Patient-Centered Development and Evaluation of a Mobile Wound Tracking Tool

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Abstract

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Surgical site infections (SSI) are a common, costly and serious problem following surgery, affecting at least 500,000 people annually. Most infections now occur after hospital discharge, placing the burden of recognizing problems and seeking care on patients who are ill-prepared for that responsibility, resulting in reduced quality of life, preventable readmission, and enormous costs on the healthcare system. Yet, few efforts have been made to systematically engage patients in early identification of SSIs to reduce their impact.

I will describe a novel approach to addressing this problem: a patient-centered mobile health (mHealth) "app" that enables patients to serially track wound symptoms and photos, and securely communicate with their providers. To this end, I first present a needs assessment among surgical patients and providers. I then describe an iterative process of engagement with these stakeholders resulting in design considerations generalizable to post-acute care mHealth (of which wound tracking is a part). Finally, I evaluate a key consideration of any tool intended to be used clinically—that the data collected (i.e. serial wound

photos/symptom data) aid in timely diagnosis of SSI and can support appropriate management decisions.

My work has implications beyond a surgical wound tracking tool. As healthcare shifts to the outpatient setting, and patients increasingly expect to access care electronically, new applications that are "patient-centered" yet also embraced by providers will be required. A key stumbling block to provider acceptance is demonstrating clinical utility of patient-generated health data collected by these applications. Addressing these shifts, my work helps map the design space of post-acute care mHealth, taking into account both areas of potential agreement and conflict between patients and providers. In addition, I propose a new heuristic method to aid design of patient-centered health IT. Finally, I demonstrate the clinical value of novel datastreams made possible by this new class of applications, characterized both by more frequent data collection (e.g. signs/symptoms) and novel data types (e.g. photos). I apply these research contributions to strengthen the development of mPOWEr, a real-world wound-tracking tool that seeks to improve clinical outcomes as well as patients' experience on their way to those outcomes.

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DEDICATION

This work is dedicated to my family.

To my wife, Tara, I could not have gotten through without your loving support and will-ingness to forgive my occasional grumpiness.

To my daughters, Zoe and Skye, you helped ground me and remind me that there are more important things in life than academic success.

To my parents, thank you for going along with my zig-zagging career path and always having confidence that I would end up in the right place.

Chapter 1. INTRODUCTION

Surgical site infections (**SSI**) are a common and serious problem following surgery. Due to shorter hospital stays, most infections now occur after hospital discharge, putting the burden of recognizing problems and seeking care on patients who are often ill-prepared for that responsibility. More than half of patients who develop post-discharge SSI are re-admitted, contributing to SSI's status as the costliest healthcare-associated infection. Yet, despite their long-recognized and significant burden on the healthcare system and on patients themselves, few efforts have been made to systematically engage patients in early identification of SSIs at home to reduce their impact.

One novel approach to this problem is a patient-centered mobile health (**mHealth**) tool that enables patients to track relevant aspects of their wound and securely communicate with their providers. Two trends in healthcare are complementary to such an approach: first, new financial incentives (e.g. bundled payments, Meaningful Use) are giving hospitals a motivation to reduce preventable complications such as SSIs and electronically engage patients in their care; second, most people now own a smartphone and increasingly expect to use technology to help manage their health (e.g. using mHealth **"apps"**).

Yet, there exist few precedents for such an "app", in content or form. There is no common or agreed-upon standard for post-discharge surveillance of SSIs (e.g. what questions to ask patients about their wound). And though much academic work has been directed toward developing mHealth apps for managing chronic diseases, relatively little work has been done to inform the design of mHealth apps to support patients during the post-acute period (i.e. during recovery after hospital discharge), despite this period following a care transition which has been recognized as a major source of preventable patient morbidity and healthcare costs. The post-acute period is a uniquely challenging time for both patients and providers due the potential for severe complications and yet, a lack of modern tools for providers to adequately assess potential problems remotely. Finally, existing research has not assessed the clinical value of serially measuring wound features (e.g., photos and

discrete wound characteristics, as collected by a wound tracking app) in diagnosing or pre-dicting SSI.

To address these gaps, in Aim 1, I initiate a mixed-method, user-centered approach to design, beginning with a needs assessment of key patient and provider stakeholders to characterize current post-discharge wound surveillance practices. Then, in Aim 2, I pursue an iterative process of engagement with varied stakeholder groups to determine essential qualities of a wound tracking tool, paying special attention to areas of agreement and disa-greement between patients and providers. Results from the first two aims help inform the design of an mHealth solution. In Aim 3, I transition to a quantitative approach to inform how patient data should be presented and used in the resulting application. Specifically, I develop and validate a predictive model incorporating serial wound data, and then assess the ability of surgical providers to use wound data for diagnosis and management of SSI.

1.1   OUTLINE OF THIS DISSERTATION

After this outline (Section 1.1), Chapter 1 is organized with Background and Signifi-cance and then Related Work. Chapters 2-3 relate to Aim 1, Chapters 4-6 relate to Aim 2, and Chapters 7-8 relate to Aim 3 (detailed below). Chapter 9 discusses conclusions, limita-tions, future work, and contributions.

1.1.1   Aim 1. To characterize patient and provider perspectives on current post-discharge wound surveillance practices.

Through this aim, I develop a foundational understanding of current **post-discharge surveillance** (**PDS**) practices, by seeking the perspectives of key stakeholders—providers and patients—who often have different priorities. In this aim, I also assess the openness of patients and providers to addressing challenges in the existing PDS system with an mHealth wound tracking tool.

The patient experience of post-discharge complications is almost completely unstud-ied; to address this deficit, I conducted semi-structured qualitative interviews of patients who experienced post-discharge SSI, focusing on their thought processes, interactions with providers, and suggestions for system improvement (**Chapter 2**). Likewise, little data exist on provider perceptions of PDS; through surveys of providers who frequently manage post-discharge SSI, I gained insight into provider perceptions of their current PDS system and solicited suggestions for improvement (**Chapter 3**).

Overall, through an understanding of the experience of patients and providers, results from this aim provided grounding for design and development of a usable wound-tracking application that meets both patient and provider needs (further addressed in Aim 2).

1.1.2 Aim 2. To determine essential qualities of a mobile post-acute care wound-tracking tool.

User-centered design is associated with a wide range of benefits (e.g., increased user productivity, fewer errors), yet applications in the healthcare domain are notorious for employing top-down approaches to software development.[1] In this aim, I engage a variety of stakeholders in the design of a wound tracking tool, helping to map the under-explored space of post-acute care mHealth. In addition to surgical providers, I engage post-discharge surgical patients and patient advisors (patients and caregivers who volunteer to represent the patient perspective in hospital decisions). Through an iterative user-centered process, I generate design considerations for post-acute care mobile health from the patient perspective (**Chapter 4**) and then extend this work by incorporating provider perspectives, allowing exploration of design challenges resulting from misalignment of patient and provider expectations (**Chapter 5**).

In conducting work for Aims 1 and 2, I realized that despite having a goal of designing a "patient-centered" application, no methods or criteria existed in the literature to evaluate the "patient-centeredness" of health IT applications. I, therefore, propose a novel "patient-centered heuristic evaluation" to fill this gap (**Chapter 6**).

1.1.3 Aim 3. To evaluate the clinical utility of serial wound data in diagnosis and prediction of SSI.

Aims 1 and 2 are intended to highlight gaps in current PDS processes and engage stakeholders in design of a useful and usable application to fill these gaps, but have not addressed a key consideration of any tool intended to be used clinically: that the data collected (i.e., serial wound photos and data) aid in diagnosis or even prediction of SSI, and can be used to make appropriate management decisions. Most related work has used **baseline (or static) patient data** (e.g. diabetes status, length of operation) to predict SSI, rather than **serial (or dynamic) data** (e.g., daily wound observations and photographs, vi-

tal signs). In addition, previous work has not assessed the impact on provider decision-making of added wound photographs in the context of post-discharge wound monitoring.

To evaluate the utility of serial wound data for prediction of SSI, I used a unique dataset consisting of daily wound observations and vital signs on 1,000 post-operative patients followed for SSI for 20 days. I assessed the predictive value of a range of wound features, and developed and evaluated a prognostic model of SSI using machine learning techniques, comparing the performance of traditional baseline data vs serial data in classifying patients as likely to develop SSI (**Chapter 7**).

Beyond traditional clinical data currently available to providers, I sought to assess the marginal utility of a new type of data—wound photos—for diagnosis and management of SSI (**Chapter 8**). A national sample of providers with expertise in surgical infections was presented with a range of real patient scenarios (including both baseline and serial data derived from the dataset used in Chapter 7) and were asked to make diagnoses, rate confidence, and make management decisions first without and then with accompanying wound photos. At each step, they ranked the most important elements contributing to their decision. Primary endpoints were change in diagnostic accuracy, confidence in diagnosis, and management with addition of photos.

1.2 BACKGROUND AND SIGNIFICANCE

I will describe the epidemiology and burden of SSIs and their shift toward the post-discharge period, including a review of current methods of PDS and their limitations (**1.2.1**). I will then discuss changing incentives and priorities within the healthcare system that increase the likelihood of adoption of an mHealth wound tracking tool **(1.2.2).**

1.2.1 Surgical site infection

SSIs are a leading cause of postoperative morbidity, occurring in 3-5% of all surgical patients and affecting at least 500,000 patients/year.[2–4] Patients with risk factors such as diabetes or undergoing particular operations are at even higher risk: for example, up to 33% of patients undergoing abdominal surgery are likely to develop an SSI.[3,5] Not captured by these statistics are the significant concerns and anxiety that many patients experience.[6,7]

1.2.1.1 Most infections happen after hospital discharge

With increasingly shorter hospitalizations, most SSIs now occur after patients go home.[8–11] Some studies have shown up to 84% of SSIs occurring post-discharge.[8,12] Particular kinds of surgery, e.g. breast, bariatric and ventral hernia repair, have the highest proportions of complications occurring post-discharge (up to 79%).[11]

Yet, the post-discharge period is a uniquely challenging time for patients. They have experienced a "voltage drop", no longer having the intense monitoring characteristic of the inpatient setting, and yet may still suffer physical and/or mental impairments (e.g. from pain medication) that make self-care challenging.[13] In addition, patients may lack knowledge about and awareness of SSI; although patients may be aware of particular SSI symptoms, they often don't recognize that they have an infection.[14,15]

Of infections occurring post-discharge, most (up to 68%) will occur prior to the follow-up visit, leaving patients with the responsibility to identify and seek treatment for these complications (see **Figure 1-1**).[11]
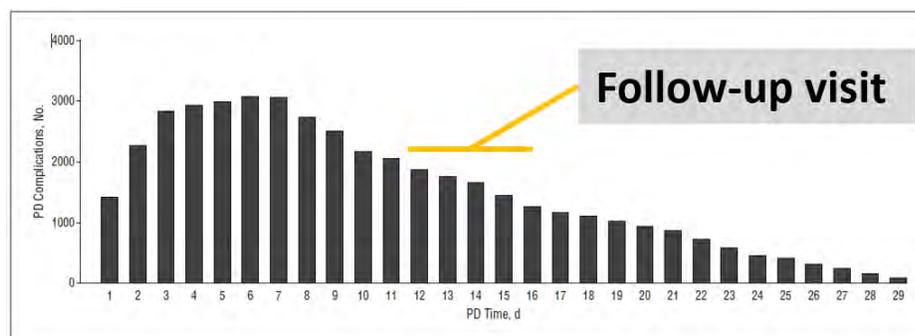
Figure 1-1. Complications following surgery. By days post-discharge (PD), adapted from Kazaure et al[11]. Typical follow-up interval is 12-16 days after discharge.

1.2.1.2 Infections are dangerous and costly

Patients with SSI are at significantly higher risk of readmission and death. More than half of patients developing SSI post-discharge were readmitted in one study (representing a 5-fold increase in readmission risk).[10,16] In addition to increased risk of readmission, patients with SSI are at least 3 times more likely to die.[17] Several studies have also found that SSI has a significant negative impact on quality of life. [3,14,18] Overall, SSI is the economically costliest healthcare-associated infection, costing up to $10 billion per year.[19,20]

1.2.1.3 Current methods of post-discharge surveillance are problematic

With the significant burden that post-discharge SSIs pose to patients and the healthcare system, it is surprising that there is no common—or even well-accepted—way to detect post-discharge SSI.[8,21,22] Many authors writing about PDS have focused on Quality Improvement (QI), i.e. with the intention to retrospectively monitor infection rates for external and internal reporting purposes. Importantly, PDS has not been described in the literature as conceived in this dissertation, i.e. for prospectively identifying infections early to improve individual patient outcomes, and, according to a 2004 systematic review, no studies have been conducted to evaluate the effect of establishing a system of PDS on patient outcomes.[21] However, conducting active PDS (see **Table 1-1**, below), *in conjunction with a*

system to feedback infection rates to individual surgeons, has been shown to reduce sub-sequent SSI rates by up to 40%, presumably by alerting surgeons to the problem.[23,24]

Table 1-1. Active vs passive post-discharge surveillance.

Active PDS	Passive PDS
• Purposefully attempting to determine who has developed an infection among all patients. • Rarely done in the US.	• Secondary recording of infections that become known to the hospital/clinic with no attempt at case finding. • Done in US to a limited extent.

Mannien et al.[25], taking a QI perspective, identified the three main goals/challenges of PDS as: (1) follow-up of all patients, (2) accurate diagnosis of presence/absence of SSI, and (3) feasibility with limited resource investment. To be clinically useful, a fourth goal should be added: timeliness of data, i.e. to allow early identification and treatment of problems (see columns of **Figure 1-2**).

Mangram et al.[8] identified four main active methods which are described below (see rows of **Figure 1-2**).

Direct observation of wound by practitioner. While direct exam of the wound is considered the gold standard of SSI diagnosis, it represents only a single point in time and relies on bringing a patient and practitioner physically together, making it expensive and labor-intensive.[26,27]

Review of medical records (ICD-9 codes, antibiotic dispensing). Review of medical records has the potential to be automated (and therefore inexpensive), but it has been shown to have variable sensitivity and specificity, and relies on retrospective data from the medical record which may be present for only the sickest patients (leading to selection bias).[28–31] The indication for antibiotics is generally poorly documented in medication administration records, which could lead to an over-estimation of the rate of SSI. Alternatively, patients may also receive antibiotics from a provider not associated with

the surgical encounter (e.g., primary care physician) who may not share the electronic medical record of the index hospital where surgery was performed, leading to under-estimation of SSI rates.

Patient surveys by mail or telephone. Patient surveys have the potential to inexpensively reach most or all patients and has been shown to have a high negative predictive value (i.e. patients can recognize the absence of infection). However, in addition to being retrospective, it has variable response rates and low positive predictive value (i.e. patients over-call infections).[8,32,33]

Surgeon surveys by mail or telephone. Surveys of surgeons are reliant on the surgeons being in post-discharge contact with the patient. In addition to being retrospective, surveys of surgeons about their patients were found to be unreliable and burdensome on surgeons.[34,35]

Qualities ► ▼Methods	Tracks all patients	Accurate diagnosis	Feasibility/ efficiency	Timely data
Direct observation of wound by practitioner [26,27]	✗	✓	✗	✗
Review of medical records (ICD-9 codes, antibiotic dispensing) [28–30]	✗	✗	✓	✗
Patient surveys by mail or telephone[8,32,33]	✗/✓	✗/✓	✓	✗
Surgeon surveys by mail or telephone[34,35]	✗	✗	✗	✗

Figure 1-2. Methods of post-discharge SSI surveillance assessed on 4 qualities.
Qualities were adapted from Mannien[25] and Methods were adapted from Mangram[8]. Red X denotes lacking the quality; green check denotes possessing the quality.

Petherick concluded that existing research "has not identified a valid and reliable method" of PDS.[21] As can be seen in **Figure 1-2**, all of the current methods for PDS are flawed: unable to track all patients, inaccurate, costly, and/or untimely. As a result, there is no generally accepted methodology for PDS and no wide acceptance of any single method of PDS.[8,21,22] Despite their limitations, current PDS methods can inform the clinical content of the wound-tracking tool. A review of PDS instruments' criteria and survey questions (e.g. asked of patients by mail or telephone) will likely yield insights into signs/symptoms patients should track.

The premise of this dissertation is that a novel patient-centered mHealth application could serve not only in a Quality Improvement role, but more importantly could aid patients and providers in early identification of problems and provide a direct route for communication during the stressful post-discharge period.

1.2.2 Healthcare system

The US healthcare system is in a state of flux, and many recent changes are conducive to the development and adoption of novel patient-directed, clinically-integrated tools that can support safer, higher-quality, cost-effective, and patient-centered care. In addition to a longer-running effort to make the US healthcare system safer, recent legislation has markedly changed incentives around hospital payments to put financial pressure on hospitals to reduce preventable complications and readmissions, and improve quality metrics and patient participation in care. The concept of "patient-centered" care has achieved new prominence with the creation of institutions like the Patient-Centered Outcomes Research Institute (PCORI) which funds comparative effectiveness research based on outcomes that are meaningful to patients. The following sections describe these changes in more detail and how a wound-tracking tool could be responsive to these changing incentives.

1.2.2.1   Increasing focus on patient safety

Since the publication of the Institute of Medicine's (IOM) report "To Err is Human: Building a Safer Health Care System" in 2000[36], increased attention has been paid to the harm caused by healthcare itself. Preventable medical conditions, including infections, are said to be at least the 6th leading cause of death in the US, contributing to the death of 98,000-440,000 patients per year.[36,37] SSIs have been associated with a 4-10% increased absolute mortality risk[16,38], representing a contribution to 20-50,000 deaths per year. A tool that allows earlier discovery and treatment of SSIs could allow for increased patient safety.

1.2.2.2   Changing payment models incentivize better patient outcomes and HIT adoption

Changing payment systems are putting pressure on hospitals to deliver cost-effective, high-quality care, thus minimizing preventable complications such as SSIs. Whereas under a traditional "fee for service" model, hospitals would be paid extra to treat preventable complications [39], newer systems such as Medicare bundled payments pay hospitals a lump sum for an entire episode of care, including post-discharge complications and readmissions. Accountable care organizations (ACOs) will have a similar payment structure that also includes bonuses for meeting quality benchmarks. Promisingly, in their first year all 32 "Pioneer" ACOs met quality performance metrics, 25 of 32 reduced readmission rates and more than a third reduced costs from the previous year.[40]

Meaningful use (MU) is a set of standards defined by the Centers for Medicare & Medicaid Services (CMS) that incentivizes adoption of Electronic Health Records (EHRs) meeting particular criteria. The core aims of MU are achieving electronic data capture and sharing, advanced clinical processes, and improved outcomes.[41] These aims are in alignment with a patient-directed, EHR-connected wound tracking tool. Some specific criteria for MU that may be especially relevant include: reporting of clinical quality measures, using information to engage patients in their care, supporting patient-controlled data, and enabling patient access to self-management tools.[41]

1.2.2.3 Care coordination during transitions of care is a cost and quality problem

Research has shown that failures of care coordination are common in the US.[42] The "voltage drop" is particularly severe as patients transition from the hospital back to the community, setting patients up for medication errors, failed follow-up, preventable readmissions and ER visits, and other adverse health outcomes related to both overuse and underuse of care.[13]

CMS, through the Medicare Coordinated Care Demonstration project, is supporting pilot programs to reduce readmissions among Medicare enrollees at high risk of near-term hospitalization. Four of 11 programs were successful in reducing readmission by 8-33%.[43] The common elements of these successful individual approaches include: more frequent and organized communication with providers; delivering evidence-based education to patients; providing strong medication management; and providing timely and comprehensive transitional care after hospitalizations.[43]

A wound-tracking tool has the ability to support each of these elements and is therefore a promising means to fill in gaps that occur during major care transitions, preventing costly readmissions as well as improving patients' experiences during this often stressful time.[13]

1.2.2.4 Patient-centered care: a new priority

The Institute of Medicine included patient-centeredness among its 6 aims for a "21st century health care system", and the recent Affordable Care Act has made it a funding priority (e.g. PCORI).[44] Patient-centered care has been associated with improved outcomes such as better recovery from discomfort, better emotional health, and decreased utilization.[45] Through focus groups, survey findings and literature review, Bechtel et al.[46] summarized the key attributes of patient-centered care as:

1. **"Whole-person" care**: understanding each patient as a whole person rather than a collection of body parts

2. **Comprehensive communication and coordination**: coordination of care across settings; clear "go-to" person to answer questions

3. **Patient support and empowerment**: partnership with providers; support for self-management; trust and respect

4. **Ready access**: getting appointments promptly, having care team available when needed by phone, email, online or in-person, including nights and weekends

A wound-tracking tool could foster patient-centered care by helping to improve communication, facilitate partnership with providers and support self-management when appropriate, and provide ready access to the care team though modes of communication which suit patients' increasingly digital preferences. Such a tool has the potential to allow the patient, the most "underused resource in healthcare", to play a more active role in managing their health, reflecting the "growth in importance of the patient as full participant in health care".[47,48]

1.3   RELATED WORK

Commercially and in research, most focus has been on chronic wounds (e.g. due to diabetes[49] or immobility[50]) and has been provider-oriented rather than patient-oriented (e.g. interfacing with a visiting home nurse to document a wound or teleconference with a specialist).[51–53] Recently, a commercial application designed to monitor post-discharge quality of recovery was described in the literature. This application, which also collected wound photographs, was found to be feasible and acceptable to patients and providers.[54] However, with limited direct precedents, I have drawn from three broader areas which can inform this work (see **Figure 1-3**, below). Work on **patient-reported outcomes** can speak to the challenges and benefits of gathering data directly from patients **(1.3.1)**. Two subareas within **telemedicine**—teledermatology and remote monitoring—can inform the provider-directed transmission and monitoring of patient data and photographs **(1.3.2)**. Finally, previous **mHealth** work may speak to design considerations for mobile "apps" **(1.3.3)**.
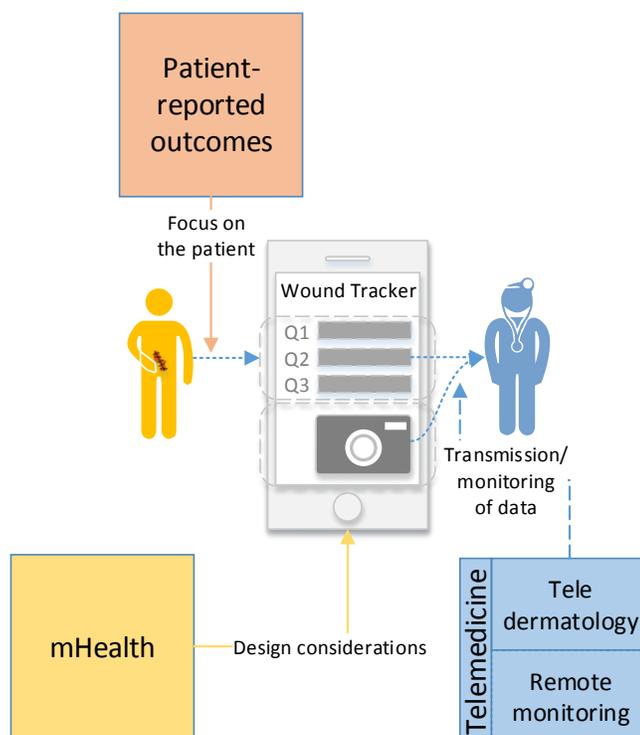
Figure 1-3. Areas of related work.

1.3.1 Patient-reported outcomes (PROs)

Patient-reported outcomes are measurements of any aspect of a patient's health status collected directly from the patient. PROs aim to capture the patient perspective on health, illness and treatment in a reliable, valid, and acceptable way.[55] Common uses for PRO instruments are as screening tools, methods to identify patient preferences, and means to improve patient-provider communication and shared decision-making.[56] The most commonly studied settings for PRO use are in mental health, primary care, cancer, and chronic illness.[56]

1.3.1.1 Evidence of benefits of PROs

In a recent systematic review, 15/23 studies measuring a process of care (e.g. rate of diagnosis, rate of referrals) observed a significant improvement, and 8/17 studies measuring a care outcome (e.g. functional status, health-related quality of life) observed a signifi-

cant improvement using PROs.[57] Despite their seemingly patient-focused nature, PROs have shown clearest benefit to providers through improved comprehensiveness, quality and timeliness of data collection.[58]

1.3.1.2 Challenge of PROs

One of the main obstacles to routine collection of PROs is incorporating them into usual clinical practice.[58] Electronic questionnaires help to address this problem (and are preferable to patients vs paper[58]), but key workflow challenges remain (i.e., how and when providers will be provided with PRO data, especially urgent data that may require real-time review). Systematic reviews have noted challenges in evaluating PRO interventions on methodological grounds and due to the heterogeneity of PRO interventions, leaving questions about the effectiveness of PROs more broadly, especially in real-world clinical settings.[56,57] Feasibility studies of the particular PRO platform (ESRA-C / cPRO) to be used for wound tracking have demonstrated its successful incorporation into clinical workflows in the context of oncology and HIV/AIDS care.[59–61]

PROs are now being collected with the hope of giving the patient more voice in their care; PROs have been shown to improve processes and outcomes in a number of settings, and hold promise in improving the post-discharge management of surgical wounds.

1.3.2 Telemedicine

Telemedicine is defined by the World Health Organization as the practice of healthcare using interactive audio, visual and/or data communications, to facilitate healthcare delivery, diagnosis, consultation, and treatment.[62] Telemedicine may be especially helpful for specialties with significant visual components such as dermatology, radiology or pathology.[53] Patients most likely to benefit are those who face travel limitations (e.g. due to expense or medical condition).[53] Jones et al. suggest that wound management may be an especially good fit for telemedicine given the key visual component and common incapacitation of patients with wounds.[53]

Wound tracking draws on two main subareas of telemedicine: teledermatology (e.g. for transmission and interpretation of wound photos), and remote monitoring (e.g. for monitoring of signs and symptoms of wound infection). Each subarea will be discussed in turn, followed by a broader discussion of benefits and concerns around telemedicine.

1.3.2.1 Teledermatology

Teledermatology is an area within telemedicine that has particular relevance to wound-tracking given the importance of photography of wounds on the skin. Many wound-related teledermatology studies have been conducted in the inpatient setting, e.g. to assess wound healing. In one recent study comparing in-person (gold standard) vs photographic diagnosis of SSI, sensitivity of photographic diagnosis averaged 42% and specificity averaged 97% in classifying wounds as infected.[63] Most studies have shown remote assessment of wounds to be generally comparable to in-person exam.[64–67]

In the outpatient setting, Pirris et al.[68] describe a case series using SMS/email to monitor the healing progress of previously diagnosed infections in the setting of pediatric neurosurgery. While they don't take a quantitative approach to evaluation, they anecdotally conclude that remote, patient-captured photos are helpful in management, and patient families reported high satisfaction, but medicolegal issues stand in the way of broad adoption.[68] Mobile phone cameras have been more quantitatively assessed in outpatient settings of ulcer monitoring [51], psoriasis monitoring (with patient-captured photos) [69], skin cancer screening [70,71], and other dermatological conditions[72], resulting in diagnostic accuracy between 59-93%[53] with good reliability[73]. Patients and providers report high acceptance of and satisfaction with such monitoring.[51,69,73] A study surveying patients who presented at an emergency department (ED) with acute wounds found that patients considered the idea of sending mobile phone photos to ED physicians for triage (i.e. getting a recommendation about whether to come to the ED) to be very acceptable—somewhat more so than for formal diagnosis.[74] Of note, all but 2 of the studies cited above involved provider-captured photos; few studies have examined the feasibility or quality of patient-captured photos.

1.3.2.2   Remote monitoring

Remote monitoring is defined as the "capture of clinically relevant data in patients' homes or other locations outside of conventional hospitals, clinics or provider offices, and the subsequent transmission of the data to central locations for review".[75] The rationale for this monitoring is that (a) "clinically significant changes in patient condition occur between regularly scheduled visits and that these changes can be detected", and (b) that patients can benefit from early detection of these changes and resulting treatment.[75] Most remote monitoring tools have automated sensor-based data capture, but because there are no physiological parameters that are particularly specific or sensitive to SSI, most or all wound-related data elements need to be manually captured by the patient.

Remote monitoring is one of the few areas within telemedicine that has (some) high quality evidence derived from RCTs. Meta-analyses, discussed further in the next section, have shown remote monitoring to reduce utilization and improve patient outcomes in a variety of settings, from diabetes to asthma to heart failure.

1.3.2.3   Benefits of telemedicine

The main proposed benefits of telemedicine are reduced costs, better patient outcomes and improved patient satisfaction. Of 80 reviews of telemedicine focusing on these areas, 21 concluded that it is effective, 18 found that it is promising, and the remainder concluded that the evidence in limited and inconsistent.[76]

Reduced costs. Telemedicine may reduce health care costs through reduced travel costs (accounting for a significant proportion of the total cost of healthcare[77]), reduced utilization and more efficient resource allocation. For example, Geisinger used a post-discharge interactive voice response system to decrease 30-day readmissions by 44%[78] while the Veterans Administration showed a 20% decrease in utilization with reduced rates of hospitalization among COPD patients randomized to a telemedicine group.[79] Telemedicine may also reduce costs through increased efficiency by centralizing data for remote analysis.[75]

Better patient outcomes. Mainly through remote monitoring, telemedicine has been shown to improve patient outcomes, helping patients to improve glycemic control (in diabetes), peak expiratory flow and quality of life (in asthma), and blood pressure (in hypertension).[80] In a large RCT in the UK involving patients with diabetes, COPD or heart failure, the telemedicine intervention group had 45% lower mortality and 20% lower ED admission rates compared to controls.[81]

Improved satisfaction. According to a systematic review of telemedicine, patient satisfaction with telemedicine is a relatively consistent theme; patients tend to feel more confident and empowered, and experience better patient-provider relationships.[76]

Other benefits specific to wound tracking. In addition to better patient and system outcomes, telemedicine may provide a benefit to researchers by helping to provide granular data on the natural history of various conditions. For example, frequent prospectively-tracked wound symptom data, when correlated to outcomes of interest (e.g. SSI, readmission) may help to refine algorithms to identify and treat surgical complications early.

1.3.2.4 Concerns around telemedicine

Major concerns related to telemedicine include unpredictable effects on utilization and provider workflow disruption.

Effect on utilization. One concern about telemedicine is that wide implementation could have unpredictable effects on patient management due to changes in the frequency of face-to-face contact with subsets of patients.[75] While most studies have shown telemedicine to have positive effects on mortality, one frequently-cited RCT among elderly patients showed a significant, unexplained increase in mortality (14.7% vs 3.9% in usual care); the authors hypothesize that increased access to healthcare (e.g. leading to unnecessary tests) may be to blame.[82] Triage via telemedicine will presumably lead to more visits by the sickest-appearing patients and correspondingly fewer visits by other patients, with potentially unknown effects on outcomes.

Provider workflows. Large scale telemedicine represents a disruption to the traditional workflow model of sequential synchronous interaction between patient and provid-

er. Providers (and/or other staff) will be receiving "streaming" information on many patients, disrupting the conventional paradigm where the fundamental unit of care is the office visit.[47] This new system will likely require a major rethinking of current workflows: providers may shift from "assembly-line workers to air-traffic controllers"[47], however providers must still adequately attend to individual patients needs and concerns even in this new context. Depending on how telemedicine is implemented, it has the potential to either disrupt or strengthen patient-provider relationships.

1.3.3   mHealth: connected patients + smarter phones

Healthcare has not moved as quickly as other industries to embrace new modes of communication. As patients increasingly use their smartphones for every other aspect of their life, many still interact with their healthcare providers through fax and telephone. Patients have long expressed their desire to have online access to their medical records and electronic communication with their providers, which studies have shown to improve the quality and efficiency of healthcare while decreasing utilization[83–87]; recent regulations such as Meaningful Use may finally make such interactions commonplace. In addition to facilitating such communication, smartphones could serve as an ideal platform for a post-acute (i.e. after discharge) wound tracking app. However, most previous research in mHealth has focused on aiding the management of chronic diseases, and it is unclear how applicable those design considerations are to the shorter-term, higher-intensity post-acute setting of a wound-tracking app. To explore the applicability of previous mHealth work in chronic disease to the proposed wound-tracking tool, I will highlight some examples of design considerations that appear universal and some that may be less applicable to a wound-tracking tool.

1.3.3.1   Growth of mHealth

Mobile technology has become integrated into almost all aspects of daily life and people increasingly expect to manage their healthcare through mobile technology. Today, 56%

of US adults own a smartphone, and 69% track at least one health indicator.[88,89] mHealth has seen significant growth in personal/consumer health domain (i.e. not mediated by providers), but has not yet been widely adopted clinically. Yet, many of the potential benefits of mHealth, such as improving access and care quality, and decreasing costs, may only be achieved once providers are "in the loop".[90]

1.3.3.2   mHealth for wound tracking

Smartphones have both technical and user relationship characteristics complementary to wound tracking. Key technical characteristics include high quality cameras, always-on internet connectivity, and powerful processors. Users' relationship to their phones are also critical: for example, users' familiarity/comfort with the device and their tendency to have the device close at hand at all times.[90] Together, these characteristics make smartphones an ideal platform for wound tracking and patient-provider communication.

1.3.3.3   mHealth design considerations

Previous work on mHealth applications may help inform the design of a wound tracking tool. Though the mHealth space is large and can't be comprehensively reviewed here, much of it has focused on self-tracking, either for wellness or managing chronic diseases such as cancer[91,92] or diabetes[93,94]. It is unclear whether design considerations for chronic mHealth tracking apps apply as well in a post-acute setting. Apps for management of chronic conditions are characterized by achieving symptom control and long-term behavioral change. In contrast, the purpose of a post-acute care app might be to help avoid escalation around a single, limited duration episode of treatment while a patient is returning to a usual health state. In the following sections, I will review some examples of mHealth design considerations that appear universal across settings and some that may be less applicable in a post-acute setting.

Universal mHealth design considerations

Some design considerations likely apply across a wide range of mHealth settings. For example, Klasnja et al[95] found that the ability for cancer patients to capture and access a variety of care-related information while on the go, in a single app, helped them manage their care and feel more in control of their information and health. Since managing information is a key task for patients in any setting, enabling the organized storage of health information is likely to be a universal mHealth theme.

Arsand et al[96] found that diabetes patients preferred to have some reward (e.g. education or feedback) at the time of data entry to provide a built-in motivation for use. This finding relates to a broader theme that, in order to continue using an app, patients must find it useful, both in the short term (e.g. providing stimulation/gratification) and long term (e.g. helping to achieve health goals).

Liu et al[97] found that parents wanted to communicate with providers in different ways to suit their needs, both synchronously (e.g. telephone) or asynchronously (e.g. email). Communication with providers can be critical across a range of chronic and acute conditions, and supportive mHealth apps should facilitate communication using means that are both efficient and acceptable to patients.

Kientz et al[98] suggest that the act of tracking health measures (e.g. infant development) has the potential to increase anxiety over trends that appear abnormal. Apps that capture patient data will have to carefully consider how to reflect that data back to patients, including whether and how to provide interpretation of that data.

Design considerations for chronic mHealth apps may not apply to post-acute care apps

Other design considerations for chronic mHealth applications might be less applicable or introduce new challenges in an acute context, ranging from privacy and self-reflection to automated feedback and engaging social networks. For example, Patel et al[91] identified giving breast cancer patients ownership over data (e.g. controlling what data is shared, capturing custom fields) as important to promote engagement in care and capture of sensitive data. Although patients should always have control over what information is shared with

others, care providers may be concerned about patients sharing *too much* data that cannot be efficiently reviewed.

Mamykina et al[93] identified promoting self-reflection as a primary design goal to aid in self-management for people with diabetes. Self-reflection is a critical element in the management of many chronic illnesses that rely on patients to make lasting behavioral changes. However, the importance of self-reflection in a post-acute setting is unclear given the short time horizons, cognitive impairments (e.g., due to pain medication), and limited control that patients often have over their care outcomes in this setting.

Harris et al[94] identified automated, programmed responses as a key design requirement for diabetes self-management. Automated responses may support self-reflection and have the benefit of giving immediate feedback and gratification to patients without burdening a provider, however more urgent or complex assessments associated with acute concerns might not be reliably made without human involvement.

Finally, much work has been done using mHealth to help patients engage social networks and online communities for support in their care (e.g., Liu et al[97] in the parenting of high-risk infants). However, the utility of online communities is unclear over short durations and highly individualized recovery periods following hospital discharge. In addition, unlike with chronic conditions, acute conditions tend not to have dedicated online communities.

Though the examples above are not exhaustive, and many design considerations for chronic mHealth applications likely apply to post-acute applications as well, I suggest that the requirements and user experience in chronic and post-acute settings are sufficiently different to warrant further research. One of the goals of my dissertation is to explore a design space for applications that improve communication and meet patient needs in the post-acute care setting.

Chapter 2. PATIENT PERSPECTIVES ON POST-DISCHARGE SURGICAL SITE INFECTIONS: TOWARDS A PATIENT-CENTERED MOBILE HEALTH SOLUTION

2.1 ABSTRACT

Background: Post-discharge surgical site infections (SSI) are a major source of morbidity, expense and anxiety for patients. However, patient perceptions about barriers experienced while seeking care for post-discharge SSI have not been assessed in depth. We explored patient experience of SSI and openness to a mobile health (mHealth) wound monitoring "app" as a novel solution to address this problem.

Methods: Mixed method design with semi-structured interviews and surveys. Participants were patients who had post-discharge surgical wound complications after undergoing operations with high risk of SSI, including open colorectal or ventral hernia repair surgery. The study was conducted at two affiliated teaching hospitals, including an academic medical center and a level 1 trauma center.

Results: From interviews with 13 patients, we identified 3 major challenges that impact patients' ability to manage post-discharge surgical wound complications, including required knowledge for wound monitoring from discharge teaching, self-efficacy for wound monitoring at home, and accessible communication with their providers about wound concerns. Patients found an mHealth wound monitoring application highly acceptable and articulated its potential to provide more frequent, thorough, and convenient follow-up that could reduce post-discharge anxiety compared to the current practice. Major concerns with mHealth wound monitoring were lack of timely response from providers and inaccessibility due to either lack of an appropriate device or usability challenges.

Conclusions: Our findings reveal gaps and frustrations with post-discharge care after surgery which could negatively impact clinical outcomes and quality of life. To address these

issues, we are developing mPOWEr, a patient-centered mHealth wound monitoring application for patients and providers to collaboratively bridge the care transition between hospital and home.

2.2 INTRODUCTION

Surgical site infections (SSI) occur in 3-5% of all surgical patients, and up to 33% of patients undergoing abdominal surgery [3,4]. With shorter hospitalizations, most SSIs now occur post-discharge, placing a burden on patients who are often ill-prepared to manage SSI [8–11]. More than half of patients who develop post-discharge SSI are readmitted to the hospital, making SSI the overall costliest healthcare-associated infection [10,19,99]. Non-financial costs of post-discharge SSIs to patients are also high, especially in decreased quality of life [18].

The transition between in-hospital and post-discharge surgical care poses special challenges that exacerbate the morbidity of post-discharge SSI. Patients experience a "voltage drop" at discharge—a sudden decrease in supervised wound assessment and patient-provider communication—yet take on primary responsibility for problem recognition and wound care at home [13]. Patients may have minimal or ineffective discharge teaching [7], resulting in lack of knowledge and awareness about SSI, and ultimately, an inability to recognize when an infection develops [14,15]. Recent studies suggest that inadequate post-discharge communication and untimely, infrequent follow-up contribute to poorer outcomes (e.g. readmission) [100,101].

Mobile health (mHealth) may present an opportunity to improve the identification and management of post-discharge SSI. Smartphones possess high quality cameras and constant internet connectivity, providing an ideal platform for multimedia clinical data collection and real-time patient-provider communication [90]. Patients are increasingly interested in and equipped to manage their health with technology, with 56% of US adults owning a smartphone and 69% tracking at least one health indicator [88,89]. To better understand how patients experience SSI following surgery and how technology could improve their experience, we addressed the following hypothesis-generating research questions:

1. What challenges do patients experience when identifying and managing surgical wound complications after discharge?

2. What are patients' perceptions about the acceptability of an mHealth wound monitoring application to address those challenges?

2.3 METHODS

We conducted a mixed-methods study comprised of semi-structured interviews and surveys with patients who experienced surgical wound complications after hospital discharge.

2.3.1 Ethics statement

The study was approved by the University of Washington Institutional Review Board and written consent was obtained from all participants prior to undergoing study procedures.

2.3.2 Participants and setting

We interviewed adult, English-speaking patients who had post-discharge wound complications after undergoing an intra-abdominal operation at high risk for SSI. Patients were recruited at two University of Washington general surgery clinics. Following the standard discharge protocol, patients were asked to call the clinic if they had concerns prior to their follow-up visit, which generally occurred 1-2 weeks post-discharge.

Using consecutive sampling, patients were identified either directly by clinic nurses at follow-up visits or through patient-initiated contact via IRB-approved recruitment flyers placed in surgery clinics.

2.3.3 Data collection

We conducted one-on-one, semi-structured interviews lasting 60-90 minutes in a private setting near the clinics. The interview consisted of two parts. First, to understand challenges patients face managing post-discharge wound complications, we used the critical incident technique to guide patients in recounting their wound complication experience [102]. Second, to understand patients' perceptions about the acceptability of mHealth for post-discharge wound monitoring and care coordination, we introduced paper mockups of a wound monitoring application that illustrated key features: symptom tracking, wound photography, secure communication, and informational content. Participants then responded to multiple-choice and open-ended survey questions about the acceptability of such mHealth for wound monitoring, level of technology experience (adapted from national surveys [88,89]), and demographics. Interviews were audio recorded and transcribed. Subject accrual continued until thematic saturation was achieved (i.e. no new data or themes were encountered) [103].

