

**DESIGNING SHARED DECISION-MAKING: A SET OF TOOLS TO TAILOR
POST-SURGERY PAIN MANAGEMENT PLANS FOR PATIENTS**

By: Prachi Bhagane

M.Des. Strategic Design Management, National Institute of Design, Ahmedabad, India, January 2017

B.E. Mechanical Engineering, Walchand College of Engineering, Sangli, India, May 2010

Thesis Submitted In Partial Fulfillment of the Requirements of the Degree of Master of Design in Integrative Design

Penny W. Stamps School of Art and Design
University of Michigan
Ann Arbor, Michigan

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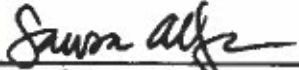
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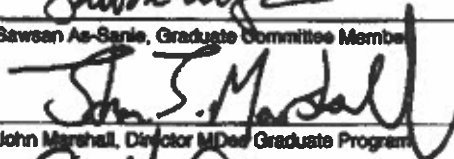
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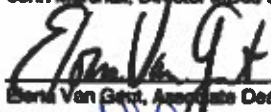
Stephanie Therp, Graduate Committee Member



Sawwan As-Sanie, Graduate Committee Member



John Marshall, Director MDes Graduate Program



Bernd Van Gent, Associate Dean for Academic Programs



Gunalan Nadarajan, Dean, Stamps School of Art and Design

Date Degree Conferred: August, 2019



UNIVERSITY OF MICHIGAN

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By: Bruna de Souza Oewel

B.A. Textile and Fashion, University of Sao Paulo, Sao Paulo, Brazil, June 2011

Thesis Submitted in Partial Fulfillment of the Requirements of the Degree of Master of Design in Integrative Design

Penny W. Stamps School of Art and Design
University of Michigan
Ann Arbor, Michigan

April 24, 2019

Approved by:



Bruce Sharp, Graduate Committee Chair



Omar Sosa Tzuc, Graduate Committee Member



Sawan As-Sanie, Graduate Committee Member



John Marshall, Director MDes Graduate Program



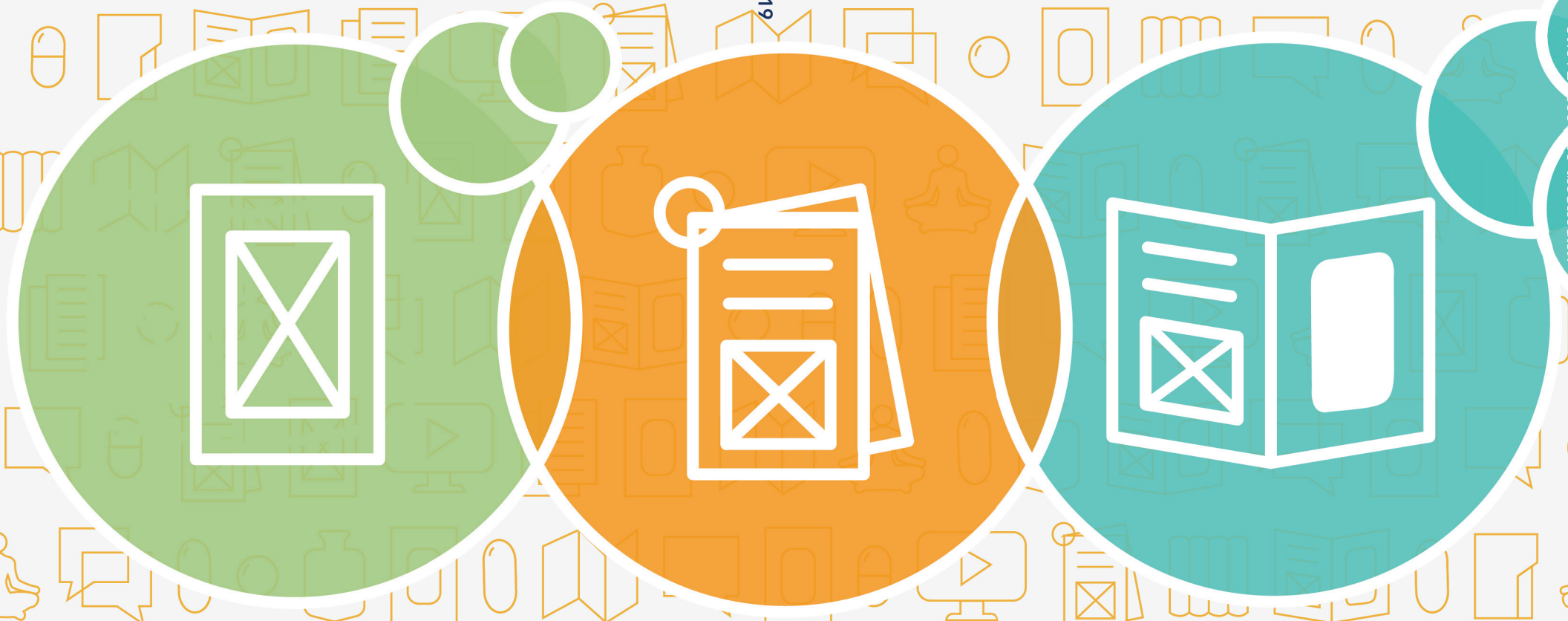
Eloha Van Gent, Associate Dean for Academic Programs



Gonatan Nadarajan, Dean, Stamps School of Art and Design

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APPROPRIATE CARE

DESIGNING SHARED DECISION-MAKING:

A Set of Tools to Tailor Post-Surgery Pain Management Plans for Patients

Prachi Bhagane, Bruna Oewel

Candidates, MDes
University of Michigan
Spring 2019

Bhagane, Oewel MDes '19



UNIVERSITY OF MICHIGAN

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Prelude

This is a collaborative thesis written by Bruna Oewel and Prachi Bhagane. We are part of the third cohort of the MDes in Integrative Design. Our cohort's umbrella topic is "Appropriate care".

Bruna comes from São Paulo, Brazil, and has a background and experience in Fashion and Textiles. Prachi is from Pune, India and has a background and experience in Mechanical Engineering and Strategic Design Management. We brought our diverse educational, professional and cultural experience as a natural influence to this work, which enriched our discussions as we collaborated on this project. With cultural backgrounds and prior experience in our countries, where opioid access is limited, we saw the stark contrast of the problem within different contexts. Hence we were motivated to work within the context of pain management in the US. Our collaboration started as we shared an interest in "Design for Behavior Change," "Service Design" and a passion for the opportunity to make a small but positive contribution within the space of "Appropriate Care."

Keywords

Shared Decision-Making, Pain Management, Decision Aids, Integrative Design, Service Design

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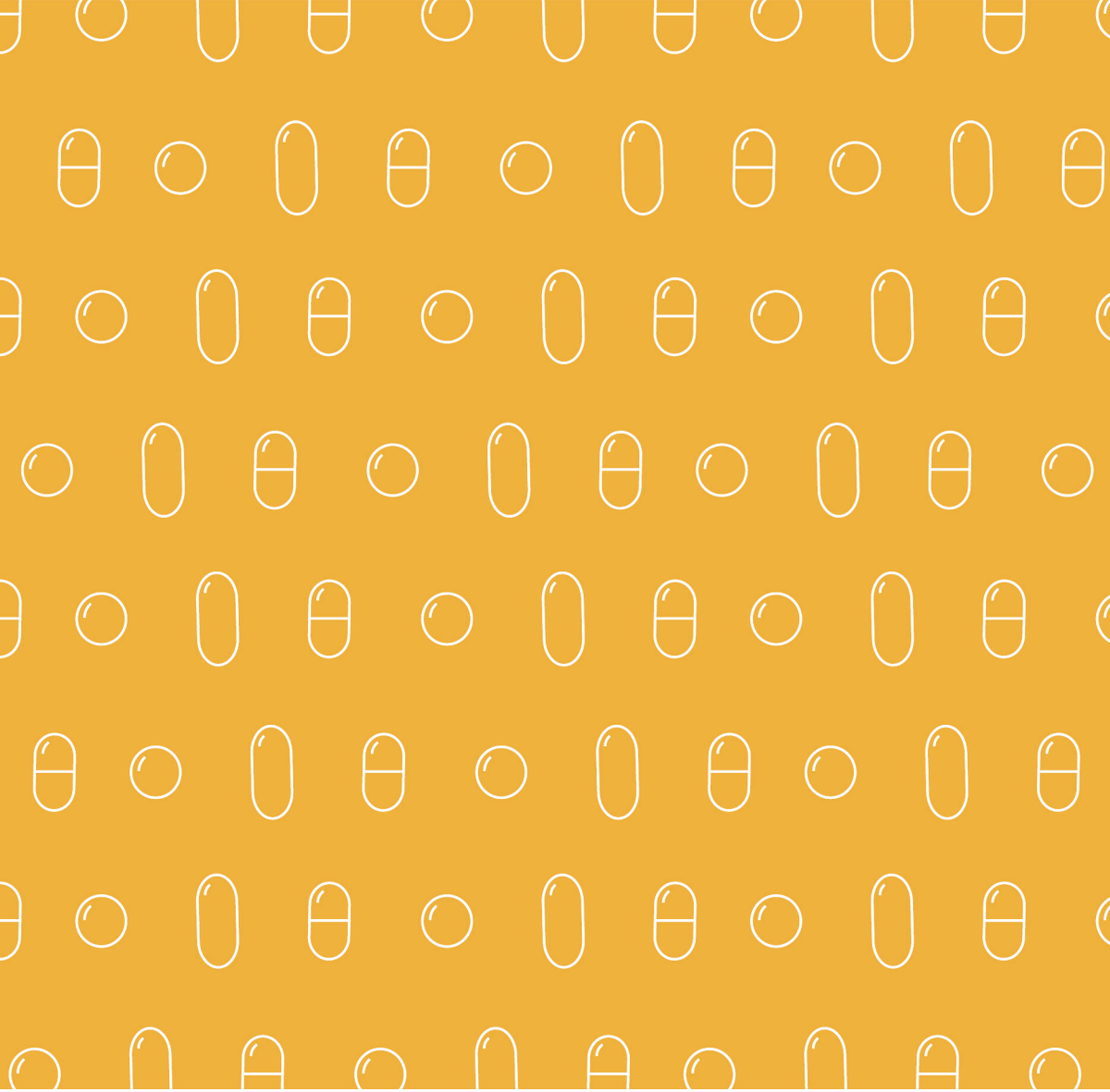
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INTRODUCTION



A. Wicked Problems

“Wicked problems” is a term coined by Rittel and Webber in 1973. Wicked problems are unlike science or economic problems, which have a definitive motive even if the problem has a solution or not. Wicked problems are challenging to define, and one has to thoroughly understand the context and connected nature of the problems before addressing them.

Each wicked problem is unique, which means that, even if the problem seems similar to another one, the same resolution cannot be applied to both. The conditions and context of each problem asks for a unique approach (Rittel and Webber 1973, 141).

Wicked problems are highly complex because understanding and resolving the immediate causal discrepancy can result in another problem (Rittel and Webber 1973, 139). System thinking approach helps seeing at the problem holistically and understand the connected nature of problems. Hence, approaching a wicked problem with a systems thinking lens (Rittel and Webber 1973, 137) and taking smaller steps can be useful.

B. Appropriate Care

Within the umbrella of wicked problems in healthcare, our cohort's umbrella topic was "Appropriate Care." "Appropriate care is a care in which the potential health benefit from a medical service exceeds its health risks as assessed by the physician and the patient" (Brook 2015, 14). Good quality care in healthcare means providing appropriate care in a technically competent manner (Schuster, McGlynn and Brook 1998, 517). This appropriate care is neither too much care nor too little care. Appropriate care can be contextual and can depend upon an individual patient's situation.

Often in the surgical context, plans for managing pain after the surgery are not made according to individual needs. Patients are prescribed with pain pills based on a "one size fits all" approach. Also, patients receive information at times when not in the best condition to understand it, or it might not be the most relevant at that point. Our thesis topic addresses the appropriateness of the care by providing a solution—a system of tools at particular points in the process which helps to tailor the best way each patient should treat their pain after surgery, in other words, their "pain management plan."

C. Project Context

According to the CDC (Centers for Disease Control and Prevention), the US has 5% of the world's population, and it consumes about 80% of the world's prescription opioids. From 1999 to 2016, more than 200,000 people died due to overdoses related to prescription opioids (CDC 2017).

Over-prescription of opioids to be used after surgery is an important factor causing the opioid epidemic (Waljee, Brummett, and Englesbe 2017, 728). The risk factor associated with persistent opioid use post-surgery has recently been studied by Brummett et al. (2017, 2). It was found that the incidence of new persistent opioid use after surgical procedures is 5.9% for major surgeries and 6.5% for minor surgeries, which means there is no relevant difference between them (Brummett et al. 2017, 2).

Our partner Dr. Sawsan As-Sanie, M.D., M.P.H., is an Associate Professor and practitioner specialized in obstetrics and gynecology at Michigan Medicine. Intending to reduce prescription opioids, she has tested a pilot of a shared decision-making tool in the context of hysterectomy surgeries. Her pilot project is a starting point for our thesis project.

Our research suggested that there needs to be a more integrated system of tools to support shared decision-making between patient and provider.

We narrowed down the scope of our project to opioid-naive patients. In our project context, the opioid-naive are people who are not chronic opioid users or have not received opioids daily for the past 30 days (Pino and Covington 2019). In the case of opioid-naive patients, there is an increased risk of chronic opioid use after surgery (Sun et al. 2016, 1292). In the case of patients who chronically use opioids (also known as the opioid tolerant), there might be multiple factors and preventative strategies to follow. However, those are not part of the scope of

this project. Also, we limited our project scope to outpatient surgeries, where patients are discharged on the same day of the surgery. In the case of inpatient surgeries more rigorous pain management options are used which might not be limited to the over-the-counter pain pills and opioids, and that is also out of our project scope.

We started our project in the Winter 2018 semester when we investigated opioid-related education received by patients during their surgical journey in Michigan Medicine. Michigan Medicine is one of the largest hospitals in Michigan. It is University of Michigan's hospital system and premier research and academic medical center. We partnered with the Institute for Healthcare Policy and Innovation (IHPI) and Michigan OPEN (Opioid Prescribing Engagement Network).

As our project context lies within patients' surgical experience, the very first step was to understand the patient journey. With our observations and conversations with providers and experts within Michigan Medicine, we illustrated the patient surgical journey. The patient surgical journey can be divided into three phases – before surgery, in the hospital, and after surgery. A typical surgical journey consists of 6 defined stages, which are as below:

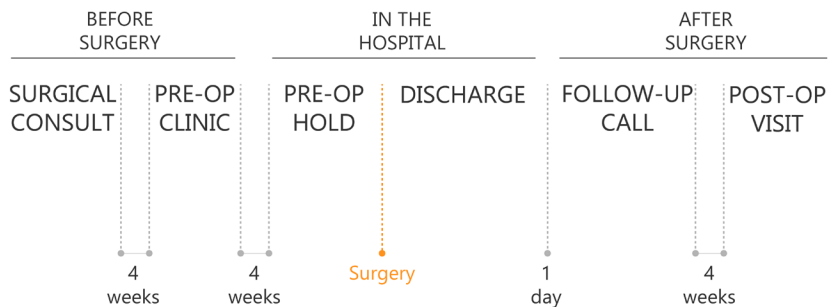


Figure 1. Surgical Journey

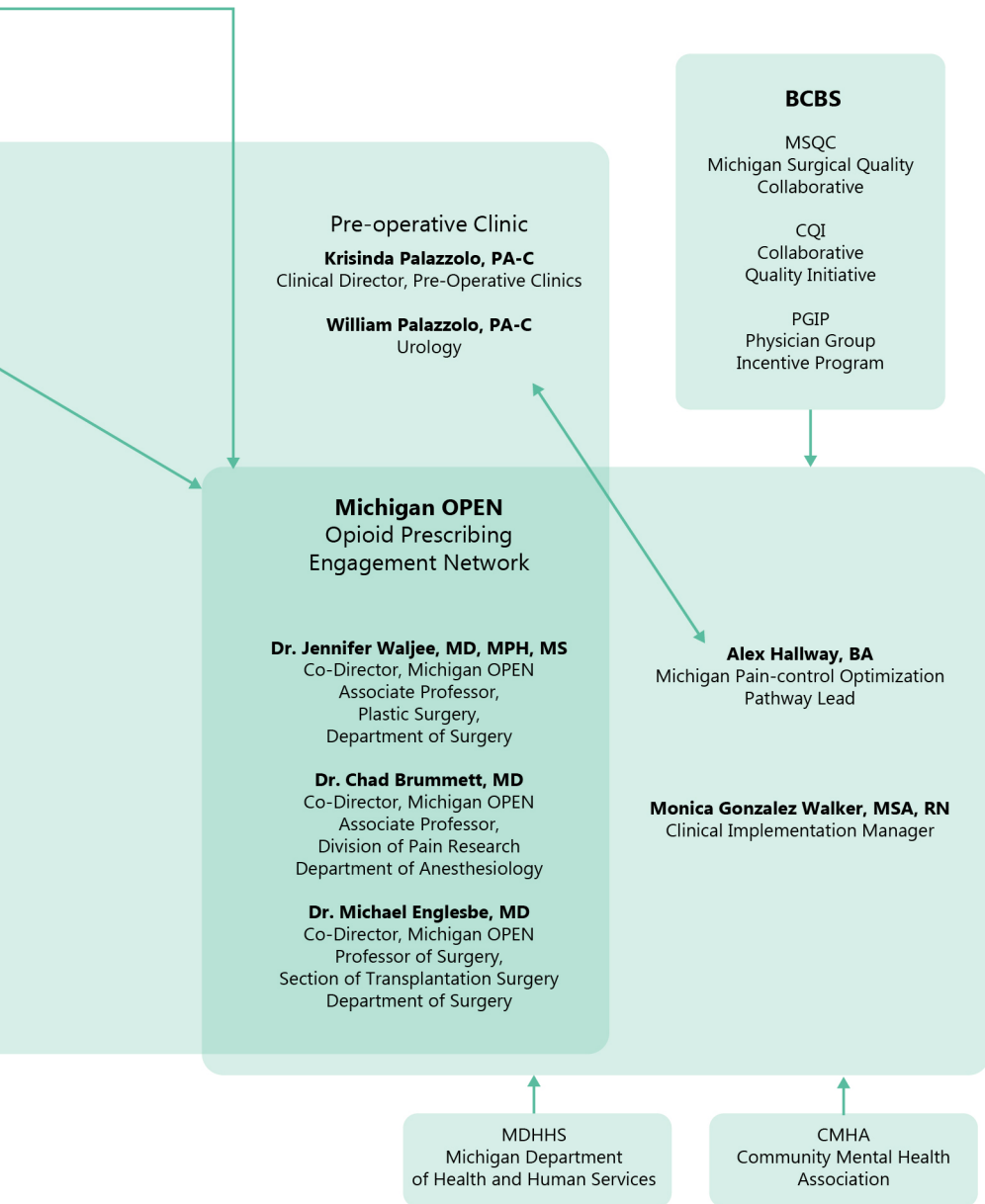
1. Surgical Consult: At the surgical consult, the patient meets the surgeon, and they start discussing the possibility of having surgery.
2. Pre-Op Clinic: The Pre-Op clinic consultation happens after 2–4 weeks from the surgical consult. The patient consults with a physician's assistant. Here, the patient gets more information about surgery and the do's and don'ts before and after surgery.
3. Pre-Op Hold: This is the moment just before the surgery. Patients wear a hospital gown, and different providers come and talk to the patient about the procedure they are having. That is the point in the journey at which pain medications are prescribed. Often, residents or fellows prescribe pain medications. Dr. As-Sanie's pilot project of shared decision-making happens at this point.
4. Discharge: Discharge (in case of outpatient surgeries) happens a few hours after the surgery. A nurse provides an after visit summary, which consists of more information about what to do about the incision, post-surgery care, and pain management at home.
5. Follow-Up call: A nurse calls the patient on the very next day to check if everything is fine.
6. Post-Op Visit: Four weeks after, the patient visits the surgeon for a check-up and follow-up on surgery.

1. Our Partners and Stakeholders

As previously stated, we partnered with Dr. Sawsan As-Sanie, M.D., M.P.H., who is an Associate Professor and practitioner specialized in obstetrics and gynecology at Michigan Medicine. Her areas of practice are minimally-invasive gynecologic surgery and robotic surgery (hysterectomy, myomectomy), endometriosis, chronic pelvic pain, uterine fibroids, and hysterectomy alternatives. Dr. As-Sanie's fellow, Annma-



Figure 2. Ecosystem map



rie Vilkins, D.O., specializes in obstetrics and gynecology.

Dr. As-Sanie provided us with access to her patients and other providers for observations, and interviews. Moreover, Dr. As-Sanie has almost 13 years of experience in treating patients and listening to their stories and concerns. She is well aware of the opioid epidemic and how prescribing excessive opioids could contribute to the current issue. She is focused on patient-centered care in her practice.

Dr. As-Sanie's priorities are improving patient safety by reducing opioid pills prescriptions, educating patients about pain management choices, and improving patient satisfaction, mainly by decreasing post-surgery pain-related anxiety.

Figure 2 presents the many different people and organizations that are working in parallel within the context of pain management, as an ecosystem map. Mapping them gave us an idea about how each of them is related, how they could provide us access to stakeholders and give us feedback at different points in our project. It also helped to understand how our project is located within the bigger context of the University of Michigan and other organizations.

