminal text on design methods, "The Sciences of the Artificial," outlined one of the first formal models of a design process [Simon 1969].

Simon's model consists of seven stages, each with component stages and methods, and was largely influential in shaping some of the most widely used "design thinking" process models. There are many versions of the design thinking processes in use today, and while they may have different numbers of stages, they are all based on the same principles featured in Simon's 1969 model. With this thesis situated at the inter-section of design and organizational change management, it is imper-ative to take a critical look at the broader context of design thinking discourse as a way of practicing co-design.

There have been two distinct discourses on design thinking: one in the design-based literature which focuses on "designerly thinking," and the other in the widely popular business management media as "design thinking" [Johansson-Sköldberg, Woodilla, Çetinkaya 2013]. In the design realm, as listed in Figure 7, there are five different discourses. These discourses focus on the nature of problems and actions and capabilities of designers.

Within the managerial realm, design thinking has been described as a way for groups to be collectively creative. This realm describes design thinking in three broad categories (1) as a cognitive style of individual designers engaged in problem solving, (2) as a general theory of design

as a field or discipline focused on taming wicked problems, and (3) as an organizational resource for businesses and other organizations in need of innovation [Kimbell 2011]. Figure 8 lists dominant paradigms in the managerial realm of "design thinking."

Seminal Work	Background	Epistemology	Concept
Simon, 1969	Economics & Political Science	Rationalism	The science of the artificial
Schön, 1983	Philosophy & Music	Pragmatism	Reflection in action
Buchanan, 1992	Art History	Postmodernism	Wicked problems
Cross, 2006	Design & Architecture	Practice perspective	Designerly ways of knowing
[Krippendorff, 2006	Philosophy & Semantics	Hermeneutics	Creating meaning

Figure 7. Discourses of "Designerly Ways of Thinking" in the design realm [Johansson-Sköldberg, Woodilla, Çetinkaya 2013].

| Seminal Work	Audience	Discourse Method	Academic Roots	Practice Mode
IDEO	Organizations	IDEO cases studies	Grounded in experience rather than research	How anyone can use design thinking
Roger Martin Educators	Team managers	Success cases from production companies	Grounded in cognitive science & management science	How 'any' company (manager/ individual) can use design thinking
Richard Boland & Fred Collopy	Academic researchers	Short essays	Grounded in individual researchers' own theoretical perspectives	Design thinking as an analogy

Figure 8. Discourses of "Design Thinking" in the managerial realm [Johansson-Sköldberg, Woodilla, Çetinkaya 2013].

We choose not to dwell deep into these themes, but to bring to view the theoretical roots of "design thinking" and its relationship to "designerly thinking." The difference in discourse stems from the difference in audience. The designerly discourse is a more scholarly discourse, whereas the popularized managerial discourse speaks to an organizational audience. Most of the design thinking discourse is anecdotal, rather than theoretically or empirically based. It is often a simplistic translation of designerly discourse. Though this approach democratizes the design process, it does not account for the situated, embodied knowledge of individuals or their contexts. It was developed as a tool for teaching problem solving that's effective in educational settings and consultancies [Jonassen 2000]. These are places where individuals encounter well-scoped projects on set timelines, with defined teams working together to solve them. This is not the reality of organizations like healthcare — where individuals are balancing urgent needs with long-term strategic work — and it's futile to judge these specific contexts with standardized design methods which were originally derived in a very different context.

Design thinking is also often equated to a toolkit [Johansson-Sköldberg, Woodilla, Çetinkaya 2013]. It is packaged as a set of design methods with the claim that anyone can quickly pick these up and solve complex problems. Popular versions focus on design methods taken out of context, as tools ready for use, but do not provide the necessary knowledge or training to individuals using the tools on how and when to use them. These toolkits are sold as one-size-fits-all solutions. While design thinking toolkits can be useful, they don't guarantee "mastery" of design or designerly thinking. They do not provide the tools needed to build design cognition, provoke reflection or support co-constructed imagination of alternative futures.

This contextual review identifies the need for design methods and processes that account for the tacit and embodied knowledge of key stakeholders in a complex system. We identify the role of stories as

a way of provoking reflection and embedding a co-design practice. We situate our design methodology and design process in this broader context and identify opportunities for creating a story-based co-design toolkit that equips stakeholders with the design methods that support discovery, provocation & reflection and co-design. By reflecting on and codifying our design practice, we have pursued the creation of a toolkit that is integrated with the practices of our partners and key stakeholders.
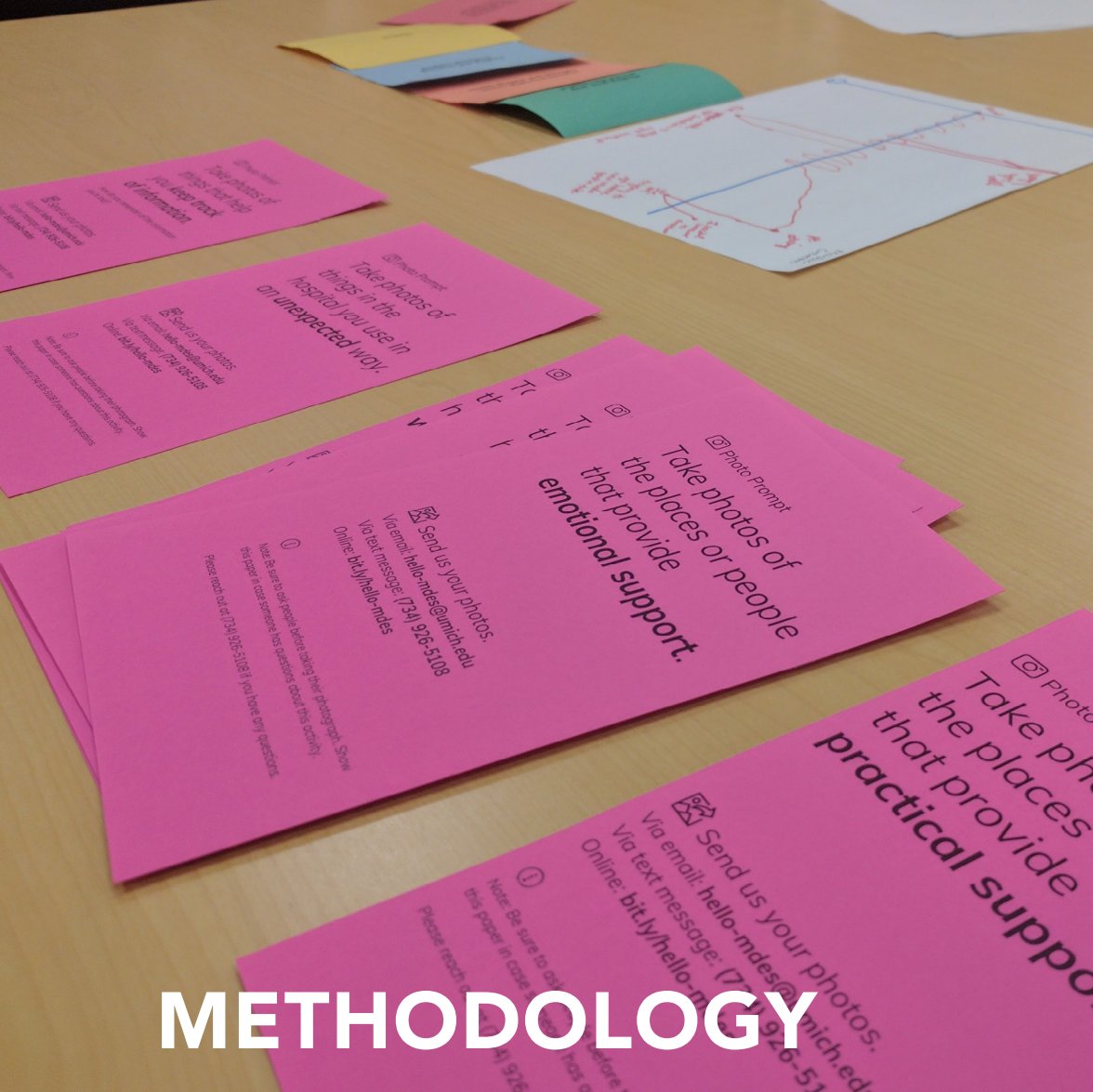
METHODOLOGY

This chapter introduces the philosophical underpinnings of the methodological framework for this collaborative Masters thesis. It also describes relevant design methods.

"The old center of the universe was the mind knowing by means of an equipment of powers complete within itself, and merely exercised upon an antecedent external material equally complete within itself. The new center is indefinite interactions taking place within a course of nature which is not fixed and complete, but which is capable of direction to new and different results through the mediation of intentional operations."

— John Dewey, 1929

Our Theoretical Framework

The pragmatist philosopher, John Dewey, in his book, *The Quest for Certainty*, argues that there are no absolute ways of knowing or acting within a new paradigm which is full of uncertainty — a universe where the nature of problems are indefinite, unfixed, and incomplete [Dewey 1929]. His philosophy has two key aspects that are crucial to understanding our approach: (1) focusing on individual concrete practices, personal experiences, and practical knowledge; (2) promoting cooperation and empowering people so that they can improve their situations [Dewey 1902, 1925]. This philosophy underpins the way we practiced and built our methodological framework of integrative design.

We had to make our disciplinary knowledge and expertise explicit over the course of the year and a half that we worked on this thesis. To collaborate, each of us had to reflect on our processes and make them explicit so that we were able to communicate them amongst ourselves, and our partners. We accomplished this through the use of boundary objects [Star 2010], objects that facilitate action and understanding between diverse groups of people. For example, before gathering together at a group meeting, each of us spent time reflecting on the issues to be discussed at the meeting and would come prepared to share our perspectives in a form that suited our working styles. Some of us
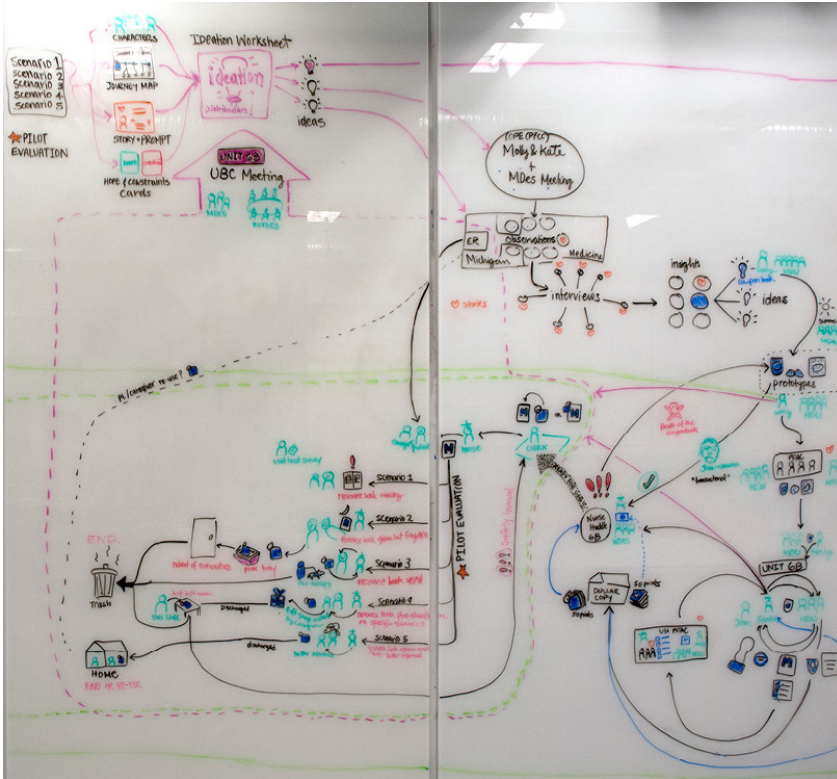
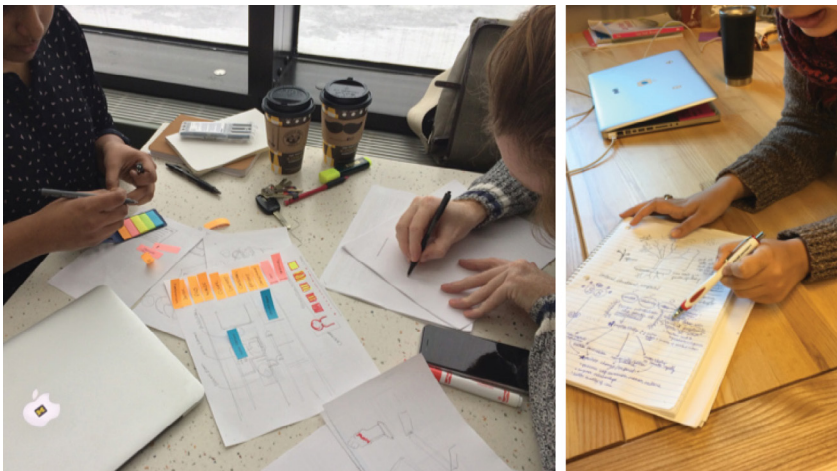Figure 9. A visualization of the journey of this thesis.

Figure 10. Examples of using boundary objects during group meetings to facilitate action and understanding amongst our team and our partners.

would take a more visual approach and bring sketches and diagrams, while others would take a narrative approach and bring notes and writing (Figures 9 and 10). Together, we would view and listen to each of our ideas, write or draw them out on a whiteboard, negotiate their meanings, and combine them into forms that were shared with our partners within the hospital. Depending on whom we met with, and the objective of the meeting, we brought either a visual or written artifact around which we could have a discussion.

Through this embodied experience and reflection on each of our individual disciplinary knowledge and practices, we built an approach that: (1) sought to facilitate communication and collaboration—integrating and making explicit knowledge, perspectives, and expertise, through the design of provotypes and a toolkit, and (2) empowered our partners, stakeholders, and constituents with design methods and tools to construct better futures for themselves. Buchanan substantiates the argument for an integrative approach: "Without integrative disciplines of understanding, communication, and action, there is little hope of sensibly extending knowledge beyond the library or laboratory to serve the purpose of enriching human life" [Buchanan 1992]. This approach, and the way we practiced it broke professional silos and asked the designers in the process to be aware and responsive to an ecosystem of distributed cognition amongst multiple stakeholders [Arias, Fischer 2000] and interconnected systems. It started with deep inquiry [Dewey 1938], and research, and moved from designing to knowing — starting from a problematic situation, and then moving — by productively combining doing and thinking — to a resolution. This movement towards resolution, however, happened not individually but collectively as we brought people together to create change in the desired direction by collaboratively learning, doing, and teaching.

Our integrative design approach necessitated the use of mixed methods and triangulation. This approach was not locked into one disciplinary design strategy — it was a paradigm shift from communities of

practice (e.g., industrial design, visual communication, architecture) to communities of interest (e.g., integrative design) [Arias, Fischer 2000]. This shift did not replace the traditional design disciplines we practiced; it brought all our disciplinary knowledge and methods together into an integrative approach. This approach erased traditional boundaries between design research and design practice and created a process-oriented and adaptive approach, one that drew from multiple disciplines, methods, and processes. For example, we drew on the Social Sciences notions of the practitioner-researcher. It gave us the freedom to work subjectively and reflexively in our wicked problem context [Gray, Malins 2004]. We also drew heavily on qualitative methods from the fields of Cultural Anthropology, Sociology, and Psychology. Using methods such as ethnographic research and interviewing as an integral component of our research process. This way of working was in line with Dewey's notion that knowledge has to be sought beyond traditional dogmatic frameworks, for a practice to be built that was appropriate to the paradigm in which it existed [Dewey 1929]. Appropriate actions were needed because we were working within a wicked problem space where every solution was a "one-shot-operation," and there weren't any opportunities to learn by trial-and-error [Rittel, Webber 1973]. So, our approach and the methods we employed can only be understood contextually, situationally, and temporally within our wicked problem space.

Relevant Methods

Some pertinent methods in the context of working within wicked problem spaces are (1) observations, (2) semi-structured interviews, (3) provotypes, (4) co-design workshops, and (5) surveys.

Observations

Observations, or participant observations, are a data gathering method used in qualitative research — primarily used in ethnography [Merriam et al. 2015]. Marshall and Rossman define observations as "the systematic description of events, behaviors, and artifacts in the social setting chosen for study" [Marshall, Rossman 1989]. Observations represent a first-hand data source as the researcher encounters and documents phenomena that occur in a given situation. They can also be combined with open-ended questions when the researcher does not know enough about a phenomenon to ask relevant questions. Observations, when done systematically, are a helpful strategy to understanding ill-defined phenomena [Merriam, Tisdell 2015]. They are also useful to triangulate emerging findings — they help uncover the gap between what people say and what they do. In ethnography, however, the limitation of this method is that it is a highly subjective data gathering technique, and relies on the researcher's perception of the situation. The researcher must understand how their presence in the situation affects what is being observed [ibid].

Semi-structured Interviews

Interviews are among the most direct methods to gather qualitative data and insights about people. DeMarrais defines an interview as, "a process in which a researcher and participant engage in a conversation focused on questions related to a research study" [DeMarrais 2004]. Interviews are necessary to understand behaviors, emotions, and perceptions that cannot be directly observed. They are also useful to understand past events that are impossible to replicate. Semi-structured interviews have a mix of more and less structured interview questions, where all questions are used flexibly. These interviews usually begin by recording demographic information or specific data from the participant that needs to be gathered before the main questions are asked. The largest portion of the interview is guided by a list of questions. However, issues can be explored as interesting or relevant information

is uncovered. There is no predetermined order to asking questions or specific wording that researchers have to use [Merriam, Tisdell 2015]. Also important to note, if multiple and leading questions are asked, they can bias the participant's answers; questions that can yield a yes-or-no answer should also be avoided [ibid].

Provotypes

Provotypes, or provocative prototypes, are defined as "ethnographi-cally rooted technically working and robust artifacts that deliberately challenge common stakeholder conceptions" [Boer et al. 2013]. Provo-typing is a method used in the early part of the design process when working with multiple stakeholders and striving for organizational change. The creation and the subsequent sharing or "critique" of the provotype materializes some of the presumptions stakeholders have around a field of interest — it brings to surface their values, beliefs, and assumptions by deliberately creating an artifact that is at odds with current conceptions [ibid]. The design researcher is not viewed as an expert or a lone provocateur; rather they can observe and analyze ten-sions that unfold in the perceptions of the multiple stakeholders when the artifact is viewed. The goal of this method is to provoke a dialec-tical process of reflection on an individual's conception as it currently is and to facilitate collaborative analysis and development of how the conception could be different [ibid]. Provotyping can be used as a means of generative design research or to engage members of a team in provoking sensemaking of the ethnographic tensions within a project [Boer, Donovan 2012].