2.3.4 Data analysis

We used a grounded theory approach to data analysis, not relying on pre-determined codes or coding schemes [103]. The initial four transcripts were each independently coded by 4 members of the research team. The group then discussed and recoded the transcripts in concert, allowing key themes to emerge in an inductive manner. We collectively developed a consensus codebook which two team members (PS, SH) used to code all interviews using Atlas.ti (Atlas.ti v7, ATLAS.ti GmbH). Other team members spot-coded interviews to inform the codebook and check coding reliability. The team met periodically to resolve coding discrepancies. Cohen's Kappa between the two primary coders during early and late coding was 0.51 and 0.71, respectively, reflecting moderate to substantial inter-coder reliability [104]. Descriptive statistics from surveys were calculated with Microsoft Excel.

2.4   RESULTS

Interviews revealed unique patient insights into the SSI experience, including challenges faced and how an mHealth solution could address those challenges. After describing our participant sample, we detail 3 major themes that emerged about barriers and facilitators that patients experience while managing surgical wounds after discharge. We then summarize participant acceptability of mHealth for post-discharge wound management, including perceived benefits and limitations.

2.4.1   Participants

Over 4 months, we identified 17 consecutive adult patients who experienced post-discharge wound infection following abdominal surgery. Of the 17 eligible patients, 13 participated (i.e., P1 – P13). The remaining 4 were willing to participate, but either faced time constraints (n=2) or had psychiatric illness (n=2).

We report participant demographics in **Table 2-1** and technology experience in **Table 2-2**. Participants described the duration of their wound problems lasting up to weeks or months after discharge, and 5 reported one or more emergency department visits or hospital readmissions related to SSI.

Table 2-1. Participant demographics.

Age	
Mean [SD]	45 [15]
Median [range]	51 [21-71]
Gender, N (%)	
Female	9 (69%)
Adults in household, N (%)	
1	4 (31%)
2	4 (31%)
3+	5 (38%)
Race, N (%)	
American Indian	1 (8%)
Asian	2 (15%)
White	9 (69%)
Other	1 (8%)
Education, N (%)	
Less than high school	1 (8%)
High school graduate	1 (8%)
Some college	6 (46%)
College graduate	5 (38%)

Table 2-2. Participant technology experience.

Experience with computers	
Some experience	3 (23%)
Intermediate	4 (31%)
Very experienced	4 (31%)
Expert	2 (15%)
Devices currently owned *	
Desktop computer	8 (62%)
Laptop computer	11 (85%)
Smartphone	8 (62%)
Tablet	6 (46%)
Cellphone	12 (92%)
Internet use *	
At least occasional use (any device)	12 (92%)
Any use on cellphone or tablet	8 (62%)
Primary use on cellphone	3 (23%)
Use of cellphone to… *	
Send or receive email	6 (46%)
Send or receive text messages	9 (69%)
Take a picture	10 (77%)
Download software or "app"	6 (46%)
Use health "apps"	2 (15%)
None of the above	2 (15%)

Asterisk (*) indicates percentages not summing to 100%. Participants could indicate one or more answers to these questions.

2.4.2   Challenges of coping with wound complications

Three major themes emerged from interviews on patient self-management of post-discharge wound complications: knowledge for self-care and self-monitoring, efficacy for self-care and wound monitoring at home, and communication with providers (**Figure 2-1**). Each theme is comprised of 3 or more sub-themes (i.e., "codes") that emerged from our analysis. Although most of the 10 sub-themes are primarily barriers (e.g., poor physical or cognitive state limiting self-care) or facilitators (e.g., help at home from a caregiver), some sub-themes serve as either a barrier or facilitator, depending on the situation (e.g., previous experience with surgery). We organized these 10 sub-themes into 3 broader themes, detailed next.
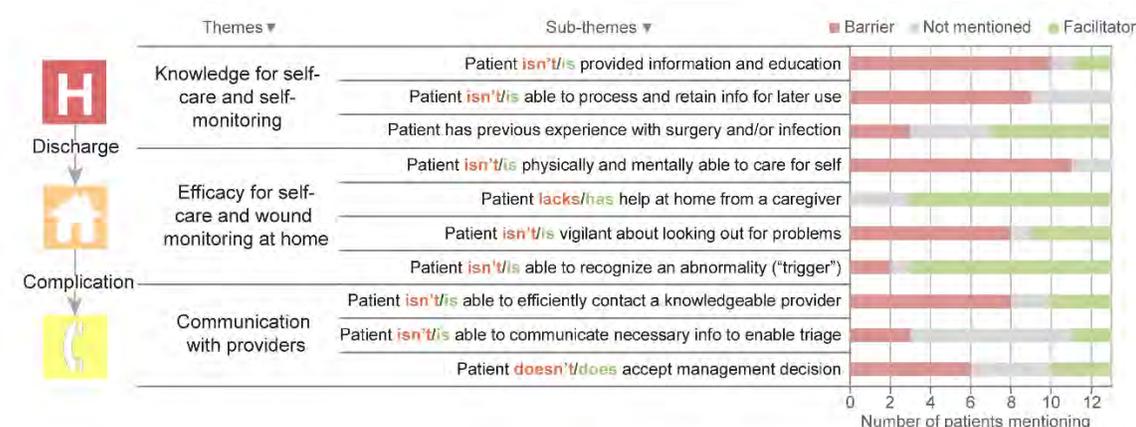
Figure 2-1. Barriers and facilitators to coping with wound complications. Ten sub-themes identified from patient interviews related to coping with post-discharge wound complications, organized into 3 major themes. The color distribution of each bar represents the number of participants who considered each sub-theme to be a barrier (red) or a facilitator (green). Grey indicates that the participant did not mention the sub-theme.

2.4.2.1   Knowledge for self-care and self-monitoring

The first theme relates to the quality of discharge teaching participants received (e.g., handouts/resources patients are provided) and the challenge of processing, retaining and

using that information. This theme also reflects differences in prior knowledge from previous surgeries, which affect patients' information needs.

Ten participants reported not receiving adequate information or education during the discharge process. They attributed their anxiety and some wound complications to this failure to teach appropriate management and monitoring skills before going home. They also mentioned a lack of reference material for use at home and material that was too generic.

*"Well, I think [the infection] developed because I wasn't changing the dressing. I wasn't made aware of how to do that." (**P1**)*

*"[My experience was] horrible. You know, I didn't have a clue what to do. I called a friend who had taken care of people in hospice or I wouldn't have known that I had to pack a wound – they didn't say what to do, they just gave me all that stuff and said 'here'." (**P2**)*

In addition to not receiving the desired information, nine participants noted their inability to process and retain the information that was provided. At the time of their discharge teaching, participants reported having pain, feeling mentally slowed and disoriented by pain medications, and overwhelmed by the amount of information they had to take in. Many participants also felt that the discharge teaching did not suit their learning preference (e.g., written instructions versus hands-on experience).

*"It [wound care instructions] might have been on paper, you know, kind of trying to explain it, but I didn't have a clue what to do with it and I had to call a friend who did know." (**P2**)*

*"I think probably I forgot a lot of what people told me… because I was very concerned about my shoulder [other injury], and also I was really drugged up." (**P7**)*

Nine participants had experienced a previous surgery or infection. For 6 participants, this experience was a facilitator -- they reported increased confidence, required less information, and were more active in monitoring their surgical wound. Conversely, 3 patients

had uncomplicated prior surgeries, leading to less engagement than in their previous experience.

> *"I've been in the hospital a lot. I mean I've been answering doctors' and nurses' questions for years, so I kind of know better what they are looking for and what I should be looking for." (P10)*

> *"No [I wasn't concerned about infection]. Because I've had four other surgeries, five other surgeries and never had an issue with any of them." (P6)*

2.4.2.2 Efficacy for self-care and wound monitoring at home

The second theme relates to challenges patients face, often with the help of caregivers, in effectively caring for themselves. In particular, this included being vigilant for wound problems, and recognizing wound problems when they surface.

After leaving the hospital, 11 participants reported that they were physically and/or cognitively incapable of caring for themselves. The most commonly reported barriers to self-care included medication use, pain, and feeling overwhelmed or squeamish about wound care. They reported that their poor state lead to decreased vigilance, less information-seeking, diminished self-care efficacy, and increased need for home assistance.

> *"I may have normally [sought information about wound care], but I was taking a fair amount of probably – was it Oxycodone? – so no, I didn't really think of that (laughs)." (P8)*

> *"I thought it was real early to have been discharged. ... I could barely walk and I couldn't hold my pee and I wasn't normal at all... and weak and out of it." (P2)*

Ten participants reported receiving help from a caregiver at home (e.g., spouse, friend, family member). Participants noted that lack of information about wound care, poor physical/cognitive state, and physical limitations due to surgery (e.g., inability to reach surgical site) contributed to their need for additional support at home.

"He [my husband] was helping me change the dressing, because I was not feeling real good. I mean I was not sleeping real well. I had a lot of pain from the surgery itself." (P8)

"Not everybody has somebody at home that can be there twice a day... I couldn't have done it myself. There's no way." (P13)

Eight participants reported a lack of vigilance about wound infection—i.e. they were not actively looking out for problems. Other participants demonstrated vigilance by closely following symptom trends or sending wound photos to providers to make sure they were healing appropriately (wound photos discussed further under "Communication with providers" below).

"No... my main concern was the weakness and the pain. I didn't really think about infection. Maybe I should have." (P2)

"There is an awful lot of people out there, I'm one of them, that says oh no, it's nothing to worry about, this will get better. I'm not going to complain." (P12)

Although many participants did not actively look for wound problems, 10 recognized when a problem surfaced, often stemming from a sense that 'something wasn't right'. In other cases participants did not have a typical symptom or know that their symptom was abnormal.

"Because I was taking pain medications and even so I started feeling pain, so that's what made me concerned. Because it wasn't getting better, it was getting worse." (P5)

"It took a long time to heal, and it oozed a lot... I thought it was normal... I didn't know that other people didn't have it, didn't have a clue. I didn't know till today [follow-up appointment] I had an infection." (P2)

2.4.2.3 Communication with providers

The third theme relates to the challenges patients face efficiently contacting providers about wound concerns, providing necessary information for triage, and then working with providers to arrive at an acceptable management decision.

After developing a wound concern, 8 participants had trouble reaching a provider who was familiar with their case. Participants reported problems contacting providers after hours or on weekends, getting 'the run around' trying to talk to the right person, not knowing who to contact, frustration with leaving messages, and even putting off care concerns until business hours. Some participants developed a routine to communicate with a specific nurse, received a direct-access number, or made use of photos, text messages, or email – all of which tended to decrease anxiety.

> *"Noticed it [infection] on Sunday, waited because I didn't want to have to go to the ER until I could talk to a nurse … I called the number and then I got put on hold and then run through like three different people before I finally got to a nurse."*
> *(P6)*

> *"First I called the nurse's hotline or whatever. And I talked to them, and it was hard to get a hold of anyone who even knew what was going on with my case or anything." (P7)*

Two participants sent wound photos to their providers (one patient-initiated, one provider-initiated) to more fully communicate their situation. Participants appreciated sending photos instead of trying to explain in words alone, and hoped that photos might prevent unnecessary visits. These two participants were asked to return to clinic early on the basis of their photos.

> *"I just sent [the photo]… thought it would just be easier… Instead of just kind of explaining it. Sometimes it's easier with pictures." (P4)*

> *"I thought that was very good to be able to send them an actual picture of what was happening… a little more hands on than 'okay - this is…' - trying to describe it*

over the phone … The nurse commented about how good that was too to have a
picture to look at." (P6)

After contacting providers about their concerns, 6 participants were unhappy with the management of their case, with several feeling unnecessarily shunted to the emergency department. Some participants delayed seeking advice over the weekend to avoid being told to go to the emergency department, while others expressed a desire for more interaction with providers at critical times.

"And again, same situation – if you're worried about it, go to an emergency room.
They never say, well, come on up and we'll check you out." (P8)

"I contacted them and they said well, you have an appointment here in a few days.
Let's just wait it out and see... I felt a little put off. Like their sense of urgency for
me wasn't really there." (P13)

2.4.3   Acceptability, perceived benefits, and potential limitations of an mHealth solution

After reviewing paper mockups of an mHealth wound monitoring application, participants expressed broad comfort with its key features and trusted that it could facilitate proper follow-up (**Figure 2-2**). **Table 2-3** shows the top 4 perceived benefits and limitations participants attributed to the application.
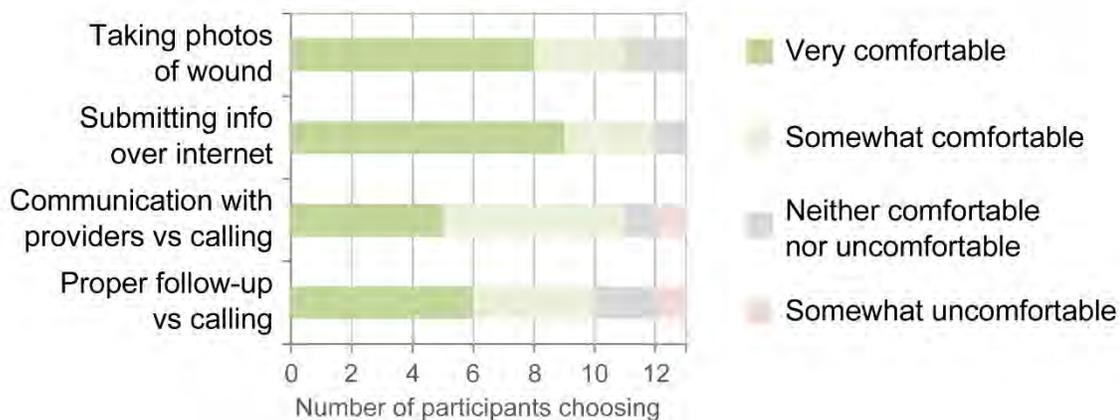
Figure 2-2. Comfort with mHealth application. Participants' comfort with 4 key elements of a wound-tracking mHealth application. Based on 4 survey questions, participants were either "Very comfortable" (dark green), "Somewhat comfortable" (light green), "Neither comfortable nor uncomfortable (grey), or "Somewhat uncomfortable" (light red). No participants selected "Very uncomfortable".

Table 2-3. Perceived benefits and limitations of mHealth approach.

	N	Exemplary quote
Perceived Benefits		
Easier/more frequent follow-up	4	*"Easier/more frequent follow-up especially just after discharge from hospital."* **P3**
Better triage (e.g., fewer ED visits)	4	*"It would save money for both patient and healthcare facility, and it would save the patient from unnecessary trips to the ER or clinic."* **P12**
Less anxiety	4	*"I think this system would promote feelings of relief... that the doctor/staff is aware of your situation and that you are being taken care of without having to go in to the office unless you have to. Peace of mind."* **P10**
Photos: clearer, easier, fuller communication	3	*"Having logged data and pictures seems better than trying to explain what's been going on for the past week or so in words to your doctor."* **P5**
Perceived Limitations		
Untimely response	4	*"I am a bit concerned with the initial turnaround on responses* [from providers]. *This would require individual providers to embrace the technology as much as patients."* **P3**
Inaccessibility	4	*"Older patients might not be as willing to use."* **P6**
Poor picture/ response quality	3	*"Getting people to answer the questions correctly."* **P12**
Security/misuse	1	*"Possible misuse, not of content, but of address info for crooks to locate someone sick and at home."* **P9**

Based on two survey questions about benefits and limitations, respectively. N denotes number of participants mentioning the particular benefit/limitation.

Most participants indicated that mHealth would be an acceptable solution to enable patients to engage in wound monitoring. More specifically, participants perceived that mHealth can address post-discharge challenges by allowing more frequent, thorough, and convenient follow-up, thus leading to less patient anxiety and fewer unnecessary emergency department visits than current practice. Participants were concerned about lack of timely response from providers and inability to use the application, either due to lack of an appropriate device or difficulty using the application itself.

2.5   DISCUSSION

Post-discharge SSIs are not only a major healthcare quality and cost problem—they are also a significant burden on patients that highlight larger failings in post-discharge care coordination [13,14,18]. Our findings reveal frustration with gaps in care that leave patients feeling disconnected from their providers at a critical time in their recovery. Concordant with a previous quantitative study of post-discharge SSI [18], our participants described major impacts of infection on their quality of life, both physically (e.g. due to pain or frequent fluid leakage, or numerous trips to hospital) and emotionally (e.g. due to anxiety related to initial identification of SSI including unsatisfactory attempts to contact providers). In our previous work, providers identified many of the same systemic problems, including challenges communicating prior to scheduled follow-up visits [100].

Historically, patients have not been engaged to prospectively monitor and communicate with providers about their surgical wounds following discharge; typically, surveillance has been passive, retrospective and under the purview of infection control [21]. However, active surveillance programs have been shown to decrease SSI rates [23,24] and engaged patients have demonstrated improved clinical outcomes and emotional health, and decreased healthcare utilization [44,45,105]. Collecting and analyzing patient-reported outcomes is increasingly recognized as key to engaging patients and providing high-quality, patient-centered care [106].

We believe that an mHealth solution can provide a means to connect patients and providers to enhance patient satisfaction and improve outcomes. As with providers we previously surveyed, patients show openness to an mHealth application for wound self-monitoring, and feel comfortable receiving follow-up through such a system. Patients identified a number of potential strengths and concerns around this mHealth approach, yielding important feedback to inform not only development, but also integration of mHealth applications into care delivery.

Based on our analysis of barriers that patients face when managing post-discharge complications, we suggest that an mHealth wound monitoring application should support enhanced knowledge, self-efficacy, and communication. Such an application could address key barriers to receiving high quality, patient-centered, post-discharge care (**Table 2-4**).

Table 2-4. Barriers to post-discharge care addressable by mHealth application.

Barriers	mHealth solutions
Inadequate discharge information	Provide personalized wound care instructions in various multimedia formats accessible before and after discharge by patients and care-givers
Lack of vigilance	Prompt patients to document wounds routinely and support remote monitoring by providers through symptom logs and serial wound photography
Poor communication and sub-optimal management	Contact designated providers familiar with the patient's case by telephone or secure message allowing earlier reassurance or escalation of care

To address these barriers, we are developing an mHealth solution, the Mobile Post-Operative Wound Evaluator (mPOWEr). Informed by user-centered design, this application

will facilitate self-monitoring and transmission of clinically actionable serial post-operative wound information, including wound photographs, to surgical providers [107]. Using a dashboard interface, providers will be able to securely monitor data from an individual patient over time, or quickly review data from a panel of patients for prioritization.

Our findings show promise for an mHealth approach, but our exploratory study design has limitations. First, we only interviewed patients who experienced wound complications. Patients without wound problems may have different perceptions about the adequacy of the discharge process or the acceptability of mHealth. To address this limitation, we are currently conducting a prospective survey of recently discharged surgical patients, the majority of whom have not experienced SSI but nonetheless reported high willingness to use a tool like mPOWEr in the future; this study also incorporates a panel of instruments, administered serially, to assess the effect of post-discharge SSI on quality of life. Second, we interviewed a small number of patients from two very different settings within the same local community. As is customary in qualitative research, the sample size was based on reaching saturation (i.e., not hearing new qualitative themes). Despite the small sample, participants were diverse in age, education, and technology experience, and sample characteristics were similar to national samples [88,89].

Our research has a number of strengths, including diverse perspectives from a multidisciplinary team comprised of a general surgeon, a patient who experienced a post-operative infection, a health informaticist, a user-centered design expert, and a medical student. The qualitative methodological approach enables us to uniquely characterize the post-discharge experience of surgical patients and reveals the need for greater focus on post-discharge care coordination. Finally, our findings form a sound basis for a patient-centered approach to software development, uncommon in the health domain, yet key to developing applications that patients and providers will actually use.

2.6 CONCLUSIONS

SSI is a common post-discharge complication and frequently results in readmission and diminished quality of life. In this study, patients who experienced SSI told us that they are not served by the current standard post-hospitalization care practice, reporting deficiencies in discharge education, wound self-monitoring at home, and communication with providers. Patients found the concept of our patient-centered mHealth wound monitoring application (mPOWEr) highly acceptable. Our application will leverage the increasing prevalence of versatile, connected mobile devices for efficient wound monitoring mediated by empowered patients. Future work will focus on the user-centered development of this application and examine its impact on patient satisfaction, quality of life, clinical outcomes, and healthcare utilization.

Chapter 3. PROVIDER NEEDS ASSESSMENT FOR MPOWER: A MOBILE TOOL FOR POST-OPERATIVE WOUND EVALUATION

3.1 ABSTRACT

Current provider workflows do not effectively capture surgical site infections (SSIs) occurring after hospital discharge. We conducted a needs assessment among providers to guide development of a patient-centered mobile tool to facilitate SSI surveillance at home. We identified concerns and prioritized features based on the survey. Despite concern about the potential for increased workload, 92% of providers were likely to adopt the tool.

3.2 INTRODUCTION

Surgical site infection (**SSI**) is a common post-operative complication, occurring in at least 3-5% of all surgical patients and up to 33% of patients undergoing abdominal surgery[3,4,108,109]. Of the estimated 500,000 infections in the US annually, more than half occur after hospital discharge.[8–11,110] Yet, the post-discharge period is a challenging time for both providers and patients. Providers recognize the limitations of a single in-person follow-up visit, yet lack well-accepted methodologies for prospectively communicating with patients to facilitate timely identification and treatment of wound complications—which increasingly factor into their quality measurements and reimbursement.[8,21,22] For their part, patients have experienced a "voltage drop", no longer having the intense monitoring characteristic of the inpatient setting, and yet may still suffer physical and/or mental impairments (e.g. from pain medication) that make self-care challenging.[13] In addition, patients may lack knowledge about and awareness of SSI, often failing to recognize when they have an infection.[14,15] Due to insufficient discharge teaching, inadequate post-discharge communication, care fragmentation, and untimely, infrequent follow-up, more than half of post-

discharge infections result in readmission, making SSI the overall costliest—yet often non-reimbursable—healthcare-associated infection. [10,19,99,101,111,112]

3.2.1 Related work

Although post-discharge SSIs place significant burdens on patients and the healthcare system, there is no common—or even well-accepted—way to detect post-discharge SSI.[8,21,22] In fact, most work in this area comes from the perspective of Quality Improvement, intended to retrospectively monitor infection rates for external and internal reporting purposes rather than prospectively identifying infections early to improve individual patient outcomes; no studies have been conducted to evaluate the effect of establishing a system of **post-discharge surveillance** (**PDS**), by itself, on patient outcomes.[21] However, conducting "active" (i.e. purposeful, systematic) PDS, *in conjunction with* a system to feed infection rates back to individual surgeons, has been shown to reduce subsequent SSI rates by up to 40%, presumably by prompting prevention efforts.[23,24]

A systematic review of PDS methods[21] identified four main active methods (**Figure 1-2**). The review concluded that all 4 methods have significant limitations and that existing research "has not identified a valid and reliable method" of PDS.[21] As a result, there is no generally accepted methodology for PDS and no wide acceptance of any single method.[8,21,22]

3.2.2 This paper

Recognizing the limitations of existing methods of wound monitoring, we propose to develop a novel, patient-directed, mobile health tool to facilitate patient-provider communication and early detection of post-discharge SSI. The tool, the Mobile Post-Operative Wound Evaluator (mPOWEr), will enable patients to transmit wound photos and standardized SSI symptomatology to providers. Herein we describe the conduct and results of a needs assessment of surgical providers to inform development of this tool.

3.3 METHODS

The study was approved by the University of Washington Institutional Review Board and consent was obtained electronically from all participants prior to undergoing study procedures.

3.3.1 Study population

We recruited surgical providers at 4 hospitals in the Seattle area via email. Providers were identified for inclusion by job description and through professional networks. Three email requests were sent to 107 providers (38 surgeons and 69 nurses) over the course of 3 weeks with a link to an anonymous web-based survey.

3.3.2 Data collection

Our survey consisted of 28 multiple choice and free-response questions with major domains of **provider characteristics**, **current workflow** around post-discharge SSI surveillance, mPOWEr **tool design**, and **expected use** of mPOWEr.

3.3.3 Data analysis

Descriptive statistics (means, medians, inter-quartile ranges) of quantitative data were calculated in Microsoft Excel 2013. Short answer questions were qualitatively analyzed on a per-question basis using an inductive process to allow summarization of key themes. For each set of qualitative themes summarized in Results tables, a percentage is provided which denotes the prevalence of that particular theme. Illustrative quotes are provided for each theme and a **bold "P#"** indicates which study participant was quoted.

3.4 RESULTS

Results are organized by provider characteristics, current workflow, tool design, and expected tool use.

3.4.1 Provider characteristics

Of 107 providers emailed, 18/38 (47%) surgeons and 6/69 (9%) nurses completed the survey. The respondents were 75% physician/25% nurse, in practice for a median of 11.5 years (see **Table 3-1**). Providers reported seeing an average of 16 post-operative patients per week, of which 1.5 typically have an infection (9% SSI rate); 56% of those infections are estimated to occur post-discharge.

Table 3-1. Participant characteristics.

Characteristic	Level	Value
N		24
Training, N (%)	MD	17 (75%)
	ARNP/PA	4 (17%)
	RN	2 (8%)
Practice setting, N (%)	Academic	22 (92%)
	Community	2 (8%)
Gender, N (%)	Male	12 (50%)
	Female	12 (50%)
Years in practice, median (IQR)		11.5 (5-19)
Post-op patients seen/month, median (IQR)		40 (19-74)
SSIs managed/month, median (IQR)		4 (2.5-7)
SSIs post-discharge, median (IQR)		50% (30-90%)
SSIs post-discharge, mean		56%

3.4.2 Current workflow

This section describes providers' perceptions of their current post-discharge wound monitoring process, i.e., its overall effectiveness, how patients usually contact them with

wound concerns, provider concerns about missing infections, and provider suggestions for improving their post-discharge wound monitoring process.

Forty-two percent of providers characterized their current PDS workflow as ineffective (**Figure 3-1**), with resulting concern for increased patient complications and delayed treatment. **Table 3-2** shows how SSIs typically come to provider attention and calls out some of the challenges surgical providers face in coordinating care with outside providers.
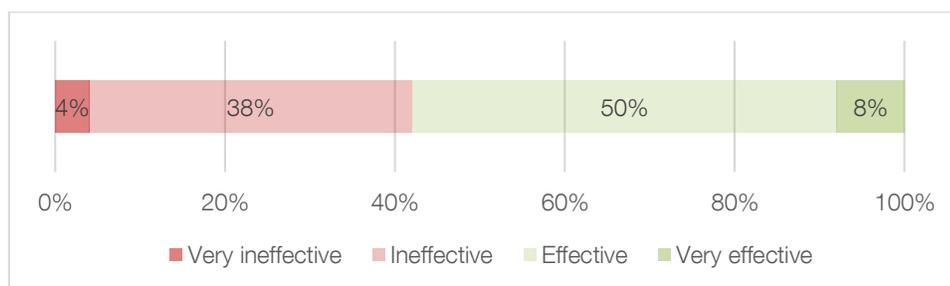
Figure 3-1. Providers rating of their current workflow effectiveness at identifying PD SSIs

Table 3-2. How SSIs come to provider attention.

%	Options*	Other comments
79%	Patient contacts clinic	"[I hear about SSIs] from primary care providers. Often erroneously diagnosed (seroma vs infection…)" (**P4**)
75%	Follow up visit	"Emailed by patient." (**P13**)
25%	Outside provider/ED notification	"Patients often present to outside ED's and get antibiotics before they even come back for their scheduled visit." (**P19**)
13%	Clinic contacts patient	"Dependent on the social support system of the individual patient. Those that have great support systems and are engaged in their personal health are vigilant about SSIs. "Sadly in our patient population (homeless, indigenous, disenfranchised) SSIs come to our attention when they re-present back to the ER." (**P23**)

* multiple choice question, allowing 1 or more answer choices, and "Other comments" box

3.4.2.1 Concerns about missing post-discharge SSI

Table 3-3 identifies providers most common concerns related to missing post-discharge SSIs, namely risk of harm to the patient, lack of feedback to the providers themselves which might allow them to improve, and concern that patients may lack the ability to identify infections on their own.

Table 3-3. Concerns about missing post-discharge SSIs

%*	Theme	Quotes
25%	Risk of progression/ untreated complications	"That they may lead to complications before detected, such as fascial infection, toxic shock, or mesh infection." (**P2**) "Risk of progression and increased requirements for therapy, including opening/debridement, readmission, rarely systemic impact." (**P11**)
13%	Lack knowledge of own SSI rate	"If the patient goes to an ER, urgent care, or their PCP for wound infection, they may be treated and I may not be alerted to that at all." (**P6**) "Unknown rate of SSIs in my population; potential need to change practice if rate actually even higher than expected." (**P14**)
13%	Patients lack education/ knowledge to identify SSI	[I worry that] patients don't know what to look for and do not call if a SSI is brewing." (**P22**)
8%	Readmission/expense	"Seems like we get infections too late and don't coordinate care after we suspect it-it means pts end up in other ERs and then get readmitted to us with expensive transfers." (**P3**)
8%	Delayed notification from outside providers of SSI	"We hear about most, though notification may be delayed. Patients are asked to call for any problems with the wound, including changes that commonly occur with SSI." (**P7**)

* theme prevalence in short answer response (not multiple choice)

3.4.2.2   Improving the process

Table 3-4 shows providers' most common suggestions for improving the PDS process, with illustrative quotes. Providers top suggestions were better communication (mainly through earlier and more frequent follow-up contact), improved patient education, and facilitating patients sending wound photos from home.

Table 3-4. Suggestions for improving PDS process.

%*	Theme	Quotes
46%	Better communication	"Daily check in by nurse to patients." (P3)
		"Better monitoring, more timely feedback from patients. Geographic distance is a big problem." (P5)
		"Maybe a follow-up call to the patient a few days after surgery to ask them if they're having symptoms." (P6)
		"Closer follow up than two weeks." (P9)
		"Follow up within week of operative procedure." (P16)
		"All patients should be seen POD [post-operative day] 7-11 and then a follow up call made a week later." (P18)
		"More frequent contact with patients in the early post-operative period." (P19)
		"We need to do a better job of tracking these patients. We also need to institute better programs of surveillance and feedback." (P23)
25%	Better patient education (e.g. signs of SSI)	"Better instruction to the patient." (P7)
		"Perhaps better education of patients ahead of time." (P13)
		"Pre-operative discussion of surgical site, and what SSI looks like. Follow-up communication with patient." (P16)
		"All patients should receive detailed instructions of what to look for and numbers to call if they experience signs and symptoms of wound infection." (P18)
		"Ensure at discharge that patient has a thermometer at home. Thorough teaching about signs/symptoms of infection." (P22)

21%	Ability to send wound photos from home	"Point of Care telemedicine application." (P7)
		"[Patients should have] the ability to text/e mail pictures to a universal/private website." (P12)
		"Teaching about how to email a picture of suspected SSI. (both patients and IT challenged staff)" (P22)
		"Patient taking a photo and emailing or texting it to a provider in the clinic." (P24)
8%	More provider availability	"[There should be] More clinic openings for follow up." (P9)
		"Make health care providers more available." (P12)
		"[Have] dedicated personnel to track [post-discharge SSIs]." (P14)

* theme prevalence in short answer response (not multiple choice)

3.4.3 Tool design

This section relates to results that impact the design of the wound tracking tool (i.e., provider dashboard and patient mobile app), including decisions about features to include, symptoms to question patients about, quantity/type of photos to take, and means of accessing the data collected by the tool.

Figure 3-2 shows the features providers considered most useful, e.g.: automatic instructions to patients based on their responses (e.g. to call the clinic or go to the emergency department); automatically reminding patients to use the application; and secure messaging between patients and providers.
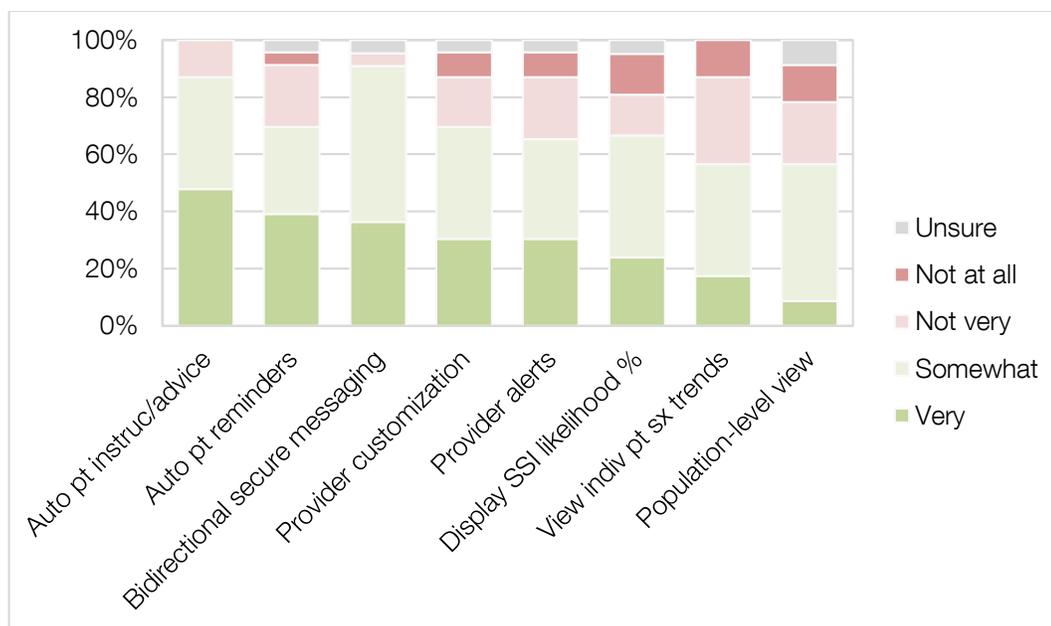
Figure 3-2. Usefulness of proposed features.

3.4.3.1 Signs and symptoms of SSI

Providers ranked the importance of symptoms to ask patients about (**Figure 3-3**) and emphasized the importance of symptom <u>trends</u> (emphasis added below).

"<u>Change in</u> condition most important, redness, pain, drainage, any/all increasing."
(P11)

"<u>Worsening</u> symptoms. They should all get better, especially on POD 3 and be-
yond." (P18)

"<u>Sudden (past 1-2d) worsening</u> of pain at surgical site." (P24)
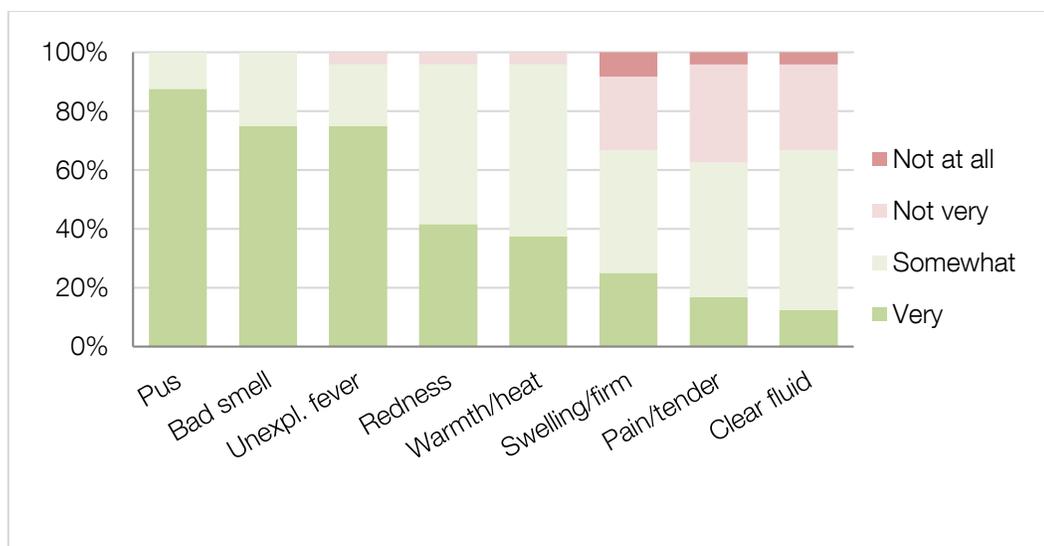
Figure 3-3. Usefulness of signs/symptoms to identify SSI.

3.4.3.2 Nature of answer choices

Participants preferred to have fewer, more concrete answer choices, e.g. preferring Yes/No/Unsure over an abstract 0-10 scale that might be more subjective. Participants were mixed about whether to include free-text fields or not, with the majority of responses which included an opinion being against.

"I favor Likert scales and computer adaptive design so if they say no to 'no prob-lems with wound', we go to [asking about] fever info instead of all the different wound questions." (P3)

"Free text entry would be helpful." (P8)

"I think the yes/no questions will give better data as the patients may think their wound is changing as they perceive themselves as ill." (P9)

"[Choices should be] graded, avoid too much free text." (P14)

"Would not put in free-text. I like less choices (yes, no, unsure)." (P23)

3.4.3.3 Photo taking

Providers were very interested in having the ability to receive wound photos from patients, with the majority wanting one *high quality* wound overview photo and one *high quality* close-up, so as not to overwhelm reviewing providers.

> *"Standardized format of taking pictures - one overview, and one closeup of anything the patient finds concerning." (P23)*

> *"One overview and a close up. Too many will be difficult to send, difficult to read, etc." (P20)*

Table 3-5 summarizes providers' main concerns with incorporating wound photos into routine practice, namely privacy/security, photo quality, and malpractice. About a fifth of respondents said they had no or minimal concerns.

Table 3-5. Concerns about photography.

% *	Theme	Quotes
38%	Privacy/ se-curity	"[Concern for] protected info. Encryption burden on providers (smartphones, etc)." (**P4**) "The photo should be taken from the app… and protected by a password… [so] I can log into and access a patients' image." (**P12**) "Security is always a concerns, but sending photos is often the most efficient way to assess and we use it frequently." (**P13**) "Mostly a [protected health information] issue, the rest is pretty straightforward with today's technology, provided they have a decent camera on their phone." (**P18**) "Privacy, HIPPA. IT skills to import it into [EMR]." (**P22**)
21%	Picture quality	"Bad lighting, no ability to scale for size, color matching issues." (**P3**) "Blurry pictures has been our experience." (**P5**) "Many people are really bad photographers, especially with using a camera phone. We may get a ton of pictures that are useless because they're blurry, the light is too dim, the colors are off, etc." (**P6**) "A photo by an unknown device is not all that reliable. Poor quality or operator error affect the photo. The wound being in an area that is not easily photographed…" (**P9**)
13%	Malpractice	"I have concerns as it relates to risk management. What would happen if patient sent info but I did not receive or did not act on it or it is not even my patient?" (**P14**)
8%	Abuse by patients	"They may somehow try to manipulate the system to get seen sooner by altering photos or by taking photos of wounds that are not accurate." (**P9**) "Providing my direct email and/or telephone number has resulted

(when I've done this) in excessive contacts by the patient to me."

(**P24**)

| 21% | No/minimal concerns | "I have no concerns… this is consistent with modern technology. Every cell phone has this capability." (**P19**) |

* theme prevalence in short answer response (not multiple choice)

3.4.3.4 Means of access and notifications

Almost all providers wanted access to wound tracking data through the EMR (**Figure 3-4**) but were split about how/when to receive notifications about patient submissions, with some wanting to be notified through the normal "chain of command" (e.g., through a triage nurse), and some wanting direct notifications (e.g. through text/email) of concerning patient responses. **Table 3-6** summarizes several themes related to notifications, namely that existing processes should be maintained, surgeons should not be relied upon due to their unpredictable schedules, and that surgeons want to be able to customize how the system works based on a variety of factors.
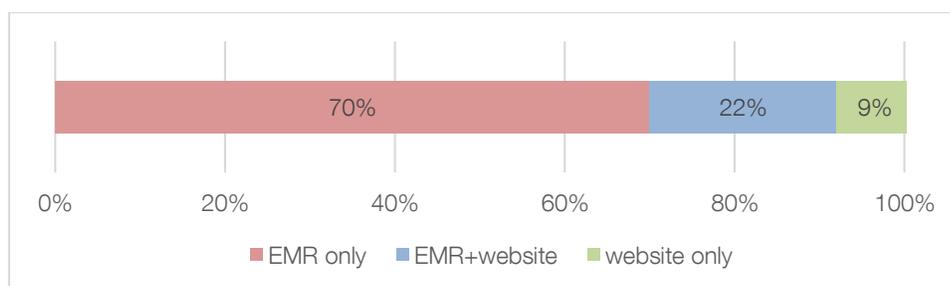
Figure 3-4. Where provider dashboard should be accessible.

Table 3-6. Preferences related to notification of patient submissions.