While we worked on the project, we met multiple experts from psychology, Michigan Medicine and Michigan OPEN, which helped us in shaping the project outcomes. Michigan Opioid Prescribing Engagement Network (Michigan OPEN) was founded in October 2016 with the goal of a preventative approach to the opioid epidemic by tailoring postoperative opioid prescription (Michigan OPEN 2017). Michigan OPEN aims to reduce excess acute care opioid prescribing, eliminate new persistent opioid use among postoperative and acute care patients, reduce unintended opioid distribution into local communities that leads to nonmedical use and abuse, and improve disposal practices to minimize the number of unused opioids in the community (Michigan OPEN 2017). Michigan OPEN does so by educating, intervening, creating guidelines, and encouraging and increasing safe disposal opportunities (Michi-

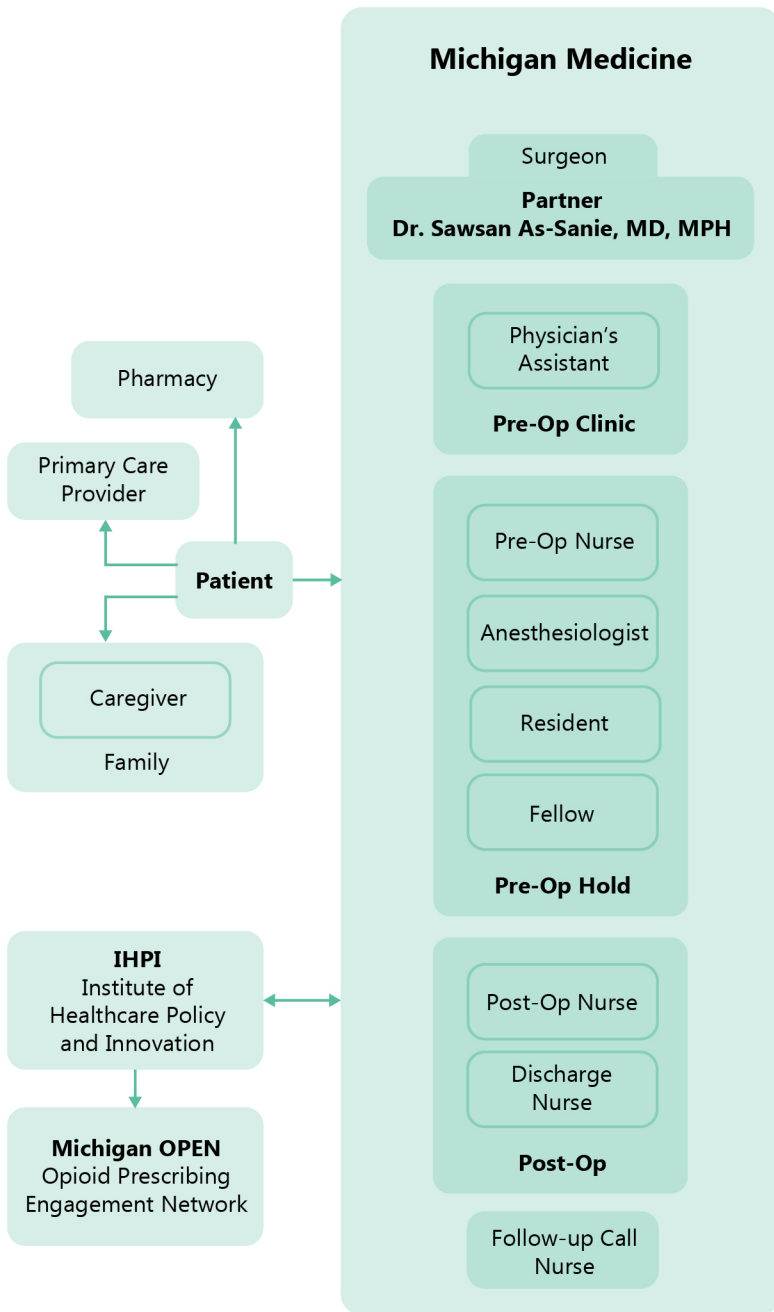


Figure 3. Stakeholder map— a visual or physical representation of the various groups involved with a particular service.

gan OPEN 2017). It supports providers with resources like prescription guidelines and opioid education material for patients.

The stakeholder map helped us in understanding the probable impact of our project on key entities, i.e., stakeholders. Our primary stakeholders consist of individuals and institutions. We identified our main stakeholders as patients who undergo surgery, and providers who interact with patients during their surgical journey.

We see Michigan OPEN as our stakeholder as well. Our intervention could support Michigan OPEN's efforts of tailoring postoperative opioid prescribing and reach the larger patient population. Through understanding our stakeholders' influence and interest in the project context, we could engage them at different times and in different capacities.

D. Problem Statement

When we analyzed the current pain management education patients receive during the surgical journey, we realized that the discussion about pain management happens at certain points in the surgical journey. Often this is rapid and inconsistent.

We found that patients have limited knowledge of pain management choices and their individualized needs (as represented in figure 4). As a consequence, they do not feel confident in making pain management decisions. Moreover, on the providers' side, there is limited understanding regarding patients' needs and values. In summary, there is a gap in patient-provider engagement regarding pain management.

Hence, we framed the problem statement as follows:

How Might We better support interactions between patients and their healthcare provider to tailor pain management decisions to their individual needs?

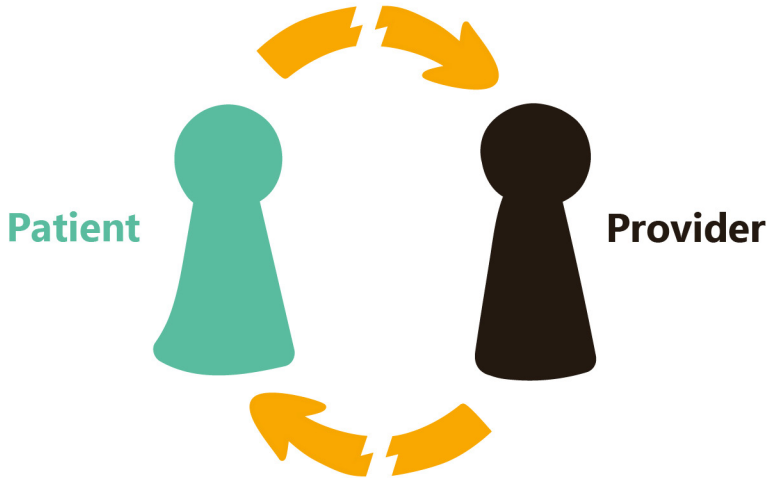


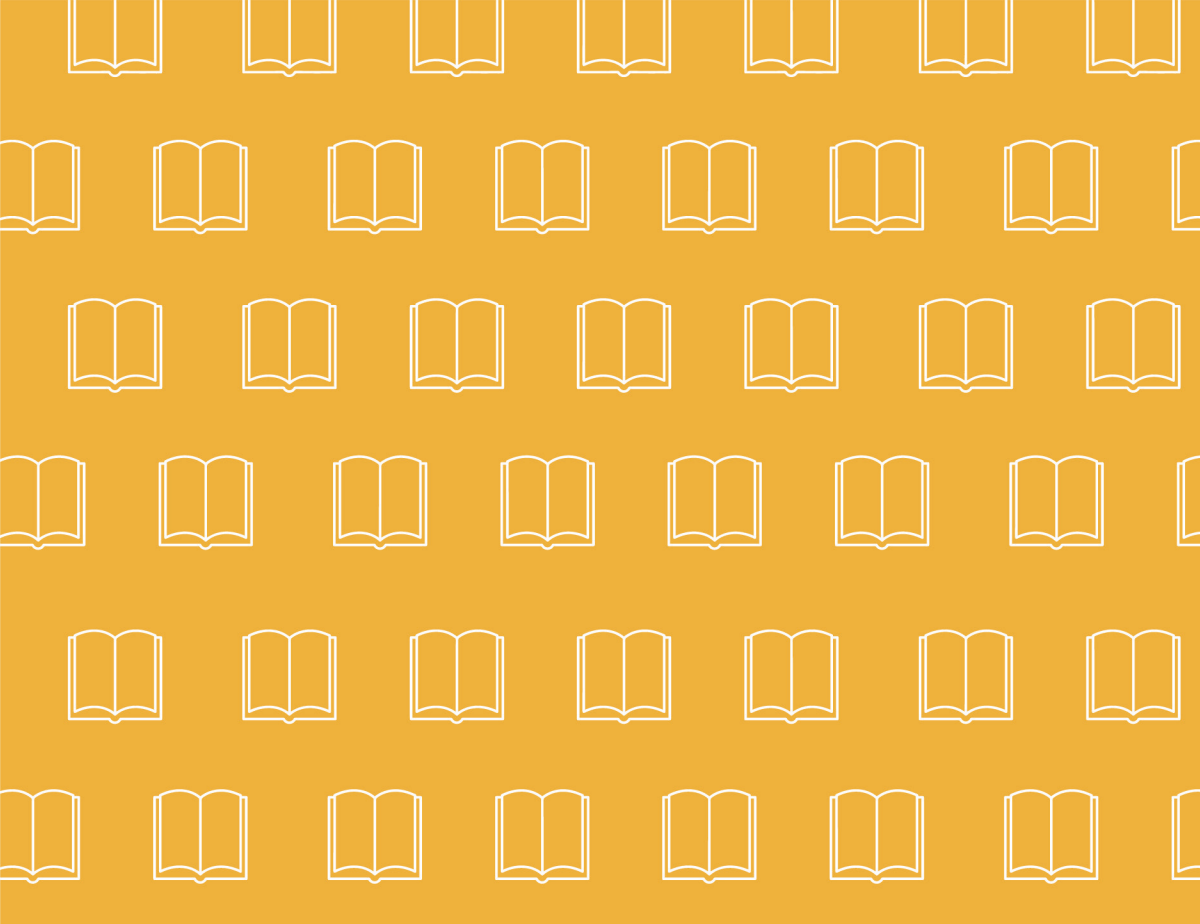
Figure 4. Broken patient-provider engagement

E. Project Aims

Through our research, we found out patients feel overwhelmed by the amount of information they receive, so they are less likely to pay attention to opioid education. Additionally, some patients feel anxious and fearful about not having access to pain medication whenever they need it.

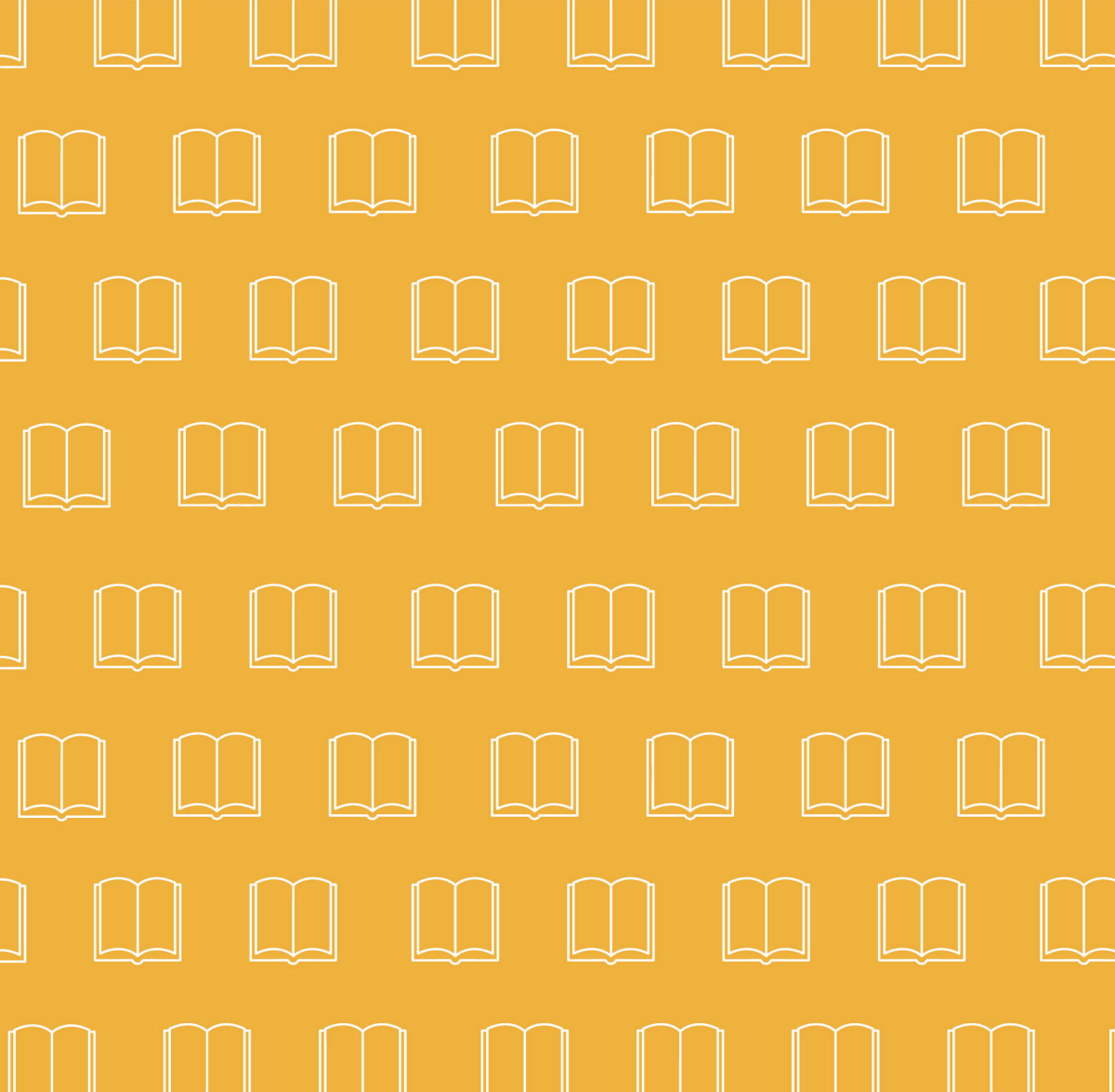
Based on our five observations (40–50 minutes each) in the preoperative holding area, where we observed Dr. As-Sanie’s pilot of shared decision-making (SDM) tool, and interviews with patients, we found that most patients are presented the tool at a time they are very anxious about the surgery. Our project aims are:

- help patients set post-surgery pain expectations ahead of time;
- give the patient time to consider the pain management information and feel confident before making a decision;
- support patients and providers ability to discuss pain management without increasing the length of the interaction.



CONTEXTUAL REVIEW





In our contextual review, we started researching the current opioid epidemic and the role of prescription opioids in it. We reviewed the literature to understand the breadth of the prescription opioids issue and efforts taken towards it at different levels. Figure 5 represents the role and causes of the prescription opioid crisis in the USA. This problem space is complex as there is no single root cause to it and it involves multiple stakeholders. Through our project, we are addressing post-surgery opioid prescriptions. A preventative approach to this issue

is to consider individual pain management needs instead of focusing just on opioids. The highlighted text in figure 5 represents the specific context of the project in the bigger problem space.

Further, in our contextual review, we focus on theories from healthcare (patient-centered care, decision-making, and shared decision-making). We also considered design areas (Service Design, Behavior Design, and Inclusive Design) to find an integrative approach.

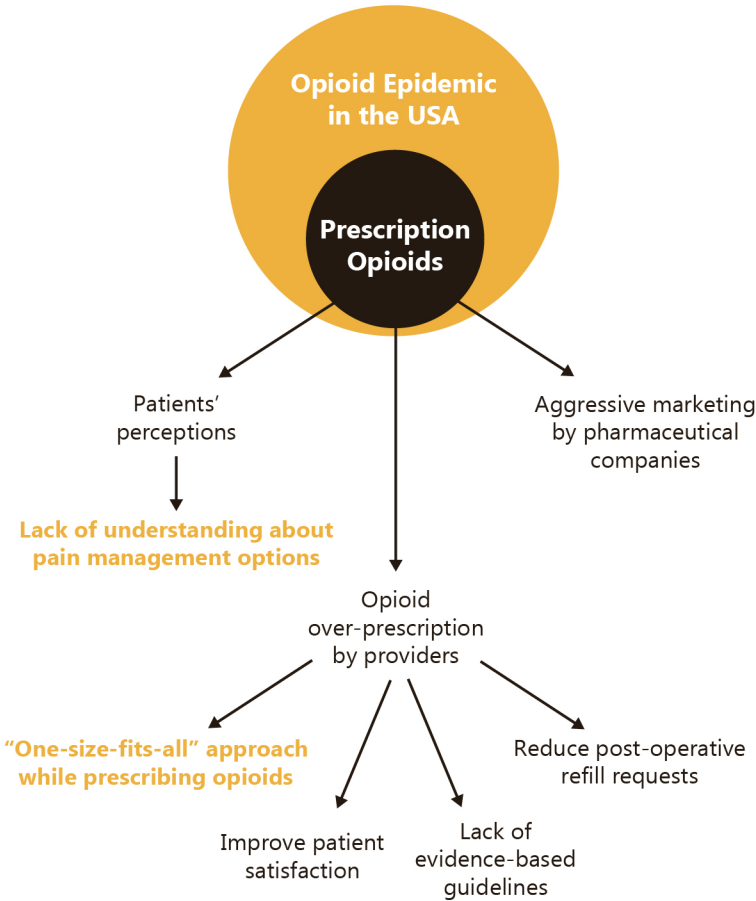


Figure 5. Project context

A. The Opioid Crisis and the Role of Prescription Opioids

1. What are Opioids?

According to the CDC, “opioids are substances that work in the nervous system of the body or in specific receptors in the brain to reduce the intensity of pain.” It includes drugs like hydrocodone, oxycodone, codeine, and morphine.

2. What are Prescription Opioids?

Prescription opioids can be used to treat moderate to high levels of pain. They are often prescribed after surgery to control the pain (CDC 2017). There are many risk factors and side effects associated with prescription opioids. Prolonged use of opioids may lead to opioid addiction. Taking too many opioids, also known as opioid overdose, can stop a person’s breathing—leading to death (CDC 2017). Opioid side effects include constipation, nausea, vomiting, dry mouth, sleepiness, dizziness, confusion, depression, itching, sweating, among others (CDC 2017). Apart from these, the prolonged use of opioids might result in physical dependence, which means that when the medication is stopped, a person might show withdrawal symptoms (CDC 2017). It also increases a person’s medication tolerance, i.e., a person might need to take more medication for the same pain relief (CDC 2017).

The risk factors that make people vulnerable to prescription opioid abuse and overdose are overlapping prescriptions from multiple providers and pharmacies; taking a daily high dosage of pain relievers; having a mental illness; having a history of substance abuse and living in a rural area or having low income (CDC 2017).

3. What is the Prescription Opioids Crisis?

From 1990, there has been an increase in the number of opioids prescribed. As the number of opioids prescribed and also the number of prescriptions increased, the number of deaths related to prescription opioids increased as well. The number of opioids prescribed per person in 2015 was three times higher than in 1999 (CDC 2017). In 2017, deaths involving prescription opioids overdose were five times higher than in 1999 (CDC 2017). From 1999 to 2017, almost 218,000 people died in the United States from overdoses related to prescription opioids (CDC 2017).

In 2017 alone, an average of 46 people died every day due to overdoses related to prescription opioids (Scholl et al. 2019, 1419).

4. When Did It Start?

Opioid use for pain control grew gradually after 1980. Pharmaceutical companies largely contributed to promoting prescription opioids. Purdue Pharma introduced OxyContin in 1995, and the rate of opioid prescribing and use began accelerating rapidly (Kolodny et al. 2015, 562). Purdue Pharma promoted OxyContin by financially supporting the American Pain Society, the American Academy of Pain Medicine, the Federation of State Medical Boards, the Joint Commission, pain patient groups and as a result, these groups advocated for the use of opioids for chronic pain treatment (Kolodny et al. 2015, 562). In 1995, the American Pain Society launched its campaign, “pain as the fifth vital sign” to have standardized pain evaluation and treatment of pain symptoms (Jones et al. 2018, 15). Later, in 2000 The Joint Commission adopted this campaign and Federally mandated patient satisfaction surveys, which asked patients about how well hospital staff helped them with pain (Jones et al. 2018, 15, Kolodny et al. 2015, 562). This made hospital staff rely on opioids to treat a patient’s pain to get good satisfaction ratings (Jones et al. 2018, 16).

5. Initiatives to Manage the Prescription Opioid Crisis

Federal Response

In March 2016, CDC released the Opioid Prescribing Guideline for primary care providers (National Institute on Drug Abuse 2017). This 12-point voluntary recommendation guideline is developed to help primary care doctors provide safer, more effective care for patients with chronic pain (CDC 2017). The CDC Guideline addressed patient-centered clinical practices which include conducting thorough assessments, considering all possible treatments, closely monitoring risks, and safely discontinuing opioids (CDC 2017). However, these guidelines are only for primary care doctors treating chronic pain.

In April 2017, the US Department of Health and Human Services (HHS) developed a five-point strategy to fight the opioid crisis (National Institute on Drug Abuse 2017). These strategies focused on providing support to reduce current addiction, overdose, and prevention measures through research and implementation of better pain management practices.

The Centers for Disease Control and Prevention (CDC), National Institutes of Health (NIH) and Food and Drug Administration (FDA) supported HHS activities by aligning their initiatives with a 5-point strategy to the opioid crisis.

6. Opioid Prescription Post-Surgery

In terms of post-operative care, there are no guidelines for surgeons regarding outpatient opioid prescribing (Waljee et al. 2017, 728). A study shows that consistent with a “one-size fits all” approach, physicians prescribed a fixed number of pills to each patient which led to over-prescribing (Bartels et al. 2016, 5). Reasons for surgeons provid-

ing excess opioids are likely multifactorial and probably relate to lack of evidence-based guidelines on appropriate postoperative opioid prescribing and the desire to improve patient satisfaction and reduce postoperative opioid refill requests (As-Sanie et al. 2017, 1266). Overprescribing has contributed to having excessive unused pills with patients and hence in communities. Approximately 75% of patients stored their leftover pills in unsecured locations which represent a potential source for non-medical opioid use and associated morbidity and mortality in patients and their families (Bartels et al. 2016, 5). Another study shows that prescribing opioids after surgery to opioid-naive patients (who never used opioids more than 30 days) may cause prolonged use. For example, according to the same study, 3.1% of opioid-naive patients continued to be prescribed opioids for more than three months after surgery (Clarke et al. 2014, 3). Though the risk of prolonged use of opioids looks only 3.1%, the number can be substantial considering the number of surgeries happening every day.

7. Safer Post-op Opioid Prescribing

The current opioid prescription challenge needs to be addressed from both the patient and the provider perspectives. A personalized approach to prescribing opioids can be feasible considering key patient factors like measures of centralized pain (As-Sanie et al. 2017, 1267). From a patient's perspective, a multidisciplinary approach is needed which includes providers informing a patient about strategies to manage postoperative pain. That could include opioid alternatives and care for patients who might struggle with opioid dependence (Waljee et al. 2017, 729). Studies suggest that better patient-provider engagement regarding post-surgery pain management can help to take an individualized approach. It would address the challenge of overprescribing and also provide appropriate pain management for patients.

B. Theoretical frameworks

1. Healthcare Context

a. Patient-centered care

The “Patient-centered care” term was coined in 1988 by the Picker Institute to shift the healthcare provider’s focus from the medical problem to the patient and their families. The institute identified eight dimensions for quality of patient-centered care: “respect for the patient’s values, preferences, and expressed needs; coordinated and integrated care; clear, high-quality information and education for the patient and family; physical comfort, including pain management; emotional support and alleviation of fear and anxiety; involvement of family members and friends, as appropriate; continuity, including through care-site transitions; and access to care” (Barry and Edgman-Levitan 2012, 780).