Co-design Workshops

Co-design workshops are collaborative design sessions where stake-holders from varying disciplines come together in the process of designing a product or service [Brandt 2007]. There is an emphasis on the shared project space where ideas and knowledge get shared by

collaboratively engaging in design-led activities. Westerlund finds that co-design sessions, where users and designers work together through design activities, can produce more sustainable desired outcomes within a short time frame [Westerlund 2007]. Sanders et al. also finds that using co-design sessions within an organization can create better alignment and commitment within the employees of an organization [Sanders et al. 2008]. Co-design workshops can include the use of visual aids, interactive tasks such as card games, mapping activities, etc. using materials such as sticky notes and large sheets of paper to collectively share and prototype ideas quickly. Some workshops also use narratives, scenarios, and personas to help communicate design concepts and envision future states. Most co-design workshops end in discussion sessions where individuals engaged in the activities within the workshop discuss their ideas and reflect on the experience. Co-design workshops can take a longer time to develop because of the relationships that need to be built with individuals within the workshop; they can also be less efficient for tasks that require quick turnarounds.

Surveys

Surveys are a secondary source of data that is collected via question-naires within social science and health research. Surveys are mostly used to count things (or people), such as inventories and measure-ments surveys. However, opinion surveys collect opinion, beliefs, be-haviors or personal characteristics on an individual person who are part of a subject of study [Navarro-Rivera, Kosmin 2011] The results of an opinion survey can be used to form generalizations about the behavior, beliefs, and characteristics of groups who are a part of the study [ibid]. Surveys should define the population and their parameters: represen-tative surveys use a random sample, while convenience surveys use a non-random sample. Surveys can be influenced by the questions asked within them, and the survey population and sample can deter-mine whether survey results can be generalized. Surveys are limited in explaining why people think or act as they do [Mathers et al. 2007].
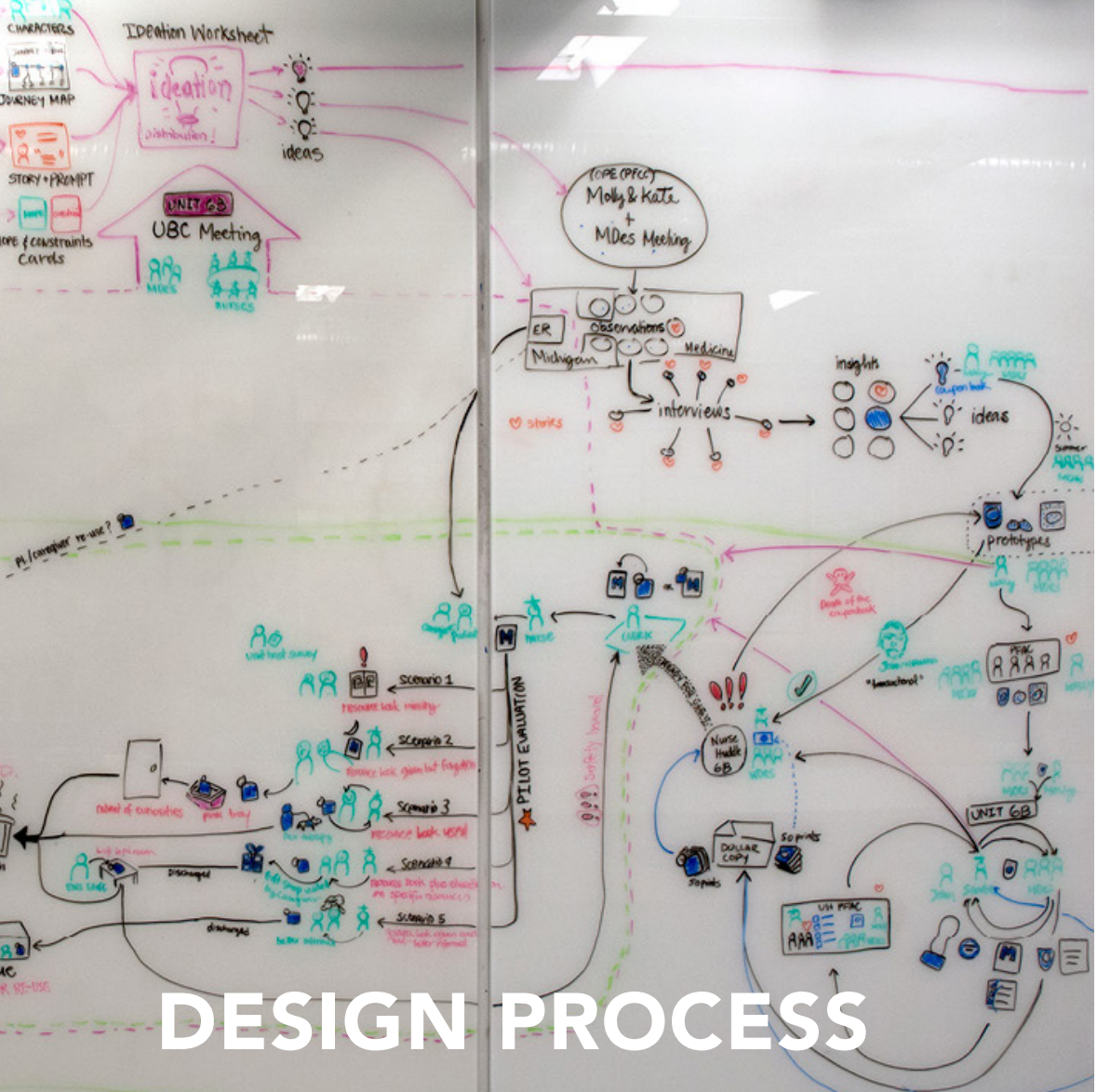
DESIGN PROCESS

In this chapter, we briefly describe the logic behind our design process model and visualize the methods used within the process. We spend the rest of the chapter describing how we have employed these methods within this thesis.

The Logic Behind Our Process

In keeping with the pragmatist philosophical theory behind our methodology, we introduce C.S. Peirce's term — abduction — to explain the logic behind our design process, and why we chose to use certain methods during the process. C.S. Peirce defines abduction about other forms of logic, "deduction proves that something must be; induction shows that something is operative; abduction merely suggests that something may be" [Pierce 1958]. Kolko describes the process of abduction as calling upon prior experience, given observed phenomenon or data, and developing a hypothesis that makes the most sense [Kolko 2010]. We have similarly used abductive logic; we chose to use certain design methods in reaction to the outcomes that were produced as we engaged with our wicked problem context and drew upon our prior professional knowledge. The process of knowing which design methods to choose and recognizing when to use them can also be understood in Cross's term of "designerly ways of knowing" [Cross 2000]. Cross finds that the designer has a form of knowledge that is special to the awareness and ability of the designer, independent of the different professional domains of design practice from which they come [Cross 2000]. As discovered by Rittel & Webber, scientific methods or positivist modes of thinking cannot be applied when attempting to work within wicked problem spaces [Rittel, Webber 1973]. Therefore, an alternative mode of designerly ways of knowing, thinking, and acting must be acknowledged to understand our design process and use of methods.

Our Integrative Design Process

Our integrative design process unfolded in four broad phases: **Discovery, Provocation & Reflection, Co-design,** and **Evaluation.** While these phases are visualized as a linear journey, they were not experienced linearly. We use the phases to structure the methods we

have employed. In Figure 11, below, we list the mixed methods we have used during each phase of our integrative design process.

Throughout this process, we worked alongside the OPE. We began by sharing insights and outcomes from our research, and as we built trust and mutual beneficence, we began co-designing and evaluating together. OPE's process and our process merged during the co-design
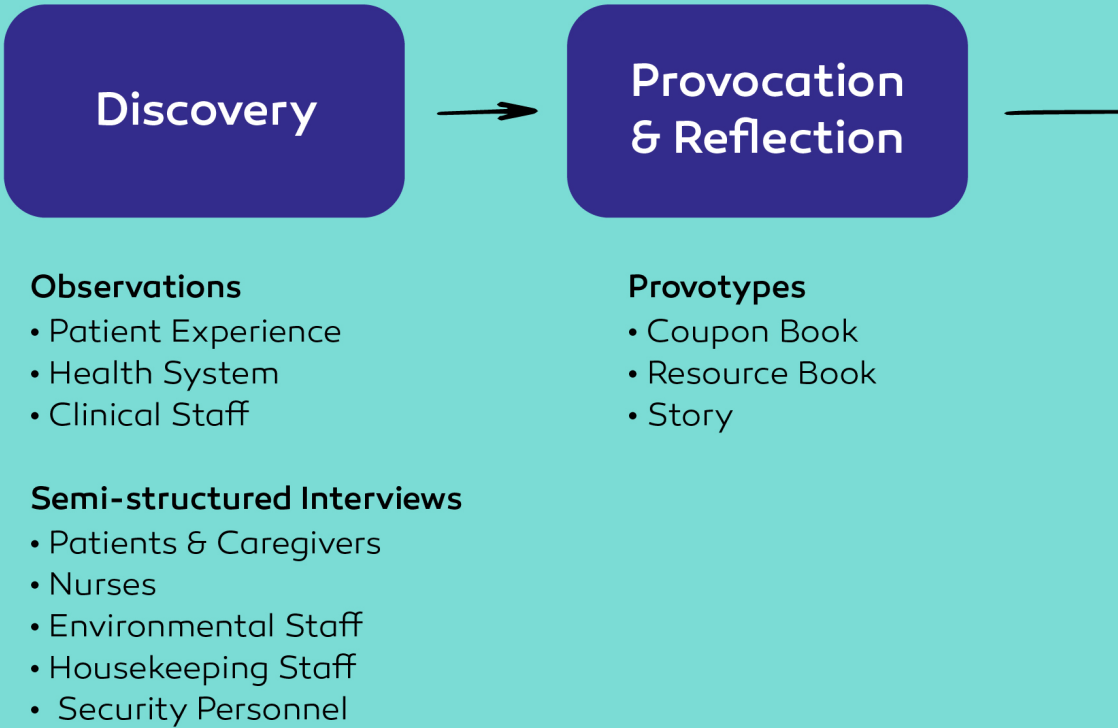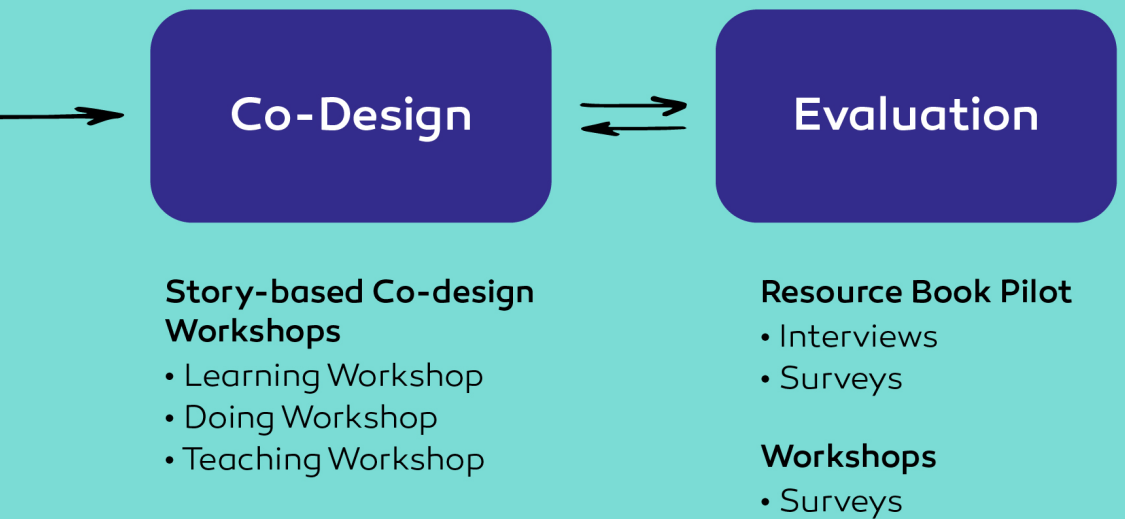

Discovery

Provocation & Reflection

Observations
• Patient Experience
• Health System
• Clinical Staff

Semi-structured Interviews
• Patients & Caregivers
• Nurses
• Environmental Staff
• Housekeeping Staff
• Security Personnel

Provotypes
• Coupon Book
• Resource Book
• Story

Figure 11. A list of all the mixed methods we have employed during each phase of our integrative design process.

phase our journey; we worked with OPE staff to co-design the Learning, Doing, and Teaching workshops. Their staff also joined us in evaluating the workshops. During the design process, our working relationship with the organization evolved into a true collaboration.

To address our first research objective of developing an understanding of the current barriers and opportunities to patient and family-cen-

Co-Design ⇄ Evaluation

Story-based Co-design Workshops
• Learning Workshop
• Doing Workshop
• Teaching Workshop

Resource Book Pilot
• Interviews
• Surveys

Workshops
• Surveys

tered care within Michigan Medicine, we began in the **Discovery** phase — conducting *observations* and *semi-structured interviews* with individuals who interface with patient experience on a daily basis. These observations ranged from following a pet therapy dog to observing a gastroenterological surgery. Our semi-structured interviews were not only with patients, caregivers, and clinicians, but we also spoke to environmental staff, housekeeping staff, and hospital security personnel who may be at the peripheries of the system, but have a significant impact on patient experience.

Our second research objective was to support the Office of Patient Experience with design methods that codify the use of stories as a tool for provocation, reflection, and collaborative making. We addressed this objective through the design of *provotypes* that provoked: reflection, discourse, and making. This was the **Provocation & Reflection** phase of our process. We brought together the provotypes and the opportunities they presented to create **Co-design** workshops centered on stories. These workshops fell into the three categories of Learning, Doing, and Teaching workshops. The workshops brought together tools of our design practice, provotyping and co-design — collective problem discovery & insight generation, creative problem-solving and collective making, reflection, and discussion — with the OPE process of Learn, Do, and Teach. Finally, we conducted **Evaluations** of our design tools to gain an understanding of how they worked within the hospital context.

Phase 1: Discovery

Observations:

Understanding Patient Experience   Our inquiry began as a cohort of five students in the Winter of 2016. We began by conducting open observations in the adult wing of the Michigan Medicine Health System. We were initially given access to conduct observations in all the public

areas within the hospital by the OPE. We completed the necessary paperwork and orientations required to become hospital volunteers, including completing occupational health and safety vaccination procedures, and volunteer training sessions. Our mandate from the OPE was open-ended — discover ways of improving patient experience.

We were not focused on one area or issue; we spread out and observed widely within the hospital (Figure 12). During this discovery phase of our research, we immersed ourselves deeply in our context for two full days. Some of us sat, individually, in multiple waiting rooms and conducted fly-on-the-wall or non-participant observations. Others took an "observer as participant" approach by engaging staff in questions about services for patients and families in high information sharing areas such as information desks, resource centers, and the gift shop. One of our cohort members combined observations and open-ended interviewing, as is done in ethnographic fieldwork, by following individuals — patients, caregivers, hospital staff — and engaging them in short open-ended interviews about their experience within the hospital.

Figure 12. Photo from our observations. A wife, a caregiver, getting help from her daughter in a Family Waiting Room.

These interviews were recorded on a smartphone with verbal consent of the participant. We used the following script:

> Hi, my name is <student name>, and I am a design graduate student working with the Office of Patient Experience to discover opportunities to improve patient experience within the hospital. If you have a few minutes, can we talk? And if you are comfortable, can I record this conversation to share with my cohort for research purposes only?

Our discovery observation process unfolded in an open-ended way; the answers to one question led to more. We needed an understanding of the patient experience within a clinical setting. The OPE organized a series of guided tours for us through three clinical units within the hospital: University Hospital Surgery Department (Pre-op, Post-op, Waiting Room), Pulmonary & Critical Care In-patient Units (ICU, Nurse & Clinician Spaces), and the Emergency Department (Operation Rooms, Hallways, Waiting Rooms). These observations included guided tours conducted by clinical staff or an administrative manager. The "tour guides" shared their perspective on the challenges they see in their jobs daily when interacting with patients and caregivers. Within these sets of observations, our cohort was only able to observe a limited range of interactions and spaces (Figure 13). We also realized that our observations could have been biased to the tour guide's framing of the challenges faced by patients and caregivers.

Observations:
Understanding the Health System's Approaches to Improve Patient Experience   To gain a better understanding of the way the health system approaches improving patient experience, our cohort, in pairs, conducted a series of observations at meetings related to improving patient and family-centered care within the hospital. These observations also occurred in the Winter of 2016 and continued through the Summer of 2017. We conducted observations based on the invitation

Figure 13. A doctor giving us a tour of a patient consultation room.

and access OPE provided and our schedule. In these sets of observations, the observer was also a participant — individuals at the meetings knew we were present to conduct observations, meaning we had the privilege to observe and interact with members and participate in the meeting without being a core member of the group.

These Winter 2016 observations were conducted by two different sets of cohort members who observed two meetings: Clinical Inpatient Tower Patient Experience Visioning Session and the Cardiovascular Center (CVC) Patient & Family Advisory Council (PFAC) Meeting.

We observed a portion of the Clinical Inpatient Tower Patient Experience Visioning Session which was facilitated by an architectural design firm working on the project. The firm invited patient and family advisors (PFAC), clinical staff, and other hospital administrators to provide inspiration and feedback to guide the design of a new inpatient clinical tower. We took part in and observed a series of visioning activities where all participants were invited to look at various mood boards and dot vote[5] according to their preferences of images on that board. The activity ended with an open discussion on why certain images were chosen.

During that same period, we observed a CVC PFAC Meeting where we learned about the ways patient and family advisors interact with the hospital, and the form in which their feedback and knowledge was captured by the system. We also learned about how initiatives within the hospital were discussed internally, within the organization. This was also an important meeting for the OPE as the Chief Patient Experience Officer announced the creation of the new Office of Patient Experience to the committee. He presented the goals of the office and the implications of its creation within the hospital.

In the Summer of 2017, we were also invited to attend and present our research at a Caregiver Engagement Committee Meeting. This meeting was coordinated by the OPE, where they graciously invited PFAC advisors who were interested in working on initiatives to benefit hospital caregivers. Our goal for the meeting was to share the results of our primary research, and elicit feedback on early concepts (See Phase 2: Provocation & Reflection). We were interested in learning about the mechanisms for gathering knowledge and information from patients and families, and observing how it was translated into initiatives within the hospital.

Observations:
Understanding Clinical Staff's Interface with Patient Experience
In Summer 2017, we partnered with two design researchers from Steelcase, to conduct week-long observations within the hospital. Our collective goal was to understand how the clinical staff interfaced with patient experience. We realized that while we had spent an extensive number of hours conducting observations within the hospital, we were still missing a crucial understanding of the daily tasks of a nurse or doctor as they interacted with patients and caregivers.

The OPE connected us with a range of clinical staff within the hospital and worked closely to schedule multiple opportunities for observation during the week. Our observations mostly entailed shadowing

Figure 14. Nurses at a medication refilling station.

practitioners or hospital staff throughout their day with the goal of understanding when, how, and why they interfaced with patients and caregivers. These were some of the most intense observations we conducted within the hospital because we spent 8-hour days over the course of a week shadowing nurses, doctors, unit hosts, hospital volunteers, a transport service employee, and a social worker (Figure 14).