Theme	Quotes
Maintain existing chain of command/ centralize submissions	"I would prefer not to be notified as the higher up residents will be notified as well and will be doing the consults." (**P9**) "There should be one focal point for submission i.e. the clinic nurse practitioner who can then consult with the attending physician as needed. Given travel etc. sending these directly to the attending would be problematic." (**P19**) "As a RN, I am probably the one notifying the MD of SSI from calls made to clinic." (**P22**)
Avoid reliance on surgeons/ attendings	"I think an RN would be better to be notified. We [surgeons] are often unavailable (scrubbed in, etc). Hours/day can go by before a surgeon can look at a picture." (**P4**) "The clinic should be notified. If a physician is out of town and an email or text is sent to him/her, they might not get it. The only way to make sure these responses are received is to set it up so they go to a clinic that is open regular business hours." (**P6**) "Should go to clinic, preferably nurse practitioner. Faculty presence unpredictable and erratic." (**P11**)
It depends…	"Different depending on the type of info, operation and patient." (**P2**) "It would depend on the patient, their education, and ability to detail the characteristics of the wound." (**P16**)

* theme prevalence in short answer response (not multiple choice)

3.4.4 Expected use

Half of providers envisioned routine use (daily, 2-3 times a week, weekly) while the other half envisioned use only with suspected problems (**Figure 3-5**). If patients or providers developed suspicion of SSI, most providers would change to more frequent or daily submissions rather than have the patient immediately seek care (**Figure 3-6**). Providers imagined using the tool for both new SSI surveillance (of previously healthy wounds) and monitoring healing progress of existing SSIs (**Figure 3-7**).
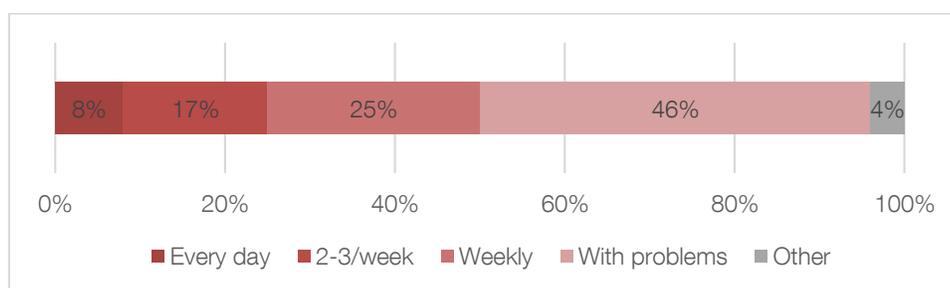
Figure 3-5. Desired frequency of tool use.
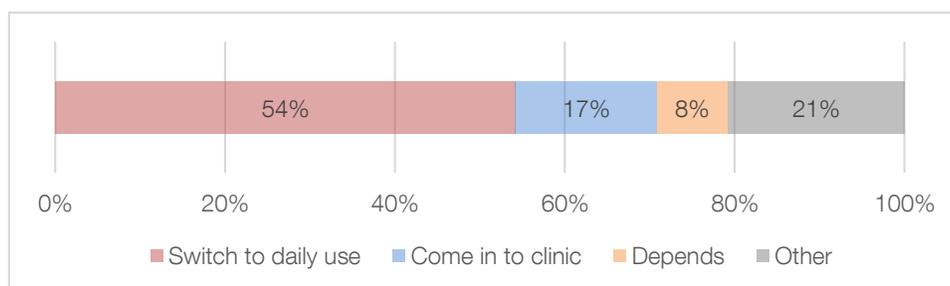
Figure 3-6. Change to use frequency with provider concern for developing SSI.
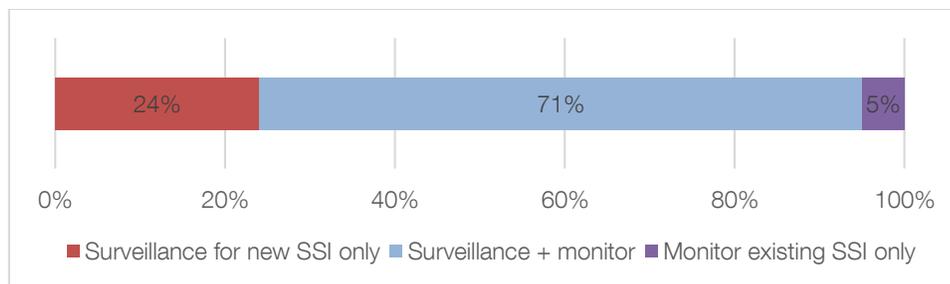
Figure 3-7. Use of tool for surveillance of new SSI vs monitoring healing progress of existing SSI.

3.4.4.1 Concerns and workflow disruption

Asked about disruption to workflow, providers' major concerns (**Table 3-7**) related to having to do more work and/or hire more staff, and potential for over-triage leading to unnecessary visits. Many providers expressed minimal concern assuming the system worked as they want it to, e.g. that the tool be used by patients on an "as needed" basis, and that non-surgeons do the initial screening. Even with concerns about impact on workflow, almost all providers were likely to adopt a wound monitoring tool in their practice (**Figure 3-7**).

Table 3-7. Themes related to impact on workflow and other concerns.

% *	Theme	Quotes
46%	More emails, time, work, staff	"Increase number of emails." (**P1**)
		"Many more pictures... financial cost of staffing (RN/PA)." (**P4**)
		"Who is going to look at all these pictures and responses? You would have to have a physician or mid-level practitioner evaluate these communications, and that is time that is not reimbursed and could take away from other clinical duties." (**P6**)
		"Patients thinking that something is wrong when there is nothing wrong still takes the providers time to respond." (**P9**)
		"May create more work than just have RN screen patient calls and bring patient in to be seen if needed." (**P13**)
		"May need to respond during off times, e.g., weekends, when out of town for business or vacation." (**P14**)
		"Another thing to do and clutter my email." (**P18**)
		"If a photo takes a long time to download or if the patient sent many many photos." (**P22**)
13%	Too much information: more decisions and unnecessary evaluation	"If not quantified it seems like continuous judgment call with patient expectation that they are being monitored 24/7." (**P3**)
		"[Could] Increase potentially unnecessary evaluation." (**P16**)
		"TMI [Too Much Information]. Isn't proven." (**P21**)
25%	Minimal concern, if...	"Minimal disruption if notifications are only [as necessary]." (**P5**)
		"Helpful, if mostly positives picked up." (**P7**)
		"Minimal if someone else is doing the screening." (**P11**)
		"It could actually decrease the number of phone calls we get." (**P17**)

"If used too much, could be disruptive..." (**P19**)

"[I would be concerned] Only if it clogs up the system, or if it is dependent only on the surgeon for surveillance (i.e. there has to be a partner in one's clinic to make sure all messages are viewed in a timely manner)." (**P23**)

"[I have concern] If it's done more than on an as-needed (for patient concern regarding their wound appearance) basis. Would add excessive work if done for every patient." (**P24**)

 * theme prevalence in short answer response (not multiple choice)
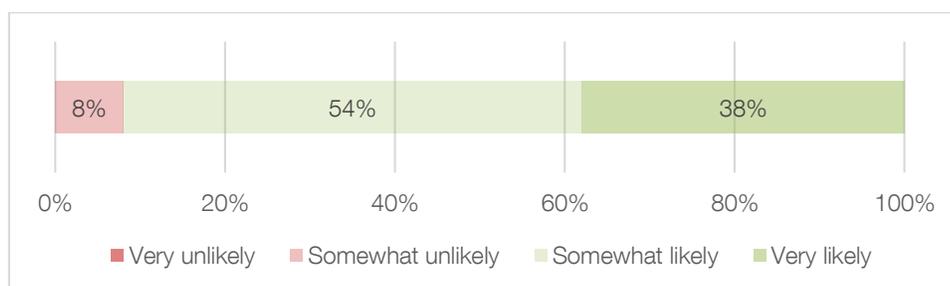
Figure 3-8. Likelihood of adopting mPOWEr in provider's practice.

3.5 DISCUSSION

Providers voiced concerns that current practices for discovering post-discharge SSIs were ineffective, leading to risk of disease progression and further complications for patients, and increased expense for all. Providers also noted that not knowing their true SSI rate impairs their ability to make improvements to their practice, as has been found previously. [23,24]

Providers made a number of suggestions to improve post-discharge practices, most commonly that post-discharge follow-up should be both earlier and more frequent than the standard single post-discharge visit. These findings echo a recent study found that cur-

rent follow-up practices do not occur early enough to detect adverse events and prevent readmission.[101]

We asked providers a number of question to inform the design of a novel wound monitoring tool (mPOWEr). The top two features considered most useful both involved autonomous use by patients (not involving a provider); this may be due to providers' concern for potential increased time requirements. Surprisingly, viewing individual patient symptom trends over time was a low-ranked feature, despite providers' emphasis that trends (e.g. worsening) were most important in assessing for SSI. This result may be due to providers concern for being overwhelmed with "too much information", perhaps wanting to limit their review to the current patient submission. Viewing population-level data was seen as least useful, at least to the surgeons surveyed, but this view might change if the metrics were reflective of e.g. Accountable Care Organization targets which fed into a pay-for-performance system or if Quality Improvement stakeholders were surveyed.

A key point raised by providers was that the system should not be reliant on individual providers, and especially not surgeons, due to their unpredictable schedules. Instead, providers wanted the system organized around "one focal point" (e.g. clinic nurse) who could then consult attendings as necessary. Providers wanted to maintain existing hierarchies (i.e. nurse → resident → attending) and workflows as much as possible to ensure smooth integration.

Indeed, impact on workflows was a major concern among providers, with almost half voicing concern about more work for screening and contacting patients. Providers also expressed concern over having "too much information" and having to make "continuous judgement calls", which might lead to overtriage (i.e. unnecessary evaluations). Many providers (46%), therefore, preferred for patients to use the tool only "as needed" (i.e., with concern) rather than routinely, while 50% did prefer routine use, on average 2-3 times per week. Future work should address how to balance impact on workflows with increasing sensitivity for SSI detection from routine use, as previous work has shown that patients are often unable to recognize an infection (which would prompt them to start submitting to providers).[14,15]

Encouragingly, despite concerns about increased workload, almost all providers would likely adopt the system in their practice, pointing toward a recognition that current post-discharge practices have significant room for improvement.

3.5.1   Limitations

Limitations of this work include a small sample size, and under-representation of non-physicians and non-academic providers. In addition, the survey nature, though it included a number of free response questions, did not allow deep understanding of participants views. Future work should engage, through in-depth interviews and other user-centered design methodologies, a diverse group of nurses and physicians in further design of mPOWEr.

3.6   CONCLUSION

Providers reported the current system for post-discharge SSI surveillance to be ineffective and wanted closer follow-up, better patient education, and wound photos from home—all of which mPOWEr can address. Through our needs assessment, we gathered valuable information from providers on core features (symptomatology questions and photos) and were able to prioritize additional features to enhance mPOWEr. Despite concern over potential increased workload and over-triage, 92% of providers were likely adopt the system. Future work will involve patients in design and usability testing, and ultimately a trial to evaluate impact on clinical outcomes and patient-provider communication in the critical post-discharge period.

Chapter 4. DESIGN CONSIDERATIONS FOR POST-ACUTE CARE MHEALTH: PATIENT PERSPECTIVES

4.1 ABSTRACT

Many current mobile health applications ("apps") and most previous research have been directed at management of chronic illnesses. However, little is known about patient preferences and design considerations for apps intended to help in a post-acute setting. Our team is developing an mHealth platform to engage patients in wound tracking to identify and manage surgical site infections (SSI) after hospital discharge. Post-discharge SSIs are a major source of morbidity and expense, and occur at a critical care transition when patients are physically and emotionally stressed. Through interviews with surgical patients who experienced SSI, we derived design considerations for such a post-acute care app. Key design qualities include: meeting basic accessibility, usability and security needs; encouraging patient-centeredness; facilitating better, more predictable communication; and supporting personalized management by providers. We illustrate our application of these guiding design considerations and propose a new framework for mHealth design based on illness duration and intensity.

4.2 INTRODUCTION

Although much mHealth research supports managing chronic illness, relatively little is known about how mHealth could apply to acute conditions. New incentives (e.g., Accountable Care Organizations, bundled payments) will lead hospitals and providers to optimize care across the whole care spectrum, including areas such as post-acute care (i.e., happening after acute hospitalization). Post-acute care mHealth could facilitate care coordination by filling in gaps that occur during this significant transition of care. This coordination could

prevent costly readmissions as well as improve patients' experiences during this often stressful time.[13]

Improving care coordination among surgical patients after discharge is of critical importance. These patients are at high risk for surgical site infections (SSI), most of which occur after discharge.[10,11] SSIs are the leading cause of readmission among surgical patients, which occurs in up to half of patients who experience SSI.[10] In our previous work we found that patients were ill equipped to recognize and manage wound complications, and faced many barriers to communicating with their providers after developing a concern. Patients found the concept of an mHealth wound tracking and communication tool highly acceptable and believed it could help address many gaps in the current system.[107]

In this paper, we extend our previous work by describing design considerations for post-acute care mHealth apps, derived from interviews with surgical patients who experienced wound complications while at home. Many of these patients had extreme experiences, both in terms of their physical and emotional state (e.g., anxiety, disorientation) and their interactions with the health care system (e.g., late night calls to triage nurses, emergency department visits, readmissions). These experiences allowed us to explore a breadth of the post-acute mHealth design space, although not all issues we identified will likely apply to every post-acute care mHealth app. In our discussion, we describe several core themes that emerged related to communication and management that could be applicable to a wider range of acute care apps. We then illustrate how we applied these design considerations to an mHealth app we are developing to engage surgical patients in post-discharge wound tracking. Finally, we introduce a new framework for mHealth design based on illness duration and intensity.

4.3 BACKGROUND

The design space around mHealth for management of chronic conditions is relatively mature, especially for conditions such as cancer[91,92] or diabetes[93,94]. It is unclear whether design considerations for chronic mHealth apps apply as well in a post-acute setting. Apps

for management of chronic conditions are characterized by achieving symptom control and long-term behavioral change. In contrast, the purpose of a post-acute care app might be to help avoid escalation around a single, limited duration episode of treatment while a patient is returning to a usual health state.

Some design considerations likely apply across a wide range of mHealth settings. For example, Klasnja et al[95] found that the ability for cancer patients to capture and access a variety of care-related information while on the go, in a single application, helped them manage their care and feel more in control of their information and health. Since managing information is a key task for patients in any setting, enabling the organized storage of health information is likely to be a universal mHealth theme. Arsand et al[96] found that diabetes patients preferred to have some reward (e.g. education or feedback) at the time of data entry to provide a built-in motivation for use. This finding relates to a broader theme that, in order to continue using apps, patients must find them to have utility—not just in a theoretical sense, but also in an immediate, concrete sense. Liu et al[97] found that parents wanted to communicate with providers in different ways to suit their needs, both synchronously (e.g. telephone) or asynchronously (e.g. email). Communication with providers can be critical across a range of chronic and acute conditions, and supportive mHealth applications should facilitate communication using means that are both efficient and acceptable to patients. Kientz et al[98] suggest that the act of tracking health measures (e.g. infant development) has the potential to increase anxiety over trends that appear abnormal. Apps that capture patient data will have to carefully consider how to reflect that data back to patients, including whether and how to provide interpretation of that data.

Other design considerations for chronic mHealth apps might be less applicable or introduce new challenges in an acute context, ranging from privacy and self-reflection to automated feedback and engaging social networks. For example, Patel et al[91] identified giving breast cancer patients ownership over data (e.g. controlling what data is shared, capturing custom fields) as important to promote engagement in care and capture of sensitive data. Although patients should always have control over what information is shared with others, acute care providers may be concerned about patients sharing *too much* data that cannot

be efficiently reviewed. Mamykina et al[93] identified promoting self-reflection as a primary design goal to aid in self-management for people with diabetes. Self-reflection is a critical element in the management of many chronic illnesses that rely on patients to make lasting behavioral changes. However, the importance of self-reflection is unclear given the short time horizons, cognitive impairments (e.g., due to pain medication), and limited control that patients often have over their care outcomes that might be common in the post-acute setting. In addition to self-reflection, Harris et al[94] identified automated, programmed responses as a key design requirement for diabetes self-management. Automated responses may support self-reflection and have the benefit of giving immediate feedback and gratification to patients without burdening a provider, however more urgent or complex assessments associated with acute concerns might not be reliably made without human involvement. Finally, much work has been done using mHealth to help patients engage social networks and online communities for support in their care (e.g., Liu et al[97] in the parenting of high-risk infants). However, the utility of online communities is unclear over short durations and highly individualized recovery periods following hospital discharge. In addition, unlike with chronic conditions, acute conditions tend not to have dedicated online communities.

Though the examples above are not exhaustive, and many design considerations for chronic mHealth apps likely apply to acute apps as well, we suggest that the requirements and user experience in acute and chronic settings are sufficiently different to warrant further research. In this paper, we report on our work to explore a design space for apps which improve communication and decision support in the post-acute care setting.

4.4 METHODS

We conducted semi-structured interviews with patients who experienced surgical wound complications after hospital discharge. The study was approved by the University of Washington Institutional Review Board.

4.4.1   Participants and setting

We interviewed patients who had post-discharge wound complications after undergoing abdominal surgery at one of two Seattle hospitals: an academic medical center or a county hospital/ regional trauma center. We identified English-speaking, adult patients using two different approaches: through clinic nurses at follow-up visits or through flyers placed in surgery clinics.

4.4.2   Data collection

We conducted one-on-one interviews lasting 60-90 minutes in clinic rooms or adjacent private conference rooms. We began by using the critical incident technique to guide participants in recounting their complication experience.[102] Then, grounded in their experience, we used scenarios to provide context to allow participants to walk through paper wireframe mockups (**Figure 4-1**) of an mHealth wound tracking application (e.g. "Imagine you are very concerned about your wound. You just clicked 'submit' to send your symptom data. What should happen now?"). We showed mockups of multiple versions of potential features such as symptom tracking, wound photography, secure communication, and informational content. Prior to showing mockups of each feature, the interviewer paused to ask the participant to describe how a particular feature might work; only then did the interviewer use the paper mockups to stimulate further discussion. Interviews were audio-recorded and transcribed. We collected data until thematic saturation was achieved.[103] We used written surveys to capture demographics and technology experience.
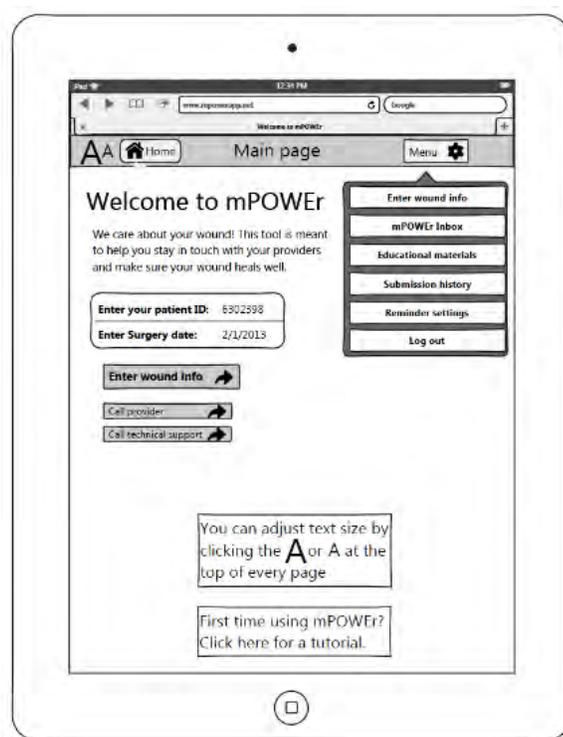
Figure 4-1. Paper mockups used during participant interviews to stimulate discussion.

4.4.3 Data analysis

We collectively developed a codebook with two team members coding all the interviews using Atlas.ti (Atlas.ti v7, ATLAS.ti GmbH) while other team members spot-coded interviews to inform the codebook and check reliability. The whole team met periodically to resolve coding discrepancies. Cohen's Kappa between the two primary coders during early and late coding was 0.51 and 0.71, respectively, reflecting moderate to substantial intercoder reliability.

4.5 RESULTS

We interviewed 13 patients ranging from age 21 to 71 (mean 45), of whom 9 were female and 9 were white. Five were college graduates, 6 had some college, 1 graduated from high school and 1 had less than high school education. They self-rated their experience

with computers as "some" (n=3), "intermediate" (n=4), "very" (n=4), or "expert" (n=2). Twelve used the internet at least occasionally and 8 owned a smartphone. Patients underwent major abdominal surgery, generally colorectal or ventral hernia repair, and struggled with complications for weeks or months after discharge. Five had one or more emergency department visits or hospital readmissions related to SSI.

From patient interviews, we identified 11 themes that we organized into 4 categories that describe qualities of a post-acute care mHealth application (**Figure 4-2**):
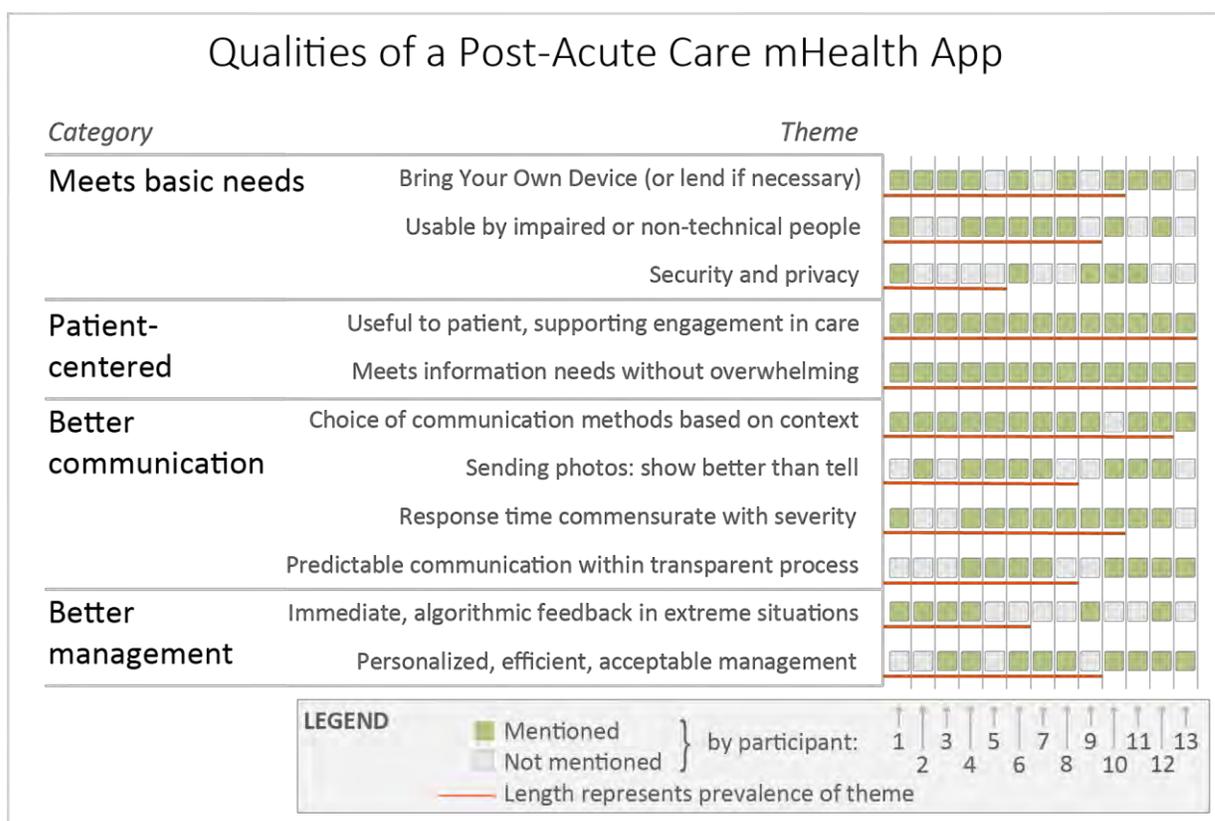
Figure 4-2. Qualities of a Post-Acute Care mHealth App. Each green square represents a participant who mentioned the theme during interviews. Length of red lines represents theme prevalence. Themes are organized into 4 major categories, visible on the left side of the figure.

4.5.1.1 Meets basic needs

One category of design qualities for a supportive mHealth tool expressed by participants revolved around meeting basic needs through accessibility of your own device, usability by impaired or non-technical people, and security to preserve privacy. P#'s following quotes are attributions to that particular participant.

Bring Your Own Device (or lend if necessary). Participants were concerned about an app being inaccessible on their preferred device or had concern for others who lacked access to a smartphone or computer. Several participants suggested that hospitals could loan patients devices.

> *What about people that don't have smart phones? Will you have this on a regular*
> *online website with it too? Because my phone is like ten years old. P12*

> *I think it's a good idea if you have someone who's technology proficient in some-*
> *thing like that. Some of the patients may not even have computer or computer*
> *access. But I think for me personally, I mean, because I'm used to computers, I*
> *think it's a great idea. P4*

Usability by impaired or non-technical people. Participants had concern for technologically inexperienced users, and did not want to be overwhelmed with information or too many pages/functions. Participants mentioned the challenge of using an app while on pain medication, and wanted simple wording, obvious alerts and clear navigation.

> *But if you don't have [a smartphone] you might not know how to work it, so then*
> *you're going to have to get into who's smarter, the phone or you? You know,*
> *somebody's going to have to show you how to even operate the thing. P10*

> *But it would make a complex website or doing something complex, it would re-*
> *quire you to remember several steps. I think [navigating a complex website under*
> *influence of drugs] would make it very difficult for a lot of people. P12*

Security and Privacy. While this was among the least prevalent themes, participants were most concerned about collection and transmission of particularly sensitive information such as photos of the groin area. Participants expressed concern that transmissions should be secure and go to the right recipients.

Some people might not want to [send pictures of private areas]. Your older gener-
ation. P6

As long as [the submissions] made it from point A to point B, it would be good.
They didn't get lost in sending... to a bakery or something. P11

4.5.1.2 Patient-centered

A second major category of design qualities pointed to the importance of patient-centeredness: being genuinely useful to the patient to support engagement in their own care and meeting their individualized information needs without overwhelming them.

Useful to patient, supporting engagement in care. All participants voiced that the app should be genuinely useful to the patient—having an obvious benefit and not feeling like a burden on them. They felt that the app should allow patients to be engaged in and make decisions about their care, especially about how often and by what means they discuss their concerns with providers. Several expressed that the app should have a "personal feel" that gives the feeling that "we want to take care of you" (P1). Participants also felt that the app should connect them with a provider familiar with their history and with whom they already have a relationship/rapport.

The biggest thing is for me to feel like this is useful, because it's being sent to my
doctor. This is a way of communication to my doctor, not just a survey I'm taking,
you know what I mean? P5

[The ability to view past photos/history would be useful] because then you could
see – oh, this is what this looked like 3 days ago and this is what it looks like now.
This looks really different. P7

Meets information needs without overwhelming. Participants generally did not feel that their information needs were met well during their hospital discharge experience. Every participant saw an opportunity for the app to make up for this deficit by providing a personalized, succinct recap of their discharge instructions. They emphasized that they did not want to be overwhelmed, asking for just the highlights with links to more resources if

needed. Most participants wanted to have information on procedures they themselves would be expected to perform after discharge (e.g. how to clean and pack wound) and how to identify problems (e.g. infection). Participants preferred concrete examples through a variety of media over reams of pages (e.g. photos of infected vs normal wound, step-by-step instructions/video of wound care procedure). Several participants were also interested in receiving information about how to optimize their healing (e.g. dietary advice). Participants wanted the app itself to be well-documented with help/tutorials.

> *Like if you forget how to clean and pack your wound or whatever, or if your wound looks like this, then [it's infected] - or if your wound looks like this, then [it's not infected]. That might be helpful... Mainly just in terms of if this happens, don't freak out. If this happens, do freak out.* **P7**

> *So if you're going to do a presentation for somebody coming out of the hospital, you should only have the highlights... [have a] mouseover if they [want] a big explanation.* **P1**

4.5.1.3 Better communication

A third major category of design qualities pointed to the potential for enhanced communication, whether through more choice of communication methods appropriate to context (e.g., secure text for non-urgent matters), the ability to send photographs, rapid provider response when necessary, and patient control over and transparency about timing and method of provider contact.

Choice of communication methods based on context. Participants wanted to be able to choose the means of communication with their provider. Context was important—if they were very concerned about an issue, participants preferred a telephone call. When participants were not very concerned (e.g. routine check-ins, non-time sensitive care questions), many preferred text or email as it was more convenient for them and less interruptive to their providers than phone calls. Two participants suggested that real-time video conferencing should be incorporated into the app.

[The app should have] an option of how would you best like to be communicated with... Would you like it email, text message, phone call and they can select that, and it can go right in with the message. ... Because [grandmother] would pick a phone call, [mother] and I would pick a text message. P6

It depends on the situation, but I don't know, for me personally, I like to do stuff through email ... Unless it's like super urgent, so obviously phone call is the best way to get [urgent] communication. But I think for this type of stuff, I wouldn't mind email, as long as I knew that the doctor's looking at it throughout the day. P4

Sending photos: show is better than tell. Participants were very interested in sending photos to providers. They wanted their provider to really see that status of their wound rather than try to explain solely over the phone. They thought that this additional visual information would facilitate triage and management, be less subjective than patient-assessed symptoms (e.g. amount of redness), and help show trends across time through serial photography. Participants recognized that photos were necessary but not sufficient– some patient-assessed symptoms would be valuable to report (e.g. heat, pain).

I have a smart phone so I used that to take the picture. I thought that was very good to be able to send them an actual picture of what was happening so that way, you know, a little more hands on than "okay - this is... " - trying to describe it over the phone... The nurse commented about how good that was too to have a picture to look at. P6

So if you had it where you could take a picture of it... [the provider] might have said "oh boy, you need to go into the hospital" [or] they could say "hey – no, it's doing what it's supposed to do, just let it be." P10

Response time commensurate with severity. Participants wanted faster response times based on their level of concern and/or the apparent severity of their wound problem—in other words, the app should facilitate triage to enable provider feedback faster based on urgency. Many participants made comparisons to the main alternative to using the app—a phone call—saying that response times should be comparable (e.g. call back within 30 minutes). Participants voiced worries that waiting for even an hour might be too long for an acute concern and that if responses are too delayed, their condition could dete-

riorate. Of those who specified how quickly they would expect a response, 2 said under 30 minutes, 1 said within an hour, 2 said within 4 hours, and 4 said within 24 hours. Participants were willing to wait longer for a response if they had confidence in the system–that their responses were being monitored regularly and not falling into a "black hole" (P4).

I think that if it would have been really hurting, I would want a quicker response time for it. So I think based on the level of pain that somebody was having as to what the response - or felt they were having, the response time back would be quicker. P6

When you pick up the phone you're getting a response. If you're using a tool and you're not getting anything back, then there's no reason to use it because the whole reason is to get communications. P1

Predictable communication within a transparent process. Participants wanted a definite timeframe for a provider response, i.e. a shared expectation between patients and providers. Generally they expected the provider to set this parameter but several wanted to select a time and/or be able to "escalate" to request a faster response. Participants wanted the process to be transparent – to know when their data was received, viewed, and acted upon. They also wanted to be able to set the contact method so they would know what to expect (e.g. wouldn't have to wait around at their computer in case of email response).

Some type of timeframe. So it's not just kind of like sitting out there and you just submit it to a black hole, you know, when someone's going to get back to you. P4

[After clicking submit, the app should say] 'please watch your email during the next three hours or something for a response'. Or whatever you guys decide the response time should be. And/or choose a phone call back. In other words, to know on here before I log off what I can expect next... P12

4.5.1.4 Better management

A final major category of design qualities pointed to the potential for better, faster, more personalized and more acceptable (to the patient) management. Participants saw

many potential benefits including earlier identification and treatment of problems, and the possibility of more efficient care through reduction in unnecessary visits.

Immediate, algorithmic feedback in extreme situations. Participants found the idea of algorithmic (i.e. immediate, app-generated) feedback most acceptable at the extremes—i.e. their situation appears very good or very bad. In less clear-cut cases, most favored the judgment of their health care provider. Participants thought algorithmic feedback was good if it was based on existing practices (e.g. algorithms used by triage nurses). Participants noted that algorithms could benefit both the patient (e.g. advise to go to emergency department immediately if reporting chest pain) and the provider (e.g. flag most concerning patients to review quickly). In general, most participants did not fully trust the computer to make unsupervised management decisions, noting that the quality of the patient input is critical; misjudgments about symptoms could lead patients to unnecessary emergency room visits.

> *I think yeah, that's all right for the extremes. But I still would feel more comfortable with the doctor responding.* **P4**

> *It's the same judgment that you would get if you called a nurse, well, it's probably the same thing you were told outright – if you see this, call the nurse or come into the emergency room. So if the app is just reinforcing that, it seems perfectly natural.* **P3**

Personalized, efficient, acceptable (to the patient) management. Almost universally, patients saw the potential for an app to facilitate better triage. For example, the app could help the patient answer the anxiety-ridden question, "What do I do? Come in or stay home?" (P8). Through better triaging, patients expected a variety of potential benefits. If they were healing normally, for example, the app could save time and unnecessary clinic/emergency room visits, which is especially important for distant patients, as well as alleviate stress and provide reassurance. If their wound was not healing normally, the app could facilitate earlier problem identification and quicker/easier re-admission than the current management process patients experienced. Patients liked the idea of giving their provider more data (especially photos) to track their progress, and would be more willing to

accept providers' management decisions based on that more complete, standardized, and personalized data. For example, they would be more willing to go to ER if advised to do so.

> *That's pretty much what the triage nurse tells you anyway. You have to come in [to the emergency room]. But if you have a picture of it, and it's nothing, then that would make it so that you wouldn't have to go in necessarily... It would be more advantageous and you wouldn't have to sit there for five hours (laughs) in the ER.*
> *P10*

> *But it would have been really helpful, especially the first time that it started getting infected, I could have sent them a picture or whatever and then if a day later - because it did, it got a lot worse. It was itching, it was bleeding and stuff - then I could have sent another picture and said it's a lot worse and they could have seen right then you need to come in now. Instead of waiting until it got really bad. P7*

4.6   DISCUSSION

Our findings illustrate the large potential benefits that patients see in post-acute care mHealth apps. Indeed, such apps are probably inevitable, but the key question is: will they be embraced by patients? Due to the hectic and stressful time during care transitions after acute illness, it is critical that apps be obviously usable and useful to patients or they will not be used. Both patients and providers will lose out if patients reject this powerful method to facilitate data gathering and communication in favor of the highly usable yet limiting alternative—the telephone. However, it is challenging to design for short-term post-acute episodes for a number of reasons. First, there are a large number of possible use cases, and acute problems do not necessarily follow a predictable disease course. Second, related to user-centered design, it is challenging to engage patients in the moment, while they are actually sick, and due to the short-term nature of acute conditions, patients may lack the expertise about managing their condition that patients with chronic illness may have. Finally, it is unclear whether prior work on mHealth for chronic illness management is applicable in a post-acute context.

Although many themes voiced by our participants were common across mHealth, several appeared novel, reflecting the specific needs of patients in a particular post-acute setting (**Table 4-1**).

Table 4-1. Common themes across mHealth vs new themes for post-acute care mHealth.

Support for known themes across mHealth	New themes specific to post-acute setting
• Bring your own device/loans • Security and privacy • Useful to the patient, supporting engagement • Algorithmic feedback when appropriate • Choice of communication methods based on context • Photos (or other sensor-based data): show is better than tell • Meeting information needs without overwhelming	• Response time commensurate with severity • Predictable patient-provider communication within a transparent process • Personalized, more efficient, more acceptable treatment plan based on patient-reported data • Usability while in a cognitively or physically impaired state

Key themes identified from patient interviews have been categorized based on whether they are already known in the mHealth literature or appear novel to a post-acute setting.

The most important insights about patient expectations for acute care mHealth apps relate to patient-provider communication and resulting management of care concerns. This prioritization likely reflects the challenges and frustrations participants faced when managing their post-discharge complications. For example, after developing a wound concern, participants described a lack of control over their situation. Related to communication, they

could not easily or quickly reach a familiar provider. Related to management, they often felt unnecessarily directed to the emergency department as the default option. Through an mHealth application, patients wanted to be empowered to choose how and when they would be contacted, and wanted to be satisfied that the provider managing their care made a personalized recommendation based on all available information (e.g. through review of serial symptom logs and wound photos). Because issues of patient-provider communication and management are essential to addressing many acute concerns, future work could explore the generalizability of these themes across a variety of acute and post-acute conditions.

Although our findings are limited to *patient* views, one of the key differentiating elements of acute mHealth is the relative importance of other stakeholders, most notably *providers*. Acute mHealth apps must be designed to satisfy two very different user groups who almost certainly have competing priorities. In our previous work, a needs assessment of providers for a post-discharge wound tracking app[100], providers expressed concern over additional time requirements, workflow disruption, issues surrounding receipt of photos (e.g. liability, poor quality), and EMR integration. Patient and provider expectations differed on such things as frequency of and trigger for wound tracking: patients expected to track their wound routinely even in the absence of an obvious problem, while providers envisioned less frequent use, generally only if a problem was suspected. Similarly, many of the key patient expectations identified in this paper are subject to provider (and organizational) buy-in and will have to be negotiated between patients and providers. Acute care mHealth apps might ultimately be disruptive, catalyzing a shift from provider-driven to patient-centered care processes.

Figure 4-3 depicts one such mHealth app we are developing to facilitate wound-tracking and patient-provider communication by surgical patients after hospital discharge. We demonstrate how the 11 guiding design considerations have informed the most recent prototype. This prototype is an interactive mockup currently undergoing heuristic evaluation and user testing; concurrently, we are using agile techniques for development of the patient-facing app and provider-facing dashboard.
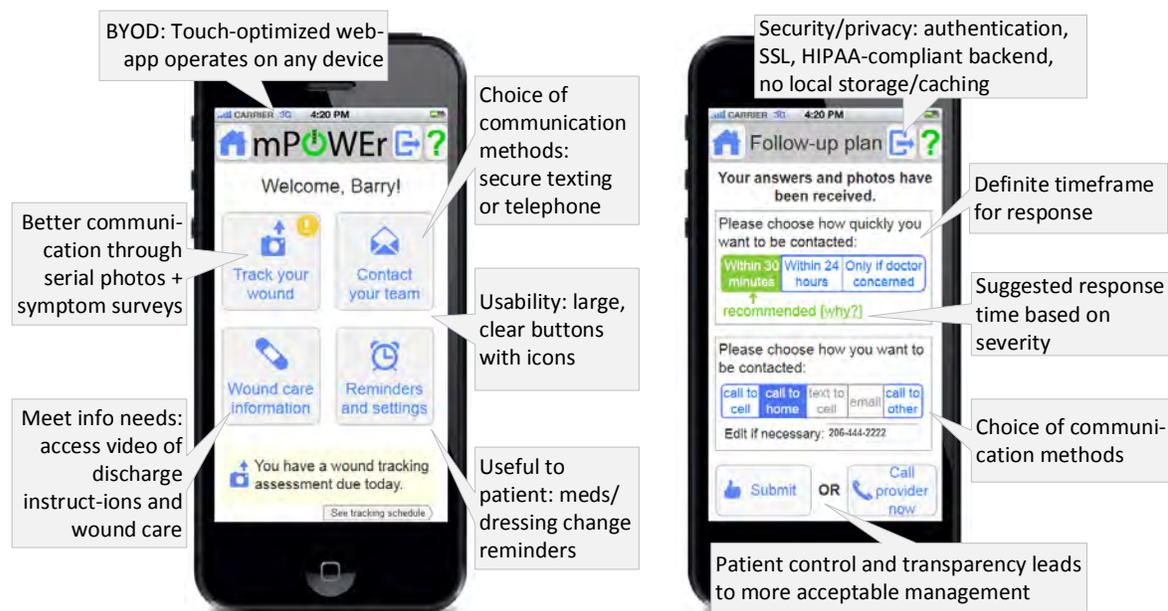
Figure 4-3. Application of design considerations to a wound tracking app. Each callout represents one of the 11 guiding themes that emerged from interviews with patients who experienced post-discharge complications.

Though the chronic vs. acute distinction is widely used, it may be more useful in generalizing mHealth design considerations to distinguish health conditions along two axes: short-term vs long-term and high-intensity vs low-intensity usage (**Figure 4-4**). Typical chronic illnesses tend to be long-term and low intensity while acute concerns tend to be short-term and high intensity, but other conditions (occupying the adjacent quadrants) can have elements of both chronic and acute conditions. Some conditions may even shift around, e.g. short-term, high-intensity surgical wound monitoring may shift to long-term, low-intensity chronic wound monitoring, or stable diabetes may become uncontrolled, shifting toward higher intensity. In designing apps for individual conditions or groups of conditions, it makes sense to consider both intensity and duration, and how these change over time. For example, short-term use may require simplicity and easy learnability, whereas long-term use may allow the possibility of more complexity and customization; high intensity use will require consideration of how to facilitate timely patient-provider

communication, whereas low intensity use may not require provider involvement, using algorithmic feedback to patients instead.

Our research has a number of strengths, including identification of new themes relevant to post-acute mHealth and affirmation of other themes that have been previously reported in the context of chronic illness mHealth. Our findings provide a sound basis for a patient-centered approach to software development, uncommon in the health domain, yet key to developing applications that patients will actually use.
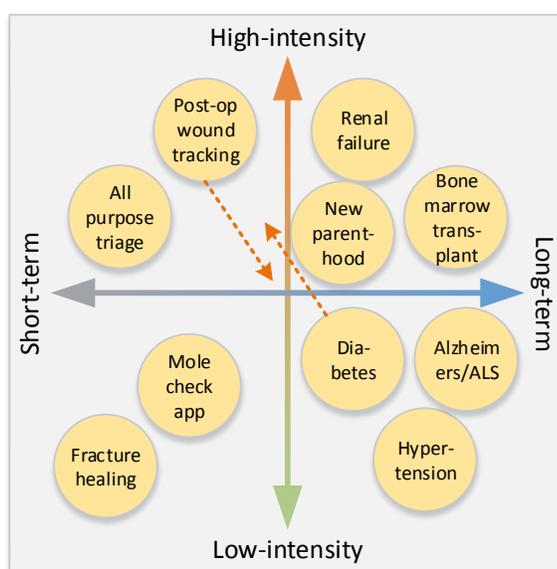
Figure 4-4. Model of mHealth apps with scales of duration and intensity. Hypothetical apps for various conditions are shown for illustrative purposes. Dotted orange lines indicate possible shifts based on disease course or progression.