In medical decision-making, promoting the patient as an equal partner is considered as a skill needed by the provider to implement patient-centered communication (Saha and Beach 2011, 386). The concept of mutuality and a “whole person” orientation to patient care are considered as basic elements of patient-centeredness (Saha and Beach 2011, 386). Here, “whole person orientation means physicians attend not only to patients’ biological needs but also to the psychological, social and behavioral dimensions of health and illness” (Saha and Beach 2011, 386).

b. Decision-making in Healthcare

Medical choices include two elements: problem-solving and decision-making (Saleh et al. 2014,11). Problem-solving is identifying the

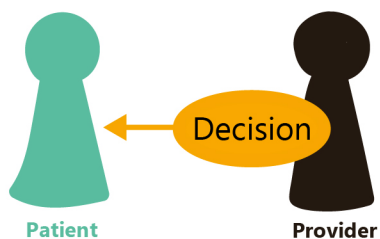
single most correct solution to the problem, which requires medical expertise while decision-making is about making a trade-off between multiple alternatives (Saleh et al. 2014, 11).

For decision-making in healthcare, it is essential to consider patient-provider communication models. Figure 6 shows the models of communication between patient and provider. One of the most common models of communication between physician and patient is paternalistic. In this model, the primary goal is patient health, not their autonomy. In this case, the physician decides the solution to the patient's problem and then information is given to the patient about it. The care provided is best considering the physician's objective medical knowledge, and the patient does not participate in the decision (Emanuel and Emanuel 1992, 2221).

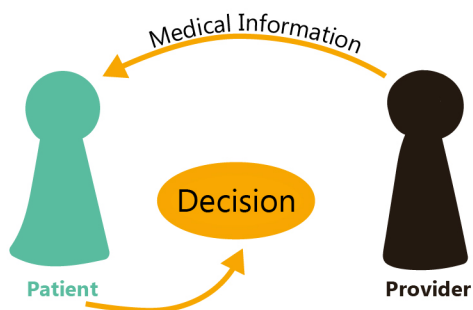
Another model of communication is informative. In this model, the healthcare provider presents the medical information and options to the patient, who knows their values and needs. The patient only lacks the medical information which, by getting it from the provider, would be able to decide about their care. There is no discussion and sharing of those values and needs and how they can relate to the different options (Emanuel and Emanuel 1992, 2221).

"Shared decision-making (SDM) is identified as a collaborative process that allows patients and their providers to make healthcare decisions together by taking into account the best scientific evidence about treatment, screening, illness management options, potential benefits, harms and that consider patients preference" (Saleh et al. 2014, 10). Implementing SDM is a way to reduce physician dominance while giving more freedom for patients. A potential downside of SDM is the fact that many patients are dependent on the physician's knowledge that can provide security and patients themselves do not have enough medical knowledge to participate in a decision about their care. Therefore, they might not want to engage in shared decision-making (Emanuel and Emanuel 1992, 2221).

Paternalistic model of communication



Informative model of communication



Libertarian Paternalistic model of communication

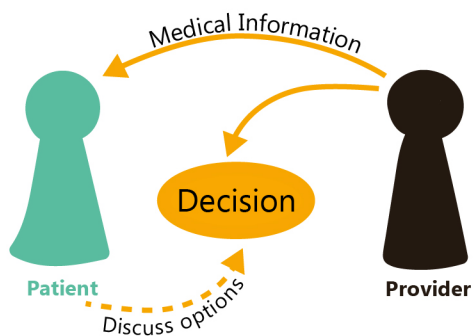


Figure 6. Patient-provider communication model

We, Bruna and Prachi, believe a realistic shared decision-making tool can be “libertarian paternalistic.” Thaler and Sunstein (2009, 5) explain that “when we use the term libertarian to modify the word paternalism, we simply mean liberty-preserving.” In practice, the provider still holds the medical knowledge that is important to make decisions and, although patients are experts about themselves, they usually want providers to decide for them. If patients have enough medical information and feel confident about their opinion, they could participate in the decision more actively, by discussing options, instead of only agreeing with a decision.

Furthermore, the balance of a shared decision is delicate. The patient has their needs and preferences, but sometimes the decision that brings the best outcomes for their health might make them a bit uncomfortable. In this case, we believe that the provider’s recommendations can nudge patients in decisions that would be best for them, even if they do not feel ready for it.

i. When is Shared Decision-Making the Most Useful?

Active patient-provider engagement is the most useful when multiple care choices are available, and decisions need to be made as different options have consequences and implications related to them, for example, decisions about major surgery, multiple medications choices and diagnostic tests that can end up having serious and stressful implications (Barry and Edgman-Levitan 2012, 780).

Some medical decisions do not need patient preferences and providers have a straightforward option for it. For example, a fractured hip needs repair, and acute appendicitis necessitates surgery (Barry and Edgman-Levitan 2012, 780). When multiple choices for treatment are available, shared decision-making can take place where providers know

about things patients care about, and they provide decision aids to patients to raise their understanding of treatment and possible outcomes (Barry and Edgman-Levitan 2012, 780).

Decision aids prepare patients for decision-making by increasing their knowledge about expected outcomes and personal values (O'Connor et al. 1999, 163). Decision aids can be delivered online, on paper or on a video that would help the patient to absorb clinical evidence and support them in identifying and communicating preferences for the possible outcomes that they have not experienced yet (Barry and Edgman-Levitan 2012, 780). Other ways to inform and prepare patients can be useful particularly considering the limited time that providers have during actual consultation.

ii. Shared Decision-Making Models

Shared decision-making is achieved by giving agency to patients. It can be done by 1) providing information, because if patients are not informed, patients would not know what is important to them and 2) supporting deliberation—patients might be surprised, uncertain about what is right for them and may feel abandoned if they are asked to decide by themselves (Elwyn et al. 2012, 1362). Hence, it is essential to support patients in deliberating their options by exploring their reactions to information (Elwyn et al. 2012, 1362).

As shown in figure 7, a shared decision model proposed by Elwyn et al. suggests three steps: choice talk, option talk and decision talk (Elwyn et al. 2012, 1363). Choice talk is about making sure that patients know that reasonable options are available, option talk refers to providing more detailed information, and decision talk refers to supporting patients by considering preferences and deciding what is best (Elwyn et al. 2012, 1363).

A systematic review of articles related to shared decision-making con-

cepts by Makoul and Clayman proposed an integrative model of shared decision-making. It defines and categorizes essential, ideal and general elements of a shared decision-making model (Makoul and Clayman 2006, 305).

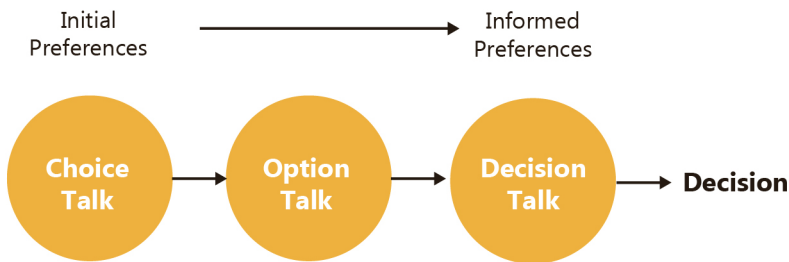


Figure 7. Elwyn et al.'s model of shared decision-making (Elwyn et al. 2012, 1363)

Figure 8 shows the elements of shared decision-making model discussed by Makoul and Clayman (2006). Though half of the shared decision-making definitions invoke the concept of partnership, it is unlikely that decision-making is shared equally in SDM (Makoul and Clayman 2006, 305). The degree of sharing can be different in each patient-provider encounter. The literature indicates that although physicians often take the leadership role considering the medical knowledge and social power they have in patient-physician engagements, this can still be shared decision-making provided essential elements from the table (figure 8) are present (Makoul and Clayman 2006, 307).

Essential Elements	Ideal Elements	General Qualities
Define/Explain Problem	Unbiased Information	Deliberation/ Negotiation
Present Options	Define Roles	Individualized Approach
Discuss Risks and Benefits	Present Evidence	Information Exchange
Patient Values/ Preferences	Mutual Agreement	Involves at least two people
Discuss Patient Ability/ Self-efficacy		Middle Ground
Doctor's Knowledge		Mutual Respect
Check/ Clarify Understanding		Patient Education
Make Decision		Patient Participation

Figure 8. Elements of a shared decision-making model (Makoul and Clayman 2006, 305).

iii. Regret Theory in Decision-Making

In the preoperative hold, we observed the use of Dr. As-Sanie's pilot of the shared decision-making tool. Many patients tended to choose the maximum number of pills, saying "just in case" as the reason for that choice. We could relate this to regret theory in decision-making where people tend to make decisions aiming to minimize anticipated regret. Anticipated emotions are expected to be experienced in the future if certain events do or do not occur (Baumgartner, Pieter, and Bagozzi 2007, 685). "Regret is experienced when people realize or imagine that their present situation would have been better had they decided differently in the past" (Zeelenberg, Marcel and Pieters 2006, 210).

We believe that patients might choose the maximum number of pills instead of the average due to anticipated regret. Given the option of choosing the quantity of opioid pills they will be prescribed, patients might anticipate the regret that they did not choose the maximum number even though they had a choice.

iv. Shared Decision-Making for Opioid Prescribing: Case

Shared decision-making has been used in the medical context in multiple cases. We are considering a case where shared decision-making is used by a team of healthcare providers to reduce opioid prescription.

According to the literature, a study was conducted by Prabhu et al. (2017) to assess if shared decision-making reduces the number of opioids prescribed after cesarean delivery. Generally, after a cesarean delivery surgical procedure, opioid pills are prescribed to control pain. The amounts of prescribed opioids are significantly higher than those that are consumed, which leads to a large number of leftover pills (Prabhu et al. 2017, 2). The study was conducted with patients with no chronic pain history (Prabhu et al. 2017, 2). An electronic tablet-based decision aid was created to facilitate shared decision-making discussions. Women were informed about typical pain resolution trajectories, informed about expected pain after cesarean delivery and then asked to choose the number of opioid pills considering a standard prescription range of 0–40 (Prabhu et al. 2017, 3). The study had excellent results where the study team was able to reduce prescription opioids by 50% without increasing refills significantly (Prabhu et al. 2017, 5).

2. Design for Healthcare Decision-Making:

Cases

Design has contributed significantly to healthcare by improving the patient experience. We found case studies where design interventions empowered patients resulting in improved patient engagement and decision-making.

a. Design at Mayo Clinic—Creation of Decision-Making Cards for Diabetes Patients

Mayo Clinic's Center for Innovation in collaboration with Dr. Victor Montori designed decision-making cards for type 2 Diabetes patients. These cards were designed to help patients decide about medications considering their own needs and lifestyle preferences. With research, Dr. Montori found that patients might not adhere to the medication if they are not given a choice to manage their Diabetes (Yale University 2010). The tool consists of six cards and enables physicians to discuss the advantages and disadvantages of medication. The cards explain possible effects of medication on six outcomes: Weight Change, Low Blood Sugar (Hypoglycemia), Blood Sugar (A1c Reduction), Daily Routine, Daily Sugar Testing (Monitoring), and Side Effects (Mullan et al. 2009, 1561). Patients prioritize the outcome and decide the sequence of the cards. The physician and patient go through the cards together until they come up with the medication. Figure 9 shows the decision-making cards developed by Mayo clinic.

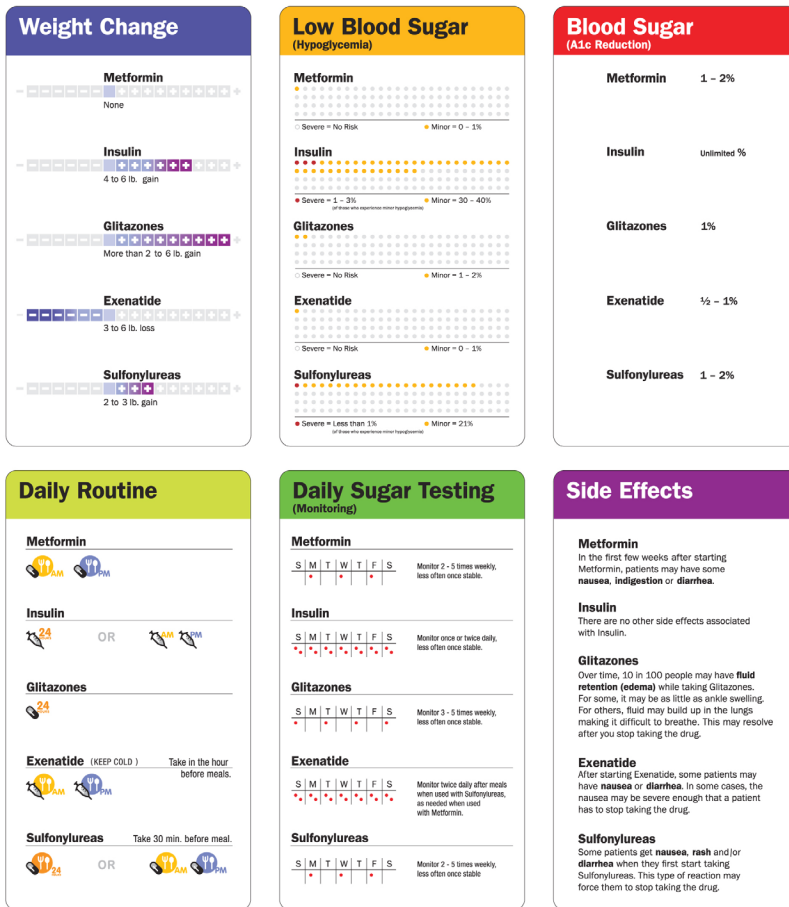


Figure 9. Shared decision-making Cards by Mayo Clinic (Mullan et al. 2009, 1561)

This project was conducted in collaboration of designers, clinicians, and researchers (Breslin et al. 2008, 466). Participatory action research and field observations were carried out to understand the problem and iterative prototyping was done to develop these tools (Breslin et al. 2008, 466). The design team did five prototype iterations and improved tools (Breslin et al. 2008, 466). With the iterations, different prototypes considered form, content, amount of text and if it is enabling the conversation between patient and physician. In the initial prototypes, only six outcomes were considered. Later, the cost was identified as an

important outcome that patients consider while choosing medication so a seventh card, “Cost”, was added. With testing, it was found that prototypes were successful in making patients and providers feel more positive and engaged as patients asked more questions to providers (Breslin et al. 2008, 471). In this case, design research is used to unveil stakeholders needs, and an iterative approach is taken to develop and test prototypes.

b. Patient Flow: Improving Acute Medical Units

This project was done in collaboration with the Helen Hamlyn Center for Design and Royal College of Physicians of Edinburgh (RCPE) in 2013. The Acute Medical Unit (AMU) is a unit where patients are admitted after an accident or an emergency and providers have to diagnose and identify in 72 hours if the patient needs to be transferred to another ward or whether to discharge them. There was a shortage of beds. The challenge was to maintain organized patient information. It resulted in the duplication of tests, delays in analysis and eventually slowing of patient flow. Through four years of research, a “visual care journey” was developed which helped staff to keep track of patient status (Helen Hamlyn Center for Design 2017, 30).

The patient booklet was designed to keep patients updated about their diagnosis and care plan. The booklet aimed to improve patient experience in the AMU by empowering them with the knowledge that would allow them to contribute to the medical decision taken (Helen Hamlyn Center for Design 2017, 30).

In this case, design contributed by providing solutions through the understanding of patient and provider perspectives. Design helped to empower patients with knowledge for better engagement and decision-making in the care process.

3. Design Context

The design approaches that had the most impact in this project were Service Design, Behavioral Design, and Inclusive Design.

Service Design is the holistic approach to this project, by understanding the patient surgical journey and the different actors, interactions, materials and other relevant elements of each touchpoint in the journey.

Behavioral and Inclusive Design brought the tenets to understand and influence the experience between the specific interactions of the patient (with or without the provider, depending on the moment in the surgical journey) with the designed artifacts.

a. Service Design

i. What is Service Design?

Service Design is a human-centered, collaborative, interdisciplinary, iterative approach that uses research, prototyping and a set of easily understood activities and visualization tools to create and orchestrate experiences that meet the needs of business, the user and other stakeholders (O'Reilly 2018, 27). Simon Clatworthy defines Service Design as “a design for experiences that happen over time and across different touchpoints” (O'Reilly 2018, 19).

Lara Penin mentions that “interactions are the core of services. Services are people-centric entities that are necessarily relational and social. They are also temporal because relationships happen over time. Because human actions and relationships are core to the services, it is essential that we acknowledge the uncertainty and unpredictability as contingent to services” (Penin 2018, 24).

Service interactions happen at the touchpoints which are the material

face of the service. These touchpoints can comprise of artifacts that support the interaction (Penin 2018, 24).

ii. Why Service Design for Healthcare?

A Service Design approach can be used to address challenges in a highly complex ecosystem, which includes multiple stakeholders interacting at different points in the system. Service Design offers tools and methods that enable the understanding of each stakeholder's perspective and allows for the design of experiences at various points in time for them. Different Service Design methods like user journeys, ecosystem mapping, service blueprints, user personas, storyboards, role plays, among others, are used to frame the problem, synthesize findings and prototype the interventions.

Patient-centered care is identified in healthcare to uncover what is valuable for individuals and to have health decisions based on individual values, needs and preferences (Fry 2017, 2). However, the term is overused in healthcare and is limited to patient involvement in understanding what is good and bad, and not necessarily uncovering why and understanding patient's needs and experiences (Bate and Robert 2006, 307). A Service Design approach, which is user-centric, helps generate empathy for not only the patient but all stakeholders to understand their needs.

Hospitals are managed by different departments in silos, which means a hospital has different departments like a preoperative clinic, pre- and post-operative care, among others, and they work parallelly. This system works for hospital management, but the patient sees the entire service as one experience (Fry, 2017, 3). Hence, working in a multidisciplinary team, especially to implement changes is necessary (Fry 2017, 3). Participatory design methods from Service Design can be effectively used to encourage stakeholders to create, evaluate and implement solutions that address their needs.

The holistic approach is necessary to understand the whole patient experience. It not only helps to design for the functionality but the whole journey including tangible and intangible aspects of experience (Fry 2017, 6).

b. Behavioral Design

Design is never neutral; it influences people’s behavior, intentionally or unintentionally. Through Behavioral Design, also known as Design for Behavior Change or Behavior Design, understanding and influencing user behavior is part of the process. To achieve that, designers integrate concepts and strategies from psychology, behavioral economics, and human factors, among others (Lockton, Harrison, and Stanton 2009) (NCCOR 2017).

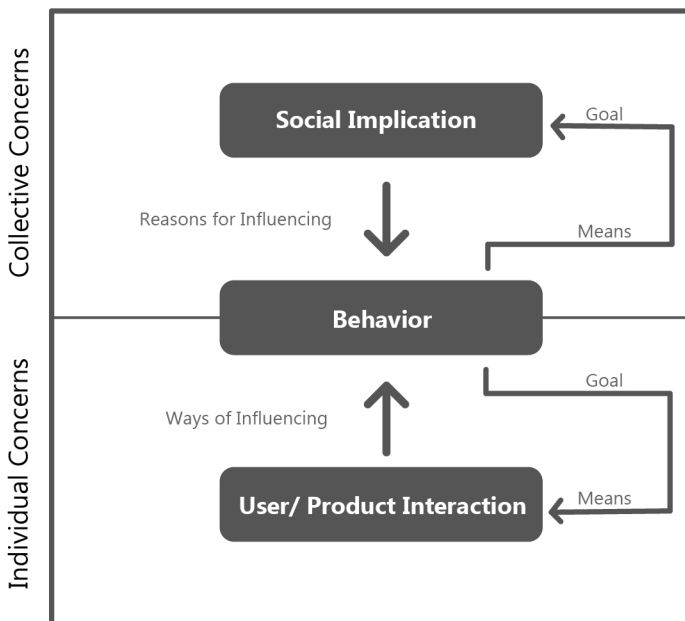


Figure 10. Individual and collective concerns (Adapted from Tromp, Hekkert, and Verbeek 2011, 6)

As shown in figure 10, Behavioral Design is used in this project because it is a means to address the collective concern of the opioid crisis. That is possible through influencing individuals and their concerns while they are interacting with the design outcome. The concerns of each individual might not match the collective concern, so Behavioral Design principles can be applied in the design for those concerns to coincide (Tromp, Hekkert, and Verbeek 2011, 7).

To match individual concerns with a collective concern, the product or service needs to influence behavior change. The Fogg Behavior Model (Fogg 2009, 4) (Fogg 2018), of the Persuasive Technology field, defined three factors for behavior change: motivation, ability, and prompt. Motivation is what makes a person engage in specific behaviors. Ability is about making the behavior easier to do. Finally, Fogg defines prompt as “something that tells people to perform a behavior now” (Fogg 2009, 6). The three factors should be present for a behavior to occur, and motivation and ability have a compensatory relationship (Fogg 2018), which means that if the motivation is high, the ability can be low and vice-versa. This project context includes a large number of stakeholders, and each patient has different motivations and abilities regarding aspects of their pain management; therefore, the prompt that best works for each patient is also different.

Design can influence behavior, but whether or not the individual will engage in that behavior also depends on the environment, their own experiences and biases. (Tromp, Hekkert, and Verbeek 2011, 5) (Johnson 2014, 1). In the context of this project, within a wicked problem space, there might be more behavior influences than are possible to identify. Hence, it would be impossible to influence all variables that affect a person’s behavior in this context. However, we recognize the main aspects of this project, such as the hospital environment, provider’s goals for patient satisfaction, and previous experience with opioids, largely influenced how the Behavioral Design approach was used for the outcomes.

We studied the MINDSPACE report by Dolan et.al (2010) to guide our design considerations. The MINDSPACE report is published by the Institute of Government, UK to influence public behavior while creating policies. This report talks about nine influences on behavior which are as follows:

Messenger	we are heavily influenced by who communicates information
Incentives	our responses to incentives are shaped by predictable mental shortcuts such as strongly avoiding losses
Norms	we are strongly influenced by what others do
Defaults	we go with the flow of pre-set options
Salience	our attention is drawn to what is novel and seems relevant to us
Priming	our acts are often influenced by subconscious cues
Affect	our emotional associations can powerfully shape our actions
Commitments	we seek to be consistent with our public promises, and reciprocate acts
Ego	we act in ways that make us feel better about ourselves

Figure 11. Influences on behavior as per MINDSPACE report (Dolan et al. 2010, 8)

We found these influences useful while we defined the design considerations because they provide a checklist of specific action items about how to nudge behavior.

c. Inclusive Design

Coleman et al. (2007) reference the British Standards Institution (BS 7000-6) to define Inclusive Design:

“Inclusive Design is an approach to the design of mainstream products and services that are accessible to and usable by as many people as reasonably possible, without the need for adaptation or specialist design.”