Semi-Structured Interviews

We began conducting semi-structured interviews in Fall 2017 as a part of the discovery phase of our research. We conducted twenty-two interviews over the course of two months. Each interview lasted for at least an hour and a half, with some interviews lasting for more than two hours. The OPE connected us with our interview participants from Michigan Medicine. Not only did we interview former and current patients, caregivers and core clinical staff, but we also spoke with security personnel, environmental staff and housekeeping services who have a considerable impact on patient experience. Individually, we also recruited participants from our networks who were pertinent to understanding patient experience. We were interested in learning about the kinds of practices and experiences individuals in other hospitals were having

about patient and family-centered care. The participants we recruited were from hospitals in Alaska (Providence Hospital), Ohio (Cleveland Clinic), and Northern California (UCSF Medical Center). The individuals we interviewed in these locations were: nurses, current caregivers, a social worker, and a doctor.

The majority of interviews we conducted were in-person at either our Stamps Faculty & Graduate Studios or in the Michigan Medicine hospital facility. For participants who resided outside the State of Michigan, we conducted interviews via phone or Skype. All interviews were transcribed and were audio recorded, with verbal consent of the interview participant. Two cohort members conducted each interview. While most interviews were with individuals, some interviews were with married couples who had been or still were, patients or caregivers. We had separate interview questions for different populations; patients and caregivers questions can be found in Appendix I, clinical staff questions in Appendix II, and hospital staff questions in Appendix III.

Our method for conducting semi-structured interviews with current and former patients and caregivers is noteworthy to mention here. We began each interview by asking participants to complete an emotions journey map of their experience as a patient or caregiver at the Michigan Medicine Health System (Figure 15 and 16, opposite). We asked participants to map instances that were highs and lows in their emotional journey. We then prompted participants to describe what happened in each instance along the journey, and why they chose to highlight certain instances. The goal of this activity was to obtain rich information about the salient characteristics of an individual's experience. This mapping exercise was the first time that many patients and caregivers had ever reflected on the entirety of their experience.

This method was conducted using a blank sheet of paper and a pen or marker — with separate colors for each person a participant was caregiving for. We explained to participants what an emotions journey map was, and drew an example as we explained it. We began by drawing a

Figure 15. The emotions journey mapping activity conducted with patients and caregivers during the semi-structured interviews.
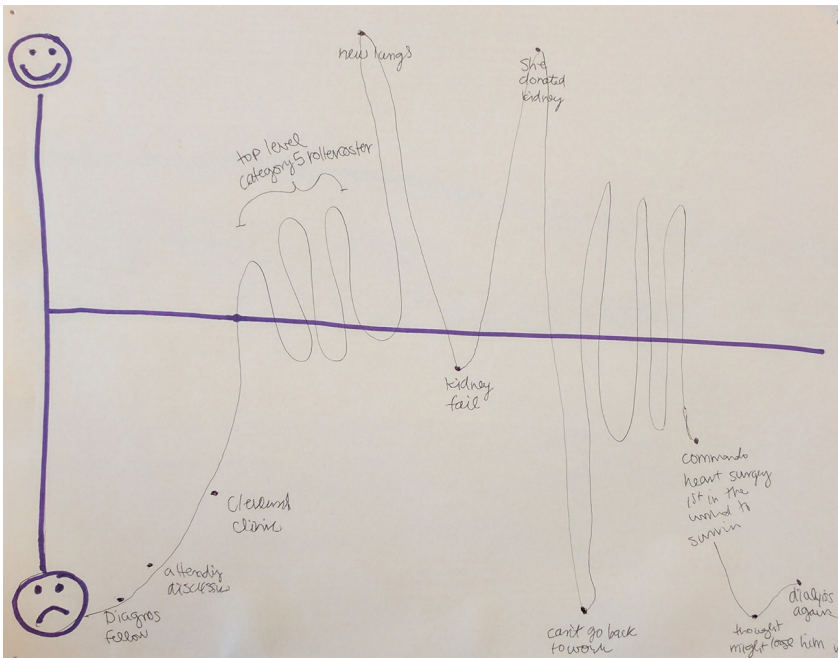

Figure 16. One caregiver's emotions journey map through the process of caring for her husband.

smiling face on the top of the vertical axis, and a frowning face on the bottom of the vertical access. We would then join the two faces on the axis with a straight line and draw a horizontal line in the center of the vertical axis. The top smiling face represented happiness or joy, and the bottom frowning face represented sadness; the horizontal line in between marked a mild or neutral feeling in the experience. Participants who felt comfortable drawing would begin marking the high and low points themselves, constructing their journey on their own. Those who weren't comfortable drawing would point to areas, and a cohort member would mark their journey on their behalf. Some caregivers became emotional as they spoke about their journey. For this reason, we began each interview with a preface that the conversation could be an emotionally triggering experience, and that they were free not to answer or share information if they felt uncomfortable.

A significant limitation of these interviews was that a large number of patients and caregivers we spoke with had not been recently ill, or were not current caregivers. Some patients we talked to had not been treated at the Michigan Medicine Health System for the past five years, so the data we gathered from their experience was subject to the vagaries of memory.

Phase 2: Provocation and Reflection

Provotyping for Provocation, Reflection, & Making

We collected ethnographic information through participant observations and semi-structured interviews with patients, caregivers, and clinical staff to gain an understanding of our context and the situation at hand — patient experience within Michigan Medicine. However, we concluded that we had reached the boundaries of traditional modes of conducting qualitative research. Here we employed our "designerly ways of knowing" and decided to use provocation to conduct research

further and create a space for reflection. By provocation, we mean pro-votyping — creating an artifact that materializes presumptions stake-holders have in a field of interest. The provocation or "critique," brings to the surface their values, beliefs, and assumptions, and provokes sensemaking of the issues at hand. We used provocation and reflection in this way, as a generative design tool. We tested our understanding of our context and situation through the creation and deployment of pro-votypes, to provoke reflection and discourse — deliberately challenging common stakeholder conceptions of patient experience. We developed three provotypes: (1) a *Coupon Book*, (2) a *Resource Book*, and (3) vari-ous forms of Story.

A Coupon Book that became a Resource Book

Coupon Book for Patients and Guests   At the beginning of Fall 2017, we collaborated with two patient and caregiver committees, a clinical nurse supervisor on a surgical step-down unit[6], and the OPE staff to iterate through the design of a provotype (Figure 17-18). *The Coupon Book for Patients and Guests* provided information about resources available within the hospital. The idea of sharing information about

Figures 17-18. Iterative process of developing the provotype of the Coupon Book with a clinical nurse supervisor.

resources is not in itself provocative — the OPE was already in the process of developing a guidebook — but the form and delivery of the information was intended to provoke discourse between nursing staff, a nursing administrator, and our team. The goal of developing this provotype was twofold: (1) to learn about OPE's process of developing initiatives for improving patient and family-centered care, and (2) developing an understanding of the challenges to implementation of an initiative within the hospital.

The *Coupon Book* was a small perforated book with information about hospital resources. It was to be distributed to patients and caregivers by nursing staff, upon admission to a surgical step-down unit. The steps required to redeem a resource were as follows:

> I. The patient or caregiver would use the nurse call light to call for a nurse.

> II. To redeem a resource, they would tear off a coupon with a specific resource and hand it to the nurse that had responded to their call light.

> III. The nurse would take the coupon and mark the back page of it with the room number of the requestor, and the time and date that the request was made.

> IV. The collected coupons would be placed in a box at the nursing station to be collected and counted by our team and the OPE to determine which resources were being requested and heavily used.

The *Coupon Book* was divided into four sections with the main ones being: (a) Amenities you or a guest can use, and (b) Additional services you or a guest can request. The other sections reminded patients or caregivers to write down information they needed to ask their doctor. The last page included a checklist used by a nurse supervisor to get feedback from patients and caregivers about their experience on the

unit. The visuals depicting services featured generic icons download-
ed from The Noun Project and the language in the book reflected the
nursing supervisor's way of speaking with patients and caregivers [The
Noun Project]. We chose which resources to include within the book
based on: (1) a list of resources compiled by OPE for a guidebook they
were creating, (2) the resources that individuals in the Caregiver En-
gagement Committee said they would have liked to know about when
they were in the hospital, and (3) the resources that the nurse supervi-
sor believed were relevant for the unit to provide.

The development of the provotype took a month. We scheduled
multiple rounds of critiques for the *Coupon Book* with our various
stakeholders (Figure 19). These critiques were necessary for provoking
reflection and sensemaking on the values and beliefs embodied in the
artifact. A crucial evaluation is described in the Results section of this
thesis. This critique was when our team and the nursing supervisor
presented the *Coupon Book* for the first time to the nursing staff on

*Figures 19. Final provotype of the Coupon Book for Patients and Guests during
nursing huddle critique.*

the surgical step-down unit where the book was to be piloted. The only time when all the nurses on the unit could congregate and provide feedback was during a ten-minute daily huddle. We were given three minutes of the huddle time to describe the provotype as an initiative that could be piloted on the unit. The resulting reflection and sensem-aking led to the creation of a provotype called the *Need Something? Resource Book for Patients & Families*.

**Need Something?** Resource Book for Patients & Families

Having had a significant amount of discourse and collaboration with multiple stakeholders on the design and critique of the *Coupon Book*, we had accomplished the first goal of creating that provotype: learning about OPE's process of developing initiatives for improving patient and family-centered care. We gained an understanding of the second goal: developing an understanding of the challenges to implementation of an initiative within the hospital. However, we still needed to conduct more research. We designed a *Resource Book* as a high-fidelity provo-type — a refinement of the *Coupon Book* with a major redesign of the form, content, and aesthetics of the artifact. Unlike the collaborative process of designing the *Coupon Book*, we designed the provotype of the *Resource Book* singularly in the design studio without much input from our partners in the hospital, but with the input and learnings from the *Coupon Book* fresh in our minds. We realized that, just as in any design process, the *Resource Book* would also have to be iterated upon, but not until we understood how it was working with the end users — patients, caregivers, and nurses. The most important critique of the provotype would have to be conducted through a pilot study of the book on the surgical step-down unit — revealing the second goal of our inquiry through provotyping.

The *Resource Book* was designed to be approachable, engaging, and entertaining to break the monotony of being stuck in the hospital. We used a square, 3.75"x 3.75" format with rounded corners, hand-let-tered typography, hand-drawn illustrations, and bound the book with

Figure 20. Need Something? Resource Book for Patients & Families high-fidelity provotype.

a binder ring so that the book was easy to flip through. The binder ring made the pages in the book interchangeable — facilitating easy removal or swapping out of pages if needed (Figure 20). The written content of the book also had a friendly tone; we designed the content to sound as if a caregiver was speaking to another caregiver through the book. Therefore, we formatted the book to answer some of the most frequent questions caregivers have during their time in the hospital. The five questions and subsequent sections of the book were: (a) Need a bite?,
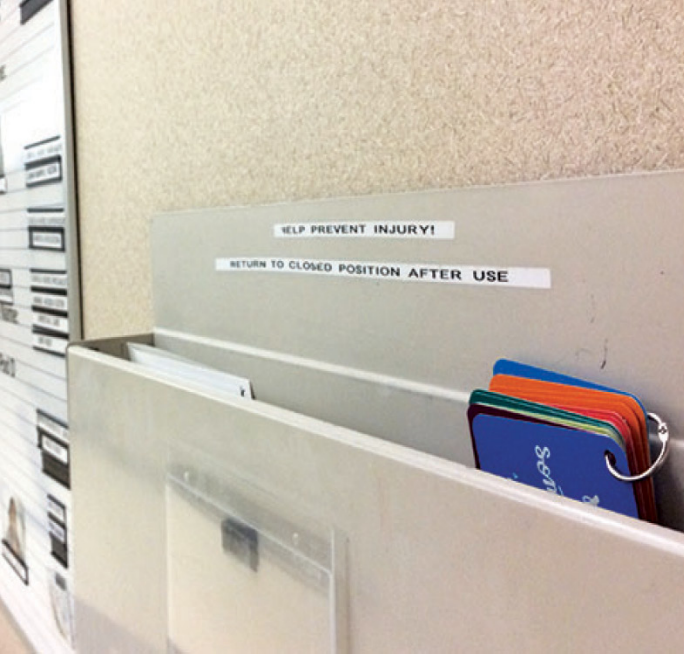
Figures 21-22. Photos from the Resource Book pilot on a surgical step-down unit.

(b) Need a distraction?, (c) Need to clean up?, (d) Need to reflect?, and (e) Need a smile?. Each section had a different distinguishing color so that it would be easy to locate within the book.

We deployed and piloted 250 copies of the *Resource Book* in the winter of 2017-2018 over five weeks on a surgical step-down unit within the Michigan Medicine Health System (Figures 21-22). We evaluated the pilot through semi-structured interviews (See Phase 4: Evaluation). The pilot study and deployment of the *Resource Book* provided us with key insights into the hospital's processes for implementing initiatives and the OPE's process of creating initiatives. These insights uncovered new needs that were explored in the next set of provotypes.

Prototyping story provotypes

A reminder to the reader that we define stories as real world, first-person accounts of a lived experience. They are curated for the emotional quality and the affective response of an individual to a specific situation or event — whether positive or negative. Stories for us could be fragments of an individual's experience lacking a narrative arc, or a plot

line — in this way, our definition aligns with the Oxford English Dictionary's definition of story as an account of past events in someone's life, or a particular person's representation of the facts of a matter. We used story as a part of a series of co-design workshops that we will describe in Phase 3: Co-Design. Here, we will describe our process of designing story provotypes to be shared with workshop participants as a part of co-design activities.

Our primary method of collecting stories was through ethnographic research such as participant observations and semi-structured interviews that occurred during the discovery and evaluations of our process. Stories were also gathered during the Learning workshops within the co-design phase, where stories were written by patients and caregivers. Stories were then chosen based on an affinity mapping activity within the workshop, or within the team, which brought to surface the problems embedded within the story. All stories chosen had an embedded issue related to patient experience that an individual within the story had experienced and vocalized. These stories were our raw material for curating and crafting stories. Once we chose a story, it either took the form of an audio recording — usually a snippet of the raw audio from the interview we recorded with a patient or caregiver — or it took the form of a written document.

For audio stories, we used audio editing software to cut audio snippets of interviews; we then uploaded it to Google Drive with a tiny.url link that was accessible by those who had the url. We received consent from individuals whose audio story was being shared via email. We sent them the following information: (a) why the story was being used, (b) where it would be used / who would be listening to the story, and (c) the actual excerpt of the story that was being shared. See Appendix IV for Consent Email Exchanges. Once we received written consent from them via email, we were able to use and share their story. The written stories we crafted had two typologies: (1) non-fiction, or (2) fiction, both heavily based on ethnographic research. Whether the
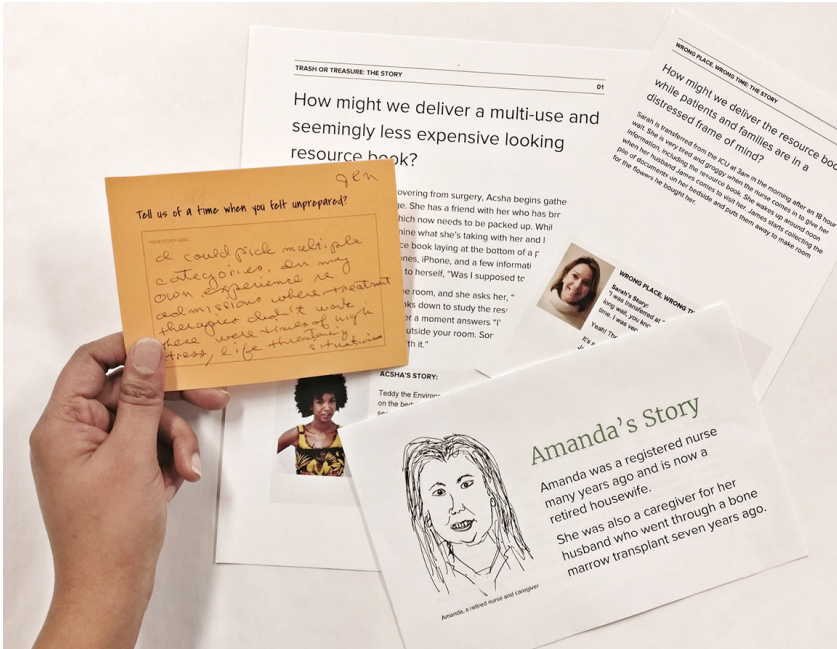
Figure 23. Various forms of the story provotype.

story was written or audio, it took form on a sheet of paper, or story cards (Figure 23). The story cards had either a hand-illustration of the individual in the story or a photograph taken from the internet of a person who looked similar to the storyteller. The image and the text were included on the same page, and if the story was in audio form, the url of the audio was provided, along with a transcribed excerpt from the audio.

We prototyped various forms of story: non-fictional, fictional, audio, and written; we also prototyped different modes of collecting stories such as through participant observations or semi-structured interviews that were transcribed and audio recorded. The use of these story pro-votypes is described in the next section.

Phase 3: Co-Design

Story-based Co-design Workshops

We designed and facilitated four story-based co-design workshops leveraging story provotypes and a set of co-design activities within the format of a 45-60 minute engagement. We conducted four workshops within the Michigan Medicine Health System, but here we chose to describe three such workshops: (1) Learning Workshop: collectively discovering problems & collaboratively generating insights, (2) Doing Workshop: creatively problem-solve & collectively make solutions, and (3) Teaching Workshop: provoking reflection and discussion around patient and family-centered care. We conducted workshops with two different units within the hospital and with a caregiver committee.

Learning Workshop

We were invited by the Administrative Director of the OPE to facilitate a workshop at a caregiver committee meeting. The caregivers we worked with, including clinical staff who identified as caregivers, were part of a Caregiver Engagement Committee who met in a hospital administrative building once a month. The committee was initiated to provide a venue for current and former caregivers to contribute to initiatives impacting caregivers within the hospital. The members who participated in our workshop were Patient and Family Advisors (PFAC), two newly inducted PFACs, and one nurse who was also a caregiver to her parents.

We engaged participants in an hour-long Learning workshop designed to facilitate structured discussion and reflection leading to the collective identification of common issues related to caregiving. After providing a moment for caregivers to reflect on the high and low moments of caregiving by completing an emotions map, we asked them to help us understand moments when they felt most and least prepared as caregivers. We asked each caregiver to describe these moments through

reflective writing. Then, being careful not to push caregivers to reveal personal information they felt uncomfortable sharing, we provided an opportunity for caregivers to discuss their reflections — which provided a moment for mutual recognition. We then transitioned the group from conversation to an invitation to help us understand where they felt the most and least prepared by asking them to mark their experiences on an affinity map of caregiving stages. We asked caregivers to pin their positive story reflection cards to an affinity map for times when they felt most prepared, and, careful to respect the privacy of their negative stories, asked them only to pin their journey maps to the affinity map of times they felt *least* prepared.

This Learning workshop (Figures 24–26) brought together the tools of our co-design process — collective problem discovery and insight generation — with the OPE's processes of learning. See Table Orange for a detailed description of the workshop activities and agenda.

Figure 24. Learning workshop facilitation.

Figure 25. Learning workshop with emotional mapping activity.

Figure 26. Learning workshop affinity mapping activity.