Despite these strengths, this study has several limitations. First, we only interviewed surgical patients. Patients affected by other conditions may have different needs and preferences. We believe ours is a good initial test population due to the challenging and often eventful post-discharge experience following major surgery. Second, we only interviewed patients who experienced post-discharge complications. We believe that patients who experienced problems are the most likely users of the app and have the most insight into current system failings. However, the "worried well" may also find significant use for self-

tracking and timely access to provider reassurance. Future prospective studies of post-operative patients should address this aspect of care as well. Lastly, we interviewed a relatively small number of patients from two very different, but related, hospital settings. As is customary in qualitative research, the sample size was based on reaching saturation; the hospital settings were diverse, including both an academic medical center and a county hospital. In the future we will address some of these issues through user-centered development of our wound-tracking mHealth platform and examine its impact on patient satisfaction, quality of life, clinical outcomes, and healthcare utilization.

4.7   CONCLUSION

Through interviews with patients who experienced post-discharge complications, we explored the design space of a post-acute care mHealth app. Patients described lack of information at discharge, lack of control over communication and mistrust about management decisions made by providers about their care. In response, they envisioned design qualities of an mHealth app that could empower patients through meeting information needs and facilitating predictable communication, and empower their providers with information to make the best decisions about their care. We present a set of design considerations for post-acute care apps and propose a new model for differentiating mHealth apps by the intensity and duration of illness. These contributions incorporate key patient preferences to expand the mHealth landscape with apps that patients will embrace.

Chapter 5. A PATIENT-CENTERED SYSTEM IN A PROVIDER-CENTERED WORLD: CHALLENGES OF INCORPORATING POST-DISCHARGE WOUND DATA INTO PRACTICE

5.1   ABSTRACT

Background: The proposed Meaningful Use Stage 3 recommendations require providers to accept patient-generated health data (PGHD) for use in the electronic health record by 2017. Yet, we still have much to learn about the tensions that arise in supporting the needs of both patients and providers. Post-discharge surgical wound monitoring using PGHD presents an excellent setting in which to examine these tensions.

Objective: To examine tensions between the needs of patients and providers when designing a novel, patient-centered technology (mPOWEr) that uses PGHD for surgical wound monitoring.

Materials and Methods: As part of the iterative design process of mPOWEr, we conducted semi-structured interviews and think-aloud sessions using mockups with surgical patients and providers. We asked participants how mPOWEr could enhance the current post-discharge process and then used grounded theory to develop themes related to conflicts and agreements between patients and providers.

Results: We identified ten themes, among them six areas of conflict: patients preferred more flexibility in data input, frequent data transfer, text-based communication, patient input in response prioritization, timely and reliable responses, and definitive diagnoses.

Discussion: We present design implications and potential solutions to conflicts for each theme, illustrated using our work on mPOWEr. Our experience highlights the importance of bringing a variety of stakeholders, including patients, into the design process for PGHD applications.

Conclusion: We have identified critical barriers to integrating PGHD into clinical care and contribute design implications to help address them. Our work informs future efforts to ensure smooth integration of essential PGHD into clinical practice.

5.2 BACKGROUND AND SIGNIFICANCE

5.2.1 Patient-generated health data… coming to an EHR near you

Patients have always shared health data with their providers, but the means and scale of this sharing are changing as rapidly as the technology to acquire and transmit novel types of data.[113,114] Although patient-reported data has traditionally lived in the "subjective" section of provider notes, this new data is often more granular and more accurate than the patient history elicited by providers in clinic.[115,116] Critically, providers participating in Meaningful Use could be obliged to integrate **patient-generated health data (PGHD)** from at least 15% of their patients into their EHR by 2017.[117–121]

Healthcare is changing as patients are becoming more autonomous, and want their providers to value their data as an "integral part of ensuring that providers and patients have adequate information to partner in making clinical care decisions".[120,122,123] However, providers often do not know how to store, interpret or act upon this heterogeneous data and have concerns about time and workflow impacts.[124] Yet, providers recognize that PGHD can improve self-management and patient engagement between visits, potentially improving clinical outcomes and patient satisfaction—measures for which they are increasingly held accountable.[125–128]

In this context, careful consideration must be paid to the new challenges that emerge when designing patient-centered systems with competing stakeholders—e.g. patients and providers—whose goals and expectations might not be aligned.[124] Increasingly tech-savvy patients[88,89] expect healthcare, like every other aspect of their life, to "Uberize"[129]—e.g., be accessible by smartphone, user-friendly, on-demand, and transparent. Yet, healthcare has

long lagged in delivering this experience, even as other industries (e.g. banking) have over-come comparable security and privacy concerns.[125]

We share our experience engaging patients and providers to examine stakeholder tensions in the design of mPOWEr, a clinically-integrated application that utilizes PGHD for post-discharge **surgical site infection (SSI)** monitoring.

5.2.2   Significance of surgical site infection (SSI)

SSI is a common occurrence after surgery, affecting at least 500,000 patients per year.[20] Due to shorter hospital stays, most SSIs now manifest at home, after hospital discharge. [10,11] Patients often lack knowledge and awareness of SSI and are frequently unable to recognize when infection develops.[14,15]

More than half of patients who develop post-discharge SSI are readmitted to the hospital, making SSI the overall costliest healthcare-associated infection.[10,19,99] At least a third of these readmissions are considered preventable.[130] In both post-acute and chronic settings, patients are taking on greater responsibility for self-management, yet do not have the right tools to support them, impacting costs, quality of life, and outcomes.[7,14,15]

5.2.3   Study context

We chose to focus on post-discharge SSI monitoring because patients and providers both perceive a need, and in many cases, are already using ad-hoc systems to capture PGHD—e.g., emailed wound photos and symptom reports via telephone. Both stakeholder groups perceive an opportunity for an mHealth application to address concerns with current ad-hoc practices, help patients transition home, improve patient-provider communication, and identify complications earlier.[100,131] However, this post-acute setting poses special challenges because its workflows (e.g. triage) exemplify the provider-centric nature of most healthcare systems.

In this paper, we describe the conflicts and agreements that we encountered in designing a patient-centered tool in a provider-centric healthcare setting. We suggest design im-

plications as well as our own solutions from mPOWEr to guide others in integrating PGHD into clinical settings.

5.3   MATERIALS AND METHODS

5.3.1   Context & overall design process

We employed an iterative, user-centered process to design mPOWEr, a platform for patients to track symptoms of infection after surgery, monitor incisions with photos, and (optionally) communicate with providers. mPOWEr consists of a patient-facing, HTML5 mobile-optimized web-app and a web-based provider-facing dashboard (**Figure 5-1**).

Figure 5-1. mPOWEr. Left: patient-facing HTML5 mobile-optimized web-app enables patients to capture and share structured SSI signs/symptoms and wound photographs. Right: provider-facing dashboard to triage and manage patients and the PGHD they communicate.

Our multidisciplinary research team consists of providers, health informaticists, interaction designers, computer scientists, and a dedicated patient advisor who previously experienced a post-discharge SSI. The patient advisor represents the patients' perspective at

team meetings and is involved in all aspects of our work, including study design, data analysis, technology development, and manuscript preparation. Throughout our design process, we engaged diverse stakeholder groups using a range of human-centered design methods (**Figure 5-2**).[100,107,131]

This paper draws on our entire design process but derives most immediately from a contrasting set of similarly structured needs assessment and design refinement interviews with surgical patients and providers, described next (highlighted by red dashed boxes in **Figure 5-2**).
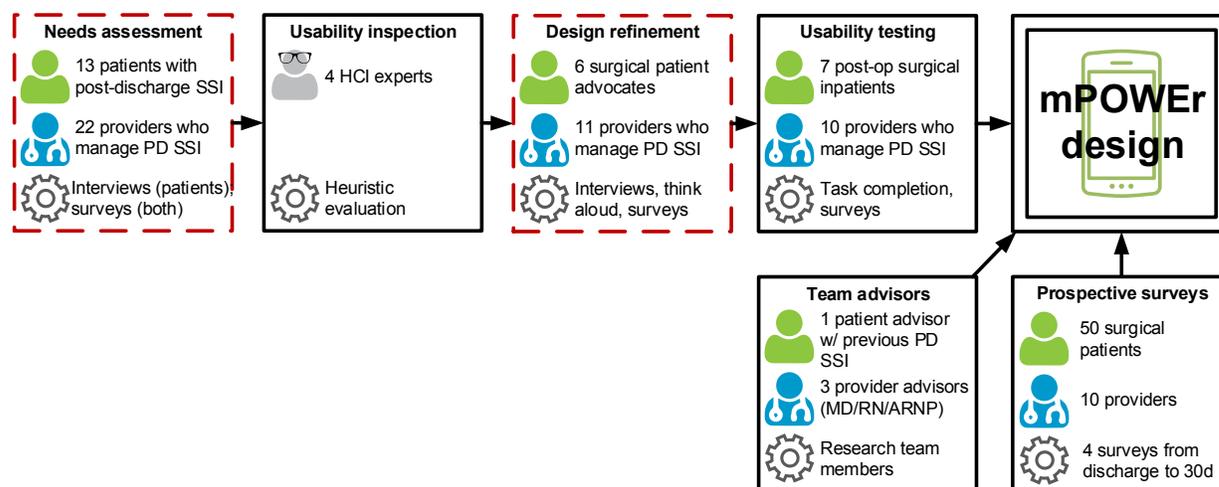
Figure 5-2. Overall design process. Green figures denote patients we engaged, blue figures denote providers we engaged, gear symbol denotes methods we applied. Red dashed boxes show key components of our design process described in this paper, including multiple rounds of engagement with patient and provider stakeholders. Boxes with arrows feeding into the "mPOWEr design" represent components of our user-centered design process, including needs assessment, usability inspection, design refinement, and usability testing (left), as well as frequent input from patient and provider team advisors (bottom left) and a prospective survey of the peri-/post-discharge experience of surgical patients (bottom right).

5.3.2 Participants and setting

We interviewed participants drawn from 2 stakeholder groups: patients and providers. Patients included people who recently experienced post-discharge SSI ("PI", n=13), and patient advocates who volunteered to advise the hospital on matters affecting patients ("PA", n=6). Surgical providers were purposively sampled by role to ensure representation of MDs, ARNP/PAs, and RNs ("S", n=11).

Groups PI and S were recruited at two University of Washington (UW) general surgery clinics; PI through clinic nurses and fliers, and S through email. PAs were recruited from a preexisting UW surgical patient advisory panel[132] through email.

The study was approved by the UW Institutional Review Board and written consent was obtained from all participants prior to undergoing study procedures.

5.3.3 Data collection

We conducted a one-on-one, semi-structured interview with each participant lasting 45-90 minutes, as previously described.[107,131] These interviews served as both a needs assessment and a vehicle for design feedback on mPOWEr mockups. Interviews were recorded and transcribed, and consisted of 3 parts:

1. We used the critical incident technique[102] to guide participants in recounting their most recent experience managing a post-discharge surgical concern, e.g. SSI, including strengths and weaknesses of the process.
2. We employed a "think-aloud" approach[133] using mockups of the patient-facing app (PI, PA) and provider-facing dashboard (S). While walking through mPOWEr, participants were prompted with open-ended questions (e.g. "how would you use this feature?", "how would this feature impact your workflow?").
3. We used surveys to collect demographics (all) and practice characteristics (S).

5.3.4 Data analysis

We conducted qualitative analysis using grounded theory[103], i.e. without a pre-determined coding scheme. Our process was iterative, using open coding (in Atlas.ti v7) to identify emergent themes in an inductive manner. Subject accrual continued until thematic saturation was achieved (i.e. no new themes were encountered).[103] Through team discussions, we collectively identified themes that were shared (i.e. in agreement or conflict) between patients and providers, and subsequently re-coded all transcripts in greater depth to look for related subthemes. Major themes were selected by consensus among the team. Descriptive statistics from surveys were calculated with Microsoft Excel.

5.4 RESULTS

Participant characteristics are shown in **Table 5-1**. **Appendix Table 5-A** provides background on current post-discharge care practices, specifically problems with current post-surgical discharge follow-up and patient/provider experiences with emailed wound photos. Next, we present ten themes related to stakeholder tensions in the design and implementation of mPOWEr. Following Shapiro and colleagues' PGHD framework[134], we group themes in four major categories: data capture, data transfer, review/documentation, and overall process (**Figure 5-3**). We name each theme and indicate whether there was primarily agreement or conflict between patient and provider stakeholders. **Appendix Table 5-B** contains additional illustrative quotes from patients and providers for each theme.

Table 5-1. Participant characteristics. Patient characteristics on left, provider characteristics on right.

	Patients with infection (PI)	Patient advocates (PA)		Providers (S)
N	13	6	N	11
Age, mean [range]	45 [21-71]	58 [33-76]	Years in practice, mean, [range]	7.4 [2-16]
Gender, female	9 (69%)	2 (33%)	Gender, female	7 (64%)
Race/ethnicity			Role	
American Indian	1 (8%)	0	Attending physician	4 (36%)
Asian	2 (15%)	0	Resident	1 (9%)
Hispanic	0	1 (17%)	Nurse practitioner	3 (27%)
White	9 (69%)	5 (83%)	Physician assistant	1 (9%)
Other	1 (8%)	0	Clinic nurse	2 (18%)
Education			Post-op patients seen per month, mean [range]	73 [2-200]
Less than high school	1 (8%)	0	Patients with SSI seen per month, mean [range]	6.1 [1-20]
High school graduate	1 (8%)	1 (17%)		
Some college	6 (46%)	0		
College graduate	5 (38%)	2 (33%)		
Post-graduate	0	3 (50%)		
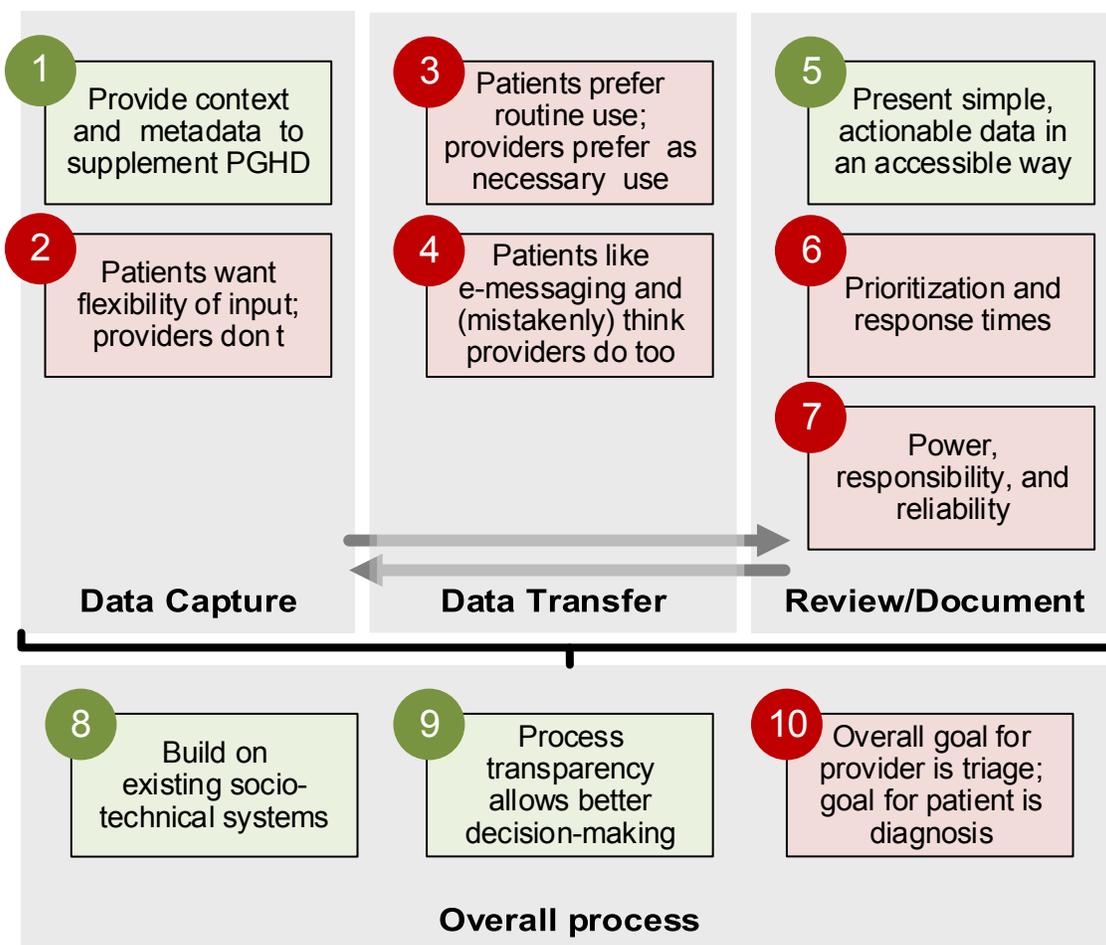
Figure 5-3. Themes organized by Shapiro's model of PGHD flow [134]. Green boxes denote areas of agreement between patients and providers; red boxes denote conflict.

5.4.1   Data capture

The following themes of contextual information/metadata and flexibility of input data types relate to the nature of data created by patients or designees.

►1. Provide context and "metadata" to supplement PGHD (agreement)

Both stakeholder groups agreed that putting 'objective' patient data into context was important, as happens with current 'analog' processes, to make sure providers know to "*get the full picture*" (**S5**), e.g. when patients provide ambiguous data. Despite their preference

for constraining patient input (see #2 on *flexibility of input*), providers were eager to collect *response-level metadata*—such as ambiguity and variability—and *patient-level contextual metadata*—such as reliability and anxious tendency—to use in making care decisions. For example, knowing that a patient has a *"pattern [of] unreliability [e.g. no-shows]... I'd probably set [that patient] up [with routine wound monitoring with mPOWEr]"* (**S7**). Patients agreed, being eager for providers to have "*all my history and all the data*" (**PA10**), including their contextual metadata—such as confidence in answers, and level of anxiety. Providers also reported assessing *other providers'* confidence, e.g. when consulting.

▶2. Patients want flexibility of input, providers don't (conflict)

Most providers wanted patient data to be limited in quantity and type, i.e. *"a fixed menu so that they're not free typing in there..."* (**S8**). Patients, however, voiced concern about constraints—that they would be faced with *"forced choices, no choice for the option that should probably be offered to me"* (**PA5**). Patients often *"had other things to say"* (**PI12**) than what is offered on medical forms. Clinic nurses, as opposed to higher-level providers, were more supportive of a small free-text box for the patient to give *"a quick overview of what's going on"* (**S10**) to help set the care agenda.

5.4.2 Data transfer

The following themes (both reflecting a conflict) relate to the communication of data between patients and providers, specifically the frequency or trigger for data transfer, as well as the mode of communication.

▶3. Patients prefer routine use; providers prefer "as necessary" use (conflict)

Both groups agreed that mPOWEr should be offered to nearly all patients, but disagreed over what should trigger its use. In our previous work[131], about a third of patients wanted to use the tool routinely in the absence of a particular concern to *"bring peace and comfort ... that their doctor is looking at [their wound]"* (**PA4**). However, providers preferred to

have only their *"high risk [patients] use it routinely"* (**S4**) to reduce staffing needs, *"information overload"* (**S1**), and liability for missed diagnoses.

Both groups had concern that for many patients, tracking their wound *"might increase anxiety"* (**PA8**), and some providers were hesitant to enroll their *"super anxious"* (**S4**) patients in monitoring. Providers wanted an objective *"risk score"* (**S11**) to help decide at discharge who to enroll and their use frequency. However, once patients developed a true wound concern, both groups foresaw continued use to *"keep an eye on how things are going."* (**S7**)

Providers were more open to routine use if the system was *"integrated into what we're already currently using [EHR], then I'd have absolutely no issues with it. But if it's going to be another application that I've got to monitor, then no, I want it to be on an as-needed basis."* (**S10**). See also theme #8, *Building on existing socio-technical systems*.

►4. Patients like electronic messaging and (mistakenly) think providers do too (conflict)

For non-urgent concerns, patients expressed a preference for electronic communication (e.g. email, texting, EHR messaging) because it is easier (*"with a smartphone by the bed"* (**PA7**)), more direct, and saved for future reference, especially important for patients who are *"post-surgery, loopy on meds"* (**PA7**); patients also perceived text-based methods as preferable to providers—a way to not *"interrupt them if they're in the middle of something"* (**PA4**), i.e. letting them respond when convenient. For urgent concerns, most patients still preferred telephone or in-person conversations.

But many providers felt that texting, even securely, is *"totally disruptive... I don't want that kind of access with patients."* (**S4**) Other providers had concern for texting being *"too casual"* (**PA2**), *"informal [but] part of their medical record..."* (**S2**) and giving an impression of real-time communication that might not be. Providers wanted patients to have *"realistic expectations of how available I am to them"* (**S11**). Both also wondered whether texting could match the *"immediate gratification [and] making a connection"* (**S5**) from calling. A bright spot for text-based communication among providers was the potential for time saved in documentation: *"a whole different ball game... I don't have to repeat everything..."* (**S10**); on the oth-

er hand, providers were resistant to using an unintegrated communication system because *"everything we do is all in Epic Care"* (**S10**).

Overall, providers thought communication preferences were a *"provider-specific thing"* (**S2**) but had concerns for security, workflow disruption, inefficiency, miscommunication, informality and exposure of personal contact information.

5.4.3   Review/documentation

The following themes relate to how providers review and respond to incoming data, including topics of data presentation, patient prioritization, and responsibility for timely follow-up.

▶5. Present simple, actionable data in an accessible way (agreement)

Both groups wanted the interface to be *"simple, obvious"* (**PA8**), *"quick, easy and better than what we have now"* (**S9**). Both want *"at a glance"* (**S6**) data that has already been condensed or interpreted into actionable information, e.g., that *"[I can use] to make decisions based on"* (**S1**). Both worried that *"repeated assessment...may [yield] too much information"* (**S1**) to easily understand. Alongside PGHD, providers also wanted to have summarized contextual information, e.g. *"how complicated this patient is"* (**S6**) that could be pulled from the EHR (see Theme #8 on *existing sociotechnical systems*). Both groups were interested in trends and summary measures, e.g. *"It's green or it's yellow or it's red... things are getting better or worse"* (**PA10**), *"It all boils down to is it getting better or is it the same?"* (**S1**).

Despite this shared preference for highly summarized data, both groups were skeptical of automated decision support with the exception of *"worst case scenarios"* (**PA6**) where patients could be in immediate danger. Despite potential for time savings with broader use, both groups worried about basing automatic recommendations on subjective symptoms, and liability for unreviewed data.

Both groups wanted the system accessible on any device both to ensure timely response from attending surgeons who are *"down in surgery... she doesn't have [EMR messages]*

on her phone" (**S10**) and to provide accessibility for recovering patients with a *"smartphone by the bed"* (**PA7**).

►6. Prioritization and response times (conflict)

Patients and providers disagreed about how patients should be prioritized and how quickly responses should occur. Although both groups thought that patients should be prioritized based primarily on providers' judgement, patients saw a greater role for their own level of concern. Some providers were dismissive of patient concern (*"some patients are overly concerned about everything"* (**S1**)) while others valued it highly (*"the more concerned they are, the more concern I feel…"* (**S5**)).

Most providers wanted to assess level of patient concern as part of data collection; however, they didn't want to imply that high patient concern would necessarily lead to a quick response. Both agreed in principle that patients judged to be higher priority should receive quicker review and further communication as necessary, and that response times should ideally be based on consideration of the patient's next step, i.e. to give them *"enough time that they could get to the clinic if they needed to…"* (**S5**), to avoid the scenario where *"meanwhile it's getting worse and the next morning you've got a 102 fever…"* (**PI8**).

But in practice, providers didn't want to guarantee a response time quicker than 24 hours (the institutional default), while patients felt a 1-4 hour response time was needed when they were particularly concerned, *"Because sometimes you're just sitting there waiting… and it's like God, what am I supposed to do?"* (**PI10**). Patients wanted to have a good estimate of a response time, and some even wanted to have direct or indirect input into that determination.

►7. Power, responsibility, and reliability (conflict)

Providers were concerned that giving too much say to patients could *"take [away] the ability for us to manage this triage process…"* **(S5)**, causing other patients or responsibilities to suffer. Although providers thought giving patients more control would be *"great for patient satisfaction"* (**S5**), providers worried about patients' *"unrealistic expectations"* **(S1)** about pro-

vider workflow. Fundamentally, providers see a *"total information asymmetry"* **(S1)** between themselves and patients, with their job being to use their clinical judgement to determine *"whether or not it's a true problem"* (**S11**). In most cases, patients are willing to let providers *"use their best judgment"* (**PA7**), provided they trust the reliability of the triage process and are kept informed (see also #9*, Process transparency*).

Patients feel that after communicating their data, *"This is in the hands of the physicians, the provider system. I've done what you've told me to do"* (**PA5**), leaving responsibility *"on the provider"* (**PA4**). Patients want providers to take responsibility for reliably reviewing their data, making an assessment, and guiding them to care in a timely way once they've sent in their data. Yet, providers want the burden to continue to remain on patients, e.g. *"You should have some sort of disclaimer… if you do not hear back… please go to the emergency room."* (**S9**). Patients had low expectations for improvement: *"knowing how the system works now, I don't think [I'd get a timely response]"* (**PA8**).

5.4.4   Overall process

The following themes relate to the overall process of handling PGHD, namely building on existing socio-technical systems, providing transparency throughout the process, and considering misalignment of patient and provider goals.

►8. Build on existing socio-technical systems (agreement)

"'Who's responsible for [monitoring] it' is the biggest question" (**S7**). Broad consensus was that the existing clinic nurse who currently handles patient calls was *"the natural person to do the screening"* (**S1**) because they are accustomed to the role and have *"procedure-specific, specialty-specific knowledge"* (**S1**). There should be a *"dedicated nurse or team [but] they're overworked as it is…"* (**S7**). Nurses expressed preference to *"touch base [frequently] with the patient"* (**P10**) both before and after discharge to maintain rapport and identify potential post-discharge difficulties early. Patients like interacting with the clinic nurse because they often already have rapport and the nurse *"knows my case"* (**PI12**), providing care continuity.

Reflecting current team-based workflows, surgeons wanted *"tiers of people [nurses/residents]"* (**S6**) screening patients, so they don't *"get alerted when I'm doing a case for something that's not real."* (**S2**) Providers saw efficiently facilitating within-team communication and consultation as a key element of mPOWEr.

Just as both groups wanted to build on existing care team hierarchies, they also wanted to build on existing technical systems. Both groups agreed that existing communication systems were fragmented and *"roundabout"* (**PI6**) and didn't want to add *"another layer"* (**S4**) of complexity. Providers stressed that *"playing within the same system"* (**S4**) to *"streamline the triage process"* (**S8**) was critical, supplementing the existing system with richer data.

Providers stressed that mPOWEr should either be accessed within or synchronize with existing EMRs, otherwise *"it might create more complexity than it was helping"* (**S8**), or would not be monitored regularly (*"I can't remember to check that"* (**S11**)). Integration would allow appropriate and efficient documentation (*"The information's already there so why not use it?"* (**S1**)); auto-population of the dashboard (otherwise, *"who's inputting all this information?"* (**S11**)); reduce the *"risk of misinformation [which] might be greater than the actual benefit of having that information come up"* (**S4**); facilitate *"quickly look[ing] at background information [like] op-notes"* (**S6**); and generally centralize provider workflows which *"always go through Epic anyways"* (**S8**). Integration could also make more frequent submissions feasible (see theme #3, *Routine vs "as necessary" use*).

►9. Process transparency allows better decision-making (agreement)

In different ways, both groups wanted the system to be transparent. For example, patients have experienced *"frustration... think[ing] they're talking [emailing] directly to their doctor, but they're not"* (**S11**). Patients wanted to *"see a log, has the doctor looked at [my wound photos]?"* (**PI4**), making clear when data have been reviewed and/or acted upon. Providers wanted similar functionality to see if other providers have reviewed their consult, because *"it leaves us [nurses] responsible until they have"* (**S11**).

With better knowledge of the care process, patients and providers could both make better decisions about next steps. For example, both groups mostly agreed that communi-

cating *"Some kind of a [response] timeline"* (**PI6**) or *"commitment"* (**S4**) to patients was important, even if it was 'too long', so that patients could seek further care with less uncertainty. Patients imagined being less anxious and more willing to give providers leeway in terms of response times if they could *see* their data was under review (see also theme #7 about *Reliability*). Clinic nurses currently try to be transparent with patients to help set reasonable expectations: *"I try to explain in simple terms that I'm going to prioritize who I'm calling [back]... people with infection concerns [are high priority]"* (**S11**).

►10. Provider goal for data collection is triage; patient goal is diagnosis (conflict)

Mirroring their current practice, providers stressed that their goal for using mPOWEr, at least initially, would be triage, not diagnosis: i.e., mPOWEr would help providers screen patients to then come into clinic (or emergency department) for definitive management. Providers shied away from diagnosis due to concerns about accuracy (especially false negatives) and that definitive diagnosis *"would take a lot of time... not feasible... for every patient that calls."* (**S1**); in addition, *"it's not built into our day"* (**S4**) in terms of time or money. By contrast, patients expect that providing more data will lead to more definitive determinations, e.g. *"you could save a visit or they could see right away, you better come in..."* (**PA9**).

Both groups saw *potential* for better triage/efficiency, i.e. earlier identification of problems and preventing unnecessary visits, but many providers had concerns for both under-triage (fewer visits could compromise care quality), and over-triage since patients *"would have more triggers to call. One concern is do we end up intervening on more patients than we should."* (**S5**). Patients tended to see only the upside of using the tool.

5.5   DISCUSSION

Based on our results, we offer implications for design of systems to facilitate incorporation of PGHD into clinical environments, illustrated using our own solutions from mPOW-

Er. We close by re-emphasizing the necessity of engaging stakeholders, especially patients, in the design of PGHD tools.

5.5.1   Design implications

We explored tensions that arise when designing a novel, patient-centered post-discharge wound-monitoring tool with both patient and provider stakeholders. Although patients and providers agreed on a broad range of design specifications for mPOWEr, several key issues emerged that have significant implications for design of patient-centered technology the era of PGHD. **Table 5-2** shows design implications most pertinent to clinically-integrated PGHD, which are informed both by *conflicts* and *agreements* between stakeholders. We show by example how we addressed design implications in mPOWEr's patient-facing application (**Figure 5-4)** and provider-facing dashboard (**Figure 5-5**). In **Figure 5-6**, we illustrate an offline or "wound diary" mode which addresses Design Implication #3 (*Consideration of routine vs on-demand use*) to enable routine use by low-risk patients while minimizing provider burden.

Table 5-2. Design implications for clinically-integrated PGHD applications.

Design implication	Challenges	Recommendations (See Figures 5-4, 5-5, and 5-6 for illustrations)
1. Include metadata	Existing "analog" processes and interactions, both patient-provider and provider-provider, are rich with metadata that are used to aid decision-making, e.g. uncertainty or patient reliability.	• Observation and interviews to identify and capture metadata that is currently used in decision-making
2. Balance flexibility of input data	Patients can feel frustrated fitting their concern into a box and worry about checking the "wrong" box, whereas providers often want to constrain patient input as much as possible to minimize review time, standardize decision making, and reduce liability for needles in a free-text haystack.	• Thoughtful answer choices, tested with users • Provide help and "nudge" users toward discrete choices but leave option for free-text input
3. Consider routine vs on-demand use	Patients may want to track their wound frequently while providers may only want to receive routine data from high-risk patients, without being burdened by the time and liability associated with low-risk submissions. Yet, historical serial data on ostensibly low-risk patients becomes useful if there is concern for complications.	• Create templates for different use cases; support providers in deciding appropriate use cases • Allow patients to use as often as they wish in "offline" mode, forwarding data when it becomes clinically useful
4. Make communication preferences explicit	Patients often prefer to communicate by email/text, but providers may find such methods disruptive, inefficient or prone to miscommunication.[135] Text-based methods do not facilitate rapport-building and may obscure who is communicating with the patient.	• Flexibly incorporate user preferences into application, i.e. enable opt-out of particular communication modes • Establish/publicize guidelines about appropriate content and timeliness of responses. • Be transparent in who is communicating and encourage rapport building through patient and provider face photographs
5. Simple, actionable presentation of data	Impaired patients and busy providers both wanted data that was condensed into simple, actionable elements. Measuring many symptoms over many time points generated too much data to be comprehended at once. Patients and surgeons	• Understand clinical reasoning, i.e. how providers think about the data and present it to support that reasoning • Provide high-level summary views, and flag complex/ contradictory presentations for

	need easy smartphone access (e.g. in operating room).	deeper review
6. Flexible prioritization schemes to support timely response	Patients and providers have varying views on how to prioritize patients for review and response (+/- incorporating patient concern). Most patients don't want to "bother the doctor" but when they do have concern, they want faster response times than providers want to guarantee. Both groups want to avoid significant worsening while waiting for a response.[136]	• Encourage patients to voice concerns and collect level of concern but clarify to patients how it is used • Allow prioritization (flagging, sorting) based on a range of factors (e.g. patient concern, symptom trends) • Advise patients under what circumstances they should seek care while waiting for a response
7. Clarify responsibility and enhance reliability	Patients and providers said that system reliability is critical, yet unlikely to achieve. Patients want providers to take responsibility for reliably reviewing their data, making an assessment, and guiding them to care in a timely way; providers want patients to continue to bear this burden. Providers were hesitant to allow patients input into setting response timeframes, worrying about losing power to manage the process, causing other patients or responsibilities to suffer.	• Create clear shared general expectations between patients and providers about timeliness of response; once data has been submitted for review, estimated response time should be clearly visible to both patients and providers and updated in real time by providers • Consider giving patients the ability to escalate their request if provider response is not meeting expectations • Track response times and escalations and take a continuous quality improvement approach to improving these measures (**Institutional barrier**)
8. Enhance existing workflows	Both patients and providers were most comfortable building on existing, clinic nurse-centered processes and workflows, while recognizing that these processes had significant problems, e.g. fragmentation. Providers were most excited about incorporating mPOWEr if it could help address these problems, rather than create another layer of complexity on top of existing processes.	• Understanding existing processes, team roles, inefficiencies; be incremental, seeking to minimize disruption • Facilitate intra-team communication and consultation • Integrate with existing health IT systems (**Institutional barrier**)
Strive for radical transparency	Patients and providers want transparency (c.f. OpenNotes[87]), not typical in healthcare, in who is viewing	• Make an "audit trail" available to both patients and providers in real time showing who has

	their data, what decisions are being made about it, and when they can expect a response.	viewed data and how they have acted on it • Provide patients a road map of typical provider processes to help gauge progress • Use historical data to set expectations for response times
10. Align goals of use	Provider goal was triage; patients' goal is definitive diagnosis, as has been seen previously.[74] Providers have concern for time requirements for review, and both under- and over-triage (i.e. too few or too many visits). Patients only see the upside of providing more data (e.g. fewer visits).	• Create shared expectations about potential for fewer or more visits. • Create institutional structures for systematic screening with dedicated provider time for monitoring (**Institutional barrier**)

Figure 5-4. Patient-facing mPOWEr application. Orange callouts highlight design implications from Table 2 (corresponding to the number in the circle). Red dotted lines indicate screen changes due to click/tap.
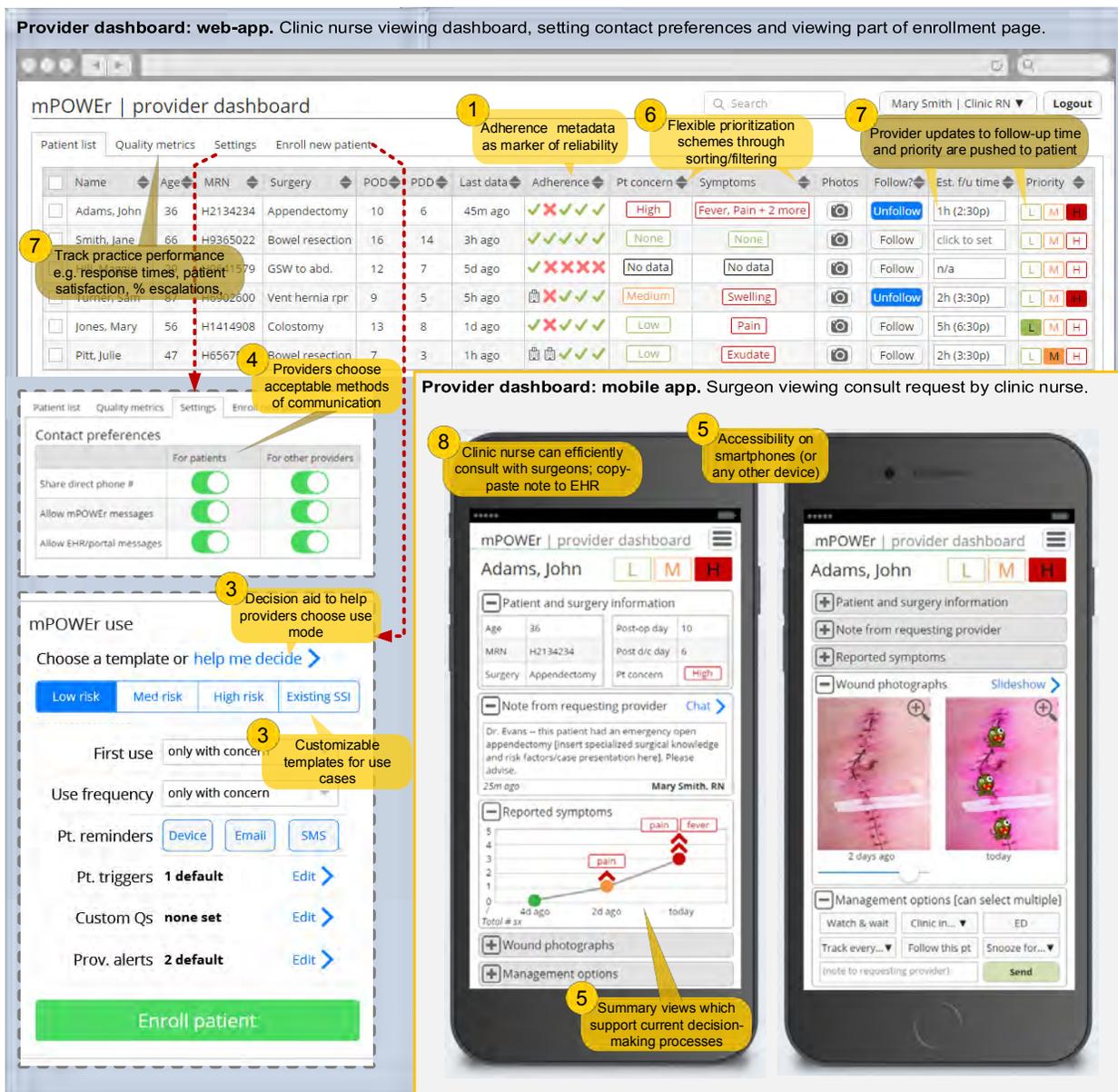
Figure 5-5. Provider-facing mPOWEr dashboard. Lower right portion shows mobile version of provider dashboard (a consult request sent from clinic nurse to surgeon). Orange callouts highlight design implications from Table 2 (corresponding to the number in the circle). Red dotted lines indicate screen changes due to click/tap.
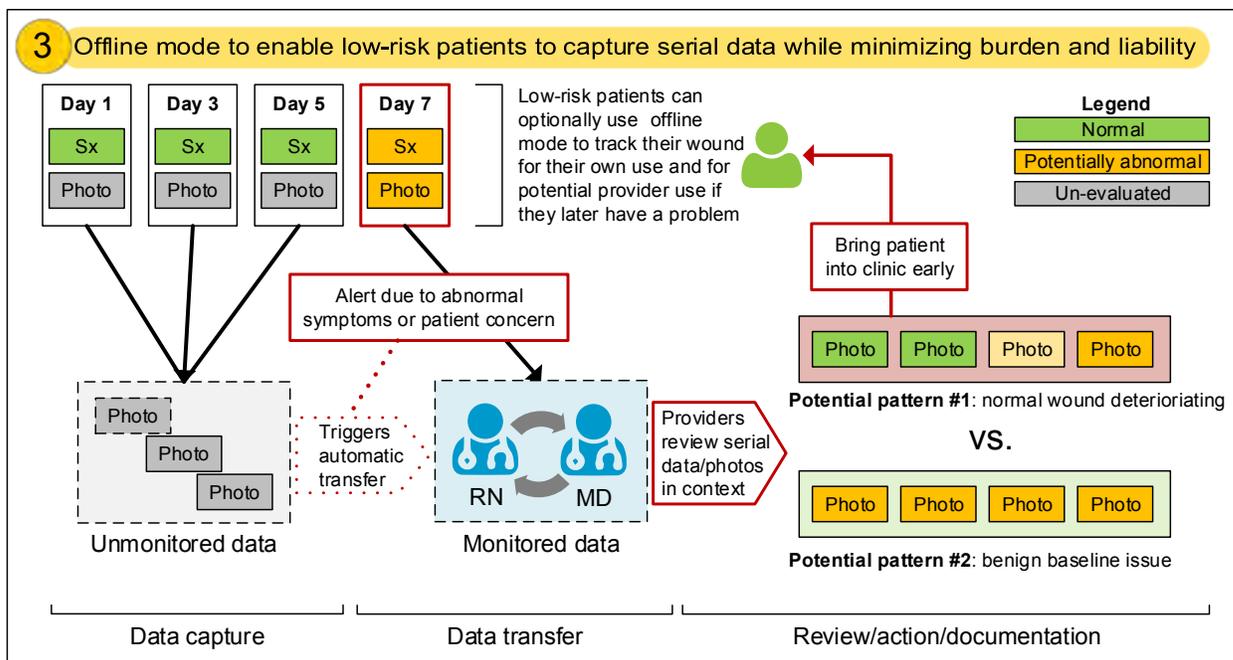
Figure 5-6. Diagram of offline or "wound diary" mode, illustrating design implication #3. Green indicates normal symptoms or photo, yellow indicates potentially abnormal, red indicates abnormal.