By understanding the limitations of many people and the needs of the target users, it is possible to design a system or product that can be used efficiently and safely by as many people as possible. Our approach was to keep in mind the challenges of inclusivity throughout the whole design process, because “without conscious effort, it is very easy to exclude by design” (Coleman et al. 2007, 17). One way to keep track of that is to test the product many times, with different people, to make sure that the users can understand and use the product.

Holmes (2018, 5) notes that inclusivity is not only about measurements and specifications to have a design artifact accessible for people with disabilities, but it should also consider the psychological and emotional impact design has on people. Inclusive Design was one of the areas used in this project, not only to make the design outcome accessible, considering physical limitations, but also because the patient population in the surgical context of this project is broad. Patients come from different backgrounds, abilities, experiences, and expectations, and the surgery will have an impact on how they feel and, consequently, how they interact with the design. Taking those aspects into consideration promotes better inclusion in healthcare, specifically surgical, context.



METHODOLOGY



A. Framework

The framework used for this project is research through design. The practice of design in a healthcare context of “changing existing situations into preferred ones” (Simon 1996, 111) was the basis from which the understanding of the design process, and therefore the contribution of the research, was developed. (Godin and Zahedi, 2014)

“Research through design (RtD) is an approach to scientific inquiry that

takes advantage of the unique insights gained through design practice to provide a better understanding of complex and future-oriented issues in the design field” (Godin and Zahedi 2014, 1).

We started the project by doing secondary research about the healthcare context, followed by primary research (observations and interviews) that informed the design process. Next, brainstorming and sketching were the first steps to think about what the outcome could be. We developed prototypes based on the key insights, and iterated on them multiple times after receiving feedbacks. Once the design outcome was more evident, the research continued to inform and support the development of the final prototypes.

It was an iterative process with moments of designing the tools, moments of getting feedback, and moments of deepening the learning through research. Through the whole process, our goal was to not only come up with an approach to addressing the needs of the partner and stakeholders in the healthcare context of this project but, more importantly, to understand how design can improve circumstances within wicked problems.

B. Collaboration Framework

We collaborated with each other and with our partners and stakeholders. This collaboration helped us to integrate our individual skills and to elicit and incorporate differences while working on this project. Developing a framework for effective collaboration was an integral part of our methodology. As we started working on the project, we identified challenges in our collaboration and found the way forward by trying and testing different options. This process helped us to come up with our own collaborative framework. The following figure 12 represents our collaborative framework.



Figure 12. Our collaborative framework

Communication: We see our collaboration as a shared decision-making process among both of us. Sharing is the basis of collaboration. It is essential to share knowledge and make tacit knowledge explicit. This helps to avoid confusion. We were mindful of being honest about our opinions and know how to listen for the opinions of one another. Gaining and developing mutual trust and respect is the first stage to it. We deliberately spent time together at the beginning of the 1st year, in order to know each other and develop mutual trust and respect.

We used real-time digital platforms to be in touch frequently and

update each other regarding progress and did not wait to update each other until the time we met. That helped us to keep on the same page and not forget any facts we wanted to discuss.

Time management: Time management is crucial when people collaborate. Hence, creating goals and deadlines, dividing individual and collaborative tasks is necessary to use collaborative time effectively. Based on the goals, we discussed and divided the tasks. Each one of us had a deadline to complete it. During the collaborative time, we discussed individual work, gave each other feedback, looked at the next steps and discussed and decided the direction forward. Collaborative tasks were deciding goals and deadlines, planning and discussing research, ideation, selecting ideas, and deciding the next steps. Individual tasks were mostly execution of what we decided together during our collaborative time.

Conflict resolution and decision-making: Conflict resolution is critical to arriving at a decision. We identified this as a challenge and tried to resolve conflicts by discussion and to seek an expert opinion if we could not resolve them among us. Our discussions were based on our internal communication code that is always making sure that the other person understands us correctly, being open to others' opinions, and being able to consent at appropriate times.

One of the strategies for conflict resolution and decision making was to share responsibility.

For example:

- One person starts being responsible for a particular activity. She would make 1 or 2 iterations of it.
- Next, both of us would discuss this iteration.

- Then, the responsibility would be transferred to the other person; that person would also make 1 or 2 iterations of it.
- Afterwards, she would transfer it back to the first person.
- This process would be as long as necessary, but none of us stayed responsible, alone, for an extended period. We tried to divide the responsibility in half for everything.

Our strategies to resolve conflicts and decision making helped us to:

1. Think critically about each other's work and our individual work.
2. Keep an open mindset for any feedback, and not get too attached to our individual ideas.
3. Provide the opportunity of not just giving constructive feedback but working on it by ourselves and to understand the challenges.

Individual skills: We have different hard skills and complementary soft skills. Our collaboration helped us enhance our hard skills and soft skills as we learned from each other. For example, at the beginning of the project, we stated each of our strengths as research and prototyping. However, by the end of the project, the one of us that described her strength as research was prototyping more, and vice-versa. We realized that we learned from each other and had reversed our roles.

Cultural outlook: We both come from different countries. In our countries opioids do not have an easy access. We realized that the culture of pain tolerance is very different in our respective countries. Having different cultural outlooks helped us see the pain management topic as a challenge we wanted to tackle as a thesis project. Our cultural outlook was our major motivation to work on this project. Our discussions were certainly very rich as well, as we had at least three different cultures to discuss and compare.

C. Service Design, Behavioral Design, and Inclusive Design

This project was done combining approaches and methods of Service, Behavioral and Inclusive Design. We started by using Service Design methods to map the elements of the journey. We also used other qualitative research methods, such as observations and interviews. Once we defined which points in the journey would be the focus of this project, approaches from Behavioral Design and Inclusive Design were used to inform better aspects of this service, such as who are the users, what are their motivations, and how we optimize their ability to engage with the system of tools. Finally, all those aspects were taken into consideration to design an outcome that facilitates the engagement of patient and provider in discussing pain management.

Our process was iterative, and frequently it was necessary to review and update what was previously done to move forward. It is important to note that each step was not necessarily completed before the next one started:

- map the elements of the journey (Service Design)
- define the project's problem statement and aims through key insights
- understand who are the users (Behavioral Design + Inclusive Design)
- optimize ability (Behavioral Design + Inclusive Design)
- facilitate goal/ target behavior (Service Design + Behavioral Design + Inclusive Design)

Each step, explained below, is first described according to how it could be applied to projects that include a service or system, and behavior change. Afterward, it is explained how we approached those steps in

this project, the service being the surgical journey and the behavior change being the engagement of patient and providers in discussions about pain management post-surgery using a set of tools.

We believe this integrative design methodology can be applied for a variety of projects that have to find resolutions in contexts of behavior change within a service. Each project might not use the same set of methods, because the context, initial information available, and goals can be different. Nevertheless, this methodology brings together important principles to take into consideration to design an integrative outcome that addresses the complexity of real-world problems. The steps of the framework are detailed below:

- map the elements of the journey (Service Design)

Service Design was the approach used to understand the problem space, in combination with other research methods. It provides a holistic view of the project. Service Design methods help to understand the service and its components, such as interactions, time the interaction takes, channels of service delivery, objects, and others that might be relevant for the context.

In this project, the Service Design methods used were a journey map and a service blueprint. Other methods used to map the elements of the journey were observations, and unstructured and semi-structured interviews. We observed the interactions of the patients with providers, what was discussed, how long it took, and gathered educational materials.

- define the project's problem statement and aims through key insights

In the design process, this is the moment where the problem space is

synthesized. With information about the journey and its components, key insights are uncovered, and those lead to the definition of the problem statement and what the intervention could be.

Our primary and secondary research led to the key insights that helped us define our problem statement and our project aims. At this point, we decided to focus our work in shared decision-making. Consequently, we could strategize the next steps by targeting our research in the points of the service that relate to the focus of our work.

- understand who are the users (Behavioral Design + Inclusive Design)

Service Design methods provide a general understanding of the system or journey. Once some points in the service are defined as the focus, the next step is to understand better the users through Behavioral and Inclusive Design.

In this project, the Service Design methods provided a general understanding of the surgical journey, materials about pain management, and interactions between patients and providers. Besides observations and interviews, we also conducted a discovery workshop.

However, those methods in qualitative research do not necessarily consider behavior change and inclusivity. Hence, we expanded and integrated our project with approaches from across many design fields.

As part of their frameworks, Coskun and Erbug (2014, 3), in Behavioral Design, and Holmes (2018, 108), in Inclusive Design, include understanding users and their characteristics during the design strategy and process.

For Behavioral Design, some of the aspects to understand about people are their attitudes, intentions, values, knowledge, personality traits, among others, that might change or influence someone's ability to per-

form a behavior. In this framework, users are grouped in types to represent the user diversity for which to design (Coskun and Erbug 2014, 7). These types of users could be represented as personas, for example.

The Fogg Behavior Model (Fogg 2009) (Fogg 2018), first mentioned in the Contextual Review, defined three factors for behavior change: motivation, ability, and prompt. We see motivation as an important element of Behavioral Design, one that changes depending on each person's experience and the environment. Fogg divided motivation into three: pleasure/pain; hope/fear; social acceptance/rejection (Fogg 2009, 4). A designer should understand the user's motivation to design accordingly. In the case of this project, for example, hope/fear of the surgical process, anticipated regret, and uncertainty of the pain management decision were the biggest motivators.

For Inclusive Design, it is considered that there is no person equal to another — everyone is different. Moreover, an “average” person does not exist. When we design for the average, we are designing for nobody. Although it is impossible to design for everyone, considering the large group of users in this project, being mindful of where exclusion happens can lead to more mindful decisions. One way to account for that is to consider users with disability (hearing, mobility, cognition, visual), older adults, as well as users that might have a temporary or situational disability (Holmes 2018) (Coleman, Dong, and Cassim 2007) (Pullin 2009).

We believe that the two approaches should not be considered separately. Both Behavioral and Inclusive Design frameworks recognize that each person might respond to a design differently and that the environment highly affects that interaction. Tromp, Hekkert, and Verbeek (2011) note that design strategies should be tailored for the environment in which the users are interacting with the design, and how we intend users to perceive and experience it.

Therefore, we considered a wide group of users and their varying de-

degrees of ability, knowledge and different values when interacting in the system. We used a Behavioral and Inclusive Design approach as a way to make the design system we are proposing stronger.

- optimize ability (Behavioral Design + Inclusive Design)

The second factor in the Fogg Behavior Model is ability (Fogg 2009). Fogg divided this aspect into six simplicity elements (time, money, physical effort, brain cycles, social deviance, non-routine) that have to function together to increase ability. Exploring the different user's abilities is important to make it simple for the person to engage in the behavior, and that means something different for each person (Fogg 2009, 6). For that reason, Inclusive Design principles can be combined with the Behavioral Design elements to create design outcomes that are easier to see and understand for as many people as possible.

For example, reading is not a natural human ability (Johnson 2014, 67). Writing in plain language helps in the understanding of the information presented on the tool, especially if we consider the healthcare context of this project, with many medical terms that are common for providers, but that patients might not know.

- facilitate goal/target behavior (Service Design + Behavioral Design + Inclusive Design)

To achieve our goal to support shared decision-making between providers and patients, we had to integrate Service, Behavioral and Inclusive Design.

The methods of Service Design consider the healthcare environment in which this project happened. The surgical journey is a delicate experience for patients, one that can make a person more anxious and sensitive. That influences how to approach the goal and target behavior.

In Behavioral Design, the concept of prompts means a call to action for the user to engage in a behavior. The Fogg Behavior Model (Fogg 2009) (Fogg 2018) defines three types of prompts: spark, signal, and facilitator. The spark prompt is used when there is high ability but low motivation. The signal prompt is used when there are high ability and high motivation. The facilitator prompt is used when there are high motivation and low ability. Considering the nature of this project—located in the hospital environment and in which the tools will reach a large number of patients, each with different abilities and motivation, having different surgeries—the prompts are questions that facilitate reflection and discussions with providers, guided by the tools. In the case of signal and spark prompt, there are discussions with providers who will guide the patient to participate in pain management decisions. In the case of signal and facilitator prompt, the reflection questions are supported by text and images explaining pain management, using principles of Inclusive Design to increase the ability of patients to understand the information.

However, the interaction of the users with the design outcomes should be considered carefully. That environment modifies how we can use the prompt. That means that, even if we facilitate a patient to engage in a behavior, the persuasion needs to be light and take in consideration the surgical context, and the physical and emotional experience of the patient.



DESIGN PROCESS





A. Our process

Our design process is based on the Double Diamond model, developed by the Design Council (Design Council 2019). The double diamond synthesized the approach that designers in different areas take for their projects. Each diamond represents divergent thinking, where there is mostly an exploration of ideas, and convergent thinking, which represents narrowing down the options for choosing one of the ideas.

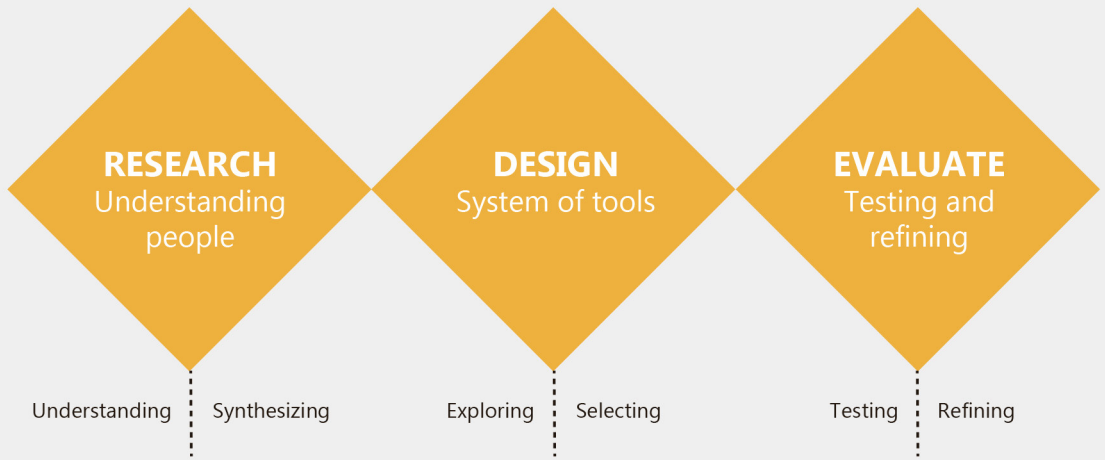


Figure 13. Design Process

The original Double Diamond model consists of four defined parts: discover and define (first diamond), develop and deliver (second diamond). The adapted model used for this project breaks down the second diamond into two parts: design and evaluate.

The first part of the project, represented by the first diamond (Research), consisted of understanding and synthesizing the problem space of patient education on pain management at Michigan Medicine. On the second part of the project, Design, we designed a system of tools to support patients and providers choosing post-surgery pain management options. On the third and last stage of the process, Evaluate, we conducted feedback sessions to understand what could be refined on each tool.

The following table shows the methods we used at different phases of our design process:

RESEARCH	Understanding	Stakeholder map
		Ecosystem map
		Observations
		Unstructured interviews
		Semi-structured interviews
	Synthesizing	Surgical journey map
		Service blueprint
		Patient workshop
DESIGN	Exploring	Brainstorming
		Sketching
		Prototyping
	Selecting	Feedback sessions
		Card sorting
EVALUATE	Testing/ Refining	Feedback sessions
		Simulation glasses
		Role-playing
		Evaluation survey

Figure 14. Methods

1. Phase I: Research

For the first part, Research, we conducted ethnographic methods, non-participant observations of patient and provider interactions during the surgical journey, to understand how communication about pain management happens between them. During that time, we collected samples of the materials that are given to patients to map the type and quantity of information they get, as well as to understand how much of it relates to pain management. We conducted unstructured interviews with healthcare providers and semi-structured interviews with patients which helped us to understand the project context and the stages that we could not observe.

a. Observations

In this technique, the researcher collects data by immersing herself into the participants' lives and observing their behavior. The researcher can ask participants about the activities they are doing, artifacts they are using, their motivations, pain points and gain points (O'Reilly 2018, 120). Generally, non-participant observations are used to find out the differences in what people say and what they do (O'Reilly 2018, 120).

We conducted 40 hours of observations of the surgical stages of Pre-op Clinic, Pre-op Hold, Discharge, and Follow-up visits. Our observations happened within Michigan Medicine, at the Pre-op Clinic at East Ann Arbor Ambulatory Surgery & Medical Procedures Center Pre-Op Clinic & PACU, Domino's Farms Pre-Op Clinic, and Von Voigtlander Women's Hospital. We spoke with patients, nurses, and physician assistants to deepen our understanding of the care process and the existing system of patient education.

b. Unstructured Interviews

In unstructured interviews, the questions are not predetermined and can be modified by a researcher during the interview (Curedale 2013, 23).

They happened as meetings to gather more information about stakeholders' and experts' views about pain management, discussing a variety of ideas related to this project and also discussing their projects. These unstructured interviews led us to talk to other experts (some of them were providers from hospital and others are experts such as the Michigan OPEN staff), explore topics related to our problem space that we have not thought about and to make sure we were aware of relevant discussions and concerns about the opioid crisis, pain management, and shared decision-making.

We had a total of 39 unstructured interviews with different experts:

17 Patients

8 Nurses

5 Physician Assistants

3 Surgeons

2 Psychology + Design Experts

1 Anesthesiologist

1 Fellow

1 Researcher

1 Patient Education Expert

c. Survey

A survey is a method to collect data from people typically from a large sample in a short time. A survey may not give a true reflection of a person's feelings, thoughts and behavior hence having observations, contextual inquiry or participatory design sessions along with is useful (Martin and Hanington 2012, 172). Typically, a survey is used to collect quantitative data which can be statistically analyzed further. We used a survey to get quantitative as well as qualitative data. Through the survey, we reached a larger patient audience and recruited them for interview and workshop sessions.

In collaboration with the OPE's (Office of Patient Experience) e-advisors, a survey was developed that was sent to patients. The survey was developed to understand:

1. Information on pain and medication management
2. The necessity of opioids for pain management
3. Anticipated pain vs. actual pain level
4. Patient information

d. Semi-structured Interviews

Interviews can be conducted with stakeholders or external experts to understand more deeply about the research subject (O'Reilly 2018, 122). Interviews are carried out when it is not possible to observe the activity. While interviewing participants, probing them when needed can give good data. Also, the researcher should avoid asking leading questions, which might bias the participant's answers. In semi-structured interviews, although a researcher has a list of predetermined questions, the conversation can be flexible to explore the issues which they feel more important.

The 17 survey responses led to a broader view of the problem space, discussed in the next section, and allowed us to conduct 11 semi-structured telephone interviews. The answers gave us a richer understanding of:

- patient’s perspective of current education;
- patient’s receptivity to education materials they receive;
- patient’s knowledge of opioid risk and use before and after they receive education;
- which providers have more influence in patient’s behavior;
- who else could influence a patient’s decisions on opioid use and disposal?

e. Patient workshop (Discovery)

Participatory design is research in which the design approach is char-



Figure 15. MDes team engaged with patients in a workshop

acterized by user involvement (Spinuzzi 2005, 163) and draws on various other design methods like ethnographic observations, interviews and analysis of artifacts (Spinuzzi 2005, 164). As per Spinuzzi (2005, 164), participatory design methods are used iteratively to construct the emerging design which itself constitutes research results as co-interpreted by designers, researchers and participants.

“Design workshops are the form of participatory design consolidating creative co-design methods into organized sessions for several participants to work with design team members” (Martin and Hanington 2012, 62). The design workshop consists of a series of design exercises with the participants which help to understand participants needs and co-create with them.

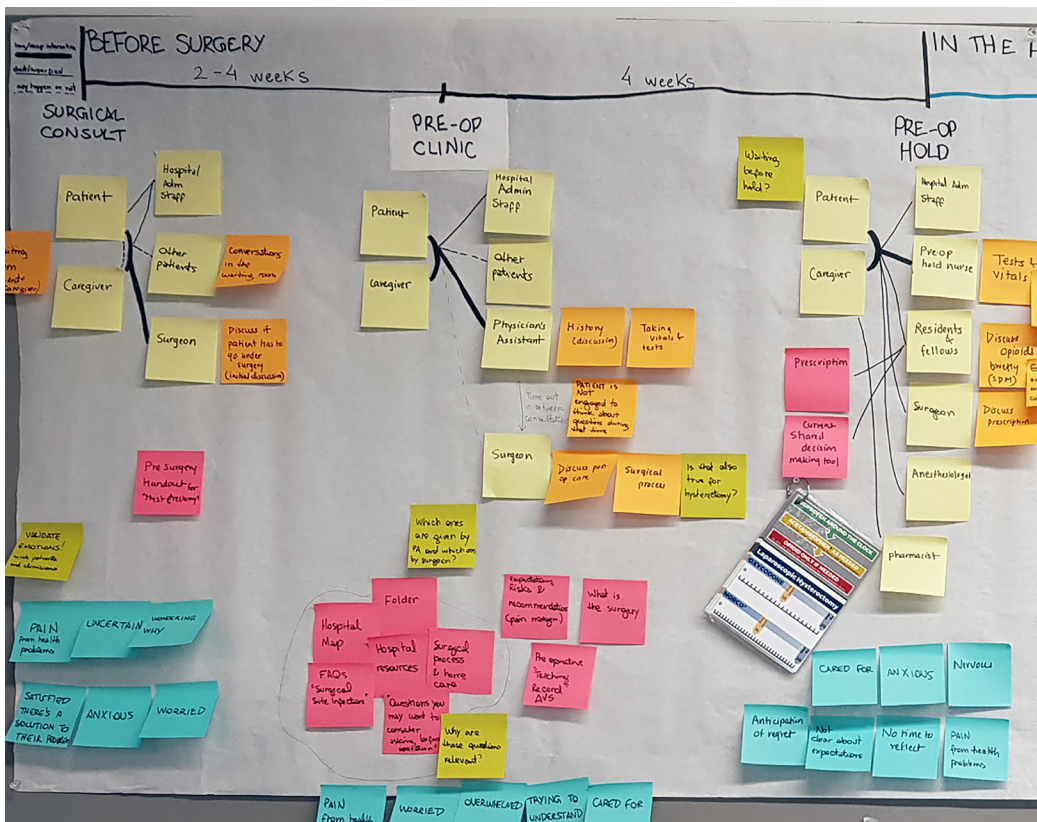
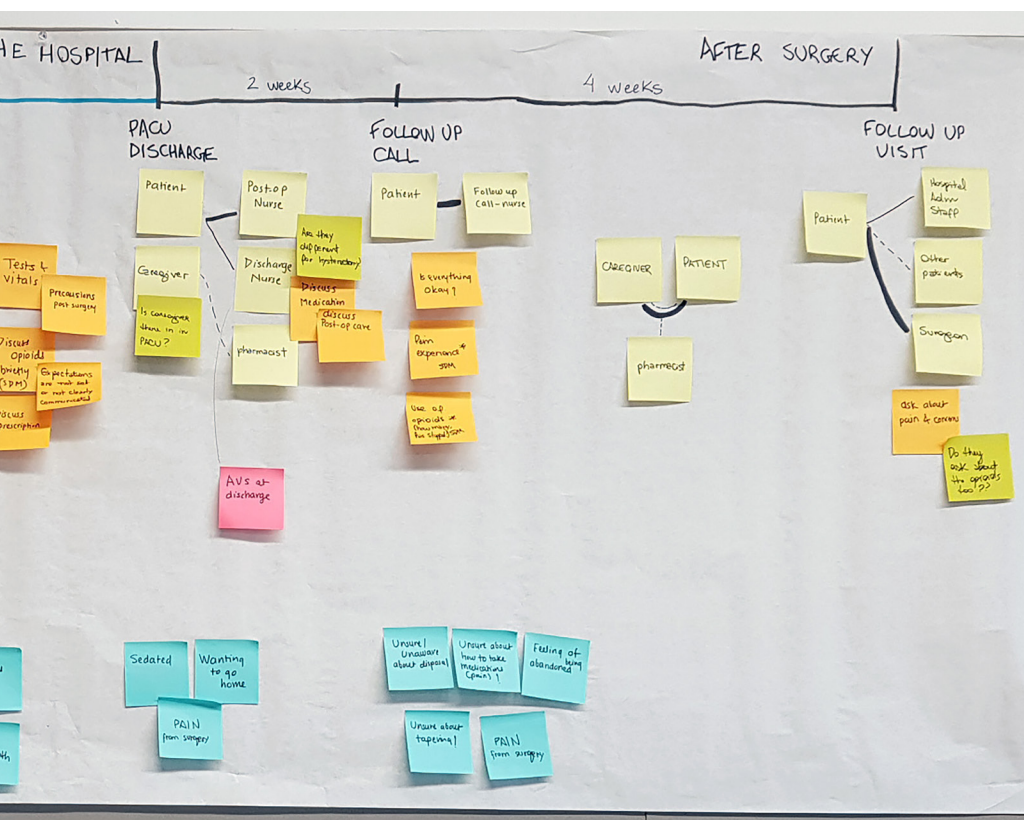


Figure 16. Patient Surgical Journey Map

Building on the patient interviews, it became clear that further investigation was needed to gain a broader understanding of the patient experience throughout their surgical journey.