Story-based Co-design Workshop for Learning Collective Problem Discovery & Collaborative Insight Generation Through Story Collection	
Who?	**Caregiver Engagement Committee Meeting** 9 Committee Members • Patient and family advisors (PFAC) • Clinical staff (Nurses who are also caregivers) • OPE staff (Administrative Director & Volunteer Coordinator) • MDes student facilitators (SD, PD, PR)
What?	**Collective Problem Discovery & Collaborative Insight Generation Through Story Collection** This hour-long workshop was designed for collecting stories, collectively discovering problems, reflecting on issues, and working together to identify challenges and create actionable insights that could inform & inspire the creation of hospital initiatives and policies.
Where?	Hospital Administrative Building, Ann Arbor, MI
When?	Winter, 2018

How?	**Agenda & Activities**
	1. *Introduction*: Shared background, opportunity, and goals of the workshop.
	2. *Emotional Journey Mapping*: Individuals mapped their emotional journey during the process of caregiving. They were given:
	    a. An empty map with "low, medium, high" on the vertical axis.
	    b. Stages of caregiving labels to place on the horizontal axis of the map, in the order in which they were experienced.
	    c. Dot stickers to map out their emotional journey during each stage.
	    d. Markers to draw: a happy face on the stage where they felt most prepared as a caregiver or a sad face where they felt least prepared as a caregiver.
	3. *Story Writing*: Cards were passed out on which they wrote a story about a time when the caregiver felt the most and least prepared.
	4. *Story Sharing*: Stories about when individuals felt they were the most prepared were shared.
	5. *Affinity Mapping Caregiver's Least Prepared Stages*: Individuals folded up their map to the stage where they felt least prepared. A poster was provided with stages of caregiving written in empty bubbles. Individuals taped their folded up map onto the poster, in a bubble where they were least prepared.
	6. *Group Discussion*: As a group, we discussed information that could be gained from looking at the clustered poster. We also discussed surprises and challenges during the activities.

	Feedback surveys via Google Forms emailed to participants the day after the workshop.

Doing Workshop

We conducted a Doing workshop with the nursing staff of a surgical step-down unit, the same unit with which we conducted the *Resource Book* pilot. This Doing workshop brought together the tools of our co-design process — creative problem-solving and collective making—with the OPE process of Doing — work with partners to collaboratively generate PFCC initiatives.

We facilitated this workshop with nurses during a Unit-Based Committee Meeting (UBC); a UBC meets monthly for four hours, and it provides an opportunity for nurses to take on leadership roles. Within UBCs, nurses come together to: identify and prioritize work that meets the needs of patients and caregivers, develop practices for improving clinical procedures, and evaluate outcomes on the unit. These meetings fit with the goals of our workshops, and therefore we were allowed to conduct a workshop within the UBC meeting time (Figures 27 and 28). We gained access to the meeting through the Nursing Administrator with whom we had familiarity through the design of the *Coupon Book* provotype. We were given 60 minutes to conduct a workshop. We framed the workshop to the nursing staff as a part of our evaluation of the *Resource Book* pilot. We provided participants with written, anonymized first-person story provotypes representative of the common problems we discovered in our semi-structured interviews with patients regarding the *Resource Book* pilot. Each story was representative of a different insight we discovered regarding the pilot evaluation. We used these stories as the grounding for the collaborative making and problem-solving activities. In these activities, we asked nursing staff to help us design better, more sustainable, solutions to the deployment of the *Resource Book*. An OPE staff member observed during this workshop and helped evaluate it, as well (Figure 29). See Table Blue for a detailed description of the workshop activities and agenda.

Figure 27. Nurses engaging in creative problem-solving activities during a Doing workshop.

Figure 28. Doing workshop with nursing staff

Figure 29. OPE Project Manager observing at Doing workshop.

Story-based Co-design Workshop for Doing Creative Problem-Solving and Collective Making Around Stories	
Who?	**Surgical Step Down Unit: Unit-Based Committee Meeting (UBC)** 10 Surgical Step Down Unit Nurses • Nurses • Nursing Administrator • MDes student facilitators (SD, PD, PR) • OPE Project Manager (observer)
What?	**Creative Problem-Solving & Evaluating** This hour-long workshop was designed to engage nurses in collective making and creative problem-solving around challenges identified within stories. Specifically, the challenges described within the stories were developed from our evaluative interviews of the *Resource Book* pilot. The goal was to involve nurses in collaboratively co-designing a better delivery of the book.
Where?	Conference Room, Michigan Medicine Hospital, Ann Arbor, MI
When?	Winter, 2018
How?	**Agenda & Activities** 1. *Introduction:* Shared background, opportunity, and goals of the workshop. 2. *Warm-up Exercise:* 30 circles ideation exercise where nurses attempted to fill all 30 circles within 30 sec. 3. *Read Story Prompt & the related 'How Might We' Problem Statement:* Pairs read stories of patients and caregivers interacting with the *Resource Book* and the challenges faced in using the book. 4. *Resource Book Journey Map:* Nurses evaluated the journey of the Resource Book from the time it arrived on the unit, to when it was delivered to patients, and afterward when patients were discharged. 5. *Pairing Up:* Individual nurses paired up into groups of two or three to begin the activities. 6. *Future Scenario Activity:* Pairs worked on brainstorming and ideating on issues with the delivery of the Resource Book to patients and caregivers. They were given Hopes & Constraints cards, and Character stickers to guide their ideation and solution creation. 7. *Group Share Out:* Groups shared the solutions and ideas they developed over the course of the hour-long workshop.
	Feedback about workshop gathered in person at the end of the workshop. Workshop results with an overview, ideas, and photographs emailed to nurses a week after the workshop.

Teaching Workshop

We also facilitated a story-based co-design Teaching workshop with nursing staff of a Cardiac step-down unit within the hospital. This Teaching workshop brought together the tools of our co-design process — reflection and discussion — with the OPE goal of teaching the values of PFCC.

The workshop was conducted within a Unit Based Committee meeting hosted and attended by nurses on the unit. However, gaining access to our participants involved many layers of trust. OPE connected us with the nursing manager for the unit, who we consulted in determining mutually beneficial goals for the workshop before gaining access to the nurses we hoped to work with.

This forty-five-minute workshop (Figure 30) was designed to use story provotypes to ground and provoke reflection and discussion around patient and family-centered care. The stories we chose to share in this workshop were representative of the broader insights about patient and caregiver experience discovered in our earlier research. See Table Green for a detailed description of the workshop activities and agenda.
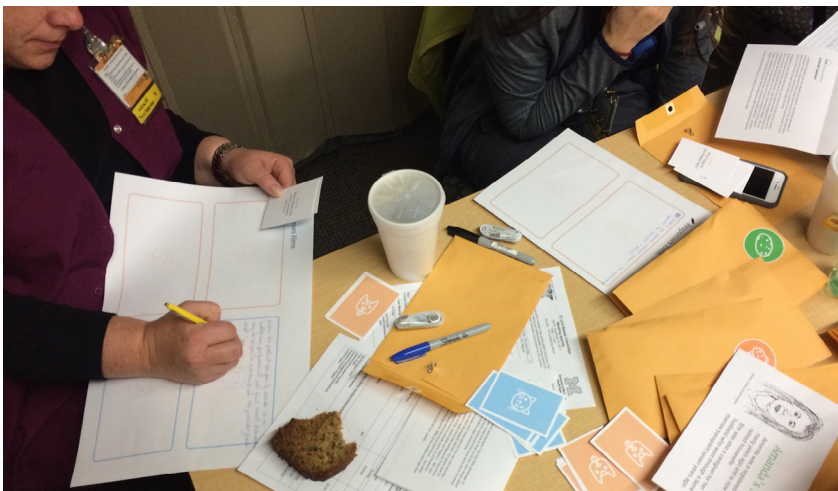

Figure 30. Teaching workshop with nurses reflecting on a caregiver story.

Story-based Co-design Workshop for Teaching	
Provoking Reflection and Discussion on Story	
Who?	**Cardiac Step Down Unit: Unit-Based Committee Meeting (UBC)** 8 Cardiac Step Down Unit Nurses • Nurses • MDes student facilitators (SD, PD, PR)
What?	**Reflecting on the Meaning of Patient and Family-Centered Care** This forty-five-minute workshop was designed to provoke reflection and discussion around patient and family-centered care through the use of a story and design activities.
Where?	Conference Room, Michigan Medicine Hospital, Ann Arbor, MI
When?	Fall, 2017

How?	**Agenda & Activities**
	1. *Introduction:* Shared background, opportunity, and goals of the workshop.
	2. *Pairing Up:* Nurses were divided into small groups based on their favorite treat: Muffins or Cookies. Each team went to a separate room to begin the activity.
	3. *Listen to Story:* In small groups, nurses heard the story of a caregiver, who used to be a former nurse, talk about how unprepared and afraid she felt about taking care of her husband at home, after discharge.
	4. *Reflection Activity:* The two small groups were each given different activities.
	    a. *Utopia / Dystopia / Present Card Sort and Discussion*
	    Nurses of Team Muffins heard the story and had to choose either a utopia, dystopia or present day card and reflect on the question written on each card. The group then discussed their answers.
	    b. *Good thing / Bad thing Cards Game, Worksheet, and Discussion*
	    Nurses of Team Cookies heard the story; they had to choose two "Good Thing" and two "Bad Thing" cards. Each card had discursive questions on it, such as:
	    "What do you disagree with in the story?" The nurses had to write their responses on the worksheet, and we had a group discussion about their responses.
	5. *Group Discussion:* Team Muffins & Team Cookies came together as a group and discussed the activities they had taken part in, and what they had learned.

	Feedback is given in person during the workshop and surveys via Google Forms emailed to participants the day after the workshop.

Co-design Sessions with OPE

We have had nearly one hundred meetings with the OPE over the course of a year and a half of our partnership. Our relationship with them began as they gave us access to the hospital to conduct primary research, such as the discovery observations mentioned earlier in this chapter. The early meetings we had with the Administrative Director of the OPE were weekly, hour-long, check-in meetings where we discussed the results of our primary research and our analysis process. Over time, as we gained mutual familiarity with one another's work and began employing their approach of partnership with units within the hospital, the nature of our relationship transformed into a collaboration — we worked together weekly in co-design sessions on developing the story-based co-design workshops, and the toolkit (See Design Outcome for details about the toolkit). Our co-design sessions involved working with the Administrative Director, and sometimes, a Project Manager at the OPE.

Stakeholder Mapping Session   An early co-design session involved working with the Administrative Director of the OPE to develop a stakeholder map of the units, departments, and individuals that were connected to the OPE within the hospital, and the nature of those connections. The exercise involved using sticky notes, a big sheet of paper and colorful markers to determine the strength of the connections (Figures 31 and 32).

Toolkit Translation Session   We called another important co-design session the "toolkit translation" session where we worked together with the OPE to translate our design terminology and language of speaking about the toolkit, into the language they use to describe their work. For this session, we worked alongside the Administrative Director and a Project Manager. The session began with a future visioning exercise to describe the future state of OPE in the next 3-5 years. We then discussed what each of us had written, and through the process, we
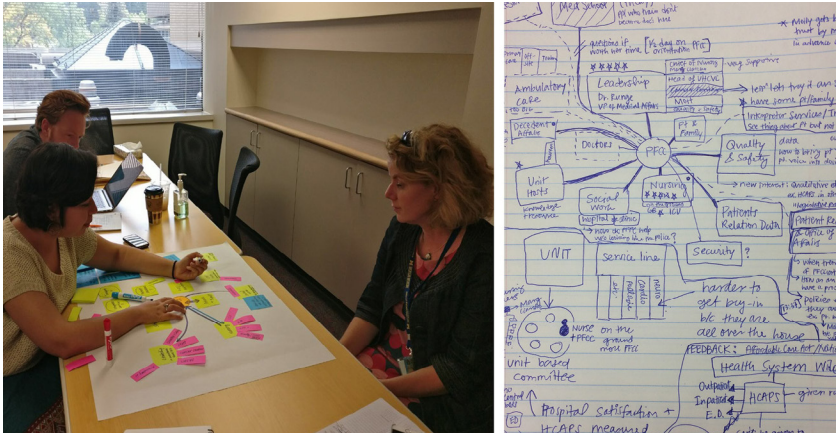
Figures 31-32. Stakeholder mapping within co-design session and our notes from the session.

learned about the OPE's internal approach to Learn, Do, Teach. We worked together to match this internal approach with our design approach. Through the exercise, we were able to align our approach with their process. The last part of the session involved an exercise where we worked through determining the forces that were helping them or holding them back in building partnerships within the hospital. This was a crucial session (Figures 33 and 34, next pages), as we were able to work through the differences in our disciplinary language and come together to develop a common language and approach that we ultimately used in the toolkit.

Phase 4: Evaluation

We conducted evaluations to evaluate two parts of our work: the *Resource Book* Pilot and the Story-based Co-design Workshops. We used semi-structured interviews and surveys, in-person and online, to conduct these evaluations. Using surveys was an efficient way for us to collect feedback for instances when we couldn't spend time conducting semi-structured interviews, or we wanted anonymous feed-

Figure 33. Our future visioning session with the Administrative Director and a Project Manager of the OPE.
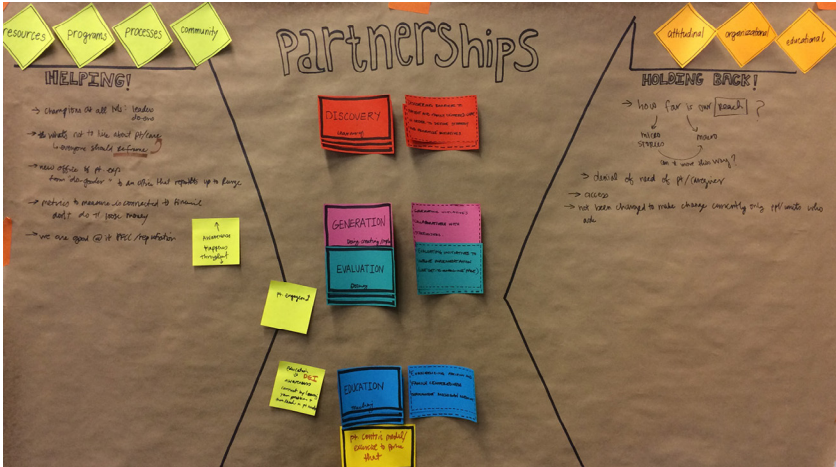
Figure 34. The exercise where we combined our approaches and determined the forces that were helping the OPE or holding them back from building partnerships within the hospital.

back. However, we recognize that this method also had drawbacks and limitations. The data gathered from the surveys was less rich than data gathered during the semi-structured interviews.

Semi-Structured Interviews of Resource Book Pilot

To evaluate the pilot of the *Need Something? Resource Book for Patients & Families* (See Phase 2: Provocation & Reflection), we used semi-structured interviews in-situ at a surgical step-down unit within Michigan Medicine. The *Resource Book* was piloted for five weeks with 250 copies on a surgical step-down unit. It was given to patients and caregivers when they were first admitted to the unit. To evaluate the effectiveness of the book, we interviewed six patients and caregivers, two nurse administrators, an environmental staff member, a unit host, and security personnel on the unit.

We asked a series of questions to patients and their caregivers on the unit (See Appendix V). The patients were chosen by a nursing adminis-trator and the unit clerk, based on when they had been admitted to the unit, and if they could engage in a conversation. In pairs, we conducted

brief 15-30 minute semi-structured interviews in patient rooms (Figure 35). We took notes while individuals spoke, and recorded audio with the verbal consent of the participant. The limitation of this approach was that in some instances, depending on the emotional state of the patient or caregiver, we were not able to gather rich feedback about their experience with the *Resource Book*.

Survey (In-person) of Resource Book Pilot

The *Resource Book* survey was conducted in-person by the Unit Host of the unit where the book was being piloted. The Unit Host volunteered to conduct the survey and recommended that he conduct the survey in-person, by going to each room within the unit to ask patients and caregivers about their opinion of the book. We developed the form of the survey and e-mailed it to the Unit Host who printed it and gathered the results. We then collected the results of the survey and conducted a brief semi-structured interview with him about his

Figure 35. A semi-structured interview with a 67-year-old-woman to gather feedback during evaluation of the Resource Book Pilot.

experience collecting the survey data. Since the Unit Host was going to do an in-person survey, we asked only one question and deliberately kept an open format for the survey (See Appendix VI).

There were challenges in conducting this survey because the population is variably available to participate and thus the sample was unpredictable. Patients recovering from surgeries are often unable to provide responses or feedback. Further, because we did not train the Unit Host in how to ask the question on the survey, we realized we could have introduced bias into the data collection.

Surveys (online and in-person) of Story-based Co-design Workshops

We tried several formats for gathering feedback to understand the participants' experiences and reactions to the workshops. The first method we used was a survey via Google Forms. We first sent the survey to the nurse administrator of the unit, for distribution to nurses on the UBCs. This method had its limitations because it was difficult to control the timeframe of when the survey reached the nurses, and there was a high chance of human error if the nurse administrator forgot, or was too busy, to forward the survey in time.

We also used in-person surveys to gather data about participant experiences of our workshops. We provided copies of a survey for nurses to fill out at the end of the workshop, collected them at the end of the workshop. We recognize that this method introduced bias into the data collection because we were present while the participants wrote their responses. This method, however, did ensure that a greater number of surveys were completed, and more data could be compiled. See examples of Surveys sent out via Google Forms and in-person sheets in Appendix VII.

Notes for Design Process

5 Dot-voting (also known as dotmocra-
cy or voting with dots) is an established
facilitation method used to describe
voting with dot stickers. In dot-voting
participants vote on their chosen op-
tions using a limited number of stick-
ers [Gray 2010].

6 In hospitals, surgical step down units
provide an intermediate level of care
between the Intensive Care Units (ICUs)
and the general medical-surgical units.

INSIGHTS

In this chapter, we describe learnings from our design process. In the first section, we share our insights into the current state of patient and caregiver experience at Michigan Medicine. We then describe our insights into how OPE approaches Patient and Family-Centered Care (PFCC). In the third section, we share our insights into the barriers faced by OPE to implement PFCC. Finally, we summarize the opportunities for supporting OPE.

Current State of Patient and Caregiver Experience

Family caregivers feel a sense of exclusion and loss of control

In discovery observations and semi-structured interviews with family caregivers, we discovered that caregivers face a pronounced sense of powerlessness in their role. They feel a real or perceived inability to affect change in their loved one's condition because they lack awareness of or access to tools that would allow them to participate in care more fully. We encountered a family early in our observations that arrived at the hospital with their father who was to undergo a routine procedure. Unexpectedly, during the procedure, doctors were forced to remove his kidney, sending his family into a tailspin of panic and surprise. By the time we met the family, they had been at the hospital for nearly two days with only a few hours of sleep, and had neither prepared for an anticipated long stay nor had they been provided detailed information about their patient's condition.

They voiced frustration that they had to keep asking the care team for information about their patient's condition. The furious wife told us in an interview, "We have to go ask them. They don't come in volunteering information! We have to go ask them! How's he doing? What's going on? I'm running on about two hours of sleep within a 24 hour time period." The family was concerned about their patient but did not feel included in his care. They had to become advocates for themselves, as well as their patient, all the while being placed in a very stressful and emotionally straining situation.