5.5.2   An increased need for stakeholder engagement, especially with patients

We identified a number of areas of conflict between patients and providers in the design of a novel system incorporating PGHD. Our experience highlights the importance of bringing a variety of stakeholders, including patients, into the design process for PGHD applications. Based on our experience, we recommend employing strategies such as bringing patient advisors directly onto the research team and/or seeking feedback from patient advisory groups maintained by healthcare organizations. We suggest engaging stakeholder groups iteratively during the design process to ensure ongoing input from key groups rather than, e.g., a "patient engagement phase" followed by a "provider engagement phase" which could allow one group to overshadow the other.

5.5.3 Limitations and future work

Our work has several limitations, including relatively small samples (based on reaching thematic saturation), conducted within a single health system, though across diverse care settings including a county hospital trauma center and university hospital. We focused on a unique post-acute surgical use case which may not perfectly generalize to medical or chronic care settings. However, we believe this use case represents an illuminating extreme in terms of patient acuity, time criticality, heterogeneity of potential PGHD (e.g. photos, subjective symptoms, sensed vital signs), and provider-centricity of post-discharge triage workflows.

In addition to design challenges that derive from patient-provider conflicts, we uncovered several issues that are challenging because they require broad, institutional changes, e.g. ensuring dedicated time and funding for providers to review incoming data, or integrating with existing IT systems. In future work, we plan to address these issues as well as evaluate the impact of mPOWEr on clinical outcomes, utilization, and patient engagement.

5.6 CONCLUSION

Despite a use case with significant buy-in from all stakeholders (post-discharge wound monitoring), we encountered patient-provider conflicts that impede the design and adoption of mPOWEr and similar patient-centered tools. We contribute a number of design implications which can inform the development of similar tools; but patient and provider engagement remains critical to working through these tensions to ensure smooth integration of PGHD into routine clinical use.

Chapter 6. APPLICATION OF A PATIENT-CENTERED HEURISTIC EVALUATION TO REDESIGN AN mHEALTH WOUND TRACKING TOOL

6.1 ABSTRACT

Background: Patient-centered care is a fundamental aim of a high-quality healthcare system, increasing patient satisfaction and empowerment, and maximizing effective use of health care resources. Health information technology (HIT) is widely regarded as a key facilitator of patient-centered care, yet no guidelines exist for evaluating patient-centered applications.

Objective: To adapt an existing framework of patient-centered HIT as the basis for a heuristic method to evaluate patient-centered design, and to apply that method to the redesign of a novel mobile health tool.

Materials and Methods: In this paper, we describe a new method for evaluating the design of patient-centered systems based upon a published model of patient-centered care. We applied this method to our current design of mPOWEr, a post-discharge surgical wound tracking and communication tool.

Results: We demonstrated that our existing design addressed 6/18 areas of patient-centeredness based on our heuristic evaluation, and our subsequent design addressed 10/18 areas. We illustrated by example how this new method helped us redesign mPOWEr to make it more patient-centered.

Discussion: Although we strove to be patient-centered in our original design process, applying our heuristic evaluation method gave us important insights for redesign. These insights included better understanding of complexity-usability tradeoffs, impact on clinical workflows, tensions between patients and providers, and other sociotechnical barriers to effective use.

Conclusion: Listening to patients is necessary but often insufficient for creating truly patient-centered systems. Incorporation of heuristic evaluation methods, such as the one we described, could enhance this process, especially when used in conjunction with stakeholder engagement.

6.2 BACKGROUND AND SIGNIFICANCE

6.2.1 Patient-Centered Care

The Institute of Medicine, in naming patient-centered care as one of six fundamental aims of the US healthcare system in 2001, defined it as "care that is respectful of and responsive to individual patient preferences, needs and values".[44] In addition to increasing patient satisfaction and empowerment, patient-centered care contributes to other system goals though minimizing underuse and overuse of healthcare resources.[137,138]

Yet, delivery of patient-centered care is still a challenge, for a multitude of reasons.[46,139,140] Patient care is fragmented across providers, in the absence of either sufficient care coordination or interoperable information systems;[141–143] payment models reward specialty care and procedures over primary care and longitudinal relationships;[144,145] care quality has been measured in terms of clinical outcomes without regard for the experience of patients on their way to those outcomes.[46,141] Perhaps the most important underlying reason is that, due to the tradition of provider-centric medicine, patients have had limited engagement in the design of healthcare systems.[46]

Health information technology (HIT) holds promise in supporting delivery of patient-centered care while improving clinical outcomes. A recent systematic review concluded that "substantial evidence exists confirming that HIT with [patient-centered care]-related components have a positive effect on health care outcomes", including process and disease-specific clinical outcomes, responsiveness to needs/preferences of patients, shared decision-making, patient-clinical communication, and access to medical information.[146]

Despite these advances, it is unclear what patient-centered HIT should look like because the informatics community lacks a unified definition of the term, and has not defined a framework of key attributes. The term "patient-centered" is used inconsistently, and while developers have similar end goals, they get there in different ways. Consensus definitions of patient-centered care have begun to emerge in clinical realms (e.g. primary care)[147–149], but aren't easily applied to HIT. In this paper we build on a published framework of patient-centered care specific to HIT prepared by the Johns Hopkins University Evidence-based Practice Center for the Agency for Healthcare Research & Quality. Through literature review, and consultation with a Technical Expert Panel and external advisors, the framework authors proposed a framework with 5 dimensions: coordination and integration of care, whole-person orientation, enhanced provider/patient relationship, clinical information systems, and socio-cultural competence.[146] We used this "Hopkins framework" as the basis for an evaluation method which we applied to an mHealth tool created via user-centered design.

6.2.2   User-centered design and heuristic evaluation

While there are models of categories[146] and domain-specific functionalities[125,150] of patient-centered HIT, no specific methods for evaluation of the "patient-centeredness" of applications have been proposed. HIT designers are increasingly employing user-centered design[151], but it is unclear whether applying traditional user-centered methods to patients, i.e. "soliciting patients' input regarding the education and support that patients require to make decisions and participate in their own care"[152] will lead to patient-centered applications.[153] Our experience designing mPOWEr, reported in this work, calls into question whether traditional user-centered methods are sufficient to ensure a patient-centered result, given how few of the subdomains of the Hopkins framework we initially addressed. We describe our prior user-centered approach in the Materials and Methods section.

Heuristic evaluation is a commonly-used "discount" (i.e., inexpensive, quick) usability inspection technique in the user-centered design toolbox. This method requires a set of

experts to evaluate an interface based on design rules of thumb (i.e., heuristics). Violations of heuristics are identified and then rated by severity to prioritize for redesign.[1,154] To be applicable to a wide range of user interfaces, heuristics tend to be general and abstract, e.g. "consistency and standards". A common drawback to heuristic evaluation is that the abstract nature of heuristics can make them challenging to instantiate in particular applications (e.g., "Recognition rather than recall").[155]

Patient-centered technologies are particularly difficult to evaluate, i.e. "is it really supporting/empowering patients?". Clinical trials to assess the impact of technology on patient empowerment are expensive and inconsistent with iterative design and short development cycles. To help address this challenge, we adapt an existing framework of patient-centered HIT as the basis for heuristic criteria which we apply as a new evaluation method to redesign mPOWEr, a novel post-discharge wound monitoring tool.

6.2.3   mPOWEr

mPOWEr is a post-discharge mHealth wound tracking and communication tool, capturing patient-generated data and integrating it into provider workflow. Its primary clinical purpose is to monitor for surgical site infection, a common complication after surgery.[20] Due to shorter hospital stays, most of these infections now manifest at home, after hospital discharge.[10,11]

In many ways, the current care transition experience after surgical discharge is "patient-centered" but in a negative sense. Patients and caregivers are required to take on primary responsibility for wound care and problem recognition at home, tasks for which they may be poorly prepared and in which they may be poorly supported.[13] Patients often receive minimal discharge teaching,[7,156] and lack knowledge and awareness of infection, resulting in an inability to recognize when infections develop.[14,15] The support they receive in determining the urgency of wound management concerns may be little more than being told to go to the emergency department if they are concerned.[131] Patients who develop post-discharge infection subsequently have significantly lower quality of life,[18] and more

than half are readmitted to the hospital, making surgical site infection the leading cause of readmission among surgical patients and the overall costliest healthcare-associated infection.[10,19,99,157] At least a third of these readmissions are considered preventable.[130]

We chose to focus on this use case of patient-centered health IT because both patients and providers perceived a need to improve post-discharge surgical wound monitoring through collection of symptoms and wound photos. Within our own institution, we had personal and anecdotal evidence of informal exchange of wound photographs already occurring, in some cases at the request of clinic staff and in some cases initiated by patients. Both patients and providers were dissatisfied with typical care delivered after surgery, and both perceived an opportunity for an mHealth application to help patients transition home, improve patient-provider communication, and identify complications earlier.[100,131] Although we developed mPOWEr to fill this gap, we decided to critically examine its features and characterize its degree of "patient-centeredness". In this paper, we describe the formulation and application of a new heuristics-based evaluation method for addressing this question.

6.3   MATERIALS AND METHODS

6.3.1   mPOWEr design process

We employed an iterative, user-centered process (**Figure 6-1**, left portion) to design mPOWEr, a platform for tracking symptoms of infection after surgery, monitoring wounds with photos, and communicating concerns with providers.[100,107,131] mPOWEr consists of a patient-facing, HTML5 mobile-optimized web-app and a web-based provider-facing dashboard (**Figure 6-2**).
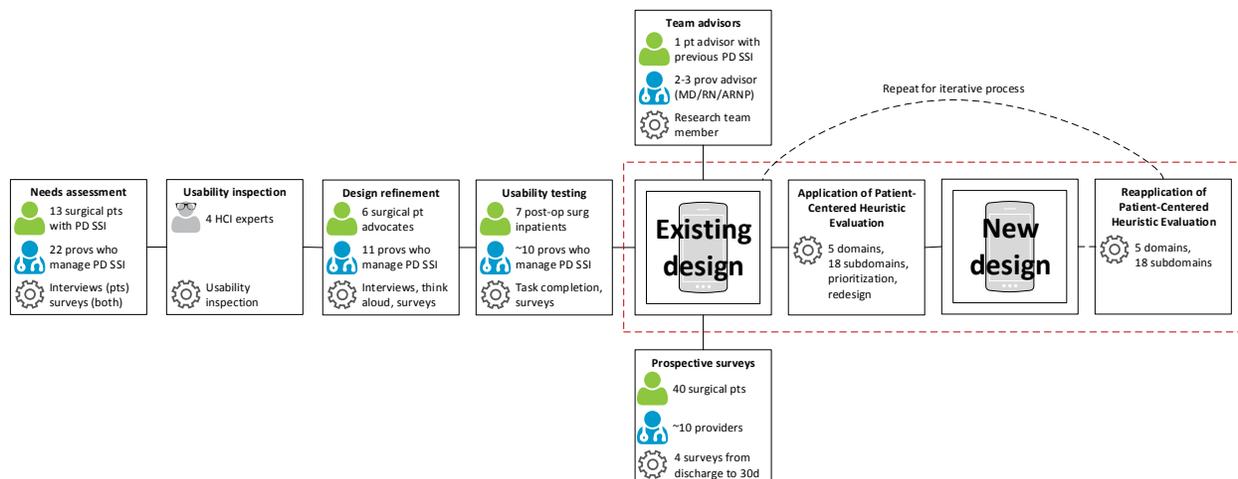
Figure 6-1. Overall design process. Green figures denote patients engaged, blue figures denote providers engaged, gear symbol denotes methods applied. Red dashed box shows key elements described in this paper, including application of the evaluation method we developed to inform refinements for new design. Portions with arrows feeding into the "Existing design" represent our previous user-centered design process, including needs assessment, usability inspection, design refinement and usability testing (left), as well as frequent input from patient and provider team advisors (top) and a prospective survey of the peri/post-discharge experience of surgical patients (bottom).
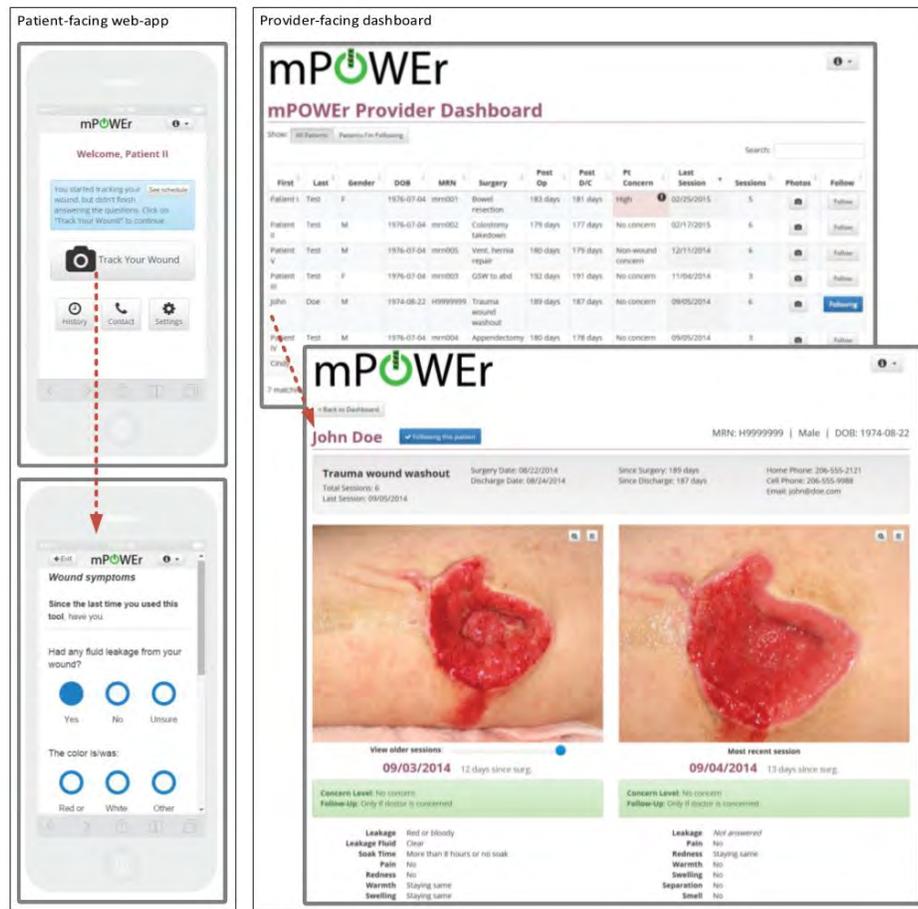
Figure 6-2. Existing mPOWEr application. Left: patient-facing HTML5 responsive web-app. Right: provider-facing dashboard.

Our multidisciplinary research team consisted of providers, health informaticists, interaction designers, computer scientists, and a dedicated patient advisor who previously experienced a post-discharge surgical site infection. The patient advisor strived to represent the patient's perspective at team meetings and was involved in all aspects of our work, including study design, data analysis, technology development, and manuscript preparation. Nurses and physicians on the team served in a similar advisory role.

Throughout our design process (**Figure 6-1**), we engaged diverse user groups including post-operative inpatients, patients with post-discharge surgical complications, hospital patient advocate groups, surgical providers, and HCI experts using a range of methods including surveys, interviews, usability inspection, think-aloud and traditional usability testing.

The study was approved by the University of Washington Institutional Review Board.

6.3.2   Development of Patient-Centered Heuristic Evaluation Method

We conducted a literature review to identify conceptual frameworks of patient-centered care specifically relevant to HIT. Although many such frameworks exist for patient-centered care broadly, we found only one which pertained specifically to HIT, prepared by the Johns Hopkins University Evidence-based Practice Center for the Agency for Healthcare Research & Quality (AHRQ).[146] This "Hopkins" framework was based on literature review, and consultation with a Technical Expert Panel and external advisors. It is comprised of 5 domains, each with 2-6 associated subdomains, for a total of 18 subdomains. The comprehensive framework was developed to be applicable to a wide range of HIT, including tools for care management, telehealth, personal health records, secure electronic messaging, and shared decision-making.[146]

Using the Hopkins framework as a basis, we identified primary sources, and then created a table of consensus definitions for each subdomain (**Appendix Table 6-A**). We then created a series of questions (analogous to those included with Nielsen's usability heuristics[158]) for each of the 18 subdomains. These questions (2-3 per subdomain) capture the key elements of each concept in a concrete way, such that users without previous knowledge of patient-centered care could apply them. These questions aim to broaden the design space and spur further discussion within the design team. **Table 6-1** presents the questions we created.

Table 6-1. Domains and subdomains of patient-centered care with associated questions for patient-centered heuristic evaluation method

Domains and subdomains of PCC	**Questions for patient-centered heuristic evaluation**
Coordination and integration of care	
Integrated care [159]	• Does the tool facilitate communication within a care-team and between disparate providers? • Does the tool provide ready access and a clear "goto" person to contact in case of questions/ concerns? • Does the tool address fragmentation of current systems, across the diagnosis- treatment- recovery spectrum?
Transition and continuity of care [160]	• Does the tool foster continuity of care with providers the patient is familiar with? • Does the tool provide information/education to patients to support self-care away from or between clinical settings? • Does the tool facilitate coordination and planning for care transitions?
Quality and safety [44]	• Which of the IOM's 6 quality domains (safe, effective, patient-centered, timely, efficient, equitable) does the tool support? • Are there tradeoffs between the domains?
Prevention and health promotion [146]	• Does the tool support healthy behavior? • Does the tool facilitate early identification of disease?
Routine patient feedback to practice [56]	• Does the tool support patient feedback to providers? • Does the tool support providers in making such data actionable? • Does the tool engage patients and providers in discussion about these data?
Quality improvement [160]	• Does the tool support quality improvement? • Were QI stakeholders consulted about specifications for data collection and presentation?

Whole-person orientation	
Alleviation of fear and anxiety [160]	• Does the tool assess/measure the patient's fear or anxiety? • Does the tool provide support directly to the patient or facilitate further connection to care, e.g. to mental health providers or social workers?
Respecting patients' values, preferences and needs [160]	• Does the tool query the patient about their values, preferences and needs, especially around quality of life and desire to be involved in decision making? • Does the tool adapt to patient values?
Emotional support [161]	• Does the tool screen for the need for emotional support and either provide it directly or facilitate further care?
Exploring the disease and illness condition [149]	• Does the tool promote reflection about the patient's unique experience of illness? • Does the tool inquire about the patients' feelings/ideas about illness, impact on functioning, and/or expectations from care?
Physical comfort [160]	• Does the tool assess and/or provide resources to address pain? • Does the tool assess and/or support activities of daily living?
Enhanced clinician-patient relationship	
Patient engagement in their care [160]	• Does the tool encourage patients to take an active role in the care process, to the extent they wish to? • Does the tool provide transparency to the patient about the care process? • Does the tool promote shared review of clinical or patient-generated health data?
Patient empowerment [162]	• Does the tool allow the patient enhanced ability to understand or influence their health status? • Does the tool support patients in self-management and/or voicing concerns to providers?
Finding common	• Does the tool help define the problem, establish goals of treatment/

ground [149]	management, and/or identify roles to be assumed by patient and provider? • Does the tool support shared decision making, where patients are supported to consider options, to achieve informed preferences?
Clinical information systems	
Publicly available information on practices [147]	• Does the tool help the patient choose a provider or practice that aligns with their needs and values? • Does the tool collect or transmit information to help other patients choose a provider or practice?
Practice-based learning [163]	• Does the tool support learning at the practice level? • Does the tool present evidence to providers (or patients) to guide decision-making? • Does the tool collect and present population data that is meaningful to patients and providers?
Socio-cultural competence	
Community outreach [164]	• Does the tool consider the particular context in which it will be used? • Were community members engaged in needs assessment and design? • Were the cultural, demographic, socio-economic, and technology adoption levels of patients considered?
Family and friend involvement in care [160]	• Does the tool enable and support caregiver participation (in caretaking and/or decision-making) to the extent the patient wants? • Does the tool consider the patient's privacy preferences? • Does the tool allow engagement of the patient's wider social network?

6.3.3 Steps for application of the patient-centered heuristic evaluation method

After developing the method, we applied it to our application, mPOWEr, using the following steps (depicted in **Figure 6-3**).

1. Evaluate the patient-centeredness of current care practices. In our case, we used data from a previous needs assessment to assess the patient-centeredness of practices surrounding and following hospital discharge.[131]

2. Reimagine an ideally patient-centered experience, whether supported by HIT or other non-HIT changes.

3. Consider the design challenges (broadly defined: interface, technical, social, policy) faced when going from [Step 1] to [Step 2].

4. Apply the heuristic criteria to evaluate the patient-centeredness of an existing design, noting strengths and weaknesses for each subdomain. Assess to what degree each subdomain is addressed by the current design (e.g. Not, Minimally, Partly, Mostly, Fully addressed).

5. Prioritize areas for improvement based on a combination of the following criteria: degree of deficiency in a particular subdomain, input from stakeholders, and consideration of challenges [Step 3]. For example, we considered subdomains to be "high" priority if they were less than mostly addressed by the previous design, we had input from stakeholders voicing a need, and challenges were not considered too great. "Low" priority subdomains were generally those we considered less salient to our application domain or those with significant technical or system barriers.

6. Re-evaluate the new design, as in [Step 4]. Steps 4-6 can be repeated to facilitate iterative redesign.
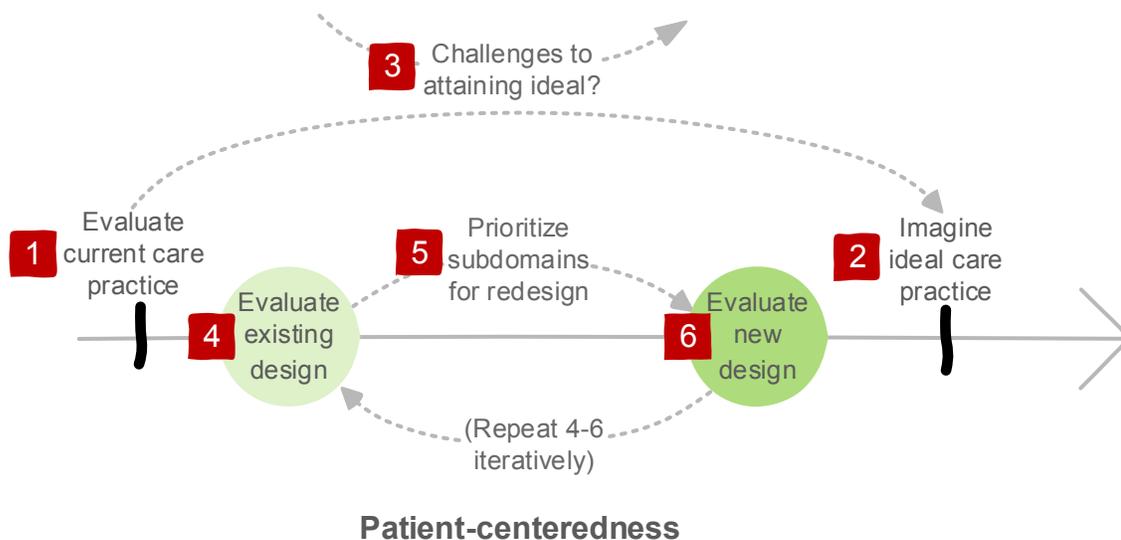
Figure 6-3. How we applied the heuristic method to redesign mPOWEr. See text for description of Steps 1-6 (red boxes).

6.4 RESULTS

We demonstrate application of our method as follows: **Table 6-2** shows our application of steps 4-5 of the method (evaluating existing design, prioritizing areas for improvement). **Table 6-3** shows step 6, summarizing the 5 prioritized subdomains for mPOWEr redesign, the limitations of the existing design and changes for the redesign. **Figure 6-4** complements **Table 6-3**, illustrating the redesigned version of mPOWEr with screenshots of key changes made to address the 5 prioritized subdomains. Because it is more domain-specific, details of the application of steps 1-3 (evaluating current practices, reimagining ideally patient-centered practices, noting challenges to achieving ideal) can be found in **Appendix Table 6-B**.

Table 6-2. Application of heuristic criteria to existing mPOWEr design to inform redesign

Domains and subdomains of PCC	Existing design [Step 4]	Degree addressed [Step 4]	Priority for redesign [Step 5] (low, med, high)
Coordination and integration of care			
Integrated care [159]	• **Strengths**: Addresses fragmentation by facilitating communication within a care team; Provides "goto" phone number to call • **Weaknesses**: Does not facilitate communication with outside providers; unclear to patient who they are reaching through "goto" number	Partially addressed	**Med**: could clarify "goto person" and facilitate outside provider coordination
Transition and continuity of care [160]	• **Strengths**: Tool connects patients to familiar providers; supports self-care in limited ways • **Weaknesses**: Does not facilitate planning for transitions e.g. discharge	Partially addressed	**Med**: challenges in overhauling discharge process; consider providing checklist aid for patient
Quality and safety [44]	• **Strengths**: Addresses equitability concerns with device-agnostic web-app and device loans; Tool is patient-centered in giving patients greater ability to direct care • **Weaknesses**: Concern about tool's effect on timeliness (if delays patient call), safety/effectiveness (lack of evidence); Concerns about efficiency of provider time to monitor	Partially addressed	**High**: significant focus on ensuring timeliness and safety: the app should "first do no harm"
Prevention and health promotion [146]	• **Strengths**: Tool promotes regular, clean dressing changes; Facilitates early identification of wound complications • **Weaknesses**: The role of prevention is unclear in post-discharge infections; potential	Mostly addressed	**Low**: role of prevention is unclear

	for over-treatment		
Routine patient feedback to practice [56]	● **Strengths**: Providers get feedback on SSI rates ● **Weaknesses**: No outcomes of interest to patients currently collected by tool	Not addressed	**Med**: unclear what feedback patients and providers want
Quality improvement [160]	● **Strengths**: QI use considered in abstract ● **Weaknesses**: QI not considered in design; no engagement with QI staff	Not addressed	**Low**: QI currently has little incentive to track post-discharge infections; QI role can be added later
Whole-person orientation			
Alleviation of fear and anxiety [160]	● **Weaknesses:** Tool does not currently assess fear or anxiety	Not addressed	**Med**: provider concern about actionable data; availability of support?
Respecting patients' values, preferences and needs [160]	● **Weaknesses**: Tool does not assess or incorporate patient values, preferences, needs	Not addressed	**High**: can inquire about patient values to present to providers
Emotional support [161]	● **Weaknesses**: Tool does not assess need for emotional support	Not addressed	**Med**: provider concern about actionable data; availability of support?
Exploring the disease and illness condition [149]	● **Weaknesses**: Tool does not facilitate exploration of disease and illness condition or expectations of care	Not addressed	**Med**: scope/ complexity issues
Physical comfort [160]	● **Strengths:** Tool assesses wound-related pain	Partially addressed	**Med**: could assess ADL and better as-

	● **Weaknesses**: Tool does not assess ADL; limited assessment of pain		sess pain
Enhanced clinician-patient relationship			
Patient engagement in their care [160]	● **Strengths:** Some transparency about how their concern will be responded to (e.g. rough timeframe); promotes review of patient-generated health data ● **Weaknesses**: Does not encourage an active role in care process – patients submit structured data based on what providers want, not what patients want to tell providers; more transparency could be provided through updates when a provider "touches" the data	Minimally addressed	**High**: patient engagement critical to sustained use to achieve desired outcomes
Patient empowerment [162]	● **Strengths:** Symptom pattern visualization and review of photos history may help patients understand health status ● **Weaknesses:** No choices presented to patients in management; self-management/ patient decision support not implemented	Minimally addressed	**Med**: technical/ knowledge limitations limit decision support
Finding common ground [149]	● **Weaknesses**: Tool does not explicitly facilitate finding common ground; Decision-making is still one-way, not shared; patient goals not made explicit	Not addressed	**High**: all parties should be on the same page to ensure "adherence" / best outcome for patient
Clinical information systems			
Publicly available information on practices [147]	● **Weaknesses:** Tool does not help patient choose a practice or contribute data to such a process for other patients	Not addressed	**Low**: post-discharge infections/ experience not a priority for CMS
Practice-based	● **Weaknesses**: Tool does not present popula-	Not ad-	**Med**: hard to present

learning [163]	tion level-data or evidence.	dressed	data due to denominator issues, risk adjustment
Socio-cultural competence			
Community outreach [164]	● **Strengths**: Tool was developed through user-centered process: patients and providers were involved in design; Demographics, SES, technology use were surveyed. ● **Weaknesses:** English-only	Mostly addressed	**Low**: mostly addressed
Family and friend involvement in care [160]	● **Weaknesses:** No explicit role for caregivers, other than logging in as patient; Does not engage wider social network	Not addressed	**High**: caregiver involvement critical during recovery
		≥ partially addressed: 6/18	**High-priority areas: 5**

Table 6-3. Five subdomains of patient-centered care identified for focused redesign of mPOWEr.

Subdomains of PCC	Weakness/limitations of existing design	How addressed in redesign [Step 6]	Degree addressed [Step 6]
1. Quality and safety [44]	● "First, do no harm": concern about whether using the tool may delay a patient call to triage nurse or 911	● Initial disclaimer about urgent concerns requiring 911 call ● Immediate alert to patient if >1 worsening symptoms ● Persistent reminder to call care team if symptoms worsen or new concerns emerge while waiting	Mostly addressed
2. Respecting patients' values, preferences and needs [160]	● Tool does not assess or incorporate patient values, preferences, needs	● During enrollment, patient prompted to specify goals of treatment, define "quality of life", and medical decision-making style	Partially addressed
3. Patient engagement in their care [160]	● Tool does not encourage an active role in care process – patients submit data providers want, not what patients want to tell providers ● General lack of process transparency	● Allow patients to decide what data to track and share ● Transparency about the triage process, e.g. when providers "touch" the data	Mostly addressed
4. Finding common ground [149]	● Tool does not explicitly facilitate finding common ground ● Decision-making is one-way, not shared ● Patient goals not made explicit	● Tools explicitly defines the problem, asks patient about goals of treatment, and provides treatment options for discussion	Mostly addressed

| 5. Family and friend involvement in care [160] | • No explicit role for caregivers, other than logging in as patient
• Does not engage wider social network | • Establish caregiver access role with unique login
• Patient can add caregivers/friends and define privacy in granular way
• Secure messaging allows communication between patients, providers and caregivers | Mostly addressed |
| | | | ≥ Partially adr'd: 10/18 |
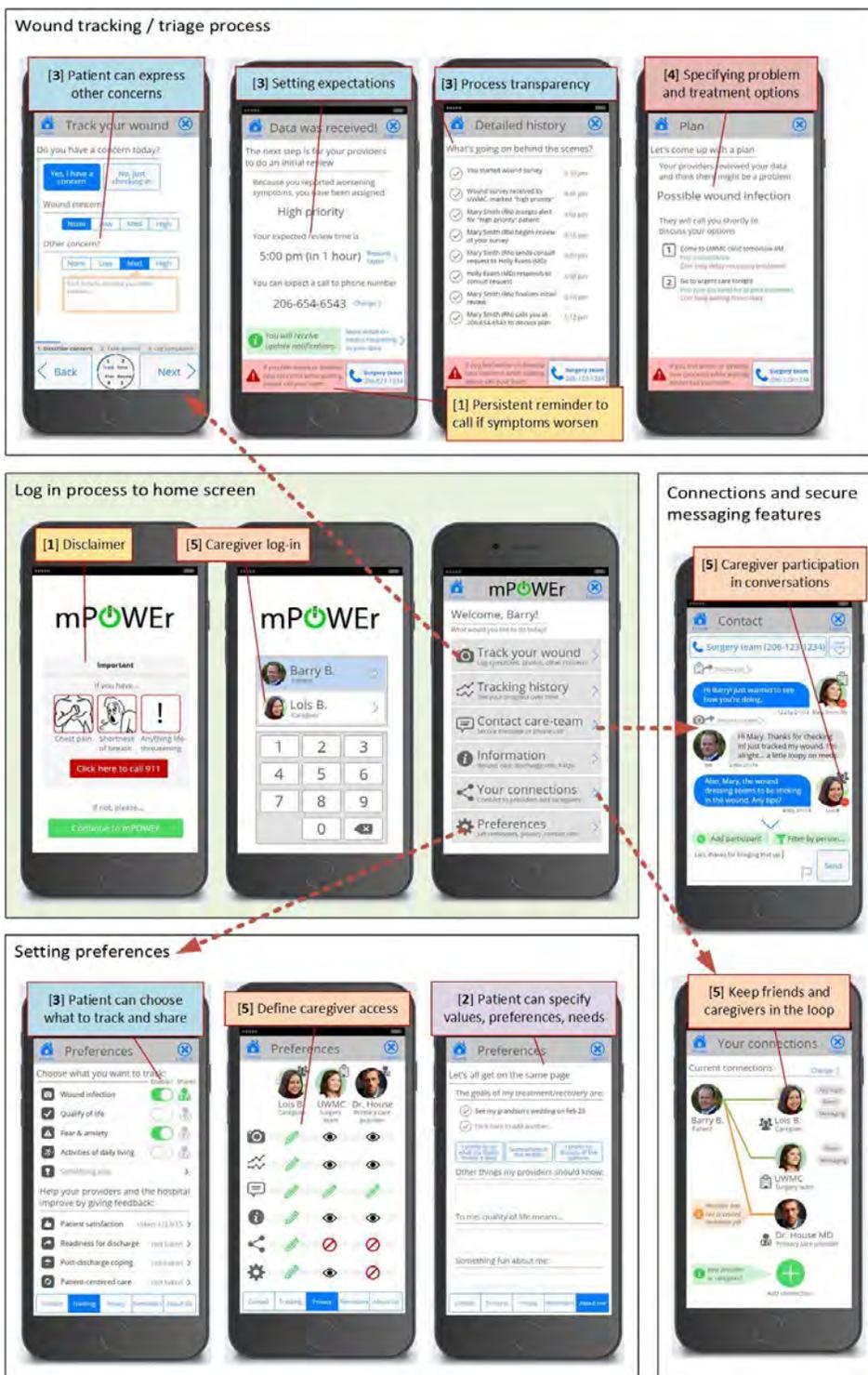
Figure 6-4. Illustration of redesigned version of mPOWEr. Labelled panels represent some of the major functions of mPOWEr (central panel shows log-in and main screen). Each call-out has a number (1-5) indicating which of the prioritized subdomains was addressed, along with a brief description of the change or addition.

6.5 DISCUSSION

We first discuss challenges we encountered in adapting and applying a patient-centered framework to redesign mPOWEr. We then address tensions we confronted in considering how to pragmatically implement a patient-centered design, and finally we provide some suggestions for other researchers who want to incorporate this method into their own work.

6.5.1   Challenges of applying the patient-centered heuristic evaluation method

We adapted an existing framework of patient-centered care, specific to HIT, for the purpose of creating the patient-centered heuristic evaluation method. Because this existing framework was not intended to be used in this way, we comment here on the challenges in adapting it and applying it to redesign mPOWEr.

Unclear and/or complex definitions. Several of the subdomains do not have a single, agreed-upon meaning, e.g. *integrated care*, *patient empowerment*, and *finding common ground*. Even those with generally agreed-upon meanings can be complex and multifactorial, e.g. *respecting patients' values, preferences and needs*, and *quality and safety*. Part of our goal was to make these subdomains more concrete and applicable to HIT design, but inevitably many concepts will be oversimplified.

Overlap. Several of the subdomains seemed to have significant overlap in meaning, e.g. alleviation of fear and anxiety and emotional support; also *practice-based learning*, *routine patient feedback to practice,* and *quality improvement*. In the future, these could be condensed into fewer subdomains.

Missing elements. Important concepts of patient-centered care—including shared decision-making, patient self-management, and ready access to care—were not explicitly included in the Hopkins framework. Because these concepts are potential strengths of HIT in delivering patient-centered care, we chose to fold them into existing subdomains (*finding common ground*, *patient-empowerment*, *integrated care*, respectively), though in the future, these categorizations could be improved upon.

Many subdomains. Applying 18 subdomains is unwieldy and could be overwhelming, especially because most HIT tools (and the rest of the healthcare system) will likely be deficient in almost all of them. To address this issue, first, we suggest simplifying the framework itself (future work). Second, we recommend that HIT designers explicitly prioritize the subdomains specific to their purposes. Prioritization could be considered based on feedback from stakeholders, consideration of design/technical/system challenges, and the degree of deficiency in the current design (if applicable).

Application to post-acute care. Distinct from most of the prior published work in the domain of chronic disease management applications and personal health records, we applied this method to an application intended for a relatively unique post-acute care setting. We acknowledge that patient-centeredness may look different in various settings and that we may have blind spots due to our particular focus. However, we believe the strength of this method is its comprehensiveness and applicability across a wide spectrum of HIT tools.

6.5.2   Ideal vs reality in patient-centered HIT

We also encountered challenges applying the method in redesigning mPOWEr, which are likely generalizable to other clinically-integrated patient-centered applications.

Complexity/broad scope vs simplicity/focus. One of the key messages we took from our prior engagement with stakeholders was that post-discharge surgical patients want a simple, highly usable application considerate of their impaired post-discharge state.[107] As a result, our existing design put a premium on simplicity and focused narrowly on monitoring for symptoms of wound infections. In applying the patient-centered heuristic method to mPOWEr, we increased the complexity and broadened the scope of the resulting product. Even with a skilled design, there are always tradeoffs between usability and functionality, and if patients reject the tool because of real or perceived usability challenges, patient-centeredness will be for naught. As others have noted, striving for patient-centeredness only increases the need for thorough consideration of usability.[152]

Patient-centered person vs patient-centered HIT. In our redesign, we asked ourselves to what extent mPOWEr should support patient-centered care delivered in-person vs via HIT. For example, to what extent can *emotional support* be provided via HIT? Is *finding common ground* (i.e. defining the problem, establishing goals of treatment, discussing options) best done by phone/in-person or is there a role for HIT? How can a tool *respect patients' values, preferences and needs*—is that something only a person can do? In previous work, we found that "patient-centered" may mean different things to different patients at different times: HIT may be preferable to some and not others (e.g. due to technology experience), or preferable only under certain circumstances (e.g. low acuity concern).[107] In general, we suggest careful consideration of how to support person-to-person care rather than supplant it.

Impact on clinical workflows. Creating a patient-centered tool in the context of a clinical relationship requires providers to support it on the back end. Patient-centeredness requires care coordination, care integration, continuous practice/quality improvement, supporting patients' emotional needs, reviewing data not considered classically "actionable", and working collaboratively with patients from diagnosis through recovery—all of which could disrupt existing workflows and increase workload on providers. On the other hand, these technologies have potential to decrease provider burden by automating triage and improving patient self-management. Obtaining provider buy-in will require careful attention to workflow, thoughtful design of provider-facing IT systems, and tangible improvements in outcomes—making it easy and satisfying to deliver patient-centered care rather than an extra burden.

Patient vs provider wants/needs. Even in a best-case scenario where both patients and providers stand to benefit from HIT, tensions between these stakeholders will likely remain. For example, patients and providers may prefer different modes of communication (text vs phone), have different preferences about what kind of data should be collected (structured vs free text), or different expectations about timeliness of response. As HIT increasingly engages both patients and providers as direct stakeholders, it will be important to understand where needs and expectations align or diverge.

System barriers. Some issues go beyond patients and providers, involving broader, system-level changes, i.e. requiring administrative/financial support. For example, ensuring equitability may require hospitals to supply loaner devices with data plans; performing Quality Improvement activities with an eye to patient-centeredness will require institutional support, given that there may be little external financial or regulatory incentive to focus on such areas and providers may resist tracking outcomes in a pay-for-performance context; overhauling discharge practices to be more patient-centered is beyond the scope of HIT, requiring a significant administrative push; and care coordination and integration may require additional staffing that improves patient experience but increases costs. Patient-centered care is a philosophy that must permeate the institution—technology cannot deliver it in a vacuum.[160]

Many of the issues identified above are significant barriers to design and adoption of patient-centered tools. In future work, we plan to explore these issues more thoroughly.

6.5.3   Recommendations to incorporate the heuristic evaluation method

We hope other researchers adopt and refine this method across a diverse set of health domains. Some suggestions we have include:

Don't use it as a replacement for stakeholder engagement. The criteria in the heuristic method relate primarily to design outcomes rather than design processes. However, a patient-centered outcome is unlikely to be achieved without a patient-centered process.

Use it early in the design process. We applied the method to an existing design that resulted from a multi-year user-centered design process. If possible, we suggest designers consider patient-centered principles from the start of their design process, e.g. when creating plans and procedures for stakeholder engagement (e.g. interview guides and surveys), to uncover stakeholder priorities at an early stage (e.g. during needs assessment). Adapting an existing provider-centric application to be "patient-centered" might prove to be even more work than starting from scratch.