Patients receive lots of information during the surgical journey and a patients' receptivity depends upon their mental and emotional condition at that point. Understanding the emotional state at a deeper level can assist in generating educational content which resonates with patients and is key to identifying their needs in making informed health decisions. Four OPE (Office of Patient Experience) e-advisors who underwent surgery within the past two years joined the MDes team to work on activities aimed to recall their patient experience.



Activity One: Assisted patients in remembering their experience within three stages of the surgical journey: before surgery, in the hospital, and after surgery, as it relates to who they met, what they learned, how they felt, and whom they spoke with, among others.

Activity Two: Assisted patients in identifying their ideal surgical journey including who they wish they had met, what they wish they were told, what they wish they had learned, what they wish they had felt, and how they wish they managed their pain.

Activity Three: As a group, patients reviewed all currently available education materials that the MDes team had identified during the observations.

f. Surgical Journey Map

Based on the journey mapping technique from Service Design, we created a patient's surgical journey map as shown in figure 16. A journey map is a tool to synthesize the research findings. A journey map structure consists of visualizing stages in the journey, and it shows the stakeholder's existing experiences within each stage (O'Reilly 2018, 129). Journey maps help to identify touchpoints, interactions, and artifacts that affect the participant's experience.

Working from our observation notes, we mapped the patient experience throughout the surgical process to deepen our understanding of the process of care and barriers that arise for both patient and staff regarding patient education.

2. Phase II: Design

The second part of our project involved constant iteration and refinement of the tools based on primary research. The findings and insights obtained from the ethnographic phase informed a design-oriented phase, which involved multiple iterations of the tool's design. Careful

analysis of the feedback from different areas (designer, psychologist, healthcare providers, and patients) was taken into account for each iteration of the design. In this sense, this project used an agile process, consisting of multiple short iterations of prototyping and the gathering of feedback. That resulted in a robust shared decision-making tool that could improve health communication around pain management between patients and providers.

a. Prototyping

Prototyping is creating a mock-up of a product or service so that one could quickly incorporate and test the ideas with users and make refinements accordingly (Stickdorn and Schneider 2011, 192). Prototyping helps iteration toward a solution. “It effectively creates a shared understanding of initial ideas and concepts, enhancing communication, collaboration, and participation of interdisciplinary stakeholders” (O’Reilly 2018, 210).

During the design phase of our process, based on our research, we started brainstorming possible solutions. After sketching some of the most promising ideas, we prototyped the tools and got feedback from patients, providers and design professors multiple times.

b. Card Sorting

Card sorting activity is a participatory design method and is used to help the participant to make meaningful categorization and comprehension (Martin and Hanington 2012, 26). We used a card sorting activity to prioritize the information content.

The card sorting activity was conducted with nurses to understand what are the most important aspects of pain management that should be reinforced with patients, in their opinion. This was important to

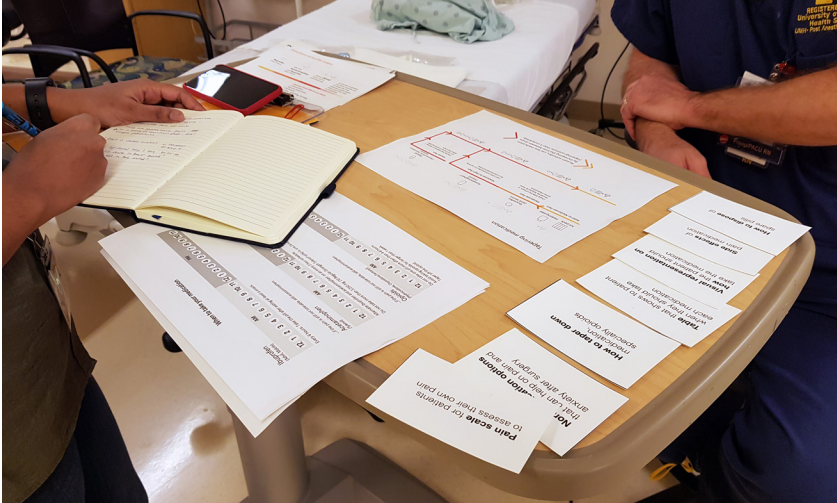


Figure 17. Card sorting activity with nurses

validate ideas or identify what was missing from our prototypes. Figure 17 shows the card sorting exercise done with the nurses. We decided not to show the prototype before so that we could get their unbiased opinion about aspects of pain management.

3. Phase III: Evaluate

The last phase of the process is evaluation. Considering the timeframe of the project, we tested the tool by engaging experts from different areas, including patients, and understood whether or not the tools were understandable and actionable.

We tested the tools to see if everyone interprets the text and images the same way, did color testing for color-blindness and used simulation glasses for Inclusive Design. The Cambridge Simulation Glasses, part of the University of Cambridge's Inclusive Design Toolkit, can be used by researchers to simulate effects of vision loss when seeing a product (Goodman-Deane et al. 2014, 43). The simulation glasses were used to evaluate if our tools were still readable by users that have difficulty



Figure 18. Feedback sessions with OPE's program managers

seeing details. They indicated required changes in color and contrast and font and icon size.

a. Feedback sessions with designers, healthcare providers, and patients

In design development, testing of prototypes by real potential users of a system is a part of evaluative research (Martin and Hanington 2012, 74). Evaluative research is iterative and can be done in a formal or informal setting. It focuses on gathering feedback from potential users not only on the performance measures but also gauges human factors and ergonomics, aesthetic response, and emotional resonance (Martin and Hanington 2012, 74).

We carried out three evaluation sessions with Patient and Family Advisors Council (PFAC) meetings which were attended by 18, 11 and 13 patients respectively.

b. Role-playing

“Role-playing is acting the role of the user in realistic scenarios can forge a deep sense of empathy and highlight challenges, presenting opportunities that can be met by design” (Martin and Hanington 2012, 148). Role-playing can be difficult to be documented by the researcher who is actually doing it themselves and hence the observer has to write notes, sketches or video to document it (Martin and Hanington 2012, 148).

We used the role-playing technique to test our prototypes. We provided a scenario and asked patients to act as they are undergoing a surgery. We enacted as a provider and role-played the process of shared decision.



Figure 19. Role-playing session

c. Evaluation Survey

The Patient Education Materials Assessment Tool (PEMAT) is developed by the Agency of Healthcare Research and Quality (AHRQ). This tool is an evaluation instrument to assess understandability and actionability of print and audio-visual patient education material (Shoe-

maker, Wolf and Brach 2014).

Based on this tool, we created a survey to evaluate the tools designed by us. The survey is attached in appendix 3. The survey consisted of questions to assess if patients understand the objective of the tool, the language, medical terms used, and if the visuals are clear. We circulated the survey through OPE (Office of Patient Experience). We received 19 survey responses evaluating the tool.

In summary, our design process consisted of three different phases — research, design, and evaluate. Based on our integrative design methodology, we combined the methods from Service Design, Behavior Design, and Inclusive Design. Methods used for research and synthesis helped us to come up with findings, which are explained in the next sections.



FINDINGS & INSIGHTS



A. Findings from Observations

Throughout our observations and interviews, we analyzed the information the patient receives at each stage by different means. The means through which a patient receives information is a discussion with providers, a patient folder, an after-visit summary document, and tri-folds.

The figure 20 and figure 21 show the information the patient receives

through various means. The time taken to discuss pain management, which does not necessarily happen consistently and even for every surgery, is also represented.

1. Pre-Op Clinic: The Physician Assistant gives a folder to the patient, with handouts and brochures. It is general information for the patient to prepare for the surgery, and a small part of it relates to pain management. The conversation about pain management happens for an average of two minutes or less. Most of the materials are letter sized white paper with black and white text.

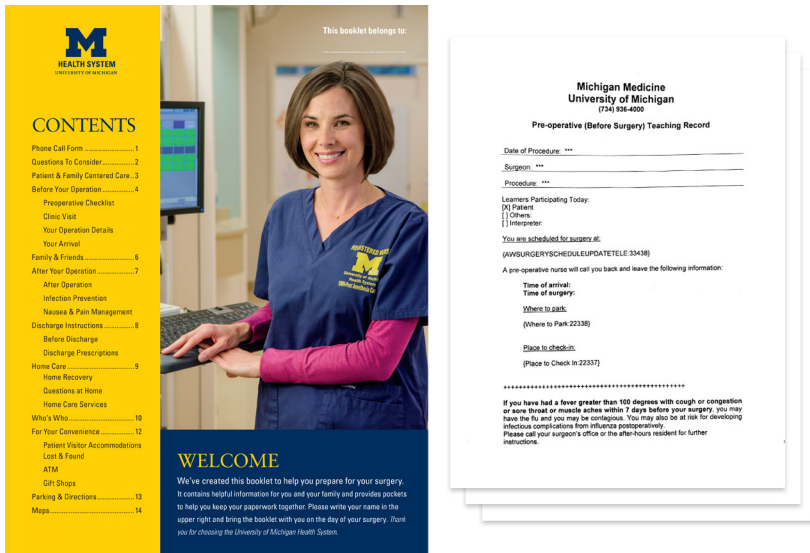


Figure 20. Materials received by patients during the Pre-Op Clinic

2. Pre-Op Hold: At this stage, a patient talks to a resident or fellow who prescribes pain medication. Dr.As-Sanie’s pilot of the shared decision-making tool is used for a one-minute discussion about pain management. This process happens only in the case of the pilot.

3. Discharge: For outpatient surgeries, discharge happens within a few hours of surgery. The patient talks to the nurse and explanations about pain management take about two minutes, but that varies according

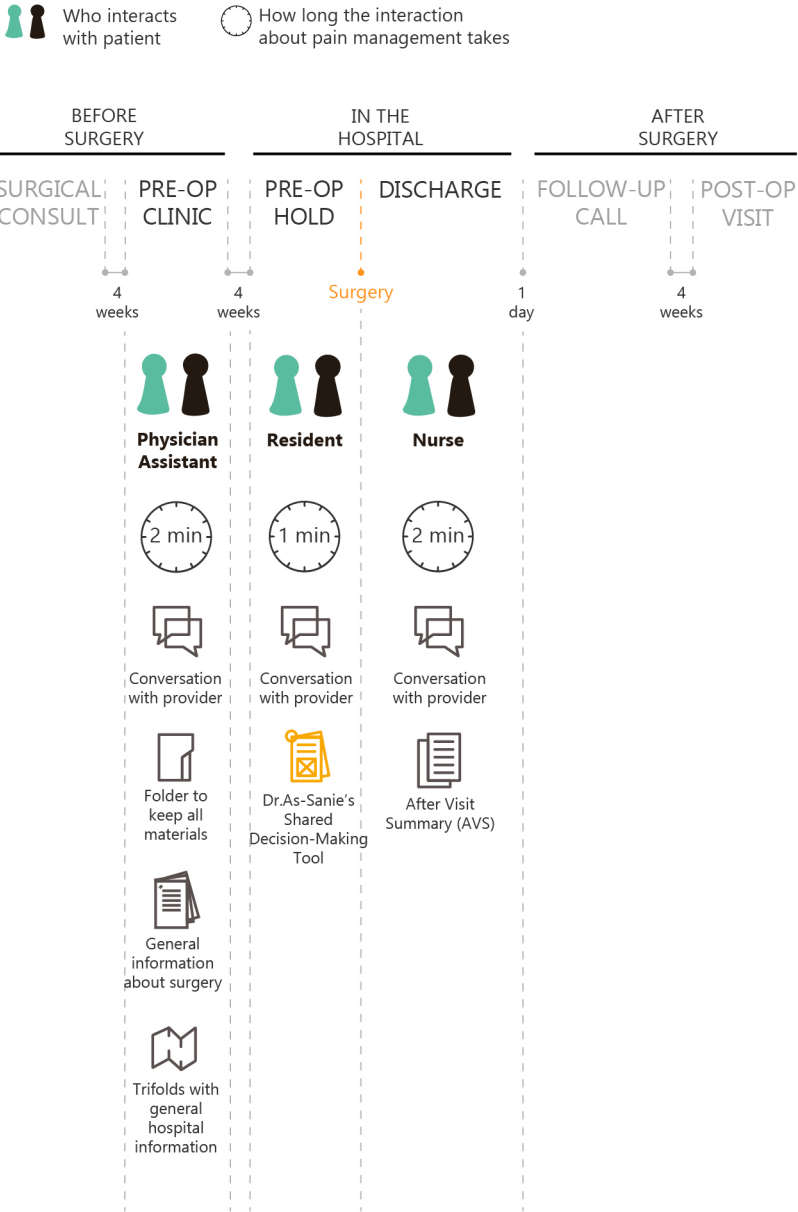


Figure 21. Information received by patients during the surgical journey

to the patient. The patient gets the after-visit summary which has information regarding their recovery.

Wendel (2013, 106) points out that a one-size-fits-all product does not work in most cases. We heard from a patient during the workshop, “Information should be simplified, downsized and related to my case.” Personalized information makes it easier for the user to relate to the information and more willing to engage in the action.

B. Findings from the Patient Survey

Through the survey and patient interviews, we realized that patients are not well aware of pain management options and do not know what to expect after surgery regarding pain. Hence, they might prefer to have more opioid pills prescribed by anticipating more pain than is experienced. Moreover, patients do not get consistent and relevant pain management information at points in the surgical journey.

We received 17 survey responses from OPE (Office of Patient Experience) e-advisors, and the significant findings were as follows:

- 10 out of 17 (>50%) patients reported that their anticipated pain level was higher than the actual pain experienced;
- 9 out of 17 (>50%) patients believe opioids are necessary to control pain;
- some patients believe they will not get addicted to opioids;
- some patients retain pills to use for other pain and do not want to dispose of them;
- there is limited awareness among patients about how leftover pills can affect those around them.

C. Findings from Patient Interviews

- both discussions with a provider and education materials to take home are valuable for patients;
- it is essential to have different information at each stage which is relevant to the experience and needs of the patient at that moment;
- reinforce the same patient education message throughout the whole journey to ensure retention and limit confusion. Patients receive varying degrees of content at each stage that can contradict the previous education;
- to limit opioid use, highlight the risks, side effects and alternatives to pain management without opioids;
- patients mentioned using the directions on their prescription pill bottle for reminders of how to manage their medication;
- patients received limited to no information regarding tapering of opioids;
- patients were unaware of the side effects and dangers of an abrupt stop in usage;
- setting pain level expectations upfront can reduce opioid use as patients would gain a clear understanding that pain is a natural result of surgery.

D. Findings from the Patient Discovery

Workshop

With the goal of understanding patient experience as a whole, we conducted the patient workshop.

1. Emotional State

Patients experience a vast array of emotions throughout their surgical journey. These emotions differed patient to patient. We were intrigued to learn that many patients felt well cared for while within the hospital, generating feelings of assurance and support.

Figure 22 shows the patient surgical journey, information received by them, and their emotional state at each point in the journey.

Patients feel overwhelmed due to the amount of information they receive at the pre-op clinic. They feel anxious and unsure at the pre-op hold as this is the time just before the surgery.

After discharge, even though patients were relieved to be home, they felt neglected as they did not have immediate access to their care team for any questions or concerns. The surgical journey as shown in figure 19 shows the typical emotions most of the patients feel during the surgical journey.

The emotions of patients are different depending on the type of surgery, the past surgery experience and before and after the surgery.

“I was looking forward to the surgery.” – Patient 4

“I felt scared and anxious as well as glad that I found a liver for transplant.” – Patient 3

2. Physical State

After learning about a patient’s emotional experience, we asked about their physical state as well.

- In the hospital, most patients felt uncomfortable and out of place.
- The physical state of the patient in the hospital makes them vulnerable (scrubbed/ naked).



Figure 22. Patient emotions during the surgical journey

- After surgery, all patients experience some pain.

3. Understanding about Opioid & Pain

Medication

The educational experience of opioid usage varied. It validated our observation that patients do not get consistent and relevant information about pain management. Also, the amount of information they receive makes it hard to pay attention to information specific to pain management.

“I got dozens of pages of information, but nothing regarding opioid medication or pain management.”

- Patient 4

“I was told about opioids from a rehab trainer and my friend who had knee surgery.”

- Patient 1

4. Communication & Support

Each patient interacted with a variety of people through different channels. Moreover, they wished to have more personal support, which would give them assurance about the surgical process.

“I wish to learn from people who have been through the same surgery.”

- Patient 2

“I wish to have someone who can support me such as life coach or patient advocate.”

- Patient 4

E. Shared Decision-Making Tool

(Dr.As-Sanie's Pilot)

When we started our project, we observed Dr. As-Sanie's pilot of a shared decision-making tool. It happens at the pre-op hold. The tool comprises three laminated sheets, each for a type of hysterectomy, attached by a key ring as shown in the figure 23. The front part of each sheet is intended to be seen by patients, and the back part includes talking points for a resident or fellow.



Figure 23. Current shared decision-making tool (Pilot)

The process of engaging a patient with this tool happens as below:

1. Provider greets patient and tells about pain medication prescription.
2. Provider tells that it is normal for patients to expect some pain after surgery.
3. Provider shows the tool to the patient and tells how to take pain medication by showing the visual on the front page.

4. Provider quickly mentions opioid side effect and risks of opioids.
5. The patient, based on the type of hysterectomy surgery she is undergoing, is shown a scale. The scale indicates the average number of pills used by patients and the maximum number of pills a provider can prescribe for that kind of surgery.
6. The patient is asked to decide the number of opioids pills they think would be good for them.

1. Findings from the Shared Decision-Making tool (Dr. As-Sanie's pilot)

With our observations, we could analyze the process and the tool. We saw both the pros and cons of the tool.

Positive Findings:

1. The tool's format is very convenient to use. Especially the use of a key ring to hold the sheets, which makes it convenient to hang or store.
2. The lamination makes it easy to clean.
3. The tool is half of the letter-size paper, which makes it easier for providers to carry it in their coat if they choose.
4. Bigger font size is easy to read for patients.

Opportunities for improvement:

1. We observed that patients get the information about opioids and they are immediately asked to decide the number of pills needed by them. They do not get enough time to digest the information they just received.

In the Netherlands, a shared decision-making process is used for better patient-provider engagement. After identifying that it is difficult for patients to make sense of all the information they get at one point in time, the researchers implemented a time-out consultation. That means that the patient gets time to reflect on their values before they make the decision (Borstkanker 2018).

2. With the scale showing the maximum number of pills they can get, often we observed patients choosing the maximum number of pills “just in case.”

This type of behavior can be explained with the help of regret theory from decision-making. People tend to make decisions aiming to minimize anticipated regret. Anticipated emotions are expected to be experienced in the future if certain events do or do not occur (Baumgartner, Pieter, and Bagozzi 2007, 685).

F. Key Findings and Insights

The key findings are the ones that led to insights for the whole system of tools:

Key finding 1:

Patients feel overwhelmed by the amount of information in general, delivered when they are not at their best emotional or physical moment.

Insights:

To avoid patients feeling overwhelmed because they do not know how much pain they would be in after the surgery, it is needed to set expectations of pain ahead of time for surgery.

The pilot of the shared decision-making happens at a moment when patients are anxious. Patients do not have enough time to think before

they make a decision. Therefore, we need to give patients time to reflect before pre-op hold, at a time they are less anxious.

Key finding 2:

Information about pain management is inconsistent, delivered by different providers and at different points, making it hard to remember relevant information.

Insight:

To avoid inconsistency, we need to reiterate the same pain management information at different points in the surgical journey.

Key finding 3:

Providers do not have enough time to have an in-depth discussion about every topic with patients, which makes the interactions regarding pain management rushed.

Insight:

We cannot change how much time providers have available, but we can support patients to feel empowered to ask questions and for patients and providers to discuss what is the appropriate, individualized way to manage the pain.



**DESIGN
OUTCOMES**



Based on the findings and insights, we propose a system of tools implemented at different points in the surgical journey to support patient-provider engagement.