The love and care that caregivers have for their patient motivate them to look for meaningful ways to impact the patient's well-being, and while hospital systems across the country now prioritize and monitor factors affecting patient experience, caregivers aren't always includ-

ed in this renewed focus on experience. The lack of formal inclusion or consistent recognition of the role of caregiver leaves them feeling helpless, further exacerbating the issue. Caregivers we spoke with in semi-structured interviews overwhelmingly reported a feeling of powerlessness after being thrust into the responsibility of taking care of a friend or loved one like the family above. Caregivers are not recognized as "customers" of the hospital in the same way that patients are, or as contributors to the patient's well-being.

Family caregivers are often not aware of resources available to them at the hospital

Another issue that many family caregivers we spoke with faced are the lack of awareness of resources already available to them in the hospital. Access is incumbent on awareness, and care team members — like doctors and nurses — are often the ones caregivers rely on to share information about available resources like guest showers, spiritual counsel, and family quiet rooms where caregivers can rest and relax without straying far from their patient. This both increases the risk that care team members may inadvertently share this information preferentially, and that access to these services is not being offered uniformly across the hospital. Most caregivers have to create improvised sleeping arrangements unexpectedly. They are often unaware of services such as access to showers, laundry services, or the availability of comfort items like oral hygiene kits.

Secondly, caregivers sometimes face a real shortage of resources and services. For example, we learned through the design and prototype of the Coupon Book and Resource Book that access to the washing machine and dryer on one unit is sometimes off-limits to patient caregivers on another unit. Infrastructure is lacking for repeated or frequent use of some patient and family resources and can create territorial battles over which floor or patient group can access them.

Barriers to Improving Patient and Family-Caregiver Experience

The shift towards PFCC is slow and shackled by the remnants of the traditional approach

From the interviews with nurses, administrative staff and OPE team members we have learned that the hospital is in the process of making the shift from a fee-for-service model focused on patient *satisfaction* to a new model which champions patient *experience* by promoting partnerships and collaboration, amongst patients, caregivers, and staff. But this shift is slow and inconsistent. The health system is still burdened by the legacy of a purely quantitative approach to measuring the quality of care. We observed a strong organizational bias towards quantitative data. Issues related to patient experience are monitored through HCAHPS scores and feedback received through patient relations data. These forms of data do not tell the complete story of patient and family caregiver experience. Finally, interpretations of patient and family-centered care and its practice vary by unit and department due to the decentralized management structure of the hospital.

Implementation of new initiatives is a long and exhaustive process

As we experienced in the design and implementation of the *Resource Book*, changes in policy or procedures are often slow to implement. The process has necessarily long loops of testing and approval. This means that the iteration loops of, for example, something as seemingly innocuous as the new approach to whiteboard utilization we discovered while shadowing an Emergency Department doctor, often include thorough pilot studies, data analysis, and a published study before the findings and recommendations are incorporated into the practice of the hospital. The hierarchies and bureaucracies that ensure patient safety *necessarily* slow changes in policy to reduce risk, making it even

more important to partner with a wide range of stakeholders to ensure the appropriateness and effectiveness of new interventions.

Front-line staff despite their motivation have limited capacity to engage in PFCC

Nurses are the crucial front-line of patient and family caregiver experience. In our discovery observations and implementation of the *Coupon Book* and *Resource Book*, we learned that nursing time and responsibilities are highly regulated and that nurses are constantly balancing priorities between urgent versus important tasks. They often lack the structured time or the support to contribute their acquired knowledge of issues in patient and caregiver experience. Their daily 10-minute nursing huddle is one of few opportunities we observed where every nurse has the opportunity and agency to voice new ideas and concerns. The units use these huddles to measure and share their performance against HCAHPS quality indexes and introduce new initiatives. These huddles are attended by any nurse who can afford to take 10 minutes out of their erratic schedule, and environmental staff and nursing administrators also join.

In our work with one such unit, we leveraged these huddles to not only introduce the *Coupon Book* but also designed a 3-minute critique into our time with them, to actively receive and document feedback. When we first introduced the *Coupon Book* in a huddle, one nurse remarked "We're not a hotel. We have to think about our patients first and foremost". She further explained that nurses were already offering the services we had included in the *Coupon Book* to patients and caregivers, and implied that distributing a book which prompts patients and caregivers to "order" services from nurses would add additional burden to their already exhausted workflow.

Embedded hierarchies cause barriers to collaboration

In our observations of PFAC meetings, nurse huddles, and visioning sessions, we recognized that the hospital makes an explicit effort to

involve patients and caregivers. By virtue of their knowledge of the health system, patients and family caregivers bring a great perspective and raise issues related to experience. However, these meetings are not always structured to counteract hierarchies and power dynamics. We observed that privileged voices, such as those of physicians and administrators, were often the loudest in the room. These barriers hinder full participation and inclusion of diverse perspectives.

Implementation of hospital-wide PFCC initiatives is a challenge due to system fragmentation

We observed that patient-care units at Michigan Medicine differ significantly in their culture, management, patient populations, and practices. Prescribing system-wide approaches to improving patient experience is challenging because of the cultural and management variances resulting in noticeable differences in practice between units. This fragmentation has led OPE to focus on building buy-in and collaborative partnerships with individuals at a unit-level before they can begin to take a more system-wide approach. While these efforts have been effective in particular contexts, this targeted approach is challenging to scale.

Varying degrees of buy-in to the value of PFCC leads to inconsistent quality of care

Because of Michigan Medicine's decentralized organizational structure, approaches to PFCC differ from department to department, or even unit to unit, as the Administrative Director of the Office of Patient Experience points out:

> We are not top-down like the Cleveland Clinic. We don't know if it will remain that way. But at the unit level — whatever the nurse and physician team brings to the floor… and how invested they are in PFCC really varies.

We noted departments and nursing units that have an existing relationship with OPE take a more proactive approach to monitoring and

addressing patient and family-centered care than those who do not. However, high levels of operational autonomy from unit to unit can lead to vastly different experiences for patients and families — even in neighboring units on the same floor.

OPE's Approach to Implement PFCC

OPE leverages stories to build empathy

We have observed the Administrative Director of the Office of Patient Experience use powerful patient and caregiver stories to share patient and caregiver issues with us, her staff and her partners. Historically, Michigan Medicine has been reliant on quantifiable measures of quality to capture and communicate performance, and the use of story as an alternative, qualitative form of evidence is a paradigm shift in the way information is conveyed. Early in our work with the Office of Patient Experience, we were struck by the power of story to provoke discussion. Because OPE laid the foundation for the use of story in this way, we were able to build on an existing familiarity with a story-based approach to understanding and sharing information about patient experience. We were the benefactors of preceding efforts to bring a renewed patient and family centeredness to the nursing teams on units we collaborated with, and the founding of Patient and Family Advisory Committees. Central to outreach efforts of the Office of Patient Experience towards both clinical and patient family groups was story — the healing, restorative, and humanizing impact of patients and caregivers *sharing* their stories with one another and representatives of the Office of Patient Experience, and the deployment of these stories at the clinical level to inspire shifts in thinking towards patient and family-centeredness.

OPE builds partnerships with motivated individuals to implement PFCC

As our collaboration with OPE progressed, we built a deeper under-
standing of the organization's vision and approach. OPE was created
in 2016 to coordinate and improve patient experience across Michigan
Medicine. They recruit, train, and place patients and family caregivers to
serve as advisors on clinical committees and boards, alongside clini-
cians, administration, and staff. Currently, they have 400+ on-site pa-
tient and family member advisors and peer mentors serving throughout
the health system. OPE is also focused on recognizing the patient and
family-centered initiatives that individuals champion within their units
or departments. OPE is interested in partnering with these individuals to
bring about systemic change across the organization. Over the course
of our partnership with OPE, we have analyzed the nature of these
partnerships and worked with the Administrative Director to explicitly
categorize them.

Opportunities for Amplifying OPE's Approach

Story

Opportunities for collective insight generation   During our Learning
workshop with current and former caregivers at the Patient and Family
Advisory Committee meeting, we discovered the power of these forums
for mutually beneficial insight generation. Current and former patients
and caregivers attend these meetings with the hopes of finding heal-
ing, support, and community while making meaningful contributions to
PFCC at Michigan Medicine. By drawing on their experience and unique
view of the hospital, they are a valuable source of perspective to OPE
— and by extension, Michigan Medicine — on current or prospective
initiatives being evaluated by the health system.

The collective sensemaking of the group discussion and affinity mapping activities during that workshop provided two major benefits for our participants and OPE. First, it provided an opportunity for mutual recognition of shared experiences amongst caregivers — in some cases contributing to a sense of healing — and secondly, their stories led to collective insight around problem areas in caregiver experience. We learned that by facilitating activities to support sharing stories and sensemaking, participants were able to articulate tacit knowledge about the health system through reflection on their experiences. Consistent with their desire for participating in PFAC meetings, we were able to collaboratively synthesize their knowledge into insights that identified problem areas in patient and caregiver experience.

This process of insight generation through story provides OPE with a more direct line of sight into the experiences of patients and families at Michigan Medicine that quantitative data from HCAHP scores and Patient Relations surveys cannot provide, and the problem areas uncovered can be used as the basis for future engagements with clinical and non-clinical staff in the hospital.

Stories as a vehicle for communicating insights   We also discovered that insights generated through either our ethnographic research, or Learning workshops, were an informative basis for determining not only relevant themes for Doing and Teaching workshops, but for identifying related stories to communicate the issue to participants in a relatable way.

Stories as a way of provoking reflection   During a Learning workshop, we asked nurses to listen to a story about a caregiver who was afraid of taking her husband home after surgery. In the recording, the woman described her fear, stating she was afraid she might kill him if she was not able to follow home-care instructions correctly. After the nurses finished listening to the story, we facilitated a discussion through a design card activity called "Utopia/Dystopia" with the intent of under-

standing the nursing perspective on this caregiver's anxiety, or what might be causing it. At one point, the discussion turned to whether or not this was a logical concern for the caregiver to be experiencing, and one nurse spoke up, saying:

> I can't disagree with the caregiver's fears. I think maybe it might be 99% exaggerated, but it is her perception, her reality. And we need to respect that.

This response to a caregiver story, and the engaging discussion that ensued amongst the nurses led us to conclude that stories provoke a deep sense of empathy and reconnect staff to the value of practicing patient and family-centered care. We have witnessed the way honest; first-person stories can provoke a new and renewed sense of empathy for patients and caregivers amongst clinical and non-clinical staff, and provide grounding to kick-start the inherent creativity of stakeholders in imagining new alternatives to existing and sometimes forgotten issues.

Story-based workshops as a way of inspiring collaborative making
In one of our Doing workshops with nurses, we sought to enlist their perspectives in designing better distribution and awareness strategies for the *Resource Book* on their unit. We shared stories crafted from the pilot evaluation interviews. One such story was about a young patient who had used the *Resource Book* to access spiritual care, but then shelved the book out of sight and — we feared — out of mind. Here, we leveraged stories as a way of sharing information that provokes creative problem-solving. Through a series of ideation activities grounded in the stories, we provided nurses with tools with which to visualize, describe, or make explicit ideas of improving issues the patient experiences as described in the stories. What resulted, much to our surprise, were not just ideas about how to modify the *Resource Book* to be more visible to patients, but a shift in ownership of the ideas. The nurses began volunteering ways they could modify their routines to include

new and better ways of spreading patient and caregiver awareness of resources and services available to them. Rather than helping us achieve our goal of improving patient and caregiver experience, they instead began volunteering their time, knowledge, and expertise in pursuit of the same goal. The stories we shared had built empathy for the patient and caregiver experience, and the collaborative making and problem-solving had empowered nursing staff to make the necessary changes — their ideas and opinions were listened to, and validated through the workshop. We believe this was the power of using a story within a co-design workshop. Not only were the stories a provocative and effective means of sharing knowledge and perspectives, providing the opportunity for concrete nursing participation in the creation of alternatives sparked an enthusiasm that grew the scope of opportunity to improve patient and caregiver access to resources and services.

Stories as a form of data and sensemaking The hospital system uses quantitative data to make policy decisions to improve patient out-comes, and more recently, HCAHPS and patient relations data to make decisions affecting patient experience. Nursing units, as we discovered, are held accountable to a litany of performance metrics in addition to HCAHPS and patient relations data that are meant to provide feed-back on their performance. While the nursing units we observed had no shortage of data available to them, we found instead in our workshops that the use of stories is a more impactful way to help clinical and non-clinical staff connect with an issue. Facts and figures alone show an incomplete perspective when paired with patient and caregiver stories, a more holistic view of the hospital emerges. Stories shape how people think about relationships, values, and expectations, and can provoke us to consider a different point of view. Stories about specifics are easier to recall than numbers or averages—stories enhance memory. While recall data offers specific, concrete insight in a quantitative sense, it lacks specificity in a qualitative one. Story offers a qualitatively specific complement to existing ways of knowing (quantitative) in the hospital.

Partnership

Building trust as a way of achieving sustained partnership   In our at-
tempts to navigate the hierarchy of the health system, we found that
reciprocal and active partnership is the most effective form of engage-
ment. Early attempts at deploying the *Coupon Book* as an interven-
tion ultimately failed, but revealed to us the mechanics of a system in
which change happens gradually. Change in this system happens most
effectively through a process of building trust from the outside in. While
we were designing, prototyping, and evaluating the *Coupon Book*, we
were concurrently building relationships and trust with constituents
whose collaboration and cooperation we needed to affect the kind of
positive change we hoped for. Gaining permission to access potential
partners is a process of building trust and frequent communication and
negotiation of objectives. When appealing to a group for collaboration
and cooperation on an issue which is not their immediate responsi-
bility, this cooperation relies on personal relationships, shared objec-
tives, and rapport.

**Partnering with crucial front-line staff for improving patient
experience**   We quickly realized that any attempt at improving the
patient and caregiver experience is incomplete without the nursing
perspective. In addition to monitoring patients for signs of distress and
health emergencies, nurses are the front-line of patient and caregiver
experience and the crucial connection between patients, families, and
clinicians. We saw the need for building a partnership that would help
in discovering challenges around patient care and generating change
which not only benefits caregivers but is sustainable for those involved
in the delivery of care. However, we noted from discovery observations
that nurses face numerous barriers to providing patient and family-
centered care. They are often forced to balance and reorder urgent
vs. important issues. One such nurse we observed struggled to deliver
a glass of water to a caregiver for an hour and a half while being
inundated with more urgent issues and requests from other nurses.

Leveraging the inherent creativity and compassion for nursing staff

The nurses we observed care deeply about their patients and the families of patients, think on their feet, improvise on the go, and come up with creative workarounds for the purpose of care. Additionally, despite the lack of structured opportunities to contribute to policy change in the hospital, we observed "champions" on each unit who find time outside of working hours to proactively produce initiatives that improve the patient and family experience. We encountered one such effort, spearheaded by a nurse who collected information about hospital resources and services available to patients in a folder. This folder had 40+ different pamphlets. However, she was repeatedly forced to drop the project due to the lack of time and support to pursue the project and implement her contribution.

Making OPE's approach explicit to build buy-in within the system

OPE has existing partnerships within the hospital. This includes PFACs, unit-based committees, nurse champions, unit hosts, clinicians, environmental staff, and administrators. These partners have varying degrees of buy-in and investment in practicing PFCC. This is partly due to the lack of concrete data evidencing the value of PFCC and value-based resource allocation. OPE's goal is to make their approach explicit and measurably improve the patient and family experience at Michigan Medicine. As they engage with new groups, they are interested in creating a transparent and accessible approach that can act as a blueprint for change within the system.

An Engagement Process

Designing tools to amplify OPE's approach within the health system

OPE believes in the use of patient and caregiver stories for creating high-quality connections among their partners. Today, these partners function in a largely hierarchical and fragmented system, and their knowledge remains contained to their unit or department. OPE is interested in being more strategic and operational in their approach

to discovering problems, implementing solutions and building capacity and understanding for patient and family-centeredness at Michigan Medicine. OPE is in need of tools that help them scale and deepen their impact as they grow in scale and responsibilities. Furthermore, OPE's approach, which has evolved organically, has not yet been codified within its team. One employee described the situation they are facing as "a lot of that information lives in people's heads, which we're finding out is really challenging." Because the organization is expanding — since its establishment in January 2017 the team has grown from a staff of 5 to an expected staff of 19 — we believe this is an excellent opportunity to help them define and share their approach with new hires, and even more broadly within the system.

Summary of Themes and Insights

1 Patient and Caregiver Experience
- Family caregivers feel a sense of exclusion and loss of control
- Family caregivers are often not aware of resources available to them at the hospital

**2 Barriers to Implementing PFCC**
- The shift towards PFCC is slow and shackled by the remnants of the traditional approach
- Implementation of new initiatives is a long and exhaustive process
- Front-line staff despite their motivation have limited capacity to engage in PFCC
- Embedded hierarchies cause barriers to collaboration
- Implementation of hospital-wide PFCC initiatives is a challenge due to system fragmentation
- Varying degrees of buy-in to the value of PFCC leads to inconsistent quality of care

3 OPE's Approach to Implementing PFCC
- OPE leverages stories to build empathy
- OPE builds partnerships with motivated individuals to implement PFCC

4   Opportunities for Amplifying OPE's Approach

- Collective insight generation with stakeholders
- Stories as a vehicle for communicating insights
- Stories as a way of provoking reflection and empathy
- Stories as a form of sensemaking
- Story-based workshops as a way of inspiring collaborative making
- Building trust as a way of achieving sustained partnership
- Partnering with crucial front-line staff for improving patient experience
- Leveraging the inherent creativity and compassion for nursing staff
- Making OPE's approach explicit to build buy-in within the system
- Designing tools to amplify OPE's approach within the system
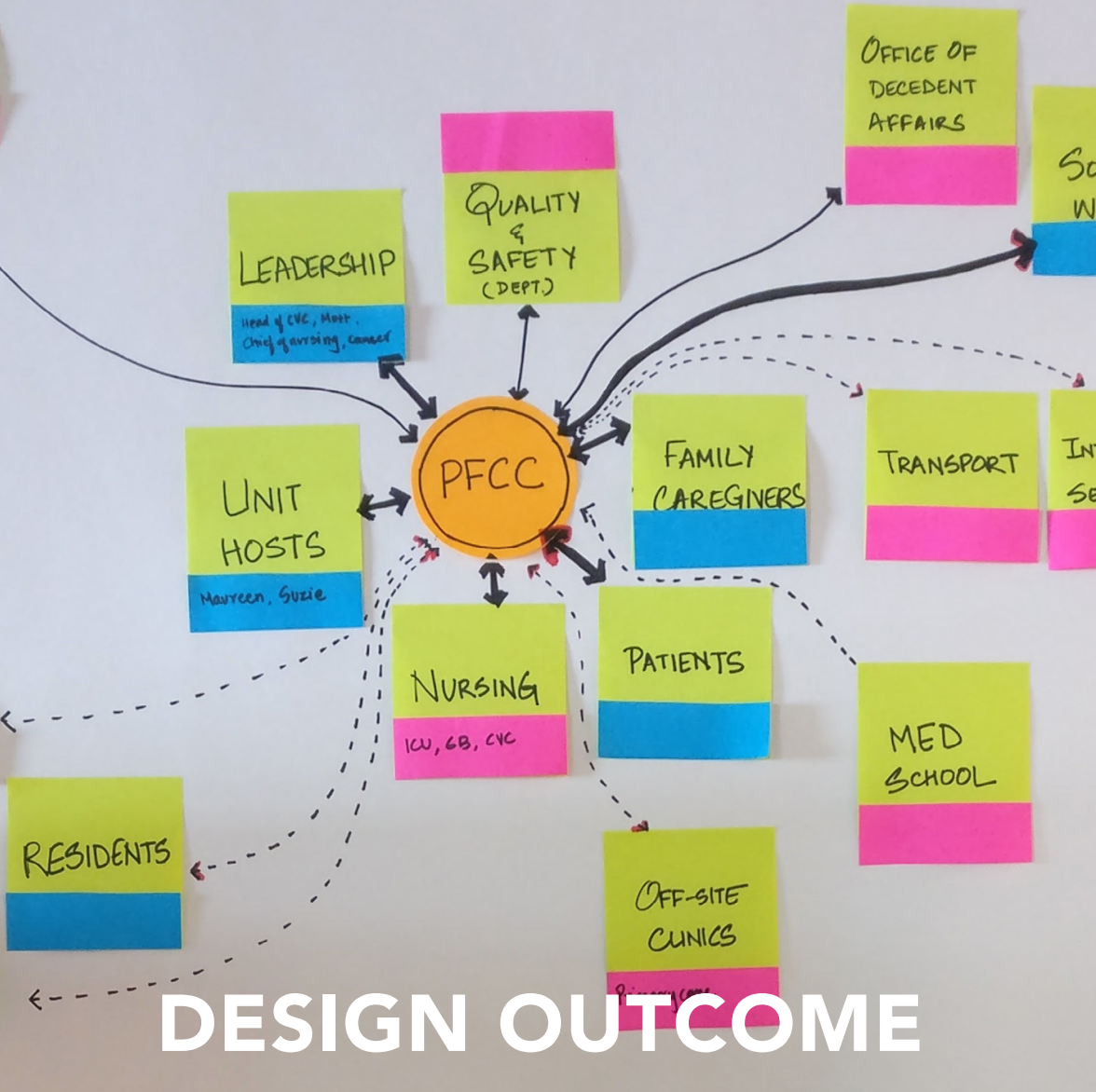
DESIGN OUTCOME

This chapter describes our Story-based Co-design Toolkit, a framework of engagements and activities as a design outcome of this collaborative Master's thesis. We discuss the components and contents of this toolkit in this chapter. The chapter ends with how this toolkit framework meets the objectives of the Office of Patient Experience.