Use it in an iterative way. Just as designers use the traditional heuristic evaluation method, we suggest using this method as part of an iterative process to enhance patient-

centeredness in an incremental way, grounded in stakeholder feedback. With each cycle, the method can help "benchmark" the design on a path towards an ideally patient-centered application. Such iterative approaches are complementary to iterative development approaches such as Agile.

Use it to engage patient experts. Based in our experience, we recommend considering bringing a patient advisor onto your research team as a full member—s/he can develop a deep understanding of the project and help you apply this method in a longitudinal way (among many other benefits!). In addition, we recommend leverage existing resources at your institution such as standing patient advisory group; in our experience, this group was easy to recruit, motivated to participate, and lent uncommon "patient expertise" to our project.

Use it to support engagement with a variety of stakeholders. Beyond patients, engage providers, administrators, patient-centered design experts, and other key personnel in applying this method. In this way, you can find obstacles early and prioritize development in a realistic and efficient manner.

6.5.4   Future work

We plan to simplify the patient-centered heuristic evaluation method, making it easier to apply. Currently, the method works best as a formative evaluation, however it may eventually be useful as a summative evaluation, i.e. a "HIT patient-centeredness index" that could facilitate comparison across a range of tools. We also plan to further explore the tensions that arise between patients and providers in the design and implementation of clinically-integrated patient-centered HIT tools.

6.6   CONCLUSION

Delivering patient-centered care is an important but largely unachieved goal of many healthcare systems. Health IT will play a key role in enabling patient-centered care, but little

guidance exists to aid evaluation of patient-centered tools. We created a patient-centered heuristic evaluation method and successfully applied it to aid redesign of mPOWEr, an existing surgical wound tracking tool developed using traditional user-centered design methods. We acknowledge that the method needs to be streamlined to ensure ease of application. Counterintuitively, we found that listening to patients is necessary but may be insufficient in creating a truly patient-centered design. Incorporation of heuristic evaluation methods, such as the one we created, could enhance this process, especially when used in conjunction with stakeholder engagement.

Chapter 7. DEVELOPING AN SSI RISK SCORE INCORPORATING DAILY OBJECTIVE WOUND ASSESSMENTS USING MACHINE LEARNING

7.1 ABSTRACT

Background: Surgical site infection (SSI) remains a common, costly and morbid healthcare-associated infection. Prediction of SSI may facilitate earlier recognition and treatment, yet previous SSI risk scoring systems only consider baseline risk factors (BF) on the day of operation, not accounting for changing risk over time after surgery.

Hypothesis: Incorporation of daily wound assessment improves the accuracy and timeliness of SSI prediction compared to traditional BF alone.

Methods: A prospective cohort of 1,000 post-open abdominal surgery patients at an academic teaching hospital were examined daily for wound features (e.g. exudate) and vital signs. These 29 serial features (SF) were analyzed using reversed time analysis. We also collected patient and procedure BF which were compared using univariate methods in patients who developed inpatient CDC-defined SSI vs patients who did not. Using supervised machine learning, we trained three Naïve Bayes classifiers with wrapper-based feature selection: one with BF, one with SF and one with both. To train the classifiers, patient data from 1-5 days prior to SSI were used to predict diagnosis. For patients without inpatient SSI, we matched 5 similar consecutive post-op days. Accuracy, predictive values, and AUC were calculated on both a training and hold-out testing set.

Results: Of 851 patients included in analysis, 19.4% had inpatient SSI. Mean prediction day for patients who developed SSI vs. no SSI was 7.25 vs. 7.29. Univariate analysis between groups showed differences in c-reactive protein, surgery duration and contamination, but no differences in ASA scores, diabetes or emergency surgery.

The BF/SF/BF+SF classifiers had AUC of 0.67/0.76/0.76. The best performing classifier (SF) had optimal sensitivity of 0.80, specificity of 0.67, PPV of 0.37, and NPV of 0.93. The most predictive features were: amount of granulation, amount of exudate, presence of nasogastric tube, heart rate, and wound temperature.

Conclusions: Serial features provided moderate PPV and high NPV for prediction of SSI in advance of clinical diagnosis. Addition of baseline patient/operative data did not improve prediction. Features of evolving wound infection are discernable prior to the day of diagnosis primarily based on visual inspection.

7.2 INTRODUCTION

Surgical site infections (SSI) occur in 3-5% of all surgical patients, and up to 33% of patients undergoing abdominal surgery.[3,4] More than 500,000 are estimated to occur in the US annually, resulting in worse outcomes, including length of stay, mortality, and health-related quality of life, and additional average costs as much as $20,000 per infection.[16,18,165–167] SSI is the overall costliest healthcare-associated infection, yet many of its associated costs are non-reimbursable.[19,111]

7.2.1 Previous SSI risk scores

Many risk scores for SSI have been developed over the years, ranging from simple (e.g. NNIS which includes only 3 predictors) to complex (e.g. SSIRS with 12 covariates and 4 interactions).[168–172] These risk score models have three main limitations.

First, existing models only incorporate baseline variables known as of the end of the operation, e.g. demographics, pre-operative laboratory results, comorbidities, and operative factors. These models do not incorporate a rich and continuing source of data: serial observations of the patient and their wound which may serve as markers for changing risk of SSI over time.

Second, these models do not provide a time-specific prediction. Predictions generally apply over a 30 day post-operative time horizon if specified at all, leaving providers without clinically-actionable data. These models facilitate surveillance and risk-adjustment more than clinical decision support.

Third, methodically, they do not incorporate modern machine learning techniques, instead frequently using univariate variable selection combined with stepwise logistic regression. Variable selection using these methods may result in both selection of a suboptimal variable set and overfitting, especially when the number of potential variables is high. Modern variable selection techniques developed to avoid overfitting in the context of high-dimensional "big data" (e.g. genomic studies) provide a more robust and reliable alternative.[173–175]

7.2.2   Machine learning

Machine learning is a branch of artificial intelligence that is used to analyze and interpret data, in many ways similar to statistics. Yet, machine learning methods go beyond conventional statistical methodologies, applying unconventional and diverse strategies to model and classify data.[176] In brief, test data are used to "train" algorithms based only on their predictive performance, and not necessarily on underlying presumptions about the model. The strength of this approach is that the resulting algorithms can closely approximate the behavior of the natural system, but the disadvantage is that the machine learning algorithm can appear to be a "black box", which can make it more difficult to trust the logical behind the results. Machine learning is especially well suited to biological systems because they tend to evolve large, noisy, non-linear and complex data sets. Widely used in other industries, machine learning is increasingly being used in healthcare, e.g. for pneumonia prediction, genomics, and cancer diagnosis and prediction.[177–179]

7.2.3 This paper

First, we describe a unique dataset that includes daily assessment of objective wound characteristics to describe the prevalence and predictive value of a variety of potential signs and symptoms of SSI.

Then, using this dataset, we report on the development of an SSI risk score that uses machine learning methods and incorporates serial wound assessment data to predict infection in a time-specific manner.

7.3 METHODS

Ethics approval was obtained for the parent study; the present analysis was deemed exempt from review by the University of Washington IRB due to the deidentified nature of the dataset.

7.3.1 Study population

A prospective cohort study of 1000 open abdominal surgery patients was conducted at a 1200-bed academic teaching hospital in the Netherlands, described previously. [180] Patients who didn't undergo surgery (n=33) or with <2 days of wound observations (n=116) were excluded from analysis, leaving 851 patients in total.

7.3.2 Data collection

Subjects in the dataset were examined daily, using a previously described protocol[181], from post-operative day 2 until discharge or 21 days, whichever was earlier. Follow-up was performed at 30 days through clinic visit, phone, or letter to ascertain post-discharge infections. Baseline data collected included demographics, preoperative labs, procedure characteristics, other risk factors, and outcomes (see Results **Table 7-2** for a full list of baseline data). **Table 7-1** shows serial data collected, including definitions of categorical wound score variables.[181]

Subjects were assessed using the CDC criteria for superficial, deep and/or organ space infections. For analysis purposes, we defined the SSI group as having any of the 3 types of SSI due to the small numbers of deep and organ-space infections. In addition, though a patient may have developed multiple types of SSI during their hospital stay, we only include their first infection in this analysis. The non-SSI group was defined as having no inpatient infection, but may have had a post-discharge infection. We grouped patients this way because preliminary analyses of the data showed that patients with post-discharge infections, while they were in the hospital, more closely resembled patients who never developed SSI.

Table 7-1. Serial data collected.

Primary wound variables		
Induration amount (mm)	0	>5 mm
	1	3-4 mm
	2	1-2 mm
	3	0 mm
Wound edge distance (mm)	0	0 mm
	1	1-2 mm
	2	3-5 mm
	3	6-10 mm
	4	11+ mm
Slough/necrosis type	0	none visible
	1	white/grey nonviable tissue
	2	loosely adherent yellow slough
	3	adherent, soft, black eschar
	4	firmly adherent, hard, black eschar
Slough/necrosis amount	0	None visible
	1	<25% of wound bed covered
	2	25 to 50% of wound covered
	3	>50% and <75% of wound covered
	4	75 to 100% of wound covered

Granulation/epithelialization score	0	Skin intact
	1	75 to 100% of wound filled &/or tissue over-growth
	2	25 to 75% of wound filled
	3	<25% of wound filled
	4	no granulation or epithelialization present
Exudate type	0	none or bloody
	1	serosanguineous: thin, watery, pale red/pink
	2	serous: thin, watery, clear
	3	purulent: thin or thick, opaque, tan/yellow
	4	foul purulent: thick, opaque, yellow/green with odor
Exudate amount	0	none (tissue is dry)
	1	scant (non measurable amount)
	2	small (exudate spread over wound, gauzes 25% wet)
	3	moderate (exudate irregularly spread over wound, gauzes >25 and <75% wet)
	4	large (large amount, widespread, gauzes >75% wet)
Wound edge color	0	pink or normal for ethnic group
	1	bright red and/or blanches to touch
	2	white or gray pallor or hypopigmented
	3	dark red or purple and/or nonblanchable
	4	black or hyperpigmented
Temperature (°C)		Wound
		1 cm from wound edge (left/right)
		3 cm from wound edge (left/right)
		5 cm from wound edge (left/right)
Wound malodor		Yes/no

Other wound variables

Hematoma*		Yes/no
wound mass palpable*		Yes/no
seroma*		Yes/no
wound culture*		Yes/no
visual analogue pain scale	1-100	Wound pain
wound length (cm)		... cm

Vital signs

heart rate	... bpm
diastolic RR	... mmHg
systolic RR	... mmHg
tympanic temperature (°C)	... °C

Other observations

cough*	Yes/no
productive cough*	Yes/no
vomiting*	Yes/no
ventilator*	Yes/no
antibiotics*	Yes/no
reoperation*	Yes/no
nasogastric tube*	Yes/no
Suspicion of ileus*	Yes/no
serial operation number	#

* in previous 24 hours

7.3.3   Data analysis

Statistical analysis was conducted using Stata 13 (StataCorp). Data was visualized with Microsoft Excel 2013.

7.3.3.1   Baseline data

We tested for differences between SSI and non-SSI groups using ANOVA for continuous variables and Pearson's chi-squared for binary and categorical variables.

7.3.3.2   Reversed time analysis of serial features data

To examine symptom trends leading up to SSI diagnosis, we registered the initial day of infection as "Day 0" and then looked backwards in time through days -10 through -1 (i.e., 10 days before SSI diagnosis to 1 day before SSI diagnosis). Patients without SSI were matched so as to have similar post-operative days included for comparison, resulting in an equal distribution (mean, SD) of SSI and non-SSI post-op days in the analysis.

7.3.4   Model development

7.3.4.1   Overview

To develop the model we first transformed the existing dataset through "feature generation"[182] to create potential features for inclusion in the model. Next, we used stratified randomization to divide the dataset into training (2/3) and testing (1/3) sets for model training. Then, we used supervised machine learning to train and optimize classifiers using only baseline features (BF), only serial features (SF), or both baseline and serial features (BF+SF). Finally, we evaluated the best performing model on the testing set.

Microsoft Excel 2013 was used for feature generation. WEKA 3.7.12 (http://www.cs.waikato.ac.nz/ml/weka/) was used to test and evaluate classifiers. Missing data were imputed using means for continuous variables and modes for categorical variables.

7.3.4.2   Feature generation

For each patient, we generated features from both the baseline data (Table 2) and the serial data (Table 1). For baseline data, we included the raw values and discretized versions using established clinical cutoffs, e.g. duration of surgery >3 hours. For serial data, we generated features from raw values, differences in values from day to day, maximums/minimums/averages over time, coefficients of variation over time, rates of change over time, and deviations from trendlines. For each of these features, we included varying lookback periods, from 1 to 5 days prior to diagnosis. Lookback periods are cumulative, e.g., a lookback period of 5 days includes data from days -5 through -1. Data from the day of diagnosis was not included in any model. We describe which features, over which lookback periods, were most influential in the model below.

7.3.4.3   Model training

We used a Naïve Bayes classifier to build models with BF, SF, and BF+SF. Feature selection was performed by using a forward wrapper-based method[183] using an Information Gain[184] heuristic to optimize area under the ROC curve (AUC). Essentially, features were added to each model until they no longer resulted in improvements in AUC. The Information Gain heuristic was used to decrease the computational complexity inherent in wrapper-based feature selection with large numbers of potential features. Within the training set, each classifier was trained and evaluated using 10-fold cross validation to avoid overfitting, (i.e. the same data was never used to both train and evaluate a classifier).

7.3.4.4   Performance evaluation

Model performance was evaluated based on accuracy, Kappa, predictive values, and AUC. All values are based on averages over 10 cross-validation runs on the training set and 1 run on the testing set. AUCs were tested for significance based on paired t-test.

7.4   RESULTS

7.4.1   Participants

Of 851 participants included in analysis, 167 (19.4%) had one or more inpatient SSIs. Of those, the first infection was superficial for 126 (75%), deep for 22 (13%) and organ-space for 19 (11%). **Figure 7-1** shows the overall distribution of SSIs based on post-operative day of diagnosis. Post-discharge infections are included for descriptive purposes, but are not further described in the paper. **Table 7-2** shows differences in baseline data, and **Table 7-3** shows differences in wound data, among patients with and without inpatient SSI.
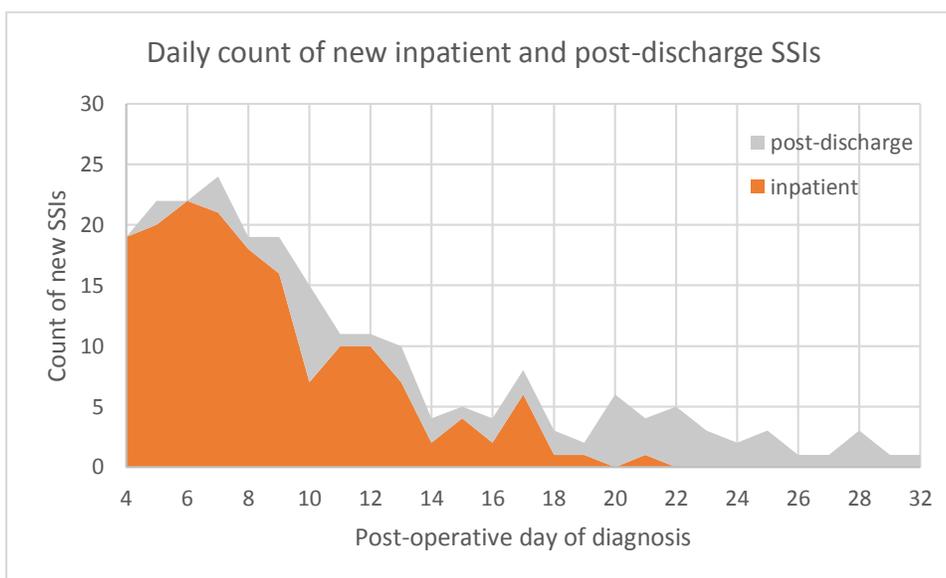
Figure 7-1. Daily count of new inpatient and post-discharge SSIs

Table 7-2. Baseline data from patient cohorts with and without inpatient SSI

	Without SSI (N=684; 80.6%)	**With SSI** (N=167; 19.4%)	**p-value**
Patient factors			
Age, mean, [95% CI], years	56.18 [55.0-57.2]	57.48 [55.4-59.5]	0.29
Male sex, N (%) [95% CI]	247 (36.1) [0.33-0.40]	62 (37.1) [0.30-0.45]	0.81
Pre-operative labs			
Hemoglobin, mean, [95% CI], mmol/L	7.91 [7.8-8.0]	7.51 [7.2-7.7]	0.001
Total protein, mean, [95% CI], g/L	67.76 [66.5-69.0]	67.38 [64.3-70.4]	0.82
Albumin, mean, [95% CI], g/L	40.99 [40.2-41.7]	37.95 [36.2-39.6]	0.002
BUN, mean, [95% CI], mg/dL	12.36 [11.4-13.3]	11.16 [8.8-13.4]	0.29
Creatinine, mean, [95% CI], umol/L	291.42 [260-322]	197.38 [149-244]	0.006
CRP, mean, [95% CI], mg/L	25.54 [19.0-32.0]	52.58 [32.6-72.4]	0.002
Platelet count, mean, [95% CI], 10^3/L	235.70 [225-245]	256.53 [229-283]	0.097
WBC count, mean, [95% CI], 10^3/L	8.18 [7.7-8.6]	8.88 [7.9-9.7]	0.15
PT, mean, [95% CI], seconds	14.29 [13.5-15.0]	15.73 [13.4-18.0]	0.15
aPTT, mean, [95% CI], seconds	34.46 [33.2-35.6]	37.69 [34.0-41.3]	0.036

Procedure-related

Duration of surgery, mean, [95% CI], minutes	253.05 [243-262]	312.10 [289-334]	0.001
Wound class, N (%)			0.001
clean	135 (19.7)	12 (7.2)	
clean-contaminated	497 (72.7)	131 (78.4)	
contaminated	21 (3.1)	7 (4.2)	
dirty	31 (4.5)	17 (10.2)	
Type of operation, N (%)			0.001
abdominal wall	44 (6.4)	3 (1.8)	
gastroduodenum	27 (3.9)	4 (2.4)	
gall bladder/bile duct	31 (4.5)	4 (2.4)	
liver	101 (14.8)	19 (11.4)	
spleen/adrenal gland & other	29 (4.2)	4 (2.4)	
small bowel	35 (5.1)	18 (10.8)	
kidney	179 (26.2)	23 (13.8)	
vascular	50 (7.3)	6 (3.6)	
esophagus	75 (11.0)	25 (15.0)	
large bowel	69 (10.1)	35 (21.0)	
pancreas	44 (6.4)	26 (15.6)	
Emergency surgery, N (%) [95% CI]	149 (21.8) [0.19-0.25]	41 (24.6) [0.18-0.32]	0.45
Kidney or liver transplantation, N (%) [95% CI]	187 (29.2) [0.26-0.33]	29 (17.8) [0.12-0.25]	0.003
Ostomy created, N (%) [95% CI]	40 (5.8) [0.04-0.08]	18 (10.8) [0.07-0.16]	0.023
Blood transfusion peri-op, N (%) [95% CI]	146 (21.4) [0.18-0.25]	50 (30.1) [0.23-0.38]	0.017

Risk factors

Smoking, N (%) [95% CI]	287 (42.0) [0.38-0.46]	59 (35.3) [0.28-0.43]	0.12
Diabetes mellitus type I or II, N (%) [95% CI]	83 (12.2) [0.10-0.15]	21 (12.6) [0.08-0.19]	0.88
Chronic lung disease, N (%) [95% CI]	58 (8.5) [0.07-0.11]	22 (13.2) [0.08-0.19]	0.063
Systemic corticosteroid use, N (%) [95% CI]	79 (11.6) [0.09-0.14]	25 (15.0) [0.10-0.21]	0.23
Chemotherapy in 3 mths pre-op, N (%) [95% CI]	46 (6.7) [0.05-0.09]	12 (7.2) [0.04-0.12]	0.83
Radiotherapy in 3 mths preop, N (%) [95% CI]	12 (1.8) [0.01-0.03]	3 (1.8) [0.00-0.05]	0.97
Ascites present, N (%) [95% CI]	16 (2.3) [0.01-0.04]	10 (6.0) [0.03-0.11]	0.014
Infection (non-SSI) at intake, N (%) [95% CI]	75 (11.0) [0.09-0.14]	14 (8.4) [0.05-0.14]	0.33
Alcohol use, N (%) [95% CI]	311 (47.1) [0.43-0.51]	70 (45.5) [0.37-0.54]	0.71
Alcohol quantity, mean, [95% CI], units per week	4.49 [3.85-5.12]	5.24 [3.54-6.94]	0.34
ASA score, N (%)			0.29
ASA 1	76 (11.1)	15 (9.0)	
ASA 2	309 (45.2)	80 (47.9)	
ASA 3	280 (40.9)	67 (40.1)	
ASA 4	19 (2.8)	4 (2.4)	
ASA 5	0 (0.0)	1 (0.6)	
Body Mass Index, N (%)			0.65
Underweight	19 (2.8)	6 (3.6)	
Normal	317 (46.3)	67 (40.1)	
Overweight	220 (32.2)	59 (35.3)	
Class 1 obesity	80 (11.7)	20 (12.0)	
Class 2 obesity	20 (2.9)	8 (4.8)	
Class 3 obesity	8 (1.2)	2 (1.2)	

Outcomes

Length of stay, mean, [95% CI], days	14.9 [13.8-16.1]	24.9 [22.0-27.8]	0.001
30 day mortality, N (%) [95% CI]	16 (2.3) [0.01-0.04]	9 (5.4) [0.02-0.10]	0.036
In-hospital mortality, N (%) [95% CI]	25 (3.7) [0.02-0.05]	15 (9.0) [0.05-0.14]	0.004

The most significant baseline risk factors identified were hemoglobin, albumin, creatinine, CRP, duration of surgery, wound class, type of operation, transplantation, blood transfusion, and presence of ascites. Length of stay and mortality were also significantly different between groups. **Table 7-3** shows that the prevalence of wound symptoms (defined as a score of >0 on any of the scales depicted in **Figure 7-1**) in the 5 days and 1 day prior to SSI is higher in the SSI group, except for wound edge color and amount of induration, which did not reliability predict SSI.

Table 7-3. Prevalence of wound symptoms in 5 days prior, 1 day prior, and day of SSI.

Abnormal Symptom* (%)	Days -5 to -1 (cumulative)**			Day -1 (only)			Day 0 (only)		
	No SSI	SSI	p	No SSI	SSI	p	No SSI	SSI	p
Granulation amount	12.5	41.8	0.001	7.1	35.0	0.001	6.2	62.7	0.001
Exudate amount	52.2	77.6	0.001	19.5	56.5	0.001	15.1	77.7	0.001
Slough amount	9.3	30.3	0.001	5.0	24.5	0.001	5.2	44.3	0.001
Edge distance	20.3	47.1	0.001	12.2	38.7	0.001	9.8	69.7	0.001
Odor	1.5	4.2	0.022	0.2	2.5	0.001	0.5	7.1	0.001
Exudate type	38.9	66.7	0.001	13.7	46.0	0.001	12.2	70.8	0.001
Slough type	9.4	30.9	0.001	5.3	25.2	0.001	5.2	44.3	0.001
Wound edge color	95.4	93.9	0.41	84.6	88.9	0.17	83.2	89.5	0.048
Induration amount	99.9	99.4	0.28	99.4	96.9	0.006	99.4	98.8	0.44

* Symptoms were considered abnormal if they had a score of >0 (see Figure 7-1)

** Abnormal symptom was considered present if it was noted on any of the 5 days leading up to infection.

Figure 7-2 depicts the total number of wound symptoms over time preceding infection. SSI and non-SSI groups have similar proportions of patients with 1 or 2 symptoms, but the SSI group diverges around day -6 by having a much larger proportion with >2 symp-

toms. Still, about 40% of patients do not have a wound-related symptom on the day prior to diagnosis and 20% do not have a wound symptom on the day of diagnosis.
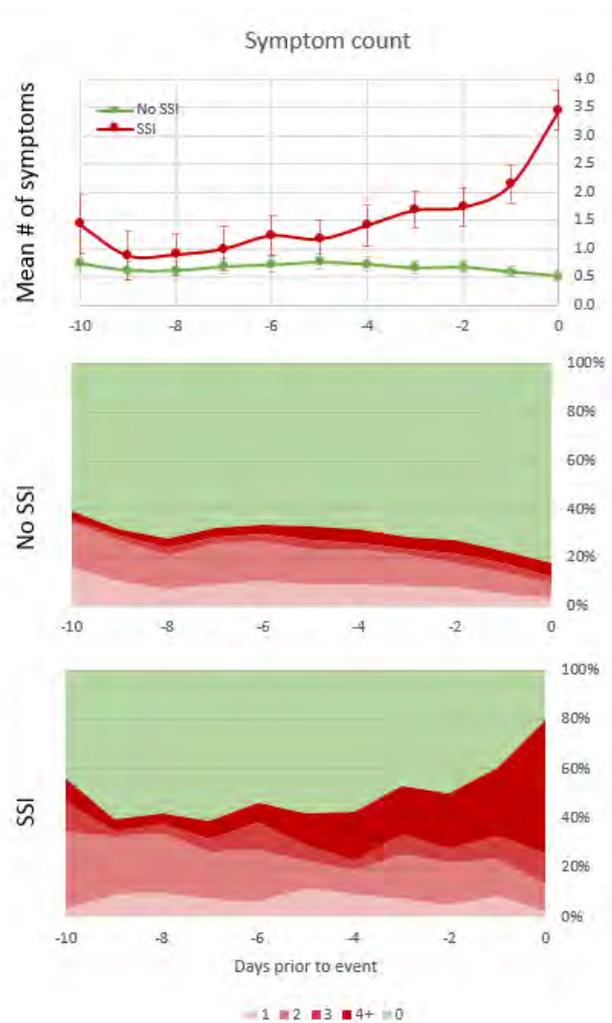
Figure 7-2. Total symptom count in 10 days prior to SSI. Possible symptoms include granulation amount, exudate amount, slough amount, edge distance, odor, exudate type, and slough type.

Figure 7-3 shows the pattern of each of 6 most predictive wound symptoms, with the symptoms other than exudate showing minimal levels in the non-SSI group and increasing levels in the SSI group starting between days -8 and -5. Exudate, mainly serosanguinous, shows persistence across recovery in both groups, with the exudate *amount* shifting to a greater extent than the exudate *type* in the SSI group.
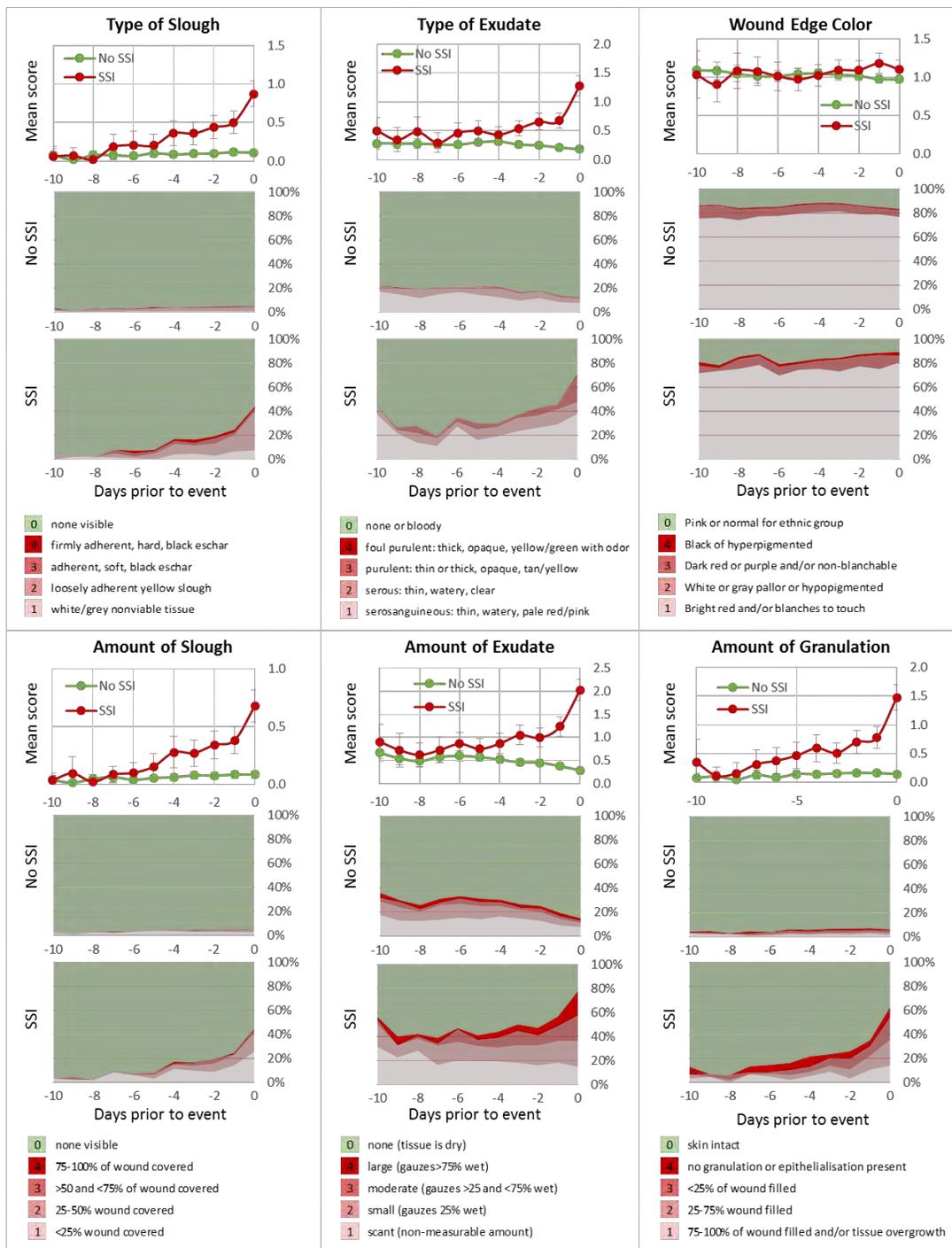
Figure 7-3. Reversed time wound features in SSI vs no SSI groups. Each of the 6 features is an ordered categorical variable varying between 0 and 4 (see legend at bottom of each panel). Top graph on each of 6 panels shows mean score over 10 days leading up to event (day 0), with 95% confidence intervals. Bottom graphs show distribution of scores in SSI vs no SSI groups.

Figure 7-4 depicts other wound related variables over time, and **Figure 7-5** depicts vitals and devices over time. Nasogastric tube use, increased heart rate, and morning temperature are each early predictors of SSI. Wound pain and wound odor are poor predictors, only increasing on the day of diagnosis.
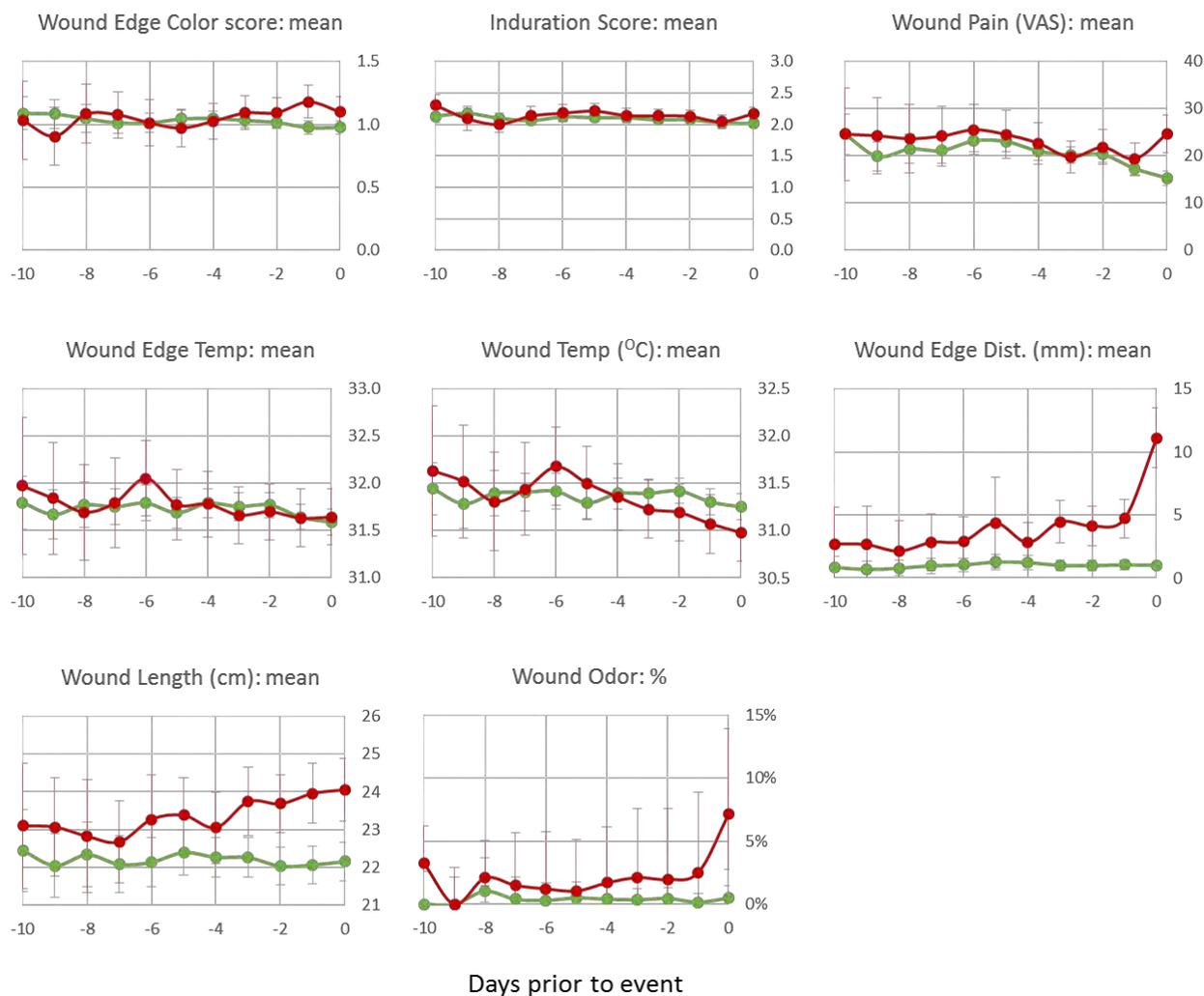
Figure 7-4. Other wound-related variables. Each graph shows mean values or % over the 10 days leading up to event (day 0), with 95% confidence intervals.
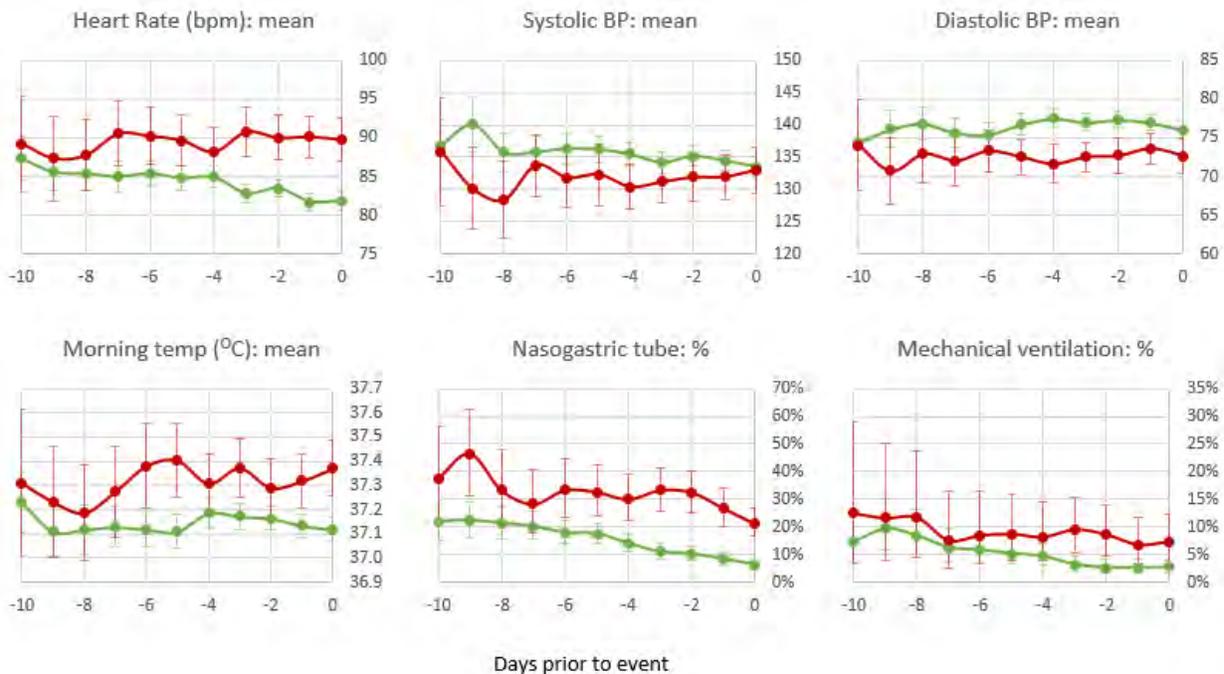
Figure 7-5. Vital signs and devices. Each graph shows mean values or % over the 10 days leading up to event (day 0), with 95% confidence intervals.

The next set of results relate to the performance of the Naïve Bayes classifiers trained on the baseline features (BF), serial features (SF) and the BF+SF datasets. **Table 7-4** demonstrates that the SF and SF+BF classifiers perform best on both the training and testing sets. The differences between AUC in the SF and BF+SF classifiers are not statistically significant. We therefore chose the simpler SF model for further evaluation.

Table 7-4. Classifier performance.

Classifier	Correct %		Kappa		AUC	
	Training	Testing	Training	Testing	Training	Testing
BF	75.1	72.5	0.158	0.133	0.670	0.634
SF	79.9	81.3	0.352	0.354	0.757*	0.735
BF+SF	79.8	81.3	0.351	0.354	0.759*	0.749

* BF vs SF, BF vs BF+SF: p<0.0001

Figure 7-6 shows the ROC curve for the SF classifier, and **Table 7-5** shows the resulting sensitivity/specificity combinations. The ROC curve is an average over 10 cross-validation runs on the training set. The points chosen on the curve were selected by eye for illustrative purposes.
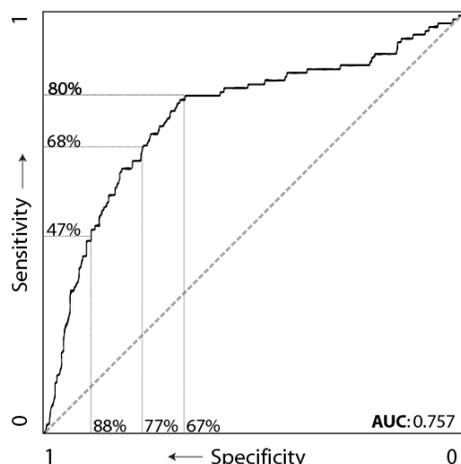
Figure 7-6. ROC curve of SF classifier with example sensitivity/specificity pairs.

Table 7-5. Predictive values of SF classifier with varying .

Goals of use	PPV	NPV	Sens	Spec
Specificity	0.49	0.87	0.47	0.88
Balanced	0.42	0.91	0.68	0.77
Sensitivity	0.37	0.93	0.80	0.67

Table 7-6 shows the features selected by the SF model using a wrapper-based feature selection method. The order of the table represents the order in which the features were added to the model, with decreasing predictive importance towards the bottom. We indicate which original data elements the selected features were based on, as well as the look-back period (ranging from cumulative 5 days to 1 day prior to SSI), and the type of transformation used to generate the feature.

Table 7-6. Features selected for final SF model, in order of predictive importance.

Original data element from which feature was derived	Lookback period (days)	Transformation type
Granulation score	2	Average value
Exudate amount score	3	Maximum value
Nasogastric tube presence	2	Maximum value
Granulation score	5	Maximum value
Nasogastric tube presence	5	Maximum value
Heart rate	3	Maximum value
Heart rate	4	Daily change
Temperature of wound minus skin	5	Deviation from trendline
Wound length	2	Average value
Wound length	2	Maximum value
Wound length	4	Deviation from trendline
Wound culture ordered	5	Average value
Wound culture ordered	5	Maximum value
Body temperature	5	Maximum value
Diastolic blood pressure	2	Raw value

7.5   DISCUSSION

Baseline data from our population supports numerous other studies identifying risk factors for SSI, e.g. differences in hemoglobin, CRP, surgery duration, wound class, and surgery type. Yet, we demonstrate that this data does not improve SSI prediction beyond that possible with wound observations alone; in other words, wound observations provide the

best prediction of infection, and may be considered without regard to surgery type, duration, etc.

We showed that patients with SSI differ in many ways from patients without SSI with regard to the prevalence of abnormal wound symptoms, especially in the 1-3 days prior to diagnosis. Of the 9 main wound-related features in **Table 7-3**, only wound edge color and amount of induration did not show highly significant differences between groups, calling into question whether these signs are reliable indicators of infection. In fact, we found that all of the sign/symptom elements of criterion C of the CDC SSI definition were either poor or very late predictors of SSI ("superficial incision that is deliberately opened by a surgeon, attending physician or other designee and is culture positive or not cultured AND patient has at least one of the following signs or symptoms: **pain or tenderness; localized swelling; erythema; or heat**.")[185] Wound pain and swelling only became significantly different on the day of diagnosis, while temperature of skin around the wound showed no difference between groups, and upwards of 90% of both SSI and non-SSI patients were deemed to have bright red skin surrounding their wound. It is unclear whether pain is truly a poor predictor or whether pain medications were confounding since we did not collect data on pain medication use.