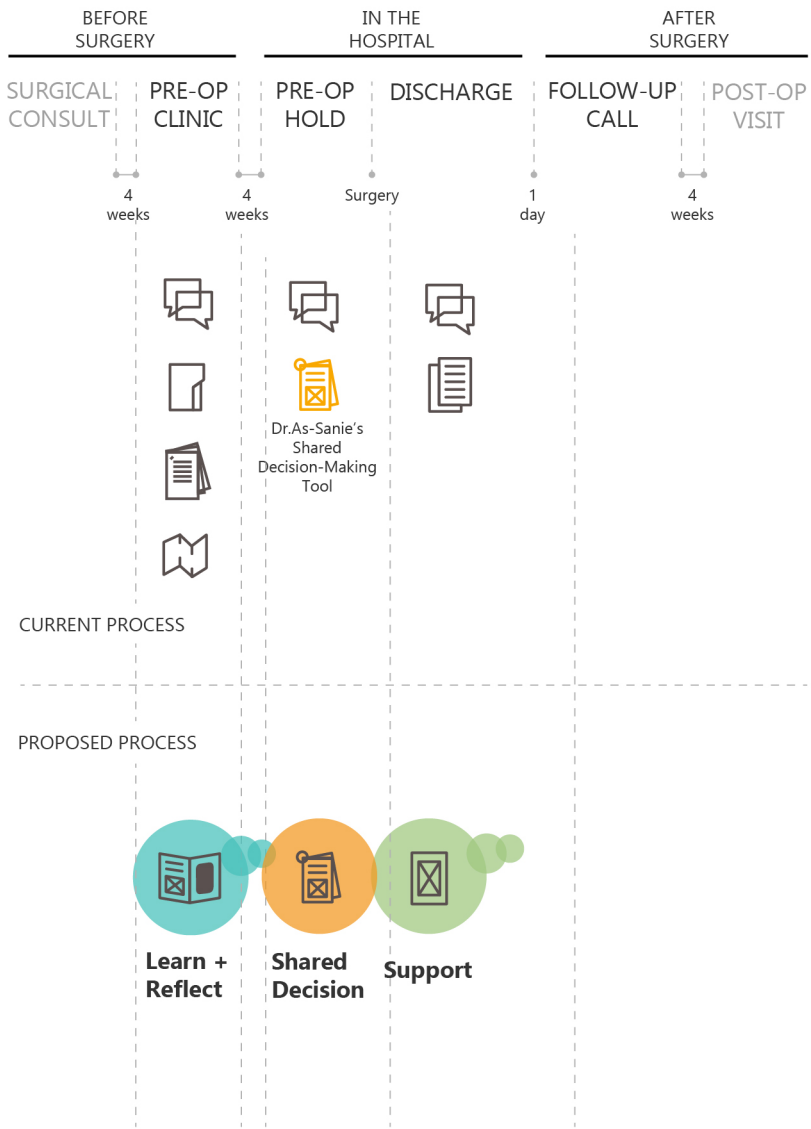


Figure 24. Current process (top) and Proposed process (bottom)

A. System of Tools

The current system diagram as shown in figure 24 shows the materials received by patients and Dr. As-Sanie's current shared decision-making tool. The proposed system diagram shows the tools at different points in the system. As shown in figure 24, in our proposed system, our version of a shared decision-making tool still happens at pre-op hold. At this point, providers prescribe pain medication; hence, it is the appropriate moment to decide the number of pills.

However, our proposed system expands beyond that. It consists of three tools which are introduced and used at different points in the journey. The tools were designed to support and reinforce each other, but they also stand individually.

The fact that each tool is delivered at different points in time with some variation in the overall information will support patients to understand the information better. (Brown, Roediger and McDaniel 2014, 3).

Some of the information will be reiterated on the other tools to facilitate recognition instead of recall of the information, which would take longer to understand the material (Brown, Roediger and McDaniel 2014, 121).

1. Learn + reflect tool: We recognized that patients need to learn about pain management choices and reflect on their own needs and values before deciding their prescription at the pre-op hold. This tool would be introduced and handed over at the pre-op clinic.

Patients would go through the tool and reflect on their preferences before the surgery when they are at home. This would prepare them for the next stage of shared decision-making.

2. Shared decision-making tool: This is a communication artifact at pre-op hold. This tool would be used by residents to discuss with pa-

tients. Pain management options and individual preferences would be discussed to decide an appropriate pain management plan.

3. Support tool: This tool would be introduced and handed over by nurses when the patient is about to be discharged. It would re-confirm the patient's decision and help them to act on their plan. This tool would support patients while they are at home and trying to manage their pain by themselves.

1. Design considerations

Our design considerations are based on primary research and Inclusive Design and Behavior Design approach. We considered the environment, people interacting with tools, and the times they are interacting with the tools.

- **Form:** Form is the fundamental consideration. Our tools would have a form that is easily accessible in the hospital setting. They should be easy to store, distribute, and carry.
- **Material:** As the tools are used in the hospital setting, the tools should be "easy to clean".

We considered the MINDSPACE framework (Dolan et al. 2010, 8) while deciding on language and aesthetics.

For example, "Salience" is one of the principles mentioned in this framework, i.e. drawing attention to what is novel. Hence, we kept our tool's look and aesthetics different from most patient materials yet, made them easy to understand and learn.

The language and aesthetic considerations were:

- Maintain clarity by using the consistency of text and visual forms

- Use plain language and avoid ambiguity
- Use high contrast colors, and an easy to read font
- Use a minimalist design approach

We considered learning theories from Brown and McDaniel as mentioned in their book “Make it Stick”. Design considerations based on learning theory were:

- Tools are delivered at different points in the journey, to make the information the most relevant at that point and to support understanding.
- These tools reiterate some of the information to facilitate recognition than recall. It is necessary to reduce the cognitive load.
- We want people to reflect on their own experiences. Reflecting and relating information to their own experiences makes it easier to remember. This process is called elaboration in the learning theory.

We used other behavior influence principles, from the MINDSPACE framework (Dolan et al. 2010, 8), as guidelines for some of the details of the tools.

- Message delivery is important. Patients trust providers, so it is necessary for the essential information to be also delivered by the provider through a conversation. This is the Messenger principle.
- Patients fear that they will not have enough pain medication. Our tool provides information about non-medicinal ways and over-the-counter medicine. Also assures patients about refills if they need it. This is the Incentives principle.
- People are influenced with what other people are already doing. With quotes extracted from other patients stories, we show how other patients approach their own pain management. This is the Norms principle.

- The tool format is novel and would grab attention of patient comparing to the other materials they get. This is the Salience principle.
- The tools have subtle focus on risks and side effects when taking opioids, compared to the other options. This is the Priming principle.

2. Content specifications

For the content of the tools related to healthcare, we relied on current patient education materials available at Michigan Medicine. We also researched about other pain management information and compared it with Michigan Medicine's material and finalized the content to be included in our prototypes. Once we developed the initial content, we got feedback from healthcare providers to validate the information. A card sorting exercise with nurses helped to validate the content in the tools. The exercise with 3 nurses revealed the importance of non-medication alternatives as it was the top priority from their perspective. Content priority from the card sorting exercise was the information about 1) non-medication options, 2) pain scale, 3) how to take medications, 4) when to take medications, 5) how to taper down, and 6) side effects of medication.

B. Tools

1. Learn + Reflect

The goal of learn + reflect in the system of tools is to have the patient learn more about pain management post-surgery and reflect on their needs and preferences before the surgery, at a time when they are

less anxious. The learn + reflect tool format is an 8-page booklet of half-letter size paper (Figure 25). That format was chosen because it stands out from the other materials that patients receive at the pre-op clinic and it could be inserted in the folders patient receive. The booklet format is smaller than the materials that patients typically get and it feels more personal.

Specific findings relating to the learn + reflect tool:

- 10 out of 17 (>50%) patients reported that their anticipated pain level was higher than actual pain;
- to limit opioid use, highlight the risks, side-effects, and alternatives to pain management without opioids;
- setting pain level expectations upfront can reduce opioid use as patients would gain a clear understanding that pain is a natural result of surgery.

Goals for the tool, considering the findings from the research:

- what to expect regarding pain after surgery;
- information about non-medication and non-opioid medication options for treating pain after surgery;
- information about how to use a multimodal plan (a combination of non-medication and different types of medication) for managing the pain;
- side effects and risks of pain management options like acetaminophen and opioids to make patients aware of their risks and side effects before they choose to take them;
- quotes from patient stories as examples of how each experience is different;
- questions for the patient to reflect about before discussing with the provider about their pain medication prescription;

- prompts for the patient to reflect what questions they might have for the provider regarding their pain management.

An after-surgery pain management journey (Figure 26), based on different informational materials for surgery, is represented visually as a way to help patients understand some of the most common experiences regarding pain after the surgery.

The first part of the learn + reflect tool shows the main ways to manage pain (Figure 26). Specifically, this page highlights non-medication



Figure 25. Learn + reflect tool as a booklet

and non-opioid medication options, because one of the findings from our research is that both patients and providers would like to see those options being shown, instead of focusing on opioids.

“I would like to see education in trying to control pain (for minor surgeries) without the use of opioids.”

– Patient, from survey 1

Medication can be adjusted to different levels of discomfort.

You can practice mindful breathing at anytime during your recovery.

Ibuprofen
Every 6 hours

Alternate **Acetaminophen*** and **Ibuprofen**
Every 3 hours

Your surgeon may prescribe you opioids such as oxycodone or hydrocodone.

Add an **Opioid** if your pain is still intolerable

Moderate Pain
I have little bit of pain, It would be helpful to have some medication.

Moderate-High Pain
I can only concentrate on a activity for a short period of time.

High Pain
I barely feel talking or eating, I can not think of anything else other than pain.

As the pain improves, use fewer opioids and increase the time between doses (taper them) and then stop it completely.

Risk and side effects of opioids

Causes drowsiness
You should not drive or operate machinery while taking these medications.

May cause nausea, vomiting, itching and/or constipation
Stomach upset can be lessened if the drug is taken with food.

May cause confusion.

Risk of addiction
Used beyond short periods creates the risk of addiction.

Risk to others
Keeping opioids you no longer need can be unsafe for others. Children or pets may accidentally swallow them. Teens or adults may take the opioids without your knowledge.

Hence, it is important to properly dispose unused opioids.

* Do not take more than 3000mg of Acetaminophen (10 regular strength Tylenol) in 24-hour day.

Many pain relievers like Norco and Percocet also contain Acetaminophen.

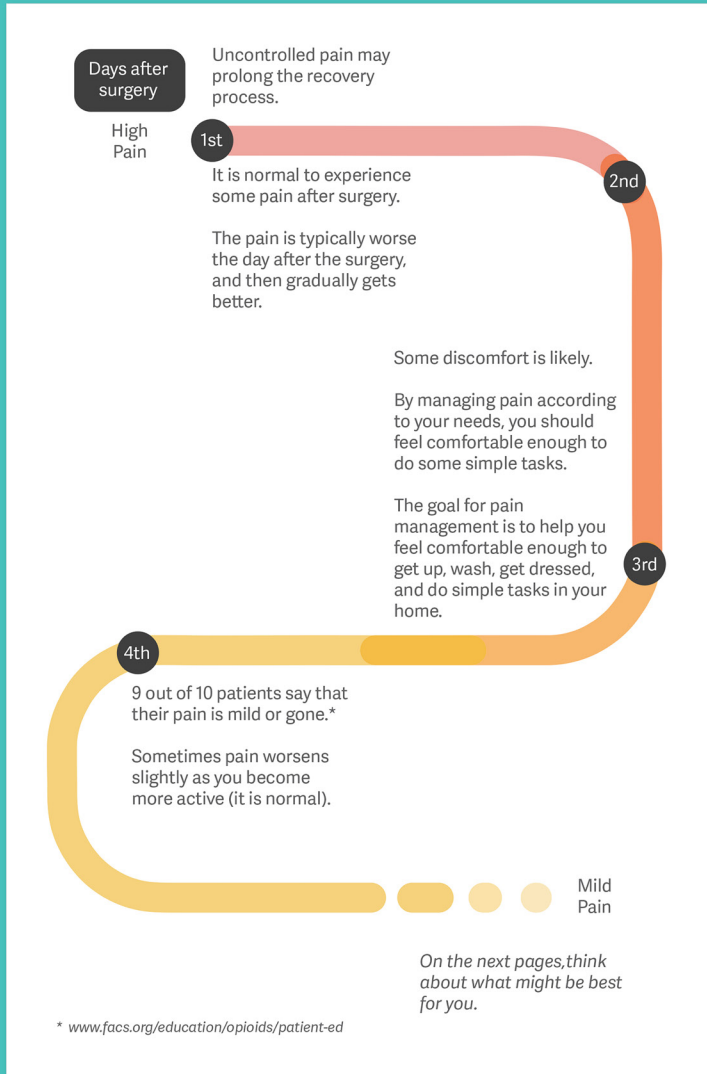


Figure 26. Page 2 and 3 from learn + reflect tool

There is no single way to manage your pain

Using multiple options is the most effective for pain management after surgery.

Non-Medication

These options can be used for everyone.



Ice pack



Heating pad



Distractions



Mindful breathing

Often people find alternatives to medicine as a useful way to manage their pain.

Distractions such as watching TV and listening to music are helpful.

You can learn more about mindful breathing at <http://michigan-open.org/patient-resources/>

Medication



Ibuprofen
(Advil, Motrin)



Acetaminophen
(Tylenol)



Opioid
(Hydrocodone, Oxycodone,
Fentanyl)

Often people can manage their pain only with over the counter medicines like Ibuprofen and Acetaminophen.

Opioid medications can be added for high pain.

They should only be used for short period of times.

Medication can be adjusted to different levels of discomfort.

You can practice mindful breathing at anytime during your recovery.



Ibuprofen
Every 6 hours

Moderate Pain

I have little bit of pain, It would be helpful to have some medication.



Alternate **Acetaminophen***
and **Ibuprofen**
Every 3 hours

Moderate-High Pain

I can only concentrate on a activity for a short period of time.

* Do not take more than 3000mg of Acetaminophen (10 regular strength Tylenol) in 24-hour day.

Many pain relievers like Norco and Percocet also contain Acetaminophen.

Figure 27. Page 4 and 5 from learn + reflect tool

Your surgeon may prescribe you opioids such as oxycodone or hydrocodone.



Add an **Opioid** if your pain is still intolerable

High Pain

I barely feel talking or eating. I can not think of anything else other than pain.

As the pain improves, use fewer opioids and increase the time between doses (taper them) and then stop it completely.

Risk and side effects of opioids

Causes drowsiness

You should not drive or operate machinery while taking these medications.

May cause nausea, vomiting, itching and/or constipation

Stomach upset can be lessened if the drug is taken with food.

May cause confusion.

Risk of addiction

Used beyond short periods creates the risk of addiction.

Risk to others

Keeping opioids you no longer need can be unsafe for others. Children or pets may accidentally swallow them. Teens or adults may take the opioids without your knowledge.

Hence, it is important to properly dispose unused opioids. Learn more at: michigan-open.org/takebackmap/

These patients had the same surgery, yet their experiences were very different from each other.

"After the first two days, I took an opioid when the pain got too strong. I kept reducing the number of opioids that first week of surgery."

Patient, age 57, managed their pain by:



Ice pack



Ibuprofen



Acetaminophen



Opioid

"This time I felt dizzy and did not like the feeling. I experienced the side effects of opioid pain medication and decided to stop taking them."

Patient, age 35, managed their pain by:



Distractions



Heating pad



Ibuprofen



Acetaminophen



Opioid

"When I have taken strong pain medication in the past I did not feel good. I prefer to feel the pain and understand how my body is responding to the recovery."

Patient, age 41, managed their pain by:



Distractions



Mindful breathing



Heating pad



Ibuprofen



Acetaminophen

Figure 28. Page 6 and 7 from learn + reflect tool

Figure 27 shows the spread that visually represents how to use a multimodal plan for pain management, considering how much pain the patient is feeling. It also shows side effects and risks when taking acetaminophen and opioids.

As discussed in the Contextual Review, people can reflect and learn from the experiences contained in stories. We chose to use quotes from the stories and pain management experience from other patients we heard during the interviews and workshop as examples of how each person has a unique experience regarding pain management (Figure 28). The persona in each quote is kept neutral as not to influence the reader's perception. Each quote has visual representations of what the persona chose as part of their pain management, which are examples for the reader of the different ways to manage pain.

By answering the reflection questions and relating the information to their own experiences (Figure 28), patients can learn and remember the information contained on the tool more easily. That is called the elaboration process (Brown, Roediger and McDaniel 2014, 3). Considering that, the last page of the tool (Figure 29) focus on reflection by prompting patients to think about their past experiences and perceptions about pain management. Those questions can help patients reflect on their values and needs and discuss with their providers, at the time of prescription, what their preference is.

Do you you have any questions or concerns you want to discuss with your provider?

- How long to take medication
- Knowing how to taper my medication over time
- Extreme pain
- Addiction
- How to dispose of extra pills
- Costs of medication
- When can I go back to my routine

Anything else?

Figure 29. Page 8 from learn + reflect tool

2. Shared Decision-Making

The goal of the shared decision-making in the system of tools is to engage the provider and the patient in a discussion about what would be the individualized pain management option for the patient.

The shared decision-making tool format is of 3 cards of half-letter size paper (Figure 30). That format was chosen because it is already familiar to Dr. As-Sanie's shared decision-making tool pilot. It is also convenient to handle and hang. When laminated, it is easy to clean, which is a requirement for artifacts in the hospital setting.

There are many aspects from Dr. As-Sanie's pilot that worked very well, such as the format, size, and lamination. Another characteristic we are maintaining is some of the organization of the information: one side of the page is for patients to see the information while talking to the provider. The back side of the same page has information for the provider to go through with the patient regarding pain management and opioid talking points required by Michigan Law.

Specific findings relating to the shared decision-making tool:

- In the hospital, most patients felt uncomfortable and out of place.
- The physical state of the patient in the hospital makes them vulnerable (scrubbed/ naked).

Goals for the tool, considering the findings from the research:

- Keep the same best practices from Dr. As-Sanie's shared decision-making tool pilot.
- Have similar visual information to the learn + reflect tool; therefore, patients can recognize that they have seen that information before.



Figure 30. Shared decision-making tool



Figure 31. Page 1 and 2 of the shared decision-making tool

It is normal to have some pain after surgery.

- Our goal is to manage your pain so that you can function: eat, sleep, deep breath, walk.
- Some people do not require any opioid medication after surgery.

Pain medication can be adjusted for different levels of discomfort.







- A multimodal plan is the most effective for pain management after surgery.
- Non medication options like heat pad, ice pack and mindful breathing are safe and can be used with medication.
- How should you take pain medication?

Opioids risks and side effects

- Drowsiness or severe sleepiness
- Confusion
- Nausea, vomiting, itching
- Constipation
- Access and misuse by others

Figure 32. The back side of the shared decision-making tool

Multimodal plan

Heating Pad 	Ice pack 	Mindful Breathing 
Ibuprofen 	Acetaminophen 	Opioids 

If you need refills, let us know!

Any questions?

Figure 33. Page 3 of shared decision-making tool

- Support a conversation between provider and patient where the average number of opioid pills can be used as an example.

The first part of the shared decision-making tool is a recapitulation of the parts from the learn + reflect tool: it is normal to feel pain after surgery, the most common way to manage pain using non-medication and medication, and the questions for the patients to consider what the best options for their needs are (Figure 31).

Presenting that information again is important for patients to remember the information they have read, if they have read, in the learn + reflect tool without having to understand that for the first time.

Similarly, to Dr. As-Sanie's pilot, on the back part of the tool are talking points for the provider to remember to discuss with the patient. (figure 32)

The last part of the tool presents visual representations of the different pain management options. It is at this point that the provider will engage the patients in a conversation about what their preferences are. (figure 33)

If the patient chooses to have opioids, the provider needs to understand what is the appropriate number of opioid pills to prescribe. When giving the average number of pills taken for a specific surgery, the patient will use it as an initial reference point, or anchor, to make a decision. That helps them to consider how many pills they would need based on the average and the information discussed with the provider (Wendel 2013, 4).

There is a reminder, at the bottom of the page, that refills are easy to get. That could avoid the patients feeling anticipated regret of the possibility of running out of medication when choosing a small number of pills.

Finally, patients are prompted to ask questions and discuss concerns before the provider leaves to fill in the prescription.

3. Support

The goal of the support in the system of tools is to make some of the nurses' activities easier and have patients be reminded, at home, of information that they get at the hospital when they are too tired to remember details.

The support tool format is one letter-size paper printed both sides. That format was chosen because it is easier for nurses to print together with other materials, and can be easily handled by patients once they are discharged.

Specific findings relating to the support tool:

- patients mentioned using the directions on their prescription pill bottle for reminders of how to manage their medication;
- patients received limited to no information regarding tapering of opioids;
- patients were unaware of the side effects and dangers of an abrupt stop in usage;
- patients felt neglected after discharge as they did not have immediate access to their care team for any questions or concerns;
- there is limited awareness among patients about how leftover pills can affect those around them.

Goals for the tool, considering the findings from the research:

- how and when the patient should take the medication.
- show patients, visually, how to taper opioids.
- remind patients about withdrawal symptoms when stopping without tapering down.

- a reminder of how to contact the care team if needed.

Nurses usually communicate to patients, before they are discharged, when they should take each medication they were prescribed. Some nurses write or draw tables with a schedule on the back of the informational materials they hand to patients.

The first page of the support tool makes it easy for nurses to highlight when patients should take each medicine. It also includes other relevant information regarding the medication, that was previously shown



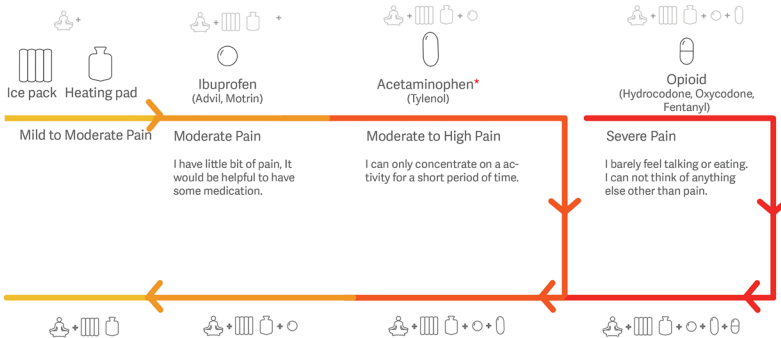
Figure 34. Front and back of the support tool

in the learn + reflect tool.

Figure 34 visually represents how to taper down medication, which many patients do not know or forget that it is necessary. The icons and colors make it easy to understand how to taper medication even without reading the text.