As we partnered with OPE through our design process and outcomes, we integrated our insights from implementing interventions in the health system and knowledge of human-centered design with the knowledge, perspectives, and expertise of our partners. This led to the co-design of a toolkit framework that is better suited to our partner's context and organizational approach. The toolkit framework embodies an approach based on empathy, reflection, inquiry, and creative problem-solving — soft skills that are often hard to build. The toolkit framework is not aimed at helping OPE address the barriers they face in implementing PFCC, but rather to *support* them with tools to build partnerships, provide a means of qualitatively discovering issues related to patient and family experience, and connect synthesized learnings from patients and caregiver engagements into opportunities for collaborative making with clinical staff. It is with the help of these partnerships that OPE can then collaboratively discover problems, implement interventions, and share knowledge. The toolkit framework was designed to act as a self-sustaining system of generating and facilitating action on insights around patient and family experience and to be a catalyst for amplifying OPE's approach to implementing PFCC.

A Story-based Co-design Toolkit

The Story-based Co-design Toolkit is a framework of engagements and activities that leverage stories as provocative data to be used in a co-design process to support the Office of Patient Experience towards building strategic and operational partnerships with patients, caregiver, clinical, and non-clinical stakeholder groups. The toolkit brings together the tools of our design practice — ethnographic research, provotyping, co-design workshops, and evaluation — with the OPE's engage-

ment approach of learning, doing, and teaching to build partnerships around patient and family-centered care values. This toolkit presents: (1) a co-design process, (2) an engagement typology and corresponding framework, (3) a list of factors that influence engagements, and (4) an insight discovery and story curation process.

Co-design Process:
Provoke, Reflect, Make, Synthesize

This co-design process is used when conducting Learning, Doing, and Teaching Engagements. It begins with **Provocation** which leads to **Reflection**. The outcome of reflection leads to **Making** and **Synthesis**. From synthesis, the process then loops back to **Reflection** (Figure 36).

Provoke: Provocation is the sharing of story as provocative data in an audio or written form. The story is a real world, first-person account of a lived experience within the hospital.

Reflect: Reflection is the critical act of sensemaking. It is the processing and analysis of the story, and the making of meaning.

Make: Making is the act of generating ideas and building solutions based on the reflections.

Synthesize: Synthesis is the act of facilitating consensus building activities around either the insights generated during the workshop (Learning engagement) or most desirable outcomes based on ideation and making activities (Doing engagement).

This co-design process was derived from our learnings and analysis of the co-design workshops we designed and facilitated within the hospital. The process is used within Learning, Doing, and Teaching engagements described in the next section.
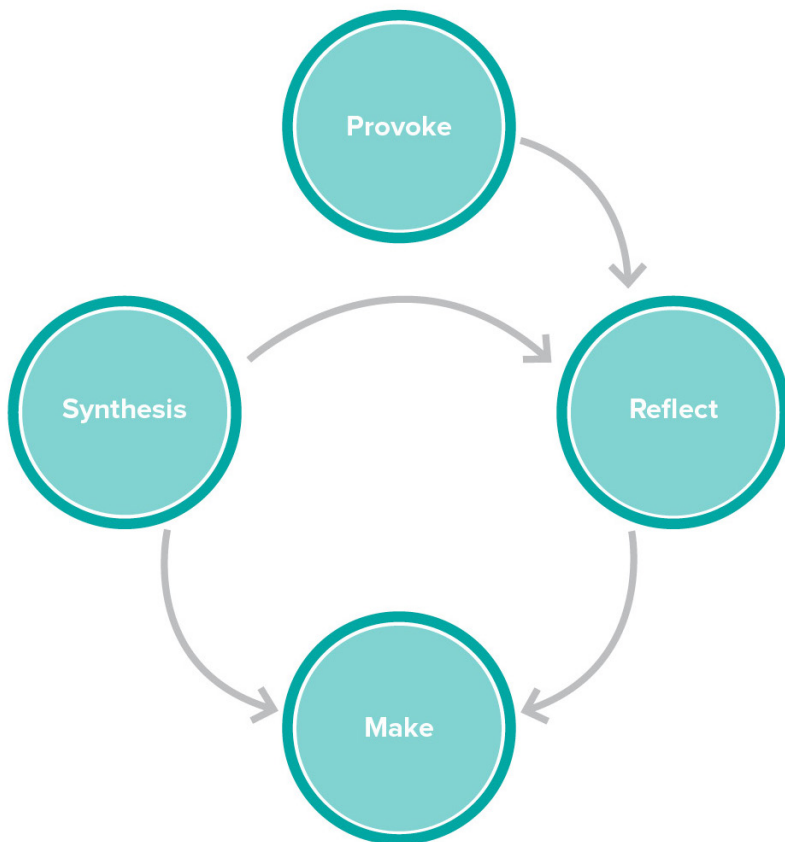
Figure 36. The co-design process within the toolkit framework.

Engagement Typogology and Corresponding Framework

The Learning, Doing, and Teaching engagement typology is derived from the way we designed and facilitated our co-design workshops — we analyzed our agendas, activities, and facilitators guides for each workshop and mapped them into a framework for how to conduct an engagement.

Learning Engagement

A Learning engagement is meant to document stories, discover problems, and generate insights. This typology of engagement is meant to acknowledge lived experiences, provide structured opportunities for participants to articulate tacit knowledge through sharing their stories, and allow participants to generate insights collectively. It supports groups to reflect on their experiences through a process of reflection and making and to collaborate in synthesizing and creating actionable insights that can inform and inspire the development of hospital initiatives and policies to improve patient experience (See How-To, opposite).

The framework for conducting a Learning engagement, mapped onto the co-design process, can be found in Table 1 below. The first stage of the engagement is meant to frame the intentions for participants.

Co-Design Process	Learning Engagement
	Framing: Articulating the purpose of the engagement, and sharing with participants that their stories will be used to help OPE develop policies and practices to improve the patient experience continually.
Provoke	**Grounding:** Sharing stories as provocative data.
Reflect	**Reflection:** An opportunity for participants to reflect on, make sense of, and identify challenges and opportunities from the situation described in the story.
Make	**Story Writing:** Asking participants to make sense of their reflection through the writing of their stories. Discretion is given to the sensitivity and personal nature of the information being shared.
Synthesize	**Synthesis & Discussion:** Facilitating the translation of individually articulated tacit knowledge into collective understanding through participatory sensemaking activities and discussion.
	Debriefing: Wrap-up remarks, re-stating purpose of the engagement, and collecting feedback.

Table 1

Learning Engagement How-To

Intention	**Collective Problem Discovery & Collaborative Insight Generation Through Story Collection** A Learning engagement is about documenting stories, finding problems, and creating insights. This typology of engagement is meant to acknowledge and collect stories; it helps groups within the hospital work to collectively to discover problems through the process of reflection and making and collaborate on synthesizing and creating actionable insights that can inform & inspire the creation of hospital initiatives and policies that improve patient experience.
Participants	Can be any group of patients, caregivers, or clinical and non-clinical staff; be aware of hierarchy.
Duration	Can range from 45-60 minutes
Process	**Framing (5 MINS):** Articulating the purpose of the engagement, and sharing with participants that their stories will be used to help OPE develop policies and practices to improve the patient experience continually. Providing a brief overview of the agenda, and establishing trust and transparency with participants. *Example of a topic: We'd like to use this time today to better understand your experiences of the discharge process at Michigan Medicine.* **Grounding (5 MINS):** Sharing stories as provocative data. Providing a printed or audio-recorded, first- person account of a lived experience for participants to read silently or listen to on an audio device. *See end of this section for types of stories and modes of delivery.* **Reflection (20 MINS):** An opportunity for participants to reflect on, make sense of, and identify challenges and opportunities from the situation depicted in the story. Activities provide structured opportunities for participants to articulate tacit knowledge of or experiences with patient experience. *Types of activities: Emotions Journey Mapping, Business Origami.*

Story Writing (20 MINS):
Asking participants to make sense of their reflection through the writing of their stories. Discretion is given to the sensitivity and personal nature of the information being shared.

Types of activities: Story Writing

Synthesis & Discussion (20 MINS):
Facilitating the translation of individually articulated tacit knowledge into collective understanding through participatory sensemaking activities. Offers participants the chance to compare stories and find healing through identifying shared experience. Offers participants the opportunity to understand better the most common issues experienced. Written and verbal modes of participation provide equal space and opportunities for all participants to contribute. The group then discusses their findings.

Types of activities: Sharing Positive Stories Verbally, Affinity Mapping Negative Stories (minus personal details)
Building collaborative, trusting, and mutually respectful relationships with participants. Identifying issues and insights that need to be brought to the attention of clinicians and staff at the Michigan Medicine.

Debriefing (5 MINS):
Thanking participants for their contributions, and re-iterating how their contributions will be used to help clinicians and staff at Michigan Medicine craft policies and practices to continually improve the hospital. Opportunity to solicit feedback or distribute feedback forms.

Types of questions: What was surprising about this experience? What was challenging? Is there anything you learned that you didn't know before?

Desired Outcomes Building collaborative, trusting, and mutually respectful relationships with participants. Identifying issues and insights that need to be brought to the attention of clinicians and staff at the Michigan Medicine.

Next, the facilitator shares a provocative story to ground the partici-
pants in the issue at hand and provoke individuals to reflect on a relat-
ed experience they may have had.

The Reflection phase is designed to facilitate structured discussion
about individual reflections, leading to the collective identification of
common issues related to caregiving through a sensemaking activity
like emotions journey mapping or business origami, followed by story
writing — a making activity.

Story writing is an opportunity for participants to make sense of their
reflection by writing about their experience with the issue at hand. Dis-
cretion is given to the sensitivity and personal nature of the informa-
tion being shared. Then, being careful not to push caregivers to reveal
personal information they feel uncomfortable sharing, the facilitator
provides an opportunity for mutual recognition of common experiences
and collective sensemaking by offering caregivers an opportunity to
discuss their reflections through conversation and structured synthesis
activities. The facilitator guides participants through affinity mapping
as an opportunity for participants to organically arrive at a consensus
around the insights generated during the workshop.

Doing Engagement

A Doing engagement is an opportunity to plan and design interven-
tions to the issues identified in Learning activities, or insights originat-
ing from other research activities at OPE. Participants are provided a
story provotype that is indicative of the problems and make solutions
together. Participants engage in collective making and creative prob-
lem-solving around challenges identified within stories. The goal is to
leverage the tacit knowledge of clinical and non-clinical staff to design
new policies, practices, and interventions with and for the people who
are affected by them (See How-To, page 115).

	Doing Engagement
Co-Design Process	**Framing:** Articulating the purpose of the engagement, and sharing with participants that their input will be used to help craft policies and practices to improve the patient experience continually.
Provoke	**Grounding:** Sharing stories as provocative data.
Reflect	**Reflection:** Activities provide structured opportunities for participants to articulate tacit knowledge of or experiences with patient experience.
Make	**Ideation:** Brainstorming, and developing ideas and solutions for problems uncovered during reflection.
Synthesize	**Synthesis & Discussion:** Providing opportunities for participants to share, combine and evaluate ideas.
	Debriefing: Wrap-up remarks, re-stating purpose, and collecting feedback.

Table 2

The framework for conducting a Doing engagement, mapped onto the co-design process, can be found in Table 2 above. The first stage of the engagement is to frame the intentions for participants and set an agenda. Next, the facilitator(s) shares provocative stories to ground the participants in the issue at hand. Participants are given activities that facilitate individual and collective discussion and reflection. In pairs, participants brainstorm and generate ideas for potential solutions and alternative future states. Ideas are shared and combined, and the participants discuss their experiences during the engagements.

Doing Engagement How-To

Intention	**Creative Problem-Solving & Collective Making** Engaging participants in collective making and creative problem-solving around challenges identified within stories. Leveraging the tacit knowledge of clinical and non-clinical staff to design new policies, practices, and interventions with and for the people who are affected by them. Increase real and perceived agency of participants through collective making and creative problem-solving around challenges identified within stories.
Participants	Clinical and non-clinical staff at Michigan Medicine. Current and former patients and caregivers.
Duration	45-60 minutes
Process	**Framing (5 MINS):** Articulating the purpose of the engagement, and sharing with participants that their input will be used to help craft policies and practices to improve patient experience within the hospital continually. Providing a brief overview of the agenda, and establishing trust and transparency with participants. *Example of a topic: Today we'd like your help in thinking of ways to approach the deployment of patient and family quiet kits on your unit.* **Grounding (5 MINS):** Sharing stories as provocative data. Providing a printed or audio-recorded, first- person account of a lived experience for participants to read silently or listen to on an audio device. *See later section regarding types of stories and modes of delivery.* **Reflection (20 MINS):** An opportunity for participants to reflect on, make sense of, and identify challenges and opportunities from the situation depicted in the story. Activities provide structured opportunities for participants to articulate tacit knowledge of or experiences with patient experience. *Types of activities: Journey Mapping, STEEPV Implications*

Ideation (20 MINS): Working in pairs participants brainstorm and develop ideas and solutions. Facilitating the translation of individually articulated tacit knowledge into actionable insights through brainstorming and solution-generation activities to assist in collaborative creative problem-solving.

Types of activities: Product Pinocchio, Attributes Worksheet, Good Thing / Bad Thing, Hopes / Constraints / Actors, Mind Mapping, The Five W's, Journey Mapping

Synthesis & Discussion (20 MINS): Providing opportunities for participants to share, combine, and evaluate ideas.

Types of activities: Affinity Mapping, Dot Voting

Debriefing (5 MINS): Thanking participants for their contributions, and re-iterating how their contributions will be used to craft policies and practices to improve the hospital continually. Opportunity to solicit feedback or distribute feedback forms.

Types of questions: What was surprising about this experience? What was challenging? Is there anything you learned that you didn't know before?

Desired Outcomes Providing structured opportunities for clinical and non-clinical staff to impact policy which affects them. Accessing and leveraging the tacit knowledge of clinical and non-clinical staff. Re-connecting staff to meaning in their work.

Teaching Engagement

A Teaching Engagement is meant to provoke critical reflection — resulting in participants writing and discussing their perceptions about a patient and caregiver issue shared via a story provotype. This typology engages participants in critical reflection activities that force them to consider alternative states and make sense of deliberately discursive prompts that build empathy. These activities lead to group discussions that bring to surface their values, beliefs, and assumptions, which are shared with the larger group (See How-To opposite).

The framework for conducting a Teaching engagement, mapped onto the co-design process, can be found in Table 3 below. The first stage of the engagement is to frame the intentions for the participants and set the agenda. Next, the facilitator(s) shares provocative stories to ground the participants in the issue at hand. Participants are given activities that facilitate individual and collective discussion and reflection.

Co-Design Process	Teaching Engagement
	Framing: Providing a brief overview of the purpose and agenda.
Provoke	**Grounding:** Sharing stories as provocative data.
Reflect	**Reflection:** An opportunity for participants to reflect on, make sense of, and empathize with perspectives described in the story.
Make	**Discussion:** Sharing results from reflection, and building empathy and shared understanding of patient and family perspectives.
	Debriefing: Wrap-up remarks, re-stating purpose, and collecting feedback.

Table 3

Teaching Engagement How-To

Intention	**Reflecting on the Meaning of Patient and Family-Centered Care** Provoke reflection and discussion around patient and family-centered care through the use of a story and co-design activities.
Participants	New hires and trainees: Clinical and non-clinical staff alike
Duration	45-60 minutes during new hire orientation

Process	**Framing (5 MINS):**
	Articulating the purpose of the workshop, and sharing with participants the way stories are used at Michigan Medicine to ground and inform strategy around patient-centeredness. Providing a brief overview of the agenda.
	Grounding (5 MINS):
	Sharing stories as provocative data. Providing a printed or audio-recorded, first-person account of a lived experience for participants to read silently or listen to on an audio device.
	See later regarding types of stories and modes of delivery.
	Reflection (20 MINS):
	An opportunity for participants to reflect on, make sense of, and empathize with perspectives described in the story.
	Types of activities: Journey Mapping, STEEPV Implications Types of activities: Good Thing / Bad Thing, DEI Activity, Business Origami, Positive / Negative Aspects of the Story
	Discussion (20 MINS):
	Sharing results from reflection, and building empathy and shared understanding of patient and family perspectives.
	Types of activities: Story Sharing, Group Discussion
	Debriefing (5 MINS):
	Thanking participants for their participation, and re-iterating the way stories are used at Michigan Medicine to ground and inform strategy around patient-centeredness at Michigan Medicine. Opportunity to solicit feedback or distribute feedback forms.
	Types of questions: What was surprising about this experience? What was challenging? Is there anything you learned that you didn't know before?
Desired Outcomes	Establishing an early understanding of patient-centeredness in new hires, and building a culture of patient-centeredness from the outset. Re-connecting current staff to meaning in their work.