On the other hand, we found many good predictors and indicators of infection, including many that are not part of current definitions. For example, we found abnormal granulation amount to be the best predictor of SSI. We found amount of exudate to be a better predictor than type of exudate. Wound edge distance was an excellent early predictor. Though not wound-related, heart rate, morning body temperature and nasogastric tube presence were also especially good predictors. Prolonged use of nasogastric decompression is a marker for delayed recovery of gastrointestinal function, which has been demonstrated by others to be associated with inpatient SSI.[186]

We demonstrated that the most predictive wound symptoms tend to be similar between SSI and non-SSI patients about a week prior to diagnosis, suggesting that wounds appear grossly similar prior to the onset of infection, and hinting at the pathophysiological timeline for SSI (i.e., beginning to develop 5-8 days prior to diagnosis). Most symptoms

started at very low levels and rose with infection, with the exception of exudate (type and amount), which had a significant prevalence throughout the post-operative period (mainly due to serosanguinous discharge).

We demonstrated that baseline features provide relatively poor prediction of SSI (AUC 0.67), while serial features have significantly better performance (AUC 0.757; p<0.0001). When the SF classifier was applied to the hold-out test set, it achieved similar performance (AUC 0.735) as to the training set, indicating that overfitting was not a significant concern. The addition of BF to the SF classifier did not improve performance significantly, indicating that serial features were both necessary and likely sufficient for optimal prediction. **Table 7-5** demonstrates that the SF classifier could be reasonably used as a screening tool, with 80% sensitivity, and 67% specificity (PPV 37%, NPV 93%).

One key limitation of current predictive models of SSI is that they have been developed to predict inpatient SSI. Yet, with shorter hospitalizations, most SSIs now occur post-discharge, with patients often ill-prepared to identify developing SSI, no standardized or reliable methods of post-discharge surveillance and relatively few risk factors identified for post-discharge infections[8–11]. Delayed diagnosis of post-discharge surgical site infections (SSIs) has significant financial and quality costs, with more than half of patients who develop post-discharge SSI readmitted to the hospital [10,99]. We hypothesize that many of the wound features identified by our model are also applicable in a post-discharge setting, allowing monitoring of these wounds using automated image analysis to predict infections in real time. Our dataset is unique in that, coming from a hospital in the Netherlands, length of stay is significantly longer than in the US (median 12 days in our dataset), allowing us to observe events that might occur after discharge in the US.

7.5.1 Limitations and next steps

Future work will address many of the limitations of the current work: we aim to simplify the model to apply at the bedside by reducing the number of features, minimizing the lookback period, and creating an easy-to-apply scoring system; second, we plan to evaluate the method's generalizability in a variety of real-world settings, prospectively testing the

daily prediction accuracy in a cohort of post-operative patients. We suggest that there shouldn't necessarily be a single, static model; the spirit of machine learning is iterative and data-driven, continuing to optimize and learn from additional populations and settings over time.

7.5.2   Contributions

Contributions of this work include a deeper understanding of course of SSI development and evolution of various signs and symptoms and a novel computational method that shows promise for predicting SSI. In addition to use in an inpatient setting, this method has potential future use in automated systems incorporating image analysis and patient-reported outcomes to predict post-discharge SSI. In both settings, infections can be identified earlier, reducing costs and morbidity associated with SSI, and ultimately improving the quality of care.

7.6   CONCLUSIONS

Features of evolving wound infection are discernable prior to the day of diagnosis primarily based on visual inspection. Serial features (i.e. serial wound photos and vital signs) provided moderate PPV and high NPV for prediction of SSI in advance of clinical diagnosis. Addition of traditional baseline patient/operative data did not improve prediction. Existing definitions of SSI may be made more reliable by incorporation of objective wound features.

Chapter 8. A Scenario-Based Study of SSI Diagnosis Incorporating Wound Photography

8.1 Abstract

Background: Most surgical site infections now occur after hospital discharge, but patients and providers have lacked tools to discover these infections early, often resulting in preventable readmission. Technological approaches to follow-up (e.g. mobile health "apps") that incorporate wound photos are being adopted, but it is unclear how adding these photos to existing data sources modifies provider decision-making.

Methods: A national sample of providers with expertise in surgical infections was presented with a range of real patient scenarios via anonymous web-based survey and were asked to make diagnoses, rate confidence, and make management decisions first without and then with accompanying wound photos. At each step, they ranked the most important elements contributing to their decision. Primary endpoints were changes in diagnostic accuracy, diagnostic confidence, and management due to addition of wound photos.

Results: Most participants (total N=44) were MDs in academic surgical specialties. Addition of photos improved overall diagnostic accuracy across all scenarios from 67% to 78% (p=0.0002), especially in non-SSI patients, and increased sensitivity from 55% to 65% and specificity from 77% to 92%. Photos increased diagnostic confidence from 5.9/10 to 7.4/10 (p<0.0001). Overtreatment among non-SSI patients decreased from 48% to 16% (p<0.0001) and undertreatment among SSI patients decreased from 28% to 23% (ns).

Conclusions: Addition of wound photos to existing data sources (e.g. chart review and telephone consultation) improved accuracy, confidence and management of patients both with and without SSI. Development and implementation of easy-to-use patient-centered

technologies to capture wound photos and other key data from patients during the post-discharge period should be encouraged.

8.2 INTRODUCTION

Surgical site infection (SSI) is a common post-operative complication, occurring in at least 3-5% of all surgical patients and up to 33% of patients undergoing abdominal surgery[3,4,108,109]. Of the estimated 500,000 infections in the US annually, more than half occur after hospital discharge, placing the burden of problem recognition on patients who are often ill-prepared to manage SSI.[8–11,110] More than half of these post-discharge infections result in readmission, making SSI the overall costliest—yet often non-reimbursable—healthcare-associated infection. [10,19,99,111] Recent studies suggest that inadequate post-discharge communication, care fragmentation, and untimely, infrequent follow-up contribute to these poorer outcomes. [100,101,112]

As providers and hospitals seek to bridge the gap between discharge and follow-up visits, many are turning to technological approaches made possible by the increasing prevalence of smartphones coupled with patients' increasing interest in tracking their own health. [88–90] Indeed, patients and providers have both expressed interest in using mobile health (mHealth) tools to facilitate improved post-discharge wound tracking.[100,131] At our institution, providers are increasingly asking for patients, especially those who must travel long distances to seek evaluation and treatment, to email wound photos to enhance their follow up care. Anecdotally, providers describe this practice as improving triage, resulting in fewer unnecessary visits and earlier identification of potential problems. Yet, the impact on provider decision-making of added wound photographs has not been previously studied in the context of post-discharge wound monitoring.

8.2.1 Related work

Several studies have evaluated the use of digital photography in assessing wound healing of inpatients.[63,187] In a study of remote diagnosis of SSI in laparotomy wounds[63], sensitivity averaged 42% and specificity averaged 97%; inter-observer agreement among remote surgeons ranged between K=0.54-0.68 for diagnosis and K=0.15-0.72 for management. In a study of remote diagnosis of SSI in vascular surgery wounds[187], sensitivity averaged 71% and specificity averaged 65% with inter-observer agreement among remote surgeons of K=0.08 and agreement among onsite surgeons of K=-0.04. The authors in the latter study concluded that, across a range of measures, agreement (i.e. kappa values) among onsite surgeons was comparable to that among remote surgeons, suggesting that photography did not independently impact the level of agreement: low remote agreement simply reflected the low agreement among on-site providers.

Skin photographs have been studied in a number of other contexts, often using mobile phone cameras, in settings of chronic wounds[51,66,188,189], psoriasis monitoring[69], skin cancer screening[70,190–192], and other general dermatological conditions[72,193,194]. Reviews of this "store-and-forward" type of telemedicine have concluded that diagnostic accuracy is variable, overall somewhat inferior to in-person examination, but management accuracy and patient satisfaction are equivalent.[53,73,195] A recent review concluded that the benefits of incorporating telemedical photographs must be evaluated in context of potential setting-specific limitations.[195]

8.2.2 Research questions

Given the uneven performance of telemedicine across previously-studied settings and the trend toward transmission of photographs of post-discharge surgical wounds to providers, we sought to answer the following questions:

RQ1. How does the addition of wound photos impact diagnostic accuracy, confidence in diagnosis, and management?

RQ2. What is the relationship between diagnostic confidence and accuracy?

RQ3. What data elements do providers consider most important for diagnosis?

8.3 METHODS

The study was approved by the University of Washington Institutional Review Board and consent was obtained electronically from all participants prior to undergoing study procedures.

8.3.1 Participants and setting

We recruited providers with experience in managing SSIs via email and though flyers at academic conferences. We emailed a membership-wide listserve for the Surgical Infection Society. We passed out flyers at annual meetings of the Surgical Infection Society, American Academy of Ambulatory Care Nursing, and Wound Healing Society.

Inclusion criteria were medical providers (e.g. physicians, nurses) who regularly manage SSIs. Exclusion criteria were inability to speak English, view wound photos or navigate a web-based survey. In addition, we excluded participants who did not complete 2 or more patient scenarios.

8.3.2 Data collection

Participants were directed to an anonymous, web-based survey delivered via the Qualtrics (www.qualtrics.com) platform (see **Figure 8-1** for study flow).
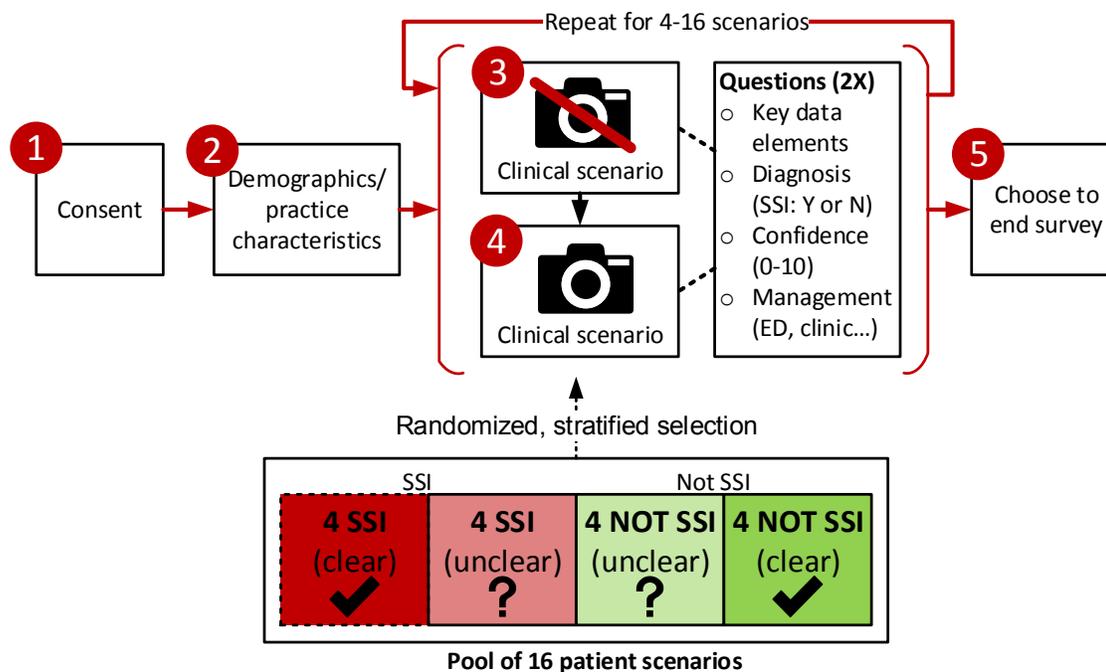
Figure 8-1. Study design overview

Briefly, participants gave consent and then answered questions covering demographics and practice characteristics. They were then asked to complete at least 4 patient scenarios (see Survey construction, below, for further details on how scenarios were chosen). Each scenario consisted of 2 pages: on the first page (**Figure 8-2**), the participants were given details about the patient including operative data, demographic/risk factors, limited vital signs, and wound features, meant to replicate the details that might be available by looking at the patient's chart and speaking to them on the phone. On this page, they chose up to 3 of the most important factors for assessing SSI (of the 20 provided), then were asked to make a diagnosis (SSI/not SSI), rate their diagnostic confidence on a 0-10 scale, then choose one or more management options. On the second page (**Figure 8-3**), they were shown a wound photograph corresponding to the post-operative day described on the first page (the 20 factors were also provided for reference). They then were asked to choose up to 3 of the most important photo-related factors (of 6 provided), followed by the same 3 questions as on the previous page (SSI/not SSI, confidence, management). Participants sequentially completed scenarios until they elected to end the session. For each par-

ticipant, scenarios were selected from a pool of 16 using stratified randomization to ensure that each participant got an even mix of each of the 4 types of scenarios depicted in Figure 8-1.

8.3.3 Survey construction

Patient scenarios were sampled from an existing database created from a prior prospective cohort study of in-hospital SSI among open abdominal surgery patients in which patient wounds were systematically examined and photographed from post-operative day 2-21 (or hospital discharge, if earlier). In the original study, wounds were assessed for SSI using CDC criteria. We selected 16 of these patients as shown at the bottom of **Figure 8-1**. The 16 scenarios were stratified so that half were SSI (either superficial or deep) and half were not SSI, and half were unclear cases and half were not, as judged by the consensus of 2 providers on our study team. Among the unclear cases, half were due to symptoms unsupportive of the diagnosis and half were due to a photo unsupportive of the diagnosis.

Although the source data (wound observations and photographs) was collected on inpatients with a median length of stay of 12 days, we were able to simulate post-discharge patients for the purpose of the current study by selecting post-operative days 6-14 for inclusion in scenarios. We specifically choose wounds that appeared comparable to post-discharge abdominal surgery patients in the US (with current median lengths of stay of 5-6 days).[165,196]

Figure 8-2. First page of scenario (without photo). Participants choose 3 most important diagnostic factors, assess SSI, rate confidence in that assessment, then choose management steps.

Figure 8-3. Second page of scenario (with photo). Participants are provided with photo in addition to data provided on previous page (Figure 2). They select the most important aspects of the photo, then make an additional assessment of SSI, confidence, and management steps.

8.3.4   Data analysis

Data was exported from Qualtrics survey platform into Stata (Stata v13, StataCorp LP) for analysis. Data visualizations were created in Microsoft Excel 2013. P-values of 0.05 or less were considered significant.

8.3.4.1 Participant-level data

Demographics and practice characteristics were summarized using counts and percentages for categorical data, means and standard deviations for normally-distributed continuous data, and medians and interquartile ranges for nonnormally-distributed continuous data.

Correlations between participant characteristics and % of scenarios correct (both with and without photos) were tested using Pearson's correlation coefficient.

8.3.4.2 Scenario-level data

The remainder of the analysis was conducted with scenarios, rather than participants, as the primary unit of analysis.

Analysis was conducted on each of the 16 scenarios and/or on the 4 scenario groups (each with combined data from 4 scenarios). When analyzing change due to addition of photos (e.g. of diagnostic accuracy or confidence), paired tests for significance were used: paired t-tests for continuous variables (e.g. confidence) and McNemar's test for binary variables (e.g. diagnostic accuracy). McNemar's exact test was used if there were fewer than 20 discordant pairs.

8.4 RESULTS

We first present participant characteristics to describe our study population. Second, we present results on diagnostic accuracy, illustrating how well providers were able to make remote SSI diagnoses both with and without photographs. Third, we present results on diagnostic confidence, showing how confidence changes with addition of photos and the relationship between confidence and accuracy. Fourth, we present results about how management decisions change with photos. Finally, we present data elements, both photo-related and non-photo-related, considered to be most important to diagnosis by providers.

8.4.1 Demographics and practice characteristics

Table 8-1 provides a summary of participant characteristics. Of 44 providers included in analysis, most were male, surgical specialists, holding MD degrees, and practicing in an academic setting. Most (66%) do not report currently receiving wound photos from patients.

Addition of photos improved the median participant's accuracy from 68% to 75%; participants in the 25th percentile improved from 50% to 67% correct. Univariate analysis showed no correlation between performance (i.e. % correct, bottom 2 elements of **Table 8-1**) and any of the other factors in **Table 8-1**, including Surgical Infection Society membership, highest degree, years in practice, time taken per scenario, or screen size.

Table 8-1. Participant characteristics

Factor	Level	Value
N		44
Level of training, N (%)	MD	35 (80%)
	PA	1 (2%)
	RN	7 (16%)
	Other	1 (2%)
Specialty, N (%)	Surgery	39 (89%)
	Primary care	1 (2%)
	Other	4 (9%)
Practice setting, N (%)	Academic	37 (84%)
	Community	7 (16%)
Gender, N (%)	Male	28 (64%)
	Female	16 (36%)
Member of professional society, N (%)	SIS	16 (36%)
	IDSA	3 (7%)
Years in practice, mean (SD)		15 (12)
Wound photos seen per month, median (IQR)		0 (0, 2)
SSIs managed per month, median (IQR)		4 (1, 5)
Age, mean (SD)		41 (13)
Time taken for survey, median (IQR), mins		14.5 (11.2, 19.6)
Number of scenarios taken, median (IQR)		5 (3.5,7)
Screen size	Smartphone	15 (34%)
	Tablet or larger	29 (66%)
Scenarios (w/o photo) correct %, median (IQR)		68 (50-87)
Scenarios (w/ photo) correct %, median (IQR)		75 (67-93)

* SIS = Surgical Infection Society,   IDSA = Infectious Disease Society of America

8.4.2 Diagnostic accuracy

8.4.2.1 Correct diagnoses

Figure 8-4 shows how photos improved diagnostic accuracy in all 4 subsets, but especially in the "unclear" non-SSI scenarios. Photos significantly changed accuracy in both establishing and ruling out diagnosis of SSI. Overall accuracy improved from 67% to 78% (p=0.0002) with photos.
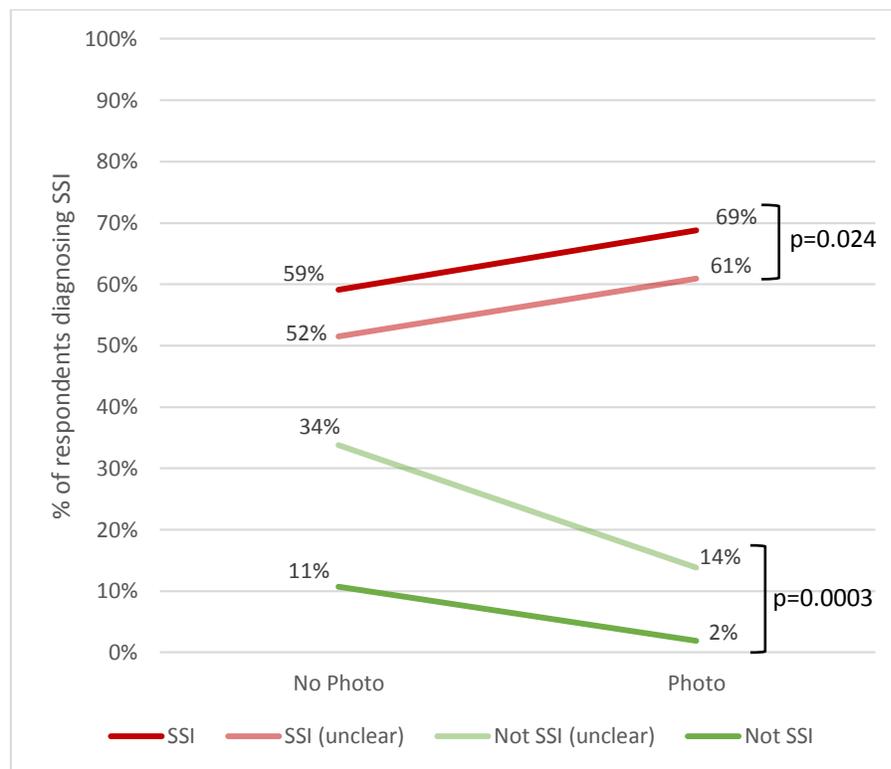
Figure 8-4. Percent of respondents diagnosing SSI. Red and green indicate SSI cases and non-SSI cases, respectively. Lighter red and green indicate less clear cases of SSI and non-SSI.

8.4.2.2 Predictive values

Figure 8-5 shows improvement in sensitivity, specificity, positive- and negative-predictive with addition of photos. This data also show that sensitivity for remote diagnosis

of SSI using symptom report and wound photos was moderate (58-64%) and specificity was high (78-92%).
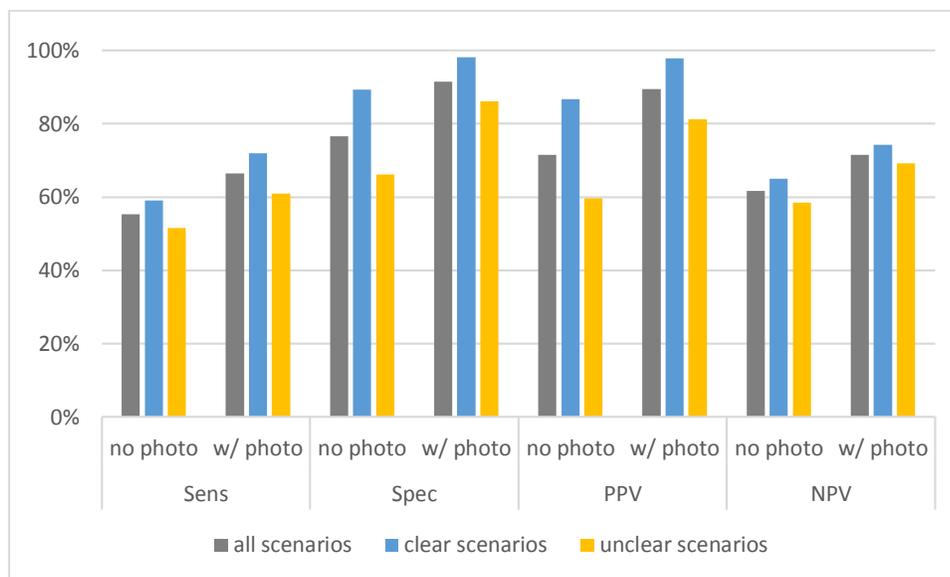
Figure 8-5. Predictive values with and without photos.

8.4.3   Diagnostic confidence

8.4.3.1   Confidence with addition of photograph

Confidence significantly increased with addition of photos in 11/16 scenarios and decreased (non-significantly) in only 1/16 scenarios. Over all scenarios, confidence increased by an average of 1.5 points out of 10, from 5.9 to 7.4 (25% increase). The SSI group had the smallest and least significant increase in confidence.

Table 8-2. Mean confidence with and without photos by scenario group.

Scenario group	w/o photo	[95% CI]	w/ photo	[95% CI]	p value
	Mean confidence (0-10)				
SSI	5.8	[5.4-6.2]	6.7	[6.2-7.2]	0.0005
SSI (unclear)	5.9	[5.5-6.3]	7.2	[6.8-7.7]	<0.0001
Not SSI (unclear)	5.8	[5.3-6.3]	7.6	[7.1-8.0]	<0.0001
Not SSI	6.3	[5.9-6.8]	8.4	[8.0-8.9]	<0.0001
Total	**5.9**	**[5.7-6.2]**	**7.4**	**[7.2-7.7]**	<0.0001

8.4.3.2 Confidence vs accuracy

Figure 8-6 shows that respondents with inaccurate answers tended to be less confident in those answers. Wound photos increased confidence among respondents with correct answers to a greater extent than among respondents with incorrect answers. This tendency was more marked in non-SSI scenarios.
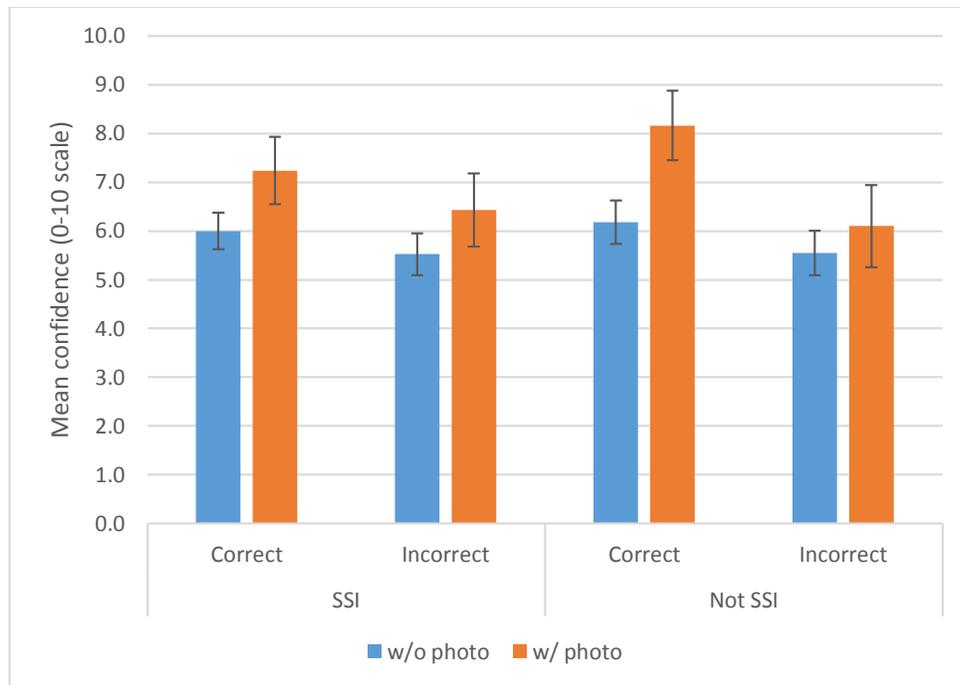
Figure 8-6. Mean confidence (out of 10) for correct vs incorrect answers +/- photos. Blue bar denotes mean confidence without photos, orange bar denotes mean confidence with photos. Error bars indicate 95% confidence intervals.

Figure 8-7 shows that for all scenarios (SSI and non-SSI), addition of photos significantly decreased recommendations to go to ED and increased reassurance, however, reassurance was disproportionately increased (12% → 73%) among non-SSI scenarios. Addition of photos particularly affected non-SSI patients through decreased antibiotics and next-day clinic visits. Relatively few providers were interested in continuing to receive symptom reports (~10%) or photos (~15%), even among patients with SSI.
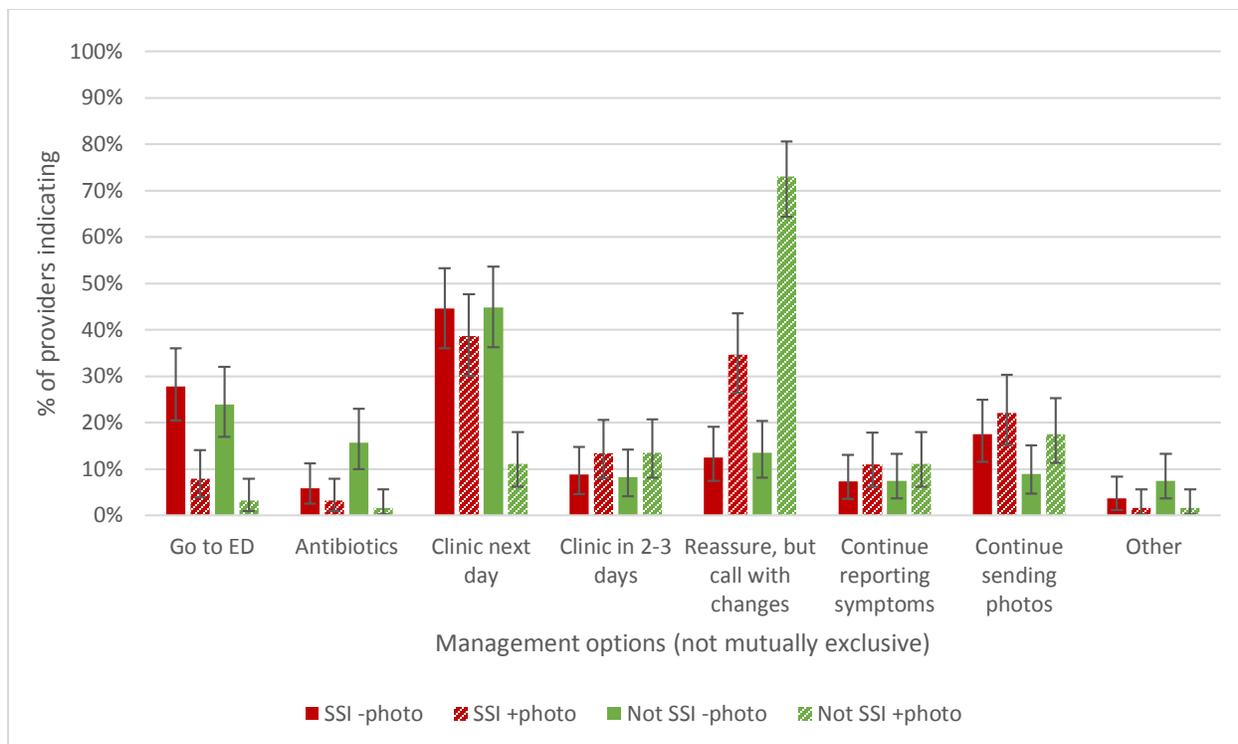
Figure 8-7. Management decisions with and without photos in SSI and non-SSI scenarios. Error bars indicate 95% confidence intervals.

Figure 8-8 shows the effect of addition of photos on undertreatment of SSI cases (i.e., *not receiving* a recommendation for ED, next day clinic or antibiotics) and overtreatment of non-SSI cases (i.e., *receiving* a recommendation for ED, next day clinic or antibiotics). Over-treatment among non-SSI patients decreased from 48% to 16% with the most significant drop occurring among clear non-SSI cases. There was a non-significant trend toward less undertreatment of SSI cases (28% to 23%). In other words, both groups received more ap-propriate treatment
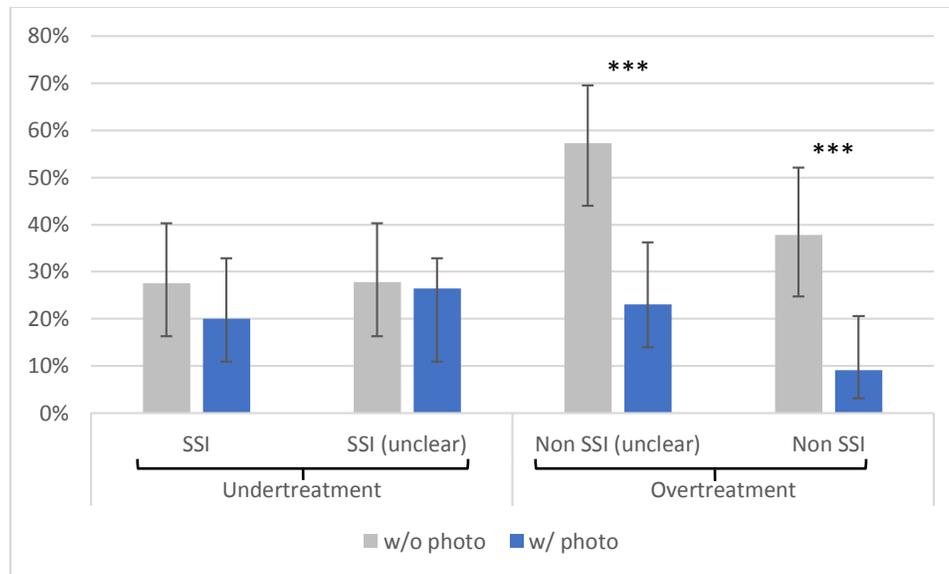
Figure 8-8. Under-treatment and over-treatment with and without photos. Under-treatment is defined as a patient with SSI who was not advised to go to ED, next day clinic visit or prescribed antibiotics. Over-treatment is defined as a patient without SSI who was advised to go to ED, next day clinic visit or prescribed antibiotics.

8.4.4   Key data elements

8.4.4.1   Non-photo-related elements

The most common highly-ranked non-photo features (i.e., features communicated in words) for SSI diagnosis (**Figure 8-9**) were skin color (ranked among the top 3 most important features in 65% of scenarios), discharge type, and discharge amount. These features did not obviously vary by type of scenario (e.g. SSI vs non-SSI), suggesting they help to both rule in and rule out SSI. Of the 20 data elements presented, the lowest ranking (ranked important in <10% of cases; omitted from Figure 8-9) were: diabetes, wound edge separation, ASA score, BMI, emergency surgery, post-operative day, smoking, age, wound odor, and sex.
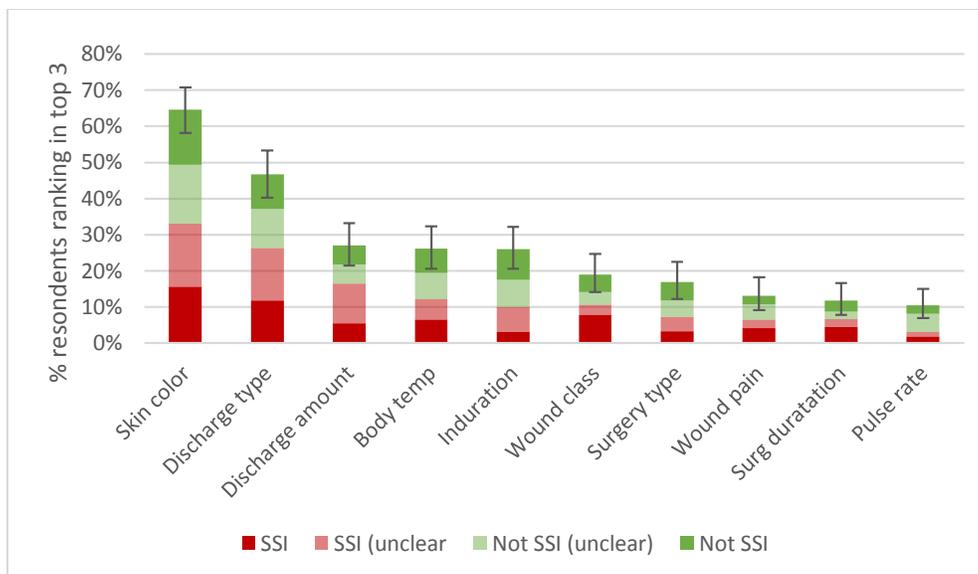
Figure 8-9. Percent of respondents ranking non-photo features among top 3 most important for diagnosis. An additional 10 elements with <10% are not shown. Error bars indicate 95% confidence intervals.

8.4.4.2 Photo-related features

Figure 8-10 shows the photo-related features (i.e., features visualized by respondents in actual wound photos) ranked most often among the top 3. As before, skin color at wound edge remains top ranked (84% of scenarios) in addition to swelling and discharge.
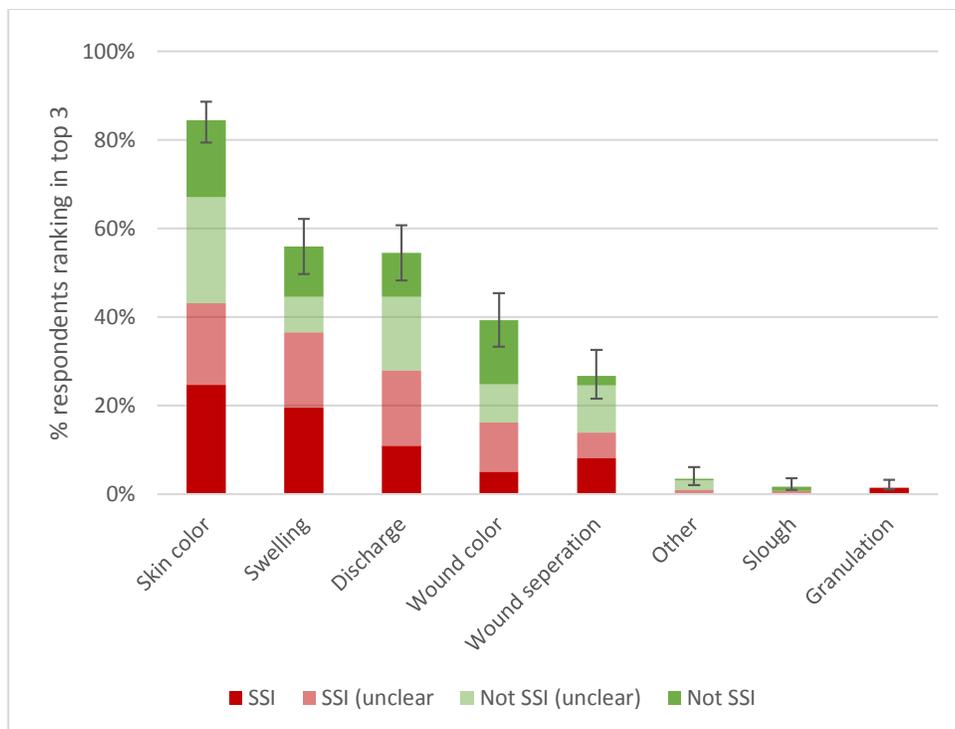
Figure 8-10. Percent of respondents ranking photo features among top 3 most important for diagnosis. Error bars indicate 95% confidence intervals.

8.5 DISCUSSION

In this study, we show significant increases in diagnostic accuracy and, especially, diagnostic confidence with addition of wound photos. Photos significantly increase confidence in correct diagnoses and decrease confidence in incorrect diagnoses.

More concretely, we show that addition of photos significantly changes management decisions, decreasing overtreatment among those without SSI from 48% to 16% and decreasing undertreatment among those with SSI from 28% to 23%. Patients without SSI receive more conservative management, with fewer antibiotics and emergency department/clinic visits and increased reassurance.

Interestingly, photos decrease ED recommendations for both patients with and without SSI, but do not decrease next day clinic visits among those with SSI, suggesting that providers are reassured by photographs enough to delay about 2/3 of patients with poten-

tial SSI to next day clinic visits instead of same day ED visits. It is unclear whether this delay would result in adverse outcomes for these patients. Further work is needed to empirically assess clinical outcomes, including the impact on both under- and over-triage associated with sending wound photos from home.

Skin color around the wound was ranked as the most important symptom by providers, both as reported by patients over the phone and as visualized in photographs by providers. However, an analysis of skin color score in the parent dataset (see **Chapter 7**) revealed no differences between patients with and without SSI.

8.5.1 Limitations

This work has several limitations; first, the original data source on which our scenarios were based came from a cohort of open abdominal surgery inpatients in the Netherlands. Although we tried to choose patients who we thought were representative of post-discharge patients in the US, these patients might not be perfectly representative. Our results might not be generalizable to patients who didn't undergo open abdominal surgeries.

Second, the photos and wound data used in this study were obtained by research team members and not patients themselves; photos and wound data entered by patients or their caregivers may be less helpful for providers due to quality issues.

Third, scenarios only included data from a single point in time and did not include trend information, which is known to be useful for provider decision-making. Future work should assess the utility of serial data and photos.

Fourth, our sample was primarily academic surgeons with almost a third being members of the Surgical Infection Society; our sample did not include enough non-MDs to detect differences based on training, and may not be generalizable to providers (MD and otherwise) in the community.

Finally, we stratified our sample scenarios on a number of dimensions that are not epidemiologically representative of SSIs in practice, e.g. 50% of scenarios were SSIs. This results in a biased estimate of PPV and NPV but not sensitivity and specificity. Based on the population that our scenarios were drawn from and other literature, we estimate the prev-

alence of SSI to be 25-30% following open abdominal surgery. [Insert prevalence of unclear SSI/unclear non-SSI]. Since addition of photos in our study most enhanced diagnosis and management among patients without SSI, it is likely that when photos are included in a more epidemiologically representative population, diagnostic accuracy would increase to an even greater extent.

8.6   CONCLUSIONS

Addition of wound photos to existing data sources (e.g. chart review and telephone consultation) improved accuracy, confidence and management among patients both with and without SSI. Development and implementation of easy-to-use patient-centered technologies to capture wound photos and other key data from patients during the post-discharge period should be encouraged.

Chapter 9. CONCLUSIONS

9.1 AIM 1. TO CHARACTERIZE PATIENT AND PROVIDER PERSPECTIVES ON CURRENT POST-DISCHARGE WOUND SURVEILLANCE PRACTICES.

Through this aim, I developed a foundational understanding of current post-discharge surveillance practices and assessed the openness of patients and providers to addressing challenges in the existing post-discharge surveillance system with an mHealth wound tracking tool.

Chapter 2. In this study, patients who experienced SSI told us that they are not served by the current standard post-hospitalization care practice, reporting deficiencies in discharge education, wound self-monitoring at home, and communication with providers. Patients found the concept of our patient-centered mHealth wound monitoring application (mPOWEr) highly acceptable.

Chapter 3. Providers reported the current system for post-discharge SSI surveillance to be ineffective and wanted closer follow-up, better patient education, and wound photos from home—all of which mPOWEr can address. Through our needs assessment, we gathered valuable information from providers on core features (symptomatology questions and photos) and were able to prioritize additional features to enhance mPOWEr. Despite concern over potential increased workload and over-triage, 92% of providers were likely adopt the system.

Overall, through an understanding of the experience of patients and providers, results from this aim provided grounding for design and development of a usable wound-tracking application that meets both patient and provider needs (Aim 2).