A small paragraph asks patients to dispose of leftover pills at pharmacies or to find disposal sites through a website.

Tapering medication



To dispose of left-over pills, take it to a pharmacy or find an opioid disposal site at michigan-open.org/takebackmap/



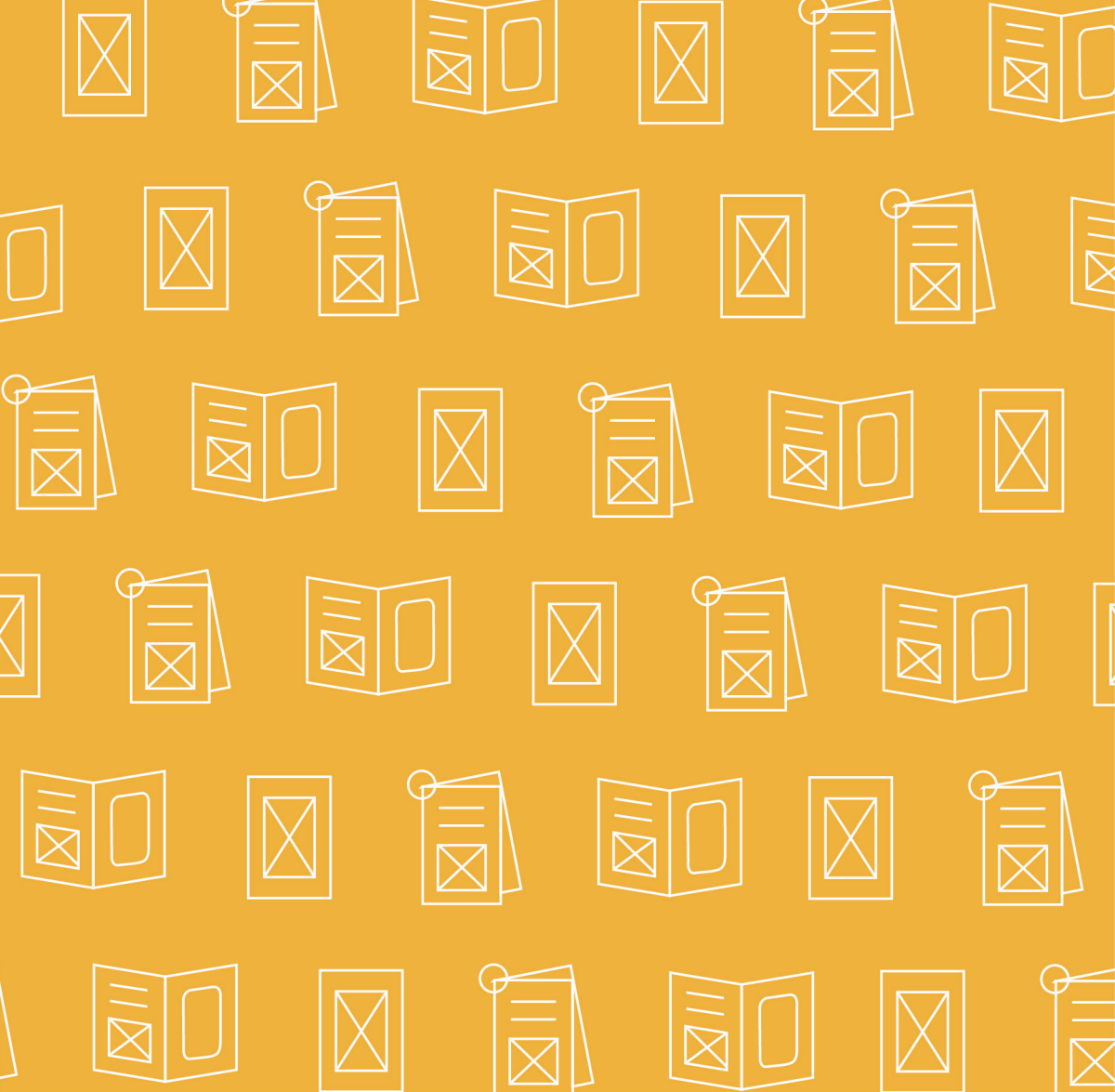
As pain subsides, use less medication by increasing the time between doses (tapering) until you stop it completely.





TESTING & EVALUATION





During the process of design, we tested and evaluated our tools multiple times. With each round of feedback, we iterated and improved it.

Feedback from designers and partner

Initial iterations were based on the feedback from field experts (Our partner Dr. As-Sanie, her fellow Dr. Annmarie, experts from Michigan OPEN and our design professors). We iterated the content and the vi-

sual representation of the tools based on the feedbacks we received.

Survey

We got 19 responses for the survey we sent to evaluate the tool. With the survey, we could get feedback over the language, visuals and overall comprehension of the tool.

When asked on a likert scale from 1 to 5 (1 being not helpful at all and 5 being extremely helpful), how this booklet helped prepare them to have pain management discussion with the physician, 16 out of 19 patients rated it as being extremely helpful.

Some feedback we received both in survey and PFAC meetings is that patients needed more information regarding non-medicinal pain management options. For that, we included a link to the website where they can find additional information (Page 3 of learn + reflect tool).

Patient and Family Advisory Council meeting

In 20-25 minute sessions with the Patient and Family Advisory Council (PFAC), we distributed the tool and asked patients to go through it and give us feedback regarding the content, format, language, and visuals. This opened a discussion which we recorded by taking notes.

The main takeaway we got from these feedback sessions is that the objective of learn + reflect tool was not very clear as some of the patients thought that they need to decide on their pain management plan by themselves. However, the tools are supposed to be read by patients before making a shared decision with providers.

This feedback made us make the objective of the tool explicit that it is for preparing them for the discussion with the provider.

Role-play

Role-play validated some of our findings, for example, not including the scale showing the maximum number of pills allowed to be prescribed by the physician. When we role-played a scenario with a patient who initially said he would never take pain medication, when saw the scale, opted for the maximum number of pills. Role-play helped in understanding how the shared decision-making tool could be used in a real-life situation where a person was not just asked the feedback but immersed in the situation.

Testing helped us to iterate on design decisions and validate our findings. It helped us to think critically about our design choices (colors, form and icons). It made us see the things which we did not see before. Testing helped further to rethink over some of our design decisions. For example, In the case of stories from the learn + reflect tool, we highlighted the pain management options a person chose to take. The meaning of the highlighted icons was not clear for some of the patients. Also, though the plain language was the initial criteria for our design, we realized some of the words (like tapering and multimodal plan) were difficult for some patients.

As discussed in the Contextual Review, one of the challenges for reflection is that current perceptions are highly biased by experiences from the past, the current context of the present and our goals for the future (Johnson 2014, 1). For example, the understanding of the images we chose to represent concepts might have a different meaning depending on the patient's experience. A representation of mindfulness as a person sitting with their legs crossed will not make sense for someone that just had knee surgery, for example.

While testing and evaluating the tool, we faced challenges managing different perspectives of the people. We received mixed feedback during a collaborative feedback session with patients for the learn

+ reflect tool. For example, we specifically heard conflicting opinions from two of the patients. Based on their past experiences, one patient perceived the tool as focused too much on the risks of opioids, while another patient said we did not talk enough about the risks. Both patients gave examples of family members or their own experiences with opioids to illustrate their opinion. Each person interpreted the tool according to their own biases.

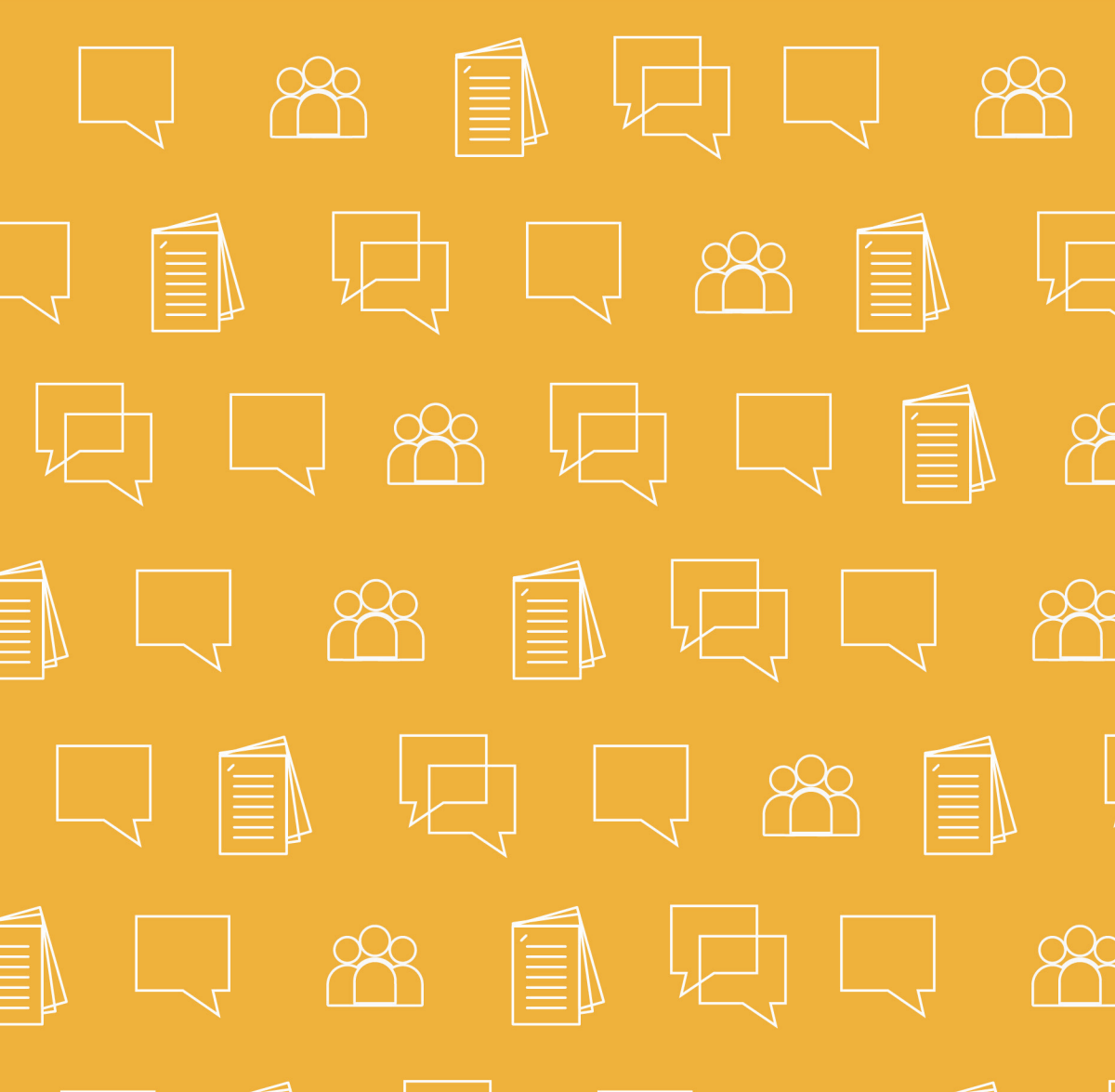
As mentioned earlier, one or two patients thought that they have to make their own decisions after reading the learn + reflect tool. Some patients needed more information about non-medicinal options. These feedbacks made us think about the objective which was providing basic information (not overwhelming them with information) and making people reflect on their experiences to prepare them for shared decision-making. We added a web link for more information and stated the objective very clearly on the tool.

Considering the influence of individual biases on people's perspectives, we tested the tool against the defined criteria on PEMAT (Patient Education Materials Assessment Tool), available in Appendix 3. The survey results and PFAC meeting discussions revealed that the tool helped prompt patients to think about their past experiences and discuss them with their provider. The majority (16 out of 19) of the survey respondents found the tool easy to understand and useful to discuss pain management with the provider.

In summary, initially testing helped us to gain our partner and expert's viewpoint which guided the design. However, when we tested the tools with patients through different ways, it made us think about our design decision and also validated our findings.



DISCUSSION



We believe this project has significance for shared decision-making practice in healthcare and the field of design.

We hope this project contributes to the practice of shared decision-making by highlighting the importance of using design methods to pinpoint what are the specific needs of patients and providers in a context, as well as the best times to deliver interventions. The tools' development was based on the emotions patients are feeling. We believe that some of the patients' emotional and physical states might be

typical at certain parts of the surgical journey, independent of the hospital, such as feeling anxious or fearful before the surgery. The decision of including a reflection tool before the surgery day, at a time patients are less anxious, could be considered for other surgical decision aids. Not many other shared decision-making aids underline the importance of reflection, which is necessary to ensure the patient's engagement with the shared decision-making tool.

For shared decision-making, the design approach can support a better understanding of the patient population and visualizing a surgical journey in a specific context. That helps to better visualize and communicate possible interventions to a non-designer audience.

For design, this project integrated the design practices of Service Design, Behavioral Design, and Inclusive Design with healthcare in order to have a more holistic approach of the surgical journey and the engagement between patients and providers regarding pain management. It can be argued that understanding human behavior and designing for inclusivity are essential parts of any design practice; however, we noticed that frequently they are not explicit and, therefore, can be overlooked.

Our approach was to, throughout the Service Design, recognize where behavior change and exclusion happened. That generated a framework that connected to our goal of appropriate care and the challenges that come with it. We believe that the methods of Service, Behavioral and Inclusive Design can be combined for many other challenges in healthcare and beyond, as one field would rarely be enough to address wicked problems. That is one of the main strengths of this methodology, the integration of methods and approaches from different design areas. Designers can use it for problems within a service in which users need to engage in a new behavior, first by focusing on the general journey, and then on the interactions between users and objects in each specific moment. For example, this integrative design methodology could be applied for a new food service for users to engage in a more

sustainable behavior, with less waste. For that, it would be necessary to understand the journey of the user, when buying and consuming the food, and their interactions and emotions at each point, which would show when and how to have an intervention for behavior change. Even though the area is not healthcare, the same methodology could be applied.

For the practice of this methodology, we recognize that the Behavioral Design and Inclusive Design approaches have to be iterated more within each new context, because that changes people's motivations and abilities and who is included or excluded from the outcome. The mindset of both areas can be applied for design projects that include people and behavior change, but the specific resolutions drawn from each area depends on iterations, testing, and goals of the project.

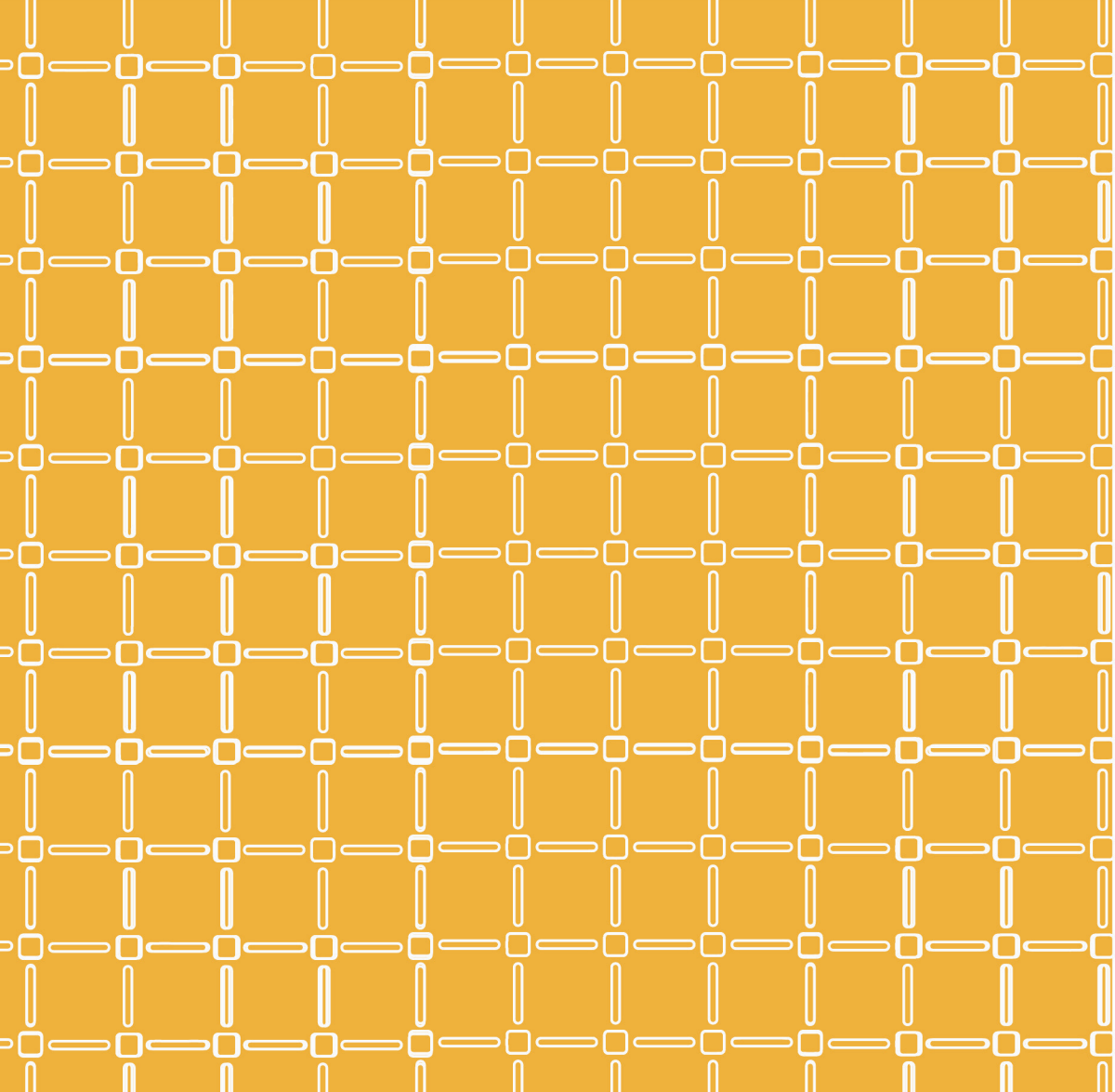
A. Our Collaboration

For this thesis we, Prachi and Bruna, collaborated; we also collaborated with our partner and stakeholders. During this collaborative experience, we faced challenges in terms of sharing responsibilities, solving conflicts, and holding each other accountable for the best outcome. We developed our collaboration framework over time while we faced the challenges. Though the proposed collaborative framework could provide a basic guideline to designers while they work on a collaborative project, it is best considering two people's collaboration and needs to be discussed and adapted for every other collaboration.

We are grateful that we could collaborate with our partner Dr. As-Sanie who helped this project with her medical knowledge and experience and provided us access to different stakeholders. This collaboration, especially with our partner, made us think about limitations and the possibility of implementation which guided our design outcome to be realistic.



LIMITATIONS



We partnered and researched within the Michigan Medicine context. The patients we interviewed are part of specific demographics, which might not be the representative of the entire patient population in the USA. Most of the patients we talked to for research and tools evaluation were recruited from the Office of Patient Experience. We recognize that this patient population is already active with the patient e-advisory board and eager to engage with projects and researchers.

During our research, we did field observations in a hospital setting. Though we tested tools with patients through surveys, role-playing, and patient and family advisors' meetings, we could not test the tools with actual patients undergoing surgeries and at specific points in their journey. We identify this as one of the main limitations of the study.

The methods used in this project were largely from qualitative research. When we circulated two surveys, we got 17 and 19 responses respectively. Although it was helpful to learn from their analysis and to identify next steps for interviews and workshops, this data may not be representative beyond the scope of this MDes thesis project.



 **FUTURE WORK &** 
CONCLUSION 



As we think about future work, implementation of the tools for different surgical procedures can be a challenge. Though the content and information presented is general for all the surgeries, tools can be improved further to make them appeal to the patient population undergoing specific surgeries. Also, as the tools are to be implemented at different points in the surgery, different providers need to be well acquainted with the tools, and they need to have a shared understanding of the objective and the system of tools.

In healthcare, appropriate care can differ for each individual and can be contextual. In this project, we investigated patient's surgical journey and designed a system of tools that would support patient-provider engagement to tailor a pain management plan for individuals.

The nature and consequences of the current opioid crisis are wicked. Prescription opioids have a substantial contribution to this epidemic. Long term solutions like preventative measures and reduction in opioid prescribing are necessary which can be done with better pain management strategies. We approached this problem with the combined lens of Service Design, Behavior Design, and Inclusive Design. This integrative approach made us seek what is relevant from each of these design fields and combine them to create a framework which could be replicated and used while addressing other wicked problems.

With our project, our goal was to integrate design and healthcare by developing tools that cater to each stakeholder's needs. We want the tools to stand individually as well as part of the system and to be the means for patients and providers to communicate and make decisions resulting in appropriate care.

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Appendix 1: Brief definitions and important terminology and central concepts.

Access

In the context of our thesis, access means being able to take prescription opioids whenever wanted by patients who had it prescribed to them. However, people who do not have a prescription could also have the ability (access) to take opioids from other means, such as from other people who are keeping extra pills.

Appropriate

1. Quality is appropriateness (providing the right treatments at the right times) with successful outcomes plus excellent service (treating patients with respect and dignity, keeping them informed, etc.) from which unnecessary, wasteful steps and processes have been eliminated.

Waste, which can come in the form of motion, defects, overproduction, time, inventory, processing and transportation, always sub-optimizes quality and the patient experience. (Shekelle et.al 1998,1894)

2. “In medical practice, pertaining to care that is expected to yield health benefits that considerably exceed risk.” (Brook, Redefining healthcare systems, 2015)

3. “the determination that the service provided is suited for the condition.”(Medical Dictionary, s.v. “appropriate.”)

In our thesis, appropriate is used in the context of opioid prescribing.

An appropriate number of opioids for each patient means the number of pills suiting each patient's needs. Needs are based on their chronic pain, physical and social environment and access to medication.

Contextual inquiry

"Contextual inquiry is a semi-structured interview method to obtain information about the context of use, where users are first asked a set of standard questions and then observed and questioned while they work in their own environments." (Usabilitybok 2018)

We plan to have conversations and ask questions to physicians and nurses when they are in a clinical setting as we want to understand how do they prescribe opioids to patients.

Fellow

"A physician who has graduated from medical school, completed a residency and is specializing in one particular area of medical care." (Michigan Medicine 2018)

In our project context, medical fellows and residents prescribe the pills to the patient when she is at pre-op hold.

Hysterectomy

Hysterectomy is an operation to remove a woman's uterus in cases of diseases or chronic pain. There are three types of hysterectomy: vaginal, abdominal and laparoscopic, which represents the area in which the surgery will be performed. (Medlineplus 2018)

We are focusing on the surgical journey of patients undergoing gynecological surgeries which include hysterectomy.