How to use the toolkit

This toolkit framework is designed specifically for and intended for use by the staff of the Office of Patient Experience to amplify efforts to grow the practice of PFCC at Michigan Medicine and build partnerships with individuals and groups within the hospital. The following sections will describe pre-work that should be done before initiating a story-based co-design workshop.

Before proposing an engagement

Before proposing an engagement it is important to gain familiarity and trust with potential stakeholders on a unit or within a patient and family advisory group. Trust based on aligned, mutually beneficial goals with stakeholders, participants, and constituents, in our experience often leads to improved outcomes.

Trusting, mutually beneficial working relationships enable the access, information sharing, and collaboration needed to deliver the intended benefits to everyone involved. Trust and familiarity can also lead to increased support and access from the leadership of a unit or group.

Consider factors that influence the engagement.

A.   Buy-in: Attitudes, Allies, and Antagonists   When engaging with clinical staff at Michigan Medicine, it is important to remember that policies, procedures, and culture can vary from unit to unit due to the decentralized organizational structure of the hospital. Because management styles and unit culture can vary significantly, it is helpful to familiarize oneself with key players early on. Connecting with enthusiastic champions for patient-centered care can provide a window into the culture of the unit, which becomes helpful when considering the type of engagement and related activities to plan.

B.   Existing relationships: Familiarity, Shared language   Utilize exist-
ing relationships to make deeper connections within a unit to strength-
en collaborative ties, and leverage shared language to build common
understanding of goals and opportunities.

C.   Context: Culture, Challenges, Hierarchy, Leaderships   Pay close
attention to formal and informal hierarchies so as not to unintentional-
ly over-step bounds, or impose unnecessarily on others.

D.   Groundwork: Place of engagement, Time Allotted, Access
Consider the location of the engagement. Is there space for the number
of anticipated participants? Will there be any special equipment needs?
Is the space available for the desired time?

E.   Explicit communication: Goals, Values, Biases   Setting the stage
for a successful and trusting engagement requires explicit transparen-
cy of goals, values and potential biases with stakeholders. Failure to
disclose goals or potential conflicts of interest may disrupt and derail
the engagement, harm the potential for future collaborations.

F.   Having fun: Breaking the ice   Consider ways to bring energy and
fun to the engagement. Physical movement, snacks, and even a little
sense of humor when it comes to planning activities (i.e., Team Muffin
and Donut, or the cat and dog cards used in the "Good Thing, Bad
Thing" activity) can raise the energy in the room and lead to a more
fruitful engagement.

G.   Collective decision making: Shared Responsibilities   Be sure to
monitor the power dynamics in the room. Dominant voices can quickly
dominate the conversation and diminish contributions from the rest
of the group. Encourage all participants to share responsibilities, and
think of ways to ensure equal space for all contributors.

H. Reciprocity: Mutual Beneficence   Planning for shared value of the engagement not only ensures longevity and durability of partnerships but can improve participation and buy-in among stakeholders. If both facilitators and participants stand to benefit from the engagement, it is more likely to succeed for all parties involved.

I. Following up: Sustaining Relationships   Maintaining a reciprocal and active partnership improves opportunities for follow-ups, increasing the likelihood that ideas born out of collaborative engagements will one day be implemented.

Select a type of engagement

OPE staff can select a type of engagement based on the outcome they desire. Types of engagements and outcomes are listed below.

Desired Outcome:
Building collaborative, trusting, and mutually respectful relationships with participants. Identifying issues and insights that need to be brought to the attention of clinicians and staff at the Michigan Medicine.

Select a **Learning Engagement-Type:**
Collective problem discovery & collaborative insight generation through reflection and story sharing.

Desired Outcome:
Providing structured opportunities for clinical and non-clinical staff to impact policy which affects them. Accessing and leveraging the tacit knowledge of clinical and non-clinical staff. Re- connecting staff to meaning in their work.

Select a **Doing Engagement-Type:**
Creative problem-solving and collective making around stories.

Desired Outcome:

Establishing an early understanding of patient- centeredness in new hires, and building a culture of patient-centeredness from the outset. Re-connecting current staff to meaning in their work.

Select a **Teaching Engagement-Type:**

Provoking reflection and discussion on stories.

Why story?

> "Sharing stories highlights the human connection that often is lost in health system protocols and policies."
> — Caregiver during a co-design workshop

Stories are a powerful tool for provocation, reflection, and action. Humans use story to educate, persuade, and better understand their experiences. Stories are the entry point to understanding a different perspective of the world — creating shared understanding and a sense of community. Within healthcare, where knowledge is shared explicitly, there is a need for methods and tools to help uncover and utilize tacit knowledge of patients, caregivers, and clinical and non-clinical staff.

Telling the story of one patient or staff experience can effectively illustrate challenges in a care pathway. Sharing the story of a patient or frontline worker with a larger team can quickly and effectively bring a situation to life, and begin to focus discussions around the patient experience. Statistics and data have an important place in monitoring and understanding services and facilitating improvement, but story has the power to motivate, change minds, and inspire listeners to consider alternative solutions.

Identifying stories for use in an engagement

Learning engagements provide opportunities for OPE to discover issues related to patient and family experience through collective synthesis
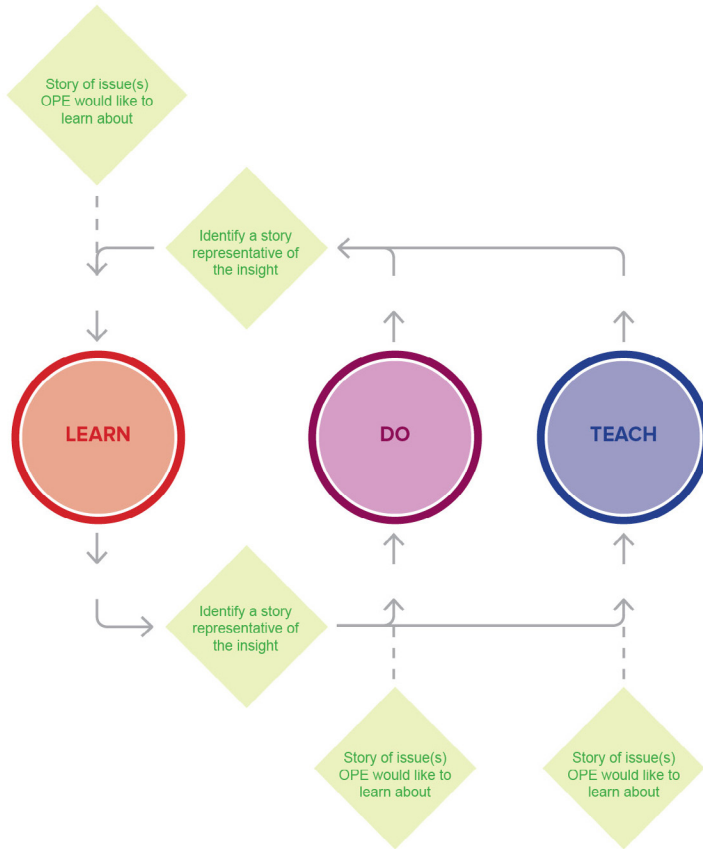
Figure 37. The flow of insights and stories in the Stories for Change toolkit framework

activities that facilitate collective sensemaking based on participant contribution of reflection and discussion. Doing and Teaching engagements then provide an opportunity for OPE to make actionable the insights discovered in Learning engagements. Similarly, Learning activities can be conducted with clinical and non-clinical hospital staff and used as the basis for Doing activities with patients and families as well.

However, this system of insight discovery (Learn), intervention creation (Do) and knowledge sharing (Teach) may be complemented by OPE's use of stories representative of issues not discovered through Learning engagements. This tool is meant to amplify OPE's goals of learning,

doing, and teaching, and therefore may not be the *only* source of new knowledge about patient and family experiences in the hospital.

Identifying stories for a Learning workshop:
The stories chosen as grounding to elicit responses and insight from participants in a Learning workshop ought to be representative of the issue or issues that the facilitator desires to learn about. In this instance, the topic of inquiry is incumbent on an informed facilitator — a representative of OPE — to use this toolkit as a means for discovering insights related to an issue which OPE desires to learn more about.

Identifying stories for a Doing or Teaching workshop:
This toolkit is designed so that stories for Doing or Teaching workshops can originate from insights discovered in the synthesis portion of Learning workshop. Stories for use in a Doing or Teaching workshop, then, ought to be representative of an issue or issues identified in a Learning workshop, and can be chosen from stories from transcribed by participants in a story writing activity which pertain to the topic issue.

Characteristics of an engaging story

We developed a framework for identifying stories to be used as provotypes based on our experiences using them in our co-design workshops. We derived our framework from our practice, and drew from the popular psychology book, *Made to Stick: Why Some Ideas Survive and Other Ideas Die*, which describes a framework for making an idea "sticky" or memorable [Heath, Heath 2007]. We modified their framework into a rubric for choosing and curating stories. See Table 4, opposite, for our story curation framework.

Characteristics of an engaging story	
Simple	The core idea/s of the story are easy to identify
Unexpected	The story is surprising and uses words or phrases that are attention-grabbing
Concrete	The story is about a specific instance or experience, narrated by a character(s)
Credible	The story projects credibility and believability; it is based in ethnographic research
Emotional	The story has an emotional quality that stirs feelings in the listener/reader

Table 4. Our framework for identifying an engaging story

Delivering a story provotype

Stories used as provotypes to provoke reflection, discourse, and action deliberately challenge common stakeholder conceptions of patient experience, and inspire action to create better solutions. The steps for preparing a story provotype for a workshop are:

1. Write a **title** for the story.

2. *Optional:* Write about **a problem embedded within the story** that summarizes the challenge described within the story.

3. Craft a **brief summary**, written in the third person, of the main issue or problem addressed within the story.

4. *Optional:* Give the url link to the audio story.

5. Transcribe or craft a **first-person account**, from an excerpt of the interview or notes from an ethnographic observation. The individual should be directly speaking to the reader about a lived experience they have had. *Always remove personally incriminating or identifying information about the subject or subjects in a story.*

Ways of sharing story

Stories can be shared in multiple forms: written, audio and written, and live testimony. Written stories allow many interpretations and a greater degree of empathy, giving the time and space for the reader to draw from their own experiences and reflect on their practice. In the case of auditory relay — audio recorded first-person stories played back for workshop participants — stories leverage human sensitivity to changes in loudness, pitch, position, etc. The live testimony of a patient or caregiver telling a story calls upon human emotions and visual cues to read expressions and body language of the storyteller. This method, while successful in certain contexts, is challenging to implement and is not effective if a group wants to have an open discussion about the story that was shared because the storyteller is present.

Forms of Stories:

1. Written Story: Distribute story to individuals, pairs, or small groups, and ask them to read silently.

2. Audio + Written Story: Distribute story and audio device (or web link to audio and ask participants to use their phones) to individuals, pairs, or small groups, and ask them to listen and read along silently.

3. Live Testimony: Arrange for a stakeholder (patient, caregiver, nurse, etc.) to tell their story to the group.

How to Facilitate an Engagement

Facilitating an engagement requires pre-planning of activities around an engagement type and preparation of materials and hosting space. Activities should be planned with the participants in mind, with careful consideration given to the buy-in and familiarity of the group, mutual goals, and concerning their availability.

Steps to Preparing for an Engagement

1. Set an agenda: Assemble a series of activities corresponding to components of chosen workshop type.

   Tip: Consider topics of mutual interest to participants. What are the issues they would like to address?

   Trick: Find someone affiliated with the group who is willing to provide input during the planning of the engagement.

2. Select Activities based on Buy-in, Group Size, Facilitation Capacity

   Tip: Consider whether the group is enthusiastically anticipating the engagement, or perhaps a bit skeptical and hard to win over.

   Trick: Be sure to outline clear objectives or plan for mutually beneficial immediate outcomes if the group feels tentative towards the story-based co-design approach.

3. Plan the logistics: Pre-groundwork, During-materials, Post-documentation

   Tip: Be sure to prepare materials far enough ahead of time to do a "dry-run" with a colleague or friend who is willing to provide honest feedback.

   Trick: Prepare alternate activities in case things don't go to plan.

4. Conduct the engagement

   Tip: Arrive early to ensure the room is prepared, and needed materials are available.

   Trick: Keep a timer or clock within eyesight to make sure the activities run according to the allotted time.

5. Measure outcomes: Build familiarity, Champions and partnerships, Empathy and awareness, Agency, Discovery of opportunities, Finding stories, Soft skills.

How the toolkit achieves OPE's objectives

The toolkit addresses four of OPE's objectives in shifting from a reactive mode of working, to a strategic and operational approach to growing the adoption of PFCC at Michigan Medicine.

1. Equipping teams with tools for learning and reflecting on patient and caregiver experience.

The toolkit framework provides OPE staff with a set of strategies for building proven story-based workshop engagements spanning and complementing their existing partnerships and building new partnerships with patient and caregiver groups, and clinical staff.

2. Facilitates the externalization of tacit knowledge so that teams can engage in discourse, dialogue, and sensemaking.

Reflection and ideation activities provide opportunities for participants to react to scenarios embedded in story. In identifying challenges, opportunities, and alternatives to the scenario presented, participants express their tacit understanding of the situation in articulating problems or potential resolutions, making it explicit and available to the group in the process.

3. Enables the framing and re-framing of problems from multiple perspectives.

The story-based engagement framework is designed to ground a broad range of participants in the same scenario and use activities for unpacking embedded challenges and opportunities, to uncover and identify a diversity of perspectives on an issue.

4. Provides a framework for visualizing problems and interventions.

Every workshop typology contains an element of making — story writing, ideation, or mapping — all of which serve to capture participant reflections and reactions to story, but also provide a visual, accessible record of knowledge and insights created and shared as a result of the engagement.

DISCUSSION
AND LIMITATIONS

This chapter describes the design contributions of our work in the areas of an (1) integrative design process, (2) the creation of a design method based in the use of provocative stories, and (3) the use of a toolkit to assist OPE in the building of strategic and operational partnerships. The chapter ends by describing implications and biases within the thesis.

Our Integrative Design Process

Our integrative design process was negotiated multi-fold — amongst ourselves, our partners, stakeholders, and constituents — it was inter-subjective, context-bound, and a result of our construction. It brought together diverse individuals and groups, integrating our and their knowledge, practice, and expertise into a design process that was built to address our wicked problem context uniquely. This process was the merging of our design process and the OPE's process. The logic used to develop it was abductive and involved "designerly ways of knowing." The way it was practiced also facilitated better communication and collaboration amongst our team, and with our partners and stakeholders within the hospital. This approach differs from other design approaches in that it locates itself within a specific context — Michigan Medicine — while addressing a specific situation — patient experience — during a certain time in the OPE's history. Other design approaches, such as design thinking, are not developed for a specific context, or to address specific stakeholder needs. Design thinking processes and methods claim to be accessible to all; their universality strips away the nuances of the designer's embodied experiential knowledge, and their easy-to-use form provides few opportunities to leverage the tacit knowledge of the stakeholders who use them. Design thinking processes suppose linear causal relationships, where insights are generated through the use of specific design thinking tools. However, this structure doesn't explicitly leave room for stakeholders to appropriate their methods for use within their specific context. Interpretations of design thinking approaches become literal, especially within organizations that don't have a history of practicing design. Individual imagination doesn't get utilized in the literal interpretation of design thinking. Our integrative design process locates itself within the 21st-century paradigm of design where wicked problems are addressed through designing with and for partners, stakeholders, and constituents. Our integrative process leaves space for interpretation, appropriation, and modification — it is the explication of our approach

taken within this collaborative thesis. It proves its use within the con-
text, situation, and temporal spaces within which it locates itself.

Story as a Provotype, a Design Method

Working to address the wicked problem of quality of care is a messy
process. Within the field, there is a lack of consensus on how to mea-
sure patient experience at a system-wide scale. At Michigan Medicine
Health System, interpretations of what quality means can vary widely
in scope and definition. This leads to a gap in the understanding and
expectation of how to deliver quality of care. Further, the remnants of
the old paradigm — where quality of care is customer-centered care —
is still lodged deep within the system. These tensions and misaligned
perceptions were discovered during our ethnographic research in the
hospital. They materialized tacitly in the language, actions, and tasks
we observed the clinical staff complete. Rather than brushing these
tensions aside, or minimizing their importance, we decided to embrace
them and use them in the form of story as a provotype, a method to
provoke reflection, discussion, and prompt collaborative making.

Stories are powerful tools that can lead to change at multiple scales,
from the individual to the organizational. At the individual scale, a story
can transform a person's perception and change their behavior. It can
disrupt their schematic understanding of a situation and propel them
into a mode of reflection that questions their assumptions and creates
empathy and connection to the person telling the story. The amount
of knowledge that a story can activate in the mind of the listener is far
greater than the relatively small amount of information that is explic-
itly coded into the story. The story as a provotype leverages principles
of Gestalt psychology. The listener or reader of the story organizes the
whole picture of an individual's experience through the excerpts of their
first-person accounts designed in the story provotype. Within a system
that prioritizes the completion of tasks and the measurement of quan-

titative data, stories provoke organizational schema disruption. They challenge the notion that all aspects of experience can be quantified, and that quality of care can be improved using clinical interventions. We've curated and crafted stories of patient or caregiver experience to use in our co-design workshops as a method to provoke nursing staff to more deeply reflect on their assumptions, actions, and practices.

A Toolkit Framework

Contemporary design toolkits attempt to equip organizations with a means for dealing with problems using an array of human-centered design and research methods. They help teams work through questions, such as: What problem am I trying to solve? How should I solve it? What do I need to do to solve the problem? What might the outcome look like? While these toolkits provide a compelling process for idea development, they fail to recognize that without due consideration of the context in the design of the toolkit and its situational use, like systemic complexity and power dynamics, even the best interventions can have limited impact. These tools, though instructive and inspiring, do not account for the context or sensibility required to deal with the complex and often frustrating circumstances where their audience seek to apply these tools. In making these tools accessible to a broad audience, they end up becoming overly generic. They fail to communicate the nuance required to address wicked problems or provide the necessary guidance needed to deal with the inevitable unpredictability of a complex problem space. They create a false illusion that usage will lead to mastery of designerly ways of knowing, thinking and acting. In the design of the Story-based Co-Design toolkits, neither we nor our partners are under such an illusion. OPE's vision is to strategically support this transformation by building partnerships that are centered on patient and caregiver stories. OPE has organically developed an approach to building partnerships at different levels of the health system, but hope to spread their reach, and are seeking tools and strategies to help scale

these efforts. They believe that for this transformation to be sustain-
able, they need to operationalize their approach; they need to act as a
mechanism for the identification, creation, and adoption of operational
patient and family-centered best practices. The Story-based Co-de-
sign Toolkit is a way of supporting this strategic and operational need.
The toolkit offers a way of codifying their approach and providing them
with design tools that provoke reflection, make individual and orga-
nizational tacit knowledge explicit, and facilitate action. This toolkit
challenges the traditional forms of "empathizing with the user" and
introduces the role of stories as evidence. While empathy is important,
it's not the whole story. Empathy is about far more than needs; it's
about developing an understanding of the complex set of interrelated
problems and collecting stories as evidence. Also, the Story-based Co-
Design toolkit is structured as a framework for engaging and embed-
ding co-design practices in an organization. It does not ask partners to
follow a set of steps but provides the support needed for individuals to
co-construct and transfer knowledge as relevant to their context.