9.2 AIM 2. TO DETERMINE ESSENTIAL QUALITIES OF A MOBILE POST-ACUTE CARE WOUND-TRACKING TOOL.

In this aim, I engaged a variety of stakeholders in the design of a wound tracking tool, helping to map the unexplored space of post-acute care mHealth, developing design recommendations for post-acute care mHealth and clinically-integrated patient-generated health data applications. In support of the previous elements of this aim, I also proposed a novel heuristic evaluation to aid design of patient-centered applications.

Chapter 4. Through interviews with patients who experienced post-discharge complications, we explored the design space of a post-acute care mHealth app. Patients described lack of information at discharge, lack of control over communication and mistrust about management decisions made by providers about their care. In response, they envisioned design qualities of an mHealth app that could empower patients through meeting information needs and facilitating predictable communication, and empower their providers with information to make the best decisions about their care. We present a set of design considerations for post-acute care apps and propose a new model for differentiating mHealth apps by the intensity and duration of illness. These contributions incorporate key patient preferences to expand the mHealth landscape with apps that patients will embrace.

Chapter 5. I extended previous work by incorporating provider perspectives, allowing exploration of design challenges resulting from misalignment of patient and provider expectations. I found major barriers in the form of patient-provider conflicts and system factors that may impede the design and adoption of mPOWEr and similar patient-centered tools. I contributed a number of design considerations which can inform the development of similar tools; but patient and provider engagement remains critical to working through these tensions to ensure smooth integration of PGHD into routine clinical use.

Chapter 6. Delivering patient-centered care is an important but largely unachieved goal of many healthcare systems. Health IT will play a key role in enabling patient-centered care, but little guidance exists to aid evaluation of patient-centered tools. I created a patient-centered heuristic evaluation method and successfully applied it to aid redesign of

mPOWEr, an existing surgical wound tracking tool developed using traditional user-centered design methods. Counterintuitively, I found that listening to patients is necessary but may be insufficient in creating a truly patient-centered design. Incorporation of heuristic evaluation methods, such as this one, could enhance this process, especially when used in conjunction with stakeholder engagement.

Through the course of engaging a variety of stakeholders in this aim, I developed a number of generalizable design implications and methods that can support design of applications that are both patient-centered and responsive to the tensions inherent in applications that have both patient and provider stakeholders.

9.3 AIM 3. TO EVALUATE THE CLINICAL UTILITY OF SERIAL WOUND DATA IN DIAGNOSIS AND PREDICTION OF SSI.

This aim addressed a key consideration of a clinical tool intended to be used in the real world: that the data it collects (i.e., serial wound photos and data) improves diagnosis and management. I also assesses whether such data can actually improve upon the gold standard by predicting infection before it is clinically apparent.

Chapter 7. In this study I demonstrated significant increases in diagnostic accuracy and, especially, diagnostic confidence with addition of wound photos. Photos significantly increased confidence in correct diagnoses and decreased confidence in incorrect diagnoses. More concretely, I showed that addition of photos significantly improves management, decreasing overtreatment among non-SSI patients and decreasing undertreatment among SSI patients.

Chapter 7. In this study I showed that patients with SSI differ in many ways from patients without SSI with regard to the prevalence of abnormal wound symptoms in the week prior to diagnosis. I demonstrate that serial wound/patient data provide significantly better prediction of infection in advance of clinical diagnosis than traditional baseline risk factors

(e.g. type of surgery). The resulting predictive model incorporating serial data could reasonably be used as a screening tool given its high sensitivity and moderate specificity.

In this aim, I demonstrated the value of wound photos and serial wound data in diagnosing and predicting SSI. I also show a discrepancy between the subjective value that providers place on skin redness around wounds and the (lack of) predictive value of redness in a large dataset. Overall, this aim provides evidence for the clinical utility of a patient-centered tool which captures wound photos and other key data from patients during the post-discharge period.

9.4 LIMITATIONS AND FUTURE WORK

9.4.1 Aims 1 and 2

Work for these aims had several limitations related to engaging patients. First, I only interviewed surgical patients. Patients affected by other conditions may have different needs and preferences. I believe ours is a good initial test population due to the challenging and often eventful post-discharge experience following major surgery. Second, I only interviewed patients who experienced post-discharge complications. I believe that patients who experienced problems are the most likely users of the app and have the most insight into current system failings. There remains an opportunity to examine the effect on the post-discharge experience for patients who do not experience complications, as even these patients could stand to benefit from reassurance offered through improved data communication and increased access to providers. Lastly, I interviewed a relatively small number of patients from two very different, but related, hospital settings. As is customary in qualitative research, the sample size was based on reaching saturation. Despite the small sample, participants were diverse in age, education, and technology experience, and sample characteristics were similar to national samples.

In relation to engaging providers, limitations include a small sample size, and under-representation of non-physicians and non-academic providers. In addition, the survey nature, though it included a number of free response questions, did not allow deep understanding of participants views. This deficiency was addressed in Aim 2 through further engagement of a diverse group of nurses and physicians in in-depth interviews and other user-centered design methods.

In relation to developing a patient-centered heuristic evaluation method, limitations stemmed mainly from using an existing framework with a large number of poorly-defined and/or overlapping subdomains. Conceiving and applying this method with an application to redesigning a relatively unique post-acute care application may also have led to blind spots, e.g. when applied to personally-controlled health records.

9.4.2 Aim 3

Both studies in Aim 3 shared several limitations due to the nature of the original dataset on which they are both based. The dataset came from a cohort of open abdominal surgery inpatients in the Netherlands. Our results might not be generalizable to patients who didn't undergo open abdominal surgeries. Second, the photos and wound data used in this study were obtained by research team members and not patients themselves; photos and wound data entered by patients or their caregivers may be less helpful for providers due to quality issues.

In relation to the provider survey study, first, although we tried to choose patients who we thought were representative of post-discharge patients in the US, these patients might not be perfectly representative. Second, scenarios only included data from a single point in time and did not include trend information, which is known to be useful for provider decision-making. Future work should assess the utility of serial data and photos. Third, our sample was primarily academic surgeons with almost a third being members of the Surgical Infection Society; our sample did not include enough non-MDs to detect differences based on training, and may not be generalizable to providers (MD and otherwise) in the community. Finally, we stratified our sample scenarios on a number of dimensions that are

not epidemiologically representative of SSIs in practice, e.g. 50% of scenarios were SSIs. This results in a biased estimate of PPV and NPV but not sensitivity and specificity. Based on the population that our scenarios were drawn from and other literature, we estimate the prevalence of SSI to be 25-30% following open abdominal surgery. Since addition of photos in our study most enhanced diagnosis and management among patients without SSI, it is likely that when photos are included in a more epidemiologically representative population, diagnostic accuracy would increase to an even greater extent.

In relation to the SSI prediction study, first, the model could be simplified to more easily apply at the bedside by reducing the number of features, minimizing the lookback period, and creating an easy-to-apply scoring system; second, the method's generalizability should be evaluated in a variety of real-world settings, prospectively testing the daily prediction accuracy in a cohort of post-operative patients.

Though beyond the scope of my dissertation, future clinical trials should evaluate the impact of mPOWEr on outcomes meaningful to patients, providers and society, e.g. patient satisfaction, quality of life, clinical outcomes, and healthcare utilization.

9.5 CONTRIBUTIONS

9.5.1 Contributions to research

Through this research, I contributed a qualitative understanding of the challenges that patients face after hospital discharge due to surgical complications, and highlighted the perceived failings of post-discharge wound surveillance as seen by patients and providers. By taking a user-centered approach that engages novel stakeholder groups, I contributed to the development of an application grounded in the needs of users; by engaging both patient and provider users, I uncovered conflicts and made resulting tradeoffs explicit during design.

I generated design considerations that begin to map the unexplored space of mHealth for post-acute care, incorporating key patient preferences to expand the mHealth land-

scape with apps that patients will embrace; in addition, I proposed a new model for differentiating mHealth apps by the intensity and duration of illness. By exploring misalignments of patient and provider expectations, I proposed a set of generalizable design implications to aid development of applications that are both patient-centered and responsive to the tensions inherent in applications that have both patient and provider stakeholders. Beyond patient-provider tensions, I pointed out the importance of several system-level barriers to implementing patient-centered applications. I also proposed a novel heuristic evaluation method to guide design and evaluation of patient-centered applications.

Finally, I demonstrate the critical contribution of wound photos in improving diagnostic accuracy, confidence, and management of existing SSIs. I also provide a deeper understanding of course of SSI development and evolution of various signs and symptoms and a novel computational method that shows promise for predicting SSI in advance of clinical diagnosis.

9.5.2 Contributions to practice

Through my work, I have aided in the development of a patient-centered wound tracking and communication platform that has the potential to be implemented in practice, improving patient engagement, quality of life, and clinical outcomes.

I have also challenged received wisdom in the field of surgical infections by pointing out the relatively weak association between SSI and "classic" symptoms of infection such as redness, swelling, pain and heat. I proposed other symptoms for inclusion in definitions including granulation, amount of exudate and elevated heart rate which are both more objective and more predictive in the patient population I analyzed. In many other ways, though, I have reinforced the notion that careful wound observations are critical to early detection of infection.

9.6 FINAL REMARKS

It's rare in any area of healthcare that so many forces align to encourage a project to go forward, but in the case of mPOWEr, there are many: a shift towards shorter post-operative lengths of stay, with most infections now occurring after discharge; general dissatisfaction with the regime of post-discharge infection surveillance among both patients who have experienced infection and providers responsible for managing those infections; a realization about the key importance of care coordination around transitions of care as a major cost driver and therefore area for improvement; payment reforms that penalize preventable medical complications like surgical infections and others that bundle payments in a way that incentive remote management and telemedicine; regulatory changes that emphasize patient engagement, and collection of patient-reported outcomes and patient-generated health data; the near ubiquity of smartphones with increasingly advanced sensors; and finally, patient expectations that medicine, aided by modern technology, should evolve to be truly centered around the needs of patients. If there was ever a time for a project like this, it is now!

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APPENDIX

Appendix 5-A. **Themes related to current practices.** S# denotes surgical provider; PA# denotes patient advisor; PI# denotes patient who experienced infection.

Patients and providers have significant problems with current post-discharge follow-up practices		
Initial patient contact is confusing and slow	• Patients receive too many phone numbers at discharge • Contact system for post-discharge follow-up is fragmented and confusing to all groups • Frustration that automated telephone systems and/or triage operators without clinical knowledge were impeding access to care • Slow response time for initial callbacks (>24h) were common, even longer to reach higher level providers	"You guys have a new phone system here now, and... it doesn't go through this front desk anymore. And you're usually having to leave messages. You don't talk to somebody specifically, unless you have a fever, unless you're vomiting. And I kind of get frustrated with that, to be honest with you." (**PI8**) "There's no medical knowledge. It's just somebody in a call tower going through it... if you do get a bump to a triage person that night, it's no one that knows anything about general surgery... A lot of the times, the information's not right. We have a terrible system. Awful." (**S9**) Often times, by the time patients are talking to us, they're frustrated because they've already talked to multiple people. Often times, the message we receive is incorrect. Sometimes it's blatantly incorrect, like saying "my arm hurts, but my leg hurts," and sometimes it's just not very thorough. (**S11**)
Care is uncoordinated	• Post-discharge care is not coordinated • Patients frequently present to outside providers without looping the surgical provider in • Often results in overtreatment	"As frustrating as it is, I've never been called by the ER, urgent care or a primary care provider by themselves to say, 'hey, I have your patient here post op and I'm concerned about this wound.' And I've never been forwarded a note from them." (**S4**) "Not typically [do I ask a patient to send serial wound photos because] the way our system works is usually I'm only monitoring for one day. Two days at the very most. Usually, the other nurse comes back and is able to pick it up from there." (**S10**)
Care is reactive, not preventative	• Default recommendation to concerned patients is to go the ED • Most issues are best handled in clinic, not ED	"I usually called during business hours and then just suffer through the night if it was something during the night. Because I don't like going to the emergency room. I always figure it should be a life and death thing to go to the emergency room." (**PI10**) "If they're reporting signs, default pathways, you've got to come in. If we have clinic space, we'll bring them in early. But because clinic is infrequent, they'll almost certainly end up in emergency." (**S1**) "There's definitely our high risk patients that it would

		be nice from the start to have a plan in place to help follow on those patients, but with our current system and the way it works, it's really not possible... For right now, no, it's more of a you catch it after. You don't really get a great chance to be preventative on most of it." (**S10**)
Patients and providers have had positive experiences with emailed wound photos		
Wounds are hard to describe	● Wounds are hard for patients to describe ● Photos are helpful in this regard	"My background as a triage nurse... was just that when patients would call with surgical site concerns, they're not very good at describing how red something is or what color the drainage is..." **(S7)** "You know, it's all relative, people see things in a different way. So what I say is pink or red might be nothing, just a benign issue for a doctor. So being able to send clear photographs of whatever wound or injury I think would be very helpful." (**PI12**) I think the photos are really helpful because it's hard for patients to try to explain a wound or what it looks like and they're often on pain medication when they're explaining it. They don't have someone with them to measure or they don't have a measuring tape. They don't know what concerning looks like. With a lot of these things, we really need to see it. That's an inherent difficulty of triage as a nurse. It's just really hard to be talking to someone about something that you can't see. (S11)
Photos help clarify decisions and improve management	● Wound photos help clarify decisions and improve confidence in decision-making ● They are considered in addition to traditional patient/wound data ● Wound photos can improve management decisions, allowing patients to avoid clinic visits or be seen urgently for a previously unsuspected wound concern ● Especially for distant patients	"We don't base everything primarily on the picture... [pictures] help with wound monitoring and management and I think it really helps triage nurses have confidence in the decision that they're making." **(S7)** "I think before we requested so many [wound photos], I was much more apt to just have somebody come in and take a look because I didn't have a good gauge of what exactly was going on." **(S8)** "Right when I noticed it... I took some pictures and I emailed it to him [doctor] and he just said monitor it. If it – the liquid became thicker or became more red, to let him know. And then it did, so that's when I came in." (**PI4**)
Once you start, you can't stop	● Once a photo has been sent, patients often send subsequent photos so providers can check in on progress.	"We often will say, 'send us a picture tomorrow, let's compare it every day to see how things are going.' So that helps with wound monitoring and management..." **(S7)** "But it would have been really helpful, especially the first time that it started getting infected, I could have

		sent them a picture... then I could have sent another picture and said it's a lot worse and they could have seen right then you need to come in now. Instead of waiting until it got really bad." (**PI7**)
Photos and EMRs don't mix	• Storing photos in EMR is discouraged by IT and results in formatting issues in clinical notes • Storing photos is a multi-step process that is time-consuming, so pictures often remain in personal email • Patient data becomes fragmented across EMR, email	"We used to [store photos in EMR] much more, but they're cracking down on it. It's taking up too much space." (**S4**) "It really was like a 15 minutes process [to put the photo in the EMR] on top of these 15-20 minute calls. [So] The photos would just sit in nurses in-boxes. Then there were questions of whether those are secured." (**S7**) I feel like it should be part of what I'm documenting about my phone triage because it's part of the whole clinical picture. It's a bit cumbersome getting them because we have an email that is only for pictures that only the nurses use and we only check it if we know a patient is sending something. (S11)

Major themes are **bolded**. Sub-themes are in the first column; summary points are in the 2nd column, and illustrative quotes are in the 3rd column with the participant attributed, e.g. surgical provider #7 = S7.

Appendix 5-B. **Additional quotes from patients and providers for each of the 10 main themes.** S# denotes surgical provider; PA# denotes patient advisor; PI# denotes patient who experienced infection.

Data capture	
1. Provide context and "metadata" to supplement PGHD (agreement)	"Then [the triage nurses] pass on these ambiguous answers and then I feel like I need to call and talk to the patient myself and make sure I'm clarifying everything and getting the full picture." (**S5**) "You start searching on the internet and I've got either leprosy or cancer or something horrible. Until somebody has all my history and all the data, any symptom can be a sign of anything…" (**PA10**) "There are some patients who… have shown patterns to be unreliable… You can tell that these patients are going to be difficult for post-operative follow up. Those are the patients I'd probably set up [with routine wound monitoring]." (**S7**) "I will try to find… the resident on call. We'll talk through things. As long as I'm feeling confident and not like they're like, 'well, maybe,' then I'm fine with that. But if it's one of those things where I'm like, 'I'm not getting that you were really confident in this answer,' then I may try to go up to the chief and talk to the chief." (**S10**)
2. Patients want flexibility of input, providers don't (conflict)	"This is a forced choice. There is no choice for the option that should probably be offered to me." (**PA5**) "…but I think you'd want it to be a fixed menu so that they're not free typing in there so that you have a maximum of six possible things that they could click or something like that." (**S8**) "Yeah, I probably would like a free text [field]. A quick overview of what's going on. 'What's the most important concern you have about this?'" (**S10**) "I could think of a lot of times where I have had other things to say." (**PI12**)
Data transfer	
3. Patients prefer routine use; providers prefer "as necessary" use (conflict)	"I'd probably have my high risk ones use it routinely… I think the two populations [I wouldn't invite to use it] are the really low risk [and the] super anxious [patients]." (**S4**) "So I think [routine use] would bring a real peace and comfort… [that] their doctor is looking at it." (**PA4**) "I think that would be a lot of information for us to sort through just as I'm thinking about our current staffing if we were having people send it on a regular basis." (**S11**) "People are going to be a bit more worried… It's like oh does this look right, I'll send it. Here's a picture. It [using the app] might increase anxiety." (**PA8**) If there was some way to integrate it into what we're already currently using, then I'd have absolutely no issues with it. But if it's going to be another application that I've got to monitor, then no, I want it to be on an as-needed basis. (**S10**) "Come up with a score [at discharge] for the risk level and then we decide based on that whether or not they're going to… take a photo everyday or if

	they're going to… take a photo only if they're concerned." **(S5)** "Once they've used it because they have a concern, then I would ask them to continuously send me a photo everyday to keep an eye on how things are going." **(S7)**
4. Patients like electronic messaging and (mistakenly) think providers do too (conflict)	"Text messaging is a great example, because I don't want to interrupt someone if they're in the middle of something." (**PA4**) "I've had patients text me. I think it's totally disruptive. It's impossible to communicate in an adequate fashion for both them and for me. I don't want that kind of access with patients." (**S4**) "Shorter is probably going to get a better response, post-surgery, loopy on meds… If you have a smartphone that is by the bed, that works very easily." (**PA7**) "I think that's going to be a very provider specific thing and how they like to communicate with patients. It seems a little informal because as soon as we're talking about symptoms, it becomes part of their medical record…" (**S2**) "Honestly, everything we do is all in Epic Care. I guess if we could, again, import that in, maybe that would be feasible. If not, which probably initially that would not be the case, honestly, I probably wouldn't use it. I would probably just do it in Epic and then have to write it anyways." (**S10**) "But again, if you can [automatically record PGHD into clinical notes], then that's a whole different ball game because then I don't have to repeat everything that's already there." (**S10**) "I like that ideas for certain populations because I want people to feel comfortable communicating and it doesn't really matter to me how I communicate. I feel like I can communicate the same things I want to say in any method. I also want people to have realistic expectations of how available I am to them. I feel like this could potentially be a setup for people thinking that we can text all day. If I could, I would, but I can't." (**S11**) "Do you expect anyone using this app to start sending too many texts to the surgery team because texting is such a casual interface that people are just used to sending short messages with?" (**PA2**) "[By calling,] They know they've made a connection, which I think the difference is that they're just filling out this thing and sending it off into hyperspace and they don't know if someone's looking at it or thinking about it. For them, they get this immediate gratification when they're calling in." **(S5)**
Review/documentation	
5. Present simple, actionable data in an accessible way (agreement)	"My biggest problem with [receiving quality of life data] is that I wouldn't know how to make decisions based on that information… Some of this repeated assessment of symptoms; it may be too much information. It all boils down to is it getting better or is it the same?" (**S1**) "I usually will email them [wound pictures] because I get a faster response on email versus [EMR message]. That's just because if the doc's down in surgery, she has email on her phone, she doesn't have [EMR message] on her phone." (**S10**) "It's green or it's yellow or it's red. Something easier for me to understand. If I'm looking at this, all I want to see is progression either in one direction, things are getting better, or things are getting worse." (**PA10**)

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	"I guess what I'm trying to get to is [in the current interface] there's no 'at a glance' way for me to understand how complicated this patient is." **(S6**) "We're on drugs and all kinds of medications… Make it nice and simple. I'm just trying to take a picture of the wound and send it and get a response." **(PA8**) "Adding an extra thing, people are not going to use it unless it's quick, easy and better than what we have now." **(S9**) "It depends on the attending. Different people are responsive in different periods of time and through different systems. I try to reach them in the way that I know they'll respond. Sometimes it's email, sometimes it's through Epicare, sometimes it's paging. It depends on how urgent it is." (**S11**)
6. Prioritization and response times (conflict)	"I really encourage them to call with anything… I wouldn't say that in this population I find that very many people are calling with benign issues." (**S11**) "I don't want to disregard the patients' concern, but at the same time, some patients are overly concerned about everything. What I think would be helpful is to see the patients that I'm concerned about…" (**S1**) "I hope it doesn't take two days. Meanwhile it's getting worse and the next morning you've got a 102 fever… I would hope that somebody would answer… within 2-4 hours I would think would probably be sufficient." (**PI8**) "They don't want to bother the doctor. That is a big barrier to success. [especially] people of the older generation that wouldn't dream of asking somebody a question…Putting doctors on a platform so that you're afraid to approach them." (**PA4**) "Because sometimes you're just sitting there waiting and waiting – you know, I was waiting for [nurse] to call. It might be an hour or two, and it's like God, you know, what am I supposed to do?" (**PI10**) "I knew it was cellulitis and I know that can spread very quickly… I contacted them and they said well, you have an appointment here in a few days. Let's just wait it out and see. I felt a little put off. Like their sense of urgency for me wasn't really there." (**PI13**) "I think that the level of concern that they have is important to me… the more concerned they are about, the more concern I feel about it probably." **(S5**) "Urgency from the patient's perspective can often be anxiety and stress which, when we're working in a clinical triage environment, we can't prioritize." (**S11**) "So I think based on the level of pain that somebody was having… the response time back would be quicker." (**PI6**) "If they pick fever and pain, that should automatically be bumped to the top. But if they just click [that they have] a few questions, then maybe put them at the bottom so it would prioritize it for us." **(S9**) "But I think if they're submitting it with some sort of concern, indicating there's a change toward the negative scores in their condition, then I think that would be reasonable to expect to hear back… within a number of hours or that same day; enough time that they could get to the clinic if they needed to…" **(S5**) "I would be very worried about how those filters are constructed because there may be information that I'm not getting that would make me liable." (**S1**) "I don't know if there's a great way to have some sort of computer system analyze that at least at this point. Again, everybody's perception of what's going on is different … I think it would just be more feasible for the staff member to

	make that call [rather than an algorithm].” (**S10**)
	“…what would be more helpful than an email [alert to provider] is the patient be instructed to go to the ER or making an earlier clinic appointment.” (**S1**)
	“The worst case scenario is that the patient has an infected wound [and] needs to be seen pretty rapidly, so… if you tick this this this and this then that equals go to your emergency room.” (**PA6**)
	“That certain questions are flagged or answered a certain way, those are danger signs, and whether you told them to a person or the computer was programmed to respond like the person would, I don't see how that part makes any difference.” (**PI9**)
	“Because so many of these things are so subjective … I think just based on symptom pattern, the things that they answer, I wouldn't feel comfortable making a recommendation until I learn more or saw more.” (**S2**)
	“If they pick fever and pain, that should automatically be bumped to the top.” (**S9**)
	“Because what if they didn't answer it correctly? What's pink to me might be red to you. What concerns me might not be a concern to you.” (**PI12**)
7. Power, responsibility, and reliability (conflict)	“And then it will be on the provider. They're assuming the provider will look at it and will call them. I've learned that that's not always the best thing. Sometimes people don't look at things.” (**PA4**)
	“As long as there's some sort of insurance at the end ‘if you do not hear back from someone and you continue to be concerned in the next four hours, please go to the emergency room.’ You should have some sort of disclaimer.” (**S9**)
	“I just know a lot of the patients that I care for can have unrealistic expectations of what our workflow is. So for them to be able to elect to say ‘I want to hear back in an hour’, it takes [away] the ability for us to manage this triage process…” (**S5**)
	“So it's not just kind of like sitting out there and you just submit it to a black hole, you know, when someone's going to get back to you.” (**PI4**)
	“Well if they're going to send anything here, then I'd have to be notified at any time because I would hate for them to be like, "hey, I sent this and nobody ever got back to me." It would definitely be something I would want a notification every time… The biggest thing [concern] would just be making sure that I remember to watch it.” (**S10**)
	“Their concerns are part of it, my concerns aren’t part of it. [After I submit my data,] This is in the hands of the physicians, the provider system. I’ve done what you’ve told me to do…” (**PA5**)
	“I doubt if anyone will get back to me within 30 minutes [if that was necessary]… knowing how the system works now, I don’t think so… it would be nice if they did.” (**PA8**)
	“The patient has no idea what other commitments I have during the day, mostly to other patients… Patient-centeredness is being taken too far… to say "just because the patients want it," I think that's ridiculous. Patients are uninformed. This is not like you want a popsicle. This is total information asymmetry. The idea that it's a consumer model is totally problematic.” (**S1**)
	“I can make my choice but it might not be the surgeon’s choice given what I said to them [so] I would probably pick [that I want a response] ‘only if the doctor is

	concerned'… what do I know? They should use their best judgment…" **(PA7)**
	"Because if somebody's concerned about their own body, it's pretty much always going to be a high priority to them and I completely respect that. Whether or not it's a true problem is what our job is." (**S11**)
	"It's great for patient satisfaction to give them the power to say something but I think it's a little unreasonable in a clinical scenario to demand to hear back in an hour on request. Indicating the level of concern, to me, is very important… But putting a time on there makes me nervous." **(S5)**
	"A really honest answer is that I wouldn't want to put any timeframe on it because I think it's an unrealistic expectation. The patient has no idea what other commitments I have during the day, mostly to other patients." **(S1)**
Overall process	
8. Build on existing socio-technical systems (agreement)	"The triage nurses will tell you they're overworked as it is and they don't have time. So ideally, if there was a dedicated triage nurse or team that utilized this… I think giving patients this tool is amazing, but who's responsible for it is the biggest question." (**S7**)
	"She happens to be knowledgeable about the things that are procedure-specific or specialty-specific. She would be a natural person to do the screening." **(S1)**
	"I guess it's more who is going to [respond]? Is it going to be the emergency room nurse? Or is it going to be Dr. So-and-so's nurse that knows my case?" (**PI12**)
	"It would be nice to be able to… touch base [frequently] with the patient: '…I'll be the one following up with you afterwards.' If the doctors have any concerns about any needs outside in the community, just making sure that that's followed through as well, resources, that kind of stuff." (**S10**)
	"I'd want one screen before a surgeon because… I don't want to get alerted when I'm doing a case for something that's not real." **(S2)**
	"I think there ought to be tiers of people… If somebody who has that [mid-level] training looks at a photo and says, 'wow, I don't really know what to say about this.' That's the photo that I would spend my time looking at." **(S6)**
	"I called the number and they were like I need to transfer you to here. Got transferred to there and then – oh no, you need to be over here. So it was kind of a roundabout way to the nurse." (**PI6**)
	"Providers don't like working in multiple systems… Even if it's another thing that's going to help them, sometimes it's just like, 'I can't remember to check that.' So any way we can keep things together." (**S11**)
	"Because it's so difficult as it is already to triage calls, playing within the same system makes a lot of sense. It's just additional information… when [nurse] opens that message, it could also include the mPOWEr data… as opposed to saying, 'all mPOWEr data is going to go to the R2 [resident] on that clinical service'." **(S4)**
	"Okay, who's inputting all this information [that populates the dashboard]?" (**S11**)
	"I think if a triage decision and a recommendation are made to the patient, there needs to be some documentation." (**S1**)
	"I think I would pretty much always go through EMR because if you're going to do any intervention… I would be doing that through Epic anyways… I think if

	this is not synced with Epic, that it might create more complexity that it was helping, just by having two different message threads for the same issue for people potentially." (**S8**)
	"The risk of having misinformation in there might be greater than the actual benefit of having that information come up." (**S4**)
	"Even then, I think I'm going to want the ability to quickly look at all the background information now, 'what did I say about this patient in clinic pre-surgery? I'm going to read my op-note.' I would want that stuff available to me quick[ly]…" (**S6**)
9. Process transparency allows better decision-making (agreement)	"Maybe something that you can go back to your account and see kind of a log, like has the doctor looked at it? So that… I know that a person has reviewed it and made an assessment." (**PI4**)
	"'It'll be roughly an hour before I can get back to you on any conclusive' or something. Some kind of a timeline as to when they would be able to respond back to it." (**PI6**)
	"Would there be a way in here to track who has looked at this? If we sent it to the [surgeon], can we somehow look back and see if they've looked at it. Because that would be super helpful. You don't want to pester someone about something they've already done, but if they haven't done it, it leaves us [nurse] responsible until they have." (**S11**)
	"There's also, now, with Epic Care, patients can send emails, but they think they're sending an email to their doctor but they're actually sending it to the nurse which can sometimes cause frustration on the patient's end as well… Because they think they're talking directly to their doctor, but they're not." (**S11**)
	"I think you have to give them a commitment of what you're going to hear back from them… I think is less than 24 hours." **(S4**)
	"What I would send back to patients is like, 'based on what you reported, this has been deemed a high level' or 'medium level of importance and will be reviewed by a provider within 'x' amount of time who will get back to you.'… So that they feel like someone is going to respond to them or it's validating." **(S2**)
	"I try to explain in simple terms that I'm going to prioritize who I'm calling. People with infection concerns are more of a priority for me than others… I'd say it's really rare with me, for what I'm responsible for, for it to be more than two hours for somebody to wait for a call back from me." (**S11**)
10. Provider goal for data collection is triage; patient goal is diagnosis (conflict)	"[with mPOWEr] they would have more triggers to call. One concern is do we end up intervening on more patients than we should." (**S5**)
	"You could save a visit or they could see right away, you better come in… and if you think you have a problem but don't really have one they could say oh you're fine and you wouldn't have to go in to hear you're fine." **(PA9**)
	"I could probably make the diagnosis on a case by case basis with pictures and talking with them, but that, it's going to take more than the information that's provided here. It would take a dialogue with the patient. It would take a lot of time. To do that for every patient is not feasible." **(S1**)
	"The hardest part is it's not built into our day. Every patient that calls, there's no way that I could sit down and talk to them all and make a good clinical judgment unless they just come in to be seen… Could they be managed on the phone? Yes, probably, some of them can be. It's just can they be managed on

	the phone within the system by an attending? Probably not." **(S4**) "I think it would prevent unnecessary visits from patients. Less drive time, less missing of work." **(S7**) "[To give quality care] I feel like I have to examine and see and have a back and forth dialogue with the patient." **(S1**)

Appendix 6-A. Definitions of elements of patient-centered care

Domains and subdomains of PCC	**Definition**
Coordination and integration of care	
Integrated care [159]	Bringing together inputs, delivery, management and organization of services related to diagnosis, treatment, care, rehabilitation and health promotion
Transition and continuity of care [160]	Related to information that will help patients care for themselves away from a clinical setting, and coordination, planning, and support to ease transitions
Quality and safety [44]	Quality care is safe, effective, patient centered, timely, efficient, and equitable
Prevention and health promotion [146]	Services to address the health of patients before getting sick as well as encouraging patients to lead healthy lives
Routine patient feedback to practice [56]	Aims to capture patients' perspectives of health, illness, and the effects of health care interventions; routine use helps evaluate and improve processes and outcomes of care
Quality improvement [160]	Steps systematically applied to improve the patient care experience, such as effectively making, measuring, and managing change
Whole-person orientation	
Alleviation of fear and anxiety [160]	Reduction of fear or anxiety about clinical status, prognosis, and the impact of illness
Respecting patients' values, preferences and needs [160]	Awareness of quality-of-life issues, involvement in decision-making, dignity, and attention to patient needs and autonomy
Emotional support [161]	Providing comfort and alleviating uncertainty, anxiety, hopelessness and depression
Exploring the disease and illness condition [149]	Understanding patients' unique experience of illness (e.g. feelings about being ill, ideas about illness, impact of illness on functioning, what they expect from care)
Physical comfort [160]	Including pain management, help with activities of daily living, and clean and comfortable surroundings
Enhanced clinician-patient relationship	

Patient engagement in their care [160]	To enable patients to take a more active role in the care process
Patient empowerment [162]	To allow patients enhanced ability to understand and influence their own health status, including by enhanced ability to self-manage.
Finding common ground [149]	Steps include defining the problem to be addressed, establishing goals of treatment or management, and identifying roles to be assumed by patient and clinician
Clinical information systems	
Publicly available information on practices [147]	Information by which a patient could choose a physician or a practice most likely to meet the patient's needs
Practice-based learning [163]	Investigating and evaluating patient care practices, appraising and assimilating scientific evidence, and improving patient care practices
Socio-cultural competence	
Community outreach [164]	Demonstrable, proactive efforts to understand and reach out to the community
Family and friend involvement in care [160]	Involvement in decision-making and awareness and accommodation of their needs as caregivers

Appendix 6-B. Defining current and ideally patient-centered practices, and challenges to achieving them

Domains and subdomains of PCC	Current practice (pre-tool) [Step 1]	Ideal practice [Step 2]	Challenges [Step 3]
Coordination and integration of care			
Integrated care [159]	• Care is not well integrated within a care team (e.g. attending may not hear about patient who reached a resident after hours), but especially when patients present to outside providers (PCP/ED) for care • Patients struggle to reach a contact person with concerns	• Integrated care where patients have a trusted single point of contact who is familiar with their care • Seamless consult within care team and direction of patient to appropriate care • Outside providers are provided necessary information and advice to improve management; original care team is kept in the loop	• Connecting patients to a changing point person throughout day/week • Looping in outside providers unfamiliar with tool; designating access, security/privacy, interoperability • Staffing challenges: dedicated time; complexity of current structures (e.g. residents, rotating clinic nurse pools); coverage on nights/weekends • Direct provider access may conflict with other institutional priorities, e.g. centralization of patient calls
Transition and continuity of care [160]	• Transitions of care are abrupt, not patient-centered • follow-up appointments are distant; surgery team is nominally responsible for care (up to 30 days PD)	• Care transitions are smooth and based on needs of patient; Tool supports planning for discharge and post-discharge self-care • continuity of care is maintained by providers who know patient with frequent check-ins	• Patient needs vary: e.g. local vs distant patients; some patients prefer written vs video vs interactive teaching • Discharge instructions and processes have significant inertia, complexity: difficult to change • Care coordination effort may not be reimbursed
Quality and safety [44]	• Current practice does not meet any of the domains • PD complication recognition relies on patients in impaired state; diagnosis and management are often untimely and inefficient (e.g. resulting in frequent readmissions)	• Complication recognition is proactive or even predictive; results in neither too much nor too little care; all patients have access to quality, patient-centered care	• Potential challenge with equitability if patients need smartphones • Potential for overtreatment • Potential tradeoff between patient-centeredness and timeliness/efficiency if provider workflows disrupted by patient requests

Prevention and health promotion [146]	• PD system is reactive, not proactive in preventing, recognizing, and treating complications • Patients often do not have wound care or problem recognition skills due to gaps in discharge teaching	• Proactive PD system focused on prevention and early problem identification • Educated patients who appropriately take care of wound and recognize problems early	• Potential to increase anxiety with self-monitoring, especially with subjectivity and uncertainty around SSI diagnosis • Early detection has potential for over-treatment • Decreased visits/utilization may affect hospital revenue
Routine patient feedback to practice [56]	• Patients do not routinely send feedback to practice, especially in post-discharge/clinic setting	• Patients give feedback routinely during PD phase to support evaluation and improvement of care processes	• What feedback is meaningful for patients to send? For providers to receive? • How is feedback received, analyzed and responded to?
Quality improvement [160]	• QI focused on inpatient, not post-discharge (PD), complications due to regulatory/ financial incentives and established surveillance techniques	• QI directed at all phases of care especially those most affecting patient experience (i.e. following post-discharge "voltage drop") • Clinical practice and QI are synergistic	• Lack of validated instrument or gold standard for assessing PD surgical site infection (SSI) • Designing for dual use: clinicians and QI staff may have competing priorities • Focusing on measures (PD SSI rate) that are not currently prioritized by regulators/ administration
Whole-person orientation			
Alleviation of fear and anxiety [160]	• Providers acknowledge fear/ anxiety are important but focus more on "real" problems	• PD management is focused on patient experience; providers screen for patient-reported fear/ anxiety (which is common), not just complications (which are rare but serious)	• Methods of assessing fear/anxiety? • Time burden on patient/provider • Who reviews data? Is it actionable?
Respecting patients' values, preferences and needs [160]	• Patient values are not explicit and providers do not measure QoL or impact on functioning • shared decision-making is uncommon in PD context	• Providers elicit patient values and assess QoL/ functional status • Patient values are reflected in shared decision making	• How to assess values/ preferences • How do providers incorporate patient values? • Possible tension between patient preferences vs guidelines/ evidence
Emotional support [161]	• emotional support is secondary to "real" problems	• Providers screen for need for emotional support and coordinate further care as neces-	• Who provides emotional support? Resource availability (e.g. social workers)? • Can app provide direct emo-

		sary	tional support?
Exploring the disease and illness condition [149]	● Post-discharge experience is disease-centered, i.e. focused on recognizing particular surgical complications; providers don't explore feelings of illness	● PD experience is person-centered, based on the patient's unique experience; feelings/ideas/impacts of illness and expectations of care are explored	● Patients may ignore or not recognize their condition ● Focused on recovery, not illness ● Who reviews data? How do they act on it? Are providers trained in exploring patient illness condition? ● Scope/complexity of tool
Physical comfort [160]	● Patients are often in significant discomfort at home but this is not monitored by providers	● Providers screen for QoL, including ADL and comfort metrics	● How to assess pain when on pain medication? ● How to assess ADL?
Enhanced clinician-patient relationship			
Patient engagement in their care [160]	● Patients feel passively engaged in care, barely holding on during a trying phase in their recovery	● Patients feel engaged in their care to the extent they wish; are provided transparency in what is going on ("nothing about me without me")	● Engagement may not be desired by patient/ no value judgments ● How to encourage pts to voice concerns, "bother the doctor" ● Transparency may increase patient anxiety ● transparency may increase provider workload and impose order on a dynamic triage process
Patient empowerment [162]	● Patients do not feel empowered in that they do not have choices that affect their health status	● Patients are given meaningful choices in their care, feeling feel to voice concerns or questions; aided in self-management	● How to aid self-management? Is patient decision-support feasible? ● Patient decision support brings liability concerns
Finding common ground [149]	● Patients sometimes feel that their preferences aren't taken into account, e.g. providers advise inconvenient care (ED) when patient think it's unnecessary	● Patients and providers define the problem and engage in shared decision making around goals of treatment to personalize care	● SDM is not the norm in potentially acute post-discharge surgical settings ● How can technology facilitate shared decision making/ personalized care? ● What if provider and patient concern is not aligned?
Clinical information systems			
Publicly available information on	● There is currently little or no available info on practices, espe-	● Patients are provided information on measures of patient	● Standardization/risk adjustment across institutions ● Clinical outcomes (e.g. sur-

practices [147]	cially around PD complications or patient satisfaction	experience and clinical outcomes, including in PD period	vival) may trade-off with patient-centered outcomes
Practice-based learning [163]	● Clinical information systems currently do not generally support PBL; PD period has unique problems of lack of data from patients and lack of knowledge of risk factors for PD complications	● Better data from patients about both clinical and patient-meaningful outcomes are presented in clear, actionable way to providers through EHR to facilitate practice improvement	● How to effectively present data to providers to motivate change ● If not all patients provide data, lack of denominator/ risk of bias. ● Providers have concerns about how they will be evaluated, want risk-adjustment
Socio-cultural competence			
Community outreach [164]	● Providers recognize the diversity of patients, especially rural/remote, non-native speakers and homeless	● Understanding of needs of local community, creating tools that are culturally appropriate (e.g. language, customs, usability)	● Many challenges (e.g. homelessness) extend beyond HIT's capability to address
Family and friend involvement in care [160]	● Family/friends highly involved in care in PD period	● Facilitating family/friend involvement while respecting privacy wishes of patient	● Consideration of needs of pts vs caregivers; ensuring patient voice is not overridden by caregiver voice ● Caregiver access to record/ HIPAA/privacy issues []

Acronyms: PD—post-discharge; SSI—surgical site infection; PCP—primary care provider; ED—

emergency department; QoL—quality of life

VITA

Patrick earned a bachelor's degree in Architecture from Yale University. He came to the University of Washington for medical school and discovered his interest in Biomedical & Health Informatics (BHI) while working on a summer project before his second year of medical school. For that project, he developed an automated system to discover catheter-associated urinary tract infections by querying the medical record. Following his interest in healthcare-associated infections and improving care quality generally, Patrick took a leave from medical school to work with a Harborview surgeon, Heather Evans, and BHI faculty and alumni Bill Lober, Wanda Pratt and Andrea Hartzler on his doctoral thesis "Patient-Centered Development and Evaluation of a Mobile Wound Tracking Tool". Patrick contributed to the design of mPOWEr, a mobile health tool that seeks to improve care quality and patient experience after hospital discharge by improving patient-provider communication about surgical site infection. Patrick will resume medical school this summer and plans to pursue an academic career focused on designing technologies that support high-quality, patient-centered care.