Informed decision

“A decision based on facts or information.” (Merriam Webster 2018)

In our project context informed decision means patients being informed about risks, benefits and alternate options and hence able to make decisions related to pain management.

Opioid

“Opioids are a class of drugs that include the illegal drug heroin, synthetic opioids such as fentanyl, and pain relievers available legally by prescription, such as oxycodone (OxyContin®), hydrocodone (Vicodin®), codeine, morphine, and many others.” (Drugabuse 2018)

Prescription Opioids

“Prescription opioids can be used to treat moderate-to-severe pain and are often prescribed following surgery or injury, or for health conditions such as cancer. In recent years, there has been a dramatic increase in the acceptance and use of prescription opioids for the treatment of chronic, non-cancer pain, such as back pain or osteoarthritis, despite serious risks and the lack of evidence about their long-term effectiveness.” (CDC 2018)

In our project, our focus is to engage patients in decision-making to tailor prescription opioids as per their individual needs.

Opioid-naive and Opioid tolerant

Opioid-naive refers to patients who are not chronically receiving opioid pills daily during one week or more.

Opioid tolerant refers to patients who are chronically receiving opioid pills on a daily basis; i.e. patients who are taking, for 1 week or longer,

at least: 60mg oral morphine/day; 25 mg transdermal fentanyl/hour; 30mg oral oxycodone/day; 8 mg oral hydromorphone/day; 25 mg oral oxymorphone/day; or an equianalgesic dose of any other opioid. (Med-scape Guidelines 2018)

Pain management

“Pain management is concerned with the reduction of suffering and enhanced quality of life rather than a reduction in the pain complaint.” (Hardy 1997,12)

Pain management in our project context is making and executing a plan that includes taking medications (opioid and non-opioids both) and doing alternate activities to reduce the suffering because of pain after surgery.

Patient context

In our thesis, patient context means understanding a patient’s physical, social and environmental setting which differs from patient to patient.

Patient satisfaction

“Patient satisfaction is defined as a health care recipient’s reaction to salient aspects of the context, process, and result of their service experience.” (Pascoe, 1983, 189)

“Patient satisfaction is an important and commonly used indicator for measuring the quality in health care. Patient satisfaction affects clinical outcomes, patient retention, and medical malpractice claims. It affects the timely, efficient, and patient-centered delivery of quality

health care.” (Bhanu, 2010, 151)

In our project context, physicians want to assure patient satisfaction by providing pain relief and avoiding refill requests.

Physician Assistant (PA)

“Physician Assistants have advanced education and work under the supervision of physicians, performing some of the same functions as MD’s.” (Michigan Medicine 2018)

Post-surgery

Postsurgical: POSTOPERATIVE

In the project, by term ‘post-surgery’ we refer to activities or events happening after hysterectomy surgery.

Resident/ House Officer

“A physician-in-training who has graduated from medical school and completed an internship.” (Michigan Medicine 2018)

Shared decision-making

Shared decision-making is a process in which one or more healthcare providers and the patient are involved to find what is the best possible option of care, considering the patient’s preferences and values. Each part will share information, which is fundamental for the process to happen: the provider shares their medical expertise through treatment options, risks, and benefits; the patient shares their preferences, expectations, and values. The trusting relationship between patient and

physician can also influence how that communication happens and, consequently, in the decision that was made. (Charles, Amiram and Whelan, 1997, 682) (Barry and Edgman-Levitan, 2012, 780)

For our thesis, “shared decision-making” is when patient and provider share information about their expertise and, considering those, make decisions about the patient’s pain management after surgery. Understanding patient’s values and preferences and sharing medical expertise with patients would help to engage both patient and provider and hence tailoring prescription as per patient’s needs.

Appendix 2: Prototype Development through iterations

The findings and insights obtained from the ethnographic phase informed a design-oriented phase, which involved multiple iterations of the tool's design. Careful analysis of the feedback from different areas (design, psychology, healthcare) was taken into account for each iteration of the design. The process consisted of short, but multiple, feedbacks and iterations. We believed this would result in a more robust system of tools that could improve communication around pain management between patients and providers.

Learn + reflect tool: 9 iterations

Shared decision-making tool: 7 iterations

Support tool: 4 iterations

Learn + reflect tool:

With the number of iterations, as we received feedback from design and healthcare community, we iterated over the form, content and the visual representations. Prototypes were useful in visualizing concepts and showing them to our partners. While we worked on the prototype iterations, we could discuss with our partner Dr. As-Sanie and come up with questions which would make patients reflect on their experiences and preferences related to pain management.

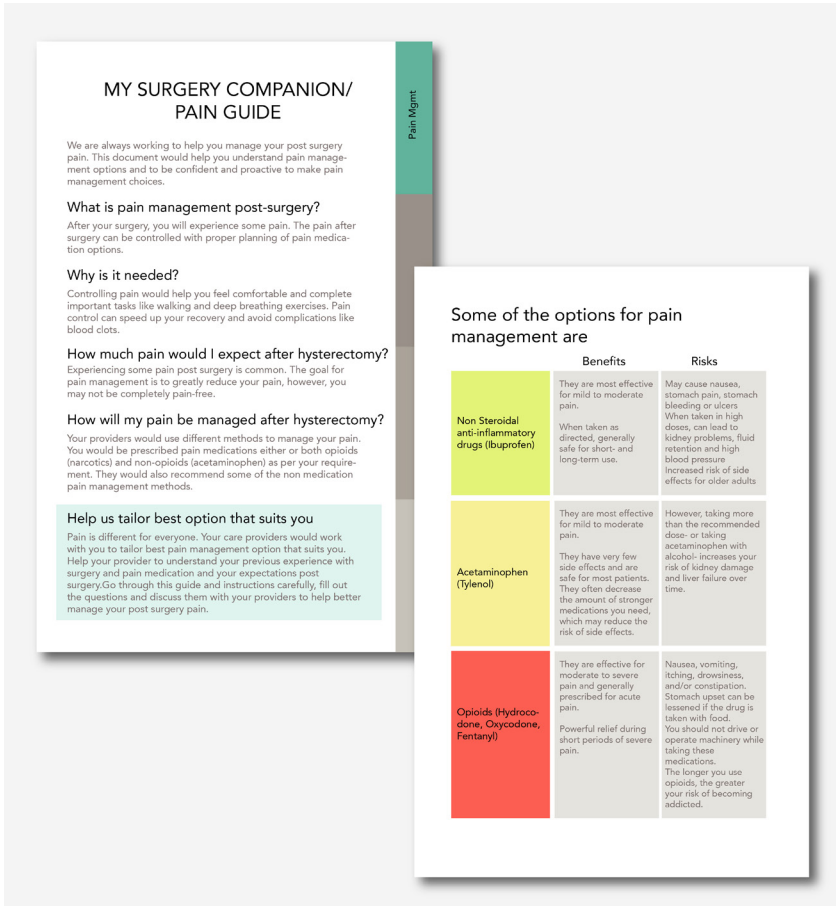


Figure 1. Learn + reflect: Iteration 1

Learnings:

1. Too much of text
2. Redundant information
3. Monotonous and not much of visual hierarchy

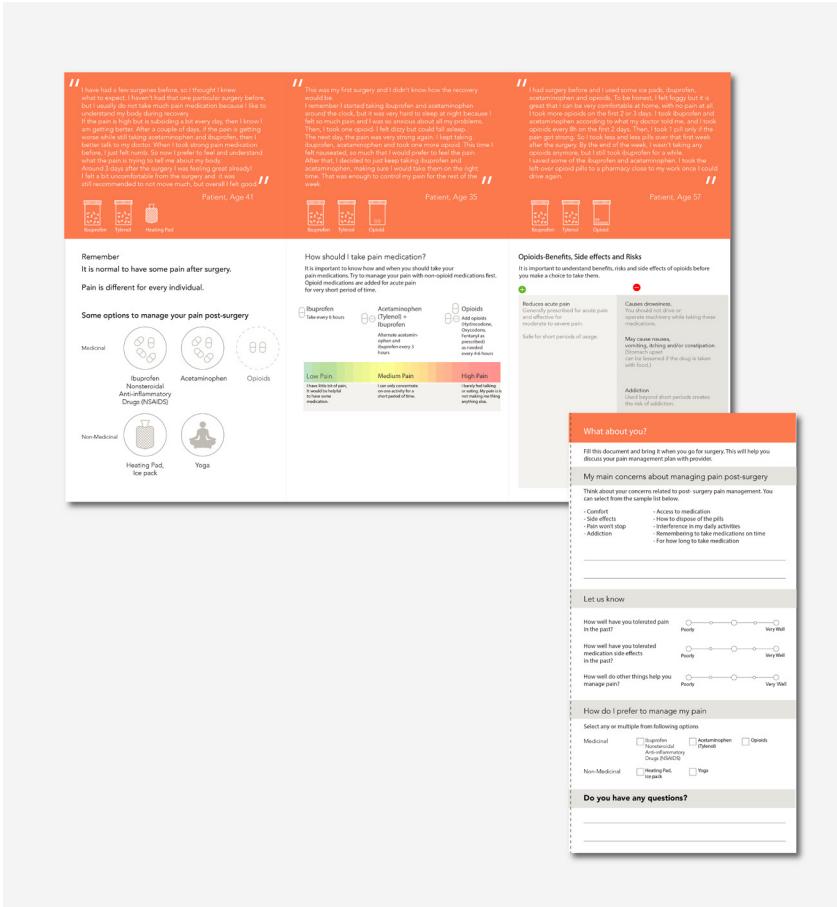


Figure 3. Learn + reflect: Iteration 7

Learnings:

1. 4 Fold form of tool not working well.
2. Information is not related to stories (The layout gives that impression)
3. Reflection questions look like an administrative document; they are not conversational.
4. Color contrast not high enough.

Shared decision-making tool:

The shared decision-making tool was shaped from understanding patients preferences and how could we prompt the discussion around provider understanding patient's preferences.

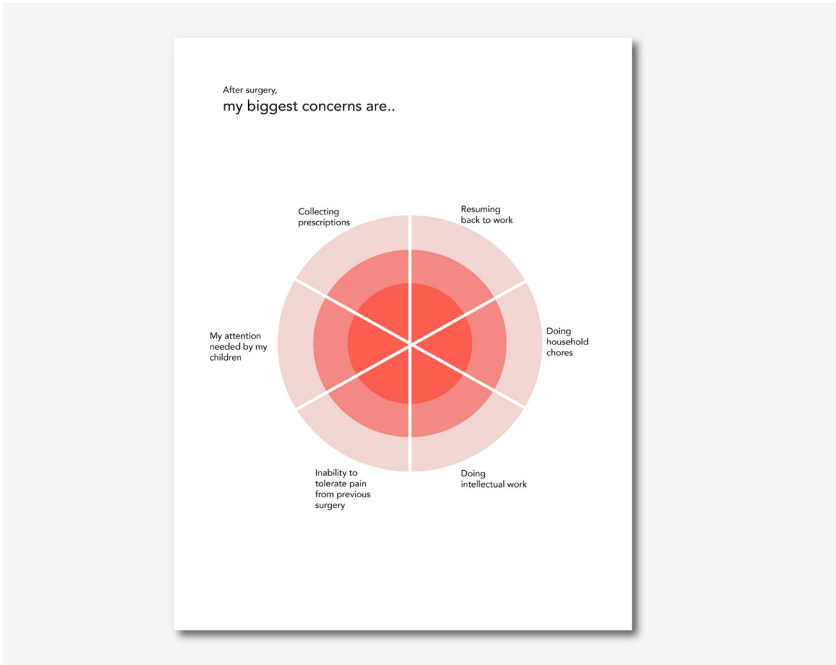


Figure 4. Shared decision-making tool: Iteration 1

Learnings:

1. This tool gives qualitative information which would not necessarily help the physician make a decision.
2. This tool could be time-consuming as it considers multiple factors.
3. Does not address previous experience with medication.



Figure 5. Shared decision-making tool: Iteration 4

Learnings:

1. The number of pills chosen and used daily might be interpreted as a standard practice by patients.
2. Access cannot be the factor deciding a pain management option. With our partner's experience, we heard that some patients might want more pills based on these criteria.
3. Too much information on one page.

Support tool:

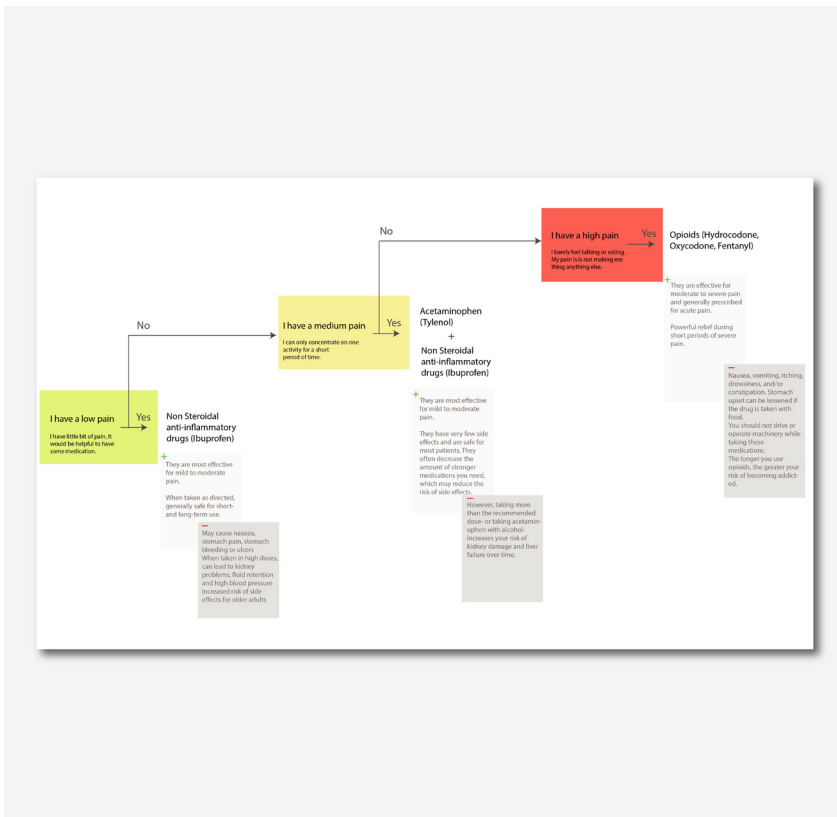


Figure 6. Support tool: Iteration 1

Learnings:

1. It was useful to show how to take medications to patients.
2. The visual form is very structured and not conversational.
3. The visual form can be complicated for some people considering the Inclusive Design factor.

		Day:											
Name of medications:	Time of day:	—											
		—											
		—											
		—											
		—											
		—											
		—											
		—											

Figure 7. Support tool: Iteration 3

Learnings:

1. This form demands too much of writing from nurses which can be time-consuming.
2. The form could be tedious to fill considering the nurse’s workload.

Appendix 3: Testing and Evaluation

1. Patient Survey based on PEMAT (Patient Education Materials Assessment Tool)

1. Please complete the sentence below:

The purpose of this material is to

2. Does the material include information or content that distracts you from its purpose?

Yes / No

3. Does this material use common everyday words?

Yes / No

4. Are medical terms used only to familiarize the audience with the terms?

Yes / No

5. When used, are medical terms defined?

Yes / No

6. Are numbers appearing in the material are clear and easy to understand?

Yes / No

7. Does the material present information in a logical sequence?

Yes / No

8. Does the material use visual cues, e.g., arrows, boxes, tables, bullets, bold, larger font, highlighting) to draw attention to key points?

Yes / No

9. Do the material's visual cues reinforce rather than distract from the content?

No visual aids=N/A

Yes / No / N/A

10. If the material includes visual aids such as illustrations and photographs, are they clear and uncluttered?

No visual aids=N/A

Yes / No / N/A

11. Does the material clearly identify at least one action the patient can take?

Yes / No / N/A

12. If the material describes a process or a series of steps, are they broken down into manageable and explicit steps?

Yes / No / N/A

13. Do you recommend adding any graphics, illustrations or photographs to this material? If yes, please describe below.

Yes / No / N/A

14. Do you recommend adding any tangible such as a checklist, planner or a diary to this material? If yes, please describe below.

Yes / No

15. Is there some type of information that you would like to know more about?

Yes, more about non-medication (heating pad, ice pack, mindful breathing, etc.)

Yes, more about non-opioid medication (ibuprofen, acetaminophen)

Yes, more about opioids

No, it was fine

Other

16. You have seen these questions on the last page of the document. Please answer them according to your own experiences.

a. How well have you tolerated pain in the past?

Comments:

b. How well have you tolerated medication side effects in the past? (for example Motrin, Tylenol, Oxycontin, Percocet, etc.)

Comments:

c. What other ways have you managed pain both with and without medication?

Comments:

17. Did you have trouble answering any of the questions from the booklet? If so, why?

18. Now consider you are having surgery in the near future. In that case, how would you manage the pain after surgery?

Heating Pad

Ice Pack

Mindful Breathing

Ibuprofen

Acetaminophen

Opioids

Other _____

19. Why do you think so?

20. Do you have an additional comment about this material?

21. On a scale from 1 to 5 (1 being not helpful at all and 5 being extremely helpful), how helpful was this booklet to prepare you to have pain management plan discussion with your physician?

22. What is your name and contact information?

Please note: this question is optional. We will only use information to contact you in case we have questions about your responses.

2. Feedback protocol (patients from PFAC Council)

Agenda:

3 min – Introduction

6 min – Reviewing Tool

5 min – Writing answers

5 min – Swapping tools

3 min – How many opioids?

7 min - Discussion

1 min – Wrap up

1a. How would you rate the usefulness of this tool?

Not at all

Not really

Undecided

Somewhat

Very Much

1b. Why do you think so?

2. What would you choose to take for your pain after the surgery?

3. Is there anything you think it is missing from this tool?

4. Is there anything you would like to know more about?
5. Is there anything you disagree with?
6. Is there anything that is confusing?
7. What do you think about the visual representations?
8. What do you think about font and color? (Is it easy to read?)

3. Test Protocol for testing tools with individual patients and providers

TEST Learn + reflect tool with Patients

Step 1: Hypothesis We believe that...

By educating patients about pain management, they feel more confident to make a decision about how to manage their pain after surgery.

Step 2: Test To verify that we will...

Testing on follow-up visit (10-15 min)

Questions before testing:

- Have you had surgery before?
- If you had surgery now, would you know how to manage your pain after being discharged?

Not at all - Not really - Undecided - Somewhat - Very Much

- How would you manage your pain?

Testing tool:

Enacting a scenario (which will be related to the surgery that the patient had, in case of the real patient)

(give background, interviewer acting as PA, hand them over reflection tool, ask them to go through it)

Questions:

- How did you manage your pain post surgery? (Show cards with some concerns pre-surgery)
- What were you most curious about/ what did you want to know when you visited the pre-op clinic?
- What were you the most concerned about?
- What did you learn from this tool?
- Is there anything new/ surprising?
- Is there anything confusing?
- How did you feel when answering the questions on the last page?
- How would you rate the usefulness of this tool? Why?
Not at all - Not really - Undecided - Somewhat - Very Much
- As you went through this, according to you, what is the best way to manage your pain?

Step 3: Metric And measure

Scale

How the patients answered the self-reflection questions on the last page

How confident was the patient about their self-reflection questions

Step 4: Criteria We are right if...

Patients considered the tool useful: somewhat or very much

Patients could answer the self-reflection questions without any questions

Patients reported feeling confident about their own assessment

TEST Learn + reflect and SDM tool with Patients

Step 1: Hypothesis We believe that...

The user will be able to assess and reflect on their pain preferences

Step 2: Test To verify that we will...

Testing tool

Enacting a scenario (which will be related to a major surgery)

(give background, interviewer acting as PA, hand them over reflection tool, ask them to go through it)

Questions

- What did you learn from this tool?
- Is there anything new/ surprising?
- Is there anything confusing?
- As you went through this, according to you, what is the best way to manage your pain for you?
- How would you rate the usefulness of this tool? Why?

Not at all - Not really - Undecided - Somewhat - Very Much

Step 3: Metric and measure

Scale

How the patients answered the self-reflection questions on the last page

How confident was the patient about their self-reflection questions

Step 4: Criteria We are right if...

People considered the tool useful: somewhat or very much

People could answer the self-reflection questions without any questions

People reported feeling confident about their own assessment

TEST Support tool with nurses

Step 1: Hypothesis We believe that...

Support tool helps nurses to explain pain management plan to patients, and it is not time-consuming for them. (1 minute or Less)

Step 2: Test To verify that we will...

Explain – learn + reflect, SDM and support tool to nurses

Show support tool to them

- According to you, how much time can you spend over pain management education?
- According to you, what are the patients' concerns at the discharge?
- What kind of questions do you get from patients?
- How would you rate the usefulness of this tool from 0-10, 10 being most useful? Why?. What is the most and what is the least useful portion of the tool?
- Is there anything confusing?
- What challenges do you see in implementing this tool?

Step 3: Metric And measure

Scale and Challenges implementing

Step 4: Criteria We are right if...

Nurses rate tool useful- 7 or more

Willing to implement the tool into their workflow

Appendix 4: Interview Protocol (Patients)

Goals:

To understand the perspective of interviewees in regard to process and problems of opioid use;

To understand if patients are reading the information materials they receive;

To understand how patients feel and understand opioid education before and after they receive it.

How influential is the conversation among providers and patients?

Who else could influence patients decisions on opioid use and disposal?

Who	When/ Point in process
Patients	Before surgery, just after pre-op clinic, 6-week post-surgery visit
Physicians	Points of education with patients
Caregivers	Before surgery, just after pre-op clinic, 6-week post-surgery visit
Call centers	Post-surgery

Questions for patients (that answered the survey) - 02.27.2018:

- Could you tell us a little bit about the information your doctor gave you regarding pain management?
- What would have been helpful to inform you?
- What medications were you prescribed to manage your pain? (Were they opioids or not?)
- Do you believe that opioids are necessary for pain management

after surgery?

- What is your perception of behaviors that lead to opioid abuse?
- Where do you think would be the ideal point within the surgery journey to receive pain management and opioid education?
- Did you receive any information regarding the disposal of leftover pills?
- Did you dispose of any leftovers pills you did not use? (Was the information useful/ Can you get to the disposal center location?) If not, why?
- What barriers did you face to dispose of the pills?
- Do you remember how many opioids you were prescribed?
- How would you feel if providers offered you fewer opioids than what you would be typically prescribed?
- If a doctor had a conversation with you about the effects and addiction of opioids, would it affect your attitude or behavior? If yes, why?
- How do you feel about the current opioid crisis in America?
- Did you have a conversation about opioids with family and friends, after your surgery experiences?