## Towards an integrative state in a world of wicked problems

The indeterminacy of wicked problems requires that organizations
engaging with them can react quickly and at scale. The fluidity of
wicked problems requires reflexivity from those engaging with it, and
the complexity of the problem often requires access to tacit knowl-
edge and distributed cognition. The scale, flexibility, and breadth of
knowledge needed to engage with wicked problems on a recurring
basis require not only an integrative approach but an embodiment of
integrative modes of interaction, with and for constituents, stakehold-
ers, and partners. While design thinking can help an organization arrive
at interventions on a case-by-case basis, an integrative approach is a
path towards changing the ways an organization operates. Hospitals
exist because — no matter how hard they try — there are always sick
people in need of care. The Office of Patient Experience exists because

— no matter how much they try — there will always be new experiences in the hospital to track, monitor, and improve. Similarly, applications of design ought to match the dynamism and fluidity of the wicked problems they seek to resolve. An integrative approach, therefore, ought to *live* within an organization because — no matter how hard we try — wicked problems are never solved, never fully determined.

Limitations & Bias

We describe some of the limitations of this thesis. Firstly, the patients, family caregivers, PFAC advisors and clinical staff we had access to are not an exhaustive representation of the groups of people to whom the results may be generalized or transferred. The patients and family caregivers we spoke with were not from varied economic or diverse ethnic backgrounds. The format of hour-long interviews and workshops privileges certain individuals who have the time and capacity to take part in research with no monetary reward. The majority of clinical staff we had access to were existing OPE partners and hence the reception to design concepts may have been biased.

Secondly, the results of this thesis are suggestive and have not been rigorously tested or evaluated in a positivist sense. We evaluated the insights and design outcomes in the form of workshops and surveys. We recognize that the in-person survey results could have been biased because of the lack of training we provided to the person conducting the survey. While we had complete engagement during workshops, the surveys performed poorly. The response rate of our surveys was 47% (HCAHPS have a response rate of 44% [Goldstein et al. 2010]). We also recognize that our insights rest on an experimental ontology and epistemology in which the world is understood as co-constituted relationally, rather than a positivist approach. While this serves the purposes of a Master's thesis such as this one, this analysis may not be fruitful for other research aims.
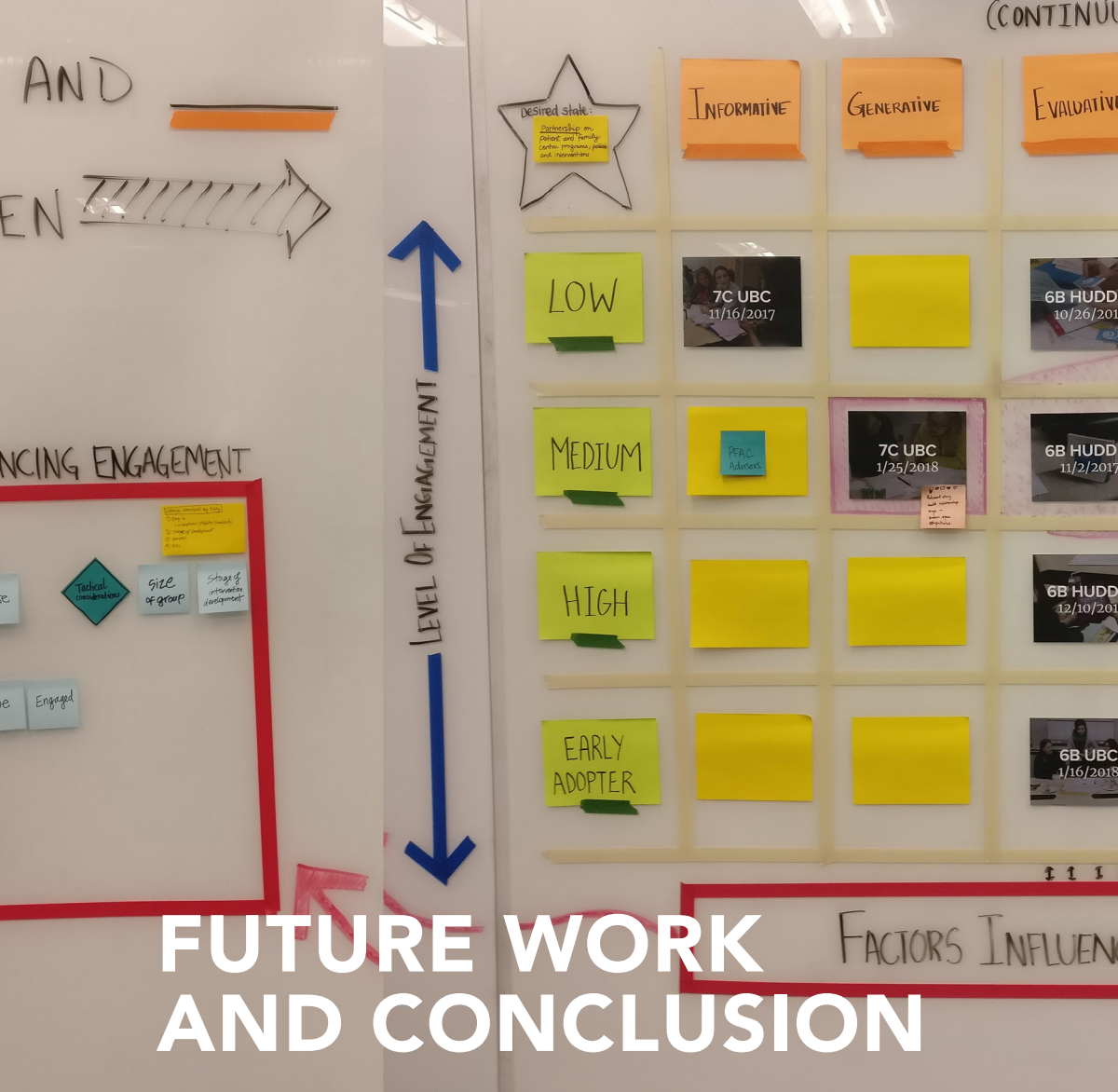
FUTURE WORK
AND CONCLUSION

This chapter describes the future work related to the Story-Based Co-Design Toolkit. We then share the conclusion of this Master's thesis situating our work in the field of co-design, design research, and health-care quality improvement.

Future and Work

At the time of writing this thesis, our work with OPE is ongoing. We have done the work of codifying our and OPE's knowledge within a toolkit, and have transferred this knowledge in an actionable form. We are now working with OPE to co-design the toolkit into a physical form so that it can be implemented at scale within the Michigan Medicine Health System. We have scheduled multiple co-design sessions in May

2018, with OPE leadership and project managers to realize a form for the toolkit (Figure 38), train staff on using this toolkit, and evaluate the transferability of the framework.

The Story-based Co-Design toolkit provides a framework that brings design tools like ethnographic research, provotyping, co-design work-shops, and evaluation to amplify OPE's approach of learning, doing, and teaching to build partnerships around patient and family-centered care values. This alignment caused a shift in the mindset of the clinical staff we engaged with — they shifted from being passive receptors to active engagers in the co-design process.

One of the immediate applications of the toolkit includes use with-in the onboarding of newly inducted clinical staff into the Michigan Medicine Health System. Traditionally, new staff are made to watch instructional videos and attend seminars which inform them of the best practices around PFCC. OPE believes they can instead influence behaviors of new staff at a deeper level by engaging them using the toolkit, specifically using a "Teaching Co-design Engagement." The Administrative Director of the OPE remarks on how this toolkit will help shape the health system's approach to onboarding.

> "PFCC has always been a presenter at these, where we talk about patients and families and the way in which we go about our work…How do we ground folks with a real patient story? How do we have them thinking about the patient experience before day one of the job? Your toolkit could be used in this setting, to create PFCC champions, on day one!"
> — Molly White, Administrative Director of OPE

This thesis does not theorize the creation of story. Instead we offer guidance in selecting stories that are compatible for use with our framework. Explorations into the effectiveness of various forms of stories can also be evaluated. The work presented in this Master's thesis represents the starting point of the authors' future work.

Figure 38. Stories for Care, an OPE Toolkit

SD, PD, and PR are deeply interested in evaluating the use of stories as a method for provocation, and the application of the toolkit for building partnerships beyond healthcare quality improvement. Potential areas of exploration include education, policy impact, and large service-based corporate organizations.

Conclusion

Health systems across the United States are in the process of making the shift from the old paradigm focused on patient satisfaction to a new model which aims to improve patient experience by promoting partnerships amongst patients, family caregivers, and clinical staff. But this shift is slow due to existing informal hierarchies and deeply rooted culture variances between different care units. This makes it challenging for implementation of system-wide quality improvement initiatives leading to inconsistent patient experience. In response to this, OPE at Michigan Medicine has successfully built strategic and operational partnerships centered on patient and caregiver stories. OPE has focused on building partnerships by engaging PFCC champions at a unit-level before they can begin to take a more system-wide approach.

As the organization is growing in scale and reach, they are seeking the tools that can help them scale their efforts. This thesis investigates the broader question of, "How might we support the Office of Patient Experience (OPE) at Michigan Medicine in building strategic and operational partnerships within the Michigan Medicine Health System around the values of patient and family-centered care?" These partnerships are aimed at exchanging knowledge to discover issues (Learn), collaboratively solve problems (Do), and build PFCC skills (Teach). These aims necessitate collaboration amongst multiple stakeholders, across various disciplines—making knowledge explicit and facilitating its flow throughout care teams within the health system. In our partnership with OPE, we have leveraged patient and caregiver stories not just as

a way of building empathy but also as a way of sharing knowledge and provoking reflection and sensemaking. We then used structured story-based co-design workshops to transform this reflection into making meaningful change happen. These stories and co-design work-shops form the basis of the Story-based Co-Design Toolkit. This toolkit brings together design tools like ethnographic research, provotyping, co-design workshops, and evaluation to amplify OPE's approach of learning, doing, and teaching to build partnerships around patient and family-centered care values.

Implicit in our design outcomes is our integrative design process. Through an embodied experience of reflection on each of our individ-ual disciplinary knowledge and practices, we built an approach that: (1) sought to facilitate communication and collaboration — integrating and making explicit knowledge, perspectives, and expertise, through the design of prototypes and a toolkit, and (2) empowered our part-ners, stakeholders, and constituents with design methods and tools to construct better futures for themselves. This approach breaks professional silos and asks designers to be aware and responsive to an ecosystem of distributed cognition among multiple stakeholders and interconnected systems. It starts with deep inquiry, and research, and moves from designing to knowing — starting from a problemat-ic situation, and then moving — by productively combining doing and thinking — to a resolution. This movement towards resolution, however, happens not individually but collectively as we bring people together to create change in the desired direction by collaboratively Learning, Doing, and Teaching.

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Appendix I

Patient and caregiver interview protocol

Demographics
- Age?
- Occupation?
- Experience with healthcare? Special training? Was this the first time you used the hospital?
- Relationship to the patient
- Describe the patient (age, traits, name, etc.)
- What type of care was the patient receiving: the basics of your loved one's hospital stay or health system experience
    - How long in the hospital?
    - How frequently are you there?
    - When was the care? Is it still in progress?
    - How complex was the treatment?

Main Questions

Emotional Map:
Exercise with people, explain what was happening

Effects:
How did providing care affect you? Your job? Your obligations? Daily routine? How did the care affect your finances? Did you rely on outside sources of support? Issues specific to the treatment/illness that occurred?

Internal Resources:
How and where do you seek help when you need it? Who do you go to? What was the process like when you tried to seek help for logistics/random items around the hospital?

External Resources:
Did you look at resources outside of the hospital? FMLA?

Information Flow:
How did you keep track of everything you were told?

Effort:
How many hours a day do you spend giving care?

Points of Contact:
What frustrations have you faced in different context: with a loved one, a doctor, a nurse?

Ideal/Desires:
What does peace of mind look like for you? What are moments of relief for you? When do you feel most calm? Are them moments when you feel like you get peace of mind?

Easy Fix
What is the one thing you always have an issue is, but is a very easy fix, but nobody is doing everything about it?

Expectations:
Did you have any expectations that the hospitals didn't live up to? Unmet expectations?

General Experience:
Tell me about a time when you had a terrible experience? Good experience? Experience before, during and after the visit(s)

Your experience includes what happened during the visit(s), who you interacted with, resources/objects/information you used, and how you felt. Bottom-line, they're looking to hear your stories about your time with UMHS.

Appendix II

Clinical staff interview protocol

Demographics
- Age?
- Occupation?
- Work experience with healthcare
    - Type of training
    - How long have you been doing this
- What kind of care do you provide?
- Workload: How many patients do you see in a single shift? How many hours a day do you spend giving care?

Main Questions
1. What is your relationship with the doctor?
2. What is your relationship with the patient?
3. What is your relationship with the caregiver?
4. Emotional Map: Exercise with nurse to explain how they feel during the caregiving process
5. What are your experiences with caregivers? How do you interact with families during and after visits?
6. What are the policies/training around caregiver/family interaction?
7. Tell me about a time when you had a terrible experience with a caregiver?
8. Tell me about a time when you had a good experience with a caregiver?
9. Have you been a caregiver, and what was that experience like from the other side?

10. What kinds of resources does your organization provide to caregivers?
    a. While they're waiting
    b. Long-term patients
11. What would you do if a caregiver asks about something you can't answer?
    a. What are your greatest frustrations or limitations in dealing with caregivers?
12. How do you help the caregiver keep track of the care-regime to be followed by them during/after transition
13. (Nicole) How is caregiving different for in-home versus clinic care?
14. Differences between hospitals you've worked at?
15. What is the one thing you always have an issue is, but is a very easy fix, but nobody is doing everything about it?

Appendix III

Hospital staff interview protocol

Demographics

- Age?
- Occupation?
- Work experience with healthcare
- What kind duties do you perform?
- Workload: How many hours do you work at a time? Is your schedule consistent?

Main Questions

1. How often do you interact with patients or their caregiver(s)? Under what circumstances?
2. What types of interactions do you have with patients and their caregiver(s)? How long are those conversations, and what are they about?
3. What is the most memorable interaction you've had with a patient or caregiver(s)? What made it so memorable?
4. Are there any policies that prescribe the ways or circumstances in which you interact with patients or caregiver(s)?
5. Has anyone in the hospital ever "opened up" to you while you were on duty? What did they talk about, and what was that like for you?
6. How much engagement do you have with patients and caregivers? What about?
7. What is your interaction with doctors, nurses and other hospital professionals?
8. Which departments have needed your services the most? Why do you think that is?

9. What is the most frequent complaint you hear from caregivers and patients? How do you think it should be addressed?
10. Where do patients and caregivers seem to congregate and why do you think they gather in those spaces? What are your favorite places in the hospital, why?
11. Anything we missed?

Appendix IV

Consent e-mail exchanges

Prema Dudani <psdudani@umich.edu>   3/13/17

to

Hi!

I was reaching out to you about the interview we recorded for our own records.

As a part of our synthesis and analysis process, we are conducting a workshop around the intersection of healthcare and cognitive technology, and would love to use an excerpt from our conversation with you to prompt discussion around some of the issues you discussed. These excerpts of course would be anonymized and any reference to a particular time, place, or person would be removed. Also, if you'd like, we can send you the excerpts we are interested in using.

There are no obligations of pressure from us here, but we would love to share the points you raised and stories you shared with the larger group in our workshop to provoke discussion around ways to improve patient experience. Your insights were extremely helpful to us!

Please let me know if this is something you may be interested in.

Thanks,
Prema

---

to me   3/13/17

Hi Prema,
I will not be able to make it, unfortunately. I have a motion and also have some catch up to do as my office was closed Wed-Fri due to the power outage last week. I hope if there are other opportunities that you keep me in mind. Thank you for the invite.

---

to me   3/13/17

Hi Prema,
Please feel free to use any excerpt from our conversation. I would be interested to know what excerpts you plan on using. But feel free to use any of it. Thank you for listening to and acting on behalf of the patient-family voice and experience. It is very encouraging to know this type of work is being done.

Appendix V

Pilot Evaluation Questions

Resource Book Pilot Evaluation Questions
1. How long have you been at the hospital? On this unit?
2. What was your first impression when you saw the Resource Book in the admission packet?
3. What do you think the book is, what it might be used for?
4. How have you, or your family used it?
5. Is there anything unclear or confusing in the book?
6. Is there anything you wish you could include in the book?
7. Have you asked nurses about it? Theri response?
8. What will you do with this when you leave?

Appendix VI

Resource Book Pilot Survey

WHAT DO YOU THINK OF THE resource BOOK?

need something?
A guide to resources for Patients and Families

Positive

Negative

Appendix VII

Evaluative Digital & In-person Surveys of Story-based Co-design Workshop Experience

Feedback on UBC Workshop with Master of Integrative Design Students

Our goal is to work collaboratively with 7C to uncover some of the barriers that nurses face in being able to provide patient centric care. In our last engagement at the UBC on Nov 16th, we used a family caregiver story to discuss issues that nurses face during patient and caregiver education.

We heard from you that this story - though engaging - was not as relevant as it could've been. We are reaching out to you to better understand how this engagement was or was not relevant or valuable.

This form is automatically collecting email addresses for University of Michigan users. Change settings

We began the workshop with an audio recording of a caregiver describing an experience in the hospital. Did you find this structure of the workshop useful?

○ Very Useful

○ Somewhat Useful

○ Not Useful

What did you like best or find most useful about the workshop topic or structure?

Long answer text

What are your suggestions on improving this workshop in the future?

	1	2	3	4	5	
Not Useful	○	○	○	○	○	Useful

Please suggest topic areas that you would like the unit to work through in the future.

Long answer text

Do you have any other comments?

Long answer text

Feedback on patient and caregiver engagement workshop

Please use this form to share some quick feedback and select a time that works best for a phone conversation.

Email address *

Valid email address

This form is collecting email addresses.   Change settings

Please select a day for a phone conversation and we will reach out to you personally to set up a call. *

○ Thursday morning 2/22

○ Thursday afteroon 2/22

○ Thursday evening 2/22

○ Friday morning 2/23

○ Friday afternoon 2/23

○ Friday evening 2/23

○ Other...

Tell us about the workshop experience. What did you like the most? What would you change about it?

Long answer text

Tell us how you felt about the journey map activity. Was it useful to see your experience in that way?

Long answer text

Tell us about the story cards. Do you think you could have shared more? What value do you see in sharing your stories with the health system?

Long answer text

Name : _____ Email : _____

1. Would you like to pilot the resource book on your unit? Please tell us why.

2. Please rate the usefulness of this workshop.

	1	2	3	4	5	
Not Useful	○	○	○	○	○	Useful

3. What did you like best or find most useful about the workshop?

4. What are your suggestions on improving this workshop?

5. Do you have any other comments?